Cancer Survivorship Among Kansas Adults
2016 Kansas Behavioral Risk Factor Surveillance System
March 2019
Cancer Survivorship Among Kansas Adults, BRFSS 2016

Kansas Department of Health and Environment
Lee A. Norman, M.D., Secretary

Ryan Lester, MPH
Director, Bureau of Health Promotion, KDHE

Julie Sergeant, PhD
Section Director, Kansas Cancer Prevention and Control Programs
Bureau of Health Promotion, KDHE

Report Preparation:
Pratik Pandya, MPH
Advanced Epidemiologist
Bureau of Epidemiology & Public Health Informatics, KDHE

Report Supervision:
Belle Federman, ScD
Senior Epidemiologist
Bureau of Epidemiology & Public Health Informatics, KDHE

For Additional Information, Please Contact:
Bureau of Health Promotion
1000 SW Jackson, Suite 230
Topeka, KS 66612
(785) 291-3742
healthpromotion@kdheks.gov
www.kdheks.gov/bhp

Kansas Department of Health and Environment (www.kdheks.gov) Mission:
To protect and improve the health and environment of all Kansans.

Project Funding: Partial funding for the 2016 Behavioral Risk Factor Surveillance System Program was provided by cooperative agreement 6NU58DP006025-02-00 and Increasing the Implementation of Evidence-Based Cancer Survivorship Interventions to Increase Quality and Duration of Life among Cancer Patients cooperative agreement DP006113 from the Centers for Disease Control and Prevention, Atlanta GA. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

Kansas Department of Health and Environment
Bureau of Health Promotion
January 2019
# Table of Contents

Executive Summary 1

Introduction 3

**Health Status of Cancer Survivors** 5

- Types of Cancer Among Cancer Survivors 10
- Age of Diagnosis Among Cancer Survivors 11
- Basic Treatment Information 15
- Source of Health Care 16
- Follow-Up Care 17
- Health Insurance Status/Issues 18
- Clinical Trial Participation 19
- Other Outcomes Such as Pain 19
- Resources for Cancer Survivors 20

Conclusion 21

Technical Notes 23

Appendix 27

References 31
Executive Summary

According to the Centers for Disease Control and Prevention (CDC), the term cancer survivor refers to a person who has been diagnosed with cancer, from the time of diagnosis throughout his or her life.\(^1\) Cancer survivors are living longer due to improvements in health care systems and advances in medical research.\(^2\) Over the years, various stakeholders have identified issues facing cancer survivors and have developed recommendations for cancer survivorship care approaches.\(^3\) The state cancer coalition, the Kansas Cancer Partnership (KCP), prioritized the need to address cancer survivorship issues and included relevant strategies in the 2012-2016 Kansas Cancer Prevention and Control Plan.

This report highlights cancer survivor health status, follow-up care (who is providing the care and where), treatment plans and pain management among the cancer survivors.

Key findings:

- In 2016, about 6.6 percent of Kansas adults aged 18 years and older had ever been diagnosed with cancer excluding skin cancer.
- About 6.2 percent of Kansas adults aged 18 years and older had ever been diagnosed with skin cancer.
- In all, about 11.5 percent of Kansas adults aged 18 years and older had ever been diagnosed with cancer, henceforth termed in this report as cancer survivors.
- A significantly higher percentage of cancer survivors were seen among females, older adults, Non-Hispanic Whites, adults who are college graduates, adults who have insurance and adults living with a disability.
- About one in five cancer survivors were current smokers; one in three cancer survivors do not participate in any physical activity; five in seven cancer survivors are overweight or obese; two in five survivors reported their health to be fair or poor; about one in five do not have a personal health care provider and about 13 percent could not see their doctor because of cost.
- Cancer survivors were more likely to have fair or poor self-perceived health status and are physically unhealthy compared to those without the diagnosis of cancer.
- About 18 percent of cancer survivors have more than one type of cancer.
- Most of the cancer survivors (50 percent) received their first diagnosis between the ages of 40 and 64 years.
• Only taking into account the most recently diagnosed cancer, skin cancers were the most prevalent in both males and females. In males, the next most prevalent were male reproductive cancers (prostate or testicular). Among female survivors, the next most prevalent were breast cancer, followed by female reproductive cancers (cervical, uterine, or ovarian).

• Among cancer survivors, 76 percent have completed their treatment (surgery, radiation therapy, chemotherapy or chemotherapy pills).

• Of those cancer survivors who have completed their treatment, 72.5 percent receive their health care through family or general practitioners.

• Only about half of the survivors (49 percent) who have completed their cancer treatment had ever received a written summary of all the cancer treatments that they received.

• About 77 percent of survivors who completed their treatment received instructions from their health care provider regarding where to return or who to see for their routine check-ups. However, among those who received instructions, only 80 percent received the instructions in writing.

• About three percent of survivors who completed their treatment reported that they did not have health insurance that paid for all or part of their cancer treatment when they were diagnosed with their most recent cancer.

• About seven percent of survivors reported that they were denied health insurance or life insurance coverage because of their cancer.

• About five percent of survivors who completed their treatment participated in a clinical trial as a part of their cancer treatment.

• About eight percent of survivors who completed their treatment were currently experiencing physical pain because of cancer or its treatment.

The information above indicates the need for implementing cancer survivorship care approaches to improve the health status of the cancer survivors and to address survivorship needs.
Introduction

According to the Centers for Disease Control and Prevention (CDC), the term cancer survivor refers to a person who has been diagnosed with cancer, from the time of diagnosis throughout his or her life.¹

Due to improvements in early detection, and better cancer treatments and research, adults who are told they have cancer are living longer.²

The CDC and the LIVESTRONG Foundation developed the National Action Plan for Cancer Survivorship: Advancing Public Health Strategies to identify and prioritize cancer survivorship needs and strategies that will ultimately improve the overall experience and quality of life of cancer survivors. It identifies and prioritizes cancer survivorship needs and proposes strategies for addressing those needs within domains: 1) surveillance and applied research, 2) communication, education, and training, 3) programs, policies and infrastructure, and 4) access to quality research; communication, education, and training; programs, policies, and infrastructure; and access to quality care and services.³ The state cancer coalition, the Kansas Cancer Partnership (KCP), prioritized the need to address cancer survivorship issues. The strategies to address these issues were included in the 2012-2016 and 2017-2022 Kansas Cancer Prevention and Control Plans.

Kansas was one of six states that received funding through a cooperative agreement with the CDC for “Kansas Survivor Care Quality Initiative” for 2015-2018. The main strategies employed included increasing surveillance using the Behavioral Risk Factor Surveillance System (BRFSS), increasing use of survivorship care plans, implementing evidence-based interventions through community-clinical linkages, increasing patient navigation programs to assist cancer survivors, and increasing education of providers on cancer survivor care. These strategies help to identify and characterize the cancer survivor population specifically, and address survivor needs from diagnosis through treatment and post-treatment.

