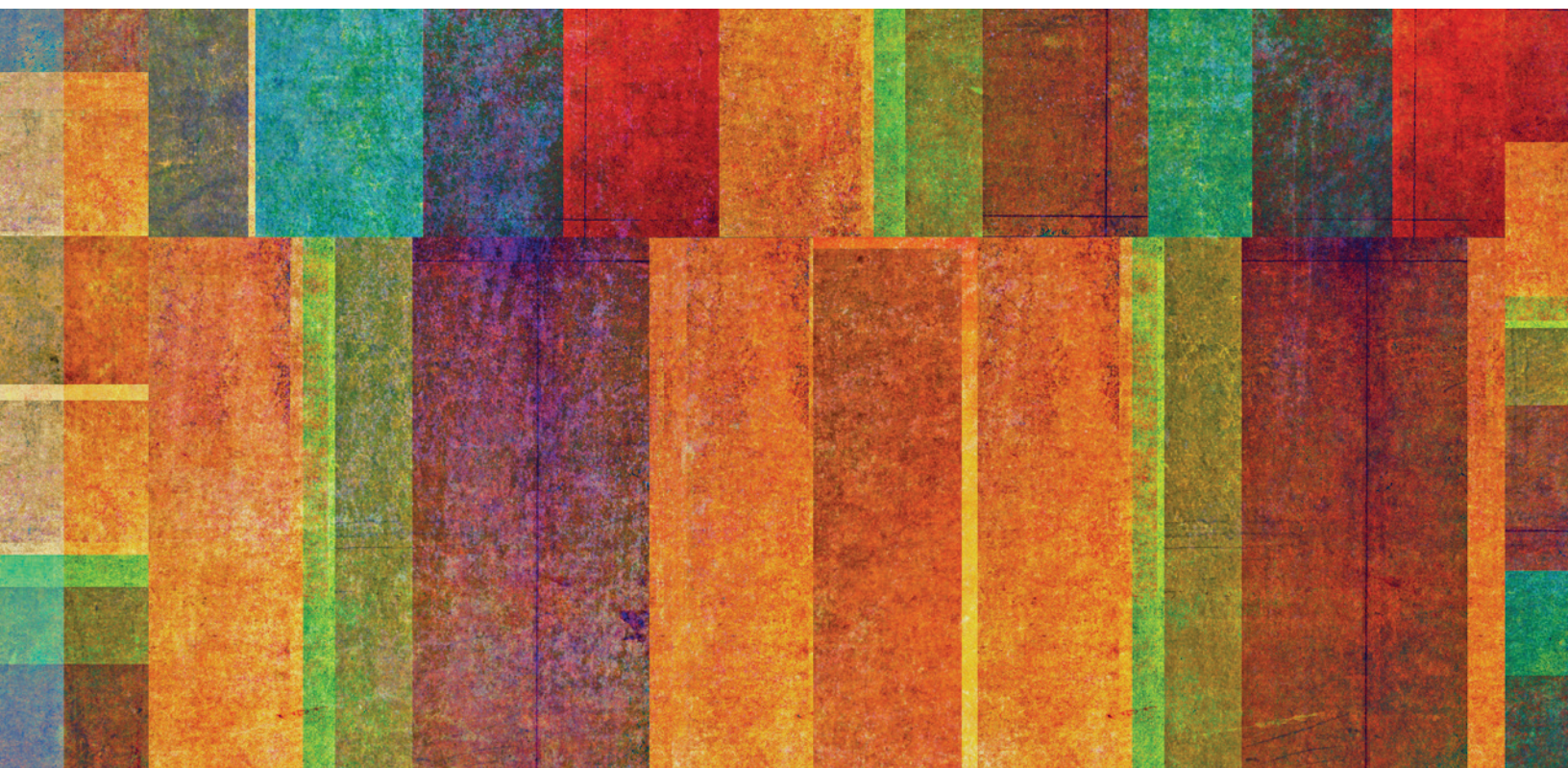



2019

Cancer in Iowa






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 physicians, researchers, public health professionals, policy makers and advocates, among others. All of these people rely on cancer data in their effort to reduce the burden of cancer. 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. The staff includes 40 people, with 16 situated throughout the state, who regularly visit hospitals, clinics, and medical laboratories in Iowa and neighboring states to collect cancer data. The Registry maintains the confidentiality of the patients, physicians, and hospitals providing data.

Since 1973 the Iowa Cancer Registry has been funded by the prestigious Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI), and is one of eighteen 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 US.

Beginning in 1990, about 5-10 percent of the Registry's annual operating budget has been provided by the state of Iowa. In 2003, the University of Iowa began providing cost-sharing funds. The Registry also receives funding through grants and contracts with university, state, and national researchers investigating cancer-related topics.

With 2019 Cancer in Iowa, the Registry makes a general report to the public on the status of cancer. Beginning this year, maps are delineated by urban/rural status to help understand any potential disparity by geographic region. This report focuses on:

- new cases and cancer deaths by county and top 10 by cancer site and sex
 - estimates of the number of cancer survivors
 - cancer versus heart disease as the leading cause of death
 - a special section on HPV-related cancers
 - a section on SEER data and the opportunity for research
- 



