Saving Lives and Reducing Suffering and Death from Cancer in Virginia

Report of the Comprehensive Cancer Needs Assessment of the West Piedmont Health District

Virginia Commonwealth University

Massey Cancer Center

and

Tobacco Indemnification and Community Revitalization Commission

Saving Lives and Reducing Suffering and Death from Cancer in Virginia

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

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

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

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

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

EXECUTIVE SUMMARY OF FINDINGS

The West Piedmont Health District is a rural region that is classified as a medically underserved area. Although the cancer incidence rates in the health district are slightly lower than that for Virginia, the cancer mortality rates, with the exception of female breast cancer, are above state averages. Medical services within the district are centralized in a few urban areas, and residents living in rural areas have difficulty utilizing available services. All facilities within the health district offer cancer screening tests and two of the three hospitals offer oncology services, including limited surgeries, chemotherapy, and radiation oncology, with one of these hospitals offering only medical oncology services. The shortage of both primary care and specialist healthcare providers, especially oncologists, has resulted in many residents seeking diagnosis and treatment outside of their county. Aside from the shortage of physicians, financial considerations, transportation issues, and insurance requirements also greatly influence resident choices pertaining to cancer screening and treatment services.

Interviews with healthcare professionals who are longtime residents and leaders in the community gave a broad perspective of the cancer health needs of the health district. The major healthcare deficiencies identified by these key leaders fell into four major categories: (1) behavioral risk factors such as poor dietary habits and tobacco use, (2) lack of health and cancer education for the residents, (3) a low number of physicians, especially oncology specialists, and (4) barriers to healthcare access. The key leaders also identified needs of the primary care providers in the areas of patient education on cancer screening recommendations, risk behavior education, and end-of-life issues. Most identified that the majority of providers are inundated with a “sick” community and that most patients seek healthcare only when sick, not for preventive care. The physicians surveyed expressed a desire for more information regarding surveillance of cancer recurrence, monitoring and palliation of long-term cancer treatment effects, wellness and recurrence prevention, and end-of-life issues. Physicians indicated a limited knowledge of cancer clinical trials, with an opportunity for education in this area.

District-wide focus groups for both the general population and cancer survivors/caregivers reinforced data collected in the Behavioral Risk Factor Surveillance survey. Although there are cancer programs offered within the communities, limited knowledge of the programs’ existence was apparent and consistent throughout the focus groups. The participants acknowledged there was an issue of obesity and tobacco in the community, but had very limited knowledge of local programs to assist individuals in healthy weight management or tobacco use cessation or prevention. Lack of funding for residents for cancer screenings was identified first and foremost as a barrier to early cancer detection. The lack of support services, including patient navigation, within the community to assist cancer patients and their families through cancer treatment, survivorship, and bereavement was widely recognized as affecting the cancer experience for the community.

Priority areas for action in the West Piedmont Health District, based on the data collected in the assessment, fell into three broad categories: community health and cancer education programs accessible in the rural communities; community physician-targeted education around cancer screening guidelines and survivorship care; and addressing the barriers to cancer care due to the medically underserved nature of this largely rural district. Highlights of recommendations include local coalition building to provide ongoing community health and cancer education that targets residents throughout their lifespan; community physician education programs to ensure best practices in cancer care throughout the cancer care continuum; and the development of patient navigation services within the health district to ensure timely diagnosis, treatment, and follow-up care of resident with cancer.

INTRODUCTION

Cancer is a significant health problem in the United States, impacting the physical, emotional, economic, and social well-being of individuals, their families, and communities. It was estimated that 1,638,910 new cases of cancer would be diagnosed nationally in 2012 (ACS), with 41,380 new cases occurring in Virginia.[5] The state cancer incidence rate of 443.2 newly diagnosed cancers per 100,000 residents ranks 38th among the 50 states and the District of Columbia, and is slightly lower than the national cancer incidence rate of 455.7 (2008).[6] Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease,[7] with 14,009 residents succumbing to their disease.[8] Virginia is poised to combat this disease with healthcare institutions, cancer care centers, state education and research institutions, city and state governments, non-profit organizations, and grass-roots community groups working to reduce the cancer burden in the state. Since 2001, a statewide network of partners, the Cancer Action Coalition of Virginia (CACV), has developed a series of state five-year cancer plans to help unify and direct the efforts of these organizations in combating cancer.

Virginia is a highly diverse state in geography, population demographics, economics, and access to healthcare. With a land mass of 40,000 square miles that spans from the shores of the Atlantic to the hills of the Appalachian Mountains, there are varying degrees of knowledge of and access to healthcare. For cancer prevention and control efforts to be effective they “must be complete, comprehensive, sustainable, community-specific, and culturally and linguistically appropriate.”[9] To accomplish this, an evaluation of the needs specific to defined communities is required. The Virginia Commonwealth University Massey Cancer Center in collaboration with the Virginia Tobacco Indemnification and Community Revitalization Commission performed a comprehensive cancer needs assessment of four health district-defined communities. The four health districts chosen had a relatively high cancer burden and large medically underserved areas. The comprehensive assessment of cancer needs specific to each community will be used to develop a holistic strategy to improve cancer outcomes that utilize strategies that are culturally appropriate to these communities.

Methods of Data Collection

Demographic and economic information was collected to get a general picture of the health district. This data was collected from a variety of web-based sources (e.g., US Census Bureau, Department of Health and Human Services, Virginia Workforce Connection). The needs related to cancer prevention, early detection, treatment, and survivorship were assessed in five broad categories: cancer burden, cancer healthcare resources, community cancer resources, healthcare provider needs, and community population needs. Personnel dedicated to data collection included a Data Manager located at the Massey Cancer Center in Richmond and four Community Health Educators (CHE) located in their respective health districts. The CHEs were

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

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

[7] CDC, National Center for Injury Prevention, WISQARS Leading Causes of Death Reports 1999 – 2007, accessed on November 1, 2011, http://webappa.cdc.gov/cgi-bin/broker.exe.

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

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

qualified, long-term residents of the health districts and were responsible for gathering all community-based information. Mechanisms used to gather information in the four categories were as follows.

Cancer Burden

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

Cancer Healthcare Resources

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

Community Cancer Resources

The Community Health Education Coordinators compiled a list of formal and informal community organizations that provided support to cancer patients, survivors, and their families before, during, and after treatment. The VDH offices were considered community resources and were able to provide information about additional local community resources. Local chapters of national and state cancer organizations were found through the main organization's website. These local chapters often guided the CHEs to other community organizations within the health district. Additional community organizations were found through personal communications with individuals working with cancer patients and their families. A questionnaire was developed to be used during personal interviews with staff of the community resource organization and was used to gather information related to the organization's mission, target population, cancer-related services provided, and needs and challenges **(Appendix A)**.

Healthcare Provider Needs

The perspectives of healthcare providers on the needs related to cancer in the community were gathered in two ways. First, key leader physicians were identified in the community. These individuals were asked to discuss the most pressing healthcare deficiencies and needs of PCPs related to cancer in their health districts **(Appendix A)**. Second, information gathered from the key leaders was used to develop a questionnaire for PCPs within the health district. The questionnaire was field tested with physicians from within the health districts prior to finalization. It was then produced both as a pre-stamped hard-copy questionnaire and as an online questionnaire. A list of PCPs in each health district was acquired from the Virginia Board of

Medicine website[10] and was modified to include only physicians with primary specializations of family practice, internal medicine, urology, dermatology, cardiology, endocrinology, gastroenterology, emergency medicine, obstetrics and gynecology, surgeons, pulmonologists, radiologists, and hospitalists. The list was provided to the CHEs, who checked it for accuracy. All physicians on the final list were asked to complete the questionnaire either via email or by a personal visit from the CHE to the physician's office. Initial contact was followed-up at least once, potentially twice for non-responders **(Appendix B)**.

Community Population Needs

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

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

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

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

FINDINGS

Demographics in West Piedmont Health District

The West Piedmont Health District is comprised of three counties (Henry, Franklin, and Patrick Counties) and one city (Martinsville City). Martinsville City and Henry County are located on the southern border of Virginia in the foothills of the Blue Ridge Mountains and consists of 382 square miles of gently rolling hills. Their economies have undergone a transition from textile and furniture manufacturing to plastic processing, distribution, and logistics companies. Both Martinsville City and Henry County are considered rural and a medically underserved population. Their culture is rich as it promotes a diverse environment and offers a multitude of recreational opportunities, including the NASCAR speedway.

Franklin County, which consists of 690 square miles, is situated in the beautiful Blue Ridge Mountains and is the eastern gateway to the crooked road. It is conveniently located between I-81 and I-40, which places all major mid-Atlantic markets within an easy drive. Recognized as one of Virginia’s fastest growing counties, Franklin County offers a diverse range of attractions for both residents and tourists. Approximately 50% of the county is considered rural and the entire county has been classified as medically underserved. Patrick County consists of 483 square miles of beautiful scenery and is located in Southwestern Virginia where the rolling hills meet the Blue Ridge Mountains. The county is bordered in the south by the Virginia-North Carolina state line, and on the west by the Blue Ridge Parkway. Despite the combination of contemporary feel and small town charm, this county is considered rural and a medically underserved area.

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

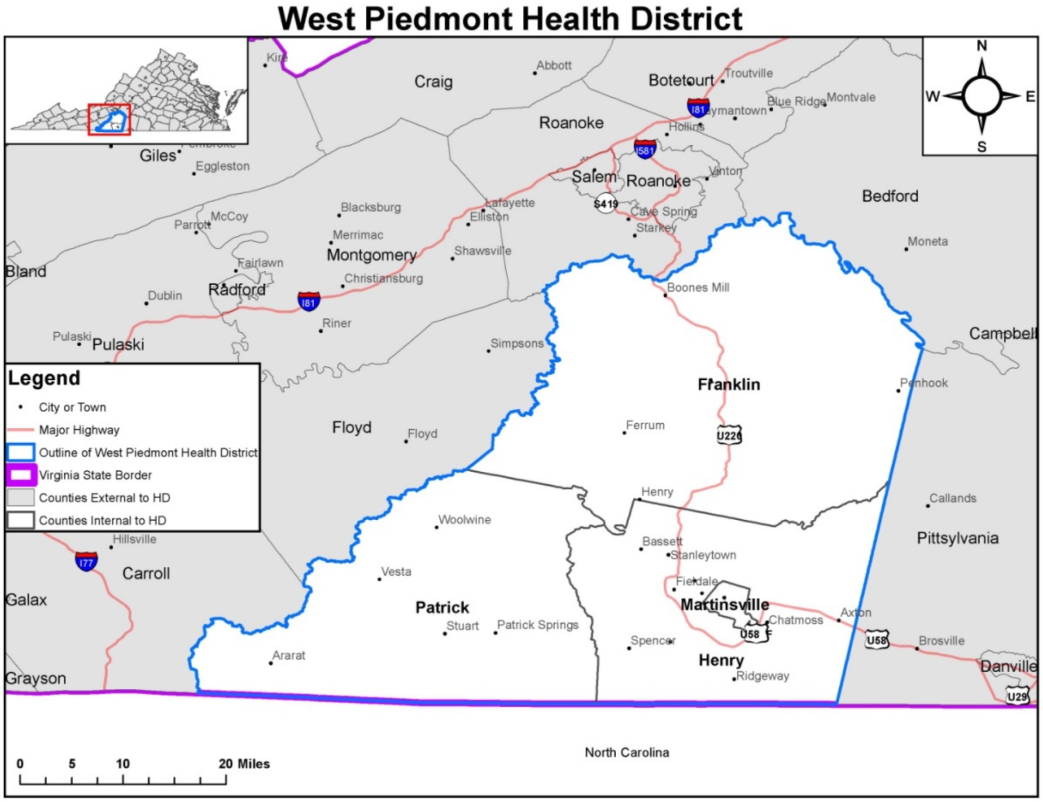

Figure 1: West Piedmont Health District

According to the 2011 US Census Bureau information, the West Piedmont Health District has 142,600 residents, of which 109,603 are ages 19 or older. There is some ethnic diversity: 80% of the population is white, 17% African American, and the remaining 3% consist of other races. The unemployment rate for the total district is 11.1%, ranging from 7.77% in Franklin County to 12.9% in Martinsville City. Of the adult population 25 years and over, 35% (31,355) have a high school diploma or equivalent, and 14% (9,810) have a Bachelor's degree or higher. Per Capita Median Income in 2010 ranged from $32,440 in Martinsville City to $47,606 in Franklin County. Compared to the rest of Virginia, the population of the West Piedmont Health District is older, less educated, and less racially diverse; has a higher unemployment rate (11.1% vs. 6.5%); and has a lower median household income ($37,450 vs. $63,302) **(Tables A & B)**.[12]

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

Table A: Demographic Profile of the West Piedmont Health District vs. Virginia

Demographic Profile of West Piedmont vs. Virginia			
Category	**Subcategory**	**West Piedmont**	**Virginia**
Gender	Male Female	48% 52%	49% 51%
Age	0-19 20-34 35-54 55-64 65+	23% 15% 29% 14% 19%	26% 21% 29% 12% 12%
Race	White Black or AA Other	80% 17% 3%	70% 19% 11%
Ethnicity	Hispanic or Latino Non-Hispanic or Latino	3% 97%	8% 92%

Table B: Economic Characteristics of West Piedmont Health District vs. Virginia

Economic Characteristics of West Piedmont vs. Virginia		West Piedmont (average)	Virginia
Unemployment[13]	Unemployment Rates	11.1%	6.5%
Income[14]	Median Household Income	$37,450	$63,302
Education[15]	% Less than high school	23%	13%
	% High school or GED	35%	26%
	% some college, no degree or an Associate's degree	28%	27%
	%Bachelor's degree or above	14%	34%

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[13] U.S. Census Bureau; American Community Survey, 2007-2011 Summary Table DP03; generated using American FactFinder; <http://factfinder.census.gov>; (April 29, 2013). Health District is an average of the counties. Population age 16 years and older.

[14] U.S. Census Bureau; American Community Survey, 2007-2011 Summary Table DP03; generated using American FactFinder; <http://factfinder.census.gov>; (April 29, 2013). Income amounts shown are adjusted to 2011 inflation dollar value. Health District is an average of the counties.

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

Access to Healthcare

The counties comprising the West Piedmont Health District are rural and medically underserved. All or part of the counties of Franklin, Henry, Patrick, and Martinsville City are designated as Health Professional Shortage Areas (HPSA). All of these counties and the City of Martinsville are federally designated as Medically Underserved Areas (all or in part), with the exception of the City of Martinsville and Henry County, which is also designated as a Medically Underserved Population. Additionally, all of these counties are designated “rural localities” by the Health Resources and Services Administration, with Franklin County being mostly rural. Three hospitals are located in the West Piedmont Health District: Memorial Hospital of Martinsville and Henry County, Pioneer Community Hospital of Patrick County, and Carilion Memorial Franklin Hospital **(Figure 2)**.

