New Jersey State Cancer Registry
Data Guidelines

ABOUT US

The New Jersey State Cancer Registry (NJSCR) is a population-based cancer registry that was established by legislation (N.J.S.A. 26:2-104 et seq.) and includes all cases of cancer diagnosed in New Jersey residents since October 1, 1978. New Jersey regulations (N.J.A.C. 8:57A) require that all hospitals, labs, physicians, dentists and other health care providers report newly diagnosed cancer cases to the NJSCR within six months of diagnosis. The NJSCR collects data in accordance with established national standards promulgated by the North American Association of Central Cancer Registries (NAACCR) (https://www.state.nj.us/health/ces/reporting-entities/njscr/). Information on New Jersey residents diagnosed or treated outside of New Jersey is obtained through interstate data exchange agreements. Data collection and use is supported by the National Cancer Institute (NCI), the Centers for Disease Control

and Prevention, as well as the State of New Jersey, the Rutgers Cancer Institute of New Jersey, as well as other state and federal sources.

ABOUT OUR DATA

Reportability Criteria

All invasive and in situ neoplasms are reportable to the NJSCR with the following exceptions:

- Carcinoma in situ of the cervix diagnosed after 1994 are not reportable.
- Basal and squamous cell carcinomas of the skin are not reportable (except when diagnosed in the labia, clitoris, vulva, prepuce, penis or scrotum).
- Benign and borderline tumors of the brain and central nervous system diagnosed on or after January 1, 2004 are reportable.
  Additional information on reportable cancers can viewed at the following link.
  https://www.nj.gov/health/ces/documents/NJSCR2018reportablelist.pdf

Data Quality

- NJSCR data meet or exceed the highest national data standards for completeness, timeliness and quality (https://www.naaccr.org/certification-criteria/).
- Data undergo rigorous quality control prior to publication. As a result, data are generally available for publication within 24 months of the end of the diagnosis year. This time frame is in line with national standards and consistent with data available from other state registries.
- Registry data are updated regularly. Rates and counts for a particular diagnosis year may change slightly as subsequent cases or additional information are reported.

Data Presentation

- Incidence data are grouped by cancer site according to the Site Recode ICD-O-3/WHO 2008 Definition (https://seer.cancer.gov/siterecode/icdo3_dwhoheme/index.html).
- Only invasive cancers are included in analysis, unless otherwise noted.
- Myelodysplastic syndrome (MDS) and chronic myeloproliferative disorder (CMD) are included in “All Sites” and “Ill-Defined & Unspecified Sites” for all reports published in 2013 and later. These conditions are not included in reports published prior to 2013.
- Due to federal restrictions, data from Veterans Health Administration (VHA) facilities diagnosed after 2005 are not included. The NJSCR estimates these account for fewer than 0.5% of cases.
- Cases with unknown year of diagnosis, county of residence, age, or gender are excluded, in accordance with standard practice. This is a small percentage of cases.
- An individual may develop more than one cancer. Following the NCI’s Surveillance, Epidemiology, and End Results (SEER) Program multiple primary rules, patients could therefore be counted more than once if they were diagnosed with two or more primary cancers.

- Because of the difficulty in interpreting language used by pathologists to describe extent of invasion for bladder cancers, in situ bladder cancers are combined with invasive bladder cancers in accordance with national standards.

Race and Ethnicity

- NJSCR conforms to NAACCR Quality standards which require <3.0 percent of cases with unknown race. If a case is reported with missing race, the person will be included in the 'Race Unknown/Other category'; however, if the race is later updated the person will be included in the race-specific cancer incidence rates and counts.
- Race-specific information is not shown separately for persons with a race other than white, black or Asian or Pacific Islander (API). These persons and persons of unknown race are included in "all races" data.
- The NAACCR Asian Pacific Islander Identification Algorithm (NAPIIA) is used to assign a more accurate race category to Asians or Pacific Islanders cases using birthplace and name. Asians or Pacific Islanders in New Jersey account for a small proportion of total cases. Missing race or misclassification of race may have a relatively greater impact on API rates than other races https://www.naaccr.org/wp-content/uploads/2016/11/NAPIIA_v1_2_1_08122011.pdf.
- The NAACCR Hispanic Identification Algorithm (NHIA) is used to assign Hispanic ethnicity to cases. This method uses data on birthplace, gender, race and surname match to the 1990 Hispanic surname list to augment the number of cases and decedents reported as Hispanic in the registry (https://www.naaccr.org/wp-content/uploads/2016/11/NHIA_v2_2_1_09122011.pdf).

