CANCER REGISTRY REPORTING MANUAL

Standards, Guidelines and Procedures

Prepared by:
Cancer Data Registry of Idaho

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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;
- maintain a database that serves 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. CDRI also receives funding through a cooperative agreement from the National Program of Central Registries at the Centers for Disease Control and Prevention (CDC) and a contract from the National Cancer Institute to participate in the Surveillance, Epidemiology, and End-Results (SEER) Program. These funds support CDRI to maintain timely, complete and accurate cancer data for the purposes outlined above.

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 (and other non-epithelial malignancies of the skin), lymphoma, and leukemia, diagnosed by histology, imaging, laboratory testing, clinical observation, autopsy, or suspicious by cytology are required to be reported to CDRI. Also reportable are benign and borderline tumors of the central nervous system (brain, spinal cord, meninges) and intracranial structures (cranial nerves, pineal gland, pituitary gland).

Hospital non-analytic cases are reportable to CDRI. Cases are reportable when a facility diagnoses (including a positive staging work-up) or treats (e.g., surgery, radiation, systemic therapy, or *active surveillance*) a cancer patient with active disease – either for the initial diagnosis or for diagnosis or treatment of recurrence. Reportability is a separate issue from class of case. Class of case is a variable that describes the patient's diagnosis/treatment relationship to the reporting facility and primarily is used by the American College of Surgeons Commission on Cancer to determine whether a case is included in the National Cancer Database (NCDB). *Class of case has no bearing on whether a case is reportable to CDRI.*

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

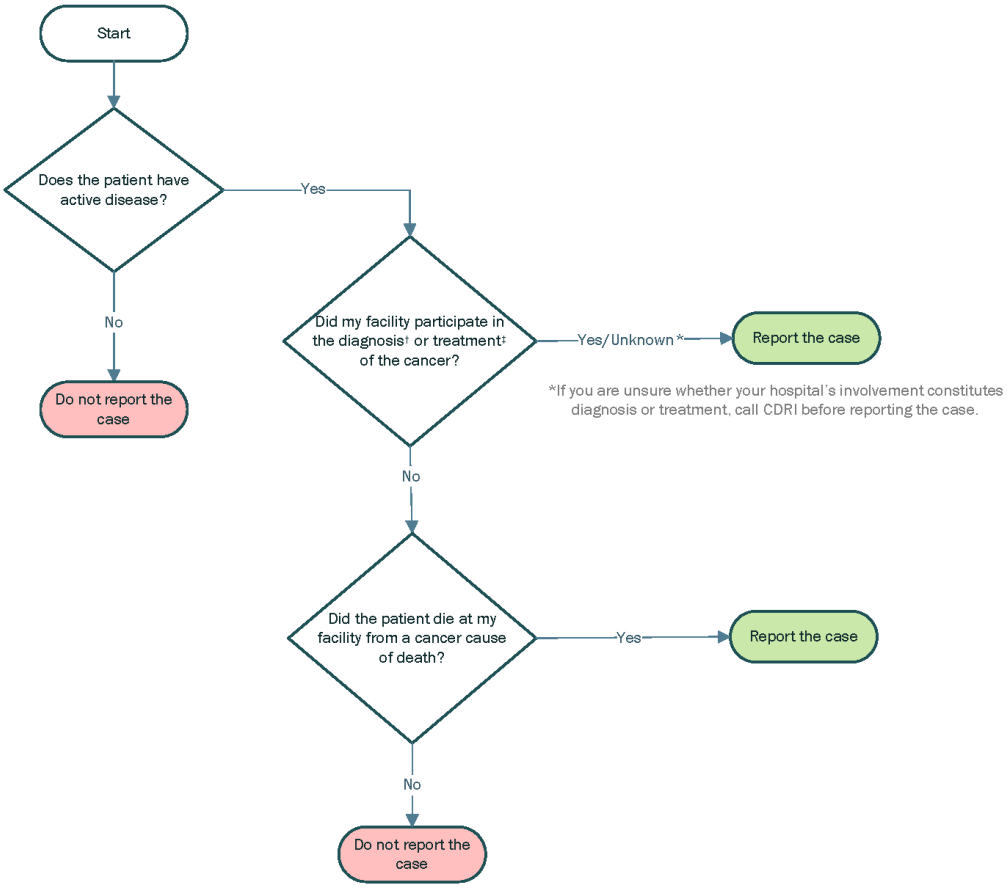
Patients with a cancer-related cause of death who expire at your facility are reportable even if no cancer diagnosis or treatment was administered at the facility. Registrars can call CDRI staff to determine if the expired patient has already been reported to determine if the case must be reported by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

