Northwest Tribal Cancer Navigator Program

Annual Report

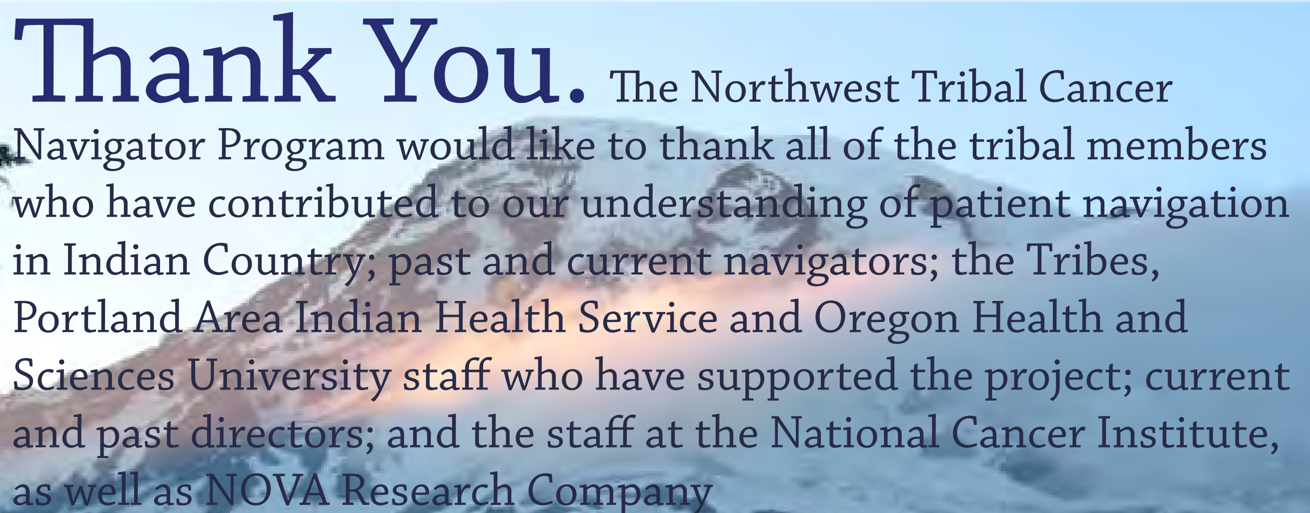
Northwest Tribal Cancer Navigator PROGRAM

Confederated Tribes of
Warm Springs Reservations

Northwest Portland Area
Indian Health Board

Our Mission

Coordinating cancer care and outreach screening with Native Communities



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Part 1

What we know...

What we know...

For many cancer sites, American Indians and Alaska Natives (AI/AN) experience worse outcomes and lower chances of survival than other racial/ethnic groups in the United States. Cancer is the third leading cause of death for AI/ANs of all ages, and the second leading cause of death for American Indians over the age of 45.[1] The burden of cancer affects people of all races and ethnicities. However, cancer survival data reveal that AI/AN people have the poorest survival of any racial group for all cancer sites combined and for eight of the ten leading sites.[2]

It is believed that part of the reason AI/ANs experience higher cancer morbidity and mortality is due to delays and obstacles in seeking and receiving cancer care. The lack of access to adequate cancer screening and treatment remain major causes of higher cancer morbidity and mortality in tribal communities. A variety of social, economic, and cultural barriers impede AI/AN patients' ability to participate in screening, diagnosis, and treatment.[3] Additionally, funding limitations of tribal health care systems, and cultural, social and geographic barriers to cancer care are further challenges and are specific to tribal communities.

While the overall population has recently seen cancer incidence rates decreasing, among AI/AN populations incidence rates for some cancers are still increasing and mortality rates remain higher than those of other races[4]. Thus, the need for comprehensive disease prevention efforts and cancer related research a top priority.

There have been significant advances in science and in understanding treatment of cancer. Yet, there are many people who do not sufficiently benefit from these research advances. This 'gap' between what is known and what is delivered is a critical determinant in cancer health disparities and ultimately...who's at risk.

One of the ideas working on filling this 'gap' is having a person work with patients on overcoming barriers and navigating the complex medical and financial systems as well as logistics. This idea was formalized and put into practice and is now referred to as the "Patient Navigation Model", which is mentioned in more detail later in this report.

While the patient navigator model has been shown to be effective in reducing barriers to care in other underserved communities, it has not been widely implemented in urban and rural AI/AN communities. Thus, The Northwest Tribal Cancer Navigator Program (NTCNP) is working to implement the model in the Northwest in order to reduce barriers to care with the hope of improving clinical outcomes and the quality of life among tribal members.

The story of how navigation came to the Northwest Tribes…

The President's Cancer Panel is charged to monitor and evaluate the development and execution of the National Cancer Program and report to the President on barriers to Program implementation. Throughout 2000 and 2001, the Panel held a series of meetings exploring issues that affect the ability of communities to provide cancer care – including prevention, education/communication, detection/diagnosis, treatment, rehabilitation, and palliative and end-of-life care – to people in the diverse neighborhoods of the nation.

Yakama tribal elder, Joe Jay Pinkham, spoke before the Panel in February 2001 at a meeting held in Los Angeles, California. As a result of his experience, Mr. Pinkham invited the Panel to hold a meeting with the Yakama Nation in Toppenish, Washington, to hear about the issues and barriers affecting cancer for AI/ANs in his community.

The full report of the Panel's meeting can be found at ***this link*** *or see the reference list*

Based on the Panel's Report and the voice of the Northwest Tribes, funds were made available to explore the Navigation Model in Indian Country. The National Cancer Institute, through a collaborative agreement with the Portland Area Indian Health Service, pilot tested navigation in two communities in the Northwest. Though funds were given to the Indian Health Service, the Northwest Portland Area Indian Health Board was selected to administer and oversee the program implementation and evaluation. Katrina Ramsey, Pilot Program Director, operated the Northwest Tribal Cancer Navigator Program from its conception in 2003 through 2006.

The full report of the Pilot Program can be found at ***this link*** *or see the reference list*

Based on the work from the Pilot Program, the Northwest Portland Area Indian Health Board was awarded additional funding to expand the Pilot Program and conduct a more extensive evaluation of navigation in Indian Country. Funding is provided to the Board from the Office to Reduce Cancer Health Disparities at the National Cancer Institute. This program is called the Northwest Tribal Cancer Navigator Program (NTCNP).

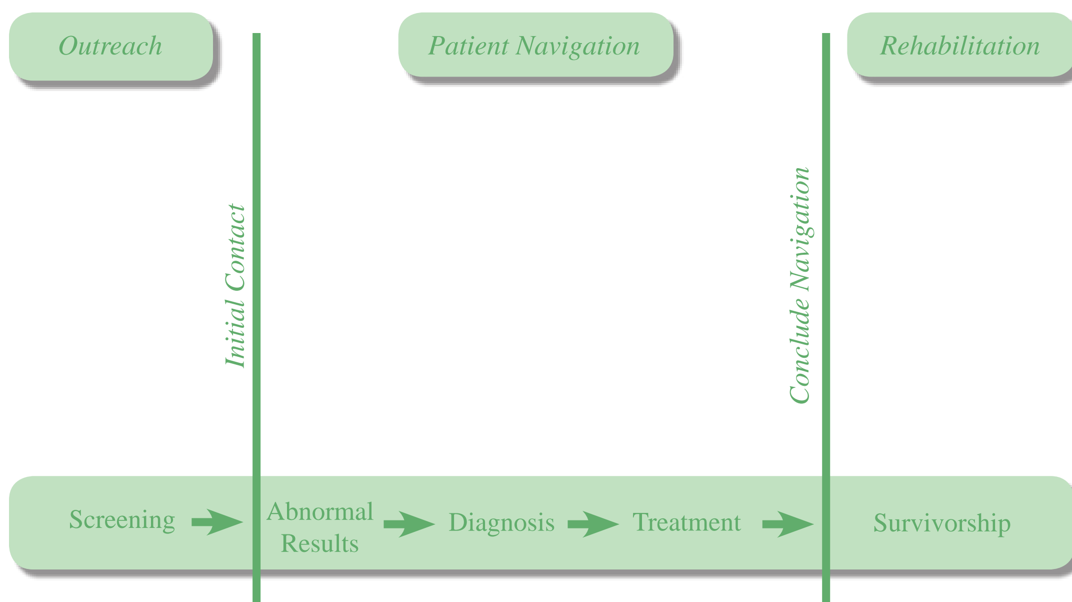
What is the Navigator Model?

The Navigator Model, as depicted below, is set up to assist people starting at an abnormal event guiding them through diagnostic work up and into treatment should they have cancer. As you can see the vertical lines indicate where patient navigation is set up to begin and end along the a patient's cancer journey.

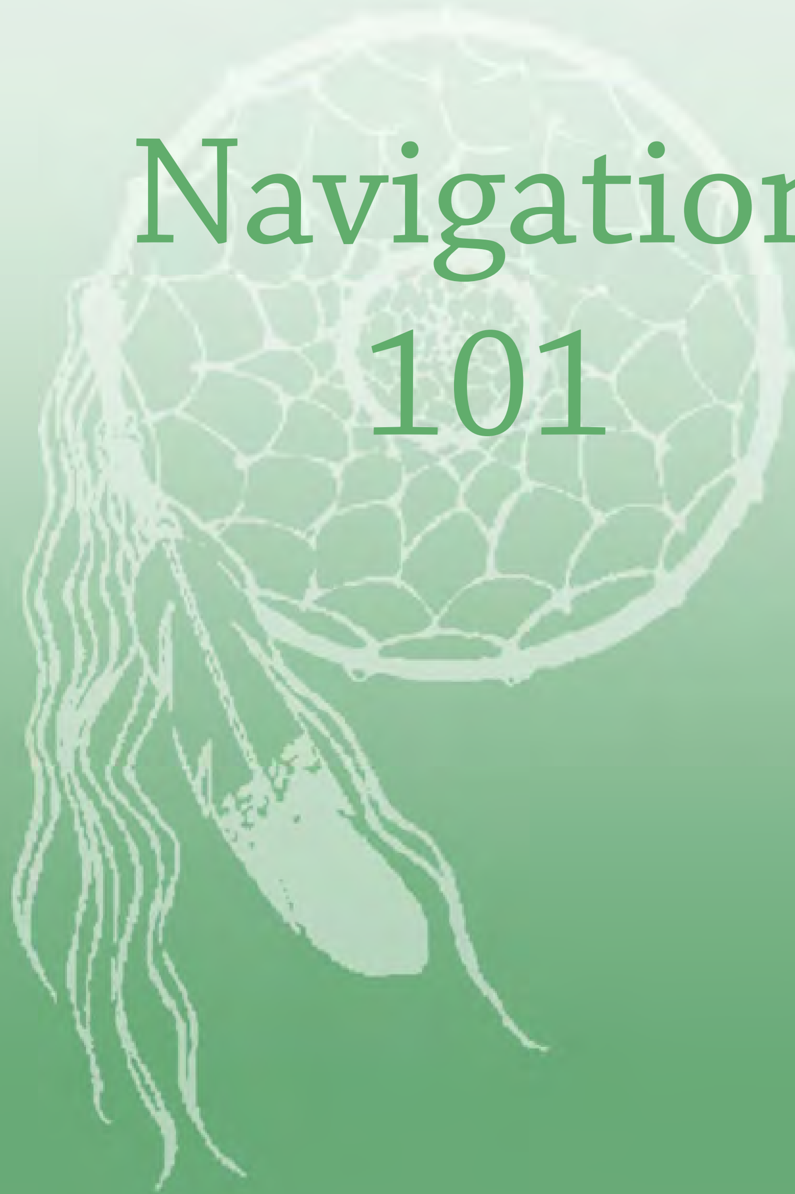
There are two reasons for patient navigation to begin at an abnormal finding. First, when a person has an abnormal finding the course of care begins to get complex; more appointments are needed, bills begin to come in, and the stress of the unknown starts to affect people's lives. If the abnormal finding turns out to be cancer, the complexity just intensifies as a new wave of appointments, providers, and time constraints begin to take over. Secondly, time becomes of increasingly important starting with an abnormal event. Research has shown those who make it from abnormal finding into treatment faster have better outcomes. Thus, the idea of having someone facilitating a patient's journey to increase efficiency and ultimately speed will improve health outcomes.

