

# CANCER IN IOWA 2022

# State Health Registry of Iowa/Iowa Cancer Registry

Two in five Iowans will be diagnosed with cancer in their lifetimes. Cancer is a major burden in Iowa and throughout the US. Reducing the nation's cancer burden requires the cooperation of many people, including providers, patients, researchers, public health professionals, policy makers and advocates, among others. To reduce the burden of cancer, we need to have access to high quality data. Because of this need for data, cancer is a reportable disease in all 50 states. In Iowa, cancer data are collected by the Iowa Cancer Registry.

Since 1973, the Iowa Cancer Registry has been part of the Surveillance, Epidemiology, and End Results Program of the National Cancer Institute. The Iowa Cancer Registry is currently one of 21 US registries providing data to this Program. Iowa represents rural and Midwestern populations, and our data are included in many publications, national estimates, and projections of cancer burden.

Patient, provider, and hospital confidentiality is important to the Iowa Cancer Registry. It is the responsibility of the Iowa Cancer Registry to balance the need to protect its data and provide researchers the information needed to conduct studies to help reduce the burden of cancer. To meet this goal, the Iowa Cancer Registry has policies around research, reporting, and release of data to safeguard the confidentiality of patients, providers, and hospitals.

The Iowa Cancer Registry helps us to study the cancer experience of Iowans and brings national attention to the issue. The Iowa Cancer Registry is primarily funded by the National Cancer Institute, as well as the University of Iowa and the State of Iowa. Research using Iowa Cancer Registry data has been funded by other federal agencies and foundations.

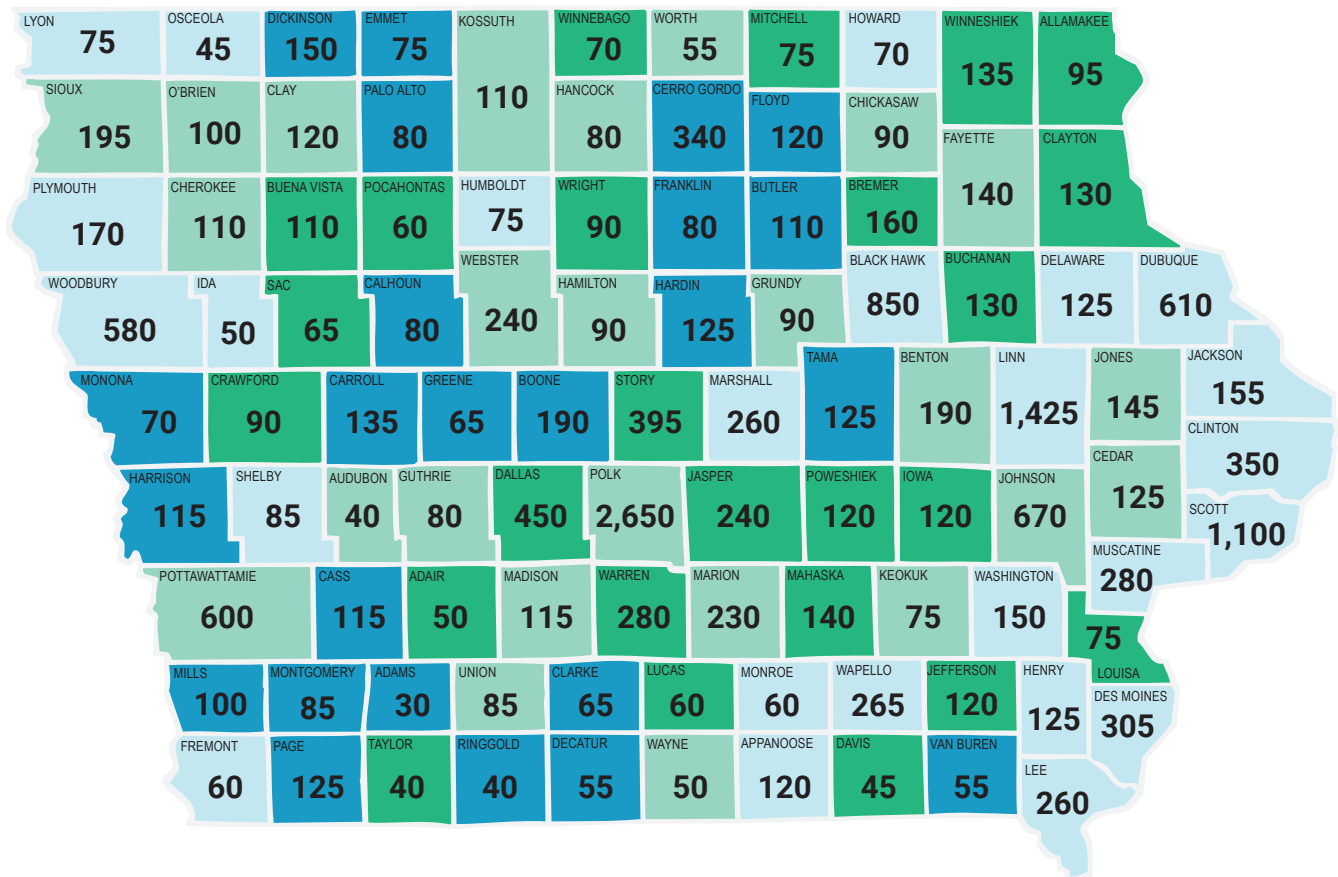
- ▶ The *Cancer in Iowa 2022* report provides information to the public on the status of cancer in our state. The report focuses on:
- Estimates of new cancer cases, cancer deaths, and cancer survivors by county
  - The importance of cancer screening
  - Information on genetic testing and counseling
  - Examples of research using Iowa Cancer Registry data

## THE REPORT CAN ALSO BE FOUND ONLINE AT

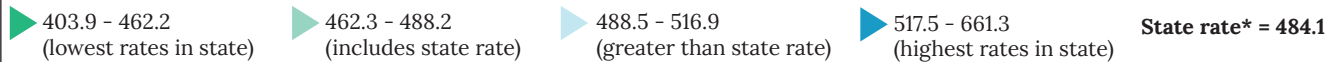
<https://shri.public-health.uiowa.edu/cancer-data/iowa-cancer-reports/>

# Estimates for New Cancers for 2022

In 2022, an estimated 20,000 new, invasive cancers (and in situ bladder cancers) will be diagnosed among Iowa residents. The numbers on the map below are estimates of new cancer cases for 2022 by county of residence at diagnosis. The color of the county shows the rate of new cancer cases for years 2014-2018, with the counties with the lowest rates shaded **dark green** and the counties with the highest rates shaded **dark blue**.



