Saving Lives and Reducing Suffering and Death from Cancer in Virginia

Report of the Comprehensive Cancer Needs Assessment of the Southside Health District

Virginia Commonwealth University

Massey Cancer Center

And

Tobacco Indemnification and Community Revitalization Commission

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Addressing Educational, Clinical and Advocacy Needs Related to Cancer in Southside and Southwest Counties

Cancer is a significant health problem in Virginia, impacting the physical, emotional, economic, and social well-being of individuals, their families, and communities. An average of 32,769 Virginia residents are diagnosed with cancer annually,[1] with an average of 13,891 succumbing to their disease.[2] Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease.[3] Virginia is poised to combat this disease with healthcare institutions, cancer care centers, state education and research institutions, city and state governments, non-profit organizations, and grass-roots community groups working to reduce the cancer burden in the state. Since 2001, a statewide network of partners, the Cancer Action Coalition of Virginia, has developed a series of state five-year cancer plans to help unify and direct the efforts of these organizations in combating cancer.

Virginia is a highly diverse state in geography, population demographics, economics, and access to healthcare. With a land mass of 40,000 square miles that spans from the shores of the Atlantic to the hills of the Appalachian Mountains, there are varying degrees of knowledge of and access to healthcare. For cancer prevention and control efforts to be effective they "must be complete, comprehensive, sustainable, community-specific, and culturally and linguistically appropriate."[4] To accomplish this, an evaluation of the needs specific to defined communities is required. The Virginia Commonwealth University Massey Cancer Center in collaboration with the Virginia Tobacco Indemnification and Community Revitalization Commission performed a comprehensive cancer needs assessment of health district-defined communities in the Southside and Southwest. The health districts chosen have a relatively high cancer burden and large medically underserved areas. The comprehensive assessment of cancer needs specific to each community will be used to develop a holistic strategy to improve cancer outcomes, and it will utilize strategies that are culturally appropriate to these communities.

[1] Statistics provided by the Virginia Cancer Registry (June, 2011), data from 2001 to 2007.
[2] Statistics provided by the Virginia Department of Health (June, 2011), data from 2005 – 2009.
[3] CDC, National Center for Injury Prevention, WISQARS Leading Causes of Death Reports 1999 – 2007, accessed on November 1, 2011, http://webappa.cdc.gov/cgi-bin/broker.exe.
[4] The Virginia Cancer Plan 2008 – 2012, Cancer Plan Action Coalition (CPAC).

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BRFSS	Behavioral Risk Factor Surveillance Survey
CACV	Cancer Action Coalition of Virginia
CHE	Community Health Educator
HPSA	Health Professional Shortage Area
MUA	Medically Underserved Area
PCP	Primary care physicians
SSHD	Southside Health District
VDH	Virginia Department of Health

EXECUTIVE SUMMARY OF FINDINGS

The Southside Health District (SSHD) is comprised of three medically underserved counties located along the Virginia-North Carolina state line. The population is evenly divided between male and female gender. Approximately 57% of residents are Caucasian and 40% are African American with 3% other races. The population is significantly older (24% above 65) in the health district when compared to Virginia (16% vs. 12% above 65 years). The economic status of the district compares unfavorably with the state; the unemployment rate in the health district is higher (9.5% vs. 5.7%) and the median household income is lower ($35,440 vs. $61,406). These employment statistics are partially responsible for the healthcare disparities that exist within the health district. Data for this cancer needs assessment was gathered from a number of federal, state, and local web based sources including the US Census Bureau, Department of Health and Human Services, and the Virginia Workforce Connection, as well as through interviews with key community leaders, surveys of healthcare facilities and physicians, and focus groups with community residents.

The total age-adjusted cancer incidence rate for the health district is lower than that for Virginia. With the exception of male genital and gastrointestinal cancer subgroups, the age-adjusted cancer incidence rates for the SSHD are either comparable to or lower than the age-adjusted cancer incidence rates for Virginia. The rates of diagnosis of early vs. late stage cancer identification are comparable to that of the state. However, the total age-adjusted mortality rate for cancer in general is significantly higher than found in Virginia (203 vs. 180.9 per 100,000 residents). Many cancers are diagnosed locally but treated outside of the district, which requires the patient to undergo extensive travel and expense to receive treatment. Although in some cases this is a reflection of personal preference, in many cases it has been due to lack of local treatment resources or financial considerations.

The district has a culture of acceptance toward tobacco use by many due to the past and present economic importance of tobacco production in the area. Tobacco heritage is a point of pride for many as evidenced by road signage which indicates this while welcoming you to Mecklenburg County. The statistics reported by the Behavioral Risk Factor Surveillance Survey show higher rates of tobacco use, sedentary lifestyle, and obesity within the district than that of the state. All three of these factors are associated with an increased risk of cancer.

Key healthcare professionals were interviewed regarding the challenges to healthcare in the health district, and the following areas were identified:

- Need for an increased number of healthcare providers (medically underserved region)
- Need for continuing education pertaining to cancer screening
- Financial barriers to healthcare access
- Community education and support around healthy lifestyles and preventative healthcare

There was a pervasive attitude among those interviewed that the shortage of healthcare providers was going to increase in the near future. Concerns were repeatedly expressed about the current providers' heavy workload and the possibility that this impacts timeliness of screening for cancer in the district. Another challenge which was frequently cited was the lack of referral sources for underinsured patients with positive screenings who require diagnostic testing. This was echoed in the focus groups. Physician surveys were conducted across the

district and the results indicated that the most compelling reason for lack of patient compliance with recommended screenings was financial constraint.

Community focus groups were held in each of the three counties which comprise the SSHD. Two types of focus groups were conducted: one with the general population regardless of cancer experience, and the other with cancer survivors and caregivers within the district. Recurrent themes included concern about financial constraints on healthcare utilization and treatment access, and a lack of interest in adopting a healthier lifestyle. Cancer survivor groups expressed dismay about the lack of information given to them by treating physicians. Several survivors indicated feelings of inadequate resources to give guidance. This finding was not unexpected as the only patient navigator in the district is located in Halifax County. Further, this group identified transportation challenges as a barrier to receiving cancer treatment. Finally, the need for support groups within all communities was discussed and it is worth noting that there is no support group in Brunswick County.

Priority areas for action based on the data collected in the assessment fell into four broad categories: patient education, physician education, community support, and patient support. The importance of accurate, understandable and timely information for residents diagnosed with cancer resulted in recommendations for information resource centers, patient navigators, accessible cancer support groups, and physician education around implications of patient health literacy to patient decision making. Barriers to early screening, diagnosis, and treatment identified in the assessment resulted in recommendations for recruitment of primary care physicians and oncologist to the health district, equitable insurance and financial support resources throughout the health district, and innovative systems for affordable transportation to cancer screenings and treatments. Finally, promotion of healthy lifestyles for cancer prevention and reduction of cancer recurrence was a priority area in the findings. Public awareness campaigns and early education programs promoting healthy lifestyles, access to programs for lifestyle change including tobacco use cessation, and referral of cancer survivors to professionals in nutrition and exercise for post-treatment lifestyle education were recommended.

INTRODUCTION

Cancer is a significant health problem in the United States, impacting the physical, emotional, economic and social well-being of individuals, their families, and communities. It was estimated that 1,638,910 new cases of cancer would be diagnosed nationally in 2012 (ACS), with 41,380 new cases occurring in Virginia.[5] The state cancer incidence rate of 443.2 newly diagnosed cancers per 100,000 residents ranks 38th among the 50 states and the District of Columbia, and it is slightly lower than the national cancer incidence rate of 455.7 (2008).[6] Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease[7] with an average of 14,009 residents succumbing to their disease.[8] Virginia is poised to combat this disease with healthcare institutions, cancer care centers, state education and research institutions, city and state governments, non-profit organizations, and grass-roots community groups working to reduce the cancer burden in the state. Since 2001, a statewide network of partners, the Cancer Action Coalition of Virginia (CACV), has developed a series of state five-year cancer plans to help unify and direct the efforts of these organizations in combating cancer.

Virginia is a highly diverse state in geography, population demographics, economics, and access to healthcare. With a land mass of 40,000 square miles that spans from the shores of the Atlantic to the hills of the Appalachian Mountains, there are varying degrees of knowledge of and access to healthcare. For cancer prevention and control efforts to be effective they "must be complete, comprehensive, sustainable, community-specific, and culturally and linguistically appropriate."[9] To accomplish this, an evaluation of the needs specific to defined communities is required. The Virginia Commonwealth University Massey Cancer Center in collaboration with the Virginia Tobacco Indemnification and Community Revitalization Commission performed a comprehensive cancer needs assessment of four health district-defined communities. The four health districts chosen had a relatively high cancer burden and large medically underserved areas. The comprehensive assessment of cancer needs specific to each community will be used to develop a holistic strategy to improve cancer outcomes that utilizes strategies that are culturally appropriate to these communities.

Methods of Data Collection

Demographic and economic information was collected to get a general picture of the health district. This data was collected from a variety of web-based sources (e.g., U.S. Census Bureau, Department of Health and Human Services, Virginia Workforce Connection). The needs related to cancer prevention, early detection, treatment, and survivorship were assessed in five broad categories: cancer burden, cancer healthcare resources, community cancer resources, healthcare provider needs, and community population needs. Personnel dedicated to data collection included a Data Manager located at the Massey Cancer Center in Richmond and Community Health Educators (CHE) located in their respective health districts. The CHEs were qualified, long-term residents of the health districts and were responsible for gathering all community based information. Mechanisms used to gather information in the four categories were as follows.

[5] Statistics provided by the Virginia Cancer Registry (June, 2011), data from 2001 to 2007.
[6] State Cancer Profiles. http://statecancerprofiles.cancer.gov/index.html
[7] CDC, National Center for Injury Prevention, WISQARS Leading Causes of Death Reports 1999 – 2007, accessed on November 1, 2011, http://webappa.cdc.gov/cgi-bin/broker.exe
[8] Statistics provided by the Virginia Department of Health (June, 2011), data from 2005 – 2009.
[9] The Virginia Cancer Plan 2008 – 2012, Cancer Plan Action Coalition (CPAC).

Cancer Burden

The most recent data on cancer incidence (2001-2007) and staging (2000-2008) was acquired from the Virginia Cancer Registry for the 24 cancer sites monitored by the cancer registry. These were grouped into larger categories by disease site. Age-adjusted mortality rates and five-year average number of deaths were requested for these larger groupings from the VDH (data from 2005-2009). Analysis was then performed for each health district and comparison made to Virginia as a whole.

Cancer Healthcare Resources

To evaluate the cancer services provided by the healthcare facilities servicing the health districts, a complete list of private and public hospitals and cancer centers, as well as community healthcare clinics, was compiled using information from web-based data sources including the Virginia Health Information website (http://www.vhi.org/hospital_region.asp), data provided from the American College of Surgeons, and information gathered from the CHEs through prior knowledge and personal communications. A questionnaire was developed to be used during personal interviews by the CHEs with staff and administrators of the healthcare facilities. Information was collected from the following areas: facility accreditation, cancer screening and treatment services, hospice and palliative care services, oncology healthcare personnel, allied health services including nutritional assessment and counseling, genetic counseling, patient navigation, cancer support groups, and cancer clinical trials (**Appendix A**).

Community Cancer Resources

The Community Health Education Coordinators compiled a list of formal and informal community organizations that provided support to cancer patients, survivors, and their families before, during, and after treatment. The VDH offices were considered community resources and were able to provide information about additional local community resources. Local chapters of national and state cancer organizations were found through the main organization's website. These local chapters often guided the CHEs to other community organizations within the health district. Additional community organizations were found through personal communications with individuals working with cancer patients and their families. A questionnaire was developed to be used during personal interviews with staff of the community resource organization, and it was used to gather information related to the organization's mission, target population, cancer related services provided, and needs and challenges (**Appendix A**).

Healthcare Provider Needs

The perspectives of healthcare providers on the needs related to cancer in the community were gathered in two ways. First, key leader physicians were identified in the community, and they were asked to discuss the most pressing healthcare deficiencies and the most pressing needs of PCPs related to cancer in their health districts (**Appendix A**). Second, information gathered from the key leaders was used to develop a questionnaire for PCPs within the health district. The questionnaire was field tested with physicians from within the health districts prior to finalization. It was then produced both as a pre-stamped hard-copy questionnaire and as an online questionnaire. A list of PCPs in each health district was acquired from the Virginia Board of Medicine website,[10] modified to include only physicians with primary specializations of family practice, internal medicine, urology, dermatology, cardiology, endocrinology, gastroenterology, emergency medicine, obstetrics and gynecology, surgeons, pulmonologists, radiologists, and hospitalists. The list was provided to the CHEs who checked it for accuracy. All physicians on

[10] Virginia Board of Medicine. http://www.vahealthprovider.com/links.asp

the final list were asked to complete the questionnaire either via email or by personal visit to the physician's office. Initial contact was followed-up at least once, and potentially twice for non-responders (**Appendix B**).

Community Population Needs

The perspectives and perceived needs of the population living in the health districts were gathered in two ways. Data from the National Behavioral Risk Factor Surveillance Survey (BRFSS) was acquired from the CDC.[11] Data was requested for responses from individuals within the health districts, and for questions that related to cancer prevention and screening behaviors. These included questions about tobacco use, diet, exercise, weight, cancer screenings, and utilization of healthcare services. Relative rates of healthy behaviors were assessed, and comparison to state averages made. Additionally, significant differences in behaviors by demographic characteristics were also evaluated.

In addition to the BRFSS data, qualitative information related to attitudes about health and cancer, experiences with cancer diagnosis and treatment, and perceived needs related to preventive health and cancer services were collected via focus groups. Focus groups were conducted with two groups: cancer survivors/caregivers and the general population. Separate lines of questioning and focus group facilitator guides were developed for each group (**Appendix C**). Selection of focus group participants was based on the demographic characteristics of the population, and every attempt was made to recruit participants within the general demographics of the health district. Focus groups were also held throughout the health district to attain regional representation.

[11] BRFSS http://www.cdc.gov/brfss/

FINDINGS

Demographics in Southside Health District

The SSHD is located in the southern Piedmont region of Virginia. It encompasses three rural counties: Brunswick, Mecklenburg, and Halifax **(Figure 1)**. All three share a southern border with the North Carolina–Virginia state line. This area of Virginia, with its gently rolling red clay hills, is often referred to as the tobacco capital, and has historically depended on tobacco production to support its economy.

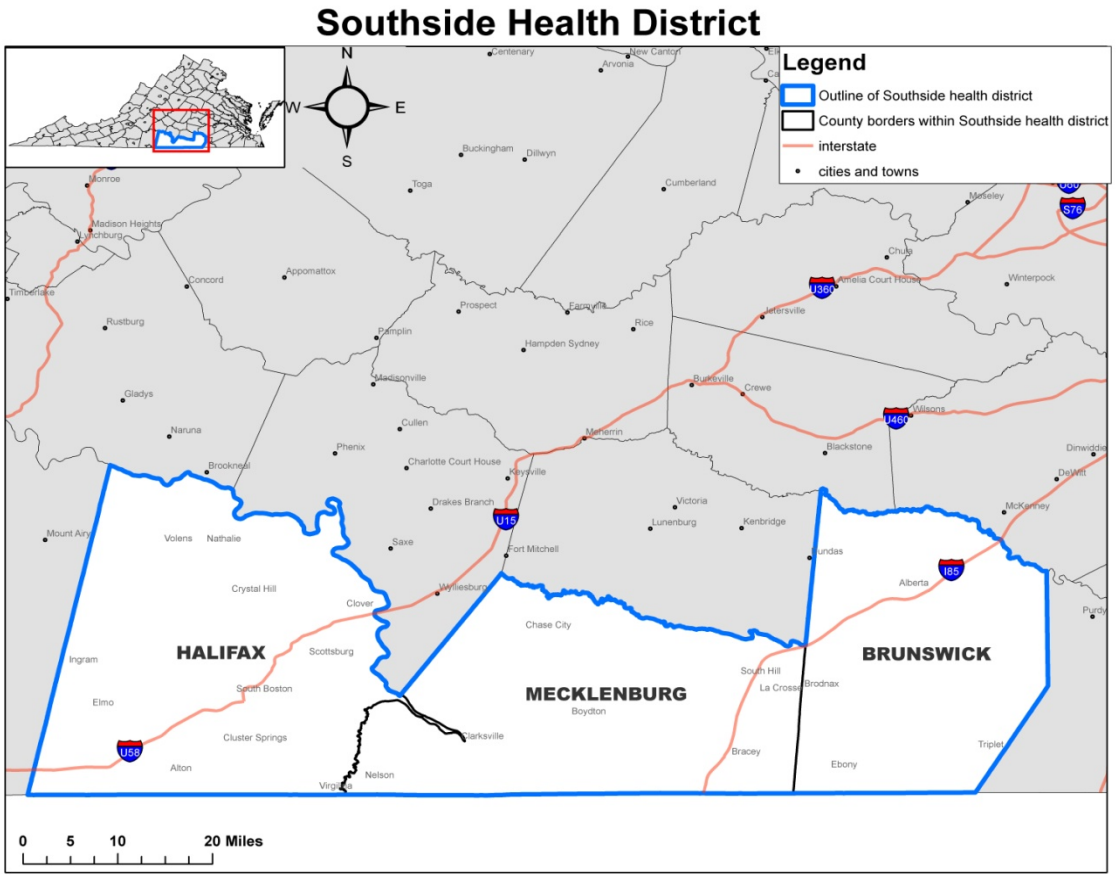


Figure 1: Southside Health District (SSHD)

The three counties making up the SSHD line up from east to west along the southern border of Virginia. The western most county is Halifax. This county is home to a population of 36,241[12] residents, and it has a population density of approximately 46 people per square mile. The largest town in Halifax County is South Boston (population 8,068). It is located north of the Dan River and has a total area of 830 square miles. In the 1850s, the Richmond and Danville

[12] U.S Census Bureau: American Fact Finder, http://factfinder2.censu.gove (accessed June 24, 2013).

Railway passed through the town making it a key center for bright leaf tobacco distribution. In 1960, South Boston was designated an independent city, and in 1995 it reverted back into a township of Halifax County. There are several other towns and communities within Halifax County ranging in population from 119 to 1,389 residents. The county is intersected by three interstate highways: US 501, US 360 and US 58. This contributes to the growing industry of warehousing and distribution that now provides many of the jobs within the county. Recently efforts have been made to transition the agribusiness of Halifax County away from tobacco toward a diverse range of timber, bio-energy products, vineyards, and food production.

Brunswick County is the eastern most county of the SSHD. It has a population of 17,434 residents and a density of approximately 34 people per square mile. It covers 569 square miles. Lawrenceville is the largest township and is the county seat. It has a population of 1,438. Three major roadways bisect the county: I-85, US 1, and US 58. The Fort Pickett Army National Guard Base is partly located in the county. Southside Community College is located in Alberta and offers many educational opportunities, which include workplace development for area residents. Brunswick County, like its sister counties Mecklenburg and Halifax, is rural. It also shares some of the same culture and heritage, much of it related to tobacco farming and marketing of tobacco. The economic downturn has taken a toll on Brunswick County in the recent years. One event which had a devastating effect on the local population and economy was the closure of a state-run prison facility in Lawrenceville. This event, along with the more recent closure of Saint Paul College, has created many challenges to area residents, which include loss of employer-sponsored health insurance.

