

Seattle Cancer Care Alliance Fred Hutch · Seattle Children's · UW Medicine

# 2016 Community Health Needs Assessment

# Better together.

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# Seattle Cancer Care Alliance's vision

is to lead the world in translating scientific discovery into the prevention, diagnosis, treatment and cure of cancer.

# Seattle Cancer Care Alliance's purpose

is to provide state-of-the-art, patient and family centered care; support the conduct of cancer clinical research and education; and enhance access to improved cancer interventions and advance the standard of cancer care regionally and beyond.



# Introduction

## About Seattle Cancer Care Alliance



This map of the world is located in SCCA House, the home away from home for many of our patients and families. Each pin (you'll find them across the entire map) represents how far a patient traveled to come here for care.

Seattle Cancer Care Alliance (SCCA) brings together the leading research teams and cancer specialists of Fred Hutchinson Cancer Research Center, Seattle Children's Hospital, and University of Washington Medicine to translate scientific discovery into the prevention, treatment, and cure of cancer. We transform groundbreaking research ideas into lifesaving realities for cancer patients, improving the standard of care regionally and beyond.

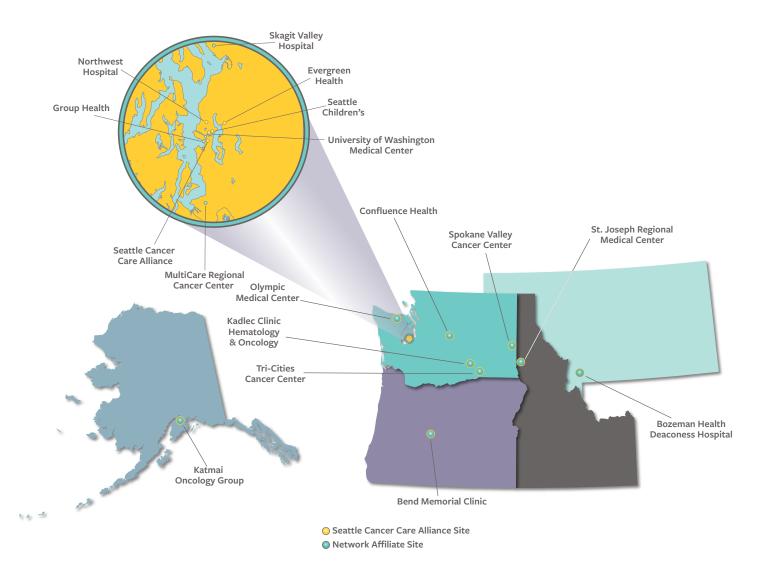
SCCA has a broad and growing reach. We provide care directly in the Seattle area; engage in

strategic partnerships throughout the Pacific Northwest region; and serve as a national and international center of excellence, drawing patients from all over the world and disseminating research that advances the standard of cancer care globally.

Based in Seattle's South Lake Union neighborhood, SCCA has four clinical care sites, including a medical oncology clinic at EvergreenHealth in Kirkland, Washington and medical and radiation oncology clinics at UW Medicine/ Northwest Hospital & Medical Center in Seattle, Washington. In addition, the SCCA Network works with communitybased physicians at partner organizations throughout the Pacific Northwest to provide access to the latest cancer research as well as diagnostic and treatment information. Oncologists and their patients at our Network Member institutions benefit from access to the most up-to-date treatment options and clinical research studies, the ability to easily consult with an SCCA physician, and the latest education and information about advancements in the treatment of cancer. Beyond the Pacific Northwest, the SCCA treats patients from across the country and around the world who travel here for our innovative care. And the research we do changes how cancer is treated across the world.

SCCA/University of Washington Medical Center has been named as one of the top five Best Hospitals in the Nation and number one in Washington state for Adult Cancer Treatment by *U.S. News & World Report* for the past 10 years. The National Cancer Institute's (NCI) 69 Comprehensive Cancer Centers are the foundation upon which the nation's efforts for studying and controlling cancer are built. Only hospitals with an established track record of expertise and excellence are awarded this distinction in recognition of their work to advance cancer treatment best practices. These NCI-Designated Centers are recognized for their scientific excellence and ability to integrate transdisciplinary research to focus on curing cancer.

One of the many advantages of receiving cancer care at an NCI-Designated Comprehensive Cancer Center is the opportunity to enroll in a clinical trial. SCCA currently has more than 550 open clinical trials and enrolled more than 1,000 patients in trials in 2015 alone. Our clinical trials investigate treatments for a wide range of cancers, and we also offer supportive trials, which focus on improving a patient's quality of life. More than 100 of our trials are cutting-edge Phase I clinical trials, many with the potential to drive significant advancement in the effort to cure cancer.



# Our Commitment to Our Community

As a nonprofit, mission-driven organization, SCCA takes seriously our commitment to the community we serve. Our mission unites the drive to improve cancer care and outcomes for patients and their families with the power of clinical research. The work we do in the community is an extension of this mission. In 2015, SCCA devoted more than \$50 million—over 11 percent of our operational costs—to benefit our community. A significant portion of this funding extended our high-quality clinical services to those who otherwise could not afford them, providing subsidized care and offering needed services at a financial loss. We also invested in services aimed at improving the health of our community and reducing the burden of cancer among underserved populations through programs such as tobacco cessation counseling, free mammography screenings, and the development and dissemination of educational materials designed to encourage people to get recommended cancer screenings.

In addition to using our clinical expertise to improve health outcomes in the community, we invested significantly in research and educational activities that benefit our patients, our community, and beyond. These funds go toward educating health professionals on the latest best practices in cancer care, as well as on cutting-edge research that improves treatment and prognosis not just for our patients, but those suffering from cancer regionally and globally.

# **The Impact of Cancer**

As clinicians, researchers, and staff who focus exclusively on cancer, we see every day the impact that cancer has on individuals and their families. However, understanding the broader population-based impact of cancer contextualizes our work and lends increased urgency to it.

The cost of cancer can be measured in both lives lost and dollars spent. Nearly 600,000 Americans lose their battle with cancer each year—1,630 people per day. It is the second leading cause of death in the United States, and the leading cause of death in Washington state, claiming the lives of more than 12,000 Washingtonians every year.



Cancer treatment results in nearly \$75 billion in direct medical costs annually, to say nothing of the lost wages that often accompany a cancer diagnosis. But cancer doesn't only target our working-age population: More than 10,000 children are diagnosed with cancer each year, and cancer claims the lives of 1,250 pediatric patients annually. Cancer is the second leading cause of death in children, despite the fact that mortality rates have dropped by 66% since the 1970s.

