CANCER SURVIVORSHIP AMONG KANSAS ADULTS, 2016 KANSAS BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS)
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>3</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>6</td>
</tr>
<tr>
<td>HEALTH STATUS OF CANCER SURVIVORS</td>
<td>8</td>
</tr>
<tr>
<td>Types of cancer among cancer survivors</td>
<td>13</td>
</tr>
<tr>
<td>Age of diagnosis among cancer survivors</td>
<td>14</td>
</tr>
<tr>
<td>Basic Treatment Information</td>
<td>19</td>
</tr>
<tr>
<td>Source of Health Care</td>
<td>20</td>
</tr>
<tr>
<td>Follow-up Care</td>
<td>21</td>
</tr>
<tr>
<td>Health Insurance Status/Issues</td>
<td>22</td>
</tr>
<tr>
<td>Clinical Trial Participation</td>
<td>22</td>
</tr>
<tr>
<td>Other Outcomes such as Pain</td>
<td>23</td>
</tr>
<tr>
<td>Resources for cancer survivors</td>
<td>23</td>
</tr>
<tr>
<td>CONCLUSION</td>
<td>24</td>
</tr>
<tr>
<td>TECHNICAL NOTES</td>
<td>25</td>
</tr>
<tr>
<td>APPENDIX</td>
<td>27</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>33</td>
</tr>
</tbody>
</table>
According to the 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.\textsuperscript{1} Cancer survivors are living longer due to improvements in health care systems and advances in medical research.\textsuperscript{2} Over the years, various stakeholders have identified issues facing cancer survivors and have developed recommendations for cancer survivorship care approaches.\textsuperscript{3} Kansas Cancer Partnership prioritized need to address cancer survivorship issues and included relevant strategies in the 2012-2016 Kansas Cancer Prevention and Control Plan.

This report highlights cancer survivors 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, those who have insurance and those adults living with a disability.
• About one in six cancer survivors are 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% 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 diagnosis of cancer.
• About 18 percent of cancer survivors have more than one type of cancer.
• Most of the cancer survivors (50%) 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 was 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 have received.
• About 77 percent of survivors who have completed their treatment have 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 got these instructions written down or printed on a paper.

• About 3 percent of survivors who have 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 7 percent of survivors were denied health insurance or life insurance coverage because of their cancer.

• About 5 percent of survivors who have completed their treatment had participated in a clinical trial as a part of their cancer treatment.

• About 8 percent of survivors who have completed their treatment are currently experiencing physical pain because of cancer or its treatment.

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

According to the 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

CDC and the LIVESTRONG Foundation developed a “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 four core public health domains: surveillance and applied research; communication, education, and training; programs, policies, and infrastructure; and access to quality care and services.⁴ Kansas Cancer Partnership prioritized the need to address cancer survivorship issues. The strategies to address these issues were included in the 2012-2016 Kansas Cancer Prevention and Control Plan.

Kansas was one of six states that received funding through a cooperative agreement with the Center for Disease Control and Prevention (CDC) for “Kansas Survivor Care Quality Initiative” for 2015-2018. Main strategies employed were to increase 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 Program and Kansas BRFSS program included the cancer survivorship module in 2016 Kansas Behavioral Risk Factor Surveillance System (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 Centers for Disease Control and Prevention (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 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 has agreed to include the cancer survivorship module annually throughout the project period. These data were also collected in 2017 survey. Currently, Kansas BRFSS is collecting these data in 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. Henceforth termed in this report as cancer survivors.

Cancer survivors often face many challenges because of their cancer diagnosis and treatment. 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 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 their cancer diagnosis or its treatment, and cancer recurrence and progression.

In 2016, approximately 1 in 9 (11.5%) Kansas adults aged 18 years and older are cancer survivors. The percentage of Kansas cancer survivors 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 are college graduate compared with adults with less than high school education
- Adults who are retired compared with adults who are employed for wages or are self-employed
- Adults who are unable to work compared with adults who are employed for wages or are self-employed
- Adults living with a disability compared with adults living without a disability
- Adults with insurance compared with adults with no insurance

**Table 1: Cancer Survivors Aged 18 Years and Older by Socio-demographic Groups, 2016 Kansas BRFSS**

<table>
<thead>
<tr>
<th>Socio-demographic Groups</th>
<th>Weighted percentage</th>
<th>95 percent 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>
</tbody>
</table>
### Disability

<table>
<thead>
<tr>
<th></th>
<th>18.9</th>
<th>17.3-20.5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living with a disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Living without a disability</strong></td>
<td>9.3</td>
<td>8.7-9.9</td>
</tr>
</tbody>
</table>

### Insurance

<table>
<thead>
<tr>
<th></th>
<th>3.7</th>
<th>2.7-4.8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Uninsured</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Insured</strong></td>
<td>12.7</td>
<td>12.0-13.3</td>
</tr>
</tbody>
</table>

*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 towards appropriate resources to address those in need.\(^11\)

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 six cancer survivors are 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% could not see their doctor because of cost.
- After adjusting for age, gender, race/ethnicity, employment status and education status, higher prevalence of self-reported fair/poor health is seen
among cancer survivors compared to those without a diagnosis of cancer (39.7 percent vs. 25.5 percent).

