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CANCER DATA REGISTRY OF IDAHO

IDAHO CANCER REPORTING STANDARDS

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Idaho Minimum Dataset
https://www.idcancer.org/ContentFiles/IdahoMinimumDataset2018.pdf

PURPOSE OF CANCER REGISTRY

Population-based cancer registries are essential for assessing the extent of cancer burden in a specified geographic area. The Cancer Data Registry of Idaho (CDRI) is a population-based cancer registry that collects incidence and survival data on all cancer patients who reside in the state of Idaho or who are diagnosed and/or treated for cancer in the state of Idaho. The goals of the CDRI are to:

- determine the incidence of cancer in the state of Idaho with respect to geographic, demographic, and social characteristics;
- monitor trends and patterns of cancer incidence over time;
- identify high risk populations;
- provide a database and serve as a resource in conducting epidemiologic studies;
- provide data to assist public health officials, hospital administrators, and physicians to effectively plan services, prioritize health resource allocations and develop and measure prevention and intervention strategies.

CDRI was established in 1969 and became population-based in 1971. The Idaho State Legislature has provided guidelines for the establishment, requirements, and funding of the statewide cancer registry. The operations of the registry are mandated by Idaho Code 57-1703 through 57-1707 and Idaho Administrative Code IDAPA 16.02.10 section 07. Funding is appropriated in Idaho Code 57-1701 and 63-2520, which delineates less than one percent of the cigarette tax to be dedicated to fund the statewide cancer registry. Additional funding has been awarded to CDRI from the Centers for Disease Control and Prevention (CDC) with a federal grant aimed at enhancing timely, complete and accurate data collection, computerization, and reporting of reliable data.

Each Idaho hospital, outpatient surgery center, and pathology laboratory is responsible for the complete ascertainment of all data on cancer diagnoses and treatments provided in its facility within six months of diagnosis. Sources for identifying eligible cases include: hospitals, outpatient surgery centers, private pathology laboratories, free-standing radiation centers, physicians (for patients not receiving cancer diagnoses and/or treatment in the above sources), death certificates, and other state cancer registries reporting an Idaho resident with cancer (as negotiated).

When a cancer case is reported from more than one source, the information is consolidated into one record.

REPORTABLE CASES

All cancer cases diagnosed or treated with cancer, in an in-patient or out-patient setting, must be reported to the Cancer Data Registry of Idaho (CDRI).

Inclusions

All in-situ or malignant neoplasms to include carcinoma, sarcoma, melanoma, lymphoma, and leukemia, diagnosed by histology, radiology, laboratory testing, clinical observation, autopsy, or suspicious by cytology are eligible for reporting to the cancer registry. Also reportable are benign and borderline tumors of the central nervous system (brain, meninges, cranial nerves, spinal cord), pineal gland, or pituitary gland. Hospital non-analytic cases are reportable to CDRI.

Intraepithelial neoplasia Grade 3 cases are reportable except for cervical intraepithelial neoplasia Grade 3 (CIN III)[1].

Patients who expire with a cancer related cause of death at your facility may be reportable even if no cancer diagnosis or treatment was administered within the facility. Registrars can call CDRI staff to determine if the expired patient has already been reported to determine if the case must be reported by the facility where the patient expired.

Exclusions

- neoplasms, malignant, NOS of the skin
- epithelial carcinomas of the skin
- New 2018 - basal or squamous cell carcinomas of the skin except when occurring on mucous membranes (Reportable Sites: C00.0 – C00.9, C21.0, C51.0 – C51.9, C52.9, C60.0 – C60.9, and C63.2)[2]
- cervix in-situ[1]

CASE ASCERTAINMENT

Sources to identify cases to report include:

- medical record disease index
- pathology laboratory (inpatient and outpatient)
- radiation treatment logs
- medical oncology logs
- surgery logs
- Imaging (in-patient and out-patient)

[1] In addition to cervix in-situ (CIN III) the Commission on Cancer does not require reporting of intraepithelial neoplasia, grade III, of the prostate (PIN III), vulva (VIN III), vagina (VAIN III), and anus (AIN III). Idaho Code and SEER only excludes cervix in-situ, leaving all other intraepithelial neoplasia's reportable.

[2] These cases are not required by the Commission on Cancer, NPCR, SEER, or Idaho Code, except for sites noted above.

REPORTABLE CASES

AMBIGUOUS TERMS

These terms DO constitute a cancer diagnosis:

Apparent(ly)
Appears to
Comparible with
Compatible with
Consistent with
Favor(s)
Malignant appearing
Most likely
Presumed
Probable
Suspect(ed)
Suspicious (for)
Typical of

Neoplasm
(only for C70.0 – C72.9, C75.1 – C75.3)
for non-malignant primary intracranial and central nervous system tumors only.

Tumor
(only for C70.0 – C72.9, C75.1 – C75.3)
for non-malignant primary intracranial and central nervous system tumors only.

Exception: If a cytology is reported as suspicious, 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.

These terms DO NOT constitute a cancer diagnosis:

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

REPORTABLE CASES

CASEFINDING LISTS

The Cancer Data Registry of Idaho (CDRI) utilizes the SEER – ICD-10-CM codes to create casefinding lists to identify reportable cases. For the most current ICD-10-CM codes for Reportable Neoplasms, please visit https://seer.cancer.gov/tools/casefinding/

The ICD-10-CM codes on the Supplemental List may be used to enhance casefinding for benign brain and CNS, hematopoietic neoplasms and other reportable diseases, but it is not required.

