Looking Back: Results of a Retrospective Survey of Delawareans Diagnosed with Cancer

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DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health
Health Promotion and Disease Prevention

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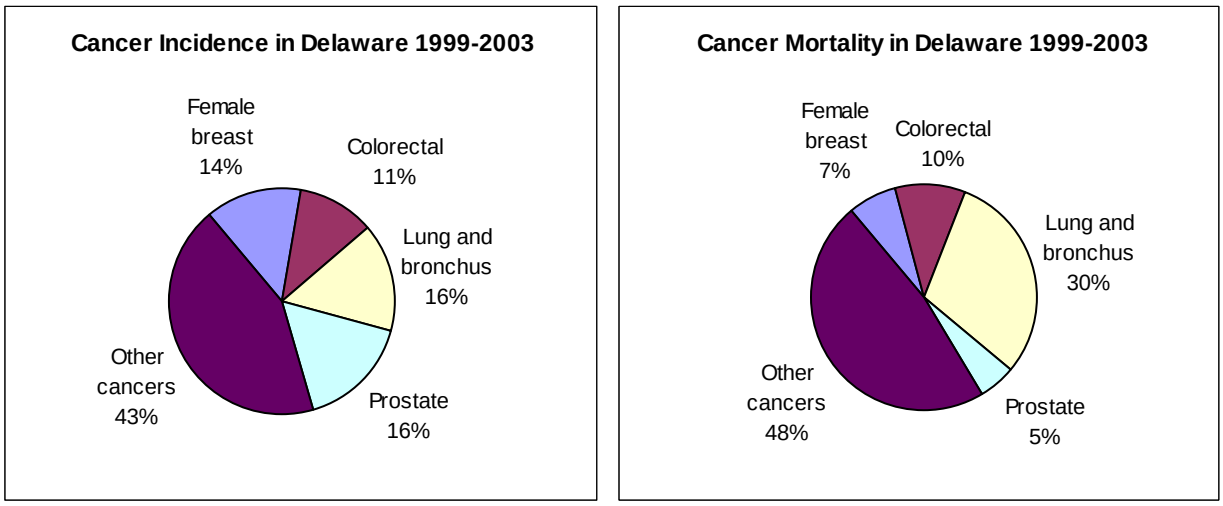
EXECUTIVE SUMMARY

The Retrospective Survey of Delawareans Diagnosed with Cancer was designed and conducted in response to the Delaware Cancer Consortium's recommendation to gain a better understanding of the factors related to incidence and mortality for the most common cancers in Delaware. Together, these four cancers accounted for 57 percent of all cancers diagnosed in Delaware and 52 percent of all deaths due to cancer during 1999–2003.



Source: Delaware Cancer Registry, Delaware's Division of Public Health

From November 2005 to April 2006, 892 survivors of these four cancers participated in a 30–45-minute telephone interview and provided answers to questions about their health, lifestyles, cancer risk factors, screening practices and diagnosis and treatment outcomes. This report summarizes the information gathered from participants for each of the four cancers. The key findings are presented here.

Health Status

- The majority of study participants (92 percent) reported their general health status prior to diagnosis as good to excellent. Lung cancer participants were less likely to report good to excellent health compared to participants with breast, colorectal or prostate cancer.
- The prevalence of chronic health conditions for study participants was similar to the prevalence of these health conditions in the general Delaware population. Six chronic health conditions were assessed: heart disease, diabetes, hypertension, high blood cholesterol, asthma and arthritis. Lung cancer respondents had higher rates of asthma, and breast cancer respondents had lower rates of asthma compared with the general Delaware population. A higher proportion of lung cancer participants reported having three or more health conditions than participants with breast, colorectal or prostate cancer.
- Body mass index (BMI) was calculated from height and weight prior to diagnosis, as reported by study respondents. Respondents with all types of cancer had a BMI similar to that of individuals in the general Delaware population. About 40 percent of study respondents were overweight (BMI= 25 to < 30) and 24 percent were obese (BMI=30+).

Occupation

- Forty-two percent of study respondents reported ever working in one or more of five high-risk industries: 21 percent worked in the chemical industry, 3 percent worked in the pharmaceutical industry, 26 percent worked in manufacturing, 10 percent worked in agriculture and 17 percent worked in the construction industry.
- About 60 percent of lung cancer respondents reported exposure to potential carcinogens in the workplace.

Diet

- Only 21 percent of study respondents reported eating five or more servings of fruits and vegetables per day at time of diagnosis. Another 40 percent ate at least three but fewer than five servings of fruits and vegetables per day. Fruit and vegetable consumption among study participants at time of diagnosis was similar to fruit and vegetable consumption reported by the general Delaware population. Breast cancer respondents were most likely, and lung cancer respondents were least likely, to meet the current recommendation.
- About 23 percent of study respondents reported eating five or more daily servings of foods high in fat at time of diagnosis, and another 40 percent reported eating at least three but fewer than five daily servings of foods high in fat.

Alcohol Consumption

- About 60 percent of the study population reported having at least one drink in the 30 days prior to diagnosis. Eight percent were classified as heavy drinkers and 13 percent were classified as binge drinkers.
- Breast cancer respondents were more likely to have reported having a drink in the 30 days prior to diagnosis and to binge drink than individuals in the general Delaware population.
- Prostate cancer participants were twice as likely to report binge drinking, heavy drinking and having a drink in the 30 days prior to diagnosis when compared with individuals in the general Delaware population
- Lung cancer respondents were two and a half times more likely to report heavy drinking, and three times more likely to report binge drinking, compared with members of the general Delaware population.

Tobacco Use

- Ninety-four percent of lung cancer patients either smoked at the time of diagnosis or were former smokers. Lung cancer patients were 27 times more likely to be current smokers and seven times more likely to be former smokers compared to the general Delaware population.
- The association between current or former smoking status and the risk for breast, colorectal or prostate cancer was not significant.
- About 67 percent of study participants who had ever smoked began before age 18.

Physical Activity

- Seventy-seven percent of the study respondents reported doing some leisure-time physical activity or exercise. About half of study participants met the requirement for moderate activity level, and 26 percent met the requirement for vigorous activity level.

Health Care Access and Utilization

- Overall, 98 percent of survey respondents had health insurance coverage at diagnosis. Lung cancer participants were less likely to have health insurance compared with participants with breast, colorectal or prostate cancer.
- About 97 percent of the study population reported that their usual source of health care was in a doctor's office or public health/community health clinic. Ninety percent of respondents reported seeing a doctor at least once a year.
- A higher percentage of colorectal cancer respondents saw a doctor less than once a year (18 percent), compared with those with prostate cancer (12 percent), lung cancer (10 percent) or breast cancer (five percent).

Screening

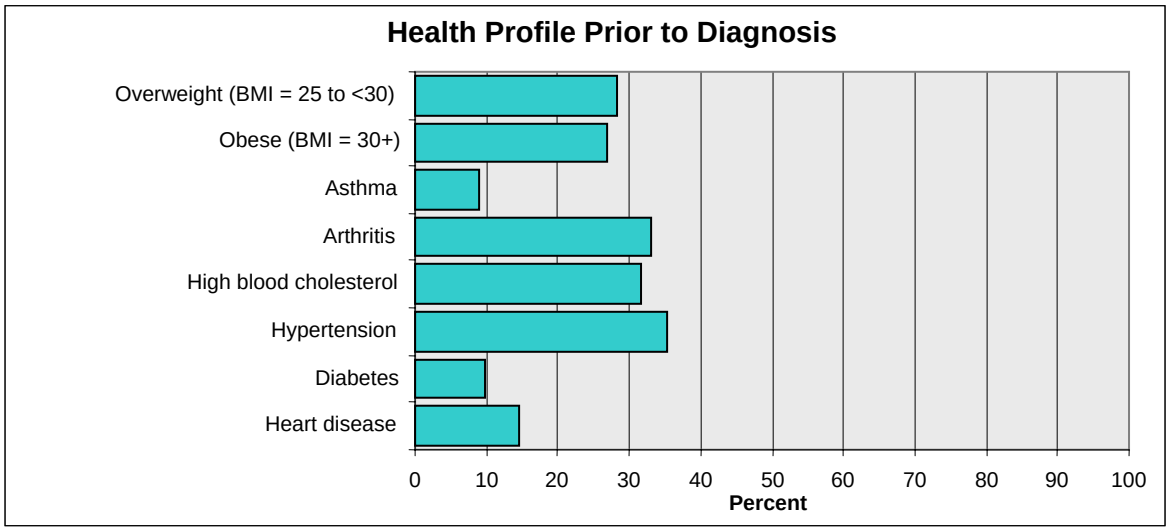
- Use of screening tests was high among respondents with breast cancer. About 83 percent reported having received both a mammogram and a clinical breast exam in the two years prior to diagnosis.
- A majority of women with breast cancer (59 percent) reported receiving their first mammogram before age 50 and then receiving one every year.
- Annual clinical breast exams were reported by 85 percent of respondents. Monthly self-breast exams were reported by 56 percent of participants with breast cancer.
- Among study respondents aged 50 and older with colorectal cancer, 18 percent had a fecal occult blood test in the two years prior to diagnosis and 55 percent had a sigmoidoscopy.
- About 55 percent of men with prostate cancer aged 40 and older received a prostate-specific antigen test in the two years prior to diagnosis and 58 percent received a digital rectal exam.
- Compared with the general population, study respondents were equally or more likely to have received mammograms, sigmoidoscopy and prostate cancer screening tests, but were 16 percent less likely to receive a clinical breast exam, and two and a half times less likely to report a recent fecal occult blood test.

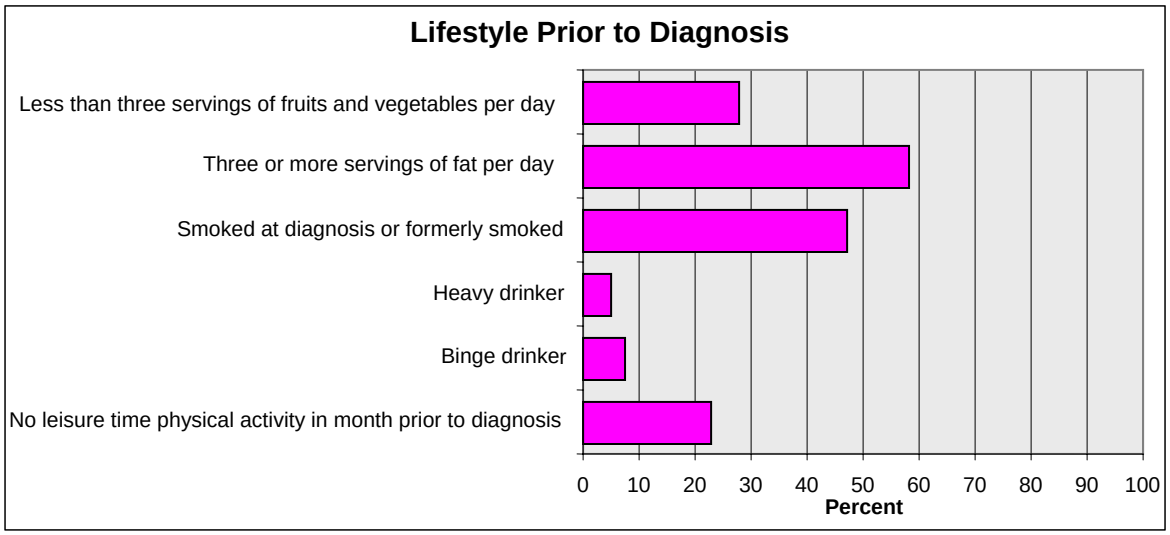
Diagnosis and Treatment

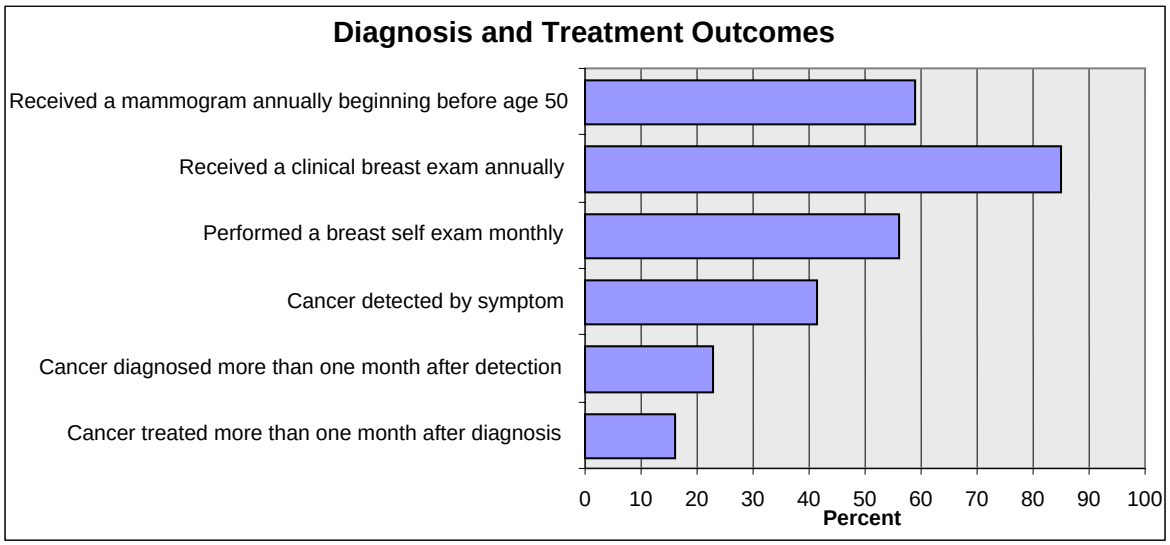
- Overall, 34 percent of study respondents had their cancer detected due to experiencing a symptom and 51 percent of cancers were detected through screening tests. Respondents with breast and prostate cancer were more likely to have their cancer detected by a screening test compared to respondents with colorectal cancer.
- The time from when cancer was detected by the patient or a health care provider until diagnosis differed by cancer type. Cancer detection refers to the first event that suggested that the respondent might have had cancer. This event could be a positive screening test, a clinical finding or the respondent experiencing a symptom. Diagnosis is the point when cancer is pathologically or clinically confirmed. Overall, about 60 percent of the respondents had less than one month between detecting their cancer and receiving a diagnosis.
- The majority of breast, colorectal and lung cancer patients received their first treatment for cancer within one month of diagnosis. The majority of men with prostate cancer began treatment within three months of diagnosis.

The charts on the following pages summarize the study results for each of the four cancers.

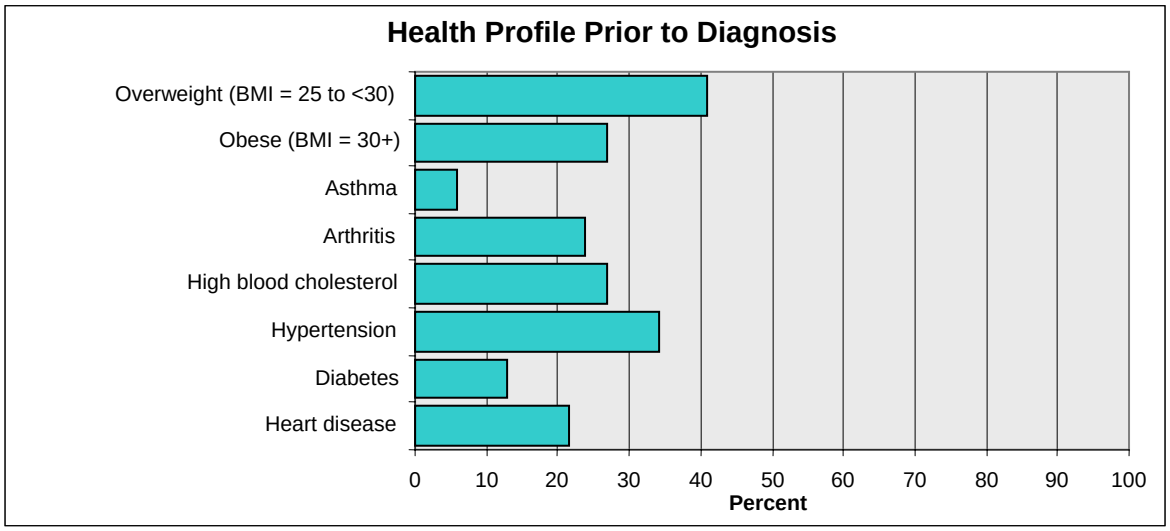
FEMALE BREAST CANCER (# respondents=335)

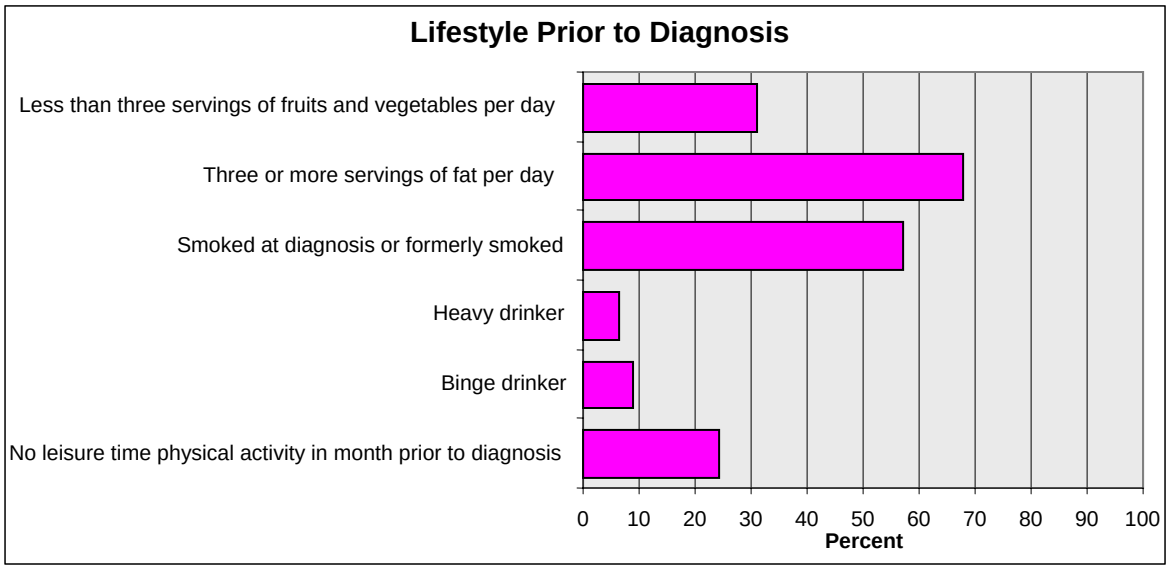


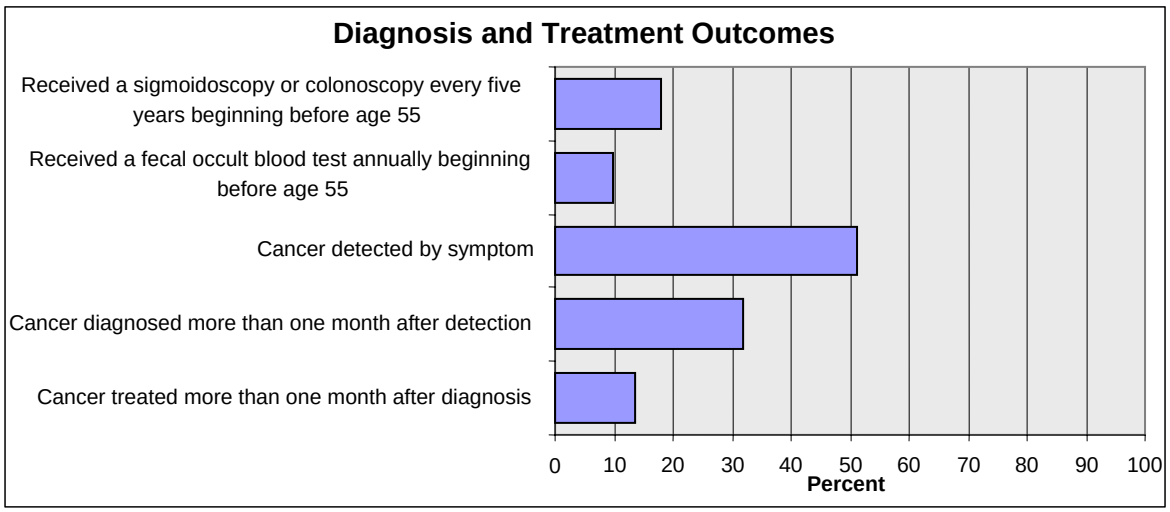




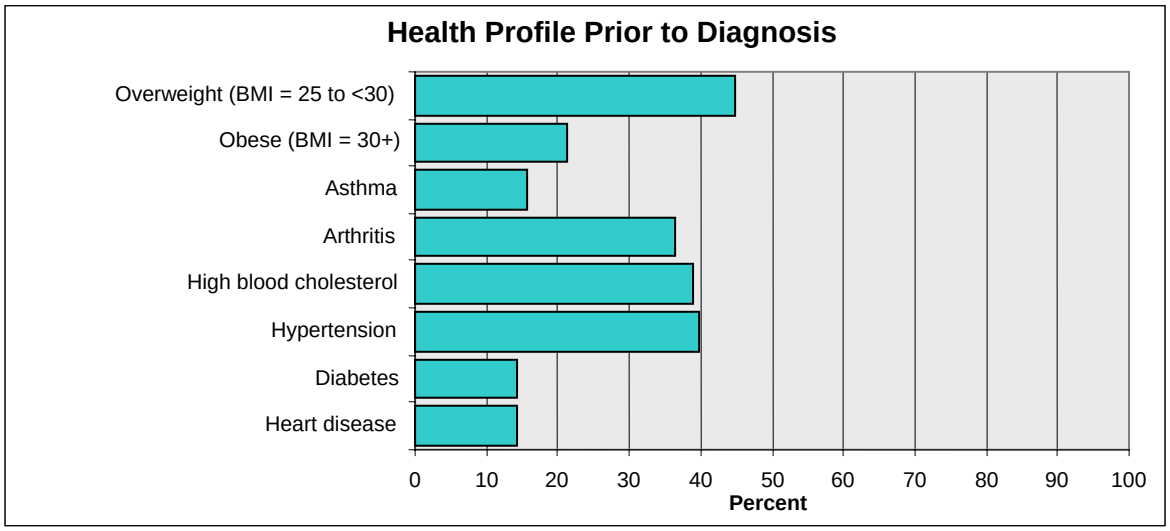
COLORECTAL CANCER (# respondents=163)

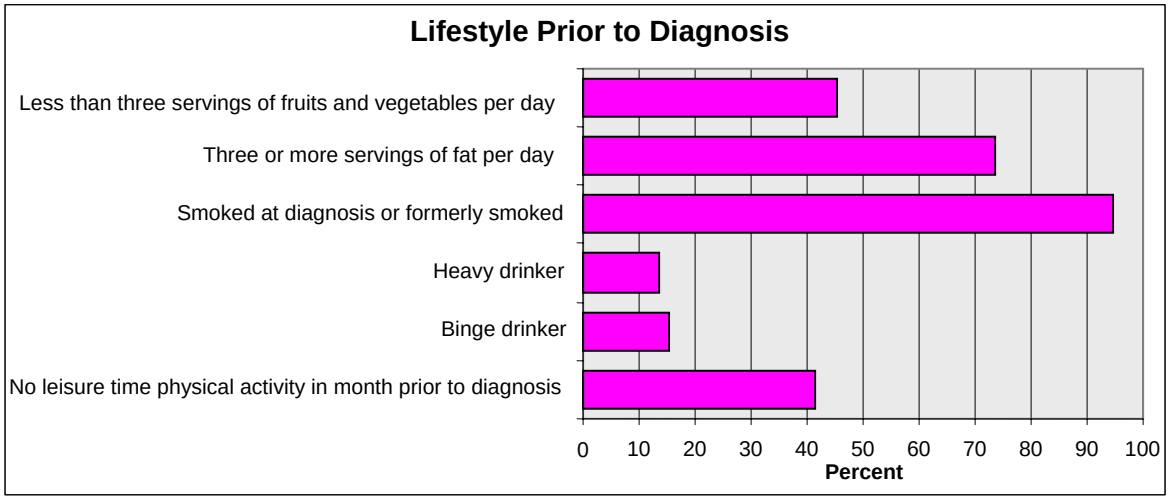


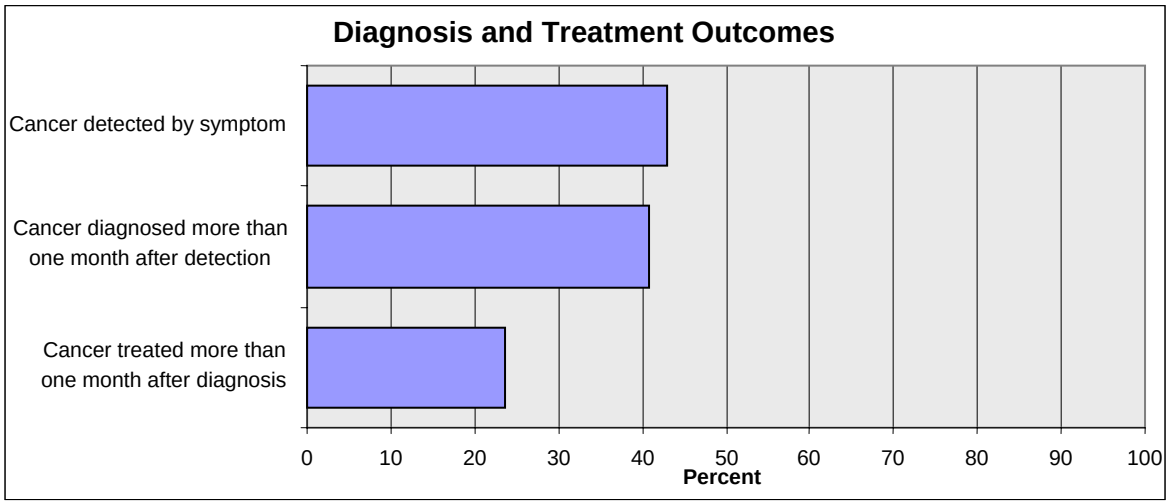




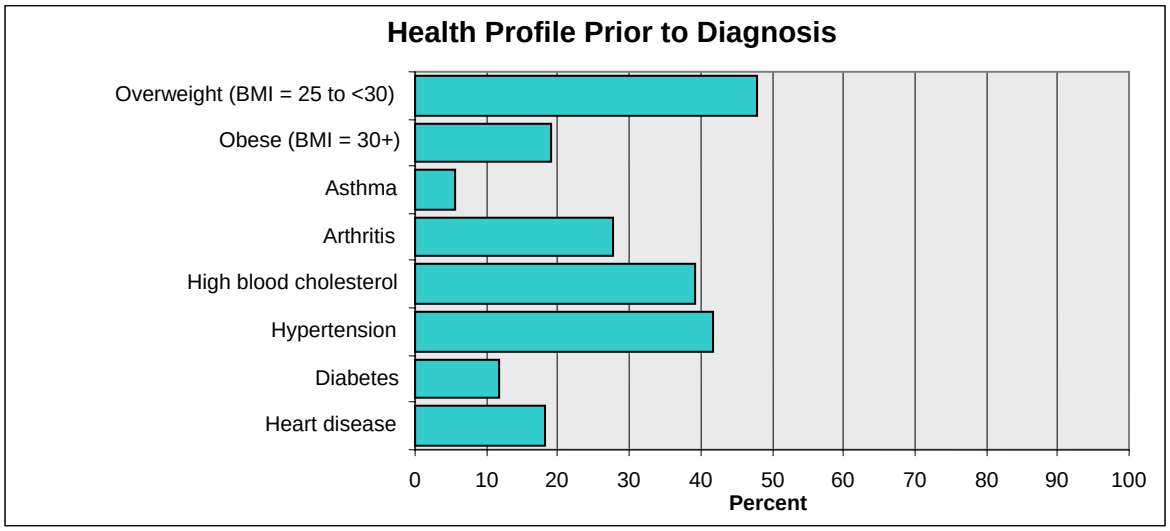
LUNG AND BRONCHUS CANCER (# respondents=95)

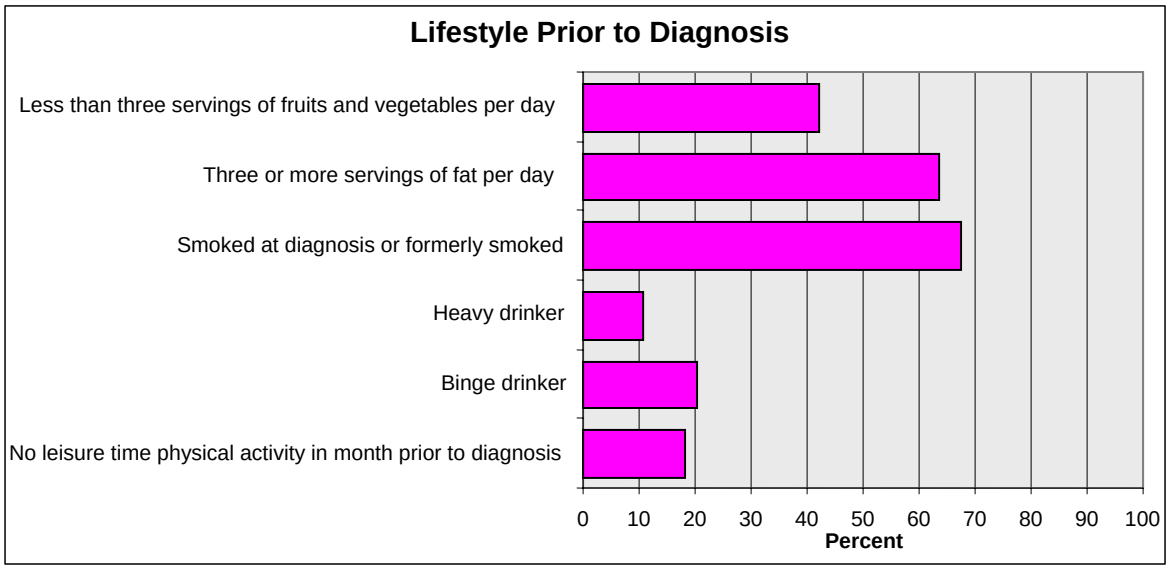


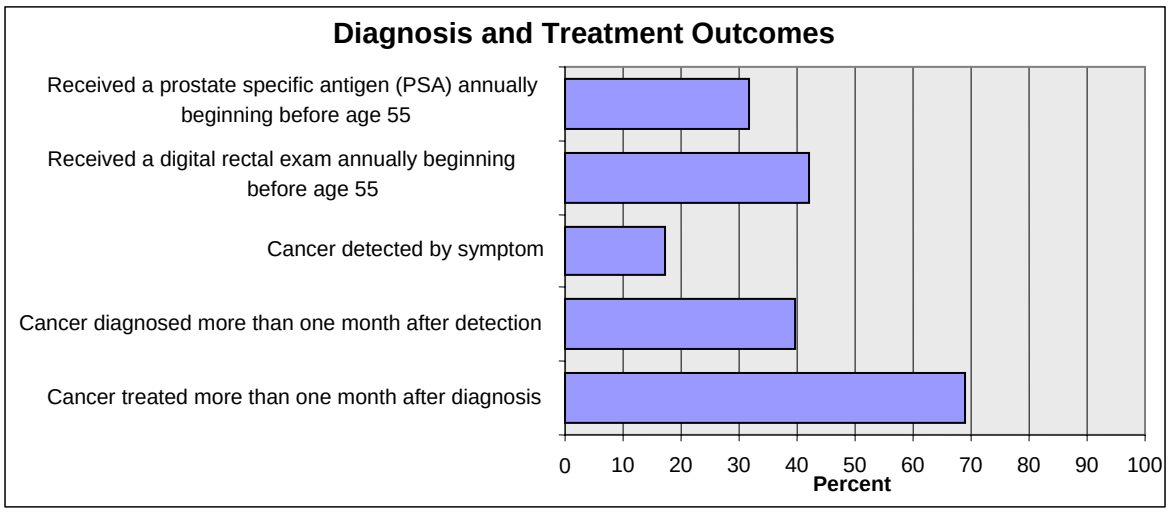




PROSTATE CANCER (# respondents=307)







1. INTRODUCTION

The Delaware Cancer Consortium was originally formed as the Delaware Advisory Council on Cancer Incidence and Mortality in March 2001 in response to Senate Joint Resolution 2 signed by Governor Ruth Ann Minner. The advisory council, consisting of 15 members appointed by the governor, was established to advise the governor and legislature on the causes of cancer incidence and mortality and potential methods for reducing both. The advisory council was later expanded and its name changed to the Delaware Cancer Consortium (DCC) in SB102.[1]

The DCC began meeting in April 2001 with the shared understanding that their work would be focused on developing a clear and usable cancer control plan for action. In their report "Turning Commitment into Action," (April 2002) the council issued the following recommendation with regard to increasing knowledge about cancer in the State of Delaware:

> "Conduct a retrospective survey of individuals with cancer or family members of patients to collect information on family history, occupation, lifestyle, diet, exercise, migration, etc. Include only those cancers for which the state is elevated in incidence or mortality. Obtain data necessary to determine which environmental factors might contribute to Delaware's heightened cancer rates."

The Retrospective Survey of Delawareans Diagnosed with Cancer was designed and conducted in response to this recommendation. Recruitment for the study began in September 2005; data collection was completed in April 2006.

1.1. Cancer in Delaware

During 1999–2003, Delaware's five-year annual age-adjusted cancer incidence rate was 503.5 per 100,000, which is higher than the estimated U.S. rate of 478.1 per 100,000.[2] Female breast cancer and prostate cancer were the most commonly diagnosed cancers, followed by lung and bronchus cancer and colorectal cancer.[3] These four cancer types accounted for 57 percent of cancers diagnosed in Delaware during 1999–2003. An estimated 4,190 new cancer cases will be diagnosed in Delaware during 2006.[4]

Delaware's five-year annual age-adjusted mortality rate was 206.9 per 100,000 during 1999–2003, compared with the U.S. rate of 195.7 per 100,000.[3,5] The death rate for lung and bronchus cancer was highest, followed by prostate, female breast and colorectal cancers. These four cancers accounted for 52 percent of cancer deaths in Delaware during 1999–2003. An estimated 1,690 Delaware residents will die from cancer during 2006.[4]

Cancer Incidence and Mortality Rates for Delaware Compared With the United States

	Delaware		United States	
	Rate per 100,000	(95% CI)	Rate per 100,000	(95% CI)
Incidence Rates (1999–2003)				
ALL CANCERS	**503.5**	**(496.7-510.3)**	**478.1**	**(476.9-479.3)**
Female Breast	129.2	(142.5-133.9)	134.1	(133.3-135.0)
Colorectal	56.7	(54.4-59.0)	52.8	(52.4-53.2)
Lung and Bronchus	77.8	(75.1-80.5)	63.9	(63.4-64.3)
Prostate	176.2	(170.1-182.3)	177.8	(176.6-178.9)
Mortality Rates (1999–2003)				
ALL CANCERS	**206.9**	**(202.5-211.3)**	**195.7**	**(195.5-196.0)**
Female Breast	26.7	(24.6-28.8)	26.0	(25.9-26.0)
Colorectal	21.0	(19.6-22.4)	20.0	(20.0-20.1)
Lung and Bronchus	61.5	(59.1-63.8)	55.1	(55.0-55.2)
Prostate	28.5	(25.7-31.3)	29.1	(28.9-29.2)

CI=Confidence Interval.
Source: Delaware Cancer Registry and the National Program of Cancer Registries Cancer Surveillance System, Centers for Disease Control and Prevention, January 2005 data submission. Rates are age-adjusted to the 2000 U.S. population.

