

Saving Lives and Reducing Suffering and Death from Cancer in Virginia



Report of the Comprehensive Cancer Needs Assessment of the Lenowisco 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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Project Manager and Local Needs Assessment Coordinators

Carlin Rafie, PhD, RD

Project Manager
Clinical Research Affiliations Coordinator
VCU Massey Cancer Center

Erik Blevins

Community Health Education Coordinator
(Lenowisco Health District)
VCU Massey Cancer Center

Loretta Cummins

Community Health Education Coordinator
(Lenowisco Health District)
VCU Massey Cancer Center

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ADVISORY COMMITTEE

Margaret Bassett, MPH, MS, RN

Board of Directors
Virginia Rural Health Association
Associate Professor, Radford University
School of Nursing

Vernal Branch

Advocacy and Constituency Coordinator
Virginia Breast Cancer Foundation

Teri Ann Brown

Program Specialist
Virginia Foundation for Healthy Youth
(formerly Virginia Tobacco Settlement
Foundation)

Karen Cameron, FACHE

Executive Director/CEO
Central Virginia Health Planning Agency

Brian Cassel, PhD

Senior analyst, Oncology Business Unit
Assistant Professor of Quality Health Care
Department of Internal Medicine
VCU Massey Cancer Center

David Cattell-Gordan, MDiv

MSW Program Director
Office of Telemedicine
University of Virginia

Faye Flemming, RN, BSN, OCN

Oncology Specialist / Service Line Director
Southside Regional Medical Center Cancer
Center

Mary Helen Hackney, MD

Associate Professor
Department of Internal Medicine
VCU Health Systems

Mary Ann Hager, RN

Associate Director of Clinical Services
VCU Massey Cancer Center

Pem Hall

Director of Community Health Programs
Susan G. Komen for the Cure

Alton Hart, MD, MPH, CTTS

Associate Scientific Director
Center on Health Disparities
VCU Associate Professor
Department of Internal Medicine, VCU

Wanda S. Hunt

Clinical Research Affiliation Coordinator
Assistant
VCU Massey Cancer Center

Resa M Jones, MPH, PhD

Associate Professor
Department of Epidemiology and
Community Health
VCU Massey Cancer Center

Jim Martin, PhD

Director
Virginia Cancer Registry
Virginia Department of Health

Kathy Meade-Goulit

Vice Chair
Virginia Prostate Cancer Coalition

Maghboeba Mosavel, PhD

Associate Professor
Department of Social and Behavioral Health
VCU

Nicole Pugar

Director of Government Relations
VCU

Kathy Rocco, RD, MPH

Program Director Every Woman's Life
Virginia Department of Health,

Christi Sheffield

VA-Comprehensive Cancer Control Program
Manager
Centers for Disease Control
UVA Cancer Center

Lisa M. Shickle, MS

Director of Analytic Services
VCU Massey Cancer Center

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TABLE OF ABBREVIATIONS

ACS	American Cancer Society
BRFSS	Behavioral Risk Factor Surveillance Survey
CACV	Cancer Action Coalition of Virginia
CHE	Community Health Educator
HPSA	Health Professional Shortage Areas
JMH	Johnston Memorial Hospital
SHD	Southside Health District
PCP	Primary care physicians
SCCH	Smyth County Community Hospital
TCRH	Twin County Regional Hospital
VDH	Virginia Department of Health

EXECUTIVE SUMMARY OF FINDINGS

Lenowisco Health District is located in the southwestern tip of Virginia. Spanning 1382 square miles, the district lies in the heart of the Appalachian Mountains with a population of slightly less than 100,000 residents. A large portion of the health district is medically underserved, with Lee and Scott counties particularly limited in healthcare facilities and providers. Unemployment rates are higher and median income lower in the health district when compared to the state. Cancer treatment is available in only one hospital, Southwest Virginia Cancer Center, in the health district, which is located in Wise county. Residents in the surrounding counties either travel to Wise County or seek oncology services outside the health district. Outpatient chemotherapy, surgical oncology and radiation treatments are available at the cancer center. There are two major community organizations offering cancer-support services within the Lenowisco Health District: Mountain Empire Older Citizen Center (MEOCC), located in Big Stone Gap, , and the American Cancer Society (ACS), which operates out of Abington, VA

Overall cancer incidence rates are comparable to the state, with the exception of lung cancer. In contrast, the mortality rate from cancer is higher in the health district compared to the state, with a particular disparity in lung cancer mortality. Key leaders from the community identified five areas impacting the cancer burden in the district: (1) patient lifestyles, (2) the financial burden of healthcare, (3) lack of access to specialists locally, (4) lack of transportation, and (5) poor access to education both for primary care physicians as well as patients. Primary care physicians from within the health district identified lung and breast cancer as the two most prevalent cancers seen in their practice. They concurred with key leaders that financial constraints and lack of insurance were significant barriers to patient compliance with cancer screenings. They were interested in receiving continuing education on cancer recurrence surveillance, end of life care, and patient wellness.

Community based information gathered for this assessment showed that residents of the health district have a higher incidence of sedentary behavior and smoking, lower intake of the recommended number of daily servings of fruits and vegetables, and a relatively high incidence of obesity when compared to the state. Additionally, screening rates for colorectal, prostate, and breast cancer are lower. Information gathered through focus groups with residents revealed that the negative community experience with cancer outcomes due to lack of ready access to timely screening and treatment as a result of lack of insurance, high financial costs, and lack of healthcare providers has resulted in a fear and aversion of a cancer diagnosis. This often results in low cancer screening rates. Cancer survivors from the community point to a need for empathetic healthcare providers, a reliable local cancer information resource, patient navigation and local support groups, and community assistance with the significant financial barriers to cancer care.

Priority areas for action to improve the cancer burden and reduce the cancer outcome disparities include (1) Expand cancer services in the health district, (2) Increase financial, insurance, and transportation support available in the community for residents undergoing cancer treatment, (3) develop community resources for cancer survivors and caregivers, (4) Increase community cancer prevention initiatives, particularly as they relate to lung cancer, and (5) Provide regular primary care physician continuing cancer related education.

The cancer causing the greatest burden in the health district is respiratory cancers. Respiratory cancer, those caused by modifiable behaviors or environmental exposures, are preventable. Efforts to evaluate the etiology of the higher incidence of this cancer and develop programs to address the modifiable causes of increased risk for these cancers in the community would have a significant impact on the cancer burden in the Lenowisco Health District. Information provided by healthcare providers and residents of the health district point to community initiatives to educate about the risk factors for respiratory cancer and promote tobacco free lifestyles is a priority.

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 the final list were asked to complete the questionnaire either via e-mail 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**).

¹⁰ Virginia Board of Medicine. <http://www.vahealthprovider.com/links.asp>

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 Lenowisco Health District

Located in the most southwestern tip of Virginia, the Lenowisco Health District is comprised of Wise, Lee, and Scott Counties as well as the City of Norton. Spanning 1382 square miles, the district lies in the heart of the Appalachian Mountains. The counties of Scott and Lee lie in the southwestern most corner of the state and border Tennessee to the south. Wise County, in which Norton city is centrally located, borders Kentucky to the west. The counties do not contain any interstate roads and are most easily accessible via US 58, in the case of Lee County, and via both 58 and US 23 in the case of Wise, Norton, and Scott Counties. (**Figure 1**)

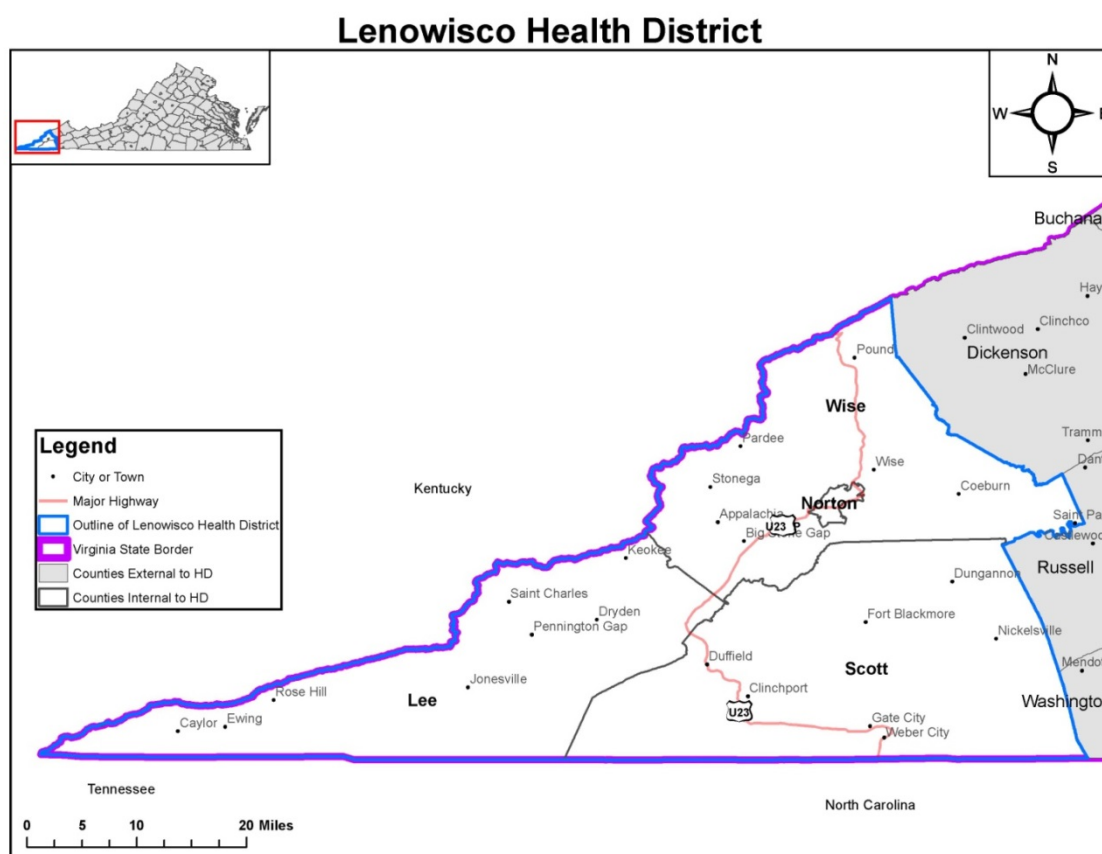


FIGURE 1: Lenowisco Health District

According to 2011 US Census Bureau information, the district has 94,054 residents. The population is racially homogeneous, with almost 95% percent of residents of white race, less than 4% African American, and the rest comprised from other races. The population is older and less well educated when compared to the Virginia population (**Table A**). The unemployment rate for residents 25 years and older is a low 5.5% in the City of Norton, which is lower than the state unemployment rate. Still, the overall unemployment for the district is 7.2% with a high of 8.5% in Wise County. Further, the overall unemployment rate

in the health district is higher (7.2% vs. 6.5%) and the median household income is lower (\$35,024 vs. \$63,302) than that for Virginia. (**Table B**)

Table A: Demographic Profile of Lenowisco vs. Virginia¹²

Demographic Profile of Lenowisco vs. Virginia			
Category	Subcategory	Lenowisco	Virginia
Gender	Male	51%	49%
	Female	49%	51%
Age	0-19	23%	26%
	20-34	19%	21%
	35-54	29%	29%
	55-64	14%	12%
	65+	16%	12%
Race	White	95%	70%
	Black or AA	4%	19%
	Other	2%	11%
Ethnicity	Hispanic or Latino	1%	8%
	Non-Hispanic or Latino	99%	92%

Table B: Economic Characteristics of Lenowisco vs. Virginia

Economic Characteristics of Lenowisco vs. Virginia		Lenowisco (average)	Virginia
Unemployment ¹³	Unemployment Rates	7.2%	6.5%
Income ¹⁴	Median Household Income	\$35,024	\$63,302
Education ¹⁵	% Less than high school	28%	13%
	% High school or GED	33%	26%
	% some college, no degree or an Associate's degree	27%	27%
	% Bachelor's degree or above	13%	34%

¹² **Data source:** 2010 Census Summary File 1 - (Virginia) [machine-readable datafiles]/prepared by the U.S. Census Bureau, 2011. All population numbers are for ages 18 and over.

