Saving Lives and Reducing Suffering and Death from Cancer in Virginia

Report of the Comprehensive Cancer Needs Assessment of the Cumberland Plateau Health District

Virginia Commonwealth University

Massey Cancer Center

and

Tobacco Indemnification and Community Revitalization Commission

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

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

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

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

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TABLE OF ABBREVIATIONS

ACS	American Cancer Society
BRFSS	Behavioral Risk Factor Surveillance Survey
CACV	Cancer Action Coalition of Virginia
CHE	Community Health Educator
HPSA	Health Professional Shortage Areas
CVMC	Clinch Valley Medical Center
CTCH	Carillion Tazewell Community Hospital
PCP	Primary care physicians
DCH	Dickenson Community Hospital
BGH	Buchanan General Hospital
VDH	Virginia Department of Health

EXECUTIVE SUMMARY OF FINDINGS

The Cumberland Plateau Health District offers an adequate range of cancer-related support services. Age-adjusted cancer incidence and mortality rates are lower than those for Virginia. The one exception to this trend is respiratory cancer, which has higher age-adjusted incidence and mortality rates than the rest of Virginia. One factor that accounts for the trend in respiratory cancer in the Cumberland Plateau region is its historical association with tobacco production. Barriers preventing improved cancer care are primarily associated with the district's rural characteristics and its status as a medically underserved area. This assessment utilized information gathered from federal, state, and local sources. Information was gathered from the local community through interviews with local physicians as well as community focus groups with cancer survivors and the general population to provide a framework for community concerns. This assessment summarizes both the strengths and weaknesses of cancer care within the Cumberland Plateau Health District.

The Cumberland Plateau Health District encompasses a 1,827 square mile area in Southwestern Virginia. It is home to 90,939 residents, of which 95%+ are Caucasian. The top three cancer types, which comprise approximately 75% of the district's cancer burden, are respiratory, GI, and female breast cancer. As compared to Virginia state averages, unemployment rates are higher, median household incomes are lower, and education levels are lower in this health district. Financial costs associated with transportation, health insurance, and general medical treatments are significant barriers preventing patients from receiving timely cancer care. Community education regarding healthy living, with a specific focus on the long-term harms of smoking and obesity, would be beneficial throughout the health district.

Data for this health district illustrate that the overall cancer rates are lower than the rest of Virginia, with the exception of respiratory cancer. Overall, identification of early-stage cancer is comparable to that for Virginia. Physicians cite four areas where cancer treatment can be improved: (1) increasing patient education regarding healthy living, particularly risk reduction through avoidance of tobacco use; (2) reducing the physical distance patients must travel to receive cancer education and services; (3) increasing financial support to patients undergoing cancer treatment; and (4) standardizing communications between the oncologist and primary care physician (PCP). Residents from the health district reiterated the difficulties that lack of transportation and financial constraints pose to seeking and receiving timely health care. Cancer survivors and community members emphasized the need for community initiatives to support healthy lifestyles and programs to provide health education in local communities. Furthermore, both clinicians and patients stress the need for locally available cancer screening, diagnostics, and treatments. This will involve innovative solutions to attract and retain healthcare professionals and systems to the health district. In conclusion, efforts to improve the burden of cancer in the Cumberland Plateau Health District should: increase health education; address the needs of a rural and medically underserved population; and streamline provider-to-provider and provider-to-patient communications.

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 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 14,009 residents succumbing to their disease.[8] Virginia is poised to combat this disease with healthcare institutions, cancer care centers, state education and research institutions, city and state governments, non-profit organizations, and grass-roots community groups working to reduce the cancer burden in the state. Since 2001, a statewide network of partners, the Cancer Action Coalition of Virginia (CACV), has developed a series of state five-year cancer plans to help unify and direct the efforts of these organizations in combating cancer.

Virginia is a highly diverse state in geography, population demographics, economics, and access to healthcare. With a land mass of 40,000 square miles that spans from the shores of the Atlantic to the hills of the Appalachian Mountains, there are varying degrees of knowledge of and access to healthcare. For cancer prevention and control efforts to be effective they "must be complete, comprehensive, sustainable, community-specific, and culturally and linguistically appropriate."[9] To accomplish this, an evaluation of the needs specific to defined communities is required. The Virginia Commonwealth University Massey Cancer Center in collaboration with the Virginia Tobacco Indemnification and Community Revitalization Commission performed a comprehensive cancer needs assessment of four health district-defined communities. The four health districts chosen had a relatively high cancer burden and large medically underserved areas. The comprehensive assessment of cancer needs specific to each community will be used to develop a holistic strategy to improve cancer outcomes that utilize 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., US Census Bureau, Department of Health and Human Services, Virginia Workforce Connection). The needs related to cancer prevention, early detection, treatment, and survivorship were assessed in five broad categories: cancer burden, cancer healthcare resources, community cancer resources, healthcare provider needs, and community population needs. Personnel dedicated to data collection included a Data Manager located at the Massey Cancer Center in Richmond and Community Health Educators (CHE) located in their respective health districts. The CHEs were qualified, long-term residents of the health districts and were responsible for gathering all community-based information. Mechanisms used to gather information in the four categories were as follows.

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

Cancer Burden

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

Cancer Healthcare Resources

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

Community Cancer Resources

The Community Health Education Coordinators compiled a list of formal and informal community organizations that provided support to cancer patients, survivors, and their families before, during, and after treatment. The VDH offices were considered community resources and were able to provide information about additional local community resources. Local chapters of national and state cancer organizations were found through the main organization's website. These local chapters often guided the CHEs to other community organizations within the health district. Additional community organizations were found through personal communications with individuals working with cancer patients and their families. A questionnaire was developed to be used during personal interviews with staff of the community resource organization and 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. These individuals were asked to discuss the most pressing healthcare deficiencies and 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] and was modified to include only physicians with primary specializations of family practice, internal medicine, urology, dermatology, cardiology, endocrinology, gastroenterology, emergency medicine, obstetrics and gynecology, surgeons, pulmonologists, radiologists, and hospitalists. The list was provided to the CHEs who checked it for accuracy. All physicians on the final list were asked to complete the questionnaire either via email or by a personal visit from the CHE to the physician's office. Initial contact was followed-up at least once, potentially twice for non-responders **(Appendix B)**.

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

Community Population Needs

The perspectives and perceived needs of the population living in the health districts were gathered in two ways. Data from the National Behavioral Risk Factor Surveillance Survey (BRFSS) was acquired from the CDC.[11] Data was requested for responses from individuals within the health districts, and for questions that related to cancer prevention and screening behaviors. These included questions about tobacco use, diet, exercise, weight, cancer screenings, and utilization of healthcare services. Relative rates of healthy behaviors were assessed, and comparisons 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 Cumberland Plateau Health District

The Cumberland Plateau is in the Southern Appalachian Plateau bordering West Virginia and Kentucky. It has an area of 1,827 square miles and has two major rivers running through it, the Allegheny and the Cumberland. The Cumberland Plateau is a deeply dissected plateau with topographic relief commonly at about four hundred feet (120 meters) and frequent sandstone outcroppings and bluffs. The plateau also contains some of the largest stretches of contiguous forest in the eastern United States. There are two major highways running through the plateau, US 19 and US 460 **(Figure 1)**.

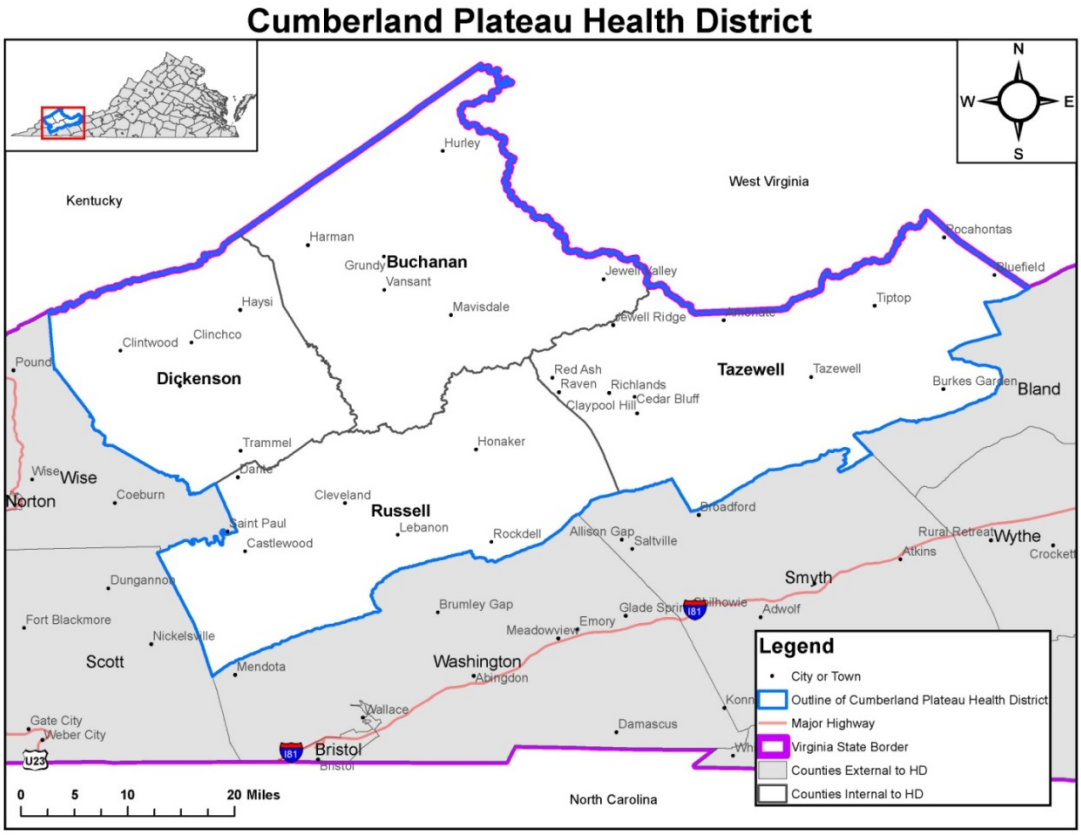

Figure 1: Cumberland Plateau Health District

According to the 2011 US Census Bureau information, the Cumberland Plateau Health District has 113,773 residents, of which 90,939 are ages 18 or older. There is little ethnic diversity: nearly 96% of the population is of the white, 2% African American, and the remainder consists of “other races”. The overall unemployment rate for the district is 8.8%, ranging from 7.6% in Russell County to 9.8% in Dickenson County, which is higher than the 6.5% unemployment rate for the entire state of Virginia. Of the adult population 25 years and over, 35% (39,821) have a high school diploma or equivalent and 11% (12,515) have a Bachelor’s degree or higher. Adults over the age of 25 years without a high school diploma or equivalent range from 24% in Tazewell County to 33% in Buchanan County and Dickenson County. The population of this health district is less educated compared to the average education level for the state of Virginia. Additionally, the median

household income in the district is $32,538, which is notably lower than the $63,302 median household income for Virginia **(Tables A** and **B)**.

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

Demographic Profile of Cumberland Plateau vs Virginia			
Category	**Subcategory**	**Cumberland Plateau**	**Virginia**
Gender	Male Female	50% 50%	49% 51%
Age	0-19 20-34 35-54 55-64 65+	22% 17% 29% 15% 17%	26% 21% 29% 12% 12%
Race	White Black or AA Other	96% 2% 2%	70% 19% 11%
Ethnicity	Hispanic or Latino Non-Hispanic or Latino	0% 100%	8% 92%

Table B: Economic Characteristics of Cumberland Plateau vs. Virginia

Economic Characteristics of Cumberland Plateau vs. Virginia		Cumberland Plateau (average)	Virginia
Unemployment[12]	Unemployment Rates	8.8%	6.5%
Income[13]	Median Household Income	$32,538	$63,302
Education[14]	% Less than high school	28%	13%
	% High school or GED	35%	26%
	% some college, no degree or an Associate's degree	26%	27%
	%Bachelor's degree or above	11%	34%

[12] 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.
[13] 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.
[14] U.S. Census Bureau; American Community Survey, 2007-2011 Summary Table DP02; generated using American FactFinder; <http://factfinder.census.gov>; (April 29, 2013). Population age 25 years and older.

