CANCER IN IOWA

2021

IOWA
College of Public Health

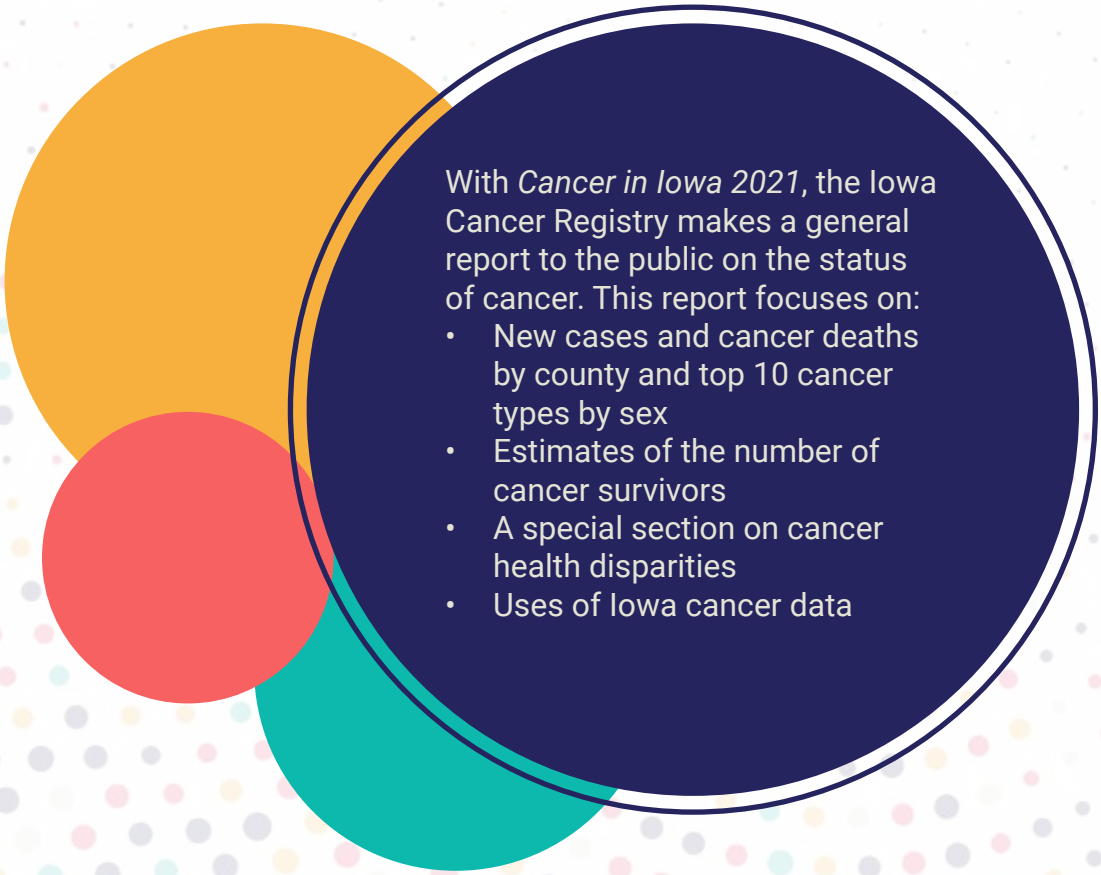
State Health Registry of Iowa/Iowa Cancer Registry

Two in five Iowans will be diagnosed with cancer in their lifetimes. Cancer is a major burden in Iowa and throughout the US. Reducing the nation's cancer burden requires the cooperation of many people, including providers, patients, researchers, public health professionals, policy makers and advocates, among others. In efforts to reduce the burden of cancer, it is imperative to have access to high quality data. 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 Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI), and is currently one of 21 US registries providing data. Iowa represents rural and Midwestern populations, and the ICR provides data representative of this population that is included in many NCI publications, national estimates, and projections of cancer burden throughout the US.

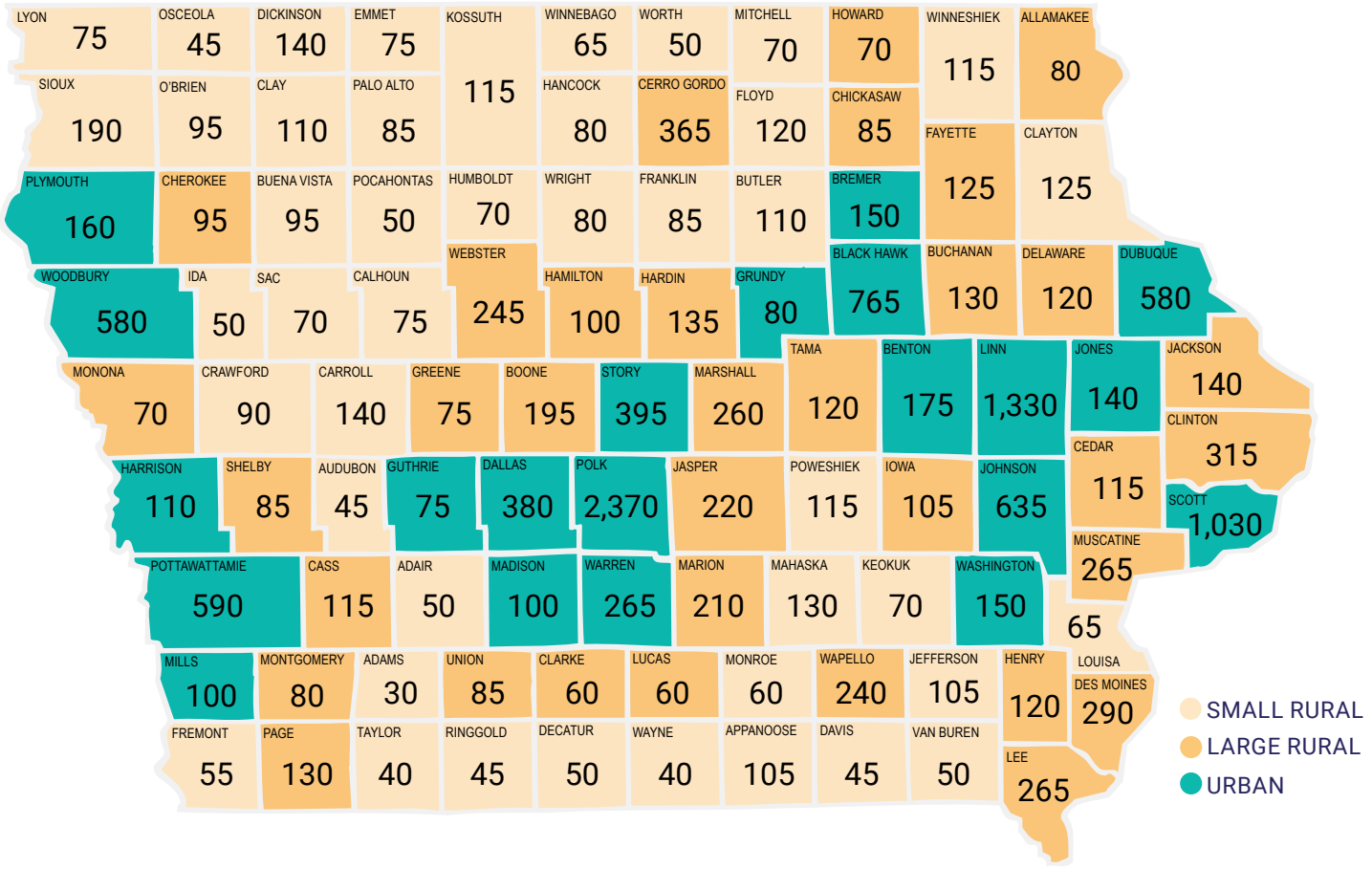
Maintaining the confidentiality of patient, provider, and hospital data located in the ICR is of paramount importance. It is the responsibility of the ICR to maintain a balance between the need to protect the collected data, while providing researchers and others with access to the information necessary to conduct studies to help reduce the burden of cancer. To meet this responsibility, the ICR has policies and procedures related to research uses, reporting, and release of Iowa cancer data to ensure its proper use and safeguard the confidentiality of patients, providers, 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, with additional funds provided through the University of Iowa and the State of Iowa. The ICR and its high-quality database have attracted research projects and funds to Iowa from other federal agencies and foundations.



