The Illinois State Cancer Registry is a program within the Illinois Department of Public Health's Division of Epidemiologic Studies and was created in 1986 by the Illinois Health and Hazardous Substances Registry Act. The Cancer Registry has a staff of seven, plus a registry manager. The registry collects information on cancer cases diagnosed or treated in Illinois. Hospitals, ambulatory surgical treatment centers, non-hospital affiliated radiation therapy treatment centers, independent pathology labs, and physicians are required to report to the registry. Eleven other state cancer registries voluntarily report cancer patient data for Illinois residents who are diagnosed and/or treated out of state.

Cancer information is collected by certified tumor registrars who have successfully completed the training and passed the examination required by the National Cancer Registrar's Association. Ongoing continuing education is required to maintain certification. The registry has staff with many years of service as cancer registrars. These legacy employees are one reason the Illinois State Cancer Registry has achieved “Gold Certification,” the highest level, from the North American Association of Central Cancer Registries for the past 19 years.

All information about the patient and the facility that reported the cancer is kept confidential.
What is cancer incidence?

A cancer incidence rate is the number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population at risk. That is:

\[
\text{Incidence rate} = \left( \frac{\text{New cancers}}{\text{Population}} \right) \times 100,000
\]

The numerator of the incidence rate is the number of new cancers; the denominator is the size of the population. The number of new cancers may include multiple primary cancers occurring in one patient. The primary site reported is the site of origin and not the metastatic site. In general, the incidence rate would not include recurrences. The population used depends on the rate to be calculated. For cancer sites that occur in only one sex, the sex-specific population (e.g., females for cervical cancer) is used.

An age-adjusted rate is a weighted average of the age-specific rates, where the weights are the proportions of persons in the corresponding age groups of a standard population. The potential confounding effect of age is reduced when comparing age-adjusted rates computed using the same standard population.

What is cancer mortality?

A cancer mortality rate is the number of deaths, with cancer as the underlying cause of death, occurring in a specified population during a year. Cancer mortality is usually expressed as the number of deaths due to cancer per 100,000 population. That is:

\[
\text{Mortality Rate} = \left( \frac{\text{Cancer Deaths}}{\text{Population}} \right) \times 100,000
\]

The numerator of the mortality rate is the number of deaths; the denominator is the size of the population. The population used depends on the rate to be calculated. For cancer sites that occur in only one sex, the sex-specific population (e.g., females for cervical cancer) is used. The mortality rate can be computed for a given cancer site or for all cancers combined.
Why collect cancer information?

The Illinois State Cancer Registry is one of 50 state central cancer registries in the United States. All central cancer registries share the same common activities and purposes. Most central cancer registries in the U.S. funnel data (but not personal identifiers) into a national cancer data base maintained by the U.S. Centers for Disease Control and Prevention.

Cancer data collection by central cancer registries is also called cancer surveillance. Cancer data are used to “see” the impact of cancer, trends in various populations, patterns of occurrence, and much more.

◆ Doctors and researchers use cancer data to learn more about the causes of cancer.
◆ Doctors and researchers use cancer data to learn how to detect cancers earlier, when they are more treatable.
◆ Cancer specialists make treatment choices based on accurate cancer data.
◆ Cancer data may point to environmental risk factors or high risk behaviors.
◆ Cancer data may be used to make important public health decisions about where to direct funds or where to implement screening programs.
◆ Cancer data may be used to show whether programs aimed at modifying risky behavior or increasing screening for people who are at risk are effective.
◆ Cancer data may be used to advance clinical, epidemiologic, and health services research.
◆ Cancer data may be used to determine what present and future resources are needed in a specific area; these could be medical resources, such as physicians, cancer specialists, hospitals, or other types of social services, or support services such as patient transport.
Every Day in Illinois...

- **183** people are diagnosed with cancer
- **28** women are diagnosed with breast cancer
- **20** men are diagnosed with prostate cancer
- **17** people are diagnosed with colorectal cancer
- **26** people are diagnosed with lung cancer
- **67** people die from cancer

Cancer is the second leading cause of death among United States and Illinois residents.