CANCER REPORTING LAWS

FEDERAL LAWS

HIPAA:

The Health Insurance Portability and Accountability act of 1996 (HIPAA) became law April 14, 2001 and most organizations have until April 14, 2003 to comply. Healthcare providers may have questions regarding how this new law impacts cancer reporting.

HIPAA regulations only minimally impact current state cancer reporting procedures. Specifically,

> **HIPAA allows for the reporting of identifiable cancer data to public health entities without a Business Associate Agreement. Because the Cancer Data Registry of Idaho (CDRI) falls under the definition of a public health entity, HIPAA allows your facility to continue to report data to us in compliance with state law. Written informed consent from cancer patients reported to public health entities is not required under HIPAA; rather hospitals and physicians must simply document that reporting has occurred.**

HIPAA privacy regulations indicate that protected health information shall not be disclosed without the written, informed consent of the individual. However, there are several exemptions to this rule to allow for disclosures. One of those exemptions are for public health purposes. The "public health" exemption states that a covered entity may disclose protected health information without specific, individual consent to a "public health authority that is authorized by law to collect and receive such information for the purpose of preventing and controlling disease, injury, or disability, including…reporting of disease… and the conduct of public health surveillance…".[1]

A public health authority is defined as 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…that is responsible for public health matters as part of its official mandate.[2]

Within this section is a copy of the Idaho Code and Idaho Rules and Regulations authorizing cancer as a reportable disease. The Idaho Hospital Association contracts with the Idaho Department of Health and Welfare to operate the statewide cancer registry under Contract No. HC282200 and, therefore, is considered a public health authority for purposes of statewide cancer reporting.

[1] 45 C.F.R. § 164.512(b)(1)(i)(2201).
[2] 45 C.F.R. § 164.501 (2001).

CANCER REPORTING LAWS

Public Law 102-515 - Cancer Registries Amendment Act

The National Program of Cancer Registries (NPCR) supports central, population-based cancer registries in 45 states, the District of Columbia, and 3 U.S. territories. Collectively, NPCR registries gather data on cancer cases occurring among 96% of the nation's population. The NPCR complements the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program; together, these programs collect cancer data for the entire U.S. population. The Cancer Registries Amendment Act authorized the Centers for Disease Control and Prevention (CDC) to establish and administer the NPCR. The Cancer Data Registry of Idaho receives partial funding from CDC under NPCR.

CANCER REPORTING LAWS

STATE LAWS

IDAHO CODE

57-1703. Cancer registry - Definitions.

(1) “Cancer” means all in-situ or malignant neoplasms diagnosed by histology, radiology, laboratory testing, clinical observation, autopsy or suggestible by cytology, but excluding basal cell and squamous cell carcinoma of the skin unless occurring on a mucous membrane and excluding in-situ neoplasms of the cervix.

(2) “Reportable benign tumors” means noncancerous neoplasms occurring in the brain, meninges, pineal gland or pituitary gland.

(3) “Confidential information” refers to information which may identify a cancer patient, health care facility or health care provider.

(4) “Contractor” means that individual, partnership, corporation or other entity performing cancer registry services under a contractual agreement with the department.

(5) “Department” means the Idaho Department of Health and Welfare.

(6) “Population-based” refers to all cancers and reportable benign tumors diagnosed and/or treated within the state of Idaho by hospitals or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer, and from physicians, surgeons, and all other health care providers diagnosing or providing treatment for cancer patients. (1999)

57-1704. Establishment of cancer registry.

(1) The department, or an authorized contractor of the department, shall maintain a uniform statewide population-based cancer registry system for the collection of data pertaining to the incidence, prevalence, management, survival, mortality, geographic distribution and risk factors associated with cancer and reportable benign tumors.

(2) All cancers and reportable benign tumors diagnosed or treated in the state shall be reported to the department or the authorized contractor of the department.

(3) Data reported to the cancer registry shall be available for use in aggregate form for analysis, bench marking, and reports of Idaho’s cancer incidence, prevalence, management, survival, mortality, health status, geographic distribution, and risk factors in comparison to the nation. (1995)

57-1705. Participation in program.

(1) Primary reporting:

(a) Any hospital, outpatient surgery center, radiation treatment center, or treatment clinic diagnosing and/or treating a patient with cancer or a reportable benign tumor, on an inpatient or outpatient basis, shall report each case of cancer or a reportable benign tumor to the department or the authorized contractor of the department within one hundred and eighty (180) days of diagnosis.

(b) Independent pathology and cytology laboratories shall report each diagnosis of cancer or a reportable benign tumor to the department or the authorized contractor within one hundred and eighty (180) days of specimen analysis.

(2) Secondary reporting: In the event that a case of cancer or reportable benign tumor was not diagnosed or treated within a hospital, outpatient surgery center, radiation treatment center, or treatment clinic, the department or authorized contractor may request the case to be reported by a physician's office.

(3) Each report of cancer or reportable benign tumor shall include information as defined by the department or the authorized contractor.

(4) The department or authorized contractor of the department shall have physical access to all records which would identify reportable cases and/or establish characteristics, treatment or medical status of reportable cases in the event that there has been a failure to report as delineated in subsections (1), (2), and (3) of this section or for the purposes of subsequent quality control studies and research projects conducted by the department or authorized contractor.