Mecklenburg County is located in the middle of the SSHD. It covers an area of 679 square miles. The county is home to 32,069 residents, and has a population density of 52 people per square mile. Located within its borders are Chase City (the only city) and several towns, the largest being South Hill (population 4650). Mecklenburg County is a rural county that is proud of its tobacco heritage. A large part of the agricultural economy is tied to the growing and sales of tobacco.

According to the U.S. Census Bureau 2010 report, the SSHD's total population is 86,579. The district statistics indicate an aging population with 19% of its residents above 65 years old[13] as compared to the Virginia rate of 12%. The racial/ethnic statistics indicate the district is 56% white, 41% African American, and 3% other races. The Latino population comprises approximately 2% of the district's population. The state population is 70% white, 19% African American and 11% other. The state Latino population is 8% **(Table A).** The unemployment rate is 10.4% compared to Virginia at 6.5%. The median income in Virginia is $63,302 per household, but the SSHD median household income is $35,043. While 87% of Virginians graduate high school, only 74% SSHD residents complete high school **(Table B).** Recent declines in employment and health insurance coverage are direct results of the closure of textile mills in Halifax County and the closure of a large state prison facility in Brunswick County. The historical Saint Paul College in Brunswick recently announced that it too would be closing July 2013.

[13] U.S. Census Bureau; American Fact Finder, http://factfinder2.census.gov (accessed June 24, 2013).

Table A: Demographic Profile of the Southside Health District vs. Virginia

Demographic Profile of Southside vs. Virginia			
Category	**Subcategory**	**Southside**	**Virginia**
Gender	Male	49%	49%
	Female	51%	51%
Age	0-19	23%	26%
	20-34	16%	21%
	35-54	27%	29%
	55-64	15%	12%
	65+	19%	12%
Race	White	56%	70%
	Black or AA	41%	19%
	Other	3%	11%
Ethnicity	Hispanic or Latino	2%	8%
	Non-Hispanic or Latino	98%	92%

Table B: Economic Characteristics of the Southside Health District vs. Virginia

Economic Characteristics of Southside vs. Virginia		Southside (average)	Virginia
Unemployment[14]	Unemployment Rates	10.4%	6.5%
Income[15]	Median Household Income	$35,043	$63,302
Education[16]	% Less than high school	26%	13%
	% High school or GED	35%	26%
	% some college, no degree or an Associate's degree	26%	27%
	%Bachelor's degree or above	13%	34%

[14] U.S. Census Bureau; American Community Survey, 2007-2011 Summary Table DP03; generated using American FactFinder; <http://factfinder.census.gov>; (April 29, 2013). Health District is an average of the counties. Population age 16 years and older.
[15] U.S. Census Bureau; American Community Survey, 2007-2011 Summary Table DP03; generated using American FactFinder; <http://factfinder.census.gov>; (April 29, 2013). Income amounts shown are adjusted to 2011 inflation dollar value. Health District is an average of the counties.
[16] U.S. Census Bureau; American Community Survey, 2007-2011 Summary Table DP02; generated using American FactFinder; <http://factfinder.census.gov>; (April 29, 2013). Population age 25 years and older.

Access to Healthcare

The counties within the SSHD **(Figure 2)** have been designated Health Professional Shortage Areas (HPSAs) and Medically Underserved Areas (MUAs) by the Health Resources and Services Authority[17].

There are two hospitals within the district: Community Memorial Hospital, which is located in South Hill (Mecklenburg), and Halifax Health Systems Hospital, which is located in South Boston (Halifax County). The majority of primary care providers, as well as specialists, are located within close proximity to these facilities.

There are family practice clinics located in several outlying communities. Several of the clinics were developed as a result of funding connected to their rural and HPSA/MUA designations. There are five major university-based medical facilities within a 2.5 hour drive. The University of Virginia is located to the northwest, the Virginia Commonwealth University Health System is Northeast, and the three others are south of the district in neighboring North Carolina.

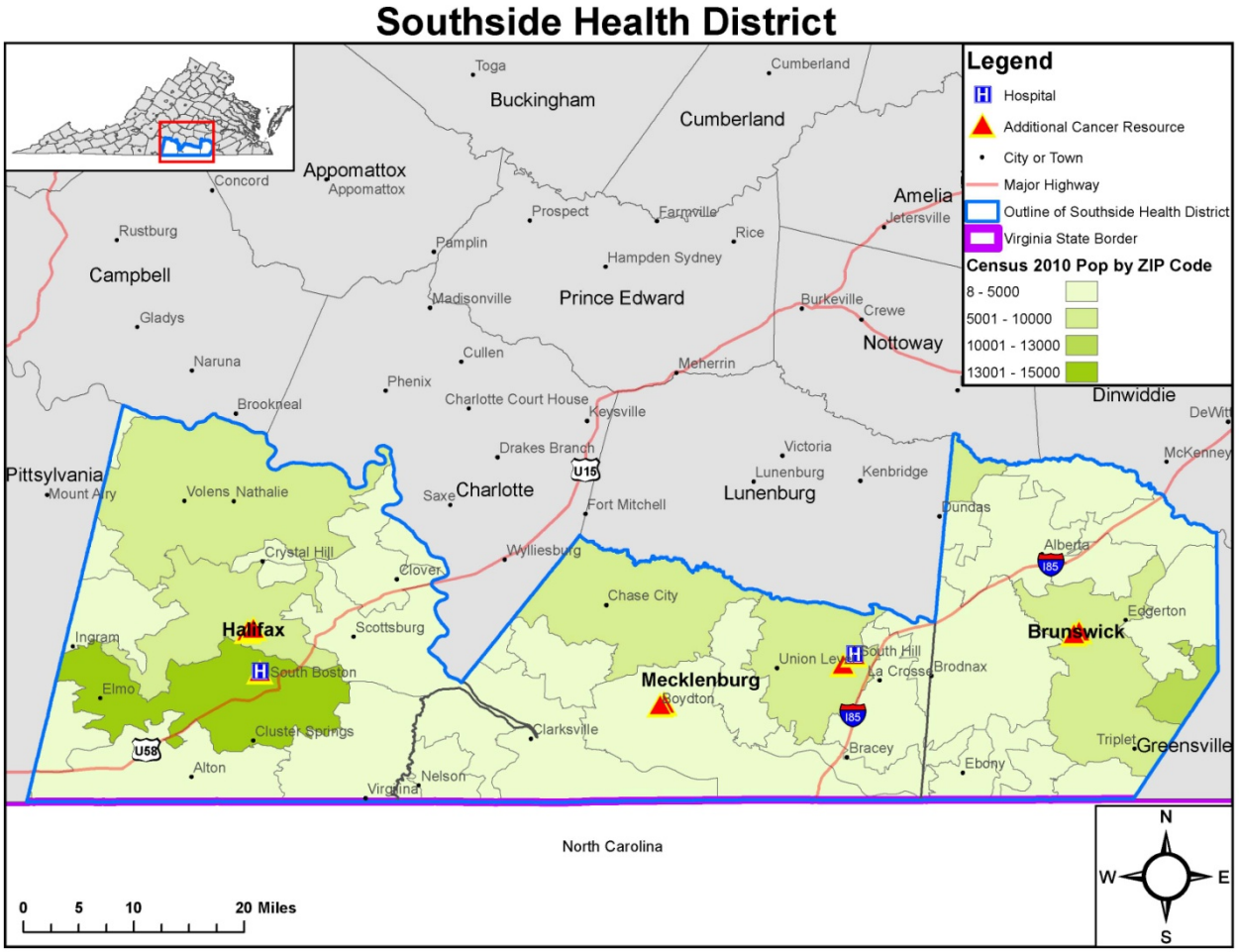


Figure 2: Healthcare Resources in the Southside Health District

[17] Health Resources and Services Administration; data warehouse;

Cancer Burden

Cancer Incidence

Cancer incidence was calculated for the SSHD for all cancer types and is reported for cancers grouped by disease site. Incidence rates of the gender specific cancers (female breast, male genital, and gynecological) were calculated from the appropriate gender populations. The cancer site groupings include respiratory, gastro-intestinal, hematologic malignancies, urinary system, brain-nervous system-eye, oral cavity-pharynx, and other cancers. Cancer incidence rates are age adjusted (**Table C**). The total age-adjusted cancer incidence rate for the health district is lower than that for Virginia. With the exception of male genital and gastrointestinal cancer subgroups, the age-adjusted cancer incidence rates for the SSHD are either comparable to or lower than the age-adjusted cancer incidence rates for Virginia.

Age-Adjusted Cancer Incidence Rates in Southside Health District vs. Virginia

Cancer Site	Southside	Virginia	*Notes*
Male Genital System	**176.2**	**167.7**	*Data Source: Virginia Cancer Registry (averaged rates for1999-2008) – all rates calculated based on populations including all ages.*
Prostate	172.6	162.0	
Other male genital organs	3.6	5.7	
Female Breast	**117.8**	**124.3**	
GI System	**87.4**	**79.8**	*Dataset ordered by descending rate for health district.*
Colon & Rectum	53.1	47.5	
All Other GI	34.3	32.3	
Respiratory	**73.3**	**72.5**	*Age-Adjusted Rate - represents an age-adjusted number of new cancer cases per 100,000 populations.*
Gynecological	**37.7**	**44.4**	
Corpus and Uterus	16.9	21.8	
Ovary	9.5	12.1	
Cervix	8.2	7.2	*Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females.*
All other Gynecological	3.1	3.4	
Heme-malignancies	**32.6**	**34.3**	
Lymphomas	18.3	19.5	
Leukemias	7.9	9.7	
Myeloma	6.3	5.2	
Urinary System	**29.5**	**32.4**	
Oral Cavity, Pharynx	**11.0**	**10.3**	
Brain, Nervous System, Eye	**5.5**	**6.5**	
All Other Sites	**30.5**	**44.5**	
All Sites	**429.8**	**446.6**	

Table C: Age-Adjusted Cancer Incidence in the Southside Health District vs. Virginia

The cancer sites with the highest incidence in the SSHD are male genital, female breast, gastrointestinal, and respiratory systems. Compared to the state, the district had significantly higher age-adjusted incidence rates for gastrointestinal cancers, but a lower age-adjusted incident rate for gynecological cancers and the "all other sites" categories (**Figure 3**).

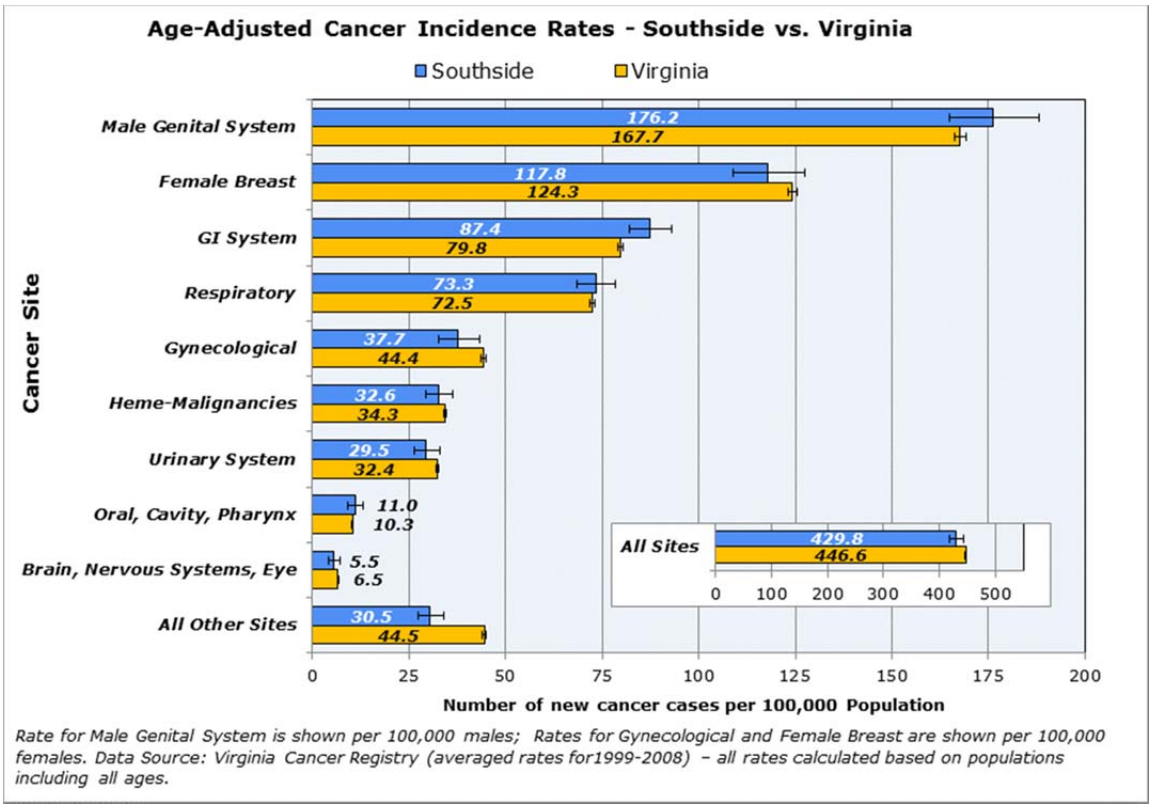


Figure 3: Age-Adjusted Cancer Incidence the Southside Health District vs. Virginia

To evaluate the impact of cancer in the community in terms of provider burden and services needed, information on the annual number of cancer diagnosis was acquired from the Virginia Cancer Registry. In the SSHD, there is an average of 489 new cancer cases a year (1999-2008). Gastrointestinal, male genital, female breast, respiratory, and heme-malignancies had the highest incidence counts. Together, they make up 78% of all the cancer cases **(Table D, Figure 4)**.

Top 5 Cancers in Southside Health District by Incidence Count		
Cancer Site	**Annual Count**	***Notes***
GI System	**100**	*Data Source: Virginia Cancer Registry*
Colon & Rectum	61	
All Other GI	39	*Annual Count - represents average number of new cases per year in the health district (averaged over period 1999-2008).*
Male Genital System	**92**	
Prostate	90	
Other male genital organs	2	
Respiratory	**86**	
Female Breast	**68**	
Heme-malignancies	**35**	*All Other Sites include Brain, Nervous System, Eye, Gynecological, Oral Cavity, Pharynx, Urinary System, and Other sites.*
Lymphomas	19	
Leukemias	9	
Myeloma	7	
All Other Sites	**108**	
All Sites	**489**	

Table D: Top 5 Cancers in the Southside Health District by Incidence Count

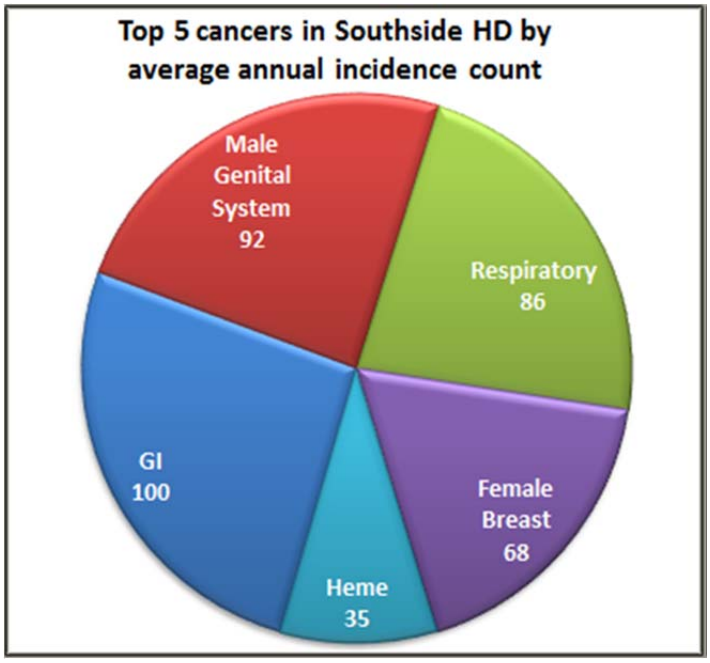


Figure 4: Top 5 Cancers in the Southside Health District by Incidence Count

The cancers with highest incidence among men in the health district are male genital, respiratory, urinary system, heme-malignancies and gastrointestinal**,** with the top three making up 73% of the annual incident cases **(Table E, Figure 5)**.

Top 5 Male Cancers in Southside			
Cancer Site	Crude Rate	Annual Count	*Notes*
Male Genital System	**214.4**	**92**	*Data Source: Virginia Cancer Registry*
Prostate	210.9	90	
Other male genital organs	3.5	2	*Crude Rate – represents number of new male cancer cases per 100,000 males.*
Respiratory	**137.9**	**59**	
GI System	**123.1**	**53**	
Colon & Rectum	72.6	31	*Annual Count - represents average number of new male cancer cases per year in the health district (averaged over period 1999-2008).*
All Other GI	50.6	22	
Urinary System	**59.7**	**26**	
Heme-malignancies	**45.4**	**19**	
Lymphomas	23.9	10	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.*
Leukemias	11.9	5	
Myeloma	9.6	4	
All Other Sites	**71.9**	**30**	
All Sites	**652.4**	**279**	

Table E: Top 5 Male Cancers in the Southside Health District

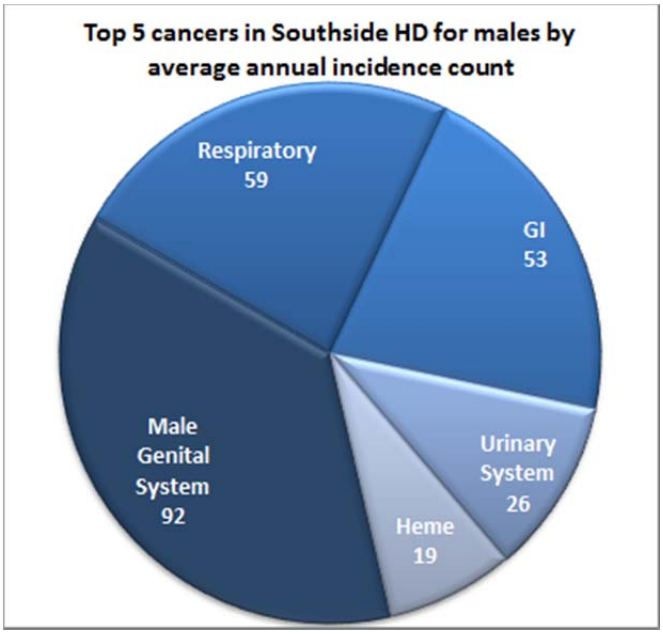


Figure 5: Top 5 Male Cancers in the Southside Health District

Cancers with the highest incidence rates for females in the district are breast, gastrointestinal, respiratory, gynecological, and heme-malignancies. These cancers represent 86.5% of the new incidences of cancer in the district each year **(Table F, Figure 6)**.