Exclusions

- Neoplasms, malignant, NOS of the skin (8000/2 – 8005/3)
- Epithelial carcinomas of the skin except when occurring on mucous membranes
- Cervix in-situ[1]

[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 only excludes cervix in-situ, leaving all other intraepithelial neoplasias reportable.

CDRI Flow Diagram for Determining Reportability



†Diagnosis may include positive findings from imaging, pathologic or cytologic examination of tissue or fluids, clinical assessment, or other means of diagnosing cancer. A positive staging work-up is included in "diagnosis".

‡Treatment includes cancer directed therapies or the choice of expectant management (e.g., active surveillance or watchful waiting) as first course of therapy.

Case Ascertainment

Sources to identify cases to report include:

- Medical record disease index
- Pathology laboratory (inpatient and outpatient)
- Radiation treatment logs
- Surgery logs
- Imaging (in-patient and out-patient)

Ambiguous Terms

These terms DO constitute a cancer diagnosis:

Apparent(ly)
Appears to
Comparable 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.

These terms DO NOT constitute a cancer diagnosis:

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

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.

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 improve 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…".[2]

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.[3]

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.

Public Law 102-515 - Cancer Registries Amendment Act

The National Program of Cancer Registries (NPCR) supports central, population-based cancer registries in 46 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.

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[2] 45 C.F.R. § 164.512(b)(1)(i)(2201).
[3] 45 C.F.R. § 164.501 (2001).

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)

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)

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[4].

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:
https://seer.cancer.gov/siterecode/

[4]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.

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

- Facilities with high annual caseloads must employ a qualified cancer registrar team, preferably Certified Oncology Data Specialists (ODS-C) or eligible. If the cancer registry becomes delinquent in reporting, Cancer Data Registry of Idaho (CDRI) will require the hospital to submit an action plan with steps to become compliant. CDRI staff are available to provide technical assistance for facilities on reporting compliance and general registry operations (see 'Consultation' below).

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

A. 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 $35.00 per abstracted case. *Note: Facilities utilizing this option will be required to provide an annual ICD-10-CM reportable cancer casefinding list (ICD-10 codes will be provided by CDRI) and secure remote access to the EHR for cancer cases reporting.*

B. 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 Oncology Data Specialist (CTR) is preferred.

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

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

Secure Remote Access: Facilities 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 TRAINING 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.

EXAMPLE LETTER OF AGREEMENT

LETTER OF AGREEMENT BETWEEN

The Cancer Data Registry of Idaho (CDRI)

And

«Facility_»

This agreement is entered into on this ___ day of _____ <<Year>> by the Cancer Data Registry of Idaho (CDRI) and «Facility_». This updated agreement will begin with cancer cases diagnosed and/or treated during <<Year>> and reported/invoiced during <<Year>>. «Facility_» is choosing to comply with Idaho Code §57-1701-1709 using the following method:

Please check the appropriate option:

A. _____ Utilize CDRI to abstract cancer cases and pay for expenses ($35.00 per abstracted case).

B. _____ Hire an in-house abstractor (Certified Oncology Data Specialist [ODS-C] preferred).

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

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

Signature and approval

«Facility_»

by:

_____ _____
Authorized Representative Date

Cancer Data Registry of Idaho

by:

