South Puget Intertribal Planning Agency

Native Women's Wellness Program

Provider and Patient Navigators Manual

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Introduction

Welcome to the Native Women’s Wellness Program (NWWP):

Welcome to the Native Women's Wellness Program (NWWP). The purpose of this manual is to summarize the program's various components as they pertain to the roles and responsibilities within each of the consortium tribal clinics. The NWWP intended to reduce breast and cervical cancer mortality among women in the Chehalis, Nisqually, Shoalwater Bay, Skokomish, and Squaxin Island Tribes through culturally appropriate outreach, education, and preventive screening services.

The NWWP has been a part of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), funded by the Centers for Disease Control and Prevention (CDC), since 1994.

Thanks to grants from the CDC and private foundations, the NWWP is committed to providing comprehensive breast and cervical cancer screening services for eligible women. These services include mammograms, clinical breast exams, pelvic exams, HPV testing, and Pap tests. We also cover diagnostic services. While the NWWP does not pay for cancer treatment, we are dedicated to helping women connect with other resources for treatment coverage.

The NWWP not only pays for the outreach supplies and incentives necessary to recruit women for screenings but also invests in staff training and ongoing education. We believe a well-trained and informed staff is crucial to our program's success.

Both Native American and non-Native women are eligible for the program according to each tribal clinic's protocol. Women are eligible for NWWP services if they meet the following criteria:

- **Live within the service areas of one of the five Tribes**
- **Have a household income equal to 250% or less of the Federal Poverty Level**
- **Are not covered by Medicaid**
- **Are 18 years of age or older**

The NWWP is centrally administered by SPIPA. The SPIPA NWWP staff includes the Health and Wellness Manager, Native Women’s Wellness Program Coordinator, Data and Systems Coordinator, Outreach Liaison, and Quality Assurance Advisor. The SPIPA staff is responsible for securing funding for the program, reporting to the funders, maintaining screening data, paying medical claims, managing the budgets, and overseeing and providing technical assistance and direction to the program.

The NWWP provides direct services at the tribal level and pays for a partial full-time equivalent Provider and a Patient Navigator at each Tribe. The Provider is responsible for screening women and providing one-on-one patient education and case management. The Provider works with the Patient Navigator to complete the necessary data using screening and diagnostic forms. The Patient Navigator is responsible for recruiting women for screening, including one-on-one patient education, sending screening reminders, organizing community education events and program promotion, maintaining the patient's clinical data, and providing data to SPIPA.

Background:

Breast cancer is the most diagnosed cancer and the second leading cause of death among women in the United States. The early detection and treatment of breast and cervical cancer through preventative screenings reduces mortality rates and greatly improves cancer patients' survival. However, there is a disproportionately low rate of screening among women of racial and ethnic minorities and under- or uninsured women, which creates a wide gap in health outcomes between these women and other women in the United States. The goal is to decrease cancer incidence, morbidity, and mortality by focusing on our tribal population, who have increased cancer risk due to health disparities.

The Native Women's Wellness Program (NWWP) provides breast and cervical cancer screening and diagnostic services for women of the consortium's tribes. The NWWP is centrally located in Shelton at the South Puget Intertribal Planning Agency (SPIPA). NWWP is one of 13 Tribal organizations across the US receiving funding from NBCCEDP to support a comprehensive breast and cervical cancer early detection program.

Purpose and Goals:

The Native Women's Wellness Program (NWWP) aims to reduce the burden of breast and cervical cancer among Native women by providing access to high-quality screening and diagnostic services. Our specific goals are:

- To increase the number of Native women who receive regular breast and cervical cancer screenings.
- To ensure timely follow-up and diagnosis for women with abnormal screening results.
- To educate the community about cancer prevention and early detection.
- To reduce cancer disparities among Native women by addressing social determinants of health.

Program Overview:

The NWWP is made up of nine program components as defined by the NBCCEDP. The strategy for each component is outlined in the annual work plan, developed collaboratively by the NWWP Program Manager, Coordinator with each clinic's navigator and director before the start of the program year. Each clinic workplan goals are then integrated into the overall workplan for the NWWP. With each year's funding request, the work plan is submitted to the CDC and serves as the primary program management tool. The work plan guides the program’s priorities, ensuring that activities are executed within the program year to meet established objectives, track performance indicators, and allocate resources efficiently. It also provides a framework for monitoring progress and adjusting to meet both clinic-specific and overall program goals.

The nine components include:

1. **Community Education and Outreach:** The purpose of public health education activities is to increase the rate of screening among women in the consortium tribal clinics and ultimately to decrease morbidity and mortality from breast and cervical cancer. Education efforts should include an appropriate mix of general community awareness-raising, community-based education and outreach, and one-on-one outreach strategies.
2. **Screening:** Screening, tracking, follow-up, and case management focus on early detection of cancer or precancerous lesions and timely intervention. Regular testing through mammography, Pap smears, and HPV tests is conducted in line with clinical standards for breast and cervical cancers.
3. **Tracking and Follow-Up:** These activities ensure women return for testing at recommended intervals and receive appropriate diagnostic and treatment services following abnormal results or diagnoses. A robust data management system is important for effective tracking and follow-up.
4. **Case Management:** Case management develops and sustains a network of clinical and support services for women in the program. Effective case management ensures that those with abnormal cancer results or diagnoses receive appropriate and timely diagnostic and treatment services.
5. **Coalitions and Partnerships:** Coalitions and partnerships aim to improve the program's ability to screen and rescreen women by building a network with outside services, resources, and opportunities. This network supports public and professional education and improves patient access to services.
6. **Professional Education:** Professional education targets healthcare providers and program staff to increase their knowledge, attitudes, and behaviors, with the goal of raising the number of women screened appropriately. This includes training professionals to perform their duties competently and promoting a health care system that achieves positive clinical outcomes.
7. **Quality Assurance:** Quality assurance ensures that NWWP clients receive timely, high-quality breast and cervical cancer screening and appropriate follow-up for abnormal screening results.
8. **Management:** Management creates, implements, and sustains a program that complies with NBCCEDP policies and procedures. It involves developing a comprehensive, effective, and efficient program with adequate staffing.
9. **Surveillance and Evaluation:** Surveillance involves collecting, analyzing, and interpreting health data for program planning, implementation, and evaluation while ensuring the timely sharing of de-identified data with relevant stakeholders. The evaluation assesses the program's operations and outcomes compared to set standards, aiming to improve quality and efficiency.

Program Objectives:

The goal of the SPIPA Native Women's Wellness Program (NWWP) is to reduce the incidence and mortality of breast and cervical cancer among women in the tribal consortium. This is achieved through regular cancer screening, timely follow-up of abnormal results, and ensuring that women diagnosed with cancer receive appropriate treatment. The program also aims to address health disparities by focusing on underserved populations who are at higher risk for these cancers.

Specific objectives include:

- **Screening the Priority Population:** A minimum of 35% of all NBCCEDP-reimbursed cervical cancer screenings should be provided to program-eligible women who have never been screened for cervical cancer or have not been screened within the past 10 years.
- **Ensure Complete and Timely Diagnostic Follow-up:**
    - **Breast Cancer:** 100% of abnormal mammograms, abnormal clinical breast exams (CBE), or diagnostic workups planned for breast cancer must have a complete work-up with a diagnostic procedure and a final diagnosis recorded (allowing for up to 10% refusal or loss to follow-up).
        - The time between an abnormal mammography result and final diagnosis must be less than 60 days, with no more than 25% taking longer than 60 days.
    - **Cervical Cancer:** 100% of abnormal Pap tests must have a complete work-up with a diagnostic procedure and a final diagnosis recorded (allowing for up to 10% refusal or loss to follow-up).
        - The time between an abnormal Pap test result and final diagnosis must be less than 60 days, with no more than 25% taking longer than 60 days.
- **Ensuring Timely Initiation of Treatment for Diagnosed Cancers:**
    - **Breast Cancer:**
        - For records showing a final diagnosis of in situ or invasive breast cancer, 100% must show that treatment was initiated (allowing for up to 10% refusal or loss to follow-up).
        - The time between a final diagnosis of breast cancer and initiation of treatment must be less than 60 days, with no more than 20% taking longer than 60 days.
    - **Cervical Cancer:**
        - For records showing a final diagnosis of CIN II, CIN III, CIS, or invasive cervical cancer, 100% must show that treatment was initiated (allowing for up to 10% refusal or loss to follow-up).
        - The time between diagnosis of CIN II, CIN III, CIS, or invasive cervical cancer and initiation of treatment must be less than 60 days, with no more than 20% taking longer than 60 days.

- **Providing Education and Outreach:** Raise awareness about breast and cervical cancer prevention and early detection through culturally appropriate education and outreach initiatives. Ensure that educational materials and outreach efforts are accessible and relevant to the target populations.
- **Developing Partnerships:** Form partnerships with healthcare providers and community organizations to enhance service delivery and support. Collaborate with local health departments, tribal health organizations, and other stakeholders to ensure comprehensive care.
- **Ensuring Culturally Appropriate Services:** Tailor program services to be culturally appropriate and accessible to all eligible women. Address cultural barriers to care and ensure that services are respectful of and responsive to the community's cultural needs.

Grant Requirements

The CDC grant for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) covers various services, including screening and diagnostics, staff salaries and benefits, clinical and medical supplies, program supplies, limited local mileage, and staff training travel. Supplemental funding from additional grants may also support the program.

SPIPA is responsible for overseeing data tracking, case management, and quality assurance to ensure the appropriate medical services are provided, which is essential for maintaining funding. The grant is renewed annually based on performance indicators and service delivery outcomes. The grant year runs **from July 1st to June 30th of the following year**.

Funding Sources:

The Native Women's Wellness Program (NWWP) operates under the primary funding of the CDC's National Breast Cervical Cancer Early Detection Program (NBCCEDP) grant, which significantly influences program operations. NBCCEDP funds are allocated primarily for staff salaries and clinical services for eligible patients. The grant also covers program supplies, outreach materials, administrative costs (capped at 10%), and training and administrative travel for program staff. Additionally, a **$3: $1 match** is required, meaning that for every $3 of grant funding received, the recipient must contribute $1 from other sources, which may include additional funding, in-kind contributions, or other resources.

Refer to the current NWWP Fee Schedule for a detailed list of covered services. For more information on CDC program requirements, consult the NBCCEDP program and data manuals. Additional grants may provide funding for program activities, each with distinct reporting requirements and restrictions.

Grant Compliance Guidelines:

Complying with grant requirements is crucial for maintaining funding, achieving program goals, and serving our communities effectively. Compliance is a shared responsibility between SPIPA program staff and partner clinic staff. Below are the essential guidelines:

Understanding the Grant Requirements:

Every team member must be familiar with the specific requirements of the grant(s) funding the program. This includes objectives, allowable costs, reporting requirements, and deadlines.

Documentation and Record-Keeping:

Maintain detailed records of activities, expenses, and participant interactions, including:

- Attendance logs for events and training sessions.
- Detailed expense reports with receipts.
- Records of outreach efforts, including contacts made and materials distributed.
- Data from pre- and post-assessments conducted during outreach events.

Reporting:

Timely and accurate reporting is critical. Reports should include:

- Progress on meeting grant objectives.
- Financial reports detailing expenditures and remaining funds.
- Summaries of outreach activities and outcomes.
- MDE and annual clinic data.
- Challenges encountered and strategies used to overcome them.
- Updates on partnerships and collaborations.

Compliance with Federal, State, and Tribal Regulations:

Ensure all activities comply with relevant laws and regulations, including HIPAA, to protect patient confidentiality.