As survival rates improve, more Americans—nearly 14.5 million—are living with cancer or a history of the

disease. The five-year survival rate for all types of cancer has steadily improved, climbing from just 49% in 1975–1977 to 69% in 2005–2011. Experts attribute this gain to both earlier diagnosis and improved treatment.

While the overall burden of cancer is significant, these numbers mask the disproportionate challenges that certain populations face. People with lower socioeconomic status (a measure that considers income, education, insurance status, and more) have higher cancer incidence rates, generally because they are more likely to demonstrate health behaviors and confront environmental circumstances that increase cancer risk. Some of these circumstances include cancer-causing infections, workplace exposures, fewer opportunities for exercise, and limited access to fresh fruit and vegetables. Individuals with lower socioeconomic status also have disproportionately higher cancer death rates than people with higher socioeconomic status because their cancers are often diagnosed at a later stage and they are less likely to receive standard treatment.

There are also racial and ethnic disparities in the burden of cancer. For example, non-Hispanic African-American men and women have higher cancer mortality rates than any other racial or ethnic group. Their cancer mortality rate is nearly double that of Asian and Pacific Islanders, who are the least likely to die from cancer. Hispanics have low rates of tobacco-related cancers, but among the highest rates of liver, stomach, and uterine cancers. American Indians and Alaska Natives have the highest kidney cancer incidence and death rates of all racial and ethnic groups, about 50% higher than other racial and ethnic groups. Most experts agree these disparities are largely due to obstacles to cancer prevention, early detection, and treatment services, and the influence of poverty on access to health care. In addition, racial and ethnic minorities are more likely to receive lower-quality health care than non-Hispanic whites, even when controlling for insurance status, disease severity, and other factors.

# **The Community We Serve**

# **Defining Our Community**

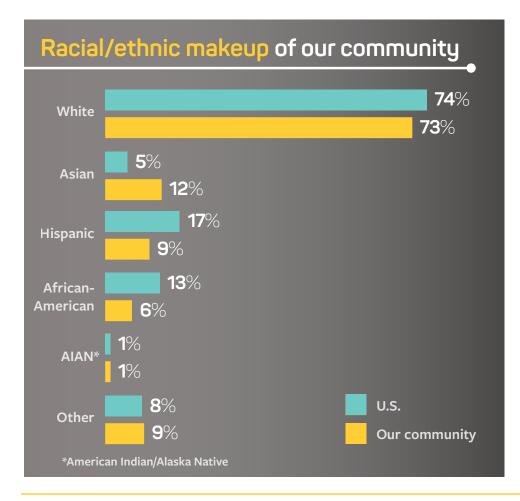


SCCA's purpose involves serving patients beyond our region, and in some ways we consider our community to be a global one, given the reach of our treatment and research. However, for the purposes of the work we do to improve cancer-related population health outcomes, we focus our efforts locally. Consistent with our last Community Health Needs Assessment, we define our community to include everyone in King County (the county in which SCCA is located) and our two neighboring counties, Pierce and Snohomish.

As an organization with a singular focus on cancer, we chose to focus on the full continuum of cancer care, including prevention, screening, treatment, and survivorship needs of this population.

This three-county area is where the majority of our patients live, where our recognition is highest, and where we believe we can make the greatest impact

on cancer-related public health outcomes. In addition, the data demonstrate significant cancer care and cancer prevention needs among medically underserved, low-income, and minority populations in these counties.



#### Socioeconomic Indicators

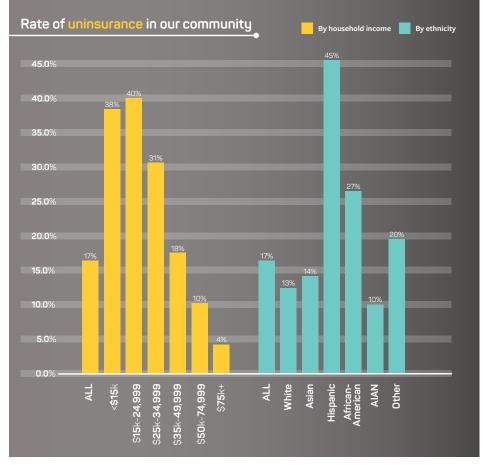
Our community generally aligns with national demographic statistics and slightly overperforms on some socioeconomic indicators. Similar to the rest of the country, our region is divided roughly in half on a gender basis, and distribution by age is very similar to the national distribution, with no more than a 2% deviation for any category. Income within our community is higher than the national average; using income ranges defined by the U.S. Census

Note: For this chart and all subsequent charts describing cancer incidence and mortality in our community by race and ethnicity, "Hispanic" may be of any race, and individuals can self-identify as both Hispanic and a separate race. Bureau, our community has a lower-than-average percentage of households with income below \$75,000 per year, and a higher-than-average percentage of households with income at or above \$75,000 per year. Individuals within our community also have more education than the national average, with a higher percentage of adults receiving advanced education, ranging from some college through a graduate or professional degree.

Our three-county region differs from the national racial and ethnic distribution in a few key respects. More of our population is Asian (12%, compared to a national average of 5%), and less of our population is Hispanic or African-American, compared to the national distribution.

Due to expansion of insurance coverage under the Affordable Care Act, more members of our community are gaining access to health insurance. The most recent estimates available indicate that just under 17% of our community are uninsured, compared to a national average of 10.4%. While this appears to be a large discrepancy, these county-level and national estimates are drawn from different surveys and rely on different questions and calculations, making a direct comparison less meaningful. Within our community, some groups have a much higher rate of uninsurance, including individuals with lower income. Those in households earning between \$15,000 and \$25,000 per year experience the most significant barriers to obtaining health insurance, with an uninsurance rate near 40%. In addition, among racial and ethnic groups in our community, Hispanics and African-Americans have uninsured rates significantly above community and national averages.

# The Health Needs of Our Community



Note: For this chart and all subsequent charts describing screening and health behavior needs in our community by race and ethnicity, "Hispanic" is a mutually exclusive category. Any other racial category is non-Hispanic.

