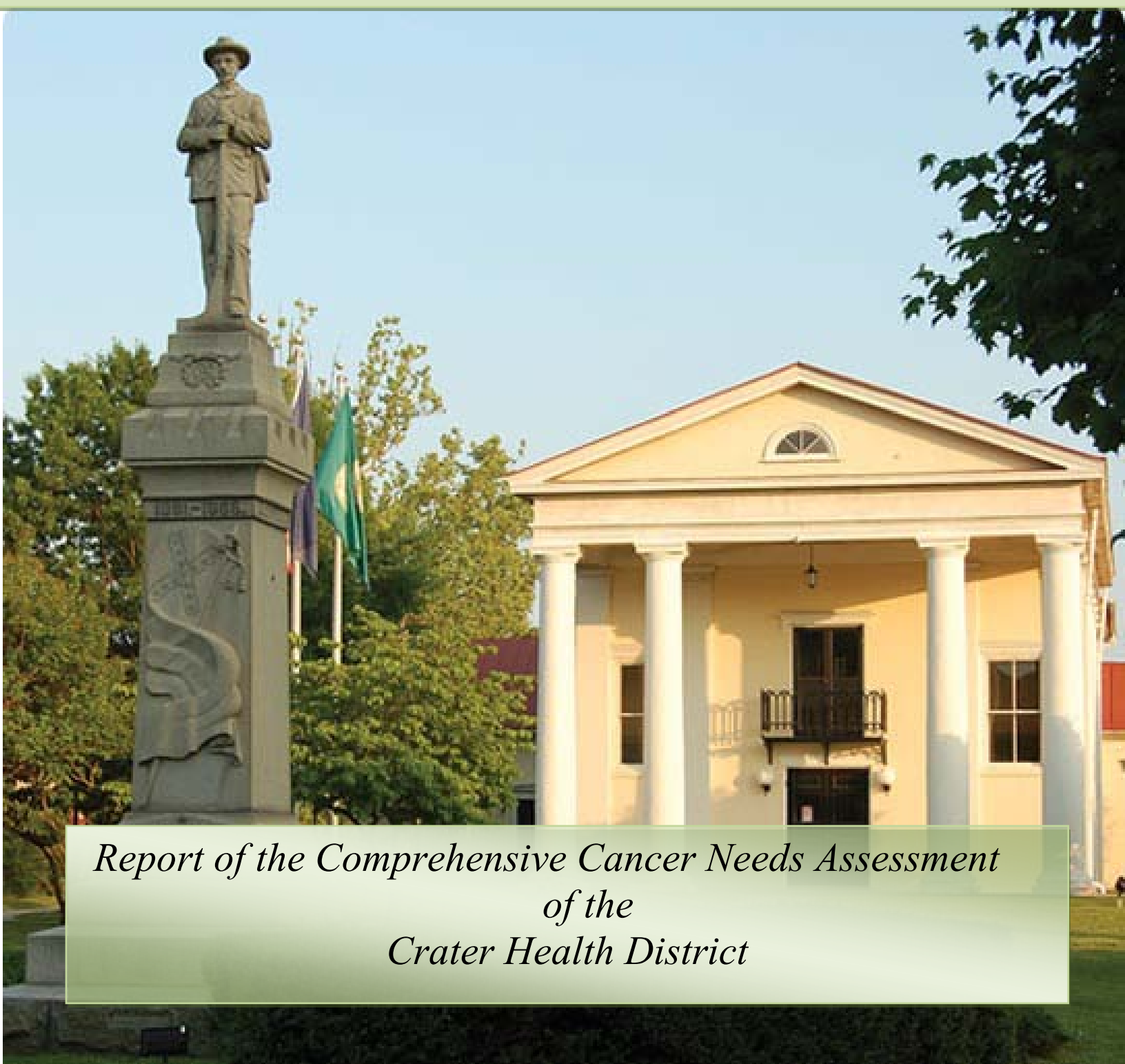


Saving Lives and Reducing Suffering and Death from Cancer in Virginia



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

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



Saving Lives and Reducing Suffering and Death from Cancer in Virginia

Addressing Educational, Clinical and Advocacy Needs Related to Cancer in

Southside and Southwest Counties

Cancer is a significant health problem in Virginia, impacting the physical, emotional, economic, and social well-being of individuals, their families, and communities. An average of 32,769 Virginia residents are diagnosed with cancer annually,¹ with an average of 13,891 succumbing to their disease.² Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease.³ Virginia is poised to combat this disease with healthcare institutions, cancer care centers, state education and research institutions, city and state governments, non-profit organizations, and grass-roots community groups working to reduce the cancer burden in the State. 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.

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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Electronic versions of the Health Districts' Cancer Needs Assessments may be found at: <http://www.massey.vcu.edu/Cancer-needs-assessments-TICRC-funded-projects.htm>

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Table of Contents

Executive Summary of Findings	1
Introduction	3
Method of Data Collection	3
Cancer Burden.....	4
Community Cancer Resources	4
Healthcare Provider Needs	4
Community Population Needs	5
Demographics in Crater	6
Cancer Burden	8
Cancer Incidence	8
Cancer Staging & Mortality	14
Cancer Healthcare Resources	18
Healthcare Facilities and Cancer Care.....	18
Cancer Services Provided.....	18
Hospices Services	19
Community Cancer Resources	19
Healthcare Provider Needs	20
Key Leader Information	20
Physician Questionnaire.....	21
Community Population Needs	24
Behavioral Risk Factor Surveillance System	24
Focus Group Information	26
Summary of Priority Needs	30
Appendices	31

List of Figures

Figure 1: Crater Health District	6
Figure 2: Healthcare Resources in Crater Health District.....	8
Figure 3: Age-Adjusted Cancer Incidence in Crater HD vs. Virginia	9
Figure 4: Top 5 Cancers in Crater HD by Incidence Count	10
Figure 5: Top 5 Cancers for Males by Incidence Count	11
Figure 6: Top 5 Cancers for Females by Incidence Count	12
Figure 7: Percent Frequency of Incidence Counts by Cancer Site and Race	14
Figure 8: Cancer Stage at Diagnosis in Crater HD vs. Virginia	14
Figure 9: Age-Adjusted Cancer Mortality Rate in Crater HD vs. Virginia	15
Figure 10: Top 5 Cancers causing Death in Males	16
Figure 11: Top 5 Cancers causing Death in Females.....	16
Figure 12: Patient Compliance with Physician Recommended Cancer Screenings	22
Figure 13: Most Useful Information coming from Treating Oncologist to Primary Care Physicians.....	23
Figure 14: Satisfaction with Communication from Treating Oncologists	23
Figure 15: Treatments Primary Care Physicians Feel Comfortable Providing to their Patients	24
Figure 16: BRFSS Lifestyle Questions	25
Figure 17: Compliance with Recommended Screening Guidelines	25
Figure 18: Access to Healthcare	26
Figure 19: Focus Groups Participation in Crater HD	26

List of Tables

Table A: Demographic Profile of Crater HD vs. Virginia	7
Table B: Economic Characteristics of Crater HD vs. Virginia	7
Table C: Age-Adjusted Cancer Incidence in Crater HD vs. Virginia	9
Table D: Top 5 Cancers in Crater HD by Incidence Count	10
Table E: Top 5 Male Cancers in Crater HD	11
Table F: Top 5 Female Cancers in Crater HD	12
Table G: Top 5 Cancers in Black residents in Crater HD	13
Table H: Top 5 Cancers in White residents in Crater HD	13
Table I: Top 5 Cancers in Crater HD by Death Count	15
Table J: Top 5 Cancers for Black residents in Crater HD by Mortality	17
Table K: Top 5 Cancers for White residents in Crater HD by Mortality	17

EXECUTIVE SUMMARY OF FINDINGS

The collection of data and information for this report came from a number of federal, state and local web-based sources including the U.S. Census Bureau, Department of Health and Human Services, Virginia Workforce Connection, as well as interviews and focus groups. This large geographic district has a population of 48% black and 47% white with the remaining 5% of all other races. The three hospitals offering cancer treatments are located within highly populated areas of a city, leaving many rural county residents in western Dinwiddie, Surry and Sussex to travel a great distance to these facilities. Five (four – medical, 1 radiation) oncologists serve 122,000+ residents. This district significantly lacks an adequate number of primary care physicians, as well as oncology specialists.

The cancer burden in the Crater Health District is high compared to the state. The incidence and mortality rate is higher than the state for most cancers; significantly higher for male genital systems, gastro-intestinal and respiratory cancers. The high incident and mortality rates of lung and bronchial cancers, correlate with some of the highest tobacco use rates in the state. Even though 52% of all cancers are caught at an early stage, the mortality rates across the district are high. All three of the hospitals in the health district have the capability to offer mammography and colonoscopy services. None offer MRI or CT screenings.

While cancers tend to be diagnosed in the local community, surgery and treatment more often take place in neighboring cities such as Richmond and Charlottesville. Treatment choices depend upon finances, type and stage of cancer. Hospital services vary at each location but may include an inpatient unit, an outpatient infusion area, chemotherapy and outpatient services such as blood transfusions, injections and biopsies. Crater Community Hospice is the only not-for-profit hospice agency located within the health district but there are several agencies located outside of the district that provide hospice services to each county.

Eight 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, awareness of community resources, and transportation. Physicians were also surveyed to gain perspectives on cancer screenings, care of patients during treatment and communication between PCP and oncologist. Approximately one-third (32%) of the responding physicians indicated a high patient compliance with recommended breast cancer screenings, but 78% felt their patients had low compliance with colon cancer screening recommendations. Financial constraints, lack of insurance, and lack of transportation were among the common reasons cited for non-compliance. Sixty-eight percent of physicians said they refer oncology surgical patients locally and only 45% of PCPs report they are satisfied with communication with the oncologists. Physicians expressed a desire for more written information regarding wellness and prevention of cancer recurrence, surveillance of cancer recurrence, long-term cancer treatment effects, and genetic counseling for family members of cancer patients, end-of-life care and planning and pain management.

District-wide focus groups for both the general population and cancer survivors/caregivers validated information collected in the Behavioral Risk Factor Surveillance Survey. Sedentary lifestyle, tobacco use and obesity were identified as the greatest issues of concern. General population groups were more concerned about various chronic diseases, cancer and obesity. Among the survivor groups, the need for more information about their disease and treatment was a common theme. Patients treated locally reported few local resources and lack of support. In general, survivors felt resources in other districts should be duplicated within the Crater Health District. Expressed needs included more and better treatment centers, and more access to educational resources.

The need for more primary care physicians and oncology specialists, community education about healthy lifestyles, access to clinical trials, and cancer information systems appropriate for rural communities including patient navigation programs 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 grassroots 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) located in their respective health districts. The CHEs were qualified, long-term residents of the Health Districts and were responsible for

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)

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, 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.⁶ 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.