_____ _____
Denise M Jozwik, RHIT, ODS-C Date
Director of Data Quality

DATA TRANSMISSION

File Transmission Criteria

Data shall be transmitted using the NAACCR record layout version that is year-appropriate: https://www.naaccr.org/xml-data-exchange-standard/

Prior to submission the data should be error free using the Edit metafile provided by CDRI (the standard NAACCR edits metafile modified to include Idaho-specific errors). Transmissions from Idaho sources must include the "full case record" in XML format. Cases reported through a National Interstate Data Exchange Agreement should be submitted in the "full case record" (NAACCR record type 'A'). Pathology data electronically transmitted shall be in the appropriate NAACCR layout according to NAACCR Standards for Cancer Registries Laboratory Electronic Pathology Reporting Guidelines.

Allowable data transmission methods to CDRI

- SEER*Transfer – This is the preferred method. SEER*Transfer is a feature of CDRI's database management system which allows secure direct file transfer. Users of this method will be required to sign an End User Software License Agreement.
- N-IDEAS - a product that was developed for CDC-NPCR that allows for sending and receiving secure interstate data exchange files.
- APHL-AIMS - a secure, cloud-based platform that accelerates the implementation of health messaging by providing shared services to aid in the visualization, interoperability, security and hosting of electronic data. This option is currently only available for pathology labs.
- Secure FTP – CDRI contracts with Myriddian, Inc. to host an sFTP site. This option can be utilized by pathology labs or physician offices
- Secure encrypted email – CDRI uses NeoCertified (https://med1.neocertifiedmail.com/). CDRI can also accept files sent via a facility's approved encrypted email system.

Contact CDRI staff for set-up and/or questions regarding any of the transmission methods listed above.

Data Submission Schedules

To ensure timely reporting and processing, data report sources use the following data submission schedule:

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 CDRI
Idaho report sources	Send to CDRI Annually (Sept)

REFERENCE MATERIALS NEEDED TO REPORT CANCER

Use Links Below to Access Current Products

Most of the coding and reference manuals you will need can be found on the SEER Manual Reference Guide website.

- Standards for Oncology Registry Entry (STORE) (Commission on Cancer)
- CTR Guide to Coding Radiation
- Surveillance, Epidemiology and End Results (SEER) Products (EOD and Summary Stage)
- SSDI
- Solid Tumor Rules
- Hematopoietic Database and Manual
- International Classification of Diseases for Oncology Version 3 ICD-O-3 (World Health Organization)
- SEER*RX Database

Additional resources include:

- AJCC Cancer Staging Manuals
https://www.facs.org/quality-programs/cancer/ajcc
Note: The AJCC has moved to rolling updates of individual chapters which will be available in electronic version only. Version 9 protocols and subscription information is found at https://www.facs.org/quality-programs/cancer-programs/american-joint-committee-on-cancer/version-9-protocols-and-ajcc-staging-online-unveiled/

- Cancer Program and Data Standards (ACoS Facilities)
https://www.facs.org/quality-programs/cancer-programs/?page=1

- NAACCR Data Standards and Data Dictionary
https://www.naaccr.org/data-standards-data-dictionary/
Note: Hospitals must use the NAACCR data standards and data dictionary version in effect for each data year.

- Compliant Cancer Reporting Software
Hospitals must collect data using cancer reporting software that is compliant with NAACCR standards for data collection and transmission.

- Idaho Cancer Reporting Standards
https://www.idcancer.org/cancerreporting.html
Revised for January 2025

IDAHO SPECIFIC REQUIREMENTS

CDRI Summary of Changes 2027

New Data Items -- CDRI

CDRI did not add any new state-specific data items for 2027.

New Data Items from Standard Setters (AJCC, CoC, NAACCR, NPCR, SEER)

There are 51 new data items, 42 of which are for recording thoracic nodal station nodes positive and examined. Five additional items are relevant for hospital-based registries (see table below). Please refer to the v27 Implementation Guide for the complete list new and revised data items.

