# Saving Lives and Reducing Suffering and Death from Cancer in Virginia

*Report of the Comprehensive Cancer Needs Assessment of the Central Virginia Health District*

**Virginia Commonwealth University**

**Massey Cancer Center**

**And**

**Tobacco Indemnification and Community Revitalization Commission**

# Saving Lives and Reducing Suffering and Death from Cancer in Virginia

## *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, the Cancer Action Coalition of Virginia (a statewide network of partners) has developed a series of 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 four health district-defined communities. The four health districts chosen (Crater, Piedmont, Pittsylvania/Danville, Mount Rogers) 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 plan to improve cancer outcomes, which 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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| | |
|---|---|
| ACS | American Cancer Society |
| BRFSS | Behavioral Risk Factor Surveillance Survey |
| CACV | Cancer Action Coalition of Virginia |
| CVHD | Central Virginia Health District |
| CHE | Community Health Educator |
| PCP | Primary care physicians |
| VDH | Virginia Department of Health |

# EXECUTIVE SUMMARY OF FINDINGS

The Central Virginia Health District (CVHD) has a wide range of professional and community-based cancer support services. With the exception of respiratory cancers, cancer mortality rates within the district are approximately equivalent to their respective mortality rates for Virginia. Barriers preventing improved cancer treatment stem from the district's rural location, lower than average median household income, and its historical association with tobacco. This assessment utilized information gathered from federal, state, and local sources. Interviews conducted with clinicians and community focus groups (which consisted of both cancer survivors and the general population) provided a framework of community concerns. The confluence of information from all these sources confirmed that there are significant healthcare resources for the care of cancer patients and their families, and identified several areas of need, which, if addressed, could improve cancer care in the CVHD.

The CVHD encompasses approximately 1600 square miles and contains approximately 218,613 residents, with large areas classified as medically underserved. Compared to Virginia averages, unemployment is higher, median household income is lower, and the population has fewer years of education. Additionally, transportation costs and infrastructure are significant barriers to the access of adequate healthcare. High quality healthcare infrastructure is present in the health district, but is concentrated in higher populated areas and is difficult to access for the majority of the population. Although the general public recognizes the importance of living a healthy lifestyle, the population requires community initiatives and support to increase motivation to institute healthy changes, specifically in the areas of smoking cessation and exercise.

Data for this health district illustrates that the overall cancer incidence rate for individuals in this heath district are comparable to the overall cancer incidence rates for the state of Virginia. Specific age-adjusted cancer incidence rates for gastrointestinal and respiratory cancers are higher than found elsewhere in Virginia. Additionally, identification of early-stage cancers is similar to the rest of Virginia. Healthcare deficiencies recognized by key leader physicians include: (1) need for healthy lifestyle education; (2) proximity of patients to healthcare infrastructure; and (3) financial burdens associated with transportation. Hospice services are viewed as adequate; however, there is a need to recognize the need for palliative care/hospice services earlier in the patient's treatment course. Patients express an overall satisfaction with the health system, but indicate the need for additional patient navigation services. Various community organizations and healthcare navigators are available to aid the patient with traversing the healthcare system. In conclusion, the quality of cancer treatment can be improved in the CVHD by increasing access to cancer screening in rural areas, providing motivation-centered patient education throughout the community, and improving the quality of physician communication for follow-up care of cancer patients returning post-treatment.

# 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 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 plan 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 four community health educators (CHEs) 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 Virginia Department of Health (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 CHEs 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

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

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**).

## *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 the Central Virginia Health District

The CVHD consists of two cities and three counties: Appomattox County, Bedford City, Bedford County, Campbell County, and Lynchburg City. Appomattox County is located approximately 20 miles from Virginia's geographic center. It consists of 333 square miles of gently rolling terrain comprised of one-half of the county being commercial forest land. Approximately 40% of Appomattox County is classified as rural and a medically underserved population.

Bedford County is located in the west-central portion of Virginia's central plateau and consists of 753 square miles of rolling terrain. Its boundaries include the Blue Ridge Mountain on the west, the James River on the northeast, and the Smith Mountain Lake and Staunton River on the south. Bedford County is approximately 40% rural and is considered a medically underserved area. Bedford City consists of seven square miles and is considered rural and also a medically underserved area. Campbell County is located in the foothills of Virginia's beautiful Blue Ridge Mountains, and consists of 504 square miles. It borders Lynchburg to the north and includes the towns of Altavista in the southwest and the town of Brookneal in the southeast. Campbell County is approximately 20% rural and is changing from a previously agricultural community into a mixture of a suburban and rural community (**Figure 1**).

Lynchburg City is nestled in South Central Virginia in the foothills of the Blue Ridge Mountains and consists of 49 square miles. The historic James River bisects the region with the Roanoke River and Smith Mountain Lake situated in the south. The region's two major highways, route 29 and 460 are the corridors for most of the industrial, commercial, and residential development. Lynchburg is considered urban; however, it is also considered a medically underserved area.

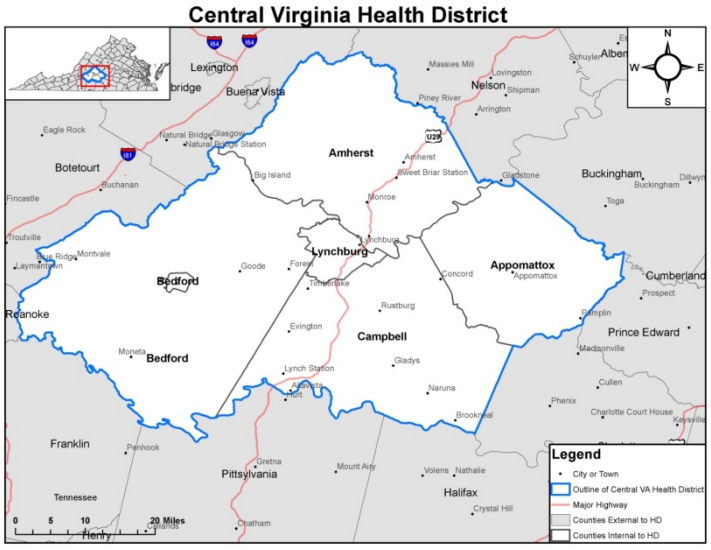


**Figure 1**: Central Virginia Health District

According to the 2011 US Census Bureau information, the Central Virginia Health District has 218,613 residents, which 162,691 are ages 19 or older. There is limited ethnic diversity: nearly 78% of the population is Caucasian, 17% are black, and 5% are "other races". These demographics roughly approximate the demographics for Virginia as a whole. The unemployment

rate for the Central Virginia Health District is 7.9%, ranging from 6% in Bedford County to 10.4% Lynchburg, which is notably higher than the average state unemployment rate of 6.5%. Of the adult population 25 years and over, 33% have a high school diploma or equivalent and 22% have a Bachelor's degree or higher. Adults over the age of 25 years without a high school diploma or equivalent range from 14% in Bedford County to 20% in Appomattox County. Per capita personal income in 2010 ranged from $34,647 in Bedford County to $56,021 in Bedford City (**Table A**, Table **B**).[12] Compared to the rest of Virginia, the population is less educated and has a lower per capita income.

**Table A**: Demographic Profile of the Central Virginia Health District Versus Virginia

| **Demographic Profile of Central Virginia vs. Virginia** | | | |
|---|---|---|---|
| **Category** | **Subcategory** | **Central Virginia** | **Virginia** |
| **Gender** | Male | 48% | 49% |
| | Female | 52% | 51% |
| **Age** | 0-19 | 26% | 26% |
| | 20-34 | 19% | 21% |
| | 35-54 | 27% | 29% |
| | 55-64 | 13% | 12% |
| | 65+ | 15% | 12% |
| **Race** | White | 79% | 70% |
| | Black or AA | 18% | 19% |
| | Other | 4% | 11% |
| **Ethnicity** | Hispanic or Latino | 2% | 8% |
| | Non-Hispanic or Latino | 98% | 92% |

[12] http://factfinder.census.gov/ accessed October 27, 2011.

**Table B**: Economic Characteristics of Central Virginia Health District Versus Virginia

| Economic Characteristics of Central Virginia vs. Virginia | | Central Virginia (average) | Virginia |
|---|---|---|---|
| **Unemployment**[13] | Unemployment rates | 7.9% | 6.5% |
| **Income**[14] | Median household income | $44,461 | $63,302 |
| **Education**[15] | % Less than high school | 16% | 13% |
| | % High school or GED | 33% | 26% |
| | % Some college, no degree or an Associate's degree | 28% | 27% |
| | % Bachelor's degree or above | 22% | 34% |

## *Access to Healthcare*

The counties comprising the Central Virginia Health District are partially rural and medically underserved. All counties and the City of Lynchburg are federally designated as medically underserved areas (all or in part),[9] with the exception of Appomattox County, which is designated as a medically underserved population. Two hospitals are located within the health district (**Figure 2**).

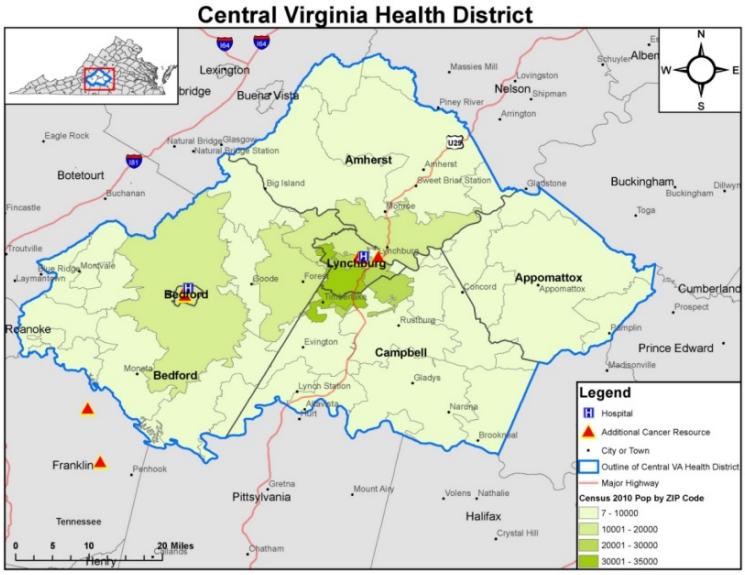


**Figure 2**: Healthcare Resources in the Central Virginia Health District

[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.

# Cancer Burden

## *Cancer Incidence*

Cancer incidence was calculated for the Central Virginia Health District for all cancer types and 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 groupings included respiratory, gastrointestinal, hematologic malignancies, urinary system, brain, nervous system, eye, oral cavity, pharynx, and other cancers. Cancer incidence rates are age adjusted.

**Table C**: Age-Adjusted Cancer Incidence in Central Virginia Health District Versus Virginia

| Age-Adjusted Cancer Incidence Rates in Central Virginia Health District vs. Virginia | | | |
|---|---|---|---|
| **Cancer Site** | **Central Virginia** | **Virginia** | ***Notes*** |
| **Male Genital System** | **165.0** | **167.7** | *Data Source: Virginia Cancer Registry (averaged rates for1999-2008) – all rates calculated based on populations including all ages.* |
| Prostate | 159.7 | 162.0 | |
| Other male genital organs | 5.2 | 5.7 | |
| **Female Breast** | **124.2** | **124.3** | |
| **GI System** | **86.8** | **79.8** | *Dataset ordered by descending rate for health district.* |
| Colon & Rectum | 54.3 | 47.5 | |
| All Other GI | 32.5 | 32.3 | |
| **Respiratory** | **83.0** | **72.5** | *Age-Adjusted Rate - represents an age-adjusted number of new cancer cases per 100,000 populations.* |
| **Gynecological** | **47.5** | **44.4** | |
| Corpus and Uterus | 23.1 | 21.8 | |
| Ovary | 13.2 | 12.1 | |
| Cervix | 7.7 | 7.2 | *Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females.* |
| All other Gynecological | 3.5 | 3.4 | |
| **Heme-malignancies** | **36.6** | **34.3** | |
| Lymphomas | 20.6 | 19.5 | |
| Leukemias | 10.7 | 9.7 | |
| Myeloma | 5.3 | 5.2 | |
| **Urinary System** | **32.9** | **32.4** | |
| **Oral Cavity, Pharynx** | **10.9** | **10.3** | |
| **Brain, Nervous System, Eye** | **7.1** | **6.5** | |
| **All Other Sites** | **42.3** | **44.5** | |
| **All Sites** | **466.7** | **446.6** | |

**Table C** compares age-adjusted cancer incident rates in Central Virginia to those of Virginia as a whole. The overall cancer incidence rate of the health district is higher than that for Virginia. When comparing cancer-specific incidence rates, those with higher incidence include: colon/rectal cancers, respiratory cancer, gynecological cancers (all forms), and heme-malignancies (all forms).

**Figure 3** displays age-adjusted cancer incident rates with corresponding standard errors for both Central Virginia and the Commonwealth of Virginia. The overall incidence rates for all cancer sites are significantly higher in Central Virginia. Furthermore, specific cancer rates are higher for gastrointestinal cancers and respiratory cancers.

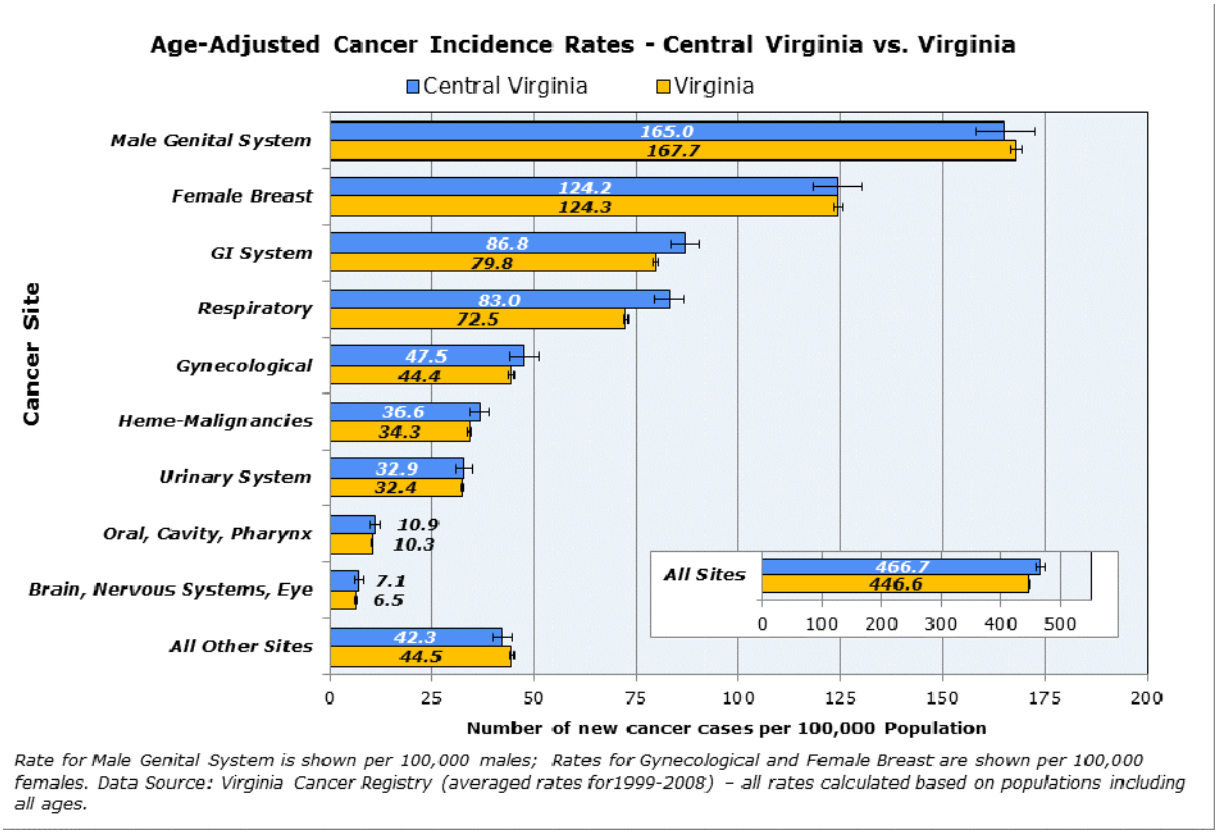


**Figure 3**: Age-Adjusted Cancer Incidence Rate in the Central Virginia Health District Versus Virginia

To evaluate the impact of cancer in the community, in terms of provider burden and services needed, information on the annual number of cancer cases diagnosed was acquired from the Virginia Cancer Registry.

