Saving Lives and Reducing Suffering and Death from Cancer in Virginia

Report of the Comprehensive Cancer Needs Assessment of the Mount Rogers Health District

Virginia Commonwealth University
Massey Cancer Center
And
Tobacco Indemnification and Community Revitalization Commission

VCU MASSEY
CANCER CENTER
Virginia Commonwealth University

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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. In addition, a statewide network of partners, the Cancer Action Coalition of Virginia (CACV), has developed a State five year cancer plan since 2001 to help unify and direct the efforts of these organizations in combating cancer.

Virginia is a highly diverse state in geography, population demographics, economics and access to healthcare. With a land mass of 40,000 square miles that spans from the shores of the Atlantic to the hills of the Appalachian Mountains, there are varying degrees of knowledge of and access to healthcare. For cancer prevention and control efforts to be effective they, “must be complete, comprehensive, sustainable, community-specific, and culturally and linguistically appropriate.”[4] To accomplish this, an evaluation of the needs specific to defined communities is required. The Virginia Commonwealth University Massey Cancer Center in collaboration with the Virginia Tobacco Indemnification and Community Revitalization Commission performed a comprehensive cancer needs assessment of four communities, defined by Health District. The four Health Districts chosen (Crater, Piedmont, Pittsylvania/Danville, Mount Rogers) 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, and will utilize strategies that are culturally appropriate to these communities.

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[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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EXECUTIVE SUMMARY OF FINDINGS

The collection of data and information for this report came from a number of federal, state and local sources, as well as personal interviews and focus groups. This large geographic district has a homogenously white population of 95% with the remaining 5% of all other races. The four hospitals and clinics offering cancer treatments are located along interstate corridors, leaving large pockets of rural residents without easy access to primary care and hospitals. Six oncologists serve the 183,000 residents, and Abingdon located in the far southwest of the district houses the only radiation treatment center. The district lacks an adequate number of primary care physicians, as well as oncology specialists.

The cancer burden in the Mt. Rogers Health district compared to the state is unremarkable, except for the high incident and mortality rates of lung and bronchial cancers, correlating directly with some of the highest tobacco use rates in the state. With mortality rates higher than incidence rates for most cancers, issues surrounding lack of primary care and early detection are apparent. On average, about 54% of cancers are caught at an early stage. The four hospitals in the district offer mammography, MRI and CT screenings. Colonoscopy is available in the hospital and outpatient surgical center in Abingdon. The VDH has a strong Every Woman's Life program, offering access to screenings for gynecological cancers to eligible patients.

While cancers tend to be diagnosed in the local community, surgery and treatment more often take place in neighboring counties or the border states of North Carolina and Tennessee. Treatment choices depend upon finances, type and stage of cancer. Johnston Memorial Hospital offers extensive surgical options for oncology patients, with the other hospitals in the district providing a limited menu. Hospice services are plentiful throughout the district.

The American Cancer Society has a large presence throughout the health district, with two resource centers in Abingdon and educational programs and services for cancer patients including financial help for travel and transportation. Individual counties also have ACS expanded programs such as the Wythe County Breast Cancer Coalition. The Cancer Outreach Foundation offers direct financial and navigation support to cancer patients.

Ten healthcare professionals who are long-time residents and leaders in their communities were interviewed to gather a broad perspective of the cancer healthcare needs of the health district. The major healthcare deficiencies identified by these Key Leaders fell into three categories, (1) effective education programs to promote healthy lifestyles, (2) number and specialization of community physicians, and (3) barriers to healthcare access. The particular needs of primary care providers identified by key leaders were help with patient education about cancer screenings and tobacco cessation. Physicians were also surveyed to gain perspectives on cancer screenings, care of patients during treatment and communication between PCP and oncologists. The majority of physicians (84%) reported high patient compliance with recommended breast cancer screenings, but only 49% felt their patients were highly compliant with colon cancer screening recommendations. Financial constraints, apprehension and lack of insurance were among the common reasons cited for non-compliance. Eighty-eight percent of physicians said they prefer to refer oncology surgical patients locally and 59% of PCPs report they are happy with communication with the oncologists. Physicians expressed a desire for more written information regarding surveillance of cancer recurrence, long-term cancer treatment effects, pain management and end of life planning and care, wellness and prevention of recurrence.

District-wide focus groups for both the general population and cancer survivors/caregivers validated information collected in the Behavioral Risk Factor Surveillance Survey. Lifestyle—obesity, tobacco use and sedentary lifestyle—were identified as the greatest issues of concern, along with lack of primary care providers, health insurance and finances for health care. Thirty-three percent of the residents in the district either don't have health insurance or a primary care provider. General population groups were more concerned about obesity, mental health and drug abuse than cancer. Among the survivor groups, the need for information about their disease and treatment was a common theme. Patients treated locally reported long wait times in oncology offices, for lab and imaging scheduling and test results. In general, survivors felt their personal needs were being met by family and community. Expressed needs include more and better treatment centers, and more access to educational resources.

The need for more primary care physicians and oncology specialists, community education about lifestyle issues including obesity, tobacco and tanning, and expanding cancer treatment in the health district are areas of focus for future research and programming.

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 is estimated that 1,638,910 new cases of cancer will be diagnosed nationally 2012 (American Cancer Society), with 41,380 occurring in Virginia.[1] The State cancer incidence rate of 443.2 newly diagnosed cancers per 100,000 residents ranks 38th among the other 49 states and the District of Columbia, and is slightly lower than the national cancer incidence rate of 455.7 (2008)[2]. Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease,[3] with an average of 14,009 residents succumbing to their disease.[4] 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. In addition, a statewide network of partners, the Cancer Action Coalition of Virginia (CACV), has developed a State five year cancer plan since 2001 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."[5] 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 communities, defined by Health District. The four Health Districts chosen had a relatively high cancer burden and large medically underserved areas. The comprehensive assessment of cancer needs specific to each community will be used to develop a holistic strategy to improve cancer outcomes that utilizes strategies that are culturally appropriate to these communities.

Methods of Data Collection

Demographic and economic information was collected to get a general picture of the health district. This data was collected from web-based sources including the U.S. Census Bureau, Department of Health and Human Services, Virginia Workforce Connection, among others. 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*, *community population needs*. Personnel dedicated to data collection included a Data Manager located at the Massey Cancer Center in Richmond, and four Community Health Education Coordinators (CHE)

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[1] Statistics provided by the Virginia Cancer Registry(June, 2011), data from 2001 to 2007.

[2] State Cancer Profiles. http://statecancerprofiles.cancer.gov/index.html

[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] Statistics provided by the Virginia Department of Health (June, 2011), data from 2005 – 2009.

[5] The Virginia Cancer Plan 2008 – 2012, Cancer Plan Action Coalition (CPAC)

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:

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 (data from 2005 – 2009). Analysis was then performed for each health district and comparison made to Virginia as a whole.

Cancer Healthcare Resources

To evaluate the cancer services provided by the healthcare facilities servicing the health districts, a complete list of private and public hospitals and cancer centers, as well as community healthcare clinics was compiled using information from web-based data sources including the Virginia Health Information website (http://www.vhi.org/hospital_region.asp), data provided from the American College of Surgeons, and information gathered from the CHEs through prior knowledge and personal communications. A questionnaire was developed to be used during personal interviews by the CHE's 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 Virginia Department of Health 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 CHE's to other community organizations within the health district, as well. 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 gathered information related to the organization's mission, target population, cancer related services provided, and needs and challenges (See Appendix A).

Healthcare Provider Needs

The perspectives of healthcare providers on the needs related to cancer in the community were gathered in two ways. First, key leader physicians were identified in the community, and asked to discuss the most pressing healthcare deficiencies, and the most pressing needs of primary care physicians related to cancer in their health districts (See Appendix A). Second, information gathered from the key leaders was used to develop a questionnaire for primary care physicians 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 PCP's in each health district was acquired from the Virginia Board of Medicine website[6], modified to include only physician's 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 CHE's, who checked it for accuracy. All physicians on the final list were asked to complete the questionnaire either via e-mail or by personal visit to the physician's office. Initial contact was followed-up at least once, and potentially twice for non-responders. (**Appendix B**).

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 was acquired from the CDC.[7] Data was requested for responses from individuals within the Health Districts, and for questions that related to cancer prevention and screening behaviors. These included questions about tobacco use, diet, exercise, weight, cancer screenings, and utilization of healthcare services. Relative rates of healthy behaviors were assessed, and comparison to State averages made. Additionally, significant differences in behaviors by demographic characteristics were also evaluated.

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

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

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

Demographics in Mount Rogers

Located in the far Southwest part of Virginia, the Mount Rogers Health district is comprised of six counties and two cities: Bland, Carroll, Grayson, Washington, Wythe and Smyth Counties, and the cities of Bristol and Galax. The District spans 2782 mountainous square miles, with the northern-most county bordering West Virginia and the southern-most counties bordering North Carolina and Tennessee. Two major interstates, I-81 and I-77, dissect the health district. (**Figure 1**)

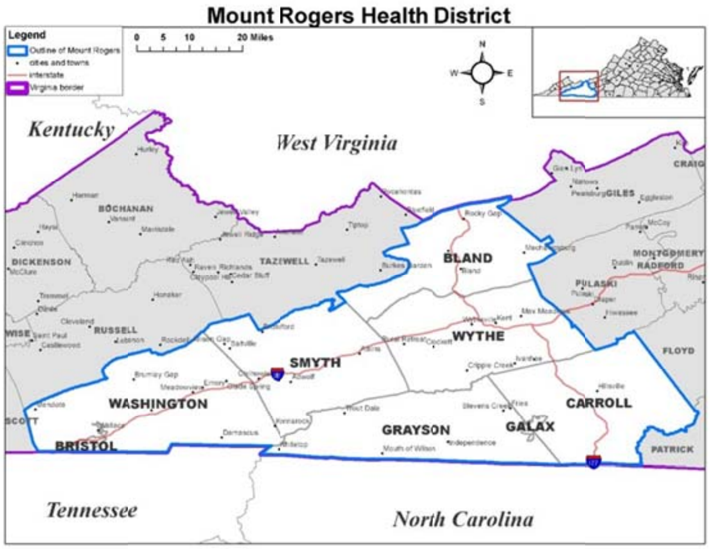

Figure 1: Mount Rogers Health District

According to 2005-2009 US Census Bureau Information, the District has 183,422 residents, 154,375 ages 18 or older. There is little ethnic diversity: Nearly 97% of the population is of the white race, 2.3% black and the remainder “other races”. The unemployment rate for the total health district is 8.8%, ranging from 7.6% in Bland County to 11.4% in Smyth. Of the adult population 25 years and over, 33 % (50,442) have a high school diploma or equivalent, and 11% (17,422) have a Bachelor’s degree or higher. Adults over the age of 25 years without a high school diploma or equivalent range from 16% in Bland County to 33% in Galax.[8] Per Capita Personal Income in 2008 ranged from $23,528 in Grayson County to $32,454 in Washington County/Bristol. (**Tables A & B**).

