2023 CANCER IN IOWA



lowa Cancer Registry/State Health Registry of Iowa



In this special edition of the Cancer in Iowa report, we celebrate 50 years of serving the state of Iowa as the trusted source for high-quality cancer data.

As cancer became the second leading cause of death in the United States, and many pushed for more public funding for cancer research, the National Cancer Act of 1971 was signed. This act represented a national commitment to making progress against cancer by creating programs that addressed critical research needs, including the Surveillance, Epidemiology, and End Results (SEER) Program, which includes the Iowa Cancer Registry. SEER provides national population-based statistics on the number of cancer cases and mortality rates. In these past 50 years, the SEER Program has collected, preserved, and provided access to data such as patient demographics, tumor morphology, and vital status.

The Iowa Cancer Registry has been part of the SEER Program of the National Cancer Institute continuously since 1973. The Iowa Cancer Registry is Iowa's statewide cancer registry, meaning it collects cancer data on all Iowa residents, and is currently one of 21 registries in the United States funded by, and providing data to, the SEER Program. The Iowa Cancer Registry is additionally funded by the University of Iowa and the State of Iowa. But the funding generated by the registry goes beyond our operational expenses: research studies using Iowa Cancer Registry data have been funded by many other federal agencies and foundations, and include large important studies such as the Agricultural Health Study. Iowa represents rural and Midwestern populations, and our data are included in many publications, national estimates, and projections of cancer burden.

Cancer is a major burden in Iowa and throughout the United States. Thus, cancer is a reportable disease in all 50 states. The Iowa Cancer Registry helps us to study the cancer experience of Iowans and brings national attention to the issue. 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. Confidentiality is critically 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 2023 Cancer in Iowa report provides information to the public on the status of cancer in our state. Highlights of the report include:

- An estimated 20,800 new invasive cancers (and in situ bladder cancers) will be diagnosed among Iowans in 2023
- An estimated 6,200 Iowans will die from cancer in 2023
- The number of cancer survivors is growing, with an estimated 164,270 survivors in Iowa as of 2018
- The Iowa Cancer Registry celebrates 50 years of cancer surveillance, highlighting changes in cancer incidence, mortality, and survival
- Examples of research projects using Iowa Cancer Registry data

The report can also be found online: https://shri.public-health.uiowa.edu/cancer-data/iowa-cancer-reports/



Estimates for New Cancers for 2023

The numbers on the map below are estimates of the 20,800 new cancer cases for 2023 by county of residence at diagnosis. The color of the county shows the rate of new cancer cases for years 2015-2019, with the counties with the lowest rates shaded **dark blue** and the highest rates shaded **dark green**.



Rates are age-adjusted to the 2000 U.S. Standard Million Population, 2015-2019

ESTIMATED NEW CANCERS AMONG IOWA RESIDENTS, 2023

ТҮРЕ	COUNT	% OF TOTAL	TYPE	COUNT	% OF TOTAL
Breast	2,920	14.0	Leukemia	720	3.5
Prostate	2,750	13.2	Uterus	700	3.4
Lung	2,700	13.0	Oral cavity and pharynx	620	3.0
Colon and rectum	1,660	8.0	Pancreas	610	2.9
Skin melanoma	1,300	6.3	Thyroid	500	2.4
Bladder	950	4.5	Myeloma	310	1.5
Non-Hodgkin lymphoma	830	4.0	Liver and intrahepatic bile	duct 300	1.4
Kidney and renal pelvis	830	4.0	All others	3,100	14.9

Estimates for Cancer Deaths for 2023

The numbers on the map below are estimates of the 6,200 cancer deaths estimated for 2023 by county of residence at time of death. These projections are based on mortality data provided by the Iowa Department of Health and Human Services. The color of the county shows the rate of cancer deaths for years 2015-2019, with the counties with the lowest rates shaded **dark blue** and the highest rates shaded **dark green**.



Rates are age-adjusted to the 2000 U.S. Standard Million Population, 2015-2019

ESTIMATED CANCER DEATHS AMONG IOWA RESIDENTS, 2023

ТҮРЕ	COUNT	% OF TOTAL	ТҮРЕ	COUNT	% OF TOTAL
Lung	1,420	22.9	Bladder	190	3.1
Colon and rectum	540	8.7	Brain	180	2.9
Pancreas	470	7.6	Esophagus	180	2.9
Breast	410	6.6	Kidney and renal pelvis	180	2.9
Prostate	340	5.5	Ovary	150	2.4
Leukemia	260	4.2	Myeloma	150	2.4
Liver and intrahepatic bile	duct 250	4.0	Uterus	125	2.0
Non-Hodgkin lymphoma	240	3.9	All others	1,115	18.0

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 1973-2018, **there are an estimated 164,270 cancer survivors among Iowans** (defined as people who are currently living with or having had cancer).