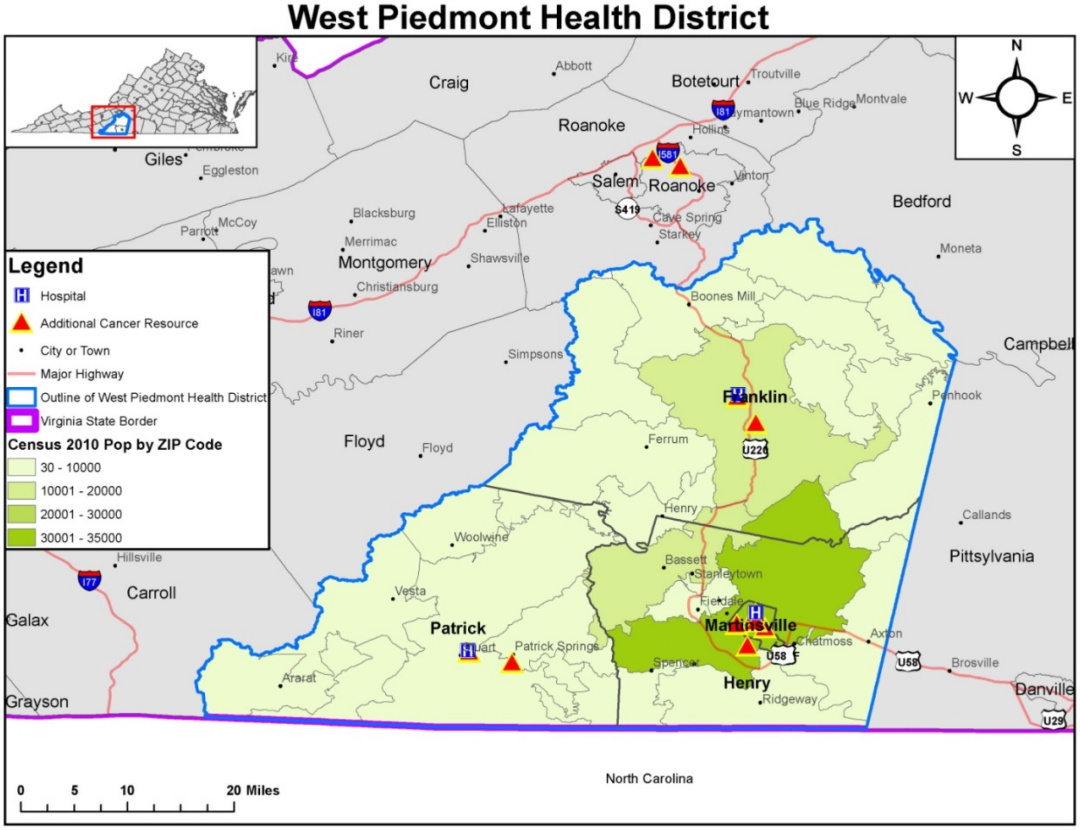


Figure 2: Healthcare Resources in West Piedmont Health District

Cancer Burden

Cancer Incidence

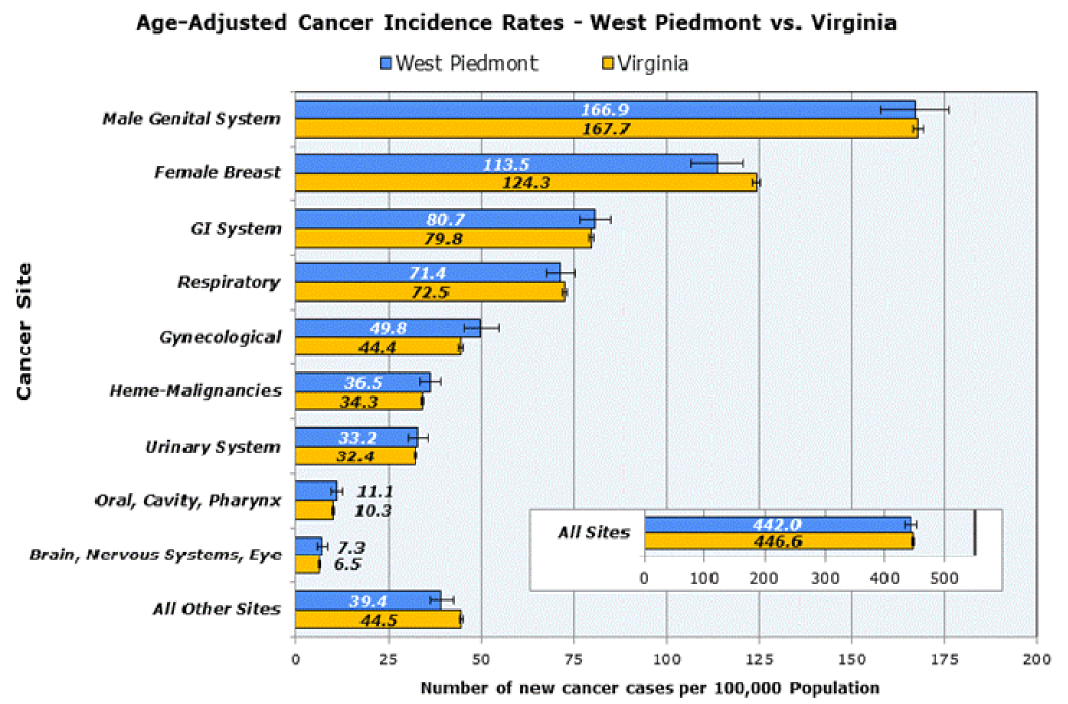
Age-adjusted cancer incidence rates were calculated for the health district for all cancer types combined and by disease site. Incidence rates for gender-specific cancers (female breast and gynecological, male genital) were calculated for the appropriate gender populations. Overall, the cancer incidence rates for the district are similar to those for Virginia as a whole. The cancer subtypes with the highest incidence rates for the district are: male genital system, female breast, gastrointestinal (GI) system cancers, respiratory cancers, and gynecological cancers **(Table C).**

Table C: Age-Adjusted Cancer Incidence in the West Piedmont Health District vs. Virginia

Age-Adjusted Cancer Incidence Rates in West Piedmont Health District vs. Virginia

Cancer Site	**West Piedmont**	**Virginia**	***Notes***
Male Genital System	**166.9**	**167.7**	*Data Source:* *Virginia Cancer Registry (averaged rates for1999-2008) – all rates calculated based on populations including all ages.* *Dataset ordered by descending rate for health district.* *Age-Adjusted Rate - represents an age-adjusted number of new cancer cases per 100,000 populations.* *Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females.*
Prostate	161.8	162.0	
Other male genital organs	5.1	5.7	
Female Breast	**113.5**	**124.3**	
GI System	**80.7**	**79.8**	
Colon & Rectum	51.3	47.5	
All Other GI	29.4	32.3	
Respiratory	**71.4**	**72.5**	
Gynecological	**49.8**	**44.4**	
Corpus and Uterus	23.9	21.8	
Ovary	12.2	12.1	
Cervix	9.4	7.2	
All other Gynecological	4.3	3.4	
Heme-malignancies	**36.5**	**34.3**	
Lymphomas	18.2	19.5	
Leukemias	13.5	9.7	
Myeloma	4.7	5.2	
Urinary System	**33.2**	**32.4**	
Oral Cavity, Pharynx	**11.1**	**10.3**	
Brain, Nervous System, Eye	**7.3**	**6.5**	
All Other Sites	**39.4**	**44.5**	
All Sites	**442.0**	**446.6**	

Female breast cancer and “other” cancer sites are significantly lower than state incidence rates, while the gynecologic cancer incidence rate appears to be slightly higher. The age-adjusted cancer incidence rates for all other cancer subtypes in the health district are approximately equal to those of the state as a whole **(Figure 3)**.

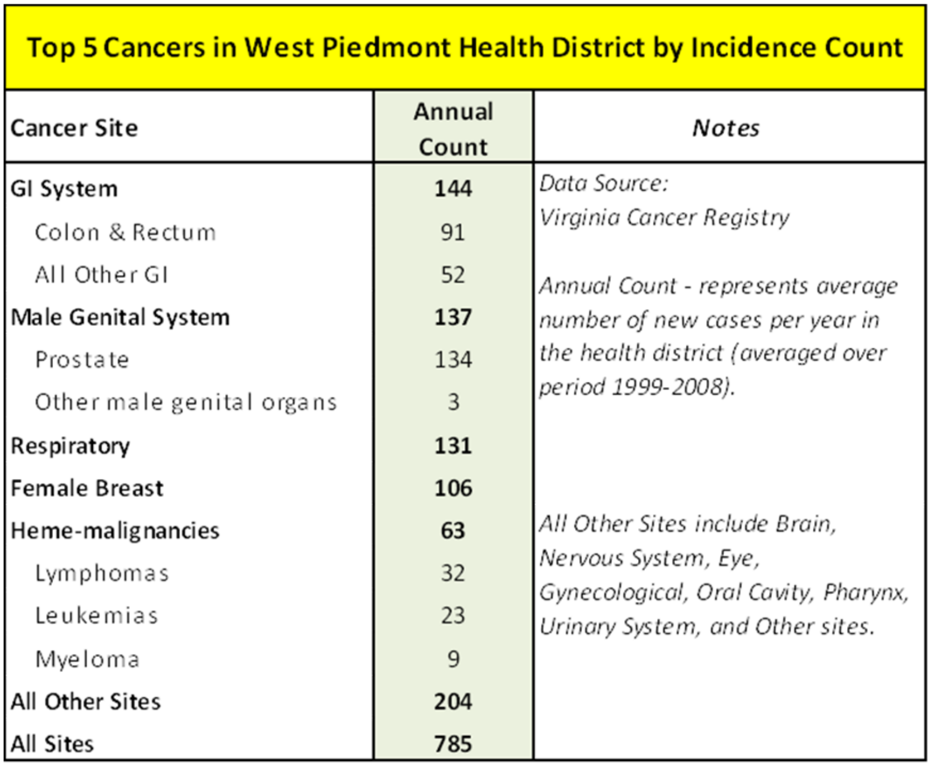


Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females.
Data Source: Virginia Cancer Registry (averaged rates for1999-2008) – all rates calculated based on populations including all ages.

Figure 3: Age-Adjusted Cancer Incidence Rate in the West Piedmont Health District vs. VA

To evaluate the impact of cancer on 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 West Piedmont Health District, there is an average of 785 cases of new cancer each year **(Table D** and **Figure 4)** based on a 10-year average (1999-2008). Male genital/prostate, female breast, GI/colorectal, respiratory, and hematological cancers had the highest average incident cases; together they make up 74% of the total cases.

Table D: Top 5 Cancers in *the* West Piedmont Health District by Incidence Count



Top 5 Cancers in West Piedmont Health District by Incidence Count

Cancer Site	Annual Count	*Notes*
GI System	**144**	*Data Source:* *Virginia Cancer Registry*
Colon & Rectum	91	
All Other GI	52	*Annual Count - represents average number of new cases per year in the health district (averaged over period 1999-2008).*
Male Genital System	**137**	
Prostate	134	
Other male genital organs	3	
Respiratory	**131**	
Female Breast	**106**	
Heme-malignancies	**63**	*All Other Sites include Brain, Nervous System, Eye, Gynecological, Oral Cavity, Pharynx, Urinary System, and Other sites.*
Lymphomas	32	
Leukemias	23	
Myeloma	9	
All Other Sites	**204**	
All Sites	**785**	

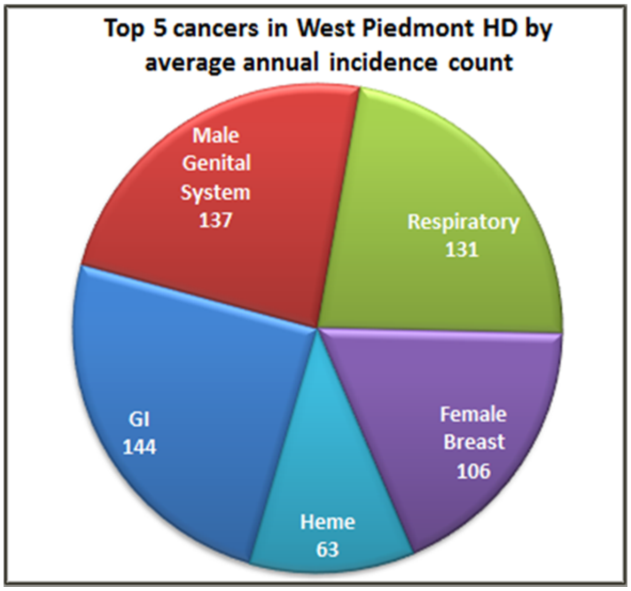


Figure 4: Top 5 cancers in the West Piedmont Health District by Incidence Count[16]

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

Men in West Piedmont develop cancer at a higher rate than women (640 vs. 487 cases per 100,000). Incidence rates and counts of specific types of cancer vary substantially by gender **(Tables E** and **F)**. Genital cancer (principally prostate) has the highest incidence in males, followed by respiratory. Breast cancer has the highest incidence in females, followed by GI cancers **(Figures 5** and **6)**.

