



NORTH DAKOTA STATEWIDE  

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CANCER REGISTRY

## **Policy and Procedure Manual**

**November 2006**  
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## **Table of Contents**

<b>Policy and Procedure Manual Maintenance .....</b>	<b>i</b>
<b>Section 1: Legal Issues .....</b>	<b>1</b>
1.0 North Dakota Law or Century Code .....	2
1.1 Administrative Rule .....	6
1.2 Confidentiality .....	12
1.3 HIPAA .....	13
1.4 Federal Law .....	13
Additional Information-	
North Dakota Department of Health Release of Health Information Policy .....	16
North Dakota Department of Health Data Use Agreement.....	24
U.S. Public Law 102-515 .....	28
Benign Brain Tumor Cancer Registries Amendment Act.....	39
<b>Section 2: North Dakota Statewide Cancer Registry General Information .....</b>	<b>41</b>
2.0 Mission Statement.....	42
2.1 Purpose.....	42
2.2 Contacts.....	43
2.3 Registry Information.....	44
2.4 Compliance .....	45
2.5 Reporting Sources .....	46
2.6 Advisory Board.....	46
<b>Section 3: Hardware and Software: Registry Operating and Data Management .....</b>	<b>47</b>
3.0 Software .....	48
3.1 Hardware.....	51
3.2 Data Security.....	54
3.3 Ownership .....	58
<b>Section 4: Cancer Data Reporting Guidelines.....</b>	<b>59</b>
4.0 Reporting Guidelines .....	60
4.1 Reporting Requirement Clarification.....	60
4.2 Required Cases.....	61
4.3 NDSCR Data Set.....	63
4.4 Reportable ICD-9 and ICD-10 Codes.....	71
4.5 Multiple Primaries .....	72
4.6 Manual Implementation Datelines .....	73
4.7 Non-registry Hospital Submission Rules and Guidelines.....	75
4.8 Multi-Facility Reporting.....	75

<b>Section 5: Data Processing .....</b>	<b>77</b>
5.0 Reporting Requirements .....	78
5.1 Case Ascertainment .....	78
5.2 Data Exchange Agreements .....	78
5.3 Abstracting .....	79
5.4 Data Entry .....	80
5.5 Internal Matching, Linking and Consolidation .....	80
CRSPlus Data Flow chart .....	83
5.6 Training/Trainer .....	89
<b>Section 6: Death Clearance .....</b>	<b>90</b>
6.0 Introduction.....	91
6.1 Procedures.....	92
6.2 Death Certificate Only Cases.....	92
6.3 Cause of Death.....	92
<b>Section 7: Quality Control.....</b>	<b>93</b>
7.0 Quality Control / Continuous Quality Improvement .....	94
7.1 EDITS, Visual Review and Data Processing .....	95
7.2 Quality Assurance Activities .....	97
Additional Information-	
Guidelines for Visual Editing .....	99
<b>Section 8: Audits: Case-findings and Re-abstracting .....</b>	<b>100</b>
8.0 Introduction.....	101
8.1 Case-finding Audits .....	101
NDSCR Case-finding Audits Guidelines and Letters.....	103
8.2 Re-abstracting Audit .....	107
NDSCR reporting facility letter .....	108

## **POLICY AND PROCEDURE MANUAL MAINTENANCE**

### **Format –**

The NDSCR Policy and Procedure Manual will be an electronic manual. Hard copies will be available upon request. The electronic manual is available at <http://www.ndhealth.gov/cancerregistry>.

### **New policies and procedures –**

The NDSCR co-program directors shall be responsible for reviewing, approving and signing of on all updates and new policies and procedures.

### **Review and update of policies and procedures schedule –**

The policy and procedure manual shall be reviewed at least annually. New policies and procedures will be written as necessary.

### **Documentation of changes –**

Original document date shall be retained. Review and/or updated policy date will be written directly underneath original document date.

# **Section 1**

## **Legal Issues**

- 1.0 North Dakota Law or  
Century Code**
- 1.1 Administrative Rule**
- 1.2 Confidentiality**
- 1.3 HIPAA**
- 1.4 Federal Law**

## **1.0 North Dakota Century Code Excerpts**

### **CHAPTER 233**

#### **HOUSE BILL NO. 1117** (Human Services Committee) (At the request of the State Department of Health)

#### **CANCER REGISTRY**

AN ACT to amend and reenact section 23-07-01 of the North Dakota Century Code, relating to authority of the state department of health to maintain a cancer registry.

**BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

**SECTION 1. AMENDMENT.** Section 23-07-01 of the North Dakota Century Code is amended and reenacted as follows:

**23-07-01. ~~Powers of state~~ State department of health - Collection of public health information.** The state department of health shall designate the diseases or conditions that must be reported. Such diseases or conditions may include contagious, infectious, sexually transmitted, or chronic diseases or any illness or injury which may have a significant impact on public health. The state department of health shall maintain a uniform statewide population-based registry system for the collection of data pertaining to the incidence, prevalence, risk factors, management, survival, mortality, and geographic distribution of cancer and reportable benign tumors.

Approved March 7, 2005  
Filed March 8, 2005

## **CHAPTER 23-07 REPORTABLE DISEASES**

**23-07-01. State department of health - Collection of public health information.** The state department of health shall designate the diseases or conditions that must be reported. Such diseases or conditions may include contagious, infectious, sexually transmitted, or chronic diseases or any illness or injury which may have a significant impact on public health. The state department of health shall maintain a uniform statewide population-based registry system for the collection of data pertaining to the incidence, prevalence, risk factors, management, survival, mortality, and geographic distribution of cancer and reportable benign tumors.

**23-07-02. Who to report reportable diseases.** Except as otherwise provided by section 23-07-02.1, the following persons or their designees shall report to the state department of health any reportable disease coming to their knowledge:

1. All health care providers, including physicians, physician assistants, nurse practitioners, nurses, dentists, medical examiners or coroners, pharmacists, emergency medical service providers, and local health officers.
2. The director, principal manager, or chief executive officer of:
  - a. Health care institutions, including hospitals, medical centers, clinics, long-term care facilities, assisted living facilities, or other institutional facilities;
  - b. Medical or diagnostic laboratories;
  - c. Blood bank collection or storage centers;
  - d. Public and private elementary and secondary schools;
  - e. Public and private universities and colleges;
  - f. Health or correctional institutions operated or regulated by municipal, county or multicounty, state, or federal governments;
  - g. Funeral establishments and mortuaries; and
  - h. Child care facilities or camps.
3. The state veterinarian, if the disease may be transmitted directly or indirectly to or between humans and animals.
4. A person having knowledge that a person or persons are suspected of having a reportable disease may notify the department and provide all information known to the person reporting concerning the reportable disease or condition of the person or persons.

If the person reporting is the attending physician or the physician's designee, the physician or the physician's designee shall report not less than twice a week, in the form and manner directed by the state department of health, the condition of the person afflicted and the state of the disease. A person making a report in good faith is immune from liability for any damages which may be caused by that act.



**23-07-21. Penalties.** Except as otherwise provided in this section, a person is guilty of an infraction:

1. Who violates or fails to obey any provision of this chapter, any lawful rule made by the state department of health, or any order issued by any state, district, county, or municipal health officer;
2. Who violates any quarantine law or regulation, or who leaves a quarantined area without being discharged; or
3. Who, knowing that the person is infected with a sexually transmitted disease, willfully exposes another person to infection.

Any person required to make a report under section 23-07-02.1 who releases or makes public confidential information or otherwise breaches the confidentiality requirements of section 23-07-02.2 is guilty of a class C felony.

## **CHAPTER 23-12 PUBLIC HEALTH, MISCELLANEOUS PROVISIONS**

**23-12-07. Violation of health laws - General penalty.** Any person who willfully violates any provision of this title, if another penalty is not specifically provided for such violation, is guilty of an infraction.

**CHAPTER 12.1-32  
PENALTIES AND SENTENCING**

**12.1-32-01.1. Organizational fines.** Any organization, as defined in section 12.1-03-04, shall, upon conviction, be subject to a maximum fine in accordance with the following classification:

7. Infraction, for which a maximum fine of five hundred dollars may be imposed. Any person convicted of an infraction who has, within one year prior to commission of the infraction of which the person was convicted, been previously convicted of an offense classified as an infraction may be sentenced as though convicted of a class B misdemeanor. If the prosecution contends that the infraction is punishable as a class B misdemeanor, the complaint shall specify that the offense is a misdemeanor.

**12.1-32-01. Classification of offenses - Penalties.** Offenses are divided into seven classes, which are denominated and subject to maximum penalties, as follows:

5. For a class B misdemeanor, a maximum fine of ten thousand dollars.

Nothing in this section shall be construed as preventing the imposition of the sanction provided for in section 12.1-32-03, nor as preventing the prosecution of agents of the organization under section 12.1-03-03.

## **1.1 Administrative Rule**

### **ARTICLE 33-06**

#### **REPORTABLE CONDITIONS**

Chapter	
33-06-01	Conditions Designated as Reportable
33-06-02	Reporting
33-06-03	Health Officer Investigation
33-06-04	Control of Specific Diseases
33-06-05	School Immunization Requirements
33-06-05.1	General Provisions
33-06-05.2	Students With Significant Contagious Diseases
33-06-05.3	Employees With Significant Contagious Diseases
33-06-05.4	Treatment of Independent Contractors With Significant Contagious Diseases
33-06-05.5	Relations With the Public
33-06-05.6	Education
33-06-06	Food Handlers [Repealed]
33-06-07	Laboratory Specimens for Carriers of Disease
33-06-08	Isolation Requirements
33-06-09	Common Carriers Federal Regulation Adopted and Shipment of Birds of the Psittacine Family
33-06-10	Disinfection
33-06-11	[Reserved]
33-06-12	[Reserved]
33-06-13	[Reserved]
33-06-14	[Reserved]
33-06-15	Preparation of Bodies and Transportation
33-06-16	Newborn Screening Program

## CHAPTER 33-06-01 CONDITIONS DESIGNATED AS REPORTABLE

Section

33-06-01-01

Reportable Conditions

33-06-01-01. Reportable conditions. All reports and information concerning reportable conditions are confidential and not open to inspection. The following designated reportable conditions must be reported to the state department of health by the persons designated in chapter 33-06-02. If any reportable condition is designated by an asterisk, an appropriate sample or isolate must be submitted to the division of microbiology (public health laboratory) in addition to the required report.

1. Anthrax\*.
2. Arboviral infection.
3. Botulism\*.
4. Brucellosis\*.
5. Campylobacter enteritis\*.
6. Cancer, all malignant and in situ carcinomas; in addition, all benign cancers of the central nervous system, pituitary gland, pineal gland, and craniopharyngeal duct. Carcinoma in situ of the cervix is not collected. Basal or squamous cell carcinoma is not collected unless diagnosed in the labia, clitoris, vulva, prepuce, penis, or scrotum.
7. All CD4 test results.
8. Chickenpox (varicella).
9. Chlamydial infections.
10. Cholera\*.
11. Clostridium perfringens intoxication\*.
12. Coccidioidomycosis\*.
13. Creutzfeldt-Jakob disease.
14. Cryptosporidiosis.
15. Diphtheria\*.
16. E. coli, shiga toxin-producing\*.
17. Enterococcus, vancomycin resistant (VRE)\*.
18. Foodborne or waterborne outbreaks.
19. Giardiasis.
20. Glanders\*.

21. Gonorrhea.
22. Hantavirus\*.
23. Haemophilus influenzae infection (invasive infection with haemophilus influenzae isolated from blood, cerebral spinal fluid, or other normal sterile site)\*.
24. Hemolytic uremic syndrome.
25. Hepatitis (specify type).
26. Human immunodeficiency virus (HIV) infection, including acquired immunodeficiency syndrome (AIDS)\*. (Any positive HIV test result.)
27. Human immunodeficiency virus (HIV) nucleic acid test result (detectable or nondetectable).
28. Human immunodeficiency virus (HIV) rapid screens (positive only).
29. Influenza.
30. Laboratory incidences involving the possible release of category A bioterrorism agents or novel influenza viruses into the laboratory environment.
31. Lead blood level greater than or equal to 10 ug/dl.
32. Legionellosis.
33. Listeriosis\*.
34. Lyme disease.
35. Malaria\*.
36. Measles (rubeola)\*.
37. Melioidosis\*.
38. Meningitis, bacterial (all bacterial species isolated from cerebrospinal fluid)\*.
39. Meningococcal disease (invasive infection with neisseria meningitidis isolated from blood, cerebral spinal fluid, or other normal sterile site)\*.
40. Mumps.
41. Nipah viral infections\*.
42. Nosocomial outbreaks in institutions.
43. Organisms with reduced susceptibility to carbapenem\*. (ex. klebsiella pneumonia carbapenemase [KPC], carbapenem-resistant enterobacteriaceae [CRE], etc.).
44. Pertussis\*.
45. Plague\*.
46. Poliomyelitis

47. Pregnancy in a person infected with hepatitis B or HIV.
48. Psittacosis.
49. Q fever\*.
50. Rabies (animal or human\*).
51. Rocky Mountain spotted fever.
52. Rubella\*.
53. Salmonellosis\*.
54. Scabies outbreaks in institutions.
55. Severe acute respiratory syndrome (SARS)\*.
56. Shigellosis\*.
57. Smallpox\*.
58. Staphylococcus aureus, methicillin resistant (MRSA), invasive sites only - excluding urine\*.
59. Staphylococcus aureus, vancomycin resistant and intermediate resistant (VRSA and VISA)\*.
60. Staphylococcus enterotoxin B intoxication\*.
61. Streptococcal infections (invasive infection of streptococcus group A or B or streptococcus pneumoniae isolated from blood, cerebral spinal fluid, or other normal sterile site)\*.
62. Syphilis.
63. Tetanus.
64. Tickborne diseases\*.
65. Vibriosis\*.

**History:** Amended effective May 1, 1984; December 1, 1986; January 1, 1988; January 1, 1989; October 1, 1990; January 1, 1991; February 1, 1992; May 1, 1994; January 1, 1995; July 1, 1996; February 1, 2000; August 1, 2002; March 1, 2003; July 1, 2004; April 1, 2007; January 1, 2011.

**General Authority:** NDCC 23-07-01

**Law Implemented:** NDCC 23-07-01

## CHAPTER 33-06-02 REPORTING

Section  
33-06-02-01            Reporting

### 33-06-02-01. Reporting.

1. **Morbidity reports.** Reporting may be conducted by completion of reporting forms, telephonic, electronic, or through other means designated by the state department of health. All morbidity reports must be made as soon as a laboratory test result is positive or a clinical diagnosis is made.
2. **Printed forms.** Reporting forms will be provided by the state department of health. For those conditions which may require investigation to prevent spread of the condition, forms are available which specify the patient's name and address, age, sex, occupation, probable source of infection, date of exposure, date of onset, and name and address of the person making the report. For those conditions which do not require investigations, forms are available for reporting the conditions by number only.
3. **Telephonic reports.** Physicians shall notify the state health officer by telephone of any unusual outbreak of food infections and poisonings, and of any case of bubonic plague, rabies, anthrax, botulism, Rocky Mountain spotted fever, and such other conditions as the state department of health may from time-to-time designate.
4. **Teacher must report suspected cases.** Whenever any school principal or teacher in any private, public, or parochial school has reason to suspect that any pupil is suffering from or has been exposed to any communicable condition, such principal or teacher shall send the child home with instructions to see the child's family physician. Any pupil so excluded shall not be permitted to attend school again until the pupil shall present a certificate from a physician licensed to practice medicine in North Dakota or from the local health department stating that the child is not suffering from a communicable condition and that it is safe for the child to return to school. Such principal or teacher shall also report any such suspected case to the local health officer, who, upon receipt of such report, shall use the officer's best judgment as to the necessity for further investigating the case.
5. All medical diagnostic laboratories are required to report any laboratory test result (serological, culture, etc.) which may be interpreted as indicative of any of the reportable conditions to the state department of health. Test results from specimens sent by in-state laboratories to out-of-state laboratories are also required to be reported.

6. In addition to reporting requirements specified under subsection 5, mandatory reporters include:
  - a. All physicians and other health care providers administering screening, diagnostic, or therapeutic services.
  - b. Hospitals, including those providing inpatient or outpatient services, or both.
  - c. Health care facilities, including basic care facilities and mobile units, providing screening, diagnostic, or therapeutic services.

**History:** Amended effective July 1, 1996.

**General Authority:** NDCC 23-01-03

**Law Implemented:** NDCC 23-01-03



## **1.2 Confidentiality**

The North Dakota Statewide Cancer Registry (NDSCR), through the amendment of the Administrative Rule in July 1996, collects cancer incidence data, and as such, acts as custodian of this data to ensure that these records are held in confidence and that the privacy of the individual patients, reporting facilities and physicians are protected.

Federal law or Public Law 102-515 provides a means for the state registry to access records of hospitals, outpatient clinics, physicians, surgeons, and all other facilities or individuals providing such services to patients that would identify cases of cancer or establish characteristics of cancer or the treatment of cancer.

NDSCR is concerned that data collection, maintenance and release be performed with attention given to data security requirements. This policy outlines the rules that govern the collection, maintenance and release of data gathered as a result of the registry's operations and applies to all cancer data that falls within the activity of NDSCR, regardless of format or physical location. Although a state of confidentiality does not guarantee appropriate conduct, it shows the intent to hold the NDSCR staff and other designated users of the data accountable for information security.

The following information on cancer patients is considered to be confidential:

- Name
- Street address
- Social Security number
- Telephone number
- Physician name
- Reporting facility

Additionally, the following will be considered confidential if requested in a combination with other items that could identify a patient or facility:

- Sex
- Race
- Date of birth or age
- City address
- County address
- Zip code
- Census tract/Block group

No information that identifies or by its nature can be used to identify individuals upon whom data has been collected may be included in any summary report of data or other compilation of data for public distribution.

All employees or contractors working with or for NDSCR are required to remove all papers, forms, notes, computer files or other materials containing patient identifier information from desk tops and lock all such materials in desks or file

cabinets at the end of each day. All documents are to be turned face down when staff are away from their desk during the day. Employees performing data collection in the field, when asking contact people for information, shall make sure forms containing other data are not shown, shall transport forms and medical records so that private information is not visible and will not comment on any information seen in the medical records reviewed.

The NDSCR coordinator has the responsibility for data security, and the registry staff is responsible for their own actions in regard to data security policies and procedures.

Confidential data must not be transmitted electronically in any means without authority from the registry coordinator or a staff member to whom such authority has been delegated. Data transmitted shall be encrypted and password protected. Paper partial abstracts, paper pathology reports and computer disks containing confidential information must be kept in a locked drawer.

In completing requests for statistical information on North Dakota residents, many of the cell sizes relating to cancer, age, gender and numbers are very small due to the population size of our state. To help in the protection of the confidentiality of the state's residents, the North Dakota Health Information Disclosure Act took effect August 1999.

Any researcher or individual requesting the use of raw data from central registry must complete a Data Use Agreement, page 23, which ensures compliance with the requirements of the Health Information Disclosure Act and the Federal Health Insurance Portability and Accountability Act (HIPAA).

### **1.3 HIPAA (Health Insurance Portability and Accountability Act)**

The NDSCR, within the Department of Pathology, University of North Dakota School of Medicine & Health Sciences acting as the bona fide agent for the North Dakota Department of Health, is authorized by law to collect cancer information for the purpose of preventing or controlling disease and to conduct public health surveillance, public health investigations and interventions. HIPAA permits covered entities to disclose protected health information without individual authorization to public health authorities such as state health departments.

The NDDoH has developed policies that address the many facets of HIPAA regulations. HIPAA Policy Number P-028, page 15, relates to release of health information and the associated Data Use Agreement for Disclosure of Protected Health Information is included at the end of this section.

### **1.4 Federal Law**

Established by Congress through the Cancer Registries amendment Act in 1992, and administered by the U.S. Centers for Disease Control and Prevention, the National Program of Cancer Registries (NPCR) collects data on the occurrence of cancer; the type,

extent, and location of the cancer; and the type of initial treatment. In 2004, Congress passed another law mandating the collection of all benign central nervous system tumors. These two laws are included at the end of this section.

North Dakota was one of several states that did not have a cancer registry due to lack of resources and legislative support to gather complete cancer data. Funding for a statewide cancer registry was initially received in 1994. Data collection of newly diagnosed or incidence cancer began in 1997. Today, funding for the state central cancer registry is received through NPCR, state general fund dollars and in-kind support from various sources.

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## North Dakota Department of Health HIPAA Policy

<b>Policy Title:</b>	<b>Release of Health Information</b>	
<b>Policy Number:</b>	P-028	<b>Version:</b> 1.2 Updated July 22, 2005
<b>Reference:</b>	45 CFR 164.502(d); 45 CFR 164.514 (d) 45 CFR 164.514(e); 45 CFR 164.512(i), 45 CFR 164.512(b)	
<b>Applicability:</b>	Department of Health	
<b>Approved By:</b>	Dr. Terry Dwelle, State Health Officer Arvy Smith, Deputy State Health Officer Darleen Bartz, HIPAA Coordinator, Privacy Officer	
<b>Effective Date:</b>	February 1, 2004	

### **Policy:**

The NDDoH may release health information data as outlined in the following procedure.

### **Exceptions:**

None

### **Procedure:**

The NDDoH may disclose:

- Protected health information with the individual's specific written authorization. Such authorization must meet all the requirements described in the Authorizations Policy (P-004); or
- De-identified health information; or
- A limited data set with a data use agreement; or
- Health information for research if the information is not de-identified or is not a limited data set, with or without the individual's authorization, if the NDDoH uses a data use agreement and obtains documentation that an alteration to, or waiver of, the individual's authorization has been approved by:
  - The NDDoH privacy board, or
  - The NDDoH Institutional Review Board (IRB) if the research is in part conducted by an NDDoH employee for the Department of Health.
- Decedents' information with a data use agreement. No IRB or privacy board review is needed. Consistent with the Minimum Necessary policy (P-012), the minimum necessary information will be disclosed. In addition, for research on decedents' information, the NDDoH will obtain:
  - Representation from the researcher that the information sought is solely for research on the PHI of decedents, and
  - Assurance that there will be no attempt to contact family members, and
  - Representation that the PHI requested is necessary for the research purpose, and

- Documentation of the death of such individuals, (if applicable).
- PHI when the NDDoH is operating as a public health authority. NDDoH is authorized to disclose individual information without authorization for the purpose of preventing or controlling disease, injury or disability and for the conduct of public health surveillance, investigation and intervention; or
- Information to a known public health authority. If the public health authority status of an organization is not known, the NDDoH will require a Business Associate Agreement or Data Use Agreement to be completed. Dependent upon the reason for the request from a public health authority, the NDDoH may require a Business Associate Agreement or Data Use Agreement be completed prior to disclosure of PHI to another public health authority; or
- Information without individual authorization to the extent that such disclosure is required or permitted by law.

