About the North Dakota Statewide Cancer Registry

What is the Cancer Registry?

The North Dakota Statewide Cancer Registry [NDSCR], located with the University of North Dakota, School of Medicine and Health Sciences [UNDSMHS], Department of Pathology collects, processes and reports comprehensive, timely, and accurate data on every North Dakotan diagnosed with cancer. The Registry is composed of several units. The case collection unit works with all reporting facilities to make sure cancer cases are reported on time either electronically or by hard copy and with high quality data. The processing unit edits data that are received and checks the data for quality and completeness through record conciliation or de-duplication processes. The analytic staff analyzes and reports the cancer statistics for data requests, cancer cluster inquiries or research requests. The purpose of the Registry is to "Support cancer control by providing data to target, monitor and evaluate programs promoting early detection, diagnosis and treatment to reduce the burden of cancer in North Dakota". Population-based cancer registries are essential for evaluating the cancer burden in a specific geographic area. The cancer registry supports efforts by community hospitals and health systems with respect to the evaluation of their cancer patient care.

What is the Cancer Registry used for?

The Cancer Registry collects information that can be used for data requests, cancer cluster inquiries or research as well as public health planning and evaluation. Because the Registry is population based, it can be used to monitor cancer incidence patterns in all of North Dakota by providing summary statistics on the distribution of cancer cases by type and the following of cancer incidence and treatment trends throughout the state. Data from the Registry (e.g., cancer incidence rates or the percentage of cases diagnosed at an advanced stage of disease) can be used to identify areas in need of public health interventions. The data also can be used to evaluate the effectiveness of public health programs.

In addition, the Registry data can be used to determine if groups of people with specific exposures, such as those who work in a particular occupation or with a particular substance, are more likely to develop cancer than people who do not have these exposures.

What does the Cancer Registry do to protect privacy?

All information reported to the North Dakota Statewide Cancer Registry is confidential, and strict procedures are in place to protect patient's privacy. All employees are trained in handling confidential information. Strict policies are in place regarding the release of data to researchers. All research studies involving data with patient identifiers must be reviewed by the Department of Health's Health Insurance Portability and Accountability Act Office (HIPAA) and possibly the HIPAA Privacy Board, which protects rights to privacy. Statistics for areas smaller than the county level are not released.

How long has the Cancer Registry been collecting and reporting cancer data?

In 1994, the North Dakota Department of Health began receiving funding from the Centers for Disease Control and Prevention's National Program of Central Cancer Registries [NPCR] under the federal Cancer Registries Amendment Act. These funds allowed for the establishment of the North Dakota Statewide Cancer Registry for the purpose of timely, accurate and complete data collection. In 1996, the department's Administrative Rules were amended to include cancer as a reportable condition. This amendment requires/mandates all facilities diagnosing and/or treating cancer to report the data to the NDSCR. [ND CC Chapter 23-07-01 and Administrative Rule Chapter 33-06-01] On July 1st, 2012, the UNDSMHS Pathology Department became the health department's bona fide agent to operate the central cancer registry.

The Cancer Registry has been collecting information about patients diagnosed with cancer including leukemia, lymphoma and central nervous system tumors since January 1997.

What information is collected about patients with cancer?

The Cancer Registry collects data about sites of the tumor, the stage at diagnosis, the cell type of the cancer and first course of treatment. When a person is diagnosed with more than one type of cancer, this information is collected for each separate tumor. The Cancer Registry also collects specific sociodemographic information [age, gender, ethnicity, race, residence at diagnosis, place of birth, etc.] for each individual diagnosed with cancer. Information about the date and cause of death of individuals diagnosed with cancer is stored in the database. In total, more than 100 different pieces of information about each person are contained in the registry database.

The Cancer Registry includes reports of all malignant cancers except selected skin cancers. Basal cell and squamous cell cancers of the skin are exempt from reporting because they are rarely fatal, can be cured upon early diagnosis and usually do not require hospitalization. Carcinoma in situ of the cervix uteri is not reportable under the recommendations of the Commission on Cancer and the North American Association of Central Cancer Registries (NAACCR). Malignant cancers include those with both invasive and in-situ behavior. In-situ cancers are very early cancers while invasive cancers have more potential to spread. The registry also collects data about brain and nervous system tumors classified as benign or that have uncertain behavior. Benign tumors are growths that do not have the potential to metastasize beyond the tissue in which they originated.

Where do reports of cancer cases come from?

Each time a person is diagnosed with a new cancer, the hospital(s) where that person is diagnosed and/or treated reports information about the person and tumor/cancer to the Cancer Registry. Reporting is not voluntary; NDCC 23-07-01 requires it, and civil penalties can be levied for noncompliance with the law. Although the law requires that all active cancer cases be reported to the Cancer Registry regardless of where they are diagnosed, cancer reports have been received mainly from hospitals throughout the state. Other types of reporting facilities – such as pathology laboratories, physicians, free-standing radiation centers and ambulatory care centers – must report cases.

In addition, interstate reporting agreements with more than 30 states help ensure the completeness of reporting. Another source of information about patients is the death certificate. Death information processing is explained in more detail below.

How are the cancer case reports sent and processed?

The information required by the Cancer Registry is abstracted from each patient's medical record. Given the numerous forms and types of cancer, abstracting must be conducted by a well-trained staff. The major medical facilities in North Dakota that diagnose and/or treat cancer patients have certified tumor registrars abstracting the data. The NDSCR continuing education trainer provides training and technical support to reporting facilities.