Top 5 Female Cancers in Southside			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Female Breast	**156.2**	**68**	*Data Source:* *Virginia Cancer Registry*
GI System	**108.6**	**48**	
Colon & Rectum	68.4	30	*Crude Rate – represents number of new female cancer cases per 100,0000 females.*
All Other GI	40.2	18	
Respiratory	**62.2**	**27**	
Gynecological	**50.5**	**22**	*Annual Count - represents average number of new female cancer cases per year in the health district (averaged over period 1999-2008).*
Corpus and Uterus	24.0	11	
Ovary	12.8	6	
Cervix	9.4	4	
All other Gynecological	4.3	2	
Heme-malignancies	**36.4**	**16**	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.*
Lymphomas	20.6	9	
Leukemias	8.2	4	
Myeloma	7.5	3	
All Other Sites	**66.8**	**29**	
All Sites	**480.6**	**210**	

Table F: Top 5 Female Cancers in the Southside Health District

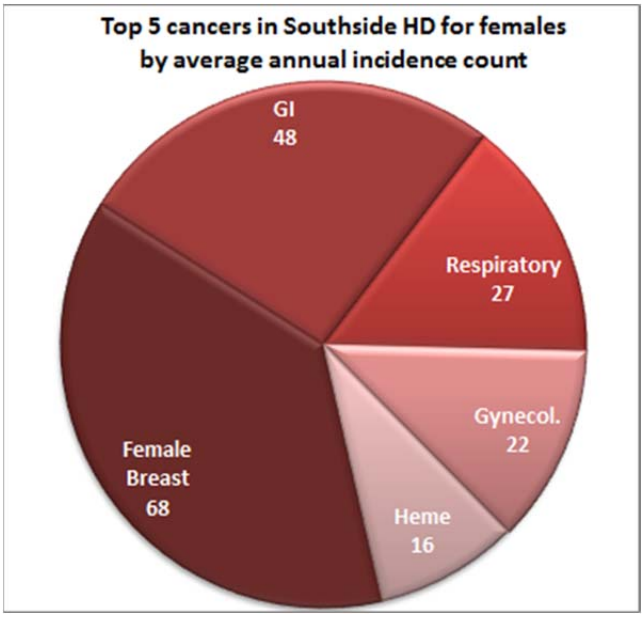


Figure 6: Top 5 Female Cancers in the Southside Health District

In the health district, males had a higher cancer incidence rate than females (671.8 vs. 525.9 per 100,000). The age-adjusted incidence rate of male respiratory cancers was 138.1 vs. 61.7 per 100,000 for females. Men also had higher rates for GI (131.1 vs. 114.3) and heme-malignancies (44.5 vs. 34.3). Breast cancer accounts for the largest incidence of cancer in women whereas genital cancer (primarily prostate) accounts for the largest incidence in men.

Both African American and Caucasian residents of the health district had slightly lower age-adjusted cancer incidence rates than Virginia with the exception of the age-adjusted cancer incidence rate for African American female breast cancer which was slightly higher in the district than the state (141.4 vs. 134.6). When compared to the white population in the district, black women had a higher incidence of breast cancer than white women (141.4 vs. 115.6). Black men in the district had higher rates of male genital cancer incidence than white men (203.0 vs.122.9) in the district, but lower age-adjusted incidence rate when compared to the state (203.0 vs. 213.1).The gastrointestinal cancer rate in the district was higher in the black population than the white population (108.3 vs.73.7), which is similar to the state (**Table G, Table H**).

Top 5 Cancers in Southside for African American Population

Cancer Site	10-year case count	Age Adjusted Incidence Rate		*Notes*
		Southside	Virginia	
Male Genital System	**415**	**240.7**	**245.7**	*Data Source:* *Virginia Cancer Registry*
Prostate	408	236.7	243.6	
Other male genital organs	7	4.0	2.1	*10-year case count – represents number of new cancer cases reported to the registry for African American population from 1999-2008.*
Female Breast	**277**	**131.1**	**122.4**	
GI System	**437**	**108.3**	**101.2**	
Colon & Rectum	250	62.4	57.2	*Age-Adjusted Incidence Rate represents age-adjusted cancer incidence rate for African American population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Incidence Rate.*
All Other GI	187	45.9	44.0	
Respiratory	**288**	**70.6**	**78.0**	
Gynecological	**79**	**36.2**	**39.2**	
Corpus and Uterus	34	14.7	18.7	
Cervix	21	10.7	8.4	
Ovary	17	7.6	9.2	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Heme-malignancies, Urinary System, and Other sites.*
All other Gynecological	7	3.2	2.8	
All Other Sites	**379**	**95.2**	**98.6**	
All Sites	**1875**	**466.2**	**472.4**	

Table G: Top 5 Cancers for the African American Population

Top 5 Cancers in Southside for White Population				
Cancer Site	**10-year case count**	**Age Adjusted Incidence Rate**		***Notes***
		Southside	**Virginia**	
Male Genital System	**481**	**137.3**	**152.6**	*Data Source:* *Virginia Cancer Registry*
Prostate	474	134.7	145.9	
Other male genital organs	7	2.7	6.8	*10-year case count – represents number of new cancer cases reported to the registry for White population from 1999-2008.*
Female Breast	**405**	**108.7**	**125.3**	
Respiratory	**568**	**74.3**	**72.5**	
GI System	**552**	**73.7**	**75.1**	
Colon & Rectum	352	46.5	45.7	*Age-Adjusted Incidence Rate represents age-adjusted cancer incidence rate for White population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Incidence Rate.*
All Other GI	200	27.2	29.3	
Gynecological	**141**	**38.8**	**45.4**	
Corpus and Uterus	70	18.4	22.5	
Ovary	39	10.8	12.7	
Cervix	20	6.6	6.7	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Heme-malignancies, Urinary System, and Other sites.*
All other Gynecological	12	3.1	3.5	
All Other Sites	**809**	**114.5**	**134.1**	
All Sites	**2956**	**402.2**	**442.4**	

Table H: Top 5 Cancers for the White Population

Gastrointestinal and male genital cancers make up 45% of the cancer burden among African American residents, while respiratory and gastrointestinal cancers make up the largest portion (38%) of the cancer burden among white residents in the health district **(Figure 7)**.

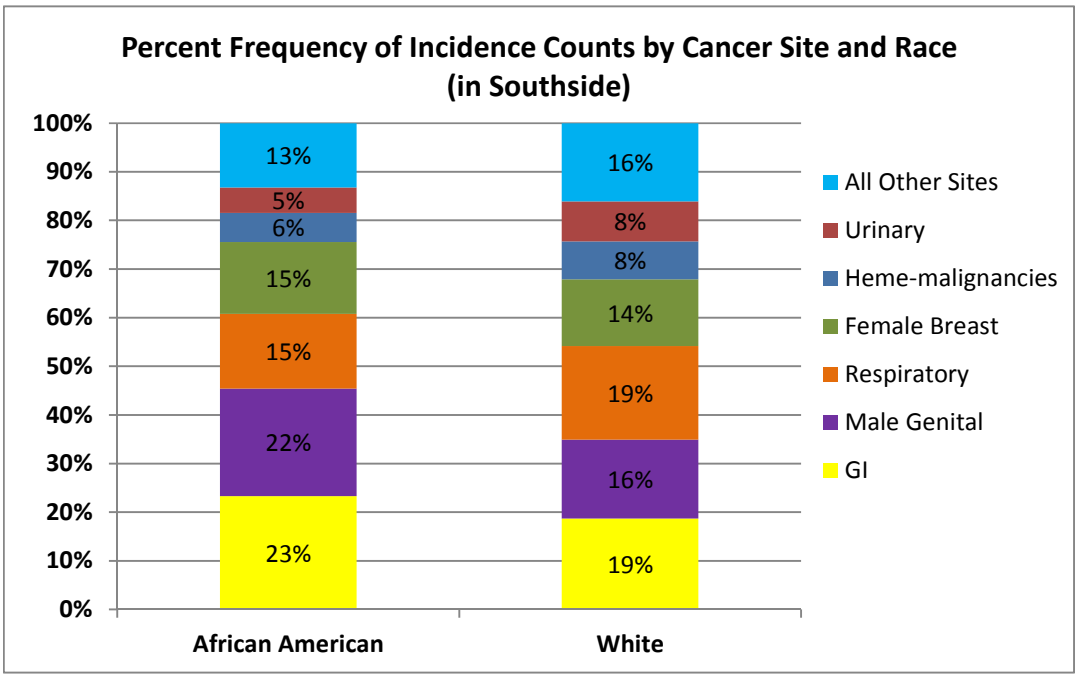


Figure 7: Percent Frequency of Incidence Counts by Cancer Site and Race

Cancer Staging and Mortality

Staging cancer is needed for proper treatment planning. Discovering cancer at the local stage is usually indicative of a better outcome and improved survivorship. In the SSHD, cancer staging is similar to that of the state at initial diagnosis with a few notable exceptions. Brain, nervous system, and eye (measured as a group) and gynecological cancers are diagnosed later in the district than in the state. Of particular interest, the cancer staging at diagnosis is similar in the district to that of the state in most types of cancer, but the mortality rate in the district is higher in most categories **(Figure 8)**.

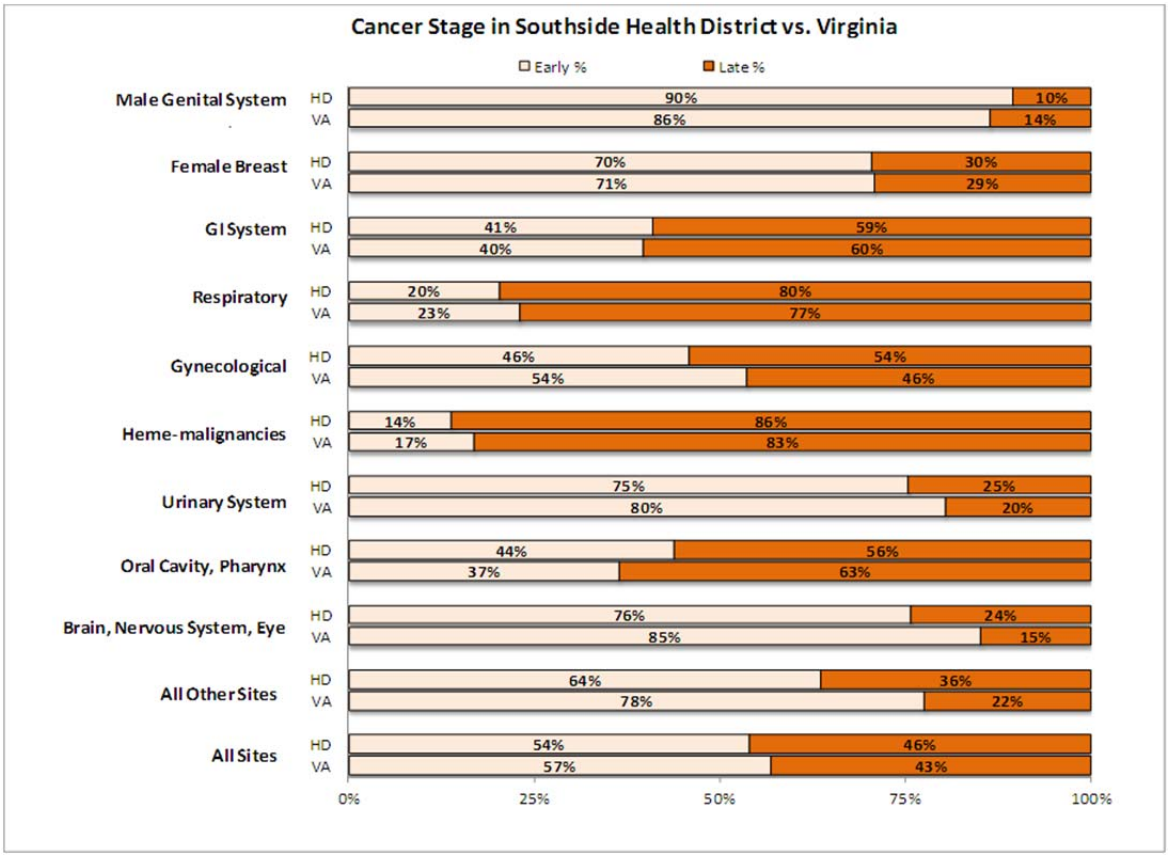


Figure 8: Cancer Stage in the Southside Health District vs. Virginia

An average of 203 residents in the SSHD succumb to cancer each year. The cancer sites with the highest mortality rates in the health district are (in order) respiratory, gastrointestinal, male genital, and female breast (**Table I**). Although the district has a lower incidence rate of cancer than the state, the mortality rate is significantly higher for all cancers taken together. When site rates are reviewed individually, mortality rates for respiratory, gastrointestinal, male genital, female breast, gynecological, and urinary system are higher than the state, with respiratory cancer significantly higher **(Figure 9)**.

Top 5 Cancers in Southside by Annual Death Count		
Cancer Site	**Annual Count**	***Notes***
Respiratory	**77**	*Data Source: Virginia Department of Health (averaged counts for 5-year period 2005-2009) - based on population for all ages.*
GI System	**52**	
All Other GI	32	
Colon & Rectum	19	
Female Breast	**17**	*Dataset ordered by descending death counts for health district.*
Heme-malignancies	**14**	
Lymphomas	5	
Leukemias	5	
Myeloma	4	
Male Genital System	**14**	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and other sites.*
Prostate	14	
Other male genital organs	0	
All Other Sites	**67**	
All Sites	**242**	

Table I: Top 5 Cancers in the Southside Health District by Death Count

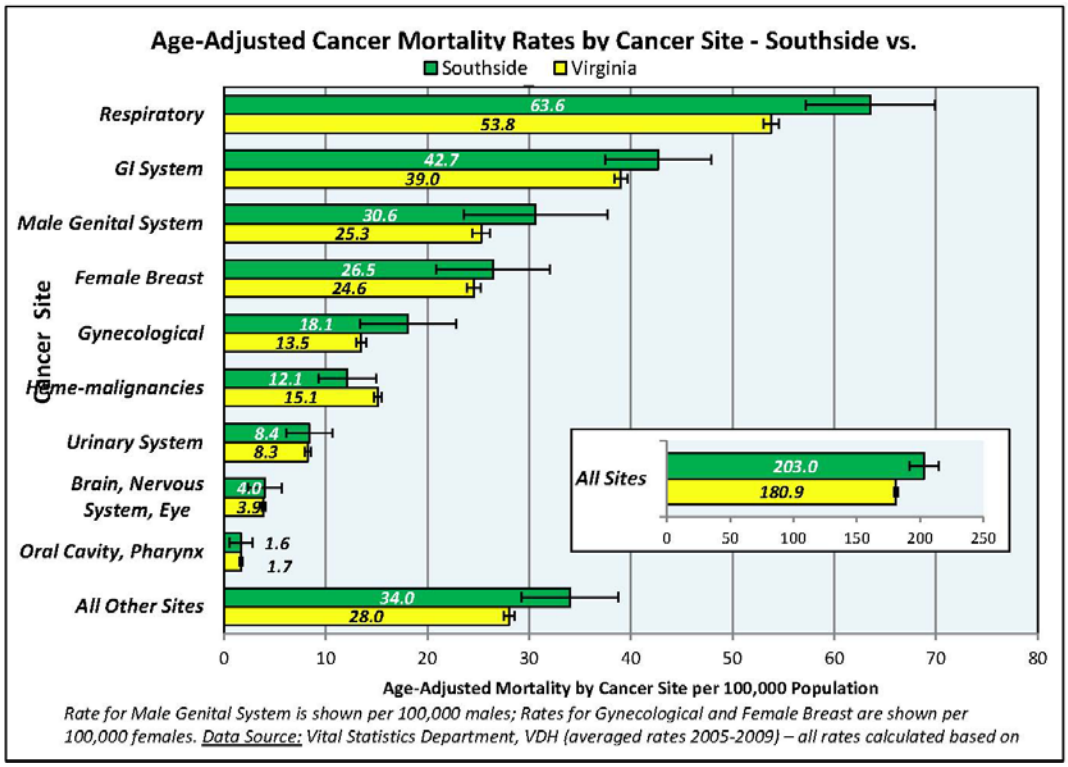


Figure 9: Age-Adjusted Mortality Rate by Cancer Site in the Southside Health District vs. Virginia

In the health district, males have a higher cancer mortality rate than females (316.3 vs. 249.1). The most notable difference is in the respiratory category. Males have a mortality rate of 119.3 vs. 61.9 for females within the district. The gastrointestinal mortality rate for men is 64.1 while the rate for women is 56.4 (**Figure 10, Figure 11**).

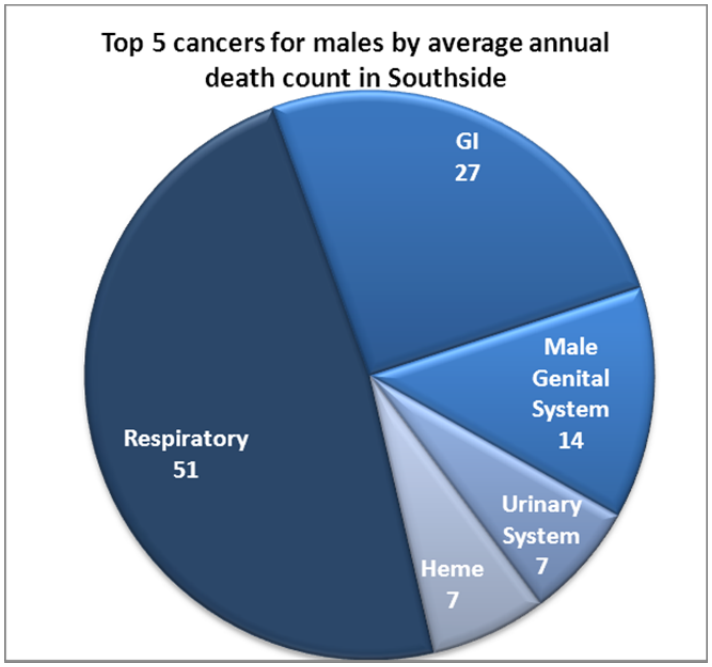


Figure 10: Top 5 Cancers Causing Death in Males

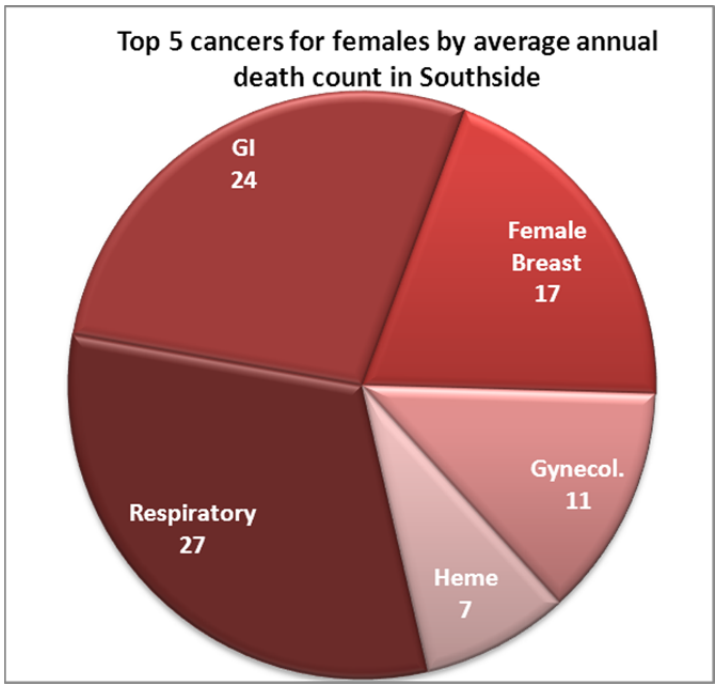


Figure 11: Top 5 Cancers Causing Death in Females

In contrast to the incidence rates, the cancer mortality rate among the district's black and white population is higher than the state rate. A comparison of the cancer site mortality rates between black and white residents of the health districts reveals that the mortality rates for breast cancer is higher in black women than white women (36.0 vs. 20.9). Similarly, the mortality rate for gastrointestinal cancer, male genital, and gynecologic cancers are higher among black residents than white residents. These rates are reflective of state trends (T**able J, Table K).**