Estimates for New Cancers in 2019

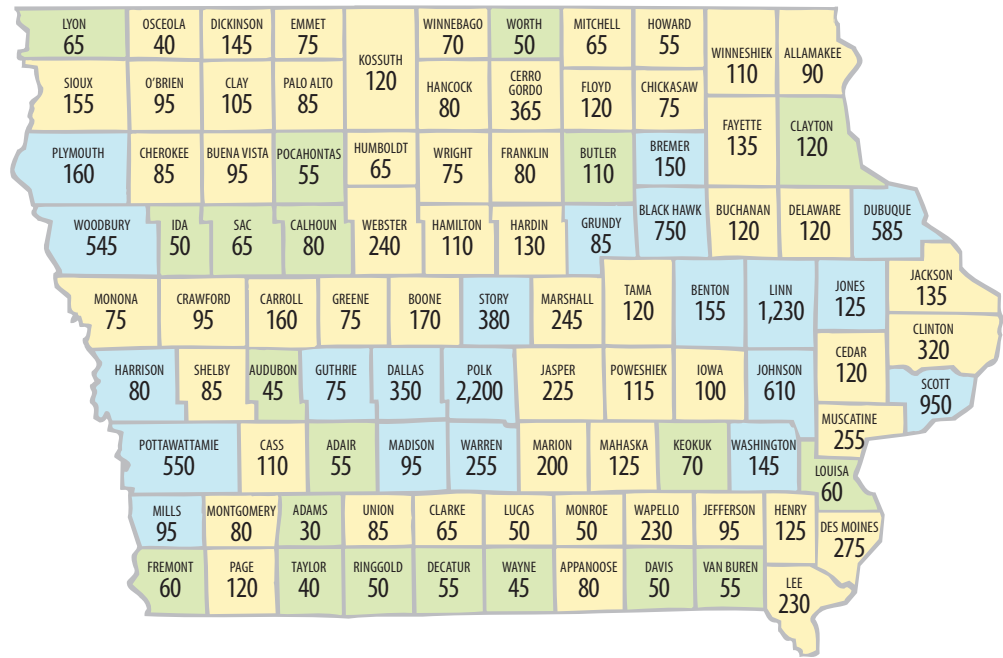
In 2019, data will be collected on an estimated 18,100 new, invasive cancers (and in situ bladder cancers) among Iowa residents. Estimates of new cancers are given by county with shading by urban/rural status as well as the top 10 by sex, below.

Based on the 2013 Rural-Urban Continuum Codes, Iowa counties were classified as:

RURAL = Completely rural or less than 2,500 urban population, adjacent or not adjacent to a metro area

SMALL URBAN = Urban population of 2,500 to 20,000 or more, adjacent or not adjacent to a metro area

LARGE URBAN = Counties in metro area of fewer than 250,000 or up to 1 million population



■ RURAL ■ SMALL URBAN ■ LARGE URBAN

New Cancers in Females

TYPE	# OF CANCERS	% OF TOTAL
Breast	2,500	28.1
Lung	1,100	12.4
Colon & Rectum	780	8.8
Uterus	630	7.1
Skin Melanoma	450	5.1
Thyroid	360	4.0
Non-Hodgkin Lymphoma	330	3.7
Leukemia	270	3.0
Kidney & Renal Pelvis	260	2.9
Pancreas	250	2.8
All Others	1,970	22.1
Total	8,900	

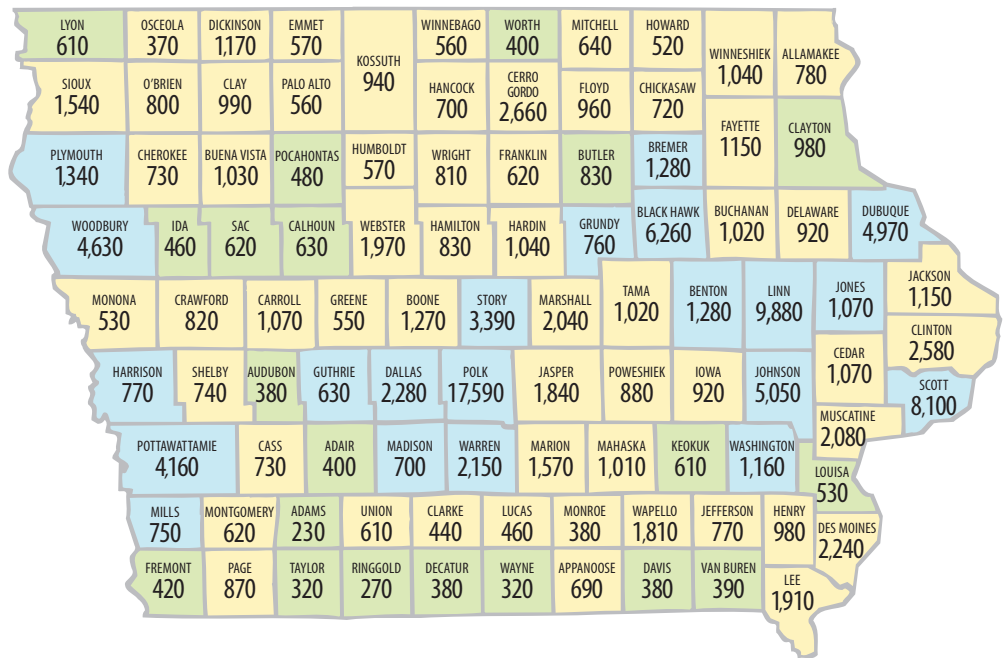
New Cancers in Males

TYPE	# OF CANCERS	% OF TOTAL
Prostate	2,050	22.3
Lung	1,280	13.9
Colon & Rectum	850	9.3
Bladder	640	7.0
Skin Melanoma	560	6.1
Kidney & Renal Pelvis	470	5.1
Non-Hodgkin Lymphoma	400	4.3
Leukemia	400	4.3
Oral Cavity	330	3.6
Pancreas	270	2.9
All Others	1,950	21.2
Total	9,200	



Living with Cancer

A follow-up program tracks more than 99% of cancer survivors diagnosed since 1973. According to Iowa Cancer Registry incidence and survival data for 1973-2014, there are 147,700 cancer survivors (defined as people who are currently living with or previously had cancer)—67,940 males and 79,760 females. The following graphics show survivorship by county and urban/rural status as well as by cancer type and sex, below.



■ RURAL
 ■ SMALL URBAN
 ■ LARGE URBAN

Female Survivors

TYPE	NUMBER	PERCENT
Breast	31,400	39.4
Uterus	7,530	9.4
Colon & Rectum	7,330	9.2
Skin Melanoma	5,230	6.6
Thyroid	4,960	6.2
Non-Hodgkin Lymphoma	3,050	3.8
Lung & Bronchus	2,500	3.1
Cervix	2,370	3.0
Ovary	2,030	2.5
Kidney & Renal Pelvis	1,960	2.5
All Others	11,400	14.3
Total	79,760	