Continuous Monitoring and Evaluation:

Review program activities regularly to ensure compliance and identify areas for improvement. This includes internal audits, feedback from participants and partners, and assessment of program goals.

Training and Capacity Building:

Provide ongoing training for staff and volunteers on grant guidelines, documentation, and reporting best practices. Regular updates on grant changes and capacity-building activities are essential to maintain program effectiveness.

Communication and Collaboration:

Foster open communication between all stakeholders, including grantors, tribal leaders, staff, and community members, to ensure alignment with program goals and grant compliance.

Data Collection and Usage:

Implement secure systems for data collection, storage, and analysis. Use data to demonstrate program impact and guide future planning and grant applications while complying with privacy laws and respecting cultural sensitivities.

Audit Preparedness:

Maintain up-to-date records and ensure all documentation is easily accessible and well-organized in preparation for potential audits.

Addressing Non-Compliance:

In the event of non-compliance, take immediate corrective action, including revising procedures, providing additional training, or communicating with grantors to resolve the issue.

By following these guidelines, we can ensure the program operates smoothly, meets its goals, and continues to receive the necessary funding to serve our communities effectively.

Reporting Obligations:

Minimum Data Elements (MDEs): The CDC requires MDEs to monitor screening performance. Each MDE record tracks a screening cycle through follow-up on abnormal findings, diagnostic evaluation, and treatment initiation. The CDC's **CaST (Cancer Screening**

and Tracking) database is used to track women screened for breast and cervical cancer. CaST supports patient-level screening and follow-up data collection and enables the creation of MDE files submitted twice a year. SPIPA utilizes this data to improve screening results and clinic processes.

Budget Management:

Patient Navigators, in coordination with clinic managers and program coordinators, must ensure that spending adheres to grant guidelines. Monthly expense reports detail available funds for outreach activities. Navigators must understand spending guidelines, interpret budgets, and submit necessary paperwork for purchases, reimbursements, and travel expenses.

Patient Confidentiality:

HIPAA guidelines and basic medical ethics require that patient information be kept confidential. Access to patient records is restricted to individuals directly involved in providing, tracking, or paying for medical services. NWWP enrollees sign an Informed Consent form allowing SPIPA to share their information. SPIPA and tribal clinics follow strict HIPAA protocols, with training provided to ensure compliance.

At SPIPA, all medical records are stored securely under lock and key or in password-protected databases. Patient information is de-identified for CDC reporting to ensure privacy.

Balancing Grant Compliance and Tribal Sovereignty:

Our program strives to balance adherence to federal grant requirements with preserving tribal sovereignty. While federal grants, like those from the CDC, have strict guidelines, we work to ensure that program operations align with grant requirements and our communities' unique needs. This involves advocating for flexibility, maintaining compliance, and fostering collaboration between tribal and federal entities. Through these efforts, we respect tribal sovereignty while ensuring continued funding and program success.

This approach ensures that we uphold our sovereignty while effectively managing and implementing our grant-funded programs.

Reporting Requirements

Reporting is a critical component of maintaining CDC compliance and demonstrating the effectiveness of the **Native Women's Wellness Program (NWWP)**. The program must submit Minimum Data Elements (MDEs), track program success, and fulfill performance indicators outlined by the CDC. All forms and documentation must be complete, timely, and in compliance with CDC reporting standards.

Minimum Data Elements (MDEs):

MDEs are essential patient demographics and clinical information used to track performance. These elements provide the data needed for the CDC to evaluate screening and diagnostic service delivery. The NWWP must report these MDEs regularly to track progress and ensure that objectives and performance indicators are being met.

Informed Consent:

- An **Informed Consent** form must be signed before every screening to ensure eligibility for NWWP coverage. The form explains eligibility criteria and outlines the client's financial responsibility for services unrelated to breast or cervical cancer screening. It also informs patients about the use of their medical information.
- This form must be submitted alongside the **NWWP Screening Services Form** or within 30 days of service.

NWWP Screening Services Form:

- The **Screening Services Form** is used to document all screenings, including mammography, Clinical Breast Exams (CBE), pelvic exams, and Pap/HPV tests.
- The top portion of the form can be completed by the patient, Medical Assistant, or the Patient Navigator. Providers are responsible for completing required fields after tests are performed and signing and dating the form.
- Test results and follow-up recommendations must be documented on this form and submitted to SPIPA within 30 days of receiving the results.

NWWP Breast and Cervical Diagnostic Forms:

- **Diagnostic Forms** must be completed for any diagnostic services required after a screening. This includes documentation of test results and recommended follow-up.
- Providers are responsible for ensuring that patients and NWWP are notified of the results and must track cases of "Lost to Follow-up" or "Work-up Refused."
- Forms must be submitted within 30 days of receipt of diagnostic results.

Managing the Tribe's NWWP Outreach Budget:

Patient Navigators, with the Clinic Director and NWWP Coordinator, manage the outreach budget within the spending guidelines of each active grant. It is required to review monthly expense reports and ensure that expenditure aligns with available funds.

Grant Spending Guidelines:

The **CDC grant** covers screening and diagnostic costs, staff salaries and benefits, supplies, and training travel. Additional funding may come from supplemental grants, which may also have their own reporting requirements.

Reading the Expense Reports:

Expense reports provide details on spending by category and track the amount budgeted, spent, and remaining for each line item. Patient Navigators must understand how to interpret these reports, including identifying negative balances (amounts in parentheses) and ensuring that spending remains within budget.

SPIPA Accounting Paperwork:

Patient Navigators must submit all program-related expenditures to SPIPA for payment. This includes:

- **SPIPA Purchase Requisitions** for supplies, educational materials, mileage, and other costs.
- **Travel Authorization Forms** and **Expense Reports** for travel-related costs.

All purchases must be supported by receipts, invoices, or other documentation. For travel, expenses such as airfare, lodging, and per diem must be documented and submitted post-trip.

Outreach Tracking and Reports:

Effective outreach is crucial to the success of the NWWP. Patient Navigators are responsible for tracking their outreach activities and reporting them to SPIPA monthly. To enhance compliance and tracking of outreach efforts, all outreach activities must be documented and reported to the CDC as part of the grant's reporting obligations. Each outreach event must include:

- **Pre- and Post-Assessments**: These assessments are important for measuring participant knowledge before and after outreach efforts and provide valuable insights into the effectiveness and impact of the education event. They help identify areas where more education is needed for the community. To ensure the program’s continued success and data-driven decision-making, it is required to have one pre- and post-assessment during each program year.
- **Community Wellness Survey (CWS)**: This survey helps track community needs and assesses the effectiveness of outreach efforts. Participation is encouraged by offering incentives, such as up to three $100 raffle prizes.

Note: When planning events that include the Community Wellness Survey (CWS), it’s important to consider setting a cap on the number of events to avoid overspending on incentives. The total number of CWS responses will vary depending on the size of the community, with an annual target of 50-150 responses per tribe.

- **General Event Incentives:**
    - $25 per person for events with approximately 30 attendees.
    - Up to $15-20 per person for events with 30-50 attendees.
    - Up to $10-15 per person for events with more than 50 attendees.

- **Outreach Activity Logs**: Document the number of participants, types of services provided, and materials distributed during the event.
- **Participant Demographics**: Collect information on the population reached to ensure alignment with program goals.
- **Follow-up Reports**: Any follow-up actions or services provided after outreach events should also be documented.

Patient Navigators must also submit their data to the **Outreach Activities Survey Link** for tracking by SPIPA. The outreach database monitors outreach effectiveness, client follow-ups, and the results of community events.

Collaboration and Intertribal Navigator Meetings:

Collaboration among **Tribal Patient Navigators**, the Program Coordinator, and other NWWP staff is critical to the program's success. Monthly **intertribal navigator meetings** are held to share updates, plan outreach, and discuss budgetary and operational concerns. Attendance at these meetings is required, as they foster information sharing and strategy development.

Medical Advisory Board Meetings:

In addition to navigator meetings, quarterly **Medical Advisory Board (MAB) meetings** are held with Women's Health Care providers, clinic administrators, and SPIPA staff to address clinical and programmatic strategies. These meetings take place centrally in Olympia and aim to coordinate broader program initiatives.

Working with Tribal Clinic Staff and Protocol Compliance:

Patient Navigators are employees of the Tribe, not SPIPA, and must adhere to **Tribal policies and protocols**. It is essential to develop close working relationships with the **Tribal Women's Health Care Provider** and clinic staff to ensure the smooth operation of the NWWP.

Patient Navigators may help with scheduling screenings, case management, or program events with clinic staff. Navigators should be aware of any Tribal-specific protocols regarding event planning, spending, and public relations. **Tribal policies** take precedence over SPIPA guidelines, and Navigators must work closely with their supervisors at the clinic to ensure compliance.

Referral and Fee Schedule:

Women referred out of clinic for screening or diagnostic services must be documented using the referral form. Ensure that all referrals meet the eligibility requirements for inclusion in the NWWP.

Form Submission:

All materials should be scanned and submitted through **Verifyle**, a secure data-sharing system to protect patient confidentiality. Each navigator has their own secure login. To sign up for Verifyle, please get in touch with our data manager for enrollment in this communication method.

If Verifyle is not an option, hard copies should be placed in sealed envelopes marked "confidential" and either hand-delivered, mailed to NWWP/SPIPA, or sent via fax to the NWWP secure fax server, as indicated below.

Please note that incomplete or unsigned forms may be returned to the clinic, and you may be contacted via phone to request missing information. Reimbursement will be processed once all the completed and signed forms have been received.

All completed forms can be scanned in to:

Verifyle

All completed forms can be mailed to:

SPIPA-NWWP

3104 SE Old Olympic Hwy

Shelton, WA 98584

OR faxed to:

360-427-1625 (secured fax server)

SPIPA STAFF RESPONSIBILITIES

SPIPA staff provide comprehensive assistance in the form of individual on-site training, telephone consultations, technical assistance, and problem-solving as needed. SPIPA is responsible for overseeing critical components of the NWWP, ensuring that the program operates smoothly and meets its objectives:

Program Management:

SPIPA is responsible for managing the following services and components of the NWWP:

- Oversight of all program operations and activities
- Preparation of grant and renewable applications to the CDC and other funders
- Development of Memorandum of Agreements (MOA) between SPIPA and each Tribe
- Preparation of Annual Workplans
- Contracting of all screening and diagnostic providers
- Budget preparation and monitoring
- Timely processing of claims and reimbursement for services
- Coordination of Health System EBI Implementation Plans with partner clinics, including baseline data collection and tracking
- Provision of technical assistance to tribal clinics

Staffing:

To achieve the program's goals and objectives, NWWP maintains permanent staff at both SPIPA and tribal levels:

At SPIPA:

- **Program Manager**: The SPIPA Health and Wellness Manager provides oversight and guidance to the NWWP and other health programs.
- **Program Coordinator**: The Cancer Programs Coordinator manages day-to-day operations of both the Native Women’s Wellness and Comprehensive Cancer Control Programs, supervising staff, managing budgets, analyzing data, evaluating activities, and reporting to funders.
- **Data Coordinator and Program Evaluator**: Responsible for managing clinical data, offering secondary case management, processing claims, and evaluating program activities.
- **Quality Assurance Advisor**: A contracted position that ensures data quality and clinical service standards. The advisor reviews medical data both at SPIPA and tribal clinics to maintain care standards.
- **Community Outreach Liaison**: Serving as a bridge between SPIPA, Tribal community members, health clinics, and cancer prevention programs, this part-time role provides technical assistance and drives culturally appropriate activities to improve survivor care and quality of life.

