# Saving Lives and Reducing Suffering and Death from Cancer in Virginia



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





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

Cancer is a significant health problem in Virginia, impacting the physical, emotional, economic, and social well-being of individuals, their families, and communities. An average of 32,769 Virginia residents are diagnosed with cancer annually,<sup>1</sup> with an average of 13,891 succumbing to their disease.<sup>2</sup> Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease.<sup>3</sup> 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."<sup>4</sup> 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.

<sup>&</sup>lt;sup>1</sup> Statistics provided by the Virginia Cancer Registry (June, 2011), data from 2001 to 2007.

<sup>&</sup>lt;sup>2</sup> Statistics provided by the Virginia Department of Health (June, 2011), data from 2005 – 2009.

<sup>&</sup>lt;sup>3</sup> CDC, National Center for Injury Prevention, WISQARS Leading Causes of Death Reports 1999 – 2007, accessed on November 1, 2011, http://webappa.cdc.gov/cgi-bin/broker.exe.

<sup>&</sup>lt;sup>4</sup> The Virginia Cancer Plan 2008 – 2012, Cancer Plan Action Coalition (CPAC)

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#### 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 Professor, Internal Medicine VCU Health Systems

#### 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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# **EXECUTIVE SUMMARY OF FINDINGS**

The assessment of the Piedmont Health District revealed major issues unique to this district from its historical educational history to the lack of local resources. While the assessment focuses on cancer, it also highlights some underlying problems within the district affecting all aspects of community health. This assessment utilized information gathered from federal, state and local sources. Interviews conducted with physicians, home health directors, hospice directors, and with community focus groups made up of both cancer survivors and general population, provide a framework of community concerns. The confluence of information from all of these sources confirms there are significant healthcare needs in the Piedmont Health District.

Data for this district indicates a high cancer rate relative to the Commonwealth. While the incidence rate is high, the more compelling evidence is the mortality rate. Even for cancers with a lower incidence rate, the mortality rate was higher. For nearly every form of cancer, the mortality rate is higher than the state. Gastro-intestinal, lung, prostate, and breast cancers are the leading killers in this community. Disparities in cancer outcomes and cancer risk related lifestyles exist in the health district related to race/ethnicity, income, and educational attainment.

The healthcare deficiencies recognized by our key leader physicians were echoed by the citizens in the focus group meetings and yet again by home health and hospice agency staff. Those deficiencies include: (1) lack of oncology specialists and general practitioners, (2) health knowledge deficit on the part of citizens and the physicians (3) absence of cancer support services and (4) lack of financial resources.

Only one hospital serves this health district with a population of over 104,000 people. Each county in this health district is designated medically underserved. There is a deficit of specialists serving the district. Many forms of standard cancer treatment are not available within the district including radiation. There are no providers of the Every Woman's Life Program in the district, which had only a 7% utilization rate in 2010. The next closest hospital and treatment services are one hour away and more for some residents, depending on their location in the district. The lone oncology office maintains part-time staff. There are no reconstructive surgical services or complex services such as lung, pancreatic or liver surgery offered in the district.

Hospice services are readily available and cover the district. Services are not utilized to maximum capacity be due to a combination of physician attitude and cultural mores. There were no support groups in this district during the initial completion of this assessment. There have been no clinical trials offered in this district and no clinical research projects until September of 2012 through VCU activities.

Community awareness and education is key to changing the cancer rate. The population needs preventive health and lifestyle programs. Events should highlight local cancer survivors. The faith leadership, particularly within the black community, is a vital resource to be tapped and educated on their role in guiding local behaviors. In effect, this community requires a transformation through education, services offered, and funding.

# INTRODUCTION

Cancer is a significant health problem in the United States, impacting the physical, emotional, economic and social well-being of individuals, their families, and communities. It is estimated that 1,638,910 new cases of cancer will be diagnosed nationally 2012 (American Cancer Society), with 41,380 occurring in Virginia.<sup>1</sup> The State cancer incidence rate of 443.2 newly diagnosed cancers per 100,000 residents ranks 38<sup>th</sup> among the other 49 states and the District of Columbia, and is slightly lower than the national cancer incidence rate of 455.7 (2008)<sup>2</sup>. Cancer was the leading cause of death in Virginia in 2007, surpassing heart disease,<sup>3</sup> with an average of 14,009 residents succumbing to their disease.<sup>4</sup> 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."<sup>5</sup> To accomplish this, an evaluation of the needs specific to defined communities is required. The Virginia Commonwealth University Massey Cancer Center in collaboration with the Virginia Tobacco Indemnification and Community Revitalization Commission performed a comprehensive cancer needs assessment of four communities, defined by Health District. The four Health Districts chosen had a relatively high cancer burden and large medically underserved areas. The comprehensive assessment of cancer needs specific to each community will be used to develop a holistic strategy to improve cancer outcomes that utilizes strategies that are culturally appropriate to these communities.

#### **Methods of Data Collection**

Demographic and economic information was collected to get a general picture of the health district. This data was collected from web-based sources including the U.S. Census Bureau, Department of Health and Human Services, Virginia Workforce Connection, among others. The needs related to cancer prevention, early detection, treatment and survivorship were assessed in five broad categories, *cancer burden*, *cancer healthcare resources*, *community cancer* 

<sup>&</sup>lt;sup>1</sup> Statistics provided by the Virginia Cancer Registry(June, 2011), data from 2001 to 2007.

<sup>&</sup>lt;sup>2</sup> State Cancer Profiles. http://statecancerprofiles.cancer.gov/index.html

<sup>&</sup>lt;sup>3</sup> CDC, National Center for Injury Prevention, WISQARS Leading Causes of Death Reports 1999 – 2007, accessed on November 1, 2011, http://webappa.cdc.gov/cgi-bin/broker.exe.

<sup>&</sup>lt;sup>4</sup> Statistics provided by the Virginia Department of Health (June, 2011), data from 2005 – 2009.

<sup>&</sup>lt;sup>5</sup> The Virginia Cancer Plan 2008 – 2012, Cancer Plan Action Coalition (CPAC)

*resources, healthcare provider needs, community population needs.* Personnel dedicated to data collection included a Data Manager located at the Massey Cancer Center in Richmond, and four Community Health Education Coordinators (CHE) located in their respective health districts. The CHEs were qualified, long-term residents of the Health Districts and were responsible for 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 (<u>http://www.vhi.org/hospital\_region.asp</u>), 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 prestamped hard copy questionnaire, and as an online questionnaire. A list of PCP's in each health district was acquired from the Virginia Board of Medicine website<sup>6</sup>, modified to include only physician's with primary specializations of family practice, internal medicine, urology, dermatology, cardiology, endocrinology, gastroenterology, emergency medicine, obstetrics and gynecology, surgeons, pulmonologists, radiologists, and hospitalists. The list was provided to the CHE's, who checked it for accuracy. All physicians on the final list were asked to complete the questionnaire either via e-mail or by personal visit to the physician's office. Initial contact was followed-up at least once, and potentially twice for non-responders. (**Appendix B**).

#### Community Population Needs

The perspectives and perceived needs of the population living in the Health Districts were gathered in two ways. Data from the National Behavioral Risk Factor Surveillance Survey was acquired from the CDC.<sup>7</sup> 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.

<sup>&</sup>lt;sup>6</sup> Virginia Board of Medicine. http://www.vahealthprovider.com/links.asp

<sup>&</sup>lt;sup>7</sup> BRFSS http://www.cdc.gov/brfss/

## **FINDINGS**

#### **Demographics in Piedmont Health District**

Located near the center of the state, the Piedmont Health District (PHD) includes the seven counties of Amelia, Buckingham, Cumberland, Charlotte, Lunenburg, Nottoway, and Prince Edward. The towns of notable size are Farmville, with the largest population at 6,845, Crewe, and Blackstone. Farmville is the cultural center of the district by size, location, and the presence of two colleges. In addition, Farmville is home to Green Front Furniture, a major retail furniture store for the southeastern United States and the Moton Museum, center of the Brown V. Board of Education Supreme Court case. The district is a very rural region without metropolitan locations. There are no interstates . Highway 460 bisects the district and highways 15 and 360

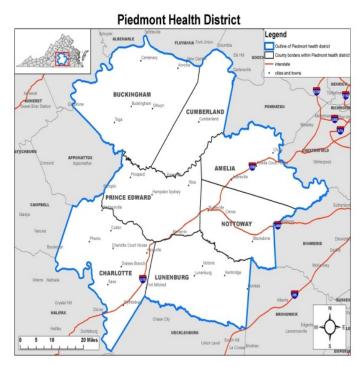


Figure 1: Piedmont Health District

run through portions of the district.

#### (Figure 1)

The district is mainly agricultural with gently rolling terrain inhabited by cattle and tobacco farms. The region remains heavily forested with significant logging. The total population of the Piedmont Health District, according to the US Census Bureau, is 104,609 with the 18 and older age group numbering 83,488. <sup>8</sup> The 65 and older age category represents 19.9% of the population compared to Virginia's rate of 15.9%. This is a popular location for retirees. The racial makeup is 64.6% white, 33.4% black, and 2% for all other races.<sup>9</sup>

The unemployment rate for the Piedmont Health District is higher than Virginia. The average for the district is 9% with a range of 7.4% in Cumberland County to 9.8% in Prince Edward County. <sup>10</sup> Amelia County is the outlier in the District. This county is a bedroom

<sup>&</sup>lt;sup>8</sup> 2010 Census Summary File-1-(Virginia) prepared by the US Census Bureau 2011

<sup>&</sup>lt;sup>9</sup> 2010 Census Summary File-1-(Virginia) prepared by the US Census Bureau 2011

<sup>&</sup>lt;sup>10</sup> www.VirginiaLMI.com

community for Richmond with a high median income of 52,421 (one of the top 10 in the state) and an unemployment rate of 7.6%. <sup>11</sup> (**Tables A & B**).

| Table A                                      |                               |          |          |  |  |
|--|-------------------------------|----------|----------|--|--|
| Demographic Profile of Piedmont vs. Virginia |                               |          |          |  |  |
| Category                                     | Subcategory                   | PIEDMONT | VIRGINIA |  |  |
| Gender                                       | Male                          | 51%      | 48%      |  |  |
| Gender                                       | Female                        | 49%      | 52%      |  |  |
|  | 18-39                         | 36%      | 40%      |  |  |
| 4.00   | 40-49                         | 18%      | 19%      |  |  |
| Age  | 50-64                         | 26%      | 25%      |  |  |
|  | 65+                           | 20%      | 16%      |  |  |
|  | White                         | 64%      | 67%      |  |  |
| Race   | Black or AA                   | 32%      | 18%      |  |  |
|  | Other                         | 4%       | 15%      |  |  |
|  | Hispanic or<br>Latino         | 2%       | 7%       |  |  |
| Ethnicity                                    | Non-<br>Hispanic or<br>Latino | 98%      | 93%      |  |  |

Table A

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

# Table B: Demographic Profile of Piedmont HDvs. Virginia

#### Table B

| Economic Character                                   | Piedmont<br>(average)                                 | Virginia |          |
|--|---|----------|----------|
| Unemployment <sup>1</sup><br>(16 years and<br>older) | Unemployment Rate                                     | 8.21%    | 6.40%    |
| Income <sup>2</sup>                                  | Median Household Income                               | \$39,432 | \$60,316 |
|  | % Less than high school                               | 27.87%   | 14.20%   |
| Education <sup>3</sup>                               | % High school or GED                                  | 39.01%   | 26.30%   |
| (25 years and older)                                 | % Some college, no degree<br>OR an Associate's degree | 20.84%   | 26.00%   |
|  | % Bachelor's degree or above                          | 12.27%   | 33.50%   |

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

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

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

The number of graduates from high school exceeds the state level. However, the number continuing on to higher learning is less than the state level. The percent with a bachelor's degree or more, age 25 or higher, ranges from 9% in Lunenburg County to 19% in Prince Edward. Those in the 25+ age range, with less than high school education, range from 18.1% in Prince Edward County to 36.8% in Buckingham County. <sup>12</sup> Prince Edward County is the only county in the district with four-year degree facilities, which include Hampden-Sydney College and Longwood University. These facilities account for the high percentage of residents with a bachelor's degree or higher within Prince Edward County. A significant outlier for the age 18-24 group was Buckingham County where 47.8% of this group had less than a high school degree. The other counties ranged from 9.4% in Prince Edward to 24.8% in Nottoway County.<sup>13</sup>

The median income in the Piedmont Health District ranges from \$35,963 in Lunenburg to \$48,897 in Amelia. The mean income ranged from \$43,663 in Lunenburg to \$56,667 in Amelia County. The percent of families below the poverty level ranges from 9.1% in Amelia County to 14.5% in Lunenburg County. In the category to include *with related children* those numbers increase from 14.8% in Buckingham to 22.4% in Lunenburg. <sup>14</sup>

<sup>&</sup>lt;sup>11</sup> http://www.vawc.virginia.gov/vosnet/Imi/area/areasummary.aspx

<sup>&</sup>lt;sup>12</sup> http://factfinder.census.gov/servlet/STTable?\_bm=y&-qr\_name=ACS\_2009

<sup>&</sup>lt;sup>13</sup> http://factfinder.census.gov

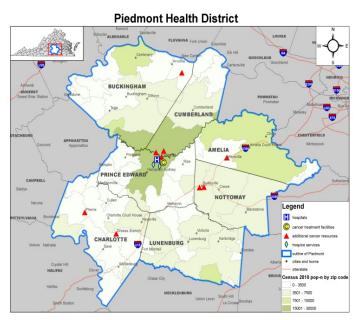
<sup>&</sup>lt;sup>14</sup> http://factfinder.census.gov

#### Access to Healthcare

The Health Resources and Services Authority (HRSA) designates five of the seven counties as rural.<sup>15</sup> Cumberland County has only one census tract designated as rural (tract 51049990200). Amelia County does not have a rural designation. Both Amelia and Cumberland include a large bedroom community from Richmond that has affected their rural status and Amelia's income level. Organizations within the rural designated tracts may apply for Rural Health Outreach, Network Development, or Rural AED Grant Programs.<sup>16</sup> All seven counties are federally designated as both a Health Professional Shortage Area (HPSA) and medically underserved.<sup>17</sup> There is only one hospital within this health district, Centra-Southside Community Hospital (Centra-SCH), located within Farmville town limits. The next closest hospital facilities are located at least one hour from the center of the district.

#### **General Healthcare Services**

General healthcare services in this district are very limited. It can take several days to obtain an appointment with your Primary Care Physician (PCP). Many of the PCP's are not accepting new patients. There is only one hospital located within the seven counties of the PHD. In the farther regions of some of the counties, it can be a 30-minute drive to a doctor's office. There are four community healthcare centers located in Buckingham, the town of Farmville, Lunenburg and Amelia. The town of Farmville is home to The Heart of Virginia Free Clinic that opened in April of 2012. There are two hospice organizations located in the PHD. They do cover the entire district and are adequate given the perceived under utilization of services.



