Northwest Portland Area Indian Health Board
Portland Area Indian Health Service

Northwest Tribal Cancer Navigator PROGRAM

PILOT PROJECT

Final Report
September 2007

For additional information

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I. Report summary and highlights

This report describes the development, implementation, and preliminary evaluation of a patient navigation program in several community clinics serving American Indians and Alaska Natives (AI/AN) in the Pacific Northwest. The Navigator model, originally developed to assist patients in negotiating cancer screening and post-screening care in Harlem, New York, was adapted by the AI/AN clinics to suit the realities and values of AI/AN communities. Navigating patients through the system, including Indian Health Service (IHS) clinics and specialty cancer care centers, requires flexibility, mobility, and clinical sophistication from Navigators. Navigators in the Northwest Tribal Cancer Navigator Program were registered nurses (RNs) or worked closely with RNs, traveled between community clinics and specialized care centers, and served all patients who had needs related to cancer. Each clinic had one or two Navigators serving a population of about 10,000 primary-care patients.

A number of instruments were created to evaluate the success of the Navigator model in this setting. Navigators documented their encounters with patients and some clinical variables in a dedicated database. The clinical information collected by Navigators was supplemented with data from the clinics' administrative databases and with data obtained from the Washington State Cancer Registry through a data linkage. Patients were interviewed for their perspectives, and providers, who were important participants in the navigation process, were surveyed.

Results indicate high levels of patient and provider satisfaction with the Navigator Program. Coordination of care proved to be an important part of navigation in Indian Country, along with assistance in completing applications and referrals, and communicating with providers. Clinical outcomes seem promising, though a more extensive study will be required to establish whether this navigation model lessens delays and dropouts from diagnosis and treatment. The following report also provides some recommendations for how the instruments can better capture the data required to determine how successfully navigation meets its goals.

Part 2

Background

Northwest Tribal Cancer Navigator Program
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II. Background

A. Setting of the Northwest Tribal Cancer Navigator Program

The pilot Northwest Tribal Cancer Navigator Program was established through a cooperative agreement between the National Cancer Institute's Center to Reduce Cancer Health Disparities and the Portland Area Indian Health Service (PAIHS). PAIHS provides access to health care for an estimated 158,000 Indian residents of Idaho, Oregon and Washington.[1] Health delivery services are provided by a mix of facilities that may be grouped into three categories: those operated directly by the IHS, those operated by the tribes through a Tribal Health Authority (THA) by contract or compact with the IHS, or those that provide services to urban AI/ANs.[2] The three sites originally selected by PAIHS to participate in the pilot represented each of these categories.

The Native American Rehabilitation Association (NARA), an urban clinic in Portland, Oregon, left the pilot in year 2 because of a reorganization that made the program difficult to administer. We wish to express our gratitude for their contribution; the main focus of this report will be on the remaining two sites.

B. Yakama Indian Health Center

History of the Yakama Indian Nation

At the signing of the Treaty of 1855, fourteen bands and tribes were united to create the Yakama Indian Nation. The newly formed nation was named "Yakama," meaning "a growing family," a "trial expansion," or "pregnant one." The tribes listed in the signing of the Treaty of 1855 included the Klickatat, the Klinquit, the Kow-was-say-ee, the Kah-milt-pah, the Li-ay-was, the Oche-chotes, the Palouse, the Pisquose, the Skin-pah, the Se-ap-cat, the Shyiks, the Wenatchapam, the Wish-ham, and the Yakama. The newly formed Yakama Nation ceded 10,828,800 acres of ancestral land to the U.S. government but retained their right to hunt, fish, access and use traditional cultural sites, gather traditional foods and medicines, pasture stock, and have water in sufficient quantity and quality in all of their "usual and customary places" within the ceded area (see Figure 1).

Figure 1. The Yakama Reservation, Yakama ceded area, and Washington State.

The tribes were distinct in their cultures but shared a common language, Sahaptian. The Yakama people changed the spelling of their name from Yakima to Yakama in the 1990s to reflect the proper Sahaptian pronunciation. The Yakama Tribal School (grades 7 to 12) was established in 1980 near Toppenish. The curriculum of the school links the past, present, and future of the Yakama people and aims to revive the Sahaptian language. The school was also designed to promote awareness of the circle of life, respect for the universe, and the need to honor the past by continuing the belief and teachings of the elders.

The Yakama Indian Reservation

The Yakama Indian Reservation is located in the south of Washington State, within the Yakima and Klickitat counties (see Figure 1 above). The reservation covers 1,371,918 acres of agricultural, forested, and range lands. Tribal headquarters are in Toppenish, twenty miles from the city of Yakima. The nearest major cities – Seattle and Portland – are about 170 miles away, and the drive to Spokane is about 200 miles. Much of the land in the western section of the reservation is reserved for Yakama Indian use; entrance is by permit only. It contains many areas of ancient root and berry grounds, hunting areas, and rangeland where wild horse herds roam.

The Yakama tribe runs a number of programs and businesses that contribute to the economic climate of Eastern Washington. Tribal enterprises include fisheries and wildlife offices, a land enterprise, forestry, forestry products, lumber mills, agriculture and orchards, a tribal radio station, banking, and tourism. Tourist attractions include the Yakama Nation Cultural Heritage Center, which houses a museum, restaurant, gift shop, theater, and library; a tribal

RV park in Toppenish; and Legends Casino and Convention Center, which hosts entertainment and community health events.

English is the primary language spoken on the reservation, though Spanish is increasingly common. The Yakima Valley is a major agricultural area – a source of famous Washington apples – and attracts immigrant laborers from Latin America. In fact, in the 2000 U.S. Census, only 25.8% of the people living on the Yakama Reservation and trust lands identified themselves as American Indian and Alaska Native (AI/AN), while half (50.4%) of residents said they were Hispanic or Latino (see Table 1 below). The traditional Sahaptian language is taught in the Yakama Tribal School mentioned above, but many of the older adults in the tribe were sent to Indian boarding schools as children and prevented from using their native language there. As a result, translation and interpretation services are rarely needed.

Salmon, the base of the traditional economy in the region, continues to play a principal role in the culture, religion, economy, and nutrition of the Yakama Nation. The tribes still gather for the First-Food Feast to give thanks to the Creator for another year of salmon, roots, and berries. The salmon remain a primary source of protein for the bands and tribes of the Yakama Nation, including some communities of subsistence fishers along the Columbia River just off the reservation. The Yakama participate in major research and advocacy efforts to restore salmon in the region and evaluate potential threats to health from fish contamination. The tribe belongs to the Columbia River Inter-Tribal Fish Commission.

The per capita annual income on Yakama lands was half that of the per capita income for Washington State in 1999, at $10,618, compared to $22,973. Accordingly, 24.4% of families and 28.0% of individuals on Yakama lands live below the Federal Poverty Level, compared to only 7.3% of families and 10.6% of individuals in Washington State. See Table 1 for more details of these and other indicators.

Selected Demographics: Yakama Indian Reservation*, Puyallup Indian Reservation*, Pierce County†, and Washington State

(Source: United States Census, 2000, accessed through the American FactFinder at http://factfinder.census.gov)

	Yakama Reservation		Puyallup Reservation		Pierce County		Washington State	
Subject	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total population	**31,799**	**100.0**	**41,341**	**100.0**	**700,820**	**100.0**	**5,894,121**	**100.0**
Land area (square miles)	2,188	--	29	--	1,807	--	71,300	--
Population density (persons/mile^2)	14.5	--	1,488.2	--	417.4	--	88.6	--
Race								
American Indian and Alaska Native	7,411	23.3					93,301	1.6
White	10,605	33.4					4,821,823	81.8
Black or African American	130	0.4					190,267	3.2
Asian	422	1.3					322,335	5.5
Native Hawaiian and other Pacific Islander	12	0.0					23,953	0.4
Some other race	11,655	36.7					228,923	3.9
Two or more races	1,564	4.9					213,519	3.6
AI/AN alone or in combination with another race	8,193	25.8					158,940	2.7
Hispanic or Latino (any race)	16,039	50.4					441,509	7.5
Median age, all races (years)	26.5	--					35.4	--
Average family size, all races	4.03	--					3.07	--
Educational Attainment (all races, population 25 years and over)								
Percent high school graduate or higher	--	56.4					--	87.1
Percent bachelor's degree or higher	--	9.3					--	27.7
Income in 1999, all races								
Per capita income (dollars)	10,618	--					22,973	--
Percent of families below poverty level	--	24.4					--	7.3
Percent of individuals below poverty level	--	28.0					--	10.6
Employment status (all races, population 16 years and over)								
In labor force	12,332	58.3					3,027,734	66.5
Not in labor force	8,831	41.7					1,525,857	33.5
Housing characteristics, all races								
Occupied housing units	8,561	100.0					2,271,398	100.0
No telephone service	487	5.7					31,110	1.4
Lacking complete plumbing facilities	139	1.6					12,457	0.5
Lacking complete kitchen facilities	95	1.1					16,173	0.7

* Reservation and off-reservation trust land; † Pierce County is the main catchment area for the Puyallup Tribal Health Authority and may be more representative of the patient population and environs than the Puyallup Reservation lands; -- = Not applicable

The Yakama Indian Health Center

The Yakama Indian Health Center in Toppenish is a federally-funded and -administered Indian Health Services facility. The tribe operates a satellite clinic in the community of White Swan, 20 miles west of Toppenish, and several community health programs housed in or near the Toppenish facility. The community programs include the federally-funded program for Women, Infants, and Children (WIC) and substance abuse treatment, as well as the Community Health Representative (CHR) program, which employs paraprofessionals to provide home-based health services.

The Yakama Indian Health Center
401 Buster Road
Toppenish, Washington 98948
(509) 865-2102

Services are available to any person from a federally recognized Indian tribe. Like other Indian Health Service facilities, the Yakama Indian Health Center (YIHC) has two levels of eligibility. Patients eligible for Direct Care are eligible only for services provided on site at the YIHC. Patients eligible for both Direct Care and Contract Health Services (CHS) may receive extended care contracted to other health care providers. To qualify for CHS, patients must be enrolled Yakama tribal members living in the clinic's catchment area. CHS services are also available to enrolled members of other tribes who live within the reservation boundaries, or who live off the reservation but are full-time employees of the Yakama Nation, the local Bureau of Indian Affairs (BIA) office, or the YIHC.[3]

Table 2. Current patients at the Yakama Indian Health Center as of September 15, 2003

Category	Number of patients
Total living patients	22,873
Tribe of membership	
Yakama*	6,451
Non-Yakama	16,422
Eligibility for services	
Direct Care† only	9,704
Direct Care† and Contract Health Services‡	12,879

*Note that total number of Yakama patients (by tribe of membership) differs from the number of people currently enrolled in the Confederated Tribes and Bands of the Yakama Nation. There are approximately 9,600 enrolled Yakama members.

† Direct Care provides only for on-site medical services at YIHC.

‡ Contract Health Services provide extended care for enrolled Yakama tribal members or members of other federally recognized tribes, currently living on the reservation or having close social and/or economic ties to the community.[3]

Direct Care covers Pap tests, clinical breast exams, digital rectal exams, and fecal occult blood tests, but other cancer-related services must be covered either by CHS or third-party payers and provided by off-site contractors. Patients who require services beyond primary care are referred to facilities in Yakima or The Dalles, Oregon, or to tertiary care centers in Seattle or Portland. Referral services include obstetrics and gynecology, ultrasound, mammography, magnetic resonance imaging (MRI), computed tomography (CT) scans, chemotherapy, radiation, dialysis, and surgery.

The Yakama Indian Health Clinic was remodeled in 1990 to create a 40,000-square-foot facility that now has 161 employees. It was constructed to accommodate 10,000 patients; the clinic now has 23,000 patient charts on file. The clinic operates from Monday through Friday, from 7:45 AM to 5:00 PM. In 2003, at the start of the pilot program, the medical department was staffed with six physicians, two nurse practitioners, six registered nurses, two licensed practical nurses, and two certified nursing assistants.

The catchment area for the Yakama Indian Health Center includes the Yakama Indian Reservation and eight (8) counties: Yakima, Klickitat, Kittitas, Grant, Skamania, Chelan, Franklin, and Lewis. This area closely resembles the ceded area that was created in the signing of the Treaty of 1855 (see Figure 1 above).

C. The Puyallup Tribal Health Authority

History of the Puyallup Tribe and PTHA

The Puyallup Tribe is part of the Puget Sound Salish Indian culture. Members of that culture traditionally spoke the Puyallup-Nisqually language. Salmon was the main food and important in their ceremonies. The Western red cedar was used abundantly for clothing, basketry, and lodging. They were fishermen, gatherers, and hunters.

The Puyallup Tribe established relations with the United States government on December 16, 1854, and soon thereafter signed the Treaty of Medicine Creek. Article 10 of that treaty provides for a physician to look after the health care of the Puyallup Tribe; hence the Puyallup Tribe sees medical care as a treaty right, paid for in vast tracts of tribal land and resources. Today, the Puyallup Tribe is governed by a seven-member Tribal Council elected by the tribal members, who also act as the Board of Directors for the Puyallup Tribal Health Authority (PTHA).

Health services were provided to the tribe in the early 1970s by the Public Health Service in the form of a mobile trailer that visited the reservation. The trailer pulled into the tribal cemetery and set up their dental facility. Contract health care was available to a few, but the system could not ensure quality care. Problems regarding eligibility, fee schedules, and billing procedures were annoyances that seemed insurmountable to many tribal members. A lack of funds was an added obstacle.

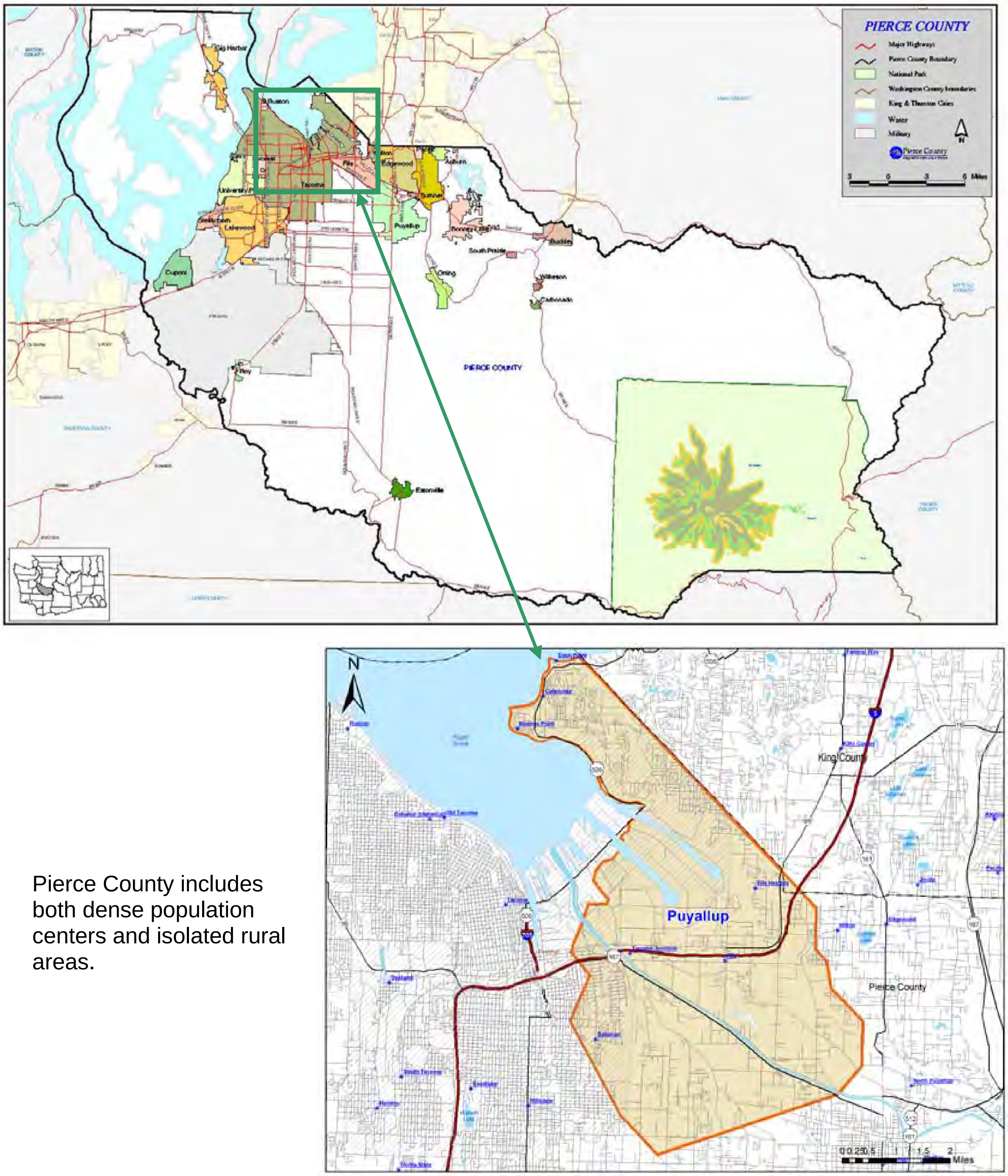
Tribal Council appointed an Education and Health Committee to address the health care needs of the tribe and other Native Americans in Pierce County. A local funding agency provided positions for lay health workers, known as “Community Health Representatives” or “CHRs.” In 1974, funds became available to support the tribe’s medical clinic. For a number of years, health care came to the Indian community of Pierce County out of a double-wide modular unit. The Puyallup Tribal Health Authority (PTHA) was established as one of the first Indian “self-determination clinics” under Public Law 93-638. Puyallup heath services have grown from that single mobile to several modern, attractive, and culturally designed buildings.

The Puyallup Indian Reservation

The Puyallup Reservation is unusual in that it is located within the corporate boundaries of a major city. The reservation occupies about 29 square miles in Tacoma, Washington (see Figure 2 inset). The reservation boundaries are locally not well-known, and much of the land within the boundaries is neither tribally owned nor owned privately by tribal members. Only 4.7% of the population residing within the reservation boundaries self-identified as American Indian or Alaska Native, alone or in combination, on the 2000 U.S. Census.[4]

Many of the 3,200 enrolled members of the Puyallup Tribe live in Pierce County, which is also the catchment area for PTHA. Pierce County covers 1,790 square miles, from the Puget Sound to Mount Rainier, and has a population of 700,820 (see Figure 2). Of those, 19,919 identify themselves as American Indian and Alaska Native.[4]

Figure 2. Pierce County, Washington,[†] and Puyallup Indian Reservation[‡] (inset)



Pierce County includes both dense population centers and isolated rural areas.

[†] Obtained from Pierce County: http://yakima.co.pierce.wa.us/MapGallery/index.cfm?event=displayMaps

[‡] Obtained from the Environmental Protection Agency: http://yosemite.epa.gov/R10/AIRPAGE.NSF/webpage/FARR+Indian+Reservations

The Puyallup Tribe faces complex challenges. As an urban clinic serving a rural population, problems common to both areas are present ranging from HIV and gangs to unanticipated pregnancies at early ages and drug usage and trafficking.

The Puyallup Tribal Health Authority

Takopid Health Center
2209 East 32nd Street
Tacoma, WA 98404

The Puyallup Tribal Health Authority (PTHA) was established as one of the first Indian “self-determination clinics” under Public Law 93-638. The Takopid Health Center, completed in 1993, integrates modern and traditional architecture and, along with the adjacent Kwawachee Center for mental health, includes spaces designed to incorporate traditional healing practices. PTHA has 23,848 patients registered under the IHS eligibility criteria. The “active user population”— patients who have used PTHA services within the past three years—numbers 8,704. There were a total of 105,603 ambulatory visits during the calendar year 2002.

As a tribally-run clinic, PTHA operates on a model similar to the model of care at IHS clinics such as the Yakama Indian Health Center. Direct Care covers Pap tests, clinical breast exams, digital rectal exams, and fecal occult blood tests, but other cancer-related services must be covered either by CHS or third-party payers and provided by off-site contractors. These off-site services are available in Tacoma. Nearby Seattle has several tertiary care centers.

Part 3

Objectives

Northwest Tribal Cancer Navigator Program
Pilot Project Final Report

III. Objectives

For the Northwest Tribal Cancer Navigator Program pilot project, the participating sites, the Northwest Portland Area Indian Health Board, and the Indian Health Service developed five main objectives:

1. Increase cancer awareness in Native communities
2. Allow for earlier detection of cancers through adequate follow-up of screening tests and abnormal results
3. Improve coordination of care between the many individuals who participate in the healing process at all stages (including diagnosis, treatment, supportive care, survivorship and the end of life)
4. Help obtain and coordinate resources for patients at all stages of their cancer journey
5. Encourage a greater sense of empowerment and good quality of life among cancer patients during all stages of their cancer journey

These objectives guided the planning of patient navigation and its evaluation. Objective 2 developed after the start of the program, when the scope of navigation was expanded to include patients needing assistance with abnormal screenings.

Part 4

Methods

Northwest Tribal Cancer Navigator Program
Pilot Project Final Report

IV. Methods

A. Formative phase

During the formative phase of the Northwest Tribal Cancer Navigator Program, the intervention sites were selected, staff hired, the IRB protocol was written and submitted, the database was created, and the first Navigator training was planned.

Funding was allocated in the fall of 2002 for a one-year pilot at $150,000. The director of the Portland Area IHS (PAIHS) designated the original three sites – the Native American Rehabilitation Association (NARA), the Puyallup Tribal Health Authority (PTHA), and the Yakama Indian Health Center – as representative of the three models of service delivery in the region (see Table 3). Each site submitted a proposal for $40,000 for one year; at this level, the sites planned for one half-time registered nurse to serve as the Navigator, with few additional costs. PAIHS withheld $30,000 for coordination and evaluation of the project, which was contracted to the Northwest Portland Area Indian Health Board (NPAIHB).

Table 3. Northwest Tribal Navigator Pilot Program Sites

Clinic name	Acronym	Service model
Native American Rehabilitation Association of the Northwest	NARA (also NARA NW)	Urban Indian clinic
Puyallup Tribal Health Authority	PTHA	Tribally-administered clinic
Yakama Indian Health Center	YIHC, or ‘Yakama’	Indian Health Service (IHS) service unit
Other participating institutions		
Portland Area Indian Health Service	PAIHS	Federal agency for programs and service units in Oregon, Idaho, and Washington; administered Navigator Pilot
Northwest Portland Area Indian Health Board	NPAIHB	Tribal organization representing 43 federally-recognized tribes in the Northwest

Later in fiscal year 2003, the funding level was raised to an overall budget of $330,000. In the revised budget, each site received approximately $90,000, which was sufficient for a full-time Navigator. NPAIHB received $40,000. PAIHS provided all of its support – including the principal investigator’s time – as in-kind contributions.

Table 4. Formative phase timeline

2002	
November 13-14	Initial planning meeting
November 27	Planning conference call
December	First Navigator hired (Yakama Indian Health Center)

Table 4. Formative phase timeline

2003	
January	Tribal site proposals submitted
January 10 & 30	Planning conference calls
February 6-7	Planning meeting
March	Project coordinator hired (NPAIHB)
March 26	Conference call. Danelle Reed-Inderbitzin (Puyallup), PhD, designated as principal investigator
March 28	First IRB protocol submitted
April	Additional Navigators hired (Puyallup Tribal Health Authority, NARA)
April 10	Planning conference call
April 24	Revisions to IRB protocol submitted
May 6-7	Navigators and project coordinator visit Ralph Lauren Center for Cancer Care and Prevention in Harlem
May 20-22	First Navigator training in Portland, OR
June 16	IRB approval of navigation services
June to October	Continued development of instruments and database
July 13-15	PI, Navigators, and project coordinator attend Special Populations Networks Cancer Health Disparities Summit IV
July 16	PI and project coordinator meet with NCI and NOVA Research Company in Bethesda, MD, to discuss and review evaluation
August 5	Planning meeting in Portland (PAIHS, NPAIHB, clinics)
November 12	IRB approval of data collection

Because the project was originally planned as a one-year pilot, the development was brief. Some of the steps normally undertaken for larger, multi-tribe projects were omitted, such as creating a detailed scope of work, putting data-sharing agreements in place, and pursuing resolutions from tribal councils. The omission of usual initial steps led to some confusion later, when the project was expanded over multiple years.

NARA left the project soon after the formative phase, in early 2004. At the time, the clinic was restructuring its care model so that providers were organized in teams. The clinic found the single-Navigator requirement of the project incompatible with its team approach and declined further participation.

B. Navigator qualifications and supervision

The first Navigators hired were bachelors-prepared registered nurses (RNs). (See Appendix A for sample position descriptions.) When NARA withdrew from the project in early 2004, PAIHS redistributed the lapsed funds to the other two sites, allowing each of them to hire a “Community Navigator.” The Community Navigator position descriptions at both sites were modeled on Community Health Representatives (CHRs), paraprofessionals widespread in IHS and tribal clinics since the late 1970s. The minimum qualifications included a high school diploma or equivalent and two years' experience in a medical setting. Native applicants who were cancer survivors or family members of survivors were particularly sought after.

Every Navigator has been required to work very independently, without the direct day-to-day supervision of the principal investigator. Navigators were hired and supervised directly by the clinics, not by PAIHS or NPAIHB. The supervisory structure was determined by the clinic and changed over time. Navigators have been supervised by their clinic directors, community health department directors, and nurse managers.

Initially, all of the Navigators worked full time, though under the initial budget only half of their time was devoted to patient navigation. When the funding level increased, PTHA and YIHC increased the FTEs of their Navigators to 1.0. NARA hired an additional 0.5 FTE Navigator. Most Navigators who had less than 1.0 FTE devoted to navigation reported stress under that arrangement, and when their FTE was fully devoted to navigation, they reported increased job satisfaction.

Over the course of the pilot phase, the program has had a total of eight Navigators. Of those eight, one is an enrolled member of a federally-recognized tribe; she is a member of the home tribe. Two other Navigators belong to non-federally-recognized tribes and have ties to their local Native communities. Seven of the eight have been women, and one is Hispanic.

Table 5. Selected demographic characteristics of Navigators (n=8)

Race		Ethnicity		Gender		Education	
Member of "home tribe"	1	Hispanic	1	Female	7	RN* with bachelor's degree	5
Indian, but not enrolled	2	Non-Hispanic	7	Male	1	Oncology-certified nurse	1
Non-Indian	5					Some college	2

*Registered nurse

Some speculate that Navigators who are racially and ethnically matched to the patient population they serve are more effective than Navigators who are not. Our pilot project is far too small to answer that question. However, conversations with patients, clinicians, and Navigators themselves have led us to believe that matching on race and ethnicity is not a priority when hiring a Navigator. When possible, matching Navigators to patients by gender seems to put patients at ease; cancer screening, in particular, involves talking about and exposing parts of the body that have associated taboos. Navigators who are good communicators, quick to respond to problems, and competent in their jobs are respected by patients and providers alike.

Table 6. Nurse Navigators and community Navigators, advantages and disadvantages in an Indian community setting

	Nurse Navigator, often not a member of the local tribe	Community (lay) Navigator, member of the tribe or having close ties to the reservation
Ability to navigate barriers in medical system	▪ Can make good judgments about patients' medical needs ▪ Clinicians appreciate working with someone who "speaks their language" ▪ Can deliver patient education, assurance of care often not provided by physicians and specialists	▪ Needs support from and access to medical and nursing staff at clinic ▪ Longer time to develop trust of clinicians at hospitals and cancer care centers ▪ May be overwhelmed by patients' medical needs
Ability to navigate barriers related to social services	▪ Very capable ▪ May have difficulty contacting patients if not a long-time resident of the community because people move often	▪ Very capable ▪ Knows community and can contact patients through family and other social connections
Cultural expertise	▪ May not be familiar with cultural norms and need to consult with tribal members	▪ Expert in cultural norms
Acceptance in community	▪ Sincere interest and good work are often rewarded with a credible reputation in community	▪ Same as for nurse. Long-standing relationships may create both opportunities and complications
Credibility to patients	▪ To some patients, "outsider" status assures confidentiality and objectivity ▪ To other patients, "outsider" may not be trustworthy	▪ Patients may trust a community member more than a non-community member ▪ Depending on relationships in the community, some patients may see this Navigator as a threat to confidentiality
Salary	▪ High compared to lay worker; low compared to physicians and some social workers or case managers who might otherwise "navigate" patients	▪ More affordable to programs with limited funds
Recruitment	▪ Can be difficult; non-Native nurses easier to recruit	▪ Relatively easy

Recommendations

- Navigators should be hired for full-time navigation. If a budget does not allow for a full-time cancer Navigator, we believe it is preferable to share time with another patient population – e.g. a Navigator for cancer and diabetes patients – rather than splitting time between navigation and other types of activities, such as ambulatory care.

- While both lay Navigators and RN Navigators can be effective, our study demonstrates that a RN is comfortable navigating a wider range of barriers and interacting with physicians.

- The Navigator model has more in common with community health or medical models than with ambulatory care nursing. If possible, we recommend that the Navigator be supervised by the community health director, the clinic director, or another supervisor of employees who spend the majority of their time working outside the clinic.

- Patient navigation is demanding, both professionally and emotionally. In addition, successful Navigators network constantly. We recommend that Navigators be encouraged to speak to each other often (at least once a week), even if they work at different clinics. In programs such as ours, where each clinic has only one or two Navigators, the Navigators from different clinics should have opportunities to meet in person multiple times each year.

C. Training

Initial training

The first group of Navigators traveled to Portland, Oregon for an orientation to the Navigator Program and a "Cancer 101" training. As later Navigators were hired, they received similar orientations on-site from the project coordinator.

In addition, Navigators were asked to introduce themselves to all local providers and community organizers who had services related to cancer or patient support. This group included oncologists, surgeons, county breast and cervical health programs, social workers, transportation volunteers, and survivor support groups, to name a few. This kind of networking is essential. It must occur on an ongoing basis, but is particularly important when a Navigator is newly hired and has not yet developed a full load of patients and a network of service providers.

At a minimum, each new Navigator covered the following:

- Introduction to NPAIHB research staff

- Orientation to the program from the project coordinator: Program history, study protocol, informed consent, documenting encounters, using the database

- Clinic operations from the direct supervisor

- Introduction to cancer (organized training or self-directed[5])

- Online course in "Human Participant Protections Education for Research Teams" hosted by the National Cancer Institute[6]

- Introductions to oncologists, nurses, social workers, volunteers, and anyone else currently or potentially involved with cancer patients in the area; visits to treatment facilities

Ongoing education and professional development

Navigators seem to require three to six months on the job before they feel confident and comfortable. At this point, we asked Navigators to pursue continuing education that they judged to be suited to their needs. We aimed to maximize training dollars by taking advantage of existing programs rather than attempting to develop our own.

The project coordinator shared notices of potential training opportunities on email and asked the Navigators to do the same. When a Navigator identified an appropriate training opportunity, the program paid for registration and salary time at training. The most successful of these courses (as reported by the Navigators) was one organized by the Puget Sound Oncology Nursing Education Cooperative to train new oncology nurses. The training lasts four full days over two weeks and is offered twice a year. Intensive oncology nursing courses are not recommended for non-nurses, who report that nursing terminology makes the entire training difficult to follow.

Navigators pursued other professional development and networking opportunities at regional and national conferences, such as the Intercultural Cancer Council's biennial symposium in Washington, DC, or the Northwest Tribal Cancer Control Program's clinicians' training sessions and coalition meetings. Conferences were used as opportunities to bring all of the program staff together. An extra day of travel was scheduled on these trips for the group to meet.

Table 7. Training and development dates, locations, and topics covered, 2003-2006

Date and location	Topics
May 20-22, 2003 *Northwest Portland Area Indian Health Board (NPAIHB)* *Portland, OR*	*Patient Navigation,* Dr. Roland Garcia, NCI, and Rian Rodriguez, Ralph Lauren Center for Cancer Care and Prevention *Cancer 101,* a CDC- and NCI-sponsored, Native-specific curriculum, Ruth Jensen (NPAIHB) *Palliative and End-of-Life Care*, Paul Bascom, MD (OHSU) *Report from the Native Survivorship Conference*, Christine Ross, RN, BSN, Navigator (YIHC) *Study protocol, patient notebooks, data collection instruments, recruitment scripts*, Katrina Ramsey, Project Coordinator (NPAIHB) *Lung Cancer*, Helen J. Ross, MD *Medicine and Traditional Healing*, John Bravehawk, Spiritual Advisor and Cancer Survivor *Epidemiology of Cancer in Indian Country*, Tom Becker, MD, PhD (OHSU)

Table 7. Training and development dates, locations, and topics covered, 2003-2006

Date and location	Topics
September 22-23, 2003 *Cancer Information Service – Pacific Region* *Fred Hutchinson Cancer Research Center* *Seattle, WA*	*Data Collection*, Katrina Ramsey, Project Coordinator (NPAIHB) *Mental Health Issues: Patients and Staff*, Danelle Reed-Inderbitzin, PhD (PAIHS) *National Cancer Institute's Cancer Information Service (CIS), Cancer.gov, and Spirit of EAGLES Overview*, Panel *Developing a Resource Library* *Social Work & Resource Overview and Tour of Seattle Cancer Care Alliance (SCCA)*, Christy Alpin (SCCA) *Cancer Pain Management*, Ellen DeBondt, RN (SCCA) *Breast Cancer Overview*, Char Jantzen, RN (SCCA) *Colorectal Cancer Overview*, Teresa Crossley-Hill, RN (SCCA) *Gynecological Cancers*, Holly Tomashek, RN (SCCA) *Prostate Cancer Overview,* Hanne Peterson, RN (SCCA) *Lung Cancer Overview,* Karen Baker, RN (SCCA)
October 23-24, 2003 *Navigator Retreat* *Rim Rock Lake, eastern Washington*	Navigators held a call-in radio show on the Yakama Reservation radio station, KYNR, and then traveled to a family cabin to share insights and contacts and to set future goals. A representative of the Cancer Information Service – Pacific Region also attended. *Call-in radio talk show at KYNR* *Discussion with representatives of the* American Red Cross, *the* National Marrow Donor Program, *and the* Cancer Information Service/Spirit of EAGLES/Fred Hutchinson Cancer Research Center *Resource sharing* *Drafting a case study for a patient shared by two Navigator sites* *Compiling literature in response to specific requests from radio show callers* *Discussion of Navigator roles and responsibilities*
December 10, 2003 *Yakama Indian Health Center (YIHC), Toppenish, WA* December 19, 2003 *Puyallup Tribal Health Authority (PTHA), Tacoma, WA*	Onsite Navigator training with Navigator and project coordinator. The Yakama Navigator traveled to PTHA on December 19 as well. *Chart review* *Computer and database use* *Discussion of data collection protocols* *Discussion of programmatic issues*
March 1,2 & March 8,9, 2004 *Puget Sound Oncology Nursing Education Cooperative* *Bellevue, WA*	*A program to provide new oncology nurses with a platform of basic core knowledge in the nursing care of people with cancer* Overview of Cancer Pathophysiology ♦ Principles of Cancer Treatment ♦ Immunology, Hematopoiesis & Growth Factors ♦ Genetics ♦ Diagnostics ♦ Radiation Therapy ♦ Fluid & Electrolyte Alterations Related to Cancer and Cancer Therapy ♦ Breast Cancer ♦ Colorectal Cancer ♦ Lung Cancer ♦ Pulmonary Alterations ♦ Prostate Cancer ♦ Lymphomas ♦ Leukemia ♦ Stem Cell Transplant ♦ Multiple Myeloma ♦ Blood Product Support ♦ Care of the Immunocompromised Patient ♦ Patient Panel ♦ Oncologic Emergencies ♦ Gastrointestinal Alterations ♦ Cancer Pain Management ♦ Symptom Management in the Terminal Patient ♦ Communication

Table 7. Training and development dates, locations, and topics covered, 2003-2006

Date and location	**Topics**
March 24-28, 2004 *Washington, DC*	From Awareness to Action: The Unequal Burden of Cancer 9th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Intercultural Cancer Council and Baylor College of Medicine. Attended by all program staff.
May 11-13, 2004 *Scottsdale, AZ*	Indian Health Service 16th Annual Research Conference Attended by project coordinator.
July 29, 2004 *Seattle, WA*	Grant Writing Workshop, Susan G. Komen Breast Cancer Foundation. Attended by PTHA Navigator.
August 20 & 30-31, 2004 *YIHC, Toppenish, WA*	Onsite Navigator training with Navigator and project coordinator. *Chart review* *Computer and database use* *Discussion of data collection protocols* *Discussion of programmatic issues*
September 9-12, 2004 *Gila River Indian Reservation, Wild Horse Pass Resort and Spa, Phoenix, AZ*	Spirit of EAGLES, American Indian/Alaska Native Leadership Initiative on Cancer, "Changing Patterns of Cancer in Native Communities: Honoring Our Families—from Prevention to Cure." Attended by PTHA Navigator, PTHA survivor (scholarship secured by Navigator); YIHC Navigators, PI, and Project Coordinator Description: "This is a conference on cancer epidemiology, cancer control, and cancer survival among Native populations in the US and in American Samoa. Our goal … is to evaluate progress in prevention of cancer in Native groups and in the early diagnosis, treatment, and survival of Native people diagnosed with cancer."
February 11, 2005 *NPAIHB, Portland, OR* March 24, 2005 *PTHA, Tacoma, WA*	A PTHA administrative assistant and interim Navigator, traveled to Portland, OR, for training from the project coordinator. The training focused on project goals and recording study data. Later, the PI and project coordinator conducted onsite training at the PTHA clinic for two new Navigators (an RN and community Navigator). Instruction included discussion of project goals, chart reviews, database and computer orientation, discussion of data collection protocols, and discussion of programmatic issues.
April 10-13, 2005 *National Institutes of Health Clinical Research Center* *Bethesda, MD*	NCI Patient Navigator Academy (PNA), sponsored by NCI's Center for Cancer Research, in collaboration with the Center to Reduce Cancer Health Disparities and the Division of Cancer Treatment and Diagnosis. Objectives included: *Understanding NCI's perspective on patient navigation and health disparities* *Recognizing the common classification systems for cancer* *Discussing cancer development* *Understanding cancer treatments* *Discussing the psychosocial impact of cancer* *Defining clinical trials and identifying the different types of trials* *Understanding how to access and enroll in clinical trials* Navigators from YIHC and PTHA attended.

Table 7. Training and development dates, locations, and topics covered, 2003-2006	
Date and location	**Topics**
May 10-12, 2005 *Alaska Native Tribal Health Consortium* *Anchorage, AK*	Alaska Palliative Care Symposium *Core competencies for caring for people who need palliative care* *Working with an interdisciplinary team to meet patient and family needs* *Resources to support the unique palliative are needs in different populations and cultures* *Developing an initial treatment approach to normal grief* *Outlining a systematic approach to communication* *"Self care" for the health care provider* Attended by the PTHA Navigator
June 1-2, 2005 *NPAIHB* *Portland, OR*	Tribal Action Planning Training, Northwest Tribal Cancer Control Program (CDC). Attended by PTHA Navigator and YIHC Navigator with Yakama cancer survivor support group (Office of Native Cancer Survivorship – Yakama) member.
June 7-8, 2005 *Fred Hutchinson Cancer Research Center* *Seattle, WA*	Cancer 101 Train-the-Trainer, Spirit of EAGLES/Cancer Information Service/Northwest Tribal Cancer Control Program. *Cancer action plans* *Taking Cancer 101 to Your Community* *Native-specific cancer education videos* *Organizational support for taking Cancer 101 to your community* *Taking it back to the community: Breakout session*
October 14, 2005 *YIHC, Toppenish, WA*	Onsite Navigator training with new Navigator and project coordinator. *Computer and database use* *Discussion of data collection protocols* *Discussion of programmatic issues*
October 26, 2005 *Portland, OR*	Tribal Clinicians' Cancer Update for Physicians, Nurses, Nurse Practitioners, and Pharmacists *Cancer study designs* *Clinical trials* *Education materials for patients* *Patient navigation* *Cancer and the environment* *Lymphoma diagnosis and management* Attended by Navigators from YIHC and PTHA as well as the PI and project coordinator.
April 19-23, 2006 *Washington, DC*	Intercultural Cancer Council's 10th Biennial Symposium on Minorities, the Medically Underserved & Cancer. The project officer, PI, project coordinator, Navigator, and a navigated patient, along with the evaluator from NOVA Research Company, presented a panel session on patient navigation. Attended by YIHC Navigators and program staff.

D. Patient navigation

Eligibility

In the first year of the program, navigation services were restricted to patients who were diagnosed with cancer, or whose diagnosis was very probable (i.e. symptomatic patients, who often needed assistance negotiating the referral process for biopsies). After the first year, eligibility was expanded to include any patient with an abnormal screening result. Navigation is similar for both sets of patients and few distinctions need to be made.

Navigation was available to any adult patient eligible for care at the study clinics. Parents of patients under 18 and caregivers of incapacitated patients were also eligible to access navigation services. While some Navigator programs restrict eligibility to certain types of cancer (e.g. those for which there are screening tests), this kind of restriction was universally rejected in the Northwest Tribal Cancer Navigator Program sites. Northwest tribal communities tend to value inclusiveness. Local leaders judged that restricting the program to certain types of cancer would damage the reputation of the program to the point that few patients would choose to participate.

Referral to Navigators

Anyone could refer a patient to the Navigator Program – the patient, a physician from the clinic, a provider from a cancer center, a family member – but Navigators could not make the initial contact. The Institutional Review Board (IRB) for the Portland Area IHS stipulated that Navigators **not** be allowed to recruit patients to the program in order to avoid potential problems, including perceived coercion, mental distress, breach of confidentiality, and having the Navigator be the first to inform the patient of a diagnosis. Referrals could be made at any point between abnormal finding and resolution.

When a provider at the participating clinic referred a patient, he or she told the patient that working with the Navigator did not necessarily mean that the patient had cancer, and that the patient could refuse or drop out at any time without explanation and without any loss of benefits or services. (See Appendix B for the referral script used.)

Navigators took action to increase the visibility of the program locally. They distributed brochures and business cards to local providers who might encounter patients who were eligible for navigation services. The reservation newspapers and clinic newsletters printed articles about the Navigator Program to inform the community at large, throughout the duration of the study (see Appendix C), and Navigators participated in health fairs and powwows.

Patient contact

Navigation encompasses a broad range of activities geared at coordinating existing resources. Navigators do what they can so that patients initiate timely care and remain in care until resolution. The project has aimed for an approach that is both “downstream” and “upstream” in the public health sense – tracking down patients who have dropped out of care, but also fixing problems before patients drop out.

Table 8. Examples of navigation activities, by type of Navigator

Any Navigator	Nursing-qualified Navigator
▪ Help patients complete referral paperwork or applications for Medicaid, Medicare, etc. ▪ Contact transportation volunteers ▪ Locate low-cost housing ▪ Talk about what to expect during chemotherapy ▪ Show a patient photos of mastectomy scars ▪ Call the night before an appointment to remind the patient of the time, transportation arrangements, and/or preparation instructions ▪ Provide educational materials ▪ Tell patients about survivor support groups ▪ Attend consultation appointments with patients and talk about the appointment afterwards; help patients identify points that need clarification and contact the provider if needed ▪ Ensure that patient records are complete by calling other facilities for copies of lab results ▪ Attend first chemotherapy appointments	▪ Check on patient periodically and respond to serious side effects if needed ▪ Notify primary care provider of medical needs ▪ Provide patient education ▪ Fix problems with routine prescriptions ▪ Contact traditional healers and providers to negotiate the relationship between traditional Native healing practices and medical practices ▪ Attend the local cancer center's weekly cancer patient care conference

We have found that it is in the best interest of patient Navigators to have a clearly defined job description, including the definition of scope. Throughout the study our experience has shown that pressure to expand the limits of navigation are fairly constant. In general, Navigators are typically compassionate, generous, and resourceful; our experience indicates that they are inclined to respond to all patient needs or worry even outside the scope of their position. In an Indian community there is often an added sense of public scrutiny, which the Navigator experiences as pressure to do more. An important realization for patients is that the Navigator is a member of a larger treatment "team." Defining the scope of patient navigation remains difficult.

Notebooks for patients

Navigators provided binders to assist patients in organizing their care. According to the Navigators, some patients loved the binders, while others declined them or took them and never used them. Thus the Navigators took a many-sizes-fit-many approach and gave patients several binders to choose from. Options included binders assembled by the program in a standard, 8.5"x11" format with 1" rings, larger binders provided at no cost by the Lance Armstrong Foundation, or smaller binders also provided at no cost by GlaxoSmithKline. The binders provided by the Lance Armstrong Foundation and GlaxoSmithKline came with pre-printed pages for record keeping and general information about cancer and treatment. They were similar, in content, to the binders assembled by the Navigators.

The Navigator-assembled binders contained the following:

- A blank, planner-style calendar
- Small pocket inserts for business cards
- Larger pockets for loose materials such as brochures
- Dividers
- Extra copies of visit records, pathology reports, prescriptions, physician contact information, and other materials relevant to the patient's diagnosis and treatment
- Journal pages
- Blank phone lists and phone call records
- Pages for insurance information

Patients brought the binders with them to appointments so that providers had additional information beyond that provided in their own institution's medical record. Navigators also brought patient records with them if they met patients to accompany them to appointments.

Monitoring abnormal screening results

Navigators tracked abnormal screening results for screening tests performed onsite as well as for offsite tests performed through referrals as requested by the patients' primary providers. Navigators received monthly reports from onsite labs with results of abnormal screenings performed by the clinic. For abnormal screenings requiring follow-up, Navigators initiated the standard clinic paperwork reminding patients to schedule appointments. After the appropriate interval, Navigators confirmed that all of the patients requiring follow-up had scheduled and attended their appointments. If not, they sent notices to the patients or alerted primary care providers. Providers referred patients to the Navigator for assistance when appropriate.

