June 2025

Breast Cancer Programs for Native Communities in Washington's Peer States

The 2023 Washington State Legislature directed the Washington State Institute for Public Policy (WSIPP) to conduct a study of breast cancer-related programming for Native American women in Washington's peer states. Specifically, WSIPP was directed to identify breast cancer prevention and education programs, as well as post-diagnosis resource and support programs, led by states, tribes, or in collaboration between states and tribes. In addition, the legislature directed WSIPP to review evidence for identified programs (see Exhibit 1 for the legislative assignment).

This report is organized as follows: Section I provides background information, including breast cancer rates, healthcare and public health funding streams, and a summary of the landscape of programs in Washington State. We describe our methodology in Section II, including our processes for identifying peer states and outreach to program representatives. Section III summarizes findings regarding programs in peer states and reviews the evidence base for identified programs. Section IV concludes this report with a review of key findings and study limitations.

Summary

WSIPP studied breast cancer related programs for American Indian and Alaska Native women in nine peer states. We focused on programs led by states, tribes, or collaborations between states and tribes. We also reviewed evidence for identified programs.

Most tribal healthcare providers are not able to offer cancer screening or treatment, requiring women to access these services from other sources.

All states and some tribes or indigenous-led organizations currently receive federal grants for breast cancer outreach, education, and screening for low-income women. State programs vary in how grants are used to improve access for native communities. Programs include a range of largely evidence-based activities, including community events, screening reminders, and patient navigators.

We identified few state or tribal led programs providing post-diagnosis supports or resources for native women.

Suggested citation: Goodvin, R., Cramer, J., & McFeely, M. (2025). *Breast cancer programs for native communities in Washington's peer states* (Document Number 25-06-3401). Olympia: Washington State Institute for Public Policy.

Exhibit 1

WSIPP's Study Assignment

(k) \$107,000 of the amounts in fiscal year 2025 is provided solely for the Washington state institute for public policy to examine programs in peer states related to breast cancer education and prevention prior to diagnosis and support and resources after diagnosis for native communities. The study must focus on programs that are operated by either the state, tribes solely, or tribes in coordination with the state. To identify peer states, the institute may consider factors such as the population of American Indians and Alaska natives, number of federally recognized tribes, and whether the state has expanded medicaid. The report shall include for each peer state the existence of any programs that meet the criteria described in this section, and summarize any research findings on these programs, if available. The institute must submit a report to the appropriate committees of the legislature by June 30, 2025, in compliance with RCW 43.01.036.

Engrossed Substitute Senate Bill 5950, Chapter 376, Laws of 2024

I. Background

In this section, we first present the most recent data on breast cancer incidence and mortality among Native American women nationally and in Washington State. Second, we review the major public programs funding healthcare and public health initiatives relevant to breast cancer for Native American women. Third, we conclude with a summary of the landscape of relevant programs in Washington.

Breast Cancer Incidence, Mortality, and Screening Rates

National Incidence and Mortality Rates

Breast cancer is the most common cancer in women in the United States. Though the national prevalence of breast cancer in American Indian and Alaska Native (AIAN) women is lower than in White or Black women, the incidence rate among AIAN populations has seen a steeper increase over the last decade compared to these groups. And while the breast cancer mortality rate has steadily declined since the 1990s across other racial and ethnic groups, the rate has remained unchanged for Native American women.

Incidence and Mortality Rates in Washington In Exhibit 2, we summarize the most recent available breast cancer incidence and mortality rate estimates for Washington State by race/ethnicity. Breast cancer rates are higher for AIAN women than for Hispanic, non-Hispanic Black, and non-Hispanic Asian women. Rates for AIAN women are lower than for non-Hispanic White and Native Hawaiian or Pacific Islander (NHOPI) women. The differences in incidence rates between AIAN and Hispanic women and between AIAN and NHOPI

women are statistically significant.³

Breast cancer mortality rates for AIAN women were significantly higher compared with rates for both non-Hispanic Asian women and Hispanic women. Although AIAN women's rates were higher relative to both White women and Black women, these differences were not statistically significant. Overall, breast cancer mortality rates for American Indian and Alaska Native (AIAN) women in Washington are high relative to most other racial/ethnic groups despite comparable incidence rates.

Prevention and National Cancer Institute, released in June 2024). The CDC notes evidence suggesting that cancer incidence and mortality data are likely underestimating rates for AIAN people.

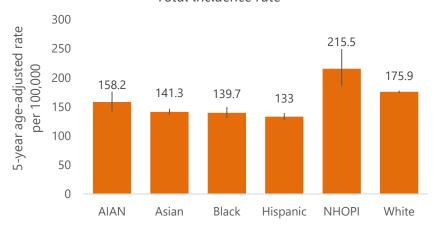
¹ American Cancer Society. (2019). *Breast cancer facts and figures 2019-2020*. Atlanta: American Cancer Society, Inc. The Centers for Disease Control and Prevention (CDC) reports breast cancer incidence rates per 100,000 (ageadjusted; 2017-2021) of 142.6 for non-Hispanic White women, and 118.6 for non-Hispanic AlAN women, restricting to PRCDA counties only to improve the accuracy of AlAN cancer statistics (U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool. U.S. Department of Health and Human Services, Centers for Disease Control and

² American Cancer Society (2019).

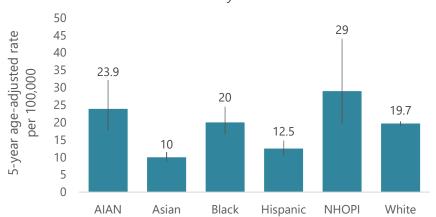
³ Incidence rates include only those individuals who have completed diagnostic testing for a confirmed diagnosis. Rates likely undercount breast cancer incidence in all groups, with underestimates more pronounced for groups with more limited access to diagnostic follow-up.

Exhibit 2Washington State 5-year Breast Cancer Incidence and Mortality Rates by Race/Ethnicity (2018-2022)

Total incidence rate



Mortality rate



Notes:

AIAN: American Indian or Alaska Native; NHOPI: Native Hawaiian or Other Pacific Islander. Race groups include single race only, non-Hispanics, except for the Hispanic group.

Rates are per 100,000 and age-adjusted to the 2000 US standard population (19 age groups); error bars show 95% confidence interval for rates. Breast cancer incidence rates reflect the total in situ and invasive stages at diagnosis.

For AIAN rates, the analysis includes only Purchased/Referred Care Delivery Areas (PRCDA) counties (Excluded counties: Adams, Asotir Benton, Columbia, Franklin, Garfield, and Walla Walla). PRCDA counties include all or part of a reservation or share a boundary with a reservation. Limiting analyses to these counties can help to address racial misclassification that can lead to underestimation of cancer rates among AIAN people.

Data include cases in 2020 and 2021, the first and second years of the COVID-19 pandemic. The pandemic disrupted health services, including delays and reductions in cancer screenings and diagnoses, impacting incidence rates.

Data Sources:

Washington State Cancer Incidence Data: Washington State Department of Health, Washington State Cancer Registry, released in January 2025. Washington State Mortality Data: Washington State Department of Health, Center for Health Statistics, released September 2023. Population Estimates: Washington State Office of Financial Management, released January 2025. Data Definitions:

Incidence data were obtained from the Washington State Cancer Registry using primary site ICD-0-3 codes C50.0-C50.9, excluding histology codes 9140, 9050-9055, and 9590-9993.

Death data were obtained from Washington State death certificates using the underlying cause of death ICD-9 codes 174.0-174.9 (1992-1998), ICD-10 codes C50 (1999-2022).

Screening Rates

Breast cancer can be detected during screening, such as clinical breast examinations or mammography, before symptoms appear. Regular screening allows for the detection of breast cancer at earlier stages when the spread of cancer cells is most limited. Across all racial/ethnic groups, survival rates are higher when diagnosis and treatment occur at earlier stages.⁴

Nationally, AIAN women have the lowest breast cancer screening rates, resulting in later-stage diagnoses.⁵ Based on a 2022 national survey, 62% of AIAN women between the ages of 50 and 74 had a mammogram within the past two years, compared to 72% of White women.

Rates in Washington State show a similar but less drastic pattern (70% of AIAN women compared with 75% for non-Hispanic White women). Screening rates are lower among women who receive care at Indian Health Service (IHS) facilities (55% of women 52-64 years old, nationally) because clinics often do not provide cancer screening services.

While AIAN women tend to be slightly younger than other groups when breast cancer is detected, their prognosis is often worse because the forms of cancer detected are in more aggressive stages.⁷

Social Determinants of Breast Cancer Screening, Incidence, and Mortality

Public health initiatives and expansion of insurance coverage through Medicaid have not been sufficient to close gaps in screening rates or health outcomes for AIAN women diagnosed with breast cancer. Numerous barriers, which are often interconnected, like geography, health insurance status, access to specialty care, and trust in healthcare systems, likely influence disparities.

About 40% of AIAN individuals live in rural areas where transportation, long travel times, and limited healthcare services are barriers to timely and quality care.⁸ Recent geographic analyses have identified inequities in AIAN individuals' access to both screening mammography and radiation therapy.⁹ When breast cancer is detected, AIAN women are less likely than non-Hispanic White women to receive evidence-based breast cancer treatment, even when they have health insurance.¹⁰

American Indian and Alaska Natives impedes population health insights. UCLA Center for Health Policy Research.).

⁴ Ibid.; Kurumety, S.K., Howshar, J.T., & Loving, V.A. (2023). Breast cancer screening and outcomes disparities persist for native American women. *Journal of Breast Imaging*, 5, 3-10.

⁵ American Cancer Society. (2022). *Special section: Cancer in the American Indian and Alaska Native population.* Atlanta: American Cancer Society, Inc.

⁶ U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute, released in June 2024. Screening rates rely on the Behavioral Risk Factor Surveillance System (BRFSS), a yearly survey to collect data on health risk and preventive practices. Underrepresentation of AIAN people is a known limitation of BRFSS data (e.g., Becker et al. (2020). *Limited access to health data on*

⁷ Kurumety et al. (2023).

⁸ Villarroel, M.A., Clarke, T.C., & Norris, T. (2020). Health of American Indian and Alaska Native adults, by urbanization level. *NCHS Data Brief*, *372*.

⁹ Amiri et al. (2022) and Pena et al. (2023).

¹⁰ Emerson et al. (2021); Herbach, E.L., Nash, S.H., Lizarraga, I.M., Carnahan, R.M., Wang, K., Ogilvie, A.C., Curran, M., & Charlton, M.E. (2023). Patterns of evidence-based care for the diagnosis, staging, and first-line treatment of breast cancer by race-ethnicity: A SEER-Medicare study. Cancer Epidemiology, Biomarkers & Prevention: A Publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology, 32(10), 1312–1322;

Further, individuals living in rural and urban areas who are members of federally recognized tribes can receive healthcare services at Indian Health Services (IHS) hospitals and clinics, but the ability of IHS to provide adequate care is hampered by limited funding and geographic dispersion, among other factors, as described in the following section.

Finally, past events related to healthcare malpractice and trauma, as well as the underrepresentation of AIAN healthcare providers at IHS hospitals and clinics and elsewhere, have resulted in long-lasting mistrust among some AIAN communities, which may discourage individuals from seeking preventive care and treatment.¹¹

<u>Landscape of Healthcare Systems and</u> <u>Cancer Control Initiatives for AIAN</u> Women

In this section, we briefly summarize select information about publicly funded healthcare systems, as well as public health initiatives targeting cancer control. These systems and initiatives are relevant to what we learned about breast cancer-related programming for Native American women in Washington and in peer states. Misunderstandings regarding overlapping program eligibility and "payer of last resort" for federal programs present ongoing challenges; we note these issues where relevant.

and Javid, S.H., Varghese, T.K., Morris, A.M., Porter, M.P., He, H., Buchwald, D., . . . Collaborative to Improve Native Cancer Outcomes (CINCO). (2014). Guideline-concordant cancer care and survival among American Indian/Alaskan Native patients. *Cancer*, *120*(14), 2183-2190.