At the Tribes:

- **Women’s Wellness Patient Navigator**: Each Tribe has a Patient Navigator funded for three days a week. They are responsible for increasing awareness about breast and cervical cancer, facilitating screening, and submitting data to the SPIPA Data Coordinator.

- **Women's Health Care Providers**: Funded for two days per week, these providers conduct cancer screenings, offer case management services, and report clinical data to SPIPA.
- **Clinic Support Staff**: Each Tribe contributes matched effort in the form of facility and clinic support staff to assist with NWWP paperwork and processes.

Mandatory Reporting:

SPIPA ensures the accurate and timely submission of the following reports to meet CDC requirements**:**

- Annual program progress reports
- Minimum Data Elements (MDE) reporting
- Evaluation Plan and updates
- Financial reports
- Clinic-level data collection for breast and cervical screenings, ensuring proper baseline and annual data are submitted to meet CDC requirements

Data Management:

SPIPA is responsible for maintaining a centralized computerized data management system, which involves:

- Maintenance of a centralized computerized data management and reporting software
- Follow-up on incomplete forms
- Management of clinic-specific screening data for ongoing monitoring of program activities

Evaluation:

SPIPA continuously evaluates program activities and outcomes, including:

- Evaluation of screening services and their impact on morbidity and mortality
- Evaluation of evidence-based interventions and workplan activities
- Monitoring of screening rates
- Monitoring progress on specific performance indicators
- Monitoring and evaluation of EBI interventions within health system partners to ensure successful implementation and improvement of screening rates

Quality Assurance:

SPIPA maintains high standards of quality assurance through:

- Review and monitoring of clinical data
- Conduct chart audits
- Monitor provider performance
- Facilitation of Medical Advisory Board
- Use of data from chart reviews to validate clinic screening rates and identify gaps in performance

Clinic Director Responsibilities

The Clinic Director plays a crucial role in the success of the Native Women's Wellness Program (NWWP) by ensuring the effective implementation of program components within their clinic. Below are the key responsibilities:

Collaborate on the Annual Work Plan:

Clinic Directors collaborate closely with the NWWP Program Manager, Coordinator, and Patient Navigator to develop the clinic's portion of the annual work plan. This plan outlines the strategy for the upcoming year and ensures alignment with program goals. Directors are responsible for ensuring the clinic's work plan is completed on time and aligns with NWWP objectives, so it can be submitted to the CDC as part of the funding request and included in MOAs.

Ensure Program Compliance:

Clinic Directors are responsible for ensuring that their clinic complies with NBCCEDP policies, procedures, and screening guidelines. This includes monitoring Providers and Navigators to ensure they fulfill the program's objectives, such as conducting screenings, follow-up, quality case management, and outreach activities.

Oversee Provider and Patient Navigator Roles:

The Director is responsible for overseeing the performance of Providers and Patient Navigators, ensuring they achieve program goals related to patient recruitment, education, and screening. It is essential that the Director ensures all activities are conducted in a culturally appropriate manner, aligning with the unique needs of the tribal community

Participate in Medical Advisory Board Meetings:

Clinic Directors are required to attend quarterly Medical Advisory Board meetings with SPIPA and other tribal clinics. These meetings provide a platform to discuss program updates, clinical guidelines, and shared goals for improving screening rates and community engagement.

Support Community Education and Outreach:

Directors play a supporting role in community education and outreach activities. While Patient Navigators and Providers are directly involved in recruitment, the Clinic Director ensures that the clinic is actively promoting and participating in these efforts. Directors should encourage Providers to engage in educational events and promote the importance of regular cancer screenings.

Manage Clinic's NWWP Budget:

Directors are responsible for managing the clinic's portion of the NWWP budget, ensuring all expenses—including those for Providers, Navigators, and clinic supplies—adhere to grant guidelines. They should work closely with SPIPA on budget-related matters, ensuring all purchases and reimbursement requests are properly documented and submitted in a timely manner. During grant applications and annual renewals, Directors coordinate with SPIPA to assess funding and modify budget requests as needed. They may also confirm match requirements with tribal fiscal staff and grant administrators.

Submitting Reimbursements for Provider, Navigator, and Clinic Supplies:

To ensure smooth program operations, Clinic Directors must ensure that all clinic-related expenses are submitted for reimbursement within 30 days of purchase or service. This includes:

- Submitting documentation for Providers' and Navigators' expenses, such as salary, travel, training, or supplies.
- Keeping accurate records of all receipts, purchase orders, and financial documents to avoid delays in reimbursement processing.
- Monitoring the clinic's budget to ensure compliance with spending guidelines and timely submission of necessary paperwork to SPIPA.

Foster Cultural Competency:

Providing culturally appropriate care is a priority for the NWWP. Clinic Directors are responsible for ensuring that the clinic staff is trained in cultural competency and understands the customs and practices of the local tribal community. If needed, cultural competency training can be requested from SPIPA to support the clinic's efforts.

Facilitate Provider Training and Continuing Education:

Clinic Directors should ensure that Providers maintain their active licensure and engage in ongoing education relevant to breast and cervical cancer screening. The NWWP provides funding for Providers to attend one annual training or conference, and Directors should work with Providers to identify opportunities for continued professional development.

Oversee Data Tracking and Follow-up:

The Clinic Director is responsible for ensuring that the clinic has an efficient system for tracking patient screenings, follow-up care, rescreening, and clinic screening rates. Electronic health record data reports for breast and cervical screening rates and eligibility for screening must be submitted annually. Directors must also ensure clinic workflows support timely referrals for diagnostic services when abnormalities are detected.

Assist with Outreach Partnerships:

Clinic Directors should collaborate with SPIPA and local health organizations to build partnerships that enhance service delivery and community outreach. By fostering relationships with external resources, Directors can help improve access to care and support for women in their communities.

PROVIDER RESPONSIBILITIES

Women’s Health Care Provider Position Overview:

The Women’s Health Care Provider position covers two days per week to provide pelvic exams, Pap tests, clinical breast exams (CBE), and related support services. The priority of this position is to:

- Screening women for breast and cervical cancer.
- Ensuring timeliness and quality of care for program enrollees.
- Raising community awareness of the importance of breast and cervical cancer early detection.

These responsibilities must be carried out in a culturally sensitive way, tailored to the tribal community. The screening, tracking, follow-up, and case management components of the program largely fall under the responsibility of the Women’s Health Care Provider.

To effectively fulfill these duties, NWWP Providers should thoroughly understand all program components and requirements by reviewing this manual and other NWWP Program materials. Providers should also familiarize themselves with the CPT codes covered by the program and the required documentation.

Maintain Best Practices:

CDC guidelines and NWWP policy require that all women enrolled in the program receive appropriate, timely, and quality care. It is the primary responsibility of the Providers to ensure this happens. Program enrollees should receive breast and cervical health services consistent with current evidence-based and clinical best practices.

All women with abnormal findings should receive follow-up services based on current clinical standards of care. CDC sets strict guidelines for the timeliness of care for patients with abnormal findings. Program enrollees are expected to receive a final diagnosis within 60 days of abnormal findings and initiate any indicated treatment within 60 days of diagnosis. While these guidelines cannot be met for every woman, it is the Provider’s job to ensure that patients receive timely follow-up services whenever possible and notify NWWP of these cases. Providers provide primary case management services to ensure this occurs.

The NWWP Program Coordinator is responsible for ensuring an adequate network of community diagnostic providers to offer follow-up services for women with abnormal findings. Contracts with outside providers are initiated and maintained as needed. Contact the Program Coordinator with any requests for contracts with community providers to fill service gaps.

Cultural Competency:

Providing appropriate services in the Tribal Community requires making them culturally relevant and sensitive. Customs, beliefs, and practices vary from tribe to tribe. The Provider’s responsible for understanding and working within the local culture. Cultural competency training can be requested from SPIPA if needed.

Maintain Licensure, Knowledge, and Skills:

Providers must maintain active licensure in the State of Washington, enabling them to provide breast and cervical cancer screening services through the NWWP.

The NWWP’s CDC grant covers a portion of the Providers’ licensing renewal costs and travel and registration costs for one yearly training or educational conference. Providers may choose their training based on their needs and preferences, as long as it is relevant to NWWP duties.

In addition to this training, Providers are expected to stay informed about current literature on breast and cervical health and to update their practices and skills, accordingly, based on recommendations from the NBCCEDP.

Provide Tracking and Case Management Services:

NWWP is required to ensure that women with abnormal screening results or a cancer diagnosis receive the necessary follow-up services. Patient Navigation's goal is to ensure timely and appropriate screening, rescreening, diagnostic, and treatment services for women enrolled in the program.

The Provider at each tribe provides primary case management for patients screened through the tribal clinic. The Provider should have a system for tracking when women are due for rescreening and follow-up procedures. Every effort should be made to set up timely referrals for follow-up care and encourage women to comply with recommendations.

Maintain and Report Program Data:

The tribes' timely submission of clinical records to SPIPA is essential for program performance. Clinical records must be submitted to SPIPA within 30 days of service. The Provider is responsible for ensuring that all forms are correctly and completely filled out and that SPIPA receives all clinical data pertaining to program functions.

Work Within the Tribe’s Budget:

Women’s Health Care Providers should be familiar with each grant's spending guidelines, know how to read the budgets, and submit appropriate paperwork to SPIPA for purchases, reimbursements, and travel. In cooperation with their tribal Patient Navigator and under the guidance of the Program Coordinator, Providers are responsible for staying within each grant's spending guidelines. Expenditure reports are provided to the Patient Navigator at the monthly outreach meeting and to the Women’s Health Care Provider at the quarterly provider meeting or as requested.

Participation on Medical Advisory Board:

The Medical Advisory Board meeting allows Providers and NWWP staff to collaborate and create a shared vision for the program. Many program goals, objectives, and activities are developed and monitored collectively between the five tribes and SPIPA. This intertribal meeting is scheduled quarterly, and attendance is mandatory for each tribal Provider and highly encouraged for the Clinic Administrator.

The meeting agenda may include, but is not limited to:

- Updates or changes in evidence-based clinical care guidelines.
- Budgets and changes in funding.
- Information on upcoming educational training and conferences.
- Brainstorming ways to improve screening rates and addressing any challenges.
- Planning for intertribal events and collaboration with community resources.

Educate Patients and Tribal Community:

While the Patient Navigators have the primary responsibility for recruiting women for breast and cervical cancer screening services, evidence shows that physician recommendation has the most influence on a woman's decision to get screened. It is important for Providers to participate in community education and screening recruitment. Providers should encourage all women seen at the clinic to receive their Pap tests and mammograms at appropriate intervals.

NWWP grants cover the cost of breast and cervical health education materials, including pamphlets, charts, posters, and anatomical models. These educational materials should be available for all women seen at the clinic and those attending women's wellness community events.

Each tribe hosts various community education and outreach events throughout the year, including health fairs, crafting & education events, and women's wellness luncheons or dinners. Additionally, SPIPA coordinates several intertribal women's health events each year, such as the annual Breast Cancer Awareness Walk. Providers are encouraged to attend these events, when possible, as they provide valuable opportunities to engage with the community, build trust, and share health information. Providers may be asked to speak at these events, provide screening services, or demonstrate skills like breast self-exam.

PATIENT NAVIGATOR RESPONSIBILITIES

Introduction:

The main responsibilities of the NWWP's Women's Wellness Patient Navigators are recruiting women for cancer screenings and raising community awareness of breast and cervical cancer. To succeed, these activities must be carried out in a culturally sensitive manner and tailored to each tribal community.

