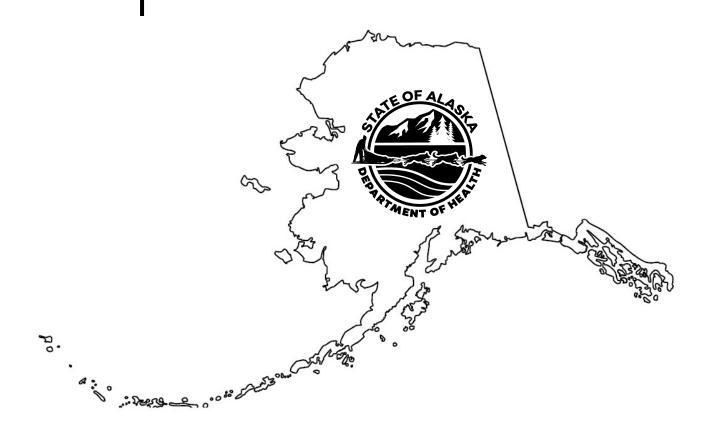


Alaska Cancer Registry

Reporting Source Manual



Alaska Division of Public Health Health Analytics & Vital Records Section (HAVRS) March 2023 This procedure manual has been prepared to assist in the reporting of cancer cases to the Alaska Cancer Registry (ACR). Any questions, comments, or concerns may be addressed to:

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PART I INTRODUCTION

I.A. Cancer in Alaska

Since 1993, cancer has been the leading cause of death in Alaska, and as such represents a significant public health concern for the residents of this state. It is through the ongoing surveillance efforts of the Alaska Cancer Registry (ACR) and the reporting efforts of health care providers that we have the data available to inform and track the burden of this devastating disease on Alaskans.

I.B. The Alaska Cancer Registry

The State of Alaska Division of Public Health received funding from the U.S. Centers for Disease Control and Prevention (CDC), National Program of Cancer Registries (NPCR), in October 1994 to establish and implement a statewide cancer registry.

On January 19, 1996, the Alaska Administrative Code (7 AAC 27.011) established reporting requirements for our statewide cancer registry. The regulations require all hospitals, health care facilities, and health care practitioners who provide screening, diagnosing, and/or treatment for cancer patients diagnosed on or after January 1, 1996, to report this information to the Alaska Division of Public Health. The reporting law was modified in February 2004 to include reporting of benign brain-related tumors.

ACR is an "incidence only" population-based, statewide cancer registry. The registry is located in the Department of Health and Social Services, Division of Public Health, Health Analytics & Vital Records Section.

I.C. Mission of the Alaska Cancer Registry

The mission of ACR is to collect, analyze, research, and disseminate high-quality, complete, accurate, and useful cancer data in a timely fashion. Through this process, ACR provides information on the over-all burden, types, and changing patterns of cancer among residents of the state, empowering health professionals, community members, and other key stakeholders to effectively reduce the incidence and mortality of cancer in Alaska.

ACR collects information about the incidence of cancer, the types diagnosed and their location within the body, the extent at the time of diagnosis (disease stage), the kinds of treatment that patients receive, and the mortality associated with the diagnosis. This information is cumulative over the lifespan of each Alaska resident who is diagnosed with cancer, and it contributes to the understanding of this disease. Timely dissemination of cancer surveillance data to public health agencies and scientists is key to designing and evaluating cancer prevention and control activities.

Annual reports of Alaska cancer data are published and available online at the Alaska Cancer Registry website: <u>http://dhss.alaska.gov/dph/VitalStats/Pages/cancer/registry.aspx</u>

I.D. Alaska Statutes and Regulations for Cancer Case Reporting

7 AAC 27.011. Reporting of Cancer and Brain Tumors

(a) A hospital, physician, surgeon, or other health care facility or health care provider diagnosing, screening, or providing treatment for a cancer patient in this state shall report the information specified in (b) of this section to the division, within six months of the date of diagnosis, screening, or treatment.

