

CHAPTER 11: GENETIC COUNSELING AND CLINICAL TRIALS

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 at-risk 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 doesn't 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.⁴⁴ Having a genetic counseling can help people make informed decisions about genetic testing and follow-up care.

Genetic Counseling among Kansas Adults

In 2015, about 28 percent of Kansas adults 18 years and older reported having a family history of breast, ovarian, or colorectal cancer (27.9%; 95% confidence interval: 26.7% to 29.0%).⁴⁵

The percentage of Kansans who received genetic counseling in 2015 was significantly higher among adults who have a family history of breast, ovarian, or colorectal cancer (23.7%; 95% confidence interval: 21.8% to 25.6%) as compared to Kansans who do not have a family history of cancer (6.0%; 95% confidence interval: 5.3% to 6.7%).⁴⁵

In 2015, the percentage of Kansans 18 years and older with family history of cancer and received genetic counseling was significantly lower among adults aged 18-39 (14.2%; 95% confidence interval: 10.7% to 17.8%) as compared to adults aged 40 and older (Table 11-1).

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, county population density or disability status subgroups (Table 11-1).

⁴⁴ American Cancer Society. Family Cancer Syndromes. Available at:

<http://www.cancer.org/cancer/cancercauses/geneticsandcancer/heredity-and-cancer>. Accessed September 1, 2016.

⁴⁵ 2015 KS BRFSS. Bureau of Health Promotion, KDHE.

http://www.kdheks.gov/brfss/Survey2015/ct2015_cafmlyhx.html. Accessed December 1, 2016.

Table 11-1. Percentage of adults with family history of cancer who received genetic counseling (Family history of breast, ovarian or colorectal cancer for females and breast or colorectal cancer for males), Kansas 2015

Characteristic	Percentage of adults with family history of cancer and received genetic counseling	95% Confidence Interval		
			to	
Total	23.7%	21.8%	to	25.6%
Gender				
Male	20.2%	16.9%	to	23.6%
Female	25.3%	23.0%	to	27.6%
Age group				
18-39	14.2%	10.7%	to	17.8%
40-64	27.9%	25.0%	to	30.8%
65 and older	28.2%	25.0%	to	31.4%
Race and Ethnicity (age-adjusted)				
White, Non-Hispanic	22.6%	20.6%	to	24.6%
African American, Non-Hispanic	29.3%	18.4%	to	40.1%
Other/Multi-Race, Non-Hispanic	26.7%	16.2%	to	37.2%
Hispanic	23.9%	14.0%	to	33.7%
Education				
Less than high school	19.0%	10.8%	to	27.1%
High school graduate or G.E.D.	24.8%	21.0%	to	28.6%
Some college	24.3%	20.9%	to	27.8%
College graduate	23.2%	20.2%	to	26.2%
Household Income				
Less than \$15,000	23.2%	15.2%	to	31.1%
\$15,000 to \$24,999	22.9%	17.5%	to	28.3%
\$25,000 to \$34,999	23.6%	17.5%	to	29.7%
\$35,000 to \$49,999	22.1%	17.2%	to	27.0%
\$50,000 or higher	25.2%	22.2%	to	28.2%
Insurance Status				
Insured	24.5%	22.4%	to	26.5%
Uninsured	17.4%	11.5%	to	23.3%
County Population Density				
Frontier	19.5%	10.6%	to	28.4%
Rural	23.2%	18.0%	to	28.3%
Densely-settled rural	25.3%	20.3%	to	30.4%
Semi-urban	22.2%	18.2%	to	26.1%
Urban	24.2%	21.4%	to	27.1%
Disability Status				
Living with a disability	24.7%	21.2%	to	28.3%
Living without a disability	23.4%	21.2%	to	25.7%

