Saving Lives and Reducing Suffering and Death from Cancer in Virginia


Virginia Commonwealth University
Massey Cancer Center
And
Tobacco Indemnification and Community Revitalization Commission
Saving Lives and Reducing Suffering and Death from

Cancer in Virginia

Addressing Educational, Clinical and Advocacy Needs Related to Cancer in

Southside and Southwest Counties

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

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

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1 Statistics provided by the Virginia Cancer Registry (June, 2011), data from 2001to 2007
2 Statistics provided by the Virginia Department of Health (June, 2011), data from 2005– 2009
4 The Virginia Cancer Plan 2008– 2012, Cancer Plan Action Coalition (CPAC)
ACKNOWLEDGEMENTS

We would like to acknowledge members of the Advisory Committee that provided invaluable guidance during the performance of the cancer needs assessment. Particular thanks go to Jim Martin of the Virginia Cancer Registry who provided the cancer burden data used for this report, and was tireless in meeting our multiple requests. We would also like to acknowledge the tireless work of Robert Houlihan, Sarah Capps, Kate Webster, and Shirley Martar for the management of the budget for the project. Finally, special thanks go to the Virginia Tobacco Indemnification and Revitalization Commission for seeing the value in addressing the disparate cancer burden in the Southside and Southwest counties through this project.

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

The project described was supported by a grant from the Tobacco Indemnification and Revitalization Commission (TICRC #2083).

The project was also supported through resources of the CTSA award No. UL1TR000058 from the National Center for Advancing Translational Sciences. Its contents are solely the responsibility of the authors and do not necessarily represent official views of the National Center for Advancing Translational Sciences or the National Institutes of Health.
ADVISORY COMMITTEE

PROJECT MANAGER AND LOCAL NEEDS ASSESSMENT COORDINATORS

Carlin Rafie, PhD, RD
Project Manager
Clinical Research Affiliations Coordinator
VCU Massey Cancer Center

Amy Smith, PhD, CHES
Community Health Education Coordinator (Mount Rogers Health District)
VCU Massey Cancer Center

Karen Gregory, MPH
Community Health Education Coordinator (Crater Health District)
VCU Massey Cancer Center

Justine Young, RN, BSN, MBA
Community Health Education Coordinator (Piedmont Health District)
VCU Massey Cancer Center

Susan Mathena, BSMT
Community Health Education Coordinator (Pittsylvania-Danville Health District)
VCU Massey Cancer Center
Office located at IALR 150 Slayton Ave, Danville VA 434-766-6649, jsmathena@vcu.edu

ADVISORY COMMITTEE MEMBERS

Margaret Bassett, MPH, MS, RN
Board of Directors
Virginia Rural Health Association
Associate Professor, Radford University School of Nursing

Vernal Branch
Advocacy and Constituency Coordinator
Virginia Breast Cancer Foundation

Teri Ann Brown
Program Specialist
Virginia Foundation for Healthy Youth (formerly) Virginia Tobacco Settlement Foundation

Karen Cameron, FACHE
Executive Director/CEO
Central Virginia Health Planning Agency

Brian Cassel, Ph.D.
Senior analyst, Oncology Business Unit
Assistant Professor of Quality Health Care, Department of Internal Medicine
VCU-Massey Cancer Center

David Cattell-Gordan, M.Div., MSW
Program Director
Office of Telemedicine, University of Virginia

Faye Flemming, RN, BSN, OCN
Oncology Specialist / Service Line Director
Southside Regional Medical Center Cancer Center

Mary Helen Hackney, MD
Associate Director of Clinical services
VCU-Massey Cancer Center

Mary Ann Hager, RN
Associate Director of Clinical Services
VCU-Massey Cancer Center

Pem Hall
Director of Community Health Programs,
Susan G. Komen for the Cure

Alton Hart, MD, MPH, CTTS
Associate Scientific Director, Center on Health Disparities,
VCU Associate Professor, Department of Internal Medicine, VCU

Wanda S. Hunt
Clinical Research Affiliation Coordinator Assistant
VCU-Massey Cancer Center

Resa M Jones, MPH, Ph.D.
Associate Professor
Dept of Epidemiology and Community Health
VCU-Massey Cancer Center

Jim Martin, Ph.D.
Director
Virginia Cancer Registry, Virginia Dept of Health

Kathy Meade-Goulit
Vice Chair
Virginia Prostate Cancer Coalition

Maghboeba Mosavel, Ph.D.
Associate Professor  
Department of Social and Behavioral Health  
VCU

Nicole Pugar  
Director of Government Relations  
VCU

Kathy Rocco, RD, MPH  
Program Director  
Every Woman’s Life  
Virginia Dept of Health

Christi Sheffield  
VA-Comprehensive Cancer Control Program Manager  
Centers for Disease Control  
UVA Cancer Center

Lisa M. Shickle, MS  
Director of Analytic Services  
VCU-Massey Cancer Center
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The data and information for this report was collected from several federal, state and local sources as well as personal interviews and focus groups. The only single county health district in the state has a population mix of 66% white, to 31% black and 3% Hispanic. Sixty-five percent of the population lives within 15 miles of the medical services available for cancer care. The district’s only hospital and several private medical practices offer cancer screening options (mammography and colonoscopy). The hospital provides diagnostic testing and radiation and surgical cancer treatment options, while chemotherapy is offered at the lone medical oncology practice.

The cancer burden in the Pittsylvania/Danville district is high compared to the state. The incidence rate is higher than the state for most cancers; significantly higher for respiratory, colorectal and gynecological cancers. Even though 56% of all cancers in the district are detected in the early stage when treatment is most effective, the mortality rate is higher than the state for most cancers. Seventy four percent of cancer deaths in the district are caused by five cancer categories: respiratory, colorectal, heme-malignancies, breast and prostate.

Several factors determine the choice for treatment location. A decade long shortage of medical providers, especially oncologists and surgeons, has resulted in many residents seeking diagnosis and treatment at one of the four university based cancer centers within one and a half to two hours travel time of the district or to medical systems in neighboring Virginia counties and North Carolina. Cancer survivors who received care locally reported a delay in getting appointments for surgical options and a long wait at the medical oncologist’s office for treatment. Aside from the shortage of physicians, local limitations on available treatment options are due to the complexity of the needed surgery and the potential side effects of a particularly toxic chemotherapy. Other factors determining location of treatment are personal finances, insurance requirements and personal choice.

The district has very limited support services for cancer survivors. The Virginia Department of Health’s Every Woman’s Life program had only a 19% utilization rate in 2010. There is only one cancer support group, sponsored by Danville Cancer Association. DCA offers financial aid for transportation, medication and aesthetic needs. The Cancer Resource Center of Southern Virginia began services for educational and informational support in 2010. The American Cancer Society has limited presence in the area with regional offices outside of the district. Although ACS provides financial, transportation and aesthetic support and educational materials, the local efforts are mainly focused on the annual Relay for Life Event. While the district has three for-profit Hospice agencies, they report that few of their patients are admitted with a cancer diagnosis.

Interviews with three healthcare professionals who are long-time residents and leaders in the community gave a broad perspective of the cancer health care needs of the health district. The major healthcare deficiencies identified by these key leaders fell into four major categories: (1) behavioral risks factors such as poor dietary habits and tobacco use, (2) lack of health
education of the residents, (3) low number of physicians especially the oncologist 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 (weight loss and tobacco cessation) and end of life issues. Primary Care Physicians were surveyed to gain perspectives on cancer screenings, care of patients during treatment and communication between PCP and oncologists. The PCPs surveyed reported a high compliance with colorectal (76%) and breast screening recommendations (80%). Sixty percent of the physicians said they prefer to refer oncologic surgeries to local surgeons. The physicians surveyed expressed a desire for more information on long term survivorship issues, including pain management, treatment side effects, prevention of recurrence and end of life issues.

District-wide focus groups for both the general population and cancer survivors/caregivers reinforced data collected in the Behavioral Risk Factor Surveillance Survey. Organizations such as the Danville Regional Foundation have previously studied the state of health in the Dan River Region and many of its findings are supported in this Cancer Needs Assessment. Since the release of the Foundation’s assessment, numerous programs have been implemented across the region to combat obesity and instill healthful living habits. However, the majority of the focus group participants were unaware of existing programs addressing these lifestyle risk factors. The participants acknowledged that the district has problems with obesity and tobacco use. The Key Leaders agreed that these behaviors are prevalent and are the major causes of disease in the area. The lack of primary care providers, lack of insurance and funds for healthcare needs are other major concerns for the residents in the focus groups. Among the survivors, the lack of oncologists and surgeons were the greatest concern. The long wait times are of a real burden for those undergoing chemotherapy and a cause for those who can, to seek care out of town. The survivors without insurance also traveled out of town to facilities who would serve them. Some delayed care or missed appointments due to transportation issues to near and distant sites. Other major concerns of the survivors were lack of information resources and support services.

Research and clinical trials are the only means to achieving progress in the fight against cancer. The community, as shown in the focus groups, is not knowledgeable about clinical trials and has a low opinion of research. Upon learning the definition, all focus group members agreed that they would want local access to trials if needed and would participate in research under specific situations. To increase trial and research participation in the area, education of the medical and general populations will be needed. Enrolling participants in smaller communities is crucial to the fight.

The greatest need in the district is in the recruitment and retaining of oncology providers. This is a difficult task since the nationwide shortage of oncology trained health care workers at all levels is increasing. With two nursing schools in the district, we should be encouraging students to investigate the field. Churches and civic groups may find a project in developing a solution for the transporting of survivors to medical appointments. The most needed support service is a complete Patient Navigation Program. Navigation uncovers an individual’s barriers and works with the patient and health care system to ensure that the patient receives screening, diagnosis and treatment needed in a timely fashion. Through
coordination with existing resources, a navigation program that encompasses screening thru resolution of disease should be established without association with a specific medical provider to best benefit the entire community. Education on risk reduction behavior is a component of a Navigation program. Awareness and acceptance of palliative care and hospice care should be increased in both the patient and medical communities. This change will require coordinated efforts of the medical providers, care agencies and spiritual community.