Any disclosures not consistent with this policy are a violation of NDDoH policies and procedures and federal HIPAA regulations. Sanctions may be imposed consistent with the Workforce Sanctions policy (P-027).

#### De-identified Health Information

- The NDDoH may disclose de-identified health information without the written authorization of the individual when the health information does not identify an individual and there is no reasonable basis to believe that the information can be used to identify an individual. The NDDoH will use reasonable discretion when disclosing de-identified health information.
- The NDDoH may use protected health information to create information that is not individually identifiable health information or disclose protected health information only to a business associate to create the de-identified information.
- The NDDoH may determine that health information is not individually identifiable health information (de-identified) if the following identifiers of the individual or of relatives, employers, or household members of the individual, are removed and if the NDDoH does not have knowledge that the information could be used alone or in combination with other information to identify the individual:
  - Names
  - All geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code if, according to the current publicly available data from the Bureau of the Census:
    - The geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people, and
    - The initial three digits of a zip code for all such geographic units containing 20,000 or fewer people are changed to 000.

- All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death, and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older
  - Telephone numbers
  - Fax numbers
  - Electronic mail addresses
  - Social security numbers
  - Medical record numbers
  - Health plan beneficiary numbers
  - Account numbers
  - Certificate/license numbers
  - Vehicle identifiers and serial numbers, including license plate numbers
  - Device identifiers and serial numbers
  - Web Universal Resource Locators (URLs)
  - Internet Protocol (IP) address numbers
  - Biometric identifiers, including finger and voice prints
  - Full face photographic images and any comparable images
  - Any other unique identifying number, characteristic or code
- The NDDoH may also determine that health information is not individually identifiable health information (de-identified) if:
    - **A person within the NDDoH who has appropriate knowledge and experience with statistical and scientific principles and methods for rendering information not individually identifiable:**
      - Determines that the risk is very small that the information could be used, alone or in combination with other reasonably available information, by an anticipated recipient to identify an individual who is a subject of the information; and
      - Documents the methods and results of the analysis that justify such determination.
- The NDDoH may assign a code or other means of record identification to allow information de-identified to be re-identified if:
    - The code or other means of record identification is not derived from or related to information about the individual and is not capable of being translated in order to identify the individual;
    - The code or other means is not used for any other purpose and does not disclose the mechanism for re-identification.
- De-identified information disclosed via internet access will be accompanied by a statement notifying the user that:

- Linking the data to other data for the purpose of identifying individuals is prohibited, and
- The user must report to the NDDoH any inadvertent discovery of the identity of any person, and
- The user must make no use of the discovery, and
- By using this data, the user signifies agreement to comply with the above statements.

#### Limited Data Sets

- The NDDoH may disclose protected health information (PHI) for research, public health or health care operations without the written authorization of the individual if the information is a limited data set and the NDDoH enters into a data use agreement with the limited data set recipient.
- A limited data set is PHI that excludes the following direct identifiers of the individual or of relatives, employers or household members of the individual:
  - Names
  - Postal address information, other than town or city, county, State and zip code
  - Telephone numbers
  - Fax numbers
  - Electronic mail addresses
  - Social security numbers
  - Medical record numbers
  - Health plan beneficiary numbers
  - Account numbers
  - Certificate/license numbers
  - Vehicle identifiers and serial numbers, including license plate numbers
  - Device identifiers and serial numbers
  - Web Universal Resource Locators (URLs)
  - Internet Protocol (IP) address numbers
  - Biometric identifiers, including finger and voice prints
  - Full face photographic images and any comparable images
- The NDDoH may disclose a limited data set only if the NDDoH obtains satisfactory assurance, in the form of a data use agreement, that the limited data set recipient will only use or disclose the PHI for limited purposes.

#### Data Use Agreements

- All requests for data which require a Data Use Agreement are to be sent to the NDDoH HIPAA Coordinator.
- A data use agreement between the NDDoH and the limited data set recipient must:



- Establish the permitted uses and disclosures of the information by the limited data set recipient. The data use agreement may not authorize the limited data set recipient to use or further disclose the information in a manner that would violate these requirements;
  - Establish who is permitted to use or receive the limited data set;
  - Provide that the limited data set recipient will:
    - Not use or further disclose the information other than as permitted by the data use agreement or as otherwise required by law;
    - Use appropriate safeguards to prevent use or disclosure of the information other than as provided for by the data use agreement;
    - Report to the NDDoH any use or disclosure of which it becomes aware not provided for by its data use agreement;
    - Ensure that any agents to whom it provides the limited data set agrees to the same restrictions and conditions that apply to the limited data set recipient with respect to this information;
    - Not identify the information or contact the individuals.
  - Be signed and dated by the Requestor, the appropriate NDDoH Division Director, and the NDDoH Privacy Officer.
- 
- The proposed Data Use Agreement will be sent to the requestor for review. The requestor must sign and date the Agreement and return to the NDDoH HIPAA Coordinator.
  - The appropriate NDDoH Division Director will be requested to review the Data Use Agreement, sign and date.
  - The NDDoH HIPAA Coordinator will review the completed Data Use Agreement, sign and date.
  - A Data Use Agreement number will be assigned to the Data Use Agreement when the Agreement has been finalized and all appropriate signatures have been obtained.
  - A copy of the signed Data Use Agreement will be given to the requestor and the appropriate NDDoH Division. A copy will also be maintained by the HIPAA Coordinator. The signed original will be forwarded by the HIPAA Coordinator to the NDDoH Administrative Services Section. The original will be maintained by the NDDoH Administrative Services Section in a secure file.
  - Documentation of the information released (actual copies and/or database fields, etc.) is to be retained by the appropriate NDDoH Division.
  - If NDDoH knows of a pattern of activity or practice of the limited data set recipient that constitutes a breach or violation of the data use agreement, NDDoH will take reasonable

steps to end the breach or violation or the NDDoH will discontinue disclosure of protected health information to the recipient and report the problem to the Secretary of the Department of Health and Human Services (DHHS).

- A Data Use Agreement may also be used in other situations as deemed necessary by the NDDoH HIPAA Coordinator.

### Privacy Board

(In relation to this section of the procedure, any reference to an IRB is to be considered an IRB from an organization outside of the NDDoH. The NDDoH IRB policies and procedures are not included in the NDDoH HIPAA policies.)

- The NDDoH privacy board must:
  - Have NDDoH staff members with varying backgrounds and appropriate professional competency as necessary to review the effect of the research protocol on the individual's privacy rights and related interests;
  - Include at least one member who is not affiliated with the NDDoH or with any entity conducting or sponsoring the research and not related to any person who is affiliated with any such entities;
  - Not have any member participating in a review of any project in which the member has a conflict of interest.
- The chair of the NDDoH Privacy Board is the HIPAA Coordinator.
- Prior to the research, the NDDoH obtains representations from the researcher that:
  - The use or disclosure of PHI is necessary to prepare a research protocol or preparatory purpose;
  - No PHI is to be removed from the NDDoH by the researcher until approval is granted;
  - The PHI requested is necessary for the research purposes.
- For a disclosure permitted based on documentation of approval of an alteration or waiver, the documentation from the researcher if an IRB or the NDDoH if a privacy board must include:
  - Identification of the IRB or privacy board and the date on which the alteration or waiver of authorization was approved;
  - A statement that the IRB or privacy board has determined that the alteration or waiver of authorization satisfies the following criteria:
    - The use or disclosure of PHI involves no more than a minimal risk to the privacy of individuals based on;
      - An adequate plan to protect the identifiers from improper use and disclosure;

- An adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is health or research justification for retaining the identifiers or retention is required by law;
- Adequate written assurances that PHI will not be reused or disclosed to any other person or entity except as required by law, for authorized oversight of the research study or for other research for which the use or disclosure of PHI would be permitted;
  - The research could not be conducted without the waiver or alteration.
  - The research could not be conducted without access to and use of the PHI.
- A brief description of the PHI for which use or access has been determined to be necessary by the IRB and/or privacy board;
- A statement that the alteration or waiver of authorization has been reviewed and approved under either normal or expedited review procedures as follows:
  - An IRB must follow the Common Rule as defined in the Federal Register.
  - A privacy board must review the proposed research at meetings at which a majority of the privacy board members are present, including one member who is not affiliated with the NDDoH or with any entity conducting or sponsoring the research and not related to any person who is affiliated with any of those entities. The alteration or waiver of authorization must be approved by the majority of the privacy board members present at the meeting unless the privacy board elects to use an expedited review procedure;
  - An expedited review procedure may be used if the research involves no more than minimal risk to the privacy of the individuals who are the subject of the PHI for which use or disclosure is being sought. The review and approval of the alteration or waiver of authorization may be carried out by the chair of the privacy board or by one or more members of the privacy board as designated by the chair.
- The documentation of the alteration or waiver of authorization must be signed by the chair or other member as designated by the chair of the IRB or the privacy board.

**Related Forms:**

Data Release Checklist

DOH Data Use Agreement for Disclosure of Protected [Individually Identifiable] Health Information

**Definitions:**

*NDDoH* – North Dakota Department of Health

*Protected Health Information* – Individually identifiable health information that is transmitted or maintained by electronic media or transmitted or maintained in any other form or medium

*Individually Identifiable Health Information* – Health information which includes demographic information that relates to the past, present or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present or future payment for the provision of health care to an individual and that identifies the individual or there is a reasonable basis to believe the information can be used to identify the individual

*Electronic Media* – Electronic storage media including memory devices in computers and any removable/transportable digital memory medium such as magnetic tape or skid, optical disk or digital memory card; or transmission media used to exchange information already in electronic storage media. Transmission media includes the internet, extranet, leased lines, dial-up lines, private networks and the physical movement of removable/transportable electronic storage media

*Research* – Systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge

*Public Health Authority* – An agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate

## **DOH Data Use Agreement for Disclosure of Protected [Individually Identifiable] Health Information**

In order to ensure the confidence of the public regarding the confidentiality of information collected and maintained by the North Dakota Department of Health [DOH], and to comply with federal and state laws, these requirements apply to the **use or disclosure** of the file(s) containing “**protected [individually identifiable] health information**” or any data derived from that (those) file(s).

1. Any term used in this Agreement that appears in **bold type** has the meaning set forth in the federal privacy rule, 45 C.F.R. § 160.103.
2. This Agreement applies to the **disclosure** of the following DOH data:

*Please specify the data files and/or information (including the “**fields of health information**” and demographic information) that are the subject of the request.*

3. Requestor Identification Information:

Name:

Title:

Company/Organization:

Street Address:

City, State and ZIP code:

Phone Number:

Fax:

Email:

4. Requestor represents and warrants that the **protected health information** described in ¶ 2 above and **disclosed** under this Agreement may be used only for (1) the project and (2) the purposes described below:

*(Describe briefly, but concretely, (1) the nature and (2) the purpose of the project. An additional description of the project may be incorporated by reference if it is attached to the DUA)*

5. Requestor may **use** protected health information (including the information in a **limited data set**) only for research or public health purposes.
6. Requestor may not **use** or **disclose** information disclosed under this Agreement in a manner that would violate the requirements of the HIPAA privacy rule if done by a **covered entity**.

7. The **protected health information disclosed** under this Agreement may be **used** only by the following individuals:

Name:

Title:

Organization:

*(Describe briefly and concretely by name, title, or position, and by organization, the persons authorized to have access to information disclosed under this Agreement)*

8. Requestor may not: (1) **use** or further **disclose** the information disclosed under this Agreement, except as specified in this Agreement or otherwise **required by law**; (2) **disclose** any **protected health information** or **aggregation of data** from the file(s) covered by this Agreement, unless the data is **de-identified**; or, (3) make any attempt to identify any individual or link records included in the file(s) to any other **individually identifiable information** without the express written authorization of DOH.

9. Requestor agrees not to contact any individual whose **protected health information** is **disclosed** to the Requestor under this Agreement without the express written authorization of DOH.

10. Requestor will use appropriate **safeguards** to prevent any **use or disclosure** of information except as provided in this Agreement.

11. Requestor will report to the Department of Health any **use or disclosure** of **protected health information** provided under this Agreement (of which the Requestor becomes aware) that is not authorized by the Agreement. Any such report must be made within three working days of the date it is discovered, except that in the case of a catastrophic breach involving (a) 25 percent or more of the records disclosed under the Agreement, or (b) the records of more than 100 individuals, a report must be made within 24 hours of the time the catastrophic breach is discovered.

12. Requestor will ensure that any agents, including a subcontractor to whom the Requestor provides any of the information **disclosed** under this Agreement, agrees to the same restrictions and conditions that apply to the Requestor with respect to the **protected health information disclosed** under this Agreement.

13. If Requestor is in material breach of any requirement of this Agreement, and fails to promptly correct the breach, the Requestor must, at the request of DOH, return to DOH all information **disclosed** to the Requestor under this Agreement, and destroy any copies of **protected health information** (including information contained in a **limited data set**) contained in, or created or derived from, **health information** provided under this Agreement.

14. Unless authorized by the next sentence, only one **disclosure** of the DOH data described in ¶ 2 of this Agreement is authorized. The Department of Health hereby authorizes periodic (or as requested) **disclosures** through the retention date. \_\_\_\_\_ [Initials of DOH HIPAA Coordinator/Privacy Officer for DOH]

15. Requestor may not amend the fields of **protected health information** (including the fields of **health information** in a **limited data set** or demographic variables) subject to periodic (or as requested) **disclosure** if authorized under ¶ 14 of this Agreement without the express prior written authorization of the Department of Health.

16. For each file, Requestor shall pay the standard fee, if any, established by DOH.

17. In the event Requestor makes an unauthorized **disclosure** of any data, or is otherwise in material breach of this Agreement, DOH may impose any or all of the following measures:

Request a formal response to an allegation of an unauthorized **disclosure**,

Require the submission of a corrective action plan formulated to implement steps to be taken to alleviate the possibility of any future unauthorized **disclosure**;

Require the return of the data; and/or

Impose further restrictions on **disclosure** of DOH data to the organization/Requestor in question.

18. The parties mutually agree that the data file(s) identified in ¶ 2 above (and/or any derivative file(s)) may be retained and used by the Requestor until \_\_\_\_\_, 200\_, (“retention date”). Requestor agrees that on \_\_\_\_\_, 200\_, the retention date, Requestor must (1) return all **protected health information disclosed** under this Agreement to the Department of Health, or (2) destroy any **protected health information disclosed** to the Requestor and any derivative files containing **protected health information** and will certify to the Department of Health that Requestor has accomplished these actions.

19. If **protected health information** is **disclosed** in violation of this data use Agreement it may result in **CIVIL OR CRIMINAL PENALTIES OR BOTH**. For example –

If the information was received from the health care data committee a person may be subject to a civil penalty not to exceed \$500 per day. N.D.C.C. § 23-01.1-07.

If the information is a vital birth or death record, and the information is **disclosed** in violation of this Agreement, the person is guilty of an infraction. N.D.C.C. § 23-02.1-32(2) (c).

If a public servant **discloses protected health information** in violation of the Agreement, the public servant may be guilty of a class C felony. N.D.C.C. § 12.1-13-01.

If the person **disclosing** information is a **covered entity** under the HIPAA privacy regulations, and the person knowingly and in violation of the regulations **discloses individually identifiable health information** to another person, they may be guilty of a criminal offense under 42 U.S.C. § 1320d-6. They also may be subject to civil money penalties of \$100 per violation, up to \$25,000 per person, per year for each requirement or prohibition of the privacy rule that is violated.

20. **Warranty**. Requestor represents and warrants that the facts and statements made in this Agreement and any research project plan or other document submitted to DOH in support of this Data Use Agreement is complete and accurate.

Name and title of Requestor

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**Signature**

**Date**

Name and title of DOH Division Director

---

**Signature**

**Date**

Dirk Wilke, DOH HIPAA Coordinator and Privacy Officer

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**Signature**

**Date**



Public Law 102-515  
102d Congress

An Act

Oct. 24, 1992  
[S. 3312]

Entitled the "Cancer Registries Amendment Act".

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

**SECTION 1. SHORT TITLE.**

This Act may be cited as the "Cancer Registries Amendment Act".

**SEC. 2. FINDINGS AND PURPOSE.**

(a) FINDINGS.—Congress finds that—

(1) cancer control efforts, including prevention and early detection, are best addressed locally by State health departments that can identify unique needs;

(2) cancer control programs and existing statewide population-based cancer registries have identified cancer incidence and cancer mortality rates that indicate the burden of cancer for Americans is substantial and varies widely by geographic location and by ethnicity;

(3) statewide cancer incidence and cancer mortality data, can be used to identify cancer trends, patterns, and variation for directing cancer control intervention;

(4) the American Association of Central Cancer Registries (AACCR) cites that of the 50 States, approximately 38 have established cancer registries, many are not statewide and 10 have no cancer registry; and

(5) AACCR also cites that of the 50 States, 39 collect data on less than 100 percent of their population, and less than half have adequate resources for insuring minimum standards for quality and for completeness of case information.

(b) PURPOSE.—It is the purpose of this Act to establish a national program of cancer registries.

**SEC. 3. NATIONAL PROGRAM OF CANCER REGISTRIES.**

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following new part:

"PART M—NATIONAL PROGRAM OF CANCER REGISTRIES

**"SEC. 399H. NATIONAL PROGRAM OF CANCER REGISTRIES.**

"(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State's cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning—

Cancer  
Registries  
Amendment  
Act.  
Diseases.  
Health and  
health care.  
42 USC 201 note.  
42 USC 280e  
note.

42 USC 280e.



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Public Health Service



"(1) demographic information about each case of cancer;

"(2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;

"(3) administrative information, including date of diagnosis and source of information;

"(4) pathological data characterizing the cancer, including the cancer site, stage of disease (pursuant to Staging Guide), incidence, and type of treatment; and

"(5) other elements determined appropriate by the Secretary.

"(b) MATCHING FUNDS.—

"(1) IN GENERAL.—The Secretary may make a grant under subsection (a) only if the State, or the academic or nonprofit private organization designated by the State to operate the cancer registry of the State, involved agrees, with respect to the costs of the program, to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs or \$1 for every \$3 of Federal funds provided in the grant.

"(2) DETERMINATION OF AMOUNT OF NON-FEDERAL CONTRIBUTION; MAINTENANCE OF EFFORT.—

"(A) Non-Federal contributions required in paragraph (1) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

"(B) With respect to a State in which the purpose described in subsection (a) is to be carried out, the Secretary, in making a determination of the amount of non-Federal contributions provided under paragraph (1), may include only such contributions as are in excess of the amount of such contributions made by the State toward the collection of data on cancer for the fiscal year preceding the first year for which a grant under subsection (a) is made with respect to the State. The Secretary may decrease the amount of non-Federal contributions that otherwise would have been required by this subsection in those cases in which the State can demonstrate that decreasing such amount is appropriate because of financial hardship.

"(c) ELIGIBILITY FOR GRANTS.—

"(1) IN GENERAL.—No grant shall be made by the Secretary under subsection (a) unless an application has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such a manner, and be accompanied by such information, as the Secretary may specify. No such application may be approved unless it contains assurances that the applicant will use the funds provided only for the purposes specified in the approved application and in accordance with the requirements of this section, that the application will establish such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement and accounting of Federal funds paid to the applicant under subsection (a) of this

section, and that the applicant will comply with the peer review requirements under sections 491 and 492.

"(2) ASSURANCES.—Each applicant, prior to receiving Federal funds under subsection (a), shall provide assurances satisfactory to the Secretary that the applicant will—

"(A) provide for the establishment of a registry in accordance with subsection (a);

"(B) comply with appropriate standards of completeness, timeliness, and quality of population-based cancer registry data;

"(C) provide for the annual publication of reports of cancer data under subsection (a); and

"(D) provide for the authorization under State law of the statewide cancer registry, including promulgation of regulations providing—

"(i) a means to assure complete reporting of cancer cases (as described in subsection (a)) to the statewide cancer registry by hospitals or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;

"(ii) a means to assure the complete reporting of cancer cases (as defined in subsection (a)) to the statewide cancer registry by physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;

"(iii) a means for the statewide cancer registry to access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities, individuals, or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;

"(iv) for the reporting of cancer case data to the statewide cancer registry in such a format, with such data elements, and in accordance with such standards of quality timeliness and completeness, as may be established by the Secretary;

"(v) for the protection of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;

"(vi) for a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research;

"(vii) for the authorization or the conduct, by the statewide cancer registry or other persons and organizations, of studies utilizing statewide cancer registry data,

including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and

“(viii) for protection for individuals complying with the law, including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.

“(d) RELATIONSHIP TO CERTAIN PROGRAMS.—

“(1) IN GENERAL.—This section may not be construed to act as a replacement for or diminishment of the program carried out by the Director of the National Cancer Institute and designated by such Director as the Surveillance, Epidemiology, and End Results Program (SEER).

“(2) SUPPLANTING OF ACTIVITIES.—In areas where both such programs exist, the Secretary shall ensure that SEER support is not supplanted and that any additional activities are consistent with the guidelines provided for in subsection (c)(2) (C) and (D) and are appropriately coordinated with the existing SEER program.

“(3) TRANSFER OF RESPONSIBILITY.—The Secretary may not transfer administration responsibility for such SEER program from such Director.

“(4) COORDINATION.—To encourage the greatest possible efficiency and effectiveness of Federally supported efforts with respect to the activities described in this subsection, the Secretary shall take steps to assure the appropriate coordination of programs supported under this part with existing Federally supported cancer registry programs.

“(e) REQUIREMENT REGARDING CERTAIN STUDY ON BREAST CANCER.—In the case of a grant under subsection (a) to any State specified in section 399K(b), the Secretary may establish such conditions regarding the receipt of the grant as the Secretary determines are necessary to facilitate the collection of data for the study carried out under section 399C.

“SEC. 399I. PLANNING GRANTS REGARDING REGISTRIES.

42 USC 280e-1.

“(a) IN GENERAL.—

“(1) STATES.—The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States for the purpose of developing plans that meet the assurances required by the Secretary under section 399B(c)(2).

“(2) OTHER ENTITIES.—For the purpose described in paragraph (1), the Secretary may make grants to public entities other than States and to nonprofit private entities. Such a grant may be made to an entity only if the State in which the purpose is to be carried out has certified that the State approves the entity as qualified to carry out the purpose.

“(b) APPLICATION.—The Secretary may make a grant under subsection (a) only if an application for the grant is submitted to the Secretary, the application contains the certification required in subsection (a)(2) (if the application is for a grant under such subsec-

tion), and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

42 USC 280e-2.

**"SEC. 399J. TECHNICAL ASSISTANCE IN OPERATIONS OF STATEWIDE CANCER REGISTRIES.**

"The Secretary, acting through the Director of the Centers for Disease Control, may, directly or through grants and contracts, or both, provide technical assistance to the States in the establishment and operation of statewide registries, including assistance in the development of model legislation for statewide cancer registries and assistance in establishing a computerized reporting and data processing system.

