

IOWA CANCER REGISTRY

# CANCER IN IOWA

2025



# Iowa Cancer Registry

Iowa continues to have the second highest age-adjusted rate of new cancers diagnosed and is one of only two states with a rising age-adjusted rate of new cancers. At the same time, improvements in detecting and treating cancer, as well as supportive services, have contributed to declining cancer mortality (death) rates. Combined, this results in an increasing number of cancer survivors, defined as an individual from the time of diagnosis through the end of life. Many survivors need long-term support from their healthcare providers, their community, and their caregivers, so it is important to better understand the impact of a quickly growing number of cancer survivors.

Each year, the Cancer in Iowa report focuses on a different topic, chosen by the Iowa Cancer Registry and its partners. The purpose of the report is to feature the data we collect at the Registry, which begins at the time of cancer diagnosis, and to educate Iowans about the cancer burden in Iowa. This year's report features cancer survivorship and the needs and challenges often faced by those diagnosed with cancer. Iowa needs more services throughout the state to provide survivorship care to the growing number of cancer survivors. These include screening for cancer recurrence and new cancers, addressing late effects and delayed symptoms of cancer treatment, and improving quality of life for cancer survivors through nutrition, physical activity/movement, tobacco use cessation, and other mental health and social support services.

The Cancer in Iowa report is produced by the Iowa Cancer Registry. The Iowa Cancer Registry is Iowa's statewide cancer registry, meaning that data are collected on all Iowa residents who are diagnosed with cancer. Given that cancer is a significant public health concern in Iowa and throughout the U.S., cancer is a reportable disease in all fifty states. The Iowa Administrative Code has designated the Iowa Cancer Registry to collect cancer data for Iowans and to use those data to track cancer trends and support efforts to reduce cancer diagnoses and deaths. Reducing Iowa's cancer burden requires the cooperation of many people and organizations, including providers, patients, researchers, public health professionals, policy makers and advocates, among others.

The Iowa Cancer Registry is funded by the National Cancer Institute through the Surveillance, Epidemiology, and End Results (SEER) Program, as well as 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 the impact of cancer.

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 the privacy of those included in the Registry 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 2025 *Cancer in Iowa* report provides information on the status of cancer in our state. Key takeaways include:

- An estimated 21,200 new, invasive cancers will be diagnosed among Iowans in 2025.
- An estimated 6,300 Iowans will die from cancer in 2025.
- The number of cancer survivors is growing, with an estimated 171,535 survivors currently living in Iowa.
- Cancer survivorship is the special focus this year, including stories of survivorship and advocacy.

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

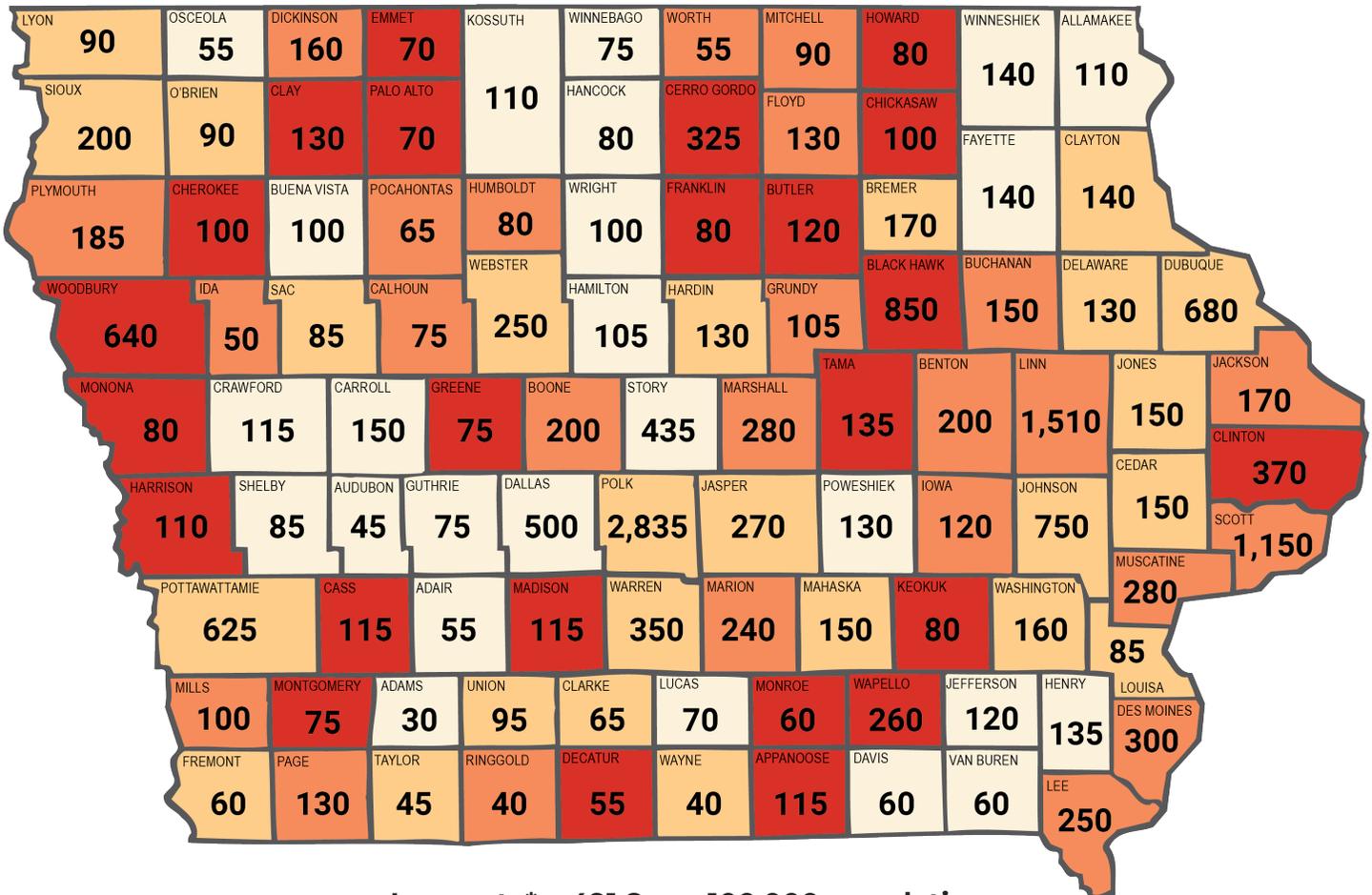


If you are a representative of the media and have questions about this report, please email: [ICR-Media@uiowa.edu](mailto:ICR-Media@uiowa.edu)



# Estimates for New Cancers for 2025

The numbers in each of the counties represent the estimated counts of new cancer cases for 2025 (meaning cancers that were diagnosed as stages 1-4, as well as in situ or stage 0 bladder cancers). The populations of each county vary widely in terms of size and age, so when comparing new cancers across counties it is important to focus on age-adjusted rates. The color of the county shows the rate of new cancers for years 2017-2021, with the counties with the lowest rates shaded cream and highest rates shaded dark red.



