Who We Are

The Illinois State Cancer Registry is the only source of population-based cancer information in Illinois.

Cancer registry staff have 143 years of combined experience as certified tumor registrars.

What We Do

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 12 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 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 15 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,

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

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.

— www.cancer.gov

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,

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

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.

— www.cancer.gov
Why is it important to 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 the eyes 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…….

- **173** people are diagnosed with cancer
- **65** people die from cancer-related causes
- **25** women are diagnosed with breast cancer
- **22** men are diagnosed with prostate cancer
- **17** people are diagnosed with colorectal cancer
- **24** people are diagnosed with lung cancer

Cancer is the second leading cause of death among Americans.

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.
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.

### Top 10 Cancers in Men–2010

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Rate (per 100,000)</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>127.0</td>
<td>25.4%</td>
</tr>
<tr>
<td>Lung and Bronchus</td>
<td>79.7</td>
<td>14.7%</td>
</tr>
<tr>
<td>Colon and Rectum</td>
<td>54.8</td>
<td>10.3%</td>
</tr>
<tr>
<td>Urinary Bladder</td>
<td>37.6</td>
<td>6.7%</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>24.3</td>
<td>4.5%</td>
</tr>
<tr>
<td>Kidney and Renal Pelvis</td>
<td>21.7</td>
<td>4.3%</td>
</tr>
<tr>
<td>Melanoma of the Skin</td>
<td>21.1</td>
<td>4.0%</td>
</tr>
<tr>
<td>Oral Cavity and Pharynx</td>
<td>17.0</td>
<td>3.5%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>16.7</td>
<td>3.1%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>14.7</td>
<td>2.7%</td>
</tr>
</tbody>
</table>


### Top 10 Cancer Deaths in Men

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Rate (per 100,000)</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung and Bronchus</td>
<td>62.1</td>
<td>29.3%</td>
</tr>
<tr>
<td>Prostate</td>
<td>22.6</td>
<td>9.6%</td>
</tr>
<tr>
<td>Colon and Rectum</td>
<td>20.1</td>
<td>9.5%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>13.0</td>
<td>6.1%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>9.9</td>
<td>4.4%</td>
</tr>
<tr>
<td>Esophagus</td>
<td>7.9</td>
<td>3.9%</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>8.3</td>
<td>3.8%</td>
</tr>
<tr>
<td>Liver</td>
<td>6.9</td>
<td>3.4%</td>
</tr>
<tr>
<td>Bladder</td>
<td>7.6</td>
<td>3.3%</td>
</tr>
<tr>
<td>Kidney</td>
<td>5.4</td>
<td>2.6%</td>
</tr>
</tbody>
</table>

U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, released April 2013.
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.

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Each year Illinois cancer registry staff process about 80,000 cancer reports for about 65,000 cancer patients.

### Top 10 Cancers in Women–2010

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Rate (per 100,000)</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>125.4</td>
<td>29.1%</td>
</tr>
<tr>
<td>Lung and Bronchus</td>
<td>58.4</td>
<td>13.8%</td>
</tr>
<tr>
<td>Colon and Rectum</td>
<td>39.1</td>
<td>9.5%</td>
</tr>
<tr>
<td>Corpus and Uterus</td>
<td>28.2</td>
<td>6.7%</td>
</tr>
<tr>
<td>Thyroid</td>
<td>19.4</td>
<td>4.1%</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>16.3</td>
<td>3.8%</td>
</tr>
<tr>
<td>Melanoma of the Skin</td>
<td>13.3</td>
<td>3.0%</td>
</tr>
<tr>
<td>Ovary</td>
<td>12.0</td>
<td>2.8%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>11.2</td>
<td>2.7%</td>
</tr>
<tr>
<td>Kidney and Renal Pelvis</td>
<td>11.7</td>
<td>2.7%</td>
</tr>
</tbody>
</table>