SURVIVORS AMONG IOWA RESIDENTS DIAGNOSED WITH CANCER

TYPE	COUNT	% OF TOTAL	ТҮРЕ	COUNT	% OF TOTAL
Breast	36,100	22.0	Lung	6,665	4.1
Prostate	29,955	18.2	Kidney and renal pelvis	6,615	4.0
Colon and rectum	15,800	9.6	Leukemia	5,375	3.3
Skin melanoma	12,920	7.9	Oral cavity and pharynx	4,670	2.8
Uterus	8,860	5.4	Testis	2,800	1.7
Thyroid	8,110	4.9	Cervix	2,510	1.5
Bladder	7,995	4.9	Ovary	2,215	1.4
Non-Hodgkin lymphoma	7,875	4.8	All others	5,805	3.5

Iowa Cancer Registry Celebrates 50 years as a Registry and Member of SEER Program

The Iowa Cancer Registry is proud to collect cancer data for the state of Iowa and, with cancer registries now in all 50 states, our data are combined to investigate the burden of cancer for the entire U.S. population.

Locally, Registry data have been used to help create the state cancer plan cancer objectives and to evaluate effectiveness of state programs, including determining whether screening efforts result in lower cancer rates. Data can also aid policy decisions, such as the increase in the state tobacco tax in 2007, which resulted in a drop in the percent of Iowans who smoke cigarettes, from 19.0% in 2008 to 14.6% in 2021.

IDPH receives CDC funding to create a comprehensive cancer control plan for lowa which helps to form lowa's cancer coalition, the Iowa Cancer Consortium. The first Iowa Cancer Plan is published in 2003. The U.S. Preventative Services Below are some of the major Congress passes Task Force (USPSTF) milestones in cancer prevention Cancer Registries and control we have seen The North American Amendment Act screening for over the last 50 years! Association of to establish CDC colorectal cancer Central Cancer support for for all persons ages Registries is formed, statewide cancer 50 or older, as well FDA approves a a professional registries, creating as advising women hepatitis B vaccine which is the first organization that CDC's National ages 50-69 years promotes uniform **Program for** anti-cancer vaccine data standards for **Central Cancer** because it can help prevent liver cancer cancer registration. Registries. 2001 1981 1987 1992 1996 973 1982 1991 1993 1998

SEER Program funds the formation of the State Health Registry of Iowa (SHRI), now known as the lowa Cancer Registry (ICR), with John W. Berg, MD, Principal Investigator

Congress passes The

National Cancer Act,

supporting

development of the

registry system.

1971

lowa administrative code is amended making cancer a reportable disease in Iowa.

The lowa Cancer Registry publishes its first Cancer in Iowa report.

lowa Department of Public Health (IDPH) is awarded its first funding through the CDC to implement the National Breast and Cervical Cancer Early Detection Program. Screening begins in 1995.

A clinical trial shows effectiveness of first at- home screening test for colorectal cancer: Guaiac Fecal Occult Blood Testing, paving the way to make colorectal cancer testing more accessible for all.

The CDC forms the National Comprehensive **Cancer Control** Program (NCCCP). The NCCCP supports state, Tribal, and territorial cancer coalitions which in turn produce comprehensive cancer control plans for their communities.

Holden Comprehensive Cancer Center at the University of Iowa receives National Cancer Institute (NCI) Comprehensive

Cancer Center designation under the

leadership of Dr. George Weiner. Research

based on the Iowa Cancer Registry played a central role in that designation.

Iowa Administrative Code amends the definition of reportable cancers and designates the ICR/SHRI as a Public Health Authority to collect cancer data for the state of Iowa.

The Iowa state cigarette tax is increased from \$0.36 to \$1.36 per pack; increasing taxes is an evidencebased strategy to lower cigarette smoking, which results in Iower cancer mortality.

2007

IDPH receives funding from the CDC's Colorectal Cancer Control Program to provide CRC screening tests to low-income, uninsured, and underinsured populations and to promote the importance of screening.