Top 5 Cancers by Mortality for African American Population in Southside				
Cancer Site	**5-Year Death Count**	**Age Adjusted Mortality Rate**		***Notes***
		Southside	**Virginia**	
Respiratory	**132**	**63.1**	**59.6**	*Data Source: Virginia Department of Health (2005 - 2009).*
GI System	**124**	**59.8**	**54.9**	
All Other GI	76	36.7	31.2	
Colon & Rectum	48	23.1	23.6	*5-year death count – represents number of cancer deaths reported for African American population from 2005-2009.*
Male Genital System	**43**	**55.8**	**51.6**	
Prostate	43	55.8	51.2	
Other male genital organs	0	0.0	0.4	*Age-Adjusted Mortality Rate - represents age-adjusted cancer mortality rate for African American population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Mortality Rate.*
Female Breast	**41**	**36.0**	**33.6**	
Gynecological	**23**	**21.5**	**14.3**	
Cervix	9	9.0	3.3	
Ovary	8	7.3	6.7	
Corpus and Uterus	4	3.3	3.2	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Heme-malignancies, Urinary System, and Other sites.*
All other Gynecological	2	1.8	1.0	
All Other Sites	**137**	**68.0**	**59.1**	
All Sites	**500**	**243.8**	**220.3**	

Table J: Top 5 Cancers by Mortality for the African American Population in the Southside Health District

Top 5 Cancers by Mortality for White Population in Southside				
Cancer Site	**5-Year Death Count**	**Age Adjusted Mortality Rate**		***Notes***
		Southside	**Virginia**	
Respiratory	**253**	**63.8**	**54.0**	*Data Source: Virginia Department of Health (2005 - 2009).*
GI System	**134**	**33.9**	**36.2**	
All Other GI	86	21.9	20.7	
Colon & Rectum	48	12.1	15.5	*5-year death count – represents number of cancer deaths reported for White population from 2005-2009.*
Female Breast	**44**	**20.9**	**23.0**	
Male Genital System	**29**	**19.5**	**21.4**	
Prostate	28	18.5	21.1	*Age-Adjusted Mortality Rate - represents age-adjusted cancer mortality rate for White population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Mortality Rate.*
Other male genital organs	1	1.0	0.4	
Gynecological	**33**	**16.1**	**13.5**	
Ovary	26	12.4	8.9	
Cervix	3	1.9	1.9	
Corpus and Uterus	4	1.7	1.8	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Heme-malignancies, Urinary System, and Other sites.*
All other Gynecological	0	0.0	0.8	
All Other Sites	**215**	**56.6**	**57.6**	
All Sites	**708**	**182.6**	**176.3**	

Table K: Top 5 Cancers by Mortality for the White Population in the Southside Health District

Respiratory cancers represent the highest mortality burden for white residents, followed by “all other site” cancers. Gastrointestinal and respiratory cancers make up an equivalent burden in black residents, representing half of the total cancer deaths **(Figure 12)**.

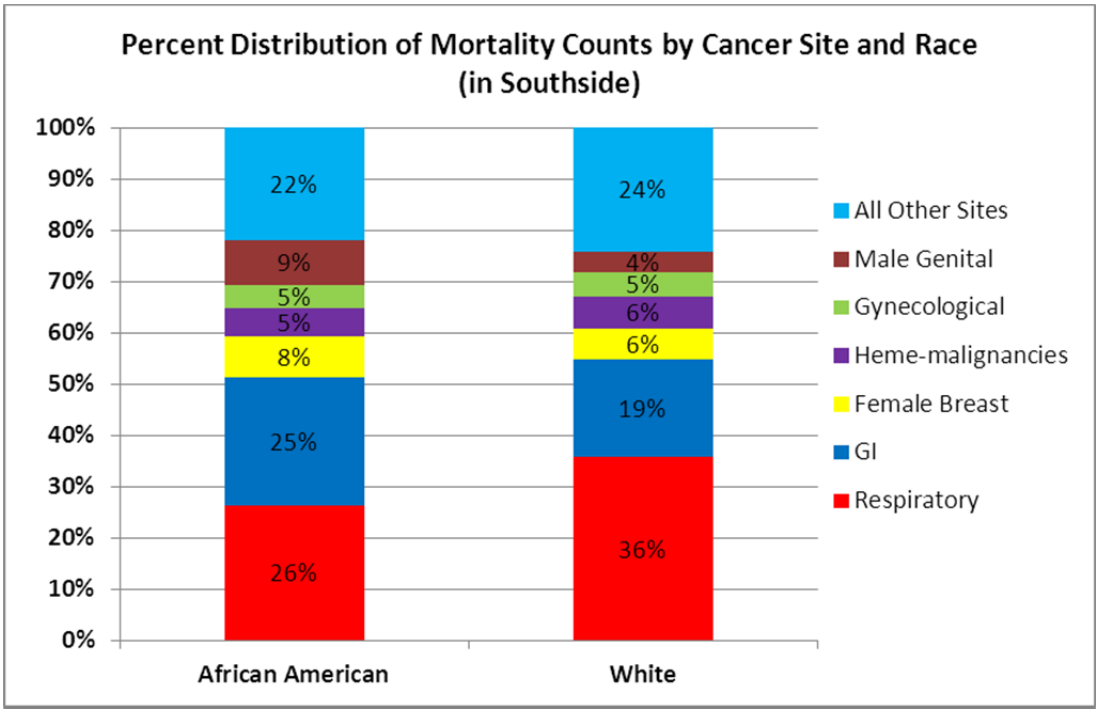


Figure 12: Percent Distribution of Mortality Counts by Cancer Site and Race in the Southside Health District

Cancer Healthcare Resources

Healthcare Facilities and Cancer Care

There are two hospitals located in the SSHD. Halifax Health System Hospital is located in South Boston, Halifax County. It currently has two Oncologists on staff and operates an infusion center. At present, patients must travel to Mecklenburg County to receive radiation therapy.

Community Memorial Hospital is located in South Hill, Mecklenburg County. It has one Medical Oncologist and one Radiation Oncologist. Community Memorial Hospital has an affiliation with VCU Massey Cancer Center that makes it possible to offer a variety of cancer treatment services, which include infusion and radiation services. The Solari Radiation center opened in the summer of 2013 and has eliminated the need to travel outside the community for radiation oncology procedures. During the interviews and focus groups conducted for this assessment, many respondents expressed how welcomed this service is in the community. Cancer survivors repeatedly mentioned how difficult it had been to travel every day for lengthy periods in order to obtain radiation therapy and how fortunate it was that the service was now available locally.

The district is classified as medically underserved and is rural in nature. Many residents must travel outside of their community to obtain healthcare. This is often an obstacle to care due to the lack of public transportation and individual funds. Once patients arrive at the medical office, they report long waits to see a healthcare provider. In Halifax County, the majority of healthcare providers are located in South Boston near the hospital or in the neighboring town of Halifax. In Mecklenburg County, the majority of providers are located in South Hill. There are rural health clinics in Boydton and Chase City which offer sliding scale fee-for-service payments. In Brunswick County, the healthcare is limited to two private clinics located in Lawrenceville and one rural health clinic in Alberta. There is no hospital or emergent care facility in the county **(See Appendix D)**.

Cancer Services Provided

Screening

Screening mammography, colonoscopy, and pap smears are available in Mecklenburg and Halifax Counties. Brunswick County offers pap smears at the local health department and private practices, but no facilities to provide mammograms or colonoscopy are located in the county.

At present, pap smears, which indicate a need for colposcopy, are problematic for patients who are uninsured or lack funds to pay for the procedure. Healthcare providers expressed frustration at the lack of availability of this procedure to their indigent patient population. In some cases, indigent patients simply opt for no further investigation due to the inability to pay.

Treatment

Within the health district, treatment modalities for cancer include chemotherapy, radiation, and surgery. Community Memorial Hospital offers all three services in South Hill (Mecklenburg County). Halifax Health System Hospital in South Boston (Halifax County) offers chemotherapy and surgery but does not offer radiation. Brunswick County has no treatment services located within the county, and residents must travel long distances for cancer care.

The recent collaboration between VCU Massey Cancer Center and Community Memorial Hospital resulted in the opening of the Solari Radiation Center in South Hill, which has improved the access to radiation treatment for many cancer patients in the district. Transportation issues have been an obstacle in the past, and although this new offering is a much appreciated improvement, transportation still remains difficult for many patients in this rural district.

Surgical treatment for breast, colon, and gynecological cancer is available in the district, but at the time of this assessment reconstruction for mastectomy was not available at either hospital. Most complex surgeries must be sent outside the health district. Additionally, genetic counseling is not offered within the district.

There is one patient navigator in the district who provides service at Halifax Health Systems Hospital. The primary resource for patients in the district remains social workers and insurance clerks.

The major deficiencies noted in the district included:

- Limited number of oncologists
- Limited number of patient navigators
- Lack of services in Brunswick County
- Lack of transportation to the services that are available as well as those which must be obtained outside of the area

Auxiliary Services

Programs that address survivorship needs, including dietary provision and counseling, genetic counseling, pain management, and end of life services are important services that effect both outcomes and quality of life. Both hospitals in the district have registered dieticians on staff and are able to address nutrition issues following the American Dietetic Association guidelines. There is no oncology certified dietician in the district. Services are provided to both in- and out-patients when referred by a physician. Pain management is provided by both hospitals and hospice. There are no palliative care dedicated programs available **(See Appendix E).**

Clinical Trials

Clinical trials are offered in Mecklenburg County at Community Memorial Hospital through the collaboration with the VCU Massey Cancer Center. The clinical trials program is expanding, and it will include access to medical oncology and radiation oncology clinical trials. Halifax and Brunswick do not offer the opportunity to participate in local cancer therapeutic clinical trials.

Hospice Services

SSHD has two non-profit hospices. Halifax Health Systems Hospice is based in South Boston and Community Memorial Hospice is based in South Hill. Both hospices are departments of a hospital. Patients are accepted based on medical criteria and not by ability to pay **(Appendix E).** There are other hospices providing services in the district in a very limited capacity. When hospice directors were interviewed, they indicated the greatest challenge for them is receiving patient referrals at a late stage in disease progression. They expressed concern that patients are not getting the advantages hospice can offer during end-of-life situations as well as the support hospice could provide to their caregivers. The directors felt that more education on the benefits and purpose of hospice is needed for both physicians and patients.

Community Cancer Resources

Cancer resources in the district exist in all three counties; however, Brunswick County lacks many resources that are available in the other two counties. Halifax and Mecklenburg Counties both have hospitals that offer various programs to educate the public and provide community outreach activities. Brunswick County residents may participate in these events, but must travel in order to do so.

Halifax County is very fortunate to have the Halifax County Cancer Association that provides services to residents of the county based on medical need without regard to income. The only requirements to receive benefits from this association are to have a cancer diagnosis and to be a resident of Halifax County. All funds for this organization are generated through private donations and fundraisers. Services include, but are not limited to, education and financial assistance. They provide various programs throughout the year aimed at early cancer detection. They supply wigs for chemotherapy patients and maintain a medical equipment loan closet. Many cancer patients have benefitted from their gas card program, which made it more affordable to travel to treatment centers.

Halifax Regional Health Systems Hospital provides a wide variety of resources to the community that range from health fairs to patient navigation services. They currently offer financial support for indigent patients requiring a colonoscopy. Hope Support Group is an active group in Halifax County that meets at Halifax Regional Health System monthly. The Halifax Health Department conducts a patient and caregiver support group called Bosom Buddies, participates in the Every Woman's Life program, provides pap smears, and has a contract with HRHS and Fuller-Roberts clinic for follow up on positive mammogram screenings. Brunswick County has limited resources located within its borders.

VCU Massey Cancer Center recently opened The Cancer Resource Center of Southern Virginia in Lawrenceville, Brunswick County. The mission of the facility is to facilitate the availability of local, state, and national cancer programs and resources to the population within the SSHD. Written materials that provide accurate, reliable, and current information related to cancer prevention, diagnosis, treatment, and survivorship are available. Staff is available to assist residents with identification of other resources and assist with community programs. The center is located on the campus of St. Paul's College.

The Brunswick Health Department also participates in the Every Woman's Life program and provides pap smears. There is no cancer support group in Brunswick County. Mecklenburg County has a cancer support group facilitated by Community Memorial Hospital's Cancer Center. In addition, the hospital provides the community with many programs aimed at encouraging healthy lifestyles, early cancer diagnosis and treatment, and support during treatment.

The American Cancer Society conducts its "Look Good, Feel Better" program in the health district. Recent plans included recruitment of volunteers for the "Road to Recovery" program, but due to recent changes within the organization the future of this program is uncertain. Mecklenburg Cancer Association is located in Boydton and provides financial assistance to cancer patients based on having a diagnosis of cancer and being a resident of Mecklenburg County. They are a private non-profit organization that depends on private donations and fundraisers to operate.

Mecklenburg Health Department offers the Every Woman's Life program and pap smears. Lake Country Area Agency on Aging provides personal care and homemaker services to elderly clients. They also provide transportation to medical appointments. The services provided are based on age and income, so they are not available to all residents. During interviews with personnel at the various resources, the concerns expressed often revolved around lack of transportation in the district. Examples mentioned included patients who are unable to drive (due to age, illness, or lack of vehicle), have no available family or friends to transport them as frequently as cancer patients often require, and lack of funds for fuel. The lack of transportation prevents patients' compliance with treatment in some cases.

Organizations that provide cancer screening services expressed concern regarding the difficulty they experience in referral of indigent patients with a positive screening result. The three health departments in the district all gave examples of incidents where patients had pap smears that required follow-up colposcopy, but could not afford to pay for the procedure. These patients are often sent to VCU for follow-up, but first they must apply for financial assistance that can take time. Also, they must travel long distances and take time off from work. As a result, in some cases patients chose to go without further investigation due to the time and expense.

Healthcare Provider Needs

Key Leader Information

Seven experienced, long-term residents who are health care professionals were interviewed in the SSHD to gather their perspectives on the healthcare system currently in place in the health district to provide cancer care and specifically, any deficiencies therein. The seven individuals were selected because they represent each of the three counties (Brunswick, Mecklenburg, and Halifax) in the SSHD. Their credentials include physicians, senior hospital administrators, registered nurses, and patient navigators. These individuals were asked first to identify the needs in the health district in the health care system as it relates to cancer risk reduction, detection, treatment, and follow-up care. Second, they were asked to identify needs of primary

care physicians specifically for cancer related continuing education, obstacles in acquiring cancer diagnosis and treatment for patients, post-treatment communication and training needs, and knowledge of palliative and hospice care.

The major health care deficiencies identified by these key leaders fell into four categories: (1) lack of healthcare providers, (2) need for continuing education related to cancer for primary care providers, (3) barriers to healthcare access, and (4) lack of programs and interest in addressing behavioral risks.

The district is a MUA. Concern that the area stands to lose many of the primary care providers in the near future due to retirement and other issues was a repeating theme. Of those interviewed, the fact that many providers are overworked, typically seeing twice the number of patients per provider as compared to other areas of the state, was considered one of the most important problems concerning healthcare in the district. The lack of trained oncologists and the workload was mentioned as a concern. This shortage was mentioned as one reason so few people are being offered the opportunity to participate in clinical trials.

Continuing education for primary care providers on topics across the cancer care continuum was identified generally as a need. Education related to cancer screening, diagnosis, care, and aftercare was mentioned as was end-of-life issues.

The lack of transportation was repeatedly mentioned as a barrier to healthcare. Many residents must travel long distances to obtain healthcare due to the rural nature of the district. Many residents are aged and do not drive. Others simply lack a dependable vehicle or the funds to purchase gas. There is no public transportation.

The high poverty rate, high number of under or uninsured, and lack of awareness of appropriate health screenings were other barriers. Many illnesses including cancer are identified only in the later stages when they have become an emergent care condition. In many cases, once a screening is positive it is difficult to arrange further testing to obtain a diagnosis due to financial reasons. There are also cases in which treatment is difficult to obtain due to financial limitations.

Key leaders in all three counties expressed concern about the high rates of obesity and the percentage of the population using tobacco products. Cultural practices, such as food preparation methods, contribute to the obesity rate. The local culture has historically prepared foods with smoked ham and many foods are fried. There was a consensus that the attitude toward tobacco use was one of acceptance in the district. This was attributed to the strong tobacco heritage in the all three counties. The availability of smoking cessation programs is limited and has been underutilized in the past when offered. Changes in public and workplace smoking policies have been met with strong resistance. The fact that educational programs in the district are so poorly attended was of concern to all those interviewed. There was consensus that reaching those most at risk was a challenge in improving healthy lifestyles in the district.

Physician Questionnaire Results

The physician survey sought to determine the thoughts of primary care providers on cancer screening, perspectives on patient compliance with screenings, care of patients during cancer treatments and follow-up, communication between PCPs and the oncology team, continuing education needs of PCPs and interest in clinical trials. Twenty nine physicians in the SSHD completed surveys, either on line or on paper, representing a 30% response rate. Forty-one percent of those responding were family practitioners and 13% specialized in obstetrics/gynecology. The remainder were general surgeons, internists, gastroenterologists, corrections medicine, and an urologist.

Cancer Screening and Compliance: Respondents identified the three most prevalent cancer diagnoses in their practice as breast 25.5%, colorectal 24.5%, and prostate 23.4**%**. When asked about recommended screening compliance among their patients, 88% and 76% of respondents indicated high or above average compliance with breast cancer and cervical cancer screening respectively. Slightly more than half (55%) indicated high to above average compliance with colorectal cancer screening (**Figure 13)**.

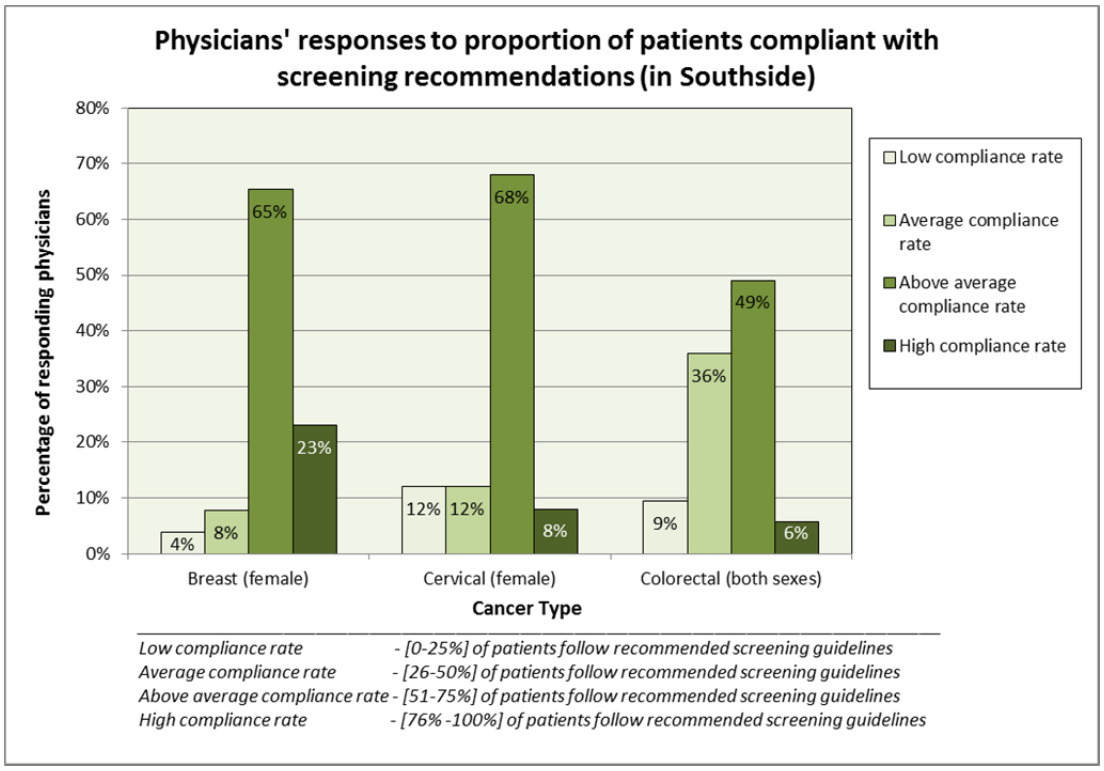


Figure 13: Patient Compliance with Screening Recommendations

The vast majority of physicians (83%) cited financial constraints as the reason for patients screening non-compliance. Over half cited apprehension (66%), lack of insurance (62%), and fear of cancer diagnosis (59%) as additional barriers to screening compliance. A lack of transportation (45%) was less frequently cited **(Figure 14)**. Half of physicians responding indicated an interest in receiving updated screening recommendations for breast, lung, prostate, colorectal, and ovarian cancers.