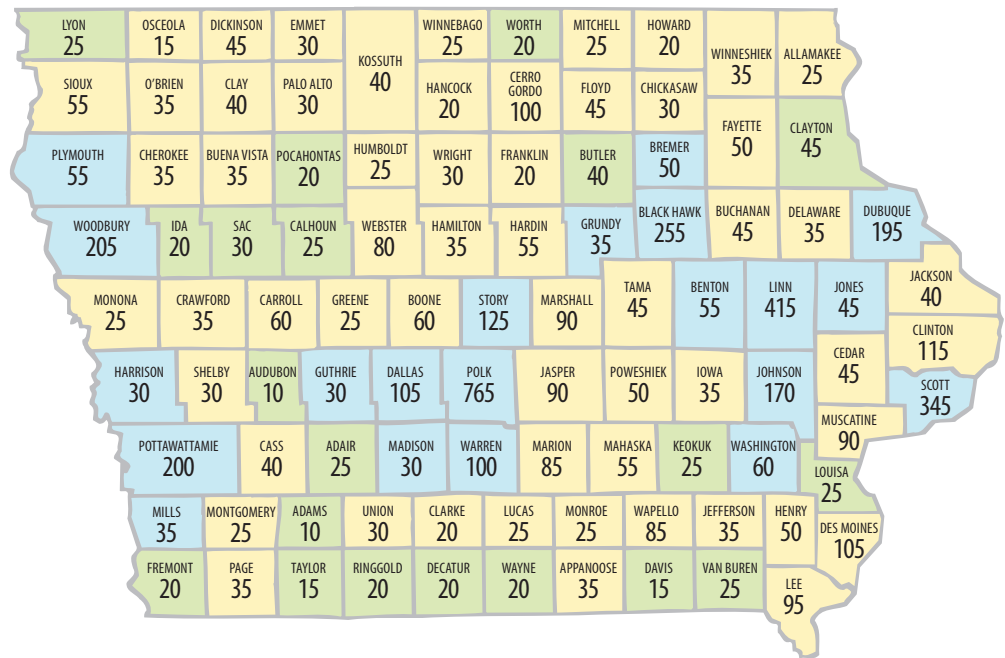
Male Survivors

TYPE	NUMBER	PERCENT
Prostate	25,740	37.9
Colon & Rectum	7,120	10.5
Bladder	4,990	7.3
Skin Melanoma	4,790	7.0
Non-Hodgkin Lymphoma	3,350	4.9
Kidney & Renal Pelvis	2,770	4.1
Oral Cavity & Pharynx	2,520	3.7
Testis	2,520	3.7
Leukemia	2,360	3.5
Lung & Bronchus	2,220	3.3
All Others	9,560	14.1
Total	67,940	



Estimates for Cancer Deaths in 2019

In 2019, an estimated 6,400 lowans will die from cancer. Heart disease and cancer are the leading causes of death in Iowa. 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 shading as well as the top 10 by sex, below.



■ RURAL ■ SMALL URBAN ■ LARGE URBAN

Cancer Deaths in Females

TYPE	# OF CANCERS	% OF TOTAL
Lung	730	24.3
Breast	390	13.0
Colon & Rectum	270	9.0
Pancreas	230	7.7
Ovary	160	5.3
Leukemia	110	3.7
Non-Hodgkin Lymphoma	110	3.7
Uterus	110	3.7
Brain	80	2.7
Multiple myeloma	70	2.3
All Others	740	24.6
Total	3,000	

Cancer Deaths in Males

TYPE	# OF CANCERS	% OF TOTAL
Lung	900	26.5
Prostate	350	10.3
Colon & Rectum	290	8.6
Pancreas	240	7.1
Leukemia	170	5.0
Esophagus	150	4.4
Non-Hodgkin Lymphoma	140	4.1
Bladder	120	3.5
Kidney & Renal Pelvis	110	3.2
Liver	110	3.2
All Others	820	24.1
Total	3,400	



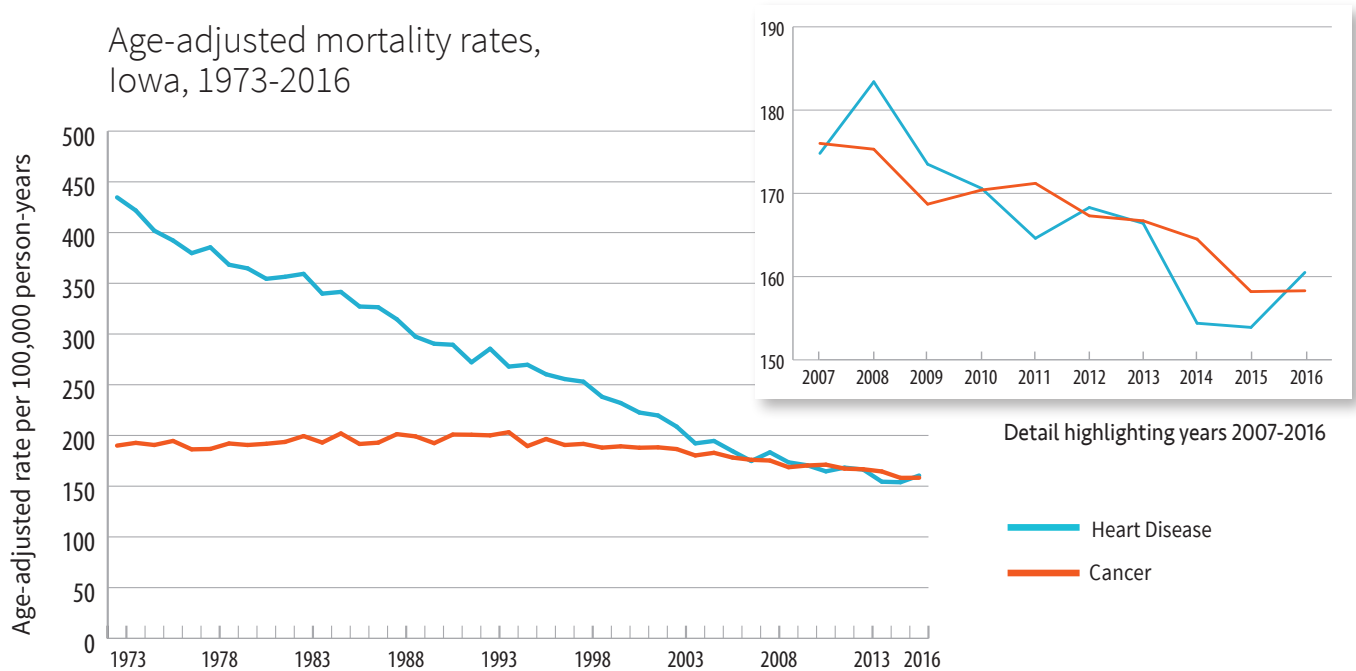
Leading Causes of Death

Heart disease has been the leading cause of death in the US for more than a century. While heart disease remains the leading cause of death overall, cancer has overtaken heart disease in many states. Cancer was the leading cause of death in two states in 2000, but in 22 states in 2014.¹