1.2. Study Objectives

Incidence and mortality rates for lung and bronchus cancer and colorectal cancer are elevated in Delaware compared with the United States. Incidence and mortality rates for prostate cancer and female breast cancer in Delaware are similar compared with the United States. This study was designed to investigate the underlying factors that may effect positive change in incidence and mortality rates for these cancers. Specific study objectives are as follows:

- Determine the prevalence of known risk factors for lung and bronchus, colorectal, female breast and prostate cancers, including environmental and occupational factors, in patients diagnosed with these cancers in Delaware.
- Examine factors that may be related to elevated mortality rates for all cancers, such as stage at diagnosis, race, co-morbid conditions, health care access, screening behaviors and diagnosis/treatment patterns.
- Determine the prevalence of behavioral risk factors, screening use and health care in cancer patients diagnosed with each of the four major cancers; compare these with prevalence rates in the overall Delaware population using data from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS).
- Examine geographic differences in cancer rates and risk factors (county level) and migration patterns of cancer patients.

1.3. Study Design

This is a retrospective study of cancer survivors in Delaware to gather risk factor data prior to their cancer diagnosis and data on diagnosis, treatment and screening behaviors for each type of cancer. The target population for the study is all individuals aged 18 or older diagnosed with

colorectal, prostate, female breast, and lung and bronchus cancers in Delaware during the five-year period, Jan. 1, 1999, to Dec. 31, 2003, and registered in the Delaware Cancer Registry (DCR).

For the risk factor analysis, a case/control design was used, comparing the Delaware cancer survivors with the Delaware BRFSS 2002 sample population. The BRFSS is a state-based system of health surveys which generates information about health risk behaviors, clinical preventive practices and health care access and use, primarily related to chronic diseases and injury. The Delaware BRFSS survey sample was selected to represent the general population of Delaware.

1.3.1. Delaware Cancer Registry

The Delaware Cancer Registry (DCR) is the state's central cancer information center and is part of Delaware's Division of Public Health. Delaware is one of 45 states supported by CDC's National Program of Cancer Registries (NPCR).

Delaware's central cancer registry is population-based, and collects data on all cancer patients who are state residents at the time of diagnosis. The DCR collects information on newly diagnosed cancer cases, cancer treatment, cancer deaths, and follow-up data. As stated in the Delaware Cancer Control Act of 1980, the purpose of the registry is to ensure an accurate and continuing source of cancer data and specified tumors of a benign nature. Additionally, the confidentiality of patient information in the registry is required by this law.

Quality assurance is performed by a Certified Tumor Registrar (CTR) to ensure that the registry includes complete and accurate data that conform to standards established by the National Program of Cancer Registries (NPCR) and the North American Association of Central Cancer Registries (NAACCR).

1.3.2. Delaware Institutional Review Board

Before beginning work on this study, a research protocol was developed and submitted to the Division of Public Health in the Delaware Department of Health and Social Services (DHSS) for review. The study was reviewed and approved by the DHSS institutional review board (IRB) in April 2005 and by the ORC Macro IRB in May 2005. As part of the review process, the Delaware IRB required that the physicians of all eligible study participants be contacted and given the option to identify any patients who they thought should be removed from the study.

2. METHODOLOGY

2.1. Identification of Study Population

For this study, a complete NAACCR version 10 dataset of eligible cancer patients was provided by the DCR according to the following inclusion and exclusion criteria:

- Delaware residents at time of diagnosis,
- Aged 18 and older at time of diagnosis,
- Diagnosed between Jan. 1, 1999, and Dec. 31, 2003,
- Diagnosed with:
  - Female breast (ICD-0-3: 500–509),
  - Prostate (ICD-0-3: 619),
  - Colorectal (ICD-0-3: 180–189, 199, 209, 260),
  - Lung and bronchus (ICD-0-3: 340–349),
- Malignant tumors only (Behavior code = 3),
- Alive, and
- Excluded patients who expressly told the American Cancer Society (ACS) Quality of Life study they did not want to be contacted for research purposes or were cognitively impaired (seven individuals).

For the remainder of this report, the term "breast cancer" will be used for female breast cancer and the term "lung cancer" will be used for lung and bronchus cancers.

There were 7,006 individuals eligible to be interviewed for the study. Since the NAACCR database included identification numbers for doctors only, the DCR provided a database with addresses and contact information for each of the physician identification numbers.

Using the databases provided by the DCR, a separate database with patient tracking information was created and merged with the physician database to obtain name and contact information for each patient's physician. Each patient record contained physician IDs for up to five physicians, as defined for NAACCR data submissions, but not all fields had valid entries. The first physician to be contacted was selected according to the following hierarchy for patients with a valid physician ID code in any of the five fields:

1) NAACCR Item #2470—follow-up physician (physician currently responsible for the patient's medical care),
2) NAACCR Item #2460—managing physician (physician responsible for the overall management of the patient during the diagnosis and/or treatment of this cancer),
3) NAACCR Item #2480—primary surgeon (physician who performed the definitive surgical procedure),
4) NAACR Item #2490—MD3 (another physician involved in the care of the patient), and
5) NAACR Item #2500—MD4 (another physician involved in the care of the patient).

Using the physician ID number for matching, separate datasets were created for individuals with physician codes that were matched to the physician database (6,289) and for individuals with

physician codes that were not matched (713). A third dataset was created with physician names and contact information for the 663 physicians that were matched to the study cancer patients.

2.2. Physician Consent

Before contacting any patients for the study, a letter was mailed to their physicians requesting they identify any patients who should not be contacted due to reasons such as they were deceased, terminally ill, not cognitively or emotionally capable of participating in the study or not informed that they had cancer.

Prior to the initial mailing, physicians with high patient loads (responsible for 20 or more patients) were identified. During June 8–10, 2005, these physicians were contacted by telephone to prepare them for the upcoming mailing and request their support in identifying patients who should not be contacted. Any physicians who expressed concern when the ACS Quality of Life study was conducted were also contacted at this time.

A personalized letter and list of patients for each physician was prepared and mailed on July 5 (see appendix 1). The following were excluded from the initial mailing: physician codes that linked to a cancer center or registry (30 codes) and physicians with a note in the cancer registry that they were retired or deceased or had moved. Physicians were asked to identify patients who should not be contacted for the study and were asked to fax their patient lists to the study center by the end of July. As the fax responses were received, the physician contact database was updated to record receipt of the fax and the date of receipt.

Approximately two weeks following the mailing, all physicians for whom no fax response had been received were called to confirm they had received the letter and to remind them to identify any study patients who should not be contacted. A computer-assisted telephone interview (CATI) script was developed and programmed for the calls. All calls were conducted by trained interviewers at the ORC Macro CATI call center in Burlington, VT. As a result of these calls, approximately 240 physicians requested the letter and patient list be resent to them via fax. These faxes were prepared and sent from ORC Macro's Bethesda, MD, office.

Responses were received from 242 physicians, which included 33 of the 67 physicians with high patient loads. Of these 33 physicians, 11 refused to give permission to contact their patients. The remaining 34 physicians with high patient loads who did not respond were contacted to confirm they had received the letter and patient list.

The objective of the physician consent process was to provide each patient's physician the opportunity to inform us if they did not want one or more of their patients to participate in the study. It was clearly stated in the letter that if we did not hear from them, we would presume that their patients could be contacted. We made a concerted effort to confirm that physicians did receive our letter and to remind them to notify us of any patients who should not be contacted for the study. Non-response from a physician who we were able to contact and verify receipt of our letter was considered a passive consent. We did not attempt to recruit any patients whose physician could not be contacted.

2.3. Patient Recruitment

2.3.1. Selection of Patients for Recruitment

In order to determine the set of patients eligible for recruitment, the physician responses and results from the CATI follow-up calls to physicians were merged with the patient dataset. A new dataset was created that included the physician response and CATI follow-up information, along with stratification variables and contact information for each patient. A patient's eligibility status for recruitment was determined according to the following criteria:

Patients eligible for recruitment:

- Physician fax received, checked yes,
- Physician fax received, nothing checked and no other comments,
- CATI follow-up with physician confirmed letter received,
- Physician contacted and faxed a second letter, and
- Patients who consented from the prior study.

Patients ineligible for recruitment:

- Physician fax received, checked no, and
- Physician fax received, patient deceased.

Patients possibly eligible for recruitment:

- Physician fax received, note that the patient is not theirs or not followed,
- Physicians who were not sent the mailing (retired or deceased),
- Physicians with invalid addresses (returned to sender),
- Physicians without phone numbers who were not contacted,
- Physicians with phone numbers who could not be contacted, and
- Patients with a physician code of the cancer center or registry.

The recruitment status of the original 7,006 patients eligible to participate in the study was determined as follows:

- 4,410 patients eligible to recruit (physician contacted),
- 1,106 patients ineligible to recruit (physician contacted, refusal or patient deceased), and
- 1,490 patients possibly eligible to recruit (unable to contact or locate physician).

All breast (1,307), colorectal (791) and lung (318) cancer patients eligible to be recruited were selected for initial recruitment, along with a subset of prostate cancer patients (1,336). Because we were expecting a 20 percent response rate and there were 2,075 prostate cancer patients eligible for recruitment, we assumed we would receive a sufficient number of positive responses if we selected a smaller subset of the eligible participants. Therefore, 739 (35.6 percent) Caucasian patients with local (stage 1) prostate cancer were not selected for recruitment.

2.3.2. Recruitment Procedures

All individuals selected for recruitment were initially sent an informed consent packet via U.S. mail between September and December 2005. The informed consent packet contained the following materials:

- A letter from DHSS requesting participation in the survey.
- A two-page survey information sheet describing the background and purpose of the study, eligibility, study plan, benefits and risks of participation, confidentiality, rights for withdrawal and contact information for DHSS and the study team.
- Two copies of the consent form, one for the patient's records and one to be signed and submitted directly to the study team.
- A stamped return envelope with the address of the study team.

The materials provided in the informed consent packet are included in appendix 2. Packets were mailed to a total of 3,687 potential participants. In addition, follow-up telephone calls were placed to all lung and some colorectal cancer patients who did not initially return their consent forms. This subset of patients received follow-up calls as we had fewer potential respondents with these cancer types, and wanted to have as many participate as possible.

A total of 1,261 consent forms were returned, a response rate of 34 percent. Of these, 988 agreed to participate. Information from the consent forms was entered into the patient tracking database as the forms were received. Patient responses were classified into four groups: refused, unable, deceased and agreed to participate. Eleven individuals were removed from the study because they informed us they did not have cancer (seven individuals), were diagnosed after 2003 (two individuals), or were ineligible because they were not diagnosed in Delaware (two individuals).

Three hundred thirty-eight individuals either declined or were unable to participate. Of these, 64 were unable to participate (36 from consent forms and 28 from telephone follow-up), and 274 refused to participate (204 from consent forms and 70 from telephone follow-up). The most common reasons given for nonparticipation were: too sick, too old, too tired, hard of hearing, not interested, no time, too busy, traveling or away.

The Social Security Death Index (SSDI) was used to further research lung cancer patients whose consent forms were not returned and all patients whose consent forms were returned due to invalid addresses. Deceased individuals, as indicated by physicians, relatives or through SSDI research were reported to the DCR for further confirmation and updating the DCR database. Since the sample size from recruitment of the eligible participants was sufficient, we did not attempt to further research and/or recruit any individuals who were possibly eligible for recruitment.

2.4. Data Collection

2.4.1. Survey Instrument

The survey instrument included questions regarding behavioral risk factors and diagnosis, treatment and screening practices specific to each type of cancer. The questionnaire was

designed to take about 30–45 minutes to complete and consisted of a core set of questions to be asked for all cancer patients and separate modules with questions specific to each type of cancer. To ensure compatibility for comparison with BRFSS data, survey questions designed to collect information regarding demographics, behavioral risk factors, screening behaviors and health care access were worded the same as on the BRFSS questionnaire. A copy of the survey instrument is included in appendix 3.

The survey instrument was programmed using Computers for Marketing Corporation software that allowed automatic control of skip and fill logic and performed range checking and other editing as the interviews were conducted. In early October 2005, the survey instrument was pilot tested and timed with eight of the initially recruited participants, two for each type of cancer. The questionnaire was further refined based on feedback from the pilot interviews and operationally tested prior to fielding.

2.4.2. Fielding of Interviews

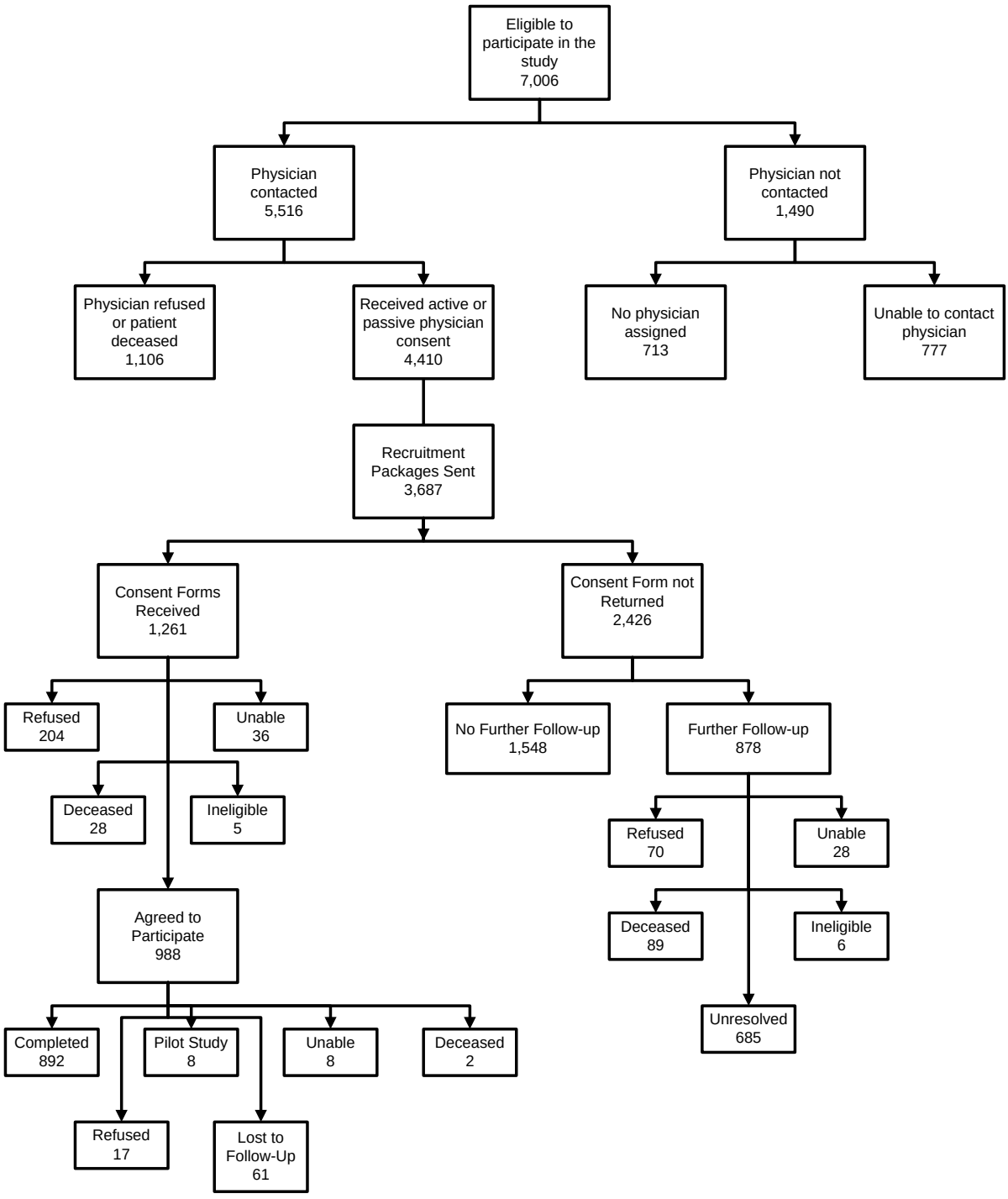
Interviews were conducted via CATI at ORC Macro's Vermont call center from November 2005 through April 2006. Due to the nature of the majority of the survey questions, which required respondents to recall behaviors and screening practices prior to their cancer diagnosis, we did not allow proxy interviews with family members or relatives. All interviews were conducted directly with study participants in order to obtain the most reliable survey data.

Interviewers with prior training in sensitive-subject surveys such as the BRFSS were selected to conduct the interviews for this study. Female interviewers were used to conduct surveys of female participants, and male interviewers conducted the surveys of male participants. A full day of intensive training was conducted specifically for this study to ensure familiarity with the survey instrument and particular areas of the instrument that needed to be reviewed or emphasized. An interviewer training manual (provided in appendix 4) was prepared for the full-day interviewer training session, which was held on Oct. 18, 2005.

2.4.3. Status of Study Participants

Interviews were completed with 892 of the 988 individuals who returned their consent forms and agreed to participate. Eight of these individuals were diagnosed with two different cancers. Twenty-five of the 988 individuals who agreed to participate voluntarily dropped out of the study. Fifteen refused to be interviewed when they were called, two started but did not complete the interview and eight were unable to be interviewed when called. Sixty-one individuals who consented to participate were dropped from the study because they could not be reached after 15 or more attempts, and two individuals were dropped due to death during the interview period.

Figure 1. Patient Recruitment and Data Collection Flowchart



2.5. Analytic Methods

All analyses for this study were conducted using Statistical Analysis Software (SAS) version 9.1. Two analytic datasets were created for the analyses. The patient-level dataset contained one record for each of the 892 completed interviews and included all variables collected in the first nine sections of the interview for all cancer types. The cancer-level dataset contained a total of 900 records, one record for each cancer type, and included the variables collected in the cancer modules and the diagnosis and treatment section of the interview.

2.5.1. Weighting

The main objective of this study was to measure the prevalence of cancer risk factors among Delawareans with the four most common cancers. Ideally, the study population should reflect all individuals diagnosed with these four types of cancer in the Delaware population. However, due to the logistics of conducting the study and the consent process, the study was conducted only among cancer survivors. We interviewed 892 of the 7,006 individuals known to be alive at the beginning of the study period. Because data were collected from anyone who was willing to participate in the study, the individuals who participated were not a random sample of all individuals eligible to participate. Therefore, the distributions of basic demographic variables, such as age, race and gender, were not necessarily the same for study participants compared with the entire eligible population. In order to account for differences in these basic variables, we adjusted the results to reflect the entire eligible population using a method called post-stratification weighting. The potential confounders shown in the table below differ in the interviewed population compared with the eligible population. The variables were used to weight the study responses to the distribution of these variables in the total eligible population. Although race was reported during the interview, we used the race coded by the DCR for weighting purposes in order to be consistent for all eligible participants. There were few differences between the two sources, and these occurred mainly for individuals who reported more than one race in the interview.

Comparison of Weighting Factors in the Eligible Population of Delaware Residents With Cancer and the Interviewed Population

	Interviewed N (Pct)	Not Interviewed N (Pct)	Total Eligible N (Pct)	P-value
TOTAL	**892 (100.0)**	**6,114 (100.0)**	**7,006 (100.0)**	
Race				<0.001
Caucasian	796 (89.3)	4,949 (81.0)	5,745 (82.0)	
African-American	93 (10.4)	1,013 (16.6)	1,106 (15.8)	
Other	3 (0.3)	46 (0.7)	49 (0.7)	
Missing*	0 (0.0)	106 (1.7)	106 (1.5)	
Gender				0.003
Male	426 (47.8)	3,291 (53.8)	3,717 (53.1)	
Female	466 (52.2)	2,822 (46.2)	3,288 (46.9)	
Missing*	0 (0.0)	1 (0.02)	1 (0.01)	
Age group (years)				<0.001
18–49	107 (12.0)	713 (11.7)	820 (11.7)	
50–59	192 (21.5)	1,281 (20.9)	1,473 (21.0)	
60–69	316 (35.5)	1,814 (29.7)	2,130 (30.4)	
70–79	234 (26.2)	1,716 (28.1)	1,950 (27.8)	
80+	43 (4.8)	590 (9.6)	633 (9.0)	

* These groups were not included for weighting purposes. The weighted population total is 6,899.

2.5.2. Prevalence Estimates

For each of the interview questions, a raw prevalence and a weighted prevalence were computed. The responses to open-ended questions and "Other" responses were reviewed and categorized where possible. For all cancer sites combined, the weighted prevalence estimates and their 95 percent confidence intervals (CI) are presented for the entire Delaware population and by county at diagnosis. For the data collected in the cancer-specific modules of the interviews, weighted prevalence for each of the variables are calculated, and data stratified by county are included. A chi-square test was conducted for each variable to identify significant differences among counties.

These analyses were conducted for the following variables:

- Demographic variables, including age at diagnosis, race, Hispanic ethnicity, gender, marital status, education, income, occupational status and length of residency in the county, Delaware and the United States. Since age, race and county at diagnosis were included in the interview questions and also included as part of the cancer registry data, these variables were compared to verify and assess level of agreement. Where differences occurred, the variable as coded in the cancer registry was used for all analyses.
- Risk factors for cancer, including diet, alcohol consumption, tobacco use, physical activity, environmental exposures and the personal, family and occupational history questions from the cancer-specific modules.
- Factors affecting cancer prognosis, including co-morbid conditions, health care access and timely and appropriate diagnosis and treatment questions from the cancer-specific modules.

In addition to the analysis by county type, an analysis of each variable by cancer type was conducted for variables answered by all respondents, as part of the core section of the interview. The weighted prevalence and 95 percent confidence interval for each variable by cancer type is presented along with the results of the chi-square test to identify differences.

Analyses of racial differences were not conducted due to insufficient numbers of patients in racial/ethnic groups other than Caucasians.

2.5.3. Comparison of Cancer Population With BRFSS Respondents

The survey questions were designed whenever possible to follow the same format as questions asked in the BRFSS. This allows for comparison of the prevalence of risk factors in the study population of cancer patients with responses provided by a random sample of Delaware residents. From the BRFSS survey questions, a series of binary behavioral risk factors have been developed. Individuals are categorized as either being at risk or not at risk for each behavior based on definitions developed by CDC. Wherever possible, these risk factor definitions were used for this analysis.

For each risk factor, a multivariate logistic regression controlling for age at diagnosis, race, gender and county at diagnosis was used to compare the two populations as specified in the following model:

$$Log\ odds\ of\ cancer = \alpha + \beta_1(risk\ factor) + \beta_2(age\ at\ diagnosis) + \beta_3(gender) + \beta 4(race) + \beta_5(county)$$

The odds ratio for each risk factor and the 95 percent confidence interval are presented for each comparison. An odds ratio with a value of 1.00 for any risk factor indicates that the odds of the outcome, in this case, cancer, is exactly the same for individuals with or without the risk factor. An odds ratio is considered significant if the value of 1.00 is not contained in the confidence interval.

In addition, age-adjusted, weighted prevalence rates and 95 percent confidence intervals were calculated for each level of the binary risk factors. Because the study population of cancer patients is much older than the general Delaware population, the potential confounding effect of age is reduced when comparing age-adjusted rates computed using the same standard million population. An age-adjusted rate is a weighted average of the age-specific (crude) rates, where the weights are the proportions of persons in the corresponding age groups of a standard million population. The 2000 U.S. Census standard million population was used for the calculation of the age-adjusted rates in this analysis.[6] Confidence intervals were computed using the method developed by Fay and Feuer.[7]

2.5.4. Predictors of Early Versus Late Stage at Diagnosis

We proposed to examine the association between screening test use, health care access and utilization, insurance status, socioeconomic status and race on diagnosis of cancer for later versus early-stage cancers. However, there were insufficient numbers of respondents with late-stage disease to conduct this analysis. The table below displays the distribution of interviewed cases by stage. The criterion for sufficient numbers was based on the analysis of Peduzzi et al., who recommended there be at least 10 people with the outcome of interest (in this case, late-stage disease) for every variable entered into the logistic regression model.[8] As the data indicate, there were not enough cases to conduct the multivariate logistic regression modeling that was originally proposed.

Frequency and Percentage of Interviewed Study Participants for Each Cancer Site by SEER Stage at Diagnosis

	Breast	Colorectal	Lung	Prostate
	N (Pct)	N (Pct)	N (Pct)	N (Pct)
Local	254 (75.8)	70 (42.9)	58 (61.0)	260 (84.7)
Regional with direct extension	3 (0.9)	46 (28.2)	10 (10.6)	34 (11.1)
Regional with lymph node involvement	70 (20.9)	14 (8.6)	10 (10.6)	2 (0.7)
Regional with direct extension and lymph node involvement	3 (0.9)	21 (12.9)	9 (9.6)	2 (0.7)
Distant	1 (0.3)	4 (2.5)	5 (5.3)	3 (1.0)
Missing	4 (1.2)	8 (4.9)	3 (3.2)	6 (2.0)
TOTAL	**335 (100.0)**	**163 (100.0)**	**95 (100.0)**	**307 (100.0)**

3. RESULTS

This section of the report describes the results from the study and is divided into two main sections. In the first section, results are presented for all variables asked in the core section of the interview, which were not specific to a particular type of cancer. These included demographics, length of residency, behavioral risk factors and health care access. The second section describes results for risk factor and screening variables from each of the cancer modules and the variables asked in the diagnosis and treatment section. Frequencies and both unweighted and weighted percentages for each interview question are provided in the survey questionnaire (appendix 3).

3.1. General Attributes

3.1.1. Demographics

This module of the interview asked about race, ethnic background, marital status, education level and income level and briefly ascertained occupational history. All questions, other than occupational history, were taken from the BRFSS.

Age at diagnosis and gender for each respondent were obtained from the cancer registry database. Age was categorized as less than 50 years, 50 to less than 65 years, 65 to less than 80 years and 80 years or more. Race was classified into three categories: Caucasian, African-American and other race, which includes Asian, Pacific Islander, American Indian, and Alaska Native. For individuals who reported more than one race, the preferred race as indicated by the respondent was used. Hispanic ethnicity was asked as a separate question. The number of Hispanics in the general Delaware population is low, and only eight of the study respondents reported Hispanic ethnicity, so it was not used as a separate racial/ethnic category.

The majority of study respondents (approximately 80 percent) were between the ages of 50 and 79. Although more females (466 respondents or 52 percent) were interviewed than males (426 respondents or 48 percent), there were more males (53 percent) in the full study population; thus the weighted percentages reflect this higher proportion of males. The racial make-up of the study population was mostly Caucasian (83 percent), with 18 percent African-American and only 0.7 percent belonging to the other race category. Again, these percentages reflect the racial distribution of the full study population. See section 2.5.1 for an explanation of the weighting for these variables.

The county-level analysis of age at diagnosis and gender shows no significant differences in these attributes of the study population by county. For race, significant differences were found. Ninety-one percent of study respondents living in Sussex County at time of diagnosis were Caucasian compared with 79 percent in Kent County and 81 percent in New Castle County.

Demographic Variables by County					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Age at diagnosis (years)					0.876
Less than 50	**11.7** (9.6–13.9) 107	**13.0** (7.6–18.5) 21	**11.8** (9.0–14.6) 63	**10.8** (6.4–15.1) 23	
50 to less than 65	**35.4** (32.1–38.7) 339	**28.9** (22.0–37.7) 49	**37.1** (32.7–41.5) 203	**32.7** (28.9–41.6) 87	
65 to less than 80	**44.4** (40.9–47.9) 403	**48.0** (38.9–57.1) 70	**42.8** (38.2–47.4) 225	**38.2** (39.2–52.7) 108	
80 or older	**8.4** (6.0–10.7) 43	**9.1** (3.2–15.1) 8	**8.3** (5.2–11.4) 25	**5.2** (3.3–12.6) 10	
Gender					0.097
Male	**53.2** (49.7–56.7) 426	**48.1** (39.0–57.2) 61	**56.5** (51.9–61.0) 266	**48.9** (42.1–55.7) 99	
Female	**46.8** (43.3–50.3) 466	**51.9** (42.8–62.0) 87	**43.5** (39.0–48.1) 250	**51.1** (44.3–57.9) 129	
Race					0.015
Caucasian	**83.3** (80.0–86.6) 796	**79.4** (69.9–90.0) 131	**81.0** (76.7–85.4) 449	**91.4** (86.6–96.1) 216	
African-American	**16.0** (12.8–19.2) 93	**20.6** (11.0–30.1) 17	**18.2** (13.9–22.4) 65	**7.7** (3.2–12.1) 11	
Other	**0.7** (0.0–1.5) 3	**—** — 0	**0.8** (0.0–1.9) 2	**1.0** (0.0–2.9) 1	

Note: Chi-square test excludes the other race category.

The analysis of age at diagnosis by cancer type shows significant differences in the age distributions of the study population for each cancer. Breast cancer patients were youngest: 23 percent were younger than age 50 compared with 11 percent of colorectal cancer patients, seven percent of lung cancer patients and only three and a half percent of patients with prostate cancer. The data suggest that more lung cancer patients were male than female (54 percent compared with 46 percent), although the difference is not significant. A slightly higher percentage of prostate cancer patients were African-American (21 percent) compared with 15 percent of colorectal patients, 13 percent of breast cancer patients, and 11 percent of lung cancer patients, although these racial differences were not statistically significant.

Demographic Variables by Cancer Type					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Age at diagnosis (years)					<0.0001
Less than 50	**22.9** (18.1–27.8) 69	**11.2** (6.2–16.2) 19	**7.4** (2.1–12.7) 7	**3.5** (1.5–5.5) 12	
50 to less than 65	**35.9** (30.7–41.1) 129	**27.2** (20.2–34.1) 53	**40.0** (29.4–49.9) 39	**38.2** (32.5–43.9) 121	
65 to less than 80	**33.5** (28.4–38.6) 124	**48.6** (39.8–57.5) 78	**45.3** (35.0–55.6) 45	**51.7** (45.8–57.6) 161	
80 or older	**7.7** (3.8–11.7) 13	**13.0** (6.5–19.5) 13	**7.7** (0.6–14.9) 4	**6.6** (3.2–10.1) 13	
Gender					NA
Male	**—** — 0	**49.7** (40.9–58.5) 79	**53.6** (43.2–64.0) 45	**100.0** (100.0–100.0) 307	
Female	**100.0** (100.0–100.0) 335	**50.3** (41.5–59.1) 84	**46.4** (36.0–56.8) 50	**—** — 0	
Race					0.145
Caucasian	**86.4** (82.0–90.8) 303	**85.4** (76.2–94.7) 151	**89.6** (82.0–97.2) 88	**78.0** (72.3–83.6) 261	
African-American	**12.9** (8.7–17.2) 31	**14.6** (5.3–24.0) 12	**10.4** (2.8–18.0) 7	**20.8** (15.3–26.4) 44	
Other	**0.7** (0.0–2.1) 1	**—** — 0	**—** — 0	**1.2** (0.0–2.9) 2	

Note: Chi-square test excludes the other race category.

3.1.2. Socioeconomic Status

Respondents were asked about their marital status, education levels and income at the time of their cancer diagnosis. Marital status was classified into two groups: those who were married or part of an unmarried couple; and those who were never married, divorced, separated or widowed. Educational attainment was categorized into four groups: less than a high school education, a high school graduate or equivalent with no further education, less than four years of college and four or more years of post-secondary education. Annual household income was categorized as less than $15,000, $15,000 to less than $50,000 and $50,000 or more. The annual household income of $50,000 corresponds to the median income level in Delaware between 2002 and 2004.[9]

The majority of study respondents were either married or part of an unmarried couple (76 percent). There were no significant differences in marital status by county of diagnosis. More than half of the study respondents (60 percent) were educated beyond the high school level, and 44 percent reported annual household income of $50,000 or more at the time of their diagnosis. Differences in educational and income levels were observed by county. More respondents living in New Castle County at time of diagnosis received a college degree (37 percent) compared with those in Sussex County (30 percent) and Kent County (24 percent). The annual household income level for more than half of respondents living in New Castle County at time of diagnosis was above the median of $50,000, while only 35 percent of residents of Sussex County and 29 percent of residents in Kent County reported incomes above the median.

Socioeconomic Variables by County

	Delaware	Kent	New Castle	Sussex	
	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	P-value
Marital status					0.754
Married or partnered	**76.4** (73.2–80.0) 690	**76.5** (69.3–83.6) 109	**75.7** (71.3–79.8) 401	**78.3** (72.6–84.1) 180	
Single	**23.6** (20.5–26.7) 202	**23.5** (16.4–30.7) 39	**24.4** (20.2–28.7) 115	**21.7** (15.9–27.4) 48	
Education					0.005
Less than high school	**9.0** (6.9–11.0) 75	**11.9** (6.3–17.6) 18	**6.8** (4.3–9.3) 31	**12.2** (7.6–16.8) 26	
High school or G.E.D.	**31.5** (28.2–34.8) 285	**27.7** (19.9–35.5) 43	**31.2** (26.9–35.5) 164	**34.8** (28.3–41.3) 78	
Some post high school	**26.5** (23.3–29.7) 229	**36.2** (27.0–45.5) 48	**25.1** (21.1–29.0) 128	**23.2** (17.5–28.9) 53	
College degree or more	**33.1** (29.8–36.3) 302	**24.2** (16.9–31.4) 38	**37.0** (32.6–41.4) 193	**29.9** (23.8–35.9) 71	
Income					<0.0001
Less than $15,000	**5.9** (4.1–7.7) 44	**10.6** (5.1–16.1) 15	**5.1** (2.7–7.5) 20	**4.5** (1.6–7.5) 9	
$15,000 to less than $50,000	**50.6** (47.0–54.3) 408	**61.2** (52.2–70.1) 80	**43.6** (38.8–48.3) 206	**60.9** (54.1–67.7) 122	
$50,000 or more	**43.5** (39.9–47.1) 372	**28.2** (20.3–36.2) 41	**51.3** (46.5–56.1) 256	**34.6** (28.0–41.2) 75	

Differences in marital status, educational level and income level were observed by cancer type. More prostate (88 percent) and colorectal (74 percent) cancer patients were married or partnered compared with lung (70 percent) and breast (67 percent) cancer patients. Respondents with prostate cancer were more highly educated and reported higher income levels. Thirty-nine percent received a college degree compared with 33 percent of breast cancer respondents, 30 percent of colorectal cancer respondents and 16 percent of lung cancer respondents. Fifty-one percent of patients diagnosed with prostate cancer were above the median income level compared with 41 percent of breast cancer patients, 39 percent of colorectal cancer patients and 31 percent of lung cancer patients.