42 USC 280e-3.

**"SEC. 399K. STUDY IN CERTAIN STATES TO DETERMINE THE FACTORS CONTRIBUTING TO THE ELEVATED BREAST CANCER MORTALITY RATES.**

"(a) IN GENERAL.—Subject to subsections (c) and (d), the Secretary, acting through the Director of the National Cancer Institute, shall conduct a study for the purpose of determining the factors contributing to the fact that breast cancer mortality rates in the States specified in subsection (b) are elevated compared to rates in other States.

"(b) RELEVANT STATES.—The States referred to in subsection (a) are Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Vermont, and the District of Columbia.

"(c) COOPERATION OF STATE.—The Secretary may conduct the study required in subsection (a) in a State only if the State agrees to cooperate with the Secretary in the conduct of the study, including providing information from any registry operated by the State pursuant to section 399H(a).

"(d) PLANNING, COMMENCEMENT, AND DURATION.—The Secretary shall, during each of the fiscal years 1993 and 1994, develop a plan for conducting the study required in subsection (a). The study shall be initiated by the Secretary not later than fiscal year 1994, and the collection of data under the study may continue through fiscal year 1998.

"(e) REPORT.—Not later than September 30, 1999, the Secretary shall complete the study required in subsection (a) and submit to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Labor and Human Resources of the Senate, a report describing the findings and recommendations made as a result of the study.

42 USC 280e-4.

**"SEC. 399L. AUTHORIZATION OF APPROPRIATIONS.**

"(a) REGISTRIES.—For the purpose of carrying out this part, the Secretary may use \$30,000,000 for each of the fiscal years 1993 through 1997. Out of any amounts used for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 399I, and not more than 10 percent may be expended for assessing the accuracy, completeness and quality of data collected, and not more than 10 percent of which is to be expended under subsection 399J.

“(b) **BREAST CANCER STUDY.**—Of the amounts appropriated for the National Cancer Institute under subpart 1 of part C of title IV for any fiscal year in which the study required in section 399K is being carried out, the Secretary shall expend not less than \$1,000,000 for the study.”.

Approved October 24, 1992.

Authorization extended through 1998.

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**LEGISLATIVE HISTORY—S. 3312:**

**CONGRESSIONAL RECORD, Vol. 138 (1992):**

Oct. 2, considered and passed Senate.

Oct. 5, considered and passed House, amended.

Oct. 7, Senate concurred in House amendment.

Title 42. The Public Health and Welfare  
Chapter 6a. The Public Health Service  
**National Program of Cancer Registries**  
42 U.S.C. § 280e (1998)

§ 280e. National program of cancer registries

(a) In general. The Secretary, acting through the Director of the Centers for Disease Control, [Director of the Centers for Disease Control and Prevention] may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State's cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning--

- (1) demographic information about each case of cancer;
- (2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;
- (3) administrative information, including date of diagnosis and source of information;
- (4) pathological data characterizing the cancer, including the cancer site, stage of disease (pursuant to Staging Guide), incidence, and type of treatment; and
- (5) other elements determined appropriate by the Secretary.

(b) Matching funds.

(1) In general. The Secretary may make a grant under subsection (a) only if the State, or the academic or nonprofit private organization designated by the State to operate the cancer registry of the State, involved agrees, with respect to the costs of the program, to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs or \$ 1 for every \$ 3 of Federal funds provided in the grant.

(2) Determination of amount of non-federal contribution; maintenance of effort.

(A) Non-Federal contributions required in paragraph (1) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

(B) With respect to a State in which the purpose described in subsection (a) is to be carried out, the Secretary, in making a determination of the amount of non-Federal contributions provided under paragraph (1), may include only such contributions as are in excess of the amount of such contributions made by the State toward the collection of data on cancer for the fiscal year preceding the first year for which a grant under subsection (a) is made with respect to the State. The

Secretary may decrease the amount of non-Federal contributions that otherwise would have been required by this subsection in those cases in which the State can demonstrate that decreasing such amount is appropriate because of financial hardship.

(c) Eligibility for grants.

(1) In general. No grant shall be made by the Secretary under subsection (a) unless an application has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such a manner, and be accompanied by such information, as the Secretary may specify. No such application may be approved unless it contains assurances that the applicant will use the funds provided only for the purposes specified in the approved application and in accordance with the requirements of this section, that the application will establish such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement and accounting of Federal funds paid to the applicant under subsection (a) of this section, and that the applicant will comply with the peer review requirements under sections 491 and 492 [42 U.S.C. §§ 289 and 289a].

(2) Assurances. Each applicant, prior to receiving Federal funds under subsection (a), shall provide assurances satisfactory to the Secretary that the applicant will--

(A) provide for the establishment of a registry in accordance with subsection (a);

(B) comply with appropriate standards of completeness, timeliness, and quality of population-based cancer registry data;

(C) provide for the annual publication of reports of cancer data under subsection (a); and

(D) provide for the authorization under State law of the statewide cancer registry, including promulgation of regulations providing--

(i) a means to assure complete reporting of cancer cases (as described in subsection (a)) to the statewide cancer registry by hospitals or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;

(ii) a means to assure the complete reporting of cancer cases (as defined in subsection (a)) to the statewide cancer registry by physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;

(iii) a means for the statewide cancer registry to access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities, individuals, or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of



any identified patient;

(iv) for the reporting of cancer case data to the statewide cancer registry in such a format, with such data elements, and in accordance with such standards of quality timeliness and completeness, as may be established by the Secretary;

(v) for the protection of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;

(vi) for a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research;

(vii) for the authorization or the conduct, by the statewide cancer registry or other persons and organizations, of studies utilizing statewide cancer registry data, including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and

(viii) for protection for individuals complying with the law, including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.

(d) Relationship to certain programs.

(1) In general. This section may not be construed to act as a replacement for or diminishment of the program carried out by the Director of the National Cancer Institute and designated by such Director as the Surveillance, Epidemiology, and End Results Program (SEER).

(2) Supplanting of activities. In areas where both such programs exist, the Secretary shall ensure that SEER support is not supplanted and that any additional activities are consistent with the guidelines provided for in subsection (c)(2) (C) and (D) and are appropriately coordinated with the existing SEER program.

(3) Transfer of responsibility. The Secretary may not transfer administration responsibility for such SEER program from such Director.

(4) Coordination. To encourage the greatest possible efficiency and effectiveness of Federally supported efforts with respect to the activities described in this subsection, the Secretary shall take steps to assure the appropriate coordination of programs supported under this part [42 U.S.C. §§ 280e et seq.] with existing Federally supported cancer registry programs.

(e) Requirement regarding certain study on breast cancer. In the case of a grant under subsection (a) to any State specified in section 399K(b) [42 U.S.C. § 280e-3(b)], the Secretary may establish such conditions regarding the receipt of the grant as the Secretary determines are necessary to facilitate the collection of data for the study carried out under section 399C [probably 42 U.S.C. § 280e-3].

#### § 280e-1. Planning grants regarding registries

(a) In general.

(1) States. The Secretary, acting through the Director of the Centers for Disease Control [Director of the Centers for Disease Control and Prevention], may make grants to States for the purpose of developing plans that meet the assurances required by the Secretary under section 399B(c)(2) [probably 42 U.S.C. § 280e(c)(2)].

(2) Other entities. For the purpose described in paragraph (1), the Secretary may make grants to public entities other than States and to nonprofit private entities. Such a grant may be made to an entity only if the State in which the purpose is to be carried out has certified that the State approves the entity as qualified to carry out the purpose.

(b) Application. The Secretary may make a grant under subsection (a) only if an application for the grant is submitted to the Secretary, the application contains the certification required in subsection (a)(2) (if the application is for a grant under such subsection), and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

#### § 280e-2. Technical assistance in operations of statewide cancer registries

The Secretary, acting through the Director of the Centers for Disease Control [Director of the Centers for Disease Control and Prevention], may, directly or through grants and contracts, or both, provide technical assistance to the States in the establishment and operation of statewide registries, including assistance in the development of model legislation for statewide cancer registries and assistance in establishing a computerized reporting and data processing system.

#### § 280e-3. Study in certain States to determine the factors contributing to the elevated breast cancer mortality rates

(a) In general. Subject to subsections (c) and (d), the Secretary, acting through the Director of the National Cancer Institute, shall conduct a study for the purpose of determining the factors contributing to the fact that breast cancer mortality rates in the States specified in subsection (b) are elevated compared to rates in other States.

(b) Relevant States. The States referred to in subsection (a) are Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Vermont, and the District of Columbia.

(c) Cooperation of State. The Secretary may conduct the study required in subsection (a) in a State only if the State agrees to cooperate with the Secretary in the conduct of the study, including providing information from any registry operated by the State pursuant to section 399H(a) [42 U.S.C. § 280e(a)].

(d) Planning, commencement, and duration. The Secretary shall, during each of the fiscal years 1993 and 1994, develop a plan for conducting the study required in subsection (a). The study shall be initiated by the Secretary not later than fiscal year 1994, and the collection of data under the study may continue through fiscal year 1998.

(e) Report. Not later than September 30, 1999, the Secretary shall complete the study required in subsection (a) and submit to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Labor and Human Resources of the Senate, a report describing the findings and recommendations made as a result of the study.

#### § 280e-4. Authorization of appropriations

(a) Registries. For the purpose of carrying out this part [42 U.S.C. §§ 280e et seq.], there are authorized to be appropriated \$ 30,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 *through 2003*<sup>1</sup>. Of the amounts appropriated under the preceding sentence for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 399I [42 U.S.C. § 280e-1], and not more than 10 percent may be expended for assessing the accuracy, completeness and quality of data collected, and not more than 10 percent of which is to be expended under subsection [section] 399J [42 U.S.C. § 280e-2].

(b) Breast cancer study. Of the amounts appropriated for the National Cancer Institute under subpart 1 of part C of title IV [42 U.S.C. §§ 285a et seq.] for any fiscal year in which the study required in section 399K [42 U.S.C. § 280e-3] is being carried out, the Secretary shall expend not less than \$ 1,000,000 for the study.

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<sup>1</sup>Italicized text shows changes made by the Women's Health Research and Prevention Amendments of 1998, Public Law 105-340, signed October 31, 1998.

## APPENDIX A

### SECTION 1. SHORT TITLE.

This Act may be cited as the 'Benign Brain Tumor Cancer Registries Amendment Act'.

### SEC. 2. NATIONAL PROGRAM OF CANCER REGISTRIES; BENIGN BRAIN-RELATED TUMORS AS ADDITIONAL CATEGORY OF DATA COLLECTED.

(a) IN GENERAL- Section 399B of the Public Health Service Act (42 U.S.C. 280e), as redesignated by section 502(2)(A) of Public Law 106-310 (114 Stat. 1115), is amended in subsection (a)--

(1) by redesignating paragraphs (1) through (5) as subparagraphs (A) through (E), respectively, and indenting appropriately;

(2) by striking '(a) IN GENERAL- The Secretary' and inserting the following:

'(a) IN GENERAL-

'(1) STATEWIDE CANCER REGISTRIES- The Secretary';

(3) in the matter preceding subparagraph (A) (as so redesignated), by striking 'population-based' and all that follows through 'data' and inserting the following: 'population-based, statewide registries to collect, for each condition specified in paragraph (2)(A), data'; and

(4) by adding at the end the following:

'(2) CANCER; BENIGN BRAIN-RELATED TUMORS-

'(A) IN GENERAL- For purposes of paragraph (1), the conditions referred to in this paragraph are the following:

'(i) Each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), including malignant brain-related tumors.

'(ii) Benign brain-related tumors.

'(B) BRAIN-RELATED TUMOR- For purposes of subparagraph (A):

'(i) The term 'brain-related tumor' means a listed primary tumor (whether malignant or benign) occurring in any of the following sites:

'(I) The brain, meninges, spinal cord, cauda equina, a cranial nerve or nerves, or any other part of the central nervous system.

'(II) The pituitary gland, pineal gland, or craniopharyngeal duct.

'(ii) The term 'listed', with respect to a primary tumor, means a primary tumor that is listed in the International Classification of Diseases for Oncology (commonly referred to as the ICD-O).

'(iii) The term 'International Classification of Diseases for Oncology' means a classification system that includes topography (site) information and histology (cell type

information) developed by the World Health Organization, in collaboration with international centers, to promote international comparability in the collection, classification, processing, and presentation of cancer statistics. The ICD-O system is a supplement to the International Statistical Classification of Diseases and Related Health Problems (commonly known as the ICD) and is the standard coding system used by cancer registries worldwide. Such term includes any modification made to such system for purposes of the United States. Such term further includes any published classification system that is internationally recognized as a successor to the classification system referred to in the first sentence of this clause.

**(C) STATEWIDE CANCER REGISTRY-** References in this section to cancer registries shall be considered to be references to registries described in this subsection.'

**(b) APPLICABILITY-** The amendments made by subsection (a) apply to grants under section 399B of the Public Health Service Act for fiscal year 2002 and subsequent fiscal years, except that, in the case of a State that received such a grant for fiscal year 2000, the Secretary of Health and Human Services may delay the applicability of such amendments to the State for not more than 12 months if the Secretary determines that compliance with such amendments requires the enactment of a statute by the State or the issuance of State regulations.

## **Section 2**

# **North Dakota Statewide Cancer Registry General Information**

- 2.0 Mission Statement**
- 2.1 Purpose**
- 2.2 Registry Information**
- 2.3 Contacts**
- 2.4 Compliance**
- 2.5 Reporting Sources**
- 2.6 Advisory Board**

## **2.0** **Mission Statement**

Support cancer control by providing data to target, monitor and evaluate programs promoting prevention, early detection, diagnosis and treatment to reduce the burden of cancer in North Dakota.

## **2.1** **Purpose**

The primary purpose of the North Dakota Statewide Cancer Registry (NDSCR) is to support cancer control by targeting, monitoring and evaluating programs promoting prevention, early detection, diagnosis and treatment of cancer. The NDSCR supports efforts by community hospitals, health systems, and treatment centers with respect to the evaluation of their cancer patient care.

The NDSCR supports state and local health-care agencies and providers by:

- Providing summary statistics on the distribution of cancer cases by type.
- Monitoring cancer incidence and treatment trends throughout the state over time.
- Facilitating rapid reporting of cancer, thereby allowing state or local health officials to assess suspected cancer clusters or suspected cancer hazards in their local communities.
- Providing accurate cancer data for cancer-related reports and research activities.
- Providing data to determine various population cancer patterns.
- Helping to set priorities for allocating health resources.
- Providing cancer data for national cancer incidence databases.

## 2.2 Contacts

### Registry Administration

- Mary Ann Sens, MD PhD, Chair, Department of Pathology, University of North Dakota School of Medicine and Health Sciences
- Yun [Lucy] Zheng, MD CTR, Co-Program Director Main Contact, [yun.zheng@med.und.edu](mailto:yun.zheng@med.und.edu), 701.777-0791
- Xudong Zhou, MD CTR, Co-Program Director [Xudong.zhou@med.und.edu](mailto:Xudong.zhou@med.und.edu), 701.777.2868

### Quality Control

- Xudong Zhou, MD CTR, Co-Program Director [Xudong.zhou@med.und.edu](mailto:Xudong.zhou@med.und.edu), 701.777.2868

### Education Training Coordinator

- Vacant  
701.777.....

### Research Analyst

- Kyle Muus, PhD  
[Kyle.muus@med.und.edu](mailto:Kyle.muus@med.und.edu), 701.293.4193

### Database Administrator/Technology Support\*

- Registry Services International, ND System Administrator, [north.dakota.ccr@gmail.com](mailto:north.dakota.ccr@gmail.com), 581.966.5143

### Administrative

- Vacant  
701.777.....

### Contact Information

North Dakota Statewide Cancer Registry  
Department of Pathology  
School of Medicine and Health Sciences  
University of North Dakota  
501 N Columbia Rd  
Stop 9037  
Grand Forks, N.D. 58203-9037

Telephone: 701.777.0791 or 701.777.2868  
Fax: 701.777.3108

\*The North Dakota Statewide Cancer Registry, University of North Dakota School of Medicine and Health Sciences, Department of Pathology contracts with Registry Services International to maintain the NDSCRs secure web-based cancer reporting system – Registry Plus.



## **2.3 Registry Information**

Cancer registries play an important role in the efforts to reduce the burden of cancer by identifying and quantifying the cancer problem. The North Dakota Statewide Cancer Registry (NDSCR) is a population-based surveillance system located in the University of North Dakota School of Medicine and Health Sciences Department of Pathology which acts as the registry operating bona fide agent for the North Dakota Department of Health. The registry is designed to collect, manage, analyze and disseminate information on the incidence of cancer among North Dakota residents. The NDSCR is the central repository of information and is a valuable and essential tool in the identification of populations at risk for cancer, monitoring of cancer incidence trends and mortality, facilitation of studies related to cancer prevention, evaluation of cancer control initiatives, planning of health-care delivery systems, and development of educational awareness programs.

One goal of the NDSCR is to reduce death and illness due to cancer by providing data about cancer incidence. Population-based cancer registries are essential for evaluating the cancer burden in a specific geographic area.

The NDSCR was established in 1994. The amendment of the Administrative Rules Article 33-06-01-01 in 1996 mandated the reporting of all invasive and in situ carcinomas (ND CC 23-07-01). Data collection on newly diagnosed cases began in 1997. The Administrative Rule amendment requires the reporting of newly diagnosed cancers to the central cancer registry for all medical diagnostic laboratories, physicians and other health-care providers who administer screening, diagnostic or therapeutic services. Also required to report are hospitals and other health-care faculties that provide inpatient and/or outpatient services and mobile units that provide screening, diagnostic or therapeutic services.

All in situ and malignant cancers are reportable. In addition, beginning with cases diagnosed in 2004, all primary intracranial and central nervous system (CNS) tumors are reportable to the NDSCR irrespective of the histological type or behavior. This includes malignant, benign and borderline tumors in meninges (C70.\_); brain (C71.\_); spinal cord, cauda equina, cranial nerves, and other parts of the CNS (C72.\_); pituitary gland, craniopharyngeal duct and pineal gland (C75.1-3).

Basal and squamous cell carcinomas of the skin (C44.\_) are not reportable unless they originate in genital sites – labia, clitoris, vulva, prepuce, penis or scrotum.

Carcinoma in situ of cervix or cervical intraepithelial neoplasia grade III (CIN III) is not reportable following the recommendations of the Commission on Cancer and the North American Association of Central Cancer Registries (NAACCR).

Prostate intraepithelial neoplasia grade III (PIN III) of the prostate is not required. Collection stopped effective with cases diagnosed 1/1/2001.

Incidence statistics are published when 95 percent completeness rate for a specific year is reached.

Mortality data is received through the Division of Vital Records, North Dakota Department of Health.

NDSCR uses the SEER (Surveillance Epidemiology and End Results) average population figures for performing data analysis.

Seventy-five percent of NDSCR's funding is from the U.S. Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR), with the remaining 25 percent shared between the state of North Dakota and in-kind support is received from various central cancer registry supporters.

The NDSCR participates in the NPCR and NAACCR groups. The program standards for NPCR and NAACCR are adhered to for completeness and timeliness of data and registry certification.

The NDSCR, under the Administrative Rule, acts as the custodian of the data. Strict state and federal policies are followed to ensure that the information received is held in confidence and that the privacy of the individual patients, reporting facilities and physicians are protected.

The guidelines and standards for cancer reporting that are contained in this manual have been established by the Centers for Disease Control and Prevention, American College of Surgeons and North American Association of Central Cancer Registries.

## **2.4 Compliance**

All records must be submitted within six months or 180 days following diagnosis. A registry facility 12-month Data Submission Calendar helps the facilities keep in compliance with monthly data reporting. A Monthly Data Tracking form monitors receipt of the facility and out-of state central cancer registry data submissions and the number of records whether newly diagnosed or updated that are included in the data file.

The following submission schedules are designed to ensure continuous data flow to the NDSCR, thereby facilitating timely cancer reporting to the NDSCR.

Registry Hospitals: Registry hospitals must submit monthly data files and completed case abstracts monthly.

*Non-registry Hospitals:* Non-registry hospitals have the opportunity to have their cases abstracted on-site by an NDSCR registrar, or they may mail pertinent sections of the cancer patient's medical records to the NDSCR for case abstracting. Non-registry hospitals participating in the mail-in option are to submit medical record documents quarterly. Non-registry hospitals electing to have on-site case abstracting completed by NDSCR staff will establish a visitation schedule with the NDSCR that is mutually agreeable.

## **2.5 Reporting Sources**

Cancer became a reportable disease in 1996 with the amendment of the North Dakota Administrative Rule Article 33-06-01-01. This amendment requires the reporting of newly diagnosed cancers to the central cancer registry for all health-care facilities that offer inpatient and/or outpatient services and that provide screening, diagnostic or therapeutic services.

The NDSCR expects between 3,200 and 3,500 new incident cases annually. Data is submitted electronically to the NDSCR's secure web-based cancer reporting system (Web Plus, part of CDC's Registry Plus software for central cancer registry's) in the current NAACCR Record Layout version.

The state's six major medical facilities and the Veteran's Administration Medical Hospital have AJCC accredited cancer programs. These registry facilities provide approximately 90 percent to 95 percent of the annual incident cases. These facilities are required to submit monthly data files to the registry's secure web-based cancer reporting system.

Additional reporting sources include all medical diagnostic laboratories, independent physicians, outpatient surgical centers, free-standing radiation centers, clinics and other health-care facilities that provide screening, diagnostic and therapeutic services. Presently, data sharing agreements are in effect with numerous states for exchange of cancer data. Efforts are continually being undertaken to receive data from all states.

In addition to receiving cases from the major medical facilities and non-registry facilities including physician offices, the NDSCR collects pathology report data. The pathology report data is matched against the complete abstract information in the central registry database as a case-finding mechanism. Cases identified through the pathology report data processing procedure are abstracted by the NDSCR staff.

## **2.6 Advisory Board**

The advisory board shall consist of members of the North Dakota Cancer Coalition's Data and Evaluation Committee, University of North Dakota's School of Medicine and Health Sciences, Centers for Rural Health, NDSCR staff and others as deemed necessary.

## **Section 3**

# **Hardware and Software: Registry Operating and Data Management**

- 3.0 Software**
- 3.1 Hardware**
- 3.2 Security**
- 3.3 Ownership**

### **3.0 Software**

The NDSCR uses the Centers for Disease Control and Prevention’s (CDC) Registry Plus software programs. Registry Plus is a suite of publicly available, free-of-charge Windows-based software programs that can be used for collecting and processing cancer registry data. Registry Plus currently includes eight applications (Table 1). These software programs are made available by the CDC to facilitate the implementation of the National Program of Cancer Registries. All of the programs are compliant with national standards and can be used separately or together for both routine and special data collection. In addition, the applications are fully customizable for NDSCR-specific needs.