### County-level All Invasive Cancers Incidence Rate\*

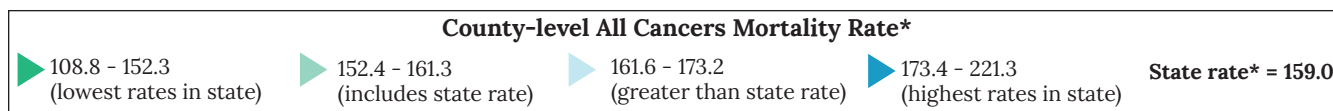
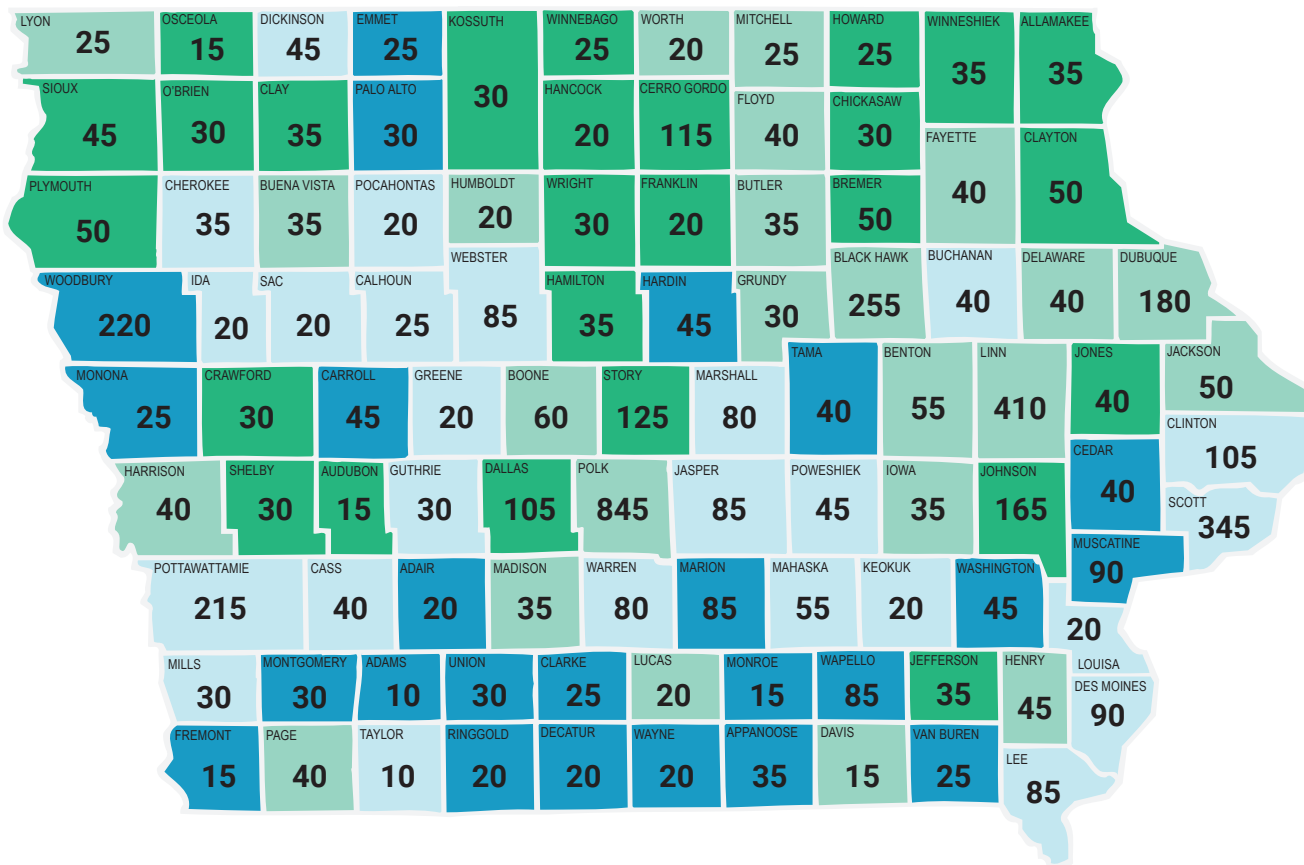


ESTIMATED NEW CANCERS AMONG IOWA RESIDENTS, 2022		
TYPE	# OF CANCERS	% OF TOTAL
Breast	2,825	14.1
Prostate	2,700	13.5
Lung	2,570	12.9
Colon and rectum	1,600	8.0
Skin melanoma	1,250	6.3
Bladder	900	4.5
Non-Hodgkin lymphoma	790	4.0
Kidney and renal pelvis	750	3.7
Leukemia	690	3.4
Uterus	650	3.2
All others	5,275	26.4
<b>TOTAL</b>	<b>20,000</b>	<b>100.0</b>

\*Rates are age-adjusted and per 100,000 population, 2014-2018

# Estimates for Cancer Deaths for 2022

In 2022, an estimated 6,300 Iowans will die from cancer. These projections are based on mortality data provided by the Iowa Department of Public Health. The numbers on the map below are estimates of cancer deaths for 2022 by county of residence at time of death. The color of the county shows the rate of cancer deaths for years 2014-2018, with the counties with the lowest rates shaded **dark green** and the counties with the highest rates shaded **dark blue**.