Education and outreach should increase knowledge, beliefs, skills, and community motivation to seek screening. It should inform women about screening and follow-up procedures, improve regularity of screenings, and increase women's ability to identify resources for screening, diagnosis, treatment, and support.

Program Knowledge and Resources:

- **Understand the Basics of Breast and Cervical Health:** Patient Navigators should be thoroughly familiar with all aspects of breast and cervical health, including anatomy, common health issues, screening procedures, and the importance of early detection. (See Appendix)
- **Understand the Basics of the NBCCEDP and the NWWP:** Navigators need to understand the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) guidelines, objectives, eligibility criteria, and services provided by the NWWP.
- **Be Aware of Available Resources:** Patient Navigators must be knowledgeable about resources for supplies, educational materials, training opportunities, cancer information, and support services.

Patient Engagement and Education:

- **Recruit Women for Screenings and Rescreening:** Develop and implement outreach strategies to recruit women for initial screenings and ensure they return for rescreening as recommended.
- **One-on-One Education & Outreach:** Engage in one-on-one contact through phone calls, home visits, clinic outreach, transporting women to appointments, and one-on-one education at community events.
- **Patient Reminders:** Send monthly reminders through cards or letters to women who are due for a mammogram or Pap test, followed by personal contact.
- **Community Education Events:** Plan and execute public education events to raise awareness about breast and cervical cancer and the services offered by the program.

Screening Coordination and Follow-up:

- **Patient Tracking:** Develop a system to track when women are due for initial screenings, annual screenings, follow-up, and other care.
- **Coordinate Community Health and Education Activities:** Plan and execute health fairs, breast cancer awareness walks, and educational workshops.
- **Mammogram Days:** Organize Mammogram Days by coordinating with the mobile mammography unit, scheduling appointments, and publicizing the event.
- **Track Patient Progress:** Maintain accurate records of patient screenings, results, and follow-up appointments.

Case Management and Support:

- **Assist with Case Management:** Provide case management services for women with abnormal screening results, ensuring they receive the necessary diagnostic and treatment services.
- **Promote Patient Advocacy:** Advocate for patients' needs and rights within the healthcare system, supporting their access to services and resources.

Cultural Sensitivity and Communication:

- **Provide Cultural Competency:** Ensure all interactions with patients and the community are culturally sensitive and appropriate.
- **Facilitate Communication between Patients and Providers:** Act as a liaison between patients and healthcare providers, ensuring clear and effective communication.

Data Management and Reporting:

- **Maintain and Report Program Data to the NWWP:**
    - Ensure accurate recording of patient interactions, screenings, results, and follow-up actions in the NWWP data management system.
    - Each outreach event, it is required to collect a data piece to report back to the CDC. This data helps evaluate the effectiveness of the outreach, track the impact on screening rates, and ensure the program reaches underserved populations. Accurate data collection allows the program to adjust strategies and allocate resources effectively

- **Support and Assist with Grant Management:** Assist in managing grant funds by adhering to spending guidelines, preparing necessary documentation, and maintaining accurate financial records.

Collaboration and Compliance:

- **Work Closely with the Tribal Women's Health Care Provider and Clinic Staff:** Develop strong working relationships with clinic staff and tribal leaders to best serve the tribe's women and comply with tribe and clinic protocols.
- **Joint Efforts with Clinic Team for Diagnostic Forms:** Ensure accurate completion and submission of NWWP breast and cervical diagnostic forms.
- **Participation in Monthly Patient Navigator Meetings:** Attend mandatory monthly intertribal meetings to collaborate with NWWP staff and other tribes. These meetings focus on shared program goals, objectives, and activities.

Outreach and Partnership Building:

- **Organizational Outreach and Partnerships:** Build relationships with other programs and organizations to strengthen outreach efforts and the program.
- **Health Fairs:** Participate in Tribal and community health fairs to raise awareness, remind women of screenings, and schedule appointments.

Community Education Events:

- **Mammogram Days:** Since Tribal clinics do not have their own mammogram facilities, the program offers mammograms by bringing in a mobile mammography unit. Patient Navigators are responsible for organizing Mammogram Days at their clinic, including tasks such as scheduling dates, sending reminders, publicizing the event, and assisting women with paperwork. Navigators may provide small incentives like gifts or raffle prizes to encourage participation, with a price limit of **$20 per item**.
- **Community Education Events:** Public education events play a vital role in raising community awareness about breast and cervical cancer. These events offer Patient Navigators the chance to:
  - Educate women and their families.
  - Address their questions.
  - Foster community trust.

While events often feature gifts, speakers, and engaging activities to create a welcoming atmosphere, it is important to note that **CDC funds cannot be used to purchase food**. To help cover costs not allowable under the CDC grant, the NWWP actively seeks donations to support these aspects of the events.

Successful examples of events include:

- Women's Wellness Education Gardening
- Breast Cancer Bingo
- Pap-A-Thons

- Breast cancer awareness walks
- Traditional Crafting activities (Ribbon skirts, beading, drum making)

Organizational Outreach and Partnerships:

Building partnerships with other organizations and Tribal programs can enhance outreach and program success. These organizations may provide valuable resources, share information, or allow on-site screening.

Steps for Putting Together a Successful Event:

- **Step One: Schedule the Event**
    - Check for conflicting events and availability of space, workers, presenters, and service providers.
    - Identify the data to be collected during the event for CDC reporting. This could include the number of women screened, number of attendees, or other relevant outreach metrics.
    - Begin documentation using the event planning tool, which should capture key details like date, location, objectives, and resources needed and send to the outreach liaison via Verifyle.
- **Step Two: Buy Supplies**
    - Plan ahead to order supplies, food, incentives, and materials. Purchase orders and supply deliveries can take time.
    - **Update Event Planning Tool**: Document any purchases or resources secured in the event planning log, including costs and estimated delivery times.
- **Step Three: Promote the Event**
    - Publicize the event through flyers, newsletters, radio, and word of mouth.
    - Provide phone reminders close to the event date for better attendance.

Tip: Timing the event well is key. Evening events may attract working women, while daytime events may draw more elders.

Program Eligibility

Age:

- Women must be 18 years of age or older to be eligible for the Native Women's Wellness Program (NWWP).
- Cervical cancer screening and diagnostic services are available to eligible women aged 21 to 64 who still have an intact cervix.
- Breast cancer screening and diagnostic services are available to eligible women aged 40 to 74.
- Younger women who are at high risk for breast or cervical cancer due to personal or family history, genetic predisposition, or other factors may also be eligible for screening services upon the recommendation of a healthcare provider.

Gender:

- The NWWP services are designed specifically for women.
- Transgender women (male-to-female) who have taken or are taking hormones and meet other eligibility requirements are eligible for breast cancer screening and diagnostic services.
- Non-binary individuals and transgender men (female-to-male) who have not undergone a mastectomy and meet other eligibility requirements may also be eligible for breast cancer screening services.

Race:

- The NWWP aims to serve both Native American and non-Native women.
- Women are eligible for the program if they receive clinical services at health clinics of the Consortium Clinic tribes.
- The program recognizes the importance of providing culturally appropriate services to Native American women who may face unique barriers to healthcare.

Income:

- To be eligible for NWWP services, women must have a household income at or below 250% of the Federal Poverty Level (FPL). Since income guidelines change with each new program year, please refer to the appendices or contact the Program Coordinator for the most up-to-date information.
- Income eligibility is determined based on the total gross income of all household members.

Insurance Status:

- The NWWP is designed to assist women who are uninsured or underinsured.
- Uninsured women are those who do not have health insurance coverage.
- Underinsured women are those with private insurance whose coverage does not adequately cover necessary breast or cervical services or who have high deductibles or co-pays that make accessing these services unaffordable.
- Women covered by Medicaid are not eligible for NWWP services, as Medicaid covers breast and cervical cancer screening and diagnostic services.
- NWWP is the payer of last resort. Before submitting claims to NWWP, seeking reimbursement through any available insurance is necessary.

Cancer Screening Services

Screening Guidelines:

The Native Women's Wellness Program (NWWP) screening guidelines for clinical care align with the U.S. Preventive Services Task Force (USPSTF), the American Society for Colposcopy and Cervical Pathology (ASCCP), and CDC program guidance.
* note* women can self-refer for breast and cervical screening services.

Breast Cancer Screening Guidelines:

- **Women under age 40:** NWWP funds can be used for symptomatic women or those identified as high risk, even if asymptomatic.
- **Women aged 40-74:** It is recommended that average-risk women undergo a screening mammogram every two years. Providers may recommend annual screening based on the individual's health status, personal preferences, or healthcare disparities in tribal populations.
- **Women aged 75 and older:** Screening is based on the individual's health status and personal preferences in consultation with their healthcare provider.
- **Clinical Breast Exam (CBE):** CBE should be offered as part of shared, informed decision-making, recognizing the uncertainty of additional benefits or harms beyond those provided by screening mammography.

High-Risk Breast Cancer Screening Guidelines:

All women should undergo a lifetime risk assessment to determine if they are at high risk for breast cancer. Providers may choose whichever method they prefer to determine the lifetime risk. The current model encouraged is the Tyrer-Cuzik IBIS model.

Women at high risk should be screened with both an annual mammogram and an annual breast MRI. Breast MRI should never be used as a standalone screening tool for breast cancer (Contact the NWWP Program Coordinator for prior authorization).

Women as high risk include:

- Known genetic mutation such as BRCA 1 or BRCA 2, first degree relatives with premenopausal breast cancer or known genetic mutations, a history of radiation treatment to the chest area before the age of 30 (typically Hodgkins's lymphoma)

AND

- a lifetime risk of 20% or more for development of breast cancer based on risk assessment models that are largely dependent on family history

Breast MRI should never be done alone as a breast cancer screening tool. Breast MRI can also be reimbursed when used to better assess areas of concern on a mammogram or for evaluation of a client with a history of breast cancer after completing treatment. Breast MRI should be done at facilities with dedicated breast MRI equipment.

Breast MRI cannot be reimbursed for assessing the extent of disease for staging in women who were recently diagnosed with breast cancer and preparing for treatment.

Cervical Cancer Screening Guidelines:

- **Women aged 21-29:** A Pap test every three years.
- **Women aged 30-65:** A Pap test every three years or co-testing (Pap test and HPV test) every five years (preferred).
- **Women aged 65 and older:** Screening may be discontinued if there is adequate prior screening and no history of CIN2 or higher in the past 25 years.
- **Women with a total hysterectomy:** No screening is required if the hysterectomy was for benign reasons and there is no history of high-grade precancerous lesions or cervical cancer.

Annual Pelvic Exams:

- For women with an intact cervix.
- Women who have had a total hysterectomy (removal of cervix) are eligible for cervical cancer screening only if they have a history of cervical cancer.

Cervical Cancer Screening for those at high risk:

- Those who are at high risk for cervical cancer need to be screened more frequently based on ASCCP guidelines. This includes those with HIV infection, who have had an organ transplantation, who may be immunocompromised from another health condition, or who had DES exposure in utero.

While these are the standard guidelines, the frequency of screening tests remains at the discretion of the NWWP Women's Health Care Provider. Symptomatic women should be clinically evaluated and scheduled for diagnostic procedures promptly.

Notification of Normal Results:

- **Timeframe for normal results Notification:** Women with normal results of their breast and cervical screening tests should be notified within 14 days of receiving the result. Mammography facilities are required to notify patients of their results. Women with normal results are sent a letter in the mail. This letter is sufficient notification, and the referring provider does not need to provide further notification of these results.
- **Method of Notification:** Notifications can be made through phone calls, letters, or secure electronic communication. The notification should include a reminder of the next recommended screening interval and any other relevant health information.

