

# **North Dakota Statewide Cancer Registry**

## **Cancer Reporting Procedures For Non-Cancer Registry Health Care Providers**

**September 2004  
November 2013  
January 2017  
February 2019**

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\*This publication was supported by Grant/Cooperative Agreement Number U158/ DP17-1701 from the U.S. Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the office views of the Centers for Disease Control and Prevention.

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**POLICIES AND PROCEDURES**  
**FOR**  
**NON-CANCER REGISTRY HEALTH CARE PROVIDERS**

**I. INTRODUCTION**

Amendment of the Administrative Rules (NDCC 33-06-01) in July 1996 made cancer a reportable disease. This amendment requires hospitals, physicians, dentists and other health-care providers to report newly diagnosed cases of cancer to the North Dakota Statewide Cancer Registry (NDSCR). This data provides information used to evaluate the North Dakota cancer burden, conduct epidemiologic studies, research, evaluate potential cancer clusters and assist in cancer control planning. In addition, federal legislation (PL102-515) established the National Program of Cancer Registries, whose goal is to develop national comprehensive cancer prevention and control strategy. Because the state receives funds through this national program, the federal law also requires reporting by all North Dakota health-care providers who diagnose or treat cancer patients. Compliance with reporting requirements by all providers will ensure complete and accurate surveillance data and enable the registry to produce meaningful cancer statistics. The NDSCR began collecting cases on all reportable cancers diagnosed in North Dakota as of January 1, 1997. Also, federal legislation passed in 2004 requires the reporting of benign central nervous tumors with a diagnosis date of January 1, 2004, or later.

The most common types of cancer diagnosed or treated outside a hospital setting include melanoma, some prostate and breast tumors, noninvasive bladder tumors, small eye tumors, carcinoma in situ of the cervix, oral or genital tumors, tumors in colorectal polyps, lymphoma, leukemia, multiple myeloma, and other bone marrow primaries.

**II. WHO MUST REPORT**

**A. Health-Care Providers Who Must Report**

All health care providers who diagnose or treat cancer patients must report confirmed cases of cancer to the state central cancer registry. The types of providers listed below are included in this requirement.

- Hospitals
- Physicians / physician clinics / physician offices
- Dentists
- Medical laboratories
- Freestanding radiation or medical oncology clinics or cancer treatment centers
- Freestanding surgery centers
- Mammography or other radiology facilities
- Nursing homes

## **B. Determining Responsibility for Reporting**

1. Physicians must report all required cancer cases that are not referred to a hospital for further diagnosis or treatment. This includes:
  - a. Patients who are clinically diagnosed and receive no further work-up or
  - b. Patients who are newly diagnosed in the physician's own laboratory facility or by sending a specimen from the office to an outside laboratory, whether hospital-based or independent
  - c. Patients who are diagnosed and then referred out of state for treatment
  - d. Patients whose first-course treatment is initiated in the physician's office or clinic. This includes cancer treatment by surgery, radiation, chemotherapy, immunotherapy or hormones

*Exception:* If a hospital reports cases diagnosed and treated in a staff physician's office, the physician need not duplicate the reports to the state.

2. Medical Laboratories: Hospital-based laboratories and private or independent laboratories licensed in North Dakota must report all required cancer cases diagnosed in the lab for patients that are not referred to a hospital for further diagnosis and treatment. This includes cases also reported by physician or dentist offices as described in paragraph 1.b. above and paragraph 5 below. For hospital-based laboratories, these are “path only” cases that are reported by the hospital registry staff, but not necessarily included in the hospital registry.
3. Surgery Centers: Freestanding surgery centers (independent centers not affiliated with any hospital) must report any patient undergoing a biopsy or other surgical procedure at the facility for a newly diagnosed reportable cancer. This includes cases also reported by either a hospital-based or a private/independent medical laboratory as described in paragraph 2 above.