Under this system, Navigators assured prompt and consistent follow-up to abnormal cancer screening tests, an important step in shifting cancer detection to earlier stages at diagnosis. When follow-up screenings returned high-grade abnormal results, Navigators were already aware of those cases and initiated timely responses from the clinic.

Community outreach

Navigators regularly participated in community events. Their reasons for doing so were to (1) increase participation in early detection and cancer control activities, (2) establish the credibility of the Navigator Program, (3) increase self-referral by patients or their family members to the Navigator Program, (4) support the efforts of cancer survivor groups to become self-sustaining, and (5) share the benefit of the Navigators' cancer expertise with the broader community.

Community events included health fairs, regular powwows, an annual Blood and Bone Marrow Donor Drive, and a "Relay on the Rez." Table 9 details the community outreach events from the first full year of the pilot program.

Table 9. Community outreach activities by Navigators, Year One (2003-2004)

Date(s)	Description	Role of Navigator(s)
September 2003 Santo Domingo Pueblo, NM	**Facilitator Training offered by People Living Through Cancer, Inc. and the Indian Health Service** The Navigator attended a free, week-long training along with several community members who later organized the Yakama cancer support group, Office of Native Cancer Survivorship – Yakama Region. The Training included the following: ▪ Information on cancer and treatments ▪ Emotional support techniques ▪ Support group facilitation ▪ Grass–roots organizing ▪ Assistance in planning community programs ▪ Fundraising ▪ Consultation with healthcare professionals ▪ Bereavement issues ▪ Visits to Santo Domingo Pueblo ▪ Opportunities for cultural exchange	Participant
October 29-30, 2003 Toppenish, WA	**Blood and Bone Marrow Donor Drive** In honor of one of the very first Navigator patients, a young mother of three who died of leukemia, the Navigator organized a blood and bone marrow donor drive at the Yakama Nation Tim Foster Retirement Center near the clinic and tribal casino. The American Red Cross ran the blood drive, while the National Marrow Donor Program enrolled potential donors. The Blood and Bone Marrow Donor Drive received wide attention in the Yakama community: ▪ The Yakama Nation's Tribal Council issued a proclamation instituting an annual drive on October 29 ▪ Flyers were posted widely around Toppenish, the administrative center of the reservation ▪ A 90-minute call-in talk show was held on October 22 with the Navigator and representatives from the Cancer Information Service-Pacific Region, the Red Cross, and the National Marrow Donor Program ▪ Two local papers, the Yakima Herald-Republic and the Review Independent (a local paper for Toppenish, Wapato, Zillah, White Swan, Harrah, and Granger) reported on the event and the Navigator Program during the drive The Blood and Bone Marrow Drive set records for participation for the reservation. (In fact, the Red Cross had been reluctant to come to the reservation because of a past history of low turnout.) Thirty people came to donate blood; three were deferred for temporary medical reasons. Twelve of the twenty-seven successful blood	Lead organizer Petitioned for Tribal Council resolution Hosted radio show

Table 9. Community outreach activities by Navigators, Year One (2003-2004)		
Date(s)	**Description**	**Role of Navigator(s)**
	donors were donating blood for the first time. **Forty-one people joined the National Marrow Donor Program**, particularly important because of the small numbers of American Indians in the bone marrow donor program.	
May 18, 2004 Tacoma, WA	**Women's Health Day,** Puyallup Tribal Health Authority and Breast Cancer Resource Center Volunteers from the Tacoma Breast Cancer Resource Center (BCRC) set up a booth in the PTHA clinic lobby along with the Navigator and a PTHA Community Health Nurse. About 50 women came by the booth and interacted with staff, picked up free materials, and asked questions. Three (3) free mammogram vouchers were distributed.	Lead organizer Staffed booth
June 30, 2004 Tacoma, WA	**Puyallup Cancer Survivorship Group Kickoff Meeting** With a $750 mini-grant from the Northwest Tribal Cancer Control Program, the Navigator organized the first Planned Community Courage and Cancer gathering at the Puyallup Spirit House. The **twenty-five attendees** (survivors, family and friends, or surviving family members) had a catered lunch and a short presentation on cancer support by Anabel Cole of the Cancer Information Service-Pacific Region. Educational materials from the National Cancer Institute, personal journals, and materials for caregivers (*The Comfort of Home* by Meyer/Derr) were provided to all participants. The Navigator and the PTHA Community Health Department solicited over $1000 in donations from local businesses, including EQC, Austin Pro-Max Car Performance, The Bayou, Tribal Grounds Espresso and Deli, etc., which were given as door prizes. Each attendee won a door prize and received a "Whale Tail" necklace made by a Puyallup family (the "Canoe Family"). Door prizes consisted of T-Shirts, EQC free dinner for two and a show, lunches, oil changes, etc.	Lead organizer Mini-grant writer
September 2004	**Other survivorship support**. The PTHA Navigator secured a scholarship for one interested survivor to attend the Spirit of Eagles conference in Phoenix, Arizona, in September 2004. The Navigator identified another survivor interested in helping to lead a survivor group and helped her apply to the free week-long national Facilitator Training offered through People Living Through Cancer, Inc. and the Indian Health Service. The sponsors of the training covered all costs for the Puyallup survivor. Organizers base their curriculum on A Gathering of Cancer Support and People Living Through Cancer's nationally recognized grassroots support programs.	Found opportunities Recruited survivors Helped with application paperwork
September 24, 2004 Tacoma, WA	**Women's Health Day,** PTHA. The Navigator had a booth at the PTHA Health Fair for the Navigator Program and general cancer information. She also gave a brief scheduled talk about the Navigator Program and the progress of the survivor group (which members are beginning to call their "Cancer Support	Staffed booth Gave presentation Recruited survivors to speak

Table 9. Community outreach activities by Navigators, Year One (2003-2004)		
Date(s)	**Description**	**Role of Navigator(s)**
	Gatherings"), and two survivors shared their stories. The Navigator reported that the impact of the survivors' stories was "very powerful."	

E. Informed consent

The informed consent process evolved over the entire study period, from a written informed consent document to an opt-out process. During the formative phase, all three sites stipulated that patients must be able to access navigation assistance whether or not they signed an informed consent document. In other words, patients did not have to consent to being navigated. Patients were required to sign informed consent before the clinic could release patient-specific study variables, which included demographic data, data on barriers navigated, and clinical information. These data were anonymous except for some weak identifiers, namely, dates of service and age.

The informed consent process assumed that patients would enroll during a clinic visit with the Navigator. The informed consent document (see Appendix D) was rated with a Flesch-Kincaid Grade Level score of 8.4, or close to the eighth grade reading level, according to Microsoft Word's readability statistics tool.[7] Because the program was intended for diagnosed patients, we assumed that the patients might be emotionally distressed during the first encounter might not fully comprehend the informed consent document. Thus we provided for a follow-up discussion and second signature during the next meeting with the Navigator.

Few patients chose to sign informed consent. In declining, they cited not wanting to "sign anything legal," not wanting to be part of a research project, or gave no reason at all, according to the Navigators. The Navigators also reported that their first meetings with patients were often too brief to approach the patients about informed consent – the patients had, after all, only scheduled time for a doctor's visit. Afterwards, patients might not return to the clinic for quite some time, but they still required navigation over the phone. Though those patients were willing to sign the informed consent document, asking them to come to the clinic created an additional barrier for them.

After consulting with the protocol's primary reviewer on the IRB, we submitted revisions to the original informed consent process. The new informed consent document split the existing document into two pieces: an information sheet about patient navigation and a more detailed informed consent document about research data (see Appendix E). To improve the clarity of the document, we asked a Navigator who had been successful in enrolling patients to hold a simulated informed consent discussion with one of the research staff. The Navigator's language was transcribed and considered during the revisions. The new process also allowed study participants to give verbal consent over the phone instead of meeting with the Navigator in person to sign the document.

In spite of the revisions, enrollment in the program remained low. Of the 501 patients who had contact with Navigators during the pilot period, only 35 patients (~7%) signed the informed consent document. Most of these (n=31) were patients who were diagnosed with cancer and had more contacts with Navigators over longer periods of time than other navigated patients. Navigators reported that mentioning informed consent diminished rapport they had developed with patients.

During the final year of the pilot intervention, research staff approached the IRB with a request to waive the informed consent process altogether. The research posed minimal risk to patients and was not feasible without the waiver, as evidenced by the low enrollment rate, which was close to seven percent of potentially eligible patients. Based on the Navigators' experiences, we believed we had been unsuccessful in communicating the nature of the research to potential enrollees (for example, at least one patient said she did not want any extra injections). Under this proposal, we would provide each participant with an information sheet about the program, either in person or by mail. This information sheet would describe the program and give contact information for the IRB in case of concerns. Any patient could ask the Navigator to withhold study data, but unless that request was made, every patient's data would be included. The dataset was limited to some basic demographic and insurance variables, Navigator encounters, stage at diagnosis, and dates of key clinical results.

The IRB agreed to approve this proposal with the support of the two tribal councils. One of the tribal councils approved the limited dataset revision; the other did not.

F. Documentation of patient information

Navigators performed the majority of the study documentation, including data on barriers navigated, clinical data, demographics, and other activities. As clinic employees – and as registered nurses practicing under their licenses – the Navigators complied with regulations relevant to documentation of patient care.

Patient charts

Navigators recorded patient encounters in each patient's clinic chart. They used the standard forms (see Appendix F for an example form) and flagged their own encounters with a "Navigator" designation. The standard charts are printed on triplicate forms. Navigators made two additional copies: one for the patient navigation file, which they kept in locked cabinets at their own desks, and the other for the patient's own records. The navigation file enabled other clinic staff to step into the Navigator position in case of emergency when the Navigator was out of the clinic. These files also assisted in tracking of navigated patients.

In addition to documenting their own activities, Navigators kept patient charts up to date with documentation from services obtained through outside referrals, often calling to request specific test results. Results of tests obtained through outside referrals were sometimes lacking altogether from patient charts. Occasionally results were not returned to the clinic because the staff at the outside agency believed that HIPAA regulations barred them from sending the results, though this was not true under the clinics' contract care programs. In addition, the clinics' internal coding could be three months behind due to inefficiencies in maintaining the computerized database, RPMS (Resource and Patient Management System), developed by the Indian Health Service and used at most American Indian facilities. Navigators updated records for their patients so that the whole patient care team had access to accurate information.

Documenting barriers of patient navigation

In the course of the pilot phase, two different coding systems were used for tracking barriers navigated. At the outset, Navigators were asked to document each patient barrier they addressed. For example, if a Navigator helped a patient to arrange transportation to an appointment, the record would include information about all of the steps the Navigator took to secure transportation services, from talking to the patient to confirming the arrangement. This model was developed after conversations with research staff from the Harlem Hospital Center's Navigator Program. Navigators recorded the date when they first discussed the barrier with the patient and the date and type of resolution, along with a number of categorical variables, including the type of encounter (at the clinic, on the phone, etc.), the time involved, and the type of barrier addressed.

This model proved impractical. Navigators struggled to operationalize barriers in a consistent way, Navigators were often behind in data entry, and when reports were generated from barrier data, they did not reflect Navigators' actual experiences. Because of these issues, documentation of barriers was redesigned to an encounter-based system. We aimed to minimize the burden of documentation on Navigators by defining the Navigator encounter as similar to a standard clinical encounter.

The revised encounter form required Navigators to check boxes of barriers addressed in each encounter, so that multiple barriers could be recorded for a single encounter. (See Table 10 below for the variables required in the revised encounter form, and Appendix G for the entire form.) Fields for describing the resolution of the barriers were retained both for the Navigators' reference and for researchers' information, but these fields were made optional.

Table 10. Minimum data elements for an encounter, revised format

Date of encounter: ____ / ____ / ________		**Type of contact:**	☐ Onsite ☐ Home visit ☐ Hospital visit ☐ Phone ☐ Mailing ☐ Other
Level of involvement:	☐ Low (20 min or less) ☐ Medium (21-90 minutes) ☐ High (90+ minutes)		

Table 10. Minimum data elements for an encounter, revised format

Barriers dealt with in this encounter (check all that apply):

☐ Abnormal finding: Passive follow-up
☐ Emotional barriers
☐ Information about cancer, Tx, health
☐ Insurance/health coverage needed
☐ Paperwork help
☐ Transportation
☐ Other financial assistance needed
☐ Family needs
☐ Appointment reminder
☐ Missed appointment
☐ Routine follow-up by Navigator
☐ Unsuccessful attempt to visit patient
☐ Communicating with providers
☐ Hospital or clinic error
☐ Medications or equipment
☐ Referral / arranging outside services
☐ Side effects and comorbidity management
☐ Other coordination of care
☐ Other: ______________________________

Explanation of barriers:

Encounter data were entered in a database (see description below). Navigators had password protected laptops that they could carry with them to appointments and also had the option of maintaining paper records and entering them in the database later. Like many care providers, Navigators sometimes got behind in data entry. However, each Navigator set a day of the week for transmitting data to the project coordinator, which kept the data entry up-to-date on a weekly basis.

Maintaining consistency in coding barriers was challenging throughout the duration of the project. The difficulty lies partly in the wide range of barriers in the list and partly in their abstract nature. If a family is skipping meals to save money for gas so that a family member will be able to drive to chemotherapy appointments, should that be coded as a financial problem, a transportation issue, or something else? A more objective coding system would have focused on the solutions that Navigators found to the problems. In the previous example, if the Navigator could provide the family with gas vouchers from the tribe, the issue would be coded as a transportation-related solution. If the Navigator had arranged financial assistance or food assistance, then the issue would have been coded as financial or other assistance. This method of coding would have been less open to varying interpretation.

<u>Intake survey</u>

In consultation with the program staff, the Navigators devised an intake survey with questions they wanted to ask diagnosed patients when they met with them for the first time. These questions were modified and supplemented to include variables relevant to study questions and reviewed again by the Navigators before being put into use. The final instrument included both required and optional items (see Table 11 below for a list of items, and Appendix H for the instrument). Required items were printed in bold font and their question numbers were marked with an asterisk (*). These items were shared with the research team if the patient had signed an informed consent document. Optional items were for the Navigator's reference only and were not shared with the research team.

When the intake survey was completed, the Navigator entered responses in the Navigator database (see below) and filed the paper copy in the patient's medical record.

The intake survey was a useful tool for learning about some patients. However, Navigators reported that introducing the intake survey could diminish their rapport with some patients, who wondered about the relevance of their marital status and household income when the Navigator was helping them sort out problems with their prescriptions.

Experience also showed that some variables were more useful than others. Among the most useful variables are ones that are also available from clinical charts, such as age, gender, tribal enrollment (which affects eligibility for services), and enrollment in third-party payer programs. Answers to questions about a working motor vehicle and working telephone in the household turned out to be more complex than anticipated: Even if there was a working motor vehicle, it might not be reliable; and a home might have telephone service at the beginning of the month but not at the end of the month. Marital status is frequently used as a proxy for social support, but American Indians and Alaska Natives often have unmarried long-term partners. They also tend to live in larger households than the general population. Extended families can be in close contact, living in the same house, within easy walking distance, or far away but willing to come on short notice to help in a family crisis.

Table 11. Required variables and optional other information included in the *Navigator Program Intake Survey* for patients who sign informed consent
See notes at end of table.

Required	Optional	Variable(s)
X		Date enrolled in program
X		**Name of clinic**
X		**Type of cancer** (categorical)
	X	Name, preferred name
	X	Mailing and other address
X		Working phone in household (Y/N/Ref)
	X	Phone and fax numbers
	X	Emergency contact name and contact information
X		Request copy of findings (Y/N)
X		Time required for patient to travel to clinic (hours, minutes)
X		Working motor vehicle in household
	X	How do you usually get around? (narrative)
X		**Age**
X		Sex
X		**Tribal enrollment**
X		Other cultural identity
X		Marital status
X		Education
X		Employment status
X		**Health care coverage** (check all that apply)
X		**Contract Health Services eligible**
X		**Direct Care only**
X		**Private insurance**
X		**Medicaid**
X		**Medicare**
X		Veteran
X		Other

Table 11. Required variables and optional other information included in the *Navigator Program Intake Survey* for patients who sign informed consent
See notes at end of table.

Required	Optional	Variable(s)
	X	Do you have children under 18 living with you?
	X	If yes, ages:
	X	Other household members
X		Household income (as percent of Federal Poverty Level)
	X	History of: (check all that apply)
	X	Angina or heart attack
	X	High blood pressure
	X	Elevated cholesterol
	X	Congestive heart failure
	X	Stroke or TIA
	X	Blocked leg or neck arteries
	X	Diabetes
	X	Serious infections
	X	Arthritis or gout
	X	Cancer
	X	Bleeding tendency
	X	Kidney failure / dialysis
	X	Dental problems
	X	Rheumatic fever
	X	Mental health conditions
X		Any of the above health conditions, if current
	X	Current and former alcohol use
	X	Current and former tobacco use
	X	Family health history
	X	Questions about support system

Notes: Required variables are entered for all patients who have signed informed consent and are transmitted to research staff with other study data.
Optional variables are for Navigators' reference only and are never transmitted.
Variables in bold are contained in clinic charts and are retrievable as summary descriptive statistics for all patients.

Unfortunately, too few patients signed informed consent for useful study information to be gleaned from the instrument. The final opt-out informed consent process did not allow for intake survey variables to be released for research purposes if the patient had not signed informed consent. Some information was retrieved from clinic database records (fields given in bold in Table 11 above). We recommend limiting patient surveys to five or fewer necessary data elements that cannot otherwise be obtained, and omitting questions about household income, which tend to have low response rates and can be inferred through health care coverage.

"Case stories"

To supplement the data on patient encounters, the Navigators wrote "case stories" on a regular basis. These were bulleted lists giving more detail than a regular encounter record, but less elaborate than a full case study or case history. Navigators sent their case stories to the project coordinator who edited the narrative to remove potential identifiers. Case stories were compiled and submitted in reports to the National Cancer Institute and are included here as Appendix O.

G. Navigator database

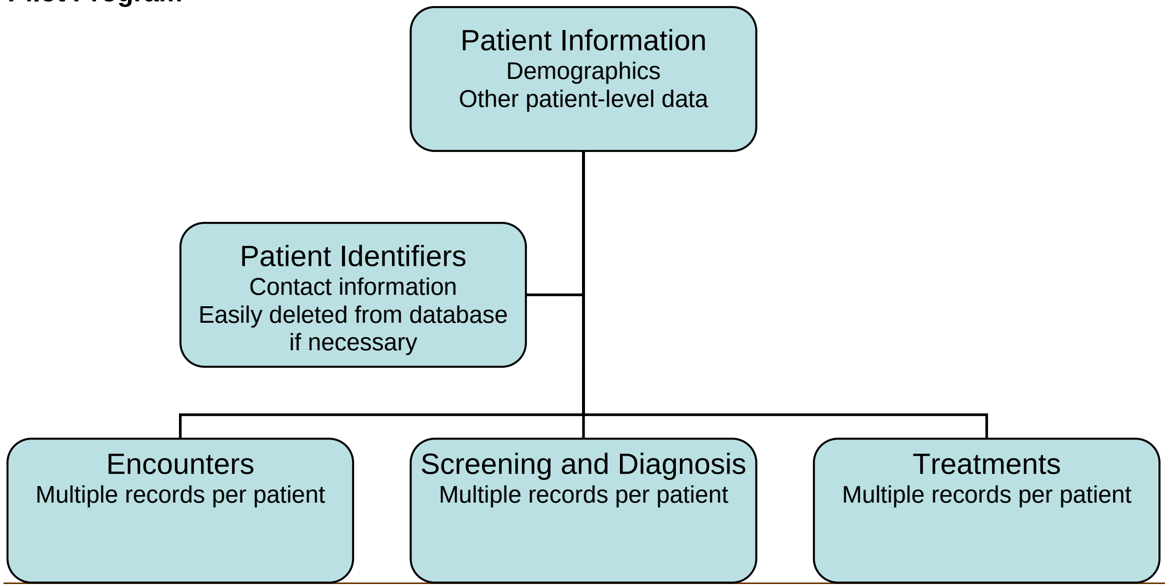
Navigators entered their own data in a relational database created by the project coordinator using Microsoft Access. The Access software had several advantages: It is readily available, inexpensive, and does not require highly specialized programming skills. Under this arrangement, the project coordinator had full control over the content and format of the database.

Database design

The database was designed with two purposes in mind: (1) to collect study data, and (2) to help Navigators track information about their patients, some of which was not included in the study design. For example, one of the early versions included provider contact information, which could be linked to individual patients. It was hoped that if the database could serve dual purposes, the Navigators would be doubly likely to keep up with data entry. In practice, however, Navigators completed data entry only for the required research variables and for patient contact information, choosing to maintain a system convenient for their clinic for patient contact information.

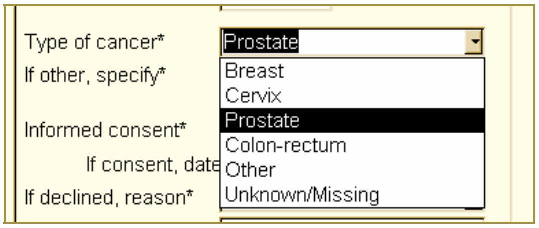
Data were organized in several tables within the database. The main patient information table contained all patient-level study variables, such as demographics and stage at diagnosis. Identifying information – accessible to the Navigators but not to research staff – was stored in a separate table. Separating these variables provided a quick way to delete identifying information in case the Navigator needed to send a copy of the database to the project coordinator in the mail. Additional tables contained encounter data, screening and diagnosis data, and treatment data. These tables could contain multiple records per patient. All tables were linked using unique identifying numbers which were generated sequentially by the database program. See Figure 3 for a diagram of the table relationships.

Figure 3. Organization of the relational database for the Northwest Tribal Cancer Navigator Pilot Program



Navigators entered and accessed the data using database forms and reports (see Appendix J for images from the database). Most variables were forced-choice fields. Navigators could choose the appropriate response from a pull-down list (using the mouse or keyboard). Though the lists displayed text values, the data were stored as numbers in the underlying tables. (See Figure 4 for an example of a pull-down list from the database.)

Figure 4. Example of a "list box" in the database created with Microsoft Access. Data are stored as numeric values.



Type of cancer* Prostate

A separate set of forms allowed the Navigators to review all data that had been entered with color coding to highlight missing or faulty data. For example, if a patient's type of cancer was not entered, that field would display "**[Missing]**" in bold red font. Probable errors, such as encounter dates earlier than 2003, were highlighted in blue. This made data entry errors easier to spot and correct. Summary statistics from the database were shared with the Navigators periodically. Later, reports were added to the database so that the Navigators could access some of these summary statistics on their own.

Navigator database separate from clinic database

The Navigator study database was not compatible with clinic databases, though that possibility was explored during the project's formative phase. Most clinics funded by the IHS use an administrative database called the Resource and Patient Management System, or RPMS. Though RPMS can be used to create custom "modules" and data can be exported to other formats, there were important reasons not to integrate the study instruments with clinic records. Even a custom RPMS module was not flexible enough to allow us to define variables exactly as we wished, and creating and maintaining such a module would have required the assistance of an RPMS programming specialist. We would not have been able to restrict data access to trained program staff; anyone with access to clinic records would have been able to alter the research record.

Research needs aside, several clinicians told us that a "cancer registry" within RPMS, similar to the modules for diabetes or women's health, would be useful. This module would bring together electronic data about a diagnosed patient's care, thus allowing for comprehensive and intensive service provision.

Data transmission

The Navigators sent their data electronically to the project coordinator on a weekly basis. This was accomplished using queries and macros built into the database. When a Navigator clicked on the "button" for sending data, the database created several tables in Microsoft Excel format and emailed them automatically to the project coordinator. The tables were based on queries that selected only the study variables (no strong identifiers) allowed for each patient, depending on whether the patient had given informed consent. If the patient had not given consent, the data were limited to a small set of variables, including types of Navigator encounters and general type of cancer. The files were sent over an encrypted email connection and the tables themselves contained numeric values; even if someone had succeeded in stealing the data, they would not have been able to interpret them without additional information. This transmission method was simple and easy to maintain.

Recommendations

- Limit the Navigator database to study variables and contact information, plus the patient's health record number.
- Separate protected information from non-protected information within the database for quick de-identification of data.
- Store forced-choice data as numeric fields; use text labels for data entry.
- Set weekly deadlines for data entry tasks.
- Create reports accessible to the Navigators so that they can monitor their own data entry progress. Format data entry errors so that they stand out using color and font.
- If feasible, create a cancer-specific module within the clinic's electronic records to track cancer diagnosis and care.

H. Record linkage for historical controls

For comparison on clinical outcomes, the sites elected to use historical controls, i.e. patients from the same clinics who were diagnosed with cancer between 1998 and 2002. Contemporaneous controls at other IHS, tribal, or urban Indian clinics were considered but rejected because of practical and ethical concerns. Because each tribal community and clinic operates in a very different context, tribes are difficult to match as controls. Cancer is also a sensitive issue for Northwest tribes and project staff could not justify asking other tribes to expend the effort to disclose potentially stigmatizing information without offering some assistance to alleviate problems discovered in the course of research.

Locating data on historical controls was problematic because of the inefficiencies in maintaining RPMS as described in the “Database” section above. An earlier chart review at Yakama had showed that 22 percent of patients identified as having cancer in RPMS were not true diagnoses (Chris Walsh, personal communication). In addition, an unknown number of patients who had cancer were assumed to lack documentation of their diagnoses in RPMS. Moreover, Navigators had improved documentation for their own patients, which meant that relying on RPMS alone to identify controls could introduce major bias.

Rather than review tens of thousands of patient charts, we partnered with the Northwest Tribal Registry Project (NTRP) and the Washington State Cancer Registry (WSCR) to perform a record linkage study. The protocol for the linkage was approved by the Washington State IRB and the Portland Area Indian Health Service IRB. The NTRP has been performing linkages with the WSCR for a number of years, linking its registry of all IHS service users in the Portland Area (i.e. Idaho, Oregon, and Washington) with the WSCR to correct racial misclassification of American Indians and Alaska Natives in the WSCR.[8] For our linkage study, we created a data file of all clinic patients from 1998 to 2006 and linked it to the WSCR using probabilistic matching software (described in greater detail below) to identify true cancer cases as controls.

Creating the data file

To create the data file for the Navigator Program sites (“Navigator File”), we ran a number of queries in RPMS and combined them using SAS statistical software.[9] The resulting file contained a number of strong identifiers that would be used to complete the linkage and then deleted. It also contained indicator variables to be analyzed, including the presence of a cancer diagnosis in RPMS (for computing sensitivity and specificity of RPMS coding for cancer), third party coverage, and a flag for navigated patients. (See Table 12 below for a listing of variables.)

Table 12. Variables used in the record linkage by the Northwest Tribal Cancer Navigator Program pilot study, the Washington State Cancer Registry, and the Northwest Tribal Registry Project

	Navigator File		Washington State Cancer Registry
Variables used for the linkage, deleted immediately	First, middle, and last names	↔	First, middle, and last names
	Social Security Number	↔	Social Security Number
	Sex	↔	Sex
	Address	↔	Address
	Date of birth	↔	Date of birth
Weak identifiers, deleted later			Date of diagnosis Date of initial treatment
Study variables	Clinic Indian blood quantum Eligibility for IHS services Tribal enrollment Medicare (Y/N) Medicaid (Y/N) Privately insured (Y/N) No third-party coverage (Y/N) Age at most recent visit At least one visit between 1/1/1998 and 12/31/1998 *[Visit variable repeated for years 1999 to 2006]* Navigated patient (Y/N) Breast cancer diagnosis at clinic between 1/1/1998 and 12/31/1998. *Breast cancer variable repeated for years 1999 to 2006; also for…* Cervical cancer Prostate cancer Colorectal cancer Other cancer In situ cancer Diabetes in 1998 *and repeated for 1999-2006*		Primary site Year of diagnosis Histologic Type ICD-O-3 Behavior Code ICD-O-3 SEER Summary Stage Time (in days) elapsed between date of diagnosis and date of initial treatment

Diabetes was included with variables from RPMS to make possible an analysis of the overlap between the diabetes patient population and the cancer patient population. Diabetes is prevalent among American Indians and Alaska Natives: In a 2001 survey of IHS service users, 12.6% of adults said that they had been diagnosed with diabetes (95% CI 10.7% - 14.7%), compared to only 5.3% of adults in the Washington State general population (4.9% - 5.9%).[10] Several national and regional initiatives in recent years resulted in improved care and documentation of diabetes services in IHS-funded facilities. This meant that RPMS was less likely to produce false positives for diabetes than for cancer, and that there are continuing opportunities for combining regular diabetes visits with cancer care.

Performing the linkage

The Tribal File was linked to the WSCR using Link Plus software from the CDC's Registry Plus package for probabilistic matching.[11] Identifiers — including first, last, and middle names, social security numbers, dates of birth, addresses, and sex — from both files were used to match individuals. The software matched records, even where the match was not exact, and gave each match a probability score. Matches with low probability scores were reviewed individually and decided by the registry manager, who was performing the linkage.

Once the linkage was complete, and before the data left the WSCR, all direct identifiers were stripped from the resulting files. Two files were retained: Records that were matches in the WSCR and tribal clinics, and tribal clinic records without matches in the WSCR ("residuals"). Both files contained variables from the Navigator File and the WSCR.

Soon after the linkage, the time elapsed between diagnosis and treatment was calculated. A variable for the year of diagnosis was created. Then both date fields were deleted. Dates of service are weak identifiers and we wished to retain a completely anonymous dataset.

Analyses

Two datasets resulted from the above methods. The first contained limited information about all 501 patients navigated at the two main participating clinics during the pilot study. The second contained data from the Washington State Cancer Registry linked to selected variables from one clinic's administrative database. Both datasets were anonymous.

The main variables of interest included third-party coverage, type of cancer, and time elapsed from diagnosis to initiation of treatment. The date of positive biopsy was used, wherever possible, as the date of diagnosis, while the date of initiation of treatment was defined as the first day of radiation, chemotherapy, or surgery to remove a tumor.

Demographic and clinical summary statistics were calculated, and controls were compared to navigated patients using Chi-square tests, Fisher's exact test, and Wilcoxon-Mann-Whitney test. Where possible, comparisons were made using the same data source for consistency. For example, demographic data on both navigated patients and controls was obtained from the clinic's database. For clinical variables, the Navigator-collected data for navigated patients was compared to the state cancer registry's variables.

I. Patient interviews

We conducted semi-structured interviews with a purposive sample of Navigator participants and family members.

Selection of respondents

The project coordinator generated a list of study participants' characteristics, including age, gender, type of cancer or screening, total Navigator encounters, and date of last encounter. From this list, another staff member selected nine women and six men from each clinic as potential participants. The potential participants were selected to represent a mix of ages, types of cancer, and degrees of participation with the program. The project coordinator gave the list of potential participants, identified by their study identification numbers, to the

Navigators, who contacted the patients or their families and invited them to participate. The Navigators told potential participants that the interview was about the Navigator Program, that it could take up to an hour, could take place at the clinic or in their homes or another place of their choosing, and that interview respondents would be given $30. If the person agreed to be interviewed, an interviewer would contact them in the near future. Once the Navigator had recruited a group of respondents, he or she provided a list of names and telephone numbers.

Interviews

Interviewers were hired specifically for the project. All were Native; one was an enrolled member of the tribe where she conducted the interviews. The interview began with informed consent (see Appendix K). As part of the informed consent, the interviewer asked permission to record the interview using a digital recorder. Some of the many Native cultures served at participating clinics prohibit such recordings. For participants who declined, the interviewer took notes during the interview. All respondents were offered a copy of the final summary from the interviews.

The instrument was a combination of forced-choice and open-ended questions (see Appendix L). The interviewer asked and recorded a multiple choice question and then prompted the respondent to elaborate on his or her response. Interviews ranged from 25 to 45 minutes in duration. Afterwards, the interviewers sent digital recordings to the project coordinator along with written notes and any other documentation. Participant incentive checks for $30 were sent from the Northwest Portland Area Indian Health Board. Contact information for respondents was stored in secure files separate from interview transcripts and recordings. All contact information was destroyed three weeks after the results had been sent to respondents, according to IRB protocol.

Data

Responses to multiple-choice questions were entered using EpiData software.[12] Frequencies were generated. Taped interviews were transcribed by project staff. The transcriptions were added to notes from non-recorded interviews and excerpted. Each excerpt was tagged with general information about the respondent—gender, type of cancer, and age (under or over 50 years old)—to give some idea of the patient's context without identifying him or her. References to specific individuals were altered or deleted to protect the anonymity of respondents. The excerpts were combined into a single file. Analysis occurred using content analysis methodology.

J. Provider survey

We solicited the opinions of providers using a brief online survey. The instrument contained 13 forced-choice, mostly Likert-scale questions, and 3 open-ended questions. In developing the instrument, we consulted the Health Resources and Services Administration (HRSA), the Centers for Medicare & Medicaid Services (CMS), and private research companies with existing instruments for evaluating provider satisfaction. None of those instruments was appropriate for our purpose, though some of the questions on other surveys informed the design of our instrument.

We invited providers (physicians and mid-level practitioners) from the participating Navigator clinics as well as from hospitals and cancer centers where navigated patients were referred. We contacted only providers who had treated patients from our Navigator Program. These providers were identified by the Navigators. We also asked Contract Health Services to identify facilities where patients have been referred for cancer care in the past year so that we could contact every provider who had any interaction with the Navigator within a recent time frame. This was done to avoid possible screening by the Navigators of physicians with poor opinions of the program.

NPAIHB staff contacted the providers first by telephone. Staff initially asked to speak with the provider's nurse. We identified ourselves as affiliated with the Navigator Program, or with "the patient advocate associated with cancer patients from the Puyallup/Yakama clinic," if the program name was unfamiliar. We explained that we would like to ask the provider that s/he works with to complete a short online survey of providers who work with the Navigator Program. The survey was described as containing 15 questions, mostly multiple choice, and requiring 5 minutes or less to complete. No incentive was offered.

We then asked the nurse or other assistant whether s/he preferred us to send the email link to him/her to forward to the provider, or whether we should contact the provider directly. If s/he preferred to forward the email, we asked for an email address. We then sent an email invitation with a link to the online survey (see Appendix M for the text of the invitation). If s/he preferred us to contact the provider directly, we asked for the best way to do so and repeated the explanation.

The invitation email contained a link to the online survey, hosted by the company SurveyMonkey.com at a cost of approximately $20 per month. The survey was constructed using the tools provided by SurveyMonkey. Any response was automatically logged and became downloadable by the project coordinator. Responses were anonymous, identified only by the IP address of the computer used to complete the survey. Please see Appendix N for images of the online survey.

The web-based survey was available for one month. Weekly reminders were sent. These reminders were sent to everyone because it was not possible to omit individuals who had already responded to the survey. Our list of targets contained 29 individuals. We had anticipated being able to confirm contacts with all of these individuals using our invitation emails, but several of our contacts forwarded our message to email lists within their organizations. The email addresses for these lists did not identify individuals, so we are unable to confirm how many people received the email invitation.

Eight providers from Navigator clinics and four from hospitals and cancer centers responded for an overall response rate of about 40%. Two providers responded that they were unfamiliar with the Navigator Program and did not complete the survey. Responses from the remaining 10 providers were included in the analysis.

Part 5

Results

Northwest Tribal Cancer Navigator Program
Pilot Project Final Report

V. Results

A. Demographics and clinical outcomes

Navigated patients were compared to both historical and contemporaneous controls with respect to age, tribal enrollment, eligibility for care, third-party coverage, and diabetes status (see Table 13 below). For these comparisons, we used two control groups. Historical controls were seen at the same clinic at least once between January 1, 1998 and December 31, 2002, and were at least 18 years old. Contemporaneous controls were all non-navigated patients (including those who refused navigation services or who were diagnosed with cancer but not referred to the program) who were seen at least once between January 1, 2003 and May 31, 2006 and were also at least 18 years old. The two groups were not mutually exclusive – i.e., if a patient had at least one visit in each period and was not navigated, he or she would be counted in both groups. Navigated patients, however, were excluded from both control groups.

Navigated patients differ from the general clinic population with respect to age, with 43.5% of navigated patients age 50 or older, compared to approximately 29% of controls in both groups. Navigated patients also differ at a statistically significant level from controls with respect to tribal enrollment, eligibility for IHS services, third party coverage, and diabetes status, though most of those differences can be explained by the difference in age distribution. When only patients 50 years old and older are compared, only differences in IHS eligibility remain statistically significant. A greater proportion of navigated patients are eligible for contract health services, Medicare, and Medicaid.

The large percentage of navigated patients who also have diabetes (22.8%) is unsurprising but has important implications for cancer Navigator programs. In the populations served by cancer Navigators, diabetes is likely to be common and navigators would benefit from training in diabetes management, particularly in ways that diabetes might affect cancer-related care. Cancer Navigators can also benefit from working closely with diabetes teams at community clinics to provide proactive care to a shared patient population.

Table 13. Demographics, Indian Health Service (IHS) eligibility, and third-party coverage for navigated patients and controls

	Navigated patients 2003-2006		Clinic patients 1998-2002			Clinic patients 2003-2006		
	N	(%)	n	(%)	*p*	n	(%)	*P*
Total[†]	232	(100.0)	11166	(100.0)		9137	(100.0)	
Age								
18-34	62	(26.7)	4758	(42.6)	>0.01	3802	(41.6)	>0.01
35-49	69	(29.7)	3223	(28.9)		2724	(29.8)	
50-64	66	(28.4)	2046	(18.3)		1744	(19.1)	
65 and older	35	(15.1)	1139	(10.2)		867	(9.5)	
Tribal enrollment								
Enrolled in home tribe[‡]	130	(56.0)	5226	(46.8)	0.01	4460	(48.8)	0.03
Enrolled in other tribe	64	(27.6)	3334	(29.9)		2536	(27.8)	
Not enrolled[§]	38	(16.4)	2606	(23.3)		2141	(23.4)	
IHS eligibility*								
Direct Care only	42	(18.1)	3308	(29.6)	>0.01	2454	(26.9)	>0.01
Contract Health	189	(81.5)	7787	(69.7)		6651	(72.8)	
Third-party coverage								
Privately insured	53	(22.8)	2476	(22.2)	0.01	2201	(24.1)	0.01
Medicaid	63	(27.2)	2221	(19.9)		1912	(20.9)	
Medicare	34	(14.7)	1169	(10.5)		939	(10.3)	
Diagnosed comorbidity								
Diabetes	53	(22.8)	1611	(14.4)	>0.01	1391	(15.2)	>0.01

[†] Total navigated patients, n=501; table based on one participating clinic.

[‡] Enrolled members of the federally-recognized tribe that hosts the clinic.

[§] May include descendents of federally-recognized tribes, members of state-recognized tribes, or non-enrolled dependents.

[*] Eligibility is determined by tribal enrollment and location of residence within reservation boundaries. Direct Care covers services provided in the IHS or tribal clinic; Contract Health Services cover most cancer care through contracts with outside providers.

Comparisons of clinical outcomes (see Table 14) are subject to important limitations in the available data. Chief among the limitations is the small number of navigated patients who consented to have their clinical data used in the Navigator pilot study. As discussed above, only 7% of patients who had contact with Navigators consented to have their detailed clinical data used for study purposes. While we lack data on the non-consenting patients for comparison, we can assume that the patients who signed informed consent differ from the non-consenting patients in ways that affect clinical outcomes. Of the 35 patients who signed informed consent, 31 were diagnosed with cancer and had high levels of contact with Navigators. This explains the high percentage of navigated patients with later-stage diagnoses (77.4%, compared to 44.2% of controls).

The mean time to treatment, measured in days, was slightly lower for navigated patients (21.6 days) than for controls (23.3 days), but not at a statistically significant level.

Table 14. Clinical characteristics of patients diagnosed with cancer, navigated patients versus controls

	With cancer diagnosis				
	Navigated patients		Clinic patients 1998-2002		
	n	(%)	n	(%)	*p*
Total	94	(100.0)	138	(100.0)	
Primary site of cancer					
Breast	15	(16.0)	30	(21.7)	0.12
Cervix	5	(5.3)	<5	**	
Prostate	<5	**	8	(5.8)	
Colon-rectum	5	(5.3)	14	(10.1)	
Lung	10	(10.6)	11	(8.0)	
Other	54	(57.4)	68	(49.3)	
Unknown	1	(1.1)	6	(4.3)	
Pilot study informed consent status					
Consent signed	31	(33.0)	na		
Not signed	63	(67.0)	na		
Stage at diagnosis					
	n=31		*n=138*		
Early (I & II)	5	(16.1)	58	(42.0)	>0.01
Late (III & IV)	24	(77.4)	61	(44.2)	
Unstaged	2	(6.5)	19	(13.8)	
Time from diagnosis to treatment (days)					
	n=26		*n=120*		
Mean	21.6		23.3		0.16
Median	17.5		13.5		
Range	0-67		0-252		

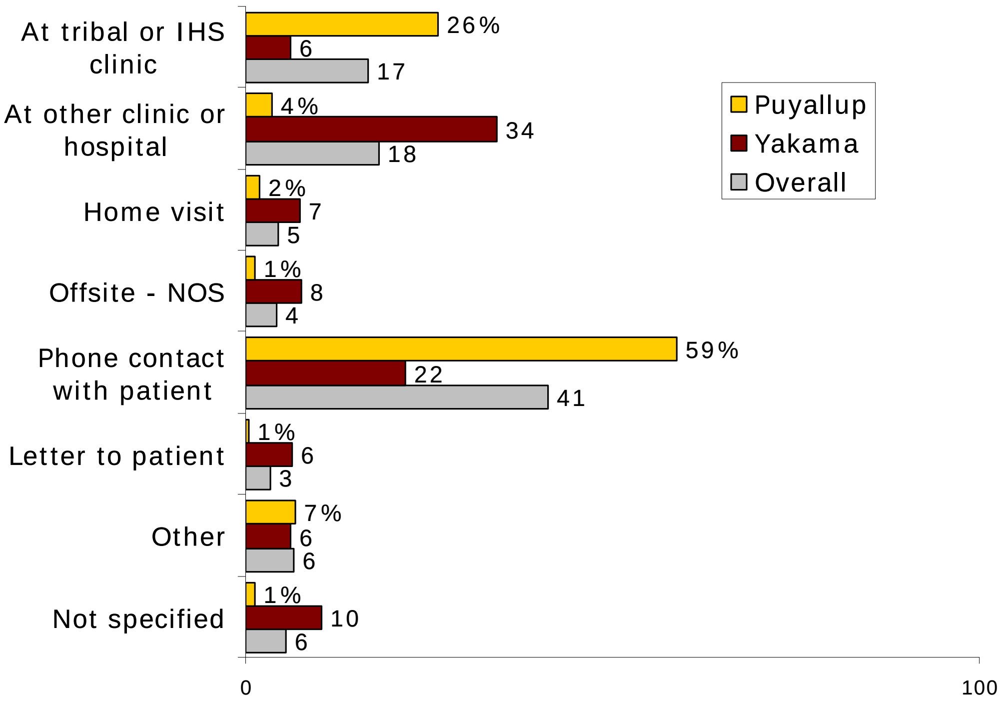
na: Not applicable

B. Navigator encounters and barriers navigated

Navigators tracked whether their patient encounters occurred in person at the clinic, at an outside clinic or hospital, at a home visit, or elsewhere, or whether the “encounter” took place over the telephone or through a letter. At the two Navigator clinic sites, the patterns looked very different (see Figure 5). In the more rural area – where telephone coverage is less complete – a third of visits took place at the oncology clinics and hospitals, and a larger percentage of encounters were home visits compared to the more urban clinic (7% versus 2% of all encounters for the clinic). In the more urban clinic, most encounters took place either over the telephone or at the tribal clinic.

These differences can be partially explained by the differing emphases of the two programs. PTHA placed great emphasis on getting patients – particularly women – to get screened for cancer. Many of their phone calls and in-clinic visits were related to arranging screening and diagnostic tests. This was particularly true when the Navigator was a (lay) community member. At Yakama, where the Navigator was an oncology-certified nurse, the Navigator Program was expected to assist diagnosed patients as a priority. Both sites, of course, navigated patients throughout the spectrum from abnormal finding to resolution.

Figure 5. Type of encounter as percent of clinic total, Northwest Tribal Cancer Navigator Program, September 2003 to May 2006



NOS: Not otherwise specified

Navigation at Indian Health Service and tribal clinics seems to be clinically intensive in comparison to navigation within hospital systems. Indian Country Navigators may be the patient's only link connecting providers at multiple facilities. Three of the top five categories of types of issues addressed (see Figure 6) relate directly to coordination of care in which the Navigators found their nursing skills to be an advantage: communication, help with prescriptions and durable medical equipment, and other care coordination. In the remaining two categories, arranging referrals and abnormal follow-up, clinical expertise is useful but less necessary. Lay Navigators provide important assistance to patients, but the response to nurse Navigators from clinicians and patients points to an unfilled need in the poorly funded Indian Health Service.