Research in Patient Navigation in the end is looking to 'navigate' patients through complex medical and social service programs and decrease delays in starting treatment will improve health outcomes.

Figure 1: The Navigator Model



Part 2



Navigation 101

Who Are Navigators?

Navigators may be nurses, social workers, Community Health Representatives, or lay people. Each intervention site selects the type of navigator that will work best for the patients at their clinic and the site administration. Intervention sites had the option of hiring a community level or nurse level navigator. Navigators are hired and supervised by the clinic management or community health program. They work as part of the clinic staff (i.e., full access to the Resource and Patient Management System (RPMS), charts, etc). Each clinic has the discretion to hire the navigator with the training level deemed to most effectively meet the needs of the clinic's patients. Each navigator was hired at 1.0 FTE, and all of the navigator's time is spent on cancer related activities. As has been the experience of the Pilot Project, some of these activities are not related to the care of specific individuals (e.g., organizing screening activities for the clinic, advocacy for increased availability of cancer services in the community, raising community cancer awareness).

Navigators may be nurses, social workers, Community Health Representatives or lay people

What do Navigators do?

Patient navigation encompasses a wide variety of activities to match the range of needs of patients seeking cancer care through the participating clinics. The navigator prioritizes the needs of those patients with a cancer diagnosis, or who have a time-sensitive need for follow-up of an abnormal cancer screening test. At the lowest level of involvement, navigators may provide printed or verbal explanations of cancer-related issues. At higher levels of involvement, navigators make home and hospital visits, arrange counseling for family members, and canvass state and private agencies to help fund a patient's treatment.

The navigator's primary tasks can be organized in the following categories*:

1. Assisting patients and their extended families.

Navigators assist patients and their extended families by providing education, psychosocial support, coordination of resources, and facilitation of services.

- Education: Navigators provide information on prevention, screening, diagnostic procedures, disease course, treatments, community resources, and clinical trials. Education is intended to prepare patients and their families for what to expect and empower patients to make informed decisions
- Support: Navigators play a role in providing emotional and psychosocial support services directly, or referring patients to mental health specialists or support groups within the community. Minimizing anxiety and building trust with patients are examples of the types of support navigators deliver
- Coordination of Resources: Navigators perform outreach activities, including assisting with physical needs that act as barriers to health care and guiding patients through the screening process
- Facilitation of Services: In addition, navigators work closely with patients to identify and address logistical barriers to care, such as transportation, child care, and financial and insurance issues, and provide referrals to community resources and social services

2. Interacting with providers and health care system.

Interacting with providers and the health care system is an additional navigator function.

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*A list of references for this section can be found in the appendix

Three Primary Navigator Activities:

Assisting Patients and their Extended Families

Interacting with Providers and Health Care System

Interacting with Community

- Navigators provide or arrange translation services, assist patients and families in preparation of questions, and ensure information is understood

- Health care system barriers commonly addressed by navigators include coordinating appointments, facilitating referrals, facilitating patient-provider communication, coordinating a multidisciplinary team of providers, and completing medical paperwork

3. Interacting with community.

- Navigators often interact with the community and engage in a variety of community activities.

- Navigators network and develop partnerships with local programs, organizations, and institutions to identify resources in the community such as screening facilities and financial assistance programs

- Navigators also participate in cultural events within the community and provide information regarding the targeted disease and services available

Who do Navigators help?

Navigators work with any patient who is eligible to be seen at one of the participating clinics. Patients are referred to the local navigator at any point between abnormal finding and resolution, through several possible routes:

1. Navigators receive monthly lists of patients with abnormal screening results performed in the clinic and then confirm, through clinic records or patient contact, that those patients received timely and appropriate follow-up tests. (An abnormal result from a Pap test, for example, typically requires a repeat Pap test in six months to confirm the abnormal finding. If a patient does not receive the second test but does in fact have cervical cancer, the benefit of the screening test is lost and the cancer will be diagnosed at a later stage, when it is more difficult to treat.). Navigators are never the first clinic staff member to inform a patient of a suspicious test result, unless that role is specifically designated to them. In most cases, they ensure that the patient has been contacted first by a clinician.

2. Providers in participating clinics refer patients to the navigator either (a) at time of positive diagnosis of cancer or (b) when a cancer diagnosis seems probable and the patient faces challenges to getting the diagnosis confirmed. This often includes any patient who needs a biopsy, mammogram, colonoscopy, or other diagnostic service not provided in-house; arranging these services poses a challenge for most patients. Especially in the instance of a new cancer diagnosis, the navigator always ensures that this has been communicated to the patient by a clinician before contacting the patient.

3. After obtaining permission from the patient, providers at local oncology clinics and hospitals who have developed a working relationship with the local navigator may inform the navigator that they are treating an AI/AN patient who is interested in navigation services.

Databases

Navigation Tracking Database

Navigators record information about their activities, the services they provide, and patient encounters in the Navigation Tracking Database. A version of this database in Microsoft Access was in use during the Pilot Project. This database has been modified to comply with the data requirements and strategies determined by consensus of the Patient Navigator Research Program (PNRP) group. When a navigator initiates contact with a patient (either via mail, phone, or in person), s/he enters minimal identifying information into the intake screen of Navigation Tracking Database.

Encounters

Patient 'encounters' are similar to appointments that navigators have with patients. They are quite flexible in definition, and depending on the patient's needs they may take place at the clinic, as a visit to the patient's home, over the phone, or the navigator may accompany the patient to an appointment. Navigators may have encounters with the patients themselves, their family or friends, members of the health care team or someone else with whom the patient requests a meeting.

Patient Clinical Database

In order to fully characterize the burden of cancer at each clinic, the cancer-related services being provided, and the impact of navigation, NTCNP collects demographic and clinical data on all patients with cancer or abnormal screening findings at both intervention and comparison sites, as well as any patients at the intervention site with whom the navigator has contact. Patients on whom data is to be collected are identified through Q-man queries of the clinic's RPMS database and through interaction with the navigator.

Qualitative Data

To better understand patient needs and to learn about how working with the navigator may affect a cancer patient's quality of life, we will conduct in-depth interviews with a representative sample of navigated patients and family members who agree to the interview and to have their (unidentified) data used in the evaluation.

> *'Encounters' are similar to appointments that Navigators have with patients*

How will we know if it works?

The findings from the Northwest Tribal Cancer Navigator Program will allow for a comprehensive evaluation of the effectiveness of the Navigator Model in Northwest tribal communities. If proven effective, the findings of NTCNP will provide policy-makers solid evidence on which to base funding decisions regarding use of this method of reducing the burden of cancer among American Indians and Alaska Natives.

The long-term goal of the NTCNP is to ensure that AI/AN patients have access to the same cancer care and services that are available to other groups. We will evaluate the cancer navigator model serving our tribal communities using the following objectives and specific aims:

There are three primary objectives for the NTCNP:

1. Increase the well-being of cancer patients

- Navigators help patients to more effectively and confidently communicate with their health care team, friends and family through:
    - Accompanying patients to appointments
    - Teaching patients communication strategies and tips

- Helping patients learn the best questions to ask of their providers, and coaching them on how to ask when it may be challenging

- Navigators help patients to make well-informed decisions about their care by:
    - Providing patients with the information about their test or diagnosis that will help them understand the options available
    - Teaching patients how to weigh difficult decisions and choose what is best for them and their family

- Navigators help patients cope with the emotional burden of a test result or cancer diagnosis through:
    - Listening to patients' concerns and offering support
    - Referring patients to support groups and other services that can help them cope

- Navigators help ensure patients' modesty needs are met by:
    - Educating patients on how to bring up modesty concerns
    - Making arrangements for modesty issues to be accommodated

- Navigators can help ensure their patients receive culturally appropriate care by:
    - Acting as a cultural "translator" between patients and providers while attending appointments
    - Making arrangements for cultural needs to be accommodated

2. Reduce the cancer burden in our AI/AN communities

- Navigators help patients to get diagnosed at an early stage by:
    - Getting patients from the first abnormal finding to diagnosis as quickly as possible

- Navigators help increase the number of cancer patients who survive by:
    - Helping patients to make and keep appointments quickly and efficiently so they receive more timely care
    - Making sure referrals to outside specialists are obtained quickly so they can receive more timely care

- Navigators help patients overcome logistic barriers to care through:
    - Helping arrange child and/or elder care
    - Finding housing when needed
    - Arranging transportation when needed

- Navigators help patients overcome financial barriers to care through:
    - Working through paperwork to establish IHS/CHS eligibility
    - Working through paperwork to establish Medicaid, Medicare or disability
    - Finding other sources of financial assistance when needed

Evaluation on three main objectives:

Increase Patient Well-being

Reduce Cancer Burden in AI/AN communities

Provide Navigation Allowing Patients to feel Respected and Comfortable

- Navigators create continuity of care for patients by:
    - Making sure charts are complete and providers have relevant results when needed
    - Contacting providers who give conflicting advice or relaying information between providers

3. To provided Navigation services that allow patients to feel respected and comfortable

- Patients should feel
    - Their navigator is easy to reach
    - Their navigator gives them enough time
    - Their navigator respects their cultural wishes
    - They would see their navigator again if they fell ill
    - They would recommend navigation to a friend or family member

Data Collection and Management

The data for evaluating the effectiveness of the NTCNP comes from three sources, each described in greater detail below:

1. Each navigator records data about activities and encounter in the Navigation Tracking Database (at interventions sites only).
2. Clinical data about all patients is obtained from the clinical data system (usually, RPMS) and paper medical charts at the Indian health clinic where the patient received care.
3. Survey and interview data regarding patient quality of life and satisfaction with navigation will be collected from those patients who express interest in participating in these activities (consenting navigated patients only).