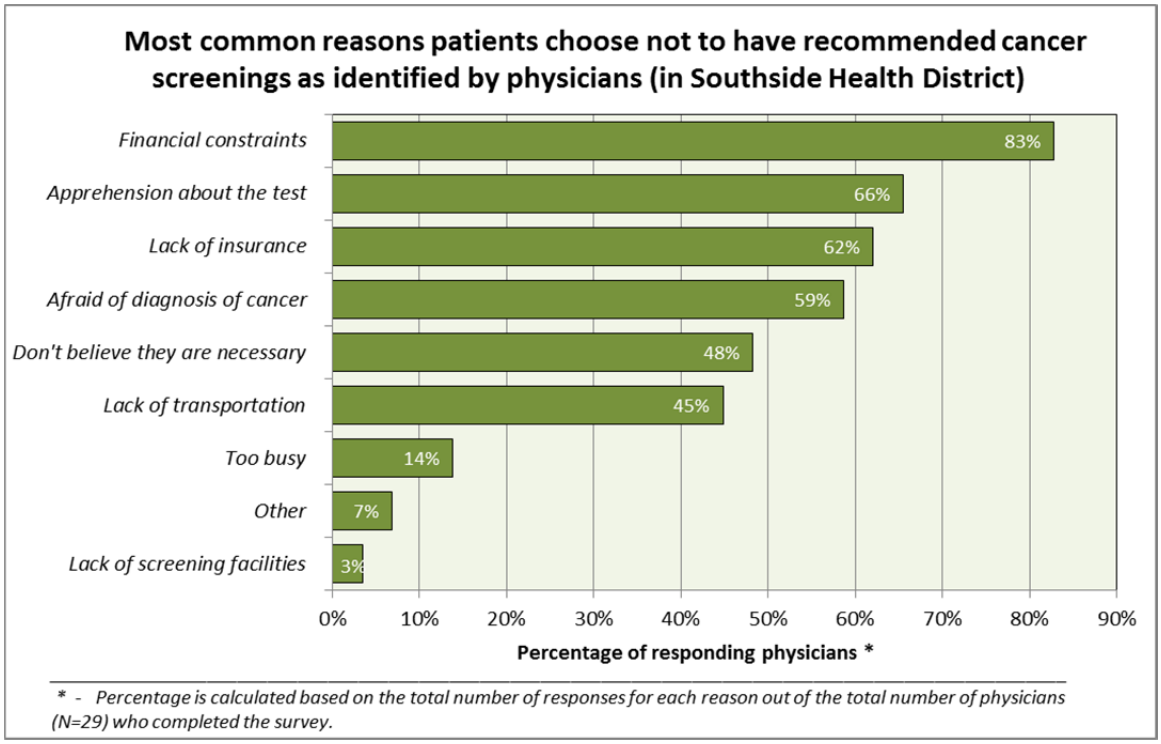


Figure 14: Most Common Reasons Patients Choose Not to Have Recommended Cancer Screenings As Identified by Physicians in the Southside Health District

Referrals and Communication: When asked where they refer their patients diagnosed with cancer, three quarters of respondents reported that they prefer to refer patients locally for oncology surgery and treatment. Their second most frequent choice was to a NCI center in Virginia (VCU, UVA). Fewer than 15% of respondents referred to oncologists outside of Virginia. The communication coming from a treating oncologist sited as most useful by over 80% of responding physicians was the initial treatment plan and end-of-treatment note. Follow-up care guidelines, pathology, and operative reports were cited by over half of physicians. Less than half (49%) of PCP's reported that they usually received satisfactory communication from treating oncologists.

Post-cancer treatment: Wellness and recurrence prevention was the continuing education topic that most physicians identified as a topic of interest. Surveillance of recurrence and monitoring and palliation of long-term effects were also significant topics of interest. There was less interest in information on genetic counseling and end-of-life care. The two most preferred methods for receiving continuing education information were in written (59%) and web based (38%) formats.

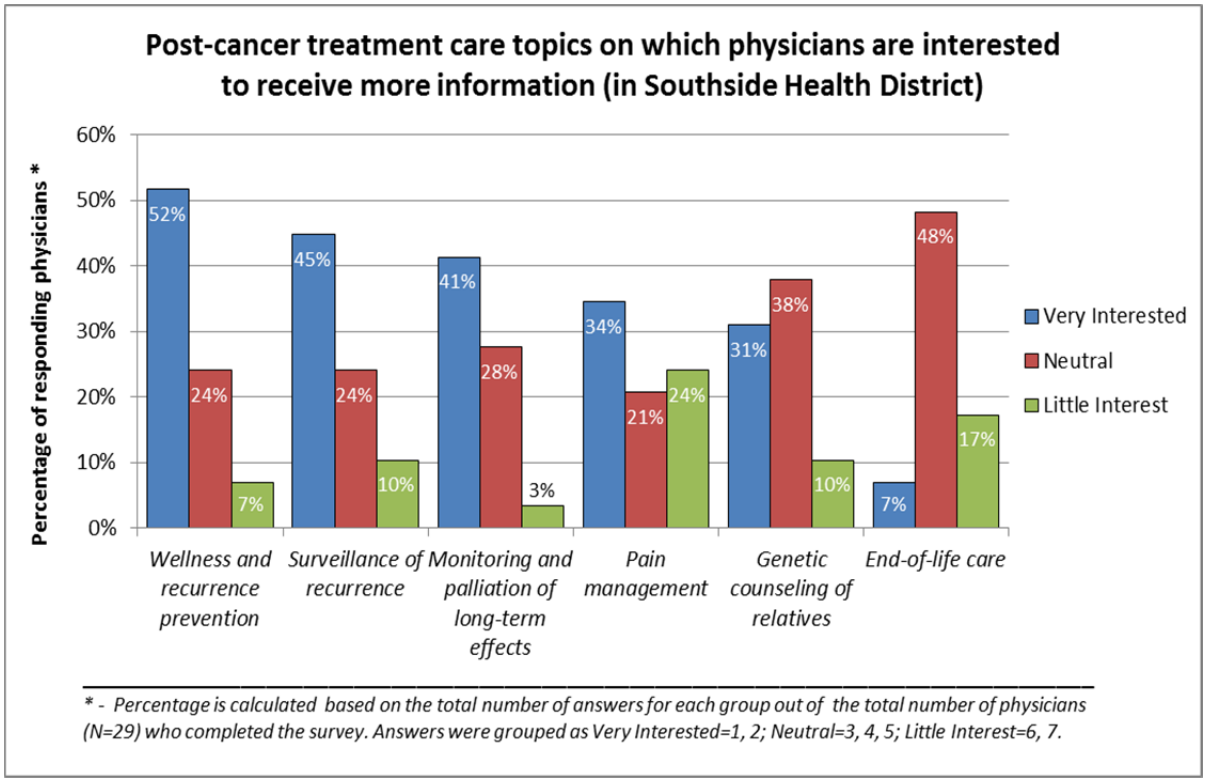


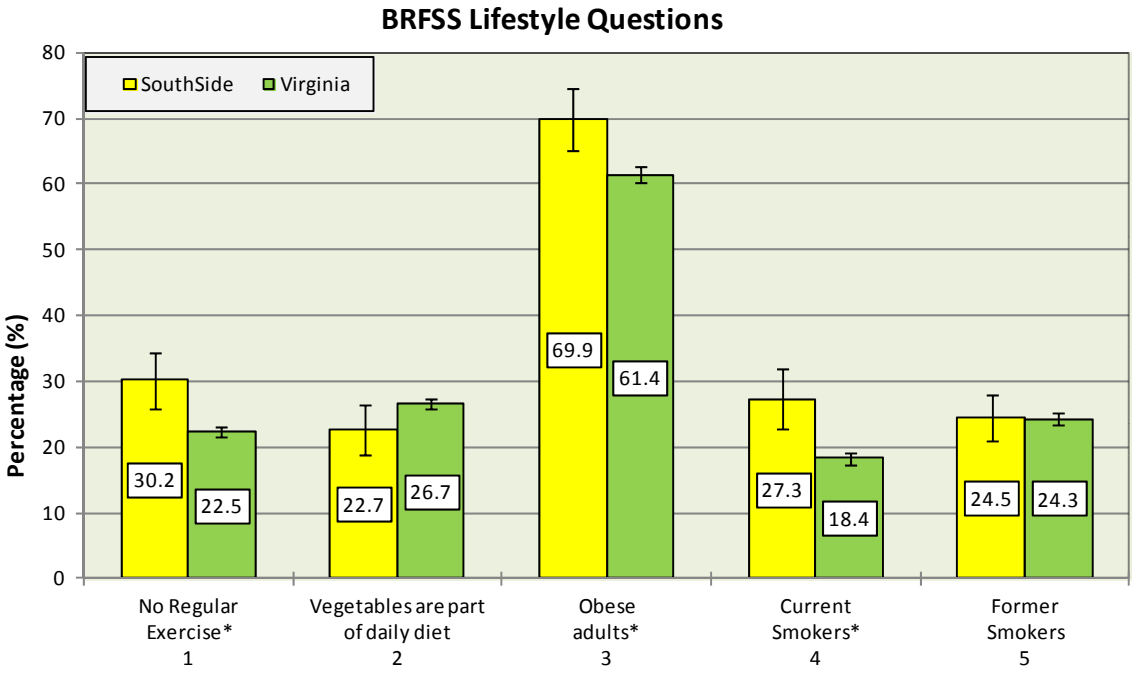
Figure 15: Post-Cancer Treatment Care Topics on Which Southside Health District Physicians are Interested in Receiving More Information

Community Population Needs

Two methods were employed to accurately assess the community resident's needs and concerns about cancer care: evaluation of the BRFSS data from the counties in the Health District and conducting focus groups with health district residents.

Behavioral Risk Factor Surveillance Survey

The Center for Disease Control conducts state-based monthly telephone surveys collecting information on health risk behaviors, preventive health practices, and health care access. Information from the BRFSS was accessed to gain perspectives at the Health District level about lifestyle factors, healthcare access, and screening practices. According to the BRFSS for adults 18 and older, the SSHD, when compared to Virginia shows a higher incidence of sedentary behavior and smoking, and has a relatively high incidence of obesity. All three factors are associated with a higher cancer risk. Thirty percent of the population reported no physical exercise in the past 30 days and only 22% included five or more fruits and vegetables in their daily diet. Greater than half (69%) of the district is overweight or obese and 27% of adults reported being current cigarette smokers (**Figure 16)**. This information is supported by comments gathered in the focus groups.

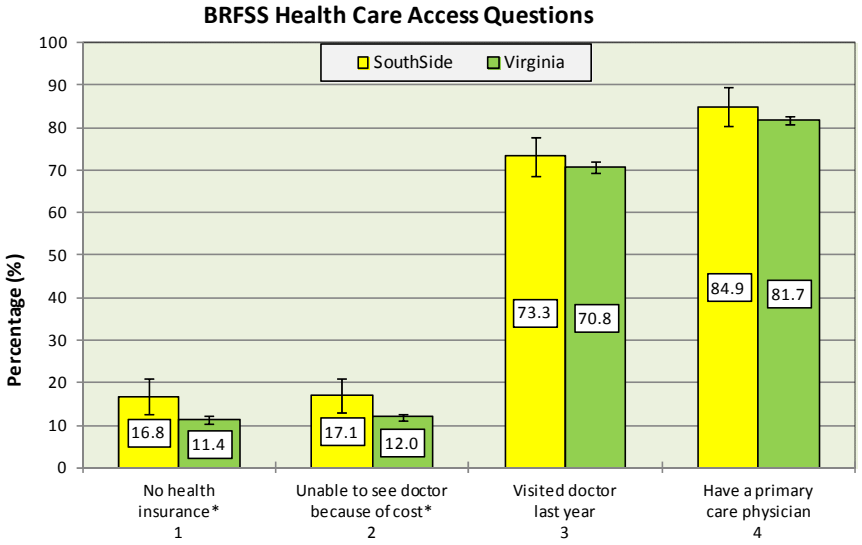


***** - *indicates a significant statistical difference between health district and state data;*
1 *- represents adults no physical activity of exercise during the past 30 days other than their regular job;* ***2*** *– represents adults who consume five or more servings of fruits or vegetables per day;* ***3*** *- represents adults with body mass index greater than 25.00 (overweight or obese);* ***4*** *- smoked 100 cigarettes in a lifetime and smoke today either daily or some days;* ***5*** *- smoked 100 cigarettes in a lifetime and do not currently smoke.*

Figure 16: BRFSS Lifestyle Questions for the Southside Health District

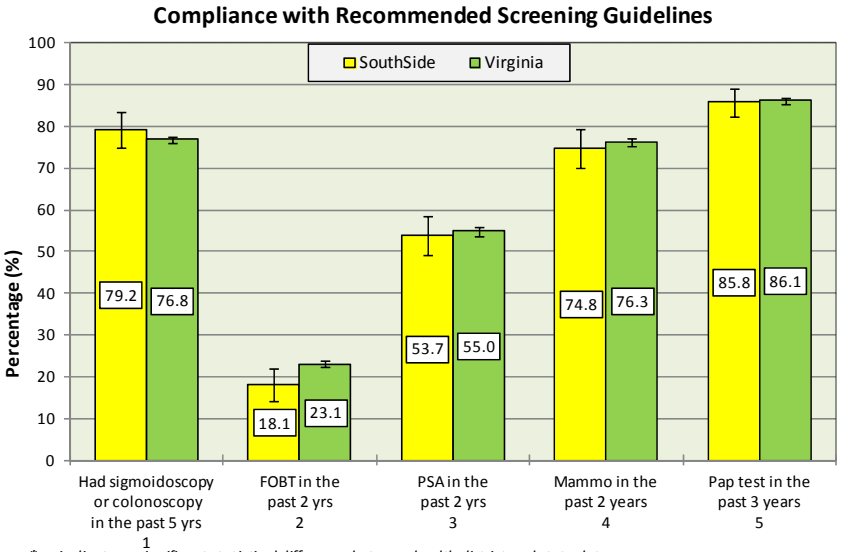
Access to healthcare for residents of the SSHD is similar to that for those in other parts of the state. The majority of residents has a primary physician and has visited their doctor in the past year. A larger proportion of individuals in the SSHD are unable to see a doctor due to cost or lack of insurance coverage when compared to the state (**Figure 17**).

Cancer screening rates in the SSHD were similar to the state rates. Despite the PCPs feeling that a lower percentage of clients were compliant with recommendations for colorectal cancer screening, 79% of residents indicated that they had had the screening. Only 18 %reported having a fecal occult blood test in the past two years, which is an alternative colorectal cancer screening to colonoscopy. Eighty five percent of women reported having a pap smear in the last three years and 74% had mammograms in the past two years. Slightly more than half of men reported having a PSA in the past two years **(Figure 18).**



** - indicates a significant statistical difference between health district and state data;*
***1** - represents adults with no health insurance; **2** – represents adults that were unable to see doctor in the past year because of cost; **3** – represents adults which had an appointment with a primary care physician within the past year; **4** – adults that have 1 or more physicians they consider their primary;*

Figure 17: BRFSS Health Care Access Questions



** - indicates a significant statistical difference between health district and state data;*
***1** - represents adults that have ever had an endoscopy exam; **2** – represents adults that have done a fecal stool blood test using a home kit in the past 2 years ; **3** - represents adult males over 40 that have had a prostate-specific antigen (PSA) test done in the past 2 years; **4** - represents adult females over 40 that have had a mammogram done in the past 2 years; **5** - represents adult females over 18 that have had a pap smear test done in the past 3 years.*

Figure 18: Compliance with Recommended Screening Guidelines

Focus Group Information

Focus Group participants were selected from the pool of volunteers who responded to mass email list-serves, flyers and personal presentations. In addition, ads were placed in area newspapers and on select radio stations. The demographics of the community were used as a guide for final selection of the participants. While the community is 49% male and 51% female, the final ratio of male to female for the focus group was 1:3 despite targeting of men for participation. Age, education, and economic distribution were better matched. The last criterion used for selection was personal experience with cancer. The general population focus groups consisted of people who had little or no experience with cancer. The survivor focus groups consisted of people who either had a diagnosis of cancer or were the primary caregiver of a cancer patient.

Cancer survivor and general population focus groups were held in each of the three counties making up the health district. Venues for the meetings were chosen by considering the convenience of the location and availability of parking for the participants. Groups were scheduled at varying times to accommodate the participants (**Figure 19**).