Cancer surveillance activities have been used to develop effective strategies to reduce cancer deaths and strategies for preventing new cases of cancer that include behavioral and environmental changes for some cancer types.
### Top 10 Cancer Cases in Men

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Rate per 100,000</th>
<th>Number of Cases</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>102.4</td>
<td>7,214</td>
<td>22.2%</td>
</tr>
<tr>
<td>Lung and Bronchus</td>
<td>76.0</td>
<td>4,878</td>
<td>15.0%</td>
</tr>
<tr>
<td>Colon and Rectum</td>
<td>49.6</td>
<td>3,225</td>
<td>9.9%</td>
</tr>
<tr>
<td>Urinary Bladder</td>
<td>36.5</td>
<td>2,261</td>
<td>7.0%</td>
</tr>
<tr>
<td>Kidney and Renal Pelvis</td>
<td>24.8</td>
<td>1,658</td>
<td>5.1%</td>
</tr>
<tr>
<td>Melanoma of the Skin</td>
<td>23.6</td>
<td>1,523</td>
<td>4.7%</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>23.1</td>
<td>1,486</td>
<td>4.6%</td>
</tr>
<tr>
<td>Oral Cavity and Pharynx</td>
<td>17.5</td>
<td>1,219</td>
<td>3.7%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>16.5</td>
<td>1,031</td>
<td>3.2%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>15.4</td>
<td>997</td>
<td>3.1%</td>
</tr>
</tbody>
</table>

### Top 10 Cancer Cases in Women

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Rate per 100,000</th>
<th>Number of Cases</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>133.5</td>
<td>10,192</td>
<td>29.8%</td>
</tr>
<tr>
<td>Lung and Bronchus</td>
<td>58.1</td>
<td>4,650</td>
<td>13.6%</td>
</tr>
<tr>
<td>Colon and Rectum</td>
<td>36.5</td>
<td>2,917</td>
<td>8.5%</td>
</tr>
<tr>
<td>Corpus and Uterus</td>
<td>29.4</td>
<td>2,367</td>
<td>6.9%</td>
</tr>
<tr>
<td>Thyroid</td>
<td>22.3</td>
<td>1,524</td>
<td>4.5%</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>17.0</td>
<td>1,321</td>
<td>3.9%</td>
</tr>
<tr>
<td>Melanoma of the Skin</td>
<td>15.4</td>
<td>1,144</td>
<td>3.3%</td>
</tr>
<tr>
<td>Kidney and Renal Pelvis</td>
<td>12.1</td>
<td>954</td>
<td>2.8%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>11.2</td>
<td>913</td>
<td>2.7%</td>
</tr>
<tr>
<td>Ovary</td>
<td>10.9</td>
<td>845</td>
<td>2.5%</td>
</tr>
</tbody>
</table>

Epidemiology is the study of the distribution and causes of diseases in human populations. It is concerned with the frequency and type of illness in groups of people, not individuals.

Central cancer registries collect data on all cancer cases within a defined population, such as a state or region.

Cancer Projections

This map shows the number of cancer cases projected for each county for 2018.

In the year 2018, Illinois anticipates a total of 70,235 cancer cases.

Cancer data in Illinois is collected in a standard format so it can be compiled with other state registries to form a national database of cancer data.

Each year Illinois cancer registry staff process about 106,000 cancer reports for about 70,000 cancer patients.

Source: Incidence projections were derived from cancer incidence data from the Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2016.
Melanoma Skin Cancer

What is Melanoma?

Melanoma is a form of skin cancer that begins in the deepest layer of your skin. Skin produces a pigment called melanin which is what gives it its color. When the skin is exposed to sun, melanocytes produce more melanin pigment, causing the skin to tan or darken. Melanocytes are the cells that can become melanoma.

Cancer starts when cells in the body begin to grow out of control, and skin cancer is by far one of the most common of all cancers. Melanoma accounts for about 1% of all skin cancers, but it is the most deadly form of skin cancer because it is more likely to spread to other parts of the body if not caught early.

The incidence and mortality rates for melanoma are highest in whites, who have a much higher risk of developing melanoma than African Americans or people with darkly pigmented skin. In fact, melanoma is 20 times more common in whites than in African Americans... but anyone can develop melanoma, regardless of skin color.

Over the last 30 years the number of new cases of melanoma has been increasing, the rate of melanoma among whites has increased by more than 60 percent from 1991 to 2011. In the U.S. in 2017, it is estimated that about 87,110 new melanomas will be diagnosed, and about 9,730 people will die of melanoma.

How do I get Melanoma?

