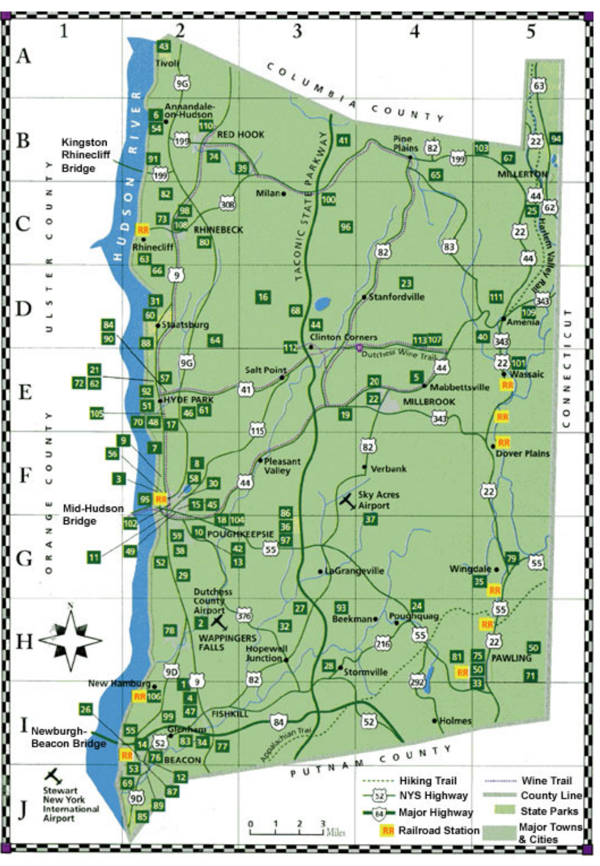
Dutchess County Comprehensive Cancer Control Plan Needs Assessment



Fall 2007

Prepared by JSI Research & Training Institute, Inc.

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Executive Summary

The Dutchess County Department of Health established its Comprehensive Cancer Control Advisory Council in 2006 to conduct a comprehensive needs assessment of cancer prevention, screening, treatment, and support services in Dutchess County. The needs assessment is presented in this document and forms the basis for development of a Comprehensive Cancer Control Plan for the County, to be coordinated with the New York State Comprehensive Cancer Control Plan.

Introduction

In Dutchess County (population approximately 295,000) cancer is the second leading cause of death, surpassed only by heart disease. The American Cancer Society estimated that about 27 individuals are diagnosed with cancer and about 11 die from cancer each week in the county.

Under the leadership of the County Executive, William R. Steinhaus, and the Health Commissioner, Dr. Michael C. Caldwell, the Dutchess County Department of Health has shown extraordinary commitment to Cancer Control in the county through their development of a Dutchess County Cancer Advisory Council (CAC) and commitment to the development of a county-level cancer control plan. The Dutchess County Department of Health, in collaboration with the CAC and community partners will work collaboratively to work toward implementation of the Dutchess County comprehensive cancer control plan.

As part of this effort, DCDOH hired JSI Research & Training Institute (JSI) to conduct a comprehensive assessment of cancer prevention, screening, treatment, and support services.

The purpose of the comprehensive assessment is to:

- Provide baseline information about the current strengths, challenges and concerns of Dutchess County residents facing a cancer diagnosis
- Develop a resource inventory of services available to support comprehensive cancer control in Dutchess County.
- Lay the groundwork for the development of a Dutchess County Comprehensive Cancer Control Plan.

Methods

As part of the comprehensive assessment, several activities were initiated including:

- A comprehensive **epidemiologic profile** of the cancer burden in Dutchess County (DC) including information about risk factors and screening

- **Key informant interviews** with a substantial number of key stakeholders engaged in cancer control activities in DC
- A **resource inventory** that systematically describes resources for comprehensive cancer control in DC and provides information about their adequacy now and in the immediate future
- **Focus groups** to learn from community health workers and consumers (and potential consumers) of cancer services about their perceptions of the availability and quality of those services

In compiling themes and recommendations, information from each of these sources has been compared to identify concerns that were noted from multiple sources or that had an evidentiary basis in the epidemiologic data or survey findings. Using this process, themes and recommendations emerged for consideration by DCDOH and the CAC.

Themes and Recommendations

Overall, the findings of the comprehensive assessment pointed to three main themes emerging in Dutchess County with respect to Comprehensive Cancer Control. Those themes are:

- Information and Education
- Access to Care and Disparities
- Quality of Care

Information and education play a key role in the prevention and early detection of cancer and in the provision of high quality care. There is significant variation among different groups of people in their level of knowledge about preventive measures, screenings, support services and, to a lesser extent, treatment. In particular, information about free and low cost screenings must be ongoing, consistent and tailored to those most in need of these services. Specific recommendations in this area are:

- **Develop an ongoing social marketing plan designed to increase awareness of risk factors around cancer prevention and screening**
- **Provide more extensive advertising and outreach of available services, especially to underserved populations**

Access to care and disparities must be addressed to reduce the unequal burden of cancer particularly among racial and ethnic minorities and people lacking adequate health insurance. In addition, populations have different cultural understandings of an illness like cancer and may need help to understand, adopt and integrate important prevention and screening recommendations. Finally, literacy and language barriers heighten disparities in utilization of a range of cancer services. Specific recommendations in this area are:

- **Promote the development of patient navigation services for cancer care utilizing the principles that patient navigators are community health workers recruited from local underserved communities, and work toward the elimination of disparities for the clients they serve**
- **Support widespread access to interpreter services for all health care service settings, particularly in Spanish**
- **Ensure access to free or low cost options for transportation to health care, including screening, treatment, and support services particularly for outlying areas such as Dover, Amenia and Red Hook**
- **Advocate for the availability of low cost or free screening and treatment for the un-insured and underinsured**

Quality of care relates to concerns that many raised about the extent to which services are not perceived as client-centered. While there was general agreement that services for the treatment of cancer had greatly improved in recent years, many found that there were still gaps in services and ways in which the delivery of services could be improved to meet the needs of every man, women or child diagnosed with cancer in Dutchess County. Specific recommendations in this area are:

- **Improve patient satisfaction through more client-centered approaches**
- **Continue to develop needed specialty services within Dutchess County**
- **Promote access to comprehensive case management for people with complicated life circumstances, co-morbidities, or both; or a lack of adequate support from their social network**

These themes and recommendations are developed in greater detail in the full report, and their relationships to various sections of the New York State Comprehensive Cancer Control Plan are noted. The findings of the assessment outline the priorities, concerns, and goals of a wide segment of stakeholders in the county. Together, these themes and recommendations form a basis and provide direction for the next stage of Comprehensive Cancer Control in Dutchess County.

Acknowledgements

A great many individuals and organizations assisted in this work.

From the Dutchess County Department of Health, Sabrina Marzouka, Evelyn Kaufmann, Lisa Cardinale and Audrey Waltner provided oversight, guidance, support and wisdom throughout the process. Rana Ali, also from the department, created an epidemiologic profile.

The members of the Dutchess County Cancer Advisory Council (CAC) provided useful input and support throughout the process. Members of the CAC helped identify participants for all phases of the assessment, helped to develop assessment questions and with analysis of findings.

Several organizations assisted with the process of organizing focus groups including providing a site for the group and recruiting participants. Solange Muller and Guillermina Vasquez were helpful in putting together two groups at Hudson River HealthCare. Sandra Cassese and Mary Luvera at Vassar Brothers Hospital assisted in providing a site and recruiting participants.

Thanks go to everyone who participated in a key informant interview, completed a resource inventory survey or shared important information at a focus group. Your contribution to this process is essential.

At JSI Research and Training Institute, Inc., Jennifer Kawatu, Josie Halpern-Finnerty and Stewart Landers conducted the assessment activities and wrote the report.

I. Introduction

Comprehensive cancer control is a collaborative process through which a community and its partners organize to promote cancer prevention, improve cancer detection, increase access to health and social services, and reduce the burden of cancer. The first ever Comprehensive Cancer Control Plan for New York was presented by the New York State Department of Health and The American Cancer Society for the years 2003-2010. The plan was developed through an unprecedented level of collaboration and community involvement over 18 months and experts from across the state participated in the development process. New York is a large culturally, ethnically, and geographically diverse state, however, and many cancer control initiatives can occur most effectively at the county and local level.

Under the leadership of the County Executive, William R. Steinhaus, and the Health Commissioner, Dr. Michael C. Caldwell, the Dutchess County Department of Health (DCDOH) has shown extraordinary commitment to Cancer Control in the county through their development of a Comprehensive Cancer Control Consortium. A core workgroup of dedicated individuals, the Cancer Advisory Council (CAC) began the process of the development of a county-level cancer control plan. DCDOH, in collaboration with the CAC and community partners will work collaboratively to work toward implementation of the Dutchess County comprehensive cancer control plan.

The CDC has defined comprehensive cancer control as “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention (primary prevention), early detection (secondary prevention), treatment, rehabilitation, and palliation.” A Comprehensive Cancer Control Plan is a reflection of the community’s priorities, current efforts, and the vision of what can and should be done in the community to reduce the burden of cancer, and is intended to serve as a “blueprint” to address cancer control.

There have been many dedicated people and organizations that have made substantial contributions toward reducing cancer morbidity and mortality, and many improvements have been made, but more remains to be done. Historically, efforts to control cancer have been categorical and have functioned as separate units focused on specific cancer sites and risk factors. The CDC and other stakeholders recognized missed opportunities for cancer prevention and control, as well as duplication of efforts at the national, state, and community levels. Comprehensive cancer control planning is the attempt to improve coordination and collaboration, to reduce cancer rates and enhance the quality of life for those with a cancer diagnosis.

As part of this effort, DCDOH hired JSI Research & Training Institute (JSI) to conduct a comprehensive assessment of cancer prevention, screening, treatment, and support services.

The purpose of the comprehensive assessment is to:

- Provide baseline information about the current strengths, challenges and concerns of Dutchess County (DC) residents facing a cancer diagnosis
- Develop a resource inventory of services available to support comprehensive cancer control in DC.
- Lay the groundwork for the development of a Dutchess County Comprehensive Cancer Control Plan.

This report includes three substantive parts and several appendices. The first part is the Epidemiologic Profile of the burden of cancer in Dutchess County. It also includes select information on risk factors and screening where data are available. The second part provides detailed findings from the three components of the needs assessment: key informant interviews; the resource inventory survey; and focus groups. The third part contains a set of themes and recommendations to DC based on these findings.

Figure 1: Dutchess County

II. Epidemiologic Profile

A. OVERVIEW

In Dutchess County (population approximately 295,000) cancer is the second leading cause of death, surpassed only by heart disease. The American Cancer Society estimated that about 27 individuals are diagnosed with cancer and about 11 die from cancer each week in the county.

The incidence of cancer has increased in men and decreased in women over the past five years. The percentages of total deaths due to cancer are higher than in the state in both men and women than in New York State (NYS) and in the nation as a whole.

As in New York State, the four most common cancer types seen in Dutchess County are cancers of the lung, female breast, prostate, and colon / rectum.

As per the observations in Dutchess County certain other types of cancer that seem to stand out include, melanoma, cancers of liver and bile duct.

Testing for early detection of cancer through cancer screening and primary health is not performed consistently across the entire population, contributing to the increased mortality rates. Risk factors that are prevalent in the county and have been associated with increased risk of cancer include increased rates of smoking, obesity, and sedentary lifestyle.

B. DUTCHESS COUNTY DEMOGRAPHICS

Total population: 295,146 (2006 estimate)
Male to Female ratio is 49:51
Population over 65 years of age: 12.1% (2005)
Population living in poverty: 6.6 % (2005)
Median household income: $61,889 (2005)
Education less than high school diploma: 12.8%
(Based on American Community Survey, US Census Bureau)

C. NATIONAL AND STATE CANCER STATISTICS

The American Cancer Society (ACS) and National Cancer Institute estimates for 2006:

New Cases in 2006

- 1,399,790 new cancer cases in the US
- 88,230 new cancer cases in New York State
- 1,404 new cases in Dutchess County

Cancer Deaths in 2006

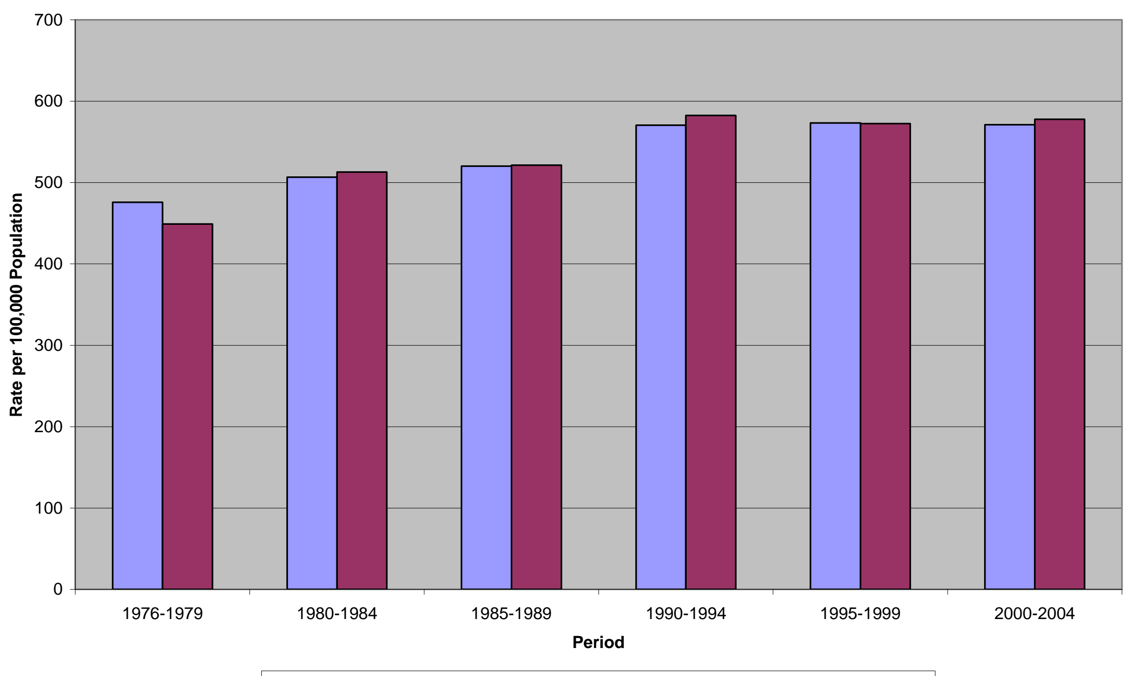
- 564,830 deaths due to cancer in the US
- 35,600 deaths in New York
- 552 deaths in Dutchess County

D. CANCER INCIDENCE IN DUTCHESS COUNTY

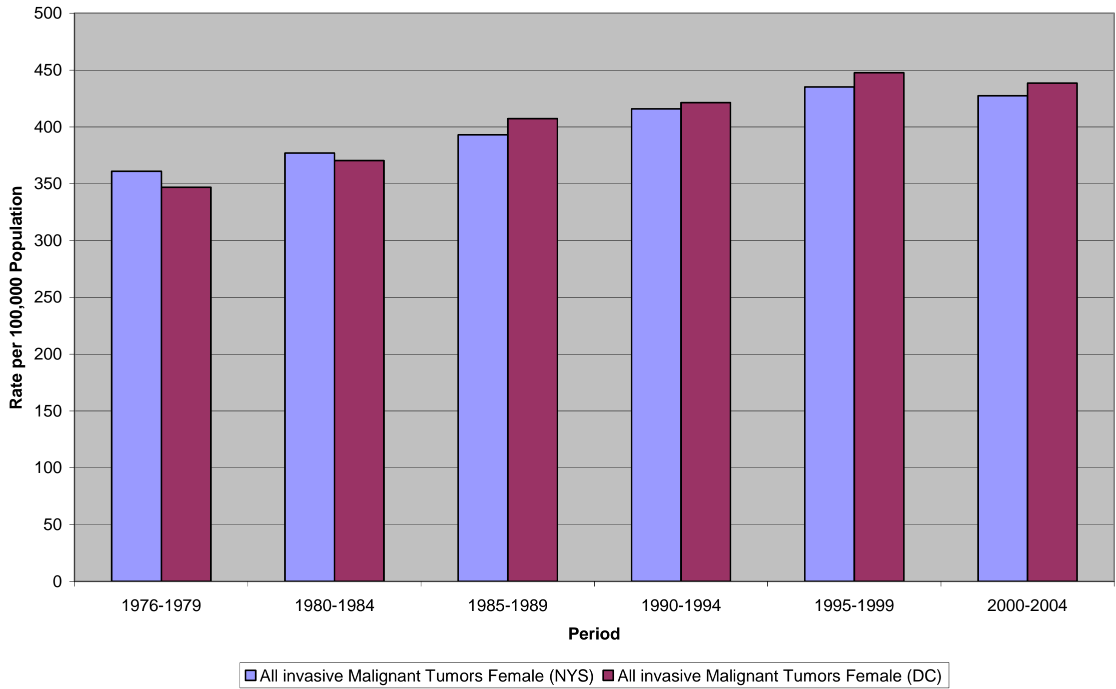
Incidence is a measure of newly diagnosed cancer in a population. The ACS estimates that about 27 individuals are diagnosed with cancer each week in Dutchess County. Incidence rates have increased in men but decreased in women since the mid-1990's.

- In men incidence rates increased from 572.6/100,000 in 1995-99 to 577.8/100,000 in 2000-2004
- In women incidence rate decreased from 447.6/100,000 in 1995-1999 to 438.5/100,000 in 2000-2004.

The average annual number of new cases of cancers in men in Dutchess County was 742.8 and about 687.6 in women in 2000-2004.



Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/



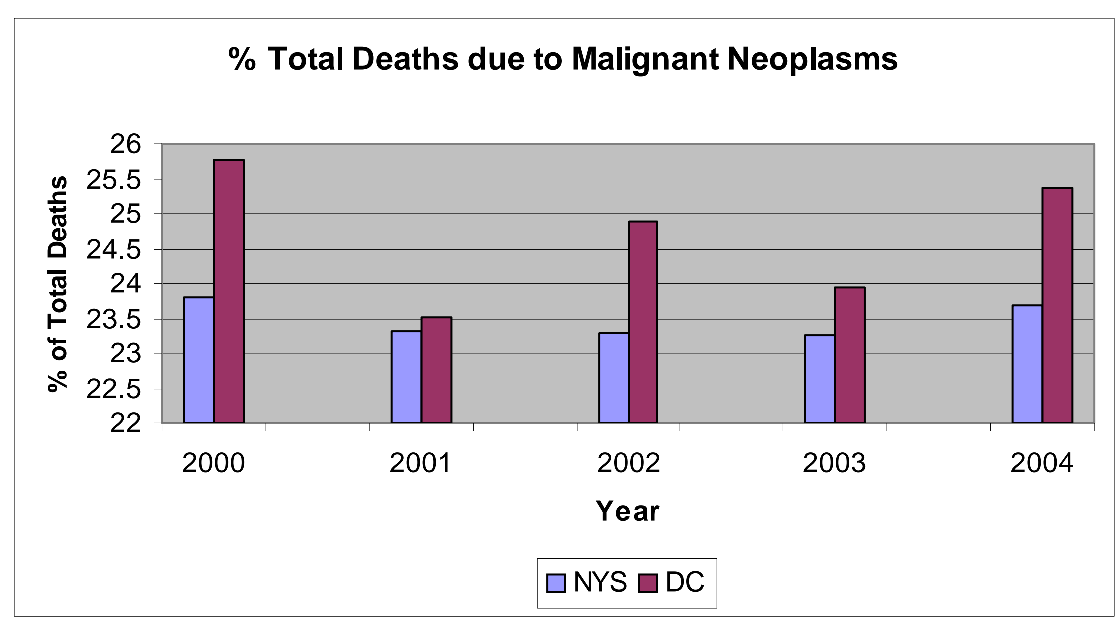
Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

E. CANCER MORTALITY IN DUTCHESS COUNTY

The ACS estimates that about 11 individuals die of cancer each week in Dutchess County.

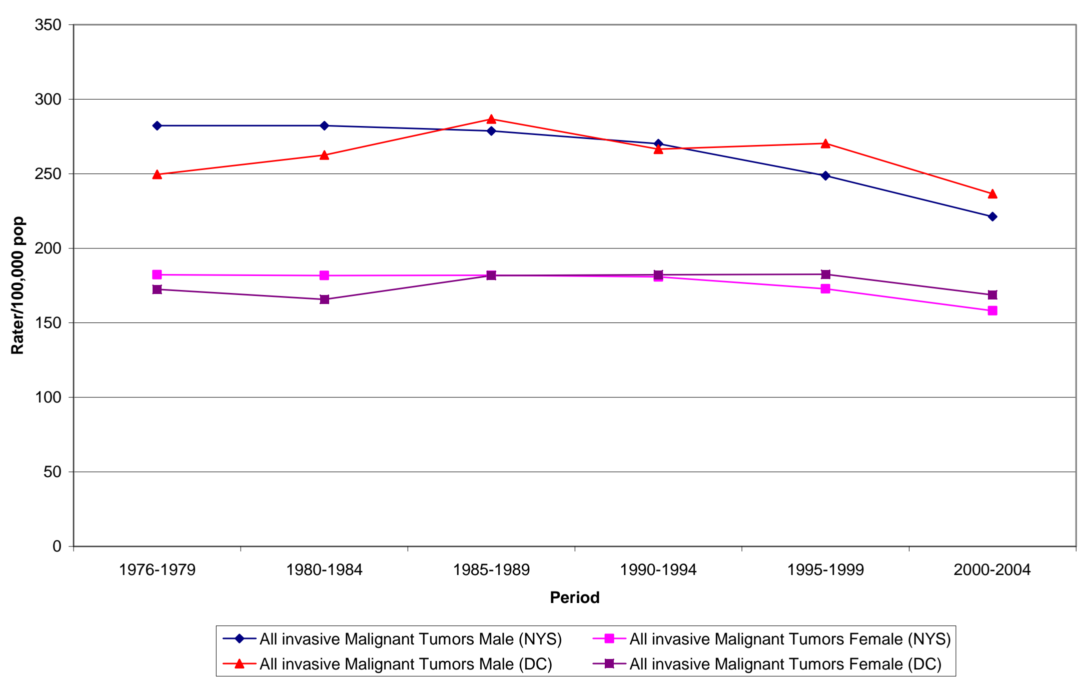
The mortality rate is the number of deaths per hundred thousand people in the population, or the death rate. In Dutchess County the cancer death rate was 193/100,000 population, second only to heart disease as a cause of death. This is higher than the cancer death rate seen in New York State of 186.5/100,000 population.