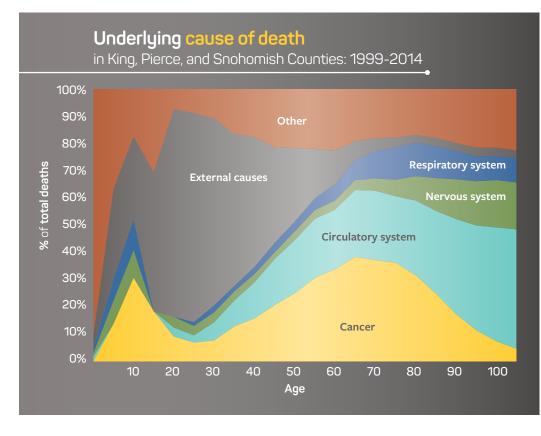
To inform our effort to address our community's cancer-related health needs, we recognize that it is critical to have a clear understanding of those needs. We first collected a wide range of quantifiable data to describe the impact of cancer on our community. Initially, we focused on describing the impact of cancer on our population, targeting incidence and mortality data on cancer generally. We also studied specific cancers that affect a significant number of individuals and for which a proven intervention, such as screening or lifestyle change, exists. Additionally, we considered whether individuals in our community receive recommended cancer screenings that identify or even prevent cancer. We also reviewed data regarding health behaviors that impact cancer risk, to better identify public health interventions that might meaningfully decrease incidence rates. Where

possible, we benchmark our community's performance on these measures against Healthy People 2020 goals for improving the health of all Americans. These national objectives, published by the Centers for Disease Control and Prevention (CDC) every 10 years, provide measurable goals for health improvement priorities and aim to increase public awareness and engagement across multiple sectors to ensure consistency in improvement efforts.

Given the limitations of these data to tell a complete story, we also sought the insight of our community stakeholders to help us create a qualitative picture of the cancer-related needs of our community. As part of our needs assessment process, we solicited the perspective of community stakeholders with deep connections to low-income, minority, and medically underserved populations, who have significant experience meeting the cancer-related needs of these groups.

# The Story the Data Tell

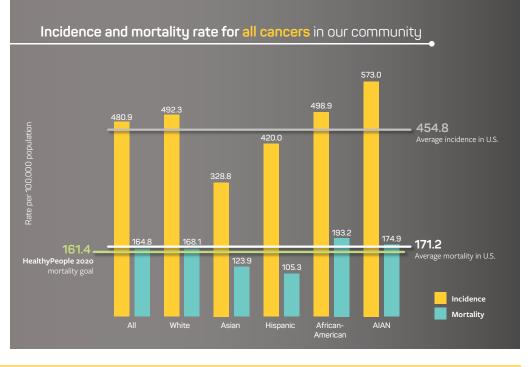
#### All Cancers



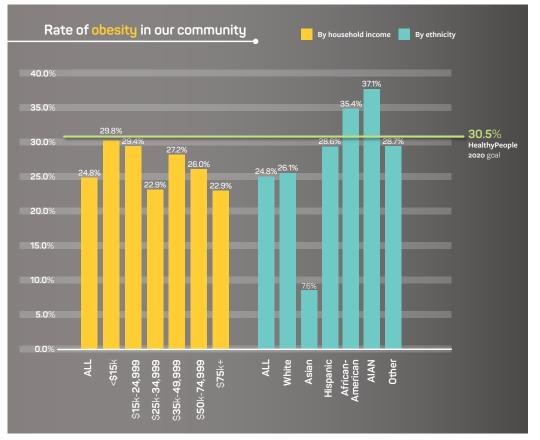
Though cancer becomes more common as people age, cancer has a more significant impact on our community across all age groups, compared to other major causes of death. Overall, our community has a higher incidence of cancer than the national average and a slightly lower mortality rate, though we have not yet achieved the Healthy People 2020 goal for cancer mortality. The data for African-American and American Indian/Alaska Native populations are of particular concern, with incidence and mortality rates higher than other racial and ethnic groups

within our community and higher than the national average. All other racial and ethnic groups within our community experience incidence and mortality rates below the national average, with the exception of whites, who have a cancer incidence are a clichtly.

incidence rate slightly above average.



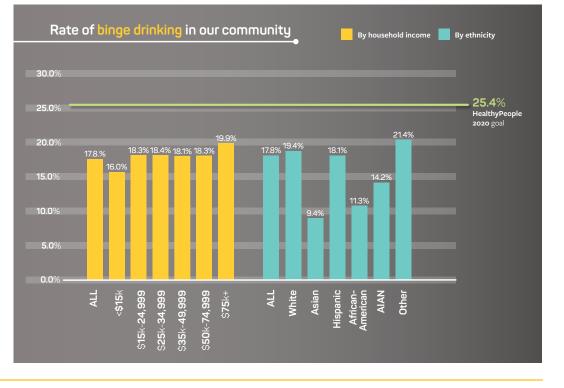
Certain health behaviors, such as diet, exercise, and alcohol intake, are known to affect risk of a number of different types of cancers. Overall, 25% of our community is obese, which meets the Healthy People 2020 goal, but there is significant variation among racial and ethnic groups and income levels.



African-American and American Indian/Alaska Native populations experience obesity rates above the Healthy People 2020 target level.

With regard to alcohol consumption, 18% of individuals in our community report binge drinking, defined as five or more drinks for men or four or more drinks for women on the same occasion, at least once during the past 30 days.

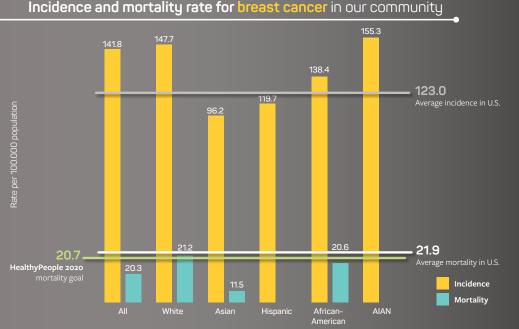
This overall rate achieves the Healthy People 2020 goal, and all racial and ethnic groups meet or exceed the goal. While obesity rates are inversely related to income, binge drinking rates show a different pattern, appearing to rise with income. Of the health behaviors for which data were available, binge drinking was the only one positively associated with income.



#### **Breast Cancer**

Overall, our community experiences a higher incidence of breast cancer than the national average, but lower mortality than average.

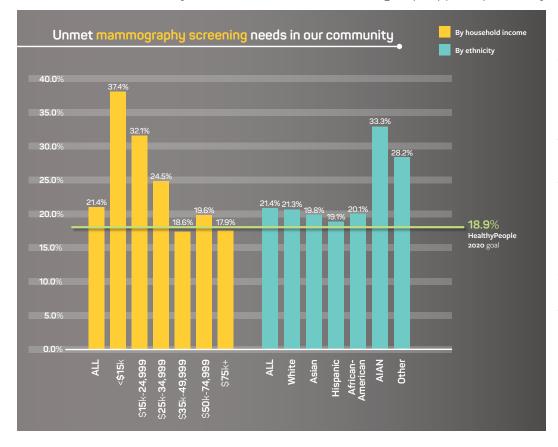
Of the racial and ethnic groups for which data exist, all are below or very close to the Healthy People 2020 mortality goal for breast cancer. The American Indian/ Alaska Native population has a breast cancer incidence rate that is significantly higher than other groups in the region and the national



Incidence and mortality rate for breast cancer in our community

Note: missing data indicates sample size too small to report

average, although due to small sample size, their mortality outcomes could not be ascertained.