¹³ 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.

¹⁴ 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.

¹⁵ 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

Lee and Scott counties in the Lenowisco Health District are designated as both medically underserved areas, and Health Professional Shortage Areas (HPSA). Parts of Wise county also have the HPSA designation. There were 5 hospitals operating in this health district, but by the completion of this assessment Lee County Regional Medical had closed its doors. The remaining four hospitals are all located in Wise County. Travel to these facilities is by rural and mountainous roads that provide a barrier to receiving medical treatment, especially in Lee and Scott counties.

Lenowisco Health District

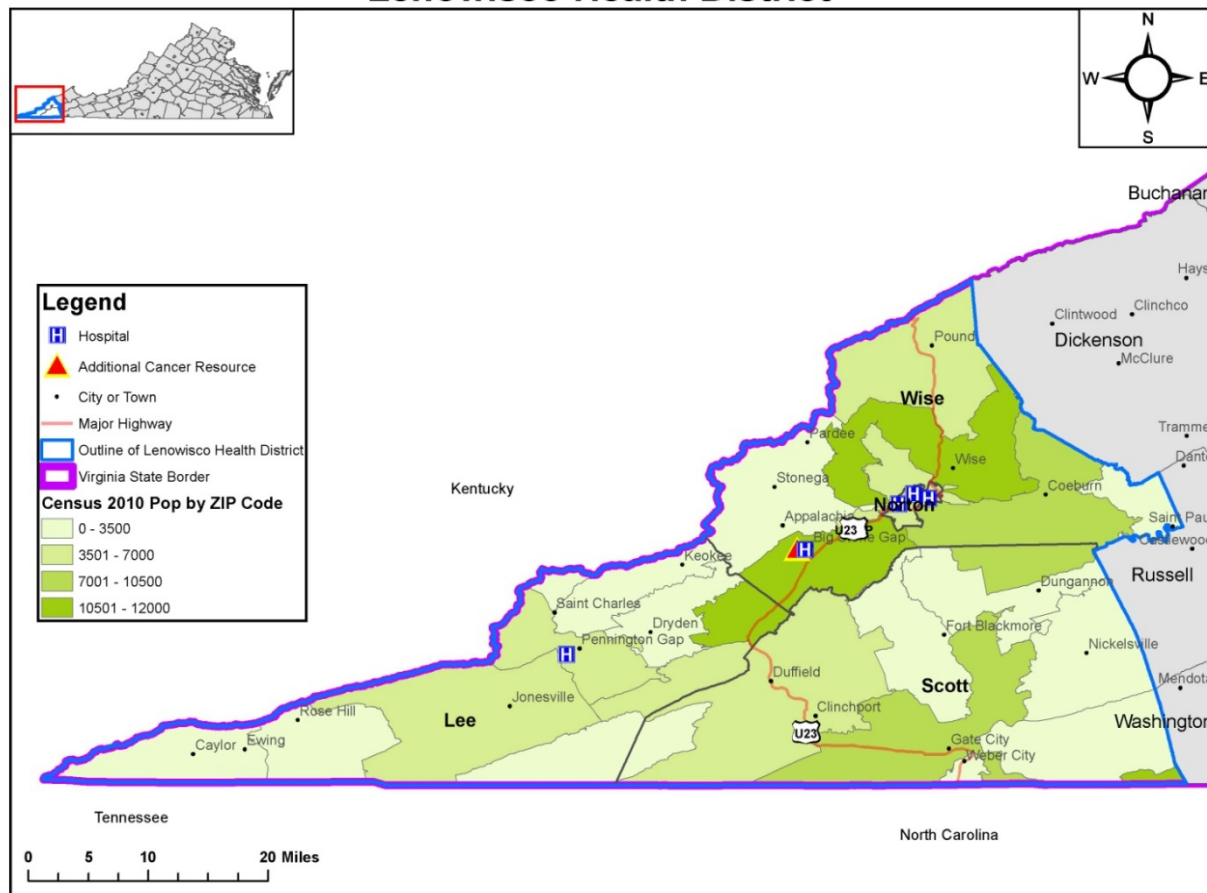


Figure 2: Healthcare Resources in Lenowisco Health District

Cancer Burden

Cancer Incidence

Cancer incidence was calculated for the Health District 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 other cancer groupings included respiratory, gastro-intestinal, hematologic malignancies, urinary system, brain- nervous system-eye, oral cavity-pharynx, and other cancers. Also, all cancer incidence rates in this study are age adjusted. Overall, the cancer incidence for the health district

is lower than that for the state (376.0 vs. 446.6 per 100,000). (**Table C**) Also, when compared to the state, Lenowisco Health District has significantly lower cancer incidence rates for female breast, male genital system, GI system, gynecological cancers, heme-malignancies, and “all other (cancer) sites”. The notable exception to this is respiratory cancers (85.1 vs. 72.5 per 100,000) which has a higher incidence within the district than that for Virginia. (**Figure 3**). The cancers with the highest incidence rates for the health district are female breast, male genital system, and respiratory cancers.

Age-Adjusted Cancer Incidence Rates in Lenowisco Health District vs. Virginia			
Cancer Site	Lenowisco	Virginia	Notes
Female Breast	97.9	124.3	<i>Data Source: Virginia Cancer Registry (averaged rates for 1999-2008) – all rates calculated based on populations including all ages.</i>
Male Genital System	92.8	167.7	
Prostate	87.1	162.0	
Other male genital organs	5.7	5.7	
Respiratory	85.1	72.5	<i>Dataset ordered by descending rate for health district.</i>
GI System	71.6	79.8	
Colon & Rectum	44.6	47.5	
All Other GI	27.0	32.3	<i>Age-Adjusted Rate - represents an age-adjusted number of new cancer cases per 100,000 populations.</i>
Gynecological	37.5	44.4	
Corpus and Uterus	19.2	21.8	
Ovary	9.5	12.1	
Cervix	5.5	7.2	<i>Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females.</i>
All other Gynecological	3.3	3.4	
Heme-malignancies	29.8	34.3	
Lymphomas	15.5	19.5	
Leukemias	10.6	9.7	
Myeloma	3.8	5.2	
Urinary System	25.1	32.4	
Oral Cavity, Pharynx	8.6	10.3	
Brain, Nervous System, Eye	6.7	6.5	
All Other Sites	36.0	44.5	
All Sites	376.0	446.6	

Table C: Age-Adjusted Cancer Incidence in Lenowisco HD vs. Virginia

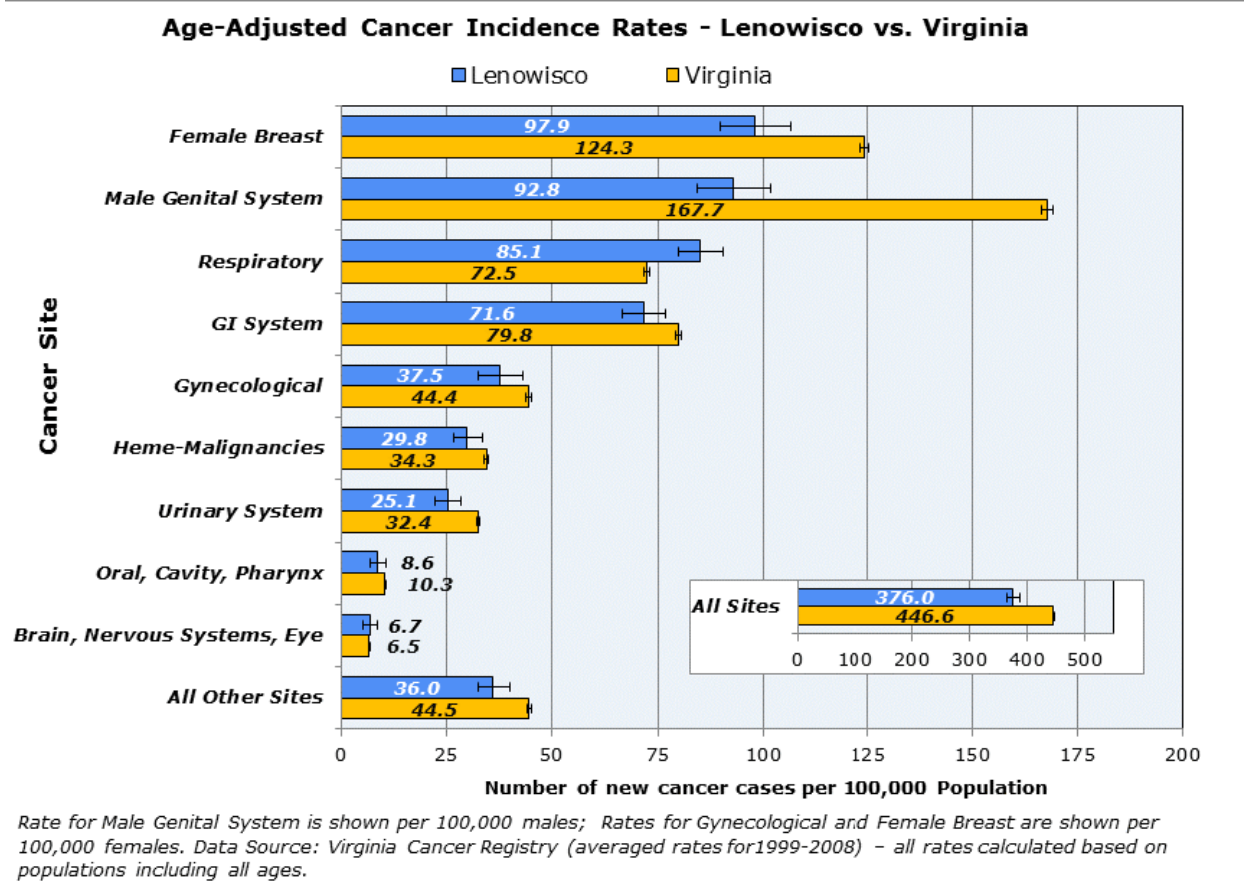


FIGURE 3: Age Adjusted Cancer Incidence Lenowisco VA Health District

To evaluate the impact of cancer in the community in terms of provider burden and services needed, information on the annual number of cancer cases diagnosed was acquired from the Virginia Cancer Registry. In the Lenowisco Health District, there was an average of 415 new cancer cases per year for the years of 1999 to 2008. Gastro-intestinal, respiratory, male genital and female breast, and heme-malignancies had the highest average incident cases and make up the majority of the cancer cases within the district. (Table D / Figure 4)