Item #	Item Name	Source of Standard
1768	Date of Cancer Status Following First Course of TX	CoC
1769	Cancer Status Following First Course of TX	CoC
2079	Over-ride Sex Assigned at Birth	NAACCR
3965	Rectal Tumor Location	AJCC
3966	Minor Salivary Tumor Location	NAACCR

Retired Data Items -- CDRI

None

Retired Data Items – Standard Setters

None

Social Security Number

Item #	Length	XML Tag	Allowable Values	Required Status
2320	9	socialSecurityNumber	See Coding Instructions; cannot be blank	All Years

Description

Records the patient's Social Security Number (SSN). This instruction allows for partial SSNs.

Rationale

Social Security Number is collected by central cancer registries for identification and matching purposes; it is not submitted to CDC or NCI SEER.

Coding Instructions

- Code the patient's Social Security Number
- Do not automatically enter a patient's Medicare claim number; it may not always be the patient's Social Security Number
- Exhaust all possible sources before coding 999999999. Partial SSN's are acceptable if the full SSN is not available. Most commonly this will be the last 4 digits but could be the first 5 digits. For partial SSNs, fill the missing characters with blanks.

Medicare Beneficiary Identifier

Item #	Length	XML Tag	Allowable Values	Required Status
2315	11	medicareBeneficiaryIdentifier	See Coding Instructions; blanks allowed	2018+

Description

Congress passed the Medicare Access and CHIP Reauthorization ACT to remove Social Security Number (SSN) from Medicare ID card and replace the existing Medicare Health Insurance Claim Numbers with a Medicare Beneficiary Identifier (MBI). The MBI will be a randomly generated identifier that will not include a SSN or any personal identifiable information.

Rationale

MBI is collected by central cancer registries for identification and matching purposes; collection of MBI does not change how registries currently collect SSN. MBI is not submitted to CDC or NCI SEER.

Coding Instructions

- Code the patient's 11-character Medicare Beneficiary Identifier
- Leave blank when MBI is not available, patient does not have Medicare, not applicable, or unknown

Note: The Medicare Beneficiary Identifier (MBI) is randomly generated and has 11 characters, consisting of numbers and letters, entered without dashes. The MBI format: https://www.cms.gov/Medicare/New-Medicare-Card/Understanding-the-MBI-with-Format.pdf

Height

Item #	Length	XML Tag	Allowable Values	Required Status
9960	2	height	See Coding Instructions; cannot be blank	2011+

Description

Records the patient's height at diagnosis.

Rationale

Used to calculate Body Mass Index (BMI), which is a risk factor and prognostic factor for many types of cancers.

Coding Instructions

- Record patient's height in inches (2 digits); round to the nearest whole number
- Record patient's height as documented at or around the time of diagnosis. If height is not recorded on date of diagnosis, use the height recorded on the date closest to date of diagnosis *before treatment started*.
- Height should be taken from the Nursing interview guide, flow chart, or vital stats section of the medical record.
- Code 98 for 98 inches or greater
- Code 99 for unknown height
- Online conversion tool centimeters to inches: http://manuelsweb.com/in_cm.htm

Examples

Code	Reason
72	Height of 72 inches
73	Height of 72.8 inches
98	Height is 98 inches (8 ft, 2 inches) or greater; this code will be rarely used, if ever
99	Height is unknown, not documented in patient record.

Weight

Item #	Length	XML Tag	Allowable Values	Required Status
9961	3	weight	See Coding Instructions; cannot be blank	2011+

Description

Records the patient's weight at diagnosis.

Rationale

Used to calculate Body Mass Index (BMI), which is a risk factor and prognostic factor for many types of cancers.