These data will comprise the dataset with which NTCNP will perform analyses specific to Northwest tribal communities. Once cleaned and validated, all data from a specific clinic will be freely available to the administration of that clinic to utilize in quality improvement activities.

Navigation can be implemented in many different ways depending on the needs of the community. The model that NTCNP uses involves navigators who may have a range of backgrounds. They are called upon to address patient education, the emotional needs of their patients and families, coordinate resources and overcome barriers to care. Our navigators work with clinic staff and outside sources to identify patients, ideally as soon after the first abnormal finding as possible. To evaluate the effectiveness of the NTCNP we will look at the patient well-being, reduction of the cancer burden in the community and patient satisfaction with the program.

Part 3

Challenges & Successes

Challenges

The Impact of Delays in Diagnosis

Delays in diagnosis and treatment have been linked to later stage at diagnosis, high patient anxiety and poor survival outcomes. [5-10] There are many reasons AI/AN populations are at particular risk for delays, despite the best intentions. Navigators can overcome barriers and help patients get timely care. However, the Northwest Tribal Cancer Navigator Program (NTCNP) has faced challenges in enrolling patients early enough to have an impact in this way. The program is focusing now on increasing early enrollment, but there is still work to be done.

Waiting for a cancer diagnosis and, if needed, treatment are a time of high anxiety and long waits can lead to poor outcomes. This topic has become the focus of a great deal of attention recently, especially in countries such as Canada and Britain which operate under national health care systems. Those systems came under heavy criticism towards the end of the last decade with patients waiting for unacceptably long periods to get a cancer diagnosis or to begin treatment. As a result, a wave of research was undertaken to identify the true impacts of delays and help to inform policy makers regarding acceptable time frames. The majority of the research at this time is international, due to the lack of a centralized system for collecting these type of data in the United States. There are some studies currently underway utilizing Medicare data but none have yet been published.

Delays in diagnosis and treatment have been linked to:

- *increased patient anxiety*
- *later stage at diagnosis*
- *poor survival outcomes*

Three of the primary issues that have been linked with delays in cancer diagnosis and treatment are increased patient anxiety, later stage at diagnosis and poor survival outcomes. Many studies have shown that delays as short as one week to find out the results of a biopsy, for example, may lead to significant increases in case level anxiety.[6] Patients report that the time between referral from their local clinic to first seeing the oncologist is the most difficult time, and women are more likely to experience this distress than men.[7] There have also been several large-scale studies on breast, colorectal and lung cancer showing a significant relationship between delays and stage at diagnosis, tumor size and survival rates.[8-10] One recent report, a meta-analysis of breast cancer patients, found that 14 out of 21 studies supported the hypothesis that tumor size and stage are significantly related to duration of symptoms prior to treatment.[9] Survival rates are also linked to delays, with one large-scale study reporting a ten percent lower survival rate in patients who waited more than 12 weeks between onset of symptoms and beginning treatment when compared to those who had less than 12 weeks delay.[8]

Although there are no regional studies on delays and outcomes, local data do show that AI/AN cancer patients tend to be diagnosed at later stages and have the worst survival rates of any race. AI/AN cancer patients have significantly lower 5-year survival rates. The relative risk of death for within five years of diagnosis is 1.8 for women and 1.7 for men when compared to non-Hispanic whites.[11]

Risk of Delays Following Abnormal Finding

Patients are particularly at risk for delays in the period between the first abnormal test result or symptom and diagnosis. Following this first concerning sign, a flurry of follow-up tests are often ordered to rule out cancer or make a definitive diagnosis. It is essential to identify the type and stage of disease so the best treatment decisions can be made. Diagnostic procedures may include a wide variety of tests requiring several appointments with specialists.

This is a crucial period for patients. During the time before a diagnosis has been reached, patients are anxious and under a great deal of stress waiting to hear whether or not they have cancer, what type, how aggressive and what the next months will hold if they do need treatment. There are few financial resources for patients during this time. Patients screened through the state breast and cervical programs are not automatically enrolled into Medicaid until a diagnosis has been reached which limits the number of providers patients can see for diagnostic procedures. Many foundations and other organizations that provide financial aid to patients with specific types of cancer require proof of diagnosis before they will accept applications. This is a time when patients are very vulnerable to all of the financial, emotional, and health system related barriers that prevent timely follow-up and adherence to provider's recommendations.

> *"There is a particularly critical window of opportunity to save lives from cancer between a point of suspicious finding and the resolution of the finding"*

For this reason, many patients who come to their provider with a concerning symptom or have their screening tests as recommended may still end up with a late stage diagnosis and a difficult fight with an advanced cancer. Dr. Harold Freeman, who created the first navigation program in the 1990s, has said "*We must ensure that any women with a positive finding will receive further diagnosis and treatment on a timely basis. There is a particularly critical window of opportunity to save lives from cancer between a point of suspicious finding and the resolution of the finding*". [12]

Barriers in AI/AN communities

Patients in our communities are even more likely to experience delays. Many are uninsured or underinsured. Poverty leads to other practical barriers such as difficulty with transportation to appointments, inability to take time away from jobs, and difficulty securing child or elder care. For many of our patients, the nearest cancer center is more than an hour's drive from home and there is no public transportation. Some face health literacy or cultural barriers. Fear and a sense of fatalism that persists regarding cancer often leaves patients unwilling to pursue a diagnosis. While it is beyond the scope and economic means of most community-based programs to solve the vast social, economic and health system problems that create these barriers, Navigation focuses on tackling the things that we do have the power to change.

The Role of the Navigator in Preventing Delays

Navigators are expert problem solvers and are extremely creative in coming up with "out of the box" thinking to overcome barriers such as these. When the NTCNP began in two communities as a pilot study, it was limited to diagnosed cancer patients. However, it soon became clear that patients needed navigation earlier and the eligibility criteria were expanded to the current status which includes patients who have received any abnormal test result or symptom suspicious for cancer requiring follow-up.[13] Some examples

include:

- Abnormal clinical breast exam requiring referral
- Abnormal screening mammogram
- Abnormal pap test, except for patients with ASCUS result and negative HPV test
- Rectal bleeding or gross blood in stool in patients age 30 or older requiring referral
- Positive FOBT or guaiac requiring referral
- Abnormal digital rectal exam requiring referral
- PSA greater than 4 ng/ml
- Abnormal PSA velocity requiring referral

(For a more comprehensive list of eligible test results and symptoms, please see Appendix B).

The list above addresses some of the symptoms and tests related to breast, prostate, colorectal and cervical cancer. Eligibility for other types of cancer is more difficult to define due to the range of symptoms that may be indicative of cancer, but navigators will enroll any patients who have symptoms suspicious for cancer or pre-cancerous conditions such as myelodysplastic syndromes.

*Navigation focuses on tackling the things we **do** have the power to change*

It is clear from the list above that many patients who are enrolled early, immediately following an abnormal test result, will not go on to be diagnosed with cancer. For example, many abnormal mammogram findings or lumps identified during breast exams turn out to be cysts or calcifications. Prostate Specific Antigen tests are rife with controversy precisely because they can often be indicative of benign conditions rather than cancer. However, navigators can still be an essential source of information, emotional support, and practical help for these patients. And, since we can't know which patients will go on to be diagnosed with cancer, navigators make sure to aid a wide range of patients through the process as smoothly, quickly and with as little anxiety as possible, thus ensuring those who do become cancer patients receive this important assistance and are already familiar with the navigator by the time treatment decisions must be made.

Case Example

The following story is an example of a best-case scenario. A patient has completed an FOBT which came back positive for blood in the stool, but the provider is fairly sure that this bleeding is from hemorrhoids and not likely to have anything to do with cancer. The next step is a colonoscopy which will make sure that there is nothing more serious to worry about. The patient is uninsured and it will be difficult to find funding to pay for this expensive procedure. The navigator works with the patient to fill out applications for Medicaid or Medicare, and contacts a specialist who has a relationship with the navigator and is willing to do the procedure at a reduced cost. The patient is reluctant to go through with the procedure due to fear, confusion about the process and concern that the diagnosis will be cancer. The navigator offers emotional support, someone with whom to discuss fears and concerns, and helps the patient understand that being referred for this test does not mean he or she will go on to have cancer. The navigator uses patient education tools such as models of the colon, print materials and online sources to describe the procedure, why it is done, what to expect on the day of the appointment and during the following days. The navigator offers patient education materials that have been designed specifically for AI/AN patients and embrace the storytelling, family-oriented values that resonate with many native patients.

The patient faces a number of practical barriers to attending the appointment. The family budget cannot find room for the cost of gas for the long trip, and there is no one to take the patient home from the appointment. The navigator inquires about gas vouchers, and tries to find a Community Health Representative or a survivor from a local support group to drive the patient to the appointment.

As anyone who has had a colonoscopy knows, the preparation is often worse than the actual procedure. All too often the test will be of limited use because the colon has not been cleared. The navigator provides the patient with information and reminders regarding the importance of fasting and completing the laxative solution, and offers tips on getting through the prep as painlessly as possible.

The day before the procedure, the navigator checks in on the patient to reinforce the need for proper prep and help the patient with any problems. The day of the appointment, the navigator accompanies the patient to the clinic. And finally, in the days following the test, the navigator checks in with the patient to make sure there is no persistent nausea, bleeding or discomfort, and helps alleviate fears while awaiting the results.

In the end, the colonoscopy has confirmed that there was no cancer. However, this patient was supported and comfortable throughout the process, attended the appointment and received the good news quickly, thereby reducing anxiety. Following this positive experience, this patient may be more likely to attend regular screenings and encourage friends and family to take care of their health.

All of these tasks are similar to what navigators do for patients post-diagnosis, but can be of great benefit to patients even if they do not go on to be diagnosed with cancer, and can ensure these patients adhere to recommendations in a timely manner and do not spend weeks or months worried about the possibility of cancer and unsure how to proceed.

Challenges to Enrolling Early

Despite the goal to identify and help patients at this early stage in the cancer journey, it has been a major challenge since the program began. During the first year of the program, the majority of patients were enrolled after a diagnosis had been reached. In fact, at that time only 14 percent of the patients in the program were enrolled before their diagnosis. Recently there has been a concerted focus on this issue and the number of patients enrolled early has more than doubled. We hope to make further progress with this so that more patients can have the benefit of navigation earlier in their cancer journey, and those who do not go on to have cancer can benefit as described above.