Finally, cancer prevention and increased survivorship has many facets: education of patient and provider, funds for prevention and early detection programs, and access to care and support services. The community should strive to change behaviors to reduce risk, educate themselves about signs and symptoms, adhere more closely to screening guidelines, and utilize the services available locally for diagnosis, treatment and support. The medical community should strive to be up to date on screening guidelines, work with patients on meeting those guidelines, and be knowledgeable about and refer to support services available locally. In order to reduce risk and increase survivorship, the entire community will need to work together.
INTRODUCTION

Cancer is a significant health problem in the United States, impacting the physical, emotional, economic, and social well-being of individuals, their families, and communities. It is estimated that 1,638,910 new cases of cancer will be diagnosed nationally2012 (American Cancer Society), with 41,380 occurring in Virginia. The State cancer incidence rate of 443.2 newly diagnosed cancers per 100,000 residents ranks 38th among the other 49 states and the District of Columbia, and is slightly lower than the national cancer incidence rate of 455.7 (2008). Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease, with an average of 14,009 residents succumbing to their disease. Virginia is poised to combat this disease with healthcare institutions, cancer care centers, state education and research institutions, city and state governments, non-profit organizations, and grassroots community groups working to reduce the cancer burden in the State. In addition, a statewide network of partners, the Cancer Action Coalition of Virginia (CACV), has developed a State five year cancer plan since 2001 to help unify and direct the efforts of these organizations in combating cancer.

Virginia is a highly diverse state in geography, population demographics, economics and access to healthcare. With a land mass of 40,000 square miles that spans from the shores of the Atlantic to the hills of the Appalachian Mountains, there are varying degrees of knowledge of and access to healthcare. For cancer prevention and control efforts to be effective, they “must be complete, comprehensive, sustainable, community -specific, and culturally and linguistically appropriate.” To accomplish this, an evaluation of the needs specific to defined communities is required. The Virginia Commonwealth University Massey Cancer Center in collaboration with the Virginia Tobacco Indemnification and Community Revitalization Commission performed a comprehensive cancer needs assessment of four communities, defined by Health District between 2010 and 2011. 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 is being used to develop a holistic strategy to improve cancer outcomes that utilizes strategies that are culturally appropriate to these communities.

Methods of Data Collection

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

5 Statistics provided by the Virginia Cancer Registry(June, 2011), data from 2001 to 2007
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)
responsible for gathering all community based information. Mechanisms used to gather information in the four categories were as follows:

**Cancer Burden**

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

**Cancer Healthcare Resources**

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

**Community Cancer Resources**

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

**Healthcare Provider Needs**

The perspectives of healthcare providers on the needs related to cancer in the community were gathered in two ways. First, key leader physicians were identified in the community, and asked to discuss the most pressing healthcare deficiencies, and the most pressing needs of primary care physicians related to cancer in their health districts (See Appendix A). Second,
information gathered from the key leaders was used to develop a questionnaire for primary care physicians within the health district. The questionnaire was field tested with physicians from within the health districts prior to finalization. It was then produced both as a pre-stamped hard copy questionnaire, and as an online questionnaire. A list of PCPs in each health district was acquired from the Virginia Board of Medicine website, 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 CHE’s, who checked it for accuracy. All physicians on the final list were asked to complete the questionnaire either via e-mail or by personal visit to the physician’s office. Initial contact was followed-up at least once, and potentially twice for non-responders. (Appendix B).

Community Population Needs

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

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

10 BRFSS: http://www.cdc.gov/brfss/
Demographics in Pittsylvania Danville

The Pittsylvania/Danville Health District is unique to other health districts in that it is contained within a single county’s borders. Pittsylvania County is the largest land mass in Virginia. Gently rolling hills extend throughout the county’s 968\(^{11}\) and the city’s 43\(^{12}\) square miles. Most of the county is rural agricultural land, while the city of Danville is in a transition from heavy industrial and textile to new and innovative hi-tech industries. The U.S. Census bureau designated the area as a metropolitan statistical area (MSA) because of the close socio/economic relationship the county has with the city. This relationship continues today, with the majority of health resources and largest employers within the city or just outside the limits. The combined population of the area is 106,561 (2010 US census), with the county having about 20,000 more residents than the city.

The city of Danville is in the center of the east/west boundary and is at the very southern end of the county. (Figure 1) The most heavily populated areas of the county in any direction are nearest to the city of Danville. The towns within the county are located along Route 29. The towns are Chatham (pop 2233), Gretna (pop 1207) and Hurt (pop 1209)\(^{13}\). Hurt, located on the very northern border of the county, is separated from Danville by 45 miles, which is nearly twice the distance to the nearest cancer facilities located in Lynchburg Virginia.\(^{14}\)

The residential and economic development of both the county and city follow the Route 29 North/South corridor and the east/west corridor of Route 58. The city of Danville’s southern most limits is the North Carolina-Virginia state line. Near this southern city limit, the city is agricultural and industrial. The largest employer\(^{15}\) in Pittsylvania/Danville, Goodyear Tire and Rubber Company, is located in this southern portion of the city. The eastern side of the city and adjoining county is populated with industrial parks that serve as the location for the technological based industries new to the area. The remainder of the county is primarily agricultural, with industrial parks located at several crossroads near the communities throughout the county. The Dan River flowing

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\(^{11}\) U.S Census Bureau; State and County Quick Facts; Pittsylvania County, Virginia; [http://quickfacts.census.gov/qfd/states](http://quickfacts.census.gov/qfd/states); (accessed 28 October 2011)

\(^{12}\) U.S Census Bureau; State and County Quick Facts; Danville, Virginia;(accessed 28 October2011)

\(^{13}\) U.S Census Bureau;State and County Quick Facts; Chatham, Virginia; Gretna, Virginia; Hurt, Virginia;(accessed 28 October 2011)


through the city serves as the water source for the residents. In the past, many industries were built on the river and memories of the resulting pollution lingers in long time residents minds.

The city has a greater proportion of people over the age of 65 than does the county, but the entire district is an aging community as shown by the higher percentages of the middle aged and the elderly (50+ years) when compared to the state. The racial/ethnic mix of the county is majority white, with approximately a quarter of the population African American, and a small, but growing Hispanic population. In comparison, the city’s white and black populations are more evenly represented, with a similar Hispanic representation. Other races have minuscule populations in both the county and city.\textsuperscript{16} \textbf{(Table A)}

When comparing the educational attainment within the district to the rest of the state, the district compares well with Associates degree holders and some college. However, the district only has half the number of people with a bachelors degree or higher when compared to the state. At the other extreme one third of the citizens have a high school diploma or less.

The median household income of the district is one half of that in the state. Within the district, the city residents have a lower income by $10,000 than the county.\textsuperscript{17} The unemployment rate in the city is higher than the county\textsuperscript{18}; both are higher than the State average as of September 2011\textbf{(Table B)}

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|c|}
\hline
\textbf{Table A: Demographic Profile of Pittsylvania-Danville vs Virginia} \\
\hline
\hline
\textbf{Category} & \textbf{Subcategory} & \textbf{Pittsylvania-Danville} & \textbf{Virginia} \\
\hline
\hline
\textbf{Gender} & Male & 47\% & 48\% \\
\hline
& Female & 53\% & 52\% \\
\hline
\textbf{Age} & 18-39 & 31\% & 40\% \\
\hline
& 40-49 & 18\% & 19\% \\
\hline
& 50-64 & 29\% & 25\% \\
\hline
& 65+ & 23\% & 16\% \\
\hline
\textbf{Race} & White & 66\% & 67\% \\
\hline
& Black or AA & 31\% & 18\% \\
\hline
& Other & 3\% & 14\% \\
\hline
\textbf{Ethnicity} & Hispanic or Latino & 2\% & 7\% \\
\hline
& Non-Hispanic or Latino & 98\% & 93\% \\
\hline
\end{tabular}
\caption{Demographic Profile of Pittsylvania-Danville vs Virginia}
\end{table}

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|c|c|}
\hline
\textbf{Table B: Economic Characteristics of Pittsylvania-Danville vs VA} \\
\hline
\hline
\textbf{Location} & \textbf{Pittsylvania} & \textbf{Danville city} & \textbf{Health District (average)} & \textbf{Virginia} \\
\hline
\textbf{Unemployment\textsuperscript{1}} (16 years and older) & Unemployment Rate & 8.00\% & 11.80\% & 9.90\% & 6.40\% \\
\hline
\textbf{Income\textsuperscript{2}} & Median Household Income & $39,765 & $29,482 & $34,624 & $60,316 \\
\hline
\textbf{Education\textsuperscript{3}} (25 years and older) & % Less than high school & 24.20\% & 25.50\% & 24.85\% & 14.20\% \\
& % High school or GED & 36.50\% & 30.10\% & 33.30\% & 26.30\% \\
& % Some college, no degree OR an Associate’s degree & 26.30\% & 28.70\% & 27.50\% & 26.00\% \\
& % Bachelor’s degree or above & 13.00\% & 15.70\% & 14.35\% & 33.50\% \\
\hline
\end{tabular}
\caption{Economic Characteristics of Pittsylvania-Danville vs VA}
\end{table}

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

\textsuperscript{16} U.S. Census Bureau; American Community Survey, 2005-2009 Fact Sheet, American Fact Finder, <http://factfinder.census.gov>,\textsuperscript{17} accessed 8 November 2011.
\textsuperscript{17} Virginia Workforce Connection, LMI Tools. <www.vawc.virginia.gov>; Unemployment Rate for Virginia, September 2011, Not Seasonally Adjusted. (7 November, 2011).
Access to Healthcare

Census tracts north of Chatham are considered rural by the Health Resources and Services Authority (HRSA)\(^1\). Organizations within these tracts may apply for Rural Health Outreach, Network Development, or Rural AED Grant Programs. The Health Resources and Services Administration (HRSA) has designated the northern end of the county as a Health Professional Shortage Area (HPSA) and the county census tracts contiguous with and within Danville city as either Medically Underserved Area and or Population (MUA, MUP).\(^2\)

The only hospital within the health district is Danville Regional Medical Center, located within the city limits. DRMC has family practice clinics in several communities within the district. Centra Health Systems, based in Lynchburg, has also established primary care clinics in the several localities in recent years. Both health systems are seeking to expand their presence throughout the district. Surrounding counties, (Halifax and Henry Counties) have similarly sized facilities as Danville within 40 minutes of the center of Danville. University of Virginia in Charlottesville, VA is a 2 hour drive. There are three large university based medical centers, multiple other hospitals and providers in North Carolina within a 2 hour drive. (Figure 2)