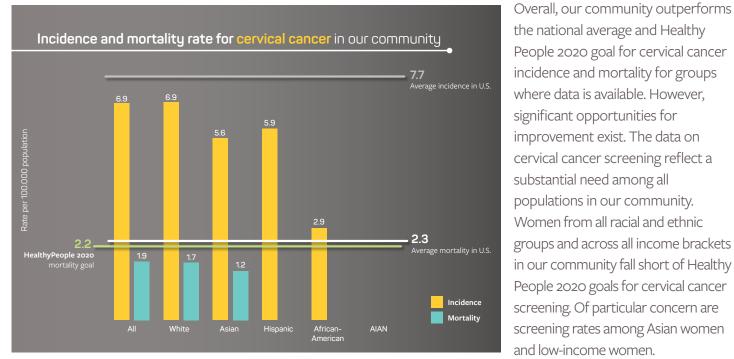
The breast cancer mortality rate for some racial and ethnic groups appears potentially related to mammography

screening needs. For example, white, African-American, and American Indian/Alaska Native populations in our community have higherthan-average breast cancer incidence. All of those groups have unmet mammography screening needs above the Healthy People 2020 goal, with American Indians/Alaska Natives experiencing the highest unmet mammography screening need. Lower-income women in our community also are less likely to receive recommended screenings.

and low-income women.

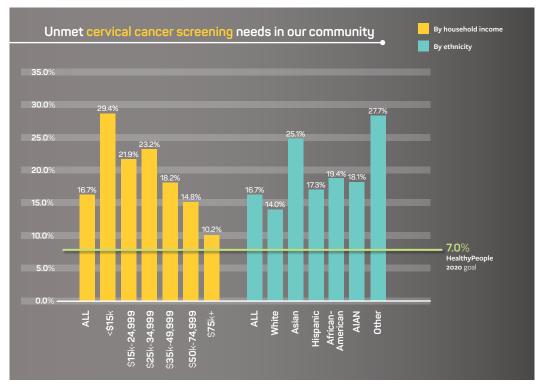
While women in households with annual income of \$35,000 to \$49,999 and at \$75,000 and above meet or exceed the Healthy People 2020 goal for mammography screening, women in households with annual income in all other ranges fall short of the target. More than one-third of women in households with income below \$15,000 need mammography screening.

#### **Cervical Cancer**



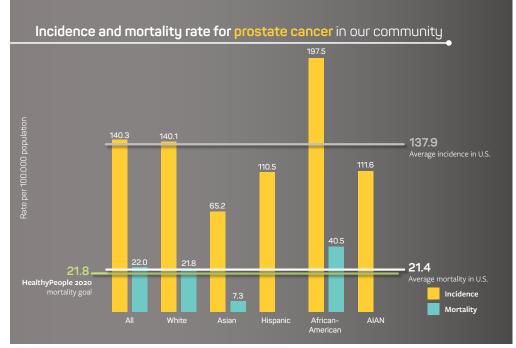
Note: missing data indicates sample size too small to report

Human papillomavirus (HPV) is a major cause of cervical cancer. HPV vaccines can protect females from cervical cancer, and can protect males and females from other cancers caused by the virus, such as head and neck cancers. We found that, despite our community's lower-than-average cervical cancer incidence and mortality rates, the HPV vaccination rate among 13- to 17-year-olds in our community is likely below the national average, though this



estimate is subject to data limitations discussed further in Appendix A. In our community, 42.5% of adolescents in this age range are reported to have received at least one vaccination out of a course of three, compared to a national average of 50.6%. While the reported vaccination rate for our community may be incomplete due to its voluntary nature, it seems likely that much work remains before our community reaches the Healthy People 2020 goal of 80% of 13- to 15-year-olds receiving all three doses of the HPV vaccine.

#### Prostate Cancer



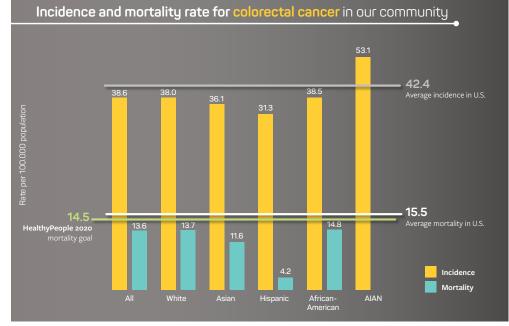
Men in our community experience higher prostate cancer incidence and mortality rates than the national average. In addition, our community's African-American population is a significant outlier, with incidence and mortality rates well above the national average and a mortality rate nearly double that of the Healthy People 2020 goal.

#### **Colorectal Cancer**

Our community experiences lower colorectal cancer

Note: missing data indicates sample size too small to report

incidence and mortality than the national average, as do nearly all racial and ethnic groups in our community, with the exception of the American Indian/Alaska Native population. This group has an above-average incidence rate, although mortality information was unavailable due to the small sample size. Overall, nearly 31% of our community has an unmet colon cancer screening need, and all but two racial and ethnic groups fall short of the Healthy People 2020 colon cancer screening goal.



#### Note: missing data indicates sample size too small to report

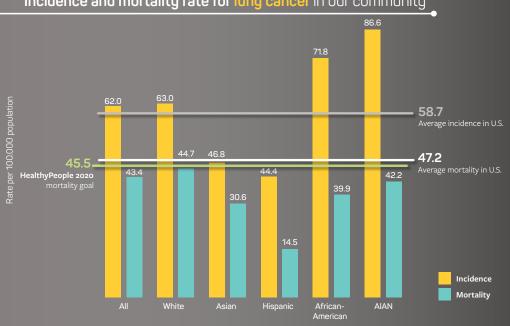
The greatest need appears to be within the Hispanic community, where more than half of all people need colon cancer screening. In spite of this, incidence and mortality rates for this population are well below the national average, and the mortality rate is well below the Healthy People 2020 goal.