Estimates for New Cancers for 2021

In 2021, an estimated 18,900 new, invasive cancers (and in situ bladder cancers) will be diagnosed among Iowa residents. Estimates of new cancers are given by county of residence with shading to indicate urban/rural status, and the top 10 cancer types are listed 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

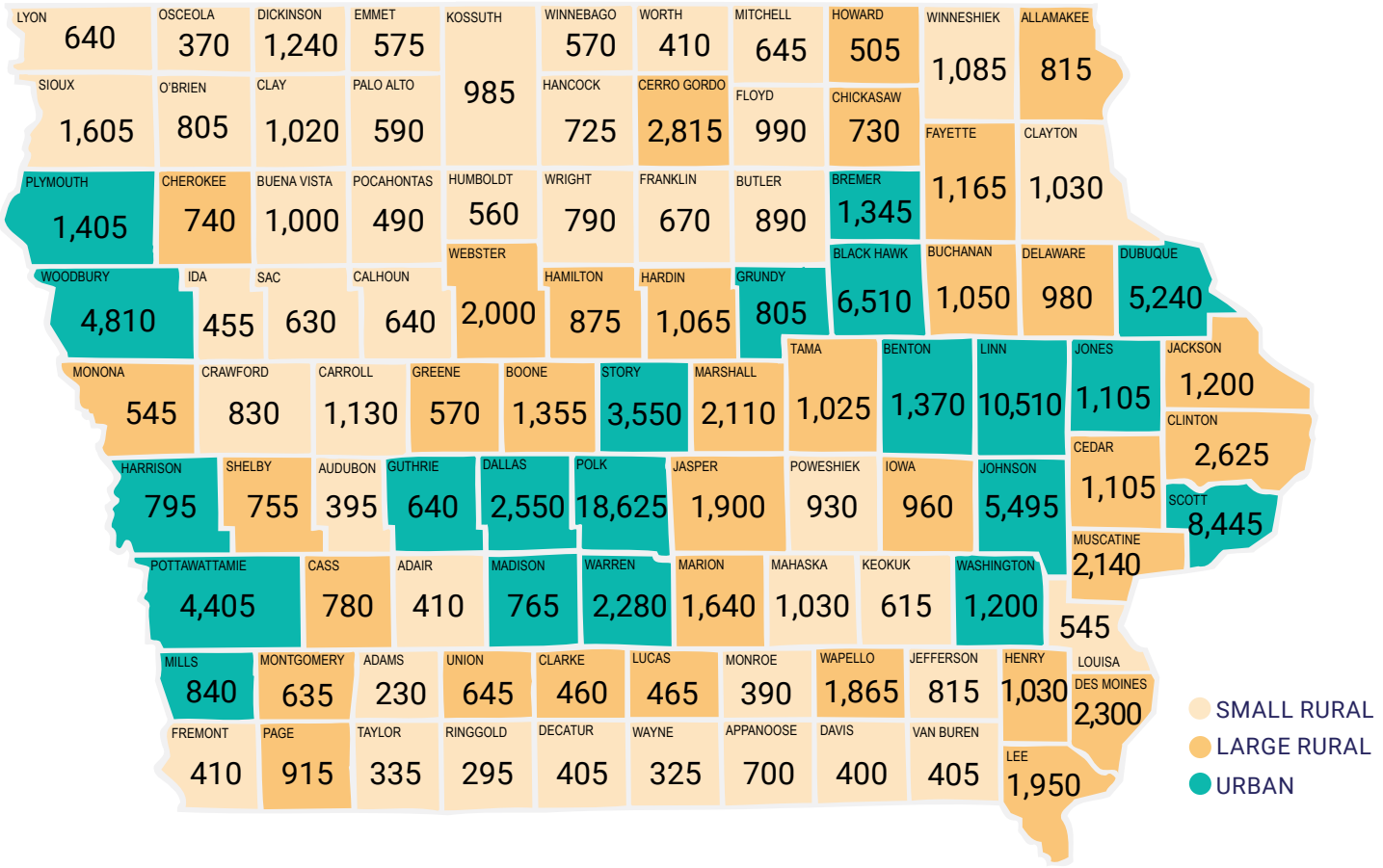
TYPE	# OF CANCERS	% OF TOTAL
Breast	2,700	29.4
Lung	1,160	12.6
Colon and rectum	800	8.7
Uterus	630	6.9
Skin melanoma	500	5.4
Thyroid	350	3.8
Non-Hodgkin lymphoma	330	3.6
Kidney and renal pelvis	270	2.9
Pancreas	270	2.9
Leukemia	260	2.8
All others	1,930	21.0
TOTAL	**9,200**	

NEW CANCERS IN MALES

TYPE	# OF CANCERS	% OF TOTAL
Prostate	2,450	25.3
Lung	1,300	13.4
Colon and rectum	800	8.3
Bladder	660	6.8
Skin melanoma	570	5.9
Kidney and renal pelvis	480	4.9
Non-Hodgkin lymphoma	430	4.4
Leukemia	400	4.1
Oral cavity and pharynx	370	3.8
Pancreas	300	3.1
All others	1,940	20.0
TOTAL	**9,700**	

Living with Cancer

Follow-up activities 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 1973-2016, there are an estimated 154,410 cancer survivors (defined as people who are currently living with or previously having cancer), of whom 83,305 are females and 71,105 are males. Survivorship by county of residence and urban/rural status and the top 10 cancer types by sex are shown below.