**Figure 2: Pittsylvania/Danville Health District Resources Map**

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\(^2\) U.S. Census Bureau; American Community Survey, 2005-2009 Summary Table S2503; generated by Timur Kornish; using American FactFinder; [http://factfinder.census.gov](http://factfinder.census.gov); (7 November, 2011).
Cancer Burden

Cancer Incidence

Cancer incidence was calculated for the Health District for all cancer types, and is reported for cancers grouped by disease site. Incidence rates of the gender specific cancers, (female breast, male genital/prostate, and gynecological/cervical/uterine/ovarian) were calculated from the appropriate gender populations. The other cancer sites reported are the gastro-intestinal/colorectal, respiratory/lung, hememalignancies, urinary system, oral cavity-pharynx, brain-nervous system-eye and all other sites combined. Cancer incidence rates are age adjusted; so that the Pittsylvania/Danville Health District’s higher percentage of elderly (by seven percent) does not confound the data. (Table C)

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Pittsylvania</th>
<th>Virginia</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male Genital System</td>
<td>175.5</td>
<td>167.7</td>
<td><strong>Data Source:</strong> Virginia Cancer Registry (averaged rates for 1999-2008) – all rates calculated based on populations including all ages.</td>
</tr>
<tr>
<td>Prostate</td>
<td>168.3</td>
<td>162.0</td>
<td></td>
</tr>
<tr>
<td>Other male genital organs</td>
<td>7.2</td>
<td>5.7</td>
<td></td>
</tr>
<tr>
<td>Female Breast</td>
<td>120.6</td>
<td>124.3</td>
<td></td>
</tr>
<tr>
<td>GI System</td>
<td>88.9</td>
<td>79.8</td>
<td><strong>Dataset ordered by descending rate for health district.</strong></td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>54.7</td>
<td>47.5</td>
<td></td>
</tr>
<tr>
<td>All Other GI</td>
<td>34.2</td>
<td>32.3</td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>80.3</td>
<td>72.5</td>
<td><strong>Age-Adjusted Rate - represents an age-adjusted number of new cancer cases per 100,000 populations.</strong></td>
</tr>
<tr>
<td>Gynecological</td>
<td>48.1</td>
<td>44.4</td>
<td><strong>Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females.</strong></td>
</tr>
<tr>
<td>Corpus and Uterus</td>
<td>21.8</td>
<td>21.8</td>
<td></td>
</tr>
<tr>
<td>Ovary</td>
<td>13.2</td>
<td>12.1</td>
<td></td>
</tr>
<tr>
<td>Cervix</td>
<td>8.5</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td>All other Gynecological</td>
<td>4.6</td>
<td>3.4</td>
<td></td>
</tr>
<tr>
<td>Heme-malignancies</td>
<td>35.0</td>
<td>34.3</td>
<td></td>
</tr>
<tr>
<td>Lymphomas</td>
<td>20.4</td>
<td>19.5</td>
<td></td>
</tr>
<tr>
<td>Leukemias</td>
<td>8.8</td>
<td>9.7</td>
<td></td>
</tr>
<tr>
<td>Myeloma</td>
<td>5.8</td>
<td>5.2</td>
<td></td>
</tr>
<tr>
<td>Urinary System</td>
<td>32.5</td>
<td>32.4</td>
<td></td>
</tr>
<tr>
<td>Oral Cavity, Pharynx</td>
<td>10.6</td>
<td>10.3</td>
<td></td>
</tr>
<tr>
<td>Brain, Nervous System, Eye</td>
<td>4.9</td>
<td>6.5</td>
<td></td>
</tr>
<tr>
<td>All Other Sites</td>
<td>39.0</td>
<td>44.5</td>
<td></td>
</tr>
<tr>
<td>All Sites</td>
<td>460.5</td>
<td>446.6</td>
<td></td>
</tr>
</tbody>
</table>
The cancer sites with the highest incidence rates in the Pittsylvania Danville Health District are male genital/prostate, female, breast, gastro-intestinal/colorectal, respiratory/lung and gynecological. The district had a higher cancer incidence rate than the state when comparing all sites combined. The district’s rates are significantly higher than the state’s for GI and respiratory cancers. The other cancer categories incidence rates are not statistically different than the state’s (Figure 3).

To evaluate the impact of cancer in the community in terms of provider burden and services needed, information on the annual number of cancer cases diagnosed was acquired from the Figure 3: Age Adjusted Cancer Incidence Rate in Pittsylvania-Danville vs Virginia

Figure 3: Age Adjusted Cancer Incidence Rate in Pittsylvania-Danville vs Virginia

- Male Genital System
- Female Breast
- GI System
- Respiratory
- Gynecological
- Heme-Malignancies
- Urinary System
- Oral, Cavity, Pharynx
- Brain, Nervous Systems, Eye
- All Other Sites

Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females. Data Source: Virginia Cancer Registry (averaged rates for 1999-2008) – all rates calculated based on populations including all ages.
Virginia Cancer Registry. In the Pittsylvania-Danville Health District, there is an average of six hundred and thirty four (634) cases of new cancer each year in the health district based on a 10 year average (1999-2008). Gastrointestinal/colorectal, respiratory/lung, male genital/prostate and female breast and heme-malignancies cancers had the highest average incident cases. Together they make up 76% of the total cases. (Table D/Figure 4)

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Annual Count</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>GI System</td>
<td></td>
<td>Data Source: Virginia Cancer Registry</td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>124</td>
<td>Annual Count - represents average number of new cases per year in the health district (averaged over period 1999-2008).</td>
</tr>
<tr>
<td>All Other GI</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>114</td>
<td></td>
</tr>
<tr>
<td>Male Genital System</td>
<td></td>
<td>Data Source: Virginia Cancer Registry</td>
</tr>
<tr>
<td>Prostate</td>
<td>106</td>
<td></td>
</tr>
<tr>
<td>Other male genital organs</td>
<td>103</td>
<td></td>
</tr>
<tr>
<td>Female Breast</td>
<td>90</td>
<td></td>
</tr>
<tr>
<td>Heme-malignancies</td>
<td>47</td>
<td>All Other Sites include Brain, Nervous System, Eye, Gynecological, Oral Cavity, Pharynx, Urinary System, and Other sites.</td>
</tr>
<tr>
<td>Lymphomas</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Leukemias</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Myeloma</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>All Other Sites</td>
<td>153</td>
<td></td>
</tr>
<tr>
<td>All Sites</td>
<td>634</td>
<td></td>
</tr>
</tbody>
</table>

Data Source: Virginia Cancer Registry

Percentage - based on annual cancer cases count (averaged over period 1999-2008) for top 5 cancers in the health district, as compared to the rest of cancer cases.
The incident rate for all cancers is higher in males than females. (Tables E & F) The cancer with the highest age adjusted incident rate for males is prostate cancer: for females the top cancer is breast. (Figures 5 & 6) Respiratory cancer is substantially higher in males than in females. Gastrointestinal (primarily colorectal) is 3rd for males and 2nd for females.

Table E:

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Crude Rate</th>
<th>Annual Count</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male Genital System</td>
<td>207.6</td>
<td>106</td>
<td>Data Source: Virginia Cancer Registry</td>
</tr>
<tr>
<td>Prostate</td>
<td>200.7</td>
<td>103</td>
<td></td>
</tr>
<tr>
<td>Other male genital organs</td>
<td>6.8</td>
<td>4</td>
<td>Crude Rate – represents number of new male cancer cases per 100,000 males.</td>
</tr>
<tr>
<td>Respiratory</td>
<td>141.3</td>
<td>72</td>
<td></td>
</tr>
<tr>
<td>GI System</td>
<td>125.3</td>
<td>64</td>
<td></td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>72.3</td>
<td>37</td>
<td>Annual Count - represents average number of new male cancer cases per year in the health district (averaged over period 1999-2008).</td>
</tr>
<tr>
<td>All Other GI</td>
<td>53.0</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Urinary System</td>
<td>61.2</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Heme-malignancies</td>
<td>48.1</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Lymphomas</td>
<td>27.0</td>
<td>14</td>
<td>All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, and Other sites.</td>
</tr>
<tr>
<td>Leukemias</td>
<td>13.7</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Myeloma</td>
<td>7.4</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>All Other Sites</td>
<td>79.3</td>
<td>41</td>
<td></td>
</tr>
<tr>
<td>All Sites</td>
<td>662.7</td>
<td>339</td>
<td></td>
</tr>
</tbody>
</table>
Table F:

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Crude Rate</th>
<th>Annual Count</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female Breast</td>
<td>159.1</td>
<td>90</td>
<td>Data Source: Virginia Cancer Registry</td>
</tr>
<tr>
<td>GI System</td>
<td>105.3</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>69.7</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>All Other GI</td>
<td>35.6</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>73.2</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>Gynecological</td>
<td>62.4</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Corpus and Uterus</td>
<td>28.7</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Ovary</td>
<td>18.0</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Cervix</td>
<td>9.7</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>All other Gynecological</td>
<td>6.0</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Heme-malignancies</td>
<td>39.7</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Lymphomas</td>
<td>23.3</td>
<td>13</td>
<td>All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.</td>
</tr>
<tr>
<td>Leukemias</td>
<td>8.3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Myeloma</td>
<td>8.1</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>All Other Sites</td>
<td>80.6</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>All Sites</td>
<td>520.3</td>
<td>295</td>
<td></td>
</tr>
</tbody>
</table>

Prostate cancer occurs at nearly twice the rate in African American males than in white males. The rate in black males in PDHD is higher than the state’s age adjusted incidence rate. Female breast cancer occurs in both races at about the same age adjusted incidence rate and is
Comparability to the state. *(Tables G & H)*