(5) Nothing in this chapter shall prevent the department or authorized contractor from identifying and reporting cases using data linkages with death records, statewide cancer registries, and other potential sources. (1995)

57-1706. Confidentiality.

(1) The department and authorized contractor will take measures to ensure that all identifying information is kept confidential.

(2) The department and authorized contractor may enter into agreements to exchange confidential information with other states' cancer registries in order to obtain complete reports of Idaho residents diagnosed or treated in other states and to provide information to other states regarding their residents diagnosed or treated in Idaho.

(3) The department and authorized contractor may furnish confidential information to other cancer registries, federal cancer control programs, or health researchers in order to collaborate research studies. Disclosure of confidential information for research purposes must comply with policies and protocols of the department and/or authorized contractor of the department. (1995)

57-1707. Liability.

(1) No action for damages arising from the disclosure of confidential or privileged information may be maintained against any reporting entities or employees of such entities that participate in good faith in the reporting of cancer registry data in accordance with this chapter.

(2) No license of a health care facility or health care provider may be denied, suspended, or revoked for the good faith disclosure of confidential or privileged information in accordance with this chapter.

(3) The immunity granted is subsections (1) and (2) of this section shall not be construed to apply to the unauthorized disclosure of confidential or privileged information when such disclosure is due to gross negligence or willful misconduct of the reporting entities. (1995)

IDAHO ADMINISTRATIVE CODE IDAPA 16.02.10
Health & Welfare, Division of Health Idaho Reportable Diseases

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07. Cancer. (11-17-83)
a. The following neoplasms are designated as reportable to the cancer data registry of Idaho within one hundred and eighty (180) days of diagnosis or recurrence: (4-5-00)

i. Each in-situ or malignant neoplasm diagnosed by histology, radiology, laboratory testing, clinical observation, autopsy, or suggested by cytology, but excluding basal cell and squamous cell carcinoma of the skin unless occurring on a mucous membrane and excluding in-situ neoplasms of the cervix is reportable. (4-5-00)

ii. Benign neoplasms are reportable if occurring in the brain, meninges, pineal gland, or pituitary gland. (9-21-92)

b. The use of the words “apparently,” “compatible with,” “consistent with,” “favor,” “most likely,” “presumed,” “probable,” “suspected,” “suspicious,” or “typical” is sufficient to make a case reportable. (9-21-92)

c. The use of the words “questionable,” “possible,” “suggests,” “equivocal,” “approaching,” and “rule out” is not sufficient to make a case reportable. (9-21-92)

d. Each case must be reported by patient's name, demographic information, date of diagnosis, primary site, metastatic sites, histology, stage of disease, initial treatments, subsequent treatment, and survival time. (9-21-92)

e. Every private, federal, or military hospital, pathology laboratory, or physician providing a diagnosis and/or treatment related to a reportable cancer is responsible for reporting or furnishing cancer-related data, including annual follow-up, to the cancer data registry. (7-1-02)

f. All data reported to the cancer data registry shall be available for use in aggregate form for epidemiologic analysis of the incidence, prevalence, survival, and risk factors associated with Idaho’s cancer experience. Disclosure of confidential information for research projects must comply with the cancer data registry’s confidentiality policies, as well as the Idaho Department of Health and Welfare's Rules, IDAPA 16.05.01, “Rules Governing the Protection and Disclosure of Department Records”. (9-21-92)

CANCER REPORTING LAWS

16.02.10 – Idaho Reportable Diseases:
https://adminrules.idaho.gov/rules/2009/16/0210.pdf

IDAPA 16
TITLE 02
CHAPTER 10

16.02.10 - IDAHO REPORTABLE DISEASES

170. CANCER.

01. Reporting Requirements. Cancer is to be reported within one hundred and eighty (180) days of its diagnosis or recurrence to the Cancer Data Registry of Idaho (CDRI). (4-2-08)

02. Handling of Report. All data reported to the CDRI is available for use in aggregate form for epidemiologic analysis of the incidence, prevalence, survival, and risk factors associated with Idaho's cancer experience. Disclosure of confidential information for research projects must comply with the CDRI's confidentiality policies as well as IDAPA 16.05.01, "Use and Disclosure of Department Records." (4-2-08)

03. Cancers Designated as Reportable. Cancers that are designated reportable to the CDRI include the following as described in Section 57-1703, Idaho Code. (4-2-08)

a. Each in-situ or malignant neoplasm diagnosed by histology, radiology, laboratory testing, clinical observation, autopsy, or suggested by cytology is reportable, excluding basal cell and squamous cell carcinoma of the skin unless occurring on a mucous membrane and excluding in-situ neoplasms of the cervix. (4-2-08)

b. Benign neoplasms are reportable if occurring in the central nervous system including the brain, meninges, pineal gland, or pituitary gland. (4-2-08)

c. The use of the words "apparently," "appears to," "comparable with," "compatible with," "consistent with," "favor," "malignant appearing," "most likely," "presumed," "probable," "suspected," "suspicious," or "typical" is sufficient to make a case reportable. (4-2-08)

d. The use of the words "questionable," "possible," "suggests," "equivocal," "approaching," "rule out," "potentially malignant," or "worrisome," is not sufficient to make a case reportable. (4-2-08)

