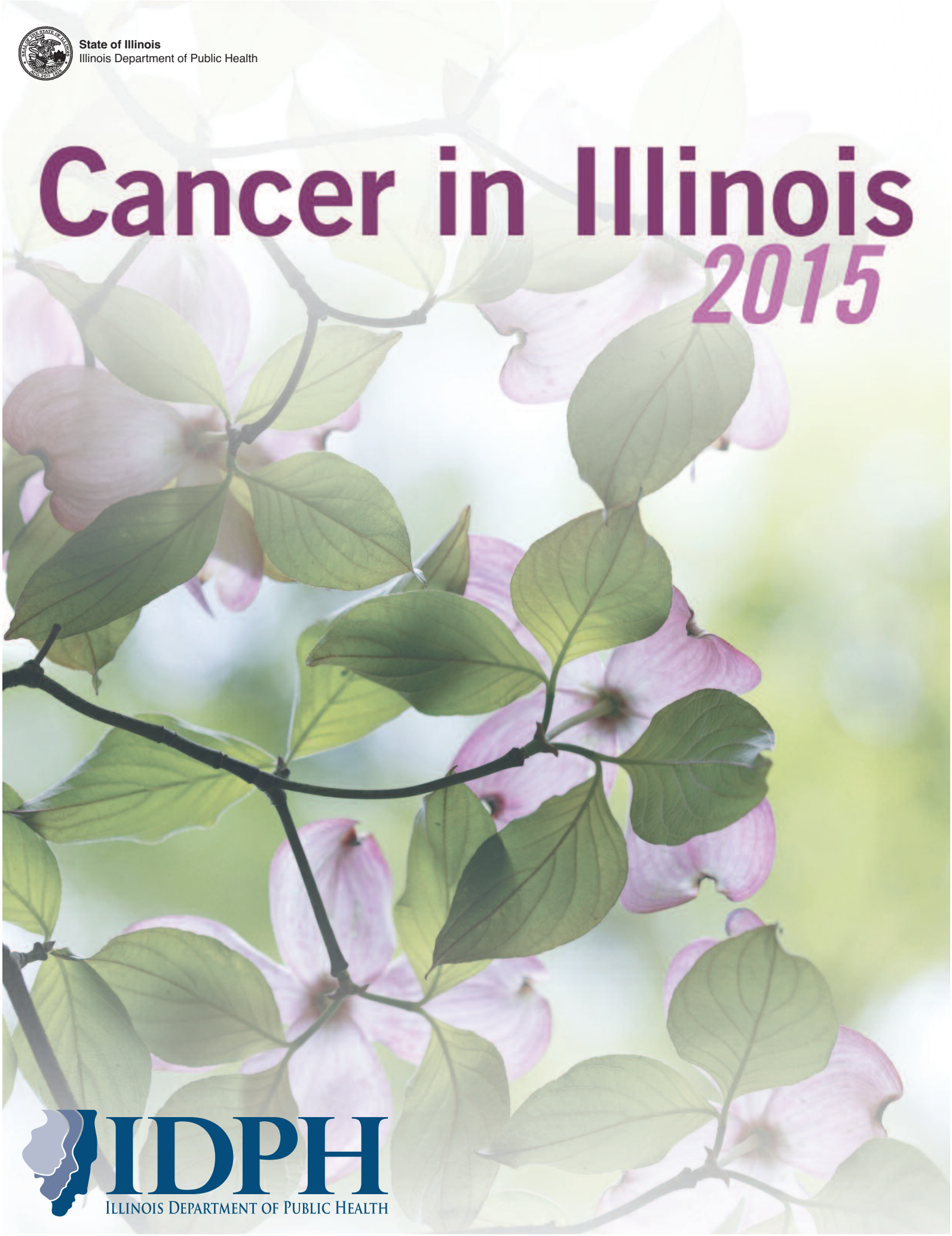
State of Illinois
Illinois Department of Public Health

Cancer in Illinois 2015



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Illinois Department of Public Health

Who We Are

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

Cancer registry staff have 119 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 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 17 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:

Incidence rate = (New cancers/Population) × 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*

For a cancer case to be complete it must have information about the person (where they were born, age, where they live), information on the type of cancer and its treatment.

What is cancer mortality?