### Table G:

#### Top 5 Cancers in Pittsylvania-Danville for African American Population

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>10-year case count</th>
<th>Age Adjusted Incidence Rate</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Pittsburgh-Danville</td>
<td>Virginia</td>
</tr>
<tr>
<td>Male Genital System</td>
<td>369</td>
<td>256.2</td>
<td>245.7</td>
</tr>
<tr>
<td>Prostate</td>
<td>365</td>
<td>253.5</td>
<td>243.6</td>
</tr>
<tr>
<td>Other male genital organs</td>
<td>4</td>
<td>2.8</td>
<td>2.1</td>
</tr>
<tr>
<td>Female Breast</td>
<td>246</td>
<td>121.0</td>
<td>122.4</td>
</tr>
<tr>
<td>GI System</td>
<td>341</td>
<td>97.9</td>
<td>101.2</td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>194</td>
<td>55.6</td>
<td>57.2</td>
</tr>
<tr>
<td>All Other GI</td>
<td>147</td>
<td>42.2</td>
<td>44.0</td>
</tr>
<tr>
<td>Respiratory</td>
<td>296</td>
<td>85.3</td>
<td>78.0</td>
</tr>
<tr>
<td>Gynecological</td>
<td>98</td>
<td>48.4</td>
<td>39.2</td>
</tr>
<tr>
<td>Corpus and Uterus</td>
<td>47</td>
<td>23.2</td>
<td>18.7</td>
</tr>
<tr>
<td>Ovary</td>
<td>31</td>
<td>15.2</td>
<td>9.2</td>
</tr>
<tr>
<td>Cervix</td>
<td>16</td>
<td>8.0</td>
<td>8.4</td>
</tr>
<tr>
<td>All other Gynecological</td>
<td>4</td>
<td>2.0</td>
<td>2.8</td>
</tr>
<tr>
<td>All Other Sites</td>
<td>314</td>
<td>88.5</td>
<td>98.6</td>
</tr>
<tr>
<td>All Sites</td>
<td>1664</td>
<td>474.6</td>
<td>472.4</td>
</tr>
</tbody>
</table>

**Notes:**
- 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.

### Table H:

#### Top 5 Cancers in Pittsylvania-Danville for White Population

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>10-year case count</th>
<th>Age Adjusted Incidence Rate</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Pittsburgh-Danville</td>
<td>Virginia</td>
</tr>
<tr>
<td>Male Genital System</td>
<td>684</td>
<td>150.1</td>
<td>152.6</td>
</tr>
<tr>
<td>Prostate</td>
<td>653</td>
<td>140.5</td>
<td>145.9</td>
</tr>
<tr>
<td>Other male genital organs</td>
<td>31</td>
<td>9.6</td>
<td>6.8</td>
</tr>
<tr>
<td>Female Breast</td>
<td>649</td>
<td>118.2</td>
<td>125.3</td>
</tr>
<tr>
<td>GI System</td>
<td>888</td>
<td>85.3</td>
<td>75.1</td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>568</td>
<td>54.2</td>
<td>45.7</td>
</tr>
<tr>
<td>All Other GI</td>
<td>320</td>
<td>31.0</td>
<td>29.3</td>
</tr>
<tr>
<td>Respiratory</td>
<td>841</td>
<td>78.8</td>
<td>72.5</td>
</tr>
<tr>
<td>Gynecological</td>
<td>251</td>
<td>48.2</td>
<td>45.4</td>
</tr>
<tr>
<td>Corpus and Uterus</td>
<td>113</td>
<td>21.5</td>
<td>22.5</td>
</tr>
<tr>
<td>Ovary</td>
<td>71</td>
<td>12.8</td>
<td>12.7</td>
</tr>
<tr>
<td>Cervix</td>
<td>37</td>
<td>8.5</td>
<td>6.7</td>
</tr>
<tr>
<td>All other Gynecological</td>
<td>30</td>
<td>5.5</td>
<td>3.5</td>
</tr>
<tr>
<td>All Other Sites</td>
<td>1297</td>
<td>130.9</td>
<td>134.1</td>
</tr>
<tr>
<td>All Sites</td>
<td>4610</td>
<td>451.6</td>
<td>442.4</td>
</tr>
</tbody>
</table>

**Notes:**
- 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.

Comparison of percent frequency of incidence counts in African Americans vs. Whites in the health district shows that male genital cancers make up a larger percentage of the overall cancer burden in African Americans, whereas cancers from ‘all other sites’ make up a relatively larger
proportion of the cancer burden in Whites. Four of the top six cancers in the district occur at a similar percentage of incidence in the black and white populations. (Figure 7)

Figure 7:

Cancer Mortality and Staging

Staging cancer is needed for proper treatment planning. Discovering cancer at the local stage is usually indicative of a better outcome and improved survivorship.

In the Health District, respiratory cancer and heme-malignancies are found in late stage nearly 80% of the time. Over half of all gastrointestinal/colorectal cancers are found in late stage. Most male genital/prostate, brain group, urinary and female breast cancers are detected while in early stage. (Figure 8) Without exception, cancers in the African American population are all staged later than in the white population. Notably, there is a difference of ten percent in the staging of male genital cancer between the races. (Figure 9)
Figure 8: Cancer Stage in Pittsylvania-Danville vs. VA

Figure 8: *Cancer Sites ordered by incidence rate (highest to lowest) in the health district– see Table B (only major sites are shown.).

HD – represents “Health District”; VA – represents “Virginia state”

Figure 9: *Top 5 cancers selected based on greatest number of people affected per year (on average) in the health district– see Table C.

Figures 8 and 9: 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.

Figure 9: Top 5 Cancers by Stage in Pittsylvania-Danville
An average of 276 residents of Pittsylvania/Danville health district succumb to cancer related causes each year. (Table I) The average is based on a ten year span (1998-2008). The respiratory/lung and gastrointestinal cancer groups have the highest cancer mortality rates and causes the highest average annual cancer related deaths in the district for both men and women. (Figure 10)

### Table I

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Annual # of deaths</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory</td>
<td>85</td>
<td>Virginia Department of Health (averaged counts for 5-year period 2005-2009) - based on population for all ages.</td>
</tr>
<tr>
<td>GI</td>
<td>58</td>
<td>Dataset ordered by descending death numbers for health district.</td>
</tr>
<tr>
<td>All other GI</td>
<td>35</td>
<td>All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Gynecological, Urinary System, and Other sites.</td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Heme-malignancies</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Lymphomas</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Myeloma</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Leukemias</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Female Breast</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Male Genital System</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Other male genital organs</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>All Other Sites</td>
<td>72</td>
<td></td>
</tr>
<tr>
<td>All Sites</td>
<td>276</td>
<td></td>
</tr>
</tbody>
</table>

*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. All Other Sites include Brain, Nervous System, Eye, Oral Cavity, Pharynx, Urinary System, and Other sites.*
The mortality rate for men is twice that of women from respiratory cancers and notably higher for gastrointestinal cancer. In contrast to incidence cases the majority of deaths from the gastrointestinal group are due to cancers of GI sites other than colorectal. Breast and male genital cancer is the third highest cancer killer in females and males respectively. (Figure 11 & 12)

Figures 11 and 12

Top 5 cancers for females in Pittsylvania-Danville by mortality

Data Source: Virginia Department of Health
Percentage - based on annual number of cancer deaths (averaged over period 2005-2009) for top 5 cancers in the health district for males and females, as compared to the rest of reported cancer deaths.
In every category except heme-malignancies, the mortality rate from cancer is higher in African Americans than in whites. Respiratory cancer has the highest mortality for both races with similar rates for each. The mortality from male genital cancer follows the incidence pattern of twice the rate for black males and is the second highest cause of cancer deaths in blacks. GI cancer has the third highest rate in blacks and is second highest for whites at about the same mortality rate. Female breast cancer has a notably higher rate in blacks than in whites. The differences in mortality rates between the races are reflective of state trends. (Tables J & K)

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>5-year death count</th>
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Cancer Healthcare Resources

Healthcare Facilities and Cancer Care

Danville Regional Medical Center, the only hospital in the district, is located in the center of the city of Danville. The for-profit facility serves the Dan River Region with a broad range of services: laboratory and pathology departments, on-site and remote radiology facilities, full range surgical service, a radiation therapy center and a 24/7, 365 days emergency department. The Center for Radiation Oncology at DRMC is conveniently located adjacent to the hospital campus. Due to lack of Medical Oncologists onsite, chemotherapy infusion is not currently available.

Natural attrition as well as loss of physicians due to issues involving the 2005 sale of the hospital has left the area short of primary care providers. Specialists, such as internists and gynecologists have been serving as Primary Care Physicians. Many of these providers have relinquished staff privileges at the hospital. DRMC employs hospitalists in various disciplines to oversee the care of inpatients.

Because of the location of the hospital in relation to the geography of the county, residents living more than 15 miles from the city are just as close to one of the health care facilities in the surrounding counties. Halifax Regional Medical Center in Halifax County, the Memorial Hospital of Martinsville and Henry County in Martinsville and Morehead Hospital in Eden, North Carolina are less than 35 miles from the center of Danville. Those living north of Gretna would travel approximately the same distance to hospitals in Lynchburg, Virginia. Three university based research cancer centers are in North Carolina within a ninety minute drive of most of the districts population.

Cancer Services provided:

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

Screening:

The Pittsylvania Danville Health District is fortunate to have several screening facilities which perform the higher level screening tests not done as part of the routine physical exam, i.e. mammograms and colonoscopy/sigmoidoscopy. However, all of the facilities are located within the city boundaries.

Screening mammography, diagnostic mammography and ultrasound breast exams are performed at four locations.

Colorectal screening (colonoscopies and sigmoidoscopies) is available at two private practices. Diagnostic colonoscopies may be performed at the hospital. The private practices have board certified gastroenterologists and internists and complete endoscopic suites.

Both of the DRMC radiology sites can perform routine and diagnostic radiology studies, CAT scans and MRIs. In addition the radiology department contracts to have a mobile PETscan at the hospital once a week.

Piedmont Access to Health Services, Inc (PATHS) has contracts with several providers for screening services to which they refer their patients. In that manner they are no different than other primary care providers who refer the patient to a facility or practice for screening. In addition, once a year PATHS contracts with the University of Virginia for the mobile mammography service to provide screening mammography to pre-registered participants.

21 Danville Regional Foundation, “Dan River Region Health Assessment” October 2007, pg 26
The Pittsylvania Danville Health Department provides access to mammograms through the Every Woman’s Life program and through grants from the Susan G. Komen Foundation. The EWL program is managed through the Health Department’s Chatham Clinic. In 2010, only 19% of eligible women utilized the EWL in the health district due to state funding.

While PAP smears are collected at any facility which performs pelvic exams, questionable results requiring a colposcopy are, at this time, referred to a gynecologist. The Pittsylvania Danville Health Department and PATHS are applying for grants for a colposcopy program to begin in 2012.