Services such as Meals on Wheels, deliver to those in need, including cancer patients. The only organization in the district that targets cancer patients is the Barksdale Foundation. A Charlotte County family, due to the high cancer rate in their own family, started the Foundation. This foundation gives a onetime grant of \$650 to any individual with cancer residing in Charlotte County.

Availability of physicians limits local services. There are very few specialists at the local hospital or

within the district. At the time of this assessment, the

 <sup>&</sup>lt;sup>15</sup> Human Resources Services Administration; List of Rural Counties And Designated Eligible Census Tracts in Metropolitan Counties; pg. 52;
 < <a href="http://ftp.hrsa.gov/ruralhealth/Eligibility2005.pdf">http://ftp.hrsa.gov/ruralhealth/Eligibility2005.pdf</a>; (accessed 28 October 2011)
 <sup>16</sup> <a href="http://www.vdh.virginia.gov/healthpolicy/primarycare/documents/rural/ORHPRRuralLocatitiesandRUCA.pdf">http://www.vdh.virginia.gov/healthpolicy/primarycare/documents/rural/ORHPRRuralLocatitiesandRUCA.pdf</a>

<sup>&</sup>lt;sup>16</sup> <u>http://www.vdh.virginia.gov/healthpolicy/primarycare/documents/rural/ORHPRRuralLocatitiesandRUCA.pdf</u> <sup>17</sup> http://muafind.hrsa.gov/index.aspx

specialists included a pulmonologist, urologist, and a cardiology practice. The HOPE Center provides limited oncology care onsite on hospital grounds. There is a new gastroenterologist providing services as of August, 2012 after a two year void in services. (**Figure 2**)

#### **Cancer Burden**

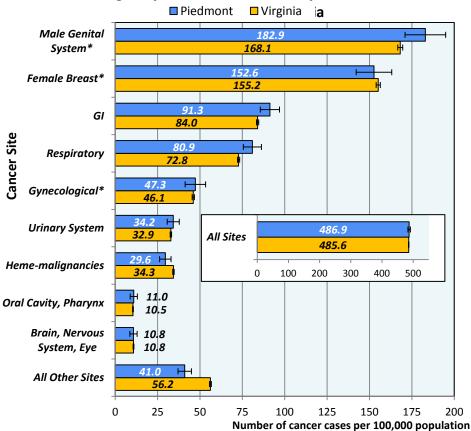
#### Cancer Incidence

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 gastrointestinal/colorectal, respiratory/lung, urinary system, heme-malignancies, oral cavity-pharynx, brain-nervous system-eye and all other sites combined. Cancer incidence rates are age adjusted; so that the Piedmont Health District's higher percentage of elderly (by five percent) does not confound the data. (**Table C/Figure 3**)

| Age-Adjusted Cancer Incidence Rates in Piedmont Health District vs. |          |          |  |  |  |  |
|---|----------|----------|--|--|--|--|
| Virginia  |          |          |  |  |  |  |
| Cancer Site   | Piedmont | Virginia | Notes  |  |  |  |
| Male Genital System   | 182.2    | 167.7    | Data Source:   |  |  |  |
| Prostate  | 178.1    | 162.0    | Virginia Cancer Registry (averaged                                 |  |  |  |
| Other male genital organs   | 4.1      | 5.7      | rates for1999-2008) – all rates<br>calculated based on populations |  |  |  |
| Female Breast   | 119.8    | 124.3    | including all ages.  |  |  |  |
| GI System   | 86.0     | 79.8     |  |  |  |  |
| Colon & Rectum  | 53.5     | 47.5     | Dataset ordered by descending rate                                 |  |  |  |
| All Other GI  | 32.5     | 32.3     | for health district.   |  |  |  |
| Respiratory   | 80.4     | 72.5     | Age-Adjusted Rate - represents an                                  |  |  |  |
| Gynecological   | 46.2     | 44.4     | age-adjusted number of new   |  |  |  |
| Corpus and Uterus   | 22.8     | 21.8     | cancer cases per 100,000   |  |  |  |
| Ovary   | 12.7     | 12.1     | populations.   |  |  |  |
| Cervix  | 8.1      | 7.2      | Rate for Male Genital System is                                    |  |  |  |
| All other Gynecological   | 2.6      | 3.4      | shown per 100,000 males; Rates                                     |  |  |  |
| Urinary System  | 34.0     | 32.4     | for Gynecological and Female                                       |  |  |  |
| Heme-malignancies   | 29.6     | 34.3     | Breast are shown per 100,000<br>females.                           |  |  |  |
| Lymphomas   | 14.5     | 19.5     | ,  |  |  |  |
| Leukemias   | 9.6      | 9.7      |  |  |  |  |
| Myeloma   | 5.5      | 5.2      |  |  |  |  |
| Oral Cavity, Pharynx  | 10.7     | 10.3     |  |  |  |  |
| Brain, Nervous System, Eye  | 6.1      | 6.5      |  |  |  |  |
| All Other Sites   | 33.1     | 44.5     |  |  |  |  |
| All Sites   | 450.0    | 446.6    |  |  |  |  |

#### Table C

#### Figure 3:



# Age-Adjusted Incidence Rate by Cancer Site - Piedmont

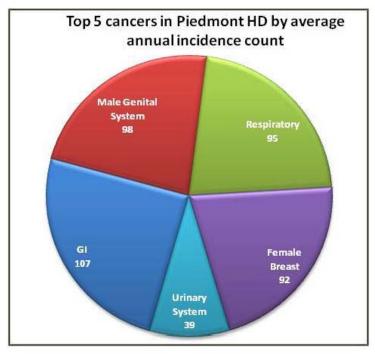
\* Rate for Male Genital System is shown per 100,000 males; Rates for Gynecological and Female Breast are shown per 100,000 females. <u>Data Source:</u> Virginia Cancer Registry(averaged rates for1999-2008) – all rates calculated based on populations including all ages.

To evaluate the impact of cancer in the community in terms of provider burden and services needed, information on the annual number of cancer cases diagnosed was acquired from the Virginia Cancer Registry. In the Piedmont Health District, there are an average of five hundred and sixty-six (566) cases of new cancer each year (**Table D/Figure 4**) based on a 10 year average (1999-2008). Gastro-intestinal, male genital, respiratory and female breast make up the greatest burden of cancers, with urinary system cancers a distant fifth. Together they make up 76% of the total cases.

#### Table D

| Top 5 Cancers in Piedmont Health District by Incidence Count |                 |  |  |  |  |
|--|-----------------|--|--|--|--|
| Cancer Site  | Annual<br>Count | Notes  |  |  |  |
| GI System  | 101             | Data Source:   |  |  |  |
| Colon & Rectum   | 63              | Virginia Cancer Registry   |  |  |  |
| All Other GI   | 38              |  |  |  |  |
| Male Genital System  | 98              | Annual Count - represents average                                    |  |  |  |
| Prostate   | 96              | number of new cases per year in                                      |  |  |  |
| Other male genital organs                                    | 2               | the health district (averaged over period 1999-2008).                |  |  |  |
| Respiratory  | 95              |  |  |  |  |
| Female Breast  | 72              | All Other Sites include Brain,                                       |  |  |  |
| Urinary System   | 40              | Nervous System, Eye,   |  |  |  |
| All Other Sites  | 118             | Gynecological, Oral Cavity, Pharynx,<br>Heme-malignancies, and Other |  |  |  |
| All Sites  | 524             | sites.   |  |  |  |



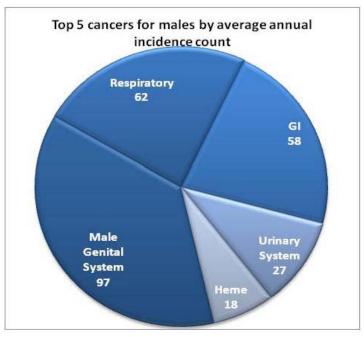


The incident rate for all cancers in the Piedmont Health District is higher in males than in females (610 vs 518). Males have respiratory cancers at twice the rate and gastrointestinal and heme-malignancies at a substantially higher rate than females. The cancer with the highest incidence rate for males is male genital cancer, principally prostate cancer. This is followed by respiratory and gastrointestinal cancers, with urinary system cancers a distant fourth. In females, breast cancer has the highest incidence rate followed by gastro-intestinal cancers Respiratory and gynecologic cancers follow. (Tables E & F; Figures 5 & 6)

# Table E

| Cancer Site               | Crude<br>Rate | Annual<br>Count | Data Source:                               |
|---------------------------|---------------|-----------------|--|
| Male Genital System       | 193.5         | 97              | Virginia Cancer                            |
| Prostate                  | 189.5         | 95              | Registry                                   |
| Other male genital organs | 4             | 2               | Crude Rate -                               |
| Respiratory               | 123.7         | 62              | represents number                          |
| GI                        | 115.7         | 58              | of new male cancer<br>cases per 100,0000   |
| Colon & Rectum            | 69.8          | 35              | males                                      |
| All other GI              | 45.9          | 23              |  |
| Urinary System            | 53.9          | 27              | <u>Annual Count</u> -<br>represents actual |
| Heme-malignancies         | 35.9          | 18              | average number of                          |
| Lymphomas                 | 18            | 9               | male cancer cases<br>per year in the       |
| Leukemias                 | 10            | 5               | health district                            |
| Myeloma                   | 6             | 3               | (averaged over<br>period 1999-2008).       |
| All Other Sites           | 45.9          | 23              |  |
| All Sites                 | 610.4         | 306             |  |

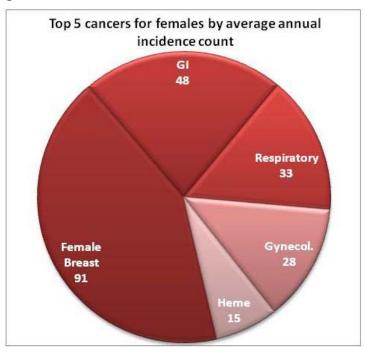




#### Table F

| Top 5 Female Cancers in Piedmont |               |                 |  |  |  |  |
|----------------------------------|---------------|-----------------|--|--|--|--|
| Cancer Site                      | Crude<br>Rate | Annual<br>Count | <u>Data Source:</u>                    |  |  |  |
| Female Breast                    | 181.5         | 91              | Virginia Cancer                        |  |  |  |
| GI                               | 95.7          | 48              | Registry                               |  |  |  |
| Colon & Rectum                   | 65.8          | 33              | <u>Crude Rate</u> –                    |  |  |  |
| All other GI                     | 29.9          | 15              | represents number                      |  |  |  |
| Respiratory                      | 65.8          | 33              | of new female<br>cancer cases per      |  |  |  |
| Gynecological                    | 55.9          | 28              | 100,0000 females                       |  |  |  |
| Corpus and Uterus                | 27.9          | 14              | Annual Count -                         |  |  |  |
| Ovary                            | 14            | 7               | represents actual                      |  |  |  |
| Cervix                           | 8             | 4               | average number of                      |  |  |  |
| All other Gynecological          | 4             | 2               | female cancer cases<br>per year in the |  |  |  |
| Heme-malignancies                | <b>29</b> .9  | 15              | health district                        |  |  |  |
| Lymphomas                        | 14            | 7               | (averaged over                         |  |  |  |
| Leukemias                        | 8             | 4               | period 1999-2008).                     |  |  |  |
| Myeloma                          | 6             | 3               |  |  |  |  |
|                                  |               |                 |  |  |  |  |
| All Other Sites                  | 43.9          | 22              |  |  |  |  |
| All Sites                        | 518.6         | 260             |  |  |  |  |

# Figure 6:



Although African Americans have an overall higher rate of cancer than whites, there are variations in the prevalent cancers for the races (**Tables G & H**). Prostate cancer occurs at almost twice the rate in African American males than in white males (223.5 vs 129.3). Black females have breast cancer at a notably higher rate than white females (141.4 vs 125.1). Gastrointestinal cancers occur in African Americans at a higher rate than in the white population, while respiratory cancers occur at a higher rate in whites (104.5 vs 76.4; 75.9 vs 82.9). Whites have a higher incidence of gynecological cancer (39.6 vs 54.8).

| Top 5 Cancers in Piedmont for African American population |                       |                                |          |   |  |  |
|---|-----------------------|--------------------------------|----------|---|--|--|
|   | 10-year<br>case count | Age-adjusted<br>incidence rate |          | Data Source:  |  |  |
| Cancer Site   | Piedmont              | Piedmont                       | Virginia | Virginia Cancer Registry<br>10-year case count –                |  |  |
| Male Genital System                                       | 451                   | 223.5                          | 213.1    | represents number of cancers                                    |  |  |
| Prostate  | 447                   | 221.0                          | 211.0    | reported to the registry for                                    |  |  |
| Other male genital organs                                 | ~                     | ~                              | 1.9      | African American patients from 1999-2008.                       |  |  |
| Female Breast   | 265                   | 141.4                          | 134.6    |   |  |  |
| GI  | 409                   | 104.5                          | 101.2    | <u>Age-Adjusted Incidence Rate</u> -<br>represents age-adjusted |  |  |
| Colon & Rectum  | 238                   | 60.9                           | 57.2     | cancer incidence rate for                                       |  |  |
| All other GI  | 171                   | 43.5                           | 44.0     | African Americans for the                                       |  |  |
| Respiratory   | 298                   | 75.9                           | 78.0     | health district (compared to state).                            |  |  |
| Gynecological   | 75                    | 39.6                           | 43.1     | 10 2122 AND 00 20   |  |  |
| Corpus and Uterus   | 39                    | 20.3                           | 20.7     | * Cancers not shown had no                                      |  |  |
| Ovary   | 23                    | 12.3                           | 10.2     | reportable rate in the health district, due to data             |  |  |
| Cervix  | ~                     | ~                              | 9.0      | suppression.  |  |  |
| All other Gynecological                                   | ~                     | ~                              | 3.3      |   |  |  |
|   |                       |                                |          |   |  |  |
| All Other Sites   | 74                    | 19.5                           | 25.1     |   |  |  |
| All Sites   | 1,839                 | 472.7                          | 472.4    |   |  |  |