2009

Congress passes the Family Smoking Prevention and Tobacco Control Act, giving the Food and Drug Administration the authority to regulate tobacco. IDPH receives annual funding from the lowa State Legislature for cervical cancer prevention and screening.

2012

Congress passes the 21st Century Cures Act, authorizing \$1.8 billion in funding for the Cancer MoonshotSM over 7 years.

2016

Governor Kim Reynolds signs The Gail Orcutt School Radon Safety Bill which requires radon testing and mitigation in Iowa schools. Radon is the leading non-smoking cause of lung cancer.

2022

President Biden reignites the Cancer MoonshotSM with a new goal to reduce the cancer death rate by half within 25 years and improve the lives of cancer survivors.

first HPV vaccine Gardasil, which protects against HPV infections that cause ~70% of all cervical cancers.

2006

2005

FDA approves the

most public areas. The USPSTF recommends screening for colorectal cancer using fecal occult blood testing, sigmoidoscopy, or

colonoscopy in adults

ages 50-75 years.

2008

The lowa State

Legislature passes

the lowa Smokefree

Air Act, which

prohibits smoking in

IDPH receives funding from Iowa State Legislature to support the Comprehensive Cancer Control Program.

Congress passes the Affordable Care Act, banning health insurers from denying coverage because of a patient's preexisting condition (including cancer) and requiring insurance plans to cover recommended preventative services, such as mammography or colonoscopy, without any patient cost-sharing.

2010

IDPH receives annual funding from the Iowa State Legislature for colorectal and cervical cancer education and screening.

The USPSTF makes its first recommendation to advise smokers over the age of 55 with a long history of smoking to receive lung cancer screening, based on the results of the National Lung

Screening Trial.

2013

Congress passes the Childhood Cancer Survivorship, Treatment, Access and Research Act to advance pediatric, adolescent and young adult cancer research and treatments, cancer surveillance, and enhance resources for survivors.

2018

Pioneers in Cancer Surveillance and Research in Iowa, 1973-2023

In this report, we honor Dr. Peter Isacson, Dr. Charles Lynch, Kathleen McKeen, and Dr. Charles Platz, whose dedication and hard work over the past 50 years set the standard of quality surveillance for the Iowa Cancer Registry. Data collected on new cancers and cancer deaths among lowans over this time informed public health programs in the state, and helped guide research to prevent or treat cancer. We celebrate Dr. George Weiner for his work as Director of the University of Iowa Holden Comprehensive Cancer Center, and President of the Iowa Cancer Consortium. Research by Dr. Elaine Smith and Dr. Bill Field led to advances in HPV-related cancers and the effects of radon on lung cancer and the importance of testing radon levels in homes and schools, respectively. These accomplished leaders and researchers have paved the way for the Iowa Cancer Registry to continue to support landmark research that will significantly reduce the burden of cancer.



Dr. Peter Isacson was the Principal Investigator of the Iowa Cancer Registry from 1977-1990. He was also Head of the University of Iowa Department of

Preventive Medicine and Environmental Health from 1972-1984, thereafter, serving as Head of the Division of Epidemiology until his retirement in 1990. He served as a mentor to Dr. Charles Lynch, who would eventually become the Principal Investigator of the Iowa Cancer Registry. Dr. Isacson died June 16, 2000.



Dr. Charles Lynch, Professor of Epidemiology and former Medical Director and Principal Investigator of the Iowa Cancer Registry, retired on July 1, 2022,

after an exceptional 40-year career at the University of Iowa. He also served as the Iowa Director of the Agricultural Health Study cohort from 1992 to 2018, a landmark study that examined agricultural exposures, particularly pesticides, and their risk for cancer, neurological disorders, and other health conditions.



Kathleen McKeen worked in the cancer registry field for 59 years, including 36 years as Director of the Iowa Cancer Registry. She was instrumental in the creation of the

Iowa Cancer Registrars Association, the National Cancer Registrars Association, and the North American Association of Central Cancer Registries, as well as mentoring others in the field of cancer registration. Kathleen died October 1, 2021.



Dr. Charles Platz is a

renowned surgical pathologist who was the core of the surgical pathology section at the University of Iowa Hospitals & Clinics. For decades he

assisted the Iowa Cancer Registry staff to accurately record the pathologic diagnosis of cancer and was widely known for his passion and dedication for "doing things the right way". He extended his immense knowledge in pathologic classification to the entire NCI SEER Program and served as an outstanding teacher in this role.