Treatment:

Treatment modalities for cancer include chemotherapy (including immunotherapy), radiation, and surgery. Treatment with all modalities is available to some extent within the Health District. There are two primary locations within the health district that provide cancer treatment.

Danville Regional Medical Center provides radiation oncology, and surgical oncology. Surgical procedures for almost all cancers including breast, gastrointestinal, prostate, lung and some brain cancers can be and are performed at DRMC. However, more complex procedures and gynecological cancer surgeries and breast reconstructions are referred to other medical centers. The Center for Radiation Oncology, affiliated with DRMC, provides radiation treatment administered with the Varian Clinac 2300 device. This device allows treatment of the affected area of the body while protecting the surrounding tissue from unneeded radiation.

There is one private medical oncology office with one full time and one part time oncologist. It provides exclusively medical oncology treatments including chemotherapy, immunotherapy, IV infusions, and genetic counseling. This medical oncology practice refers acute leukemia, cancers with transplant treatment options and complex surgeries (especially GYN) to tertiary care centers. The practice is capable of treating chronic leukemia and managing acute leukemia once stabilization has been achieved.

There is one chemotherapy-certified registered nurse at the medical oncology practice.

There are no Cancer Patient Navigators available at any of the facilities. Navigators identify barriers to needed medical services for individual patients. The barriers are eliminated so that the patient receives the needed care. Currently, Social Workers and insurance clerks are the primary resources of help for getting financial assistance and support services for the patient.

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

- Lack of medical oncologists
- Limited chemotherapy services
- Lack of surgeons
- No availability for reconstruction and other complex procedures
- No patient navigators

Auxiliary Services

Programs that address Survivorship needs, including dietary provision and counseling, genetic counseling, pain management and end of life services are important services that effect both outcomes and quality of life.
Dietary issues can be addressed by the registered dieticians on staff at DRMC. Though not oncology certified, the R.D. will perform nutritional risks assessments following American Dietetic Association’s guidelines. If the patient is at risk, a plan will be provided for the patient. Outpatient consultations are available with a provider’s referral, but according to the DRMC dietician, the service is not often utilized.

Genetic counseling is available and provided by the medical oncologists at the two medical oncology clinics. Genetic counseling is not available at the hospital. While all of the treatment facilities offer treatment for pain management and quality of life issues, none have a dedicated palliative care program.

**Clinical Trials**

Clinical trials are offered in the medical and radiation oncologist practices.

**Hospice Services**

The three hospice providers in the district are for-profit agencies which offer similar services throughout the health district and have offices within the city limits. Commonwealth Home Nursing and Hospice is locally privately owned, Liberty HomeCare and Hospice Services is a national chain, and Legacy Hospice of the Piedmont is owned by Danville Regional Medical Center. Their patient populations have a variety of diagnoses; only a small portion of them have cancer. During the interview process, all of the administrators were asked what they considered to be the largest problem in Hospice care. Each administrator responded that the lack of referrals soon enough in the patient’s course of disease hindered delivering the type of care that Hospice is meant to provide. The services offered by the agencies include: counseling for the patient, family and staff, provided by the chaplain of the agency; personal care for the patient provided by ancillary services of the same agency; respite care usually provided by volunteers. None of the agencies sponsor support groups at the time of the interview. The nurses are not currently hospice certified at any of the agencies, although one agency is mandating certification for its nurses in 2012. While all of the agencies provide palliative care, none have a developed program. The nursing staff assesses the patient for nutritional deficiencies as there are no Registered Dieticians on staff at any of the agencies. Insured as well as the uninsured are accepted at all agencies. Programs for the uninsured vary from utilizing funds available through community resources to absorbing the cost of care.

**Community Cancer Resources**

There are three support resources dedicated to caring for cancer patients within the community. These and other resources not dedicated solely to the support of cancer survivors are listed in Appendix E.

The American Cancer Society maintains an area office Martinsville, west of the PDHD. Limited stipends are issued for cancer related medications. A visit to the office is required to pick up wigs and available medical equipment and supplies. Educational material is available through the office and website, at a kiosk at DRMC and in a more limited quantity at other medical facilities. Active ACS programs within the district are “Look Good, Feel Better”, “Reach for Recovery” and “Road to Recovery”. Descriptions of these programs may be found in the
Appendix. A community manager is assigned to Pittsylvania/Danville and is working on enhancing services in the district. Funding for the programs comes primarily from the American Cancer Society.

**Danville Cancer Association** is a local non-profit with strong ties to the community. It began assisting residents of the Dan River Region in 1976. It fulfills its mission of “providing patient aid to cancer patients” by providing funds for prescription medications related to cancer treatment, funds for travel to appointments, loans of medical equipment and donations of supplies and aesthetic aids. Educational material is available at the office located in Danville. They are supported by individual donations, grants and several annual events. The only cancer support group in the district, “Coping”, is sponsored by Danville Cancer Association. It welcomes all cancer survivors and caregivers at any point in their journey on the last Tuesday of each month at 1 p.m at Trinity United Methodist Church, 409 Arnett Blvd, Danville, VA.

The **Cancer Resource Center of Southern Virginia** acts as a facilitator in promoting, developing and coordinating cancer related services and events within the Southside counties. CRC, opened in March 2010, provides educational material for disbursement at physician offices and other sites, provides contact information for local, state and national resources, (including resources which provide financial aid to individual patients), and keeps abreast of any services which may be of benefit for the cancer survivor. It has coordinated events with Danville Regional Medical Center, American Cancer Society, Danville Cancer Association, the Pittsylvania Danville Health Department and other local groups in the past year. CRC is currently supported through a Tobacco Commission Grant.

The **Wayles R. Harrison Memorial Fund** is administered by the Community Foundation of the Dan River Region. The funds are used exclusively for cancer patients.

**Healthcare Provider Needs**

**Key Leader Information**

Three physicians and a healthcare administrator were interviewed to gather a broad perspective of the cancer healthcare needs of the health district. The key leaders were chosen on the basis of their professional and personal involvement with the community. These individuals were asked to identify the most pressing healthcare deficiencies in the community relating to cancer risk reduction, detection, diagnosis, treatment and follow-up care. In addition, they were asked to identify needs of community primary care providers for cancer continuing education, difficulties acquiring cancer diagnoses or treatment for their patients, post-treatment communication and training needs and palliative care knowledge.

The major healthcare deficiencies identified by these Key Leaders fell into four categories: (1) behavioral risks factors such as poor dietary habits and tobacco use, (2) lack of health education of the residents, (3) low number of physicians especially the oncologist specialists and (4) barriers to healthcare access. The Key Leaders feel that the residents have a poor record in taking care of themselves as the continued high usage of tobacco products and the increasing obesity issues.

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22 Danville Cancer Association: brochure Mission Statement; 2011
The role of tobacco use and obesity as risk factors for cancer are areas to target for community education. Generally poorly educated in health care, the residents frequently fail to recognize the signs and symptoms of disease and delay seeking care until treatment options are limited.

The Leaders cited the lack of providers for oncology patients, and the perception of low quality of care available locally as reasons for residents to seek care out of town, especially at the larger university medical centers in North Carolina. The Leaders stated that it is their experience that the District’s Medical Oncologists and the one Radiation Oncologist accept patients as quickly as possible for treatment, but there may be a several week wait for the appointment. They acknowledged a longer wait for surgical diagnosis and treatment. It was strongly stated by the Key Leaders that the facilities in the district are capable of providing the same treatment options for the common cancers, but there is a perception that the level of care locally is inadequate.

The Key Leaders noted that although many of the residents of the health district have lost employer funded health insurance, people need to feel responsible for maintaining their health and obtaining their healthcare, with or without insurance. Residents have moved away from having a consistent provider and depend on urgent care clinics as needed. Those with insurance often travel to Lynchburg or to the North Carolina cities to obtain healthcare. Patients are unaware of assistance programs for treatments and transportation issues. The Key Leaders have seen cases in which treatment was delayed due to lack of insurance or funds to pay for treatment. They reported that transportation to and from treatments is often a financial drain as well as a logistical problem for patients and families.

The Key Leaders identified several needs for the Primary Care Providers in the district. Noting that guidelines for screening tests can be confusing, they stated that some PCPs may not be aware of recent changes in the guidelines. The Key Leaders acknowledged the strong relationship between the cancer patient and the oncology team and the reluctance of the survivor to return to the PCP for routine and follow-up care. If the oncologist questions whether the patient will get proper follow up care from a PCP, the patient is encouraged to return to the oncologist for routine care. The Key Leaders recognized that there should be more attention to working with PCPs to increase their knowledge on follow up and survivorship issues.

According to the Key Leaders, hospice care is underutilized in the community as it is perceived by physician and patient as giving up hope. One key leader said “Hope is critical to survivorship”. Accordingly, when providers do suggest hospice care, it is often at the very end of life. The same Key Leader stated that a cultural change may be needed to accept hospice and the benefits it provides to the patient and family. He suggested that this cultural change would be best lead by the many churches in the district.

**Physician questionnaire results**

The Physician survey sought to determine the thoughts of the providers on: cancer screening; perspective on patient compliance with screening; care of patient during cancer treatment and follow-up; communication between the PCP and the oncology team; continuing education needs of the PCP on screening and follow-up care.

The survey targeted seventy three primary care providers of which twenty responded for a 27% response rate. Providers’ in the Pittsylvania Danville Health District were contacted a minimum of three times to encourage completion of the survey.

According to the survey, physicians agree with the Virginia Cancer Registry’s rating for the top four cancers diagnosed in the district. Colorectal, lung, breast and prostrate were the most
commonly diagnosed cancers by the physicians surveyed. Over eighty percent (80%) of those surveyed indicated that female patients comply with the recommended breast and cervical cancer screening guidelines. Seventy five percent (75%) of responding physicians believe their patients have an above average compliance rate for colorectal screening. (Figure 13) Skin cancer and prostate cancer is routinely screened for by most of the PCPs surveyed.

Figure 13: Patient Compliance with Cancer Screening Recommendations

The surveyed physicians agreed with the Key Leaders that the most common reason for patients’ failure to be screened relates to financial constraints. (Figure 14) The PCPs surveyed did not indicate a desire on more information about screening guidelines.

Only sixty percent of responding physicians report that they refer patients requiring oncological surgery to local surgeons, whereas 75% refer to local medical oncologists. The majority of the PCPs find all communication from the oncology team useful, and most of those surveyed find the communication between them and the oncology team satisfactory.