Iowa rate\* = 491.8 per 100,000 population

- 396.9-466.9  
(lowest rates in state)
- 467.8-492.3  
(includes state rate)
- 493.8-513.6  
(greater than state rate)
- 514.1-580.0  
(highest rates in state)

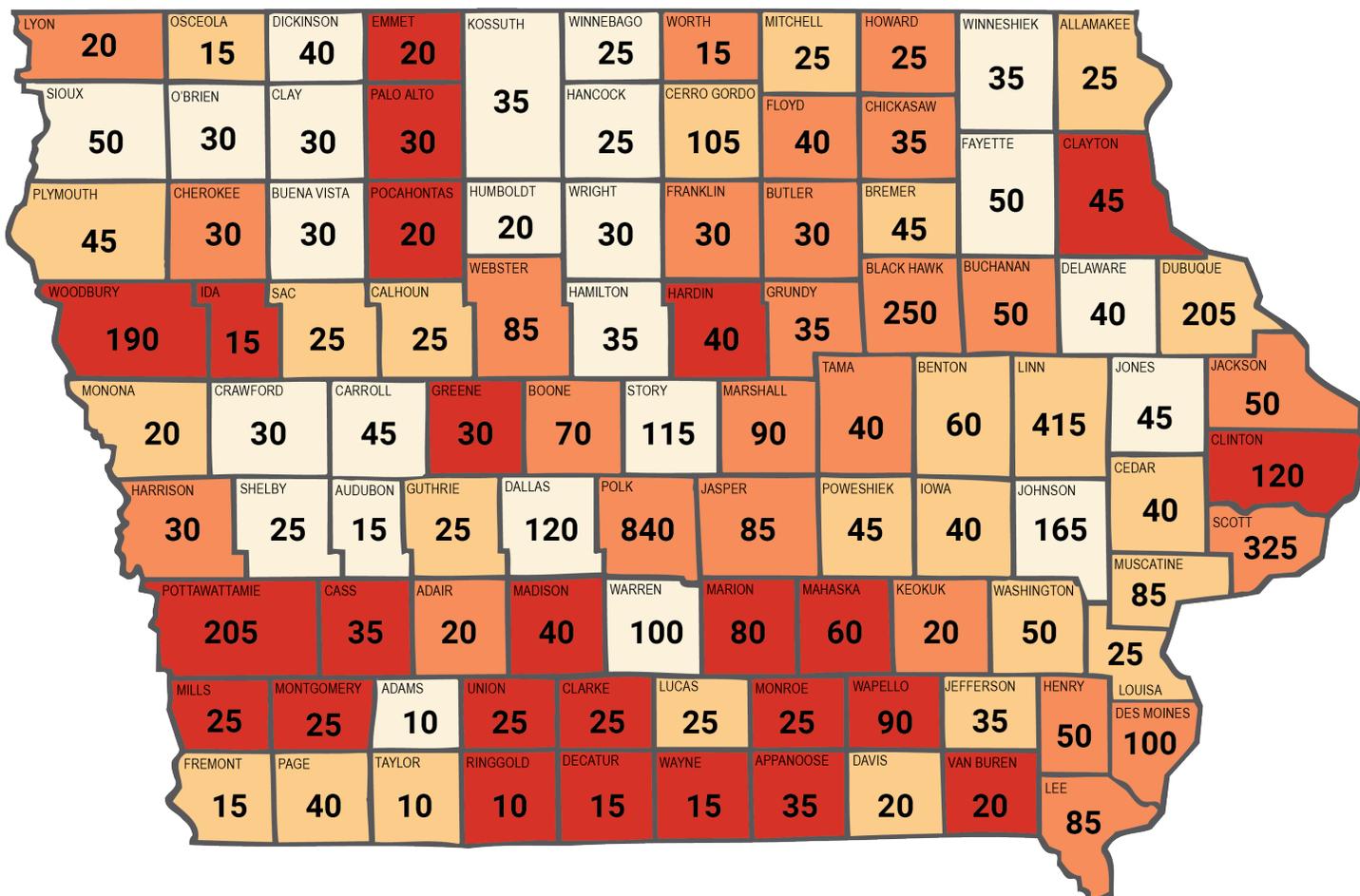
\*Rates are age-adjusted and per 100,000 population, 2017-2021

## ESTIMATED NEW CANCERS AMONG IOWA RESIDENTS, 2025

TYPE	COUNT	% OF TOTAL	TYPE	COUNT	% OF TOTAL
Breast	2,940	13.9	Leukemia	730	3.4
Prostate	2,900	13.7	Uterus	700	3.3
Lung	2,560	12.1	Pancreas	650	3.1
Colon and rectum	1,650	7.8	Oral cavity and pharynx	620	2.9
Skin melanoma	1,420	6.7	Thyroid	500	2.4
Bladder	940	4.4	Liver and intrahepatic bile duct	330	1.6
Non-Hodgkin lymphoma	890	4.2	Myeloma	320	1.5
Kidney and renal pelvis	860	4.0	All others	3,190	15.0
<b>TOTAL COUNT: 21,200</b>					

# Estimates for Cancer Deaths for 2025

The numbers in each of the counties represent the estimated counts of cancer deaths for 2025. The populations of each county vary widely in terms of size and age, so when comparing deaths across counties it is important to focus on age-adjusted rates. The color of the county shows the rate of cancer deaths for years 2017-2021, with the counties with the lowest rates shaded cream and highest rates shaded dark red.