- After adjusting for age, gender, race/ethnicity, employment status and education status, higher prevalence of being physically unhealthy for ≥ 14 days in past 30 days is seen among cancer survivors compared to those without a diagnosis of cancer (21.2 percent vs. 14.0 percent).
- After adjusting for age, gender, race/ethnicity, employment status and education status, no significant difference is 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 personal health care provider, and not being able to see doctor because of cost among cancer survivors compared to those without a diagnosis of cancer.
- However, please note that higher prevalence of being emotionally unhealthy for ≥ 14 days in past 30 days is seen among cancer survivors (excluding skin cancer) compared to those without diagnosis of cancer (14.6 percent vs. 9.1 percent).

Table 2. Adjusted prevalence of health risk behaviors, health status, and health care access indicators among Kansas adults 18 years and older, by history of cancer diagnosis, Kansas, 2016

<table>
<thead>
<tr>
<th></th>
<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>
<td>Adj. % 95% CL</td>
</tr>
<tr>
<td>Adults diagnosed with cancer</td>
<td>18.5</td>
<td>9.1</td>
<td>4.5</td>
</tr>
<tr>
<td>Adults diagnosed with cancer</td>
<td>15.2-22.3</td>
<td>6.9-11.9</td>
<td>3.1-6.5</td>
</tr>
<tr>
<td>Adults without diagnosis of</td>
<td>18.7</td>
<td>8.1</td>
<td>3.5</td>
</tr>
<tr>
<td>Adults without diagnosis of</td>
<td>16.5-20.9</td>
<td>6.7-9.7</td>
<td>2.6-4.7</td>
</tr>
</tbody>
</table>

Adj. % = Percentage are predicted population margins; adjusted for age, gender, race/ethnicity, employment status, and education level. Unadj. % = Unadjusted percentage. 95% CL = 95 percentage Confidence Interval.
Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
### No physical activity in past 30 days

<table>
<thead>
<tr>
<th></th>
<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><strong>Adj. %</strong></td>
<td><strong>Adj. %</strong></td>
<td><strong>Adj. %</strong></td>
<td><strong>Adj. %</strong></td>
</tr>
<tr>
<td><strong>95% CL</strong></td>
<td><strong>95% CL</strong></td>
<td><strong>95% CL</strong></td>
<td><strong>95% CL</strong></td>
</tr>
<tr>
<td>Adults diagnosed with cancer (Cancer Survivors)</td>
<td>31.8</td>
<td>70.5</td>
<td>32.1</td>
</tr>
<tr>
<td></td>
<td>27.9-36.0</td>
<td>66.3-74.3</td>
<td>28.3-36.2</td>
</tr>
<tr>
<td>Adults without diagnosis of cancer</td>
<td>31.1</td>
<td>72.9</td>
<td>35.5</td>
</tr>
<tr>
<td></td>
<td>28.3-34.0</td>
<td>69.9-75.7</td>
<td>32.5-38.5</td>
</tr>
</tbody>
</table>

Adj. % = Percentage are predicted population margins; adjusted for age, gender, race/ethnicity, employment status, and education level. Unadj. % = Unadjusted percentage. 95% CL = 95 percentage Confidence Interval.

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

### Self-reported fair/poor health

<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><strong>Adj. %</strong></td>
<td><strong>Adj. %</strong></td>
<td><strong>Adj. %</strong></td>
<td><strong>Adj. %</strong></td>
</tr>
<tr>
<td><strong>95% CL</strong></td>
<td><strong>95% CL</strong></td>
<td><strong>95% CL</strong></td>
<td><strong>95% CL</strong></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 diagnosis of cancer</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>

Adj. % = Percentage are predicted population margins; adjusted for age, gender, race/ethnicity, employment status, and education level. Unadj. % = Unadjusted percentage. 95% CL = 95 percentage Confidence Interval. Bolded and red numbers indicate statistically significant between-group differences.

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
<table>
<thead>
<tr>
<th></th>
<th>Uninsured</th>
<th>Do not have personal health care provider</th>
<th>Could not see doctor because of cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<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>11.3 8.1-15.4</td>
<td>18.0 14.2-22.6</td>
<td>13.2 10.2-16.8</td>
</tr>
<tr>
<td>Adults without diagnosis of cancer</td>
<td>14.7 12.5-17.2</td>
<td>23.8 21.3-26.6</td>
<td>13.8 12.0-15.9</td>
</tr>
</tbody>
</table>

Adj. %= Percentage are predicted population margins; adjusted for age, gender, race/ethnicity, employment status, and education level. Unadj. %= Unadjusted percentage. 95% CL = 95 percentage Confidence Interval.