Cancer is expected to surpass heart disease as the leading cause of death in the US by 2020.² In Iowa, this shift began in 2007, as shown in the graphic below. Heart disease mortality rates have declined 63% in Iowa since 1973 while cancer mortality rates have decreased 13% during this same time period. Much of the decline in heart disease mortality can be explained by the

decline in smoking, treatment of heart disease risk factors such as lowering cholesterol levels and blood pressure levels, improved treatment after a cardiac event such as a heart attack, and increased physical activity. The decline in cancer deaths is attributable to the decline in deaths from cancers of the lung and prostate in males, breast cancer in females, and a continued decline in colorectal cancer deaths in both males and females. Heart disease and cancer share many risk factors including tobacco use, obesity, and physical inactivity. Objectives focusing on risk factors, early diagnosis/use of screening guidelines, and access to health care may lead to further reductions in deaths.

Age-adjusted mortality rates, Iowa, 1973-2016



Several type of infectious agents are associated with cancer. These include Hepatitis B & C Viruses, Human Immunodeficiency Virus, Human Papillomaviruses, Human T-Cell Leukemia/Lymphoma Type 1 Virus, Kaposi Sarcoma-associated Herpesvirus, and Merkel Cell Polyomavirus. Bacteria, such as *Helicobacter pylori*, and parasites, including *Opisthorchis viverrini* and *Schistosoma hematobium*, are also associated with specific types of cancer. Given this, we have elected to discuss cancers associated with Human Papillomaviruses in this year's report.

Human Papillomavirus (HPV) Related Cancers

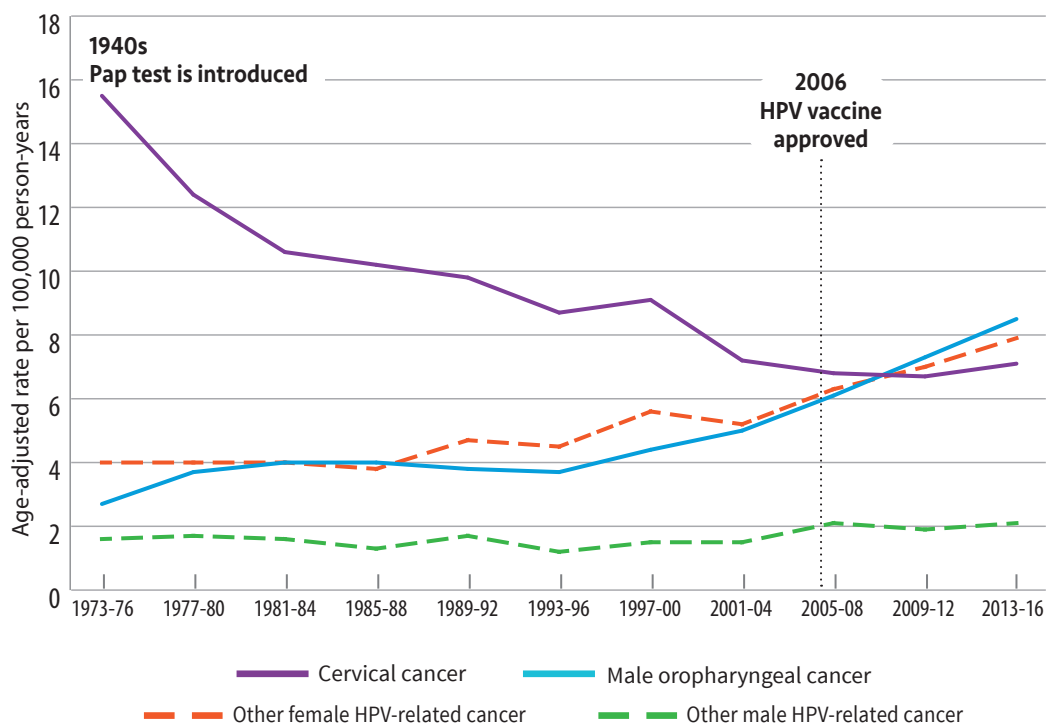
Human Papillomavirus (HPV) is a group of viruses that includes more than 150 different high- and low-risk types. High-risk HPV types can cause cancer in addition to inflammatory lesions. In the US, about 79 million people are currently infected with HPV, and about 14 million will become newly infected with HPV each year,³ making HPV the most common sexually transmitted infection. Most sexually active men and women will be infected with HPV at some point in their lives and most will never know they have been infected. A vaccine to prevent HPV was introduced in 2006. **The HPV vaccine could prevent 90% of HPV-related cancers every year.**

HPV and Cancer

In the US, HPV causes nearly 34,000 cases of cancer each year. In addition, about 300,000 US women undergo invasive treatment for cervical precancers (cell changes on the cervix that might become cervical cancer if they are not treated) caused by HPV. Currently, women are more likely than men to be diagnosed with HPV cancers, however the burden of HPV cancers among men is

increasing, largely driven by increases in HPV-positive oropharyngeal cancers over the past three decades. **In the US, the number of oropharyngeal cancers attributed to HPV is now higher than the number of cervical cancers.** In Iowa, this trend is also evident. **Figure A** provides age-adjusted incidence rates of HPV-related cancers in Iowa by sex from 1973-2016. Cervical cancer rates have been decreasing in Iowa since 1973, although rates have increased slightly within the last few years. As seen nationally, the rate of male oropharyngeal cancer in Iowa has been steadily increasing over time, especially from the mid-1990s on. Since 1987, the rate of other female HPV-related cancer has been steadily increasing, and since 2002, has mimicked that of male oropharyngeal cancer. Of the HPV-related cancers in Iowa, oropharyngeal cancer makes up the largest proportion of HPV-related cancers (38%). Of these, 82% are male. Uptake of the HPV vaccine has been slow. The Iowa HPV vaccination rate was only 38% in 2017. **As vaccination rates increase, HPV-related cancer incidence rates will decrease.**

Figure A Age-adjusted incidence rates of HPV-related cancers by sex, Iowa, 1973-2016



Cervix (squamous cell carcinoma, adenocarcinoma, and other carcinoma of cervix)

Oropharynx (squamous cell carcinoma of base of tongue, pharyngeal tonsils, anterior and posterior tonsillar pillars, glossotonsillar sulci, anterior surface of soft palate and uvula, and lateral and posterior pharyngeal walls)

Other female HPV-related (squamous cell carcinoma of the vulva, vagina, anus, rectum, and oropharynx)

Other male HPV-related (squamous cell carcinoma of the penis, anus, and rectum)

While most high-risk HPV infections are cleared from the body within two years in 90% of infected persons, the remaining 10% have a persistent infection.³ Persistent infections can ultimately lead to high-grade lesions and cancer an average of 5-14 years later if undetected and untreated. The length of time it takes persistent HPV infections to develop into cancer likely explains the increase in incidence rates of HPV-related cancers even after the introduction of the HPV vaccine in 2006.