Iowa rate\* = 152.2 per 100,000 population

- 105.7-140.8  
(lowest rates in state)
- 141.1-154.6  
(includes state rate)
- 154.9-166.1  
(greater than state rate)
- 166.3-233.3  
(highest rates in state)

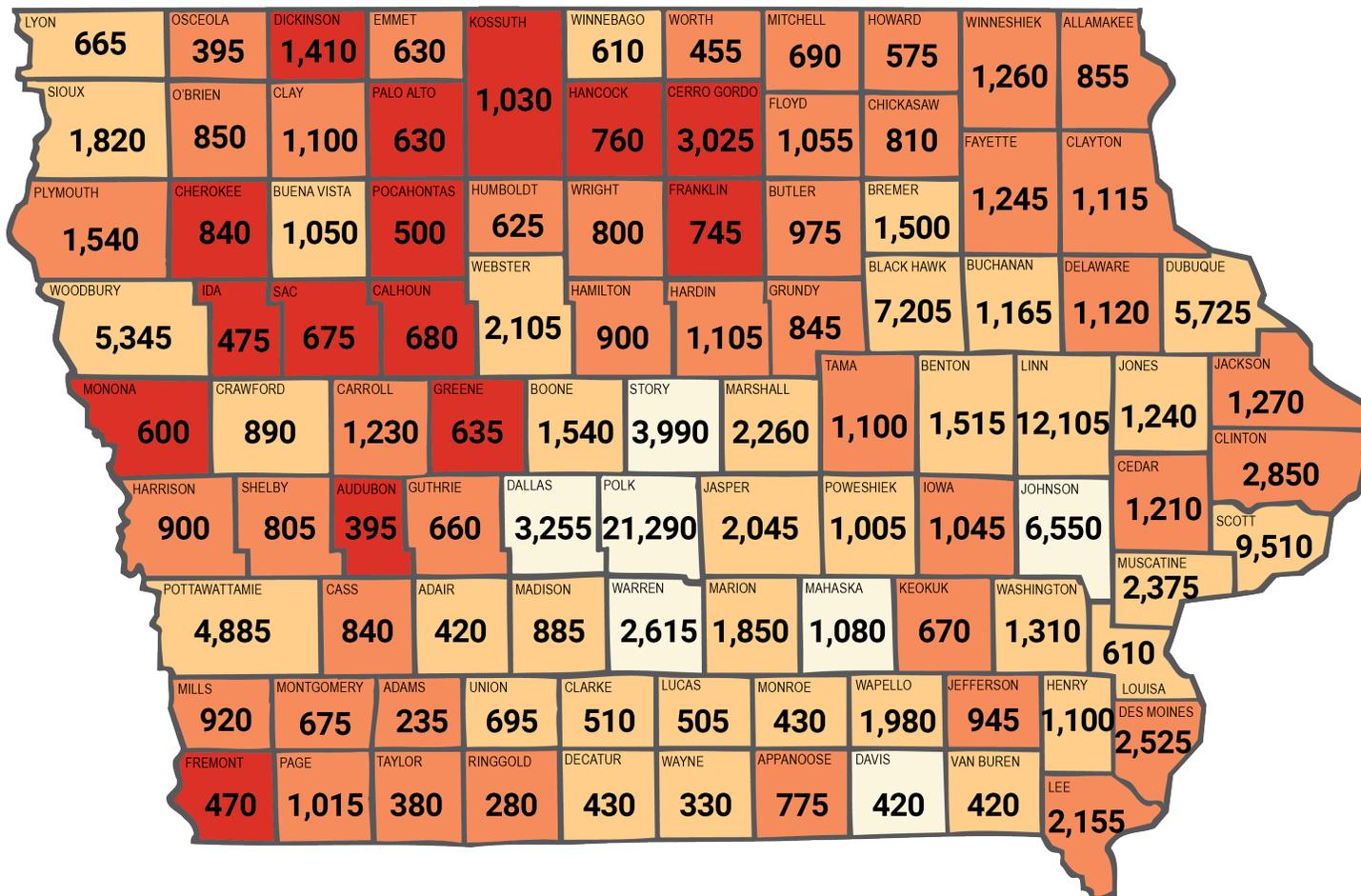
\*Rates are age-adjusted and per 100,000 population, 2017-2021

## ESTIMATED CANCER DEATHS AMONG IOWA RESIDENTS, 2025

TYPE	COUNT	% OF TOTAL	TYPE	COUNT	% OF TOTAL
Lung	1,430	22.7	Esophagus	200	3.2
Colon and rectum	550	8.7	Bladder	180	2.8
Pancreas	490	7.8	Brain	170	2.7
Breast	390	6.2	Kidney and renal pelvis	170	2.7
Prostate	340	5.4	Myeloma	130	2.1
Leukemia	260	4.1	Uterus	130	2.1
Liver and intrahepatic bile duct	250	4.0	Ovary	120	1.9
Non-Hodgkin lymphoma	240	3.8	All others	1,250	19.8
<b>TOTAL COUNT: 6,300</b>					

# Living with Cancer

The number of cancer survivors is growing in Iowa, and nationwide. The Iowa Cancer Registry has tracked the vital status of more than 98 percent of cancer survivors diagnosed since 1973. According to Iowa Cancer Registry incidence and survival data for 1973-2020, there are an estimated 171,535 cancer survivors among Iowans (defined as people who are currently living with or having had cancer).



Number of Survivors as Percent of the County Population

<5%
  5-6%
  6-7%
  >7%

## SURVIVORS AMONG IOWA RESIDENTS DIAGNOSED WITH CANCER

TYPE	COUNT	% OF TOTAL	TYPE	COUNT	% OF TOTAL
Breast	37,490	21.8	Kidney and renal pelvis	7,200	4.2
Prostate	31,720	18.5	Lung	7,180	4.2
Colon and rectum	15,570	9.1	Leukemia	5,680	3.3
Skin melanoma	14,020	8.2	Oral cavity and pharynx	4,925	2.9
Uterus	9,110	5.3	Testis	2,950	1.7
Thyroid	8,670	5.0	Cervix	2,540	1.5
Non-Hodgkin lymphoma	8,230	4.8	Hodgkin lymphoma	2,260	1.3
Bladder	8,165	4.8	All others	5,825	3.4

**TOTAL COUNT: 171,535**

For more on cancer survivorship, please see the special focus of this year's report, pages 6-14.