Death rates from cancer in Dutchess continue to following the general declining trend seen in the nation as a whole. But the death rates for both genders in Dutchess County have remained higher than those seen in the state. During 2000-2004 period, the death rate in Dutchess County death rate was 236.6/100,000 population deaths in men and 168.8/100,000 population death in women.



Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

In 2000, about 26% of all deaths in Dutchess County were attributed to cancers. This was higher than in New York State (23.8%). In 2001 this declined to 23.5 and was comparable to New York State rate of 23.4%, but rose again to 25% in 2002. In 2004 about 25.3% of all deaths were attributed to cancer in Dutchess County as compared to New York State (23.8%).



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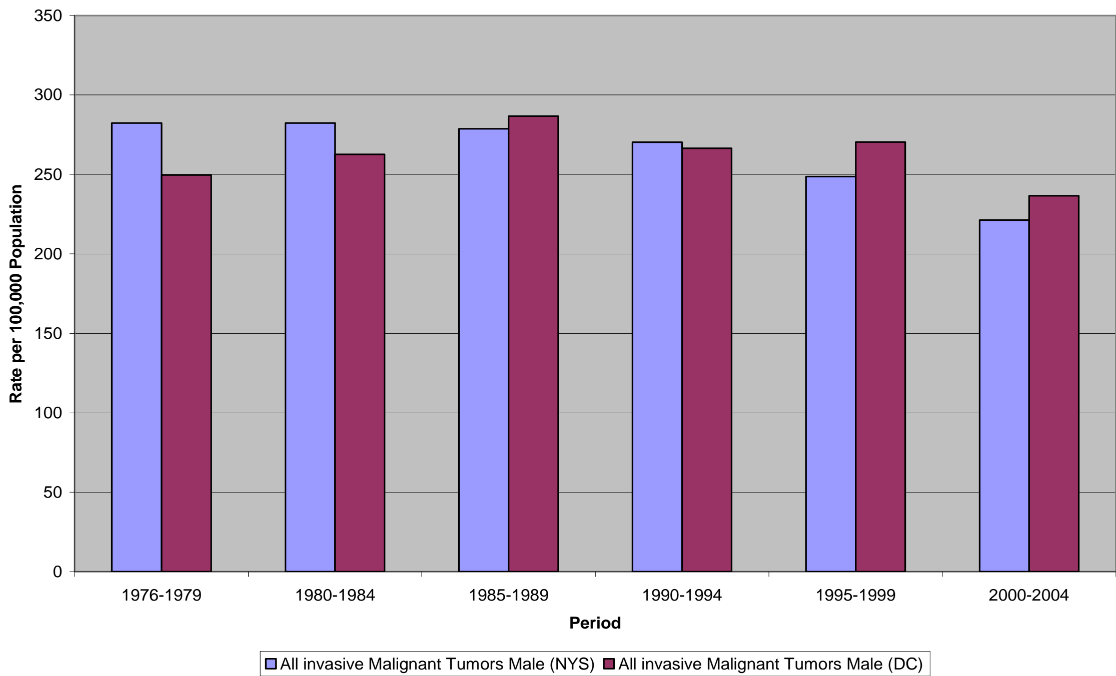

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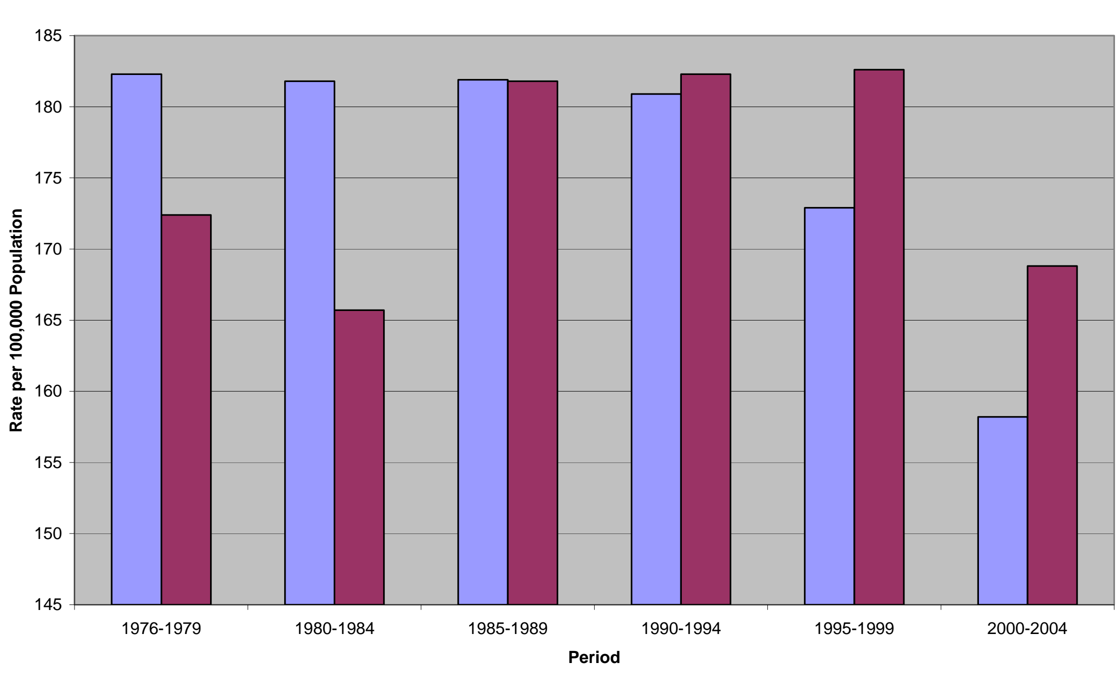
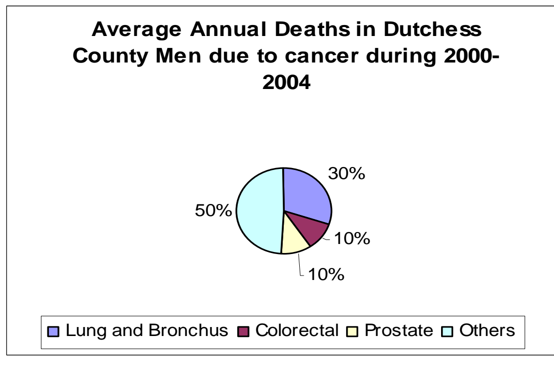
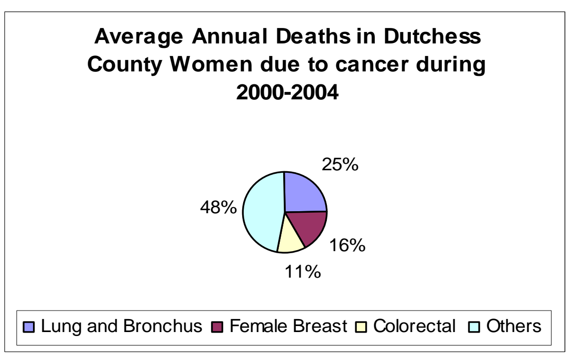


Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

The decline in mortality is observed in both genders but more recently in women. However, in both genders the Dutchess County cancer death rates remain higher than those of the NYS.

Lung cancer accounts for about 25% of all cancer deaths in women and about 30% of all cancer deaths in men. Breast cancer accounts for about 16% of all cancer deaths in women and prostate cancer accounts for about 10% in men.





Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

Disparities in cancer morbidity and mortality by race and ethnicity are substantial in Dutchess county, as across the nation as a whole. African American males have the highest cancer rate of any sub-group by race and gender. African American females have lower rates of cancer incidence than their white counter parts. However, both Black males and Black females have significantly higher cancer mortality rates despite the fact that Black females have lower incidence rates.

Cancer Incidence, Dutchess County, 2000-2004, by Race and Ethnicity

	Male Rate	**Female Rate**
White	579.4	446.2
Black	593.4	346.8
Asian or Pacific Islander	278.2	238.8
Hispanic (of any race)	359.3	321.8

Rates are per 100,000 and age-adjusted to the 200 US Pop.
New York State Cancer Registry, as of March 2007.

Cancer Mortality, Dutchess County, 2000-2004, by Race and Ethnicity

	Male Rate	Female Rate
White	239.9	170.2
Black	287.2	184.9
Asian or Pacific Islander	-	-
Hispanic (any race)	209.6	136.3

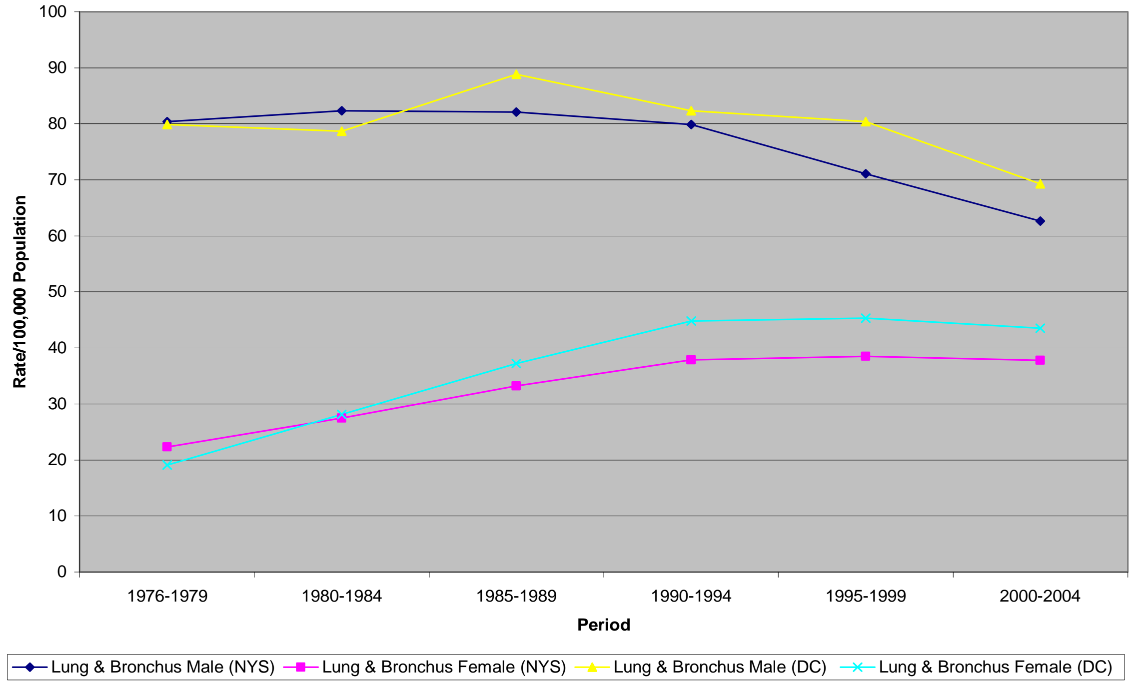
Rates are per 100,000 and age-adjusted to the 200 US. Pop.
Source: New York State Cancer Registry, March 2007
Asians not reported due to small numbers (<5 deaths per year).

F. BIG FOUR CANCERS IN DUTCHESS

Dutchess County has high cancer rates of the lung, colorectal, female breast and prostate than NYS or the U.S. as a whole.

1. Lung Cancer:
The ACS estimated that about 9,900 individuals were newly diagnosed with lung cancer and about 9,220 died in New York in 2006 alone.
Lung cancer incidence rates and mortality rates in both genders are higher in Dutchess than in NYS.

Lung Cancer 2000-2004	**Incidence Rate / 100,000 Population**		**Mortality Rate /100,000**	
Gender	Male	Female	Male	Female
Dutchess	91.1	59.7	69.3	43.5
NYS	82.2	53.9	62.6	37.8



Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

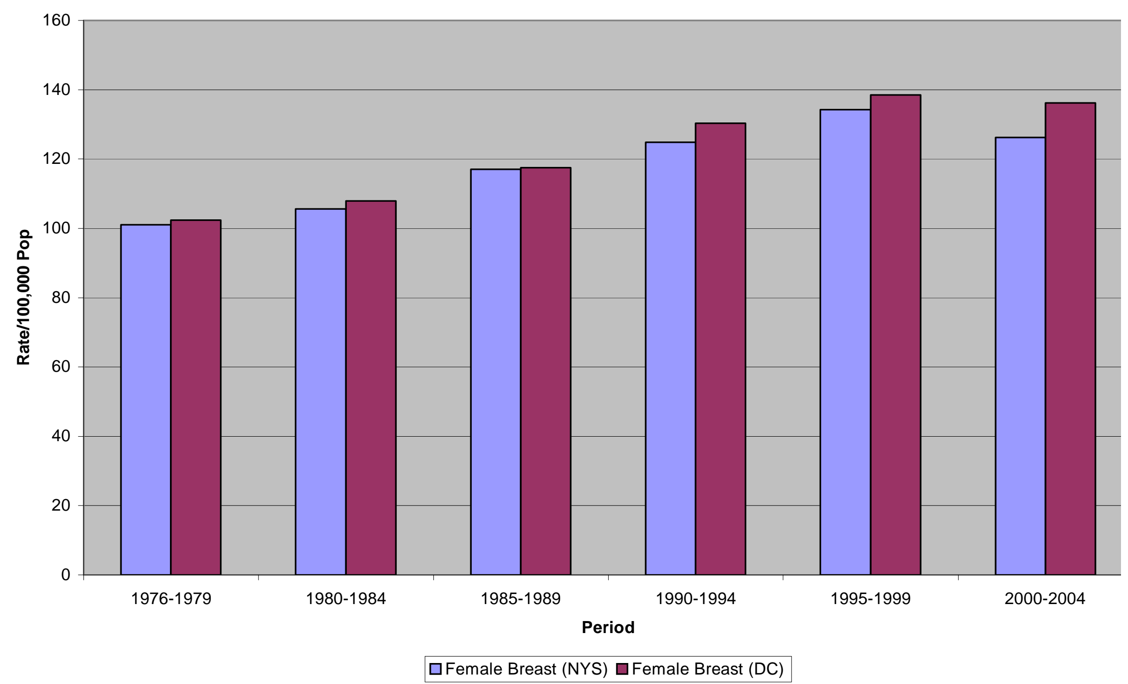
In Dutchess County, the incidence of lung cancer has shown a declining trend in men since the mid 1990's and has stabilized in women.

The lung cancer death rates among males have been on the decline, although Dutchess county males still have a higher rate than the average NYS rate. The lung cancer death rate in Dutchess County females is both above the state rate and is increasing.

2. Breast Cancer:
In 2006 there were estimated 14,400 women diagnosed with breast cancer in New York and about 2,770 deaths (ACS).

Breast Cancer 2000-2004	**Incidence Rate / 100,000 Population**	**Mortality Rate /100,000**
Dutchess	136.2	27.4
NYS	126.2	26

Both incidence and mortality from breast cancer in Dutchess County have decreased in Dutchess County but has not decreased as much as NYS, and deaths from breast cancer remain higher in Duthchess than in NYS.



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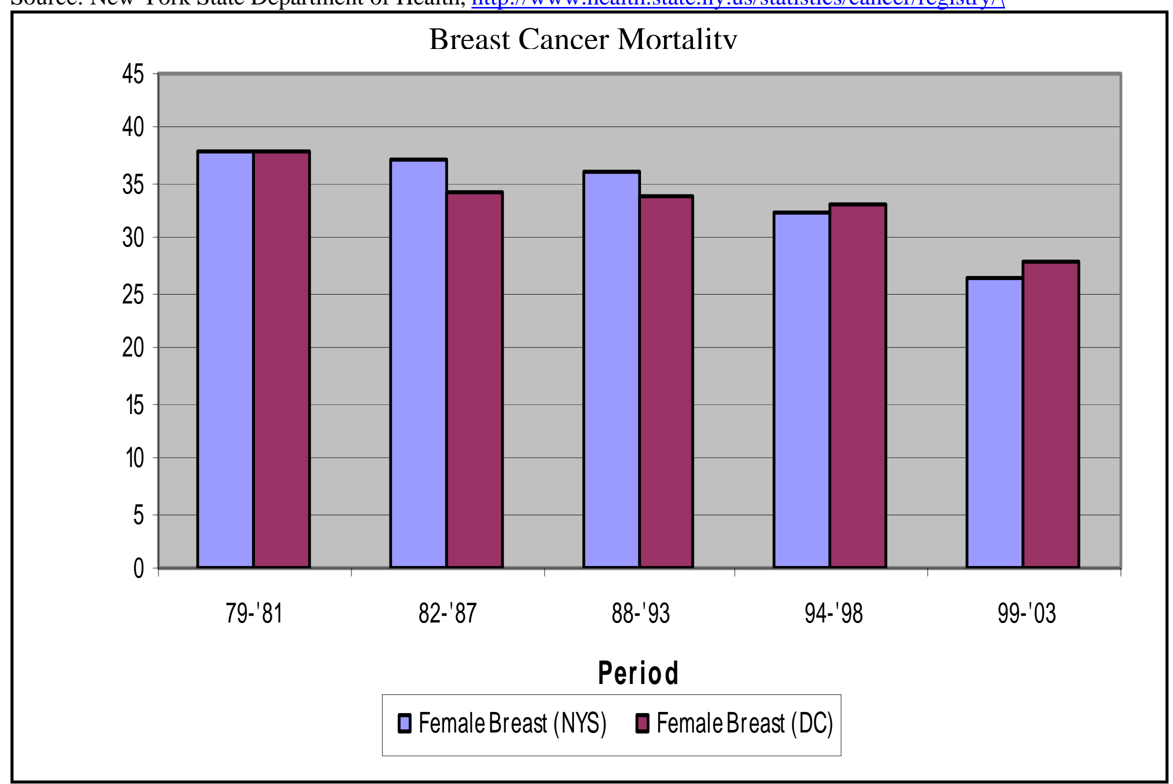


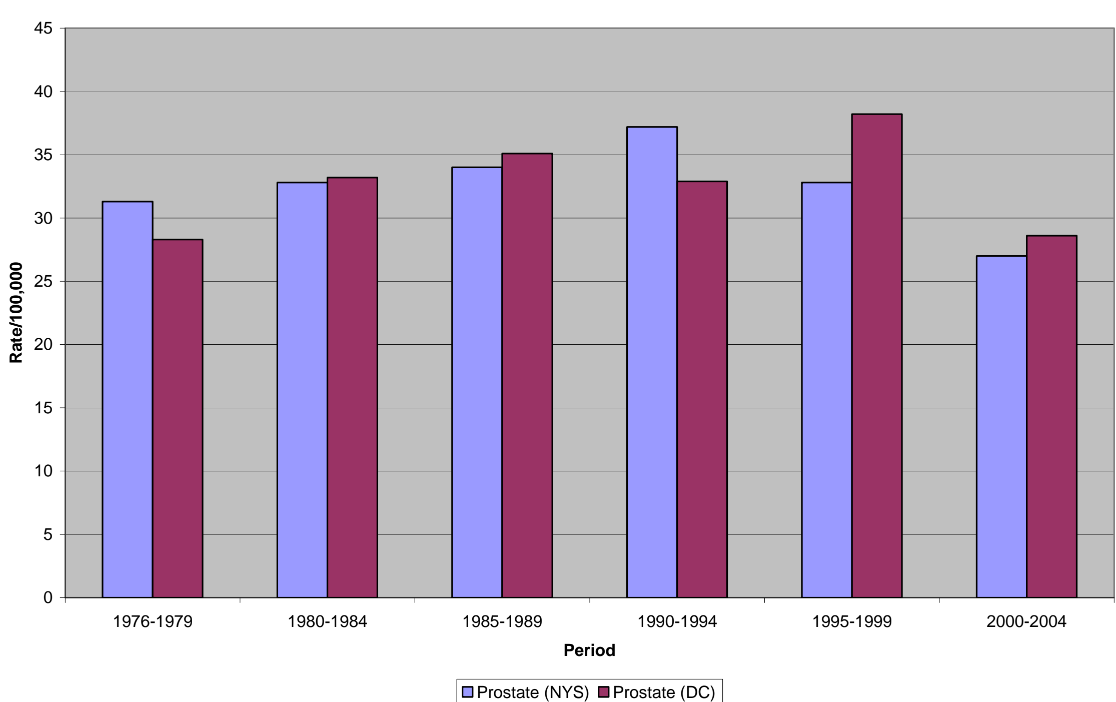
Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/\

3. Prostate Cancer:

In 2006 there were 14,400 estimated new prostate cancers diagnosed and approximately 2,260 deaths in New York State.

Prostate Cancer 2000-2004	Incidence Rate / 100,000 Population	Mortality Rate /100,000
Dutchess	168.6	28.6
NYS	170.3	27

As seen in the state the incidence of prostate cancer is on the rise, which may be attributed to increased screening. This screening, combined with advanced treatment options, the mortality rate from prostate cancer has started to show a decline in the last 5 years.