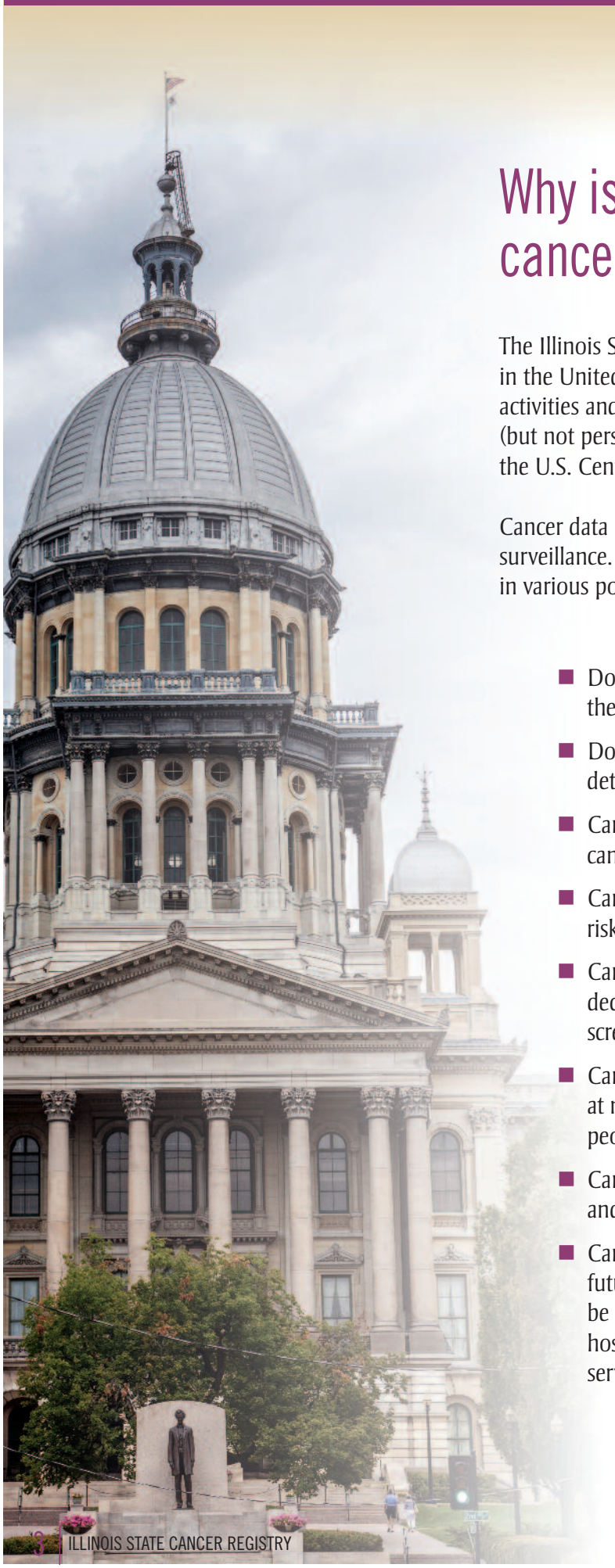
A **cancer mortality rate** is the number of deaths, with cancer as the underlying cause of death, occurring in a specified population during a year. Cancer mortality is usually expressed as the number of deaths due to cancer per 100,000 population. That is:

Mortality Rate = (Cancer Deaths/Population) × 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*

To determine a cancer rate, researchers must have the population characteristics of the area. This is usually obtained from the U.S. Census.



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 (CDC).

Cancer data collection by central cancer registries also is 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.....

- **176** people are diagnosed with cancer
- **26** women are diagnosed with breast cancer
- **21** men are diagnosed with prostate cancer
- **17** people are diagnosed with colorectal cancer
- **25** people are diagnosed with lung cancer
- **67** people die from 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 Cancer Cases in Men

Type of Cancer	Rate per 100,000	Number of Cases	Percent of Total
Prostate	112.3	7,526	23.6%
Lung and Bronchus	77.4	4,734	14.8%
Colon and Rectum	51.5	3,194	10.0%
Urinary Bladder	35.8	2,121	6.6%
Kidney & Renal Pelvis	23.1	1,507	4.7%
Melanoma of the Skin	23.1	1,430	4.5%
Non-Hodgkin Lymphoma	22.2	1,357	4.3%
Oral Cavity & Pharynx	17.8	1,191	3.7%
Leukemia	17.3	1,047	3.3%
Pancreas	14.3	899	2.8%

Illinois Department of Public Health, Illinois State Cancer Registry, public data file, data as of November 2014.

