## CHAPTER 12: SHARING FAMILY HISTORY & GENETIC COUNSELING



## **Genetic Counseling**

The National Cancer Institute describes cancer genetics as having implications for all aspects of cancer management, including prevention, screening, and treatment. The etiology of cancer is multifactorial, with genetic, environmental, medical, and lifestyle factors interacting to produce a given malignancy. Knowledge of cancer genetics is rapidly improving understanding of cancer biology, helping to identify atrisk individuals, establishing treatment tailored to the molecular fingerprint of the disease, and leading to the

development of new therapeutic modalities.

Some cancers are caused by an abnormal gene that is passed from generation to generation. Only about 5-10 percent of all cancers result directly from inherited genetic mutations. Having a genetic risk does not mean that a person will develop cancer; not having a genetic risk does not mean that a person will not develop cancer. Cancer is such a common disease that most families have at least a few members who have had cancer. Sometimes, this is because family members have risk factors in common, such as tobacco use or obesity, which can cause cancer or influence cancer risk.<sup>53</sup> Having a genetic counseling can help people make informed decisions about genetic testing and follow-up care.

## Sharing collected family history of chronic diseases including cancer among Kansas Adults

In 2019, about 93 percent of Kansas adults 18 years and older who actively collected family history of chronic diseases including cancer have shared it with their healthcare providers (92.6%; 95% Confidence Interval (CI): 91.1% to 94.2%) (Table 12-1). It was also estimated that about 32.1% of Kansas adults have already collected family history of chronic diseases including cancer in 2019 (data not shown).

The percentage of Kansans who collected family history of chronic diseases including cancer and shared it with healthcare providers in 2019 was significantly lower among males (87.1%; 95% CI: 83.6% to 90.6%) as compared to females (95.5%; 95% CI: 94.1% to 96.9%).

In 2019, the percentage of Kansans 18 years and older who collected family history of chronic diseases including cancer and shared it with healthcare providers was significantly lower among adults aged 18-24 years (84.7%; 95% CI: 76.5% to 92.8%) as compared to adults aged 65 years and older (95.3%; 95% CI: 93.3% to 97.3%).

In Kansas, all those in the Asian/Pacific Islander group shared the family history of chronic diseases they collected with their healthcare providers in 2019. There was no significance difference between the other racial groups regarding sharing collected family history of chronic diseases including cancer.

In Kansas, the percentage of Kansans 18 years and older who collected family history of chronic diseases including cancer and shared it with healthcare providers was significantly lower among adults without insurance (82.8%; 95% CI: 75.1% to 90.5%) as compared to adults with insurance (93.9%; 95% CI: 92.5% to 95.4%).

<sup>&</sup>lt;sup>53</sup> American Cancer Society. Family Cancer Syndromes. Available at: <a href="http://www.cancer.org/cancer/cancercauses/geneticsandcancer/heredity-and-cancer">http://www.cancer.org/cancer/cancercauses/geneticsandcancer/heredity-and-cancer</a>. Accessed August 19, 2020.

The percentage of Kansans 18 years and older with family history of cancer and received genetic counseling did not differ significantly by ethnicity, education level, annual household income level, disability status, or county population density subgroups.

Table 12-1. Percentage of adults who shared collected family history of chronic diseases including cancer with their healthcare provider during the past year, Kansas 2019

Characteristic	Percentage of adults shared collected family history with healthcare providers	95% Confidence Interval		
Total	92.6%	91.1%	to	94.2%
Gender				
Male	87.1%	83.6%	to	90.6%
Female	95.5%	94.1%	to	96.9%
Age group				
18-39	84.7%	76.5%	to	92.8%
25-34	89.3%	84.5%	to	94.1%
35-44	94.3%	90.6%	to	97.9%
45-64	94.0%	92.1%	to	96.0%
65 and older	95.3%	93.3%	to	97.3%
Race				
White	93.3%	91.8%	to	94.8%
African American	88.4%	77.2%	to	99.7%
American Indian/Alaskan Native	94.2%	86.2%	to	100.0%
Asian/Pacific Islanders	100.0%	100.0%	to	100.0%
Ethnicity				
Hispanic	92.7%	85.0%	to	100.0%
Non-Hispanic	92.6%	91.0%	to	94.1%
Education				
Less than high school	95.1%	89.0%	to	100.0%
High school graduate or GED	89.5%	85.3%	to	93.6%
Some college	91.9%	89.0%	to	94.7%
College graduate	94.4%	92.5%	to	96.2%
Household Income				
Less than \$15,000	84.7%	76.3%	to	93.2%
\$15,000 to \$24,999	93.6%	89.4%	to	97.9%
\$25,000 to \$34,999	93.8%	89.7%	to	97.9%
\$35,000 to \$49,999	90.0%	84.3%	to	95.6%
\$50,000 or higher	94.6%	92.8%	to	96.4%
Insurance Status				
Insured	93.9%	92.5%	to	95.4%
Uninsured	82.8%	75.1%	to	90.5%
County Population Density				
Rural	92.9%	90.5%	to	95.3%
Urban	92.5%	90.6%	to	94.4%
Disability Status				
Living with a disability	93.8%	91.4%	to	96.3%
Living without a disability	92.0%	90.1%	to	94.0%