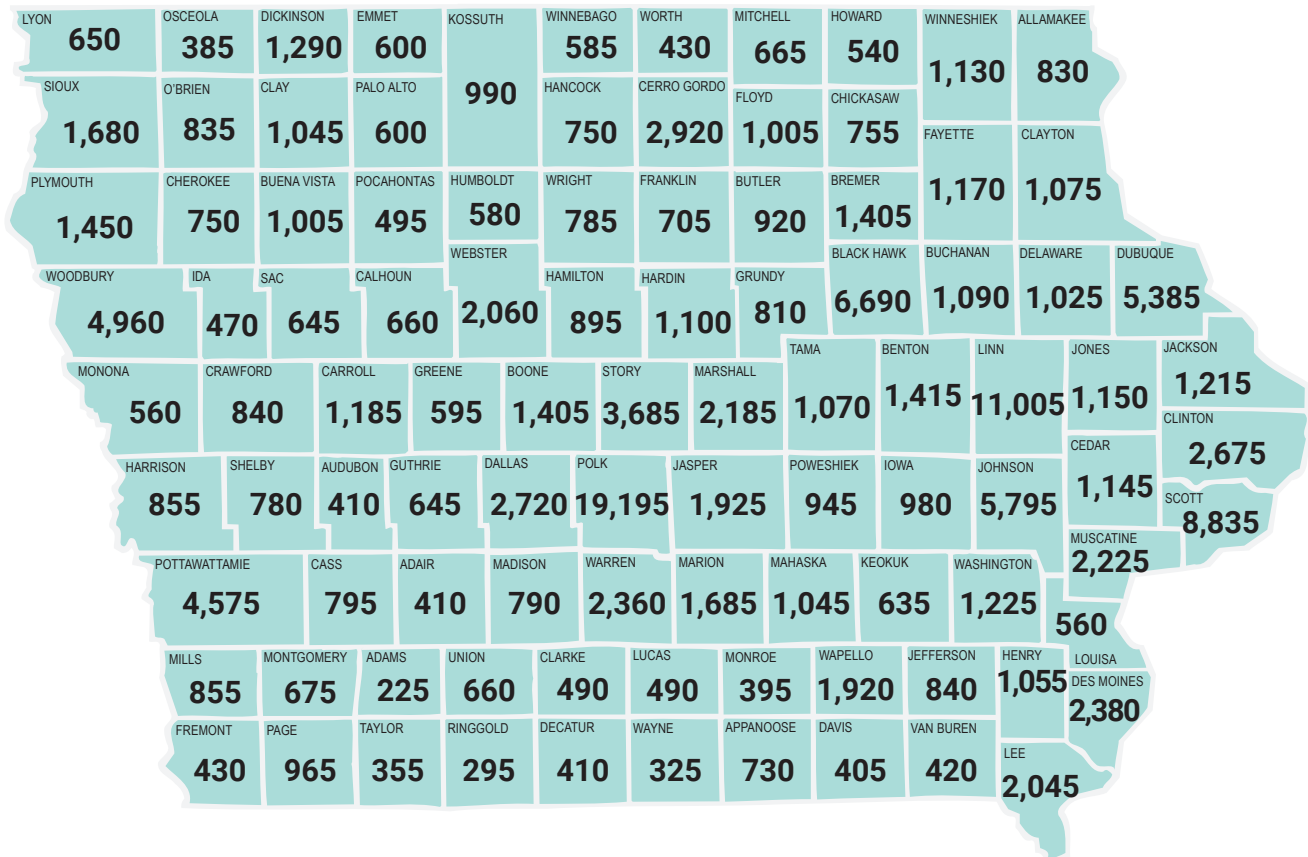


ESTIMATED CANCER DEATHS AMONG IOWA RESIDENTS, 2022		
TYPE	# OF DEATHS	% OF TOTAL
Lung	1,500	23.8
Colon and rectum	540	8.6
Pancreas	470	7.5
Breast	405	6.4
Prostate	350	5.6
Leukemia	250	4.0
Liver and intrahepatic bile duct	230	3.6
Non-Hodgkin lymphoma	230	3.6
Esophagus	195	3.1
Brain	185	2.9
All others	1,945	30.9
<b>TOTAL</b>	<b>6,300</b>	<b>100.0</b>

\*Rates are age-adjusted and per 100,000 population, 2014-2018

# Living with Cancer

The number of cancer survivors is growing in Iowa, and nationwide. Follow-up activities help track the vital status of more than 99 percent of cancer survivors diagnosed since 1973. According to Iowa Cancer Registry incidence and survival data for 1973–2017, there are an estimated 159,700 cancer survivors among Iowans (defined as people who are currently living with or having had cancer).



SURVIVORS AMONG IOWANS DIAGNOSED WITH CANCER		
TYPE	# OF SURVIVORS	% OF TOTAL
Breast	35,155	22.0
Prostate	29,150	18.3
Colon and rectum	15,830	9.9
Skin melanoma	12,285	7.7
Uterus	8,635	5.4
Bladder	7,835	4.9
Thyroid	7,745	4.8
Non-Hodgkin lymphoma	7,665	4.8
Lung	6,385	4.0
Kidney and renal pelvis	6,255	3.9
All others	22,760	14.3
<b>TOTAL</b>	<b>159,700</b>	<b>100.0</b>

# Cancer Screening

Cancer screening tests are intended to detect cancer early when it may be easier to cure. Screening helps to find out whether a person has precancer or cancer before any symptoms appear<sup>1</sup>. Effective screening tests:

- Reduce the chance that someone who is screened regularly will die from the cancer
- Have more potential benefits than harms

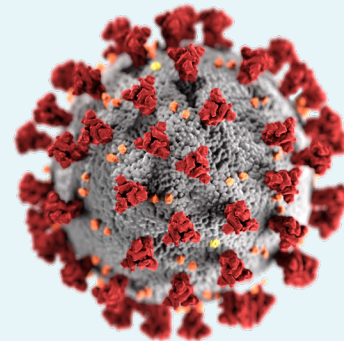
The US Preventive Services Task Force (USPSTF) is a panel of volunteer experts who review and discuss data regarding the benefits and potential harms of different ways to prevent disease, including cancer screening tests. USPSTF guidelines for cancer screening help people of *average risk* decide whether they should be screened for cancer, at what age they should start screening, how often they should get screened, and by which method. People should be involved in decision-making with their provider as much as feels comfortable.

Recommendations are given one of five letter grades (A, B, C, D, or I) as shown in Table 1. The USPSTF revisits existing recommendations as new research becomes available and can revise them if necessary<sup>1</sup>. For this report's special section on cancer screening, we focus on cancers with USPSTF grade recommendations of A or B. The Affordable Care Act requires most private insurers and Medicare to cover the costs of cancer screening tests, because these tests are recommended by the USPSTF. This generally includes no out-of-pocket costs for patients, such as co-pays or deductibles. Other guidelines exist including those by the American Cancer Society and other organizations and some recommendations may differ slightly. But all are united in their belief that regular and appropriate cancer screening helps save lives.

The following pages will provide additional information on colorectal, cervical, breast, and lung cancer screening. Additional information regarding genetic testing and counseling is provided on pages 13 and 14 for those outside the recommended screening age or known to be higher-than-average risk.

## COVID-19 AND CANCER SCREENING

When COVID-19 was declared a global pandemic by the World Health Organization on March 11, 2020, elective medical procedures, including cancer screenings, were largely put on hold to prioritize pandemic health care, resulting in a drop in cancer screening rates. We do not yet know the extent of the impact of this decrease, but it may lead to delayed diagnoses and increases in avoidable cancer deaths<sup>2</sup>. By June 30, 2020, an estimated 41% of US adults had delayed or avoided medical care<sup>3</sup>. Today, however, most healthcare facilities have returned to offering cancer screenings with many safety precautions in place. There is a National Call to Action on Cancer Screening and Early Detection<sup>4</sup>. The goal of this Call is to get back on track after more than 9.5 million individuals missed cancer screenings in the US because of the COVID-19 pandemic. Talk to your healthcare provider about whether you should get screened for cancer.



**Table 1. US Preventive Services Task Force Grade Definitions**

- A** The USPSTF recommends the service. There is high certainty that the net benefit is substantial.
- B** The USPSTF recommends the service. There is high certainty that the net benefit is moderate or there is moderate certainty that the net benefit is moderate to substantial.
- C** The USPSTF recommends selectively offering or providing this service to individual patients based on professional judgment and patient preferences. There is at least moderate certainty that the net benefit is small.
- D** The USPSTF recommends against this service. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits.
- I** The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.

# Cancer Screening

## KEY POINTS

- Colorectal, cervical, breast, and lung cancers are all common cancers for which there are USPSTF recommended screening tests.
- Regular screening and follow-up for abnormal screening results are very important.
- About two-thirds of colorectal cancer deaths in the US could be prevented through screening. The percent of eligible Iowans getting screened has not yet reached the National Colorectal Cancer Roundtable goal of 80% in every community. Eligibility guidelines have recently changed to include those 45 and older.
- Nearly all cases of cervical cancer are caused by infection with high risk types of human papillomavirus (HPV). Screening for cervical cancer and HPV vaccination are two effective tools in eliminating cervical cancer.
- Mammography can find breast cancers that are too small to feel or may find ductal carcinoma in situ, which can become invasive in some individuals.
- Guidelines for lung cancer screening have changed to include people ages 50-80 years with a 20 pack-year or greater smoking history.