To identify cancer survivorship needs and the health issues among survivors, the Kansas Comprehensive Cancer Prevention and Control Programs and Kansas BRFSS program included the cancer survivorship module in the 2016 Kansas BRFSS survey.

BRFSS is the world’s largest annual population-based survey system tracking health conditions and risk behaviors in the United States since 1984. It is coordinated by the CDC and is conducted in every state and several U.S. territories. The Kansas Department of Health and Environment (KDHE), Bureau of Health Promotion (BHP) conducted the first BRFSS survey in Kansas in 1990 as a point-in-time survey. Since
1992, BHP has conducted the Kansas BRFSS survey annually, thus providing the ability to examine the burden and monitor the trends of various diseases and risk factors/behaviors. BRFSS is the only source of population-based data for several public health indicators in Kansas. The 2016 Kansas BRFSS was conducted among non-institutionalized adults aged 18 years and older living in private residences and college housing with landline and/or cell phone service.

The BRFSS survey methodology includes: 1) use of the dual sampling frame (landline and cellular telephone samples) and 2) use of more advanced and statistically sophisticated “Iterative Proportional Fitting” weighting methodology (also referred to as “Raking” methodology).

The data obtained from the cell phone survey component is combined with the data obtained from the landline telephone survey component and then weighting techniques, using the iterative proportional fitting (raking), are applied to generate a combined, weighted dataset. This process accounts for unequal selection probability resulting from the sample design and for differential response rates by demographic groups. The resulting weighted dataset was used to generate representative, state-level estimates of the adult population ages 18 years and older. (For more information, please see technical notes provided at the end of the report)

The BRFSS Cancer Survivorship Module includes questions related to follow-up care (who is providing the care and where), treatment plans, and pain management among the cancer survivors. Kansas BRFSS agreed to include the cancer survivorship module in its entirety annually throughout the project period. These data were also collected in the 2017 survey. Currently, Kansas BRFSS is collecting these data in the 2018 survey.

This population-based surveillance information will help in cancer control planning and implementing activities for cancer survivors in Kansas.
Health Status of Cancer Survivors

In 2016, about 6.6 percent of Kansas adults aged 18 years and older had ever been diagnosed with cancer excluding skin cancer. About 6.2 percent of Kansas adults aged 18 years and older had ever been diagnosed with skin cancer. In all, about 11.5 percent of Kansas adults aged 18 years and older had ever been diagnosed with cancer and are henceforth termed in this report as cancer survivors.

Cancer survivors often face many challenges because of their cancer diagnoses and treatments. Moreover, cancer survivors are at higher risk for recurrence and developing second cancers due to effects of treatment, lifestyle behaviors, genetics or risk factors that contributed to the first cancer. Other concerns may arise in cancer survivors like cognitive decline, emotional issues and physical limitations.

Cancer survivors can enhance their quality of life, maintain their health and improve survival. We need to address the needs of cancer survivors and provide care to reduce disability, other health outcomes related to these cancer diagnosis or its treatment, and cancer recurrence and progression.

In 2016, approximately one in nine (11.5 percent) of Kansas adults aged 18 years and older were cancer survivors. The percentage of Kansas cancer survivor adults aged 18 years and older was significantly higher among:

- Females compared with males
- Older adults compared with younger adults
- Non-Hispanic White adults compared with Non-Hispanic African-American, Non-Hispanic Other/Multiracial or Hispanic adults
- Adults who were college graduates compared with adults with less than high school education
- Adults who were retired compared with adults who are employed for wages or are self-employed
- Adults who were unable to work compared with adults who are employed for wages or are self-employed
- Adults who were living with a disability compared with adults who were living without a disability
- Adults who had insurance compared with adults who had no insurance
Prevalence estimates were also analyzed by rural-urban status. The population density peer groups are defined as follows: Frontier (fewer than 6 persons per square mile), Rural (6 to less than 20 persons per square mile), Densely-Settled Rural (20 to less than 40 persons per square mile), Semi-Urban (40 to less than 150 persons per square mile), and Urban (150 or more persons per square mile).

In this report, frontier, rural and densely-settled rural were grouped together and classified as rural counties; semi-urban and urban were grouped together and classified as urban counties. In other words, counties with less than 40 persons per square mile were termed as rural and more than 40 persons per square mile were termed as urban.

In 2016, approximately 11.8 percent (95% CI: 10.8%-12.9%) of Kansas adults aged 18 years and older living in rural counties were cancer survivors. Approximately 11.4 percent (95% CI: 10.6%-12.1%) of Kansas adults aged 18 years and older living in urban counties were cancer survivors.

There was no significant difference in the percentage of cancer survivors by rural-urban status.
**Table 1: Cancer Survivors Aged 18 Years and Older by Socio-demographic Groups, 2016 KS BRFSS**