⁶ BRFSS <http://www.cdc.gov/brfss/>

FINDINGS

Demographics in Crater

The Crater Health District is located in the southeastern portion of Virginia. It encompasses approximately 1800 square miles and is comprised of three cities Emporia, Hopewell, Petersburg and five counties Dinwiddie, Greensville, Prince George, Surry, and Sussex. Dinwiddie, Hopewell, Petersburg and Prince George are part of the Richmond-Petersburg Metropolitan Statistical Area (MSA).⁷ Two major interstates, I-95 and I-85, along with route 460 dissect the health district. (Figure 1)

⁷<http://www.vdh.state.va.us/lhd/crater/>

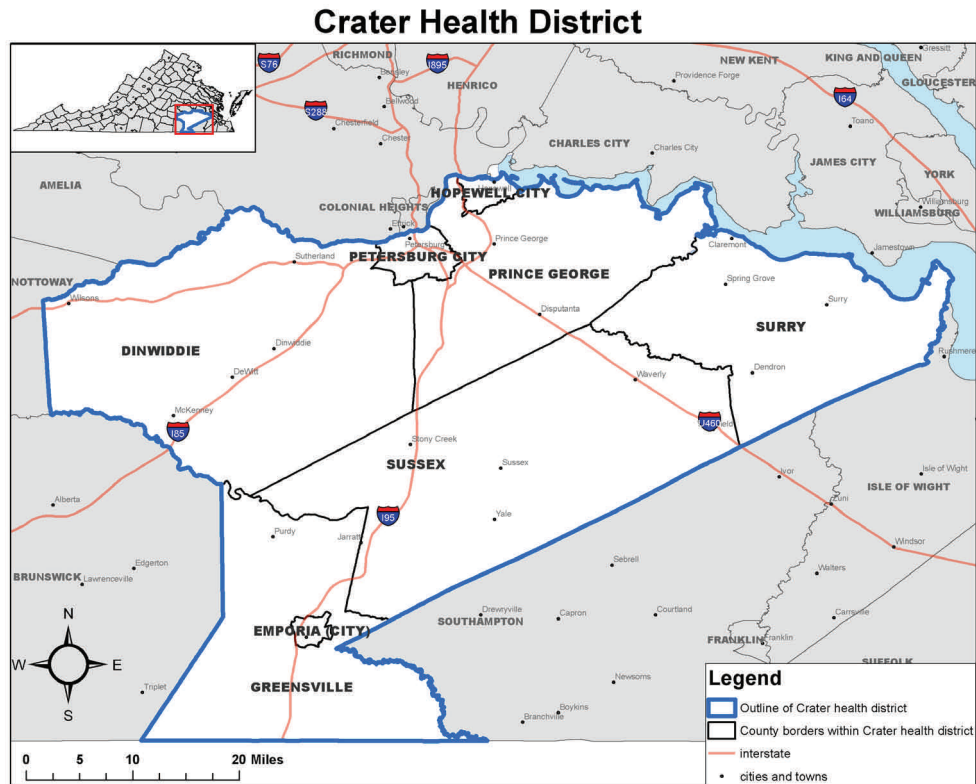


Figure 1: Crater Health District

According to the 2010 U.S. Census, the District has a population of 122,193 residents which is equally distributed by gender, and of whom 17% is age 65 years or older. Racial comparison of white and African American is approximately equal with 5% other races. Only 3% of the population within the Crater Health District reports Hispanic or Latino ethnicity, although this population is the fastest growing ethnic group in the district. Unemployment rates vary within the health district with the lowest rates of 7.1-7.8% in Dinwiddie, Prince George and Surry, and the highest rate of 12.8% in Petersburg. The overall health district unemployment rate of 9.9% is substantially higher than that of the state. Median income varies as well; \$33,412-\$35,874 in Emporia and Petersburg, and \$66,049 in Prince George. Virginia's median income is \$60,316. Greensville and Sussex counties have the lowest educational attainment within the health district with 30.1-34.9% of citizens with less than a high school diploma.⁸ There are two community colleges located within the district; Richard Bland College in Petersburg and Southside Virginia Education Center in Emporia which are two-year higher

⁸U.S. Census Bureau; American Community Survey, 2005-2009 Summary Table S1501; generated by Timur Korshin; using American Fact Finder; <<http://factfinder.census.gov>>; (7 November 2011).

education institutions. In the area surrounding the Crater Health District, there are multiple higher education institutions that exist. (Tables A & B).

<i>Demographic Profile of Crater vs. Virginia</i>			
Category	Subcategory	CRATER	VIRGINIA
Gender	Male	51%	48%
	Female	49%	52%
Age	18-39	37%	40%
	40-49	20%	19%
	50-64	26%	25%
	65+	17%	16%
Race	White	47%	67%
	Black or AA	48%	18%
	Other	5%	15%
Ethnicity	Hispanic or Latino	3%	7%
	Non-Hispanic or Latino	97%	93%

Table A: Demographic Profile of Crater vs. VA

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.

<i>Economic Characteristics of Crater vs. Virginia</i>		Crater (average)	Virginia
Unemployment¹ (16 years and older)	Unemployment Rate	9.59%	6.40%
Income²	Median Household Income	\$44,689	\$60,316
Education³ (25 years and older)	% Less than high school	24.94%	14.20%
	% High school or GED	38.29%	26.30%
	% Some college, no degree OR an Associate's degree	23.76%	26.00%
	% Bachelor's degree or above	13.01%	33.50%

Table B: Economic Characteristics of Crater vs. VA

¹Virginia 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).

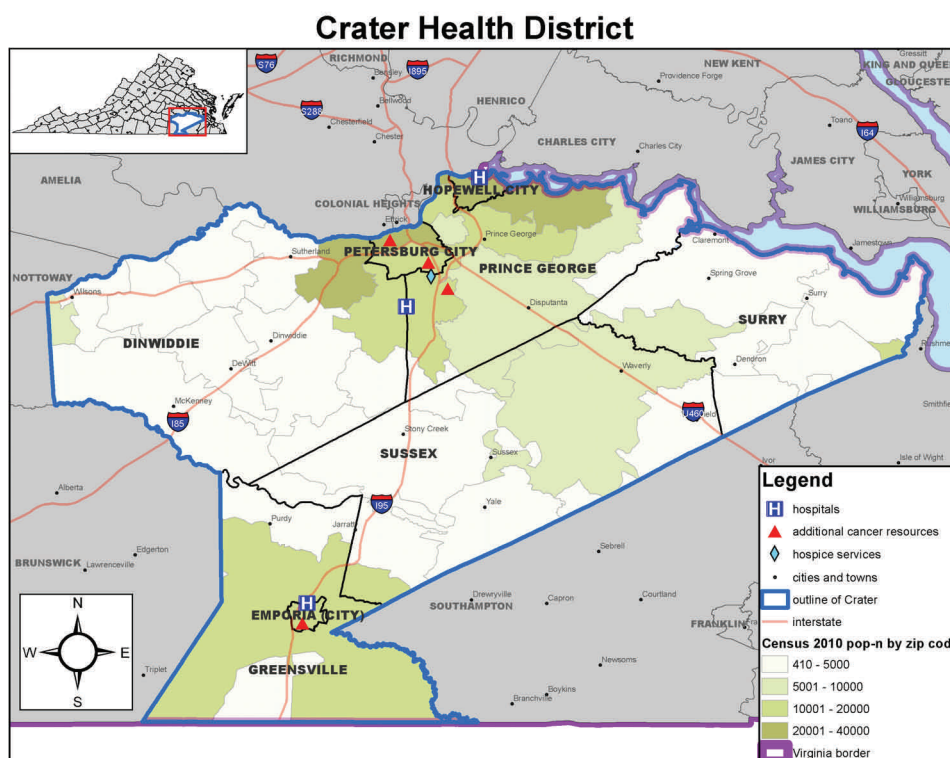
³ U.S. Census Bureau; American Community Survey, 2005-2009 Summary Table S1501; generated by Timur Korshin; using American Factfinder; <<http://factfinder.census.gov>>; (7 November 2011).

Access to Healthcare

Approximately 1/4 of the Crater Health District has been designated as rural and 3/4 of the area is designated as medically underserved areas/populations (MUA/ MUP). There are three medical hospitals within the Crater Health District: John Randolph Medical Center (part of HCA Virginia Health System) in Hopewell is a licensed 147-bed facility, about 30 minutes south of Richmond. Southside Regional Medical Center in Petersburg is a licensed 300-bed facility with 20 skilled nursing beds, located about 20 minutes south of Richmond. Southern Virginia Regional Medical Center in Emporia is a licensed 80-bed facility, 70 miles from Richmond. Each hospital has a

financial counseling department to assist uninsured or underinsured patients with the cost of services. **(Figure 2)** There is at least one community healthcare center in each locality.

Figure 2: Resources in the Crater Health District



Southern Dominion Health Systems, Inc. manages Dinwiddie Medical Center and Emporia Medical Center. Central Virginia Health Services manages the following locations, Hopewell/Prince George Healthcare Center, Petersburg Healthcare Alliance and Appomattox Area Health & Wellness Center (AAHWC). Horizons Health Services manages Surry Medical Center and Waverly Medical Center. Pathways to Health Specialty Clinic and Surry Area Free Clinic are the only two free clinics in the district. Each center offers sliding scale or free health services to citizens that qualify. Uninsured patients are referred to VCU Massey Cancer Center for oncology and follow-up services.

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 include respiratory, gastrointestinal, hematologic malignancies, urinary system, brain-nervous system-eye, oral cavity-pharynx, and other cancers. Cancer incidence rates are age adjusted. **(Table C)**

Age-Adjusted Cancer Incidence Rates in Crater Health District vs. Virginia		
Cancer Site	Crater	Virginia
Male Genital System	209.3	167.7
Prostate	205.9	162.0
Other male genital organs	3.4	5.7
Female Breast	122.4	124.3
Respiratory	95.3	72.5
GI System	94.0	79.8
Colon & Rectum	56.0	47.5
All Other GI	38.0	32.3
Gynecological	45.7	44.4
Corpus and Uterus	20.3	21.8
Ovary	12.0	12.1
Cervix	9.6	7.2
All other Gynecological	3.8	3.4
Heme-malignancies	37.3	34.3
Lymphomas	19.1	19.5
Leukemias	10.3	9.7
Myeloma	7.9	5.2
Urinary System	33.7	32.4
Oral Cavity, Pharynx	13.6	10.3
Brain, Nervous System, Eye	5.3	6.5
All Other Sites	36.2	44.5
All Sites	497.3	446.6

Table C: Age Adjusted Cancer Incidence in Crater vs. VA

Data Source: Virginia Cancer Registry (averaged rates for 1999-2008 - all rates calculated based on populations including all ages.

Dataset ordered by descending rate for health district.

Age-Adjusted Rate - represents on 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.