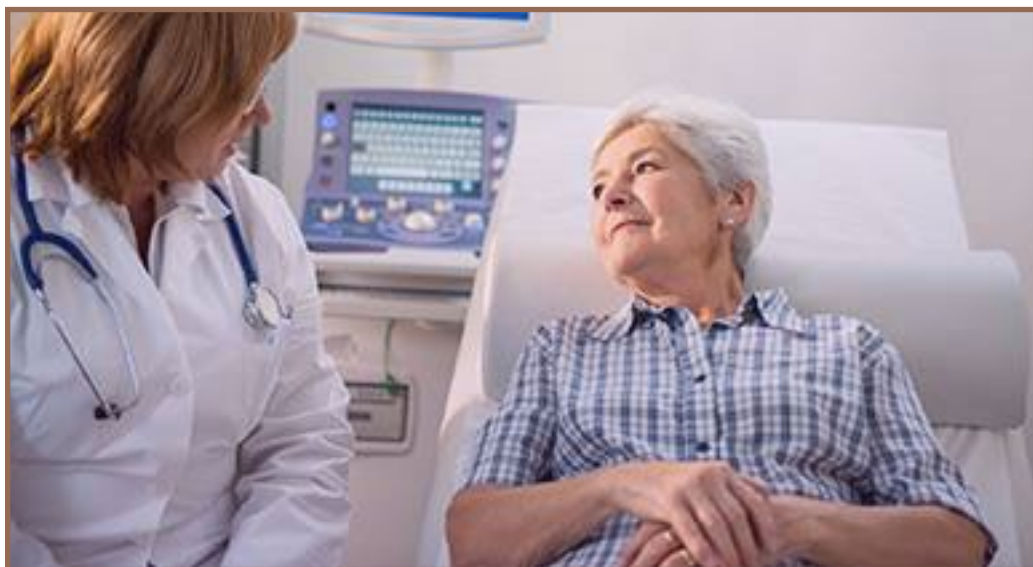
Source: 2015 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, Kansas Department of Health and Environment. Prevalence estimates for race and ethnicity were age-adjusted to the U.S. 2000 standard population. See Technical Appendix for details on how prevalence estimates were calculated. County population density peer groups are based on the population for each county in the 2000 population and are defined as follows: 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), Semi-Urban (40 to 149.9 persons per square mile), and Urban (150 or more persons per square mile).

Clinical Trials

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.

The biggest barrier to completing clinical trials is that not enough people participate. Fewer than 5% of adults with cancer take part in a clinical trial. The main reason people give for not taking part in a clinical trial is that they did not know the studies were an option for them.⁴⁶ Clinical trials are much more commonly used to treat children with cancer. In fact, 60% of children under age 15 participate in clinical trials. This is one reason that survival rates for childhood cancer have increased so dramatically in the last few decades.

Kansas BRFS has collected a population-based data related to prevalence estimates of adults having discussion with their health care provider about participating in a cancer clinical trial and adults actually enrolled in a cancer clinical trial managed by their health care provider, which is publicly available in 2015 Kansas BRFS.



⁴⁶ Clinical Trials: What You Need to Know — American Cancer Society, 2016. Available at:

In 2015, about 4 percent of Kansas adults 18 years and older reported ever talked to their health care provider about participating in a clinical trial (4.0%; 95% confidence interval: 3.5% to 4.4%) (Table 11-2).

The percentage of Kansans who have ever talked to their health care provider about participating in a clinical trial in 2015 was significantly higher among females (4.7%; 95% confidence interval: 4.0% to 5.4%) as compared to males (3.2%; 95% confidence interval: 2.6% to 3.8%) (Table 11-2).

In 2015, the percentage of Kansans 18 years and older who have ever talked to their health care provider about participating in a clinical trial was significantly higher among adults aged 65 and older (5.8%; 95% confidence interval: 4.9% to 6.8%), followed by adults aged 40-64 (4.2%; 95% confidence interval: 3.5% to 4.9%), as compared to adults aged 18-39 (2.7%; 95% confidence interval: 1.9% to 3.4%) (Table 11-2).

The percentage of Kansans 18 years and older who have ever talked to their health care provider about participating in a clinical trial did not differ significantly by race/ethnicity (Table 11-2).

In 2015, the percentage of Kansans 18 years and older who have ever talked to their health care provider about participating in a clinical trial was significantly higher among those who were college graduates (5.5%; 95% confidence interval: 4.6% to 6.4%) as compared to those who attained lower levels of education (Table 11-2).

The percentage of Kansans who have ever talked to their health care provider about participating in a clinical trial was significantly higher among adults whose annual household income was \$50,000 or more (4.6%; 95% confidence interval: 3.8% to 5.4%) as compared to those whose annual household income was \$25,000 to \$34,999 (2.1%; 95% confidence interval: 1.5% to 3.7%) (Table 11-2).

The percentage of Kansans 18 years and older who have ever talked to their health care provider about participating in a clinical trial was significantly higher among those who lived in urban counties (5.4%; 95% confidence interval: 4.7% to 6.2%) as compared to those living in any other areas (Table 11-2).