Challenges to enrolling patients early

- *Identifying patients with abnormal test results*
- *Locating test results*
- *Stigma around referring to the 'cancer person'*
- *Building relationships with providers*

One of the primary hurdles faced in enrolling patients early in the cancer journey was simply identifying those who had an abnormal test result or symptom. Although some test results are recorded in the clinic medical database, the Resource and Patient Management System (RPMS), there is no dedicated module designed to look at cancer. This means that navigators have had to cobble together a few different ways of searching for abnormal test results, and none of these are ideal. In some cases, inconsistent and delayed data entry has added to the challenge. A number of different search templates were tested and the navigators were trained in the use of RPMS to perform these scans. They are becoming adept at scanning these reports for patients who may need assistance with follow-up and the process is becoming more streamlined all the time.

Another challenge that continues to prevent early enrollment of patients is obtaining test results. Most imaging tests, colonoscopies and biopsies take place outside of the clinic. Some of the tests are done on-site, but processed at outside labs. Navigators have found it is often difficult to track down the results of these tests in a timely manner. They have taken on the task of calling outside providers to request test results be returned to the clinic and getting them back into the patient's chart.

Another issue that has emerged is that the program materials themselves have created a barrier to early enrollment in positioning the program as a service for 'cancer patients'. This has caused some confusion about who is eligible and what the program can offer for patients who have not yet received a cancer diagnosis. Providers in the clinics have found it difficult to understand what the navigator's role would be in those cases. There is also some concern that referring patients to the 'cancer person' if they are unlikely to end up having cancer would cause unnecessary alarm. To combat these issues, we have tried to explain the role of the navigator in the case of a patient who has an abnormal test result or a symptom that is unlikely to be cancer but needs follow-up to rule it out. Navigators have met with clinic staff, given presentations and explained how they can help to coordinate this kind of follow-up care. We are also working to get the word out that the navigator program is not just for cancer patients and move away from using the title 'Cancer Navigator' in favor of 'Patient Navigator', 'Community Navigator' or 'Nurse Navigator'.

Gaining support and building relationships with providers in the clinic is also essential. Some of our navigators have medical training, while others do not. They each have a slightly different approach to navigation depending on their community, clinic policies, and their own personalities.

Navigators have been instrumental in bringing services and resources to their communities

However, providers must have confidence in the navigator, who often spends more time with their patients than any other member of the health care team. Keeping the lines of communication open and having regular conversations with the medical staff has helped to establish these relationships. However, frequent changes in clinic staff have hindered the navigators' ability to rely on these relationships and made building confidence within the clinic administration and medical staff more difficult.

Looking Ahead

The research has clearly shown just how serious delays in diagnosis and treatment can be. The navigator program is poised to make a real difference in these wait times and so we hope to continue to find ways to enroll patients early. Navigators have the tools to help overcome barriers that cause long waiting times for cancer diagnosis and treatment, and can help patients through the process with less anxiety. There is still work to be done in getting the word out, identifying patients early, and streamlining the process. But with the support of providers in the clinics, the outside facilities which process the test results, and the patients themselves, we are confident that we will continue to see increasing numbers of patients partnered with the navigator early and experiencing the benefits of navigation when it can really make an impact.

Success Stories

Improving Access to Care

Navigators have been instrumental in bringing services and resources to their communities since the inception of the pilot project in 2003.[13] This progress has continued in the current project. Navigators have increased access to care by working with clinic administration to bring mobile mammography units to their reservations, and identified private foundations which fund mammograms for women who do not qualify under any other program. Navigators usually schedule about 15 to 20 patients to be screened each month when the van comes to the reservation, and provide courtesy letters and reminder phone calls to improve attendance rates. They have also played a role in establishing contracts with the state breast and cervical screening programs to ensure that women who are uninsured can receive standard screenings and the clinic's underfunded Contract Health Service (CHS) funds are reimbursed for these costs. This is a long, complicated process and involves a number of people within the clinic to establish; however, the navigators have been leaders and advocates for this.

Bringing Support to AI/AN Communities

Navigators have also responded to a need for cancer support groups within their communities, and in two of the communities they have established groups which are now coming into their own. Navigators have attended Native-specific support group trainings so that they may better direct the conversation - however, the groups have become quite self-sufficient and are relying less on the navigators for direction as time passes. Navigators also arrange speakers for the groups and organize other events. The support group meetings are well attended and tribal members come from hundreds of miles away to participate. Survivors who are part of the groups have taken on other community projects related to cancer such as fund raisers.

Raising Awareness

Navigators have done a great deal in their communities to increase awareness of the importance of preventative care and screening through displays in the clinics and around the community, presentations, health fairs and outreach services. For example, one Navigator obtained a mini-grant to organize a

presentation on HPV and cancer prevention for the local students. Another regularly attends the substance abuse treatment center to give cancer prevention classes. Navigators also partner with other disease prevention and health promotion committees at their clinics such as the diabetes groups to put on health events. They have utilized media including local tribal newspapers, newsletters, radio stations and have appeared on national radio programs focusing on Native American issues.

To bring the idea of cancer prevention to the youth of their communities, one navigator organized essay and poster contests in the schools. Newspaper articles have been helpful in getting the word out about the program and raising the profile of NTCNP. One such article stated, "*Perhaps one of the greatest life changing moments is receiving a diagnosis of cancer .... Now, Tribal members, their spouses and other members of Native American Tribes have an advocate at the [clinic] to help them navigate the potentially confusing landscape of the cancer health care system .... Bottom line, the navigator helps patients receive timelier and better cancer care.*"

Navigators have become fixtures in their communities, bringing cancer prevention messages to schools, pow wows, and other community events. The health fairs, run/walks, "health days" and other events planned by navigators continue to be well-attended and have increased screenings in these communities, due in no small part to a number of innovative strategies the navigators have employed to encourage community members to attend. Some of these strategies included:

- Advertised around the clinics, administrative buildings, local shops and cafes, and even above the urinals for a men's health fair
- Obtained mini-grants from the Northwest Tribal Cancer Control Project to help pay for catering and door prizes
- Required attendees to have a card stamped at each health station (i.e., blood pressure check, blood draw for PSA, etc.) in order to enter into a raffle
- Solicited donations from local businesses for power tools and fishing equipment to raffle at a men's health event
- Worked with tribal administration to grant all tribal employees a couple of hours of administrative leave to attend a health fair

Financial, Housing and Transportation Assistance

Navigators have built up essential partnerships with other community groups which they draw on to assist with financial distress, transportation costs and other patient needs. In one case, the navigator has become an active member of a coalition of local community resource groups which has created a strong network of resources for clinic patients. Resources in rural areas are always difficult to come by and NTCNP has found that one of the most important underpinnings of a successful navigation program is a strong network of partners and community linkages on which they can draw.

Transportation is always a major problem in our communities as treatment centers are usually far away, and in these rural communities there is rarely any public transportation available. Navigators have obtained gas vouchers for patients, organized free flights through Angel Flight and helped to link patients with shuttle services which provides transport for as little as $1 each way for their patients. The use of Angel Flight has been of particular significance for patients who are not eligible for Contract Health Service (CHS) funding. This happens in the case of patients who are living away from the Tribe in which they are enrolled. These patients are only eligible for services provided on-site at the clinic, which means most cancer diagnostic tests and treatments are not covered. However, Angel Flights have allowed these patients to travel for free to their home Tribe and receive care.

Navigators have also worked with a number of different organizations to obtain housing for patients who required extended treatments at cancer centers far from their homes. Also, in some cases patients find themselves facing homelessness due to loss of employment after their cancer diagnosis. One navigator was able to work with the Tribal Housing organization to move such a patient into suitable housing with subsidized rent.

Finding financial assistance is difficult but NTCNP navigators have tapped in to a number of resources, both local and national. In Oregon, navigators have worked with a foundation at a local cancer center which provides support for low income patients, as well as the county service agencies and as a result have been able to relieve the financial burden for a number of patients. Other navigators have made use of Tobacco Tax funds and the Native American Cancer Research Memorial Fund, and CancerCare among others.

Coordination of Care

Coordinating the many players in a cancer patient's health care team takes up a lot of a navigator's time. Ensuring that charts are complete and test results, consult letters and pathology reports are communicated between providers is one of the most important tasks the navigators carry out. In addition, they attend case management meetings and keep the clinic staff informed of their patient's progress throughout their treatment.

At this point it is a little too early to draw any conclusions about the specific effects navigators have had on delays and stage of cancer patients. But it is clear that, on a community level, there have been numerous successes and the NTCNP navigators continue to approach their work with a passion and commitment to make positive changes in the health of their communities.

Part 4

Results

Enrollment and Demographics

As of the end of the second year, the Northwest Tribal Cancer Navigator Program has enrolled 326 participants. The majority of these (217) have been enrolled as comparison cases at the three comparison sites. The remaining 109 are enrolled and working with navigators.

The first year of the study was a slow period for enrollment as clinics worked through hiring, training new navigators, establishing community networks and gaining physician support for the program. At the end of the first year, we had only conducted data collection at one comparison site.

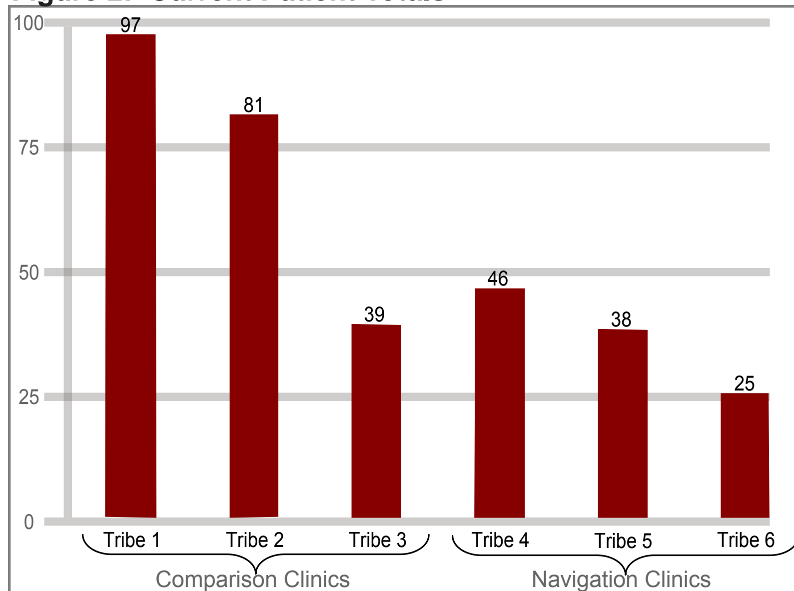
In the second year we have come a great distance. Enrollment has improved dramatically and navigators have become adept at data collection so that we now have less than one percent erroneous or missing data. We have also established our relationships with three comparison clinics and have done extensive data collection at those sites.