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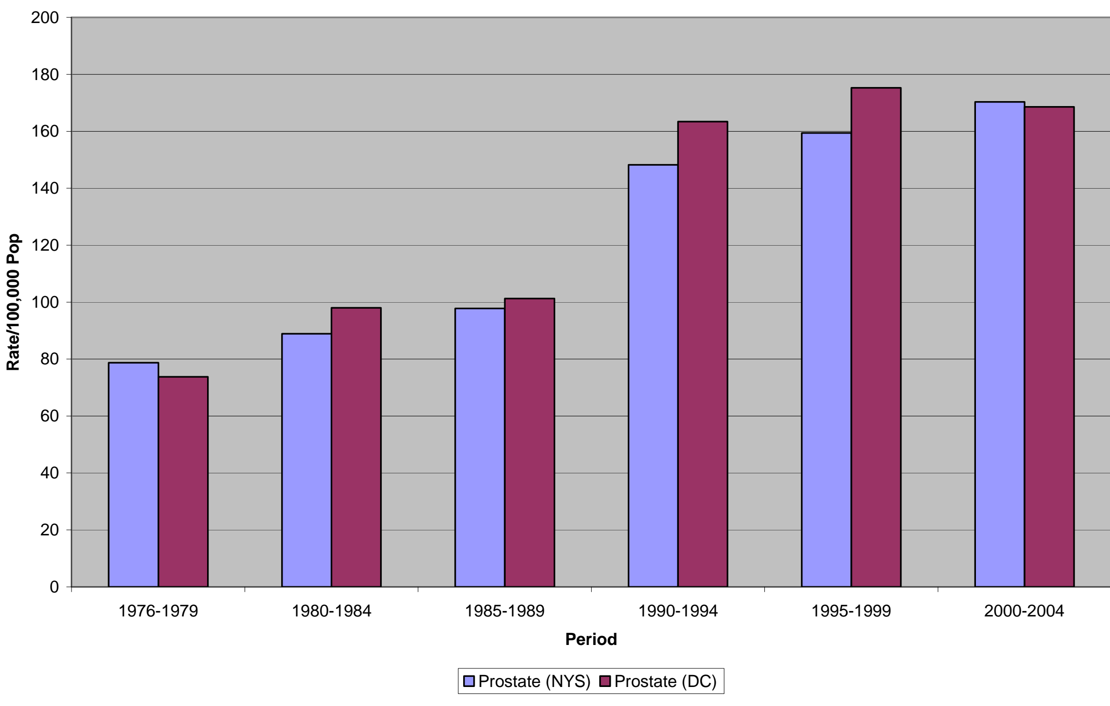
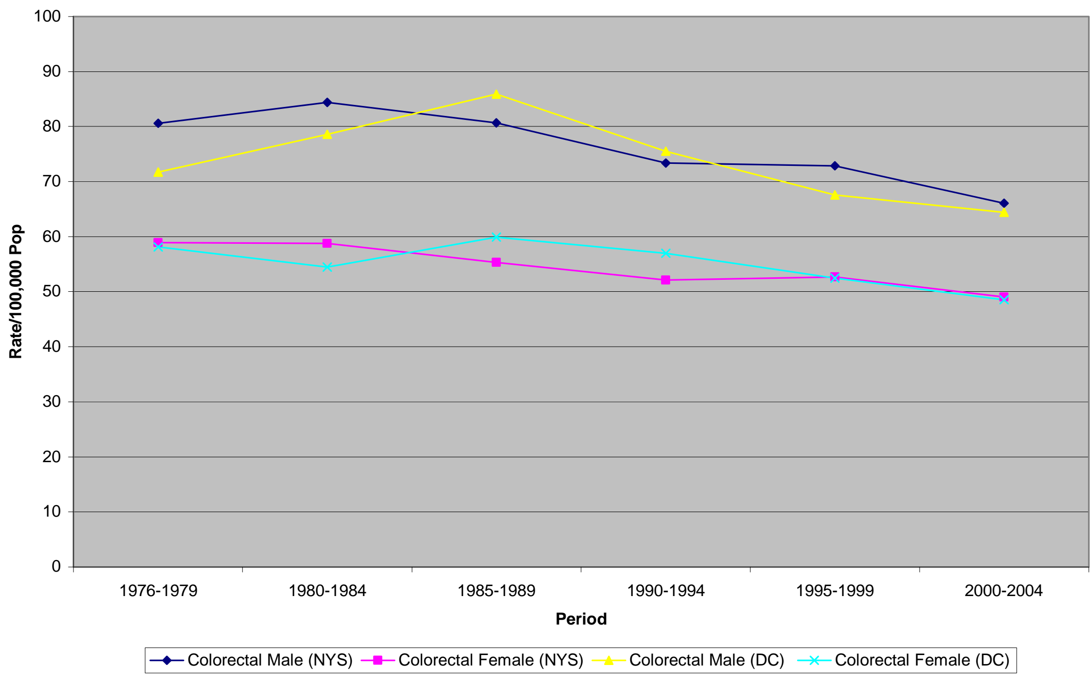


Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

4. Colorectal Cancer:

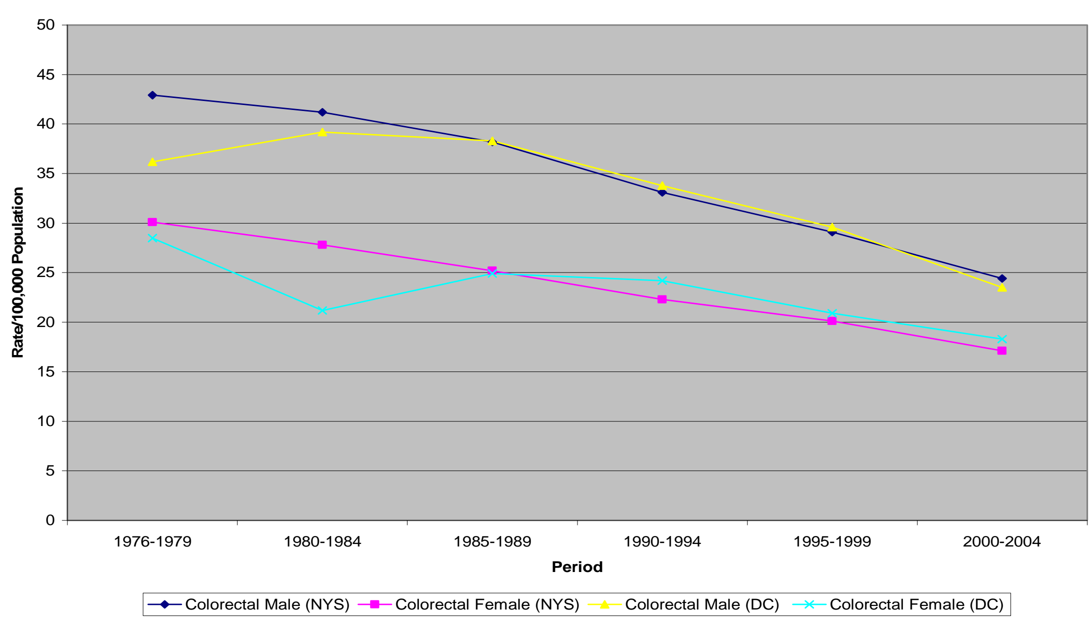
In New York there were 9,540 newly diagnosed cases of colorectal cancer in 2006 alone and approximately 3,540 deaths. Although the incidence rates of colorectal cancer in both genders are below those of the state, the mortality rates in women were observed to be slightly higher than those of the state.

Colorectal Cancer 2000-2004	**Incidence Rate / 100,000 Population**		**Mortality Rate /100,000**	
Gender	Male	Female	Male	Female
Dutchess	***64.4***	***48.5***	***23.5***	***18.3***
NYS	66.1	49	24.4	17.1



Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

The numbers of new cases in Dutchess have been declining similar to the decline seen in the New York State. The concern with this observation is that this might be due to lack of better screening and / or awareness.



Source: New York State Department of Health, http://www.health.state.ny.us/statistics/cancer/registry/

G. EARLY DETECTION

Early detection of cancer is a key factor determining better outcomes of treatment and a longer survival rate.

Dutchess County is lags behind New York State in the number of cancers detected early in certain cancers.

% Diagnosed Early 2000-2004	Male		Female	
	DC	NYS	DC	NYS
Oral	28.7	32.4	40.5	45.9
Colorectal	41.0	41.0	38.8	39.1
Lung	27.0	20.6	23.1	23.4
Melanoma	79.7	81	86.0	84.4
Prostate	90.4	88	N/A	N/A
Testis	65.5	74	N/A	N/A
Breast	N/A	N/A	63.7	63.8
Cervical	N/A	N/A	49.0	52.1
Uterine	N/A	N/A	77.4	72.4
Ovarian	N/A	N/A	17.9	20.2

Source: New York State Department of Health

In Dutchess County, the percentage of male lung, prostate and breast cancer cases diagnosed in early stages are higher than that in New York State. But Dutchess County lags behind in early diagnosis of other cancers as seen in the table above, such as testicular, cervical, ovarian and oral.

1. Mammography (BRFSS 2003):
90% of women over 40 responded yes to having ever had a mammography and about 72% had had it done in the last 2 years (71% of those 40-64 years of age and 72.5 % of those ≥65). This is above the HP 2010 goal of 70% coverage for mammogram in the past two years, above the NYS rate of 79.3% and the U.S. rate of 74.9%.

2. Prostate Specific Antigen Test, Men 40 years and old (BRFSS, 2003):
63% of men had had a PSA test done (56.5% among men 40-64 years of age and 84.5 % among those ≥65). Of these, 58% had had one done in the past 2 years (51.5% among men 40-64 years of age and 80 % among those ≥65).

3. Sigmoidoscopy or Colonoscopy, 50 years or older (BRFSS 2003):

About 56% of 50 years or older had ever had a colonoscopy or sigmoidoscopy done, (57% of men and 55% of women). 51.3% of adults over 50 had a colonoscopy or sigmoidoscopy done in the past 10 years.

BRFSS 2002-2004, Dutchess and Putnam Counties

	Male	**Female**	**Low Income**	**Moderate to High income**
Ever had Sigmoidoscopy or Colonoscopy (Over 50 Years Old)	42.8	60.0	39.4	61.6
Recent Sigmoidoscopy or Colonoscopy (Over 50 Years Old)	42.0	53.5	34.0	61.6

4. Pap Smears, Women 18+:

Among women 18 years and older, 86.1% had a pap smear, or cervical cancer screening, in the past three years in Dutchess county compared to 85.1% in NY State. When stratified by income level, however, only 82.6% with incomes under $35,000 report having a recent pap compared to 91.9% among those with incomes over $35,000 in Dutchess County. This disparity is greater than that seen in NYS which reports 82% and 87.5% respectively.

H. ACCESS TO HEALTHCARE

As per the table below the number of enrollees in Child health Plus and the number of self paid and Medicaid child births have increased over the years. The use of prescription discount drug programs and Elderly Prescription Insurance Coverage (EPIC) have also gone up. These figures indicating an increasing need for subsidized health insurance coverage. The Health Resources and Services Administration (HRSA) has designated areas in the Dutchess County as having health professional shortage.

Access to Health Care, Dutchess County

	2002	**2003**	**2004**	**2005**	**2006**
Uninsured Population[1]	n/a	11%	n/a	n/a	n/a
Enrollments in Child Health Plus[2]	4,467	4,105	4,654	5149	5,959

Enrollments in Family Health Plus[2]	953	1,138	2,113	2,020	1,975
Population Using NACO Prescription Discount Drug Program[3] Price Savings % Savings per prescription	n/a n/a n/a	n/a n/a n/a	n/a n/a n/a	3,530 $110,097 23%	6,586 $216,754 24%
Health Professional Shortage Area [4]	Yes	Yes	Yes	n/a	n/a
Community/Migrant Health Centers [4]	Yes	Yes	Yes	Yes	Yes
Elderly Prescription Insurance Coverage (EPIC) [4]	4,470	4,593	4,709	4,732	4,949
Medicaid/Self Pay Births [5] (per 100 live births)	23.9	23.3	21.9	26.4	26.2
Medicare Enrollment [4] - Elderly (age 65+) - Disabled	34,191 7,211	34,676 7,407	n/a	n/a	n/a

[1] *Expanded BRFSS 2003 for Dutchess/Putnam*

[2] *NYSDOH. Family Health Plus began operations in Upstate New York on 10/1/2001*

[3] *National Association of Counties. Program began operations in Dutchess County in February 2005*

[4] *Health Resources and Services Administration*

[5] *NYSDOH Bureau of Biometrics. Percentage does not include births where health insurance information is not stated on birth record. Rates for 2005 and 2006 are preliminary estimates*

The Many Voices One Valley Survey conducted in 2007 indicated 22% people surveyed (and about 15% children) have had a gap in health insurance in the last one year, 10% have no health insurance currently. About 36% indicated that healthcare had a significant strain on household income and about 43% found that health insurance had a significant strain on household income. The figures below give some insight into the issue of access to healthcare.

(BRFSS 2003)
Dutchess and Putnam Counties:

	Dutchess County	NYS Excluding NYC
% of Adults with Health Insurance	90.5%	88.8%
% Adults that answered they did not receive medical	4.1%	5.3%

care because of the cost		

The New York State conducted Behavioral Risk Factor Surveillance Systems' (BRFSS) survey which indicates that 90.5% had health insurance and about 4% and indicates that cost was the reason they did not receives medical care.

I. CANCER RISK FACTORS

Characteristics of individuals that increase their chances of getting cancer are referred to as 'risk factors'. Some risk factors commonly associated with cancers include family history, overweight/obesity, and sedentary lifestyle, use of tobacco and alcohol, exposure to sun and environmental toxins. The American Cancer Society (ACS) estimates that 1/3 of all cancer related death can be linked to diet, sedentary lifestyles, and being overweight or obese and that smoking is responsible for another 30% of cancer-related deaths.

1 .Smoking:

According to the 2002-2004 BRFSS, about 23.4% of Dutchess County adults smoked cigarettes, which is higher than the NYS rate of 20.3. More male adults smoked than female adults. In addition, the % of the population that reported trying to quit smoking was only 51.6%, and lower than the state rate of 58.0. More Dutchess county residents smoked, and fewer had attempted to quit smoking during this time period.

In 2003 Dutchess county middle and high students were surveyed to determine their use of tobacco. About 37% of the kids' ages 9-18 years had smoked and about 13% had smoked in the last 30 days.

2. Obesity:

According to self-reported BMI (Body Mass Index based on weight and height) from the 2002-2004 BRFSS: 55% of men and 26.9% of women said that they were overweight and 23.7% men and 22.6% women said that they were obese. Overall, 64.9% of the population can be classified as either overweight or obese in Dutchess County, which has been associated with an increased risk of certain types of cancer.

In 2004 Dutchess County children between the ages of 2-17 years were examined for obesity. About 19% had BMI above the 95th percentile for their age and gender, which put them in the 'obese' category and about 17% had BMI between 85th and 95th percentile for their age and gender, which set them up 'at risk for overweight'. Combined, 36% of children and adolescents were classified as overweight or at risk for overweight, which is associated with an increased risk of obesity in adulthood.

3. Dietary Factors:

As per the 2003 BRFSS only about 29% of the respondents said that they had a daily intake of 5 fruits and vegetables daily (22% men and 35% women).

4. Physical Exercise:

As per the responses received on BRFSS Survey in 2003, about 79% of the adults (82% men and 76% women) were taking part in a leisure time physical activity or exercise. This indicates that about 21% have sedentary lifestyles, a risk factor associated with increased cancer risk.

5. Alcohol Consumption:

According to BRFSS 2003, 15% (23% men and 8% women) surveyed responded that they were at risk for binge drinking (i.e. men having five or more drinks, women having four or more drinks on one occasion.) In addition, 4% (4.2% men and 4.6% women) who responded to the survey that they were heavy drinkers (i.e. more than two drinks per day for men more than one drink per day for women).

III. Assessment

A. KEY INFORMANT INTERVIEWS

As stated on its Comprehensive Cancer Control Initiative website, "The Dutchess County Department of Health, working together with community partners and interested residents, will share information and resources to better promote cancer prevention, improve cancer detection, increase access to health and social services and reduce the burden of cancer. Our combined efforts will aid in helping to reduce cancer risks, detect cancers earlier, improve treatment and enhance quality of life for those touched by this disease."

As a first step in its needs assessment activities, JSI staff conducted key informant interviews with a core group of fifteen individuals who work in the area of Comprehensive Cancer Control. The interview guide asked informants twenty-six questions divided into five areas:

- Overview;
- Prevention and Screening;
- Early Detection and Treatment;
- Support Services; and
- The Cancer Advisory Council

A list of key informants was developed by the Dutchess County Department of Health. Additional informants were suggested by people who were interviewed and they were interviewed to bring additional perspectives to the process. A list of all key informants is provided in Appendix A. Findings on fifteen key informant interviews are included in this report.

1. Introduction

Of the fifteen individuals interviewed, all agreed to have the interview tape recorded. This allowed the interview to focus on asking questions, probes and other follow-ups. The tape was reviewed by the interviewer to help in completing the write-up of that interview. The tape was not listened to by anyone else.

Demographics
All except one of the fifteen individuals interviewed work in Dutchess County. Some work in other counties in the Hudson Valley region as well as in Dutchess County. The median length of time informants had worked to provide cancer-related services in Dutchess County was seven years. The median length of time informants had worked in their particular field was ten years.

Eleven of the fifteen informants identified their race/ethnicity as White, one as African American, one as Hispanic/Latino and two chose "other." Two informants identified themselves as being between 31-40 years old, six as between 41-50, five as between 51-60 and two as over 61. Four informants reported speaking English exclusively. In addition to speaking English, six informants reported speaking Spanish, three speak French, one speaks Italian, one speaks Chinese, and one speaks Filipino.

2. Prevention Services

Table 1: Summary of Close-ended Questions – Prevention and Screening

Question	Yes	No	DK
Are services well advertised?	42%	33%	25%
Are there organizations that do outreach?	61.5%	30.5%	8%
Are there populations groups who may experience more difficulty accessing services?	74.5%	8.5%	17%
Overall do you feel that the services in Dutchess County meet or do not meet the needs?	33%	42%	25%
Are you aware of current efforts in Dutchess County to address barriers or enhance promotion of these services?	82%	18%	

Available Services
When asked what prevention services existed in Dutchess County, several participants mentioned the difficulty and importance of differentiating prevention and screening services. One informant stated "prevention is not about getting mammograms, prevention means not getting cancer in the first place." Other respondents felt there is a need for the public to understand that screening for colon cancer is also a preventative measure.

Several informants stated that most organizations providing support services for cancer patients also do some kind of prevention activities along with outreach to promote their services. As one informant said, “every facility offers its own preventative type services, but there isn’t a lot of dedicated money for prevention services.” For example, one informant described the Sister’s Network “Gift of Life Block Walk,” where in addition to raising money, participants hand out literature on cancer risk reduction and screening and invite community members back to a central location such as a church to discuss health topics such as healthy eating or tobacco cessation.

Other prevention activities performed by cancer support or advocacy organizations included participation in health fairs, organization of community education events, and providing programs and literature in local schools. Two informants described the partnership between Breast Cancer Options and Vassar College around breast cancer and environmental risk factors, through which an educational calendar and CD have been developed and distributed.

Informants reported that smoking cessation is one of the main cancer prevention services available in Dutchess County. Informants mentioned that smoking cessation programs are offered through the American Cancer Society (ASC) and through the hospitals. Other smoking cessation programs mentioned were the Great American Smoke-out and the NY State Smoker’s Quit Line. Other county-run programs mentioned by informants included healthy eating, childhood obesity, and exercise promotion initiatives.

Gaps in Services

Several informants stated that prevention activities were insufficient in general in Dutchess County. Others indicated a lack of knowledge about prevention services and suggested that if prevention programs exist there may be a gap in communication between prevention services and other types of cancer services. One gap mentioned was aggressive tobacco cessation programs targeted specifically at teens. Several informants felt that discussion of environmental risk factors was a major gap in prevention services. They noted that some discussion and research on the possible links between cancer and environmental toxins was taking place but felt much more discussion and work in this area is necessary.

Outreach Efforts

Some of the specific outreach activities mentioned by informants were the Miles of Hope “Family Fun Run” and women’s sports tournaments whose target population is women. The Sister’s Network block walk and also their faith-based program “Pink Ribbon Brunches” target African American women. Other prevention activities by cancer support service organizations include developing and distributing literature about risk reduction in schools or at events. Informants mentioned a seminar series on prevention topics and educational calendars distributed quarterly. Many organizations hand out flyers at health fairs, other community events and at local malls. Some organizations (such as the ACS) have radio and print advertisements of all events.

Barriers
Many informants had difficulty pinpointing specific barriers to prevention services. More often mentioned was a simple lack of services or even conversations focused specifically on prevention. One barrier mentioned was awareness of services such as smoking cessation. Another was the difficulty organizations have getting prevention messages out to individuals not already part of their service population. One informant stated that they felt NY state curriculum on health can be a barrier in getting prevention messages to high school students, as it has a pre-set specific agenda already prescribed.

Populations with Disparate Access
Informants mentioned that it is difficult to pinpoint who does not have access to prevention services and some identified this as an area they would like to know more about. Some informants felt that the Hispanic community has a great deal of difficulty accessing prevention services. Other population groups mentioned include African Americans, young people, and homeless, uninsured, undocumented and low income people.

Recent/Pending Initiatives
Two informants described the partnership between Breast Cancer Options and Vassar College around breast cancer and environmental risk factors.

Recommendations
a. The importance of wide-spread use of the new HPV vaccine as prevention for cervical cancer was mentioned.
b. Legislators should send information to their constituents telling them where there are wellness programs and where they can be screened.
c. The Advisory Council should link to information about activities to monitor and reduce environmental toxins.

3. Screening Services

Available Services
Informants reported that there are free screening programs for breast, cervical, colorectal, and skin cancer through the Healthy Dutchess Partnership. The hospitals have screening days in partnership with the ACS and others. Informants reported that all current screening tests – pap smears, mammograms, colonoscopies, the fecal occult blood test, and the prostate specific antigen test – are available in Dutchess County and many for free or at discounted rates for the uninsured or underinsured. There was confusion about the existence of a mobile "mammogram van" as some informants were aware that it had been discontinued while others still listed it as an available screening service.

Gaps in Services
Communication and coordination of screening services were identified as major gaps in services. A number of respondents reported that free screening services are available, but

people do not know about them or how to access them. Informants mentioned that transportation assistance is nonexistent for screening services and saw this as a major gap.

Outreach Efforts

Healthy Dutchess Partnership does outreach at health fairs and malls and at community events they have programs called "Ask Me" that provide information on screening. Outreach efforts for screening overlapped to a large extent with those for prevention. Again, informants mentioned a seminar series and educational calendars distributed quarterly. Flyers advertising screening recommendations and services are handed out at health fairs and other community events by several organizations. Again, some organizations (such as the ACS) have radio and print advertisements that advertise screening services. Brochures and posters by the DOH, ACS and others about screening are available in Spanish. These same agencies were reported to do outreach to Latina women and Hispanic populations through Spanish-speaking staff members or volunteers. The Sister's Network does outreach to African American women and women of color and has organized community breast cancer screening events with the hospitals to reach these populations.

Barriers

The barriers to screening most commonly mentioned were cost/insurance, lack of awareness, transportation, and fear. Informants stated that although free or discounted screening was available in the county, cost and insurance still play a major role in who gets screened. Those without insurance are less likely to know when or where to be screened, and those with insurance often still found co-pays to be a barrier. When the cost of screening was eliminated, informants reported that the cost of childcare, transportation and having to take time off from work to get screened are still major barriers.

Several informants felt that lack of awareness around screening in general and in how to access free screening services is a barrier. Transportation was mentioned as a highly significant barrier to screening. Ride programs or reimbursement available for treatment often do not extend to screening or early diagnostic exams. Geography may be a factor in the County with less access from the eastern and southern part of the County. Fear was identified by the interviewees as a barrier to screening. Fear might mean anything from fear of mammography because it hurts to fear of being diagnosed with cancer – particularly if a person is unsure how they would pay for treatment or is undocumented and fears being deported. Language was described as a barrier to screening but many felt it less significant a barrier compared with insurance or citizenship status.

Populations with Disparate Access

The groups most often mentioned as receiving disparate services were the uninsured and underinsured; followed by Hispanics and African-Americans. Migrant workers, undocumented immigrants and the homeless were also mentioned.