#### Table G

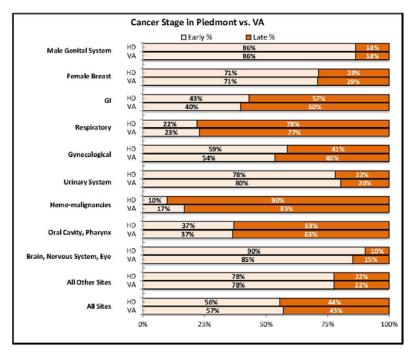
#### Table H

| Top 5 Cancers in Piedmont for White population |                       |                                |          |   |  |
|--|-----------------------|--------------------------------|----------|---|--|
|  | 10-year<br>case count | Age-adjusted<br>incidence rate |          | Data Source:                                      |  |
| Cancer Site                                    | Piedmont              | Piedmont                       | Virginia | Virginia Cancer<br>Registry                       |  |
| Male Genital System                            | 521                   | 129.3                          | 138.5    | <u>10-year case count</u> –                       |  |
| Female Breast                                  | 465                   | 125.1                          | 134.3    | represents number of                              |  |
| Prostate                                       | 506                   | 124.1                          | 131.8    | cancers reported to the<br>registry for White     |  |
| Other male genital organs                      | ~                     | ~                              | 6.7      | patients from 1999-                               |  |
| Respiratory                                    | 652                   | 82.9                           | 72.5     | 2008.   |  |
| GI   | 595                   | 76.4                           | 75.1     | Age-Adjusted Incidence                            |  |
| Colon & Rectum                                 | 388                   | 49.4                           | 45.7     | <u>Rate</u> - represents age-                     |  |
| All other GI                                   | 207                   | 27.1                           | 29.3     | adjusted cancer<br>incidence rate for             |  |
| Gynecological                                  | 199                   | 54.8                           | 48.3     | White population for                              |  |
| Corpus and Uterus                              | 102                   | 27.2                           | 23.9     | the health district                               |  |
| Ovary  | 53                    | 14.4                           | 13.7     | (compared to state).                              |  |
| Cervix   | 31                    | 9.7                            | 6.9      | * Cancers not shown                               |  |
| All other Gynecological                        | ~                     | 0.0                            | 3.8      | had no reportable rate<br>in the health district, |  |
|  |                       |                                |          | due to data                                       |  |
| All Other Sites                                | 293                   | 39.8                           | 48.2     | suppression.                                      |  |
| All Sites                                      | 3,373                 | 438.3                          | 442.4    |   |  |

#### Cancer staging & mortality

For proper treatment planning, cancer must be staged. Discovering cancer at the local stage is usually indicative of a better outcome and improved survivorship. Nearly eighty percent of respiratory cancers are found in a late stage, similar to the Commonwealth as a whole. Over half of all gastro-intestinal/colorectal cancers are found in late stage, as are oral cancers. Less than half of gynecologic cancers are diagnosed at a late stage, and most male genital/prostate, brain group, urinary and female breast cancers are detected while in early stage. (Figure 7)

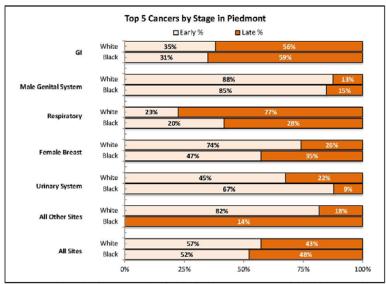
A higher percentage of female breast cancers in black women are found in the late stage when compared to white women in this district, similar to the Commonwealth and Nation as a whole. Gastrointestinal and male genital cancers also show a slightly higher percentage of whites staged at an early stage vs. blacks. Respiratory cancer, which is found at a higher rate in whites, is found in the late stage at a higher percent in whites than in blacks. Of note, the local pulmonologist, Dr. Donkor, is originally from Ghana. Urinary cancer is found at an early stage in a larger proportion of the black population versus the white population. (**Figures 8**)



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

Handreich nied werden gemeinter der gemeinter der gemeinter Virginia state? Handreich Beiter der Mitter der Virginia state? <u>Early</u> stage combines "In Situ" and "Local" cancer stages; <u>Late</u> stage combines "Regional" and "Distant" stages. Data presents cancer cases with reported stage only. Percentage of anstaged cancer cases was eliminated from calculations. Data Source: Virginia Cancer Registry (1999-2008) – all percentages calculated based on populations including all ages.





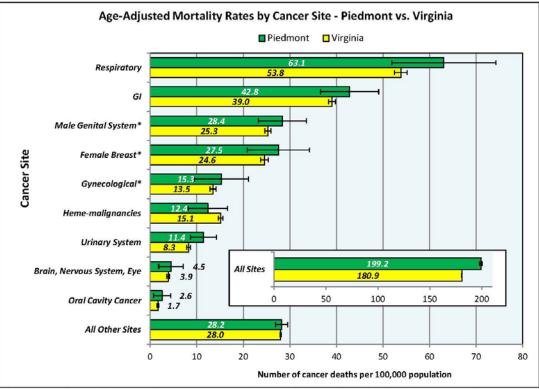
\* Top 5 cancers selected based on greatest number of people affected per year (on average) in the health district—see Table C. <u>Early</u> stage combines 'in Situ' and 'ilocal' cancer stages; <u>late</u> stage combines 'Regional' and 'Ilostant' stages. Data presents cancer cases with reported stage 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 8: Cancer Stage at Diagnosis by Race

Approximately 244 residents of the Piedmont Health District succumb to cancer related causes each year based on a ten-year span (1998-2008). The cancer sites with the highest mortality rates in Piedmont Health District are respiratory, gastro-intestinal, female breast, hematologic cancers, and urinary system in that order (**Table I**). In contrast to incident cases, the majority of deaths from the gastrointestinal group are due to GI cancers other than colorectal. Cancer mortality rates for all cancers as a whole are significantly higher in the health district than the Commonwealth. Only urinary system cancers appear to have a significantly higher mortality rate. (**Figure 9**).

| Top 5 Cancers in Piedmont Health District by Annual |           |  |  |  |  |  |
|---|-----------|--|--|--|--|--|
| Death Count   |           |  |  |  |  |  |
| Cancer Site   | Annual #  | <u>Data Source:</u>                              |  |  |  |  |
|   | of deaths | Virginia Department of                           |  |  |  |  |
| Respiratory   | 78        | Health (averaged counts                          |  |  |  |  |
| GI  | 53        | for 5-year period 2005-<br>2009) - based on      |  |  |  |  |
| All other GI  | 29        | population for all ages.                         |  |  |  |  |
| Colon & Rectum                                      | 24        | Deterate address differ                          |  |  |  |  |
| Female Breast                                       | 17        | Dataset ordered by<br>descending death numbers   |  |  |  |  |
| Heme-malignancies                                   | 15        | for health district.                             |  |  |  |  |
| Leukemias   | 6         | All Other Sites include                          |  |  |  |  |
| Lymphomas   | 5         | Brain, Nervous System,                           |  |  |  |  |
| Myeloma   | 4         | Eye, Oral Cavity, Pharynx,                       |  |  |  |  |
| Urinary System                                      | 14        | Gynecological, Male<br>Genital System, and Other |  |  |  |  |
| All Other Sites                                     | 67        | sites.   |  |  |  |  |
| All Sites   | 244       |  |  |  |  |  |

#### Table I



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

Women have higher overall cancer mortality rates than men in the Piedmont Health District (226.3 vs 133). For both men and women, respiratory and gastrointestinal cancers have the highest cancer mortality rates and cause the highest average annual cancer related deaths in the district. The mortality rate for women is twice that of men for gastrointestinal cancer and notably higher for respiratory malignancies. Breast and male genital cancer is the third highest cancer killer in females and males respectively. (**Tables J and K**)

# Table J

| Top 5 Cancers for Males in Piedmont by Annual Death Count |               |                 |  |  |  |  |
|---|---------------|-----------------|--|--|--|--|
| Cancer Site   | Crude<br>Rate | Annual<br>Count | Data Source:   |  |  |  |
| Respiratory   | 95.3          | 49              | Virginia Department of Health (2005-   |  |  |  |
| GI  | 56.0          | 29              | 2009) – rates calculated based on<br>population for all ages.                    |  |  |  |
| All other GI  | 34.2          | 18              | population for an ages.  |  |  |  |
| Colon & Rectum  | 21.8          | 11              | Dataset ordered by descending count  |  |  |  |
| Male Genital System                                       | 26.9          | 14              | for health district.   |  |  |  |
| Prostate  | 26.1          | 13              | <u>Crude Rate</u> - represents number of   |  |  |  |
| Other male genital organs                                 | 0.8           | 0               | male cancer deaths per 100,000   |  |  |  |
| Urinary System  | 19.1          | 10              | males.   |  |  |  |
| Heme-malignancies   | 17.1          | 9               | <u>Annual Count</u> - represents average   |  |  |  |
| Lymphomas   | 6.6           | 3               | number of male cancer deaths per<br>year in the health district (averaged        |  |  |  |
| Leukemias   | 6.6           | 3               | over period 2005-2009).  |  |  |  |
| Myeloma   | 3.9           | 2               |  |  |  |  |
| All Other Sites   | 44.0          | 23              | All Other Sites include Brain, Nervous<br>System, Eye, Oral Cavity, Pharynx, and |  |  |  |
| All Sites   | 258.4         | 133             | Other sites.   |  |  |  |

#### Table K

| Top 5 Cancers for Females in Piedmont by Death Count |               |                 |  |  |  |
|--|---------------|-----------------|--|--|--|
| Cancer Site  | Crude<br>Rate | Annual<br>Count | Data Source:   |  |  |
| Respiratory  | 58.9          | 29              | Virginia Department of Health (2005-   |  |  |
| GI   | 48.7          | 24              | 2009) – rates calculated based on population for all ages.                   |  |  |
| Colon & Rectum                                       | 25.2          | 12              | ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,                                      |  |  |
| All other GI   | 23.6          | 12              | Dataset ordered by descending count  |  |  |
| Female Breast  | 35.3          | 17              | for health district.   |  |  |
| Gynecological  | 20.7          | 10              | Crude Rate - represents number of  |  |  |
| Ovary  | 11.4          | 6               | female cancer deaths per 100,000 females.                                    |  |  |
| Cervix   | 4.9           | 2               | jennules.  |  |  |
| Corpus and Uterus                                    | 2.8           | 1               | Annual Count - represents average  |  |  |
| All other Gynecological                              | 1.6           | 1               | number of female cancer deaths per<br>year in the health district (averaged  |  |  |
| Heme-malignancies                                    | 13.0          | 6               | over period 2005-2009).  |  |  |
| Leukemias  | 4.5           | 2               |  |  |  |
| Myeloma  | 4.5           | 2               | All Other Sites include Brain, Nervous<br>System, Eye, Oral Cavity, Pharynx, |  |  |
| Lymphomas  | 4.1           | 2               | Urinary System, and Other sites.   |  |  |
| All Other Sites                                      | 49.6          | 24              |  |  |  |
| All Sites  | 226.3         | 111             |  |  |  |

Overall, blacks have a greater mortality rate from cancer than do whites in the Piedmont Health District (213.8 vs 191.9). Respiratory cancers are the number one cancer killer for both racial populations, with whites succumbing at a slightly higher rate. Gastrointestinal cancers have the second highest mortality rate for whites and male genital cancers for blacks. Black males die at greater than twice the rate from prostate cancer than do white males and female breast cancer claims the lives of black females at a slightly higher rate than white females. The difference in mortality rates between the races is reflective of state trends. (**Tables L and M**)

| Table L |
|---------|
|---------|

| Top 5 Cancers in Piedmont for African American Population by Mortality |                          |                                |          |  |
|--|--------------------------|--------------------------------|----------|--|
|  | 5-year<br>death<br>count | Age-adjusted<br>mortality rate |          | <u>Data Source:</u><br>Virginia Department of Health                       |
| Cancer Site  | Piedmont                 | Piedmont                       | Virginia | <u>5-year death count</u> – represents<br>number of cancer deaths reported |
| Respiratory  | 124                      | 60.9                           | 59.6     | for African American population<br>from 2005-2009.                         |
| Male Genital System  | 40                       | 51.8                           | 51.6     |  |
| Prostate   | 39                       | 50.8                           | 51.2     | <u>Age-Adjusted Mortality Rate</u> -<br>represents age-adjusted cancer     |
| Other male genital organs  | 1                        | 1.1                            | 0.4      | mortality rate for African American  |
| GI   | 100                      | 49.7                           | 54.9     | population for the health district   |
| All other GI   | 55                       | 27.2                           | 31.2     | (compared to state). Top 5 Cancers<br>are based on Age-Adjusted            |
| Colon & Rectum   | 45                       | 22.5                           | 23.6     | Mortality Rate.  |
| Female Breast  | 33                       | 30.7                           | 33.6     | All Other Sites include Brain,   |
| Gynecological  | 17                       | 14.1                           | 14.3     | Nervous System, Eye, Oral Cavity,  |
| Ovary  | 9                        | 6.9                            | 6.7      | Pharynx, Heme-malignancies,  |
| Cervix   | 4                        | 3.7                            | 3.3      | Urinary System, and Other sites.   |
| Corpus and Uterus  | 4                        | 3.5                            | 3.2      |  |
| All other Gynecological  | 0                        | 0.0                            | 1.0      |  |
| All Other Sites  | 116                      | 57.7                           | 59.1     |  |
| All Sites  | 430                      | 213.8                          | 220.3    |  |

#### Table M

| Top 5 Cancers in Piedmont for White Population by Mortality |                          |                                |          |  |  |
|---|--------------------------|--------------------------------|----------|--|--|
|   | 5-year<br>death<br>count | Age-adjusted<br>mortality rate |          | <u>Data Source:</u><br>Virginia Department of Health                       |  |
| Cancer Site   | Piedmont                 | Piedmont                       | Virginia | <u>5-year death count</u> – represents<br>number of cancer deaths reported |  |
| Respiratory   | 266                      | 64.4                           | 54.0     | for White population from 2005-<br>2009.                                   |  |
| GI  | 163                      | 39.5                           | 36.2     |  |  |
| All other GI  | 90                       | 22.1                           | 20.7     | <u>Age-Adjusted Mortality Rate</u> -<br>represents age-adjusted cancer     |  |
| Colon & Rectum  | 73                       | 17.4                           | 15.5     | mortality rate for White population  |  |
| Female Breast   | 53                       | 25.1                           | 23.0     | for the health district (compared to                                       |  |
| Male Genital System   | 29                       | 17.6                           | 21.4     | state). Top 5 Cancers are based on<br>Age-Adjusted Mortality Rate.         |  |
| Prostate  | 28                       | 16.9                           | 21.1     | <u> </u>   |  |
| Other male genital organs                                   | 1                        | 0.7                            | 0.4      | All Other Sites include Brain,<br>Nervous System, Eye, Oral Cavity,        |  |
| Gynecological   | 33                       | 15.7                           | 13.5     | Pharynx, Heme-malignancies,  |  |
| Ovary   | 18                       | 7.8                            | 8.9      | Urinary System, and Other sites.   |  |
| Cervix  | 8                        | 4.8                            | 1.9      |  |  |
| All other Gynecological                                     | 4                        | 1.7                            | 0.8      |  |  |
| Corpus and Uterus   | 3                        | 1.3                            | 1.8      |  |  |
| All Other Sites   | 242                      | 59.1                           | 57.6     |  |  |
| All Sites   | 786                      | 191.9                          | 176.3    |  |  |

#### **Cancer Healthcare Resources**

#### Healthcare Facilities and Cancer Care

There is only one hospital in the PHD, Centra-Southside Community Hospital (Centra-SCH), located in Farmville. The next closest hospital, CentraHealth, is located one hour away in Lynchburg, VA. The local hospital is small with limited specialists and services.