**Table 1. Registry Plus Suite of Software Programs**

Product	Function and Use
Abstract Plus	<ul style="list-style-type: none"> <li>• Used to abstract and code cancer cases using standard data items and codes</li> <li>• Customized by central registries for distribution to and use by hospitals and other reporting sources to abstract reports of cancer</li> <li>• Also used for special projects and start-up registries</li> </ul>
Web Plus	<ul style="list-style-type: none"> <li>• Used to abstract, code, and collect cancer data securely over the Internet</li> <li>• Customized by central registries for abstracting and reporting of cancer by physician’s offices, low-volume facilities, and for interstate data exchange and follow-back efforts aimed at increased cancer reporting</li> <li>• Supports upload of files of abstracts in NAACCR format; used by hospitals and non-hospital reporting sources for submission of files of cancer reports to central registries</li> <li>• Eliminates need to distribute and maintain software at reporting facilities</li> </ul>
eMaRC Plus	<ul style="list-style-type: none"> <li>• Used currently to view and work with HL7 files and messages</li> <li>• Imports HL7 files manually/directly from PHIN MS queue, and tests messages for existence of required data items</li> <li>• Parses HL7 messages and maps HL7 data elements to NAACCR data elements (also used for abstracting additional information)</li> <li>• Supports mapping of pipe-delimited format described in NAACCR Standards for Cancer Registries, Volume V</li> <li>• Searches cancer terms to mark potential cancer case</li> <li>• Builds a pathology lab database (MS Access, SQL Server, Oracle, or Sybase)</li> </ul>
Data File Mapper Plus	<ul style="list-style-type: none"> <li>• Used to map data elements from any fixed width or delimited file to the NAACCR data elements in a NAACCR formatted file</li> <li>• Will assist registries with: <ul style="list-style-type: none"> <li>- Death clearance linkage efforts</li> <li>- Follow-back file generation for follow-back efforts in Web Plus</li> <li>- Mapping of NBCCEDP data for linkage with cancer registry data</li> <li>- Files received in formats other than NAACCR-formatted files</li> </ul> </li> </ul>
Prep Plus	<ul style="list-style-type: none"> <li>• Used to receive and apply data quality and completeness edits to batches of abstracts</li> <li>• Customized by central registries for processing, reviewing and editing reported abstracts</li> </ul>

Product	Function and Use
CRS Plus (including TLC Plus)*	<ul style="list-style-type: none"> <li>• Used to link and consolidate edited abstracts in the central registry</li> <li>• Creates consolidated patient and tumor tables for the same person and tumor with the best values from multiple sources</li> <li>• Provides for automatic determination of multiple primary tumors and consolidation of data items from multiple case reports into incidence records</li> <li>• Produces extracts for NPCR and NAACCR call-for-data submission</li> <li>• Provides standard management reports</li> </ul>
Link Plus	<ul style="list-style-type: none"> <li>• Uses probabilistic methods to link records</li> <li>• Configured by central registries for: <ul style="list-style-type: none"> <li>- Detecting duplicates within the registry to reduce over-counting of cancers</li> <li>- Linking cancer registry files to external files for follow-back and research purposes</li> </ul> </li> </ul>
Registry Plus Online Help	<ul style="list-style-type: none"> <li>• Used to look-up abstraction and coding information</li> <li>• Contains current versions of all standard abstracting and coding manuals (NAACCR, FORDS, CS, ICD-O-3, SEER &amp; ROADS)</li> <li>• Facilitates abstraction by centralizing information into one easy-to-use resource</li> <li>• Eliminates need to purchase and maintain manuals in hardcopy form</li> </ul>

\*CRS: Central Registry System, TLC: Tumor Linkage and Consolidation

The NPCR Registry Plus suite of applications offers the NDSCR reporting solutions for all levels of data reporting sources. The online abstracting capability of Web Plus is suitable for reporting from physicians' offices and other low-volume reporting sources, while the file upload feature can be used for electronic submission of data from all other reporting sources (often along with the offline abstraction capability of Abstract Plus). Web Plus also supports death certificate and pathology lab follow-back efforts. The file mapping functions of the eMaRC Plus and Data File Mapper Plus Tools can be used to generate follow-back files for loading into Web Plus, as well as to map files received by central registries in formats other than NAACCR-formatted files. Once received, the data may be cleaned and edited with Prep Plus, and then consolidated and maintained using CRS Plus. In addition, Link Plus provides the capability to detect duplicates within a cancer registry or to link files of cancer registry data to external files.

### **Benefits to NDSCR of Using Registry Plus Products**

- All software and user support, including user training, provided free-of-charge by NPCR
- Certified Tumor Registrar (CTR) support also provided free-of-charge by NPCR
- All applications are customizable for state- and project-specific needs
  - Customizable user interfaces
  - Support state-specific data items and edit sets
  - Databases are not proprietary; central registry can develop their own queries and reports

- Central registry System (CRS Plus) provides for automation of central registry patient record linkage and consolidation, as well as for tumor and data item consolidation tasks
  - Potential central registry savings in processing time and cost
- Software updates and enhancements developed with input from users, and upon request
- Monthly Registry Plus Users Group (RPUG) teleconference meeting
  - Used to communicate Registry Plus software updates, discuss development plans with users of the applications, and gather feedback from users
  - Promotes exchange of software issues, successes, and ideas for implementation among users
- Updates to database are timely and user friendly
  - Provided via a secure FTP site
  - IT support for updates provided by NPCR free-of-charge
  - All applications kept up-to-date with national standards and requirements

Using the Centers for Disease Control and Prevention's Registry Plus suite of software programs for collecting and processing cancer registry data allows NDSCR to meet the functional requirements of a central cancer registry as specified in NAACCR Standards for Cancer Registries, (Vol. III) Data Standards for Completeness, Quality, Analysis, Management, Security, and Confidentiality of Data.

The Registry Plus suite handles the various functional requirements specified in NAACCR Standard Volume III, as they pertain to the NDSCR's data collection system. These include:

- Submission of new cancer reports from hospital cancer registries via secure web submission. Hospital registries upload their NAACCR flat-files directly into Web Plus.
- At the discretion of the NDSCR, abstracted and uploaded data are validated by the CDC EDITS Engine running on the web server. Hospital registries can validate their data submission upon file upload to the system. This helps ensure that the quality of data being submitted from the hospital registry meets the state registry's validation requirements.
- Complete death clearance follow-up and follow-back processing.
- Seamless system upgrades to reflect national cancer registry standards.
- Reconciliation of duplicate records through deterministic and probabilistic methods; provision of patient and cancer-report record merging.
- Provision online new cancer report data entry (abstracting). New cancer reports can be entered directly into the registry's database via a web browser and Web Plus program, thus providing the ability for rapid reporting of incidence data from other non- registry facilities (i.e., clinics, labs, physician offices).
- The ability to download records in various file formats, including the

- NAACCR data exchange record layout.
- Tighter integration of EDITS into the single-record-interface (data entry) component.
- Custom query capability via access database query module.

The NDSCR also utilizes existing third-party software. The SEER Prep/Stat programs are used to prepare various epidemiological statistics for the annual report. Microsoft Access and Excel are used for simple statistical analysis. SAS will be used when conducting more sophisticated analysis.

### **Data Edits**

EDITS is a set of CDC-developed software tools that can be used to improve data quality and standardize the way data items are checked for validity.

Data quality edits are written and maintained using the EditWriter software, and are applied to cancer data using GenEDITS Plus. The NDSCR uses standardized data edits developed by the NAACCR EDITS Committee, distributed on the NAACCR website in the form of the NAACCR metafile. These individual data edits are grouped into separate edit sets to differentially edit incoming data in Web Plus and Prep Plus, as well as abstract-level data and consolidated data in the CRS Plus database. Currently, the NDSCR uses comprehensive state-specific edit sets developed by NDSCR Certified Tumor Registrars (CTRs) that include demographic, diagnosis, staging and treatment edits.

The EDITS are supported and maintained by the NDSCR Data Administrator with updates to the EDITS metafile and edit-sets as new versions are released by the NAACCR EDITS Committee.

## **3.1 Hardware**

### **Server Hardware Used:**

- 3 hard drives:
  - Hard Drive: 250GB SATA, HDD RPM: 7200, GB Hard Drive: 250
  - Hard Drive: 250GB SATA, HDD RPM: 7200, GB Hard Drive: 250
  - Hard Drive: 250GB SATA, HDD RPM: 7200, GB Hard Drive: 250
- IP Allocation: 2 IPs, # IPs: 2
- Included Bandwidth: Included Bandwidth, GB Bandwidth: 1000
- License: Windows 2003 (x64) Standard Edition
- Memory: 2GB DDR RAM, GB Memory: 2



- OS: Windows 2003 Standard - 64 bit
- Processor: Single Socket Dual Core AMD Opteron 2214HE, #Cores per Proc: 2, #Processors: 1
- RAID: SATA RAID Controller (RAID 5)
- Whitebox Tower: Whitebox Tower

**Antivirus Protection: The antivirus utilized is Sophos:**

- Provides proactive, sustained protection against viruses, worms, Trojans, spyware, PUAs, malicious behavior and root kits
- Uses Behavioral Genotype Protection to identify programs that will behave maliciously before they execute. Behavioral Genotype Protection identifies malicious code at the gateway or on file servers and deletes it before it ever reaches endpoint computers
- Provides automatic updates with the latest protection. The smallest, most rapidly issued protection is automatically updated as frequently as every 10 minutes, at pre-set times or on demand.
- End-user quarantine manager for deleting or disinfecting infected files
- Developed by Sophos, a world leader of IT security and control that protects over 100 million users in more than 150 countries
- Anti-Virus and Regulatory Compliance:
  - HIPAA requires entities to implement “procedures for guarding against, detecting and reporting malicious software.” The managed Anti-Virus solution implemented by NDSCR meets this important requirement.

**Other server services:**

Monitoring: Daily basic monitoring

User Support: Daily, on call support

Terminal Services: Terminal Services 10 users

WIN2K3 (x64) Standard Required: WIN2K3 (x64) Standard Required

Database Support: MS SQL basic support, Access data base support

The NDSCR uses the Centers for Disease Control and Prevention’s Registry Plus™ suite of programs (described above). These programs work with 32- and 64- bit Microsoft® Windows® operating systems on x86-compatible processors. The minimum hardware requirements are the same as those of the Microsoft Windows operating system. The programs are written in Microsoft Visual Basic, version 6. Many of the programs incorporate Dynamic Link Libraries (DLLs) written in C.

**Hardware Description for CRS Plus**

CRS Plus is a client-server application which has the registry database on a server computer and the client application running on individual workstations.

In order to be fully functional, the registry database must reside on an MS SQL Server.

**Database Server**

The table below lists the minimum specifications for the database server computer which is installed within an existing, larger IT infrastructure with connectivity, security, and operational features established by local policy. The above-described NDSCR server meets these minimum requirements:

<b>System Component</b>	<b>Database Server Computer</b>
RAM	2 GB, more memory will result in better performance
Hard Disk	RAID-5 for data, RAID-1 for log files
Size of data file	$(3 * 7000 * \text{estimated\_number\_of\_cases}) / 1048576$ MB
Size of transaction log file	25% of the data file size
System drive for caching	At least 2GB of free space
CPU	Dual processor with latest processor speed
OS	Windows Sever 2K/2003/2008 (Server 2008 Enterprise will meet the NIST FIPS 140-2 standard)
Database server	SQL 2000/2005/2008

**Client PC**

The table below lists CRS Plus specifications for the Client computer, which are all met by the computers used by NDSCR staff.

<b>System Component</b>	<b>Client Computer</b>
RAM	500 MB or more
Hard Disk	200 MB of free space
OS	Windows 2K/Windows XP/Vista/Windows 7
Applications	MS Access 2000 or above, make sure scripts are permitted to execute

### **Hardware Description for Prep Plus**

Prep Plus is in client-server mode, and has a database to store tracking information. A database server is required to host the tracking database. Note that this database is hosted on the same database server that has the CRS Plus database, as no dedicated server is required.

### **Database Server**

Plus. The database server used for CRS Plus database is also being used for Prep Plus. There are some local temporary databases (MS Access databases) that are located on the shared network drive.

### **Client PC**

The table below lists Prep Plus specifications for the Client computer, which are all met by the computers used by NDSCR staff.

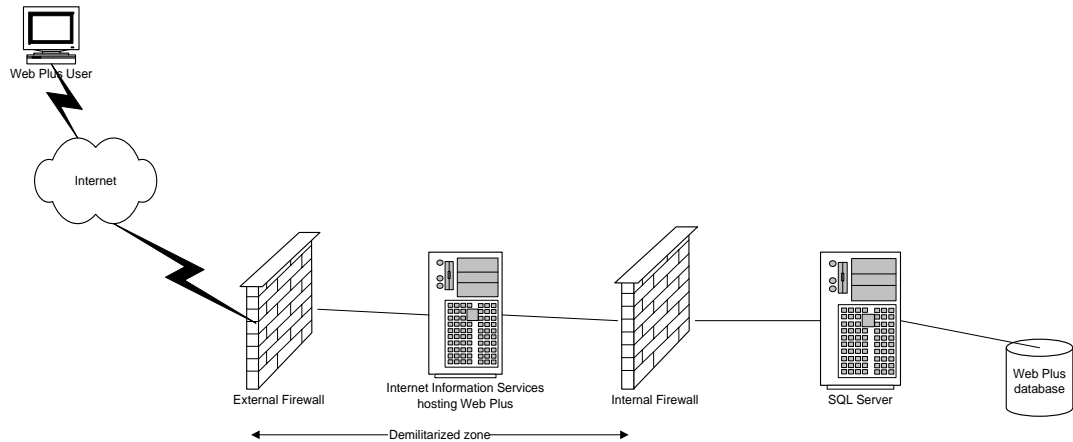
<b>System Component</b>	<b>Client Computer</b>
RAM	500 MB or more
Hard Disk	200 MB of free space
OS	Windows 2K/Windows XP/Vista/Windows 7
Applications	MS Access 2000 or above

## **3.2 Data Security**

### **Web Plus Security Features**

Web Plus has been designed as a highly secure application that can be used to transmit confidential patient data between reporting locations and a central registry safely over the public internet. Security is achieved by a combination of software features and network infrastructure.

Web Plus is a form-authenticated, ASP.NET application that is hosted on Internet Information Services (IIS) running on Windows 2000 or later server operating systems. In the NDSCR system, the web server sits in the demilitarized zone between the external and internal firewalls while SQL Server, where the Web Plus database is stored, resides inside the internal firewall as part of the trusted network.



The security of Web Plus is based on the security of the client computer, the communication channel between the client and the web server, the web server, the base operating system, and the configurations of firewalls on either side of the web server. Use of strong logon passwords for logging in to Web Plus is utilized and the sharing of user accounts by users is prohibited.

### **Security Features of the Web Plus Application**

#### **Form-Based Authentication**

Web Plus uses form-based authentication where users are required to enter their user IDs and passwords to be authenticated by the application.

#### **Role-Based Access**

Web Plus also implements a role-based access where users are granted different levels of access depending on their roles. There are currently five roles defined in Web Plus:

<b>Users</b>	<b>Description</b>
Facility Abstractor	Works in a local facility or doctor's office and handles patients' medical records and paperwork. When a patient is diagnosed with cancer, the facility abstractor reports the case to the state's central cancer registry.
Central Registry Abstractor/Reviewer	Reviews abstracts submitted to the central registry for completeness and accuracy and may abstract additional data items from submitted text; also abstracts new cases.
Central Registry Administrator	Sets up the local facilities with access to the Web Plus software to report their data, manages facility

<b>Users</b>	<b>Description</b>
	accounts and users at both central registry and facilities, configures display types, edit sets and system preferences, manages assignment of abstracts to central registry staff, exports data and views reports.
Local Administrator	Manages local users of a facility
File Uploader	Uploads files of abstracts in the appropriate NAACCR format that were not abstracted using Web Plus, views EDITS error report and cleans, or works with abstractors to clean, errors on rejected files prior to re-uploading.

### **Other Application Security Features**

Other security features of the application include:

- Facilities and offices have access only to those abstracts entered at their facility or office.
- Web Plus keeps an extensive log of user logins, data accesses, and updates for auditing purposes.
- User accounts can be locked out if invalid login attempts exceed a threshold value, configurable by the Central Administrator.
- Current user activities are visible to the Central Administrator through the Current User Activities page.
- Display types and edit set configurations are centrally controlled.
- User passwords are stored in the database using a one-way hash encryption method.
- The Web Plus configuration file can store the connection string to the SQL Server database in encrypted format.

### **Security Features of the Operating Infrastructure**

#### **Security on the Client Computer**

The client computer is protected from any kind of Trojan horse or spyware attacks via UND anti-virus and anti-spyware software, and ensuring that these programs are up-to-date.

#### **Secure Communication Channel and Server Certificate**

Web Plus relies on the existence of a Secure Sockets Layer (SSL) channel between the web server and client browser for the protection of data exchanged over the Internet. In order to set up an SSL channel, the web server has a server certificate installed and the website containing the application and has SSL encryption turned on. The certificate for the server is

purchased from a commonly trusted third party commercial organization called a Certificate Authority (CA). The employed certificate of 128-bit cyber strength is the industry standard for secure communication over the Internet.

### **Secure Connection to the Database**

Windows authentication is used for secure connection to the database, so the user's credentials are not included in the connection string; the connection string is encrypted hiding the database server's IP address, port number, etc.

Windows authentication is the preferred method from security point of view because this mode does not transmit the user's credentials over the network. In order for Windows authentication to work, a mirrored ASPNET process account has been created as a local Windows account with the same name and password on the database server. ASPNET is a least privileged account created at the time of installing .NET Framework on the web server. By default, all ASP.NET applications run under the security context of this account.

The SQL Server listens on a port number different from the default port, 1433. This port is opened in the internal firewall to allow web server to access the database.

### **Firewall Protection**

The NDSCR system utilizes a custom-configured Cisco PIX 501 firewall to provide added security. The PIX 501 delivers enterprise-class security in a reliable, plug-and-play security appliance. Ideal for securing high-speed, broadband environments, the PIX 501 provides robust security capabilities, networking features, and powerful remote management capabilities:

- Stateful inspection security based on state-of-the-art Adaptive Security Algorithm (ASA).
- Supports over 100 predefined applications, services, and protocols for flexible access control.
- Virtual Private Networking (VPN) for secure remote network access using IKE/IPSec standards.
- Intrusion protection from over 55 different network-based attacks
- URL filtering of outbound web traffic via industry-leading, third-party URL filtering products.
- Integrated switch allows multiple users to share a single broadband connection.

A firewall is a mechanism that enforces a boundary between two points on a network, for example a web server and the Internet. The NDSCR uses a custom-configured firewall setup, where one firewall protects the web server and a second, internal firewall resides between the web server and the database server; through this, an encrypted channel is used for database connections. In this way, as described above, the Web server sits between the

external and internal firewalls while the SQL Server, where the Web Plus database is stored, resides inside the internal firewall as part of the trusted network.

### **IP Lock Down and Daily Monitoring**

Access to the NDSCR server is locked down to only the IP addresses of authorized users, preventing professional hacker attacks on the system. Firewall rules are updated on a regular basis to accommodate any changes in IP address of NDSCR staff computers. In addition, the NDSCR Data and System Manager monitors the system daily for any break-in attempts.

## **3.3 Ownership**

The NDSCR leases server hardware from Registry Services International, LLC through a third party server service provider. The NDSCR retains ownership of its data.

## **Section 4**

# **Cancer Data Reporting Guidelines**

- 4.0 Reporting Guidelines**
- 4.1 Reporting Requirements**
- 4.2 Required Cases**
- 4.3 NDSCR Data Set** [NAACCR v12.2]
- 4.4 Reportable ICD-9 Codes**
- 4.5 Multiple Primaries**
- 4.6 Manual Implementation  
Datelines**
- 4.7 Non-registry Hospital  
Reporting**
- 4.8 Multi-facility Reporting**



## **4.0 Reporting Guidelines**

### **Reference Date**

All cases diagnosed on or after January 1, 1997, are reportable to NDSCR.

### **Residence Requirements**

Patient's residency at the time of diagnosis should be recorded as the patient's "usual" census and is as follows:

- Patient's "usual residence" is where the patient lives and sleeps most of the time.
- For military personnel and their families living on a military base, the residency is that of the military base. For personnel living off base, the residency is the address where they live.
- For institutionalized patients, including those who are confined in a nursing, convalescent or rest home, the residency is the address of the institution.
- For college students, residency is the place of the current residence. For boarding school students, a parent's residence is the place of residency.
- For the homeless population with no usual address, code the address as unknown, code the city and the county where the diagnosing hospital is located, and code the state as North Dakota.
- For persons with more than one residence (i.e., snowbirds), residency is the place they designate as their residence at the time of diagnosis if the usual residence cannot be determined.

## **4.1 Reporting Requirements Clarification**

### **a. Text**

Text is a very important section of the abstract. Completion of the text fields is **required** by both the Commission on Cancer and the NDSCR. Documentation in the required text fields includes information used to verify the coding of numerous data items. Documentation **must** include treatment dates, justification of primary site, histology and collaborative staging coding selections.

### **b. Malignant Neoplasms**

An individual is considered to have a malignant neoplasm or tumor when indicated by a recognized medical practitioner. A positive pathology report takes precedence over all other reports or statements. When a pathology report is unavailable, information contained in the record is used to determine if the case is reportable.

c. **Ambiguous Terminology for Reportable ICD-9 / ICD-10 Codes**

**Diagnosis** (from FORDS Revised for 2012)

**-Ambiguous Terms that Constitute a Diagnosis**

Interpret the following terms as a diagnosis of cancer. The database must include patients who have a diagnosis using one or more of these terms:

Apparent(ly)	Presumed
Appears	Probable
Comparable with	Suspect(ed)
Compatible with	Suspicious (for)
Consistent with	Tumor* ( <i>beginning with</i>
Favors	<i>2004 diagnoses and only for</i>
Malignant appearing	<i>C70.0–C72.9, C75.1–75)</i>
Most likely	Typical of
Neoplasm* ( <i>beginning with</i>	
<i>2004 diagnoses and only for</i>	
<i>C70.0–C72.9, C75.1–75.3)</i>	

\* additional terms for nonmalignant primary intracranial and central nervous system tumors only

**EXCEPTION:** If a cytology is identified only with an ambiguous term, do not interpret it as a diagnosis of cancer. Abstract the case only if a positive biopsy or a physician’s clinical impression of cancer supports the cytology findings.

**-Ambiguous Terms That Do Not Constitute a Diagnosis *without additional information***

Cannot be ruled out	Questionable
Equivocal	Rule out
Possible	Suggests
Potentially malignant	Worrisome

**4.2 Required Cases**

**Reportable Patients**

All patients first seen at the reporting facility after January 1, 1997 [NDSCR’s reference date], whether as an inpatient or an outpatient in an ambulatory care setting, who meet one or more of the following criteria must be reported:

- a. All patients with an active, malignant neoplasm, whether being treated or not.
- b. All patients with benign central nervous system neoplasm.
- c. All clinically disease-free (NED) patients who are receiving prophylactic or adjuvant cancer-directed therapy.