Recent/Pending Initiatives
The Cancer Consortium was the recent initiative most often mentioned by informants. Informants expressed excitement about the process, several expressed a hope that it will lead to more coordination of screening services. Also mentioned is the recent hiring of a geneticist who educates providers and the community about the role of genetic markers in screening for cancer. The Healthy Living Partnership was also mentioned as a key initiative.

Recommendations
- Recommendations focused upon coordination of services and collaboration between organizations providing screening.
- Communication between agencies and from them to the public was a key concern.
- Several informants stated that they knew many agencies were doing excellent screening outreach, but that as no one agency or hospital could reach everyone agencies needed to work together.
- Another suggestion was that mammography results be given the same day in order to reduce the fear of awaiting results and increase mammography rates.

4. Early Detection and Treatment Services

Table 2: Summary of Close-ended Questions – Early Detection and Treatment

Question	Yes	No	DK
Are services well advertised?	69%	31%	
Are there organizations that do outreach?	78%	22%	
Are there populations groups who may experience more difficulty accessing services?	92%	8%	
Overall do you feel that the services in Dutchess County meet or do not meet the needs?	50%	33%	17%
Are you aware of current efforts in Dutchess County to address barriers or enhance promotion of these services?	89%	11%	

Available Services
Overall, treatment is seen as high quality in Dutchess County and continually improving. Informants reported that nearly all treatment options are available in Dutchess County. There are two major Poughkeepsie hospitals with Cancer Centers – Vassar and St. Francis – and based out of these are oncologists with links to teaching hospitals. There are also 6-7 private cancer practices, such as Radiation/Oncology or Hematology/ Oncology practices. Based on information from transportation programs, fewer individuals are seeking treatment in NYC, Dana Farber, etc. Both hospital Cancer Centers provide treatment for Medicaid patients and the uninsured. Both local hospital Cancer Centers provide translation services for Spanish-speaking patients. It was also mentioned that there is a growing naturopathic community and that they are beginning to work with some oncologists to provide complementary services.

Gaps in Services

There has been a shortage for surgical oncology that is being addressed. Lack of specifically breast surgeons was mentioned. Access to clinical trials is limited without a teaching hospital in the County. Dental services for Medicaid patients are limited. Informants also described a gap in pediatric oncology, stating that you still had to leave the county for these services.

Outreach Efforts

Informants stated that outreach for treatment services is often done through primary care physicians rather than community outreach. Several informants mentioned that the big thrust in outreach is screening rather than treatment exactly; organizations like the ACS (and others) try to provide screening to people who wouldn't normally receive it and then follow up with them through getting their results and connecting them to treatment if necessary.

Barriers

Insurance status, financial issues, and transportation were described as by far the biggest barriers to treatment in Dutchess County. Even those with insurance often find co-pays unaffordable; many people's insurance is fragmented and coverage incomplete. Informants mentioned that hospitals and cancer support agencies do their very best to alleviate the financial burden of treatment and help people negotiate their options, but stated that the financial burdens of cancer far outweigh the support available for many patients. For patients who don't qualify for Medicaid but cannot afford other insurance the options are extremely limited.

Transportation was cited as the second major barrier to treatment. Informants stated that existing ride programs and are already full to capacity, and have limited service areas or populations. The ACS Ride to Recovery program, for example, cannot transport non-ambulatory persons. Informants stated that if you are over 65, ambulatory and schedule well in advance there are some transportation options, but that for those under 65 there are very few options at all. Hospitals and support service organizations do reimburse patients for cab fare when necessary, but this is limited by available funds and, for certain organizations, by the type of cancer the patient has.

Other major barriers to treatment mentioned by informants include awareness of services and options, language and citizenship. Informants reported that once a person is diagnosed with cancer they are almost always immediately connected to treatment, but that the coherence of the treatment plan varies depending on a person's ability to connect to support or research their options. Literacy plays a role in this; it was noted that literature from big Pharma tends to be at too high a literacy level for most patients.

Populations with Disparate Access

Individuals who are uninsured and underinsured are seen as the major population groups facing disparate access. It was noted that many middle class people can't afford the co-

pays needed for treatment services or early detection services such as mammograms. Insurance status is seen as cutting across other categories such as race or ethnicity, but informants noted that disparities also existed along these lines, with African American and Hispanic populations more likely to face difficulties accessing treatment. Informants also mentioned that undocumented workers facing a cancer diagnosis are also extremely likely to face difficulties accessing treatment.

Recent/Pending Initiatives

Informants again mentioned the Consortium and the Dutchess County Department of Health's work to develop a comprehensive cancer control plan. Also mentioned were the presence of individual local activist groups, of survivors for example, that link people to services. Informants also mentioned HCAP, a coalition spearheaded by Hudson River HealthCare to identify and remove barriers to care and make sure that every resident had a medical home. The coalition included the ACS, Healthy Women's Partnership, and representatives from those that run the local shelter, DSS, and community action agency. Also noted was the ACS network of advocates that pushed for legislative changes – such as the ability to fast track someone diagnosed with cancer to Medicaid.

Recommendations

- Some informants recommended increased communication between support service agencies, treatment providers and patients.
- One informant thought it would be helpful to hire a dedicated health educator to provide education about cancer prevention, screening and treatment throughout the county.
- Also mentioned was the need to support efforts to continue and expand one-on-one advocacy programs such as companion/peer programs or patient navigation.

5. Support Services

Table 3: Summary of Close-ended Questions – Support Services

Question	Yes	No	DK
Are services well advertised?	70%	30%	
Are there organizations that do outreach?	75%	25%	
Are there populations groups who may experience more difficulty accessing services?	50%	40%	10%
Overall do you feel that the services in Dutchess County meet or do not meet the needs?	87.5%	12.5%	
Are you aware of current efforts in Dutchess County to address barriers or enhance promotion of these services?	60%	30%	10%

Available Services

Informants noted that many people are looking for information from support groups and support from friends, family and faith groups. Attendance at support groups may be

reduced by national on-line groups and resources. There are many different support groups through the hospitals, including a friends and family group and special support groups for: Laryngectomy; Ostomy; Man to Man (men facing Prostate CA); Side by Side (wives/partners of men with Prostate CA); Breast Cancer; Stage IV group; Living with Lymphedema; and a Head and Neck Cancer Support and Education group. Informants mentioned that through the hospitals, restorative yoga is available as well as smoking cessation services, and a boutique with wigs, scarves, and prosthetics (at Vassar). Informants also mentioned that there are a number of other programs such as Community Education Forums, Road to Recovery, Reach to Recovery, "I Can Cope" and "Look Good, Feel Better."

Informants reported that there are individual organizations providing advocacy and support and different groups dealing with survivorship. Sister's Network has had a support group in the past (and would again if there was a need) and offers peer-to-peer support. Miles of Hope provides some services such as a Medical Gap Care Fund and a scholarship program for teenagers that have been affected by breast cancer. Miles of Hope also funds a string quartet that plays every Monday morning, massage therapists, and an acupuncturist.

Many informants mentioned that hospice care in Dutchess County is of excellent quality, although many were uncertain about the rate at which it is utilized.

Gaps in Services

Transportation is a major need. The current resources used to support transportation programs may exceed the resources spent on support groups and there is still unmet need, particularly for outlying areas (such as Dover, Amenia, and Red Hook). Some informants felt there was a need for more one-on-one advocacy programs such as companion/peer programs or patient navigation. Informants reported that pain control services for Medicaid patients are limited. Support for childcare was also mentioned as a gap. Some informants stated that hospice care is underutilized due to lack of available information.

Outreach Efforts

Informants reported similar outreach efforts under support services as for prevention, screening and treatment. Many organizations place flyers at clinics and hospitals, distribute at events and health fairs. Many churches have health ministries that can connect people to services. Various fund-raisers and events are also intended to build awareness about services. Some organizations have larger advertising budgets for print media or radio.

Barriers

Communicating information about support services through advertising and other methods is challenging. Not everyone has access to the Internet, and informants mentioned that funds for print or other forms of advertising are limited. Support services

are generally free so money is not a barrier in the same way, but informants noted that money is an issue in terms of prioritization. Informants stated that patients struggling to get to or pay for treatment are often less able to avail themselves of support groups or services, particularly if transportation or childcare are issues. Transportation is a barrier to support services and there are few resources to help. Some informants felt information about hospice was a gap and that families do not avail themselves of hospice because the information isn't available.

Populations with Disparate Access
Populations that may experience disparate access are people with rarer cancers, low income individuals, rural individuals or others with transportation issues.

Recent/Pending Initiatives
The Family Partnership was mentioned as a group trying to pull together social service programs but the informant was not sure if they have crossed into cancer. Other initiatives mentioned were similar to those in treatment and screening, including the Consortium.

Recommendations

- Expand one-on-one advocacy programs such as companion/peer programs or patient navigation.
- Coordination of resources and communication between agencies and medical providers was mentioned.
- Informants mentioned that there is often no consistent community network and stressed that the engagement of non-traditional partners (those who provide other forms of community support such as the United Way or religious organizations) is key here.

6. The Dutchess County Comprehensive Cancer Advisory Consortium

Key Activities
Coordination of transportation resources could be helpful. Through planning, the County needs a more detailed analysis of the services currently being offered and where the gaps are.

Other key activities suggested would be to continue and expand educational efforts that are science-based and help make that complex and complicated information (prevention or treatment information) available to the public. Ensure that screening guidelines are adhered to properly. Work on collaboration between the county, the ACS, and local hospitals to encourage patients to go for their annual exams – perhaps have a public services announcement or advertising to get people to screening.

Another key activity mentioned is for the Consortium to talk about the high quality of cancer treatment in Dutchess County, to let people know they don't have to go to NY for treatment.

Role of Agencies

All key informants were willing to be active participants in the process. There was widespread support for the Consortium and the effort being made by Dutchess County. Informants who are not currently Consortium members expressed a desire to be a part of the process as it continues.

Other Key Potential Participants

Informants suggested a number of agencies and individuals as potential partners in Dutchess County cancer control planning and activities. Some of those mentioned are already involved in the Consortium or these interviews. Important contributors mentioned by informants were: American Cancer Society (particular mentioned was their huge data base of resources that is updated routinely); Board of Continuing Education; Breast Cancer Options; Catherine Street Community Center; Clearwater; colleges; Dutchess County Community Action Partnership; Eastern Dutchess Coalition; The Rural Health Network; educational institutions (post-secondary and secondary); local insurers; Miles of Hope; PCAP (prenatal assistance for care during pregnancy); physicians; primary care providers; smoking cessation program; Social Services – Medicare / Medicaid offices; United Way; and Vassar Specialty Programs.

Main Challenges Facing Dutchess County Residents with a Cancer Diagnosis

A number of informants summed up the main challenge of facing a cancer diagnosis as knowing where to go and what ones options are for treatment and also support. They stated that the most difficult thing is to know what the next steps are and how to reach out to individuals and groups that can help. Some informants stressed the importance of having non-cancer-related community supports available so that people don't have to make a choice between having to pay for their medical care and their basic needs such as food, clothing and shelter.

Aside from the challenges of awareness that affect every aspect of a cancer diagnosis, informants again mentioned that insurance and financial issues are a main challenge for many if not most cancer patients. Transportation was again cited as a main challenge, and one that has an impact on both medical treatment and ability to find other forms of support from mental to financial. Some informants also mentioned language as a main challenge, and stressed the need for more focus on medical interpretation on a state and local level. These informants felt that although language barriers affect a smaller group of people and hospitals do have translation services, the need is greater for those affected than the services available.

B. RESOURCE INVENTORY

Introduction

The second step in the needs assessment process was for the Dutchess County Department of Health (DOH) to initiate a needs assessment, including a resource inventory that looks at existing resources, as well as identifying gaps and areas of resource need.

The purpose of the resource inventory is NOT to provide a comprehensive directory of services. It is, instead, intended to review what is known about the availability of cancer prevention, detection, treatment and support services and provide information about the sufficiency of these services.

Methods

To produce this resource inventory, JSI conducted 15 key informant interviews (reported on separately) as well as an electronic (online) survey of 56 individuals representing 35 organizations. Individuals were offered a $50 online gift certificate for completing the survey. We received 22 surveys for a 40% response rate. These responses came from individuals at 15 different organizations or practices and represented services that ranged from a full-service tertiary hospital to a tele-radiology group; and social work services to health promotion and education. Findings from the survey were compiled and analyzed with help of Survey Monkey, an online survey software program.

The survey asked respondents to comment on a number of services and indicate whether they offered the services and if so was there “insufficient capacity,” “sufficient capacity,” or “more than sufficient capacity.” The survey listed 16 services under prevention and screening; 18 services under detection and treatment; and 10 services under support services. Since many of the responding organizations provide only a few of the services asked about, the actual “n” for most questions is less than 22. In addition, only half of respondents answered questions about the demographics of the population for which they provide services.

Findings

The findings are presented in three sections. First, we describe respondent characteristics such as the services they offer, where they are sited, and the population(s) they serve. Second, we provide lists of services and gaps in services in the areas of Health Promotion and Disease Prevention; Early Detection; Treatment; Quality of Life; Palliative Care; Health Personnel; Research; Data and Surveillance; and Public Policy. Third, we provide the information gathered with respect to plans to reduce, maintain or expand services.

Section One: Respondents

1. Services Provided

Twenty-two individuals representing 15 organizations or private practices contributed to the online resource inventory. Figure 1 lists how respondents described their services.

Figure 1: Listing of Services Provided

1. Primary and Specialty Health Care Services including WIC, prenatal care, HIV primary care, GI, GYN, Podiatry, nutrition counseling, diabetes education and behavioral health services
2. Tele-radiology
3. in-patient and out-patient oncology
4. Education in the primary areas of youth development, nutrition, financial management, environment, agriculture, horticulture
5. Support, Advocacy, Information
6. Grant making
7. Gynecology
8. Skilled Nursing, Rehabilitation, Alzheimer's/Dementia
9. Full Service, tertiary care hospital
10. Radiation oncology
11. Medical imaging with biopsy
12. primary healthcare, prenatal, podiatry, dental, patient assistance
13. Health promotion and education
14. Physical Medicine & Rehabilitation
15. Clinical Social Work
16. Hospital based Inpatient and Outpatient health care services
17. Community hospital comprehensive services available
18. medical, counseling
19. 2-1-1 info/referral, fundraising, grant making
20. ACUTE CARE
21. Comprehensive healthcare for terminally-ill at the end-of-life

22. Services for cancer patients and their families

2. Area Served

Most of the individuals and organizations responding to the resource inventory were located in Dutchess County. However, some were based elsewhere in the Hudson River Valley but did include Dutchess County as part of its catchment area. For "Primary Office," 17 of 22 (77%) respondents listed Poughkeepsie. In addition, 2 listed Peekskill, NY as its primary office, 1 each listed Kingston, Milbrook and Atlanta. **Figure 2** describes how respondents described the "other service sites" of their organization. Six organizations indicated "none" and one said "one" when asked about "other service sites."

Figure 2: Primary and Other Service Sites

1. Poughkeepsie, Beacon, Walden, New Paltz, Monticello, Goshen, Greenport(Long Island), Amenia, Dover Plains, Pine Plains.
2. Nationwide
3. Poughkeepsie, Beacon
4. Dutchess, Columbia, Greene, Orange, Sullivan
5. Red Hook, Beacon
6. Kingston, Fishkill
7. Fishkill, NY; Kingston, NY
8. FISHKILL
9. Poughkeepsie, New Paltz, Beacon, Amenia, Pine plains, Dover Plains, Walden, Goshen, Monticello
10. Dutchess County
11. Beacon, NY
12. Westage Business Center, Fishkill; Ulster Radiation Facility - on Benedictine Hospital campus
13. Fishkill, Kingston
14. Kingston, NY
15. Each county and region has offices

3. Cost and Insurance

With respect to cost, 63% of respondents indicated that they charged clients for the services they offer while 37% do not. Of those who charge clients, 100% indicate they accept private insurance, public insurance and self-pay, while only 71% accept veteran's administration benefits. Of those who take self-pay, all but one have a sliding scale.

4. Population(s) Served

Respondents were asked to "estimate your clinic or agency's total patient or client caseload in 2006." This ranged greatly from "561 callers" to "440,000 patient visits." Six respondents answered between 800 and 8,000. One indicated almost 22,000 patient discharges. Another indicated 75,000 patient visits and another 160,000. One respondent did not know and another "needed to talk to us" as there were "too many in and out patients."

More detailed demographics of the population served was obtained from the respondents with respect to age, gender, race and ethnicity, and other special characteristics. All age ranges were served by multiple agencies, with no noted gaps in services for any particular age group. Gender was evenly spread for most agencies, although there appear to be some specialty services for women only and none of the organizations polled work with men only.

Most agencies reported between 1-25% of their service population in each racial category (including Black, Asian, etc) other than White. Organizations varied more greatly in the percentage of their service population identified as White – some reported that 1-25% of their service population is White while others reported a percentage of White clients between 76-100%. Findings represented the broader community and no one racial category was noted as having no services available Most agencies reported that between 1-25% of their population served is of Hispanic Ethnicity which again is representative of the community.

The majority of respondents reported that clients with the following special characteristics each made up between 1-25% of the total caseload: LGBT persons, foreign-born, migrant workers, and the homeless, reflecting the make-up of the general population. Notably, Hudson River HealthCare reported that over 50% of the population they serve is foreign-born. Inmates / Prisoners were reported as served by Vassar Brothers Medical Center and Planned Parenthood.

Section Two: Services and Gaps

This section builds upon both the key informant interviews and the resource inventory survey to describe the comprehensive cancer services that are currently available in Dutchess County. In addition to describing available services, identified service gaps are also described. This "inventory" is not meant as a complete resource guide, but a snapshot based upon the interviews and surveys conducted as part of the needs assessment.

1. Health Promotion and Disease Prevention

a. Available Services
- American Cancer Society (ACS) develops and distributes prevention materials and hosts a prevention-related speaker series and events.
- School programs and literature distribution at schools through ACS and other advocacy organizations.
- ACS, Miles of Hope, Breast Cancer Options and others distribute prevention materials at county health fairs, malls and other events.
- Miles of Hope, Breast Cancer Options and Sister's Network organize prevention and health promotion events and materials around breast cancer.
- Sister's Network holds community education events such as "Gift of Life Block Walk" or "Pink Ribbon Brunches."
- Many area churches have health ministries that promote healthy lifestyles and disease prevention.
- Vassar College and Breast Cancer Options have an environmental risk factors and breast cancer initiative.
- Smoking cessation services are offered through the ACS, St. Francis and Vassar Brother Medical Center.
- Other smoking cessation programs include the Great American Smoke Out and the NY State Smoker's Quit Line.
- Sun Safety program offered through the Dutchess County DOH.
- Healthy eating program offered through the Dutchess County DOH.
- Childhood obesity prevention program offered through the Dutchess County DOH.
- Exercise promotion program offered through the Dutchess County DOH, Miles of Hope holds sports events to promote exercise and breast cancer awareness.
- Healthy Dutchess Partnership has programs called "Ask Me" that provide information on cancer screening.
- The Children's Services Council provides funding and counter marketing to reduce youth obesity, alcohol and tobacco use.

b. Identified Gaps
- Aggressive tobacco cessation program specifically for teens.

- Discussion of environmental risk factors.
- Lack of knowledge about what prevention means and can include.
- Medical home and insurance coverage for all Dutchess County residents.
- Services identified as being offered in insufficient quantity:
    - Nutrition Education
    - Exercise Promotion
    - HPV Vaccine
    - Dermatology Screening

TABLE 1: PREVENTION AND SCREENING SERVICES FOR DUTCHESS COUNTY OVERVIEW			
OFFERED IN DUTCHESS COUNTY AND SUFFICIENT	**OFFERED BUT IN INSUFFICIENT QUANTITY**	MORE THAN SUFFICIENT	NOT OFFERED AT ALL
Cancer Education for Public Hepatitis Vaccines Outreach Colonoscopy Mammography Prostate Screening Sigmoidoscopy Sun Safe Promotion Tobacco Cessation Tobacco Education	**Nutrition Education** **Exercise Promotion** **HPV Vaccine** **Dermatology Screening**	Pap Screening Clinical Trials	None

2. Early Detection

a. Available Services

- All common recommended screening tests – pap smears, mammograms, colonoscopies, sigmoidoscopy and the fecal occult blood test, and the prostate specific antigen test – are available in Dutchess County.
- Sometimes screening tests are available for free or at discounted rates for the uninsured or underinsured.
- Healthy Dutchess Partnership provides some free screening for breast, cervical, colorectal and skin cancer.
- Hospitals, including Vassar Brothers, St. Francis and Northern Dutchess Hospital, offer screenings and sometimes hold events to raise awareness about and provide screenings in partnership with local advocacy organizations
- ACS and DCDOH have flyers, radio and print ads in English and Spanish advertising free/discounted screening services.
- Organizations including the ACS, Miles of Hope, Breast Cancer Options and Sister's Network offer free screenings at various county Health Fairs, malls and community events.
- Sister's Network partners with hospitals to advertise and hold breast cancer screening events for African American women and other women of color.
- A geneticist has recently been hired at one cancer center to educate providers and the community about the role of genetic markers in screening for cancer.
- HCAP, a Dutchess County coalition led by Hudson River HealthCare, is currently working to ensure all residents have a medical home.

b. Identified Gaps

- Communication and coordination of screening services.
- Public information on available free and discounted screening tests.
- Transportation assistance for screening services.
- Local radio station that makes public health announcements on screenings and other services.
- Medical home and insurance coverage for all Dutchess County residents.