Top 5 Cancers in Lenowisco Health District by Incidence Count		
Cancer Site	Annual Count	Notes
Respiratory	97	Data Source: Virginia Cancer Registry Annual Count - represents average number of new cases per year in the health district (averaged over period 1999-2008).
GI System	79	
Colon & Rectum	49	
All Other GI	30	
Female Breast	56	
Male Genital System	46	All Other Sites include Brain, Nervous System, Eye, Gynecological, Oral Cavity, Pharynx, Urinary System, and Other sites.
Prostate	44	
Other male genital organs	3	
Heme-malignancies	32	
Lymphomas	17	
Leukemias	11	
Myeloma	4	
All Other Sites	105	
All Sites	415	

Table D--Top 5 Cancers in Lenowisco Health District by Incidence Count

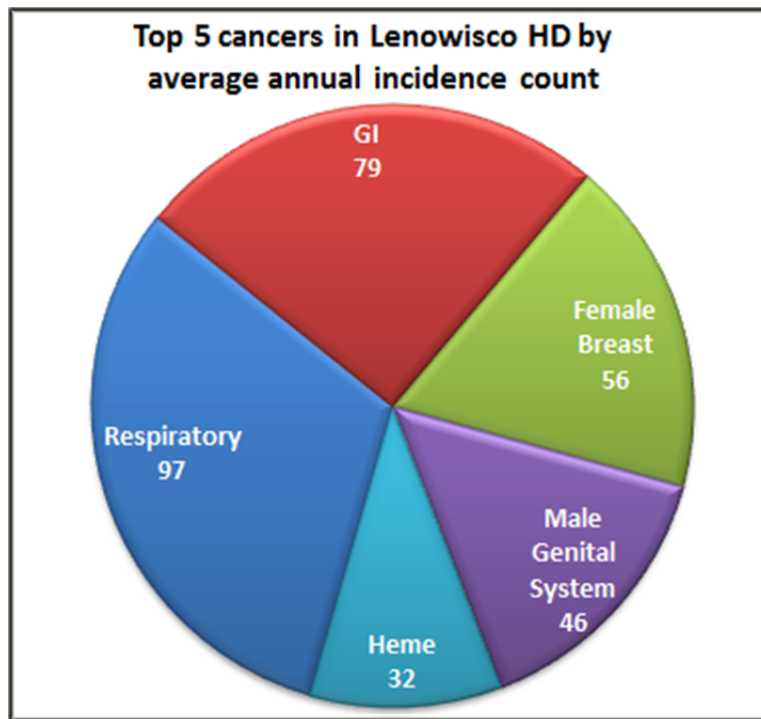


Figure 4: Top 5 cancers in Lenowisco HD by Incidence count

Cancer incidence rates are equivalent in males and females (448.1 vs. 445.6 per 100,000). The cancers with the highest incidence for men are respiratory, male genital, and gastro-intestinal in that order, with these three representing approximately 70% of annual male cancer cases. (Table E & Figure 5)

Top 5 Male Cancers in Lenowisco			
Cancer Site	Crude Rate	Annual Count	Notes
Respiratory	122.0	57	Data Source: Virginia Cancer Registry
Male Genital System	99.6	46	
Prostate	93.8	44	
Other male genital organs	5.8	3	Crude Rate – represents number of new male cancer cases per 100,000 males.
GI System	88.0	41	
Colon & Rectum	53.3	25	
All Other GI	34.7	16	Annual Count - represents average number of new male cancer cases per year in the health district (averaged over period 1999-2008).
Urinary System	40.3	19	
Heme-malignancies	35.8	17	
Lymphomas	19.2	9	All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.
Leukemias	11.9	6	
Myeloma	4.7	2	
All Other Sites	62.3	28	
All Sites	448.1	208	

Table E- Top 5 Male Cancers in Lenowisco HD

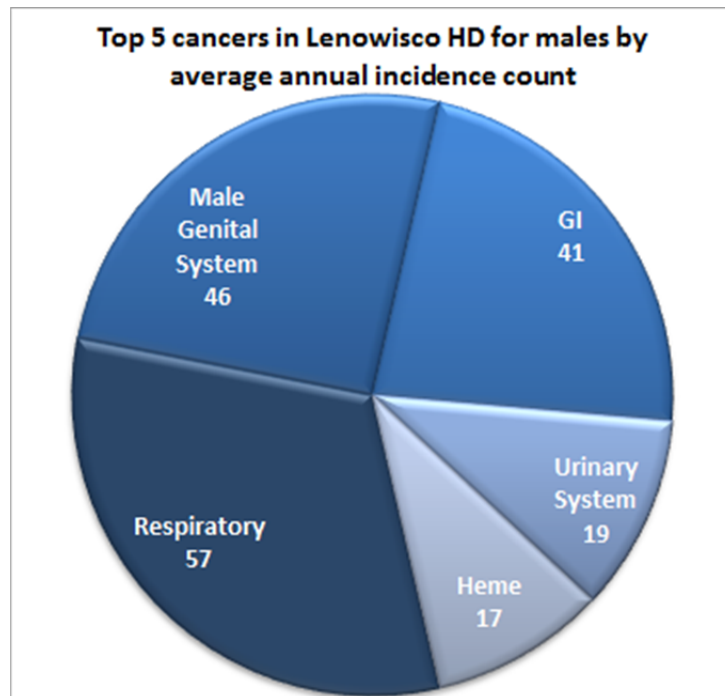


Figure 5 - Top 5 Male Cancers in Southside HD

Breast cancer has the highest incidence rate for females in the district, followed by respiratory, and gastro-intestinal cancer. These cancers represent 65% of new incident cases of cancer in the district each year. **(Table F & Figure 6)** The small black population in Lenowisco Health District (4%) made comparison of cancer burden by race impossible.

Top 5 Female Cancers in Lenowisco Plateau			
Cancer Site	Crude Rate	Annual Count	Notes
Female Breast	121.1	56	Data Source: Virginia Cancer Registry
Respiratory	86.4	40	
GI System	82.5	38	Crude Rate – represents number of new female cancer cases per 100,000 females.
Colon & Rectum	52.6	24	
All Other GI	29.9	14	Annual Count - represents average number of new female cancer cases per year in the health district (averaged over period 1999-2008).
Gynecological	46.1	21	
Corpus and Uterus	24.1	11	
Ovary	12.1	6	
Cervix	5.8	3	
All other Gynecological	4.1	2	All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.
Heme-malignancies	33.8	16	
Lymphomas	16.8	8	
Leukemias	12.5	6	
Myeloma	4.5	2	
All Other Sites	75.8	36	
All Sites	445.8	207	

Table F - Top 5 Female Cancer Lenowisco HD

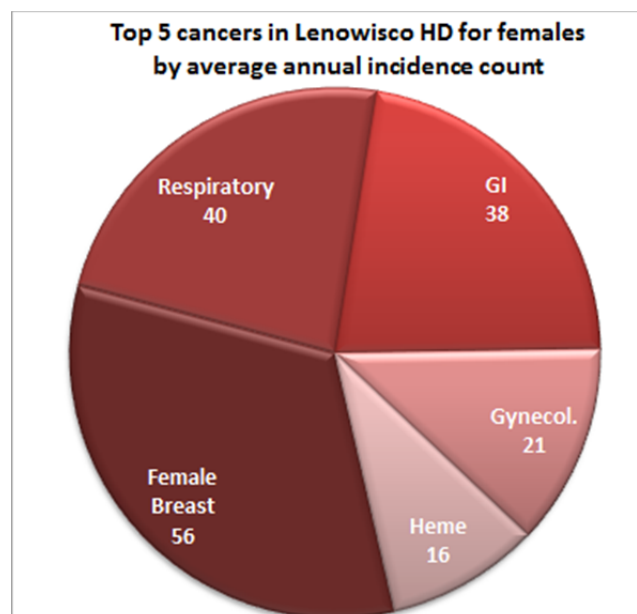


Figure 6 - Top 5 Female Cancers in Lenowisco HD

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. Overall, the percentage of cancers identified as “early” in the health district is lower than that of Virginia (49% versus 57%). The cancers with the largest differences in the percentages found early are urinary system and gynecologic cancers, heme-malignancies, and cancers of “all other sites”. (**Figure 7**)

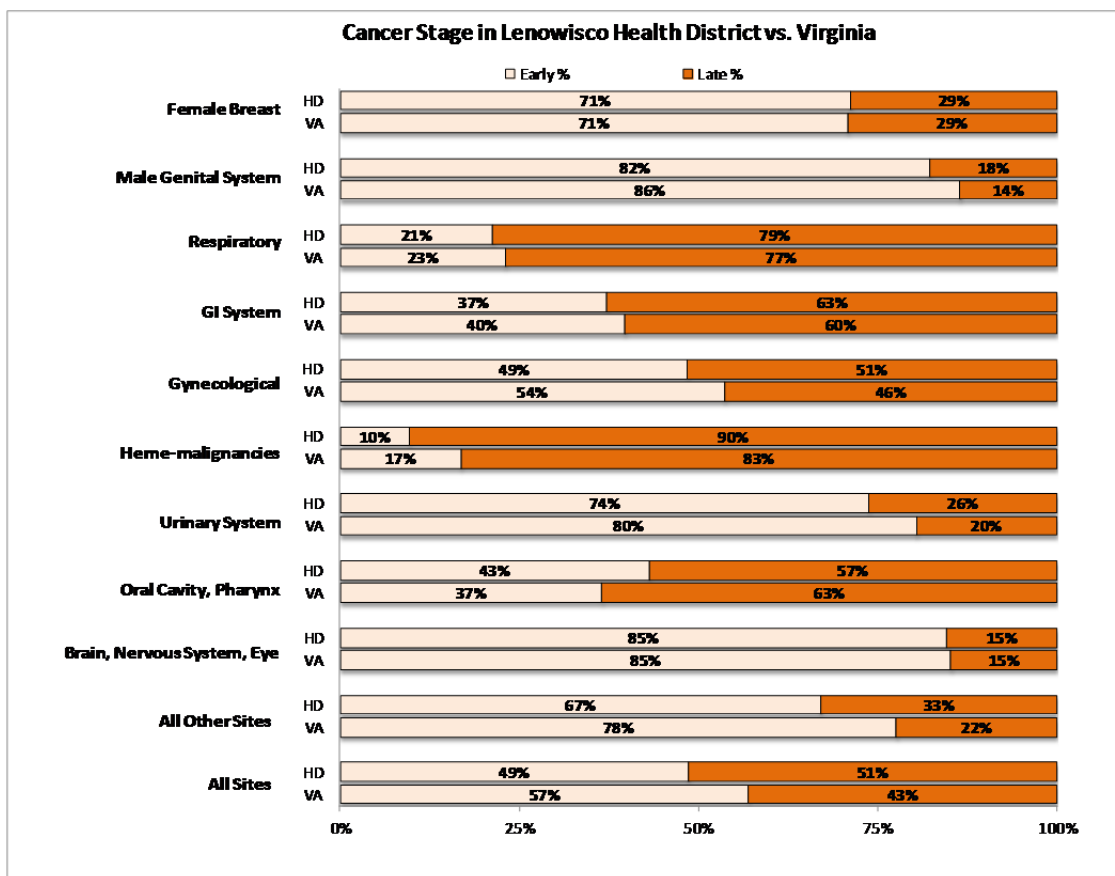


Figure 7: Cancer Stage in Lenowisco Health District vs. Virginia¹⁶

There are 247 average annual deaths from cancer in the health district, with respiratory cancer deaths making up over one-third of those (36.8%). (**Table G**) Overall, the cancer age-adjusted mortality rates in the health district are higher than that for Virginia (217.7 vs. 180.9 per 100,000). The cancers with the highest mortality rates are respiratory (78.8 per 100,000), GI system (39.0 per 100,000), and female breast cancers (29.2 per 100,000). Similar to the incident rate, respiratory cancer mortality is dramatically and significantly higher in the health district than the state. (**Figure 8**)

¹⁶ **Early** stage combines “In Situ” and “Local” cancer stages; **Late** stage combines “Regional” and “Distant” stages. Data presents cancer cases with reported stage only. Percentage of unstaged cancer cases was eliminated from calculations. Data Source: Virginia Cancer Registry (1999-2008) – all percentages calculated based on populations including all ages.