Top 10 Cancer Cases in Women

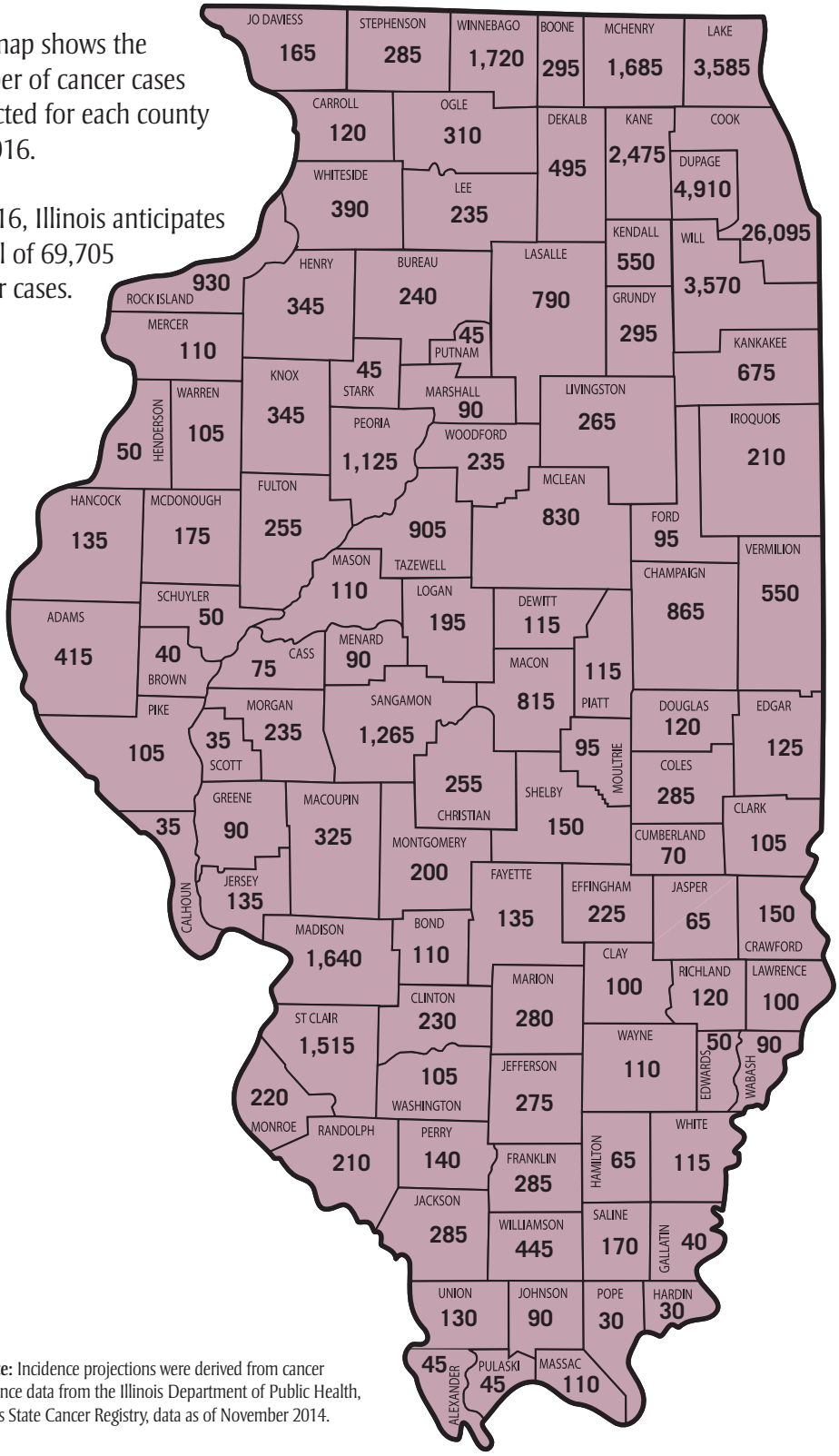
Type of Cancer	Rate per 100,000	Number of Cases	Percent of Total
Breast	126.0	9,426	29.0%
Lung and Bronchus	57.5	4,428	13.6%
Colon and Rectum	37.0	2,893	8.9%
Corpus and Uterus	28.5	2,227	6.9%
Thyroid	22.6	1,532	4.7%
Non-Hodgkin Lymphoma	15.7	1,196	3.7%
Melanoma of the Skin	15.6	1,114	3.4%
Kidney and Renal Pelvis	12.4	938	2.9%
Pancreas	11.5	905	2.8%
Ovary	11.2	846	2.6%