Dr. George Weiner was first appointed as Director of the University of Iowa Holden Comprehensive Cancer Center in 1998 and will be stepping down from

this role at the end of March 2023. Dr. Weiner led the cancer center to NCI comprehensive designation in 2001 and successful renewal applications in 2005, 2011, 2016, and 2021, which brings substantial cancer research funds and infrastructure to Iowa. He has played an integral role in the creation and growth of the Iowa Cancer Consortium and has been a strong advocate for using Iowa Cancer Registry data to drive cancer control strategies.



Dr. Elaine Smith initiated studies in 1985 on the molecular epidemiology of human papillomavirus (HPV) infection in cancer of the uterine cervix,

often using data from the Iowa Cancer Registry. Thanks in part to her research, it is now understood that nearly all cases of cervical cancer are caused by infection with high-risk types of HPV and that HPV infection is linked with a subset of head and neck cancers. Dr. Smith died Jan. 21, 2021.



Dr. Bill Field

is recognized internationally for his expertise in radon and radiation health effects. He and Dr. Lynch led the Iowa Radon Lung Cancer Study, which

used outcome data from the Iowa Cancer Registry. He served on the Presidential Advisory Board for Radiation and Worker Health until his death in 2022. He worked with professional organizations to improve radon testing, educate the public on health risks from radon, and championed policy and systems change to reduce radoninduced lung cancer in Iowa.

50 Years of Cancer Data for Iowa

Iowa began data collection in 1973 as one of the original SEER 9 registries with Connecticut, New Mexico, Utah, Hawaii and the metropolitan areas of Detroit, San Francisco-Oakland, Atlanta, and Seattle. By collecting data on all Iowa residents diagnosed with cancer, the registry can calculate rates of new cancers (incidence) for the state of Iowa and track the burden of cancer. Rates of cancer deaths (mortality) can also be produced with data provided to us by the Iowa Department of

Health and Human Services and the National Death Index.

The picture of cancer has changed in the last 50 years in Iowa. We now record almost twice as many cases than we did when the registry was first established. One reason for this is Iowa's aging population, as advancing age is the leading risk factor for cancer. In fact, persons over age 65 accounted for almost 60% of newly diagnosed cancers and 75% of all cancer deaths during the last five years (2015-2019). Another reason for the increased number of cases includes the increasing size of Iowa's population from 2,864,031 in 1973 to 3,207,779 in 2023. A third reason is the overall increase in the development and detection of cancer among Iowans.

Figure 1 shows how cancer rates have changed over time in Iowa. Cancer incidence has slightly increased over time, while cancer mortality has decreased. Iowa's rates were similar to the other SEER registries through 2013. In 2014, Iowa's incidence rate began increasing, while the others continued to decrease or stay the same. Iowa now has the second highest overall cancer incidence of all U.S. states.

Changes in age-adjusted incidence rates over time largely reflect changes in risk factors, screening, and diagnostic practices. The main reason for the decline seen in mortality rates is the decrease in smoking over time and the drop in lung cancer and other smoking-related cancer deaths. Screening and treatment advancements have also contributed to a decrease in cancer death rates. **Figure 2** shows that the five-year survival among those diagnosed with cancer has substantially improved since the 1970s. In 1973, the Iowa Cancer Registry recorded 10,140 new cases of cancer among Iowans. Now, we record over 20,000 a year.

While the number of cases has doubled in the past 50 years, the four leading cancersfemale breast, lung, colorectal, and prostate cancers- still make up almost 50% of new cases and cancer deaths. These four cancers are strongly linked to lifestyle factors and have available screenings. It is very important to get your age- and risk-appropriate screening and engage in healthy behaviors such as eating fruits and vegetables, being active, and not using tobacco.