In 2015, the percentage of Kansans 18 years and older who have ever talked to their health care provider about participating in a clinical trial was significantly higher among those living with a disability (7.8%; 95% confidence interval: 6.6% to 9.1%) as compared to those living without a disability (2.8%; 95% confidence interval: 2.4% to 3.3%) (Table 11-2).

Table 11-2. Percentage of adults who have ever talked to their health care provider about participating in a clinical trial, Kansas 2015

Characteristic	Percentage of adults who have ever talked to their health care provider about participating in a clinical trial	95% Confidence Interval		
Total	4.0%	3.5%	to	4.4%
Gender				
Male	3.2%	2.6%	to	3.8%
Female	4.7%	4.0%	to	5.4%
Age group				
18-39	2.7%	1.9%	to	3.4%
40-64	4.2%	3.5%	to	4.9%
65 and older	5.8%	4.9%	to	6.8%
Race and Ethnicity (age-adjusted)				
White, Non-Hispanic	4.1%	3.6%	to	4.6%
African American, Non-Hispanic	5.2%	2.7%	to	7.7%
Other/Multi-Race, Non-Hispanic	3.0%	1.2%	to	4.8%
Hispanic	3.7%	0.9%	to	6.4%
Education				
Less than high school	2.7%	1.2%	to	4.1%
High school graduate or G.E.D.	2.7%	2.0%	to	3.5%
Some college	4.1%	3.3%	to	4.9%
College graduate	5.5%	4.6%	To	6.4%
Household Income				
Less than \$15,000	5.1%	3.1%	to	7.1%
\$15,000 to \$24,999	4.1%	2.9%	to	5.3%
\$25,000 to \$34,999	2.6%	1.5%	to	3.7%
\$35,000 to \$49,999	3.4%	2.3%	to	4.4%
\$50,000 or higher	4.6%	3.8%	to	5.4%
Insurance Status				
Insured	4.2%	3.7%	to	4.6%
Uninsured	2.8%	1.5%	to	4.1%
County Population Density				
Frontier	1.2%	0.2%	to	2.3%
Rural	2.8%	1.6%	to	4.0%
Densely-settled rural	2.2%	1.5%	to	2.9%
Semi-urban	2.5%	1.7%	to	3.3%
Urban	5.4%	4.7%	to	6.2%
Disability Status				
Living with a disability	7.8%	6.6%	to	9.1%
Living without a disability	2.8%	2.4%	to	3.3%

Source: 2015 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, Kansas Department of Health and Environment. Prevalence estimates for race and ethnicity were age-adjusted to the U.S. 2000 standard population. 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 and are defined as follows: 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), Semi-Urban (40 to 149.9 persons per square mile), and Urban (150 or more persons per square mile).

In 2015, about 9 percent of Kansas adults 18 years and older who have ever been diagnosed with cancer reported ever talked to their health care provider about participating in a cancer clinical trial (8.5%; 95% confidence interval: 7.0% to 10.0%) (Table 11-3).

The percentage of Kansans with cancer diagnosis who have ever talked to their health care provider about participating in a cancer clinical trial in 2015 did not differ significantly by gender, age group, race and ethnicity status, education level, annual household income, and insurance status.

In 2015, the percentage of Kansans 18 years and older who have ever been diagnosed with cancer and have ever talked to their health care provider about participating in a cancer clinical trial was significantly higher among those who lived in urban counties (12.0%; 95% confidence interval: 9.4% to 14.6%) as compared to those living in densely-settled rural and semi-urban areas (Table 11-3).

The percentage of Kansans 18 years and older with cancer diagnosis who have ever talked to their health care provider about participating in a cancer clinical trial was significantly higher among those living with a disability (11.6%; 95% confidence interval: 8.6% to 14.7%) as compared to those living without a disability (6.6%; 95% confidence interval: 5.0% to 8.2%) (Table 11-3).