As mentioned previously, in the early part of the study, navigators struggled to identify cases early in the disease trajectory, before definitive diagnosis had been reached. The model of navigation this project aims to evaluate involves identifying and navigating participants as early as possible, ideally as soon as they receive an abnormal test result. It has been stated that, "the navigator's most important role is to ensure that a patient with an abnormal test result suggestive of cancer receives a diagnosis and, if necessary, treatment in a timely manner"[12]. However, the program encountered many barriers to identifying participants prior to diagnosis.

As discussed in the section outlining challenges, navigators use the RPMS query program to search for participants who have had recent screening tests. However, this has proven difficult as RPMS is not designed with a module specifically focused on cancer. As a result, navigators have to piece together searches that don't always quite hit the mark. Another issue is the lack of systematic follow-up for abnormal test results, which means navigators have to try and plug into less-than-perfect existing systems, or create new systems from scratch. Many screening tests such as mammograms and colonoscopies are not done on site, and others, such as pap tests, may occur on site but be sent to an external lab for processing. We have found that tracking down the results of tests which are occurring off site can be difficult. Another barrier has been lack of physician support for referring participants at this early point. And, again, as stated earlier, many physicians did not want to concern participants unnecessarily by engaging the "Cancer Navigator" in their care while they had only an abnormal result that may be only mildly suspicious for cancer.

At the beginning of the second year, only 14% of navigated participants were meeting with the navigator prior to their diagnosis. In the past six months, we have focused on this issue and developed strategies to overcome these barriers. As a

Figure 2: Current Patient Totals



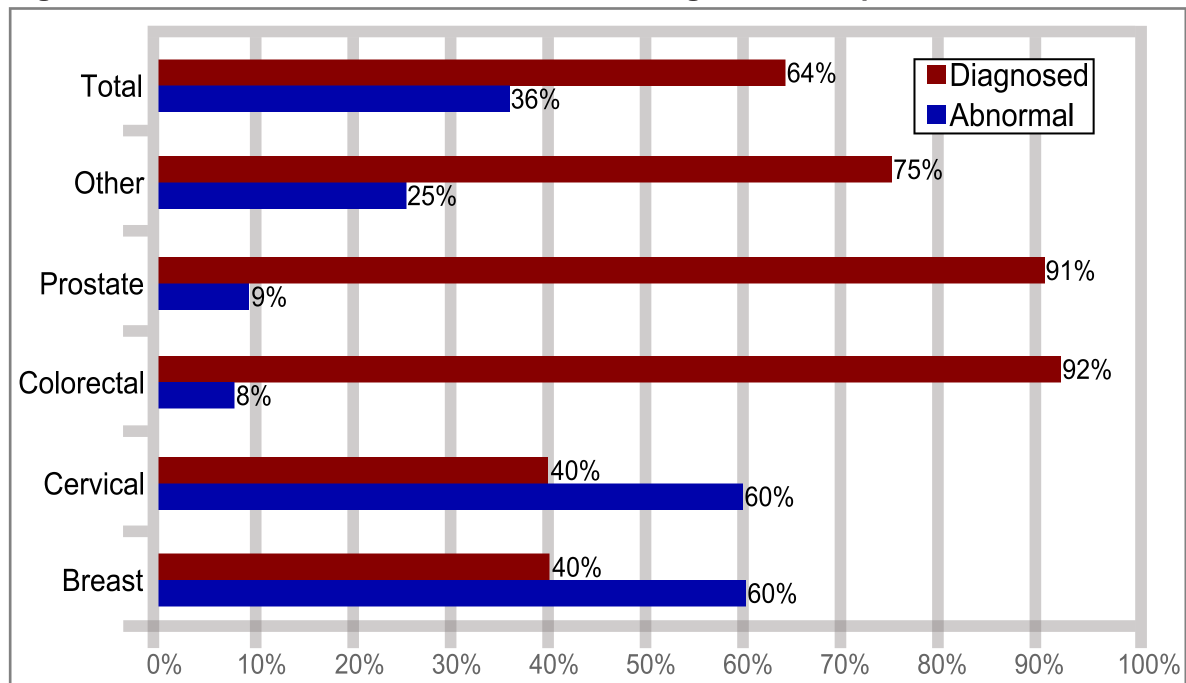
result there have been marked improvements and the proportion of participants who begin working with the navigator before definitive diagnosis has more than doubled. However, this issue continues to be challenging and we would like to see many more participants receiving the benefits of navigation earlier on when the program can be of the most help in getting the patient a timely diagnosis and, if necessary, treatment.

Figure 3 shows the breakdown of navigated patients by cancer site and disease status. Overall, nearly two-thirds have received a breast or cervical cancer diagnosis or abnormal test result. Mammogram and Pap test rates are much higher than other cancer prevention tests, so these participants are easier to identify and enroll into the study. Many of these participants, particularly enrolled at comparison sites, have had an abnormal pap test or mammogram which did not lead to cancer. At comparison sites, participants are enrolled through chart reviews and never contacted by NTCNP directly. This, in addition to the fact that there is no time component to enrolling comparison participants as charts can be reviewed at any time, are the main reasons more participants are enrolled early on the comparison side.

The most difficult patients to identify thus far have been those with abnormalities suggesting colorectal cancer. Fecal occult blood tests (FOBTs) are not ideal screening tests for colorectal cancer and do not seem to be widely used in the study clinics. Furthermore, navigators believe colonoscopy rates to be low at their clinics due to patient non-compliance and lack of funding. In some cases navigation is not necessary as colonoscopy allows for treatment (i.e., removal of polyps) at the time of the screening test. In these cases, the usual follow-up needed is simply another colonoscopy in ten years, so they are not candidates for navigation.

Prostate cancer screening is not without its share of controversy; researchers have recently started questioning the value of the PSA test which may lead to over-treatment cancers which are not aggressive and would remain asymptomatic for many years. This could potentially leave patients with unnecessary side effects from surgery or radiation therapy such as impotence or incontinence. While recognizing this controversy, our study does seek to navigate men who have elevated PSA, suspicious findings on a digital rectal exam, or a prostate cancer diagnosis. We also

Figure 3: Disease Status at Enrollment – All Navigated Participants



focus on PSA velocity, which measures the change in PSA level over time and is arguably a more accurate way to detect cancer. Navigators become involved if the physician determines that the PSA or other symptoms warrant further diagnostic procedures. At this point, one may argue that these men may be at most in need of navigation precisely because the issues surrounding treatment decisions are not clear. However, identifying these participants has also proven difficult for our study.

Figure 5: Patient Gender

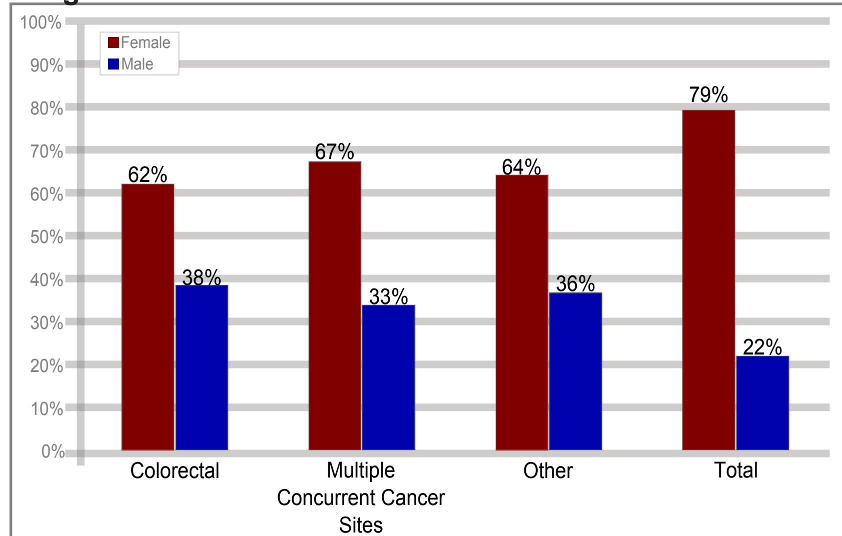


Figure 4 shows the breakdown of cancer sites for all patients enrolled to date. Cancer sites other than the four major "screenable" cancers included lung (35%), non-melanoma skin cancer (24%), and blood cancers such as multiple myeloma and leukemia (14%). All other cancer types occurred in less than five cases.

Overall, the program has served many more women than men, as seen in Figure 5. Part of the reason is certainly because of the high proportion of breast and cervical participants enrolled. Anecdotally, navigators report that it is much more difficult to get men to comply with screening recommendations. This may also contribute to the low numbers of males enrolled. The navigators have made this issue a focus and have held several outreach events targeted specifically at men. For example, several Tribes have held Men's Health events complete with raffles of tools and fishing equipment. Men were entered into the raffle only after getting a check list of health screenings signed off. Other sites have done similar events highlighting the community need and inviting male survivors to tell the story of their cancer journey. Community support has be great for these events, and in fact one Tribe event granted administrative leave for tribal employees to attend the health fair. Although these events had great turnout, and men who attended did have PSAs and other tests done, this is just a start. To really turn the tide and bring about a change in men's screening rates will require a concerted effort from the entire community and a commitment to broaching this topic among men, even though it is difficult to discuss. NTCNP also has two male navigators on staff at this time and there is some thought that male

Figure 4: Cancer Sites

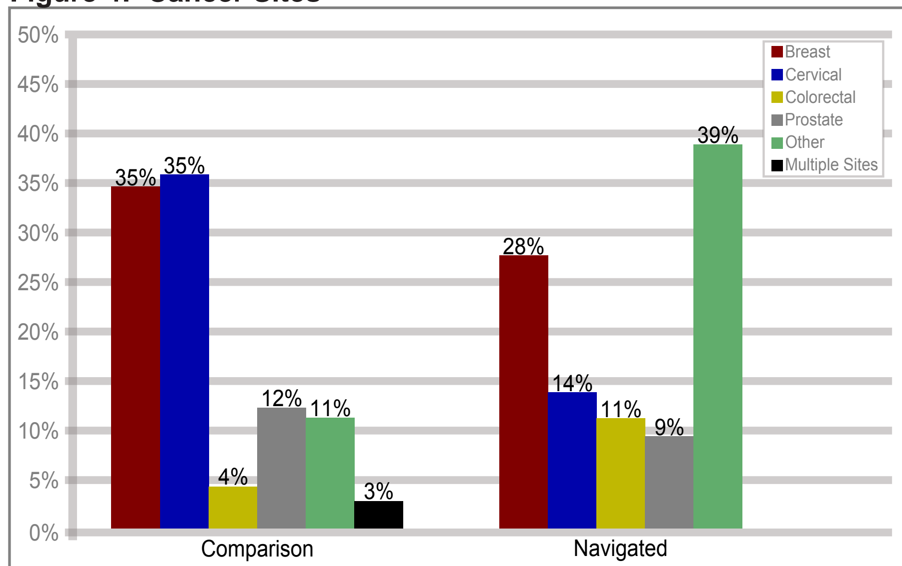
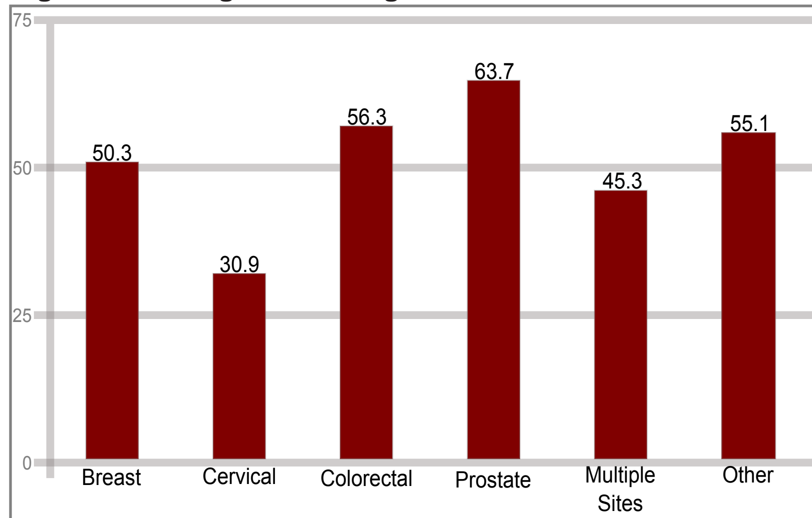