Socioeconomic Variables by Cancer Type

	Breast	Colorectal	Lung	Prostate	
	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	P-value
Marital status					<0.0001
Married or partnered	**66.5** (61.0–72.0) 232	**74.1** (65.8–82.4) 123	**70.2** (60.3–80.1) 68	**87.5** (83.4–91.7) 273	
Single	**33.5** (28.1–39.0) 103	**25.9** (17.6–34.2) 40	**29.8** (19.9–39.7) 27	**12.5** (8.3–16.6) 34	
Education					0.002
Less than high school	**6.4** (3.7–9.0) 22	**9.9** (5.0–14.8) 16	**12.7** (5.0–20.4) 11	**9.7** (6.0–13.4) 27	
High school or G.E.D.	**33.8** (28.5–39.0) 113	**33.3** (24.8–41.8) 55	**47.6** (37.1–58.1) 45	**24.6** (19.5–29.7) 75	
Some post high school	**27.0** (22.0–32.0) 88	**27.2** (18.8–35.6) 41	**23.7** (14.8–32.5) 23	**26.4** (21.1–31.6) 79	
College degree or more	**32.9** (27.7–38.1) 111	**29.6** (22.1–37.1) 51	**16.0** (8.7–23.3) 16	**39.3** (33.6–45.0) 126	
Income					0.019
Less than $15,000	**5.3** (2.5–8.2) 14	**6.1** (2.0–10.3) 9	**10.8** (4.3–17.2) 10	**4.9** (1.9–8.0) 11	
$15,000 to less than $50,000	**54.0** (48.1–59.8) 160	**55.2** (46.0–64.4) 75	**58.4** (47.8–69.1) 48	**44.2** (38.2–50.1) 129	
$50,000 or more	**40.7** (35.0–46.3) 129	**38.7** (30.0–47.4) 61	**30.8** (20.9–40.6) 28	**50.9** (44.9–57.0) 157	

3.1.3. Length of Residency

Study participants were asked about where they had lived and how long they lived there. These questions were developed specifically for this interview to determine patterns of migration and acculturation in the study population. Respondents were asked to report how long they had lived in their county at diagnosis, Delaware and the United States, as well as whether they were born in the United States and the language most often spoken in their home. Thirty-three respondents were born in a foreign country, and eight respondents reported speaking a language other than English at home.

Length of residency was classified into four groups: five years or less, six to 20 years, 20 years or more (excluding lifetime residents) and lifetime residency. About 50 percent of study participants reported living in their county at diagnosis for 20 years or more, and about 22 percent of respondents reported living in their county at diagnosis all their lives. Similar results were observed for length of state residency. The majority of study participants lived in the United States all their lives (93 percent). There were no differences in length of U.S. residency observed at the county level.

There were reported differences in length of county and state residency at the county level. Residents of New Castle County at time of diagnosis lived in their county and Delaware the longest compared with residents of Kent County and Sussex County. More than 80 percent were either lifetime residents or lived in the county more than 20 years compared with 73 percent of Kent County residents and 47 percent of Sussex County residents. The same pattern was observed for length of residency in Delaware, with higher percentages of New Castle County residents living in Delaware longer compared with residents of Kent County or Sussex County.

There were no observed differences in residency patterns by cancer type. Respondents with each type of cancer followed similar patterns as the entire study population.

Length of Residency by County					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
County residency					<0.0001
5 years or less	**5.5** (3.7–7.4) 46	**6.1** (2.3–9.9) 10	**3.8** (1.2–6.3) 14	**9.4** (5.5–13.2) 22	
6 to 20 years	**22.6** (19.7–25.5) 208	**21.3** (13.9–28.7) 30	**14.0** (10.8–17.1) 73	**44.3** (37.6–51.0) 105	
More than 20 years but not lifetime	**50.2** (46.7–53.8) 451	**59.6** (50.8–68.4) 87	**54.9** (50.3–59.5) 289	**32.5** (26.2–37.8) 75	
Lifetime	**21.6** (18.7–24.5) 184	**13.0** (7.2–18.8) 20	**27.3** (23.2–31.5) 138	**13.8** (8.6–19.1) 26	
Delaware residency					<0.0001
5 years or less	**4.2** (2.5–5.9) 34	**4.4** (1.1–7.7) 7	**2.6** (0.3–5.0) 9	**8.0** (4.3–11.6) 18	
6 to 20 years	**19.4** (16.7–22.2) 174	**17.7** (10.7–24.7) 24	**12.9** (9.7–16.0) 64	**36.6** (30.1–43.1) 86	
More than 20 years but not lifetime	**48.9** (45.4–52.4) 449	**56.6** (47.3–65.8) 88	**53.5** (48.8–58.1) 285	**32.5** (26.2–38.7) 76	
Lifetime	**27.5** (24.2–30.7) 233	**21.3** (12.6–30.1) 28	**31.0** (26.8–35.3) 158	**23.0** (16.9–29.0) 47	

3.1.4. Occupational History

Respondents were first asked whether they had ever worked outside their home, and if they answered yes, they were asked to list the three jobs they held for the longest time. Each of the three jobs was classified into an industry and occupation group using the National Center for Health Statistics scheme for coding death certificates,[10] which is based on the North American Industry Classification System (NAICS) and Standard Occupational Classification (SOC) codes. There are 20 and 23 broad classifications for industry and occupation, respectively. The information provided by the respondent was used to code industry based on the place of work and occupation based on the type of work. If the information provided was not descriptive enough to classify the job for either industry or occupation, it was coded as "unable to determine." After the coding was completed, one variable was created for each occupational category to represent whether a study respondent had reported working in that occupation for any of the three jobs. Since the objective of this question was to determine the individual's

occupation, the industry codes were used to aid in verifying the high-risk industry questions asked later and are not presented here.

Twenty study participants reported never working outside their home. Of the remaining 872 respondents, 355 provided three job titles, 248 provided two job titles, 246 provided one job title and 23 did not provide any job title. We were unable to code at least one occupational category for 26 study participants. The most common occupations reported were management (15 percent), education (15 percent), office and administrative support (26 percent), production (14 percent) and sales (13 percent). Together these five occupational groups included 84 percent of the study population. The following differences were observed by county:

- Respondents living in Kent County at time of diagnosis reported more computer/ mathematical jobs, jobs in the life, physical and social sciences and jobs in construction/extraction compared with Sussex County or New Castle County,
- More participants living in New Castle County at time of diagnosis reported working in military or transportation/moving jobs compared with Sussex County or Kent County, and
- More production jobs were reported by participants living in New Castle County or Sussex County at time of diagnosis compared with Kent County.

Occupation by County

	Delaware	Kent	New Castle	Sussex	
	Percent (CI) N	**Percent** (CI) N	**Percent** (CI) N	**Percent** (CI) N	Chi-Square P-value
Occupation					
Architecture and engineering	**3.9** (2.7-5.2) 37	**2.0** (0.0-4.4) 3	**4.7** (2.9-6.6) 26	**3.3** (1.0-5.5) 8	0.278
Arts, design, entertainment, media	**3.3** (2.2-4.5) 32	**2.7** (0.0-5.4) 4	**3.8** (2.1-5.4) 21	**2.7** (0.7-4.6) 7	0.651
Building and grounds cleaning	**2.9** (1.8-3.9) 28	**0.9** (0.0-2.4) 2	**3.2** (1.8-4.6) 19	**3.3** (0.8-5.8) 7	0.288
Business and financial operations	**7.9** (6.1-9.8) 73	**6.3** (2.5-10.1) 11	**9.1** (6.5-11.7) 46	**6.2** (3.2-9.2) 16	0.284
Community and social services	**2.8** (1.7-3.9) 26	**4.2** (0.7-7.6) 6	**3.3** (1.6-4.9) 18	**0.8** (0.0-1.9) 2	0.098
Computer and mathematical	**1.9** (0.5-3.4) 14	**5.4** (0.0-12.7) 4	**0.9** (0.1-1.7) 5	**0.9** (0.2-3.8) 5	0.028
Construction and extraction	**5.5** (3.9-7.1) 50	**13.3** (7.3-19.3) 20	**2.7** (1.3-4.0) 15	**6.9** (3.4-10.5) 15	<.0001
Education, training and library	**15.4** (12.9-17.9) 136	**14.7** (8.9-20.5) 24	**14.4** (11.0-17.7) 69	**18.4** (13.2-23.6) 43	0.399

Occupation by County					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percent (CI) N	**Percent** (CI) N	**Percent** (CI) N	**Percent** (CI) N	Chi-Square P-value
Farming, forestry and fishing	**1.5** (0.7-2.2) 15	**1.2** (0.0-2.9) 2	**1.7** (0.6-2.8) 10	**1.1** (0.0-2.3) 3	0.757
Food prep and serving related	**5.0** (3.6-6.5) 48	**2.9** (0.4-5.6) 5	**4.5** (2.7-6.3) 25	**7.7** (4.2-11.3) 18	0.079
Healthcare practitioners/technical	**6.0** (4.4-7.7) 53	**3.3** (0.7-5.9) 6	**6.6** (4.3-8.9) 33	**6.6** (2.9-10.3) 14	0.303
Health care support	**2.7** (1.5-3.9) 24	**1.6** (0.0-3.5) 3	**3.6** (1.8-5.4) 18	**1.3** (0.0-2.7) 3	0.105
Installation and maintenance	**6.4** (4.7-8.1) 55	**7.2** (2.5-11.9) 10	**6.5** (4.2-8.7) 33	**5.6** (2.5-8.8) 12	0.848
Legal	**1.8** (0.9-2.7) 16	**1.3** (0.0-3.2) 2	**1.9** (0.8-3.2) 11	**1.6** (0.0-3.6) 3	0.859
Life, physical and social services	**4.6** (3.2-6.0) 43	**9.0** (4.6-13.6) 15	**3.2** (1.6-4.7) 16	**5.1** (2.2-7.9) 12	0.011
Management	**15.1** (12.6-17.5) 138	**16.9** (10.6-23.3) 26	**14.7** (11.5-17.9) 77	**14.6** (9.9-19.3) 35	0.788
Military	**8.4** (6.2-10.7) 67	**5.3** (1.3-9.3) 8	**10.7** (7.3-14.0) 47	**5.2** (2.2-8.2) 12	0.031
Office, administrative support	**26.6** (23.5-29.7) 236	**20.7** (13.5-27.8) 29	**28.8** (24.7-32.9) 150	**25.2** (19.3-31.2) 57	0.154
Personal care and services	**3.5** (2.3-4.8) 31	**1.3** (0.0-3.1) 2	**3.9** (2.2-5.7) 20	**4.0** (1.4-6.7) 9	0.276
Production	**14.1** (11.8-16.5) 131	**6.1** (1.8-10.3) 9	**14.6** (11.5-17.7) 80	**18.6** (13.3-23.9) 42	0.005
Protective services	**2.2** (1.3-3.2) 21	**2.7** (0.3-5.1) 5	**1.9** (0.7-3.2) 10	**2.6** (0.4-4.7) 6	0.770
Sales and related	**13.3** (10.9-15.7) 119	**13.1** (7.1-19.7) 19	**11.5** (8.7-14.3) 61	**17.9** (12.6-23.2) 39	0.095
Transportation and moving	**6.6** (4.6-8.6) 56	**3.5** (0.7-6.4) 6	**8.9** (5.8-11.9) 43	**3.2** (0.8-5.6) 7	0.006

There were three significant occupational differences found by cancer type: 1) respondents with prostate cancer reported fewer management jobs, 2) respondents with prostate cancer reported more jobs in installation, repair and maintenance, and 3) respondents with colorectal cancer reported more computer and mathematical jobs. For all other occupations, the distribution for each cancer was similar to that of the entire study population.

Occupation by Cancer					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percent (CI) N	**Percent** (CI) N	**Percent** (CI) N	**Percent** (CI) N	P-value
Occupation					
Architecture and engineering	**3.8** (1.8-5.9) 14	**3.3** (0-6.2) 5	**1.9** (0-4.7) 2	**4.8** (2.5-7.2) 16	0.605
Arts, design, entertainment, media	**4.8** (2.5-7.0) 17	**3.0** (.3-5.8) 5	**2.2** (0-5.4) 2	**2.5** (.7-4.3) 8	0.418
Building and grounds cleaning	**2.7** (1.0-4.4) 10	**2.7** (0.3-5.1) 5	**2.8** (0.0-6.8) 2	**3.1** (1.3-4.9) 11	0.991
Business and financial operations	**8.9** (5.8-11.9) 31	**4.5** (1.3-7.7) 8	**13.4** (5.4-21.3) 11	**7.4** (4.4-10.4) 23	0.098
Community and social services	**3.3** (1.5-5.2) 12	**2.2** (0-4.5) 4	**3.9** (0-7.8) 4	**2.4** (0-4.5) 6	0.795
Computer and mathematical	**0.9** (0-1.9) 3	**4.9** (0-11.4) 4	**2.7** (0-5.8) 3	**1.2** (0-2.3) 4	0.048
Construction and extraction	**7.1** (4.3-9.9) 24	**3.5** (0.9-6.2) 7	**4.6** (0.1-9.0) 4	**5.3** (2.5-8.2) 15	0.430
Education, training and library	**18.7** (14.1-23.3) 58	**13.2** (7.9-18.4) 24	**20.2** (11.8-28.6) 19	**12.5** (8.4-16.6) 35	0.099
Farming, forestry and fishing	**2.2** (0.7-3.7) 8	**0.7** (0.0-1.9) 1	**4.0** (0.1-7.9) 4	**0.6** (0.0-1.4) 2	0.056
Food prep and serving related	**5.1** (2.7-7.5) 18	**2.4** (0.3-4.5) 5	**8.7** (2.3-15.0) 7	**5.4** (2.9-7.8) 18	0.170
Healthcare practitioners/technical	**5.0** (2.7-7.3) 18	**6.3** (2.3-10.2) 10	**7.7** (2.2-13.3) 7	**6.3** (3.3-9.4) 18	0.810
Health care support	**2.5** (.8-4.2) 9	**2.2** (0-4.5) 4	**3.7** (.1-7.2) 4	**2.9** (.6-5.1) 7	0.921
Installation and maintenance	**5.2** (2.8-7.6) 18	**3.9** (0.7-7.1) 6	**3.6** (0.0-7.6) 3	**9.4** (5.9-12.9) 28	0.042

Occupation by Cancer					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percent (CI) N	**Percent** (CI) N	**Percent** (CI) N	**Percent** (CI) N	P-value
Occupation					
Legal	**1.5** (0.2-2.8) 5	**2.7** (0-5.4) 4	**---** **---** 0	**2.1** (0.5-3.6) 7	NA
Life, physical and social services	**6.3** (3.7-8.9) 22	**3.7** (0-6.9) 5	**1.9** (0-2.8) 1	**4.6** (2.3-6.9) 15	0.187
Management	**17.6** (13.3-21.9) 58	**19.2** (12.9-25.6) 33	**17.6** (9.5-25.7) 16	**10.2** (6.7-13.8) 31	0.023
Military	**7.2** (4.3-10.1) 24	**10.3** (3.1-17.6) 12	**6.8** (1.5-12.2) 6	**8.9** (5.4-12.5) 25	0.414
Office, administrative support	**26.0** (21.1-30.9) 85	**22.1** (15.3-29.0) 37	**25.9** (16.9-35.1) 25	**29.5** (24.0-34.9) 89	0.395
Personal care and services	**1.9** (0.5-3.4) 7	**3.4** (0.3-6.4) 5	**4.1** (0.1-7.9) 4	**4.8** (2.4-7.2) 15	0.284
Production	**16.0** (11.9-20.1) 54	**9.9** (5.3-14.4) 18	**13.9** (6.6-21.2) 13	**14.8** (10.6-18.9) 46	0.328
Protective services	**1.9** (0.3-3.4) 6	**2.9** (0.6-5.3) 6	**---** **---** 0	**2.8** (0.9-4.6) 9	NA
Sales and related	**12.9** (8.9-16.8) 40	**10.6** (5.8-15.3) 19	**20.2** (11.5-28.9) 18	**13.4** (9.4-17.3) 42	0.217
Transportation and moving	**5.8** (3.2-8.3) 20	**11.8** (4.6-19.1) 16	**1.9** (0.0-5.8) 1	**5.9** (3.3-8.5) 19	0.056

In addition to the general question asked about jobs, respondents were asked whether they had ever worked in one of the following high-risk industries: chemical, pharmaceutical, manufacturing, agriculture and construction. If they answered yes, they were asked for up to three job titles and the length of time worked in each job. Each job title was coded using the SOC classification system as described above. Individuals were then classified into either high-risk or low-risk categories depending on whether the coded occupation might have involved direct exposure to carcinogens. One variable was created with three levels: 1) never worked in a high-risk industry, 2) any work in a high-risk industry in a low-risk job, and 3) any work in a high-risk industry with a high-risk job.

Twenty-one percent of study respondents reported ever working in the chemical industry, three percent in the pharmaceutical industry, 26 percent in manufacturing, 10 percent in agriculture,

and 17 percent in the construction industry. In each of these industries, the majority of study participants worked in high-risk occupations, with the exception of the pharmaceutical industry, where the percentage of low-risk and high-risk jobs was similar. The only significant county-level difference was for the chemical industry. More respondents living in New Castle County at time of diagnosis were ever employed in the chemical industry (26 percent) compared with Kent County (10 percent) or Sussex County (16 percent).

High-Risk Industry by County

	Delaware	Kent	New Castle	Sussex	
	Percent (CI) N	**Percent** (CI) N	**Percent** (CI) N	**Percent** (CI) N	P-value
Agriculture/Farming					0.294
Worked in the industry	**10.2** (8.1-12.4) 87	**12.8** (6.8-18.8) 17	**8.8** (6.3-11.4) 44	**11.9** (7.5-16.3) 26	
Did not work in the industry	**89.8** (87.6-91.9) 784	**87.2** (81.2-93.2) 121	**91.2** (88.6-93.8) 463	**88.1** (83.7-92.5) 200	
Chemical					<.0001
Worked in the industry	**21.0** (18.1-23.9) 177	**9.9** (4.6-15.3) 14	**26.3** (22.3-30.4) 131	**15.7** (10.5-21.0) 32	
Did not work in the industry	**79.0** (76.1-81.9) 694	**90.1** (84.9-95.4) 125	**73.7** (69.6-77.7) 375	**84.3** (79.1-89.5) 194	
Construction					0.787
Worked in the industry	**16.9** (14.1-19.6) 136	**15.3** (8.2-22.4) 18	**17.7** (14.1-21.2 85	**16.0** (10.8-21.2) 33	
Did not work in the industry	**83.1** (80.4-85.9) 736	**84.7** (77.6-91.8) 121	**82.3** (78.8-85.9) 422	**84.0** (78.9-89.2) 193	
Manufacturing					0.121
Worked in the industry	**25.8** (22.6-29.1) 212	**33.4** (23.8-43.0) 40	**24.8** (20.8-28.8) 122	**23.2** (17.3-29.1) 50	
Did not work in the industry	**74.2** (71.0-77.4) 660	**66.6** (57.0-76.2) 99	**75.2** (71.2-79.2) 385	**76.8** (70.9-82.7) 176	
Pharmaceutical					0.209
Worked in the industry	**3.1** (1.9-4.2) 27	**2.6** (0.03-5.2) 4	**3.9** (2.2-5.6) 20	**1.4** (0.0-3.0) 3	
Did not work in the industry	**96.9** (95.8-98.1) 844	**97.4** (94.8-100) 44	**96.1** (94.4-97.8) 487	**98.6** (97.0-100) 222	

With the exception of the pharmaceutical industry, differences were observed by cancer type for participants working in each of the other high-risk industries. However, because males are more likely to work in high-risk industries, gender was a confounding factor in this analysis. The

analysis was rerun controlling for gender, and significant differences by cancer were no longer present except for in the farming industry. More males with colorectal cancer (25 percent) and lung cancer (24 percent) worked in the farming industry as compared with males with prostate cancer (11 percent). No differences were observed for females working in the farming industry.

High-Risk Industry by Cancer Type

	Breast	Colorectal	Lung	Prostate	
	Percent (CI) N	Percent (CI) N	Percent (CI) N	Percent (CI) N	P-value
Agriculture/Farming					0.001
Worked in the industry	**4.4** (2.0-6.9) 13	**15.3** (9.6-21.1) 26	**15.5** (7.2-23.8) 13	**10.9** (7.4-14.5) 35	
Did not work in the industry	**95.6** (93.1-98.0) 311	**84.7** (78.9-90.4) 133	**84.5** (76.2-92.8) 81	**89.1** (85.5-92.6) 267	
Chemical					<.0001
Worked in the industry	**7.8** (4.9-10.6) 181	**21.9** (14.9-28.9) 34	**28.6** (19.1-38.1) 26	**30.3** (25.0-35.7) 94	
Did not work in the industry	**92.2** (89.4-95.1) 698	**78.1** (71.2-85.1) 125	**71.4** ((61.9-81.0) 68	**69.7** (64.3-75.0) 207	
Construction					<.0001
Worked in the industry	**5.1** (2.6-7.7) 16	**15.1** (9.2-20.9) 24	**21.2** (12.5-29.8) 19	**26.3** (21.0-31.5) 78	
Did not work in the industry	**94.9** (92.3-97.4) 309	**84.9** (79.1-90.8) 135	**78.8** (70.2-87.5) 75	**73.7** (68.5-79.0) 224	
Manufacturing					<.0001
Worked in the industry	**13.5** (9.7-17.3) 45	**30.6** (21.8-39.3) 42	**25.5** (16.2-34.8) 23	**34.1** (28.5-39.7) 105	
Did not work in the industry	**86.5** (82.7-90.3) 280	**69.4** (60.7-78.2) 117	**74.5** (65.2-83.8) 71	**65.9** (60.3-71.5) 197	
Pharmaceutical					0.409
Worked in the industry	**2.7** (0.8-4.6) 8	**1.5** (0.0-3.2) 3	**4.7** (0.2-9.3) 4	**3.7** (1.6-5.7) 27	
Did not work in the industry	**97.3** (95.4-99.2) 316	**98.5** (96.8-100.0) 156	**95.3** (90.7-99.8) 90	**96.3** (94.3-98.4) 852	

3.1.5. Health Status

Several interview questions addressed health status; all were taken from the BRFSS. Participants were asked about their general health in the year prior to their diagnosis and categorized into those who reported excellent, very good or good health and those who reported fair or poor health. Respondents were asked whether they had ever been told by a health practitioner that they had the following conditions: heart disease, diabetes, hypertension, high blood cholesterol,

arthritis or asthma. Individual variables were created for each condition, and a co-morbidity index ranging from zero to six was created. Each study participant was asked to report his or her height and weight just before diagnosis, and the most he or she ever weighed. These variables were used to calculate the respondent's body mass index (BMI) using the formula:

$$BMI = \text{weight (kg)}/\text{height (m)}^2$$

For weight just before diagnosis and highest reported weight, BMI was categorized into three groups: <25, 25 to <30 and 30+. These groups correspond to the CDC definitions for healthy weight, overweight and obesity.[11]

The majority of study participants reported good to excellent health in the year prior to diagnosis (92 percent). A higher proportion of respondents were classified as either overweight (39 percent) or obese (24 percent) compared with those who were neither overweight nor obese (37 percent). For highest weight reported, 40 percent of respondents were overweight, 36 percent were obese and 24 percent were neither overweight nor obese. About 31 percent of respondents did not have any of the six co-morbid conditions, 49 percent reported having one or two co-morbid conditions and the remaining 20 percent reported three or more co-morbid conditions. The prevalence of each of the six co-morbid conditions in the study populations was reported as follows: 17 percent with heart disease, 12 percent with diabetes, 38 percent with hypertension, 35 percent with high blood cholesterol, 30 percent with arthritis and 8 percent with asthma.

There were no significant differences in any of these health status variables at the county level, indicating that the health status of the study population was similar in each of Delaware's three counties. However, differences were observed in health status among the four cancer types. Fewer lung cancer patients reported good to excellent health before diagnosis (81 percent) when compared with patients with prostate, breast or colorectal cancer (90 percent or more for each cancer). More breast cancer patients reported a healthy weight prior to diagnosis (45 percent) compared with colorectal (32 percent), lung (34 percent) and prostate (33 percent) cancer patients. A similar pattern was seen for highest reported weight.

More lung cancer patients reported three or more co-morbid conditions (27 percent), and fewer lung cancer patients reported not having any co-morbid conditions (19 percent) compared with the other cancer patients. This is consistent with the finding that lung cancer patients were less likely to report good to excellent health prior to diagnosis compared with the other cancer patients. Differences were also observed in the prevalence of each condition separately. Patients with lung and prostate cancer were more likely to have high blood cholesterol (40 percent and 39 percent, respectively) compared with patients with breast cancer or colorectal cancer (32 percent and 27 percent, respectively). Lung cancer patients were more likely to have asthma (16 percent) compared with patients with breast cancer, colorectal cancer or prostate cancer (all less than 10 percent).

Health Status by Cancer Type

	Breast	Colorectal	Lung	Prostate	
	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	P-value
Health status					0.001
Good or better	**93.8** (91.2–96.4) 314	**89.7** (85.0–94.5) 145	**80.9** (72.9–88.8) 76	**93.6** (90.6–96.5) 288	
Fair or poor	**6.2** (3.6–8.8) 21	**10.3** (5.5–15.0) 18	**19.1** (11.2–27.1) 19	**6.4** (3.5–9.4) 19	
Weight classification					<0.001
Neither overweight nor obese	**44.7** (39.1–50.3) 146	**32.2** (24.4–40.0) 57	**34.0** (24.0–43.9) 32	**33.2** (27.5–38.9) 95	
Overweight	**28.3** (23.3–33.3) 96	**41.0** (31.8–50.2) 58	**44.7** (34.3–55.2) 42	**47.8** (41.9–53.7) 149	
Obese	**27.0** (22.1–31.9) 91	**26.8** (19.5–34.1) 45	**21.3** (12.4–30.1) 20	**19.0** (14.5–23.4) 62	
Highest weight classification					0.008
Neither overweight nor obese	**31.0** (25.8–36.1) 103	**20.3** (11.1–26.6) 39	**19.4** (11.0–27.7) 18	**21.0** (16.1–25.6) 62	
Overweight	**31.5** (26.3–36.7) 105	**42.5** (33.6–51.4) 63	**47.2** (36.8–57.7) 45	**45.8** (39.9–51.7) 139	
Obese	**37.5** (31.2–42.3) 126	**37.2** (28.4–45.9) 59	**33.4** (23.5–43.4) 32	**33.2** (27.7–38.7) 105	
Co-morbid conditions*					0.048
None	**36.7** (31.3–42.1) 121	**36.3** (28.3–44.3) 65	**20.3** (11.9–28.7) 19	**27.4** (22.2–32.7) 85	
One to two	**43.2** (37.7–48.8) 146	**44.9** (36.1–53.8) 70	**54** (43.5–64.5) 52	**53.3** (47.4–59.2) 162	
Three or more	**20.1** (15.5–24.6) 66	**18.7** (10.9–26.6) 28	**25.7** (16.2–35.2) 24	**19.3** (14.6–23.9) 58	

*Respondents were asked about the following conditions: heart disease, diabetes, hypertension, high blood cholesterol, arthritis and asthma.

Health Conditions by Cancer Type					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Heart disease					0.317
Yes	**14.7** (10.5–18.8) 45	**21.7** (13.5–30.0) 29	**14.4** (7.1–21.7) 14	**18.2** (13.6–22.8) 54	
No	**85.3** (81.2–89.5) 289	**78.3** (70.0–86.5) 133	**85.6** (78.3–92.9) 81	**81.8** (77.2–86.4) 250	
Diabetes					0.675
Yes	**9.9** (6.5–13.2) 32	**12.8** (7.6–18.0) 23	**14.2** (6.1–22.4) 12	**11.9** (8.1–15.7) 36	
No	**90.1** (86.8–93.5) 303	**87.2** (82.0–92.4) 140	**85.8** (77.6–93.8) 83	**88.1** (84.3–91.9) 269	
Hypertension					0.321
Yes	**35.2** (29.9–40.5) 117	**34.1** (24.8–43.4) 47	**39.7** (29.4–50.0) 38	**41.8** (36.0–47.7) 125	
No	**64.8** (59.5–70.1) 217	**65.9** (56.6–75.2) 115	**60.3** (50.0–70.6) 56	**58.2** (52.3–64.0) 181	
High blood cholesterol					0.042
Yes	**31.7** (26.5–36.9) 106	**26.8** (18.6–35.0) 43	**38.9** (28.6–49.2) 37	**39.3** (33.6–45.0) 125	
No	**68.3** (63.1–73.5) 224	**73.2** (65.0–81.4) 120	**61.1** (50.8–71.4) 58	**60.7** (55.0–66.4) 180	
Arthritis					0.124
Yes	**33.1** (27.8–38.3) 111	**23.8** (15.7–31.9) 38	**36.5** (26.5–46.4) 37	**27.7** (22.2–33.1) 78	
No	**66.9** (61.7–72.2) 223	**76.2** (68.1–84.3) 125	**63.5** (53.6–73.5) 57	**72.3** (66.9–77.8) 228	
Asthma					0.017
Yes	**8.9** (5.8–11.9) 31	**5.8** (1.9–9.6) 9	**15.8** (7.6–23.9) 14	**5.7** (3.0–8.4) 18	
No	**91.1** (88.1–94.2) 304	**94.2** (90.4–98.1) 154	**84.2** (76.1–92.4) 80	**94.3** (91.6–97.0) 289	

3.1.6. Diet

Diet questions were designed to measure consumption of fruit and vegetables and dietary fat intake at the time of diagnosis. Respondents were asked how often they usually ate certain foods. These questions were taken from the BRFSS and grouped to form two indices:

- **Fruit and vegetable intake—**This index reflects the daily number of servings of fruit and vegetables the respondent eats. The index categorizes respondents into four groups: those who ate fruit and vegetables less than once per day, once to less than three times per day, three to less than five times per day and five or more times per day. The index was derived from the SAS code provided by BRFSS.[12]

- **Dietary fat intake—**The 13-item dietary fat screener was developed by Block (1989) to identify groups of individuals with high or low fat intake by estimating intakes of fat and saturated fat in the few foods believed to contribute the most to total fat intake.[13] These questions were used in the BRFSS from 1990–94. The fat index was derived using the same algorithm as for the fruit and vegetable index and categorized respondents into the same four categories.

About 20 percent of the study population met the current recommendation for eating five or more servings of fruits and vegetables per day. More than 60 percent of respondents reported eating foods high in fat three or more times per day. There were no differences in fruit and vegetable intake or dietary fat intake at the county level.

Dietary Variables by County					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Fruit and vegetable consumption					0.218
Less than once per day or never	**2.7** (1.6–3.9) 23	**1.1** (0.0–2.6) 2	**3.6** (1.8–5.4) 17	**1.8** (0.0–3.6) 4	
Once but less than three times per day	**33.0** (29.7–36.3) 283	**35.7** (27.2–44.2) 53	**32.1** (27.8–34.5) 159	**33.2** (26.7–39.7) 71	
Three but less than five times per day	**43.8** (40.3–47.3) 404	**38.4** (29.8–46.9) 59	**43.4** (38.9–48.0) 230	**48.5** (41.7–55.2) 115	
Five or more times per day	**20.5** (17.6–23.4) 182	**24.8** (16.1–33.6) 34	**20.8** (17.2–24.5) 110	**16.5** (11.5–21.5) 38	
Dietary fat consumption					0.270
Less than once per day or never	**4.2** (2.7–5.7) 35	**1.0** (0.0–2.4) 2	**5.2** (3.0–7.4) 25	**3.9** (1.1–6.8) 8	
Once but less than three times per day	**32.3** (28.9–35.6) 286	**33.7** (24.5–43.0) 46	**31.8** (27.5–36.1) 163	**32.2** (26.0–38.5) 77	
Three but less than five times per day	**40.2** (36.8–43.7) 366	**37.9** (29.4–46.4) 59	**41.8** (37.2–46.3) 221	**38.1** (31.5–44.7) 86	
Five or more times per day	**23.3** (20.4–26.3) 205	**27.4** (19.6–35.1) 41	**21.2** (17.5–24.9) 107	**25.7** (19.7–31.7) 57	

Significant differences were found for fruit and vegetable consumption for each cancer type. Breast cancer patients ate the most servings of fruits and vegetables per day, while lung cancer patients ate the fewest servings of fruits and vegetables per day. Differences in fat consumption were borderline significant. The data suggest that lung cancer and colorectal cancer patients tend to eat high-fat foods more often than breast cancer and prostate cancer patients.

Dietary Variables by Cancer Type					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Fruit and vegetable consumption					<0.001
Less than once per day or never	**3.0** (1.0–4.9) 9	**1.7** (0.0–3.6) 3	**9.6** (2.3–16.9) 7	**1.8** (0.3–3.2) 6	
Once but less than three times per day	**24.7** (19.8–29.6) 80	**29.2** (21.8–36.7) 50	**36.7** (26.6–46.9) 35	**40.2** (34.3–46.0) 118	
Three but less than five times per day	**46.1** (40.6–51.6) 159	**49.1** (40.3–57.9) 82	**36.6** (26.7–46.5) 37	**41.2** (35.4–47.0) 130	
Five or more times per day	**26.3** (21.3–31.2) 87	**20.0** (11.9–28.0) 28	**17.0** (9.3–24.8) 16	**16.9** (12.6–21.1) 53	
Dietary fat consumption					0.070
Less than once per day or never	**3.0** (1.1–4.9) 10	**3.7** (0.8–6.5) 7	**3.6** (0.0–8.0) 3	**5.5** (2.6–8.4) 15	
Once but less than three times per day	**38.9** (33.5–44.4) 129	**28.4** (20.1–36.6) 46	**23.0** (14.4–31.7) 23	**30.8** (25.3–36.4) 90	
Three but less than five times per day	**40.6** (35.1–46.1) 138	**40.4** (31.6–49.2) 64	**42.8** (32.4–53.1) 41	**39.0** (33.3–44.6) 126	
Five or more times per day	**17.5** (13.3–21.7) 58	**27.6** (20.2–35.0) 46	**30.6** (20.9–40.2) 28	**24.7** (19.6–29.8) 76	

3.1.7. Alcohol Consumption

Respondents were asked a series of three questions regarding alcohol consumption. These questions were taken from the BRFSS survey and designed to measure usual consumption of alcohol, heavy drinking and binge drinking. Respondents were asked whether they had at least one drink of alcohol in the 30 days prior to diagnosis. A drink of alcohol was defined as one 12 oz. can or bottle of beer, one glass of wine, one 12 oz. can or bottle of wine cooler, one cocktail or one shot of liquor. Respondents were asked how many drinks they drank per day on average and how many times in the 30 days prior to diagnosis they had five or more drinks. Heavy drinkers were defined as males who consumed on average three or more drinks per day or females who consumed on average two or more drinks per day. Binge drinkers were defined as respondents who reported having a drink in the past 30 days and who drank five or more drinks on one or more occasions in the past month.