Access to Healthcare

All of the counties in the Cumberland Plateau Health District are considered to be rural and medically underserved. The counties of Dickenson and Buchanan are designated as low income, uninsured, isolated and medically vulnerable. According to the Health Professional Shortage Areas (HPSA), Russell and Tazewell counties are also designated as having too few primary care doctors, high infant mortality rates, high poverty rates, and a high percentage elderly population. There are five hospitals within the health district: Buchanan General Hospital, Russell County Medical Center, Dickenson Community Hospital, Carillion Tazewell Community Hospital, and Clinch Valley Medical Center also in Tazewell. Although each county has a hospital providing healthcare, in the counties of Buchanan and Dickenson, travel to the hospital is by rural, mountain roads with long travel times for many who live there **(Figure 2)**.

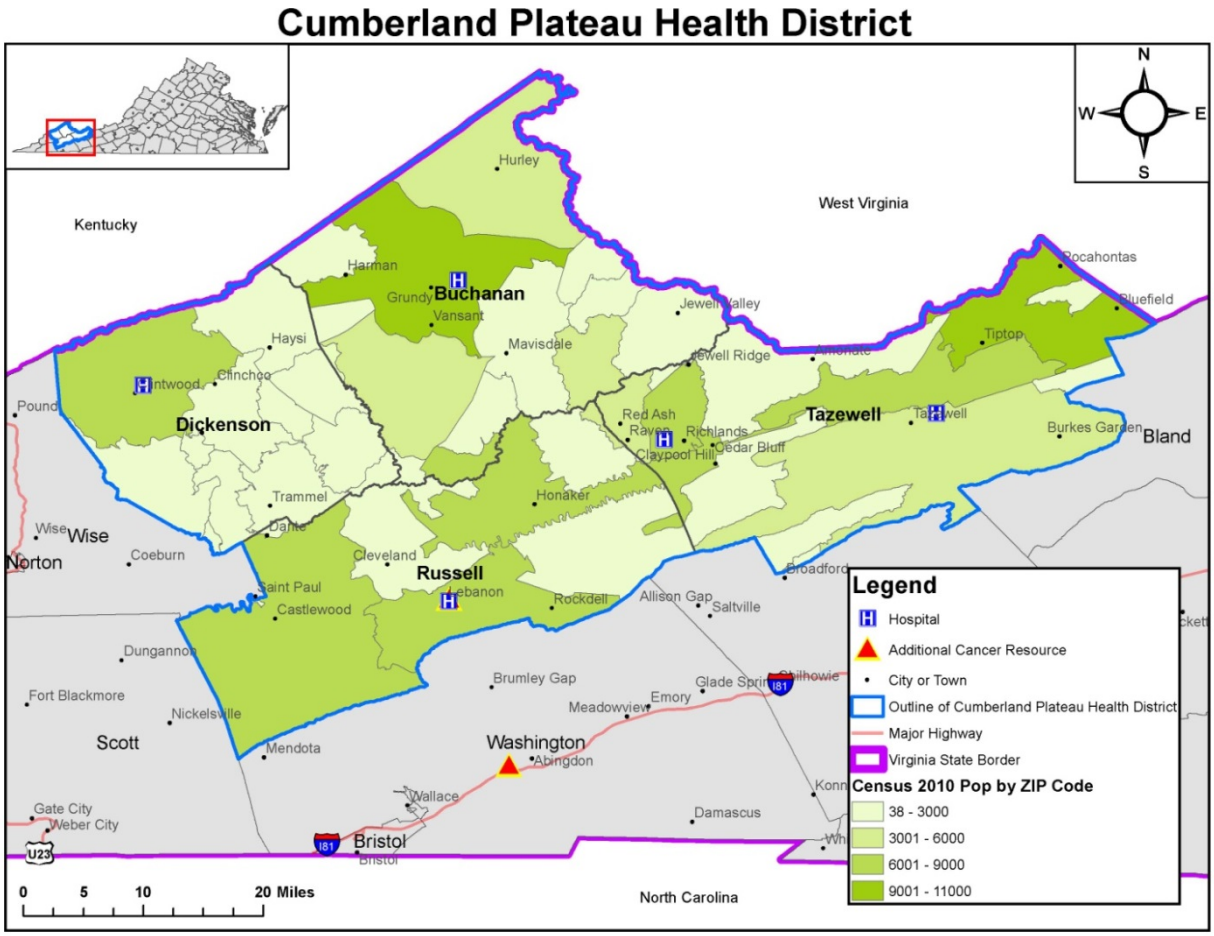

Figure 2: Healthcare Resources in the Cumberland Plateau Health District

Cancer Burden

Cancer Incidence

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

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

Age-Adjusted Cancer Incidence Rates in Cumberland Plateau Health District vs. Virginia			
Cancer Site	**Cumberland Plateau**	**Virginia**	***Notes***
Male Genital System	**108.9**	**167.7**	*Data Source: Virginia Cancer Registry (averaged rates for1999-2008) – all rates calculated based on populations including all ages.* *Dataset ordered by descending rate for health district.* *Age-Adjusted Rate - represents an age-adjusted number of new cancer cases per 100,000 populations.* *Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females.*
Prostate	104.9	162.0	
Other male genital organs	4.0	5.7	
Female Breast	**98.7**	**124.3**	
Respiratory	**81.2**	**72.5**	
GI System	**66.5**	**79.8**	
Colon & Rectum	40.2	47.5	
All Other GI	26.3	32.3	
Gynecological	**41.0**	**44.4**	
Corpus and Uterus	18.4	21.8	
Ovary	12.2	12.1	
Cervix	7.2	7.2	
All other Gynecological	3.1	3.4	
Heme-malignancies	**36.0**	**34.3**	
Lymphomas	19.3	19.5	
Leukemias	12.0	9.7	
Myeloma	4.6	5.2	
Urinary System	**28.4**	**32.4**	
Oral Cavity, Pharynx	**6.6**	**10.3**	
Brain, Nervous System, Eye	**6.3**	**6.5**	
All Other Sites	**39.5**	**44.5**	
All Sites	**387.0**	**446.6**	

The cancer sites with the highest age-adjusted incidence rates in the Cumberland Plateau Health District are: male genital, female breast, respiratory, GI, and gynecologic cancers. When compared to age-adjusted cancer incidence rates for Virginia, the district had a lower overall

age-adjusted cancer incidence rate, as well as lower age-adjusted cancer incidence rates for the majority of the site-specific cancers. Incidence rates were significantly lower for female breast cancer, male genital cancers, and GI cancers. Only respiratory cancer incidence rates were significantly higher than rates for Virginia **(Figure 3)**.

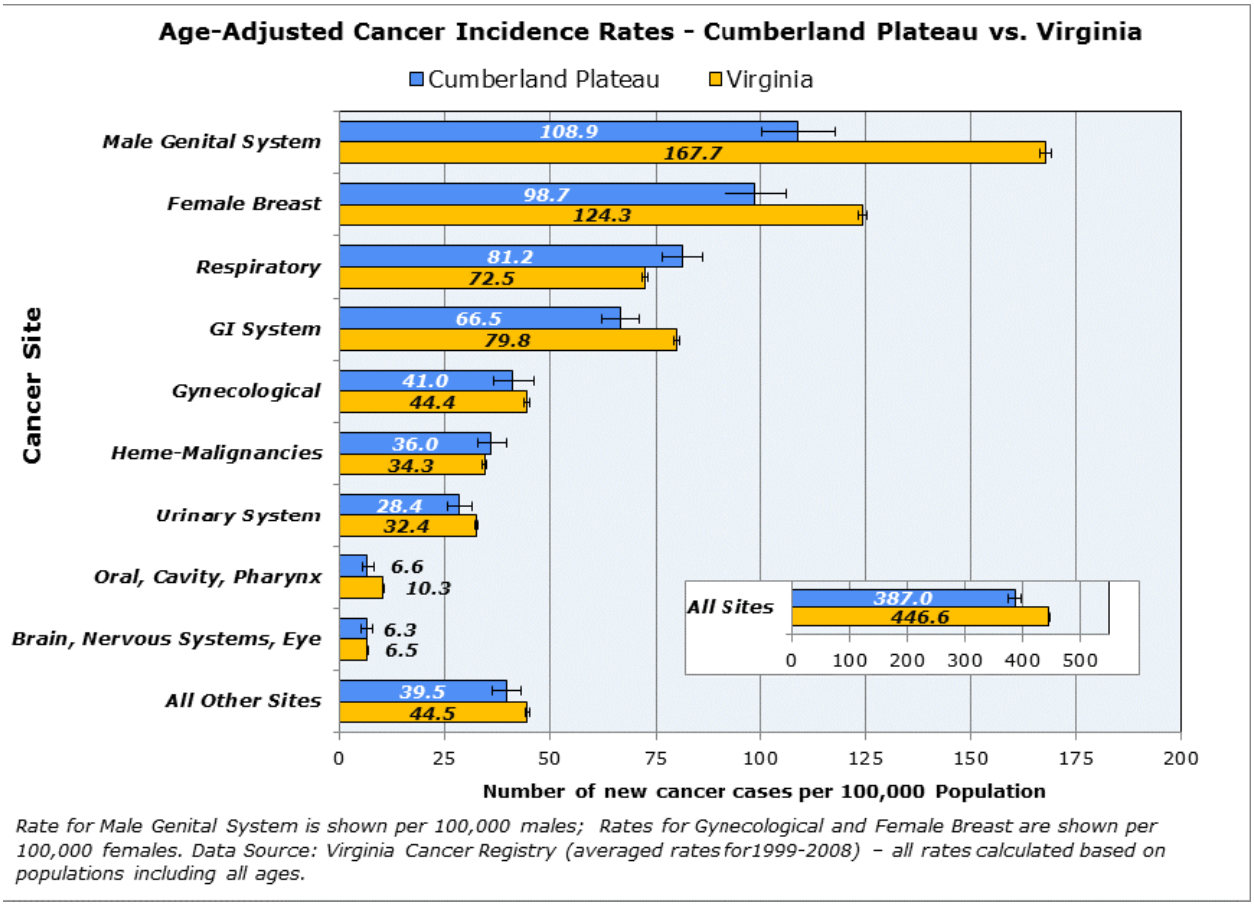

Figure 3: Age-Adjusted Cancer Incidence in the Cumberland Plateau Health District

To evaluate the impact of cancer on the community, in terms of provider burden and services needed, information on the annual number of cancer diagnoses was acquired from the Virginia Cancer Registry. In the Cumberland Plateau Health District, based on a 10-year average (1999-2008), there is an average of 533 cases of new cancers each year **(Table D** and **Figure 4)**. Respiratory, GI, female breast, and male genital system cancers had the highest average number of new cases; together they make up 74% of the total cases.