Figure 6: Average Patient Age



participants may be more comfortable working with a male navigator. We are looking forward to investigating this, and are hopeful that our male navigators may help encourage men to talk about prevention and seek the support of a navigator if they need it.

Figure 6 shows that the average age of participants enrolled is just under 50 years old. Not surprisingly, cervical participants tend to be younger as most abnormal Pap test results are found in young women who have recently acquired an HPV infection. As the charts on insurance coverage will show, this has implications for Navigation as these younger participants also tend to have fewer options to pay for follow up testing and treatment, and are more transient.

Navigators working in Indian Country face a unique challenge in trying to work within the Indian Health System. For the sites involved in this study, only ambulatory care is available at the clinics on the reservation. Enrolled members of a federally recognized Tribe receive on-site care within these clinics at no cost. For care not available within the clinic, patients are referred out to private sector providers and services are purchased through the Contract Health Service program (CHS).

On the face of things, this should provide a great "safety net" for members of our Tribal communities and make Navigation easier. However, in reality there are severe limitations to this system. Since the vast majority of cancer screening, diagnosis and treatment services must be done outside of the clinic, CHS funding becomes extremely important. However, this program is consistently under funded and thus there are strict limits on who is eligible and establishing eligibility can be challenging. [14]

Most participants who are living away from the Tribe in which they are enrolled are not eligible for CHS funding. This means they may be faced with a difficult choice between foregoing care or moving back to their home Tribe. This can often mean

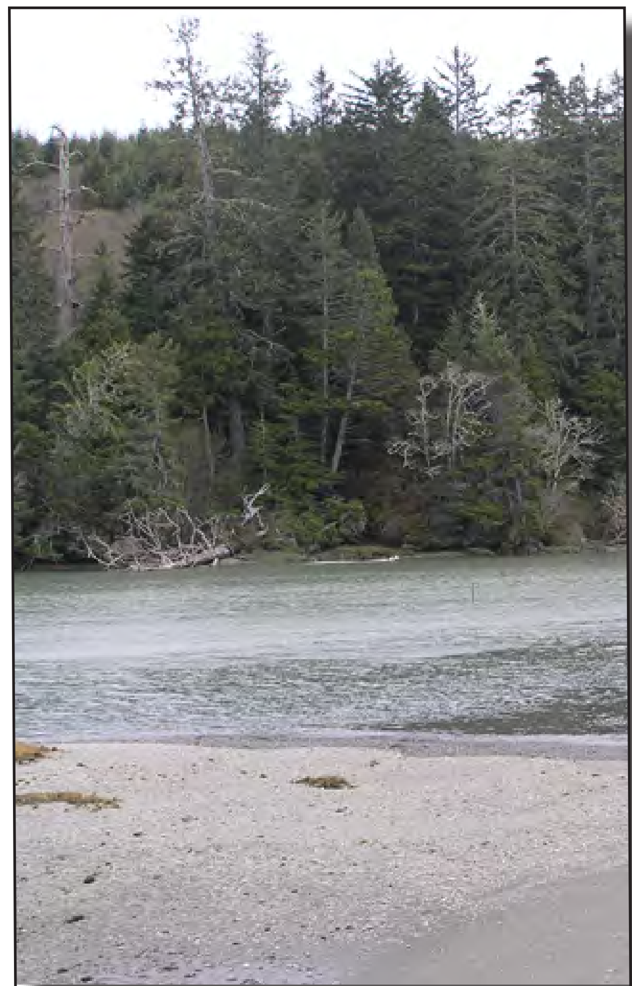
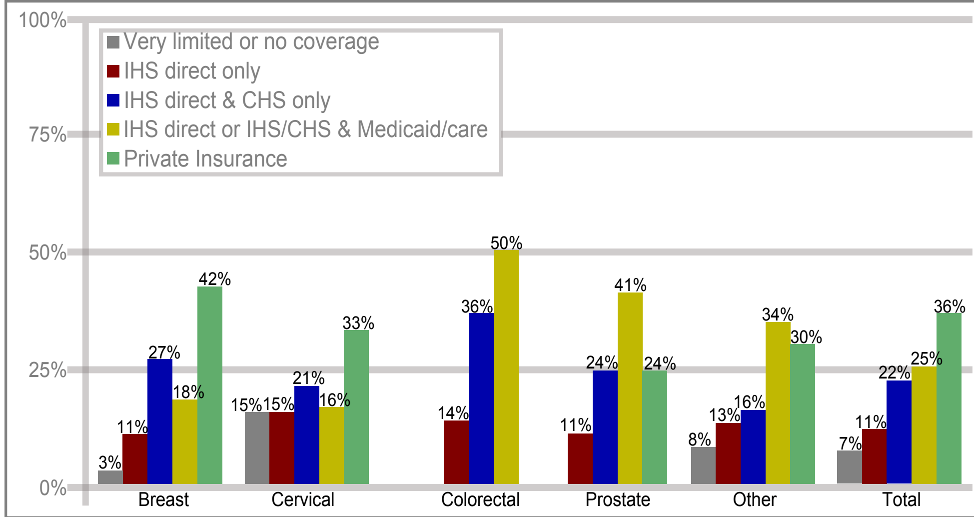


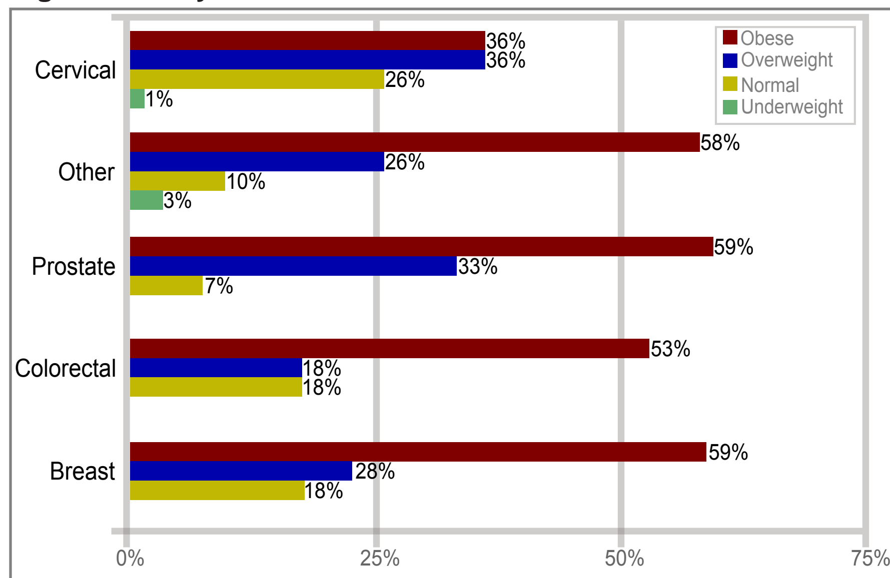
Figure 7: Insurance Coverage at Enrollment



moving away from their immediate families, jobs and extended support network. As Figure 7 shows, about 10 percent of participants enrolled in the program are in this situation. Participants who have a cervical abnormality or diagnosis face the biggest hurdle to paying for care. Nearly a third of these young women have limited or no coverage, or rely solely on IHS direct services.

Even for those who are CHS eligible, the lack of funding for this program means that clinics are often forced to limit reimbursements to the highest priority issues – immediate threat to life or limb. As a result, participants may be turned down for preventative care such as screening tests. Nearly one third of all participants enrolled in the program are in this category, relying on only IHS direct services and CHS to pay for care. Participants who have a breast or colorectal diagnosis or abnormality are the most likely to have private insurance coverage (42-50%), probably due to the fact that they tend to be middle aged and are likely in the work force with coverage through their employers. However, among all participants enrolled in the study, only about one third have private coverage.

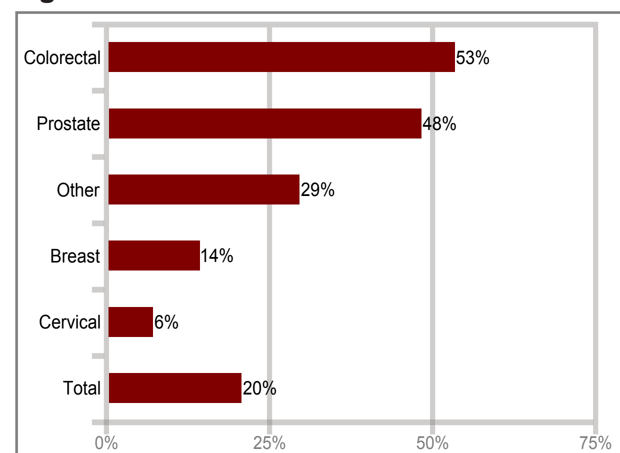
Figure 8: Body Mass Index



Body mass index for these participants is another issue that may impact treatment. As seen in Figure 8, over half of participants enrolled are obese (BMI above 30). The relatively younger cervical participants are the exception here, with only about one third in the obese category. However, another third are overweight, which may indicate a trend towards increasing BMI as these women get older. This can lead to co-morbidities and make treatment more difficult.

Co-morbid conditions identified by the study are those included in the Charlson Co-morbidity Index. The index comprises 15 major conditions including myocardial infarction, congestive heart failure, renal and liver disease, AIDS and diabetes. Overall, 20 percent of all participants enrolled have at least one co-morbid condition; however it varies widely between cancer sites. About half of the participants who have a colorectal or prostate abnormality or cancer diagnosis have a co-morbid condition. The most common is diabetes.