04 Report Content. Each reported case must include the patient's name, demographic information, date of diagnosis, primary site, metastatic sites, histology, stage of disease, initial treatments, subsequent treatment, and survival time. Reporting of cases must adhere to cancer reporting standards as provided in "Standards for Cancer Registries, Vol. II." as incorporated by reference in Section 004 of these rules. (4-2-08)

05. Reported By Whom. Every private, federal, or military hospital, out-patient surgery center, radiation treatment center, pathology laboratory, or physician providing a diagnosis or treatment related to a reportable cancer is responsible for reporting or furnishing cancer-related data, including annual follow-up, to CDRI. (4-2-08)

022. PENALTY PROVISIONS.

These rules may be enforced under the civil and criminal penalties described in Sections 39-108, 39-109, 39-607, 39-1006, 39-1606, and 56-1008, Idaho Code, and other applicable statutes and rules. Penalties may include fines and imprisonment as specified in Idaho Code. (4-2-08)

STANDARD SITE ANALYSIS CATEGORIES

Many data items in a cancer registry are collected using code categories more numerous than are desirable or practical for analysis. Primary site, histologic type, age, race and ethnicity, and extent of disease are all examples. To facilitate interpretation of data and comparisons across registries, the registry should use standardized groupings of these detailed codes into a smaller number of analysis categories.

While conventional standards do exist, the choice of methods depends on many factors, including the number of cases available for study, the availability of comparison data, and the needs of the investigator.

The selection of standard categories for analysis and presentation may depend on the choice and/or availability of comparison data. For example, central cancer registries that want to compare their incidence data with those of the SEER Program will need to conform to the methods by which SEER data were derived. Some investigators may need to develop special categories of data that are not routinely published. For example, the incidence rates for specific histologic types of cancer are not always published in routine reports, and investigators may have difficulty obtaining comparison data on them. Nonetheless, the cancer registry should be flexible enough to accommodate these investigators on an ad hoc basis[1].

To view site categories which are routinely used by the Cancer Data Registry of Idaho as well as the SEER Program for analysis go to:
http://seer.cancer.gov/siterecode/icdo3_d01272003/

[1]Standards for Cancer Registries, Volume III, "Standards for Completeness, Quality, Analysis, and Management of Data". North American Association of Central Cancer Registries.

REPORTING OPTIONS

These reporting options are available to Idaho hospitals, out-patient surgery centers, radiation treatment centers, and treatment clinics diagnosing and/or treating cancer patients on an inpatient or outpatient basis.

Option 1: FACILITIES WITH 150 OR MORE REPORTABLE CASES PER YEAR:

- Facilities with high annual caseloads must employ a qualified cancer registrar, preferably a certified tumor registrar (CTR) or eligible. If the cancer registrar becomes delinquent in reporting, Cancer Data Registry of Idaho (CDRI) staff persons are available to assist the facility with abstracting. This service can be used one time per year for up to one-week duration as this service is meant only to assist with backlog. Fees for this service are charged by the hour depending on the staffing needs plus travel expenses. There are also outsourcing companies which will abstract and report your cases to meet the state's reporting requirements. The charge for this type of service varies depending on the outsourcing company.

Option 2: FACILITIES WITH <150 REPORTABLE CASES PER YEAR:

A. Designate a staff person to report eligible cancer cases: This person would be required to meet established standards for submitting complete, timely and accurate data electronically to CDRI in the required format. This person should have a background that includes, at a minimum, anatomy and physiology and medical terminology, a Certified Tumor Registrar (CTR) is preferred.

B. Utilize CDRI Staff: CDRI staff will abstract and electronically report your facility's reportable cancer cases in a complete, timely, and accurate manner. Fees for this service are $23.00 per abstracted case. *Note: Facilities utilizing this option will be required to provide an annual ICD-10-CM reportable cancer case list (ICD-10 codes will be provided by CDRI) and secure remote access to the EHR for cancer cases reporting.*

C. Hire a third-party vendor: There are outsourcing companies which will abstract and electronically report your cases to meet the state's reporting requirements. The fees for this type of service vary.

Option 3: FACILITIES WITH 15 OR FEWER REPORTABLE CASES PER YEAR:

Secure Remote Access: Hospitals with 15 or fewer reportable cases per year will provide an annual ICD-10-CM reportable cancer list (ICD-10 codes will be provided by CDRI) and secure remote access to your hospital's EHR for cancer case reporting by CDRI staff. Hospitals are required to meet the timeliness and completeness of case finding standards. *Note: Hospitals who exceed the allowable case limit for Option 3 for three consecutive years will automatically be moved to Option 2 and a Letter of Agreement (below) will be initiated.*

CONSULTATION and EDUCATION AVAILABLE:

Staff from CDRI are available for consultation and training. In addition, CDRI provides periodic cancer registry workshops to continually provide education on reporting standards, coding, staging, and general registry operations

REPORTING OPTIONS

LETTER OF AGREEMENT BETWEEN

THE CANCER DATA REGISTRY OF IDAHO (CDRI)
and
Hospital Name

This agreement is entered into on this _____ day of _____ 20xx by the Cancer Data Registry of Idaho (CDRI) and (Hospital Name). This agreement will begin with cancer cases diagnosed and/or treated during (Year) and reported/invoiced during (Year). (Hospital Name) has chosen to comply with Idaho Code §57-1701 through 1709 using the following method:

Please check the appropriate option:

A. _____ Hire an in-house abstractor (Certified Tumor Registrar (CTR) preferred).

B. _____ Utilize cancer case reporting provided by CDRI and pay for expenses ($23.00 per abstracted case).

C. _____ Hire an outside abstracting consultant of hospital's choice.

Reportable cases constitute any inpatient and/or outpatient admissions where cancer or benign tumors of the central nervous system are diagnosed and/or treated.