About 60 percent of the study population reported having at least one drink in the 30 days prior to diagnosis, 8 percent were classified as heavy drinkers and 13 percent were classified as binge drinkers. Differences were seen for all three alcohol indicators by county. Respondents living in New Castle County at time of diagnosis were more likely to have had a drink in the 30 days prior to diagnosis and were more likely to be both heavy drinkers and binge drinkers compared with respondents living in either Kent County or Sussex County.

Alcohol Consumption by County

	Delaware	Kent	New Castle	Sussex	
	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	P-value
At least one drink of alcohol in the past 30 days					0.001
Yes	**59.3** (55.8–62.9) 531	**46.2** (37.3–55.2) 72	**63.8** (59.3–68.3) 326	**57.6** (50.9–64.3) 133	
No	**40.7** (37.1–44.2) 356	**53.8** (44.8–62.7) 74	**36.2** (31.7–40.7) 187	**42.4** (35.7–49.1) 95	
Heavy drinkers					0.016
Yes	**8.3** (6.3–10.3) 69	**3.4** (0.4–6.4) 5	**10.4** (7.4–13.4) 48	**6.6** (3.4–9.8) 16	
No	**91.7** (89.7–93.7) 815	**96.6** (93.6–99.6) 140	**89.6** (86.6–92.6) 463	**93.4** (90.2–96.6) 212	
Binge drinkers					0.015
Yes	**13.4** (11.0–15.8) 111	**11.6** (5.9–17.2) 16	**16.2** (12.7–19.6) 78	**7.9** (4.2–11.6) 17	
No	**86.6** (84.2–89.0) 770	**88.4** (82.8–94.1) 128	**83.8** (80.4–87.3) 432	**92.1** (88.4–95.8) 210	

Alcohol consumption also differed by cancer type. A higher proportion of prostate cancer patients (68 percent) reported having a drink in the 30 days prior to diagnosis compared with the lung (57 percent), breast (57 percent) and colorectal (45 percent) cancer patients. More lung and prostate cancer patients were classified as heavy drinkers and binge drinkers than respondents with breast cancer or colorectal cancer.

Alcohol Consumption by Cancer Type					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
At least one drink of alcohol in the past 30 days					<0.0001
Yes	**56.6** (51.0–62.1) 192	**45.4** (36.7–54.1) 78	**57.3** (47.0–67.6) 51	**68.4** (62.8–73.9) 212	
No	**43.4** (37.9–49.0) 142	**54.6** (46.0–63.3) 83	**42.7** (32.4–53.0) 43	**31.6** (26.1–37.2) 94	
Heavy drinkers					0.024
Yes	**5.0** (2.6–7.4) 17	**6.3** (2.6–10.0) 11	**13.4** (5.5–21.3) 11	**10.6** (6.8–14.4) 30	
No	**95.0** (92.6–97.4) 315	**93.7** (90.0–97.4) 150	**96.6** (78.7–94.5) 83	**89.4** (85.6–93.2) 275	
Binge drinkers					<0.0001
Yes	**7.4** (4.4–10.4) 23	**8.8** (4.4–13.1) 15	**15.5** (7.6–23.4) 13	**20.2** (15.5–25.0) 61	
No	**92.6** (89.6–95.6) 310	**91.2** (86.9–95.6) 145	**84.5** (76.6–92.4) 80	**79.8** (75.0–84.5) 242	

3.1.8. Tobacco Indicators

The questions regarding tobacco use were taken from the BRFSS. The BRFSS definitions for smoking status were used to categorize respondents as current smokers, former smokers or never smoked based on their smoking history prior to diagnosis. Current smokers were defined as individuals who had smoked at least 100 cigarettes in their lifetime and smoked every day or some days at the time of diagnosis. Former smokers were defined as individuals who had smoked at least 100 cigarettes in their lifetime and did not smoke at time of diagnosis. Individuals who had not smoked at least 100 cigarettes in their life at the time of diagnosis were classified as never having smoked. Age of smoking initiation was categorized into two groups: individuals who started smoking before age 18 and those who started smoking at age 18 or older.

Respondents were also asked questions regarding passive tobacco exposure. These questions were taken from the BRFSS and used to determine the probability of passive exposure to tobacco smoke based on the reported smoking rules in the home and at work. Respondents were categorized into four categories: possibly exposed at home, possibly exposed at work, possibly exposed at both home and work, and probably not exposed. Exposure was defined based on the reported smoking rules. If respondents reported that smoking was allowed either anywhere or in some places at home, or in public or work areas at their job, then they were classified as possibly

exposed. Respondents who reported that smoking was not allowed anywhere at home, or in public or work areas at their job, were considered probably not exposed. The passive tobacco exposure status of respondents who reported that there were no rules about smoking at home or in public or work areas at their job was considered unknown.

Overall, 19 percent of study respondents reported smoking at the time of their diagnosis, and 43 percent reported formerly smoking. Sixty-seven percent of study participants who had ever smoked started smoking before the age of 18. No differences in smoking status or age first smoked were observed at the county level.

Forty-two percent of study participants reported that smoking was not allowed at either home or work, and only five percent reported that smoking was allowed at both home and work. Twenty-six percent reported that smoking was allowed at home only, and 27 percent reported that smoking was allowed at work only. There were no reported differences by county regarding smoking rules at home or work.

Tobacco Indicators by County

	Delaware	Kent	New Castle	Sussex	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Smoking status					0.977
Smoked at diagnosis	**18.8** (16.1–21.5) 170	**20.5** (13.6–27.4) 32	**18.4** (14.8–22.0) 93	**18.7** (13.6–23.8) 45	
Formerly smoked	**42.8** (39.3–46.3) 379	**40.5** (31.8–49.3) 59	**43.3** (38.7–47.9) 220	**43.3** (36.6–50.1) 100	
Never smoked	**38.4** (34.9–41.8) 343	**39.0** (29.8–48.1) 57	**38.3** (33.9–42.8) 203	**38.0** (31.3–44.6) 83	
Age first smoked (years)					0.192
Less than 18	**67.2** (62.9–71.6) 371	**73.2** (63.6–82.7) 66	**64.1** (58.2–70.1) 205	**70.6** (63.0–78.3) 100	
18 or older	**32.8** (28.4–37.1) 176	**26.8** (17.3–36.4) 25	**35.9** (29.9–41.8) 107	**29.4** (21.7–37.0) 44	
Exposure to passive smoke					0.973
Both at home and at work	**4.7** (2.2–7.3) 15	**4.7** (0.0–10.1) 3	**5.1** (1.7–8.5) 10	**3.5** (0.0–8.6) 2	
At home only	**26.3** (21.5–31.2) 95	**30.5** (18.3–42.7) 19	**26.0** (19.8–32.2) 56	**24.1** (14.5–33.8) 20	
At work only	**26.7** (21.6–31.7) 87	**27.1** (13.8–40.5) 12	**25.7** (19.6–31.8) 55	**29.1** (17.9–40.4) 20	
No exposure	**42.3** (36.8–47.7) 151	**37.5** (24.6–50.3) 23	**43.2** (36.2–50.2) 93	**43.2** (31.5–54.9) 35	

As would be expected, a much higher proportion of lung cancer patients were smokers at the time of diagnosis or formerly smoked (93 percent) compared with patients with breast cancer (47 percent), colorectal cancer (57 percent) or prostate cancer (68 percent). Eighty-two percent of respondents with lung cancer who had ever smoked reported that they started smoking before the age of 18, compared with 73 percent of respondents with prostate cancer, 57 percent of breast cancer respondents and 55 percent of respondents with colorectal cancer. Lung cancer patients were also more likely to report that smoking was allowed at either home or work or both (86 percent).

Tobacco Indicators by Cancer Type

	Breast	Colorectal	Lung	Prostate	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Smoking status					<.0001
Smoked at diagnosis	**17.6** (13.4–21.9) 59	**10.5** (5.8–15.2) 19	**52.7** (42.2–63.1) 49	**15.3** (10.9–19.6) 45	
Formerly smoked	**29.7** (24.7–34.6) 106	**46.7** (37.9–55.6) 73	**41.8** (31.5–52.1) 40	**52.3** (46.5–58.2) 164	
Never smoked	**52.7** (47.1–58.2) 170	**42.8** (34.0–51.5) 71	**5.5** (1.2–9.8) 6	**32.4** (26.9–37.9) 98	
Age first smoked (years)					<.0001
Less than 18	**56.9** (49.0–64.7) 95	**55.2** (43.3–67.0) 53	**81.5** (73.5–89.5) 71	**72.7** (66.2–79.2) 155	
18 or older	**43.1** (35.3–51.0) 69	**44.8** (32.9–56.7) 38	**18.5** (10.5–26.5) 18	**27.2** (20.8–33.8) 54	
Exposure to passive smoke					<0.001
Both at home and at work	**3.9** (0.8–7.0) 6	**23.0** (0.0–7.1) 2	**11.0** (0.0–23.5) 3	**5.4** (0.3–10.4) 5	
At home only	**29.9** (19.7–34.1) 41	**25.8** (14.1–37.5) 15	**40.6** (23.8–57.5) 15	**21.8** (13.5–30.1) 24	
At work only	**18.8** (12.4–25.2) 29	**14.9** (5.3–24.5) 8	**34.5** (17.5–51.4) 11	**39.1** (29.2–49.1) 40	
No exposure	**50.4** (42.3–58.6) 78	**56.4** (43.2–69.6) 33	**13.9** (2.4–25.4) 5	**33.7** (24.0–43.3) 36	

3.1.9. Physical Activity

Questions about physical activity were designed to determine the respondents' level of physical activity in their leisure time and while at work. These questions were taken from the BRFSS, and SAS code from the BRFSS was used to calculate the length and duration of leisure-time activity levels. Respondents who worked at the time of their diagnosis were asked about the level of activity that their job required. They were categorized as working either at jobs where they were mostly sitting or standing or working at jobs that required walking or more physically demanding work. Three variables were created for leisure-time activity levels based on BRFSS definitions. The first variable measured whether the respondent reported participating in any type of leisure-time activities or exercise such as running, calisthenics, golf, gardening or walking for exercise. Respondents were also asked about moderate and vigorous activity levels. For moderate activity level, respondents were classified based on whether they met the requirement for doing moderate activities for at least 30 minutes, on five or more days per week. For vigorous activity level, respondents were classified based on whether they met the requirement for doing vigorous activity for at least 20 minutes, on three or more days per week.

Overall, 68 percent of study participants who worked at the time of their diagnosis reported sitting or standing at work, and 32 percent reported working at jobs that were more physically demanding. Seventy-seven percent of the study population reported doing some leisure-time physical activity or exercise. About half of study participants met the requirement for moderate activity level, and 26 percent met the requirement for vigorous activity level. The only observed difference in activity levels at the county level was for leisure-time activity. More respondents living in Sussex County at time of diagnosis (81 percent) reported participating in leisure-time activities or exercise than respondents living in New Castle County (78 percent) or Kent County (69 percent).

Physical Activity Levels by County					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Activity level at work					0.326
Sitting or standing	**67.9** (63.1–72.7) 284	**66.1** (53.8–78.3) 43	**70.4** (64.6–76.2) 191	**61.0** (49.4–72.7) 50	
Walking or more	**32.1** (27.3–36.9) 127	**33.9** (21.7–46.2) 22	**29.6** (23.8–35.4) 76	**39.0** (27.3–50.6) 29	
Leisure-time physical activity in month prior to diagnosis					0.029
Yes	**77.0** (74.0–79.9) 688	**68.7** (60.5–77.0) 102	**77.6** (73.8–81.4) 400	**81.2** (75.8–86.6) 186	
No	**23.0** (20.1–26.0) 202	**31.3** (23.0–39.5) 46	**22.4** (18.6–26.2) 115	**18.9** (13.4–24.2) 41	
Moderate activity for at least 30 minutes on five or more days per week					0.187
Yes	**52.2** (48.6–55.8) 467	**44.9** (35.8–54.0) 67	**53.3** (48.6–57.9) 273	**54.7** (47.8–61.6) 127	
No	**47.8** (44.2–51.4) 400	**55.1** (46.0–64.2) 75	**46.7** (42.1–51.4) 231	**45.3** (38.4–52.2) 94	
Vigorous activity for at least 20 minutes on three or more days per week					0.399
Yes	**26.4** (23.3–29.5) 230	**21.8** (14.8–28.8) 33	**27.2** (23.0–31.3) 134	**27.8** (21.8–33.8) 63	
No	**73.6** (70.5–76.7) 637	**78.2** (71.2–85.2) 109	**72.8** (68.7–77.0) 370	**72.2** (66.2–78.2) 158	

There were no observed differences in reported work activity levels among the four cancer types. However, the data suggest that lung cancer respondents worked in more physically demanding jobs compared with respondents with other cancers. Prostate cancer patients were the most physically active during their leisure time and were more likely to meet the recommendations for moderate and vigorous activity levels as compared with lung, breast and colorectal cancer patients.

Physical Activity Levels by Cancer Type					
	Breast	Colorectal	Lung	Prostate	
	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	P-value
Activity level at work					0.698
Sitting or standing	**70.6** (63.1–78.0) 113	**65.9** (54.5–77.3) 47	**60.8** (44.9–76.6) 26	**68.4** (60.3–76.6) 101	
Walking or more	**29.4** (22.0–36.9) 45	**34.1** (22.7–45.5) 23	**39.2** (23.4–55.1) 16	**31.6** (23.4–39.7) 44	
Leisure-time physical activity in month prior to diagnosis					<.001
Yes	**77.3** (72.5–82.1) 262	**75.6** (68.6–82.5) 120	**58.4** (48.0–68.8) 57	**81.9** (77.3–86.6) 254	
No	**22.7** (17.9–27.5) 72	**24.4** (17.5–31.4) 42	**41.6** (31.2–52.0) 38	**18.1** (13.4–22.7) 53	
Moderate activity for at least 30 minutes on five or more days per week					0.006
Yes	**47.2** (41.6–52.9) 159	**46.7** (37.8–55.6) 78	**45.7** (35.1–56.3) 42	**59.7** (53.9–65.6) 189	
No	**52.8** (47.1–58.4) 163	**53.3** (44.4–62.2) 79	**54.3** (43.7–64.9) 50	**40.4** (34.4–46.1) 115	
Vigorous activity for at least 20 minutes on three or more days per week					<.0001
Yes	**18.6** (14.4–22.8) 63	**17.3** (11.1–23.4) 29	**30.1** (20.1–40.2) 26	**36.0** (30.4–41.6) 113	
No	**81.4** (77.2–85.6)	**82.7** (76.6–88.9)	**69.9** (59.8–79.9)	**64.0** (58.4–69.6)	

3.1.10. Health Care Access

The questions about health care access were taken from the BRFSS. Respondents were asked about availability of health insurance, their usual source of care, health care utilization and satisfaction with care. Those without insurance or who had other barriers to care were asked their reasons. Usual source of care was categorized as seeking non-emergency care in a doctor's office, public health clinic or community health clinic; seeking care in a hospital or urgent care center; and other or no usual source of care. Health care utilization was categorized based on the frequency of seeking care; the three categories were: seeing a medical professional at least every six months, seeing one every seven months to a year, or seeing one less than once a year.

Overall, 98 percent of survey respondents had health insurance at time of diagnosis, so there were too few without health insurance to explore reasons for that lack. Additionally, 95 percent of the study participants (850 respondents) reported having at least one personal doctor. The 42 remaining respondents were asked their reasons for not having a personal doctor. They were read a list of reasons and given the option to answer yes to any that applied. The most common answers given were:

- Was healthy so didn't need one (35 respondents or 83 percent),
- Cost (15 respondents or 36 percent),
- No health insurance (10 respondents or 24 percent),
- Didn't believe it would help (six respondents or 14 percent), and
- Hadn't found a doctor they liked (five respondents or 12 percent).

The analysis of health care coverage by county revealed fewer respondents in Kent County (95 percent) had health insurance compared with respondents in New Castle County (99 percent) and Sussex County (97 percent). Overall 97 percent of the study population reported their usual source of care was in a doctor's office or public health or community health clinic, and 90 percent of respondents reported seeing a doctor at least once a year. There were no differences in these variables at the county level.

Health Care Access and Utilization by County					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Health care coverage					0.030
Yes	**97.6** (96.6–98.6) 869	**94.8** (91.2–98.5) 140	**98.6** (97.5–99.6) 508	**97.1** (94.9–99.3) 221	
No	**2.4** (1.4–3.5) 23	**5.2** (1.5–8.8) 8	**1.4** (0.4–2.5) 8	**2.9** (0.7–5.1) 7	
Usual source of care					0.393
Non-emergency care*	**95.6** (94.2–97.0) 854	**96.1** (93.2–99.0) 141	**96.6** (94.9–98.3) 499	**92.9** (89.1–96.6) 214	
Hospital or urgent care center	**2.4** (1.4–3.4) 22	**2.1** (0.0–4.2) 4	**2.0** (0.8–3.2) 11	**3.5** (0.9–6.2) 7	
Other or none	**2.0** (1.0–3.0) 16	**1.7** (0.0–3.8) 3	**1.4** (0.2–2.6) 6	**3.6** (0.9–6.3) 7	
Health care utilization					0.069
At least once every six months	**59.0** (55.5–62.4) 515	**67.4** (59.3–75.5) 96	**56.8** (52.3–61.4) 288	**58.2** (51.4–64.9) 131	
Once every seven months to a year	**30.5** (27.3–33.7) 274	**23.7** (16.5–30.9) 38	**30.9** (26.7–35.2) 158	**34.3** (27.9–40.8) 78	
Less than once a year	**10.5** (8.4–12.6) 95	**8.9** (4.3–13.5) 14	**12.2** (9.3–15.1) 64	**7.5** (3.9–11.0) 17	

* Includes doctor's office, public health clinic or community health center.

There were significant differences in health care access and utilization among the cancer types. Lung cancer patients were less likely to have health insurance compared with the other cancer patients. A higher percentage of colorectal cancer patients saw a doctor less than once a year (18 percent), compared with those with prostate cancer (12 percent), lung cancer (10 percent) or breast cancer (5 percent). Breast and prostate cancer patients reported non-emergency care as their usual source of care (97 and 96 percent, respectively) more often than colorectal or lung cancer patients (93 and 92 percent, respectively).

Health Care Access and Utilization by Cancer Type					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Health care coverage					0.008
Yes	**96.9** (95.0–98.9) 325	**97.5** (94.9–100.0) 159	**93.1** (88.1–98.1) 88	**99.4** (98.5–100.0) 305	
No	**3.1** (1.1–5.0) 10	**2.5** (0.0–5.1) 4	**6.9** (1.9–11.9) 7	**0.6** (0.0–1.5) 2	
Usual source of care					0.063
Non-emergency care*	**97.4** (95.6–99.1) 326	**93.0** (88.8–97.2) 152	**92.5** (87.5–97.6) 87	**96.3** (94.0–98.6) 297	
Hospital or urgent care center	**1.9** (0.4–3.4) 6	**2.4** (0.0–5.0) 4	**5.4** (1.1–9.6) 6	**2.0** (0.4–3.5) 6	
Other or none	**0.8** (0.0–1.6) 3	**4.6** (1.1–8.1) 7	**2.1** (0.0–5.0) 2	**1.7** (0.0–3.4) 4	
Health care utilization					0.003
At least once every six months	**62.3** (56.9–67.6) 205	**57.5** (48.9–66.0) 87	**62.2** (52.0–72.4) 59	**55.7** (49.9–61.6) 167	
Once every seven months to a year	**32.4** (27.2–37.6) 110	**24.6** (17.5–31.7) 41	**28.2** (18.7–37.7) 26	**32.6** (27.0–38.1) 100	
Less than once a year	**5.3** (2.8–7.8) 18	**17.9** (11.9–23.9) 32	**9.6** (3.5–15.6) 9	**11.7** (8.1–15.3) 38	

* Includes doctor's office, public health clinic or community health center.

3.1.11. Comparison of Risk Factors With the General Delaware population

In this section, the health risk factors previously described are compared for each of the four cancer types with the results from the 2002 BRFSS survey of the general Delaware population. We were not able to compare all the risk factors previously described because some were not asked on the 2002 BRFSS survey. These include four of the health conditions (heart disease, hypertension, high blood cholesterol and arthritis) and dietary fat intake.

The odds ratios presented for each risk factor are for the at-risk group compared with the not-at-risk group for individuals with cancer compared with the general Delaware population. The at-risk group for each risk factor is defined as follows:

- Health status: respondents who report having fair or poor health,
- Body mass index: respondents who are overweight and/or obese,
- Diabetes: respondents who have been told by a doctor, nurse or health professional that they had diabetes,
- Asthma: respondents who have been told by a doctor, nurse or health professional that they had asthma,
- Fruit and vegetable consumption: respondents who report they never consume fruits and vegetables or consume fewer than five servings per day,
- Alcohol consumption: respondents who report drinking alcohol in the past 30 days,
- Heavy drinkers: male respondents who report having more than two drinks per day, or female respondents who report having more than one drink per day,
- Binge drinkers: respondents who report they did drink in the past 30 days and had five or more drinks on one or more occasions in the past month,
- Smokers: respondents who report having smoked at least 100 cigarettes in their lifetime and smoked at time of diagnosis,
- Former smokers: respondents who report having smoked at least 100 cigarettes in their lifetime and did not smoke at time of diagnosis,
- Smoking initiation: respondents who report they smoked their first cigarette before the age of 18,
- Work activity: respondents who report mostly sitting or standing at their job,
- Physical activity: respondents who report doing no moderate or vigorous physical activity or exercise,
- Moderate activity: respondents who report doing insufficient moderate or vigorous physical activity to meet recommendations, or respondents who report doing no moderate or vigorous physical activity, and
- Vigorous activity: respondents who report doing insufficient vigorous physical activity to meet recommendations, or respondents who report doing no vigorous physical activity.

For each of these risk factors, the odds ratio for the at-risk group compared with the not-at-risk group is reported for individuals with cancer compared with those without cancer. The odds ratios are adjusted for five-year age group, sex, race and county of residence. An odds ratio significantly greater than one indicates respondents with cancer are more likely to be at risk compared with the general Delaware population, and an odds ratio significantly less than one indicates that respondents with cancer are less likely to be at risk. If the value of one falls outside the confidence interval, the odds ratio is significant.

Breast, colorectal and prostate cancer patients were all less likely to report being in fair or poor health prior to diagnosis compared with the Delaware population. There was no difference in reported health for lung cancer patients.

For BMI, there were no differences between any of the four cancer types and the Delaware population. With the exception of colorectal cancer patients, the data suggest cancer patients are somewhat less likely to be overweight and/or obese compared with the Delaware population.

There were no differences between the cancer population and the Delaware population regarding diabetes. The data do suggest cancer patients are somewhat less likely to have diabetes than the general Delaware population.

Breast cancer patients were almost half as likely to have asthma when compared with the Delaware population. For colorectal, prostate and lung cancer, there were no differences, although the data suggest lung cancer patients were somewhat more likely to have asthma than the general Delaware population.

The consumption of fruits and vegetables less than five times a day does not appear to be a significant risk factor for the cancer population, although the data show cancer patients are slightly more likely to eat less than five servings a day compared with the Delaware population.

Several differences were observed for alcohol consumption. Breast cancer patients were one and a half times more likely and prostate cancer patients were almost two times more likely to report having had a drink in the past 30 days compared with the Delaware population. Lung cancer patients were three times more likely to be heavy drinkers, and prostate cancer patients were two times more likely to be heavy drinkers compared with the Delaware population. Breast cancer patients were 2.7 times more likely, lung cancer patients were 2.4 times more likely and prostate cancer patients were twice as likely to report binge drinking compared with the Delaware population. The risk for binge drinking for colorectal cancer patients was elevated but not significant.

Lung cancer patients were 27 times more likely to smoke at the time of their diagnosis and more than seven times more likely to formerly smoke compared with the Delaware population. They were almost twice as likely to begin smoking before the age of 18. For the other cancers, current or former smoking status was not a significant risk factor. Breast and colorectal cancer patients were about half as likely to report that they began smoking before the age of 18, compared with the Delaware population.

In general, the activity levels of the cancer population before diagnosis are higher than that of the general Delaware population, with the exception of work activity levels. Work activity level is not significantly different for any of the four cancers, but the data suggest colorectal and prostate cancer patients are somewhat more likely to report mostly sitting and standing at work compared with the Delaware population, and breast and lung cancer patients are somewhat less likely to report sitting or standing at work.

Breast, colorectal and prostate cancer patients are about three times more likely to report being physically active or exercising compared with the Delaware population and are also more likely to meet the requirements for moderate physical activity levels. Breast and prostate cancer respondents are also more likely to meet the requirements for vigorous activity levels. Lung cancer patients show no differences for any physical activity or moderate physical activity but are more than twice as likely to meet the requirements for vigorous activity levels.

Risk Factor Comparisons With the General Delaware Population				
	Breast	**Colorectal**	**Lung**	**Prostate**
	Odds Ratio (CI)	**Odds Ratio** (CI)	**Odds Ratio** (CI)	**Odds Ratio** (CI)
Health status **Fair or poor versus good or better**	**0.23** (0.14–0.38)	**0.32** (0.18–0.58)	**0.82** (0.45–1.47)	**0.18** (0.10–0.33)
BMI **Overweight and/or obese versus neither overweight nor obese**	**0.85** (0.65–1.11)	**1.12** (0.76–1.65)	**0.92** (0.57–1.48)	**0.77** (0.52–1.12)
Diabetes **Yes versus no**	**0.97** (0.62–1.52)	**0.87** (0.51–1.49)	**0.93** (0.47–1.84)	**0.62** (0.39–1.00)
Asthma **Yes versus no**	**0.63** (0.41–0.96)	**0.47** (0.22–1.00)	**1.50** (0.79–2.84)	**0.50** (0.24–1.03)
Fruit and vegetable consumption **Less than five or more times per day versus five or more times per day**	**1.01** (0.75–1.36)	**1.20** (0.71–2.05)	**1.40** (0.77–2.54)	**1.09** (0.71–1.67)
At least one drink of alcohol in the past 30 days **Yes versus no**	**1.58** (1.20–2.08)	**0.89** (0.62–1.28)	**1.36** (0.86–2.16)	**1.92** (1.31–2.80)
Heavy drinker **Yes versus no**	**1.33** (0.74–2.39)	**1.45** (0.73–2.90)	**2.98** (1.41–6.33)	**2.06** (1.13–3.77)
Binge drinker **Yes versus no**	**2.68** (1.54–4.69)	**1.38** (0.69–2.77)	**2.43** (1.15–5.14)	**2.00** (1.19–3.35)
Smoked at diagnosis **Yes versus never smoked**	**0.93** (0.65–1.34)	**0.69** (0.37–1.20)	**27.40** (11.30–66.51)	**0.83** (0.48–1.43)
Formerly smoked **Yes versus never smoked**	**0.92** (0.69–1.23)	**1.11** (0.73–1.69)	**7.22** (3.00–17.40)	**0.90** (0.62–1.30)
Age first smoked (years) **Less than 18 versus 18 or older**	**0.66** (0.44–0.97)	**0.52** (0.32–0.85)	**1.92** (1.09–3.38)	**1.02** (0.61–1.71)
Activity level at work **Sitting or standing versus walking or more physically demanding**	**0.93** (0.60–1.45)	**1.11** (0.63–1.97)	**0.68** (0.33–1.39)	**1.29** (0.72–2.30)
Physical activity **None versus any**	**0.26** (0.14–0.48)	**0.34** (0.16–0.71)	**0.70** (0.34–1.44)	**0.30** (0.15–0.62)
Moderate activity for at least 30 minutes on five or more days per week **No versus yes**	**0.71** (0.55–0.93)	**0.67** (0.46–0.96)	**0.78** (0.49–1.22)	**0.37** (0.25–0.53)
Vigorous activity for at least 20 minutes on three or more days per week **No versus yes**	**0.64** (0.45–0.90)	**0.76** (0.47–1.24)	**0.43** (0.25–0.73)	**0.37** (0.25–0.55)

3.2. Cancer-Specific Attributes

The previous sections describe the results of general questions all study respondents were asked. The sections below present the results of the cancer site-specific questions. In particular, results are presented from questions about specific cancer risk factors and cancer-specific screening usage.

3.2.1. Breast Cancer

This section of the report outlines the questions included in the breast cancer module and displays the summarized information. There were 335 respondents with breast cancer; for some of the variables the total will be less due to missing values from respondents not knowing the answer to a question or choosing not to answer it.

Exposure to estrogen is associated with breast cancer risk. Therefore, many reproductive events in a woman's life have been shown to affect her risk of breast cancer. A reproductive risk variable was created that counts the number of reproductive risk factors a woman has.[14] This variable included the following risk factors:

- Never pregnant or a first pregnancy after age 35,
- Never breast fed,
- Took hormone replacement therapy for more than five years,
- Reached menarche before age 12, and
- Reached menopause after age 55.

A second variable of other non-reproductive risk factors for breast cancer was created. This variable counted the number of other breast cancer risk factors a respondent had:

- Took diethylstilbestrol,
- Received radiation to the chest,
- History of abnormal breast biopsies, and
- Previous diagnosis of breast cancer.

Family history of breast cancer was examined by adding up the number of close family relatives who were diagnosed with breast cancer. Close family relatives include grandmothers, mother, aunts, sisters and daughters.

Overall, 21 percent of respondents did not have any reproductive risk factors for breast cancer. The data suggest more women in Sussex County have reproductive risk factors than in Kent County and New Castle County. A majority of the participants had one or two reproductive risk factors; none of the participants had all five. The most common risk factors were never having breast fed (149 women) and taking hormone replacement therapy for more than five years (91 women).

The non-reproductive risk factors were rarely present; 75 percent of the survey population had none of these risk factors. This prevalence did not differ by county of residence. Of the risk

factors included in this variable, the most common risk factor was a history of an abnormal breast biopsy (62 women).

Overall, 66 percent of the study population did not have an immediate family member with breast cancer, and there was no evidence of a difference by county of residence. Mothers and aunts were the most commonly reported family member with breast cancer (40 and 45 women, respectively).

Breast Cancer Risk Factors

	Delaware	Kent	New Castle	Sussex	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Number of reproductive risk factors					0.19
0	**20.9** (16.2–25.5) 65	**22.4** (11.6–33.3) 13	**22.4** (15.9–28.9) 38	**16.7** (8.3–25.2) 14	
1	**35.8** (30.3–41.3) 114	**28.0** (16.2–39.9) 16	**37.6** (30.0–45.2) 63	**37.1** (26.8–47.3) 35	
2	**28.2** (23.1–33.2) 92	**31.9** (19.9–44.0) 19	**29.7** (22.7–36.7) 53	**22.8** (13.5–32.0) 20	
3	**12.5** (8.7–16.2) 42	**12.9** (4.4–21.3) 8	**8.9** (4.5–13.2) 16	**19.4** (10.8–28.0) 18	
4	**2.7** (1.0–4.4) 10	**S**	**S**	**S**	
Number of other breast cancer risk factors					0.54
0	**75.1** (70.2–79.9) 240	**68.9** (57.3–80.5) 41	**76.3** (69.7–83.0) 132	**76.5** (67.6–85.3) 67	
1	**17.2** (13.1–21.3) 60	**24.9** (14.1–35.7) 16	**15.3** (10.0–20.6) 29	**16.1** (8.3–23.8) 15	
2+	**7.7** (4.6–10.9) 24	**S**	**8.4** (3.6–13.2) 12	**7.5** (2.4–12.5) 8	
Number of immediate family members diagnosed with breast cancer					0.72
0	**65.7** (60.5–71.0) 219	**63.8** (51.5–76.0) 39	**65.7** (58.5–72.9) 118	**67.1** (57.2–76.9) 62	
1	**26.2** (21.3–31.1) 88	**29.6** (18.0–41.2) 18	**27.1** (20.3–34.0) 48	**22.2** (13.6–30.7) 22	
2+	**8.1** (5.1–11.0) 28	**S**	**7.2** (3.5–10.9) 14	**10.7** (4.1–17.4) 10	

S = suppressed.

Respondents with breast cancer were asked about their history of screening for breast cancer by mammography, clinical breast exams and breast self-exams. For each of the three tests the following was determined:

- The percentage of women who ever received or performed the test, and
- The percentage of women who followed the current recommendations regarding the age to begin testing and the frequency of testing.[15]

For mammography, a woman was considered to have followed recommendations if she received her first mammogram before age 50 and reported receiving at least a yearly mammogram afterward. Currently, women are recommended to have a mammogram beginning at age 40, but many of the study respondents were in their 40s before this recommendation was enacted, so we used the previous recommendation of receiving a first mammogram beginning at age 50. For clinical breast exams, the recommendation is to receive annual exams, and for self-exams, the recommendation is for monthly exams.

Overall, the usage of breast cancer screening tests is very high. Of the respondents in this study, 93 percent have received a mammogram, 90 percent have received a clinical breast exam and 85 percent have performed a breast self-exam. There were 25 women who had never received a mammogram. Of these, nine women were younger than 40 when they were diagnosed with breast cancer, so they were not eligible for mammography.

A majority of women (58 percent) began receiving mammography at the recommended age and are receiving the tests yearly. For the remaining 42 percent of women who did not meet this criterion, the majority did not meet the age-at-first-mammogram criterion.

The question about the average frequency of mammography was compared with the data from the question regarding the last screening mammogram before diagnosis. Of the 284 women who reported they generally have a mammogram every year or more than once a year, 161 reported that their last screening mammogram was less than 12 months ago, 101 women reported it was more than one year but less than two years before diagnosis and the remainder reported it had been more than two years.

Annual clinical breast exams were reported by 85 percent of the population. Again, the frequency of screening was compared with last screening before diagnosis, and for clinical breast exams 279 respondents reported receiving a clinical breast exam at least once a year, 186 reported a clinical breast exam in the 12 months before diagnosis, 77 reported a test more than one year but less than two years before diagnosis and the remaining respondents reported it had been more than two years since their last clinical breast exam before diagnosis.

Monthly breast exams were reported by 56 percent of the population.

There were no county differences in mammography usage or performance of self-exams, but the data suggest lower receipt of annual clinical breast exams in Kent County compared with New Castle County or Sussex County.