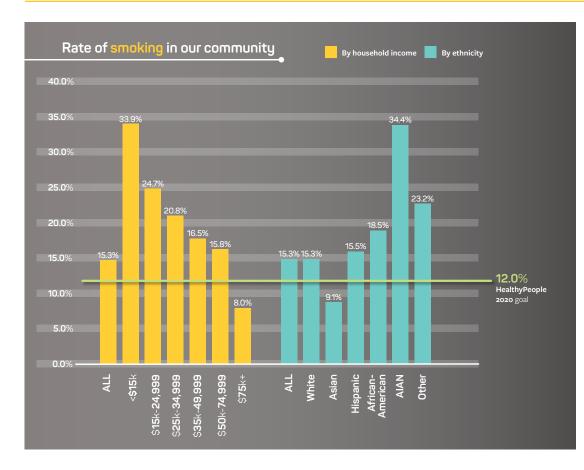
#### Lung Cancer

Despite higher-than-average lung cancer incidence rates for several racial and ethnic groups, all racial and ethnic groups within our community outperform the national average mortality rate and the Healthy People 2020 goal.

Overall, our community experiences slightly fewer lung cancer diagnoses than the national average and a better mortality rate.



#### Incidence and mortality rate for lung cancer in our community



Tobacco use is an area of concern for certain groups within our community, with more than 15% of people in our community reporting they smoke every day or some days. The data also indicate tobacco use rates well above the Healthy People 2020 goal for some racial and ethnic groups and among individuals in lowerincome households.

# The Story Our Stakeholders Share

We recognize that for a number of reasons, the data available on cancer do not tell the full story about the needs of our community. For example, viewing the data by income or race and ethnicity may not fully explain challenges that subpopulations within these groups face. Furthermore, even if a significant challenge can be clearly identified by the data, often the root cause of this problem and its solution are often not discernable. We were committed to going beyond the quantifiable data to paint a clearer picture of the health needs of our community. We consulted with community stakeholders across a range of organizations in different sectors to learn about community health needs and the resources available to meet those needs. In particular, we focused our research on the needs of medically underserved, low-income, and minority populations by requesting meaningful input from organizations serving and representing these groups.

In total, we reached out to more than 40 individuals at organizations representing state, county, and tribal government health programs, cancer advocacy groups, cancer resource and support groups, community health centers, hospitals, and groups serving specific racial and ethnic populations. A complete list of the organizations that graciously shared their experience and expertise is available in Appendix A.

We received a wide range of feedback from our stakeholders, but community needs within several themes emerged: more cancer screening, a stronger focus on prevention, removing barriers to accessing clinical services, survivorship care, and improving community health infrastructure.

#### Screening

Stakeholders identified the need for more screening for a range of cancers, including colon cancer (especially among men), breast cancer, and cervical cancer. Many cancer screening resources are available from organizations throughout our community, but stakeholders note that funding cuts in the past several years have reduced the capacity of free screening programs. While waiting lists for several screening programs have been reduced, stakeholders do not feel this is related to a diminished need for screening. Rather, they sense that more outreach is required to find individuals who need screening, but some screening grants do not allow for expenditures on outreach or education. Patient education is another area of need with regard to screening. Patients may not realize they need certain screenings or may be averse to being screened despite recommendations, due to cultural reasons or to fears that they will not be able to afford treatment. Certain providers, such as federally qualified health centers (FQHCs), identified a need for support in connecting positively screened patients with additional services. As an example, one stakeholder described a program focused on expanding fecal immunochemical testing and fecal occult blood testing, which can increase the access to colon cancer screening, particularly for those who are initially averse to having a colonoscopy. However, enhanced communication is needed between federally qualified health centers, who may conduct the initial screening, and providers of colonoscopy services in order to ensure patients who require a colonoscopy receive one. Finally, stakeholders report the need for a systematized effort to identify, target, and reach out to patients who are due for cancer screening.

#### Prevention

Stakeholders also identified a strong need for greater work in the area of cancer prevention, particularly in the area of tobacco use, which continues to emerge as an area of need. While our community-wide rate of tobacco use is below the Healthy People 2020 goal, certain racial and ethnic groups, certain immigrant populations, and lower-income populations have higher smoking rates. Another opportunity in cancer prevention identified in the data and echoed by stakeholders is HPV vaccination. Stakeholders reported low vaccination rates across most demographic groups, with a particular hesitancy to vaccinate among middle- and upper-income families, reportedly due to vaccine aversion and concerns about sexual activity among adolescents. This suggests a need for enhanced provider and family education about the



vaccine. Stakeholders also reported the need for more vaccination among boys. Finally, providers identified the need for systematic improvements in connecting with parents to ensure their children receive all three doses of the HPV vaccine.

#### **Barriers to Access**

Stakeholders noted that many individuals face significant financial barriers to receiving needed services, a primary one being lack of health insurance. Despite gains in insurance coverage due to the Affordable Care Act, many individuals in our community are uninsured. Some groups, such as recent immigrants, undocumented workers, and individuals with very low income, are either excluded from coverage assistance under the Affordable Care Act or find their expected contribution is not affordable.

Since the Affordable Care Act has changed the landscape of who is insured, safety net providers and other organizations report a shifting focus in the type of patients they serve, and they are changing their outreach efforts and other organizational strategies to identify and engage this new population in need of free or reduced-cost services. While insurance market reforms included in the Affordable Care Act made cancer screening and prevention much more affordable, some patients are hesitant to take advantage of these services out of fear of "surprise" bills, such as when a preventive colonoscopy identifies a polyp for removal, which generates a charge. Further, when cancer screenings yield positive results, patients—whether insured or not—may need financial assistance with care and treatment costs.

Stakeholders also noted access to reliable transportation is another financial barrier for individuals in need of clinical services. Transportation can be particularly problematic for cancer patients who are very ill and unable to drive themselves or take public transportation, or who must travel long distances for care. Community organizations offering transportation services for cancer patients report they are not able to meet the needs of all who request help.



In addition to these financial barriers, stakeholders identified a number of non-financial barriers to access, including cultural beliefs, language barriers, limited health literacy, and distrust of the medical system, particularly among undocumented immigrants who fear being identified by immigration authorities. Many suggested that a greater focus was needed among providers on cultural diversity and cultural and linguistic competency in the provision of health care services. Stakeholders often mentioned patient navigators as a valuable resource for addressing these barriers to access, noting that navigators could serve as a resource for improving patient understanding of and access to services and improving health literacy. Many stakeholders identified the need to focus on broader language and translation services, especially for recent immigrants.