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

Table A: Demographic Profile of Mount Rogers HD vs. Virginia

Demographic Profile of Mount Rogers HD vs. Virginia			
Category	**Subcategory**	**Mount Rogers**	**Virginia**
Gender	Male	48%	48%
	Female	52%	52%
Age	18-39	31%	40%
	40-49	18%	19%
	50-64	28%	25%
	65+	23%	16%
Race	White	95%	67%
	Black or AA	2%	18%
	Other	3%	14%
Ethnicity	Hispanic or Latino	2%	7%
	Non-Hispanic or Latino	98%	93%

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

Table B: Economic Characteristics of Mount Rogers HD vs. Virginia

Economic Characteristics of Mount Rogers Health District vs. Virginia		**Mount Rogers (average)**	**Virginia**
Unemployment[1] *(16 years and older)*	Unemployment Rate	8.41%	6.40%
Income[2]	Median Household Income	$34,707	$60,316
Education[3] *(25 years and older)*	% Less than high school	24.34%	14.20%
	% High school or GED	34.14%	26.30%
	% Some college, no degree OR an Associate's degree	27.13%	26.00%
	% Bachelor's degree or above	14.40%	33.50%

[1] Virginia Workforce Connection, LMI Tools. <www.vawc.virginia.gov>; *Unemployment Rate for Virginia, September 2011, Not Seasonally Adjusted.* (7 November, 2011).

[2] U.S. Census Bureau; American Community Survey, 2005-2009 Summary Table S1903; generated by Timur Korshin; using American FactFinder; <http://factfinder.census.gov>; (7 November 2011).

[3] U.S. Census Bureau; American Community Survey, 2005-2009 Summary Table S1501; generated by Timur Korshin; using American FactFinder; <http://factfinder.census.gov>; (7 November 2011).

Access to Healthcare

The counties comprising the Mount Rogers Health District are primarily rural and medically underserved. All or part of the counties of Bland, Carroll, Washington and Smyth are designated as Health Professional Shortage Areas (HPSA). All Counties and the City of Bristol are federally designated as Medically Underserved Areas (all or in part),[9] with the exception of the City of Galax, which is designated as a Medically Underserved Population. Additionally, all counties are designated "rural localities" by the Health Resources and Services Administration, with the exception of Washington County/Bristol, which is designated a Rural Urban Commuting Area with several census tracts within the area designated as rural.[10] Three hospitals are located on the I-81 corridor, and a fourth hospital in the City of Galax. The City of Bristol straddles the Virginia-Tennessee border, with a fifth hospital located on the Tennessee side of this dual-state city. (**Figure 2**) Though there are 4 hospitals in the district; travel on rural, mountainous roads makes access to these hospitals difficult for the majority of residents.

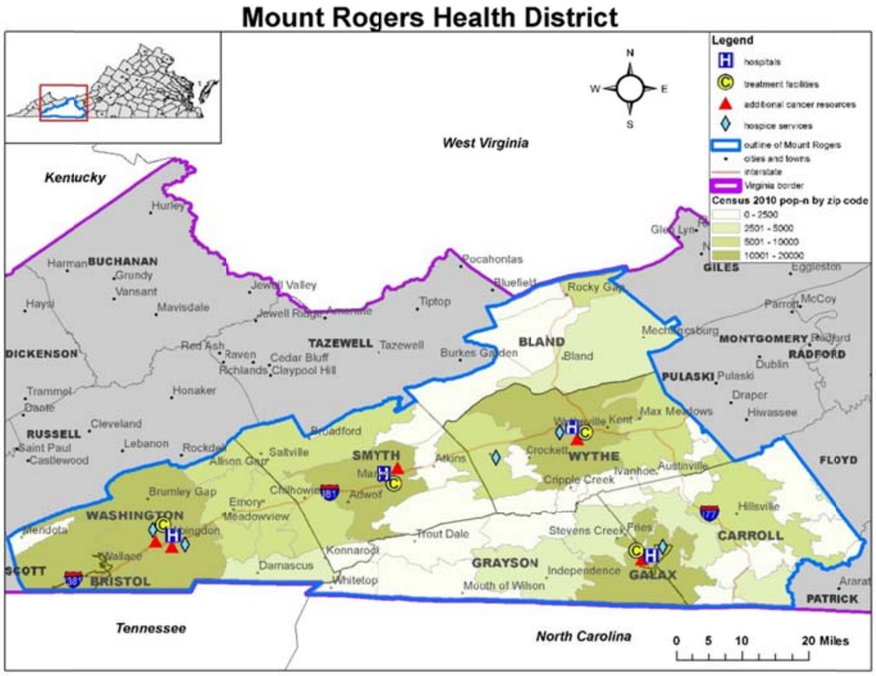

Figure 2: Healthcare Resources in Mount Rogers Health District

Cancer Burden

Cancer Incidence

Cancer incidence was calculated for the Health District for all cancer types, and is reported for cancers grouped by disease site. Incidence rates of the gender specific cancers, (female breast, male genital and gynecological), were calculated from the appropriate gender populations. The other groupings included respiratory, gastro-intestinal, hematologic malignancies, urinary system, brain-nervous system-eye, oral cavity-pharynx, and other cancers. Cancer incidence rates are age adjusted. (**Table C**)

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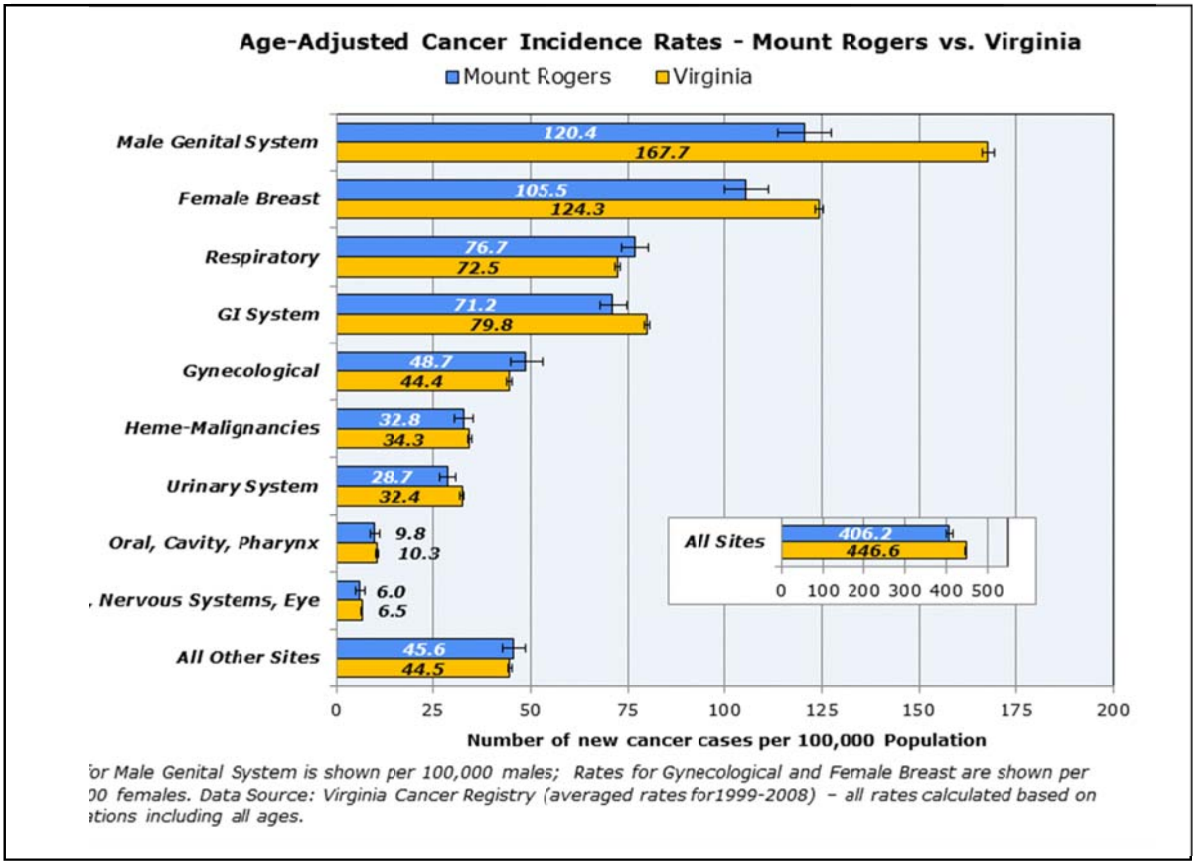
[9] http://www.hhs.gov/ accessed October 27, 2011

[10] http://www.hrsa.gov/index.html Accessed October 27, 2011

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

Age-Adjusted Cancer Incidence Rates in Mount Rogers Health District vs. Virginia			
Cancer Site	**Mount Rogers**	**Virginia**	***Notes***
Male Genital System	**120.4**	**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	114.3	162.0	
Other male genital organs	6.1	5.7	
Female Breast	**105.5**	**124.3**	
Respiratory	**76.7**	**72.5**	
GI System	**71.2**	**79.8**	
Colon & Rectum	43.1	47.5	
All Other GI	28.1	32.3	
Gynecological	**48.7**	**44.4**	
Corpus and Uterus	24.8	21.8	
Ovary	13.0	12.1	
Cervix	7.7	7.2	
All other Gynecological	3.2	3.4	
Heme-malignancies	**32.8**	**34.3**	
Lymphomas	18.3	19.5	
Leukemias	10.1	9.7	
Myeloma	4.5	5.2	
Urinary System	**28.7**	**32.4**	
Oral Cavity, Pharynx	**9.8**	**10.3**	
Brain, Nervous System, Eye	**6.0**	**6.5**	
All Other Sites	**45.6**	**44.5**	
All Sites	**406.2**	**446.6**	

The cancer sites with the highest incidence rates in the Mount Rogers Health District are male genital system, female breast, , respiratory, gastro-intestinal (GI), and gynecologic cancers. The district had a lower cancer incidence rate than the state when comparing all sites combined, as well as for the majority of the grouped sites. Incidence rates were significantly lower for female breast cancer, male genital cancers, and for gastro-intestinal cancers. On the contrary, respiratory and gynecologic cancer incidence rates are significantly higher than the state. (**Figure 3**).



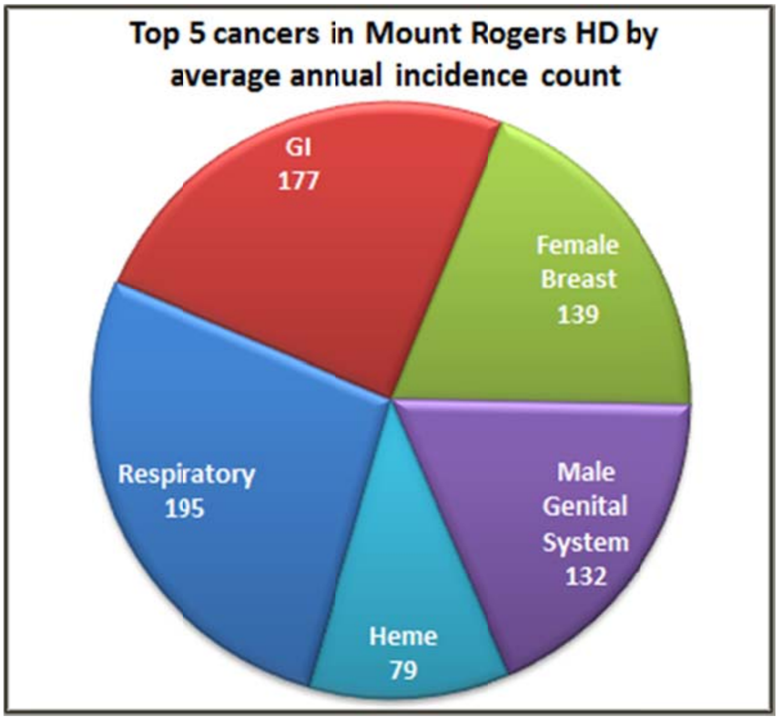
or Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 00 females. Data Source: Virginia Cancer Registry (averaged rates for1999-2008) – all rates calculated based on tions including all ages.