Trends in Incidence and Mortality

Figure 3 shows incidence rates and mortality rates by cancer type by decade. The **dark blue**→**light blue** bars show incidence rates over time, and the **red**→**light red** bars show mortality rates over time. Below are some of the cancer-specific patterns we see:

FEMALE BREAST CANCER	PROSTATE CANCER	LUNG CANCER	COLORECTAL CANCER
Rates of new cases increased in the 1970s-1990s, and then leveled off somewhat. However, it has been increasing in the most recent 5-year period and we now have the 15 th highest rate in the U.S. Mortality continues to decrease over time, due in part to mammography and improvements in treatment.	Rates of new cases peaked in the 1990s when prostate specific antigen (PSA) testing was strongly recommended, and have been decreasing over time since PSA testing is no longer recommended as usual care. In the most recent 5-year period it has started to rise again and we have the 16 th highest rate in the U.S. Mortality has been decreasing over time.	Rates of new cases and deaths peaked in the 1990s, but have been declining since that time. See Figure 4 .	Rates of new cases have been decreasing since the 1980s, largely due to the removal of potentially problematic polyps during colonoscopies. However, Iowa continues to rank high (7 th) in colorectal cancer incidence in the U.S. Mortality rates have been decreasing over time, thanks in part to colorectal cancer screening and improvements in treatments.

OTHER CANCERS WITH INCREASING RATES

Cancer Type	Ranking among all 50 states
Oral Cavity/Pharynx	1 st
Leukemia	2 nd
Melanoma	5 th
Non-Hodgkin Lymphoma	6 th
Uterine	11 th
Bladder	12 th
Pancreatic	17 th
Thyroid	20 th



Focus on: Lung cancer

Trends in lung cancer differ by sex and are strongly driven by smoking, which accounts for 90% of all lung cancer cases. Rates of smoking have decreased among males more quickly than among females. As a result, there has been a substantial decrease in new lung cancers and cancer deaths among Iowa males, while the rate of new lung cancers in females has begun to level off and a decline in deaths is seen in the most recent decade. Radon is the leading cause of non-smoking related lung cancers. Lung cancer is the leading cause of cancer death in Iowa.



Survival and Survivorship

Overall cancer survival has increased in Iowa since the 1970s. Many factors can affect survival, including type of cancer, screening, stage of disease, general health of the individual, and available treatments.

Figure 5 shows survival over time for the most common cancers in Iowa. **Five-year prostate and female breast cancer survival is now over 90% for all stages combined.** The drivers of the trends in survival vary by cancer site. For example, prostate cancer survival has increased mostly due to improvements in treatment. Breast cancer survival has improved due to several advances, including screening, advances in surgery, better treatments, and hormonal therapy which lowers risk of hormone-receptor-positive cancer recurrence.

There are currently more than 164,000 cancer survivors in Iowa.

Hospital-based survivorship clinics may help identify and address needs that individuals may have post diagnosis and/or treatment.

Five-year colorectal cancer survival is 67%, an increase from 49% in the 1970s. Improvements in survival are largely due to early detection efforts including colonoscopies and stool-based fecal immunochemical tests (FIT), as well as advances in treatment. However, this impact has leveled off in the last decade.

Five-year survival for lung cancer is relatively low at 20%, but this varies widely by stage. Cases diagnosed at local stage (limited to one lung) have a five-year survival of 55%, whereas cases diagnosed at late stage (cancer has spread to the other lung or other distant parts of the body) have a five-year survival of 13%. Lung cancer survival rates have increased in the last decade due to recommendations for screening with low dose computed tomography, detection of cases at an earlier stage, and advances in treatment including targeted therapies and immunotherapy. Survival will likely continue to increase with increasing use of screening.

Five-year survival rates for many of Iowa's other top 10 sites have increased since the 1970s including thyroid, skin melanoma, oral cavity and pharynx, kidney, non-Hodgkin lymphoma, leukemia, and pancreatic cancers, though survival for pancreatic cancer remains very poor. Survival for uterine cancer and bladder cancer has remained stable over time.



How Have Racial Disparities Changed?

For the most recent five years, the state of Iowa has the 2nd highest incidence rate and the 3rd highest mortality rate for all cancers combined in the Black population. Furthermore, Iowa has one of the greatest differences between the rate of cancer deaths in Black vs. White people. Race is a social construct created by society to group people; it is not a biological attribute, meaning that different races do not have different genes. Income, education level, occupation, and access to healthcare differ by race and contribute to cancer health disparities. In the figures below, we focus on the three cancers with the largest racial disparities that have emerged over time: prostate, female breast, and uterine cancer.



Risk Factors for Cancer

Iowa has the second highest incidence rate for cancer in the U.S., (behind Kentucky), and is the only state with an increasing rate of cancer. Increasing awareness of risk factors can help Iowans lower their risk for cancer and inform policies, programs and initiatives designed to address cancer risk factors at a population level.