Centra-SCH does offer a 24/7 Emergency Department that is quite active due to the size of the service area and the fact that there is no other competition. There are surgical services available but only two surgeons to perform them. Laboratory Services are on site but lab work is also sent to the parent hospital, Centra-Health. Onsite and remote radiology services are available. There are no radiation services or CT colonography offered within the Piedmont Health District. No surgical services related to breast reconstruction, lung, or pancreatic cancers are offered. Pathology is also outsourced. There is not a cancer navigator on site. Dieticians with specialty training are not available on site. Patients generally must travel 1-2 hours to obtain specialty cancer services. The hospital does offer scheduled transportation for patients undergoing cancer treatment, free of charge, to the Alan Pearson Cancer Center in Lynchburg, located at Centra Health's main campus. UVA HOPE Oncology Services, owned by University of Virginia but operated out of the Centra-SCH hospital main building, offers rotating physicians four days a week. Chemo infusions are provided in the HOPE offices.

#### Cancer Services Provided:

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

## Screening:

The Piedmont Health District has some limitations on screening facilities performing the higher level screening tests not done as part of the routine physical exam, i.e. mammograms and colonoscopy/sigmoidoscopy.

Centra-SCH offers screening and diagnostic mammography and was the recipient of a Susan G. Komen Grant for the year 2012. This grant enabled the hospital to provide mammograms at no charge to uninsured and underinsured women. Ultra sound breast exams are also available.

The only colonoscopies and sigmoidoscopies in the health district are also performed at Centra-SCH. There was a period of approximately two years without a gastroenterologist but one arrived in August 2012. The hospital has a complete endoscopic suite. The hospital also offers routine and diagnostic radiology studies, CAT scans and MRI's.

Some of the healthcare centers are able to provide mammograms and cervical cancer screenings. The Heart of Virginia Free Clinic has obtained a grant from Komen for mammograms in 2013. They have an OB-GYN who is doing some pap smears for them as needed.

The Piedmont Health Department does not offer mammograms or participate in Every Woman's Life, but they do offer cervical cancer screenings. Colposcopies are performed at the Center for Women and Families in Farmville and at their parent office Central Virginia Community Health Center in Buckingham County. While PAP smears are collected at any facility performing pelvic exams, questionable results requiring a colposcopy are, at this time, referred to a gynecologist at one of the health centers or the hospital.

The Every Woman's Life Program is not offered within the health district. There are no providers. In 2010, only 7% of eligible women utilized the EWL in the health district. As of 2012 the only EWL provider in the district, Central Virginia Community Health Center, stopped participating in EWL.

#### Treatment:

Treatment modalities for cancer include chemotherapy (including immunotherapy), radiation, and surgery. Treatment with all modalities is limited to an extent within the Health District. HOPE is the only organization within the health district that provides cancer treatment and that is limited to chemotherapy. There are no radiation services. Centra-SCH does not provide any oncology treatment options. Patients needing chemotherapy treatments are referred to UVA HOPE Oncology Services located in the hospital or sent to another facility.

There is no radiation offered within the district. Patients requiring radiation must travel to Lynchburg, Richmond, and Charlottesville or even to Duke in North Carolina. Mastectomies are performed at Centra-SCH but, as previously stated, no lung, pancreatic, or liver surgeries are performed in the district. The general surgeons perform GI surgeries.

There are no cancer patient navigators in the health district. There is a general patient navigator at Centra-SCH who also serves as the Diabetic Specialist and Nurse Clinical Specialist.

The major deficiencies in cancer treatment for the district were:

- Lack of surgical services: No reconstruction and other complex procedures
- No radiation services offered in the district
- No cancer patient navigators in the district
- No CT colonography
- No oncology certified dietician
- Limited Chemotherapy
- No Every Woman's Life Participating Providers

#### **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 are addressed by registered dieticians at Centra-SCH. The R.D., not oncology certified, performs nutritional risks assessments following American Dietetic Association's guidelines.

Genetic counseling is available and provided by the medical oncologists at the Hope oncology clinic. 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.

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

#### **Hospice Services:**

There are two hospice organizations in the Piedmont Health District, located centrally in Farmville. One agency, Hospice of Virginia, serves the entire district and the other, Centra Health's Hospice of the Hills, serves all counties in the district except Amelia. In addition, there are agencies outside of the district that do come into the area. The hospices are not utilized to their maximum capacity due to cultural issues in our district as well as general practitioner to try and manage their patients through any illnesses.

#### **Community Cancer Resources**

There are very limited resources in the Piedmont Health District. There is no central location for cancer patients to obtain information. The Heart of Virginia Free Clinic has collaborated with Massey Cancer Center to keep a display of cancer related brochures and information in their clinic. In addition, The Southside Virginia Family YMCA obtained a Virginia Department of Health grant for a cancer information display case that will provide information of interest to local cancer survivors. There is only one cancer specific organization, **The Barksdale Fund,** started by a family in Charlotte County. Only residents of Charlotte County can obtain a one-time grant of \$650 to use in any way they wish, once they have provided a physician statement of proof of cancer.

Other resources are small faith based organizations that offer small amounts of money for assistance with gas or utility bills. There are no national or regional cancer organizations with a presence in the district. The nearest regional American Cancer Society office is in Richmond. While most ACS educational programs can be accessed through a toll free phone number or online, there are no active ACS programs in the district.

There is an isolated community in Buckingham County focused on health and wellness. This community is known as Yogaville and was started in the early 1980's by a world-renowned yoga teacher. The regional community has become more accepting of this community but still considers to it as a cult. However, many published and recognized yoga and medical teachers have lived on campus at Yogaville. Travelers come from all over the world at a rate of approximately 150 people per week. The resident medical doctor has a focus on wellness.

Healthcare and community cancer resources are highlighted in **Figure 10**. Details about each of these organizations are in **Appendix E**.

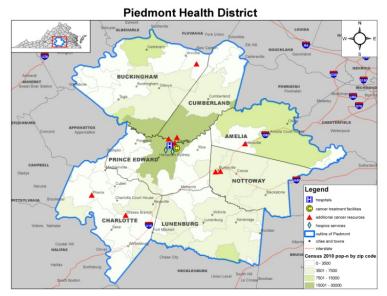


Figure 10: Map of cancer healthcare and support services in the Piedmont Health District

#### Healthcare Provider Needs

#### Key Leader Information

Interviews conducted with eight physicians provided a broad perspective of the cancer healthcare needs of the health district. They were selected from throughout the health district and were chosen based on their professional and personal involvement with the community as well as the number of years residing in 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.

#### Cancer Risk Reduction:

The key leaders interviewed believe screening guidelines are not clear to either patient or physician; education on screenings is not targeted toward the right age groups. Several suggested that the faith community become involved in screening and risk reduction education programs. In addition, the physicians stated that their own training was insufficient and that there were insufficient medical personnel in the cancer practice area. Two of the physicians noted that doctors and scientists are poor communicators.

#### Detection and Diagnosis

The physicians indicated that the problems in detection and diagnoses resulted from lack of physician training, lack of cohesive messages from providers to patients, and the issues of travel distance and cost to the patient. They also pointed out that it was difficult to get a farmer out of the fields and into the office for screening.

#### Treatment and Survivorship care

The key leaders stated that the lack of radiation, chemotherapy and surgical treatment options result in long travel times for patients. Patients are limited by the lack of oncologists and only one chemotherapy site.

The Key Leaders noted that continuity of care is lacking in all stages from initial diagnoses to hospice services. In this small community physicians worry about losing their patients when they go to specialists or are transferred to hospice. The physicians recognize their own limitations in understanding hospice drug use and are not comfortable without specific guidance regarding the high narcotic doses. The Key Leaders did acknowledge that there were sufficient hospice services available. If and when patients return to them after treatment, the physicians feel they do not get adequate information on past treatment.

Key Leaders Summary According to the Key Leaders, the underlying themes in the district are:

- 1. Lack of specialists and general practitioners
- 2. Health knowledge deficit on the part of citizens and the physicians
- 3. Complete absence of cancer support services
- 4. Lack of financial resources

#### 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 Primary Care Physician (PCP) and the oncology team; continuing education needs of the PCP on screening and follow-up care. Eighty-eight physicians in the Piedmont Health District were sent a Physician Survey. We excluded pediatricians and several other sub-groups. A 30% return rate was obtained.

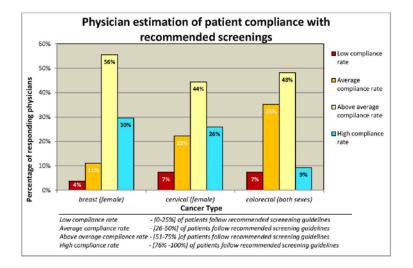


Figure 11: Patient Compliance with Cancer Screening Recommendation

Screenings: According to the survey, the physicians agree with the Virginia Cancer Registry's listing of the top four cancers diagnosed in the district: cancers are colorectal, lung, prostate, and breast. Eighty six percent (86%) of those surveyed reported female patients are above average in compliance with guidelines for breast screening, seventy percent (70%) reported above average compliance for cervical cancer screening and fifty seven percent (57%) reported above compliance with colorectal screening guidelines. (Figure 11)

The surveyed physicians stated that the most common reason for patients' failure to be screened relates to financial constraints. Apprehension about being screened and fear of the diagnosis were significant factors affecting screening compliance, as was lack of transportation for screening appointments. (Figure 12) Less than half of the providers surveyed did not indicate a desire to receive more information about screening guidelines. This directly contradicts the Key Leaders viewpoint that area physicians need more information and education about the guidelines.

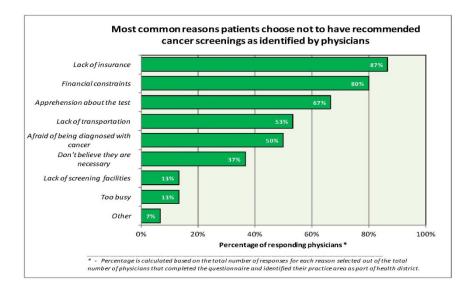


Figure 12: Primary Reasons for Non-Compliance with Cancer Screening Recommendations

# Referrals and Communication:

The physicians indicate that they prefer to refer patients requiring surgical and medical oncology consultations locally most often (57% and 70% respectively), but that National Cancer Institute designated Cancer Centers are referred to frequently as well. Both UVA and Massey Cancer Center are equi-distant from Farmville and both are NCI designated facilities. All communication from the oncology team is considered useful by the practitioners surveyed, primarily initial treatment plans, end of treatment notes and follow up care guidelines. However, over 50% of the providers surveyed indicated that communication from the treating oncologist was not consistently satisfactory.

Post-cancer treatment: From the survey only 52.9% of primary care physicians appear to feel comfortable providing non-oncology care during the time the patients are being treated for cancer. Less than half as many appear to feel comfortable in providing joint care with the oncology team and long term follow up care. Correspondingly, when queried about post-cancer treatment care topics for which they would like continuing education, providers surveyed were overwhelmingly interested in receiving more information on pain management, with significant interest in topics on surveillance of cancer recurrence and long-term follow-up. This corresponds to comments from the Key Leaders about lack of understanding of drug usage in the Hospice setting. Most physicians in this community expressed a preference to receive this information in written format vs. via the internet. (Figure 13)

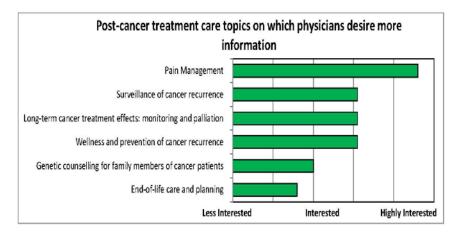


Figure 13: Post Cancer Treatment Topics of Interest by Physicians

#### **Community Population Needs**

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

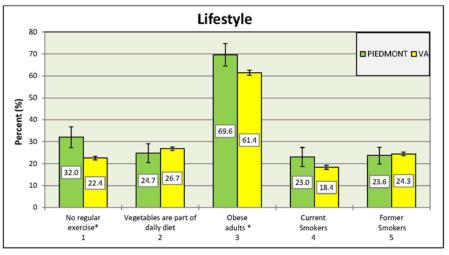
# Behavioral Risk Factor Surveillance Survey

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

# Lifestyle Behaviors:

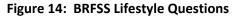
From the BRFSS data, for adults eighteen and older, the Piedmont Health District, when compared to Virginia shows a higher incidence of sedentary behavior 32% of the population) and has a relatively high incidence of overweight/obesity (69.6% of the population). (Figure 14) Both factors are associated with higher cancer risk. In addition, nearly one half of residents are

current or former smokers and nearly one quarter do not get the recommended minimum daily servings of vegetables and fruits.



\* - 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.

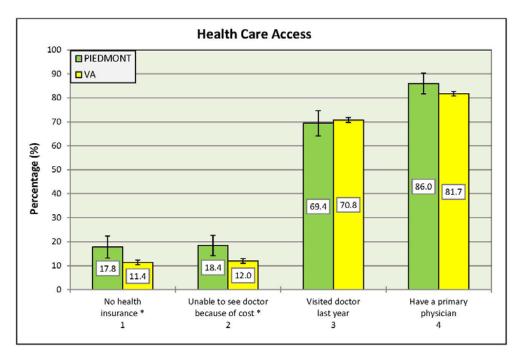


A closer look at the Lifestyle topics:

- Blacks are twice as unlikely to have exercised in the last 30 days as whites.
- The tendency to exercise is related to the level of income and education; those with a lower income and less education are twice as likely to be sedentary and not exercise as those with higher income and education.
- Similar associations exist for obesity and fruit and vegetable intake.

### Access to Healthcare:

Fewer people in the district have access to healthcare compared to the state. BRFSS reports that nearly eighteen percent (17.8%) of the district's population have no health insurance compared to only 11.4% for the rest of Virginia. Cost is a prohibitive factor in seeking health care for 18.4% of the district's residents, a factor supported by focus groups, Key Leaders and the Physician Survey. Black residents in the district were more than twice as likely not to see the doctor due to cost as whites. For those with income less than \$25,000, 34.7% were unable to see the doctor due to cost. (Figure 15 & 16)



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

1 - represents adults with no health insurance; 2 – represents adults that were unable to see doctor in the past year because of cost; 3 – represents adults which had an appointment with a primary care physician within the past year; 4 – adults that have 1 or more physicians they consider their primary;



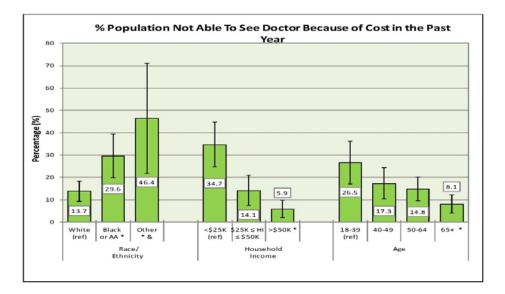


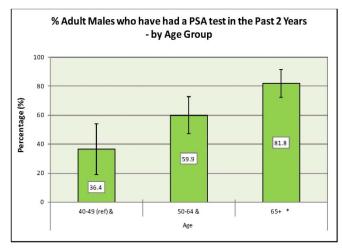
Figure 16: Race/ethnicity, income, and age associations with access to doctor visits

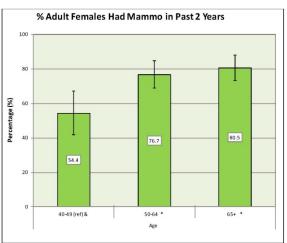
### Compliance with Screenings:

Compliance to recommended screening guidelines was similar to the rest of the state except for the districts reporting a higher percentage having a PSA in the last two years.