Illinois Department of Public Health, Illinois State Cancer Registry, public data file, data as of November 2014.

Cancer Projections

This map shows the number of cancer cases projected for each county for 2016.

In 2016, Illinois anticipates a total of 69,705 cancer cases.

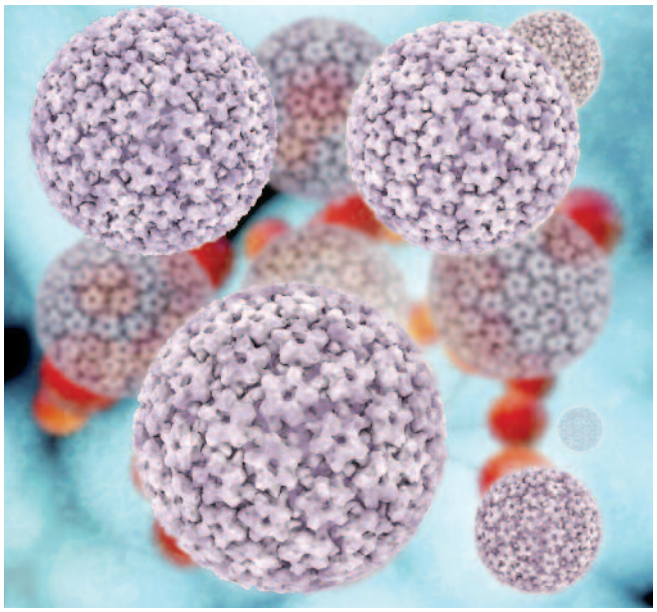


Cancer data in Illinois is collected in a standard format so it can be compiled with other state registries to form a national database of cancer data.

Each year Illinois cancer registry staff process about 92,000 cancer reports for about 65,000 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 2014.

HPV-Related Cancer



What is HPV?

HPV or Human papillomavirus (pap-ah-LO-mah- VYE-rus) is a group of more than 150 separate but related viruses that can lead to conditions such as genital warts and certain cancers. About 79 million people in the United States are infected with HPV. With 14 million new infections every year, it is the most common sexually transmitted disease. Almost all sexually active persons will become infected with HPV at some point in time in their lifetime. This is true for both men and women. Lacking symptoms of an HPV infection does not mean a person is not infected. You may be infected with HPV and never know; this is true especially for men.

Each of the 150 types of HPV are given or assigned a number and categorized into low and high risk, based on the ability of the HPV type to cause cancer. Low risk types, such as HPV 6 and HPV 11 don't lead to cancer, but they are responsible for 90 percent of all genital warts. High risk HPV types have the ability to cause cancer of the genitals, mouth, anus, and other regions. It is important to know that you can be infected by more than one type of HPV at a time. This includes being infected with a high risk type and a low risk type at the same time.

More than 40 HPV types can infect the genital areas of men and women, including the skin of the penis, vulva, and anus, and the linings of the vagina, cervix, and rectum. These types can also infect the lining of the mouth and throat. About 90 percent of HPV infections have no symptoms and go away within two years when the immune system fights off HPV naturally. But when HPV does not go away, it can cause health problems like genital warts and cancer. Genital warts usually appear as a small bump or group of bumps in the genital area. They can be small or large, raised or flat, or shaped like a cauliflower. A health care provider can usually diagnose warts by looking at the genital area.

http://www.cdc.gov/hpv/whatishpv.html accessed 7/20/15; http://www.cdc.gov/std/hpv/hpv-factsheet-march-2014.pdf; http://www.cdc.gov/std/stats/sti-estimates-fact-sheet-feb-2013.pdf

How do I get HPV?