Age 25-39 Screening Recommendations	Age 40-49 Screening Recommendations	Age 50+ Screening Recommendations
<ul style="list-style-type: none"> <li>• <b>Cervical cancer screening</b> recommended for people with a cervix</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Breast/chest cancer screening</b> recommended beginning at age 45, with the option to begin at age 40.</li> <li>• <b>Cervical cancer screening</b> recommended for people with a cervix</li> <li>• <b>Colorectal cancer screening</b> recommended for everyone beginning at age 45</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Breast/chest cancer screening</b> recommended</li> <li>• <b>Cervical cancer screening</b> recommended for people with a cervix</li> <li>• <b>Colorectal cancer screening</b> recommended</li> <li>• People who currently smoke or formerly smoked should discuss <b>lung cancer screening</b> with a doctor</li> </ul>

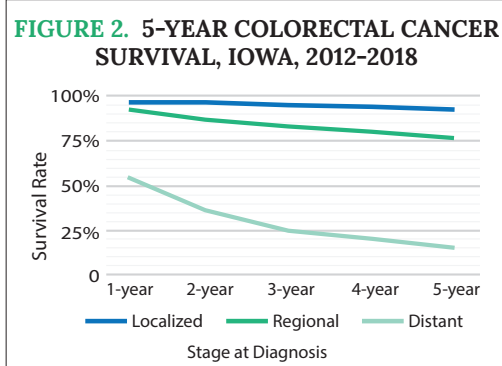
## KEY TERMS

- ▷ **Average Risk:** People who do not have signs or symptoms of the cancer being screened for, with no prior precancer or cancer, or any conditions that put one at increased risk for that cancer.
- ▷ **Primary site:** The originating location of a precancer or invasive cancer (the lung, for example).
- ▷ **Precancer:** Cells (on the surface of the cervix, for example) that have abnormal growth without risk of spread (metastasis) from the primary site.
- ▷ **Invasive cancer:** Cells (in the prostate, for example) that have abnormal growth and demonstrate spread within the primary site or spread to nearby or distant parts of the body (metastasis).
- ▷ **Localized cancer:** An invasive cancer that is present only in tissue very near the primary site.
- ▷ **Regional cancer:** An invasive cancer that has spread from the primary site to draining lymph nodes.
- ▷ **Distant cancer:** An invasive cancer that has spread from the primary site to one or more separate body cavities, regions, or organs.
- ▷ **Healthy Iowans:** Iowa's health improvement plan which sets our public health agenda.
- ▷ **BRFSS:** Behavioral Risk Factor Surveillance System uses a telephone survey to collect data on health-related risk behaviors, chronic health conditions, and use of preventive services (such as cancer screening tests). Responses from 2011 onward were collected from a cell phone sample in addition to landline. While our graphics show data from 1994-2019, data collected up to 2010 should not be compared with data collected from 2011 onward. For more information, go to <https://idph.iowa.gov/brfss>.

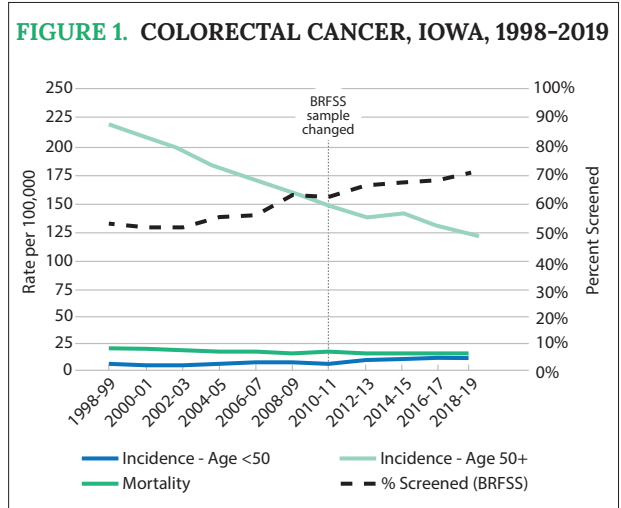


# Colorectal Cancer

Colorectal cancer usually begins as a polyp, a noncancerous growth that develops in the inner lining of the colon or rectum. Polyps are common, with fewer than 10% estimated to progress to invasive cancer. The percent of Iowans screened for colorectal cancer has been increasing since 2004 [Figure 1]. **Screening can prevent cancer by finding and removing polyps before they progress to cancer and can find cancer at an early stage when treatment is typically more successful.** This corresponds to a decline in the rate of new cases for those ages 50+ and deaths due to colorectal cancer in Iowa. By working



to increase the percent screened in Iowa, more cancers can be detected earlier, at localized stage, with better 5-year survival rates as shown in Figure 2. About 40% of colorectal cancer in Iowa is found localized to the colon or rectum. Figure 1 also shows the increasing rate of colorectal cancer incidence among Iowans <50 years of age. As a result of this trend occurring nationally, the USPSTF recently lowered the screening age from 50 to 45.



## USPSTF COLORECTAL CANCER SCREENING RECOMMENDATIONS:

For all adults ages 45-49 years (Grade B) and all adults ages 50-75 years (Grade A), one of the following:

- ▶ **STOOL-BASED** (sample collected at home and sent in)
  - Fecal immunochemical test (FIT) or high-sensitivity guaiac fecal occult blood test (HSgFOBT) every year
    - checks for blood in your stool
  - Stool DNA-FIT (Cologuard) every 1 to 3 years
    - checks for DNA changes and blood in your stool
- ▶ **DIRECT VISUALIZATION** (of colon and rectum by provider)
  - Colonoscopy screening every 10 years (or sooner if polyps detected)
    - colonoscopy examines entire colon and can remove polyps
  - Flexible sigmoidoscopy every 5 years
  - Flexible sigmoidoscopy every 10 years + annual FIT
  - Computed tomography colonography every 5 years

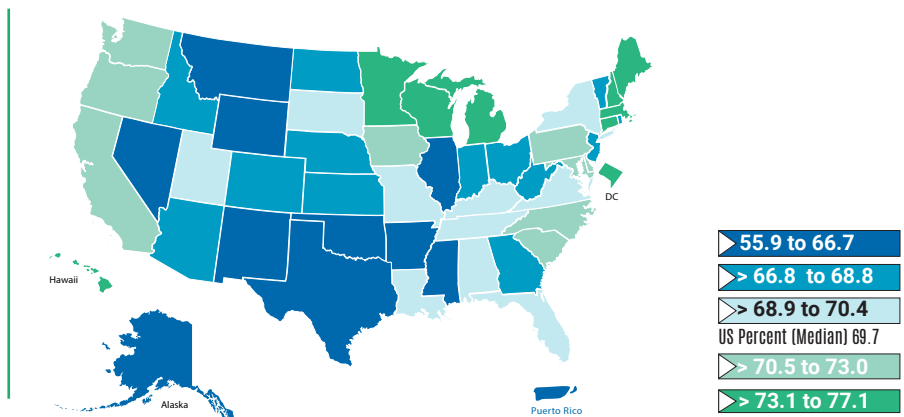
## HOW CAN I GET SCREENED?

