



CANCER IN IOWA

2020



College of
Public Health

The State Health Registry of Iowa

Two in five Iowans will be diagnosed with cancer in their lifetimes. Cancer is a major burden in Iowa and throughout the U.S. Reducing the nation's cancer burden requires the cooperation of many people, including physicians, researchers, public health professionals, policy makers and advocates, among others. All these people rely on cancer data in their effort to reduce this burden. Because of the critical need for data, cancer is a reportable disease in all 50 states. In Iowa, cancer data are collected by the State Health Registry of Iowa, also known as the Iowa Cancer Registry (ICR).

Since 1973 the ICR has been funded by the prestigious Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI), and is currently one of nineteen registries nationwide providing data. Iowa represents rural and Midwestern populations and provides data included in many NCI publications and national estimates and projections of the cancer burden throughout the U.S. Maintaining the confidentiality of patient, physician, and hospital data located in the ICR is of paramount importance. It is the responsibility of the ICR to maintain a balance between the need to protect the data from unauthorized access and release, while providing researchers and others with access to the important information necessary to conduct studies to help reduce the burden of cancer. To this end, the ICR has policies and procedures related to research uses, reporting, and release of Iowa cancer data to safeguard the confidentiality of patients, physicians, and hospitals.

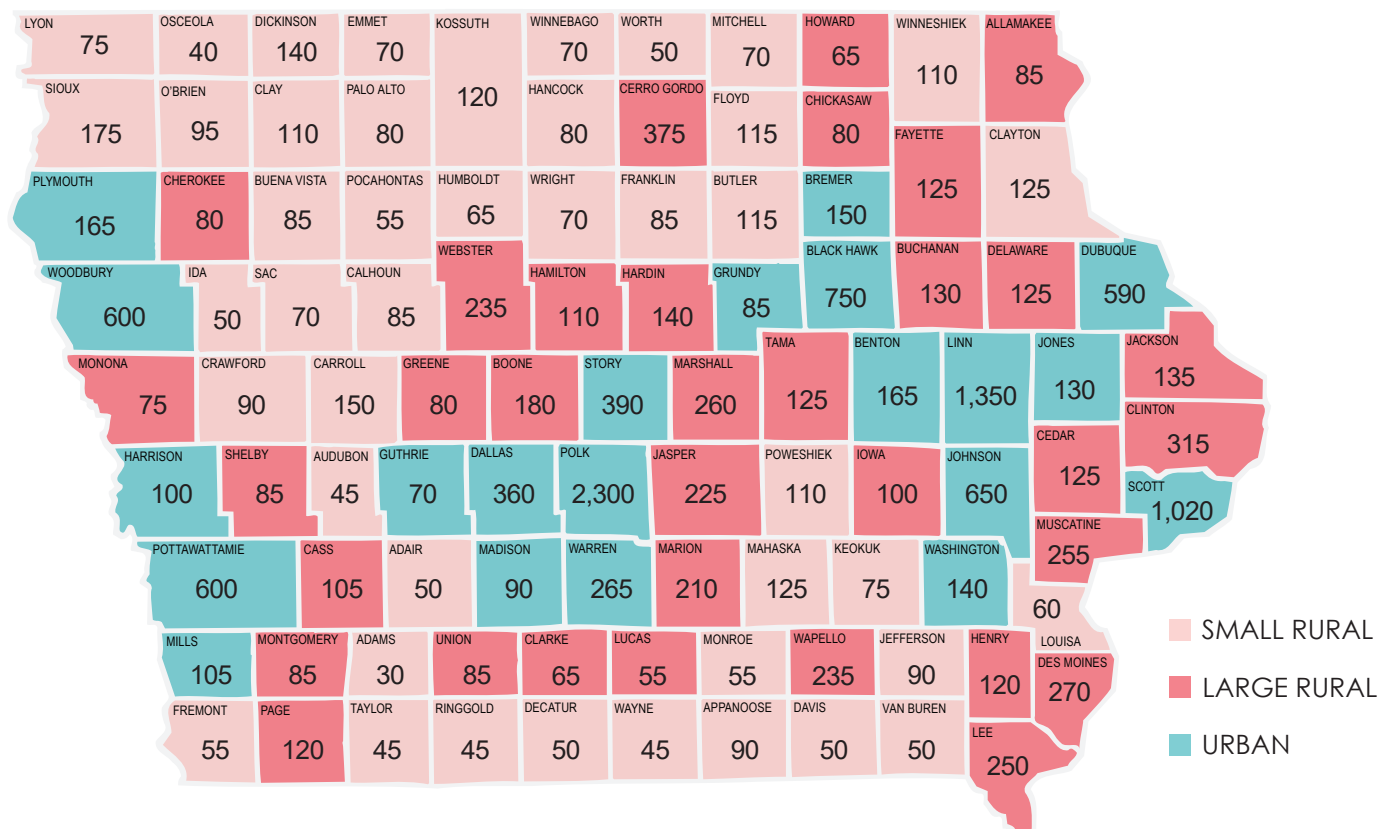
The existence of the ICR allows for the study of the cancer experience of Iowans and focuses national attention and research dollars on this issue. The ICR is primarily funded through a contract with the NCI, but the contract requires a portion of the funding for the ICR be obtained from non-federal sources such as the state of Iowa. The University of Iowa also provides cost-sharing funds to support the work of the ICR. Additionally, the presence of the ICR and its database have helped attract research projects and funds to Iowa from other federal agencies and foundations.

With *Cancer in Iowa 2020*, the Registry makes a general report to the public on the status of cancer. This report focuses on:

- **New cases and cancer deaths by county and top 10 cancer types by sex**
- **Estimates of the number of cancer survivors**
- **A comparison of changes in mortality for 2012-2016 for Iowa and the nation**
- **A special section on ovarian cancer**
- **A section on questions to ask when diagnosed with cancer and ways to cope with your emotions**

Estimates for New Cancers for 2020

In 2020, an estimated 18,700 new, invasive cancers (and in situ bladder cancers) will be diagnosed among Iowa residents. Estimates of new cancers are given by county with shading by urban/rural status as well as the top 10 cancer types by sex. Based on the 2013 Rural-Urban Continuum Codes, Iowa counties were classified as small rural, large rural, and urban as shown in the figure below.