Table E: Top 5 Male Cancers in the West Piedmont Health District

Top 5 Male Cancers in West Piedmont			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Male Genital System	**201.7**	**137**	*Data Source:* *Virginia Cancer Registry* *Crude Rate – represents number of new male cancer cases per 100,000 males.* *Annual Count - represents average number of new male cancer cases per year in the health district (averaged over period 1999-2008).* *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.*
Prostate	196.9	134	
Other male genital organs	4.9	3	
Respiratory	**124.0**	**84**	
GI System	**117.9**	**80**	
Colon & Rectum	72.9	50	
All Other GI	45.0	31	
Urinary System	**59.6**	**41**	
Heme-malignancies	**54.1**	**37**	
Lymphomas	25.1	17	
Leukemias	22.2	15	
Myeloma	6.8	5	
All Other Sites	**83.2**	**57**	
All Sites	**640.5**	**436**	

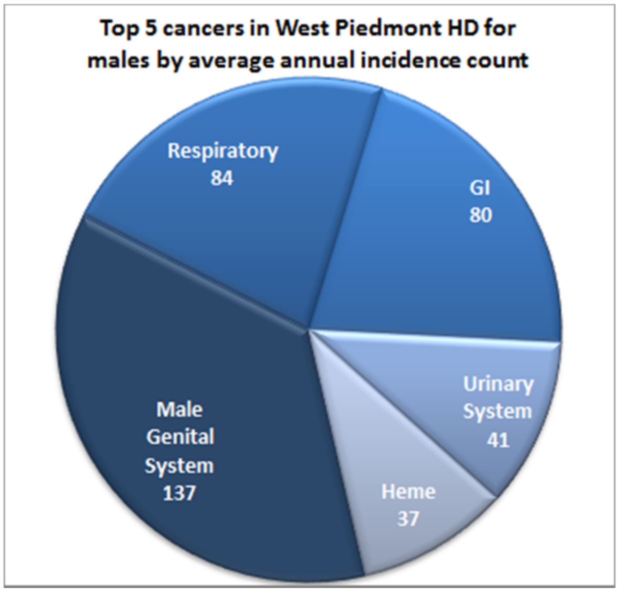

Figure 5: Top 5 Male Cancers in the West Piedmont Health District

Table F: Top 5 Female Cancers in the West Piedmont Health District

Top 5 Female Cancers in West Piedmont			
Cancer Site	**Crude Rate**	**Annual Count**	***Notes***
Female Breast	**148.1**	**106**	*Data Source:* *Virginia Cancer Registry*
GI System	**88.3**	**63**	
Colon & Rectum	58.0	42	*Crude Rate – represents number of new female cancer cases per 100,0000 females.*
All Other GI	30.3	22	
Respiratory	**65.5**	**47**	
Gynecological	**64.3**	**46**	*Annual Count - represents average number of new female cancer cases per year in the health district (averaged over period 1999-2008).*
Corpus and Uterus	32.2	23	
Ovary	16.0	12	
Cervix	10.2	7	
All other Gynecological	5.9	4	
Heme-malignancies	**36.8**	**26**	
Lymphomas	20.5	15	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.*
Leukemias	10.9	8	
Myeloma	5.4	4	
All Other Sites	**84.7**	**62**	
All Sites	**487.7**	**350**	

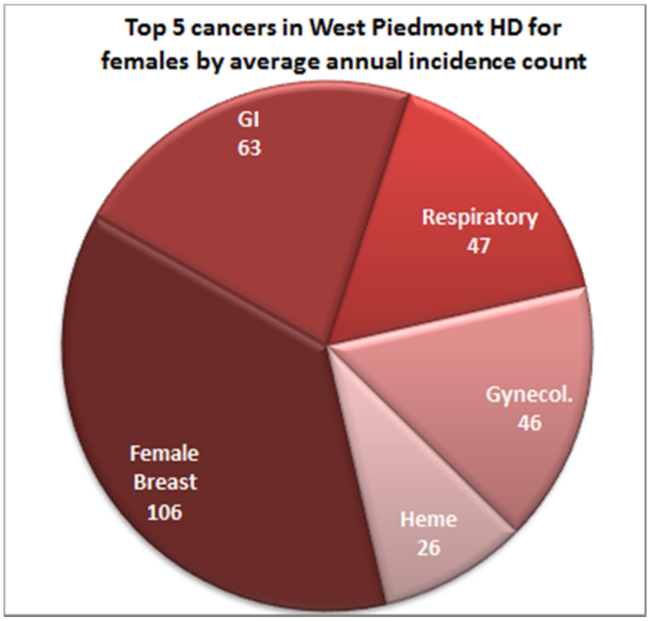

Figure 6: Top 5 Female Cancers in the West Piedmont Health District

At both the state and district levels, prostate cancer occurs more frequently in African American males than in white males. The top five cancers in the white and African American population include: male genital, female breast, GI/colorectal, respiratory, and gynecological **(Tables G** and **H)**. GI, male genital, and breast cancers create the greatest cancer burden for African American residents, making up 59% of the annual cancer cases in that population. In contrast, “other cancer types,” GI, respiratory, and male genital cancers create the greatest burden for white residents (71%) **(Figure 7)**. Of note, the GI/colorectal and male genital system cancer incidence rates were substantially higher in African American residents than white residents. The racial differences are the same at both the local and state levels. Importantly, both racial groups within the health district had lower age-adjusted all site cancer incidence rates than race-matched groups at the state level.

Table G: Top 5 Cancers in West Piedmont for African American Residents

Top 5 Cancers in West Piedmont for African American Population				
Cancer Site	**10-year case count**	**Age Adjusted Incidence Rate**		***Notes***
		West Piedmont	**Virginia**	
Male Genital System	**257**	**222.7**	**245.7**	*Data Source:* *Virginia Cancer Registry* *10-year case count – represents number of new cancer cases reported to the registry for African American population from 1999-2008.* *Age-Adjusted Incidence Rate represents age-adjusted cancer incidence rate for African American population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Incidence Rate.* *All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Heme-malignancies, Urinary System, and Other sites.*
Prostate	255	220.8	243.6	
Other male genital organs	2	1.9	2.1	
Female Breast	**177**	**121.8**	**122.4**	
GI System	**273**	**106.3**	**101.2**	
Colon & Rectum	171	66.5	57.2	
All Other GI	102	39.9	44.0	
Respiratory	**159**	**61.1**	**78.0**	
Gynecological	**72**	**49.8**	**39.2**	
Corpus and Uterus	42	28.5	18.7	
Ovary	18	12.6	9.2	
All other Gynecological	12	8.6	11.3	
All Other Sites	**258**	**98.3**	**98.6**	
All Sites	**1196**	**459.2**	**472.4**	

Table H: Top 5 Cancers in West Piedmont for White Residents

Top 5 Cancers in West Piedmont for White Population				
Cancer Site	**10-year case count**	**Age Adjusted Incidence Rate**		***Notes***
		West Piedmont	**Virginia**	
Male Genital System	**1088**	**154.6**	**152.6**	*Data Source:* *Virginia Cancer Registry* *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.*
Prostate	1057	148.7	145.9	
Other male genital organs	31	5.9	6.8	
Female Breast	**880**	**111.1**	**125.3**	
GI System	**1155**	**76.3**	**75.1**	
Colon & Rectum	737	48.9	45.7	
All Other GI	418	27.4	29.3	
Respiratory	**1150**	**73.1**	**72.5**	
Gynecological	**383**	**49.6**	**45.4**	
Corpus and Uterus	185	22.9	22.5	
Ovary	96	12.1	12.7	
Cervix	64	10.2	6.7	
All other Gynecological	38	4.4	3.5	
All Other Sites	**1929**	**131.9**	**134.1**	
All Sites	**6585**	**436.5**	**442.4**	

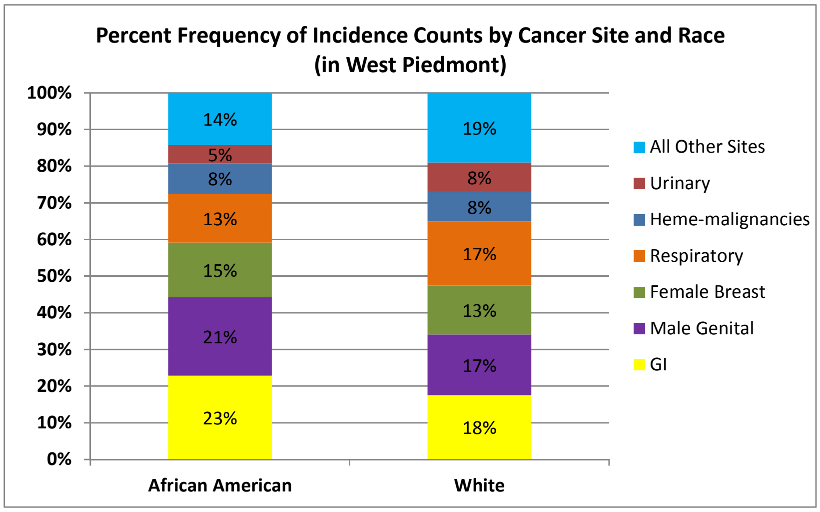

Figure 7: Percent Frequency of Incidence Counts by Cancer Site and Race in the West Piedmont Health District

Cancer Staging and Mortality

Cancer staging is needed for proper treatment planning. Discovering cancer at the local stage is usually indicative of a better outcome and improved survivorship. Compared to the rest of Virginia, the ratio of early vs. late stage cancer diagnoses is approximately equal (~1:1). Of note, the percentage GI cancers diagnosed in the early stage in the West Piedmont Health District is higher than that for the rest of Virginia **(Figure 8)**.

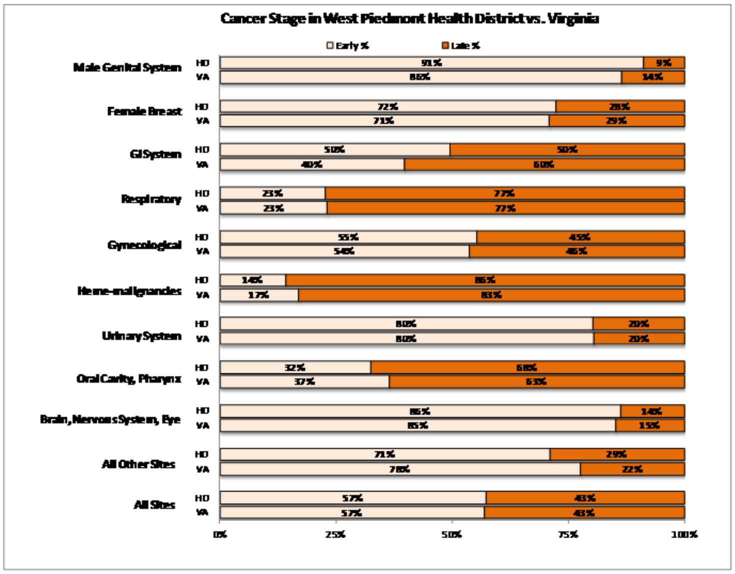

Figure 8: Cancer Stage at Diagnosis: West Piedmont Health District vs. Virginia[17]

An average, 360 residents of West Piedmont Health District succumb to cancer each year. The cancer sites with the highest mortality rates in the West Piedmont Health District are respiratory, GI, hematologic, female breast, and male genital cancers, in that order **(Table I)**. The district has higher mortality rates than Virginia for all cancer sites, with the exception of female breast and the oral cavity, although those differences are not statistically significant **(Figure 9)**. Respiratory and GI cancer deaths account for 51% of the cancer deaths in the health district.

Table I: Top 5 Cancers in the West Piedmont Health District by Death Count

Top 5 Cancers in West Piedmont by Annual Death Count		
Cancer Site	**Annual Count**	***Notes***
Respiratory	**107**	*Data Source:*
GI System	**77**	*Virginia Department of Health*
All other GI	44	*(averaged counts for 5-year period*
Colon & Rectum	34	*2005-2009) - based on population*
Heme-malignancies	**31**	*for all ages.*
Lymphomas	13	
Leukemias	11	*Dataset ordered by descending*
Myeloma	8	*death counts for health district.*
Female Breast	**23**	
Male Genital System	**20**	*All Other Sites include Brain,*
Prostate	19	*Nervous System, Eye, Oral Cavity,*
Other male genital organs	0	*Pharynx, Gynecological, Urinary*
All Other Sites	**101**	*System, and Other sites.*
All Sites	**360**	

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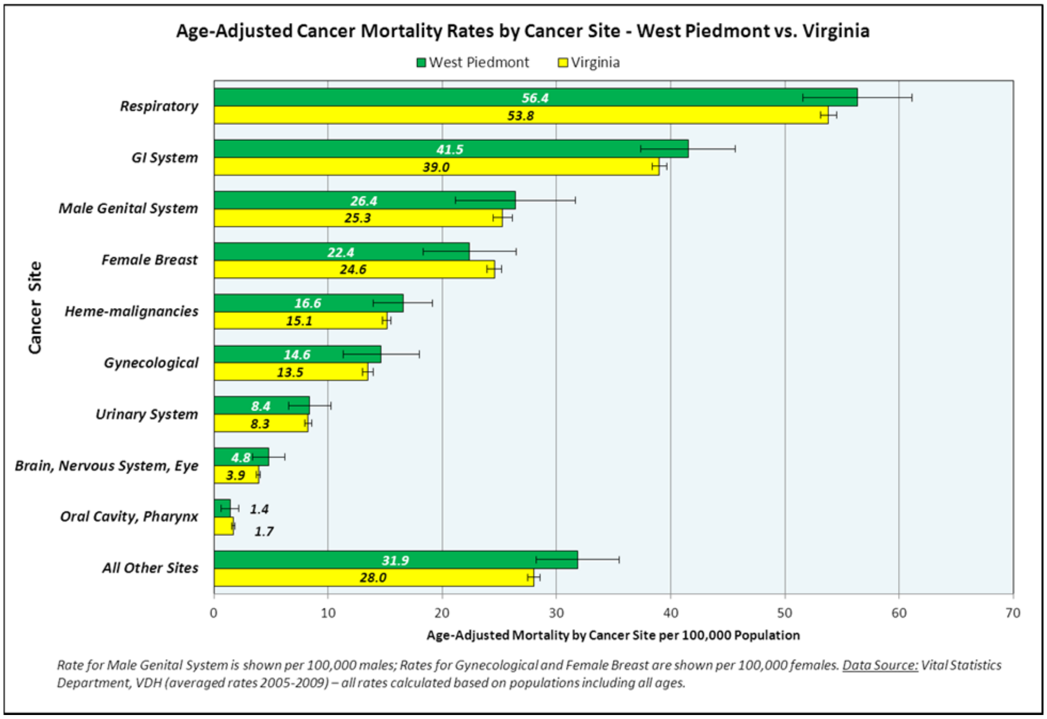
[17] ***Early*** *stage combines "In Situ" and "Local" cancer stages;* ***Late*** *stage combines "Regional" and "Distant" stages. Data presents cancer cases with reported stage only. Percentage of unstaged cancer cases was eliminated from calculations. Data Source: Virginia Cancer Registry (1999-2008)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


Age-Adjusted Cancer Mortality Rates by Cancer Site - West Piedmont 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: Vital Statistics Department, VDH (averaged rates 2005-2009) – all rates calculated based on populations including all ages.

Figure 9: Age-Adjusted Cancer Mortality Rate in West Piedmont vs. VA

Men have higher mortality rates from cancer than women in the West Piedmont Health District (155 vs. 128 cases per 100,000). Respiratory and GI cancers cause the greatest number of deaths in both men and women, with the annual death count from respiratory cancers higher in men than women (67 vs. 40 cases per year) **(Figures 10** and **11)**.