U.S. Incidence Data

- U.S. cancer incidence data are obtained from the NAACCR' publication, Cancer in North America (https://www.naaccr.org/cancer-in-north-america-cina-volumes/).

Mortality Data

- New Jersey and U.S. cancer mortality data are obtained from NCI's SEER Program (www.seer.cancer.gov) with underlying data from the National Center for Health Statistics (NCHS) (www.cdc.gov/nchs).
- Mortality data are grouped by cancer site according to the revised SEER Cause of Death Recode (http://seer.cancer.gov/codrecode/), unless otherwise specified.

Population Data

- New Jersey population estimates are provided by the NCI's SEER Program (http://www.seer.cancer.gov/popdata/download.html). The population estimates represent annual time series of July 1 county population estimates by age, sex, race, and Hispanic origin produced by the US Census Bureau's Population Estimates Program. The bridged single-race estimates and a description of the methodology used to develop them are available from NCHS (http://www.cdc.gov/nchs/nvss/bridged_race.htm).

Data Considerations

- Caution should be used when comparing rates among Hispanics with the rates in the different race groups (e.g., black, white) because Hispanic ethnicity and race are not mutually exclusive. In New Jersey, the majority of Hispanics identify themselves as white. The Hispanics who identify themselves as white, black, or API are included in the white, black, or API race categories, as well as the 'all races' category. Researchers can create a classification variable that combines race and Hispanic ethnicity to compare Hispanics, non-Hispanic whites, non-Hispanic blacks, and non-Hispanic API.
- The impact of missing race for a relatively small proportion of cases can result in slightly lower race-specific cancer incidence rates and counts.
- Due to inconsistencies in reporting by non-hospital sources, cancers routinely diagnosed and treated outside the hospital setting may be underrepresented. Likewise, data from non-hospital sources may have a disproportionate number of cases with unknown characteristics, such as race.
- Up to 1.5% of all cases may be derived from death certificates only (DCO), in accordance with national standards. Cancers with high mortality and short survival times may have a higher proportion of DCO. Cases derived from DCO may contain less specific information with regards to demographics, staging and treatment.

FINDING NEW JERSEY DATA

Each year the Cancer Surveillance Research Program report on New Jersey cancer incidence, mortality, survival, and prevalence. They are available online as Reports (https://www.state.nj.us/health/ces/reports.shtml) or Data Briefs (https://www.nj.gov/health/ces/briefs.shtml).

Additionally, our interactive cancer statistics mapping application provides incidence and mortality counts and rates statewide and at the county level by year, sex, race, and ethnicity for the years 1990 and later at http://cancer-rates.info/nj/ . Other New Jersey and U.S. cancer data can be found on the following websites:

- Cancer Control Planet, http://cancercontrolplanet.cancer.gov/
- North American Association of Central Cancer Registries' *Cancer in North America*, https://www.naaccr.org/cancer-in-north-america-cina-volumes/
- Surveillance, Epidemiology and End Results (SEER) Program's *Cancer Statistics Review*, http://www.seer.cancer.gov/
- Centers for Disease Control and Preventions, *United States Cancer Statistics*, https://nccd.cdc.gov/uscs/
- State Cancer Profiles, http://statecancerprofiles.cancer.gov/

DATA ANALYSIS

Counts, Crude Rates, and Age-Adjusted Rates

"Count" and "frequency" are terms to describe the actual number of cases of a particular cancer type. The number of cases (counts) with a specific characteristic during a time period divided by the total number of cases will provide proportions for that time period.

A cancer incidence rate is defined as the number of new cases of cancer detected during a specified time period in a specified population. Crude rates are calculated by dividing the total number of cases in a given time period by the total number of people in the population at risk for the same period of time (see formula below). This allows comparisons of the disease burden in two different populations. Crude rates are often displayed for specific age groups (age-specific rates). Caution must be used when comparing rates for populations with different age distributions. For example, several of New Jersey's southern counties have higher proportions of older individuals compared to the remainder of the state. This results in an elevation in the crude cancer incidence and mortality rates for these southern counties compared to the state as well as the central and northern counties. In this case, crude rates could incorrectly lead one to believe that the higher cancer rates are due to some characteristic of the area other than age. Since cancer occurs at different rates in different age groups, and population subgroups defined by gender and race have different age distributions, standardization should be considered before comparing rates.

Age-adjusted rates are weighted averages of crude (age-specific) rates, where the weights represent the age distribution of a standard population. Such adjustment eliminates differences in rates due to changes in the age of a population over time or differences in the age distribution between population groups. While age standardization facilitates the comparison of rates among different populations, there can be important age-specific differences in disease occurrence, which are not apparent in comparisons of the age-adjusted rates (Breslow and Day, 1987).