Too much UV radiation can damage the DNA in your skin cells. The main source of UV rays is the sun, as well as man-made sources such as tanning beds. There are two wavelengths that play a role in the sun's effect on your skin:

- **UVA rays** are mainly linked to long-term skin damage such as wrinkles, but they are also thought to play a role in the development of skin cancers.
- **UVB rays** are the main rays that cause sunburns, they play a key role in the development of skin cancer.

While many risk factors have been found, it's not always clear exactly what causes melanoma skin cancer. Ultraviolet (UV) rays damage the DNA of skin cells, cancers begin when this damage affects the genes that control skin growth.

*American Cancer Society, released May 2016; Centers for Disease Control and Prevention, released August 2016*
Think it can’t happen to you?

- About 1.1 million people in the United States are living with melanoma of the skin
- Even if your skin does not burn after tanning you are still damaging your skin and are at a higher risk of melanoma
- Having darkly pigmented skin lowers your risk of melanoma at the more common sites; such as your chest, back, and legs…but anyone can develop melanoma on the palms of hands, soles of feet, and under the nails
- While the average age of diagnosis is 63 years old, melanoma is not uncommon among those younger than 30, it is one of the most common cancers in young adults…especially young women
- Being female doesn’t mean that you aren’t at risk of melanoma; women younger than 50 years old are at a higher risk than men of the same age group

How can I prevent Melanoma?

Protection from the sun: History of blistering sunburns at a young age increases your risk of developing melanoma as an adult.

Watch for abnormal moles: Checking your skin regularly may help you spot any new or abnormal moles; most melanomas are brought to a doctor’s attention because of signs or symptoms a person is having.

Limit exposure to UV rays: Seek shade, apply sunscreen, wear protective clothing, and avoid using tanning beds and sunlamps.

Consult a doctor if needed: If you have any concerns, ask your doctor, no matter how small it might seem. The earlier the melanoma is caught, the easier it is to treat.
Risk of Melanoma

Am I at risk for Melanoma?

A risk factor is anything that increases your chances of developing a disease. It is unknown why one person gets melanoma and another does not; however, evidence has shown that people with certain risk factors are more likely than others to develop melanoma.

You are considered at “high risk” of melanoma if you have multiple risk factors. Having a risk factor, or many risk factors, does not mean that you will develop melanoma. Many high-risk individuals never get melanoma, while others with this disease may have no known risk factors. The following factors put you at risk for melanoma:

- UV light exposure
- Many common moles
- Fair skin that burns easily, freckles, light hair, blue or green eyes
- At least one severe, blistering sunburn
- Being older
- Being male, although this varies by age
- Family history of melanoma
- Personal history of melanoma or other skin cancers
- Having a weak immune system

What is my overall lifetime risk of getting melanoma?

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Risk Rate</th>
<th>(1 in X)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whites</td>
<td>2.5%</td>
<td>(1 in 40)</td>
</tr>
<tr>
<td>Hispanics</td>
<td>.5%</td>
<td>(1 in 200)</td>
</tr>
<tr>
<td>Blacks</td>
<td>.1%</td>
<td>(1 in 1,000)</td>
</tr>
</tbody>
</table>

How does melanoma in Illinois compare to the United States?

Data from 2014 shows the incidence rate of melanoma in Illinois is significantly lower than the incidence rate in the United States.

The mortality rate in Illinois is relatively similar to the mortality rate in the U.S., although the Illinois rate is slightly lower.

Protecting Your Skin from Ultraviolet Rays

UV Radiation and UV Index

It is important to pay attention to the UV Index, a tool used to forecast the risk of overexposure to UV rays—letting you know when to take caution when working, playing, or relaxing outside. The UV index is based on several factors, and is updated regularly. There are several apps available for your phone which will tell you the current UV index in your area.

<table>
<thead>
<tr>
<th>UV INDEX</th>
<th>Sunburn Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 TO 2</td>
<td>1 HOUR OR MORE</td>
</tr>
<tr>
<td>3 TO 5</td>
<td>40 MIN.</td>
</tr>
<tr>
<td>6 TO 7</td>
<td>30 MIN.</td>
</tr>
<tr>
<td>8 TO 10</td>
<td>20 MIN.</td>
</tr>
<tr>
<td>11 +</td>
<td>15 MIN. OR LESS</td>
</tr>
</tbody>
</table>

NO DANGER TO THE AVERAGE PERSON
LITTLE RISK OF HARM FROM UNPROTECTED SUN EXPOSURE
HIGH RISK OF HARM FROM UNPROTECTED SUN EXPOSURE
VERY HIGH RISK OF HARM FROM UNPROTECTED SUN EXPOSURE
EXTREME RISK OF HARM FROM UNPROTECTED SUN EXPOSURE

UV Exposure and Tanning Beds

UV rays are likely a major cause of melanoma. UV radiation from the sun and artificial sources, such as tanning beds and sunlamps, has been declared a known carcinogen, or cancer-causing substance.