NEW CANCERS IN FEMALES

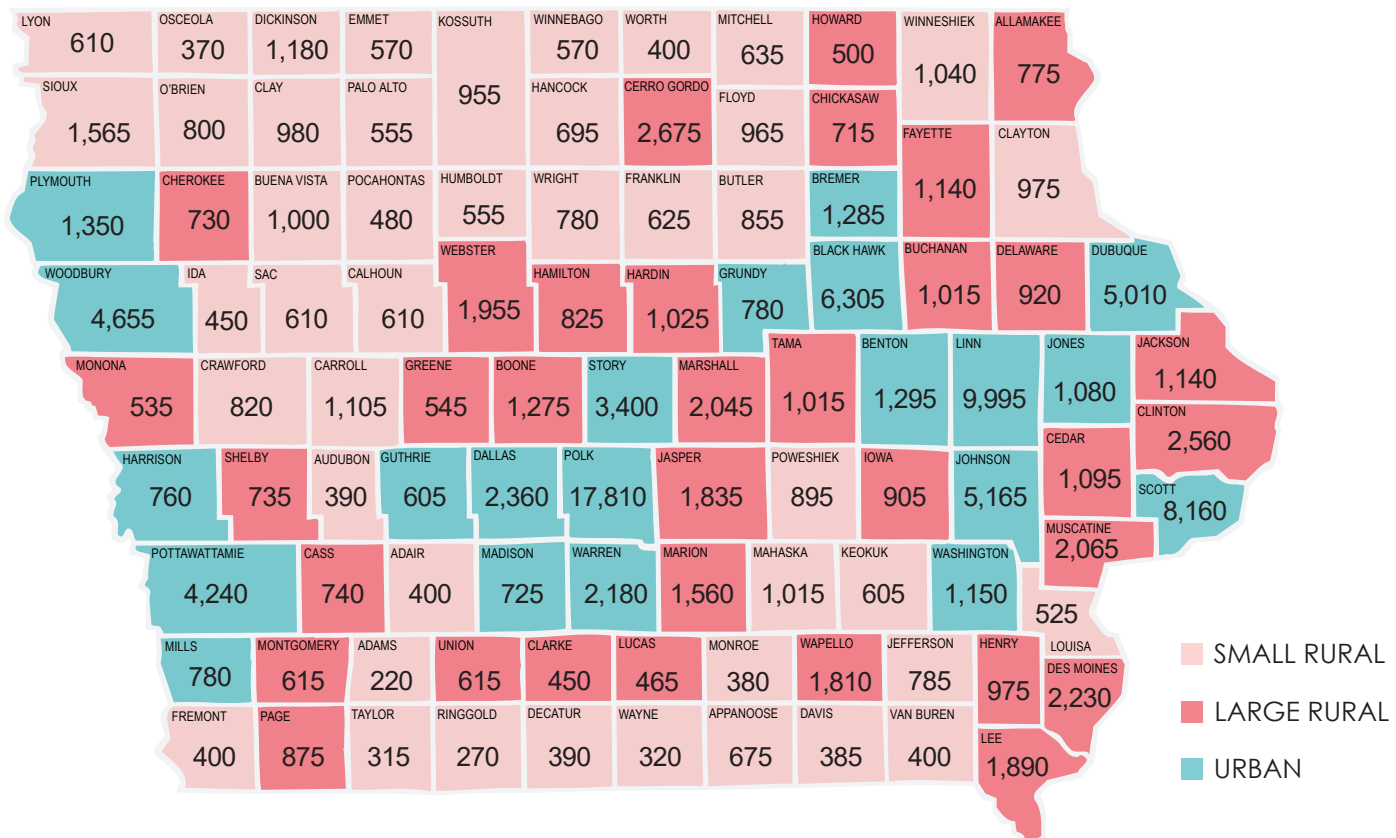
TYPE	# OF CANCERS	% OF TOTAL
Breast	2,700	29.7
Lung	1,150	12.6
Colon and rectum	780	8.6
Uterus	600	6.6
Skin melanoma	470	5.1
Thyroid	350	3.8
Non-Hodgkin lymphoma	330	3.6
Leukemia	260	2.9
Kidney and renal pelvis	260	2.9
Pancreas	260	2.9
All others	1,940	21.3
TOTAL	9,100	

NEW CANCERS IN MALES

TYPE	# OF CANCERS	% OF TOTAL
Prostate	2,500	26.0
Lung	1,350	14.1
Colon and rectum	800	8.3
Bladder	650	6.8
Skin melanoma	560	5.8
Kidney and renal pelvis	460	4.8
Non-Hodgkin lymphoma	410	4.3
Leukemia	400	4.2
Oral cavity and pharynx	330	3.4
Pancreas	300	3.1
All others	1,840	19.2
TOTAL	9,600	

Living with Cancer

A follow-up program tracks more than 99 percent of cancer survivors diagnosed since 1973. According to Iowa Cancer Registry incidence and survival data for 1973-2015, there are an estimated 148,465 cancer survivors (defined as people who are currently living with or previously had cancer), 79,560 females and 68,905 males. The following graphics show the survivorship by county and urban/rural status as well as the top 10 cancer types by sex, below.