HPV is transmitted through intimate skin to skin contact (i.e. vaginal, oral, or anal sex) with someone who is infected. Oral and anal sex are the most common ways to spread the virus. If you are sexually active, you can have HPV, even if you have had only one partner or have not been sexually active in years. http://www.cdc.gov/hpv/whatishpv.html accessed 7/20/15

The following are factors that put you at risk for becoming infected:

- Age: Adolescents and young adults
- Having other sexually transmitted infections
- Number of sexual partners
- Smoking
- Alcohol Use
- Use of Illegal Drugs
- Risky sexual behavior
- Immunosuppression

Human Papillomavirus: The Usefulness of Risk Factors in Determining Who Should Get Vaccinated, released summer 2008

Think it can't happen to you?

80 percent of sexually active people will contract HPV at some point in time during their lifetime.

http://www.ashasexualhealth.org/stdsstis/hpv/fast-facts

HPV and Cancer

When a person's immune system cannot get rid of an infection from a high risk HPV virus, the virus can change normal cells into abnormal cells. These cell changes are known as pre-cancers. If these groups of abnormal cells are not found and treated or removed, they have the ability to turn into cancer. This is not a short process. It could take many years for an HPV infection to lead to cancer.

Researchers combined their knowledge of HPV types known to cause cancer, the locations that cancer occurs, and cancer registry data to estimate the percentage of cancers that are likely to be caused by HPV. The most common HPV-related cancer is cervical cancer and is more common than cancers of the other sites. It is thought that almost all cervical cancer and 90 percent of anal cancer can be linked to HPV, while anywhere from 60-75 percent of vulvar, vaginal, and penile cancer is related to HPV. About 72 percent of oropharyngeal cancers (cancers of the back of the throat, including the tongue and tonsils) are linked to HPV.

Cdc.gov/hpv/cancer.html

Cancer Key terms

Biopsy: Looking at a group of cells under a microscope to help diagnosis a disease.

Oncologist: A doctor who specializes in treating and diagnosing cancer.

Risk Factor: A characteristic or behavior which puts you at higher risk for a certain disease.

Squamous Cell Carcinoma: Cancer of the flat cells which create the lining of most of your organs and make up the top layer of skin.

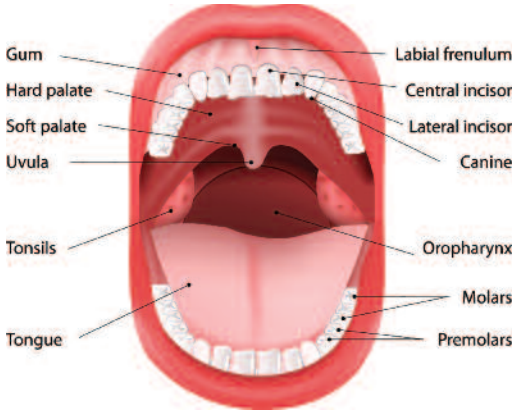
Oropharyngeal Cancer

The oropharynx is composed of three parts: the pharynx, back of the tongue, and tonsils. The pharynx is the back of your throat in an area between your mouth and where your esophagus and trachea spilt. Oropharyngeal cancer is a type of head and neck cancer found in the oropharynx and is most commonly squamous cell carcinoma. In Illinois, there are approximately 607 cases of oropharyngeal cancer each year. Of these cases, more than half - 382 cases - of oropharyngeal cancer have been related to HPV infection.

National Cancer Institute, Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2014.

You can decrease your chances of getting oropharyngeal cancer by decreasing your risk factors including the avoidance of alcohol and tobacco. These are the symptoms to be aware of:

- Sore throat which does not go away
- Trouble swallowing, opening mouth fully, trouble moving your tongue
- Coughing up blood
- Unexplained weight loss
- Ear Pain
- Lump in the oropharynx
- Change in voice



If you are experiencing these symptoms, a doctor will likely perform an exam and get a health related history from you. In addition to an exam, a doctor may do more tests, including a biopsy or imaging such as an MRI.