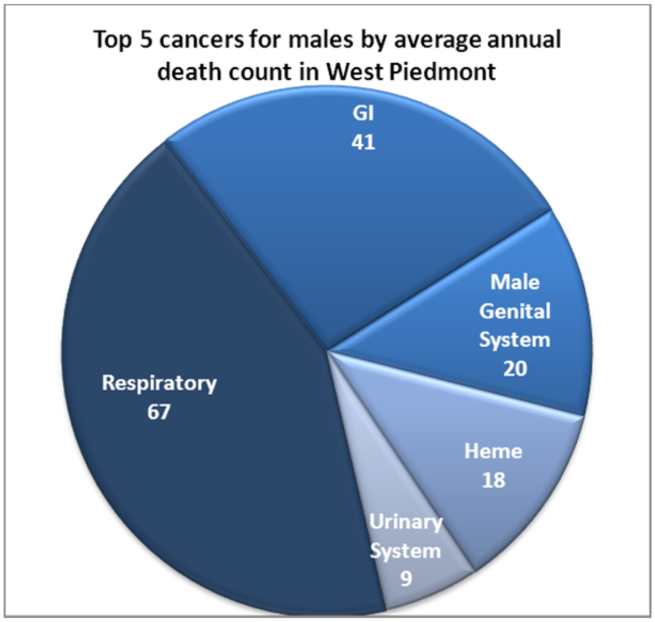

Top 5 cancers for males by average annual death count in West Piedmont

Figure 10: Top 5 Cancers Causing Death in Males in the West Piedmont Health District

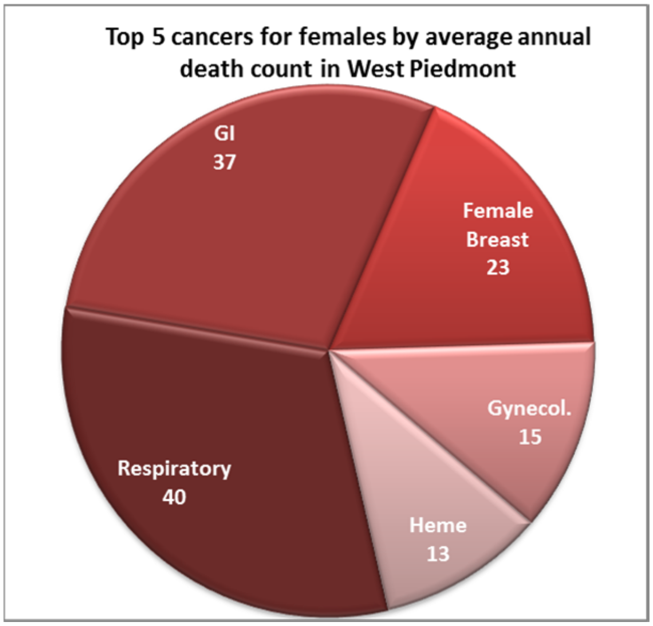


Figure 11: Top 5 Cancers Causing Death in Females in the West Piedmont Health District

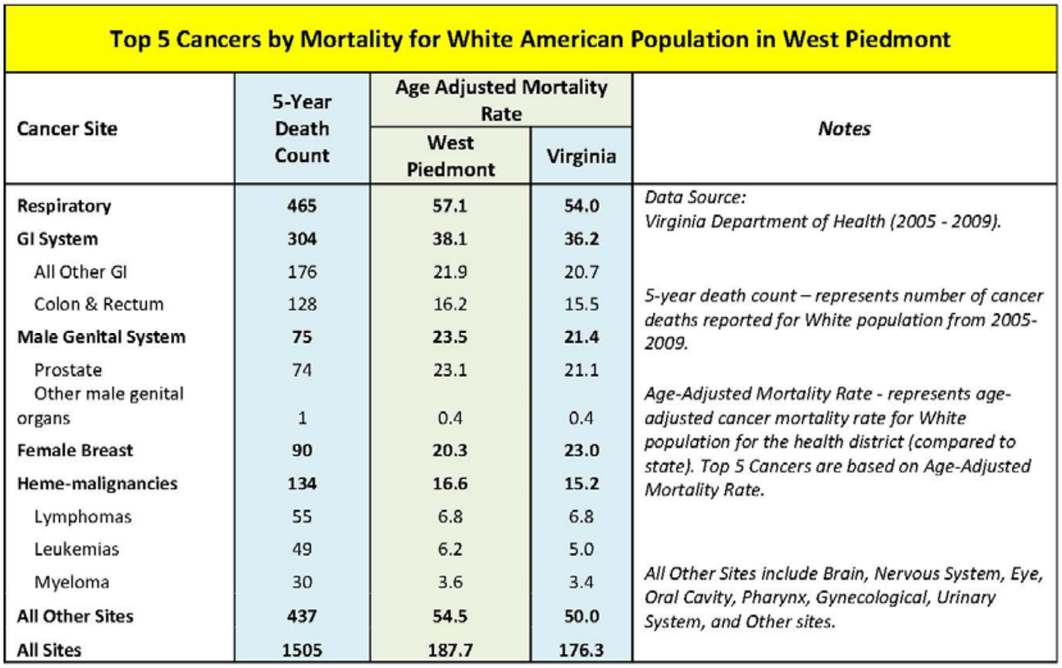
African American district residents had a higher age-adjusted mortality rate for GI system cancers and lower mortality rates for respiratory and male genital cancers than African Americans in the state as a whole **(Table J)**. In contrast, mortality rates for respiratory, GI, male genital, and "other sites," were higher for white residents of the district compared to the entire white population of Virginia **(Table K)**. GI and respiratory cancers represent approximately half of the cancer deaths for both whites and African Americans in the health district **(Figure 12)**.

Table J: Top 5 Cancers by Mortality for African American Residents in **the** West Piedmont Health District

Top 5 Cancers by Mortality for African American Population in West Piedmont

Cancer Site	5-Year Death Count	Age Adjusted Mortality Rate		*Notes*
		West Piedmont	Virginia	
GI System	**82**	**62.8**	**54.9**	*Data Source:* *Virginia Department of Health (2005 - 2009).*
All Other GI	43	32.4	31.2	
Colon & Rectum	39	30.3	23.6	
Respiratory	**70**	**52.3**	**59.6**	*5-year death count – represents number of cancer deaths reported for African American population from 2005-2009.*
Male Genital System	**23**	**47.2**	**51.6**	
Prostate	23	47.2	51.2	
Other male genital organs	0	0.0	0.4	*Age-Adjusted Mortality Rate - represents age-adjusted cancer mortality rate for African American population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Mortality Rate.*
Female Breast	**25**	**32.0**	**33.6**	
Heme-malignancies	**22**	**16.2**	**15.7**	
Lymphomas	9	6.2	4.5	
Myeloma	8	6.2	7.4	
Leukemias	5	3.8	3.8	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.*
All Other Sites	**70**	**52.6**	**52.6**	
All Sites	**292**	**219.3**	**220.3**	

Table K: Top 5 Cancers by Mortality for White Residents in the West Piedmont Health District



Top 5 Cancers by Mortality for White American Population in West Piedmont

Cancer Site	5-Year Death Count	Age Adjusted Mortality Rate		*Notes*
		West Piedmont	Virginia	
Respiratory	**465**	**57.1**	**54.0**	*Data Source:* *Virginia Department of Health (2005 - 2009).*
GI System	**304**	**38.1**	**36.2**	
All Other GI	176	21.9	20.7	
Colon & Rectum	128	16.2	15.5	*5-year death count – represents number of cancer deaths reported for White population from 2005-2009.*
Male Genital System	**75**	**23.5**	**21.4**	
Prostate	74	23.1	21.1	
Other male genital organs	1	0.4	0.4	*Age-Adjusted Mortality Rate - represents age-adjusted cancer mortality rate for White population for the health district (compared to state). Top 5 Cancers are based on Age-Adjusted Mortality Rate.*
Female Breast	**90**	**20.3**	**23.0**	
Heme-malignancies	**134**	**16.6**	**15.2**	
Lymphomas	55	6.8	6.8	
Leukemias	49	6.2	5.0	
Myeloma	30	3.6	3.4	*All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.*
All Other Sites	**437**	**54.5**	**50.0**	
All Sites	**1505**	**187.7**	**176.3**	

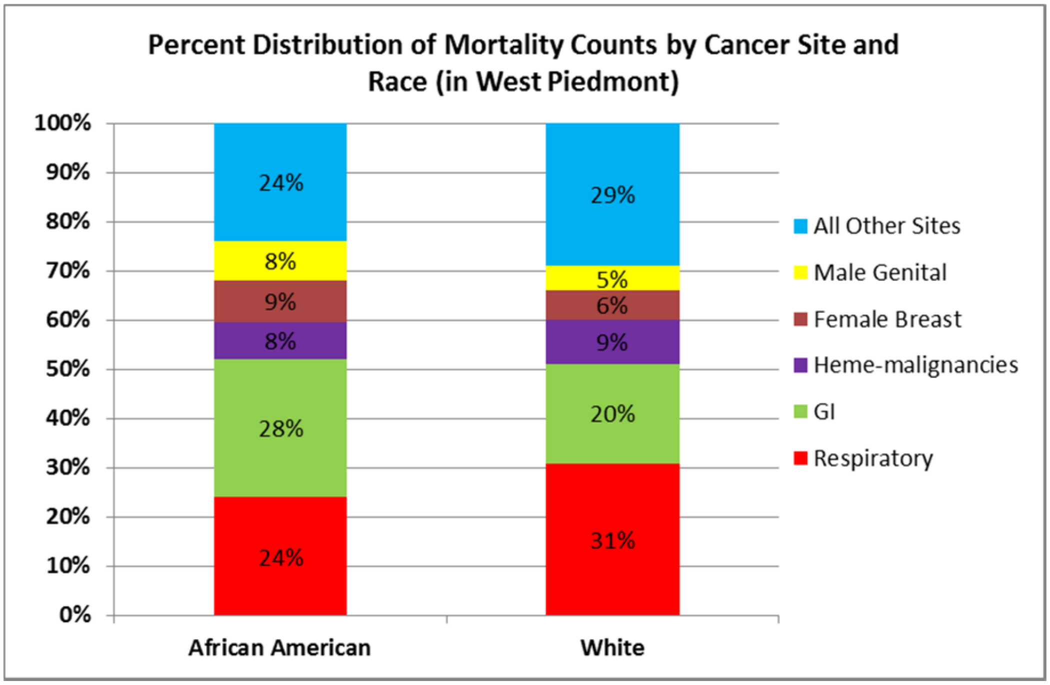


Figure 12: Percent Distribution of Mortality Counts by Cancer Site and Race in the West Piedmont Health District

Cancer Healthcare Resources

Healthcare Facilities and Cancer Care

There are three hospitals in the West Piedmont Health District: Memorial Hospital of Martinsville and Henry County (MHMHC), Carilion Memorial Franklin Hospital, and Pioneer Community Hospital of Patrick County. MHMHC primarily serves Martinsville and Henry County, as well as residents from Franklin and Patrick counties. Carilion Memorial Franklin Hospital serves residents from Franklin County and some residents from Basset, which is located in Henry County. Pioneer Community Hospital serves the residents in Patrick County **(Figure 2)**. Three oncology physicians provide services to the health district. One medical oncology physician practices in Franklin County, and one medical oncologist and one radiation oncologist practice in Martinsville City. Travel within the health district, and even within the counties, can involve long, winding secondary roads that present a barrier to receiving cancer treatment.

Cancer Services Provided

The following cancer-related services are available within the West Piedmont Health District (see Appendix D for further details):

Screening

Breast, colorectal, and cervical cancer screening facilities are available throughout the health district. Mammography is available in two of the three hospitals in the district, and colonoscopies are available in all three counties. Colonoscopy is available in gynecology offices in Martinsville.

Treatment

Treatment modalities for cancer include chemotherapy (including immunotherapy), radiation, and surgery. Treatment with all modalities is available within the West Piedmont Health District. The most comprehensive cancer services are concentrated in the City of Martinsville. Large portions of the district’s population must travel long distances to receive care at these locations.

MHMHC provides medical and radiation oncology consults, as well as radiation and in/out-patient chemotherapy. Franklin Memorial Hospital provides medical oncology consults during cancer clinic days. Memorial Hospital offers the most extensive surgical options for cancer in the health district, with the other hospitals offering limited options. There is a deficiency in specialized surgical services in the areas of brain, lung, and prostate. Finally, patient navigation services are only available at one Memorial Hospital and to patients with breast cancer.

Auxiliary Services

Programs that address survivorship needs and improve quality of life include: dietary provision and counseling; genetic counseling; palliative care; and end-of-life services. Genetic and nutritional counseling specific to cancer and cancer support services are limited in the health district. Genetic testing is available to patients referred out for counseling related to results. Dietary services and nutrition counseling are available in all healthcare facilities, but nutrition counseling specific to cancer is not available. Martinsville has a very engaged and active Man to Man cancer support group that meets monthly and has been in place for many years. With the exception of breast and prostate cancer subtypes, there is a lack of specific cancer support groups; finding active support groups within the health district proved to be a difficult task. Availability and active advertising of these groups would increase participation and provide support for those seeking services within the health district. Cancer research is available in a limited way at Memorial Hospital in Martinsville and Henry County.

Hospice Services

Martinsville City, Henry County, and Franklin County are served by Mountain Valley Hospice services, as well as Hospice of Franklin County and Hospice of Memorial Hospital. Patrick County is served by Hospice of Patrick County and Mountain Valley Hospice, providing each county/city with at least two hospices serving their communities. The hospices provide services at home and in nursing facilities. Hospice services are underutilized throughout the district, and commonly are only utilized by patients in their last weeks of life. Key leaders confirmed that finances are available for hospice services. Underutilization of hospice services can be attributed to both family hesitancy to contact hospice providers and physicians being slow to recommend hospice services to patients.

Community Cancer Resources

The West Piedmont Health District hosts a number of cancer-related resources for patients and their families outside of the hospitals and oncology offices. These resources offer an array of services including education, information, and direct services (see **Appendix E** for details):

- The American Cancer Society
- Reach to Recovery
- Susan G. Komen for the Cure
- The Virginia Department of Health Every Woman’s Life
- PATHS
- American Breast Cancer Society
- Local Cancer Association
- Comfort Zone, Inc.
- Camp Tree House
- Bernard Healthcare Center
- Helping Hands
- Man to Man support group
- Ladies First

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

Despite these services, focus group participants expressed a desire for a wider range of cancer support groups. Additionally, they thought that more education on cancer prevention and screening would benefit the health district, especially in relation to skin, lung, prostate, and breast cancer. Because mountainous and winding roads, as well as distances to hospitals from outlying areas of the district, make traveling to educational activities difficult for the rural population, these educational events should be brought to the people.

Healthcare Provider Needs

Key Leader Information

Five experienced, long-term residents who are healthcare professionals in the West Piedmont Health District were interviewed to gain a knowledge base of the healthcare system currently in place as relates to cancer care and specifically, any deficiencies therein. These five individuals were selected because they represent all of the three counties (Patrick, Henry, Franklin, and Martinsville City) in the West Piedmont Health District. Their credentials include physicians, senior hospital administrators, and registered nurses. These individuals were asked to identify deficiencies in the healthcare system first, as it relates to cancer risk reduction, detection, treatment, and follow-up care. Second, they were asked to identify deficiencies for primary care physicians (PCPs), specifically for cancer-related continuing education, obstacles in acquiring cancer diagnosis and treatment for patients, post-treatment communication and training needs, and knowledge of palliative and hospice care.

The major healthcare deficiencies identified by these key leaders fell into four categories: (1) education for physicians AND the general population to promote healthy lifestyles; (2) availability and proximity to adequate treatment services, devices, and facilities; (3) financial burdens as related to transportation, reliable transportation, and time constraints as related to family duties that would need support be it internal or external; and (4) lack of specialists and supporting diagnostics, labs, and communication services.

Educational deficiencies were overwhelmingly voiced from each county. These deficiencies include a lack of statistical data that providers, residents, and community resources can understand and use as a resource that will benefit the entire health district. Many voiced that statistics regarding educational deficiencies are available; however, they tend to be voluminous and in a format that may not be easily accessible or in a format that is not conducive to the general population easily using or understanding. Standardization of statistics for the health district that is provided in a timely manner could create an efficient and comparable educational tool that residents, providers, and other constituents within the community can use to create a culture of overall understanding of health concerns.