Figure 9: One or More Co-morbid Conditions



Characteristics of Encounters

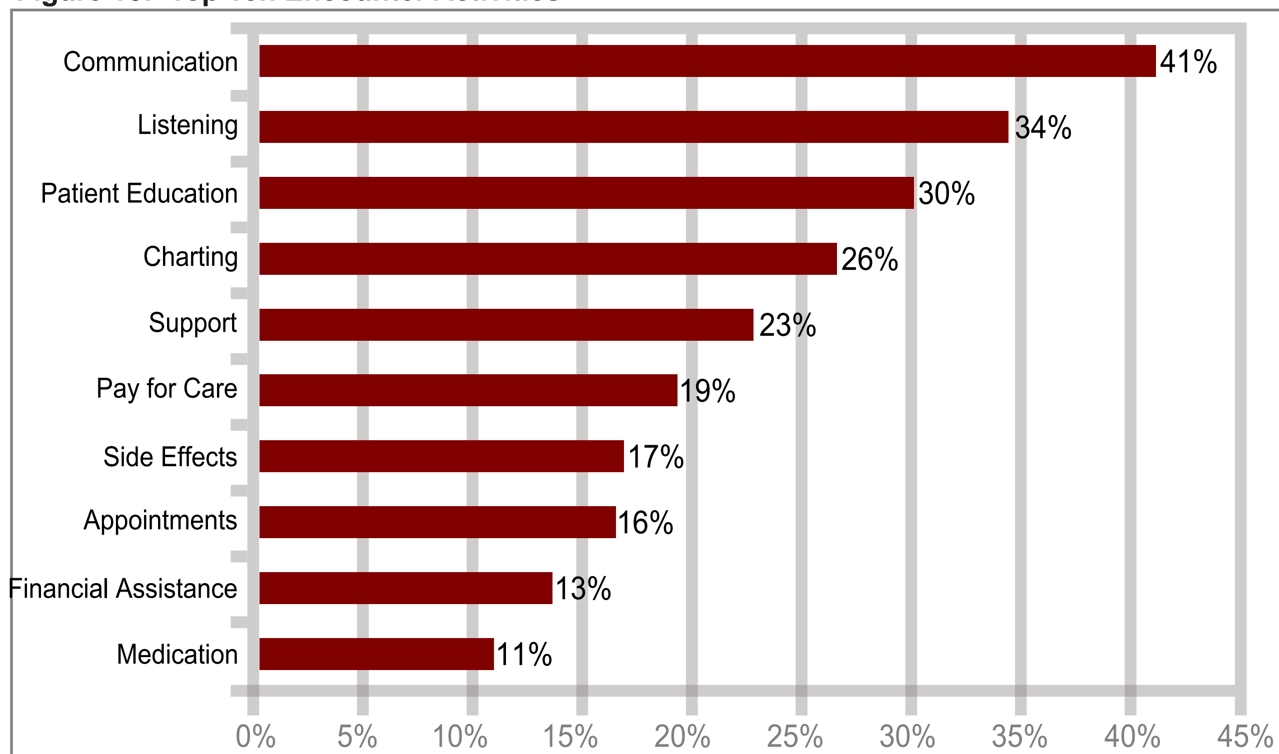
Overall, 1,490 encounters have been documented at this time.

Patient "encounters" are similar to appointments that navigators have with participants. They are quite flexible in definition, and depending on the patient's needs they may take place at the clinic, as a visit to the patient's home, over the phone, or the navigator may accompany the patient to an appointment. Navigators may have encounters with the participants themselves, their family or friends, members of the health care team or someone else with whom the patient requests a meeting. Navigators routinely check in with participants to make sure they are feeling and coping well, and to give them updates on issues they are trying to coordinate such as benefit eligibility or obtaining gas vouchers. They may come to the home to make sure participants are correctly using medical equipment or taking medications at the right time. At the patient's request, navigators often attend milestone appointments with the participants, such as appointments to discuss the findings of biopsies, first chemotherapy or radiation treatments and so on. The navigator is the ideal patient advocate to attend appointments as they are emotionally removed from the situation and know the medical jargon better than most participants or their family members. They act as a translator of sorts, filtering through the overwhelming and foreign information to help participants understand what is being said.

Figure 10 shows the top ten encounter activities. The variety seen in this list gives some insight to the wide range of topics in which navigators must become expert. To be successful, navigators must know clinical details about the vast spectrum of cancer types, be able to translate medical literature into information to suit any level of health literacy, be able to tap into resources which provide financial assistance for bills, rent, utilities and other expenses that come under pressure during major illness, and be adept at finding low-cost options for care.

The most common skill navigators are asked to employ is coordinating care – communicating between members of the health care team, the

Figure 10: Top Ten Encounter Activities



patient, family, insurers and others to make the process run more smoothly and quickly. In this fractured system, it is clear that having one central person such as a navigator to pull together all the pieces of the puzzle is essential. Close to half of all encounters include at least some time spent on this kind of communication which includes bringing providers up to date on the case, helping participants communicate their needs, fears and preferences, and making sure the many programs designed to support medically needy participants are engaged to help where they are most essential.

Beyond these day-to-day practical tasks it is clear from these data that one of the most valuable skills navigators supply is the simple ability to listen to participants and make them feel less alone. While understanding that most navigators are not licensed counselors, they do listen and provide emotional support for their participants in one third of all encounters. This issue is also expanded upon in the "support" activity, which encompasses the work navigators do in referring participants to social workers or support groups when they need support beyond what the navigator can provide.

Navigators also spend a good deal of time charting. In addition to the data collection needed for this study and the standard clinic forms, this activity includes following up on test results, making sure charts and records are sent to the appropriate places, and making sure the many providers involved have the information they need to make decisions about the patient's case.

As this Figure 11 shows, navigators are required to be many things to many people. The job calls for the ability to problem solve very quickly, adapt easily and be creative. It is our hope that, as the field matures, the skill set needed to be a navigator will become clear and perhaps more streamlined. At this time, however, with navigation in its infancy, our navigators are paving the way and helping us to understand what is needed to guide participants through the system and get them the care they need.

The way in which navigators have to approach participants who are enrolled prior to diagnosis versus those who are enrolled after they have been diagnosed with cancer differs. For participants enrolled following an abnormal test result, navigators spend more time on patient education, charting and communication with providers.

For those enrolled after a cancer diagnosis, encounters focus on dealing with side effects and medications, financial issues and paying for care, and referral to social workers and other support providers.

Figure 11: Encounter Activities by Status at Enrollment

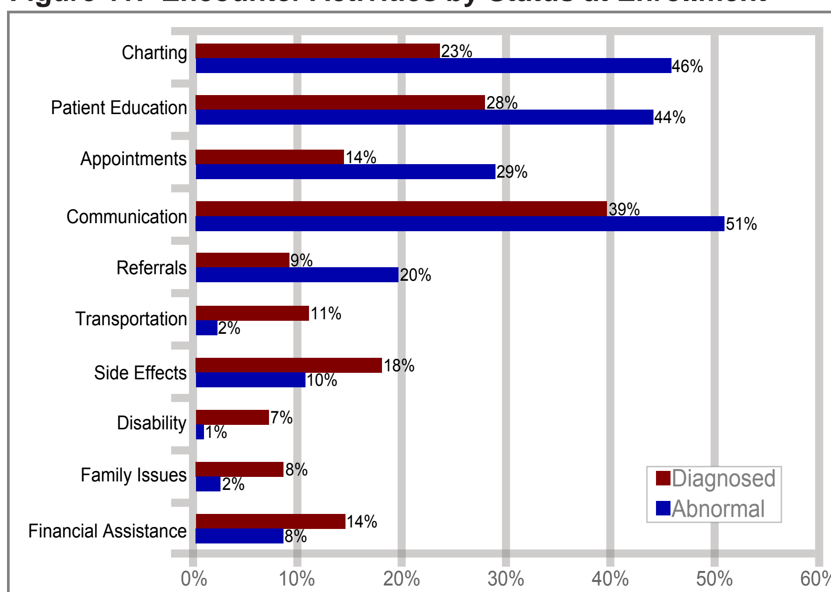
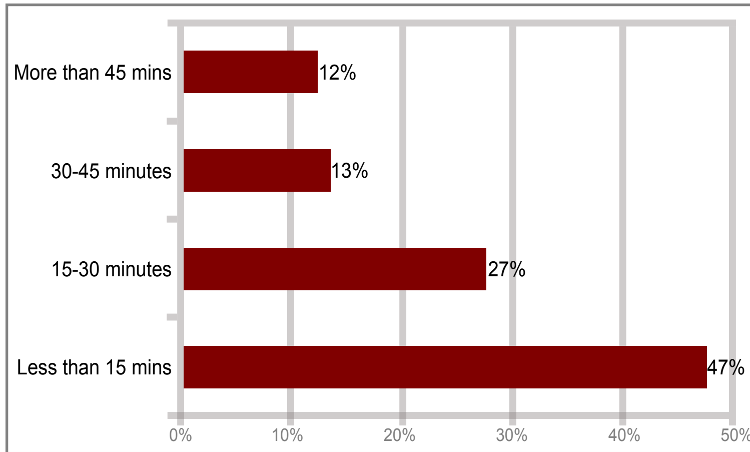
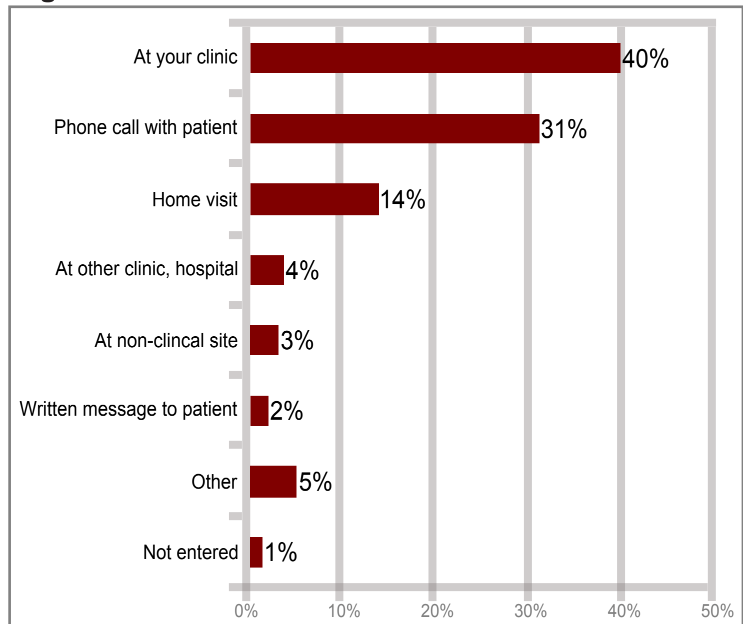


Figure 12: Encounter Length



Nearly half of all encounters are less than fifteen minutes long. These shorter encounters tend to be initiated by the navigator, for example a routine follow-up call. They are usually phone calls or appointments at the clinic. Longer encounters are usually home visits or accompanying the patient to an appointment.