Obesity

Studies show that obesity, often defined as having a body mass index (BMI) greater than 30 kg/m², is linked to a higher risk of postmenopausal breast, colorectal, endometrial, esophageal, kidney, and pancreatic cancer. Since weight itself is generally not a good marker of health, it is more important to focus on having a nutritious diet and being physically active.



Physical Activity

Studies show that people who are physically active have a lower risk of certain cancers than those who are not. Physical activity may particularly protect against postmenopausal breast cancer and endometrial cancer.



Diet

The foods that you eat on a regular basis make up your diet and may increase or decrease risk for cancer. While the studies are complex and often conflicting, research shows that a diet filled with a variety of vegetables, fruit, whole grains, beans and other plant foods helps lower risk for many cancers.



Alcohol

Studies have shown that drinking alcohol is linked to an increased risk of oral cavity, esophageal, breast, liver, and colorectal cancer.



Cigarette Smoking and Tobacco Use

Tobacco use is strongly linked to an increased risk for 12 types of cancer including lung, acute myelogenous leukemia, bladder, cervical, colorectal, esophageal, kidney, oral cavity, pancreatic, and stomach. Cigarette smoking is believed to cause almost 30% of all cancer deaths in the U.S., and 90% of all lung cancers.



Radiation

The two main types of radiation linked with an increased risk for cancer include ultraviolet radiation from sunlight (main cause of nonmelanoma skin cancers) and ionizing radiation including radiation treatment for medical reasons.

Radon gas in homes is also a source of ionizing radiation and the #2 cause of lung cancer behind smoking/tobacco. Iowa has the highest radon levels of any state, according to the Environmental Protection Agency (EPA). More than 70% of Iowa homes measure at or above 4 picocuries per liter (pCi/L), the level at which EPA recommends homes be fixed. The average radon level in Iowa homes is 8.5 pCi/L compared with a U.S. average of 1.3 pCi/L.

Radiation may increase risk of leukemia, thyroid, and breast cancer, among others.

Infections

Some viruses cause cancer, but there are vaccines available to prevent them. These include human papillomavirus (HPV) which increases the risk for cancers of the cervix, penis, vagina, anus, and oropharynx. Adolescents should receive the HPV vaccine series to eliminate their risk of HPV-related cancer. Hepatitis B increases the risk for liver cancer. The vaccine is typically initiated at birth but can be given at any age.



Environmental Risk Factors

Being exposed to chemicals and other substances in the environment has been linked to some cancers. These include links between lung cancer and secondhand tobacco smoke, outdoor air pollution, and asbestos. Drinking water with a large amount of arsenic has been linked to skin, bladder, and lung cancers. Studies continue to examine the relationships between pesticides, other pollutants, and cancer.

The Future of Cancer Surveillance in Iowa

Much work is needed to decrease the burden of cancer among Iowans. Currently, Iowa ranks #2 in the U.S. for incidence of all cancers combined and #21 for all cancer mortality. Iowa is the only state in the U.S. with a significant increase in incidence from 2015-2019 (the most recent data available for all 50 states). Public health professionals, health care providers, researchers, policymakers, and residents of Iowa will need to work together to reduce the burden of cancer in our state. The Iowa Cancer Registry is committed to helping reduce the burden of cancer in Iowa through the collection of data that can be used to investigate why cancer incidence in Iowa is increasing, develop ways to find cancers earlier, and treat cancers more effectively, with fewer side effects.

The Iowa Cancer Registry has seen many improvements in the process of data collection since it was established in 1973. We have become more efficient by increasing automation, and we increasingly collect more information on the characteristics of each cancer and its treatment to support our clinical and research community, all while upholding the high-quality standards set by the National Cancer Institute's SEER Cancer Registry Program. We continuously assess the need for new and better information to reduce the cancer burden for all Iowans. For example, health disparities can be better monitored and addressed by collecting sexual orientation and gender identity data, and ensuring that race and ethnicity data are more consistently captured from self-reported information in the medical record. Also, it is important to collect information on specific cancer characteristics and treatments used in precision medicine (also known as personalized medicine) that help cancer doctors find the treatments that will work best for each patient. This information will help assess whether Iowans are receiving standard of care treatment and how new treatments are working to reduce the burden of cancer in Iowa.