Signature and approval

Hospital Name

by:_____ _____
Authorized Representative date

Cancer Data Registry of Idaho

by:_____ _____
Denise M Jozwik, RHIT, CTR date
Director of Data Quality

DATA TRANSMISSION PROCEDURES

FILE TRANSMISSION CRITERIA

Data shall be transmitted using the NAACCR record layout version that is year-appropriate http://www.naaccr.org/StandardsandRegistryOperations/VolumeI.aspx.
Prior to submission the data should be error free using the Edit metafile provided by CDRI (NAACCR edit metafile modified to include Idaho-specific errors). Transmissions from Idaho sources must include the "full case record" containing 24,194 characters in length (22,824 characters in length for v16 and earlier cases). Cases reported through a National Interstate Data Exchange Agreement should be submitted in the "full case record", but a "confidential record" containing 6,934 characters in length (5,564 for NAACCR v16) will be accepted ONLY if text is not available[1]. Pathology data electronically transmitted shall be in the appropriate NAACCR layout according to "NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting"
http://www.naaccr.org/StandardsandRegistryOperations/VolumeV.aspx.

ALLOWABLE DATA TRANSMISSION METHODS TO CDRI

- Use the CDRI document server which includes dual firewall DMZ application server security that requires the application server to obtain valid network and database user authentication. Web traffic is secured with sha 256 bit encryption provided via SSL technology. Full audit trail tracking including user information linkage and date/time stamps for record creation and record modification are utilized.
- Web Plus - a web based software that is part of CDC-NPCR's Registry Plus Suite that contains an option for secure file transfer.
- N-IDEAS - a product that was developed for CDC-NPCR that allows for sending and receiving secure interstate data exchange files.
- PHIN-MS - a secure messaging system for public health usage, which uses the ebXML (electronic business XML) standard and certificate-based encryption for electronic pathology reports.
- Contact CDRI staff for set-up and/or questions regarding any of the transmission methods listed above.

[1]The North American Association of Central Cancer Registries (NAACCR) record layout Version 15 (or later) has been adopted by CDRI. There are three basic types of exchange using the NAACCR standard: incidence records (non-confidential data containing 3,339 characters), confidential records (includes confidential data items containing 5,564 characters), and full case abstracts (includes codes and text containing 22,824 characters).

DATA TRANSMISSION

DATA SUBMISSION SCHEDULES

In order to ensure timely reporting and processing, data report sources use the following data submission schedule for:

New Cases Schedule

	Transmissions sent to CDRI
Idaho report sources	Send to CDRI by 5th of each month
Inter-state exchange	Annual or bi-annual

Follow-up Schedule

	Transmissions sent to CRS
Idaho report sources	Send to CDRI Annually (Oct)

REFERENCE MATERIALS NEEDED TO REPORT CANCER

Use Links Below to Access Current Products

Standards for Oncology Registry Entry (STORE) (Commission on Cancer)
https://www.facs.org/~/media/files/quality%20programs/cancer/ncdb/store_manual_2018.ashx
- Revised for 2018

Surveillance, Epidemiology and End Results (SEER) Products
- ✓ SEER Summary Staging Manual 2018
- ✓ http://seer.cancer.gov/tools/ssm/
- ✓ Solid Tumor Rules (NCI-SEER)
  https://seer.cancer.gov/tools/solidtumor/
- ✓ SEER*Rx Interactive Antineoplastic Drug Database
  http://seer.cancer.gov/tools/seerrx/index.html
- ✓ SEER Hematopoietic & Lymphoid Neoplasm Database
  http://seer.cancer.gov/tools/heme/index.html
- ✓ SEER Website – Cancer Registrar Training
  http://seer.cancer.gov/training/index.html
- ✓ Site Specific Data Items (SSDIs) (Site specific SSDIs can be accessed through EOD)
  https://staging.seer.cancer.gov/eod_public/home/1.0/
- ✓ Extent of Disease 2018 (EOD)
  https://staging.seer.cancer.gov/eod_public/home/1.0/

International Classification of Diseases for Oncology Version 3 ICDO-3 (World Health Organization)
http://codes.iarc.fr/
http://seer.cancer.gov/icd-o-3/index.html
• Errata's and SEER Site/Histology Validation List

AJCC Cancer Staging Manual, 8th Edition
http://www.cancerstaging.org
• Revised for 2018

Cancer Program and Data Standards (ACoS Facilities)
http://www.facs.org/cancer/coc/programstandards.html

NAACCR Version 18 Standards and Data Dictionary (Vol. II)
http://www.naaccr.org/StandardsandRegistryOperations/VolumeII.aspx
• Effective 01/01/2018
• Revised 10/2014 and 02/2015

Compliant Cancer Reporting Software

Idaho Cancer Reporting Standards – Revised April 2018
Cancer Data Registry of Idaho (CDRI)
P.O. Box 1278
Boise, ID 83701
208-338-5100

Idaho State-Required Clinical Trial Variables
Introductory Language

Beginning with cases diagnosed in 2015, CDRI is requiring the collection of information about clinical trial enrollment. For treatment-related clinical trials, the primary interest is on first course of treatment for analytic cases. Collect information as available for non-analytic cases and subsequent treatments. For treatment trials, the accrual date should reflect the date that treatment started rather than the date the patient consented. If a patient consents to a study, but then declines participation for any reason before treatment starts, enter 0 – "No, patient was not enrolled in a clinical trial." The clinical trial accrual date will be used in conjunction with other treatment dates in order to be able to differentiate between first course therapy and subsequent treatments. CDRI realizes we will need to process update records from hospitals to obtain information added after the initial data submission. If a patient enrolls in more than one treatment-related clinical trial, record values for only the first trial in which treatment started. For other types of clinical trials (prevention, supportive care, biorepository, etc.), the accrual date should reflect the date that the patient consented to participate.