FEMALE SURVIVORS

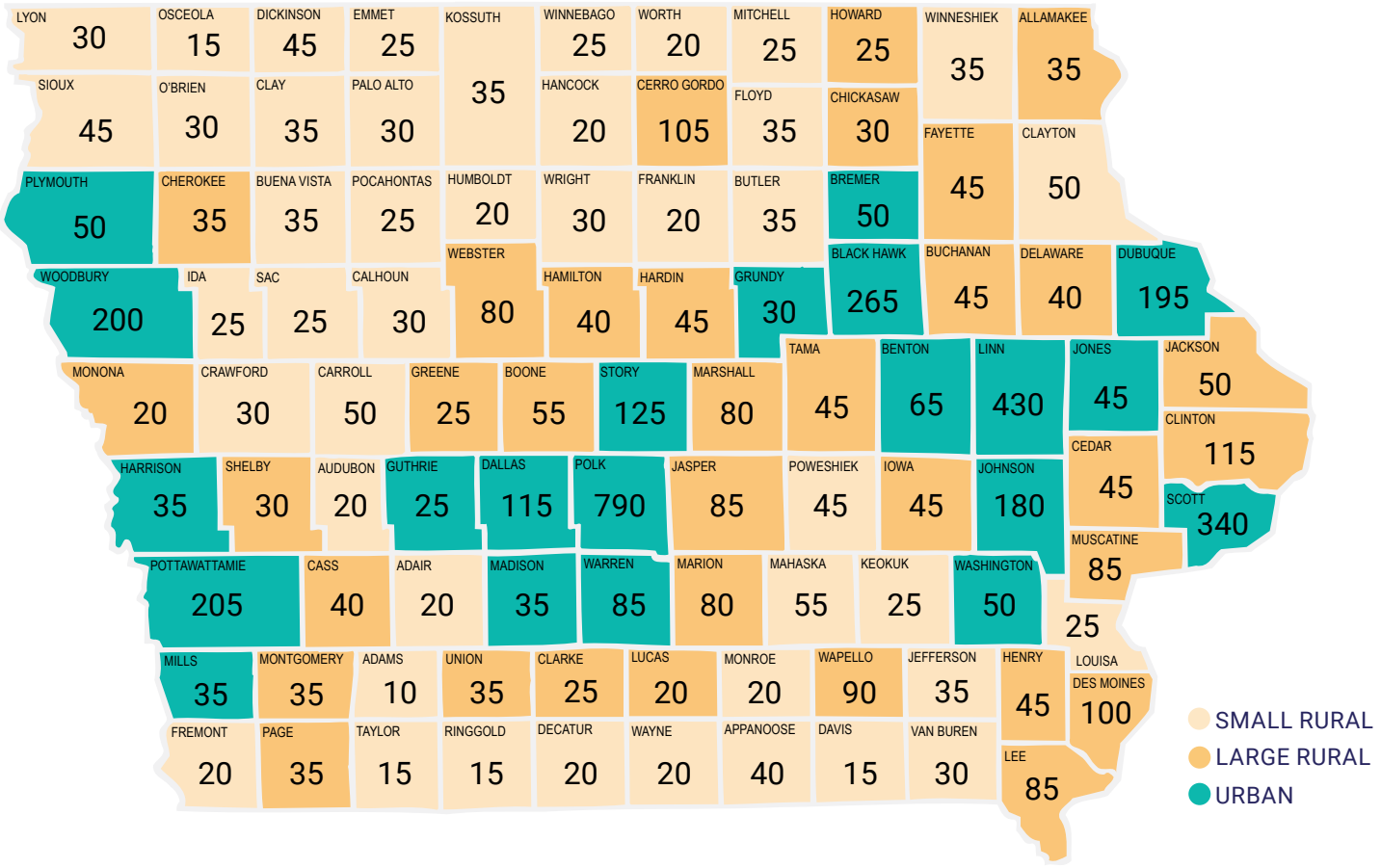
TYPE	# OF SURVIVORS	% OF TOTAL
Breast	34,180	41.0
Uterus	8,480	10.2
Colon and rectum	7,950	9.5
Thyroid	6,050	7.3
Skin melanoma	5,745	6.9
Non-Hodgkin lymphoma	3,535	4.2
Lung and bronchus	3,215	3.9
Cervix	2,405	2.9
Kidney and renal pelvis	2,405	2.9
Ovary	2,205	2.6
All others	7,135	8.6
TOTAL	**83,305**	

MALE SURVIVORS

TYPE	# OF SURVIVORS	% OF TOTAL
Prostate	28,370	39.9
Colon and rectum	7,920	11.2
Bladder	5,855	8.2
Skin melanoma	5,655	8.0
Non-Hodgkin lymphoma	3,935	5.5
Kidney and renal pelvis	3,610	5.1
Oral cavity and pharynx	2,965	4.2
Leukemia	2,865	4.0
Lung and bronchus	2,795	3.9
Testis	2,650	3.7
All others	4,485	6.3
TOTAL	**71,105**	

Estimates for Cancer Deaths for 2021

Heart disease and cancer are the leading causes of death in Iowa and the US. In 2021, an estimated 6,400 Iowans will die from cancer. These projections are based upon mortality data provided by the Iowa Department of Public Health. Estimates of cancer deaths are presented by county of residence with urban/rural status and the top 10 cancer types by sex are shown below.



CANCER DEATHS IN FEMALES

TYPE	# OF DEATHS	% OF TOTAL
Lung	720	24.0
Breast	390	13.0
Colon and rectum	280	9.3
Pancreas	230	7.7
Ovary	150	5.0
Uterus	120	4.0
Leukemia	100	3.3
Non-Hodgkin lymphoma	100	3.3
Brain	80	2.7
Multiple myeloma	60	2.0
All others	770	25.7
TOTAL	**3,000**	

CANCER DEATHS IN MALES

TYPE	# OF DEATHS	% OF TOTAL
Lung	820	24.1
Prostate	370	10.9
Colon and rectum	290	8.6
Pancreas	240	7.1
Leukemia	160	4.7
Esophagus	150	4.4
Non-Hodgkin lymphoma	140	4.1
Bladder	130	3.8
Liver	130	3.8
Kidney and renal pelvis	120	3.5
All others	850	25.0
TOTAL	**3,400**	

Why It Is Important to Consider Cancer Differences by Race/Ethnicity

Race/ethnicity is a social construct, which means that it is something that exists because our society created the construct as a tool to group people. Race/ethnicity is not biological, meaning there is no gene or cluster of genes common to only Black people or White people or Hispanic people. Race/ethnicity is therefore not in and of itself a risk factor for cancer, though it is often listed as one. However, inequalities in socioeconomic status, including factors such as income, education level, occupation, and access to healthcare are important social factors that may differ by race/ethnicity and therefore contribute to cancer health disparities. The socioeconomic status of individuals and neighborhoods can affect environmental (e.g., housing, exposure to hepatitis viruses), psychological (e.g., stress), and behavioral (e.g., tobacco and alcohol use) factors that influence health. One recent study estimated that eliminating socioeconomic disparities could prevent 34% of cancer deaths among all US adults ages 25 to 74 (1).

Even after accounting for socioeconomic status, institutional and structural racism play an important role in causing inequalities, and they can also directly influence health outcomes. For example, residential segregation (the physical separation of two or more groups) can make it harder for some racial/ethnic groups to engage in healthy behaviors, such as accessing healthy foods, spaces for physical activity, and health care. Inequalities in access to preventive care (e.g., smoking cessation), screening services (e.g., colonoscopy and mammography), and the quality of care received are important modifiable clinical factors that contribute to cancer health disparities. Quality is often measured based on whether individuals receive guideline-recommended care and whether they are treated at a facility that has the experience and infrastructure to care for cancer patients. Research has shown that racial and ethnic minority patients often receive lower quality care compared to White patients (2-3). Factors that contribute to these differences among minority populations include lower representation in clinical trials/studies, mistrust in the healthcare system, treatment from less experienced providers/hospitals, and health care providers' beliefs and biases. Also, health insurance status is one of the most important factors determining access to quality cancer care. Individuals who lack health insurance have a higher risk of poor outcomes from cancer compared with those who are insured (4-8), and racial and ethnic minorities have lower rates of health insurance compared to the White population.

Key Terms Used in This Section:

Institutional & Structural Racism

Institutional Racism
Policies, practices, and procedures that work better for White people than for people of color; sometimes unintentionally or inadvertently

Structural Racism
A history and current reality of institutional racism across all social, economic, and environmental institutions, combining to create a system that negatively impacts communities of color

There are some examples of racial/ethnic differences in cancer burden that researchers cannot yet fully explain. One example is prostate cancer. Black males are at higher risk of developing prostate cancer compared to other racial/ethnic groups and tend to have more aggressive disease. Another example is female breast cancer. Black women are more likely to be diagnosed with triple-negative breast cancer, which is more biologically aggressive than other sub-types and has a poorer prognosis (9). Possible explanations may include different risk exposures, interactions between genes and environmental exposures, and health care access and utilization, among others. It is critical for researchers to gain a clearer understanding of the drivers of these differences to develop interventions that can improve cancer-related health outcomes. The focus of this report is to describe cancer disparities in terms of the differences in rates of new cancer cases and cancer deaths between racial/ethnic groups in Iowa.

Cancer Disparities in Iowa

Key Terms Used in This Section: Race & Ethnicity

Racial/Ethnic Groups
Socially defined identity/community groups with shared histories

For the purposes of this report, racial/ethnic groups include Non-Hispanic White, Non-Hispanic Black, Non-Hispanic American Indian/Alaska Native, Non-Hispanic Asian/Pacific Islander, and Hispanic—any race.