Stool-based samples are collected at home while other tests, such as sigmoidoscopy and colonoscopy are often outpatient procedures done at a hospital. Talk to your primary care physician about scheduling your colonoscopy. If you need assistance paying for or help in scheduling your screening test, view the resources available to Iowans on page 12.

## ARE IOWANS GETTING SCREENED? FIGURE 3. 2018 PERCENT SCREENED FOR COLORECTAL CANCER BY STATE

In 2020, approximately 74% of eligible Iowans were up-to-date on colorectal cancer screening (BRFSS).

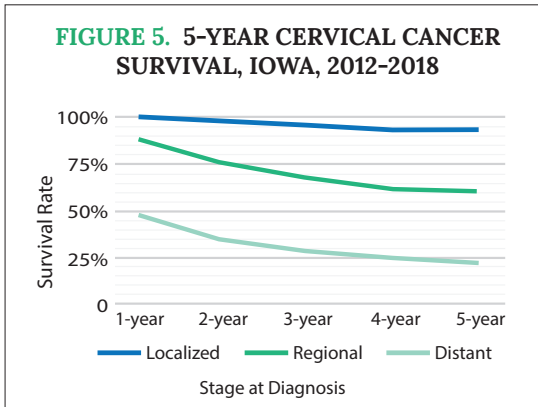
There is room for improvement to meet the Healthy Iowans goal of 80% by year 2025. Iowa is slightly higher than the median screening percent for the US in 2018 and is in the second highest grouping as shown in Figure 3. The neighboring states of Wisconsin and Minnesota have a higher percent screened than Iowa.



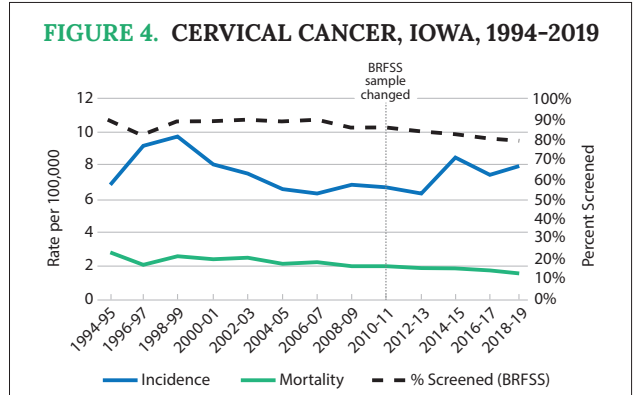


# Cervical Cancer

Nearly all cases of cervical cancer are caused by infection with high-risk types of human papillomavirus (HPV). The primary goal of screening with a Pap Test is to identify precancer or to find cancer at an early stage, when it can be treated more successfully. The goal of screening for HPV is to determine if the high-risk types that can cause cancer are present. Unlike the success seen with colorectal cancer screening, the rate of new cases of cervical cancer has been increasing since 2012. The percent of Iowans screened for cervical cancer



has been decreasing since 2008 [Figure 4].



The decline in deaths has stalled. Only half of the cases in Iowa are found at a localized stage, where survival rates are much higher than for regional or distant-stage cervical cancer [Figure 5]. **Screening and HPV vaccination are two effective, readily available tools in eliminating cervical cancer.** The HPV program in England has nearly eliminated cervical cancer in the generation since the vaccine was developed<sup>6</sup>. **Information on HPV vaccination can be found on page 12.**

## USPSTF CERVICAL CANCER SCREENING RECOMMENDATIONS:

For those ages 21–29 years with a cervix (Grade A):

- ▶ Pap Test every 3 years
  - a Pap Test collects cells from the cervix to be looked at in the lab for precancer and cancer

For those ages 30–65 years with a cervix (Grade A):

- ▶ Pap Test every 3 years, high-risk HPV (hrHPV) testing alone every 5 years, or hrHPV testing in combination with a Pap Test (co-testing) every 5 years
  - the hrHPV test reveals the types of HPV most likely to cause cervical cancer by detecting HPV DNA in cervical cells

## HOW CAN I GET SCREENED?

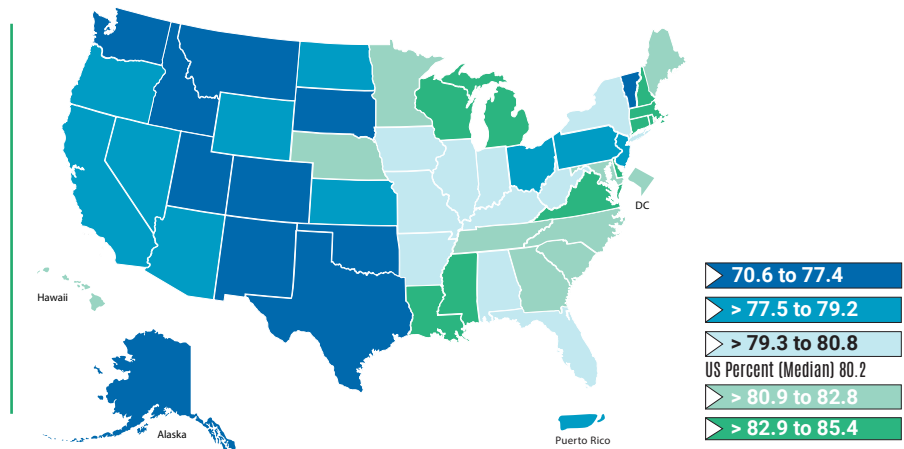
The Pap Test and hrHPV tests are done at your doctor or nurse's office. Cervical cancer screening guidelines for transgender and non-binary people can be found at National LGBT Cancer Network TRANSforming Cancer (<https://cancer-network.org/transgender-and-gender-non-conforming-care/>). If you need assistance paying for or help in scheduling your screening test, view the resources available to Iowans on page 12.

## ARE IOWANS GETTING SCREENED?

In 2020, approximately 77% of eligible Iowans ages 21 to 65 had been screened for cervical cancer within the past three years (BRFSS).