The first step in the age-standardization procedure is to determine the age-specific rates. For each age group for a given time interval, the following formula is applied:

$$r_a = \frac{n_a}{t \times P_a}$$

where

- a = the age group (5-year age groups)
- r_a = the age-specific rate for age group a,
- n_a = the number of events (cancer diagnoses) in the age group a during the time interval,
- t = the length of the time interval (in years), and
- P_a = average size of the population in the age group a during the time interval (mid-year population or average of mid-year population sizes).

In order to determine the age-adjusted rate, a weighted average of the age-specific rates is calculated, using the age distribution of the standard population to derive the age-specific weighting factors (Rothman, 1986). This is the technique of direct standardization which uses the following formula:

$$R = \frac{\sum_{a=1}^{n} r_a \times Std.P_a}{\sum_{a=1}^{n} Std.P_a}$$

where

a =	the age group (5-year age groups)
n =	the number of age groups,
R =	the age-adjusted rate,
r_a =	the age-specific rate for age group a, and
$Std.P_a$ =	the size of the standard population in age group a.

Rates for general population and adults are commonly reported as the number of new cases (incidence) or deaths (mortality) in specific age groups per 100,000 persons each year and are age-adjusted to the 2000 United States standard population. Childhood rates are commonly reported per 1 million (International Classification of Childhood Cancer [ICCC] groupings of childhood cancers) as they are rarer and smaller numbers.

Counts, frequencies, and rates are calculated using SEER*Stat (https://seer.cancer.gov/seerstat/), a statistical software package distributed by the NCI.

Trend Analysis

Annual Percent Change (APC) represents the average percent increase or decrease in cancer rates over a specified time period. The estimated Annual Percent Change (APC) of the age-adjusted rates are calculated by fitting a least squares regression line to the natural logarithm of the rates, using the year within the time period as a regressor variable using the following formula:

$$\ln(r_{ij}) = a_i + m_i j$$

where

r_{ij}	= annual rate in the j^{th} year of the i^{th} time period,
a_i	= intercept from the regression of (annual age-adjusted) rate against time (years) over the i^{th} time period,
m_i	= slope coefficient from the regression of the natural logarithm of the (annual age-adjusted) rate against time (years) over the i^{th} time period, and
j	= year (of the i^{th} time period).

Then the APC for the i^{th} time period is calculated as

$$APC_i = 100 \times (\exp\{m_i\} - 1)$$

where

APC_i = Annual Percent Change over the i^{th} time period and
m_i = slope coefficient from the regression of the natural logarithm of the (annual age-adjusted) rate against time (years) over the i^{th} time period.

Testing the hypothesis that the annual percent change is equal to zero is equivalent to testing the hypothesis that the regression parameter is equal to zero. The hypothesis is rejected at a significance level $p<0.05$.

Joinpoint models or piecewise regression models use statistical algorithms to detect joinpoints, points in time where the slope of the regression line significantly changes. Thus, the model describes trends during different time segments. At each segment, trends in rates are measured using the estimated APC, which assumes that rates change by a constant percentage each year.

The Average Annual Percent Change (AAPC) is a summary measure of a trend over a pre-specified fixed interval. It allows the use of a single number to describe the average APCs over a period of multiple years. It is computed as a weighted average of the APCs from the joinpoint model, with the weights equal to the length of the APC interval.

$$AAPC = \left\{ \exp\left(\frac{\sum w_i m_i}{\sum w_i} \right) - 1 \right\} \times 100$$

where

w_i = length (years) of the i^{th} time period, and
m_i = slope coefficient from the regression of the natural logarithm of the (annual age-adjusted) rate against time (years) over the i^{th} time period.

APCs and AAPCs are calculated using SEER*Stat (https://seer.cancer.gov/seerstat/), a statistical software package distributed by the NCI. Joinpoint models are calculated using NCI's Joinpoint Regression Program (https://surveillance.cancer.gov/joinpoint/).

Standardized Proportion Ratio

A weight from a standard population can be applied to a proportion producing a Standardized Proportion Ratio (SPR). In the example below, the standardized proportion ratio for stage can be calculated using the following formula.

$$\% \text{ of late stage cases} = \frac{\text{Number of regional and distant stage cases}}{\text{Total number of cases}} \times 100$$

$$\text{Standardized proportion ratio} = \frac{\text{Late stage proportion among diagnosed patients in the county}}{\text{Statewide late stage proportion}}$$

The SPR allows the reader to compare the percentage of late or early stage of incidence cancers in a geographic area (County) that are standardized to the reference population (State of New Jersey). Counties with a SPR less than 1.0 had a lower proportion of cancer cases diagnosed in the later stages compared to the statewide proportion. **Note**: Caution should be used when interpreting this figure since it has no population denominator.

