2019 **COMMUNITY HEALTH NEEDS ASSESSMENT:**

A REPORT TO THE COMMUNITY

FRED HUTCH / UNIVERSITY OF WASHINGTON
CANCER CONSORTIUM

OUR MISSION

Our goal is to eradicate cancer as a
cause of human suffering and death.

OUR VISION

To ensure cancer health equity for
all individuals in our catchment
area, regardless of race/ethnicity,
socioeconomic status, geographic
residence, or any other potentially
limiting factor.

LETTER TO THE COMMUNITY

Dr. Gary
Gilliland

*President and
Director*

Dear Community Members,

Fred Hutch/UW Cancer Consortium, a Comprehensive Cancer Center, is pleased to provide you this Report to the Community. The Consortium includes faculty and staff from Fred Hutch, the University of Washington (UW), Seattle Children's, and the Seattle Cancer Care Alliance (SCCA). As a Cancer Center, we are indebted to the communities we serve for their support of and commitment to the Consortium. As researchers, clinicians, and staff, we focus on cancer and related diseases and the impact they have on individuals, families, and communities. The story of cancer is a mixed one. On one hand, cancer's impact remains huge as it is the second leading cause of death in our country. Almost every family has had loved ones impacted by cancer. On the other hand, there are more cancer survivors now than ever before; almost 15 million people who have a history of cancer are still alive. The Consortium adds to that survival factor by developing treatment and cures for cancer.

The participating institutions in the Consortium work together across basic, clinical and public health sciences. Fred Hutch scientists address basic science, early detection, treatment and cures, and cancer survivorship. UW is a top-ranked scientific research institution. Seattle Children's is internationally recognized for advances in cancer, genetics, immunology, infectious diseases, injury prevention, and bioethics. SCCA brings together the leading research teams and cancer specialists of all three institutions (Fred Hutch, Seattle Children's, and UW Medicine) and provides clinical care to cancer patients. The Consortium is a National Cancer Institute-designated Comprehensive Cancer Center that successfully meets a spectrum of rigorous competitive standards associated with scientific and organizational merit. The Consortium supports collaboration and transdisciplinary research productivity.

We could not do our work without the support of our communities throughout western Washington. This needs assessment reflects the cancer incidence and mortality rates of different cancers in our region. It notes the barriers and facilitators encountered by individuals residing in the community we serve. We are committed to fighting cancer and related diseases in the region we serve. Thank you for taking time to read this report. Working together will help us address the cancer burden in western Washington.

Sincerely,

Gary

PATIENT IMPACT ON RESEARCH

FRED HUTCH/ UNIVERSITY OF WASHINGTON CANCER CONSORTIUM

Fred Hutch/University of Washington Cancer Consortium (the Consortium) is a research collaboration comprising Fred Hutch and its strong collaborators, the University of Washington (UW), Seattle Children's, and the Seattle Cancer Care Alliance (SCCA). The four participating institutions in the Consortium have a history of collaboration across the disciplines of basic, clinical and public health sciences.

- Fred Hutch scientists address basic science, early detection, treatment and cures, and cancer survivorship. Researchers at Fred Hutch pioneered bone marrow transplantation for the treatment of blood cancers and is home to the nation's first and largest cancer prevention program.

- UW is a top-ranked scientific research institution and its School of Medicine (UW SOM) is a leader in the training of physicians. UW School of Public Health (SPH) trains Master's and PhD students in the art and science of public health. Consortium members based at UW have primary faculty

MAP OF CONSORTIUM CATCHMENT AREA

Catchment Area

Expanded area of research
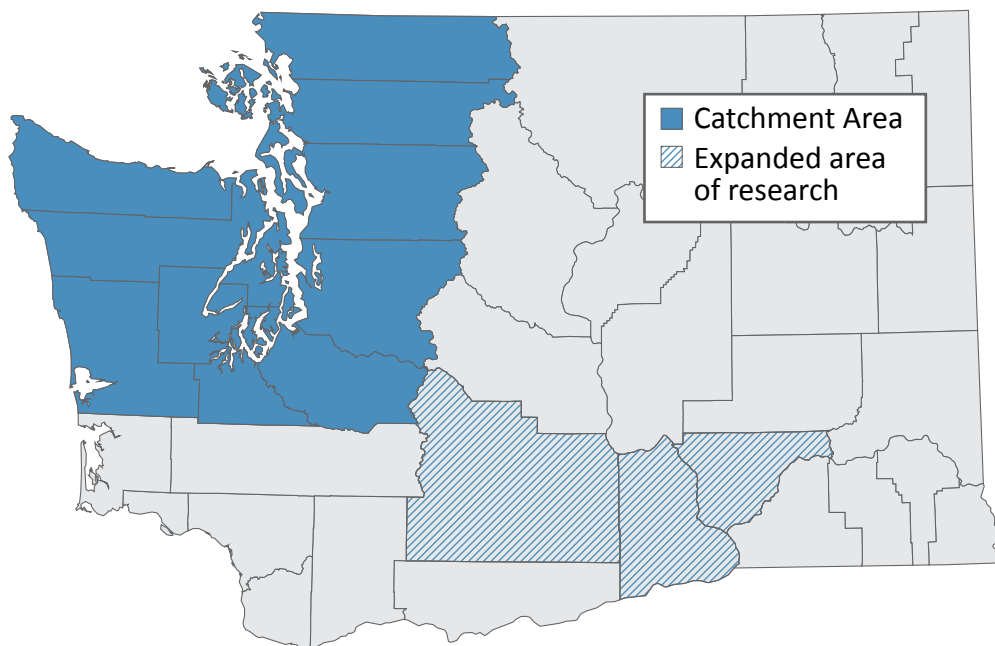
appointments in the UW SOM and UW SPH.

- Seattle Children's is internationally recognized for advancing discoveries in cancer, genetics, immunology, pathology, infectious disease, injury prevention and bioethics. Children's also serves as the primary clinical, research and teaching site for the Department of Pediatrics at the UW SOM

- SCCA is a nationally designated, prospective payment system exempt cancer center formed in 1998 by Fred Hutch, UW, and Seattle Children's. The SCCA provides an optimal environment for clinical treatment and research

by bringing the leading clinical research physician/scientists of the three outstanding partner institutions together in a single cancer care delivery system.

The Consortium is recognized as a National Cancer Institute (NCI)-designated Comprehensive Cancer Center through its dedication to developing research programs, faculty, and facilities that will lead to better approaches to prevention, diagnosis, and treatment of cancer. The Consortium brings together over 620 faculty with interests in basic science, clinical and translational research, public health sciences, and global health related to cancer.

THE OFFICE OF COMMUNITY OUTREACH AND ENGAGEMENT (OCOE)

The Consortium has long had an interest in reaching the population of Washington State. A significant step in starting to work with communities began in 2010 when Fred Hutch provided pilot funds for the Health Disparities Research Center (HDRC) under the direction of Dr. Beti Thompson. This work has included a NCI-funded National Outreach Network Community Health Educator (CHE) working in the HDRC since that time. After five years of pilot funding, the HDRC became a part of the Consortium in 2015. The HDRC partnered with community-based organizations (CBOs) serving underrepresented populations in the catchment area in order to promote cancer awareness and education. Since 2010, the HDRC engaged over 80 partners in the catchment area, ranging from CBOs serving non-Hispanic Black (NHB), Hispanic, Indigenous people, (referred to as American Indian/Alaska Native (AI/AN) in this report),and lesbian, gay, bisexual, transgender, queer (LGBTQ) communities, to medical centers, state and county health departments, and regional cancer-related organizations. In 2017, the HDRC became the central infrastructure of the Consortium's Office of Community Outreach and Engagement (OCOE) in order to better serve our population.