A closer look at the compliance data reveals:

- There is an increase in PSA and mammogram testing with increasing age
- By age 50-64, sixty percent of men have had a PSA, and seventy-seven percent of women have had a mammogram within in the last two years.







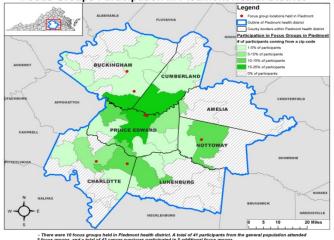


### Focus Group Information

Focus Group participants came from the pool of volunteers who responded to mass email list-serves, flyers, area newspaper ads, radio PSA's and personal presentations.

The demographics of the community were used as a guide for final selection of the participants in the five general population and five survivor groups. The participants closely mirrored the male-female population and the black/white population ratio. Residential representation was also considered. The only distinct area with a notable population not represented was the county of Amelia. The last criterion used for selection was personal experience with cancer. The General Population Focus groups consisted of people who had little or no experience with cancer. The 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. These meetings were held at the hospital, district health offices, local fire and rescue squad buildings and town hall offices. (Figure 19)



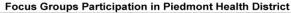


Figure 3: Focus Groups Participation in Piedmont Health District

### **General Population Group Synopsis:**

Five focus groups with the general population were held in five areas distributed throughout the Health District. There were a total of forty-five participants, with an average group attendance of eight. The topics for the general population group were designed to determine the community's knowledge and feelings about health issues in the community, including cancer, lifestyle factors influencing health (nutrition, exercise, weight and tobacco use), environmental influences on health, cancer screening tests, and cancer research.

### <u>Lifestyle</u>

Participants were aware of the prevailing health problems in their communities including the major chronic disease of diabetes, heart disease, respiratory disease and arthritis. Obesity was consistently mentioned as a chronic health problem in the health district. Mental illness, malnutrition, and Alzheimer's were also identified as concerns. Cancer was recognized as a significant health problem. Citizens perceived from their personal experience that there was high cancer rate in the district and want to know why. "I had nine people within a three mile radius of my home with cancer. Seven had breast cancer." (Keep in mind that some of the houses are a mile apart and population is sparse.)

The prevailing themes related to lifestyle factors affecting health were:

Environmental barriers to a healthy lifestyle: Processed foods were clearly identified as negative food sources but also recognized as very well packaged and marketed. "They make processed foods look so much more appealing." "Eating healthy is expensive!" The convenience factor and reduced cost was repeatedly stated. Exercise was considered necessary and important but not really feasible due to the time constraints of work, housekeeping, general activities of daily living, and lack of accessible facilities. Tobacco is recognized as a health problem in all counties of the. It is seen as more prevalent with the youth. "I'm 18 now; I'd say 80% of my friends smoke." The

community recognizes the negative impact, but feel people don't have adequate resources to stop smoking. Current education is viewed as ineffective.

Need for community activism to promote healthy lifestyles: The groups did not generally feel the public was concerned with weight, but the participants individually stated they were concerned. In addition the groups did not feel that the community as a whole valued exercise.

"The community is not geared toward exercise."

There was repeated recommendation that community public organizations promote policies and programs that encouraged healthy eating, exercise, weight, and smoking cessation. Increasing community awareness of healthy lifestyles through effective public education was a consistent recommendation.

The most commonly mentioned organizations to which the community looks for education around health were:

- The agriculture extension office
- The Department of Health
- Primary Care physician
- The Dietitian at the hospital

Programs to educate youth about healthy lifestyle and tobacco avoidance.

### **Environment**

Environmental contamination by industry as a source of health problems was a repeated theme in the focus groups. Multiple environmental issues were discussed in relation to common health problems including cancer. In Charlotte County in particular, there is a great fear resulting from historical toxic dumping into the water system by textile factories.

"They put up signs about a year ago not to drink the water at work." Uranium concerns were also stated numerous times in different groups. Arial spraying was a concern specific to Buckingham County and bio-solids were a concern to multiple counties. There was a common call for responsible agencies to investigate these concerns.

### Cancer screening and research

A sense of isolation due to the rural setting and the effects of travel distances on screening, early diagnosis and treatment of cancer and other diseases was a common theme.

"I have to go all the way to South Hill for a mammogram, over an hour away." Fear of medical procedures and the diagnosis were recurring themes. People do not get screenings due to fear, denial, and cost, as well as distance to an physician's office.

Clinical research was generally viewed very negatively in the region. Similar to the historic distrust of industry in the area, pharmaceutical companies were viewed as seeking profit as the sole motivator for drug research, and were, therefore, viewed skeptically. Several participants expressed that drug companies are profiting by refusing to cure diseases. There is limited research taking place in the region and people had very little knowledge of what research is or

entails. Despite this, when asked if they would participate in research investigating a local concern, most participants said yes.

### 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. Cancer patients ranged from recently diagnosed to 10 year survivors. Longer term survivors were not included as their experiences may not have been relevant to current community needs. For the purpose of our discussion, both patients and caregivers were considered survivors.

The topics for the Survivors group were designed to find out what the district needs to do better in providing care and support. The line of questioning elicited many heartbreaking and inspiring stories of their individual journeys. Discussed were:

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

Five focus groups with cancer survivors were held in five areas distributed throughout the Health District. There were forty-four participants, with an average group attendance of seven.

### Experiences with local medical resources

The region's survivors expressed their fear of diagnoses and subsequent shock upon diagnosis.

"You don't hear another word after you are told your diagnosis of cancer." They described how this experience with diagnosis promoted fear and inhibited pro-active screening for early detection and treatment. Information provided in a personal way and coordination of care were generally recognized needs locally.

"I needed more coordination of events. I was drowning."

The lack of services in the PHD was mentioned in all focus groups. This situation forces patients to drive long distances for screening, diagnosis and treatment, and is a large influence on screening and treatment decisions.

"It takes too long to get results." (She was speaking of the local hospital because the mammogram is read elsewhere.)

"Southside did my surgery here. If not I would have hesitated a bit." (The travel distance was what she referred to.)

There are no radiation facilities and only one office administers chemotherapy treatment. Patients travel so far for treatment that it takes the entire day and, therefore, they lose a whole day of work.

"You lose your job, you lose your insurance."

There were repeated stories of people depending on family and friends for transportation, and the understanding of employers to allow them to take the time needed for treatment and recovery.

Major themes coming from these discussions were as follows:

- > Need for patient navigation from screening through treatment and survivorship
- > Lack of sufficient oncology providers and treatment facilities within the health district
- Coordination of follow-up care and capacity if local primary care physicians
- > Education on healthy lifestyle post-cancer treatment.
- Transportation systems to facilitate early cancer detection and support people requiring health care outside of the health district
- Employer education around the rights and needs of cancer patients.

### Local Support Resources and Survivorship

The general consensus across the focus groups was that there were minimal to no community resources to support cancer patients and their caregivers. Most cited family and their faith community as the primary resource for financial, physical and emotional needs.

"There is no support besides my family. There is nothing, nobody. Most men will not talk about prostate CA."

Hospice was referenced as the only real support, but that it does not help those who are not terminal. Mental health support for both patient and caregiver were found to be lacking.

"There is nothing here!"

The need for accurate information at diagnosis and during treatment was a significant theme. Repeated descriptions of the fear that the patient and family members felt, compounded by a lack of information were repeated. Use of the internet for information was common, often with negative results due to inaccurate or misinterpreted information. Again, the perpetuation of fear and inaction due to lack of information was expressed.

"Women wait too long; they are so scared of it."

Cancer survivors were identified as a good source for information.

### Cancer Research:

Participants generally related cancer research with the word a "cure". Similar to the general population focus groups, participants repeatedly expressed a distrust of corporate pharmaceuticals, expressed a feeling that a cure for cancer had been found and was being withheld for profit.

" It is being held back by the drug companies. Too much money is being made. They can only cure you one time but they can treat you forever."

Clinical trials are not being offered at treatment locations available in the health district leading participants to declare that clinical trials are,

"Someplace far away....Boston, New York, Mayo Clinic."

"It is happening somewhere, but I don't know where it is."

Despite this, five participants were offered participation in a clinical trial during their treatment outside the health district, and when asked if they would participate in a local research study, most participants indicated yes. Most participants believed that having access to cancer clinical trials locally was very important.

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

> Development of a community health task force

To address issues highlighted in this report a task force was formed to include representatives from the healthcare facilities, the Department of Health, local government, the school systems, the faith community, and proactive citizens. The task force would facilitate community action to promote healthy lifestyles, advance healthcare related policy changes, and obtain grants to fund resources, among other initiatives.

Promotion and removal of barriers to early cancer detection

Screening opportunities must be promoted throughout the community in new ways. Screenings should be made available in the more rural parts of the community at more venues for easier access to care. Public education to reduce fear by dispelling myths about cancer screening should be planned throughout the community. Utilizing the faith community could be an effective tool, as could currently accessed organization like the Department of Health, Agriculture Extension Service, hospitals and clinics. Local organizations such as the fire departments and rescue squads can be approached for screening locations. Local organizations must be incorporated in order to promote screening opportunities.

Local treatment options need to be expanded

Recruitment and retention of primary care physicians, oncologists, and advanced practice nurses to the health district is needed. Additionally, opportunities lie in partnerships between the University of Virginia & Virginia Commonwealth University, and the local hospital (Centra-Southside Community Hospital), clinic (Heart of Virginia Free Clinic) and/or Community Healthcare Centers. Leveraging these partnerships could bring cancer clinical trials to the community as an additional treatment option.

Systems for patient education and support from screening through treatment and survivorship

A cancer patient navigator is vital to creating the web of care needed. The navigator can educate, promote healthcare events and screening activities, direct patients to appropriate treatment as well as information resources. The navigator would also be in a position to strengthen existing partnerships and help create new ones.

> Innovative transportation solutions for rural residents to local hospitals and clinics for cancer screening and other recommended health screenings, as well as to the major cancer care centers outside of the health district for treatment and follow-up.

Development of community resources for the support of cancer patients and caregivers.

Multiple national organizations exist that have programs that can be implemented in

the health district. These include the American Cancer Society, Susan G. Komen for the Cure, Livestrong Foundation, and the Leukemia and Lymphoma Society. Connections can be made between these organizations and local community groups, potentially faith-based organizations, the YMCA, the local university, the local hospital, among others, to implement established educational and support programs within the health district.

Continuing education for local healthcare providers around palliative care/pain management, cancer follow-up care, and end-of-life care.

Education in the area of hospice and palliative care must be provided to both the community at large and the medical community. Cultural issues must be addressed publicly and with sensitivity. Engaging the faith community would again be helpful for the community. Bringing in experts from the larger university settings would help the medical community in clarifying the care opportunities that exist and keeping them updated on medication regimens appropriate for end of life care.

### Resource acquisition for programs

Unfortunately without resources it will be difficult to effect change. Resources in the nature of grants need to be explored and obtained. These grants can fund screening, education, and treatment options. Harnessing the resources of vested community organizations is essential. An example is the the local YMCA's. The YMCA makes a great local healthcare partner, already has the support of the CDC and other organizations and is in a position to obtain significant grants geared toward healthy lifestyles. Additional local organizations that can be engaged include the Virginia Department of Health, the Agriculture Extension Service, the Sheriff's Department and local fire departments, the local hospital, Longwood University, among others.

## **APPENDICES**

### Appendix A:

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

**Appendix B:** Primary Care Physician Questionnaire

**Appendix C:** Focus Group Facilitator Guides

Appendix D: Cancer Healthcare Resources within the Health District

**Appendix E:** Community Cancer Resources within the Health District

## **APPENDIX A**

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

## **CHES** questionnaire

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

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

INSERT ORGANIZATION's

NAME\_

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

### **FACILITY**

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

| 1. | First, do you have a cancer registry at your facility? Yes No   |
|----|---|
|    | - If YES, What is the name of the registrar?  |
|    | <ul> <li>If NO, Is the registry maintained by another medical center/facility?</li> <li>Yes No</li> </ul> |
|    | <ul> <li>If YES,</li> <li>What is the name of that facility?</li> </ul>                                   |
|    | What is the name of registrar at that facility?   |
| 2. | Does any other board report oncological data to the state? Yes No<br>Unknown                              |
|    | If YES, what is the name of the board?  |
|    |   |
| 3. | Does the facility have a cancer committee?YesNoUnknown  |
| 4. | What Cancer Certifications does this facility hold? (Mark all that apply.)                                |

| ACOS (American College of Surgeons Commissie Coming soon   | on on Cancer)     | Yes            | No                    |
|--|-------------------|----------------|-----------------------|
| NAPBC (National Accreditation Program for Brea<br>Coming soon  | ast Centers)      | Yes            | No                    |
| Other (please specify)   |                   |                |                       |
| <ul> <li>5. Is the list of oncologists that I have document</li> <li>Yes No</li> <li>Please list all oncologists:</li> </ul> | nted as being or  | n staff at the | e hospital accurate?  |
|  |                   |                |                       |
| <ul><li>6. Are services for the following items provided</li></ul>   | d by your oncold  | ogists at this | facility?             |
|  | No<br>No          | _              |                       |
| Radiation therapy Yes No_  |                   |                |                       |
| 7. Are you currently trying to recruit Oncologis<br>No   | ts to practice at | this facility  | ? Yes                 |
| 8. Could you provide me with annual report of treated at your facility?  | f the number and  | d types of c   | ancers that are       |
|  | try               |                | _ No Wi               |
| SCREENING/DIAG   | SNOSTIC SER       | VICES          |                       |
| The next few questions are about cancer screen facility.   | ings and diagno   | ostic procec   | lures offered at your |
| <ul> <li>1. For Breast Cancer do you offer:</li> <li>Screening mammography?</li> <li>a) Film</li> </ul>                      | Yes               | No             | Unknown               |

|              | b) Digital  | Yes              | No                | Unknown               |
|--------------|---|------------------|-------------------|-----------------------|
|              | <ul> <li>Diagnostic mammography?</li> </ul>   | Yes              | No                | Unknown               |
|              | Breast ultrasound?  | Yes              | No                | Unknown               |
|              | Breast MRI?   | Yes              | No                | Unknown               |
|              | Breast Biopsy (radiology guided)?   | Yes              | No                | Unknown               |
| IF RE        | SPONDENT ANSWERED "NO" TO ALL BREAST CA   | ANCER SCREE      | NING/DIAG         | NOSTIC MODALITIES:    |
| 2.           | Where are patients referred for breast cancer   | diagnostics?     |                   |                       |
| 3.           | Does your facility offer gynecology care?<br>Colposcopy?  | Yes<br>Yes       | No<br>No          |                       |
| IF RE        | SPONDENT ANSWERED "NO" TO COLPOSCOPY  | <b>/</b> :       |                   |                       |
| 4.           | Where are patients referred for colposcopy?   |                  |                   |                       |
| Unkı<br>Unkı | For Colorectal Cancer do you offer: (Mark all t<br>Sigmoidoscopy?<br>nown<br>Colonoscopy (invasive)?<br>nown<br>CT Colonography - Virtual Colonoscopy (no |                  | Yes<br>Yes<br>Yes | No                    |
|              | SURGICAL S  | SERVICES         |                   |                       |
| 6.           | What type of <u>Cancer related</u> surgeries are per  | rformed at thi   | s facility? (N    | fark all that apply.) |
| •            | <ul> <li>Breast segmental/complete mastectomy?<br/>Unknown</li> <li>If YES to mastectomy, do you perform so<br/>No</li> </ul>                             |                  |                   | o<br>Yes              |
|              | Breast Reconstruction?  | Yes              | N                 | 0                     |
|              | <ul> <li>Unknown</li> <li>Gynecologic (hysterectomy/oophorectom<br/>Unknown</li> <li>Gastrointestinal (resection)</li> </ul>                              | y)? Yes <u>.</u> | N                 | 0                     |
|              | -upper tract Yes_   | No               | Unkr              | nown                  |
|              | -lower tract Yes_   |                  |                   | 10WN                  |
|              |   |                  |                   |                       |