**Table D** and **Figure 4** display average cancer counts per year between 1999 and 2008. The average number of cancer diagnosis per year over this time span is 1,276 cases. When examining cancer by gender, males have a higher average number of cancer diagnoses per year than females (608.9 for men vs. 485 for female). For specific cancer types, men have a higher number of cancer diagnoses per year for each cancer type, with the exception of female breast. **Figure 4** shows that the top overall cancer types for the health district are gastrointestinal, respiratory, male genital, and female breast.

**Table D**: Top 5 Cancers in the Central Virginia Health District by Incidence Count

| Top 5 Cancers in Central Virginia Health District by Incidence Count | | |
|---|---|---|
| **Cancer Site** | **Annual Count** | ***Notes*** |
| **GI System** | **239** | *Data Source: Virginia Cancer Registry* |
| Colon & Rectum | 150 | |
| All Other GI | 89 | *Annual Count - represents average number of new cases per year in the health district (averaged over period 1999-2008).* |
| **Respiratory** | **231** | |
| **Male Genital System** | **206** | |
| Prostate | 200 | |
| Other male genital organs | 6 | |
| **Female Breast** | **181** | |
| **Heme-malignancies** | **98** | *All Other Sites include Brain, Nervous System, Eye, Gynecological, Oral Cavity, Pharynx, Urinary System, and Other sites.* |
| Lymphomas | 55 | |
| Leukemias | 28 | |
| Myeloma | 15 | |
| **All Other Sites** | **321** | |
| **All Sites** | **1276** | |

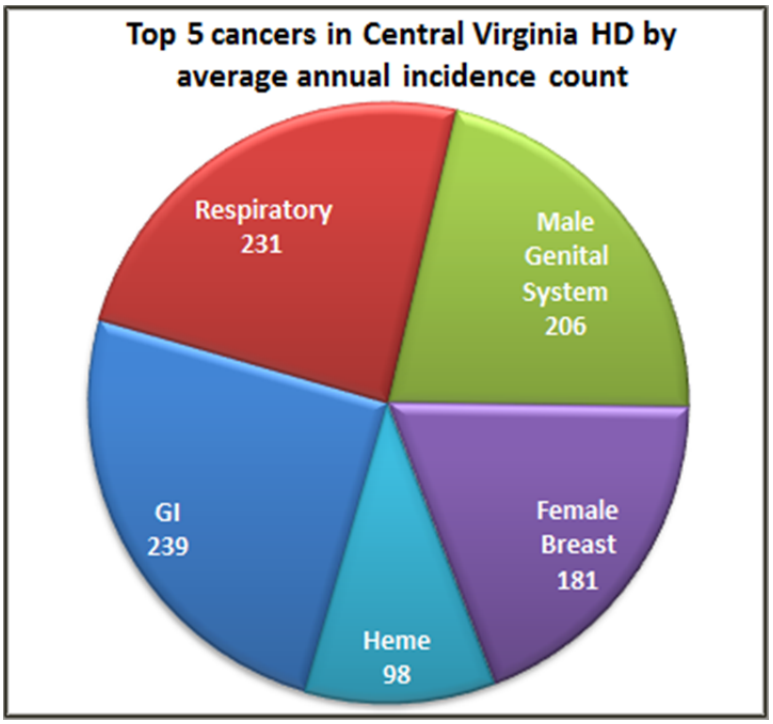


**Figure 4**: Top 5 Cancers in the Central Virginia Health District by Incidence Count[16]

[16] *Data Source: Virginia Cancer Registry Percentage -based on annual cancer cases count (averaged over period1999-2008) for top 5cancers in the health district, as compared to the rest of cancer cases.*

Crude cancer rates and annual cancer counts for the top 5 cancer types in males and females are found in **Tables E** and **F**. Men in Central Virginia have a higher crude cancer rate than women (608.9 vs. 485.2 cases per 100,000). In males, genital cancer (principally prostate) has the highest crude incidence rate, which is followed by the incidence rates of respiratory and gastrointestinal cancers. In females, breast cancer has the highest crude incidence rate, which is followed by the incidence rates for gastrointestinal and respiratory cancers.

**Figures 5** and **6** graphically display the annual cancer counts for the top 5 cancer types for men and women, respectively. For men, genital, respiratory, and gastrointestinal cancer counts make up more than two-thirds of all new cancers. For women, breast, gastrointestinal, and respiratory cancer counts comprise the majority of new cancers.

**Table E**: Top 5 Male Cancers in the Central Virginia Health District

| Top 5 Male Cancers in Central Virginia | | | |
|---|---|---|---|
| **Cancer Site** | **Crude Rate** | **Annual Count** | ***Notes*** |
| **Male Genital System** | **183.2** | **206** | *Data Source:* *Virginia Cancer Registry* |
| Prostate | 178.1 | 200 | |
| Other male genital organs | 5.1 | 6 | *Crude Rate – represents number of new male cancer cases per 100,000 males.* |
| **Respiratory** | **126.5** | **142** | |
| **GI System** | **116.1** | **131** | |
| Colon & Rectum | 69.2 | 78 | *Annual Count - represents average number of new male cancer cases per year in the health district (averaged over period 1999-2008).* |
| All Other GI | 46.9 | 53 | |
| **Urinary System** | **56.6** | **64** | |
| **Heme-malignancies** | **47.2** | **53** | |
| Lymphomas | 25.4 | 29 | |
| Leukemias | 14.4 | 16 | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.* |
| Myeloma | 7.4 | 8 | |
| **All Other Sites** | **79.3** | **89** | |
| **All Sites** | **608.9** | **685** | |

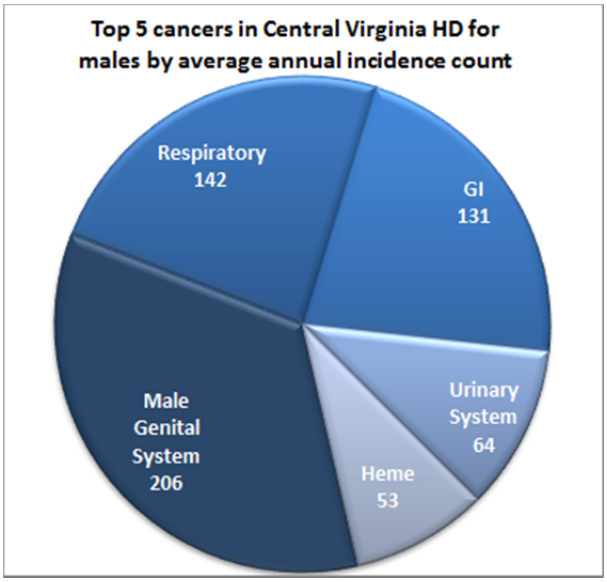


**Figure 5**: Top 5 Male Cancers in the Central Virginia Health District

**Table F**: Top 5 Female Cancers in the Central Virginia Health District

| Top 5 Female Cancers in Central Virginia | | | |
|---|---|---|---|
| **Cancer Site** | **Crude Rate** | **Annual Count** | ***Notes*** |
| **Female Breast** | **148.5** | **181** | *Data Source: Virginia Cancer Registry* |
| **GI System** | **88.8** | **108** | |
| Colon & Rectum | 58.8 | 72 | *Crude Rate – represents number of new female cancer cases per 100,0000 females.* |
| All Other GI | 30.0 | 37 | |
| **Respiratory** | **72.8** | **89** | |
| **Gynecological** | **57.0** | **70** | *Annual Count - represents average number of new female cancer cases per year in the health district (averaged over period 1999-2008).* |
| Corpus and Uterus | 28.6 | 35 | |
| Ovary | 16.2 | 20 | |
| Cervix | 8.0 | 10 | |
| All other Gynecological | 4.3 | 5 | |
| **Heme-malignancies** | **36.9** | **45** | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.* |
| Lymphomas | 21.7 | 27 | |
| Leukemias | 9.9 | 12 | |
| Myeloma | 5.3 | 6 | |
| **All Other Sites** | **81.2** | **98** | |
| **All Sites** | **485.2** | **591** | |

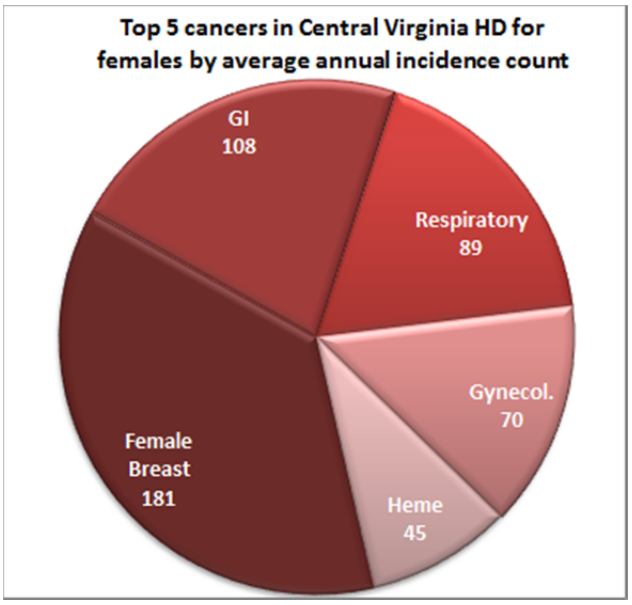


**Figure 6**: Top 5 Female Cancers in the Central Virginia Health District

Cancer counts over a 10-year period and corresponding age-adjusted incidence rates for the top five most common cancers affecting the African American population are found in **Table G**. Compared to the African American population of Virginia, there is a higher age-adjusted cancer incidence rate for African Americans in the health district (495.1 vs. 472.4). Incidence rates for gastrointestinal, respiratory, and heme-malignancy cancers are higher for African Americans in the health district when compared to rates for African Americans in Virginia.

**Table G**: Top 5 Cancers in Central Virginia for the African American Population

| Top 5 Cancers in Central Virginia for African American Population | | | | |
|---|---|---|---|---|
| **Cancer Site** | **10-year case count** | **Age Adjusted Incidence Rate** | | ***Notes*** |
| | | **Central Virginia** | **Virginia** | |
| **Male Genital System** | **417** | **238.6** | **245.7** | *Data Source: Virginia Cancer Registry* |
| Prostate | 415 | 237.4 | 243.6 | |
| Other male genital organs | 2 | 1.2 | 2.1 | *10-year case count – represents number of new cancer cases reported to the registry for African American population from 1999-2008.* |
| **Female Breast** | **269** | **114.4** | **122.4** | |
| **GI System** | **456** | **111.0** | **101.2** | |
| Colon & Rectum | 265 | 65.1 | 57.2 | *Age-Adjusted Incidence Rate represents age-adjusted cancer incidence rate for African American population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Incidence Rate.* |
| All Other GI | 191 | 45.9 | 44.0 | |
| **Respiratory** | **376** | **91.2** | **78.0** | |
| **Heme-malignancies** | **162** | **39.4** | **32.9** | |
| Lymphomas | 74 | 17.7 | 14.8 | |
| Leukemias | 45 | 11.0 | 8.3 | |
| Myeloma | 43 | 10.6 | 9.8 | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.* |
| **All Other Sites** | **366** | **88.3** | **88.2** | |
| **All Sites** | **2046** | **495.1** | **472.4** | |

Compared to the Caucasian population for Virginia, the age-adjusted cancer incidence rates for Caucasians in the health district is higher than the rates for Virginia (461.4 v 442.4). The age-adjusted cancer incidence rates for Caucasian male genital and female breast cancers within the health district are roughly equivalent to their corresponding rates for Caucasians in Virginia. However, the age-adjusted cancer incidence rates for gastrointestinal, respiratory, and gynecological cancers within the health district are higher than Virginia rates (**Table H**).

**Table H**: Top 5 Cancers for the White Population

| Top 5 Cancers in Central Virginia for White Population | | | | |
|---|---|---|---|---|
| **Cancer Site** | **10-year case count** | **Age Adjusted Incidence Rate** | | ***Notes*** |
| | | **Central Virginia** | **Virginia** | |
| **Male Genital System** | **1626** | **152.6** | **152.6** | *Data Source: Virginia Cancer Registry*<br><br>*10-year case count – represents number of new cancer cases reported to the registry for White population from 1999-2008.*<br><br>*Age-Adjusted Incidence Rate represents age-adjusted cancer incidence rate for White population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Incidence Rate.*<br><br>*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Heme-malignancies, Urinary System, and Other sites.* |
| Prostate | 1571 | 146.4 | 145.9 | |
| Other male genital organs | 55 | 6.2 | 6.8 | |
| **Female Breast** | **1525** | **126.1** | **125.3** | |
| **GI System** | **1911** | **82.2** | **75.1** | |
| Colon & Rectum | 1221 | 52.4 | 45.7 | |
| All Other GI | 690 | 29.8 | 29.3 | |
| **Respiratory** | **1919** | **81.5** | **72.5** | |
| **Gynecological** | **596** | **49.5** | **45.4** | |
| Corpus and Uterus | 299 | 24.0 | 22.5 | |
| Ovary | 171 | 13.8 | 12.7 | |
| Cervix | 81 | 8.1 | 6.7 | |
| All other Gynecological | 45 | 3.7 | 3.5 | |
| **All Other Sites** | **3030** | **134.3** | **134.1** | |
| **All Sites** | **10607** | **461.4** | **442.4** | |

When comparing **Tables G** and **H**, the age-adjusted cancer incidence rates for all cancers sites combined is higher in the African American population. Furthermore, African Americans have higher incidence rates for male genital, gastrointestinal, and respiratory cancers, and Caucasians have a higher rate of female breast cancer.

The relative burden of the various cancer types in African American and Caucasian residents of the health district is distinct. Whereas male genital and gastrointestinal cancers represent 42% of the cancer incident burden in African American residents, cancers from all other sites represent the largest cancer burden in Caucasians (**Figure 7**).