From the survey, the PCPs appear to feel comfortable in providing non-oncology care during cancer treatment, but not as comfortable providing joint oncology care or long term oncology follow-up care. They are interested in learning more about things that would affect the patient as the patient transitions from oncology treatment to long term survivorship: surveillance for recurrence, monitoring for long term treatment effects, palliative care and end of life management. (Figure 15) This information seems to explain the findings from the Key Leaders on patients’ and oncologists’ choice for post-treatment care and the underutilization of hospice care.
Figure 14: Primary reasons for non-compliance with cancer screenings according to PCPs

**Most common reasons patients choose not to have recommended cancer screenings as identified by physicians**

- **Financial constraints**: 80%
- **Apprehension about the test**: 70%
- **Lack of insurance**: 60%
- **Don't believe they are necessary**: 50%
- **Too busy**: 30%
- **Lack of transportation**: 20%
- **Lack of screening facilities**: 5%
- **Other**: 0%

*Percentage of responding physicians* *

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

Figure 15: Post-cancer treatment topics

**Post-cancer treatment care topics on which physicians are interested to receive more information**

- Surveillance of cancer recurrence
- Long-term cancer treatment effects: monitoring and palliation
- End-of-life care and planning
- Pain Management
- Wellness and prevention of cancer recurrence
- Genetic counselling for family members of cancer patients

Less Interested | Interested | Highly Interested
Community Population Needs

Two methods were employed to accurately assess the community residents’ needs and concerns about cancer care: evaluation of the Behavioral Risk Factor Surveillance Survey data and conducting focus groups with health district residents.

Behavioral Risk Factor Surveillance Survey

The Centers for Disease Control conducts state-based monthly telephone surveys collecting information on health risk behaviors, preventative health practices and health care access for adults 18 years old and over. Information from the Behavioral Risk Factor Surveillance Survey (BRFSS) was accessed to gain perspectives on the Health District level about Lifestyle, healthcare access and screening practices.

From the BRFSS data, we see a lifestyle in the district that includes many risks factors for cancer. One third of those surveyed admit to not exercising; one half are smokers or formerly smoked; nearly seventy percent of the District’s residents are obese; and five or more servings of fruits and vegetables are not a part of their daily diet in over seventy five percent of the population. In all categories, the district compares negatively to the state. (Figure 16) The amount one exercises is related to the level of income and education: those with a lower income and education exercise less frequently than those in the higher income and education brackets. The largest group of smokers is under the age of 65. The survey is supported by the comments of the Key Leaders and Focus Group participants (see next section). The Key Leaders previously noted the prevalence of tobacco use and obesity in the community.

Figure 16 BRFSS Lifestyle questions

* indicates a significant statistical difference between health district and state data; 1 - represents adults no physical activity of exercise during the past 30 days other than their regular job; 2 - represents adults who consume five or more servings of fruits or vegetables per day; 3 - represents adults with body mass index greater than 25.00 (overweight or obese); 4 - smoked 100 cigarettes in a lifetime and smoke today either daily or some days; 5 - smoked 100 cigarettes in a lifetime and do not currently smoke.
Compared to the state, fewer people in the health district have health insurance. (Figure 17) BRFSS reports that almost twenty percent of the district is uninsured, a number which is supported by the U.S. Census Bureau’s American Community Survey.\(^{23}\) Cost is a prohibitive factor in seeking health care for twenty percent of adults surveyed, a factor supported by focus groups, Key Leaders and the Physician Survey. A closer look at these items reveal that:

- Cost of health care affects even the highest income brackets
- The younger the adult and the less educated, the less likely to be insured.
- 25% without a primary physician

**Figure 17:** BRFSS Healthcare Access questions

![Health Care Access](image)

* 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;

Compliance to recommended cancer screenings was similar to the rest of the state except for the district’s lack of compliance for colorectal screening using the Fecal Occult Blood test. (Figure 18)

A closer look at the Compliance data reveals having screening tests is a function of insurance status.

- Men with insurance are more likely to have the PSA for prostate (59% vs 27%)
- Women with insurance are more likely to have a mammogram (84% vs 48%)

This substantiates the Key Leaders and the physicians’ statements that cost is the main factor in screening compliance.

\(^{23}\) US Census Bureau: American Community Survey; 2008-2010 3 year survey: Table 2S2701; http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_3YR_S2701&prodType=table accessed 1/1/2012
Focus Group Information
Focus Group participants were selected from the pool of volunteers who responded to flyers placed in physician offices, stores, markets, meeting venues, and churches throughout the district. 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 in the four general population and four survivor groups. While the community is almost equal male: female, the final ratio of male to female for the focus group was about 1:3. Age, race, education and economic distribution were better matched. Residential representation was also considered. The only distinct area with a notable population not represented was the town of Hurt, the northern most community of the district. The last criterion used for selection was personal experience with cancer. The survivors 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. Three meetings were held at The Institute for Advanced Learning and Research at the intersection of Route 29 and Route 58; one at First Presbyterian Church on Main Street, Danville; one at Trinity Methodist Church on Arnett Blvd, Danville and three at Open Bible Baptist Church on Route 29 in Chatham. Three meetings were held during daytime hours and five were in the evening. Because of the unique geography of the district, there was no attempt to separate county from city residents; or separate groups by race or gender. (Figure 19)
Figure 19: Focus Groups in Pittsylvania-Danville

There were 3 focus groups held in Pittsylvania-Danville Health district. A total of 36 participants from the general population attended 4 focus groups, and a total of 27 cancer survivors participated in 4 additional focus groups.

General Population Group Synopsis

Four focus groups with the general population were held in areas distributed throughout the Health District. There were a total of 36 participants, with an attendance between 6 to 12 participants in each group. Participants were aware of major chronic diseases and lifestyle factors that cause or exacerbate the chronic diseases in the community (obesity, tobacco and other substance abuse, sedentary lifestyle, poor diet). Chronic diseases noted repeatedly were heart disease, diabetes, kidney disease and arthritis. There is an overall concern about cancer although it was not the top concern for most participants.

Participants recognized that eating healthy, exercising regularly, controlling weight and avoiding tobacco are essential components in maintaining good health. In addition all groups mentioned the importance of stress management for a healthy lifestyle. Stress management techniques include enough sleep, proper attitude, good self esteem and having a spiritual belief system. They acknowledged that it is not easy to practice a healthy lifestyle and most have difficulty incorporating the components into their daily lives.

The prevailing themes from the general population focus groups included:

- Concern about the state of healthcare in the district: the shortage of providers, denial of access due to lack of insurance or funds, and quality of care at local facilities.
- Confusion about nutrition and the feeling that mixed messages is a marketing strategy: “Are eggs good or bad for you?” “Do people really know (what is in the food)?” Most have little confidence in reading labels properly. One apparent food savvy person
said “if you can’t pronounce it, you shouldn’t eat it”. Several county residents brought up that it is difficult to buy fresh foods when they shop only once a month. Canned goods are cheaper, store better and have less waste

- Difficulty in following a healthy lifestyle is blamed on not having time to exercise and inconvenience. While many residents enjoy the River Walk Trail in the city, the county has no equivalent facility. When some bemoaned the costs of gyms and exercise classes, others mentioned the Danville Parks and Recreation Department’s many activities offered throughout the year.

- Obesity is a pervasive problem within our community, even while agreeing that:
  - “Being obese no longer carries the stigma that it once did”
  - “Being overweight should not be a problem as long as a person is able to do the things they want to do”

Several participants expressed a desire to have another community weight loss challenge. They claimed success in a previous challenge (Live Healthy America Challenge) and would like to see a future one expanded for more involvement. Most participants had no knowledge of previous challenges.

- The addictive nature of tobacco and the link of using to many health problems: They noted that the use of tobacco product is less socially acceptable than it was previously. No one could name an effective means for cessation or of specific programs in the district. All agreed that tobacco prevention is the key and the program must start early, before children begin using products.

- Concerns about the environment: Past, present and future industries were named as culprits for poor water quality and general pollution. City residents were concerned about asbestos and lead paint: county residents about agricultural contamination into well water.

- Lack of knowledge on cancer screening guidelines. Most did not know when or where to be screened. Fear of procedure and lack of funds were primary reasons for not being screened.

- Distrust of institutions responsible for cancer research and drug testing: In every group, there were individuals that believe there is already a cure, that the pharmaceutical companies are “holding out”.

- Attitudes about clinical trials: Being used as “guinea pigs”; getting a sugar pill rather than a real treatment, funds raised used for questionable practices, were common comments in all of the groups.

- Willingness to learn and help: after “cancer clinical trial” was defined, all of the participants feel that it is important to have clinical trials available at the local level.

Cancer Survivor Group Synopsis

The Cancer survivor group participants either had been diagnosed with cancer or were the primary care giver (living in the house, going to appointments, tending to personal needs, thus having an intimate knowledge of what the patient experienced) of a person with cancer. Most caregivers had lost at least one loved one to 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 in the survivors’ groups were:

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

Four focus groups with cancer survivors were held in areas distributed throughout the Health District. There were a total of 25 participants, with an attendance between 4-10 participants in each group. The majority of the survivors obtained screening, diagnosis and treatment in Danville. The recurring theme for this group was the extended wait at the oncologist’s office on appointment day. There is great concern from the survivors of not having a sufficient number of oncologists. The survivors not treated locally offered a variety of reasons for leaving the area:

- not able to treat specific cancer locally
- bad experience with provider or facility
- unable to get surgical procedure desired
- insurance/Medicare requirements
- family/friends encouraged them to go elsewhere.

At the time of diagnosis, few survivors were provided with printed information. Most stated that at the time, they believed they were provided with enough information. However, as time passed, many wanted to learn more about their diagnosis and the lack of information added to their sense of being overwhelmed. The majority of the survivors searched for any information they could find in libraries, on the internet and from friends and family. They felt “Knowledge is power”. Others were confused by their quest for knowledge and resorted to depending on only what the physician provided. The “Knowledge is power” group felt better prepared to ask questions. The ones who did not research stated they had questions, but did not know where or what to begin asking. Both groups stated it was difficult to discern reliable information and that it was easy to get information overload: “sometimes, you just have to put it down and think about something else”.

Several breast cancer patients of a local surgeon had an opportunity to meet with a volunteer survivor at the office. This experience with lay navigation with someone who had gone through the same journey was seen as invaluable in preparing them for their own journey.