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

Top 5 Cancers in Cumberland Plateau Health District by Incidence Count		
Cancer Site	**Annual Count**	***Notes***
Respiratory	**115**	*Data Source: Virginia Cancer Registry*
GI System	**92**	
Colon & Rectum	55	*Annual Count - represents average number of new cases per year in the health district (averaged over period 1999-2008).*
All Other GI	37	
Female Breast	**73**	
Male Genital System	**67**	
Prostate	64	
Other male genital organs	3	
Heme-malignancies	**48**	*All Other Sites include Brain, Nervous System, Eye, Gynecological, Oral Cavity, Pharynx, Urinary System, and Other sites.*
Lymphomas	26	
Leukemias	15	
Myeloma	7	
All Other Sites	**138**	
All Sites	**533**	

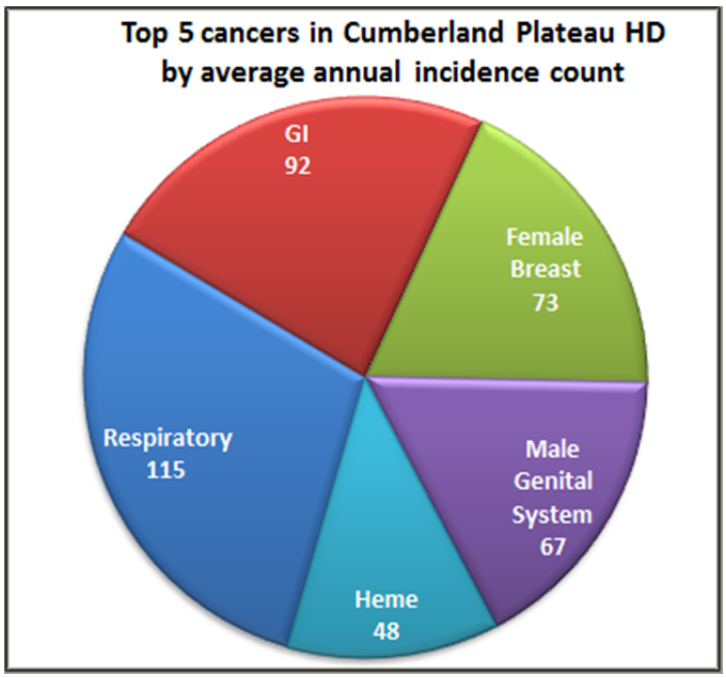

Figure 4: Top 5 cancers in the Cumberland Plateau Health District by Incidence Count[15]

[15] Data Source: Virginia Cancer Registry Percentage based on annual cancer cases count (averaged over period 1999-2008 for top 5 cancers in the health district as compared to the rest of cancer cases

The top three cancers for males in the health district are respiratory, genital, and GI cancers, with crude rates of 124.3, 118.6, and 87.3 cases per 100,000 men, respectively. These three cancer subtypes comprise approximately 75% of the cancers in men in this district **(Table E** and **Figure 5)**.

Table E: Top 5 Male Cancers in the Cumberland Plateau Health District

Top 5 Male Cancers in Cumberland Plateau			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Respiratory	**124.3**	**70**	*Data Source: Virginia Cancer Registry*
Male Genital System	**118.6**	**67**	
Prostate	114.2	64	*Crude Rate – represents number of new male cancer cases per 100,000 males.*
Other male genital organs	4.4	3	
GI System	**87.3**	**49**	
Colon & Rectum	51.1	29	*Annual Count - represents average number of new male cancer cases per year in the health district (averaged over period 1999-2008).*
All Other GI	36.3	20	
Heme-malignancies	**45.9**	**26**	
Lymphomas	24.5	14	
Leukemias	14.4	8	
Myeloma	6.9	4	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.*
Urinary System	**45.7**	**26**	
All Other Sites	**64.7**	**36**	
All Sites	**486.7**	**274**	

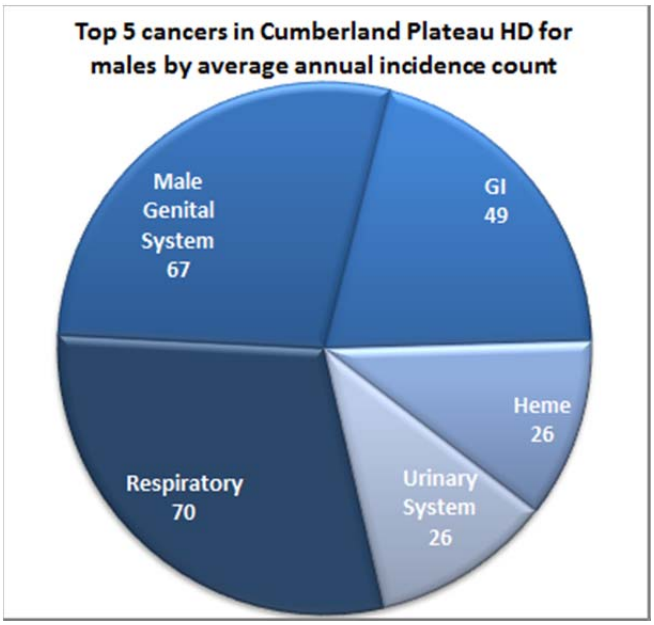

Figure 5: Top 5 Male Cancers in the Cumberland Plateau Health District

Cancers with the highest incidence rates for females in the district are breast, respiratory, and GI cancers, with crude rates of 124.6, 77.3, and 73.2 cases per 100,000 women, respectively. These cancers represent 75% of new incidences of cancer in women in the district each year **(Table F** and **Figure 6)**.

Table F: Top 5 Female Cancers in the Cumberland Plateau Health District

Top 5 Female Cancers in Cumberland Plateau			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Female Breast	**124.6**	**73**	*Data Source:* *Virginia Cancer Registry*
Respiratory	**77.3**	**45**	
GI System	**73.2**	**43**	*Crude Rate – represents number of new female cancer cases per 100,0000 females.*
Colon & Rectum	45.6	27	
All Other GI	27.6	16	
Gynecological	**50.9**	**30**	*Annual Count - represents average number of new female cancer cases per year in the health district (averaged over period 1999-2008).*
Corpus and Uterus	23.3	14	
Ovary	15.4	9	
Cervix	8.2	5	
All other Gynecological	3.9	2	
Heme-malignancies	**37.9**	**22**	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.*
Lymphomas	21.1	12	
Leukemias	12.3	7	
Myeloma	4.5	3	
All Other Sites	**80.9**	**47**	
All Sites	**444.7**	**260**	

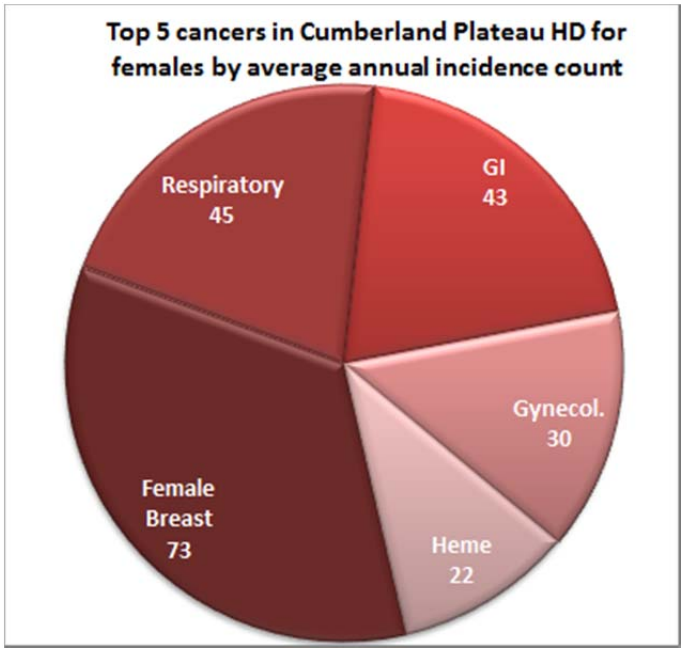

Figure 6: Top 5 Female Cancers in the Cumberland Plateau Health District

Men and women in the Cumberland Plateau Health District develop cancer at similar rates (487 vs. 445 cases per 100,000 people, respectively). However, the incidence rates and counts of specific cancer types vary substantially by gender. Respiratory cancer rates are much higher in men (124.3 vs. 77.3) and represent the cancer with the highest incidence in males. Men also had higher rates for GI cancers (87.3 vs. 73.2) and hematologic malignancies (45.9 vs. 37.9). Female breast cancer has the highest occurrence rate in women followed by respiratory and GI system cancers. Breast cancer accounts for the largest incidence of cancer in women, whereas respiratory cancer accounts for the largest incidence in men in this district.

The African American population in the Cumberland Plateau Health District is approximately 2% of the total population of this health district, which made comparison of cancer incidence, staging, and mortality rates by race difficult. For example, there were only 17 reported cancer cases annually in African American residents over a 10 year period. For this reason, a comparison was not performed.

Cancer Staging and Mortality

Cancer staging is needed for proper treatment planning. Discovering cancer at the local stage is usually indicative of a better outcome and improved survivorship. Compared to Virginia, cancers are found at approximately the same early to late stage ratio in the Cumberland Plateau Health District as the rest of the state **(Figure 7)**. Of particular interest, the cancer staging at diagnosis is similar in this district to that of the state for respiratory cancers; however, the mortality rate in this district is significantly higher for this cancer type.

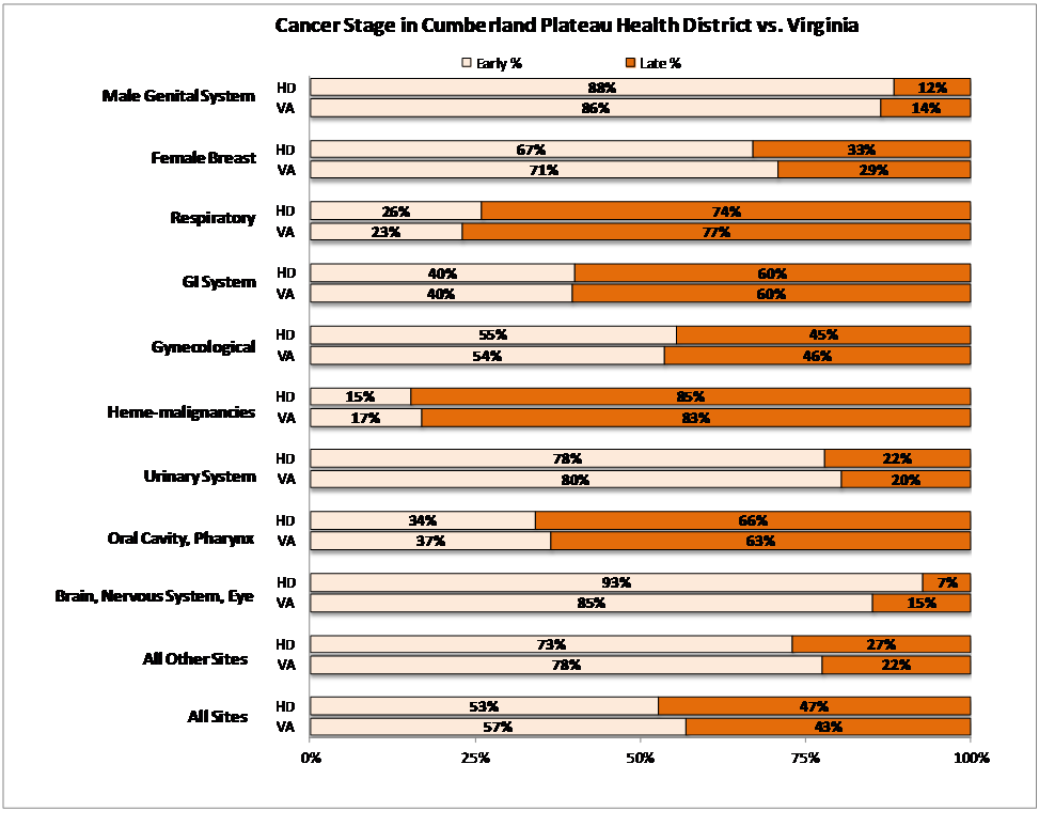

Figure 7: Cancer Stage in the Cumberland Plateau Health District vs. Virginia[16]

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

An average of 289 residents in the Cumberland Plateau Health District succumb to cancer-related causes of death each year. The cancers resulting in the greatest number of deaths in the Cumberland Plateau Health District are respiratory, GI, hematologic, female breast, and urinary system cancers, in that order **(Table G)**. In contrast to cancer incidence, the district has a higher age-adjusted mortality rate than Virginia when all cancer sites are grouped together. Notably, the mortality rate for respiratory cancers in the district is significantly higher when compared to that of Virginia **(Figure 8)**. Respiratory and GI cancer deaths account for 53% of the cancer deaths in the district.