Melanoma is increasing faster in women 15 to 29 years old than in young men of the same age—It is likely that the reason the rate of melanoma is higher in young women than young men is due to the widespread use of indoor tanning among females.

◆ 70 percent of tanning salon patrons are young Caucasian females
◆ Indoor tanning before age 35 can increase your risk of melanoma by 75%, and the risk increases with each use

There is no safe level of UV exposure from the sun or indoor tanning devices without increasing the risk of skin cancer. However, that does not mean that you can’t enjoy the sun responsibly. Avoiding extended sun exposure, paying attention to the UV index, and using sunscreen may reduce your risk of melanoma. Choosing the right sunscreen is important – you should look for a sunscreen that states on the label...

◆ Broad Spectrum, which means that the sunscreen protects the skin from both UVA and UVB rays
◆ SPF 30 or Higher, SPF (sun protection factor) indicates how well a sunscreen protects you from sunburn
◆ Water Resistant, it is important to remember that sunscreens are not waterproof or sweatproof, and should be reapplied every 40 to 80 minutes

American Academy of Dermatology

Centers for Disease Control and Prevention, released August 2016

Illinois Indoor Tanning Legislation and Regulations — IL Administrative Code Title 77; Section 795.190

In May of 2014 Illinois legislation, the “Tanning Facilities Code”, went into effect stating that no minors under the age of 18 years old are allowed to use tanning equipment, regardless of parental consent.

Illinois is one of 15 states that have banned the use of ultraviolet tanning devices for all persons under 18 years of age.
Screening Recommendations

Melanoma Screening

Early detection of melanoma allows for more treatment options and a higher rate of survival. Everyone should perform self skin-exams about once a month, and contact a health care professional if there is anything out of the ordinary. Melanomas often start as small, mole-like growths that increase in size and change color. Know the pattern of moles, blemishes, and freckles so that any new moles or changes in existing skin markings are evident. In addition to self-skin exams, see a health care professional for annual skin exams.

The ABCDE rule of melanoma is a good tool to use during regular self-skin exams, to help identify some of the most common signs of melanoma. In addition to the ABCDE rule, look for any warning signs of melanoma.

It is important for people who are at high risk of melanoma to have regular skin exams with a health care professional. Some doctors will perform skin exams as part of a routine health check-up or physical, but it may be beneficial to see a dermatologist, a doctor who specializes in skin, on a regular basis.

Warning Signs of Melanoma

- A sore that doesn’t heal
- Spread of pigment from the border of the spot into surrounding skin
- Redness or a new swelling beyond the border of the mole
- Change in sensation, such as itchiness, tenderness, or pain
- Change in the surface of a mole, such as scaliness, oozing, bleeding, or the appearance of a lump

What if I find an abnormal area?

If you find an abnormal area that might be skin cancer, the next step is to contact a health care professional. It is important to have honest, open discussions with your doctor. The doctor will examine affected skin to determine if it is melanoma, another form of skin cancer, or some other skin condition. If melanoma is found, there are tests that may be done to find out if it has spread to other parts of the body.

If the doctor suspects that the abnormal area might be melanoma, the area will be removed and sent to a lab to be looked at under a microscope. This is called a skin biopsy, this will help your doctor determine how the melanoma should be treated.

American Cancer Society, released May 2016
ABCDE Rule of Melanoma

The ABCDE rule should be used as a guide to some of the usual signs of melanoma. Tell your doctor about markings that have any of the following features:

**Asymmetry:**
halves of mole do not match

**Border:**
edges are irregular, ragged or blurred

**Color:**
inconsistent and may include shades of brown or black, sometimes with pink, white, red, or blue

**Diameter:**
mole or birthmark larger than 6 millimeters across

**Evolving:**
changing in size, shape, or color
Research Projects

The Illinois State Cancer Registry has a long history of participating in valuable research. When the registry is contacted to provide data or linkages for studies, an extensive process is used to guarantee patient confidentiality is protected. Part of this process is review and approval from an institutional review board (IRB). An IRB ensures research is conducted in accordance with rules outlined by the Code of Federal Regulations, which governs human subjects research and is designed to protect patients. A few of the studies the registry participated in are listed below. Several of these studies have been ongoing for many years and have contributed significantly to the knowledge about cancer.