There are rural/urban differences with regard to the trend in incidence over time for HPV-related cancers. As shown in **Figure B**, there was a distinctly higher annual average percent change in male oropharyngeal cancer incidence in rural areas when compared to more urban areas. Conversely, the decreasing annual average percent change in cervical cancer incidence was less in rural areas when compared to larger urban centers.

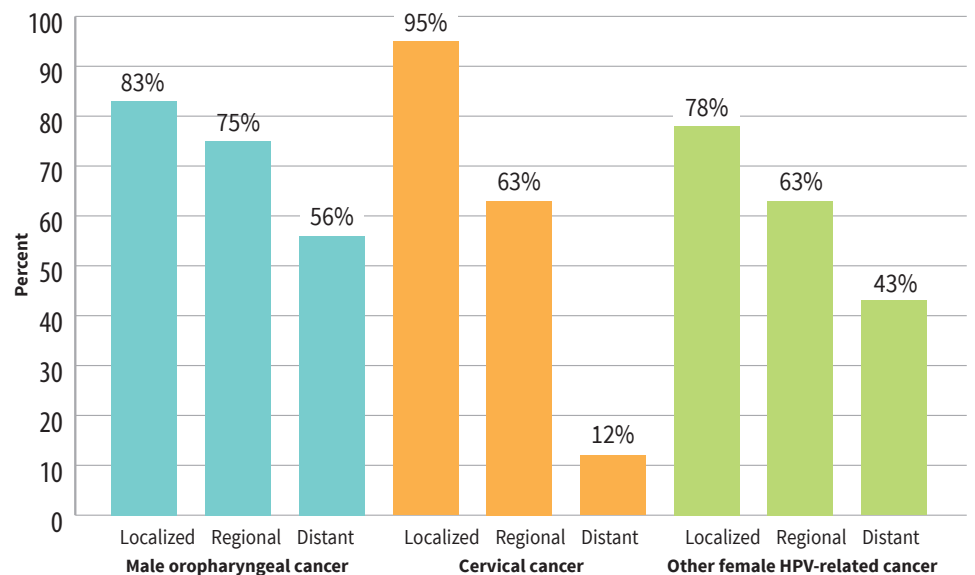
Figure C provides the 5-year relative survival of male oropharyngeal, cervical, and other female HPV-related cancer by stage in Iowa from 2008-2014. Localized stage means the cancer is only in the area where it started and has not spread. Regional stage means the cancer has spread to nearby tissues or lymph nodes. Distant stage means the cancer has spread to distant sites in the body, such as the lungs or liver.

Figure B Trends in HPV-related cancer incidence by geographic area, Iowa, 1997-2016

Population Density	Cervical cancer	Other female HPV-related cancer	Male oropharyngeal cancer
	Average annual % change (95% CI)*	Average annual % change (95% CI)	Average annual % change (95% CI)
Rural	-1.4 (-4.7, 2.0)	2.3 (-0.7, 5.5)	7.2 (4.4, 10.1)†
Small Urban	-1.1 (-2.2, 0)	3.4 (2.4, 4.5)†	4.2 (2.9, 5.6)†
Large Urban	-1.7 (-3.0, -0.4)†	2.0 (0.6, 3.4)†	3.7 (2.7, 4.8)†
State of Iowa	-1.5 (-2.5, -0.5)†	2.6 (1.9, 3.4)†	4.3 (3.5, 5.1)†

* CI=Confidence Interval; 95% CI means that one can be 95% confident that the true population mean is between the lower and upper values of the interval
 † Statistically significant difference from 0 (no change) at p-value < 0.05

Figure C 5-year relative survival of selected HPV-related cancers by stage, Iowa, 2008-2014



When the cancer is diagnosed at a localized stage, the 5-year relative survival for these cancers is very good (95% for cervical cancer, 83% for male oropharyngeal cancer, and 78% for other female HPV-related cancer). Differences were also seen in overall survival rates by geographic region. The 5-year relative survival rates for cervical, other female HPV-related cancer, and male oropharyngeal cancer were markedly lower in rural areas compared to small and large urban areas. Cervical cancer saw differences of 61% in rural areas compared to 73% in small urban areas, rates for female HPV-related cancer were 57% in rural areas and 68% in large urban centers, and male oropharyngeal rates were 64% in rural areas compared to 72% in large urban areas.

Screening and Prevention of HPV-related Cancers

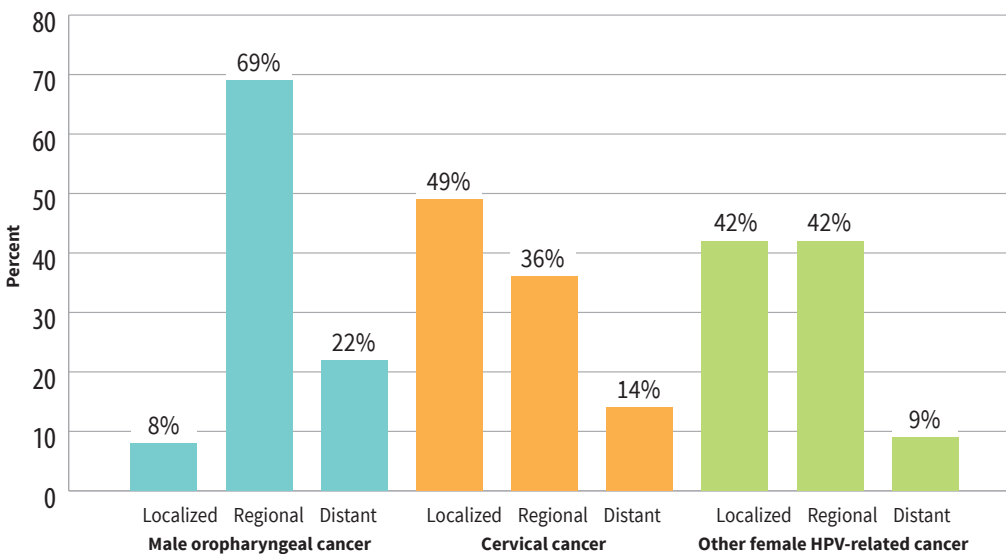
Cervical cancer is the only HPV-related cancer with a recommended and effective screening test. The Pap test (or Pap smear) has been available to women since the 1940s as a method to detect potentially pre-cancerous and cancerous processes in the cervix. The decrease in cervical cancer incidence rates for Iowa women is likely due to earlier treatment of disease detected through Pap testing.