The cancer sites with the highest incidence rates in the Crater Health District are gastro-intestinal (GI), respiratory, and male genital cancers. Incidence rates were significantly higher than the State for male genital system, GI, and respiratory cancers, correlating with some of the highest tobacco use rates in the state. The district has a higher cancer incidence rate than the state when comparing all cancer sites together. All other combined cancer sites are significantly lower than the state. (**Figure 3**)

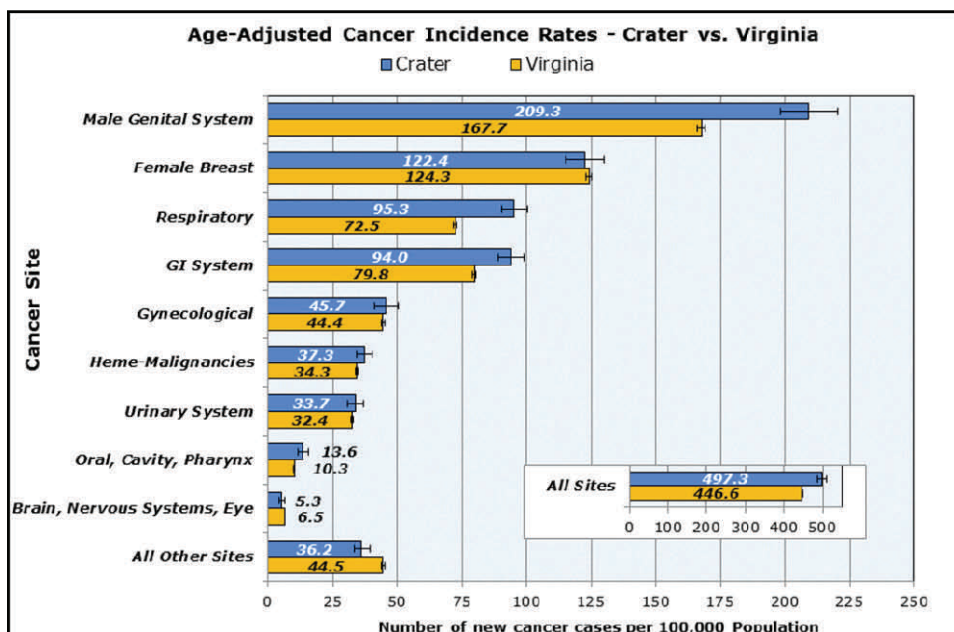


Figure 3: Comparison of Age-Adjusted Cancer Incidence Rates in Crater Health District vs. Virginia

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: Virginia Cancer Registry (averaged rates for 1999—2008) - all rates calculated based on populations including all ages.

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 Crater Health District, there is an average of seven hundred and eighty-three (783) new cancer cases each year in the health district based on a 10 year average (1999-2008). Respiratory, gastrointestinal/colorectal, male genital, female breast, and hematological cancers had the highest average incident cases. Together they make up 77% of the total cases. (Table D/Figure 4)

Top 5 Cancers in Crater Health District by Incidence Count	
Cancer Site	Annual Count
Respiratory	150
GI System	147
Colon & Rectum	87
All Other GI	60
Male Genital System	146
Prostate	143
Other male genital organs	3
Female Breast	103
Heme-malignancies	58
Lymphomas	30
Leukemias	16
Myeloma	12
All Other Sites	179
All Sites	783

Table D: Top 5 Cancers in Crater by Incidence Count

Data Source: Virginia Cancer Registry

Annual Count—represents average number of new cases per year in the health district (averaged over period 1999 - 2008).

All Other Sites include brain, nervous system, eye, gynecological, oral cavity, pharynx, urinary system and Other sites.

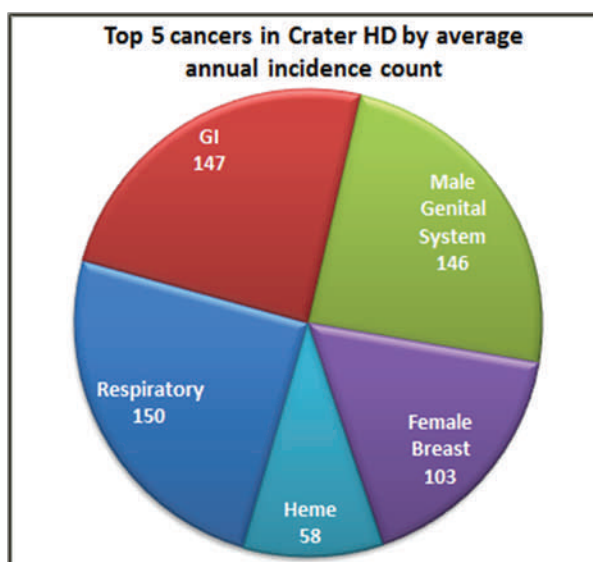


Figure 4: Top 5 Cancers by incidence counts in the Crater Health District

The cancers with the highest incident rates for males in the health district are male genital system cancers (mainly prostate), respiratory cancers (principally lung), gastrointestinal cancers (GI), urinary system cancers and heme-malignancies, in that order. These cancers make up 86% of the average male cancer cases each year. **(Table E)** Of these, male genital, respiratory and GI cancers have the highest incident rates and annual incident counts. **(Figure 5).**

Top 5 Male Cancers in Crater		
Cancer Site	Crude Rate	Annual Count
Male Genital System	187.6	146
Prostate	184.0	143
Other male genital organs	3.6	3
Respiratory	119.3	93
GI System	105.4	82
Colon & Rectum	59.9	47
All Other GI	45.6	35
Urinary System	47.0	37
Heme-malignancies	41.3	32
Lymphomas	20.6	16
Leukemias	10.9	9
Myeloma	9.8	8
All Other Sites	66.4	51
All Sites	567.1	441

Table E: Top 5 cancer types in males in the Crater Health District by incident rate and annual incident count

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.

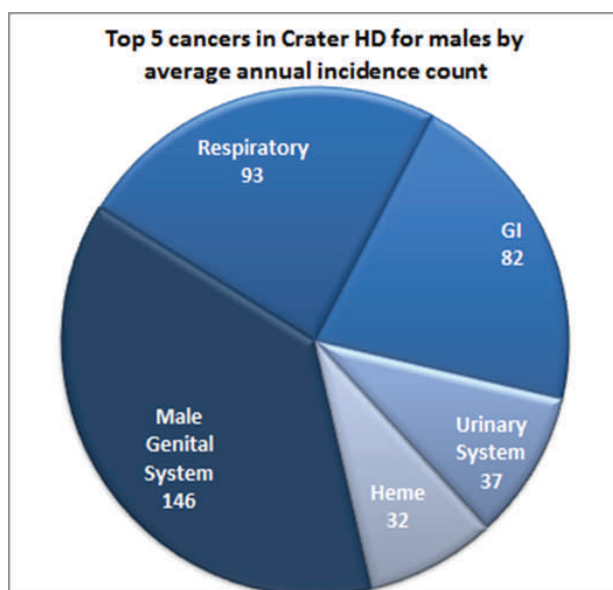


Figure 5: Proportion of incident count of the top 5 cancers in males in the Crater Health District

The cancers with the highest incident rates for females in the health district are female breast cancer, gastrointestinal cancers (GI), respiratory cancers (principally lung), gynecological cancers, and heme-malignancies, in that order.

These cancers make up 85% of the average cancer cases each year. **(Table F)** Of these, female breast, GI, and respiratory cancers have the highest incident rates and annual incident counts. **(Figure 6)**. Males have a higher annual cancer incident count than females overall, with higher incident rates of respiratory, gastrointestinal, and heme-malignancies.

Top 5 Female Cancers in Crater		
Cancer Site	Crude Rate	Annual Count
Female Breast	138.5	103
GI System	87.3	65
Colon & Rectum	54.8	41
All Other GI	32.4	24
Respiratory	77.2	58
Gynecological	52.3	39
Corpus and Uterus	23.9	18
Ovary	13.9	10
Cervix	10.2	8
All other Gynecological	4.3	3
Heme-malignancies	34.9	26
Lymphomas	18.6	14
Leukemias	9.8	7
Myeloma	6.4	5
All Other Sites	69.3	52
All Sites	459.5	343

Table F: Top 5 cancer types in females in the Crater Health District by incident rate and annual incident count

Data Source: Virginia Cancer Registry

Crude Rate – represents number of new female cancer cases per 100,000 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.

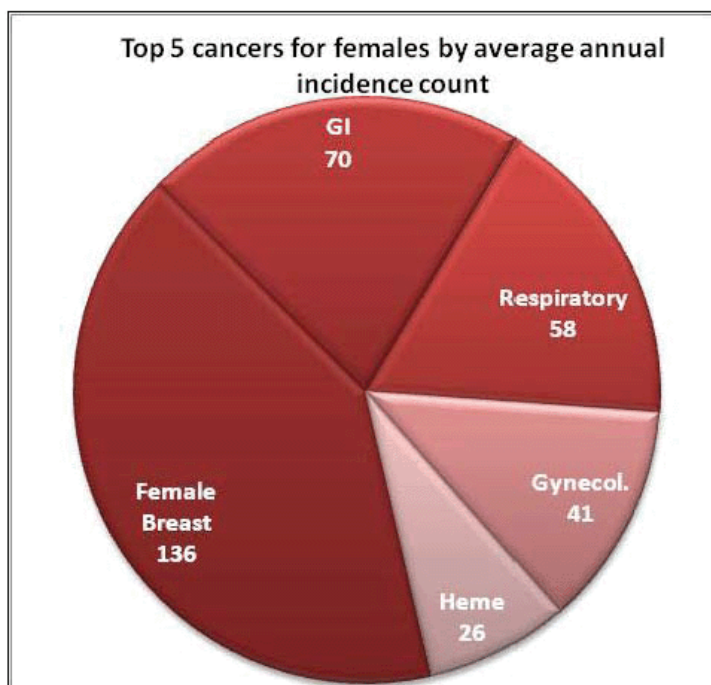


Figure 6: Proportion of incident count of the top 5 cancers in females in the Crater Health District

Black residents of the health district have higher incidence rates of male genital system cancers, female breast cancer, and GI cancers, while white residents have higher incident rates of gynecological cancers and the Other cancer site group. Respiratory cancer incident rates are practically equal for the two races. Incident rate for cancers as a whole is higher for black residents. **(Tables G & H)**

Top 5 Cancers in Crater for African American Population			
Cancer Site	10-year case count	Age Adjusted Incidence Rate	
		Crater	Virginia
Male Genital System	796	281.0	245.7
Prostate	795	280.8	243.6
Other male genital organs	1	0.2	2.1
Female Breast	477	127.0	122.4
GI System	680	101.9	101.2
Colon & Rectum	390	58.2	57.2
All Other GI	290	43.8	44.0
Respiratory	641	96.3	78.0
Gynecological	159	42.1	39.2
Corpus and Uterus	68	17.9	18.7
Ovary	40	10.6	9.2
Cervix	33	8.8	8.4
All other Gynecological	18	4.8	2.8
All Other Sites	708	104.0	98.6
All Sites	3461	513.0	472.4

Table G: Top 5 cancers in Black residents in the Crater Health District by incidence rate

Data Source: Virginia Cancer Registry

10-year case count – represents number of new cancer cases reported to the registry for Black population from 1999-2008.

Age-Adjusted Incidence Rate represents age-adjusted cancer incidence rate for Black population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Incidence Rate.

Top 5 Cancers in Crater for White Population			
Cancer Site	10-year case count	Age Adjusted Incidence Rate	
		Crater	Virginia
Male Genital System	637	157.3	152.6
Prostate	611	150.6	145.9
Other male genital organs	26	6.7	6.8
Female Breast	531	115.0	125.3
Respiratory	850	94.8	72.5
GI System	766	86.6	75.1
Colon & Rectum	473	53.3	45.7
All Other GI	293	33.2	29.3
Gynecological	225	49.5	45.4
Corpus and Uterus	108	22.9	22.5
Ovary	62	12.5	12.7
Cervix	41	11.1	6.7
All other Gynecological	14	2.9	3.5
All Other Sites	1242	143.2	134.1
All Sites	4251	483.1	442.4

Table H: Top 5 cancers in White residents in the Crater Health District by

incidence rate

10-year case count – represents number of new cancer cases reported to the registry for White population from 1999-2008.