Figure 6. Types of issues addressed in encounters, Northwest Tribal Cancer Navigator Program, September 2003 to May 2006

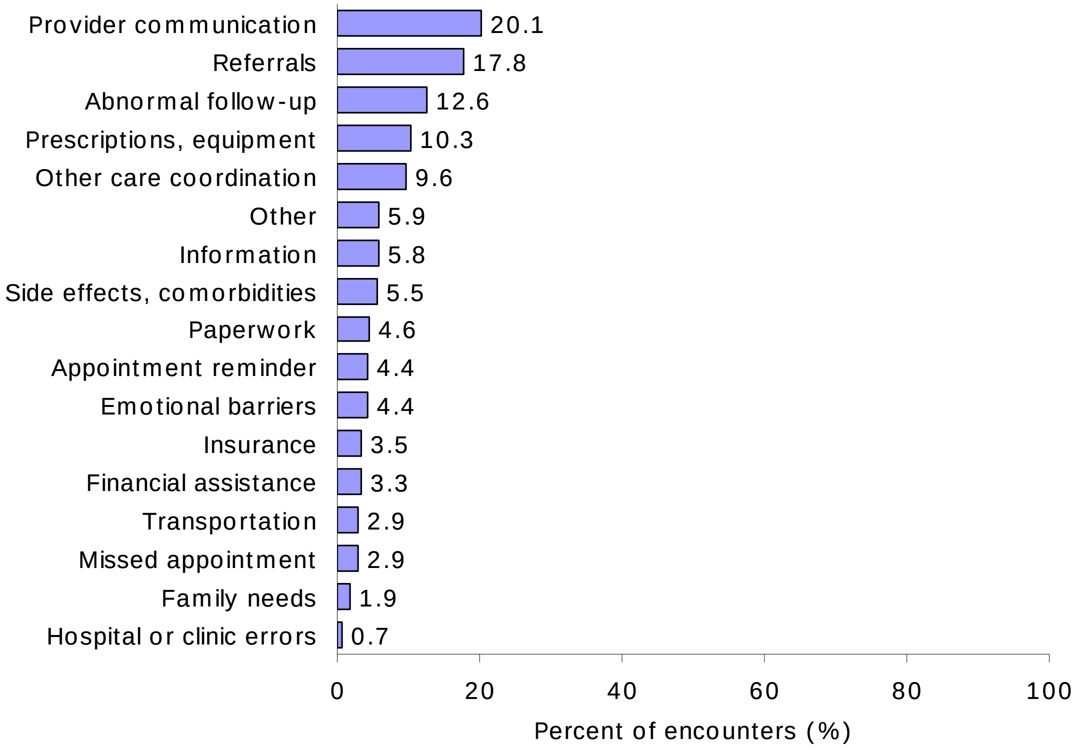


Table 15. Navigator-coded barriers and definitions

Issue or barrier	Definition
Provider communication	Facilitating communication between patients and providers or between different providers
Referrals	Helping a patient with the necessary steps and paperwork to receive care outside the clinic
Abnormal follow-up	Making sure that patients with abnormal screening findings come in for follow-up at the appropriate time by sending letters and making phone calls
Prescriptions, equipment	Solving problems with prescriptions and/or durable medical equipment
Other care coordination	Care coordination not directly related to other categories already specified
Other	Barriers or activities not otherwise specified
Information	Providing patient education or written materials
Side effects, comorbidities	Responding to severe side effects or monitoring comorbidities
Paperwork	Helping patients complete paperwork for Medicaid, housing, Social Security, or other applications

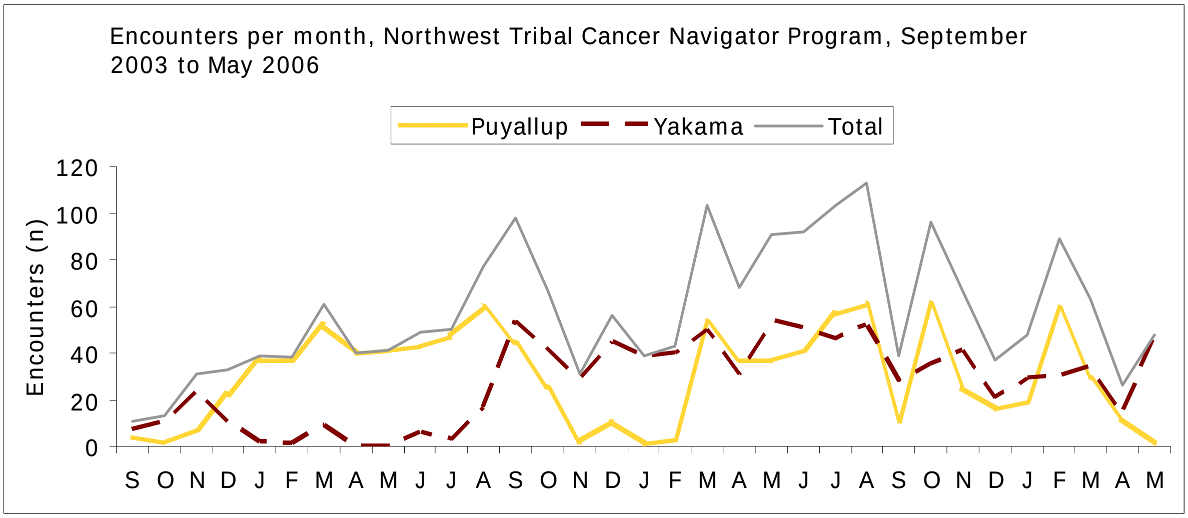
Table 15. Navigator-coded barriers and definitions	
Issue or barrier	**Definition**
Appointment reminder	Calling a patient the day before an appointment and checking that transportation arrangements are still in place, giving any fasting instructions (usually for higher-risk patients with a history of missed appointments)
Emotional barriers	Talking to a patient or referring to counseling for major emotional barriers (such as fear or denial) that are preventing a patient from receiving appropriate care
Insurance	Assisting patients with any insurance-related needs
Financial assistance	Helping patients apply or process any type of financial assistance
Transportation	Arranging transportation or subsidies
Missed appointment	Contacting a patient after a missed appointment and helping to reschedule
Family needs	Includes childcare, social support for family caregivers, or prioritizing early screening for first-degree relatives
Hospital or clinic errors	Correcting problems with paperwork or medical care (such as prescribing a medication to which the patient is allergic)

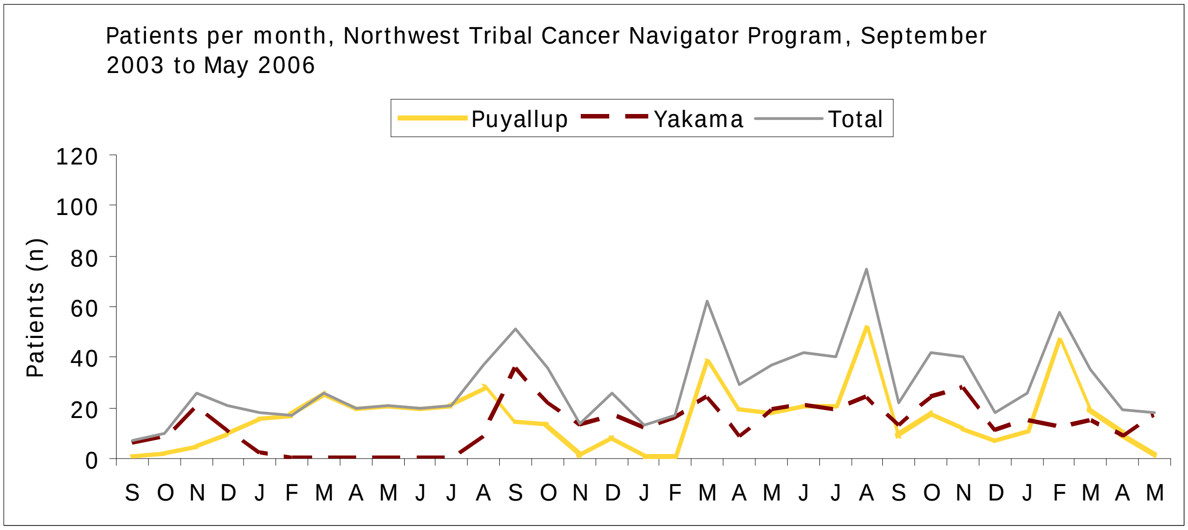
The remaining categories of coded barriers made up smaller pieces of the overall distribution, ranging from “other” and “information” at 5.9% and 5.8% of all barriers, respectively, to family needs and hospital or clinic errors at 1.5% and 0.7%. Navigators took on a wide range of roles and responsibilities.

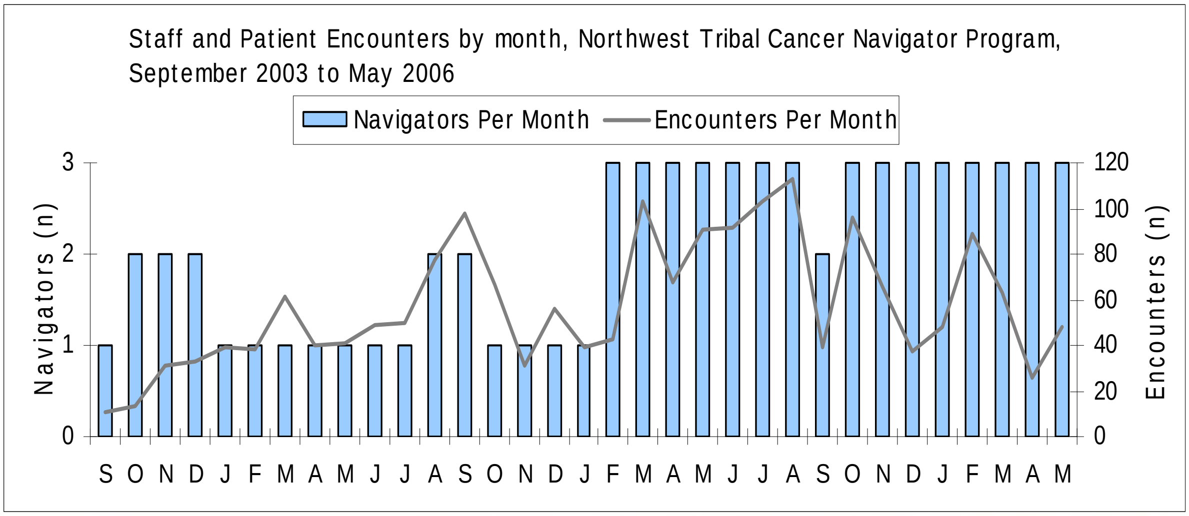
In quarterly written reports, Navigators provided “case stories” to illustrate the issues with which their patients were dealing and how the Navigators were responding. These case stories are a rich source of information about patient navigation but are too numerous to include here.

The next series of graphics (Figure 7) plots three types of data in parallel over time. Each type of data is displayed for the individual clinics as well as for both sites combined. The first graphic shows the number of Navigator encounters per month. The second graphic shows the number of patients navigated per month, including both new and existing patients. The third graphic shows staffing levels over time. All three graphs are very closely related. When the number of Navigators increases, the number of patients in the caseload also increases and the number of encounters goes up. The close correlation between encounters, patient load, and staffing levels seems to indicate that Navigators worked at close to capacity almost all of the time, and that when staffing levels decreased, some patient needs went unmet.

Figure 7. Encounters, patients, and Navigator staffing levels by month, Northwest Tribal Cancer Navigator Pilot Program, September 2003 to May 2006


Encounters per month, Northwest Tribal Cancer Navigator Program, September 2003 to May 2006


Patients per month, Northwest Tribal Cancer Navigator Program, September 2003 to May 2006


Staff and Patient Encounters by month, Northwest Tribal Cancer Navigator Program, September 2003 to May 2006

C. Patient satisfaction

We selected a purposive sample of 18 patients using a list from the Navigator database that identified patients only by unique identification number, gender, age, type of cancer or screening, clinic, and number of Navigator encounters. Of those, 15 agreed to give in-depth interviews. Most described positive experiences with their Navigators. Patients were asked a series of forced-choice questions with open-ended follow-up discussion. Responses to the forced-choice questions are tabulated below (Table 16). Only one of the fifteen respondents described a negative experience with the Navigator, while the rest were quite satisfied.

Nine respondents said that when they contacted the Navigator, he or she responded within one business day all or most of the time. The program standard of one business day to respond seems to have been adequate, as nine respondents said that the response time was adequate “all of the time,” and two said it was adequate “most of the time.”

Navigators were highly rated with respect to providing information and respecting the patient’s values and needs. Most patients agreed that the Navigator was either able to answer questions or find another source. Navigators were more highly rated than other providers when it came to listening to patients and respecting their values and choices. According to respondents, Navigators adequately included friends and family almost all of the time.

Overall, seven respondents called the Navigator Program “great,” five rated the program as “good,” and one each called the program “acceptable” or “terrible.” Thirteen of fifteen respondents said that if someone they cared about got sick, they would want them to meet with the Navigator.

Table 16. Forced-choice questions in patient interviews (n=15 interviews), Northwest Tribal Navigator Program

When contacted, the Navigator responded within one business day

All of the time	5
Most of the time	4
Sometimes	0
Never	2
Refused	4

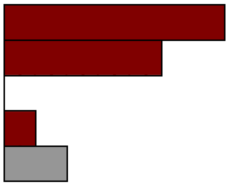
The Navigator’s response was quick enough for the patient's needs

All of the time	9
Most of the time	2
Sometimes	0
Never	2
Refused	2

Table 16. Forced-choice questions in patient interviews (n=15 interviews), Northwest Tribal Navigator Program

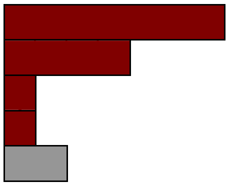
The Navigator was able to answer questions or find another source

All of the time	7
Most of the time	5
Sometimes	0
Never	1
Refused	2



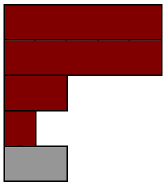
The Navigator listened and respected the patient's values and choices

All of the time	7
Most of the time	4
Sometimes	1
Never	1
Refused	2



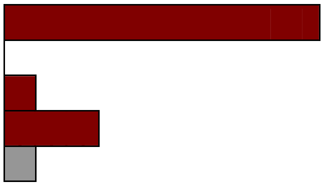
Other providers listened and respected the patient's values and choices

All of the time	5
Most of the time	5
Sometimes	2
Never	1
Refused	2



The Navigator included friends and family as much as the patient wanted them to be included

All of the time	10
Most of the time	0
Sometimes	1
Never	3
Refused	1



Overall program rating

Great	7
Good	5
Acceptable	1
Terrible	1
Refused	1

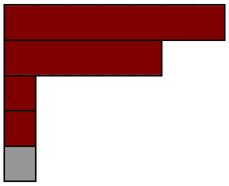


Table 16. Forced-choice questions in patient interviews (n=15 interviews), Northwest Tribal Navigator Program

“If someone you cared about got sick, would you want them to meet with the Navigator?”

Yes, definitely	13
Maybe	1
No	1
Refused	0

While the respondents included both patients who had been diagnosed with cancer and those who reached non-cancer resolutions, the responses from patients with cancer were longer than others.

In the open-ended comments, common themes emerged:

Qualities of a Navigator: Respondents expressed appreciation for Navigators’ expertise – clinical and otherwise – and professional demeanor. There is often an implied appreciation of the Navigator’s patience. Though all respondents and all interviewers were Native, no one mentioned the Navigators’ ethnic backgrounds.

Not alone: Several respondents mentioned that they initially felt ambivalent about having the Navigator involved with their care because they wanted to handle it on their own or were shy, but that they changed their minds and were glad to have the Navigators working with them. Navigators understood the patients’ experience with cancer in ways that friends and family could not.

Including family: Respondents appreciated that the Navigators included their families when they asked them to.

Availability: Some respondents (often elders) reported that Navigators were hard to find when one dropped in at the clinic, but other respondents said that Navigators were easy to reach by telephone.

Help at the beginning: Many respondents said that the Navigator was particularly helpful immediately following their diagnosis with cancer. Specifically, they mentioned that the Navigator explained what to expect, went with them to consultations and helped them understand what was discussed, and helped them with paperwork.

Clinical expertise: Respondents mentioned that the Navigator was helpful when it came to understanding their care. Specifically, they mentioned that the Navigator attended appointments and talked to them afterwards, helped with side effects, alerted the patients to signs and symptoms to watch for, and facilitated prescription refills.

System savvy: Respondents mentioned specific and general help with filling out paperwork, finding lower-cost options, and finding providers that they felt comfortable with. Several said that they would not have been able to perform those tasks on their own.

Selections from interviews

> Well, we didn't know nothing [sic] about cancer. The Navigator girl for the tribe, she's really good at what she does, and … really knowledgeable and experienced. She explained everything from A to Z, what I need to do and what people feel. She answered any question that we had. Like "So when am I going to lose my hair?" And she'd tell me that. "What happens through chemo?" And she said, "Well, the first time that people have chemo…" She told me what the symptoms would be like, what I might expect and stuff like that. Or if I needed some medicine, she'd have a doctor go sign something for me then I could go pick up something, like if something happened during chemo that was really affecting me bad.
>
> There is no way I would understand a lot of that paper work. She did a lot of the paper work, a lot of referrals and stuff like that at the beginning. I didn't know anything. She saved a lot of the shoulder work that was too much for me at the time.
>
> It would have been a thousand times worse if it wasn't for [the Navigator] being there at the meetings. Or helping me out with paper work, understanding medicines and symptoms, stuff like that.
>
> I hope that a lot of the other Navigators are like the one that helped me. I hope it reaches a lot of people like it affected me. It's been really nice having [the Navigator] there. She's been supportive, she's been helpful, she knows what she's doing. She's educated. She's professional and I like that.
>
> I just said if I wanted my family there. She said 'Okay, that's fine.'
>
> [The Navigator] used to come to my appointments the first six months, because I kept having questions. She came to my appointments all the time, like during a CAT scan, PET scan or bone scan, and explained to me what's going on during these and what I may experience and what I need to look out for and stuff like that. Every time I went to these appointments she always included my family.
>
> I thought that I was going to have to go through this by myself. I thought this was the only way I could do it, you know, without putting stress on my family. I didn't want to bother them. I didn't even want my brother or sister to know, but my daughter eventually let them know. ... But then these people told me that it was nice to think this way, but a lot of the time you do need help. Well, I get a more positive attitude about it now when I talk to them – before I didn't, I thought that I was going through some kind of punishment. It wasn't that. They helped me see that this, this is part of living… I wouldn't want to have to go through it again but if had to go through it I'd like to contact them earlier because it would have been a whole lot easier on me.

Selections from interviews

> The only problem I had with them, they was never there. I understand that they have other people to deal with. But every time I use to go the clinic I'd knock and there'd be nobody there. But other than that – whenever they were there I got a little respect … I kind of felt like they knew what I was going through, where other people had a vague, vague idea what a cancer patient has to put up with.
>
> Every time I contacted them, they've gotten back to me, they've talked to me as soon as I've called them. I've never had to wait to talk to them.
>
> They found cheaper accommodations for me, and they referred me to [a patient support organization] when I went over there. I went to [a hotel connected to the hospital] and it was costing me $125 a night, where I could have been staying at this [other hotel]. Well, it was a few blocks away but the price was cut in half, plus this [second hotel] I was getting shuttle services where at [the first hotel] I would climb up there.
>
> It's nice to send a person to church and pray and everything, but [Navigators] have the background and stuff to give you advice and their facts are more up to date. Technology in the cancer field is advancing in these last two years… They are really the only one I could recommend. To me this would be the saintliest job because no one really understands the situations of cancer.
>
> I had a problem up here with this [doctor] in [a nearby city]. He's the radiologist. Me and him didn't hit it off when I went up there. That was the first time I got angry at a doctor. The Navigator was there with us. He put us in a room for an hour and a half. Three of us, just kept waiting and waiting and waiting. The Navigator walked out and would check and see every half hour or so. 'No, not yet, not yet, he's not here.' I got to my appointment about 20 minutes early, so I'd be there early. … As soon as he came in, he says I'm not the only one who has cancer, he told me. In a bad-attitude way, I guess you'd call it. "You're not the only one who's got cancer." That verily upset me. So I wouldn't even take the treatment he was offering me, the radiation. … I ended up just walking out of his office. He said, Well, there's nothing I can do for you, I guess. He walked to the door and opened up the door for us and we just marched right out. … [The Navigator has] been with us at just about every appointment I've been to.
>
> At first, I was really uneasy because I'm a person that didn't want other people in the same room with me that I didn't know. After a few times with the Navigator, it came real easily being around her. Myself, I just didn't want to have strangers around me. It all worked out good, working with her. She's been very helpful.
>
> It was a lot better, a lot easier with the Navigator because she helped me on everything I needed.

D. Clinic- and Community-level process outcomes

Partnerships formed

Navigators pursued partnerships with a wide variety of organizations to bring resources to their clients. A number of these partnerships are listed in Table 17 below. Partnering organizations range from those with national scope, such as Native C.I.R.C.L.E., which provides Native-specific cancer information, to local volunteer organizations, such as the Yakima area People 4 People, which arranges for volunteer drivers to transport patients to chemotherapy appointments. All of the partnerships listed here were formed by Navigators after the organization of the program and represent a significant improvement in the scope and quality of services available to the clinic.

Table 17. Partnerships formed at the tribal level, Northwest Tribal Cancer Navigator Program

Puyallup	Yakama
Downtown Family Medicine Dr. Steven Hammer for general surgery referrals Hematology/Oncology NW Native C.I.R.C.L.E Northwest Cancer Support Group Northwest Urology Center Obstetrics Medical Group Pacific Nephrology Associates Pearl Place Women's Care Pierce County Health Dept OB Access Clinic/Tacoma Family Medicine Pulmonary Consultants South Puget Sound Planning Agency (SPIPA) Spirit of Eagles/Cancer Information Service (NCI) Tacoma Area Coalition of Individuals with Disabilities (TACID) Tobacco Education Outreach Team Women to Women OB/GYN	American Cancer Society Communication Cancer Research Coalition Native C.I.R.C.L.E North Star Lodge Office of Native Cancer Survivorship (ONCS) People 4 People Spirit of Eagles/Cancer Information Service (NCI) The Memorial Hospital Tumor Board Tribal Tobacco Prevention Program Wellness House Yakima Breast and Cervical Health Program Yakima Native Americans Speak Out Yakima Neighborhood Health

Screening rates

The individuals who served as Navigators tended to look for systemic solutions to gaps in service. For example, one Navigator persuaded the providers at her clinic to undertake a month-long hemocult study to examine possible reasons for the low rates of colorectal cancer screening by the fecal occult blood test. She asked physicians to complete a form (designed by the Navigator) each time they issued a fecal occult blood test kit to a patient, who was then expected to complete the sample at home and return the kit to the clinic. The results of the study showed that physicians were issuing the tests more often than had been thought, but a majority of patients failed to return the completed samples to the clinic. (In fact, many patients accepted the kits out of politeness without intending to complete the test.)

Other Navigators met with representatives from the county Breast and Cervical Cancer Prevention programs to discuss gaps in services for their patients – women who fell just outside the income or age limits but were unable to secure life-saving tests with their own finances. By documenting these needs over time, Navigators were able to justify arrangements with the county programs to find services for many of these women.

E. Provider satisfaction

Feedback from the provider opinion survey was quite positive. (See results in Tables 18 and 19.) We were unable to calculate an exact response rate, as planned, because the survey link was forwarded to several email groups by people within cooperating agencies, rather than to individual email addresses. However, our best estimate is an approximate 35% response. Seven respondents from the Navigators' tribal or IHS clinics and three respondents from hospitals or cancer centers are included here. All respondents had at least one patient who had been navigated.

Nine of ten respondents (90%) reported improved communications with their patients, better coordination between providers, success in helping patients understand their care and diagnosis, and greater ease in managing the care of cancer patients. The same number said that it was easy to refer patients to the program.

Seven of ten respondents (70%) judged that their communities' perception of cancer care had improved thanks to the Navigator Program. Similarly, seven respondents reported that navigated patients trusted the medical system more, followed through with medical recommendations better, and missed fewer appointments than non-navigated patients, while the remaining three respondents thought that navigated and non-navigated patients were about the same.

All providers (100%) said that they would recommend the Navigator model to other clinics with limited resources.

Table 18. Responses to the provider survey multiple-choice questions (n=10 providers familiar with the Navigator Program)

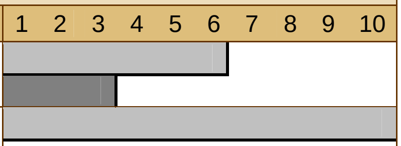
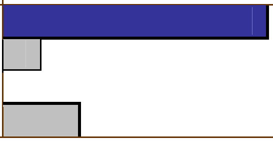
Question	Possible responses	#	1 2 3 4 5 6 7 8 9 10
What type of facility do you primarily work from?	Tribal or IHS facility Hospital or cancer center	7 3	
To you knowledge, have any of your patients worked with the Northwest Tribal Cancer Navigator Program?	Yes No	10 0	
In your opinion, how has the Navigator Program affected the community perception of cancer care?	Perceived higher quality of care No change Perceived lower quality of care I have no idea	7 1 0 2	

Table 18. Responses to the provider survey multiple-choice questions (n=10 providers familiar with the Navigator Program)

Question	Possible responses	#	1 2 3 4 5 6 7 8 9 10
In your opinion, how do the Navigator patients follow through with medical recommendations compared to non-Navigator patients from the tribal clinic?	Much more consistently	4	
	More consistently	3	
	Similarly	3	
	Less consistently	0	
	Much less consistently	0	
How has the Navigator Program affected coordination between providers?	Greatly improved	4	
	Improved somewhat	5	
	No change	1	
	Somewhat worse	0	
	Much worse	0	
How has the Navigator Program affected communication between you and your patients?	Greatly improved	4	
	Improved somewhat	5	
	No change	0	
	Somewhat worse	1	
	Much worse	0	
How easy is it to report abnormal screenings or refer cancer patients to the Navigator?	Extremely easy	7	
	Somewhat easy	2	
	Neither easy nor difficult	1	
	Somewhat difficult	0	
	Extremely difficult	0	
The Navigator Programs seems to help patients trust the health care system.	Agree strongly	4	
	Agree	3	
	Neither agree nor disagree	3	
	Disagree	0	
	Disagree strongly	0	
The Navigator Programs helps patients understand diagnosis and treatment.	Agree strongly	3	
	Agree	6	
	Neither agree nor disagree	0	
	Disagree	1	
	Disagree strongly	0	
Patients miss fewer appointments because of the Navigator Program	Agree strongly	7	
	Agree	0	
	Neither agree nor disagree	3	
	Disagree	0	
	Disagree strongly	0	
The Navigator Program makes it easier to manage care of cancer patients.	Agree strongly	6	
	Agree	3	
	Neither agree nor disagree	1	
	Disagree	0	
	Disagree strongly	0	
Would you recommend the Navigator model to other clinics with limited resources?	Yes	9	
	Yes, but with considerations	1	
	No	0	
If you answered "Yes -- with considerations" above, please describe those considerations here.			The [individual/s] in our program [do/es] not meet my expectations for the Navigator model.

Responses to open-ended questions (Table 19) underscored the importance of the Navigator as a coordinator ("Better exchange of treatment information") and as someone who can give patients individual attention ("[It helped] a specific patient of mine … comply with chemotherapy, appointments, and discussions with his local oncologist").

The main problems identified were related to managing information (e.g. "Need to keep the problem list or treatment plan updated"). One provider noted an instance where a Navigator failed to respect a patient's wishes.

While not explicitly mentioned, it is clear that the Navigator model itself could not be successful without the interpersonal skills and expertise of individual Navigators. The benefits listed by these respondents would not be realized without Navigators who can communicate well with both patients and providers, who are proactive and independent, and who understand cancer.

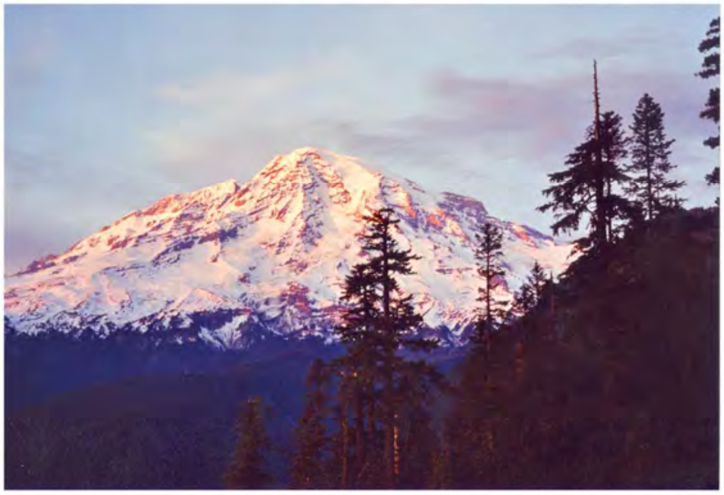
Table 19. All responses to the provider survey open-ended questions
Briefly describe a specific BENEFIT the Navigator Program has provided to you or your patients:
▪ I am thinking of a specific patient of mine. It helped him comply with chemotherapy, appointments, and discussions with his local oncologist. Helped immensely in building trust. Would NOT have helped without the Navigator Program. ▪ Helping patients and family members get the needed appointments done and contact person within the clinic to answer questions, concerns and support services in the area. ▪ My understanding of cancer treatment improved, which makes my dialogue with clients more specific and appropriate. My clients have greatly benefited from the individualized attention to their questions, concerns, and apprehensions about cancer treatment. Absolutely great program! ▪ Easier access to care and the importance of following cancer care guidelines ▪ Better communication with local medical providers. Better exchange of treatment information.
Describe a specific PROBLEM you have encountered with Navigator Program:
▪ None. All my interactions have been very positive ▪ Having only one Navigator to service our rather large patient population. ▪ None. This program should become a permanent part of all clinics who serve clientele who have cancer. ▪ Need to keep the problem list or treatment plan updated. ▪ A patient wanted to handle her own communication with [her clinic]. … The Navigator was not sensitive to this issue and did not consult me.
Do you have any other comments?
▪ Please keep this program going!!! ▪ The cancer Navigator has been an invaluable service in our clinic. The patient response has been positive and often very grateful for the support she provides to them. ▪ Particularly the oncology nurse with the Navigator Program at the Yakama Indian Health Center has been of great benefit to this community. She is quite skilled, compassionate, and capable. I am blessed to have met her. ▪ Excellent concept. The cancer registry should be easier to maintain and follow than I witness. We … utilize the RPMS system and the Navigator should be able to run QMAN reports and keep the treatment plan up to date. Not only is it important for the patient follow the plan but also the primary provider. Many times the patient may be gone from our primary care facility and we may not see them for 6-12 months.

Limitations

The results of this survey are subject to respondent bias. About half of invited providers responded, and those who worked more closely with Navigators and/or had positive interactions with the program were likely more inclined to respond. However, the satisfaction of this many providers is itself a positive outcome of the program.

Part 6

Discussion



Northwest Tribal Cancer Navigator Program
Pilot Project Final Report

VI. Discussion

A. Research questions

The pilot Navigator study was formulated with the aim of answering the following research questions:

1. Do participants in the NW Navigator Program complete their first diagnosis and treatment appointments in shorter time than patients of the same clinics before establishment of the program (i.e., historical controls)?
2. Do participants in the NW Navigator Program miss fewer appointments and comply with treatment recommendations more than cancer patients who are not working with the Navigators?
3. Does working with the Navigators improve the quality of life experienced by cancer patients during treatment?
4. Which patient needs do Navigators meet, and how do they do so?
5. How do Navigators affect clinic operations, particularly with respect to cancer-related activities such as screening and outreach?
6. Are the pilot data collection instruments effective and efficient means of collecting information?

B. Discussion

Time to treatment

While over 500 patients were navigated in the pilot period, the extremely low number that granted permission to look at their medical records makes the answers to the first two research questions tentative at best. The mean time elapsed between diagnosis and treatment, as measured in days, was slightly lower for navigated patients than for controls, but not at a statistically significant level. We were unable to ascertain resolution dates for controls who were not diagnosed with cancer. The level of funding for the pilot study did not allow for the detailed chart reviews that would have been required and that have been incorporated in the ongoing Patient Navigator Research Program (PNRP).

Missed appointments and compliance with provider recommendations

Similarly, documentation of missed appointments and treatment compliance was not as accessible in administrative databases as had been anticipated and insufficient data were retrieved for testing those hypotheses. Navigators encountered patients who expressed intentions to discontinue their courses of care – because of dissatisfaction with providers or financial difficulties – or who failed to show up for multiple appointments. While we lack quantitative evidence that navigated patients complied with treatment better than controls, the Navigators were successful in finding alternatives for these patients that allowed them to pursue recommended care to its conclusion.

Quality of life

Formulating a measure of quality of life for navigated patients proved challenging. When we consulted key informants during the project's formative phase, they placed high priority on quality of life as a goal that the project should pursue. When asked to elaborate on what the definition of "quality of life" included, key informants mentioned the ability to continue to participate in family activities and in traditional practices such as dancing, berry picking, and clam digging. Several key informants also said that they wanted to reduce the fear and suffering experienced by people who faced possible or confirmed diagnoses of cancer.

At the time, no existing quality of life measure had been validated in or modified for American Indians with cancer.[13] Most quality of life measures targeted physical function or mental health indicators, while key informants had identified priorities that were not reflected in these instruments. Moreover, many existing quality of life measures were designed for comparisons within groups of patients with the same types of cancer and we were not confident of recruiting sufficient numbers of patients in those subgroups for meaningful comparisons.

Key informants also strongly discouraged project staff from pursuing contact with control subjects for quality of life measures. In their opinions, the benefit that would have been gained by such interviews was not sufficient to justify the emotional pain that we would cause to controls by asking them to describe their experiences with cancer and not having any services or solutions to offer them. For Native people in particular, talking about cancer often means a personal sacrifice requiring them to violate their personal privacy and/or tribal taboos. Tape recording is also taboo for a number of indigenous groups, particularly among elders who constitute the majority of cancer patients.

The interview instrument was formulated with some structured questions to allow for summaries across interviews. The structured questions were followed by open-ended prompts to allow respondents to talk about their own priorities and give us their opinion as to whether or not the program was worthwhile.

The responses we received from patients was positive. Of the 15 patients and family members who agreed to interviews, only one had a consistently negative experience with the Navigator. Patients gave the program high ratings overall and 13 of the respondents said that if someone they cared about got sick, they would definitely want them to meet with the Navigator.

From the patient's point of view, the main advantages to having a Navigator seem to be the Navigator's expertise in navigating the medical system; the Navigator's ability to help patients understand their care and communicate with medical professionals; the Navigator's clinical expertise, especially in anticipating and responding to side effects of treatment; the understanding and sympathy offered by the Navigator; respect for the patient's wishes; and promptness in responding to patient-initiated contacts. These were important goals of the Navigator pilot study, and though the patient interviews represent a small, preliminary study of patient navigation, the consistency of the results indicates that the program was successful in meeting those goals.

Patient needs

Navigators tracked the barriers addressed in each encounter they had with a patient. The most common barrier addressed was "provider communication," which was recorded for 20% of all encounters and included both communication between patients and providers and communication among different providers. In overcoming this barrier, Navigators might attend an appointment with a patient and talk about the conversation afterward to help the patient clarify the discussion. Navigators also marked this barrier when they called to request medical records be sent from one facility to another or relayed updates about the patient's care to the patient's primary provider at the home clinic. Some of these interactions required a level of clinical expertise; the Navigators who were registered nurses (RNs) said that their nursing backgrounds were important to them as Navigators, and other providers seemed to develop a rapport with nurses more quickly than with lay Navigators. However, many of the "provider communication" barriers were resolved by non-nurse Navigators.

Referrals were the next most common barrier navigated (17.8% of encounters). Because tribal Navigators work at community clinics, most of the care received by navigated patients was provided by contractors or other outside agencies. Tribal clinics report that they lose patients to follow-up in the referral process, though exact numbers are difficult to tabulate because referrals are not logged in the computerized databases until patients receive services that require payment by the clinics.

Tracking abnormal screenings to ensure follow-up was the third most commonly reported barrier (12.6% of encounters). In the initial study protocol, navigation was limited to patients who had been diagnosed with cancer. As the Navigators became the "go-to" people for cancer, and as the need for better tracking of abnormal tests became evident, tracking the abnormal results was added to the Navigators' scope of work. As described in the study methods, Navigators received lab reports and confirmed that patients received additional testing as indicated – most often a repeat Pap test in six months. Most patients were contacted by Navigators only if they failed to schedule follow-up testing. Some patients were referred for more proactive follow-up by providers if they had a history of missed appointments, noncompliance, or significant non-medical barriers to care that were known to their providers. Navigators often contacted these patients in advance of the scheduled follow-up date to ensure that the patient was able to schedule an appointment and had necessary transportation and childcare arrangements, etc.

Approximately 5% of all encounters in the pilot study were home visits. Home visits are more common and more significant for Native communities than for many other social groups, as American Indians and Alaska Natives are a highly mobile population and a number – especially those living on reservations – live without phone service. Though they represent a small proportion of the encounters in the study, these home visits were sometimes pivotal encounters for tracking down patients who had been lost to follow-up. In another home visit, the Navigator discovered that an older patient had not understood the instructions for most of the patient's prescribed medications and was not taking them. The Navigator sorted the medications and trained the patient and the patient's immediate family as to how the medications should be administered. Elders exhibit a particular preference for in-person encounters, whether at home, at the clinic, or at a hospital.

Clinic operations

The Navigators unquestionably benefited their host clinics. Because the Navigators received additional cancer training and networked extensively among providers of cancer-related and patient services, they were consulted on a range of issues. Navigators formed a number of formal and informal partnerships with local and regional groups. They participated in local health fairs, helped start up a survivor support group, attended coalition meetings, met with state Breast and Cervical Cancer Program representatives, and assured that the clinic followed up with patients who had abnormal screenings. They successfully petitioned their host tribes for financial aid for patients in the form of donations and gas vouchers, and persuaded the local transit authority to charge cancer patients a discounted "disabled" rate and to move a bus stop to improve access to the clinic for disabled patients.

We included a provider survey in our study because provider cooperation affects the success of the navigation process. In our small survey, tribal and non-tribal providers perceived a number of benefits that resulted from the Navigator Program to the community:

- Improved community perception of cancer care
- Better compliance with provider-recommended care
- Improved coordination between providers
- Improved provider-patient communication
- Better patient trust in the health care system
- Help for patients to understand diagnosis and treatment
- Fewer missed appointments
- Greater ease in managing patient care

The providers – typically a group familiar with the limitations on resources in the Indian Health Service – were unanimous in recommending the Navigator model to other clinics with limited resources. Though our survey was too small to be definitive, it shows that a number of providers involved with the Navigator Program found that it improved their patients' care.

Pilot data collection instruments

Measuring the effectiveness of patient navigation in the community settings where American Indian and Alaska Native people access care requires a creative approach that can balance information needs, the limits of available data housed in multiple clinical systems, and ethical and legal restrictions on access to patients and their records. With our pilot data collection instruments, we aimed for a system that would be both complete and cost-effective. Now, at the end of the pilot study, we can provide useful recommendations for how to maximize the efficiency of the instruments at answering the questions most relevant to determining the success of patient navigation.

Clinical data was obtained in the pilot study from two sources: Navigators' data entry in the Navigator database, and a data linkage between clinic records and the state cancer registry. The scope of the pilot study did not allow for systematic chart reviews.

The Navigator database was a successful tool for collecting data about patient encounters. The database contained some internal reports that allowed Navigators to review their data entry. Some reports contained special formatting to highlight potential data entry errors. Weekly reporting deadlines were also useful in maintaining Navigators' data entry. Using one record per encounter proved to be the most intuitive system. With one record per encounter, Navigators checked all barriers that were dealt with in that encounter.

In addition to their own encounter data, Navigators entered some clinical variables in the database. The initial Navigators requested a database where they would be able to enter and retrieve key information about patients' clinical histories. In practice, Navigators entered data but few used the database for later retrieval of information. The data obtained were limited by the relatively small number of patients who signed paperwork to make their clinical records available for the study. This data entry placed an additional burden on the Navigators and introduced a potential for bias; in the future, we recommend separate, systematic chart abstraction by non-Navigator staff, limiting the Navigators' database to encounter information and limited notes about individual patients. The same database would be useful for recording encounters with individuals who are not patients, such as when the Navigator is networking to find new resources for the clinic.

We also recommend a change in how barriers are operationalized. Instead of focusing on the patient's barriers, we recommend recording the Navigator's solution or attempted solution. This method is more objective and will result in greater consistency in the data. As an example, one Northwest Navigator learned that a family was skipping meals so that they could afford gas for the car trips to chemotherapy for the female head of household. This barrier could be classified in a number of different ways: as a transportation problem, a financial problem, a family caregiving issue, or a nutritional deficiency. Different Navigators would likely document this barrier in different ways. If Navigators instead recorded their attempted solutions – finding financial aid, arranging transportation, providing tribal gas vouchers, enrolling the family in a supplemental food program, or by a combination of similar measures – they would document that barrier with much greater consistency. This definition has the added advantage of reflecting Navigators' activities.

The data linkage was a quick and efficient method for gathering data about diagnosed cancer cases. Data obtained from the state cancer registry is collected by individuals who are not associated with the Navigator Program and who collect data consistently across all sites, which minimizes the bias introduced by having program staff collect clinical data. The state cancer registries can also identify cancer cases that would not be found in the clinics' administrative databases. In our pilot study, the clinic databases correctly identified only 50.8% of patients who were diagnosed with cancer. The gap is likely due to the fact that clinic databases are designed to document care provided at the clinic, and the clinics do not treat cancer onsite. The state cancer registries have strict privacy and confidentiality protections that preclude using data linkages to identify individuals for chart review. Nonetheless, the patients who are missed in clinic databases are least likely to have received navigation services and may differ from navigated patients in ways that affect their care and outcomes. Data linkages provide a means to evaluate the resulting bias.

While the data linkage method is quick, efficient, and consistent across study groups, the method has some important weaknesses in the context of the Navigator Program. The state cancer registries do not contain any information about patients whose screening and diagnostic tests resolved in non-cancer diagnoses, and even for the patients who were diagnosed, data on screening tests are not complete. The state cancer registries also have a lag of three or four years, meaning that data on cancer cases diagnosed in 2006 will not be complete until 2009 or 2010. We recommend using a linkage study to validate results from chart abstraction rather than as a primary source of data.

The patient and provider surveys provided the pilot study with useful feedback but would not be robust for comparisons across multiple navigator-style programs. Instead, each navigator program should develop an open-ended mechanism to solicit feedback from patients, providers, and others with important roles in patient navigation.

C. Conclusions

Navigation improves cancer prevention, detection, and treatment in clinics serving AI/AN, according to both patients and providers. Our study tested a model that followed the specifications of the clinic leadership and reflects the realities and values of AI/AN community health care. IHS, tribal, and urban Indian clinics have pioneered programs similar to many patient navigation models, such as the Community Health Representative program, which employs lay health workers, or the diabetes programs for case management. For the current Navigator Program, the participating clinics drew on past experience to design a model particularly suited to the needs of people accessing cancer-related care in the system funded by the IHS.

All participating clinics specified that Navigators should be certified as registered nurses (RNs) as a minimum qualification. They predicted that navigating patients through the cancer-related care provided under IHS funding would require clinical sophistication. Indeed, the Navigators in this pilot program devoted much of their time to coordination of care. Comments from both patients and providers indicate that the Navigators' role in coordination of care is important and appreciated.

While based at their community clinics, Navigators in this AI/AN program spend much of their time seeing people in oncology centers, hospitals, and in their homes. Providing health care to community members in the community has, anecdotally, been key to the success of other programs serving AI/AN. In cancer navigation, being onsite helps Navigators guide patients in accessing care from multiple institutions. Navigators develop relationships with providers who otherwise have little or no personal connection to the AI/AN clinics that refer patients to them for care. By making visits and being at appointments, Navigators quickly become familiar with the patients' needs and can identify potential problems before they become crises. The Navigators' presence is also important to the people they serve; most of the patients we spoke with mentioned their Navigator's willingness to attend important appointments and talk with them later about what was said, and many described their Navigators as sources of understanding, motivation, and respect.

It was important to those who planned and implemented this project that the eligibility requirements be broadly inclusive. Anyone who was eligible for care at the clinic and who had needs related to cancer screening, diagnosis, or treatment could access the Navigator Program, regardless of type of cancer or previous history. Navigators also participated in health promotion activities, such as health fairs, that served the broader community. The broad scope of navigation was challenging to Navigators, who might have benefited from having a more narrowly defined role. However, many people believe that to restrict a program in such a way so as to be perceived as exclusive by community members is to doom the project to failure, though it is outside the scope of this project to prove conclusively whether this is true.

The instruments designed to evaluate the clinical success of this pilot project proved inconclusive. This was not completely unanticipated, as the three-year span of the project was a short time to establish changes in clinical outcomes for cancer. The primary obstacle to evaluating clinical outcomes, however, was the informed consent process. Even after the informed consent document was revised to be comprehensible to patients with low literacy, the process itself proved too cumbersome and few patients signed the document that allowed the research team to examine their clinical data. In close consultation with the Portland Area IHS Institutional Review Board (IRB), a new informed consent process was developed for the Navigator Program to use after the close of the pilot phase. This new process allows patients to request that their clinical information not be used, rather than requiring them to sign the informed consent document, which functioned in the pilot phase as permission to release information. The new process has been carefully reviewed by the IRB to ensure that patient rights will be protected without creating barriers to participation.

The clinical results that we were able to obtain show that the Navigator model has potential to reduce time to treatment, as measured by the average number of days between diagnosis and treatment for all cancers combined. The expanded Navigator Program, which includes more clinics and better systems for data capture, will help establish whether patients experience fewer delays and dropouts when assisted by Navigators.