Breast Cancer Screening Tests					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Ever received a mammogram					0.82
Yes	**92.6** (89.7–95.5) 310	**91.7** (84.7–98.7) 56	**92.1** (88.0–96.2) 166	**94.0** (89.2–98.7) 88	
No	**7.4** (4.5–10.3) 25	**S**	**7.9** (3.8–12.0) 14	**6.0** (1.3–10.8) 6	
Received an annual mammogram beginning before age 50					0.52
Yes	**59.0** (53.5–64.5) 196	**53.6** (40.9–66.3) 32	**58.5** (51.0–66.1) 105	**63.1** (52.8–73.5) 59	
No	**41.0** (35.5–46.5) 137	**46.4** (33.7–59.1) 29	**41.5** (33.9–49.0) 74	**36.9** (26.5–47.2) 34	
Ever received a clinical breast exam					0.49
Yes	**89.5** (86.0–92.9) 300	**85.2** (76.2–94.2) 52	**90.8** (86.1–95.5) 165	**89.4** (83.3–95.4) 83	
No	**10.5** (7.1–14.0) 35	**14.8** (5.8–23.8) 9	**9.2** (4.5–13.9) 15	**10.6** (4.6–16.7) 11	
Received a annual clinical breast exam					0.07
Yes	**84.9** (80.9–88.9) 279	**75.0** (64.0–86.1) 46	**87.7** (82.5–93.0) 156	**85.3** (78.3–92.4) 77	
No	**15.1** (11.1–19.1) 51	**25.0** (13.9–36.0) 15	**12.3** (7.0–17.5) 21	**14.7** (7.6–21.7) 15	
Ever performed a breast self-exam					0.69
Yes	**81.5** (77.1–86.0) 273	**77.3** (66.3–88.4) 48	**82.2** (76.1–88.3) 149	**82.7** (74.6–90.7) 76	
No	**18.5** (14.0–22.9) 59	**22.7** (11.6–33.7) 13	**17.8** (11.7–23.9) 30	**17.3** (9.3–25.4) 16	
Performed a breast self-exam monthly					0.45
Yes	**55.9** (50.4–61.5) 188	**48.2** (35.5–61.0) 30	**57.2** (49.6–64.8) 103	**58.0** (47.5–68.5) 55	
No	**44.1** (38.5–49.6) 147	**51.8** (39.0–64.5) 31	**42.8** (35.2–50.4) 77	**42.0** (31.5–52.5) 39	

S = suppressed.

The women in our study population were compared with the general Delaware population using data from the BRFSS. The BRFSS does not collect information about breast self-exams. Therefore, the table below examines the percentages of women who reported having a mammogram or a clinical breast exam within the past two years. The past two years is defined based on the date of interview for the BRFSS population, and on the date of diagnosis in our cancer population. Our screening definitions were modified from above to allow comparisons with the BRFSS data. The data on mammograms are restricted to women aged 40 and older. Even with this restriction, the age distribution of the general population and the cancer population differ substantially, so the age-adjusted prevalence in our population and the general population are presented. In addition, an odds ratio and 95-percent confidence interval are displayed. The odds ratios have been adjusted for five-year age groups, race and county of residence. For each test we are comparing the percentage of women in the cancer population who have not received the screening test within the past two years with the percentage in the general population who have not received the test in the past two years. The reference group for the odds ratio is women who received a screening test. Therefore, odds ratios greater than one indicate women in the cancer population were less likely to have received a screening test than women in the general population, while odds ratios less than one indicate women in the cancer population were more likely to receive a screening test than women in the general population.

There were no differences in the percentage of women with breast cancer compared with the general female Delaware population regarding the likelihood of receiving a mammogram. However, women with breast cancer were 16 percent more likely to have not received a clinical breast exam in the past two years compared with the general Delaware population.

Breast Cancer Screening Test Comparisons With the General Delaware Population

	Cancer Population	General Delaware Population	
	Percentage (CI) N	**Percentage** (CI) N	**Odds Ratio** (CI)
Received a mammogram in past two years			
Yes	**82.5** (77.3–88.5) 268	**83.5** (82.9–84.0) 1,349	Reference
No	**17.5** (8.2–31.8) 51	**16.5** (15.3–17.8) 273	1.09 (0.75–1.60)
Received a clinical breast exam in past two years			
Yes	**83.1** (76.5–90.4) 273	**84.7** (84.3–85.1) 2,043	Reference
No	**16.9** (6.0–35.6) 62	**15.2** (14.3–16.2) 273	1.16 (1.04–1.30)

3.2.2. Colorectal Cancer

Survey respondents with colorectal cancer were asked questions about specific risk factors for colorectal cancer, family history of colorectal cancer and usage of colorectal cancer screening tests. There were 163 respondents with colorectal cancer; some variables may have fewer numbers due to missing values.

The non-behavioral risk factors for colorectal cancer were added together to create a summary variable. The factors were:

- Previous diagnosis of colorectal cancer,
- History of intestinal polyps, and
- History of chronic inflammatory bowel disease.

A family history of colorectal cancer includes a diagnosis of colorectal cancer in the respondent's grandparents, parents, siblings and children.

The colorectal cancer-specific risk factors were rare in this population, with 79 percent of the total survey respondents having none of the risk factors. None of the respondents had all three risk factors. The most common risk factor was intestinal polyps (20 respondents).

Overall, 79 percent of the study respondents did not have any immediate family members who were diagnosed with colorectal cancer. Parents were the most commonly reported family members with colorectal cancer (19 respondents).

The data suggest respondents in Sussex County were least likely to have a colorectal cancer risk factor but most likely to have a family history of colorectal cancer compared with respondents in other counties.

Colorectal Cancer Risk Factors					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Number of colorectal cancer risk factors					0.39
0	**78.8** (70.5–87.1) 134	**71.1** (48.0–94.3) 27	**78.5** (68.8–88.2) 71	**87.4** (76.4–98.4) 36	
1+	**21.2** (12.9–29.5) 29	**28.9** (5.7– 52.0) 7	**21.5** (11.8–31.2) 17	**S**	
Number of immediate family members diagnosed with colorectal cancer					0.28
0	**78.8** (71.9–85.7) 126	**77.3** (61.2–93.4) 25	**83.4** (74.9–91.9) 73	**69.5** (54.5–84.4) 28	
1	**17.6** (11.2–24.0) 28	**20.7** (5.0–36.4) 7	**13.8** (6.1–21.4) 12	**23.4** (9.4–37.4) 9	
2+	**3.6** (0.6–6.5) 6	**S**	**S**	**S**	

S = suppressed.

Survey respondents were asked about two screening tests for colorectal cancer:

- Fecal occult blood test, and
- Sigmoidoscopy/colonoscopy.

For each test, the proportion of respondents who had never received the test was calculated, and the proportion of respondents who followed the recommendation regarding age to begin screening and frequency of screening was calculated.[16] Respondents were considered to have met the criteria for following the recommendations for a fecal occult blood test if they indicated they received their first test by age 55 and were screened every year afterward. For sigmoidoscopy and colonoscopy we will consider respondents to have met the screening requirements if they received one of these procedures beginning before age 55 and at least every five years afterward.

Overall, the use of colorectal cancer screening tests is lower than breast cancer, with 36 percent of the population having ever received a fecal occult blood test and 54 percent having ever received a sigmoidoscopy or colonoscopy. Only 19 of the respondents with colorectal cancer were diagnosed before age 50, so the low rate of screening is not due to ineligibility. Overall, 10 percent of the study respondents followed guidelines for the fecal occult blood test and 18 percent for sigmoidoscopy. Study respondents in Sussex County were less likely to have received a sigmoidoscopy. The data suggest residents of Sussex County were least likely to have ever received a fecal occult blood test; however, among those who have ever received the test, Sussex County residents may be most likely to receive annual screening compared with respondents in the other counties.

Colorectal Cancer Screening Tests					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Ever received a fecal occult blood test					0.20
Yes	**35.6** (26.8–44.4) 56	**48.7** (27.2–70.1) 13	**33.0** (22.3–43.6) 31	**28.3** (14.1–42.5) 12	
No	**64.4** (55.6–73.2) 105	**51.3** (29.9–72.8) 20	**67.0** (56.4–77.7) 57	**71.7** (57.5–85.9) 28	
Received an annual fecal occult blood test beginning before age 55					0.87
Yes	**9.9** (5.0–14.7) 17	**S**	**10.3** (3.9–16.7) 10	**S**	
No	**90.1** (85.3–95.0) 143	**92.5** (81.4–100.0) 31	**89.7** (83.3–96.1) 77	**88.8** (79.2–98.3) 35	
Ever received a sigmoidoscopy or colonoscopy					0.03
Yes	**54.5** (45.8–63.2) 82	**54.2** (34.0–74.4) 16	**63.4** (52.5–74.2) 52	**34.1** (18.8–49.4) 14	
No	**45.5** (36.8–54.2) 80	**45.8** (25.6–66.0) 18	**36.6** (25.8–47.5) 36	**65.9** (50.6–81.2) 26	
Received a sigmoidoscopy or colonoscopy ever five years beginning before age 55					0.10
Yes	**18.1** (11.7–24.4) 30	**S**	**24.4** (14.8–34.0) 22	**S**	
No	**81.9** (75.6–88.3) 130	**86.9** (74.4–99.4) 29	**75.6** (66.0–85.2) 65	**91.7** (82.6–100.0) 36	

S = suppressed.

The screening history of the study respondents with colorectal cancer was compared with the general population using the BRFSS data. To compare our data with the BRFSS data, the percentage of respondents who had received a fecal occult blood stool test in the past two years and the percentage who had ever received a sigmoidoscopy or colonoscopy were examined. The BRFSS asks respondents only aged 50 and older whether they received screening for colorectal cancer. Therefore, to be able to compare our data on cancer patients with the BRFSS data we restricted our data to colorectal patients who were at least 50 years old at diagnosis. The percentages reported are age-adjusted to address the differences in age in the cancer and general populations. The odds ratios are adjusted for five-year age group, sex, race and county of residence and examine the odds of not being screened in the cancer population as compared with the general population. The reference group for the odds ratio is respondents who received a

screening test. Therefore, odds ratios greater than one indicate respondents in the cancer population were less likely to have received a screening test than respondents in the general population, while odds ratios less than one indicate respondents in the cancer population were more likely to receive a screening test than respondents in the general population.

Respondents with colorectal cancer were two and a half times less likely to have received a fecal occult blood stool test in the two years before diagnosis, compared with the general Delaware population. There is no difference in receipt of a sigmoidoscopy or colonoscopy.

Colorectal Cancer Screening Test Comparisons With the General Delaware Population

	Cancer Population	General Delaware Population	
	Percentage (CI) N	**Percentage** (CI) N	**Odds Ratio** (CI)
Had a fecal occult blood test in the past two years			
Yes	**18.3** (4.3–43.4) 27	**33.1** (32.3–33.9) 654	Reference
No	**81.7** (74.0–92.5) 115	**66.9** (66.4–67.4) 1,204	2.46 (1.39–4.33)
Ever had a sigmoidoscopy			
Yes	**54.8** (44.9–66.4) 80	**57.2** (56.7–57.8) 1,047	Reference
No	**45.2** (35.6–58.7) 63	**42.8** (42.1–43.4) 827	0.99 (0.65–1.52)

3.2.3. Prostate Cancer

There were no risk factors that are specific for prostate cancer, so survey respondents with prostate cancer were asked about family history and usage of screening tests. There were 307 men with prostate cancer in the survey; variables with less than this number are due to missing values.

A family history of prostate cancer was determined based on the number of immediate family members who were diagnosed with prostate cancer. This includes grandfathers, father, uncles and brothers.

Overall, 71 percent of participants did not have any family members who had been diagnosed with prostate cancer. The data suggest respondents in Sussex County were less likely to report a family history than respondents in Kent or New Castle counties. Of the men who reported a family history, the most commonly reported relative with prostate cancer was a father (43 men).

Prostate Cancer Risk Factors					
	Delaware	Kent	New Castle	Sussex	
	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	P-value
Number of immediate family members diagnosed with prostate cancer					0.16
0	70.6 (65.1–76.2) 215	64.6 (48.1–81.2) 28	68.8 (62.0–75.6) 136	81.4 (70.8–92.0) 51	
1	25.3 (19.9–30.7) 72	33.3 (16.7–49.8) 11	26.0 (19.4–32.5) 51	17.1 (6.7–27.4) 10	
2+	4.1 (0.0–6.1) 14	S	5.2 (2.7–8.4) 12	S	

S = suppressed.

There are two screening tests available for prostate cancer: the prostate-specific antigen test and digital rectal exams. The efficacy of these screening tests for prostate cancer has not been definitively established.[17] For each of the two tests, the proportion of men who had ever received the test and the proportion who reported an annual test beginning before age 55 were calculated.

Study respondents commonly received both prostate-specific antigen tests and digital rectal exams. Before their prostate cancer diagnosis, 82 percent of men had received a prostate-specific antigen test, and 93 percent of men had received a digital rectal exam. However, a smaller proportion of men reported receiving annual prostate-specific antigen tests and digital rectal exams (32 and 42 percent, respectively). There is no evidence that the use of prostate cancer screening tests differs by county of residence.

Prostate Cancer Screening Tests					
	Delaware	**Kent**	**New Castle**	**Sussex**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Ever received a prostate-specific antigen test					0.68
Yes	**81.6** (77.0–86.2) 251	**76.8** (62.5–91.0) 31	**82.0** (76.4–87.6) 168	**83.6** (74.2–93.0) 52	
No	**18.4** (13.8–23.0) 55	**23.2** (9.0–37.5) 9	**18.0** (12.4–23.6) 36	**16.4** (7.0–25.8) 10	
Received an annual prostate-specific antigen beginning before age 55					0.96
Yes	**31.8** (26.3–37.2) 101	**33.5** (18.0–49.0) 14	**31.6** (24.9–38.3) 68	**31.0** (18.9–43.1) 19	
No	**68.2** (62.8–73.7) 202	**66.5** (51.0–82.0) 25	**68.4** (61.7–75.1) 134	**69.0** (56.9–81.1) 43	
Ever received a digital rectal exam					0.25
Yes	**93.3** (90.4–96.2) 284	**98.1** (94.4–100.0) 38	**91.8** (87.9–95.8) 187	**95.0** (89.3–100.0) 59	
No	**6.7** (3.8–9.6) 21	**S**	**8.2** (4.2–12.1) 17	**S**	
Received an annual digital rectal exam beginning before age 55					0.49
Yes	**42.2** (36.1–48.2) 122	**44.1** (27.0–61.2) 17	**39.8** (32.5–47.1) 77	**49.1** (35.9–62.4) 28	
No	**57.8** (51.8–63.9) 164	**55.9** (38.8–73.0) 19	**60.2** (52.9–67.5) 115	**50.9** (37.6–64.1) 30	

S = suppressed.

The use of prostate cancer screening tests in the study population was compared with the general population. Men who indicated during the BRFSS interview that they had been diagnosed with prostate cancer were excluded from this analysis. In addition, the BRFSS asks only men aged 40 and older the prostate cancer screening questions, so our study population was restricted to men aged 40 and older. To compare our data with the BRFSS data, the percentages of men who had received a prostate-specific antigen test or digital rectal exam in the past two years were calculated. The odds ratios are adjusted for five-year age group, race and county of residence and examine the odds of not being screened in the cancer population as compared with the general population. The reference group for the odds ratio is men who received a screening test. Odds ratios greater than one indicate respondents in the cancer population were less likely to have received a screening test than respondents in the general population, while odds ratios less than

one indicate respondents in the cancer population were more likely to receive a screening test than respondents in the general population.

There was no difference in ever having received a prostate-specific antigen test comparing the study population with the general Delaware population; however, after adjusting for confounders, the study respondents with prostate cancer were more than twice as likely to have received a digital rectal exam than the general population (odds ratio 0.42).

Prostate Cancer Screening Test Comparisons With the General Delaware Population

	Cancer Population	General Delaware Population	
	Percentage (CI) N	**Percentage** (CI) N	**Odds Ratio** (CI)
Had a prostate-specific antigen in the past two years			
Yes	**55.0** (48.4–62.6) 226	**58.6** (57.9–59.3) 616	Reference
No	**45.0** (34.5–58.2) 80	**41.4** (40.4–42.5) 392	1.10 (0.74–1.64)
Had a digital rectal exam in the past two years			
Yes	**58.3** (51.8–65.9) 237	**48.3** (47.6–49.1) 530	Reference
No	**41.7** (29.2–58.2) 68	**51.7** (50.9–52.4) 516	0.42 (0.29–0.61)

3.2.4. Lung Cancer

This section of the report outlines the questions included in the lung cancer module and displays the summarized information. There were 95 respondents with lung cancer; for some variables, the total will be less due to missing values. Currently, there is no population-based screening test for lung cancer, so screening usage was not included in the lung cancer module.

The number of non-behavioral lung cancer-specific risk factors was calculated for each respondent with lung cancer. The risk factors included in this variable are:

- Prior diagnosis of lung cancer,
- Prior diagnosis of tuberculosis,
- History of radiation to the chest, and
- Lived in a home with high radon levels.

A family history of lung cancer was determined by adding the number of immediate relatives who had been diagnosed with lung cancer. Eligible relatives were grandparents, parents and siblings.

Among the respondents with lung cancer, 88 percent reported no non-behavioral lung cancer risk factors. There was no difference in the prevalence of lung cancer risk factors by county of residence. The most commonly reported risk factor was radiation to the chest (seven respondents). None of the respondents who have tested their homes for radon (19 respondents) reported high levels of radon.

In this population, 75 percent of the respondents had no family history of lung cancer, and the maximum number of relatives with lung cancer was two. The most commonly reported relative with lung cancer was a father (10 respondents).

Lung Cancer Risk Factors

	Delaware	Kent	New Castle	Sussex	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Number of lung cancer risk factors					0.57
0	**88.3** (81.5–95.2) 84	**79.6** (53.7–100.0) 12	**89.2** (80.7–97.7) 45	**90.7** (80.5–100.0) 27	
1+	**11.7** (4.8–18.5) 11	**S**	**10.8** (2.3–19.3) 6	**S**	
Number of immediate family members diagnosed with lung cancer					0.41
0	**75.1** (66.1–84.0) 67	**85.4** (66.3–100.0) 11	**70.0** (56.9–83.1) 34	**79.4** (65.0–93.8) 22	
1+	**24.9** (16.0–33.9) 25	**S**	**30.0** (16.9–43.1) 16	**20.6** (6.2–35.0) 7	

S = suppressed.

There is evidence that occupational exposure to carcinogens may be a risk factor for lung cancer. Respondents were asked whether they had any occupational exposure to a list of 20 occupational chemicals, which included: solvents; asbestos; mineral or mining dust; silica/sand and mineral dust; gasoline, diesel fuel and engine exhaust fumes; welding fumes; electroplating fumes; ether (chloromethyl and/or bischloromethyl); pesticides; arsenic; nickel; cadmium; radon; plutonium; uranium; vinyl chloride; nickel chromates; coal; mustard gas; and formaldehyde. The proportion of respondents who were exposed to any of the chemicals was calculated, as well as the number of chemicals to which a respondent was exposed.

Overall, 60 percent of respondents with lung cancer were exposed to at least one of the potential lung carcinogens while they were employed. The data suggest respondents in Sussex County were most likely to be exposed, and respondents in Kent County were least likely to be exposed.

The top three most commonly reported exposures were solvents, asbestos and gasoline, and diesel and engine exhaust fumes (33, 24 and 24 respondents, respectively). None of the respondents were exposed to radon, plutonium, nickel chromates or mustard gas.

Occupational Lung Cancer Risk Factors

	Delaware	Kent	New Castle	Sussex	
	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	Percentage (CI) N	P-value
Occupational exposure to potential lung carcinogens					0.53
Yes	**60.1** (49.8–70.5) 55	**49.7** (22.1–77.2) 7	**58.5** (44.4–72.6) 28	**67.4** (49.7–85.1) 20	
No	**39.9** (29.5–50.2) 40	**50.3** (22.8–77.9) 7	**41.5** (27.4–55.6) 23	**32.6** (14.9–50.3) 10	
Number of chemicals with occupational exposure					NA
0	**39.9** (29.5–50.2) 40	**50.3** (22.8–77.9) 7	**41.5** (27.4–55.6) 23	**32.6** (14.9–50.3) 10	
1	**17.7** (9.6–25.8) 17	**S**	**17.1** (6.5–27.7) 9	**26.4** (9.5–43.4) 8	
2	**10.3** (4.0–16.6) 10	**S**	**S**	**S**	
3+	**32.2** (21.9–42.4) 28	**43.4** (16.2–70.5) 6	**31.2** (16.9–45.4) 14	**28.8** (11.3–46.3) 8	

S = suppressed.

3.2.5. Diagnosis and Treatment

This section displays the results from the data provided by the respondents regarding their cancer diagnosis process and their decision process regarding treatment and the treatment they received. These questions were used in the Maryland Department of Health and Mental Hygiene's *Look Back Study of Invasive Cervical Cancer & Late Stage Breast Cancer* and were adapted for this interview.

3.2.5.1. Cancer Diagnosis

Respondents were asked to report how their cancer was detected: by a screening test; by experiencing a symptom, including a lump that caused them to seek medical attention; or by a physician during an unrelated visit or procedure; or the respondent was allowed to provide another response. For the most part, the responses given were recoded into the available categories. A number of respondents indicated their cancer was found through a diagnostic test;

however, from the information they provided, the indication for the test could not be determined, so they were coded as unknown.

Respondents were asked the specialty of the physician who diagnosed their cancer. This variable was categorized as: 1) a primary care physician, which included gynecologists, 2) oncology specialists, which included surgeons and radiologists and 3) non-oncology specialists, which included urologists, gastroenterologists, proctologists and pulmonologists.

The time from detection to diagnosis was measured from the time that respondents experienced a symptom, had a positive screening test or had a suspicious clinical finding until they were told they had cancer. The time from detection to diagnosis was categorized as less than one month, one to three months and more than three months.[18]

All three of the variables that examined cancer detection differed by cancer type. The majority of breast cancer was found by a screening test, but 41 percent of respondents reported a symptom. Of the women who reported that their cancer was found by a symptom, 67 percent reported having a normal mammogram within a year of diagnosis, and 23 percent reported having a mammogram within two years of diagnosis. Half of the respondents with colorectal cancer reported that a symptom led to their cancer diagnosis. The majority of prostate cancers were detected by a screening test. Lung cancer was more likely to have been found by a physician than the other cancers. Currently, the data do not support reducing lung cancer mortality by population-based screening. However, both chest x-rays and sputum cytology can be used to detect lung cancer in asymptomatic patients, which is why 28 percent of the lung cancer patients reported that their cancer was detected by a screening test.[19]

Primary care physicians were most likely to diagnose lung cancer, oncologists were most likely to diagnose breast cancer and non-oncology specialists were most likely to diagnose colorectal and prostate cancer (gastroenterologists and urologists, respectively).

Overall, about 60 percent of the respondents had less than one month between detecting their cancer and receiving a diagnosis. The data suggest that on average women with breast cancer had the shortest time from detection to diagnosis. Of the respondents with less than one-month between cancer detection and diagnosis, 75 percent were respondents whose cancer was detected by a physician or a screening test. Of the respondents with more than three months between cancer detection and diagnosis, 69 percent were respondents whose cancer was detected by a symptom.

Cancer Diagnosis					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Method of cancer detection					<0.0001
Screening test	**52.5** (46.9–58.1) 180	**39.0** (29.9–48.1) 58	**28.0** (18.7–37.4) 26	**61.7** (55.9–67.5) 192	
Physician detected	**6.5** (3.7–9.3) 21	**8.5** (4.2–12.8) 15	**24.0** (14.9–33.0) 22	**14.7** (10.6–18.8) 40	
Symptom	**40.7** (35.2–46.2) 133	**51.6** (42.7–60.4) 88	**41.6** (31.3–52.0) 40	**17.5** (12.9–22.1) 52	
Unknown	**S**	**S**	**S**	**6.1** (3.0–9.3) 16	
Type of doctor who diagnosed their cancer					<0.0001
Primary care physician	**13.8** (9.9–17.6) 46	**14.5** (8.8–20.2) 25	**36.3** (26.2–46.5) 33	**9.3** (5.7–12.9) 27	
Non-oncology specialist	**2.2** (0.6–3.9) 7	**53.0** (44.0–62.0) 78	**24.6** (15.2–34.1) 22	**85.0** (80.6–89.5) 260	
Oncology specialist	**84.0** (79.9–88.1) 275	**32.5** (24.4–40.6) 51	**39.0** (28.8–49.3) 38	**5.6** (2.7–8.5) 15	
Time from cancer detection to diagnosis					<0.0001
Less than or equal to 30 days	**77.0** (72.4–81.7) 255	**68.1** (60.2–76.0) 105	**59.3** (48.8–66.1) 56	**60.4** (54.6–66.1) 179	
31–90 days	**14.5** (10.7–18.4) 50	**9.5** (4.6–14.4) 15	**25.5** (16.2–34.9) 24	**20.2** (15.5–25.0) 62	
91+ days	**8.5** (5.3–11.6) 28	**22.4** (15.6–29.2) 38	**15.2** (7.2–23.1) 13	**19.4** (14.8–24.0) 59	

S = suppressed.

3.2.5.2. Cancer Treatment

Cancer treatment was examined by asking the respondents to recall whether specific treatment modalities had been recommended and received. The treatment modalities were surgery, radiation therapy, chemotherapy and hormone therapy for breast and prostate cancer respondents.

Time from diagnosis to treatment was measured from the time respondents were told they had cancer until receipt of their first cancer treatment. It was categorized as less than one month, one to three months and more than three months.

Recommendations and receipt of each of the treatment modalities differed by cancer site. Respondents with breast cancer were most likely to have surgery recommended, while the data suggest men with prostate cancer were the least likely to have surgery recommended. The majority of breast, colorectal and lung cancer patients received surgery, while about half of prostate cancer patients received surgery.

Surgery					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Surgery recommended					<0.0001
Yes	**86.9** (82.9–90.9) 295	**68.3** (59.6–77.0) 118	**56.5** (46.0–66.9) 54	**49.3** (43.4–55.2) 155	
No	**13.1** (9.1–17.1) 40	**31.7** (23.0–40.4) 45	**43.5** (33.1–54.0) 41	**50.7** (44.8–56.6) 152	
Surgery received					<0.0001
Yes	**98.6** (97.4–99.9) 330	**96.4** (93.5–99.3) 157	**87.3** (80.9–93.7) 81	**52.5** (46.6–58.4) 170	
No	**S**	**3.6** (0.7–6.5) 6	**12.7** (6.3–19.1) 14	**47.5** (41.6–53.4) 137	

S = suppressed.

Radiation therapy was recommended for the majority of respondents with breast and prostate cancer but less frequently for respondents with colorectal and lung cancer. The pattern for receipt of radiation therapy across cancers mirrored the recommendations.

Radiation Therapy					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Radiation recommended					<0.0001
Yes	**69.2** (63.9–74.4) 236	**10.5** (5.9–15.0) 20	**21.9** (13.6–30.3) 22	**58.3** (52.5–64.0) 176	
No	**30.8** (25.6–36.1) 99	**89.5** (85.0–94.1) 143	**78.1** (69.7–86.4) 73	**41.7** (36.0–47.5) 131	
Radiation received					<0.0001
Yes	**66.8** (61.5–72.1) 227	**13.1** (5.9–20.3) 20	**29.7** (20.2–39.1) 29	**50.5** (44.6–56.3) 151	
No	**33.2** (27.9–38.5) 108	**86.9** (79.7–94.1) 143	**70.3** (60.9–79.8) 66	**49.5** (43.7–55.4) 156	

Recommendations of chemotherapy differed by cancer site, from 16 percent of respondents with prostate cancer to 42 percent of respondents with breast cancer.

Chemotherapy					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Chemotherapy recommended					<0.0001
Yes	**42.0** (36.5–47.5) 141	**32.7** (25.2–40.0) 62	**23.0** (14.5–31.5) 23	**15.9** (11.6–20.2) 49	
No	**58.0** (52.5–63.5) 194	**67.3** (59.7–74.8) 101	**77.0** (68.5–85.5) 72	**84.1** (79.8–88.4) 258	
Chemotherapy received					<0.0001
Yes	**41.6** (36.1–47.0) 139	**42.0** (33.3–50.7) 72	**33.8** (24.0–43.5) 33	**3.2** (1.2–5.2) 10	
No	**58.4** (53.0–63.9) 196	**58.0** (49.3–66.7) 91	**66.2** (56.5–76.0) 62	**96.8** (94.8–98.8) 297	

Respondents with breast or prostate cancer were asked about recommendations and receipt of hormone therapy. Respondents with breast cancer were more likely to be recommended and receive hormone therapy than respondents with prostate cancer.

Hormone Therapy			
	Breast	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	P-value
Hormone therapy recommended			0.0001
Yes	**42.7** (37.2–48.2) 148	**27.5** (22.2–32.8) 81	
No	**57.3** (51.8–62.8) 187	**72.5** (67.2–77.8) 226	
Hormone therapy received			0.002
Yes	**41.8** (36.4–47.3) 144	**29.7** (24.2–35.1) 86	
No	**58.2** (52.7–63.6) 191	**70.3** (64.9–75.8) 221	

Respondents who chose not to follow all of their physician's recommendations were asked to provide their reasons. This was asked as an open-ended question, but the responses followed some general themes. There were 68 respondents in total who answered this question. For 31 respondents, it was a personal choice to not receive the recommended treatment. Twenty-two respondents were given recommendations for multiple treatment plans that were mutually exclusive, 11 respondents received a second option and four respondents had a co-morbidity that prevented them from receiving the recommended treatments.

More than 75 percent of respondents with breast, colorectal and lung cancer began their cancer treatment within one month of diagnosis, and more than 90 percent began treatment within three months. In contrast, only about one-third of men with prostate cancer began treatment within one month of diagnosis, and 22 percent began treatment more than three months after diagnosis.

Time from Diagnosis to Treatment					
	Breast	**Colorectal**	**Lung**	**Prostate**	
	Percentage (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	**Percentage** (CI) N	P-value
Time from diagnosis to treatment					<0.0001
≤30 days	**84.0** (80.0–88.0) 276	**86.5** (81.1–91.8) 130	**76.3** (66.8–85.8) 70	**31.3** (25.5–37.1) 83	
31–90 days	**14.6** (10.8–18.5) 50	**13.0** (7.7–18.3) 23	**17.9** (9.9–26.0) 17	**46.2** (40.0–52.3) 129	
91+ days	**S**	**S**	**S**	**22.6** (17.3–27.8) 62	

S = suppressed.

4. DISCUSSION AND SUMMARY OF FINDINGS

This study was designed to gain a better understanding of factors affecting cancer incidence and mortality in Delaware residents. The following sections discuss and summarize the limitations of the study and the study findings.

4.1. Limitations

This study gathered retrospective information regarding risk factors and the diagnosis and treatment experience of individuals diagnosed with the four most common cancers in Delaware. Because of the consent process and the nature of the study data, the population eligible for this study consisted only of patients who were alive at the beginning of the study period. Therefore, the study results cannot be generalized to the full cancer population, but only to cancer survivors. An additional 4,246 individuals were diagnosed in Delaware between 1999 and 2003 with one of the four cancers but died before the study began, and another 117 were discovered to be deceased during the study period. Since deceased individuals were more likely to be diagnosed with distant disease (40 percent versus three percent of survivors), the study findings for factors related to stage at diagnosis, such as screening practices and diagnosis and treatment outcomes, can be interpreted only within the context of living cancer patients. The selection of survivors for this study is less likely to impact the findings for lifestyle risk factors, since the likelihood of systematic differences with respect to these factors in those diagnosed with early-stage versus late-stage disease is not as great.

Due to the nature of the recruitment process, the low response rate and the self-selection of study participants, there is a likelihood of selection bias. Selection bias exists if individuals who participate differ systematically from those who do not. Many studies have shown that those volunteering to participate are healthier and more likely to comply with medical recommendations than those who do not volunteer. Several of the comments made by individuals contacted for this study who refused or were unable to participate indicated this to be true. If the study participants were different in these respects compared with those who did not participate, then prevalence estimates for variables related to health, screening or medical treatments would reflect higher rates of healthy living practices and higher rates of compliance with screening and treatment recommendations than are actually present for the full study population. In addition, these inflated rates would reduce the measured effect of the variables for cancer patients compared with the general Delaware population if the same selection bias were not present for participants in the BRFSS. Since the BRFSS sample of the general Delaware population is randomly selected, it is unlikely this type of selection bias is present. Through the use of weighting, we were able to adjust for selection differences in basic demographic variables such as age, race and gender, and we controlled for these differences in comparisons of the study population with the general Delaware population.

This study attempted to determine the prevalence of lifestyle risk factors, health conditions, health care access and screening practices for cancer patients prior to their cancer diagnosis. Because cancer patients were asked to recall these practices prior to diagnosis—and for some this may have been as long as six years—their responses may not be as accurate as those provided by participants in the BRFSS. The possibility of recall bias exists if systematic

differences in the respondents' ability to recall their past behaviors occurred between the two groups.

A related type of bias is called reporting bias, in which a participant may be reluctant to report an exposure due to perceived beliefs and attitudes. If such underreporting exists more among cancer patients than among the BRFSS participants, a bias may result. For example, cancer patients may be more likely to deny certain exposures related to lifestyle, such as smoking or drinking, because they seek to show that the disease is not their fault. The term "wish bias" was coined by Wynder et al. to describe this type of reporting bias.[20]

Since the interviewers who conducted the interviews for the cancer patients were not the same as those who conducted the interviews for the BRFSS, interviewer bias is another type of information bias that may be present in this study. To minimize this bias, a very structured interview format was used, and interviewers were trained to not deviate from the standard format. In addition, interviewers who had prior experience conducting BRFSS interviews were selected to conduct the interviews for this study. Due to these factors and the nature of the BRFSS questions, the likelihood of interviewer bias is considered to be small.

4.2. General Attributes

The prevalence of demographic, lifestyle and health care access factors in the study population were analyzed by county. Differences were observed in race, education and income levels, length of residency, occupation, alcohol consumption, leisure-time physical activity levels and health care coverage.

A higher proportion of residents of Sussex County at time of diagnosis were Caucasian compared with residents of Kent County or New Castle County. Education and income levels for residents of New Castle County at time of diagnosis were higher than those reported by residents of Kent County or Sussex County. These results are consistent with the racial and socioeconomic distributions of the general Delaware population in these counties as reported in the 2000 U.S. Census.[21]

Residents of New Castle County at time of diagnosis had lived in their county and in Delaware longer than residents of Kent County or Sussex County. This result is also consistent with U.S. Census estimates of population change, which show a lower rate of population change in New Castle County (4.5 percent) during the period 1995–2000 compared with that in either Kent County (13.6 percent) or Sussex County (12.7 percent).[22]

Although some county-level differences were found for occupational categories, these associations were based on very small numbers and may not be reliable. These differences may be explained by the concentration of industries in each county that require more of specific occupational categories—such as construction or production—than others. Similarly, county-level differences in participants that worked in high-risk industries can be explained by the geographic locations of these industries in each of the three counties.

Residents of New Castle County at the time of diagnosis were more likely to be heavy drinkers and to binge drink compared with residents of Kent County or Sussex County. These

county-level patterns of alcohol use were also observed in the general Delaware population.[23] However, county-level differences in leisure-time physical activity levels for study participants differed from those in the general Delaware population. Leisure-time activity levels for study participants were highest in residents of Sussex County, but these were lowest in residents in Sussex County in the general Delaware population.[24] This inconsistency may be explained by a selection bias of healthier, more physically active study participants in Sussex County.

For each cancer, the prevalence of health status variables and behavioral risk factors were compared with that reported in the general Delaware population to determine which factors are associated with cancer incidence in Delaware.