Age-Adjusted Incidence Rate represents age-adjusted cancer incidence rate for White population for the health district (compared to state).

Top 5 Cancers are based on Age-Adjusted Incidence Rate.

All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Heme-malignancies, Urinary System, and Other sites.

The highest burden cancers for Black residents, as a percent of total incident counts, are male genital (prostate), GI, and respiratory (lung) cancers. For White residents, respiratory (lung), gastrointestinal, and Other cancers carry the highest burden. **(Figure 7)**

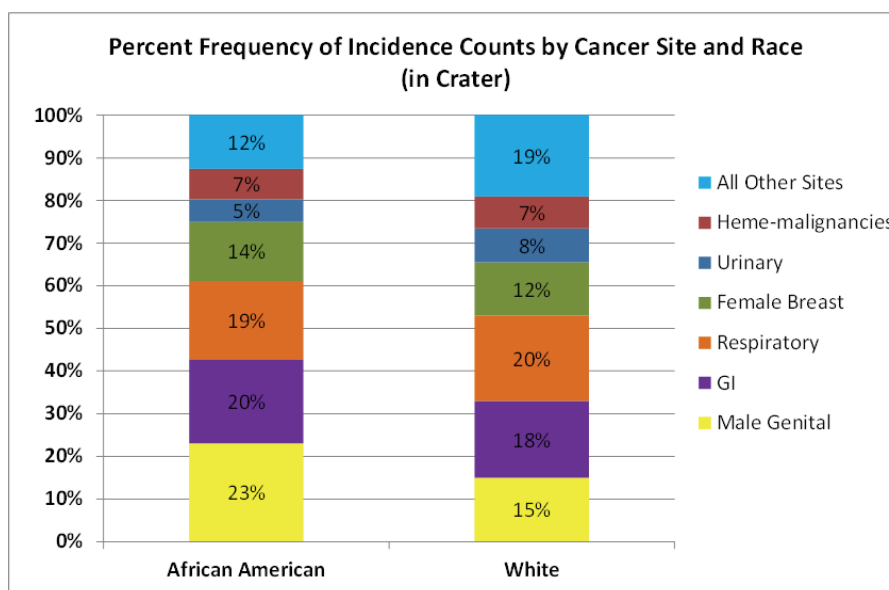


Figure 7: Proportional burden of cancer types by incident count for Black and White residents of Crater Health District

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 lower percentage of cancers are detected at a local stage in the health district than in the State as a whole. Notably, fewer gynecologic, oral, brain, and Other cancers are detected at a local stage than in the State. (**Figure 8**)

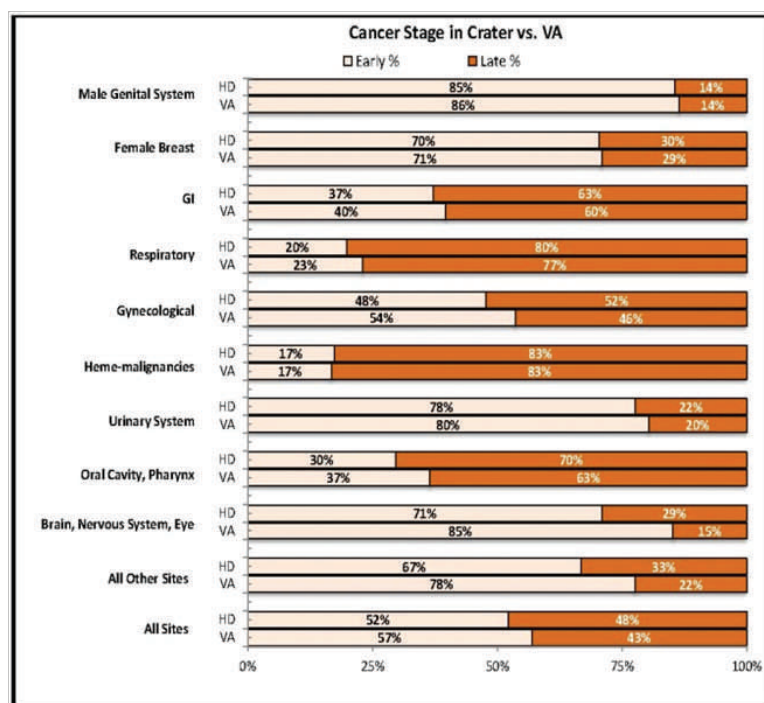


Figure 8: Comparison of cancer staging in the Crater Health District vs. Virginia

Data Source: Virginia Cancer Registry (1999 - 2008) - all percentages calculated base on populations including all ages.

Cancer sites ordered by incidence rate (highest to lowest) in the health district.

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.

An average of 370 residents of Crater health district succumb to cancer each year. The cancer sites with the highest mortality rates in the health district are respiratory, gastro-intestinal, hematologic cancers, male genital, and female breast cancer in that order (**Table G**). The district has a significantly higher mortality rate than the State for all cancer sites considered together. Notably, the mortality rate for respiratory, GI, male genital (prostate), and Other cancers is significantly higher than the State. (**Figure 9**) The five cancers resulting in the greatest number of deaths in the health district account for 74% of the cancer deaths in the MRHD.

Top 5 Cancers in Crater by annual death count	
Cancer Site	Annual # of deaths
Respiratory	121
GI	82
All other GI	70
Colon & Rectum	33
Heme-malignancies	26
Lymphomas	9
Leukemias	8
Myeloma	8
Male Genital System	23
Prostate	23
Other male genital organs	0
Female Breast	23
All Other Sites	55
All Sites	370

Table G: 5 cancers with the highest mortality by death count in the Crater Health District.

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.

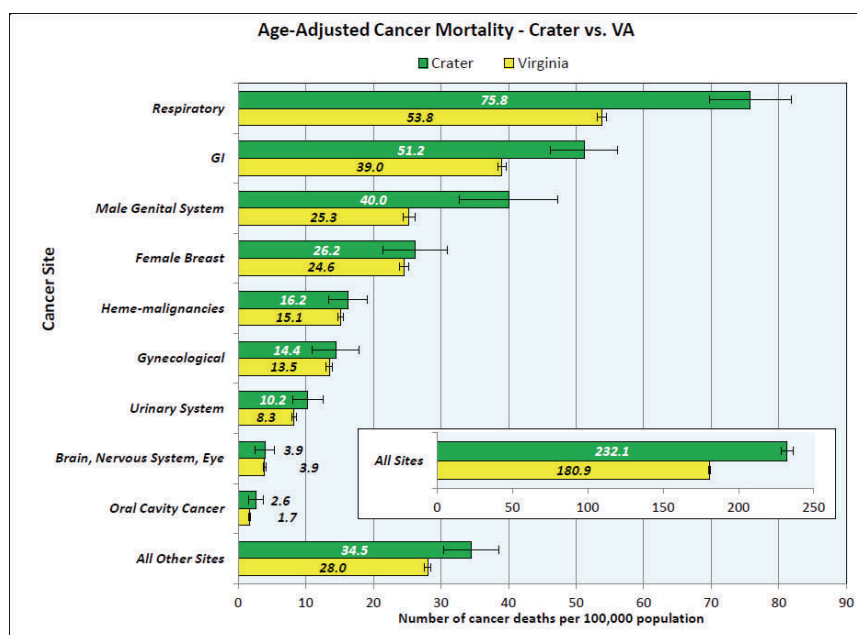


Figure 9: Cancer Mortality Rate in Crater Health District vs. Virginia

Data Source: Vital Statistics Department, VDH (averaged rates 2005-2009) – all rates calculated based on populations including all ages.

Rate for Male Genital System is shown per 100,000 males;

Rates for Gynecological and Female Breast are shown per 100,000 females.

Men have higher mortality rates from cancer than women in the MRHD (258 vs. 220 cases/100,000). Respiratory and gastro-intestinal cancers cause the greatest number of deaths in both men and women, with death rates from both notably higher in men than women (89 vs. 67 deaths/100,000 for respiratory; 60 vs. 46 deaths/100,000 for GI respectively). The majority of deaths from gastro-intestinal cancers for both men and women are due to sites other than the colon or rectum. Prostate, heme-malignancies, and urinary systems cancers for men, and female breast, gynecologic cancers and heme-malignancies for women, complete the top 5 cancers by gender. (Figures 10 & 11)

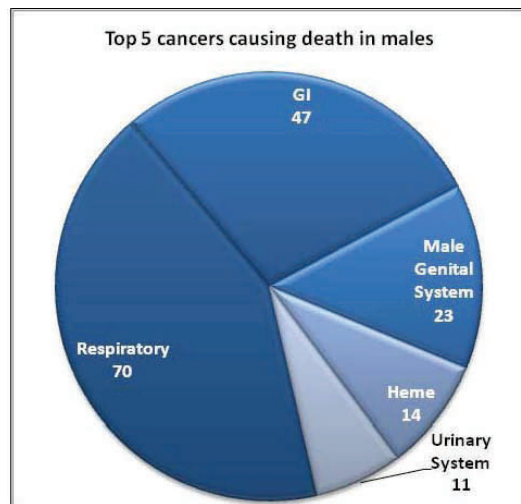


Figure 10: 5 cancers with the highest mortality by death count in males in the Crater Health District

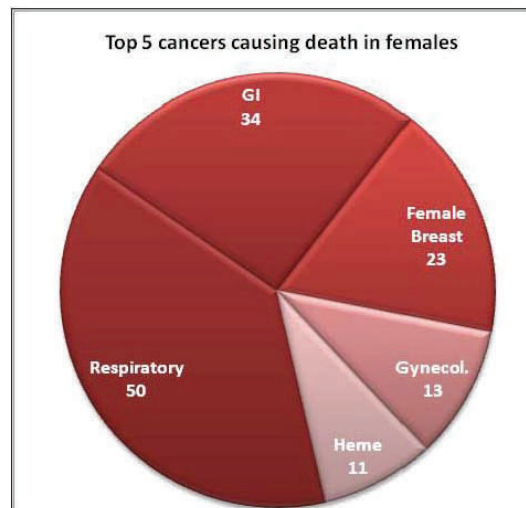


Figure 11: 5 cancers with the highest mortality by death count in females in the Crater Health District

Data Source: Virginia Department of Health (2005-2009) – rates calculated based on population for all ages.

Annual Count - represents average number of female or male cancer deaths per year in the health district (averaged over period 2005-2009).

The mortality rate from cancer is higher in black residents than in white residents for every cancer type except respiratory cancer. Respiratory cancer has the highest mortality for both races with similar rates for each. The mortality from male genital cancer follows the incidence pattern of twice the rate for black males and is the third highest cause of cancer deaths in blacks. GI cancer has the second highest rate in both black and white residents, with about the same mortality rate.