### Top 10 Cancer Deaths in Women

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Rate (per 100,000)</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung and Bronchus</td>
<td>41.2</td>
<td>26.1%</td>
</tr>
<tr>
<td>Breast</td>
<td>22.6</td>
<td>14.7%</td>
</tr>
<tr>
<td>Colon and Rectum</td>
<td>14.3</td>
<td>9.6%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>10.2</td>
<td>6.7%</td>
</tr>
<tr>
<td>Ovary</td>
<td>7.8</td>
<td>5.0%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>5.6</td>
<td>3.7%</td>
</tr>
<tr>
<td>Corpus and Uterus</td>
<td>5.3</td>
<td>3.4%</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>4.8</td>
<td>3.2%</td>
</tr>
<tr>
<td>Brain and Nervous System</td>
<td>3.3</td>
<td>2.0%</td>
</tr>
<tr>
<td>Kidney</td>
<td>2.9</td>
<td>1.9%</td>
</tr>
</tbody>
</table>

U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, released April 2013
Colorectal Cancer in Illinois

Colorectal cancer (CRC) is currently the third most commonly diagnosed cancer in the state of Illinois for both men and women and all races, representing 9.9% of all cancer diagnosed in 2010. It is the second most common cause of cancer-related deaths, causing 9.5% of cancer deaths in 2010. Colorectal cancer can affect organs that include the colon, rectum, and appendix. There is no exact cause known for CRC, but several risk factors have been identified. They include:

- Age — most cases occur after age 50
- Personal or family history of CRC or polyps
- Conditions that cause inflammation of the colon
- Diet high in fat and low in calcium, folate, and fiber
- Obesity
- Physical inactivity
- Long-term smoking
- Heavy alcohol consumption

What is the Colon and Rectum?

The colon and rectum are parts of the digestive system, which is also called the gastrointestinal (GI) system. The first part of the digestive system (the stomach and small intestine) processes food for energy while the last part (the colon and rectum) absorbs fluid to form solid waste (fecal matter or stool) that then passes from the body.

The small intestine joins the large intestine (or large bowel) in the right lower abdomen. Most of the large intestine is made up of the colon, a muscular tube about 5 feet long. The colon absorbs water and salt from food matter and serves as a storage place for waste matter.

The rectum is the final 6 inches of the digestive system. Waste matter goes into the rectum where it is stored until it passes out of the body through the anus.

Regular colorectal cancer screening is one of the most powerful weapons for preventing colorectal cancer. Screening is the process of looking for cancer or precancer in people who have no symptoms of the disease.

— American Cancer Society
What Kind of Tests are Done to Find Colorectal Cancer?

**Colonoscopy:** For this test, the doctor looks at the entire length of the colon and rectum with a colonoscope. The colonoscope has a video camera on the end that is connected to a display monitor so the doctor can see and examine the inside of the colon. Special instruments can be passed through the colonoscope to remove any suspicious-looking areas such as polyps, if needed.

**Virtual colonoscopy:** This test is an advanced type of computed tomography (CT or CAT) scan of the colon and rectum. A CT scan is an x-ray test that produces detailed cross-sectional images of your body.

**Stool occult blood testing:** This test is used to find occult blood (blood that can’t be seen with the naked eye) in feces.

**Sigmoidoscopy:** During this test, the doctor looks at part of the colon and rectum with a sigmoidoscope—a flexible, lighted tube about the thickness of a finger with a small video camera on the end.

— American Cancer Society

Are We Getting Screened?

Prevention and control of colorectal cancer focuses on screenings, which include colonoscopies, sigmoidoscopies, and blood stool tests for people older than 50 years of age. The U.S. Preventive Services Task Force recommends the following:

- sigmoidoscopies should be done every five years,
- colonoscopies should be done every 10 years, and
- blood stool tests should be done every year.

You should check with your doctor to see if you need to schedule one of these life-saving preventive procedures.