Survival Analysis

Cancer survival statistics are typically expressed as the proportion of patients alive at some point subsequent to the diagnosis of their cancer. Observed survival is the actual percentage of patients still alive at some specified time after diagnosis of cancer. It considers deaths from all causes, cancer or otherwise. The relative survival rate is the ratio of the observed survival rate and the expected survival rate. The expected survival rate is calculated using U.S. life tables for the same state, age, sex, and race group/ethnicity, where feasible. For additional information on survival analysis please visit (https://surveillance.cancer.gov/survival/). For additional information on survival life tables please visit (https://seer.cancer.gov/expsurvival/).

Quality of the survival analysis is dependent on accurate and up-to-date reporting of vital status. Vital status for each cancer patient in the NJSCR is updated annually through linkage with state and national death certificate and social security data. In addition, state hospital discharge data, motor vehicle registration records and immunization records are linked with the NJSCR to update vital status.

Survival analysis is limited to first primary invasive cancer cases except for cases identified only from death certificates or autopsy records. Survival time is calculated from the date of diagnosis to the date of death, the date last known to be alive if there was no date of death, or at a specified end date, whichever

occurred earliest. Missing days or months are imputed using a standard procedure and cases with zero survival time are excluded.

Geographic Analysis

Several NJSCR data products, including the interactive data and mapping tool (https://www.cancer-rates.info/nj/), present data at the county level. Geographic variations of cancer incidence rates are not uncommon and usually arise from differences in sociodemographic characteristics of the population (age, race and ethnicity, geographic region, urban or rural residence), screening use, health-related behaviors (for example, tobacco use, diet, physical activity). Because both the U.S. and New Jersey show variation in these characteristics by geography, caution is advised when interpreting regional cancer data. For example, in New Jersey the Southern counties tend to have a higher prevalence of cigarette smoking and obesity, both of which account for a higher incidence of cancers related to these health behaviors for these counties compared to the remainder of the state.

As with all analysis using small counts, presentation of the data at the geographic level, such as county, can for some less common cancers, reduce the statistical reliability of the data due to smaller case counts. For this reason, it is advised that 95% confidence intervals be reviewed to determine if significant differences between geographic areas exist.

Maps are created using ArcGIS software by Esri (www.esri.com).

Lifetime Analysis

Statistical models are used to compute the probability of being diagnosed or dying of cancer from birth or conditional on a certain age. Life time risk data are calculated using DevCan - Probability of Developing or Dying of Cancer (https://surveillance.cancer.gov/devcan/). DevCan takes cross-sectional counts of incident cases from the standard areas of NCI's SEER Program, and mortality counts for the same areas from data collected by the NCHS and uses them to calculate incidence and mortality rates using population estimates from census data for these areas. These rates are converted to the probabilities of developing or dying from cancer for a hypothetical population.

Prevalence

Prevalence (existing cases) accounts for all New Jersey residents alive on a specific date that have a history of a certain cancer by a specified date. These cases include individuals that no longer have evidence of cancer or those undergoing treatment that still have evidence of the disease. Limited-Duration Prevalence represents the proportion of people alive on a certain day who had a diagnosis of the disease within the past x years (e.g. x = 5, 10 or 20 years). Registries of shorter duration, less than 40 or 50 years of data collection, can only estimate limited-duration prevalence. Limited-duration Prevalence statistics can be calculated using NCI's SEER*Stat software (https://seer.cancer.gov/seerstat/).

DATA INTERPRETATION

Suppression of Rates and Counts

Annual rates for relatively uncommon cancers tend to fluctuate substantially from year to year because of small numbers of cases, particularly in minority populations or smaller geographic areas such as counties. Rates generated from small numbers should be interpreted with caution. Typically, incidence rates and counts are suppressed where counts are fewer than five to ensure statistical reliability and patient confidentiality. The mortality rates and counts are suppressed where counts were fewer than ten.

Statistical Significance

Test for statistical significance is a valuable tool for conveying the reliability and precision of a statistic. The statistical significance of observed differences in age-adjusted rates is determined by comparing 95 percent confidence intervals around each rate. Whenever confidence intervals overlap differences are deemed non-significant, otherwise they are considered significant at alpha = 0.05. Rates, APCs, AAPC, probabilities and correlations can be presented with significance tests.