Female breast cancer has a notably higher rate in black women than in white women in the health district. The differences in mortality rates between the races are reflective of state trends. (Tables J & K)

Top 5 Cancers in Crater for African American population by mortality			
Cancer Site	5-year death count	Age-adjusted mortality rate	
	Crater	Crater	Virginia
Respiratory	245	72.6	59.6
GI	206	62.5	54.9
All other GI	174	52.9	45.6
Colon & Rectum	86	26.3	23.6
Male Genital System	69	60.4	51.6
Prostate	69	60.4	51.2
Other male genital organs	0	0.0	0.4
Female Breast	68	34.8	33.6
Heme-malignancies	72	21.4	15.7
Myeloma	33	10.1	7.4
Leukemias	19	5.7	3.8
Lymphomas	20	5.6	4.5
All Other Sites	126	37.0	30.4
All Sites	871	260.4	220.3

Table J: 5 cancers with the highest mortality by death count in black residents in the Crater Health District

Top 5 Cancers in Crater for White population by mortality			
Cancer Site	5-year death count	Age-adjusted mortality rate	
	Crater	Crater	Virginia
Respiratory	358	79.2	54.0
GI	200	44.1	36.2
All other GI	173	38.1	30.0
Colon & Rectum	78	17.2	15.5
Male Genital System	47	26.9	21.4
Prostate	47	26.9	21.1
Other male genital organs	0	0.0	0.4
Female Breast	47	18.6	23.0
Heme-malignancies	54	12.2	15.2
Lymphomas	23	5.1	6.8
Leukemias	22	5.1	5.0
Myeloma	9	2.0	3.4
All Other Sites	146	32.6	28.0
All Sites	967	214.3	176.3

Table K: 5 cancers with the highest mortality by death count in white residents in the Crater Health District

Data Source: Virginia Department of Health
5-year death count – represents number of cancer deaths reported for black or white patients from 2005-2009.

Age-Adjusted Mortality Rate - represents age-adjusted cancer mortality rate for black or white population for the health district (compared to state).

* Cancers not shown had no reportable rate in the health district, due to data suppression.

Cancer Healthcare Resources

Healthcare Facilities and Cancer Care

There are three hospitals in the Crater Health District: John Randolph Medical Center (JRMCM) in Hopewell (part of HCA Virginia Health System) is a licensed 147-bed facility, about 30 minutes south of Richmond, Southside Regional Medical Center (SRMC) in Petersburg is a licensed 300-bed facility with 20 skilled nursing beds, located about 20 minutes south of Richmond and Southern Virginia Regional Medical Center (SVRMC) in Emporia is a licensed 80-bed facility, 70 miles from Richmond. (See Figure 2) Each hospital has a financial counseling department to assist uninsured or underinsured patients with the cost of services.

There is at least one community healthcare center in each locality. Southern Dominion Health Systems, Inc. manages Dinwiddie Medical Center and Emporia Medical Center. Central Virginia Health Services manages Hopewell/Prince George Healthcare Center, Petersburg Healthcare Alliance and Appomattox Area Health & Wellness Center (AAHWC). Horizons Health Services manages Surry Medical Center and Waverly Medical Center. Pathways to Health Specialty Clinic and Surry Area Free Clinic are the only two free clinics in the district. Each center offers sliding scale or free health services to citizens that qualify. Uninsured patients that receive care through a community healthcare center are referred to VCU Medical Center for specialized services.

There were 5 oncologists serving the health district at the time of writing of this assessment, 4 medical oncologists and 1 radiation oncologist.

Cancer Services provided:

The following cancer related services are available within the Crater Health District: (see Appendix D for details)

Medical Services:

John Randolph Medical Center (JRMCM) provides medical and surgical oncology treatments. JRMCM also offers outpatient services for colonoscopy, nutrition and genetic counseling, palliative care and a cancer support group. Southside Regional Medical Center (SRMC) provides medical, surgical and radiation oncology treatments. Outpatient services for colonoscopy, and a breast cancer support group is also offered. Southern Virginia Regional Medical Center (SVRMC) provides medical oncology services through a collaboration with VCU Massey Cancer Center. Massey has been providing the oncology treatments at SVRMC since 1988 through the Rural Outreach Program. Outpatient services for colonoscopy are offered.

The major deficiencies noted in cancer treatment for the district were as follows: No Cancer Care in Dinwiddie, Prince George, Surry or Sussex; lack of Oncology specialists throughout the district; no breast MRI; no CT colonography; no outpatient oncology nutrition counseling; no clinical trials; and a lack of a patient navigation program.

Hospice Services

Crater Community Hospice (CCH) is the only community-based, non-profit hospice agency in the Crater Health District. The CCH office is located in Petersburg and provides services to all counties and cities within the Health District. Medicare, Medicaid, and other private insurances offer Hospice benefits, but do not cover all costs incurred. Everyone who is referred to CCH, that is medically appropriate, receives services regardless of their ability to pay. There are numerous hospice agencies with offices based in Richmond and Colonial Heights that provide hospice services across the district. Hospice care is provided at home, in nursing facilities, and in qualifying cases at the hospital.

The Hospice Support Group of Southside Virginia, Inc., a non-profit, volunteer organization, is located in Emporia. Volunteers working within this organization have provided supportive services to terminally ill patients and their families for 26 years at no cost. Services include personal supportive care and a loan closet with durable medical equipment and medically necessary supplies. Areas serviced within the district by this organization are: Greenville, Emporia, Sussex, Jarratt and Stony Creek.

Community Cancer Resources

Health resources exist across the entire district, but awareness by citizens and physicians of the existence of these resources is limited in some cases. All three hospitals offer patient education and community outreach activities. SVRMC and SRMC have Senior Circle groups that provide health and disease management programs. Hope-well/Prince George Healthcare Center in Prince George and Appomattox Area Health & Wellness Center in Petersburg have community outreach programs such as lay health promoter programs that cover a range of health topics including cancer.

There are numerous support groups for cancer survivors and caregivers in the health district. John Randolph Medical Center (JRMC) offers a monthly cancer support group for patients with all types of cancer, and Look Good, Feel Better, an American Cancer Society (ACS) initiative program is scheduled every third Monday from 6-8pm. Southside Regional Medical Center (SRMC) also offers a breast cancer support group, and in Surry County, the Martha J. Watson cancer support group meets on a monthly basis. A new social group of cancer survivors has recently begun in Petersburg called the Pink Challengers, and Sussex County has a cancer support group called The Pink Pearls.

Multiple organizations have programs to provide access to cancer screenings for early detection in the health district. HCA facilities offer free and low cost screenings for Lung, Prostate, Colorectal, Skin cancer 4 times per year. Susan G. Komen vouchers are available through Virginia State University, Dinwiddie Medical Center, Central VA Health Services and Pathways Specialty Clinic. Komen voucher locations vary each year pending request by each agency. The Greenville Health department offers mammogram vouchers to be used at SVRMC in Emporia. Paint it Pink Petersburg is an active coalition to promote breast cancer awareness through various

collaboration efforts.

Bon Secours Health System and HCA Richmond Health Systems partner with the Every Woman's Life (EWL) program to provide screening services to all counties within the Crater Health District. Services are rendered outside of the district. The American Cancer Society (ACS) has an office in Glen Allen and in Virginia Beach to service all localities within the health district. All citizens can contact ACS by phone to obtain various resource and referral services for cancer care. Informational videos and gas cards may be provided to those that qualify.

There are several informational resources that have online services in the Crater Health District. ConnectVA (formerly Southside Community Partners) is a non-profit resource center that merged three independent nonprofit programs: the Southside Virginia Nonprofit Resource Center, Focus INC, and Connect Southside into one operating program that is located at the Appomattox Regional Library System. Partners in Healthcare is an online community healthcare resource. Crater Health blog is a blog managed by the Crater Health District to advertise Crater community health events. The Health Information & Advocacy at your library (HIA) is a program that offers one on one counseling to direct individuals to reliable health information, with a branch located at the Richardson Memorial Library in Emporia.

Additional resources include the United Way of Greater Richmond & Petersburg provides various resource assistance and programs. Clay Home Medical in Petersburg and Reliacare in Hopewell have charity applications for durable medical equipment for citizens that qualify. Goodwill Industries has a Medical Adaptive Assistive Technology Program for medical equipment as well.

Healthcare Provider Needs

Key Leader Information

Eight healthcare professionals who are long-time residents and/or leaders in their communities were interviewed to gather a broad perspective of the cancer healthcare needs of the health district. They were selected from various locations across the health district and included physicians with the following specialty credentials: Family Practice, Radiation Oncology, Cardiology, Internal medicine, General Surgery, and Medical Oncology. Their experience ranged from 9-36 years. 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) education for residents and physicians, (2) barriers to access to healthcare including number and specialization of community physicians, and (3) systems to facilitate awareness of community resources by residents and healthcare providers

alike. Educational topics important for residents included education on cancer screening guidelines and about hospice care in order to dispel common myths about these topics. Similarly, a major area for continuing medical education of primary care physicians identified by the Key Leaders was up-to-date information on cancer screening guidelines. Important barriers to care included reliable transportation to medical appointments, insurance and financial assistances, as well as on-going medical care and follow-up for healthy and sick visits.

The Key Leaders believe, in general, that hospice care is strong in the community, saw a need for a true palliative care program in the area. Several physicians expressed the need for more oncology services such as more physicians, a cancer center, and a central location to refer patients for cancer education.

Key Leaders stressed the need for assistance with the promotion of existing services, and local physician attendance on cancer committees and surveillance teams as a means for networking. Communication and collaboration with all physicians is very significant in bridging gaps in cancer care in the community. Specialists and Primary Care Physicians (PCPs) agreed that increased collaboration and communicate is needed to adequately care for patients.

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 Crater health district completed the 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 Internal medicine. The remainder specialized in obstetrics/gynecology, urology, surgery, gastroenterology, emergency medicine, and public health.

Respondents identified breast, colorectal, and lung cancers 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, only 32% of responding physicians indicated a high or above average compliance rate with screenings for female breast cancers while 69% reported the rate to be average or low compliance. Compliance with cervical cancer screenings was higher with 43% of physicians indicating high or above average compliance, while 57% reported average to low compliance. Colorectal cancer screening had the lowest compliance, with 78% of responding physicians indicating that their patients had average to low compliance with their screening recommendation. **(Figure 12)**

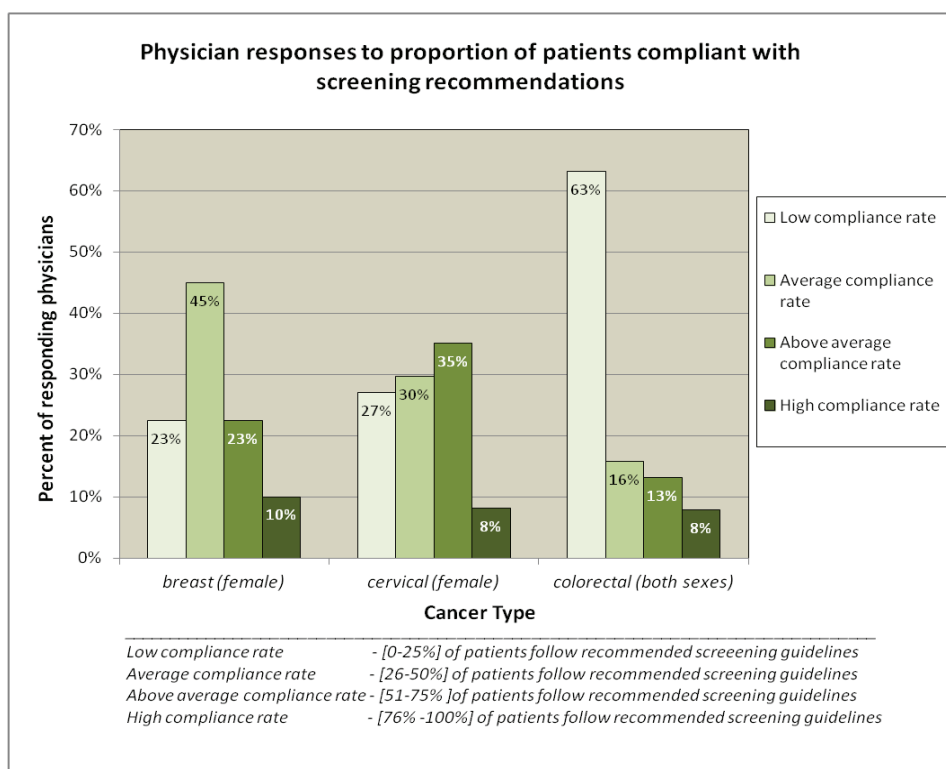


Figure 12: Patient Compliance with physician recommended cancer screenings.