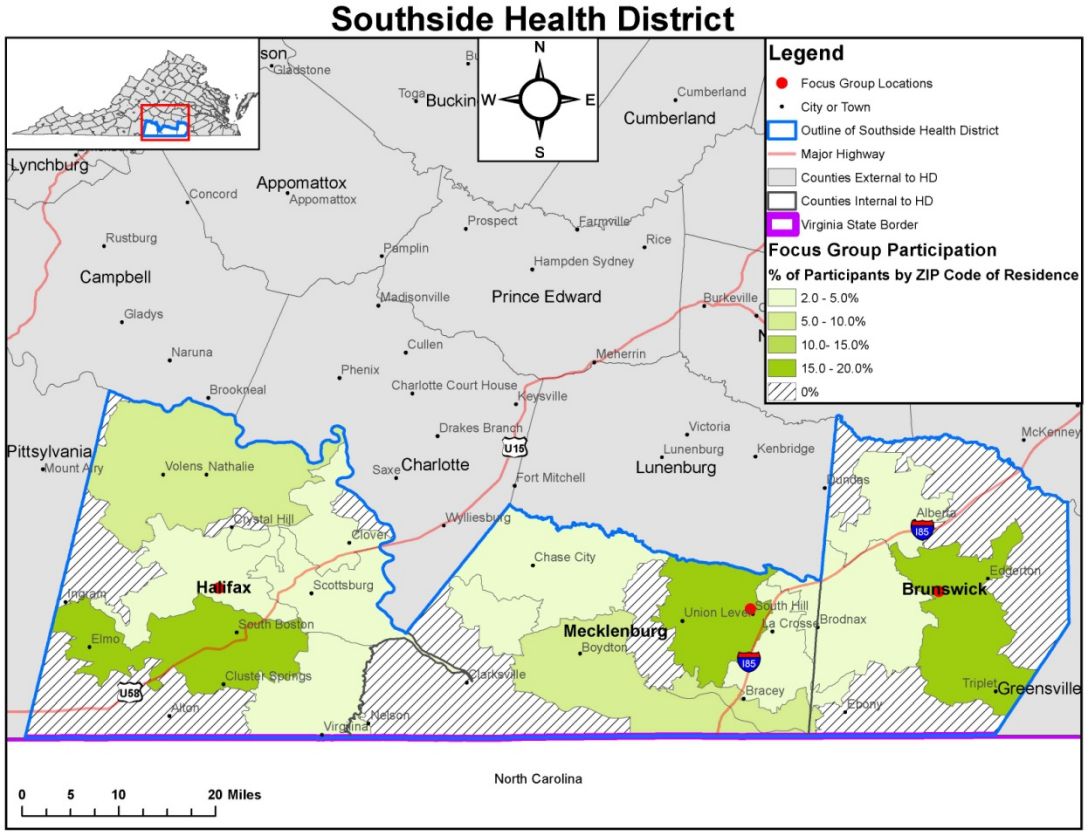


Figure 19: Focus Groups Participation in the Southside Health District

General Population Group Synopsis

Three general population focus groups were held in the SSHD. One group was held in each of the three counties making up the district. There were a total of 20 participants with an average group attendance of 7. Cancer was identified as the most important health problem in the community by all three groups followed by lung disease, heart disease, diabetes, and stroke. The groups expressed concern about getting cancer and mentioned the hardship it places on the family, the difficulty cancer patients have with transportation to treatment, and the extent of the problem as things they worry about. The genetic link to cancer was another concern mentioned by all groups. The high incidence of cancer in the area was named as a concern.

All three groups were able to identify some healthy lifestyle habits as well as unhealthy habits. Although many participants readily identified tobacco use as an unhealthy lifestyle, there was a pervasive feeling that the local culture was one of tobacco use acceptance. Statements were made about the “tobacco heritage” of the district being a source of financial security for many residents. Many residents who do stop smoking turn to chewing tobacco as a substitute. Smoking bans are met with resistance and frowned upon. All three groups felt there were insufficient smoking cessation programs and those available in the past were poorly utilized.

Awareness of the importance of healthy eating was evident but a recurring theme was the high cost of healthy foods. It was generally felt that the local availability and the expense of healthy foods were barriers to people eating nutritious diets. The need for additional educational programs was often cited as key to bringing about positive changes. Suggestions included linking free food distribution programs with an education component such as healthy cooking techniques, promoting farmers markets, and improving the healthy food choices available in the local supermarkets.

Obesity was recognized as a problem in the community. Factors which were felt to contribute to this problem included: people not wanting to openly discuss the problem; food being the main focus of most social events; obesity accepted as a norm; and depression. When asked how hard it is for residents to be physically active or get exercise, the lack of affordable, safe, and convenient facilities for formal exercise was mentioned as a possible barrier. Some felt that it was easy to be active and was a matter of personal preference and lack of discipline for those who had a sedentary lifestyle. Others pointed out that activity such as walking could be dangerous in rural areas due to lack of sidewalks and dangerous animals. The need for additional programs to encourage weight control was identified as a need.

The groups were aware of many of the recommended cancer screenings. The attitude toward screening was positive. The benefit of early detection was generally understood. The main concern associated with screening was cost. The primary reason for failing to follow guidelines was inability to afford the tests followed by fear and anxiety associated with the procedures or the outcome.

The focus groups from Halifax County and Mecklenburg County had facilities and programs available to them that Brunswick County residents did not have. The statements made during the focus group in Brunswick County reflected this difference and their opinion that the resources would most likely remain unavailable. They were very concerned about the lack of availability of free screenings, limited shopping choices for healthy food and the need to travel outside the county to participate in programs aimed at healthy lifestyles. Of the three groups, the Brunswick group demonstrated the greatest need for education related to cancer prevention and screening.

Participants had very limited experience with research. Some participants associated the words “cancer clinical study” with “lab rat,” “guinea pig,” and “experimentation,” while others associated

the phrase with “testing” and ”learning”. There was reluctance to be involved in cancer research unless it was involving direct benefit to the community or a family member. The decision to participate would also hinge on the degree of invasiveness.

Cancer Survivor Group Synopsis

Three cancer survivor focus groups were held in the SSHD. One group was held in each of the three counties making up the district. There were a total of 30 participants with an average group attendance of 10. The initial line of questioning during the focus group revolved around cancer patient’s information needs and their experience with access to information. Fear and shock were identified as initial responses to the diagnosis that impacted the ability to understand the information being provided at the time of diagnosis. This combined with poor health literacy about cancer, impacted the communication of the diagnosis and treatment options provide by the physician at the time. Many described their efforts to acquire the information they needed afterward, and their frustration at the lack of local resources, especially a local person who could explain to them the information that they were finding about their diagnosis. Testimonies of misinformation resulting patient choices that resulted in delayed diagnosis or treatment were given.

Most participants had been diagnosed locally, but had been treated outside of the health district. Reasons included a lack of treatment options available locally. Brunswick County is particularly devoid of treatment resources, and residents from this county expressed the lack of care resources, as well as support services. This contrasted with Halifax and Mecklenberg residents who identified local resources where they acquired financial, transportation, and home health support services. The residents from Mecklenburg expressed a real appreciation for the improved treatment resources at the local hospital, including the new radiation oncology facility. Resources identified by participants as most helpful to their treatment decision making and treatment journey were information provided by other cancer survivors, and where available, the services of a patient navigator. The most consistently referenced resources identified as beneficial to residents experiencing cancer and their caregivers were local treatment facilities, financial and transportation resources, home healthcare for assistance with everyday living, and support groups throughout the process. Brunswick County residents expressed a lack of all of these services in their area.

Participants in the focus groups were positive about the follow-up care information they were provided after treatment, most indicating that they received written information and good follow-up medical care. Information about lifestyle behaviors to decrease risk of recurrence and maintain health was less consistently received, and very few received any referral to local resources that could help them. Many expressed the desire to be seen by a healthcare professional other than their doctor for information related to specialized fields including nutrition, exercise, and emotional support. They wanted an individualized plan based on a review of their situation.

When queried about cancer clinical research, responses that are stereotypical were received including words like “experiments,” “lab coats,” “petri dish.” The majority of responses were positive, associating clinical research with “cure,” “improvement,” and new treatments. Seven participants had either been approached or were on a clinical trial during their treatment. All recognized the need for clinical trials to be available as a treatment option, but acknowledged that individuals undergoing cancer treatment in general want the best established treatment.

SUMMARY OF PRIORITY NEEDS

The SSHD is classified as a MUA. Within this health districts, compared to the rest of Virginia, residents are older, less well educated, and have a lower median household income. Also, the unemployment rate within this district is higher than that of Virginia. Although cancer screening and treatment are available within the district, in many cases patients must travel long distances to utilize these services, which is a significant barrier to receiving healthcare. Based on the qualitative and statistical information gathered for this project, the following are recommendations/suggestions for action:

Patient Education

- Public awareness campaigns to promote risk reduction with a focus on tobacco use.
- Youth education programs for cancer prevention and avoidance of tobacco use.
- Promote awareness of current resources within the district which provide information on wellness and cancer.
- Increase availability of affordable smoking cessation and exercise programs.
- Provide education to promote earlier enrollment in hospice care to assure maximum benefit.

Physician Education

- Develop continuing education programs for primary care providers which include updates on screening guidelines, wellness and prevention of cancer recurrence, and monitoring and palliation of long-term treatment effects.
- Provide education to promote earlier enrollment in hospice care to assure maximum benefit.
- Programs to increase physician awareness of the impact of health literacy on understanding and compliance of patients to physician recommendations, especially related to cancer diagnosis and treatment decisions.

Community Level Support

- **I**ncrease the number of available programs to improve nutrition and reduce obesity.
- Provide support to localities in recruiting primary care providers as well as additional specialists including oncologists.
- Establish support groups within any county without current availability.
- Accessible cancer information resource centers.
- Increase screening opportunities in Brunswick County.

Patient Level Support

- Develop affordable transportation for cancer screening, diagnostics, and treatment.
- Equitable access to quality insurance and financial support for timely, effective diagnosis and treatment of cancer for all.
- Availability of patient navigators to cancer patients at time of diagnosis and through treatment.
- Increase referrals of cancer survivors to professionals in nutrition and exercise for post-treatment healthy lifestyle guidance and planning.

APPENDICES

Appendix A:

Surveys used to gather data from healthcare facilities, Community Resource Organizations, and Key Leader physicians.

Appendix B:

Primary Care Physician Questionnaire

Appendix C:

Focus Group Facilitator Guides

Appendix D:

Cancer Healthcare Resources within the Health District

Appendix E:

Community Cancer Resources within the Health District

APPENDIX A

Surveys used to gather data from Healthcare Facilities, Community Resource Organizations, and Key Leader physicians.

Healthcare Facility Questionnaire

Provider:
Provider's Organization:
Person Interviewed:
Date of the interview (MM/DD/YY):

Thank you for agreeing to provide information for the needs assessment of cancer services and resources in your area. The information you provide us given your role at (Insert organization name_____) ***will contribute to our understanding and will ultimately lead to improved cancer services and programs in Southwest Virginia. Your responses will be kept completely confidential and your name will not be included in any report we publish.***

FACILITY

The first few questions are about cancer registries and certification your facility may have.

1. ***First, do you have a cancer registry at your facility?*** Yes_____ No____

   - If YES, ***What is the name of the registrar?*** _____
   - If NO, ***Is the registry maintained by another medical center/facility?*** Yes_____ No____
     - If YES,
       - ***What is the name of that facility?*** _____
       - ***What is the name of registrar at that facility?*** _____

2. ***Does the facility have a cancer committee?*** Yes_____ No____ Unknown____

3. ***What Cancer Certifications does this facility hold?*** (Mark all that apply.)

ACOS (American College of Surgeons Commission on Cancer) Yes_____ No____ Coming soon____

NAPBC (National Accreditation Program for Breast Centers) Yes_____ No____ Coming soon____

Other (American College of Radiology (ACR), Foundation for Accreditation of Cellular Therapy (FACT), etc. please specify) _____

4. ***Is the list of oncologists that I have documented as being on staff at the hospital accurate?*** Yes___ No___
   - CHE to bring list of oncologists with specialties. List additional oncologists and specializations:

_____
_____
_____

5. ***Are services for the following items provided by your oncologists at this facility?***

Chemotherapy Inpatient: Yes_____ No____
Outpatient: Yes_____ No____

- If NO to Inpatient, where are patients sent for chemotherapy?
  _____

- If NO to Outpatient, where are patients sent for chemotherapy?
  _____

Radiation therapy Yes_____ No____

6. ***Are you currently trying to recruit Oncologists to practice at this facility?*** Yes_____ No____
   Which specializations?_____

7. ***Could you provide me with annual report of the number and types of cancers that are treated at your facility?***

   Yes_____ No____ Will try ____

SCREENING/DIAGNOSTIC SERVICES

The next few questions are about cancer screenings and diagnostic procedures offered at your facility.

1. ***For Breast Cancer do you offer:***
   - Screening mammography?
     a) Film Yes_____ No____ Unknown____
     b) Digital Yes_____ No____ Unknown____
   - Diagnostic mammography? Yes_____ No____ Unknown____
   - Breast ultrasound? Yes_____ No____ Unknown____
   - Breast MRI? Yes_____ No____ Unknown____
   - Breast Biopsy (radiology guided)? Yes_____ No____ Unknown____

IF RESPONDENT ANSWERED "NO" TO ALL BREAST CANCER SCREENING/DIAGNOSTIC MODALITIES:

2. ***Where are patients referred for breast cancer diagnostics?***
   _____
   _____

3. ***Does your facility offer gynecology care?*** Yes_____ No____ Unknown____
   Colposcopy? Yes_____ No____ Unknown____

IF RESPONDENT ANSWERED "NO" TO COLPOSCOPY:

4. ***Where are patients referred for colposcopy?***
   _____
   _____

5. ***For Colorectal Cancer do you offer:*** (Mark all that apply)
   Sigmoidoscopy? Yes_____ No____ Unknown____
   Colonoscopy (invasive)? Yes_____ No____ Unknown____
   CT Colonography - Virtual Colonoscopy (non-invasive)? Yes_____ No____ Unknown____

SURGICAL SERVICES

6. ***What type of <u>Cancer related</u> surgeries are performed at this facility?*** (Mark all that apply.)

   - Breast segmental/complete mastectomy? Yes_____ No____ Unknown____

- If YES to mastectomy, do you perform sentinel nodes sampling? Yes_____ No____

- Breast Reconstruction? Yes_____ No____ Unknown____
- Gynecologic (hysterectomy/oophorectomy)? Yes_____ No____ Unknown____
- Gynecologis (ovarian debulking)? Yes_____ No____ Unknown____
- Gastrointestinal (resection)
  - -upper tract Yes_____ No____ Unknown____
  - -lower tract Yes_____ No____ Unknown____
  - -liver Yes_____ No____ Unknown____
  - -pancreas Yes_____ No____ Unknown____
- Lung? Yes_____ No____ Unknown____
- Prostatectomy? Yes_____ No____ Unknown____
- Ears, Nose, Throat? Yes_____ No____ Unknown____
- Brain? Yes_____ No____ Unknown____
- Other (please specify):_____

COUNSELING SERVICES

7. Do you have a Registered Dietician to provide nutritional services specific to cancer patients? Yes__ No__

i. If YES, ***name of Dietician*** _____

- If YES, ***is he/she board certified in oncology nutrition?*** Yes_____ No____

Which nutritional services does he/she offer?

One-on-one assessment and diet prescription? Yes_____ No____ Unknown____
Individual oncology nutrition counseling? Yes_____ No____ Unknown____
Outpatient oncology nutrition counseling? Yes_____ No____ Unknown____
Cancer control and prevention education programs? Yes_____ No____ Unknown____

8. In the last 12 months, has your healthcare center facilitated genetic testing for cancer risk?

If YES, which genetic tests:

___BRCA1/2
___Others _____

9. Do you offer genetic counseling for cancer risk? Yes_____ No____

If YES,

a. Is the counseling offered at ____ at your facility or _____ referred out for counseling
b. Who provides the counseling? (RN, NP, MP, GC, etc.)_____
   1. Are they certified? Yes_____ No____

10. Does your facility offer routine screening of colon and/or endometrial cancers for Lynch syndrome (Hereditary Nonpolyposis Colorectal Cancer)?

If Yes, which cancers do you screen?

___ Colorectal only
___ Endometrial only
___ Both Colorectal and Endometrial

What laboratory method do you use for screening?

___ immunohistochemistry staining for Lynch syndrome proteins (MLH1, MSH2, PMS2, and MSH6)
___ microsatellite instability (MSI) testing

FINANCIAL/INSURANCE

11. Do you accept all insurance including Medicaid and Medicare?

YES_____

NO_____ IF NO: ***What types of insurance do you NOT accept?***

Medicare_____

Medicaid_____

Other (please specify): _____

12. What programs do you have in place to financially assist under and uninsured patients?

1.

2.

3.

4.

5.

13. Do you accept uninsured patients? Yes_____ No____

- ***If you are unable to provide help to uninsured patients, where are they sent?***

_____

_____

CLINICAL TRIALS

The next few questions are about research related issues.

14. Does the facility have a Federal Wide Assurance number (FWA) required to perform federally sponsored clinical trials? Yes_____ No____ Unknown____

15. Does the facility use an Institutional Review Board (IRB)? Yes_____ No____ Unknown____

- IF YES, ***What is the name of the IRB?*** _____

- ***Is the IRB hosted at your facility or at a partner hospital?*** This facility____ Partner hospital_____ Name:_____

16. Do you have a cancer clinical trials program? Yes_____ No____ Unknown____

- If YES, ***can you provide us with the clinical trials menu?*** Yes_____ No____ Unknown____
- If YES, ***with whom are you affiliated?***

_____

_____

- If NO, ***would you like to start a clinical trials program?*** Yes_____ No____ Unknown____

17. Do you have affiliations with other Cancer Centers or national organizations? Yes____ No___ Unknown____

If YES, please, list all organizations and centers that you are affiliated with:

_____
_____
_____
_____

HOSPICE / PALLIATIVE CARE SERVICES

Now the next several questions are about services provided at your facility.

18. What Hospice Services are offered to patients?

- Inpatient hospice
  - Facility Supported Yes_____ No____ Unknown____
  - Private organization Yes_____ No____ Unknown____
- Outpatient hospice
  - Facility Supported Yes_____ No____ Unknown____
  - Private organization Yes_____ No____ Unknown____

19. Do you have a Palliative Care program? Yes_____ No____ Coming soon____

- If YES,
  - What medical professionals compose your team:
    ___ MD/DO Board Certified palliative care ___ NP/APRN ___ RN ___ SW
    ___ Chaplaincy ___ Care coordination ___ RD
  - What are the characteristics of your program:
    ___ consult service (providing recommendation to the attending service to treat palliative needs)
    ___ in patient beds (a palliative care unit in the hospital)
    ___ outpatient clinic (clinic specific to palliation of symptoms)

SUPPORT / EDUCATIONAL PROGRAMS

20. Do you have a cancer patient navigator at this facility? Yes_____ No____ Unknown____

- If YES:
- ***How many PNs do you have?*** _____
- ***For which cancer types?***_____
- ***Credentials? ___ nurse ____ social worker ____ lay person ____ ACS partner ____ other***

21. Do you host patient and family cancer support groups at this facility? Yes_____ No____

- If YES, ***please, list all support groups:***

_____
_____
_____
_____

- If NO, ***would you like to start a support group?*** Yes_____ No____ Unknown____

What cancer site would you like to start a support group for?

breast cancer_____ prostate cancer_____ lung cancer_____ brain cancer_____
cervical cancer_____ testicular cancer_____other_____

22. Do you host or hold Cancer prevention education programs? Yes_____ No____ Unknown____

- If YES, ***Please, list names of each program:***

_____
_____

Thank you for your time! Those are all my questions. Do you have any additional comments?

Cancer Resources Questionnaire

My name is _____. I am the Community Health Education Coordinator for a cancer needs assessment project being conducted by the Virginia Commonwealth University Massey Cancer Center and the Virginia Tobacco Indemnification and Community Revitalization Commission. Thank you for agreeing (I am calling to ask if you would be willing) to answer some questions related to your organization and the cancer related services that you provide. You will be contributing to the cancer needs assessment for the _____ Health District, the purpose of which is to identify the existing resources available to cancer patients and their families, and those that are needed for the Health District. The information gathered will be used to inform relevant private and public organizations to mobilize resources to meet identified needs.