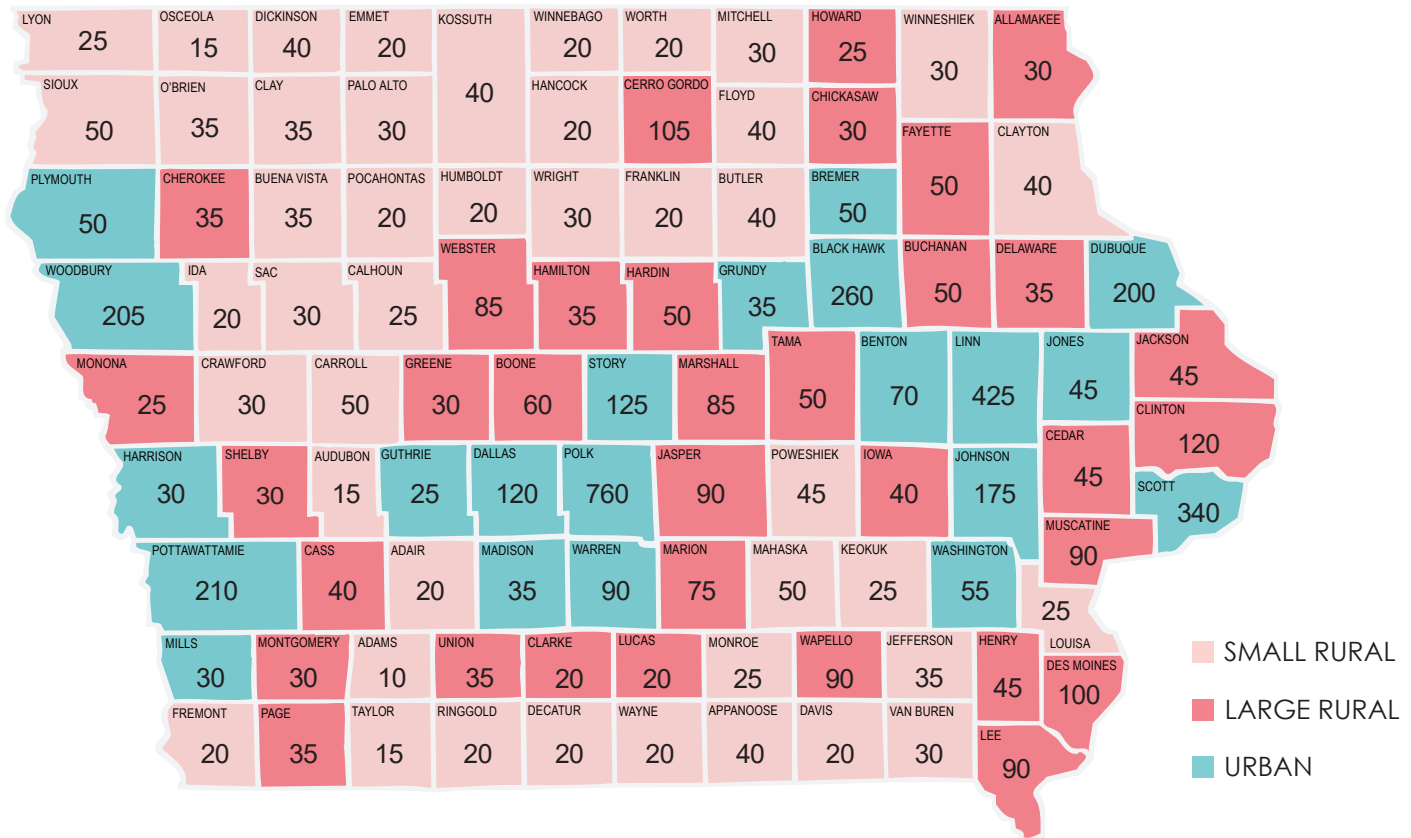


FEMALE SURVIVORS		
TYPE	# OF SURVIVORS	% OF TOTAL
Breast	31,295	39.3
Uterus	7,570	9.5
Colon and rectum	7,055	8.9
Skin melanoma	5,415	6.8
Thyroid	5,105	6.4
Non-Hodgkin lymphoma	3,050	3.8
Lung	2,410	3.1
Cervix	2,360	3.0
Kidney and renal pelvis	1,995	2.5
Ovary	1,985	2.5
All others	11,320	14.2
TOTAL	79,560	

MALE SURVIVORS		
TYPE	# OF SURVIVORS	% OF TOTAL
Prostate	26,020	37.8
Colon and rectum	7,100	10.3
Bladder	4,975	7.2
Skin melanoma	4,940	7.2
Non-Hodgkin lymphoma	3,420	5.0
Kidney and renal pelvis	2,890	4.2
Oral cavity and pharynx	2,605	3.8
Testis	2,600	3.8
Leukemia	2,465	3.5
Lung	2,210	3.2
All others	9,680	14.0
TOTAL	68,905	

Estimates for Cancer Deaths for 2020

Heart disease and cancer are the leading causes of death in Iowa. In 2020, an estimated 6,400 Iowans will die from cancer. These projections are based upon mortality data the Iowa Cancer Registry receives from the Iowa Department of Public Health. Estimates of cancer deaths are presented by county with urban/rural status as well as the top 10 cancer types by sex, below.

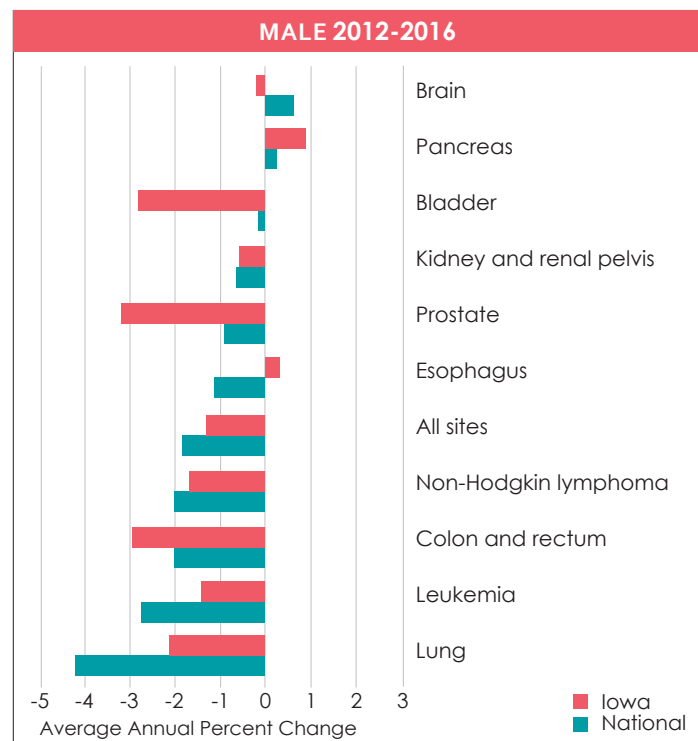
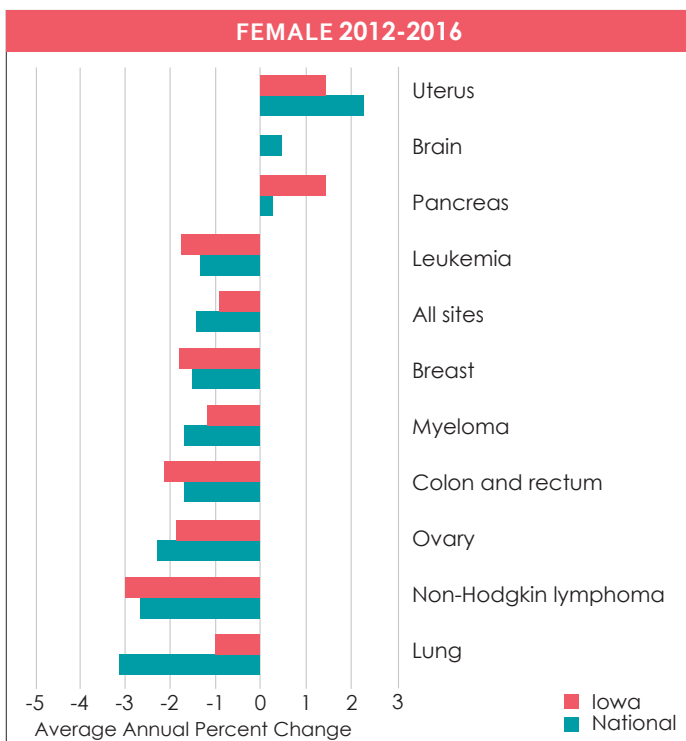