The three most prevalent reasons cited by physicians for patients not having a recommended screening were financial constraints (88% of responding physicians), lack of insurance (80%), and lack of transportation (60%). Slightly less than half of physicians also cited fear of the test or a cancer diagnosis as a reason for non-compliance, as well as a belief that the tests are not necessary. No more than half of responding physicians expressed a desire for information on cancer screening guidelines. Screening updates of most interest included lung (53%), ovarian (50%), colorectal (48%), breast (43%), and cervical cancer (43%), with prostate (33%) and skin cancer (23%) of less interest.

When asked where they refer their patients diagnosed with cancer, the majority indicated that they preferred to refer their patients locally for surgical oncology (68%) and medical oncology (74%). Half of responding physicians also indicated that they would refer to one of the two National Cancer Institute Designated Cancer Centers in Virginia (UVA or VCU) for oncology surgery or medical oncology. Less than 5% of responding physicians would refer to other locations in or out of state.

The most useful communication coming from the oncology team according to the responding PCPs included the initial treatment plan (78%), end of treatment notes (70%), follow up care guidelines (68%). **(Figure 13)** Only 45% of respondents, however, were usually to always satisfied with the communication received from the oncologist. **(Figure 14)**



Figure 13: Most useful information coming from treating oncologists to primary care physicians

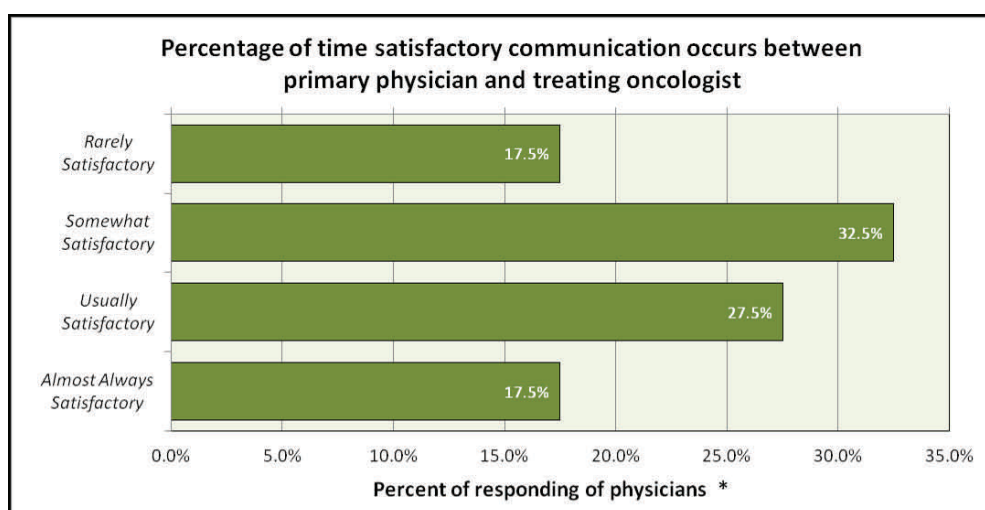


Figure 14: Satisfaction with communication from treating oncologist.

Rarely Satisfactory - indicates 0-25% of the time communication is considered satisfactory; **Somewhat Satisfactory** - indicates 26-50% of the time communication is considered satisfactory; **Usually Satisfactory** - indicates 51-75% of the time communication is considered satisfactory; **Almost Always Satisfactory** - indicates 76-100% of the time communication is considered satisfactory.

When asked what treatments they were comfortable providing to their patients receiving cancer treatment, less than half of responding physicians indicated they were most comfortable providing non-oncology care to their patients diagnosed with cancer during treatment (48%). Fewer respondents were comfortable providing joint management of oncology care with oncology team (28.6%), and long-term oncology follow-up care (19.6%). **(Figure 15)** The post-cancer treatment care topic of greatest interest to responding physicians was *wellness and prevention of cancer recurrence*. Other topics of interest included the *surveillance of cancer recurrence, genetic counseling, and*

*Percentage is calculated based on the total number of responses for each information piece from the oncology team physicians consider valuable, out of the total number of physicians that completed the questionnaire and identified their practice area as part of health district

monitoring and palliation of long-term cancer treatment effects. They prefer that this information come to them in written (paper) form (43%) or through web-based sources (33%),.

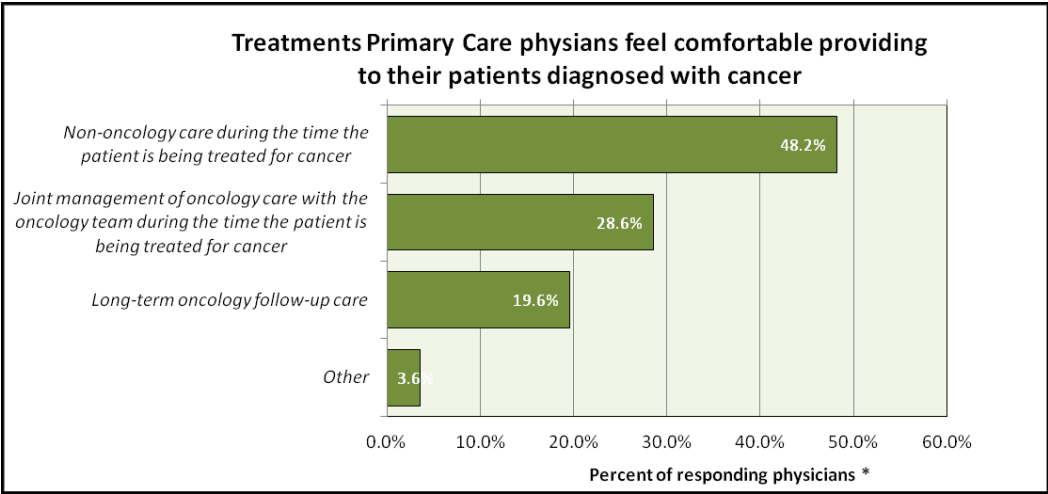


Figure 15: Treatments primary care physicians feel comfortable providing to their patients with cancer.

** Percentage is calculated based on the total number of responses for each treatment physicians feel comfortable providing on their own, out of the total number of physicians that completed the questionnaire and identified their practice area as part of health district*

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 Centers for Disease Control and Prevention (CDC) conducts state-based telephone surveys to collect information on health risk behaviors, preventive health practices and health care access. Information from the Behavioral Risk Factor Surveillance System (BRFSS) gathered from residents of the health district 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 Crater Health District when compared to Virginia shows a higher incidence of sedentary behavior and smoking, and has a relatively high incidence of obesity. All three factors are associated with a higher cancer risk. One third of the population reported no physical exercise in the past 30 days and only 26% included fruits and vegetables in their daily diet. Greater than half (74%) of the district residents are overweight or obese. On average, about 25% of adults smoke, with the highest group of smokers in the age group of 40-49 at 30%. **(Figure 16)** All three factors are associated with a higher cancer risk. This information is supported by comments gathered in our focus groups.

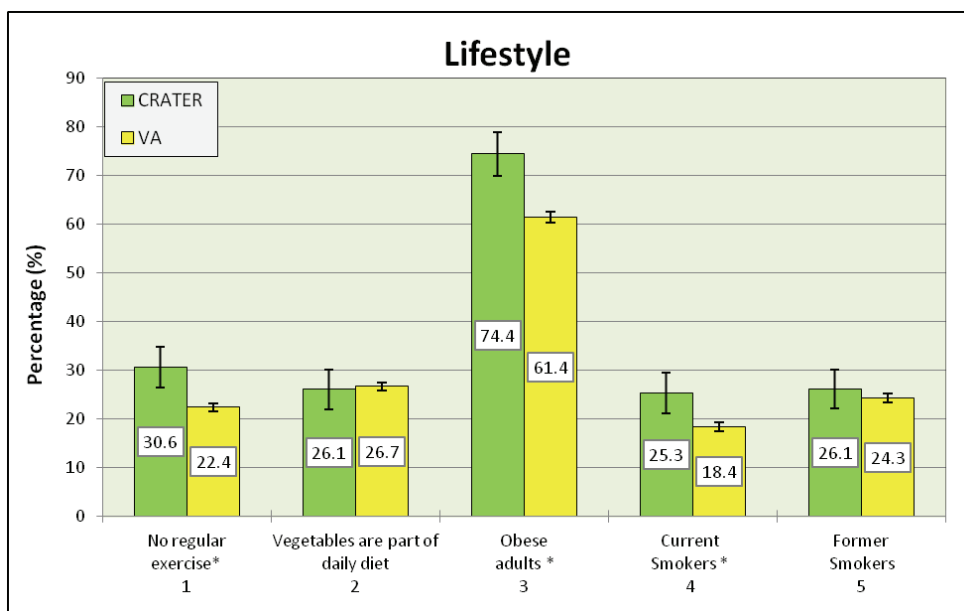


Figure 16: Behavioral Risk Factor Surveillance Survey lifestyle related questions.

*- 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.

Cancer screening rates in the Crater Health District were comparable to the state rates. Despite the PCPs feeling that a lower percentage of clients were compliant with recommendations for colorectal cancer screening, 75% of responding residents indicated that they had had the screening. A similar percentage of women indicated they had received a mammogram (80%). (Figure 17)

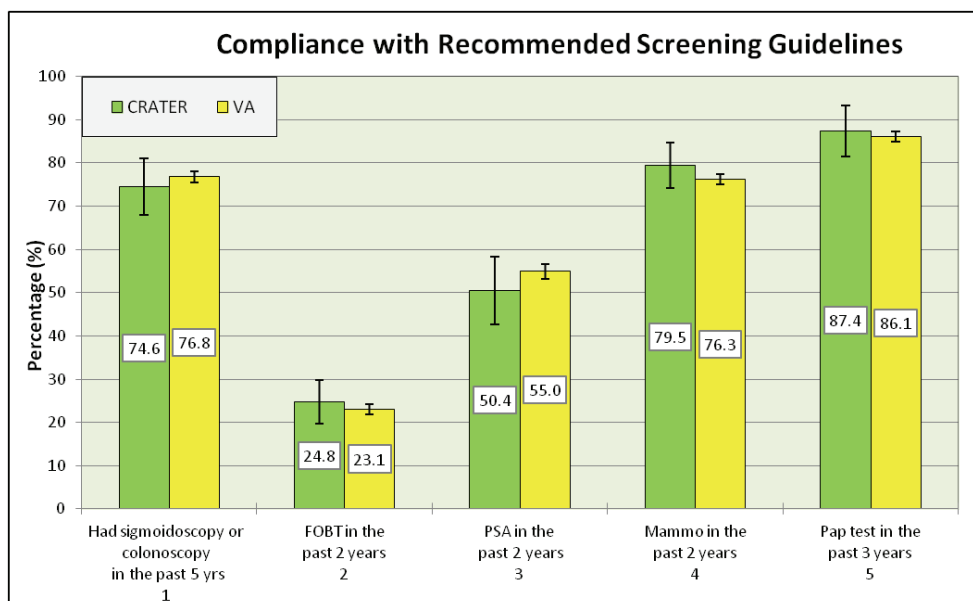


Figure 17: Cancer Screening Compliance

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.