- d. All patients diagnosed at autopsy.
- e. All patients with a previous diagnosis of a malignant and/or benign central nervous system neoplasm.
- f. All patients with a non-analytic\* Class of Case 30 and higher.

### **Outpatient Only Cases**

Outpatient-only cases should be reported if there is sufficient documentation in the medical chart (positive pathology report, positive radiology report, physician documentation, etc.) that definitively establishes that the patient has been diagnosed or has active malignancy and/or is currently undergoing therapy for malignancy.

### **Non-Analytic Cases\***

Although the American College of Surgeons/Commission on Cancer does not require accredited facilities to abstract non-analytic cases, NDSCR **does** require the collection and reporting of all cases that meet the NDSCR reporting requirements regardless of class of case. All fields need to be completed with the information available in the record being reviewed. Text is especially helpful in processing non-analytic cases.

The NDSCR is a population-based registry and is responsible for the recording of all cancer cases seen in the state of North Dakota, regardless of the place of diagnosis or class of case.

If a patient is seen at the reporting facility for a medical condition that is not related to active cancer but does have evidence of active cancer at any time during the hospital visit (inpatient or outpatient), the case is reportable to NDSCR.

### **Historical Cases**

Patients diagnosed with any cancer during their lifetime are likely to develop new cancers. It is very important for NDSCR to know the number and types of any and all cancers each patient has during his/her lifetime in order to effectively research and evaluate cancer incidence.

If a patient had a reportable in situ or malignant primary diagnosed prior to NDSCR reference date, the primary sequence number, date of diagnosis and primary site **must be** included in text field and submitted to NDSCR.

### **Reportable Neoplasms**

Determination of whether or not a given primary malignant neoplasm or benign central nervous system (CNS) neoplasm is reportable is made by reference to the morphology and behavior codes of the *International Classification of Disease for Oncology*, Third Edition, 2000, (ICD-O-3).

- **In-situ and Malignant Cancers** – NDSCR collects primary malignancies that are either in-situ or malignant. Therefore, any cancer with an ICD-O-3 behavior code of /2 (in-situ) or /3 (malignant) is reportable to NDSCR.

**Exceptions** – Carcinoma in-situ of the cervix (CIS) and intraepithelial neoplasia grade III of the cervix (CIN III) are not reportable. Intraepithelial neoplasia of the prostate (PIN III) is not reportable.

- **Benign and Borderline Cancers** – Pilocytic/Juvenile/Piloid Astrocytoma (ICD-O-3 morphology code M-9421) is a borderline cancer according to the ICD-O-3 behavior code /1. This tumor is still considered malignant by the American College of Surgeons, the U.S. Centers for Disease Control and Prevention and the National Cancer Institute SEER program. Therefore, these tumors are required to be reported to NDSCR. These tumors are reported using a malignant behavior code (/3). Cases should be submitted with the histology code 9421/3.
- **Skin Cancers** – Basal cell carcinoma and squamous cell carcinoma of non-genital skin sites are common malignancies and do not need reporting.

Note: Only the following malignant neoplasms of the skin (C44.0-C44.9) are not reportable.

M 8000 – M 8004	Neoplasms, NOS of the skin
M 8010 – M 8043	Epithelial neoplasms, NOS of the skin
M 8050 – M 8082	Papillary and squamous cell neoplasms of the skin
M 8090 – M 8110	Basal cell neoplasms of the skin

**All other malignant neoplasms of the skin must be reported.**

Note: Reportable basal and squamous cancers include the following sites:

C51.0 – C51.1	Labia	C51.2	Clitoris
C51.8 – C51.9	Vulva	C60.0	Prepuce
C60.9	Penis	C63.2	Scrotum

### **4.3 NDSCR Data Set**

The NDSCR collects clinical and demographic data on the state’s residents diagnosed with cancer. To ensure that data items and their corresponding codes and definitions are consistent across statewide cancer registries and national databases, the NDSCR recognizes the importance of the national standard and adopts the current NAACCR data record layout for use. See the following pages for current required data elements.

**NAACCR RECORD LAYOUT VERSION 12.2**

	Item Name Collect	NPCR	NDSCR	CoC		Item # Collect	Source of Standard	Note
		Transmit	Collect	Collect	Transmit			
<b>Record ID</b>	Record Type	R	R	.	R	10	NAACCR	
	Patient ID Number	R	R	.	.	20	Rpting Registry	
	Registry ID	R	R	.	.	40	NAACCR	
	NAACCR Record Version	R	R	.	R	50	NAACCR	
<b>Patient Confidential</b>	Name--Last	R	R	R	.	2230	CoC	
	Name--First	R	R	R	.	2240	CoC	
	Name--Middle	R	R	R	.	2250	CoC	
	Name--Alias	R	R	.	.	2280	CoC	
	Name--Maiden	R	R*	.	.	2390	CoC	
	Name--Spouse/Parent	.	R	.	.	2290	NAACCR	
	Medical Record Number	R	R	R	.	2300	CoC	
	Social Security Number	R	R	R	.	2320	CoC	
	Addr at DX--No & Street	R	R	R	.	2330	CoC	
	Addr at DX--Supplemental	R	R	R*	.	2335	CoC	
	Addr Current--No & Street	.	R	R	.	2350	CoC	
	Latitude	R*	R*	.	.	2352	NAACCR	
	Longitude	R*	R*	.	.	2354	NAACCR	
	Addr Current--Supplemental	.	R*	R*	.	2355	CoC	
	Telephone	.	R	R	.	2360	CoC	
	DC State File Number	R	▲	.	.	2380	State	
DC State		▲	.	.	2370			
<b>Demographic</b>	Addr at DX--City	R	R	R	R	70	CoC	
	Addr at DX--State	R	R	R	R	80	CoC	
	County at DX	R	R	R	R	90	FIPS/SEER	
	Addr at DX--Postal Code	R	R	R	R	100	CoC	
	Census Tract 1970/80/90	RH*	RH*	.	.	110	SEER	
	Census Cod Sys 1970/80/90	RH*	RH*	.	.	120	SEER	
	Census Tract 2000	R	R	.	.	130	NAACCR	
	Census Tract 2010	R*	R*	.	.	135	NAACCR	
	Marital Status at DX	.	.	.	.	150	SEER	
	Race 1	R	R	R	R	160	SEER/CoC	
	Race 2	R	R	R	R	161	SEER/CoC	
	Race 3	R	R	R	R	162	SEER/CoC	
	Race 4	R	R	R	R	163	SEER/CoC	
	Race 5	R	R	R	R	164	SEER/CoC	
	Race Coding Sys--Current	.	R	R	R	170	NAACCR	
	Race Coding Sys--Original	.	R	R	R	180	NAACCR	
	Spanish/Hispanic Origin	R	R	R	R	190	SEER/CoC	
	NHIA Derived Hisp Origin	D	▲	.	.	191	NAACCR	
	IHS Link	R*	▲	.	.	192	NPCR	
	Race--NAPIIA(derived API)	R	▲	.	.	193	NAACCR	
	Computed Ethnicity	R	▲	.	.	200	SEER	
	Computed Ethnicity Source	R	▲	.	.	210	SEER	
	Sex	R	R	R	R	220	SEER/CoC	
	Age at Diagnosis	R	R	R	R	230	SEER/CoC	
	Date of Birth	R	R	R	R	240	SEER/CoC	
	Date of Birth Flag	R	R	R	R	241	NAACCR	
Birthplace	R*	R	R	R	250	SEER/CoC		
Occupation Code--Census	R*	R	.	.	270	Census/NPCR		

	Item Name	NPCR	NDSCR	CoC		Item #	Source of	Note
				Collect	Transmit			
Demographic Continued	Industry Code--Census	R*	R	.	.	280	Census/NPCR	
	Occupation Source	R*	R	.	.	290	NPCR	
	Industry Source	R*	R	.	.	300	NPCR	
	Text--Usual Occupation	R*	R	.	.	310	NPCR	
	Text--Usual Industry	R*	R	.	.	320	NPCR	
	Occup/Ind Coding System	R*	▲	.	.	330	NPCR	
	GIS Coordinate Quality	R*	▲	.	.	366	NAACCR	
	Census Tr Cert 1970/80/90	RH*	▲	.	.	364	SEER	
	Census Tr Certainty 2000	R	▲	.	.	365	NAACCR	
	Census Tr Certainty 2010	R*	▲	.	.	367	NAACCR	
	CensusBlockGroup 70/80/90	.	▲	.	.	368	Census	
	RuralUrban Continuum 1993	D	▲	.	.	3300	NAACCR	
	RuralUrban Continuum 2003	D	▲	.	.	3310	NAACCR	
Cancer Identification	Sequence Number--Central	R	R	.	.	380	SEER	
	Date of Diagnosis	R	R	R	R	390	SEER/CoC	
	Date of Diagnosis Flag	R	R	.	.	391	NAACCR	
	Primary Site	R	R	R	R	400	SEER/CoC	
	Laterality	R	R	R	R	410	SEER/CoC	
	Histology (92-00) ICD-O-2	RH	R	RH	RH	420	SEER/CoC	
	Behavior (92-00) ICD-O-2	RH	R	RH	RH	430	SEER/CoC	
	Date of Mult Tumors Flag	.	R	R	R	439	NAACCR	
	Histologic Type ICD-O-3	R	R	R	R	522	SEER/CoC	
	Behavior Code ICD-O-3	R	R	R	R	523	SEER/CoC	
	Grade	R	R	R	R	440	SEER/CoC	
	Grade Path Value	R*	R	R	R	441	AJCC	
	Ambiguous Terminology DX	.	R	R	R	442	SEER	
	Date of Conclusive DX	.	R	R	R	443	SEER	
	Mult Tum Rpt as One Prim	.	R	R	R	444	SEER	
	Date of Multiple Tumors	.	R	R	R	445	SEER	
	Multiplicity Counter	.	R	R	R	446	SEER	
	Date Conclusive DX Flag	.	R	R	R	448	NAACCR	
	Grade Path System	R*	R	R	R	449	AJCC	
	Site Coding Sys--Current	R	R	R	R	450	NAACCR	
Site Coding Sys--Original	.	R	R	R	460	NAACCR		
Morph Coding Sys--Current	R	R	R	R	470	NAACCR		
Morph Coding Sys--Original	.	R	R	R	480	NAACCR		
Diagnostic Confirmation	R	R	R	R	490	SEER/CoC		
Type of Reporting Source	R	R	.	.	500	SEER		
Casefinding Source	R*	R	.	.	501	NAACCR		
Hospital Specific	Reporting Facility	R	R	R	R	540	CoC	
	NPI--Reporting Facility	R*	R	R	R	545	CMS	
	Accession Number--Hosp	.	R	R	R	550	CoC	
	Sequence Number--Hospital	.	R	R	R	560	CoC	
	Abstracted By	.	R	R	R	570	CoC	
	Date of 1st Contact	R	R	R	R	580	CoC	
	Date of 1st Contact Flag	R	R	R	R	581	NAACCR	
	Class of Case	R	R	R	R	610	CoC	
	Primary Payer at DX	R*	R	R	R	630	CoC	
	RX Hosp--Surg App 2010	.	R	R	R	668	CoC	
	RX Hosp--Surg Prim Site	.	R	R	R	670	CoC	
	RX Hosp--Scope Reg LN Sur	.	R	R	R	672	CoC	
	RX Hosp--Surg Oth Reg/Dis	.	R	R	R	674	CoC	
	RX Hosp--Reg LN Removed	.	RH	RH	RH	676	CoC	

	Item Name	NPCR	NDSCR	CoC		Item #	Source of	Note
				Collect	Transmit			
<b>Hospital Specific Continued</b>	RX Hosp--Radiation	.	.	.	.	690	SEER	
	RX Hosp--Chemo	.	R	R	R	700	CoC	
	RX Hosp--Hormone	.	R	R	R	710	CoC	
	RX Hosp--BRM	.	R	R	R	720	CoC	
	RX Hosp--Other	.	R	R	R	730	CoC	
	RX Hosp--DX/Stg Proc	.	R	R	R	740	CoC	
	RX Hosp--Surg Site 98-02	.	RH	RH	RH	746	CoC	
	RX Hosp--Scope Reg 98-02	.	RH	RH	RH	747	CoC	
	RX Hosp--Surg Oth 98-02	.	RH	RH	RH	748	CoC	
	RX Hosp--Palliative Proc	.	R	R	R	3280	CoC	
<b>Stage and Prognostic Factors</b>	SEER Summary Stage 2000	R+	RH	RH	RH	759	SEER	
	SEER Summary Stage 1977	RH	RH	RH	RH	760	SEER	
	EOD--Tumor Size	.	RH	RH	RH	780	SEER/CoC	
	Regional Nodes Positive	R	R	R	R	820	SEER/CoC	
	Regional Nodes Examined	R	R	R	R	830	SEER/CoC	
	TNM Path T	.	R*	R*	R*	880	AJCC	
	TNM Path N	.	R*	R*	R*	890	AJCC	
	TNM Path M	.	R*	R*	R*	900	AJCC	
	TNM Path Stage Group	.	R*	R*	R*	910	AJCC	
	TNM Path Descriptor	.	R*	R*	R*	920	CoC	
	TNM Path Staged By	.	R*	R*	R*	930	CoC	
	TNM Clin T	.	R	R	R	940	AJCC	
	TNM Clin N	.	R	R	R	950	AJCC	
	TNM Clin M	.	R	R	R	960	AJCC	
	TNM Clin Stage Group	.	R	R	R	970	AJCC	
	TNM Clin Descriptor	.	R	R	R	980	CoC	
	TNM Clin Staged By	.	R	R	R	990	CoC	
	TNM Edition Number	.	R	R	R	1060	CoC	
	Lymph-vascular Invasion	RS*	R	R	R	1182	AJCC	
	CS Tumor Size	R	R	R	R	2800	AJCC	
	CS Extension	R+	R	R	R	2810	AJCC	
	CS Tumor Size/Ext Eval	R+	R	R	R	2820	AJCC	
	CS Lymph Nodes	R+	R	R	R	2830	AJCC	
	CS Lymph Nodes Eval	R*	R	R	R	2840	AJCC	
	CS Mets at DX	R+	R	R	R	2850	AJCC	
	CS Mets at Dx-Bone	.	R	R	R	2851	AJCC	
	CS Mets at Dx-Brain	.	R	R	R	2852	AJCC	
	CS Mets at Dx-Liver	.	R	R	R	2853	AJCC	
	CS Mets at Dx-Lung	.	R	R	R	2854	AJCC	
	CS Mets Eval	R*	R	R	R	2860	AJCC	
	CS Site-Specific Factor 1	RS	RS	RS	RS	2880	AJCC	
	CS Site-Specific Factor 2	RS	RS	RS	RS	2890	AJCC	
	CS Site-Specific Factor 3	RS	RS	RS	RS	2900	AJCC	
CS Site-Specific Factor 4	RS*	RS	RS	RS	2910	AJCC		
CS Site-Specific Factor 5	RS*	RS	RS	RS	2920	AJCC		
CS Site-Specific Factor 6	RS*	RS	RS	RS	2930	AJCC		
CS Site-Specific Factor 7	RS*	RS	RS	RS	2861	AJCC		
CS Site-Specific Factor 8	RS	RS	RS	RS	2862	AJCC		
CS Site-Specific Factor 9	RS	RS	RS	RS	2863	AJCC		
CS Site-Specific Factor10	RS	RS	RS	RS	2864	AJCC		
CS Site-Specific Factor11	RS	RS	RS	RS	2865	AJCC		
CS Site-Specific Factor12	RS	RS	RS	RS	2866	AJCC		
CS Site-Specific Factor13	RS	RS	RS	RS	2867	AJCC		

	Item Name	NPCR	NDSCR	CoC		Item #	Source of	Note
				Collect	Transmit			
<b>Stage and Prognostic Factors Continued</b>	CS Site-Specific Factor14	RS	RS	RS	RS	2868	AJCC	
	CS Site-Specific Factor15	RS	RS	RS	RS	2869	AJCC	
	CS Site-Specific Factor16	RS	RS	RS	RS	2870	AJCC	
	CS Site-Specific Factor17	RS*	RS	RS	RS	2871	AJCC	
	CS Site-Specific Factor18	RS*	RS	RS	RS	2872	AJCC	
	CS Site-Specific Factor19	RS*	RS	RS	RS	2873	AJCC	
	CS Site-Specific Factor20	RS*	RS	RS	RS	2874	AJCC	
	CS Site-Specific Factor21	RS*	RS	RS	RS	2875	AJCC	
	CS Site-Specific Factor22	RS*	RS	RS	RS	2876	AJCC	
	CS Site-Specific Factor23	RS*	RS	RS	RS	2877	AJCC	
	CS Site-Specific Factor24	RS*	RS	RS	RS	2878	AJCC	
	CS Site-Specific Factor25	RS	RS	RS	RS	2879	AJCC	
	Derived AJCC-6 T	.	R	D	R	2940	AJCC	
	Derived AJCC-6 T Descript	.	R	D	R	2950	AJCC	
	Derived AJCC-6 N	.	R	D	R	2960	AJCC	
	Derived AJCC-6 N Descript	.	R	D	R	2970	AJCC	
	Derived AJCC-6 M	.	R	D	R	2980	AJCC	
	Derived AJCC-6 M Descript	.	R	D	R	2990	AJCC	
	Derived AJCC-6 Stage Grp	.	R	D	R	3000	AJCC	
	Derived AJCC-7 T	D*	R	D	R	3400	AJCC	
	Derived AJCC-7 T Descript	D*	R	D	R	3402	AJCC	
	Derived AJCC-7 N	D*	R	D	R	3410	AJCC	
	Derived AJCC-7 N Descript	D*	R	D	R	3412	AJCC	
	Derived AJCC-7 M	D*	R	D	R	3420	AJCC	
	Derived AJCC-7 M Descript	D*	R	D	R	3422	AJCC	
	Derived AJCC-7 Stage Grp	D*	R	D	R	3430	AJCC	
	Derived SS1977	.	R	D	R	3010	AJCC	
	Derived SS2000	D+	R	D	R	3020	AJCC	
	Derived AJCC--Flag	.	R	D	R	3030	AJCC	
	Derived SS1977--Flag	.	R	D	R	3040	AJCC	
	Derived SS2000--Flag	D+	R	D	R	3050	AJCC	
	CS Version Input Original	R	R	R	R	2935	AJCC	
	CS Version Derived	R+	R	R	R	2936	AJCC	
	CS Version Input Current	R	R	R	R	2937	AJCC	
	ICD Revision Comorbid	.	R	R	R	3165	CoC	
	Comorbid/Complication 1	.	R	R	R	3110	CoC	
	Comorbid/Complication 2	.	R	R	R	3120	CoC	
	Comorbid/Complication 3	.	R	R	R	3130	CoC	
	Comorbid/Complication 4	.	R	R	R	3140	CoC	
	Comorbid/Complication 5	.	R	R	R	3150	CoC	
Comorbid/Complication 6	.	R	R	R	3160	CoC		
Comorbid/Complication 7	.	R	R	R	3161	CoC		
Comorbid/Complication 8	.	R	R	R	3162	CoC		
Comorbid/Complication 9	.	R	R	R	3163	CoC		
Comorbid/Complication 10	.	R	R	R	3164	CoC		
<b>Treatment -- 1st Course</b>	RX Date--Surgery	R	R	R	R	1200	CoC	
	RX Date--Surgery Flag	R	R	R	R	1201	NAACCR	
	RX Date--Most Defn Surg	.	R	R	R	3170	CoC	
	RX Date Most Defn Srg Flag	.	R	R	R	3171	NAACCR	
	RX Date--Surgical Disch	.	R	R	R	3180	CoC	
	RX Date Surg Disch Flag	.	R	R	R	3181	NAACCR	
	Readm Same Hosp 30 Days	.	R	R	R	3190	CoC	



	Item Name	NPCR	NDSCR	CoC		Item #	Source of	Note
				Collect	Transmit			
<b>Treatment -- 1st Course Continued</b>	RX Date--Radiation	RS	R	R	R	1210	CoC	
	RX Date--Radiation Flag	RS	R	R	R	1211	NAACCR	
	Rad--Boost RX Modality	.	R	R	R	3200	CoC	
	Rad--Boost Dose cGy	.	R	R	R	3210	CoC	
	RX Date--Radiation Ended	.	R	R	R	3220	CoC	
	RX Date Rad Ended Flag	.	R	R	R	3221	NAACCR	
	RX Date--Chemo	RS	R	R	R	1220	CoC	
	RX Date--Chemo Flag	RS	R	R	R	1221	NAACCR	
	RX Date--Hormone	RS	R	R	R	1230	CoC	
	RX Date--Hormone Flag	RS	R	R	R	1231	NAACCR	
	RX Date--BRM	RS	R	R	R	1240	CoC	
	RX Date--BRM Flag	RS	R	R	R	1241	NAACCR	
	RX Date--Other	RS	R	R	R	1250	CoC	
	RX Date--Other Flag	RS	R	R	R	1251	NAACCR	
	RX Date--Systemic	.	R	R	R	3230	CoC	
	RX Date Systemic Flag	.	R	R	R	3231	NAACCR	
	RX Summ--Transplant/Endocr	R	R	R	R	3250	CoC	
	RX Summ--Palliative Proc	.	R	R	R	3270	CoC	
	Date of Initial RX--SEER	R#	.	.	.	1260	SEER	
	Date of Initial RX Flag	R#	.	.	.	1261	NAACCR	
	Date of 1st Crs RX--CoC	R#	R	R	R	1270	CoC	
	Date of 1st Crs Rx Flag	R#	R	R	R	1271	NAACCR	
	RX Date--DX/Stg Proc	.	R	R	R	1280	CoC	
	RX Date--Dx/Stg Proc Flag	.	R	R	R	1281	NAACCR	
	RX Summ--Treatment Status	RS#	R	R	R	1285	SEER/CoC	
	RX Summ--Surg Prim Site	R	R	R	R	1290	SEER/CoC	
	RX Summ--Scope Reg LN							
	Sur	R	R	R	R	1292	SEER/CoC	
	RX Summ--Surg Oth Reg/Dis	R	R	R	R	1294	SEER/CoC	
	RX Summ--Reg LN Examined	.		RH	RH	1296	SEER/CoC	
	RX Summ--Surgical Approach	.	.	RH	RH	1310	CoC	
	RX Summ--Surgical Margins	.	R	R	R	1320	CoC	
	RX Summ--Reconstruct 1st	.	RH	RH	RH	1330	SEER	
	Reason for No Surgery	R	R	R	R	1340	SEER/CoC	
	RX Summ--DX/Stg Proc	.	R	R	R	1350	CoC	
	RX Summ--Radiation	RH	▲	.	.	1360	SEER	
	RX Summ--Surg/Rad Seq	RS	R	R	R	1380	SEER/CoC	
	RX Summ--Chemo	RS	R	R	R	1390	SEER/CoC	
	RX Summ--Hormone	RS	R	R	R	1400	SEER/CoC	
	RX Summ--BRM	RS	R	R	R	1410	SEER/CoC	
	RX Summ--Other	RS	R	R	R	1420	SEER/CoC	
	RX Summ--Transplnt/Endocr	RS	R	R	R	3250	SEER/CoC	
	Reason for No Radiation	RS	R	R	R	1430	CoC	
	RX Coding System--Current	R	R	R	R	1460	NAACCR	
	First Course Calc Method	R	R	.	.	1500	NAACCR	
	Rad--Regional Dose: CGY	.	R	R	R	1510	CoC	
	Rad--No of Treatment Vol	.	R	R	R	1520	CoC	
	Rad--Treatment Volume	.	R	R	R	1540	CoC	
	Rad--Location of RX	.	R	R	R	1550	CoC	
	Rad--Regional RX Modality	RS	R	R	R	1570	CoC	
	RX Summ--Systemic/Sur Seq	R	R	R	R	1639	CoC	
	RX Summ--Surg Site 98-02	.	RH	RH	RH	1646	SEER/CoC	
RX Summ--Scope Reg 98-02	.	RH	RH	RH	1647	SEER/CoC		
RX Summ--Surg Oth 98-02	.	RH	RH	RH	1648	SEER/CoC		