<table>
<thead>
<tr>
<th>Socio-demographic Groups</th>
<th>Weighted percentage</th>
<th>95% Confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>11.5</td>
<td>10.9-12.1</td>
</tr>
<tr>
<td>Gender*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10.5</td>
<td>9.7-11.3</td>
</tr>
<tr>
<td>Female</td>
<td>12.5*</td>
<td>11.7-13.3</td>
</tr>
<tr>
<td>Age Groups*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24 years</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>25-34 years</td>
<td>2.0</td>
<td>1.2-2.7</td>
</tr>
<tr>
<td>35-44 years</td>
<td>4.7</td>
<td>3.3-6.0</td>
</tr>
<tr>
<td>45-54 years</td>
<td>9.8</td>
<td>8.4-11.3</td>
</tr>
<tr>
<td>55-64 years</td>
<td>15.3</td>
<td>13.7-16.9</td>
</tr>
<tr>
<td>65+ years</td>
<td>30.8</td>
<td>29.2-32.4</td>
</tr>
<tr>
<td>Race/Ethnicity ¶*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, NH</td>
<td>11.1</td>
<td>10.5-11.7</td>
</tr>
<tr>
<td>African American, NH</td>
<td>5.1</td>
<td>3.4-6.9</td>
</tr>
<tr>
<td>Other/Multi-Race, NH</td>
<td>7.1</td>
<td>4.6-9.5</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5.2</td>
<td>3.0-7.5</td>
</tr>
<tr>
<td>Education*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>7.8</td>
<td>3.6-7.3</td>
</tr>
<tr>
<td>High school graduate or G.E.D.</td>
<td>11.3</td>
<td>10.2-12.4</td>
</tr>
<tr>
<td>Some college</td>
<td>11.4</td>
<td>10.3-12.4</td>
</tr>
<tr>
<td>College graduate</td>
<td>13.2</td>
<td>12.2-14.2</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $15,000</td>
<td>9.7</td>
<td>7.5-11.9</td>
</tr>
<tr>
<td>$15,000 to $24,999</td>
<td>11.2</td>
<td>9.5-13.0</td>
</tr>
<tr>
<td>$25,000 to $34,999</td>
<td>13.3</td>
<td>11.3-15.3</td>
</tr>
<tr>
<td>$35,000 to $49,999</td>
<td>12.6</td>
<td>10.8-14.4</td>
</tr>
<tr>
<td>$50,000 or more</td>
<td>10.7</td>
<td>9.8-11.6</td>
</tr>
<tr>
<td>Employment Status*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed for wages/Self-employed</td>
<td>6.9</td>
<td>6.3-7.6</td>
</tr>
<tr>
<td>Out of work</td>
<td>7.8</td>
<td>5.0-10.6</td>
</tr>
<tr>
<td>Homemaker/Student</td>
<td>5.1</td>
<td>4.0-6.3</td>
</tr>
<tr>
<td>Retired</td>
<td>29.8</td>
<td>28.1-31.6</td>
</tr>
<tr>
<td>Unable to work</td>
<td>20.2</td>
<td>16.5-24.0</td>
</tr>
<tr>
<td>Disability*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with a disability</td>
<td>18.9</td>
<td>17.3-20.5</td>
</tr>
<tr>
<td>Living without a disability</td>
<td>9.3</td>
<td>8.7-9.9</td>
</tr>
<tr>
<td>Insurance*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uninsured</td>
<td>3.7</td>
<td>2.7-4.8</td>
</tr>
<tr>
<td>Insured</td>
<td>12.7</td>
<td>12.0-13.3</td>
</tr>
<tr>
<td>Population Density</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>11.8</td>
<td>10.8-12.9</td>
</tr>
<tr>
<td>Urban</td>
<td>11.4</td>
<td>10.6-12.1</td>
</tr>
</tbody>
</table>

* Indicates statistically significant between-group differences (see narrative)

¶ Prevalence estimates for race and ethnicity were age-adjusted to the U.S. 2000 standard population

— Insufficient sample

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
Health Risk Behaviors, Health Status and Health Care Access Among Cancer Survivors

Cancer survivors are at increased risk for cancer recurrence compared with persons who have never had cancer.\(^9,10\) Engaging in healthy lifestyle behaviors has been shown to prevent new cancer and help decrease the chances of recurrence. Moreover, public health practitioners, researchers, and comprehensive cancer control programs can guide cancer survivors to appropriate resources for behavior change.\(^11\)

To compare health status, health risk behaviors and health care access between cancer survivors and those who do not have cancer in Kansas, an adjusted prevalence analysis was conducted by adjusting for age, gender, race/ethnicity, employment status and education status.

After adjusting for age, gender, race/ethnicity, employment status and education status:

- About one in five cancer survivors were current smokers; one in three cancer survivors did not participate in any physical activity; five in seven cancer survivors were overweight or obese; two in five survivors reported their health to be fair or poor; about one in five did not have a personal health care provider and about 13 percent could not see their doctor because of cost.
- Higher prevalence of self-reported fair/poor health was seen among cancer survivors compared to those without a diagnosis of cancer (39.7 percent vs. 25.5 percent).
- Higher prevalence of being physically unhealthy for ≥ 14 days in the past 30 days was seen among cancer survivors compared to those without a diagnosis of cancer (21.2 percent vs. 14.0 percent)
- No significant difference was seen in the prevalence of current smoking, binge drinking, heavy drinking, not being physically active in the past 30 days, weight status, being emotionally unhealthy for ≥ 14 days in past 30 days, insurance status, not having a personal health care provider, and not being able to see a doctor because of cost among cancer survivors compared to those without a diagnosis of cancer.
Table 2: Adjusted prevalence of health risk behaviors, health status, and health care access indicators among Kansas adults 18 years and older, by the history of cancer diagnosis, 2016 KS BRFSS

<table>
<thead>
<tr>
<th>Current Smoker</th>
<th>Binge Drinking</th>
<th>Heavy Drinking</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adj. % 95% CL</td>
<td>Adj. % 95% CL</td>
</tr>
<tr>
<td>Adults diagnosed with cancer (Cancer Survivors)</td>
<td>18.5 15.2-22.3</td>
<td>9.1 6.9-11.9</td>
</tr>
<tr>
<td>Adults without cancer diagnosis</td>
<td>18.6 16.5-20.9</td>
<td>8.1 6.7-9.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No physical activity in past 30 days</th>
<th>Overweight/obese (BMI≥25 kg/m²)</th>
<th>Obese (BMI≥30 kg/m²)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adj. % 95% CL</td>
<td>Adj. % 95% CL</td>
<td>Adj. % 95% CL</td>
</tr>
<tr>
<td>Adults diagnosed with cancer (Cancer Survivors)</td>
<td>31.8 27.9-36.0</td>
<td>70.5 66.3-74.3</td>
</tr>
<tr>
<td>Adults without cancer diagnosis</td>
<td>31.1 28.3-34.0</td>
<td>72.9 69.9-75.7</td>
</tr>
</tbody>
</table>

Adj. % = Percentages are predicted population margins; adjusted for age, gender, race/ethnicity, employment status, and education level.
Unadj. % = Unadjusted percentage.
95% CL = 95 percent confidence interval.
Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
### Table 2: (cont.) Adjusted prevalence of health risk behaviors, health status, and health care access indicators among Kansas adults 18 years and older, by the history of cancer diagnosis, 2016 KS BRFSS

<table>
<thead>
<tr>
<th></th>
<th>Self-reported fair/poor health</th>
<th>Physically unhealthy for ≥ 14 days in past 30 days</th>
<th>Emotionally unhealthy for ≥ 14 days in past 30 days</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adj. %</td>
<td>Adj. %</td>
<td>Adj. %</td>
</tr>
<tr>
<td></td>
<td>95% CL</td>
<td>95% CL</td>
<td>95% CL</td>
</tr>
<tr>
<td>Adults diagnosed with cancer (Cancer Survivors)</td>
<td>39.7*</td>
<td>22.5*</td>
<td>14.4</td>
</tr>
<tr>
<td></td>
<td>34.8-44.9</td>
<td>18.6-27.0</td>
<td>11.4-18.0</td>
</tr>
<tr>
<td>Adults without cancer diagnosis</td>
<td>25.5*</td>
<td>15.0*</td>
<td>11.6</td>
</tr>
<tr>
<td></td>
<td>22.7-28.6</td>
<td>12.8-17.4</td>
<td>9.8-13.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Uninsured</th>
<th>Do not have personal health care provider</th>
<th>Could not see the doctor because of cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adj. %</td>
<td>Adj. %</td>
<td>Adj. %</td>
</tr>
<tr>
<td></td>
<td>95% CL</td>
<td>95% CL</td>
<td>95% CL</td>
</tr>
<tr>
<td>Adults diagnosed with cancer (Cancer Survivors)</td>
<td>11.3</td>
<td>18.0</td>
<td>13.2</td>
</tr>
<tr>
<td></td>
<td>8.1-15.4</td>
<td>14.2-22.6</td>
<td>10.2-16.8</td>
</tr>
<tr>
<td>Adults without cancer diagnosis</td>
<td>14.7</td>
<td>23.8</td>
<td>13.8</td>
</tr>
<tr>
<td></td>
<td>12.5-17.2</td>
<td>21.3-26.6</td>
<td>12.0-15.9</td>
</tr>
</tbody>
</table>