Idaho State-Required Clinical Trial Variables

Variable 1 - Clinical Trial Enrollment

"Was the patient enrolled in a clinical trial?"

0 No, patient was not enrolled in a clinical trial
1 Enrolled in treatment-related clinical trial at this facility
2 Enrolled in other type of clinical trial (prevention, supportive care, biorepository, etc.) at this facility
3 Enrolled in treatment-related clinical trial outside this facility
4 Enrolled in other type of clinical trial outside this facility
8 Patient enrolled in a clinical trial, but the type of trial is unknown
9 Unknown – It is unknown if patient enrolled in a clinical trial

Columns in NAACCR V15 layout: 2700-2700

Variable 2 – Clinical Trial Accrual Date

If 1-8 selected above, enter the date that the patient began the clinical trial. Use YYYYMMDD format.

Columns in NAACCR V15 layout: 2701-2708

Variable 3 – Clinical Trial Text

If 1-8 selected above, enter the Protocol ID and any additional information known such as sponsor, phase, or protocol arm. If patient enrolled in more than one clinical trial, use this space for additional details.

Columns in NAACCR V15 layout: 2711-2960

Coding Instructions for "Forever 7" Variables

Data Collection started with January 1, 2011 cases and is required on all analytical cases going forward.

I. HEIGHT
   a. Record in inches (2 digits) round to nearest whole number
   b. 98 for 98 inches or greater
   c. 99 Unknown
   d. Online height conversion calculator http://manuelsweb.com/in_cm.htm
   e. Height should be taken from the Nursing interview guide, flow chart, or vital stats section of the medical record.
   f. Height entered should be that listed at or around the time of diagnosis. If no height listed on data of diagnosis, use height recorded on the date closest to the date of diagnosis before treatment was started.

*Note: When coding cases that include chemotherapy or other drugs, please exhaust all potential sources for height before using code 99 (unknown). Blanks are not permitted and code 99 should be used to reflect unknown height. The volume of cases coded to 99 will be used by the CDC to help determine the availability of information related to height in the medical record.

II. WEIGHT
   a. Record in pounds (3 digits) round to nearest whole number, less than 100 precede with zero.
   b. 999 Unknown
   c. Online weight conversion calculator http://manuelsweb.com/kg_lbs.htm
   d. Weight should be taken from nursing interview guide, flow chart, or vital stats section from the medical record.
   e. Weight entered should be that listed on the date of diagnosis. If no weight was listed on the date of diagnosis, use weight recorded on the date closest to the date of diagnosis and before treatment was started.

*Note: When coding cases that include chemotherapy or other drugs, please exhaust all potential sources for weight before using code 999 (unknown). Blanks are not permitted and code 999 should be used to reflect unknown weight. The volume of cases coded to 999 will be used by the CDC to help determine the availability of information related to weight in the medical record.

III. TOBACCO USE (4 of the Forever 7 variables are for Tobacco Use)

a. Cigarette
b. Smoking products other than cigarettes (pipes, cigars, kreteks, etc.)
c. Smokeless tobacco (chewing tobacco, snuff, etc.)
d. Tobacco NOS
    i. Codes used
        1. 0 Never
        2. 1 Current user (i.e. current user as of date of diagnosis)
        3. 2 Former user, quit w/I 1 yr. of date of diagnosis
        4. 3 Former user, quit more than 1 yr. prior to date of diagnosis
        5. 4 Former user, unknown when quit
        6. 9 Unknown/not stated/no smoking specifics provided
e. Tobacco use should be recorded from nursing interview guide, flow chart, vital stats or nursing assessment section of the medical record.
f. If medical record only indicates “no” use code 9 rather than never used, if medical record indicates “none” code 0 never used.

*Note: Blanks are not permitted and code 9 should only be used to reflect unknown tobacco use. The volume of cases coded to 9 will be used by the CDC to help determine the availability of information related to tobacco use in the medical record

IV. COMORBIDITY SOURCE - Record the data source from which comorbidities/complications were collected.

a. Use codes:
    i. 0 No comorbid condition or complication identified/not applicable
    ii. 1 Collected from facility face sheet
    iii. 2 Linkage to facility/hospital discharge data set
    iv. 3 Linkage to Medicare/Medicaid data set
    v. 4 Linkage with another claims data set
    vi. 5 Combination of two or more sources above
    vii. 9 Other source

CDRI DATA DICTIONARY OVERVIEW

Based on Version 18 of NAACCR Record Layout

DEFINED VALUES

Defined values for items listed in this dictionary can be found in the following resources:

- North American Association of Central Cancer Registries (NAACCR), Standards for Cancer Registries Volume 2, Data Standards and Data Dictionary. To find this document please visit the NAACCR website at: http://www.naaccr.org/StandardsandRegistryOperations/VolumeII.aspx

- American College of Surgeons Commission on Cancer (CoC) "Facility Oncology Registry Data Standards (FORDS) (Commission on Cancer)". To find this document please visit the CoC website at: http://www.facs.org/cancer/coc/fordsmanual.html.