Part 7

Citations

Northwest Tribal Cancer Navigator Program
Pilot Project Final Report

VII. Citations

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Part 8

Supplemental Materials

Northwest Tribal Cancer Navigator Program
Pilot Project Final Report

VIII. Supplemental materials

Appendix A: Sample position descriptions
Appendix B: Referral script
Appendix C: Selected articles about the Northwest Tribal Cancer Navigator Program
Appendix D: Original informed consent document
Appendix E: Revised informed consent document
Appendix F: Standard IHS medical record form (Patient Care Component [PCC] form)
Appendix G: Navigator encounter form
Appendix H: Navigator intake survey
Appendix I: Pilot program brochure
Appendix J: Database images
Appendix K: Informed consent for patient interviews
Appendix L: Instrument for patient interviews
Appendix M: Email invitation for provider satisfaction survey
Appendix N: Online provider satisfaction survey
Appendix O: Navigators' "case stories"

Appendix A: Sample position descriptions

PUYALLUP TRIBAL HEALTH AUTHORITY
JOB DESCRIPTION

JOB TITLE: Nurse Navigator-Cancer Project **REPORTS TO:** Nursing Director
(Current Grant Project-funding ends 9/30/05, future funding available on a year-by-year basis)
TEAM: Health Services **DEPT:** Medical Clinic

FLSA STATUS: Exempt **GRADE:** 8

The Puyallup Tribal Health Authority is accredited and the employee in this position is required to participate in job related quality improvement activities.

GENERAL FUNCTION: Provides intensive nursing case management as an integral part of the cancer screening and treatment health care team. Main goal is to decrease the amount of time between diagnosis and on-set of treatment. Provides intensive follow-up with patients regarding satisfaction with cancer care. *This position is grant funded and is scheduled to end 9/30/05, future grant monies are funded on a year-by-year basis.*

ESSENTIAL JOB FUNCTIONS:
The essential duties and responsibilities regularly assigned to this position include:
- Assesses the progress of patients treated for cancer by PTHA or outside providers, including routine health care problems, routine lab testing, provide test results, and provide care follow-up appropriate to the identified concerns as well as assistance with referrals to outside and specialty providers.
- Provide sustained follow up of patients who require periodic or prolonged phone consultation, nursing advisement, or other essential care as part of clinical care.
- Track and monitor all care and services rendered, outcomes, performance improvement, and progress on a regular basis to clinical management. Prepare monthly reports of face-to-face, telephone encounters, other contacts with clients/patients and submit on a timely basis.
- Document all visits on PCC form with in 48 hours of care rendered.
- Provide outcome-driven goals/objectives for each patient, provide specific health education and information driven by diagnosis or current health concern, continuously re-evaluate plan of care.
- Reports outcomes as needed on a case-by-case basis to the appropriate provider/physician.
- Maintains a high degree of communication with the physician/provider staff on problem cases.
- Consults with physicians, PA/ARNP, nursing staff regarding care; patients response to care rendered.
- Performs intensive medical case management on high-risk patient findings (abnormal pap smears, abnormal blood tests, abnormal exams) and reports outcomes/findings to provider/physician staff.
- Communicate constructively and in a timely manner on cases where contact is desired but has not been successful. Collaborates with other health professionals on recalcitrant patients.
- Maintains Navigator database as required by Navigator Program.
- Maintains ambulatory clinic competency.

AGE SPECIFIC RESPONSIBILITIES: Must be able to demonstrate knowledge, skill, and ability necessary to provide care to specific age groups served in his/her assigned area

INFECTION CONTROL RESPONSIBILITIES: Follow PTHA policies and procedures and use proper protection from blood born pathogens and body fluids. Proper use and disposal techniques for sharps.

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SAFETY RESPONSIBILITIES: Keep work and patient areas clear and free of sharps and chemicals. Certification in CPR and First Aid. Follow facility policies and attend in-services and committee meetings.

ROLES IN THE HAZARDOUS MATERIAL PROGRAM: Follow the PTHA policy and procedure regarding proper disposal of infectious waste and bio-hazards.

ACTIVITIES UNIQUE TO THE WORK SETTING OF THIS POSITION: The work is performed on a Native American reservation in an urban environment. Frequent exposure to communicable diseases, toxic substances, ionizing radiation, and medical preparations.

SUPERVISORY RESPONSIBILITIES: None.

MACHINES, TOOLS, EQUIPMENT, AND/OR OFFICE MACHINERY UTILIZED: Standard office equipment, including computer. Standard ambulatory medical clinic equipment and instruments.

WORKING CONDITIONS: Work is primarily performed indoors in an office setting; some work is performed in the community.

PHYSICAL AND ENVIRONMENTAL FACTORS: Frequent sitting, standing, and walking. Frequent demands which require mobile dexterity to include bending, stooping, pushing, pulling, and reaching.

KNOWLEDGE, SKILLS, AND ABILITIES: Sensitivity to and knowledge of Indian customs, traditions, and culture. In depth knowledge of professional nursing care theory, policies, and practices. Ability to interact and communicate professionally, both verbally and written, with physicians, nurses, patients, patients families, staff members, insurance carriers and other community providers. Strong organizational and time management skills with the ability to work independently.

MINIMUM REQUIREMENTS (EDUCATION AND EXPERIENCE): Graduation from an accredited school of nursing with a Bachelor of Nursing degree. Case Manager Certification desirable.

- As a Federally recognized Sovereign Nation and according to law, Indian preference will be utilized in the selection
- All requirements are subject to possible modification to reasonably accommodate individuals with disabilities. However, some requirements may exclude individuals who pose a direct threat or significant risk to the health and safety of themselves or other employees.
- While requirements may be representative of minimum levels of knowledge, skills, and abilities to perform this job successfully, the incumbent will possess the abilities or aptitudes to perform each duty proficiently.
- This job description does not imply that these are the only duties to be performed. Employees occupying the position will be required to follow any other job-related instructions and to perform any other job related duties requested by their supervisor.

I have read and understand this job description.

Employee	**Date**	**Supervisor**	**Date**

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PUYALLUP TRIBAL HEALTH AUTHORITY
JOB DESCRIPTION

JOB TITLE: Community Cancer Navigator Assistant **REPORTS TO:** Nursing Director

(Current Grant Project-funding ends 9/30/05, future funding available on a year-by-year basis)

TEAM: Health Services **DEPT:** Medical Clinic

FLSA STATUS: Exempt **GRADE:** 3

The Puyallup Tribal Health Authority is accredited and the employee in this position is required to participate in job related quality improvement activities.

GENERAL FUNCTION: Provide outreach and referral services related to cancer prevention, diagnosis, and treatment for PTHA patients and their families. To resolve personal, social, and health care needs. (*The Northwest Cancer Navigator Program is a research project funded by the National Cancer Institute and administered by the Northwest Portland Area Indian Health Board. The goal of the program is to help patients obtain proper follow-up of abnormal cancer screening results and adequate medical care and support if they have cancer. The Community Cancer Navigator Assistant will work with the Nurse Navigator to achieve these goals. This position is grant funded and is scheduled to end 9/30/05, future grant monies are funded on a year-by-year basis.)*

ESSENTIAL JOB FUNCTIONS:

The essential duties and responsibilities regularly assigned to this position include:

- Coordinate closely with the Nurse Navigator to divide up duties and activities to ensure that all patients and participants in the program receive the attention and support that their condition warrants
- Keep track of abnormal results of routine cancer screening tests in Puyallup clinic patients to make sure that all patients with an abnormal result receive the necessary follow-up tests. These routine screenings include Pap tests, clinical breast exams and mammograms, prostate-specific antigen (PSA) tests and digital rectal exams, fecal occult blood tests (FOBT), sigmoidoscopies and colonoscopies.
- Assist in arranging appointments and other follow-up for patients with abnormal screening results.
- Follow up with missed appointments and identify primary barriers to keeping future appointments; con with patients and their families to overcome those barriers
- Contact patients and their families and determine what resources are required to meet their personal, social, and health care needs.
- Request and follow up on results of laboratory tests, scans, studies, and hospitalizations, both at the Takopid Health Center and from outside facilities.
- Develop and distribute outreach materials in cooperation with Nurse Navigator.
- Represent the Cancer Patient Navigator Program at area health fairs as deemed appropriate.
- Assist support gatherings of patients and survivors at their request.
- Identify and pursue outside resources to support client needs and overall project goals in cooperation with Nurse Navigator.
- Coordinate care between medical and specialist offices in cooperation with Nurse Navigator.
- Maintain a file on each patient participating in the Navigator Program; send faxes of medical records and paperwork; photocopy materials as needed.
- Assist with research activities and documentation required by funding agencies; document activities to support billing and program certification requirements.
- Provide support and facilitate access to care for patients in crisis situations if necessary.

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- Provide orientation to participants of services available and options for resolving needs.
- Assist in arranging appointments, transportation, and completion of forms/applications for DSHS, SSI, WIC, and other external services and assistance available.
- Assign patients to Nurse Case Manager where appropriate based on past interaction and caseload.

AGE SPECIFIC RESPONSIBILITIES: Must be able to demonstrate knowledge, skill, and ability necessary to provide care to specific age groups served in his/her assigned area

INFECTION CONTROL RESPONSIBILITIES: Follow PTHA policies and procedures and use proper protection from blood born pathogens and body fluids. Proper use and disposal techniques for sharps.

SAFETY RESPONSIBILITIES: Keep work and patient areas clear and free of sharps and chemicals. Certification in CPR and First Aid. Follow facility policies and attend in-services and committee meetings.

ROLES IN THE HAZARDOUS MATERIAL PROGRAM: Follow the PTHA policy and procedure regarding proper disposal of infectious waste and bio-hazards.

ACTIVITIES UNIQUE TO THE WORK SETTING OF THIS POSITION: The work is performed on a Native American reservation in an urban environment. Frequent exposure to communicable diseases, toxic substances, ionizing radiation, and medical preparations.

SUPERVISORY RESPONSIBILITIES: None.

MACHINES, TOOLS, EQUIPMENT, AND/OR OFFICE MACHINERY UTILIZED: Standard office equipment including computer. Medical equipment includes glucometer and sharps (lancets).

WORKING CONDITIONS: Work is primarily performed indoors in an office setting; some work is performed in the community.

PHYSICAL AND ENVIRONMENTAL FACTORS: Frequent sitting, standing, and walking. Frequent demands which require mobile dexterity to include bending, stooping, pushing, pulling, and reaching. Able to lift 20 lbs. Able to visit patients in their homes.

KNOWLEDGE, SKILLS, AND ABILITIES: Sensitivity to and knowledge of Indian customs, traditions, and culture. Knowledge of procedures and operations of a medical office. Able to interact with patients, families, and staff in a courteous and professional manner. Familiarity with medical terminology, either through work/personal experience or through formal training. Good organizational skills. Willingness to attend and participate in occasional trainings (such as Puget Sound Oncology Nursing Education Cooperative training). Current, valid Washington State drivers license. Requires CPR, First Aid training, CPR instructor training, Washington State HIV/AIDS Pre/Post counseling certificate.

MINIMUM REQUIREMENTS (EDUCATION AND EXPERIENCE): High School Diploma or GED. Two years experience in a medical office setting. Certificate of completion of an approved course in medical terminology.

- As a Federally recognized Sovereign Nation and according to law, Indian preference will be utilized in the selection
- All requirements are subject to possible modification to reasonably accommodate individuals with disabilities. However, some requirements may exclude individuals who pose a direct threat or significant risk to the health and safety of themselves or other employees.
- While requirements may be representative of minimum levels of knowledge, skills, and abilities to perform this job successfully, the incumbent will possess the abilities or aptitudes to perform each duty proficiently.
- This job description does not imply that these are the only duties to be performed. Employees occupying the position will be required to follow any other job-related instructions and to perform any other job related duties requested by their supervisor.

I have read and understand this job description.

Employee	**Date**	**Supervisor**	**Date**

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DEPARTMENT OF HEALTH & HUMAN SERVICE
PORTLAND AREA INDIAN HEALTH SERVICE
DIVISION OF PERSONNEL MANAGEMENT PORTLAND AREA IHS IS A SMOKE FREE AGENCY
Preference in filling vacancies is given to qualified Native American Indian candidates in accordance with the INDIAN PREFERENCE ACT, TITLE 25, US CODE, SECTION 472 & 473. In other than the above, the Indian Health Service is an Equal Opportunity Employer.

ANNOUNCEMENT NUMBER: **PO-04-35** **OPEN DATE: March 31, 2004** **CLOSE DATE: April 20, 2004**

POSITION TITLE/SERIES/GRADE: **Clinical Nurse (Cancer Patient Navigator), GS-0610-7/9**

STARTING SALARY: **GS-07 $44,731 - $53,677 GS-09 $48,638 - $59,582**
(May be adjusted for previous or current Federal employees)

PROMOTION POTENTIAL: **Yes to GS-09**

SUPERVISORY/MANAGERIAL: **No**

RELOCATION EXPENSES: **May be authorized in accordance with Federal Travel Regulations ~ Negotiable**

APPOINTMENT/WORK SCHEDULE: **Full-Time Temporary NTE: Two Years**

AREA OF CONSIDERATION: **Nation Wide**

LOCATION: **Yakama Service Unit, Toppenish, Washington**

JOB DESCRIPTION: Serves as the staff nurse in the health center located on the Yakama Indian Reservation. The nurse assists the physician and gives quality-nursing care demanded in an outpatient clinical setting. In the absence of the physician, provides minor and emergency treatment under approved protocols. Provides and documents nursing care for patients; administers drugs prescribed for patients; attends in-service and continuing education programs. Actively participates in Quality Assurance activities. Focus of the nursing efforts is cancer patients and coordination of services for the cancer patients. Data collection skills are needed to assist in coordination.

WHO MAY APPLY:

- Excepted Service Examining Plan Candidates (ESEP) – Individuals entitled to Indian Preference who wish to be considered for excepted appointment in IHS, under authority of 5 CFR, Part 213, Schedule A 213.3116(B)(B).
- Merit Promotion Plan Candidates (MPP) – Current permanent competitive Federal status employees, reinstatement eligibles, and current IHS Indian Preference individuals and/or individuals who are eligible for excepted appointment in IHS under some other authority (e.g., handicapped authority, etc).
- PHS Commissioned Corps Officers – Current active or inactive Commissioned Officers may apply.
- Veteran's Preference – Preference eligible veterans who have been separated from the armed forces under honorable conditions after 3 years or more of continuous active service may apply.
- Any qualified U.S. Citizen.

Indian Preference applicants must indicate on their applications whether they are applying under the MPP, ESEP, or both. If not indicated, they will be considered under the MPP.

Qualified disabled applicants (Rehabilitation Act of 1973) and disabled veterans with 30% or more disability are encouraged to apply. Reasonable accommodations will be made for qualified applicants with disabilities, except when doing so would impose undue hardship on the Indian Health Service.

CONDITIONS OF EMPLOYMENT:

1. Selectee(s) are required to be immunized against Measles and Rubella and provide medical documentation prior to or at the time of their start date. Special consideration may be allowed to individuals who are allergic to a component of the vaccine or are currently pregnant.
2. Selectee(s) are required to complete a Security questionnaire and fingerprint chart for investigative purposes under PL 101-630 Indian Child Protection and Family Violence Prevention Act. Persons who have been arrested for or charged with a crime involving a child, or violent crime against a person, are not eligible for employment with IHS under PL 101-630.
3. Selectee(s) are required to complete a "Declaration of Federal Employment - Optional Form 306" to determine your suitability for Federal employment, and to certify the accuracy of all the information in your application. Persons making false statements in any part of the application may not be hired; or fired after employment starts; or may be fined.
4. Males born after December 31, 1959 are required to be registered with the Selective Service System in order to be eligible for employment with the Federal Government.
5. Selectee(s) are required to have a viable bank account at a financial institution for electronic direct deposit of salary payment.

QUALIFICATION REQUIREMENTS:

Licensure Required: All applicants for nurse position must have active, current registration as a professional nurse in a State, District of Columbia, the Commonwealth of Puerto Rico, or a territory of the United States.

In addition to meeting the basic qualifications for degree, training, and licensure requirements, applicants must meet the following:

GS-7: Completion of a Professional nursing program **and** 1 year of experience equivalent to the GS-5 level; **or** 1 full year of graduate education **or** bachelor's degree **with** superior academic achievement with no experience.

GS-9: 2 full years of progressively higher level graduate education OR a master's OR equivalent degree. Or 1 year of experience equivalent to the GS-7 level.

Specialized Experience:
Experience that equipped the applicant with the particular knowledge, skills, and abilities to perform successfully the duties of the position and that is typically in or related to the work of the position to be filled.

LEGAL AND REGULATORY REQUIREMENTS: Must meet qualification requirements within 30 calendar days after the closing date of the vacancy announcement.

KNOWLEDGE, SKILLS, AND ABILITIES (KSA): On a separate sheet of paper discuss how you have performed the particular knowledge, skill, or ability listed below. Failure to submit written responses may result in an ineligible rating or substantially lower score.

Element 1: **Knowledge of scientific and psychosocial nursing theory, principles, and techniques and the nursing process as it applies to the appropriate nursing specialization**. The work of this position requires a knowledge of the theories, principles, practices and techniques of nursing, and nursing process as it relates to the appropriate nursing specialization in order to assess a patient's condition distinguishing between normal and abnormal development; implement and evaluate a nursing care plan; administer therapeutic measures and interventions for emergencies.

Element 2: **Ability to identify, assess, analyze and evaluate data and solve problems**. The works of this position requires the ability to identify, assess, analyze and evaluate data and solve problems in order to recognize changes in patient's condition; analyze results of medical procedures; making a nursing diagnosis; develop a care plan with nursing interventions and excepted outcomes; and assess learning needs in patients and families.

Element 3: **Ability to independently plan, manage and organize work, and set priorities and goals**. The work of this position requires the ability to independently plan, manage and organize work, and set priorities and goals in order to coordinate a nursing care plan with a nursing team; determine and accomplish the goals of the patient care plan.

Element 4: **Ability to counsel and teach**. The work of this position requires the ability to counsel, teach and motivate patients and families of different cultural backgrounds to adopt health maintenance and disease prevention measures; a knowledge of communication theory and counseling techniques is implied in this ability.

HOW TO APPLY/REQUIRED FORMS:

1. Applicants may use one of the following to apply: (1) OF-612 Optional Application for Federal Employment, **or** (2) Resume (see requirements in **Attachment A**).
2. If claiming Indian Preference, BIA Form 4432 "Verification of Indian Preference for Employment in BIA and IHS".
3. If claiming Veteran's Preference, copy of DD-214 Form, and SF-15 if claiming 10 point Veteran's Preference.
4. Copy of latest Personnel Action (SF-50), if a current or former Federal employee, and/or if requesting Reinstatement Eligibility.
5. Copy of most recent performance appraisal, if a current Federal employee.
6. **Copy of current nursing License.**
7. Completed PL 101-630 Questionnaire (form attached)
8. Completed Optional Form 306 (form attached)
9. Completed Selective Service Registration Form, if applicable (form attached)
10. Written Responses to the Knowledge, Skills, and Abilities (OPTIONAL ~ failure to submit may result in an ineligible rating or substantially lower score).
11. Commissioned Corps Officer: (a) latest COER, and (2) current Billet Description, (3) BIA FORM 4432 if claiming Indian Preference.

Application and required forms must be identified by this announcement number and submitted to the address below:

Portland Area Indian Health Service
Division of Personnel Management
1220 SW Third Avenue, Room 476
Portland, Oregon 97204

ATTN: Christina Smith (Human Resource Specialist)
Phone: (503) 326-2015
Fax: (503) 326-5787

All submitted materials are subject to retention by this office. You should duplicate and retain copies, since requests for copies will not be honored. Additional information regarding Federal job openings can be obtained at www.opm.gov, or check the IHS Website at www.ihs.gov, all documents are subject to the provisions of the Privacy Act (PL 93-579) and become the property of DHHS.

Additional selections of candidates may be possible within 90 days from the date the certificate of eligibles is issued for this announcement, for filling additional or similar positions.

Personnel Officer:__________________________________ Date:______________

ATTACHMENT A

Resume Requirements **-** Your resume or other application format ***must*** contain the following information to allow for qualification determination. ***Failure to submit a complete application may result in your application not being considered for this position***.

1. **Job Information** (announcement number, title and grade(s) of the job you are applying for).

2. **Personal Information**
   - Full Name (first, middle, last ~ include other names used, i.e., maiden name)
   - Mailing Address
   - Phone Number you can be reached at.
   - Email Address (if applicable)
   - Social Security Number
   - Country of Citizenship (U.S. citizenship required)

3. **Education**: list high school and colleges attended, type of degrees (list major) received, date of degree conferred, city and state of school. ***If no degree received, please document the number of credit hours you possess.***

4. **Work Experience**: (include non-paid work as well as paid)
   - Job Title (if Federal employment, indicate series and grade)
   - Duties and Accomplishments
   - Employer's name and address
   - Supervisor's name and phone number
   - Starting and ending dates of employment (month/year)
   - Hours of work per week
   - Salary
   - Indicate if you do not want us to contact your current supervisor (if not specified, it will be assumed that we may do so)

5. **Other Qualifications**
   - List job related training (title, year obtained, hours of training)
   - Honors or awards received
   - License or certificates obtained (submit with application)
   - Special accomplishments (i.e., publications, memberships, leadership and community recognition, etc)

****

COMMON OMISSIONS – from applicants

1. ***No transcript or copy of diploma. If you are substituting education for experience you must include a copy of your transcripts/list of courses OR copy of your diploma.***
2. ***Missing starting and ending dates of employment (month/year).***
3. ***Missing total number of hours worked per week.***
4. ***Missing OF-306***
5. ***Missing Selective Service form***

Missing BIA form 4432 (if claiming Indian Preference)

ATTACHMENT B

Special Instructions for Surplus or Displaced Employees

1. You may be eligible for special selection priority consideration under the Career Transition Assistance Program (CTAP) if you are a current career or career-conditional (tenure group I or II) employee of the DHHS Agency at the GS-15 grade level or below or equivalent, and who has received a specific RIF separation notice or a Certificate of Expected Separation indicating your job is surplus, or notice of removal for declining a directed reassignment or transfer of function outside the local commuting area. To qualify for special selection priority consideration under CTAP you MUST also meet the criteria shown in paragraph 3 below.

2. You may be eligible for special selection priority consideration under the Interagency Career Transition Assistance Program (ICTAP) if you are a current or former career-conditional (tenure group I or II) employee of any agency in the competitive service at the GS-15 grade level or below or equivalent, who has received a specific RIF separation notice or a notice of proposed removal for declining a directed reassignment or transfer of function outside the local commuting area. You may also be eligible if you were separated because of a compensable injury and your compensation has been terminated; or you retired with a disability and your disability annuity has been or is being terminated; or you were in receipt of a RIF separation notice and retired on the effective date of the RIF or under discontinued service; or you are a former Military Reserve Technician or National Guard Technician who is receiving a special disability retirement annuity from OPM. To qualify for special selection priority consideration under ICTAP you MUST also meet the criteria shown in paragraph 3 below.

3. To qualify for special selection priority consideration under CTAP or ICTAP for this vacancy, you MUST also meet ALL of the following:

   (a) Have a current or last performance rating of record of at least fully successful or equivalent. A copy MUST be submitted with your application package. (Note: this requirement does not apply to candidates who are eligible due to compensable injury or disability retirement).

   (b) Be applying for a position at or below the grade level from which you will be, or have been separated, and which does not have a greater promotion potential that the position from which you will be, or have been separated.

   (c) Occupy or be displaced from a position in the same local commuting area of the position for which you are requesting priority consideration.

   (d) File your application by the vacancy announcement closing date and meet all the applicable criteria. Your application MUST include ALL documents that support your claim of eligibility for priority consideration – RIF separation notice, or notice of proposed removal for declining a directed reassignment or transfer of function to another commuting area; SF-50 Notification of Personnel Action, showing that they were separated as a result of RIF, or for declining a transfer of function or directed reassignment to another commuting area; official certification from an agency stating that it cannot place an individual whose injury compensation has been or is being terminated; official notification from OPM that an individual's disability annuity has been or is being terminated; or official notification from the Military Department or National Guard Bureau that the employee has retired under 5 USC 8337(h) 0r 8456.

   (e) Be rated "well qualified" for this position. A numerical rating of 85 is considered to be well qualified for this position.

OF-306
Declaration for Federal Employment

Form Approved: September 1994 - US Office of Personnel Management - OMB No. 3206-01827775 NSN 7540-01-368-5306-101

GENERAL INFORMATION

1. FULL NAME: ________________________________ 2. SS NUMBER: ______________________________

3. PLACE OF BIRTH: __________________________ 4. DATE OF BIRTH (MM/DD/YY): _______________

5. OTHER NAMES EVER USED (for example, maiden name, nickname, etc.): _____________________________

6. PHONE (include area codes) Day: _____________________ Night: _______________________________

MILITARY SERVICE:

7. Have you served in the United States Military Service? If your only active duty was training in the Reserves or National Guard, answer "No."
Yes________ No_________

If you answered "Yes," list the branch, dates (MM/DD/YY), and type of discharge for all active duty military service.
BRANCH: ____

FROM____________________ TO: _____________________

TYPE OF DISCHARGE: ____

BACKGROUND INFORMATION

For all questions, provide all additional information requested information under item 15 or on attached sheets. The circumstances of each event you list will be considered. However, in most cases you can still be considered for Federal jobs.

For questions 8, 9 and 10, your answers should include convictions resulting from a plea of nolo contendre (no contest). But omit (1) traffic fines of $300 or less, (2) any violation of law committed before your 16th birthday, (3) any violation of law committed before your 18th birthday if finally decided in juvenile court or under a Youth Offender law, (4) and conviction set aside under the Federal Youth Corrections Act or similar State Law, and (5) any conviction whose record was expunged under Federal or State law.

8. During the last 10 years, have you been convicted, been imprisoned, been on probation, or been on parole? (Includes felonies, firearms or explosives violations, misdemeanors, and all other offenses.) If "Yes," use item 15 to provide the date, explanation of the violation, place of occurrence, and the name and address of the police department or court involved.
Yes { } No { }

9. Have you been convicted by a military court-martial in the past 10 years? (If no military service, answer "No.") If "Yes," use item 15 to provide the date, explanation of the violation, place of occurrence, and the name and address of the military authority or court involved.
Yes { } No { }

10. Are you now under charges for any violation of law? If "Yes," use item 15 to provide the date, explanation of the violation, place of occurrence, and the name and address of the police department or court involved.
Yes { } No { }

11. During the last 5 years, were you fired from any job for any reason, did you quit after being told that you would be fired, did you leave any job by mutual agreement because of specific problems, or were you barred from Federal employment by the Office of Personnel Management? If "Yes," use item 15 to provide the date, an explanation of the problem and reason for leaving, and the employer's name and address.
Yes { } No { }

12. Are you delinquent in any Federal debt? (Includes delinquencies arising from Federal taxes, loans, overpayment of benefits, and other debts to the U.S. Government, plus defaults of Federally guaranteed or insured loans such as student and home mortgage loans.) If "Yes," use item 15 to provide the type, length, and amount of the delinquency or default, and steps that you are taking to correct the error or repay the debt.
Yes { } No { }

CONTINUATION SPACE/AGENCY OPTIONAL QUESTIONS
ADDITIONAL QUESTIONS

13. Do any of your relatives work for the agency or organization to which you are submitting this form? (Includes father, mother, husband, wife, son, daughter, brother, sister, uncle, aunt, first cousin, nephew, niece, father-in-law, mother-in-law, son-in-law, daughter-in-law, brother-in-law, sister-in-law, stepfather, stepmother, stepson, stepdaughter, stepbrother, stepsister, half brother, and half sister.) If "Yes," use item 15 to provide the name, relationship, and the Department, Agency, or Branch of the Armed Forces for which your relative works.

Yes { } No { }

14. Do you receive, or have you ever applied for, retirement pay, pension, or other pay based military, Federal, civilian, or District of Columbia Government service?

Yes { } No { }

15. Provide details requested in items 8 through 13 and 17c in the continuation space below or on attached sheets. Be sure to identify attached sheets with your name, social security number, and item number, and the include Zip codes in all addresses. If any questions are printed below, please answer as instructed (these questions are specific to your position, and your agency is authorized to ask them).

CERTIFICATIONS/ADDITIONAL QUESTION

APPLICANT: If you are applying for a position and have not yet been selected, carefully review your answers on this form and any attached sheets. When this form and all attached materials are accurate, complete item 16/16a.

APPOINTEE: If you are being appointed, carefully review your answers on this form and any attached sheets, including any other application materials that your agency has attached to this form. If any information requires correction to be accurate as of the date you are signing, make changes on this form or the attachments and/or provide updated information on additional sheets, initialing and dating all changes and additions. When this form and all attached materials are accurate, complete item 16/16b and answer item 17.

13. I certify that, to the best of my knowledge and belief, all of the information on and attached to this Declaration for Federal Employment, including any attached application materials, is true, correct, complete, and made in good faith. I understand that a false or fraudulent answer to any question on any part of this declaration or its attachments may be grounds for not hiring me, or for firing me after I begin work, and may be punishable by fine or imprisonment, I understand that any information I give may be investigated for purposes of determining eligibility for Federal employment as allowed by law or Presidential order. I consent to the release of information about my ability and fitness for Federal employment by employers, schools, law enforcement agencies, and other individuals and organizations to investigators, personnel specialists, and other authorized employees of the Federal Government. I understand that for financial or lending institutions, medical institutions, hospitals, health care professionals, and some other sources of information, a separate specific release may be needed, and I may be contacted for such a release at a later date.

16a. Applicant's Signature (sign in ink) Date

16b. Appointee's Signature (sign in ink) Date

17. Appointee Only (Respond only if you have been employed by the Federal Government before): Your elections of life insurance during previous Federal employment may affect your eligibility for life insurance during your new appointment. These questions are asked to help your personnel office make a correct determination.

17a. When did you leave your last Federal job? Date: _______________________________________

17b. When you worked for the Federal Government the last time, did you waive Basic Life insurance or any type of optional life insurance?

Yes { } No { }

17c. If you answered "Yes" to item 17b, did you later cancel that waiver(s)? If your answer to item 17c is "No" use item 15 to identify the type(s) of insurance for which waivers were not canceled.

Yes { } No { }

Addendum to Declaration for Federal Employment (OF 306)
Indian Health Service
Child Care & Indian Child Care Worker Positions

==

Item 15a. Agency Specific Questions

Name: ___________________________ Social Security Number: _________________
(Please print)
Job Title in Announcement: ____________________ Announcement Number: ___________

Section 231 of the Crime Control Act 1990, Public Law 101-647, requires that employment applications for Federal child care positions contain a question asking whether the individual has ever been arrested for or charged with a crime involving a child and for the disposition of the arrest or charge.

Section 408 of the Miscellaneous Indian Legislation, Public Law 101-630, contains a related requirement for positions in the Department of Health and Human Services that involve regular contact with or control over Indian children. The agency must ensure that persons hired for these positions have not been found guilty of or pleaded nolo contendere or guilty to certain crimes.

To assure compliance with the above laws, the following questions are added to the Declaration for Federal Employment:

1) Have you ever been arrested for or charged with a crime involving a child? *YES_____ NO______*
[If AYES@, provide the date, explanation of the violation, disposition of the arrest or charge, place of occurrence, and the name and address of the police department or court involved.]

2) Have you ever been found guilty of, or entered a plea of nolo contendere (no contest) or guilty to, any felonious or misdemeanor offense under Federal, State, or tribal law involving crimes of violence; sexual assault, molestation, exploitation, contact or prostitution; or crimes against persons; or offenses committed against children? *YES______ NO______*
[If AYES@, provide the date, explanation of the violation, disposition of the arrest or charge, place of occurrence, and the name address of the police department or court involved.]

I certify that (1) my response to these questions is made under penalty of perjury, which is punishable by fines of up to $2,000 or 5 years imprisonment, or both; and (2) I have received notice that a criminal check will be conducted. I understand my right to obtain a copy of any criminal history report made available to the Indian Health Service and my right to challenge the accuracy and completeness of any information contained in the report.

____ __________________
Applicant=s Signature (sign in ink) Date

Public Burden Statement: In accordance with Paperwork Reduction Act (5 CFR 1320.8 (b)(3), a Federal agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Respondents must be informed (on the reporting instrument, in instructions, or in a cover letter) the reasons for which the information will be collected; the way the information will be used to further the proper performance of the functions of the agency; whether responses to the collection of the information are voluntary, required to obtain a benefit (citing authority), or mandatory (citing authority); and the nature and extent of confidentiality to be provided, if any (citing authority). Public reporting burden for this collection of information is estimated to average 15 minutes per response, including time for reviewing instructions, searching existing data sources, gathering and maintaining the necessary data, and completing and reviewing the collection information. Send comments regarding the burden estimate or any other aspect of this collection of information to the IHS PRA Information Collection Clearance Staff, 12300 Twinbrook Parkway, Suite 450, Rockville, MD 20852. ***Please do not send completed data collection instruments to this address.***

FORM APPROVED: O.M.B. NO. 0917-0028 Expires 11/30/2005

APPLICANT'S STATEMENT OF SELECTIVE SERVICE REGISTRATION STATUS

If you are a male born after December 31, 1959, and are at least 18 years of age, civil service employment law {5 U.S.C. 3328} requires that you must be registered with the Selective Service law, unless you meet certain exemptions under Selective Service law. If you are required to register but knowingly and willfully fail to do so, you are ineligible for appointment by executive agencies of the Federal Government.

CERTIFICATION OF REGISTRATION STATUS

Check one:

{ } I certify I am registered with the Selective Service System.

{ } I certify I have been determined by the Selective Service System to be exempt from the registration provisions of Selective Service law.

{ } I certify I have not registered with the Selective Service System.

{ } I certify I have not reached my 18th birthday and understand I am required by law to register at that time.

NON-REGISTRANTS UNDER AGE 26

If you are under age 26 and have not registered as required, you should register promptly at a United States Post Office or consular office if you are outside the United States.

NON-REGISTRANTS AGE 26 OR OVER

If you were born in 1960 or later, are 26 years of age or older, and were required to register but did not do so, you can no longer register under Selective Service law. According, you are not eligible for appointment to an executive agency unless you can prove to the Office of Personnel agency Management (OPM) that your failure to register was neither knowing nor willful. You may request an OPM decision through the agency that was considering you for employment by returning this statement with your written request for an OPM determination together with any explanation and documentation you wish to furnish to prove that your failure to register was neither knowing nor willful.

PRIVACY ACT STATEMENT

Because information on your registration status is essential for determining whether you are in compliance with 5 U.S.C. 3328, failure to provide the information requested by the statement failure to provide the information requested by this statement will prevent any further consideration of your application for appointment. This information is subject to verification with the Selective Service System and may be furnished to other Federal agencies for law enforcement or other authorized use in implementing this law.

FALSE STATEMENT NOTIFICATION

A false statement may be grounds for not hiring you, or for firing you if you have already begun work. Also, you may be punished by fine or imprisonment. (Section 1001 of title 18, United States Code.)

____

Legal signature of individual **{Please use ink}**

____

Date signed **(Please use ink)**

Appendix B: Referral script

Recruitment Script for physicians or other clinic personnel

Clinic Referral to Northwest Tribal Cancer Navigator Program

I would like to introduce you to our Navigator Program. A navigator is a support person for cancer patients in treatment. The Navigator Program is a research project to see if this kind of support person can help American Indians get better care for cancer.

We invite anyone from our clinic to participate who needs to be seen outside the clinic for treatment related to cancer. Taking part in this study is completely up to you. If you do not take part, you will have no penalty. You will lose no care or services from [clinic], IHS, [Tribe], or others. You may quit at any time, with no penalty or loss of any care or services for which you are qualified.

If you are interested in the program, I will introduce you to the navigator.

Appendix C: Selected articles about the Northwest Tribal Cancer Navigator Program

YAKIMA HERALD-REPUBLIC

Thursday
October 30, 2003

HomeFront

Yakamas Part of Cancer Care Pilot Project

'Navigator' program to help tribal patients who are referred out of area for treatment

By CHARLENE KOSKI
YAKIMA HERALD-REPUBLIC

It's been 16 months since a presidential advisory group visited Toppenish to hear about obstacles American Indians face getting cancer care.

About 100 people from throughout the Northwest attended a meeting with the President's Cancer Panel in July 2002. They took turns telling panel members their stories — of long drives to see a doctor, long waits to see a cancer specialist, financial struggles and difficulties navigating the cancer-care system.

Their comments paid off.

As a direct result, the National Cancer Institute decided to fund a pilot project called the Northwest Native American Navigator Program — and Yakama Indian Health Center is one of three participating organizations. The other two are Puyallup Tribal Health Authority in Tacoma and Native American Rehabilitation Association in Portland.

The new program involves having a "navigator" assigned at each of the locations. At the Indian Health Center, that person is registered nurse Christine Ross.

Yakama patients who have cancer are referred to other cities and programs that specialize in cancer treatments, Ross said.

When that happens, many of the patients get lost. They often don't understand where they should go, who they should see, how they will pay for services or even what's happening to them.

Ross will help them find their way. She will put them in contact with financial services, follow up on their appointments and answer their questions.

To bring attention to the new program, which just became fully operational at the Indian Health Center this month, the center this week is hosting its first blood and bone marrow donor drive.

The Yakama Tribal Council proclaimed Wednesday — the first day of the drive — Northwest Native American Patient Navigator Blood Drive Day and encouraged tribal members to participate.

The event is dedicated to Sara Hoptowit, 32, a Yakama woman, wife and mother of three who died in August from leukemia. She was the first person to use the new program when it was still being designed earlier this year. She appreciated the service so much, she had decided that when she got better, she would help keep it going, said her husband, Robert Rodarte.

He was the first to give blood Wednesday. Hoptowit's parents, David and Susan Hoptowit, attended the event's kick-off as well.

Their daughter had a terrible time finding financial help, they said. A college graduate and daycare manager, she didn't qualify for welfare. She had insurance and thought it would cover her bills.

But it didn't cover all of them. She had to raise thousands of dollars. The stress devastated her, her parents said.

The family said they are still trying to find ways to pay $400,000 in outstanding medical bills.

The Hoptowits are allowing the Indian Health Center to share Sara's story in an effort to raise awareness of the difficulties cancer patients face and the importance of programs designed to help them.

The Navigator program is funded for two years. It's already making a huge difference for individual patients, said Dr. Donn Kruse, medical director for Indian Health Services in Toppenish.

"It's night and day," he said.

The blood and bone marrow drive will be an annual event, Ross said. American Indian cancer patients who need bone marrow need Indian marrow, and there's a nationwide shortage.

Anyone who would like to be a marrow donor can go to the Tim Foster Retirement Center at 171 Wishpush Road in Toppenish from 9:30 a.m. to 4 p.m. today. A sample of bone marrow will be taken and the donor's name added to the national registry of potential donors. If a donor is a match for a patient needing marrow, the donor will be contacted to start the process.

The drive gives the Yakama community a chance to help itself, Ross said.

And it gives Sara Hoptowit a chance, too, her father said.

"She did a lot to help her people," he said. "But I think she helped everybody."

Wednesday
October 29,
2003

VOLUME 99,
NO. 44
50¢

Review Independent

The Hometow
Newspaper Fo
- Toppenish
- Wapato
- Zillah
- White Swan
- Harrah
- Granger

Serving The Central Yakima Valley Since 1905

Indian Health Center seeks blood, bone marrow matches

By David Sale

TOPPENISH—The Yakama Indian Health Center is conducting a blood and bone marrow donation drive today and tomorrow, Oct. 29 and 30, to launch its new case management service, a Northwest pilot program.

The donation drive is being held at the Tim Foster Retirement Center on 171 Wishpoosh Road, near the Yakama Nation RV Park. Hours are from 9:30 a.m. to 4 p.m. both days. The event is in honor of Sara Hoptowit.

Both Native and non-Native donors are invited to give blood, and to be screened for possible bone marrow donation to cancer victims. The event is sponsored by the Red Cross and the National Marrow Donor Program together with the IHS.

This event also marks the launch of the Patient Navigator Program, a proactive case management service for members of the IHS. The Yakama Nation is one of three sites in the Northwest for this pilot program, which is designed to address the needs of cancer sufferers in the Native American community.

The Patient Navigator Program provides routine screenings and promotes cancer prevention education, and assists patients diagnosed with cancer through their treatment process.

Registered nurse Christine Ross holds the position of "patient navigator" at the Yakama IHS.

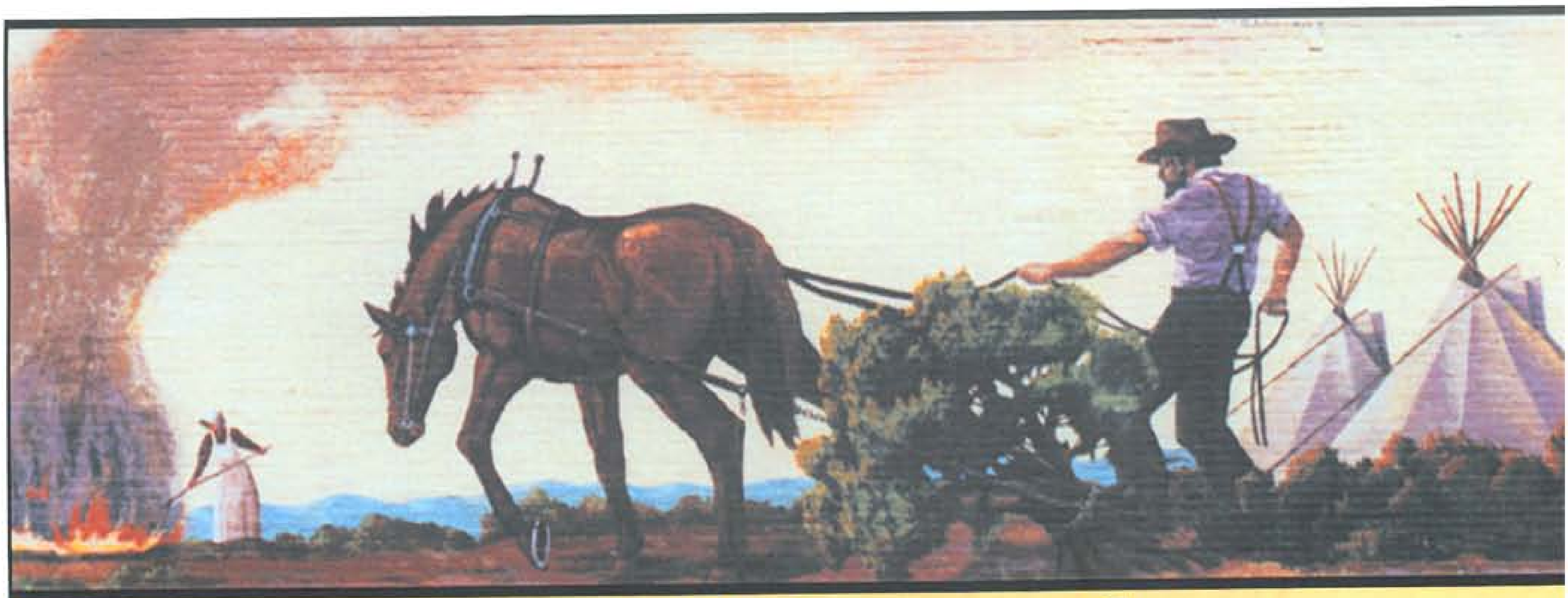
"My work is to retain contact with the patient through the screening process, and to stay with them as they go into specialty care at other hospitals," she said. "I assist patients in dealing with these institutions, and serve as a point of contact for their family."

The Patient Navigator Program is funded by a $330,000 grant from the National Cancer Institute, which has identified Native Americans as an under-served population in cancer diagnosis and treatment.

The Patient Navigator program hopes to address this shortfall by providing patient advocates to the Native community, to insure prompt diagnosis and assist cancer sufferers through the complex treatment process.

"We're hoping to improve the process of detection, and follow-up treatment," Ross added. "Typically when IHS patients are sent to specialty care, we lose track of them. One of the program goals is to make sure that the primary care doctors can follow their progress, and keep a complete medical record, which is necessary for following up with them and potentially with other family members."

The Patient Navigator Program is available to any patient eligible for IHS care. For more information, or to request program services, contact Christine Ross at 865-2102, extension 391.