None of the survivors expressed an inability to obtain care, though a few shared stories of delayed diagnosis, dissatisfaction of local care and the need to go elsewhere for diagnosis and treatment. Several patients were required to go out of town for insurance or Medicare related issues. Most denied problems with communication between the oncologist and primary care provider. Many post treatment survivors continue to utilize the oncologist for follow-up care and combine that with a routine annual physical.

Only about half of the survivors had utilized local support resources, primarily Danville Cancer Association, to obtain financial aid for medication and transportation and aesthetic aids. Others had not heard of the organization or felt they would not qualify for assistance.
The most beneficial support came from family, friends, and church family. Assistance with daily household chores, yard work, meals, transportation and child care are the most appreciated support services post surgery and during treatment. Survivors have heard about services offered at “cancer centers”, such as yoga, massage and nutrition classes and would like to see these offered in the district.

The Key Leaders’ and the Hospice administrators’ comments about end of life care were reiterated by the caregivers within the survivors groups. Few participants recognized the phrase “Palliative care”, fewer had utilized Hospice. Of those who did, (caregiver survivors) all stated that they wished they had called in Hospice earlier, but did not know how or were discouraged by the physician.

Few of the survivors had been offered participation in a clinical trial. Of these, only one qualified and participated. The attitudes toward clinical trials were similar to those of the general population groups. There was a willingness to consider a trial and an insistence that they should be available locally.
Based on the qualitative and statistical information gathered for this project, the following are recommendations/suggestions for action.

- Work to include cancer risk reduction information in existing programs aimed at adopting healthy lifestyles to reduce chronic disease: diet, exercise and tobacco cessation
- Develop innovative programs directed at cancer prevention and lowering risks
- Develop education programs on early detection of cancer; signs and symptoms and screening guidelines.
- Work with health care providers and facilities to improve access to and utilization of cancer screening opportunities
- Improve utilization of the Every Woman’s Life program;
- Establish a community wide Patient Navigation program which will serve to:
  - Guide people to cancer screening by working in the community in various venues.
  - Lead those with suspicious findings to more timely diagnosis
  - Explore with the newly diagnosed and their physician the treatment options available both locally and out of area.
- Effectively engage the at risk communities, particularly minorities and underserved, with programs addressing risk reduction, early detection and treatment, and access to care to reduce the cancer mortality disparity that exists in the health district.
- Increase awareness of and community support of existing survivor support agencies
- Establish community cancer support groups across the health district to be more accessible to the survivors
- Increase the public awareness and acceptance of Hospice care and options for end-of –life care
- Provide continuing education opportunities to medical providers to learn more about end-of life care and palliative care
- Assist the hospital and medical practices in recruiting more primary care providers and oncology specialists
Appendix A:
Surveys used to gather data from Healthcare Facilities, Community Resource Organizations, and Key Leader physicians.

Appendix B:
Primary Care Physician Questionnaire

Appendix C:
Focus Group Facilitator Guides

Appendix D:
Cancer Healthcare Resources within the Health District

Appendix E:
Community Cancer Resources within the Health District
APPENDIX A

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

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

Thank you for agreeing to provide information for the needs assessment of cancer services and resources in your area. The information you provide us given your role at

INSERT ORGANIZATION’s NAME

will contribute to our understanding and will ultimately lead to improved cancer services and programs in Southwest Virginia. Your responses will be kept completely confidential and your name will not be included in any report we publish.

FACILITY

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

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

3. Does any other board report oncological data to the state? Yes_____ No_____ Unknown____  
   If YES, what is the name of the board? ____________________________________________  

4. Does the facility have a cancer committee? Yes____ No____ Unknown____  

5. 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____ Othr (please specify) ____________________________________________  

6. Is the list of oncologists that I have documented as being on staff at the hospital accurate?  
   Yes___ No___ Please list all oncologists:  

7. Are services for the following items provided by your oncologists at this facility?  
   Chemotherapy Inpatient: Yes_____ No_____ Outpatient: Yes_____ No_____  
   If NO to Inpatient, where are patients sent for chemotherapy? Radiation therapy Yes____ No____  

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

9. 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.

10. 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 Bipsy (radiology guided)? Yes_____ No____ Unknown____  

   IF RESPONDENT ANSWERED “NO” TO ALL BREAST CANCER SCREENING/DIAGNOSTIC MODALITIES:  
   Where are patients referred for breast cancer diagnostics?

11. Does your facility offer gynecology care? Yes_____ No_____ Unknown____  
   Colposcopy? Yes_____ No_____ Unknown____
IF RESPONDENT ANSWERED “NO” TO COLPOSCOPY:

Where are patients referred for colposcopy?

12. 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____

SURGICAL SERVICES

13. What type of Cancer related surgeries are performed at this facility? (Mark all that apply.)

☐ Breast segmental/complete mastectomy? Yes____ No____ Unknown____ If YES to mastectomy, do you perform sentinel nodes sampling? Yes____ No____

☐ Breast Reconstruction? Yes____ No____ Unknown____ ☐ Gynecologic (hysterectomy/oophorectomy)? Yes____ No____ Unknown____ ☐ Gastrointestinal (resection)

- upper tract Yes____ No____

- lower tract Yes____ No____

☐ Lung? Yes____ No____ Unknown____ ☐ Prostatectomy? Yes____ No____

☐ Other (please specify): ____________________________________________________________

COUNSELING SERVICES

14. Do you have a Registered Dietician to provide nutritional services specific to cancer patients? Yes___ No___

- If YES, is he/she board certified in oncology nutrition? Yes___ No___

• If YES, name of Dietician ________________________________________________________

• If NO, name of general Dietician ________________________________________________

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

  One-on-one assessment and diet prescription? Yes___ No___ Unknown___

  Individual oncology nutrition counseling services? Yes___ No___

  Unknown___ Outpatient oncology nutrition counseling services? Yes___ No___

  Unknown___ Cancer control and prevention education programs? Yes___ No___

15. Do you offer genetic counseling for cancer risk? Yes____ No____

- If YES, Who provides the counseling? (RN, NP, MP, GC, etc.) ______________________

  Are they certified? Yes___ No___

FINANCIAL/INSURANCE

16. 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): ________________________________________________________

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

18. 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.

1. Does the facility have a Federal Wide Assurance number (FWA) required to perform federally sponsored clinical trials? Yes___ No___ Unknown___

2. Does the facility use an Institutional Review Board (IRB)? Yes___ No___

Unknown___ If YES, What is the name of the IRB? _______________________________________

This facility___ Partner hospital___ Name: __________________________

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____

4. 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.

1. What Hospice Services are offered to patients?
   - Inpatient hospice Facility Supported Yes____ No____ Unknown____
   - Facility Supported Private organization Yes____ No____ Unknown____
   - Outpatient hospice Facility Supported Yes____ No____ Unknown____
   - Facility Supported Private organization Yes____ No____ Unknown____

2. Do you have a Palliative Care program? Yes____ No____ Coming soon____
   - If YES, could you describe it?

SUPPORT / EDUCATIONAL PROGRAMS

1. Do you have a cancer patient navigator at this facility? Yes____ No____ Unknown____
   - If YES, for which cancer types?

2. 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____

3. 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

4. What is the major source of funds for your organization? Competitive grants Federal funds Service fees /charges Donations Other
4. What is the primary service population for your organization (check all that apply): Cancer patients Cancer survivors Cancer caregivers/family members Other:

5. What are the qualification criteria for individuals to access your services? Must be uninsured/underinsured Financial qualification No qualification criteria Other:

6. Which of the following cancer related services do you provide? (Check all that apply)
   - Provision of written information on cancer care and support resources
   - Management of cancer support groups
   - Financial support for cancer control/care
   - Funding of projects related to cancer
   Other:

7. How do you advertise your organization and services?
   - Local media
   - Organization website
   - Distribution of pamphlets describing services
   - Word of mouth
   Other:

8. Approximately how many people needing cancer related services do you see annually?
   - < 50
   - 50 – 100
   - 150 – 250
   - > 250

9. What are the areas of need of your organization?
   - Financial support
   - Human resources (skilled employees, volunteers, etc.)
   - Access to experts for consultation
   Other:

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

11. What are the goals of your organization for the next 1 – 5 years?
Physician Key Leader Interviews to inform CME
I. What are the most pressing healthcare deficiencies (personnel, level of training, healthcare facilities and services offered) related to:
   a. The risk reduction of cancer in your community
   b. The detection/diagnosis of cancer in your community
   c. The treatment of cancer
   d. Post-treatment and survivorship care
   e. Palliative/hospice care

II. What are the most pressing needs of primary care physicians in your community related to:
   a. Continuing education related to cancer & cancer survivorship
   b. Patient cancer diagnosis
   c. Patient referral for cancer treatment and communication pre & post treatment
   d. Post-treatment and survivorship care of oncology patients

   e. Palliative/hospice care related to cancer patients __________________________
APPENDIX B

Primary Care Physician Questionnaire
Cancer Needs Assessment VIP Physician Survey

Please complete the survey below. Thank you!

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 the 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:
- [ ] Chester
- [ ] Henrico
- [ ] Pittsylvania-Danville

Please indicate your primary area of practice:
- [ ] Family Medicine
- [ ] Internal Medicine
- [ ] Urology
- [ ] Obstetrics/Gynecology
- [ ] Dermatology
- [ ] Other

1. What are the three most common cancers that are diagnosed in your patients each year (check 3)?
- [ ] Breast
- [ ] Colorectal
- [ ] Prostate
- [ ] Lung
- [ ] Cervical
- [ ] Other

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 (Pap/Smear)
      - [ ] 0-25%
      - [ ] 26-50%
      - [ ] 51-75%
      - [ ] 76-100%
   c. Colorectal
      - [ ] 0-25%
      - [ ] 26-50%
      - [ ] 51-75%
      - [ ] 76-100%

3. What percentage of your age-risk-appropriate male patients would you estimate have cancer screenings for the following cancers according to recommended guidelines?
   a. Colorectal
      - [ ] 0-25%
      - [ ] 26-50%
      - [ ] 51-75%
      - [ ] 76-100%

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

5. What do you feel are the most common reasons your patients chose not to have recommended cancer screenings (check all that apply)?
   - [ ] Financial constraints
   - [ ] Lack of insurance
   - [ ] Fear of being diagnosed with cancer
   - [ ] Don't believe they are necessary
   - [ ] Other

6. For which of the following cancers would you like information on screening challenges and/or updated screening recommendations (check all that apply)?
   - [ ] Breast
   - [ ] Colorectal
   - [ ] Prostate
   - [ ] Lung
   - [ ] Cervical
   - [ ] Other

7. After one of your patients is diagnosed with cancer, where are you most likely to refer them for treatment:
   - [ ] Local surgeon
   - [ ] Surgeon at a Virginia National Cancer Institute Designated Cancer Center (VCU or UVA)
   - [ ] Surgeon outside of Virginia
   - [ ] Other

   Would refer for Medical Oncology to:
   - [ ] Local Medical Oncologist
   - [ ] Oncologist at a Virginia National Cancer Institute Designated Cancer Center (VCU or UVA)
   - [ ] Oncologist outside of Virginia
   - [ ] Other

8. What information coming from the oncology team about your patient is most useful to you? (Check all that apply)
   - [ ] Initial treatment plan
   - [ ] End of treatment note
   - [ ] Pathology report
   - [ ] Operative reports
   - [ ] Follow-up care guidelines
   - [ ] Other

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

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11. For which of the following post-cancer treatment care topics would you like further information? (Please, number in order of interest?)