Key Points

- Advancing age is the most important risk factor for cancer. The incidence rate of cancer in a racial/ethnic group with a younger population will be lower than in a group with an older population.
- While the White population in Iowa has higher rates of cancer because it is older, Iowa's Black population bears the greater burden of cancer when we account for their differing age distribution.
- Iowa's Black population has the highest cancer incidence rates of all racial/ethnic groups for those ages 50-79 years, whereas Iowa's White population has the highest rate among those 80 and older. Cancer is striking the Black population at a much younger age compared to the White population.
- Aside from suicide and liver disease, Iowa's Black population has the highest mortality rate in every single major cause of death, including cancer. Consequently, the life expectancy of the Black population in Iowa is only 74.8 years compared to 79.3 years for the White population.
- Some of the largest differences in mortality between Iowa's Black and White populations include prostate, lung, and liver cancers. Iowa's Black population also has higher colorectal and breast cancer mortality rates compared to other racial/ethnic groups.
- Black males and females have higher cancer mortality rates compared to all other racial/ethnic groups. Black males have experienced the greatest decrease in cancer mortality over the past few decades.
- Cancer mortality rates are declining for each racial/ethnic group, and the difference is narrowing between Iowa's Black and White populations.

As shown on the left side of **Table 1**, the Hispanic population is the largest racial/ethnic minority group in Iowa representing 6% of the population. Iowa's Black population makes up almost 4% of the population and the Asian and Pacific Islander population makes up almost 3%. These groups grew by 133%, 93%, and 122%, respectively, between 2000 and 2018. **Table 1** compares the number and percent of the Iowa population by racial/ethnic group in 2018 to the number of and percent of the population of Iowans who were diagnosed with cancer in 2018. The cancer data come from the Iowa Cancer Registry. **It is important to note that Iowa Cancer Registry race and ethnicity data are collected from the medical record, which may be self-reported by a patient or noted by a patient's provider. In the latter case, it may not accurately reflect the individual's racial/ethnic identity as the selection was left to a provider's interpretation of the patient's identity**.

Table 1. Population of Iowa Residents and Iowa Cancer Cases by Race/Ethnicity

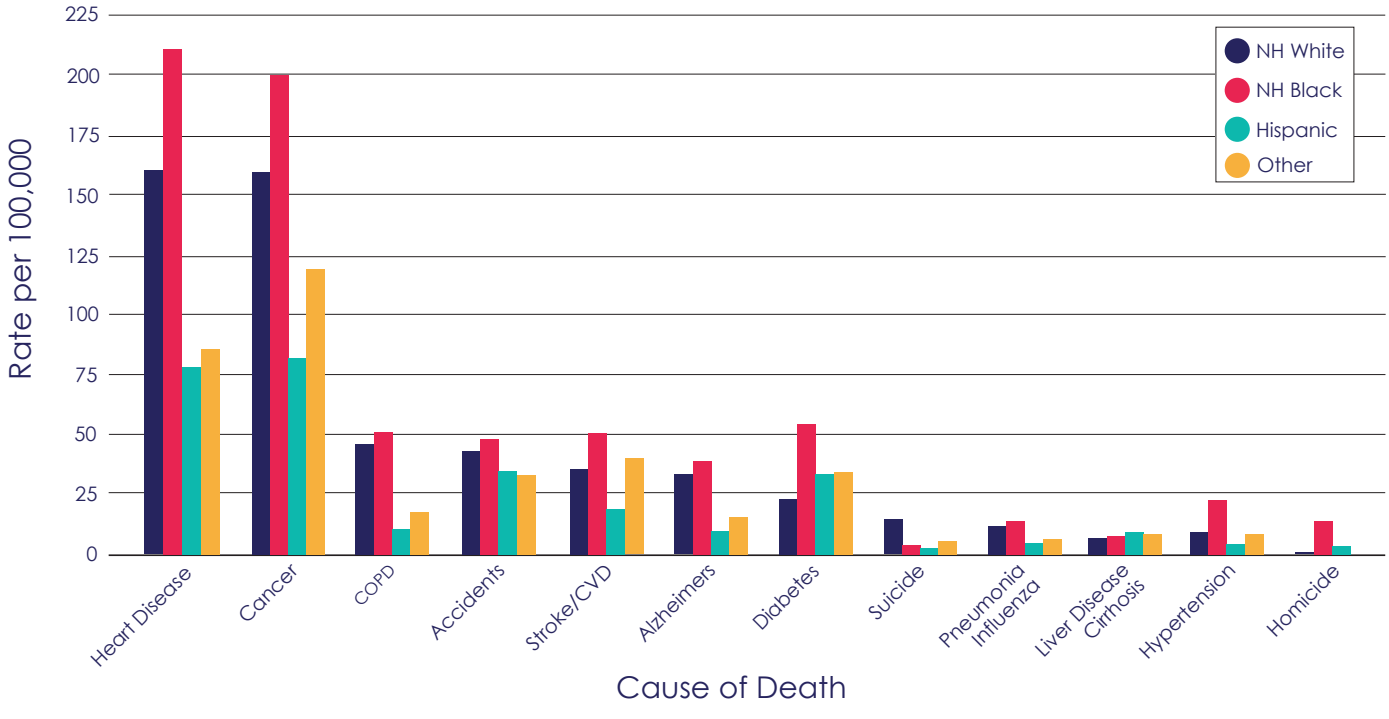
	State of Iowa 2018		Iowa Cancer Registry 2018	
	N	%	N	%
Total Population	3,156,145		18,166	
NH White	2,695,583	85.4	17,179	94.6
NH Black	113,562	3.6	413	2.3
Hispanic, any race	191,473	6.1	239	1.3
NH Asian/Pacific Islander	82,588	2.6	147	0.8
NH American Indian/Alaska Native	9,710	0.3	27	0.1
Other	4,000	0.1	7	0.0
Unknown	0	0.0	154	0.8

NH – Non-Hispanic

Those who were recorded as being Hispanic were categorized as Hispanic regardless of any other race that was also recorded. Everyone else was categorized as being non-Hispanic (NH) White, Black, American Indian/Alaska Native, or Asian/Pacific Islander. Less than 1% of people diagnosed with cancer in 2018 were documented as identifying as more than one race. These cases were classified as their non-White race/ethnicity per the standardized classification system used across cancer registries. At times it was necessary to combine multiple groups together into an 'Other' category to avoid showing small numbers that could compromise privacy/confidentiality.

The information in **Table 1** suggests the percent of Iowa cancer cases who are White is larger than the percent of Iowa residents who are White, whereas the opposite is true for all other racial/ethnic groups. As we will discuss more on the next page, one major reason for this is because the White population in Iowa is older than all of the other populations, and cancer is more common among people of older ages. It is noteworthy that aside from suicide and liver disease, Iowa's

Figure 1. Age-Adjusted Mortality Rates by Cause of Death and Race/Ethnicity, Iowa, 2014-2018



Black population has the highest mortality rate in every single major cause of death (**Figure 1**), including cancer. Consequently, the life expectancy of the Black population in Iowa is only 74.8 years compared to 79.3 years for the White population (10). This could mean that many Black people die of some other cause before they ever develop cancer or are unable to access cancer services to diagnose their cancer before they die of another cause. The Hispanic population, on the other hand, has the lowest mortality rate in several of the major causes of death, including cancer. Despite having greater challenges including high poverty rates, poor healthcare access, and high rates of obesity, the Hispanic population in Iowa generally experiences better health and lives longer (life expectancy = 81.8 years) than non-Hispanic populations (10).