Adj. % = Percentages are predicted population margins; adjusted for age, gender, race/ethnicity, employment status, and education level.
Unadj. % = Unadjusted percentage.
95% CL = 95 percent confidence interval.
* Indicate statistically significant between-group differences.
Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
Types of Cancer Among Cancer Survivors

Among Kansas adult cancer survivors in 2016, 81.6 percent had only one type of cancer. However, 15 percent had two types of cancers, and 3.4 percent had three or more types of cancer.

There is no significant difference in the percentage of types of cancer among cancer survivors by rural-urban status.

Figure 1: Percentage of different types of cancer among cancer survivors aged 18 years and older, 2016 KS BRFSS

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
Age of Diagnosis Among Cancer Survivors

About 50 percent of adults in Kansas were told they had cancer when they were 40 to 64 years old, 19 percent when they were 65 to 74 years old, 15 percent when they were 20 to 39 years old, 13 percent when they were 75 years old and older, and 3 percent when they were 19 years old or younger.

There is no significant difference in age of diagnosis among cancer survivors by rural-urban status.

Figure 2: Age at first diagnosis of cancer among cancer survivors aged 18 years and older, 2016 KS BRFSS

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
The most prevalent cancers among all cancer survivors in 2016 were skin cancers (41.0 percent), followed by breast cancer (15.2 percent), female reproductive cancers (10.0 percent) and male reproductive cancers (9.4 percent).

No significant difference is seen in the percentage of skin, gastrointestinal, male reproductive cancers, female reproductive cancers, breast, and other cancers among cancer survivors by rural-urban status.

Due to inadequate sample, estimates are not generated for all types of cancers.

**Figure 3: Prevalence of cancer type among cancer survivors aged 18 years and older, 2016 KS BRFSS**

- **Skin Cancers**: 41.0 percent (95 percent CL: 37.0-44.9)
- **Breast Cancer**: 15.2 percent (95 percent CL: 12.5-18.0)
- **Female Reproductive (Gynecologic) Cancers**: 10.0 percent (95 percent CL: 7.2-12.7)
- **Male Reproductive Cancers**: 9.4 percent (95 percent CL: 7.4-11.5)
- **Others**: 8.3 percent (95 percent CL: 6.2-10.4)
- **Gastrointestinal Cancers**: 6.3 percent (95 percent CL: 4.4-8.4)
- **Urinary Cancers**: 2.9 percent (95 percent CL: 1.5-4.3)
- **Leukemia/Lymphoma (Lymph Nodes and Bone Marrow)**: 2.7 percent (95 percent CL: 1.5-4.0)
- **Head/Neck Cancers**: 2.7 percent (95 percent CL: 1.4-4.0)
- **Thoracic (Heart and Lung) Cancers**: 1.5 percent (95 percent CL: 0.3-2.7)

95 percent CL = Confidence interval at the 95 percent probability level.
For cancer survivors who reported more than one cancer diagnosis, the cancer type reported was the most recently diagnosed cancer.
Female Reproductive (Gynecological) Cancer includes cervical, endometrial, and ovarian cancer.
Male Reproductive Cancers includes prostate and testicular cancer.
Other Cancers includes bone, brain, neuroblastoma, and other not specified cancer types.
Gastrointestinal Cancers includes colon, esophageal, liver, pancreatic, rectal, and stomach cancer.
Head/Neck Cancers includes head and neck, oral, throat, thyroid, and larynx cancer.
Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
The most prevalent cancers among male cancer survivors in 2016 were skin cancers (48.4 percent), followed by male reproductive cancers (22.3 percent) and gastrointestinal cancers (9.1 percent).

Due to inadequate sample, estimates were not generated for all types of prevalent cancers among male cancer survivors.

**Figure 4: Prevalence of cancer type among male cancer survivors aged 18 years and older, 2016 KS BRFSS**

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Prevalence</th>
<th>95 percent CL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin Cancers</td>
<td>48.4%</td>
<td>12.5-18.0</td>
</tr>
<tr>
<td>Male Reproductive Cancers</td>
<td>22.3%</td>
<td>17.7-26.9</td>
</tr>
<tr>
<td>Gastrointestinal Cancers</td>
<td>9.1%</td>
<td>5.1-13.0</td>
</tr>
<tr>
<td>Others</td>
<td>8.8%</td>
<td>5.3-12.3</td>
</tr>
<tr>
<td>Urinary Cancers</td>
<td>4.8%</td>
<td>2.1-7.5</td>
</tr>
<tr>
<td>Leukemia/Lymphoma (Lymph Nodes and Bone Marrow)</td>
<td>3.7%</td>
<td>1.3-6.1</td>
</tr>
<tr>
<td>Head/Neck Cancers</td>
<td>1.8%</td>
<td>0.4-3.1</td>
</tr>
<tr>
<td>Thoracic (Heart and Lung) Cancers</td>
<td>0.9%</td>
<td>0.0-2.1</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>0.2%</td>
<td>0.0-0.6</td>
</tr>
</tbody>
</table>

95 percent CL= Confidence interval at the 95 percent probability level.
For cancer survivors who reported more than one cancer diagnosis, the cancer type reported was the most recently diagnosed cancer.
Male Reproductive Cancers includes prostate and testicular cancer.
Gastrointestinal Cancers includes colon, esophageal, liver, pancreatic, rectal, and stomach cancer.
Other Cancers includes bone, brain, neuroblastoma, and other not specified cancer types.
Head/Neck Cancers includes head and neck, oral, throat, thyroid, and larynx cancer.
Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
The most prevalent cancers among female cancer survivors in 2016 were skin cancers (35.5 percent), followed by breast cancer (26.2 percent) and female reproductive cancers (17.3 percent). Due to inadequate sample, estimates were not generated for all types of prevalent cancers among female cancer survivors.