Top 5 Cancers in Lenowisco by Annual Death Count		
Cancer Site	Annual Count	Notes
Respiratory	91	Data Source: Virginia Department of Health (averaged counts for 5-year period 2005-2009) - based on population for all ages.
GI System	46	
All Other GI	25	
Colon & Rectum	21	
Heme-malignancies	21	Dataset ordered by descending death counts for health district.
Lymphomas	9	
Leukemias	7	
Myeloma	4	
Female Breast	18	All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.
Male Genital System	10	
Prostate	10	
Other male genital organs	0	
All Other Sites	62	
All Sites	247	

Table G: Top 5 Cancers in Lenowisco HD by Death Count

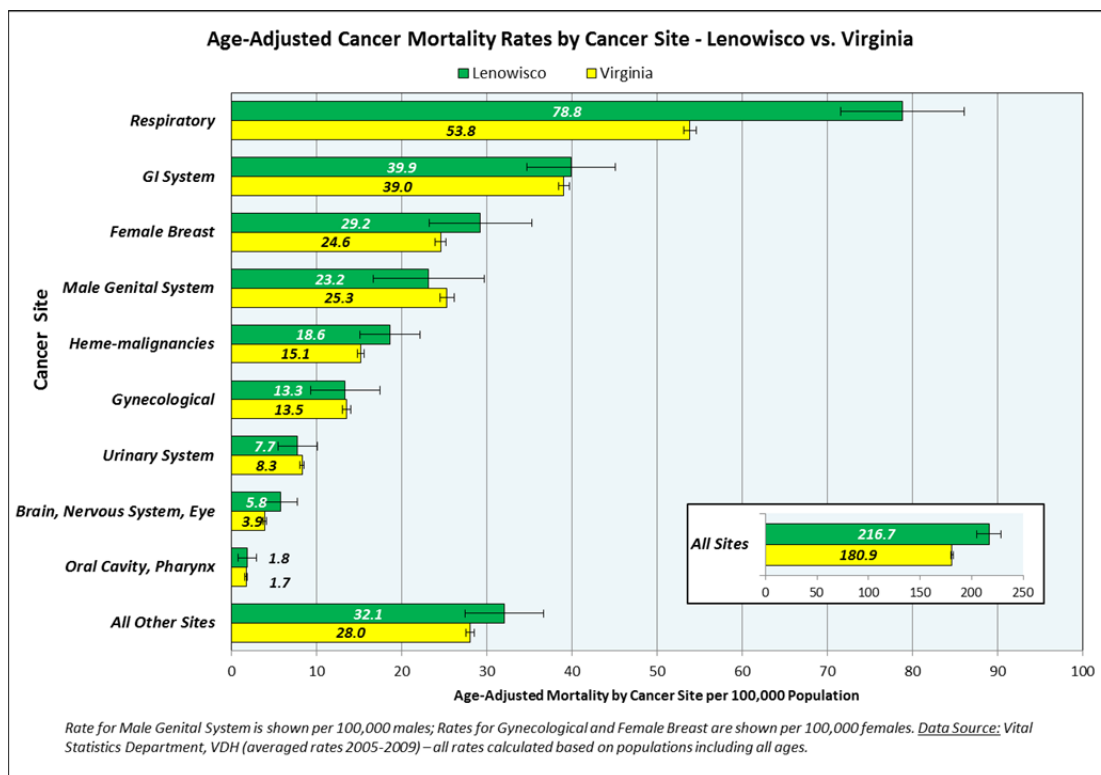


Figure 8: Age Adjusted Mortality Rate by Cancer Site in the Lenowisco HD vs. Virginia

The greatest number of cancer deaths in both men and women in the district result from respiratory and GI cancers. In men, these two cancers make up 75% of all of the cancer deaths, and in women 62% of all cancer deaths that occur annually in the health district. (Figures 9 & 10)

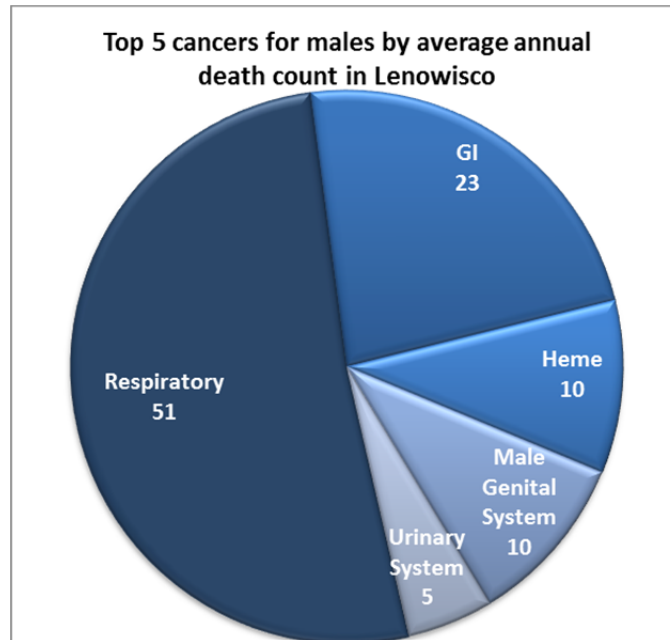


Figure 9: Top 5 cancers causing death in males

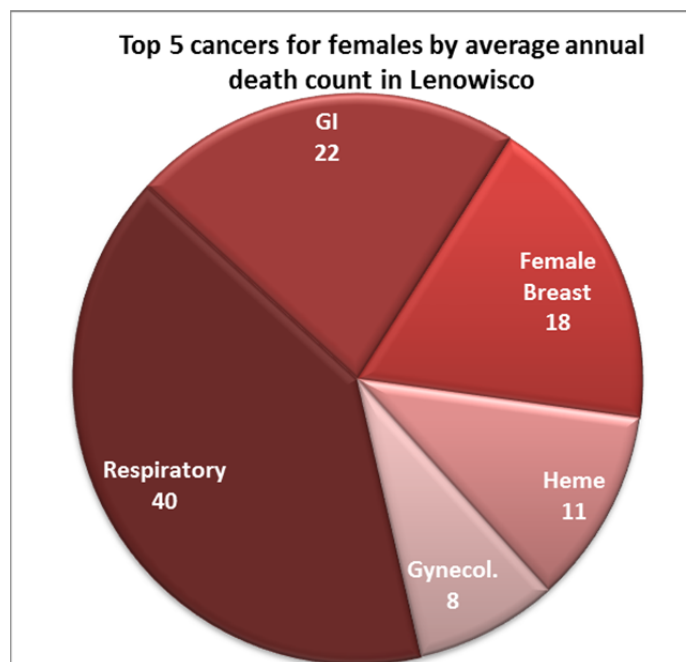


Figure 10: Top 5 cancers causing death in females

Cancer Healthcare Resources

Healthcare Facilities and Cancer Care

At the beginning of this study there were five medical facilities providing healthcare to the Lenowisco Health District: Lee Regional Medical Center in Lee County, and Norton Community Hospital, Southwest Virginia Cancer Center, Mountain View Regional Medical Center, and Lonesome Pine Hospital, all in Wise County. Norton Community Hospital is a 129 bed acute care facility that is part of the Mountain States Health Alliance. The Lonesome Pine Hospital, located in Big Stone Gap, Mountain View Regional Medical Center a full service hospital and Southwest Virginia Cancer Center in Norton are part of the Wellmont Health System. Lee Regional Medical Center in Pennington Gap is also part of the Wellmont Health System, however, at the time of writing this assessment, the hospital had closed its operation. Of the remaining four healthcare facilities, only Southwest Virginia Cancer Center offered specialist oncology care. One medical oncologist recently retired, and one medical oncologist and one nurse practitioner provided oncology care there at the time of this assessment. Further, this is the only facility offering outpatient medical oncology and radiation oncology services in the health district. **(See Appendix D).**

Cancer Services Provided

Screening:

Cancer screening services are available at most of the aforementioned healthcare facilities located in Wise county. Breast cancer screening / diagnostics services are available in the form of screening mammography, diagnostic mammography, breast biopsy, and breast MRI. Additionally, colorectal cancer screening services are available at the four functioning healthcare facilities in the form of sigmoidoscopy and colonoscopy procedures.

Treatment:

In addition to outpatient medical oncology services previously mentioned, the following surgical oncology procedures are available in Wise county: breast mastectomy and reconstruction; sentinel node sampling; gynecological hysterectomy and oophorectomy; upper and lower GI-tract procedures; prostatectomy; and ENT surgeries.

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. Limited cancer support services are available at healthcare facilities in the Lenowisco Health District. All healthcare facilities offer various forms of cancer specific nutrition services, however, as well as general nutritional education to decrease cancer risks within the general population. One facility offers BRCA gene screening and cancer-specific genetic counseling. One facility offers palliative care services but does not have in-patient palliative care beds or outpatient palliative care clinics. There are no patient navigators or cancer support groups at any of the hospitals. **(See Appendix E).**

Clinical Trials:

One facility offers clinical trials through membership in the Southwest Cancer Control Consortium, a National Cancer Institute Community Clinical Oncology Program.

Hospice Services:

Each of the four healthcare facilities within the Lenowisco Health District operate facility-supported hospice services. Additionally, two privately funded hospice facilities operate in the district. One healthcare facility operates a consulting palliative care service consisting of a board certified palliative care specialist, social worker, and dietician.

Deficiencies in cancer-specific services:

This survey identified areas where cancer services were lacking. All cancer treatment services are located in a single county in the health district, Wise County and residents in the surrounding counties either travel to Wise County or seek oncology services outside the health district.

Oncology services offered in Wise County are limited. No inpatient chemotherapy services are offered, and several surgical oncology services are not available within the health district, which include: liver and pancreas, lung, and brain. Also, there are no board certified oncology dietitians or patient navigation services in the health district. Additionally, there is a need for expanding current community cancer resources and recruiting additional cancer support organizations to the district. No patient support groups are offered at healthcare facilities in Wise County and patients must rely on limited community-based support opportunities. Finally, there are no inpatient palliative care units or outpatient palliative care clinics available in the district.

Community Cancer Resources

There are two major community organizations offering cancer-support services within the Lenowisco Health District: Mountain Empire Older Citizen Center (MEOCC), located in Big Stone Gap, VA, and the American Cancer Society (ACS), which operates out of Abingdon, VA, but provides some services to Lenowisco Health District residents. The MEOCC is a local non-profit organization located in Wise County, and the ACS is a national non-profit organization with its regional office in Abingdon. Both non-profit organizations offer cancer support services to patients, survivors, and caregivers in the Lenowisco Health District. Additionally, they provide cancer prevention and screening education to the general public. The MEOCC states that it specifically faces challenges keeping up with demands for their services and securing ongoing donations to continue its operations. The ACS states that its primary challenge is recruiting volunteers that are able to offer transportation services to cancer patients within Lenowisco Health District. **(See Appendix D for additional details)**

Healthcare Provider Needs

Key Leader Information

Five healthcare professionals were selected based on their experience in the chosen communities. Those interviewed had varying professional involvement in the healthcare system, including hospital administration, nursing, and primary care in different geographic locations within the health district. Interviewees were asked to identify resources and needs in the community relating to cancer risk reduction, detection and diagnosis, treatment and follow-up care. They were also asked about pressing needs for community primary care providers related

to continuing education, patient cancer diagnoses and referral for care, as well as survivorship care.