Figure 3: Age-Adjusted Cancer Incidence Mount Rogers HD vs. VA

To evaluate the impact of cancer in the community in terms of provider burden and services needed, information on the annual number of cancer cases diagnosed was acquired from the Virginia Cancer Registry. In the Mount Rogers Health District, there is an average of one thousand and seventy-four (1074) cases of new cancer each year (**Table D/Figure 4**) based on a 10 year average (1999-2008). Gastro-intestinal, respiratory, male genital and female breast, and heme-malignancies had the highest average incident cases. Together they make up 74% of the total cases.

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

Top 5 Cancers in Mount Rogers Health District by Incidence Count		
Cancer Site	**Annual Count**	***Notes***
Respiratory	**195**	*Data Source:* *Virginia Cancer Registry*
GI System	**177**	
Colon & Rectum	108	*Annual Count - represents average number of new cases per year in the health district (averaged over period 1999-2008).*
All Other GI	70	
Female Breast	**139**	
Male Genital System	**132**	
Prostate	126	
Other male genital organs	6	
Heme-malignancies	**79**	*All Other Sites include Brain, Nervous System, Eye, Gynecological, Oral Cavity, Pharynx, Urinary System, and Other sites.*
Lymphomas	43	
Leukemias	24	
Myeloma	11	
All Other Sites	**276**	
All Sites	**997**	



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.

Figure 4: Top 5 cancers in Mount Rogers HD by incidence count

Men in Mount Rogers develop cancer at slightly higher rate than women (558 vs. 499 cases per 100,000). Incidence rates and counts of specific types of cancer vary substantially by gender, however. (**Tables E & F**) Genital cancer (principally prostate) has the highest incidence in males followed by respiratory and gastro-intestinal cancers. Breast cancer has the highest incidence in females, followed by gastro-intestinal cancers and then respiratory cancers. (**Figures 5 & 6**)

Table E- Top 5 Male Cancers in Mount Rogers HD

Top 5 Male Cancers in Mount Rogers			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Male Genital System	**143.6**	**132**	*Data Source:* *Virginia Cancer Registry* *Crude Rate – represents number of new male cancer cases per 100,000 males.* *Annual Count - represents average number of new male cancer cases per year in the health district (averaged over period 1999-2008).* *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.*
Prostate	137.6	126	
Other male genital organs	6.0	6	
Respiratory	**127.1**	**117**	
GI System	**102.3**	**94**	
Colon & Rectum	60.6	56	
All Other GI	41.8	38	
Urinary System	**55.1**	**51**	
Heme-malignancies	**47.5**	**44**	
Lymphomas	25.3	23	
Leukemias	15.9	15	
Myeloma	6.2	6	
All Other Sites	**83.2**	**74**	
All Sites	**558.8**	**512**	

Figure 5 - Top 5 Male Cancers in Mount Rogers HD

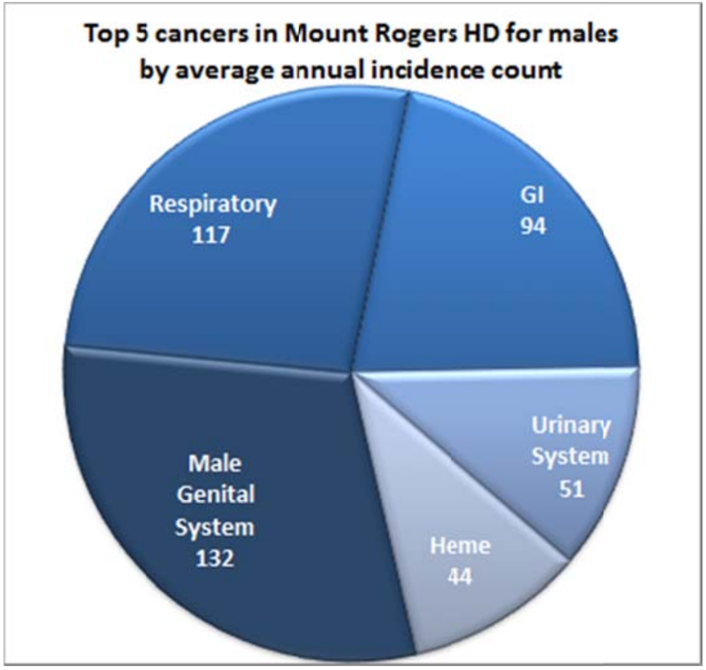
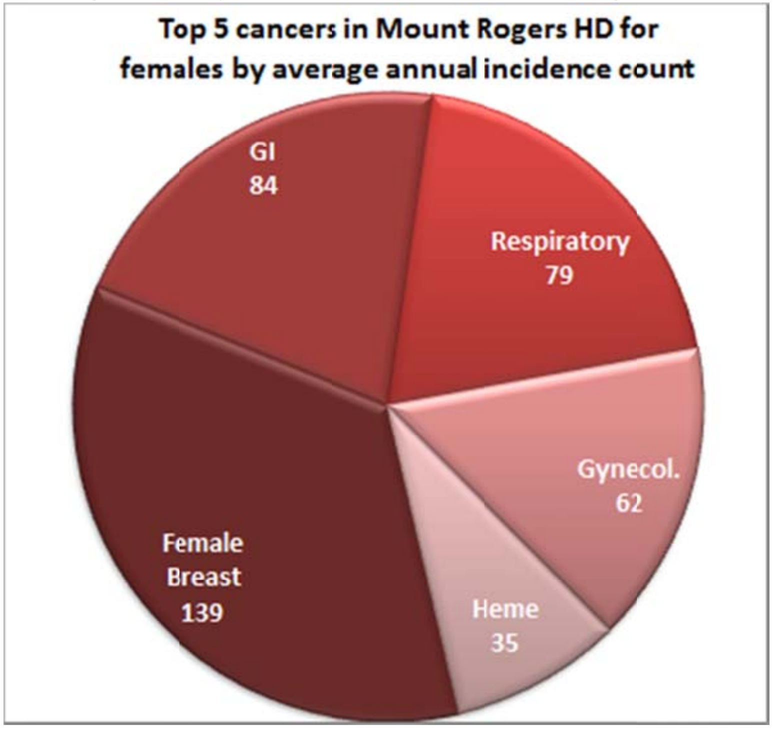


Table F - Top 5 Female Cancers in Mount Rogers HD

Top 5 Female Cancers in Mount Rogers			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Female Breast	**142.6**	**139**	*Data Source:* *Virginia Cancer Registry* *Crude Rate – represents number of new female cancer cases per 100,0000 females.* *Annual Count - represents average number of new female cancer cases per year in the health district (averaged over period 1999-2008).* *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.*
GI System	**86.0**	**84**	
Colon & Rectum	53.8	52	
All Other GI	32.2	31	
Respiratory	**80.8**	**79**	
Gynecological	**64.2**	**62**	
Corpus and Uterus	33.6	33	
Ovary	17.8	17	
Cervix	8.4	8	
All other Gynecological	4.3	4	
Heme-malignancies	**36.1**	**35**	
Lymphomas	20.7	20	
Leukemias	9.8	10	
Myeloma	5.7	6	
All Other Sites	**89.3**	**86**	
All Sites	**499.0**	**485**	

Figure 6 - Top 5 Female Cancers in Mount Rogers HD



The small black population in the Mount Rogers Health District (2%) made comparison of cancer incidence, staging and mortality rates by race difficult. There was only an average of 17 reported cancer cases from all cancer types annually in black residents over a 10 year period. For this reason, a comparison was not performed.

Cancer staging & mortality

Staging cancer is needed for proper treatment planning. Discovering cancer at the local stage is usually indicative of a better outcome and improved survivorship. A higher percentage of respiratory, oral, gynecological and brain cancers are detected at a local stage in the health district than in the State as a whole. Conversely, a lower percentage of breast cancers are found at the local stage in the health district compared to the State. Notably, a large portion of respiratory and gastro-intestinal cancers are discovered at a late stage. (**Figure 7)**

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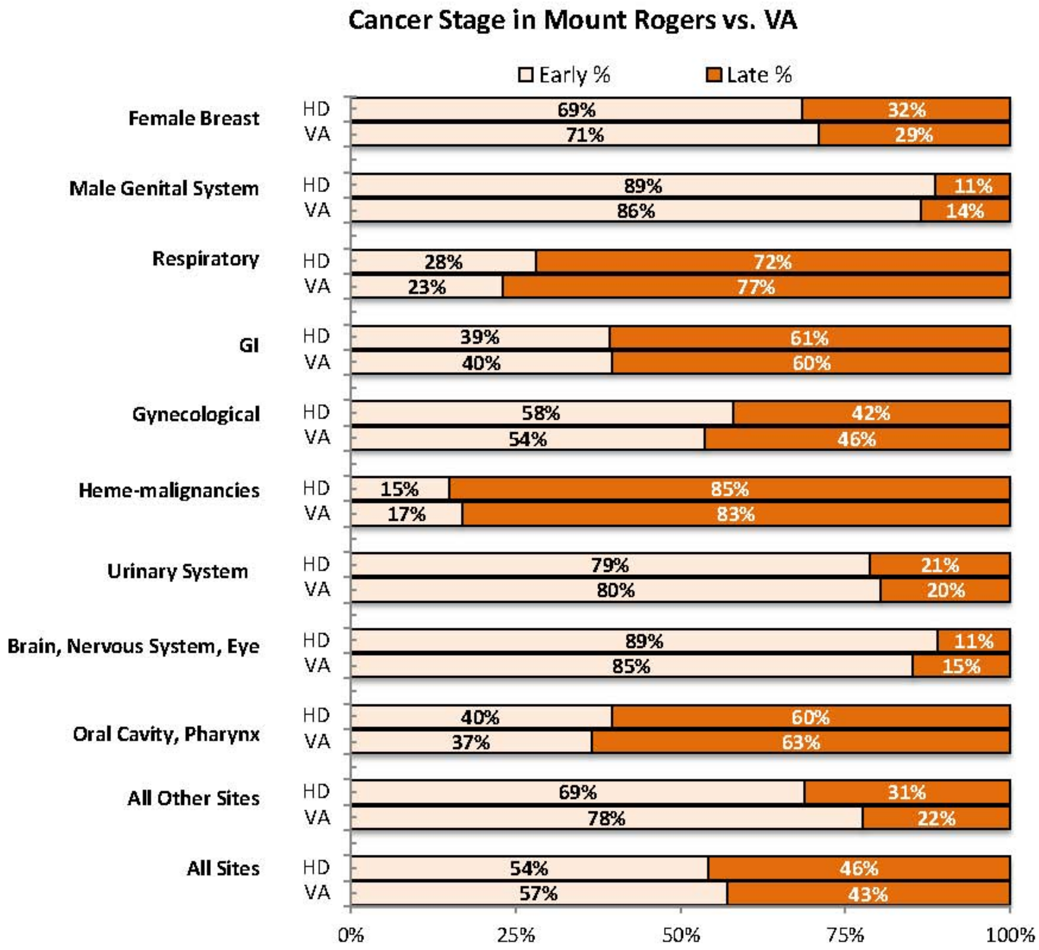


Early stage combines "In Situ" and "Local" cancer stages; Late stage combines "Regional" and "Distant" stages. Data presents cancer cases with reported stage only. Percentage of unstaged cancer cases was eliminated from calculations. Data Source: Virginia Cancer Rigistry (1999-2008) - all precentages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

An average of 499 residents of Mount Rogerǎ lŜl·ŧűK 5ǐăŕrict succumb to cancer related causes each year. The cancer sites with the highest mortality rates in the Mount Rogers Health District are respiratory, gastro-intestinal, hematologic cancers, female breast, and male genital in that order (**Table G**). In contrast to cancer incidence, the district has a higher mortality rate than the State for all cancer sites considered together. Notably, the mortality rate for respiratory cancers is significantly higher than the State. (**Figure 8**) The five cancers resulting in the greatest number of deaths in the health district are respiratory, gastro-intestinal, heme-malignancies, female breast and the male genital system cancers. Respiratory and gastro-intestinal cancer deaths account for 53% of the cancer deaths in the MRHD.