Public Healthcare

Health insurance coverage impacts access to care, including cancer screening, diagnosis, and treatment. According to a 2021 Census report, AIAN adults aged 19-64 have the highest uninsured rate (24.8%) of any racial or ethnic group (the national uninsured rate for adults is 12.2%). A majority of AIAN adults in the U.S. (58.7%) report having public health insurance.¹²

Medicaid. Medicaid provides public health insurance to low-income individuals and is jointly funded by the states and the federal government. Medicaid reimbursement is a major funding source for healthcare services across many settings, including those established to serve AIAN communities.¹³

States determine specific income thresholds for Medicaid eligibility; since 2014, many states have expanded coverage to adults with incomes up to 138% of the federal poverty level. ¹⁴ Eligible AIAN individuals can enroll in Medicaid. Access to care through Indian Health Services—described in the following section—does not impact Medicaid eligibility. Medicaid expansion increased the number of AIAN individuals reporting healthcare coverage. This increase was largest for AIAN women living on or near reservation land. ¹⁵

Health Insurance Program [CHIP]), individual state health plans, and CHAMPVA (Civilian Health and Medical Program at the Department of Veterans Affairs), as well as care provided by the Department of Veterans Affairs.

¹¹ Kurumety et al. (2023).

¹² Branch, B., & Conway, D. (2022). Health insurance coverage by race and Hispanic origin: 2021. *American Community Survey Briefs. ACSBR-012*. The American Community Survey (ACS) public insurance coverage category includes federal programs (such as Medicare, Medicaid, and the Children's

¹³ Kaiser Family Foundation (2024). *Medicaid state fact sheets*.
¹⁴ Ibid

¹⁵ Artiga, S., & Lyons, B. (2016). Medicaid coverage and access to care for American Indians and Alaska Natives under the Affordable Care Act. *JAMA Internal Medicine*, *176*(6), 860-861 and Strully et al. (2024).

Medicaid expansion programs are currently required to cover, without cost sharing, a range of recommended preventive services, including screening mammography at least every two years for women ages 40-74 at average risk for breast cancer and other imaging services as indicated. Although states vary, Medicaid may also cover some post-diagnosis cancer supports such as principal illness navigation.

Indian Health Service and Tribal Healthcare.

The Indian Health Service is a federal agency created in the 1950s to provide primary care services to members of federally recognized tribes. The IHS has twelve regional offices, each of which works with Tribes in their region. Members can receive healthcare at IHS hospitals and clinics located largely on rural reservation land or at Urban Indian Organization (UIO) health clinics. The IHS does not provide insurance coverage or specific healthcare benefits. ¹⁸

The IHS has been consistently funded at an insufficient level to cover the average healthcare costs for the intended population. For example, the federal IHS budget provides annual healthcare expenditures of about \$4,000 per patient compared to a national average of about \$13,500 per patient. Due to these low funding levels, IHS facilities typically cannot provide specialty services like cancer screening and treatments.

Specialty services are contracted to private providers, and AIAN individuals sometimes must travel long distances and face out-of-pocket costs to receive these services. Additionally, the vast majority of IHS's budget is directed to rural facilities, and there are relatively few UIO health clinics, so AIAN individuals living in urban areas often depend instead on insurance coverage for basic healthcare. ²¹

Under the Indian Self-Determination Act, ²² some tribes and tribal organizations assume the management and control of healthcare programs from the IHS to increase flexibility in healthcare program development. Additionally, some tribes manage a Purchased Referred Care program operated by the IHS, which allows tribes to pay for eligible members' healthcare services from private or non-IHS providers when IHS or tribal health facilities cannot meet demand.

Cancer Control Initiatives

Two major federal initiatives currently support grants to states for cancer control through the Centers for Disease Control and Prevention (CDC). All state governments currently receive grants through these programs; CDC funds are the primary and often sole source of program funding. Tribes and tribal organizations are also eligible to apply directly for both grant mechanisms.

¹⁶ Cancer-Related Preventive Health Services for Adults Covered by the ACA | KFF.

¹⁷ Principal Illness Navigation Services | Medicare.gov.

¹⁸ AIAN individuals with only IHS healthcare are considered uninsured in the Census because coverage is not comprehensive (Health Insurance Coverage by Race and Hispanic Origin: 2021).

¹⁹ IHS Profile | Fact SheetsR.

²⁰ GAO-05-789 Indian Health Service: Health Care Services Are Not Always Available to Native Americans.

²¹ Strully, K.W., Chatterji, P., Liu, H., Han, S., & Schell, L. (2024). Effects of Medicaid expansions on coverage, prenatal care, and health among American Indian/Alaska Native Women. *Health Affairs*, *43*(3), 344-353.

 $^{^{\}rm 22}$ The Indian Self-Determination Act is also known as Public Law 93-638, so these contracts are sometimes referred to as a "638 contract."

First, the National Comprehensive Cancer Control Program (NCCCP), initiated in 1998, provides funds, guidance, and technical assistance to help coalitions²³ work together to implement effective and sustainable plans to prevent and control cancer. This program is not specific to breast cancer but plans typically include breast cancer-related objectives. Plans may address a wide range of activities, including reducing environmental risks, education, and survivorship support. There are currently seven tribal NCCCP grantees across the country.

Second, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) was funded through the CDC starting in 1990 to help low-income (at or below 250% of the federal poverty level) uninsured and underinsured women gain access to breast and cervical cancer screening, diagnostic, and treatment services. Grantees can contract or pass-through funds to other organizations to implement the program. Tribes and tribal organizations have been eligible for direct grant funding through this program since 1993. There are currently 13 tribal NBCCEDP grantees across the country.

Additionally, CDC funds can be used to reimburse IHS for NBCCEDP screening services for eligible women; IHS is considered the payer of last resort.²⁴

Under the Breast and Cervical Cancer Treatment Program (BCCTP), uninsured women diagnosed with cancer through an NBCCEDP screening program are automatically eligible to enroll in Medicaid coverage for treatment. In 2021, Congress clarified that this automatic eligibility option also applies to AIAN women, including women eligible for health services through IHS or a tribal organization. Some states require that women be screened through the state's NBCCEDP; others allow Medicaid enrollment for all women who are eligible for the state's NBCCEDP program but diagnosed outside of the program.

Washington's Landscape of Healthcare Systems and Cancer Control Initiatives for AIAN Women

Public Healthcare

In Washington State, uninsurance rates are also high for AIAN individuals relative to other groups, although rates are lower than the national average. Estimates suggest that approximately 16% of AIAN individuals are uninsured, compared with 6.4% of the total population.²⁸

²³ Cancer control coalitions may include a range of stakeholders, including state and tribal government agencies, hospitals, academic partners, public health programs, community groups, professional healthcare provider associations, businesses, and policymakers (National Comprehensive Cancer Control Program. Coalitions. Communities. Commitment.).

²⁴ Summarized in Espey et al. (2014).

²⁵ H. Rept. 106-486 Part 1- BREAST AND CERVICAL CANCER PREVENTION AND TREATMENT ACT OF 1999 - Content Details - CRPT-106hrpt486-pt1.

²⁶ About the National Breast and Cervical Cancer Early Detection Program | NBCCEDP | CDC; French, C., True, S.,

McIntyre, R., Sciulli, M., & Maloy, K.A. (2004). State implementation of the Breast and Cervical Cancer Prevention and Treatment Act of 2000: A collaborative effort among government agencies. *Public Health Reports (Washington, D.C.: 1974), 119*(3), 279–285.

https://doi.org/10.1016/j.phr.2004.04.007

²⁷ In Washington State, women are eligible for the Breast and Cervical Cancer Treatment Program only if screened through the state's NBCCEDP. See Breast & Cervical Cancer Screening & Treatment | Triage Cancer.

²⁸ U.S. Census Bureau, U.S. Department of Commerce. (2023). Selected characteristics of health insurance coverage in the

In Washington, approximately 44% of AIAN individuals report public health insurance, while 57% report holding private insurance coverage.²⁹

Medicaid. In 2014, Washington expanded eligibility for Medicaid coverage to adults with incomes up to 138% of the federal poverty level. Like programs in other expansion states, Washington's program covers recommended breast cancer screenings. Washington requires women to be screened through an NBCCEDP to be eligible for Medicaid coverage of treatment through the Medicaid Breast and Cervical Cancer Treatment Program. States' Medicaid programs are federally required to engage in meaningful consultation and collaboration with Tribal officials.

Indian Health Service and Tribal Healthcare.

There are 29 federally recognized tribes in Washington. Nearly all of these 29 tribes manage their own healthcare, so there are few IHS-run health centers and no hospitals or specialty care clinics supported by IHS in the state. Only 22% of AIAN individuals in Washington report having healthcare through IHS.³³

Washington is home to four IHS clinics and two UIO health centers, mapped in Exhibit 3. An additional UIO serving some Washington residents is located in Portland, Oregon.³⁴ Many tribes operate independent tribal health clinics (not shown in Exhibit 3).³⁵ None of the IHS or UIO providers in Washington or Oregon provide on-site mammograms for breast cancer screening. Of the approximately 30 tribal health clinics where AIAN women may have an established care provider, none offer breast cancer screening or treatment.

One not-for-profit organization—Salish Cancer Center—is run by the Puyallup Tribe of Indians. Located in Western Washington along the I-5 corridor, the Center provides integrative oncology care, including care for breast cancer treatment and support, to the surrounding community. Treatment plans may include Traditional Native Healing, Traditional Chinese Medicine, naturopathic medicine, and medical oncology. Additionally, Salish Cancer Center provides some survivorship support and resource referrals. The Center accepts insurance, including Medicaid and Medicare. 36

United States. American Community Survey, ACS 5-Year Estimates Subject Tables, Table S2701.

²⁹ Health coverage types are not mutually exclusive; individuals could report holding more than one type of insurance. Health insurance coverage rate estimates for AIAN (alone or in combination with other races) and White individuals in Washington State rely on 2023 American Community Survey 5-year Public Use Microdata (HICOV, PRIVCOV, and PUBCOV).

³⁰ Further detail on variation in coverage by plan and service type are outside the scope of this study.

³¹ Individuals screened through either NBCCEDP program in Washington State (Washington DOH or SPIPA) are eligible for this program. According to KFF State Health Facts,

approximately 500 individuals per year enrolled in this program for Medicaid coverage of breast cancer or cervical cancer treatment in Washington from 2019-2021.

³² Centers for Medicare & Medicaid Services (2015). Tribal Consultation Policy.

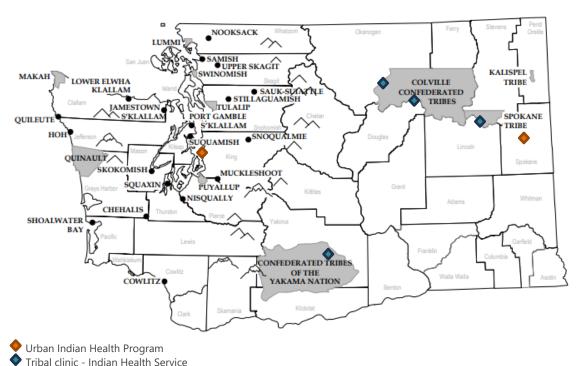
³³ This estimate is for individuals identifying as AIAN alone or in combination with one or more other races in the ACS 5-Year Estimates Public Use Microdata Sample (2023).

³⁴ Washington health plan finder; Tribal Members.

³⁵ Locations of tribal health clinics are available using the Health Care Authority's Tribal Health Clinics map.

³⁶ Salish Cancer Center - Fife, Washington. Summary information regarding Salish Cancer Center is based on information available on their website.

Exhibit 3Federally Recognized Tribes of Washington State and Location of IHS and UIO Clinics



Notes: Base map showing reservation land and federally recognized tribes is available through Washington's Governor's Office of Indian Affairs. We mapped the approximate location of IHS and UIO clinics based on the Washington Health Care Authority's map of Tribes and Tribal Health Clinics in Washington State.

Cancer Control Initiatives in Washington

Washington State's CDC-funded NCCCP and NBCCEDP grants are administered by the Department of Health (DOH). In FY 2023, DOH received approximately \$6.2 million in federal funding for both grant programs combined; most of these funds were for the NBCCEDP.³⁷

Washington's CCCP supports Washington's comprehensive cancer coalition and the development of the Cancer Action Plan of Washington (CAPOW). The coalition, reestablished in 2023, is co-led by a group of public, private, and tribal health organizations.