3. Treatment

a. Available Services

- Nearly all treatment options available in or around Dutchess County.
- Major Hospitals with cancer centers include:
  - Vassar Brothers Medical Center (Dyson Center);
  - St. Francis Hospital.
- There are 6-7 private cancer practices, including:
  - Hudson Valley Hematology/ Oncology Associates;
  - Mid-Hudson Valley Radiation/Oncology Associates.
- Both cancer centers provide treatment for Medicaid patients, privately insured patients, and the uninsured.
- Both cancer centers provide language interpretation services (for Spanish and other languages).
- Transportation services exist through the ACS Ride to Recovery program and hospital reimbursements.
- Growing naturopathic community beginning to work with some oncologists to provide complimentary services.

b. Identified Gaps

- There was a shortage for surgical oncology that is currently being addressed.
- Some feel there is a lack of surgeons who specialize in breast surgery.
- Access to clinical trials is limited without a teaching hospital in the county.
- Dental services for Medicaid patients are limited.
- More low-literacy and Spanish language materials explaining treatment options are needed.
- More transportation services are needed.
- More financial assistance is always needed, as is more and better insurance coverage and assistance negotiating insurance and financial questions.
- Need to continue and expand one-on-one advocacy programs such as companion/peer programs and patient navigation.
- Services identified as being offered but in insufficient quantity:
  - GYN Specialty Care
  - Pediatric Oncology

TABLE 2: DETECTION AND TREATMENT SERVICES FOR DUTCHESS COUNTY OVERVIEW			
OFFERED IN DUTCHESS COUNTY AND SUFFICIENT	**OFFERED BUT IN INSUFFICIENT QUANTITY**	MORE THAN SUFFICIENT	NOT OFFERED AT ALL
Chemotherapy Colposcopy Dermatology Endocrinology Gastroenterology Neurology Oncology Care Pathology Primary Care Surgery - General Surgery - Laser Urology Clinical Trials	**GYN Specialty Care** **Pediatric Oncology**	Biopsies CAT Scans Radiology	None

4. Quality of Life

a. Available Services

- There are many different support groups through the hospitals and ACS, including a friends and family group and special support groups for:
  - Laryngectomy;
  - Ostomy;
  - Man to Man (men facing Prostate CA);
  - Side by Side (wives/partners of men with Prostate CA);
  - Breast Cancer;
  - Stage IV group;
  - Living with Lymphedema;
  - Head and Neck Cancer Support and Education group.
- Restorative yoga is available through the hospitals.
- Dyson Center has a boutique with wigs, scarves, and prosthetics.
- Other support programs include Community Education Forums, "I Can Cope" and "Look Good, Feel Better" through the hospitals and ACS.
- Breast Cancer support organizations serving Dutchess county offer email news list, informational website, resource guide with local resources and up to date information; Camp Lightheart is available for the children of breast cancer survivors.
- Many area churches have health ministries that support cancer patients and their families and provide referrals to other supportive services.
- Other individual organizations provide advocacy and support and deal with survivorship, including:
  - Sister's Network has had a support group in the past (and would again if there was interest and offers peer-to-peer support.)
  - Miles of Hope provides some services such as a Medical Gap Care Fund and a scholarship program for teenagers that have been affected by breast cancer. Miles of Hope also funds a string quartet, massage therapists and an acupuncturist at one of the hospital cancer centers.
  - Breast Cancer Options provides peer-to-peer information, advocacy and support for patients and survivors.
  - 2-1-1 information referral line is available for questions about referrals around health or social service needs.

b. Identified Gaps

- Transportation is still a major need, particularly for outlying areas (such as Dover, Amenia, and Red Hook).
- 75% of service providers polled do not offer transportation services.

- More one-on-one advocacy programs such as companion/peer programs or patient navigation.
- Childcare assistance while seeking support.
- Services offered in languages other than English, particularly Spanish.
- Coordinated community network of support services that includes non-traditional partners for cancer control like United Way or religious organizations.
- Services identified as being offered in insufficient quantity:
  - Caregiver Support
  - Financial Assistance
  - Patient Navigation

5. Palliative Care

a. Available Services

- Hospital Cancer Centers offer pain management and a variety of psychosocial services such as those listed above.
- Advocacy and support organizations listed above offer psychosocial support and referrals to other palliative care services.
- Hospice Inc. provides hospice care for Dutchess County.

b. Identified Gaps

- Expanded pain control services for Medicaid patients.
- Services offered in languages other than English, particularly Spanish.
- Hospice care is underutilized due to lack of available information.

TABLE 3: SUPPORT SERVICES FOR DUTCHESS COUNTY OVERVIEW			
OFFERED IN DUTCHESS COUNTY AND SUFFICIENT	**OFFERED BUT IN INSUFFICIENT QUANTITY**	MORE THAN SUFFICIENT	NOT OFFERED AT ALL

Cancer Education for Patients Hospice Care Nutrition Information Palliative Care Respite Support Groups	**Caregiver Support** **Financial Assistance** **Patient Navigation**	Survivorship Support	None

6. Health Personnel

a. Available Services

- Interpreter services offered by majority of service providers

b. Identified Gaps

- Trained Interpreters on Staff
- Bilingual Staff

Most providers indicated that they had interpreter service. Of the providers offering (non-telephone) interpreter services, 100% said they had Spanish interpretation; 38% said they had French and Indian languages (Hindi, Urdu, etc.) interpretation and 31% had Mandarin Chinese, American Sign Language or an "other" language. Among the "other" languages that organizations indicated they handle were Italian, Korean, Polish, Hungarian and Russian.

Table 4 summarizes the findings of the resource inventory survey that asked about the various forms of interpretation that are available on site.

Table 4: Interpretation Services Overview

Type of Interpretation Service	Yes – Provide Service	No	Capacity is insufficient (overlaps with those providing the service)
Provides any interpretation services	68.8%	31.3%	25%
Trained Interpreters on Staff	60%	40%	33.3%
Trained Interpreters available with advance notice	75%	25%	25%
Bilingual Staff available	80%	20%	26.7%
Telephone Interpretation service used	60%	40%	6.7%

7. Research

a. Available Services

- Clinical Trials are available in Dutchess county through the hospitals and provider network.
- 1-800 number offered 24 hours a day year round and website access to information about clinical trials.

b. Identified Gaps

- Access to local clinical trials is somewhat limited without a teaching hospital in the County.

8. Data and Surveillance

a. Available Services

- Dutchess County DOH
- Tumor Registry
- BRFSS
- HP 2010
- Hospital Data
- HEDIS

b. Identified Gaps

- Directory of Services
- Data on disparities
- Utilization of existing data
- Publicly available, county-specific data.

9. Public Policy

a. Available Services

- ACS has a network of advocates that push for legislative changes such as the ability to fast-track someone diagnosed with cancer to Medicaid.
- 80% of service providers polled responded that they would be willing to make adjustments in service patterns based on data gathered through this analysis.

b. Identified Gaps

- Comprehensive Health Care Coverage
- County-specific cancer control plan – currently underway.

Section Three: Plans to Reduce, Maintain or Expand Services

We asked respondents which services, out of a list of 43 services, they planed to reduce, maintain at the same level or increase over the five year period, 2008-2012. Not surprisingly, given the rise in cancer rates, there were no services that providers currently planned to reduce. At the same time, given the increase in cancer rates, a substantial number of service providers projected increases in services over the next five years.

Table 5 lists the services asked about in this section along with the percentage of providers who offer the services who indicated they expected to increase these services over the five-year period 2008-2012. The table also indicates which of these services overlap with an identified gap from Section Two of the Resource Inventory.

TABLE 5: PERCENT OF PROVIDERS THAT EXPECT TO INCREASE SERVICE OVER THE NEXT FIVE YEARS

SERVICES:	PERCENT OF RESPONDENTS OFFERING THE SERVICE WHO SAY SERVICE WILL BE INCREASED:	OVERLAP WITH IDENTIFIED GAP:
HPV Vaccine (N = 5)	80%	x
Patient Navigation (N = 9)	78%	x
Clinical Trials (N = 6)	75%	
Palliative Care (N = 8)	75%	x
Support Groups (N = 10)	70%	
GYN Specialty Care (N = 6)	67%	x
Oncology Care (N = 6)	67%	
Primary Care (N = 6)	67%	
Homecare (N = 5)	60%	
Surgery – Laser (N = 5)	60%	
CAT Scans (N = 7)	57%	
Colposcopy (N = 7)	57%	
Radiology (N = 7)	57%	
Biopsies (N = 9)	56%	
Cancer Education for Patients (N = 9)	56%	
Mammography Screening (N = 9)	56%	
Outreach (N = 9)	56%	
Survivorship Support (N = 9)	56%	
Tobacco Cessation Programs (N = 9)	56%	

Nutrition Information (N = 11)	55%	x
Cancer Education for Public (N = 10)	50%	
Chemotherapy (N = 6)	50%	
Dermatology (N = 6)	50%	x
Hepatitis Vaccine (N = 4)	50%	
Neurology (N = 6)	50%	
Surgery – General (N = 6)	50%	x
Urology (N = 6)	50%	
Caregiver Support	44%	x
Exercise Promotion (N = 9)	44%	x
Hospice Care (N = 7)	43%	x
Pediatric Oncology (N = 5)	40%	x
Pap Tests (N = 8)	38%	
Prostate Screening (N = 8)	38%	
Sun Safety Promotion (N = 8)	38%	
Colonoscopy (N = 6)	33%	
Gastroenterology (N = 6)	33%	
Pathology (N = 6)	33%	
Sigmoidoscopy (N = 6)	33%	
Dermatology (N = 8)	25%	
Endocrinology (N = 5)	20%	
Financial Assistance (N = 8)	0%	x
Home Delivered Meals (N = 1)	0%	

When asked if service providers would be willing to make adjustments in service patterns based on this data, assuming those changes were feasible, 80% of providers indicated that they would be willing to do so.

C. FOCUS GROUPS

1. Introduction

In conducting its Comprehensive Cancer Control Plan ("Cancer Plan"), the Dutchess County Department of Health (DCDOH) and the Dutchess County Cancer Advisory Council ("the Council") agreed to conduct focus groups to obtain additional information from consumers of cancer prevention, screening, treatment and support services. The groups were to be conducted as part of a comprehensive needs assessment, including key informant interviews and a resource inventory. Given that Dutchess County is in the early stages of developing its Cancer Plan, strategic thinking went into the decision of whom to recruit as focus group participants.

Based upon the key informant interviews, a consensus emerged about how the focus groups could best be used to obtain key information. It was agreed that the general purpose of these focus groups was to hear from a range of consumer about their need for comprehensive cancer services in the areas of prevention, screening and early detection, treatment and support services such as support groups and palliative care.

The process of determining the target audience for the focus groups encompassed several steps. Again, as part of the key informant interviews, JSI staff asked informants who it was important that we speak with. The suggestions for focus group participants included people who need cancer screening, people who are uninsured and underinsured, racial and ethnic minorities, and cancer survivors. It was also suggested that there be representation from geographic areas outside of the Poughkeepsie area, including eastern Dutchess County. These choices were reviewed with the Council and the DCDOH. Several members of the Council generously volunteered to host focus groups. Some of the discussion included consideration of more specific at-risk groups such as women being screened for breast cancer or men with prostate cancer.

Based upon the recommended groups and the Council's discussion, DCDOH decided to conduct two groups for individuals eligible for cancer screening services (but not necessarily cancer survivors) and one group for cancer survivors. At this point in the Comprehensive Cancer planning process, the focus of activities needs to be broad, so that the Council can have a comprehensive overview of the needs and concerns of consumers.

DCDOH agreed that in order to reach the general population, utilizing their own base of employees would make sense. Thus DCDOH agreed that all County employees would be eligible to attend one group. Hudson River HealthCare (HRHC) was among the volunteers that specifically could recruit a group with many uninsured and underinsured persons. Also a focus group conducted at HRHC that would include members of the African–American and Latino communities. In addition, Vassar Brothers Medical Center agreed to host a group of cancer survivors.

2. Methods

Two focus group guides were developed in anticipation of conducting the focus groups. The first guide was called the "general" guide and included a substantial focus around cancer prevention, detection and screening. The second guide was called the "survivors" guide and included a substantial focus on treatment and support services. Both guides were circulated among DCDOH staff prior to finalization. Both guides are attached as an Appendix.

JSI staff worked with contacts at Dutchess County, HRHC and Vassar to develop recruitment language, plan for appropriate space and refreshments, and insure that approximately 10 people would be available to attend each group. One of the questions that emerged in this planning, was whether we also wanted to speak with the patient advocates who work with many un-insured and under-insured clients at HRHC. Patient advocates have a great deal of knowledge regarding the challenges of providing services to the un-insured and under-insured and thus it was agreed that a fourth group would be held for them. As part of the recruitment process, consumer participants (not patient advocates) were told they would receive a $50 gift certificate for participation in the group.

Four groups were held on September 25 and 26, 2007. There were a total of 43 participants in four groups including the patient advocate group. In addition to participating in the group discussion, individuals were given a short demographic form to help us determine the specifics of who participated in the groups. Forty of the 43 individuals completed the demographic form, though not every person answered every question.

<u>Demographics</u>

A slim majority of participants, 52%, gave a Poughkeepsie zip code as their residence. The second largest area of residence was Poughquag with 10% followed by Fishkill and Wappinger Falls, each with 7%. The remaining participants came from Beacon, Cold Spring, Coipake Falls, Highland, Hopewell Junction, Hyde Park, Milton, Pleasant Valley, Port Ewen, and Rhinebeck.

With respect to race, 74% identified as Caucasian/White, 16% as Hispanic/Latino, 7% as African-American/Black and 2% as Asian. When asked separately about Hispanic/Latino ethnicity, 26% identified as Latino. With respect to gender, 23% were male and 77% were female.

A wide range of ages participated in the focus groups. The most common age range for participants was 51-60 (38%). In addition, 18% of participants were 41-50 and 18% were 61-70. There were some younger participants: 10% were 21-30 and 8% were 31-40 and a few older participants: 10% were 71-80.

Finally, we asked people whether they themselves had had a cancer diagnosis or if they had a close friend or family member who received a cancer diagnosis. Half of the people (50%) had received their own cancer diagnosis and half had not. However, 88% of the people had a close friend or family member who received a cancer diagnosis. Thus almost all of the people in the focus groups were impacted by cancer.

See Appendices for complete demographics in tabular form.

3. Findings

Prevention

Themes

- People understand that tobacco avoidance, good diet, physical activity, and healthy weight can reduce the risk of cancer.

- There is awareness that environmental factors may increase cancer risk. Many people believe that due to environmental pollution from farms and factories that Dutchess County has an elevated rate of cancer.

- Some Dutchess County residents hold cultural beliefs about cancer prevention that are not evidence-based and can interfere with the process of obtaining needed prevention, screening and treatment services.

- Prevention services are generally not covered by either public or private insurance.

- People see information about cancer screenings in Dutchess County and people associate screening with cancer prevention

- Low literacy individuals may not have access to information about cancer screening activities.

Quotes

"I think there does need to be more focus on prevention, particularly on obesity. The programs they have, they are more about when people get to the 2nd stage of things."

"I'd like to see more insurance support of prevention – insurance doesn't allow prevention to get done – you can't follow up on anything."

"Literacy is a big issue. I have patients who don't look at flyers because they can't read. Word of mouth is better." – A patient advocate

"Not smoking, good diet, exercise – those all prevent cancer."

"Where you work affects whether you get cancer – if you are in a factory you might be more likely to get cancer."

"Bird peppers prevent cancer. My mother had blood cancer and she swallowed these peppers three times a day and they got rid of the cancer."

"I use screening to prevent cancer, there's a free program."

Screening and Detection

Themes

- Screening presents a range of challenges for individuals at all socioeconomic levels that include awareness of the tests, potential costs of the tests and concerns about sensitivity and specificity of tests.

- There are disparities in both knowledge about screening tests for cancer and access to these services based on socioeconomic levels.

- There is knowledge about the availability of "free" screening, but some uncertainty about extent of "free" services.

- Interpretation services exist at some sites but not all, especially private doctor offices.

- Some people resist screening tests if they believe they will be uncomfortable or embarrassing.

- People without legal immigration status documentation may not be able to access screening services.

- Despite use of routine screening tests, many diagnoses require self-advocacy and persistence when symptoms present and tests inconclusive.

- People with insurance may be deterred from screening by increases in co-pays for routine screening tests.

Quotes

"I think a lot of people are afraid, they think that no news is good news." - A County employee and cancer survivor

"… [I]f you go to the doctor, get your results. Even if they treat you like your crazy for requesting them. If they know you are seeing it, maybe they will be more careful."

"That's one of the major, major problems in Dutchess County – translation."

"…[T]hey start with the FOBT, and if something shows up they'll go on to a sigmoidoscopy or colposcopy, but it all depends."

"Some patients, particularly with cultural backgrounds outside the US, don't understand, don't think they need the procedure." Patient advocate

"I found out about colonoscopies, that this is a way of detecting, because my sister had one. Now that I know the test exists, I will get one. My sister had it as part of her yearly."

"I'm 58, but no one ever told me I needed to get one (a colonoscopy) even though I've had pap and mammograms."

"People don't get mammograms because of insurance and experience – people don't know what you need."

"If you don't have the right paperwork (aren't a citizen) you can't get payment through the______________ program."

"I don't know why I don't want to go. Maybe the preparation. Drinking all that water. I'm gonna have to do it. They made a big deal of this on TV, they saved a lot of lives showing this on TV."

Treatment

Themes

- Dutchess County has made significant progress with respect to treatment. Where few people sought treatment in Dutchess County 20 years ago, many people do so today. People obtaining treatment services in Dutchess County are satisfied with those services and appreciate the convenience, especially under stressful circumstances.

- While people were generally positive about cancer treatment services in Dutchess County there were some negative experiences and a sense that there were limited choices, especially in several specialty areas such as breast surgery and colon cancer.

- Some people utilize cancer treatment services outside of Dutchess County for a second opinion, i.e. confirmation of a treatment protocol.

- Survivors who obtain cancer treatment services outside of Dutchess County have found doctors coordinate successfully with primary care providers and other specialists inside of Dutchess.

- The issue of payment for cancer treatment services raises considerable resentment. People were angry when life saving treatment appears to be (or is) conditioned on advance payments, co-pays or letters promising coverage from insurers. Insensitive billing staff were favorite targets.

- Individuals without insurance had some knowledge of emergency Medicaid but were also aware of limitations to the service in terms of required time for approval (long for an "emergency" service) and limited services that would be funded (treatment but not necessarily ancillary services.)

- Sensitivity of doctors was raised by many. There were many people who wanted doctors to hear the tape of the focus group or witness or be part of a discussion like this.

Quotes

"I don't feel I've been led at all. They just put a million confusing things on the table and say – ok, decide. And at the same time as giving me all the decisions, they've said "you're awfully involved, aren't you?" - A daughter caring for her elderly mother with breast cancer.

"[I]t's not just chemo that's a business. Health care is a business. Insurance is a business." - A County employee and cancer survivor

"I got my treatment here, but I went and conferred with doctors at Sloane." - A survivor who receives her treatment in Dutchess County.

"There was a long wait to get a biopsy here in Poughkeepsie and it was too much stress; I'm being treated at Sloane." – Woman with stage IV cancer

"I was treated here at ________, because I didn't have the opportunity to go elsewhere. I am being followed up here; so far I'm very satisfied and will fight like hell if I'm not."

"I'm glad I had the radiation near where I live, because it made me really sick." – Woman with head and neck cancer.

“Everyone said I should go to ______ in New York City, but I am glad I stayed here. I had chemo at the ________ and radiation at _________. My husband had to take me everyday, so it was so much easier. I wouldn’t have gone anywhere else.” – Woman attending group with her supportive husband.

“There’s a couple of things they should tell you – but maybe not everything. Like, maybe I didn’t need to hear them say “two months!” They couldn’t have said, “possibility of 6!” – Woman with stage IV cancer

“I get cardiac care, whatever here. But nothing to do with my cancer. I bring all my reports to my cancer doctor, and then back to my primary.”

“I don’t think a matter of finances should be discussed in an open window. And it should not be done at the same time as the chemotherapy. The privacy is just not there.”

“Treatment should be separate. It shouldn’t be connected to billing. That should be at another time.”

“You can apply for emergency Medicaid if you are undocumented, but that’s about it. There only a very few specialists that participate with us. Social Services can be really hard to get into.”

“A big problem with Medicaid is memberships expiring. People change addresses, don’t or can’t fill out forms.” – A patient advocate

“All that I make goes towards it (medical bills – for prostate cancer) because I don’t have any insurance. I’m grateful, but I don’t have any idea what they do to my body.”

“The staff is the problem (in terms of racism, discrimination). There should be an inspector.”

Support Services

Themes

- Support services were an integral part of care for most cancer survivors.
- People travel outside and around Dutchess County to find the support services that they need.
- Due to relatively small numbers, especially for less common cancers, there are some specific cancers that don’t have enough members for a support group. Some survivors with these cancers use online or telephone support.

- Currently support services for children who have parents with cancer face a lack of support services.

- Transportation is a major need to assist people in obtaining screening, treatment and support services, but is not easily accessible. Some services are not easy to use (Medicaid transport) and others are not well publicized.

- There was high praise for breast cancer support services generally and assistance with wigs for women with hair loss.

- Survivors use family and friends as first line of support. However, support organizations are important resources for people who need an understanding voice.

- The notion of learning about how to navigate the cancer treatment service system from someone who has been through it was appealing to many people.

Quotes

"The [support] group is a great group – we have a lot of fun – it is not at all depressing. We laugh, we all know what it is, everybody has been through it … so no-one has to ask you how you feel – they know how you feel." - woman with Stage IV cancer.

"I've called _______ when I was alone and upset and just needed someone to listen. They were very kind. They just talked to me, answered questions."

"Transportation is a problem up near Amenia, for repeat visits."

"I don't think a Spanish support group would be well-attended. … These are people working 1-2 jobs, they have children, and they don't have time. The support they need is health insurance – we try to meet any need with people in the community through organizations that give food vouchers, clothes, cribs." – A Hispanic patient advocate

"If privileged people get sick they have support groups and walks, but for poor people when they get sick it's just another obstacle in a life that's been full of a lot of obstacles." – A patient advocate

Palliative Care

Themes

- Most people have a positive image of local hospice services.

- Requirements around prognosis to receive services is double-edged sword. Sometimes patient doesn't want to receive 6-month time frame; sometimes provider doesn't want to proffer it.

Quotes

"At-home and in the hospital hospice is good, hospice in nursing home is not so good. They never showed up, but billed me anyway"

"We have hospice programs here, they are very good. We access hospice for patients, we've had very positive feedback. They really go out of their way for people." – A patient advocate

Clinical Trials

Themes

- Most people had been offered opportunities to participate in clinical trials.

- Survivors didn't participate because they had other treatment options, or, if they had no options, did not want to undergo the potential demands and damage of the trial.

Quotes

"I was offered one but declined – too extensive. I said – let me know how it goes and then maybe I'll try it!"

"I was going to do one, but did not qualify. I wasn't sure about it anyway. I would be afraid of a trial – I want what is proven!"

General Suggestions

"Out of all this discussion, I think a case manager is the most positive idea."

"A forum for professionals where they could hear what it's like for patients would be good." - A cancer survivor.

"Being a Dutchess County resident all my life, you didn't used to stay here for cancer treatment – you went to Albany or Westchester – but we've come a long way. I'd like to see even more. Case management and transportation services should be included…. One-stop shopping." – Lifelong Dutchess County resident.