Upon review, there were a number of themes that could be identified. Those that were most prominent from these interviews were (1) patient lifestyles impacting health, (2) financial burden of healthcare on residents, (3) lack of access to specialists and sub-specialists locally, (4) lack of transportation as a barrier to early detection and care and (5) poor access to education both for primary care physicians as well as patients. Each of these themes was mentioned recurrently in a majority of the interviews and was applicable to more multiple stages along the continuum of cancer care.

Most prominent of all of the issues identified was the financial burden. This was also voiced by community residents during the focus groups. There are a large number of uninsured and underinsured in the district. Patients foregoing screenings or discontinuing cancer care due to the financial burden of care was oft-mentioned as a hindrance through the continuum of care. An annual Remote Area Medical (RAM) event provides a number of free screenings and healthcare opportunities to the uninsured in the area, but it is limited in scope in relation to the need. For those who are not financially capable of securing insurance, access to affordable and free screenings and diagnostics, and better education about screenings for patients were mentioned as possible solutions. Transportation to the RAM, primary care clinics, not to mentioned specialized care is a significant barrier to health care in general, and prevents some patients from receiving recommended cancer screening and treatment services.

Various factors were mentioned as being contributors to an unhealthy general lifestyle in the area. These included the high incidence of tobacco use, overall sedentary lifestyle, as well as poor nutrition and exercise habits. A need for community education on tobacco use prevention and cessation and programs to promote healthy lifestyles was voiced. Again, community residents expressed the same need during focus groups.

The Key Leaders identified better access to cancer continuing education locally for primary care physicians as a need and identified that lack of availability in the rural areas of the district as a significant contributing factor to deficiencies in cancer early diagnosis and timely treatment. Programs aimed at bringing education to the more remote healthcare areas as well as increased utilization of internet sources as an education medium for doctors were suggested as possible solutions.

Many patients will travel long distances for cancer diagnosis and treatment to facilities that possess more specialists or diagnostic capabilities on site. Usually, this entails a trip to more established facilities in Tennessee or possibly Abingdon, which can be a long trip for some residents of the district. Some interviewees indicated that a disparity in the perceived level of care between local facilities and these older, more established facilities in surrounding health districts may also lead to patients leaving the health district for care. Likewise, those patients who need a sub-specialist are often looking at trips of several hours to facilities such as UVA or Duke.

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, and continuing education needs of PCPs. A total of 20 physicians in the Lenowisco Health District offered their insights into the status of cancer services in the district, which represents a 47%

response rate. The physicians were from the following medical specialties: family medicine (13), internal medicine (5), and surgery (1), with one respondent not identifying a specialty.

Cancer Screening and Compliance: Respondents identified the three most prevalent cancer diagnoses in their practice as lung 31.5%, breast 27.8%, and colorectal 20.4%. When asked about recommended screening compliance among their patients, 75% of respondents indicated high or above average compliance with breast cancer screening, but only 48% and 45% of respondents indicated high to above average compliance with cervical and colorectal cancer screening. (**Figure 11**)

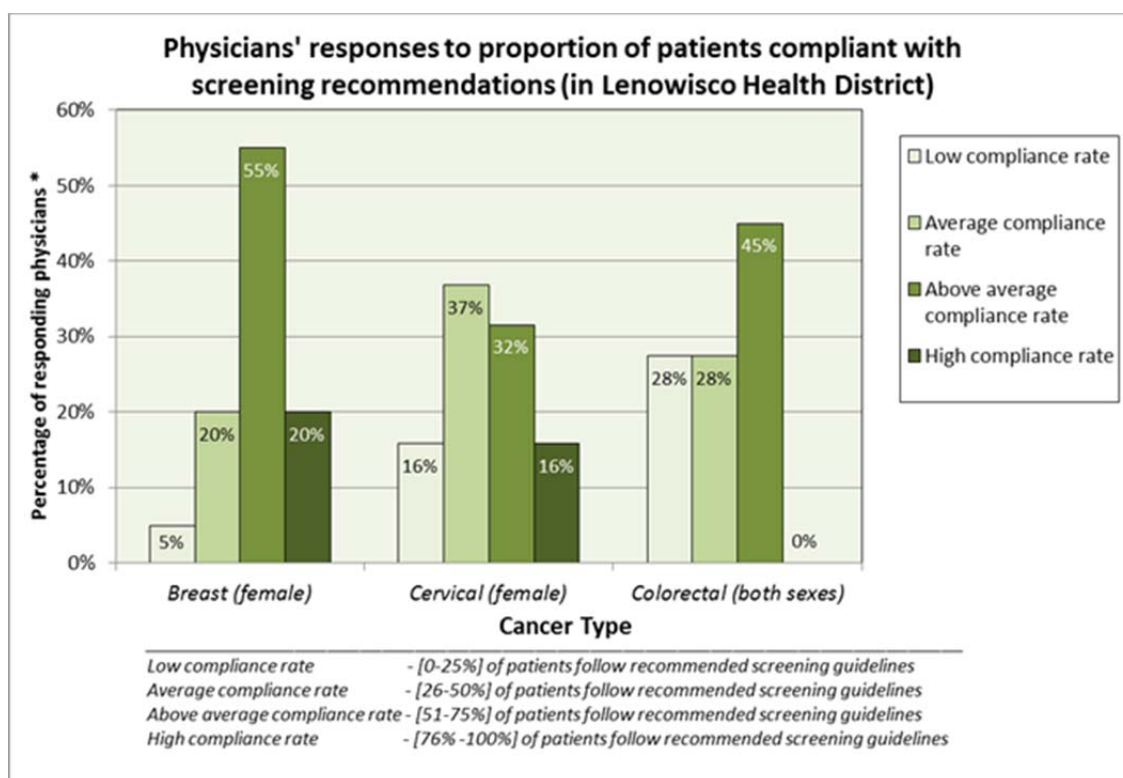


Figure 11: Patient compliance with screening recommendations

The vast majority of physicians (90%) cited financial constraints as the reason for patients screening non-compliance. Lack of insurance (70%) and apprehension about the exam (70%), were also identified as significant barriers to screening compliance. A lack of transportation (40%) was less frequently cited. (**Figure 12**) A significant percentage of the responding physicians were interested in receiving updated screening recommendations for lung (60%), breast (55%), prostate, cervical, and colorectal cancer (each 50%).

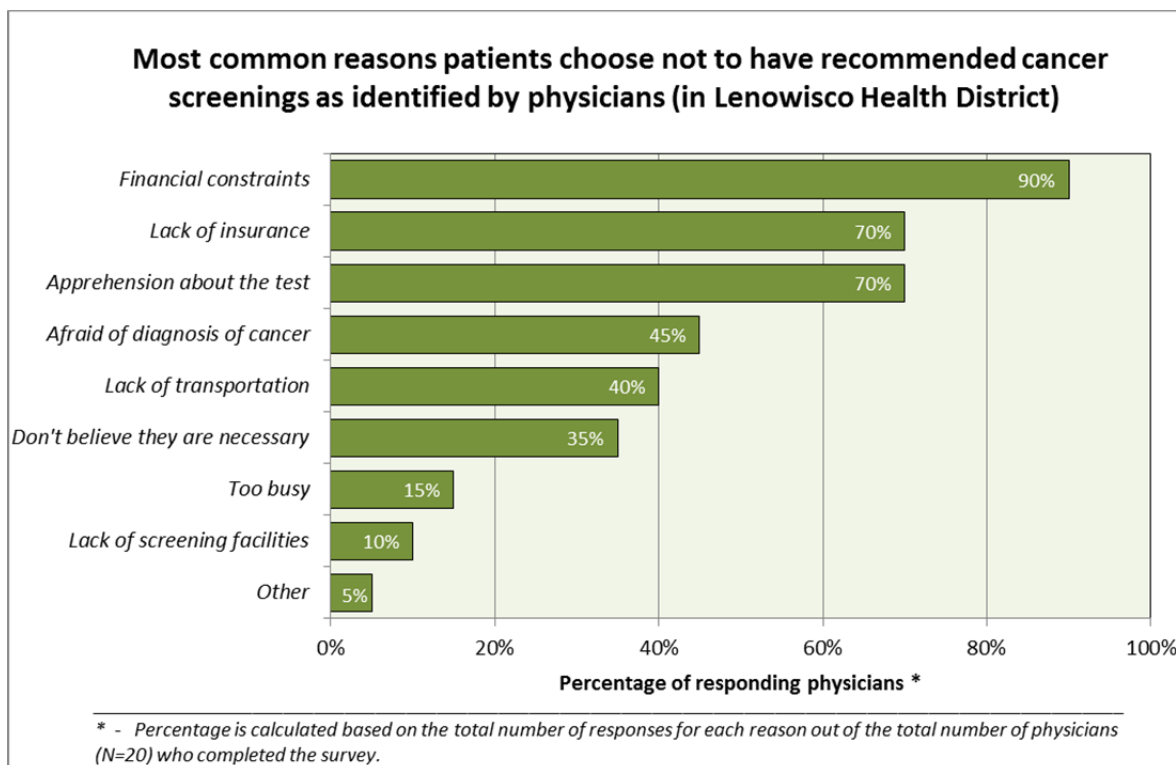


Figure 12: Most common reasons patients choose not to have recommended cancer screenings as identified by physicians in Lenowisco HD

Referrals and Communication: When asked where they prefer to refer their patients diagnosed with cancer for treatment, sixty percent refer patients locally for oncology surgery and seventy percent refer locally medical oncology treatment. One quarter indicated that they refer their patients outside of Virginia for both treatment modalities. Fewer than 10% of respondents referred to oncologists to Virginia NCI designated cancer centers.

The communication coming from a treating oncologist sited as most useful by over 90% of responding physicians was follow up care guidelines, followed by the initial treatment plan and pathology report. **(Figure 13)** The majority of respondents (80%) indicated that the usually or almost always received satisfactory communication from treating oncologists.