(b) The following must be provided for each form of in-situ and invasive cancer, with the exception of basal cell and squamous cell carcinoma of the skin and in-situ carcinoma of the cervix uteri, and must be provided for each brain-related tumor, whether malignant or benign, occurring in the brain, the meninges, the spinal cord, the cauda equina, a cranial nerve, the pituitary gland, the pineal gland, the craniopharyngeal duct, or any other part of the central nervous system:

(1) information about the patient, including as a minimum, name, date of birth, sex, race, ethnicity, community of residence, date of diagnosis, primary site, and name of attending or admitting health care provider.

(2) pathological data characterizing the cancer, including the cancer site, stage of disease, and type of treatment.

AS 09.65.161. Immunity for Disclosure of Required Health Care Data.

A person who reports health care data required to be reported under AS 18.05 and regulations adopted under that chapter for conditions or diseases of public health importance may not be held liable for the disclosure to the Department of Health and Social Services or for the use of the data by the department.

AS 18.05.042. Access to Health Care Records.

(a) The department may, during reasonable business hours, inspect health care records maintained by physicians and other health care professionals, hospitals, out-patient clinics, nursing homes, and other facilities or agencies providing health care services to patients that would identify patients or establish characteristics of an identified patient with cancer required to be reported under 42 U.S.C. 280e - 280e-4, or a birth defect or infectious disease required to be reported to protect the public health under this chapter and regulations adopted under this chapter. Disclosure of these health care records to the department does not constitute a breach of patient confidentiality.

(b) The department may conduct research using health care data reported under (a) of this section. The department may provide data obtained under (a) of this section to other persons for clinical, epidemiological, or other public health research.

(c) Data obtained or a record inspected under this section that identifies a particular individual:

(1) is confidential;

(2) may not be further disclosed to other persons except by the department under (b) of this section; and

(3) is not subject to inspection or copying under AS 40.25.110 - 40.25.125.

PART II CONFIDENTIALITY

ACR will follow the Division of Public Health policies and procedures for data confidentiality and security. In addition, ACR will comply with the data confidentiality and security standards as set forth in the latest edition of the North American Association of Central Cancer Registries (NAACCR) Standards for Cancer Registries, Volume III.

II.A. Disclosures for Public Health Purposes

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule allows "covered entities" (health care providers) to disclose protected health information to public health authorities when required by federal, tribal, State, or local laws [45 CFR 164.512(a)(1)]. Central cancer registries are considered public health authorities because state laws mandate their duties. Written authorization from the individual before reporting protected health information to the state cancer registry is not required under HIPAA. The provision of the Privacy Rule authorizing disclosure of protected health information as required by law is an exception to the requirement for written authorization.

II.B. Confidential Data

Any information that specifically identifies an individual cancer patient, the physician, hospital, or other health care provider involved in that patient's care is confidential. Patient identification information (e.g., name, address, and social security number), treating physician name, or the hospital where treatment was administered are examples of confidential data. Information that characterizes the caseload of a specific institution or health care professional is also confidential.

II.C. Summary Data

Data provided by ACR will include summary information grouped by age, sex, or geographic area and displayed so that individual patients or institutions cannot be identified. Summary statistics will not be reported for fewer than six cases in any one substrate.

II.D. Transmission of Confidential Data

ACR will routinely receive and periodically transmit confidential data. Hard copy data being transmitted to ACR by mail must be clearly marked "Confidential", and the envelope must include the sender's name and return address.

All hard copy data transmitted by fax must also be clearly marked "Confidential". Information received by ACR is done through a secure fax line. All data transmitted by ACR via fax will contain a cover sheet with the following disclaimer:

"This transmission is intended only for the use of the individual or entry to which it is addressed and may contain information that is privileged and confidential. If the reader of the message is not the intended recipient, you are hereby notified that any disclosure, distribution, or copy of this information is strictly prohibited. If you have received this in error, please notify us immediately by telephone and destroy this transmission." When receiving confidential information from ACR, it is the responsibility of the ACR registrar to ensure that the fax transmission is being provided to the intended recipient. The ACR registrar will call the intended recipient immediately before the transmission for notification that confidential data is being sent via fax. During the notification call the registrar will verify that the fax phone number being used for transmission is valid. Directly after transmission, the registrar will telephone the intended recipient to verify that the transmission of the confidential data was successful.