# Key Points

-  Each year the Iowa Cancer Registry's annual report focuses on a different cancer-related topic to increase awareness. This year, the topic chosen is **cancer survivorship**.
-  While the Iowa Cancer Registry and its partners are working together to address Iowa's high cancer rates, survivorship is the focus this year because as more people are being diagnosed, and surviving longer with their cancer diagnosis, **the number of cancer survivors is increasing**. Thus, **cancer survivorship care is expected to become even more critically important in Iowa** in the coming decades.
-  **More than 1 in 20 people in Iowa have had a diagnosis of cancer at some point in their lives.**
-  The most common cancers that survivors in Iowa are living with are **breast, prostate, and colorectal cancers, and skin melanoma**.
-  **Cancer survivors have unique needs** that must be considered by all healthcare providers. Needs may include: screening for cancer recurrence and new cancers; addressing late effects and delayed symptoms of cancer treatment; and, improving quality of life for cancer survivors through nutrition, physical activity/movement, tobacco use cessation, and other mental health and social support services.
-  **Survivorship resources are underdeveloped across the U.S.** While many healthcare and community partners are invested in supporting Iowa's cancer survivors, **there is an opportunity to increase these services**.
-  **Providing and improving survivorship care works to increase length and quality of life among Iowa's cancer survivors.**

## THE CANCER IN IOWA REPORT THROUGH THE YEARS

Each year, this report focuses on a different topic relevant to Iowans. Here are a few of the most recent topics covered:

**2024**

Alcohol-related cancers

**2023**

50 years of cancer surveillance for Iowans

**2022**

Cancer screening

**2021**

Cancer disparities

**2020**

Ovarian cancer



# Definitions/Key Terms

**Cancer survivor:** According to the National Cancer Institute, an individual is considered a cancer survivor from the time of diagnosis through the end of life. There are many types of survivors, including those living with cancer and those free of cancer.

**Prevalence:** The proportion of the population currently living with a previous diagnosis of cancer. The prevalence of cancer in Iowa (i.e., the number of cancer survivors) can be impacted by the rate of new cancers and by the rate of death among those with cancer.

**Incidence rate:** The number of **new** cases of cancer in a population, over a defined time-period.

**Crude rates:** The “true” cancer rate in a population, without taking into account the age composition of the population. These rates are helpful to understand the number of cases of cancer being diagnosed but are not directly comparable between different populations (e.g., between U.S. states or Iowa counties) because the crude rate is highly dependent on the proportion of older people in the population. **In this section crude rates are presented**, as these rates are more directly relevant to the actual number of survivors in Iowa.

**Age-adjusted rates:** Populations differ with respect to their age composition, and age is strongly related to cancer diagnoses and death. So, rates are often age-adjusted to be able to compare between different populations. For example, Iowa has a large proportion of residents over the age of 65 years compared to the rest of the U.S. However, when adjusted for the age, the cancer rates become more similar – although Iowa's age-adjusted rates are still higher than the U.S. average, the difference is not as stark. Usually in the Cancer in Iowa report, age-adjusted rates are presented to allow for these types of comparison; however, in this specific section, some crude rates are used for the reasons described above.

# Cancer Survivorship in Iowa

Iowa continues to have the second highest age-adjusted rate of new cancers in the U.S. and is one of only two states with a rising rate. Iowa is second only behind Kentucky, which has a high rate of smoking-related cancers. Iowa is also highly ranked in incidence among U.S. states for many specific cancers, including oral cavity and pharynx (tied 1<sup>st</sup>), non-Hodgkin lymphoma (3<sup>rd</sup>), leukemia (4<sup>th</sup>), esophagus (4<sup>th</sup>), and melanoma (4<sup>th</sup>).

The Iowa Cancer Registry estimates that there are **nearly 172,000 cancer survivors in Iowa, about 5.4% of the population**. More than 20,000 people are newly diagnosed with cancer each year in Iowa. Two out of three Iowa cancer survivors (67%) were diagnosed more than five years ago, while one out of three were diagnosed within the past 5 years (Figure 1). Nearly two-thirds (64%) are aged 65 years or older. About one in ten (11%) of survivors are less than 50 years of age. Among these survivors, there are 790 cancer survivors 14 years and younger and 520 cancer survivors aged 15 to 19 years.

Figure 2 shows that Iowa's rate of new cancers (crude incidence rate, blue) is increasing (about 0.7% each year). At the same time, the proportion of people living five years beyond their diagnosis is increasing about 0.4% each year (survival, red), and the mortality (death) rate is decreasing (about 0.5% each year) (crude mortality rate, orange). Together, these patterns result in an increased number of cancer survivors over time.

While cancer rates are leveling off, **there may still be undiagnosed cases of cancer resulting from a lack of cancer screening during the COVID-19 pandemic**. The increases in cancer cases in 2021 and 2022 were not large enough to account for the drop in cases observed in 2020; suggesting more undiagnosed cases of cancer are yet to be found.