Table G: Top 5 Cancers in Mount Rogers by Death Count

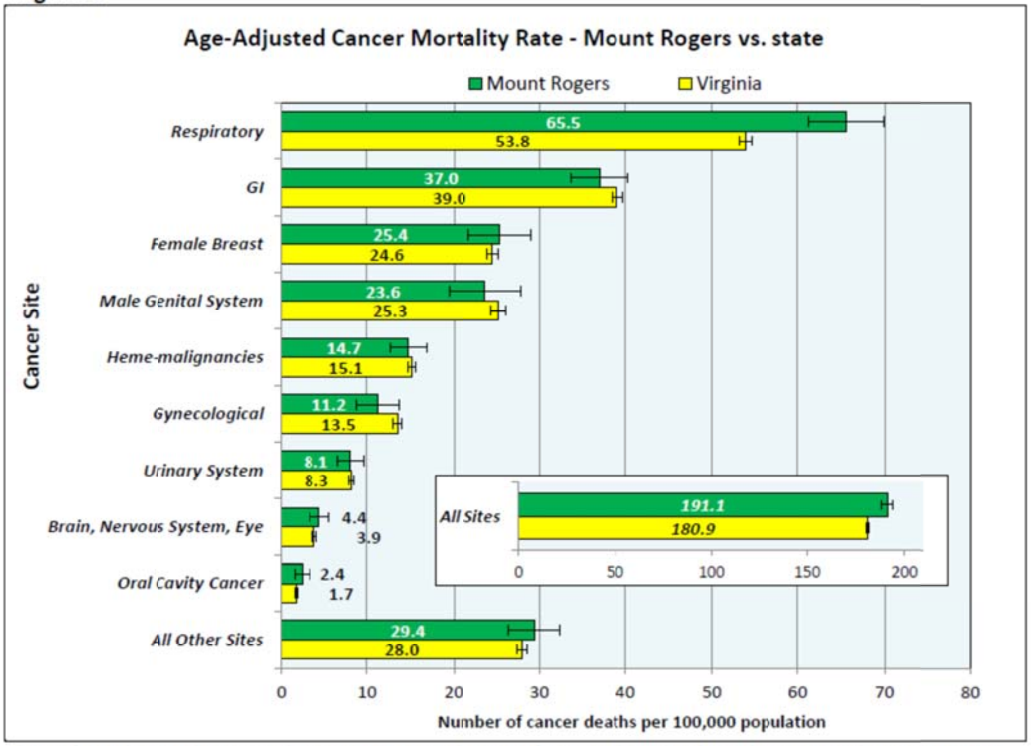
Top 5 Cancers in Mount Rogers by Death Count

Cancer Site	Annual # of deaths
Respiratory	**173**
GI	**96**
All other GI	79
Colon & Rectum	43
Heme-malignancies	**38**
Lymphomas	20
Leukemias	9
Myeloma	9
Female Breast	**37**
Male Genital System	**24**
Prostate	23
Other male genital organs	1
All Other Sites	**75**
All Sites	**499**

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 numbers for health district.

Figure 8



** Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females. Data Source: Vital Statistics Department, VDH (averaged rates 2005-2009) – all rates calculated based on populations including all ages.*

Men have higher mortality rates from cancer than women in the MRHD (288 vs. 243 cases/100,000). Respiratory and gastro-intestinal cancers cause the greatest number of deaths in both men and women, with death rates from respiratory cancers significantly higher in men than women (115 vs. 69 cases/100,000). In contrast to incident cases, the majority of deaths from gastro-intestinal cancers are due to sites other than the colon or rectum. (**Figures 9 & 10**)

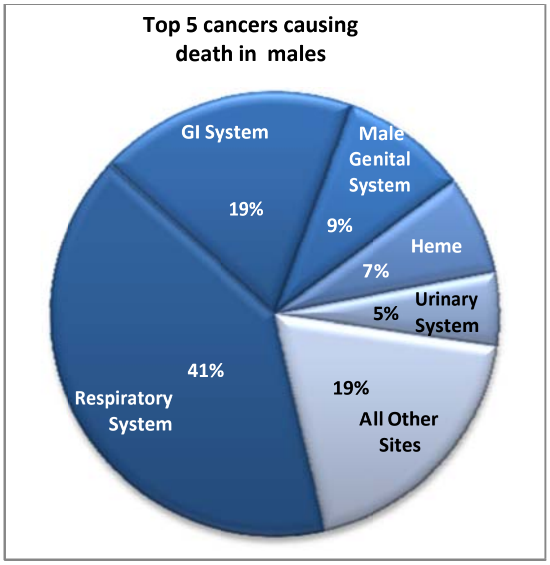


Figure 9: Top 5 cancers causing death in males

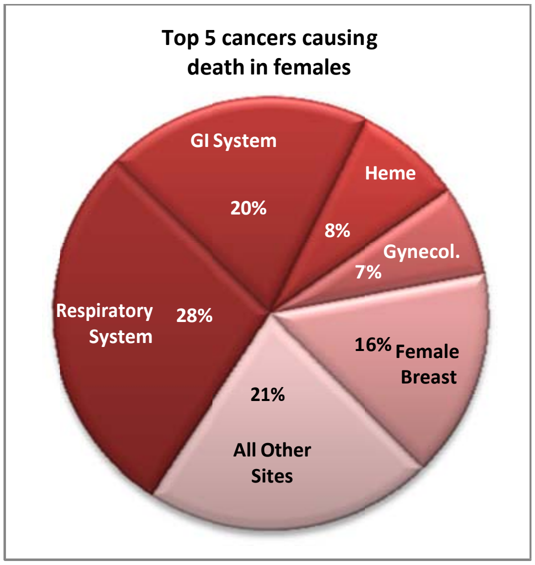


Figure 10: Top 5 cancers causing death in females

Cancer Healthcare Resources

Healthcare Facilities and Cancer Care

There are four hospitals in the Mt. Rogers Health District, Johnston Memorial Hospital and Cancer Center (JMH) in Abingdon, the Smyth County Community Hospital in Marion (SCCH), Wythe County Community Hospital in Wytheville (WCCH), and the Twin County Regional Hospital in Galax. JMH primarily serves Washington and Smyth Counties, Wythe County Community Hospital serves Wythe and Bland Counties, and Twin County Regional Hospital in Galax serves the city of Galax, Carroll and Grayson Counties. (Figure 2) There were 6 oncologists serving the health district at the time of writing of this assessment, 5 medical oncologists and 1 radiation oncologist. Travel within the health district, and even within counties can involve long and winding roads. A trip from Whitetop to the hospital in Galax (Grayson County) is about 50 miles but travel time can be double that on mountainous roads. From the northern tip of Bland County to the cancer center in Abingdon is about a two hour drive in good weather.

Cancer Services Provided:

The following cancer related services are available within the Mount Rogers Health District: (See Appendix D for details)

Screening:

Breast, colorectal, and cervical cancer screening facilities are available throughout the health district. Mammography is available in all four of the hospitals in the district as are colonoscopies. Colonoscopy is also available in the outpatient surgery center in Abingdon. Colposcopy is available in gynecologist offices. MRI and CT scans are available in the four hospitals, as well.

Treatment:

Treatment modalities for cancer include chemotherapy (including immunotherapy), radiation, and surgery. Treatment with all modalities is available to some extent within the Health District. The most comprehensive cancer services are concentrated in the southwestern portion of the health district, which requires large portions of the population to travel long distances to receive care.

Johnston Memorial Hospital and Cancer Center (JMH) provides medical oncology consults, as well as radiation and in/out-patient chemotherapy. JMH primarily serves Washington and Smyth Counties and also offers outpatient services for colonoscopy and a breast cancer navigator. JMH and Smyth County Community Hospital (SCCH) were recently acquired by Mountain States Health Alliance, which has a large cancer center in Johnston City, TN. JMH has expanded cancer services to Smyth County Community Hospital (SCCH), offering medical oncology consultation and outpatient chemotherapy at that facility. Blue Ridge Cancer Care, a division of US Oncology, has established offices in Wytheville, Marion. They also provide medical oncology consultation and chemotherapy infusion. JMH offers the most extensive surgical options for cancer in the health district with the other hospitals offering limited options. Breast reconstruction is not performed at any of the local facilities.

JMH houses the only radiation linear accelerator for external beam - 6X and 18X photons, also with electrons. Regional choices for patients requiring radiation therapy include Christiansburg, Pulaski, Bristol TN and Johnston City, TN outside of the Health District. Many patients from Abingdon and Bristol, Virginia utilize the medical oncology physicians and treatment services at Bristol Regional Medical and Cancer Center (Wellmont) in Bristol, TN, as well as the Johnson City Medical Center in Johnston City, TN.

Those from the upper end of the district travel to Bluefield, VA, Pulaski, Christiansburg, Roanoke or cross over the mountain into North Carolina.

The major deficiencies noted in cancer treatment for the district were as follows:

- Limited chemotherapy services offered in Galax and no cancer services in Bland County
- Sparse health care & no cancer care off the I-81 corridor
- All radiation therapy is concentrated in the western tip of the district.
- Lack of Oncology specialists throughout the district
- No patient navigators except for Breast Cancer (JMH)
- Limited lung cancer surgery
- No CT colonoscopy

Auxiliary Services:

Programs that address Survivorship needs, including dietary provision and counseling, genetic counseling, pain management and end of life services are important services that effect both outcomes and quality of life.

JMH offers genetic and nutritional counseling and a breast cancer support group. Wythe County has a breast cancer support group that is very active and there is a newly-formed but very active Colon Cancer Screening Coalition in Galax. None of the hospitals or affiliated cancer organizations offers a support group for cancers other than breast.

Clinical Trials:

Since opening offices in Wytheville and Marion, Blue Ridge Cancer Care is participating in clinical trials and JMH Cancer Center in Abingdon has begun the process to offer Clinical Trials.

Hospice Services:

The Mt. Rogers Health District is fortunate to have at least eight active hospice providers serving the health district, with additional providers, especially through home health services, becoming certified. Each county/city has at least two hospices serving their communities, although some of these have their offices outside of the Health District (See Figure 2). Each of the hospitals in the district host hospice patients and the Wellmont Hospice House in Bristol, TN serves Southwest Virginia. The hospices provide services at home and in nursing facilities. Key leader providers agreed that the Mt. Rogers Health District is well served by hospice, even for under and uninsured patients. Hospice services are well utilized throughout the district, though mostly for patients in their last weeks of life. Many are non-profit, absorb the cost for indigent patients and accept the Medicare benefit for hospice services.

Community Cancer Resources

The Mt. Rogers Health District hosts a number of cancer related resources for patients and their families outside of the hospitals and oncology offices. These resources offer an array of services including education, information and some direct services. Seven organizations were identified including:

1. The American Cancer Society, which has two resource centers in Abingdon and has 5 staff members serving the district. They assist the hospitals in the region with resources and events.
2. Susan G. Komen for the Cure (Tri Cities) offers some educational forums related to breast cancer to local residents.