Coding Instructions

- Record patient's weight in pounds (3 digits); round to the nearest whole number. For weights less than 100 pounds, precede with a zero.
- Record patient's weight as documented at or around the time of diagnosis. If weight is not recorded on date of diagnosis, use the weight recorded on the date closest to date of diagnosis *before treatment started*.
- Weight should be taken from the Nursing interview guide, flow chart, or vital stats section of the medical record.
- Code 998 for 998 pounds or greater
- Code 999 for unknown height
- Online conversion tool kilograms to pounds: http://manuelsweb.com/kg_lbs.htm

Examples

Code	Reason
051	Weight of 51 pounds
175	Weight of 174.6 pounds
998	Weight is 998 pounds or greater; this code will be rarely used, if ever
999	Weight is unknown, not documented in patient record.

APPENDIX A – TEXT DOCUMENTATION

Text Documentation Requirements

General Guidance

- **Be Concise:** Focus solely on the cancer story, not the patient's entire life history.
- **Use Phrases:** Avoid complete sentences. Use periods (.) or semicolons (;) to separate phrases for clarity.
- **Standard Abbreviations:** Use **NAACCR-approved** abbreviations only. Avoid stylistic shorthand; when in doubt, type it out.
- **Review Copy/Paste:** If copying/pasting, delete information not relevant to the cancer being reported.
- **Relevant Information Only:** Edit documentation to include only "relevant-to-this-cancer" details. For multiple primaries, separate the text for each primary reported.
- **Mixed Case:** Use both uppercase and lowercase letters; **avoid all caps.**
- **No Blank Fields:** If information is missing, state **"None," "NR," or "NA"** for quality review.
- **Chronological Order:** List every procedure, test, and treatment by date (or estimated date) in chronological order.
- **Manage Overflow:** Limit text carried between fields by editing for brevity. If necessary, continue in an empty field marked with an asterisk (*) to show the connection.
- **Validate Coded Elements:** Ensure all coded data is supported by the text. **If it isn't documented, it wasn't done.**

Required Components (Per Exam/Test/Treatment)

- **Dates:** Include both start and end dates where applicable.
- **Location:** Specify if the event occurred at your facility or an outside facility.
- **Description of Event:** Provide the specific name of the test, study, or treatment.
- **Detailed Findings:** Record findings that validate primary site, histology, EOD, treatment, and outcome.
- **Physician Interpretation:** Include the physician's impression to support diagnosis, stage, or planned treatment.
- **Treatment Plans:** Document all planned systemic or radiation therapies, even if not yet initiated.
- **Supplemental Information:** Note non-numerical data or special circumstances (e.g., insurance delays, history of prior cancers, or moving states).

Text – Physical Exam H&P (NAACCR Item: #2520)

- **Sources:** Review H&P, physician, nurse, or consult notes.
- **Core Info:** Exam date, facility, physician, and reason for visit (symptoms/screening).
- **Exam Findings:** Tumor location, size, and LN status.
    - **Prostate:** Must include DRE (if not done, state "No DRE").

    - **Lymphoma:** Must include B-symptoms (if none, state "None" or "Unknown").
    - **Active Surveillance:** Include the date the decision for surveillance/watchful waiting was made.
- **Patient Factors:** HT/WT, tobacco, insurance, age, sex, race, ethnicity, marital status, and occupation at DX.
- **History:** Prior cancers (type/date) and family history of cancer/genetic abnormalities.
- **Residency:** If not an Idaho resident at DX, include where/when they were diagnosed and any treatment given there.

Example: 04/10/2021 (Facility, Dr Phil) 74 y/o white non-Hispanic married male c/o trouble urinating and elevated PSA. No hx of previous cancers; Father pos for prostate ca. Occupation unknown. PE: DRE revealed LT prostatic nodule. LNS neg. HT: 72", WT: 220#; never tobacco; Blue Cross.

Text – X-rays/Scans (NAACCR Item: #2530)

- **Logistics:** Test date, facility, and type (chronological). Do **not** include the ordering physician.
- **Review:** Read the entire report body, not just the impression.
- **Positive Findings:** Include tumor size, EOD, LN status, and metastatic sites.
- **Precision:** Record ambiguous terms exactly as stated. Only report findings related to the specific tumor being abstracted.
- **Staging:** Include relevant negative findings required to establish stage.