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|   | -liver/pancreas | Yes | No  | Unknown |
|---|-----------------|-----|-----|---------|
| • | Lung?           |     | Yes | No      |
|   | Unknown         |     |     |         |
| • | Prostatectomy?  |     | Yes | No      |
|   | Unknown         |     |     |         |
| • | Other (please   |     |     |         |
|   | specify):       |     |     |         |

### **COUNSELING SERVICES**

7. Do you have a Registered Dietician to provide nutritional services specific to cancer patients? Yes\_ No\_

|    | <ul> <li>If YES, is he/she board certified in oncology nutrition? Yes_</li> <li>If YES, name of Dietician</li> <li>If NO, name of general Dietician</li> </ul> |     |    |
|----|--|-----|----|
|    | - If YES, Which nutritional services does he/she offer?  |     |    |
|    | One-on-one assessment and diet prescription?<br>Unknown  | Yes | No |
|    | Individual oncology nutrition counseling services?   | Yes | No |
|    | Outpatient oncology nutrition counseling services?   | Yes | No |
|    | Cancer control and prevention education programs?<br>Unknown   | Yes | No |
| 8. | Do you offer genetic counseling for cancer risk? Yes_  | No  | D  |
|    | - If YES, Who provides the counseling? (RN, NP, MP, GC, etc.)  |     |    |
|    | Are they certified?     Yes_   | No_ |    |

## **FINANCIAL/INSURANCE**

9. Do you accept all insurance including Medicaid and Medicare? YES\_\_\_ NO\_\_\_\_\_ IF NO: What types of insurance do you NOT accept?

Medicare\_\_\_\_

Medicaid\_\_\_\_\_

| Other (please specify):   |                 |
|---|-----------------|
| <b>10. What programs do you have in place to financially assist under and uning</b><br>1.   | sured patients? |
| 2.  |                 |
| 3.  |                 |
| 4.  |                 |
| 5.  |                 |
| 11. Do you accept uninsured patients?       Yes No         -       If you are unable to provide help to uninsured patients, sent?                 |                 |
|   |                 |
| CLINICAL TRIALS   |                 |
|   |                 |
| The next few questions are about research related issues.   |                 |
| 12. Does the facility have a Federal Wide Assurance number (FWA) required federally sponsored clinical trials? Yes No Unknown                     | to perform      |
| <b>13. Does the facility use an Institutional Review Board (IRB)?</b> Yes<br>Unknown  | No              |
| - IF YES, What is the name of the IRB?  |                 |
| <ul> <li>Is the IRB hosted at your facility or at a partner hospital? This facilit hospital</li> </ul>  | y Partner       |
| Name:   |                 |
| 14. Do you have a cancer clinical trials program?       Yes         Unknown       Yes   | No              |
| <ul> <li>If YES, can you provide us with the clinical trials menu? Yes</li> <li>Unknown</li> <li>If YES, with whom are you affiliated?</li> </ul> | No              |
|   |                 |
|   |                 |

- If NO, would you like to start a clinical trials program? Yes\_\_\_\_ No\_\_\_\_ Unknown\_\_\_\_
- 15. Do you have affiliations with other Cancer Centers or national organizations? Yes\_\_\_\_\_ No\_\_\_ Unknown\_\_\_\_

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

## HOSPICE / PALLIATIVE CARE SERVICES

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

### 16. What Hospice Services are offered to patients?

\_\_\_\_\_

\_\_\_\_\_

| <ul> <li>Inpatient hospice</li> </ul>  |        |               |
|--|--------|---------------|
| Facility Supported<br>Unknown          | Yes    | No            |
| Private organization<br>Unknown        | Yes    | No            |
| Outpatient hospice                     |        |               |
| Facility Supported Unknown             | Yes    | No            |
| Private organization                   | Yes    | No            |
| Unknown                                |        |               |
| Do you have a Palliative Care program? | Yes No | _ Coming soon |
| - If YES, Could you describe it?       |        |               |
|  |        |               |
|  |        |               |
|  |        |               |
|  |        | _             |

## SUPPORT / EDUCATIONAL PROGRAMS

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17.

| Unknown   |
|---|
| - If YES, For which cancer types?   |
|   |
| 19. Do you host patient and family cancer support groups at this facility? Yes No                       |
| - If YES, please, list all support groups:  |
|   |
|   |
|   |
|   |
|   |
| <ul> <li>If NO, would you like to start a support group? Yes No</li> <li>Unknown</li> </ul>             |
| What cancer site would you like to start a support group for?   |
| breast cancer prostate cancer lung cancer brain cancer  |
| cervical cancer testicular cancerother  |
| 20. Do you host or hold Cancer prevention education programs?       Yes No         Unknown       Yes No |
| - If YES, Please, list names of each program:   |
|   |

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

## **Cancer Resources Questionnaire**

My name is \_\_\_\_\_\_. I am the Community Health Education Coordinator for a cancer needs assessment project being conducted by the Virginia Commonwealth University Massey Cancer Center and the Virginia Tobacco Indemnification and Community **Revitalization Commission**. Thank you for agreeing (I am calling to ask if you would be willing) to answer some questions related to your organization and the cancer related services that you provide. You will be contributing to the cancer needs assessment for the Health District, the purpose of which is to identify the existing resources available to cancer patients and their families, and those that are needed for the Health District. The information gathered will be used to inform relevant private and public organizations to mobilize resources to meet identified needs. Organization's name: \_\_\_\_\_ Address: Ph: \_\_\_\_\_ Fax: \_\_\_\_\_ Website?: CONTACT person: \_\_\_\_\_ Best time to contact? Date of meeting/interview:

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

2. Which category best describes your organization:

- National non-profit
- Local non-profit
- For profit service organization
- Federal governmental organization

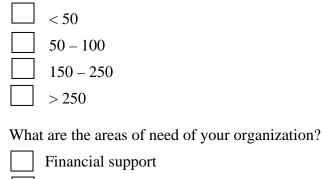
|    | State/municipal government organization   |
|----|---|
|    | Other   |
| 3. | What is the major source of funds for your organization?                              |
|    | Competitive grants  |
|    | Federal funds   |
|    | Service fees charges  |
|    | Donations   |
|    | Other   |
| 4. | What is the primary service population for your organization (check all that apply):  |
|    | Cancer patients   |
|    | Cancer survivors  |
|    | Cancer caregivers/family members  |
|    | Other:  |
|    |   |
| 5. | What are the qualification criteria for individuals to access your services?          |
|    | Must be uninsured/underinsured  |
|    | Financial qualification   |
|    | No qualification criteria   |
|    | Other   |
| 6. | Which of the following cancer related services do you provide? (Check all that apply) |
|    | Provision of written information on cancer  |
|    | Provision of information on cancer care and support resources                         |
|    | Management of cancer support groups   |
|    | Financial support for cancer control/care   |
|    | Funding of projects related to cancer   |
|    | Other:  |
|    |   |
| 7  | How do you advantice your anonization or d corriges?                                  |
| 7. | How do you advertise your organization and services?                                  |
|    | Local media   |
|    | Organization website  |

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|  | Distribution | of pamphlets | describing services |  |
|--|--------------|--------------|---------------------|--|
|--|--------------|--------------|---------------------|--|

| Word of mouth |
|---------------|
| Other         |

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



- Human resources (skilled employees, volunteers, etc.)
- Access to experts for consultation
- Other \_\_\_\_\_

8.

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

\_\_\_\_\_

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

## **APPENDIX B**

Primary Care Physician Questionnaire

### Cancer Needs Assessment VIP Physician Survey

#### Please complete the survey below. Thank you!

Thank you for participating in this survey. As an important physician within your community, your contribution is vital to our effort to gather information about cancer care. The information we gather will be published in a Cancer Needs Assessment that will be publicly available, and will be used to direct efforts to address the cancer care needs of this community. The Cancer Needs Assessment is being sponsored by the Tobacco Commission and the VCU Massey Cancer Center. The information you provide will be kept confidential. Please, indicate the primary health district in which Crater Mount Rogers you practice: Piedmont Pittsylvania-Danville Please indicate your primary area practice: Family medicine ☐ Internal medicine ☐ Obstetrics/gynecology Urology Dermatology Internal Hospitalist Surgeon Other Please specify 1. What are the three most common cancers that are diagnosed in your patients each year (check 3)? Colorectal Prostate Cervical Melanoma Breast Lung Hematologic Other \* \* Please specify 2. What percentage of your age/risk-appropriate female patients would you estimate have cancer screenings for the following cancers according to recommended guidelines: a) Breast 0-25% 51-75% 76-100% 26-50% b) Cervical (PapSmear) 0-25% 26-50% 51-75% 76-100% c) Colorectal 0-25% 26-50% 51-75% 76-100% 3. What percentage of your age/risk-appropriate male patients would you estimate have cancer screenings for the following cancers according to recommended guidelines: a. Colorectal 0-25% 26-50% 51-75% 76-100% 4. Do you screen your patients for other cancers? (please, select yes or no for cancers listed below) Prostate □Yes 🗆 No □ Yes □ No Lung ∐Yes Skin □ No Ovarian ☐ Yes 🗌 No 5. What do you feel are the most common reasons your patients choose not to have recommended cancer screenings (check all that apply)? Financial constraints Lack of Screening facilities Lack of transportation Apprehension about the test Afraid of being diagnosed with cancer Don't believe they are necessary Lack of insurance Other Too busy (please specify) 6. For which of the following cancers would you like information on screening challenges and/or updated screening recommendations (check all that apply)? Breast Colorectal Cervical Ovarian Prostate Lung Skin Other (please specify) 7. After one of your patients is diagnosed with cancer, where are you most likely to refer them for treatment: would refer for Surgery to: Local surgeon Surgeon at a Virginia National Cancer Institute Designated Cancer Center (VCU or UVa) □ Surgeon at other Virginia cancer center (not VCU or UVa) □ Surgeon outside of Virginia Other\_ (please specify) would refer for Medical Oncology to: Local Medical Oncologist Oncologist at a Virginia National Cancer Institute Designated Cancer Center (VCU or UVa) Oncologist at other Virginia cancer center (not VCU or UVa)

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|        | Oncologist outside of Virginia     Other  |   | (please                   | e specify)           |                    |             |               |        |   |
|--------|---|---|---------------------------|----------------------|--------------------|-------------|---------------|--------|---|
| 8. W   | hat information coming from the oncolo<br>Initial treatment plan<br>Operative reports<br>(please  |   | -                         |                      | ology repo         |             |               |        |   |
| 9. W   | hat percentage of the time do you recei   |   | m the oncologi<br>76-100% | st treating          | your patien        | t?          |               |        |   |
| 10.    | What kind of treatment are you comfort<br>Non-oncology care during the tim<br>Joint management of oncology ca<br>Long-term oncology follow-up car | e the patient is being treated for care with the oncology team during | cancer.                   |                      |                    |             |               |        |   |
|        | ☐ Other   |   |                           |                      | (plea              | se specify) |               |        |   |
| 11. Fo | or which of the following post-cancer tre   | atment care topics would you like                                     |                           | atio <u>n (</u> Plea | se, <u>nu</u> mber |             |               | _      |   |
| ,      | Pain Management   |   | □1                        | 2                    | 3                  | 4           | 5             |        |   |
| 6      | 7<br>Sumulillance of connect requirement  |   |                           | <b>—</b> 2           | <b>—</b> 2         | <b>—</b> 4  |               | _      | _ |
| 6      | Surveillance of cancer recurrence   |   | 1                         | 2                    | 3                  | 4           | 5             |        |   |
| 0      | Long-term cancer treatment effects:   | monitoring and palliation   | □1                        | 2                    | 3                  | 4           | 5             |        | П |
| 6      | 7   |   |                           | <b>—</b> –           |                    |             |               |        |   |
|        | End-of-life care and planning   |   | 1                         | 2                    | 3                  | 4           | 5             |        |   |
| 6      | 7   |   |                           |                      |                    | - 4         |               | _      | _ |
| 6      | Genetic counselling for family memb   | ers of cancer patients  | 1                         | 2                    | 3                  | 4           | 5             |        |   |
| 0      | Wellness and prevention of cancer re  | ecurrence   | □1                        | □2                   | 3                  | 4           | 5             |        |   |
| 6      | 7   |   | <u> </u>                  | <u> </u>             |                    |             |               |        |   |
|        | ,<br>Other  | (please specify)  | Π1                        | 2                    | 3                  | 4           | 5             |        |   |
| 6      | 7   |   |                           |                      |                    |             |               |        |   |
|        | what form would you prefer to receive   |   | active capability         | 1                    | □Web               | -based info | ormation, se  | elf-   |   |
| paced  | Written information   | Other   |                           |                      | (please            | specify)    |               |        |   |
| 13 PI  | ease comment on what you believe to l   | no the most pressing challenges a                                     | and harriers for          | nhysician            | in your co         | mmunity in  | relation to ( | rancer |   |

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

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

## **APPENDIX C**

Focus Group Facilitator Guides

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

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

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

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

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

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

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

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

Does anyone have any questions? [Answer any questions]

### WARM-UP [8 minutes]

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

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

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

### CANCER IN COMMUNITY: GENERAL DISCUSSION [15 minutes]

So let us get started.