National Cancer Institute

Anal Cancer

The anus is the last part of the digestive system where solid waste leaves the large intestine. The anus has two muscular rings, called sphincters, which act as doors opening to allow stool to pass out of the body. Anal cancer is most commonly squamous cell carcinoma. In Illinois, there are approximately 214 cases of anal cancer each year. Of these cases, 198 cases of anal cancer have been related to HPV infection.

National Cancer Institute Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2014

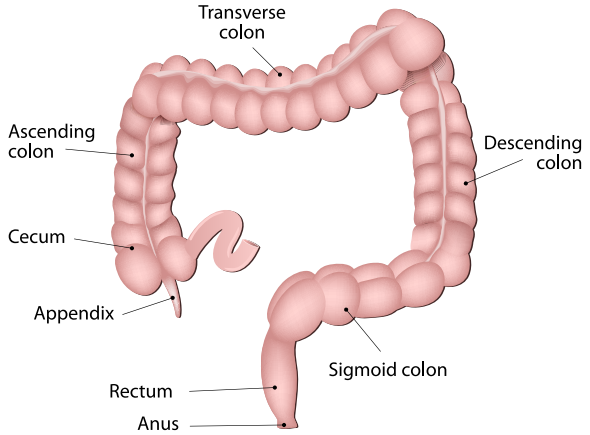
Being vaccinated for HPV and limiting your number of sex partners can decrease your chances of getting anal cancer by decreasing your risk factors. These are the symptoms to be aware of:

- Rectal bleeding or itching
- Lump on the anal opening
- Pain in the anal area
- Feeling of fullness in the anal area
- Stool changes (color, shape, etc.)
- Unusual discharge
- Swollen lymph nodes in the groin
- Swollen lymph nodes around the anus

If you are experiencing these symptoms, a doctor will likely perform an exam and get a health related history from you. Individuals who are at high risk for anal cancer will most likely receive screening tests, such as a digital exam, on a regular basis

American Cancer Society, released February 2015

ANATOMY OF THE LARGE INTESTINE



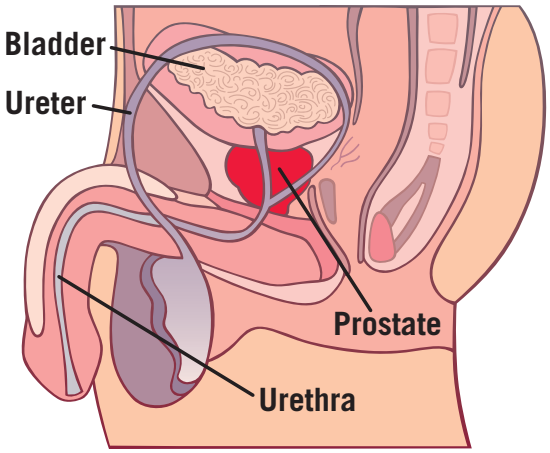
Penile Cancer

The penis is the male organ which passes urine and sperm. All men are at risk for getting penile cancer. Cancer of the penis is most commonly squamous cell carcinoma and found on the foreskin, a thin piece of skin which covers the end of the penis. In Illinois, there are approximately 47 cases of penile cancer each year. Of these cases, 16 cases of penile cancer have been related to HPV infection.

National Cancer Institute Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2014

Avoiding tobacco or limiting your number of sex partners can decrease your chances of getting penile cancer by decreasing your risk factors. Even men who do not have these risk factors may still get penile cancer. These are the symptoms to be aware of:

- Redness or irritation on the penis
- Sore on the penis
- Lump on the penis



If you are experiencing these symptoms, a doctor will likely perform an exam and get a health related history from you. The doctor may also perform a biopsy.

http://www.cancer.gov/types/penile

Vaginal and Vulvar Cancer

The vagina and vulva are both parts of the female genitals. The vagina, also known as the birth canal, is a long, muscular tube which acts as a path from the bottom of the uterus to the outside of the body. The vulva is the external part of the female genitals which includes the two flaps of skin known as the labia. All women are at risk for getting vaginal and vulvar cancers, but both are rare. In Illinois, there are approximately 37 cases of vaginal cancer and 160 cases of vulvar cancer each year. Of these cases, 24 cases of vaginal cancer and 82 cases of vulvar cancer have been related to HPV infection.

