FAQ on Cancer Registry

What is the New Jersey State Cancer Registry?

The New Jersey State Cancer Registry, which is mandated by state law, collects data on all cancer cases that have been diagnosed and/or treated in the state since October 1, 1978. The state Department of Health's cancer registry webpage is located at https://www.nj.gov/health/ces/reporting-entities/njscr/.

Under the state regulations, all hospitals, physicians, ambulatory care facilities, radiation treatment facilities and laboratories are required to report newly diagnosed cancer cases electronically to the registry within six months of first contact with the patient.

How do people verify if their cancer has been documented in the cancer registry?

If you would like to verify that your information has been included in the New Jersey State Cancer Registry, go to https://www.nj.gov/health/ces/ and click on "Form for Patients" located on the panel to the right. You will be taken to a form for individuals to obtain a summary report of the information that is under your name.

The form will provide detailed instructions, including a list of acceptable forms of identification which can be submitted with your request. Including identification is a key component of the request as the cancer registry is prohibited from releasing private identifying information and private health information without verification. There is no cost for this information.

Is my data protected?

The registry has policies in place to protect the confidentiality of the data. When requesting a copy of your summary information, you must provide a photocopy of a valid photo identification.

What if I've had cancer and I'm not in the registry?

The registry does not take self-reported information. The law prohibits the cancer registry from collecting information directly from cancer patients.

There could be a number of reasons for why your cancer is not in the registry. For example, you could have been a resident of another state when you were diagnosed or the cancer that you were diagnosed with was not reportable to the cancer registry. Individuals can reach out to your healthcare provider for clarification and encourage them to provide the information to the registry if none of the above circumstances apply to you.

What information is collected?

The New Jersey State Cancer Registry collects very detailed information about each cancer case following strict reporting guidelines. These data include demographic and medical information on each patient for each cancer diagnosis (such as the stage of disease and treatment, and other details). In order to monitor survival rates, the cancer registry also collects information on the vital status of each case, annually documenting whether the individual is alive or deceased and, if deceased, documenting the underlying cause of death. Documenting vital status and cause of death is accomplished by linking cancer registry data to state death records and the National Death Index, which captures deaths that occur out of state.

How will this information be used?

This information is widely used by clinicians, scientists, and researchers. Data on cancer patterns in the population can be very useful for preventing and controlling cancer and improving treatment and patient care. The data are used to respond to New Jersey residents on cancer issues and concerns. For example, cancer registry data may be used to conduct an evaluation comparing the number of cancers diagnosed in a community to the estimated number of cancers for a community based on age-specific population and the background rates. This would provide some insight into whether the number of cancers diagnosed in a community is higher (or lower) than otherwise expected.

Also, the incidence rates in New Jersey are compared with other states and added to the national cancer statistics. The data collected by the registry can be useful for describing cancer patterns in the population, discovering causes of cancer, planning programs for people affected with cancer, and other related research.

Cancer screening programs, such as for cervical, breast, colon, prostate, uterine and lung cancers use the data to plan screening services to help improve survival outcomes. Healthcare providers also use the data for planning and researchers use these data for studying ways to increase survival and identify risk factors. For additional information on cancer screening guidelines, please visit https://www.cancer.org/cancer/screening/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html.

Can I get an overall report on cancers in my area?
The cancer registry publishes reports and provides cancer statistics in a number of ways through online sources. Go to https://www.nj.gov/health/ces/cancer-researchers/surv-research/ for more information. If the type of information you seek is not already available, you can submit a request at https://healthapps.state.nj.us/forms/ces4.aspx. There you will be asked to provide your contact information along with more details on the kind of data or statistics you need.

DOH Webpage: Cancer Concerns in your community:
https://www.nj.gov/health/ces/public/community.shtml

For more specific information on cancer inquiries in communities:
Inquiries About Cancers in Communities

For more specific information on cancer inquiries in schools:
Cancer Concerns Among Staff in Schools