Table G: Top 5 Cancers in the Cumberland Plateau Health District by Death Count

Top 5 Cancers in Cumberland Plateau by Annual Death Count		
Cancer Site	**Annual Count**	***Notes***
Respiratory	**99**	*Data Source: Virginia Department of Health (averaged counts for 5-year period 2005-2009) - based on population for all ages.* *Dataset ordered by descending death counts for health district.* *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Male genital System, and Other sites.*
GI System	**56**	
All Other GI	32	
Colon & Rectum	24	
Heme-malignancies	**27**	
Lymphomas	13	
Myeloma	7	
Leukemias	7	
Female Breast	**20**	
Urinary System	**15**	
All Other Sites	**73**	
All Sites	**289**	

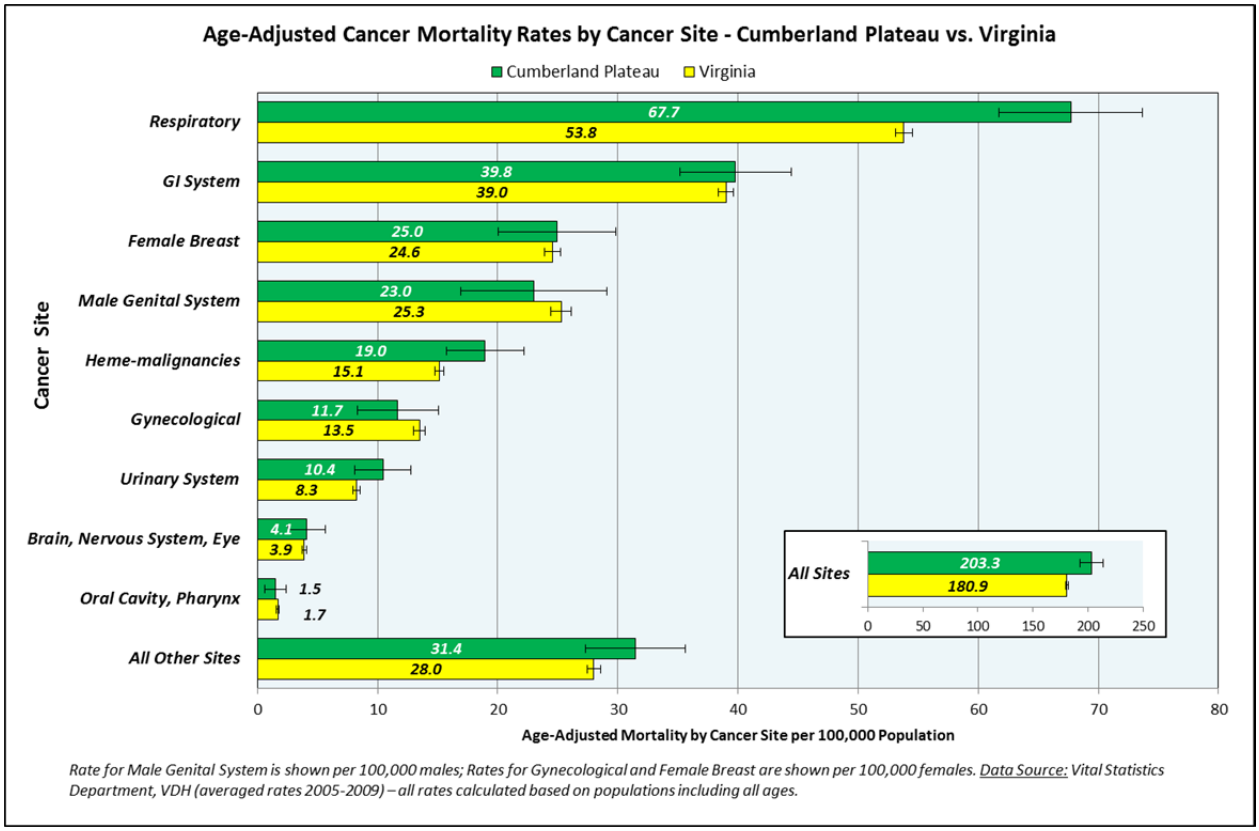

Figure 8: Age-adjusted Mortality Rate by Cancer Site in the Cumberland Plateau Health District vs. Virginia

Men have a higher crude cancer mortality rate than women in the health district (283.3 vs. 227.3). In both genders, the top two cancer types responsible for deaths are respiratory and GI, with the crude mortality rates in both subtypes higher in men than women (107 vs. 67.9 and 58.9 vs. 40.5 per 100,000 deaths, respectively). Similarly, hematologic malignancies cause significant mortality in both genders in the health district, with crude mortality rates higher in men than women (27.3 vs 19.7) **(Tables H** and **I)**.

Respiratory and GI cancers represent close to 60% of the mortality burden in men. In women, respiratory, GI, and breast cancer make up a similar burden (62.5%). Mortality burden from breast and GI cancers is practically equivalent in women **(Figures 9** and **10)**. The small African American population (2%) in the Cumberland Plateau Health District made comparison of cancer incidence, staging, and mortality rates by race impossible.

Table H: Crude Death Rates and Annual Counts in Men in the Cumberland Plateau Health District

Top 5 Male Cancers in Cumberland Plateau by Mortality			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Respiratory	**107.0**	**60**	*Data Source:*
GI System	**58.9**	**33**	*Virginia Department of Health (2005-2009) – rates calculated based on population for all ages.*
All Other GI	35.2	20	
Colon & Rectum	23.7	13	
Heme-malignancies	**27.3**	**15**	*Dataset ordered by descending count for health district.*
Lymphomas	13.3	7	
Leukemias	7.2	4	*Crude Rate - represents number of male cancer deaths per 100,000 males.*
Myeloma	6.8	4	
Male Genital System	**19.7**	**11**	*Annual Count - represents average number of male cancer deaths per year in the health district (averaged over period 2005-2009).*
Prostate	19.7	11	
Other male genital organs	0.0	0	
Urinary System	**19.0**	**11**	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.*
All Other Sites	**51.3**	**29**	
All Sites	**283.3**	**158**	

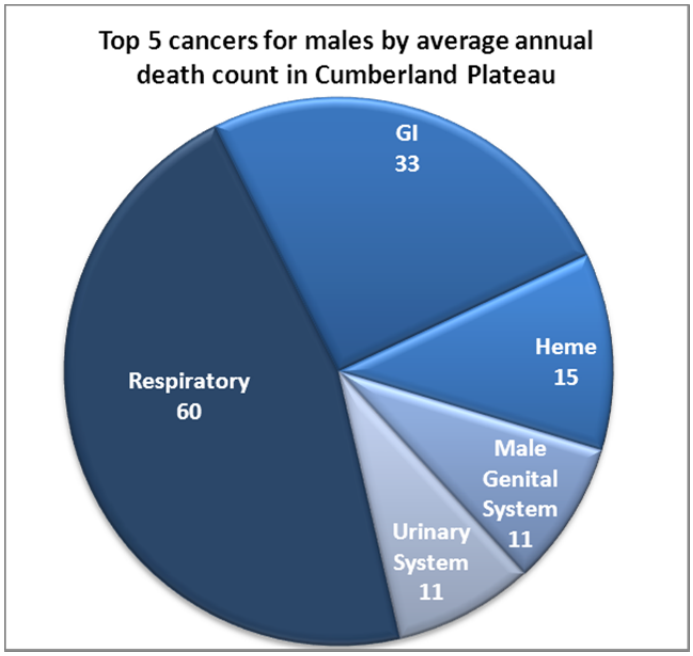

Figure 9: Top 5 Cancers Causing Death in Males in the Cumberland Plateau Health District

Table I: Crude Death Rates and Annual Counts in Women in Cumberland Plateau Health District

Top 5 Female Cancers in Cumberland Plateau by Mortality			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Respiratory	**67.9**	**39**	*Data Source:*
GI System	**40.5**	**23**	*Virginia Department of Health (2005-2009) – rates calculated based on population for all ages.*
All Other GI	21.5	12	
Colon & Rectum	19.1	11	
Female Breast	**34.6**	**20**	*Dataset ordered by descending count for health district.*
Heme-malignancies	**19.7**	**11**	
Lymphomas	9.7	6	*Crude Rate - represents number of female cancer deaths per 100,000 females.*
Myeloma	5.5	3	
Leukemias	4.5	3	
Gynecological	**15.9**	**9**	*Annual Count - represents average number of female cancer deaths per year in the health district (averaged over period 2005-2009).*
Ovary	9.7	6	
Cervix	3.8	2	
Corpus and Uterus	1.0	1	
All other Gynecological	1.4	1	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.*
All Other Sites	**48.9**	**28**	
All Sites	**227.6**	**131**	

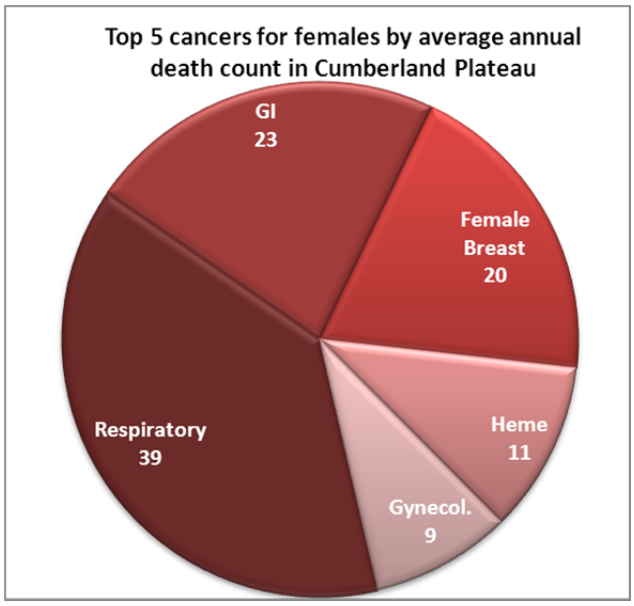

Figure 10: Top 5 Cancers Causing Death in Females in the Cumberland Plateau Health District

Cancer Healthcare Resources

Healthcare Facilities and Cancer Care

There are five hospitals in the Cumberland Plateau Health District: Clinic Valley Medical Center (CVMC) in West Tazewell, Carillion Tazewell Community Hospital (CTCH) in East Tazewell, Dickenson Community Hospital (DCH) in Clintwood, Buchanan General Hospital (BGH) in Grundy, and Russell County Medical Center in Lebanon. There are three oncologists serving the health district at the Clinch Valley Medical Center as of this assessment: one medical oncologist, one radiation oncologist, and one hematologist. Almost all of this health district is designated as rural and medically underserved. Travel within the health district, and even within the counties, can involve long and very winding roads. Many residents in this health district have the further challenge of not having personal transportation, requiring them to depend on their ability to get a "ride" from family or friends.

Cancer Services Provided

The following is a summary of cancer-related services within the Cumberland Plateau Health District. For additional information see **Appendix D**.

Screening

Breast mammography and breast ultrasound are available at all five hospitals, with digital mammography offered at CVMC, BGH, and Russell County Medical Center. All facilities offer diagnostic mammography, with only CVMC, BGH, and CTCH performing radiology-guided breast biopsy. The two remaining hospitals refer their patients to Johnson City Memorial Medical Center. Only CVMC offers colposcopy. Colorectal cancer screening, either sigmoidoscopy or colonoscopy, is available at the CVMC, BGH, and CTCH.

Treatment

Within the health district, treatment modalities for cancer include chemotherapy, radiation, and surgery. CVMC is the only hospital that offers all three treatment modalities and is the only hospital in the health district that offers chemotherapy and radiation therapy. Partial and complete mastectomies are performed at CVMC and BGH, but breast reconstruction is not available in the health district. Ear, nose, and throat surgeries are also performed at these two hospitals. CVMC also offers gynecologic and GI cancer surgery, including liver resection. No lung, pancreas, prostatectomy, or brain surgery is offered at any of the hospitals.

Auxiliary Services

Programs that address treatment effects and survivorship needs, including dietary provision and counseling, genetic counseling, pain management and end-of-life services, are important services that effect both outcomes and quality of life. Three of the five hospitals in the district have registered dieticians on staff to address nutrition issues specific to cancer patients following the American Dietetic Association guidelines. Only CVMC has a dietitian with oncology certification. The most comprehensive nutrition services are provided at CVMC, including in- and out-patient nutrition counseling specific to oncology as well as cancer prevention and control nutrition education programs.

None of the hospitals indicated that they perform genetic testing to determine cancer risk or offer genetic counseling services. Only Russell County Medical Center indicated that they have a palliative care program that makes recommendations to the attending physicians, with team members including an MD board certified in palliative care, a registered nurse, social worker,

case worker, and chaplain, but no registered dietitian. The program does not have in-patient beds, or offer outpatient services. None of the hospitals have a patient navigator.