Confidential data may also be transmitted by telephone. Do not leave confidential information in a voicemail message. Provide your name, phone number, and best time to reach you, and an ACR registrar will call you back to discuss confidential information. When information is to be transmitted by an ACR registrar by telephone, it is the responsibility of the ACR registrar to ensure that the telephone transmission is being provided to the intended recipient.

Electronic files can be transmitted by a reporting facility to ACR using any of the following methods:

- As an attachment using the facility's secure email system.
- The facilities secure FTP site.
- ACR's Web Plus software using the "File Uploader" function. The ACR Data Analyst will provide the facility with a Web Plus user ID and password if they do not already have an account.
- As an attachment using the statewide Direct Secure Messaging (DSM) secure email system. DSM is managed through the healtheConnect Alaska. Facilities need to sign up for an account at https://www.healtheconnectak.org/. There is a nominal annual fee for the DSM service.

Acceptable electronic data file formats are as follows:

- Hospital = NAACCR record layout version specified in year-appropriate
- Pathology Laboratories = *NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting* (version 2.2 or higher) or reporting through CDC's PHNMS system.
- Physician (MU) & Non-Hospitals = Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries, Release 1.1, August 2014.
- Physician (non-MU) & Non-Hospitals = HL7 CDA® Release 2 Implementation Guide: Reporting to Public Health Cancer Registries from Ambulatory Healthcare Providers, Release 1, DSTU Release 1.1 – US Realm

When ACR receives data from reporting sources electronically, the data are transferred to the network for inclusion into the source document archive files. Hospitals, physicians, and other reporting facilities can implement their own internal procedures for transmitting confidential data to ACR, provided one of the above methods of transmission is used.

II.E. Release of ACR Data to Other State Central Cancer Registries

To allow for the automatic exchange of cancer patient data between ACR and another state central cancer registry, a case-sharing agreement must be completed and signed by the two state registries. The signed agreement will be kept on file by ACR. Case-sharing agreements can be initiated by ACR or from other state central registries. Exchange data includes patient identifiers

along with cancer identification and treatment information for residents of the requesting state only.

To reduce the need for multiple interstate agreements, NAACCR maintains a National Interstate Data Exchange Agreement. Alaska and most of the other states have signed this agreement; however, not all states that signed an agreement with ACR have signed the NAACCR agreement. Information about the National Interstate Data Exchange Agreement and associated state-specific data restrictions are available online at the following website: https://www.naaccr.org/national-interstate-data-exchange-agreement/

Variations in data exchange guidelines may exist between ACR and other state central registries. It is the responsibility of the ACR registrar to follow the specific guidelines listed in the appropriate state case-sharing agreement when exchanging data with or releasing data to other state cancer registries.

II.F. Requests for ACR Data

All requests for data will be reviewed by the ACR Manager for approval. The ACR Manager/Deputy Section Chief of HAVRS is required to review any external reports prior to their dissemination to ensure that confidentiality has been respected.

Requests for data submitted to ACR must include the following:

- Specific data elements requested
- Detailed purpose of the data request
- Manner in which the data will be utilized

Non-confidential data requests must be made by completing the ACR Data Request form. This is a fillable PDF form available as a link from the ACR website. The direct link address is: http://dhss.alaska.gov/dph/VitalStats/Documents/cancerregistry/assets/ACR_DataRequestForm.pdf

Requests for confidential level data for research purposes must be approved by the ACR Manager/Deputy Section Chief of HAVRS and/or the Alaska DPH Privacy Board, per the Deputy Section Chief's discretion. Requests meet the following ACR standards:

- Researcher must complete the ACR Data Use for Research application form.
- For research requiring confidential or identifying data, approval from a recognized Academic or Institutional Review Committee for the Protection of Human Subjects is required in accordance with Part 46 of Title 45 of the Code of Federal Regulations.
- Applications will be reviewed to determine if data will be provided and to what extent.
- An ACR Research Agreement must be signed by the principal investigator.
- Reports by the principal investigator derived from confidential data are subject to review by the ACR Manager/Deputy Section Chief of HAVRS prior to publication or release to ensure that confidentiality has been maintained.

Hospitals with commercial registry software can contact ACR for periodic (not more than annual) linkage with the state mortality database for updating patient vital status. A list of patient identifiers must be sent electronically by secure email, FTP, or Web Plus file upload. ACR will provide a list of linked patients, date of death, and other relevant vital status data items specifically requested (such as cause of death, state of death, and death certificate number).