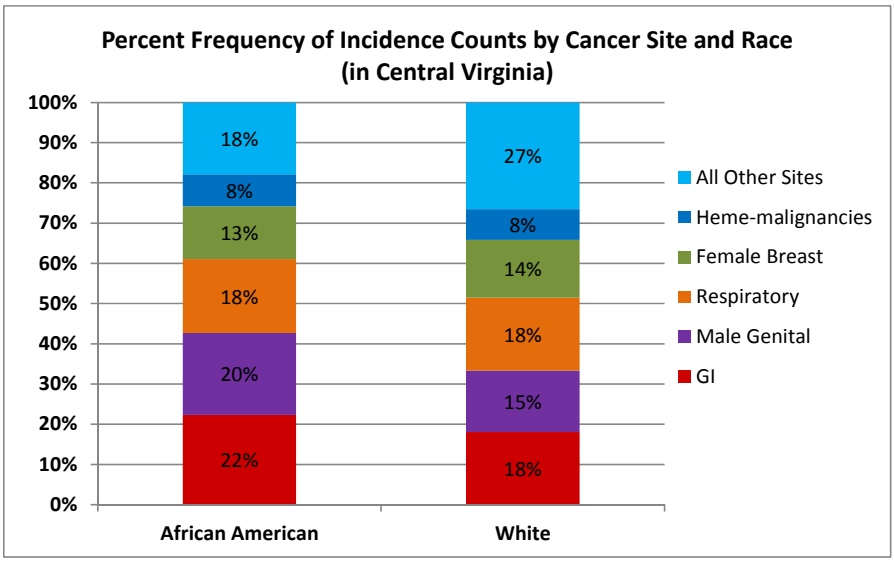


**Figure 7**: Percent Frequency of Incidence Counts by Cancer Site and Race in the Central Virginia Health District

## *Cancer Staging and Mortality*

**Figure 8** compares cancer staging results of the Central Virginia Health Districts to Virginia results. Finding cancer earlier leads to improved prognosis and better treatment outcomes. Overall, screening results within the district are comparable to those for the state. Of note, the percentage of patients being diagnosed with oral and neck cancers at an early stage is higher for the health district. Also, the percentage of patients being diagnosed with heme-malignancies at an early stage is lower than the state rates.

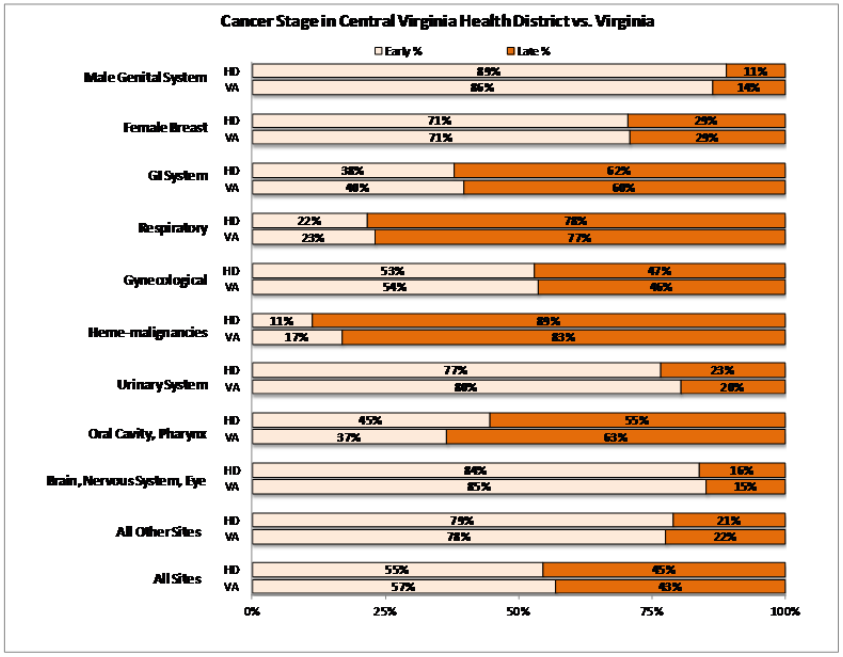


**Figure 8**: Cancer Stage at Diagnosis: Central Virginia Health District Versus Virginia[17]

[17] ***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*

An average of 563 residents in the Central Virginia Health District succumb to cancer-related deaths each year (**Table I**). The five cancers resulting in the greatest number of deaths in the health district are respiratory, gastro-intestinal, heme-malignancies, female breast and the male genital system cancers. Similar to cancer age-adjusted incidence rates, the health district has a higher cancer mortality rate than Virginia for respiratory, gastrointestinal and heme-malignancies, with respiratory cancer mortality rates significantly higher (**Figure 9**).

**Table I:** Top 5 Cancers in Central Virginia by Death Count

| Top 5 Cancers in Central Virginia by Annual Death Count | | |
|---|---|---|
| **Cancer Site** | **Annual Count** | ***Notes*** |
| **Respiratory** | **185** | *Data Source: Virginia Department of Health (averaged counts for 5-year period 2005-2009) - based on population for all ages.*<br><br>*Dataset ordered by descending death counts for health district.* |
| **GI System** | **120** | |
| All Other GI | 66 | |
| Colon & Rectum | 54 | |
| **Heme-malignancies** | **46** | |
| Lymphomas | 22 | |
| Leukemias | 13 | |
| Myeloma | 12 | |
| **Female Breast** | **38** | |
| **Male Genital System** | **27** | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.* |
| Prostate | 26 | |
| Other male genital organs | 0 | |
| **All Other Sites** | **147** | |
| **All Sites** | **563** | |

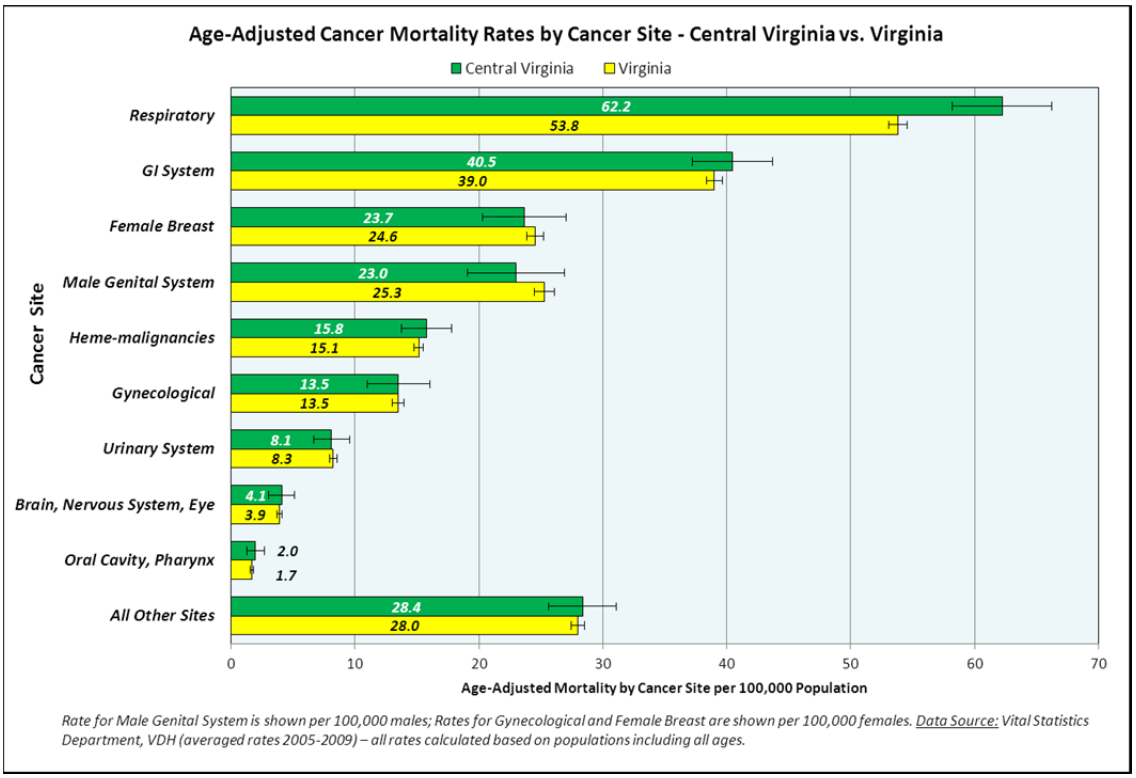


**Figure 9**: Age-Adjusted Cancer Mortality Rate in Central Virginia Versus Virginia

**Figures 10** and **11** depict the average number of cancer deaths per year for men and women, respectively. More men of the Central Virginia Health District succumb to cancer than women annually (302 deaths per year vs. 262 deaths per year). Respiratory and gastrointestinal cancers cause the greatest number of deaths per year in both men and women.

The age-adjusted mortality rates for the top 5 cancers among males in Central Virginia reveal that respiratory cancer has the highest mortality rate (94.4 per 100,000) followed by gastrointestinal cancers (57.1 per 100,000). These two cancer types make up 58.6% of the total average annual male cancer deaths in the Central Virginia Health District (**Table J**, **Figure 10**).

Similar to men, the cancers representing the greatest mortality burden in women are respiratory (95.4 per 100,000), and gastrointestinal (42.4 per 100,000) cancers. These two cancers make up 48.8% of the total average annual female cancer deaths. Female breast cancer mortality represents 14.5% of the female cancer deaths in the health district (**Table K**, **Figure 11**).

Comparing the cancer mortality rates between males and females shows that the top two cancer types are respiratory and gastrointestinal cancers. For these cancers, males have a higher mortality rate than females, with the rate of respiratory cancer deaths per year for men notably higher than that for women (94.4 vs 59.4).

**Table J**: Top 5 Male Cancers in Central Virginia by Mortality

| Top 5 Male Cancers in Central Virginia by Mortality | | | |
|---|---|---|---|
| **Cancer Site** | **Crude Rate** | **Annual Count** | ***Notes*** |
| **Respiratory** | **94.4** | **110** | *Data Source:* |
| **GI System** | **57.1** | **67** | *Virginia Department of Health (2005-2009) – rates calculated based on population for all ages.* |
| All Other GI | 32.9 | 38 | |
| Colon & Rectum | 24.2 | 28 | |
| **Male Genital System** | **22.8** | **27** | *Dataset ordered by descending count for health district.* |
| Prostate | 22.4 | 26 | |
| Other male genital organs | 0.3 | 0 | *Crude Rate - represents number of male cancer deaths per 100,000 males.* |
| **Heme-malignancies** | **20.9** | **24** | |
| Lymphomas | 9.6 | 11 | *Annual Count - represents average number of male cancer deaths per year in the health district (averaged over period 2005-2009).* |
| Leukemias | 6.5 | 8 | |
| Myeloma | 4.8 | 6 | |
| **Urinary System** | **14.4** | **17** | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.* |
| **All Other Sites** | **48.8** | **57** | |
| **All Sites** | **258.4** | **302** | |

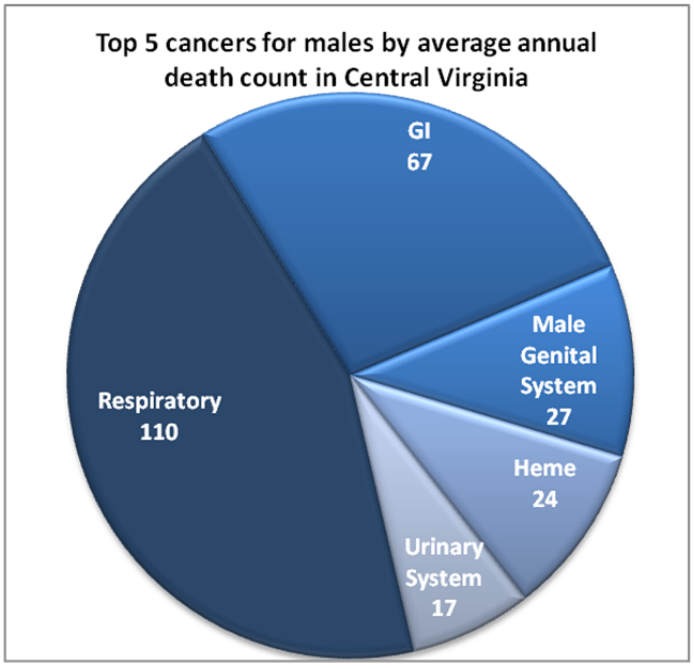


**Figure 10**: Top 5 Cancers Causing Death in Males

**Table K**: Top 5 Female Cancers in Central Virginia by Mortality

| Top 5 Female Cancers in Central Virginia by Mortality | | | |
|---|---|---|---|
| **Cancer Site** | **Crude Rate** | **Annual Count** | ***Notes*** |
| **Respiratory** | **59.4** | **75** | *Data Source:* |
| **GI System** | **42.4** | **53** | *Virginia Department of Health (2005-2009) – rates calculated based on population for all ages.* |
| All Other GI | 21.9 | 28 | |
| Colon & Rectum | 20.5 | 26 | |
| **Female Breast** | **30.5** | **38** | *Dataset ordered by descending count for health district.* |
| **Gynecological** | **17.5** | **22** | |
| Ovary | 10.5 | 13 | *Crude Rate - represents number of female cancer deaths per 100,000 females.* |
| Cervix | 3.0 | 4 | |
| Corpus and Uterus | 2.5 | 3 | |
| All other Gynecological | 1.4 | 2 | *Annual Count - represents average number of female cancer deaths per year in the health district (averaged over period 2005-2009).* |
| **Heme-malignancies** | **17.2** | **22** | |
| Lymphomas | 8.3 | 10 | |
| Myeloma | 4.8 | 6 | |
| Leukemias | 4.1 | 5 | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.* |
| **All Other Sites** | **41.0** | **52** | |
| **All Sites** | **207.9** | **262** | |

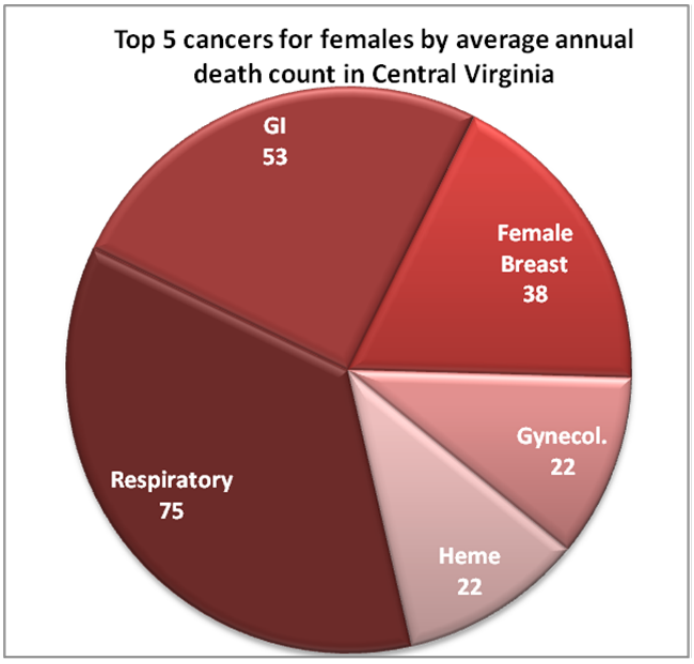


**Figure 11**: Top 5 Cancers Causing Death in Females

### *Race-Based Mortality Rates*

The top five cancers causing mortality in the African American residents of the health district are gastrointestinal, respiratory, male genital, female breast and heme-malignancies, in that order. The mortality rate for African Americans for cancers from all sites taken together is approximately equal to the mortality rates for African Americans in Virginia. Site-specific cancer mortality rates for African Americans in the health district show some distinction, however, when compared to mortality rates of African Americans in the state as a whole. Specifically, gastrointestinal, and respiratory cancer mortality rates are higher in the CVHD than the state, and male genital and female breast cancer mortality rates are lower in the CVHD than the state.