CANCER DEATHS IN FEMALES		
TYPE	# OF DEATHS	% OF TOTAL
Lung	730	24.3
Breast	390	13.0
Colon and rectum	280	9.3
Pancreas	230	7.7
Ovary	150	5.0
Leukemia	110	3.7
Uterus	110	3.7
Non-Hodgkin lymphoma	100	3.3
Brain	80	2.7
Myeloma	60	2.0
All others	760	25.3
TOTAL	3,000	

CANCER DEATHS IN MALES		
TYPE	# OF DEATHS	% OF TOTAL
Lung	820	24.1
Prostate	400	11.8
Colon and rectum	290	8.5
Pancreas	230	6.8
Leukemia	160	4.7
Esophagus	150	4.4
Non-Hodgkin lymphoma	140	4.1
Bladder	120	3.5
Kidney and renal pelvis	110	3.2
Brain	110	3.2
All others	870	25.7
TOTAL	3,400	

Trends in Cancer Death Rates

The average annual percent change (AAPC) is a summary measure that allows the use of a single number to describe the average of annual percent changes over a period of multiple years. Below, AAPCs are presented by sex for mortality rate changes in the top 10 cancers in Iowa compared to the nation between 2012 and 2016.¹ In Iowa, most of these cancers have seen decreases in the AAPC except for uterine cancer in females, esophageal cancer in males, and pancreatic cancer in both sexes. The largest decreases in AAPC in Iowa have been seen in prostate cancer in males and non-Hodgkin lymphoma in females. For the most part, Iowa and national AAPCs are moving in the same direction with the greatest AAPCs across the nation being seen for lung cancer in both sexes. However, national data show substantially larger decreases in lung cancer in both sexes compared to Iowa data. Conversely, Iowa data show much larger decreases in prostate and bladder cancer in males compared to national data.



AAPCs FOR TOP 10 CANCERS IN IOWA

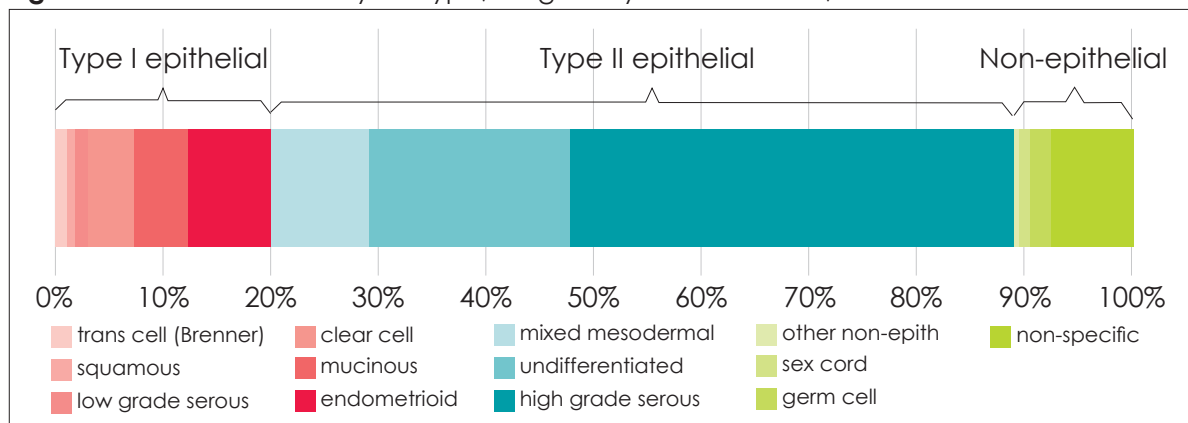
FEMALE	NATIONAL	IOWA	MALE	NATIONAL	IOWA
Lung	-3.1	-1.0	Lung	-4.3	-2.1
Non-Hodgkin lymphoma	-2.6	-3.0	Leukemia	-2.6	-1.4
Ovary	-2.3	-1.9	Colon and rectum	-2.0	-2.9
Colon and rectum	-1.6	-2.1	Non-Hodgkin lymphoma	-2.0	-1.7
Myeloma	-1.6	-1.1	All sites	-1.8	-1.3
Breast	-1.5	-1.8	Esophagus	-1.1	0.3
All sites	-1.4	-1.0	Prostate	-0.9	-3.2
Leukemia	-1.3	-1.7	Kidney and renal pelvis	-0.7	-0.6
Pancreas	0.2	1.4	Bladder	-0.1	-2.8
Brain	0.5	0.0	Pancreas	0.2	0.8
Uterus	2.3	1.4	Brain	0.6	-0.1

Ovarian Cancer

Among cancers of the female reproductive system, ovarian cancer is the deadliest. It is estimated that 13,940 women will die of ovarian cancer in the United States in 2020.² While it is the 11th most common cancer in women, it is the 5th leading cause of cancer-related deaths.

The ovaries are a pair of organs that are part of the reproductive system in women. Each ovary is about the size and shape of a walnut and is covered by a layer of tissue made of epithelial cells. Approximately 90% of ovarian cancers start in epithelial cells. Type I epithelial ovarian cancers often present at an early stage and typically have a good prognosis. Type II epithelial ovarian cancers typically present at an advanced stage and have a poorer prognosis.³ Non-epithelial ovarian cancers are typically less aggressive than epithelial cancers.⁴ Figure 1 displays ovarian cancer cases in Iowa by cell type for diagnosis years 2008-2017, resulting in a breakdown of 20% Type I epithelial, 70% Type II epithelial, and 10% non-epithelial.