- Pain Management
- Surveillance of cancer recurrence
- Long-term cancer treatment effects: monitoring and palliation
- End-of-life care and planning
- Genetic counseling for family members of cancer patients
- Wellness and prevention of cancer recurrence
- Other ______________________ (please specify)

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

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

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

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

Focus Group Facilitator Guides
INTRODUCTION TO FOCUS GROUP PROCESS AND INFORMED CONSENT  [7 MINUTES]

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

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

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

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

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

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

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

Does anyone have any questions? [Answer any questions]
WARM-UP [8 minutes]

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

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

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

CANCER IN COMMUNITY: GENERAL DISCUSSION [15 minutes]

So let us get started.

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

2. [IF NO ONE COMMENTS ON CANCER]: What about cancer? Is that something that you think is a health problem in your community? Review list on flip chart.

3. Is getting cancer something that you worry about for yourself?

☐ What kinds of cancer are you most worried about? ☐ What worries you most about getting cancer?

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

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

LIFESTYLE FACTORS: [30 minutes total]

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

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

1. What are some behaviors or ways of living (lifestyles), that may have a good affect on a person’s health? (Assistant lists on flip chart)

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

Review the list.

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

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

8. Do you think that what a person eats, or their eating habits, can affect their chances of getting cancer? (Looking for a count)
   b. If yes, what should a person eat, or what eating habits should they have to stop them from getting cancer?
   c. What foods or eating habits or ways of eating can cause cancer?

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

1. 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?)

2. 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?)

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

Review points made during nutrition discussion before moving on.

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

Exercise

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

12. What do you think of when you hear the word exercise? What about the word ‘physical activity’, is there a difference?

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

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

2. How easy is it for people in your community to be physically active? (PROBE: Where do people go to exercise or get physical activity? What stops people from being more physically active in your community?)
15. What are some ways to make it easier for people in your community to exercise or be physically active? (PROBE: If you were designing a plan or project to help people in your community be physically active, what would it look like?)

Summarize exercise comments before moving on to weight control.

Weight Control Not being overweight was also on the list of things that can improve health.

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

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

18. Do you think that being overweight or obese can increase someone’s chances of getting cancer?

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

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

1. 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?)

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

Summarize weight comments before moving on to weight control.

BREAK

TOBACCO

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

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

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

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

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

27. What do you think would be the best ways to help people stop using tobacco in your community? _
ENVIRONMENTAL FACTORS

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

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

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

DISCUSSION OF CANCER SCREENING [15 minutes TOTAL]

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

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

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

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

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

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

CANCER RESEARCH SECTION [15 MINUTES]

34. Now we are going to talk about research. First, has anyone ever participated in a research study, or know someone who has participated in a research study?

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

35. When you hear the words, “cancer research” what comes into your mind?

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

(Facilitators will give the following definition of cancer research for the purposes of the questions that follow)

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

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

36. Does anyone know someone or heard about someone who participated in a cancer research study?

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

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

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

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

OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]

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

Do a final summary of the information.

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

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

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

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

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

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

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

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

We will be taking a break about half way through our discussion, but if you need to get up before that please do so as quietly as possible. You are free to stop participating in the discussion at any time or even leave.
If you stay to the end of the two-hour period you will receive $50 as our way of saying thanks. If you must leave early you will receive $25. You should have been given a paper to fill out that provides us with the mailing address to which the money should be mailed. A check should arrive within a week of this event. We have also given you a paper with the names and numbers of people you can call in the future if you have questions.

Does anyone have any questions? [Answer any questions]

**WARM-UP [10 minutes]**

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

Tape recorder turned OFF here to maintain confidentiality.]

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

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

Tape recorder turned on here

**Experiences getting cancer information (10 minutes)**

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

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

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

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

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

1. 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.

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

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

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

a. Were there things that made it difficult to get treated?
b. Were/Are there circumstances that affected your decisions about treatment? For example financial circumstances, distance from treatment center, transportation, or work schedules.

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

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

BREAK

Post-Treatment (20 Minutes)
Now we are going to focus on the time after you (or the person you cared for) completed treatment. I would like to stress that the discussion is not about the details of your personal medical history. It is about the experience you had after your treatment was completed.

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

9. Do you think that the physicians are working together in you cancer treatment?

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

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

a. What information would you like to have related to staying healthy.
11. Were you referred to any support services after your treatment? Which? The following questions relate to resources in your local community to support cancer patients and their caregivers. (20 Minutes)

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

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

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

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

CANCER RESEARCH SECTION [15 MINUTES]

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

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

National cancer Institute defines clinical research as:

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

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

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

18. If you were given the option, why did you participate or why did you not participate?
19. How important is it to have cancer research available to people with cancer in your community?

OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]

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

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

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

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

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

Cancer Healthcare Resources within the Health District
### Results of Facilities Questionnaires for Pittsylvania Danville Health District

**Available facilities:** Danville Hematology and Oncology; Danville Regional Medical Center; Center for Radiation Oncology, Danville Diagnostic Imaging Center, Internal Medicine Associates, Danville Gastroenterology Center, OB-Gyn Associates of Danville.

| # of Oncologists 2.5 | Breakout: 1.5 medical oncologists; 1 radiation oncologist |

### Cancer-Related Screenings and Treatment

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<th>Number of Facilities</th>
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<td>breast biopsy</td>
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<td>CT colonography</td>
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### Other Related Services

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### Clinical Trials

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<tr>
<td>OP hospice - facility supported</td>
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<td>OP hospice - private org</td>
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<td>PalCare program</td>
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<td>Patient Navigator</td>
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<td>Contact information for Cancer HealthCare Resources Available in the Pittsylvania Danville Health District</td>
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<td><strong>SCREENING SERVICES</strong></td>
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<td><strong>Mammography</strong></td>
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<tr>
<td>Danville Regional Medical Center Radiology Department:</td>
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</tr>
<tr>
<td>434-799-3883 142 South Main Street  Danville 24541</td>
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<td></td>
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<tr>
<td>Danville Diagnostic Imaging Center:</td>
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<td></td>
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<tr>
<td>434-799-3883 125 Executive Dr.  Danville 24541</td>
<td></td>
<td></td>
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<tr>
<td>OB-GYN Associates of Danville</td>
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<tr>
<td>434-792-7765 101 Holbrook Street  Danville 24541</td>
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<tr>
<td>Danville Women’s Care</td>
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</tr>
<tr>
<td>434-797-7620 927 South Main St  Danville 24541</td>
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<tr>
<td>Every Woman’s Life Pittsylvania Danville Health</td>
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<tr>
<td>434-432-7232 200 H. G. McGee Drive  Chatham 24531</td>
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<td>PATHS</td>
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<td>434-791-4122 705 Main Street  Danville 24541</td>
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<td><strong>Colonoscopy</strong></td>
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<td>Internal Medical Associates</td>
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<td>434-792-4041 101 Holbrook St  Danville 24541</td>
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<tr>
<td>Danville Gastroenterology Center</td>
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<tr>
<td>434-791-1152 501 Rison Street Suite 130  Danville 24541</td>
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<td><strong>Chemotherapy</strong></td>
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<td>Danville Hematology and Oncology</td>
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<td>434-793-0044 125 Executive Dr  Danville 24541</td>
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<td><strong>DIAGNOSIS AND TREATMENT</strong></td>
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<td><strong>Radiation Treatment</strong></td>
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<td>The Center for Radiation Oncology</td>
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<td>434-799-4592 188 S. Main St  Danville 24541</td>
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<td>434-799-5964 159 Executive Dr Suite B  Danville 24541</td>
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<td>Danville Surgical Center</td>
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<td>434-792-7874 201 South Main St Suite 3300  Danville 24541</td>
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<td><strong>Genetic Counseling</strong></td>
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<td>Commonwealth Home Nursing and Hospice</td>
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<td>434-792-4663  Danville</td>
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<td>Legacy Hospice of the Piedmont</td>
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<tr>
<td>434-799-2308  Danville</td>
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APPENDIX E

Community Cancer Resources within the Health District
## PITTSYLVANIA DANVILLE - CANCER RESOURCES SURVEY RESULTS

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<thead>
<tr>
<th>Organization Information</th>
<th>Number of Organizations that have this resource</th>
<th>Health District</th>
<th>Wayles R. Harrison Memorial Fund</th>
<th>Danville Cancer Association, Inc</th>
<th>American Cancer Society</th>
<th>Cancer Resource Center of Southern Virginia</th>
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<th>Number of Organizations that have this resource</th>
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<td>Qualification Criteria to access services</td>
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<td>Must have cancer OR catastrophic illness</td>
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<th>Funding of projects related to cancer</th>
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<td>Funds for living and medical expenses for those affected with cancer</td>
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| Contact info                                    | CFDRR 434-793-0884 541 Loyal St PO Box 1039 Danville VA 24543 | 434-791-3227 2323 Riverside Dr Suite J Danville VA 24540 | 276-656-2579 1079 Spruce St Suite C Martinsville, VA 24112 | 434-766-6650 150 Slayton Ave Danville VA 24541 | Facilitating availability of local services including support groups and financial services local, state, and national. |