"There's wedding planners – why not cancer planners? They need a business card that says 'how to get through cancer 101.' That could be a county service."

"I agree that DOH could put together some type of resource list, handbook to give doctors. The information is not all collected in one place."

"The internet actually has too much information – I had to stop – I had my husband search because I just couldn't see everything. "

Doctors should sit down with patients. A major forum where they get to hear what we say – how it feels to have cancer. They need education on how it feels to be uneducated. Doctors don't realize how frightened we all are. There could be a peer-to-peer group.

"Offering ways of screening people. I think they should have one every month. Like colonoscopy. Improve screening. Awareness and access. Tell people which ones they need and where to get."

"From my own experience, I think they need to be more willing to use the MRI for people whose doctors think there is a reason to do it. I know it's expensive, but it saved my life."

"More education so people know how to prevent cancer."

"Prevention and financial help. Don't ask for money or social security numbers. If you don't have money they need to help anyway – people are afraid to go to the doctor because they can't pay and they aren't permanent residents."

"More information on the local TV channel. Talk about it all – local news, on the TV. Let women know that there are services for free – a commercial, maybe, that says "for cancer screening, call the Healthy Women's Partnership at . . ."

"Something for kids – something healthy and active – maybe with parents? They need a place to address their feelings – parents of adults with cancer too. All the organizations have these fundraisers that are great but they are just about getting money."

4. Summary of Findings

Most respondents were aware of the presence of cancer prevention, screening, treatment and support services in Dutchess County. While there were a variety of complaints and suggestions for improvement in each of these areas, there was also high praise for almost all of the existing providers of these services.

There were requests for practical resources that could help people navigate the system of care. These included suggestions for guidebooks that listed the recommended screening tests and where to get them and how to pay for them. In the same vein, more routine offering of free or low cost screenings with widespread publicity could help improve access to such services. Screening continues to be an area characterized by substantial amounts of complicated and speculative information, with many individuals using that complexity and uncertainty as a pretext for forgoing recommended tests.

For individuals who were un-insured and under-insured there were concomitant gaps in knowledge about cancer prevention, screening and treatment. Advocates working with that population struggled to help individuals integrate knowledge about cancer and comprehensive cancer services and access the services that each individual needed. Cultural gaps in understanding were usually associated with the un-insured and underinsured which increased the difficulty of accomplishing this task. Compounded by other difficulties in people lives (such as having adequate resources for education, housing, food, and transportation), the task of providing comprehensive care services to this population was often overwhelming.

Individuals with adequate financial resources still found navigation of the cancer world to be daunting. The challenges of detection and screening, choosing treatment (or having it chosen for you) and finding support was likened to a full-time job. Almost every cancer survivor noted the need to find the time and strength for self-advocacy or the importance of having a close friend or family member to assist them through the process. Many survivors told stories of early or delayed detection that meant the difference between life and death and most people now knew about other people for whom such differences had resulted in tragedy.

While many cancer survivors lacked ready access to the specific support services they needed, most could travel outside of Dutchess County or make use of telephone or internet services to fill these gaps.

Despite the many advances, receiving a cancer diagnosis remains a life changing event for almost all survivors. Faced with such an event, the routine manner of many in the treatment world was often viewed as callousness. This held true especially for those involved in obtaining payment for cancer treatment services. Many survivors wanted more than anything to be treated with respect and kindness throughout their course of treatment and focus group participants reported mixed results in this area.

IV. Themes and Recommendations

As a result of going through the needs assessment process, and after reviewing the subsequent data and information, the information has been organized along several recurring themes. The concerns, barriers, gaps, and suggestions that arose during the process have been organized under the general themes of Information and Education, Access to Care and Disparities, and Quality of Care. This is by no means a comprehensive list of concerns from the community. These represent the concerns that arose repeatedly and consistently throughout the process and seemed to rise to the top out of the wider list of concerns.

The following are recommendations that have arisen from the needs assessment process to consider going forward into the planning and implementation process:

A. Information and Education

The theme of information and education arose repeatedly through community members thirsty for more knowledge and more information about cancer prevention, cancer screening, and cancer services. There was a wide variation in level of knowledge about what steps one could take to prevent and detect cancer early – some people seemed to have a great deal of knowledge while others had very little. Overall, however, community members said that they would value and appreciate more education and information as well as increased awareness about opportunities for cancer prevention services or screenings, particularly free or low cost services.

A main challenge around addressing issues of Information and Education is how to make efforts sustainable. The recommendations, then, are to develop *ongoing efforts* that would not be a one-time event but would be ongoing, integral parts of communication in DC. The goals would be to increase knowledge about prevention and screening to those with limited baseline knowledge, and opportunities for services related to prevention and screening available in the DC.

1. **Develop an ongoing social marketing plan designed to increase awareness of risk factors around cancer prevention and screening outreach based on:**
    - **a.** Knowledge about risk factors and prevention strategies including:
        - **i.** Tobacco Avoidance
        - **ii.** Nutrition and Exercise
        - **iii.** Sun Exposure
        - **iv.** Environment
    - **b.** Knowledge about screening and what screening tests are recommended at what time. The current screening recommendations with widespread consensus are:
        - **i.** Clinical breast exam for women
        - **ii.** Mammography after age 40 for women

iii. Pap Smears for women over 18
iv. Colon Cancer Screening after age 50 for men and women
v. Education about Prostate Screening as an option
c. Increase public and provider education about palliative care as an option

2. **Provide more extensive advertising and outreach of available services, especially to underserved populations.**
   a. Increase public awareness of ways to access low cost or free screening, treatment, and prevention services
   b. Use the media that are being used by your target population (i.e. Radio and T.V. – news spots, advertisements).
   c. Make information available in different languages especially Spanish.
   d. Create low literacy, culturally appropriate materials that target populations disproportionately affected by cancer, with high risk factors, or with lower screening rates.

These proposed action steps for Information and Education work toward the following goals in the NYS Comprehensive Cancer Control Plan:

Health Promotion and Disease Prevention

Goal 7: FOCUSED COMMUNITY EDUCATION / OUTREACH: By 2010, develop and implement community-based strategies for public awareness activities.
Goal 1: TOBACCO: By 2010, reduce tobacco use by adolescents to 12%. By 2010, reduce tobacco use by adults to 15% for cigarette use.
Goal 2: REDUCE ENVIRONMENTAL EXPOSURE: By 2010, reduce population risks associated with environmental exposures to known or likely environmental risk factors for cancer.
Goal 4: SUN EXPOSURE: By 2010, increase the proportion of New Yorkers who use sun protective measures to prevent excessive sun exposure to 75%.
Goal 5: HEALTHY LIFESTYLE: By 2010, decrease the proportion of adults who are clinically obese to 15%. By 2010, decrease the proportion of children and adolescents who are clinically obese to 5%.

Early Detection

Goal 1: KNOWLEDGE, AWARENESS AND UTILIZATION: By 2010 enhance public and professional awareness, knowledge and utilization of age-appropriate, evidence-based comprehensive screening guidelines.
Goal 2: BREAST CANCER EARLY DETECTION: By 2010, increase the proportion of breast cancers detected at an early stage to 75%.
Goal 3: COLORECTAL CANCER EARLY DETECTION: By 2010, increase the proportion of colon and rectum cancers detected at an early stage to 50%.
Goal 4: PROSTATE CANCER EARLY DETECTION: By 2010, increase the proportion of prostate cancers detected at an early stage to 95%.
Goal 5: CERVICAL CANCER EARLY DETECTION: By 2010, increase the proportion of cervical cancers detected at an early stage to 65%.

Goal 6: SKIN CANCER EARLY DETECTION: By 2010, increase the proportion of cases of melanoma skin cancer detected at an early stage to 90%.

Palliative Care:

PUBLIC AWARENESS OF PALLIATIVE CARE: By 2010, increase awareness that palliative care is available and an integral part of cancer care at any stage of diagnosis, treatment and survival. Also, encourage earlier referral to hospice care as a means of providing palliative care in the last months of life.

Public Policy:

Goal 2: HEALTH COMMUNICATION AND LITERACY: By 2010, encourage development of policies to promote health literacy on cancer issues.

B. Access to Care and Disparities

Although anyone can develop cancer, some populations are disproportionately affected, and have higher death rates than others. Although some differences can be related to risk factors such as genetics and lifestyle, many of these disparities persist even when these factors are controlled for. Access to care is one of the primary areas of concern and opportunities for addressing disparities in cancer mortality across populations. Disparities in cancer nationwide have decreased in recent years, but still persist and represent the greatest challenge in cancer control planning. The primary recommendation that arose out of the community assessment process is the suggestion to offer Patient Navigation services for cancer care, and other recommendations address specific areas of concern that were brought up by the community.

1. **Promote the development of patient navigation services for cancer care utilizing the principles that patient navigators are community health workers recruited from local underserved communities, and work toward the elimination of disparities for the clients they serve.**

    a. President George W. Bush signed into law the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (P.L. 109-18).

    b. Patient navigation is a process by which an individual – a patient navigator – guides patients with a suspicious finding or new diagnosis through the complex cancer care system to help ensure timely diagnosis and treatment and quality care, while helping the patient to navigate potential barriers that fall into categories such as:

    - Financial, economic
    - Language and cultural
    - Communication
    - Health care system
    - Transportation
    - Bias
    - Fear

c. A patient navigator essentially is a problem solver and a highly resourceful individual from the community. The navigator is trained to anticipate, address, and overcome barriers to care and to guide patients through the health care system during a very difficult time.
d. Patient navigators can help improve the quality of care patients receive. Improving the quality of care may help extend or even save patients' lives. With the help of a patient navigator, patients are:

- Guided through the complex treatment "maze"
- Given help with insurance paperwork, transportation to medical appointments, identifying local resources (including elder or child care), and communicating effectively with health care professionals
- Provided emotional support and encouragement

e. The result is that patients with suspicious findings have a greater chance of receiving a quick and timely diagnosis and any necessary treatments. In addition, services may be better coordinated and more consistent, resulting in improved outcomes.

3. **Support widespread access to interpreter services for all health care service settings, particularly in Spanish.**
   a. Promote the development of a diverse workforce including bilingual staff to help alleviate language barriers, particularly with Spanish speakers.
   b. Promote the use of long distance Telephone-based language lines for (settings such as private practices and for less commonly spoken languages in Dutchess county.
   c. Enforce the federally mandated "Culturally and Linguistically Appropriate Services" (CLAS) Standards for institutions receiving federal funding.

4. **Ensure access to free or low cost options for transportation to health care, including screening, treatment, and support services particularly for outlying areas such as Dover, Amenia and Red Hook.**
   a. Eliminate barriers to accessing existing services.
   b. Increase public and professional awareness of existing services.
   c. Provide increased access for populations and locations that are currently underserved.

5. **Advocate for the availability of low cost or free screening and treatment for the un-insured and underinsured.**
   a. Eliminate barriers and delays in the use of emergency Medicaid
   b. Establish a "fast track" system of preliminary assessment for emergency Medicaid
   c. Advertise the availability of services and who qualifies for them
   d. Increase access to healthcare coverage for all residents of Dutchess County.

These proposed action steps work toward the following goals in the NYS Comprehensive Cancer Control Plan:

Public Policy

Goal 4: DISPARITY REDUCTION: By 2010, address health disparities in access to cancer screening and treatments.

Treatment

Goal 5: GEOGRAPHIC ACCESS TO CARE: By 2010, geographic access issues will be identified and reduced.

Goal 6: FINANCIAL ACCESS TO CARE: By 2010, assure that high quality cancer treatment and services are accessible to New York State residents, regardless of socioeconomic status, geography, or race/ethnicity.

C. Quality of Care

Quality of care, then, is the final theme that encompasses concerns of the community, primarily around cancer related care and treatment. Patients are asking for a client-centered approach that takes the harsh reality of a cancer diagnosis into account. Patients want to be treated in a compassionate, respectful, and confidential manner, and require a wide range of supportive services to support the range of concerns that inevitably arise with a cancer diagnosis. Most patients were deeply grateful and appreciative for all of the services and hard work in Dutchess County already. County residents stated they saw clear and consistent improvement in the quality of cancer care over the past 20 years, but they also offered areas that presented opportunities for improvement.

1. **Improve patient satisfaction through more client-centered approaches.**
    - **a.** Use quality management techniques (and needs assessment findings) to identify areas of dissatisfaction and strategies to improve those areas
    - **b.** Address sensitive areas such as billing and maintaining privacy for patients.
    - **c.** Provide public forum with opportunities for dialogue between patients and providers

2. **Continue to develop needed specialty services within Dutchess County.**
    - **a.** Link people to support services in and around Dutchess County, including neighboring communities, if necessary.
    - **b.** Develop a Resource Guide for a newly diagnosed patient with Cancer that is widely available to patients and is kept up to date with services available across institutions and even including neighboring communities and national resources when applicable.

3. **Promote access to comprehensive case management for people with complicated life circumstances, co-morbidities, or both; or a lack of adequate support from their social network.**

a. Identify existing case management resources for clients needing more intensive coordination of care and ancillary services.
b. Support the development of a comprehensive Case Management System which the most complicated cases would be directed to.

These proposed action steps work toward the following goals in the NYS Comprehensive Cancer Control Plan:

Treatment:

Goal 1: QUALITY OF CARE: CURRENT TREATMENT: By 2010, increase the availability of the best cancer care to all New Yorkers.

Goal 2: COMPREHENSIVE QUALITY OF CARE RESOURCES: By 2010, encourage best practice delivery systems recognizing the chronic nature of cancer, including ongoing supports and navigation for families, rehabilitation, education, social and legal services.

Quality of Life:

Goal 2: PSYCHOSOCIAL SUPPORT: By 2010, increase the availability of psychosocial support services for cancer survivors, their families, and friends through all phases of the cancer experience.

Appendices

A. Survey Results
B. List of Key Informants
C. Focus Group Guides
D. Dutchess County Focus Group Demographics
E. Key Informant Interview Guide
F. Web Based Survey

Dutchess County Comprehensive Cancer Control Plan

1. Organization Name:		
		Response Count
		22
	answered question	22
	skipped question	0

2. Types of service(s) Provided:		
		Response Count
		22
	answered question	22
	skipped question	0

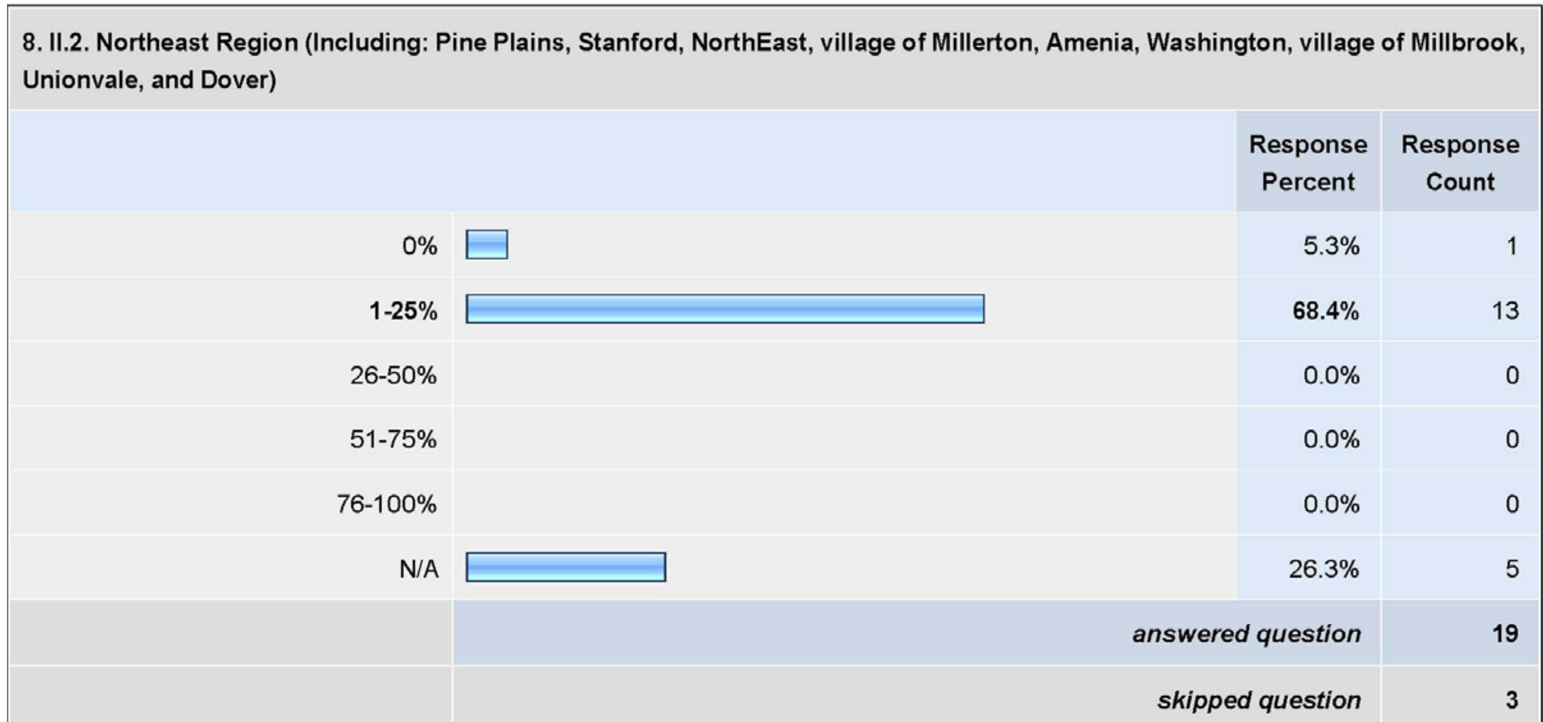
3. City/town of Primary Office:		
		Response Count
		22
	answered question	22
	skipped question	0

4. Other sites of service:		
		Response Count
		22
	answered question	22
	skipped question	0

5. Name of Contact person:		
		Response Count
		22
	answered question	**22**
	skipped question	**0**

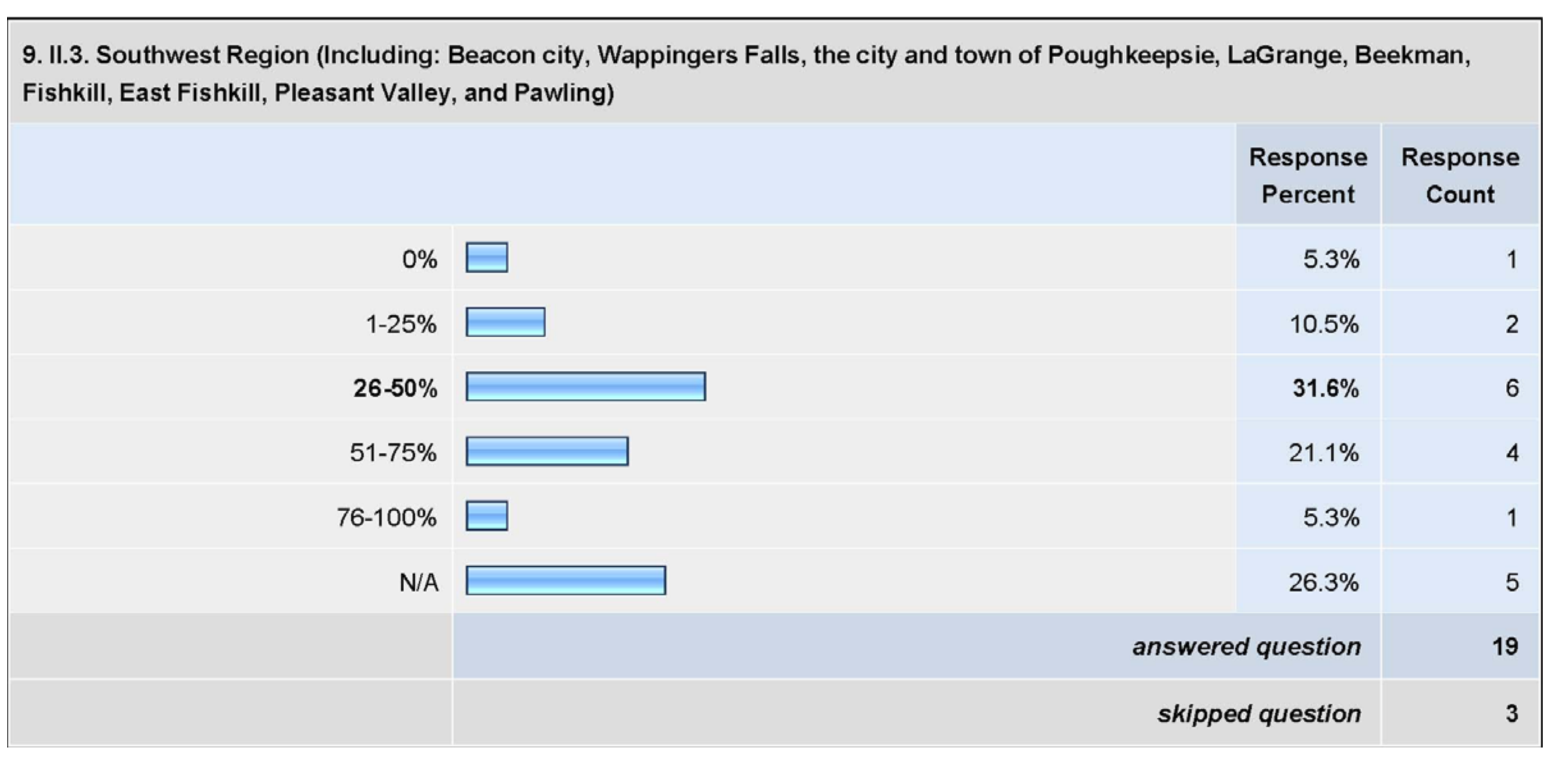
6. Best way to contact person above (telephone or e-mail):		
		Response Count
		22
	answered question	**22**
	skipped question	**0**

7. II.1. Northwest Region (Including: Red Hook, villages of Tivoli & Red Hook, Rhinebeck, Milan, Clinton, and Hyde Park)		
	Response Percent	Response Count
0%	5.3%	1
1-25%	**52.6%**	10
26-50%	15.8%	3
51-75%	0.0%	0
76-100%	0.0%	0
N/A	26.3%	5
	answered question	**19**
	skipped question	**3**



8. II.2. Northeast Region (Including: Pine Plains, Stanford, NorthEast, village of Millerton, Amenia, Washington, village of Millbrook, Unionvale, and Dover)

	Response Percent	Response Count
0%	5.3%	1
1-25%	**68.4%**	13
26-50%	0.0%	0
51-75%	0.0%	0
76-100%	0.0%	0
N/A	26.3%	5
	answered question	**19**
	skipped question	**3**



9. II.3. Southwest Region (Including: Beacon city, Wappingers Falls, the city and town of Poughkeepsie, LaGrange, Beekman, Fishkill, East Fishkill, Pleasant Valley, and Pawling)

	Response Percent	Response Count
0%	5.3%	1
1-25%	10.5%	2
26-50%	**31.6%**	6
51-75%	21.1%	4
76-100%	5.3%	1
N/A	26.3%	5
	answered question	**19**
	skipped question	**3**

10. III.1. Prevention and screening services: please indicate whether you offer the service and if so, whether there is sufficient capacity to meet client needs.					
	No	Yes with insufficient capacity	Yes with sufficient capacity	Yes with more than sufficient capacity	**Response Count**
Nutrition Education	16.7% (2)	33.3% (4)	**41.7% (5)**	8.3% (1)	12
Cancer Education for Public	33.3% (5)	13.3% (2)	**46.7% (7)**	6.7% (1)	15
Exercise Promotion	**33.3% (5)**	**33.3% (5)**	**33.3% (5)**	0.0% (0)	15
Hepatitis Vaccines	**78.6% (11)**	7.1% (1)	14.3% (2)	0.0% (0)	14
HPV Vaccine	**71.4% (10)**	14.3% (2)	14.3% (2)	0.0% (0)	14
Outreach	33.3% (5)	0.0% (0)	**66.7% (10)**	0.0% (0)	15
Primary Care Screening – Colonoscopy	**64.3% (9)**	0.0% (0)	35.7% (5)	0.0% (0)	14
Screening – Dermatology	**46.7% (7)**	13.3% (2)	40.0% (6)	0.0% (0)	15
Screening – Mammography	**43.8% (7)**	6.3% (1)	**43.8% (7)**	6.3% (1)	16
Screening – Pap Tests	**46.7% (7)**	0.0% (0)	40.0% (6)	13.3% (2)	15
Screening – Prostate	**46.7% (7)**	6.7% (1)	**46.7% (7)**	0.0% (0)	15
Screening – Sigmoidoscopy	**71.4% (10)**	0.0% (0)	28.6% (4)	0.0% (0)	14
Sun Safety Promotion	**53.3% (8)**	0.0% (0)	46.7% (7)	0.0% (0)	15
Tobacco Cessation Programs	**53.3% (8)**	13.3% (2)	26.7% (4)	6.7% (1)	15
Tobacco Education	**40.0% (6)**	13.3% (2)	**40.0% (6)**	6.7% (1)	15
Clinical Trials	**46.7% (7)**	6.7% (1)	33.3% (5)	13.3% (2)	15
				answered question	**16**
				skipped question	**6**

11. III.2. Detection and treatment services: please indicate whether you offer the service and if so, whether there is sufficient capacity to meet client needs.