The general trend suggested by the data for health status variables and health conditions was that our study population appeared to be healthier before diagnosis than the general Delaware population. This phenomenon may be explained by a selection bias, as discussed previously, in which the healthiest individuals are those who are most likely to volunteer to participate in such a study. Study participants with breast, colorectal and prostate cancer were three to four times more likely to report being in good or better health before diagnosis compared with the general Delaware population. This may be due to a combination of selection bias and the perception of cancer patients that their health was much better before they were diagnosed compared with after diagnosis. Lung cancer patients reported being less healthy and having more co-morbid conditions compared with the other cancer patients.

Although higher BMIs have been associated with increased risk for colorectal cancer,[25, 26] the odds ratio of 1.12 (CI 0.76–1.65), although elevated, was not significant in our study. Selection bias may have weakened the effect of this association.

The data for fruit and vegetable consumption suggest study participants with lung, prostate and colorectal cancers were less likely to eat the currently recommended amounts of five or more servings per day compared with the general Delaware population; however, these associations were not significant. Studies of the association between fruit and vegetable consumption and colorectal, breast and prostate cancers have not conclusively supported the protective effect of higher fruit and vegetable intake; however, a consistent protective effect has been noted for lung cancer in case-control and cohort studies in many different countries.[27]

About 23 percent of study respondents reported eating foods high in fat five or more times per day and another 40 percent reported eating foods high in fat at least three times but less than five times per day. Fat intake is the aspect of diet that has been singled out to be most importantly related to cancer.[28,29] Scientific evidence currently supports an association between high fat intake and breast, colorectal and prostate cancers.

It is no surprise that the strongest risk factor association detected in this study was for smoking and lung cancer. This has been known since the early 1950s when case-control studies documented the association between lung cancer and smoking.[30, 31] Ninety-four percent of lung cancer patients were either current or former smokers. Lung cancer patients were 27 times more likely to be current smokers and seven times more likely to be former smokers compared with the general Delaware population. The associations between smoking and breast, prostate or

colorectal cancers were not significant, and the scientific evidence regarding the association between smoking and these cancers is not conclusive.

Alcohol use was positively associated with the risk for lung, prostate and breast cancer. Breast cancer patients were more likely to have reported having a drink in the 30 days prior to diagnosis (OR=1.58, CI 1.20–2.08) and to binge drink (OR=2.68, CI 1.54–4.69) than individuals in the general Delaware population. The association between alcohol consumption and breast cancer risk has been evaluated in more than 100 investigations that now clearly support a causal relation.[32] Prostate cancer patients were twice as likely to report binge drinking, heavy drinking and having a drink in the 30 days prior to diagnosis when compared with individuals in the general Delaware population. Recent prospective studies have supported a modest direct association between alcohol consumption and prostate cancer.[33,34] Lung cancer patients were two and a half times more likely to report heavy drinking and three times more likely to report binge drinking compared with members of the general Delaware population. The possibility of confounding due to the known positive association between smoking and drinking may be responsible for these elevated risks. A recent meta-analysis of both cohort and case-control studies reported that smoking was responsible for the elevated risks in studies of alcoholics and lung cancer.[35] Colorectal cancer patients had elevated odds ratios for heavy drinking (OR=1.45, CI 0.73–2.90) and binge drinking (OR=1.38, CI 0.69–2.77), but these associations were not significant. The association between alcohol consumption and colorectal cancer has been controversial and not conclusively supported by the literature; however, the weight of evidence suggests that high intake of alcohol increases the risk of colorectal cancer.[36]

The results for the relationship between leisure-time physical activity levels and the risk for cancer were surprising. For all cancers, a significant positive effect between higher activity levels and the risk for cancer was shown. These findings are contrary to the current scientific evidence for colorectal and breast cancer that indicates an inverse relationship between physical activity and these cancers. The current evidence for lung and prostate cancer do not support an association with physical activity levels. These results may be explained by a selection bias of healthier patients and may possibly reflect a systematic difference in the perceived intensity of physical activity levels in cancer patients. Since cancer patients may have experienced reduced activity levels after their diagnosis due to surgery and other treatments, there is the likelihood they might over-report activity levels prior to diagnosis if they used their post-diagnosis activity levels as a benchmark. The wish bias effect may also explain this difference, with cancer patients more likely to intentionally over-report physical activity levels so as not to be held responsible for their disease.

4.3. Cancer-Specific Attributes

Overall, almost 80 percent of the women with breast cancer in the study had at least one reproductive risk factor, while risk factors that relate to former medical events and a family history were more rarely observed in this population. The literature suggests reproductive risk factors, which are common, are moderate risk factors (OR between 1 and 2) while other risk factors, although more rare, are stronger risk factors (OR greater than 2).[37] Unfortunately, reproductive, medical history and genetic risk factors, while important, are less amenable to intervention.

Use of breast cancer screening tests was high among respondents with breast cancer. About 83 percent received a mammogram and a clinical breast exam in the past two years. This is higher than the current Healthy People 2010 objective that 70 percent of all women receive a mammogram in the past two years.[38] There is about a 50-percent overlap in the women who did not receive a mammogram and the women who did not receive a clinical breast exam, suggesting a group of vulnerable women who are not receiving any breast cancer screening.

Colorectal cancer-specific risk factors were observed in 22 percent of participants with colorectal cancer, and a similar proportion had a family history of colorectal cancer. The use of colorectal screening tests was less common. Among study respondents aged 50 and older, 18 percent of the respondents had a fecal occult blood test in the past two years, and 55 percent had a sigmoidoscopy. The Healthy People 2010 objective is that 50 percent of all adults aged 50 and older will have received a fecal occult blood test in the past two years and will have ever received a sigmoidoscopy.[39]

Despite the fact that screening for prostate cancer has not been proven to decrease prostate cancer mortality, 55 percent of the men with prostate cancer aged 40 and older received a prostate-specific antigen test in the past two years, and 58 percent received a digital rectal exam.

Among our respondents with lung cancer, 60 percent had occupational exposure to at least one of the potential lung cancer carcinogens. Among those with occupational exposure, 93 percent were ever smokers; these two risk factors may act synergistically.

The way in which cancer was first detected differed by cancer type. Respondents with breast or prostate cancer were most likely to have their cancer detected by a screening test. Population-based screening programs are available for both breast and colorectal cancers, but as the colorectal screening is more invasive and involved, it has lower uptake than breast or prostate cancer screening, which may be why fewer colorectal cancers are detected by screening. More than 40 percent of study respondents had their cancer detected as a result of experiencing a symptom. The time from when cancer was first detected until diagnosis differed by cancer type. The time ranged from eight percent of breast cancer patients to 22 percent of colorectal cancer patients reporting three or months between initial detection and diagnostic confirmation. Studies have shown that longer times from cancer detection to diagnosis are associated with a poorer prognosis.[40, 41]

For all four treatment modalities, the percentage of respondents who received the treatment differed by cancer type. Almost all breast and colorectal cancer patients (99 and 96 percent, respectively), most lung cancer patients (88 percent) and half of prostate cancer patients were treated with surgery. Radiation therapy was received by two-thirds of breast cancer patients, half of prostate cancer patients, about 30 percent of lung cancer patients and 13 percent of colorectal cancer patients. Between one-third and one-half of breast, colorectal and lung cancer patients were treated with chemotherapy, which was rarely received by prostate cancer patients. Forty-two percent of breast cancer patients and 30 percent of prostate cancer patients received hormone therapy. These differences reflect the current knowledge regarding appropriate treatment for each cancer type, especially considering the majority of our study respondents had early-stage cancer.[42] The cancer treatment received does not always match the treatment that was

recommended. This may be due to respondents having better recall of the treatment they received than what was recommended, choosing not to follow their physician's recommendation or requesting a treatment that was not the physician's initial recommendation.

The majority of breast, colorectal and lung cancer patients received their first treatment for cancer within one month of diagnosis while the majority of men with prostate cancer began treatment within three months of diagnosis. The longer time to first treatment seen among men with prostate cancer may reflect the fact that for early stage prostate cancer "watchful waiting" is an accepted treatment plan.[42]

4.4. Future Directions

The findings from this study have highlighted several lifestyle behaviors that are associated with increased risk for cancer in Delaware residents. These results can be used to develop cancer-control plans targeted to specific lifestyle factors that may reduce the incidence of cancer in the future. It should be noted that lifestyle risk factors were evaluated individually, and other lifestyle factors were not controlled for in this analysis. There is a strong possibility many of these lifestyle factors are interrelated. A future analysis of the combined effects of these risk factors will help gain a better understanding of their role in the etiology of these cancers in Delaware. In addition, the identification of high-risk sub-populations for these lifestyle risk factors will allow a more targeted approach for cancer control programs to reach those individuals at greatest risk.

A second area that merits further investigation is the method by which cancer was detected and the effect of recent cancer screening on time-to-diagnosis in respondents whose cancer was detected from experiencing a symptom. Although our study participants had high rates of cancer screening, about 40 percent reported that their cancer was diagnosed when they experienced a symptom. A more detailed analysis of the tumor and demographic characteristics for these individuals, their screening history, and the time from detection to diagnosis may provide answers that will help to develop recommendations for increased awareness of cancer symptoms regardless of screening history.

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July 5, 2005

«First_Name» «Last_Name», MD
«Address1»
«Address2»
«City», «State» «Zip_Code»

RE: **Delaware Study of Colorectal, Prostate, Female Breast, Lung and Bronchus Cancers**

Dear Dr. «Format_LN»,

Since Delaware has a cancer incidence and mortality that is higher than the United States average, cancer control is especially important. The Advisory Council on Cancer Incidence and Mortality established by the Governor was given the task of developing a cancer control plan for Delaware. One of their recommendations was to conduct a study of cancer patients to investigate factors that may help to explain the increased incidence and mortality observed in Delaware. The Division of Public Health at the Delaware Department of Health and Social Services is overseeing this study and has contracted with ORC Macro International Inc. to conduct the study. We are recruiting all Delaware residents aged 18 and older who were diagnosed with colorectal, prostate, female breast, or lung/bronchus cancer between 1999 and 2003. The study involves a 30-45 minute telephone interview asking participants about demographics, access to health care, behavioral and occupational risk factors, screening history and factors related to their diagnosis and treatment. Our goal is to interview a total of 800 patients with one or more of these four cancers.

Before the Delaware Cancer Registry allows researchers to contact individuals listed in their registry, they require that the patients' physicians have the option to indicate that specific patients may not be contacted. **Please review the attached list of individuals who are listed in the registry as your patients and identify those who are deceased, terminally ill, not cognitively or emotionally capable of participating in the study, or have not yet been informed of their cancer diagnosis.** Please mark those that you do not want to be contacted and fax the list back to 1-800-368-1394 as soon as possible. **If we may contact all your patients it is not necessary to return the form. If we have not received a fax from you by July 29, 2005 we will presume that we have your permission to contact your patients.**

We will be contacting you in about one week to ensure that you received this form and to answer any questions that you might have. We may have contacted you at an earlier phase of this study; however, both the study population and physician consent procedures have changed.

Thank you in advance for your assistance with this study. We appreciate the time that you are taking to help us. Together, we can learn more about cancer in Delaware. If you have any questions about this study or need more time to review your patient list please contact Aliza Fink at 1-888-638-2803. Thank you again.

Sincerely,

Leroy Hathcock, PhD
Delaware State Epidemiologist
Division of Public Health

[Date]

[First Name] [Last Name]
[Address1]
[Address2]
[City], [State] [Zip Code]

Dear [Title]. [Last Name],

We are inviting you to take part in a study of cancer patients in Delaware. Because Delaware cancer rates are higher than the national average, the Governor established the Advisory Council on Cancer Incidence and Mortality. The members of this council spoke with medical professionals, government workers, cancer survivors and family members of cancer patients to develop a plan for reducing the number of new cases of cancer and deaths from cancer in Delaware. One of the council's recommendations was that the Delaware Division of Public Health conduct a study of cancer patients. This is the study we are asking you to take part in.

We are sending this letter to Delaware residents aged 18 and older who were diagnosed with female breast, prostate, colorectal, lung or bronchus cancer between 1999 and 2003 that have been reported to the Delaware Cancer Registry. Delaware Cancer Registry (DCR) collects, maintains, and reports on cancer incidence and mortality in the State of Delaware. Physicians are required by law to submit data to DCR. Registry data are kept in strict confidence with strong controls in place to ensure that the data and the confidentiality of individuals with cancer are protected. This project has been reviewed and approved by the Delaware Department of Health and Social Services' Human Subject Review Board as is required for the use of Cancer Registry data for research.

We are asking you to agree to take part in a 30-45 minute telephone interview that asks you questions about yourself and your cancer experience. There will be no costs to you for participating in this study and if you participate in the interview we will send you $25 as a thank you gift. All of the information in this study will remain confidential, including your name, and your responses to the interview. The information gathered from this study will help to provide information to the Advisory Council about the experiences of Delaware residents with cancer so that they may develop appropriate recommendations and plans for reducing new cases of cancer and improving the lives of those who develop cancer in Delaware.

If you have any questions about this study, please call Denese Welch from the Delaware Division of Public Health at (302) 744-4541 or Benita O'Colmain, Study Investigator, at 1-800-368-1394. If you have any questions regarding your rights as a participant in this study please call Dr. Linda Barnett at the Delaware Department of

Health and Social Services, Human Subjects Review Board, at (302) 255-9133. If you would like to learn more about the Advisory Committee's recommendations you can visit http://www.state.de.us/dhss/dph/dpc/consortium.html.

With this letter is additional information about this study and a consent form. Please read about the study and then complete the consent form. There are two copies of the consent form. Please complete both, keep one copy for your records and **mail the blue copy back to us in the envelope provided.** If you would like to participate please complete section one and tell us the best phone number and time to call you. Once we receive your form, within two weeks our interviewers will try to call you. If you do not want to participate please complete section two. Once we receive your form, we will not contact you again.

Thank you for your time.

Sincerely,

Denese Welch

Denese Welch
Manager, Statistics and Research
Division of Public Health

Delaware Study
of Colorectal, Prostate, Female Breast, Lung and Bronchus Cancers

Information Sheet

Background: Cancer rates in Delaware are higher overall then those in the United States. To understand why this is the case, the Governor created the Advisory Council on Cancer Incidence and Mortality. One of the suggestions of the Council was to learn more from Delaware residents who were diagnosed with cancer.

Purpose: To learn about the characteristics of Delaware residents who were diagnosed with female breast, prostate, colorectal, lung and bronchus cancers.

Eligibility: Delaware residents aged 18 and older diagnosed with female breast, prostate, colorectal, lung or bronchus cancers from 1999 through 2003.

Study Plan: Participating in the study involves taking part in a 30-45 minute telephone interview that will be conducted by a trained interviewer. This interview will ask you questions about yourself and your cancer experience. We will use your answers to compare people in Delaware with cancer to people without cancer and to people in the United States.

Possible Risks: There are no major risks to you from participating. It is possible that you may experience some temporary mild anxiety or sadness responding to some of the questions, but remember that you are free to skip any questions that you feel are too upsetting—there will be no adverse effects from not answering all the questions. Your participation in this study is voluntary and refusal to participate involves no penalty or loss of benefits to which you are otherwise entitled.

Possible Benefits: While you will receive no personal health benefits from this study, the information you provide will help us to develop prevention strategies to lower the number of newly diagnosed cases of these types of cancer and to better assist people diagnosed with these types of cancer in the future. You may also derive personal satisfaction from the knowledge that you are doing something positive and beneficial by contributing to the understanding of the cancer experience of people in Delaware.

Confidentiality: The study protocol has been approved by the Delaware Department of Health and Social Services. Information collected for this study will be used only for this study. Your identity will not be released or disclosed at any time and your information will be locked in cabinets or on password protected files. Any study results that are released will only include groups of people so that you cannot be identified. If you have any questions regarding your rights as a participant in this study contact Linda Barnett, Delaware Department of Health and Social Services, Human Subjects Review Board, (302) 255-9133.

Withdrawal: If you consent to participate in this study, you have the right to withdraw at any time without penalty. You also have the right to revoke your authorization to use your personal information any time before the study results are released. To let us know of your decision, please contact Benita O'Colmain at 1-800-368-1394.

Costs: There are no costs to you for participating in this study. If you participate in the interview, you will receive a $25 money order as a thank you gift.

Study Team: A team of researchers at ORC Macro International is conducting the study on behalf of the Division of Public Health in the Delaware Department of Health and Social Services. If you have any questions or would like more information about the study please feel free to contact Denese Welch of the Division of Public Health at (302) 744-4541 or Benita O'Colmain, an ORC Macro study investigator, at 1-800-368-1394.

CONSENT FOR PARTICIPATION

Delaware Study of Colorectal, Prostate, Female Breast, Lung and Bronchus Cancers

By signing any part of this form I acknowledge that I have received and read the information on the study entitled, “Delaware Study of Female Breast, Prostate, Colorectal, Lung and Bronchus Cancers”.

Please complete one of the three sections below.

Section 1: Agree to Participate

☐ I agree to participate in the telephone interview for the Delaware Study of Female Breast, Prostate, Colorectal, Lung and Bronchus Cancers.

Name (please print): _____

Signed: _____ Date: _____

A trained interviewer at ORC Marco International Inc. may call me at the following phone number and times.

Telephone Number: (_____)_____

Best Times to Call (check all that apply):
☐ Weekday mornings ☐ Weekday afternoons ☐ Weekday evenings
☐ Weekends

Section 2: Do not wish to Participate

☐ I do not wish to participate in the telephone interview for this study.

Name (please print): _____

Signed: _____ Date: _____

Section 3: Unable to Participate

☐ If the patient is not physically or cognitively able to complete the telephone interview and sign this form, then the next of kin or legal authority for medical decisions should please complete this section.

Name (please print): _____

Relationship to patient: _____

Signed: _____ Date: _____

Delaware Study of
Colorectal, Prostate, Female Breast, Lung and Bronchus Cancers

Final Questionnaire
November 8, 2005

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PROLOGUE

Hello, My name is (name) and I'm calling on behalf of the Delaware Department of Health and Social Services. May I speak with _____? *[Proceed according to interview protocol]*

To the correct respondent: **I would like to thank you for agreeing to participate in the Delaware Study of Colorectal, Prostate, Female Breast, Lung and Bronchus Cancers. As mentioned in the information sheet provided with your consent form, we're gathering information on residents of Delaware who were diagnosed with female breast, prostate, colorectal, lung and bronchus cancers to learn more about how we can prevent new cases of these cancers and how we can improve the experience of those diagnosed with these cancers in the future. There are no major risks to you for participating in this interview, although you may experience some temporary anxiety or sadness. You don't have to answer any question you don't want to and you can take a break during the interview or end the interview at any time.**

The interview takes about 30-45 minutes and any information you give me will be used only for the study's purposes, and will not be shared with anyone outside of the study team, not even your doctor. If you have any questions about this survey, I will provide telephone numbers for you to call to get more information.

For this interview please answer the questions as they relate to your diagnosis of *{Type}* **cancer on** *{ Date of Diagnosis MMDDYYYY}***.**

We will begin the interview with some general questions about where you live and have lived in the past.

1 CORE Section 1. Migration

1.1 What county do you live in (*or if moved out-of-state*), what county did you live in when you were diagnosed?

1 Kent
2 Sussex
3 New Castle
7 Don't know/not sure
9 Refused

//if 1.1=7 or 9, skip to 1.3//

//From this point on, If patient withdraws during the interview please read the closing statement to them ,obtain address, and they will still receive the $25 gift//

1.2 How long have/had you lived in //insert county name from 1.1// county?

[NOTE TO INTERVIEWER: *For questions 1.2-1.4, if a respondent answers since xxxx (year), please give them some time to calculate the length of time; or if they are having trouble, help them by calculating the length of time and offering them the answer so they can verify.*

__ __years [RANGE 1-76]
0 0 Less than one year
8 8 All my life (skip to Q1.6)
7 7 Don't know/not sure
9 9 Refused

1.3 How long have/had you lived in Delaware?

__ __ years [RANGE 1-76
0 0 Less than one year
8 8 All my life (skip to Q1.6)
7 7 Don't know/not sure
9 9 Refused

1.4 How long have you lived in the United States?

__ __ years [RANGE 1-76]
0 0 Less than one year
8 8 All my life (skip to Q1.6)
7 7 Don't know/not sure
9 9 Refused

1.5 Where you born in the United States?

1 Yes
2 No
7 Don't know/not sure
9 Refused

1.6 What is your age in years?

__ __ years [RANGE 1-76]
7 7 Don't know/not sure
9 9 Refused

1.7 What language is most often spoken in your home?

1 ENGLISH
2 SPANISH
3 OTHER (SPECIFY) _____
7 DON'T KNOW
9 REFUSED

Now I'm going to ask you some general questions about your health BEFORE your diagnosis.

2 CORE Section 2. Health Status

2.1 In the year before your diagnosis, would you say that in general your health was:

1	Excellent
2	Very good
3	Good
4	Fair
5	Poor
7	Don't know/not sure
9	Refused

2.2 Prior to your diagnosis, had a doctor, nurse, or other health professional ever told you that you had?

2.2.1 Heart Disease
2.2.2 Diabetes
2.2.3 Hypertension (High blood pressure)
2.2.4 High blood cholesterol
2.2.5 Arthritis
2.2.6 Asthma

1	Yes
2	No
7	Don't know/not sure
9	Refused

2.3 In the month prior to your diagnosis, about how much did you weigh without shoes?

__ __ __	Weight in pounds
7 7 7	Don't know/not sure
9 9 9	Refused

2.4 Prior to your diagnosis, what was the most you have ever weighed?

[INTERVIEWER: IF FEMALE RESPONDENT READ "Excluding when you may have been pregnant"]

__ __ __	Weight in pounds
7 7 7	Don't know/not sure
9 9 9	Refused

2.5 Had a doctor, nurse, or other health professional ever given you advice about your weight?

1 Yes, lose weight
2 Yes, gain weight
3 Yes, maintain weight
4 No
7 Don’t know/not sure
9 Refused

These next questions are about the foods you usually ate or drank BEFORE your diagnosis. Please tell me how often you usually ate or drank each one, for example once a day, twice a week, three times a month, and so forth. Include all foods you ate, both at home and away from home.

3 CORE Section 3. Diet

3.1 Prior to your diagnosis, how often did you drink fruit juices such as orange, grapefruit, or tomato?

1 __ __ per day [RANGE 101-105]
2 __ __ per week [RANGE 201-238]
3 __ __ per month [RANGE 301-399]
4 __ __ per year [RANGE 401-499]
5 5 5 never
7 7 7 don't know/Not sure
9 9 9 refused

3.2 Prior to your diagnosis, not counting juice, how often did you eat fruit?

1 __ __ per day [RANGE 101-105]
2 __ __ per week [RANGE 201-238]
3 __ __ per month [RANGE 301-399]
4 __ __ per year [RANGE 401-499]
5 5 5 never
7 7 7 don't know/Not sure
9 9 9 refused

3.3 Prior to your diagnosis, how often did you eat green salad?

1 __ __ per day [RANGE 101-105]
2 __ __ per week [RANGE 201-238]
3 __ __ per month [RANGE 301-399]
4 __ __ per year [RANGE 401-499]
5 5 5 never
7 7 7 don't know/Not sure
9 9 9 refused

3.4 Prior to your diagnosis, how often did you eat potatoes, not including French fries, fried potatoes, or potato chips?

1 __ __ per day [RANGE 101-105]
2 __ __ per week [RANGE 201-238]
3 __ __ per month [RANGE 301-399]
4 __ __ per year [RANGE 401-499]
5 5 5 never
7 7 7 don't know/Not sure
9 9 9 refused

3.5 Prior to your diagnosis, how often did you eat carrots?

1 __ __ per day [RANGE 101-105]
2 __ __ per week [RANGE 201-238]
3 __ __ per month [RANGE 301-399]
4 __ __ per year [RANGE 401-499]
5 5 5 never
7 7 7 don't know/Not sure
9 9 9 refused

3.6 Prior to your diagnosis, not counting carrots, potatoes, or salad, how many servings of vegetables did you usually eat?

1 __ __ per day [RANGE 101-105]
2 __ __ per week [RANGE 201-238]
3 __ __ per month [RANGE 301-399]
4 __ __ per year [RANGE 401-499]
5 5 5 never
7 7 7 don't know/Not sure
9 9 9 refused

3.7 Prior to your diagnosis, how often did you eat the following foods?

3.7.1 Hot dogs, ham or lunch meats
3.7.2 Bacon or sausage
3.7.3 Pork other than ham, bacon or sausage
3.7.4 Hamburgers, cheeseburgers or meatloaf
3.7.5 Beef other than hamburgers, cheeseburgers or meatloaf
3.7.6 Fried chicken
3.7.7 French fries or fried potatoes
3.7.8 Cheese or cheese spreads (not including cottage cheese)
3.7.9 Donuts, cookies, cake, pastry or pies
3.7.10 Snacks such as chips or buttered popcorn
3.7.11 Butter or margarine added to bread, rolls or vegetables
3.7.12 How many eggs did you usually eat?
3.7.13 How many 8 oz. glasses of WHOLE milk did you usually drink?

1 __ __ per day [RANGE 101-105]
2 __ __ per week [RANGE 201-238]
3 __ __ per month [RANGE 301-399]
4 __ __ per year [RANGE 401-499]
5 5 5 never
7 7 7 don't know/Not sure
9 9 9 refused

4 CORE Section 4. Tobacco Use

Now I'm going to ask some questions about your use of tobacco BEFORE your diagnosis.

4.1 At the time of your diagnosis, had you smoked at least 100 cigarettes in your entire life?

1 Yes
2 No **(Skip to next section)**
7 Don't know/not sure **(Skip to next section)**
9 Refused **(Skip to next section)**

4.2 At the time of your diagnosis, did you smoke cigarettes every day, some days, or not at all?

1 Every day
2 Some days
3 Not at all
9 Refused **(Skip to next section)**

4.3 How old were you the first time you smoked a cigarette, even one or two puffs?

__ __ Insert age in years [RANGE = 1-76 76=76+]
7 7 Don't know/not sure
9 9 Refused

4.4 How old were you when you first started smoking cigarettes regularly?

__ __ Insert age in years [RANGE = 1-76 76=76+]
8 8 Never smoked regularly **(Skip to next section)**
7 7 Don't know/not sure
9 9 Refused

//have program verify that age started smoking regularly is not more than age specified in 4.3//

//If Q4.2=3 then continue. Otherwise go to Q4.6//

4.5 At the time of your diagnosis, about how long had it been since you last smoked cigarettes regularly?

1 Less than 1 month prior to the diagnosis
2 1 to less than 3 months prior to the diagnosis
3 3 to less than 6 months prior to the diagnosis
4 6 months to less than 1 year prior to diagnosis
5 1 to less than 5 years before the diagnosis
6 5 to 10 years before the diagnosis
8 More than 10 years before the diagnosis
7 Don't know/not sure
9 Refused

4.6 About how many packs of cigarettes did you smoke daily?

[INTERVIEWER NOTE: 1 pack=20 cigarettes]

__ Insert number of packs [1-5]
6 Less than one pack
8 Never smoked daily
7 Don't know/not sure
9 Refused

4.7 Prior to your diagnosis, about how many years had you smoked cigarettes?

__ __ Insert number of years
7 7 Don't know/not sure
9 9 Refused

4.8 Prior to your diagnosis, had a doctor, nurse, or other health professional ever advised you to quit smoking?

1 Yes
2 No
7 Don't know/not sure
9 Refused

5 CORE Section 5. Alcohol Consumption

The next few questions ask about alcohol consumption. Please try to remember as accurately as possible your use of alcohol just BEFORE your diagnosis.

5.1 A drink of alcohol is one 12 oz. can or bottle of beer, one glass of wine, one 12 oz. can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor. In the 30 days prior to your diagnosis, how many days per week or per month did you have at least 1 drink of any alcoholic beverage?

1 __ __ Days per week (specify number of days) [RANGE 1-7]
2 __ __ Days per month before diagnosis (specify number of days) [RANGE 1-30]
3 3 3 No drinks in 30 days prior to diagnosis
7 7 7 Don't know/not sure
9 9 9 Refused

//If 5.1=333, 777, or 999, skip to next section//

5.2 On the days when you drank, about how many drinks did you drink on the average?

__ __ Number of drinks [1-30]
7 7 Don't know/not sure
9 9 Refused

5.3 Considering all types of alcoholic beverages, how many times during the 30 days prior to your diagnosis did you have 5 or more drinks on an occasion?

__ __ Number of times [1-30]
8 8 None
7 7 Don't know/not sure
9 9 Refused

6 CORE Section 6. Demographics

Now I am going to ask you some questions about yourself for general classification purposes.

6.1 At the time of your diagnosis, about how tall were you without shoes?

__/__ __ Height in ft/inches
7 7 7 Don't know/not sure
9 9 9 Refused

6.2 Are you Hispanic or Latino?

1 Yes
2 No
7 Don't know/not sure
9 Refused

6.3 Which one or more of the following groups would you say best represents your race? **(MUL=6)**

1 American Indian, Alaska Native
2 Black or African American
3 Asian
4 Native Hawaiian or Other Pacific Islander
5 White
6 Other (specify) _____
7 Don't know/not sure
9 Refused

//If more than one response to Q6.3 continue, otherwise, go to Q6.5//

6.4 Which one of these groups would you say best represents your race?

//insert responses from 6.3//

1 American Indian, Alaska Native
2 Black or African American
3 Asian
4 Native Hawaiian or Other Pacific Islander
5 White
6 Other (specify) _____
7 Don't know/not sure
9 Refused

6.5 At the time of your diagnosis, were you…?

1 Married
2 Divorced
3 Widowed
4 Separated
5 Never married
6 A member of an unmarried couple
9 Refused

6.6 At the time of your diagnosis, what was the highest grade or year of school you completed? **(Read as necessary)**

1 Never attended school or only attended kindergarten
2 Grades 1 through 8 (elementary school)
3 Grades 9 through 11 (some high school)
4 Grade 12 or GED (high school graduate)
5 College 1 year to 3 years (some college or technical school)
6 College 4 years or more (college graduate)
9 Refused

6.7 At the time of your diagnosis, was your annual household income from all sources:

01 Less than $25,000 *(If "no," skip to 5, if "yes," ask 2)*
02 Less than $20,000 *(If "no," code 1, if "yes," ask 3)*
03 Less than $15,000 *(If "no," code 2, if "yes," ask 4)*
04 Less than $10,000 *(If "no," code 2, if "yes" code 4)*
05 Less than $35,000 *(If "no," ask 6, if "yes" code 5)*
06 Less than $50,000 *(If "no," ask 7, if "yes" code 6)*
07 Less than $75,000 *(If "no," code 8, if "yes" code 7)*
08 $75,000 or more
77 DON'T REMEMBER / DON'T KNOW
99 Refused

6.8 At the time of your diagnosis, what was your employment status?

[MUL=7]

1 Employed for wages/salary
2 Self-employed
3 Out of work for more than 1 year
4 Out of work for less than 1 year
5 Homemaker
6 Student
7 Retired
8 Unable to work
9 Refused

6.9 Have you ever worked outside your home?

1 Yes
2 No **(skip to next section)**
7 Don't Know / Not Sure **(skip to next section)**
9 Refused **(skip to next section)**

6.10 Over the course of your entire working life before you were diagnosed with cancer, please tell me the three jobs that you had for the longest time:

NOTE TO INTERVIEWER: *If they give a company name, ask for the job title also. If they offer the length of time at the job, please record that along with the job title.*

6.10.1 _____

6.10.2 _____

6.10.3 _____

6.11 Prior to your diagnosis, had you ever worked in any of the following industries:

6.11.1 Chemical
6.11.2 Pharmaceutical
6.11.3 Manufacturing
6.11.4 Agriculture / Farming
6.11.5 Construction

1 Yes
2 No **(go to next industry)**
7 Don't Know / Not Sure **(go to next industry)**
9 Refused **(go to next industry)**

6.12 What was your job title? **_____ (If more than one job title in these industries start with first and repeat questions 6.13 and 6.14 for each job title.)**

6.13 How long did you work at this job?

__ __ months,__ __ years _ _Weeks
7 7 Don't know
9 9 Refused

6.14 How long has it been since you stopped working at this job?

[INTERVIEWER: THIS IS FROM PRESENT DAY TO LAST DAY OF WORK]

__ __ months,__ __ years _ _Weeks
8 8 Still Working
7 7 Don't know
9 9 Refused

7 CORE Section 7. Physical Activity

The next few questions ask about your usual level of physical activity BEFORE your diagnosis.

If Q6.8=1 or 2, continue. Otherwise go to Q7.2.

7.1 Prior to your diagnosis, when you were at work, which of the following best described what you did?

1 Mostly sitting or standing
2 Mostly walking
3 Mostly heavy labor or physically demanding work
7 Don't know/not sure
9 Refused

7.2 During the month prior to your diagnosis, *// if 6.8=1 or 2, insert* "other than your regular job"//, did you participate in any physical activities or exercise, such as running, calisthenics, golf, gardening, or walking for exercise?

1 Yes
2 No
7 Don't know/not sure
9 Refused

We are interested in two types of physical activity: vigorous and moderate. Vigorous activities cause large increases in breathing or heart rate while moderate activities cause small increases in breathing or heart rate.

7.3 Now thinking about the moderate physical activities that you did prior to your diagnosis **[fill in (when you were not working) if employed or self employed from Q6.8]**, in a usual week, did you do moderate activities for at least 10 minutes at a time, such as brisk walking, bicycling, vacuuming, or anything else that causes small increases in breathing or heart rate?

1 Yes
2 No **(Go to Q7.6)**
7 Don't know/not sure **(Go to Q7.6)**
9 Refused **(Go to Q7.6)**

7.4 How many days per week did you do these moderate activities for at least 10 minutes at a time?

__ __ Days per week
8 8 Did not do any moderate activity for at least 10 minutes at a time
7 7 Don't know/not sure
9 9 Refused

//If 7.4=88,77 or 99, skip to 7.6//

7.5 On days when you did moderate activities for at least 10 minutes at a time, how much total time per day did you spend doing these activities?

__:__ __ Hours and minutes per day [RANGE 0:10 – 7:00]
7 7 7 Don't know/not sure
9 9 9 Refused

7.6 Now thinking about the vigorous physical activities that you did prior to your diagnosis **[fill in (when you were not working) if employed or self employed from Q6.8]**, in a usual week, did you do vigorous activities for at least 10 minutes at a time, such as running, aerobics, heavy yard work, or anything else that causes large increases in breathing or heart rate?

1 Yes
2 No **(Skip to next section)**
7 Don't know/not sure **(Skip to next section)**
9 Refused **(Skip to next section)**

7.7 How many days per week did you do these vigorous activities for at least 10 minutes at a time?

__ __ Days per week
8 8 Did not exercise at least 10 minutes weekly
7 7 Don't know/not sure
9 9 Refused

//If 7.7=88, 77 or 99, skip to next section//

7.8 On days when you did vigorous activities for at least 10 minutes at a time, how much total time per day did you spend doing these activities?

__:__ __ Hours and minutes per day [RANGE 0:10 – 7:00]
7 7 7 Don't know/not sure
9 9 9 Refused

8 CORE Section 8. Environmental Exposures

Now I am going to ask you some questions about smoking rules at home or work. Please try to remember these rules BEFORE your diagnosis.