Key Terms Used in This Section:
Incidence & Mortality

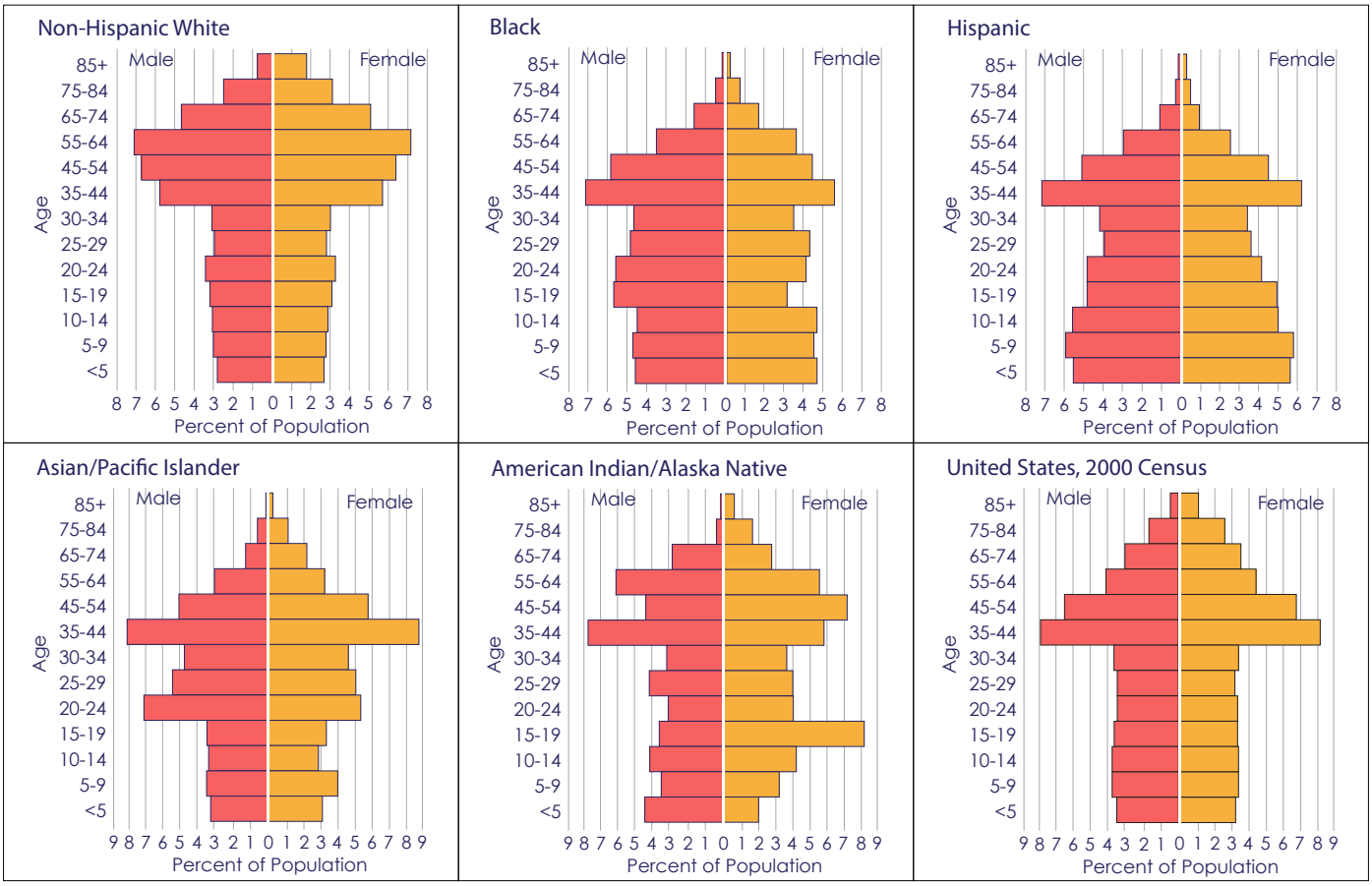
Incidence
Number of *new cancers* diagnosed during a specified time divided by the population at risk for developing cancer

If a county in Iowa has 100 cases in a population of 50,000 people, the rate would be 100/50,000 or .002, expressed as 200 per 100,000 people

Mortality
Number of *cancer deaths* that occurred during a specified time divided by the population

One issue that must be considered when comparing cancer rates between different racial/ethnic groups is that some groups tend to be much older than others. According to the National Cancer Institute, advancing age is the most important risk factor for cancer. Thus, the incidence rate of cancer in a racial/ethnic group with a younger population will be lower than in a group with an older population. **Figure 2** shows how the age/sex patterns differ by racial/ethnic group. The White population has a narrow base (fewer people in the younger age groups) and a wider top (more people in the older age groups) compared to the Black and Hispanic populations. When compared to the US population (shown in bottom right corner), Iowa has more of its people in the older age groups as reflected most by the non-Hispanic White population.

Figure 2. Age Distribution by Race/Ethnicity*, Iowa, 2018 5-year Estimates



*American Community Survey data do not separate Hispanic and non-Hispanic for Black, Asian/Pacific Islander, and American Indian/Alaska Native

Figure 3. Crude Cancer Incidence Rates by Race/Ethnicity, All Sites, Male & Female, Iowa, 1994-2018

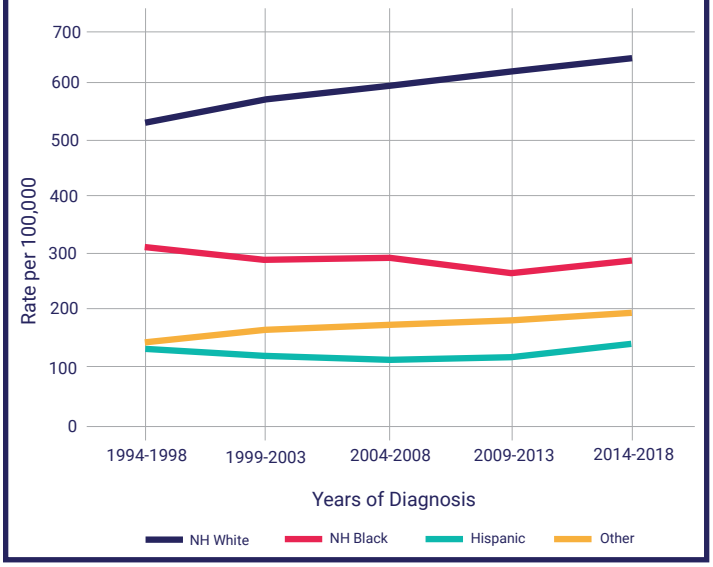


Figure 4. Age-Adjusted Cancer Incidence Rates by Race/Ethnicity, All Sites, Male & Female, Iowa, 1994-2018

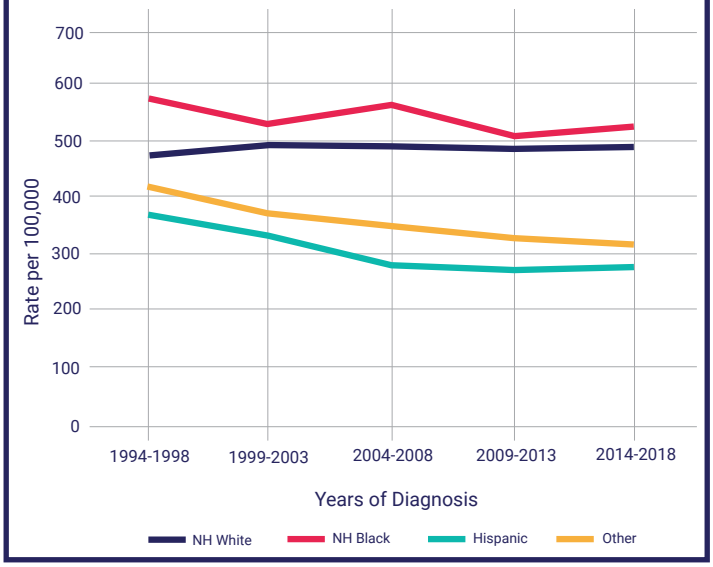
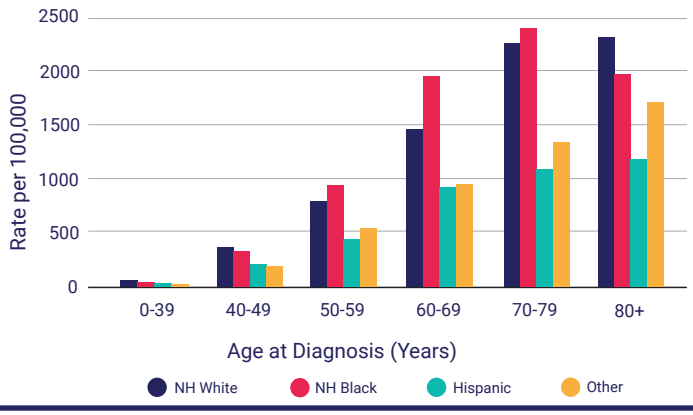