Availability of treatment was also a major concern within each health district that shows a lack of practitioners to adequately provide healthcare within the health district. Family practice shortages are significant, which also increases the lag in time for diagnosis and referral patterns. Most communities have an acute care system and/or a sick care system. Prevention and end-of-life resources are lacking in all communities due to time restraints of providers maximizing their patient volume due to shortage and also shortage of providers to see patients who are seeking acute care issues and not interested of prevention at the time of their visit.

Financial burdens include lack of funding for those who may have insurance but are burdened with high co-pays and deductibles. These benefits may be offered through employment and a reduced rate; however affording the deductibles and co-pays are often overlooked and most community services only provide screening and/or assistance to those without insurance. A significant breakdown exists with uninsured and underinsured residents who may not seek healthcare services due to not having the ability to pay upfront collections for these co-pays and deductibles. Multiple agencies offer free screening test and resources for the uninsured; however, limited services are available for those who need some financial assistance to assist with the co-pays and deductibles. Other financial barriers include transportation for residents who have no access to public transportation or funds for accessing transportation.

Smoking cessation, screening practices and chronic obesity concerns are certainly identified within each health district; however, battling the barriers of educating the public and actually getting residents engaged in these issues is a constant concern and work in progress. Discussing risk factors is important to the providers and healthcare providers within each health district; however, each of them face the same barriers of time, resources, and engagement from residents; finances; and provider shortage increasing the burden of healthy lifestyle choices. Many populations are very vulnerable and the increase in chronic illness in the younger population is increasing at an alarming rate.

Tobacco use was universally cited as creating a significant cancer risk in the West Piedmont Health District. There is an urgent need for educational programs to encourage the promotion of awareness as to the extreme health risks associated with tobacco usage. Also repeatedly cited was the need for education relating to lifestyle choices, with specific emphasis on the correlation between lifestyle choices and cancer causative factors. Additionally, long travel times, lack of dependable transportation, and lack of community support for extended family needs of a cancer patient were repeatedly mentioned.

Lack of specialists is an issue throughout the health district and the overall perception of residents within each community is that there is a shortage of skilled healthcare. This perception causes residents to look outside of the health district, even before inquiring about local resources.

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. Twenty-seven physicians in the West Piedmont Health District completed a cancer questionnaire, either on paper or online. A 30% response rate was obtained from the physicians contacted. Over half of the responding physicians were family practice physicians, with the next largest group being internal medicine. The remainder specialized in gynecology, surgery, and urology.

Screenings

When asked about their perceptions regarding the most common types of cancer diagnosed in their practice, the top three cancers were breast (29%), colorectal (19%) and lung cancers (18%). Over 80% of respondents felt that their patients had above average or high compliance with their referrals for breast and cervical cancer screening. In contrast, 49% of responding physicians felt that fewer than half of their patients were compliant with their referral for colorectal cancer screening **(Figure 13)**. The most compelling reasons physician cited for patients not having a recommended cancer screening were financial constraints (73%), patients perception of screenings as unnecessary (73%), and test apprehension (67%) **(Figure 14)**. Over half of the physicians were interested in receiving updates on screening guidelines for ovarian cancer, while greater than a third were interested in lung and prostate screening updates.

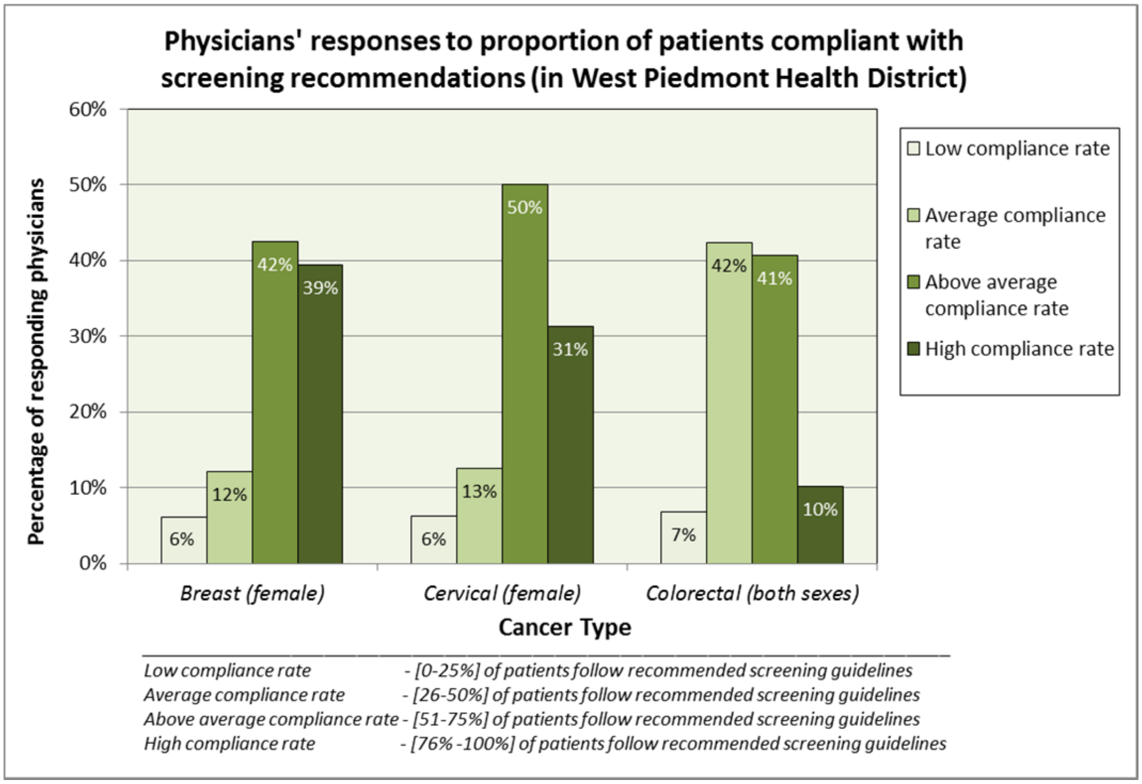


Figure 13: Physician Estimation of Patient Compliance with Recommended Screenings in the West Piedmont Health District

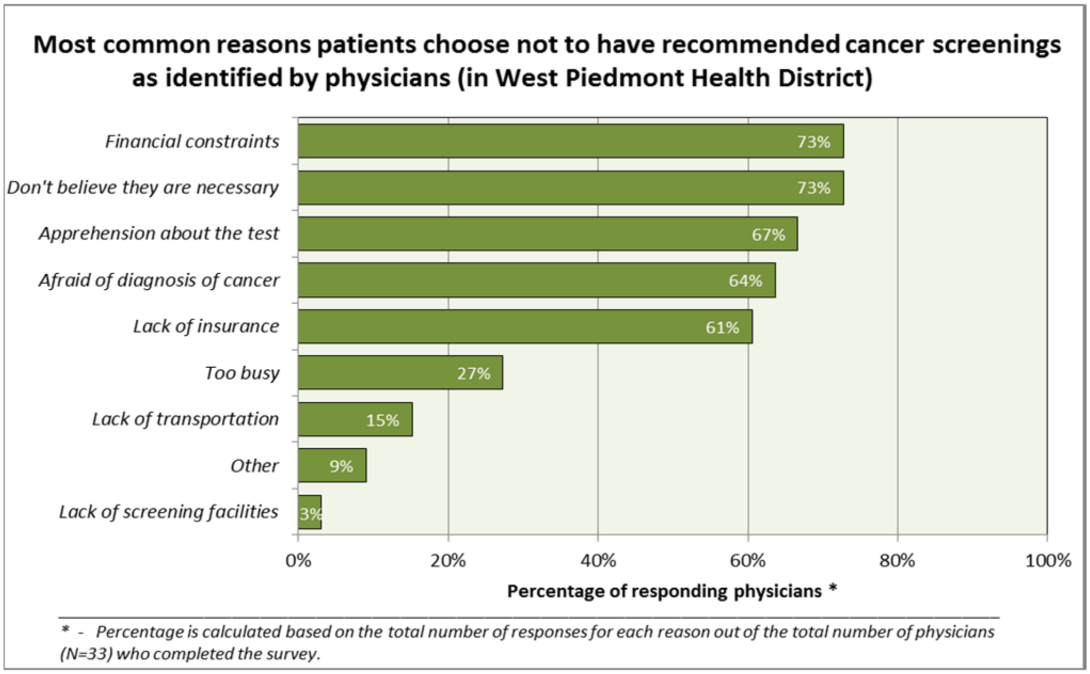


Figure 14: Physician Identified Reasons for Patient Non-Compliance with Recommended Screenings in the West Piedmont Health District

Oncologist Referrals and Preferred Communication

When asked where they refer their patients diagnosed with cancer, the vast majority of physicians expressed a preference to refer their patients to surgical oncologists and medical oncologists within the health district (82% & 88% respectively). Furthermore, communication coming from treating oncologists that were considered most useful by primary care physicians were follow-up care guidelines; initial treatment plans and pathology reports **(Figure 15)**. The majority of physicians indicated that they were usually satisfied with the communication with oncologists treating their patients, with 61% indicating that they were almost always satisfied. Only 14% were somewhat or rarely satisfied.

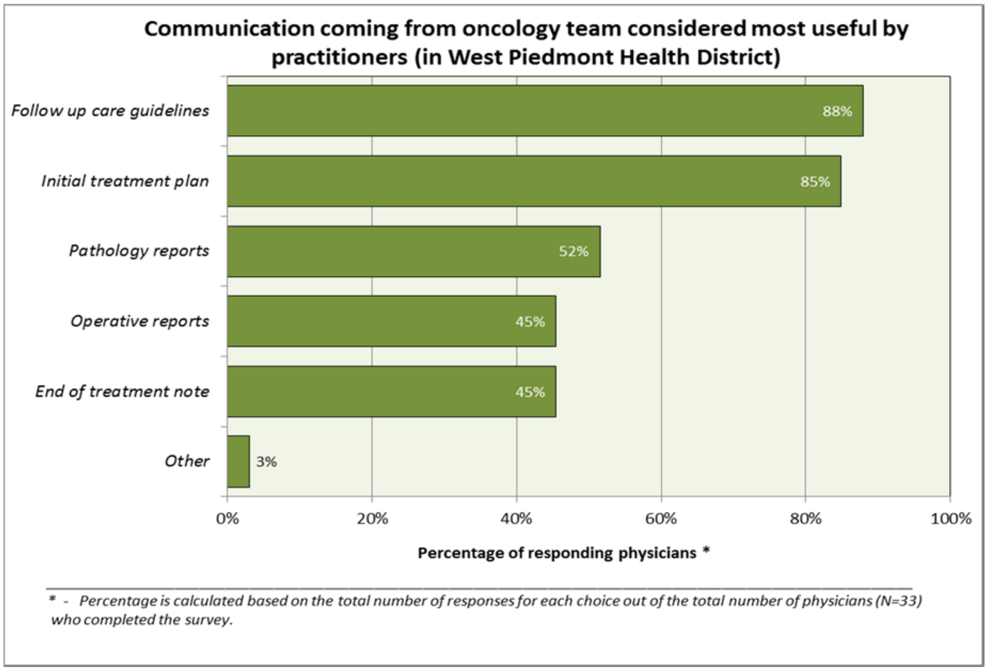
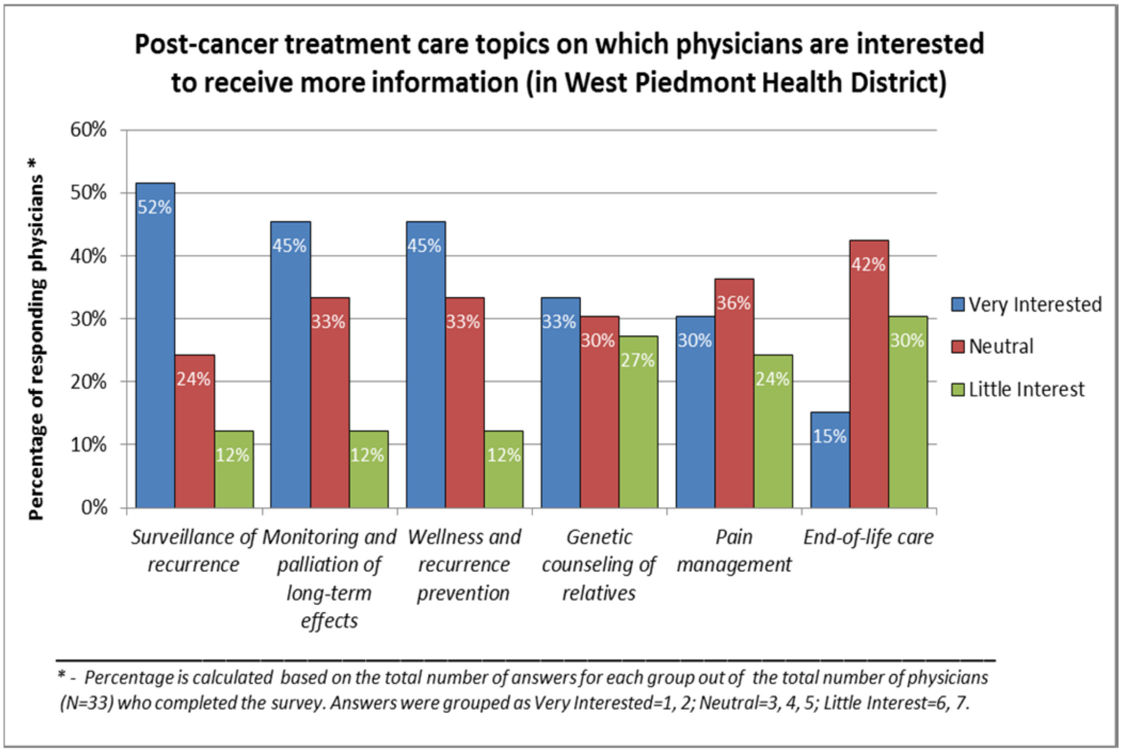


Figure 15: Usefulness of Communications from Treating Oncologists in the West Piedmont Health District

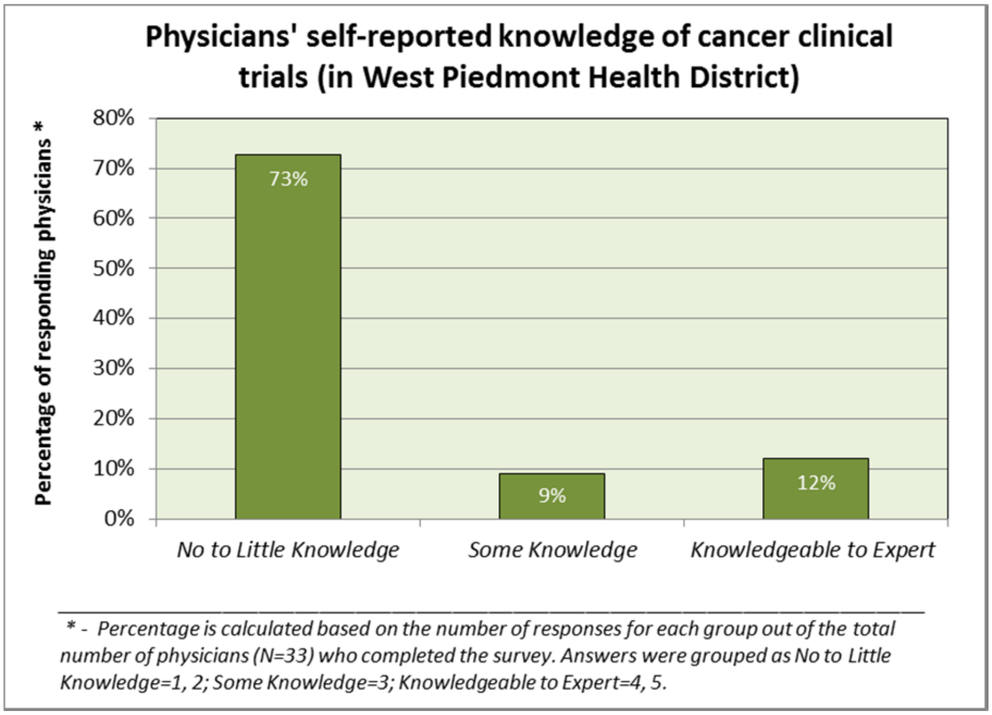
Post-cancer Treatment

Physicians were asked about their level of comfort providing various types of treatment to cancer patients within their practice. The majority (82%) was comfortable giving non-oncology care during active cancer treatment, while only one-third were comfortable providing joint management of oncology care during active cancer treatment. Importantly, less than half were comfortable providing long-term oncology follow-up care. This is consistent with their response to post-cancer treatment care topics of interest. About half of respondents indicated that they were very interested in information on cancer recurrence surveillance, monitoring and palliation of long-term effects of cancer treatment, and post-cancer wellness and recurrence prevention **(Figure 16)**. When asked about their knowledge of cancer clinical trials, the majority of responding physicians indicated little to no knowledge of cancer clinical trials. They desire more information on clinical trials, from education to participation **(Figure 17).**



* - Percentage is calculated based on the total number of answers for each group out of the total number of physicians (N=33) who completed the survey. Answers were grouped as Very Interested=1, 2; Neutral=3, 4, 5; Little Interest=6, 7.