- First, I would like you to tell me what you think are the *most important health problems* in your community. In other words, what illnesses, diseases, or other health conditions do you think are affecting your community the most? (Assistant lists on flip chart)
- 2. [IF NOONE COMMENTS ON CANCER]: What about cancer? Is that something that you think is a health problem in your community?

### Review list on flip chart.

- 3. Is getting cancer something that you worry about for yourself?
  - What kinds of cancer are you most worried about?
  - What worries you most about getting cancer?
- 4. Do friends, family, or others in your neighborhood talk about cancer? What do they talk about?

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

### LIFESTYLE FACTORS: [30 minutes total]

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

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

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

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

### Review the list.

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

#### Nutrition:

- 7. You mentioned (did not mention), that what a person eats can affect their health. Tell me more about that.
  - a. Probe:
    - What illnesses or disease can be affected by what we eat? What foods, or ways of eating, can improve health? What foods, or ways of eating can harm health?
- 8. Do you think that what a person eats, or their eating habits, can affect their chances of getting cancer? (Looking for a count)
  - b. If yes, what should a person eat, or what eating habits should they have to stop them from getting cancer?
  - c. What foods or eating habits or ways of eating can cause cancer?

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

- How easy is it for people you know in your community to eat healthy or eat in a way that can improve their health? (PROBE: What are some barriers to eating healthy for people in your community?)
- 10. Where would you go in your community for help eating a healthier diet? (PROBE: Is there a program that people have access to that teaches them how to eat a healthier diet?)
- 11. What are some ways to make it easier for people in your community to eat healthier? (PROBE: If you were designing a plan or project to help people in your community eat healthier, what would it look like?)

### Review points made during nutrition discussion before moving on.

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

#### Exercise

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

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

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

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

13. What kind of physical activity or exercise do you think will help improve a person's health?

(PROBES: What kind, intensity, duration, and frequency?)

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

### Summarize exercise comments before moving on to weight control.

#### Weight Control

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

- 16. What are your thoughts on weight? Are you and/or people in your community concerned about being overweight? (PROBE: At the community level, is there concern over obesity as a health problem?)
- 17. What kinds of health problems do you think can be caused by being overweight?
- 18. Do you think that being overweight or obese can increase someone's chances of getting cancer?
- 19. People's ideas about what a healthy weight is may be different. What do you think is a "healthy weight". (PROBE: How do you decide if a person has a healthy weight?)

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

- 20. Where would you go in your community for help losing weight? (PROBE: Is there a program that people have access to that helps people lose weight?)
- 21. What could be done in your community to help/encourage people to have a healthy weight?

Summarize weight comments before moving on to weight control.

## <u>BREAK</u>

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### TOBACCO

- 22. Do you think that tobacco use, (smoking tobacco, chewing or dipping tobacco) is a problem in your community? PROBE: About how many people use tobacco, not very many, a lot, about half...
- 23. What kinds of issues or problems do you think tobacco has caused for people you know in your community?
- 24. Are there any community wide efforts to change the smoking habit of people who live here?
- 25. What resources or programs are available in your community to help someone quit using tobacco? How effective do you think they are?
- 26. What are some reasons that people in your community do not quit using tobacco?
- 27. What do you think would be the best ways to help people stop using tobacco in your community?

### ENVIRONMENTAL FACTORS

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

- 28. Do you think there are any things in the environment of your community that might cause cancer?
- 29. What are your thoughts about someone's history of cancer in their family? Can that effect someone's chances of getting cancer?

### DISCUSSION OF CANCER SCREENING [15 minutes TOTAL]

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

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

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

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

- 32. Has your doctor ever told you to have a test for any cancer? If so, what test (if you don't mind saying)?
- 33. What are some reasons people you know don't get a cancer test when their doctor tells them they should?

### CANCER RESEARCH SECTION [15 MINUTES]

- 34. Now we are going to talk about research. First, has anyone ever participated in a research study, or know someone who has participated in a research study?
  - a. Can you tell us anything about the experience you or they had?
- 35. When you hear the words, "cancer research" what comes into your mind?

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

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

The National cancer Institute defines clinical research as:

"A type of research (study) that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease."

A cancer research may test a newly developed treatment on real patients before it is available for general use. This type of cancer research has very strict guidelines for accepting patients and monitors side effects, complications, and dosage issues very closely. Clinical trial participants are monitored closely and are taken off the clinical trial if they are doing poorly.

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

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

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

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

### **OVERALL PERSPECTIVE AND WRAP UP [5 MINUTES]**

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

### Do a final summary of the information.

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

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

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

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

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

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

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

Second, I would ask that we call each other only by first names or the names that you have selected and written on your name tag. Do any of you have other ground rules

that you think would be good to allow opportunity for everyone to express themselves freely?

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

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

Does anyone have any questions? [Answer any questions]

## WARM-UP [10 minutes]

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

## Tape recorder turned OFF here to maintain confidentiality.]

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

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

### Tape recorder turned on here

### Experiences getting cancer information (10 minutes)

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

- When you were first diagnosed, what kind of information did you need? Were you able to get the information you needed? If not, why not? What got in the way of your getting that information?
- 2. Has the kind of information you need **changed over time**? How? Have you turned to different sources for information as your needs have changed?

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

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

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

- 4. Thinking back to the time when you were *first diagnosed* with cancer, were there people or things in your community that were particularly helpful in getting the cancer diagnosis. We are not asking you to give specific names, but more about what helped you get diagnosed.
  - a. Were there things that delayed or made it hard for you to get the diagnosis easily or quickly?
- 5. Now, thinking about the time during which you (or the person you cared for) were *treated for cancer*, were there things that were particularly helpful to you as you went through treatment. (PROBE: Anything that helped you understand, get to, or pay for your treatments?)
  - a. Were there things that made it difficult to get treated?
- b. Were/Are there circumstances that affected your decisions about treatment? For

example financial circumstances, distance from treatment center, transportation,

or work schedules.

- 6. Did any of you get help from anyone to work your way through the system and put all of the pieces together? Sometimes this can be a team of medical people who work with you or an individual. (PROBES: patient navigator, case manager, social worker, cancer survivor, etc.) Who? Was it helpful?
- 7. From your experience, what is lacking in your community that could make the treatment of cancer easier?

# BREAK

# 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?
- 14. Was there a time that you needed help or information and were unable to get it in your community? What was that?
- 15. Have you heard of any resources from OTHER areas, that would have been helpful to you had you had access to them locally?

### **CANCER RESEARCH SECTION [15 MINUTES]**

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

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

National cancer Institute defines clinical research as:

The National cancer Institute defines clinical research as:

"A type of research (study) that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease."

A cancer research may test a newly developed treatment on real patients before it is available for general use. This type of cancer research has very strict guidelines for accepting patients and monitors side effects, complications, and dosage issues very closely. Clinical trial participants are monitored closely and are taken off the clinical trial if they are doing poorly.

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

- 17. What were you told about clinical trials as an option for treatment? OR Did you have the option of participating in a clinical trial?
- 18. If you were given the option, why did you participate or why did <u>you not</u> 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 o                            | f Facilities Questionnaires for F   | Piedmont Health Dist             | rict  |  |
|--------------------------------------|---|----------------------------------|---|--|
| Names of Facilities                  | Centra Southside Community H  | ospital; H.O.P.E. (Hem           | otology                                       |  |
| Oncology Patient Enterprises) Clinic |   |                                  |   |  |
|                                      | ogists available at these facilities:<br>ogists within the health district: | 2<br>2 Medical Oncolog           | ists (part time)                              |  |
| Cancer-Related Service               | s and Screenings  | Available in Health<br>District? | Number of<br>Facilities<br>Where<br>Available |  |
|                                      | Chemo IP  | Yes                              | 1   |  |
| Services provided                    | Chemo OP  | No                               | 0   |  |
|                                      | Radiation   | Yes                              | 1   |  |
|                                      | mammo - film  | Yes                              | 1   |  |
|                                      | mammo - digital   | Yes                              | 1   |  |
| Breast Cancer                        | mammo - diagnostic  | Yes                              | 1   |  |
| screening and                        | breast ultrasound   | Yes                              | 1   |  |
| diagnostic procedures                | breast MRI  | Yes                              | 1   |  |
|                                      | breast biospy   | Yes                              | 1   |  |
|                                      | gynecology care   | Yes                              | 1   |  |
| Gyn/Colposcopy                       | colposcopy  | Yes                              | 1   |  |
|                                      | sigmoidoscopy   | Yes                              | 1   |  |
| Colorectal Cancer                    | colonoscopy   | Yes                              | 1   |  |
|                                      | CT colonography   | No                               | 0   |  |
|                                      | Breast segmental/complete<br>mastectomy                                     | No                               | 0   |  |
|                                      | Breast reconstruction   | No                               | 0   |  |
|                                      | Gyn   |                                  |   |  |
|                                      | (hysterectomy/oophorectomy)   | Yes                              | 1   |  |
| Cancer related                       | GI - resection upper tract  | Yes                              | 1   |  |
| surgeries                            | GI - resection lower tract  | Yes                              | 1   |  |
|                                      | GI - liver/pancreas   | No                               | 0   |  |
|                                      | Lung  | No                               | 0   |  |
|                                      | Prostatectomy   | Yes                              | 1   |  |
|                                      | Sentinel nodes sampling   | Yes                              | 1   |  |
| Other Related Services               | p   |                                  |   |  |
|                                      | Registered dietician to provide   |                                  |   |  |
|                                      | nutritional services specific to  |                                  |   |  |
| Cancer Dietary needs                 | cancer patients   | No                               | 0   |  |
|                                      | 1on1 assessment   | No                               | 0   |  |
|                                      | Individual onc nutrition  |                                  |   |  |
|                                      | counseling  | No                               | 0   |  |
|                                      | OP onc nutrition counseling   | No                               | 0   |  |
|                                      | Cancer control and prevention   |                                  |   |  |
|                                      | education programs  | No                               | 0   |  |
| Constin accurrently                  | is it offered?  | Yes                              | 1   |  |
| Genetic counseling                   | are they certified?   | Yes                              | 1   |  |

| Insurance and                             | accept all insurance (including |     |   |
|---|---------------------------------|-----|---|
| programs for                              | Medicaid/care)                  | Yes | 2 |
| uninsured                                 | Accept uninsured patients       | Yes | 2 |
| Clinical Trials                           | any clinical trial programs?    | No  | 0 |
| Affiliations with other<br>Cancer Centers | have affiliations?              |     | 2 |
|   | IP hospice - facility supported | Yes | 1 |
|   | IP hospice - private org        | Yes | 1 |
| Hospice Service and<br>Palliative Care    | OP hospice - facility supported | Yes | 1 |
|   | OP hospice - private org        | Yes | 2 |
|   | PalCare program                 | No  | 0 |
| Cancer Patient<br>Navigation              | Patient Navigator               | No  | 0 |

# **APPENDIX E**

Community Cancer Resources within the Health District

| PIEDMONT - CAN<br>RESULTS           | CER RESOURCES SURVEY                     | Health District                                      | Piedmont Senior Resources Area<br>Agency on Aging, Inc. | Church of Christ Apostolic                  |
|-------------------------------------|--|--|---|---|
| Organization<br>Information         |  | Number of<br>Organizations that<br>have his resource |   |   |
|                                     | national non-profit                      | 1  | -   | -   |
|                                     | local non-profit                         | 7  | x   | x   |
|                                     | for profit service org                   | 0  | -   | -   |
| Organization Category               | fed. Gov. org                            | 0  | -   | -   |
|                                     | state/municipal gov. org                 | 0  | -   | -   |
|                                     | Other                                    | 0  | -   | -   |
|                                     | Other (specified)                        | (see organizations'<br>answers)                      |   |   |
|                                     | Other (specified)                        | 2  | -   | _   |
|                                     | competitive grants<br>fed. Funds         | 4  | -   | x   |
|                                     | service fees                             | 4  | -   | -   |
| Major sources of funds              | donations                                | 7  | -   | X   |
| for organization                    | Other                                    | 3  | X   | -   |
|                                     | other                                    | s<br>(see organizations'                             | ^   | -   |
|                                     | Other (specified)                        | answers)   | community   |   |
| ancer Resources                     |  |  |   |   |
|                                     | cancer patients                          | 1  | -   | -   |
|                                     | cancer survivors                         | 0  | -   | -   |
|                                     | cancer caregiver/fam. Members            | 0  | -   | -   |
| Primary service                     | Other                                    | · ·  | x   | Х   |
| population of the organization      |  | (see organizations'                                  |   | out of work, elderly, disabled,             |
|                                     | Other (specified)                        | answers)   | elderly, disabled                                       | families                                    |
|                                     | must be under(un)insured                 | 0  | -   | -   |
|                                     | financial qualification                  | 3  | -   | х   |
| Qualification Criteria to           |  | 1  | -   | _   |
| access services                     | Other                                    | 5  | x   | _   |
|                                     |  | (see organizations'                                  |   |   |
|                                     | Other (specified)                        | answers)   | 60+ age   |   |
|                                     | written info on cancer                   | 1  | -   | -   |
|                                     | info on cancer care/supp resources       | 2  | x   | -   |
|                                     | management of can.supp.groups            | 0  | -   | _   |
| Type of cancer related              | fin.supp. For cancer control/care        | 2  | -   | x   |
| services that are                   | Funding of projects related to cancer    | 0  | -   | -   |
| provided                            | Other                                    | 5  | X   | -   |
|                                     |  | (see organizations'                                  |   |   |
|                                     | Other (specified)                        | answers)<br>(see organizations'                      | Referrals for CA patients for care.                     |   |
| # of cancer pts seen                |  | (see organizations<br>answers)                       | less than 50  | less than 50                                |
| annually<br>Other Information A     | hout Organization                        | answersj   |   |   |
|                                     | local media                              | 4  | X   | X   |
|                                     |  |  | ^   | <b>∧</b>                                    |
|                                     | website                                  | 2  | -<br>X  | -   |
| Advortising for the                 | pamphlets<br>word of mouth               | 2 8  | X   | -<br>X                                      |
| Advertising for the<br>organization | word of mouth                            |  | X   |   |
| organization                        | Other                                    | 3  |   | -   |
|                                     |  |  | Triad meetings - for prevention of                      |   |
|                                     | Other (marified)                         | (see organizations'                                  | Elder Abuse Daily Bread plates once                     |   |
|                                     | Other (specified)                        | answers)   | a week  | ~   |
| Organizational Needs                | fin. Support                             | 6  | -   | X   |
|                                     | human resources (skilled employees, etc) | 4  | -   | X   |
|                                     | access to experts for consultation       | 2  | -   | -   |
|                                     | Other                                    | 2  | X<br>Tanana atatian finanaini ananatifan                | -   |
|                                     | Other (specified)                        | (see organizations'<br>answers)                      | Transportation, financial support for clients           |   |
| Challenges                          |  | (see organizations'<br>answers)                      | Finances  | Men to assist with heavy lifting            |
| Goals for the next 5 yrs            |  |  |   |   |
|                                     |  | (see organizations'<br>answers)                      | To stay in business through all the<br>cuts             | Person to operate pantry; purcha<br>a truck |