**Table L**: Top 5 Cancers by Mortality for the African American Population in Central Virginia

| Top 5 Cancers by Mortality for African American Population in Central Virginia | | | | |
|---|---|---|---|---|
| **Cancer Site** | **5-Year Death Count** | **Age Adjusted Mortality Rate** | | ***Notes*** |
| | | **Central Virginia** | **Virginia** | |
| **GI System** | **150** | **66.9** | **54.9** | *Data Source:* *Virginia Department of Health (2005 - 2009).* |
| All Other GI | 86 | 38.0 | 31.2 | |
| Colon & Rectum | 64 | 29.0 | 23.6 | |
| **Respiratory** | **137** | **62.7** | **59.6** | *5-year death count – represents number of cancer deaths reported for African American population from 2005-2009.* |
| **Male Genital System** | **33** | **45.2** | **51.6** | |
| Prostate | 33 | 45.2 | 51.2 | |
| Other male genital organs | 0 | 0.0 | 0.4 | *Age-Adjusted Mortality Rate - represents age-adjusted cancer mortality rate for African American population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Mortality Rate.* |
| **Female Breast** | **27** | **20.7** | **33.6** | |
| **Heme-malignancies** | **38** | **17.7** | **15.7** | |
| Myeloma | 19 | 8.7 | 7.4 | |
| Lymphomas | 10 | 4.5 | 4.5 | |
| Leukemias | 9 | 4.5 | 3.8 | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.* |
| **All Other Sites** | **108** | **49.0** | **52.6** | |
| **All Sites** | **493** | **223.9** | **220.3** | |

The age-adjusted cancer mortality rates for the Caucasian population within the district are similar to the state rates with the exception of respiratory cancers (**Table M**). Respiratory cancer age-adjusted mortality rates are notably higher for the health district when compared to the state (62.6 vs 54).

The relative burden of various cancer types among Caucasian and African American residents of the health district is depicted in **Figure 12**. For both the African American and Caucasian populations, the combination of respiratory and gastrointestinal cancer makes up greater than 50% of the overall cancer burden. However, gastrointestinal cancer makes up a greater portion of the total cancer burden in the African American population, whereas respiratory cancer makes up a greater portion of the total cancer burden in the Caucasian population.

**Table M**: Top 5 Cancers by Mortality for the White Population in Central Virginia

| Top 5 Cancers by Mortality for White American Population in Central Virginia | | | | |
|---|---|---|---|---|
| **Cancer Site** | **5-Year Death Count** | **Age Adjusted Mortality Rate** | | ***Notes*** |
| | | **Central Virginia** | **Virginia** | |
| **Respiratory** | **785** | **62.6** | **54.0** | *Data Source:* |
| **GI System** | **449** | **36.1** | **36.2** | *Virginia Department of Health (2005 - 2009).* |
| All Other GI | 243 | 19.5 | 20.7 | |
| Colon & Rectum | 206 | 16.6 | 15.5 | *5-year death count – represents number of cancer deaths reported for White population from 2005-2009.* |
| **Female Breast** | **164** | **24.5** | **23.0** | |
| **Male Genital System** | **100** | **20.0** | **21.4** | |
| Prostate | 98 | 19.6 | 21.1 | *Age-Adjusted Mortality Rate - represents age-adjusted cancer mortality rate for White population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Mortality Rate.* |
| Other male genital organs | 2 | 0.4 | 0.4 | |
| **Heme-malignancies** | **192** | **15.5** | **15.2** | |
| Lymphomas | 98 | 7.7 | 6.8 | |
| Leukemias | 55 | 4.6 | 5.0 | |
| Myeloma | 39 | 3.2 | 3.4 | *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.* |
| **All Other Sites** | **625** | **50.2** | **50.0** | |
| **All Sites** | **2315** | **186.0** | **176.3** | |

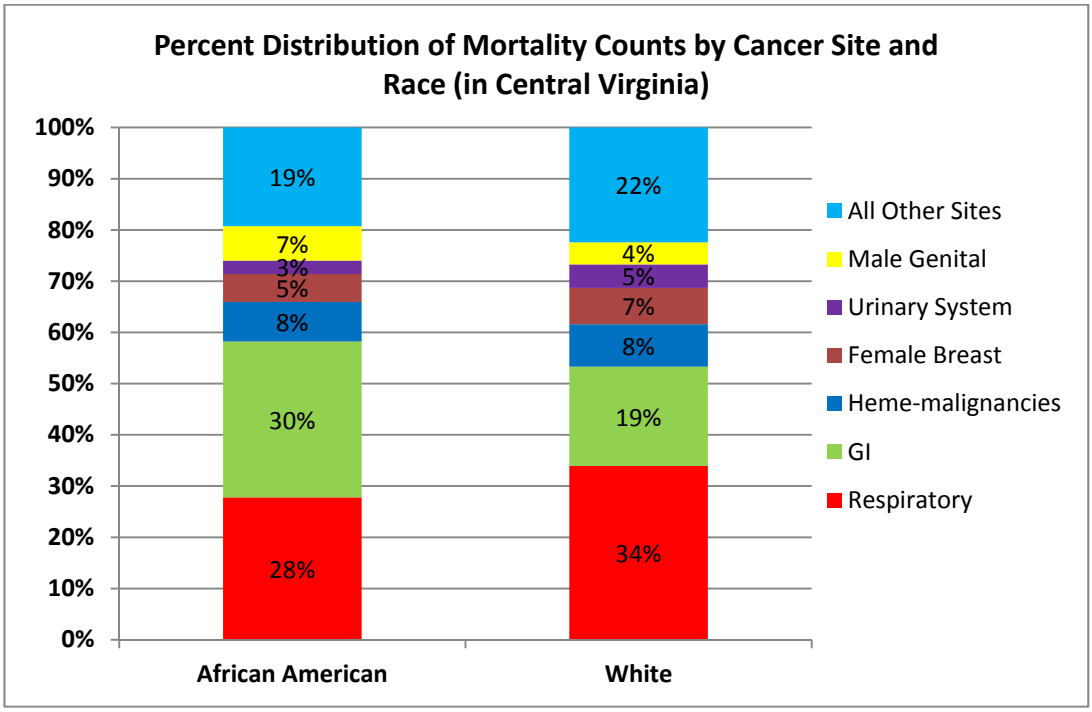


**Figure 12**: Percent Distribution of Mortality Counts by Cancer Site and Race

# Cancer Healthcare Resources

## *Healthcare Facilities and Cancer Care*

The Central Virginia Health District has two large medical facilities that deliver cancer care: Bedford Memorial Hospital and the Alan B. Pearson Regional Cancer Center. The oncology staff at the Bedford Memorial Hospital consists of one visiting medical oncologist. The Alan B. Pearson Regional Cancer Center offers both inpatient and outpatient oncology services in addition to radiation oncology. At the time of writing this assessment, the oncology staff at the Alan B. Pearson Regional Cancer Center consists of eight medical oncologists, three medical oncology nurse practitioners, three radiation oncologists, and two radiation oncology nurse practitioners. Routine cancer screening services, such as mammography and colonoscopy, and surgical oncology services are available at both healthcare facilities. The medical oncology practice has an active cancer clinical research program staffed by a full-time research nurse coordinator and two research associates. The program offers therapeutic and cancer prevention and control research studies to their patients and is part of the Virginia Commonwealth University Massey Cancer Center Research Affiliation Network, which provides research support and access to cutting edge research trials.

Ancillary cancer support services are readily available in the Central Virginia Health District. Patient counseling is available through registered dieticians, genetic counselors, and patient navigators. Furthermore, although the Central Virginia Health District lacks an inpatient palliative care hospital unit, specialist palliative care services are available for hospital consultation.

Hospice services are provided through hospital hospice services as well as private facilities throughout the health district. Key leader providers agreed that the Central Virginia Health District is well served by hospice, even for under and uninsured patients. Hospice services are utilized throughout the district, though mostly for patients in their last weeks of life. There were some areas of concern regarding the use of hospice and the delay in getting more patients admitted in a more effective manner that will maximize the patient and family experience with hospice care. Many are non-profit, absorb the cost for indigent patients, and accept the Medicare benefit for hospice services.

The Alan B. Pearson Regional Cancer Center offers multiple counseling and support services, which include Look Good Feel Good, On Eagles Wings (breast cancer support group), BRCA Mutation Support Group, Woman of Hope, support for anyone currently undergoing treatment or surviving cancer, and a caregiver support group.

Mind and body expressive support services include Off the Needle - PCC Knitting Group, Knitting Sisters, Drawing with Charcoals, Expression with Watercolors, Yoga Classes, Mindful Meditation, and Tai Chi Classes.

# Community Cancer Resources

The Central Virginia Health District hosts a number of cancer-related resources for patients and their families outside of the hospitals and oncology offices. These resources offer an array of services including education, information and some direct services. For additional information on community resources refer to **Appendix E**.

Seven organizations were identified that provided cancer-related services including:

- The American Cancer Society
- Bedford and Gentle Shepherd Hospice
- Discovery Shop West Lake – collaborates with ACS to raise funds for cancer through the sale of donated items.

- Susan G. Komen for the Cure The Cancer Outreach Foundation, located in Abingdon, offers financial and transportation assistance to local cancer patients, as well as emotional counseling to patients going through treatment, and their families.
- The VDH Every Woman's Life Program is managed out of the VDH off, is administered at all of the VDH offices in the health district, and is one of the strongest in the state. This program provides access to screenings for female cancers to income-eligible women. For women diagnosed with cancer under this program, access to treatment is streamlined.
- Alan B. Pearson is the primary service provider for the majority of services throughout the health district. Most organizations had no qualification criteria to receive services, and the services provided included written cancer information, management of cancer support groups, financial support for cancer treatment, and management of projects related to cancer. The VDH is very active in promoting the Every Women's Life Program that provides free screenings for gynecologic and breast cancer to eligible women.

Focus group participants expressed a desire for support groups for cancers other than breast, and more education on cancer prevention and screening, especially in relation to skin, lung, prostate and breast cancer. Because mountainous and winding roads, as well as distances to hospitals from outlying areas of the district make travel at times difficult, providing access to educational activities locally is an area of need.

# Healthcare Provider Needs

## *Key Leader Information*

Six experienced, long-term residents who are health care professionals or intimately involved within their community were interviewed in the Central Virginia Health District to gain a knowledge base of the healthcare system currently in place as relates to cancer care and specifically, any deficiencies therein. These six individuals were selected because they represent all of the four counties (Bedford, Appomattox, Campbell, and Lynchburg) also in the cities of Bedford and Lynchburg all within the Central Virginia Health District. Their credentials include physicians, and registered nurses and a member from the Economic Development. These individuals were asked to identify deficiencies in the health care system first, as relates to cancer risk reduction, detection, treatment, and follow-up care. Second, they were asked to identify deficiencies in primary care physicians specifically for cancer-related continuing education, obstacles in acquiring cancer diagnosis and treatment for patients, post-treatment communication and training needs and knowledge of palliative and hospice care.

The major health care deficiencies identified by these key leaders fell into four categories: (1) education - for physicians, cancer patients, AND the general population, (2) availability and proximity to adequate treatment services, devices, and facilities, (3) financial burdens related to transportation, and time constraints for patients related to work and family responsibilities needing support be it internal or external, and (4) lack of specialists and supporting diagnostics, labs, and communication services.

After meeting with each key leader, the following items were identified:

Physician Education:

- Regular reporting of new cancer cases noting diagnosis trends
- Continuing medical education on updated cancer screening tests and guidelines
- Oncologist orientation to thorough follow-up plan and not continuing to hold onto the patients

Patient Care:

- Streamlined access to financial, medical and supportive services for patients, especially in rural areas
- Utilization of patient-centered care plans to improve patient's understanding and involvement in treatment process
- Improved communication and information transfers between physicians
- Recruit additional physicians corresponding to increasing number of patients

Patient Education:

- Increased patient education on importance of smoking cessation and nutrition
- Increased frequency of community education activities

Tobacco use was universally cited as creating a significant cancer risk in the CVHD. There is an urgent need for educational programs to encourage the promotion of awareness as to the extreme health risks associated with tobacco usage. Also repeatedly cited was the need for education relating to lifestyle choices with specific emphasis on the correlation between lifestyle choices and cancer causative factors. Poor availability of screening services in the surrounding counties as well as a lack of patient urgency to seek screening was also identified as a deterrent to patient care. Additionally, long travel times, lack of dependable transportation and lack of community support for extended family needs of a cancer patient were repeatedly mentioned.

## *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. Fifty-eight physicians in the CVHD completed a cancer questionnaire, either on paper or on-line, which represents a 30% response rate from physicians contacted. Over half of the responding physicians were family practice physicians, with the next largest group being gynecologists. The remainder specialized in internal medicine, public health, surgery, family planning and emergency medicine.

Physicians were questioned about their perceptions of the percentage of their patients that were compliant with routine screening for breast, cervical, and colorectal cancers (**Figure 13**). For each cancer screening category, physicians believe that over half of their patients have either high or above average compliance rates with receiving recommended cancer screening services. Additionally, for each screening category, physicians state that only a small percentage of their patients have low compliance rates. Taken together, physicians believe that their patients in the CVHD are responsive to their cancer screening recommendations.

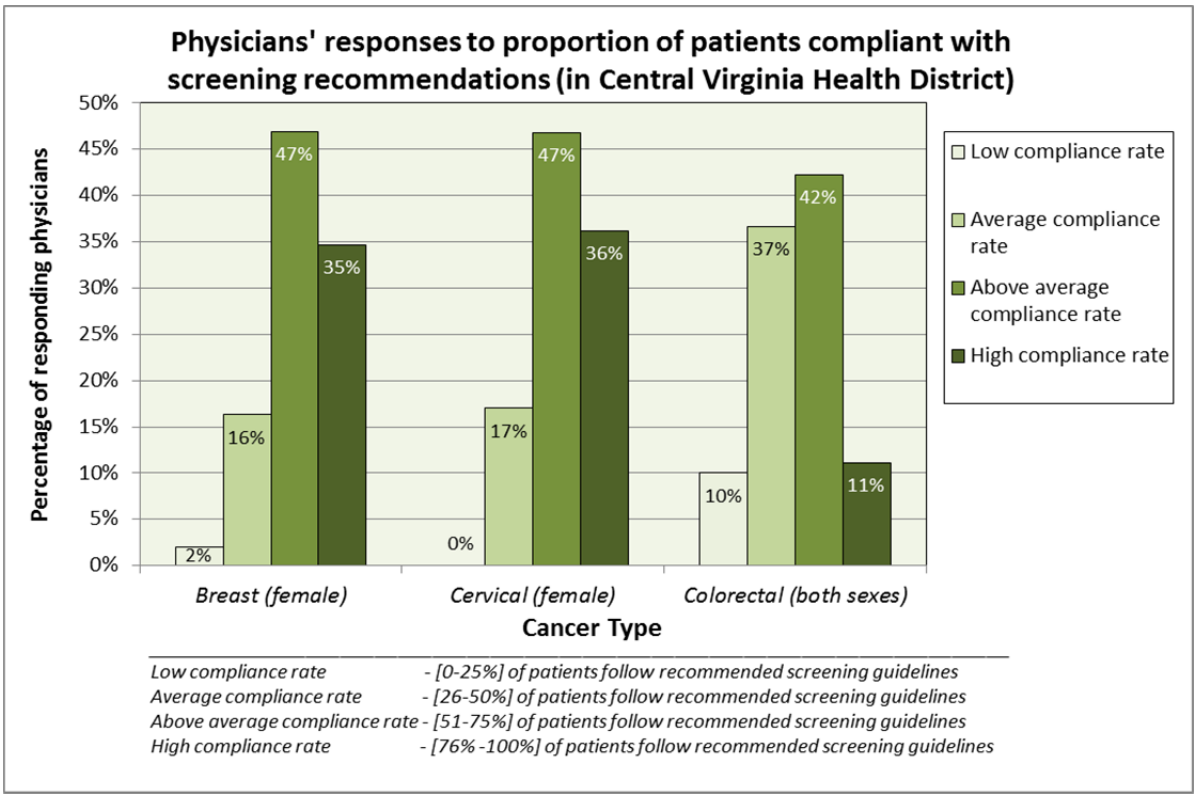


**Figure 13**: Physician's Perception of Percentage of Patients that are Compliant with Screening Recommendations

Physicians were requested to assess the most common barriers preventing patients from receiving recommended cancer screenings (**Figure 14**). Two of the top three reasons they cited involved the inability of patients to financially afford the screenings. In addition to lack of health insurance, additional financial constraints could include the inability to take time additional time off from work or the costs of additional child care. Also of note, only a small percentage of physicians believed that a lack of transportation was a significant barrier, and no physicians cited the lack of screening facilities as a barrier to receiving recommended screening exams.