Figure 16: Physician Interest in Post-Cancer Treatment Topics in the West Piedmont Health District



* - Percentage is calculated based on the number of responses for each group out of the total number of physicians (N=33) who completed the survey. Answers were grouped as No to Little Knowledge=1, 2; Some Knowledge=3; Knowledgeable to Expert=4, 5.

Figure 17: Physicians' Self-Reported Knowledge of Cancer Clinical Trials in the West Piedmont Health District

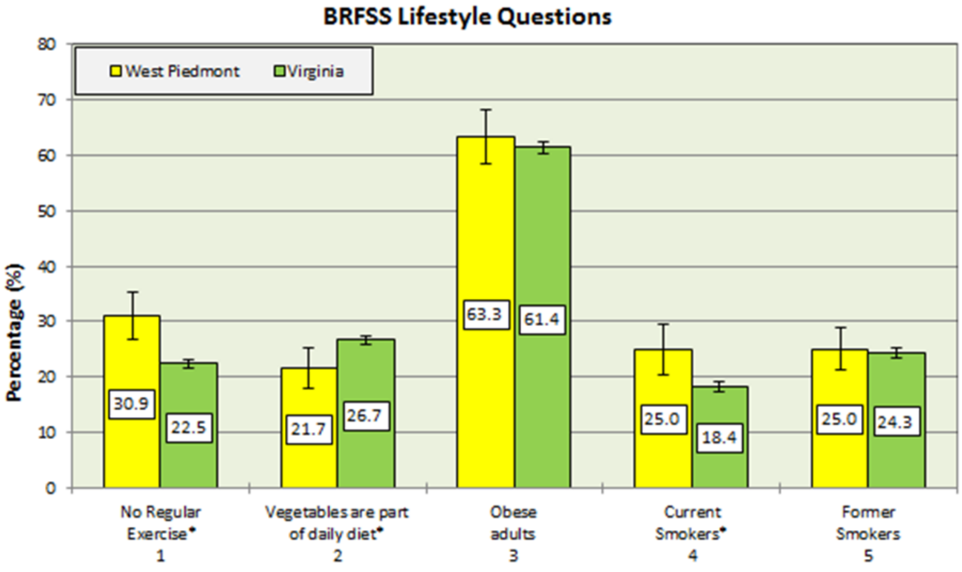
Community Population Needs

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

Behavioral Risk Factor Surveillance Survey

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

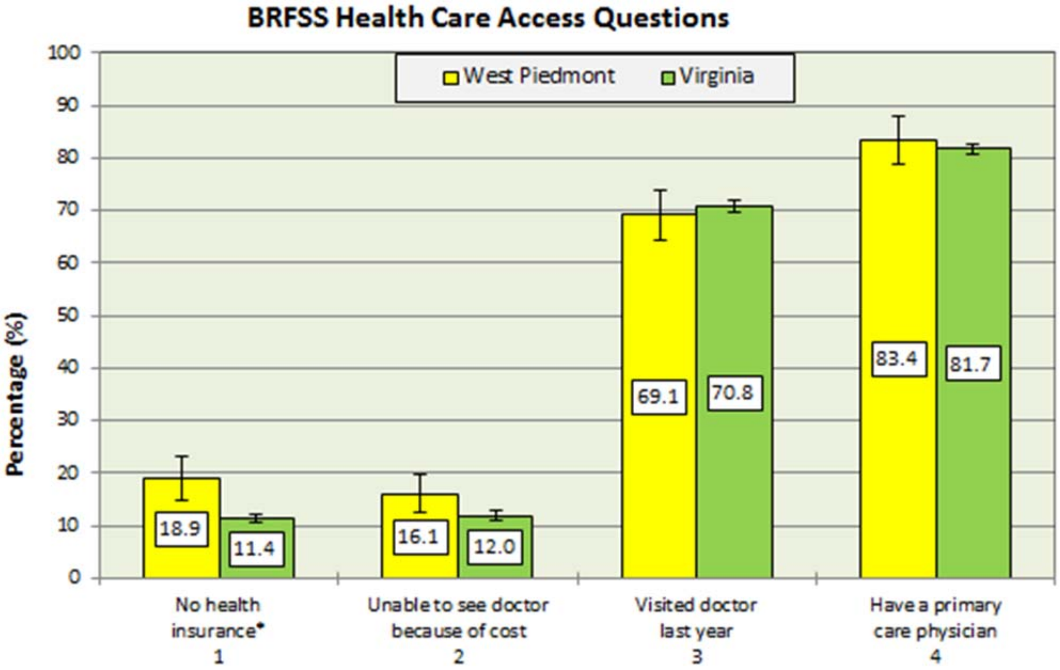
According to the BRFSS, for adults eighteen and older the West Piedmont Health District, when compared to Virginia, shows a higher incidence of sedentary behavior and smoking, and has a relatively high incidence of obesity **(Figure 18)**. All three factors are associated with a higher cancer risk. Thirty percent of the population reported no physical exercise in the past 30 days and only 22% included five or more fruits and vegetables in their daily diet. Greater than half (63%) of the residents in the district are obese.



** - 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.*

Figure 18: BRFSS Lifestyle Questions for the West Piedmont Health District

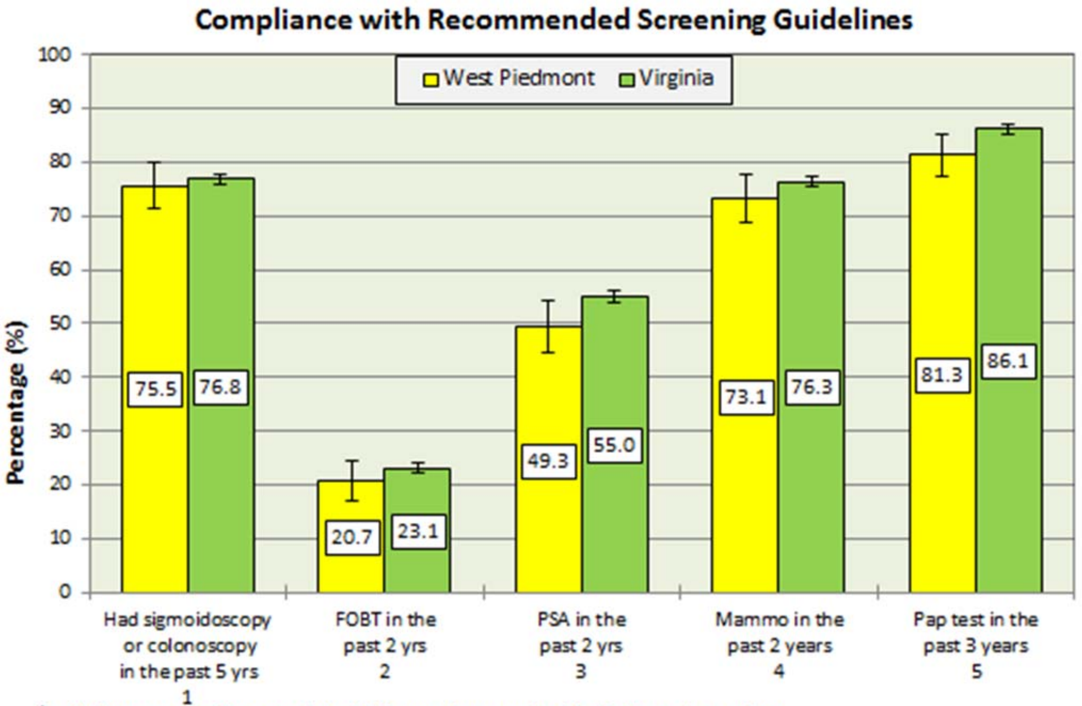
Access to healthcare for residents of the West Piedmont Health District is similar to that for those in other parts of the Commonwealth. The majority of residents have a primary physician and have visited their doctor in the past year **(Figure 19)**.



** - 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;*

Figure 19: BRFSS Healthcare Access Questions for the West Piedmont Health District

Cancer screening rates in the West Piedmont Health District are slightly lower than the Virginia state screening rates. Despite the PCPs feeling that a lower percentage of clients were compliant with recommendations for colorectal cancer screening, 76% of residents indicated that they have had the screening. Seventy-three percent of women indicated they had received a mammogram **(Figure 20)**.



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

Figure 20: BRFSS Compliance with Recommended Screening Guidelines in the West Piedmont Health District

Focus Group Information

Focus group participants were selected from the pool of volunteers who responded to mass email list-serves, flyers, and personal presentations. In addition, ads were placed in area newspapers and on select radio stations. The demographics of the community were used as a guide for final selection of the participants. While the community is almost equal male:female, the final ratio of male to female for the focus group was 1:3. This occurred despite targeting of men for participation. Age, education, and economic distribution were better matched. Residential representation was also considered. The last criterion used for selection was personal experience with cancer. The general population focus groups consisted of people who had little or no experience with cancer. The survivor focus groups consisted of people who either had a diagnosis of cancer or were the primary caregiver of a cancer patient. Venues for the meetings were chosen for the convenience of the participants, considering location, parking convenience, and time schedules. Focus groups were held in each county to access overall information from the entire health district **(Figure 21)**.

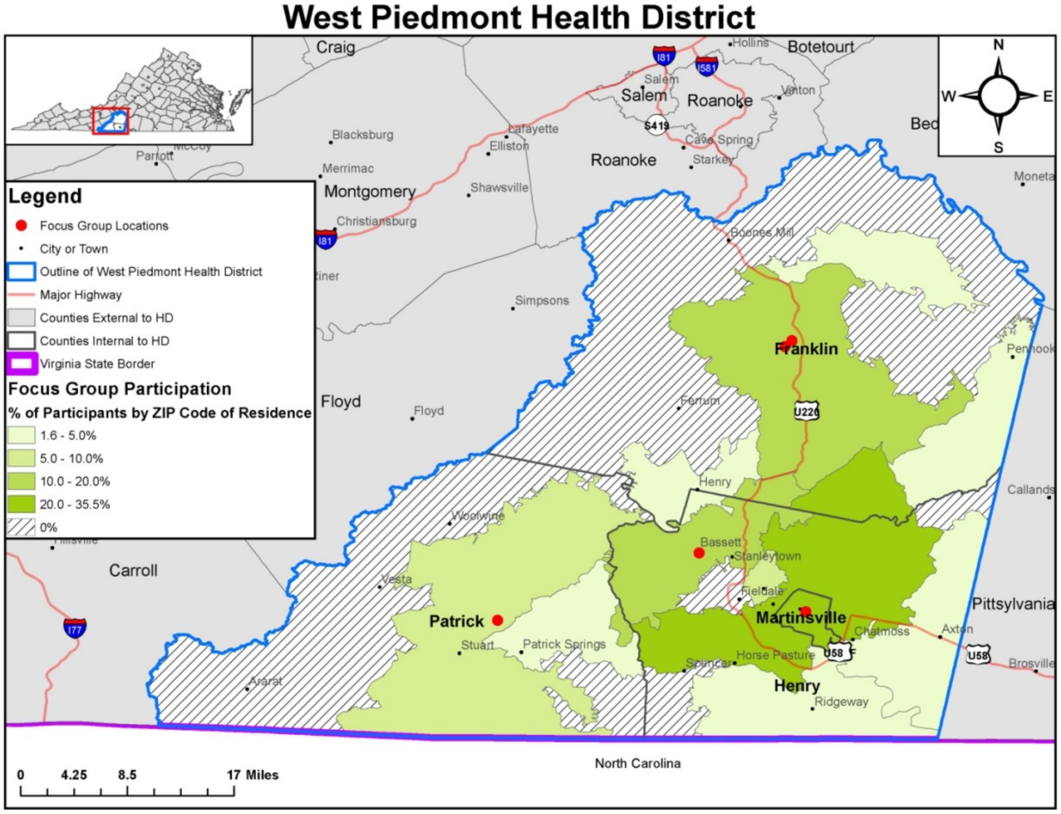


Figure 21: Focus Groups Participation in West Piedmont Health District

General Population Group Synopsis:

Four focus groups with the general population were held in four areas distributed throughout the health district. There was a total of 29 participants, with an average group attendance of seven. Participants were able to identify prevailing health problems in their communities, including arthritis, fibromyalgia, and the diseases that have the highest impact on mortality: heart disease, obesity, drug abuse, COPD, and cancer. Mental illness and prescription drug use were also identified as concerns. Most focus group participants were aware of healthy lifestyle habits, including eating a healthy diet, maintaining an appropriate weight, and avoiding smoking.

However, they identified barriers for residents to follow this prescription due to a strong tobacco heritage within the communities and also lifestyle choices consisting of unhealthy fast food options and lack of nutrition education. Many of the participants felt that weight certainly translated to health and identified its importance in impacting the community healthcare concerns.

The prevailing themes from the general population focus groups included:

- Poor health education and financial barriers prevent residents from eating a healthy diet of fruits and vegetables.
- Many residents commute to work outside of their community, which limits time for healthy cooking at home and also limits exercise time.