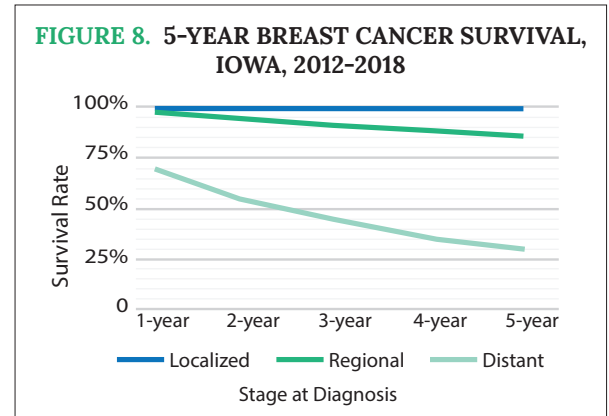
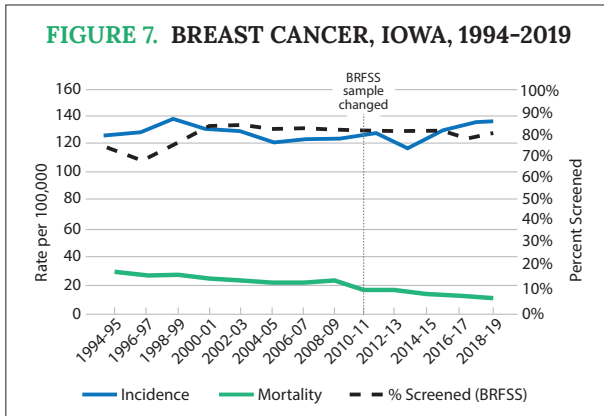
There is room for improvement as the percent screened is declining in Iowa, and we are still not reaching the Healthy Iowans goal of 92% set for 2022<sup>5</sup>. Iowa is slightly higher than the median screening percent for the US in 2018 and is in the middle grouping as shown in Figure 6. The neighboring states of Wisconsin, Minnesota and Nebraska have a higher percent screened than Iowa.

**FIGURE 6. 2018 PERCENT SCREENED FOR CERVICAL CANCER BY STATE**



# Breast Cancer

A mammogram may find cancers that are too small to feel. It may also find ductal carcinoma in situ that can become invasive. The percent of Iowans screened for breast cancer has been stable at around 80% since the year 2000 [Figure 7]. The mortality rate has been slowly decreasing over the last 20 years. Some of the decline in mortality may be due to improved cancer treatments or an increase in the number of cancers being diagnosed at a localized stage through mammography. The rate of new cases of breast cancer has been increasing since 2013. In Iowa, 70% of new breast cancer diagnoses are localized to the breast. **By working to increase the percent screened in Iowa, more cancers can be found at localized stage, where 5-year survival rates are nearly 100%**, as shown in Figure 8.



## USPSTF BREAST CANCER SCREENING RECOMMENDATIONS:

For those ages 50 to 74 years with breast/chest tissue (Grade B):

- ▶ Screening mammogram (an X-ray picture of the breast) every two years

## HOW CAN I GET SCREENED?

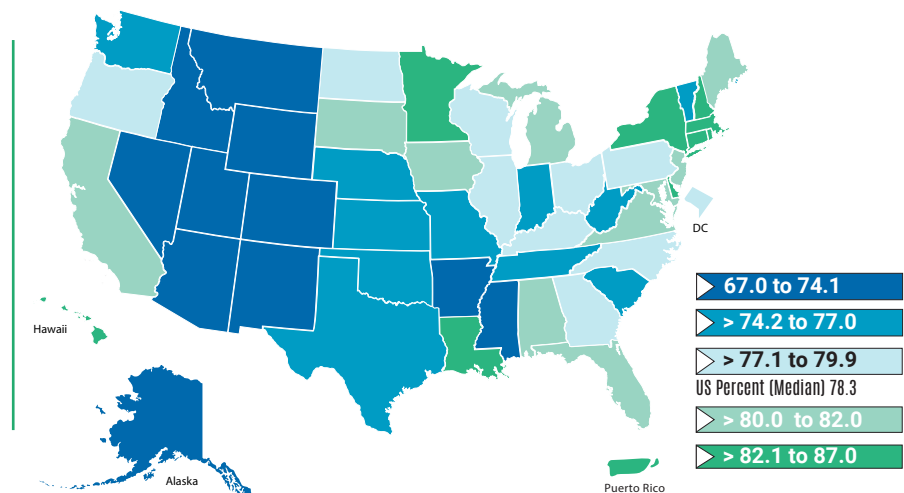
Mammograms are often performed at the hospital, breast health center, or an imaging center. There may be a mobile mammography unit that might be coming to a location near your home or work. Talk to your primary care provider about whether mammography could be right for you. Breast cancer screening guidelines for transgender and non-binary people can be found at National LGBT Cancer Network TRANSforming Cancer (<https://cancer-network.org/transgender-and-gender-non-conforming-care/>). If you need assistance paying for or help in scheduling your mammogram, view the resources available to Iowans on page 12.

## ARE IOWANS GETTING SCREENED?

In 2020, approximately 81% of eligible Iowans ages 50 to 74 had a mammogram within the past two years (BRFSS).

There is room for improvement as we are still not quite reaching the Healthy Iowans goal of 85%, set for 2022<sup>5</sup>. Iowa is higher than the median screening percent in the US in 2018 and is in the second highest grouping as shown in Figure 9 but is behind our neighboring state of Minnesota.

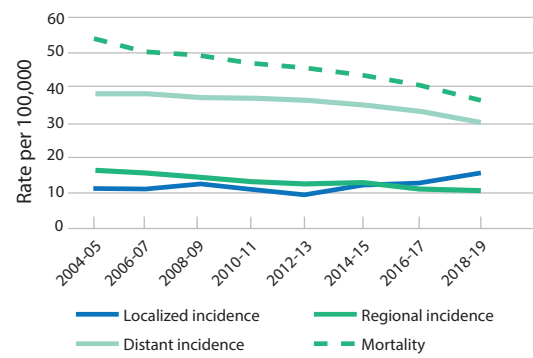
**FIGURE 9. 2018 PERCENT SCREENED FOR BREAST CANCER BY STATE**



# Lung Cancer

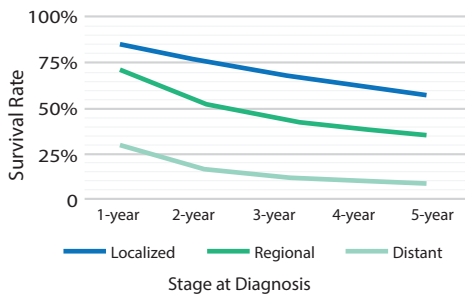
Lung cancer is the number one cause of cancer death in the US and the state of Iowa. The biggest risk factor for lung cancer is tobacco smoking and the best way to prevent lung cancer is to not smoke. The percent of lowans who smoke has been decreasing over time and this corresponds to decreasing rates of new lung cancers and cancer deaths (mortality) as shown in **Figure 10**. The decrease in new cancers is seen for cases with spread beyond the lung (regional and distant-stage disease). Screening for lung cancer has been recommended since 2013. An increase in cancers confined to the lung (localized) is seen beginning in 2014.

**FIGURE 10. LUNG CANCER, IOWA, 2004-2019**



However, only one in four cases in Iowa is diagnosed at a localized stage. By increasing awareness of this available screening test for lung cancer, more cancers can be found and treated earlier. This allows for improved survival, as shown in **Figure 11**.