**Figure 5: Prevalence of cancer type among female cancer survivors aged 18 years and older, 2016 KS BRFSS**

- **Skin Cancers**: 35.5 percent (95 percent CL: 30.3-40.7)
- **Breast Cancer**: 26.2 percent (95 percent CL: 21.7-30.8)
- **Female Reproductive (Gynecologic) Cancers**: 17.3 percent (95 percent CL: 12.8-21.8)
- **Others**: 7.9 percent (95 percent CL: 5.3-10.5)
- **Gastrointestinal Cancers**: 4.3 percent (95 percent CL: 2.3-6.3)
- **Head/Neck Cancers**: 3.4 percent (95 percent CL: 1.3-5.4)
- **Leukemia/Lymphoma (Lymph Nodes and Bone Marrow)**: 2.0 percent (95 percent CL: 0.7-3.2)
- **Thoracic (Heart and Lung) Cancers**: 1.9 percent (95 percent CL: 0.1-3.8)
- **Urinary Cancers**: 1.5 percent (95 percent CL: 0.2-2.9)

95 percent CL= Confidence interval at the 95 percent probability level.
For cancer survivors who reported more than one cancer diagnosis, the cancer type reported was the most recently diagnosed cancer.
Female Reproductive (Gynecological) Cancer includes cervical, endometrial, and ovarian cancer.
Other Cancers includes bone, brain, neuroblastoma, and other not specified cancer types.
Gastrointestinal Cancers includes colon, esophageal, liver, pancreatic, rectal, and stomach cancer.
Head/Neck Cancers includes head and neck, oral, throat, thyroid, and larynx cancer.
Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
Basic Treatment Information

Deciding which treatment to take depends on the type, stage of cancer, the person’s age, overall health, and personal needs. The common treatments for cancer are surgery, chemotherapy/chemotherapy pills and radiation. Other options like stem cell transplants and hormone, biologic and targeted therapies also exist.\textsuperscript{12}

Among cancer survivors in Kansas, 75.9 percent had completed their treatment (surgery, radiation therapy, chemotherapy or chemotherapy pills), 11.6 percent had not started their treatment, 10.8 percent were receiving their treatment, and about 1.7 percent refused to take the treatment.

There was no significant difference in the percentage of cancer survivors receiving treatment (surgery, radiation therapy, chemotherapy or chemotherapy pills) by rural-urban status.

Figure 6: Percentage of cancer survivors aged 18 years and older who were currently receiving treatment, 2016 KS BRFSS

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
Source of Health Care

The type of cancer, the age of the patient, other health conditions and many other factors are taken into consideration to determine cancer survivor follow-up recommendations after treatment is completed.\textsuperscript{12}

In Kansas, among those cancer survivors who had completed their treatment, 72.4 percent received the majority of their health care through general or family practitioners.

There was no significant difference in the percentage of cancer survivors who had completed their treatment through general or family practitioners by rural-urban status.

\textbf{Figure 7: Type of doctor that provided the majority of health care to cancer survivors}

\begin{table}[h]
\centering
\begin{tabular}{l|c}
\hline
Type of Doctor & Percent \tabularnewline \hline
Family Practitioner & 44.5% \\
General Practitioner, Internist & 27.9% \\
Others & 17.0% \\
Medical Oncologist & 3.3% \\
Gynecologic Oncologist & 2.1% \\
General Surgeon & 1.5% \\
Cancer Surgeon & 1.2% \\
Urologist & 1.1% \\
Plastic or Reconstructive Surgeon & 0.9% \\
Radiation Oncologist & 0.4% \\
\hline
\end{tabular}
\end{table}

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
Follow-Up Care

The report *From Cancer Patient to Cancer Survivor Lost in Transition* by the Institute of Medicine recommends that all cancer patients receive an individualized survivorship care plan containing guidelines for monitoring and maintaining their health\(^\text{13}\). Survivorship care plans assist cancer survivors in receiving appropriate cancer treatment and follow-up care. Follow-up care is vital as it may help detect new cancers and recurrence through routine checkups and tests. Also, follow-up care provides psychological support to help cancer survivors manage secondary conditions stemming from cancer treatment.\(^\text{7}\)

Only about half of the cancer survivors (49 percent) who completed their cancer treatment ever received a written summary of all the cancer treatments that they received.

In 2016, approximately 42.8 percent (95% CI: 34.8%-50.7%) of cancer survivors residing in rural counties and approximately 51.4 percent (95% CI: 45.2%-57.5%) of cancer survivors residing in urban counties ever received a written summary of all the cancer treatments that they completed. No significant difference was seen by rural-urban status.

---

**Figure 8:** Percentage of cancer survivors who ever received a written summary for all the cancer treatments that they have received

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
About 77 percent of survivors who completed their treatment received instructions from their health care provider regarding where to return or whom to see for their routine check-ups. However, among those who received instructions, only 80 percent received the instructions in writing.

In 2016, approximately 75.4 percent (95% CI: 68.6%-82.2%) of cancer survivors residing in rural counties and approximately 78.2 percent (95% CI: 73.4%-83.0%) of cancer survivors residing in urban counties who completed their treatment received instructions from their health care provider regarding where to return or who to see for their routine check-ups. However, among those who received instructions, only 82.4 percent (95% CI: 75.9%-89.0%) residing in rural counties and only 78.5 percent (95% CI: 73.0%-84.0%) residing in urban counties received the instructions in writing. No significant difference was seen by rural-urban status.

**Health Insurance Status/Issues**

Studies have found that uninsured cancer patients have poorer outcomes than insured cancer patients.\(^\text{14,15,16}\)

About three percent of survivors who completed their treatment did not have health insurance that paid for all or part of their cancer treatment when they were diagnosed with their most recent cancer.

About seven percent of survivors reported that they were denied health insurance or life insurance coverage because of their cancer.

In 2016, approximately 9.1 percent (95% CI: 4.6%-13.5%) of survivors residing in rural counties and approximately 5.6 percent (95% CI: 3.1%-8.2%) of survivors residing in urban counties reported that they were denied health insurance or life insurance coverage because of their cancer.

There was no significant difference in the percentage of survivors who reported that they were denied health insurance or life insurance coverage because of their cancer by rural-urban status.

**Clinical Trial Participation**

Some clinical trials study treatments and others look at new ways to prevent, detect, diagnose or learn the extent of disease. Many trials are drug trials, and some test other forms of treatment, such as new surgery or radiation therapy techniques, or complementary or alternative medicines.\(^\text{17}\)

The biggest barrier to completing clinical trials is that not enough people participate. Fewer than five percent of adults with cancer take part in a clinical trial. The main reason people give for not participating in a clinical trial is that they did not know the studies were an option for them.\(^\text{18}\)

Kansas BRFSS collected population-based data related to prevalence estimates of adults with cancer having participated in a cancer trial.
About five percent of survivors that have completed their treatment participated in a clinical trial as a part of their cancer treatment.