- **Documentation:** Documentation of the notification and the patient's understanding of the results should be recorded in the patient's medical record.

Notification of Abnormal Screening Results:

- **Timeframe for Notification:** Women with abnormal screening results should be notified as soon as possible, preferably within **7 business days** of receiving the results and notated on screening form in case management section.
- **Method of Notification:** Notifications should be done in a sensitive and confidential manner, ideally through a personal phone call or face-to-face meeting.
- **Content of Notification:** The notification should include:
    - An explanation of the abnormal results.
    - The need for additional diagnostic tests or follow-up procedures.
    - Information about available support services and resources.
- **Follow-Up:** Follow-up appointments and referrals should be scheduled promptly to ensure timely diagnostic evaluation and management.
- **Documentation:** Documentation of the notification, patient understanding, and planned follow-up should be recorded in the patient's medical record.

Diagnostic Services

Results Requiring Referral for Diagnostic Work-up:

When a patient has an abnormal screening result, she should be notified as quickly as possible and given a referral to a participating NWWP Diagnostic Provider for recommended work-up procedures. NWWP will cover the following diagnostic services when performed by a participating NWWP Diagnostic provider. The current listing of NWWP-approved CPT procedure codes can be found in the Appendix.

Abnormal breast cancer screening tests that require diagnostic work-up:

- Abnormal clinical breast examination (CBE), suspicious for cancer
- Mammogram result: Assessment Incomplete (BI-RADS 0) Suspicious abnormality (BIRADS 4); and Highly Suggestive of Malignancy (BI-RADS 5)

NOTE: A negative mammogram is not considered adequate work-up for a CBE finding of palpable lump that has not been previously evaluated and determined to be benign. All palpable lumps need to be evaluated beyond a negative mammogram, preferably with a referral to diagnostic ultrasound to a breast specialist or a surgeon.

Breast Diagnostic Procedures:

- Ultrasound
- Diagnostic Mammography
- Fine-Needle Aspiration
- Breast biopsy (non-excisional and excisional)
- Pathology of breast biopsy
- Surgical consult

Abnormal cervical cancer screening tests that require a diagnostic work-up include:

- Abnormal pelvic examination, suspicious of cervical cancer
- Pap test result: Atypical Squamous cells of undetermined significance (ASC-US) with a positive High-Risk HPV test result
- Atypical Squamous cells cannot exclude HSIL (ASC-H)
- High Grade SIL
- Squamous Cell Cancer

Cervical Diagnostic Procedures:

- Colposcopy without biopsy
- Colposcopy with biopsy and/or endocervical curettage (ECC)
- Endocervical curettage (ECC)
- Loop Electrosurgical Excision Procedure (LEEP)
- Colposcopy with biopsy with LEEP
- Cold Knife Conization (CKC)

- Endometrial biopsy
- GYN Consultation

Non-Covered Diagnostic Procedures:

- Services not related to breast or cervical cancer screening or diagnostics
- Services provided by non-NWWP participating providers (Refer to Appendix for Approved Contracted Vendors)
- EMB for excessive or post-menopausal bleeding only
- Hospital in-patient services
- Treatment of breast cancer, cervical intraepithelial neoplasia and cervical cancer

Referral Process

Diagnostic Referral process:

The Women's Health Care Provider must clinically manage follow-up services for their patients with abnormal screening test results, by assuring that they are appropriately referred and receive necessary diagnostic and treatment services. Tracking all patients with abnormal screening results is required to ensure that the diagnostic work-up is completed, and a final diagnosis is obtained in a quality and timely manner. NWWP expectation is that the diagnostic workup shall be completed, and a final diagnosis obtained, within 60 days of when the screening test was performed.

The Patient Navigator will work with all patients, to identify and overcome immediate barriers to care and will provide information and education to women to enhance their skills in navigating the health care system.

Approved Vendor Verification:

- Confirm the referral is made to an NWWP approved diagnostic provider.
- If the site is not approved, contact the NWWP Coordinator to request the site be added to the program.

Referral Authorization:

- If the necessary service is unavailable at the Tribal clinic, the designated clinic staff initiates a referral to an external provider for the required screening or diagnostic service.
- Gather required referral paperwork, including patient information, the type of service required, and relevant medical records and SPIPA NWWP Billing Packet.

NWWP Billing Packet includes:

- **Referral Letter:** A detailed explanation of the services being requested and the rationale for the referral.
- **Signed Informed Consent Form:** The patient's signed consent for the referral and the diagnostic service to be performed.
- **Fee Schedule:** A document outlining the fees for services, including NWWP coverage limits and expectations for any remaining balance billing.

Patient Instructions and Financial Information:

- Give the patient a copy of the referral, including the external provider's contact details and any instructions related to the service.

- Inform the patient of any potential financial responsibility if the service is outside the coverage of the NWWP (e.g., non-cancer-related screenings).

Service and Billing:

- The external provider completes the necessary screening or diagnostic service.
- If the patient has insurance, the provider bills the insurance and submits any remaining balance to SPIPA NWWP, following the NWWP Fee Schedule and billing instructions provided in the referral packet.
- The diagnostic provider is required to report the results directly to the referring provider.

Results and Follow Up:

- Ensure the results from the external provider are received by the clinic, Patient Navigator, and SPIPA.
- Record the results in the patient's file and update the NWWP Screening Services Form or Diagnostic Services Form accordingly.
- Based on the diagnostic results, coordinate with the clinic or the external provider to schedule any necessary follow-up care.
- Document the follow-up appointments and additional steps in the patient's record to ensure continuity of care.

Self-referral process:

Washington State women can self-refer for breast and cervical cancer screenings through programs like SPIPA NWWP and the Washington Breast, Cervical, and Colon Health Program (BCCHP). This process eliminates the need for a physician's referral, making it easier for women to access these vital preventive services. The Patient Navigator plays a crucial role in supporting patients throughout the self-referral process.

Patient Eligibility:

- Women eligible for SPIPA NWWP services are encouraged to self-refer for breast and cervical cancer screenings.
- Self-referral empowers women to take proactive control over their healthcare, ensuring timely screenings. This is especially important for those who may face barriers, such as limited access to regular healthcare, low income, or lack of insurance.

Patient Navigator Support This Process:

- The Patient Navigator is the primary contact for women who choose to self-refer, providing essential guidance, education, and support throughout the process. Their role ensures that women have a clear understanding of the steps involved and access to necessary resources and to the provider chosen by the patient is on the NWWP approved vendor list. If the provider is not listed, they will contact the NWWP Coordinator to initiate the provider's inclusion in the program.

- Women are encouraged to reach out to the Patient Navigator if they need assistance with:
    - Understanding eligibility for screenings
    - Selecting an approved vendor
    - Clarifying the self-referral process
    - Addressing potential financial concerns or barriers to care

For detailed steps related to referral authorizations, service delivery, and billing, refer to the "Diagnostic Referral Process" above.

Documentation and Tracking:

- The Patient Navigator will ensure that all referral and diagnostic services are properly documented in the patient's file, including any follow-up care.
- NWWP screening or diagnostic services forms **must** be updated accordingly for program compliance and patient care continuity.

Women Diagnosed with Cancer:

When a woman receives a final diagnosis of breast or cervical cancer, **<u>NWWP must be notified immediately</u>.** NWWP expectation is that treatment services will start within **60 days** of when the diagnostic tests confirmed breast and/or cervical cancer. NWWP does not reimburse for cancer treatment services. However, women enrolled in NWWP that receive a cancer diagnosis, are eligible to receive Medicaid coverage for their treatment through the Breast and Cervical Cancer Prevention and Treatment Act. SPIPA will work with the Patient Navigator to initiate enrollment onto Medicaid and will maintain regular contact with them until the woman’s treatment is complete.

Lost to Follow-up:

Ensuring that women with abnormal screening results or a cancer diagnosis receive timely follow-up care is a critical responsibility of the NWWP. Each patient should receive follow-up services based on the highest clinical standards to prevent delays that could worsen health outcomes. The program aims to provide a final diagnosis within 60 days of abnormal findings and initiate treatment (if needed) within 60 days of diagnosis.

Tracking and Initial Follow-up:

Once an abnormal screening result is identified, the Provider is responsible for notifying the patient of the results and making a referral to an approved vendor for follow-up services. Simultaneously, the Patient Navigator is informed and becomes actively involved in the follow-up process.

Initial Notification and Referral:

The Provider contacts the patient to explain the abnormal result and recommends the necessary follow-up. The patient is referred to an approved diagnostic vendor (following the referral process guidelines).

Coordination Between Provider and Patient Navigator:

The Provider informs the Patient Navigator about the follow-up plan. The Patient Navigator then completes and submits the signed screening form to SPIPA.

Patient Support and Appointment Scheduling:

The Patient Navigator reaches out to the patient to assist with scheduling the follow-up appointment and addresses any barriers that may prevent the patient from attending (e.g., transportation, financial concerns, or understanding of the process).

Ongoing Communication and Follow-up Efforts:

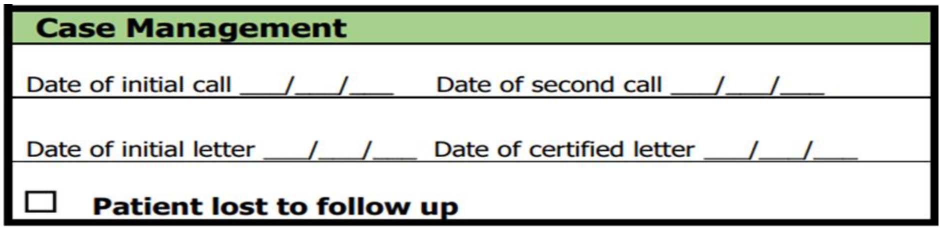
In cases where a patient does not schedule or attend the recommended follow-up, the Patient Navigator is responsible for making further contact attempts and documenting in the Case Management portion of the screening form.

Follow-Up Calls and Letters:

If the patient has not scheduled a follow-up appointment, the Patient Navigator will make two phone calls spaced one week apart. If these attempts are unsuccessful, a letter is sent to the patient, followed by a certified letter if needed.

Escalation to Lost to Follow-up:

If 60 days pass without a scheduled follow-up, the patient is classified as "Lost to Follow-up." At this point, the Patient Navigator documents all communication attempts, including calls and letters, in the case management section of the screening forms (see example below), and submits this information to SPIPA.



Case Management

Date of initial call ___/___/___ Date of second call ___/___/___

Date of initial letter ___/___/___ Date of certified letter ___/___/___

☐ **Patient lost to follow up**

Special Circumstances and Documentation:

At times, patients may refuse diagnostic or treatment services or opt for care outside the NWWP program. These cases are recorded as “Work-up Refused.” Additionally, certain circumstances may classify a patient as "Lost to Follow-up," such as:

- The patient is deceased.
- The patient’s phone has been disconnected or is no longer in service.
- The patient no longer resides at their last known address.
- A letter sent to the patient is returned as undeliverable (e.g., “moved, no forwarding address”).
- Emergency contacts are unable to provide current information.

In each of these cases, the Patient Navigator must notify the NWWP of the patient’s status and ensure all efforts to locate the patient are documented.

Continuity and Re-engagement:

Even after a patient is classified as "Lost to Follow-up," ongoing efforts may be made to re-engage the patient during future program interactions. The Patient Navigator should remain open to reconnecting with the patient if new contact information becomes available or circumstances change.