Figure 1. Ovarian cancer by subtype, diagnosis years 2008-2017, Iowa



Incidence and Mortality

In 2020 in the U.S., an estimated 21,750 new cases of ovarian cancer will be diagnosed.² A woman's risk of getting ovarian cancer in her lifetime is about 1 in 78.⁴ The incidence of ovarian cancer has decreased 36% in Iowa from 1988-1992 to 2013-2017 as shown in Figure 2. Some of this decrease is the result of decreased use of menopausal hormones after a landmark report in 2002 linked menopausal use of estrogen plus progestin therapy to an increased breast cancer risk.⁴ Another contributing factor in the decrease in ovarian cancer is the increased use of oral contraceptives (i.e., birth control pills), which lowers one's risk of ovarian cancer.⁴

Mortality rates in Iowa have decreased 35% from 1973-1977 to 2013-2017 due in part to the decrease in new cases of ovarian cancer as well as advances in treatment.⁴ Mortality rates would improve if more cases of ovarian cancer could be detected at an earlier stage, before the disease has spread to other parts of the body, but unfortunately no effective screening methods have been identified.

Figure 2. Age-adjusted incidence and mortality rates, ovarian cancer, 1973-2017, Iowa



Staging

Cancer staging is the process of determining how far cancer has grown and spread in the body at the time of diagnosis. Ovarian cancer stages are numbered from 1 to 4 and generally, earlier cancer stages have better outcomes.

Stage I: tumor limited to one ovary only or limited to both ovaries

Stage II: spread of ovarian tumor to other **pelvic** organs (the uterus, for example) and/or pelvic tissue

Stage III: spread of ovarian tumor to **abdominal** lining tissue, abdominal organs (the liver capsule, for example), and/or abdominal lymph nodes

Stage IV: spread of ovarian tumor **beyond** any location in the pelvis or abdomen (to the lungs, for example)

Figure 3 shows the breakdown of ovarian cancer stage for cases diagnosed in Iowa from 2009-2015. Only 22% of cases were detected while the cancer was confined to the ovaries. Over half the cases (57%) were diagnosed with spread to the abdomen or to distant areas in the body.

Figure 4 shows the 5-year relative survival rates in Iowa for ovarian cancer by stage of disease at diagnosis for years 2009-2015. When ovarian cancer is detected early, when it is still confined to the ovaries, the 5-year relative survival rate is 95%. This rate decreases in relation to how far the disease has spread at time of diagnosis, to 73% for stage II, 35% for stage III and 18% for stage IV. Unstaged disease has the poorest prognosis at 9% reflective of signs and symptoms of extensive disease at diagnosis where staging was not performed or if death occurred with insufficient time for staging.

Figure 3. Ovarian cancer by stage, diagnosis years 2009-2015, Iowa

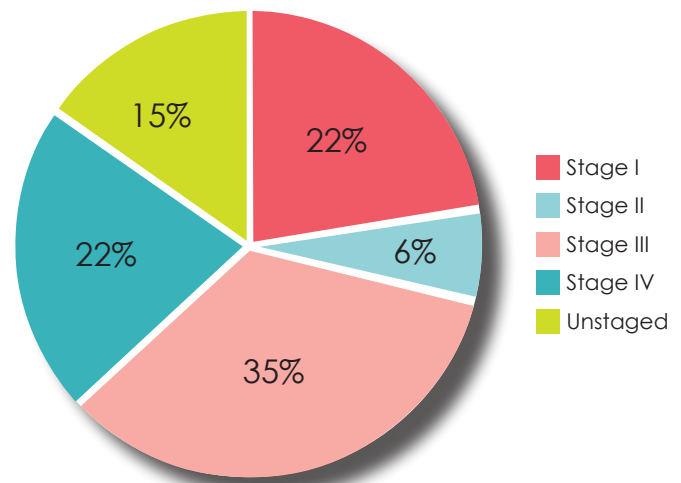
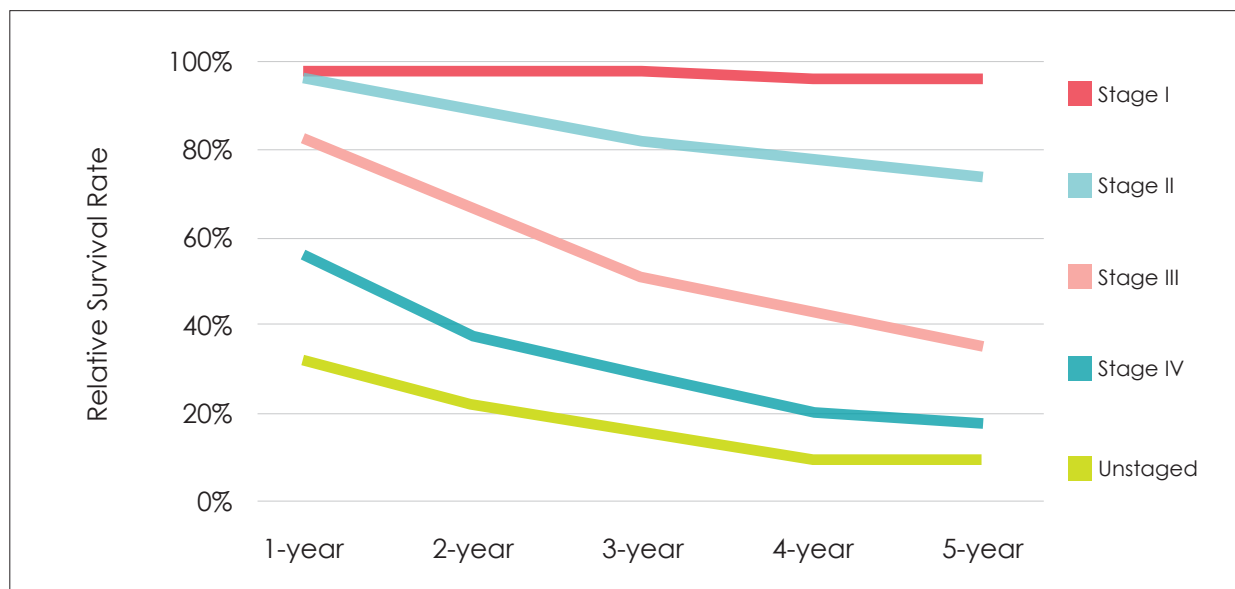


Figure 4. 5-year relative survival, ovarian cancer by stage, diagnosis years 2009-2015, Iowa



Screening and Clinical Presentation

There is currently no effective routine screening for ovarian cancer in asymptomatic low-risk women as the tests available have not been shown to reduce mortality from ovarian cancer.⁵ Screening may be beneficial however, for women who have hereditary cancer syndromes.