In 2016, approximately 5.0 percent (95% CI: 1.7%-8.2%) of survivors residing in rural counties and approximately 5.0 percent (95% CI: 2.7%-7.3%) of survivors residing in urban counties who completed their treatment participated in a clinical trial as a part of their cancer treatment.

There was no significant difference in the percentage of survivors who completed treatment and participated in a clinical trial as a part of their cancer treatment by rural-urban status.

### Pain-Related Outcomes

Pain is an unwelcome symptom that is frequently associated with cancer. It reduces the quality of life, interferes with normal activities, prevents relaxation and sleep, and increases anxiety, stress, and fatigue. It may cause people to withdraw and reduce contact with family and friends. Most cancer-associated pain can be relieved by proper treatment.\(^{17}\)

About 8.1 percent of survivors who completed their treatment were currently experiencing physical pain because of cancer or its treatment.

In 2016, approximately 9.6 percent (95% CI: 4.8%-14.5%) of survivors residing in rural counties and approximately 7.3 percent (95% CI: 4.3%-10.3%) of survivors residing in urban counties who completed their treatment were currently experiencing physical pain because of cancer or its treatment.

There was no significant difference in the percentage of survivors who completed treatment and were currently experiencing physical pain because of cancer or its treatment by rural-urban status.

### Resources for Cancer Survivors

Evidence-based chronic disease self-management programs are a community resource available to survivors and cancer centers. Get Active Kansas, Walk with Ease and the Kansas Tobacco Quitline are evidence-based resources available to cancer survivors in many communities.

The Kansas Early Detection Works program pays for clinical breast exams, mammograms, Pap tests and diagnostic services for low-income, uninsured Kansas women who qualify.

Regular screening and prompt treatment can reduce deaths from breast and cervical cancer.

The statewide End-of-Life Nursing Education Consortium training of health care professionals is designed to increase cancer survivor access to palliative, or “comfort care,” to improve quality of life during and after treatment.
Conclusion

Disparities were seen in the prevalence of cancer survivorship among different socio-demographic groups. High prevalence of health risk behaviors, poor health status, and poor health care access was seen among cancer survivors. Cancer survivors had a higher prevalence of fair or poor health status and poor physical health as compared to adults without cancer.

Results from this analysis indicate the need for health education and access to care for cancer survivors that target healthy lifestyle behaviors. Also, ongoing education on guidelines about treatment and survivor care for primary care physicians and oncologists would be beneficial. Less than half of the cancer survivors who completed their treatments ever received their written summary which is helpful in receiving appropriate follow-up care. Increased access to survivorship support resources will be helpful to survivors. Also, more participation in clinical trials and access to experts in pain management are needed for optimal cancer survivor health.

The KDHE Cancer Prevention and Control Programs work with the Kansas Cancer Partnership, a network of partners who are interested in reducing the burden of cancer in Kansas. Their shared goal is to reduce the morbidity and mortality from cancer through prevention of cancer when possible and routine screening when appropriate. Other areas of interest include access to quality diagnostic services and treatment including access to clinical trials, as well as survivorship issues and if necessary, compassion and care at the end of life. Activities undertaken by the coalition will help address some of the disparities identified in this report and improve the quality of life of cancer survivors.
Technical Notes

1. Background
BRFSS is the world’s largest, annual population-based survey system, tracking health conditions and risk behaviors in the United States since 1984. It is coordinated by the Centers for Disease Control and Prevention (CDC) and is conducted in every state and several territories in the United States. The Bureau of Health Promotion (BHP) conducted the first BRFSS survey in Kansas in 1990 as a point-in-time survey. Since 1992, BHP has conducted the Kansas BRFSS survey annually, thus providing an ability to examine and monitor the trends of various diseases and risk factors/behaviors that are of public health importance in Kansas.

To account for the changes in the use of different sources of telephone service in the general population, differences in the socio-demographic profile of persons who live in cellular telephone only or mostly households and to maintain the representativeness, coverage and validity of data, the CDC has made the adjustments in the BRFSS survey methodology from 2011 onwards. The changes in the BRFSS survey methodology include: 1) use of dual sampling frame (landline and cellular telephone samples); and 2) use of more advanced and statistically sophisticated “Iterative Proportional Fitting” weighting methodology (also referred as “Raking” methodology) to further reduce potential of bias and maintain validity of the population-based estimates generated through dual frame sampling method of the BRFSS survey.

The 2016 Kansas BRFSS survey used the dual frame sampling method with landline telephone survey and cellular telephone survey components and raking weighting methodology.

2. Survey Methods:
The 2016 Kansas BRFSS landline and cellular telephone survey components are designed to comprise a population-based random digit dial telephone survey of Kansas adults ages 18 years and older residing in private residences and college housing with landline telephone service. The landline service over the internet including Vonage, Magic Jack, and other home-based phone services were counted as landline service.

2a. Survey Participants:
Landline Telephone Survey Component: All adults in Kansas ages 18 years and older residing in a private residence or college housing with a landline telephone service were eligible for 2016 BRFSS landline survey component. Primary subjects were randomly selected adults ages 18 years and older from sampled households (private residences and college housing with landline telephone service including landline telephone service through the internet).

Cellular Telephone Survey Component: All adults in Kansas ages 18 years and older living in private households or college housing with a working cell phone service or living in households with both cell phone and landline service, irrespective of the amount of calls they receive on their cell phone number were eligible for 2016 Kansas BRFSS cell phone survey component. Primary subjects were the adults living in randomly selected households from the cell phone sampling frame.

Data resulting from these surveys were weighted to represent the population of Kansas.

2b. Inclusion / Exclusion Criteria:
Landline Telephone Survey Component: As mentioned earlier, non-institutionalized adults who are 18 years and older were included for participation as primary subjects for the landline telephone survey component. Primary subjects of the survey were the adults who were randomly selected from sampled households (private residences and college housings) with landline telephones.
These surveys were conducted using random digit dial telephone methodology, therefore, adults living in households without a landline telephone were excluded from the sampling frame of BRFSS Landline Component. In addition, adults living in institutions (e.g., long-term care facilities, prisons, military bases, etc.) except college housing were also be excluded.

**Cellular Telephone Survey Component:** The persons who are 18 years or older, live in private residences or college housings with cell phone service only or in dual landline and cell phone service private residences or college housings, irrespective of the amount of calls they receive on their cell phone number were included for participation as primary subjects for the cellular telephone survey.

The adults living in households with a landline telephone service only or less than 18 years of age were excluded from the sampling frame. Adults living in institutions except college housing were also excluded. The adults who use their cell phones exclusively for business purposes were also excluded from the cell phone survey.