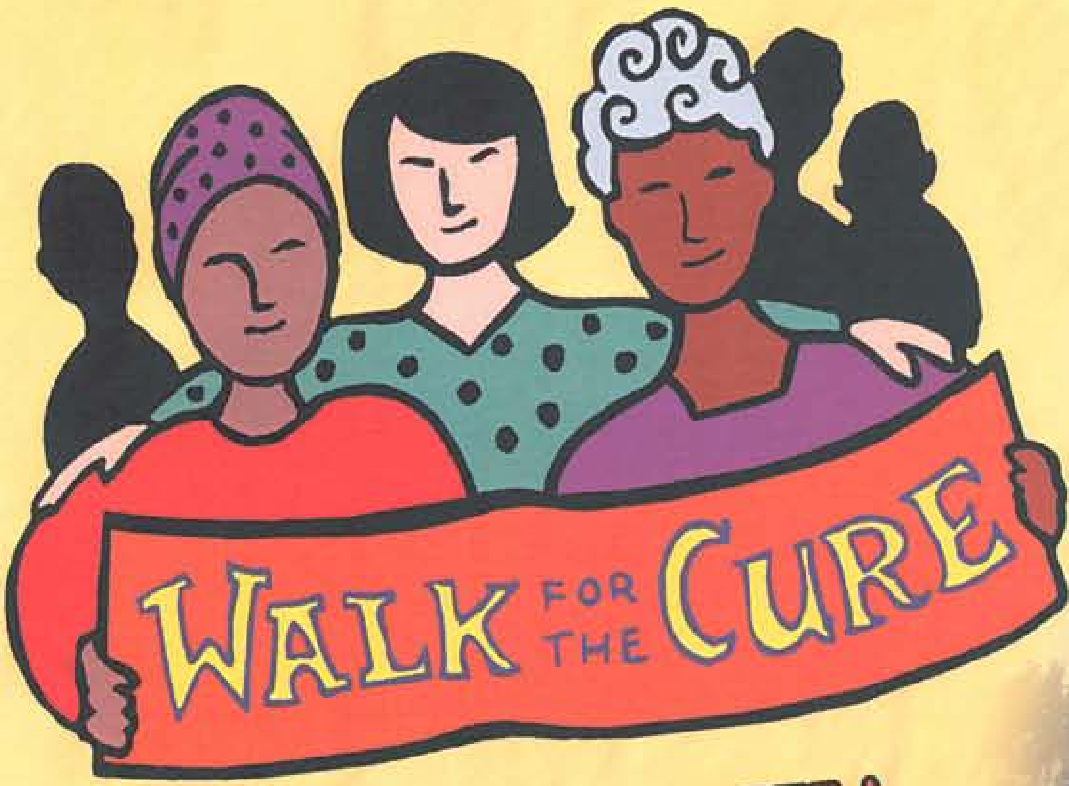


5th Annual

Mural Walk

FOR CANCER AWARENESS

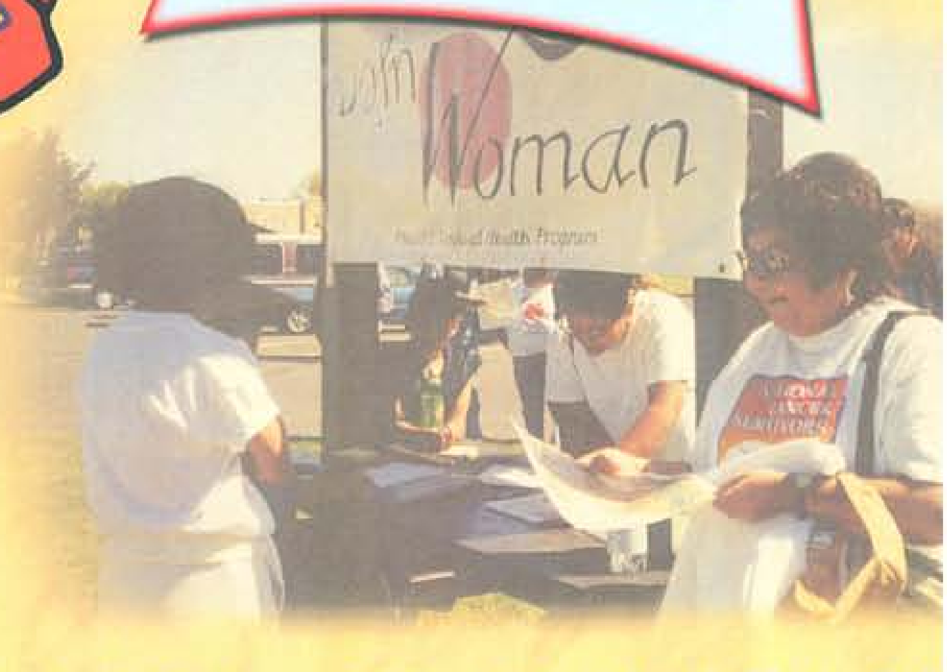
Help support the Yakama Nation promote Breast Cancer Awareness



May 7th, 2005

Free T-shirts and Gifts!

Toppenish, WA
10:00 A.M.
Railway Park



For more information call: 509.249.6512 or 509.865.2102 Ext. 39

This event is sponsored by the Yakima Region Office of Native Cancer Survivalship,
Indian Health Center Navigator Program and The South Central Region Breast & Cervical Health Program -

Navigator Training participants: (standing in back, L-R) Anabel Cole, Katrina Ramsey, Pamela Young, Michelle Joseph
(front row) Christine Ross, Nancy Zbaren, Kathy Briant, Teresa Guthrie, Carrie Nass, Susan Stanford, Danelle Reed-Inderbitzen

Regional Spotlight

The Northwest Native American Navigator Program Pilot Study, funded by the National Cancer Institute (NCI) through a cooperative agreement with the Indian Health Service (IHS), has been launched at three sites in the Portland Area of the IHS – Yakama Indian Health Center in Toppenish, WA; Puyallup Tribal Health Authority in Tacoma, WA; and Native American Rehabilitation Associates (NARA) in Portland, OR. These three organizations represent a tribally managed clinic, a federal service unit, and an urban clinic.

The Northwest Native American Navigator Program Pilot Study is designed to identify, understand, and overcome the unique barriers and experiences of American Indians and Alaska Natives (AI/AN) during diagnosis and treatment of cancer. This pilot study is the result of a dialogue held in July 2002 during the President's Cancer Panel, attended by Dr. Freeman, Yakama Nation leaders, cancer survivors from the Yakama Nation and other Northwest tribes, and representatives from the NCI. The pilot will continue until February 2004. The original Patient Navigator Program, founded by Dr. Harold Freeman in Harlem, NY, grew out of the 1989 American Cancer Society's national hearings on cancer and the poor. Those hearings noted: 1) gaps in service, 2) fragmentation of care, 3) delayed or missed appointments, 4) barriers to care, and 5) lack of social support. The Patient Navigator Program evolved to address those problems – all of which can cause patients to miss appointments or delay treatment. The Patient Navigator model is being adapted to AI/AN communities to improve the infrastructure of health care systems providing cancer care.

The Cancer Information Service (CIS) and the Spirit of EAGLES (SoE) partnered with the Seattle Cancer Care Alliance to provide the staff from the Northwest Native American Navigator Program (NNANP) training on cancer resources and cancer site-specific overviews on September 22nd and 23rd, 2003. NNANP staff include: Principal Investigator, Danelle Reed-Inderbitzen, PhD (Puyallup); Project Coordinator, Katrina Ramsey; Patient Navigators, Christine Ross, RN-ICP, at Yakama, Pamela Young (Powhattan), RN, BSN at NARA, and Michelle Joseph (Steilacoom), RN, BSN at Puyallup.

SPOTLIGHT ON YOUR ORGANIZATION
Please contact the CIS Partnership Program Manager, Kathy Briant, if there is an aspect of your program that you would like us to profile in our monthly Cancer Bulletin.

PUYALLUP TRIBAL HEALTH AUTHORITY

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The Healing Path

The Healing Path - Volume 26

April/May/June 2004

The Navigator Program

Michelle Joseph, RN, BSN

My name is Michelle Joseph, (Steilacoom). For the past three years I have been a Registered Nurse in the PTHA medical clinic. I am now the Nurse Navigator and I'd like to tell you about the Patient Navigator program. Through the efforts of the President's Cancer Panel and a grant from the National Cancer Institute, PTHA was selected to be a Navigator pilot program site.

The Patient Navigator program was created because advances in cancer prevention, detection, and treatment are not reaching Indian communities. Cancer has a greater impact on the lives of people who have trouble getting medical care because of poverty, lack of transportation, and/or living too far from medical services.

Difficulty in getting medical care means a delay in patients' diagnosis with cancer, the cancer may be farther along and may have spread. A delay in diagnosis limits treatment options.

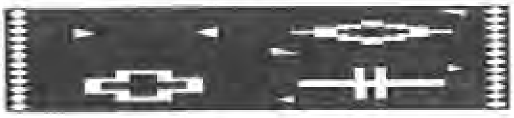
My role in cancer care includes:

- Providing cancer education
- Promoting early cancer screenings
- Arranging timely treatments of cancer
- Maintaining contact with the patient through the cancer journey
- Involve the patient

My goal is to help the patient with questions, concerns, or treatment options that are not well understood. Understanding treatment language helps the patient to make good decisions in their care.

Another role in my work is to help guide the patient through the healthcare system. I can help with scheduling appointments, reminder calls, as well as rescheduling when necessary. Another part of my role is to help the patient prepare for appointments and find help with things like transportation, so the patient can keep appointments. I also seek local resources to help with problems the patient and family identify.

I am also here to help the patient and their family with information and resources to make informed decisions about their care and treatment. To make an appointment with me, call the clinic at 593-0232.



Helpful hints to make your appointment to any specialist run as smoothly as possible:

1. Be prepared to fill out a health history form that includes:

- your name, address, and phone number
- date of birth and social security number
- emergency contact's name and number
- list of all medications (including herbs, vitamins, and over the counter)
- your primary care doctors name, address, phone, and fax number

2. Bring all insurance cards. If you don't have your cards, you will need the subscribers name and social security number (the subscriber is the person the plan is under), the address to send claims to, a contact phone number, ID number, and group number.

3. Bring any X-rays, CT scans, and PET scans.

4. Bring Medical records if they were not faxed.

"Staph" Skin Infections

Excerpted from Wa State DOH and Los Angeles County Public Health web sites, March 2004

What is a Staph skin infection? Bacteria live on everyone's skin and usually cause no harm. But when **staphylococcus** bacteria get into your body through a break in the skin, they can cause a "staph" infection. Staph infections may spread to other people by skin-to-skin contact and from shared items such as bedding, towels, clothes, and sports equipment. **Symptoms of a Staph infection are redness, warmth, swelling, tenderness, and boils or blisters.**

What is an antibiotic-resistant staph skin infection? Penicillin and some other antibiotics that used to kill bacteria may no longer work against staph germs. These particular staph germs are "resistant" to the antibiotics. They are called methicillin-resistant staphylococcus aureus (MRSA). MRSA infections most often happen in nursing homes and hospitals but are occurring in people of all ages in the community. These "community cases" of MRSA can often be treated with other kinds of antibiotics and daily wound care if you have an abscess or wound. An abscess is an infection with a collection of pus that comes to a "head."

(Continued on next page)

T'S
DE

See Chief Leschi school news / PAGE 6-7

Marlon Brando remembered / PAGE 3

PUYALLUP TRIBAL NEWS

, NO. 7 SERVING THE PUYALLUP TRIBE OF INDIANS AUGUST/SEPTEMBER 2004

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Ron Simchen presens the Daffodil Princess plaque to Jane Wright at this year's Tribal Membership Meeting.

and asked the membership for support at the polls on voting no to I-892.

The amendment to the compact is to authorize gaming on fee land in the new Fife facility. (Fee land means land not in trust.) Tribal Council had traveled to Vancouver, Wash., on Aug. 12 and met with the State gambling commission for approval. This is an urgent matter for the tribe because of the closure of Alexander. Alexander is the main road to the riverboat casino located next to Port of Tacoma. The expected closure date for Alexander is for Nov. 1, 2004.

Council Chairman Herman Dillon open the microphone to the membership allowing each person to have five mintues to express themselves with question, concerns, security, fairness, thank yous and what ever was on their mind. Many members stood and spoke on how important it is to vote. Tribal member Charles Satiacum spoke from his heart on Indians standing together in the past and on how we need to stand together now and vote. Satiacum said, "Don't allow the white man to keep coming in our backyard and taking what we have earned and built, what our ancestors have worked so hard for, for many years."

See MEETING, page 3

s banding together against I-892

HN LARSON

Washington's most powerful political fig- discussed efforts to inform ethnic minori-

Navigator Program focuses on cancer prevention, treatment

My name is Michelle Joseph (Steilacoom). For the past three years I have been registered nurse in the PTHA medical clinic. I am now the nurse navigator and I'd like to tell you about the patient navigator program. Through the efforts of the President's Cancer Panel and a grant from the National Cancer Institute, PTHA was selected to be Navigator pilot program site.

The patient navigator program was created because advance in cancer prevention, detection and treatment are not reaching Indian communities. Cancer has a greater impact on the lives of people who have trouble getting medical care because of poverty, lack of transportation, and/or living too far from medical services.

Difficulty in getting medical care means a delay in patient's diagnosis with cancer and so the cancer may be farther along and may have spread. A delay in diagnosis limits treatment options.

My role in cancer care includes:

- Providing cancer education.
- Promoting early cancer screenings.
- Arranging timely treatment of cancer.
- Maintaining contact with the patient through the cancer journey.
- Involve the patient.

My goal is to help the patient with questions, concerns, or treatment options that are not well understood. Understanding treatment language helps the patient to make good decisions in their care.

Part of my work is to help guide the patient through the healthcare system. I can help with scheduling appointments, reminder calls, as well as rescheduling when necessary. Another part of my role is to help with things like transportation, so the patient can keep appointments. I also seek local resources to help with problems the patient and family identify.

I am also here to help the patient and their family with information and resources to make informed decisions about their care and treatment.

To make an appointment with me, call the clinic (253) 573-0232 ext. 427

People In the News

Navigator program is blessing for people

By TIFFINY O. SHILOW
Yakama Nation Review

TOPPENISH – The Patient Navigator Program is the first line of support for Yakama Nation Indian Health Center patients who learn they have cancer.

A fairly new program that was developed through the National Cancer Institute in November 2002, it's a proactive case management service designed to assist minority, medically underserved populations with cancer-related healthcare issues, and according to Patient Navigator Nurse, Christine Merenda cancer is, "becoming more common in small communities."

Although the number of cancer patients is small, the rapid increase – per year – needs attention.

According to Merenda, there were 70 new cases reported over the past two years. Having records for only the past four years, Merenda said the number of cases has jumped from 25 a year to 35.

NAVIGATORS: (L) Carol Komaromy and Christine Merenda. – [Yakama Nation Review photo by Tiffiny Shilow]

"We're trying to work toward a better outcome and long term survival," said Merenda. "The goal is to help patient's access cancer-related services by addressing barrier issues that may be as simple as getting a telephone hooked up in your home."

Other barrier issues that may delay or prevent a patient from participating in cancer-related healthcare services include poverty, lack of childcare, lack of transportation, inadequate food/housing, stressful living conditions, distance to medical facilities and lack of experience with healthcare settings outside of the Yakama Indian Health Center according to the Patient Navigator Program informational pamphlet.

Other responsibilities include promoting patient participation; provide decisional support, and cancer education and as Merenda added, "an ear to listen if that's all that is needed."

Guiding patients through the healthcare system and be available to answer any questions is what Merenda prides her work on.

"Our goal is to improve the outcome of late stage cancer patients in Native America," she said.

October is Breast Cancer and Awareness Month, Merenda highlighted that breast cancer is ranked in the top three types of cancers listed for Yakama Indian Health Center patients.

Oral cancer and esophageal cancer are ranked the top two due to smoking habits among Native Americans, followed by breast and cervical cancer, according to Merenda.

"These types of cancer's are aggressive and do not respond well to treatment. They usually spread to other parts of the body and are fast growing, as most of these get a four to six month prognosis," said Merenda.

However, as scary as those statistics sound, Merenda said it is how soon you act and treat your cancer that makes a difference.

Cancer Survivor

Cancer may be new territory, but working with the Patient Navigator Program not only offers assistance, but someone who has had cancer and been through the process.

"There's nothing like getting ready to meet death," said Carol Komaromy, a Patient Navigator Program advocate and LPN Nurse at the Yakama Indian Health Center who discovered a lump in her breast in 2000.

Komaromy, an enrolled Yakama member, prided herself with her long black hair that was below her waist in 2000, the year she was diagnosed with breast cancer.

"You find a lump, don't wait," she said as her first reaction to finding hers. "Once you're diagnosed, and as confusing as it is, you do whatever you can to stay alive."

Komaromy, who may be a nurse, said she had new words to learn when it came to cancer, as well as what she could and could not do, and felt horrible at the endless decisions she had to make.

"Your trying to think 'Oh great, I don't want to lose my breast, just take the lump out' and you only have a 20 minute doctor appointment, so you are trying to think 'What I am going to do?'" said Komaromy.

Deciding to the lumpectomy, which is removal of the lump, Komaromy spent the following months going through chemotherapy followed by intense radiation at North Star Lodge in Yakima.

"You are introduced to the place and you meet a lot more medical teams and doctors, and no matter how comfortable they may try to make you feel, it's still scary," she said. "But you don't have to do anything you do not want to do if you are unsure, and they don't force you."

Komaromy said that going through treatment, especially Chemotherapy does have its side affects like the loss of her long black hair, but overall you are glad when the experience is over.

"I bought two expensive wigs when I lost my hair," she said explaining that her only son, Adrian Komaromy, did not like seeing her without her wig. "I also went and bought myself something nice after my chemotherapy."

As Komaromy's hair grows back, she still lives in fear that her cancer could return.

"You have so much to worry about when you have cancer that it takes a lot out of your normal life and you have to make time for cancer that you're constantly tired," she said. "In nursing, you think as a nurse that it's not supposed to happen to you, it's supposed to happen to them. You are a nurse; you are supposed to help these other people. But it happens to everybody."

However, she said the support is there and that no questions are dumb question, "and tears are better than holding it in."

She said it was hard to work for the Patient Navigator Program at first because it was scary to think that her cancer could return.

"But its okay, because this is a good program," she said. "We have a great staff, and this job is taken day-by-day."

Its sharing her experience with patients that gives them hope.

"They look at me and realize that my hair has grown back, and than they start to think, 'Oh I can make it too,'" she said. "They realize that treatment is not doom, its not death, its just treatment and this program is here to support that."

The Patient Navigator Program grew out of the 1989 American Cancer Society's national hearings on cancer and the poor, which noted gaps in service that lead to fragmentation of care, greater number of missed or delayed appointments, lack of social support and substantial barriers to care.

On July 29, 2002 the Presidents' Cancer Panel met with the Yakama tribal leaders to discuss cancer disparity relating to Native Americans.

The Cancer Panel delivered copies of their report, "Facing Cancer in Indian Country: The Yakama Nation and Pacific Northwest Tribes," May 5, during a Yakama Tribal Council session.

Appendix D: Original informed consent document

Northwest Native American Navigator Program: Informed Consent for Participants

Yakama Indian Health Center
PO Box 424
Toppenish, WA 98948
(509) 865-2102

We would like to invite you to meet with a Navigator.

A Navigator is a support person for cancer patients. He or she is a nurse who has been trained to know about cancer and has made connections with local people involved in getting treatment for cancer.

This project is a research project. We have never run a program like this before, and we want to see if Navigators help people get better treatment for cancer. The project is paid for by the Yakama Indian Health Center, the National Cancer Institute, and the Indian Health Service.

We will invite anyone from our clinic to participate who has been diagnosed with cancer.

The Navigator will help you with issues that might keep you from getting to your appointments.

If you agree to sign up for the Navigator Project, the Navigator will keep in touch with you. She may call you on the telephone, write letters, or meet with you in person. She will take notes on the times she contacts you, including how many times the two of you connect, the problems you run into, and the solutions that you find. She may read your medical records for details of your treatment. Some of her notes will be included with your medical records for doctors or nurses to see. You can ask to see the records she keeps any time.

Some people need to talk to the Navigator every day. Other people get contacted once a week, and some people once a month.

The amount of contact you have with the Navigator is up to you.

The first time you meet with the Navigator, it might take an hour. During the first meeting, the Navigator will ask you questions about yourself and your family's health. This will help her to understand your needs.

After the first meeting, you decide how much help you want from the Navigator. You can change your mind at any time.

We hope that the Navigator will be in contact until your cancer is resolved or until you choose to stop. We know that we can run the Navigator Project at least until December 2005. The Yakama Indian Health Center hopes to continue the program much longer, but we do not know for sure that this will be possible.

You may benefit if you work with a Navigator.

There are several ways that we **hope** some people could benefit from having a Navigator.

- Having reminders about appointments
- Being able to talk about what happened at an appointment and ask questions afterward
- Learning about your cancer and about your treatment options
- Talking to your family and loved ones about cancer and treatment
- Get help in finding organizations that do transportation, child and elder care, insurance, and alternate funding sources to see specialists when needed
- Find support in dealing with the emotional stress that many people feel when they are diagnosed with cancer

Other issues might come up for you. The Navigator will try to help, but she might not always have solutions.

There are some risks in the Navigator Project as well.

Some people may feel upset or afraid. The Navigator is trained to recognize when you might benefit from talking to a behavioral health specialist. She will refer you if this seems appropriate.

All of the benefits of the navigator are free to you. Sometimes we may refer you to services that will bill your insurance. We will ask your permission before doing so.

If you give permission, some information about you will become part of our research project.

We will use your information to try to understand if the Navigator Program helps people in their cancer journeys. We will look at demographic information, how long it takes to diagnose and treat cancer, what kinds of treatments people have, and what kinds of problems stand in the way of treatment.

The navigator will send your information to the project coordinator in Portland, Oregon. Your information will be added to a database with other patients in the Yakama Indian Health Center's Patient Navigator Program and two other programs that serve Indian people. The project coordinator's job is to look at that information to decide if the program makes a difference. The coordinator has worked with similar medical records in the past. She has signed a confidentiality statement promising to protect your privacy.

Sometimes the project coordinator may need to go into your medical record for details about your treatment. She will only do this when necessary and will only get the pieces of information she needs to answer questions about your health and treatment.

If you would like, the Navigator can show you which information is related to the research project. If you do not want to answer a question, you do not have to. You can change your mind whenever you want to.

The Yakama Indian Health Center may benefit because we may be able to help future patients with cancer.

We will keep your information private.

Records will be stored in your medical file, locked in your Navigator's office, or saved under passwords in the navigator's computer.

The Navigator will keep some records in a computer protected with passwords. When the information gets sent to Portland, it goes without personal information. Instead, we will identify you using a number that we make up. Because there are no names, no one can know what issues you have with your cancer.

You should know that <u>it is not always possible to make records completely anonymous</u>**.** Sometimes names or other identifiers get included by mistake. All of the people involved in this project have signed confidentiality statements in which they agree to respect your privacy. <u>We will not publish any reports</u> where people can identify you personally.

You don't need to be part of the Navigator Program to get treatment for cancer.

If you do not want to have a Navigator, you will have no penalty and will lose no care or services by IHS, the Yakama Nation, or others. You can quit at any time, with no penalty or loss of any care or services for which you are qualified.

You also do not have to give permission for us to use your information if you want to work with a Navigator.

We may ask you to talk to us about your experience in the future.

Some of the people from this program will be asked to participate in a series of interviews. This will not happen for several months. If you are asked for an interview, we will give you another informed consent form like this one and discuss it with you at that time. The interviews will have more detailed questions about your journey.

If you have questions about this project, please call Christine Ross at (509) 865-2102, extension 391, or Katrina Ramsey, Project Coordinator, at 1-877-664-0603 (toll free number).

You may use a clinic phone for this call. You can also visit Christine Ross, Patient Navigator, at the Health Center, 401 Buster Road, in Toppenish, WA.

If you have any questions about **your rights** or **concerns** about this project, you may call either Francine C. Romero, Chair, Portland Area Indian Health Service Institutional Review Board, at 1-877-664-0604 (toll free), or Rena Gill, Co-Chair, Portland Area Indian Health Service Institutional Review Board, at 503-326-2014. **They are not involved with this project** and are responsible for making sure it is conducted in an ethical way.

You can change your mind about this study whenever you want to.

The next time you speak with the Navigator, she will talk to you about this form again. She will check with you to see if you still want to take part in the study. If you do not want to be part of the Navigator Program, **<u>you can stop at any time</u>**. You do not need to sign any papers to quit. You do not even have to talk to the Navigator directly. You can talk to someone else at the clinic or call the toll-free number in Portland, 1-877-664-0603.

You will still receive all of the services that you normally would at Yakama Indian Health Center.

We would like to share the results of this study with you.

If you would like to hear about the results of this study, the Navigator will keep your contact information so that we can reach you then. You can also talk to your Navigator about the study.

We will give you a copy of this form.

I understand that I am being invited to take part in a research project for a cancer navigator program. I will be able to talk to a Navigator as I am being treated for cancer.

I understand that I can refuse to take part with no penalty or loss of IHS care or other care for which I qualify. I can also change my mind later and quit the study.

All my questions have been answered to my satisfaction. I understand that I can ask any question in the future. I received a copy of this form.

I give permission for the Navigator Project to access my medical records for information relating to my cancer.

______________________________	____________
Respondent Signature [or thumbprint]	Date
______________________________	____________
Witness Signature	Date

Copies: ☐ Respondent ☐ Principal Investigator

Second Review

I have discussed this form for a second time.

☐ I do **<u>not</u>** wish to change my consent. I **<u>want to take part</u>** in the Navigator Program.

☐ I wish to **<u>change</u>** my consent. I do **<u>not</u>** want to take part in the Navigator Program.

______________________________	____________
Respondent Initials [or thumbprint]	Date

Appendix E: Revised informed consent document

Northwest Tribal Cancer Navigator Program

Puyallup Tribal Health Authority
2209 East 32nd Street
Tacoma, WA 98404
(253) 593-0232

What is a Navigator?

The Navigator is a nurse or community member who helps people prevent, diagnose, and treat cancer.

Navigators have been successful in other communities. Our Navigator Program is a research project to see if Navigators help people in our community. This project is sponsored by the Puyallup Tribal Health Authority, the Indian Health Service, and the National Cancer Institute.

Why have a Navigator?

Clients meet with the Navigator to make decisions and solve problems in their cancer journeys. Some people need help with information, medications, insurance, transportation, doctors, or family needs. These are a few of the issues that the Navigators have experience in.

Who is the Navigator for?

Any client at PTHA who needs testing or treatment for cancer can use Navigator services.

Where and when can I find the Navigator?

The Navigator is based at the PTHA clinic during normal business hours. The program will operate at least until October 2005, depending on funding.

Our clinic coordinates with the Yakama Indian Health Center in Toppenish, WA, and the Native American Rehabilitation Association in Portland, OR. Those clinics also have nurse Navigators.

Who do I ask for more information?

You can ask your doctor or nurse about the Navigator Program, or you can call the Navigator at (253) 593-0232.

You can also call the program coordinator, Katrina Ramsey, in Portland at 1-877-664-0603 (toll free).

Informed Consent for Participants
Northwest Tribal Cancer Navigator Program

Puyallup Tribal Health Authority
2209 East 32nd Street
Tacoma, WA 98404
(253) 593-0232

We ask your permission to share anonymous information about your cancer journey with researchers from our Navigator Program.

As you know, the Navigator Program is a research project to find out if Navigators help Native Americans through their cancer journeys. The project is sponsored by the Puyallup Tribal Health Authority, the Indian Health Service, and the National Cancer Institute. Two other sites also have Navigator Programs. These sites are the Yakama Indian Health Center in Toppenish, WA, and the Native American Rehabilitation Association in Portland, OR.

Working with the Navigator does NOT mean that you are part of our research. Unless you give permission, we will not share details of your cancer journey with anyone outside the PTHA clinic.

If you give permission, the Navigator will send information to the project coordinator in Portland. This information includes your age, whether you are male or female, what kind of cancer you were tested for, what treatments you had and when, and what kinds of issues the Navigator talked to you about. Your information will be put together with other patients from PTHA and the other Navigator programs.

The Navigator will keep your personal information private. Researchers will not know your name, date of birth, address, or other personal information.

The risks involved in sharing your information are small. There is a chance that someone could figure out who you are, even from anonymous information. However, everyone involved with the project has signed Confidentiality Statements promising to respect your privacy.

If you agree to share your cancer journey with others, **the benefits to you are also small**. We hope that the research will benefit people who have cancer in the future. We hope to know whether Navigator Programs make a difference in cancer at tribal clinics in the Pacific Northwest. We will share the results with the Indian Health Service, the National Cancer Institute, and other tribes and organizations.

Sharing your information is completely up to you. If you choose not to share information about your cancer journey, you can still work with the Navigator. You will not lose any services from PTHA, the Indian Health Service, your tribe, or others. You can also change your mind in the future.

The next time you speak with the Navigator, s/he will check with you to see if you still want to take part in the study. Some time in the future, the Navigator will also ask you if you would be willing to be interviewed about your experiences.

If you have questions about this project, please call the Navigator at (253) 593-0232 or Katrina Ramsey, Project Coordinator, at 1-877-664-0603 (toll free number). You can also visit the Navigator or Anlot Wright at the PTHA clinic.

If you have any questions about your rights or concerns about this project, you may call Rena Gill, Co-Chair, Portland Area Indian Health Service Institutional Review Board, at 503-326-2014. She is not involved with this project and is responsible for making sure it is conducted in an ethical way.

We will give you a copy of this form.

I understand that I am being invited to take part in a research project for the Northwest Tribal Cancer Navigator Program. Anonymous information about my cancer journey will be shared with researchers.

I understand that I do not have to agree to share information with researchers. If I choose not to, I will not lose any services. I can also change my mind later and ask the Navigator not to share my information.

Respondent signature (or thumbprint) **OR** Navigator signature (phone consent) — Date

Witness signature — Date

Copies: ☐ Respondent ☐ Principal Investigator

Second Review: I have talked about the research project a second time.

☐ I **<u>want to share information</u>** about my experience in the Navigator Program.

☐ I do **<u>not</u>** want to share any information with researchers.

Signature — Date

Appendix F: Standard IHS medical record form (Patient Care Component [PCC] form)

IHS-803 (5/98) P.L. 86-511 N.A.

PCC AMBULATORY ENCOUNTER RECORD

Date ______________________

Arrival Time ________ : ________ AM PM

Clinic ______________________

Appt. ________ Walk-in ________

PROBLEM LIST UPDATE
(Enter Problem Numbers From Health Summary)

Remove	Move to Inactive	Move to Active

	AFFIL.	DIS.		INITIALS / CODE		
PROVIDERS						
PRIMARY PROVIDER						

TEMP PULSE RESP

CHIEF COMPLAINT

SUBJECTIVE/ OBJECTIVE

Injury? ☐ Yes ☐ No If yes, Date: ☐ ETOH Related ☐ Employ. Rel.

Cause: Place:

OTHER TESTS/ PROCEDURES ORDERED

PROBLEM LIST A-AI-C	#	PURPOSE OF VISIT *(PRINT ONLY IN THIS SECTION; DO NOT ABBREVIATE)*	Health Factors

REPRODUCTIVE FACTORS G P LC SA TA LMP FP METHOD DATE BEGUN

PROBLEM LIST NOTES STORE NOTE FOR PROB. # REMOVE NOTE #

STORE NOTE FOR PROB. #

MEDICATIONS

MEDICATIONS / TREATMENTS / PROCEDURES / PATIENT EDUCATION

REVISIT/ REFERRAL TO: DATE TIME

PURPOSE:

INSTRUCTIONS: TO PATIENT: ☐ SIGN RELEASE

PROV. SIGNATURE

B/P

WT. ☐ GM ☐ KG ☐ LB-O

HT. ☐ CM ☐ IN

HEAD ☐ CM ☐ IN

VISION - UNCORRECTED

R | L

VISION - CORRECTED

R | L

✓	ORDER	INITIALS
	HCT.	
	UA	
	HCG	
	BS-F/BS-R	
	CBC	
	Urine culture	
	Throat culture	
	Stool culture	
	STS	
	GC	
	PAP	
	Pelvic	
	Breast	
	Mammogram	
	Rectal	
	Chest X-ray	
	EKG	
	Soak	
	Hep B #	
	Hep A #	
	OPV #	
	DTP #	
	DT aP #	
	DT	
	Td	
	MMR #	
	Varicella	
	Influenza	
	Hib TITER/ ActHIB #	
	Pedvax HIB #	
	Pneumo Vax	
	PPD	mm

■	Type of Decision Making
	Straightforward
	Low Complexity
	Moderate Complexity
	High Complexity

Appendix G: Navigator encounter form

Patient name: ______________________ Health record/chart number: ___________

Navigator ID: ___ ___ ___ ___
(created by database)

Encounter number: ___ ___ ___ ___ ___
(created by database)

Detach this section if copies are needed for research.

✂- -

Northwest Tribal Cancer Navigator Program

Encounter Record

Navigator ID: ___ ___ ___ ___
(created by database)

Encounter number: ___ ___ ___ ___ ___
(created by database)

Date of encounter: ____ / ____ / ________	**Type of contact:** ☐1 Onsite ☐7 Home visit ☐6 Hospital visit ☐3 Phone ☐4 Mailing ☐5 Other
Level of involvement: ☐1 Low (20 min or less) ☐2 Medium (21-90 minutes) ☐3 High (90+ minutes)	

Barriers dealt with in this encounter (check all that apply):

- ☐14 Abnormal finding: Passive follow-up
- ☐13 Emotional barriers
- ☐ 4 Information about cancer, Tx, health
- ☐ 1 Insurance/health coverage needed
- ☐ 3 Paperwork help
- ☐10 Transportation
- ☐ 2 Other financial assistance needed
- ☐11 Family needs
- ☐18 Appointment reminder
- ☐12 Missed appointment
- ☐16 Routine follow-up by navigator
- ☐17 Unsuccessful attempt to visit patient
- ☐ 5 Communicating with providers
- ☐ 7 Hospital or clinic error
- ☐ 6 Medications or equipment
- ☐15 Referral / arranging outside services
- ☐ 8 Side effects and comorbidity management
- ☐ 9 Other coordination of care
- ☐25 Other: _______________________________

Explanation of barriers:

Needs follow-up? ☐1 Yes ☐2 No

Date of next f/u (if yes): ____ / ____ / __________

Description of resolution(s): (Include description of follow-up needed)

Check when data entry is complete ☐

Appendix H: Navigator intake survey

Northwest Native American Navigator Program
Intake Survey

Participant ID:

Date enrolled in Navigator Program*:

Navigator Program*: ○ **Yakama** ○ **Puyallup**

Site of cancer*:
- Breast
- Cervix
- Prostate
- Colon-rectum
- Other

If other, specify:

NAME (Last):________________(First):_______________(Preferred):_________

Address: PO Box: ____

Street: ________________________________ Apt. ____________

____

City: __________________ State: _____ ZIP: _____________

Phone: ***<u>Working phone in household</u>**? Yes/No/*Prefer not to say*

Home ________________________________

Work ________________________________

Cell ________________________________

Message only ____________________________

Emergency contact: ___________________________ Phone: _______________

☐ Would like a copy of findings

---

*Research questions are starred and in bold. Other questions are optional for Navigators to use at their discretion

1.* How long does it usually take you to get to [site] clinic?

_______ HOURS _______ MINUTES

2.* Is there a working motor vehicle in your household?

☐ Yes
☐ No
☐ *Prefer not to say*

How do you usually get around? [*Form of transportation, who helps*]

3.* What year were you born? ________

So you are ________ years old?

4.* Sex: Female
Male

5.* Are you tribally enrolled?

☐ Yes, enrolled
☐ No, but descendent
☐ No, but eligible to enroll
☐ No, but some ancestry
☐ Prefer not to say

Which tribe? _____________________

6.* Is there another culture you identify with strongly?

☐ Yes ----------------------Explain _____________________
☐ No
☐ Prefer not to say

*Research questions are starred and in bold. Other questions are optional for Navigators to use at their discretion.

7.* What is your current marital status?

- ☐ Married
- ☐ Living with someone/A member of an unmarried couple
- ☐ Separated
- ☐ Divorced
- ☐ Widowed
- ☐ Single
- ☐ *Prefer not to say*

8.* What is your highest level of school?

- ☐ None
- ☐ Primary School (Grade 1 – 6)
- ☐ Secondary School (Grade 7-12)
- ☐ High School Graduate (Diploma) / GED
- ☐ Some College (1-4 years post High School)
- ☐ College Graduate (Bachelor's degree)
- ☐ Some Post-Graduate (1-3 years post College)
- ☐ Post-Graduate (Master's degree or higher)
- ☐ *Prefer not to say*

9.* What is your current employment status?

- ☐ Full-time employed
- ☐ Part-time employed
- ☐ Self employed
- ☐ Unemployed
- ☐ Disabled
- ☐ Retired
- ☐ *Prefer not to say*

10*. Do you have health insurance? [*Mark all that apply*]

	Yes	No	DK/NS
Indian Health—Contract Health	☐	☐	☐
Indian Health—Direct Services	☐	☐	☐
Medicare	☐	☐	☐
Medicaid	☐	☐	☐
Employer provided: ________________________	☐	☐	☐
Buy through employer: ______________________	☐	☐	☐
Veteran	☐	☐	☐
Other	☐	☐	☐

*Research questions are starred and in bold. Other questions are optional for Navigators to use at their discretion.

Do you have children under 18 years old living in the house?

☐ Yes ☐ No

Ages: ______ ______ ______ ______ ______

Other household members (name/relationship):

____

____

____

11.* Which category in this row corresponds to the total yearly income of everyone in your household? <u>CIRCLE THE AMOUNT</u>.

<u>AMOUNTS IN DOLLARS</u>

Household Size					DON'T KNOW	Prefer not to say
1	<6,960	6,961 – 13,470	13,471 – 19,960	19,961+	☐	☐
2	<12,120	12,121 – 16,160	16,161 – 24,240	24,241+	☐	☐
3	<15,260	15,261 – 22,690	22,691 – 30,520	30,521+	☐	☐
4	<16,400	16,401 – 27,600	24,601 – 32,800	32,800+	☐	☐
5	<21,540	21,541 – 32,310	32,311 – 43,080	43,080+	☐	☐
6	<24,660	24,661 – 36,990	36,991 – 49,320	49,320+	☐	☐
7	<27,620	27,621 – 41,430	41,431 – 55,240	55,240+	☐	☐
8 +	<30,960	30,961 – 46,440	46,441 – 61,920	61,920+	☐	☐

12.* Health History:

	Yes	**No**	**Current***	**Comments**
Angina or heart attack	☐	☐	☐	
High blood pressure	☐	☐	☐	
Elevated cholesterol level	☐	☐	☐	
Congestive heart failure	☐	☐	☐	
Stroke or TIA	☐	☐	☐	
Blocked leg or neck arteries	☐	☐	☐	
Diabetes	☐	☐	☐	
Serious infections	☐	☐	☐	
Arthritis or gout	☐	☐	☐	
Cancer	☐	☐	☐	
Bleeding tendency	☐	☐	☐	
Kidney failure/dialysis	☐	☐	☐	
Rheumatic fever	☐	☐	☐	
Mental illness	☐	☐	☐	
Current dental problems		☐	☐	

Do you ever drink beer, wine, or other drinks containing alcohol?

☐ Never
☐ Rarely
☐ 1-2 a day
☐ More than 2 a day
☐ Used to drink but quit _____________
☐ *Don't know/not sure*
☐ *Refused*

Have you ever used cigarettes or chewing tobacco on a regular basis? (Non-ceremonial)

☐ Never
☐ Current: _____________ / day
☐ Quit _______________
☐ *Don't know/not sure*
☐ *Refused*

*Research questions are starred and in bold. Other questions are optional for Navigators to use at their discretion.

Family health history:

	Age	Diseases	If deceased, cause of death
Father			
Mother			
Sisters & brothers			
Children			

Other family health history:

Support system:

Who do you have available to help you at this time? ______________________________

How has your family or significant other responded? ___________________________________

____

Appendix I: Pilot program brochure

The Northwest Tribal Navigator story

On July 29, 2002, the President's Cancer Panel visited the Yakama Nation in response to an invitation from Yakama Tribal Elder Joe Jay Pinkham. Members of the Yakama Nation and other Northwest tribes told the Panel about the problems that Native people face in obtaining adequate medical care and surviving cancer.

What are you going to do for my people?

Months later, the National Cancer Institute (NCI) funded the Indian Health Service to test a new model of cancer care: the "cancer navigator." The NCI has heard the message that cancer is a crisis in Native communities, and they hope that the navigator model will start to help with some of the problems facing Indian people that the President's Cancer Panel heard about at the visit to the Yakama Nation.

So far, two clinics have navigators to help patients with understanding and coordinating screening tests, diagnosis, and treatment for cancer: The Yakama Indian Health Center and the Takopid Tribal Health Center operated by the Puyallup Tribal Health Authority. The Northwest Portland Area Indian Health Board is collecting research data about the effectiveness of the navigator model in increasing access for Indian people to good cancer care.

To speak to a Navigator ...

Yakama Indian Health Center
Toppenish, Washington
509.865.2102 ext. 391

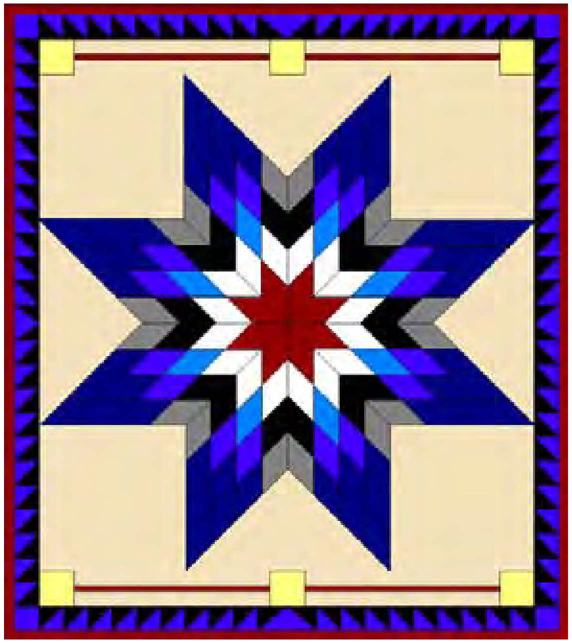
Puyallup Tribal Health Authority
Tacoma, Washington
253.593.0232 ext. 396

For questions about the research program:

Northwest Portland Area
Indian Health Board
Portland, Oregon
877.664.0603
www.npaihb.org

Northwest Tribal Cancer Navigator Program

Coordinating cancer care and outreach from screening through diagnosis, treatment, and resolution.



What is a Navigator?

The Navigator is a **person** who works with people to make sure they get the **proper diagnosis** and—if they need it—**treatment** for **cancer**. Some Navigators are **nurses** and others are **community members**. Navigators have special training in helping people with their cancer care.

Navigators are already breaking down barriers to good care in many communities. The Northwest Tribal Cancer Navigator Program is a research project to see if Navigators work for Northwest Indian communities.

Learning about the journey

If you work with the Navigator, you may be asked to share information about your cancer journey with researchers. You do **not** have to share your information; the Navigator will work with you even if you choose not to share your information.

Why have a Navigator?

Clients meet with the Navigator to make decisions and solve problems in their cancer journeys.

Some people need help with:

- Information on cancer
- Managing medications
- Figuring out how to pay for procedures
- Finding transportation
- Making appointments
- Communicating with doctors
- Family needs

The Navigator Program cannot pay for services. Instead, we will try to connect you with other organizations that can.

Who is the Navigator for?

For you—the Navigators are for **all** patients at the Yakama and Puyallup clinics who have cancer—or who have screening tests or symptoms that mean they **could** have cancer.

How do I get started?

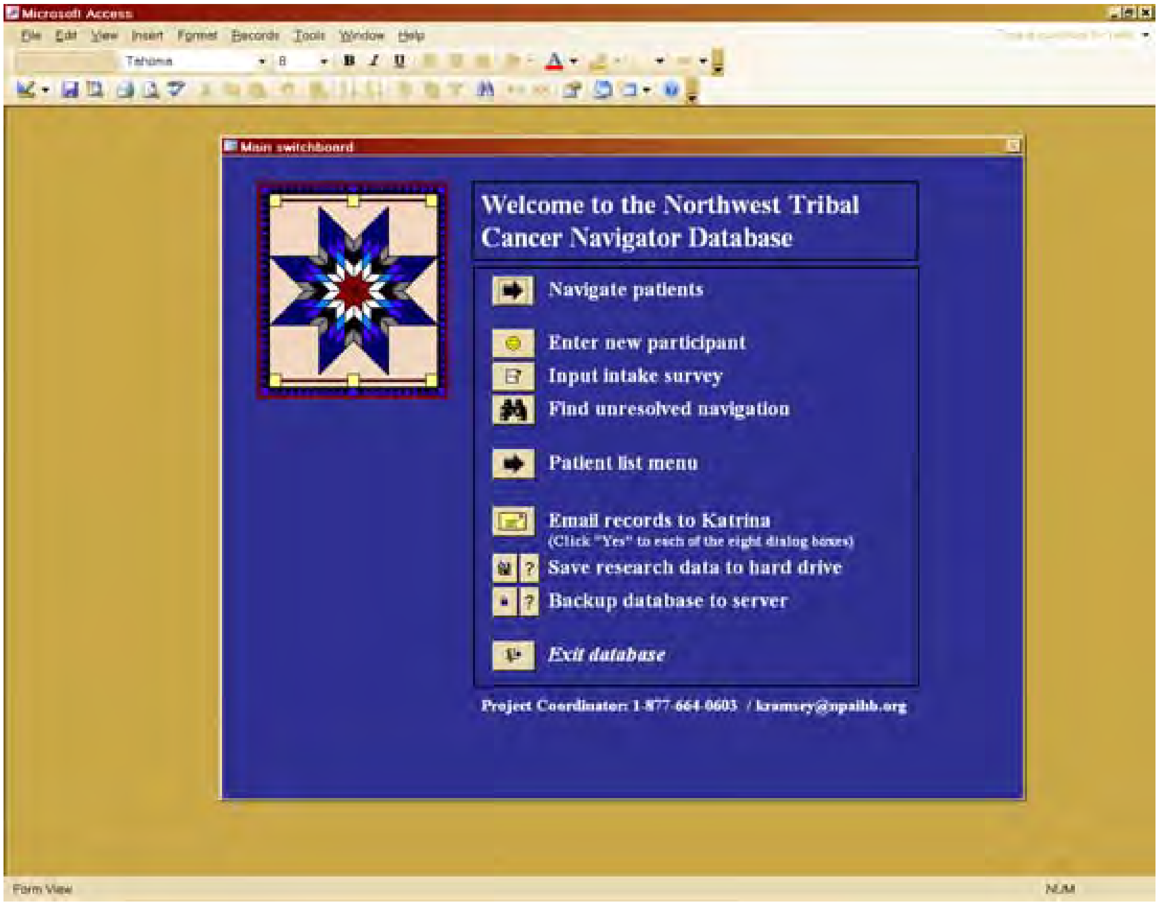
To contact a Navigator, call one of the numbers on the back of this brochure. You can also visit the clinic during regular hours and ask to page the Navigator.

This project is sponsored by
The Puyallup Tribal Health Authority
The Yakama Indian Health Center
The Northwest Portland Area Indian Health Board, & the Portland Area Office of the Indian Health Service.

Funding for the program comes from the National Cancer Institute.