- Although overall access to exercise was positive, the lack of motivation is a tremendous barrier for residents.

Many participants were interested in healthy lifestyle choices and desire more education; however, finding an effective communication tool to educate the public is challenging. Also, participants were very interested in group activities and resources to promote a culture of buddy systems that will promote health and support. Accountability was among the forefront of interest of the general population in hopes of increasing healthy lifestyle changes that promote a healthy community. Increasing education and decreasing chronic illness is a focus for many; however, significant barriers, including poverty, lack of education, and lack of understanding of the impacts of unhealthy lifestyles, are creating a “sick” community.

Many participants were aware of the impacts of cancer within the community but were unsure of the causative factors. Almost all participants agreed that the internet and confusing statistics made it difficult to understand the magnitude of the impact of cancer. Other concerns were the conflicting facts of “good” foods and now those previously labeled as good are no longer healthy. Controversy over what is healthy has caused significant barriers for those who already have a limited educated knowledge base that is now more limited due to conflicts. Most information shared among participants regarding cancer were when family, friends, loved ones, or someone they knew distantly was diagnosed. This creates a limited amount of information that is based upon the current recent diagnosis. The second chain of information is the internet, which seems to overwhelm and confuse constituents. All agree that the media has a significant impact on the overall perception of cancer, its impacts, and healthy lifestyle choices, including diet and nutrition. Although everyone agreed there is a correlation between diet and cancer, all agreed they were uncertain and undereducated regarding the proper foods and nutrients to fight off cancer.

Exercise was discussed and certainly offered opportunities for communities to engage residents. Although there was little motivation from most participants, there was a general interest in programs, activities, and increased educational sessions on health and nutrition. Almost all identified that it is important and that it was necessary. They also recognized the need to increase their exercise regimen to not only include daily activities. Financial barriers were recognized slightly, but overall residents have access to walk and the local YMCA and other community resources are available.

Weight within the community is an overall concern and was overwhelmingly focused on the younger population. It was unanimous that education must start with the younger population regarding exercise, nutrition, and healthy lifestyle choices. Although all participants discussed weight, and their overall perception of weight was individualized and related to how one feels, BMI was not favored by most participants and felt it was too stringent and mostly unachievable.

Smoking within the health district is a controversy that manifests as a struggle between the heritage and lifestyle of many who raise tobacco and those who are unrelated or unconnected to the tobacco heritage.

Although there is a rich tobacco heritage throughout the West Piedmont health district, smoke-free campuses are becoming more prevalent and smoking cessation is a focus for all communities. There is desire for more smoking cessation and in all communities in this health district. Although many areas are impoverished throughout the health district, smoking is still an issue that is affecting the health and wellness of constituents due to primary and secondary smoking. Employers are basing insurance premiums on smoking cessation and other incentives are creating more focus on smoking cessation and the negative effects of smoking.

Cancer screening was perceived as positive and important throughout each focus group. Although most agreed that getting screened for cancer is important, there continues to be significant barriers to actually getting screened. The primary barrier was the perception of financial restraints. Many participants commented that screening tests are available to those “whom have insurance” or “whom already have a primary care provider that is accepting their insurance.” The second major barrier to cancer screening was fear. Most of the participants agreed that stress caused by fear of a positive diagnosis created sufficient mental distress to avoid being screened as long as possible, regardless of their insurance status. With the combination of financial restraints and fear, screening tests are viewed with an “I will get to it when I can” approach, potentially increasing the lag in time to screening compliance.

Each focus group showed a tremendous opportunity to increase awareness and education regarding cancer research, clinical trials, focus groups, and clinical studies. There were limited numbers of participants who were aware of research in any detail. Of course, many hear of “research” but this is a generalized term and most are unaware of the details of what research entails. Focus groups were new to many of the participants; however, after participating they were very happy they did. Potentially, educating the public on the benefits of clinical trials, clinical studies, research, and focus groups could increase participation and support for cancer patients when offered these services. Increasing the education of the general public could assist with navigating more cancer patients to the appropriate resources.

Cancer Survivor Group Synopsis

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

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

Four focus groups with cancer survivors were held in four areas distributed throughout the health district. There were a total of 31 participants, with an average group attendance of seven. A recurring theme with cancer survivors was the financial impact of treatment. Participants felt that patients from higher economic brackets were more apt to go to bigger cancer centers located outside of the health district, whereas those with limited resources were treated at the facility closest to them. Transportation barriers also deterred patients from seeking treatment outside of the health district either due to financial restrictions or lack of support for transportation. The type and stage of cancer also dictated where the patient decided to be treated, with the more severe or rarer cancers being treated elsewhere.

West Piedmont Health District cancer survivors indicated they had difficulty understanding information regarding their prognosis and treatment options after receiving a cancer diagnosis, and when information was provided it was too much to comprehend. Sources used to gather information on their diagnosis came from: the internet, conversations with other cancer patients, and patient navigation services. Cancer diagnoses were rarely made within the health district; rather, they often occurred further away in Virginia and in states as far away as New Jersey and Vermont. Health professionals and social workers were helpful in getting the diagnosis, although there were difficulties with finances and in coordinating services between doctors and labs. Transportation, appointment availability, need for patient navigators, and a lack of availability of local physicians were indicated as barriers to receiving cancer screening and treatment services. Further, they identified a lack of physicians and treatment availability and/or alternatives as the largest medical gaps within the community.

In general, there was no written plan for follow-up care and communication between their oncologist and other physicians varied greatly. Information about nutrition, mental health, and stress management were most often referenced as needed to stay healthy; however, patients were rarely referred to formal support services. Cancer research was thought of as clinical trials, advancing knowledge, and providing cures/preventions, as well as a money making venture. There were some trial participants, although most focus group participants were not offered trials as an option. Reasons provided by trial participants for their participation were to advance knowledge and receive better care, while those who declined did not want to feel like “guinea pigs.” All focus groups agreed that cancer research is very important and should be offered in their communities.

Barriers to accessing cancer services consistently mentioned in the focus groups included financial and insurance barriers as well as difficulties in prescription and disability acquisitions. Community service gaps identified the lack of support groups, local treatment options, easily accessible health information resources, transportation and financial assistance, and patient navigators as barriers. Additional recommendations were for hospitals to hear and act on feedback from residents, utilizing nurse practitioners as accepted caregivers, and hospice as a resource beyond just palliative care.

SUMMARY OF PRIORITY NEEDS

The majority of the West Piedmont Health District is rural and medically underserved. Compared to the rest of the Virginia, this health district has a lower median household income and a higher unemployment rate. Although cancer incidence is similar to that of the state, cancer outcomes, i.e. mortality, are higher for most cancer types. Based on the qualitative and quantitative information gathered for this project, the following are recommendations for action:

Patient/General Public Education and Support

- Partner with local coalitions and other resources in each county to increase general health, cancer prevention, and nutrition education.
- Provide additional health and nutrition education to children at school.
- Educate the public about the availability of hospice programs in the community.
- Provide additional financial support and innovative programs for patients who cannot afford cancer screening or treatment services.
- Develop locally based and sustained education programs for the public on the importance of cancer screening and the benefits of early cancer detection.

Physician Education

- Provide physicians with up-to-date cancer incidence and mortality statistics for the health district.
- Targeted continuing medical education for community physicians on updated cancer screening guidelines, long-term follow-up care of cancer patients, palliation, and wellness and recurrence prevention.
- Provide physicians with information regarding the availability of clinical trials.
- Program development to increase awareness of available hospice services in the district, accurate information about the services provided, and appropriate time to utilize their services.

Medically Underserved Area

- Expand the use of patient navigation services throughout the health district and for a range of cancer types to help streamline cancer treatment and follow-up care.
- Develop strategies to reduce the distance residence must travel to receive cancer screening and treatment and to increase awareness of available transportation services within the health district.
- Develop innovative programs to recruit and retain both primary care and oncology specialist physicians to the health district.

APPENDICES

Appendix A:

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

Appendix B:

Primary Care Physician Questionnaire

Appendix C:

Focus Group Facilitator Guides

Appendix D:

Cancer Healthcare Resources within the Health District

Appendix E:

Community Cancer Resources within the Health District

APPENDIX A

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

Healthcare Facility Questionnaire

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

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

FACILITY

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

1. ***First, do you have a cancer registry at your facility?*** Yes_____ No____
   - If YES, ***What is the name of the registrar?*** ____
   - If NO, ***Is the registry maintained by another medical center/facility?*** Yes_____ No____
     - If YES,
       - ***What is the name of that facility?*** ____
       - ***What is the name of registrar at that facility?*** _______________________________

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

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

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

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

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

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

____
____
____

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

Chemotherapy	Inpatient:	Yes_____	No____
	Outpatient:	Yes_____	No____

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

  ____

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

Radiation therapy Yes_____ No____

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

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

   Yes_____ No____ Will try ____

SCREENING/DIAGNOSTIC SERVICES

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

1. ***For Breast Cancer do you offer:***

• Screening mammography?			
a) Film	Yes_____	No____	Unknown____
b) Digital	Yes_____	No____	Unknown____
• Diagnostic mammography?	Yes_____	No____	Unknown____
• Breast ultrasound?	Yes_____	No____	Unknown____
• Breast MRI?	Yes_____	No____	Unknown____
• Breast Biopsy (radiology guided)?	Yes_____	No____	Unknown____

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

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

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

IF RESPONDENT ANSWERED “NO” TO COLPOSCOPY:

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

5. ***For Colorectal Cancer do you offer:*** (Mark all that apply)

Sigmoidoscopy?	Yes_____	No____	Unknown____
Colonoscopy (invasive)?	Yes_____	No____	Unknown____
CT Colonography - Virtual Colonoscopy (non-invasive)?	Yes_____	No____	Unknown____

SURGICAL SERVICES

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

- Breast segmental/complete mastectomy? Yes_____ No____ Unknown____

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

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

COUNSELING SERVICES

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

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

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

    Which nutritional services does he/she offer?

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

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

    If YES, which genetic tests:
    ___BRCA1/2
    ___Others ____

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

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

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

    If Yes, which cancers do you screen?
    ___ Colorectal only
    ___ Endometrial only
    ___ Both Colorectal and Endometrial

    What laboratory method do you use for screening?
    ___ immunohistochemistry staining for Lynch syndrome proteins (MLH1, MSH2, PMS2, and MSH6)
    ___ microsatellite instability (MSI) testing

FINANCIAL/INSURANCE

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

YES_____

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

Medicare_____

Medicaid_____

Other (please specify): ______________________________

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

1.

2.

3.

4.

5.

13. Do you accept uninsured patients? Yes_____ No____

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

____

____

CLINICAL TRIALS

The next few questions are about research related issues.

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

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

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

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

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

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

____

____

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

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

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

HOSPICE / PALLIATIVE CARE SERVICES

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

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

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

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

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

SUPPORT / EDUCATIONAL PROGRAMS

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

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

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

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

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

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

breast cancer_____ prostate cancer_____ lung cancer_____ brain cancer_____
cervical cancer_____ testicular cancer_____ other_____

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

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

____

____

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

Cancer Resources Questionnaire

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

Organization's name: _______________________________________

Address: ____

Ph: _____________________________ Fax: ______________________

Website?: ____

CONTACT person: ____

Best time to contact? ____

Date of meeting/interview:_______________________________________

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

2. Which category best describes your organization:
   - ☐ National non-profit
   - ☐ Local non-profit
   - ☐ For profit service organization
   - ☐ Federal governmental organization
   - ☐ State/municipal government organization
   - ☐ Other ____

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

☐ Competitive grants
☐ Federal funds
☐ Service fees charges
☐ Donations
☐ Other ____

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

☐ Cancer patients
☐ Cancer survivors
☐ Cancer caregivers/family members
☐ Other: ____

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

☐ Must be uninsured/underinsured
☐ Financial qualification
☐ No qualification criteria
☐ Other ____

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

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

____

7. How do you advertise your organization and services?

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

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

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

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

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

____

____

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

____

____

____

____

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

____

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

____

____

13. Would you be interested in collaboration?

____

Key Leader Interview Questions

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

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

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

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

APPENDIX B

Primary Care Physician Questionnaire

Cancer Needs Assessment VIP Physician Survey

Please complete the survey below. Thank you!

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

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

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

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
   - ☐ Other *__________________________________* Please specify
   - ☐ Lung
   - ☐ Cervical
   - ☐ Melanoma

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

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

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

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

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

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

5. What do you feel are the most common reasons your patients choose not to have recommended cancer screenings (check all that apply)?
   - ☐ Financial constraints
   - ☐ Apprehension about the test
   - ☐ Too busy
   - ☐ Lack of Screening facilities
   - ☐ Afraid of being diagnosed with cancer
   - ☐ Lack of insurance
   - ☐ Lack of transportation
   - ☐ Don't believe they are necessary
   - ☐ 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
   - ☐ Operative reports
   - ☐ End of treatment note
   - ☐ Follow up care guidelines
   - ☐ Pathology report
   - ☐ Other _____________________________(please specify)

9. What percentage of the time do you receive satisfactory communication from the oncologist treating your patient?
   - ☐ 0-25%
   - ☐ 26-50%
   - ☐ 51-75%
   - ☐ 76-100%

10. What kind of treatment are you comfortable providing after your patient has received a cancer diagnosis (Check all that apply)?
    - ☐ Non-oncology care during the time the patient is being treated for cancer.
    - ☐ Joint management of oncology care with the oncology team during the time the patient is being treated for cancer.
    - ☐ Long-term oncology follow-up care.
    - ☐ Other ____(please specify)

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

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

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

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

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

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

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

1☐ 2☐ 3☐ 4 ☐ 5 ☐

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

1☐ 2☐ 3 ☐ 4 ☐ 5☐

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

1☐ 2 ☐ 3 ☐ 4☐ 5 ☐

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

1☐ 2☐ 3☐ 4☐ 5☐

APPENDIX C

Focus Group Facilitator Guides

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

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

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

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

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

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

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

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

Does anyone have any questions? [Answer any questions]

WARM-UP [8 minutes]

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

Turn off tape recorder for this section of the discussion

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

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

CANCER IN COMMUNITY: GENERAL DISCUSSION [15 minutes]

So let us get started.

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

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

Review list on flip chart.

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

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

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

LIFESTYLE FACTORS: [30 minutes total]

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

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

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

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

Review the list on flip chart

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

Nutrition:

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

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

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

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

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

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

Review points made during nutrition discussion before moving on.

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

Exercise

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

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

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

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

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

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

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

Summarize exercise comments before moving on to weight control.

Weight Control

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

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

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

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

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

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

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

Summarize weight comments before moving on to weight control.

BREAK

Continue LIFESTYLE FACTORS: [15 minutes total]

Welcome back! We are going to keep working on some topics about community health starting with tobacco. If everyone is settled we can get started.

TOBACCO

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

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

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

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

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

ENVIRONMENTAL FACTORS

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

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

DISCUSSION OF CANCER SCREENING [15 minutes TOTAL]

Now I would like to talk about your thoughts on tests that can check if a person has cancer.