Example: 02/17/2022 (Facility) CT C/A/P: 4 cm RUL lung mass, involves adjacent rib, rt hilar LNs pos. Diffuse liver mets.

Text – Scopes (NAACCR Item: #2540)

- **Logistics:** Date, facility, and type of endoscopic exam (bronchoscopy, colonoscopy, EGD, etc.).
- **Findings:** Tumor location, size, involvement/extent of spread, and clinical assessment.
- **Procedures:** Note site and type of any endoscopic biopsies taken. If no findings, state "negative."

Example: 05/20/2022: (Facility) Colonoscopy: Sigmoid stricture at 30cm. Nearly circumferential mass involving the posterior part of the sigmoid colon. Biopsy taken of mass at stricture.

Text – Lab Tests (NAACCR Item: #2550)

- **Relevance:** Only record tests relevant to cancer (chronological order).
- **SSDIs:** Record all SSDI info (ER/PR/Her2, Oncotype, PSA, KRAS, NRAS, etc.).
- **Results:** Include values with normal reference ranges; if unknown, state "elevated" or "not elevated."
- **Heme/Lymph:** Include labs/genetics/immunophenotyping to support DX Confirmation codes.

Example: 02/17/2020 ER 95% +, PR 95% +, Her2 equivocal 2+; FISH neg; Ki-67: 10%; Oncotype 30

RX Text – Op (NAACCR Item: #2560)

- **Logistics:** Date(s) and facility of procedures (chronological).
- **Findings:** Surgeon's observations, descriptions of biopsies, and surgical procedures used for staging.
- **Tumor Stats:** Tumor size, number of LNs removed, residual tumor, and evidence of invasion.

Example: 07/05/2021 (Facility, MD name) Lt breast lumpectomy w/LT axillary SLN bx; tumor found in the UOQ, 3 LNs removed.

Text – Pathology (NAACCR Item: #2570)

- **Identifiers:** Specimen date, facility, and Pathology Accession #.
- **Tumor Details:** Procedure type, site, size, Grade, LVI/PNI, and extent of spread.
- **Histology:** Include all modifying adjectives (predominantly, w/features of, etc.).
- **Nodes/Margins:** Final margins, Name of LNs, and count (Number pos/Number examined).
- **Comments:** Treatment effect (neoadjuvant), SSDI info, and outside consult results; outside consults take priority over in-house pathology.

Example: 02/06/2022 (Facility, Path Accession #: Lt breast lumpectomy: Invasive ductal carcinoma, Nottingham 9/9, G3; LT UOQ, 1.5 cm; All margins neg; LVI neg; Lt axillary SLNs neg 0/3; pT1cpN0(sn)

RT Text – Staging (NAACCR Item: #2600)

- **AJCC Staging:** Include all appropriate staging (yc/yp) and suffixes (m, f, sn).
- **Summary:** Document EOD Tumor/Nodes/Mets and Summary Stage.
- **Personnel:** Note who performed staging (MD or ODS).

Example: Clinically staged by ODS: cT1c (12 mm imaging) cN0, cM0 G1, stage IA; path staged by ODS/Path: pT1c (15 mm) pN0(sn) (0/2 sln) cM0 G2 stage IA. EOD T: 100, EOD N: 070, EOD M: 00, SS: 1

RX Text – Surgery (NAACCR Item: #2610)

- **Details:** Date(s), facility, procedure type, and approach (e.g., Robotic).
- **Removal:** Document LNs, regional tissues, or metastatic sites removed. Note if procedures were aborted.

Example: 04/25/2021 (Hospital, surgeon) Robotic-assisted radical prostatectomy w/bilateral pelvic LN dissection.

RX Text – Radiation Beam/Other (NAACCR Item: #2620 / #2630)

- **Logistics:** Start/end dates, facility, and MD.
- **Target:** Site(s) treated and specific lymph nodes.
- **Dosage:** Modality, planning, fractions, dose/fraction, phases, and total course dose.
- **Status:** Document if refused, stopped early (include reason), or not recommended.