	Item Name	NPCR	NDSCR	CoC		Item #	Source of	Note
				Collect	Transmit			
<b>Edit Overrides / Conversion History / System Administration</b>	Over-ride Acsn/Class/Seq	.	R	R	R	1985	CoC	
	Over-ride HospSeq/DxConf	.	R	R	R	1986	CoC	
	Over-ride CoC-Site/Type	.	R	R	R	1987	CoC	
	Over-ride HospSeq/Site	.	R	R	R	1988	CoC	
	Over-ride Site/TNM-StgGrp	.	R	R	R	1989	CoC	
	Over-ride Age/Site/Morph	R	R	R	R	1990	SEER	
	Over-ride SeqNo/DxConf	R	R	.	.	2000	SEER	
	Over-ride Site/Lat/SeqNo	R	R	.	.	2010	SEER	
	Over-ride Surg/DxConf	R	R	R	R	2020	SEER	
	Over-ride Site/Type	R	R	R	R	2030	SEER	
	Over-ride Histology	R	R	R	R	2040	SEER	
	Over-ride Report Source	R	R	.	.	2050	SEER	
	Over-ride Ill-define Site	R	R	.	.	2060	SEER	
	Over-ride Leuk, Lymphoma	R	R	R	R	2070	SEER	
	Over-ride Site/Behavior	R	R	R	R	2071	SEER	
	Over-ride Site/Lat/Morph	R	R	R	R	2074	SEER	
	ICD-O-2 Conversion Flag	.	RH	RH	RH	1980	SEER	
	Date Case Completed--CoC	.	.	R	R	2092	CoC	
	Date Case Last Changed	.	.	D	R	2100	NAACCR	
	Date Case Report Exported	R	▲	.	.	2110	NPCR	
	Date Case Report Received	R	▲	.	.	2111	NPCR	
	Date Case Report Loaded	R	▲	.	.	2112	NPCR	
	Date Tumor Record Availbl	R	▲	.	.	2113	NPCR	
	ICD-O-3 Conversion Flag	R	▲	.	.	2116	SEER/CoC	
	CoC Coding Sys--Current	.	R	R	R	2140	CoC	
	CoC Coding Sys--Original	.	R	R	R	2150	CoC	
	Vendor Name	.	R	R	R	2170	NAACCR	
	State/Requestor Items	.	.	.	.	2220	Varies	
	Over-ride CS 1	R	R	.	.	3750	AJCC	
	Over-ride CS 2	R	R	.	.	3751	AJCC	
	Over-ride CS 3	R	R	.	.	3752	AJCC	
	Over-ride CS 4	R	R	.	.	3753	AJCC	
	Over-ride CS 5	R	R	.	.	3754	AJCC	
	Over-ride CS 6	R	R	.	.	3755	AJCC	
	Over-ride CS 7	R	R	.	.	3756	AJCC	
	Over-ride CS 8	R	R	.	.	3757	AJCC	
	Over-ride CS 9	R	R	.	.	3758	AJCC	
	Over-ride CS 10	R	R	.	.	3759	AJCC	
	Over-ride CS 11	R	R	.	.	3760	AJCC	
	Over-ride CS 12	R	R	.	.	3761	AJCC	
Over-ride CS 13	R	R	.	.	3762	AJCC		
Over-ride CS 14	R	R	.	.	3763	AJCC		
Over-ride CS 15	R	R	.	.	3764	AJCC		
Over-ride CS 16	R	R	.	.	3765	AJCC		
Over-ride CS 17	R	R	.	.	3766	AJCC		
Over-ride CS 18	R	R	.	.	3767	AJCC		
Over-ride CS 19	R	R	.	.	3768	AJCC		
Over-ride CS 20	R	R	.	.	3769	AJCC		
<b>Follow-up/Recurrence/Death</b>	Date of Last Contact	R	R	R	R	1750	SEER/CoC	
	Date of Last Contact Flag	R	R	R	R	1751	NAACCR	
	Vital Status	R	R	R	R	1760	SEER/CoC	
	Cancer Status	.	R	R	R	1770	CoC	

	Item Name	NPCR	NDSCR	CoC		Item #	Source of	Note
				Collect	Transmit			
<b>Follow-up / Recurrence / Death Continued</b>	Follow-Up Source	R*	R	R	.	1790	CoC	
	Place of Death	R	▲	.	.	1940	NPCR	
	Cause of Death	R	▲	.	.	1910	SEER	
	Follow-up Source Central	R	▲	.	.	1791	NAACCR	
	Next Follow-Up Source	.	R	R	.	1800	CoC	
	Addr Current--City	.	R	R	.	1810	CoC	
	Addr Current--State	.	R	R	.	1820	CoC	
	Addr Current--Postal Code	.	R	R	.	1830	CoC	
	County--Current	.	R	.	.	1840	NAACCR	
	Unusual Follow-Up Method	.	▲	.	.	1850	CoC	
	Recurrence Date--1st	.	R	R	R	1860	CoC	
	Recurrence Date--1st Flag	.	R	R	R	1861	NAACCR	
	Recurrence Type--1st	.	R	R	R	1880	CoC	
	ICD Revision Number	R	▲	.	.	1920	SEER	
<b>Hospital and Other Confidential</b>	Archive FIN	.	R	R	R	3100	CoC	
	NPI--Archive FIN	.	R	R	R	3105	CMS	
	NPI--Inst Referred From	.	R	R	.	2415	CMS	
	NPI--Inst Referred To	.	R	R	.	2425	CMS	
	NPI--Physician--Managing	.	R	R	.	2465	CMS	
	NPI--Physician--Follow-Up	.	R	R	.	2475	CMS	
	NPI--Physician--Primary Surg	.	R	R	R	2485	CMS	
	NPI--Physician 3	.	R	R	R	2495	CMS	
	NPI--Physician 4	.	R	R	R	2505	CMS	
<b>Text - Diagnosis / Treatment / Miscellaneous</b>	Text--DX Proc--PE	R^	R^	.	.	2520	NPCR	
	Text--DX Proc--X-ray/Scan	R^	R^	.	.	2530	NPCR	
	Text--DX Proc--Scopes	R^	R^	.	.	2540	NPCR	
	Text--DX Proc--Lab Tests	R^	R^	.	.	2550	NPCR	
	Text--DX Proc--Op	R^	R^	.	.	2560	NPCR	
	Text--DX Proc--Path	R^	R^	.	.	2570	NPCR	
	Text--Primary Site Title	R^	R^	.	.	2580	NPCR	
	Text--Histology Title	R^	R^	.	.	2590	NPCR	
	Text--Staging	R^	R^	.	.	2600	NPCR	
	RX Text--Surgery	R^	R^	.	.	2610	NPCR	
	RX Text--Radiation (Beam)	R^	R^	.	.	2620	NPCR	
	RX Text--Radiation Other	R^	R^	.	.	2630	NPCR	
	RX Text--Chemo	R^	R^	.	.	2640	NPCR	
	RX Text--Hormone	R^	R^	.	.	2650	NPCR	
	RX Text--BRM	R^	R^	.	.	2660	NPCR	
	RX Text--Other	R^	R^	.	.	2670	NPCR	
	Text--Remarks	.	R^	.	.	2680	NPCR	
Text--Place of Diagnosis	.	R	.	.	2690	NPCR		

Codes for Recommendations:

- R = Required
- RH = Historically collected and currently transmitted.
- RS = Required, site specific.
- D = Derived
- .
- . = No recommendations.
- \* = When Available
- # = Central registries may code available data using either the SEER or CoC data item and associated rules.
- ^ = These text requirements may be met with one or several text blocks.
- ▲ = NDSCR data field only

#### 4.4 Reportable ICD-9 –ICD-10 Codes [2013 NDSCR Case-Finding List]

2013 ICD-9-CM Casefinding List		Abbreviated listing from SEER website
2012 Comprehensive ICD-9-CM Casefinding Code List for Reportable Tumors (with equivalent ICD-10-CM codes)		
ICD-9-CM Code*	ICD-10-CM Code**	Explanation of ICD-9-CM Code
140._ – 172._, 174._ – 209.36, 209.7_	C00._ – C96._	Malignant neoplasms stated or presumed to be primary (of specified sites), and certain specified histologies
173.00, 173.09	C44.00, C44.09	Unspecified and other specified malignant neoplasm of skin of lip
173.10, 173.19	C44.101, C44.191	Unspecified and other specified malignant neoplasm of eyelid, including canthus
173.20, 173.29	C44.201, C44.291	Unspecified and other specified malignant neoplasm of ear and external auricular canal
173.30, 173.39	C44.30, C44.39	Unspecified and other specified malignant neoplasm of skin of other and unspecified parts of face
173.40, 173.49	C44.40, C44.49	Unspecified and other specified malignant neoplasm of scalp and skin of neck
173.50, 173.59	C44.50_, C44.59_	Unspecified and other specified malignant neoplasm of skin of trunk, except scrotum
173.60, 173.69	C44.601, C44.691	Unspecified and other specified malignant neoplasm of skin of upper limb, including shoulder
173.70, 173.79	C44.701, C44.791	Unspecified and other specified malignant neoplasm of skin of lower limb, including hip
173.80, 173.89	C44.80, C44.89	Unspecified and other specified malignant neoplasm of other specified sites of skin
173.90, 173.99	C44.90, C44.99	Unspecified and other specified malignant neoplasm of skin, site unspecified
225.0 – 225.9	D32._ – D33._	Benign neoplasm of brain and spinal cord neoplasm
227.3, 227.4	D35.2, D35.3	Benign neoplasm of pituitary gland, craniopharyngeal duct (pouch) and pineal gland
228.02	D18.02	Hemangioma; of intracranial structures
228.1	D18.1	Lymphangioma, any site <i>Note: Includes only lymphangioma of the brain, other parts of nervous system and endocrine gland</i>
230.0 – 234.9	D00._ – D09._	Carcinoma in situ
237.0 – 237.1	D44.3 – D44.5	Neoplasm of uncertain behavior of endocrine glands and nervous system: pituitary gland, craniopharyngeal duct and pineal gland
237.5, 237.6, 237.9	D42._, D43.0, D43.2 – D43.4, D43.7 – D43.9	Neoplasm of uncertain behavior of endocrine glands and nervous system: brain and spinal cord, meninges, endocrine glands and other and unspecified parts of nervous system
238.4	D45	Polycythemia vera
238.6	D47.Z9	Plasma cells
238.7_	D46._, D47._	Other lymphatic and hematopoietic diseases
239.6, 239.7	D49.6	Neoplasms of unspecified nature, brain, endocrine glands and other parts of nervous system
273.3	C88.0	Macroglobulinemia (Waldenstrom's macroglobulinemia)
277.89	C96.5, C96.6	Other specified disorders of metabolism <i>Reportable includes terms: Hand-Schuller-Christian disease; histiocytosis (acute)(chronic); histiocytosis X (chronic)</i>
288.4	D76.1 – D76.3	Hemophagocytic syndrome (histiocytic syndromes)
289.6	D45	Familial polycythemia (synonym for polycythemia vera)
795.0_, 795.1_	R87.6_	Papanicolaou smear of cervix and vagina with cytologic evidence of malignancy

2012 SUPPLEMENTARY LIST #2 ICD-9-CM CODE LIST TO SCREEN FOR CANCER REGISTRY CASES NOT IDENTIFIED BY OTHER CODES (with equivalent ICD-10-CM codes)		
ICD-9-CM CODE*	ICD-10-CM CODE**	EXPLANATION OF ICD-9-CM CODE
V10.0_ – V10.9_	Z85.0_ – Z85.8_	Personal history of malignancy <i>Note: Screen for recurrences, subsequent primaries, and/or subsequent treatment</i>
V12.41	Z86.011	Personal history of benign neoplasm of the brain
V13.89	Z86.000, Z86.008, Z86.011	Personal history of unspecified malignant neoplasm and history of in-situ neoplasm of other site
V15.22	Z98.871	Personal history of undergoing in utero procedure during pregnancy <i>Note: includes procedures on fetus for cancer related diagnosis</i>
V15.3	Z92.3	Other personal history presenting hazards to health or radiation <i>Note: Personal history of therapeutic radiation</i>
V16.0_	Z80.0_	Family history of malignant neoplasm
V42.81, V42.82	Z94.81, Z94.84	Organ or tissue replaced by transplant bone marrow, stem cell
V51.0	Z42.1	Encounter for breast reconstruction following mastectomy
V52.4	Z44.3	Fitting and adjustment of prosthetic device and implant (breast)
V54.2	M84.5	Aftercare for healing pathologic fracture
V58.0, V58.1	Z51.0, Z51.1	Encounter for radiotherapy, chemotherapy, immunotherapy
V66.1, V66.2	Z51.89	Convalescence and palliative care following radiotherapy, chemotherapy
V66.7	Z51.5	Encounter for palliative care
V67.1, V67.2	Z08	Follow up examination: following radiotherapy or chemotherapy
V71.1	Z03.89	Observation for suspected malignant neoplasm
V72.83	Z01.818	Other specified pre-operative examination (including chemotherapy)
V76.0_	Z12.0_	Special screening for malignant neoplasms
V78.8, V78.9	Z13.0	Other and unspecified disorders of blood and blood forming organs
V86.0_	Z17.0_	Estrogen receptor positive status [ER+], negative status [ER-]
V87.41	Z92.21	Personal history of antineoplastic chemotherapy
V87.43	Z92.23	Personal history of estrogen therapy
V87.46	Z92.25	Personal history of immunosuppression therapy

<http://seer.cancer.gov/tools/casefinding/>

## **4.5 Multiple Primaries**

NDSCR follows the instructions for determining multiple primary cancers that were prepared by the SEER/NCI and CDC. New multiple primary determination rules went into effect Jan. 1, 2007.

Coding of single and subsequent hematologic primary malignancies is challenging. The Hematopoietic Database and a case reportability and coding manual have been developed by SEER effective with cases *diagnosed January 1, 2010 and after*. The database and manual may be found at <http://seer.cancer.gov/registrars/>.

## 4.6 Manual Implementation Datelines

The International Classification of Diseases for Oncology, 3<sup>rd</sup> Edition (ICD-O-3) must be used to code the primary cancer site and the cell type of tumor information for all cases diagnosed Jan. 1, 2001, and forward. The following table showing the reference manual changes was taken from NAACCR Volume II: Data Standards and Data Dictionary.

Table 1. Record Layout Table With References. \*[www.naacr.org/Applications/ContentReader/Default.aspx?c=2](http://www.naacr.org/Applications/ContentReader/Default.aspx?c=2)

NAACCR Version	Release Date	Effective Date*	Reference Manuals Accommodated	NAACCR Metafile Version
Version 13	06/2012	1/1/2013	CoC <i>FORDS Revised for 2012</i> <b>SEER Program Coding and Staging Manual, 2012, with 2013 Changes</b> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Seventh Edition, 2010</i> <i>Collaborative Stage Data Collection System**</i>	Metafile Version 13
Version 12.2	06/2011	1/1/2012	CoC <i>FORDS Revised for 2012</i> <b>SEER Program Coding and Staging Manual, 2012</b> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Seventh Edition, 2010</i> <i>Collaborative Stage Data Collection System**</i>	Metafile Version 12.2
Version 12.1	06/2010 Revised 12/2010	1/1/2011	CoC <i>FORDS Revised for 2011</i> <i>SEER Program Coding and Staging Manual</i> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Seventh Edition, 2010</i> <i>Collaborative Stage Data Collection System**</i>	Metafile Version 12.1
Version 11.3	4/1/2008	1/1/2009	CoC <i>FORDS Revised for 2007</i> <b>SEER Program Coding and Staging Manual 2007, Revision 1</b> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Sixth Edition, 2002</i> <i>Collaborative Staging Manual and Coding Instructions**</i>	Metafile Version 11.3
Version 11.2	4/1/2007	1/1/2008	Same as Version 11.1	Metafile Version 11.2
Version 11.1	4/1/2006	1/1/2007	CoC <i>FORDS Revised for 2007</i> <b>SEER Program Coding and Staging Manual 2007</b> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Sixth Edition, 2002</i> <i>Collaborative Staging Manual and Coding Instructions**</i>	Metafile Version 11.1
Version 11	10/1/2004	1/1/2006	CoC <i>FORDS: Revised for 2004</i> <i>SEER Program Code Manual</i> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Sixth Edition, 2002</i> <i>Collaborative Staging Manual and Coding Instructions**</i>	Metafile Version 11

NAACCR Version	Release Date	Effective Date*	Reference Manuals Accommodated	NAACCR Metafile Version
Version 10.2	3/1/2004	1/1/2005	Same as Version 10.1	Metafile Version 10
Version 10.1	3/1/2003	1/1/2004	<b>CoC FORDS: Revised for 2004</b> <b>SEER Program Coding and Staging Manual 2004</b> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Sixth Edition, 2002</i> <i>Collaborative Staging Manual and Coding Instructions (implementation 01/01/2004)</i>	Metafile Version 10
Version 10	3/20/2002	1/1/2003	<b>CoC FORDS (2003)</b> <i>SEER Program Code Manual</i> <i>WHO ICD-O-3, 2000</i> <i>SEER Summary Staging Manual, 2000</i> <i>AJCC Staging Manual, Sixth Edition, 2002</i>	Metafile Version 10
Version 9.1	3/21/2001	1/1/2002	Same as Version 9	Metafile Version 9
Version 8	3/30/1999	1/1/2000	Same as Versions 6 and 7	Metafile Version 8
Version 7	4/13/1998	1/1/1999	Same as Version 6	Metafile Version 7
Version 6	1/23/1998 Revised 3/20/1998	1/1/1998	<b>CoC/ROADS, 1996, Rev. 1998</b> <i>WHO ICD-O-2, 1990</i> <i>SEER Summary Staging Guide, 1977</i> <b>AJCC Staging Manual, Fifth Edition, 1997</b> <b>SEER Extent of Disease Manual, 1998</b>	Metafile Version 6
Version 5.1	3/12/1997	1/1/1997	Same as Version 5	Metafile Version 5
Version 5	4/10/1996	1/1/1996	<b>CoC/ROADS, 1996</b> <i>SEER Program Code Manual, 1992</i> <i>WHO ICD-O-2, 1990</i> <i>SEER Summary Staging Guide, 1977</i> <i>AJCC Staging Manual, Fourth Edition, 1992</i> <i>SEER Extent of Disease Manual, 1992</i>	Metafile Version 5
Version 4	2/14/1994	1/1/1994	<i>CoC/ACoS Data Acquisition Manual, 1994</i> <i>SEER Program Code Manual, 1992</i> <i>WHO ICD-O-2, 1990</i> <i>SEER Summary Staging Guide, 1977</i> <i>AJCC Staging Manual, Fourth Edition, 1992</i> <i>SEER Extent of Disease Manual, 1992</i>	Metafile Version 4

Bolded text indicates changes from previous version.

\* Either the date of diagnosis or year first seen for this cancer may have been used by some standard setters. Refer to the Data Dictionary or to the standard setter reference manuals for clarification of date requirements.

\*\* Refer to <http://www.cancerstaging.org/cstage/> for Collaborative Stage version information.

Reporting Central Nervous System [CNS] neoplasms/tumors to NDSCR is not a new requirement. Reporting of CNS neoplasms/tumors to NDSCR began August 2002. Mandatory reporting of all benign CNS began January 2004 following passage of a federal law by Congress.

For reporting hematopoietic disease data collection rules, refer to SEER's Hematopoietic Project at <http://seer.cancer.gov/tools/heme/> updated May 23, 2012. This site provides 2012 and 2010 data collection rules for hematopoietic and lymphoid neoplasms. There are two tools for use with these rules: (1) Hematopoietic & Lymphoid Database, (2) Hematopoietic Coding Manual. The hematopoietic database has two formats and the capability of switching between the 2012 and 2010 versions of the data.

#### **4.7 Non-registry Hospital Submission Rules and Guidelines**

Non-registry hospitals may elect to have their cases abstracted on-site by NDSCR staff or by mailing pertinent medical record sections to NDSCR. Additionally non-registry hospital health information department staff may enter the required data elements directly into the Registry Plus secure web-based reporting system's Web Plus application for real-time case reporting. This may be done following receipt of login, password and reporting system training.

*Mail-in Option Non-registry Hospitals:* Non-registry hospitals participating in the mail-in option are to submit the following medical record documents:

1. Summary sheet (face sheet)
2. History and physical
3. Discharge summary
4. Surgery report
5. Pathology report
6. Laboratory and radiology reports

Mail these documents to:

Xudong Zhou, MD. CTR  
North Dakota Statewide Cancer Registry  
Department of Pathology  
School of Medicine & Health Sciences  
University of North Dakota  
501 N Columbia Road  
Stop 9037  
Grand Forks N.D. 58203-9037

#### **4.8 Multi-Facility Reporting**

NDSCR requires that any cancer case that meets NDSCR case reporting requirements must be submitted by every facility providing services to the patient. Therefore, facilities that are members of shared, combined or joint cancer registries and/or cancer programs must report each cancer case seen in each facility separately.



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## **Section 5**

### **Data Processing**

- 5.0 Reporting Requirements**
- 5.1 Case Ascertainment**
- 5.2 Data Exchange Agreements**
- 5.3 Abstracting**
- 5.4 Data Entry**
- 5.5 Internal Matching, Linking  
And Consolidation**
- 5.6 Training**

## **5.0 Reporting Requirements**

See *Section 3 – Cancer Data Reporting Guidelines* for a description of the required format, reportable cases, reportable list, required dates for data file submissions, multiple primary rules and ambiguous terminology.

### **5.1 Case Ascertainment**

Reportable cancer cases are received from registry medical facilities, non-registry medical facilities, outpatient surgical centers, clinics, pathology laboratories, radiation or oncology treatment centers and independent physician offices. Following Commission on Cancer regulations, newly diagnosed cancers are to be reported within six months of diagnosis.