The coalition is currently working to finalize the 2025-2030 five-year CAPOW. This plan includes several breast cancer-specific objectives, including decreasing breast cancer incidence and mortality rates, increasing 5-year survival rates, and increasing breast cancer screening rates.³⁸ Part of the coalition's role is coordinating efforts and addressing challenges together. The group is in the process of identifying and conducting outreach to engage new coalition members, including members from the AIAN health community. The coalition works with the two NBCCEDP programs in Washington, described in the following paragraphs.

³⁷ Centers for Disease Control and Prevention Fiscal Year 2023 Grants Detail Profile Report for Washington.

³⁸ Washington State 5-Year Strategic Cancer Plan 2025-3030.

The NBCCEDP grant program—the Breast, Cervical, and Colon Health Program—contracts with six regional providers to deliver breast cancer education, mammography and diagnostic services, and access to cancer treatment across the state. Regional contractors may conduct outreach with Tribes as a priority population, along with rural populations.

The South Puget Intertribal Planning Agency (SPIPA) is a non-profit independent tribalorganization holding federal NCCCP and NBCCEDP grants. The agency co-leads Washington's cancer coalition. It also connects five tribes in and around Puget Sound and runs the Native Women's Wellness Program.³⁹ The South Puget Intertribal Planning Agency administers this program, and four tribal clinics deliver services to the community. Activities include education about breast cancer risk and protective factors and the importance of early detection, personalized screening reminders, community education events, and mobile mammography events. The agency contracts with mobile mammography units to provide screening services; patient navigators and providers in tribal clinics register women for screening events and manage scheduling and followup.40

Additionally, through the NCCCP, ⁴¹ the SPIPA hosts tribal cancer survivorship retreats for survivors and caregivers and is working to re-establish survivor support groups post-COVID-19. ⁴² They facilitate information and traditional native healing practices for patients with a diagnosis, as well as financial support for travel to receive treatment. Breast cancer survivorship is a major part of SPIPA's 10-year NCCCP plan. SPIPA received approximately \$1.3 million in federal funding in FY 2023 for both grant programs combined. ⁴³

Successes, Barriers, and Challenges

We met with representatives from both state- and tribal-led programs in Washington to learn about the programming described above. Additionally, in these conversations, we learned about perceived successes, barriers, and challenges to breast cancer care for AIAN women in Washington. In Exhibit 4, we summarize these themes.

³⁹ 2024-2034 SPIPA Tribal Cancer Plan.

⁴⁰ This differs from the Washington State program, where mobile mammography unit teams provide follow-up and referral to care.

⁴¹ A federal NCCCP grant is the primary program funding source, however some program activities are also funded by

small grants through Fred Hutchinson Cancer Center, a National Cancer Institute (NCI)—Designated Cancer Center.

⁴² J. Nikander, Health and Wellness Program Manager, SPIPA, (personal communication, April 10, 2025).

⁴³ Centers for Disease Control and Prevention fiscal year 2023 grants detail profile report for Washington.

Exhibit 4

Successes and Challenges for Breast Cancer Programs for AIAN Women in Washington

What is working well?

- Patient navigation to increase screening in tribal communities has improved screening participation, especially in rural areas. It is most effective at increasing screening to have a familiar person from inside the patients' regular tribal clinic.
- Recent expansion of federal NCCCP supplemental funding to specifically focus on survivorship support has allowed SPIPA to provide more services in this area.

What are the barriers or challenges?

- There are too few mobile mammography (MM) units in Washington to visit tribal communities as often as is wanted. Mobile mammography services, run by hospital groups and private businesses, are largely limited to Western Washington and do not typically reach tribal communities in Eastern Washington due to a range of logistical challenges.
- MM units in Oregon cannot cross state lines, even if they would be the closest screening provider.
- The MM units' minimum number of appointments is prohibitive. A small number of appointments is valuable for the community, but too few for the MM unit to schedule a trip.
- There are gaps in access to diagnostic follow-up after initial screening, especially for remote communities.
- When women must be referred to non-tribal healthcare facilities, the facilities may not share medical information and billing with tribal clinics in a timely manner.
- A higher level of funding is needed for survivorship support. Additionally, federal funding has limitations that sometimes prevent funding cultural practices.
- There are concerns about the accuracy of tribal-specific cancer incidence and prevalence data due to potential racial misclassification. Data sharing between the state and tribes is challenging due to data sovereignty and administrative data systems.

Note:

Source: Personal communication with representatives of Washington's Department of Health, the South Puget Intertribal Planning Agency (SPIPA), the American Indian Health Commission, and the Native American Rehabilitation Association – Northwest.

II. Methodology

This section describes our approach to identifying peer states, conducting outreach, and facilitating interviews to learn about breast cancer programs in other states.

<u>Selecting Peer States</u>

The legislative assignment language stated that WSIPP may identify peer states to conduct its review, using "factors such as the population of American Indian and Alaska Native (AIAN) individuals in the state, number of federally recognized tribes, and whether the state has expanded Medicaid."44 In Washington, about 3% of individuals identify as AIAN as their only race or one of multiple races; there are 29 federally recognized tribes, and the state expanded Medicaid in 2014. We reviewed states with characteristics similar to Washington's and identified 13 states in which to conduct our review of breast cancer programs.⁴⁵

Peer states are comparable to Washington with respect to population and Medicaid expansion. The population identifying as AIAN ranged from 2%-5% across the peer states. Most peer states expanded Medicaid starting in 2014. The number of federally recognized tribes in Washington is relatively high at 29; among this set of peer states, the number is only higher in California, with 107 federally recognized tribes. Arizona and Nevada are the peer states most comparable to Washington, with 22 and 17 federally recognized tribes in the states, respectively.

See Appendix I for additional information about how we selected peer states and state comparisons.

Outreach

We were assigned to focus on programs in peer states that are operated either by the state, tribes, or in coordination between the two. We focused outreach on individuals working in state health departments and healthcare authorities, tribal- or indigenousled organizations, IHS area agencies, and UIOs. We also contacted nonprofits and educational institutions to inquire if they operated or were aware of programs focused on breast cancer education, screening, or post-diagnosis services for Native American women in their region. Many of these initial contacts connected us to other individuals. Whenever possible, we asked staff in state health agencies or IHS area offices with established relationships to introduce us to individuals in tribal organizations and agencies. We supplemented this outreach with internet research on relevant programs in each peer state.

Due to our project timeline, we focused outreach on tribal- or indigenous-led organizations rather than every tribe in each peer state. As a result, we may not be representing all relevant programs operated by tribes in every peer state.

⁴⁴ ESSB 5950, Chapter 376, Laws of 2024.

⁴⁵ Peer states include Arizona, Arkansas, California, Colorado, Idaho, Louisiana, Maine, Minnesota, Nebraska, Nevada, North Carolina, Oregon, and Utah.

Further, since the assignment scope directed us to learn about state- and triballed programs, we did not conduct targeted outreach to organizations like higher education institutions, foundations, or cancer research institutions and, therefore, may be missing relevant programming in these settings.

Interviews

From February through March 2025, we contacted 125 individuals during our outreach phase. Between February and May 2025, we interviewed 23 individuals across 19 organizations (20 unique programs) doing relevant work in 9 of the 13 identified peer states. 46 Program representatives in Arkansas, Louisiana, and Maine did not respond to our inquiries. Exhibit 5 lists the organizations we interviewed. Additionally, 13 organizations submitted a written response only. Six individuals sent detailed answers to our questions about programs, and seven responded that their organization does not conduct intentional outreach with AIAN communities.

We conducted remote "Computer-Assisted Personal Interviews" (CAPI) on Zoom. We displayed questions while talking with interviewees and recorded responses on the computer screen. This strategy allows interviewees to ask for clarification and ensures that we accurately record answers, so data quality for CAPI tends to be relatively high.⁴⁷

We asked interviewees questions about the following topics:

- Program activities: including whether the program focused on breast cancer education, prevention, screening, or post-diagnosis support;
- Program eligibility: including whether the program specifically serves native communities;
- Program administration: service delivery and funding, including whether the program is a collaboration between the state and one or more tribes; and
- Program outcomes: successes, challenges or barriers, and evaluation of program success.⁴⁸

NM, and UT. We categorized this agency as doing work in a peer state.

⁴⁶ Three of the organizations/agencies we spoke with were doing relevant work across multiple states, at least one of which was a peer state. For example, one agency (Navajo Dept. of Health) operates an NBCCEDP grant program for the Navajo Nation, which serves individuals residing in AZ,

⁴⁷ De Leeuw, E., & Nicholls, W. (1996). Technological innovations in data collection: Acceptance, data quality and costs. *Sociological Research Online*, *1*(4), 23-37.

⁴⁸ See Appendix II for the full list of interview questions.

Exhibit 5States and Agencies or Organizations Represented in Findings

State	Agency or organization	Туре
Arizona	Native Health UIO	
Arizona	Navajo Department of Health	Tribal agency
Arizona	Hopi Cancer Support Services	Tribal agency
Arizona	Colorado River Service Unit	Indian Health Service
California	California Rural Indian Health Board	Tribal-led organization
California	California Consortium for Urban Indian Organizations	Indigenous-led organization
California	Department of Health Care Services	State
Colorado	Department of Public Health and Environment	State
Colorado	Denver Indian Health & Family Services	UIO
Idaho	Department of Health and Welfare	State
Minnesota	Department of Health	State
Nevada	Nevada Health Centers	Nonprofit
Nevada	Department of Health and Human Services	State
North Carolina	Department of Health and Human Services	State
Oregon	Native American Rehabilitation Association	Indigenous-led organization
Utah	Department of Health and Human Services	State
Utah	Department of Health and Human Services Office of Native American and Alaskan Native Health and Family Services	State
Multi-state	Great Plains Tribal Leaders' Health Board	Tribal-led organization
Multi-state	American Indian Cancer Foundation	Indigenous-led organization

Notes:

UIO = Urban Indian Organization.

We spoke with two individuals representing two separate programs administered by Idaho's Department of Health and Welfare, hence 19 organizations/agencies listed, representing 20 unique organizations.

The American Indian Cancer Foundation, based in Minnesota, described providing programming in Illinois, Texas, and Kansas. The Great Plains Tribal Leaders' Health Board, based in South Dakota, described providing programming mostly in South Dakota, North Dakota, and Iowa, though some programming is planned for Nebraska.

IV. Findings

This section describes breast cancer programming for native women in Washington's peer states. First, we review the range of models identified by peer states for reaching AIAN women using resources from federal NCCCP and NBCCEDP grants. Second, we review specific interventions and activities aimed at prevention, education, and early detection, many of which were identified as core activities of the grant-funded programs. Third, we review identified supports and resources for women following a breast cancer diagnosis. Finally, we review the evidence base for identified programs.

States' Use of Federal Grants Under Cancer Control Initiatives to Support/Implement Programs

As described in Section I, all states and some tribes or tribal organizations receive federal grant funding to address breast cancer education and early detection for low-income women without health insurance coverage. Many of our peer state contacts represented programs funded fully or largely by these programs through the CDC.

Fifteen organizations reported funding information to us. Most (13) received all or the majority of their funding through the CDC.

As discussed in Section I, tribes and tribal organizations have been eligible to apply for direct NBCCEDP grants from the CDC since 1993. Four of the ten tribal respondents are CDC grant recipients.⁴⁹

In all peer states, departments of health (or equivalent) administer these federal programs. Seven out of ten states we heard from reported specific outreach to tribes through their state NBCCEDP grants to increase screening rates. Among these states with specific outreach, we identified several models for how NBCCEDP grant funds have been used to reach tribal community members. We summarize models and examples in Exhibit 6.

Evidence suggests that outreach funded by NBCCEDP improved access to screening for AIAN women. The rate of AIAN women screened for breast cancer through the NBCCEDP increased from 35% in the five years following program implementation to approximately 50% between 2001 and 2012. The share of those women screened through tribal programs (relative to state programs) increased across that interval, suggesting that the program strengthened local tribal screening capacity. ⁵⁰

Eight of the 13 organizations also received supplemental funding through state appropriations or other sources like tribal funds, donations, and grants. Only two organizations represented in our interviews were entirely funded by the state or through a combination of state appropriations, donations, grants, and tribal funds.