Surgery centers affiliated with a hospital must report any patient undergoing a biopsy or other surgical procedure at the facility for a newly diagnosed reportable cancer if the patient was not referred to the hospital for further diagnosis or treatment. This includes cases also reported by either hospital-based or private/independent medical laboratories as described in paragraph 2 above.

4. Freestanding Radiation or Medical Oncology Clinics must report any patient initially diagnosed with reportable cancer or when first-course treatment is initiated at the non-hospital based facility. This includes cancer treatment by surgery, radiation, chemotherapy, immunotherapy or hormones.
5. Mammography or Other Radiology Facilities: Facilities that provide screening, diagnostic or therapeutic cancer services must report confirmed cases of reportable cancer.

6. Dentists must report all required cancer cases that are not referred to a hospital for further diagnosis or treatment. This includes:
  - a. Patients who are diagnosed or treated by a dentist who performs a biopsy and/or receives a pathology report of a malignant diagnosis.
  - b. Cases also reported by either hospital-based or private/independent medical laboratories as described in paragraph 2 above
  
7. Nursing Homes must report the following types of newly diagnosed required cancer cases:
  - a. Cases clinically diagnosed but not confirmed through biopsy, cytology or other microscopic methods.
  - b. Cases for whom the first course of cancer treatment is initiated at the facility. Treatment may include chemotherapy, immunotherapy or hormone therapy.

### **III. REQUIRED CASES**

#### **A. General**

All confirmed cases of cancer that have been diagnosed or treated in North Dakota January 1, 1997, or later must be reported to the NDSCR. A complete list of ICD-10-CM Codes for the reportable tumors are showing on Appendix 4, or can be found at <https://ndcancer.org/files/NDSCRReportableList.pdf>. This includes solid and hematopoietic malignancies. A clinical diagnosis or any case that is stated to be cancer by a recognized medical practitioner is reportable, even if there is no histological or cytological confirmation. Any cancer or malignancy listed on the death certificate is reportable. In addition:

- Juvenile astrocytoma is reportable.
- Basal or squamous cell carcinoma of the skin of genitalia is reportable.
- All benign and borderline neoplasm's of the brain and central nervous system diagnosed January 1, 2004, or later are reportable. This also includes the pituitary gland, pineal gland, or craniopharyngeal duct.
- All neoplasms with behavior code two (in situ) or three (malignant) in the most current edition of the *International Classification of Diseases for Oncology (ICD-O)* are reportable.

Exceptions to the above are described in Section B below.

#### **B. Exceptions: Cases That Are Not Required or Reportable**

- Basal or squamous cell carcinoma of congenital skin.
- Preinvasive cervical neoplasia, including carcinoma in situ of the cervix or cervical intraepithelial neoplasia, grade III (CIN III).
- Prostatic intraepithelial neoplasia, grade III (PIN III) unless it states in situ as well as PIN III.
- A patient whose primary malignancy has previously been reported and who is receiving subsequent or second line/salvage treatment for recurrence or progression of disease.

- A patient who was diagnosed or treated at a hospital and is receiving additional or follow-up treatment at the physician's office or clinic.

**C. Terminology**

- All neoplasms, either histologically or clinically diagnosed, are reportable to NDSCR.
- Malignant diagnoses that are not histologically confirmed, but are described by one of the following ambiguous terms, are considered confirmed cases and are reportable:

apparent (ly)	appears to	comparable with
compatible with	consistent with	favor (s)
malignant appearing	most likely	presumed
probable (ly)	suspect (ed)	suspicious (for)
typical of	neoplasm [Beginning with 2004 diagnoses and only for non-malignant primary intracranial and CNS tumors.]	

Diagnoses described as “cannot be ruled out,” “equivocal,” “possible,” “questionable,” “suggests,” “rule out,” “worrisome,” “potentially malignant,” etc., are not to be reported.

**IV. WHEN TO REPORT**

Cases must be reported to the state central cancer registry no later than six (6) months after the date of diagnosis.