**2c. Sampling Methodology:**

The dual frame sampling methodology was used for the 2016 Kansas BRFSS survey. This methodology included two sampling frames: 1) Landline telephone sampling frame; and 2) Cellular telephone sampling frame.

**Landline Telephone Survey Component:** The sampling methodology for the landline telephone survey component of this dual frame sampling method was identical to the sampling method for 2009, 2010, 2011, 2012, 2013, 2014 and 2015. It implemented a disproportionately stratified sampling methodology that was included in the selection of landline telephone numbers within 10 geographic strata comprised of county grouping instead of the random selection of telephone numbers from the entire state as a single geographic stratum. These 10 geographical strata include: Johnson County, Sedgwick County, Shawnee County, Wyandotte County, Northwest public health district, Southwest public health district, North Central public health district, South Central public health district excluding Sedgwick County, Northeast public health district excluding Johnson, Shawnee and Wyandotte counties, and Southeast public health district. The sample drawn from each geographical stratum was based on population size within each geographical stratum, the confidence level and the margin of error. The confidence level is the amount of certainty that the estimated prevalence is accurate. Since 2009, the sampling from 10 strata of the state has been done to target collection for geographically identifiable subpopulations, for example, people in rural areas. It also increases the accuracy of prevalence estimates for a small subpopulation.

The landline telephone component sampling was designed to reach non-institutionalized adults ages 18 years old and older living in the private residences and college housings in Kansas. The landline service over the internet was counted as landline service. This include Vonage, Magic Jack, and other home-based phone services. As in previous years, the method of probability sampling involved assigning sets of one hundred telephone numbers with the same area code, prefix, and first two digits of the suffix and all possible combinations of the last two digits ("hundred blocks") into two strata. Those hundred blocks that have at least one known household number were designated as high density (also called "one-plus blocks"); a hundred blocks with no known household numbers were designated as low density ("zero blocks"). The high-density stratum was sampled at a rate 1.5 times higher than the low-density stratum, resulting in greater efficiency (sampling from listed telephone numbers pool were done at a higher rate than unlisted telephone numbers pool). This sampling method improves survey efficiency as sampling from listed telephone numbers is done at a higher rate than unlisted telephone numbers. The unequal sampling rates were accounted for by applying weights to the survey data. After reaching an eligible telephone number, one adult member of the household
Cancer Survivorship Among Kansas Adults

was randomly selected and invited to participate in the survey. If the eligible telephone number is for college housing, then the respondent answering the phone is selected for the interview.

The sample of telephone numbers to obtain 5,000 complete interviews were purchased by the CDC on behalf of the Kansas BRFSS in 2016. The CDC purchased state samples from a commercial sample vendor, Marketing Systems Group (MSG) through a centralized contract with the CDC. The vendor pre-screened the sample to eliminate businesses, institutions and non-working numbers.

**Cellular Telephone Survey Component:** The sampling methodology for the cellular telephone survey component of this dual frame sampling method were include the sampling frame comprised of all 1000-series blocks dedicated to cellular devices serving the state with a nonzero chance of inclusion. In 2016, a disproportionately stratified sampling methodology for selection of cellphone telephone numbers within 10 geographic strata comprised of county grouping was used. These 10 geographical strata were same as landline, which include; Johnson County, Sedgwick County, Shawnee County, Wyandotte County, Northwest public health district, Southwest public health district, North Central public health district, South Central public health district excluding Sedgwick County, Northeast public health district excluding Johnson, Shawnee and Wyandotte counties, and Southeast public health district. The sample drawn from each geographical stratum was based on population size within each geographical stratum, the confidence level and the margin of error. The confidence level was the amount of certainty that the estimated prevalence is accurate. The sampling from 10 strata of the state was done to target collection for geographically identifiable subpopulations, for example, people in rural areas.

This sampling frame was based on the Telecordia database of telephone exchanges (e.g., 785-368-000 to 785-368-9999) and 1,000 banks (e.g., 785-368-0000 to 785-368-0999). The dedicated cellular 1,000 banks were sorted on the basis of area code and exchange within a state. An interval, K, was formed by dividing the population count of telephone numbers in the frame, N, by the desired sample size, n. The frame of telephone numbers was divided into n intervals of size K telephone numbers. From each interval, one 10-digit telephone number was drawn at random.

The cellular telephone survey component sampling method was designed to reach non-institutionalized adults 18 years old and older living in the private residences and college housing with cellular telephone only service in Kansas, as well as adults living in private households and college housing with both cell phone and landline service, irrespective of the amount of calls they receive on their cell phone number.

Cell phone sampling frames were available from a commercial sample vendor, Marketing Systems Group (MSG) through a centralized contract with the CDC. Through this contract, the CDC provided the random samples of cell phone numbers to obtain 10,000 complete interviews. The CDC also used a new development from MSG, which allowed them to use Genesys-CSS to flag sample landline telephone numbers that have been ported from landline to cellular service. A high percentage of these numbers were working cell phones and they were much more likely to belong to cell phone-only adults. No additional sampling was needed for adding ported numbers to the cell phone sample because they were selected as a part of the landline RDD sample. The vendor pre-screened the sample to eliminate non-working numbers.

**2d. Sample Size:**

The combined total target sample size for the 2016 Kansas BRFSS (landline and cell phone components) was 10,000 complete interviews (core section of the questionnaire was asked from all 10,000 respondents and approximately 5,000 respondents were assigned to each branch of the survey).
2e. Statistical Consideration (weighting of data, analysis and reporting of data)

Please note that the data obtained from the cell phone survey component were combined with the data obtained from the landline telephone survey component and then weighting techniques using the iterative proportional fitting (also referred to as raking) were applied to generate a combined weighted dataset.

Thus, sample weights were applied to the data obtained from both landline and cell phone surveys (combined landline and cell phone BRFSS) to account for unequal selection probability resulting from the sample design. This also accounted for differential response rates by demographic groups (weighting using raking methodology). The resulting weighted data were representative of the adult population of Kansas. Please note that the CDC is using raking weighting methodology for BRFSS data for all states that took into account age, gender, race/ethnicity, marital status, education status, house rental/ownership of the population and telephone source (landline/cellular) to adjust for the dual sampling frame. According to the CDC the new weighting methodology further improves the precision of the estimates generated through BRFSS. (Abt. Associates. Behavioral risk Factor Surveillance System Methodological Enhancements: Cell Phone Pilot. Report published in August 2007.)

Detailed analyses of data were performed using SAS software. These analyses include calculation of the prevalence estimates with 95 percent confidence intervals. Cross-tabulations of prevalence estimates by a variety of demographic factors were also presented according to availability of scientifically adequate sample size for various variables.