The NDSCR staff reviews case ascertainment/case finding sources such as disease indices, pathology reports (including cytology and autopsy reports), outpatient records, radiation therapy logs, and oncology logs for missing cases. Facilities are periodically selected for a casefinding audit which is a systematic method of identifying all reportable cases in order to assess completeness and timeliness.

Every inpatient and/or outpatient admission with active disease and/or receiving cancer-directed therapy must be reported to NDSCR, **regardless of the patient's state or country of residence.**

Through a series of management reports, all types of reporting medical facilities are monitored for any type of data reporting changes. This includes the number of cases expected, number of cases actually received and data quality.

### **5.2 Data Exchange Agreements**

The primary purpose of central cancer registries is to collect complete, timely and high-quality data that are available for cancer control use and research. The identification of residents diagnosed in other states is essential for complete population-based reporting. Confidentiality policies and procedures are an essential part of the data sharing agreements to protect the privacy of the individual patient and facility reporting the case and to provide assurance that the data will not be abused.

The NDSCR has data sharing agreements with many state central cancer registries for reciprocal exchanging of cancer information. Therefore, it is essential that registry facilities complete abstracts on all out-of-state residents diagnosed and/or treated at their facility and submit these cases to NDSCR.

The NDSCR also has signed the North American Association of Central Cancer Registrar's Association National Interstate Data Exchange Agreement for the reciprocal exchange of cancer information.

### **5.3 Abstracting**

It is the responsibility of every abstractor to know the content of the FORDS (Facility Oncology Registry Data Standards) and to update it upon receipt or notification of any changes. It also is the responsibility of the abstractor to **read** and follow the FORDS, Collaborative Staging Manuals and Coding Instructions, Hematopoietic Database and Manual and Multiple Primary and Histology Manuals for correct abstracting and coding of data. Do not rely on memory, since codes and abstracting rules change frequently.

All TEXT fields are to be completed for coding justification and to substantiate the coding of the data items for which they are identified. Documentation **must include** treatment dates, justification of primary site, histology and collaborative staging coding selections.

#### **Case Ascertainment**

The central cancer registry is ultimately responsible for accurate and complete reporting of cancer incidence for the state. This requires collaboration with all reporting sources. The reporting of cancers is mandated by state law NDCC 23-07-02(2)(a) and NDCC23-12-07 and Administrative Rule Chapter 33-06.

Case ascertainment or collection and/or abstracting are performed by all central registry staff.

#### **Case Abstracting Requirements**

Individual cases must be abstracted no later than six months after the date of diagnosis.

#### **Analytic/Non-analytic Cases (Class of Case)**

The class of case registry data item is used to designate a case as analytic or non-analytic. An analytic case is diagnosed and/or treated (first course of therapy or all treatment) at a reporting facility. A non-analytic case is one that is diagnosed and received the first course of therapy or all treatment before admission to the reporting facility. Although the ACoS does not require accredited facilities to abstract non-analytic cases, as population-based cancer registry **NDSCR *must record all cancers regardless of class of case, place of diagnosis or date of diagnosis.*** Non-reporting of these cases to the state central cancer registry affects the overall statewide cancer totals and inhibits accurate reporting to surveillance, research and cancer prevention activities; therefore, it is important that they are submitted to the central cancer registry.

## **Multiple Primaries**

The determination of how many primary cancers a patient has needs operational rules in order to ensure consistency of reporting by all participants. Basic factors include the site of origin, date of diagnosis, histology/morphology, behavior and laterality.

In 2007 new multiple primary and histology coding rules were developed to help guide and standardize the process of determining the number of primaries and promote consistent and standardized coding by cancer registrars. The rules contains site-specific rules for lung, breast, colon, skin melanoma, head and neck, kidney, renal pelvis/ureter/bladder, malignant brain and benign brain/CNS systems. The MPH rules can be found at [https:// seer.cancer.gov/tools/mphrules/](https://seer.cancer.gov/tools/mphrules/).

## **5.4 Data Entry**

Health facilities diagnosing and/or treating cancer may submit an electronic data file to the registry's electronic reporting system, Web Plus, or enter data directly into the system.

If a data file is uploaded electronically, a data file loading documentation receipt is provided. This documentation contains the facility file/bundle name, internal file name, hospital/state file/bundle received from, total number of abstracts, edit set name, total number of errors, total number of abstracts with errors and the date the file/bundle was created. Instructions, password and login information must be obtained from the central cancer registry's data administrator.

Hard copies of records submitted from non-registry facilities, pathology laboratories, clinics and physicians are manually abstracted, coded and entered by central registry staff.

Source documents, electronic or hard copy, are kept in locked files. Electronic data file uploads are through an encrypted, secure, password-protected system and are accessible to limited personnel.

If a facility so chooses, data may be directly entered in the NDSCR's database through the Web Plus application. Following clearance, password and login information is obtained by the central registry's program director. Direct database data entry training is then started.

## **5.5 Internal Matching, Linking and Consolidation**

Case reports from multiple facilities may have discrepancies that affect case reportability. Central registries use several methods to evaluate and reconcile inter-field inconsistencies. The central registry relies on information found in the text provided with each case to verify the coded values.

### **Duplicate File Submission Identification**

The NDSCR registry software system, CDC's Registry Plus suite of software programs, is designed to automatically identify duplicate cases through deterministic and probabilistic matching processes to identify and resolve duplicate records. NAACCR flat-files that are uploaded from hospital registries and out-of-state central cancer registries via Web Plus are duplicate-checked via a deterministic algorithm that checks all fields across all records in the file. The file submission is rejected to the submitting facility if it is a duplicate of a file that was already uploaded. The hospital registry submitting the NAACCR flat-file receives an error message upon file upload that the uploaded file was a duplicate of a file previously uploaded.

### **Record Consolidation**

Record consolidation is an essential function of a central cancer registry to improve data quality. Consolidation is performed to ensure that each cancer is counted only once and that the combined record includes the best information available from all data sources. Consolidation is a necessary function that must deal with multiple record sources, multiple submissions for each cancer, and variation in quality and completeness of records. Failure to link and consolidate records carefully and correctly leads to over-counts in the data, either as a result of the same person being counted more than once or because the same tumor is recorded multiple times for the same patient, affecting state rates and trends.

Linkage is the process of using defined criteria to determine whether source records refer to the same patient and/or cancer based upon the degree of agreement between the data fields. The record consolidation maintains relational linkage to all original cancer report documentation (i.e., cancer abstracts, path reports). Cancer reports received from the same or multiple sources on the same patients are merged together to form one accurate cancer record (i.e., a "patient cancer profile"). See pages 81 through 85 for more details.

### **CRS Plus Incoming Record Processing**

Central Registry Software (CRS Plus) is the Registry Plus application used to manage the central registry database. The program provides for automatic determination of multiple primary tumors and consolidation of data items from multiple case reports into incidence records. CRS Plus supports the linkage of incoming abstracts against the existing database, with software-assisted consolidation into patient, cancer, and facility tables.

All records imported into the CRS Plus database proceed through a series of automated linkage and consolidation routines including Patient Linkage, Sequence Number Check, Tumor Linkage, Data Item Consolidation and

Duplicate Reporting Hospital Check. At any point that the program is unable to reach a definitive linkage, sequence number assignment or consolidation decision, or the record is identified as a duplicate, the record is sent to pending for manual intervention.

The process begins with Patient Linkage. The incoming source record is compared to all patients on the database. If the incoming record does not match a patient on the database, the abstract is disposed to the database and a new patient is created. If the incoming record does potentially match a patient on the database, the record is sent to pending.

The next step is tumor linkage determination. If the tumor does not match a patient and tumor on the database, a new tumor summary is created in the database. Otherwise, the record will go to pending to manually review for tumor linkage.

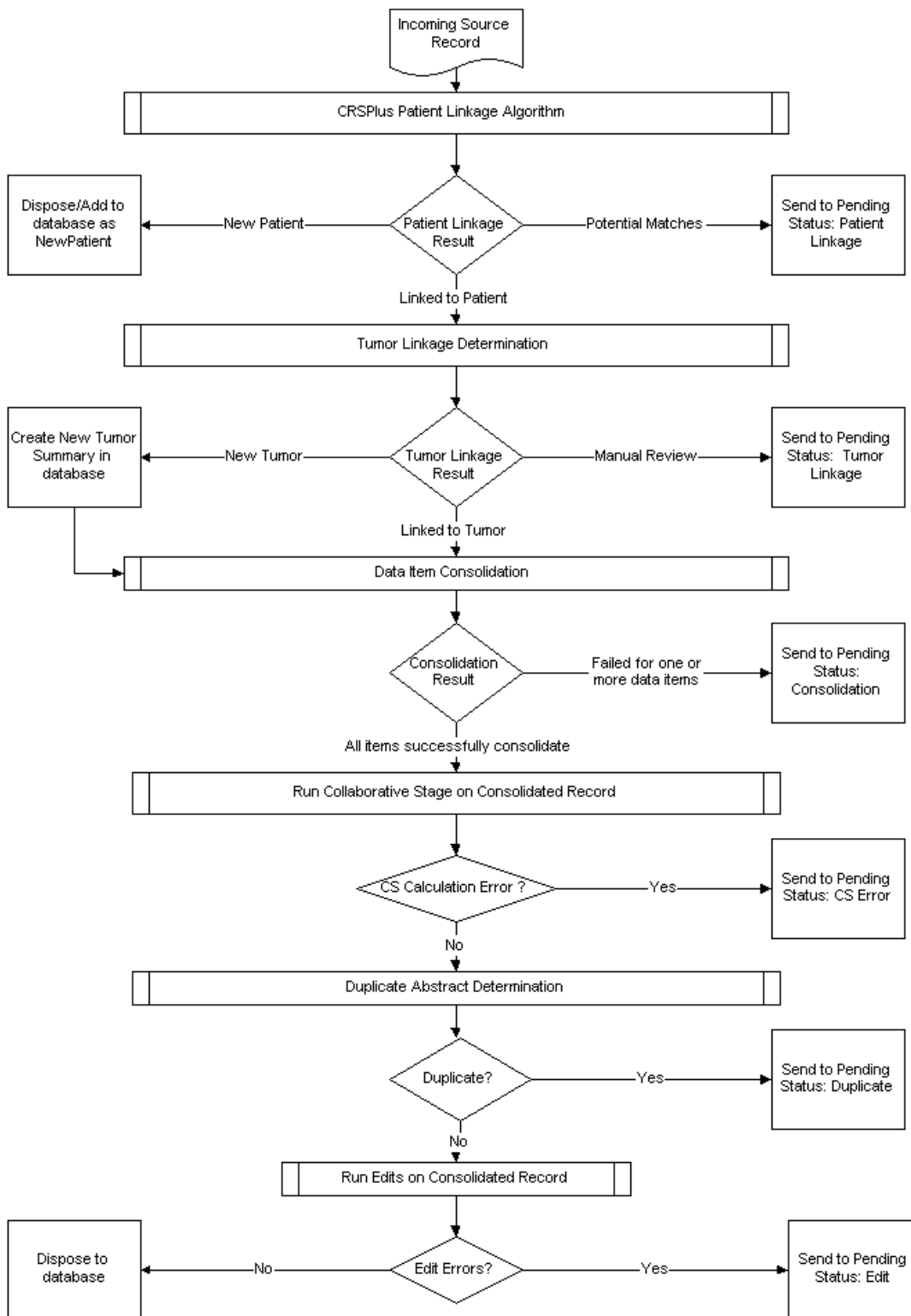
If a record links to a patient and tumor, the next step is Data Item Consolidation. If there are differing values for the data items in the source records, the best value must be determined for the consolidated record. If the best values can be determined from the automated directives, data item consolidation will be successful and the record will move on to Collaborative Stage. If the automated directives fail, the record will go to pending for manual consolidation.

The record runs through the Collaborative Stage algorithm. If it fails, the record will be sent to pending to correct the CS data item. If the record runs through the CS algorithm successfully, it will proceed to the next step, Duplicate abstract determination.

If identified as a duplicate record, the record will be sent to pending for manual review. If not found to be a duplicate, it will proceed to the final step – running EDITS on the consolidated record.

If there are no edit errors, the record will be disposed to the database, and if there are edit errors, it will be sent to pending for correction.

**CRSPlus Data Flow**  
(excludes Sequence Number Central logic)





## **Patient Linkage**

When a file is imported into CRS Plus each incoming record enters the patient linkage process to determine if the record should be linked to an existing patient in the database. The first step in the Patient Linkage process is known as 'blocking' which is performed to identify all consolidated records similar to the incoming record for (1) Soundex of last name, (2) birth date or (3) social security number. Blocking enables the system to complete patient linkage more efficiently. The second step of Patient Linkage involves the matching of specific data items from the incoming record against all consolidated records identified during blocking to assign a match score. The data items used to compute this score are:

- Date of Birth
- First Name
- Middle Name
- Last Name
- Social Security Number
- Sex
- Race1

The matching algorithm assigns different scores for matched or partially matched data items. For example a record with identical Social Security Number will receive a higher match score than a record matching only five of nine digits of the Social Security Number. Since blocking is performed on SSN, a transposition of one number will not significantly impact because the first three digits are reviewed, then the next two digits, then the final four digits.

CRS Plus uses two cut-off scores to identify potential matches. All records with a match score less than 80 are eliminated as non-matches. This low score can be determined by individual registries based on evaluation of registry data. All records with a match score of 155 or higher are considered definite matches. The highest possible match score is 170.

Potential dispositions of the patient linkage process are:

- New Patient – no records with match score 80 or greater. Record is sent for sequence number check after which a new Patient record and Tumor record are created in the CRS Plus database.
- Pending Patient Linkage - one or more records have a score within the 80 - 154 range; or one record with match score 155 or higher but another record matched with a score of 125 or greater points. Record is sent to pending for manual patient linkage.
- Linked to Patient - only one record with match score 155 or greater; or one record with match score 155 or higher and other record(s) matched with score(s) 124 points or lower. PatientID of the matching patient is assigned to the incoming record and the record proceeds to TLC Plus for tumor linkage.

### **Sequence Number Check**

Records designated as a New Patient enter a sequence number check. If the Sequence Number--Hospital value is 00, 99 or blank, the record is assigned a Sequence Number--Central of 00. If the Sequence Number--Hospital equals any other value the abstract is sent to pending for manual Sequence Number--Central assignment.

### **Tumor Linkage**

Once an incoming abstract is linked to an existing patient record, the abstract enters the TLC Plus automated tumor linkage process to determine if the record should be linked to a tumor already in the database for the patient. As in patient linkage, tumor linkage involves the matching of specific data items from the incoming record against the linked consolidated records. Data items used to determine tumor linkage include:

- Primary Site
- Laterality
- Histologic Type (ICD-O-3)
- Behavior (ICD-O-3)
- Diagnosis Date
- Reporting Hospital

Abstracts proceed through a series of logic routines until a final outcome is determined or all routines are exhausted. Dispositions of the tumor linkage process are:

- New Tumor: Tumor is determined to be a new primary, not currently in the database for the patient. A new Tumor record is created in the CRS Plus database and the record proceeds to TLC Plus for automated consolidation (patient data items only).
- Pending Tumor Linkage: Automated tumor linkage cannot be determined; record is sent to pending for manual tumor linkage.
- Consolidate: Tumor is determined to be same primary as an existing tumor in the database for the patient. The MedRefID (unique identifier assigned to each individual tumor in the CRS Plus database) of the linked tumor is assigned to the incoming record and the record proceeds to TLC Plus for automated consolidation (patient and tumor data items).

### **Data Item Consolidation**

To complete data item consolidation, TLC Plus applies consolidation rules for each field as defined by the user and entered in the TLC\_DATA.mdb of CRS

Plus. Consolidation rules define how data from two or more linked records are evaluated to select a final "best" value for each data item (field). Application of consolidation rules may be automated, manual, or a combination of automated and manual rules. In TLC Plus, consolidation rules are applied on a field-by-field basis whenever multiple values have been reported for the same field. For a field without defined consolidation rules, the field value from the first abstract received for the patient or tumor will be maintained in the consolidated record, unless manually updated.

Unlike the prior linkage processes the consolidated record value is not utilized. Consolidation compares values from the incoming record and all historical source records on file for the patient or tumor. All linked records undergo consolidation of patient-specific data items, however only records linked to an existing tumor undergo consolidation of tumor-specific data items. For each patient and tumor data item there are two potential dispositions from consolidation:

- Update: All automated consolidation rules were processed successfully, the consolidated record is updated and the incoming record disposed to the database.
- Manual Review: Consolidation rules did not complete successfully for all fields (although it will have completed all fields that it can). The record is sent to pending for manual data item consolidation of only those fields for which consolidation failed.

In TLC Plus consolidation rules are carried out via the application of Directives, or automated evaluation criterion used to select a final best value. There are many available directives that may be applied in any order determined by the user.

### **Collaborative Stage Algorithm - Introduction**

The Collaborative Staging (CS) System schemas consist of several data input fields necessary to derive T, N, M, and Stage Group according to the sixth and seventh editions of the AJCC Cancer Staging Manual; Summary Stage 1977; and SEER Summary Stage 2000. Collaborative Staging schemas apply to cases diagnosed January 1, 2004 and later and should not be used for cases diagnosed prior to 2004. It is important for primary site to be coded correctly since most schemas are site-specific (although there are a few schemas such as melanoma and lymphoma that are based on histologic type).

Once the CS input data items are completed, the coded values are passed to a computer algorithm that generates the correct stage for the case in the four staging systems: AJCC TNM, 6<sup>th</sup> edition, AJCC TNM, 7<sup>th</sup> edition, SEER Summary Stage 1977, and SEER Summary Stage 2000. The program returns a set of output values or numeric codes to be stored in the record.

### **How the Algorithm functions in CRS Plus**

The incoming record runs through the Collaborative Stage algorithm. If it fails, the record will be sent to pending to correct the CS input data items and have CS derived fields re-derived. If the record runs through the CS algorithm successfully, it will proceed to the next step, Duplicate abstract determination.

In CRS Plus, the Collaborative Stage Algorithm can also calculate the derived stage fields upon Save and on demand (F5).

### **Duplicate Check**

All incoming records linked to an existing patient and existing tumor (tumor linkage result was Consolidate) undergo comparison of the Reporting Hospital before final disposition in the CRS Plus database:

- If the Reporting Hospital numbers are different the record is disposed to the database.
- If the Reporting Hospital numbers are identical the record is sent to Pending for manual intervention.

Duplicate records may then be assigned one of three dispositions:

- ADD: Facility record is added to the database with appropriate patient and tumor linkages.
- VOID: Facility record is voided and does not become a structured record in the database. The voided records are retained but in a separate location. Voided records can be reassigned back to the database if voided accidentally since all data including text is retained.
- UPDATE: Facility record is added to the database with appropriate patient and tumor linkages and the user is immediately taken to the update case window. This option allows the user to update values on the original reporting facility source record from the duplicate record, and then VOID the duplicate from the update window.

### **Edits Check**

The final step of record processing in CRS Plus is to run edits on the consolidated record. If there are no edit errors, the incoming record will be disposed to the database, and if there are edit errors, it will be sent to pending for error resolution.

### **Processing of Pending Records**

NDSCR staff manually reviews and resolves all records sent to pending due to failure at some point during the automated processes described above. The below table describes the pending status options and the corresponding actions.

<b>Pending Status Code</b>	<b>Pending Status</b>	<b>Action</b>
1	Sequence New Patient	Does not link to patient in database; Assign Sequence Number > 00
2	Patient Linkage	Potential Patient Match; Review Patient demographics to determine a patient match
4	Tumor Linkage	Potential Tumor Match; Review tumor-specific fields to determine a tumor match
8	Data Item Consolidation	One or more data items requires manual review; Review the specified data items and select the best value for the consolidated record
9	Duplicate Check	Based on Reporting Facility; Determine whether information can be gleaned from the duplicate record prior to voiding
10	Edit Error	Sent to Pending for Edits; Resolve edit error(s)
11	Collaborative Stage Calculation Error	Cannot derive Collaborative Stage – one or more CS items is invalid; Review/Recode CS input data items and re-derive CS derived data items
12	Sequence New Tumor	Potential New Tumor; Review Sequence Number

### **Independent De-duplication of the CRS Plus Database**

On a twice annual basis, an extract of the CRS Plus database is generated and run through a de-duplication linkage using Link Plus probabilistic linkage software. During de-duplication linkages in Link Plus records in the same file are blocked, compared, and scored against each other, and the result is a ranked list of record pairs, and high-scoring pairs are potential duplicates. The advanced probabilistic matching methods included in Link Plus find partial, approximate, or fuzzy matches, and generate values of match on a particular field that can be other than “yes” or “no”, 1 or 0.

These matching methods incorporate partial matching, value-specific matching, or both, are customized for the content of specific data items or types, and enable identification of duplicate records in the CRS Plus database that other methods would miss.

## **5.6 Training/Trainer**

The NDSCR staff provides training at various times during the year for all facility and state registrars. Training may be provided at the annual cancer registrar's association meeting.

All state staff participates in training provided by national organizations to increase their knowledge of cancer data collection and other registry procedures either through webinars, town hall meetings or conferences.

In addition to training presented by the state staff, the central registry staff trainer will provide in-depth training on new abstracting regulations and requirements.

## **Section 6**

### **Death Clearance**

- 6.0 Introduction**
- 6.1 Procedures**
- 6.2 Death Certificate Only  
Cases**
- 6.3 Cause of Death**

## **6.0 Introduction**

The primary purpose of a cancer registry is to collect complete, timely and high-quality data for use in surveillance, decision-making, cancer control, research, and policy development. The use of mortality files to update death information and increase reporting completeness in the central registry is referred to as “death clearance”.

Death clearance is defined as the process of matching registered deaths in a population against reportable conditions in the registry database. Population-based cancer registries use death certificates for two purposes:

- (1) To update mortality and other information on cases in the registry database, and
- (2) As a case-finding source.

This linkage is performed annually. The central registry data files for a specific year and the death certificate file from the Division of Vital Records need to be complete before the death clearance process can begin. Abstracts produced during the resolution of death clearance cases are used to update the registry’s incidence database.

A computerized linkage program separates the death certificates into three categories:

**(1) Positive matches.** Those patients already registered in the incidence database. If it is the same cancer, then the incidence database is updated with the death information. If the cancer death does not match the incidence record, then the case is followed back to a facility, physician, etc.

**(2) Inconclusive matches.** Inconclusive matches must be manually reviewed. There are two possible outcomes to this review:

- a. If it is a definite match, then the process continues with the path for a definite match.
- b. If it is a possible match, then the case is followed back.

**(3) Non-matches.** These are patients who are not registered in the incidence database, but cancer information is present on the death certificate and is manually reviewed. Non-match cancer deaths must be followed back to the facility, physician, nursing home, etc.

If it is determined that the cancer listed on the death certificate is a missed registry facility case, the registry is required to abstract and submit the case.