Source: 2019 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, Kansas Department of Health and Environment. See Technical Appendix for details on how prevalence estimates were calculated. County population density peer groups are based on the population for each county in the 2000 population, where rural group included Frontier (fewer than 6 persons per square mile), Rural (6 to 19.9 persons per square mile), Densely-Settled Rural (20 to 39.9 persons per square mile), while urban included Semi-Urban (40 to 149.9 persons per square mile), and Urban (150 or more persons per square mile).

## **Genetic Counseling for Cancer among Kansas Adults**

In 2019, about 13 percent (12.9%; 95% Confidence Interval (CI): 11.3% to 14.5%) of Kansas adults 18 years who have a family history of cancer have received genetic counseling for cancer (Table 12-2).

The percentage of Kansans who have a family history of cancer and have received genetic counseling for cancer in 2019 was significantly lower among males (9.4%; 95% CI: 7.5% to 11.3%) as compared to females (15.4%; 95% CI: 13.1% to 17.7%).

In 2019, the percentage of Kansans adults with family history of cancer and received genetic counseling for cancer was significantly lower among adults aged 25-34 years (7.4%; 95% CI: 4.0% to 10.8%) as compared to adults in older age groups.

In Kansas, the percentage of Kansans 18 years and older with family history of cancer and received genetic counseling for cancer was significantly lower among adults living without a disability (11.1%; 95% CI: 9.4% to 12.8%) as compared to adults live with a disability (17.1%; 95% CI: 13.8% to 20.3%).

The percentage of Kansans 18 years and older with family history of cancer and received genetic counseling did not differ significantly by race/ethnicity, education level, annual household income level, insurance status, or county population density subgroups.

Table 12-2. Percentage of adults with family history of cancer who received genetic counseling, Kansas 2019

Characteristic	Percentage of adults with family history of cancer and received genetic counseling	95% Confidence Interval		
Total	12.9%	11.3%	to	14.5%
Gender				l.
Male	9.4%	7.5%	to	11.3%
Female	15.4%	13.1%	to	17.7%
Age group				
18-39*	-	-	-	-
25-34	7.4%	4.0%	to	10.8
35-44	11.3%	6.9%	to	15.6%
45-64	15.2%	12.6%	to	17.8%
65 and older	16.1%	13.5%	to	18.2%
Race				l.
White	12.4%	10.8%	to	14.1%
African American	15.5%	5.9%	to	25.1%
American Indian/Alaskan Native	21.1%	7.9%	to	34.2%
Ethnicity				
Hispanic*	-	-	-	-
Non-Hispanic	13.2%	11.6%	to	14.8%
Education				
Less than high school	16.2%	7.3%	to	25.1%
High school graduate or GED	13.2%	10.4%	to	16.1%
Some college	11.7%	9.2%	to	14.2%
College graduate	13.1%	10.7%	to	15.4%
Household Income				
Less than \$15,000	12.6%	7.2%	to	17.9%
\$15,000 to \$24,999	16.5%	10.3%	to	22.8%
\$25,000 to \$34,999	12.4%	7.3%	to	17.5%
\$35,000 to \$49,999	9.7%	6.3%	to	13.0%
\$50,000 or higher	13.1%	10.9%	to	15.2%
Insurance Status				
Insured	12.6%	11.0%	to	14.2%
Uninsured	15.3%	8.9%	to	21.8%
County Population Density				
Rural	14.0%	11.5%	to	16.6%
Urban	12.4%	10.5%	to	14.5%
Disability Status	<u>'</u>			
Living with a disability	17.1%	13.8%	to	20.3%
Living without a disability	11.1%	9.4%	to	12.8%

<sup>\*</sup>Prevalence estimates are unable to be presented due to insufficient counts.

Source: 2019 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, Kansas Department of Health and Environment. See Technical Appendix for details on how prevalence estimates were calculated. County population density peer groups are based on the population for each county in the 2000 population, where rural group included Frontier (fewer than 6 persons per square mile), Rural (6 to 19.9 persons per square mile), Densely-Settled Rural (20 to 39.9 persons per square mile), while urban included Semi-Urban (40 to 149.9 persons per square mile), and Urban (150 or more persons per square mile).