Post-cancer treatment: Almost all (90%) of responding physicians felt comfortable providing non-oncology care during active cancer treatments, with half indicating comfort with joint management of oncology care. Fewer (35%) were comfortable providing long-term oncology follow-up care. **(Figure 13)** Surveillance of recurrence, end-of-life care, and wellness and recurrence prevention were continuing education topics that physicians were “very interested” in. The preferred methods for receiving continuing education information were in written and web based formats formats.**(Figure 14)**

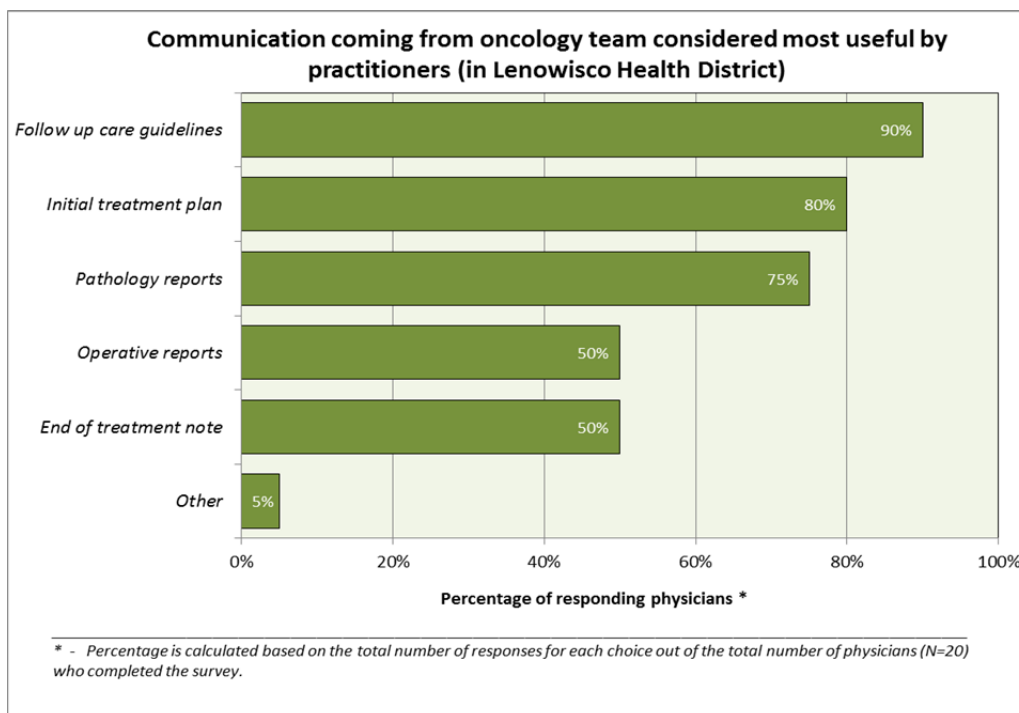


Figure 13: Most useful communication coming from treating oncologist

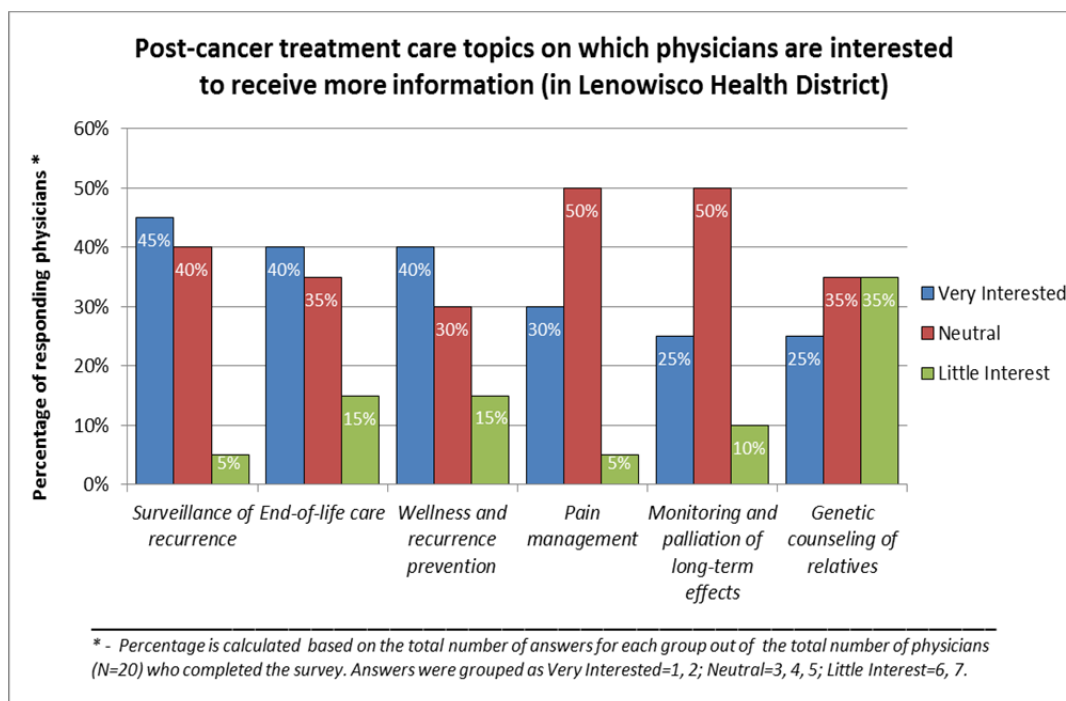


Figure 14: Post-cancer treatment topics of interest to physicians in Lenowisco HD

Cancer clinical research: Half of responding physicians indicated that they had little knowledge of cancer clinical trials, and no, to little interest in learning about clinical research. Not surprisingly, 45% felt that having cancer clinical trials in their practice area was of little or no importance. Despite this, 45% were very interested in learning about cancer clinical trials being offered in the practice area.

Community Population Needs

Two methods were employed to accurately assess the community resident's needs and concerns about cancer care: evaluation of the Behavioral Risk Factor Surveillance Survey 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 Behavioral Risk Factor Surveillance Survey (BRFSS) was accessed to gain perspectives at the Health District level about lifestyle factors, healthcare access and screening practices. According to the Behavioral Risk Factor Surveillance System (BRFSS) for adults eighteen and older, the Lenowisco Health District, when compared to Virginia shows a higher incidence of sedentary behavior and smoking, lower intake of the recommended number of daily servings of fruits and vegetables, and has a relatively high incidence of obesity. All four factors are associated with a higher cancer risk. Thirty-six percent of the population reported no physical exercise in the past 30 days and only 20% included 5 or more fruits and vegetables in their daily diet. Greater than half (67.5%) of the district is overweight or obese and 30% of adults reported being current cigarette smokers. **(Figure 15)** This information is supported by comments gathered in the focus groups.

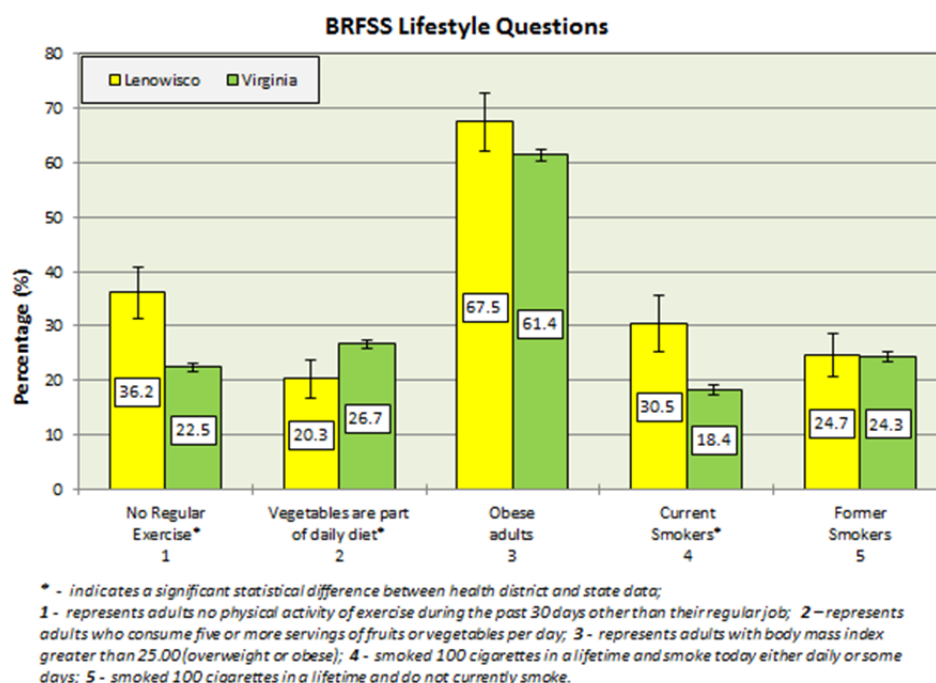


Figure 15: BRFSS Lifestyle Questions for Lenowisco HD

Residents of the Lenowisco Health District have less access to health care providers compared to those in other parts of the state. A larger proportion of individuals have no health insurance and are unable to see a doctor due to cost or lack of insurance coverage when compared to the State. Despite this, a similar percentage of residents had visited a doctor in the last year and have a primary care physician. **(Figure 16)**

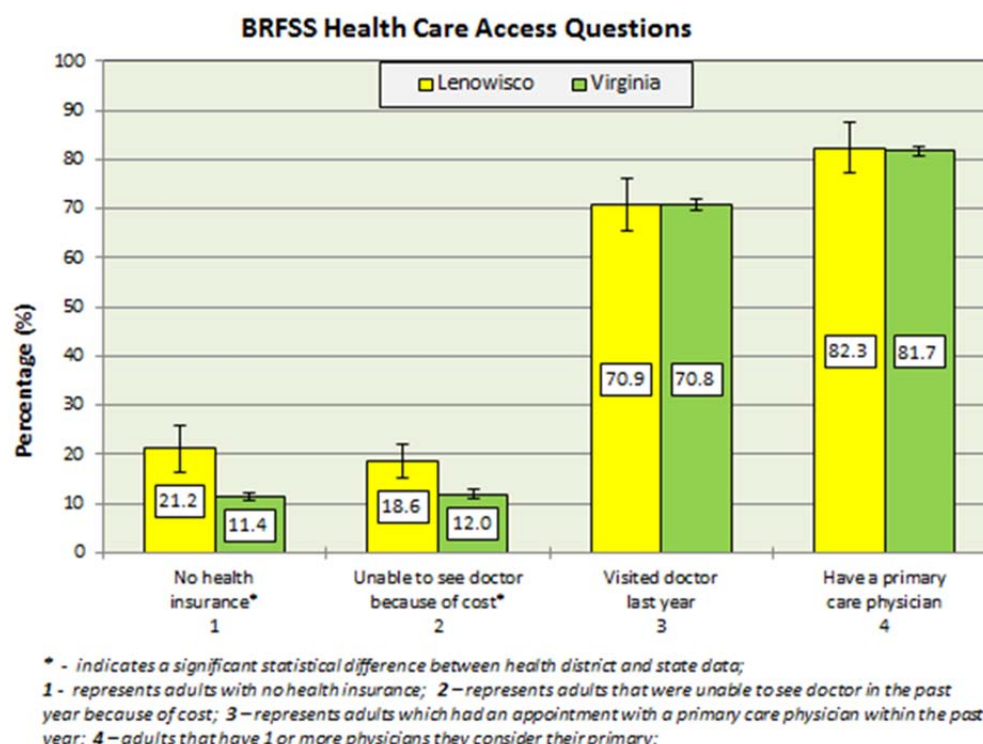


Figure 16: BRFSS Health Care Access Questions

Cancer screening rates are somewhat lower than state rates in Lenowisco Health District. Despite primary care physicians perception of a low compliance with recommendations for colorectal cancer screening, 70% of age eligible residents indicated that they had had the screening. Only twenty-two percent of respondents reported having a fecal occult blood test in the past two years, which is an alternative colorectal cancer screening to colonoscopy. Only seventy percent of women reported having a mammogram in the past two years, while a higher percentage (87%) had a pap smear in the last three years. Less than half of men reported having a PSA in the past two years. **(Figure 17)**