Figure 13: Encounter Location



Most encounters take place at the clinic or through a phone call with participants. This varies a lot between navigators with some tending towards many more phone encounters and others more home visits or clinic appointments. This is influenced by clinic policies, the individual navigator's style, and the clinic population. For example, some clinics have a large proportion of participants for whom primary care is elsewhere. They may not live near the clinic or be seen there very often. In cases like these, navigators do more of their work over the phone.

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Appendix B: Eligibility Criteria

Breast, Cervical, Colorectal & Prostate Cancers

- Abnormal finding on clinical breast exam, Mammogram, Breast Ultrasound, or Breast MRI
- Diagnosis of breast cancer
- Abnormal Pap test result except ASCUS with negative HPV test, visual/suspicious lesion on cervix
- Diagnosis of cervical cancer or precancerous lesion
- Rectal bleeding or blood in stool in patients age 30 or older with referral to specialist
- Positive FOBT or guaiac with referral to specialist
- Palpable rectal mass with referral to specialist
- Abnormal sigmoidoscopy, virtual colonoscopy, double contrast barium enema, or colonoscopy without biopsy
- Diagnosis of colorectal cancer including CIS
- Abnormal DRE requiring referral
- PSA over 4 ng/ml
- PSA < 4 with abnormal PSA velocity requiring referral to or care by a urologist
- Diagnosis of prostate cancer

Other cancers

- Non-screenable cancers are a little more difficult to define eligibility criteria for, but Navigators will see any patients who have an abnormal finding that is suspicious for cancer or a cancer diagnosis.

Appendix C: Glossary

- **Pap Test** - a screening test for cervical cancer
- **Abnormal finding** - results of a cancer screening test which indicate something suspicious that requires further follow up to rule out cancer
- **Mammogram** - an x-ray of the breast to screen for breast cancer
- **Colonoscopy** - a screening test during which the doctor looks inside the large intestine. This test can identify pre-cancerous growths or cancer in the colon and rectum.
- **Stage** - describes how much the cancer has spread throughout the body. Stage is important because cancers caught at an earlier stage (i.e., less spread) are easier to treat and patients have a higher chance of surviving them.
- **Biopsy** - a small sample of tissue taken to determine whether or not a suspicious lump or area shows evidence of cancer, and if so what type.
- **ASCUS** (Atypical squamous cells of undetermined significance). Results of a pap test that show slight abnormality in the cells.
- **HPV** (human papillomavirus). A family of common viruses. If infected with certain HPV strains, it can increase the risk for cervical cancer.
- **FOBT** (fecal occult blood test). A screening test to check for hidden blood in the stool. The presence of blood can sometimes indicate colorectal cancer, although it can also be caused by many other conditions.
- **Guaiac** - A type of FOBT using the chemical guaiac to detect hidden blood.
- **PSA** (Prostate specific antigen). A substance produced by the prostate. High levels of PSA may indicate an enlargement of the prostate which may be due to an infection, benign condition or prostate cancer.
- **PSA velocity** - the rate at which a patient's PSA value changes over time.
- **IHS** (Indian Health Service) - Department of Health and Human Services agency responsible for providing federal health services to American Indians and Alaska Natives enrolled in federally recognized tribes.
- **RPMS** (Resource Patient Management System) - medical database used to record patient information.
- **Direct service or Direct Care** - services provided at an IHS or tribal health care facility.
- **CHS (Contract Health Services)** - funds used to contract with providers outside of IHS/tribal system for services not available at the IHS/tribal facility.
- **BMI** (Body Mass Index) - A ratio of height and weight used to determine if a person is at a healthy weight for their height.
- **Co-morbid condition** - two or more diseases present at the same time.

FEBRUARY 1, 2008

Smoke Signals

A Publication of the Grand Ronde Tribe

www.grandronde.org

UMPQUA ■ MOLALLA ■ ROGUE RIVER ■ KALAPUYA ■ CHASTA

New navigator helps cancer patients combat disease

Jasen Henderson aids people in tapping into resources

By Dean Rhodes
Smoke Signals editor

Perhaps one of the greatest life-changing moments is receiving a diagnosis of cancer.

The medical finding can detour patients from their comfortable daily routine to a scary, unanticipated journey.

Now, Grand Ronde Tribal members, their spouses and other members of Native American Tribes have an advocate at the Grand Ronde Health and Wellness Center to help them navigate the potentially confusing landscape of the cancer health care system.

Starting on Jan. 1, Jasen Henderson, who has worked for the Tribe for almost seven years and is a certified medical assistant, became the clinic's cancer navigator.

Henderson's new job entails helping cancer patients with understanding their diagnosis, managing their medications, figuring out how to pay for treatment, making and finding transportation to appointments, communicating with

See NAVIGATOR on page 3

Photo by Dean Rhodes

New Tribal cancer navigator Jasen Henderson will help patients battle cancer. Henderson has worked at for the Tribe for almost seven years.

FEBRUARY 1, 2008 SMOKE SIGNALS 3

Goal is timelier, better cancer care

NAVIGATOR continued from front page

doctors and, if necessary, assisting with other family needs.

Bottom line, the navigator helps patients receive timelier and better cancer care.

Henderson's new position is funded by a $5 million National Cancer Institute grant to the Indian Health Board for a trial cancer navigator program. It is part of the Northwest Tribal Epidemiology Center's five-year research program to find out if the navigator model – used successfully to improve cancer care in other underserved communities, such as African-American breast cancer patients in Harlem – can cut cancer deaths among Native populations.

In addition to the Grand Ronde Health and Wellness Center receiving funding for a cancer navigator, the Shoshone-Bannock Tribe in Idaho, the Siletz Tribe in western Oregon and the Yakama Tribe in eastern Washington are participating.

Currently, Native American cancer patients are more likely to be diagnosed in the later, more virulent stages of the disease and, consequently, have lower chances of survival than other racial or ethnic groups in the United States because of a lack of access to adequate cancer screenings and treatment.

Also affecting the Native American cancer death rate are funding limitations in Tribal health care systems, and cultural, social and geographic hurdles.

"There is an incredible need," Henderson said, citing the number of Grand Ronde Tribal member deaths attributed to cancer in recent months. "I felt sorrow for people who couldn't get help because the program was not yet in place."

> *"I try to help people stay headstrong, in high spirits, and I tell them this can be a life-changing event, not a life-ending one."*
> **~ Jasen Henderson, Tribal cancer navigator**

The navigator program does not pay for medical appointments or medication. However, Henderson, through networking, can help Tribal cancer patients tap into funding sources to pay medical bills or find support groups to help in the battle against the disease.

Currently, Henderson said he has a list of 15 Tribal members who are in varying degrees of battling cancer, from remission to receiving treatment.

Henderson said he has contacted 17 organizations from Salem to McMinnville to Portland that provide financial and emotional resources to cancer patients. In addition to finding financial support for cancer patients, one of Henderson's goals is to start a Grand Ronde cancer support group to provide the emotional bolstering patients also need.

"There is nothing local," he said. "Not even in McMinnville."

Among his many goals, Henderson said outreach and education are priorities because increased awareness about cancer screenings can help lower the death rate among Native Americans. As with any disease, the earlier cancer is detected, the better the chance a patient will survive.

"Screenings are the first line of defense against cancer," Henderson said. "I want to increase awareness about when and where screenings are offered."

He said Oregon Health and Science University in Portland will be offering free screenings for breast and cervical cancer on Saturday, March 1. There will be no fees. For more information, Tribal members can call 503-418-4506.

Lung, colorectal and breast cancers are the top three that affect Native Americans.

Henderson receives his clients through a physician referral. When a patient is diagnosed with cancer, he or she is given Henderson's information.

Patients, however, still decide how much, if any, of their cancer journey they want to share with a navigator.

"I try to help people stay headstrong, in high spirits, and I tell them this can be a life-changing event, not a life-ending one," Henderson said. "The gratification that I get from this job is in helping people."

As part of the program, Henderson will collect data that will hopefully show that the navigator model is effective in reducing the cancer death rate among Native Americans. These numbers, in turn, could affect future Congressional funding for Native health care.

Tribal members, spouses or other Native American Tribal members who would like to contact Henderson can reach him at jasen.henderson@grandronde.org or by calling 503-879-1395.

The cancer navigator service is available to all Grand Ronde Tribal members, no matter where they live, Henderson added. ■

HEALTH
Updated
April 10, 2008

Cancer: Key is prevention

By Leah Hardy,
Cancer Patient Navigator

It is interesting that most of us take better care of our vehicles than our bodies.
In fact, most of us will take our car in for a routine oil & lube to prevent future costly repairs but put off monthly and annual health exams that can prevent illness or disease. In truth, it is more costly both physically and financially to overcome an extensive illness; Cancer being one of those unexpected incidences. The key here is Prevention and Early Detection.

The American Cancer Society states that colorectal cancer is the third most common cancer for men and women but the second leading cause of cancer-related deaths for both sexes. Many of us are not aware that Colorectal (colon & rectum) Cancer is regarded as one of the most preventable types of cancers simply because it develops slowly.
Colon cancer begins with abnormal tissue growths called polyps. Occasionally polyps develop within the colon and if left untreated, may become cancerous. Since polyps develop slowly there is time to find the growth and remove them; several procedures are available to detect polyps with little discomfort.

Certain risk factors may increase your risk of developing colorectal cancer such as tobacco use, alcohol consumption, obesity, a diet high in fat and low in fiber, and inactivity. In its early stage, colorectal cancer may have no symptoms until the disease has advanced. Symptoms may include: Changes in bowel habits — diarrhea or constipation; Rectal bleeding; Blood in or on stool/s; Decreased appetite and/or weight loss; Abnormal weakness or fatigue; Vomiting Persistent abdominal discomfort- cramps or pain. Successful treatment of colorectal cancer is greatest when it is detected early. If you are 50 years and older, you should begin annual screening for colon cancer, but if either of your parents had been diagnosed with colon cancer, you should seek screening ten years ahead of the recommended guideline. It should be noted that colorectal cancer may occur in individuals younger than 50 in either sex and is preventable with a healthy lifestyle. If you have any questions, please contact your health provider. For further information on colorectal cancer contact the Cancer Patient Navigation Program at 238-5435.

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WHEN - Thursday May 15th 2008 / 6pm - 7pm

WHERE - Adult Education

COME JOIN US

Dinner and prizes will be provided

Please Contact :
Jasen Henderson, Cancer Navigator to RSVP
503-879-1395 or
503-883-3497 (cell)

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