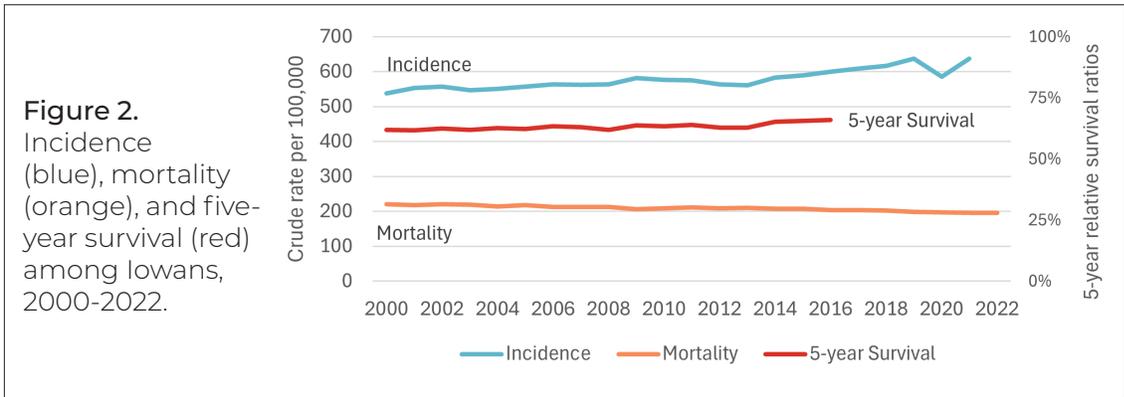
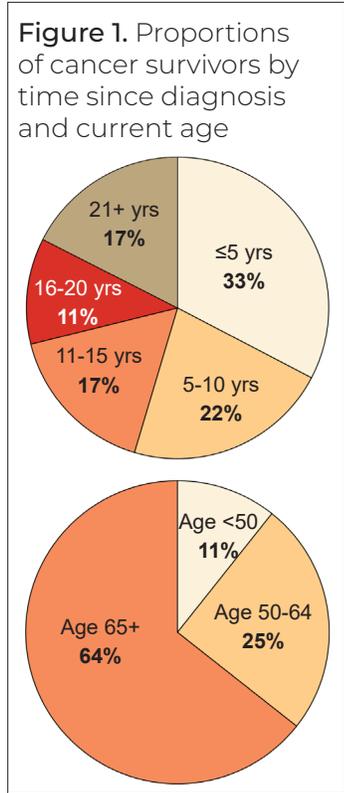
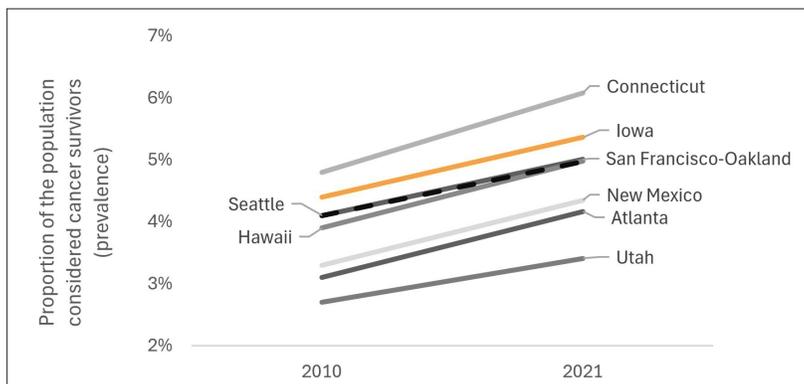
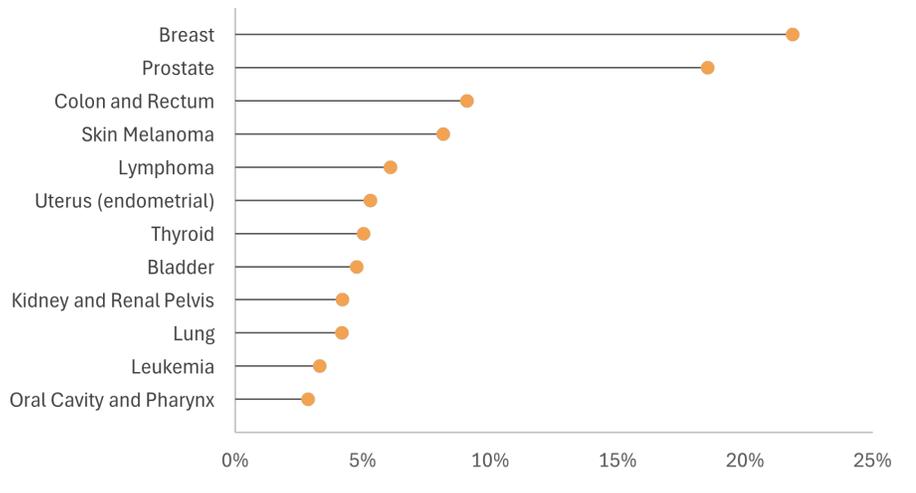


Figure 3 shows the proportion of the population considered cancer survivors in Iowa compared to other cancer registries that have over 50 years of cancer data collected. Compared to the other SEER 8 registries, **Iowa has the second highest prevalence of cancer**, after Connecticut. Connecticut has a lower age-adjusted cancer incidence rate compared to Iowa, but they also have a significantly lower cancer mortality rate than Iowa, so Connecticut's cancer survivors are living longer. **As of 2022, it is estimated that there are 18.1 million cancer survivors in the U.S., representing 5.4% of the population. By 2040, the number of survivors is expected to grow to 26 million.**<sup>2</sup> The rate of growth in Iowa's cancer survivor population may be even higher, given the high incidence rates.



The leading cancers contributing to Iowa's survivor population are breast, prostate, colon and rectum, and skin melanoma. Figure 4 shows that these four cancers combined account for over half of Iowa's cancer survivors.

**Figure 4.** Most common types of cancers diagnosed among Iowa's cancer survivors.

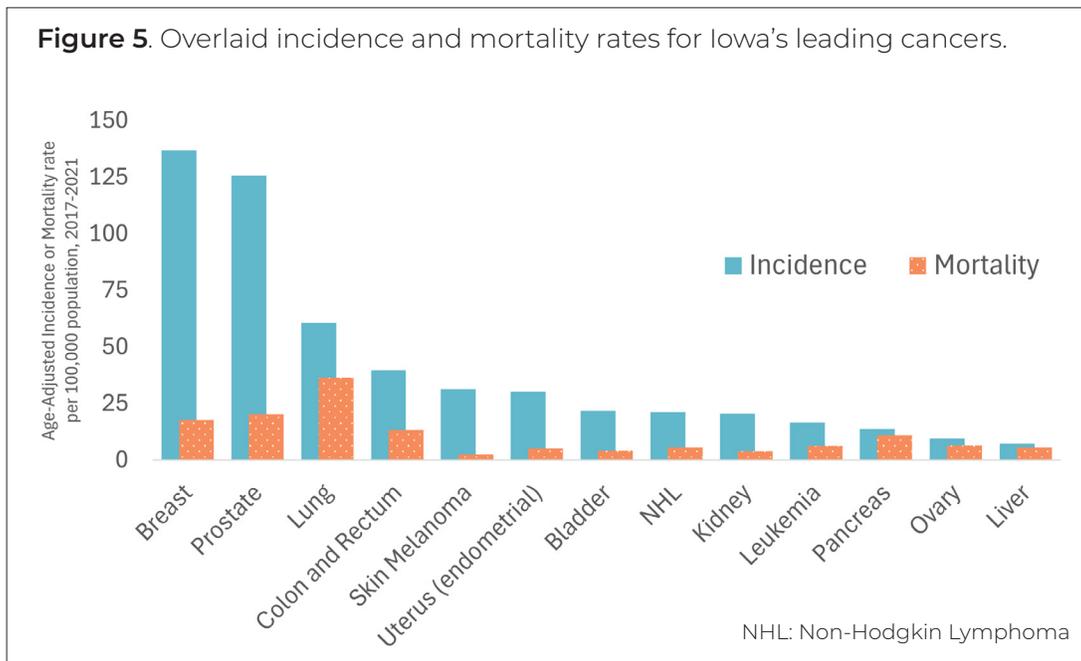


**Breast and prostate cancer survivors account for the largest proportions of Iowa's survivor population.** This is expected because breast and prostate cancers are the most common cancers in Iowa and have long survival times. When incidence (new cases) is high and mortality (deaths) is low, then there will be a larger survivor population.

Figure 5 shows the incidence and mortality rates overlaid for different cancers over time. **The larger the difference between incidence and mortality (i.e., the larger the blue area), the more cancer survivors there will be, as is seen with breast and prostate**

**cancers. This is different than what is seen with lung cancer,** for example. While lung cancer is the third most common cancer diagnosed among Iowans, it is very deadly. Only about 15% of individuals with lung cancer will live five years beyond their diagnosis, so lung cancer represents a smaller proportion of Iowa's survivor population. This is another reason that it is so important to prevent lung cancer through tobacco use prevention and cessation, radon testing and mitigation, and detecting lung cancer at a more treatable stage through regular screening among eligible current or former tobacco users.