Table 11-3. Percentage of adults diagnosed with cancer who have ever talked to their health care provider about participating in a clinical trial, Kansas 2015

Characteristic	Percentage of adults who have ever talked to their health care provider about participating in a clinical trial	95% Confidence Interval		
Total	8.5%	7.0%	to	10.0%
Gender				
Male	6.4%	4.4%	to	8.4%
Female	10.2%	8.0%	to	12.5%
Age group				
18-39*	-	-	to	-
40-64	9.7%	6.9%	to	12.6%
65 and older	8.0%	6.3%	to	9.8%
Race and Ethnicity (age-adjusted)				
White, Non-Hispanic	7.7%	4.8%	to	10.6%
African American, Non-Hispanic	19.8%	3.6%	to	35.9%
Other/Multi-Race, Non-Hispanic*	-	-	to	-
Hispanic*	-	-	to	-
Education				
Less than high school*	-	-	to	-
High school graduate or G.E.D.	6.0%	3.4%	to	8.7%
Some college	9.4%	6.4%	to	12.5%
College graduate	10.8%	8.2%	To	13.4%
Household Income				
Less than \$15,000	10.8%	3.2%	to	18.3%
\$15,000 to \$24,999	10.7%	6.3%	to	15.2%
\$25,000 to \$34,999	5.1%	2.0%	to	8.1%
\$35,000 to \$49,999	10.6%	5.9%	to	15.3%
\$50,000 or higher	8.8%	6.3%	to	11.3%
Insurance Status				
Insured	8.6%	7.0%	to	10.2%
Uninsured*	-	-	to	-
County Population Density				
Frontier*	-	-	to	-
Rural	6.8%	3.0%	to	10.6%
Densely-settled rural	3.4%	1.3%	to	5.5%
Semi-urban	6.0%	2.8%	to	9.1%
Urban	12.0%	9.4%	to	14.6%
Disability Status				
Living with a disability	11.6%	8.6%	to	14.7%
Living without a disability	6.6%	5.0%	to	8.2%

* Prevalence estimates are unable to present due to insufficient counts.

Source: 2015 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, Kansas Department of Health and Environment. Prevalence estimates for race and ethnicity were age-adjusted to the U.S. 2000 standard population. 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 and are defined as follows: 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), Semi-Urban (40 to 149.9 persons per square mile), and Urban (150 or more persons per square mile).

In 2015, about 31 percent of Kansas adults 18 years and older reported ever enrolled in a clinical trial managed by their health care provider (31.4%; 95% confidence interval: 23.1% to 39.8%) (Table 11-4).

The percentage of Kansans 18 years and older who have ever enrolled in a clinical trial managed by their health care provider did not differ significantly by gender, age group, education level, annual household income, county population density or disability status subgroups (Table 11-4).

Table 11-4. Percentage of adults diagnosed with cancer who have ever enrolled in a cancer clinical trial managed by their health care provider, Kansas 2015

Characteristic	Percentage of adults diagnosed with cancer who have ever enrolled in a cancer clinical trial managed by their health care provider	95% Confidence Interval		
			to	
Total	31.4%	23.1%	to	39.8%
Gender				
Male	22.3%	10.5%	to	34.1%
Female	36.4%	25.6%	to	47.2%
Age group				
18-39*	-	-	to	-
40-64	33.9%	20.1%	to	47.7%
65 and older	32.0%	21.4%	to	42.6%
Race and Ethnicity (age-adjusted)				
White, Non-Hispanic	21.7%	15.6%	to	27.7%
African American, Non-Hispanic*	-	-	to	-
Other/Multi-Race, Non-Hispanic*	-	-	to	-
Hispanic*	-	-	to	-
Education				
Less than high school*	-	-	to	-
High school graduate or G.E.D.	32.8%	12.8%	to	52.7%
Some college	30.2%	16.1%	to	44.3%
College graduate	34.7%	22.2%	To	47.2%
Household Income				
Less than \$15,000*	-	-	to	-
\$15,000 to \$24,999	21.5%	5.8%	to	37.2%
\$25,000 to \$34,999*	-	-	to	-
\$35,000 to \$49,999	33.0%	11.2%	to	54.8%
\$50,000 or higher	34.8%	21.8%	to	47.9%
Insurance Status				
Insured	30.8%	22.3%	to	39.2%
Uninsured*	-	-	to	-
County Population Density				
Frontier*	-	-	to	-
Rural	36.2%	9.4%	to	63.0%
Densely-settled rural*	-	-	to	-
Semi-urban*	-	-	to	-
Urban	31.8%	21.5%	to	42.1%
Disability Status				
Living with a disability	28.5%	17.0%	to	40.0%
Living without a disability	34.6%	22.5%	to	46.7%

* Prevalence estimates are unable to present due to insufficient counts.

Source: 2015 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, Kansas Department of Health and Environment. Prevalence estimates for race and ethnicity were age-adjusted to the U.S. 2000 standard population. 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 and are defined as follows: 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), Semi-Urban (40 to 149.9 persons per square mile), and Urban (150 or more persons per square mile).