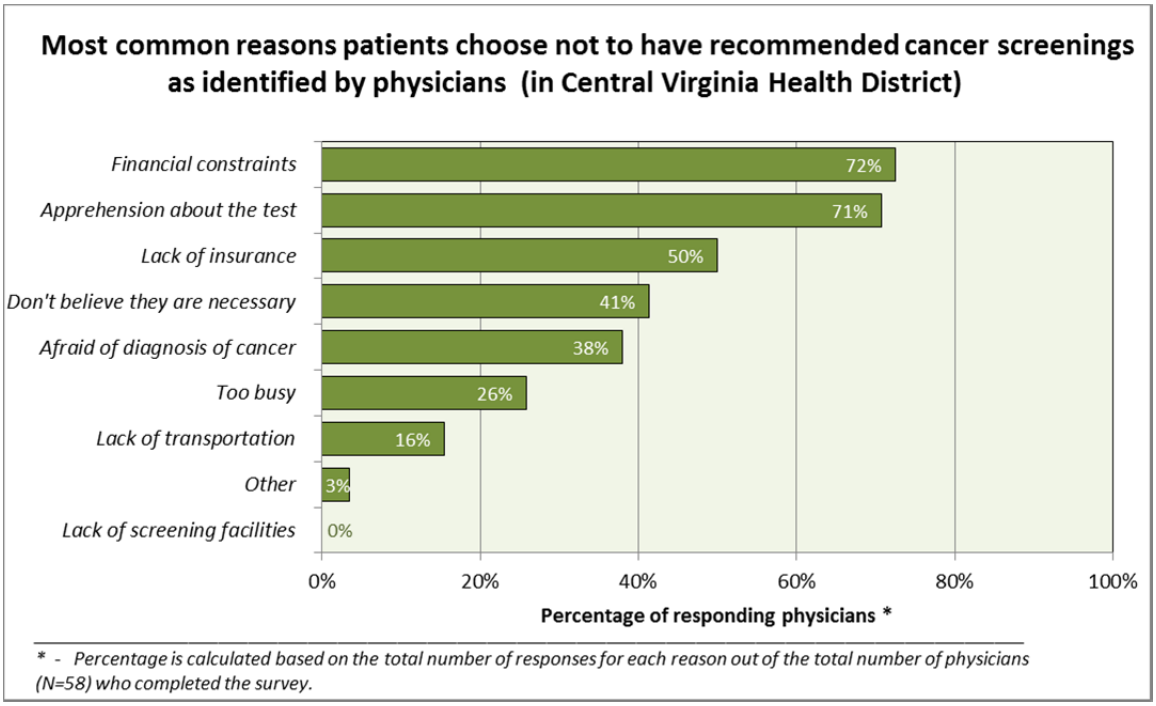


**Figure 14**: Physician's Perception of Reasons That Patients Choose Not To Receive Recommended Cancer Screenings

Physicians were asked about their location preference when seeking sub-specialty medical and surgical oncology services for their patient (**Figure 15**, **Figure 16**). The majority of physicians preferred to refer their patients to subspecialists within their local communities.

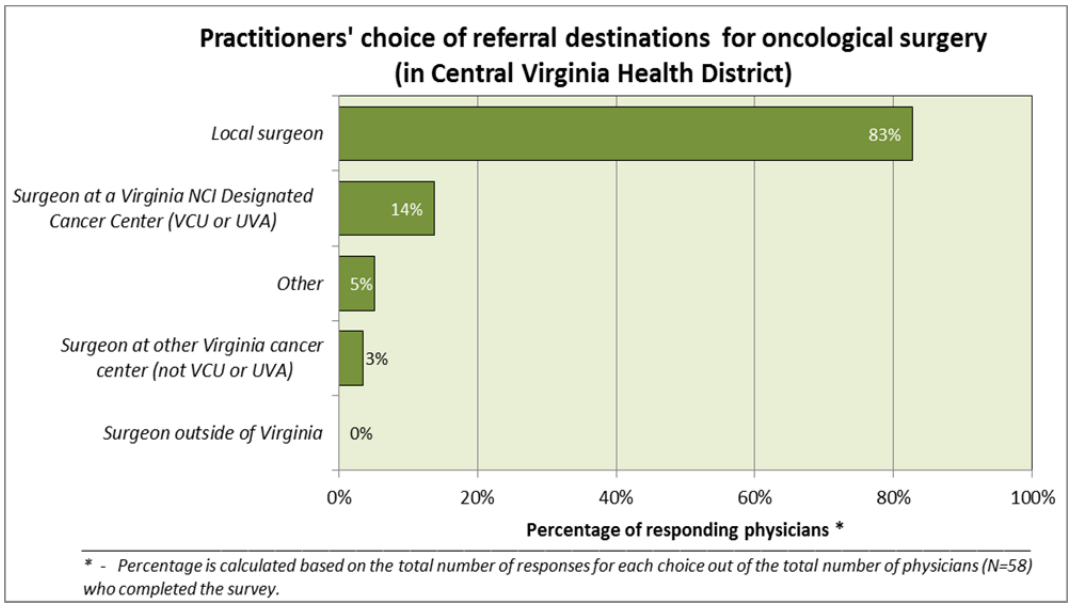


**Figure 15**: Physicians' Preference for Surgical Oncology Referral Location

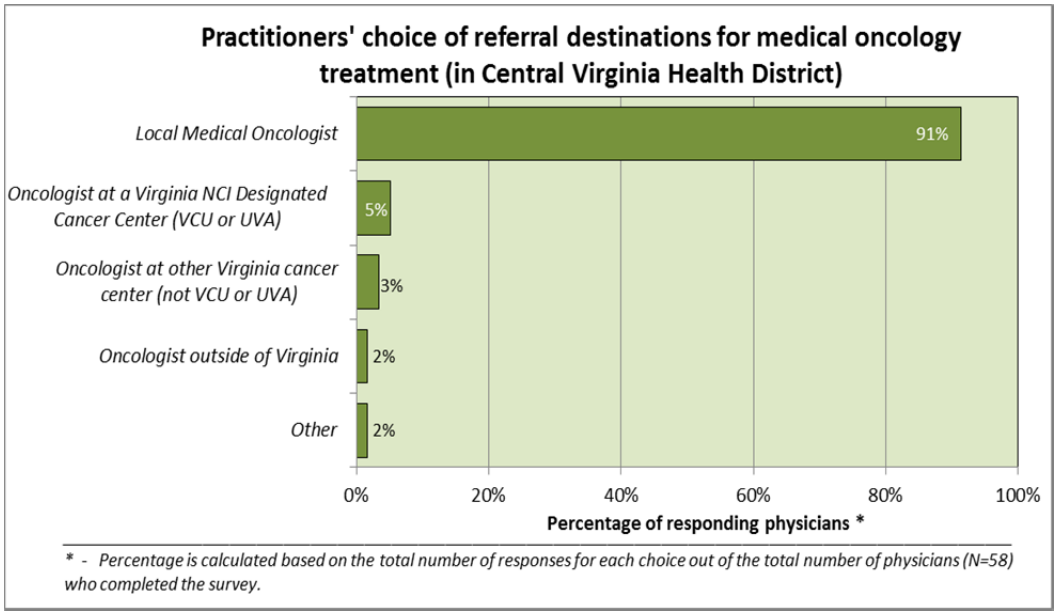


**Figure 16**: Physicians' Preference for Medical Oncology Referral Location

Physicians in the CVHD were asked what types of information is most useful for patient care when receiving a patient from an oncology specialist (**Figure 17**). Physicians surveyed stated that the initial patient admission note with the admitting physician's treatment plan would be most useful for their care. Following as a close second, physicians believed that a patient care plan, would be useful to their practice.

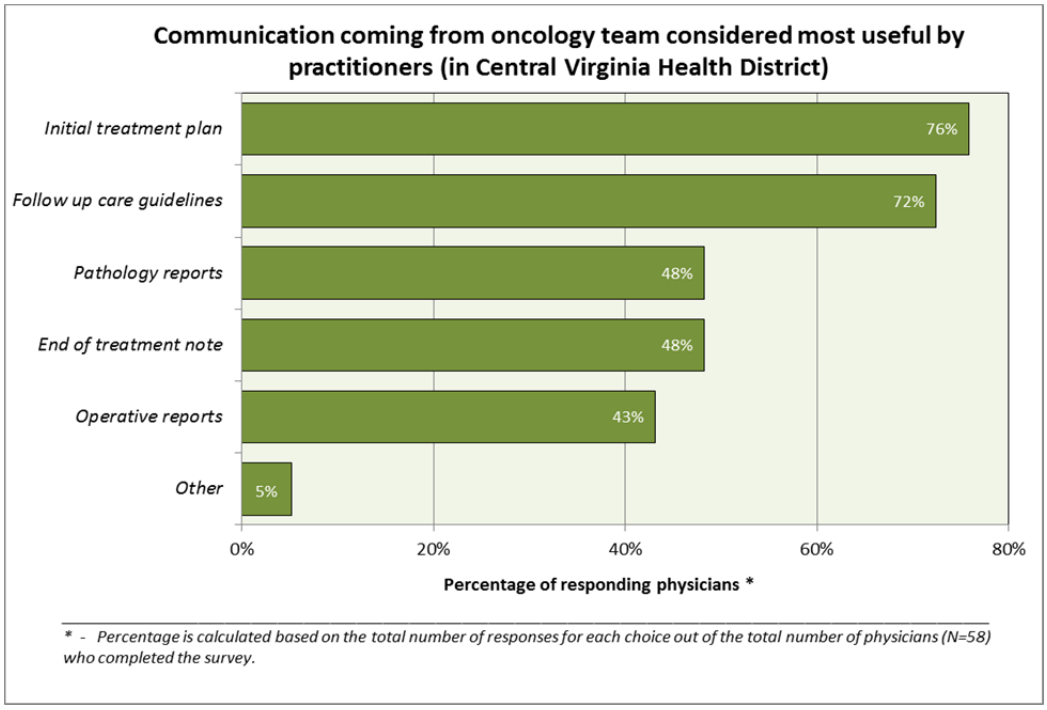


**Figure 17**: Most Useful Information from an Oncology Specialist.

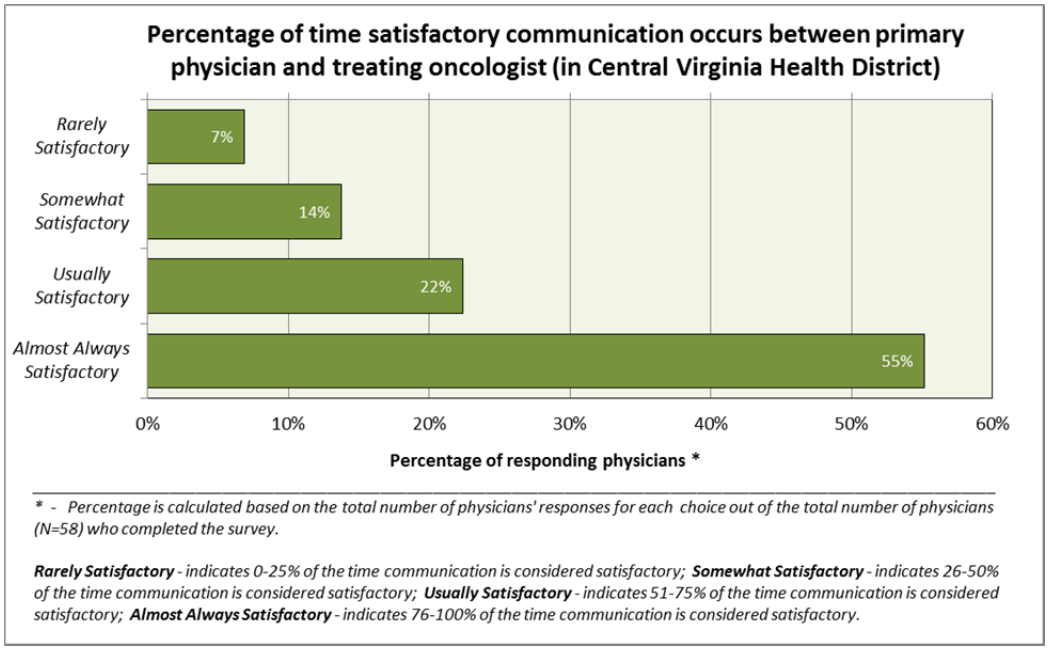


**Figure 18**: Percentage of Satisfactory Communication Between a Patient's Primary Physician and Oncologist

Physicians were queried about the quality of communication that occurs between themselves and their patient's oncology specialists (**Figure 18**). While the percentage of physicians that are "Almost Always Satisfied" with the quality of communication they receive is higher than other health districts in Southern Virginia, nearly half of the physicians surveyed are not "Almost Always Satisfied." Although current policies have shown some success there is still additional room for improvement.

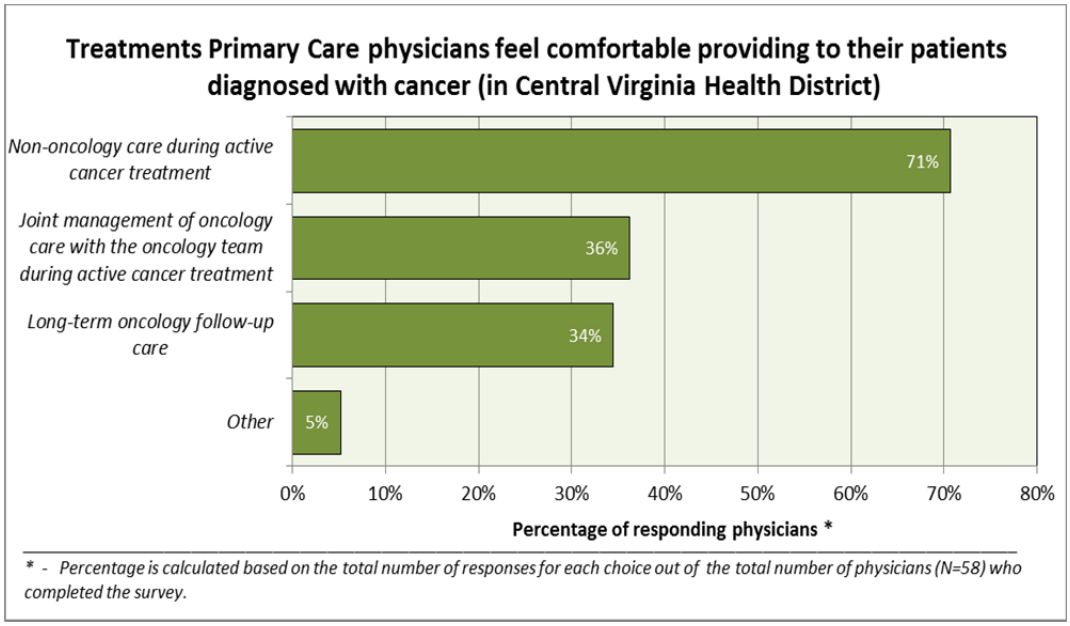


**Figure 19**: Non-Oncology Specialist Comfort Level in Caring for Oncology Patients

**Figures 19** and **20** address physicians comfort level with post-oncology follow-up treatment. **Figure 19** shows that the majority of physicians surveyed are comfortable delivering non-oncology medical treatments post-oncology treatment; however, only a third of physicians surveyed feel comfortable delivering oncology-related follow up. **Figure 20** identifies areas where non-oncology physicians in the CVHD would like additional information. Of note, the majority of physicians would like more education pertaining to signs and symptoms of cancer reoccurrence in patients during post-oncology treatment. Together, these figures show that physicians surveyed would prefer to refer patients back to their oncologist for cancer-related assessment.