The comprehensive nature of the 2016 Kansas BRFSS enabled us to analyze data to examine questions regarding the relationships between a variety of health conditions and behaviors.

In order to maintain confidentiality of the information, all data were reported and published in an aggregate form. In addition, any information based on very small number of responses was not published to maintain confidentiality of the information.

Several considerations should be considered when interpreting BRFSS estimates:

- The prevalence estimates from 2016 Kansas BRFSS are representative of noninstitutionalized adults ages 18 years old and older living in private residences and college housing with landline and/or cell phone service.
- BRFSS estimates do not apply to individuals residing in residences without telephone service and those who reside in military bases, prisons or nursing homes.

For more information on BRFSS methodology, visit [www.kdheks.gov/brfss/technotes.html](http://www.kdheks.gov/brfss/technotes.html).
## Appendix

Respondents were asked the following cancer survivorship questions.

### Module 17: Cancer Survivorship

**CATI note:** If Core Q6.6 or Q6.7 = 1 (Yes) or Q17.6 = 4 (Because you were told you had prostate cancer) continue, else go to next module.

You’ve told us that you have had cancer. I would like to ask you a few more questions about your cancer.

1. How many different types of cancer have you had?
   - 1  Only one
   - 2  Two
   - 3  Three or more
   - 7  Don’t know / Not sure  [Go to next module]
   - 9  Refused  [Go to next module]

2. At what age were you told that you had cancer?
   - _ _  Code age in years  [97 = 97 and older]
   - 9 8  Don’t know / Not sure
   - 9 9  Refused

**CATI note:** If Q1 = 2 (Two) or 3 (Three or more), ask: “At what age were you first diagnosed with cancer?”

**Interviewer note:** This question refers to the first time they were told about their first cancer.

**CATI note:** If Core Q6.6 = 1 (Yes) and Q1 = 1 (Only one): ask “Was it “Melanoma” or “other skin cancer”? then code 21 if “Melanoma” or 22 if “other skin cancer”

**CATI note:** If Core Q16.6 = 4 (Because you were told you had Prostate Cancer) and Q1 = 1 (Only one) then code 19.

3. What type of cancer was it?

   **If Q1 = 2 (Two) or 3 (Three or more), ask:** “With your most recent diagnoses of cancer, what type of cancer was it?”

   **Interviewer note:** Please read list only if respondent needs prompting for cancer type (i.e., name of cancer) [1-30]:

---

Cancer Survivorship Among Kansas Adults
Breast
0 1 Breast cancer

Female reproductive (Gynecologic)
0 2 Cervical cancer (cancer of the cervix)
0 3 Endometrial cancer (cancer of the uterus)
0 4 Ovarian cancer (cancer of the ovary)

Head/Neck
0 5 Head and neck cancer
0 6 Oral cancer
0 7 Pharyngeal (throat) cancer
0 8 Thyroid
0 9 Larynx

Gastrointestinal
1 0 Colon (intestine) cancer
1 1 Esophageal (esophagus)
1 2 Liver cancer
1 3 Pancreatic (pancreas) cancer
1 4 Rectal (rectum) cancer
1 5 Stomach

Leukemia/Lymphoma (lymph nodes and bone marrow)
1 6 Hodgkin's Lymphoma (Hodgkin’s disease)
1 7 Leukemia (blood) cancer
1 8 Non-Hodgkin’s Lymphoma

Male reproductive
1 9 Prostate cancer
2 0 Testicular cancer

Skin
2 1 Melanoma
2 2 Other skin cancer

Thoracic
2 3 Heart
2 4 Lung

Urinary cancer
2 5 Bladder cancer
2 6 Renal (kidney) cancer

Others
2 7 Bone
2 8 Brain
2 9 Neuroblastoma
3 0 Other

Do not read:
7 7 Don’t know / Not sure
9 9 Refused
4. Are you currently receiving treatment for cancer? By treatment, we mean surgery, radiation therapy, chemotherapy, or chemotherapy pills.
   1. Yes  [Go to next module]
   2. No, I’ve completed treatment
   3. No, I’ve refused treatment  [Go to next module]
   4. No, I haven’t started treatment  [Go to next module]
   7. Don’t know / Not sure  [Go to next module]
   9. Refused  [Go to next module]

5. What type of doctor provides the majority of your health care?

   **Interviewer note:** If the respondent requests clarification of this question, say: “We want to know which type of doctor you see most often for illness or regular health care (Examples: annual exams and/or physicals, treatment of colds, etc.).”

   **Please read [1-10]:**
   0 1 Cancer Surgeon
   0 2 Family Practitioner
   0 3 General Surgeon
   0 4 Gynecologic Oncologist
   0 5 General Practitioner, Internist
   0 6 Plastic Surgeon, Reconstructive Surgeon
   0 7 Medical Oncologist
   0 8 Radiation Oncologist
   0 9 Urologist
   1 0 Other

   **Do not read:**
   7 7 Don’t know / Not sure
   9 9 Refused

6. Did any doctor, nurse, or other health professional EVER give you a written summary of all the cancer treatments that you received?

   **Read only if necessary:** “By ‘other healthcare professional’, we mean a nurse practitioner, a physician’s assistant, social worker, or some other licensed professional.”

   1. Yes
   2. No
   7. Don’t know / Not sure
   9. Refused

7. Have you EVER received instructions from a doctor, nurse, or other health professional about where you should return or who you should see for routine cancer check-ups after completing your treatment for cancer?

   1. Yes
   2. No  [Go to Q9]
   7. Don’t know / Not sure  [Go to Q9]
   9. Refused  [Go to Q9]
8. Were these instructions written down or printed on paper for you?
   1   Yes
   2   No
   7   Don’t know / Not sure
   9   Refused

9. With your most recent diagnosis of cancer, did you have health insurance that paid for all or part of your cancer treatment?
   1   Yes
   2   No
   7   Don’t know / Not sure
   9   Refused

**Interviewer note:** “Health insurance” also includes Medicare, Medicaid, or other types of state health programs.

10. Were you EVER denied health insurance or life insurance coverage because of your cancer?
    1   Yes
    2   No
    7   Don’t know / Not sure
    9   Refused

11. Did you participate in a clinical trial as part of your cancer treatment?
    1   Yes
    2   No
    7   Don’t know / Not sure
    9   Refused

12. Do you currently have physical pain caused by your cancer or cancer treatment?
    1   Yes
    2   No   [Go to next module]
    7   Don’t know / Not sure   [Go to next module]
    9   Refused   [Go to next module]

13. Is your pain currently under control?

**Please read:**
   1   Yes, with medication (or treatment)
   2   Yes, without medication (or treatment)
   3   No, with medication (or treatment)
   4   No, without medication (or treatment)

**Do not read:**
   7   Don’t know / Not sure
   9   Refused
References