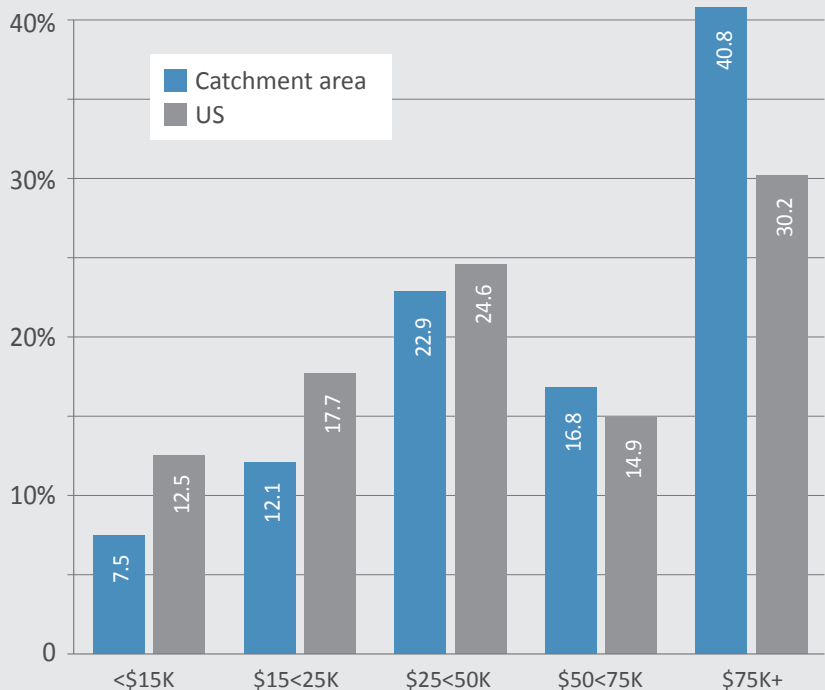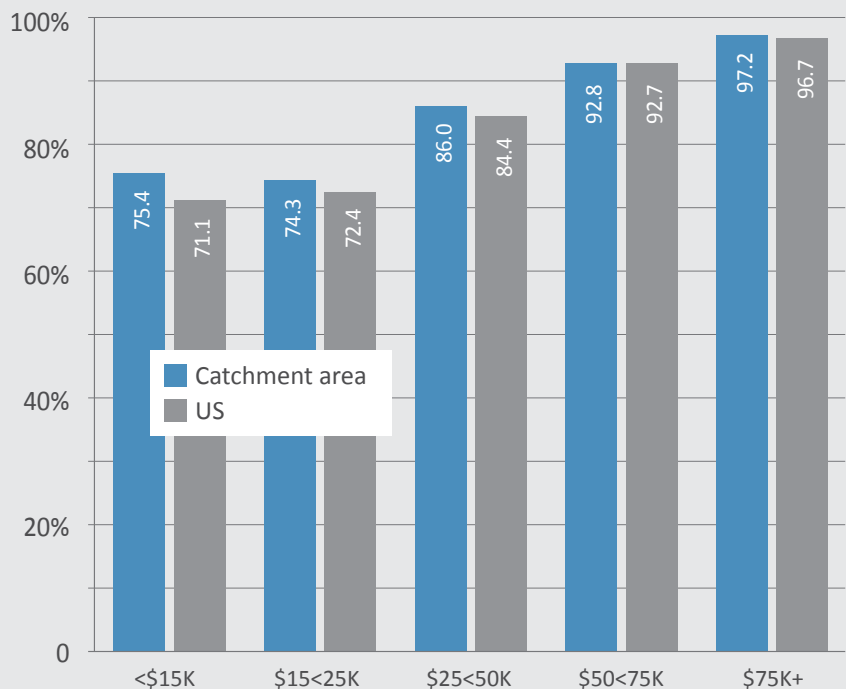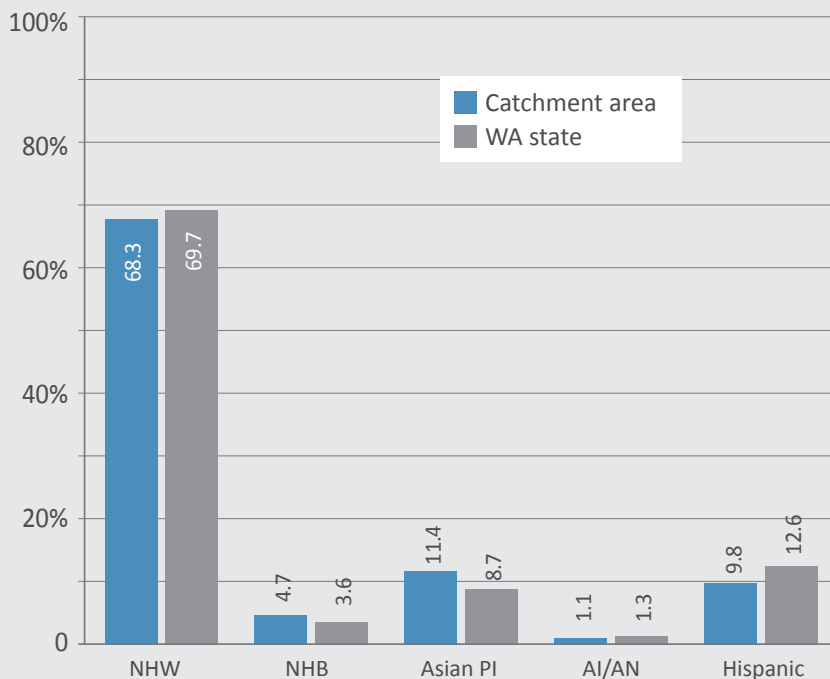FIGURE 2: DISTRIBUTION OF INCOME IN THE CATCHMENT AREA AND THE U.S.
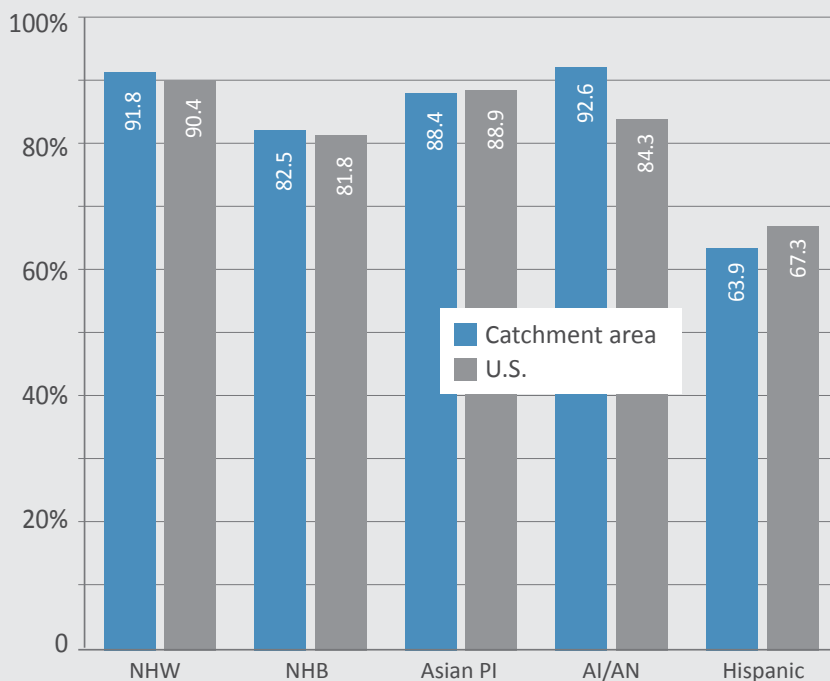

FIGURE 2: HAVE HEALTH INSURANCE, by income

Sources: Behaviorial Risk Factor Surveillance System (BRFSS), 2012-2016. Age Standardized to US Population, 2000

FIGURE 3: DEMOGRAPHICS*

Catchment area
WA state

	NHW	NHB	Asian PI	AI/AN	Hispanic
Catchment area	68.3	4.7	11.4	1.1	9.8
WA state	69.7	3.6	8.7	1.3	12.6

*Numbers do not add up to 100% because other/multiple/unknown not shown.
Source: Washington State Office of Financial Mangement, 2016

FIGURE 4: HAVE HEALTH INSURANCE, by race/ethnicity

Catchment area
U.S.

	NHW	NHB	Asian PI	AI/AN	Hispanic
Catchment area	91.8	82.5	88.4	92.6	63.9
U.S.	90.4	81.8	88.9	84.3	67.3

Source: Behaviorial Risk Factor Surveillance System (BRFSS), 2012-2016. Age Standardized to US Population, 2000

In November 2017, Dr. Jason "Jay" Mendoza became the Director of the OCOE and Dr. Thompson became Director Emeritus of the OCOE. The OCOE is a structured approach to making sure our Consortium reaches the communities we serve. Consisting of a number of Consortium faculty and staff, the OCOE has hired individuals who are specifically oriented to reach the communities we serve. This includes Community Health Educators (CHEs) who travel throughout the region, and Patient Navigators (PNs) who help patients manage the cancer treatment and control systems that exist in our Consortium.
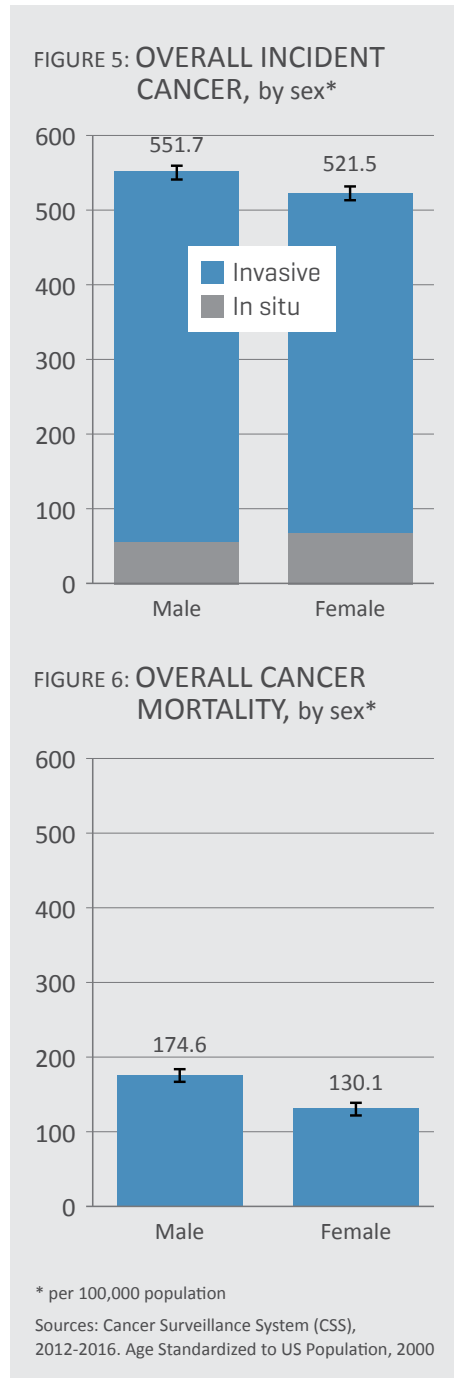
THE COMMUNITY WE SERVE

Our Consortium is partially funded by the NCI which mandates that all NCI-designated Cancer Centers, such as the Fred Hutch/ UW Cancer Consortium, identify the catchment area in which they are located. Catchment area refers to the geographical area that the Consortium serves. Our catchment area consists of the 13 counties west of the Cascade Mountains, south of the Canadian border, and north of Lewis county. As can be seen from the map on page 2, this area includes the main urban core of Snohomish, King, and Pierce Counties, as well as a number of rural counties.