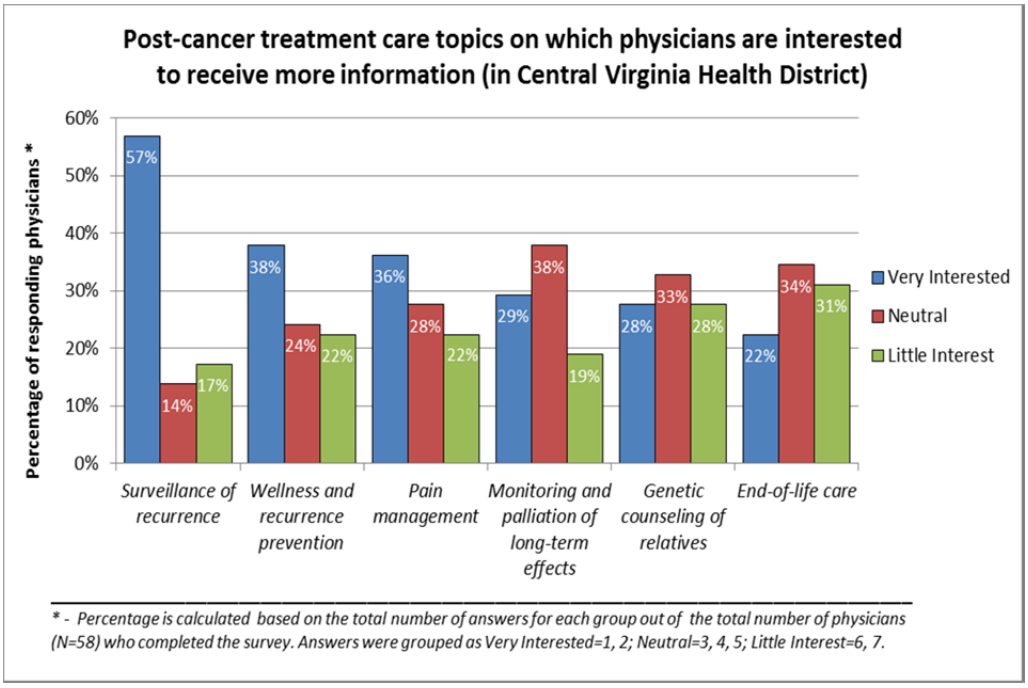


**Figure 20**: Non-Oncology Specialist's Interest in Continuing Oncology Education

Physicians were questioned regarding their preferred method of receiving cancer-related educational materials. The majority of those surveyed would prefer to receive educational materials in a written format.

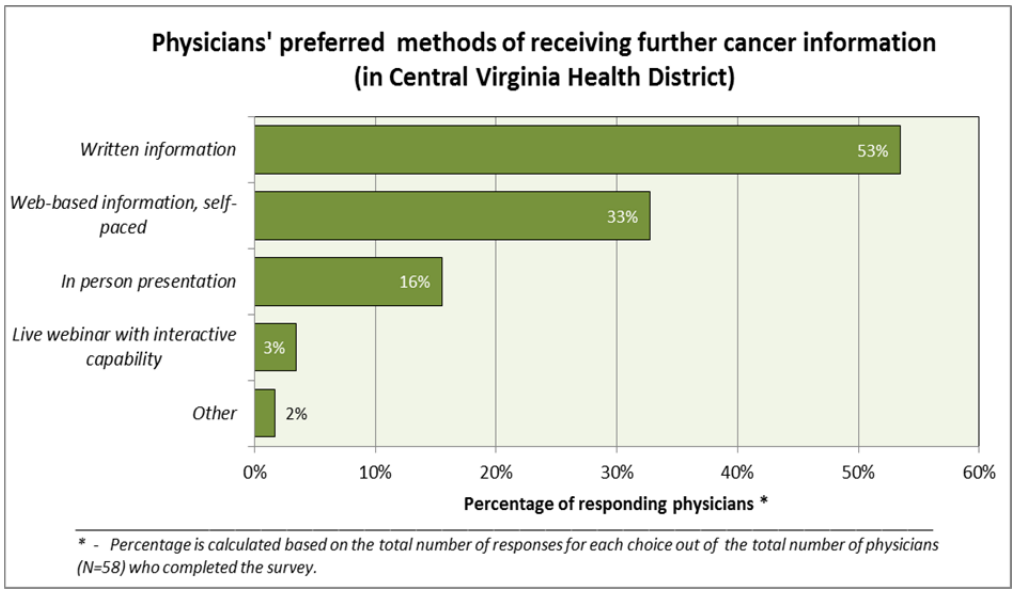


**Figure 21**: Physician's Preferred Method of Receiving Further Cancer Educational Information

Survey questions related to physician's views on oncology clinical trials revealed that the majority of physicians in the CVHD have "little to no knowledge" about the clinical trials being offered within their health district. Physicians are evenly divide on the importance of oncology clinical trials to their everyday clinical practice (**Figures 22**, **23**, and **24**).

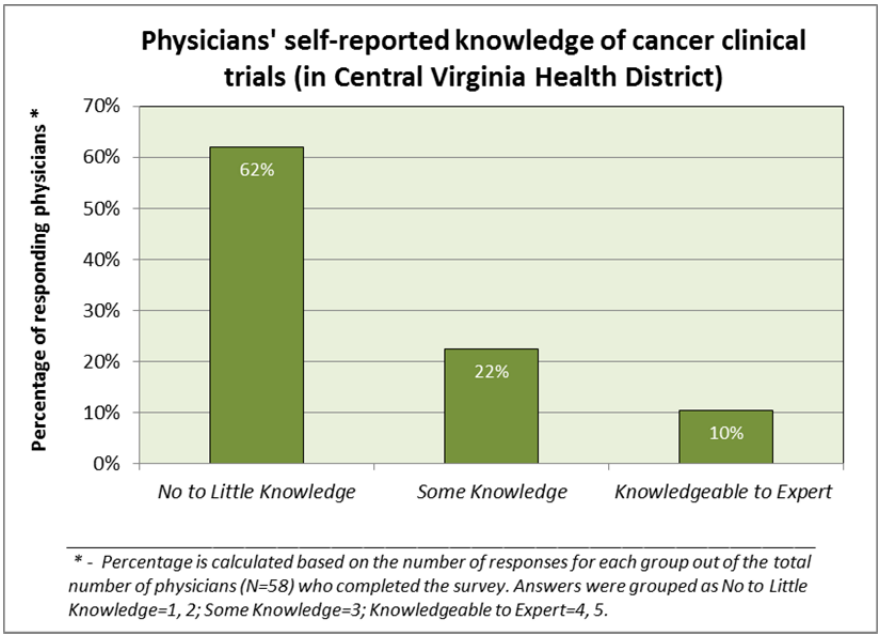


**Figure 22**: Physician's Awareness of Cancer Clinical Trials

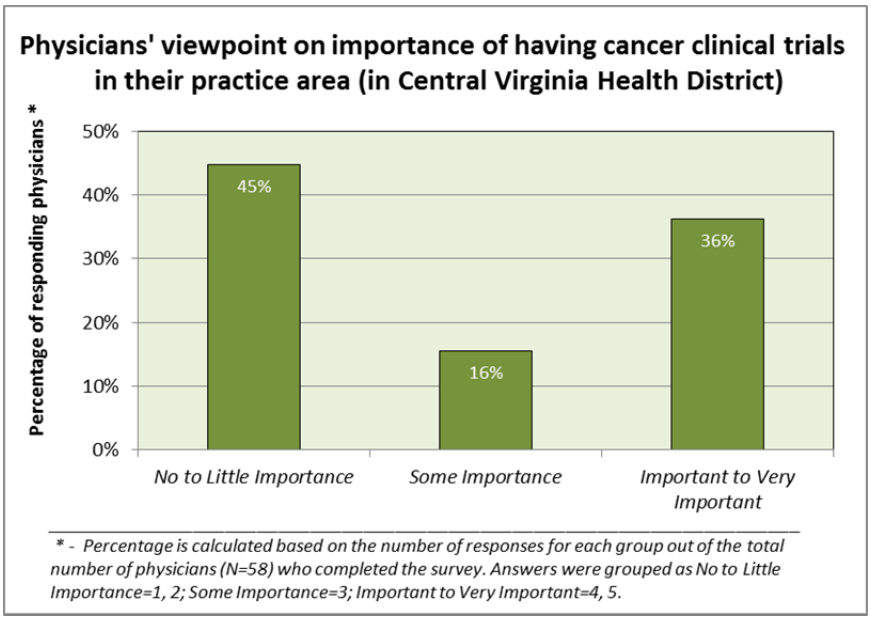


**Figure 23**: Physician Perception on the Importance of the Availability of Clinical Trails within the Central Virginia Health District

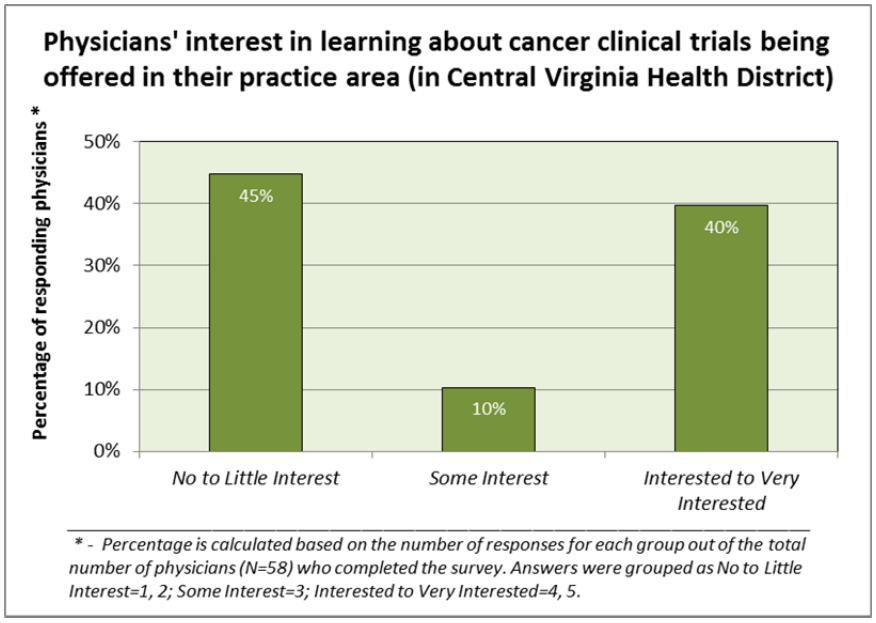


**Figure 24**: Physician Interest in Learning About Clinical Trials Available in the Central Virginia Health District

# Community Population Needs

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

## *Behavioral Risk Factor Surveillance Survey*

The Center for Disease Control conducts state-based monthly telephone surveys collecting information on health risk behaviors, preventive health practices and health care access. Information from the BRFSS was accessed to gain perspectives at the health district level about lifestyle factors, healthcare access and screening practices.

According to the BRFSS for adults eighteen and older, the Central Virginia Health District, when compared to Virginia, shows a higher incidence of sedentary behavior and smoking, and has a significantly higher prevalence of obesity (**Figure 25**). All three factors are associated with a higher cancer risk. Twenty-six percent of the population reported no physical exercise in the past 30 days and only 27% included five or more fruits and vegetables in their daily diet. Greater than half (69%) of the district is obese. On average, about 20% of adults are current smokers.

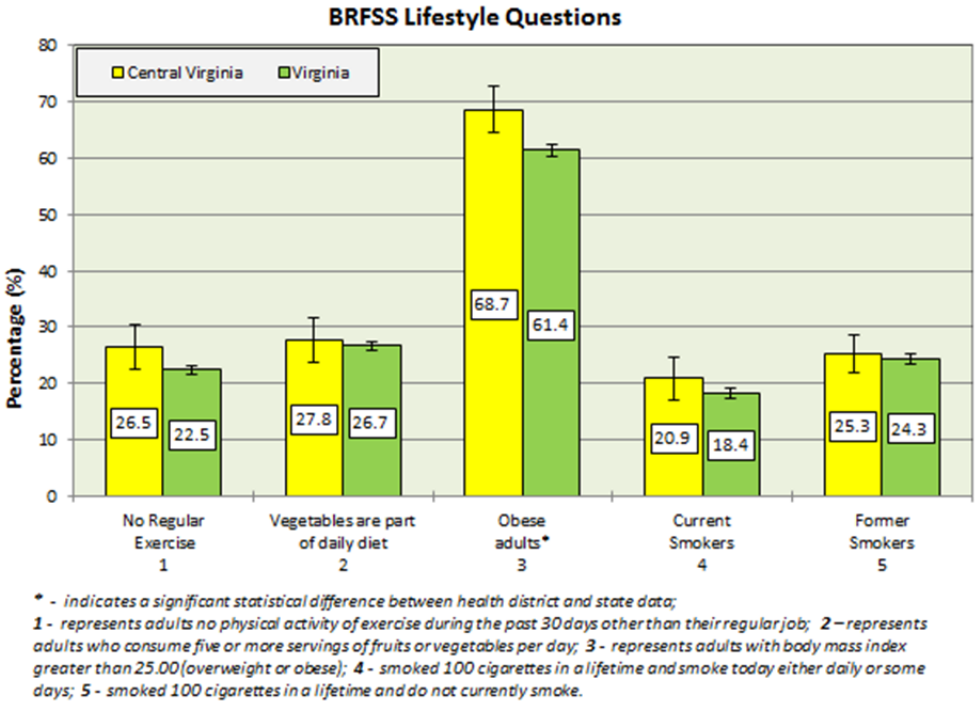


**Figure 25**: BRFSS Lifestyle Questions

Access to healthcare for residents of the Central Virginia Health District is similar to that for those in other parts of Virginia. The majority of residents has a primary physician and has visited their doctor in the past year. A small proportion of individuals (13%) in the health district were unable to see a doctor due to cost (**Figure 26**).

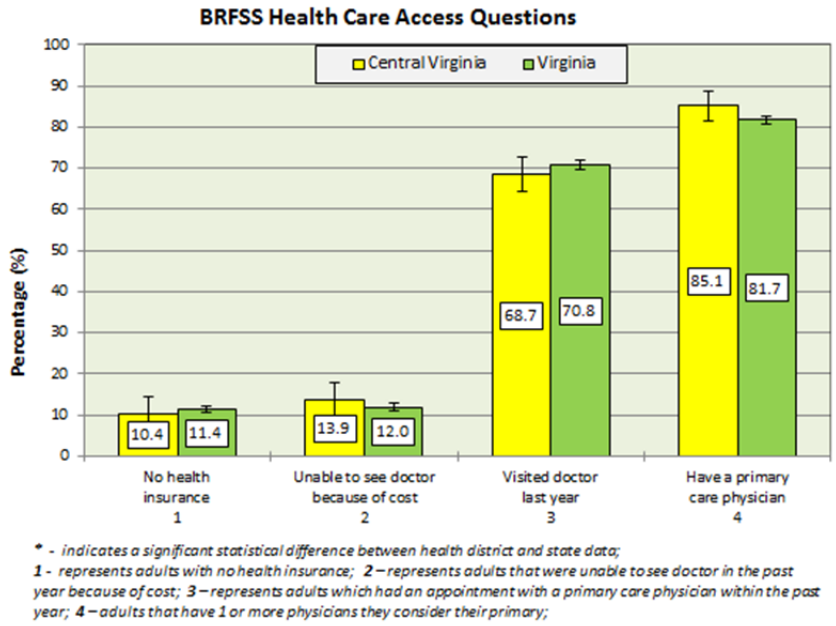


**Figure 26**: BRFSS Health Care Access Questions

Residents of the health district reported cancer screenings at rates similar to that of Virginia. Seventy-one percent of women had a mammogram in the past 2 years, and 76% had a sigmoidoscopy or colonoscopy in the past 5 years (**Figure 27**).