Stakeholders also identified a need to broaden access to clinical trials—a barrier to access that can be traced to both financial and non-financial causes. Increasing access to clinical trials has the potential to improve both use of cuttingedge therapies in underserved populations and trial outcomes. However, national data suggest disparities exist in access to cancer treatment clinical trials for both lower-income populations and certain racial and ethnic minorities. A recent study found that patients with annual incomes below \$50,000 are one-third less likely to participate in clinical trials than patients with higher incomes. While health insurance and other sources of coverage, such as Medicare, are required to pay for routine costs associated with clinical trials (e.g. drugs, procedures, and services that would normally be covered), significant insurance barriers to full coverage of trial expenses still exist. Stakeholders identified insurance barriers to full coverage of clinical trial participation across multiple payers and types of payers. They noted that additional expenses, such as coinsurance or copayments, travel costs, and lost wages, may also be barriers for potential trial participants with lower incomes. Several organizations pointed to a distrust of clinical research among some racial/ethnic populations.

#### Survivorship

As cancer mortality rates improve and more members of our community survive and live with cancer or a history of cancer, stakeholders note the need to address issues related to survivorship and improve resources for this population. Many cancer survivors struggle with physical and emotional changes that occur during and after cancer treatment, and some face sexual health impacts due to side effects of treatment. Some cancer survivors would benefit from connection to mental health services and support to address these and other challenges survivors face, such as fear of recurrence. Additionally, cancer survivors often have different screening and follow-up recommendations from the general population, and it is critical to integrate survivors back into their previous medical home and ensure their primary care physician is aware of the survivor's cancer history and health needs. These care transitions can be especially challenging for survivors who traveled long distances for their cancer care and for primary care physicians whose patient population does not have a high incidence of cancer.

#### Community Health Infrastructure

Stakeholders also described challenges with the public health infrastructure that limit our ability to successfully address cancer in our community. Organizations representing racial and ethnic groups identified a number of concerns with the available data and qualitative information about the health and outcomes of the individuals they serve. They note that the broad racial and ethnic minority classification system utilized by most surveys obscures variations within these groups. For example, among Asians and Pacific Islanders, the Vietnamese, Cambodian, and Korean communities often have very different health indicators and needs both from each other and from the Asian population as a whole. Further,



variation between recent immigrants and those who have lived in the U.S. longer is obscured, if it is captured at all, because recent immigrants may be less likely to respond to surveys. One likely reason is that health surveys are often conducted in English and Spanish, while members of many racial and ethnic groups speak neither of these languages. Some stakeholders have found that recent immigrants have a greater need for behavioral health care services, and this unmet need impacts all other health outcomes. Classification continues to be a problem; some racial and ethnic minorities may be misclassified in the data as another race, such as American Indian/Alaska Native populations misclassified as white. Beyond the quantitative data, stakeholders identified the need for better qualitative data to understand why people make certain choices with regard to cancer prevention, screening, and treatment. Importantly, community leaders and our internal stakeholders agreed upon the need for ongoing, consistent, meaningful community engagement—especially for unrepresented and underrepresented communities—more than once every three years, when organizations conduct their community health needs assessments.

Finally, stakeholders identified the need for greater systematization and infrastructural support, particularly surrounding outreach and communication with all community members and patients. Along these lines, internal and external stakeholders suggested that providers should consider ways to leverage their existing resources, better communicate their community benefit priorities, and work with community members and organizations.

## **Potential Community Health Resources**

Our community is fortunate to have a range of resources and community organizations dedicated to addressing cancer-related health needs, though gaps persist in many areas.

SCCA is proud to partner with many of these organizations to serve populations we may not otherwise reach.

The Washington State Department of Health facilitates robust programs for connecting diverse populations, the uninsured, and individuals in low-income households to tobacco cessation resources and screening for certain cancers, such as breast, cervical, and colon cancer. Locally, community health centers improve access to care for underserved populations and offer a sliding fee scale and comprehensive primary care services, including screening and vaccination. Pierce and King counties have an extensive network of community health centers, while Snohomish County has just five. In all geographic areas of



our community, stakeholders report substantial screening needs and the importance of ensuring that screening programs are replicable and financially sustainable.

While many organizations within our community offer patient navigator services (sometimes called case managers or social workers) for individuals who are newly diagnosed with cancer or undergoing treatment, stakeholders report this is another area where the need is far greater than the available resources.

Throughout our community, patient advocacy organizations provide individuals with services to address the many non-medical needs that arise when cancer enters their lives, such as peer support groups, referrals to therapists

experienced in working with people facing cancer, financial assistance for medical and non-medical needs, services for family members supporting a cancer patient, lodging for patients who must travel to receive treatment, and transportation to and from treatment and other cancer-related health care services. Stakeholders representing organizations that offer these types of services indicate the need is far greater than their resources can meet.

# **Previous Community Health Reports**

SCCA conducted its first community health needs assessment in 2013. At that time, we used similar criteria for reviewing the cancer-related health needs of our community and identified the following prioritized needs: tobacco cessation education, Hispanic community outreach, mobile mammography outreach, colon cancer educational outreach, and access to health care.

As part of our implementation plan to address these needs, we awarded more than \$50,000 in Community Health Improvement Grants to seven organizations working toward similar health goals:

- The American Cancer Society partnered with a Pierce County health center serving the Latino and medically underserved communities to increase colorectal cancer screening by training the clinical team on skills and opportunities to improve screening rates.
- Cornerstone Medical Services, which serves Asians and Pacific Islanders and other immigrant communities, leveraged its Everyday Cancer Program to address colorectal cancer prevention and screening and increase tobacco prevention and cessation awareness.
- El Centro de la Raza, an organization serving the Latino community, conducted culturally and linguistically competent workshops with Latino youth and adults about the risks of tobacco use, provided strategies to reduce secondhand smoke exposure, and offered tobacco cessation resources.
- HealthPoint, a local network of community health centers, addressed language as a significant barrier to health care by improving breast cancer screening and early detection, as well as providing colorectal cancer prevention, screening, and treatment for patients who speak Somali, Nepali, Burmese, Arabic, and Amharic.
- Neighborcare Health, a network of 28 nonprofit medical, dental, and school-based clinics, focused on increasing colorectal cancer prevention, screening, and treatment in the African-American and Hispanic communities through English- and Spanish-language patient education materials, and automated screening reminder calls.
- WithinReach, a local organization that connects families to food, health, and other resources and works to create healthy communities, adapted existing intervention tools to increase human papillomavirus (HPV) vaccination rates to focus on educating and training providers that serve Hispanics and Latinos, especially those at federally qualified health centers.
- The Women's Access Department at the YWCA Seattle | King | Snohomish serves a diverse population of women in King and Snohomish counties, with a focus on African-American, Latina, homeless, and LGBTQ communities. YWCA provided those it serves with presentations and coaching on cancer prevention and screening.