**FIGURE 11. 5-YEAR LUNG CANCER SURVIVAL, IOWA, 2012-2018**



## USPSTF LUNG CANCER SCREENING RECOMMENDATIONS:

For adults ages 50 to 80 years who have a 20 pack-year smoking history and currently smoke or have quit within the past 15 years (Grade B):

- ▶ **LOW-DOSE COMPUTED TOMOGRAPHY (LDCT)**
  - Annual screening with LDCT (computer linked to X-ray machine)
  - Screening should be stopped once a person has not smoked for 15 years or develops a health problem that limits life expectancy or the ability/willingness to have curative lung surgery
- ▶ As of March 2021, the screening age was lowered to 50 and the minimum smoking history was dropped from 30 to 20 pack-years, allowing screening to more high-risk individuals

## ARE YOU ELIGIBLE FOR SCREENING?

One pack-year equals smoking an average of 20 cigarettes (one pack) per day for a year. A person could have a 20 pack-year history by smoking one pack a day for 20 years or two packs a day for ten years.

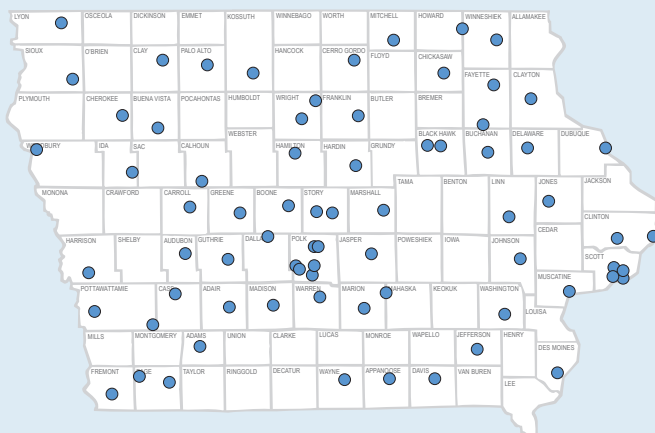
## DID YOU KNOW?

Radon (a colorless and odorless gas) is the number one cause of lung cancer among nonsmokers. Iowa is considered high risk for radon gas in homes, so it is important for everyone to test their homes (more on page 12).

## HOW CAN I GET SCREENED?

Screening should ideally be done at a location with experience and expertise in lung cancer screening. This will usually be a hospital or imaging facility. There are 86 screening locations in Iowa (<https://www.acr.org/Clinical-Resources/Lung-Cancer-Screening-Resources/LCS-Locator-Tool>) as shown in **Figure 12**.

**FIGURE 12. LUNG CANCER SCREENING LOCATIONS IN IOWA**



## ARE IOWANS GETTING SCREENED?

Lung cancer screening data among lowans will be collected as part of BRFSS beginning in 2022.

The American Lung Association “State of Lung Cancer” 2021 report<sup>7</sup> shows the percent of lowans screened for lung cancer (55–80 years of age with 30+ pack years) was 11%, almost double the national figure of 6%. **By improving access and communication regarding screening, more of the high-risk population can be screened, reducing the lung cancer mortality rate.**

# Resources Available in Iowa

## BREAST AND CERVICAL CANCER

The **Iowa Care for Yourself** program is part of the National Breast and Cervical Cancer Early Detection Program that helps reduce risks from breast cancer and cervical cancer. The Care for Yourself program offers free or low-cost cancer screenings and diagnostic services to eligible individuals in the state of Iowa.

### You may qualify if you:

- Are between 21-64 years of age;
- Have a monthly income of \$2,683 (take home pay) or less; add \$946 for each additional household member

**PROGRAM STAFF CAN HELP CONNECT YOU TO A PROGRAM WHERE YOU LIVE**

**Call 1-866-339-7909**

## HPV VACCINE


Nearly all cases of cervical cancer are caused by infection with high-risk types of HPV. The Centers for Disease Control and Prevention's Advisory Council on Immunization Practice recommends routine HPV vaccination. HPV vaccination provides safe, effective, and lasting protection against the HPV infections that most commonly cause cancer. For more information visit <https://www.cdc.gov/vaccines/vpd/hpv/public/index.html>.

## COLORECTAL CANCER

The Iowa Department of Public Health **Iowa Get Screened: Colorectal Cancer Program** partners with Iowa's Federally Qualified Health Centers and local public health agencies to increase screenings for colorectal cancer. Eligibility Requirements at the local public health agencies include: Iowans at average or increased risk of colorectal cancer, 300% at or below the Federal Poverty Level, and uninsured or under-insured.

### LOCAL PROGRAM CONTACT INFORMATION:

 **Polk County Health Department**  
1907 Carpenter Avenue  
Des Moines, IA 60314  
515-286-3921

 **Black Hawk County Health Department**  
1407 Independence Avenue, 5th Floor  
Waterloo, IA 50703  
319-292-2225

## QUITLINE IOWA: A FREE TOBACCO CESSATION PROGRAM

Whether you are thinking about quitting, are not yet ready to quit, or have already quit, Quitline Iowa can help you each step of the way. To learn more about tobacco cessation, go to <https://www.quitlineiowa.org/en-US/> or call **1-800-QUIT-NOW**.

## IOWA'S RADON HOTLINE

You can reach the Hotline by calling **1-800-383-5992** to order low-cost radon test kits and find answers to your radon questions.

## ADDITIONAL RESOURCES

The National Cancer Network has screening guidelines available for transgender and non-binary people. Please visit National LGBT Cancer Network TRANSforming Cancer (<https://cancer-network.org/transgender-and-gender-non-conforming-care/>).

# Genetic Testing and Counseling

Most types of cancer screenings are for people of particular ages with average risk of getting cancer. However, some people have certain genetic changes that give them a higher-than-average risk for certain types of cancer. Some genetic changes can be screened for using a DNA test, often done with a blood or saliva sample. The results may provide information to help prevent cancer or detect it at its earliest stages. Individuals may be a candidate for genetic screening if they have a personal and/or family history of cancer or clinical characteristics suggestive of hereditary cancer.

## Signs a cancer might be hereditary:

- Cancer occurs at a young age (typically under age 50 for many types of cancer)
- Multiple different cancers in a single individual
- Cancer that occurs in both paired organs, such as both breasts or both kidneys
- Several family members with the same or related forms of cancer
- Cancers occur in multiple generations of a family
- Occurrence of some rare tumors
- Occurrence of epithelial ovarian, fallopian tube, and peritoneal cancers
- Being from certain geographic regions or ethnic populations, such as having Ashkenazi Jewish ancestry

**Genetic testing may help estimate your chance of developing a hereditary cancer.** It does this by searching for specific changes in your genes, called genetic mutations, known to increase risk for cancer. Genetic testing may help predict your risk of getting a particular cancer and find if you have genetic mutations that may pass an increased cancer risk to your children. It can also provide information to guide your health care.

Genetic testing is recommended in the following situations:

- A personal or family history suggests a genetic cause of cancer
- The results will help with your health care. For example, earlier and more frequent screening can detect cancer at earlier stages, or sometimes surgery, medication, or lifestyle changes can lower your risk to get cancer. If you already have cancer, genetic testing may provide additional treatment options in some cases.