In addition to the Pap test, patients can obtain a test that looks for the specific HPV viruses that can cause pre-cancerous cell changes. The United States Preventive Services Task Force recommends screening for cervical cancer in women 21 to 29 years with the Pap test every three years. For women 30 to 65 years, several options for screening are possible:

- 1) A Pap test only and, with normal results, repeating every three years,
- 2) An HPV test only and, with normal results, repeating screening tests every five years, or
- 3) An HPV test and Pap test, and if both results are normal, repeating screening every five years.⁴

Early detection of cancer at the localized stage is important for improving relative survival. **Figure D** provides the distribution of stage at diagnosis for patients diagnosed in Iowa between 2008 and 2014 for some HPV-related cancers. Almost half (49%) of all cervical cancer patients were diagnosed with localized disease. Yet, only 8% of male oropharyngeal patients were diagnosed with localized disease. **There is no approved, effective screening test for other HPV-related cancers such as oropharyngeal cancer.** Some dentists and doctors recommend to their patients, specifically those who routinely use tobacco or drink alcohol, to look in their mouths in a mirror every month to check for changes, like white patches, sores, or lumps. Regular dental check-ups that include an exam of the entire mouth are also encouraged for all patients as a way to detect oropharyngeal cancers at an early stage. However, although some precancers and cancers in this area can be found early during visual examinations, HPV lesions tend to be located on the posterior oral cavity, an area difficult to see.⁵ Thus, prevention of HPV infection and reducing the development of HPV lesions through vaccination is recommended as a way to reduce oropharyngeal and other HPV-related cancers.

Figure D Distribution of selected HPV-related cancers by stage at diagnosis, Iowa, 2008-2014



*%s do not add up to 100% because unstaged cancers are not included

HPV Vaccine

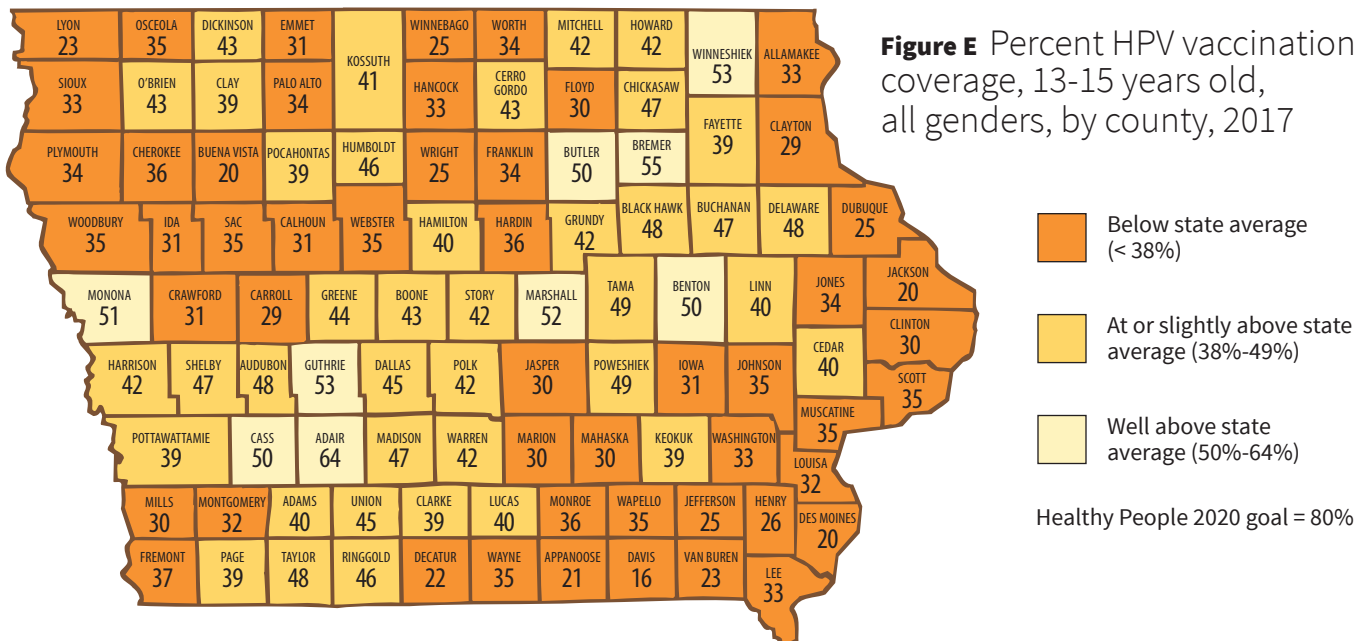
National studies indicate HPV is responsible for more than 90% of anal and cervical cancers, 75% of vaginal cancers, 70% of vulvar and oropharyngeal cancers, and 60% of penile cancers⁶, so HPV vaccination provides a powerful opportunity to prevent cancers. *When given before initial exposure to the virus, the most recently approved HPV vaccine provides almost 100% protection from nine HPV types, which makes it highly effective in preventing infection with the types of HPV that can cause cancer.*⁷

The first HPV vaccine was approved in 2006 with two additional vaccines approved in 2009 and 2014. For all adolescents, vaccines are given as a 2-dose series (separated by 6-12 months) if the series is initiated before age 15. If the series is begun at age 15, 3 doses of vaccine indicate a complete series. Current recommendations for HPV vaccination for males and females⁸ include:

- Routine vaccination for all children age 11-12 years. The vaccine can be administered as young as age 9.
- Catch-up vaccination is recommended for females age 13-26 years and males age 13-21 years who have not been vaccinated previously or who have not completed the series. Males age 22-26 years may be vaccinated.