8.1 Which statement best described the rules about smoking inside your home?

1 Smoking was not allowed anywhere inside your home
2 Smoking was allowed some places or at some times
3 Smoking was allowed anywhere inside the home
4 There were no rules about smoking inside the home
7 Don't know/Not sure
9 Refused

//If employed or self-employed at time of diagnosis (Q6.8=1 OR 2), continue. Otherwise skip to next section (Cancer Module).//

8.2 While working at your job, were you indoors most of the time?

1 Yes
2 No **(Skip to Cancer Module)**
7 Don't know/Not sure **(Skip to Cancer Module)**
9 Refused **(Skip to Cancer Module)**

8.3 Which of the following best described your place of work's official smoking policy for indoor public or common areas, such as lobbies, rest rooms and lunch rooms?

1 Not allowed in any public areas
2 Allowed in some public areas
3 Allowed in all public areas
4 No official policy
7 Don't know/Not sure
9 Refused

8.4 Which of the following best described your place of work's official smoking policy for work areas?

1 Not allowed in any work areas
2 Allowed in some work areas
3 Allowed in all work areas
4 No official policy
7 Don't know/Not sure
9 Refused

9 CORE Section 9. Health Care

The next section asks about your interactions with the health care system and with various health care professionals. We are still interested in answers related to the time before your cancer diagnosis.

9.1 At the time of your diagnosis, did you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

1 Yes **(Go to Q9.4)**
2 No
7 Don't know/not sure **(Go to Q9.4)**
9 Refused **(Go to Q9.4)**

9.2 What was the main reason you were without health care coverage? **(Read only if necessary)**

01 Lost job or changed employers
02 Spouse or parent lost job or changed employers
03 Became divorced or separated
04 Spouse or parent died
05 Became ineligible because of age or because left school
06 Employer didn't offer or stopped offering coverage
07 Cut back to part time or became temporary employee
08 Benefits from employer or former employer ran out
09 Couldn't afford to pay the premiums
10 Insurance company refused coverage
11 Lost Medicaid or Medical Assistance eligibility
12 Other (specify) _____
77 Don't know/not sure
99 Refused

9.3 About how long were you without health care coverage?

1 Less than 6 months (any time less than 6 months)
2 Less than 1 year (6 months but less than 1 year)
3 Less than 2 years (1 year but less than 2 years)
4 Less than 5 years (2 years but less than 5 years)
5 5 or more years
7 Don't know/not sure
9 Refused

9.4 In the year prior to your diagnosis was there a time when you needed medical care, but could not get it?

1 Yes
2 No **(Go to Q9.6)**
7 Don't know/not sure **(Go to Q9.6)**
9 Refused **(Go to Q9.6)**

9.5 What was the **main** reason you could not get medical care?

[INTERVIEWER NOTE: **If more than one instance ask about the most recent]**

01 Cost or no insurance
02 Distance
03 Office wasn't open when I could get there
04 Too long of a wait for an appointment
05 Too long of a wait in waiting room
06 No childcare
07 No transportation
08 No access for people with disabilities
09 The medical provider didn't speak my language
10 Other (specify) _____
77 Don't know/not sure
99 Refused

9.6 In the year prior to your cancer diagnosis, when you were sick or needed advice about your health, to which one of the following places did you usually go?

1 A doctor's office
2 A public health clinic or community health center
3 A hospital outpatient department
4 A hospital emergency room
5 Urgent care center
6 Some other kind of place (specify) _____
8 NO USUAL PLACE
7 DON'T REMEMBER / DON'T KNOW
9 REFUSED

9.7 Before your cancer diagnosis, how often did you regularly see a health care provider?

1 Every month
2 Every 2 to 6 months
3 Every 7 months to a year
4 Less than once a year but more than every two years
5 Less than every two years but more than every three years
6 Less than every three years
7 DON'T REMEMBER / DON'T KNOW
9 REFUSED

9.8 In the year before your cancer diagnosis, did you have one person you thought of as your personal doctor or health care provider?

1 Yes, only one
2 Yes, more than one
3 No **(Go to Q9.10)**

7 Don't know/not sure **(Go to Q9.10)**
9 Refused **(Go to Q9.10)**

9.9 Before your cancer diagnosis, how satisfied were you with the care provided by your personal doctor **(or the doctor you see most often if more than one from Q9.8)**?

1 Very satisfied
2 Satisfied
3 Somewhat satisfied
4 Unsatisfied
7 DON'T REMEMBER / DON'T KNOW
9 REFUSED

//Ask Q9.10 if 9.8=03,77,99 (those who do not have one or more personal doctors)//

9.10 I am going to read a list of reasons why someone may not have a personal doctor. For each reason please tell me whether or not this reason applied to you.

9.10.1 Cost of seeing a doctor

9.10.2 Too difficult to get to the doctor

9.10.3 Couldn't take time off from work to see a doctor

9.10.4 Too busy taking care of children or other people

9.10.5 Hadn't been able to find a doctor who speaks your language

9.10.6 Hadn't found a doctor you like

9.10.7 You were healthy so you didn't need one

9.10.8 No health insurance

9.10.9 Didn't believe it would help

1 Yes
2 No
7 Don't know/not sure
9 Refused

//SKIP to appropriate CANCER MODULE//

Now we are going to talk about the process by which your cancer was diagnosed and treated.

10 CORE Section 10. Diagnosis and Treatment

10.1 Did you experience any symptoms of this cancer before you saw a doctor?

1 Yes **(skip to Q10.3)**
2 No
7 Don't know/not sure
9 Refused

10.2 How was your cancer first found? (READ THE ANSWERS)

1 Screening test (mammography, PSA, colonoscopy, etc.)
2 Doctor found during routine visit
3
4 Other (specify) _____
7 DON'T REMEMBER / DON'T KNOW
9 Refused

10.3 How much time passed from the time you experienced symptoms (from Q10.1) or cancer was first found (from Q10.2) until you were told that you had cancer?

NOTE TO INTERVIEWER: *If additional tests and/or biopsies were needed before the diagnosis was made, we want the time from when the symptoms were first experienced (Q10.1) or the test/exam when the cancer was first found (Q10.2) to the time they were told.*

1__ __ days [RANGE 1-30]
2__ __ weeks [RANGE 1-51]
3 __ __ months [RANGE 1-11]
4__ __ years [RANGE 1-76]
77 Don't know
9 9 Refused

10.4 What type of doctor diagnosed you with cancer?

1 PRIMARY CARE PHYSICIAN
2 GYNECOLOGIST
3 UROLOGIST
4 GASTROENEROLOGIST
5 ONCOLOGIST
6 OTHER (SPECIFY) _____
7 DON'T REMEMBER / DON'T KNOW
9 REFUSED

10.5 How were you first told that you had cancer? (READ THE ANSWERS)

1 Doctor told me over the phone
2 Doctor called me into his/her office to tell me
3 Nurse/lab told me over the phone
4 I received a letter in the mail
5 Other (specify) _____
7 Don't know/not sure
9 Refused

10.6 Was any cancer treatment recommended to you by a health care professional?

1 Yes
2 No **(Go to Q10.10)**
7 Don't know/not sure **(Go to Q10.10)**
9 Refused **(Go to Q10.10)**

10.7 Were any of the following treatments recommended?

10.7.1 Surgery
10.7.2 Radiation
10.7.3 Chemotherapy
10.7.4 Hormone therapy **(*if breast or prostate cancer*)**
10.7.5 Pain Management
10.7.6 Other (specify) _____

1 Yes
2 No
7 Don't know/not sure
9 Refused

10.8 Did you decide to follow all your doctor's treatment recommendations?

1 Yes **(Go to Q10.10)**
2 No
7 Don't know/not sure **(Go to Q10.10)**
9 Refused **(Go to Q10.10)**

10.9 What were your reasons for not following your doctor's recommendation?

_____
_____
_____

10.10 I am going to read a list of sources of guidance that you may have used to make decisions about cancer treatment. For each item please tell me whether you used this source.

10.10.1 Religious advice
10.10.2 A friend's advice
10.10.3 A doctor's advice
10.10.4 Internet sources
10.10.5 Family's advice
10.10.6 Other (specify) _____

1 Yes
2 No
7 Don't know/not sure
9 Refused

Now, we are going to discuss the cancer treatments that you received.

10.11 Was your cancer treated with surgery?

1 Yes
2 No **(Go to Q10.13)**
7 Don't know / Not Sure **(Go to Q10.13)**
9 Refused **(Go to 10.13**)

10.12 How long after you were told that you had cancer did you receive your surgery?

1__ __ days, [RANGE1-30]
2__ __ weeks, [RANGE1-51]
3 __ __ months, [RANGE 1-11]
4__ __ years[RANGE 1-76]
7 7 Don't know
9 9 Refused

10.13 Was your cancer treated with radiation?

1 Yes
2 No **(Go to Q10.17)**
7 Don't know / Not Sure **(Go to Q10.17)**
9 Refused **(Go to Q10.17)**

10.14 How long after you were told that you had cancer did you begin your radiation therapy?

1__ __ days, [RANGE 1-30]
2__ __ weeks, [RANGE1-51]
3 __ __ months, [RANGE 1-11]
4__ __ years[RANGE 1-76]
7 7 Don't know
9 9 Refused

10.15 Were you able to complete the radiation therapy?

1 Yes **(Go to Q10.17)**
2 No
7 Don't know / Not Sure **(Go to Q10.17)**
9 Refused **(Go to Q10.17)**

10.16 What was the reason for not completing the radiation therapy?

_____
_____
_____

10.17 Was your cancer treated with chemotherapy?

1 Yes
2 No **(Go to Q10.21)**
7 Don't know / Not Sure **(Go to Q10.21)**
9 Refused **(Go to Q10.21)**

10.18 How long after you were told that you had cancer did you begin your chemotherapy?

1__ __ days, [RANGE 1-30]
2__ __ weeks, [RANGE1-51]
3 __ __ months, [RANGE 1-11]
4__ __ years[RANGE 1-76]
7 7 Don't know
9 9 Refused

10.19 Were you able to complete the chemotherapy?

1 Yes **(Go to Q10.21)**
2 No
7 Don't know / Not Sure **(Go to Q10.21)**
9 Refused **(Go to Q10.21)**

10.20 What was the reason for not completing the chemotherapy?

_____
_____
_____

//For breast and prostate cancer patients only: Otherwise, skip to 10.23//

10.21 Was your cancer treated with hormonal therapy?

1 Yes
2 No **(Go to Q10.23)**
7 Don't know / Not Sure **(Go to Q10.23)**
9 Refused **(Go to Q10.23)**

10.22 For how long were your treated with hormonal therapy?

1__ __ days
2__ __ weeks, [RANGE1-51]
3 __ __ months
4 __ __ years
666 Still taking
777 Don't know / Not Sure
999 Refused

10.23 Can you think of anything about your diagnosis and treatment that we have not covered, that you would like to tell me about?

_____
_____

For patients with a second diagnosis please read the following, otherwise go to the ending.

Now, I'm going to ask some questions about your diagnosis of *{Type}* **cancer on** *{Date of Diagnosis MMDDYYYY}***.**

The remaining questions should only take another 5 minutes or so. If you would like to take a break or are unable to continue with the interview now, we can resume the interview at a later time. (*Reschedule second part if needed***)**

Go to second cancer module.

Ending

This is the end of the interview. As we mentioned, we would like to send you a $25 money order to thank you for your participation. May I please have the address to send this to:

[VERIFY ADDRESS WITH RESPONDENT BEFORE CONTINUING]

Address:_____
City: _____ State: __ __ Zip Code: __ __ __ __ __

Would you like to have a copy of the study results mailed to this address when they become available? ____YES ____NO

Thank you for your time and for participating in this study.

Now I am going to ask you some questions about your reproductive and medical history prior to your diagnosis.

1 BREAST CANCER MODULE (for breast cancer patients only)

Section 1. Risk factors

1.1 Have you ever been pregnant?

1 Yes
2 No **(Go to Q1.6)**
9 Refused **(Go to Q1.6)**

1.2 How many pregnancies have you had that resulted in a live birth?

__ __ Insert number [1-14]
8 8 NONE **(Go to Q1.6)**
7 7 Don't know/not sure
9 9 Refused

1.3 How old were you when you had your first child?

__ __ Insert age in years
7 7 Don't know/not sure
9 9 Refused

1.4 Did you breastfeed any of your children?

1 Yes
2 No **(Go to Q1.6)**
7 Don't know/not sure **(Go to Q1.6)**
9 Refused **(Go to Q1.6)**

1.5 How many months (total) did you breastfeed your children?

1 Less than 6 months (any time less than 6 months)
2 Less than 12 months (6 months but less than 12 months)
3 Less than 2 years (1 year but less than 2 years)
4 Less than 5 years (2 years but less than 5 years)
5 5 or more years
7 Don't know/not sure
9 Refused

1.6 *//Ask of all respondents//* Had you ever taken hormone replacement therapy (HRT) medications such as Premphase, Prempro, Premarin, Activella)?]

1 Yes
2 No **(Go to Q1.9)**
7 Don't know/not sure **(Go to Q1.9)**
9 Refused **(Go to Q1.9)**

1.7 For how long were you on hormone replacement therapy?

1 Less than 5 years
2 5 to 9 years
3 10 to 14 years
4 15 years or more
7 Don't know/not sure
9 Refused

1.8 About what age were you when you started hormone replacement therapy?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

1.9 Had you ever taken oral contraceptives?

1 Yes
2 No **(Go to Q1.11)**
7 Don't know/not sure **(Go to Q1.11)**
9 Refused **(Go to Q1.11)**

1.10 For how long did you take oral contraceptives?

1 Less than 5 years
2 5 to 9 years
3 10 to 14 years
4 15 years or more
7 Don't know/not sure
9 Refused

1.11 Has anyone in your family been diagnosed with breast cancer?

1 Yes
2 No **(Go to Q1.13)**
7 Don't know/not sure **(Go to Q1.13)**
9 Refused **(Go to Q1.13)**

1.12 Including maternal and paternal relatives, who in your family was diagnosed with breast cancer? [MUL=7]

1 Mother
2 Sister
3 Daughter
4 Grandmother
5 Aunt
6 Granddaughter
8 Other (specify) _____
7 Don't know/not sure
9 Refused

1.13 Prior to your diagnosis, did you ever have any breast biopsies that were abnormal?

1 Yes
2 No
7 Don't know/not sure
9 Refused

1.14 Prior to this diagnosis, had you ever been diagnosed with breast cancer before?

1 Yes
2 No
7 Don't know/not sure
9 Refused

1.15 Had you ever received radiation therapy to the chest for any condition?

1 Yes
2 No
7 Don't know/not sure
9 Refused

1.16 Had you ever taken diethylstilbestrol (DES) therapy during pregnancy to prevent miscarriage or for any other reason?

[INTERVIEWER NOTE: DIETHYLSTILBESTROL IS PRONOUNCED: dye-eth-il-stil-BES-trole]

1 Yes
2 No
7 Don't know/not sure
9 Refused

1.17 About how old were you when you had your first menstrual period?

__ __ Insert age in years
77 Don't know/not sure
99 Refused

1.18 The next few questions are about menopause. Menopause is what some women refer to as the "change of life," when menstruation ends. Have you gone through or are you now going through menopause?

1 Yes, have gone through menopause
2 Yes, now going through menopause
3 No **(Go to PREQ1.20)**
7 Don't know/not sure **(Go to PREQ1.20)**
9 Refused **(Go to PREQ1.20)**

1.19 About how old were you when you began going through menopause?

__ __ Insert age in years [RANGE 1-76, 76=76+]
77 Don't know/not sure
99 Refused

Pre1.20 This next section asks about any screening tests for cancer that you may have received. Screening tests are medical tests that can find cancer in individuals who feel healthy.

Section 2. Screening Behaviors

1.20 A mammogram is an x-ray of each breast to look for breast cancer. Before your diagnosis, not including a diagnostic mammogram, had you ever had a mammogram?

1 Yes
2 No **(Go to Q1.24)**
7 Don't know/not sure **(Go to Q1.24)**
9 Refused **(Go to Q1.24)**

1.21 Prior to your diagnosis, not including a diagnostic mammogram, how long had it been since you had your last mammogram?

[READ IF NECESSARY]

1 Within the past year (anytime less than 12 months ago)
2 Within the past 2 years (1 year but less than 2 years ago)
3 Within the past 3 years (2 years but less than 3 years ago)
4 Within the past 5 years (3 years but less than 5 years ago)
5 5 or more years ago
7 Don't know/not sure
9 Refused

1.22 At what age did you have your first mammogram?

__ __ Insert age in years [RANGE 1-76, 76=76+]
77 Don't know/not sure
99 Refused

1.23 Generally, how often do you have a mammogram?

1 More than once a year
2 Every year
3 Every 2 years
4 Every 3 years
5 Every 5 years
7 Don't know
9 Refused

1.24 Prior to your diagnosis, were you ever recommended to have a screening mammogram but were unable to receive the test?

1 Yes
2 No **(Go to Q1.26)**
7 Don't know/not sure **(Go to Q1.26)**
9 Refused **(Go to Q1.26)**

1.25 Was there any particular reason why you did not receive the recommended test?

__//TEXT=270//_____
_____

1.26 A clinical breast exam is when a doctor, nurse, or other health professional feels the breast for lumps. Prior to your diagnosis, excluding a diagnostic clinical breast exam, had you ever had a clinical breast exam?

1 Yes
2 No **(Go to Q1.30)**
7 Don't know/not sure **(Go to Q1.30)**
9 Refused **(Go to Q1.30)**

1.27 Prior to your diagnosis, about how long had it been since your last clinical breast exam?

[INTERVIEWER: **Exclude diagnostic clinical breast exam]**

1 Within the past year (any time less than 12 months ago)
2 Within the past 2 years (1 year but less than 2 years ago)
3 Within the past 3 years (2 years but less than 3 years ago)
4 Within the past 5 years (3 years but less than 5 years ago)
5 5 or more years ago
7 Don't know/not sure
9 Refused

1.28 At what age did you have your first clinical breast exam?

__ __ Insert age in years [RANGE 1-76, 76=76+]
77 Don't know/not sure
99 Refused

1.29 Generally, how often do you have a clinical breast exam?

1 More than once a year
2 Every year
3 Every 2 years
4 Every 3 years
5 Every 5 years
7 Don't know
9 Refused

1.30 Prior to your diagnosis, about how often did you examine your breasts for lumps?

1	__ __ Times per day
2	__ __ Times per week
3	__ __ Times per month
4	__ __ Times per year
555	Never
777	Don't know/not sure
999	Refused

***Skip to* CORE Section 10. Diagnosis and Treatment**

Now I am going to ask you some questions about your medical history.

2 COLORECTAL CANCER MODULE (for colorectal cancer patients only)

Section 1. Risk factors

2.1 Prior to this diagnosis, had you ever been diagnosed with colorectal cancer before?

1 Yes
2 No **(Go to Q2.3)**
7 Don't know/not sure **(Go to Q2.3)**
9 Refused **(Go to Q2.3)**

2.2 About how old were you when you were previously diagnosed with colorectal cancer?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

2.3 Prior to your diagnosis, had you ever been diagnosed with intestinal polyps?

1 Yes
2 No **(Go to Q2.5)**
7 Don't know/not sure **(Go to Q2.5)**
9 Refused **(Go to Q2.5)**

2.4 About how old were you when you were diagnosed with intestinal polyps?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

2.5 Prior to your diagnosis, had you ever been diagnosed with chronic inflammatory bowel disease (ulcerative colitis)?

1 Yes
2 No **(Go to Q2.7)**
7 Don't know/not sure **(Go to Q2.7)**
9 Refused **(Go to Q2.7)**

2.6 About how old were you when you were diagnosed with chronic inflammatory bowel disease?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

2.7 Has anyone in your family been diagnosed with colorectal cancer?

1 Yes
2 No **(Go to Q2.9)**
7 Don't know/not sure **(Go to Q2.9)**
9 Refused **(Go to Q2.9)**

2.8 Including maternal and paternal relatives, who in your family was diagnosed with colorectal cancer?

[MUL=7]

1 Mother
2 Father
3 Sister
4 Brother
5 Grandfather
6 Grandmother
8 Other (specify) _____
7 Don't know/not sure
9 Refused

2.9 Has anyone in your family been diagnosed with intestinal polyps?

1 Yes
2 No (**Go to Q2.11)**
7 Don't know/not sure (**Go to Q2.11)**
9 Refused (**Go to Q2.11)**

2.10 Who in your family was diagnosed with intestinal polyps?

[MUL=7]

01 Mother
02 Father
03 Sister
04 Brother
05 Grandfather
06 Grandmother
08 Other (specify) _____
77 Don't know/not sure
99 Refused

This next section asks about any screening tests for cancer that you may have received. Screening tests are medical tests that can find cancer in individuals who feel healthy.

Section 2. Screening Behaviors

2.11 A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood. Not including a diagnostic blood stool test, have you ever had this test with a home kit?

1 Yes
2 No **(Go to Q2.15)**
7 Don't know/not sure **(Go to Q2.15)**
9 Refused **(Go to Q2.15)**

2.12 Prior to your diagnosis, how long had it been since you had your last blood stool test using a home kit?

[INTERVIEWER: Exclude diagnostic blood stool test]
[READ IF NECESSARY]

1 Within the past year (anytime less than 12 months ago)
2 Within the past 2 years (1 year but less than 2 years ago)
3 Within the past 3 years (2 years but less than 3 years ago)
4 Within the past 5 years (3 years but less than 5 years ago)
5 5 or more years ago
7 Don't know/not sure
9 Refused

2.13 At what age did you have your first blood stool test?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 7 Refused

2.14 Generally, how often do you have a blood stool test?

1 Less than once a year
2 More than once a year
3 Every year
4 Every 2 years
5 Every 3 years
6 Every 5 years
7 Don't know
9 Refused

2.15 Prior to your diagnosis, were you ever recommended to have a blood stool test but did not receive the test?

1 Yes
2 No **(Go to Q2.17)**
7 Don't know/not sure **(Go to Q2.17)**
9 Refused **(Go to Q2.17)**

2.16 Was there any particular reason why you did not receive the recommended test?

____//TEXT=270//_____
_____
_____

2.17 Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the bowel for signs of cancer or other health problems. Not including diagnostic exam, had you ever had either of these exams?

1 Yes
2 No **(Go to Q2.21)**
7 Don't know/not sure **(Go to Q2.21)**
9 Refused **(Go to Q2.21)**

2.18 Prior to your diagnosis, not including a diagnostic exam, how long had it been since you had your last sigmoidoscopy or colonoscopy?

1 Within the past year (any time less than 12 months ago)
2 Within the past 2 years (1 year but less than 2 years ago)
3 Within the past 5 years (2 years but less than 5 years ago)
4 5 or more years ago
7 Don't know/not sure
9 Refused

2.19 At what age did you have your first sigmoidoscopy or colonoscopy?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

2.20 Generally, how often did you have a sigmoidoscopy or colonoscopy?

1 More than once a year
2 Every year
3 Every 2 years
4 Every 3 years
5 Every 5 years
7 Don't know
9 Refused

2.21 Prior to your diagnosis, were you ever recommended to have a sigmoidoscopy or colonoscopy but did not receive the test?

1 Yes
2 No **(*Skip to* CORE Section 10. Diagnosis and Treatment)**
7 Don't know/not sure **(*Skip to* CORE Section 10. Diagnosis and Treatment)**
9 Refused **(*Skip to* CORE Section 10. Diagnosis and Treatment)**

2.22 Was there any particular reason why you did not receive the recommended test?

__//TEXT=270//_____
_____
_____
_____

***Skip to* CORE Section 10. Diagnosis and Treatment**

Now I am going to ask you some questions about your medical history.

3 PROSTATE CANCER MODULE (for prostate cancer patients only)

Section 1. Risk factors

3.1 Has anyone in your family been diagnosed with prostate cancer?

1 Yes
2 No **(Go to Q3.3)**
7 Don't know/not sure **(Go to Q3.3)**
9 Refused **(Go to Q3.3)**

3.2 Including paternal relatives, who in your family was diagnosed with prostate cancer?

[MUL=7]

1 Father
2 Grandfather
3 Brother
4 Son
5 Grandson
6 Uncle
8 Other (specify) _____
7 Don't know/not sure
9 Refused

3.3 Prior to this diagnosis, were you ever told by a doctor, nurse, or other health professional that you had prostate cancer?

1 Yes
2 No **(Go to Q3.5)**
7 Don't know/not sure **(Go to Q3.5)**
9 Refused **(Go to Q3.5)**

3.4 About how old were you when you were previously diagnosed with prostate cancer?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

This next section asks about any screening tests for cancer that you may have received. Screening tests are medical tests that can find cancer in individuals who feel healthy.

Section 2. Screening Behaviors

3.5 A prostate-specific antigen test, also called a PSA test, is a blood test used to check men for prostate cancer. Not including a diagnostic test, had you ever had a PSA test?

1 Yes
2 No **(Go to Q3.9)**
7 Don't know/not sure **(Go to Q3.9)**
9 Refused **(Go to Q3.9)**

3.6 Prior to your diagnosis, not including a diagnostic test, how long had it been since you had your last PSA test?

[READ IF NECESSARY]

1 Within the past year (anytime less than 12 months ago)
2 Within the past 2 years (1 year but less than 2 years ago)
3 Within the past 3 years (2 years but less than 3 years ago)
4 Within the past 5 years (3 years but less than 5 years ago)
5 5 or more years ago
7 Don't know/not sure
9 Refused

3.7 At what age did you have your first PSA test?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

3.8 Generally, how often did you have a PSA test?

1 More than once a year
2 Every year
3 Every 2 years
4 Every 3 years
5 Every 5 years
7 Don't know
9 Refused

3.9 Prior to your diagnosis, were you ever recommended to have a PSA test but did not receive the test?

1 Yes
2 No **(Go to Q3.11)**
7 Don't know/not sure **(Go to Q3.11)**
9 Refused **(Go to Q3.11)**

3.10 Was there any particular reason why you did not receive the recommended test?

_____//TEXT=270//_____
_____
_____

3.11 A digital rectal exam is an exam in which a doctor, nurse, or other health professional places a gloved finger into the rectum to feel the size, shape, and hardness of the prostate gland. Not including a diagnostic exam, had you ever had a digital rectal exam?

1 Yes
2 No **(Go to Q3.15)**
7 Don't know/not sure **(Go to Q3.15)**
9 Refused **(Go to Q3.15)**

3.12 Prior to your diagnosis, not including a diagnostic exam, how long had it been since you had your last digital rectal exam?

1 Within the past year (any time less than 12 months ago)
2 Within the past 2 years (1 year but less than 2 years ago)
3 Within the past 5 years (2 years but less than 5 years ago)
4 5 or more years ago
7 Don't know/not sure
9 Refused

3.13 At what age did you have your first digital rectal exam?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

3.14 Generally, how often did you have a digital rectal exam?

1 More than once a year
2 Every year
3 Every 2 years
4 Every 3 years
5 Every 5 years
7 Don't know
9 Refused

3.15 Prior to your diagnosis, were you ever recommended to have a digital rectal exam but did not receive the test?

1 Yes
2 No **(*Skip to* CORE Section 10. Diagnosis and Treatment)**
7 Don't know/not sure **(*Skip to* CORE Section 10. Diagnosis and Treatment)**
9 Refused **(*Skip to* CORE Section 10. Diagnosis and Treatment)**

3.16 Was there any particular reason why you did not receive the recommended test?

_____/TEXT=270//_____
_____
_____
_____

***Skip to* CORE Section 10. Diagnosis and Treatment**

Now I am going to ask you some questions about your medical history and some occupational history.

4 LUNG CANCER MODULE (for lung cancer patients only)

Section 1. Risk factors

4.1 Prior to this diagnosis, had you ever been diagnosed with lung cancer before?

1 Yes
2 No **(Go to Q4.3)**
7 Don't know/not sure **(Go to Q4.3)**
9 Refused **(Go to Q4.3)**

4.2 About how old were you when you were previously diagnosed with lung cancer?

__ __ Insert age in years [RANGE 1-76, 76=76+]
7 7 Don't know/not sure
9 9 Refused

4.3 Has anyone in your family been diagnosed with lung cancer?

1 Yes
2 No **(Go to Q4.5)**
7 Don't know/not sure **(Go to Q4.5)**
9 Refused **(Go to Q4.5)**

4.4 Including maternal and paternal relatives, who in your family was diagnosed with lung cancer?

[MUL=7]

1 Mother
2 Father
3 Sister
4 Brother
5 Grandfather
6 Grandmother
8 Other (specify) _____
7 Don't know/not sure
9 Refused

4.5 Prior to your diagnosis, had you ever been told by a doctor, nurse or other health professional that you had tuberculosis?

1 Yes
2 No **(Go to Q4.7)**
7 Don't know/not sure **(Go to Q4.7)**
9 Refused **(Go to Q4.7)**

4.6 At what age were you when you were told you had tuberculosis?

_____ Insert age in years [RANGE 1-76, 76=76+]
77 Don't know/not sure
99 Refused

4.7 Had you ever received radiation therapy to the chest for any condition?

1 Yes
2 No
7 Don't know/not sure
9 Refused

4.8 At the time of your diagnosis, which of the following best describes your residence:

1 Single family, duplex or townhouse
2 Apartment or condominium on the basement 1st or 2nd floor
3 Apartment or condominium above the 2nd floor
4 Trailer or mobile home
5 Other (specify) _____
7 Don't know/Not sure
9 Refused

4.9 Was this residence ever tested for radon?

1 Yes
2 No (Skip to 4.11)
7 Don't know / Not Sure (Skip to 4.11)
9 Refused (Skip to 4.11)

4.10 Did your home pass the test for normal radon levels?

1 Yes
2 No
7 Don't know / Not Sure
9 Refused

//Ask this question to anyone who answered yes to Q6.9.//

4.11 While AT WORK OUTSIDE OF YOUR HOME were you ever exposed to any of the following prior to your diagnosis?

4.11.1 Solvents
4.11.2 Asbestos
4.11.3 Mineral or mining dust
4.11.4 Silica/sand and mineral dust
4.11.5 Gasoline, Diesel Fuel, and Engine Exhaust Fumes
4.11.6 Welding Fumes
4.11.7 Electroplating fumes
4.11.8 Ether (Chloromethyl and/or bischloromethyl
4.11.9 Pesticides
4.12 Arsenic
4.13 Nickel
4.14 Cadmium
4.15 Radon
4.16 Plutonium
4.17 Uranium
4.18 Vinyl chloride
4.19 Nickel chromates
4.20 Coal
4.21 Mustard gas
4.22 Formaldehyde.

1 Yes
2 No
7 Don't know/not sure
9 Refused

//Ask 4.23 and 4.24 questions for each YES answer on Q4.11 above.//

4.23 On average, how often were you exposed to {insert chemical} while working at your job?

1 __ __times per day
2 __ __times per week
3 __ __times per month
4 __ __ times per year
7 7 7 don't know/Not sure
9 9 9 refused

4.24 In total, how long did you work at the job where you were exposed to {insert chemical}?

__ __ months,__ __ years __Weeks
7 7 Don't know
9 9 Refused

Skip to **CORE Section 10. Diagnosis and Treatment**

Delaware Study of Colorectal, Prostate, Female Breast, and Lung and Bronchus Cancers

Interviewer Training Manual

Oct. 18, 2005

Overview

Background

The State of Delaware Advisory Council for Cancer Incidence and Mortality, formed in March 2001, through the Concept Mapping project, compiled its recommendations in the report, *Turning Commitment into Action.* The Council issued the following recommendation with regard to increasing knowledge about cancer in the State of Delaware:

"Conduct a retrospective survey of individuals with cancer or family members of patients to collect information on family history, occupation, lifestyle, diet, exercise, migration, etc. Include only those cancers for which the state is elevated in incidence or mortality. Obtain data necessary to determine which environmental factors might contribute to Delaware's heightened cancer rates."

In response to this recommendation, the State of Delaware, Division of Management, Delaware Health and Social Services (DHSS) issued RFP No. PSC0572 requesting proposals to conduct this survey and other activities related to the Council's recommendations. ORC Macro International was selected as the contractor to work with DHSS to carry out these activities.

Cancer in Delaware

During 1997-2001, Delaware's five-year annual age-adjusted cancer incidence rate was 504.2 per 100,000, 4.8 percent higher than the estimated U.S. rate of 479.7 per 100,000. For men, prostate (28.7 percent), lung (17.7 percent), and colorectal (11.4 percent) were the most commonly diagnosed cancers. For women, breast (29.9 percent), lung (14.1 percent), and colorectal (12.1 percent) were most common. An estimated 4,390 new cases of cancer were diagnosed in Delaware during 2004 (American Cancer Society, Cancer Facts and Figures 2004. Atlanta: American Cancer Society: 2004).

Delaware's five-year annual age-adjusted mortality rate was 218.7 per 100,000 during 1997-2001. Although Delaware's mortality rate decreased for the seventh consecutive five-year time period, Delaware still has one of the highest cancer mortality rates in the nation (ranked sixth for the period 1997-2001). For men, lung (33.6 percent), prostate (10.6 percent), and colorectal (9.4 percent) were the most common causes of cancer deaths. For women, lung (25.7 percent), breast (15.8 percent), and colorectal (10.6 percent) were the most common causes of cancer deaths. An estimated 1,810 Delaware residents died from cancer in 2004 (American Cancer Society, Cancer Facts and Figures 2004. Atlanta: American Cancer Society: 2004).

Delaware has elevated incidence rates when compared to the U.S. for lung and colorectal cancer and elevated mortality rates for lung, colorectal, breast and prostate cancer (Table 1). The incidence/mortality ratio (IMR) compares the death rate to the incidence rate; a ratio of 1.00 indicates for each new case of cancer diagnosed there is one corresponding death from that cancer. A high IMR indicates fewer deaths per case when compared to a lower IMR. For lung and colon cancer, the IMR for Delaware is higher than the U.S. indicating that Delaware's mortality experience compared to incidence for these cancers is better than the U.S. The IMR for breast and prostate cancer in Delaware is lower than the U.S., indicating that Delaware's mortality experience compared to incidence for these cancers is worse than the U.S.

Table 1. Cancer incidence/mortality rates for Delaware compared to the U.S.

	Incidence Rate	Mortality Rate	Incidence/Mortality Ratio
Delaware 1997-2001			
All Cancers	**504.2**	**218.7**	**2.30**
Lung	79.7	64.1	1.24
Colorectal	59.9	22.1	2.71
Breast	135.1	30.2	4.47
Prostate	167.3	32.9	5.09
U.S. 1997-2001			
All Cancers	**470.3**	**199.8**	**2.35**
Lung	61.7	56.2	1.10
Colorectal	53.7	20.8	2.58
Breast	135.2	27.0	5.01
Prostate	172.3	31.5	5.47

Source: Delaware Health and Social Services, SEER, Rates are age-adjusted to the 2000 U.S. Population
Rates highlighted in red are elevated compared to the U.S.