Figure 3 shows the actual cancer incidence rates for the racial/ethnic populations in the state of Iowa from 1994-2018. These rates are called "crude rates" because they are a true reflection of the population, and do not account for differences in age distributions. The crude rates show that Iowa's White population has a higher cancer rate compared to other racial/ethnic groups, which is expected since they have a larger population in the older age groups. However, the purpose of this report is to compare differences in cancer rates between racial/ethnic groups among people of similar ages. A process called age-adjustment was therefore used to allow populations with different age distributions to be fairly compared. The age-adjusted incidence rates in **Figure 4** show a much different pattern than in **Figure 3**, with the Black population having the highest age-adjusted cancer incidence rate. The cancer incidence rates have been declining since the 1994-1998 time period in all groups with the exception of the White population. The key takeaway from these graphs is that while the White population in Iowa has higher rates of cancer because it is older, Iowa's Black population bears the greater burden of cancer when we account for their differing age distribution.

Figure 5. Cancer Incidence Rates by Race/Ethnicity and Age at Diagnosis, All Sites, Male & Female, Iowa, 1994-2018



Examination of cancer incidence rates by racial/ethnic group and age at diagnosis (**Figure 5**) displays more concerning differences. Rates of cancer incidence are fairly similar across racial/ethnic groups in the 0-39 and 40-49 age ranges, but larger differences begin to emerge thereafter. Iowa's Black population had the highest cancer incidence rates of all racial/ethnic groups for the 50-59, 60-69 and 70-79 year age ranges, whereas Iowa's White population had the highest rate among those 80 and older. This shows that cancer is striking the Black population at a much younger age compared to the White population. The Hispanic population, on the other hand, has the lowest cancer incidence rates across all age groups.

Figure 6. Age-Adjusted Mortality Rates for All Malignant Cancers by Race/Ethnicity, Male & Female, Iowa, 1994-2018

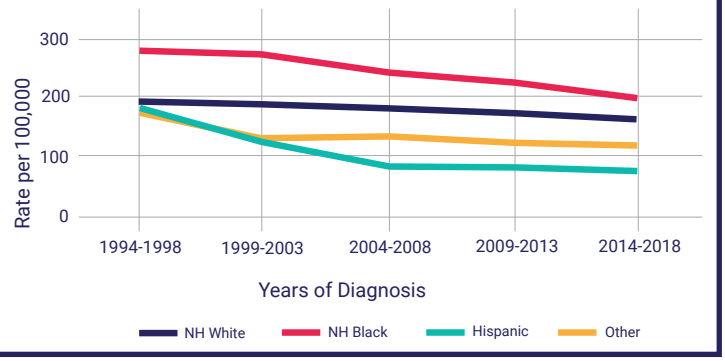
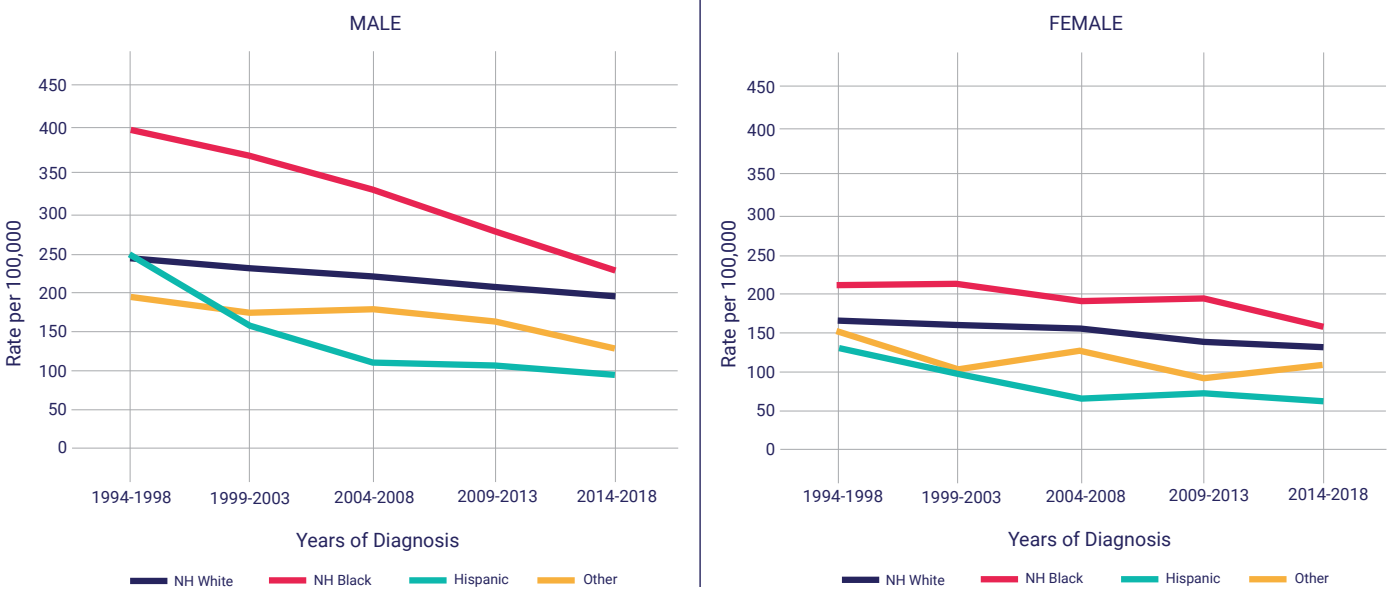


Figure 6 shows the Black population in Iowa had the highest overall age-adjusted cancer mortality (death) rate of any racial/ethnic group since the 1994-1998 time period. The cancer mortality rates are declining for each group, and the difference is narrowing between Iowa's Black and White populations. Cancer mortality rates by racial/ethnic group are shown separately for males and females in **Figure 7**. Per the standardized classification system used across cancer registries, information about the patient's sex assigned at birth is collected from the medical record and recorded as male, female, or other. This information may be self-reported by a patient or noted by a patient's provider based on their previous medical record. The Registry does not collect information on the gender identity of patients, and the way patients get classified could differ from the way they identify or from their sex assigned at birth, depending on who reported the information. Black males have historically had much higher cancer mortality rates compared to all other racial/ethnic groups, and much higher cancer mortality rates compared to Black females. Black males have experienced

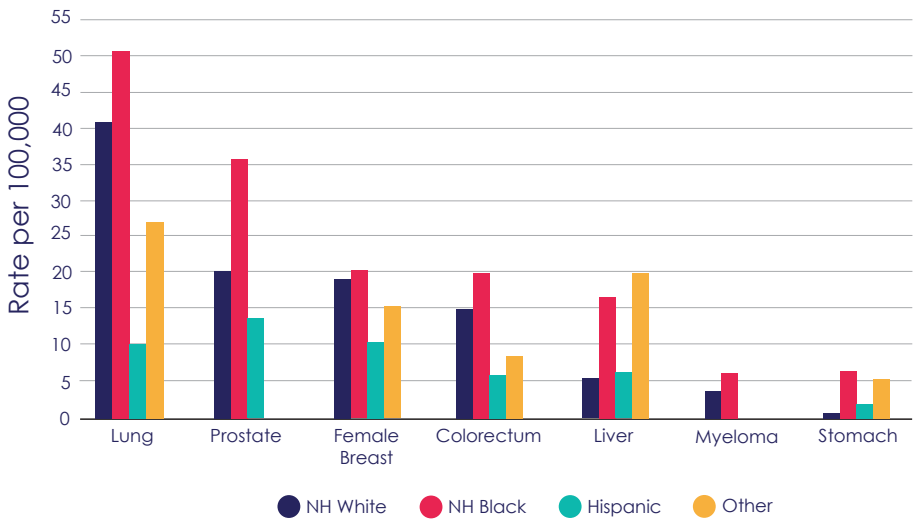
Figure 7. **Age-Adjusted Mortality Rates for All Malignant Cancers by Race/Ethnicity and Sex, Iowa, 1994-2018**



the greatest decrease in cancer mortality from 1994-1998 to 2014-2018. Black females have also had the highest mortality across all time periods, but the difference between rates among Black and White females was smaller than it was for males. Hispanic males and females had cancer mortality rates that were similar to White males and females in the 1994-1998 time period, but then experienced much larger decreases over time and had substantially lower rates in the 2014-2018 time period.