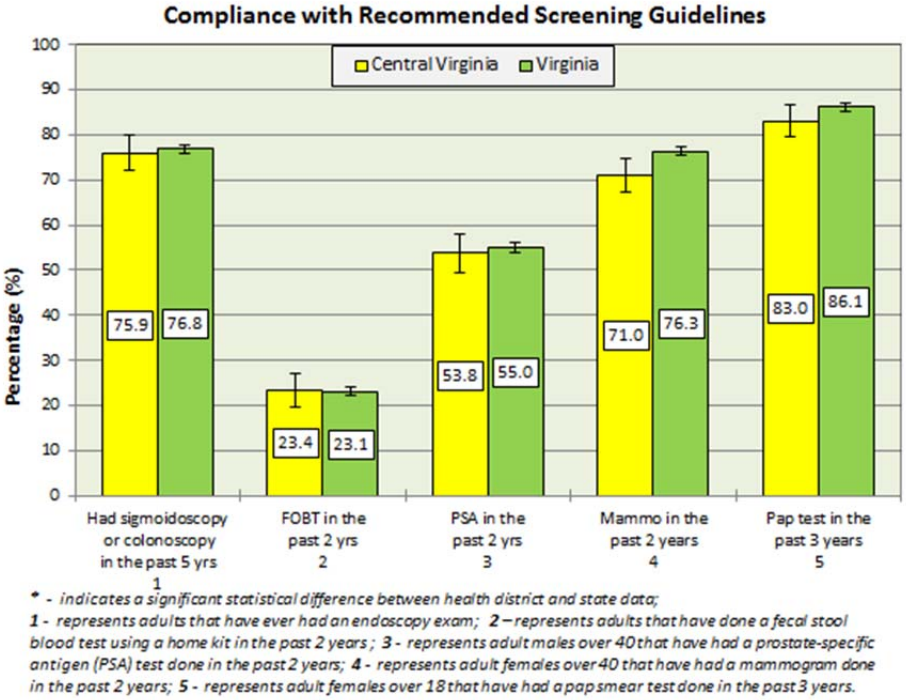


**Figure 27**: Compliance with Recommended Screening Guideline

## *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, advertisements were placed in area newspapers and on select radio stations.

The demographics of the community were used as a guide for final selection of the participants.

While the ratio of men and women in the community is almost equal, the final male to female ratio for the focus group was 1:3. Age, education, and economic distribution were equally matched. Residential representation was also considered. 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.

Venues for the meetings were chosen for the convenience of the participants, considering location, parking convenience, and time schedules. Focus groups were held in the townships with hospitals because they are central to each county (**Figure 28**).

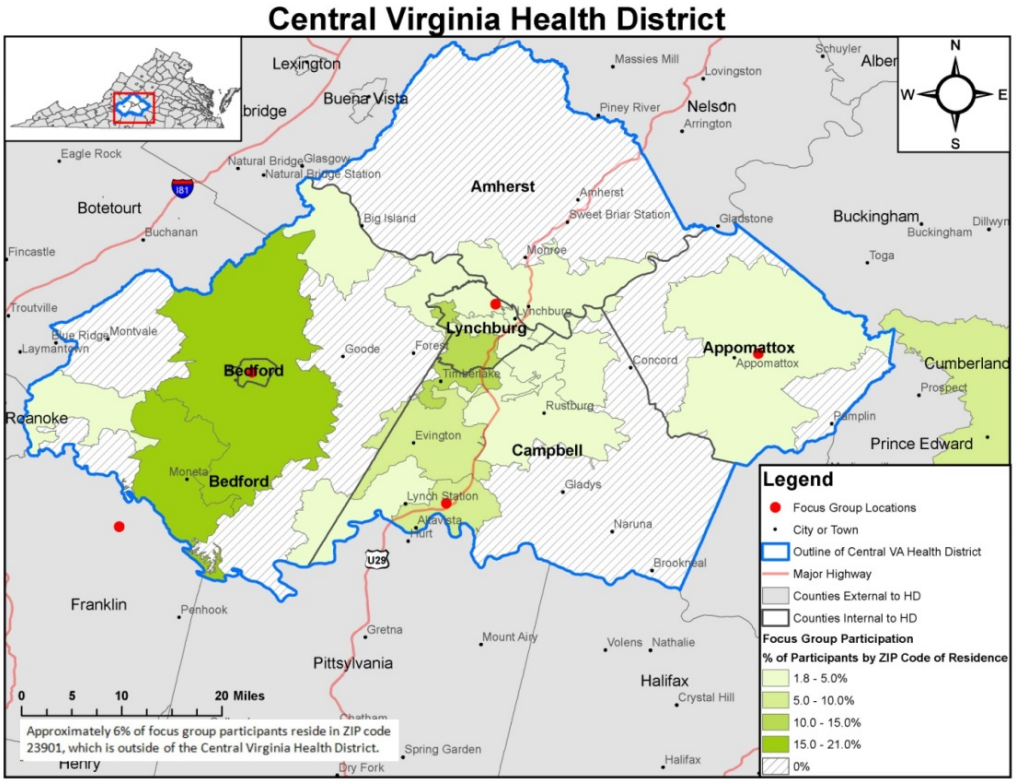


**Figure 28**: Focus Groups Participation in Central Virginia Health District

### *General Population Group Synopsis*

Four focus groups with the general population were held in four areas distributed throughout the health district. There were a total of 22 participants, with an average group attendance of 6. Participants were able to identify prevailing health problems in their communities, including high blood pressure, HIV, alcohol and drug abuse, mental health, and fibromyalgia. Furthermore, they

identified the diseases with the highest mortality, which included heart disease, obesity, drug abuse, chronic obstructive pulmonary disease, and cancer.

Most focus group participants were aware of healthy lifestyle habits including eating a healthy diet, maintaining an appropriate weight, and avoiding smoking. However, they expressed difficulty in following this prescription. Many of the participants felt that weight did not necessarily translate to health issues, but that a healthy, happy attitude did have a significant impact on promoting health. Although tobacco was considered part of the health district's heritage and is generational, it is viewed as "not cool" and a pesky habit that offends many. Support from family, religion, and meditation were noted to be present throughout the entire health district, and noted to have a positive effect on health.

The prevailing themes from the general population focus groups included:

1. Poor community motivation to address general health topics, including: exercise, nutrition, and smoking cessation.
2. Financial and transportation barriers preventing easy access to nutritious foods.
3. Stress was considered a significant problem in the health district, and was blamed for an increase in smoking with an increase in smokeless tobacco as well.
4. Limited knowledge of cancer research, and no knowledge of cancer research going on in the community.

### *Cancer Survivor Group Synopsis*

The cancer survivor group participants either had been diagnosed with cancer or were the primary care giver (living in the house, going to appointments, tending to personal needs; thus, having an intimate knowledge of what the patient experienced) of a person with cancer. The topics for the survivors group were designed to find out what the district needs to do better in providing care and support. The line of questioning elicited many heartbreaking and inspiring stories of their individual journeys. Discussed were:

- Experiences with medical resources, during diagnosis, treatment and survivorship specifically where they were treated, what kind of information they received and their feelings about their care
- Experiences with local support resources
- Cancer Research
- Needs in the community from a survivors perspective

Five focus groups with cancer survivors were held in four areas distributed throughout the health district. There were a total of 31 participants, with an average group attendance of eight (See **Figure 18**). A reoccurring theme with cancer survivors was the relationship of economic status to decisions about treatment. Participants felt that patients from higher economic brackets were more apt to go to bigger cancer centers located outside of the health district, whereas those with limited resources were treated at the facility closest to them. The type and stage of cancer also dictated where the patient decided to be treated, with the more severe or rarer cancers being treated elsewhere.

The cancer survivors and caregivers relayed a common theme throughout the health district regarding the importance of support, communication, and compassion while getting their diagnosis. Stories of the personal experiences of participants with a cancer diagnosis in the health district included positive experiences with navigation through both understanding and adjusting to the diagnosis, and moving through the continuum of care, as well as stories of very negative

experiences of a lack of support upon diagnosis. Examples include the comment received from one participant after her diagnosis from a health professional --

> "We are sorry but there is nothing we can do"

without being provided further detail or recommendations for a second opinion. Other comments included a disturbing phone call received at the end of the day by a patient to impart the news of her unfortunate diagnosis. Most participants that had a positive story regarding their diagnosis and treatment had a patient navigator who was able to spend time explaining the diagnosis and upcoming treatment decisions. These individuals were more than complimentary of the services provided and supported by a navigator. Comments regarding the navigation care included,

> "I don't know what I would have done without the navigator", and
>
> "they support helped me get through this",
>
> "I cannot image patients going through cancer without a navigator" and
>
> "I was so blessed to have someone to help guide me through this".

Patient advocacy was also important to focus group attendees. They indicated that cancer survivors were there best advocate or a family member who was able to "oversee" their care and assist with the overwhelming amount of information regarding diagnosis, treatment, financial assistance and support services. The need for a person to assist with understanding the financial impacts of cancer treatment and help with managing payments was important later on in the patient's cancer journey.

The majority of participants expressed satisfaction with their follow-up care after treatment and indicated that they were provided follow-up information of some kind. Communication between their PCP and treating oncologist did not always occur, which left the PCP out of the loop of follow-up care in some cases. A desire for individual counseling on lifestyle behaviors for the prevention of cancer recurrence, particularly nutritional counseling, was uniformly expressed, although referral by the treating oncologist to these services was uncommon. Finally, most participants had positive attitudes about cancer research and recognized its importance to advancing treatment.

# SUMMARY OF PRIORITY NEEDS

The Central Virginia Health District is a geographically large area comprised of a racial makeup resembling that of the Commonwealth of Virginia. Large portions of the district are classified as medically underserved. The district's residents have, on average, fewer years of education and a lower income than the residents of the state. The district has statistically higher cancer age-adjusted cancer rates than the rest of Virginia. The top three cancer types for males are genital (prostate), gastrointestinal, and respiratory cancers, and the top three cancer types for females are breast, gastrointestinal, and respiratory cancers. Comparing racial groups within the health district, African Americans have a higher age-adjusted cancer incidence rate for gastrointestinal, male genital, and respiratory cancers, and female breast cancer is higher in the Caucasian population. Cancer screening and early identification percentages for the health district are similar to that of the rest of Virginia. The highest cancer-related cause of death is gastrointestinal and respiratory cancers in African Americans and respiratory cancer in Caucasians. Data from BRFSS indicates that the lifestyle habits of residents are similar to those of the rest of the state, specifically relating to smoking, exercise, nutrition, and obesity. There is wide range of cancer diagnostic, treatment, and support services located in the Central Virginia Health District. The two primary cancer treatment facilities are Bedford Memorial Hospital and the Alan B. Pearson Regional Cancer Center. Additionally, there is a wide range of educational and screening services offered to the community through community organizations.

Based on the qualitative and statistical information gathered for this project, the following are recommendations/suggestions for action:

**Access to Cancer Screening**

- Increased access for screening procedures in rural areas
- Continued community education around the importance of cancer screening
- Expand programs that feature mobile cancer screening to more rural locations
- Provide additional financial support to patients with need

**Healthcare Providers**

- Standardize a patient-centered care plan that can be easily understood by patients
- Increase healthcare provider awareness of community organizations that address cancer-related needs
- Create a trending report for physicians that outlines statistical data that is easy to read and understand
- Continuing education for healthcare providers regarding cancer recurrence monitoring; specifically when to refer patients to an oncologist
- Educate physicians on availability of community resources

**Community Support**

- Create motivation-centered education programs focusing on: nutrition, cancer screening, and tobacco cessation
- Allocate additional community funding to year round educational programs
- Increase the number of patient navigators and widen their scope of services

# APPENDICES

## Appendix A:

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

## Appendix B:

Primary Care Physician Questionnaire

## Appendix C:

Focus Group Facilitator Guides

## Appendix D:

Cancer Healthcare Resources within the Health District

## Appendix E:

Community Cancer Resources within the Health District

# APPENDIX A

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

# *Healthcare Facility Questionnaire*

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

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

## FACILITY

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

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

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

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

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

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

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

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

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

_____
_____
_____

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

Chemotherapy Inpatient: Yes_____ No____
Outpatient: Yes_____ No____

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

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

Radiation therapy Yes_____ No____

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

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

   Yes_____ No____ Will try ____

## SCREENING/DIAGNOSTIC SERVICES

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

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

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

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

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

IF RESPONDENT ANSWERED "NO" TO COLPOSCOPY:

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

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

## SURGICAL SERVICES

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

   - Breast segmental/complete mastectomy? Yes_____ No____ Unknown____

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

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

## COUNSELING SERVICES

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

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

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

***Which nutritional services does he/she offer?***

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

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

If YES, which genetic tests:

___BRCA1/2
___Others _____

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

If YES,

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

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

If Yes, which cancers do you screen?

___ Colorectal only
___ Endometrial only
___ Both Colorectal and Endometrial

What laboratory method do you use for screening?

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

## FINANCIAL/INSURANCE

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

YES_____

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

Medicare_____

Medicaid_____

Other (please specify): _____

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

1.

2.

3.

4.

5.

***13. Do you accept uninsured patients?*** Yes_____ No____

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

_____

_____

## CLINICAL TRIALS

***The next few questions are about research related issues.***

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

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

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

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

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

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

_____

_____

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

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

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

_____
_____
_____
_____

## HOSPICE / PALLIATIVE CARE SERVICES

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

***18. What Hospice Services are offered to patients?***

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

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

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

## SUPPORT / EDUCATIONAL PROGRAMS

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

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

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

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

_____
_____
_____
_____

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

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

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

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

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

_____
_____

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

## Cancer Resources Questionnaire

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

Organization's name: _____

Address: _____

Ph: _____ Fax: _____

Website?: _____

CONTACT person: _____

Best time to contact? _____

Date of meeting/interview:_____

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

2. Which category best describes your organization:

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

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

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

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

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

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

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

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

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

_____

7. How do you advertise your organization and services?

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

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

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

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

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

_____

_____

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

_____

_____

_____

_____

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

_____

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

_____

_____

13. Would you be interested in collaboration?

_____

# Key Leader Interview Questions

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

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

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

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

# APPENDIX B

Primary Care Physician Questionnaire

# Cancer Needs Assessment VIP Physician Survey

Please complete the survey below. Thank you!

[redacted]

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

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

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

Please indicate your primary area practice:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

would refer for Medical Oncology to:

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

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

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

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

☐ 0-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

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

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

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

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

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

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

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

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

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

1☐ 2☐ 3☐ 4☐ 5☐

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

1☐ 2☐ 3☐ 4☐ 5☐

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

1☐ 2☐ 3☐ 4☐ 5☐

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

1☐ 2☐ 3☐ 4☐ 5☐

# APPENDIX C

Focus Group Facilitator Guides

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

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

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

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

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

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

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

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

Does anyone have any questions? [Answer any questions]

**WARM-UP [8 minutes]**

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

Turn off tape recorder for this section of the discussion

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

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

**CANCER IN COMMUNITY: GENERAL DISCUSSION [15 minutes]**

So let us get started.