⁴⁹ We did not have the opportunity to interview a program representative from one additional NBCCEDP grant recipient from a peer state, the Fond Du Lac Band in Minnesota. However, we learned about their program through email correspondence and existing public documentation.

⁵⁰ Espy et al. (2014). Strengthening breast and cervical cancer control through partnerships: American Indian and Alaska Native women and the National Breast and Cervical Cancer Early Detection Program. *Cancer, Vol.* 2557-2565.

Exhibit 6Peer State Models for State NBCCEDP Outreach to Tribes

Models	Examples	States
Pass through funds to tribes	Pass-through grant funds go directly to tribes and a UIO to implement the program according to their communities' needs. ⁵¹	Colorado
Collaborate with tribal grantees	The state and tribal grantee programs collaborate by sharing knowledge and cohosting events.	Arizona
Contract or partner with tribal- or IHS-run healthcare	States contract or partner with existing tribal providers and/or UIOs to deliver the state program.	Utah California
Contract with tribal health consultant	A tribal health consultant was contracted to develop and establish new outreach with rural tribal communities. Indigenous expertise facilitated trust within the tribal communities.	California
Contract with non-tribal organizations to deliver program services	zations to deliver organization conducts intentional outreach and	
Direct outreach	The state program conducts some direct outreach to tribes.	

Notes

State NBCCEDP representatives in Oregon, Idaho, and Nebraska communicated that they do not conduct specific outreach to tribes or AIAN women.

<u>Source</u>: WSIPP interviews with states' program representatives.

⁵¹ We interviewed a program provider at the Colorado UIO and describe program activities in the next subsection. We reached out to tribal clinics in Colorado receiving funds through the NBCCEDP, but did not receive a response.

Breast Cancer Prevention, Education, and Early Detection Programming

Most organizations we spoke with focused on preventive screening rather than diagnostic screening or post-diagnosis programming. Programs used a range of activities to increase the enrollment of AIAN women in breast cancer screening, including educational outreach for patients and health professionals, personalized reminders, incentives and gifts, outreach events, mobile units, and patient navigators. We describe these activities below based on the frequency of organizations' reporting.

Exhibit 7 summarizes these activities and notes the number of peer states and organizations reporting each intervention.

Educational Activities for Patients

Most organizations we spoke with provide educational materials about breast cancer risk, protective measures, and screenings, including all NBCCEDP and NCCCP state and tribal grantees.

Tribal- or indigenous-led organizations emphasized the importance of using culturally relevant materials. For example, one organization used traditional talking circles to discuss myths and facts about breast cancer as well as healthcare-related trauma that the community experienced. Several interviewees reported using American Indian Cancer Foundation resources because messages and imagery are relevant to native communities.

One interviewee said that healthcare clinics in the Navajo Nation use materials that have been translated into the Navajo language.

Three interviewees also reported using community health workers who were either health professionals or trained laypeople to provide educational information. Often, these individuals were familiar with or a part of the community they served.

Community Events

Most organizations in peer states described using community events to share information about breast cancer awareness, schedule screenings, connect individuals with health providers, and organize mobile mammography units.

Tribal- and indigenous-led organizations described the importance of creating culturally relevant events centered around food and inviting community members to participate in traditional practices like painting beads, storytelling, making regalia, and holding talking circles. At these events, organizations share information about breast cancer, the importance of regular screenings, and schedule individuals for mammograms. Local physicians sometimes attend and share information as well.

In Oregon, the Native American Rehabilitation Association (NARA) of the Northwest coordinates with a tribe to visit an imaging center and provides screenings to tribal members. NARA explained that if tribes are involved in facilitating these events, it builds more trust in the community, and more people attend.

⁵² Talking circles are an Indigenous practice in which people sit in a circle and pass a talking piece around. The talking piece identifies the person speaking, while others listen.

State-led programs and other organizations reported coordinating or attending health fairs, where various healthcare professionals provide services and information. The organizations we spoke to sometimes schedule screenings for people at these events. We also heard about walkathons or mammogram-specific events scheduled in October, breast cancer awareness month.

In Nevada, the Department of Health and Human Services Women's Health Connection program collaborates with insurance companies and sports teams to get cancer awareness messaging to the public. In Utah, one organization works with the Utah Indian Health Advisory Board to undergo formal consultation agreements with tribes in the state. Throughout the year, the organization staff meets with tribal members to learn what the community needs and, if the tribe invites them, provides breast cancer information.

Educational Activities for Health Professionals

Organizations provide educational information to healthcare professionals. Tribal- or indigenous-led organizations reported providing health professionals with information that included culturally attuned care or information about referral and screening for Native women.

We heard that IHS clinics often do not have providers from their communities, and providers may not always understand the culture of the native population they serve. Staff from the Hopi Tribe's Women's Health Program provide training to local IHS clinic staff to help them understand the needs of the native community.

We were also told that physicians benefit from reminders to share breast cancer information with their AIAN patients. One organization reported connecting with physicians in small and rural communities in Nevada to make sure they were using available mobile units and connecting local community members with its services.

Finally, some interviewees described the importance of training physicians to identify health disparities among AIAN communities and provide trauma-informed care. Several interviewees also mentioned that health clinics should try to hire women and AIAN physicians when possible, as community members will be more likely to trust these individuals and seek preventive care for breast cancer specifically.

Personalized Patient Screening Reminders

Organizations reported providing personalized screening reminders to AIAN individuals so they know when to receive mammograms. All NBCCEDP state and tribal grantees provide patient reminders as part of their services.

Women's Health Check, a screening program operated by Idaho's Department of Health and Welfare, employs local coordinators to enroll women and provide information. The local coordinators play an important role in sending patients screening reminders, ensuring that women are continuously enrolled and receiving services year after year.

Mobile Mammography

Many interviewees described the use of mobile mammography. One organization owns its mobile mammography units. The remaining interviewees described partnering with organizations to schedule services.

Interviewees often reported that tribal clinics, IHS clinics, and UIOs do not have imaging services, and mobile mammography helps fill service gaps.⁵³

The Nevada Health Centers (NHC) owns a mobile unit that travels the state and visits tribes and reservations. The NHC noted that tribal clinic staff schedule with individuals in the community, which builds trust and ensures women use the service. The NHC uniquely described facilitating collaboration between tribes and neighboring rural communities to gather a large enough group of women to meet the minimum number of patients required to contract with a mobile mammography unit. This has required compromise regarding event location (e.g., allowing non-tribal members access to the reservation) and transportation support.

Many of the NBCCEDP grantee organizations we spoke to contract with others who own mobile mammography units to supplement services at tribal health clinics and within tribal communities. The NBCCEDP grantees cover the costs of screenings at the mobile units and some assist with travel costs. For example, the Sage Breast and Cervical Cancer Screening Program in Minnesota works with tribal clinics to connect with the nearest mobile mammography unit and schedule individuals in the local community. This group also convenes a mobile mammography workgroup to identify challenges and find solutions to issues related to mobile mammography in the state. In a comparable example from a tribal health department, the Navajo Department of Health contracts with a partner organization to send mobile units to rural areas and smaller clinics that do not have imaging services.

Mobile Mammography Challenges. Several interviewees reported challenges with mobile units that reflected what we heard in Washington. For example, staffing and maintaining mobile units can be difficult. When contracting, providers often require a minimum number of women to be scheduled and to plan appointments far in advance, which requires appointment reminders. Meeting the minimum number of scheduled appointments can be challenging in less populated communities.

One interviewee highlighted that insurance will only cover one mammogram per year for an individual, which makes it difficult to schedule mobile units, particularly in rural and remote areas, because staff have to track when women were served last and be sure not to offer screenings again within a 365-day window.

Sometimes, mobile units are limited by long distances or state borders. We also heard that post-screening follow-up protocols must be in place if women receive an abnormal result so women have information about the next steps for access to diagnostic services.

program. Since not all tribal-run and IHS clinics have imaging services, they often refer patients to other clinics or receive imaging support from mobile mammography units like those operated by the Navajo Nation.

⁵³ Utah's NBCCEDP state grant program, administered by the Department of Health and Human Services, partners with multiple tribal-run clinics in the state. If the clinics have imaging services, they will refer patients to the state program so that their screenings at the clinic can be covered by the

Gifts for Participation

Most of the organizations we spoke to that provided gifts or incentives to individuals for participating in program activities were tribal- or indigenous-led. Some interviewees described the cultural importance of offering even small gifts to individuals who participate to show respect for their time.

Some organizations reported they cannot provide monetary incentives. Instead, they provide care packages to individuals who get screened, including items like water bottles, menstruation products, self-care products, health and wellness toolkits, or even meals.

Sometimes, gifts were designed to support women's access to care. Several organizations provide individuals with gas cards if transportation to screenings is a barrier. Some organizations provide Amazon gift cards or other financial incentives to individuals who complete mammograms, and one organization handed out calendar magnets so patients can track their next screening.

Patient Navigators

Some organizations reported having patient navigators or some other form of coordinator on staff to support patients up to the point of a breast cancer diagnosis. Typically, patient navigators schedule individuals for screenings and provide patients with referrals if there are abnormal results or diagnoses.

In some organizations, navigators help individuals address barriers, including providing transportation, paying for travel costs, and finding childcare assistance.

Exhibit 7Prevention, Education, and Early Detection Interventions

Interventions identified in interviews	Description	
Educational activities for patients	- Informational materials are used to educate about the risk of breast cancer, protective factors, and the importance of regular screenings. Tribal- and Indigenous-led organizations often use culturally adapted materials. - Brochures, websites, social media, one-on-one conversations, email, newsletters, letters, radio, and magazines to disseminate information.	
Community events	- Events in community spaces like community centers and churches. Programs often coordinate activities that include traditional practices like eating food and storytelling. Programs educate individuals about breast cancer and the importance of screenings. Some events provide screenings.	15 organizations (7 Tribal- or indigenous-led) 9 peer states (AZ, CA, CO, ID, MN, NV, NC, UT, OR)
Educational activities for health professionals	- Educational information for healthcare providers about breast cancer, risks among populations, and how to share information with individuals that is culturally appropriate.	13 organizations (8 Tribal- or indigenous-led) 9 peer states (AZ, CA, CO, ID, MN, NV, NC, UT, OR)
Personalized patient screening reminders	- Reminders are sent to individuals to schedule a mammogram screening. Reminders can be automated or sent manually by program staff or navigators by text message, phone, or letter.	12 organizations (5 Tribal- or Indigenous-led) 9 peer states (AZ, CA, CO, ID, MN, NV, NC, UT, OR)
Mobile mammography	- Mammogram screenings are conducted with a mobile unit. Most organizations contract with other organizations that own a mobile unit. Programs schedule these units to travel to a specific community for mammogram screenings.	12 organizations (5 Tribal- or Indigenous-led) 8 peer states (AZ, CA, ID, MN, NV, NC, UT, OR)
Gifts for participation	- Small gifts to encourage individuals to receive mammogram screenings or as a reward for completing a screening.	7 organizations (4 Tribal- or Indigenous-led) 6 peer states (AZ, CA, CO, MN, NV, OR)
Patient navigators	- Individuals who provide information to individuals about breast cancer risks and screenings. They often help individuals schedule a screening; if an abnormal result is found, they provide information about the next steps.	7 organizations (4 Tribal- or Indigenous-led) 6 peer states (AZ, CO, MN, NV, NC, OR)

Post-Diagnosis Programming

As mentioned earlier, most of the programming we learned about in interviews was concentrated on educating people about breast cancer and the importance of routine screenings. However, several organizations we spoke with offered post-diagnosis services, including treatment navigation, traditional native medicine, and honoring survivors.

Exhibit 8 provides descriptions of these post-diagnosis interventions and the number of peer states and organizations with each intervention.

Treatment Navigation

Some organizations reported providing post-diagnosis care coordination or treatment navigation.⁵⁴

Descriptions of specific activities included ensuring that women with a cancer diagnosis receive referrals to treatment providers and receive support enrolling in Medicaid if needed. One state NBCCEDP program described having a dedicated care coordinator who also connects patients with additional resources, such as caregiver support or wigs. One UIO described that care coordinators may support patients by attending treatment appointments with patients when needed. Another UIO noted that integrative behavioral health staff are embedded in their medical clinic and help with referrals, mental health support, family support coordination, and other needs.