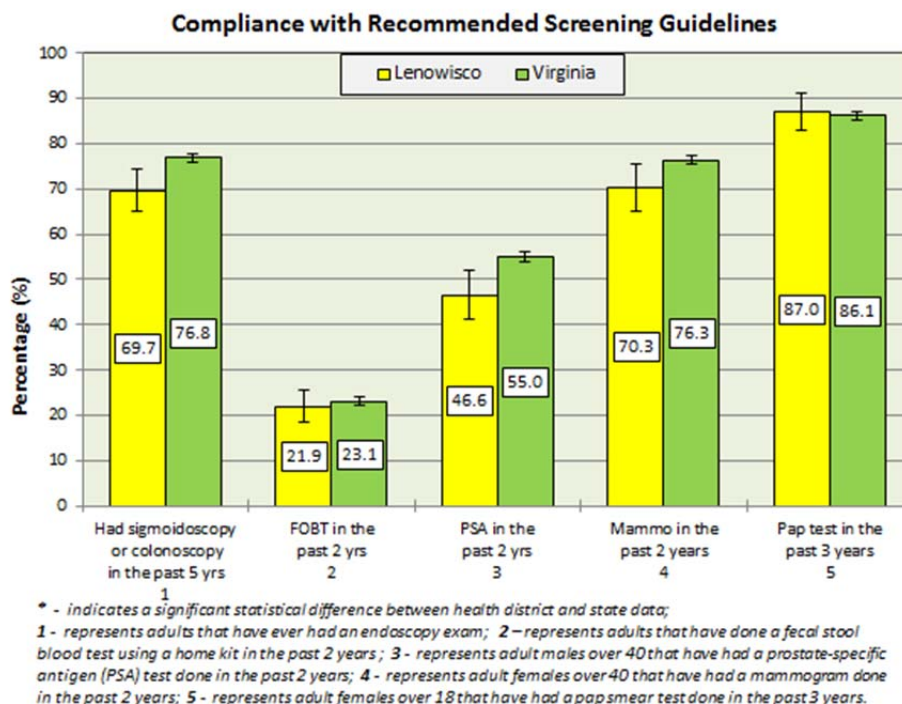


Figure 17: Compliance with Recommended Screening Guidelines

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. Age, gender, education and economic distribution were matched as closely as possible. 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 18)

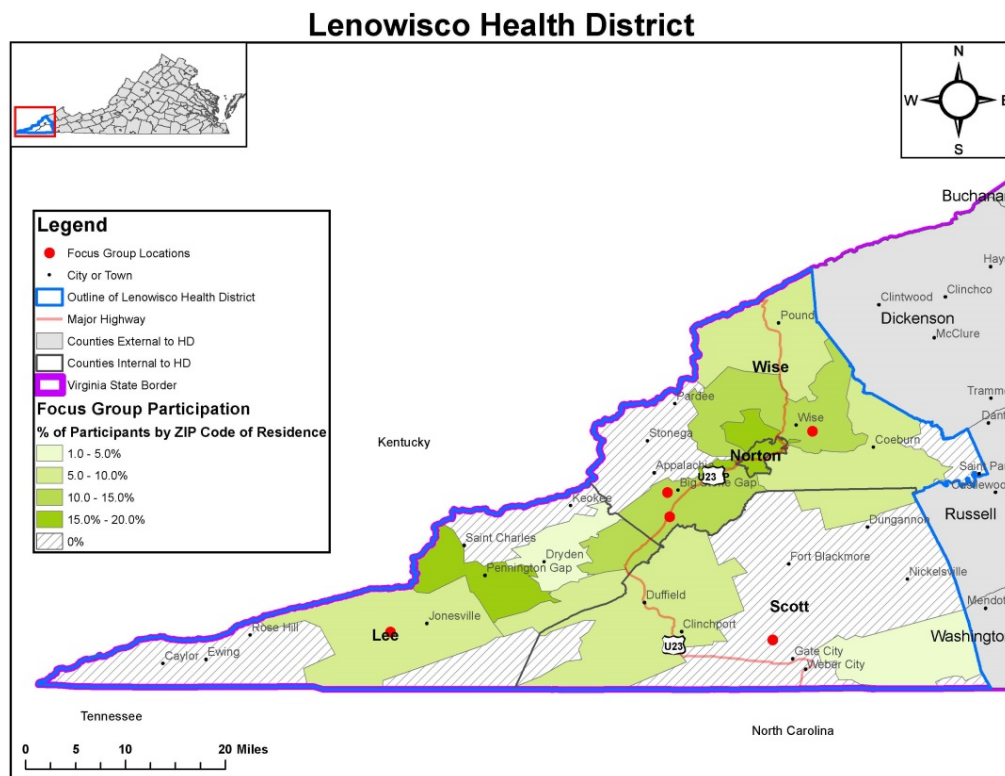


Figure 18: Focus Groups Participation in Lenowisco Health District

General Population Group Synopsis:

Four general population focus groups were held in the Lenowisco Health District. Two groups were held in Wise county, and one in each of the other two counties that make up the district. There were a total of 23 participants with an average group attendance of 6. Cancer was identified as an important health problem in the community by all groups followed by lung disease, heart disease, and diabetes. Drug and alcohol abuse were also commonly identified as a health concerns. Fear of diagnosis driven by negative experiences with cancer outcomes of relatives and the significant burden of lack of insurance, finances, and local access to treatment was the prominent theme in all groups.

Participants from all groups identified diet, exercise, and tobacco use as lifestyle behaviors that could impact health. Faith, nutrition literacy, and preventive health care were mentioned as having a positive impact on health, while environmental hazards were repeatedly mentioned as having a negative impact on health in the community. 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, and even promotion in the family. This attitude is primarily due to the importance of tobacco production into the local economy. There is an absence of tobacco cessation programs in the district, and little prevention education in the schools. Smoking bans in public places, raising cost of tobacco products and stricter laws restricting use were recommended as strategies to curb tobacco use

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. Government agencies and programs were

most often referenced as sources for nutrition education, and although multiple programs were cited as having been available in the past, few current programs were identified. The Extension service was noted as a community resource for nutrition education. The need for additional educational programs was often cited as key to bringing about positive change. Bringing these programs to where the people are was cited as essential for success.

Lack of motivation and incentives were the most common reasons mentioned for people not maintaining a lifestyle of exercise and appropriate weight. All of the groups felt that there were adequate resources in the community for people to exercise regularly. Obesity was recognized as a problem in the community, and contrary to exercise, there were very limited resources to help individuals maintain a healthy weight. There was significant confusion about what a healthy weight is, highlighting the need for education around the topic. The cultural importance of cooking and eating in the community was emphasized, necessitating community based programs that effectively shift the culture to more healthful lifestyles.

When questioned about cancer screenings, there was a general negative response. Both accessing the screenings and the significant financial burden of a diagnosis of cancer were significant barriers to getting screened. Fear of the consequences to themselves and family was significant. Transportation was also mentioned as a barrier to screening.

Finally, participants had very limited experience or knowledge of cancer research. Some participants associated the words “cancer clinical study” with “lab rat”, “guinea pig” and “experimentation”. Cancer research was felt to be only for people for whom it was a last resort. There was reluctance to be involved in cancer research unless it was involving direct benefit to the community or a family member.

Cancer Survivor Group Synopsis:

Three cancer survivor focus groups were held in the health district, one in each county. There was a total of 18 attendees, with an average group size of 6. Cancer survivors residing within the Lenowisco Health District indicated that the information that they needed after receiving a cancer diagnoses included: general information about what cancer is; lifestyle habits that increase the risk of developing cancer; alternative cancer treatment options; and why their cancers were not diagnosed earlier. The amount of information that participants received from healthcare providers differed based on when they were diagnosed, with more detailed information being provided with later diagnoses. Some participants described physicians who were “rude” when telling them about their diagnosis, as well as physicians who provided unreliable information throughout their cancer treatment. Survivors and caregivers indicated that they researched information on their own during diagnosis and treatment, and often felt overwhelmed by the amount of information. Much of the publically available information changed frequently and sources would often contradict one and other.

Cancer diagnoses and treatment were received both locally and outside of Virginia (Tennessee and Maryland). Healthcare personnel, such as nurses and physicians, were often mentioned as being helpful in getting a diagnosis, as well as other cancer survivors and family members. These groups, along with patient advocates and churches were mentioned as helping survivors and caregivers to navigate through the system while receiving cancer treatment.

A lack of information and education were cited as significant factors in delaying diagnosis. Additional barriers to cancer treatment mentioned included: lack of insurance, financial constraints, and lack of availability of services locally. Finally, transportation was a factor in delayed diagnosis and treatment.

Communication by the oncologist to the participant's primary care physician, and post-treatment communication to the patient were discussed in the focus group. In general, treating

oncologists provided post treatment care instructions verbally and included some limited paperwork, but no detailed written survivorship care plans were mentioned by participants. The level of communication between oncologists and primary care physicians varied. Participants noted a lack of cancer specific knowledge by local primary care physicians, and incidents of oncologists blaming local physicians for missed diagnoses. Additionally, participants varied on whether they received the health information they needed after their treatment, citing conflicting information and a need for more local physician assistance in post-treatment care.

The major patient support before, during, and after treatment came from family, friends, neighbors, churches, and even hospice services. Social services, local cancer centers, and financial support were identified as resources that would be helpful but are unavailable in the health district. These services, along with social workers, bereavement counselling and support groups, massage therapists, and dedicated personnel to answer questions at medical centers were indicated as resources that would be helpful to the area.

Cancer research was viewed from conflicting perspectives. Although it was considered important to lead to earlier detection and improved treatments, it also had negative associations like being treated as a guinea pig, or a money making activity for large pharmaceutical companies. Cancer research is available in a limited way to patients in the health district; those who had experience with research were treated outside of the district. Survivors who participated in research did so with the belief that they would receive better treatment. Those who did not participate in cancer research indicated that it was not an option for them, or their physician recommended traditional treatment.

The major concerns related to cancer care mentioned by participants included the lack of empathy/caring people, reliable cancer information resources locally, cancer screening and treatment resources, and problems with accessibility and affordability. Additionally, the high turnover rate of physicians in the area was mentioned as a cause for concern.

SUMMARY OF PRIORITY NEEDS

The Lenowisco Health District is a medically underserved community with higher unemployment and low median income compared to the state. The majority of the cancer screening, support, and treatment options are centered in Wise County, and many of the residents of the health district must travel outside the district to meet their cancer-related needs. Although cancer incidence rates are lower for residents of the Lenowisco Health District than the rest of Virginia, respiratory cancer incidence rates and overall cancer mortality rates are higher. Specifically, mortality rates for respiratory cancer are 46% higher in the district as compared to the state. Relevant to this are the higher tobacco use rates in the health district, and the historical economic importance of tobacco in the area. Key Leaders and community members agreed on the importance community based programs to promote healthy lifestyles. The negative community experience with cancer outcomes due to lack of ready access to timely screening and treatment as a result of lack of insurance, high financial costs, and lack of healthcare providers and facilities has resulted in a fear and aversion of a cancer diagnosis.

Based on the qualitative and statistical information gathered for this project, the following are recommendations for priority areas for action.:

Expand cancer services in the health district, particularly Lee and Scott Counties:

- Innovative approaches to provide cancer treatment locally.
- Innovative programs to incentivize physicians and oncologists to come the area.
- Patient navigation for residents to access cancer screenings.
- Patient navigation for residents diagnosed and/or undergoing cancer treatment relevant to the local context.

Increase support for patients receiving cancer treatment:

Lack of insurance and financial constraints were identified by physicians and residents as major barriers to cancer screening and treatment.