As of 2017, less than 50% of adolescents in the US were fully vaccinated against HPV, far short of the Healthy People 2020 goal of 80% of adolescents aged 13-15 years. In Iowa in 2017, HPV vaccination rates increased from previous years; however, **only 38% of adolescents in Iowa aged 13-15 had received a complete series of HPV vaccine recommended for full protection.** This is much lower than the 76% of 13-15 year olds in Iowa who received the Tdap vaccine, which protects against tetanus, diphtheria, and pertussis, which demonstrates the crucial role providers play in improving the uptake of the HPV vaccine. Furthermore, a gender disparity exists in Iowa regarding HPV vaccination among 13-15 year olds with 42% of females having completed the HPV series compared to 36% of males.⁹ This is particularly important given the steady increase in male HPV-related oropharyngeal cancers and the lack of any effective screening method for those cancers.

Figure E provides a map of HPV vaccination rates in Iowa. In 2017, **over half (51) of the counties in Iowa had less than the state average in percentage of adolescents aged 13-15 who received a complete HPV vaccine series.** An additional 39 counties were either at or above the state average of 38% but still less than 50% coverage. In nine counties, over half of adolescents had received a completed series but no counties in Iowa had achieved the Healthy People 2020 goal of 80% coverage. There is much work to be done to increase HPV vaccination uptake in Iowa with the ultimate goal of reducing the numbers of people who develop HPV-related cancers.



Goals to Increase HPV Vaccine Uptake

The 2018 report to the President from the Chair of the President's Cancer Panel¹⁰ outlined three goals to increase HPV vaccine uptake in the US which are also valuable guides for increasing HPV vaccine rates in Iowa.

Goal 1. Reduce Missed Clinical Opportunities to Recommend and Administer the HPV vaccine

Campaigns to actively encourage healthcare providers to strongly recommend HPV for all eligible adolescents need to be developed and implemented and should include other non-physician providers.

In Iowa,

- Collaborative efforts between the Cancer Prevention and Control Research Network (CPCRN), the Iowa Department of Public Health (IDPH) Immunization Bureau, the American Cancer Society, and Iowa's Medicaid Managed Care Organizations (MCOs) have resulted in several pilot projects aimed at health care provider education to encourage HPV vaccination consistent with other recommended adolescent vaccines.
- IDPH, in partnership with the Iowa Cancer Consortium, has worked toward increasing HPV vaccination rates by promoting educational materials targeting all health care providers and using database tools to track provider-specific rates, offer feedback, and conduct reminder activities to providers with lower rates to encourage them to promote vaccination.
- Iowa Medicaid MCOs are promoting HPV vaccination by providing clinics with evidence-based interventions that can be implemented to increase vaccination rates.
- Scope of practice rules have recently changed to allow pharmacists in Iowa to administer the HPV vaccine to adolescents.

Goal 2. Increase Parents' Acceptance of HPV Vaccination

Through the use of trusted organizations such as state and local public health departments, develop and implement evidence-based communication strategies to provide clear and accurate information about the HPV vaccine to increase parental acceptance.

In Iowa,

- IDPH has a comprehensive communication campaign targeted to the public, with emphasis on reaching parents of children 11-18 years.
- Medicaid MCOs are promoting vaccination by sending reminder postcards to some Medicaid members whose children have not completed the series.

Goal 3. Maximize Access to HPV Vaccination Services

Ensure that HPV vaccination is affordable and convenient for all US adolescents; identify and address any barriers to access that may exist that could hinder efforts to improve HPV vaccination rates.

In Iowa,

- IDPH administers the Vaccines for Children (VFC) Program which provides the HPV vaccine to providers at no cost for children 9-18 years of age who are American Indian, insured through Medicaid, uninsured, or who have health insurance that does not cover immunizations.

Future Steps to Further Understand and Prevent HPV-related Cancers

Research continues to play a role in further understanding and developing methods to prevent HPV-related cancers. Research priorities in the coming years include:

- Establishing the natural history of oral HPV infections and develop tools to detect precancers.
- Identifying ways to harness social media to communicate about HPV and HPV vaccination.
- Determining efficacy and duration of protection of a single HPV vaccine dose.
- Understanding and addressing inequities among populations with high rates of HPV cancers, such as those seen between urban and rural populations in Iowa.



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Complete citation list can be found on page 15.