Known Risk Factors for Lung, Colorectal, Breast and Prostate Cancers

Known risk factors for each of the four major cancers are listed below (American Cancer Society, Cancer Reference Information, http://www.cancer.org). The risk for all four cancers increases with age. Lung cancer is the only cancer that has known environmental/occupational risk factors and the only cancer that has not been conclusively linked to behavioral risk factors of diet, obesity and, physical inactivity. Smoking is responsible for over 80% of lung cancers and also has been linked to increased incidence for colorectal cancer.

a) Lung cancer

- Smoking or passive exposure to tobacco smoke
- Radon
- Occupational carcinogens:
  - inhaled chemicals or minerals
  - asbestos
  - radioactive ores
  - fuels
  - diesel exhaust
- Radiation therapy to the lung
- Personal history
- Family history
- Recurring inflammation (tuberculosis or pneumonia)

b) Colorectal cancer

- Personal History
- Family History [Familial Adenomatous Polyposis (FAP) or Hereditary Nonpolyposis Colorectal Cancer (HNPCC)}

- Colorectal Polyps, Chronic Inflammatory Bowel Disease, Diabetes
- High fat diet (animal fats)
- Physical Inactivity
- Obesity
- Smoking
- Alcohol Intake

c) Breast Cancer

- Genes (mutations in the BRCA1 or BRCA2 genes)
- Race (more common in Whites)
- Family history
- Personal history
- Prior abnormal breast biopsy
- Previous breast radiation as child or young adult
- Diethylstilbestrol (DES)
- Early age at menarche
- Nulliparity
- Oral contraceptive use
- Hormone replacement therapy
- Breast-feeding and pregnancy
- Alcohol intake
- Obesity
- High fat diet
- Physical inactivity

d) Prostate Cancer

- Race (more common in African Americans)
- Nationality (more common in North America and Northwestern Europe)
- Family history
- High fat diet
- Obesity
- Physical inactivity

Factors that affect Mortality

The following factors may influence survival for cancer patients:

- Not receiving screening tests for cancer
- Advanced stage at diagnosis
- Diagnostic delays
- Not receiving appropriate cancer treatment
- Treatment delays
- Access to care
- Co-morbid conditions

Study Objectives

Incidence and mortality rates for lung and colorectal cancer are elevated in Delaware compared to the U.S. Incidence rates for breast and prostate cancer in Delaware are lower compared to the U.S. but mortality rates are elevated compared to the U.S. This study will address the underlying reasons for these differences. Specific study objectives are as follows:

- Determine the prevalence of known risk factors for lung, colorectal, breast, and prostate cancers, including environmental and occupational factors, in patients diagnosed with these cancers in Delaware.
- Examine factors that may be related to elevated mortality rates for all cancers, such as stage at diagnosis, race, co-morbid conditions, health care access, and diagnosis/treatment patterns.
- Determine the prevalence of behavioral risk factors, screening use and health care in cancer patients diagnosed with each of the four major cancers, and compare with prevalence rates in the overall Delaware population and with national rates using the Behavioral Risk Factor Surveillance Survey (BRFSS) data.
- Examine screening behaviors for breast, colorectal, and prostate cancer and their relationship with stage at diagnosis.
- Examine geographic differences in cancer rates and risk factors (county level) and migration patterns of cancer patients.

Study Design

This will be a descriptive study of Delaware cancer patients to collect information with respect to risk factors, screening behaviors and health care access prior to their diagnosis, and to collect diagnosis and treatment information related to survival.

The target population for the study will be all patients diagnosed with breast, colorectal, lung or prostate cancer in Delaware during the five-year period, January 1, 1999 to December 31, 2003. All subjects must have been Delaware residents at the time of diagnosis and registered in the Delaware Cancer Registry (DCR). Only new cancer cases among Delaware residents 18 years of age or older for the cancers being studied will be included. Cases identified as deceased will be excluded from the database of individuals eligible for interview. Subjects who have asked not to be contacted through the DCR will also be excluded.

Our goal is to conduct a total of 800 interviews with cancer patients. We will attempt to complete 250 interviews each for breast and prostate cancer and 150 interviews each for lung and colorectal cancer. Due to lower incidence and lower 5-year survival rates for lung and colorectal cancers, we expect the number of completed interviews to be lower for these cancers than for breast and prostate cancers.

Informed Consent

All subjects eligible for interview will be sent a study informed consent packet (Appendix A). Individuals who return the consent form refusing to participate will not be contacted. Additionally, those individuals for whom we are unable to obtain an informed consent response will not be contacted for interview. Only those individuals who return the signed consent form agreeing to participate will be contacted for interview.

Survey Instrument

The survey instrument consists of a core set of questions to be asked for all cancer patients and four separate modules with questions specific to each type of cancer.

The Core component of the survey includes the following sections:

1. Migration
2. Health Status
3. Diet
4. Tobacco Use
5. Alcohol Consumption
6. Demographics
7. Physical Activity
8. Environmental
9. Health Care
10. Diagnosis and Treatment

Modules for each specific cancer cover the following topics:

1. Risk factors specific to the type of cancer
2. Screening use and behaviors

General Instructions

The survey instrument has been pre-tested and should take about 30-45 minutes, depending on the type of cancer.

Many of the questions concerning risk factors and screening behaviors are the same as those on the 2002 Behavioral Risk Factor Surveillance Survey (BRFSS) so that we will be able to make comparisons between cancer patients in Delaware and the general Delaware population using the BRFSS data.

Most of the core sections are concerned with general behavioral and environmental risk factors that were present ***before*** the cancer diagnosis. Individuals will be required to remember as far back as 6 years (for those diagnosed in 1999). It may be difficult for some to remember their lifestyle habits, particularly food consumption and physical activity levels. Please keep this in mind when asking these questions and allow the patient time to recall as best they can. They may be hesitant to answer these questions because they feel they can't remember accurately enough. Please convey that answers don't have to be exact but as close as they can recall. Their best guess is better than no answer at all.

Detailed Instructions for Specific Questions

Introduction

All respondents will already have consented to participate in the interview. The first paragraph is read to confirm their written consent before the interview begins.

At the end of the introduction, we indicate that the questions in the interview should be answered as they relate to their diagnosis for the specific type of cancer and the specific month and year indicated. This is important for three reasons. First, there may be some individuals who have been diagnosed with more than one type of cancer during the time period; these individuals will be asked the core questions only once and then the specific modules for each type of cancer. Second, we are looking at cases between 1999 and 2003; it is possible that an individual has had a subsequent diagnosis for this cancer or a different type of cancer since that time period. Third, the patient may have experienced a recurrence. A recurrence is when the cancer returns after the initial tumor has been treated. A recurrence is technically part of the original diagnosis but the patient may consider it a separate diagnosis. Therefore, we will remind each patient of the date of the diagnosis and the type of cancer that we are interested in.

Section 1 – Migration

All questions in this section are asked from the present time. We are concerned with the number of years the respondent has lived in the county, in Delaware, and in the United States. An estimate is acceptable if the respondent cannot remember exactly.

Section 2 – Health Status

Question 2.2: List of diseases

In general, we will define hypertension, heart disease, diabetes, arthritis and asthma very broadly. So, we will include anyone with one of these diseases whether or not it is treated with medication or insulin. We will include all types of heart disease, from ailments that patients were born with to diseases that have developed over time. For asthma, include it even if it they can manage it currently without medication. High blood cholesterol is defined as anything over 180. Do not include any diseases that developed after the cancer diagnosis.

Questions 2.3 and 2.4 Weight

Again we are concerned with weight just before the diagnosis. This may be difficult for the respondent to recall but please probe to get the best estimate if they are having trouble.

Section 3 - Diet

All questions in this section are concerned with food consumption patterns prior to the cancer diagnosis. Please stress this prior to asking the food frequency questions. Best guesses are O.K. since it is difficult to recall eating patterns even if it were only a week ago.

Section 4 – Tobacco Use

Question 2.1

This is a screener question to determine whether the respondent is considered to be a smoker or non-smoker. Anyone who has smoked less than 100 cigarettes in their lifetime prior to their diagnosis is considered a non-smoker and will not be asked any additional smoking questions.

The remaining questions are concerned with smoking history prior to the diagnosis and whether the respondent was a smoker at the time of diagnosis. If the respondent was not smoking at the time of their diagnosis, we are still interested in past smoking history.

Section 5 – Alcohol Consumption

These questions are concerned with alcohol consumption patterns in the 30 days prior to the cancer diagnosis. Again, this may be difficult for the respondent to recall, but please help them to remember as best they can.

Section 6 - Demographics

Question 6.2: Ethnicity

We will use the NIH definition of ethnicity. A respondent is considered to be Hispanic if he/she is a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. Respondents who do not meet this criterion are considered to be not Hispanic.

Question 6.3 and 6.4: Race

It is up to the respondent to decide which racial group he/she belongs to. If the respondent is truly multiracial, then they should answer Question 2.3 with the race they feel is most representative and Question 2.4 with the secondary race.

We will use the NIH definitions of race as follows:

- American Indian or Alaska Native: A person having origins in any of the original peoples of North, Central, or South America, and who maintains tribal affiliations or community attachment.
- Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- Black or African American: A person having origins in any of the black racial groups of Africa.
- Native Hawaiian or Other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- White: A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Question 6.10: Employment History

If a respondent has worked outside of their home, we are interested in the three jobs they have held for the longest time. If a respondent answers with a job title, such as manager or supervisor, try to determine the industry in which they held this position.

Questions 6.11 to 6.14: Specific Industries

This series of questions targets specific industries where exposures to carcinogenic substances are possible. If the respondent has worked in any of the listed industries, we want to know what their job title was, how long they worked in the job, and how long it has been from the present time since they worked in the job. If a respondent had more than one job title in the industry, we ask the same questions for up to three job titles (those they held for the longest time).

Section 7 – Physical Activity

These questions are concerned with physical activity patterns in the 30 days prior to the cancer diagnosis. We are concerned with two levels of physical activity, moderate and vigorous. Again, this may be difficult for the respondent to recall, but please help them to remember as best they can.

Section 8 – Environmental Exposures

This section is concerned with exposure to second-hand tobacco smoke both at home and in the work place.

Section 9 – Health Care

In this section we are collecting data about access to health care and health care utilization. All of this information pertains to the time period before their cancer diagnosis.

Questions 9.1 and 9.2: Health Insurance

We are interested in any form of health insurance, whether it is through the government, an employer, or the respondent pays for it. If the respondent did not have health insurance, we ask why not. Only read the listed responses if the respondent is not able to give an answer.

Questions 9.4 and 9.5: Medical care

We are interested in whether the respondent had a need for medical care before their diagnosis but were not able to get it. This could be for any medical condition. If they were not able to get medical care then we ask for why not. If there was more than one instance where they were not able to receive medical care, then we are concerned with the latest one.

Question 9.8: Health care provider

This question is asked to determine whether the respondent had a primary health care provider. A primary care provider is responsible for medical and health care, preventive care, help to manage care and will give referrals to specialists. General practitioners, internists, family care doctors, physician assistants, nurse practitioners, and certified nurse midwives are all trained to deliver many aspects of primary care.

Question 9.10: Reasons for no health care provider

In this question, we are trying to systematically collect data on some reasons for not having a primary care provider. Each reason should be read and answered separately.

After completing Section 9 we will skip to the specific cancer module and then return to Section 10.

Section 10 – Diagnosis and Treatment

Question 10.1: Method of detection

This is a close-ended question where we do not read the response categories. However, the three categories provided should account for the majority of the diagnoses. If their cancer was

diagnosed from a screening test then code 01. If they went to the doctor for a routine checkup, then code as 02. Include in this category anyone who had a family member or friend who was recently diagnosed and they were concerned and wanted to be checked as long as they didn't actually have a symptom. If they had any symptoms or were feeling at all unwell and that visit to the doctor led to their cancer diagnosis then code as 03.

Question 10.2: Time to cancer diagnosis

Depending on the answer to 10.1, time is measured from either the screening test, the doctor's visit, or when they experienced their first symptoms to when the diagnosis was clinically confirmed. Sometimes a diagnosis of cancer is confirmed but additional tests are needed to determine the extent of the cancer. For this question we are only concerned with the length of time to when the cancer diagnosis was confirmed and the patient was informed of the diagnosis.

Question 10.5 to 10.7: Recommended treatments

If any type of treatment was recommended to the respondent, the answer to 10.5 should be yes, regardless of whether they actually received the treatment. Treatment recommendations can be made by the doctor that diagnosed the cancer or any other health care provider the patient consulted for the cancer diagnosis. If the patient answers yes then continue to 10.6. Please make sure you read each type of treatment listed and confirm whether the treatment was recommended or not. If more than one treatment was recommended and the patient did not follow through with ANY of the recommended treatments, the answer to 10.7 should be no. Be very sensitive when asking the respondent his/her reasons for not following through with the recommended treatment. Treatment decisions are very stressful for some patients and they may feel threatened if they did not follow their doctor's recommendations.

The remaining questions in this section ask about each type of treatment received, the time from initial diagnosis to the beginning of the treatment, and whether the treatment was completed. If not completed, an open-ended question is asked to find out why. Again, be sensitive since cancer treatments can be very traumatic. We are concerned with surgery, radiation therapy, and chemotherapy for all patients; and with hormonal therapy for breast and prostate cancer patients. For breast cancer, the most common hormonal therapy is Tamoxifen and is usually used in conjunction with some other form of treatment.

Question 10.22: Additional comments

This is the last question of the interview and gives the patient the opportunity to express any other concerns or experiences they may have had with respect to their cancer diagnosis and/or treatment. Please try to keep the respondent focused on issues related to the diagnosis and/or treatment of their cancer.

Closing

At the end of the interview we ask the respondent for their current address so that we may mail them the $25 thank you gift for participating. The closing should be read to all respondents even if they terminate the interview before completing it. Anyone who participates for any part of the interview is entitled to the thank you gift.

We also ask respondents whether they would like to have a copy of the study results mailed to the same address. Study results will be posted on the DHSS website when they become available. You can mention this to the respondent if he/she inquires.

Cancer Modules

Risk factors

For each type of cancer, we ask a series of questions with respect to known risk factors. These include questions about the respondent's past history with cancer and other related diseases or conditions, and the past history of their family members with cancer. If the patient responds that they have been diagnosed with the same type of cancer previously, please make sure that it was a separate diagnosis and not a prior diagnosis of the same cancer. If the respondent is unsure whether it was a separate diagnosis do not include it.

For breast cancer, there is an extensive set of questions with respect to the woman's reproductive history. Most of these questions are very sensitive in nature so please keep this in mind when you reach this part of the interview.

For lung cancer, we ask about radon testing in their homes, and a series of questions about occupational exposures. There is a list of 23 carcinogenic substances that we are interested in. Please make sure that you read through the entire list. If the respondent has been exposed to any of these substances then we ask how long they were in the job that exposed them and how long ago they stopped working that job.

Screening Modules

For breast, prostate and colorectal cancer, we ask a series of questions about screening behaviors. Screening tests are medical tests in healthy individuals to detect cancer before there are any clinical signs or symptoms. If the only time the respondent had the test was for diagnosis of their current cancer, then this is not considered a screening test, but a diagnostic exam and it should not be included. For each type of screening test we are interested in:

- whether the respondent ever had the test
- how long since the last test
- age at which respondent had the test for the first time
- how often they have the test
- if the test was recommended but the respondent was unable to have the test
- the reason they were unable to have the test

We are interested in the following screening tests:

Breast cancer:	*Mammography* – an x-ray of each breast
	Clinical breast exam – health care provider feels the breast for lumps
Prostate cancer:	*PSA* – prostate-specific antigen test, blood test
	Digital rectal exam – health care provider places a gloved finger into the rectum to feel the size, shape and hardness of the prostate gland
Colorectal cancer:	*Home blood stool test* – test kit provided to the respondent to be used at home. The test is used to determine whether the stool contains blood.
	Colonoscopy or *sigmoidoscopy* – tube is inserted into the rectum to view the bowel for signs of cancer or other disease.

Interviewing Policies

Interviewing Individuals with Cancer

This study is comprised of individuals who were diagnosed with colorectal, prostate, female breast, lung or bronchus cancer. For many, this was a definitive event in their life; for others, it was just another medical issue. Also, individuals will be in different places depending on the type of cancer, stage at diagnosis and whether they were diagnosed in 1999 or 2003. So, you will need to be prepared for a wide variation in reactions to the survey in general and to specific questions. One issue to keep in mind, as these individuals went through diagnosis and treatment and learned more about cancer risk factors and screening they may blame themselves for engaging in risk factors or for not receiving appropriate screening. Throughout the interview, please be conscious of never implying that the behavior was to blame for the diagnosis or that had something been done differently the outcome would be different. If at any point during the interview, the respondent asks you for help or support refer them to the American Cancer Society hotline (1-800-ACS-2345).

Protecting Patient Confidentiality

Under the Health Insurance Portability and Accountability Act (HIPAA) of 1996 the Department of Health and Human Services (HHS) developed the Standards for Privacy of Individually Identifiable Health Information (the Privacy Rule). This Rule established national standards for the protection of health information that identifies people, including information of deceased individuals. Three categories of covered entities must comply with the Privacy Rule: health plans, health care clearinghouses, and health care providers who conduct certain health care transactions, such as billing, electronically.

The Delaware Department of Health and Social Services and the Delaware Cancer Registry are NOT covered entities, and therefore, this study does NOT require HIPAA compliance. If a respondent asks about HIPAA or the confidentiality of their data, you can say:

"This study does not fall under HIPAA privacy rules, however, the study has been approved by the Delaware Department of Health and Social Services which requires that the confidentiality of all patient data be strictly protected. Information collected for this study will be used only for this study. Your identity will not be released or disclosed at any time and your information will be locked in cabinets or on password protected files. Any study results that are released will only include groups of people so that you cannot be identified. If you have any questions regarding your rights as a participant in this study contact Linda Barnett, Delaware Department of Health and Social Services, Human Subjects Review Board, (302) 255-9133."

What can we do to ensure that the patient's right to privacy is protected?

- Never walk away from your computer with a respondents' record up on the screen. Always make sure you go back to the "quit" screen before walking away.
- Do not use the word **"cancer"** until you have confirmed that you are speaking with the selected respondent.
- Abide by ORC Macro's standard practice of not discussing respondent's answers or information with people who are not working on this project.

What we do with this study and how we do it makes a difference.

The validity of this survey is important so please:

- Encourage the respondent to complete the interview while being sensitive to their condition.
- Be sensitive to the situation the respondent is in, the lifestyle changes they have had to make because of cancer and the daily challenges they face.
- Be familiar with the questionnaire. Know what each questions is getting at, so you can answer questions the respondents may have, probe to clarify ambiguous answers, and most importantly so that you can quickly start a survey once you see an opportunity, and move quickly through it once you start.
- Know the study's dispositions. Accurately dispositioning calls helps to ensure the efficient management of the sample, and this helps move the study towards completion quickly.
- Know the purpose of the study and recognize its importance so that you can address common respondent issues and concerns.
- Be confident, calm, concerned, interested, respectful, and professional. Your attitude can make all the difference in the world, thus affecting to someone's decision to participate.

Refusals

This survey has a **"1 refusal" policy** for selected respondents. This means:

Only the selected respondent (person who agreed to complete the survey) can refuse to participate.

Please note that hang-ups alone are not considered refusals **(including hang-ups after the name of the client have been read)**. To be considered a refusal, the person needs to explicitly say that they will not do the survey.

Encouraging Participation and Avoiding Refusals

The cancer patients forwarded to Vermont for this survey are willing participants. A few weeks ago, they were sent a packet that included an introductory letter requesting their participation, an information sheet describing the most important aspects of the study, and a consent form. They have already taken the time to fill out their consent form and return it. They have provided telephone numbers and the best times to reach them. Therefore, refusals should be the exception.

There is a lenient "verbatim" policy and protocol on the survey introduction. Please confirm that you are talking to the right person before you mention the study. You have permission to tailor answer respondent concerns and questions as part of encouraging participation and converting refusals. If in the process of introducing the survey, you are interrupted -- obviously you go off script to address the respondent's concerns. After that, please confirm the date of diagnosis and type of cancer before you ask the first question.

We ask that you try to address the reason why the person seems to be refusing and to try and convert it then and there, using whatever means available to you. You have a lot of leeway on how you do this, and the quality assurance staff knows this to be the case. The refusal statement may be a good place to start, but you do not have to rely on only this statement to try and convert the refusal. If you need help the following statements can be read:

- "We received your written consent to participate in this study and are following up with you today to conduct the interview. Is there a reason you are no longer interested in participating in this research? "

- "This is an important survey sponsored by the Delaware Department of Health and Social Services. Its purpose is to expand our understanding of the experience of Delaware residents with cancer."

Tips for Avoiding Survey Refusals

Over the years, ORC Macro has developed an approach to securing interviews. Most respondents who try refusing to complete a survey do so because they feel their important questions or concerns have not been or cannot be addressed by the survey interviewer. ORC Macro's approach to avoiding survey refusals follows a five-step process:

1. Listen to what the respondent is saying: The most important tool interviewers have in avoiding survey refusals is listening to what the respondent is saying or, in some cases not saying, and providing appropriate responses.

2. Answer the respondent's questions and address their concerns. Respondents have many valid reasons for not wanting to participate in the survey. Interviewers must address each reason and provide thoughtful answers to their questions and concerns. Demonstrating respect for respondents in this manner builds the trust and rapport necessary to gain their cooperation.

3. Provide incentives for participation. Underscore the positive reasons for survey participation (e.g., helping to improve healthcare).

4. Offer opportunities to verify the survey. If respondents are suspicious about the survey's validity or purpose, it is important that you provide them with opportunities to verify the survey. Respondents may verify the survey by speaking with the project's supervisor or management staff, calling the 800 number or independently verifying the project with DHSS.

5. Get help. If you encounter a situation where a respondent is upset or has issues you cannot resolve, ask the respondent if they would like to speak with your supervisor or have a member of the project's management team call them back. Sometimes a fresh approach by another person makes a difference.

Be Respectful and Sensitive at all Times

Remember that in agreeing to participate in a survey, the respondents are revealing parts of their character and behavior to a total stranger. This alone deserves respect. Many of the questions on this survey can be extremely personal, and interviewers should be especially alert to respondents' reactions.

Be sensitive at all times. The topic of cancer is potentially painful and distressing for some. While it is important that respondents answer as many questions as possible, we are concerned for their emotional well-being. Interviewers must be able to read the situation and discern if it is difficult for the participant to recall past events or articulate complex emotions, as opposed to another type of resistance to completing the survey.

In sensitive or potentially sensitive situations, keep in mind:

- Any question may be sensitive to a particular respondent. For example, a respondent who has just lost a job may react emotionally to questions on that topic.
- Listen carefully. Adjust your pace or tone of voice if necessary.
- Many respondents who become emotional are adamant that they want to continue the survey. They understand that this is their opportunity to be represented when public policy is being made.
- It is possible to be both neutral and sensitive.

All of these strategies help interviewers stay in control of the interview. Done smoothly and confidently, with a pleasant voice and manner, these techniques can also help you to build rapport with the respondent.

Above all, maintain focus, and listen. Adjust your pace and tone of voice, if necessary. If the respondent is upset, you can offer to suspend the interview until a later time. In general, as long as the respondent is able to focus, and can understand and answer the questions, continue the interview.

Stay In Control of the Interview

The interviewer must establish, and maintain control of, the interview. Here are some situations that can lead to a loss of control:

- The respondent is rushed and "just wants to get this over with."
- The respondent is overly chatty and gives a narrative.
- The respondent is confused or unable to focus.
- The respondent is argumentative.
- The respondent is emotional or giving answers that may be sad, depressing, or alarming.

When presented with these situations, interviewers are sometimes tempted to abbreviate the script, rush the interview, or engage in off-task conversation or other practices that compromise gathering valid data. An interviewer who does these things has lost control of the interview!

Be Prepared to Deal with Problem Situations

Experienced interviewers build up a repertoire of phrases to use in difficult situations that arise during an interview. Here are some suggestions for dealing with difficult situations. Other approaches also may work. Keep track of these in your notes.

The rushed respondent: "We have only about five minutes (give an honest estimate) left until the end. We can do this quickly if we both focus on the questions." Or, "It is possible to

suspend this interview and complete it at another time. We can arrange a time at your convenience. Would you prefer to do that?"

The abrupt respondent: If a respondent has answered a question previously and cuts you off, say, "I have to read every question as it comes up on my screen."

The chatty respondent: "You are making some good points. We'll be getting to some of those questions in a little while. If there is anything we haven't covered by the end of the survey, you can tell me then." Then re-read the question and the choices provided.

The confused respondent: When the respondent is not able to decide on an answer or does not seem to understand the question, the entire question should be repeated. Repeat the question more slowly, making sure you are speaking directly into the mouthpiece. Repeat the answer choices if necessary. The respondent may not have heard the question fully the first time, or might have missed the question's emphasis.

The distracted respondent: Re-read the question and the choices. Try to move the survey along, bringing the respondent back to the next question. Offer to suspend if the respondent is distracted by something else going on in the house. (Offering to suspend sometimes helps a person to focus better!) Listen carefully and try to analyze what's going on. In these situations, you need to use good judgment and deal with the situation accordingly.

The argumentative respondent: Once you get into the survey questions, it is rare to have a respondent become argumentative on this study. You can say, "These are the questions the CDC and your State Department of Health consider to be important." "You can refuse to answer any question you don't want to answer. Remember, all your answers are confidential."

The forward respondent: One way to deal with a respondent who answers the question before you have read the whole question is to go ahead and read the whole question every time or say, "I have to read every question in full." Respondents then get the idea that they will have to listen to the whole question before giving an answer.

The emotional respondent: Above all, maintain focus, and listen. Adjust your pace and tone of voice, if necessary. If the respondent is upset, you can offer to suspend the interview until a later time. In general, as long as the respondent is able to focus, and can understand and answer the questions, continue the interview. After a difficult interview, take a deep breath and count to five to clear your mind before beginning the next interview. Promise yourself to take extra good care of yourself on the next break.

Because this survey deals with some sensitive issues, you may find that respondents offer very long responses to multiple-choice or open-ended questions. When this happens, it is important NOT to dismiss the respondent while s/he shares his/her experiences, but at the same time, it is necessary to quickly move the conversation back to the survey questions. This can be very tricky and requires the interviewer to balance sensitivity with directness.

Recording Open-Ended Responses

There are very few open-ended questions in this study. Please accurately record the respondents answers VERBATIM and be careful with your spelling. The response is only useful if it can be read and understood. Some respondents may have difficultly keeping focus and keeping their answers relevant to the question being asked. In such cases, gently guide the

respondent back to a relevant response. This does not mean leading the respondent to answer in a particular way but rather repeating the question or asking the respondent how their answer applies to the question.

Survey Information

Contact Information: A respondent may seek to verify the validity and legitimacy of the study. Please provide the following information so that he/she can do this:

Denise Welch, DHSS, Division of Public Health at 302-744-4541, or
Linda Barnett, DHSS, Human Subjects Review Board at 302-255-9133

If the respondent is extremely angry and demands to speak with someone in charge, you should allow the respondent to speak with your supervisor, who may then refer the respondent on to project management.

Answering Machines: Interviewers are able to leave answering machine messages about the study on respondent answering machines. The CATI script is automated to prompt interviewers to leave a message every 4th and 9th answering machine disposition. There is a script provided for the appropriate message. It reads as follows:

"Hello, I am calling from ORC Macro on behalf of the Delaware Department of Health and Social Services with regard to the study you recently consented to participate in. I'm sorry to have missed you. We will try again later. You may also call us at 1-800-639-2030 to schedule a time for the interview."

Privacy Managers: Occasionally, it is not possible to complete a telephone call because of call blocking or a privacy manager system. If the dialer should give you a call that has a privacy manager or calling blocking system on it do the following:

- If you have the option to say a name, say "Calling for the Delaware Department of Health and Social Services".
- If you have the option to press a specified number to indicate you are not soliciting, press the specified number.
- If you are presented with no options and simply told there is call blocking or a privacy manager, then code the call as a 017- Privacy Manager.

Respondents with privacy managers and call blocks that we are unable to get through will be followed-up by mail. The respondents will be given the toll-free number, 1-800-639-2030 for the call center to call-in and complete the study at their convenience.

Callbacks: Callbacks are to be kept at a minimum for this project. A scheduled callback (104) should only be used if the respondent will give a specific day and time to be called back. And when scheduling a callback, only schedule between the hours of 9:00AM and 8:45PM. For any other situation that requires a callback use the unscheduled callback option (105).

Special Interviewer Types: There are no special interviewer types for this study.

Quality Assurance: Quality assurance monitors will be paying particular attention to the following items: that you accurately, correctly, and completely record address information, correct dispositioning of calls, working hard to avoid refusals and encourage participation, and adhering to confidentiality procedures.

Table of Survey Dispositions

Terminal Dispositions

Disposition Code	Name	Description
002	Hard Refusal	Study has a one-refusal policy for selected respondents. Hang-ups are not considered refusals. However, after 5 hang-ups (disposition 156) a hard refusal is automatically assigned. A refusal by a nonselected respondent does not count as a refusal.
003	Language Barrier	Respondents or households that speak a language other than English should be assigned a language barrier disposition. Interviewers should always attempt to determine whether there is someone in the household who speaks English prior to assigning a “language barrier” disposition.
005	Non-working Number	This option should be used in cases where the respondent provides a non-working number (e.g., number disconnected, current number forwarded to a new phone number) .
006	Business Phone	Should be assigned to phone numbers where it is determined that the phone number does not belong to the selected respondent; instead, the number belongs to a business, government office, etc. where the selected respondent does NOT work. Fax machine and computer modem answers should NOT be assigned to the business number disposition.
007	Pager, Phone Booth	Use for any pager number if you get a recording from the service. If you get an operator recording informing you this is a pay phone.
015	Unable to Be Interviewed	Use for respondents are unable to be interviewed for reasons such as physical impairment

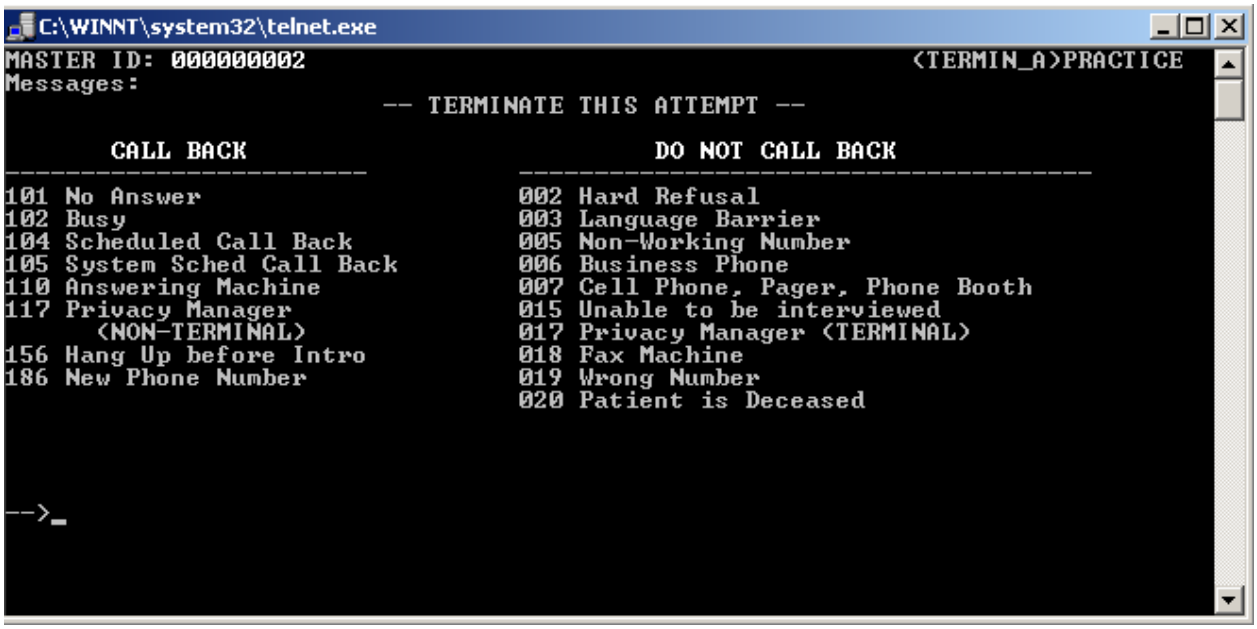
Disposition Code	Name	Description
017	Privacy Manager/ Call Blocking	Some phone numbers may have an electronic call blocking or privacy manager feature that does not accept calls unknown phone numbers. Generally speaking, you will hear a recording that indicates something to this effect. The "privacy manager/call blocking" disposition should be assigned to these cases.
016	Wrong number	It is possible that the respondent gave us a bad telephone number or the number was entered incorrectly. Use if the number called connects with a place where the respondent cannot be reached.
018	Fax Machine/ Modem	Generally speaking, there should not be fax machine or modem answers to interviewers. Accordingly, this option should only be used in cases where the respondent provided a fax machine or modem answered phone number.
019	Mid-terminate Refusal	The respondent terminates the call or refuses to complete the survey after completing the interview screener (Q. 1-4). The computer assigns this disposition. **NOTE: If the respondent just hang-ups during the interview, you must try the number again before suspending. If you reach the respondent and they refuse, code as a mid-terminate refusal. If they do not answer, code as a mid-terminate callback.**
020	Patient Deceased	When the interviewer is told that the patient is no longer living

Non-Terminal Dispositions

Disposition Code	Name	Description
101	No Answer/ Still Ringing	Call attempt to phone number results in repeated ringing without an answer from an individual or answering machine. Generally speaking, the dialer should not give "no

Disposition Code	Name	Description
		answer"/ "still ringing" telephone numbers to interviewers. Accordingly, this option should only be used in cases where the dialer incorrectly provides an interviewer with an answer/still ringing telephone number.
102	Busy	Call attempt to number results in repeated busy signal. Generally speaking, the dialer should not give busy telephone numbers to interviewers. Accordingly, this option should only be used in cases where the dialer incorrectly provides an interviewer with busy phone number.
104	Scheduled Call Back	To be used when an eligible respondent will commit to a specific time and date. For example, "October 31, 2003 at 10:00 AM" and not " Evenings after 6:00 PM" or "Mondays." Interviewers should not schedule a callback for date or time call room is not open.
105	System Scheduled Call Back	All calls that do not result in an ANSWERING MACHINE, SCHEDULED CALL BACK, BUSY, or NO ANSWER should be given a system scheduled call back disposition.
110	Answering Machine	Call attempt to a number results in a residential answering machine recording. Interviewers should not leave answering machine messages about the study unless prompted by the script.
117	Privacy Manager	Numbers that have a privacy manager in which you are able to enter information in attempt to make contact with the respondent. **If the privacy manager contacts you to an answering machine- Dispo the call as 110-answering machine**
156	Hung-up	Respondent terminates call prior to hearing survey introduction or "Delaware Department of Health and Social Services."

Disposition Code	Name	Description
		There is a “3 Hang-up” Policy. After the third hang-up a record should be terminated as a hard refusal (disposition 02) automatically by the computer.
186	New Phone Number	Use if the number called connects with a place where the respondent cannot be reached but you are able to obtain a new number to try the respondent



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