Organization's name: _____

Address: _____

Ph: _____ Fax: _____

Website?: _____

CONTACT person: _____

Best time to contact? _____

Date of meeting/interview:_____

1. What is the resource organization's MISSION statement:

2. Which category best describes your organization:

- ☐ National non-profit
- ☐ Local non-profit
- ☐ For profit service organization
- ☐ Federal governmental organization
- ☐ State/municipal government organization
- ☐ Other _____

3. What is the major source of funds for your organization?

- ☐ Competitive grants
- ☐ Federal funds
- ☐ Service fees charges
- ☐ Donations
- ☐ Other _____

4. What is the primary service population for your organization (check all that apply):

- ☐ Cancer patients
- ☐ Cancer survivors
- ☐ Cancer caregivers/family members
- ☐ Other: _____

5. What are the qualification criteria for individuals to access your services?

- ☐ Must be uninsured/underinsured
- ☐ Financial qualification
- ☐ No qualification criteria
- ☐ Other _____

6. Which of the following services do you provide to cancer patients? (Check all that apply)

- ☐ Provision of written information on cancer
- ☐ Provision of information on cancer care and support resources
- ☐ Management of cancer support groups
- ☐ Financial support for cancer control/care
- ☐ Funding of projects related to cancer
- ☐ Psychosocial support
- ☐ Navigational services
- ☐ Transportation
- ☐ Other: _____

_____

7. How do you advertise your organization and services?

- ☐ Local media
- ☐ Organization website
- ☐ Online
- ☐ Distribution of pamphlets describing services
- ☐ Word of mouth
- ☐ Other _____

8. Approximately how many people needing cancer related services do you see annually?

- ☐ < 10
- ☐ 11 - 25
- ☐ 26 – 50
- ☐ 51 – 150
- ☐ > 150

8. What are the areas of need of your organization?

- ☐ Financial support
- ☐ Human resources (skilled employees, volunteers, etc.)
- ☐ Access to experts for consultation
- ☐ Physical space/facilities
- ☐ Collaborators
- ☐ Volunteers
- ☐ Other _____

_____

_____

10. .What are the greatest challenges that your organization has in meeting its mission?

_____

_____

_____

_____

11. What are the goals of your organization for the next 1 – 5 years?

_____

12. Are there organizations in the community you partner with? (list)

_____

_____

13. Would you be interested in collaboration?

_____

Key Leader Interview Questions

I. What are the most pressing ***healthcare deficiencies*** (personnel, level of training, healthcare facilities and services offered) related to:

a. The risk reduction of cancer in your community
b. The detection/diagnosis of cancer in your community
c. The treatment of cancer
d. Post-treatment and survivorship care
e. Palliative/hospice care

II. What are the most pressing ***needs of primary care physicians*** in your community related to:

a. Continuing education related to cancer & cancer survivorship
b. Patient cancer diagnosis
c. Patient referral for cancer treatment and communication pre & post treatment
d. Post-treatment and survivorship care of oncology patients
e. Palliative/hospice care related to cancer patients

APPENDIX B

Primary Care Physician Questionnaire

Cancer Needs Assessment VIP Physician Survey

Please complete the survey below. Thank you!

[redacted]

Thank you for participating in this survey. As an important physician within your community, your contribution is vital to our effort to gather information about cancer care. The information we gather will be published in a Cancer Needs Assessment that will be publicly available, and will be used to direct efforts to address the cancer care needs of this community. The Cancer Needs Assessment is being sponsored by the Tobacco Commission and the VCU Massey Cancer Center. The information you provide will be kept confidential.

Please, indicate the primary health district in which you practice:

☐ Southside ☐ Central Virginia ☐ Lenowisco
☐ West Piedmont ☐ Cumberland ☐ New River

Please indicate your primary area practice:

☐ Family medicine ☐ Internal medicine
☐ Urology ☐ Obstetrics/gynecology
☐ Dermatology ☐ Internal Hospitalist
☐ Surgeon ☐ Other_____Please specify

1. What are the three most common cancers that are diagnosed in your patients each year (check 3)?

☐ Breast ☐ Colorectal Prostate ☐ Lung ☐ Cervical ☐ Melanoma
☐ Hematologic ☐ Other *_____* Please specify

2. What percentage of your age/risk-appropriate female patients would you estimate have cancer screenings for the following cancers according to recommended guidelines:

a) Breast ☐ 0-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%
b) Cervical (PapSmear) ☐ 0-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%
c) Colorectal ☐ 0-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

3. What percentage of your age/risk-appropriate male patients would you estimate have cancer screenings for the following cancer according to recommended guidelines:

a. Colorectal ☐ 0-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

4. Do you screen your patients for other cancers? (please, select yes or no for cancers listed below)

Prostate ☐ Yes ☐ No Lung ☐ Yes ☐ No
Skin ☐ Yes ☐ No Ovarian ☐ Yes ☐ No

5. What do you feel are the most common reasons your patients choose not to have recommended cancer screenings (check all that apply)?

☐ Financial constraints ☐ Lack of Screening facilities ☐ Lack of transportation
☐ Apprehension about the test ☐ Afraid of being diagnosed with cancer ☐ Don't believe they are necessary
☐ Too busy ☐ Lack of insurance ☐ Other _____(please specify)

6. For which of the following cancers would you like information on screening challenges and/or updated screening recommendations (check all that apply)?

☐ Breast ☐ Colorectal ☐ Cervical ☐ Ovarian
☐ Prostate ☐ Lung ☐ Skin ☐ Other_____(please specify)

7. After one of your patients is diagnosed with cancer, where are you most likely to refer them for treatment:
would refer for Surgery to:

☐ Local surgeon
☐ Surgeon at a Virginia National Cancer Institute Designated Cancer Center (VCU or UVA)
☐ Surgeon at other Virginia cancer center (not VCU or UVA)
☐ Surgeon outside of Virginia
☐ Other _____(please specify)

would refer for Medical Oncology to:

☐ Local Medical Oncologist
☐ Oncologist at a Virginia National Cancer Institute Designated Cancer Center (VCU or UVA)
☐ Oncologist at other Virginia cancer center (not VCU or UVA)
☐ Oncologist outside of Virginia
☐ Other _____(please specify)

8. What information coming from the oncology team about your patient is most useful to you? (Check all that apply)

☐ Initial treatment plan ☐ End of treatment note ☐ Pathology report
☐ Operative reports ☐ Follow up care guidelines ☐ Other _____(please specify)

9. What percentage of the time do you receive satisfactory communication from the oncologist treating your patient?

☐ 0-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

10. What kind of treatment are you comfortable providing after your patient has received a cancer diagnosis (Check all that apply)?

☐ Non-oncology care during the time the patient is being treated for cancer.
☐ Joint management of oncology care with the oncology team during the time the patient is being treated for cancer.
☐ Long-term oncology follow-up care.
☐ Other _____(please specify)

11. Number the following post-cancer treatment care topics in order of interest to receive further information (1 – most interest; 7 least interest)?

Pain Management	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7
Surveillance of cancer recurrence	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7
Long-term cancer treatment effects: monitoring and palliation	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7
End-of-life care and planning	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7
Genetic counseling for family members of cancer patients	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7
Wellness and prevention of cancer recurrence	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7
Other _____(please specify)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7

12. In what form would you prefer to receive further cancer information?

☐ In person presentation ☐ Live webinar with interactive capability ☐ Web-based information, self-paced
☐ Written information ☐ Other _____(please specify)

13. Please comment on what you believe to be the most pressing challenges and barriers for physicians in your community in relation to cancer screening and diagnosis.

14. Please comment on what you believe to be the most pressing challenges and barriers for physicians in your community in relation to providing adequate care of patients after completing cancer treatment.

15. Rank your knowledge of cancer clinical trials on a scale of 1 (no knowledge) to 5 (expert).

1☐ 2☐ 3☐ 4 ☐ 5 ☐

16. Are you interested in learning more about the development and management of cancer clinical trials? Scale 1 (not interested) to 5 (very interested)

1☐ 2☐ 3 ☐ 4 ☐ 5☐

17. How important is it to you to have cancer clinical trials in your area? Scale of 1 (not important) to 5 (very important)

1☐ 2 ☐ 3 ☐ 4☐ 5 ☐

18. Would you like to learn about the cancer clinical trials being offered in your area? Scale of 1 (not interested) to 5 (very interested)

1☐ 2☐ 3☐ 4 ☐ 5 ☐

APPENDIX C

Focus Group Facilitator Guides

INTRODUCTION TO FOCUS GROUP PROCESS AND INFORMED CONSENT [7 MINUTES]

Thank you all for coming today/tonight. My name is <<INSERT YOUR NAME>>, and this is <<INSERT ASSISTANT'S NAME>>. Thank you for agreeing to be here. Your opinions are important to us.

To begin, I would like to give you an overview of how this focus group will work. As you know, the focus group will last for about two hours. During these two hours, I will ask you some questions about your opinions on cancer prevention, cancer screening, and research. We want you to draw on your experiences. We do not need to know the details of your medical history. The goal is for you to discuss the questions as a group. The most important information will come from the range of everyone's thoughts and ideas. It is very important that everyone feels free to speak and share, especially if you have a different idea or view from others in the group. There are no "right" or "wrong" answers to the questions.

My role is to help guide the discussion. I may ask specific people about their thoughts or ideas if they have not had a chance to share very much in the discussion. If we need to move on to another topic, I may ask you to hold your thoughts on that topic for us to come back to. I do not want to keep you longer than the two hours so my job is to make sure that I keep the discussion moving along at a good pace. However, I don't want you to hold back on your thoughts – as I said, if I need to move us along, I will but until then please express yourself!

I would like to go over a couple of ground rules for our discussion as a group, and then would like to ask you what other rules you think we should follow to make our time most productive. First, as facilitators, we will respect the privacy of all group members and keep the content of our talk confidential. By confidential we mean that it will be kept private. We will be tape recording the discussion, and you may see us taking notes. These steps are needed for us to accurately record what is said today, but we will not include any information that will personally identify you in our notes or recordings. When we review our notes from this meeting, we will be most interested in what the group as a whole has to say. When we write up and report of these focus group discussions, no person will ever be identified by name.

Second, I would ask that we call each other only by first names or the names that you have selected and written on your name tag. Do any of you have other ground rules that you think would be good to allow opportunity for everyone to express themselves freely?

We will be taking a break about half way through our discussion, but if you need to get up before that please do so as quietly as possible. You are free to stop participating in the discussion at any time or even leave.

If you stay to the end of the two-hour period you will receive $50 as our way of saying thanks. If you must leave early you will receive $25. You should have been given a paper to fill out that provides us with the mailing address to which the money should be mailed. A check should arrive within a week of this event. We have also given you a paper with the names and numbers of people you can call in the future if you have questions.

Does anyone have any questions? [Answer any questions]

WARM-UP [8 minutes]

Before moving on to the main topic of our discussion, I would like to take a few moments for everyone to introduce himself or herself. Please tell us something about your experience in this community, how long you have lived here, etc.

Turn off tape recorder for this section of the discussion

[Moderator: Introduces herself in the format they would like everyone else to use and then goes around the table.]

[Facilitator: Will take notes on where particular people are sitting by creating a diagram similar to the room and focus group layout. Individual first names will then be associated with a numbered position in the diagram. These numbers make it possible to document more easily who in the group is speaking when taking notes.]

CANCER IN COMMUNITY: GENERAL DISCUSSION [15 minutes]

So let us get started.

1. First, I would like you to tell me what you think are the ***most important health problems*** in your community. In other words, what illnesses, diseases, or other health conditions do you think are affecting your community the most?
   (List on flip chart)

2. [IF NOONE COMMENTS ON CANCER]: What about cancer? Is that something that you think is a health problem in your community?

   Review list on flip chart.

3. Is developing cancer something that you worry about for yourself?
   - What kinds of cancer are you most worried about?
   - What worries you most about getting cancer?

4. Do friends, family, or others in your neighborhood talk about cancer? What do they talk about?

[IF GROUP HAS A HARD TIME GETTING STARTED REMIND THEM THAT: We want to hear your opinions, there aren't any right or wrong answers. We just want to learn what you think about your community.]

LIFESTYLE FACTORS: [30 minutes total]

We have talked about the important health problems in your community.

Ok – let's talk about the way people live, their habits and lifestyle, and how these affect their health?

5. What are some behaviors or ways of living (lifestyles) that may have a good effect on a person's health? (List on flip chart)

6. What about some behaviors or ways of living that may affect their health in negative ways? What are some of the things that people do that may influence their own health in negative ways?
   (List on flip chart)

Review the list on flip chart

Let's talk a little more about some of the things on this list (and others that you did not mention):

Nutrition:

7. You mentioned (did not mention), that what a person eats can affect their health. Tell me more about that. (PROBES: What illnesses or disease can be affected by what we eat? What foods, or ways of eating, can improve health? What foods or ways of eating can harm health?)

8. Do you think that what a person eats, or their eating habits, can affect their chances of getting cancer? (PROBES: Are there eating habits that can reduce a person's chances of getting cancer? What foods or eating habits or ways of eating can increase risk for getting cancer?)

Summarize their statements about diet, health and cancer. Then ask:

9. How easy is it for people you know in your community to eat healthy or eat in a way that can improve their health?
(PROBE: What are some barriers to eating healthy for people in your community?)

10. Where would you go in your community for help eating a healthier diet? (PROBE: Is there a program that people have access to that teaches them how to eat a healthier diet?)

11. What are some ways to motivate or make it easier for people in your community to eat healthier? (PROBE: If you were designing a plan or project to help people in your community eat healthier, what would it look like?)

Review points made during nutrition discussion before moving on.

I would like to change our discussion now to exercise and how it can affect our health.

Exercise

Exercise is also (is not) on the list of things that you said can improve health.

12. What do you think of when you hear the word exercise?

I would like to give you a definition of exercise and physical activity for the following discussion:
Physical activity is - "any body movement produced by skeletal muscles that results in energy expenditure above resting level."

Exercise - physical activity that is planned, structured, and repetitive for the purpose of conditioning any part of the body.

13. How easy is it for people in your community to be physically active? (PROBE: Where do people go to exercise or get physical activity?

14. What stops people from being more physically active in your community?

15. What are some ways to make it easier or motivate people in your community to exercise or be physically active? (PROBE: If you were designing a plan or project to help people in your community be physically active, what would it look like?)

Summarize exercise comments before moving on to weight control.

Weight Control

Not being overweight is also/is not on the list of things that can improve health. (If that is not on the list: Not being overweight is important to have improved health.)

16. What are your thoughts on weight in your community?

17. Are you and/or people in your community concerned about obesity? (PROBE: At the community level, is there concern over obesity as a health problem?)

18. What do you think about the relationship between being overweight or obese and chances of getting cancer?

19. People's ideas about what a healthy weight is may be different. What do you think is a "healthy weight" (PROBE: How do you decide if a person has a healthy weight?)

20. Where would you go in your community for help losing weight? (PROBE: Is there a program that people have access to that helps people lose weight?)

21. What could be done in your community to help/encourage people to have a healthy weight?

Summarize weight comments before moving on to weight control.

BREAK

Continue LIFESTYLE FACTORS: [15 minutes total]
Welcome back! We are going to keep working on some topics about community health starting with tobacco. If everyone is settled we can get started.

TOBACCO

22. In general, how do people in your community feel about tobacco use?

23. How much of a problem do you think tobacco use, (smoking tobacco, chewing or dipping tobacco) is in your community? (PROBE: About how many people use tobacco, not very many, a lot, about half…)

24. Are there any community wide efforts to change the smoking habit of people who live here?

25. What resources or programs are available in your community to help someone quit using tobacco? How effective do you think they are?

26. What do you think would be the best ways to get people to stop using tobacco in your community?

ENVIRONMENTAL FACTORS

For the following question, I would like to first explain what I mean when I use the term "environmental factor". For our discussion, I would like this term to mean anything that exists in the natural surroundings of the neighborhood where you live or in the location where you work that could affect your health.

27. Do you think there are any environmental factors, or things in the environment of your community that might cause cancer?

DISCUSSION OF CANCER SCREENING [15 minutes TOTAL]
Now I would like to talk about your thoughts on tests that can check if a person has cancer.

28. Do you know of any tests that a person can have done to see if they have cancer? (List on flip chart in columns of screening vs. diagnostic)

Good, I think you have listed most of them. (Identify the cancers and tests that they have not mentioned – add them to the list)

29. I would like you to tell me about your thoughts and feeling about each one of these tests, so we will answer the following questions for each one individually: "What are your thoughts and feelings about:

- **a.** Pap-smears
- **b.** Mammograms
- **c.** Colonoscopy
- **d.** FOBT
- **e.** Digital rectal prostate exam
- **f.** PSA

30. Is it easy for people in your community to get these screening tests?

31. What are some reasons people you know don't get a cancer test when their doctor tells them they should?

CANCER RESEARCH SECTION [15 MINUTES]

32. Now we are going to talk about research. First, has anyone ever participated in a research study, or know someone who has participated in a research study? (PROBE: Can you tell us anything about the experience you or they had?)

33. When you hear the words, "***cancer clinical study"*** what comes into your mind?

[IF GROUP HAS A HARD TIME GETTING STARTED REMIND THEM THAT: We want to hear your opinions? As soon as I said the words, what were the first things that popped into your mind?]

(Facilitators will give the following definition of clinical study for the purposes of the questions that follow)

The National cancer Institute defines a clinical study as:
"A type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Also called a clinical trial.
A cancer study may test a newly developed treatment on real patients before it is available for general use. This type of cancer study has very strict guidelines for accepting patients and monitors side effects, complications, and dosage issues very closely. Clinical trial participants are monitored closely and are taken off the clinical trial if they are doing poorly.

Other kinds of cancer studies may not involve cancer treatment. It may be investigating better methods of preventing or finding cancer, or trying to improve quality of life during and after cancer treatment.

34. Does anyone know someone or heard about someone who participated in a ***cancer*** clinical study?

35. I would like you to think about yourselves, and whether you would be in clinical study that ***did not*** involve cancer treatment if you were asked? Please state why or why not.

36. Now, if you knew someone who had cancer and they were asked to participate in cancer research that was testing a new medication or procedure, do you think you would advise them to be in the study? Please state why or why not.

37. Would you feel differently about being in cancer research, if the research was about a problem specific to your community? (If people identified a problem in their community related to cancer, and developed a research study to find out more about that problem)

Summarize the information that they have provided about cancer screenings and cancer research before moving on to the final wrap-up.

OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]

What haven't we discussed about cancer and issues relating to cancer that you think are important to keep in mind?

Do a final summary of the information.

Thank you so much for helping us with this project. We appreciate your time and candid thoughts on this important subject. On your way out there are packets of information you are welcome to take with you, and you can make sure the information on your payment forms are correct.

INTRODUCTION TO FOCUS GROUP PROCESS AND INFORMED CONSENT [7 MINUTES]

Tape recorder turned on at beginning of remarks, which are to be made by the facilitator]

Thank you all for coming today/tonight. My name is <<INSERT YOUR FIRST NAME>>, and this is <<INSERT FACILITATOR'S FIRST NAME>>. Thank you for agreeing to be here. Your opinions are important to us.

To begin, I would like to give you an overview of how this focus group will work. As you know, the focus group will last for about two hours. During these two hours, I will ask you some questions about your experiences with cancer diagnosis, treatment, follow-up care and cancer research. We do not need to know the details of your medical history. For our purposes, a cancer survivor is defined as anyone who has ever had a diagnosis of cancer or anyone who has been the primary care giver for someone who has had cancer. We want you to draw on your experiences as survivors, and know that no two survivors' experiences are the same. The goal is for you to discuss the questions as a group. The most important information will come from the range of everyone's thoughts and ideas. It is very important that everyone feels free to speak and share, especially if you have a different idea or view from others in the group. There are no "right" or "wrong" answers to the questions.

My role is to help guide the discussion. I may ask specific people about their thoughts or ideas if they have not had a chance to share very much in the discussion. . If we need to move on to another topic, I may ask you to hold your thoughts on that topic for us to come back to. I do not want to keep you longer than the two hours so my job is to make sure that I keep the discussion moving along at a good pace. However, I don't want you to hold back on your thoughts – as I said, if I need to move us along, I will but until then please express yourself!