**Genetic counseling is recommended both before and after genetic testing.** Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic health information. The process may provide information on:

- How inherited conditions might affect you or your family
- How your family and medical history may impact the chance for you and your family members to get cancer
- Which genetic tests may or may not be right for you, and what those tests may or may not tell you
- Potential consequences of genetic testing, such as possible psychosocial, familial, and insurance implications
- How to make the most informed choices about health care conditions
- Resources for families with a hereditary cancer syndrome or those that are at an increased risk of developing cancer

## Prior to ordering your genetic test, a genetic counselor will:

- Review your personal and family history of cancer
- Create a family tree, so that they can understand your family history of cancer better
- Provide a personalized cancer risk assessment
- Discuss whether genetic testing is recommended

## WHAT IS A HEREDITARY CANCER?

A hereditary cancer is any cancer caused by an inherited gene mutation that is passed from parent to child within a family. These inherited genetic variants or mutations are thought to contribute to about 5 to 10% of all cancers<sup>8</sup>.

## WHAT CANCERS MIGHT BE HEREDITARY?

**BONE** (sarcoma)

**BREAST**

**ENDOCRINE** (thyroid, pituitary, adrenal, parathyroid)

**GASTROINTESTINAL** (colon, rectal, pancreatic, gastric)

**GENITOURINARY** (kidney, prostate)

**GYNECOLOGIC** (ovarian, fallopian tube, peritoneal, uterine)

**SKIN** (melanoma)

## ARE ALL CANCERS THAT RUN IN FAMILIES HEREDITARY?

No, cancer can affect family members even if it is not caused by an inherited genetic mutation. A shared environment or lifestyle factors such as tobacco use can cause similar cancers to develop among family members.

After you receive your genetic test results, genetic counselors will discuss the test results with you. They will explore ways to cope and talk about your specific fears and concerns. They can discuss cancer screening and risk-reducing options, which may include more frequent cancer screenings, risk-reducing surgery, and/or chemoprevention, which is taking medication to reduce the chance of developing specific types of cancer.

**You have to decide if genetic testing is right for you and your family.** Genetic testing has limitations and emotional implications which may include:

- **Depression, anxiety, or guilt.** A positive test result means a gene mutation exists that puts you at an increased risk to get cancer. This result may bring difficult emotions. Some people may think of themselves as sick, even if they never develop cancer. Negative test results may also cause difficult emotions as some people may experience guilt if they do not have a gene mutation that other family members have.
- **Family tension.** People are generally encouraged to tell family members about test results because they can be important for the health of family members. But this information could also complicate family dynamics.
- **A false sense of security.** A negative result means a specific genetic mutation is not present. But people with negative results may still develop cancer. A negative result only means the person does not have a higher-than-average cancer risk. Each person's risk for cancer is also affected by other factors besides genetics, including lifestyle, environmental exposure, family history, and medical history.
- **Unclear results.** All genes have variation, but not all genetic variants are linked with cancer risk. Sometimes a genetic variant is found, but it is unknown if it increases cancer risk. This is called a variant of unknown significance. Other times, people may have mutations that current genetic tests cannot find. Also, cancer can be due to genes interacting in unknown ways with other genes or environmental factors. These uncertainties can make it difficult to calculate your cancer risk.
- **Cost.** Genetic testing for hereditary cancer is often covered by insurance. While genetic testing used to be very expensive, the cost of testing has gone down over the past few years. You and the genetic counselor should discuss your specific options based on your insurance coverage before starting the test. **Genetic counselors often know of more affordable testing options when insurance does not cover testing.**
- **Discrimination and privacy concerns.** Some people fear genetic discrimination from test results. Others worry about the privacy of their genetic information. The Genetic Information Nondiscrimination Act (GINA) protects against employment and health insurance discrimination. However, current federal laws do not prohibit the use of family history or genetic test results by life, long-term care, or disability insurers. Discuss any concerns with a genetic counselor or visit [www.ginahelp.org](http://www.ginahelp.org).

A genetic counselor can help you consider these implications and figure out if genetic testing is right for you. If you are concerned about your personal or family history of cancer, ask your doctor for a referral to a genetic counselor or visit <https://findageneticcounselor.nsgc.org> to find one in your area.

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# Research Using Iowa Cancer Registry Data

## COMMUNITY ENGAGEMENT TO BETTER UNDERSTAND CANCER DISPARITIES IN IOWA

The 2021 Cancer in Iowa report showed that Black and African American Iowans have some of the highest cancer mortality rates in the country. Three projects from the Holden Comprehensive Cancer Center will address this issue. The first is led by Dr. Natoshia Askelson in collaboration with the Iowa Cancer Consortium. This project will build relationships with Black and African American communities in Black Hawk County, discuss cancer data with community members, and identify interventions that may address cancer disparities. The second is led by Dr. Whitney Zahnd. This project will look more closely at cancer registry data to explore racial disparities in incidence, staging, and mortality. The project will focus on breast, colorectal, lung, and prostate cancers. Dr. Zahnd will interview Black and African American cancer survivors to understand their treatment experiences. The goal of this project is to inform future interventions to address inequities. The third project is led by Dr. Sarah Nash. This project will use community-engaged research principles to develop a survey to understand community members' cancer priorities. Through interviews with community members, Dr. Nash hopes to understand what cancer priorities are in the Black and African American community in Iowa, and the barriers or facilitators to pursuing healthy behaviors. The goal of this project is to help inform the development of a survey that can then be more widely disseminated across the state.



## IMPROVING QUALITY OF CARE AND OUTCOMES FOR RURAL CANCER PATIENTS

Rural residents have lower cancer rates than urban residents, but higher rates of cancer deaths. This is partly due to the difficulty in accessing high-quality cancer treatment in rural areas. In Kentucky, they showed that when larger hospitals share their expertise and resources with smaller community hospitals, this improves quality of care. Following Kentucky, Dr. Mary Charlton is working with four rural Iowa community hospitals to support system-level quality improvement. This will be shown through achievement of the American College of Surgeons Commission on Cancer standards for quality cancer care. This work could lead to improved quality of care and outcomes for many rural cancer patients. It could also provide rural hospitals an avenue to demonstrate their quality of care. The Iowa Cancer Registry will be assisting rural community hospitals in collecting the information needed to assess quality of cancer care and guide quality improvement initiatives.

## COLLECTING HEALTH DATA FROM PEOPLE LIVING WITH CANCER

The Iowa Cancer Registry did a study to collect data about health from people living with cancer. Iowans with breast, prostate, or colorectal cancer filled out an online survey. Survey questions asked about experiences getting cancer care and quality of life after treatment was over. Dr. Natalie Del Vecchio analyzed the study data. One report compared people who were active in choosing their cancer surgeon to people who relied on their local doctor to refer them. People that were actively involved were more likely to get surgery at a hospital that was larger or known for quality cancer care. People who were actively involved also had better quality of life after treatment<sup>1</sup>. A second report compared people who said they had one person coordinating their cancer care with people who said that they did not. People who had a coordinator had better quality of life<sup>2</sup>, but this was only true for people with low health literacy. These findings show that health literacy may play a role in being able to figure out the health care system - and a care coordinator or patient navigator may help.



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