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 have only one type of cancer. However, 15 percent have two cancers, and 3.4 percent have three or more types of cancer.
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 adults in Kansas were told they had cancer when they were 40 years to 64 years, 19 percent when they were 65 to 74 years, 15 percent when they were 20 to 39 years old, 13 percent when they were 75 years and older, and 3 percent when they were below 20 years.
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).
Figure 3: Prevalence of cancer type among cancer survivors aged 18 years and older, 2016 KS BRFSS

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

95 percent CI =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).
Figure 5: Prevalence of cancer type among female cancer survivors aged 18 years and older, 2016 KS BRFSS

Female Reproductive (Gynecological) Cancers 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.

95 percent CI = 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.
BASIC TREATMENT INFORMATION

Deciding which treatment to take depends on the type, stage of cancer, and 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.12

Among cancer survivors in Kansas, 76 percent have completed their treatment (surgery, radiation therapy, chemotherapy or chemotherapy pills), 11.6 percent have not started their treatment, 10.8 percent were receiving their treatment, and about 1.7 percent refused to take the treatment.

**Figure 6: Percentage of cancer survivors aged 18 years and older who are 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 patient, co-morbid conditions and many other factors are taken into consideration by cancer survivors for follow-ups after their treatment is completed.\textsuperscript{12}

In Kansas, those cancer survivors who have completed their treatment, 72.5 percent receive their majority of health care through family or general practitioners.

**Figure 7: Type of doctor that provides the majority of health care to cancer survivors**

![Graph showing the percentage of cancer survivors receiving care from different types of doctors.]

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
FOLLOW-UP CARE

A report by the Institute of Medicine recommends that all cancer patients receive an individualized survivorship care plan containing guidelines for monitoring and maintaining their health. 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-ups provide psychological support to help cancer survivors manage secondary conditions stemming from cancer treatment.\(^7\)

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

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

![Figure 8](image-url)

Source: 2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, KDHE.
About 77 percent of survivors who have completed their treatment have 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 got these instructions written down or printed on a paper.

HEALTH INSURANCE STATUS/ISSUES

Studies have found that uninsured cancer patients have poorer outcomes than insured cancer patients.\textsuperscript{13,14,15}

About 3 percent of survivors who have 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 7 percent of survivors were denied health insurance or life insurance coverage because of their cancer.

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.\textsuperscript{16}

The biggest barrier to completing clinical trials is that not enough people participate. Fewer than 5 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.\textsuperscript{16}

Kansas BRFSS has collected population-based data related to prevalence estimates of adults with cancer having participated in a cancer trial.
About 5 percent of survivors who have completed their treatment participated in a clinical trial as a part of their cancer treatment.

OTHER OUTCOMES SUCH AS PAIN

Pain is the most common symptom associated with cancer. It reduces 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 percent of survivors who have completed their treatment are currently experiencing physical pain because of cancer or its treatment.

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 Quit Line 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.

Statewide End-of-Life Nursing Education Consortium trainings 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 are seen in the prevalence of cancer survivorship among different socio-demographics groups. High prevalence of health risk behaviors, poor health status and poor health care access is seen among cancer survivors. Cancer survivors have 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 targeting lifestyle behaviors associated with cancer. 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 have 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 clinical trials participation and pain management are needed for optimal cancer survivor health.

The KDHE Cancer Prevention and Control Program works 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.

The Early Detection Works program provides breast and cervical cancer screening services for low-income and uninsured Kansas women through service providers located across the state.
TECHNICAL NOTES

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 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.

For the 2016 Kansas BRFSS survey, the target total (combined landline and cell phone sample) sample size was 10,000 complete interviews with a target of 5,000 complete interviews for the landline telephone survey component (50 percent of total sample) and 5,000 complete interviews for the cellular telephone survey component (50 percent of total sample).

The weighted data analysis was conducted to estimate the overall prevalence of the specific indicators among adults aged 18 years and older in Kansas. Also, when comparing within subgroups to overall prevalence estimates, stratified analyses were done to examine the burden of the indicators within different population subgroups based on socio-demographic factors, risk behaviors, and co-morbid conditions.

Several considerations should be considered when interpreting BRFSS estimates:

- The prevalence estimates from 2016 Kansas BRFSS are representative of noninstitutionalized adults aged 18 years 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 on 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]:

- **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
19  Prostate cancer
20  Testicular cancer
Skin
21  Melanoma
22  Other skin cancer
Thoracic
23  Heart
24  Lung
Urinary cancer:
25  Bladder cancer
26  Renal (kidney) cancer
Others
27  Bone
28  Brain
29  Neuroblastoma
30  Other
Do not read:
77  Don’t know / Not sure
99  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
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