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

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

   Review list on flip chart.

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

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

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

**LIFESTYLE FACTORS: [30 minutes total]**

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

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

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

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

Review the list on flip chart

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

Nutrition:

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

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

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

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

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

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

***Review points made during nutrition discussion before moving on.***

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

Exercise

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

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

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

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

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

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

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

***Summarize exercise comments before moving on to weight control.***

Weight Control

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

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

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

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

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

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

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

***Summarize weight comments before moving on to weight control.***

## BREAK

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

TOBACCO

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

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

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

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

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

ENVIRONMENTAL FACTORS

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

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

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

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

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

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

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

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

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

**CANCER RESEARCH SECTION [15 MINUTES]**

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

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

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

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

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

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

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

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

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

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

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

**OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]**

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

***Do a final summary of the information.***

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

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

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

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

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

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

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

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

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

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

Does anyone have any questions? [Answer any questions]

## WARM-UP [10 minutes]

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

**Tape recorder turned OFF here to maintain confidentiality.]**

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

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

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

## Experiences getting cancer information (10 minutes)

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

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

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

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

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

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

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

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

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

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

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

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

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

    a. Who? Was it helpful?

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

**BREAK**

**Post-Treatment (20 Minutes)**

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

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

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

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

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

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

**LOCAL RESOURCES AND NEEDS:**

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

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

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

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

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

**CANCER RESEARCH SECTION [15 MINUTES]**

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

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

National cancer Institute defines clinical research as:

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

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

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

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

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

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

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

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

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

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

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

# APPENDIX D

Cancer Healthcare Resources within the Health District

## Results of Facilities Questionnaire for Central Virginia Health District

| | | |
|---|---|---|
| **Available Facilities:** | Bedford Memorial Hospital; Alan B. Pearson Regional Cancer Center | |
| **# of Oncologists:** | 12 oncologists and 5 nurse practitioners | Breakout: 1 visiting medical oncologist at Bedford; 8 medical oncologists and 3 medical nurse practitioners, 3 radiation oncologists and 2 radiation nurse practitioners at Alan B. Pearson Cancer Center |

### Available in Health District

| Services | | | # of facilities where available |
|---|---|---|---|
| **Cancer Treatment** | **Services Provided** | Chemo Inpatient | 1 |
| | | Chemo Outpatient | 1 |
| | | Radiation | 1 |
| **Cancer Screening** | **Breast Cancer Screening and Diagnostic Procedures** | Screening Mammography (film/digital) | 1 / 2 |
| | | Diagnostic Mammography | 2 |
| | | Breast Ultrasound | 2 |
| | | Breast Biopsy | 2 |
| | | Breast MRI | 1 |
| | **Colorectal Cancer** | Sigmoidoscopy/Colonoscopy | 2 |
| | | CT Colonography | 1 |
| | **Lynch Syndrome** | Screening for Colorectal cancer | 1 |
| | | Screening for Endometrial cancer | 1 |
| | | Immunohistochemistry staining test | 1 |
| **Surgeries** | **Cancer Related Surgeries** | Breast Segmental/Complete Mastectomy | 2 |
| | | Breast Reconstruction | 2 |
| | | Sentinel Nodes Sampling | 1 |
| | | Gynecological Hysterectomy/Oophorectomy | 2 |
| | | GI - Upper/Lower Tract | 1 / 2 |
| | | GI - Liver | 1 |
| | | GI - Pancreas | 1 |
| | | Lung | 1 |
| | | Prostatectomy | 2 |
| | | Ears, Nose, Throat | 1 |
| | | Brain | 1 |
| | | Other | 1 |
| **Counseling** | **Cancer Dietary Needs** | Registered dietician to provide nutritional services specific to cancer patients | 1 |
| | | One-on-one assessment and diet prescription | 1 |
| | | Individual oncology nutrition counseling services | 1 |
| | | Outpatient oncology nutrition counseling | 1 |
| | | Cancer control and prevention education programs for dietary needs | 1 |
| | **Genetic Tests** | Offer genetic tests for cancer risk (BRCA1 and BRCA2) | 1 |
| | | Offer genetic tests for cancer risk (Others) | 1 |
| **Other Services** | **Clinical Trials** | Offer clinical trials | 1 |
| | **Hospice Service** | Facility Supported: Inpatient / Outpatient Hospice | 2 / 2 |
| | | Private Organization: Inpatient / Outpatient Hospice | 1 / 2 |
| | **Palliative Care** | Palliative Care Program | 1 |
| | | Medical professionals in the team | MD/DO Board Certified palliative care, NP/APRN, RN, SW, Chaplaincy, Care coordination |
| | | Offer consult service | 1 |
| | **Cancer Patient Navigation** | Patient Navigator | 1 |
| | | Navigation for the following cancers: | Lung, Breast, Prostate, GI |
| | | Credentials of patient navigator | Nurse |
| **Cancer Support Groups** | **Existing Support Groups** | Availability of cancer support groups | 1 |
| | | Support groups for the following cancers: | Breast and others |
| | **Future Support Groups** | Want to start a support group | 1 |
| **Specialists** | **Oncology** | Currently recruiting oncologists | 1 |
| | | Which specializations | Radiation and medical oncology |

### Not Available in Health District

| | | |
|---|---|---|
| **Cancer Screening** | **Lynch Syndrome** | Microsatellite instability testing |
| **Counseling** | **Cancer Dietary Needs** | Board certified dietician in oncology nutrition |
| | **Genetic Counseling** | Genetic counseling (at the facility or referred out for counseling) |
| **Other Services** | **Palliative Care** | Inpatient beds |
| | | Outpatient clinic |

# APPENDIX E

Community Cancer Resources within the Health District

| CENTRAL VIRGINIA HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS | | Health District | Centra Hospice | Bedford Hospice Care | Gentle Shepherd Hospice | Discovery Shop West Lake |
|---|---|---|---|---|---|---|
| **Organization Information** | | Number of Organizations | | | | |
| Organization category | National non-profit | 1 | - | - | - | - |
| | Local non-profit | 6 | X | X | - | X |
| | For profit service organization | 2 | - | - | X | - |
| | Federal governmental organization | 0 | - | - | - | - |
| | State/municipal government organization | 0 | - | - | - | - |
| | Other | 0 | - | - | - | - |
| Major sources of funds for organization | Competitive grants | 0 | - | - | - | - |
| | Federal funds | 2 | - | X | X | - |
| | Service fees charges | 2 | X | - | - | - |
| | Donations | 5 | - | X | - | X |
| | Other | 3 | - | - | - | X |
| **Cancer Resources** | | | | | | |
| Primary service population of the organization | Cancer patients | 7 | X | X | X | X |
| | Cancer survivors | 2 | - | - | - | X |
| | Cancer caregiver/family members | 2 | - | - | - | X |
| | Other | 2 | - | - | - | - |
| Qualification criteria to access services | Must be uninsured/underinsured | 0 | - | - | - | - |
| | Financial qualification | 0 | - | - | - | - |
| | No qualification criteria | 7 | X | X | X | X |
| | Other | 2 | - | - | - | - |
| Type of cancer related services that are provided | Written information on cancer | 3 | - | - | - | X |
| | Information on cancer care/support resources | 6 | X | X | X | X |
| | Management of cancer support groups | 3 | - | X | - | X |
| | Financial support for cancer control/care | 5 | - | X | X | X |
| | Funding of projects related to cancer | 4 | - | X | - | X |
| | Psychosocial support | 4 | - | X | X | X |
| | Navigational services | 5 | - | X | X | X |
| | Transportation | 3 | - | - | X | X |
| | Other | 0 | - | - | - | - |
| Number of cancer patients seen annually | | (see organizations' answers) | 51 - 150 | 51 - 150 | greater than 150 | 26 - 50 |
| **Other Information About Organization** | | | | | | |
| Advertising for the organization | Local media | 7 | X | X | X | X |
| | Organization website | 7 | X | X | X | - |
| | Online | 8 | X | X | X | X |
| | Pamphlets describing services | 6 | X | X | X | - |
| | Word of mouth | 9 | X | X | X | X |
| | Other | 1 | - | - | - | - |
| Organizational needs | Financial support | 4 | - | X | - | - |
| | Human resources (skilled employees, volunteers, etc.) | 1 | - | - | - | - |
| | Access to experts for consultation | 0 | - | - | - | - |
| | Physical space/facilities | 3 | X | - | - | X |
| | Collaborators | 1 | - | - | - | - |
| | Volunteers | 7 | - | X | X | X |
| | Other | 0 | - | - | - | - |
| Challenges | | (see organizations' answers) | Having the appropriate diagnosis for hospice. | Helping families accept loss of loved one. | Medicare regulations and limiting patient needs. | None at this time. |
| Goals for the next 5 years | | (see organizations' answers) | Continue to provide care to terminally ill patients. | Expand services and increase census. | | Assist with the cure for cancer. |
| Partner organizations | | | None provided | Other agencies within the Carilion organization | Straight Street Rescue Mission | ACS |
| Interested in collaboration | | | Yes | Maybe | Yes | Yes |
| Comments | | (see organizations' answers) | | | | This is a unique opportunity for the American Cancer Society as there are two of these shops in Virginia. One is located in Roanoke and the other in Maneta, which is in the Central Virginia Health District. All items are donated to the shop for sale and all proceeds go to the American Cancer Society. The shop has been open for eight years and they have raised 1 million dollars for donations. A great deal of furniture is donated from the furniture market for sale. Other items are welcomed. |

| CENTRAL VIRGINIA HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS | | Health District | Free Clinic of Central Virginia | Bedford Community Health Foundation | Blue Ridge Cancer Center | American Cancer Society |
|---|---|---|---|---|---|---|
| **Organization Information** | | Number of Organizations | | | | |
| Organization category | National non-profit | 1 | - | - | - | X |
| | Local non-profit | 6 | X | X | - | - |
| | For profit service organization | 2 | - | - | X | - |
| | Federal governmental organization | 0 | - | - | - | - |
| | State/municipal government organization | 0 | - | - | - | - |
| | Other | 0 | - | - | - | - |
| Major sources of funds for organization | Competitive grants | 0 | - | - | - | - |
| | Federal funds | 2 | - | - | - | - |
| | Service fees charges | 2 | - | - | X | - |
| | Donations | 5 | X | - | - | X |
| | Other | 3 | X | X | - | - |
| **Cancer Resources** | | | | | | |
| Primary service population of the organization | Cancer patients | 7 | X | - | X | X |
| | Cancer survivors | 2 | - | - | - | X |
| | Cancer caregiver/family members | 2 | - | - | - | X |
| | Other | 2 | - | X | - | - |
| Qualification criteria to access services | Must be uninsured/underinsured | 0 | - | - | - | - |
| | Financial qualification | 0 | - | - | - | - |
| | No qualification criteria | 7 | - | - | X | X |
| | Other | 2 | X | X | - | - |
| Type of cancer related services that are provided | Written information on cancer | 3 | - | - | X | X |
| | Information on cancer care/support resources | 6 | - | - | X | X |
| | Management of cancer support groups | 3 | - | - | - | X |
| | Financial support for cancer control/care | 5 | - | - | X | X |
| | Funding of projects related to cancer | 4 | - | - | X | X |
| | Psychosocial support | 4 | - | - | X | - |
| | Navigational services | 5 | - | - | X | X |
| | Transportation | 3 | - | - | - | X |
| | Other | 0 | - | - | - | - |
| Number of cancer patients seen annually | | (see organizations' answers) | 26 - 50 | 11-25 | greater than 150 | greater than 150 |
| **Other Information About Organization** | | | | | | |
| Advertising for the organization | Local media | 7 | - | - | X | X |
| | Organization website | 7 | X | - | X | X |
| | Online | 8 | X | - | X | X |
| | Pamphlets describing services | 6 | - | - | X | X |
| | Word of mouth | 9 | X | X | X | X |
| | Other | 1 | - | X | - | - |
| Organizational needs | Financial support | 4 | - | X | - | X |
| | Human resources (skilled employees, volunteers, etc.) | 1 | - | X | - | - |
| | Access to experts for consultation | 0 | - | - | - | - |
| | Physical space/facilities | 3 | - | - | X | - |
| | Collaborators | 1 | - | X | - | - |
| | Volunteers | 7 | - | X | X | X |
| | Other | 0 | - | - | - | - |
| Challenges | | (see organizations' answers) | Finances for providing services. | Getting the vision out to the community. May help people in the community to see the importance of the legacy foundation. | Reaching patients at the appropriate time. Education to patients regarding resources. | Volunteers needed. |
| Goals for the next 5 years | | (see organizations' answers) | | Help promote the vision of the foundation. It wants Bedford to be one of the healthiest communities in the area. | Expand and grow resources and increase satisfaction. | Eliminate cancer. Long Term - 1,000 lives saved a day by 2015. Current is 400 per day. Early detection and prevention. |
| Partner organizations | | | Carilion | Energize Bedford Schools, YMCA, and Chamber Senior Citizens Organizations | | Bedford - Central Virginia Agency on Aging |
| Interested in collaboration | | | Maybe | Yes | Yes | Not sure |
| Comments | | (see organizations' answers) | | | | Getting the word out is a major barrier. Limited exposure from the radio and competitive funding within the community. Limited marketing funds. |

| CENTRAL VIRGINIA HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS | | Health District | Camp Tree House |
|---|---|---|---|
| **Organization Information** | | **Number of Organizations** | |
| Organization category | National non-profit | 1 | - |
| | Local non-profit | 6 | X |
| | For profit service organization | 2 | - |
| | Federal governmental organization | 0 | - |
| | State/municipal government organization | 0 | - |
| | Other | 0 | - |
| Major sources of funds for organization | Competitive grants | 0 | - |
| | Federal funds | 2 | - |
| | Service fees charges | 2 | - |
| | Donations | 5 | X |
| | Other | 3 | - |
| **Cancer Resources** | | | |
| Primary service population of the organization | Cancer patients | 7 | - |
| | Cancer survivors | 2 | - |
| | Cancer caregiver/family members | 2 | - |
| | Other | 2 | X |
| Qualification criteria to access services | Must be uninsured/underinsured | 0 | - |
| | Financial qualification | 0 | - |
| | No qualification criteria | 7 | X |
| | Other | 2 | - |
| Type of cancer related services that are provided | Written information on cancer | 3 | - |
| | Information on cancer care/support resources | 6 | - |
| | Management of cancer support groups | 3 | - |
| | Financial support for cancer control/care | 5 | - |
| | Funding of projects related to cancer | 4 | - |
| | Psychosocial support | 4 | - |
| | Navigational services | 5 | - |
| | Transportation | 3 | - |
| | Other | 0 | - |
| Number of cancer patients seen annually | | (see organizations' answers) | less than 10 |
| **Other Information About Organization** | | | |
| Advertising for the organization | Local media | 7 | X |
| | Organization website | 7 | X |
| | Online | 8 | X |
| | Pamphlets describing services | 6 | X |
| | Word of mouth | 9 | X |
| | Other | 1 | - |
| Organizational needs | Financial support | 4 | X |
| | Human resources (skilled employees, volunteers, etc.) | 1 | - |
| | Access to experts for consultation | 0 | - |
| | Physical space/facilities | 3 | - |
| | Collaborators | 1 | - |
| | Volunteers | 7 | X |
| | Other | 0 | - |
| Challenges | | (see organizations' answers) | Financial cost of the camp. |
| Goals for the next 5 years | | (see organizations' answers) | Grow the camp offerings and look at extending services. |
| Partner organizations | | | United Way, Family Services of Roanoke |
| Interested in collaboration | | | Maybe |
| Comments | | (see organizations' answers) | |