3. The Cancer Outreach Foundation, located in Abingdon, offers financial and transportation assistance to local cancer patients, as well as emotional counseling to patients going through treatment, and their families.
4. The Wythe County Breast Cancer Coalition is a monthly support group that also provides information and education about breast cancer to women in Wythe County.
5. The Virginia Department of Health Every Woman's Life Program is managed out of the VDH office in Marion, is administered at all of the VDH offices in the Health District, and is one of the strongest in the state. This program provides access to screenings for female cancers to income-eligible women. For women diagnosed with cancer under this program, access to treatment is streamlined.
6. The Colon Cancer Screening Task Force in Galax provides community education about colorectal cancer, and screening opportunities in Galax.
7. The Wellmont Regional Cancer Network located in Bristol provides cancer education and information to the community and manages a cancer support group. Details about each of these organizations can be found in **Appendix E**.

Cancer patients and their caregivers are the primary service population of the majority of these organizations. Most had no qualification criteria to receive services, and the services provided included written cancer information, management of cancer support groups, financial support for cancer treatment, and management of projects related to cancer. The Virginia Department of Health is very active in promoting the Every Women's Life Program that provides free screenings for gynecologic and breast cancer to eligible women. Programs offered by the American Cancer Society throughout the district, either in conjunction with the Mt. Rogers Health Department or the local hospitals, include Reach to Recovery, Road to Recovery, Look Good, Feel Better, a number of breast cancer support groups, as well as occasional educational events.

Focus group participants expressed a desire for support groups for cancers other than breast, and more education on cancer prevention and screening, especially in relation to skin, lung, prostate and breast cancer. Because mountainous and winding roads, as well as distances to hospitals from outlying areas of the district make travel at times difficult access to educational activities located in the cities along the 81 corridor presents a barrier. Cancer survivors and caregivers who participated in the focus groups indicated that they had access to transportation as needed for their cancer care, although it did pose a relative hardship.

Healthcare Provider Needs

Key Leader Information

Ten healthcare professionals who are long-time residents and leaders in their communities were interviewed to gather a broad perspective of the cancer healthcare needs of the health district. They were selected from throughout the health district and included physicians, hospital and clinic administrators and Nurse Practitioners. These individuals were asked to identify the most pressing healthcare deficiencies in their community related to cancer risk reduction, detection, treatment, and follow-up care. In addition, they were asked to identify the needs of community primary care physicians for cancer continuing education, difficulties acquiring cancer diagnoses or treatment for their patients, post-treatment communication and training needs, and palliative care knowledge.

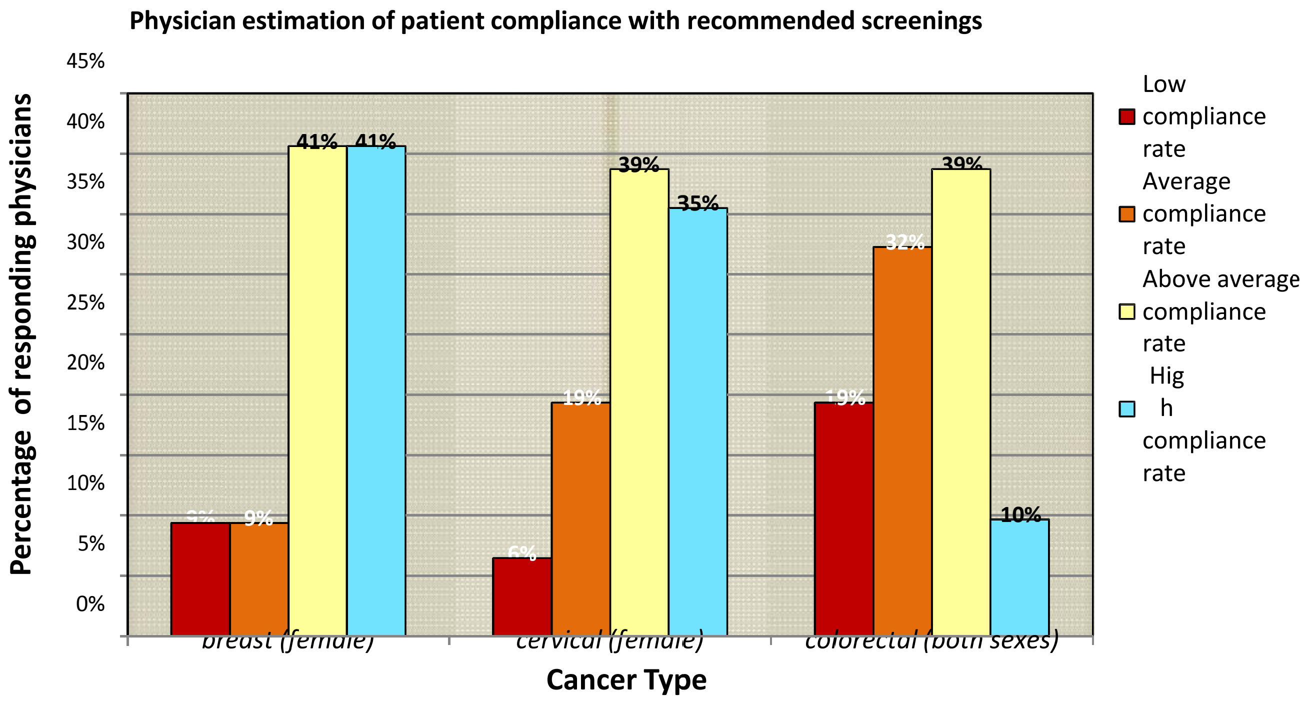
The major healthcare deficiencies identified by these Key Leaders fell into three categories, (1) effective education programs to promote healthy lifestyles, (2) number and specialization of community physicians, and (3) barriers to healthcare access. Tobacco use was seen as a significant cancer risk for the health district, with a need for promotion of tobacco cessation and education at all levels of the age spectrum. The physician to patient ratio was seen as a significant problem, as was the lack of sub-specialty oncologists. A lack of treatment centers in the upper part of the health district was identified as a barrier to preventive screenings and cancer treatment, in part because of the lack of and under-utilization of primary care. In addition, travel time, lack of transportation, financial resources and insurance were additional, significant barriers. Physicians also cited long wait time in oncology offices, long wait time for treatments, scheduling tests, getting test results and follow-up visits as a barrier to timely cancer services and treatment.

The particular needs of primary care providers identified by key leaders were help with patient education about cancer screenings and tobacco cessation. Physician continuing education on current cancer screening guidelines and guidance on physician responsibility for recommending the screenings (PCP VS Specialist) was identified as a need. Continuing education around cancer survivorship issues was also identified as a need.

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. Thirty-two physicians in the MRHD completed a cancer questionnaire, either on paper or on-line, which represents a 30% response rate from physicians contacted. Over half of the responding physicians were family practice physicians, with the next largest group being gynecologists. The remainder specialized in internal medicine, public health, surgery, family planning and emergency medicine. The findings of the survey are as follows:

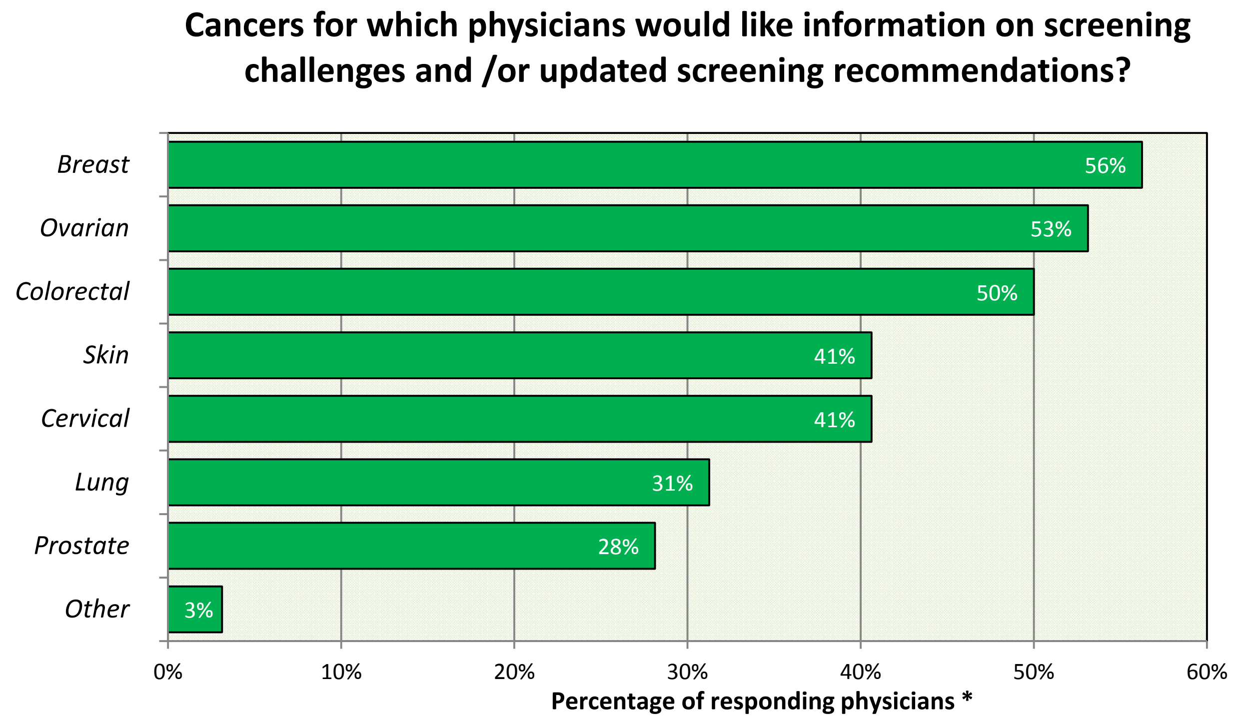
Screenings: Respondents identified breast, lung and colorectal cancer as the 3 most prevalent cancer diagnoses in their practices. When asked about the percentage of their patients who comply with recommendations for cancer screenings, 84% of responding physicians indicated a high compliance rate (> 50% compliance) with screenings for female cancers. In contrast, only 49% of responding physicians felt their patients had high compliance with their colon cancer screening recommendation. (**Figure 11**) The most compelling reasons physician cited for patients not having a recommended screening are financial constraints (84%), apprehension about the tests (78%), lack of insurance (69%) and fear of cancer diagnosis (56%). Other screenings conducted regularly by physicians include skin (75%), prostate (59%), ovarian (34%) and lung (31%). Physicians expressed a desire for updates on screening guidelines and development of screenings for several cancers including breast, ovarian, colorectal, skin, cervical, lung, and prostate. (**Figure 12**)



Low compliance rate - [0-25%] of patients follow recommended screeening guidelines

Average compliance rate - [26-50%] of patients follow recommended screening guidelines Above average compliance rate - [51-75%]of patients follow recommended screening guidelines

Figure 11: Physician estimation of patient compliance with recommended screenings



** - Percentage is calculated based on the total number of responses for each cancer out of the total number of physicians that completed the questionnaire and identified their practice area as part of health district.*

Out of 32 physicians who responded to this question, 6 did not indicate interest in any category, 5 indicated interest in 1 cancer, 6 indicated interest in 2 cancers, 4 indicated interest in 3 cancers, 2 indicated interest in 4 cancers, 1 indicated interest in 5 cancers, 1 indicated interest in 6 cancers, and 7 indicated interest in 7 all cancers for any information on screening challenges/update screening recommendations.