The major medical facilities are required to submit their data monthly electronically via secure Internet encryption to a secure database. The other reporting sources submit paper reports, which are then abstracted at the central cancer registry office. Additionally, the state circuit rider travels to some reporting sources to collect the data.

Once the cancer report is received at the central cancer registry in Grand Forks, it runs through a series of computerized and manual operations before it can be used for data analysis. One of the primary strengths of a central cancer registry is the multiple sources reporting for diagnosed cases, and more than one report is received for most patients. All incoming reports are matched electronically against records on file for patients diagnosed since the beginning of the Cancer Registry. Nationally, about 14 to 16 percent of all cancers are second primaries (new cases occurring among those who already were diagnosed with a previous cancer). For some sites, the number of multiple primaries in an individual may be quite high. Cancer Registry staff must look at all tumor reports that match to reports already in the database to determine if the new report represents a new primary cancer or a cancer previously diagnosed.

Some of the data received are entirely in paper / text form and are coded by the Cancer Registry staff. For example, a cancer case report might read "upper outer quadrant left breast well differentiated ductal carcinoma, stage T2a N0 M0," which is then assigned codes for anatomic site (upper outer quadrant of the breast), side of the body (left), cell type of cancer (ductal carcinoma), behavior (malignant), grade (well differentiated) and stage at diagnosis (two to five centimeters, no fixation to muscles, confined to the breast). Because of the complex nature of this coding, it cannot be entirely computerized. Hospitals with a cancer program approved by the code their data before transmission.

Other data elements (e.g., gender, race and ethnicity) are assigned codes when the data is entered into the computer and needs reviewing only if there is a discrepancy. In a process called geocoding, the address information is used to assign a census tract. A large percentage of addresses cannot be geocoded due to incomplete address information on the record, mailing addresses not identified by street name and newly added streets.

Cancer registration is a dynamic process with additions, corrections and deletions to the data being made daily. The Cancer Registry staff monitor the number of cases submitted by each hospital and the total number of cancer cases for a given diagnosis year. Facilities are required to submit cases within six months. The registry actively works to monitor the timeliness of reporting. When most of the data for a given year are received and processed, then death information processing begins.

What is death information processing?

When the Division of Vital Records receives a death certificate, the underlying cause of death is assigned based on the entire list of primary and secondary causes of death as stated on the death certificate. Whether or not cancer was mentioned anywhere on the death certificate is also recorded, even if the person did not die as a direct result of cancer. All records of people who die from cancer or with a mention of cancer are matched to the Cancer Registry database. If no match is found, or if the site of cancer on the death certificate is different from that recorded on the Registry database, then follow-back information is needed. The hospital where the death occurred is contacted and asked for additional information. This is an important process because year of diagnosis, stage, histology and many other important pieces of information are not available on the death certificate. Since 1997, less than 3 percent of all tumors recorded in the registry are reports from death certificates for which no additional information is available. This usually occurs because the deaths occurred at home, in nursing homes or out of state. In some cases, the death occurs at a hospital other than the one in which the patient had been diagnosed and treated for cancer, and further information cannot be found. These are then called “death certificate only cases”, and are a measure of the completeness of reporting. Since cancer registration is a very dynamic process, the proportion of cases that are “death certificate only” for any one year decreases as time goes on because reports for these cases might be received after the death information processing is complete. In addition to indicating incomplete registration, a high proportion of “death certificate only” cases affect the analysis of several key data elements including year of diagnosis and site of cancer.

Are there other measures of quality applied to the Cancer Registry?

NDSCR has been recognized by the Centers for Disease Control and Prevention’s National Program of Cancer Registries for its achievement in meeting their standards for data completeness, timeliness and quality. Meeting these standards allows the NDSCR’s data to be included in the United States Cancer Statistics report. The North Dakota Statewide Cancer Registry participates in the North American Association of Central Cancer Registries (NAACCR) certification process. As part of this process, the NDSCR submits data annually to be evaluated for timeliness, completeness and quality such as percentage of cases with information about key data items (county of residents at diagnosis, race, gender and age), prevalence of unresolved duplicates, percentage of cases reported from death certificates only and the percentage of cases passing interfiled data edits. Throughout the years since NDSCR’s reference date, the statewide cancer registry has met NAACCR standards and received Gold-level and Silver-level certification awards.

How long does it take to process the cancer data?

The Cancer Registry receives approximately 7,000 reports of cancer per year, representing between 3,300 and 3,500 new cancers. The Cancer Registry waits until the death files are complete before doing the necessary death information processing. Because death information processing and final data collection from all reporters takes more than six months, the data are not ready for use until two years after the end of the diagnostic year. (e.g. Data for the diagnostic year of 2009 will not be available for release until the end of 2011.)

Are there national cancer data or data from other states to compare with North Dakota?

Quick cancer statistics from all states individually or the United States combined may be found at https://nccd.cdc.gov/uscs/ , www.cancer-rates.info/naaccr, http://cancercontrolplanet.cancer.gov, and http://cancernet.nci.nih.gov/statistics.

What kinds of data does the Cancer Registry release?

This electronic report is the Cancer Registry's principal publication. It can be found at https://ndcancer.org . A printed copy is available upon request from NDSCR. The report provides the number of cancer cases or deaths and the age-adjusted rates by county, site of cancer and gender for the most recent five-year period. Only aggregate data are released or published.

NDSCR staff also responds to special requests for cancer data and to answer cancer cluster concerns. Registry staff must balance the needs of requesters with the Cancer Registry mandate to maintain strict confidentiality.

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NDSCR has strict policies and procedures developed to maintain confidentiality in use and disclosure of data.

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