- Establish local initiatives to ensure that residents are enrolled in affordable insurance programs to increase access to early detection and preventive screenings.
- Develop hospital and community based programs for financial support of ancillary costs related to cancer treatment
- Collaboration with existing programs and organizations (American Cancer Society) to develop innovative solutions to assisting with transportation needs, and payment for the cost of transportation during treatment.

Community Level Support for cancer survivors and caregivers:

- Establish local cancer support groups within each county.
- Establish accessible cancer information resource centers with trained health information specialists
- Promote awareness of current resources within the district which provide information on wellness and cancer.

Increase Community Cancer Prevention (especially lung cancer):

- Public awareness campaigns to promote risk reduction with a focus on tobacco use.
- Youth education programs for cancer prevention and avoidance of tobacco use.
- Increase availability of affordable smoking cessation and exercise programs.
- Increase the number of available programs to improve nutrition and reduce obesity.

Physician Education:

- Develop continuing education programs provided locally to Primary Care Providers which include updates on screening guidelines, surveillance of recurrence, wellness and prevention of cancer recurrence, and end of life care.
- There is a need for physician education on empathetic physician-patient communication.

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 YES to mastectomy, do you perform sentinel nodes sampling? Yes_____ No_____

- Breast Reconstruction? Yes_____ No_____ Unknown_____
- Gynecologic (hysterectomy/oophorectomy)? Yes_____ No_____ Unknown_____
- Gynecologic (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,
 - o What medical professionals compose your team:
____ MD/DO Board Certified palliative care ____ NP/APRN ____ RN ____ SW
____ Chaplaincy ____ Care coordination ____ RD
 - o 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!

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:

- | | | |
|--|---|------------------------------------|
| <input type="checkbox"/> Southside | <input type="checkbox"/> Central Virginia | <input type="checkbox"/> Lenowisco |
| <input type="checkbox"/> West Piedmont | <input type="checkbox"/> Cumberland | <input type="checkbox"/> New River |

Please indicate your primary area practice:

- | | |
|--|---|
| <input type="checkbox"/> Family medicine | <input type="checkbox"/> Internal medicine |
| <input type="checkbox"/> Urology | <input type="checkbox"/> Obstetrics/gynecology |
| <input type="checkbox"/> Dermatology | <input type="checkbox"/> Internal Hospitalist |
| <input type="checkbox"/> Surgeon | <input type="checkbox"/> Other _____ Please specify |

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

- | | | | | | |
|--------------------------------------|---|-----------------------------------|-------------------------------|-----------------------------------|-----------------------------------|
| <input type="checkbox"/> Breast | <input type="checkbox"/> Colorectal | <input type="checkbox"/> Prostate | <input type="checkbox"/> Lung | <input type="checkbox"/> Cervical | <input type="checkbox"/> Melanoma |
| <input type="checkbox"/> Hematologic | <input type="checkbox"/> 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 | <input type="checkbox"/> 0-25% | <input type="checkbox"/> 26-50% | <input type="checkbox"/> 51-75% | <input type="checkbox"/> 76-100% |
| b) Cervical (PapSmear) | <input type="checkbox"/> 0-25% | <input type="checkbox"/> 26-50% | <input type="checkbox"/> 51-75% | <input type="checkbox"/> 76-100% |
| c) Colorectal | <input type="checkbox"/> 0-25% | <input type="checkbox"/> 26-50% | <input type="checkbox"/> 51-75% | <input type="checkbox"/> 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 | <input type="checkbox"/> 0-25% | <input type="checkbox"/> 26-50% | <input type="checkbox"/> 51-75% | <input type="checkbox"/> 76-100% |
|---------------|--------------------------------|---------------------------------|---------------------------------|----------------------------------|

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

- | | | | | | |
|----------|------------------------------|-----------------------------|---------|------------------------------|-----------------------------|
| Prostate | <input type="checkbox"/> Yes | <input type="checkbox"/> No | Lung | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Skin | <input type="checkbox"/> Yes | <input type="checkbox"/> No | Ovarian | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

- | | | |
|--|--|---|
| <input type="checkbox"/> Financial constraints | <input type="checkbox"/> Lack of Screening facilities | <input type="checkbox"/> Lack of transportation |
| <input type="checkbox"/> Apprehension about the test | <input type="checkbox"/> Afraid of being diagnosed with cancer | <input type="checkbox"/> Don't believe they are necessary |
| <input type="checkbox"/> Too busy | <input type="checkbox"/> Lack of insurance | <input type="checkbox"/> 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)?

- | | | | |
|-----------------------------------|-------------------------------------|-----------------------------------|---|
| <input type="checkbox"/> Breast | <input type="checkbox"/> Colorectal | <input type="checkbox"/> Cervical | <input type="checkbox"/> Ovarian |
| <input type="checkbox"/> Prostate | <input type="checkbox"/> Lung | <input type="checkbox"/> Skin | <input type="checkbox"/> 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)

- | | | |
|---|--|---|
| <input type="checkbox"/> Initial treatment plan | <input type="checkbox"/> End of treatment note | <input type="checkbox"/> Pathology report |
| <input type="checkbox"/> Operative reports | <input type="checkbox"/> Follow up care guidelines | <input type="checkbox"/> Other _____ (please specify) |

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

- | | | | |
|--------------------------------|---------------------------------|---------------------------------|----------------------------------|
| <input type="checkbox"/> 0-25% | <input type="checkbox"/> 26-50% | <input type="checkbox"/> 51-75% | <input type="checkbox"/> 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	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Surveillance of cancer recurrence	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Long-term cancer treatment effects: monitoring and palliation	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
End-of-life care and planning	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Genetic counseling for family members of cancer patients	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Wellness and prevention of cancer recurrence	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Other _____(please specify)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7

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

<input type="checkbox"/> In person presentation	<input type="checkbox"/> Live webinar with interactive capability	<input type="checkbox"/> Web-based information, self-paced
<input type="checkbox"/> Written information	<input type="checkbox"/> 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 them 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 or 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 your 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 **you not** participate?
19. How important is it to have cancer research available to people with cancer in your community?

OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]

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 Lenowisco Health District			
Available Facilities:	Norton Community Hospital; Lee Regional Medical Center; Southwest Virginia Cancer Center; Mountain View Regional Medical Center; Lonesome Pine Hospital		
# of Oncologists:	2	Breakout: 2 medical oncologists in Southwest Virginia Cancer Center	
Available in Health District			
Services			# of facilities where available
Cancer Treatment	Services Provided	Chemo Outpatient	1
		Radiation	1
Cancer Screening	Breast Cancer Screening and Diagnostic Procedures	Screening Mammography (film, digital)	3
		Diagnostic Mammography	4
		Breast Ultrasound	4
		Breast Biopsy	3
		Breast MRI	3
	Colorectal Cancer	Sigmoidoscopy/Colonoscopy	4
Surgeries	Cancer Related Surgeries	Breast Segmental/Complete Mastectomy	3
		Breast Reconstruction	1
		Sentinel Nodes Sampling	2
		Gynecological Hysterectomy/Oophorectomy	3
		GI - Upper/Lower Tract	3
		Prostatectomy	2
		Ears, Nose, Throat	2
Counseling	Cancer Dietary Needs	Registered dietician to provide nutritional services specific to cancer patients	4
		One-on-one assessment and diet prescription	4
		Individual oncology nutrition counseling services	4
		Outpatient oncology nutrition counseling	4
		Cancer control and prevention education programs for dietary needs	4
	Genetic Tests	Offer genetic tests for cancer risk (BRCA1 and BRCA2)	1
		Offer genetic tests for cancer risk (Others)	1
	Genetic Counseling	Genetic counseling (at the facility / referred out for counseling)	1 / 0
		Certified genetic counselor	1
Genetic counseling provided by :		MS	
Other Services	Clinical Trials	Offer clinical trials	1
	Hospice Service	Facility Supported: Inpatient / Outpatient Hospice	4 / 2
		Private Organization: Outpatient Hospice	2
	Palliative Care	Palliative Care Program	1
		Medical professionals in the team	MD/DO Board Certified palliative care, SW, RD
		Offer consult service	1
Cancer Support Groups	Future Support Groups	Want to start a support group	1

Not Available in Health District			
Cancer Treatment	Services Provided	Chemo Inpatient	
Cancer Screening	Colorectal Cancer	CT Colonography	
	Lynch Syndrome	Screening for Colorectal and Endometrial cancers	
		Immunohistochemistry staining test	
Surgeries	Cancer Related Surgeries	Microsatellite instability testing	
		GI - Liver	
		GI - Pancreas	
		Lung	
Counseling	Cancer Dietary Needs	Brain	
		Board certified dietician in oncology nutrition	
		Private Organization: Inpatient Hospice	
		Inpatient beds	
Other Services	Palliative Care	Outpatient clinic	
		Cancer Patient Navigation	
	Cancer Patient Navigation	Patient Navigator	
Cancer Support Groups	Existing Support Groups	Cancer support groups	
Specialists	Oncology	Currently recruiting oncologists	

APPENDIX E

Community Cancer Resources within the Health District

LENOWISCO HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Mountain Empire Older Citizens Center	American Cancer Society
Organization Information		Number of Organizations		
Organization category	National non-profit	1	-	X
	Local non-profit	1	X	-
	For profit service organization	0	-	-
	Federal governmental organization	0	-	-
	State/municipal government organization	0	-	-
	Other	0	-	-
Major sources of funds for organization	Competitive grants	0	-	-
	Federal funds	0	-	-
	Service fees charges	0	-	-
	Donations	2	X	X
	Other	1	X	-
Cancer Resources				
Primary service population of the organization	Cancer patients	2	X	X
	Cancer survivors	2	X	X
	Cancer caregiver/family members	2	X	X
	Other	1	-	X
Qualification criteria to access services	Must be uninsured/underinsured	0	-	-
	Financial qualification	0	-	-
	No qualification criteria	2	X	X
	Other	0	-	-
Type of cancer related services that are provided	Written information on cancer	2	X	X
	Information on cancer care/support resources	2	X	X
	Management of cancer support groups	1	-	X
	Financial support for cancer control/care	2	X	X
	Funding of projects related to cancer	2	X	X
	Psychosocial support	1	-	X
	Navigational services	2	X	X
	Transportation	2	X	X
	Other	0	-	-
Number of cancer patients seen annually		(see organizations' answers)	greater than 150	greater than 150
Other Information About Organization				
Advertising for the organization	Local media	2	X	X
	Organization website	2	X	X
	Online	2	X	X
	Pamphlets describing services	2	X	X
	Word of mouth	2	X	X
	Other	0	-	-
Organizational needs	Financial support	2	X	X
	Human resources (skilled employees, volunteers, etc.)	2	X	X
	Access to experts for consultation	0	-	-
	Physical space/facilities	0	-	-
	Collaborators	1	X	-
	Volunteers	2	X	X
	Other	0	-	-
Challenges		(see organizations' answers)	Keeping up with the demand and securing funding.	Volunteers, particularly for help with transportation.
Goals for the next 5 years		(see organizations' answers)	Continued support and to continue to secure funding.	To continue to expand support abilities in Cumberland Plateau and Lenowisco health districts.
Partner organizations			Southwest Virginia Cancer Center, Susan G. Komen, American Cancer Society, RAM, Health Department	Any cancer organization
Interested in collaboration			Yes	Yes
Comments		(see organizations' answers)		The Abingdon office services the health districts of Lenowisco as well as Cumberland Plateau as there are no offices there.