Additionally, organizations provide notebooks summarizing care materials in one place for individuals who do not have internet access. None of these programs was described as specific to native women with breast cancer.

Traditional Native Health Practices

Two tribal organizations indicated that they make traditional native health practices available to patients following a breast cancer diagnosis to honor spiritual, emotional, social, and cultural needs.

One organization provides educational materials on traditional native healing practices, foods, and honoring culture. Another organization gives patients cancer support bags with traditional healing medicines, including sage, cedar, and sweetgrass, prior to treatment appointments.⁵⁵

In 2024, three of our peer states—Arizona, California, and Oregon—and New Mexico received Medicaid waivers to support coverage for traditional healthcare practices. ⁵⁶ These waivers allow traditional health practices to be offered alongside Western medical treatments and to be reimbursed through state Medicaid agencies. Program representatives in peer states did not reference these waivers directly.

⁵⁴ Care coordination and principal illness navigation are distinct reimbursable services through Medicaid. However, organizations did not clearly differentiate roles or activities specific to these titles. Some organizations indicated that they did not submit for reimbursement for either, due to administrative burden. For the purpose of describing support

services and their evidence base, we combine these two categories under treatment navigation.

⁵⁵ Four Sacred Medicines | American Indian Health Service of Chicago, Inc.

⁵⁶ CMS-Approved Waivers Break New Ground for Medicaid Coverage of American Indian and Alaska Native Traditional Health Care Practices - Center for Health Care Strategies

However, we heard from several key informants in Washington—which does not currently have a waiver for coverage of traditional healthcare practices—that being unable to seek reimbursement for these practices is a challenge for breast cancer survivorship care because of the perceived benefit to native communities and individuals.

Honoring Breast Cancer Survivors

We identified two tribal organizations that have offered special events or programs intended to honor and celebrate native cancer survivors. In addition to honoring survivors, these events may raise awareness, reduce misconceptions, and reduce shame or stigma. ⁵⁷ The Fond du Lac Band (Minnesota) brings together survivors and caregivers in an annual Cancer Survivor's Celebration. ⁵⁸ The NARA Northwest in Oregon has used a blanket ceremony to honor breast cancer survivors.

Other Supports and Resources

We inquired about whether organizations provide financial support for travel or treatment, as well as whether they provide support groups or talking circles for native women diagnosed with breast cancer.

As described in the background section, uninsured women diagnosed with cancer through an NBCCEDP screening program can enroll in Medicaid coverage for treatment through the Breast and Cervical

We heard informally and through a review of tribal government websites that some tribes provide members with limited financial support for travel and/or treatment for cancer (not specific to breast cancer). Additionally, one UIO described that they refer patients with a breast cancer diagnosis to two non-profit organizations for financial support.

None of the organizations that we spoke with indicated that they provide support groups or talking circles specific to breast cancer. One state NBCCEDP provides referrals to support groups, including a tribal-led support group specific to breast cancer.⁶¹

One tribal organization developed and hosts a free web-based platform using culturally aligned imagery and language to connect and coordinate cancer survivors, caregivers, and broader support systems.⁶²

Cancer Treatment Program (BCCTP). While all states fund this Medicaid eligibility program, only one organization in California explicitly shared information with us about it. ⁵⁹ California was also unique in describing the use of Indian Health Care Providers (IHCPs) who conduct outreach and assist AIAN individuals with BCCTP program enrollment.

⁵⁷ Burhansstipanov, L., & Olsen, S.J. (2004). Cancer prevention and early detection in American Indian and Alaska Native populations. *Clinical Journal of Oncology Nursing*, 8(2), 182-186.

⁵⁸ Underwood, J.M., Lakhani, N., Finifrock, D., Pinkerton, B., Johnson, K.L., Mallory, S.H., Migliore Santiago, P., & Stewart, S.L. (2015). Evidence-based cancer survivorship activities for comprehensive cancer control. *American Journal of Preventive Medicine*, 49(6 Suppl 5), S536–S542.

⁵⁹ California's BCCTP program covers costs for breast cancer treatments like surgery, chemotherapy, radiation, and follow-up care for eligible individuals.

⁶⁰ J. Olson, Consultant, American Indian Health Commission, (personal communication, February 4, 2025); Cancer Support Services - The Hopi Tribe.

⁶¹ Fond du Lac Human Services - Community Health Cancer Services

⁶² The American Indian Cancer Foundation (AICAF) is an NBCCEDP and NCCCP tribal grantee.

Exhibit 8Post-Diagnosis Interventions

Interventions identified in interviews	Description	Implementation frequency
Treatment navigation	- Care coordinators or individuals who help patients navigate treatment if they receive a diagnosis. Supports include referrals to treatment providers, assistance enrolling in Medicaid, and information about mental health and caregiver support.	6 organizations (3 tribal-or indigenous-led) 5 peer states (AZ, CO, MN, NC, OR)
Traditional native medicine	- Providing educational information about traditional health practices and foods, and supplying traditional medicines like sage, cedar, and sweetgrass to patients undergoing treatment.	2 tribal-or indigenous-led organizations. 1 peer state (OR)
Honoring breast cancer survivors	- Events or programs that honor and celebrate native cancer survivors. Events can also be used to raise awareness about breast cancer, reduce misconceptions, and reduce shame or stigma.	2 tribal-or indigenous-led organizations. 2 peer states (MN, OR)

<u>Summary of Evidence for Identified</u> <u>Programs</u>

This section summarizes evidence about the effectiveness of each program or practice identified in peer states. Where available, we use the Community Preventive Services Task Force's (CPSTF) findings for cancer prevention and control as our starting point. ⁶³

The CPSTF designates programs as recommended (sufficient evidence), recommended (strong evidence), insufficient evidence, or recommended against. Interventions with *strong* or *sufficient* recommendations indicate that CPSTF is confident the intervention has beneficial effects based on information from study designs, the number of studies, and reported effects.⁶⁴ Interventions with "insufficient" designations mean that studies did not have enough evidence to determine effectiveness and that additional information is needed. Interventions with "recommended against" designations indicate that studies show evidence that the program is harmful or not effective. 65

For programs that have not been evaluated using the CPSTF framework, we conducted a rapid evidence review.⁶⁶

In addition, for each program category, we summarize findings from rapid evidence reviews on the state of evidence for breast cancer programming within AIAN communities. For each intervention, we indicate if we found any evaluations of identified programs or practices specific to AIAN communities and if the evidence indicates program effectiveness. We did not find evidence regarding program effectiveness for AIAN communities for three intervention categories.⁶⁷

Prevention, Education, and Early Detection Programs

Exhibit 9 summarizes findings on evidence of effectiveness for prevention, education, and early detection programs.

Educational Activities for Patients. CPSTF reviewed programs focusing on breast cancer education interventions for patients.

Group and one-on-one interventions

include health professionals or trained lay people who provide information to patients, either one-on-one or in groups, about signs of breast cancer, the importance of screenings, and ways to reduce barriers like transportation or costs. CPSTF indicates there is evidence supporting the use of both group education and one-on-one interventions.

⁶³ Summary CPSTF Findings Table for Cancer Prevention and Control | The Community Guide. Established by the U.S. Department of Health and Human Services, the CPSTF is an independent panel of public health and prevention experts that issues evidence-based recommendations and findings on public health interventions, based on systematic reviews of evidence.

⁶⁴ The magnitude of effects and quality of research determines whether evidence is considered "strong" vs "sufficient". The Community Guide website, Methods Manual Part 1: Effectiveness Review Methods.

⁶⁵ The Community Guide website. *Understanding CPSTF Findings and Recommendations*.

⁶⁶ Garrity, C., Gartlehner, G., Nussbaumer-Streit, B., King, V.J., Hamel, C., Kamel, C., Affengruber, L., & Stevens, A. (2021). Cochrane rapid reviews methods group offers evidence-informed guidance to conduct rapid reviews. *Journal of Clinical Epidemiology, 130*, 13-22. See Appendix III for details on our evidence review protocol.

⁶⁷ Educational activities for health professionals, personalized screening reminders, and gifts for participation.

Mass- and small-media interventions

include using television, radio, newspapers, magazines, billboards, videos, letters, brochures, and newsletters to disseminate information about breast cancer and motivate individuals to get screened. CPSTF reports insufficient evidence for mass media interventions but strong evidence for small media interventions.

Community health workers are trained health professionals or lay people who act as liaisons between a healthcare system and a community and are typically from or familiar with the communities they serve. They provide information to communities related to breast cancer awareness and screening and may help reduce structural barriers to screening. CPSTF reported strong evidence for this intervention.

We identified studies that focus on providing education interventions to AIAN populations specifically, though the quality of research studies varies. Several studies examined the use of one-on-one educational materials delivered by community health workers and found evidence to suggest the program increased mammography screening rates among participants. Another study focused on the use of educational materials written in the Navajo language and found that individuals who received these materials were more likely to get screened compared to women who received materials in English only. 69

Other qualitative research indicates that educational outreach may increase screenings among native women, but the quality of these findings is limited by their research designs.⁷⁰

We also identified several feasibility studies examining the use of an app-based education program and a telemedicine program to deliver breast cancer awareness and screening information to native communities. Both studies reported that users supported the interventions as approaches for disseminating information.⁷¹

Community Events. CPSTF reviewed group education interventions and found sufficient evidence to support these approaches. The National Cancer Institute's Evidence-Based Cancer Control Program (EBCCP) has also reviewed several programs, including The Witness Project, Life is Precious, Friend-to-Friend, and Targeting **Cancer in Blacks (TCiB)**, which generally include gathering people in communitybased settings like churches or community centers, providing food and culturally relevant activities, and sharing information about breast cancer and screenings, sometimes with health professionals. EBCCP reports that all of these interventions increase mammogram screenings among participants.

⁶⁸ Burhansstipanov et al. (2000) and Dignan et al. (1998).

⁶⁹ Sinicrope et al. (2020).

 $^{^{70}}$ Orians et al. (2004) and vonFriederichs-Fitzwater et al. (2010).

⁷¹ Roh et al. (2023) and Pruthi et al. (2013).

We identified two studies that reported the effects of community events to provide breast cancer education and screenings among native women.⁷² These interventions included events that had culturally and linguistically tailored activities and health information, brought community members together to get screened, and assisted with things like transportation and scheduling. The reports' authors indicate that the programs increased knowledge about breast cancer and screenings among participants and increased the likelihood of getting a mammogram screening. The studies are qualitative in nature and did not include comparison groups, so results should be interpreted cautiously.

Educational Activities for Health
Professionals. CPSTF reviewed one
intervention focused on **provider**assessment and feedback, including giving
health providers feedback on how they are
providing breast cancer screenings. CPSTF
reports there is sufficient evidence for this
intervention.

The National Cancer Institute's Evidence-Based Cancer Control Program has also reviewed the **Empowering Physicians to Improve Breast Cancer Screening (EPICS)** program. This program uses an educational curriculum to increase primary care physicians' efforts to encourage women to receive mammogram screenings. EBCCP reports evidence from one study showing that this program increased screenings among women whose physicians received the educational materials compared to women who received regular reminders as usual.

CPSTF reviewed one intervention focused on **client reminders**. Client reminders are written or telephone messages that inform individuals they are due for a mammogram screening. Sometimes, these reminders are tailored to reduce barriers to screening and may offer scheduling assistance. In CPSTF's review, client reminders include those tailored to specific individuals and general reminders to a larger target audience. CPSTF reports strong evidence for the use of client reminders.

Mobile Mammography. CPSTF and EBCCP have not evaluated mobile mammography as an independent intervention. CPSTF included mobile mammography within its broader review of interventions to **reduce structural barriers for clients**. These interventions aim to reduce barriers to breast cancer screenings by reducing the time it takes clients to get to a health center, changing service hours to meet client needs, offering mobile mammography, and offering scheduling assistance and support for transportation and translation services. CPSTF reports strong evidence for interventions that reduce barriers.

While we did not identify any studies examining the impact of mobile mammography among AIAN women specifically, we did find one study that analyzed what factors predict the use of mobile mammography services. To One study, which analyzed the use of mobile mammography, reported that AIAN race was a stronger predictor of the use of mobile services than any other measured demographic, geographic, socio-economic, or medical characteristic.