Appendix J: Database images

A. Opening screen of Northwest Tribal Cancer Navigator Program Database, pilot phase



Welcome to the Northwest Tribal Cancer Navigator Database

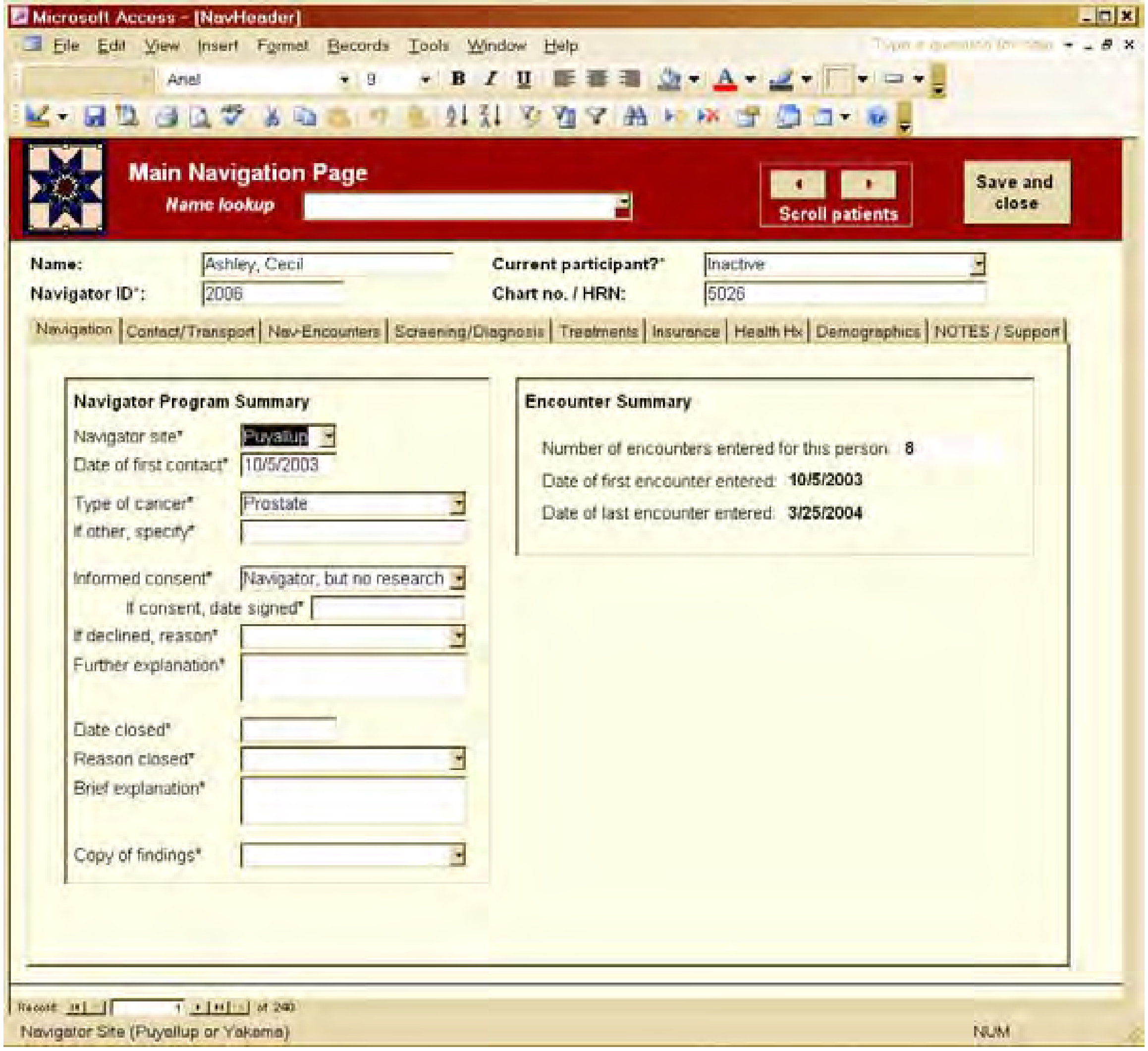
(Click "Yes" to each of the eight dialog boxes)

Project Coordinator: 1-877-664-0603 / kramsey@npaihb.org

B. First tab, “Navigation,” in main data access form

This tab summarizes the patient’s standing in the research program.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil
Navigator ID*: 2006
Current participant?* Inactive
Chart no. / HRN: 5026

Navigator Program Summary

Navigator site* Puyallup
Date of first contact* 10/5/2003
Type of cancer* Prostate
If other, specify*
Informed consent* Navigator, but no research
If consent, date signed*
If declined, reason*
Further explanation*
Date closed*
Reason closed*
Brief explanation*
Copy of findings*

Encounter Summary

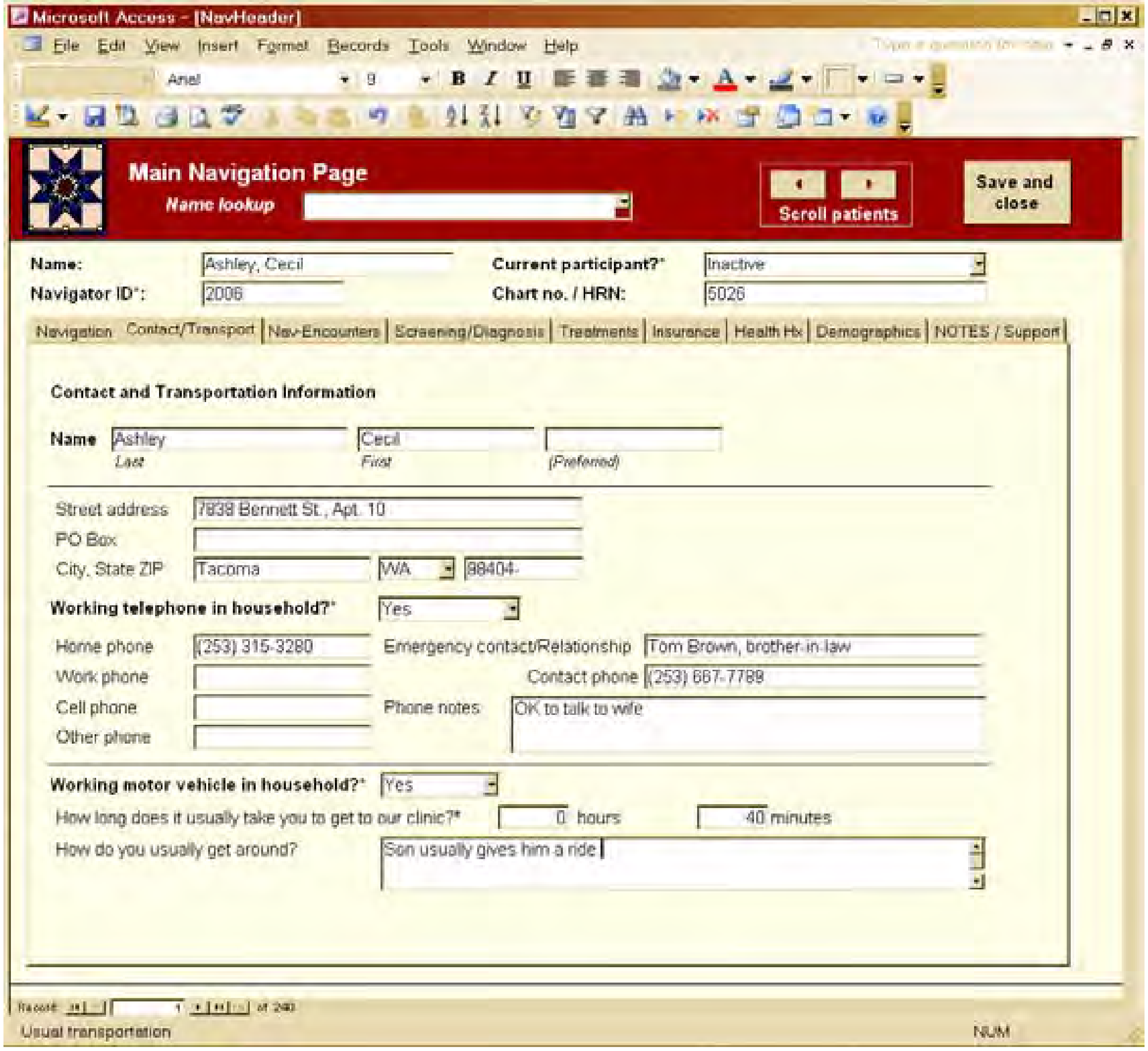
Number of encounters entered for this person: 8
Date of first encounter entered: 10/5/2003
Date of last encounter entered: 3/25/2004

Record: 1 of 240
Navigator Site (Puyallup or Yakama)

C. Second tab, “Contact/Transport,” in main data access form

This tab presents contact information. The fields accessible to research staff are in bold and marked with an asterisk (*); all others are stored only in the database and accessible to the Navigator.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil
Current participant?* Inactive
Navigator ID*: 2006
Chart no. / HRN: 5026

Contact and Transportation Information

Name Ashley (*Last*) Cecil (*First*) (*Preferred*)

Street address 7838 Bennett St., Apt. 10
PO Box
City, State ZIP Tacoma WA 98404-

Working telephone in household?* Yes

Home phone (253) 315-3280
Work phone
Cell phone
Other phone
Emergency contact/Relationship Tom Brown, brother-in-law
Contact phone (253) 667-7789
Phone notes OK to talk to wife

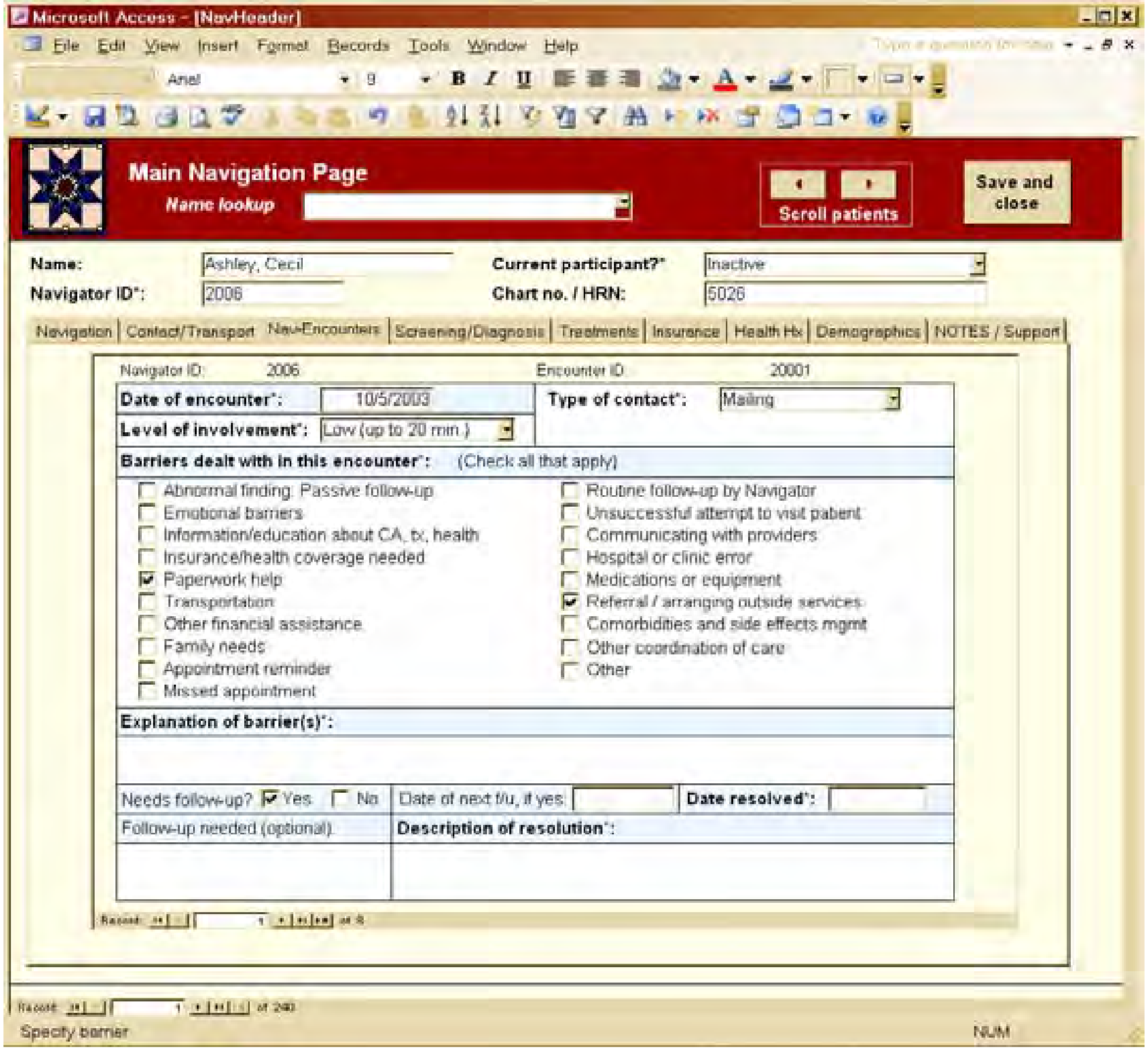
Working motor vehicle in household?* Yes

How long does it usually take you to get to our clinic?* 0 hours 40 minutes
How do you usually get around? Son usually gives him a ride

D. Third tab, “Navigator-Encounters,” in main data access form

This tab is modeled after the paper encounter form used by the Navigators. It is possible to scroll through all encounters for a given patient.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil

Current participant?* Inactive

Navigator ID*: 2006

Chart no. / HRN: 5026

Navigator ID: 2006

Encounter ID: 20001

Date of encounter*: 10/5/2003

Type of contact*: Mailing

Level of involvement*: Low (up to 20 min.)

Barriers dealt with in this encounter*: (Check all that apply)

☐ Abnormal finding: Passive follow-up
☐ Emotional barriers
☐ Information/education about CA, tx, health
☐ Insurance/health coverage needed
☑ Paperwork help
☐ Transportation
☐ Other financial assistance
☐ Family needs
☐ Appointment reminder
☐ Missed appointment
☐ Routine follow-up by Navigator
☐ Unsuccessful attempt to visit patient
☐ Communicating with providers
☐ Hospital or clinic error
☐ Medications or equipment
☑ Referral / arranging outside services
☐ Comorbidities and side effects mgmt
☐ Other coordination of care
☐ Other

Explanation of barrier(s)*:

Needs follow-up? ☑ Yes ☐ No

Date of next f/u, if yes:

Date resolved*:

Follow-up needed (optional)

Description of resolution*:

Record: 1 of 8

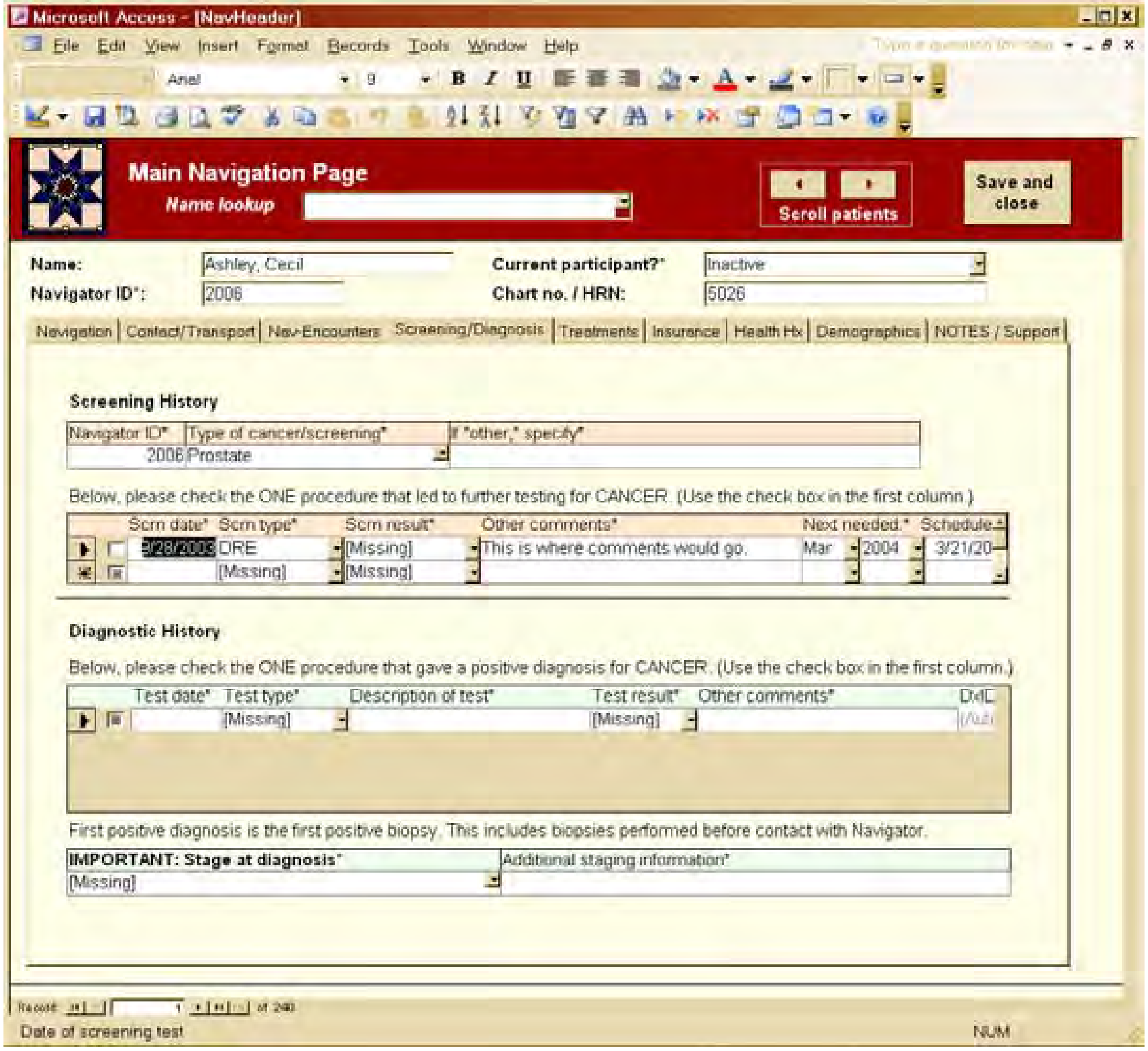
Record: 1 of 240

Specify barrier

E. Fourth tab, “Screening/Diagnosis,” in main data access form

This tab summarizes the patient’s screening and diagnostic history.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil
Current participant?* Inactive
Navigator ID*: 2006
Chart no. / HRN: 5026

Screening History

Navigator ID*	Type of cancer/screening*	If "other," specify*
2006	Prostate	

Below, please check the ONE procedure that led to further testing for CANCER. (Use the check box in the first column.)

		Scrn date*	Scrn type*	Scrn result*	Other comments*	Next needed.*		Schedule
▶	☐	3/28/2003	DRE	[Missing]	This is where comments would go.	Mar	2004	3/21/20
*	☒		[Missing]	[Missing]				

Diagnostic History

Below, please check the ONE procedure that gave a positive diagnosis for CANCER. (Use the check box in the first column.)

		Test date*	Test type*	Description of test*	Test result*	Other comments*	DxD
▶	☒		[Missing]		[Missing]		

First positive diagnosis is the first positive biopsy. This includes biopsies performed before contact with Navigator.

IMPORTANT: Stage at diagnosis*	Additional staging information*
[Missing]	

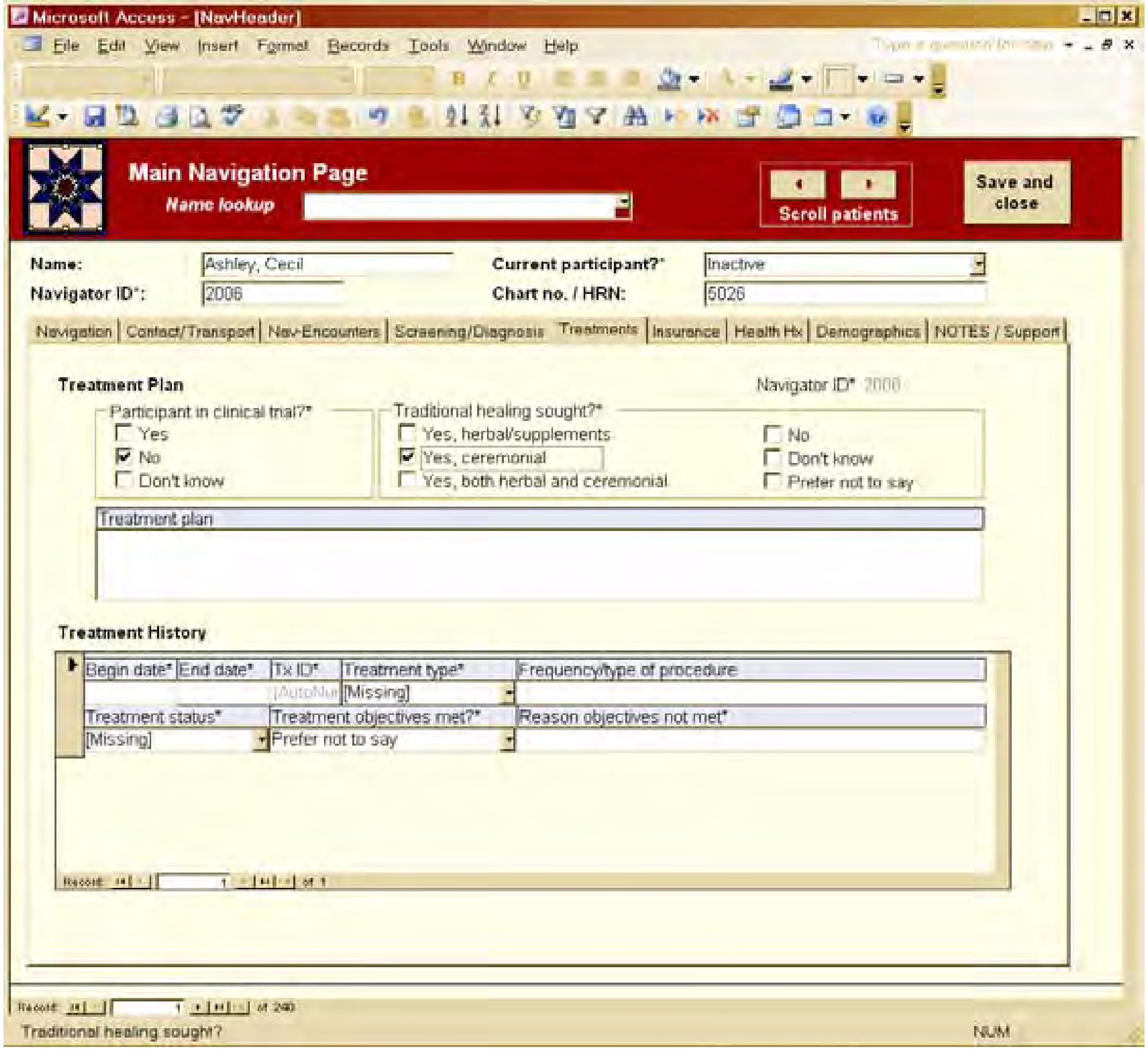
Record: 1 of 240

Date of screening test

F. Fifth tab, “Treatments,” in main data access form

This tab summarizes the patient’s treatment plan and history.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil
Current participant?*: Inactive
Navigator ID*: 2006
Chart no. / HRN: 5026

Treatment Plan

Navigator ID* 2006

Participant in clinical trial?*
☐ Yes
☑ No
☐ Don't know

Traditional healing sought?*
☐ Yes, herbal/supplements
☑ Yes, ceremonial
☐ Yes, both herbal and ceremonial
☐ No
☐ Don't know
☐ Prefer not to say

Treatment plan

Treatment History

Begin date*	End date*	Tx ID*	Treatment type*	Frequency/type of procedure
		(AutoNu	[Missing]	

Treatment status*	Treatment objectives met?*	Reason objectives not met*
[Missing]	Prefer not to say	

Record: 1 of 1

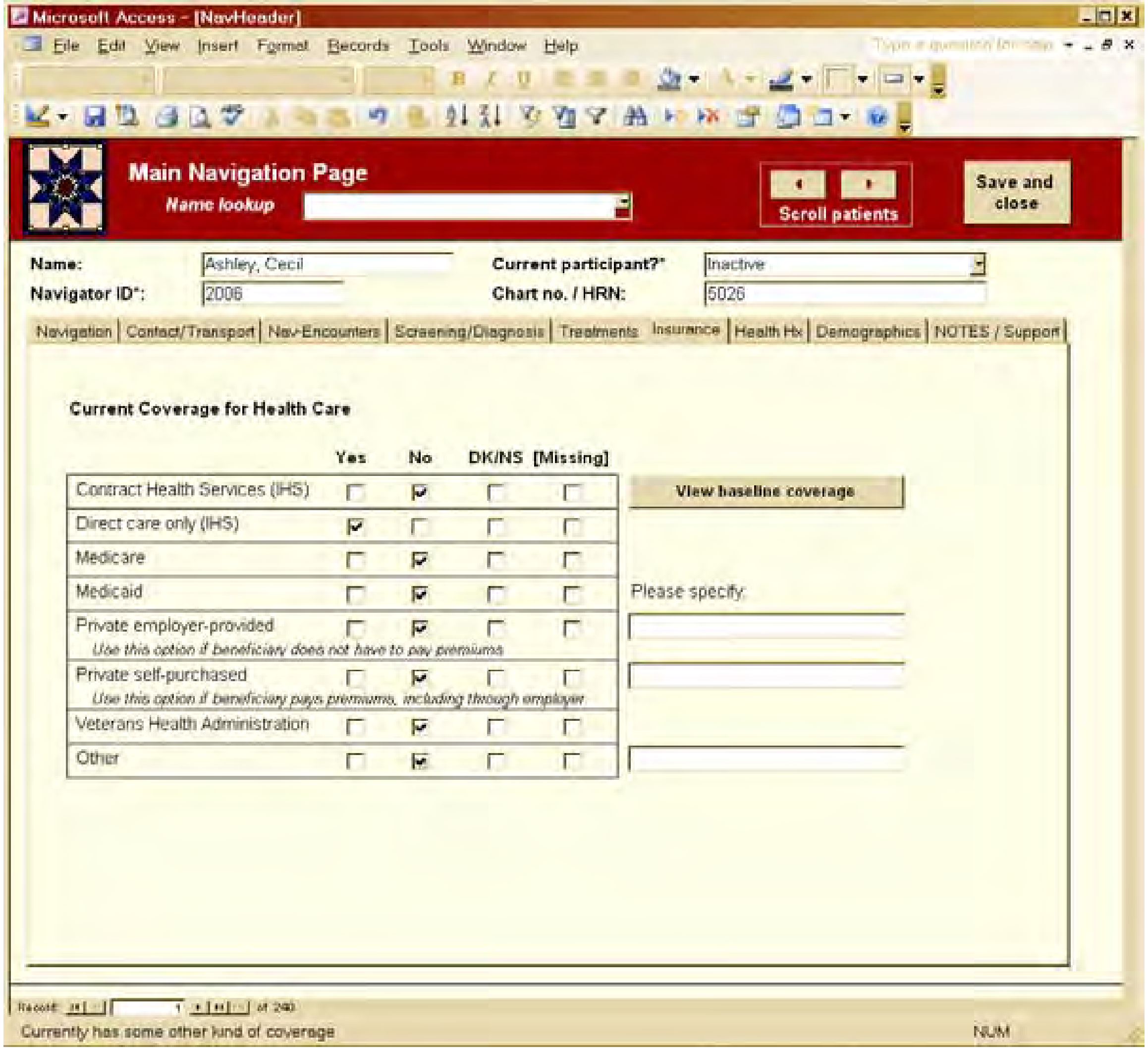
Record: 1 of 240

Traditional healing sought?

G. Sixth tab, “Insurance,” in main data access form

This tab summarizes the patient’s current coverage by the IHS and other payors. The patient’s baseline insurance is entered on a separate screen and can be viewed by clicking on the “View baseline coverage” button.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil

Navigator ID*: 2006

Current participant?* Inactive

Chart no. / HRN: 5026

Current Coverage for Health Care

	Yes	No	DK/NS	[Missing]
Contract Health Services (IHS)	☐	☑	☐	☐
Direct care only (IHS)	☑	☐	☐	☐
Medicare	☐	☑	☐	☐
Medicaid	☐	☑	☐	☐
Private employer-provided *Use this option if beneficiary does not have to pay premiums*	☐	☑	☐	☐
Private self-purchased *Use this option if beneficiary pays premiums, including through employer*	☐	☑	☐	☐
Veterans Health Administration	☐	☑	☐	☐
Other	☐	☑	☐	☐

Please specify:

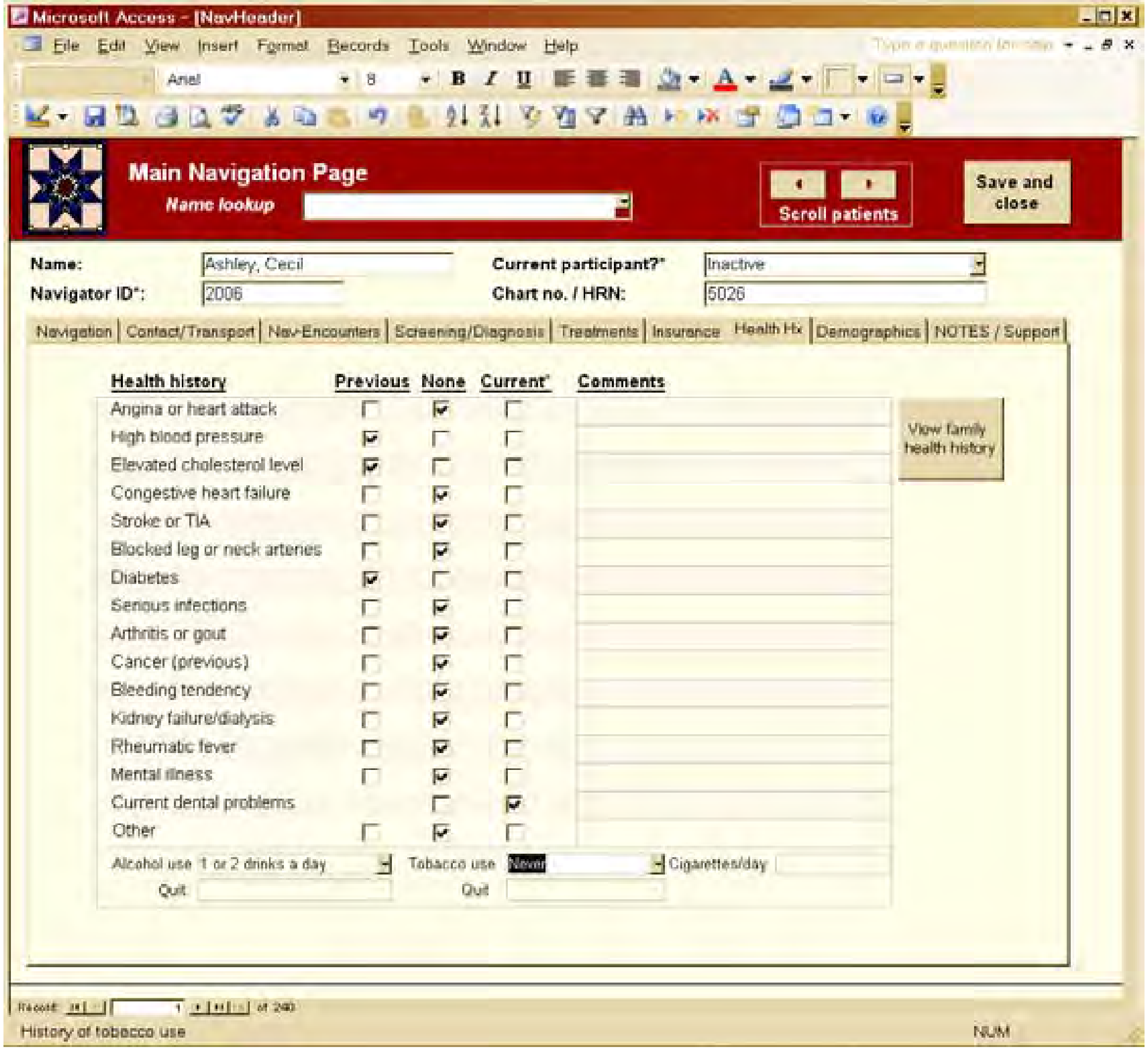
Record: 1 of 240

Currently has some other kind of coverage

H. Seventh tab, “Health Hx,” in main data access form

This tab summarizes the patient’s health history. Only current conditions are included in datasets for research purposes.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil
Current participant?* Inactive
Navigator ID*: 2006
Chart no. / HRN: 5026

Health history	Previous	None	Current*	Comments
Angina or heart attack	☐	☑	☐	
High blood pressure	☑	☐	☐	
Elevated cholesterol level	☑	☐	☐	
Congestive heart failure	☐	☑	☐	
Stroke or TIA	☐	☑	☐	
Blocked leg or neck arteries	☐	☑	☐	
Diabetes	☑	☐	☐	
Serious infections	☐	☑	☐	
Arthritis or gout	☐	☑	☐	
Cancer (previous)	☐	☑	☐	
Bleeding tendency	☐	☑	☐	
Kidney failure/dialysis	☐	☑	☐	
Rheumatic fever	☐	☑	☐	
Mental illness	☐	☑	☐	
Current dental problems		☐	☑	
Other	☐	☑	☐	

Alcohol use 1 or 2 drinks a day
Quit
Tobacco use Never
Quit
Cigarettes/day

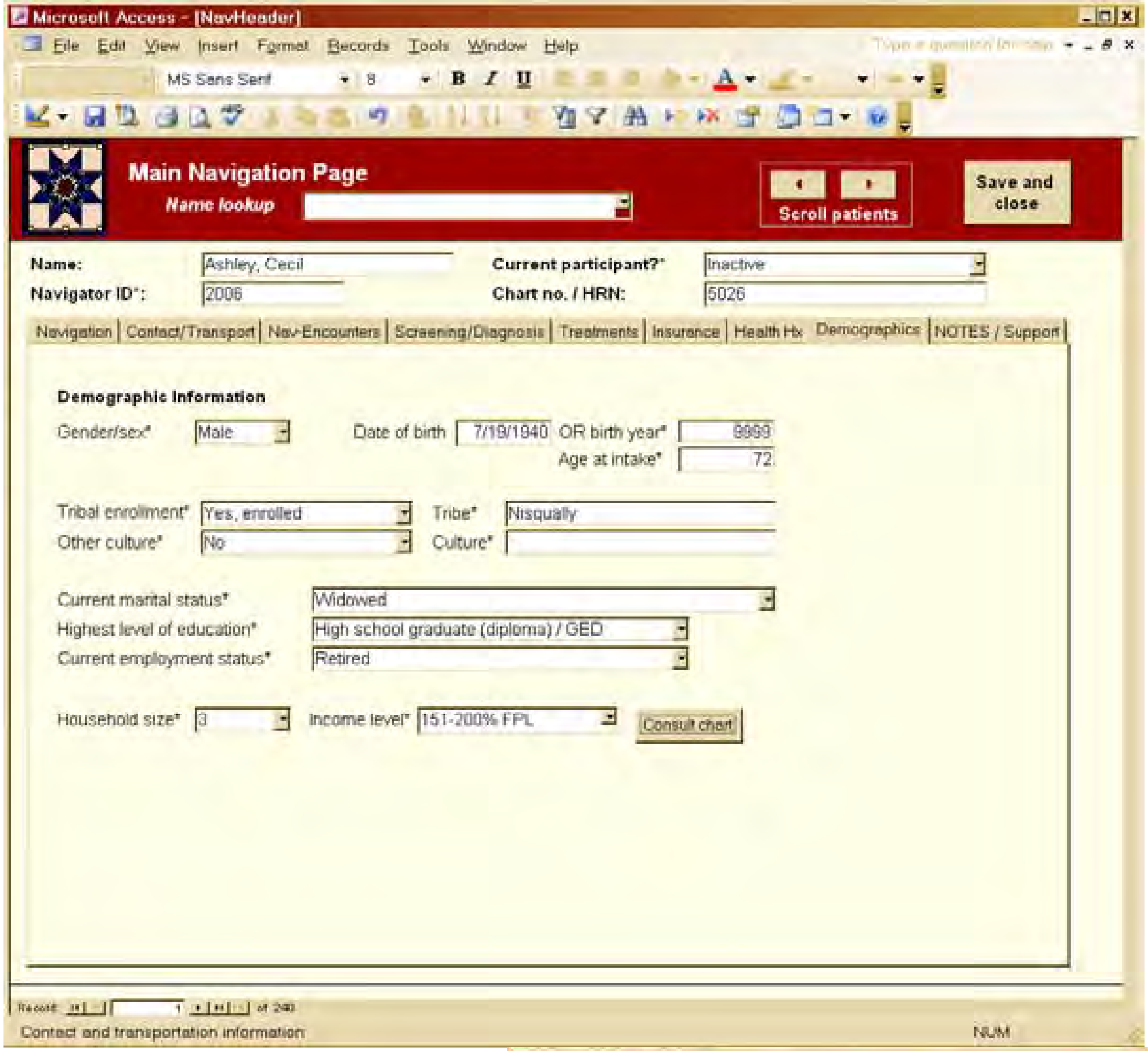
Record: 1 of 240

History of tobacco use

I. Eighth tab, “Demographics,” in main data access form

This tab summarizes the patient’s responses to demographic questions on the intake survey. The second box (“2004 Federal Poverty Levels”) appears when the “Consult chart” button is clicked.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name:	Ashley, Cecil
Current participant?*	Inactive
Navigator ID*:	2006
Chart no. / HRN:	5026

Demographic Information

Gender/sex*	Male
Date of birth	7/19/1940
OR birth year*	9999
Age at intake*	72
Tribal enrollment*	Yes, enrolled
Tribe*	Nisqually
Other culture*	No
Culture*	
Current marital status*	Widowed
Highest level of education*	High school graduate (diploma) / GED
Current employment status*	Retired
Household size*	3
Income level*	151-200% FPL

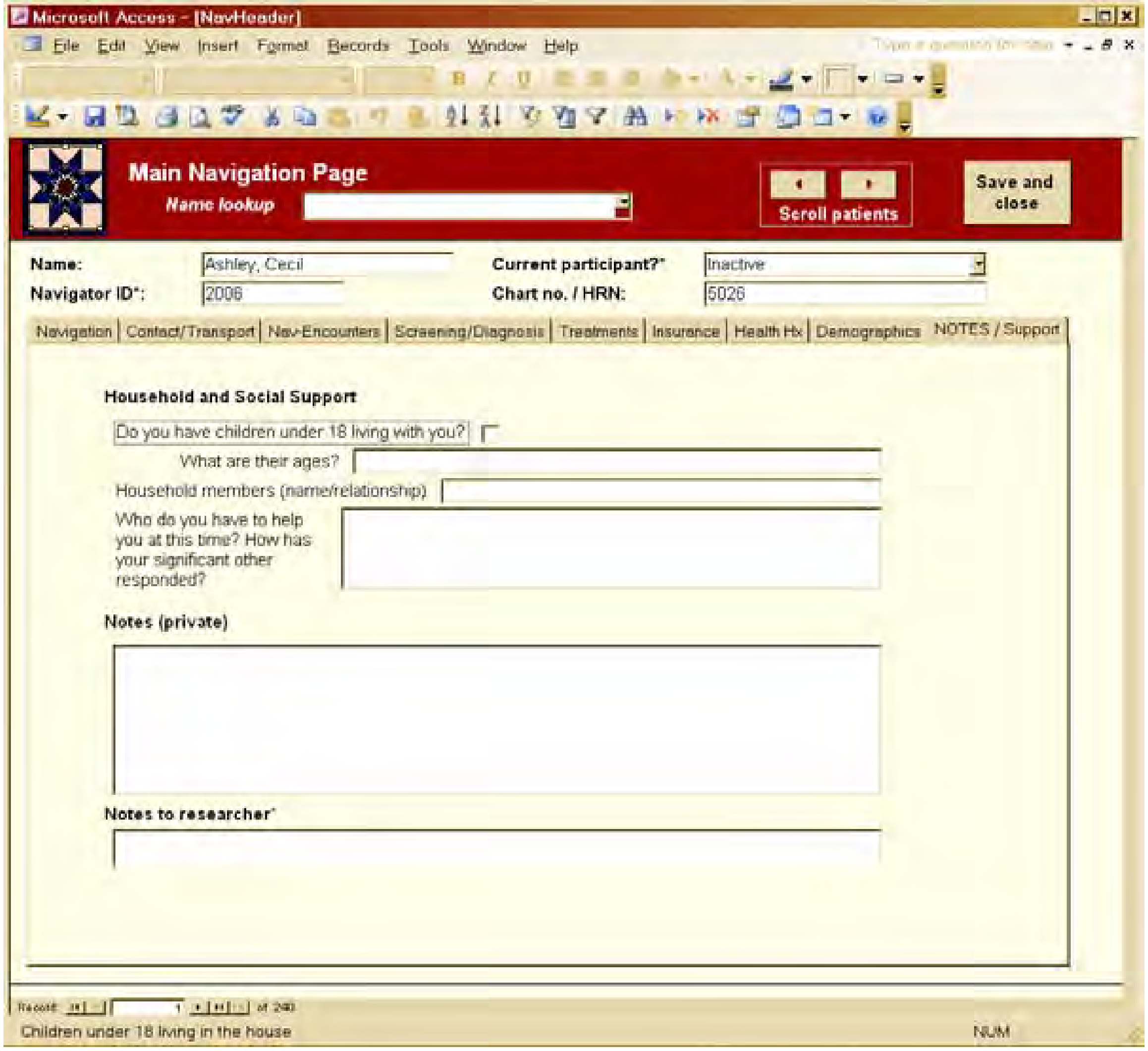
2004 Federal Poverty Levels for 48 Contiguous United States and D.C.

Household Size	100% FPL or less	101-150% FPL	151-200% FPL	Over 200% FPL
1	<$9,310	$9,311 - $13,965	$13,966 - $18,620	$18,621+
2	<12,490	12,491 - 18,735	18,736 - 24,980	34,981+
3	<15,670	15,671 - 23,505	23,506 - 31,340	31,341+
4	<18,850	18,851 - 28,275	28,276 - 37,700	37,701+
5	<22,030	22,031 - 33,045	33,046 - 44,060	44,061+
6	<25,210	25,211 - 37,815	37,816 - 50,420	50,421+
7	<28,390	28,391 - 42,585	42,586 - 56,780	56,781+
8+	<31,570	31,571 - 47,355	47,356 - 63,140	63,141+

J. Ninth tab, “NOTES/Support,” in main data access form

This tab displays general notes and social support notes on each patient.

Note: All data printed here were invented by research staff and do not represent actual participants.



Name: Ashley, Cecil

Navigator ID*: 2006

Current participant?*: Inactive

Chart no. / HRN: 5026

Household and Social Support

Do you have children under 18 living with you? ☐

What are their ages?

Household members (name/relationship)

Who do you have to help you at this time? How has your significant other responded?

Notes (private)

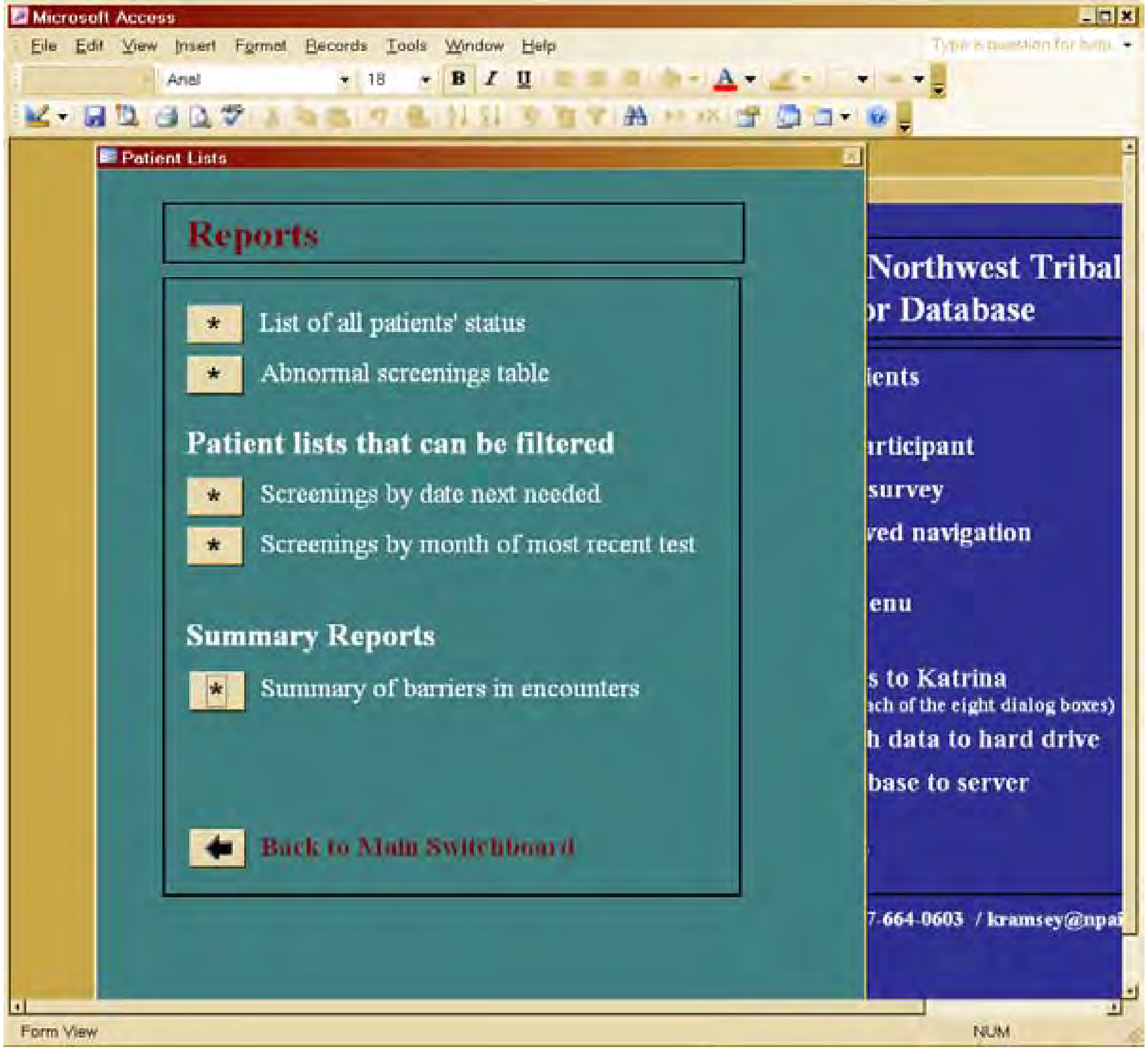
Notes to researcher*

Record: 1 of 240

Children under 18 living in the house

K. Report menu

This menu is accessible from the main screen. Clicking on each of the buttons brings up a different report. Reports can be customized for date ranges or groups of patients.