Figure 12: Cancer for which physicians would like information on screening challenges

Referrals and Communication: When asked where they refer their patients diagnosed with cancer, 88% percent of respondents reported that they prefer to refer oncology patients locally for surgery and treatment, while 13% sent patients outside of Virginia, 13% to other Virginia cancer centers (non-NCI) and 13% referred to a NCI center in Virginia (VCU, UVA). Preferred communication between PCP and the oncologist included treatment plans, follow up care guidelines, end of treatment notes and pathology reports. Over half (59%) of PCP's reported that they were happy with the communication they received from treating oncologists.

Post-cancer treatment: When asked what continuing education topics related to the care of cancer patients post-treatment would be of interest, the majority of responding physicians indicated updated information about surveillance of cancer recurrence, long-term cancer treatment effects, pain management, end-of-life care and planning, wellness and prevention of cancer recurrence, and genetic counseling for family members of cancer patients. (**Figure 13**) They prefer that this information come to them in written form or through web-based sources.

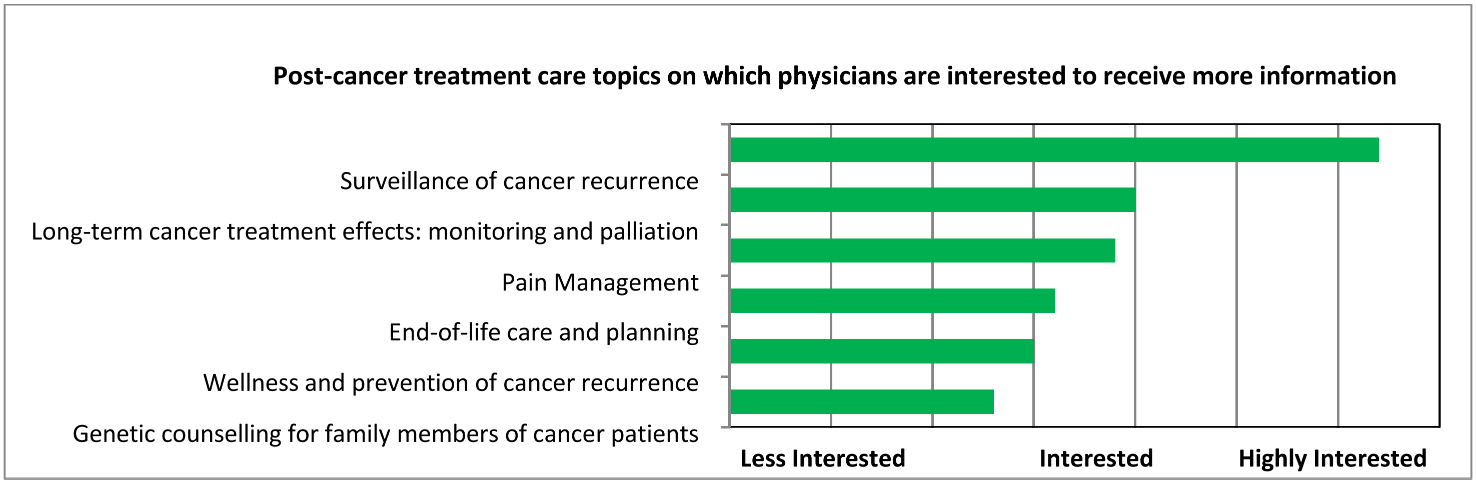


Figure 13: Post-cancer treatment care topics on which physicians are interested to receive more information

Community Population Needs

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

Behavioral Risk Factor Surveillance Survey

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

According to the Behavioral Risk Factor Surveillance System (BRFSS) for adults eighteen and older, the Mt. Rogers Health District, when compared to Virginia shows a higher incidence of sedentary behavior and smoking, and has a relatively high incidence of obesity. (**Figure 14**) All three factors are associated with a higher cancer risk. One third of the population reported no physical exercise in the past 30 days and only 22% included 5 or more fruits and vegetables in their daily diet. Greater than half (66%) of the district is obese. On average, about 27% of adults smoke, with the highest group of smokers in the age group of 18-39 at 35%. This information is supported by comments gathered in our focus groups.

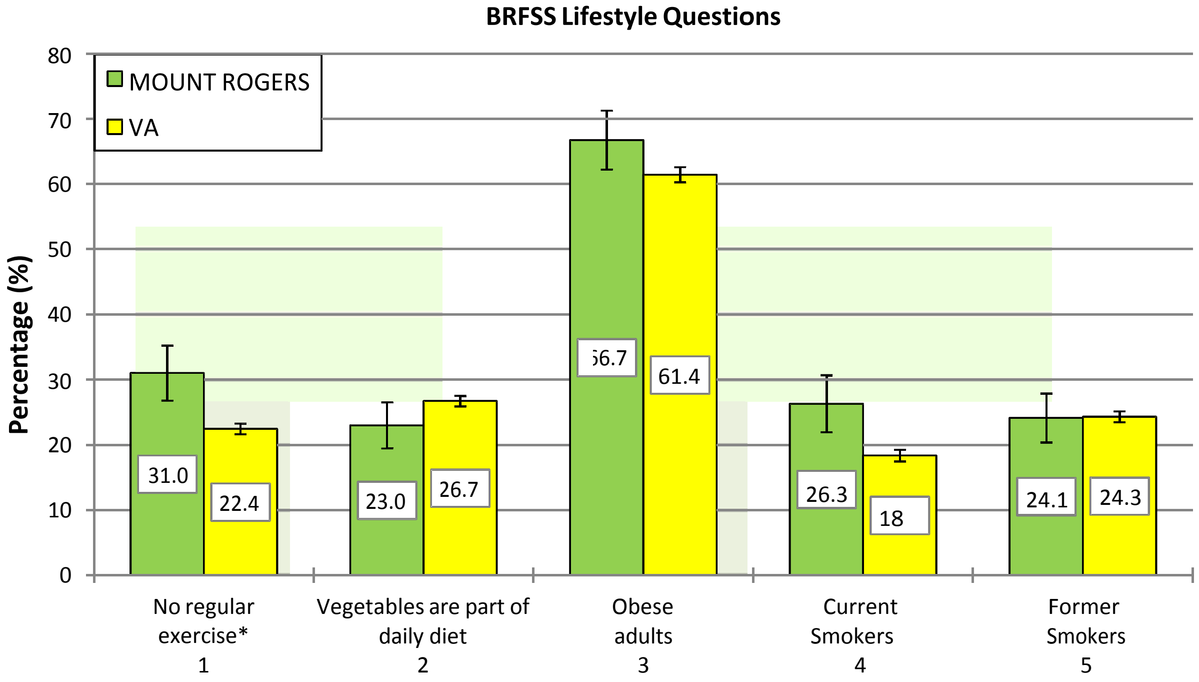
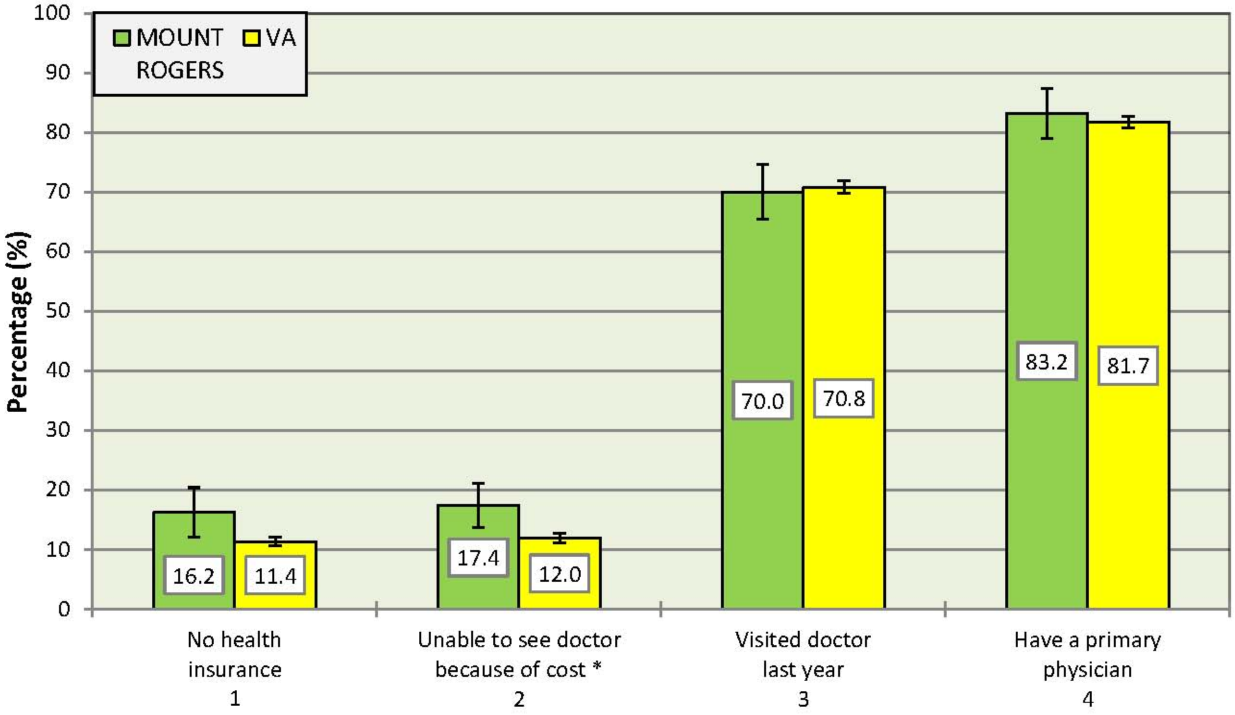


Figure 14: BRFSS Lifestyle Questions

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

Access to healthcare for residents of the Mount Rogers Health District is similar to that for those in other parts of the Commonwealth. The majority of residents has a primary physician and has visited their doctor in the past year. A larger proportion of individuals in the MRHD are unable to see a doctor due to cost, however, compared to the State. (**Figure 15**)

Figure 15: BRFSS Health Care Access Questions



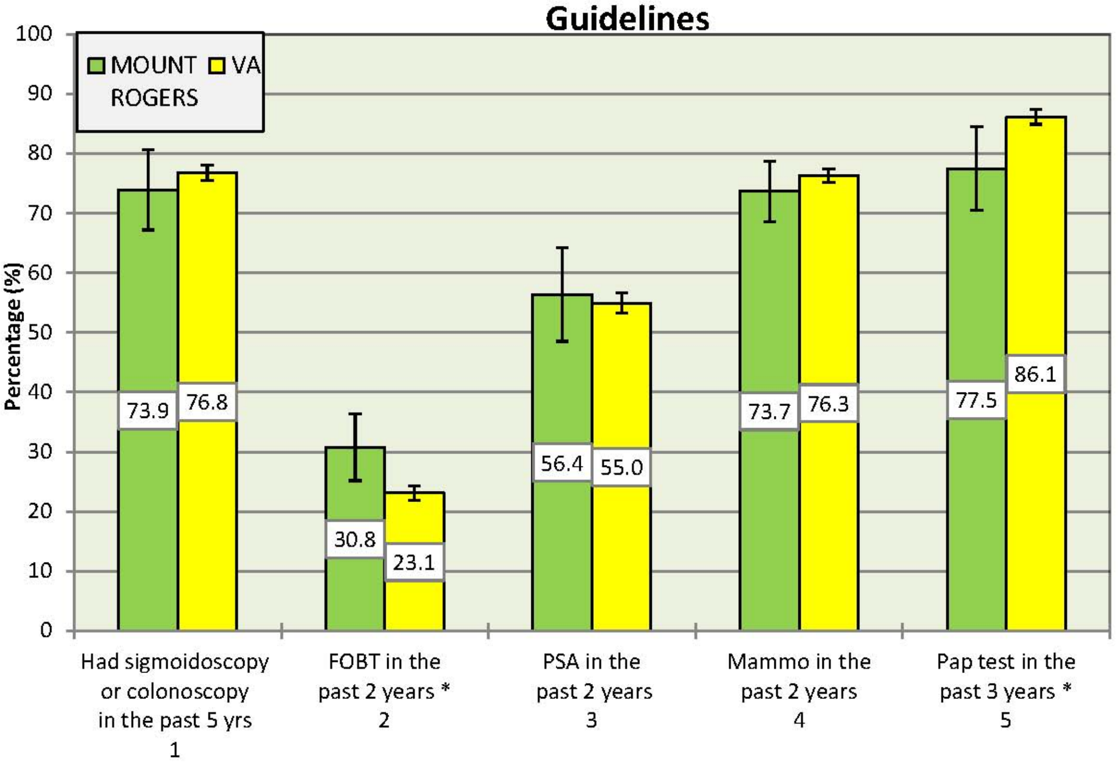
** - indicates a significant statistical difference between health district and state data.*