Although not part of our catchment area, we serve other parts of Washington State. The cross-hatched

area on the map signifies another area where the Consortium has a presence. This report, however, focuses on the solid blue colored catchment area, which includes over five million people, of whom 32.3 percent are racial/ethnic minorities. Of all the cancer cases seen by the Consortium, 83 percent come from this catchment area. Our catchment area is fortunate in that the area is covered by the NCI's Surveillance, Epidemiology, and End Results program (SEER) registry that assesses cancer rates in the area.

The catchment area is evenly distributed by gender with 50.1% females and the remainder males. Graphs (Figures 1 through 4) show some of the characteristics of individuals in our catchment area. From Figure 1, the income distribution in the catchment area is higher than that of the US as a whole, with almost 41% of individuals earning more than $75,000 annually. From Figure 2 we see that having health insurance varies by income with those who have lower income ($25,000 annually or less) being less likely to have health insurance. The catchment area is racially/ethnically diverse (Figure 3). Overall, having health insurance varies by race/ethnicity with NHB and Hispanics being less likely to have insurance (Figure 4). These figures are similar to those we see in the US as a whole.

In addition to providing the best cancer treatment and care in the region, we strive to benefit the communities and population in the

FIGURE 5: OVERALL INCIDENT CANCER, by sex*

FIGURE 6: OVERALL CANCER MORTALITY, by sex*

* per 100,000 population

Sources: Cancer Surveillance System (CSS), 2012-2016. Age Standardized to US Population, 2000

catchment area in a number of ways. Our CHEs travel throughout the region and talk with people about the cancer prevention and control challenges they face. In turn, they then work with local communities to address those challenges.

CANCER IN OUR CATCHMENT AREA

Our Consortium faculty and staff see the effects of cancer on individuals and their families every day. The overall burden of cancer is tremendous ranging from high treatment costs (National cost of cancer care is $157 billion in 2010 dollars), to individual emotional and physical challenges. Further, cancer is not only an individual disease; family members and caretakers are also affected and have a huge burden in caring for the cancer patient. Even survivors, whose numbers increase every year, have extra burdens such as related illnesses and chronic diseases that may be linked to their cancer treatment.

Perhaps most concerning are the challenges faced by specific groups of people. Racial/ethnic cancer disparities have continued for decades. NHBs nationally have higher cancer incidence rates and death rates than any other ethnic group. Hispanics, while having lower rates of many cancers, have high death rates from many cancers. AI/AN have higher incidence rates of most cancers and have very high death rates from cancer. Other groups that suffer from disparities are those people who have lower rates of education and income. Not only are they hampered by lack of insurance for treatment, they also have lower general health rates than those with higher education and income levels.

FIGURE 7: TOP 5 CANCER INCIDENCE SITES
Incidence per 100,000

Legend: Lung, Prostate, Breast, Colorectal, Hematologic

Year of diagnosis
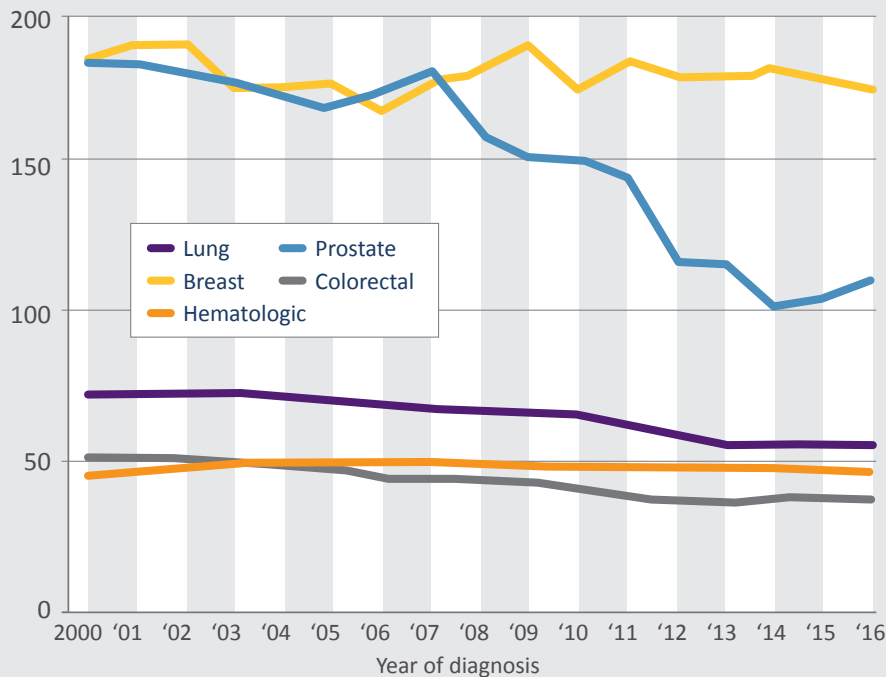
Source: Cancer Surveillance System (CSS), 2012-2016. Age Standardized to US Population, 2000

FIGURE 8: TOP 5 CANCER MORTALITY SITES
Mortality per 100,000

Legend: Lung, Prostate, Breast, Colorectal, Hematologic

Year of death
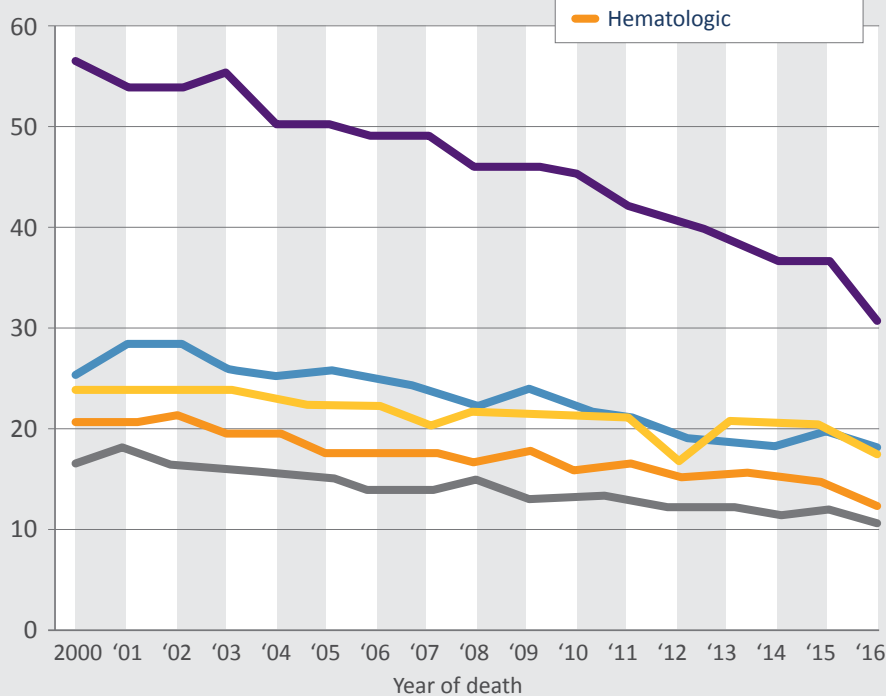
Source: WA state death certificates, 2016

In the pages that follow, we will provide graphs on some cancers in our catchment area. There are things to know as you read these graphs. First we talk about "cancer incidence." These are the rates of new cancers diagnosed annually per 100,000 population; the lower the number, the lower the rate of cancer in the community. So an overall cancer incidence rate of 551.7 for males is higher than that of 521.5 for females. Secondly, we talk about "cancer mortality" which are the rates of cancer-related deaths per 100,000 people. For mortality rates, the lower rate is better, so an overall cancer mortality rate of 130.1 for females is better than that of 174.6 for males. We will begin by looking at cancer incidence and mortality rates by race/ethnicity in our catchment area compared to the US averages.

As with the rest of the US, cancer rates are higher for males than females. From Figure 5, we note that there are two types of cancers for both males and females. In situ cancers are those that remain in place where they are first formed; this is also called stage 0 disease. Invasive cancers are those that have spread beyond the layer of tissue in which they developed and are growing into surrounding healthy tissue. Invasive cancers are more common than in situ ones. In Figure 5, the incidence of cancer is 551.7 for males in our catchment area. This means that the average incidence in the time period 2012 to 2016 was

551.7 cases per 100,000 population members for males.