**Figure 5.** Overlaid incidence and mortality rates for Iowa's leading cancers.



# Cancer Survivor Needs

**Cancer survivors have specific needs**, and these needs can vary from person to person. Some survivors experience physical and psychosocial symptoms during treatment and/or long after treatment has ended. For example, while curative treatments for cancer are often successful, survivors may be left with long-term impacts on quality of life and physical function. People who have had a diagnosis of cancer can also have an elevated risk of recurrence or of developing a second, unrelated cancer. Therefore, to promote health and decrease risk of recurrence or a second cancer, it is important that survivors engage in healthy behaviors such as eating nutritious food, engaging in physical activity, getting appropriate cancer screenings, and avoiding tobacco and alcohol. Due to changes resulting from their cancer diagnosis, cancer survivors may need increased support to engage in health-promoting behaviors. **Because of these unique and diverse needs, many survivors require long-term support from the health care system, their community, and caregivers.**

Cancer survivorship services may include, but are not limited to: survivorship care plans, screening programs for cancer recurrence, screening programs for new cancers, lifestyle support including nutrition, physical activity, and tobacco cessation, psychological support, support groups and services, referrals to specialty care, including cardiology, pulmonary services, sexual dysfunction and fertility counseling, workplace reintegration support, and financial support services.

**Cancer survivorship care is complex.** Survivorship care involves coordination of health care across different types of cancer treatment, primary care, and other local community providers who manage day-to-day health care. In Iowa, rural cancer survivors may travel to urban areas for their treatment but when this is complete, often rely on local community services for survivorship care. Some survivors receive long-term follow-up from their oncologist, which can be difficult for rural residents who travel long distances. Further, as the number of cancer survivors increases, the current number of providers in Iowa will be inadequate to meet needs if the number of providers does not also increase. Thus, it is imperative that survivorship services are expanded and strengthened across the state.

**Cancer survivorship resources are underdeveloped across the U.S.** While some healthcare facilities provide excellent resources to support cancer survivors, others do not have well-developed programs. Thus, there is an opportunity for Iowa to develop programs to support cancer survivors. This is especially true in rural areas. To inform the development of survivorship programs across the U.S., the National Cancer Institute and partners recently developed the [National Standards for Survivorship Care](#). These standards provide guidance on the kinds of services that should be provided to survivors, and ways to evaluate the qualities of these services.

**Cancer survivorship guidelines vary by cancer type.** There are recommendations for long-term follow-up and survivorship support for some cancer types (e.g., breast, colon and rectum, head and neck, childhood cancers). Guidelines may indicate how often survivors should visit their doctor for check-ups, get screened for cancer, and evidence-based ways to stay well. For some cancer types, guidance is less developed.

## IOWA CANCER PLAN AND SURVIVORSHIP

The Iowa Cancer Plan has five chapters. One chapter is focused on prevention and risk reduction (chapter 2), which is critical for decreasing the number of Iowans getting cancer. Another is focused on cancer survivorship and end of life care (chapter 5). This chapter includes five priorities, each of which includes goals and objectives that cancer control partners can use to guide activities in cancer survivorship:

- Priority 1** Utilize best-practices to support a cancer patient's transition from active treatment to post-treatment care.
- Priority 2** Increase provider, patient, and caregiver awareness of the importance of cancer risk reduction behaviors and cancer screening for cancer survivors.
- Priority 3** Achieve excellent quality of life for all Iowans with cancer and their caregivers.
- Priority 4** Improve long-term follow-up care for childhood cancer survivors.
- Priority 5** Increase availability and access to quality end-of-life care.



**Iowa Cancer Plan**

2023 - 2027

Cancer survivors' needs may vary by their diagnosis, between individuals, and over time. Figure 6 shows some of the challenges that may be experienced by cancer survivors along their survivorship journey.

The needs of cancer survivors may vary across different phases of cancer survivorship. For example, when a survivor is first diagnosed, they may need support coming to terms with their diagnosis and then deciding on the best treatment path for them. Later during the transition to long-term survivorship, survivor needs may shift to addressing financial hardship that may have occurred during cancer treatment, understanding how to regain a healthy lifestyle with any physical changes caused by the cancer, relationship changes and/or sexual health, re-entering the workplace and/or school, and managing risk and concern of cancer recurrence or new cancer diagnoses. In addition, as cancer treatments continue to improve, some patients may live with advanced, incurable cancer for many years. These survivors have distinct needs related to maximizing quality of life and support for end-of-life planning.

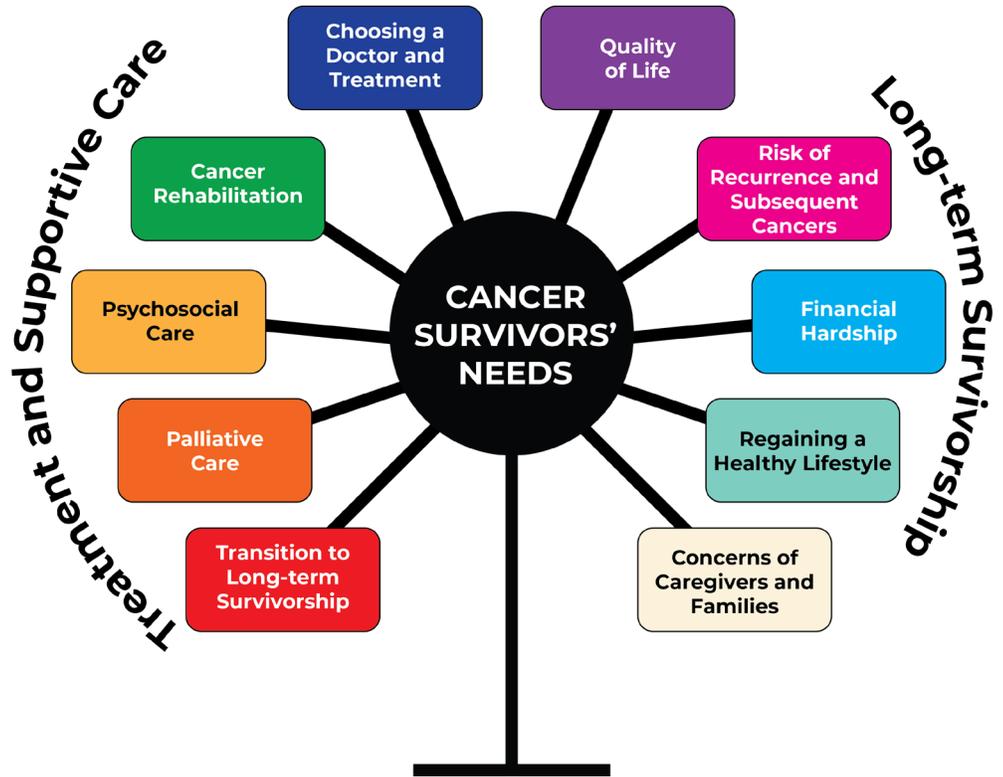


Figure 6. Cancer survivors' unique needs. Redrawn from the [American Cancer Society](#).