Written feedback received from our grantees highlighted the need to engage people in cancer screening when they are being seen by a health care provider for any reason. Providers serving medically underserved and minority populations noted the difficulty in following up with patients once they walk out the door and convincing them to return for screening when they feel well. Some providers noted that grants focused on clinical workflow and process improvement to increase screening rates would be most welcome.

In addition to the implementation activities undertaken by our grantee organizations, SCCA engaged in a number

of activities to improve the health of our community in the areas we prioritized. For example, our mobile mammography van conducts outreach year-round to bring this critical cancer screening to women who might not otherwise be reached. In partnership with the National Breast Cancer Foundation, the SCCA's mobile mammography van provided mammography and follow-up care to women facing financial barriers to these services. The mobile mammography van was an integral part of a Remote Area Medical event in October 2014, where mammography was a key service offered to more than 3,400 individuals with health care needs.

Our tobacco cessation programs were presented at numerous community events and we offered tobacco cessation education and coaching on a one-on-one basis to individuals throughout our community. We leveraged the geographic reach of our mobile mammography van to disseminate tobacco cessation materials in English and Spanish for women receiving breast cancer screening. Stakeholders commented that they appreciated our focus on tobacco cessation. While many agencies have turned their focus to alcohol and substance use disorders, tobacco use and resulting health issues remain a substantial challenge among medically underserved populations and certain racial and ethnic groups within our community.

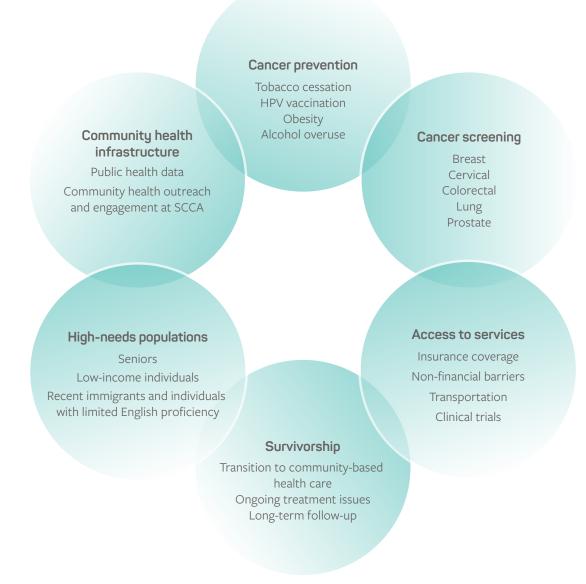
We evaluated and enhanced our outreach efforts to the Hispanic community by engaging our staff to identify cultural and learning barriers and increasing staff understanding of those barriers. We expanded our direct outreach to this community through participation at numerous health fairs and community events and via our ongoing work with Sea Mar Community Health Centers, which provide health services to the Hispanic and Latino community, among others.

As we complete our second community health needs assessment and end the implementation of our first assessment, we are reviewing our efforts to ensure we are thoughtfully incorporating all lessons learned from this process. We take seriously our responsibility to help those we serve understand our community benefit work and to ensure the work we undertake drives deeper, more meaningful connections with our community.

# **Priority Health Needs**

SCCA is dedicated to ensuring that our purpose, which unites the drive to improve cancer care and outcomes for patients and their families with the power of clinical research, is meeting our community's health needs. The health needs identified by the data available to us, our stakeholders' input, and feedback on our previous health needs assessment and implementation strategy led us to prioritize cancer-related health needs that are clearly identified in the community and for which an evidence-based intervention exists that can improve cancer care and outcomes for individuals, their families, and our community.

By using this framework, we are able to prioritize community health needs where our involvement can contribute meaningfully to health improvement. Using this lens, we identified many potential health needs, which we grouped into six high-level areas of focus: cancer prevention, cancer screening, access to high-quality cancer care services, survivorship, high-needs populations, and community health infrastructure.



### **Cancer Prevention**

The risk for some cancers can be reduced significantly with lifestyle and behavioral changes, including receiving certain cancer vaccines and making healthy lifestyle choices. Two possible areas of improvement that arose in our assessment included *HPV vaccination* and *tobacco cessation*. While the human papillomavirus (HPV) vaccine is shown to significantly reduce rates of cervical and certain head and neck cancers, our needs assessment indicates the rate of vaccination is low in our community. In addition, despite its well-documented connection to lung cancer and other health problems, smoking is still a significant problem in our community, particularly in certain populations. *Obesity* and *alcohol overuse* are two additional areas that, if addressed, could improve cancer outcomes.



### **Cancer Screening**

Identifying cancer in early stages has a significant positive impact on mortality rates, and in some cases screening can actually prevent cancer. Screening tests and evidence-based recommendations exist for many different types of cancer, including **breast**, **cervical**, **colorectal**, **lung**, and **prostate cancer**, all of which were shown to significantly impact our population in our needs assessment.

### Access to High-Quality Cancer Care Services

Our research and stakeholders helped us to identify ways to meet the access needs of our community which align with our mission. Despite passage of the Affordable Care Act, a significant part of our community remains uninsured, putting them at risk of being unable to afford cancer screening and treatment. Improving **access to health insurance** could improve outcomes for a significant number of individuals in our population. However, even for those with health insurance and adequate financial resources, barriers to accessing clinical services persist. Stakeholders shared that certain members of the population distrust or have difficulty navigating the medical system for a myriad of reasons, including cultural beliefs, language barriers, and limited health literacy. These **non-financial barriers to access** can often be successfully addressed with education or patient navigators, eventually improving outcomes. **Transportation** to screening and treatment also emerged as a barrier to access for many in our community. Getting to an appointment can be expensive and time-consuming, particularly if patients and their loved ones must take time from work to attend an appointment. Finally, robust and equitable **access to clinical trials** has proved challenging, particularly for low-income, minority, and other underrepresented groups in our community. In many cases, clinical trials represent a patient's best hope for improving his or her outcome. However, insurance barriers to clinical trial coverage exist, and additional costs associated with trial participation are often not covered by insurance.

### Survivorship

Our data show an increasing number of cancer survivors living well beyond their initial diagnosis. Our stakeholders have affirmed that a number of unique needs exist for these individuals, including psychosocial support, the transition back into a community-based health-care setting, help addressing ongoing issues related to treatment, and long-term follow-up. Survivorship services can prove essential for helping former patients successfully transition out of a period of active treatment.