Support groups for cancer patients and caregivers are offered at CVMC and BGH. CTCH is interested in starting a support group for breast cancer and lung cancer patients. Two hospitals, RCMC and CTCH offer smoking cessation programs, but these are the only cancer prevention programs indicated as being offered through the hospitals in the health district **(see Appendix D)**.

Clinical Trials

None of the hospitals have a cancer clinical trials program at the time of this assessment. All of the hospitals indicated that they are not interested in starting a cancer clinical trials program at this time.

Hospice Services

Hospice services are offered on an in-patient and outpatient basis at three of the five hospitals in the health district: CVRC, Russell County Medical Center, and CTCH. Russell County Medical Center Hospice is a hospital-owned hospice provider. All of the counties have licensed hospice providers within the county. Special Care Hospice is a located in Buchanan county and serves Dickenson County, as well. Dickenson City Home Health and Hospice, Inc., is located in Clintwood and is locally owned. Tazewell County is serviced by several hospice providers, including Legacy Hospice and Total Homecare Hospice. Finally, in addition to the hospital owned hospice provider in Russell County, Home Nursing Company provides hospice services for and is located in Lebanon.

Areas to Improve Cancer Services

Although various surgical oncology services are offered within the district, some surgical procedures are not available, including lung and prostate surgeries. Clinical trials, which used to be offered at CVMC, were discontinued in March 2013 due to funding issues. Currently, no cancer clinical trials are offered in the health district. Also, cancer-related patient navigation services and genetic counseling are not available in the health district.

Community Cancer Resources

The Cumberland Plateau 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 direct services. Six organizations were identified including:

- The American Cancer Society, which has one resource center in Abingdon and three staff members serving both the Cumberland Plateau and Lenowisco health districts. They assist the hospitals in the region with resources and events. They also offer $100 gift cards for gas for cancer patients.

- Susan G. Komen for the Cure (Tri Cities) offers some educational forums related to breast cancer to local residents.

- The Health Wagon is a free mobile clinic that serves the remote mountains of Southwest Virginia. The clinic is a customized Winnebago, which though domiciled

in Clintwood Virginia, maintains a regular travel schedule on narrow two lane highways to serve the underserved, poverty stricken people in the Cumberland Plateau and Lenowisco health districts. The Health Wagon travels to eight sites in Buchanan, Dickenson, Russell, and Wise counties. There is also a new, 4,900 square foot specialty clinic which is stationary in Wise.

- Healthy Appalachia is a coalition between the University of Virginia College at Wise, the University of Virginia, the Southwest Virginia Graduate Medical Education Consortium, the Appalachian Regional Commission, Virginia Department of Health PD I & II, and the Virginia Community Healthcare Association. Healthy Appalachia is working to develop a common understanding of the region's health status and a strategic vision of a healthier future for the residents of far Southwest Virginia.

- The Cancer Outreach Foundation, located in Abingdon, offers financial and transportation assistance to cancer patients in the region, as well as emotional counseling to patients going through treatment and their families.

- The Virginia Department of Health Every Woman's Life Program is managed out of the VDH office in Lebanon and serves all four counties in the health district. 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.

Details about each organization within the health district can be found in **Appendix E**.

Healthcare Provider Needs

Key Leader Information

Five experienced, long-term residents who are health care professionals in the Cumberland Plateau Health District were interviewed to gain a knowledge base of the healthcare system currently in place as relates to cancer care and specifically, any deficiencies therein. These five individuals were selected because they represent all of the four counties (Tazewell, Dickenson, Buchanan, and Russell) in the Cumberland Plateau Health District. Their credentials include physicians, senior hospital administrators, and registered nurses. 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 the needs of PCPs, 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 AND the general population to promote healthy lifestyles; (2) proximity to adequate treatment services, devices, and facilities; (3) financial burdens as related to transportation, reliable transportation, and time constraints as related to family duties that would need support be it internal or external; and (4) lack of effective communication between oncologists and PCPs.

Tobacco use was universally cited as creating a significant cancer risk in the Cumberland Plateau Health District. There is an urgent need for educational programs to encourage the promotion of awareness of 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. 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. There are also financial deficits causing longer wait periods to qualify for cancer diagnostics and detection services as well as treatment and post-treatment care.

It was also pointed out that very few of the students (who are awarded rural county grants to enable them to be trained in the medical field of their choice) remain in the rural districts that are in desperate need of physicians in all areas of health care, from PCPs to specialized surgeons.

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. Twelve physicians in the Cumberland Plateau Health District completed a cancer questionnaire, either on paper or online. A 30% response rate was obtained from the physicians contacted. Over half of the responding physicians were family practice physicians, with the next largest group being internal medicine doctors. The remainder specialized in gastroenterology and for-profit clinic work generalists. The findings of the survey are as follows:

Cancer Screening and Compliance:

Respondents identified breast, lung, and colorectal cancer as the three most prevalent cancer diagnoses in their practices. When asked about the compliance of their patients to screening recommendations, the majority of responding physicians (63%) felt their patients had above average compliance with breast cancer screenings, while half indicated average compliance with cervical cancer screenings. In contrast, the vast majority (78%) felt their patients had low to average compliance with colorectal cancer screening recommendations **(Figure 11)**. The most compelling reasons physicians cited for patients not having a recommended screening were financial constraints, apprehension about the tests, lack of insurance, and disbelief of necessity. Physicians were interested in receiving updates on screening challenges and updated screening recommendations, especially for lung, colorectal, and female cancers **(Figure 12)**. The preferred method to receive this information was in a written format.

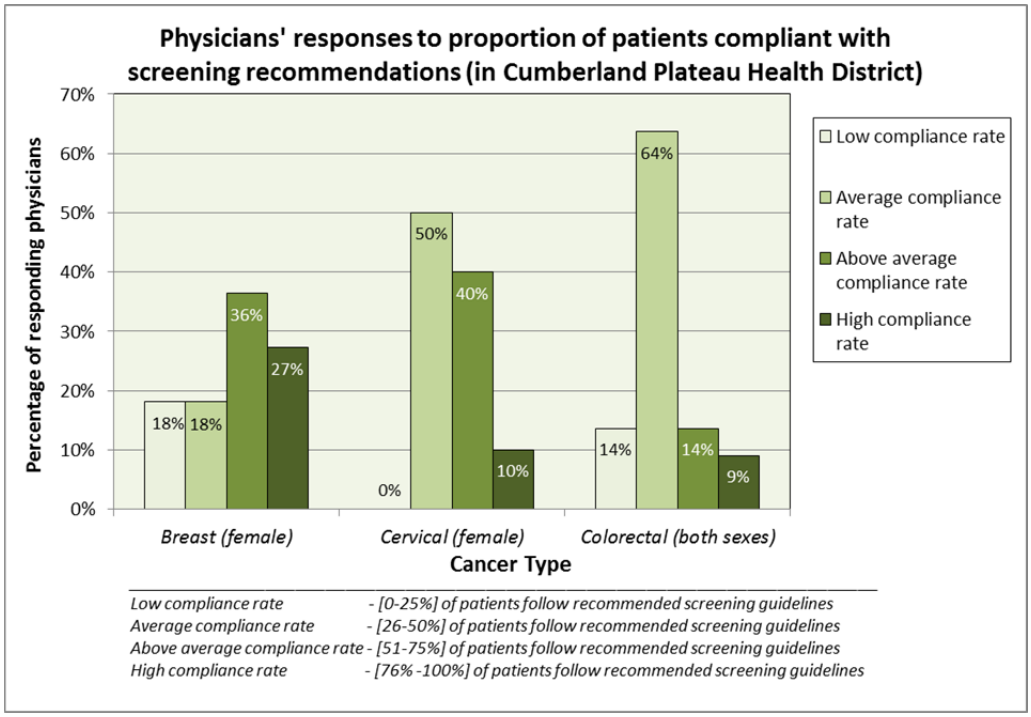

Figure 11: Patient Compliance with Screening Recommendations

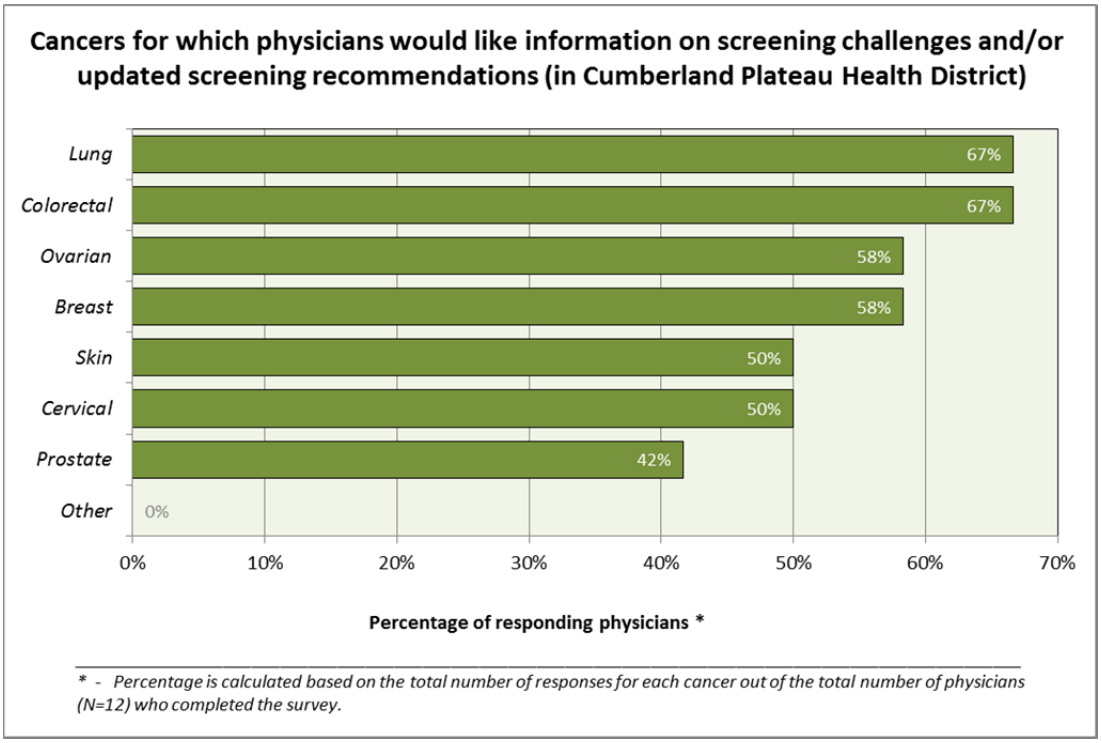

Figure 12: Most Common Reasons Patients Choose Not to Have Recommended Cancer Screenings as Identified by Physicians in the Cumberland Plateau Health District

Referrals and Communication:

When asked where they refer their patients diagnosed with cancer, 100% percent of respondents reported that they prefer to refer oncology patients locally for surgery and treatment, while 17% additionally sent patients outside of Virginia, to other Virginia cancer centers (non-NCI), or to a NCI center in Virginia (VCU or UVA). Communication coming from oncologists that was found to be useful to all community physicians was the initial treatment plans **(Figure 13)**. Slightly more than half of responding physicians reported that they were usually to almost always satisfied with the communication they received from treating oncologist, while a quarter of respondents were rarely satisfied with the communication **(Figure 14)**.