## SELF-ADVOCACY

Self-advocacy is a way for cancer survivors to take charge while managing an overwhelming environment of tests, treatment, and doctors' offices. Self-advocacy can include many aspects, including arming oneself with good information and knowing how to ask the right questions of the doctor, seeking second opinions, and finding the support you need. Personal empowerment can mean the difference between maintaining hope and enhancing quality of life or feeling helpless and uncertain. For more information on how to be a more effective self-advocate, or advocate for a loved one, see these resources from the [National Coalition for Cancer Survivorship \(NCCS\)](#).

Questions to ask your healthcare providers are likely to vary upon where you are in your cancer survivorship journey. For example, those in active treatment might need to ask questions on second opinions, finding the right treatment, or psychosocial concerns; whereas those in longer-term follow-up may want to inquire about the long-term effects of cancer treatment, or screening recommendations. The [Self-Advocacy Handbook](#) from the NCCS provides a comprehensive list of questions for all stages of the cancer survivorship journey.

## UNIQUE NEEDS OF YOUNG CANCER SURVIVORS

In Iowa, approximately 150 cancers are diagnosed each year among children and adolescents (ages 0-19 years old), accounting for about 1% of all cancers. The most common cancers in those less than 20 years old are leukemias, brain tumors, and lymphomas. About 85% of people diagnosed before 20 years of age are still alive five years after diagnosis, and these individuals may have **unique needs**, including:

- Developing a new identity after cancer and adjusting to the “new normal”
- Navigating the long-term effects of cancer treatment
- Managing healthcare needs, fertility concerns, and risk of second cancers

## RURAL VERSUS URBAN SURVIVOR NEEDS

In Iowa, a higher percentage of people in rural areas are living with a previous diagnosis of cancer (6.1%) compared to those living in urban areas (4.9%). There may be distinct challenges faced by rural cancer survivors, including:

- Lack of cancer survivorship care in the community
- Distance to travel for follow-up care or cancer screening
- Lower access to healthy food and places to be physically active

## RACIAL DIFFERENCES IN SURVIVORSHIP

Survivorship needs may vary by race and ethnicity.

National data show that people from racial and ethnic minority groups experience higher rates of adverse side effects, poorer quality of life, and higher financial burden related to cancer diagnoses compared to non-Hispanic White (NHW) individuals. Further, in Iowa, **non-Hispanic Black (NHB) and Hispanic Iowans have an earlier average age of diagnosis** (60 among NHB, 55 among Hispanic, 67 among NHW) **and lower survival** (67% among NHB, 70% among Hispanic, 69% among NHW) compared to NHW individuals. This means they often experience the effects of cancer earlier in life and are less likely to live as long with their diagnosis. To improve the survivorship experience for people from racial and ethnic minority groups, patient navigators, patient advocates, and culturally sensitive intervention/navigation programs need to be available and accessible to all Iowans.

More information is available at the [American Association for Cancer Research Cancer Disparities Progress Report](#).



# Cancer Survivor Stories

Stories are a powerful way of understanding cancer survivors' needs and challenges. Here, we highlight three Iowa cancer survivors, and their journeys into survivorship.

## **BRIAN LYNNER (DES MOINES, IOWA)**

*Diagnosed with esophageal cancer, January 2020*



The basic question I faced was “how to have cancer and hope?” The basic answer was a combination of treatment and healing. Medical providers would handle treatment; healing was up to me. Available medical data on surviving (esophageal) cancer was discouraging, so I developed a mindset I called “Radical Optimism”: choosing an outcome you are going to work toward regardless of the odds of success. Radical Optimism included developing and using affirmations and visualization of me as a vibrant, healthy, delighted man in love with his life. And it worked for me! I am four years out from surgery and every scan comes back “no evidence of disease.”

## **KATIE MCKENZIE (BEAVERDALE, IOWA)**

*Diagnosed with multiple myeloma, August 2019*



I was diagnosed with multiple myeloma in August 2019. After four months of induction chemotherapy treatment, I had a stem cell transplant in January 2020. I have been on active treatment since. There is no cure for multiple myeloma. Cancer survivorship programming through Above + Beyond Cancer and John Stoddard Cancer Center have played a very important role in my learning to live with cancer. The compassionate community of cancer survivors that these programs bring together is key to my mental and physical health. Within this community you can say a little and get a lot of understanding. Without these opportunities I know that cancer would be in the driver seat of my life instead of in the back seat where it belongs while I am busy living! I wish that all Iowans had these tremendous cancer survivorship programs in their communities, especially in this time of increasing cancer diagnoses statewide. More funding is needed to make this happen.

## **CATHY KETTON (WATERLOO, IOWA)**

*Diagnosed with breast cancer, August 2022*



I never thought I would be diagnosed with cancer. I thought since my mom and daughters had cancer, it would pass me by. Initially I was depressed, and I knew I had to change my mindset. When I started my treatment, I was still sad that I was actually going to my first chemo treatment. When I walked into the center, the receptionist was so nice. Everyone was smiling, helpful, and caring. At the end of my time at the center, my mindset had shifted. Having a support system of my family, my medical team, and the [Splash of Color Breast Cancer Support Group](#) was key for me. The ladies from Splash of Color were there for me in ways I couldn't imagine they would be. No one deserves to travel this journey alone... We are better together.

More survivor stories and resources can be found by visiting the Iowa Cancer Consortium [website](#) and [YouTube page](#).

# Survivorship Care and Research in Iowa

Iowa is fortunate to have several healthcare providers and researchers interested in advocating for cancer survivors and researching ways to support Iowa's survivors to live longer, healthier lives. Here we feature three stories of those working to support and advocate for Iowa's cancer survivors.