## **High-Needs Populations**

In the course of our data analysis and stakeholder interviews, we identified several populations with high needs for cancer clinical or support services across most or all of the indicators we considered. While cancer can affect individuals throughout their lifetime, cancer incidence and mortality become more common as people age, suggesting a disproportionate need among **seniors** for outreach and services. Additionally, the socioeconomic status indicators we were able to review for our community, as well as relevant literature, suggested that low-income individuals are disproportionately affected by cancer. Our stakeholder interviews reinforced the fact that significant barriers for this



population exist. Finally, conversations with many stakeholders identified significant barriers to cancer services for **recent immigrants** and **individuals with limited English proficiency**.

### **Community Health Infrastructure**

Two issues arose in our assessment that we believe are impediments to efforts to improve cancer outcomes in our community. First, limitations in existing **public health data** with respect to cancer made it difficult to accurately target populations most in need of cancer services. We found both in our own quantitative research and in discussions with stakeholders that in some cases, data are not precise enough to expose gaps in care for smaller populations. Second, in assessing and evaluating our performance during our last community health needs assessment cycle, and in speaking with stakeholders, we identified **opportunities at SCCA** to improve our existing community benefit initiatives with community and internal stakeholders.

# Appendices

### Appendix A: Community Health Needs Assessment Process Process and Methods Used to Assemble Quantitative Data

We gathered data about individuals in our community (i.e. residing in King, Pierce, and Snohomish counties) from publicly available datasets cited in Appendix B, most of which are maintained by government agencies or programs. When possible, we accessed data for the whole three-county region directly from these datasets. In other instances, we needed to query data for each county separately and combine them into a weighted average. These data were then analyzed and interpreted to understand the community and its cancer burden overall, as well as the disparities of certain populations within the community.

We used demographic data from the U.S. Census Bureau's 2010–2014 American Community Survey five-year estimates to describe the three-county region's demographics, including age, race, ethnicity, and socioeconomic status. We combined county-specific data into a weighted average for our three-county community and benchmarked these numbers against state and national data.

The Washington State Cancer Registry and the National Cancer Institute's Surveillance, Epidemiology, and End Results dataset provided cancer-related incidence and mortality data to understand the distribution of the community's cancer burden across a range of ages, races, and ethnicities. Cancer rates for each county were combined into a weighted average and benchmarked against state and national data.

With assistance from the King, Pierce, and Snohomish counties' health departments, we combined data from the 2011–2014 Behavioral Risk Factor Surveillance System for each county and, using weighting adjustment, analyzed the data by age, sex, race, ethnicity, and income level to identify the distribution of cancer-related health behaviors in our community, as well as the uptake of recommended cancer screenings.

Data on HPV vaccination as a preventive measure against cervical cancer and other HPV-related cancers were gathered from the Washington State Immunization Information System (WA IIS), the only data source offering county-level estimates of this measure. However, Washington State Department of Health employees indicate that because reporting to this registry is voluntary, WA IIS estimates of immunization coverage are likely lower than the true immunization rate.

An online environmental scan for cancer-related health services, screenings, and support identified existing community resources within our community. We collected information about local community-based organizations, local branches of national cancer nonprofits, county and state health department programs, community health centers, Federally Qualified Health Centers, and other regional hospitals.

#### Process and Methods Used to Solicit Community Input

As part of our needs assessment process, we solicited the perspective of community stakeholders with deep connections to low-income, minority, and medically underserved populations, who have significant experience meeting the cancer-related needs of these communities. These organizations serve low-income individuals; a wide range of racial and ethnic minorities, including Asians, Hispanics, African- Americans, and American Indian/Alaska Natives; recent immigrants; and other marginalized groups with significant barriers to accessing cancer services. The insight of our community stakeholders helped us to overcome some of the data limitations we encountered and offered us a qualitative picture of the cancer-related needs of our community.

In total, we reached out to more than 40 individuals at organizations representing state, county, and tribal government health programs, cancer advocacy groups, cancer resource and support groups, community health centers, hospitals, and groups serving specific racial and ethnic populations. The following organizations graciously shared their experience and expertise through in-person interviews, telephone interviews, and email responses during the first four months of 2016:

- American Cancer Society
- American Society of Clinical Oncology
- Cancer Lifeline
- Fred Hutchinson Health Disparities Research Center
- Hutchinson Institute for Cancer Outcomes Research
- HealthPoint Community Health Centers
- King County Department of Public Health
- Korean Women's Association
- MultiCare Health System
- National Asian Pacific Center on Aging

- Sea Mar Community Health Centers
- Seattle Indian Health Board
- Snohomish Health District
- South Puget Intertribal Planning Agency
- Tacoma Urban League
- Tacoma-Pierce County Health Department
- Urban Indian Health Institute
- Washington State Department of Health Comprehensive Cancer Control Program
- YWCA Seattle | King | Snohomish

#### **Process Limitations**

Identifying, assessing, and prioritizing the health needs of our community is primarily a research endeavor, and all research faces some limitations. We want to be aware of and transparent about the limitations we identified during this process.

We identified a number of data limitations as we sought to understand our community. Often, the data we wanted simply did not exist—not all of the measures we hoped to review were collected, local data were not exactly comparable to national data, local sample sizes were often too small to yield meaningful results (particularly at the racial and ethnic group level), and different studies categorized types of cancer in different ways.

In addition, while the available county-level data on health behaviors and cancer screening rates identifies individuals of Hispanic ethnicity in a mutually exclusive way from individuals of other races, in the available county-level data on cancer incidence and mortality, Hispanic is not mutually exclusive from all other races. This difference in group definition may make linkages of cancer incidence and mortality to health behaviors or cancer screening less meaningful, although we anticipate the trends we observe still hold true.

One stakeholder also pointed out that the racial and ethnic categories that most surveys utilize obscure substantial variation within each group—such as different subpopulations within, for example, the Asian population. In addition, many racial and ethnic groups have wide variation among more recent immigrants, who may have significant cultural and linguistic barriers to care, and second- or third-generation members of that group. Furthermore, recent immigrants who have limited English proficiency are less likely to respond to surveys, so their experience is less likely to be reflected in the data.

In addition to limitations in available data, we encountered resource limitations in our efforts to gather the input of our stakeholders. We would have liked to gain the perspective of many more organizations within our community, but faced our own resource limitations, and the limitations of our stakeholders. We did not hear back from every organization that we contacted, and while we cannot know for sure, we hypothesize there might be some engagement fatigue among those who did not respond. Hospitals and other organizations may rely on similar lists of stakeholders for a variety of survey needs, and those stakeholders also have limited resources for responding.

Finally, we recognize that there are other medically underserved or disadvantaged populations whose health needs we were not able to accurately distill, due to data limitations. For example, most of the survey data we utilized to understand cancer-related health needs does not identify members of the LGBTQ community, and we anticipate there are other community groups whose needs are not apparent due to data limitations.

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