I would like to go over a couple of ground rules for our discussion as a group, and then would like to ask you what other rules you think we should follow to make our time most productive. First, as facilitators, we will respect the privacy of all group members and keep the content of our talk confidential. By confidential we mean that it will be kept private. We will be tape recording the discussion, and you may see us taking notes. These steps are needed for us to accurately record what is said today, but we will not include any information that will personally identify you in our notes or recordings. When we review our notes from this meeting, we will be most interested in what the group as a whole has to say. When we write up the report of these focus group discussions, no person will ever be identified by name.

Second, I would ask that we call each other only by first names or the names that you have selected and written on your name tag. Also, I would ask that you turn your phones to silent or vibrate, and have the placed out of sight for the duration of the discussion, unless you are expecting a call. I will have my phone out solely for the purpose of keeping track of time. Other than that, do any of you have other ground rules that you think would be good to allow opportunity for everyone to express themselves freely?

We will be taking a break about half way through our discussion, but if you need to get up before that please do so as quietly as possible. You are free to stop participating in the discussion at any time or even leave.

If you stay to the end of the two-hour period you will receive $50 as our way of saying thanks. If you must leave early you will receive $25. You should have been given a paper to fill out that provides us with the mailing address to which the money should be mailed. A check should arrive within a week of this event. We have also given you a paper with the names and numbers of people you can call in the future if you have questions.

Does anyone have any questions? [Answer any questions]

WARM-UP [10 minutes]

Before moving on to the main topic of our discussion, I would like to take a few moments for everyone to introduce himself or herself. Please tell us your first name, or name you like to be called, something about your experience living in this community and how long you have lived here.

Tape recorder turned OFF here to maintain confidentiality.]

[Moderator: Introduces herself and then goes around the table.]

[Facilitator: Will take notes on where particular people are sitting by creating a diagram similar to the room and focus group layout. Individual first names will then be associated with a numbered position in the diagram. These numbers make it possible to document more easily who in the group is speaking when taking notes.]

Tape recorder turned on here:
In today's discussion, we will be discussing various aspects of your cancer experience, including diagnosis, treatment, and aftercare, along with your views on resources, research, and the community. To keep us on schedule, I may ask that you hold a particular thought until a later portion of the discussion.

Experiences getting cancer information (10 minutes)

I'm going to start by asking you some questions about getting information about things related to your cancer. We'll start with when you were first diagnosed, and then about how your needs may have changed over time.

1. When you were **first diagnosed**, what kind of information did you need?
   Were you able to get the information you needed?
   If not, why not? What got in the way of your getting that information?

2. Has the kind of information you need **changed over time**? How?
   Have you turned to different sources for information as your needs have changed?

Experiences with local resources for your cancer diagnosis and treatment [40 minutes]

Now I'm going to ask you some questions about your experiences with medical care, and cancer diagnosis and treatment.

3. First, I'd like to go around the table and have everyone say whether your cancer was ***diagnosed and treated in the community where you live***, or whether you traveled outside of your community for your diagnosis and/or treatment. If you do/did travel outside of your community for either your diagnosis of treatment, please tell us why.

4. Thinking back to the time when you were ***first diagnosed*** with cancer, were there people or resources in your community that were particularly helpful in getting the cancer diagnosis. We are not asking you to give specific names, but more about what helped you get diagnosed.

    a. Were there situations or other things that delayed or made it hard for you to get the diagnosis easily or quickly?

    b. From your experience, what is lacking in your community that could make the diagnosis of cancer easier?

5. Now, thinking about the time during which you (or the person you cared for) were ***treated for cancer***, were there things that were particularly helpful to you as you went through treatment. (PROBE: Anything that helped you understand, get to, or pay for your treatments?)

    a. Were there things that made it difficult to get treated?

    b. Were/Are there circumstances that affected your decisions about treatment? For example, financial circumstances distance to treatment center, transportation, or work schedules.

6. Did any of you get help from anyone to work your way through the system and put all of the pieces together? Sometimes this can be a team of medical people who work with you or an individual. (PROBES: patient navigator, case manager, social worker, cancer survivor, etc.)

    a. Who? Was it helpful?

7. From your experience, what is lacking in your community that could make the treatment of cancer easier?

BREAK

Post-Treatment (20 Minutes)

We have finished discussed cancer diagnosis and treatment, so now we are going to focus on the time after you (or the person you cared for) completed treatment. I would like to stress that the discussion is not about the details of your personal medical history. It is about the experience you had after your treatment was completed.

8. Do you think that your oncologist told you enough about the follow-up care that you would need after you completed your treatment? Did they provide a written plan for your follow-up care?
   PROBES:
   - Was it clear to you what doctor would follow up on your cancer, and how often you should go for check-ups?
   - Was it clear who you should see for your more routine health care needs and preventive screenings?

9. Do you think that the physicians are working together in you cancer treatment? For those of you who were treated outside of your community, what was the communication like between your oncologist and the physician you see at home?

10. Do you feel that you are getting the help and information you need to stay well and have good quality of life – things like nutrition, physical activity, stress management and how to live better during recovery?

    a. What information would you like to have related to staying healthy.

11. Were you referred to any support services after your treatment? Which? By whom?

LOCAL RESOURCES AND NEEDS:

The following questions relate to resources in your local community to support cancer patients and their caregivers. **(20 Minutes)**

12. How many of you could have used some assistance with aspects of living your everyday life during your treatment or recovery? What kind? (PROBES*: caring for yourself, housework, cleaning, chores, shopping, cooking, child care, support for family, paying bills)*

13. What kinds of help did you get LOCALLY during your **diagnosis**, **treatment,** or **after** treatment? From whom? (PROBE: Did you get involved with cancer support groups, or get help with bills, transportation?

14. Was there a time that you needed help or information and were unable to get it in your community? What information or help was that?

15. Have you heard of any resources from OTHER areas, that would have been helpful to you had you had access to them locally?

CANCER RESEARCH SECTION [15 MINUTES]

16. Now we are going to talk about cancer research. First, when you hear the words, “cancer research” what comes to your mind?

[IF GROUP HAS A HARD TIME GETTING STARTED REMIND THEM THAT: We want to hear your opinions? As soon as I said the words, what were the first things that popped into your mind?] (list ideas)

National cancer Institute defines clinical research as:

The National cancer Institute defines clinical research as:
"A type of research (study) that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease."
A cancer research may test a newly developed treatment on real patients before it is available for general use. This type of cancer research has very strict guidelines for accepting patients and monitors side effects, complications, and dosage issues very closely. Clinical trial participants are monitored closely and are taken off the clinical trial if they are doing poorly.

Other kinds of cancer research may not involve cancer treatment. It may be investigating better methods of preventing or finding cancer, or trying to improve quality of life during and after cancer treatment.

17. What were you told about clinical trials as an option for treatment? OR Did you have the option of participating in a clinical trial?

18. If you were given the option, why did you participate or why did **<u>you not</u>** participate?

19. How important is it to have cancer research available to people with cancer in your community?

<u>OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]</u>

We've talked about what cancer survivors need, and about things that have been helpful to you as well as times when you haven't gotten what you need. We're getting towards the end of our time, and I want to ask a few questions to make sure we haven't left anything out.

20. Are there any other things that haven't come up yet that get in the way of your getting services and supports that you need? Are there other barriers that have kept you from getting what you need?

21. What do you think is the biggest gap in your community in the programs, services, or supports for cancer survivors? I'd like to hear from everybody on this question, too.

22. What haven't we discussed about cancer and issues relating to cancer that you think are important to keep in mind?

Thank you so much for helping us with this project. We appreciate your time and candid thoughts on this important subject. On your way out there are packets of information you are welcome to take with you, and you can make sure the information on your payment forms are correct.

APPENDIX D

Cancer Healthcare Resources within the Health District

Results of Facilities Questionnaire for Southside Health District

Available Facilities:	Halifax Regional Health System; Community Memorial Healthcenter	
# of Oncologists:	4	Breakout: 3 medical oncologists, 1 radiation oncologist

Available in Health District

Services			**# of facilities where available**
Cancer Treatment	**Services Provided**	Chemo Inpatient	1
		Chemo Outpatient	2
		Radiation	1
Cancer Screening	**Breast Cancer Screening and Diagnostic Procedures**	Screening Mammography (film, digital)	2
		Diagnostic Mammography	2
		Breast Ultrasound	2
		Breast Biopsy	2
	Colorectal Cancer	Sigmoidoscopy/Colonoscopy	2
		CT Colonography	2
	Lynch Syndrome	Screening for Colorectal cancer	2
		Screening for Endometrial cancer	2
		Microsatellite instability testing	2
Surgeries	**Cancer Related Surgeries**	Breast Segmental/Complete Mastectomy	2
		Sentinel Nodes Sampling	1
		Gynecological Hysterectomy/Oophorectomy	2
		GI - Upper/Lower Tract	2
		GI - Liver	2
		GI - Pancreas	2
		Lung	1
		Prostatectomy	2
		Ears, Nose, Throat	2
		Other (Skin)	2
Counseling	**Cancer Dietary Needs**	Registered dietician to provide nutritional services specific to cancer patients	2
		One-on-one assessment and diet prescription	2
		Individual oncology nutrition counseling services	2
		Outpatient oncology nutrition counseling	2
		Cancer control and prevention education programs for dietary needs	2
Other Services	**Clinical Trials**	Offer clinical trials	1
	Hospice Service	Facility Supported: Inpatient / Outpatient Hospice	1 / 2
		Private Organization: Inpatient / Outpatient Hospice	1 / 2
	Palliative Care	Palliative Care Program	1
		Medical professionals in the team	RN, SW, Chaplaincy, Care coordination, RD
		Offer consult service	1
		Inpatient beds	1
	Cancer Patient Navigation	Patient Navigator	1
		Navigation for the following cancers:	All cancers
		Credentials of patient navigator	Social worker
Cancer Support Groups	**Existing Support Groups**	Availability of cancer support groups	2

Not Available in Health District

Cancer Screening	**Breast Cancer Screening and Diagnostic Procedures**	Breast MRI
	Lynch Syndrome	Immunohistochemistry staining test
Surgeries	**Cancer Related Surgeries**	Breast Reconstruction
		Brain
Counseling	**Cancer Dietary Needs**	Board certified dietician in oncology nutrition
	Genetic Tests	Genetic tests for cancer risk (BRCA1 and BRCA2)
		Genetic tests for cancer risk (Others)
	Genetic Counseling	Genetic counseling (at the facility or referred out for counseling)
Other Services	**Palliative Care**	Outpatient clinic

APPENDIX E

Community Cancer Resources within the Health District

SOUTHSIDE HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Mecklenburg County Health Department	Halifax County Health Department	Brunswick County Health Department	Halifax County Cancer Association
Organization Information		**Number of Organizations**				
Organization category	National non-profit	2	-	-	-	-
	Local non-profit	5	-	-	-	X
	For profit service organization	0	-	-	-	-
	Federal governmental organization	0	-	-	-	-
	State/municipal government organization	5	X	X	X	-
	Other	2	-	-	-	-
Major sources of funds for organization	Competitive grants	4	-	-	-	-
	Federal funds	7	X	X	X	-
	Service fees charges	7	X	X	X	-
	Donations	7	-	-	-	X
	Other	5	X	X	X	X
Cancer Resources						
Primary service population of the organization	Cancer patients	6	-	-	-	X
	Cancer survivors	4	-	-	-	-
	Cancer caregiver/family members	5	-	-	-	-
	Other	5	X	X	X	-
Qualification criteria to access services	Must be uninsured/underinsured	3	X	X	X	-
	Financial qualification	4	X	X	X	-
	No qualification criteria	4	-	-	-	-
	Other	4	-	-	-	X
Type of cancer related services that are provided	Written information on cancer	10	X	X	X	X
	Information on cancer care/support resources	10	X	X	X	X
	Management of cancer support groups	7	-	X	X	X
	Financial support for cancer control/care	3	-	-	-	X
	Funding of projects related to cancer	3	-	-	-	-
	Psychosocial support	5	-	-	-	-
	Navigational services	4	-	-	-	-
	Transportation	2	-	-	-	-
	Other	2	X	-	-	-
Number of cancer patients seen annually		(see organizations' answers)	51 - 150	51 - 150	51 - 150	greater than 150
Other Information About Organization						
Advertising for the organization	Local media	6	-	-	-	X
	Organization website	11	X	X	X	X
	Online	5	X	-	-	-
	Pamphlets describing services	10	X	X	X	X
	Word of mouth	11	X	X	X	X
	Other	3	-	-	-	-
Organizational needs	Financial support	9	X	X	X	X
	Human resources (skilled employees, volunteers, etc.)	2	-	-	-	-
	Access to experts for consultation	4	X	X	X	-
	Physical space/facilities	0	-	-	-	-
	Collaborators	0	-	-	-	-
	Volunteers	3	-	-	-	-
	Other	1	-	-	-	-
Challenges		(see organizations' answers)	Funding	Referrals after screening is done.	Finding follow up care provider for patients with positive screenings.	Educating the public about the risk of cancer and cancer prevention. Finding additional funding.
Goals for the next 5 years		(see organizations' answers)	Increase funding for screening. Identify follow up care providers for clients with positive screening.	Identify and collaborate with source for follow up care when screening is positive.	Identify providers for patients with positive screenings. Increase number screened.	Increase amount of financial assistance provided to patients.
Partner organizations			Fuller-Roberts Clinic, VCU	VCU, Fuller Roberts Clinic	VCU	Hope Support Group Halifax Regional Hospital
Interested in collaboration			Yes	Yes	Yes	Yes
Comments		(see organizations' answers)				

SOUTHSIDE HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Piedmont Access to Healthcare	Lake Country Area Agency on Aging	Southside Cancer Resource Center	American Cancer Society Mecklenburg
Organization Information		Number of Organizations				
Organization category	National non-profit	2	-	X	-	X
	Local non-profit	5	X	-	-	-
	For profit service organization	0	-	-	-	-
	Federal governmental organization	0	-	-	-	-
	State/municipal government organization	5	-	X	X	-
	Other	2	-	X	X	-
Major sources of funds for organization	Competitive grants	4	X	X	X	-
	Federal funds	7	X	X	-	-
	Service fees charges	7	X	X	-	-
	Donations	7	X	X	-	X
	Other	5	-	-	-	-
Cancer Resources						
Primary service population of the organization	Cancer patients	6	-	-	X	X
	Cancer survivors	4	-	-	X	X
	Cancer caregiver/family members	5	-	-	X	X
	Other	5	X	X	-	-
Qualification criteria to access services	Must be uninsured/underinsured	3	-	-	-	-
	Financial qualification	4	-	X	-	-
	No qualification criteria	4	-	-	X	X
	Other	4	X	X	-	-
Type of cancer related services that are provided	Written information on cancer	10	X	-	X	X
	Information on cancer care/support resources	10	X	-	X	X
	Management of cancer support groups	7	-	-	-	X
	Financial support for cancer control/care	3	-	-	-	-
	Funding of projects related to cancer	3	-	-	-	X
	Psychosocial support	5	-	-	X	X
	Navigational services	4	-	-	X	X
	Transportation	2	-	X	-	X
	Other	2	X	-	-	-
Number of cancer patients seen annually		(see organizations' answers)	greater than 150	11-25	26 - 50	51 - 150
Other Information About Organization						
Advertising for the organization	Local media	6	-	-	X	X
	Organization website	11	X	X	X	X
	Online	5	-	-	X	X
	Pamphlets describing services	10	X	X	X	X
	Word of mouth	11	X	X	X	X
	Other	3	-	X	X	-
Organizational needs	Financial support	9	X	X	-	-
	Human resources (skilled employees, volunteers, etc.)	2	X	-	X	-
	Access to experts for consultation	4	X	-	-	-
	Physical space/facilities	0	-	-	-	-
	Collaborators	0	-	-	-	-
	Volunteers	3	-	-	-	X
	Other	1	-	-	-	-
Challenges		(see organizations' answers)	Getting care for uninsured following positive screenings. Need additional providers in area. Need local pharmacy.	Funding	Publicity about the center.	Education of the population served.
Goals for the next 5 years		(see organizations' answers)	Provide services for all citizens regardless of income.	Continue to provide highest level of quality care and survive the funding cuts.	Create awareness in the community about the center and the services provided.	Strengthen the patient service programs by recruiting additional volunteers and emphasize prevention, diagnosis and screening.
Partner organizations				Social Services	Komen CMH Svrmc	Hospitals, National Cancer Asso.,Cancer Coalition of Va., various volunteer groups
Interested in collaboration			Yes	Yes	Yes	Yes
Comments		(see organizations' answers)				

SOUTHSIDE HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Community Memorial Cancer Support Group	Halifax Home Health and Hospice	Community Memorial Hospice
Organization Information		Number of Organizations			
Organization category	National non-profit	2	-	-	-
	Local non-profit	5	X	X	X
	For profit service organization	0	-	-	-
	Federal governmental organization	0	-	-	-
	State/municipal government organization	5	-	-	-
	Other	2	-	-	-
Major sources of funds for organization	Competitive grants	4	-	X	-
	Federal funds	7	-	X	X
	Service fees charges	7	-	X	X
	Donations	7	X	X	X
	Other	5	X	-	-
Cancer Resources					
Primary service population of the organization	Cancer patients	6	X	X	X
	Cancer survivors	4	X	-	X
	Cancer caregiver/family members	5	X	X	X
	Other	5	-	-	-
Qualification criteria to access services	Must be uninsured/underinsured	3	-	-	-
	Financial qualification	4	-	-	-
	No qualification criteria	4	X	X	-
	Other	4	-	-	X
Type of cancer related services that are provided	Written information on cancer	10	X	X	X
	Information on cancer care/support resources	10	X	X	X
	Management of cancer support groups	7	X	X	X
	Financial support for cancer control/care	3	-	X	X
	Funding of projects related to cancer	3	-	X	X
	Psychosocial support	5	X	X	X
	Navigational services	4	-	X	X
	Transportation	2	-	-	-
	Other	2	-	-	-
Number of cancer patients seen annually		(see organizations' answers)	11-25	greater than 150	51 - 150
Other Information About Organization					
Advertising for the organization	Local media	6	X	X	X
	Organization website	11	X	X	X
	Online	5	-	X	X
	Pamphlets describing services	10	-	X	X
	Word of mouth	11	X	X	X
	Other	3	-	-	X
Organizational needs	Financial support	9	X	X	X
	Human resources (skilled employees, volunteers, etc.)	2	-	-	-
	Access to experts for consultation	4	-	-	-
	Physical space/facilities	0	-	-	-
	Collaborators	0	-	-	-
	Volunteers	3	-	X	X
	Other	1	-	-	X
Challenges		(see organizations' answers)	Increasing awareness.	Reduced funding, burdensome regulatory process.	Limited resources due to isolation in rural location.
Goals for the next 5 years		(see organizations' answers)	Increase number participating through education.	Growth, larger presence legislatively, in house palliative care program, promotion of awareness in community.	Growth and providing quality care.
Partner organizations			CMH	Mecklenburg Cancer Association H.O.P.E. (support group)	Social Services, Lake Country Area Agency On Aging
Interested in collaboration			Yes	Yes	Yes
Comments		(see organizations' answers)			Resources in the community are very limited. Transportation is a big problem for clients.