In addition to our surveillance activities, the Iowa Cancer Registry engages in many other activities that serve Iowans. Our Cancer in Iowa report is released annually to update Iowans on the burden of cancer by providing incidence, mortality, and survival data. We also investigate all concerns of potential cancer clusters (higher than expected numbers of cases) in Iowa. We provide reports to cancer treatment facilities that allow them to track their own progress in cancer outcomes. We will continue to produce the data that guide the state cancer plan and help to evaluate the state's cancer prevention and control interventions. Moving forward, we will navigate ways to increase both the use and accessibility of our data as a public health and research resource while protecting the privacy of Iowans with cancer.



MARY CHARLTON. Associate Professor of Epidemiology at the University of Iowa, became the Director and Principal Investigator of the Iowa Cancer

Registry in 2019, and was elected President of the Iowa Cancer Consortium in 2022. Her research focuses on extending the resources and data of the Iowa Cancer Registry and the Holden Comprehensive Cancer Center to help reduce the burden of cancer throughout Iowa, and to help Iowa's rural cancer centers offer comprehensive, high-quality cancer care closer to patients' homes.

Current Iowa Cancer Registry Leadership



became the Director of Operations for the Iowa Cancer Registry in 2018. She manages the overall operation of the registry with a focus on modernizing data collection, maintaining

high quality data, and ensuring the privacy and confidentiality of the information collected.



SARAH NASH,

Assistant Professor of Epidemiology at the University of Iowa, joined the Iowa **Cancer Registry in** 2021. Before then, she was the Principal Investigator of the

Alaska Native Tumor Registry. She oversees research and data use at the Iowa Cancer Registry as Director of Research, Analytics, and Dissemination. Her research focuses on leveraging registry data to address health disparities and achieve health equity.

Addressing Cancer Burden in Iowa: The Iowa Cancer Plan

Cancer is a complex and costly disease, and addressing it is difficult to do alone. Iowa is fortunate to have the Iowa Cancer Consortium, which helps Iowans develop partnerships, find funding, and build skills and knowledge to reduce the burden of cancer.



The Iowa Cancer Plan was created to provide direction and support

for those who want to work collectively to reduce the burden of

cancer. The plan encompasses the entire cancer control continuum, including equitable actions to reduce the risk of developing cancer, find cancer early, and ensure the best treatment and quality of life for individuals affected by cancer.

DID YOU KNOW?

The Iowa Cancer Consortium has strong ties with the Iowa Cancer Registry. Not only do we provide data to support the Iowa Cancer Plan and its evaluation, but the PI and Director of the Iowa Cancer Registry, Dr. Mary Charlton, was recently elected the President of the Iowa Cancer Consortium Board of Directors! Congratulations, Mary! The 2023-2027 Iowa Cancer Plan was just launched, and has the following goals:

- 1. Health Equity: identify and eliminate cancer health disparities.
- 2. Prevention: whenever possible, prevent cancer from occurring.
- 3. Early Detection and Screening: promoting the benefits of screening tests to ensure early diagnosis.
- 4. Diagnosis and Cancer-Directed Therapy: reduce barriers to care, promote evidence-based practices and encourage participation in clinical trials.
- 5. Survivorship and End-of-Life Care: ensure resources to optimize quality of life for cancer survivors and their families.

Learn more about the Iowa Cancer Plan and how to become a member of the Iowa Cancer Consortium at www.canceriowa.org



Addressing Cancer Burden in Iowa Through Research:

There is growing evidence that limited access to high-quality cancer treatment is one of the main drivers of higher cancer mortality rates among rural cancer patients. Many rural hospitals and cancer centers lack the resources to collect and monitor data on their quality of cancer care. They also tend to have more limited supportive care resources including navigators, social workers, and mental health care providers, as well as more limited access to clinical trials. Given patients' needs and preferences to receive cancer care locally, a promising strategy to improve quality of cancer care and outcomes in rural populations is to extend the resources of larger cancer centers out to the community hospitals in these areas.

Following the successful approach of the Markey Cancer Center Affiliate Network of the University of Kentucky Markey Cancer Center, Dr. Charlton and her co-investigators are working toward establishing the Iowa Cancer Affiliate Network. The goals of this network are to help rural cancer centers meet the standards of care established by the American College of Surgeons Commission on Cancer (CoC), and to develop the infrastructure to collect and monitor data to drive quality improvement efforts. They have identified four rural Iowa community hospitals to participate in this intervention trial and developed expert support teams to assist key stakeholder groups within each hospital. They will assess determinants and outcomes of the implementation process, along with stakeholders' feedback on the value and utility of the CoC standards and the intervention itself to improve the quality of cancer care for their patients.