L. Sample report: Screenings by month of most recent test

Note: All data printed here were invented by research staff and do not represent actual participants.

Cancer Screening Report

Patients with cancer screening tests by month of most recent test

Pap test

Date	Result	Comments	Next needed	Scheduled
September 2004				
Hillaire, Holly		HRN: 2445 ID: 2327 Status: Active		
9/22/2004	[Missing]	This is where comments would go.	Mar 2005	
Muschamp, Isabel		HRN: 7893 ID: 2334 Status: Active		
9/17/2004	[Missing]	This is where comments would go.	Mar 2005	
August 2004				
Moran, Tina		HRN: 3591 ID: 2304 Status: Active		
8/4/2004	[Missing]	This is where comments would go.	Feb 2005	1/31/2005
July 2004				
Fry, Melody		HRN: 7818 ID: 2307 Status: Active		
7/15/2004	[Missing]	This is where comments would go.	Jan 2005	1/13/2005
May 2004				
Jones, Lynette		HRN: 4445 ID: 2324 Status: Active		
5/19/2004	[Missing]	This is where comments would go.	Nov 2004	11/18/2004
April 2004				
Butterfield, Lou		HRN: 3297 ID: 3109 Status: Active		
4/12/2004	[Missing]	This is where comments would go.	Oct 2004	10/27/2004
March 2004				
Cleaver, Gloria		HRN: 3589 ID: 3122 Status: Active		
3/3/2004	[Missing]	This is where comments would go.	Sep 2004	9/17/2004
Moss, Earnestine		HRN: 5456 ID: 3106 Status: Active		
3/17/2004	[Missing]	This is where comments would go.	Sep 2004	9/28/2004

Appendix K: Informed consent for patient interviews

Informed Consent for Northwest Tribal Cancer Navigator Program Participant Interview

I want to thank you for talking to me about your cancer journey and your experiences with the Navigator Program.

I have some specific questions to ask you about your journey. Some of these questions will be multiple-choice, but I am also interested in your comments and opinions. Depending on how much we end up talking, the interview could take up to an hour.

I would like to use a tape recorder to record our conversation, if that is comfortable for you. If you prefer that I not record our conversation, I will take notes while we talk. Is it OK to use a tape recorder?

Tape recorder used: ☐ Yes ☐ No

I will also be talking to other people who have had cancer at your local clinic and from other Indian clinics with Navigator program. I will look at the results with others from the Navigator Program. We will share what we learn from these interviews with the Navigators. We will do our best to make sure that nobody can identify you personally. We may also share the results with other groups, such as other Navigator groups, Indian health care clinics, or national cancer programs. At the end of the study, we will send you a summary. If you don't get a copy and want one, you can call 1-877-664-0603, which is the toll-free number for the Navigator Program in Portland.

You can stop this interview at any time. Nothing you say will affect your health care or other services in any way. If you have concerns about this project, you can contact the ethics board at (503) 326-2014.

This is *your* journey. I'm not looking for specific answers; I want to know where the bumps were and how we can help.

I understand that I am being invited to take part in a research project for the Northwest Tribal Cancer Navigator Program. Anonymous information about my cancer journey will be shared with researchers.

I understand that I do not have to agree to share information with researchers. If I choose not to, I will not lose any services. I can also change my mind later and ask the Navigator not to share my information.

Respondent signature (or thumbprint)	**OR**	Navigator signature (phone consent)	Date

Appendix L: Instrument for patient interviews

Northwest Tribal Cancer Navigator Program
Semi-Structured Patient Interview

COVER PAGE -- CONFIDENTIAL

Interview number: ______ ______ ______ ______ ______

Name: ____

Phone number: ____

Date of diagnosis: ____

Date of resolution: ____

Wishes to review results: ☐ Yes ☐ No

IF YES: What address should I send the results to for you to look over?

Street, Apt.: ____

City, State, ZIP: ____

CHECK sent: ☐ Yes ☐ No Date: __________
Send to address, if different from above:

Street, Apt.: ____

City, State, ZIP: ____

Remove this sheet and place it in the INTERVIEW CONTACTS file.

Northwest Tribal Cancer Navigator Program
Semi-Structured Patient Interview

Interview number: ______ ______ ______ ______ ______

Interview date: ____

Navigator site: ☐ Puyallup ☐ Yakama

Interviewee is: ☐ Patient ☐ Family member

This is *your* journey. I'm not looking for specific answers; I want to know where the bumps were and how we can help.

1. **Before I ask you about the Navigator program, I would like to know a little about your experiences with medical care before you were introduced to the Navigator. Have you ever had a major illness that involved more than one doctor for more than one month?**

[EXAMPLES: diabetes, kidney disease, major injury, chronic conditions, previous cancer]

Yes No *Refused*

IF YES: Just thinking about the care you got for your __________, how would you describe that experience?

Great Good Acceptable Terrible *Refused*

> **Now I'd like to ask you about the Navigator and the Navigator Program. I'll read a question to you along with some possible answers. I'd like you to choose the answer you agree with. Then I might also ask you for more explanation or examples.**

2. **a. When you contacted the Navigator, did s/he respond within one business day?**

All of the time Most of the time Sometimes Never *Refused*

b. Was that response quick enough to meet your needs?

All of the time Most of the time Sometimes Never *Refused*

3. **Was the Navigator able to answer your questions, or find someone who could?**

All of the time Most of the time Sometimes Never *Refused*

Can you share a specific example? What about written information?

4. **a. Did the Navigator listen to you and respect your values and choices?**

   All of the time   Most of the time   Sometimes   Never   *Refused*

   b. Did the other doctors and nurses you visited listen to you and respect your values and choices?

   All of the time   Most of the time   Sometimes   Never   *Refused*

   Can you share a specific example?

5. **Did the Navigator include your family and friends as much as you wanted them to be included?**

   All of the time   Most of the time   Sometimes   Never   *Refused*

   Can you share an example to help us understand? What else do you want to tell us about this?

6. **Most people feel worried or stressed during their cancer journeys. In your journey, would you guess that you felt better, worse, or about the same as you would have without the Navigator?**

   Better   Worse   About the same   *Refused*

   Can you explain?

7. ASK ONLY IF PATIENT IS NO LONGER ACTIVELY BEING NAVIGATED: **When you finished working with the Navigator, did you feel like you knew what to do to meet your health needs in the future?**

   Yes, definitely   Maybe/it depends   No   *Refused*

   Can you explain?

8. **What were the most important issue or issues for you that the Navigator was involved with?**
   [*If having difficulty, suggest examples: Choosing a provider, talking about treatment options, finding transportation*]

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9. Overall, would you rate the Navigator Program as:

Great Good Acceptable **or** Terrible? *Refused*

Do you have any other comments about the quality of the Navigator Program?

10. If someone you cared about got sick, would you want them to meet with the Navigator?

Yes, definitely Maybe/it depends No *Refused*

Why/why not?

11. This is the end of my questions for you today. Is there anything else I should know about your journey, the Navigator Program, or cancer care in your community?

Earlier I mentioned that I can send results to you when they are ready. Are you interested in receiving results?

What address should I send them to?

Thank you very much for your time.

Appendix M: Email invitation for provider satisfaction survey

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Sent on behalf of the Northwest Tribal Cancer Navigator Program:

The Northwest Tribal Cancer Navigator Program asks for five minutes of your time to answer a brief set of questions as part of our research.

We hope to answer whether a “navigator” – a nurse or lay health worker coordinating care – can **improve cancer outcomes for patients from tribal clinics**. Our navigators have been working with patients who are seen at [fill in blank] since 2003.

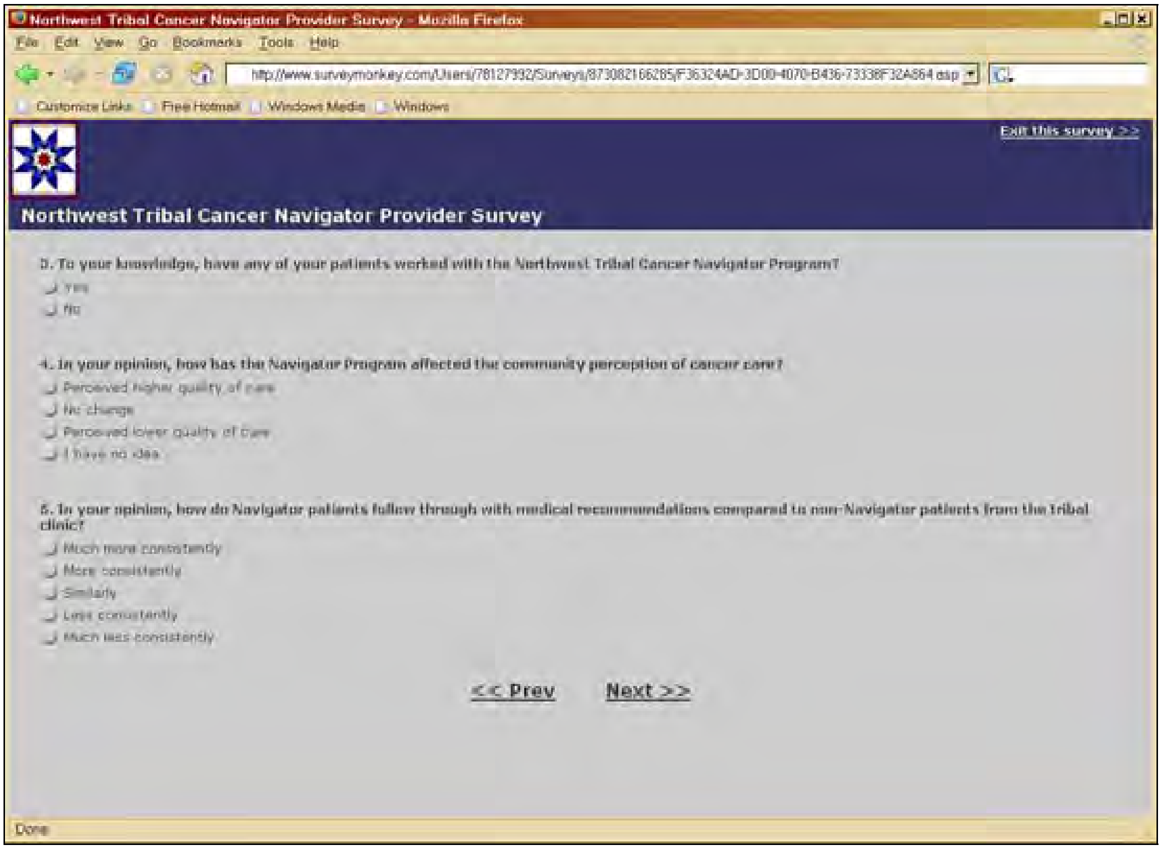
The questions are online and anonymous and should take less than five minutes to complete. Click here to be taken to the survey:
http://www.surveymonkey.com/s.asp?u=873082166285

Thank you!

If you are **not** familiar with the Navigator Program, please let us know by answering the **first two questions**.

If you have questions about the survey or the Navigator Program, contact Katrina Ramsey: kramsey@npaihb.org or 1-877-664-0603. Concerns or ethical complaints can be addressed to the chair of the regional Indian Health Service’s Institutional Review Board (IRB), Rena Gill, at 503-326-2014 or rena.gill@ihs.gov. This research is supported by the National Cancer Institute and the Indian Health Service.

Appendix N: Online provider satisfaction survey



Northwest Tribal Cancer Navigator Provider Survey

3. To your knowledge, have any of your patients worked with the Northwest Tribal Cancer Navigator Program?
○ Yes
○ No

4. In your opinion, how has the Navigator Program affected the community perception of cancer care?
○ Perceived higher quality of care
○ No change
○ Perceived lower quality of care
○ I have no idea

5. In your opinion, how do Navigator patients follow through with medical recommendations compared to non-Navigator patients from the tribal clinic?
○ Much more consistently
○ More consistently
○ Similarly
○ Less consistently
○ Much less consistently

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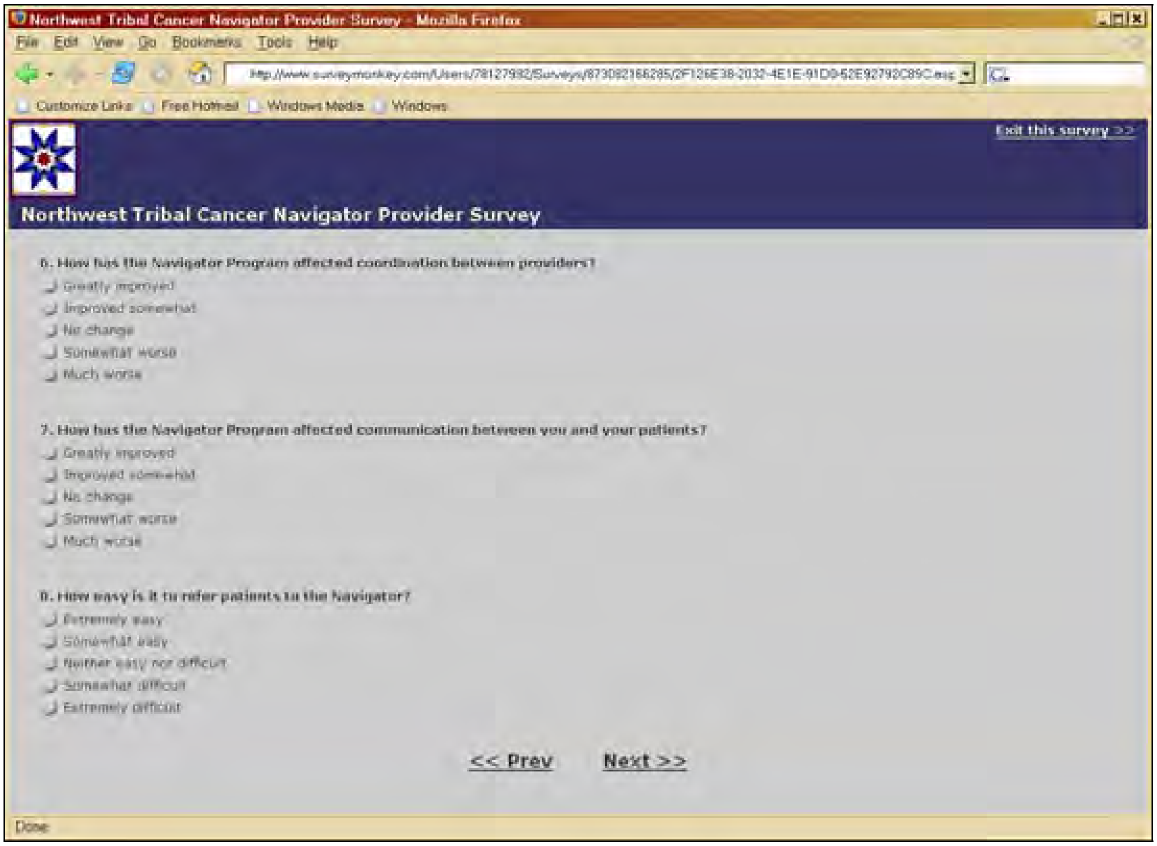

Northwest Tribal Cancer Navigator Provider Survey

6. How has the Navigator Program affected coordination between providers?
○ Greatly improved
○ Improved somewhat
○ No change
○ Somewhat worse
○ Much worse

7. How has the Navigator Program affected communication between you and your patients?
○ Greatly improved
○ Improved somewhat
○ No change
○ Somewhat worse
○ Much worse

8. How easy is it to refer patients to the Navigator?
○ Extremely easy
○ Somewhat easy
○ Neither easy nor difficult
○ Somewhat difficult
○ Extremely difficult

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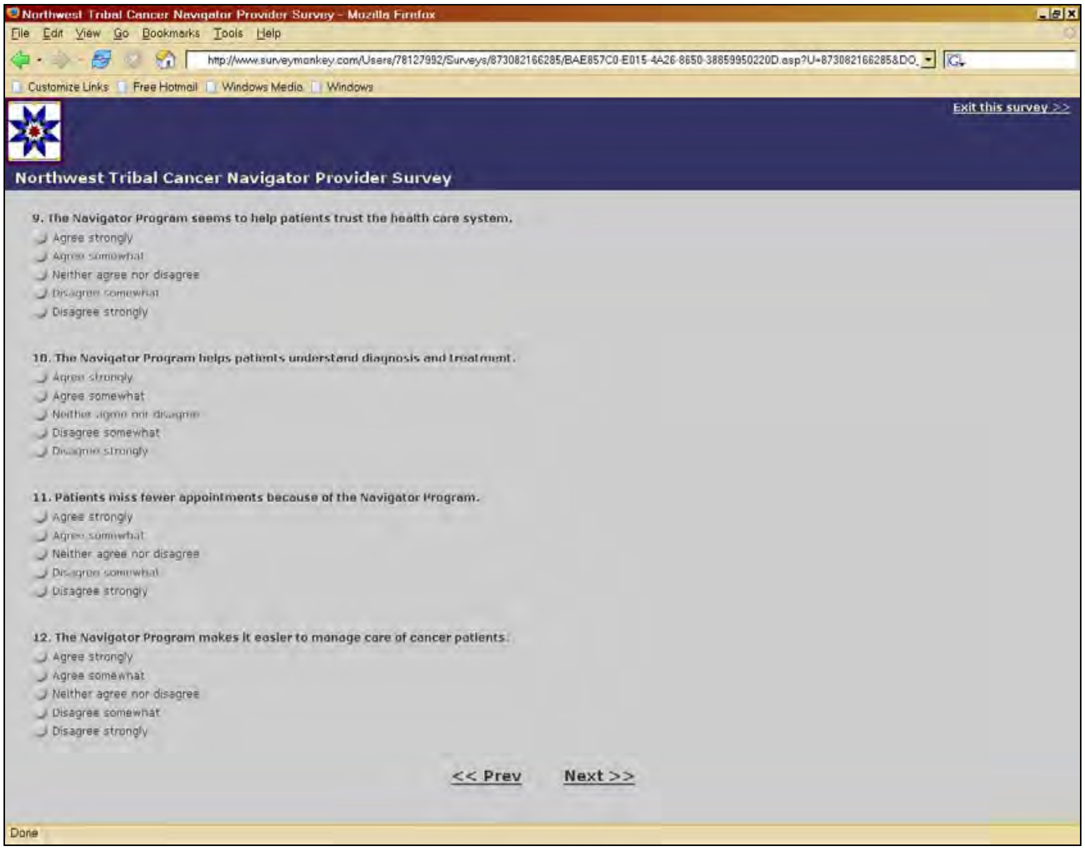

Northwest Tribal Cancer Navigator Provider Survey

9. The Navigator Program seems to help patients trust the health care system.
○ Agree strongly
○ Agree somewhat
○ Neither agree nor disagree
○ Disagree somewhat
○ Disagree strongly

10. The Navigator Program helps patients understand diagnosis and treatment.
○ Agree strongly
○ Agree somewhat
○ Neither agree nor disagree
○ Disagree somewhat
○ Disagree strongly

11. Patients miss fewer appointments because of the Navigator Program.
○ Agree strongly
○ Agree somewhat
○ Neither agree nor disagree
○ Disagree somewhat
○ Disagree strongly

12. The Navigator Program makes it easier to manage care of cancer patients.
○ Agree strongly
○ Agree somewhat
○ Neither agree nor disagree
○ Disagree somewhat
○ Disagree strongly

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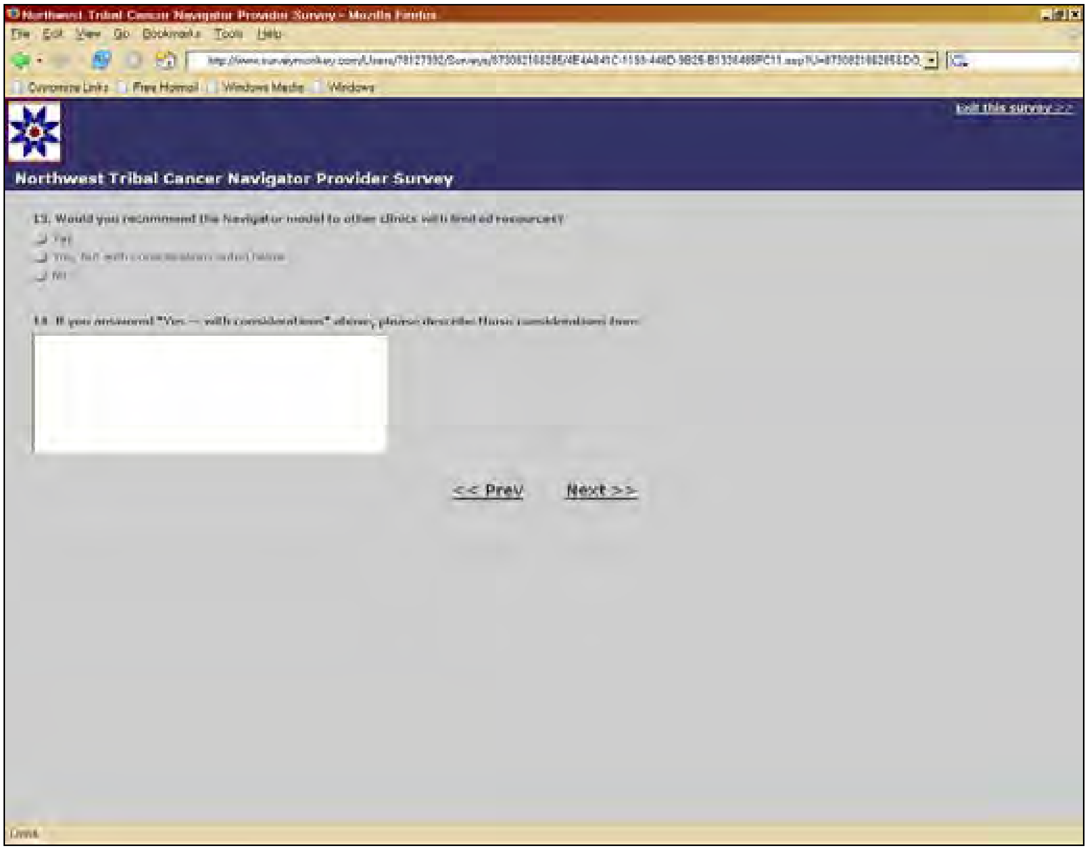

Northwest Tribal Cancer Navigator Provider Survey

13. Would you recommend the Navigator model to other clinics with limited resources?
○ Yes
○ Yes, but with considerations noted below
○ No

14. If you answered "Yes -- with considerations" above, please describe those considerations here:

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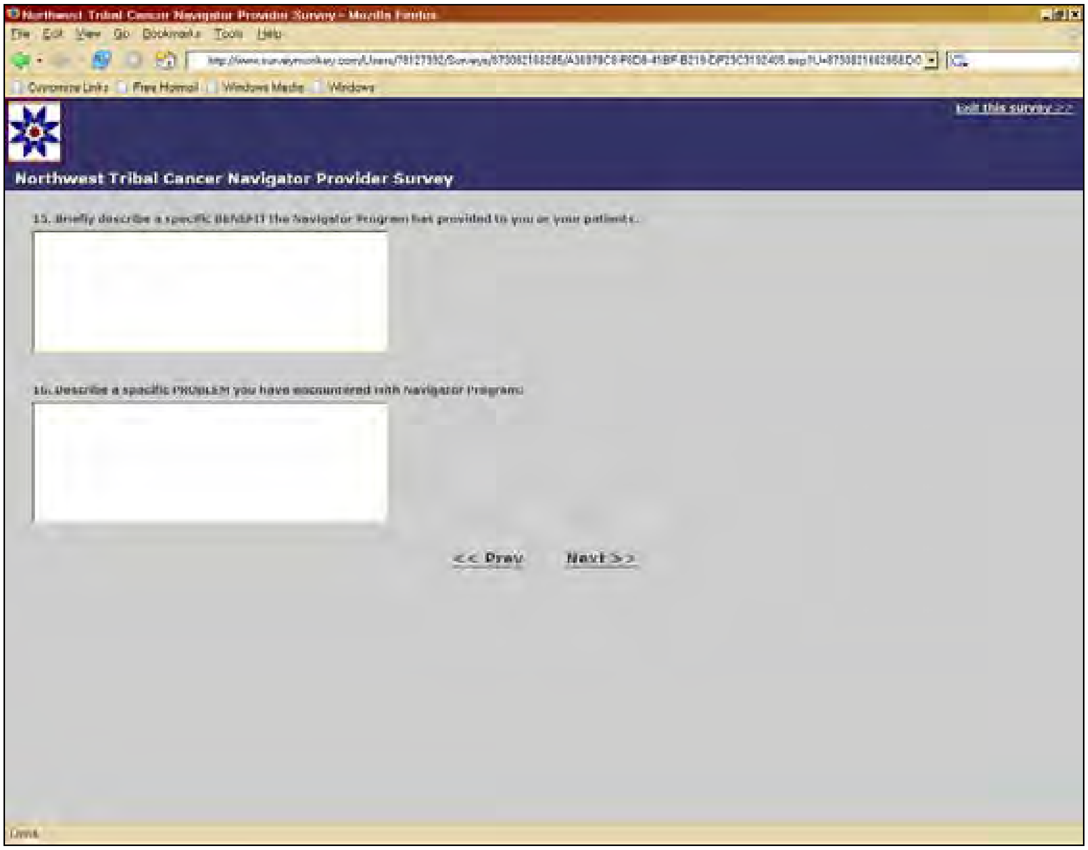
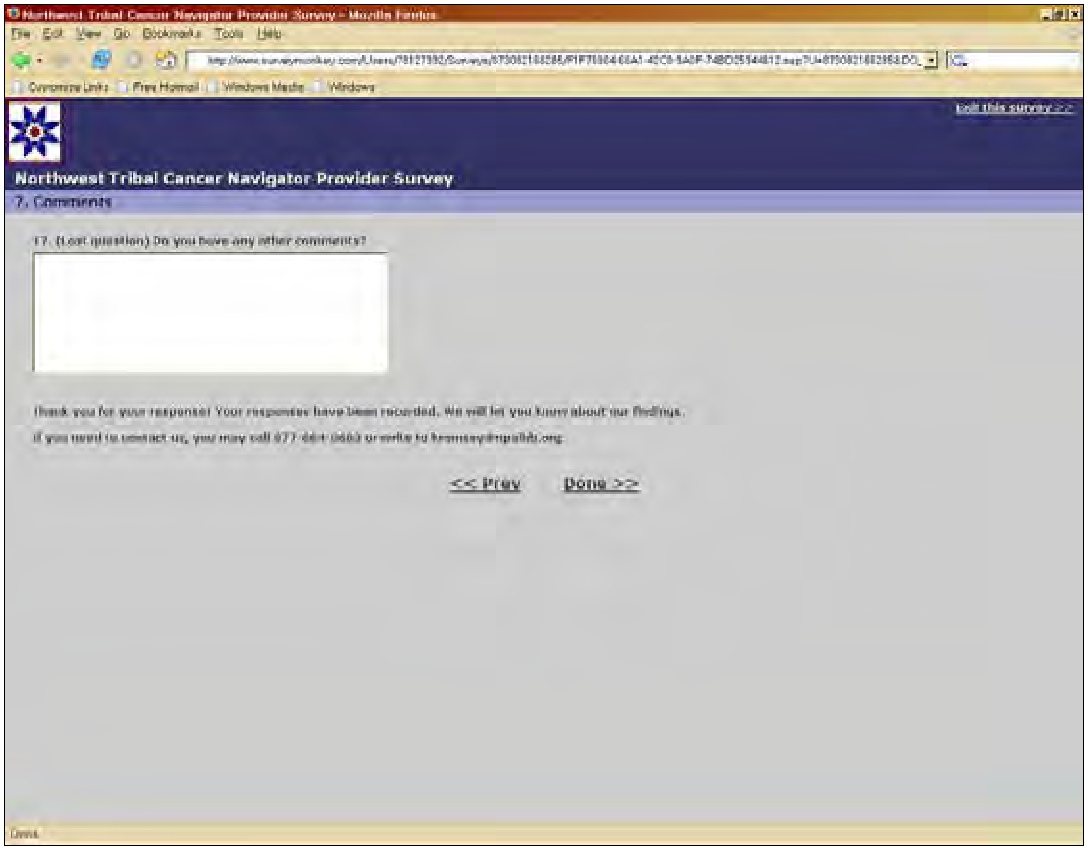


15. Briefly describe a specific BENEFIT the Navigator Program has provided to you or your patients.

16. Describe a specific PROBLEM you have encountered with Navigator Program:



7. Comments

17. (Last question) Do you have any other comments?

Thank you for your response! Your responses have been recorded. We will let you know about our findings.

If you need to contact us, you may call 877-664-0663 or write to kramsey@npaihb.org

Appendix O: Navigators' "case stories"

Introduction to the appendix

The "case stories" below were authored by Navigators and originally reported in the Navigator Pilot Program quarterly reports. In the case stories, the Navigators describe encounters with patients to enhance readers' understanding of what the job of Navigator entails. The selection in this appendix is representative rather than comprehensive.

To preserve the privacy of both patients and Navigators, all narratives have been edited to remove as many potentially identifying details (such as age, dates of service, type of cancer, or location) as possible. "Tribal clinic" is used interchangeably for a tribal clinic or for an IHS clinic. The case stories are presented in random order.

The Navigator received a call from a patient who said that, according to the pharmacy, the medical oncologist would not order a refill for Arimidex. The Navigator called the medical oncologist's office and spoke to the nurse, who agreed to have the physician call the pharmacy with the order for a refill.

The nurse manager for contract health services informed the Navigator that a clinic patient was in the hospital recovering from cancer-related surgery. The Navigator visited the patient in the hospital. The patient reported that surgery went well and the plan was to go home in a few days. The Navigator gave the patient some printed materials with general information about cancer as well as materials specific to the Navigator Program. When asked how the treatment decision was made, the patient said that he discussed his options with his physician and "surgery seemed the best option." The patient had not seen a radiation oncologist.

Assisted with medications renewals and refills. One patient needed a medication that could only be obtained in Yakima. The Navigator delivers the new prescription to the pharmacy each time, since narcotics can not have refills and the pharmacy can not take a faxed prescription.

Ordered Boost through the ACS Medically Indigent Grant Program for a patient with end-stage cancer.

A patient and her family presented at the clinic requesting a second opinion. After a breast biopsy, the general surgeon told the patient that she had breast cancer, needed a mastectomy, and scheduled the surgery. The Navigator scheduled an appointment for the patient with another general surgeon. The Navigator attended the surgery consult. The surgeon stated that the patient had inflammatory breast cancer, and referred her to a medical oncologist. The Navigator attended the appointment with the medical oncologist, who ordered a PET scan, bone scan, and chest port placement. The Navigator attended the outpatient surgery and supported the patient and her family, who were anxious about the procedure.

The Navigator called a cancer patient to see if she was having any problems with diarrhea and if she was eating better. The patient reported that she had not had any more episodes of diarrhea, but that she was still not eating much. The Navigator inquired about the patient's medications, but the patient could not remember their names. The patient agreed to have the

Navigator come to her home to review her medications. The Navigator found that the patient was lacking a medication that had been prescribed. The Navigator called the patient's pharmacy, which reported that the order had not been called in. The Navigator then called the medical oncologist, explained the situation, and physician called the prescription in to the pharmacy. The Navigator followed up with the patient the following week.

The Navigator completed a hospital visit for a patient with terminal cancer who was admitted for an arm fracture. The patient had refused Navigator services in the past, but after the discussion at chart rounds that morning, the Navigator decided to visit the patient. The patient remembered the Navigator and seemed happy to see her. The patient was talkative, reported doing better, and said that the medical oncologist was going to restart chemotherapy in the hospital. The Navigator agreed to visit the patient again.

The Navigator met a patient at the hospital for a scheduled surgery and stayed with the patient until she was taken into the operating room suite. The next day, the Navigator visited the patient again at the hospital and found her out of bed and talking with hospital staff. The patient reported that her pain was well controlled and that she didn't have nausea or vomiting. The Navigator stayed with the patient until her family arrived to take her home.

The Navigator reported a case where a patient was confused by conflicting advice from different providers. After surgery, the patient was told by the surgeon that he "got all the cancer and (the patient) didn't need any more treatment." The Navigator consulted with the radiology oncologist, who disagreed and said the patient would benefit from adjuvant treatment. The Navigator discussed case with the patient's primary care physician, who agreed to refer the patient to the medical oncologist and the radiology oncologist. The Navigator explained the situation to the patient, who agreed to go to consults. The Navigator then scheduled the appointments for the patient. The patient's case was discussed at a Tumor Board at Yakima Memorial Hospital where the Navigator was in attendance.

For the last chemotherapy appointment (cycle six of six) of a patient, the Navigator brought a cake and card to mark the "graduation."

The Navigator attended the radiation oncologist appointment with a patient with recurring cancer. The primary care physician reported that the patient had recurring dizziness and referred the patient to the radiation oncologist. The patient had a history of chemotherapy, external radiation therapy, and excisions. The physician explained to patient that she is not a candidate for surgery, chemotherapy, or radiation, since all three have failed in the past. The patient was told that this was terminal, but the physician felt she was not a candidate for hospice at this time and offered to treat her headaches with medication. The patient said this news was unexpected. The patient agreed to try the medication. The physician requested that patient complete a living will and gave the Navigator the documents. The Navigator consulted with the primary care physician regarding the patient's living will; he felt she was not competent to understand and complete the documents herself.

When the Navigator received a CT report that indicated possible metastatic cancer, she contacted the urologist, who requested an X-ray to verify findings. The Navigator contacted the patient to arrange the referral.

A breast cancer patient was referred by a nurse practitioner at the clinic. When the Navigator eventually reached the patient by phone, the patient said that she had received the Navigator's previous calls but felt she did not need assistance because of her strong network of family and friends. The Navigator discussed the patient's treatment to date with her and brought up breast reconstruction and prosthesis options. The patient was interested in breast reconstruction, so the Navigator assisted her with referral paperwork to see a surgeon.

The Navigator traveled to [a cancer center] where a cancer patient had a follow-up appointment with the medical oncologist. The patient was too weak to stand, and could not be weighed. Previously, the patient had shown significant weight loss. The patient had severe diarrhea, and the Navigator had brought a new anti-diarrhea prescription which the Navigator administered per physician's orders. The oncologist reported that the previous month's CT showed no signs of cancer, but the patient's continued weight loss and weakness were concerning. The physician encouraged the patient to eat more and offered to admit the patient to the hospital to begin physical therapy, or send the patient home and call the following week to schedule outpatient physical therapy. The patient and family decided to go home and call the following week for outpatient physical therapy.

A patient in the hospital receiving chemotherapy reported being short of breath and having chills. The Navigator visited and found the patient was visibly using accessory muscles to breathe, but oxygen saturation measures were normal on room air. Several days later the Navigator returned to find the patient's condition deteriorating. The hospital nurse explained that the patient's counts were low, so the nurse was administering platelets and antibiotics. The patient was still short of breath. The following day, the Navigator was notified that the patient had been transferred to the intensive care unit. The Navigator went to the hospital in the morning and contacted the primary care provider to update him on the patient's status. The Navigator stayed with the patient, who eventually died. The Navigator left the hospital after prayer services with the family and later attended the dressing ceremony, longhouse services, and burial.

The Navigator called a patient to check in after surgery. The patient reported significant pain. The patient had not picked up pain medication because the pharmacy was closed when the patient was discharged. The Navigator picked up the prescription papers at the patient's home, had the tribal pharmacy fill the prescription, and delivered the medications to the patient.

The Navigator attended a follow-up surgery appointment and brought documentation of previously completed referrals as well as paperwork for a follow-up appointment with a plastic surgeon. The patient did not show up. The Navigator called the patient's home but no one answered. The Navigator planned to reschedule the appointment after talking with the patient.

Delivered urgently-needed supplies to patients' homes when other services were unavailable to make deliveries (included a Kangaroo® Pump for nasojejunal tube feeding; a wheeled walker; Isosource® feeding solution when a patient was discharged without supplies and the home health agency failed to make the delivery)

At the request of a patient, attended a repeat bone marrow biopsy.

The Navigator attended a medical oncology appointment with a breast cancer patient. The patient wanted a second opinion on treatment options. The physician reviewed the chart, examined the patient, and reaffirmed that the best treatment option for the patient was a mastectomy followed by radiation. After the appointment, the patient told the Navigator that she wanted a second opinion because she wanted to have both breasts removed and she didn't like her radiation oncologist. The Navigator offered to speak to the surgeon about having both breasts removed, and discussed switching radiation oncologists. Four days later, the Navigator attended another medical oncology appointment with the patient. The patient had requested to see pictures of patients with mastectomies, so the Navigator brought a book for her to look at. After looking at the pictures, the patient said she still wanted a double mastectomy. The Navigator agreed to call the surgeon to schedule surgery. The patient reported to the medical oncologist that she was experiencing severe muscle aches. The physician said that it was likely a side effect of hormonal treatment and recommended trying a different hormonal treatment. The patient agreed to try the new therapy. The following week, the Navigator attended the patient's medical oncologist appointment and reported to the physician that surgery had been scheduled in one week. The patient reported that her muscle pain had resolved. The patient received her infusion and injection. The next week, the Navigator attended the patient's pre-operative appointment. The patient expressed that she was nervous about the surgery and reaffirmed that she wanted to go through with surgery and still wanted a double mastectomy. The surgeon explained the procedure, the need for surgical drains, and the potential complications from surgery. Following the consult, the Navigator and patient went to the hospital to complete the pre-operative planning. While at the hospital, the Navigator requested that lab work be drawn that afternoon at [the cancer center] when the patient received her infusion; the hospital agreed with the plan. A few days later, the patient was admitted to the hospital for the double mastectomy. The Navigator escorted the patient to the pre-operative holding area. The patient's heart rate was elevated, so the Navigator requested a sedative for the patient. The Navigator waited with the patient's family during the surgery. On the following day, the Navigator visited the patient in the hospital and found her in high spirits and tolerating the pain medication well. The Navigator discussed possible complications of surgery and educated the patient on signs and symptoms that should be reported immediately. The following day, the Navigator returned to the hospital to give the patient a survivor's notebook. The patient was anxious about removal of a drain so the Navigator stayed through the procedure. The Navigator informed the patient that she should be seen in six weeks by the radiation oncologist and the radiation therapy would begin in seven weeks. The patient requested that the Navigator schedule the appointment and call her with the date and time.

The Navigator made a home visit to a patient with suspected metastatic cancer who was unable to be reached by phone. The patient's primary care physician had referred the patient to the Navigator because of failure to keep appointments with the medical oncologist for additional scans. The patient was not at home, but the Navigator spoke to the patient's son, left her business card, and asked that the patient call her. The son gave the Navigator the patient's cell phone number, but the patient did not return the Navigator's calls.

A patient requested a nutritional supplement (Ensure® or Boost®). She had experienced nausea and vomiting and loss of appetite with subsequent weight loss due to chemotherapy but could not afford to pay for the nutritional supplement. Neither Medicare nor Medicaid covers those kinds of supplements unless it is the sole source of nutrition. The Navigator contacted the American Cancer Society and was faxed an application, which she completed and submitted. The patient received the complimentary Boost about two weeks later.

The Navigator visited a nursing home to see a patient with recurrent cancer. The patient was not a candidate for surgery, chemotherapy or radiation since the treatments had failed previously. The patient had continued to fall at home and had stopped taking her medication for headaches. The patient admitted that she could not stay at her home, and her husband said he could not take care of her. It was agreed that she should enter a nursing home on hospice care. The patient reported a headache, but otherwise was in good physical health and condition.

The Navigator attended the medical oncology appointment of a Navigator cancer patient who had missed the previous two appointments. The Navigator scheduled this appointment with the patient's agreement, but the patient failed to show up for the appointment. The Navigator then contacted the patient to reschedule the appointment for another time.

A Navigator patient was evicted by her landlord and needed low-income housing. The patient moved in with her daughter, then was hospitalized due to chemotherapy toxicity (peripheral neuropathy). The patient was discharged and went to live with her sister. The patient was contacted for an apartment that is HUD, low-income housing.

A cancer patient stopped by the Navigator's office to report the inability to get a prescription from the pharmacy. [The cancer center] reported that the prescription was called into the tribal clinic. The clinic does not stock this prescription and the patient had already missed several days of the drug. The Navigator called [the cancer center] and asked that they call the prescription into the patient's pharmacy, and patient would pick up the written prescription the same afternoon.

The Navigator attended the medical oncology appointment for a cancer patient. The patient completed the last cycle of treatment and had minimal side effects. The oncologist would like to see the patient yearly for follow-up.

The Navigator met a cancer patient at [a cancer center] for a biopsy. The Navigator reminded the physician of their agreement to medicate the patient before the procedure, so both intravenous and intramuscular medications were given. The physician successfully obtained the samples, and the patient tolerated procedure. The Navigator educated the patient on post-operative care of the biopsy site. The Navigator requested that the patient's pain medications be called in to the local pharmacy, and advised the patient to pick up the prescription before going home. The patient will return in one week for the biopsy results to be admitted for another cycle of induction chemotherapy.

A patient was lost to follow-up after a second surgery. The Navigator located the patient, who was taking care of a relative who had a medical emergency in a larger city in the

Northwest. The patient did not have health insurance and had not been able to apply to the Washington Breast and Cervical Health Program (BCHP) before her surgeries. The Navigator completed referral so that the patient's upcoming radiation consult would be covered through IHS and will pursue BCHP enrollment.

The Navigator attended the follow-up reconstructive surgery appointment for a cancer patient. The patient questioned part of an in-office procedure being done at the appointment, and the Navigator reminded the patient of the physician's previous explanation that the need for the procedure was normal and expected.

The Navigator attended the follow-up endocrinology appointment for a patient with a tumor. The Navigator turned in the completed referral to the office staff. She gave the patient a Lance Armstrong Foundation Survivor's Binder. The Navigator explained to the nurse practitioner (NP) that the patient had had a 70 pound weight gain and amenorrhea since surgery. The NP ordered new lab work to check the patient's hormone levels and asked to see the patient when the results were ready.

On a Saturday, the Navigator visited a cancer patient in the hospital. The patient reported receiving several units of blood and was feeling stronger afterwards. The floor nurse reported that if the patient's blood count stayed up, the physician would discharge the patient on Monday. The Navigator returned for a visit three days later when the patient was being re-scoped. The nurse reported that the patient's blood counts had fallen, so they were looking for the source of the blood loss. The patient's cultures also came back positive for Methicilline Resistant Staphylococcus Aureus (MRSA) and the patient was being treated with Vancomycin. The Navigator called Contract Health Services and gave the person there a report because the Navigator was going on leave.

Helped a young pregnant patient with HGSIL pap results get an outside referral for a colposcopy.

The Navigator attended a follow-up surgery appointment. The physician was pleased with the patient's progress. The Navigator answered the patient's questions.

The Navigator arranged for IV fluids for dehydration, medications for pain and nausea, as well as assistive devices such as orthotic shoes, canes, and shower chairs. She aided Navigator patients in arranging rehabilitation therapy with physical, speech, and occupational therapists.

In June the Navigator received a call from a primary care provider about a new patient with an abnormal abdominal ultrasound. The primary care provider had ordered an urgent computed tomography (CT) scan of the chest, abdomen, and pelvis for that day. The Navigator met the patient and family at the appointment (outside the [tribe's] clinic) and answered questions and explained the procedure. The family reported that the primary care provider had also wanted a liver biopsy, which had not been ordered. The Navigator returned to the clinic to consult with the primary care provider about the biopsy, then arranged that appointment and completed and submitted referral paperwork.

The Navigator attended a follow-up appointment for a cancer patient with the medical oncologist. The patient had failed to show up for the appointment twice, and the office nurse called the Navigator to say the patient could not reschedule the appointment without the Navigator. The Navigator spoke with the patient and rescheduled the appointment. The Navigator called the patient the morning of the appointment to remind the patient of the appointment and they met at the cancer center. The appointment went well.

At a follow-up medical oncology appointment, a patient reported significant hand-foot syndrome with the current cycle of chemotherapy. The oncologist recommended delaying the next and final chemotherapy cycle for an additional 10 days to allow the hand-foot syndrome to resolve. In addition, the results of that day's labs showed that a change needed to be made in the patient's medication. The oncologist advised the specific change and had the patient follow up with the primary care provider in one week. The Navigator scheduled the primary care appointment and called the patient with the date and time.