STANDARDS

CDRI	Cancer Data Registry of Idaho
COC	American College of Surgeon's "Commission on Cancer"
SEER	National Cancer Institute's "Surveillance, Epidemiology, and End Results" Program
NPCR	"National Program of Cancer Registries" operated by CDC
NAACCR	North American Association of Central Cancer Registries
AJCC	American Joint Committee on Cancer
ICD-O-3	International Classification Diseases for Oncology, 3rd edition
CMS	Centers for Medicare & Medicaid Services
HL7	Health Level 7
CENSUS	
CER	NPCR/CDC Special Project
PCOR	NPCR/CDC Special Project

CDRI DATA DICTIONARY OVERVIEW

ABSTRACTING

Facilities that do not have a CoC-approved cancer program use abstracting screens containing all variables marked (R) in the CDRI column ONLY.

Facilities that do have a CoC-approved cancer program use abstracting screens containing all variables marked in the CDRI column AND all variables marked in the CoC column *(Note: There maybe additional variables required ONLY by the CoC that are not listed in CDRI's Data Dictionary)*

(R) – Required Data Items
These data items must be abstracted using the standard codes and reported to CDRI as part of the minimum data set for Idaho.

DATA EXCHANGE

Source: Standards for Cancer Registries, Volume I "Data Exchange Standards and Record Descriptions" Version 18 March 2018.
http://www.naaccr.org/StandardsandRegistryOperations/VolumeI.aspx

PURPOSE AND USE OF DATA EXCHANGE LAYOUTS

The NAACCR data exchange record layouts were designed to facilitate electronic transmission of cancer registry data among registries for multiple purposes. The layouts can be used to provide standardized data from reporting sources to central registries; to share tumor reports on residents of other states/provinces from one central registry to another; or to report data from diverse facilities or states/provinces contributing to a combined study. The NAACCR data set is comprised of all data items recommended for use by the major cancer registry standard-setting organizations. For some types of data, more than one coding system is provided in the layout. For example, information on stage of the tumor at diagnosis is represented by many items comprising TNM, SEER EOD, Summary Stage, and Collaborative Stage. Any single registry is unlikely to collect all of the items in the layouts. It is hoped that all items collected by an individual registry can be accommodated in the NAACCR layouts and thus shared in a common data format with other registries.

The layouts were intended to provide a common language for cancer registry systems. It was not NAACCR's intent to require that systems would use the NAACCR data item names and layouts internally. However, it has proven convenient for some systems to do so. The standard has been widely accepted both for data exchange and local use.

CDRI DATA DICTIONARY OVERVIEW

RECORD LAYOUT DESIGN DECISIONS

The simplest method for encompassing the Incidence, Confidential and Full Case Abstract record types was chosen: each longer record type builds on the next shorter record type by adding fields. The incidence-only records use only the first section of the overall layout, while the case abstract records use the full layout. Thus shorter, efficient records can be used for the smaller data set without requiring separate formats.

In selecting data items, it was decided to include more rather than less. All data items that currently are standardized by NAACCR, SEER, or the Commission on Cancer have been included. Additional items were added that are currently used by several systems and which probably could become standardized. Other fields were added to help coordinate the data exchange. Data items that were used in the past are usually maintained in the record so that historically collected information can still be exchanged.

Data Exchange Records

- **Incidence Record (record type I)** These records include all the coded fields for each case, including demographic, tumor, staging, treatment, and follow-up fields. The primary use of the incidence record is to transmit data for multi-registry research projects or surveillance. See Appendix C for the Incidence Record layout (columns 1-4048).

- **Confidential Record (record type C)** These records include all the data items in the incidence record, plus items such as patient name and Social Security Number that identify the case. Also included are quasi-confidential data items such as referring hospital or primary physician, items, which some agencies are required to keep confidential.
  This record type can be used to exchange cases between registries, whether central-based or hospital-based. See Appendix C for the Confidential Record layout (columns 1-6154).

- **Full Case Abstract (record type A)** These records contain all fields noted above, plus the supportive text required for the transmission of full case abstracts. The full case abstract allows the receiving registry to perform a higher degree of quality control with each case report. See Appendix C for the Full Case Abstract Record layout (columns 1-24194).

Pathology Laboratory Record (record type L)

The Pathology Laboratory record is designed for electronic transmission of reports from pathology laboratories to central registries. Health Level 7 (HL7) or a character delimited flat file is recommended as the data format for transmitting pathology laboratory reports. A standard pathology laboratory dataset, data dictionary, and HL7 transmission format and flat file were developed to enhance the completeness, timeliness, consistency, and efficiency with which tumor data are transmitted by pathology laboratories and received and processed by central cancer registries (see Standards for Cancer Registries, Volume V).

Update/Correction (record type U) and Modified Records (record type M)

Two record layout types, an update/correction record and a modified record, provide data layouts to transmit changes or revisions to data that have already been sent to a receiving registry.