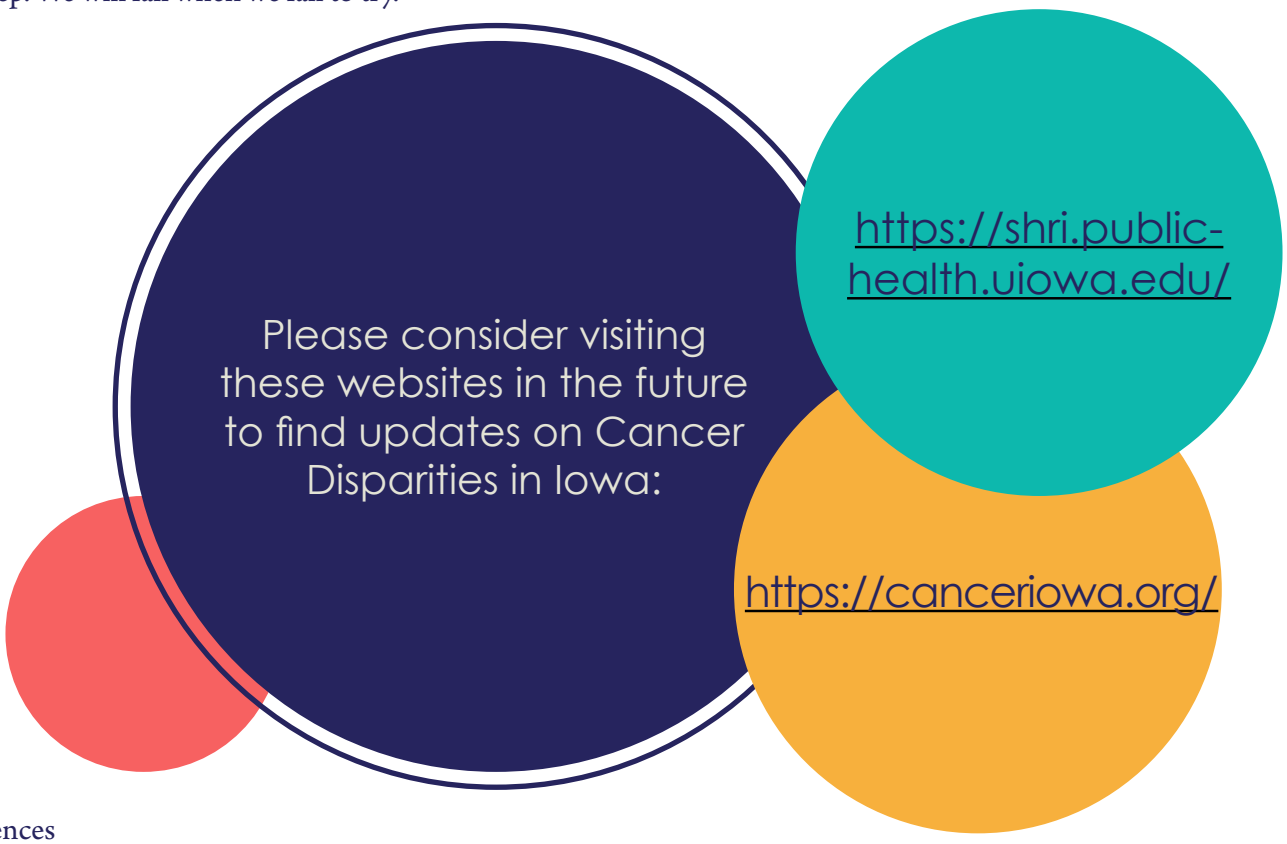
Figure 8 shows mortality rates by racial/ethnic groups for several of the top cancers in Iowa (lung, prostate, female breast, colorectum, liver, myeloma, and stomach). Some of the largest differences in mortality between Iowa's Black and White populations include prostate, lung, and liver cancers. Iowa's Black population also has higher colorectal and breast cancer mortality rates compared to other racial/ethnic groups. While the breast cancer mortality rate is only slightly higher among Black females compared to

Figure 8. **Age-Adjusted Mortality Rates by Cancer Site and Race/Ethnicity, Iowa, 1994-2018**



White females, it is important to consider that the breast cancer incidence rate is higher among White females. In other words, Black females get breast cancer less often than White females but die from it more often. Liver and stomach cancers are among the very few cancer sites for which the Hispanic population have higher mortality rates than the non-Hispanic White population.

This report serves as a first step in documenting the highly concerning racial/ethnic disparities in cancer in Iowa. We are planning ongoing analyses to further describe these disparities so that policymakers, public health practitioners, health care providers, community and advocacy groups, researchers and the people of Iowa can carry out the hard work it will take to eliminate these disparities. In the words of Rosa Parks, "To bring about change, you must not be afraid to take the first step. We will fail when we fail to try."



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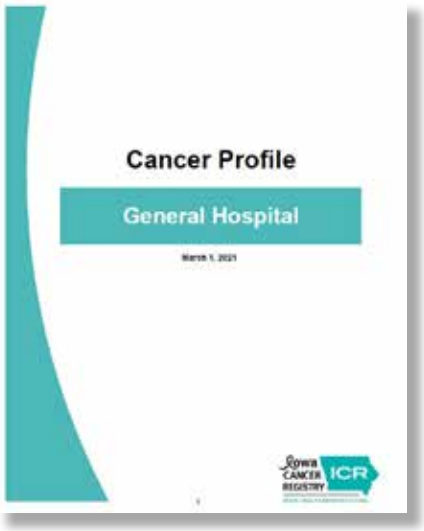
Cancer Profile Reports



The Iowa Cancer Registry can use the data it collects to help communities and hospitals better understand the burden of cancer in their population and allow them to plan for needed services.

If you are interested in a community or hospital cancer profile report, please contact **Mary Charlton** at mary-charlton@uiowa.edu.