Following a radiation oncology consult, a Navigator helped a patient with referrals for the physician-requested immediate baseline mammogram and colonoscopy in six months.

The Navigator attended a follow-up appointment for a cancer patient. The physician explained that her bone marrow and blood work showed only slight improvement with current treatment. The physician recommended switching to a new therapy. The patient agreed to the plan. The patient complained of edema and the physician called in a diuretic to the patient's pharmacy, and requested that the Navigator re-evaluate the patient's edema in two weeks. After one week, the Navigator spoke with the patient about her edema. The patient reported that the edema had greatly improved. The patient had run out of her diuretic, so the Navigator agreed to call the medical oncologist's office to re-order the pills.

The Navigator attended [the local cancer center's] Combined Modality/Chart Rounds. A physician reported that a patient was no longer a candidate for external radiation therapy because of advanced disease and the patient and family did not seem to understand. The social worker reported that the patient and family were aware of the circumstances. The Navigator explained that the patient had refused Navigator services, but recommended that the physician discuss the situation with the patient's primary care provider. Afterwards, the Navigator visited a Navigator patient who was receiving high-dose external radiation therapy via implants.

The Navigator received a call from a patient with a history of cancer. The patient reported having back pain and was concerned about a possible recurrence. The Navigator encouraged the patient to come to the clinic for an exam and x-rays. She spoke with the patient's primary care provider who said that the patient had a muscle strain. The Navigator followed up with the patient who said that the analgesic and exercises had helped with the pain.

Provided assistance to patient in getting Social Security coverage reinstated.

When a patient reported shortness of breath from chemotherapy, the Navigator called the cancer center and reported the problem to the patient's nurse there. The physician was contacted and was not concerned, but requested that the patient call back if the shortness of breath worsened. The following day, the Navigator contacted the patient, who said that the shortness of breath had resolved.

The Navigator met a patient in the office to complete the Breast and Cervical Health Program (BCHP) paperwork and schedule an appointment with the surgeon. The patient has a history of cancer with no treatment, and is currently having pain and discomfort. The Navigator spoke with the county BCHP representative who agreed to cover the patient's visit to the surgeon.

After obtaining a pathology report, the Navigator asked the patient's primary care provider to call the patient with the results. By 4:00 PM the provider had not contacted the patient, but the patient was calling for the results. The Navigator returned the patient's call and told the patient that there was not cancer. The patient was relieved and thanked the Navigator for the news.

The Navigator met with a cancer patient in the office. The patient was on hormonal therapy. The patient had no insurance, was not Contract Health Services eligible, and could not afford to pay for the medication out-of-pocket. The Navigator helped the patient complete a Patient Assistance Program application, made copies of the patient's financial documents, had the physician write a prescription, and mailed the application packet. The Navigator asked the patient to call her when the drug manufacturer responded.

The Navigator attended the consult of a new patient with an extreme abnormal result to a screening test. Further testing had also returned abnormal results and the physician recommended a biopsy. The Navigator completed the referral for the biopsy and attended the biopsy to assess for medication needs. No follow-up appointment was scheduled, so the Navigator contacted the specialist's office and scheduled a follow-up appointment to review the pathology results. The bilateral biopsy was positive for cancer. The Navigator arranged the referral for a bone scan requested by the physician to stage the cancer.

The Navigators attended [the local cancer center's] Cancer Awareness Day. They supplied cancer literature for distribution and set up a Navigator Program display. They helped with registration. There, the Navigators spoke with a young lady who had an abnormal clinical breast exam and had been referred for a mammogram. Contract Health Services (CHS) refused to authorize the referral because the woman had no proof of residing on the reservation. The Navigator gave the woman her business card and asked her to come to the office with all her documentation and the Navigator would advocate with CHS on the woman's behalf.

The Navigator received a message from the friends of a patient in a nursing home that the patient was not doing well. The patient's primary care provider confirmed that the patient's tumor had advanced. The Navigator visited the patient in the nursing home and found the patient wheelchair bound and needing assistance to eat. Speech was unintelligible.

The Navigator received a phone call from a cancer patient requesting a refill of pain medication, stating that the current pain medication was not alleviating the pain and it was making her nauseated and dizzy. The Navigator expressed concern for possible liver damage from the large dose of medication. The Navigator spoke with the patient's provider who agreed to write a prescription for enough pills to cover the weekend, if the patient would come into the clinic on Monday to be reassessed for her increased pain and numbness in her leg. The patient agreed with plan. The Navigator delivered the prescription to the patient's local pharmacy for filling.

Helped newly diagnosed patient define a pain medication regimen and bowel program, helping patient achieve adequate pain relief and bowel function.

At a patient's request, the Navigator attended a radiation oncology appointment. The patient was experiencing edema in the feet along with decreased vision and hearing. According to the patient, the Dilantin was not being monitored and reached toxic levels. The radiation oncologist said that the radiation was going well and the last treatment was within days, so the Navigator assisted in setting up an appointment with the patient's primary care provider to discuss the edema, vision, and hearing problems.

At a home visit, the Navigator assessed a patient's comprehension of and willingness to continue in-home physical and occupational therapy, which the Navigator had previously arranged. The patient chose to discontinue the therapy, expressing understanding that improvement is unlikely without those services. At another home visit to the same patient, the Navigator delivered antibiotics and educated the patient and the patient's family about the need and use of the patient's medications.

The Navigator provided medication management (pill count) at the request of the primary care provider after a patient accidentally overdosed on narcotic pain medication. The Navigator completed three home visits in April to monitor this patient's medication usage and arranged for a Tribal Home Health RN to continue monitoring while the Navigator was away at training (Navigator Academy).

The Navigator attended a medical oncology appointment for a patient with metastatic cancer who had been hospitalized for peripheral neuropathy and had required rehabilitation. The patient's medical oncologist had left the practice and another oncologist took over. The Navigator helped to make the transition as the physician reviewed the patient's history, prescriptions, and tests. The patient is on follow-up every six weeks.

The Navigator attended the radiation oncology consultation with a cancer patient. The Navigator had arranged a ride for the patient with the Community Health Representative (CHR). The patient had been diagnosed 2 years previously, but never followed through with treatment. The patient's recent biopsy was negative. The physician reviewed the history and discussed treatment options. The patient ruled out certain treatment options because of the resulting lifestyle changes. The physician recommended 6-8 weeks of radiation therapy. The Navigator discussed the patient's transportation problems with a social worker who agreed to work on getting rides with People for People.

The Navigator attended a radiation oncology consult. The patient agreed to radiation treatment, which was later delayed until the completion of physical therapy. The Navigator also attended the patient's first appointment where an error was discovered in the patient's

Medicaid coupon. The Navigator contacted the Washington Breast and Cervical Health Program (BCHP) to resolve the error.

The Navigator provided support to a patient making difficult choices about treatment. She attended the radiation oncology appointment with the patient, where the oncologist explained that the patient had an "amazing response to chemotherapy," seen in about 15-25% of patients. The oncologist also explained that the patient still needed to have a mastectomy and radiation therapy. The patient cried because she had hoped she could avoid surgery. The Navigator encouraged her to go see the surgeon and listen to what he had to say, and then make a decision. She reminded the patient that the choice was hers, she could choose not to follow medical advice and she didn't have to make a decision that day. At the surgery consult, the surgeon also recommended a mastectomy with complete axillary node dissection for the best chance of control. The patient again became tearful and the Navigator raised the possibility of reconstruction. The surgeon agreed that the patient could see the plastic surgeon for consideration of reconstruction if she is interested. The doctor was honest but supportive of patient. The Navigator offered to have the patient speak to other women who have had mastectomies to help her decide and reaffirmed that this was her decision, and she could decide not to have surgery. The Navigator explained that the patient needed to know the risks and benefits of both options to make an informed decision, that she would support her decision no matter what it was, and that she would give her time to think and talk with her family.

The Navigator met a patient at the hospital for admission for chemotherapy. She gave admission orders to the unit staff and assisted the staff to get the patient settled and admitted. The patient asked the Navigator to pick up her mail and a check. Later, the Navigator went to the post office and picked up the patient's mail and went to the school to pick up the check. The Navigator delivered those items to the patient at the hospital.

The Navigator attended a follow-up medical oncology appointment. The physician was pleased with the patient's post-surgical healing. The patient reported no arthralagias or lymph edema, but the physician referred the patient to the lymph edema clinic as a prophylactic measure. The Navigator stayed with the patient during the treatment. The Navigator scheduled the patient's appointment with the lymph edema clinic to coincide with the radiology oncologist appointment.

Made three home visits to deliver flu shots with a home health nurse.

Attended a radiation oncology appointment with a patient who was new to the Navigator Program. The patient had previously canceled and rescheduled the appointment twice because of high anxiety about diagnosis and treatment.

Contract Health Services (CHS) asked the Navigator to have a patient come in to sign up for Medicaid. The patient had applied twice before and been denied. The Navigator went to the patient's home but initially went to the wrong house, which had three large guard dogs. After being escorted off the property by the homeowner, the Navigator located the correct house and visited with the patient, who was frustrated with the request but agreed to come to the CHS office.

The Navigator met a cancer patient at the hospital for her scheduled surgery and stayed with the patient up until she was taken into the operating room. The patient was very anxious about the surgery because with her last surgery she developed an air embolus and was admitted to Intensive Care. The Navigator visited the patient after being moved to her room, and she reported significant axillary pain and being hot. The Navigator adjusted the room temperature, replaced her damp cloth, and repositioned her in the bed.

The local cancer center contacted the Navigator about a patient who was not keeping appointments for radiation therapy, and the transportation organization was not able to transport the patient because of no-shows. The Navigator visited the patient at home and asked about the appointments. The patient agreed to keep the next day's appointment and to call the transportation provider or the Navigator if unable to keep the appointment.

Arranged for repeat pregnancy tests for a patient on Thalidomide as part of her treatment for cancer. The patient needs a pregnancy test each month before she can pick up her medicine. The Navigator arranged for one pregnancy test in conjunction with an oncology appointment in Yakima, then had a physician at the tribal clinic write an order for monthly tests, which will be a more convenient location and overall arrangement for the patient. The pharmacy failed to order the medication in time, so the Navigator helped the patient to get re-tested on the same day.

A primary care provider (PCP) had reported an abnormal clinical breast exam. The Navigator followed up and found that the patient's scheduled breast biopsy had been cancelled by the radiologist in favor of an additional course of antibiotics for suspected mastitis. The PCP confirmed that he had prescribed the antibiotics and they had led to some improvement, but the PCP could still feel the lump. A biopsy showed that the patient was positive for ductal carcinoma in situ, which was detectable by ultrasound but not by mammogram. The Navigator attended the patient's surgery consult and helped her to schedule a lumpectomy. Later, the Navigator attended this patient's medical oncology appointment. The physician explained the pathology report from the patient's lumpectomy, which showed positive margins. The patient agreed to return in a month to discuss hormonal therapy and scheduled a follow-up appointment with the surgeon to discuss treatment options. A month later, the Navigator attended the surgical follow-up appointment for this patient, where the patient agreed to a mastectomy. Though on leave, the Navigator visited the patient at hospital to assess her condition and help deal with high levels of post-operative pain. After the Navigator returned the next morning, the patient was discharged to home.

The Navigator received a message from Contract Health Services that a Navigator patient was being taken to the hospital after losing consciousness. The Navigator met the patient in the Emergency Department, where the patient was diagnosed with an infection and a gastrointestinal bleed. The medical oncologist and internist were contacted for consultation.

The Navigator received a call from a patient requesting a pain medication refill. The patient reported taking two pills per day. The Navigator consulted with the primary care provider who agreed to renew the medication. The Navigator delivered the prescription to the patient's pharmacy and called the patient to report that the prescription was ready for pick-up.

Both the Ambulatory Care Nursing staff and scheduling staff referred a patient to the Navigator who claimed to have cancer. When questioned, the patient could not say what kind of cancer and said that there had not been a biopsy. The patient was from another reservation with a health center but was unwilling to return because of a family conflict. The Navigator contacted the patient's home clinic for records, which showed an abnormal diagnostic test for a screenable cancer. A biopsy had been scheduled, but the patient had left the reservation before keeping the appointment. The Navigator visited the patient's home to complete insurance information, then consulted with the local tribe's Contract Health Services (CHS) to enroll the patient in Medicaid and schedule a biopsy in [a nearby city]. Later, the Navigator contacted that provider to confirm that the patient had kept the biopsy appointment, but the patient had not. The Navigator was unable to reach the patient or patient's relatives. She later received a call from the patient's home clinic reporting that the patient had come in for care. The Navigator explained the treatment plan. The patient's home clinic agreed to schedule the biopsy there and concurred with the Navigator's suggestion to have a Community Health Representative (CHR) take the patient to the appointment to guarantee attendance.

A patient requested that the Navigator attend a PET scan appointment, because during the previous PET scan the patient "freaked out." With the Navigator present, the patient successfully completed the scan.

The CT scan for a patient on three-month follow-up showed no recurrence of disease, but the patient had lost 15 pounds, and at the appointment was hypotensive and complaining of edema in the legs and loose bowels. The specialist ordered a dietary consult and will call the patient's primary care provider. The Navigator helped the patient fill prescriptions at the onsite pharmacy and picked up and delivered additional medications from the pharmacy in Toppenish. The Navigator also contacted the tribal dietician to assist the patient.

The Navigator attended the biopsy of a patient who had had a previous excisional biopsy of the same areas. The patient wanted another excisional biopsy, but the surgeon explained that core needle biopsy is more accurate. The patient reluctantly agreed to the biopsy after being offered oral pain and anti-anxiety medication. The patient successfully completed the biopsy, reported the medications helped, and the pathology report was negative.

The Navigator received a cancer screening report on a cancer patient who had had surgery and radiation therapy. The radiologist reported abnormalities at the incision and recommended additional screening. The Navigator met the patient at her medical oncologist appointment where the patient reported that she completed the additional screenings and they were normal.

For a new patient, the Navigator attended the initial radiation oncology consult, submitted a referral for the visit, and checked on the status of the patient's DSHS application (Medicaid). The patient had already filed the application but had not yet received the coupons. The Navigator also discussed pain medication with the primary care provider, who agreed to prescribe another two weeks of medications.

The Navigator went to a patient's house at 0430 to accompany the patient for a bone marrow transplant evaluation at Seattle Cancer Care Alliance in Seattle. The volunteer transportation People for People van arrived earlier than expected, would not wait for the Navigator, and the patient did not take a cell phone to contact the Navigator to arrange a meeting place. Both the patient and the Navigator were upset by this mistake.

The Navigator visited a new cancer patient in the hospital. The midlevel practitioner reported that the patient came in for a visit and the patient met the criteria for routine cancer screening and had insurance coverage, so she referred the patient for a screening test. The screening came back positive for cancer, so the patient had surgery. The Navigator gave the patient information on cancer and treatment options, plus a brochure on the Navigator Program. The patient was interested in the Navigator Program and thankful for the information. The patient had lots of questions and was interested in meeting with a dietician to discuss making dietary changes. The Navigator agreed to refer patient to the tribal clinic dietician who would contact the patient to schedule a consultation.

The Navigator received call requesting information on a certain type cancer. The Navigator had worked with this person and knew that there was a family history of cancer. This person's son had been recently diagnosed.

The Navigator attended a medical oncologist appointment with a patient. The physician reported that the patient was still in remission, but he would like to refer the patient to the Fred Hutchinson Cancer Research Center in Seattle for consideration of a transplant. The physician felt the patient was not a candidate for transplant due to cardiac and kidney failure with chemotherapy, but would like an expert opinion. The Navigator agreed to travel with the patient to Seattle and discussed transportation with the social worker at [the local cancer center].

The Navigator attended the medical oncology appointment of a cancer patient. The patient was scheduled for a biopsy to determine response to drug therapy. The patient received conscious sedation and the samples were successfully obtained. The Navigator remained with the patient through recovery, educated the patient on care of the biopsy site, scheduled a follow-up appointment to review the biopsy results, and assisted the patient to the car.

Helped facilitate patient's appointments to two different oncologists.

The Navigator met a cancer patient at her medical oncology appointment. The patient had requested that the Navigator bring her credit card insurance application to [a cancer center] to have it completed. The Navigator went there and spoke with the social worker, who agreed to fill out the application and have it signed.

The Navigator completed a home visit with a patient with metastatic cancer. The patient had severe peripheral neuropathy, and as a result, had impaired mobility. The patient had been denied a new walker, but the Navigator knew of another Navigator patient who had died and that patient's walker was available. The Navigator delivered the new walker to the patient.

The Navigator attended the surgical consult for a new patient whose physical disabilities required services through Access Washington. Later, the Navigator attended the medical oncology appointment, where the physician offered to treat the patient with oral chemotherapy, as opposed to 24-hour infusion. All agreed this would be more manageable for the patient, given the physical disabilities.

The Navigators attended the radiation appointment of a cancer patient. The Navigators had not met the patient in-person before this appointment, but had previously arranged to have a member of a cancer support group transport the patient to her appointments. The Navigators introduced themselves to the patient and explained the Navigator program and offered services.

Applied for food baskets for Christmas for seven patients.

The Navigator went to the medical oncology appointment with a cancer patient. The physician reported that Seattle Cancer Care Alliance did not think the patient was a candidate for a transplant. They did recommend an additional cycle of chemotherapy to reduce the risk of relapse from 70% to 50%. The patient was visibly upset to hear the recommendation for more chemotherapy but agreed to the treatment plan.

The Navigator completed a home visit for a patient with a recurring cancer. The patient had called and reported that she received an application for re-certification of her Medicaid and didn't know how to complete it. The Navigator reviewed the paperwork and agreed to help the patient complete it. The Navigator asked the patient to collect the financial documents that were necessary to complete the forms, while the Navigator consulted with the social worker at [a cancer center] on how to proceed with the application. The Navigator scheduled a follow-up visit with the patient in one week. After the patient called to report that she had all her financial documents ready, the Navigator visited her in her home, completed the DSHS re-certification application, and had the patient sign it. The Navigator returned the following day with originals and copies of application and documents, then went to the DSHS office and turned in the patient's application.

The Navigator met a patient for a follow-up medical oncology appointment. The patient was tolerating chemotherapy well and had resumed activities. The oncologist wished to refer the patient to a specialty practice in Seattle to determine if surgery was an option and recommended two surgeons; the Navigator scheduled an appointment with the first available. The Navigator advised the patient and the patient's family of transportation assistance options and offered to help with arrangements.

A patient's caregiver called a Navigator to say that the patient had declined rapidly and the hospice nurse felt that the patient would not live through the weekend. The caregiver wanted the Navigator to know because the Navigator had been assisting the patient for a year an a half. The Navigator visited and found the patient bed-bound and unresponsive to voice or touch. The next morning, the caregiver called again to tell the Navigator that the patient had passed early in the morning. The Navigator thanked the caregiver and reported the death to the patient's primary care physician.

The Navigator attended the [local cancer center's] Combined Modality/Chart Rounds.

The Navigator received a call from a patient with metastatic cancer who needed a refill on pain medication. The Navigator reviewed the patient's chart which showed that the patient had been ordered a refill two weeks previously. The Navigator asked the patient if the prescription had been picked up, and it had. The Navigator then consulted with the patient's physician and explained that the patient had gone through the entire prescription. The Navigator was concerned that the patient's pain was increasing and that the patient was at risk for liver toxicity from the large amounts of pain medication. The physician agreed and suggested a trial of a different pain medication to see if this better controlled the patient's pain and did not cause significant or troublesome side effects. The Navigator delivered the prescription to the patient's pharmacy.

A newly diagnosed cancer patient came to the Navigator office. The patient was scheduled for surgery at Virginia Mason in Seattle needed assistance with hotel costs. The patient had already arranged for White Swan Ambulance for transportation to Seattle. The patient had previously taken out a loan to pay for the bus ticket and hotel for the initial surgery consult. The Navigator spoke with the Cancer Support Group and they agreed to reimburse the patient for the loan. The Navigator called People for People regarding a hotel voucher, and the organization agreed to arrange the hotel pending a letter from the hospital stating the patient's schedule. The Navigator contacted Virginia Mason, and they agreed to fax a letter to People for People. The Navigator contacted People for People, who reported receiving the necessary documentation, and agreed to contact the patient with the hotel arrangements.

The Navigator received a call from a patient requesting treatment for contrast allergy. The Navigator checked the patient's chart, which did report iodine allergy. The Navigator contacted the imaging center who confirmed they will order the required medications. The Navigator called the patient back with the reassurance that the medications had been ordered and that the center was equipped to handle allergic reactions.

The Navigator consulted with a cancer patient and his primary care provider about his back pain. The patient had been seen by a chiropractor and was diagnosed with three vertebral factures. The physician ordered a brace to stabilize the patient's spine which would promote healing and alleviate pain. The Navigator visited the patient at home to explain the physician's recommendations to the patient and his spouse, and they agreed to try the back brace. The Navigator called and scheduled an appointment for the patient to get the brace and met the patient for the appointment at the orthotics shop.

The Navigator attended the follow-up appointment for a new cancer patient. The physician reviewed the diagnostic tests and explained to patient that the diagnosis was metastatic cancer. The physician recommended hormonal therapy for cancer, since surgery and other therapies were not an option for this metastatic cancer. The patient agreed with the treatment plan, and was given an injection and an oral prescription. The patient will return to the doctor in one month.

The Navigator attended the hospital pre-operative appointment for a patient. The Navigator turned in a copy of the patient's lab work, which the hospital nurse reviewed.

On one day, a Navigator submitted a mammogram referral to Contract Health Services, delivered CT scan results to the local oncology center for treatment planning, and delivered the patient's application to Tribal Housing with medical letters of support from the patient's physicians at the tribal clinic and the oncology center.

The Navigator attended the medical oncology appointment of a patient who was scheduled to be admitted to the hospital for treatment. The hospital had no available beds so the patient had to return the next day for admission. The patient reported that she still did not have her car fixed which was making getting to appointments difficult. The Navigator went to the car dealership and spoke to the manager. The manager explained that the engine timing was off, causing the car not to start. The heat did not work, which required an expensive part to fix. The manager agreed to adjust the timing the next day so the patient could get her car back.

[A local clinic] called regarding an abnormal screening. The procedure had not been done after all, and the patient needed anti-coagulation medication. The Navigator consulted with the primary care provider, who declined to order Lovenox because of cost, but called the clinic to discuss and ordered Coumadin instead. The Navigator delivered the medications to the patient's home and helped prepare for the biopsy procedure.

The Navigator completed a home visit for a patient needing telephone service who had previously submitted an application for Sprint Lifeline. The patient received a letter from Sprint saying patient could not be enrolled in program because service had not been established. The Navigator returned a week later having contacted Sprint about their Lifeline program. She was told that the patient needed to establish local telephone service before enrolling in the Lifeline program. The Navigator explained the situation to the patient and called Sprint to establish local service. The Navigator program located a donated phone for the patient to use.

The Navigator completed a home visit with the public health nurse. The patient had been referred to the endocrinologist for amenorrhea and 70 lb weight gain since surgery. A nurse practitioner had diagnosed the patient with depression and recommended an anti-depressant. The public health nurse and the Navigator disagreed, since anti-depressant would cause more weight gain and did not address the amenorrhea. They explained their point of view to the patient and her mother, assured them that they believed there was a problem, and offered to refer the patient to a neurosurgeon. They also discussed the need to get the patient permanent coupons, since the patient would not be able to return to work any time soon.

The Navigator visited a patient in the hospital. The patient was sleeping, so the Navigator did not wake the patient. The Navigator left a note and a Lance Armstrong Foundation Survivor's Binder.

The Navigator attended the medical oncology consult for a cancer patient who recently had surgery. The oncologist reviewed the pathology report and explained that she would not benefit from additional therapy. The oncologist said she did not need to see the patient again and discontinued her care.

The Navigator attended the endocrinology appointment of the patient who had previously reported amenorrhea and a 70lb weight gain since surgery. The nurse practitioner ordered more labs and a Magnetic Resonance Imaging (MRI) and will schedule a follow-up appointment after the results are back.

The Navigator completed a home visit with a patient who had an abnormal cancer screening. The patient was referred to the Navigator Program because the patient does not have a home phone. The patient was not home when the Navigator came to visit, but the Navigator spoke with the patient's granddaughter and left her business card and asked that the patient call her.

The Navigator received a phone call from a Navigator patient's son who reported that the patient was doing poorly. The patient died. The Navigator went to the nursing home to pay her respects and offer comfort for the family. The Navigators attended the traditional dressing ceremony the following day and attended the burial services at the longhouse and the sunrise interment at the cemetery later in the week.

The Navigator called and spoke to a cancer patient who wanted to know the results of her HLA typing, but results were not yet available. The Navigator explained to patient that neither her brother nor sister were a match, then offered to start a discussion at her next medical oncologist appointment as to what the next step is.

The Navigator attended the follow-up surgery appointment for a biopsy with no cancer; the surgeon requested repeat testing in six months. The surgeon also wrote a note for light duty, because the patient works in an industrial setting.

The Navigator attended the pre-operative appointment with a cancer patient. The Navigator had arranged for a Community Health Representative (CHR) to drive the patient to the appointment because the patient had no car. The Navigator helped the patient complete the paperwork at the physician's office and at the hospital. The Navigator agreed to meet the patient the following week for the biopsy. The Navigator arranged to have the CHR transport the patient to the hospital for the surgery. The Navigator met the patient at the hospital and stayed until the patient was taken in for surgery.

The Navigator completed a hospital visit for a cancer patient admitted for decreased level of consciousness. The patient was unresponsive to voice, was unaware of people in the room, but did respond to pain. The cause of the problem was unknown. The Navigator visited the hospital the following day and the staff reported that the patient had elevated liver function tests and ammonia level. The patient's condition had not improved. The next day, the medical oncologist ordered a nasogastric tube placed to administer Lactoluse. After one dose of Lactoluse, the patient's ammonia level decreased. The patient began to respond to voice and touch, but only had brief periods of consciousness. The Navigator visited the patient on the following day, and found the patient alert and talking with family. The family was concerned that the patient had had nothing to eat in several days and was interested in total parenteral nutrition (TPN) or tube feedings. The RN reported that the patient's ammonia level had returned to normal and there were no orders to begin TPN or tube feeds. The Navigator visited the patient three days later and the family reported that the medical oncologist had ordered TPN the previous day. The patient was alert and visiting with family and friends and had stable labs.

The Navigator attended the first radiation oncologist appointment with a newly diagnosed cancer patient. The patient had been seen at the University of Washington by a specialist who said that surgery was not an option, and instead radiation and chemotherapy were needed. The oncologist reviewed notes and examined the patient and was concerned that the cancer might have spread to another site. The physician proposed doing a procedure to determine the extent of the involvement. The patient agreed to receive treatment contingent with a complete explanation of procedures to be done and potential side effects of treatment. The following day, the Navigator accompanied the patient to the first medical oncologist appointment. The physician reviewed notes and examined the patient, then explained the recommended chemotherapy regimen and side effects. The patient expressed willingness to go ahead with treatment as discussed. The physician suggested that the patient get a portacath for infusion and asked the Navigator to coordinate the surgery consult and the surgery, since the treatment plan could change following the scheduled PET scan. The Navigator scheduled the patient to see the surgeon the following week, with a tentative date for port placement set for the following day. The Navigator planned to follow-up with both the radiation and medical oncologists following the patient's PET scan. The following week, the Navigator attended the patient's surgical consult. The physician explained the procedure for placing the port. The Navigator discussed the timing of the surgery with the patient and the physician; it was decided that surgery should be delayed until after the PET scan. The port placement was then scheduled accordingly. The Navigator attended the outpatient surgery and stayed with the patient until taken into the surgical suite. The physician reported that the surgery went well and that the port was working.

A patient called asking for a refill of Percocet. When asked, the patient reported difficulty ambulating, so the Navigator offered an available wheeled walker, which the patient agreed to try, and delivered the prescription to the patient's home.

A social worker at a local oncology center called regarding a patient lost to follow-up. The Navigator called the patient, who had missed the follow-up appointment because of school and work; the patient was willing to be seen. The Navigator completed a referral and scheduled the appointment, calling the patient back to communicate the date and time and that the necessary paperwork would be available at the CHS office.

A clinic employee came to the Navigator Program office to ask for help for a friend experiencing abdominal cramping. The friend had a history of incomplete chemotherapy treatment for a non-cancer diagnosis. The Navigator visited the patient at home. The patient explained that she didn't finish treatment because she lost her eligibility for Medicaid, and currently has no insurance. The Navigator arranged for an appointment for a pregnancy test the following day. The pregnancy test was positive, fetal heart tones were heard, and the patient was referred to an OB/GYN for prenatal care.

A patient with a history of cancer was admitted to the hospital for abdominal pain. A CT scan revealed enlarged lymph nodes. The patient's primary care provider referred the findings to the Navigator, who faxed the CT scan results to a medical oncologist and set up an appointment, which the Navigator attended with the patient. The oncologist explained the findings from the CT scan and discussed the possibility of recurrent disease, recommending a PET scan, which the patient agreed to. The Navigator referred the patient to a support group for psychosocial support.

A Navigator attended a specialty appointment with a patient in Seattle where the physician reported that the cancer had direct, regional spread which would require radiation therapy. The physician explained a genetic test on the tissue and requested that the patient visit the High Risk Clinic for genetic counseling. The physician also encouraged the patient to include older children in testing. The physician agreed to coordinate the next appointment with the High Risk Clinic and to call the patient's home physician, who requested medical records.

The Navigators went to the surgery consult of a new breast cancer patient. The patient was very sensitive about confidentiality, so the Navigators wanted to see the patient outside the clinic. They gave the patient information on breast cancer and the treatment options and offered Navigator program services. The community Navigator offered support as a fellow breast cancer survivor. The patient thanked the Navigators for coming, but the patient's boyfriend became angry and said the Navigators upset the patient. The Navigators returned to the clinic and spoke with the nurse practitioner who had referred the patient to the Navigators. The nurse practitioner reported that the patient had previously been in an abusive marriage and suspected that the current relationship might be abusive also. The nurse practitioner reported that the partner was very controlling and they had just recently reconciled. The Navigators agreed to contact the patient again. Later, a Navigator called the patient to see how she was doing post-operatively. The patient apologized for her boyfriend's behavior at the last meeting. The patient said that she was having skin irritation from the tape at the incision site. The Navigator explained that she was probably allergic to the adhesive and recommended padding between her skin and clothing. The patient agreed to try it. The Navigator gave the patient several different types of bandages and paper tape to try. Two days later, the patient called the Navigator to say that the ABD pads worked best and that she needed more supplies. The Navigator collected the requested supplies and gave them to the patient.

The Navigator visited a patient who was admitted to the hospital for fever, with suspected infection. The Navigator returned three days later to check on the hospitalized patient. The patient inquired about the status of her application for gas vouchers from People for People. The Navigator agreed to contact them again and follow-up.

The Navigator met a new cancer patient at the surgeon's office for a pre-operative consultation. The patient had a Benton County Health Plan (BCHP) form for a biopsy, and the Navigator agreed to contact BCHP to see if and who needed to complete the form for enrollment in the program. The patient had decided on a treatment plan and chose not to receive further assistance from the Navigator Program at this time.

The Navigator visited a terminal cancer patient in the hospital. The family reported that the patient was being discharged to home the next day, but a hospital bed had not been delivered to the home. The Navigator left a message with the primary care provider asking for an order for the hospital bed. She also left a message with the hospital's home health department to call her regarding the patients discharge plans. The following day, the Navigator spoke with the patient's daughter who reported that the patient had been discharged, the hospital bed had been delivered, and the home health nursing had already stopped by.

The Navigator attended the follow-up medical oncology appointment for a patient. The patient is scheduled for radiation implants, so the Navigator requested that they draw her pre-operative labs along with her scheduled labs, and the physician agreed. The physician wanted to give the patient chemotherapy along with the implants, so the Navigator reminded the physician to send the orders to the hospital. The Navigator obtained copies of lab results for the hospital. The following week, the Navigator met the patient at the hospital for admission and radiation implants. The hospital did not receive the orders, so the surgery was delayed. The Navigator escorted the patient down to pre-operative area where an IV and epidural were started. The Navigator left after the patient was taken to the operating room suite.

The Navigator received a call from the Contract Health Services Nurse Manager who had a patient in her office who reported that she was scheduled for surgery but didn't know what for. The patient had recently seen a medical oncologist for her cancer history and was referred for a screening exam. The patient explained that she did not receive a call from the medical oncologist or from the surgeon, and the hospital staff would not tell her what the surgery was for. The Navigator apologized to patient for the poor handling of her case and assured her that she would talk with the medical oncologist and have him call her and explain what was going on. The Navigator encouraged the patient to keep her appointment with the surgeon and offered to attend appointment with her. The Navigator went to the medical oncologist's office and explained the situation. The oncologist thought that the surgeon had contacted the patient, but agreed to call the patient that same day today, apologize, and explain what was going on. The following week, the Navigator met the patient at the surgeon's office. Based on the patient's screening and history of cancer, the physician recommended a biopsy. The Navigator scheduled the patient's biopsy and follow-up appointments. The patient expressed her thanks to the Navigator for her assistance.

The RN case manager for CHS contacted the Navigator about a patient who had previously received assistance in getting an appointment for a biopsy for a screenable cancer. The patient had brought a prescription to the tribal clinic that would cost $1600 to fill. The Navigator consulted with one of the physicians, who agreed to order five days' worth of medication pending pathology results. The Navigator delivered the medication to the patient's home and provided patient teaching on how to administer injections, dispose of syringe, and possible side effects. The patient gave the dates and times of upcoming appointments, and the Navigator scheduled rides for those appointments through the tribal Community Health Representatives Program (CHR Program).

The Navigator attended a follow-up surgery appointment for a patient who recently had surgery for cancer. The surgeon was pleased with the appearance and healing of the incision. An additional follow-up appointment was recommended in one week.

A provider referred a patient to the Navigator Program who had failed to complete a referral. The patient had a history of cancer and was having suspicious symptoms. The Navigator called the patient's home and learned that the patient had relocated to another part of the state and was receiving care there. The Navigator reported back to the provider and closed the file.

The Navigator attended the biopsy of a patient who had previously called off the same procedure during the needle localization due to pain. The Navigator had worked with Contract Health Services staff to arrange for a biopsy to be performed by a surgeon at a local hospital under general anesthesia. The doctors decided to delay the procedure an additional week when the patient developed cold symptoms, including a productive cough, so that the patient could complete a course of antibiotics. The Navigator assisted the patient in rescheduling the procedure and had the prescription sent to a pharmacy near the patient's home. When the biopsy was eventually performed, despite residual cold symptoms, the Navigator stayed with the patient through needle localization, pre-operation, and post-operation procedures. The Navigator's presence seemed to alleviate the patient's considerable anxiety, which might otherwise have led the patient to call off the procedure again. The Navigator spoke with the surgeon and arranged for the primary care provider to deliver the pathology results because the surgeon would be out for two weeks. The Navigator also obtained a note excusing the patient from work during recovery and had the patient's prescriptions sent to the patient's local pharmacy.

The Navigator visited a patient in the nursing home who had just undergone surgery for cancer. The social worker from Virginia Mason had called and reported that the patient was having difficulty with tube feeding. The Navigator explained that patient had no family support, so a nursing home was the best option. The Navigator gave the social worker the names and numbers of nursing homes to check for availability. The RN reported that patient's tube feeding was only overnight and the patient had advanced to eating yogurt. The patient said that the nursing home was not bad, though the patient wanted to go home but understood the need to be there. The patient thanked the Navigator for her visit.

Assisted a patient with enrolling in the Breast and Cervical Health Program (BCHP) and scheduled an appointment for a mammogram.

While on leave, the Navigator received a call from a patient who reported that having a stinging rash on the back of the legs. The Navigator suspected shingles, so advised the patient to go to the clinic for a same day appointment to have it checked. The patient agreed. Three days later, the Navigator received a message from the patient who reported going to the clinic, receiving a diagnosis of shingles, and also receiving a flu shot. The patient wanted to know if the patient would still be admitted to the hospital the following week for chemotherapy. The Navigator consulted with the physician who confirmed the shingles diagnosis and explained that the oncologist would evaluate the patient at the next week's appointment and make a decision about chemotherapy. The Navigator called the patient back and explained the situation. The patient was unhappy with the uncertainty. The Navigator agreed to meet the patient at the following week's appointment.

The Navigator contacted a newly-diagnosed patient who had been referred from the tribal clinic's director of nursing. On the phone, the patient was not interested in the program, in discussing cancer, or getting any informational materials. The Navigator followed up with a letter to this patient extending Navigator services, and the patient returned to the Navigator Office in person and apologized and arranged for the Navigator to visit after the first surgery.

The Navigator received a call after hours from the son of one a cancer patient. The patient had returned home from the hospital that day. The patient's feeding pump was not working and the family did not know how to restart it. The Navigator went to the patient's home, and found the feeding pump beeping. The patient was unresponsive to voice, responded to touch, but quickly relapsed. More than 30 minutes later, the Navigator was finally able to restart the feeding pump.

The Navigator attended the medical oncology appointment of a patient with cancer. The patient requested that the Navigator attend since the patient was having a biopsy. The Navigator stayed with the patient through the procedure and gave the patient post-operative care and bathing instructions.

A recently-diagnosed patient referred herself to the Navigator Office asking for information about her disease and about pain management. The patient had been seen at [local clinic] but she was interested in coming back to the Indian Health Service clinic. The Navigator gave the patient information about her disease and arranged an appointment with an IHS doctor for the next day to re-establish her as a patient and to address her poorly-controlled pain. The patient had the Navigator accompany her to her next medical oncology appointment to help her communicate with that provider.

The Navigator saw a cancer patient in the dental clinic who had previously declined Navigator services. When passing by, the Navigator inquired about how things were going, and the patient had some questions for the Navigator. The patient came to the Navigator office where the Navigators answered questions about the therapy the patient was receiving. The Navigators also gave the patient brochures on cancer and treatment, which the patient accepted with appreciation. The Navigators offered the patient additional assistance if needed.

The Navigator visited a patient at home after an emergency department visit. The patient said that she had been fatigued, which brought her to the emergency department. She was diagnosed with an infection and was taking an antibiotic.

Near the end of a day, a Navigator received a call from a patient who said that her mother was not going to drive her to Seattle for surgery as planned. The Navigator contacted the Tribal Emergency Funds office which confirmed that the check to cover travel expenses was in the mother's name and they would be unable to approve and issue a new check to the patient before closing. The Navigator called the patient and explained the situation, asking her if she would be comfortable taking the bus to Seattle alone. The patient said she would. The next day, the Navigator contacted the bus company, purchased a round-trip ticket to Seattle, and delivered the ticket to the patient's home. A local volunteer group later reimbursed the ticket cost.

Provided information to a self-referred survivor about possible treatments for weight loss and decreased appetite. The survivor had heard the Navigator speak at the Cancer Awareness Day about medications to treat this problem. The Navigator saw this visit as a sign of increased trust in the program on the part of community members.

A new cancer patient began the first cycle of chemotherapy and radiation. The pharmacy staff recommended a prescription to help the patient with a troubling side effect. The Navigator explained to the patient that the prescription works well but is expensive, and recommended that the patient apply for the Patient Assistance Program. The patient completed the application and successfully completed her chemotherapy.

The Navigator attended a radiation consult with a patient who was unhappy with the physician, so the Navigator arranged to have another physician assume care. The new physician discussed radiation therapy, the length of treatment, and side effects. The patient was initially reluctant and did not understand why the radiation was necessary after chemotherapy and surgery. After the discussion, the patient agreed to treatment. When the Navigator inquired, the patient reported liking the new physician better.

The Navigator completed a home visit to deliver pain medication after the local cancer center had called to report that patient had missed two appointments for her bone scans and the hospital was threatening to charge the patient for the radioactive dye. The Navigator spoke with the patient about the missed bone scans and was told she did not have a working car to get to the appointments. Patient agreed to let the Navigator reschedule the bone scan. On the day of the appointment, the Navigator met the patient at home, according to their previous arrangement. The patient's daughter drove the patient to the appointment and the Navigator followed. The radioactive dye was successfully administered. However, when the patient was scheduled to return to the hospital to complete the scan, the patient was late and calls to the patient were unanswered. Just as the Navigator was leaving to go to the patient's home, the patient arrived for the scan, which was successfully completed.

A patient who was reluctant to undergo radiation treatment was encouraged by the Navigator to go to a consult and hear what the physician had to say. After the consult, the patient agreed to the treatment, which is the standard of care for this diagnosis. The Navigator attended the consult and delivered medicine to the patient's home later that same day.

The Navigator attended the follow-up surgical consult for a patient with an abnormal screening test and a history of cancer. The physician reported that the patient's biopsy was normal and ordered a repeat screening in six months.

The local cancer center phoned the Navigator to say that a patient had not kept a follow-up appointment with their medical oncologist. The Navigator, knowing that the patient did not have a telephone, visited the patient's home. The patient was not present, but the Navigator left a business card and a note with the patient's son.

The Navigator went to the hospital to see the terminal cancer patient who had previously been discharged to home. The patient's primary care provider had informed the Navigator that the patient was back in the hospital. The patient had shortness of breath and pain control issues. The patient and family thanked the Navigator for coming.

At 2:00 AM one night, the Navigator received a call from the patient's family, stating that the patient was in uncontrollable pain. The Navigator advised the family to take the patient to a hospital [in a nearby city]. She visited the hospital two days later, but the patient was out getting a biopsy. The Navigator again returned and spoke with the patient, the family, and the medical oncologist. The biopsy was negative but CEA level remained high. The doctor explained treatment options and the prognosis to the patient and family. Later the Navigator received a call from the patient's family stating that the patient was weaker, pain continued, and episodes of nausea and vomiting continued. The Navigator advised the family to come to the clinic early the next morning, where they saw the patient's primary care provider. The provider contacted the medical oncologist for records and reviewed treatment options. The patient and family agreed to hospice care. The provider ordered multiple prescriptions for pain control and nausea and vomiting, which the Navigator delivered that evening to the patient's home.

Assisted patient in applying for Social Security and disability benefits, including attending the patient's Social Security interview. Like many American Indian elders, this person lacks some of the standard documents (e.g. birth certificate) and did not realize that applying for benefits would be possible.

The Navigator received a call from a new cancer patient who was approached about participating in a clinical trial. The patient reported that Tribal Insurance and Contract Health Services (CHS) would not pay for the clinical trial. The Navigator spoke with Tribal Insurance and CHS who confirmed that they would not pay. The Navigator asked the patient for permission to speak with Tribal Council about the situation, and the patient agreed. The following day, the Navigator went to the tribal administration building and met with the chair of the tribal council's Health, Education, and Welfare (HEW) committee, as well as two HEW committee members, about passing a Tribal Resolution for covering the clinical trial. The Navigator explained that the clinical trial covered the same medications and the patient might get better care in the clinical trial. The committee members agreed to pass a Tribal Resolution authorizing payment of the clinical trial by both Tribal Insurance and CHS. When the Navigator received a copy of the Tribal Resolution for the clinical trial, she called the patient and told her the good news and sent a copy of the Resolution. The patient was very happy to be able to participate. The Navigator also gave a copy of the Resolution to CHS.

The Navigator met a cancer patient for her medical oncology appointment. The physician wrote orders for the patient to be admitted to the hospital for another cycle of induction chemotherapy. The biopsy results from the previous week were not available yet. The Navigator met the patient at [the local hospital], gave the RN on staff the admission paperwork, and helped the patient get settled in her room.

The Navigator attended the radiation oncology consult for a breast cancer patient after a lumpectomy with positive margins. The patient expressed a preference for a mastectomy over radiation therapy, and the doctor felt that a mastectomy would be prudent. The Navigator completed a referral and scheduled an appointment with a plastic surgeon to discuss breast reconstruction. The Navigator also scheduled another surgical appointment for the mastectomy.

The Navigator completed three hospital visits with a patient who had a resected tumor. The patient had problems with ambulation after surgery and was receiving physical therapy. The RN case manager for CHS notified the Navigator that the patient left the hospital after refusing to go to the rehabilitation unit for ongoing physical therapy; the patient came to the clinic office for approval of follow-up care with the neurosurgeon and endocrinologist and was visibly ataxic. The Navigator and public health nurse practitioner (who had referred the patient for the initial problem) completed a home visit to convince the patient to go for outpatient physical therapy. The patient and the patient's mother agreed with the treatment plan and came into the office to complete the referral.

A patient in the hospital had her teeth pulled because of significant infection in her gums, causing fevers. The Navigator followed up to check on the results of the extraction.

The Navigator assisted a patient in renewing a prescription for anti-emetic medication and delivered the prescription to the patient's home.

The Navigator called a cancer patient to see how her last appointment went with the medical oncologist. The patient reported that the cancer remains in remission, but she continued to have trouble with tremors and ambulation. The patient inquired about using a medication to treat her tremors. The Navigator discussed adding this prescription with the physician, who agreed to try it, but asked that the Navigator monitor the patient for lowered blood pressure and heart rate. The Navigator then called the patient to notify her that a trial prescription had been called into her pharmacy. The nurse educated the patient on signs and symptoms of low blood pressure and heart rate.

A primary care provider referred a patient who was in the hospital. The physician reported that resection and diverting colostomy had been completed, contrary to the standard of care for this diagnosis, which would have been diverting colostomy, radiation therapy and chemotherapy, then resection. The Navigator visited the patient in the ICU following surgery; the patient expressed appreciation for the visit. Three days later, the Navigator returned to the hospital but the patient was not there. CHS reported that the patient had been transferred over the weekend to a larger hospital due to septic shock. The Navigator visited the patient every two days, including weekends, until the patient's death two weeks later.

A primary care provider referred a newly diagnosed patient to the Navigator, who called to offer further assistance. The patient reported that she was doing better. The Navigator mailed information about cancer and resources to the patient's home.