Conclusion

The NWWP plays a vital role in improving the health and well-being of women within our tribal communities. By providing high-quality, culturally sensitive breast and cervical cancer screening and diagnostic services, we aim to reduce cancer mortality and address disparities in healthcare access.

Program Structure and Oversight:

This manual outlines the various components of the NWWP, including the responsibilities of SPIPA Staff, clinic directors, providers, and patient navigators. These roles ensure that the program operates smoothly and delivers the best possible outcomes for the women we serve. The manual also outlines the critical elements of grant compliance, reporting obligations, and program processes, which are essential to maintaining our funding, meeting federal and tribal guidelines, and ensuring that patient confidentiality is always upheld.

Success Through Collaboration:

The success of the NWWP is not just measured by the number of screenings we conduct or the services we provide, but also by the quality of care we offer and the trust we build within our communities. To achieve this, we rely on the collective commitment of every team member to adhere to the guidelines outlined in this manual. Your role is fundamental to our success, and it is through this shared commitment that we can maintain high standards of care, sustain program funding, and, ultimately, save lives.

Our continued success in the NWWP depends on our collective compliance with the outlined guidelines and our commitment to maintaining open communication with all team members. By aligning with our shared goals and fostering a collaborative environment, we can make a significant and lasting impact on the lives of Native women.

Continued Support:

We deeply appreciate the dedication and passion that each of you brings to the program. Your role in supporting women’s health is invaluable, and together, we are making a lasting difference in the lives of Native women and their families. Your efforts are not unnoticed, and with your ongoing commitment, we will continue to expand access to life-saving screenings, improve health outcomes, and reduce the burden of cancer on our communities.

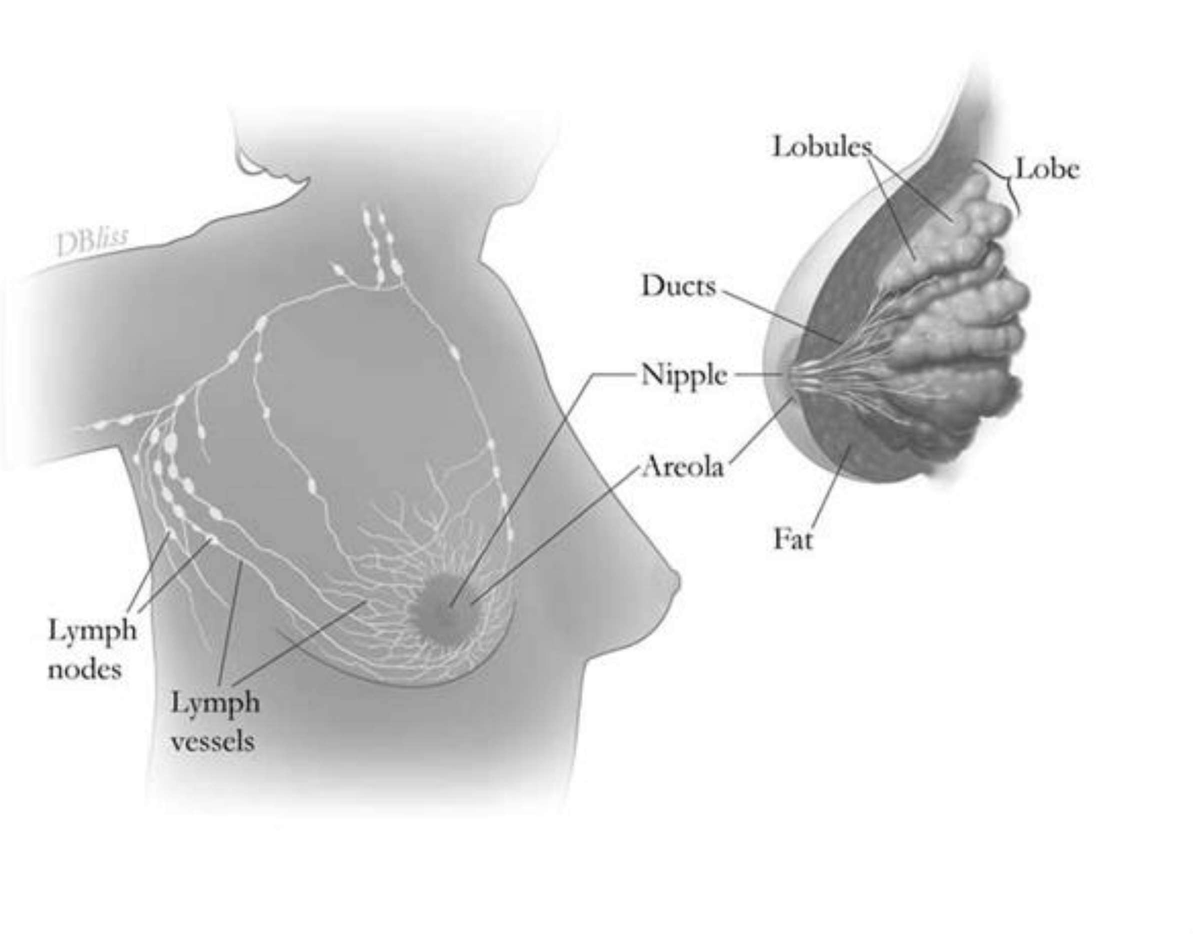
If you have any questions or need additional support, please refer to the SPIPA Staff Contact Information in the appendices or contact the NWWP Program Coordinator.

Thank you for your ongoing commitment to the Native Women’s Wellness Program. Together, we are building healthier futures for generations to come.

Breast and Cervical Anatomy:

Patient Navigators need to have a basic knowledge about female anatomy, breast and cervical cancer (and other changes), cancer risk factors, screening and diagnostic procedures, and cancer treatment. They also need to be able to comfortably explain these to women in an understandable way. While the Women's Health Care Provider will be able to offer more technical information to women on these subjects, the Patient Navigator does a great deal of public and one-on-one education with community members and should have a working knowledge of the basics.

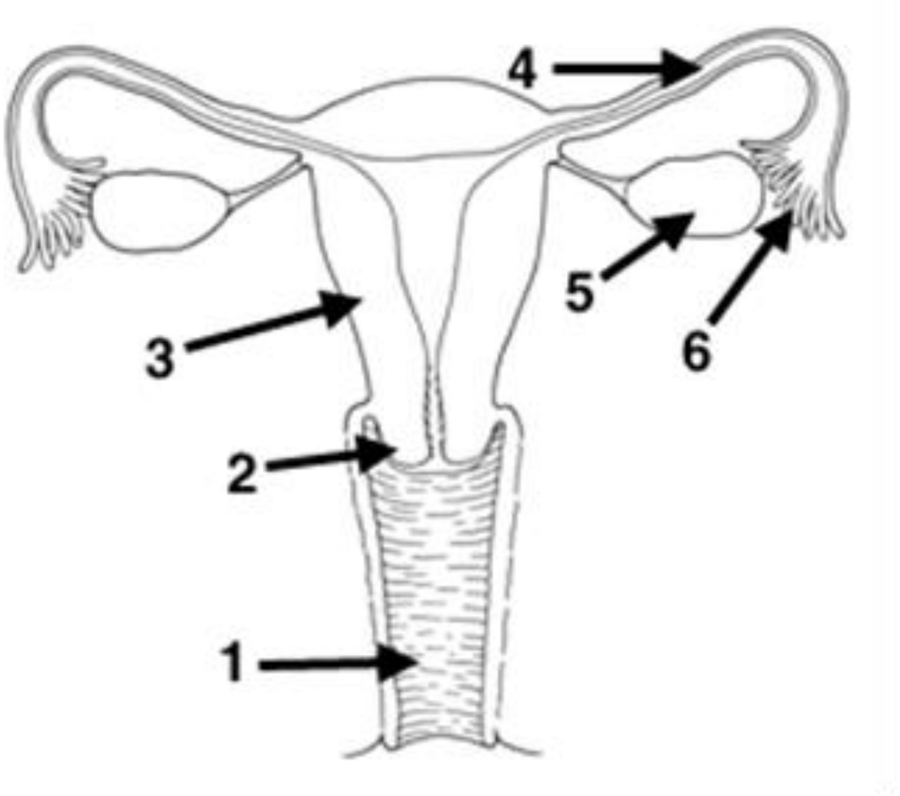
Anatomy of the Breast:



- **Lobes:** Each breast has 15 to 20 sections called lobes. Each lobe contains many smaller lobules.
- **Lobules:** Lobules are contained in each lobe and end in dozens of tiny bulbs that produce milk during pregnancy and breastfeeding.
- **Ducts:** Ducts lead to the nipple and carry milk from the lobules after childbirth.
- **Nipple:** The nipple allows the ducts to release milk during breastfeeding.
- **Areola:** The areola is the dark area of skin that surrounds the nipple.

- **Lymph Nodes & Lymph Vessels:** Lymph nodes filter lymph fluid from your breast through the lymph vessels and help your body fight infections. Lymph nodes are found under the arms and above the collarbone, as well as other parts of the body.
- **Fat: Fatty:** tissue surrounds the lobules and ducts and adds to the size of your breast.

Female Reproductive Anatomy:



1. **Vagina:** The vagina, also known as the birth canal, is the tube that extends from the vaginal opening in the vulva into the female body towards the uterus.
2. **Cervix:** The cervix is the small, rounded opening to the uterus that protrudes into the vaginal canal.
3. **Uterus:** The uterus is a hollow, pear-shaped organ where the human fetus is nourished and develops during pregnancy. The uterus is located in the female pelvis.
4. **Fallopian tubes:** The fallopian tubes are two thin tubes 3-4 inches that extend from the uterus to the ovaries on each side of the body. The tubes are the passageways through which eggs travel on their way to the uterus.
5. **Ovaries:** The ovaries are small organs that produce both eggs and female hormones. The ovaries produce two types of hormones: estrogen and progesterone. Both are necessary for female sexual maturation and reproductive processes.
6. **Fimbriae:** The fimbriae are finger-like projections that extend from the fallopian tubes towards the ovaries. The fimbriae move around the ovaries and reach out and draw eggs into the fallopian tubes, after they are released from the ovaries.

What is Cancer:

Cancer occurs when cells become abnormal and begin dividing and forming more cells without control or order. Normally, cells divide to produce more cells only when the body needs them and die at a regular rate. This process keeps the body healthy. But if cells keep dividing when not needed, or they don't die when they are supposed to, then they grow into a mass of tissue, or a tumor. This growth can be benign or malignant.
Benign tumors are not cancer. They are usually not life threatening, can generally be removed, and do not often grow back. Malignant tumors are cancer. Cancer cells can invade and damage nearby tissues and organs. They can also break away and travel through the bloodstream or lymphatic system to new sites. The spread of cancer is called **metastasis**. Cancer is much easier to treat if it is detected early, when it is small and ***before*** it metastasizes.

Breast Cancer:

- **Risk Factors for Breast Cancer:** Risk Factors for Breast Cancer: The causes of breast cancer are not fully understood. However, there are several risk factors that have been identified. The number one risk factor for breast cancer is being a woman. While men do get breast cancer, this disease is about 100 times more common for women. The second most important risk factor is age. Women who have a history of breast cancer also are at higher risk. Other risk factors include a family history of breast cancer (especially if in a mother, daughter, or sister), early onset of menstruation (before 12), late menopause (after 50), late childbearing (after 30 for the first child) or never having been pregnant, heavy alcohol use (2 or more drinks daily), and obesity. The Women's Health Care Providers participating in the NWWP currently utilizes the Tyrer-Cuzick risk model to help determine if a patient is high-risk for breast cancer.