**V. WHERE TO REPORT**

The reporting forms and supporting documentation, as described in Section VIII below, should be mailed in a sealed envelope that is clearly labeled "CONFIDENTIAL" to:

North Dakota Statewide Cancer Registry  
 Department of Pathology  
 School of Medicine & Health Sciences  
 University of North Dakota  
 1301 N Columbia Rd Stop 9037  
 Grand Forks, N.D. 58203-9037  
<https://ndcancer.org>

Questions may be directed as follows:

Telephone 701.777.2868 or 701.777.0791

Fax 701.777.3108

E-mail [xudong.zhou@med.und.edu](mailto:xudong.zhou@med.und.edu) or [yun.zheng@med.und.edu](mailto:yun.zheng@med.und.edu)

## **VI. CONFIDENTIALITY ISSUES**

### **A. Reporting**

State law requires the reporting of cancer cases. The law does not require patient consent to report a case.

In addition, federal law includes provisions for state cancer registry access to patient records of all health-care providers whose services involve identifying, establishing the characteristics of, treating or assessing the medical status of cancer cases.

### **B. State Registry Disclosure**

North Dakota Statewide Cancer Registry disclosure of confidential information that could lead to the identification of an individual cancer patient, except to other state cancer registries and local and state health officers, is strictly prohibited by state and federal regulations. Those regulations are reflected in the North Dakota Statewide Cancer Registry policies and procedures and in their operating practices.

### **C. HIPAA**

The North Dakota Statewide Cancer Registry is considered an exempt entity according to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule at 45 CFR 164.512(a) (see appendix 1) because North Dakota State Administrative Rules mandate cancer reporting and the data submitted is used for public surveillance. Therefore, HIPAA-covered entities, such as the health-care providers described in Section II.A, are permitted to disclose protected health information (PHI) to the state central cancer registry without patient (or their personal representative's) consent.

## **VII. DATA QUALITY**

State central cancer registry staff performs extensive visual and computerized edits of reports for the completeness and accuracy of the data submitted. State central cancer registry staff may contact reporting entities when the edits identify incomplete or unclear information or discrepancies in data reported by multiple providers for one patient. Contact will be made in writing or by telephone.

## **VIII. INSTRUCTIONS FOR REPORTING CANCER DATA**

### **General**

Cases may be reported by (1) sending abstracted records electronically; (2) sending hard copies of medical records. The NDSCR participates in cancer data sharing agreements with other out-of-state central cancer registries. Because of this, cases that have been diagnosed and / or treated at your facility also need to be abstracted. This abstracted information is shared with the other state central cancer registries annually. This procedure enables each state to have more accurate data to address their specific states cancer burden.

## 1. Electronic Cancer Reporting

Reporters interested in electronic submission or submission through a secure internet reporting system.

These electronic submissions may be completed either by abstracting and entering the data directly into a PC-based program called Abstract Plus and monthly submit a data file to the NDSCR or by entering the data directly into the registry's web-based reporting system Web Plus which is the preferred method. Please contact NDSCR for further information in using either of these programs for doing electronic submissions from your facility.

See Attachment 2 for an example of the Web Plus data entry abstracting form.

See Attachment 3 for list of City, County, County Number and Zip Code in ND.  
(<https://ndcancer.org/files/NorthDakotaCityCountyandZipCodeDirectory.pdf> )

See Attachment 4 for list of ICD-9 and ICD-10 codes.  
(<https://ndcancer.org/files/NDSCRReportableList.pdf> )

## 2. Medical Record Hard Copy Reporting

If a reporter chooses to submit medical record hard copies, the following Documents are required to be submitted.

- a. Summary Sheet/Admission Sheet containing demographic information.
- b. History and Physical.
- c. Discharge Summary.
- d. Consultations.
- e. Surgery/Operative Report.
- f. Cytology and/or Pathology Report.
- g. Laboratory and Radiology Reports
- h. Autopsy Report [if applicable]