Personalized Patient Screening Reminders.

⁷² Chilton et al. (2013) and English et al. (2008).

⁷³ Pelzl et al. (2025).

Gifts for Participation. CPSTF reviewed evidence related to client incentives, which include small rewards like cash or coupons that motivate people to get screened. CPSTF found insufficient evidence for the use of these types of incentives but did find sufficient evidence for the use of interventions that reduce out-of-pocket costs for patients, which include things like offering vouchers, reimbursements, or insurance coverage for screenings.

Patient Navigators. CPSTF reviewed patient navigation services, which often focus on supporting historically disadvantaged communities and include client reminders, reducing structural barriers, and helping reduce out-of-pocket costs. CPSTF finds strong evidence for the use of patient navigators. A meta-analysis also found that women supported by patient navigators were 32% more likely to get screened for breast cancer than those without a navigator.

One study estimated the relative benefits of patient navigation support for AIAN women when offered in person versus by telephone. Authors reported that women in both treatment arms experienced increased screening rates but suggest that services over the telephone may be more convenient for women in rural areas where traveling to clinics or having a navigator visit may be more challenging.

Another literature review of patient navigation programs for native women found positive results, such as increased screening adherence and fewer treatment delays. The However, the authors indicate some researchers did not statistically control for differences between women in treatment and comparison conditions, and therefore, other factors besides patient navigation may explain results.

NBCCEDP Grantee Work. Of the 18 organizations or agencies we spoke to, 12 were state or tribal NBCCEDP grantees. CPSTF conducted a review of multicomponent interventions for breast cancer, much of which encompasses NBCCEDP components. CPSTF reports strong evidence for the use of multicomponent interventions.

We identified several studies that examined the implementation of the NBCCEDP program or multicomponent interventions among AIAN communities. Three studies focused on how the NBCCEDP program was implemented by tribal organizations and examined the challenges and successes the organizations or tribes experienced. These studies reported that mammography screening rates increased after program implementation. The Studies were qualitative in nature and often based on case studies, surveys, and focus groups.

⁷⁴ Dignan et al. (2005).

 $^{^{75}}$ Whop et al. (2012).

 $^{^{76}}$ Brown et al. (2011); Espey et al. (2014); and Lantz et al. (2003).

NBCCEDP activities are focused on prediagnosis breast cancer supports and services, while BCCTP focuses on covering treatment costs post-diagnosis; we examined research on the Breast and Cervical Cancer Treatment Program (BCCTP). Some research reports that the program increases the likelihood of enrollment into Medicaid, decreases the time between diagnosis and enrollment, and increases the likelihood of receiving treatment.⁷⁷

However, one national study reported that state adoption of the BCCTP did not impact the time to treatment for breast cancer but was associated with a decrease in the probability of initiating treatment within 60 days of a cervical cancer diagnosis. Additionally, one recent study reported that BCCTP participants have shorter survival rates compared to others with pre-existing insurance. The authors suggest that lower survival rates may be related to barriers to care and more limited surveillance after treatment. We did not identify any research examining the impact of the program specifically for AIAN populations.

for breast cancer through the BCCTP. Post-treatment surveillance was the only care domain that was not as good or better than a benchmark sample.

 $^{^{77}}$ Adams et al. (2009) and Adams et al. (2012). Both of these studies are specific to Georgia.

⁷⁸ Lantz & Soliman (2009).

⁷⁹ Nelson et al. (2020). One additional California study by Malin et al. (2010) found high care quality for women treated

Exhibit 9Evidence Summary: Prevention, Education, and Early Detection Interventions

Intervention identified in interviews	Relevant interventions (CPSTF & EBCCP)	# Peer states implementing	Community guide evidence rating (increased screening rates) ^a	Evidence for AIAN
	Group education	10 (and WA)	Sufficient (5.5-24 pp)	Educational materials by community health workers may
	One-on-one education	10 (and WA)	Strong (2-14 pp)	encourage screenings.
Educational activities for	Mass media	7 (and WA)	Insufficient	Materials in Native languages
patients	Small media	10 (and WA)	Strong (0.3-13 pp)	can be more effective at disseminating information.
	Community health workers	3	Strong (10-30 pp)	App-based and telemedicine programs are effective ways to share information.
	Group education	10 (and WA)	Sufficient (5.5-24 pp)	Events with culturally and linguistically tailored activities and health information can increase knowledge about screenings, and increase the likelihood of receiving a screening.
	Friend to Friend	0	N/A – EBCCP review	
	Life is Precious	0	N/A – EBCCP review	
Community events	Targeting Cancer in Blacks (TCiB)	0	N/A – EBCCP review	
	The Witness Project	0	N/A – EBCCP review	
Educational activities for health professionals	Provider assessment and feedback	2	Sufficient (6-22 pp)	
	Empowering Physicians to Improve Breast Cancer Screening (EPICS)	0	N/A – EBCCP review	No identified studies
Personalized patient screening reminders	Client reminders	9 (and WA)	Strong (3-19 pp)	No identified studies
Mobile mammography	Reducing structural barriers for clients	9 (and WA)	Strong ^b	No studies evaluated the impact of mobile mammography alone. One study found that AIAN race strongly predicts mobile service use.

Exhibit 9 (Continued)

Evidence Summary: Prevention, Education, and Early Detection Interventions

Intervention identified in interviews	Relevant interventions (CPSTF & EBCCP)	# Peer states implementing	Community guide evidence rating (increased screening rates) ^a	Evidence for AIAN
	Client incentives	6 (and WA)	Insufficient	
Gifts for participation	Interventions to reduce out-of-pocket costs	6 (and WA)	Sufficient (6-29 pp)	No identified studies
Patient navigators	Patient navigation services	6	Strong (12-55 pp)	Patient navigation in person and over the telephone are both effective, but telephone services may be better for serving women in rural areas. Some evidence of an association between patient navigation and increased screening rates and fewer treatment delays.
NBCCEDP grantee work	Multicomponent interventions	9 (and WA)	Strong (6-63 pp)	Some evidence of higher screening rates when individuals receive NBCCEDP services.

Notes:

^a If the program was reviewed by the Community Preventive Services Task Force (CPSTF), we indicate CPSTF's evidence rating (e.g., strong, insufficient). Parentheses include the reported impact on mammogram screening rates (in percentage points) Information is "N/A" if evidence review was conducted by the National Cancer Institute's Evidence-Based Cancer Control Program (EBCCP).

^b CPSTF did not review the effect of mobile mammography alone, so we omit the percentage point change.

Post-diagnosis Programs

During our interviews with peer state organizations, we were told about two main types of post-diagnosis supports: Treatment navigation and traditional native health practices. Since the CPSTF and EBCCP primarily focus on cancer prevention and do not provide summary statements on the effectiveness of post-diagnosis interventions, we reviewed published metanalyses and systematic reviews to summarize research from other sources. 80,81

Exhibit 10 summarizes findings on evidence of effectiveness for post-diagnosis activities.

Treatment Navigation. We identified two systematic literature reviews addressing the effectiveness of navigation following an abnormal breast cancer screening result⁸² and two recent reviews on treatment navigation for cancer (including breast cancer).⁸³ Additionally, the Patient Navigation Research Program (PNRP) has reported meta-analytic results from a large multi-site evaluation.⁸⁴ These reviews included over two dozen studies, and most were conducted with low-income, uninsured, or underinsured women.

Higher quality research provides evidence that navigation improves time to diagnosis, time to treatment, and post-treatment surveillance mammography. There is less evidence of benefits with respect to treatment adherence and time to treatment completion. Studies included in these reviews did not allow for subgroup analyses on the effectiveness of navigation for AIAN women with breast cancer.⁸⁵

Although there is limited research on the effectiveness of treatment navigation for AIAN women diagnosed with breast cancer, navigation has been viewed as a valuable approach for AIAN cancer patients. Several studies, including two major National Cancer Institute-funded studies of native patient navigation, have demonstrated promising findings. These demonstrations include AIAN women diagnosed with breast cancer but are not breast cancer-specific. Findings suggest that native treatment navigation is associated with a higher likelihood of a diagnosis within one year, 86 a shorter time to treatment initiation, 87 and fewer treatment interruptions. 88 One report that focused specifically on breast cancer patients reported an improved likelihood of treatment that allows for breast conservation.89

⁸⁰ The National Cancer Institute's list of Evidence-Based Cancer Control Programs (EBCCP) does include several programs aimed at breast cancer survivorship or supportive care. These programs were web-based educational interventions for women following breast cancer diagnosis, and did not align with activities described by organizations in peer states.

⁸¹ See Appendix III for details on our evidence review

⁸² Baik et al. (2016) and Robinson-White et al. (2010).

⁸³ Chen et al. (2024) and Roland et al. (2017).

⁸⁴ Battaglia et al. (2016); Ko et al. (2014); and Ko et al. (2016).

⁸⁵ Most studies did not include a large enough sample of AIAN women for subgroup analysis. The PNRP was implemented at one site primarily serving an AIAN community. However, data sharing agreements prevented the inclusion of data from this site from being included in the aggregate dataset (as cited in Battaglia et al. 2016).

⁸⁶ Warren-Mears et al. (2013).

⁸⁷ Burhansstipanov et al. (2014).

⁸⁸ Guadagnolo et al. (2011) and Petereit et al. (2008).

⁸⁹ Petereit et al. (2016).

Consistent with findings from two early review papers, 90 conclusions from the research on native treatment navigation remain limited by methodology. As a whole, though, existing research suggests that AIAN community members may view culturally tailored post-diagnosis navigation as an acceptable intervention. This practice may build trust with healthcare providers and thus reduce barriers to treatment. 91

Traditional Native Health Practices. Our search for systematic reviews or metaanalyses in this area returned two reviews that included interventions consistent with what we heard in peer-state interviews. 92 This review identified no quantitative research on traditional native medicine and health outcomes. However, several qualitative studies of AIAN cancer survivors suggest that incorporating culture into conventional Western cancer care and health providers' respect for integrating traditional native healing and medicine may reduce barriers to treatment and contribute to greater satisfaction with cancer treatment.93 These findings were not exclusive to individuals receiving treatment for breast cancer.

Notably, a recent report by the National Council of Urban Indian Health summarized the views of UIO communities that empirical research tracking health outcomes associated with sacred traditional healing practices may not be appropriate.⁹⁴ Honoring Breast Cancer Survivors. We did not identify any studies examining the impact of honoring cancer survivors in the general population or among AIAN women. We reviewed one study that recommended honoring cancer survivors in the context of community education, based on a qualitative study of the needs of AIAN women cancer survivors.⁹⁵

Finally, while we described other postdiagnosis supports and resources like financial support for travel or treatment earlier, these activities are not included in our evidence review because interviewees did not describe them in enough detail to identify the intervention or because they were singular examples.

⁹⁰ Neither of these reviews was specific to breast cancer. Eschiti et al. (2012) and Whop et al. (2012).

⁹¹ Belkora et al., (2009); Guadagnolo, Cina, et al. (2011); and Petereit et al. (2011).

⁹² Gall et al. (2018). Our search returned a number of systematic reviews and meta-analyses of complementary or traditional medicine as a supplement to conventional treatment. However most reports focused on Traditional Chinese Medicine, or else encompassed interventions such

as yoga, mindfulness, and homeopathy, among other approaches.

 $^{^{93}}$ Hohl et al. (2016); Itty et al. (2014); and McKinley et al. (2020).

 ⁹⁴ National Council of Urban Indian Health (2023). Recent trends in third-party billing at Urban Indian Organizations: Thematic analyses of traditional healing programs at Urban Indian Organizations and meta-analysis of health outcomes.
 ⁹⁵ Burnette et al. (2019).