Black Women’s Health Study

Black women are more likely to develop certain health problems than white women. Until the 1990s, most of the studies of women’s health included only small numbers of black women or none at all. Improving the health of black women required more knowledge of the causes of these health problems and also more knowledge about how women stay healthy. More knowledge meant more research. The Black Women’s Health Study (BWHS) was begun in 1995 to play a key role in carrying out this research.

The BWHS gathers information on many conditions that affect black women, including breast cancer, lupus, premature birth, hypertension, colon cancer, diabetes, and uterine fibroids. The BWHS is a “follow-up” study, following the 59,000 women who enrolled in 1995 over time. When the participants entered the study, they provided information on factors that might influence health and disease, such as contraceptive use, cigarette smoking, and diet. At regular intervals, participants provide updated information on these factors and on any illnesses they develop.

www.bu.edu.bwhs/history

Assisted Reproductive Technology Study

Women who have never been able to conceive are at increased risk of uterine and ovarian cancers. Certain factors or conditions, such as endometriosis, older age at first pregnancy, polycystic ovarian syndrome, and pelvic inflammatory disease, have each been associated with greater risk of gynecologic cancers. The use of assisted reproductive technology (ART), defined as medical procedures involving the ex vivo manipulation of gametes to achieve conception, has risen steadily in the United States during the past two decades and women have increasingly turned to ART to address infertility issues. In Illinois, there are more than 3,000 ART births per year and the state ranks fifth in the nation for total number of births per year. The Assisted Reproductive Technology and the Risk of Cancer in Women study is designed to examine the cancer risk among women treated for infertility with assisted reproductive technologies between 2004 and 2009 in three states, including Illinois. The study is funded by the National Cancer Institute.
The Nurses’ Health Study I and The Nurses’ Health Study II

These two studies are among the largest and longest running investigations of factors that influence women’s health. Started in 1976 and expanded in 1989, the information provided by the 238,000 dedicated nurse-participants has led to many new insights on health and disease. While the prevention of cancer is still a primary focus, the study also has produced landmark data on cardiovascular disease, diabetes, and many other conditions. Most importantly, these studies have shown diet, physical activity, and other lifestyle factors can powerfully promote better health. These studies are funded by the National Institutes of Health.

www.channing.harvard.edu/nhs

The Health Professionals Follow-up Study

The Health Professionals Follow-Up Study began in 1986. The purpose of the study is to evaluate a series of hypotheses about men’s health relating nutritional factors to the incidence of serious illnesses, such as cancer, heart disease, and other vascular diseases. This all-male study is sponsored by the Harvard School of Public Health and is funded by the National Cancer Institute.

www.hsph.harvard.edu/hpfs

Cancer Prevention Study II (CPS II)

The Cancer Prevention Study II (CPS-II), which began in 1982, is a prospective mortality study of approximately 1.2 million American men and women. The registry participates in the subset CPS-II Nutrition Survey. The CPS-II Nutrition Survey was established: (1) to obtain detailed information on dietary exposures and to update with additional exposure information, and (2) to conduct prospective cancer incidence follow-up in addition to mortality follow-up. The Illinois State Cancer Registry performs a data linkage to validate self-reported cancers as part of the ongoing cancer incidence follow-up for the survey. This study is performed and funded by the American Cancer Society.

www.cancer.org/research/researchtopreventcancer

Transplant Cancer Match Study

Cancer is a major adverse outcome of solid organ transplantation. The elevated risk of cancer is largely due to immunosuppression. The Transplant Cancer Match Study linked the U.S. solid organ transplant registry with state and regional cancer registries to get an overview of the cancer risk in more than 175,000 transplant recipients of all organ types. The study was designed to get a better understanding of cancer risk in transplant recipients to help clarify the role of the immune system, infections and other factors in the development of malignancy, and to identify opportunities to improve transplant safety.

JAMA, November 2, 2011—Vol. 306, No. 17

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The Illinois Department of Public Health, Illinois State Cancer Registry, makes the cancer incidence data available as a public service. Use of these data does not constitute an endorsement of the user’s opinion or conclusions by the Department and none should be inferred.

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