	No	Yes with insufficient capacity	Yes with sufficient capacity	Yes with more than sufficient capacity	Response Count
Biopsies	**50.0% (8)**	0.0% (0)	25.0% (4)	25.0% (4)	16
CAT Scans	**50.0% (8)**	0.0% (0)	37.5% (6)	12.5% (2)	16
Chemotherapy	**60.0% (9)**	6.7% (1)	26.7% (4)	6.7% (1)	15
Colposcopy	**64.3% (9)**	7.1% (1)	21.4% (3)	7.1% (1)	14
Dermatology	**66.7% (10)**	13.3% (2)	13.3% (2)	6.7% (1)	15
Endocrinology	**66.7% (10)**	6.7% (1)	20.0% (3)	6.7% (1)	15
Gastroenterology	**53.3% (8)**	6.7% (1)	33.3% (5)	6.7% (1)	15
GYN Specialty Care	**46.7% (7)**	20.0% (3)	26.7% (4)	6.7% (1)	15
Neurology	**60.0% (9)**	6.7% (1)	26.7% (4)	6.7% (1)	15
Oncology Care	**60.0% (9)**	0.0% (0)	33.3% (5)	6.7% (1)	15
Pathology	**60.0% (9)**	0.0% (0)	33.3% (5)	6.7% (1)	15
Pediatric Oncology	**73.3% (11)**	13.3% (2)	13.3% (2)	0.0% (0)	15
Primary Care	**53.3% (8)**	6.7% (1)	40.0% (6)	0.0% (0)	15
Radiology	**50.0% (8)**	0.0% (0)	37.5% (6)	12.5% (2)	16
Surgery – General	**60.0% (9)**	0.0% (0)	33.3% (5)	6.7% (1)	15
Surgery – Laser	**64.3% (9)**	0.0% (0)	35.7% (5)	0.0% (0)	14
Urology	**60.0% (9)**	6.7% (1)	26.7% (4)	6.7% (1)	15
Clinical Trials	**53.3% (8)**	13.3% (2)	26.7% (4)	6.7% (1)	15
				answered question	**16**
				skipped question	**6**

12. III.3. Support services: please indicate whether you offer the service and if so, whether there is sufficient capacity to meet client needs.

	No	Yes with insufficient capacity	Yes with sufficient capacity	Yes with more than sufficient capacity	Response Count
Cancer Ed. for Patients	33.3% (5)	13.3% (2)	**40.0% (6)**	13.3% (2)	15
Caregiver Support	35.7% (5)	21.4% (3)	**42.9% (6)**	0.0% (0)	14
Hospice Care	**53.3% (8)**	0.0% (0)	46.7% (7)	0.0% (0)	15
Financial Assistance	**42.9% (6)**	35.7% (5)	21.4% (3)	0.0% (0)	14
Nutrition Information	20.0% (3)	13.3% (2)	**53.3% (8)**	13.3% (2)	15
Palliative Care	**46.7% (7)**	6.7% (1)	**46.7% (7)**	0.0% (0)	15
Patient Navigation	**40.0% (6)**	20.0% (3)	33.3% (5)	6.7% (1)	15
Respite Program	**73.3% (11)**	6.7% (1)	20.0% (3)	0.0% (0)	15
Support Groups	26.7% (4)	13.3% (2)	**46.7% (7)**	13.3% (2)	15
Survivorship Support	40.0% (6)	0.0% (0)	**46.7% (7)**	13.3% (2)	15
				answered question	**15**
				skipped question	**7**

13. III. 4. Please indicate whether you charge for your services

	Response Percent	Response Count
Yes	**62.5%**	10
No	37.5%	6
answered question		**16**
skipped question		**6**

14. III. 5. If you charge for your services, do you accept patients/clients with the following payment mechanisms			
	Yes	No	Response Count
Private insurance	**100.0% (9)**	0.0% (0)	9
Public insurance	**100.0% (9)**	0.0% (0)	9
Self-pay (no insurance)	**100.0% (9)**	0.0% (0)	9
- if yes, is there a sliding scale for people with no insurance?	**87.5% (7)**	12.5% (1)	8
Veteran's Administration	**71.4% (5)**	28.6% (2)	7
ADAP	33.3% (1)	**66.7% (2)**	3
		answered question	**9**
		skipped question	**13**

15. III. 6. Translation and interpretation services provided by your agency:					
	No	Yes with insufficient capacity	Yes with sufficient capacity	Yes with more than sufficient capacity	Response Count
Organization does provide translation / interpretation services (of any kind)	31.3% (5)	25.0% (4)	**43.8% (7)**	0.0% (0)	16
Trained interpreters on staff	**40.0% (6)**	33.3% (5)	26.7% (4)	0.0% (0)	15
Trained interpreters available with advance notice	25.0% (4)	25.0% (4)	**50.0% (8)**	0.0% (0)	16
Bilingual staff available	20.0% (3)	26.7% (4)	**53.3% (8)**	0.0% (0)	15
Telephone interpretation service used	26.7% (4)	6.7% (1)	**53.3% (8)**	13.3% (2)	15
				answered question	**16**
				skipped question	**6**

16. III. 7. For which of the following languages can your organization provide interpretation services on site (i.e. besides telephone interpretation)?

	Response Percent	Response Count
American Sign Language	30.8%	4
French	38.5%	5
Indian Language – (Hindi, Urdu, Punjabi)	38.5%	5
Mandarin Chinese	30.8%	4
Spanish	**100.0%**	13
Other (please list)	30.8%	4
	answered question	**13**
	skipped question	**9**

17. III. 8. Does your organization provide transportation for clients needing services?

	Response Percent	Response Count
Yes	25.0%	4
No	**75.0%**	12
	answered question	**16**
	skipped question	**6**

18. IV. 1. For each of the following services, please indicate whether you expect to reduce, maintain or expand those services during the five-year period 2008-2012. If you don't offer the service, check "N/A" for "not applicable" at the end of the column.					
	Reduce	Stay the same	Increase	N/A	Response Count
Cancer Education for Public	0.0% (0)	31.3% (5)	31.3% (5)	**37.5% (6)**	16
Clinical Trials	0.0% (0)	12.5% (2)	37.5% (6)	**50.0% (8)**	16
Exercise Promotion	0.0% (0)	31.3% (5)	25.0% (4)	**43.8% (7)**	16
HPV Vaccine	0.0% (0)	6.3% (1)	25.0% (4)	**68.8% (11)**	16
Hepatitis Vaccines	0.0% (0)	13.3% (2)	13.3% (2)	**73.3% (11)**	15
Homecare	0.0% (0)	12.5% (2)	18.8% (3)	**68.8% (11)**	16
Home Delivered Meals	0.0% (0)	6.3% (1)	0.0% (0)	**93.8% (15)**	16
Nutrition Information	0.0% (0)	31.3% (5)	**37.5% (6)**	31.3% (5)	16
Outreach	0.0% (0)	25.0% (4)	31.3% (5)	**43.8% (7)**	16
Screening – Colonoscopy	0.0% (0)	25.0% (4)	12.5% (2)	**62.5% (10)**	16
Screening – Dermatology	0.0% (0)	37.5% (6)	12.5% (2)	**50.0% (8)**	16
Screening – Mammography	0.0% (0)	25.0% (4)	31.3% (5)	**43.8% (7)**	16
Screening – Pap Tests	0.0% (0)	31.3% (5)	18.8% (3)	**50.0% (8)**	16
Screening – Prostate	0.0% (0)	31.3% (5)	18.8% (3)	**50.0% (8)**	16
Screening – Sigmoidoscopy	0.0% (0)	25.0% (4)	12.5% (2)	**62.5% (10)**	16
Sun Safety Promotion	0.0% (0)	31.3% (5)	18.8% (3)	**50.0% (8)**	16
Tobacco Cessation Programs	0.0% (0)	25.0% (4)	31.3% (5)	**43.8% (7)**	16
Biopsies	0.0% (0)	25.0% (4)	31.3% (5)	**43.8% (7)**	16
CAT Scans	0.0% (0)	18.8% (3)	25.0% (4)	**56.3% (9)**	16
Chemotherapy	0.0% (0)	18.8% (3)	18.8% (3)	**62.5% (10)**	16
Colposcopy	0.0% (0)	18.8% (3)	25.0% (4)	**56.3% (9)**	16
Dermatology	0.0% (0)	18.8% (3)	18.8% (3)	**62.5% (10)**	16
Endocrinology	0.0% (0)	25.0% (4)	6.3% (1)	**68.8% (11)**	16
Gastroenterology	0.0% (0)	25.0% (4)	12.5% (2)	**62.5% (10)**	16

Pediatric Oncology	0.0% (0)	18.8% (3)	12.5% (2)	**68.8% (11)**	16
Primary Care	0.0% (0)	12.5% (2)	25.0% (4)	**62.5% (10)**	16
Radiology	0.0% (0)	18.8% (3)	25.0% (4)	**56.3% (9)**	16
Surgery – General	0.0% (0)	18.8% (3)	18.8% (3)	**62.5% (10)**	16
Surgery – Laser	0.0% (0)	12.5% (2)	18.8% (3)	**68.8% (11)**	16
Urology	0.0% (0)	18.8% (3)	18.8% (3)	**62.5% (10)**	16
Cancer Education for Patients	0.0% (0)	26.7% (4)	33.3% (5)	**40.0% (6)**	15
Caregiver Support	0.0% (0)	31.3% (5)	25.0% (4)	**43.8% (7)**	16
Hospice Care	0.0% (0)	25.0% (4)	18.8% (3)	**56.3% (9)**	16
Financial Assistance	0.0% (0)	**50.0% (8)**	0.0% (0)	**50.0% (8)**	16
Nutrition Information	0.0% (0)	31.3% (5)	**37.5% (6)**	31.3% (5)	16
Palliative Care	0.0% (0)	12.5% (2)	37.5% (6)	**50.0% (8)**	16
Patient Navigation	0.0% (0)	12.5% (2)	**43.8% (7)**	**43.8% (7)**	16
Respite Program	0.0% (0)	18.8% (3)	12.5% (2)	**68.8% (11)**	16
Support Groups	0.0% (0)	18.8% (3)	**43.8% (7)**	37.5% (6)	16
Survivorship Support	0.0% (0)	25.0% (4)	31.3% (5)	**43.8% (7)**	16
				answered question	**16**
				skipped question	**6**

19. IV. 2. Would you be willing to make adjustments in service patterns (assuming they are feasible) based on the information gathered for this project?

		Response Percent	Response Count
Yes		80.0%	12

20. V. 1. Please estimate your clinic or agency's total patient or client caseload in 2006		
		Response Count
		13
	answered question	**13**
	skipped question	**9**

21. V. 2. Please estimate the percentage of those patients/clients who were seen for services related to cancer (prevention, treatment, support, etc.)							
	0%	1-25%	26-50%	51-75%	76-100%	N/A	Response Count
Patients/clients	7.1% (1)	**28.6% (4)**	14.3% (2)	14.3% (2)	21.4% (3)	14.3% (2)	14
						answered question	**14**
						skipped question	**8**

22. Gender							
	0%	1-25%	26-50%	51-75%	76-100%	N/A	Response Count
Female patient/clients	7.7% (1)	0.0% (0)	23.1% (3)	15.4% (2)	15.4% (2)	**38.5% (5)**	13
Male patient/clients	8.3% (1)	8.3% (1)	**41.7% (5)**	0.0% (0)	0.0% (0)	**41.7% (5)**	12
						answered question	**13**
						skipped question	**9**

23. Age							
	0%	1-25%	26-50%	51-75%	76-100%	N/A	Response Count
Children (12 and younger)	23.1% (3)	23.1% (3)	7.7% (1)	0.0% (0)	0.0% (0)	**46.2% (6)**	13
Adolescent (13-19)	15.4% (2)	30.8% (4)	0.0% (0)	7.7% (1)	0.0% (0)	**46.2% (6)**	13
Adult (20-64)	7.7% (1)	7.7% (1)	**38.5% (5)**	0.0% (0)	7.7% (1)	**38.5% (5)**	13
Senior (65 and older)	7.7% (1)	7.7% (1)	15.4% (2)	15.4% (2)	15.4% (2)	**38.5% (5)**	13
						answered question	**13**
						skipped question	**9**

24. Insurance Status							
	0%	1-25%	26-50%	51-75%	76-100%	N/A	Response Count
No Insurance	8.3% (1)	25.0% (3)	0.0% (0)	25.0% (3)	0.0% (0)	**41.7% (5)**	12
Private Insurance (e.g. MVP, GHI, Blue Cross)	8.3% (1)	**41.7% (5)**	8.3% (1)	0.0% (0)	0.0% (0)	**41.7% (5)**	12
Public Insurance (Medicare, Medicaid)	8.3% (1)	8.3% (1)	25.0% (3)	8.3% (1)	8.3% (1)	**41.7% (5)**	12
Veteran's Administration	25.0% (3)	33.3% (4)	0.0% (0)	0.0% (0)	0.0% (0)	**41.7% (5)**	12
ADAP	22.2% (2)	22.2% (2)	0.0% (0)	0.0% (0)	0.0% (0)	**55.6% (5)**	9
						answered question	**12**
						skipped question	**10**

25. Race							
	0%	1-25%	26-50%	51-75%	76-100%	N/A	Response Count
African-American (Black)	8.3% (1)	**58.3% (7)**	0.0% (0)	0.0% (0)	0.0% (0)	33.3% (4)	12
Asian/Pacific Islander	8.3% (1)	**58.3% (7)**	0.0% (0)	0.0% (0)	0.0% (0)	33.3% (4)	12
Caucasian (White)	8.3% (1)	16.7% (2)	0.0% (0)	25.0% (3)	16.7% (2)	**33.3% (4)**	12
Native American/Alaskan Native	18.2% (2)	**45.5% (5)**	0.0% (0)	0.0% (0)	0.0% (0)	36.4% (4)	11
Other	22.2% (2)	11.1% (1)	11.1% (1)	0.0% (0)	0.0% (0)	**55.6% (5)**	9
						answered question	**12**
						skipped question	**10**

26. Ethnicity							
	0%	1-25%	26-50%	51-75%	76-100%	N/A	Response Count
Hispanic/Latino	8.3% (1)	**41.7% (5)**	8.3% (1)	8.3% (1)	0.0% (0)	33.3% (4)	12
						answered question	**12**
						skipped question	**10**

27. Additional Groups								
	0%	1-25%	26-50%	51-75%	76-100%	N/A	Rating Average	Response Count
Foreign Born	9.1% (1)	**45.5% (5)**	0.0% (0)	9.1% (1)	0.0% (0)	36.4% (4)	2.14	11
Homeless Persons	27.3% (3)	**36.4% (4)**	0.0% (0)	0.0% (0)	0.0% (0)	**36.4% (4)**	1.57	11
Inmates/Prisoners	**45.5% (5)**	18.2% (2)	0.0% (0)	0.0% (0)	0.0% (0)	36.4% (4)	1.29	11
Lesbian, Gay, Bisexual or Transgender Persons	9.1% (1)	**54.5% (6)**	0.0% (0)	0.0% (0)	0.0% (0)	36.4% (4)	1.86	11
Migrant workers	18.2% (2)	**45.5% (5)**	0.0% (0)	0.0% (0)	0.0% (0)	36.4% (4)	1.71	11
							answered question	**11**
							skipped question	**11**

28. Would you like to tell us anything else about your services?		
		Response Count
		8
	answered question	**8**
	skipped question	**14**

Appendix B: Key Informants

1. **Sandra Cassese,**
   Assistant Vice President for Oncology, Emergency & Imaging Services
   Vassar Brothers Hospital Cancer Center
2. **Pari Forood**
   Executive Director
   Miles of Hope Foundation
3. **Janet Gray**
   Professor with Environment Risks and Breast Cancer Project
   Vassar College
4. **Leslie Larsen**
   Director of Comprehensive Cancer Control
   NYSDOH Cancer Services Program
5. **Arianna Landino**
   Senior Director of Cancer Control
   American Cancer Society, Hudson Valley Region
6. **Suzanne Lezon**
   Cancer Program Manager
   St Francis Hospital
7. **May Mamiya**
   Director of Case Management Department
   Vassar Brothers Medical Center
8. **Roberto Martinez**
   Hematologist / Oncologist
   Hudson Valley Oncology Group
9. **Solange Muller**
   Associate Vice-President for Personnel and Training
   Hudson River HealthCare
10. **Hope Nemiroff**
    Executive Director
    Breast Cancer Options
11. **Linda Squires**
    DOH Director of Communicable Disease
    Dutchess County Health Department
12. **Debbie Stein**
    Executive Director
    Dutchess County American Cancer Society
13. **Cathy Varunok**
    Co-founder, Miles of Hope Foundation
    Occupational Therapist, Vassar Brother Medical Center
14. **Amy Wen**
    Patient Care Coordinator
    American Cancer Society
15. **Margaret White**

Founder, Sister's Network

Appendix C: Dutchess County Focus Group Guides

GENERAL FOCUS GROUP MODERATOR'S GUIDE

Introduction

Thank you for coming to today's focus group meeting. My name is Xxxxx Xxxxx, and I will be facilitating this group. My colleague, Xxxx Xxxxxxx is here to help with this group, take notes, and assist in whatever way possible.

The group will last approximately one and ½ hours. Please feel free to get some food, use the rest room or get as comfortable as you can and then we will begin.

We are here to discuss your experiences in Dutchess County that might have an impact on your risk for, prevention of, or treatment for cancer. This information will be used to help guide the Comprehensive Cancer Control Planning for Dutchess County. Comprehensive Cancer Control covers cancer prevention, early detection of cancer, cancer treatment and support services, as well as workforce issues and research. As the name suggests, it is about taking a *comprehensive* approach to reducing the burden of cancer – by combining many different approaches in a coordinated effort.

This group is one of three that will be conducted in Dutchess County to get a sense of the atmosphere and experience of residents in the county. The goals of the focus group are: 1) to describe the general experience and needs of individuals at risk for cancer in Dutchess County around cancer control, and 2) identify the services used and any gaps in services that the group can identify and 3) to develop specific recommendations around what can be done to improve the services around cancer prevention, detection, care and support in Dutchess County.

Guidelines for Discussion

Please answer the questions to the best of your ability. There are no right or wrong answers. We would like to hear from each of you, so at times, if I'm concerned about time, *I may have to gently interrupt you and get us to move on*. The ground rules for the group include:

- Creating an atmosphere of mutual respect
- Speaking in "I" statements, unless specifically relating the stories of others
- Strict confidentiality: nothing said during this discussion should be related to others outside the group. The report that will be written to summarize the information and ideas that come out of the discussion will not include any identifying information about the participants in the group.
- You may "pass" if you do not feel comfortable answering a question.

You will be given a $50 gift certificate at the end of the meeting to thank you for your participation. Xxxxxx Xxxxxx can help you get that taken care of and processed when we are through.

Findings from all 3 of the focus groups will be compiled and included in a report that will be joined with the results of interviews and surveys done in the County and used to guide the development of a Comprehensive Cancer Control Plan.

Do you have any questions before we begin?

Demographics Focus Group Questions

Introductions:
First name:
Quick Questions:
How many of you are in your: 40s, 50s, 60s, etc.
Icebreaker: *Tell the group one thing you like to do to have fun*

I. Prevention and Health Promotion

Warm up question: Can you tell me some things that you can do to prevent cancer?

1. **Are there any services in Dutchess County that encourage cancer prevention?**

   1A. What about services around:
   - Breastfeeding
   - Tobacco Prevention / Cessation
   - Obesity Prevention (Exercise, Nutrition)
   - HPV Vaccine
   - Radon Testing
   - Water sources

   1B. Probes:
   - Do you use any of these services? Why / Why not?
   - Do your friends or family members use any of these? Why / Why not?
   - What prevention messages do you hear around these areas, and where do you hear them? Do you trust them? Why / Why not?
   - Do they affect you in any way?