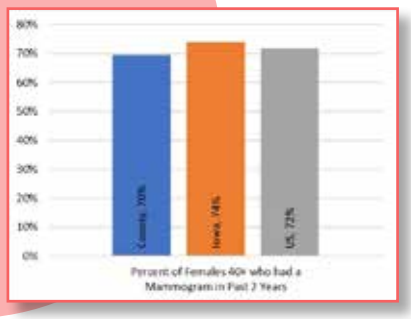
Table of patient demographics in the geographic area of interest

		N	%
Age at diagnosis (in years)	0-39	952	6%
	40-49	1159	8%
	50-59	2661	18%
	60-69	4473	30%
	70-79	3558	23%
	80+	2357	16%
Gender	Male	7603	50%
	Female	7557	50%
Race	White	13931	92%
	Other	1229	8%
Marital status	Married	8532	56%
	Unmarried/unknown	6628	44%
Insurance	Private	5046	33%
	Medicaid	849	6%
	Medicare	6987	46%
	IHS/Military/TRICARE/VA	427	3%
	Uninsured/Unknown	1851	12%
Stage at diagnosis	Stage 0	391	3%
	Stage 1	4756	31%
	Stage 2	2545	17%
	Stage 3	1829	12%
	Stage 4	2700	18%
	Stage Unknown	2934	19%

Number of new cancer diagnoses in the geographic area of interest, and information about the services received (surgery, chemotherapy, or radiation)

	Total	Received Surgery N	%
Total	13,506	8,120	60%
County A	2,074	1,188	57%
County B	1,727	1,080	63%
County C	3,570	2,223	62%
County D	6,135	3,629	59%

We are also able to compile publicly available data about cancer-related risk factors and screening practices in the geographic area of interest compared to the State of Iowa and the US



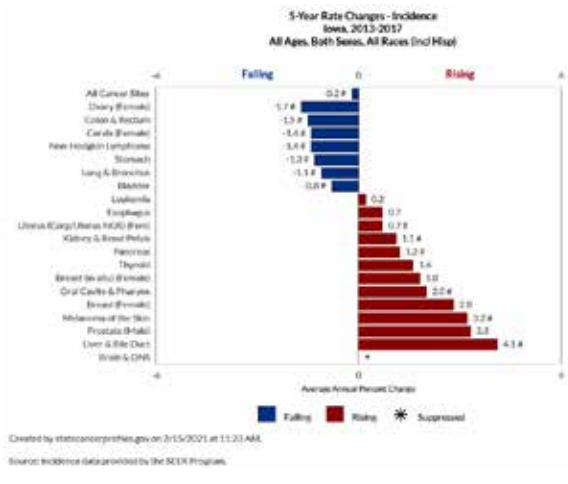
Comparison of stage at diagnosis of selected cancers between populations in the geographic area of interest and the State of Iowa

Cancer Site and Catchment area	Stage at Diagnosis: Stage 1 N	Stage 1 Row %	Stage 2 N	Stage 2 Row %	Stage 3 N	Stage 3 Row %	Stage 4 N	Stage 4 Row %	Unknown N	Unknown Row %	Total N
Breast											
Catchment area	1,376	60%	575	25%	146	6%	110	5%	101	4%	2,308
State of Iowa	4,665	59%	1,918	24%	609	8%	402	5%	354	4%	7,948
Lung											
Catchment area	453	23%	157	8%	289	15%	927	47%	132	7%	1,958
State of Iowa	1,606	22%	560	8%	1,174	16%	3,487	47%	602	8%	7,429
Prostate											
Catchment area	208	12%	778	45%	247	14%	189	11%	326	19%	1,748
State of Iowa	926	13%	3,112	45%	1,014	15%	785	11%	1,058	15%	6,895
Colorectal											
Catchment area	312	26%	256	21%	284	24%	232	19%	123	10%	1,207
State of Iowa	1,122	23%	1,039	22%	1,163	24%	910	19%	461	10%	4,695
Melanoma											
Catchment area	495	59%	103	12%	69	8%	32	4%	135	16%	834
State of Iowa	1,956	61%	375	12%	255	8%	118	4%	478	15%	3,182
Bladder											
Catchment area	109	36%	82	27%	30	10%	35	12%	45	15%	301
State of Iowa	482	19%	313	12%	110	4%	178	7%	155	6%	1,238

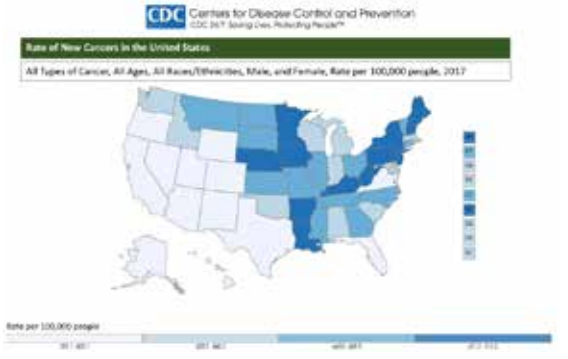
Online Data Sources

Below are sources where individuals can generate cancer statistics themselves. A variety of statistics can be generated on these websites, which includes frequency counts, incidence and mortality rates, and risk factor information. These data can be displayed in graphic format or in tabular data that can be exported.

Iowa Cancer Registry has an interactive data tool that 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/.



State Cancer Profiles can 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/.



United States Cancer Statistics are the official government statistics on cancer. The statistics provide information on newly diagnosed cancer cases and cancer deaths for the whole US population. This national coverage enables the public, including researchers, clinicians, policy makers, and public health professionals, to monitor populations most affected by cancer, evaluate the success of programs designed to prevent cancer and diagnose cancer at early stages, and identify additional needs for cancer prevention and control efforts at national, state, and local levels, https://gis.cdc.gov/Cancer/USCS/DataViz.html.

Other Data Sources to Explore:

- **SEER*Explorer:** https://seer.cancer.gov/explorer/
- **Cancer Stat Facts:** https://seer.cancer.gov/statfacts/
- **Annual Report to the Nation on the Status of Cancer:** https://seer.cancer.gov/report_to_nation/

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/.

Research Projects

Patterns of Care/Quality of Care Studies

SEER Patterns of Care/Quality 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." Investigators have examined disparities in receipt of cancer therapies, diagnostic tests, and biomarkers by age, race/ethnicity, and residential urbanicity/rurality. Cancer sites with multi-year data can provide trends in cancer therapy and survival over time. Access to POC data can be requested at https://healthcaredelivery.cancer.gov/poc/.

SEER Linked Databases

In the early 1990s, the cancer incidence and survival data from the ICR were first combined with other SEER Registry data and linked to Medicare data. This has become an important data resource for epidemiologic and health services research related to diagnosis and treatment procedures, costs, and survival of cancer patients. More information on obtaining data can be found at https://healthcaredelivery.cancer.gov/seermedicare/obtain/.

In 2003, the ICR linked SEER data with the Centers for Medicare and Medicaid (CMS) Medicare Health Outcomes Survey (MHOS). SEER-MHOS provides a wide range of potential research applications focused on health-related quality of life of cancer patients and cancer survivors. More information can be found at https://healthcaredelivery.cancer.gov/seer-mhos/.

In 2009, linkages were made to the Consumer Assessment of Healthcare Providers & Systems (CAHPS) surveys. SEER-CAHPS focuses on patient experiences with care across health plan types. More information can be found at https://healthcaredelivery.cancer.gov/seer-cahps/.

The ICR is participating in over 70 studies during 2021 that have been approved by the University of Iowa Human Subjects Office.

This past year the ICR participated in three projects investigating ovarian cancer treatment patterns in Iowa. The first was a qualitative study funded by the Centers for Disease Control and Prevention (CDC) in which the ICR worked in partnership with the Iowa Department of Public Health and the Iowa Cancer Consortium toward the goal of investigating the viewpoints of patients and providers on referral patterns, surgeon selection decision making patterns, and barriers to receipt of guideline-recommended treatment for ovarian cancer care in Iowa. The second was a special quantitative study through the ICR with extended abstraction of variables for ovarian cancer patients with residences in Iowa that explored the interaction between patient rurality at diagnosis and the specialty of their surgeon on outcomes and survival. The third project was a series of population-based cohort studies investigating rurality, surgeon specialty, and chemotherapy provider specialty on ovarian cancer outcomes and survival utilizing a CDC created dataset of state cancer registry data in Iowa, Kansas, and Missouri.

Interested in Research?

Individuals interested in requesting ICR data can contact the Registry. Protocols vary on the level of data requested (aggregate vs individual-level). Investigators and others who wish to use registry data for research purposes must provide a description of the proposed study, justification of the necessity of the research, assurances of upholding confidentiality of the data, and if requested, documentation of project approval by the Institutional Review Board.

Requests should be submitted to: **Suzanne Bentler** at suzanne-bentler@uiowa.edu

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