  There are many misconceptions about breast cancer risk. Breast cancer is not caused by injuries, such as bumps or bruises, to the breast. The risk of breast cancer is not related to the size of the breasts. It is not contagious; one woman cannot "catch" it from another. Some people worry that the radiation from mammograms can cause breast cancer. Mammograms use a very low dose of radiation; women who do not get mammograms are actually at a much higher risk of dying of breast cancer than those who do get routine mammograms.

- **Symptoms of Breast Cancer:** Any breast changes should be followed up with a health care provider as soon as possible. Most lumps or breast changes are not cancerous, but still should be medically evaluated to rule out the following are trouble signs that should not be ignored: The following are trouble signs that should not be ignored:
    - Any new, hard lump or thickening in any part of the breast
    - A change in the size or shape of either breast
    - Dimpling or pitting of the skin on or around the breast
    - Swelling, redness, or warmth that does not go away
    - Pain in one spot that is not connected with an injury or with the menstrual cycle
    - Pulling in of the nipple
    - Unusual nipple discharge
    - An itchy, sore, or scaling area on one nipple or the areola

Types of Breast Cancer:

There are different kinds of breast cancer. It can occur in the lobules or the ducts and be invasive or noninvasive. With noninvasive breast cancer, the cancer cells are confined to the ducts or lobules of the breast. Invasive cancer involves the spread of abnormal cells beyond the ducts or lobules. The cells first invade the surrounding breast tissue. From there, they can move into the lymph system or the bloodstream and begin growing in other areas of the body.

- **Ductal carcinoma in situ (DCIS)**: Involves abnormal division of cells that has stayed within the duct. Cancer can remain in situ (in one spot), or it can become invasive. Breast cancer most often occurs in the ducts. Lobular carcinoma in situ (LCIS) involves abnormal cell division that stays within the lobules. LCIS rarely becomes invasive but is a sign of increased risk for invasive breast cancer. Inflammatory breast cancer is a type of cancer that has spread locally and blocks the lymph vessels in the skin of the breast. This causes the breast to become inflamed, or red and swollen.

  A breast cancer diagnosis considers several factors that may affect survival chances and treatment options. The **cancer stage** (from 0-4) is based on the size of the tumor, whether lymph nodes are involved, and whether the cancer has spread beyond the breast. The **cancer grade** (from 1-3) is a comparison of the cancer cells to normal cells. Cells are examined to see how much they look like normal cells and how fast they are growing. The cells are examined to see if they have hormone receptors or genetic abnormalities. A physician will take all these factors into account to help the woman develop her treatment plan.

- **Non-cancerous breast changes: Most** lumps and changes in the breast are not breast cancer. Women often get worried about the many lumps that are in their breasts when they begin to do breast self-exams. Normal breast tissue often feels quite lumpy because of the ducts, lobes, and normal fibrous tissue. Breasts also change throughout the menstrual cycle and as women age, in response to hormones, and can feel lumpier at sometimes than others.

Some common breast changes that are not cancerous are **cysts** (fluid-filled pockets), **fibroadenomas** (small round lumps that are painless and moveable), benign growths inside the ducts, breast infections, and inflamed blood vessels. Nipple discharge is often non-cancerous, and most breast pain is not cancer related. Unusual changes in the breasts, especially if they only appear on one side, should still always be checked by a health care provider.

Screening Tests for Breast Cancer:

Breast cancer is one of the most curable forms of cancer if diagnosed early. When breast cancer is found before it spreads, women have a 96% chance of surviving. Early detection affords a woman more choices for treatment and a good chance of complete recovery. This is why regular screening for breast cancer is so important.

- **Mammogram:** A mammogram is a low-dose x-ray of the breast. Mammograms can detect a cancer too small to feel with a self- or clinical breast exam. Screening mammograms are the best available tool for finding breast cancer early. However, mammograms cannot detect every abnormality in the breast. This is especially true for younger women, who tend to have greater breast density that can make mammograms hard to read. Mammograms are best used in combination with clinical breast exams and breast self-exams.

- **Clinical breast exam (CBE):** The clinical breast exam is an exam of the breast done by a health care provider. The provider examines the breasts visually and by hand. This exam is generally a routine part of the women's wellness exam. Health care providers can tell a lot about a lump by feeling it and the surrounding tissue. Benign lumps often feel different from cancerous ones. If the provider feels anything abnormal, they should refer the woman for diagnostic tests.
- **Breast self-exam (BSE):** Monthly breast self-exams help women become familiar with their breasts and learn to recognize their normal lumps and cyclical changes. NWWP's policy is to encourage all women over the age of 20 to do a BSE every month. Because women's breasts can change dramatically throughout the menstrual cycle, the BSE should be done at the same time each month, usually within 3-5 days after the end of their period. To do a BSE, the pads of the fingers should be used to examine the breast in up-and-down rows, with light, medium, and then deep pressure. The entire breast and surrounding area, including the armpits and up to the collarbone, should be examined with the woman on her back. The breasts should also be examined in a mirror from different angles and in different positions to notice any dimpling or changes in size, shape, or skin texture.
- **Screening magnetic resonance imaging (MRI):** The American Cancer Society recommends that all women who are high-risk for breast cancer receive a breast MRI and a mammogram every year.
- **Diagnostic Procedures for Breast Abnormalities:**
  - **Diagnostic mammogram:** Mammograms can give a provider important information about a breast lump. Mammograms can often distinguish between cancerous tumors and benign changes. If an area of the film is diagnosed as suspected of cancer, a biopsy or other surgery might be recommended.
  - **Ultrasound:** Ultrasounds use high-frequency sound waves to create a visual image of the breast tissue. Ultrasounds can often show whether a lump is a cyst (a fluid-filled lump that is not cancer) or a solid mass (which may or may not be cancer).
  - **Biopsy:** A biopsy is when fluid or tissue is taken from the breast for evaluation. There are several different kinds of biopsies. **Fine needle aspiration (FNA)** uses a thin needle to remove fluid from a breast lump. **Needle biopsy** uses a larger needle that can remove a small amount of tissue. Needle biopsies can be done in the provider's office. **Surgical biopsy** removes either a portion or the whole of a lump through an incision in the breast. This is generally done as an outpatient surgery. A pathologist examines tissue samples from biopsies through a microscope for cancer cells.

Treatment of Breast Cancer:

The treatment of breast cancer depends on the type of cancer, whether it has spread, and the choices of the woman. **Local therapies** such as surgery and radiation are used to treat the disease in the breast, or to other parts where the cancer has spread. **Systemic treatments** such as chemotherapy and hormonal and biological therapies are used to destroy or control cancer throughout the body. Depending on the diagnosis and the woman's choice, these treatments can be used in combination or alone.

- **Surgery:** Surgery is the most common treatment for breast cancer. There are several kinds of surgery to remove breast cancer. The one used will depend on the diagnosis and the woman. **Lumpectomy** and **segmental (or partial) mastectomy** are intended to remove the cancer while still conserving part or most of the breast. They remove either just the cancer or an area of surrounding tissue, or the cancer with a larger section of normal breast tissue. **Mastectomy** removes the entire breast. In combination with these, the surgeon will often remove lymph nodes under the arm to determine whether cancer cells have entered the lymphatic system. Women who have a mastectomy may want to have breast reconstruction at the same time or later.
- **Chemotherapy:** Chemotherapy uses a drug or a combination of drugs to kill cancer cells. These drugs can either be in pill form or given by injection. Chemotherapy can be given on an outpatient basis or at home.
- **Radiation therapy:** Radiation therapy uses high-energy rays to kill a localized area of cancer cells. The radiation may be directed externally at the breast by a radiation machine. It may also be used internally, with radioactive material placed in thin plastic tubes that are implanted in the breast. These can also be used in combination. Implant radiation requires a hospital stay. External radiation is usually done on an outpatient basis over the course of several weeks. Radiation therapy generally follows breast-conserving surgery, and sometimes mastectomy as well. This destroys any breast cancer cells remaining in the area.
- **Hormonal therapy:** Hormonal therapy works on cancer cells that are hormone-receptor positive, meaning they grow in response to hormonal messages. **Tamoxifen** is a type of hormonal therapy. Hormonal therapy deprives cancer cells of the hormones they respond to, either by blocking the receptors or by reducing the body's production of the particular hormone that the cancer needs for growth. This affects cancer cells throughout the body. Hormone therapy may continue for several years after the initial treatment.
- **Biological therapy:** Biological therapy is designed to stimulate the body's natural defenses against cancer. It is used for cancers caused by a genetic abnormality that tells cells to grow too fast. Drugs (such as Herceptin) are used to work against the gene to slow or stop the growth of these cells.
- **Alternative therapies:** Many women may choose to use alternative therapies for breast cancer. These therapies are best used in combination with more conventional cancer treatments, and in communication with the patient's conventional health care providers. Alternative therapies may include nutrition and lifestyle changes, acupuncture, herbal medicine, energy healing such as reiki, meditation and prayer, and other traditional healing practices.

After Cancer Treatment and Survivorship:

- **Reconstruction:** After mastectomy, a woman may choose to have her breast reconstructed. This involves putting in a breast implant or using tissue from other areas of the body to recreate a breast. Reconstruction may require a period of stretching the skin and chest wall muscle to make room for the implant. Reconstruction can be done at the time of mastectomy, or at a later time. If nipple reconstruction is desired, it is generally performed two or more months after initial reconstruction. Breast reconstruction after mastectomy is covered by insurance.

  Women who choose not to get reconstructive surgery might need a professionally fitted **breast prosthesis** that can either be attached to the chest during the day or worn in a special bra. Prostheses are important for women who have had just one breast removed. They help a woman balance the weight of her other breast and maintain her posture after surgery.

- **Recovery:** Recovery time varies greatly depending on several factors, including the extent of the treatment, the age and general health of the woman, and other factors. Women may need extra support while recovering, such as in-home nursing care, help with household tasks, and regular check-ups with her health care providers. Exercise and nutrition can also play key roles in recovery from cancer treatment.
- **Follow-up care:** Women should make sure to follow their health care providers' recommendations on appropriate follow-up care. Women who have had cancer are more at risk for developing recurrences, other types of cancer, and other health conditions such as lymphedema. It is very important that they follow all screening recommendations, get regular preventive care, and understand what signs or symptoms are of concern and should be watched for.
- **Support:** Cancer survivors often need extra support to aid in their recovery and quality of life after treatment. Support comes in many forms. It may include information, emotional support, community support, and material support. Cancer treatment that causes a woman to miss work may result in her needing temporary financial help or assistance finding a new job. Sexual intimacy may be an issue after surgery, and she may need emotional support from her partner or professional support such as counseling. Because of misconceptions or fears about cancer, she may feel cut off from her community and need help reconnecting.

  There are many sources of informational support available for cancer survivors. Some of these may be found in the Resources section of this manual. Many communities also have cancer survivor support groups or other resources. It may also be possible to find free or low-cost breast prostheses or head coverings for women who cannot afford them. Holding a community event to honor cancer survivors can be a great way to increase a sense of community support.