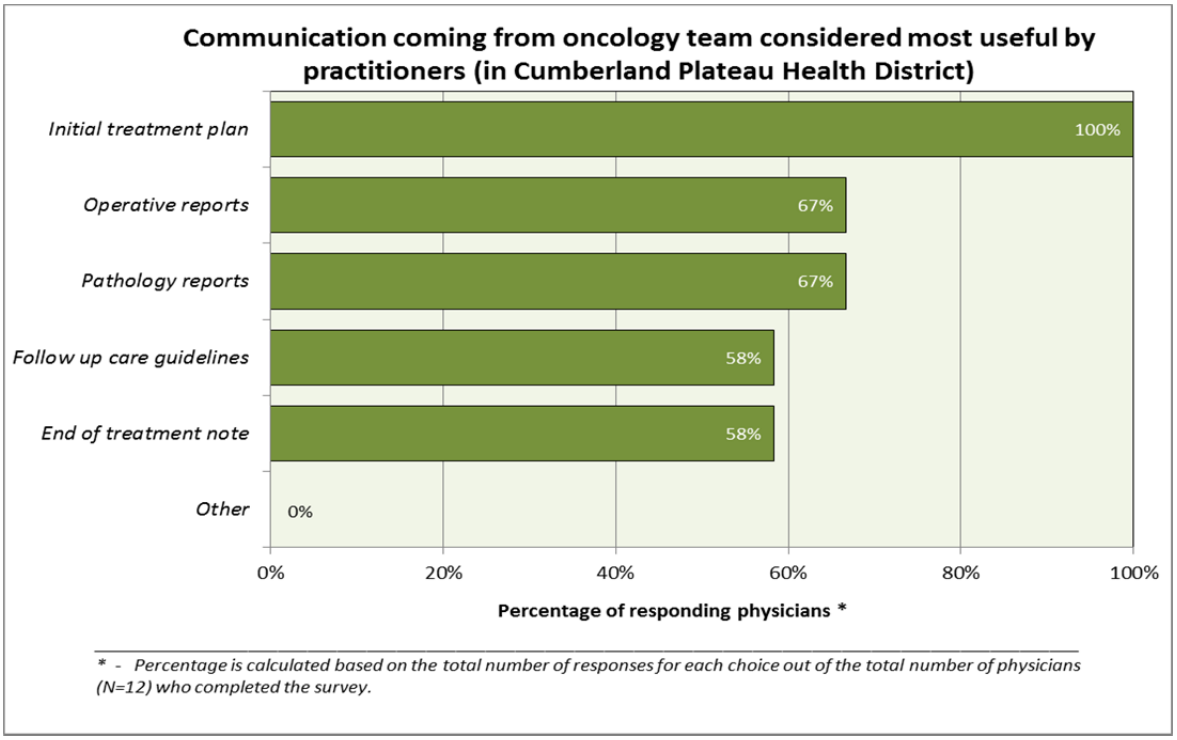

Figure 13: Communication from Oncologist Most Useful to Practitioners

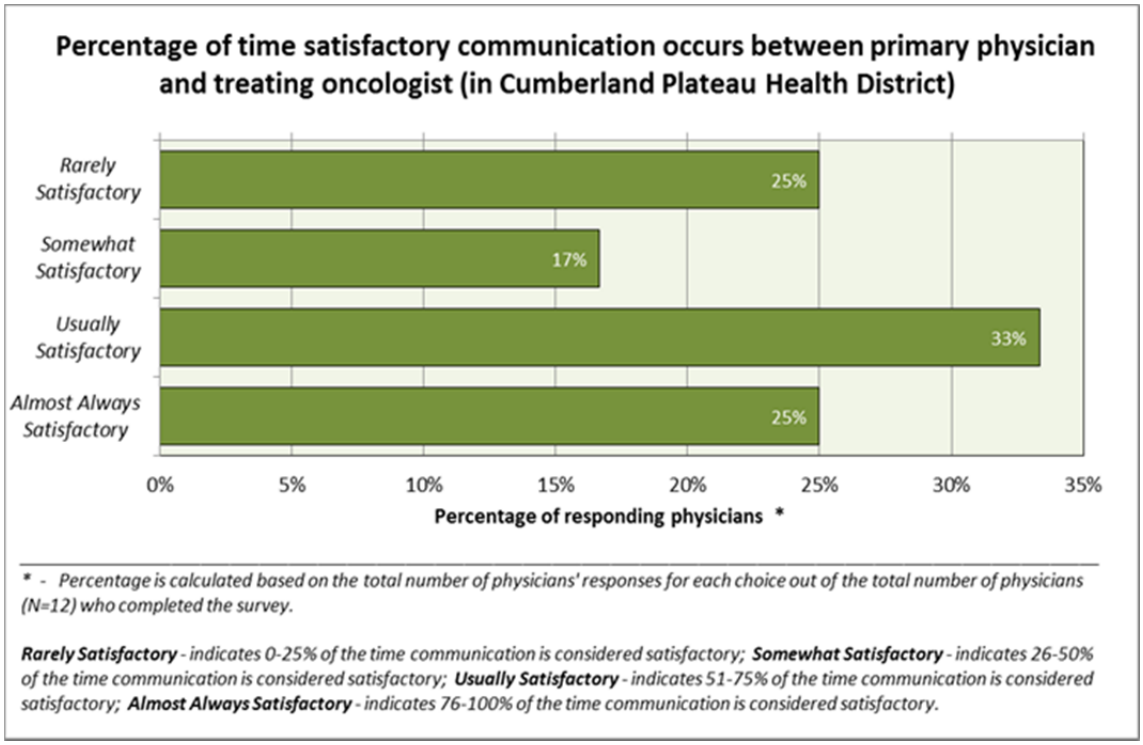

Figure 14: Physician Satisfaction with Communication Coming from Treating Oncologists

Post-cancer Treatment:

Post-treatment continuing education topics of interest to the majority of physicians included updated information about surveillance of cancer recurrence, long-term cancer treatment effects, pain management, and end-of-life care and planning. In line with this, physicians indicated that they were only comfortable providing non-oncology care during active cancer treatment (80%) with only a small percentage indicating they were comfortable performing long-term oncology follow-up (33%) or join management of oncology care (25%) **(Figure 15)**.

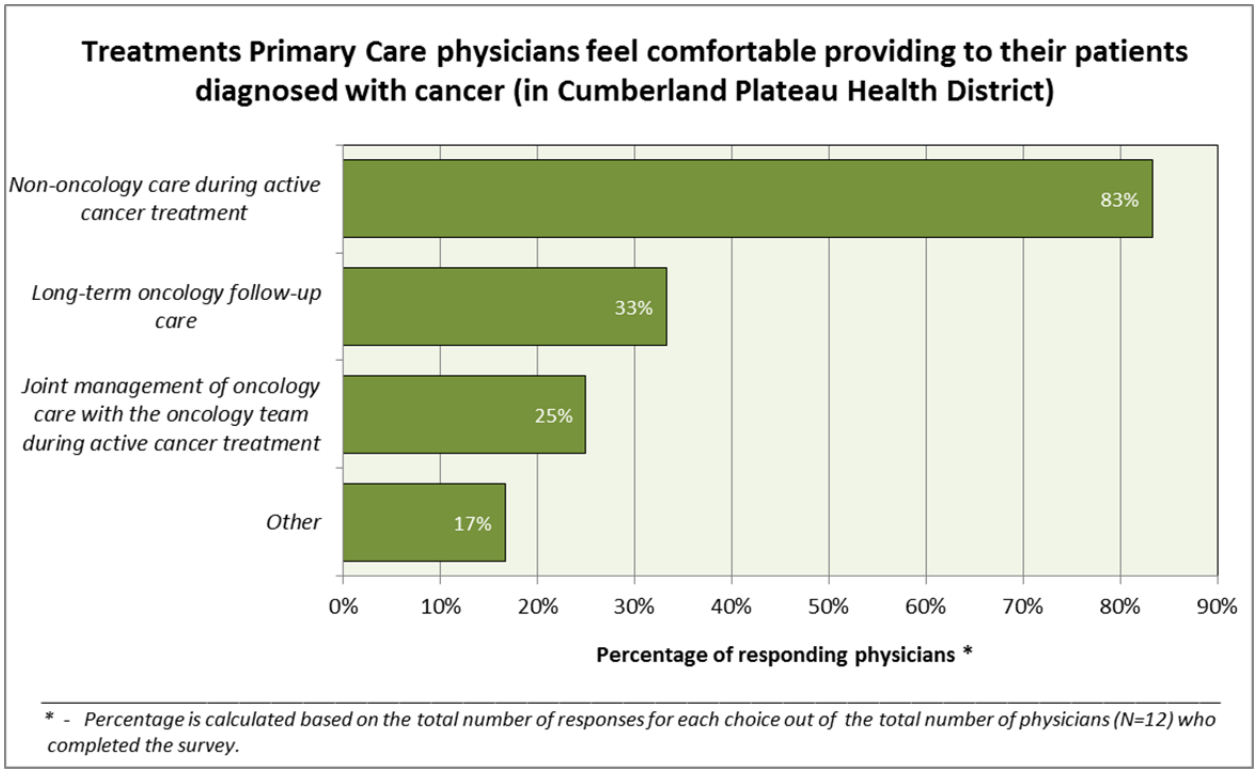

Figure 15: Treatments Primary Care Physicians are Comfortable Providing to Cancer Patients

Community Population Needs

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

Behavioral Risk Factor Surveillance Survey

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

According to BRFSS results, adults 18 years and older in the Cumberland Plateau Health District have higher rates of sedentary behavior, tobacco use, and obesity than Virginia as a whole. All three of these factors are associated with a higher cancer risk. One-third of the Cumberland Plateau Health District residents had had no regular physical exercise in the past 30 days, and only 24% included vegetables and fruits in their daily diet. Approximately 25% of the residents in the health district currently smoke, which is significantly higher that the state smoking rates (18%) **(Figure 16)**. This information is supported by comments gathered in the focus groups.

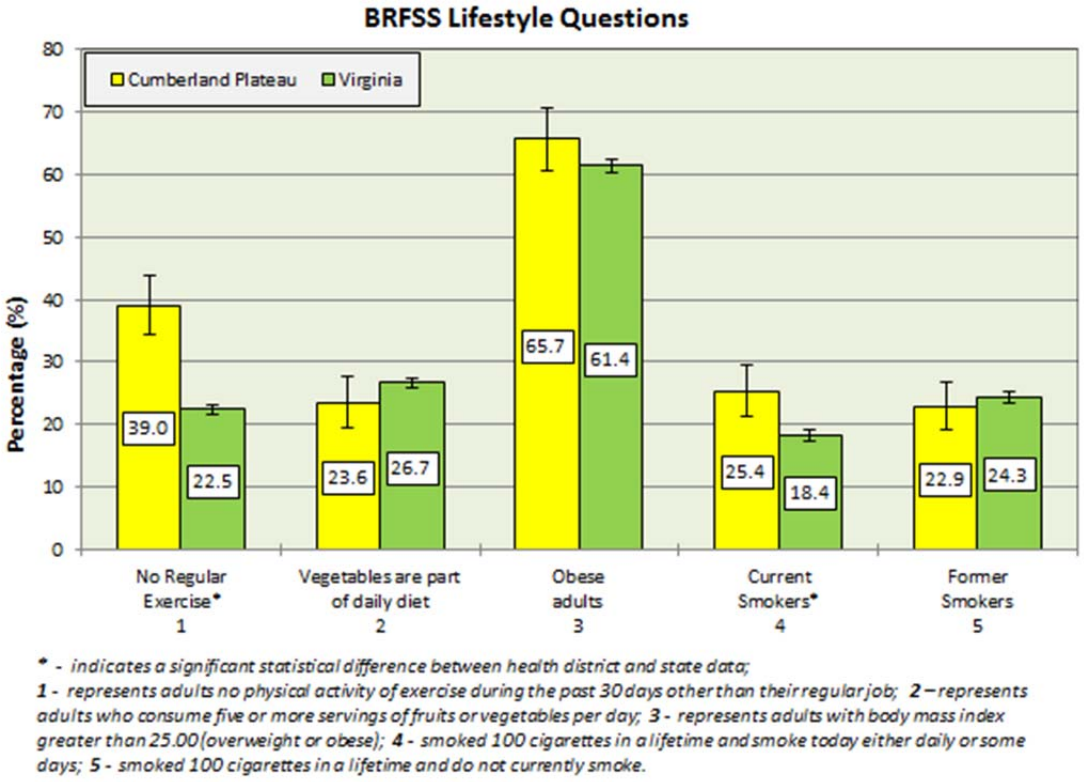

Figure 16: BRFSS Lifestyle Questions for the Cumberland Plateau Health District

Access to healthcare for residents of the Cumberland Plateau Health District is similar to that for those in other parts of the Commonwealth. The majority of residents have a PCP and have visited their doctor in the past year. When compared to the state of Virginia, however, a larger proportion of individuals in this district are unable to see a doctor due to costs or not having health insurance **(Figure 17)**.