Part of the reason for the high mortality rate with ovarian cancer is that it is often diagnosed after the disease has spread. Unfortunately, ovarian cancer may not cause any early signs or symptoms, or the symptoms are often vague, which may delay diagnosis. The **most common symptoms of ovarian cancer** include:

- feeling bloated
- indigestion
- pain in the pelvis or abdomen
- trouble eating or feeling full fast (satiety)
- feeling the need to urinate often or urgently

If these symptoms are new (began less than 1 year ago) and occur more than 12 days each month, **tell your doctor about your symptoms.** The graphic below utilizes the acronym B.E.A.C.H. in recognizing the subtle symptoms of ovarian cancer.⁶ Recognizing these symptoms and discussing them with your doctor may help find ovarian cancer earlier, leading to a better prognosis from this disease.

Talk About Ovarian Cancer

Share the B.E.A.C.H. Symptoms



BLOATING

A persistently bloated stomach is one of the key symptoms of ovarian cancer. Talk to your doctor before you dismiss the bloating as being a 'natural body change.'



EARLY SATIETY

If you have trouble eating or feeling full quickly on a consistent basis, pay attention. Appetite changes may be symptoms of ovarian cancer.



ABDOMINAL PAIN

Pay attention if you experience persistent pressure, and/or abdominal and pelvic pain as it may be a sign of ovarian cancer. You may also experience lower back pain.



CHANGES IN BOWEL & BLADDER HABITS

Frequent urge to urinate and/or changes in bowel movements can be symptoms of ovarian cancer. Persistent indigestion & nausea may also be present. Pay attention.



HEIGHTENED FATIGUE

Persistent fatigue may be a sign of ovarian cancer, especially when accompanied with other listed symptoms. If constant fatigue is interfering with your work/leisure, it may be more than stress.

Prevention

Many women have one or more risk or protective factors for ovarian cancer which only marginally increase or decrease their risk. Most of what is known about risk and protective factors has not translated into practical ways to prevent most cases of ovarian cancer. Thus, if you are concerned about your risk for developing ovarian cancer, it is important to talk to your doctor or healthcare professional.

Risk Factors

- **Family history of ovarian cancer**
- **Inherited risk (passed down through genes)**
- **Hormone replacement therapy**
- **Overweight and taller height**
- **Endometriosis**

Protective Factors

(potential to lower one's risk)

- **Having used oral contraceptives**
- **Having had a tubal ligation**
- **Having given birth**
- **Having breastfed**
- **Having had a salpingectomy (removal of one or both fallopian tubes)**
- **Risk-reducing salpingo-oophorectomy (removal of fallopian tubes and ovaries with no signs of cancer)**

More information can be found at:
www.cancer.gov/types/ovarian/patient/ovarian-prevention-pdq.

Treatment

Surgery is the primary treatment for most ovarian cancers. The National Comprehensive Cancer Network experts recommend that **ovarian cancer surgery should be done by a gynecologic oncologist.**⁷ A gynecologic oncologist is a surgeon who has received highly specialized training in treating cancers that start in a woman's reproductive organs. Ovarian cancer patients treated by gynecologic oncologists have better outcomes compared to patients who are not treated by these specialists.⁸ The two main goals of surgery are to find out how far the cancer has spread and to remove all or as much of the cancer from the body as possible. Surgical treatment often involves removing both ovaries, both fallopian tubes, and the uterus, commonly called a total hysterectomy. If cancer has spread outside of the ovaries, the doctor will perform a debulking or cytoreductive surgery to remove as much of the cancer as possible. Optimal debulking is linked with better treatment outcomes, especially if there are no visible remaining cancer cells.

Most women with ovarian cancer receive chemotherapy after primary treatment with surgery. Most of the chemotherapy drugs used to treat ovarian cancer are usually given by an intravenous (IV) infusion. Chemotherapy can also be injected into the abdomen (peritoneal cavity) to allow higher doses of the drugs to be delivered directly to the cancer cells in the area.

Targeted therapy

Targeted therapy is a type of treatment that uses drugs or other substances to identify and attack specific cancer cells without harming normal cells. Antibodies are produced in our bodies by specialized white blood cells and can be used to kill cancer cells, block their growth, or keep them from spreading. Bevacizumab is a monoclonal antibody that can be used with chemotherapy to treat epithelial ovarian cancer that has recurred. Poly (ADP-ribose) polymerase inhibitors (PARP inhibitors) are targeted therapy drugs that block DNA repair and may cause cancer cells to die.

A new treatment called Hyperthermic Intraperitoneal Chemotherapy (HIPEC) has shown an improvement of 3.5 months in recurrence-free survival and 11.8 months in overall survival when HIPEC was added to interval cytoreductive surgery in patients with stage III disease who were not eligible for primary surgery because of the extent of their disease.⁹ Following cytoreductive surgery, the surgeon will administer a heated sterile solution containing a chemotherapeutic agent throughout the peritoneal cavity. The HIPEC procedure is designed to attempt to kill any remaining cancer cells. HIPEC increases concentrations of chemotherapy directly within the peritoneal cavity compared with the intravenous route. The heat also increases tissue penetration and is synergistic with the chemotherapy agents used. As this technique was first established as treatment for patients with gastrointestinal cancers, it is most commonly done by a team of gynecologic oncologists, as well as surgical oncologists.