PART III GENERAL PROCEDURES

III.A. Who Reports to ACR

In accordance with state law 7 AAC 27.011, the following entities are required to report cancer cases to ACR:

III.A.1. Hospitals: This includes general and specialized (e.g., psychiatric) facilities.

III.A.2. Non-hospital Facilities:

- Outpatient centers such as private or public clinics, health maintenance organizations, and ambulatory surgery centers
- Free-standing outpatient cancer centers such as radiation therapy centers, medical oncology centers, diagnostic imaging centers, urology centers, and digestive centers
- Free-standing pathology or diagnostic laboratories
- Physicians

III.B. When to Report to ACR

The timeframe for reporting cancer cases to ACR, as defined in Alaska Statute 7 AAC 27.011, is within six months of the date of diagnosis, screening, or treatment. If the cancer diagnosis was made prior to the patient being seen at that facility, the reporting timeframe is within six months from the patient's first visit to that facility (Date of 1st Contact) following the cancer diagnosis. If the patient is seen for treatment only, report of the case is due within six months of the first visit.

III.C. What to Report to ACR

III.C.1. Delay adjustment factors

In the past, ACR requested reporting facilities to send all reportable cancer cases diagnosed 1996 forward; however, a coordinated effort between the National Cancer Institute (NCI), NAACCR and NPCR, using NCI's statistical analysis model to generate delay adjustment factors has indicated that late submissions have no significant effect on increasing incidence rates. As such, ACR established in 2018 that reporting sources need only submit cases diagnosed within 10 years of the current diagnosis year.

III.C.2. Identifying Cancer Cases

Reporting sources must develop their own internal process for identifying cancer cases diagnosed, screened, or treated at their facility. This process known as casefinding is an integral step for ensuring that all eligible cases are identified and reported.

III.C.3. Procedure for Casefinding

Casefinding is a system for identifying every cancer case seen by a facility whether for screening, diagnosis, or treatment. It is an integral step for ensuring that all eligible cases are identified and reported. Active casefinding involves reviewing the Medical Disease Index (MDI) weekly, monthly, or quarterly by the hospital registrar to identify potential cancer cases.

Hospital registrars can also use treatment, surgery, radiation therapy, and diagnostic imaging logs; if the hospital has a pathology department, path reports should be reviewed for reportable cancer cases as well. Once cases have been identified, the registrar will need to review the medical records to determine if the case is reportable. Once determined to be reportable, the registrar will need to abstract the case.

Abstracting cases via Web Plus:

- Hospitals designated as small Web Plus hospitals will complete a demographic abstract in Web Plus and send support documents to ACR for completion of the abstract.
- Hospitals designated as medium Web Plus hospitals will complete a partial abstract in Web Plus and send support documents to ACR for completion of the abstract.
- Hospitals designated as large Web Plus hospitals will complete a full abstract by a CTR and are not required to send support documents.

Hospitals that abstract in Metriq will transmit their cases via hospital secure email or Web Plus. See *Appendix E* for more information on casefinding and for the list of ICD-10 codes.

III.C.3.a. Treatment Logs

Chemotherapy and radiation therapy logs. Patients seen by a facility for continuation of a treatment plan - regardless of where the diagnosis was made - is required to be reported, but only if it is known a) the year of diagnosis and b) which state the patient was a resident of at the time of diagnosis and at least the year of diagnosis. If you do not have this information, do not abstract the case. If the patient is a resident of Alaska, the registrar should check with their ACR contact to see if this has been reported by another facility.

III.C.3.b. Surgery Logs

Operative and endoscopic logs. Reports with positive or indicative diagnoses supplement pathology reports and can often provide information on involvement of organs or tissues that may not have been resected and assist in the appropriate staging of the case.

III.C.3.c. Radiation Therapy Logs

Radiation therapy log and treatment summaries. Reports and office visit notes can provide information on first course of treatment and/or identify cases in which the patient was not admitted into the facility.