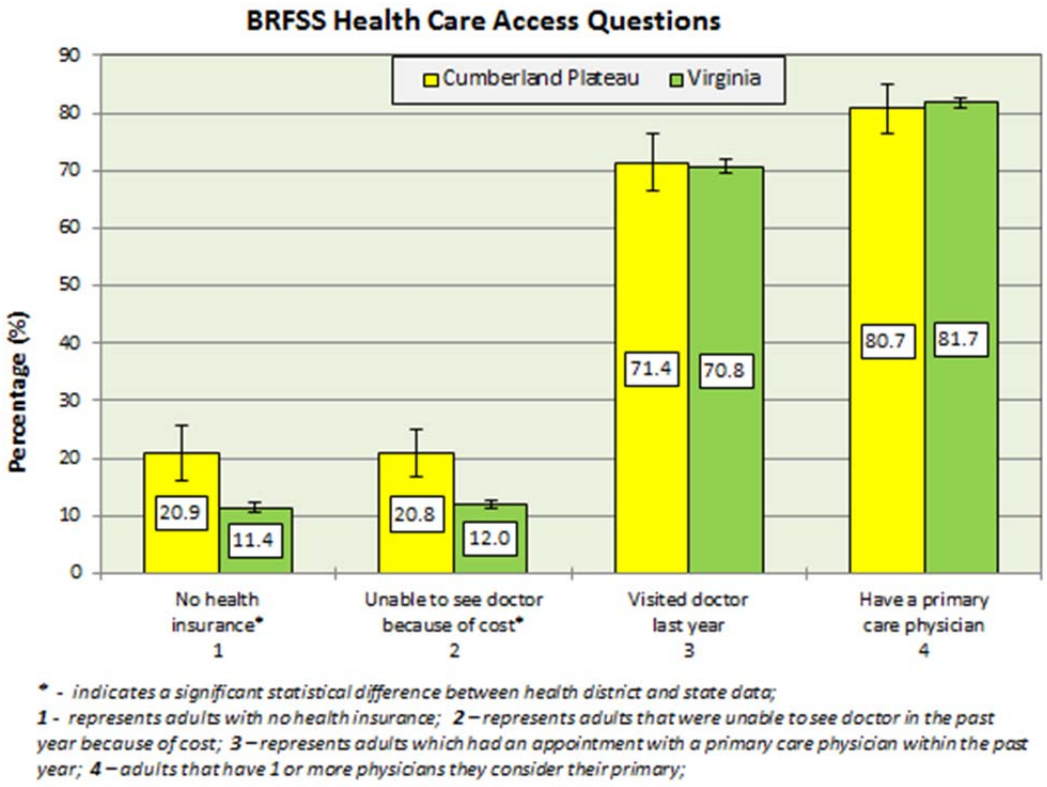

Figure 17: BRFSS Health Care Access Questions

The percentage of patients who are compliant with treatment guidelines for colorectal and cervical cancers in the health district is similar to that of the state of Virginia. This does not hold true for PSA screening for prostate cancer, mammography for breast cancer screening, or fecal occult blood test (FOBT) screening tests for colorectal cancer, which are lower than for Virginia as a whole **(Figure 18)**.

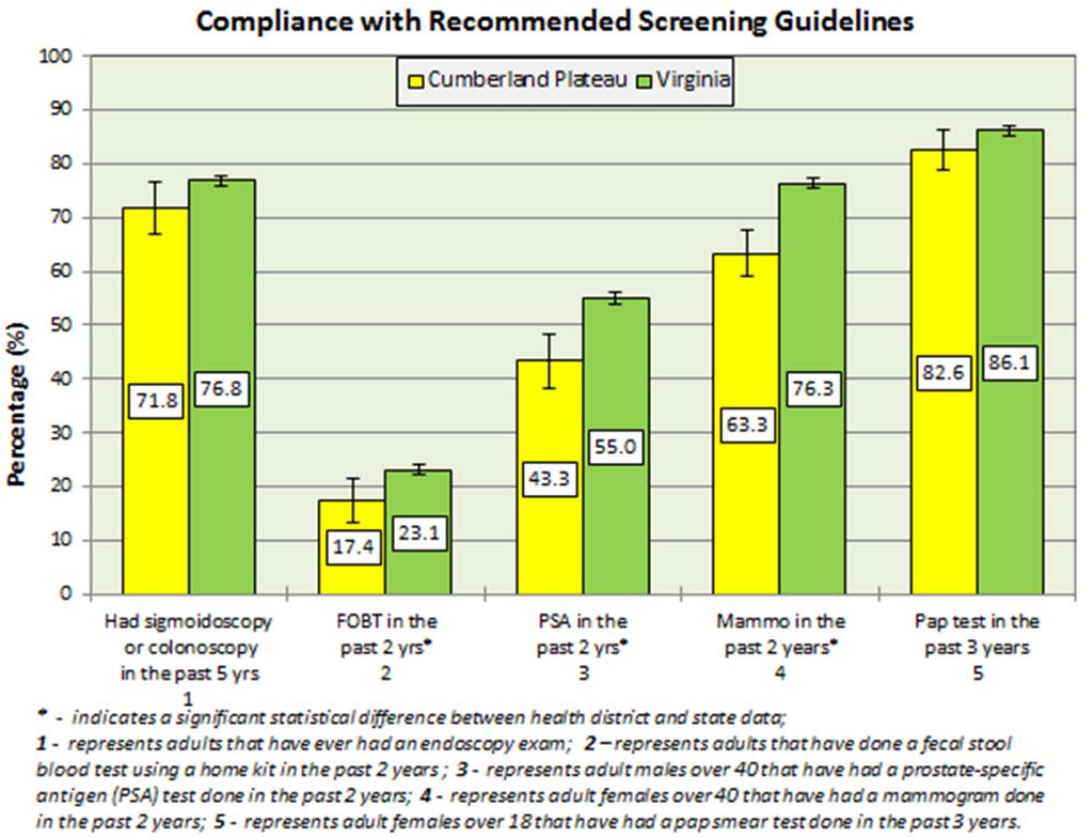

Figure 18: Compliance with Recommended Screening Guidelines

Focus Group Information

Focus group participants were selected from the pool of volunteers who responded to mass email list-serves, flyers, and personal presentations. In addition, ads were placed in area newspapers and on select radio stations. The demographics of the community were used as a guide for final selection of the participants. Gender, age, education, and economic distribution of the focus groups were matched to the health district as closely as possible. Personal experience with cancer was a criterion for placing volunteers into either the general population or cancer survivor focus groups. The general population focus groups consisted of people who had little or no experience with cancer. The survivor focus groups consisted of people who either had a diagnosis of cancer or were the primary caregiver of a cancer patient.

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

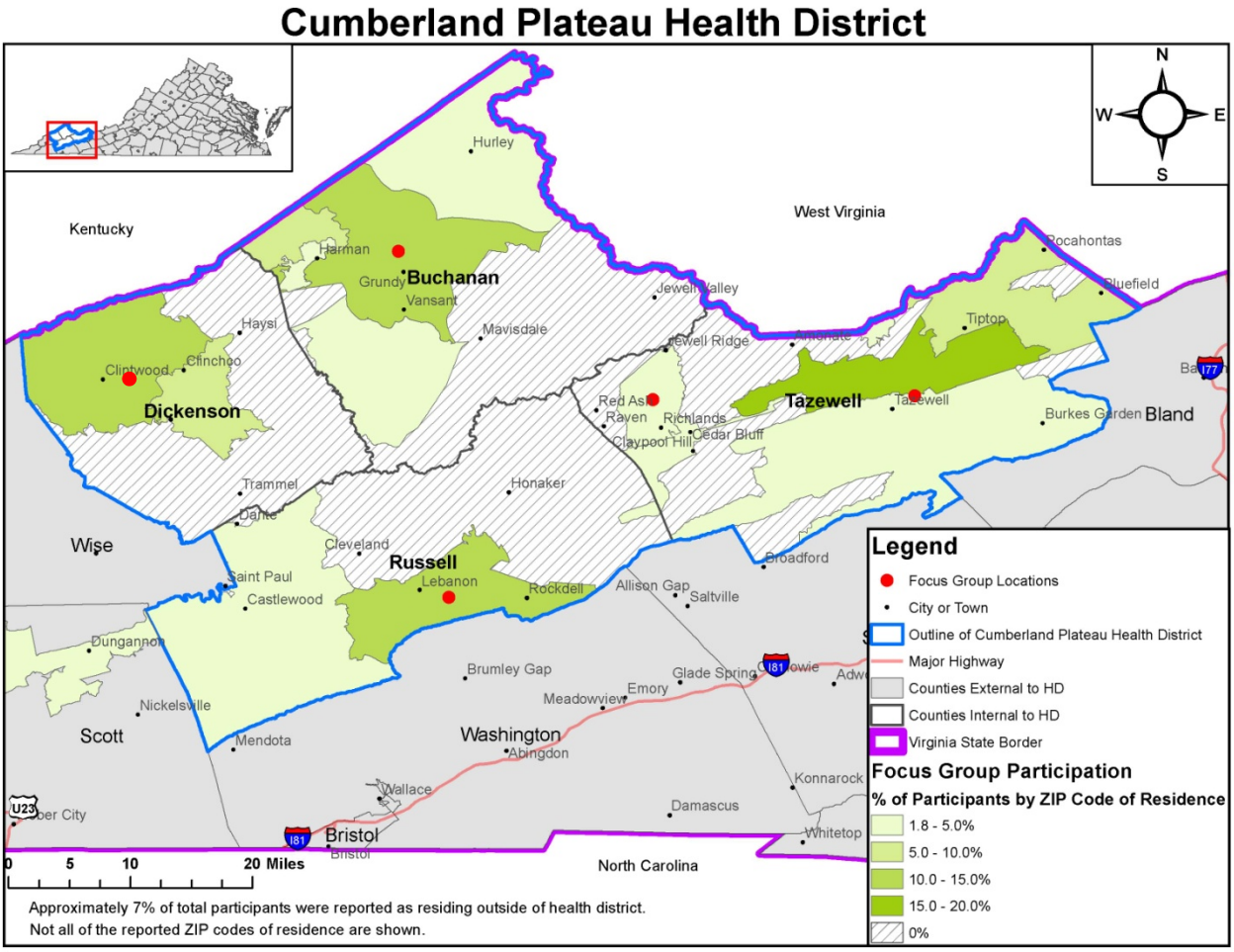

Figure 19: Focus Groups Participation in the Cumberland Plateau Health District

General Population Group Synopsis:

Five focus groups with the general population were held in four areas distributed throughout the health district. There was a total of 30 participants, with an average group attendance of 6. Participants were able to identify prevailing health problems in their communities, including diabetes, black lung, and the diseases that have the highest impact on mortality: heart disease, obesity, drug abuse, COPD, and cancer. Pollution, access to clean water, and second-hand smoke exposure were of greater concerns to participants than cancer. Mental illness, arthritis, and smoking were also identified as concerns.

Cancer was identified as a significant concern in all of the focus groups. Having had a relative with cancer and the resulting difficulties with accessing care and financing treatment costs was thought to create a heightened awareness and concern about cancer in the community. The

difficult experiences resulting from the limited resources available in the health district for cancer treatment has contributed to the fear of diagnosis expressed in most of the focus groups.

> "If I have cancer in my body, I don't want to know it. I wouldn't have treatment anyway."
> "I would devastate the family finances and die anyway, so no way would I have cancer treatment."

Participants readily identified lifestyle behaviors that have a positive and negative impact on health, including a healthy diet, avoiding tobacco and substance use, and performing medical screenings. Dietary habits most often identified as having a negative impact on health included high fat foods, foods from fast food restaurants, and processed foods. Those specifically associated with increased cancer risk were fats, preservatives, and additives in foods. Organic foods, fresh vegetables, and washing your fresh vegetables prior to eating were identified as decreasing cancer risk. There was a general feeling that eating healthy was expensive and that people lacked the knowledge of how to eat healthy on budget.

> "We are poor here," "It's expensive to eat healthy."
> "We've always had too much sugar and fat in our diets."

This was a major barrier to healthy eating in their community. Promotion of healthy eating and education across the age spectrum were offered as strategies toward promoting healthier eating. Government and health agencies were identified as the major providers of education and information about nutrition in the community.