Access to health care was similar to that of the state. Approximately 12% of residents have no health insurance and an equal number were unable to see a doctor in the past year due to cost. Despite this, 84% report having a primary care physician, and 73% were seen by a physician in the past year. (Figure 18)

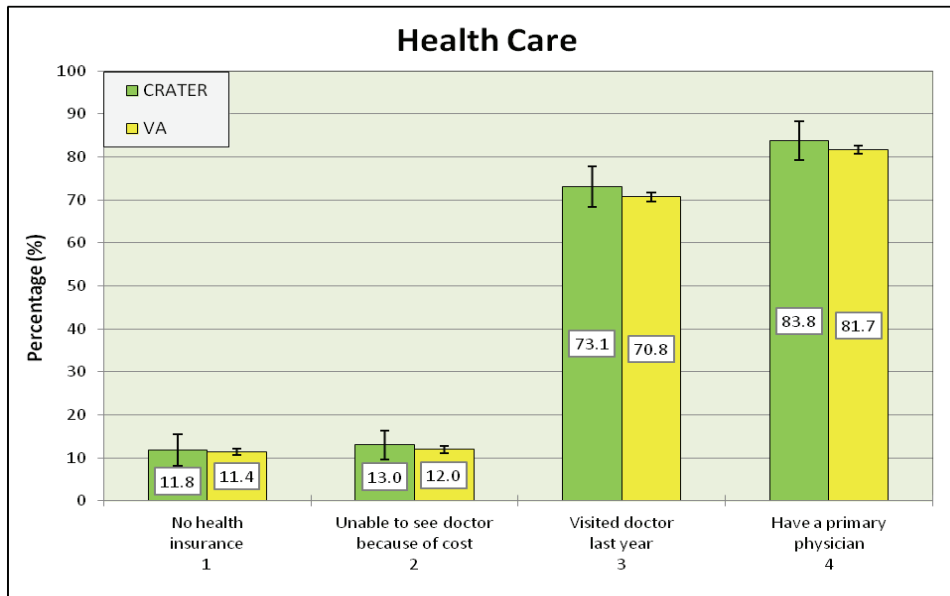


Figure 18: Access to Healthcare

* 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;

Focus Group Information

Focus Group participants were selected from citizens who responded to mass email list-serves, flyers posted within the community, and by word of mouth. In addition, public service announcements (PSAs) were placed in area newspapers, community news television stations and on select radio stations. The demographics of the community were used as a guide for final selection of the participants. (Figure 19) 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 most counties through-out the

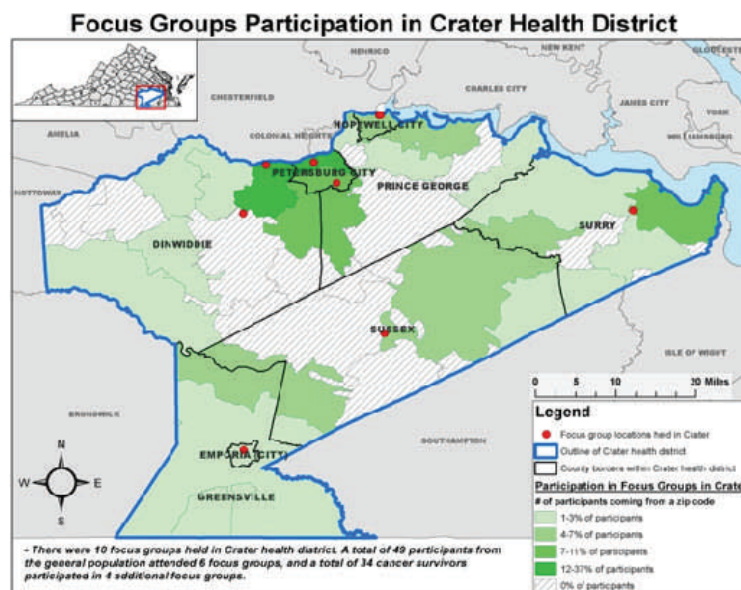


Figure 19: Map of Focus Group Participation in the Crater Health District

health district in hospitals, nursing homes, churches, a rehabilitation center and a school due to their central location.

General Population Group Synopsis

There were six focus groups held among the general population, age >18 years and residing in the Crater Health District. There were a total of 49 participants with an average attendance of eight per group. The major health problems identified in the health district included cardiac disease, obesity, teen pregnancy, cancer, and other various chronic diseases. Cancer was identified as a major community concern in all focus groups, although not necessarily as the top concern. The level of concern about cancer varied, but major concerns common to all focus groups were the association of cancer with death. Additionally, there was a concern about the level of suffering for individuals receiving cancer treatment. Practical concerns about the need for transportation, the cost of treatment, and support for caregivers and patients was common.

There was an awareness of healthy lifestyle habits including eating a healthy diet, maintaining an appropriate weight, and avoiding smoking across all focus groups, although a skepticism about the ability to follow this prescription was common. Community resources to assist residents to live healthy lifestyle and quit smoking were readily identified in focus groups held in the more urban areas of the health district, while the rural communities expressed a lack of resources available for this purpose. Weight was often considered an inaccurate way of evaluating health, which didn't necessarily translate into being healthy.

The prevailing themes from the general population focus groups included:

Barriers to a healthy lifestyle:

- Nutrition
 - Affordability and access to healthy foods
 - Influence of culture on eating habits; difficulty in changing these culturally engrained habits
 - Lack of awareness of community services to eating healthy
- Physical Activity
 - Cultural and personal attitudes toward exercise identified as a barrier, despite the availability of exercise resources
 - Rural areas need affordable, safe, local recreation. Wild animals are barriers to safe activities.
- Tobacco Use
 - Resources for cessation readily identified. There was a repeated call for community wide efforts to help people stop smoking,
 - Schools identified as a key to preventing youth from starting tobacco use.
- Inconsistent messages have resulted in confusion about the relationship between specific lifestyle recommendations, particularly diet, and cancer risk.

Community Initiatives to Support Health Lifestyles

A repeated theme for nutrition, exercise, weight maintenance and tobacco use prevention/cessation was for community wide programs to incentivize healthy lifestyles. Motivation through community programs, employer based programs, and school based programs were emphasized.

Personal responsibility for health:

- A lack of personal responsibility for preventive health was a recurrent theme in all focus groups.
- Legitimate barriers to being physically active were identified, but a lack of discipline was always mentioned as a problem.
- Preventive cancer screenings were recognized as a positive health measure. Multiple barriers were identified, including cost, insurance, and time. Fear and cost were most often cited as a reason people do not get preventive cancer screenings.

Attitudes about cancer research:

Personal experience with research was minimal among focus group participants. Common attitudes about cancer research were expressed among focus group participants, including the association between cancer research participation as a last resort for treatment. Positive attitude toward cancer research was expressed in all focus groups, while a distrust of research physicians motivation was presented in a limited number of focus groups. The importance of full disclosure about the research and assistance with financial burden of participation were commonly cited. Motivation for participating in a cancer study included if it would help a community issue, to help find a cure, and to help others.

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, having an intimate knowledge of what the patient experienced) of a person with cancer. Most caregivers had lost a loved one to cancer. The topics for the Survivors group were designed to identify needs of the health district to facilitate the early detection of cancer, and support cancer patients and their caregivers across the continuum of their care. The line of questioning elicited many heartbreaking and inspiring stories of their individual journeys. Discussed were participants experiences with local medical resources during diagnosis, treatment and survivorship, experiences with local support resources, cancer research, and needs in the community from a survivors perspective

Five focus groups with cancer survivors were held throughout the Health District. There were a total of 34 participants, with an average group attendance of 6. The ma-

majority of participants had been treated for cancer outside of the health district. In general, those who were treated outside of the health district expressed satisfaction with the availability of information related to their cancer and assistance navigating through their treatment and follow-up. This was not generally the case for those who were treated in the health district. The prevailing themes across the focus groups were as follows:

Lack of treatment resources within the health district:

All groups expressed a need for an increased number of oncologists, oncology specialists, and oncology treatment centers within the health district.

Local patient navigators to assist patients and their families navigate through diagnosis, treatment and survivorship.

Lack of local support services:

A lack of local services for the support of cancer patients and caregivers was a repeated theme. Support services that exist are in the form of family, friends, and faith-based organizations.

Transportation services were repeatedly identified as an area of need for patients to get to cancer treatments.

Support services for activities of daily living for patients undergoing cancer treatment was an area of need.

Local resource for cancer information and directory to local support services:

A lack of a resource for information about cancer in the health district was a repeated theme. The need for accurate information upon diagnosis of cancer was a concern, to include information about services available locally for cancer patients and caregivers.

Community education about cancer prevention and early detection was identified as an important need.

Clinical Research:

There was general agreement that cancer research is very important to have available as a treatment option for patients treated in the health district.

Several participants had been in a cancer clinical trial as part of their treatment. They expressed satisfaction with their experience in the clinical trial.

SUMMARY OF PRIORITY NEEDS

Based on the qualitative and statistical information gathered for this project, the following are recommendations for action in three broad categories:

Cancer Healthcare Resources

- Support local healthcare facilities in the recruitment of more oncologists and oncology specialists to the health district.
- Establish a local patient navigation program
- Develop and maintain local cancer support groups that meet the needs of cancer patients and their caregivers.
- Develop cancer research capacity within the health district
- Establish innovative mechanisms to provide affordable transportation to cancer patients undergoing treatment.

Communication and Information Systems

- Establish a centralized, easily accessible, cancer information resource center.
- Create a mechanism for collaboration of organizations to provide coordinated cancer services and resources to the community.
 - Work with health care providers and screening facilities to improve access to and utilization of cancer screening opportunities
 - Increase awareness and community support of existing survivor support agencies
- Increase the public awareness and acceptance of Hospice care and options for end-of-life care

Education

- Develop a public awareness campaign to increase cancer screenings with a special component targeting men for prostate cancer and both sexes for lung and colorectal cancers.
- Work to include cancer risk reduction information in existing programs aimed at adopting healthy lifestyles to reduce chronic disease:
 - Develop innovative education programs for youth directed at cancer prevention and lowering risks, particularly avoidance of tobacco use.
 - Develop and implement education programs on early detection of cancer; signs and symptoms and screening guidelines
- Develop and implement continuing medical education programs for physicians in the topic areas of cancer screening guidelines, post-treatment cancer care, and pain management.