Example: 08/30/2021 - 10/15/2021 (Facility, MD) 6 MV photon IMRT to the LT temporal lobe for 4500 cGy in 25 fxs (180 cGy/FX) followed by 6 MV photon IMRT boost for 1440 cGy in 8 FXS (180 cGy/FX), total 5940 cGy in 33 FXS over 2 phases.

RX Text – Chemo (NAACCR Item: #2640)

- **Agents:** Name(s) of chemotherapy per **SEER*Rx**.
- **Status:** Document start date, facility, and MD. Note if not recommended, refused, or incomplete.
- **Neoadjuvant:** Include neoadjuvant therapy treatment response.

Example: 02/15/2022 (Facility, MD) R-CHOP x 6 cycles
Example: 10/17/2021 (Facility, MD) Due to patient's Alzheimer's disease, no treatment given

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RX Text – Hormone (NAACCR Item: #2650 | Field Length: 1000)

- **Agents:** Name(s) of hormone per **SEER*Rx**.
- **Details:** Include HRT given in combination with chemotherapy. Note if refused/not recommended.

Example: 02/15/2022 (Facility, MD) R-CHOP x 6 cycles
Example: 09/13/2022 (Facility, MD) Tamoxifen x 10 years.

RX Text – BRM/Immunotherapy (NAACCR Item: #2660 | Field Length: 1000)

- **Agents:** Name(s) of BRM/Immunotherapy per **SEER*Rx**.
- **Details:** Include combinations with chemotherapy. Note if refused/not recommended.

Example: 02/15/2022 (Facility, MD) R-CHOP x 6 cycles
Example: 05/12/2021 (Facility, MD) Keytruda.

RX Text – Other (NAACCR Item: #2670)

- **Definition:** Treatments not defined as surgery, radiation, or systemic (e.g., clinical trials, phlebotomy).

Example: 11/12/2021 (Facility, MD) Blinded clinical trial, treatment not specified.
Example: 08/12/2022 (Facility, MD) Phlebotomy

RX Text – Remarks (NAACCR Item: #2680)

- **History:** HT/WT, race, ethnicity, marital status, occupation, and family/social history (if not in PE).
- **Rules:** Document Solid Tumor Rules used (Primary Site or Histology rules).
- **Follow-up:** Include NED or recurrence information.

Example: 04/24/2022 (Facility, MD) Pt NED
Example: Per STR Breast MPH 7-multiple primary
Example: 03/13/2022 (Facility, MD) Pt moved to Arizona during treatment to be near family.
Example: Pt originally dx in Arizona. No other information regarding address at diagnosis.

Text – Address

- **Coding PO Boxes:** Record **"UNKNOWN"** in the Street field. Record the PO Box in the **Address – Supplemental** field.
- **Residency:** Code street address of usual residence. If the patient was diagnosed out-of-state and then patient moves to Idaho, please note in the “Remarks” section where the patient was originally diagnosed. This will be the address at diagnosis.

Example:
Street: UNKNOWN
Supplemental: PO BOX 589
City: Somewhere
State: ID
Zip: 99999
County: 999

Example (Pt not Idaho resident at diagnosis):
Street: If known, otherwise “unknown”
Supplemental: If known, otherwise “unknown”
City: If known, otherwise “unknown”
State: State pt lived when diagnosed
Zip: If known, otherwise “unknown”
County: If known, otherwise “unknown”

Text – Usual Occupation/Industry (NAACCR Item: #310 / #320)

- **Occupation:** Kind of work performed for most of the working life. **Do not record "retired."**
- **Industry:** Primary type of activity of the business (e.g., manufacturing vs. retail).

Example: High School Teacher | **Industry:** Secondary Education
Example: Homemaker | **Industry:** Own home

APPENDIX B – ID COUNTY CODES

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