Dr. Charlton and her team will use Iowa Cancer Registry data to evaluate how well the approach worked in terms of improving quality of cancer care and will assess the factors that make this type of approach more successful in the different hospitals. This work could lead to dissemination of similar models across rural settings, thereby improving quality of care, reducing rural disparities in cancer outcomes, and giving rural hospitals an avenue to demonstrate their quality of care.

Research and Data Use at the Iowa Cancer Registry

Research highlight: Rural-urban differences in breast cancer care

Rural Iowans with cancer can face barriers in accessing care due to issues of travel, inadequate health insurance, and shortages of cancer specialists. These barriers can lead to less-than-optimal cancer treatments and poor health outcomes. To better understand rural-urban differences in the management of early-stage breast cancers, the Iowa Cancer Registry supported three research projects for Danielle Riley's (PhD 2021) dissertation. The first investigated rural-urban differences in surgery type (mastectomy versus lumpectomy) and the use of radiation therapy among patients diagnosed with ductal carcinoma in situ. Despite an increase in the use of lumpectomy over time, rural patients were less likely to receive radiation therapy after their lumpectomy. The second project looked at rural-urban differences in the use of lymph nodes to stage breast cancer in patients undergoing mastectomy. Rural patients were less likely to receive any type of lymph node staging. The third project assessed rural-urban differences in the use of genomic testing (e.g., Oncotype Dx) and chemotherapy use among patients diagnosed with stage I/II breast cancer. Genomic testing can be used by physicians to help predict how breast tumors will behave and which treatments might work best. Patients treated at hospitals in small rural areas were less likely to receive genomic testing than patients treated at urban hospitals.

Data use highlight: Investigating cancer concerns in Iowa

Riley D, Chrischilles EA, Lizarraga IM, Charlton M, Lynch CF. Rural-urban differences in secular trends of locoregional treatment for ductal carcinoma in situ: A patterns of care analysis. Cancer Med. 2022 Jun;11(11):2284-2295. doi: 10.1002/ cam4.4605. Epub 2022 Feb 11. PMID: 35146946; PMCID: PMC9160801.

Riley D, Chrischilles EA, Lizarraga IM, Charlton M, Smith BJ, Lynch CF. Influence of rurality on lymph node assessment among women diagnosed with ductal carcinoma in situ and treated with mastectomy, SEER 2000-2015. Breast Cancer Res Treat. 2022 Feb;192(1):211-222. doi: 10.1007/s10549-021-06495-y. Epub 2022 Jan 24. PMID: 35067778; PMCID: PMC9839433.

Riley D, Charlton M, Chrischilles EA, Lizarraga IM, Phadke S, Smith BJ, Skibbe A, Lynch CF. Hospital Rurality and Gene Expression Profiling for Early-Stage Breast Cancer among Iowa Residents (2010-2018). Breast J. 2022 Aug 30;2022:8582894. doi: 10.1155/2022/8582894. PMID: 36111211; PMCID: PMC9448596.

Iowa Cancer Registry data have also been used to evaluate concerns of excess cancer cases in particular areas in Iowa, commonly known as "cancer cluster investigations". In 2022, we investigated three cancer concerns: the first was a concern of high numbers of pancreatic cancer and possible relationship to farm chemicals in Atlantic, Iowa; the second was a concern regarding environmental exposures for those living near the area of the former Chamberlain Manufacturing Plant in Waterloo, Iowa; the third was a concern around breast cancer among employees of Hudson schools over the last 12 years. Below we provide more detail about our process for investigating these concerns.

To investigate the Hudson Schools concern, we started by identifying cases of cancer diagnosed among employees of Hudson Schools after they started working for the school district. Based on this information, we then determined if breast cancer made up a greater proportion of the cancers diagnosed among Hudson Schools employees compared to other groups with similar characteristics. We chose three comparison groups for these analyses: 1) the remainder of Hudson, 2) the Dike ZIP code, and 3) the Cedar Falls ZIP code. We did not find evidence that the proportion of breast cancers among Hudson Schools staff was greater compared to the other groups, but this does not definitively rule out a potential cluster. We plan to monitor the cancer experience of the Hudson Schools staff in future years to look for any signals of an emerging cluster.

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