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____

Yes_____ No_____

Yes____ No____

Chemotherapy Inpatient: Yes_____ No_____
 Outpatient: Yes_____ No_____

No_____

Yes_____ No_____ Will
try _____

• Screening mammography?	Yes_____	No_____	Unknown_____
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____
 - lower tract Yes____ No____ Unknown____
 - liver/pancreas Yes____ No____ Unknown____
- 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____
Private organization Yes____ No____
Unknown____
- Outpatient hospice
Facility Supported Yes____ No____
Unknown____
Private organization Yes____ No____
Unknown____

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?

APPENDIX B

Primary Care Physician Questionnaire

Cancer Needs Assessment VIP Physician Survey

Please complete the survey below. Thank you!

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

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

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

Please indicate your primary area practice:

- ☐ Family medicine
☐ Urology
☐ Dermatology
☐ Surgeon
☐ Internal medicine
☐ Obstetrics/gynecology
☐ Internal Hospitalist
☐ Other _____ Please specify

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

- ☐ Breast
☐ Hematologic
☐ Colorectal Prostate
☐ Lung
☐ Cervical
☐ Melanoma
☐ 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
b) Cervical (PapSmear)
c) Colorectal
- ☐ 0-25%
☐ 0-25%
☐ 0-25%
- ☐ 26-50%
☐ 26-50%
☐ 26-50%
- ☐ 51-75%
☐ 51-75%
☐ 51-75%
- ☐ 76-100%
☐ 76-100%
☐ 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
Skin ☐ Yes ☐ No
Lung ☐ 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
☐ Apprehension about the test
☐ Lack of Screening facilities
☐ Afraid of being diagnosed with cancer
☐ Lack of transportation
☐ 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
☐ Prostate
☐ Colorectal
☐ Lung
☐ Cervical
☐ Skin
☐ Ovarian
☐ 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)?

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

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

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

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

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

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 NO ONE 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 – let's talk about the way people live, their habits and lifestyle, and how these affect their health?

5. What are some behaviors or ways of living (lifestyles), that may have a good 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 study? 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 or 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

Post-Treatment (20 Minutes)

Now we are going to focus on the time after you (or the person you cared for) completed treatment. I would like to stress that the discussion is not about the details of your personal medical history. It is about the experience you had after your treatment was completed.

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

For those of you who were treated outside of your community, what was the communication like between your oncologist and the physician you see at home?

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

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

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

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 Questionnaires for Crater Health District			
Names of Facilities	Southside Regional Medical Center; John Randolph Medical Center; Southern Virginia Regional Medical Center		
Total number of Oncologists available at these facilities: 3	Total number of Oncologists within the health district: 1 full-time radiation oncologist (2 additional available as needed). 4 medical oncologists in Hopewell/Petersburg. Massey oncologists go to Emporia.		
Cancer-Related Services and Screenings		Available in Health District?	Number of Facilities Where Available
Services provided (chemo IP or OP or Radiation)	Chemo IP	Yes	3
	Chemo OP	Yes	1
	Radation	Yes	1
Breast Cancer screening and diagnostic procedures	mammo - film	Yes	2
	mammo - digital	Yes	2
	mammo - diagnostic	Yes	3
	breast ultrasound	Yes	2
	breast MRI	No	0
	breast biopsy	Yes	2
Gyn/Colposcopy	gynecology care	Yes	2
	colposcopy	Yes	2
Colorectal Cancer	sigmoidoscopy	Yes	2
	colonoscopy	Yes	2
	CT colonography	No	0
Cancer related surgeries	Breast segmental/complete mastectomy	Yes	2
	Breast reconstruction	Yes	1
	Gyn (hysterectomy/oophorectomy)	Yes	2
	GI - resection upper tract	Yes	2
	GI - resection lower tract	Yes	2
	GI - liver/pancreas	Yes	2
	Lung	Yes	2
	Prostatectomy	Yes	2
	Sentinel nodes sampling	Yes	2
Other Related Services			
Cancer Dietary needs	Registered dietician to provide nutritional services specific to cancer patients	Yes	2
	1on1 assessment	Yes	1
	Individual onc nutrition counseling	Yes	1
	OP onc nutrition counseling	No	0

	Cancer control and prevention education programs	No	0
Genetic counseling	is it offered?	Yes	1
	are they certified?	Yes	1
Insurance and programs for uninsured	accept all insurance (including Medicaid/care)	Yes	3
	Accept uninsured patients	Yes	3
Clinical Trials	any clinical trial programs?	No	0
Affiliations with other Cancer Centers	have affiliations?	Yes	2
	list of affiliates		0
Hospice Service and Palliative Care	IP hospice - facility supported	Yes	1
	IP hospice - private org	Yes	1
	OP hospice - facility supported	Yes	1
	OP hospice - private org	Yes	2
	PalCare program?	Yes	1
Cancer Patient Navigation	Patient Navigator?	No	0

APPENDIX E

Community Cancer Resources within the Health District

CRATER - CANCER RESOURCES SURVEY RESULTS		Health District	Crater District Area Agency on Aging	Cancer Support Group
Organization Information		Number of Organizations that have his resource		
Organization Category	national non-profit	0	-	-
	local non-profit	4	X	X
	for profit service org	0	-	-
	fed. Gov. org	0	-	-
	state/municipal gov. org	0	-	-
	Other	2	X	-
	Other (specified)	(see organizations' answers)	Joint exercise power, local government	
Major sources of funds for organization	competitive grants	0	-	-
	fed. Funds	1	X	-
	service fees	0	-	-
	donations	4	-	X
	Other	1	X	-
	Other (specified)	(see organizations' answers)	Older Americans Act & subsequent reauthorizations	
Cancer Resources				
Primary service population of the organization	cancer patients	4	-	X
	cancer survivors	4	-	X
	cancer caregiver/fam. Members	1	-	-
	Other	2	X	-
	Other (specified)	(see organizations' answers)	60+ living in Crater Health District	
Qualification Criteria to access services	must be under(un)insured	0	-	-
	financial qualification	0	-	-
	no qualification	1	-	-
	Other	4	X	X
	Other (specified)	(see organizations' answers)	60+, live in district, have a need	cancer patient
Type of cancer related services that are provided	written info on cancer	2	-	X
	info on cancer care/supp resources	0	-	-
	management of can.supp.groups	0	-	-
	fin.supp. For cancer control/care	0	-	-
	Funding of projects related to cancer	0	-	-
	Other	3	X	X
	Other (specified)	(see organizations' answers)	Offers education, multi disease information, referrals, support services.	
# of cancer pts seen annually				
Other Information About Organization				
Advertising for the organization	local media	1	X	-
	website	1	X	-
	pamphlets	1	X	-
	word of mouth	4	X	X
	Other	0	-	-
	Other (specified)			
Organizational Needs	fin. Support	1	X	-
	human resources (skilled employees, etc)	0	-	-
	access to experts for consultation	1	X	-
	Other	1	X	-
	Other (specified)	(see organizations' answers)	1) Financial support, 2) Transportation, 3) Assist with	
Challenges		(see organizations' answers)	Funding	
Goals for the next 5 yrs		(see organizations' answers)	Sustain current programs, concerned about constant budget	

CRATER - CANCER RESOURCES SURVEY RESULTS		Health District	Cancer Support Group, Mount Olivet Baptist Church	The Hospice Support Group of Southside Virginia, Inc
Organization Information		Number of Organizations that have his resource		
Organization Category	national non-profit	0	-	-
	local non-profit	4	X	X
	for profit service org	0	-	-
	fed. Gov. org	0	-	-
	state/municipal gov. org	0	-	-
	Other	2	-	-
	Other (specified)	(see organizations' answers)		
Major sources of funds for organization	competitive grants	0	-	-
	fed. Funds	1	-	-
	service fees	0	-	-
	donations	4	X	X
	Other	1	-	-
	Other (specified)	(see organizations' answers)		
Cancer Resources				
Primary service population of the organization	cancer patients	4	X	X
	cancer survivors	4	X	X
	cancer caregiver/fam. Members	1	-	-
	Other	2	-	-
	Other (specified)	(see organizations' answers)		
Qualification Criteria to access services	must be under(un)insured	0	-	-
	financial qualification	0	-	-
	no qualification	1	-	-
	Other	4	X	X
	Other (specified)	(see organizations' answers)	cancer patient	hospice patient
Type of cancer related services that are provided	written info on cancer	2	X	-
	info on cancer care/supp resources	0	-	-
	management of can.supp.groups	0	-	-
	fin.supp. For cancer control/care	0	-	-
	Funding of projects related to cancer	0	-	-
	Other	3	-	X
	Other (specified)	(see organizations' answers)		This agency provides support to patients & families during hospice care. A medical equipment loan
	# of cancer pts seen annually			
Other Information About Organization				
Advertising for the organization	local media	1	-	-
	website	1	-	-
	pamphlets	1	-	-
	word of mouth	4	X	-
	Other	0	-	-
	Other (specified)			
Organizational Needs	fin. Support	1	-	-
	human resources (skilled employees, etc)	0	-	-
	access to experts for consultation	1	-	-
	Other	1	-	-
	Other (specified)	(see organizations' answers)		
Challenges		(see organizations' answers)		need for volunteers & donations
Goals for the next 5 yrs		(see organizations' answers)		Continue to provide support to cancer patients

CRATER - CANCER RESOURCES SURVEY RESULTS		Health District	Martha J. Watson Breast Cancer Support Group at Mt Nebo Baptist Church
Organization Information		Number of Organizations that have his resource	
Organization Category	national non-profit	0	-
	local non-profit	4	-
	for profit service org	0	-
	fed. Gov. org	0	-
	state/municipal gov. org	0	-
	Other	2	X
	Other (specified)	(see organizations' answers)	support group
Major sources of funds for organization	competitive grants	0	-
	fed. Funds	1	-
	service fees	0	-
	donations	4	X
	Other	1	-
	Other (specified)	(see organizations' answers)	
Cancer Resources			
Primary service population of the organization	cancer patients	4	X
	cancer survivors	4	X
	cancer caregiver/fam. Members	1	X
	Other	2	X
	Other (specified)	(see organizations' answers)	Cancer support for women
Qualification Criteria to access services	must be under(un)insured	0	-
	financial qualification	0	-
	no qualification	1	X
	Other	4	-
	Other (specified)	(see organizations' answers)	
Type of cancer related services that are provided	written info on cancer	2	-
	info on cancer care/supp resources	0	-
	management of can.supp.groups	0	-
	fin.supp. For cancer control/care	0	-
	Funding of projects related to cancer	0	-
	Other	3	-
	Other (specified)	(see organizations' answers)	
# of cancer pts seen annually			
Other Information About Organization			
Advertising for the organization	local media	1	-
	website	1	-
	pamphlets	1	-
	word of mouth	4	X
	Other	0	-
	Other (specified)		
Organizational Needs	fin. Support	1	-
	human resources (skilled employees, etc)	0	-
	access to experts for consultation	1	-
	Other	1	-
	Other (specified)	(see organizations' answers)	
Challenges		(see organizations' answers)	N/A
Goals for the next 5 yrs		(see organizations' answers)	N/A