## **6.1   Procedures**

The NDSCR follows NAACCR Procedure Guidelines for Cancer Registries, *Death Clearance Manual July 2009*. Refer to this manual at [www.naaccr.org/StandardsandRegistryOperations/RegOpsGuidelines.aspx](http://www.naaccr.org/StandardsandRegistryOperations/RegOpsGuidelines.aspx) for complete death clearance guidelines.

Unknown values in the registry record are replaced with the death certificate values. This could include date of birth, Social Security number, middle name or initial, race, occupation/industry, birthplace, marital status and maiden name.

## **6.2   Death Certificate Only Cases**

Information on a death certificate is entered as a Death Certificate Only (DCO) case when all attempts at securing correct date of diagnosis, diagnostic facility and treatment has failed. Date of death is used as the date of diagnosis. Less than three percent DCO cases are permitted per year to achieve gold registry certification.

## **6.3   Cause of Death**

Population-based cancer registries are required to use the ICD-10 Underlying Cause of Death code as recorded on the death certificate even when the central registry has more complete or detailed information.

# **SECTION 7**

## **QUALITY CONTROL**

- 7.0 Quality Control**
- 7.1 EDITS, Visual Review,  
Data Processing**
- 7.2 Quality Assurance Activities**

## **7.0 Quality Control/Continuous Quality Improvement**

Quality control or continuous quality improvement is an ongoing series of functions designed to promote accuracy, timeliness and completeness of cancer reporting to NDSCR. These functions are necessary to measure and evaluate the completeness of cancer case reporting and to thoroughly assess data quality and are an integral part of NDSCR. They also are necessary to ensure complete, accurate and valid cancer surveillance.

Completeness is the extent to which all required cases have been reported to NDSCR. NDSCR file completeness is assessed using:

- On-site case-finding audits of registry and non-registry facilities.
- Management reports.

Accuracy is the extent to which the data submitted have been correctly coded and match the information contained in the text fields in the submitted data file. Accuracy encompasses correct interpretation and application of coding rules and guidelines, identifies data entry and data submission errors and evaluates case correctness. Accuracy is assessed using:

- Field-item, inter-item and intra-item data edits.
- Visual record view.
- On-site case-finding audits.
- Re-abstracting audits.

Timeliness involves how quickly each reporting facility submits cases to NDSCR once a patient enters the health-care system. Timeliness is assessed using:

- Facility Data Submission Report.
- Facility Record Counts by Diagnosis Year Report.

To ensure completeness and accuracy of the NDSCR cancer data, the NDSCR has established a formalized continuous quality improvement (CQI) program. This CQI program consists of routine (i.e., daily) data processing, as well as periodic auditing and monitoring activities. Routine data processing activities consist of duplicate report consolidation and electronic data editing. Electronic reports, pathology reports and partial abstracts received and imported into the NDSCR database undergo extensive data processing routines to ensure unduplicated and accurate data. Periodically, the NDSCR staff will perform various retrospective audits and monitors cancer reporting from all reporting facilities. The audits aid in monitoring case reporting completeness and accuracy. See Section 7.2.

NAACCR has established gold or silver standard certification awards for central cancer registries meeting various quality data requirements. Quality data elements reviewed by NAACCR identify areas of strengths and weaknesses in

completeness, accuracy and timeliness.

### **NAACCR Criteria for Certification**

<b>Criteria</b>	<b>Certification</b>
Data Years	2003
Completeness	90% Silver 95% Gold
% Passing EDITS	97% Silver 100% Gold
Death Certificate Only Cases	<=5% Silver <=3% Gold
Timeliness	Received by December 2, 2005 (Within 23 Months)
Duplicate Reports*	<=2/1,000 Silver <=1/1,000 Gold
Missing Data Field Sex, Age, County	<=3% Silver <=2% Gold
Missing Data Field Race	<=5% Silver <=3% Gold

Section 7.1 describes the routine data processing activities performed by the NDSCR staff. Section 7.2 describes the quality assurance activities (i.e., periodic auditing and monitoring activities).

## **7.1 EDITS, Visual Review and Data Processing**

To ensure completeness and accuracy and timeliness of the cancer data reporting, all cancer data received undergoes extensive visual and computerized edit checks for quality and completeness of data.

### **EDITS**

Computerized edit checks are completed using the NAACCR, CDC and CoC WebEDITS and is only one small but very important component of the overall NDSCR quality control program. The Registry Plus suite of programs includes validation measures to ensure that only valid codes are submitted through data uploads or data entry by abstraction.

Empty fields are completed with correct information. Correct data is obtained for those items coded incorrectly or where there is a conflict of information. The electronic edits are applied to all (100%) of the data received by the NDSCR.

Cancer reports not passing the electronic edits are corrected and rechecked with the electronic edits. Electronic edits are performed before and after record consolidation. General edits and inter-record data edits are performed on data transmissions compiled for the NAACCR and NPCR/CDC Calls-for-Data. Accredited hospital registries should be running an edit program against each data submission file and should fix any data discrepancies before completing the final data submission.

### **Completeness Check**

The NDSCR database verifies completeness of each cancer report. This completeness check scans the reported cancer record and identifies missing required data elements (fields) as required by the NDSCR, NPCR and NAACCR. Each cancer report can be incomplete with respect to patient, cancer and/or treatment data. Incomplete cancer reports are flagged to allow NDSCR staff to complete the incomplete data items. Completeness also refers to the extent to which all required cases have been reported to NDSCR.

### **Visual Review**

Visual edit review is performed by reviewing the submitted data for correct cancer, treatment and demographic information to verify accurate abstracting/coding. NAACCR “Standards for Cancer Registries, Volume II” is utilized for data standards and allowable codes. Corrections are made to those records that show discrepancies. Data abstracted is checked against text to ensure accuracy of coding.

### **Data Processing**

The NDSCR database is designed with a continuous data quality concept with respect to routine data processing. There are three areas within data processing where the NDSCR database performs and/or monitors data quality:

1. *Test Import QC Checking:* Analyzes the submitted data file with electronic edits and performs completeness checks; accepts or rejects submitted data file for further data processing by the NDSCR database; incomplete or inaccurate files may be returned to the facilities for correction.
2. *Record Consolidation:* Accepted submitted data files are checked to identify duplicate patients and cancers (primary cancers); utilizes a probabilistic duplicate checking algorithm; consolidates duplicate patient and cancers into relational linkage to all original cancer report documentation (i.e., cancer abstracts, path reports); reports received from the same or multiple sources on the same patient are merged together to form one accurate cancer record. If necessary, the NDSCR

contacts all reporting sources for verification of data to ensure that patients and/or their primary cancer diagnoses are in the system only once to prevent duplicate reporting.

3. *QC Module*: Allows NDSCR staff to continuously check "patient cancer profiles" with electronic edits and completeness; allows NDSCR staff to record data discrepancies and notate corrections.

The NDSCR database provides several quality control "feedback" reports to the reporting facilities submitting cancer data to the NDSCR. A "reporting summary" report is distributed to each reporting facility showing data on the facility's reporting timeliness, quality and completeness yearly.

## **7.2 Quality Assurance Activities**

As part of the formalized CQI program, NDSCR staff performs various retrospective audits and monitors cancer reporting from all reporting facilities as part of the quality assurance activities. This auditing and monitoring benefits case reporting completeness and accuracy. The quality assurance activities consist of the following:

### **Visual Review of Text**

Data is critiqued so that assigned codes meet the allowable code standards and submitted text documentation included with the cancer abstract. Examples of this visual review include:

- Audit correct site and histology codes that match the descriptive text
- Sites are coded correctly for male or female
- Demographic codes match for city, county and state
- Text supports stage
- Earliest treatment date is recorded
- Treatment is appropriate for type of cancer and is it recorded correctly

Visual review of text is not performed on all reported cancers. Visual review of text is performed on (1) all cases failing completeness checks and/or electronic edits and (2) selected cases passing completeness and/or electronic edits.

### **Re-abstracting Audits**

These audits describe the process of independently re-abstracting cancer cases from the source patient records and then comparing the re-abstracted case with the original abstracted case in the registry. The objective of the re-abstracting audits is to ensure that the data in the cancer registry accurately reflects original medical record documents. The re-abstracting audits are performed periodically on selected cases. The methodology of case selection will vary with each audit (i.e.,

by site, reporting facility, geographic location, etc.). The NDSCR database will be used to perform re-abstracting audits through the QC module. A re-abstracting audit will take place every five years with a different primary site being audited. Re-abstracting audits will be performed on a random sample of abstracted cases submitted by cancer registries in the state.

### **Case-finding Audits**

The only way to document the true level of completeness of case ascertainment is through audits to identify and document deficiencies in the registry's data collection operations. These audits describe the process of independently locating unreported cancer cases from the source medical records. The objective of the case-finding audits is to ensure that cancer reporting covers the defined population of the cancer registry. NDSCR quality control staff will perform the case-finding audits. The methodology of each audit varies (i.e., by reporting facility, source document type, etc.). A case-finding audit will be scheduled at a different hospital registry each year, and two case-finding audits will be conducted at non-registry facilities each year.

### **Death Clearance**

Death clearance is essential in achieving complete reporting. This process identifies those cancer deaths not reported to the NDSCR and recorded in the cancer registry, as well as updated vital status information for patients reported to the NDSCR. The NDSCR Database facilitates death clearance activities. Death clearance follow-up (updating death certificates matching reported cancer patients) is done continuously throughout the year. Death clearance follow-back (identifying and abstracting death certificate only cases) is done at least once a year.

### **Monitoring Reporting Completeness and Timeliness**

Each reporting facility is monitored for accuracy, completeness and timeliness of reporting. The NDSCR Database provides several quality control "feedback" reports to the reporting facilities submitting cancer data to the NDSCR. A "reporting summary" report is distributed to each reporting facility showing data on the facility's reporting timeliness, accuracy and completeness. Timeliness of data submission is monitored to observe how many cases were submitted more than six months after diagnosis date. Completeness is monitored by comparing the actual number of cases received to an expected number of cases per hospital.



## Guidelines for Visual Editing

### Demographic information

Patient Name:	Check first name against sex; verify if suspect.
City/County/State:	Is state consistent with city? Is county code consistent with city? Is name of city spelled correctly?
Address:	Is address abbreviated properly?
Zip Code:	Check zip code/city against county code.
Race:	Is race appropriate for name? Appropriate for place of birth?
Occupation/Industry:	Retired must not be entered.
Sex:	Does sex match name and type of cancer?
Birth Date:	Check birth date against age in record.
Date of Last Contact:	Does date of last contact follow a logical sequence with Dx/Admit/Rx dates?

### Tumor Information

Sequence:	Are other primary cancer diagnoses documented in text?
Primary Site:	Primary site requires text justification. Is it coded correctly?
Histology:	Is histology documented in text? Is it coded correctly?
Behavior:	Supporting text is required for behavior code. If behavior is in-situ, stage must be in-situ.
Grade:	Grade code requires supporting text. Is it coded correctly?
Laterality:	Is laterality correct based on text? If primary site is unknown, laterality is "0."
Summary Stage:	Is there text to support assigned stage? In-situ must have pathological confirmation. If site is unknown, stage must be unknown. Are distant metastases documented?

### Treatment Information

Surgery:	All surgical treatment should be documented in text. Is surgical date recorded correctly?
CS Site Specific Factors	Are CS site specific factors correct for primary site?
CS Extension	Is CS extension coded correctly? Verify per text.
Radiation:	Is radiation appropriate for this tumor? Is date recorded?
Chemotherapy:	Is chemotherapy treatment recorded? Ancillary drugs should not be coded. Is date recorded?
Hormone:	Is hormone treatment recorded? Is date recorded?
BRM:	Is BRM treatment recorded? Is date recorded?
Other treatment:	Is other treatment recorded? Is data recorded?



## **SECTION 8**

### **Audits: Case-finding and Re-abstracting**

**8.0 Introduction**

**8.1 Case-finding Audits**

**8.2 Re-abstracting Audits**

## **8.0 Introduction**

NDSCR will perform three case-finding audits per year by auditing case-finding sources within each facility. These audits will include cancer registry facilities and non-registry facilities. Case-finding audits typically involve a statistically controlled study whereby case-finding sources are examined for possible missed cases. The audits provide the most direct estimate of completeness. Case-finding and quality control involves a carefully planned continuous loop of measurement, communication and action leading to continuous quality improvement.

NDSCR will also conduct one re-abstracting audit every five years. A re-abstracting audit is done to characterize the level of agreement between data already in NDSCR and data re-abstracted and recoded from source records (the hospital medical record in most cases). From each case, codes are compared to determine if data items reported to the state registry are accurate. Cases are identified for the re-abstracting audit through a process of the NDSCR computer program, which randomly selects a percentage of cases for re-abstracting. Additional cases in an area of specific concern may be requested as needed.

## **8.1 Case-finding Audits**

### **Case-finding Audits at Cancer Registry Facilities**

Case-finding audits to access completeness of ascertainment will be performed at North Dakota hospitals to determine the level of completeness of reporting newly diagnosed cancer cases to the NDSCR. NDSCR case-finding audits are done on a rotating schedule with cancer registry and non-cancer registry facilities and are designed to locate records with cancer diagnosis that may not have been reported to the NDSCR. One case-finding audit will take place each year. The hospital to be audited will be randomly chosen by the NDSCR with consideration to the date of a previous case-finding audit, the size of the facility, location of the hospital and the number of days available to perform the audit. The months of the year chosen to be audited at each source will be based on the size of the hospital.

The quality control staff will review cases from the following departments of the hospital:

- Pathology laboratory reports.
- Autopsy reports.
- Health Information indices of all reportable ICD-9/ICD-10 codes.

Quality control staff will review pathology reports for the diagnosis and comments for each specimen to determine reportability. When a reportable case is identified, information in the pathology report is compared to those cases already in the NDSCR database. When a reportable case or pathology report is not found in the NDSCR database, the pertinent cancer information is printed; the information brought back to the state office for further investigation by quality control staff. Once the determination is made regarding the reportability of the cancer case, if the case was missed by the registry, the hospital registrar is asked to abstract the case and submit it to the NDSCR.

### ***Flow Chart for Case-Finding Audits at Registry Facilities***

Eligible case identified at hospital in NDSCR: Yes = END

Eligible case identified at hospital in NDSCR: No = Missed Case

Procedure:

- Complete a listing of patients' from a previously requested Medical Record Disease Index (MRDI) of reportable cancer cases not in NDSCR database.
- After reviewing MRDI, mail a list of missing cancer cases to the hospital registrar of the facility being audited.
- Hospital registrar locates patient record.
- Quality control personnel review records for reportability.
- If cases are reportable, hospital registrar abstracts cancer case.
- Case is submitted electronically to NDSCR.
- A complete case finding audit report is written and mailed to the hospital cancer registry. This report includes findings and recommendations.

### **Case-finding Audits at NON-Registry Facilities**

The quality control staff of the NDSCR will complete a case-finding audit of reporting facilities in the state without cancer registries. NDSCR case-finding audits are done on a rotating basis. There will be two case-finding audits completed yearly by the NDSCR quality control staff. The hospitals chosen to be audited for completeness will be chosen on a rotating basis. Case-finding audits on non-registry facilities will be performed on a complete year's data of reportable ICD-9/ICD-10 codes.

### ***Flow Chart for Case-Finding Audits - Non-registry Facilities***

Eligible case identified at hospital in NDSCR: Yes = END

Eligible case identified at hospital in NDSCR: NO = Missed case

Procedure:

- Complete a listing of patients' from a previously requested Medical Record Disease Index (MRDI) of reportable cancer cases not in NDSCR database.
- After reviewing MRDI, mail a list of missing cancer cases to the hospital Health Information Department Director.
- Request copies of pertinent cancer information to be mailed to the quality control manager.
- Quality control manager abstracts the missing cancer case into the NDSCR database.
- A complete case-finding audit report including the findings and recommendations is written and mailed to the audited facility.

## **North Dakota Cancer Registry Case-finding Audit Guidelines For Hospitals to Resolve Unmatched Cases**

Following comparison of the Medical Record Disease Index (MRDI) against the central cancer registry's database, review of all highlighted cases are considered a non-match. Determination will then be made if the case should or should not have been abstracted and sent to the NDSCR. Indicate the outcome of each unmatched case on the list.

- 1) Diagnosed prior to 1997
- 2) Non-reportable (specify why not reportable)
- 3) Other (specify reasons)
- 4) Missed case
- 5) Matched case (Patient registered under another name)

**Note: If an unmatched case is matched in your system, re-send the case electronically to the NDSCR.**

### NDSCR Responsibilities

The NDSCR quality control staff will notify the facilities to be audited six weeks in advance of the planned audit date. Resolution of unmatched discrepancies will be completed within eight weeks or documentation of the reason the case was not abstracted or included in the NDSCR database of cancer cases made. Following the resolution of cases, the staff person performing the audit will write a final summary report containing the findings and recommendations. A copy of the report will be sent to the hospital cancer registry.

### FACILITY Responsibilities

Compile and send the requested MRDI of reportable malignant and non-malignant reportable ICD-9/ICD-10 codes for the months requested. Once the MRDI has been reviewed, the facility will make available the required/requested records for the dates noted or will make copies of the requested records and mail them to the NDSCR. The registry facility will provide a work area with desk space and the records necessary to complete the audit.

(NDSCR / UND letterhead)

Date

Hospital  
Address  
City, State, Zip Code

Dear Registrar:

The North Dakota Statewide Cancer Registry (NDSCR) will be conducting case-finding audits of North Dakota facilities who submit cancer cases to the state cancer registry. Facility case-finding audits are a requirement of CDC's National Program of Cancer Registries. Three case-finding audits will be performed this year. Facilities with cancer registries and facilities without cancer registries are chosen randomly. Your registry has been chosen to participate. We will be reviewing all (insert year) pathology laboratory reports, autopsy reports, medical record indices and radiation log books at your facility.

Quality control staff of the NDSCR will arrive at your facility at \_\_\_\_\_AM on \_\_\_\_\_. They will plan to meet with you upon their arrival to review procedures and learn where and when they will have access to records.

Thank you for your participation in our NDSCR case-finding audit.

Sincerely,

Mary Ann Sens, MD, PhD  
Chair, Department of Pathology  
UND School of Medicine & Health Sciences

Yun [Lucy] Zheng, MD, CTR  
Co-Program Director  
North Dakota Statewide Cancer Registry

Encl.



**Hospital Audited:**

**Date of Audit:**

**Audit Summary: Results Following Reconciliation of Data**

**Number of Cases Identified:**

Number of cases found in NDSCR database:

Number of identified unmatched cases at the hospital:

Total cases identified:

**Resolution of unmatched cases:**

A) Missed cases

Cases missing from the NDSCR

B) Resolved case

Cases abstracted and in NDSCR database

Case to be abstracted into NDSCR database

No abstract needed: Cases were diagnosed prior to  
NDSCR reference date 01/01/1997

Non-reportable diagnosis, recurrence

Resident of another state at diagnosis

C) Unresolved cases

**Total number of cases identified in the audit:**

Number missed + number matched + number unresolved

**Percent of cases missed: (not reported to NDSCR)**

$$100 \times \frac{\text{number missed} + \text{number unresolved}}{\text{Number identified}}$$

## **NORTH DAKOTA STATEWIDE CANCER REGISTRY GUIDELINES FOR CASE-FINDING REVIEW**

Review all admissions within the dates requested and the following reports and logs for the audit.

### Pathology Reports

Check numerical order for missing reports.  
Look for malignant disease diagnosis.  
Look for reports with residual disease.  
Watch for reports that mention “no residual disease”.  
Review all reports with orchiectomy as a surgical procedure.  
Watch for reports with terminology such as “re-excision” or “wide re-excision”.  
Check “comments” area of report.

### Autopsy Reports

Check numerical order for missing reports.  
Look for malignancy as cause of death.  
Review summary/history for mention of malignant disease.

### Radiation Logs

Report all patients with a malignancy noted in the log.  
Review all reports with a specific site recorded.  
Investigate records of patients treated for “pain control”.

## **8.2 Re-abstracting Audits**

A re-abstracting study is done to characterize the level of agreement between data already in the NDSCR and data re-abstracted and recoded from source records (the hospital medical record in most cases). For each case, codes are compared to determine if data items reported to the state registry are accurate.

NDSCR re-abstracting audits vary in size and content. Every five years different primary sites and data items are audited. The number of cases re-abstracted per registry also fluctuates depending on the focus of the study. Cases are identified from the re-abstracting audit through a process of the NDSCR computer program which randomly selects a percentage of cases for re-abstracting. Additional cases in an area of specific concern may be requested on an as needed basis.

Six weeks prior to the re-abstracting audit, a phone call plus a follow-up letter is sent to the head registrar of each registry facility. Instructions are given as to what procedures the hospital registry should follow. NDSCR will request that facilities make copies of records and that the copied records be mailed to the state central registry in one month's time.

Quality control staff re-abstracts data from the source record supplied by the registry hospital. The recoded data is then compared to the previously submitted cancer case. Discrepancies are noted. The facility that submitted the case is phoned and reconciliation of the case ensues. Quality control staff will work with the hospital registrar to resolve data items in question. All unresolved discrepancies following reconciliation of a cancer case is tracked. A report is prepared for each hospital registry on data quality/discrepancies. A re-abstracting audit report is also written describing all North Dakota hospital cancer registry discrepancy totals following reconciliation. The hospital report is confidential to the affected facility, but the overall report is shared with all registries. The overall report can be used as an education tool to help registries see where they fit in with other registries, identify common areas of difficulty or interpretation of coding rules when abstracting a cancer case. The process of re-abstracting audits can serve to increase the quality of data being collected.



(NDSCR / UND letterhead)

Date

Hospital  
Address  
City, State, Zip Code

Dear Registrar:

The North Dakota Statewide Cancer Registry (NDSCR) will be conducting a re-abstracting and recoding audit. Re-abstracting audits are a requirement of CDC's National Program of Cancer Registries.

A random sample of computer-selected cancer cases previously submitted to the NDSCR will be re-abstracted and recoded. The re-abstracting audit will focus on a random sample of site-specific cancer cases. Quality control staff will re-abstract specific predetermined data items.

A list of patient names will be mailed to your facility. NDSCR will request that facilities make copies of patient records and mail them to us at the NDSCR no later than one month from the date of this letter. Please provide a copy of the front face sheet, H&P, discharge summary, operative report, pathology report, laboratory reports and x-ray reports. Also include any other information in the chart that would seem necessary to accomplish re-abstracting and recoding of the patient record.

Once the audit is complete a report will be compiled and written with the results of the study. The NDSCR systems analyst also will prepare a statistical outcome report using data from findings of the re-abstracting audit. These reports will be mailed to you upon completion.

Thank you for your participation in the NDSCR re-abstracting and recoding audit.

Sincerely,

Mary Ann Sens, MD, PhD  
Chair, Department of Pathology  
UND School of Medicine & Health Sciences

Yun [Lucy] Zheng, MD, CTR  
Co-Program Director  
North Dakota Statewide Cancer Registry