There was a positive attitude expressed toward exercise, with participants feeling that exercise was readily available in their communities. Unlike healthy eating, the most significant barrier to exercise was motivation; the communities did not have a culture of exercise and did not promote it.

> "There is little motivation to exercise every day."

Community-wide promotion of physical activity with engagement of the churches and schools was felt to be an effective strategy to increase physical activity.

Obesity was overwhelmingly seen as a significant health problem in the health district, starting with the children. Excess consumption of fast food was identified as a contributor in all focus groups. There was recognition of a connection between obesity and cancer risk, although all of the groups felt that obesity was relative, depending on the individual's personal characteristics. In contrast to resources to help improve diets, the major community resources to lose weight were identified as commercial businesses and healthcare providers. Strategies thought to have potential to help people maintain a healthy weight were community education programs starting in the schools, making weight loss resources accessible, and providing incentives to people to lose weight.

Tobacco use was recognized as pervasive in the community and the historical economic dependence on tobacco production recognized.

> "Virginia is a tobacco state. Its' (tobacco) put food on the table for years."

There was general skepticism expressed about strategies for decreasing tobacco use and conflicting feelings about the relative impact of legal restrictions versus education to decrease tobacco use. All communities expressed a lack of resources to help people quit smoking.

Positive peer pressure was felt to be essential to change the tobacco culture in the health district. In addition to tobacco as a cancer risk, environmental factors were a concern, including coal, asbestos, and lead in old housing, radon, and water contamination from manufacturing. There was a feeling in all focus groups that environmental carcinogens were a significant source of the high cancer rates in the health district.

Early detection of cancer through screening was viewed positively by all focus group participants. There was some lack of knowledge about the types of screenings, particularly the FOBT for colorectal cancer screening. Additionally there was recognition that some screenings were uncomfortable or invasive, which could be a barrier to some. The most often identified and highly significant barriers to screening were the lack of local availability of the screening test (requiring distant travel) and the financial burden that the screening represented. Another repeated reason for patients not following a physician recommendation to be screened was the fear of a diagnosis.

Cancer clinical trials are not currently available in the health district, and this was reflected in a general lack of knowledge of participants about cancer research. Associations of research with information collection, measurements, and a “last resort” were commonly expressed. Although the majority of participants would be hesitant to participate in a research study themselves, they indicated that they would recommend that a friend or family with cancer consider participating in a clinical trial. Participants said that they would be much more interested in participating in cancer research specifically relevant to the local community.

Cancer Survivor Group Synopsis

Five cancer survivor focus groups were held in the health district. A focus group was held in each of the four counties making up the district. There were a total of 22 participants with an average group attendance of 4-5 individuals. Cumberland Plateau Health District cancer survivors indicated that their cancer diagnoses caused fear and that they needed information on treatment, prognoses, and navigating resources to help handle their diagnoses. Additionally, if their cancer treatment changed, then the information needs also changed. Many survivors and patients utilized the internet to acquire needed information.

Of those who participated in the focus groups, cancer diagnoses were rarely made locally, often occurring further away in Virginia, but also in Tennessee. Some treatment was local, although treatment most often occurred in parts of Virginia outside of the health district, as well as in North Carolina, Tennessee, and West Virginia. Travel to treatment outside of the area proved difficult for many survivors. The lack of available physicians, physician knowledge, and lack of information were cited in the majority of focus groups as barriers to timely diagnoses and resulting in missed or incorrect diagnoses. Transportation was most often cited as a barrier to treatment and impacting treatment decisions. Lack of organizational support and finances were also commonly mentioned. Local treatment and more doctors were the most commonly identified need to improve cancer care in the health district.

Receiving treatment outside of the local community creates the potential for lack of communication between the treating oncologist and PCP. The majority of participants indicated that they were provided post-treatment follow-up instructions verbally, if they were discussed at all. Those who received written follow-up plans were treated by oncologists outside of the area. Despite being treated outside of the local community, the majority of survivors expressed good or great communication between oncologists and physicians.

In general, participants felt that they did not receive enough post-treatment education on how to stay healthy. Education regarding diet, exercise, and well-being were the areas most often requested. Participants did receive referrals to counseling, support groups, and cosmetic support; however, there was a general feeling that support services are lacking in the local community. The needs of cancer survivors included help with general home cleaning, companionship, financial assistance, and meal support. These things are being provided through informal support systems including family, churches, and the community.

When asked about cancer research, participants overwhelmingly felt that it was important, but also used words such as “human guinea pigs,” “scary,” “politics,” “money,” and “big institutions” to describe them. Several participants had clinical trials mentioned to them as a treatment option, but the majority either did not have them discussed or they were a non-option.

The major gaps in programs, services, or support identified by focus group participants were the community’s lack of knowledge of cancer and cancer treatment resulting in misperceptions and delayed diagnoses; the lack of locally available facilities and doctors to diagnose and treat cancer; financial support for cancer screening and treatment to reduce the fear that a diagnosis will be untreatable due to lack of finances; and local cancer support groups and advocates to support people through their cancer journey.

SUMMARY OF PRIORITY NEEDS

The Cumberland Plateau Health District is comprised of 1,827 square miles that border both Kentucky and West Virginia. The district is comprised of 90,939 residents, the majority of whom are Caucasian. All four counties in the district are rural and considered medically underserved. Overall, cancer incidence and mortality rates are lower for the Cumberland Plateau Health District as compared to Virginia as a whole, with the noted exception of respiratory cancer. The top three cancer subtypes in the district are respiratory, GI, and female breast cancers. BRFSS data indicate that residents of the Cumberland Plateau Health District have higher rates of smoking and obesity than the state of Virginia. There is a range of available cancer-related screening, diagnostic, and treatment services; however, due to the wide geographic area, these services are not equally accessible to all residents of the health district. Financial barriers impose a significant burden to receiving cancer-related medical care throughout the health district. Based on the qualitative and statistical information gathered for this project, the following are recommendations/suggestions for action:

Community Education

- Innovative community-engaged public awareness campaigns to promote risk reduction, with a focus on tobacco use.
- Youth education programs for cancer prevention and avoidance of tobacco use.
- Increase the availability of affordable smoking cessation and exercise programs throughout the health district.
- Community campaigns that incentivize and support residents to live healthy lifestyles, including diet and physical activity.

Rural Community Support:

- Improve access to cancer screening services in the most rural areas of the health district, specifically devising strategies to minimize the distance needed to travel to access cancer-related healthcare.
- Streamline access to treatment post-diagnosis, including financial support and transportation throughout treatment.
- Provide support to localities in recruiting primary care providers as well as additional specialists, including oncologists.
- Introduce innovative models for cancer support groups in rural communities.

Healthcare Community:

- Develop a patient navigator program within the cancer care centers to guide patients from the time of diagnosis through treatment and survivorship.
- Standardize a patient-centered care plan post-treatment that can be easily understood by the patient and serve as a communication tool for the PCP.
- Devise strategies to recruit and retain cancer specialists.
- Develop continuing education programs for primary care providers that include updates on screening guidelines, wellness and prevention of cancer recurrence, and monitoring and palliation of long-term treatment effects.

APPENDICES

Appendix A:

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

Appendix B:

Primary Care Physician Questionnaire

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Cancer Healthcare Resources within the Health District

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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 Cumberland Plateau Health District

Available Facilities:	Clinch Valley Medical Center; Dickenson Community Hospital; Buchanan General Hospital; Russell County Medical Center; Carilion Tazewell Community Hospital	
# of Oncologists:	5	Breakout: 1 medical oncologist, 1 radiation oncologist, 1 hematologist in Clinch Valley Medical Center; 2 visiting medical oncologists at Buchanan General Hospital

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)	2 / 3
		Diagnostic Mammography	5
		Breast Ultrasound	5
		Breast Biopsy	3
		Breast MRI	1
	Colorectal Cancer	Sigmoidoscopy/Colonoscopy	3 / 4
Surgeries	**Cancer Related Surgeries**	Breast Segmental/Complete Mastectomy	3
		Sentinel Nodes Sampling	1
		Gynecological Hysterectomy/Oophorectomy	2
		GI - Upper/Lower Tract	2
		GI - Liver	1
		Ears, Nose, Throat	2
Counseling	**Cancer Dietary Needs**	Registered dietician to provide nutritional services specific to cancer patients	3
		Board certified dietician in oncology nutrition	1
		One-on-one assessment and diet prescription	3
		Individual oncology nutrition counseling services	2
		Outpatient oncology nutrition counseling	2
		Cancer control and prevention education programs for dietary needs	1
Other Services	**Hospice Service**	Facility Supported: Inpatient / Outpatient Hospice	2 / 2
		Private Organization: Inpatient / Outpatient Hospice	2 / 2
	Palliative Care	Palliative Care Program	1
		Medical professionals in the team	MD/DO Board Certified palliative care, RN, SW, Chaplaincy, Care coordination
		Offer consult service	1
Cancer Support Groups	**Existing Support Groups**	Availability of cancer support groups	2
	Future Support Groups	Want to start a support group	1

Not Available in Health District

Cancer Screening	**Colorectal Cancer**	CT Colonography
	Lynch Syndrome	Screening for Colorectal and Endometrial cancers
		Immunohistochemistry staining test
		Microsatellite instability testing
Surgeries	**Cancer Related Surgeries**	Breast Reconstruction
		GI - Pancreas
		Lung
		Prostatectomy
		Brain
Counseling	**Genetic Tests**	Genetic tests for cancer risk (BRCA1 and BRCA2)
		Genetic tests for cancer risk (Others)
	Genetic Counseling	Genetic counseling (at the facility or referred out for counseling)
Other Services	**Clinical Trials**	Clinical trials
	Palliative Care	Inpatient beds
		Outpatient clinic
	Cancer Patient Navigation	Patient Navigator
Specialists	**Oncology**	Currently recruiting oncologists

APPENDIX E

Community Cancer Resources within the Health District

CUMBERLAND PLATEAU HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Every Woman's Life	American Cancer Society
Organization Information		**Number of Organizations**		
Organization category	National non-profit	1	-	X
	Local non-profit	0	-	-
	For profit service organization	0	-	-
	Federal governmental organization	1	X	-
	State/municipal government organization	0	-	-
	Other	0	-	-
Major sources of funds for organization	Competitive grants	0	-	-
	Federal funds	1	X	-
	Service fees charges	0	-	-
	Donations	1	-	X
	Other	0	-	-
Cancer Resources				
Primary service population of the organization	Cancer patients	2	X	X
	Cancer survivors	1	-	X
	Cancer caregiver/family members	1	-	X
	Other	1	-	X
Qualification criteria to access services	Must be uninsured/underinsured	1	X	-
	Financial qualification	1	X	-
	No qualification criteria	1	-	X
	Other	1	X	-
Type of cancer related services that are provided	Written information on cancer	1	-	X
	Information on cancer care/support resources	1	-	X
	Management of cancer support groups	1	-	X
	Financial support for cancer control/care	2	X	X
	Funding of projects related to cancer	1	-	X
	Psychosocial support	1	-	X
	Navigational services	2	X	X
	Transportation	1	-	X
	Other	0	-	-
Number of cancer patients seen annually		(see organizations' answers)	51 - 150	greater than 150
Other Information About Organization				
Advertising for the organization	Local media	1	-	X
	Organization website	1	-	X
	Online	2	X	X
	Pamphlets describing services	1	-	X
	Word of mouth	2	X	X
	Other	0	-	-
Organizational needs	Financial support	1	-	X
	Human resources (skilled employees, volunteers, etc.)	1	-	X
	Access to experts for consultation	0	-	-
	Physical space/facilities	0	-	-
	Collaborators	1	X	-
	Volunteers	1	-	X
	Other	1	X	-
Challenges		(see organizations' answers)		Volunteers, particularly for help with transportation.
Goals for the next 5 years		(see organizations' answers)		To continue to expand support abilities in Cumberland Plateau and Lenowisco health districts.
Partner organizations				Any cancer organization
Interested in collaboration			Yes	Yes
Comments		(see organizations' answers)		The Abingdon office services the health districts of Lenowisco as well as Cumberland Plateau as there are no offices there.