Figure 6 shows the mortality rate in the catchment area. Note that mortality is much lower than incidence because many cancers can be cured. For men, the mortality rate was 174.6 per 100,000 compared to 130.1 per 100,000 for women.

The top five incident sites for the catchment area are breast, prostate, lung, hematologic, and colorectal, which is consistent with national data. The next five incident sites are melanoma (invasive), endometrial, bladder, kidney, and thyroid (results not shown).

The incidence rate ranges from a high in 2016 for breast cancer to a low in that same year for colorectal cancer. The mortality rates for these cancers are shown in Figure 8. Lung cancer remains the primary cause of cancer deaths, followed by breast and prostate, then hematologic and colorectal cancer.

Not all race/ethnic groups experience identical rates of cancer incidence or mortality. Looking at lung cancer (Figure 9), incidence is highest in NHBs, and AI/AN and lowest in Asians and Hispanics. Similarly, mortality is highest in AI/AN and NHBs and lowest in Asians and Hispanics.

For breast cancer, (Figure 10) NHW women have the highest incidence of breast cancer, but mortality is highest
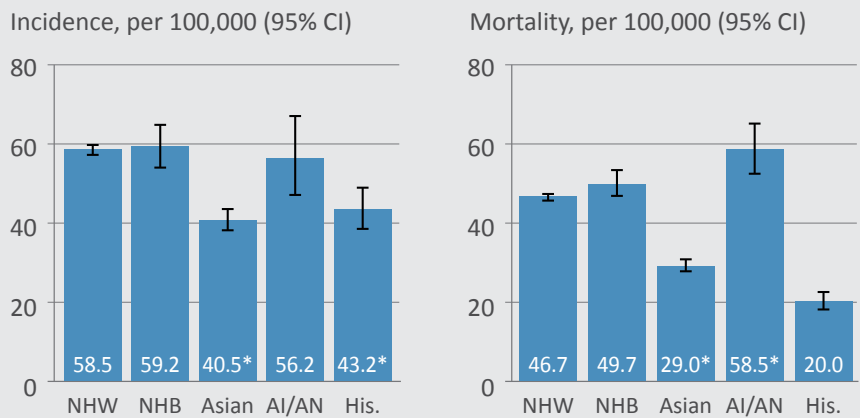
FIGURE 9: LUNG CANCER BY RACE/ETHNICITY 2012-2016

Incidence, per 100,000 (95% CI)

Mortality, per 100,000 (95% CI)

FIGURE 10: BREAST CANCER BY RACE/ETHNICITY 2012-2016

Incidence, per 100,000 (95% CI)

Mortality, per 100,000 (95% CI)
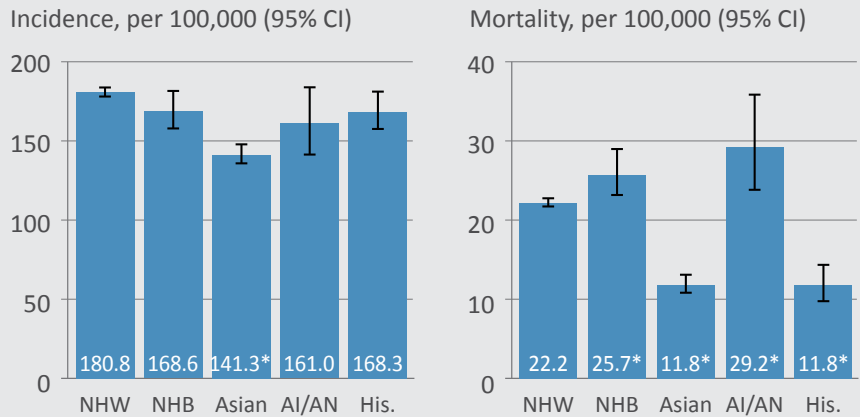
FIGURE 11: PROSTATE CANCER BY RACE/ETHNICITY 2012-2016
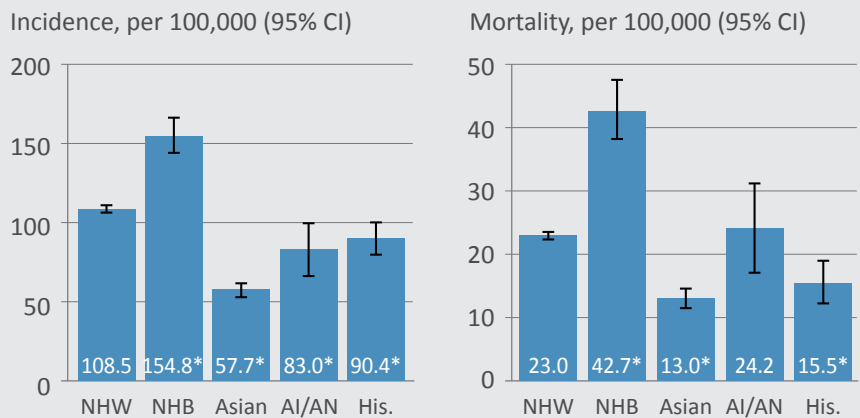
Incidence, per 100,000 (95% CI)

Mortality, per 100,000 (95% CI)

* Rate differs from that in NHWs
Sources: Cancer Surveillance System (CSS) & WA State Death Certificates, 2012-2016 Age-standardized to US population, 2000.

FIGURE 12: COLORECTAL CANCER, by race/ethnicity 2012-2016
Incidence, per 100,000 (95% CI)   Mortality, per 100,000 (95% CI)

NHW	NHB	Asian	AI/AN	His.
36.5	40.4	33.0*	43.0	37.7

NHW	NHB	Asian	AI/AN	His.
14.1	18.7*	10.8*	20.7*	9.5*

FIGURE 13: HEMATOLOGIC CANCER, by race/ethnicity 2012-2016
Incidence, per 100,000 (95% CI)   Mortality, per 100,000 (95% CI)

NHW	NHB	Asian	AI/AN	His.
47.5	46.7	30.2*	35.2*	41.0*

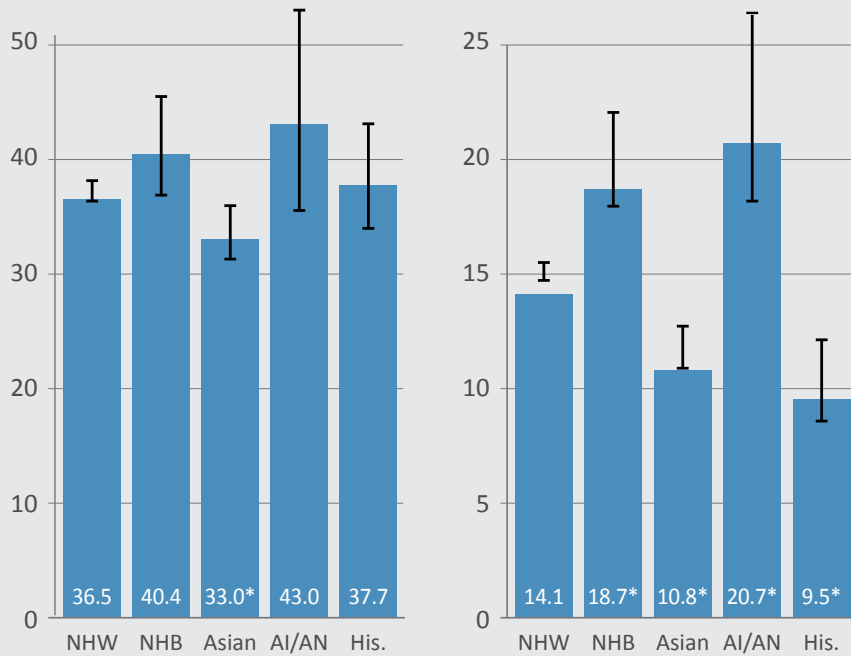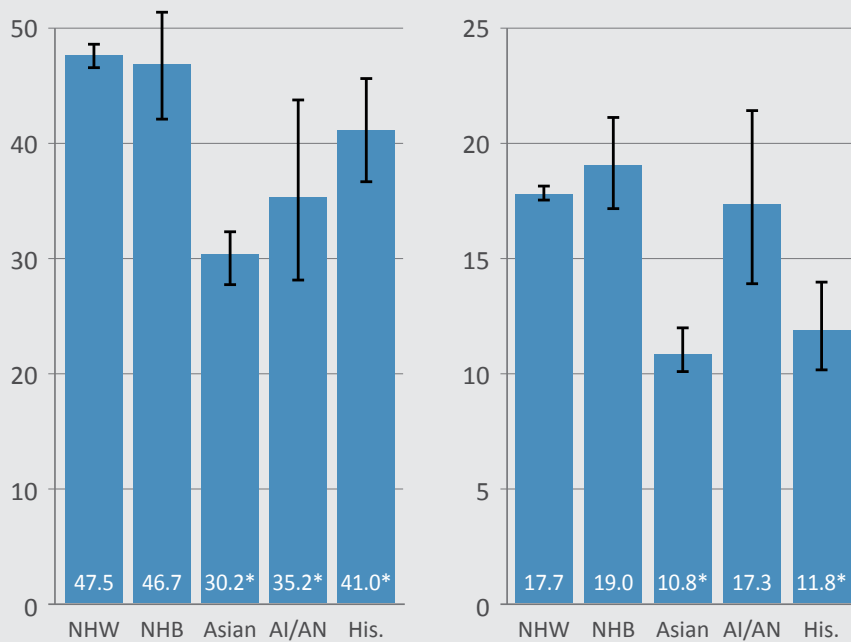| NHW	NHB	Asian	AI/AN	His.
17.7	19.0	10.8*	17.3	11.8*

*Rate differs from that in NHWs
Sources: Cancer Surveillance System (CSS) & WA State Death Certificates, 2012-2016 Age-standardized to US population, 2000.

in AI/AN and NHBs. Again Asians and Hispanics have the lowest mortality rates. Prostate cancer (Figure 11) has the highest incidence among NHBs. It also has the highest mortality with NHBs being almost twice as likely to die from prostate cancer than NHWs.