The role of BRCA mutations

BRCA is an abbreviation for BReast CAncer gene. BRCA1 and BRCA2 are two different genes that normally play a big role in preventing breast cancer. They help repair DNA breaks that can lead to cancer and the uncontrolled growth of tumors. However, when a gene becomes altered or broken, it doesn't function correctly. This is called a gene mutation. One of the biggest developments in the management of ovarian cancer has been the discovery of the important role that BRCA mutations play in treatment and prognosis for ovarian cancer. While we have known for several years that BRCA mutations can increase the risk of developing ovarian cancer, we now know these mutations also play a major role in response to certain treatments, such as platinum agents and PARP inhibitors. Because BRCA mutation information is critical to the selection and planning of treatment and because it allows for genetic testing of family members to help them understand and reduce their risk of ovarian cancer, the Society of Gynecologic Oncology and the National Comprehensive Cancer Network recommend that all women diagnosed with epithelial ovarian cancer should be offered BRCA testing and genetic counseling.^{10,11} In addition, patients who have been diagnosed with early-onset breast cancer (age <45) and patients diagnosed with triple negative breast cancer prior to age 60 should also be tested for BRCA mutations.

Research

The focus of much of the ovarian cancer research in the U.S. and abroad is on creating new targeted therapies and understanding the role of BRCA and other gene mutations in the development and outcomes of ovarian cancer. This research could lead to significant breakthroughs in the prevention of ovarian cancer and more effective treatments that could improve quality of life and survival for patients diagnosed with ovarian cancer. Researchers in Iowa are also focusing on other aspects of ovarian cancer prevention and treatment. The ICR is currently collaborating on a multi-institutional retrospective study to determine if aspirin can be used to help prevent ovarian cancer.

The ICR also participated in a study funded by the Centers for Disease Control and Prevention (CDC) to better understand treatment patterns and survival for patients with ovarian cancer living in the Midwestern U.S. Building on the findings of this study, the ICR has partnered with the Iowa Department of Public Health and the Iowa Cancer Consortium on a CDC-funded project to study the barriers that patients in Iowa may face in receiving guideline-recommended treatment for ovarian cancer. A limited number of gynecologic oncologists in a small number of large, urban medical centers may create referral challenges for healthcare providers across the state. The rural population in the Midwest likely experiences distance and access barriers to up-to-date ovarian cancer treatments provided by experts. In addition, there is general lack of awareness among patients about the importance of receiving treatment from gynecologic oncologists, which may lead them to be reluctant to travel long distances to have their surgery performed. Investigators from the University of Iowa have conducted interviews with gynecologic oncologists, obstetrician-gynecologists, and hospital administrators throughout Iowa and are using that information to develop strategies to facilitate standard of care treatment for all Iowans with ovarian cancer.

References

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Questions to Ask When Diagnosed with Cancer

Learning that you have cancer can be a shock and you may feel overwhelmed at first. When you meet with your doctor, you will hear a lot of information. Ask your doctor questions and don't be afraid to say when you don't understand. It may be helpful to take someone with you when you meet with the doctor.

Questions about Your Cancer and What to Expect

- What type of cancer do I have?
- What is the stage of my cancer?
- Has it spread to other areas of my body?
- Will I need more tests before treatment begins? Which ones?
- Will I need a specialist(s) for my cancer treatment?
- Will you help me find a doctor to give me another opinion on the best treatment plan for me?
- How serious is my cancer?
- What are my chances of survival?

Questions about Cancer Treatment

- What are the ways to treat my type and stage of cancer?
- What are the benefits and risks of each of these treatments?
- What treatment do you recommend? Why do you think it is best for me?
- When will I need to start treatment?
- Will I need to be in the hospital for treatment? If so, for how long?
- What is my chance of recovery with this treatment?
- How will we know if the treatment is working?
- Would a clinical trial (research study) be right for me?
- How do I find out about studies for my type and stage of cancer?

Questions about Types of Treatment

- Where will I go for treatment?
- How is the treatment given?
- How long will each treatment session take?
- How many treatment sessions will I have?
- Should a family member or friend come with me to my treatment sessions?

Questions about Side Effects

- What are the possible side effects of the treatment?
- What side effects may happen during or between my treatment sessions?
- Are there any side effects that I should call you about right away?
- Are there any lasting effects of the treatment?
- Will this treatment affect my ability to have children?
- How can I prevent or treat side effects?

Other Questions to Ask

- Will my insurance pay for this treatment? If not, is there a resource I can look into that might help me pay for treatment?
- How will treatment affect my daily life? Will I still be able to work? Can I still exercise?



NCI. Questions to Ask Your Doctor about Your Diagnosis. 2018; <https://www.cancer.gov/about-cancer/diagnosis-staging/questions>.
NCI. Questions to Ask Your Doctor about Your Treatment. 2018; <https://www.cancer.gov/about-cancer/treatment/questions>.

Ways to Cope with Your Emotions

Express Your Feelings

People have found that when they express strong feelings like anger or sadness, they're more able to let go of them. Some sort out their feelings by talking to friends or family, other cancer survivors, a support group, or a counselor. But even if you prefer not to discuss your cancer with others, you can still sort out your feelings by thinking about them or writing them down.

Look for the Positive

Sometimes this means looking for the good even in a bad time or trying to be hopeful instead of thinking the worst. Try to use your energy to focus on wellness and what you can do now to stay as healthy as possible.

Don't Blame Yourself for Your Cancer

Some people believe that they got cancer because of something they did or did not do. But scientists don't know why one person gets cancer and one person doesn't. All bodies are different. Remember, cancer can happen to anyone.

Don't Try to Be Upbeat If You're Not

Many people say they want to have the freedom to give in to their feelings sometimes. As one woman said, "When it gets really bad, I just tell my family I'm having a bad cancer day and go upstairs and crawl into bed."

You Choose When to Talk about Your Cancer

It can be hard for people to know how to talk to you about your cancer. Often loved ones mean well, but they don't know what to say or how to act. You can make them feel more at ease by asking them what they think or how they feel.

Find Ways to Help Yourself Relax

Whatever activity helps you unwind, you should take some time to do it. Meditation, guided imagery, and relaxation exercises are just a few ways that have been shown to help others; these may help you relax when you feel worried.

Be as Active as You Can

Getting out of the house and doing something can help you focus on other things besides cancer and the worries it brings. Exercise or gentle yoga and stretching can help too.

Look for Things You Enjoy

You may like hobbies such as woodworking, photography, reading, or crafts. Or find creative outlets such as art, movies, music, or dance.

Look at What You Can Control

Some people say that putting their lives in order helps. Being involved in your health care, keeping your appointments, and making changes in your lifestyle are among the things you can control. Even setting a daily schedule can give you a sense of control. And while no one can control every thought, some say that they try not to dwell on the fearful ones, but instead do what they can to enjoy the positive parts of life.