Centers for Disease Control, released March 2014. Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2014

Avoiding tobacco and taking precautions to avoid HPV infection can decrease your chances of getting these cancers by decreasing your risk factors. Even women who do not have these risk factors may still get vaginal or vulvar cancer. These are the symptoms to be aware of:

Vaginal Cancer Symptoms

- Abnormal discharge or bleeding from the vagina
- Pain in the pelvic area
- Change in bathroom habits

Vulvar Cancer Symptoms

- Itching, burning or bleeding on the vulva which does not go away
- Changes in the skin of your vulva (skin color, rashes, warts, etc.)
- Pain in your pelvis

If you are experiencing these symptoms, a doctor will likely perform a pelvic exam and other diagnostic tests to determine if you have vaginal or vulvar cancer. If diagnosed, you will likely be referred to a gynecological oncologist.

Centers for Disease Control, released March 2014

Cervical Cancer

The cervix is the narrow end of the uterus and part of the female genitals. All women are at risk for getting cervical cancer, but it is most commonly found in women over the age of 30. In Illinois, there are approximately 535 cases of cervical cancer each year. Of these cases, the vast majority - 512 cases - of cervical cancer have been related to HPV infection.

Centers for Disease Control, released March 2014. Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2014.

You can decrease your chances of getting cervical cancer by decreasing your risk factors, such as not smoking or limiting how many sex partners you have. Even women who do not have these risk factors may still get cervical cancer. These are the symptoms to be aware of:

Early stages: Few to no symptoms

Later stages: Abnormal discharge or bleeding from the vagina

If you are experiencing these symptoms, a doctor will likely perform a pelvic exam and a Pap smear or Pap Test. This is a test that can be done to find these pre-cancer areas in the cervix and prevent them from progressing on to cancer. Pap smears are recommended for all women 21-65 years of age, according to the Centers for Disease Control (CDC). The frequency of these tests is determined by your doctor based on several factors. Pap smears only look for pre-cancer in the cervix. If diagnosed with cervical cancer, you will likely be referred to a gynecological oncologist.

Centers for Disease Control, released March 2014

How can I prevent HPV?

The only sure way to prevent HPV is to abstain from sex. If abstaining from sex is not an option, removing risk factors, such as a high number of sexual partners, also will reduce the risk of becoming infected. There are three ways to lower the risk of becoming infected with HPV.

Vaccines

Vaccines, for men and women, are available for the most common types of HPV including some of the high risk HPV types. As with other vaccines, the HPV vaccine is safe and effective. The vaccine has been shown to continue to be effective for at least 10 years without losing effectiveness. There is no evidence it will lose its effectiveness over time. As with any pharmaceutical, there are possible side effects. These tend to be mild to moderate and typically are short lived and will resolve on their own:

- Pain at the injection site (8 out of 10 people)
- Redness or swelling (1 out of 4 people)
- Mild (100°F) fever (1 out of 10 people)
- Moderate (102°F) fever (1 out of 65 people)
- Headache (1 out of 3 people)

Centers for Disease Control, released June 2015

The vaccine is most effective when given before an individual begins any sexual activity; therefore, it is recommended that girls and boys 11-12 years of age should receive this vaccine. The vaccine is also most effective at this age because it produces a higher immune response than at other ages. It can be given as late as early adulthood (up to 26 years of age for women and 21 years of age for men) if the series was incomplete or no doses of the vaccine were administered. The vaccine can also be given after someone has had sex, as there is a chance that they have not yet been exposed to some or all of the HPV types that the vaccines protect against.

Boys	Girls
Age: 11-21 years of age	***Age:*** 11-26 years of age
Protect from types of HPV causing: Genital warts Penile cancer Anal cancer Throat cancer	***Protect from types of HPV causing:*** Most cervical cancers Genital warts Anal cancer Vulvar cancer Vaginal cancer

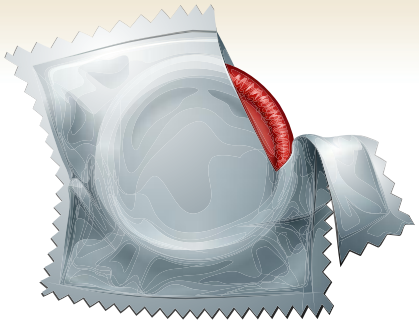
The vaccine not only protects the individual, but makes it less likely that they will spread the virus to their current and future partners.