Colorectal cancer is shown in Figure 12. Incidence is highest among AI/AN, followed by NHBs and then Hispanics. Mortality is much higher for AI/AN followed by NHBs. Mortality rates are lowest for Asians and Hispanics.

Finally, hematologic cancers are shown in Figure 13. NHWs and NHBs have the highest incidence rates and Asians have the lowest rates. In mortality, NHBs are slightly higher than NHWs with the other three groups showing lower rates.

BEHAVIORS RELATED TO CANCER

Although it is often not clear what causes cancer, some behaviors have been linked with certain types of cancer. From the Behavioral Risk Factor Surveillance System (BRFSS) that assesses behaviors and health factors throughout the US, we know of certain factors that make a difference in cancer incidence and mortality. Smoking, for example, is closely linked to lung cancer with approximately 90% of lung cancers related to smoking. Smoking in our catchment area is slightly lower than that for the US overall (Figure 14). Overweight and obesity is linked to

a number of cancers including breast and colorectal cancers. Again, as seen in Figure 14 our rates are slightly lower than those for the US. Another factor thought to be protective against some cancers is aerobic physical activity such as running, walking, bicycling, etc. In the catchment area, people are more physically active than in the US as a whole.

Despite our success in keeping people from harmful behaviors, the results vary by race/ethnicity and are nowhere near the Healthy People 2020 goals. Healthy People 2020 provides science-based, 10-year national objectives for improving the health of all Americans. In terms of healthy behaviors, Figure 15 shows that all groups, with the exception of Asians, are higher than the Healthy People 2020 goals. This indicates that there remains much work to be done to reach those goals.

When examining the individual behaviors by race/ethnicity, we see that for smoking AI/AN have more than twice the smoking rates compared to NHWs (Figure 16). NHBs are also higher than non-Hispanic NHWs and Asians and Hispanics have the lowest rates.

NHBs, AI/AN and Hispanics are more likely to be obese than either NHWs or Asians (Figure 17). In terms of aerobic activity, Figure 18 shows NHWs as having the highest rates of physical activity with NHBs, AI/AN, and Hispanics having the lowest rates.

FIGURE 14: HEALTH BEHAVIORS
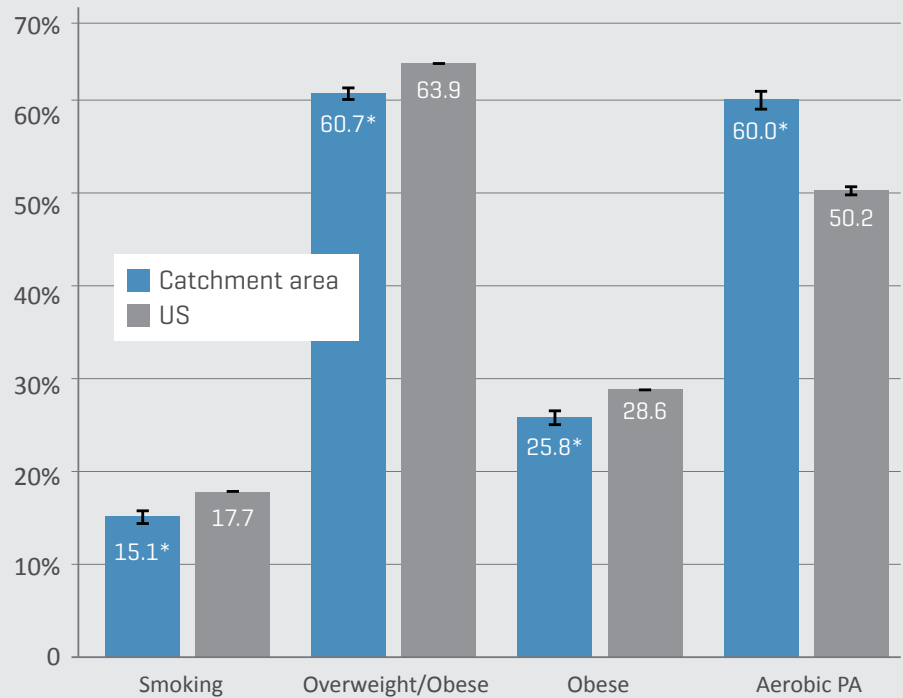
*Percent differs from overall US percent

FIGURE 15: HEALTH FACTORS, BY RACE/ETHNICITY
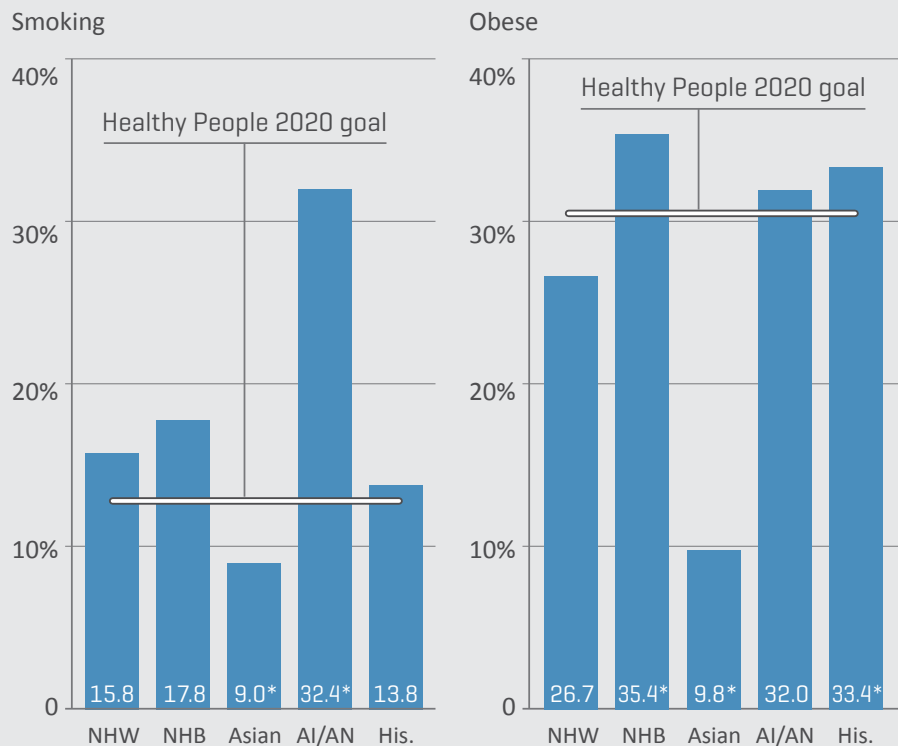
*Percent differs from that in NHWs
Source: Behaviorial Risk Factor Surveillance System (BRFSS), 2012-2016. Age Standardized to US Population, 2000

FIGURE 16: HEALTH BEHAVIORS,
Smoking, by race/ethnicity

	NHW	NHB	Asian	AI/AN	His.
	15.8	17.8	9.0*	32.4*	13.8

FIGURE 17: HEALTH BEHAVIORS,
Obese, by race/ethnicity
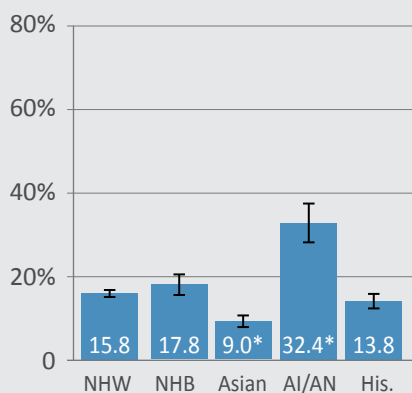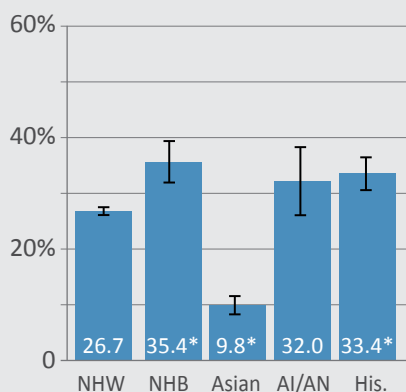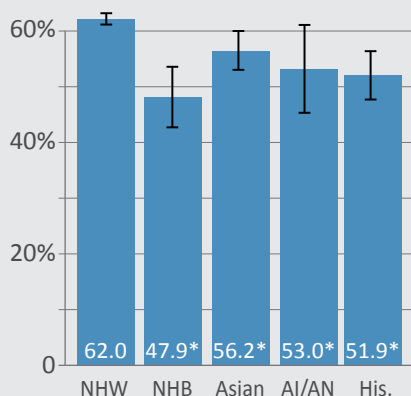
	NHW	NHB	Asian	AI/AN	His.
	26.7	35.4*	9.8*	32.0	33.4*

FIGURE 18: HEALTH BEHAVIORS,
Aerobic, by race/ethnicity

	NHW	NHB	Asian	AI/AN	His.
	62.0	47.9*	56.2*	53.0*	51.9*

*Percent differs from that in NHWs
Source: Behaviorial Risk Factor Surveillance
System (BRFSS), 2012-2016. Age Standard-
ized to US Population, 2000

We also examined behaviors by place of residence. Using the US Census definition of Rural-Urban Commuting Area Codes (RUCAs), we classified residences by urban core, suburban, large towns, and small town/rural to understand if there were differences in health-related behaviors depending on residence area. Figure 19 shows that smoking is less common in the urban core than other areas. For obesity, the highest rates are in the large towns, which also have the lowest rates for physical activity.