Data from the Illinois Behavioral Risk Factor Surveillance System (BRFSS) showed that in 2010, 61.7 percent of people in Illinois reported ever having a colonoscopy or sigmoidoscopy. This percent has increased steadily since 2002. However, the percent of Illinois residents ever having a blood stool test has decreased since 2002; 34 percent of residents reported having this test.
The Illinois age-adjusted colorectal cancer incidence rate for both genders and all races from 2006-2010 was 50.21 cases per 100,000. Nine counties across Illinois had incidence rates that were significantly higher than the rate for Illinois, and seven counties had rates that were significantly lower. Counties with the highest incidence rates include Crawford, Gallatin and Hamilton.

### Illinois Rate 50.21

- **Purple**: significantly higher than Illinois rate
- **Green**: not significantly different than Illinois rate
- **Orange**: significantly lower than Illinois rate
- **Gray**: count not sufficient to produce stable rating

**Source:** Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2012.
The age-adjusted colorectal cancer mortality rate for both genders and all races in Illinois was 18.1 per 100,000 for 2006-2010. Five counties showed rates that were significantly higher than that for Illinois, and five counties had significantly lower rates. Illinois counties with the highest mortality rates include Hamilton, Clinton and Saline.

Illinois Rate 18.1

- significantly higher than Illinois rate
- not significantly different than Illinois rate
- significantly lower than Illinois rate
- count not sufficient to produce stable rating

Did you know there is a world-wide shortage of certified tumor registrars? More information about this rewarding career can be found at www.ncra-usa.org.

According to the National Cancer Institute, cancer care cost the United States an estimated $125 billion in 2010 and costs are expected to rise to at least $158 billion by 2020.

This map shows the number of cancer cases projected for each county for 2014.

In 2014, Illinois expects a total of 66,190 cancer cases.

Source: Incidence projections were derived from cancer incidence data from the Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2012.
Research Projects

The Illinois State Cancer Registry has a long history of participating in valuable research through data sets or data linkages. When the registry is contacted to provide data or linkages for studies, an extensive process is used to guarantee that patient confidentiality is protected. Part of this process is review and approval from an institutional review board (IRB). An IRB ensures that 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 that the registry participated in are listed below. Several of these studies have been ongoing for many years and have contributed significantly to our 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 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](http://www.bu.edu.bwhs/history)
The 13 employees of the Illinois State Cancer Registry have 187 combined years of experience with the Illinois Department of Public Health.

The Illinois State Cancer Registry has been certified as a “Gold Registry” for the past 15 years. Gold certification is the highest level and cancer data must meet strict guidelines for quality, completeness and timeliness to qualify.

Cancer Among U.S. Firefighters

In 2010, the National Institute of Occupational Safety and Health (NIOSH), with funding assistance from the U.S. Fire Administration, launched a multi-year study to examine whether firefighters have a higher risk of cancer and other causes of death due to job exposures. It is the largest study of U.S. firefighters ever undertaken and both non-white and female firefighters are represented. www.cdc.gov/niosh/firefighters/cii07.html

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 that 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 (HPFS) 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. ISCR 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

Cancer Resources
Illinois Department of Public Health
Office of Women’s Health
http://www.idph.state.il.us/about/womenshealth/concern.htm
American Cancer Society
www.cancer.org
National Cancer Institute
www.cancer.gov
U.S. Centers for Disease Control and Prevention
www.cdc.gov
Illinois Breast and Cervical Cancer Program
http://www.cancerscreening.illinois.gov
Illinois Tobacco Quitline
www.quityes.org • 1-866-QUIT-YES

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The Illinois Department of Public Health, Illinois State Cancer Registry (ISCR), 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.

This publication would not have been possible without the assistance of the Illinois State Cancer Registry staff, the personnel at the reporting facilities who diagnose or treat cancer patients throughout Illinois, and the staff members at other state central cancer registries with data exchange agreements.