***1** - represents adults with no health insurance; **2** – represents adults that were unable to see doctor in the past year because of cost; **3** – represents adults which had an appointment with a primary care physician within the past year;*

***4** – adults that have 1 or more physicians they consider their primary;*

Cancer screening rates in the MRHD were similar to the state rates. Despite the PCPs feeling that a lower percentage of clients were compliant with recommendations for colorectal cancer screening, 74% of residents indicated that they had had the screening. A similar percentage of women indicated they had received a mammogram. Only pap test rates were lower than the state average. (Figure 16)

Figure 16: Compliance with Recommended Screening Guidelines



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

Focus Group Information

Focus Group participants were selected from the pool of volunteers who responded to mass email list-serves, flyers and personal presentations. In addition, ads were placed in area newspapers and on select radio stations.

The demographics of the community were used as a guide for final selection of the participants. While the community is almost equal male:female, the final ratio of male to female for the focus group was 1:3. This despite targeting of men for participation. Age, education and economic distribution were better matched. Residential representation was also considered. The last criterion used for selection was personal experience with cancer. The general population Focus groups consisted of people who had little or no experience with cancer. The survivor Focus groups consisted of people who either had a diagnosis of cancer or were the primary caregiver of a cancer patient.

Venues for the meetings were chosen for the convenience of the participants, considering location, parking convenience and time schedules. Focus groups were held in the townships with hospitals because they are central to each county. (**Figure 17**)

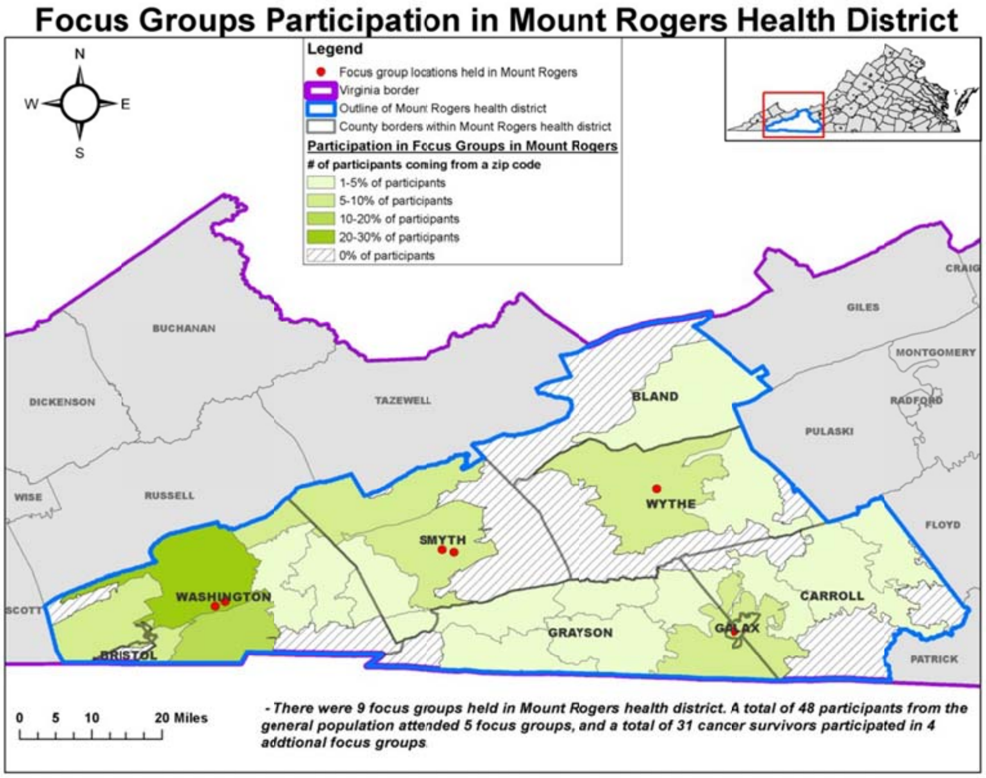


Figure 17: Focus Groups Participation in Mount Rogers Health District

General Population Group Synopsis:

Five focus groups with the general population were held in four areas distributed throughout the Health District. There were a total of 48 participants, with an average group attendance of 9. Participants were able to identify prevailing health problems in their communities including arthritis, fibromyalgia and the diseases that have the highest impact on mortality; heart disease, obesity, drug abuse, COPD and cancer. Obesity, Illicit drug use and poverty were greater concerns to participants than cancer. Mental illness, malnutrition, and Alzheimer's were also identified as concerns.

Most focus group participants were aware of healthy lifestyle habits including eating a healthy diet, maintaining an appropriate weight, and to avoid smoking. However, they expressed difficulty in following this prescription. Many of the participants felt that weight didn't necessarily translate to health and being undernourished (poverty related) was as much a concern as obesity.
The prevailing themes from the general population focus groups included:

- Barriers to healthy lifestyle: Participants living outside the central towns along the I-81 corridor, where grocery stores are located, felt that access to healthy foods was difficult. They also felt that cultural activities and access to healthy lifestyle options was limited.
  "Organic is best but we can't get it in our grocery stores here."
  "We cook with too much fat!"
  "Tobacco is a part of our culture."

- Taking responsibility for one's own health: Most participants knew what healthy habits are but choose not to observe many of them. Obesity and tobacco use were cited as prime examples.
  "I know what to do, I just don't do it."
- Early education for health: Participants in general felt that we need to reach children, but we also need to reach the parents with healthy lifestyle messages.
  "Maybe if we teach our kids in school they can teach their parents."
- Distrust of institutions responsible for drug development and testing: At least one person in all 10 focus groups felt like someone knows how to cure cancer.
  "I think the government knows what cures cancer but cancer is big business so they aren't going to tell us everything."
- Environmental causes of cancer including cluster areas specific to environmental concerns, such as pesticides and old factories.
- Attitudes about cancer research - Most participants saw research as hope and cure, but it's unavailable in some areas.

Cancer Survivor Group Synopsis:

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

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

Five focus groups with cancer survivors were held in four areas distributed throughout the Health District. There were a total of 31 participants, with an average group attendance of 8 (See Figure 18). A reoccurring theme with cancer survivors was the relationship of economic status to decisions about treatment. Participants felt that patients from higher economic brackets were more apt to go to bigger cancer centers located outside of the Health District, whereas those with limited resources were treated at the facility closest to them. The type and stage of cancer also dictated where the patient decided to be treated, with the more severe or rarer cancers being treated elsewhere.

An additional recurring theme was related to the need for information about their cancer diagnosis. Participants consistently reported that they had to be proactive to get helpful and accurate information. What they didn't get from their doctors, they found at the local ACS office or on the internet. There was a general perception that greater quality care could be obtained outside of the Health District, and there were several reports of misdiagnoses or delayed diagnoses that occurred locally as supporting evidence of this. Patients treated locally all reported long wait times (up to 8 hours) in oncologists' offices and long wait times for lab and imaging test results. This was also a concern of Key Leader physician that we interviewed.

Participants generally felt that their basic support needs during their cancer experience were met by friends, family and the community. “Cancer is a devastating word” was a reoccurring theme. “My family and church friends helped me…” “I’m very active with the ACS and Road to Recovery.” Patients did express a desire for support groups so that they could gain information from other cancer survivors.

Needs for cancer patients, caregivers, and survivors include more local treatment centers, hospitality houses, oncologists and specialists, patient advocates and assistance with transportation for treatments. Patients also expressed a desire for a clearinghouse for information on oncologists, doctors and treatment facilities such as physician profiles and reviews and details about services offered at offices and hospitals. Educational needs include preventive care, more resources for specific types of cancer and after-care.

SUMMARY OF PRIORITY NEEDS

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

1. Assist hospitals and medical practices in recruiting more primary care physicians to the area
2. Increase the volunteer capacity at the JMH cancer center to include more help for families outside of Abingdon, but within the health district to meet basic needs related to care (home care, transportation, personal services)
    a. May include the organization of faith-based entities to serve their congregants and the greater community
3. Develop a public awareness campaign to increase screenings with a special component targeting men for prostate cancer and both sexes for lung and skin cancer.
4. Increase public awareness of the dangers of tobacco use and offer FREE cessation information and aids, as well as prevention education.
5. Work with the Virginia Department of Education to find curriculum with healthy living/lifestyle information integrated into all subjects
6. Form community health/cancer support groups (not limited to breast cancer) in each community, maybe affiliated with a primary care practice
7. Encourage further environmental research where there are perceived clusters of cancer
8. Form a task force in the district whose members are key stakeholders in the medical and health community to review the information in this document and consider ways to fund and implement these suggestions. This may include:
    a. Administrative members of the various hospitals and cancer centers
    b. Administrative or outreach members of the Health Department, including one from each county
    c. Family/Internal medicine physicians
    d. Members of the American Cancer Society
    e. Members from the Cancer Survivor population
    f. Community members at-large
    g. School administrators
    h. Recreation representatives

APPENDICES

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

Appendix B:
Primary Care Physician Questionnaire

Appendix C:
Focus Group Facilitator Guides

Appendix D:
Cancer Healthcare Resources within the Health District

Appendix E:
Community Cancer Resources within the Health District

APPENDIX A

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

CHES 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's 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 any other board report oncological data to the state?*** Yes_____ No____ Unknown____

If YES, ***what is the name of the board?*** ______________________________________

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

4. ***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 (please specify)____

5. ***Is the list of oncologists that I have documented as being on staff at the hospital accurate?*** Yes___ No___

- Please list all oncologists:

____
____
____

6. ***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?
  ____

Radiation therapy Yes_____ No____

7. ***Are you currently trying to recruit Oncologists to practice at this facility?*** Yes_____ No____

8. ***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 Cancer related 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____
- Gastrointestinal (resection)
  - -upper tract Yes_____ No____ Unknown____ Unknown__ Unknown_____
  - -lower tract Yes_____ No____
  - -liver/pancreas Yes_____ No____
- Lung? Yes_____ No____ Unknown____
- Prostatectomy? 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__

- If YES, ***is he/she board certified in oncology nutrition?*** Yes_____ No____
  - If YES, ***name of Dietician*** ________________________________
  - If NO, ***name of general Dietician*** ________________________________

- If YES, ***Which nutritional services does he/she offer?***

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

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

- If YES, ***Who provides the counseling?*** (RN, NP, MP, GC, etc.)________________________________
  - ***Are they certified?*** Yes_____ No____

FINANCIAL/ INSURANCE

9. 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): ____________________________

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

1.