EARLY DETECTION OF CANCERS

Early detection is critical to cancer treatment and cure. Regular screening for various cancers leads to early detection when cancers are much more treatable. Screening is very common for specific cancers like breast cancer, colorectal cancer and cervical cancer. Although screening rates have been increasing over time, they are still below the Healthy People 2020 goals.

Screening rates are difficult to determine for racial/ethnic minorities. Although we sought to compare cancer screening rates for different racial/ethnic groups, it was clear that data for minorities was inadequate. The most commonly used data for screening behaviors comes from the Behavioral Risk Factor Surveillance System (BRFSS). Evidence indicates that BRFSS data gives a higher estimate for colorectal,

breast, and cervical cancer screening among racial/ethnic minorities and among those who are of lower socioeconomic status compared to the National Health Interview Survey, another way of obtaining national data. The differences observed in the data were significant and might be due to a number of factors, including low response rates of minorities, nonresponse bias, the wording of the questionnaires, the sampling scheme, or the validity of the survey. All of this suggests that caution should be used in interpreting rates of screening among marginalized populations, such as racial/ethnic minorities. Thus, we do not include comparisons among racial/ethnic minorities for cancer screening in this document.

We can, however, look at comparisons for screening in urban and rural areas. Figure 20 shows that women residing in urban areas are more likely to receive a mammogram and to be screened for breast cancer than those residing in rural areas. Mammography is the usual screening mechanism and mammography units are more likely to be in urban compared to rural areas. From the graph, we see that women who live in rural areas or small towns are considerably less likely to have had a mammogram than women living in urban areas.

Almost 90% of colorectal cancer can be prevented if people are screened for it.   Screening involves one of two major types. Annually, individuals can have a stool test to check for blood

in the stool. If that test is positive, they need a colonoscopy to identify polyps and potentially, cancerous cells in the colon. A colonoscopy is an endoscopic procedure where a scope examines the entire colon, looking for and removing pre-malignant polyps. The US Preventive Services Task Force recommends screening for colorectal cancer in adults beginning at age 50.

Although colorectal cancer screening varies by the type of test used, we are still a long way from reaching the Healthy People 2020 goal of 80% screening for colorectal cancer. Results also vary by urban/rural residence. In Figure 21, we see rural populations are slightly less likely to be screened for colorectal cancer than urban populations; further, none of the rates reach the 80% goal.

Cervical cancer has greatly decreased with the advent of the Papanicolau (Pap) test. Despite the success of the Pap test, screening rates remain less than optimal. Again, women in rural areas are less likely to be screened than women in urban areas. Figure 22 shows the rates of cervical cancer screening by means of the Pap test decrease as one goes from urban to rural areas.

Figure 23 compares screening rates in our catchment area, that is those who have met the screening guidelines, compared to the US rates. For mammography, the rates are similar although slightly lower for the catchment area. Pap screening is also

slightly lower. Only colorectal cancer screening is slightly higher for our catchment area than for the US.

Even more impressive is the discovery of the role of the human papillomavirus (HPV) and the development of a vaccine that is effective against HPV. If girls and boys are vaccinated against HPV, cervical cancer would virtually disappear. Rates of HPV vaccination remain low. The map in Figure 24 shows HPV vaccination rates throughout the catchment area. The urban cores have the highest rate of completion with the more rural cores having the lowest rates. Even in the urban cores, the rates are well below those desired for an anti-cancer vaccine. Besides being effective against cervical cancer, HPV vaccination prevents some head and neck cancers.

WHAT DOES OUR COMMUNITY THINK?

We spent some time trying to understand what our communities thought the successes, barriers, and challenges were to dealing with cancer in our catchment area.

WHAT THE COMMUNITY SHARED: BARRIERS

The data on rates of cancer tell us much about cancer in the catchment area, but are not the whole story. To understand the factors related to cancer prevention and control, we need an appreciation of the

FIGURE 19: HEALTH BEHAVIORS, Smoking, by RUCA category

Urban Core 14.3 | Suburban 19.8* | Lg. Town 21.5* | Sm. Town/Rural 19.9*
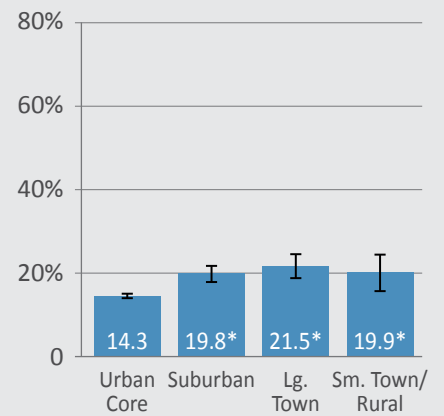
HEALTH BEHAVIORS, Obese, by RUCA category

Urban Core 25.1 | Suburban 28.6* | Lg. Town 33.5* | Sm. Town/Rural 27.8
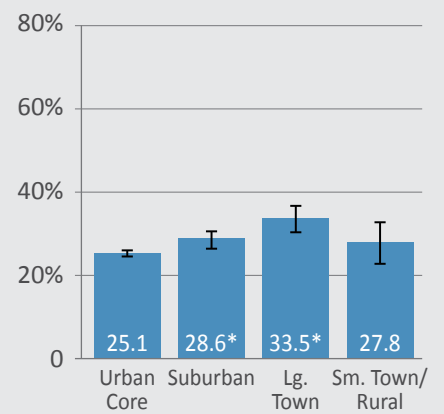
HEALTH BEHAVIORS, Aerobic, by RUCA category
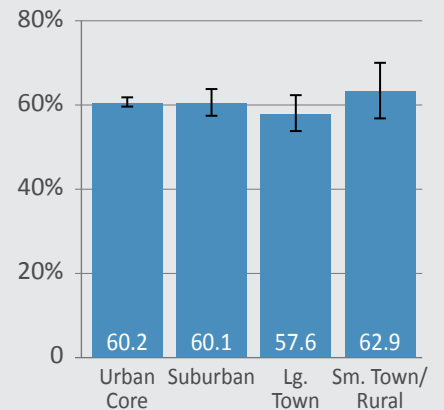
Urban Core 60.2 | Suburban 60.1 | Lg. Town 57.6 | Sm. Town/Rural 62.9

*Percent differs from that in urban core
Source: Behaviorial Risk Factor Surveillance System (BRFSS), 2012-2016. Age Standardized to US Population, 2000

FIGURE 20 **SCREENING RECOMMENDATIONS,** Mammogram, RUCA

	Urban Core	Suburban	Lg. Town	Sm. Town/ Rural
	78.7	73.8*	73.7	72.4*

FIGURE 21 **SCREENING RECOMMENDATIONS,** Colorectal cancer, RUCA

	Urban Core	Suburban	Lg. Town	Sm. Town/ Rural
	72.5	69.8	69.8	67.5
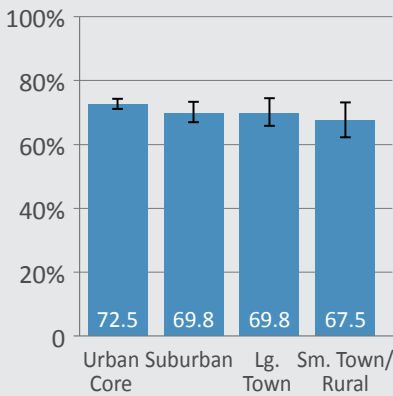
FIGURE 22 **SCREENING RECOMMENDATIONS,** Pap test, RUCA
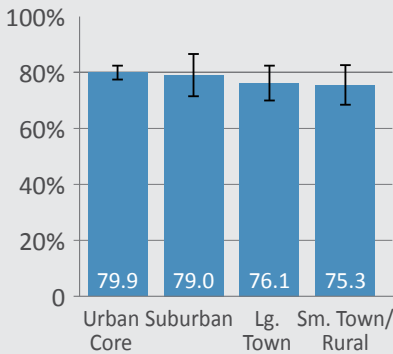
	Urban Core	Suburban	Lg. Town	Sm. Town/ Rural
	79.9	79.0	76.1	75.3

*Percent differs from that in urban core
Source: Behaviorial Risk Factor Surveillance System (BRFSS), 2012-2016. Age Standardized to US Population, 2000

human experience that is linked to cancer. So, although we may note that cancer rates are higher in a particular county or ethnic group, we need to u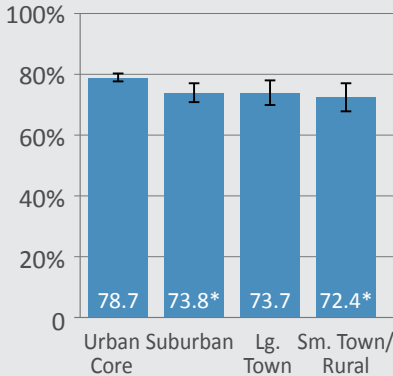nderstand why they are higher. To do this we turn to people in the catchment area. Talking with people about the barriers and facilitators that affect cancer-related behaviors helps us to understand the context within which cancer prevention and control occurs.