| PIEDMONT - CAN<br>RESULTS           | CER RESOURCES SURVEY                     | Health District                 | Alma House                    | Operation Blessing 1983              |
|-------------------------------------|--|---------------------------------|-------------------------------|--------------------------------------|
| 0                                   |  | Number of                       |                               |                                      |
| Organization                        |  | Organizations that              |                               |                                      |
| Information                         |  | have his resource               |                               |                                      |
|                                     | national non-profit                      | 1                               | -                             | -                                    |
|                                     | local non-profit                         | 7                               | x                             | x                                    |
|                                     | for profit service org                   | 0                               | -                             | _                                    |
|                                     | fed. Gov. org                            | 0                               | -                             | _                                    |
| Organization Category               | state/municipal gov. org                 | 0                               | -                             | -                                    |
|                                     | Other                                    | 0                               | -                             |                                      |
|                                     |  | (see organizations'             |                               |                                      |
|                                     | Other (specified)                        | answers)                        |                               |                                      |
|                                     | competitive grants                       | 2                               | -                             | -                                    |
|                                     | fed. Funds                               | 4                               | -                             | -                                    |
|                                     | service fees                             | 1                               | -                             | -                                    |
| Major sources of funds              | donations                                | 7                               | x                             | x                                    |
| for organization                    | Other                                    | 3                               | x                             | -                                    |
|                                     |  | (see organizations'             |                               |                                      |
|                                     | Other (specified)                        | answers)                        | Churches                      |                                      |
| Cancer Resources                    |  |                                 |                               |                                      |
|                                     | cancer patients                          | 1                               | -                             | -                                    |
|                                     | cancer survivors                         | 0                               | -                             | -                                    |
|                                     | cancer caregiver/fam. Members            | 0                               | -                             | -                                    |
| Primary service                     | Other                                    | -                               | x                             | X                                    |
| population of the<br>organization   |  |                                 |                               |                                      |
|                                     | Other (specified)                        | (see organizations'<br>answers) | other                         | people in need                       |
|                                     | must be under(un)insured                 | 0                               | -                             | -                                    |
|                                     | financial qualification                  | 3                               | -                             | -                                    |
| Qualification Criteria to           |  | 1                               | x                             | -                                    |
| access services                     | Other                                    | 5                               | -                             | x                                    |
|                                     |  | (see organizations'             |                               | must demonstrate need+ability to     |
|                                     | Other (specified)                        | answers)                        |                               | pay bill in future                   |
|                                     | written info on cancer                   | 1                               | -                             | -                                    |
|                                     | info on cancer care/supp resources       | 2                               | -                             | -                                    |
|                                     | management of can.supp.groups            | 0                               | -                             | -                                    |
| Type of cancer related              | fin.supp. For cancer control/care        | 2                               | -                             | -                                    |
| services that are                   | Funding of projects related to cancer    | 0                               | -                             | -                                    |
| provided                            | Other                                    | 5                               | -                             | X                                    |
|                                     |  | (see organizations'             |                               | one time per year assistance to help |
| # of opposed at                     | Other (specified)                        | answers)<br>(see organizations' |                               | someone out - med bills, rent, heat  |
| # of cancer pts seen<br>annually    |  | answers)                        | less than 50                  | less than 50                         |
| Other Information A                 | hout Organization                        |                                 |                               |                                      |
|                                     | local media                              | 4                               | -<br>-                        | _                                    |
|                                     | website                                  | 2                               |                               | _                                    |
|                                     | pamphlets                                |                                 | -                             |                                      |
| Advanticin - f th                   |  | 2                               |                               |                                      |
| Advertising for the<br>organization | word of mouth                            | 8                               | X                             | X                                    |
| organization                        | Other                                    | 3                               | Х                             | -                                    |
|                                     |  |                                 |                               |                                      |
|                                     |  | (see organizations'             | <b>a</b> t t                  |                                      |
|                                     | Other (specified)                        | answers)                        | Churches                      |                                      |
| Organizational Needs                | fin. Support                             | 6                               | <u>x</u>                      | x                                    |
|                                     | human resources (skilled employees, etc) | 4                               | x                             | -                                    |
|                                     | access to experts for consultation       | 2                               | -                             | -                                    |
|                                     | Other                                    | 2                               | -                             | -                                    |
|                                     | Other (specified)                        | (see organizations'<br>answers) |                               |                                      |
| Challenges                          |  | (see organizations'             |                               |                                      |
|                                     |  | answers)                        | Volunteer services            | Funding                              |
|                                     |  |                                 |                               |                                      |
| Goals for the next 5 yrs            |  | (see organizations'             | To increase number of clients |                                      |

| PIEDMONT - CAN                    | CER RESOURCES SURVEY                     | Health District                 |                                       |                                     |
|-----------------------------------|--|---------------------------------|---------------------------------------|-------------------------------------|
| RESULTS                           |  |                                 | Scope/Meals on Wheels                 | Hope Community Services, Inc.       |
| Organization                      |  | Number of                       |                                       |                                     |
| Information                       |  | Organizations that              |                                       |                                     |
|                                   |  | have his resource               |                                       |                                     |
|                                   | national non-profit                      | 1                               | -                                     | -                                   |
|                                   | local non-profit                         | 7                               | X                                     | х                                   |
|                                   | for profit service org                   | 0                               | -                                     | -                                   |
| Organization Category             | fed. Gov. org                            | 0                               | -                                     | -                                   |
|                                   | state/municipal gov. org                 | 0                               | -                                     | -                                   |
|                                   | Other                                    | 0                               | -                                     | -                                   |
|                                   | Other (specified)                        | (see organizations'<br>answers) |                                       |                                     |
|                                   | Other (specified)<br>competitive grants  | 2                               | x                                     | x                                   |
|                                   | fed. Funds                               | 4                               | x                                     | X                                   |
|                                   | service fees                             | 1                               | ×                                     | -                                   |
| Major sources of funds            | donations                                | 7                               | ×                                     | ×                                   |
| for organization                  | Other                                    | 3                               | ×                                     | -                                   |
|                                   | other                                    | s (see organizations'           | ^                                     |                                     |
|                                   | Other (specified)                        | answers)                        | county provides offices               |                                     |
| Cancer Resources                  | ··· ·                                    |                                 |                                       |                                     |
|                                   | cancer patients                          | 1                               | -                                     | -                                   |
|                                   | cancer survivors                         | 0                               | -                                     | -                                   |
| <b>.</b>                          | cancer caregiver/fam. Members            | 0                               | -                                     | -                                   |
| Primary service                   | Other                                    |                                 | x                                     | x                                   |
| population of the<br>organization |  |                                 |                                       |                                     |
| organization                      |  |                                 |                                       | Individuals below poverty level &   |
|                                   |  | (see organizations'             |                                       | challenges that prevent self-       |
|                                   | Other (specified)                        | answers)                        | elderly and disabled                  | sufficiency such as cancer patients |
|                                   | must be under(un)insured                 | 0                               | -                                     | -                                   |
|                                   | financial qualification                  | 3                               | -                                     | х                                   |
| Qualification Criteria to         | no qualification                         | 1                               | -                                     | -                                   |
| access services                   | Other                                    | 5                               | X                                     | Х                                   |
|                                   |  | (see organizations'             | sliding scale for fees but will serve |                                     |
|                                   | Other (specified)                        | answers)                        | anyone                                | special need                        |
|                                   | written info on cancer                   | 1                               | -                                     | Х                                   |
|                                   | info on cancer care/supp resources       | 2                               | -                                     | х                                   |
|                                   | management of can.supp.groups            | 0                               | -                                     | -                                   |
| Type of cancer related            | fin.supp. For cancer control/care        | 2                               | -                                     | -                                   |
| services that are                 | Funding of projects related to cancer    | 0                               | -                                     | -                                   |
| provided                          | Other                                    | 5                               | X                                     | X                                   |
|                                   |  |                                 |                                       |                                     |
|                                   |  | (see organizations'             | help connect people to other          | Funding of projects related to      |
|                                   | Other (specified)                        | answers)                        | providers if possible + necessary     | cancer; build ramps, provide WC     |
| # of cancer pts seen              |  | (see organizations'             | less than 50                          | 50 - 100                            |
| annually<br>Other Information A   | haut Organization                        | answers)                        | less than 50                          | 50 - 100                            |
| Other Information A               | local media                              | 4                               |                                       | ×                                   |
|                                   |  |                                 | X<br>X                                | x                                   |
|                                   | website<br>pamphlets                     | 2                               | -                                     | X X                                 |
| Advertising for the               | word of mouth                            | 8                               | -<br>X                                | X X                                 |
| organization                      | Other                                    | 3                               | -                                     |                                     |
| 015011201011                      |  | 3                               | -                                     | -                                   |
|                                   |  |                                 |                                       |                                     |
|                                   | Other (specified)                        | (see organizations'<br>answers) |                                       |                                     |
|                                   | Other (specified)<br>fin. Support        | 6 6                             | Х                                     | х                                   |
| Organizational Needs              | human resources (skilled employees, etc) | 4                               | X X                                   | -                                   |
|                                   | access to experts for consultation       | 2                               | X                                     | X                                   |
|                                   | Other                                    | 2                               | -                                     | -                                   |
|                                   |  |                                 |                                       | -                                   |
|                                   | Other (specified)                        | (see organizations'<br>answers) |                                       |                                     |
|                                   | other (specified)                        |                                 |                                       |                                     |
|                                   |  |                                 |                                       | Rural community lack of             |
| Challenges                        |  |                                 |                                       | transporation, poverty challenges,  |
|                                   |  | (see organizations'<br>answers) | finances+manpower                     | depressed employment.               |
|                                   |  |                                 | mances+manpower                       |                                     |
|                                   |  |                                 | maintain CSCH (Centra Southside       | To enhance citizens understanding   |
| Goals for the next 5 yrs          |  | (see organizations'             | Community Hospital) relationship;     | of empowerment; promote health      |
|                                   |  | answers)                        | modernize operations                  | and education.                      |
|                                   |  |                                 | modernize operations                  |                                     |

|                            | CER RESOURCES SURVEY                     | Health District                 |                                     |  |
|----------------------------|--|---------------------------------|-------------------------------------|--|
| RESULTS                    |  |                                 | Salvation Army                      | Barksdale Cancer Foundation  |
| Organization               |  | Number of                       |                                     |  |
| -                          |  | Organizations that              |                                     |  |
| Information                |  | have his resource               |                                     |  |
|                            | national non-profit                      | 1                               | х                                   | -  |
|                            | local non-profit                         | 7                               | -                                   | x  |
|                            | for profit service org                   | 0                               | -                                   | -  |
| Organization Category      | fed. Gov. org                            | 0                               | -                                   | -  |
| Organization Category      | state/municipal gov. org                 | 0                               | -                                   | -  |
|                            | Other                                    | 0                               | -                                   | -  |
|                            |  | (see organizations'             |                                     |  |
|                            | Other (specified)                        | answers)                        |                                     |  |
|                            | competitive grants                       | 2                               | -                                   | -  |
|                            | fed. Funds                               | 4                               | X                                   | -  |
| Major sources of funds     | service fees                             | 1                               | -                                   | -  |
| for organization           | donations                                | 7                               | X                                   | x  |
|                            | Other                                    | 3                               | -                                   | -  |
|                            |  | (see organizations'             |                                     |  |
|                            | Other (specified)                        | answers)                        |                                     |  |
| Cancer Resources           |  |                                 |                                     |  |
|                            | cancer patients                          | 1                               | -                                   | x  |
|                            | cancer survivors                         | 0                               | -                                   | -  |
| Primary service            | cancer caregiver/fam. Members            | 0                               | -                                   | -  |
| population of the          | Other                                    |                                 | X                                   | -  |
| organization               |  |                                 |                                     |  |
|                            |  |                                 |                                     |  |
|                            |  | (see organizations'             |                                     |  |
|                            | Other (specified)                        | answers)                        | homeless people                     |  |
|                            | must be under(un)insured                 | 0                               | -                                   | -  |
|                            | financial qualification                  | 3                               | х                                   | -  |
| Qualification Criteria to  | no qualification                         | 1                               | -                                   | -  |
| access services            | Other                                    | 5                               | -                                   | х  |
|                            |  | (see organizations'             |                                     | Have an MD sign a form verifying   |
|                            | Other (specified)                        | answers)                        |                                     | cancer dx.   |
|                            | written info on cancer                   | 1                               | -                                   | -  |
|                            | info on cancer care/supp resources       | 2                               | -                                   | -  |
|                            | management of can.supp.groups            | 0                               | -                                   | -  |
| Type of cancer related     | fin.supp. For cancer control/care        | 2                               | -                                   | х  |
| services that are          | Funding of projects related to cancer    | 0                               | -                                   | -  |
| provided                   | Other                                    | 5                               | x                                   | -  |
|                            |  |                                 |                                     |  |
|                            |  | (see organizations'             |                                     |  |
|                            | Other (specified)                        | answers)                        | pastoral care + general resources   |  |
| # of cancer pts seen       |  | (see organizations'             |                                     |  |
| annually                   |  | answers)                        | less than 50                        | less than 50   |
| <b>Other Information A</b> | bout Organization                        |                                 |                                     |  |
|                            | local media                              | 4                               | -                                   | -  |
|                            | website                                  | 2                               | -                                   | -  |
|                            | pamphlets                                | 2                               | -                                   | -  |
| Advertising for the        | word of mouth                            | 8                               | x                                   | x  |
| organization               | Other                                    | 3                               | x                                   | -  |
|                            |  |                                 |                                     |  |
|                            |  | (see organizations'             |                                     |  |
|                            | Other (specified)                        | answers)                        | visible sheet presence at Christmas |  |
| Organizational Needs       | fin. Support                             | 6                               | X                                   | _  |
|                            | human resources (skilled employees, etc) | 4                               | X                                   | _  |
|                            | access to experts for consultation       | 2                               | -                                   | -  |
|                            | Other                                    | 2                               | -                                   | x  |
|                            |  | (see organizations'             |                                     |  |
|                            | Other (specified)                        | answers)                        |                                     | website  |
|                            | other (specifica)                        |                                 |                                     | website  |
|                            |  |                                 |                                     |  |
| Challenges                 |  | (coo organizations)             | Volunteers pulled to multiple       |  |
|                            |  | (see organizations'<br>answers) | organizations                       | manpower for fundraisers   |
|                            |  | answers)                        | organizations                       |  |
|                            |  |                                 |                                     | A scholarship for a student in cancer  |
| Goals for the next 5 yrs   |  |                                 | Increase awareness; Reach more      | A scholarship for a student in cancer<br>studies Develop a web site Increase |
|                            |  | (see organizations'             | mercase awareness, reduit more      | -  |
|                            |  | answers)                        | people                              | donations  |