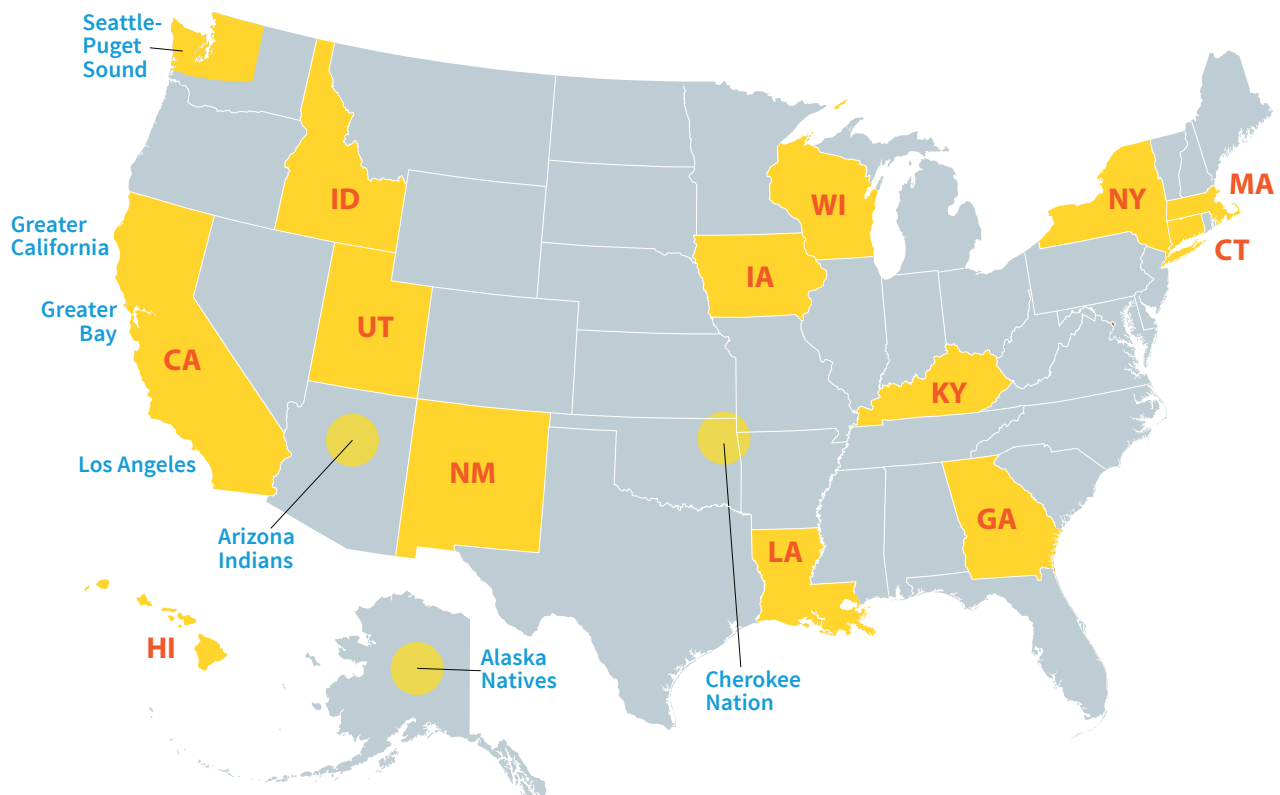
Research

The Surveillance, Epidemiology, and End Results (SEER) Program provides information on cancer statistics in an effort to reduce the cancer burden among the US population. SEER began collecting data on cancer patients on January 1, 1973 in the states of Connecticut, Iowa, New Mexico, Utah, and Hawaii and the metropolitan areas of Detroit and San Francisco-Oakland. Since then SEER expanded in 2018 and currently collects cancer incidence and survival data from the population-based cancer registries shown below, covering approximately 34% of the US population.

One of the most important goals of the SEER Program is to collect complete and accurate data on all cancers diagnosed among residents of the geographic areas covered by SEER Registries. The Iowa Cancer Registry is a population-based registry that records all cases of cancer in the state of Iowa. Registries routinely collect data on patient demographics, primary tumor site, tumor morphology and stage at diagnosis, first

course of treatment, and follow-up for vital status. Registries play a critical role in cancer surveillance, which tells us where we are in the efforts to reduce the cancer burden.

Surveillance data may also serve as a foundation for cancer research. After the SEER Program receives the de-identified information—free of any identifiers of cancer patients—it makes the data available to researchers and the public who are looking for cancer statistics including incidence (new cases), mortality (cancer deaths), survival, and prevalence (people living with cancer). The SEER research data include SEER incidence and population data associated by age, sex, race, year of diagnosis, and geographic areas, including SEER registry and county. SEER releases new research data every spring based on the previous November's submission of data. Contact information for questions regarding research opportunities utilizing Iowa data can be found on the Iowa Cancer Registry website, <https://shri.public-health.uiowa.edu/>.



SEER disseminates data in fact sheets, reports, publications, research databases, and websites.

Here are some links to published data as well as interactive tools to generate cancer data.

Annual Report to the Nation on the Status of Cancer

update of rates for new cases and deaths as well as trends for the most common cancers in the United States, https://seer.cancer.gov/report_to_nation/.

Cancer Statistics Review

the most recent cancer incidence, mortality, survival, prevalence, and lifetime risk statistics, https://seer.cancer.gov/csr/1975_2015/.

Cancer Stat Facts

statistical summaries for a number of common cancer types, with links to additional resources from NCI including risk factors, treatment, and clinical trials, <https://seer.cancer.gov/statfacts/>.

Cancer Trends Progress Report

summarizes the nation's advances against cancer in relation to Healthy People targets set forth by the Department of Health and Human Services, <https://progressreport.cancer.gov/>.

Iowa Cancer Registry interactive data tool

allows users to compute counts, incidence and mortality rates for specific cancer sites by year of diagnosis, gender, race (white/black), and county, <https://shri.public-health.uiowa.edu/cancer-data/data-tools/>.

Twitter @NCICancerStats

SEER*Stat Software is a powerful PC tool to view cancer records and to produce statistics for studying the impact of cancer on a population. SEER*Stat software is distributed with the SEER Research Data and one must have approved access to the data before using the software, <https://seer.cancer.gov/seerstat/>.

State Cancer Profiles characterize cancer burden in a standardized manner to motivate action, integrate surveillance into cancer control planning, characterize areas and demographic groups, and expose health disparities. The focus is on cancer sites with evidence-based control interventions, <https://statecancerprofiles.cancer.gov/>.



The Iowa Cancer Registry (ICR) is participating in over 80 open studies during 2019 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 disease (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 275 publications from this study linked to PubMed are available at the website.

Early Life Exposures In Agriculture

The Agricultural Health Study studied farmers and their spouses in North Carolina and Iowa. It also included people who worked with pesticides in Iowa. They answered a questionnaire and gave data about their children born since 1975. Researchers want to link this data to public data like birth and death certificates and to study how early life exposures to farms are linked to cancer and other adverse health outcomes. More information is provided at <https://clinicaltrials.gov/ct2/show/NCT02743481>.

Patterns Of Care Studies

SEER Patterns of Care Studies are conducted to satisfy a US 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/>.

SEER-Medicare

In the early 1990s, the cancer incidence and survival data from the ICR was 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 1,800 publications have resulted from this linked data set, including over 130 during 2018, listed at <http://healthservices.cancer.gov/seermedicare/overview/publications.html>.

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://healthcaredelivery.cancer.gov/seer-mhos/> for more details). The SEER-CAHPS linked data allows for research applications focused on patient experiences with care across health plan types (see <https://healthcaredelivery.cancer.gov/seer-cahps/> for more details).

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 US 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-clis/>.

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 US transplant recipients with information on cancer from 17 US 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

Adding Patient And Provider Viewpoints to Rectal Cancer Practice Variation Data

It has been shown that only a small proportion of Iowa patients with rectal cancer receive treatment from highly-experienced surgeons, despite the evidence indicating better survival and sphincter preservation rates are achieved by these experienced surgeons. The goal of this project is to identify 1) patient factors that affect choice of surgeon and hospital, and 2) physician/system factors that affect referral pathways; these


can inform interventions to better match patients to surgeons, potentially improving health outcomes.

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.

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