We reached out to community organizations in our catchment area. We spoke with 32 individuals about the challenges as well as facilitators of meeting cancer needs in their specific areas. Our interviewees represented community-based organizations (n=16), state and county health departments (n=10) and healthcare providers (n=6). The following sections reflect their experiences.

ACCESS TO CARE

Many of our informants talked about the problems in obtaining access to care. They noted that specific populations suffered discrimination in obtaining care. One individual commented that the American Indian community was not provided adequate treatment at specific clinics and hospitals. Another commented that the Black community was not receiving early, adequate treatment once they were diagnosed. Others noted that the diversity of languages in the catchment area meant that interpreters were needed and this affected the kind of care they received.

Another access to care factor focused on screening. Respondents stated that screening guidelines were often not consistent with reality. For example, the guidelines for breast cancer screening focus on women aged 50 and older, but many NHB women develop breast cancer at earlier ages. Another factor related to screening was the cost and availability of screening. As one respondent noted, funding for rural areas was limited because state funding gets smaller and smaller as one goes to less populated areas. An example is quit smoking programs which are sorely needed in rural American Indian communities, but where resources for such programs are scarce.

Insurance gaps were identified as a major barrier to cancer prevention and control. The programs that cover screening do not necessarily cover treatment and vice versa. Although Washington is an "expansion state" for Medicaid, many individuals remain uninsured or underinsured. A further issue is that even with insurance, many of the rural areas have problems finding primary care providers to make recommendations regarding screening.

Our interviewees also noted that there was an overall lack of resources available to community members. They noted that we need simpler, more visual materials to reach individuals of minority status and those with low English
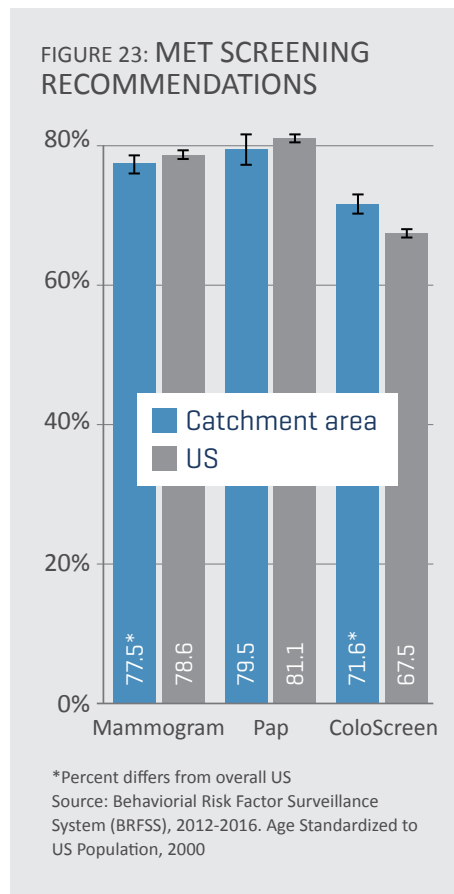
proficiency. Further, individuals commented on the need for materials in languages other than English and Spanish.

Finally, in access to care, our respondents stated that there was a lack of coordination of efforts. There was a stated belief that organizations and healthcare facilities were not sharing information with each other so that people could take advantage of prevention or treatment initiatives. Respondents called for better communication between organizations so that funding and resources could work together.

THE SOCIAL CONTEXT

The influence of the social context was frequently mentioned by respondents. Mistrust and fear were two ideas often expressed by the people with whom we spoke. Many ethnic populations have experienced social injustices that affect how they see scientists and the health care system. As a result, the population views institutions such as the Consortium with mistrust which can impact cancer prevention and control efforts.

Language and culture were other barriers to cancer prevention and control. The fact that many materials are now in both English and Spanish was seen as positive, but other languages were lacking. It was often the case that a provider would use a patient's child as an interpreter for an adult patient. Similarly, cultural beliefs

FIGURE 23: MET SCREENING RECOMMENDATIONS

Catchment area
US

Mammogram: 77.5* | 78.6
Pap: 79.5 | 81.1
ColoScreen: 71.6* | 67.5

*Percent differs from overall US
Source: Behaviorial Risk Factor Surveillance System (BRFSS), 2012-2016. Age Standardized to US Population, 2000

and attitudes play a role in cancer-related activities. In some cultures, for example, cancer is considered a very negative word and individuals do not wish to talk about it.

Another barrier in the social context was geographical location. The primary care physician shortages in rural populations affect cancer-related services. Similarly, distance from cancer care clinics are a barrier as individuals do not have the time or resources to travel to more urban areas.

THE INDIVIDUAL FACTORS

Navigating the healthcare system was described as a major barrier

for many individuals. This was especially true of individuals of low socioeconomic status and those who were previously uninsured or underinsured. In addition, individuals were fearful that they would have to pay high deductibles for healthcare services. Some noted that the lack of patient navigators was a real barrier to going through the health care system.

Health illiteracy was a significant barrier to cancer prevention and control. The very language of the health care field is full of jargon and often difficult to understand. It would be helpful to have individuals on staff who can put the language into more understandable formats.

Documentation was an issue for specific subpopulations. Lack of documentation made it difficult for such individuals to receive any kind of health care or screening.

WHAT THE COMMUNITY SHARED: FACILITATORS

Respondents identified many community facilitators in the different populations they served. One respondent noted the strength and resiliency of the American Indian community. They noted that American Indian individuals had the ability to laugh in the "face of darkness" and to find help in tribal communities, culture, and values. Others described the cohesion of subgroups as a strength. Leadership and motivation

were described as strengths of black communities, and the extended family of Hispanics was also seen as a strength. One person commented that families were a strength of many population groups and that diagnosis of a cancer led to support by the entire family.

Another facilitator mentioned by both urban and rural community-based organizations was the use of community health workers. Such workers are trusted members of the community and share language and cultural beliefs of the individuals they are reaching. The community health workers are often able to bring individuals into screening events as well as treatment clinics. Because they are like the people they serve, there is a deeply embedded sense of trust and acceptance.

CONSORTIUM INFRASTRUCTURE AND PLANS

The Consortium's Office of Community Outreach and Engagement (OCOE) has developed an infrastructure to make best use of the facilitators of the catchment area as well as to address the barriers. Our team consists of a number of faculty and staff who are committed to doing activities throughout the catchment area. Figure 25 describes the infrastructure of the OCOE. As can be seen, the infrastructure includes four Community Health Educators (CHEs) The four groups they focus on are

FIGURE 24: HPV VACCINATION RATES, CATCHMENT AREA

Percent complete

15.5%   37.5%

Source: WA State DOH
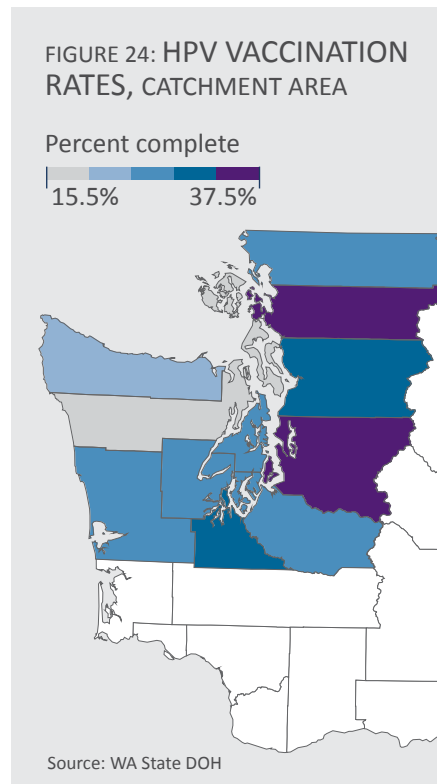
AI/AN populations, (Craig Dee) Black populations (Danté Morehead), urban populations (Liszet Bigelow), and rural populations (Dillon van Rensburg). These four CHEs will work throughout the catchment area to address the barriers to cancer prevention and control.

Another feature of the OCOE is the focus on patient navigators within the healthcare system. These navigators assist patients in navigating the system, answering payment questions, and ensuring that treatment is given in a timely way. Our navigators are Carmen Cunningham, Anne Devine, and Michelle Watson.