2. **What other services related to cancer prevention or health promotion would you like to see offered?**

II. Early Detection

3. What kind of cancer screening tests do you know about, and which ones do you have experience with?

3A. Probes:

- Pap Smears (Cervical Cancer Screening)
- Mammograms (Breast Cancer Screening
- Colorectal Cancer Screening
- Prostate Cancer Screening
- Dermatological Screening (Skin Cancer)

4. If you have gotten these screenings done, why do you do it? If not, why not?

4A. Probes:

- Why do you think some people don't participate in cancer screening – such as getting Pap Tests, Mammograms, or Colonoscopy?
- If you think a bout your friends and family, you can probably think of someone who does not get all the recommended screenings. What do you think stands in the way of someone not getting screened?

5. One of the most important ways to catch cancer early is through regular visits to a provider, such as going for an annual exam with a primary care doctor. What are some of the reasons that you know of for people not going for regular exams?

5A. Probe:

- Do you know of any services in Dutchess to help people with this problem?

III. Treatment

6. Some of you probably have experience with cancer treatment either for yourself or with loved ones. If you were to receive a cancer diagnosis, where do you think you would go for treatment? Why?

6A. Probes:

- Sometimes people seek care in neighboring communities, or travel as far as NYC. How does this seem to work for people and what do you think of that?

- What is your impression of cancer treatment available to the residents of Dutchess County?

7. What would be your biggest fear if you or a loved one was facing a cancer diagnosis?

IV. Palliative Care

8. Do you know what hospice care is, and would you consider using for yourself or a loved one facing a terminal diagnosis of cancer? Why or why not?

8A. Probes:
- What do you think of hospice care?
- What is your impression of hospice care in Dutchess County?

V. General

9. What is one thing related to Cancer Control in Dutchess County that you would change?

10. Is there anything you would like to add that we haven't touched on today?

Thank you for sharing your views with us today!!!

SURVIVORS FOCUS GROUP MODERATOR'S GUIDE

Introduction

Thank you for coming to today's focus group meeting. My name is Xxxxx Xxxxx, and I will be facilitating this group. My colleague, Xxxx Xxxxxxx is here to help with this group, take notes, and assist in whatever way possible.

The group will last approximately one and ½ hours. Please feel free to get some food, use the rest room or get as comfortable as you can and then we will begin.

We are here to discuss your experiences in Dutchess County as a Cancer Survivor. We appreciate your taking the time to come and share your experience with us today and hope that your experience can help us understand the needs around cancer treatment, support services, and survivor services in Dutchess County. This information will be used to help guide the Comprehensive Cancer Control Planning for the County. Comprehensive Cancer Control covers cancer prevention, early detection of cancer, cancer treatment and support services, as well as workforce Issues and research. As the name suggests, it is about taking a *comprehensive* approach to reducing the burden of cancer – by combining many different approaches in a coordinated effort.

This group is one of three that will be conducted in Dutchess County to get a sense of the experience of cancer survivors in the County. The goals of the focus group are: 1) to describe the experience of cancer treatment and subsequent quality of life in Dutchess County, and 2) identify the services used and any gaps in services that the group can identify and 3) to develop specific recommendations around what can be done to improve the services around cancer prevention, detection, treatment and support in Dutchess County.

Guidelines for Discussion

Please answer the questions to the best of your ability. There are no right or wrong answers. We would like to hear from each of you, so at times, if I'm concerned about time, *I may have to gently interrupt you and get us to move on*. The ground rules for the group include:

- Creating an atmosphere of mutual respect
- Speaking in "I" statements, unless specifically relating the stories of others
- Strict confidentiality: nothing said during this discussion should be related to others outside the group. The report that will be written to summarize the information and ideas that come out of the discussion will not include any identifying information about the participants in the group.
- You may "pass" if you do not feel comfortable answering a question.

You will be given a $50 gift certificate at the end of the meeting to thank you for your participation. Xxxxxx Xxxxxx can help you get that taken care of and processed when we are through.

Findings from all 3 of the focus groups will be compiled and included in a report that will be joined with the results of interviews and surveys done in the County and used assist in the development of a Comprehensive Cancer Control Plan.

Do you have any questions before we begin?

Demographics Focus Group Questions

Introductions:
First name:
Quick Questions:
How many of you are in your: 40s, 50s, 60s, etc.
Icebreaker: *Tell the group one thing you like to do to have fun*

I. Detection and Diagnosis

1. What were the circumstances surrounding your cancer diagnosis?

1A. Probes:

- Was the diagnosis received through routine screening or another method?
- Were there any barriers for you in accessing cancer screening tests or diagnostic work?
- What is your impression of screening tests or other diagnostic procedures for cancer in Dutchess County?

II. Treatment

2. Where did you or do you go for Cancer Treatment, and why did you choose that facility for treatment?

2A. Probes:

- Sometimes people seek care in neighboring communities, or travel as far as NYC. How does this seem to work for people and what do you think of that?
- What is your impression of cancer treatment available to the residents of Dutchess County?
- What was the biggest obstacle around accessing Cancer Treatment for you?

III. Quality of Life & Support Services

3. Did you have all of the information you needed around your cancer diagnosis?

3A. Probes:

- What was the most difficult thing about finding resources or information you needed?
- What did you find the most helpful?
- Do you know of resources for survivors?

4. Have you ever felt discriminated against when seeking cancer detection, treatment, or support services? (Can you tell me a little more about that?)

4A. Probes:

- Does language limit access to information that is available? If so, how?
- Are there parts of your cultural background that affect the quality or type of services you might need?

5. What type of support services have you accessed? What support services were or are missing that might you find useful?

5A. Probes:

- Do you feel there are enough support groups for cancer patients or survivors?
- Is there adequate support (financial or otherwise) for transportation needs, help with life transitions, wigs or other supplies not covered by insurance?
- Is there adequate support (financial or otherwise) for family members, particular children – such as camps for kids, etc.?

IV. Palliative Care

6. Do you know what hospice care is, and would you ever consider using hospice care for yourself or a loved one facing a terminal diagnosis of cancer?

6A. Probes:

- What is your experience with hospice care?
- What is your impression of hospice care in Dutchess County?

V. Research

7. Are you aware of any clinical trials going on around cancer treatment?

7A. Probes:

- Has a doctor ever talked to you about joining a clinical trial?
- How many of you have ever been enrolled in a clinical trial related to your cancer diagnosis?
- Would you know how to find out information about clinical trials if you were interested?
- Where would you go for information?

VI. General

8. What is one thing related to Cancer related services in Dutchess County that you would change if you could change something?

9. Is there anything you would like to add that we haven't touched on today?

Thank you for sharing your views with us today!!!

Appendix D: Dutchess County Focus Group Demographics (Total)

Table 1: Focus Group Participants by Zip Code		
Primary ZIP Code	**Area**	**Number (%) of Participants**
10516	Cold Spring	1 (2.4%)
12466	Port Ewen	1 (2.4%)
12508	Beacon	1 (2.4%)
12516	Copake Falls	1 (2.4%)
12524	Fishkill	3 (7.1%)
12528	Highland	1 (2.4%)
12533	Hopewell Junction	1 (2.4%)
12538	Hyde Park	1 (2.4%)
12547	Milton	1 (2.4%)
12569	Pleasant Valley	1 (2.4%)
12570	Poughquag	4 (9.5%)
12572	Rhinebeck	1 (2.4%)
12590	Wappingers Falls	3 (7.1%)
12601/12603	Poughkeepsie	22 (52.4%)
TOTAL		42 (100%)

Table 2: Focus Group Participants by Race	
Race	**Number (%) of Participants**
African American/Black	3 (7.0%)
American Indian/Alaskan Native	0 (0%)
Native Hawaiian/Pacific Islander	0 (0%)
Asian	1 (2.3%)
White	32 (74.4%)
Other: Latino	7 (16.3%)
TOTAL	43 (100%)

Table 3: Focus Group Participants by Hispanic Ethnicity	
Hispanic/Latino?	**Number (%) of Participants**
Yes	11 (25.6%)

No	32 (74.4%)
TOTAL	43 (100%)

Table 4: Focus Group Participants by Age Range	
Age Range	**Number (%) of Participants**
20 or under	0 (0%)
21-30	4 (10%)
31-40	3 (7.5)
41-50	7 (17.5%)
51-60	15 (37.5%)
61-70	7 (17.5%)
71-80	4 (10%)
80 and over	0 (0%)
TOTAL	40 (100%)

Table 5: Focus Group Participants by Sex	
Sex	**Number (%) of Participants**
Male	10 (23.3%)
Female	33 (76.7%)
Transgender	0 (0%)
TOTAL	43 (100%)

Table 6: Cancer Survivor (Self)	
Have you ever received a cancer diagnosis?	**Number (%) of Participants**
Yes	20 (50%)
No	20 (50%)
TOTAL	40 (100%)

Table 7: Cancer Survivor (Family/Friend)	
Has a close friend or family member received a cancer diagnosis?	**Number (%) of Participants**
Yes	35 (87.5%)
No	5 (12.5%)

TOTAL	40 (100%)

Appendix E: Key Informant Interview Guide

Dutchess County Comprehensive Cancer Control Plan

DCDOH Key Informant Interview Guide

Name of Interviewee: ____

Title: ____

Organization: ____

Date of Interview: _____________

Start time: ____________________

End time: ____________________

Any Interruptions? Yes ___ No ___ #: ___

Nature of Interruptions: _______________

____

____

Interviewer: __________________

INRODUCTION:

My name is Xxxxxxxx Xxxxxxx. I work for JSI Research and Training Institute and have been hired by the Dutchess County Department of Health to help with the development of a Comprehensive Cancer Control Plan. As you may know, a Comprehensive Cancer Control Plan is developed by community stakeholders to guide decision-making and coordinate cancer control activities for the county. The plan proposes strategies, or a blueprint for action, to address identified needs and sets the priorities for the Dutchess County Cancer Control Program. I'd like to ask you a series of questions regarding cancer prevention, treatment and support in Dutchess County that will help us work collaboratively with the Dutchess County Cancer Advisory Board to develop the Plan. All of your answers will remain confidential in that our report will not connect individual names to responses.

We have divided some of the questions into three areas: Prevention and screening; early detection and treatment; and support services including palliative care and survivorship.

I expect this interview to take approximately one hour. Do you have time to do this now or can we schedule a time?

To be sure that I write down all of your answers accurately, it would be very helpful if you would allow me to tape record our conversation. I would be the only one reviewing the tape and would then erase it. Would that be all right? But if you prefer not, then that is okay too.

PERMISSION REQUESTED for tape recording: ___ Recorded Yes ___
No ___
(confirm recording permission once recorder is on)

SECTION 1: Overview Questions

1) Do you work in Dutchess County?

2) How long have you been providing cancer related services in Dutchess County?

____

3) How long have you been working in your field? __________

4) How is your organization connected to cancer prevention, treatment or support in Dutchess County? (e.g. provide services, coordinate services/agencies, referrals, etc…)

This is basically a description of services and coordination of services

SECTION 2: Prevention and screening services (these include public information campaigns, cancer screening, tobacco cessation, immunizations for hepatitis and HPV, obesity, etc.)

1) What prevention and screening services are available in Dutchess County?

2) Do you think that these services are well advertised to the community? Yes No
   a) Please explain
   b) Are there organizations that do prevention and screening outreach in the community?
      (e.g. clinics, community based orgs, faith-based orgs, media...) Yes No

      If Yes, please identify and describe the type of outreach they do
      (e.g. flyers at clinics, cbos, community centers, stores; radio announcements; presentations, …)
      i) What specific populations if any are targeted by any of these organizations?

3) What kinds of problems/barriers (if any) does the community face when accessing prevention and screening services? **(All of the following topics must be addressed)**
   - ✓ Financial barriers (health insurance issues, access to formulary/specialists, such as limitations set by HMOs…)
   - ✓ Transportation (geographic distance from services, availability, most commonly used methods…)
   - ✓ Clinical experience (wait times, time with provider, patient provider relationship)
   - ✓ Awareness/unawareness of services
   - ✓ Provider/staff cultural competence/awareness
   - ✓ Patient and provider attitudes, stigma, prejudice
   - ✓ Language barriers (materials, staff…)
   - ✓ Literacy
   - ✓ Access to clinical trials
   - ✓ Fear of diagnosis, denial, differences in cultural beliefs

4) Are there population groups who may be experiencing more difficulties accessing services than others? (e.g. certain races, Hispanics, women) Yes No

a) If so, which groups are they?

b) Please describe the disparities you have observed for each of these groups

(Use the following topics as probes)

- ✓ Financial barriers (health insurance issues, access to specialists, non-coverage by HMOs…)
- ✓ Transportation (geographic distance from services, availability, most commonly used methods…)
- ✓ Clinical experience (wait times, time with provider, patient provider relationship)
- ✓ Awareness/unawareness of services
- ✓ Provider/staff cultural competence/awareness
- ✓ Patient and provider attitudes, stigma, prejudice
- ✓ Language barriers (materials, staff…)
- ✓ Literacy
- ✓ Access to clinical trials

c) Why do you think these groups are experiencing greater obstacles than others?

(e.g. education, socioeconomic status, apathy, discrimination, …)

5) Overall, do you feel that the prevention and screening services in Dutchess County meet or do not meet the needs of the community? Yes No

a) Please explain why or why not

(All of the following topics must be addressed)

- ✓ Quality of services (actual service, patient/provider relationship…)
- ✓ Gaps in services (absence of services, referrals…)
- ✓ Overlap/duplication of services
- ✓ Coordination of services

6) Are you aware of any current efforts in Dutchess County *(e.g. programs, coalitions)* that are addressing barriers or enhancing promotion of prevention and screening services?

Yes No

a) If Yes, please describe these efforts

b) Do you think that these efforts are helping/not helping?

   i) Why/why not

7) Are there specific services/organizations that you feel knowledgeable enough about to rank their quality on a scale of 1 to 5, where1 is the poorest quality and 5 is the highest quality?

Service Provider/Org:________________________
1 2 3 4 5
Service Provider/Org:________________________
1 2 3 4 5
Service Provider/Org:________________________
1 2 3 4 5
Service Provider/Org:________________________
1 2 3 4 5
Service Provider/Org:________________________
1 2 3 4 5

SECTION 3: Early detection and treatment (these include detection of cancer and treatment including surgery, radiation, chemotherapy, etc.)

8) What early detection and treatment services are available in Dutchess County?

9) Do you think that these services are well advertised to the community? Yes No

   a) Please explain

   b) Are there organizations that do early detection and treatment outreach in the community?
   (e.g. clinics, community based orgs, faith-based orgs, media…) Yes No

   If Yes, please identify and describe the type of outreach they do
   (e.g. flyers at clinics, cbos, community centers, stores; radio announcements; presentations, …)

      i) What specific populations if any are targeted by any of these organizations?

10) What kinds of problems/barriers (if any) does the community face when accessing early detection and treatment services? **(All of the following topics must be addressed)**

   ✓ Financial barriers (health insurance issues, access to formulary/specialists, such as limitations set by HMOs…)

- ✓ Transportation (geographic distance from services, availability, most commonly used methods…)
- ✓ Clinical experience (wait times, time with provider, patient provider relationship)
- ✓ Awareness/unawareness of services
- ✓ Provider/staff cultural competence/awareness
- ✓ Patient and provider attitudes, stigma, prejudice
- ✓ Language barriers (materials, staff…)
- ✓ Literacy
- ✓ Access to clinical trials

11) Are there population groups who may be experiencing more difficulties accessing services than others? (e.g. certain races, Hispanics, women) Yes No

a) If so, which groups are they?

b) Please describe the disparities you have observed for each of these groups

(Use the following topics as probes)

- ✓ Financial barriers (health insurance issues, access to specialists, non-coverage by HMOs…)
- ✓ Transportation (geographic distance from services, availability, most commonly used methods…)
- ✓ Clinical experience (wait times, time with provider, patient provider relationship)
- ✓ Awareness/unawareness of services
- ✓ Provider/staff cultural competence/awareness
- ✓ Patient and provider attitudes, stigma, prejudice
- ✓ Language barriers (materials, staff…)
- ✓ Literacy
- ✓ Access to clinical trials

c) Why do you think these groups are experiencing greater obstacles than others?

(e.g. education, socioeconomic status, apathy, discrimination, …)

12) Overall, do you feel that the early detection and treatment services in Dutchess County meet or do not meet the needs of the community? Yes No

a) Please explain why or why not

(All of the following topics must be addressed)

- ✓ Quality of services (actual service, patient/provider relationship…)
- ✓ Gaps in services (absence of services, referrals…)
- ✓ Overlap/duplication of services
- ✓ Coordination of services

13) Are you aware of any current efforts in Dutchess County *(e.g. programs, coalitions)* that are addressing barriers or enhancing promotion of early detection and treatment services?

    Yes No

    a) If Yes, please describe these efforts
    b) Do you think that these efforts are helping/not helping?
        i) Why/why not

14) Are there specific services/organizations that you feel knowledgeable enough about to rank their quality on a scale of 1 to 5, where1 is the poorest quality and 5 is the highest quality?

Service Provider/Org:__________________________
1 2 3 4 5
Service Provider/Org:__________________________
1 2 3 4 5
Service Provider/Org:__________________________
1 2 3 4 5
Service Provider/Org:__________________________
1 2 3 4 5
Service Provider/Org:__________________________
1 2 3 4 5

<u>SECTION 4: Support Services (these include support groups, survivorship, palliative care, etc.)</u>

15) What support services are available in Dutchess County?

16) Do you think that these services are well advertised to the community? Yes No

    a) Please explain
    b) Are there organizations that do support services outreach in the community?

(e.g. clinics, community based orgs, faith-based orgs, media…) Yes No

If Yes, please identify and describe the type of outreach they do *(e.g. flyers at clinics, cbos, community centers, stores; radio announcements; presentations, …)*

i) What specific populations if any are targeted by any of these organizations?

17) What kinds of problems/barriers (if any) does the community face when accessing support services? **(All of the following topics must be addressed)**

- ✓ Financial barriers (health insurance issues, access to formulary/specialists, such as limitations set by HMOs…)
- ✓ Transportation (geographic distance from services, availability, most commonly used methods…)
- ✓ Clinical experience (wait times, time with provider, patient provider relationship)
- ✓ Awareness/unawareness of services
- ✓ Provider/staff cultural competence/awareness
- ✓ Patient and provider attitudes, stigma, prejudice
- ✓ Language barriers (materials, staff…)
- ✓ Literacy
- ✓ Access to clinical trials

18) Are there population groups who may be experiencing more difficulties accessing support services than others? (e.g. certain races, Hispanics, women) Yes No

a) If so, which groups are they?

b) Please describe the disparities you have observed for each of these groups

(Use the following topics as probes)

- ✓ Financial barriers (health insurance issues, access to specialists, non-coverage by HMOs…)
- ✓ Transportation (geographic distance from services, availability, most commonly used methods…)
- ✓ Clinical experience (wait times, time with provider, patient provider relationship)
- ✓ Awareness/unawareness of services
- ✓ Provider/staff cultural competence/awareness

- ✓ Patient and provider attitudes, stigma, prejudice
- ✓ Language barriers (materials, staff…)
- ✓ Literacy
- ✓ Access to clinical trials

c) Why do you think these groups are experiencing greater obstacles than others? *(e.g. education, socioeconomic status, apathy, discrimination, …)*

19) Overall, do you feel that the support services in Dutchess County meet or do not meet the needs of the community? Yes No

a) Please explain why or why not

(All of the following topics must be addressed)

- ✓ Quality of services (actual service, patient/provider relationship…)
- ✓ Gaps in services (absence of services, referrals…)
- ✓ Overlap/duplication of services
- ✓ Coordination of services

20) Are you aware of any current efforts in Dutchess County *(e.g. programs, coalitions)* that are addressing barriers or enhancing promotion of support services?

Yes No

a) If Yes, please describe these efforts

b) Do you think that these efforts are helping/not helping?

i) Why/why not

21) Are there specific services/organizations that you feel knowledgeable enough about to rank their quality on a scale of 1 to 5, where1 is the poorest quality and 5 is the highest quality?

Service Provider/Org:__________________________

1 2 3 4 5

Service Provider/Org:__________________________

1 2 3 4 5

Service Provider/Org:__________________________

1 2 3 4 5

Service Provider/Org:__________________________

1 2 3 4 5

Service Provider/Org:__________________________

1 2 3 4 5

SECTION 5: The Cancer Advisory Council

1. As you may know, the Dutchess County Department of Health is in the process of launching a Comprehensive Cancer Control Advisory Council. What do you think are the key activities the Advisory Council could engage in to help improve Comprehensive Cancer Control in Dutchess County?
    Probe: Are there new initiatives in Dutchess County with respect to the delivery of cancer care, support or prevention that you are involved with?

2. What role do you see yourself or your agency playing in this project as it moves forward? What would you make as priorities for the Advisory Council?

3. Who are the other key individuals or groups within Dutchess County working in cancer control that you think it would be important for us to speak with?

4. Based on your experience, what is your sense of the main challenges facing Dutchess County residents who receive a cancer diagnosis?

5. Is there anything else you would like to add about Comprehensive Cancer Control in Dutchess County?

SECTION 6: Closing and Demographic Questions

Finally, I have a few demographic questions. You don't have to answer them if you don't want to.

1. How would you identify your racial/ethnic group?

____African American ____Hispanic / Latino ____White
____Other

2. What age group do you fall into?

____ ≤20 ____ 21-30 ____ 31-40 ____ 41-50 ____ 51-60 ____ 61+

3. Do you speak a language other than English? [If Yes, which languages?]

Thank you for your time!

Appendix F: Web Based Survey

General Population Web-Based Survey: Dutchess County

This survey is going to ask questions about "Cancer Control" in Dutchess County. This means activities related to the prevention of, early detection of, care and treatment for, or support related to cancer including activities carried out by the Health Department, by healthcare providers, or by other organizations and individuals.

1. Name (optional)

2. Contact Information (optional)

3. Are you involved in Cancer Control in any way personally? If so, how?

4. What do you see as the strengths of Dutchess County for providing cancer prevention, detection, treatment, and support services?

5. What do you think are the barriers for the people of Dutchess County in getting adequate cancer prevention, detection, treatment, and support services:

6. Why do you think some people don't participate in cancer screening – such as getting Pap Tests, Mammograms, or Colonoscopy?

7. Sometimes people seek care in neighboring communities, or travel as far as NYC. How does this seem to work for people and what do you think of that?

8. What is one thing related to Cancer Control in Dutchess County that you would change?

9. Is there anything else you would like to add about Comprehensive Cancer Control in Dutchess County?