2.

3.

4.

5.

11. 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.

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

13. 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:_______________

14. 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____

15. 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.

16. What Hospice Services are offered to patients?

- Inpatient hospice

Facility Supported Yes_____ No____ Unknown____ Unknown__
Private organization Yes_____ No____

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

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

- If YES, ***Could you describe it?***

SUPPORT / EDUCATIONAL PROGRAMS

18. Do you have a cancer patient navigator at this facility? Yes_____ No____Unknown_____
- If YES, ***For which cancer types?***

19. 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_____

20. 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 cancer related services do you provide? (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
☐ Other: ____

____

7. How do you advertise your organization and services?

☐ Local media
☐ Organization website
☐ Distribution of pamphlets describing services
☐ Word of mouth
☐ Other ____

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

☐ < 50
☐ 50 – 100
☐ 150 – 250
☐ > 250

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

☐ Financial support
☐ Human resources (skilled employees, volunteers, etc.)
☐ Access to experts for consultation
☐ 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?

____

____

____

____

Physician Key Leader Interviews to inform CME

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:
☐ Crater ☐ Mount Rogers
☐ Piedmont ☐ Pittsylvania-Danville

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 cancers 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. For which of the following post-cancer treatment care topics would you like further information (Please, number in order of 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 counselling 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 yor community in relation to providing adequate care of patients after completing cancer treatment.

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.

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

[Moderators Assistant: 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?
   (Assistant lists 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 getting 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 – lets 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 affect on a person's health? (Assistant lists 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?
   (Assistant lists on flip chart)

Review the list.

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.
    a. Probe:
       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? (Looking for a count)
    b. If yes, what should a person eat, or what eating habits should they have to stop them from getting cancer?
    c. What foods or eating habits or ways of eating can cause 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 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? What about the word 'physical activity', is there a difference?

So, we have talked about exercise as (define according to what they have said),

and physical activity as (define according to what they have said)

13. What kind of physical activity or exercise do you think will help improve a person's health?
    (PROBES: What kind, intensity, duration, and frequency?)

14. How easy is it for people in your community to be physically active? (PROBE: Where do people go to exercise or get physical activity? What stops people from being more physically active in your community?)

15. What are some ways to make it easier for 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 was also on the list of things that can improve health.

16. What are your thoughts on weight? Are you and/or people in your community concerned about being overweight? (PROBE: At the community level, is there concern over obesity as a health problem?)

17. What kinds of health problems do you think can be caused by being overweight?

18. Do you think that being overweight or obese can increase someone's 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?)

Show Figure Rating Scale and ask the group to identify which figure would represent someone who is at a weight where that was not good for their health. Document all number of figures chosen by group members.

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

TOBACCO

22. Do you think that tobacco use, (smoking tobacco, chewing or dipping tobacco) is a problem in your community? PROBE: About how many people use tobacco, not very many, a lot, about half…

23. What kinds of issues or problems do you think tobacco has caused for people you know in your community?

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 are some reasons that people in your community do not quit using tobacco?

27. What do you think would be the best ways to help people 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.

28. Do you think there are any things in the environment of your community that might cause cancer?

29. What are your thoughts about someone’s history of cancer in their family? Can that effect someone’s chances of getting 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.

30. Do you know of any tests that a person can have done to see if they have cancer?
(Assistant lists them out)

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

31. What do you think of tests or screenings for cancer?
(PROBE: How important is it to have these tests done?)

32. Has your doctor ever told you to have a test for any cancer? If so, what test (if you don’t mind saying)?

33. 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]

34. 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?
    a. Can you tell us anything about the experience you or they had?

35. When you hear the words, “***cancer research***” 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 cancer research for the purposes of the questions that follow)

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.

36. Does anyone know someone or heard about someone who participated in a ***cancer*** research study?
37. I would like you to think about yourselves, and whether you would be in cancer research that ***did not*** involve cancer treatment if you were asked? Please state why or why not.
38. Now, if you knew someone who had cancer and they were asked to participate in cancer research that was testing a new medication, do you think you would advise them to be in the stude? Please state why or why not.
39. 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 we would like you to sign a receipt for your $50.

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 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 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. 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 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.]

[Moderators Assistant: 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

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 things 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 things that delayed or made it hard for you to get the diagnosis easily or quickly?

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 from 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.)
   Who? Was it helpful?

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

BREAK

<u>Post-Treatment (20 Minutes)</u>

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?

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? (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 was that?

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

CANCER RESEARCH SECTION [15 MINUTES]

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

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

National cancer Institute defines clinical research as:

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

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

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

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

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

OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]

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

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

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

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

Thank you so much for helping us with this project. We appreciate your time and candid thoughts on this important subject. On your way out we would like you to sign a receipt for your $50.

APPENDIX D

Cancer Healthcare Resources within the Health District

Results of Facilities Questionnaire for Mount Rogers Health District

Available Facilities:	Johnston Memorial Hospital & Cancer Center; Twin County Regional Hospital; Smyth County Community Hospital; Wythe County Community Hospital; Blueridge Cancer Care/US Oncology; Blue Ridge Cancer Care/US Oncology; Bristol Regional Medical Center	
# of oncologists:	6	Breakout: 5 medical oncologists, 1 radiation oncologist

Available in Health District

Services			**# of facilities where available**
Cancer Treatment	**Services provided**	Chemo Inpatient	5
		Chemo Outpatient	2
		Radiation	2
Cancer Screening	**Breast Cancer screening and diagnostic procedures**	Screening Mammography	4
		Diagnostic Mammography	4
		Breast Biopsy	2
		Breast MRI	3
	Colorectal Cancer	Sigmoidoscopy/Colonoscopy	4
Surgeries	**Cancer related surgeries**	Breast Segmental/Complete Mastectomy	4
		Breast Reconstruction	2
		Gynecological Hysterectomy/Oophorectomy	2
		GI - Resection Upper/Lower Tract	4
		GI - Liver/Pancreas	2
		Prostatectomy	4
		Sentinel Nodes Sampling	1
Counseling	**Cancer Dietary needs**	Registered dietician to provide nutritional services specific to cancer patients	4
		Board certified dietician in oncology nutrition	1
		Outpatient oncology nutrition counseling	3
		Cancer control and prevention education programs for dietary needs	2
	Genetic counseling	Genetic counseling available	4
		Certified genetic counselor	2
		Genetic counseling provided by:	RN, NP
Other Services	**Clinical Trials**	Offer clinical trials	2
	Hospice Service and Palliative Care	Facility Supported: Inpatient / Outpatient Hospice	2 / 3
		Private Organization: Inpatient / Outpatient Hospice	3 / 4
		Palliative Care Program	4
	Cancer Patient Navigation	Patient Navigator	2
		Navigation for the following cancers:	breast cancer
Cancer Support Groups	**Existing Support Groups**	Availability of cancer support groups	2
		Support groups for the following cancers:	breast cancer
	Future Support Groups	Want to start a support group	3
Specialists	**Oncology**	Currently recruiting oncologists	3

Not Available in Health District

Cancer Screening	**Colorectal Cancer**	CT colonography
Cancer Surgeries	**Cancer related surgeries**	Lung

APPENDIX E

Community Cancer Resources within the Health District

		Health District	American Cancer Society	Colon Cancer Screening Taskforce	Cancer Outreach Foundation	VDH--Every Woman's Life	Wythe County Brest Cancer Coalition	Susan G. Komen for the Cure
Organization Information		**Number of Organizations that have his resource**						
Organization Category	**national non-profit**	**2**	**X**	-	-	-	-	**X**
	local non-profit	**2**	-	-	**X**	-	**X**	-
	for profit service org	**0**	-	-	-	-	-	-
	fed. Gov. org	**0**	-	-	-	-	-	-
	state/municipal gov. org	**1**	-	-	-	**X**	-	-
	Other	**2**	-	**X**	-	-	**X**	-
	Other (specified)	**(see organizations' answers)**		hospital affiliated			conjunction with the Community Outreach division of the WCCH.	
Major sources of funds for organization	**competitive grants**	**1**	-	**X**	-	-	-	-
	fed. Funds	**1**	-	-	-	**X**	-	-
	service fees	**0**	-	-	-	-	-	-
	donations	**5**	**X**	**X**	**X**	-	**X**	**X**
	Other	**2**	-	-	**X**	**X**	-	-
	Other (specified)	**(see organizations' answers)**			i the form of donations	State funds		
Cancer Resources								
Primary service population of the organization	**cancer patients**	**4**	**X**	-	**X**	-	**X**	**X**
	cancer survivors	**4**	**X**	-	**X**	-	**X**	**X**
	cancer caregiver/fam. Members	**4**	**X**	-	**X**	-	**X**	**X**
	Other	**2**	-	**X**	-	**X**	-	-
	Other (specified)	**(see organizations' answers)**		Grayson & Carroll Counties		women ages 50-64		
Qualification Criteria to access services	**must be under(un)insured**	**1**	-	-	-	**X**	-	-
	financial qualification	**1**	-	-	**X**	-	-	-
	no qualification	**4**	**X**	**X**	-	-	**X**	**X**
	Other	**1**	-	-	**X**	-	-	-
	Other (specified)	**(see organizations' answers)**			to all patients, but financial services to uninsured cancer			
Type of cancer related services that are provided	**written info on cancer**	**6**	**X**	**X**	**X**	**X**	**X**	**X**
	info on cancer care/supp resources	**5**	**X**	-	**X**	**X**	**X**	**X**
	management of can.supp.groups	**2**	**X**	-	-	-	**X**	-
	fin.supp. For cancer control/care	**1**	-	-	**X**	-	-	-
	Funding of projects related to cance	**2**	**X**	-	-	-	-	**X**
	Other	**2**	-	**X**	-	**X**	-	-
	Other (specified)	**(see organizations' answers)**		and awareness programs		exam, pap test, clinical breast exam		
# of cancer pts seen annually		**(see organizations' answers)**	greater than 250	greater than 250		greater than 250	50 - 100	greater than 250
Other Information About Organization								
Advertising for the organization	**local media**	**3**	**X**	-	**X**	-	-	**X**
	website	**4**	**X**	-	**X**	**X**	-	**X**
	pamphlets	**6**	**X**	**X**	**X**	**X**	**X**	**X**
	word of mouth	**6**	**X**	**X**	**X**	**X**	**X**	**X**
	Other	**1**	-	-	-	-	-	**X**
	Other (specified)	**(see organizations' answers)**						Twitter, Facebook, Social networks

		Health District	American Cancer Society	Colon Cancer Screening Taskforce	Cancer Outreach Foundation	VDH--Every Woman's Life	Wythe County Brest Cancer Coalition	Susan G. Komen for the Cure
Organizational Needs	fin. Support	4	X	X	-	-	X	X
	human resources (skilled employee	3	X	-	-	-	X	X
	access to experts for consultation	1	-	-	-	X	-	-
	Other	0	-	-	-	-	-	-
	Other (specified)							
Challenges		(see organizations' answers)		Funding		and people to agree to the screenings.	that the services are available.	
Goals for the next 5 yrs		(see organizations' answers)		To have more people screened for colon cancer		To bring in more patients for screenings.	To increase the number of volunteers and patients/survivors needing the services.	
Comments		(see organizations' answers)				This program is part of the Mt.Rogers Health District Clinical outreach program.	number of programs in conjunction with the WCCH Communit Outreach educator, Barbara Patton. They offer the following: care giver's support group, hospice information, Reach to Recovery, Road to Recovery, Look Good, Feel Better, Ladies Night Out and an Expo on Prostate Cancer. They offer educational seminars when appropriate.	