Exhibit 10Evidence Summary: Post-Diagnosis Interventions

Intervention identified in interviews	Overall research evidence	# Peer states implementing	Evidence for AIAN
Treatment navigation	High-quality research indicates that post-diagnosis navigation improves the time to diagnosis and treatment and post-treatment surveillance.	5	Several studies suggest that native patient navigation is associated with a higher likelihood of diagnosis, lower time to treatment, and fewer treatment interruptions for cancer treatment in general. Breast cancer treatment navigation is associated with a higher rate of breast conservation. Qualitative research suggests AIAN individuals like post-diagnosis navigation, which may build trust and reduce barriers.
Traditional native health practices	Systematic reviews or meta-analyses did not include quantitative analysis of these interventions.	1 (and WA)	Qualitative studies suggest that incorporating cultural values in cancer care and health providers' respect for traditional native healing may reduce barriers to cancer treatment. Findings were not specific to breast cancer. Empirical research using health outcomes associated with sacred and highly personal traditional health practices may not be appropriate.
Honoring breast cancer survivors	No identified studies	2	One qualitative study found that honoring cancer survivors in the context of community education would meet needs related to community support for their experience.

IV. Conclusions and Limitations

Based on learning from the nine peer states represented in our summary, we identified a range of state-led, Tribal-led, and collaborative efforts to improve breast cancer screening rates and health outcomes for AIAN women. Programs are largely supported by federal funds through NBCCEDP and NCCCP grants and utilize a common set of evidence-based activities. All peer states deliberately providing programming for AIAN women described the importance of partnerships between state and tribal government agencies, healthcare systems, and private organizations.

Most organizations we spoke with offered education and screening programming for all women, not just for AIAN women. This was true for state programs and UIO clinics serving their communities. Peer states use a wide range of models to prioritize and ensure the delivery of screening services to AIAN women.

Although our assignment was specific to breast cancer, multiple informants emphasized that **coordinating preventive healthcare services can increase community interest and participation**. For example, when mobile mammography events *also* offer women an opportunity to address heart health, diabetes, and/or cervical cancer screening, participation in all preventive care opportunities increases.

In contrast to prevention/early detection programs, we identified few programs in peer states providing support or resources to AIAN women following a breast cancer diagnosis. This may be a result of identifying NBCCEDP grantees for outreach in each state, which focused our sample toward prevention/early detection programs.

Alternatively, these findings may accurately reflect the state of the field. Survivorship care is fragmented, and there are gaps in this area. There is ongoing work to develop and implement national standards. For example, the National Cancer Institute (NCI) recently offered supplemental grants to support the assessment and enhancement of survivorship care. Findings of the state of the state

Additionally, relevant post-diagnosis supports for AIAN women with breast cancer may be present in cancer treatment settings that were outside of WSIPP's assignment scope because they are not state- or tribal-led organizations. For example, the Huntsman Cancer Institute at the University of Utah—an NCI-designated Cancer Center—hosts American Indian Patient Navigators who provide a range of support to patients and families.⁹⁸

This may be particularly important in rural areas where community members have difficulty visiting providers due to travel time and cost.

⁹⁶ Mollica, M.A., McWhirter, G., Tonorezos, E., Fenderson, J., Freyer, D.R., Jeffort, M., et al. (2024). Developing national cancer survivorship standards to inform quality of care in the United States using a consensus approach. *Journal of Cancer Survivorship*, *18*, 1190–1199.

⁹⁷ National Standards for Cancer Survivorship Care | Division of Cancer Control and Population Sciences (DCCPS)

⁹⁸ American Indian Patient Navigators | Huntsman Cancer Institute | University of Utah Health. We note that Washington's Fred Hutch Cancer Center is developing an Indigenous Cancer Health Equity Initiative to build capacity in this area.

In general, we observe that current federal funding for cancer control supports the work of organizations to fill gaps in state efforts to address social determinants of cancer prevention, while services after diagnosis are approached as biomedical issues and are therefore left to state Medicaid programs, private insurers, and cancer treatment centers to address.

The education, prevention, early detection, and post-diagnosis interventions we learned about in peer states are also offered in Washington, though services for AIAN women are concentrated in Western Washington. WSIPP could complete a more detailed analysis of current services, regional access, and program barriers and strengths in Washington if directed to do so.

During our interviews, we learned about several policy-relevant approaches in peer states that we did not hear about in Washington.⁹⁹ Examples of these approaches are included in Exhibit 11.

Several study limitations should be noted. First, this report does not comprehensively account for all programs and practices in peer states. We report only on information volunteered by our contacts or documented online. Although we connected with some tribal health organizations (10 groups total in 4 states), we did not receive a response from everyone. The duration of WSIPP's assignment allowed limited time for relationship building, which may have particularly impacted response rates from tribal health organizations. Tribal-led programs may be underrepresented in our report as a result.

⁹⁹ Although informants in Washington did not identify these strategies in our conversations, we cannot definitely state that they do not occur in Washington.

Second, we identified little research from which to summarize evidence of the effectiveness of programs and practices specific to AIAN communities. A robust body of evidence supports the overall effectiveness of most of the prevention programs and practices we identified. Although it is possible that such activities would be equally effective for AIAN communities, we are not able to definitively draw this conclusion, and note that existing research may under- or over-estimate program effectiveness. Further, it is possible that additional nuance or adaptations should be identified to implement programs for AIAN communities effectively. For example, we heard from several interviewees about the importance of cultural activities at both community education and screening events.

Finally, this report summarizes breast cancer-related programming identified in peer states during early 2025. Many interview participants, as well as those who declined to be interviewed, described uncertainty regarding future federal funding for healthcare and public health. Most of the programs described in this report currently rely fully or partially on federal funding. Changes to funding for the CDC's National Center for Chronic Disease Prevention and Health Promotion (housing the NBCCEDP and NCCCP), Medicaid, or IHS would impact the availability of these programs in peer states and Washington.

Exhibit 11

Examples of Policy or Structural Approaches in Peer States, Not Identified in Washington

State mobile mammography workgroup: The Sage Breast and Cervical Cancer Screening Program in Minnesota convenes a mobile mammography workgroup with the American Indian Cancer Foundation, mobile providers in the state, and tribal health clinics. This group discusses challenges and barriers to providing mobile services and brainstorms solutions. The group also identifies organizations in the state that may be interested in hosting mobile mammography units in their communities.

Locating mobile units to maximize access: The Nevada Health Centers, which operates its own mobile mammogram units, aims to locate mobile units in places that can serve both tribal and non-tribal community members. For example, non-tribal members living just outside a reservation may not have access to a unit parked on the reservation. Nevada Health Centers described parking the unit in locations that can serve everyone, working to gain agreements for non-tribal members to access the reservation, and supporting with transportation. They also described alternating locations between a reservation and the neighboring community town hall so tribal and non-tribal members can all be served.

Further, we heard in Washington about the challenge of mobile units crossing state lines and serving communities across borders. This may be due to state regulations or insurance requirements. However, we learned that the Sage Breast and Cervical Cancer Screening Program in Minnesota has been able to contract with the closest mobile units—even if this unit is across a state line—so that they can more easily serve a community.

Passing through funds to tribes: Colorado's Department of Public Health and Environment (CDPHE) has a long-established relationship with tribes and a UIO in the state. CDPHE distributes a portion of its funding to tribes and the UIO through a state grant. This strategy allows tribes and the UIO to manage funds as they see fit and carry out CDPHE's cancer prevention and early detection program in a way that meets the specific needs of their communities.

State program contracts with tribal-or IHS-run healthcare or health consultant: Utah's Breast & Cervical Cancer Program has strong partnerships with tribal-run and IHS clinics in the state that deliver program services to native communities. For example, tribal and IHS clinics do not always have imaging services on site so they refer patients to clinics with this technology and connect patients with the program, which covers screening costs. The interviewee we spoke with explained that the state's Primary Care Association has been a champion of identifying and building new partnerships in the state. The association works with Federally Qualified Health Centers to support clinics, increase equity, and reduce barriers, particularly for underserved and uninsured native communities.



Breast Cancer Programs for Native Communities in Washington's Peer States

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I. Selecting Peer States

Legislative language indicated that WSIPP can identify peer states using factors like the population of American Indian and Alaska Native (AIAN) individuals in the state, the number of federally recognized tribes, and whether the state has expanded Medicaid. ¹⁰⁰ We first reviewed these indicators for Washington and then searched for states with similar characteristics. Table 1 depicts the 13 peer states we identified.

American Indian and Alaska Native Population

About 3% of individuals in Washington identify as AIAN (either their only race or as one of multiple races). ¹⁰¹ We included states with similar populations of AIAN individuals, between 2% and 5% of the population, as potential peer states.

Medicaid Expansion Status

Medicaid expansion refers to states' option to expand Medicaid coverage to adults with incomes up to 138% of the federal poverty level. Medicaid is a major source of funding for healthcare services across many settings. ¹⁰² Individuals who identify as AIAN may be served in the general Medicaid population, as well as in Indian Health Services settings that Medicaid funds also support. Medicaid expansion has increased the number of AIAN women reporting healthcare coverage, particularly for women living in areas with a relatively high percentage of reservation land. ¹⁰³ Washington expanded its Medicaid program in 2014. We consider states that have adopted expansion to be peers. ¹⁰⁴ Three states that met our AIAN population criteria (Kansas, Wisconsin, and Wyoming) have not expanded Medicaid and, therefore, were eliminated from our list of peer states.

¹⁰⁰ ESSB 5950.

¹⁰¹ ACS Demographic and Housing Estimates, 5-year estimates. Table DP05, 2023.

¹⁰² Kaiser Family Foundation website. Medicaid State Fact Sheets.

¹⁰³ Artiga & Lyons (2016). Medicaid coverage and access to care for American Indians and Alaska Natives under the Affordable Care Act. *JAMA Intern Medicene*, *176*(6), 860–861; Strully et al. (2024). Effects of Medicaid expansions on coverage, prenatal care, and health among American Indian/Alaska Native women. *Health Affairs*, *43*(3), 344-353.

¹⁰⁴ Status of State Medicaid Expansion Decisions, Kaiser Family Foundation.

Federal-and State-Recognized Tribes

We also considered the number of federally recognized and state-recognized tribes associated with each state. In Washington, there are 29 federally recognized tribes and no state-recognized tribes. The number of tribes residing in each state varies widely, but most states have few. Among the states we initially considered peers, many had fewer than ten federally recognized tribes. To avoid further reducing the pool of peer states, we decided not to use this criterion to determine peer status. During outreach to states, we prioritize learning from states that met our initial AIAN population and Medicaid expansion criteria, as well as states with a higher number of tribes, as this is more similar to Washington's landscape.

Exhibit AISummary of 13 Peer States Identified to Review Breast Cancer Programs

% AIAN in state ^a	Medicaid expansion year ^b	# of federally- and state-recognized tribes ^c
Washington (3%)	2014	29 (federal)
Arizona (5%)	2014	22 (federal)
Arkansas (2%)	2014	0 (federal)
California (2%)	2014	107 (federal)
Colorado (2%)	2014	2 (federal)
Idaho (2%)	2020	4 (federal)
Louisiana (2%)	2016	4 (federal), 11 (state, no overlap with federal tribes)
Maine (2%)	2019	6 (federal)
Minnesota (2%)	2014	12 (federal)
Nebraska (2%)	2020	4 (federal)
Nevada (2%)	2014	17 (federal)
North Carolina (2%)	2023	1 (federal, 8 (state, 1 overlaps with federal)
Oregon (3%)	2014	9 (federal)
Utah (2%)	2020	5 (federal)

Notes:

^a ACS Demographic and Housing Estimates, 5-year estimates. Table DP05, 2023.

^b Status of State Medicaid Expansion Decisions | KFF

^c Tribal Leaders Directory | opendata-1-bia-geospatial.hub.arcgis.com

¹⁰⁵ Tribal Leaders Directory | opendata-1-bia-geospatial.hub.arcgis.com

II. Interview Protocol

Introduction

[We started each interview with individual introductions]

We'll start by introducing our organization and our purpose here.

WSIPP is a non-partisan research organization. We conduct public policy research at the direction of the WA State legislature and summarize our findings in publicly available reports. The legislature uses our work to inform policy-making, but we do not advocate or make recommendations.

We reached out to you to learn about <u>breast cancer prevention efforts and post-diagnosis supports and resources for native communities</u>. Decision makers in our state are interested in <u>what programs are working well</u> in similar states to improve health for native communities, specifically with respect to breast cancer.