Confidence Intervals

A confidence interval is a range around a measurement that conveys how precise the measurement is. A statistical interpretation of the 95 percent confidence interval is that if the random sampling procedure was conducted an infinite number of times, then the true value would be contained by 95% of the confidence intervals calculated from those samples.

Confidence intervals are calculated based on the standard error (se) of the rate. The standard error, in turn, is based on the rate and the number of cases or deaths. In the simplest terms, an age-adjusted breast cancer incidence rate of 124.5 cases per 100,000 women with a confidence interval of 122.5 - 126.6 cases per 100,000 means that we are 95% confident that the true rate lies between 122.5 and 126.6 cases per 100,000.

Confidence intervals are often used in research to measure rate stability, which arises from random fluctuations in the number of cases over time or between different communities. A stable rate is one that would be close to the same value if the measurement was repeated, i.e., if the rate did not vary greatly from one year to the next. An unstable rate is one that varies greatly from one year to the next due to chance alone. Wider confidence intervals in relation to the rate itself indicate instability. For example, if the rate is 5 cases per 100,000 persons, but the 95 percent confidence interval is plus or minus 2.5 cases per 100,000 persons, then the rate is relatively unstable. In one year, you might have a rate of 3 cases per 100,000 and in the next year have 6 cases per 100,000. This would be a 100 percent increase in the rate but may still be within the range of the confidence intervals.

On the other hand, narrow confidence intervals in relation to the rate tell you that the rate is relatively stable, and you would not expect to see large fluctuations from year to year. If differences are observed

between stable rates (those with narrow confidence intervals), then it is likely that the differences are not due to random fluctuations alone.

P-value

A p-value is a term in statistics that helps show whether a difference found between groups that are being compared is due to chance. The p-value can vary between 0 and 1. A p-value close to 0 (say less than 0.05) usually means that the difference between groups is not likely to be due to chance alone. A large p-value usually means that the difference between groups is probably due to chance alone.

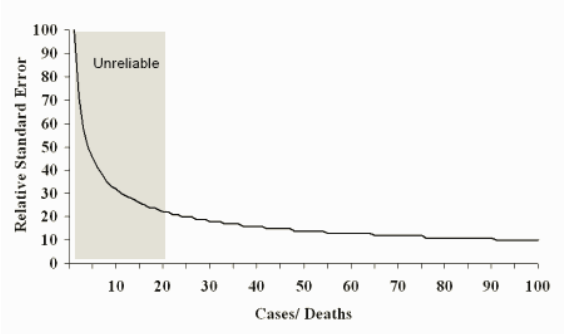
Reliability

Annual rates based on fewer than 20 cases or five-year average rates based on fewer than 4 cases per year are considered unstable because they have a large relative standard error (RSE). The RSE is the standard error as a percent of the measure itself. For incidence and mortality rates, the RSE is equal to $1 \div \sqrt{cases}$. A RSE of 50 percent indicates that the standard error is half the size of the rate. The RSE of an incidence or mortality rate is based on the number of cases or deaths, unlike the standard error and confidence intervals, which are based on both the number of cases and the size of the population.

When rates are based on only a few cases, small changes in the number of cases have a much bigger effect than small changes in a large number of cases or deaths. In other words, going from 10 cases to 20 cases reduces the RSE from 32 percent to 22 percent, while going from 60 cases to 70 cases reduces the RSE from 13 percent to 12 percent. It is somewhere around 20 cases that the curve seen in the chart starts to level out. Hence, rates based on fewer than 20 cases, in the steep end of the curve shown, are highly variable and, for that reason, are unreliable.

Relative Standard Error of an Incidence or Mortality Rate

as a Function of the Number of Cases or Deaths



Citing New Jersey Data

Any publication resulting using New Jersey State Cancer Registry must be submitted to the NJSCR for review prior to publication and appropriately acknowledge services provided by the New Jersey State

Cancer Registry, New Jersey Department of Health, Rutgers Cancer Institute of New Jersey. Final references to publications should be submitted to NJSCR for inclusion in registry's bibliography.

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Abbreviations

AAPC- Average Annual Percent Change

APC- Annual Percent Change

API- Asian or Pacific Islander

CMD- chronic myeloproliferative disorder

DCO- Death Certificates only

ICCC- International Classification of Childhood Cancer

MDS- Myelodysplastic syndrome

NAACCR- North American Association of Central Cancer Registries

NCHS- National Center for Health Statistics

NCI- National Cancer Institute

NAPIIA- NAACCR Asian Pacific Islander Identification Algorithm

NHIA- NAACCR Hispanic Identification Algorithm

NJSCR- New Jersey State Cancer Registry

SEER- Surveillance, Epidemiology, and End Results

SPR- Standardized Proportion Ratio

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