The Update/ Correction, record type U, which has its own record version data items (see section 2.3.1), is a short format record that can be used to transmit individual, field specific corrections to data already submitted. The record length is 1543 bytes. This record type is for use by those registries and software providers that do not already have a well-functioning corrections system, or who wish to use a standardized format. In this volume, version 18 of the update/correction record is documented. Version 18 of the “U” record can be used only to update data that are already coded according to the standards documented in version 18 of the NAACCR data exchange record types I, C, and A. See Appendix D for the Update/Correction Record layout.

The Modified Record, record type M, is the same length (24194 characters) and contains the same fields, in the same locations, as the Full Case Abstract, record type A. A Modified Record represents an alternative way for submitting changed information to a receiving registry, on tumor records that have already been submitted. It is designed for transmitting an entire tumor record in which one or more modifications, updates, or corrections have been made since the last time the tumor record was submitted to the receiving registry. Like record type ‘U’, the ‘M’ record may be used to transmit corrections or follow-up.

Like the “U” record, a version 18 “M” record can be used only to update data already coded according to the standards documented in version 18 of the NAACCR data exchange record. This is because the definitions, data length, and code meanings for certain variables changed between version 18 and previous versions.

Virtual Pool Registry (record type V)

These records include the confidential record with a subset of data items necessary to perform linkages. This code is reserved for future use by the Virtual Pooled Registry.

SUMMARY OF NAACCR DATA EXCHANGE RECORD TYPES

Record Type is a generated field that identifies which of the six NAACCR data exchange record types is being used in a file of data exchange records. Since Record Type R (Analysis/Research Record) is not used it has been removed from Standards Volume I Version 12.1. Data dictionary descriptions for record types I, C, A, and M (data item numbers 10 – 7600) can be found in the NAACCR Standards for Cancer Registries Volume II: *Data Standards and Data Dictionary*. The record layout for these record types can be found in Appendix C of this document. Record Type V was added in Standards Volume I Version 18.

RECORD TYPE I: INCIDENCE RECORD (coded data without direct personal identifiers)

Contents: Demographic, Tumor and Staging, Treatment, and Follow-up (Optional)
Use: Combined studies
Length: 4048 characters

RECORD TYPE C: CONFIDENTIAL RECORD (incidence record plus personal identifiers)
Contents: Demographic, Tumor and Staging, Treatment, Follow-up, and Pathology, plus Patient Identifiers and Physicians
Use: Case sharing between central registries
Length: 6154 characters

RECORD TYPE A: FULL CASE ABSTRACT (confidential record plus text; used for reporting to central registry)
Contents: Demographic, Tumor and Staging, Treatment, Follow-up, and Pathology, Patient Identifiers & Physicians, plus Text
Use: Sending abstracts between registries
Length: 24194 characters

RECORD TYPE L: PATHOLOGY LABORATORY
Contents: Demographic, Tumor, and partial Staging (content varies dependent on availability at pathology laboratories and agreement between pathology laboratory and central registry)
Use: Electronic transmission of tumor reports from pathology laboratories to central registries
Length: No standard length

RECORD TYPE U: UPDATE/CORRECTION RECORD (short format record used to submit changes to data already submitted)
Contents: Sender ID Section, Record ID Section, Correction Section
Use: Transmitting changes for previously submitted cases
Length: 1543 characters

RECORD TYPE M: RECORD MODIFIED SINCE PREVIOUS SUBMISSION TO CENTRAL REGISTRY (identical in format to the A record type; used to submit changes to data already submitted)
Contents: Demographic, Tumor and Staging, Treatment, and Follow-up, Patient Identifiers and Physicians, plus Text
Use: Transmitting changes for previously submitted cases
Length: 24194 characters

RECORD TYPE V: VIRTUAL POOLED REGISTRY (confidential record with a subset of data items necessary to perform linkages)
Note: This code is reserved for future use by the Virtual Pooled Registry.
Contents: Demographic, Tumor and Staging, Treatment, Follow-up, and Pathology, plus Patient Identifiers and Physicians
Use: Performing linkages
Length: 6154 characters

RECORD TYPES FOR SUBMISSION OF CORRECTED, UPDATED, OR MODIFIED DATA

Two record types, an update/correction record and a modified record, provide data layouts to transmit changes or revisions to records that have already been sent to a receiving registry. Two methods exist because of parallel development that occurred in the registry community. Both methods work. Some central registries require changes to be submitted using the “U” record type; other central registries require changes to be submitted using the “M” record type

APPENDIX A

COUNTY FIPS CODES FOR STATE OF IDAHO

For Coding County at Time of Diagnosis

Ada	001	Gem	045
Adams	003	Gooding	047
Bannock	005	Idaho	049
Bear Lake	007	Jefferson	051
Benewah	009	Jerome	053
Bingham	011	Kootenai	055
Blaine	013	Latah	057
Boise	015	Lemhi	059
Bonner	017	Lewis	061
Bonneville	019	Lincoln	063
Boundary	021	Madison	065
Butte	023	Minidoka	067
Camas	025	Nez Perce	069
Canyon	027	Oneida	071
Caribou	029	Owyhee	073
Cassia	031	Payette	075
Clark	033	Power	077
Clearwater	035	Shoshone	079
Custer	037	Teton	081
Elmore	039	Twin Falls	083
Franklin	041	Valley	085
Fremont	043	Washington	087

998 = Patient resides outside of the state of the reporting institution.

999 = Unknown county/country