Centers for Disease Control, released January 2015

Condoms

Condoms are thought to lower the risk of giving HPV to your partner. To be most effective they must be used with EVERY partner, EVERY time, from start to finish. This is true even if your partner is on another form of birth control, such as the pill, IUD, etc. While this is likely to lessen the chance of becoming infected, areas which are not covered by the condom may still be infected with HPV and can spread the virus.

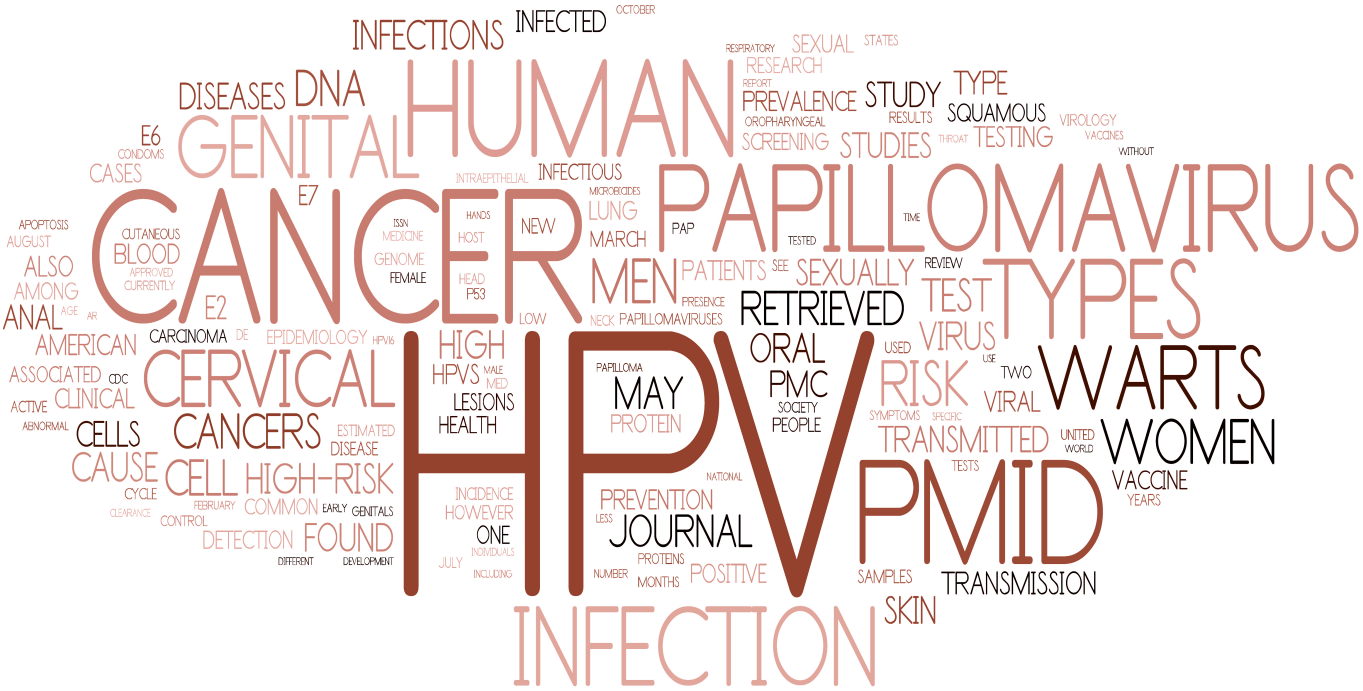
Centers for Disease Control, released March 2013



Monogamous Relationship

A mutually monogamous relationship will lessen the chances of becoming infected with HPV. It is important that this is mutual and your partner has sex with you only. If one partner in a relationship is not monogamous, both partners will have an increased risk of becoming infected.

American Sexual Health Association, released 2015



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.

The cancer registry receives funding from the state of Illinois general revenue fund, the U.S. Centers for Disease Control and Prevention's National Program of Cancer Registries, and researchers who use cancer data.

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 11 employees of the Illinois State Cancer Registry have 172 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 17 years. Gold certification is the highest level and cancer data must meet strict guidelines for quality, completeness and timeliness to qualify.

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.

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.

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