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

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

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

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

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

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

CANCER RESEARCH SECTION [15 MINUTES]

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

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

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

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

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

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

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

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

36. Now, if you knew someone who had cancer and they were asked to participate in cancer research that was testing a new medication or procedure, do you think you would advise them to be in the study? Please state why or why not.
37. Would you feel differently about being in cancer research, if the research was about a problem specific to your community? (If people identified a problem in their community related to cancer, and developed a research study to find out more about that problem)

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

OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]

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

Do a final summary of the information.

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

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

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

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

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

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

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

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

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

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

Does anyone have any questions? [Answer any questions]

WARM-UP [10 minutes]

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

Tape recorder turned OFF here to maintain confidentiality.]

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

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

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

Experiences getting cancer information (10 minutes)

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

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

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

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

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

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

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

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

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

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

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

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

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

    a. Who? Was it helpful?

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

BREAK

Post-Treatment (20 Minutes)

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

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

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

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

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

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

LOCAL RESOURCES AND NEEDS:

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

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

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

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

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

CANCER RESEARCH SECTION [15 MINUTES]

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

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

National cancer Institute defines clinical research as:

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

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

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

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

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

OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]

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

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

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

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

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

APPENDIX D

Cancer Healthcare Resources within the Health District

Results of Facilities Questionnaire for West Piedmont Health District

Available Facilities:	Pioneer Community Hospital; Memorial Hospital of Martinsville and Henry County; Carilion Franklin Memorial Hospital	
# of Oncologists:	3+	Breakout: 2 medical oncologists, 1 radiation oncologist, 1 part-time medical oncologist

Available in Health District

Services			**# of facilities where available**
Cancer Treatment	**Services Provided**	Chemo Inpatient	1
		Chemo Outpatient	1
		Radiation	1
Cancer Screening	**Breast Cancer Screening and Diagnostic Procedures**	Screening Mammography (film / digital)	1 / 2
		Diagnostic Mammography	1
		Breast Ultrasound	1
		Breast Biopsy	2
		Breast MRI	1
	Colorectal Cancer	Sigmoidoscopy/Colonoscopy	3
Surgeries	**Cancer Related Surgeries**	Breast Segmental/Complete Mastectomy	1
		Breast Reconstruction	1
		Gynecological Hysterectomy/Oophorectomy	2
		GI - Upper/Lower Tract	2
		GI - Liver	1
		GI - Pancreas	1
		Lung	1
		Ears, Nose, Throat	1
Counseling	**Genetic Tests**	Offer genetic tests for cancer risk (BRCA1 and BRCA2)	1
		Offer genetic tests for cancer risk (Others)	1
	Genetic Counseling	Genetic counseling (referred out for counseling)	1
Other Services	**Clinical Trials**	Offer clinical trials	1
	Hospice Service	Facility Supported: Inpatient / Outpatient Hospice	1 / 2
		Private Organization: Inpatient / Outpatient Hospice	1 / 2
	Palliative Care	Palliative Care Program	1
		Medical professionals in the team	MD/DO Board Certified palliative care, Chaplaincy
		Inpatient beds	1
	Cancer Patient Navigation	Patient Navigator	1
		Navigation for the following cancers:	Breast
		Credentials of patient navigator	Nurse
Cancer Support Groups	**Existing Support Groups**	Availability of cancer support groups	2
Specialists	**Oncology**	Currently recruiting oncologists	2
		Which specializations	Medical oncology

Not Available in Health District

Cancer Screening	**Colorectal Cancer**	CT Colonography
	Lynch Syndrome	Screening for Colorectal and Endometrial cancers
		Immunohistochemistry staining test
		Microsatellite instability testing
Surgeries	**Cancer Related Surgeries**	Prostatectomy
		Brain
		Sentinel Nodes Sampling
Counseling	**Cancer Dietary Needs**	Registered dietician to provide nutritional services specific to cancer patients
	Genetic Counseling	Genetic counseling (at the facility)
Other Services	**Palliative Care**	Consult service
		Outpatient clinic

APPENDIX E

Community Cancer Resources within the Health District

WEST PIEDMONT HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Gentle Shepherd Hospice	Bernard Healthcare Center	Grace Network	Second to Nature
Organization Information		Number of Organizations				
Organization category	National non-profit	2	-	-	-	-
	Local non-profit	8	-	X	X	-
	For profit service organization	3	X	-	-	X
	Federal governmental organization	0	-	-	-	-
	State/municipal government organization	0	-	-	-	-
	Other	0	-	-	-	-
Major sources of funds for organization	Competitive grants	5	-	X	X	-
	Federal funds	3	X	-	-	-
	Service fees charges	2	-	-	-	X
	Donations	7	-	-	X	-
	Other	3	-	-	X	-
Cancer Resources						
Primary service population of the organization	Cancer patients	10	X	X	-	X
	Cancer survivors	5	-	X	-	X
	Cancer caregiver/family members	4	-	X	-	X
	Other	3	-	-	X	-
Qualification criteria to access services	Must be uninsured/underinsured	2	-	X	-	-
	Financial qualification	0	-	-	-	-
	No qualification criteria	8	X	-	X	X
	Other	4	-	-	-	X
Type of cancer related services that are provided	Written information on cancer	6	-	X	-	X
	Information on cancer care/support resources	10	X	X	X	X
	Management of cancer support groups	5	-	-	-	X
	Financial support for cancer control/care	7	X	-	X	X
	Funding of projects related to cancer	6	-	-	-	-
	Psychosocial support	7	X	-	-	-
	Navigational services	7	X	-	-	-
	Transportation	6	X	-	-	-
	Other	2	-	-	-	-
Number of cancer patients seen annually		(see organizations' answers)	greater than 150	26 - 50	11-25	greater than 150
Other Information About Organization						
Advertising for the organization	Local media	11	X	X	X	X
	Organization website	9	X	-	-	X
	Online	11	X	X	-	X
	Pamphlets describing services	9	X	X	-	X
	Word of mouth	11	X	X	X	X
	Other	3	-	-	-	X
Organizational needs	Financial support	10	-	X	X	-
	Human resources (skilled employees, volunteers, etc.)	5	-	-	-	-
	Access to experts for consultation	3	-	X	-	-
	Physical space/facilities	6	-	-	X	-
	Collaborators	8	-	X	X	X
	Volunteers	10	X	X	X	-
	Other	0	-	-	-	-
Challenges		(see organizations' answers)	Medicare regulations and limiting patient needs.	Funding.	Funding and space restrictions. Currently have 90 volunteers who work on a regular basis.	None at this time. This is a new business that has just opened within the past month. Have a successful business in Greensboro that has been open for over 20 years.
Goals for the next 5 years		(see organizations' answers)		In the process of becoming a Rural Health Clinic.	Strategic Plans are in place. Need additional space for food pantry. Start educational programs for patrons. Implement a database and to create an endowment rather than be working year to year.	Serve those in need and to reach out to surrounding areas. Empower women in the area with education.
Partner organizations			Straight Street Rescue Mission	Carilion Franklin Memorial	Martinsville Health Coalition, United Way, 100 partner congregations, Non-profit network, and Chamber of Commerce Smart Beginnings	Wigs Unlimited, American Cancer Society, Ravenel Oncology, and Plastic Surgeons
Interested in collaboration			Yes	Yes	Yes	Yes! Would love any educational information.

WEST PIEDMONT HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Gentle Shepherd Hospice	Bernard Healthcare Center	Grace Network	Second to Nature
Comments		(see organizations' answers)				

WEST PIEDMONT HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Mountain Valley Hospice	Martinsville YMCA	American Cancer Society	Susan G. Komen
Organization Information		**Number of Organizations**				
Organization category	National non-profit	2	-	-	X	X
	Local non-profit	8	X	X	-	X
	For profit service organization	3	-	-	-	-
	Federal governmental organization	0	-	-	-	-
	State/municipal government organization	0	-	-	-	-
	Other	0	-	-	-	-
Major sources of funds for organization	Competitive grants	5	X	X	-	-
	Federal funds	3	-	-	-	-
	Service fees charges	2	X	-	-	-
	Donations	7	-	X	X	X
	Other	3	-	X	-	-
Cancer Resources						
Primary service population of the organization	Cancer patients	10	X	-	X	X
	Cancer survivors	5	-	-	X	X
	Cancer caregiver/family members	4	-	-	X	-
	Other	3	-	X	X	-
Qualification criteria to access services	Must be uninsured/underinsured	2	-	-	-	-
	Financial qualification	0	-	-	-	-
	No qualification criteria	8	X	X	X	X
	Other	4	-	-	-	X
Type of cancer related services that are provided	Written information on cancer	6	-	-	X	X
	Information on cancer care/support resources	10	X	-	X	X
	Management of cancer support groups	5	-	-	X	X
	Financial support for cancer control/care	7	X	-	-	X
	Funding of projects related to cancer	6	X	-	X	X
	Psychosocial support	7	X	-	X	X
	Navigational services	7	X	-	X	X
	Transportation	6	X	-	X	X
	Other	2	-	X	-	-
Number of cancer patients seen annually		(see organizations' answers)	51 - 150	less than 10	greater than 150	greater than 150
Other Information About Organization						
Advertising for the organization	Local media	11	X	X	X	X
	Organization website	9	X	X	X	X
	Online	11	X	X	X	X
	Pamphlets describing services	9	X	X	X	X
	Word of mouth	11	X	X	-	X
	Other	3	-	X	-	-
Organizational needs	Financial support	10	X	X	X	X
	Human resources (skilled employees, volunteers, etc.)	5	-	X	X	X
	Access to experts for consultation	3	-	-	-	X
	Physical space/facilities	6	-	X	X	X
	Collaborators	8	-	-	X	X
	Volunteers	10	X	-	X	X
	Other	0	-	-	-	-
Challenges		(see organizations' answers)	Need volunteers.	Financial barriers. Limited to charge due to economic restraints. Concerns with universal healthcare and also an increase in minimum wage will affect salary budgets.	Getting the word out. Clear understanding of getting the information out.	Maintaining donations, volunteers, early detection and prevention, research for better treatment.
Goals for the next 5 years		(see organizations' answers)	Continue to provide quality care to patients. Working on veterans programs. Would love to have a hospice home in Virginia.	Grow capacity to serve more people inside and outside of the YMCA. Collaboration with the hospital in health and wellness programs.	Eliminate cancer. Saving 350 now and the goal is 1,000.	Strategic Plan to increase funding to provide more funding for survivors. Increase volunteer base. Community profile to increase impacts.
Partner organizations			Local Food Banks, Utilize as many community resources for patients	SPCA Stone Memorial, Christian Church, First Baptist Church, JCPenny, EDC, Virginia Museum of Natural History, and Harvest Foundation	Cancer Resource Center of Southern Virginia, Most of the hospitals, Second to Nature, Social Services, Health Department, Ravenel Oncology, and Breast Center Grace Network	Martinsville Health Coalition
Interested in collaboration			Yes. Anything that could increase care for patients.	Yes. Always interested.	Yes	Yes. Currently working with VCU on educational sessions.

WEST PIEDMONT HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		**Health District**	**Mountain Valley Hospice**	**Martinsville YMCA**	**American Cancer Society**	**Susan G. Komen**
Comments		**(see organizations' answers)**		Although the YMCA does not specifically deal with cancer patients directly, the YMCA is looking to expand services to focus on health and wellness which includes screening practices and prevention. The YMCA does not require payment for cancer patients if there is a need for financial support. The YMCA also has started a program called The Doctors Orders. This program is for a patient to go to the provider and if they need services at the YMCA, they can get a membership for 3 months for $30.00.		

WEST PIEDMONT HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Helping Hands in Franklin County	Memorial Hospital of Martinsville	Hospice of Franklin County	Caring Hearts Free Clinic
Organization Information		**Number of Organizations**				
Organization category	National non-profit	2	-	-	-	-
	Local non-profit	8	X	-	X	X
	For profit service organization	3	-	X	-	-
	Federal governmental organization	0	-	-	-	-
	State/municipal government organization	0	-	-	-	-
	Other	0	-	-	-	-
Major sources of funds for organization	Competitive grants	5	-	-	-	X
	Federal funds	3	-	X	X	-
	Service fees charges	2	-	-	-	-
	Donations	7	X	-	X	X
	Other	3	-	-	-	X
Cancer Resources						
Primary service population of the organization	Cancer patients	10	X	X	X	X
	Cancer survivors	5	-	-	-	X
	Cancer caregiver/family members	4	-	-	-	X
	Other	3	-	-	-	-
Qualification criteria to access services	Must be uninsured/underinsured	2	-	-	-	X
	Financial qualification	0	-	-	-	-
	No qualification criteria	8	-	-	X	-
	Other	4	X	X	-	-
Type of cancer related services that are provided	Written information on cancer	6	-	X	-	X
	Information on cancer care/support resources	10	-	X	X	X
	Management of cancer support groups	5	-	X	X	-
	Financial support for cancer control/care	7	-	-	X	X
	Funding of projects related to cancer	6	-	X	X	X
	Psychosocial support	7	-	X	X	X
	Navigational services	7	-	X	X	X
	Transportation	6	-	X	-	X
	Other	2	-	X	-	-
Number of cancer patients seen annually		(see organizations' answers)	11-25	26 - 50	51 - 150	11-25
Other Information About Organization						
Advertising for the organization	Local media	11	-	X	X	X
	Organization website	9	-	X	X	X
	Online	11	X	X	X	X
	Pamphlets describing services	9	-	X	X	-
	Word of mouth	11	X	X	X	X
	Other	3	-	-	-	X
Organizational needs	Financial support	10	X	X	X	X
	Human resources (skilled employees, volunteers, etc.)	5	-	X	-	X
	Access to experts for consultation	3	-	X	-	-
	Physical space/facilities	6	-	X	-	X
	Collaborators	8	X	X	-	X
	Volunteers	10	X	X	X	X
	Other	0	-	-	-	-
Challenges		(see organizations' answers)	Financial barriers, funding.	Community education of what hospice services include and to help educate the public on funding and the benefits of using hospice.	Education of the community.	Providers. Need volunteers to cover for the clinic. Referrals for cancer are difficult.
Goals for the next 5 years		(see organizations' answers)	Increase general exposure to general public to increase public awareness and donations.	Increase community awareness and patients served by hospice.	Increase census.	Secure more funding and to expand the dental services. Becoming a RHC soon.
Partner organizations			Salvation Army, and United Way	Assisted living facilities, Senior healthcare networking group, and Church organizations		
Interested in collaboration			Yes	Yes	Yes	Yes

WEST PIEDMONT HEALTH DISTRICT - CANCER RESOURCES SURVEY RESULTS		Health District	Helping Hands in Franklin County	Memorial Hospital of Martinsville	Hospice of Franklin County	Caring Hearts Free Clinic
Comments		**(see organizations' answers)**				Employees of the hospital and a local provider volunteer their time for patients to have a colonoscopy for $300.00 for those who are uninsured. The hospital only charges the minimum amount to cover the basic expenses and the hours are volunteered by the nursing staff and provider.