Research Projects During 2020

The Iowa Cancer Registry (ICR) is participating in over 80 open studies during 2020 that have been approved by the University of Iowa Human Subjects Office. Brief descriptions of a few of these studies are provided.

Agricultural Health Study

The Agricultural Health Study is a long-term study of agricultural exposures (including pesticides) and chronic diseases (especially cancer) among commercial or private pesticide applicators (and their spouses, if married) in Iowa and North Carolina. The study is funded through the National Cancer Institute (NCI) and involves several federal agencies and is in the 27th year of the study. Results from this study, the study background, frequently asked questions, other resources for agricultural health information, references for publications to date, and information for scientific collaborators can be found at the website, <http://aghealth.nci.nih.gov/>.

This study's data have also been pooled with data from other cohort studies and analyzed as collaborative activities. The titles for over 300 publications from this study linked to PubMed are available at the website.

Patterns of Care Studies

SEER Patterns of Care Studies are conducted to satisfy a U.S. Congressional directive to the NCI to "assess the incorporation of state-of-the-art cancer treatment into clinical practice and the extent to which cancer patients receive such treatments." The ICR began to collaborate in these types of studies in 1987 and they have continued, typically on an annual basis, to the present. More information is provided at <https://healthcaredelivery.cancer.gov/poc/>.

Virtual Pooled Registry – Cancer Linkage System

This is a web-based system designed to allow researchers with databases containing large numbers of participants to perform minimal risk linkages with cancer registries across the U.S. including the ICR. The goal is to provide timely access while providing for a secure and standardized linkage process. More details are provided at <https://www.naaccr.org/about-vpr-clsl/>.

Transplant Cancer Match Study

Solid organ transplantation provides life-saving treatment for end-stage organ disease but is associated with substantially elevated cancer risk, largely due to the need to maintain long-term immunosuppression. Important questions remain concerning the role of immunosuppression and other factors in causing cancer in this setting. Staff at two federal agencies, the NCI and the Health Resources and Services Administration (HRSA), have created a database through linkage of information beginning in 1987 on over 290,000 U.S. transplant recipients with information on cancer from 17 U.S. cancer registries, including the ICR. More information is provided at <https://transplantmatch.cancer.gov/>.

Online Way for Patients to Augment Registry Data (ONWARD) Study

ONWARD was one of several NCI-sponsored pilot studies to explore web-based options for collecting patient generated health data to extend the value of registry data. The Iowa Personal Health Record (PHR), developed by University of Iowa researchers, was used as the online tool in this study. It is an integrated web app that includes online enrollment, data collection, and delivery of education and self-care tools. A sample of 2,385 Iowa residents age 50+ with a history of breast, prostate or colorectal cancer were surveyed on two occasions four months apart. They answered questions about their symptoms, cancer care, medications, and quality of life. The Iowa PHR web app contained resources for patients to explore, including cancer care information, personal health record keeping, and personalized reports. Overall, 17% of invited persons enrolled in the study, with over 91% of participants completing the follow-up survey. Respondents generally found the system easy to use. The final report is available for download at https://herce.public-health.uiowa.edu/research/ONWARD_Final_Report.pdf.

CDC Ovarian Study

The main objectives of this study are to assess the receipt of appropriate first line treatment for 1,000 ovarian cancer patients and to identify patient, tumor- specific, and clinical factors associated with receipt of non-guidelines-based treatment. Iowa, Kansas, and Missouri are taking part in the study, looking at the extent of gynecologic oncologists in the Midwest, an area with one of the highest rates of ovarian cancer, and how this affects ovarian cancer treatment and survival.

Pregnancy Outcomes in Cancer Survivors

Iowa birth certificate, newborn screening, and ICR data are being linked to construct a cohort of cancer survivors matched to women without cancer to address two specific aims. First, to estimate the prevalence of adverse birth outcomes stratified on time since cancer diagnosis, cancer stage and treatment, and second, to evaluate whether maternal history of cancer results in metabolic vulnerability in newborns with targeted metabolomics.

SEER-Medicare

In the early 1990s, the cancer incidence and survival data from the ICR were combined with other SEER Registry data and linked to Medicare data. This linked data set has been updated on several occasions since and has become an important data resource for cancer research involving epidemiologic and health services research related to the diagnosis and treatment procedures, costs, and survival of cancer patients. Thus far, over 2,000 publications have resulted from this linked data set, including over 200 during 2019, listed at <http://healthservices.cancer.gov/seermedicare/overview/publications.html>.

Viewpoints on Ovarian Cancer Treatment and Referral

The purpose of this study is to understand the viewpoints and referral practices of hospital administrators, medical oncologists, and obstetrics and gynecology physicians in Iowa when treating ovarian cancer patients. The goal is to improve our understanding of the viewpoints and experiences shaping the state of ovarian cancer treatment in Iowa.

SEER-Medicare Health Surveys

In 2003, the ICR obtained human subjects research approval for a new project to link SEER data with the Centers for Medicare and Medicaid (CMS) Medicare Health Outcomes Survey (MHOS). Similar approval was obtained in 2009 for linkage to the Consumer Assessment of Healthcare Providers & Systems (CAHPS) surveys. The SEER-MHOS linked data provided a wide range of potential research applications focused on health-related quality of life of cancer patients and cancer survivors (see <https://healthcaresdelivery.cancer.gov/seer-mhos/> for more details). The SEER-CAHPS linked data allow for research applications focused on patient experiences with care across health plan types (see <https://healthcaresdelivery.cancer.gov/seer-cahps/> for more details).

Rectal Cancer Provider Referral Patterns

The purpose of this study is to determine key considerations or knowledge gaps of Iowa patients in the referral process of their stage II/III rectal adenocarcinoma to ultimately inform patient-provider communication, decision support strategies, and quality improvement efforts across surgeons and hospitals.

Evaluation of Data Received from ICR Data Linkage with CancerLinQ

The purpose of this project is to evaluate the data received from American Society of Clinical Oncology CancerLinQ to determine the completeness and representativeness of the information. This evaluation will establish the benefit of the linkage for supplementing the ICR's data, both to fill in gaps in the data currently collected and in determining the feasibility of collecting new data items. The evaluation will also investigate the ability of the linked data to calculate specific Quality of Patient Care (QOPI) measures.

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