Cervical Cancer:

- **Risk factors for cervical cancer:** The greatest risk factor for developing cervical cancer is infection with the human papillomavirus (HPV). Almost all cervical cancers are caused by HPV infection, although most HPV infections clear up on their own and most women with HPV will not develop cancer. HPV is sexually transmitted, and some types cause genital warts. However, the types of HPV that cause genital warts are not the same ones that cause cervical cancer (referred to as "high-risk" types). High-risk HPV infections do not have any visible symptoms. Women may not know whether they have contracted the virus, but women who began having sexual intercourse and those who have had many sexual partners are at highest risk. Cigarette smoking is also linked with a greater risk of developing cervical cancer.
- **Symptoms of Cervical Cancer:** Precancerous cervical conditions do not usually cause pain or any other symptoms. They are usually only detected during a pelvic exam, Pap or HPV testing. The most common symptom of invasive cervical cancer is abnormal bleeding between menstrual periods or after intercourse, douching, or a pelvic exam. Other possible symptoms include menstrual bleeding that is heavier or longer lasting than usual, bleeding after menopause, or increased vaginal discharge.
- **Precancerous changes of the cervix:** Cells on the surface of the cervix may change to appear abnormal but not cancerous. Some of these abnormal changes may develop into cancer over time. These changes may be considered low-grade or high-grade.
    - **Low-grade SIL** (Squamous Intraepithelial Lesion—may also be referred to as mild dysplasia or cervical intraepithelial neoplasia 1 [CIN 1]) means early abnormal changes in the surface layer of cervical cells. These low-grade lesions often go away on their own. They are most common in women between 25 and 35 years old. These lesions most often do not require treatment, but the health care provider may suggest short-term rescreening and/or HPV testing.
    - **High-grade SIL** (also referred to as moderate or severe dysplasia, CIN 2 or 3, or carcinoma in situ) means there are a large number of surface cells that look very different from normal cells. They are most commonly found in women between the ages of 30 and 40. While high-grade SIL is not yet invasive cervical cancer, the health care provider will most likely recommend destruction or removal of the lesion to prevent further spread.
    - **Cervical cancer:** A cervical lesion is considered to be invasive cervical cancer if it has spread beyond the surface cells of the cervix. It may have spread to deeper layers of cervical cells, or to the bladder, rectum, lymph nodes, or lungs. The earlier invasive cervical cancer is detected, the better the chances of successful treatment. Once the cancer has spread beyond the cervix and uterus to other organs, it is much harder to treat.

Screening Tests for Cervical Cancer:

Cervical cancer is slow-growing and usually develops over many years, making it a prime candidate for early detection. Precancerous changes have few or no symptoms, so regular screening is essential. If women all received regular pelvic exams and pap tests, most precancers would be detected and treated before cervical cancer ever developed, or invasive cervical cancer would be caught early when it is still highly treatable. When cervical cancer is diagnosed at an early stage, the five-year relative survival rate is 92%.

- **Pap test:** The Pap test is the best way to check for cervical cancer. During a pelvic exam, a health care professional collects a sample of cells from the upper vagina and cervix with a small brush or stick. These cells are placed on a slide and examined under a microscope for signs of cancer or other abnormalities. Women should get a pap test when they are not menstruating. They should not have intercourse, douche, or use any vaginal products in the two days before the test.
- **Pelvic exam:** The pelvic exam is used to check for cervical cancer as well as other cancers or problems in the pelvis. The health care provider checks the uterus, vagina, ovaries, fallopian tubes, bladder, and rectum. This is to feel the organs for any abnormality in shape or size. The provider uses a speculum to open the vagina so that he or she can see the upper part of the vagina and cervix. While numerous cancers and pelvic disorders can be detected with a pelvic exam, NWWP funds can only be used to cover screening and diagnostic services for cancer and precancerous conditions ***of the cervix**.*

Diagnostic Procedures for Cervical Abnormalities:

The Pap test and pelvic exam are used to detect abnormal changes in the cervix. If changes are found, additional procedures are taken to find out what the problem is.

- **Colposcopy:** During a colposcopy, the provider uses an instrument called a **colposcope** (similar to a microscope) to look closely at the cervix. The provider may apply a solution to the cervix to make abnormal cells more apparent. If abnormal areas are found, the provider may also choose to do some a biopsy at this time. Colposcopy can be done in a provider’s office.
- **Biopsy:** Biopsy is the removal of a small piece of cervical tissue for examination by a pathologist. The provider may use an instrument to pinch a small piece of tissue off the cervix. Another type of biopsy uses an electric wire loop to slice off a thin, round piece of tissue. This is called a **LEEP** (loop electrosurgical excision procedure). **Conization** is a type of biopsy that checks to see if abnormal cells have invaded tissue deeper than the surface of the cervix. Conization (also called cone biopsy) removes a cone of tissue. Most biopsies can be done in a provider’s office, and usually require only local anesthesia. Conization may also be done in the hospital and may require general anesthesia.
- **Endocervical Curettage (ECC):** ECC is used if the health care provider wants to check inside the opening of the cervix. In this procedure, a small, spoon-shaped instrument called a curette is used to scrape tissue from inside the cervical opening.

Treatment of Cervical Cancer:

- **Treatment of precancerous lesions:** Treatment of cervical precancers depend on what grade the lesion is, whether the woman wants to have children in the future, and the preference of her and her health care provider. Low-grade lesions may not require treatment. Lesions that do require treatment can be destroyed using **cryosurgery** (freezing), **cauterization** (burning), or **laser** surgery. These methods destroy the abnormal area but don’t harm surrounding healthy tissue. In some cases, the woman may also choose to have a **hysterectomy**.
- **Treatment of cervical cancer:** Most often, treatment for cervical cancer involves a combination of methods:

    - **Surgery:** Surgery removes abnormal tissue in or near the cervix. It is a local therapy, meaning that if the cancer has spread beyond the cervical region, other therapies must be used to kill cancer cells that may be throughout the body. If the cancer is only on the surface of the cervix, it can be removed or destroyed in similar ways as precancerous lesions. If it involves deeper levels of the cervix but has not spread beyond that, the provider may remove just the tumor and leave the uterus and ovaries. In other cases, or if the woman does not want to have children, the woman may need a hysterectomy. **Hysterectomy** is the removal of the entire uterus and cervix, and sometimes the ovaries and fallopian tubes as well. Lymph nodes may also be removed to see if the cancer has spread.
    - **Chemotherapy:** Chemotherapy uses a drug or a combination of drugs to kill cancer cells. These drugs can either be in pill form or given by injection. Chemotherapy is used in combination with surgery when cervical cancer has spread to other parts of the body. Chemotherapy can be given on an inpatient or an outpatient basis, or at home.
    - **Radiation therapy:** Radiation therapy uses high-energy rays to kill or damage a localized area of cancer cells and stop them from growing. The radiation may come from a radiation machine or may be implanted in the cervix in the form of small capsules containing radioactive material. External radiation is usually done on an outpatient basis over the course of several weeks. Radiation implanted internally requires a hospital stay.
    - **Biological therapy:** Biological therapy uses drugs designed to improve the body's immune system to fight cancer cells that have spread. **Interferon** is the most common form of biological therapy for cervical cancer. It is used in combination with surgery and other therapies. It can be given on an outpatient basis.

After Cancer Treatment:

- **Reconstruction:** After mastectomy, a woman may choose to have her breast reconstructed. This involves putting in a breast implant or using tissue from other areas of the body to recreate a breast. Reconstruction may require a period of stretching the skin and chest wall muscle to make room for the implant. Reconstruction can be done at the time of mastectomy or later. If nipple reconstruction is desired, it is generally performed two or more months after initial reconstruction. Breast reconstruction after mastectomy is covered by insurance.

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Additional Resources:

Available resources for supplies, educational materials, training, cancer information, and cancer support services. There are hundreds of resources for free cancer information, materials, education, and various kinds of support services. This is a partial list of sources the NWWP has used. If you discover a resource that you feel should be listed here, contact the Program Coordinator to have it added.

- **American Cancer Society (ACS):** The American Cancer Society offers a variety of free educational materials on cancer as well as a 24-hour phone information and referral service. 1-800-ACS-2345. All Resources for (cancer.org)
- **American Indian Cancer Foundation (AICAF):** Reclaiming Indigenous health and healing with culture. Addresses cancer inequities faced by Native communities with infographics, toolkits, webinars, Powwow for Hope, survivorship, and more. Resource Library – American Indian Cancer Foundation
- **American College of Obstetricians and Gynecologists (ACOG):** professional organization with guidelines and resources for women's health. Resources for You | ACOG
- **American Society for Colposcopy and Cervical Pathology (ASCCP):** an organization with guidelines for providers to manage and evaluate cervical neoplasia. Mobile web-based app available Guidelines - ASCCP
- **Carol Milgard Breast Center:** Breast health services and education. Located in Tacoma, WA; Local Resources - Carol Milgard Breast Center
- **CancerCare:** CancerCare is a national non-profit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance. CancerCare also offers technical assistance to the community and health care professionals. Cancer Caregiver Resources
- **Cancer Lifeline:** Cancer Lifeline, in Seattle, offers a Patient Assistance Fund which provides financial assistance to women in treatment for breast cancer. They also offer a wide range of programs, support groups, classes, activities, and presentations aimed at optimizing the quality of life for cancer patients and cancer survivors and their families, friends, co-workers, and caregivers. Highlights include healing arts classes and a 24-hour emotional support line. 1-800-255-5505 Lifeline – Cancer Lifeline
- **CDC (Centers for Disease Control) (Centers for Disease Control) NBCCEDP**: About the National Breast and Cervical Cancer Early Detection Program | NBCCEDP | CDC
- **Fred Hutch Cancer Center:** cancer treatment, support, resources, survivorship events and education organization that provides the latest cancer treatment options, support and resources. Recommended Resources | Fred Hutchinson Cancer Center
- **Harmony Hill:** Harmony Hill offers a variety of no-cost cancer retreats for people living with cancer. Retreats vary in length & offer participants practical resources and strategies for dealing with a cancer diagnosis and support in finding emotional, mental, and spiritual healing. 7362 E State Route 106, Union, WA 98592, (360) 898-2363, Cancer Program Offerings - Harmony Hill Retreat Center
- **Livestrong Foundation:** survivorship resources, counseling, financial support. Cancer Resource Center - Livestrong

- **Native American Cancer Research:** organization offering Native American information and support to cancer survivors, caregivers, and educators. (303) 838-9359, Survivors Network 1-800-537-8295; Overview | Native American Cancer Initiatives, Inc. (NACI) (natamcancer.org)
- **National Native Network/ Keep it Sacred:** A public health resource to decrease commercial tobacco use and cancer health disparities among tribal nations. Resource Library | Keep It Sacred (itcmi.org)
- **North Portland Area Indian Health Board (NPAIHB):** non-profit tribal advisory organization that engages in many areas of Indian health, including legislation, health promotion and disease prevention. www.npaih.org
- **Prevent Cancer Foundation:** Research, education, outreach, and advocacy. www.preventcancer.org
- **Salish Cancer Center:** Traditional cancer treatment, naturopathic medicine, acupuncture, and nutritional counseling, a holistic approach to cancer care. 3700 Pacific Hwy E #100, Fife, WA 98424 253-382-6300 Salish Cancer Center - Fife, Washington
- **Susan G. Komen Breast Cancer Foundation**: The Susan G. Komen Patient Care Center offers a comprehensive range of resources to support individuals affected by breast cancer. Key services include: Educational Materials, Financial Assistance, Support Groups, Interactive Learning Tools, Personalized Support-Komen Patient Care Center - Susan G. Komen®
- **United States Preventive Services Task Force (USPSTF):** professional organization with evidence-based recommendations about clinical preventive services such as cancer screenings.
- **Washington Healthplan Finder:** Free or low-cost health insurance coverage. www.wahealthplanfinder.org