Although advancements in medical care have drastically improved cancer survival rates, cancer survivors face worse physical and mental health-related quality of life outcomes and a greater risk for additional cancer diagnoses compared with adults without cancer. Many cancer survivors experience ongoing physical, emotional, psychosocial, financial, spiritual, and philosophical issues related to their cancer diagnosis and/or their cancer treatment. Survivorship care is an important part of the cancer journey, but one that is often under-appreciated by cancer centers and patients alike. As a consequence, we have established a Survivorship Clinic to address survivors' needs beyond the important role of on-going surveillance for the cancer for which the survivor was treated. Our clinic also addresses the late side effects of surgery, chemotherapy, and radiation. We also have mental health counselors, sexual health counselors, social workers, mindfulness coaches, and rehabilitation specialists to provide a holistic approach to survivorship. A good cancer center takes care of treating cancer. A great cancer center takes care of the patient and their family.

– RICHARD DEMING, MD, Mercy One, [Above + Beyond Cancer](#)

## Highlighted Research

[Read about 27 survivors](#)<sup>3</sup> who participated in physically and emotionally challenging journeys and how new experiences and social support enabled them to develop new meaning, growth, and a new sense of their capabilities.



I direct the Physical Activity and Cancer Survivorship Lab where our mission is to help improve the lives of cancer survivors using exercise in research contexts, we define cancer survivors as individuals from the moment they are diagnosed throughout the balance of their lives. Cancer survivors can have latent and long-term effects following treatment that can be improved by exercise, and we know that physical activity and exercise are associated with many physical, mental, and psychosocial benefits; yet fewer than 1 in 10 cancer survivors report sufficient exercise. Research during the survivorship period is critical for not only improving clinical outcomes like mortality and recurrence, but is also critical for maximizing quality of life following a cancer diagnosis. As our detection and treatments improve, we must be prepared for the clinical and research needs of the ever-growing population of cancer survivors in Iowa and beyond.

– JESS GORZELITZ, PhD, MS, University of Iowa

## Highlighted Research

[In this study](#)<sup>4</sup>, Dr. Gorzelitz and colleagues showed that home-based muscle-strengthening exercise improved physical function among endometrial cancer survivors after a ten-week program. Dr. Gorzelitz and her team are now investigating how home-based physical activity can improve Iowa cancer survivors' lives.



With the growing population of people living with a cancer history, it is imperative that we meet cancer survivors where they are at in terms of providing necessary survivorship care support. And we know that isn't always happening. For example, Iowa has the highest rate of oral cavity and pharyngeal cancer in the country. Yet, in our work in head and neck cancer, we have shown that almost one-fourth of cancer survivors step away from survivorship care at the hospital where they were treated and that many do so while they are still at a high risk of cancer recurrence. Our fragmented care system makes it almost impossible to determine what care needs these survivors still have and if those needs are being met. We need to marshal the dedicated clinicians, researchers, and policymakers across the state to make sure we are reaching all survivors with the services they need, when they need them, and where they can access them.

–AARON SEAMAN, PhD, University of Iowa

## Highlighted Research

[In this paper](#)<sup>5</sup>, Dr. Seaman and his colleagues looked at why Iowa head and neck cancer patients do or do not continue to get survivorship care from the same providers who treated their cancer. They found that people who had to drive farther to the treating facility, those who were unmarried, and those who only got one type of cancer treatment were more likely to discontinue survivorship care at Iowa Health Care.

## RESOURCES FOR IOWA'S CANCER SURVIVORS

Because of Iowa's increasing number of cancer survivors, survivorship care is only expected to become more important in Iowa over the coming decades. While many healthcare and community partners are invested in supporting Iowa's cancer survivors, we currently do not have robust enough services to provide survivorship care to Iowa's growing number of survivors. These services include: screening for cancer recurrence and second cancers; addressing late effects and delayed symptoms of cancer treatment; and, improving quality and quantity of life for cancer survivors through nutrition, exercise, smoking cessation, and other lifestyle and psychosocial support measures. However, **there are several resources available both to cancer survivors, and for those caring for cancer survivors in Iowa:**

**Above + Beyond Cancer:** Above + Beyond Cancer provides programs for survivors and caregivers, primarily in the central Iowa area.

**American Cancer Society Survivorship Resources:** The ACS provides a wealth of information for cancer survivors and caregivers on staying active and healthy during and after cancer treatment, as well as managing health care as a cancer survivor. ACS also manages the **Hope Lodge**, which provides patients a place to stay in the Iowa City area, as well as offers a hotel program for other locations in the state.

**A Time to Heal Cancer Foundation:** A Time to Heal provides support groups and programming for survivors and caregivers in Nebraska and Western Iowa.

**Cervivor:** Cervivor is a global community of patient advocates who inspire and empower those affected by cervical cancer by educating and motivating them to use their voices for creating awareness to end stigma, influence decision and change, and end cervical cancer.

**Cancer Care:** Professional oncology social workers provide free emotional and practical support for people with cancer, caregivers, loved ones, and the bereaved.

**Children's Cancer Connection (CCC):** Connects Iowa families affected by childhood cancer by providing opportunities that encourage relationships and strengthen community. CCC serves families treated, living, or diagnosed in the state of Iowa, regardless of treatment outcome, providing unique and unforgettable programming for the entire family through their entire journey.

**Cancer Support Community Iowa & NW Illinois at Gilda's Club:** Gilda's Club provides free support groups, educational programming, social activities, healthy lifestyle workshops, and more.

**National Coalition for Cancer Survivorship (NCCS):** NCCS is an advocacy group that works for quality cancer care for all people touched by cancer. Their **survivorship checklist** may be particularly helpful.

**Beyond Pink TEAM:** The Beyond Pink TEAM is a local breast cancer coalition located in the Cedar Valley.

## RESOURCES FOR HEALTHCARE PROVIDERS

**American Cancer Society Survivorship Care Guidelines:** ACS's survivorship care guidelines provide information for healthcare providers on how to care for those who are living with a prior diagnosis of cancer.

**American Cancer Society National Navigation Roundtable:** ACS's National Navigation Roundtable provides a wealth of resources on patient navigation and how it can support cancer care.

**National Coalition for Cancer Survivors (NCCS):** The NCCS also has tools for healthcare providers to help them understand how to better advocate for their patients.

**Centers for Disease Control and Prevention:** This resource from the CDC provides specific guidance and training for providers who are interested in better learning how to talk to their patients about mental health concerns.

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## REFERENCES

1. Data are from registries participating in the SEER 8 program, which were the original 8 registries funded by the National Cancer Institute's Surveillance, Epidemiology, and End Results Program back in 1973. Because these registries have data going so far back in time, we feel more confident that cancer prevalence estimates including all cases diagnosed for the last 50 years will be representative of the "true" prevalence of cancer.
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