Each CHE and navigator is directed by a faculty advisor who is skilled in the particular area of concern.

For example, Dr. Myra Parker is an expert in AI/AN affairs and she works closely with the CHE for AI/AN populations. Dr. John Gore is experienced in cancers that affect the Black community. Dr. Wendy Barrington has expertise in urban populations, and Dr. Rachel Ceballos is a rural population expert. These four faculty meet regularly with the CHEs and leadership (Dr. Jay Mendoza and Ms. Kathy Briant) to carry out the mission of the OCOE. Dr. Casey Lion directs the activities of the patient navigators to ensure that individuals receive navigation through the healthcare system. Finally, Dr. Peggy Hannon focuses on screening activities, and Dr. Stephen Schwartz works with Mr. Dave Doody to ensure that all catchment area incidence and mortality rates are kept up to date. The entire team meets quarterly to review progress.

NEXT STEPS

Now that we have a needs assessment of the communities we serve, we need to discuss how to meet those needs. The Consortium has formed a Community Action Coalition (the Coalition) to help us address the needs. This coalition is made up of members from the 13 counties in our catchment area. The members are very aware of the barriers and facilitators to cancer prevention and control. The Coalition has met with OCOE faculty and staff to develop a five-year Strategic Plan for the Consortium's outreach

and engagement activities. The Strategic Plan will be the guide to introduce the Consortium's outreach and engagement activities to the communities in the catchment area. This can be considered the "Master Plan" or blueprint for implementing activities. Constructing this plan will be a major task; however, this needs assessment will guide input into the plan.

We asked the Coalition to begin the plan by conducting a SWOT analysis. SWOT stands for Strengths, Weaknesses, Opportunities, and Threats. The SWOT analysis is a framework used to evaluate an organization's position by identifying its strengths, weaknesses, as well as opportunities and threats in the landscape. Specifically, SWOT analysis is a foundational assessment model that measures what an organization can and cannot do, and its potential opportunities and threats. Some questions that are addressed in a SWOT analysis include the following:

- How can the Consortium achieve the goals and activities described in the needs assessment?
- How can the outreach and engagement activities be linked to research in the Consortium?
- What are some of the community characteristics that will affect intervention activities?
- What kinds of human, program, and in-kind resources will be needed to complete the activities?

As representatives from the catchment area, the Coalition knows a great deal about the catchment area. We are committed to involving the communities in the catchment area in our plans. Thus, we work closely with the Coalition on developing our strategic plan.

Once the Strategic Plan has been developed, we will all work together to prepare an Annual Action Plan. The Annual Action Plan will specify exactly:

- What will be done? (Project tasks)
- Who will do it? (Participants and their responsibilities)
- When will it be done? (Project objectives and deadlines)
- How much will it cost? (Resources development)
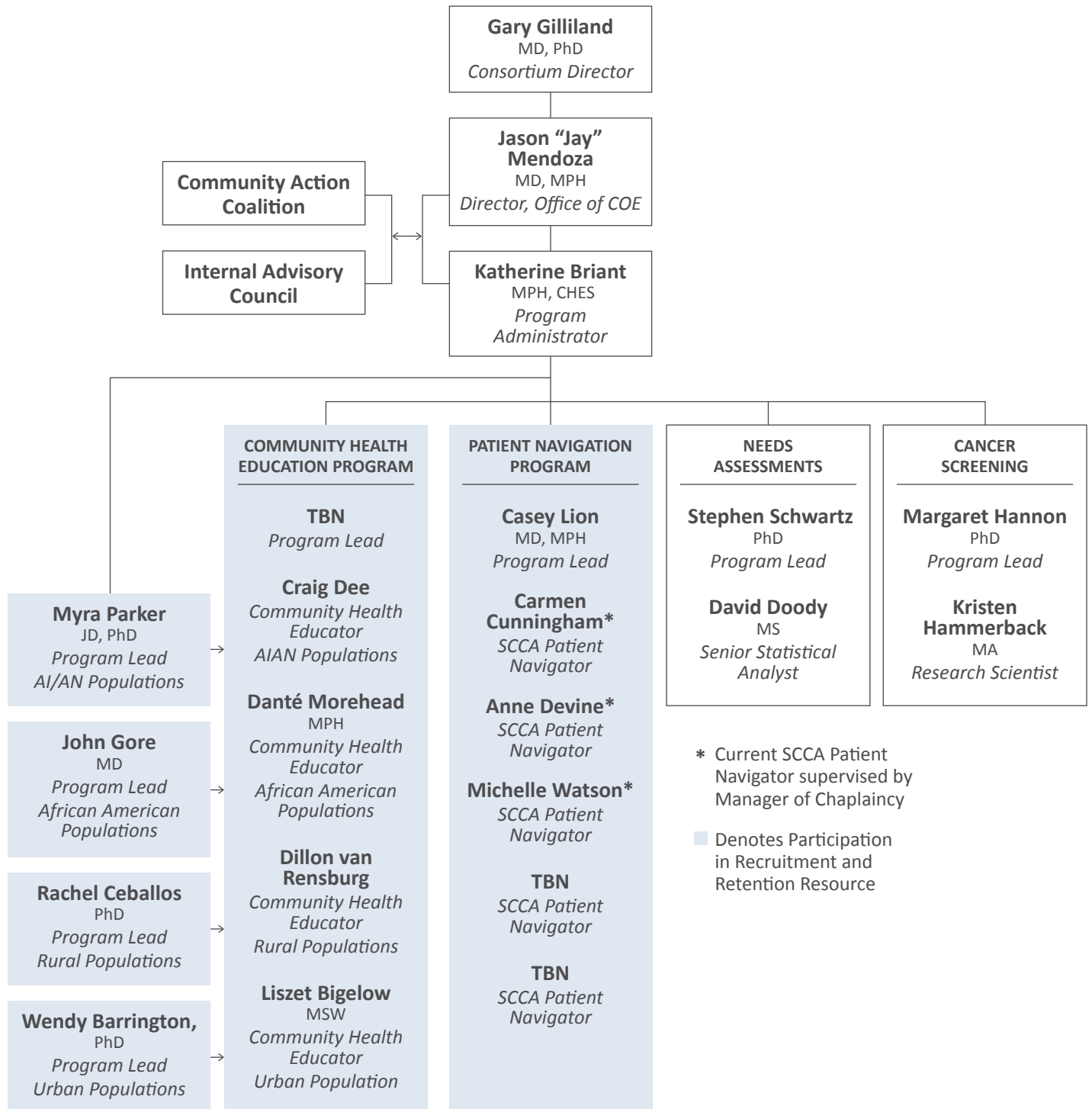- How it will be measured? (Evaluation)

Each year, the previous Annual Action Plan will be reviewed and the outcomes used to develop the next year's Annual Action Plan. The Coalition will be given materials describing how to develop each part of the plan as well as sample scenarios expressing how activities will be implemented.

The Community Action Coalition will be assisted by the Internal Advisory Committee (IAC). The IAC is a Consortium committee that serves

as the liaison between the Coalition and Consortium leadership to ensure that the Annual Action Plans receive the support of and resources from the Consortium. The IAC also will inform the Coalition of research findings or issues that may be important to the catchment area. For example, the finding that older women benefit from the HPV vaccine may mean that an Annual Action Plan includes activities to acquaint health care providers and older women of the importance of HPV vaccination. This bi-directional approach will lead to activities that benefit all.

In summary, the Consortium's OCOE is well poised to address the cancer burden in the catchment area. Our organizational structure shows we have the leadership, expertise, resources, and infrastructure to address the burden of key cancers in our catchment area. Further, we have experienced personnel to work on these issues. We have the capacity, people, and experience to deliver on our vision.

FIGURE 25: OCOE ORGANIZATIONAL CHART

Gary Gilliland
MD, PhD
Consortium Director

Jason "Jay" Mendoza
MD, MPH
Director, Office of COE

Community Action Coalition

Internal Advisory Council

Katherine Briant
MPH, CHES
Program Administrator

Myra Parker
JD, PhD
Program Lead AI/AN Populations

John Gore
MD
Program Lead African American Populations

Rachel Ceballos
PhD
Program Lead Rural Populations

Wendy Barrington,
PhD
Program Lead Urban Populations

COMMUNITY HEALTH EDUCATION PROGRAM

TBN
Program Lead

Craig Dee
Community Health Educator AIAN Populations

Danté Morehead
MPH
Community Health Educator African American Populations

Dillon van Rensburg
Community Health Educator Rural Populations

Liszet Bigelow
MSW
Community Health Educator Urban Population

PATIENT NAVIGATION PROGRAM

Casey Lion
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Program Lead

Carmen Cunningham*
SCCA Patient Navigator

Anne Devine*
SCCA Patient Navigator

Michelle Watson*
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SCCA Patient Navigator

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NEEDS ASSESSMENTS

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David Doody
MS
Senior Statistical Analyst

CANCER SCREENING

Margaret Hannon
PhD
Program Lead

Kristen Hammerback
MA
Research Scientist

* Current SCCA Patient Navigator supervised by Manager of Chaplaincy

Denotes Participation in Recruitment and Retention Resource