We understand that you work on or know about a program in <<STATE>> that is operated by the state, tribes, or in collaboration, and addresses either:

- Breast cancer education or prevention for native communities; OR
- Supports or resources after a breast cancer diagnosis for native community members

We'd like to ask you questions about that program. To make sure we understand your answers, we'd like to share the screen with our questions and notes, so that you can review all of our notes. We will not record audio or video of this conversation.

We have about 15-20 questions that we'd like to ask about your program during our scheduled time. You are welcome to let us know if there are any questions you would prefer not to answer. Finally, please let us know if there are questions that do not make sense or fit your context. This type of feedback will be valuable for us to continue learning.

Questions

Program type

- 1. State
- 2. Contact Type
 - State government
 - IHS (federal govt)
 - Tribal clinic
 - Urban Indian Organization clinic
 - Academia
 - Other (specify)
- 3. Interviewee initials
- 4. What is the program name?
- 5. What is the focus of this program?
 - Breast cancer education, prevention, or early detection
 - Post-diagnosis supports or resources
 - Both

Education, prevention, early detection programs (IF INDICATED)

- 6. Which of the following activities does the program include?
 - Educational materials regarding breast cancer risk or protective factors
 - Educational materials regarding regular screening for early detection of breast cancer
 - Personalized screening reminders
 - Gifts for participation
 - Community event
 - Providing imaging services in a tribal-run clinic
 - Mobile mammograms
 - Educating health professionals about culturally attuned care
 - Educating health professionals about referral and screening
 - Other (please describe)
- 7. What formats are used for educational outreach?
 - Letter
 - Phone call
 - Email
 - Text message
 - Brochure/pamphlet
 - Website/social media
 - Local media (radio/television)
 - Magazine
 - Person to person
 - Other (specify)
- 8. What formats are used for personalized screening reminders?
 - Letter
 - Phone call
 - Email
 - Text message
 - Person to person
 - Other (specify)
- 9. Please tell us more about how gifting works in your program?
- 10. Please describe the community event.
- 11. Please tell us more about providing imaging services in a tribal-run clinic.
- 12. Please describe how the mobile mammogram program works.
- 13. Please tell us more about how you educate health professionals.

Post-diagnosis supports or resources (IF INDICATED)

- 14. Which of the following activities does the program include? [select all that apply]
 - Traditional native healing practices
 - Care coordination
 - Principle illness navigation
 - Financial support for treatment
 - Financial or other support for travel
 - Support groups
 - Other (please specify)
- 15. Is there anything more you can share with us about providing traditional native healing practices after a breast cancer diagnosis?
- 16. Please tell us more about how care coordination after a breast cancer diagnosis in your program.

- 17. Please tell us more about how principal illness navigation after a breast cancer diagnosis works in your program.
- 18. Is there any detail you can share with us about the program's financial support for treatment after a breast cancer diagnosis?
- 19. Is there any detail you can share with us about the program's financial or other support for travel after breast cancer diagnosis?
- 20. Please tell us more about your program's support groups after a breast cancer diagnosis.

Program description and eligibility

- 21. Is this program:
 - Specifically for native communities
 - For native communities and other groups
 - Other (specify)
- 22. This program primarily serves:
 - Rural communities
 - Urban communities
 - Both rural and urban communities
- 23. How is eligibility for the program determined (select all that apply)
 - Tribal enrollment
 - American Indian/Alaska Native people (self-identified)
 - Age
 - Medicaid/Medicare eligibility
 - Income
 - Place of residence
 - Risk of breast cancer
 - No eligibility requirements
 - Other (specify)

Program funding and operation

- 24. How is the program funded?
 - State, federal, tribal, other
 - [For each source, is the funding: Primary, secondary, tertiary, other, unknown]
- 25. Where relevant, name the specific funding source
 - State
 - Federal
 - Tribal
 - Other
- 26. Who administers the program (entity in charge of policy, funding, materials, staff)?
- 27. Who delivers program services?
- 28. Is the program a collaboration between the state and one or more Tribes?
- 29. [If yes to 28] What role does the state play? What role do Tribes play?

Program evaluation

- 30. What's working well?
- 31. What are challenges or barriers?
- 32. Has your organization done any work to look at your program's effectiveness, however you define success. What can you tell us about that work?

Is there anything we did not ask that you think we should know about?

III. Evidence Review: Method and Bibliography

WSIPP was directed to summarize any available research on programs identified in peer states. We aimed to summarize general evidence on effectiveness and to identify—and summarize, where available—any population-specific evidence for AIAN women.

We utilized the following strategies to collect research for review:

- 1) We included relevant program evaluations, systematic reviews, and meta-analyses identified while completing standard background research for this study.
- 2) For general evidence regarding intervention effectiveness, where possible, we rely on relevant existing systematic evidence reviews in the Community Guide, published by the Community Preventive Services Task Force (CPSTF), 106 and the research evaluating relevant programs listed in the National Cancer Institute's Evidence-Based Cancer Control Programs (EBCCP) database. We reviewed EBCCP programs listed under Breast Cancer Screening and Follow-up to Screening.
- 3) Because the CPSTF and EBCCP focus largely on prevention, we could not rely on their evidence reviews for general evidence of the effectiveness of post-diagnosis programs. 107 Instead, we conducted rapid evidence reviews for the three categories of supports and resources identified in our interviews. We focused on existing meta-analyses and systematic reviews where available.
- 4) To identify any available population-specific research for each intervention, we reviewed all references in each relevant CPSTF summary and EBCCP listing.
- 5) Additionally, for each intervention, we also completed a population and topic-specific search using Google Scholar.
- 6) Finally, to improve the likelihood of collecting all available population-specific research, we conducted an additional systematic search for evaluations of interventions related to breast cancer for AIAN women.

The section below provides more detail on search strategies 3, 5, and 6. Finally, we include a bibliography of studies summarized in Section III of this report. We do not reproduce the CPSFT and EBCCP bibliographies in this report. However, in Exhibit 9, we provide direct links to their reviews.

this listing were consistent with the post-diagnosis resources and supports that we identified in peer state interviews.

¹⁰⁶ The CPSTF is an independent, nonfederal panel of public health and prevention experts.

¹⁰⁷ The EBBCP include a category for Survivorship / Supportive Care Evidence-Based Programs. However, none of the programs in

Search Strategies

3) General evidence for post-diagnosis resources and supports (not population-specific)

Database: Google Scholar

Search string structure: ("breast cancer") AND ("[intervention name]") AND ("review" OR "meta")

Screening process:

- Review title and abstract of first 100 results; review full text if indicated
- Retain meta-analyses or systematic reviews
- Retain original evaluation studies if no meta-analyses or systematic reviews

General inclusion/exclusion criteria:

- Include studies of treatment or complementary treatment
- Exclude studies focused on screening mammography
- Include studies focused on treatment for breast cancer exclusively or cancers including breast cancer
- Exclude studies that do not include breast cancer patients

Topic	Search string	Additional limiters
Treatment navigation	("breast cancer") AND ("navigation" OR "coordination" OR "navigator") AND ("review" OR "meta")	Include studies published in 2010 or later
Traditional medicine	("breast cancer") AND ("traditional medicine" OR "plant medicine" OR "indigenous medicine" OR "complementary medicine") AND ("review" OR "meta")	Exclude studies with only non-US samples Exclude studies specific to Traditional Chinese Medicine Include studies published in 2010 or later
Honoring survivors	("breast cancer") AND ("honor" OR "honoring" OR "celebrate" OR "celebrating" OR "celebration" OR "blanket") AND ("review" OR "meta")	Include studies published in 2010 or later

5) Population-specific evidence by topic

Database: Google Scholar

Search string structure: ("breast cancer") AND ("[intervention names]") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Native American" OR "Native Women" OR "Indigenous")

Screening process:

- Review title and abstract of first 50 results; review full text if indicated
- Retain meta-analyses, systematic reviews, and original evaluations

General inclusion/exclusion criteria:

- Include studies focused on treatment for breast cancer exclusively
- Exclude studies that do not include breast cancer patients
- The included date range varies and depends on when the CPSTF review was published

Topic	Search string	Additional limiters
Educational activities for patients	("breast cancer") AND ("group education" OR "one-on-one education" OR "indigenous medicine" OR "mass media" OR "small media" OR "community health worker") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")	Include studies published in 2000 or later
Educational activities for health professionals	("breast cancer") AND ("education for physicians" OR "provider assessment" OR "provider feedback" OR "provider education") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")	Include studies published in 2008 or later
Personalized screening reminders	("breast cancer") AND ("gifts" OR "client gifts" OR "patient gifts" OR "incentive" OR "participation gifts" OR "participation incentive") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")	Include studies published in 2008 or later
Gifts for participation	("breast cancer") AND ("gifts" OR "client gifts" OR "patient gifts" OR "incentive" OR "participation gifts" OR "participation incentive") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")	Include studies published in 2005 or later
Community events	("breast cancer") AND ("community event" OR "health fair" OR "event" OR "community" OR "gathering" OR "screening") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous").	Include studies published in 2000 or later
Mobile mammography	("breast cancer") AND ("mobile mammography" OR "mobile screening" OR "mammography" OR "mobile") AND ("American Indian" OR "Alaska Native" OR	Include studies published in 2000 or later

	"Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous").	
Patient navigation	("breast cancer") AND ("navigation" OR "coordinator " OR "navigator" OR "coordination") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous").	Include studies published in 2014 or later
National Breast and Cervical Cancer Early Detection Program and/or other multicomponent interventions	("breast cancer") AND ("national breast and cervical cancer early detection program " OR "multicomponent intervention" OR "intervention") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous").	Include studies published in 2000 or later
Treatment navigation	("breast cancer") AND ("navigation" OR "coordination" OR "navigator") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")	Include only studies published in 2000 or later
Traditional medicine	("breast cancer") AND ("traditional medicine" OR "plant medicine" OR "indigenous medicine" OR "complementary medicine") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")	Exclude studies with only non-US samples Exclude studies specific to Traditional Chinese Medicine Include only studies published in 2000 or later
Honoring survivors	("breast cancer") AND ("honor" OR "honoring" OR "celebrate" OR "celebrating" OR "celebration" OR "blanket") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")	Include only studies published in 2000 or later

6) Population-specific intervention research related to breast cancer

Databases: Google Scholar, MedLine, PsychInfo, Cochrane Library (Trials)

Search string: ("breast cancer") AND ("American Indian" OR "Alaska Native" OR "Tribal" OR "Tribe" OR "Native American" OR "Native Women" OR "Indigenous")

Search limiters:

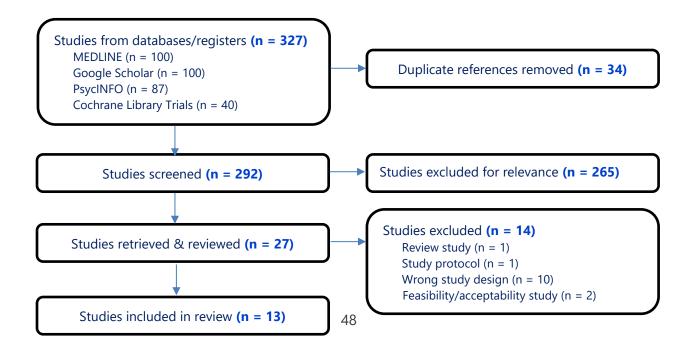
- Search terms in "All Text" or "Anywhere"
- Peer reviewed
- Publication date 1/1/2000 through 4/16/2025

Search and screening process:

- Retain the first 100 results from Google Scholar, MedLine, and PsycInfo, and all results from the Cochrane Library (Trials)
- Integrate results in Covidence
- Review the title and abstract for relevance; review the full text of all relevant studies
- Retain original intervention evaluation studies
- Search citations of meta-analyses or systematic reviews
- Designate studies by specific intervention types

General inclusion/exclusion criteria:

- Include quantitative intervention evaluation studies
- Include qualitative intervention evaluation studies
- Exclude quantitative evaluations with no comparison group
- Exclude descriptive or correlational studies
- Include studies focused on breast cancer exclusively or cancers including breast cancer
- Exclude studies that do not include breast cancer patients



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Education activities for health professionals (AIAN population-specific)

No research specific to AIAN populations found.

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No research specific to AIAN populations found.

Gifts for participation (AIAN population-specific)

No research specific to AIAN populations found.

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No relevant meta-analyses, systematic reviews, or evaluation studies found.

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