III.C.3.d. Diagnostic Imaging Logs

Imaging logs, including logs of scans (e.g., CT scan, MRI, PET scan, chest film/X-ray, mammogram, bone scan, ultrasonic scan). Reports with positive or indicative diagnoses provide pertinent information about the primary tumor, date of diagnosis, stage of disease, and lymph node involvement.

III.C.4. Data Items Collected by ACR

Each initial and subsequent diagnosis of cancer for the primary site only will be collected separately following the rules in Solid Tumor Rules 2018 for diagnosis years 2018 and forward and 2007 Multiple Primary and Histology Coding Rules for diagnosis years 2017 and prior. Information on patients with newly diagnosed metastatic cancer from a primary site that was either diagnosed prior to the ACR reference date or had been previously reported will not be collected.

Reporting facilities must provide ACR with all pertinent information available on each patient diagnosed and/or treated for cancer at the time of diagnosis. While the information supplied to ACR will vary depending on the nature of the reporting facility (i.e., hospital vs. non-hospital), it is necessary for obtaining a complete record. In addition to these items, all reporting facilities are required to provide ACR with supporting text within the submitted record to substantiate tumor diagnosis, staging, histology, treatment, and other coded fields.

ACR realizes that a reporting source may have limited information to report for some of their patients. Since ACR will be able to consolidate information received from several reporting facilities with respect to a particular cancer case, it is important that all reporting facilities involved in the cancer screening, diagnosis, and/or treatment of patients report all available information, no matter how limited, to ACR.

Example: If the patient came into the facility for port placement, re-staging, follow-up imaging, or lab for disease progression and you do not have any other information, please check with an ACR contact to see if the case has been reported by another facility. If it has been reported, an abstract will not be needed.

If the only information in the medical record is patient has history of cancer and active disease status and the date of diagnosis is unknown, add this to the exclusion list and do not abstract the case.

A reporting facility is required to provide ACR with the following:

III.C.4.a. Patient Identifiers:

- Full name
- Maiden name (and/or alias)
- Date of birth
- Sex
- Race and ethnicity
- Social security number
- Residence at time of diagnosis or first contact (street, city, state, zip code)
- Payer at diagnosis (no insurance, self-pay, insurance type, etc.)
- Tobacco history, five fields:
 - Tobacco Use Smoking Status records the patient's past or current smoking of any tobacco products (cigarettes, pipes, cigars, or kreteks/flavored products). Only applicable starting DxYear 2022 and uses different codes than the next 3 tobacco use fields.

- Tobacco Use Cigarettes records the patient's past or current cigarette smoking, or when tobacco use is indicated but type is not specified.
- Tobacco Use Other Smoke records the patient's past or current use of smoking tobacco products other than cigarettes (e.g., pipes, cigars, kreteks/flavored products)
- Tobacco Use Smokeless records the patient's past or current use of smokeless tobacco (e.g., chewing tobacco, snuff, iqmik)
- Number of Years Smoked records the number of years that the patient has smoked tobacco products (does not including vaping)
- Marijuana Smoking records the patient's past or current use of smoking marijuana.
- E-Cigarette Vaping records the patient's past or current use of electronic vaping devices. Abstractors should note in the Text--Remarks field if the vaping is nicotine (tobacco) or THC (marijuana).
- Height at diagnosis
- Weight at diagnosis

III.C.4.b. Cancer Identifiers:

- Date of first contact
- Date of diagnosis
- Primary site
- Histology
- Behavior
- Tumor grade
- Tumor sequence
- Laterality (i.e., if paired organ)
- Diagnostic confirmation
- Stage of disease at diagnosis (i.e., Summary Stage, AJCC TNM Stage)
- Size of tumor
- Number of lymph nodes examined and positive
- Site Specific Data Items (SSDIs) for diagnosis 2018 and forward
- Site Specific Factors (SSF) for diagnosis 2017 and prior

III.C.4.b.1. Date of First Contact

- Record the date the patient first had contact with the facility as either an inpatient or outpatient for diagnosis and/or first course treatment of a reportable tumor.
- The date of first contact may be the date of an outpatient visit for imaging, lab tests, biopsy, or the date a pathology specimen was collected at the facility.
- If this is a death certificate only (DCO) case, then use the date of death.
- If the patient was diagnosed in a staff physician's office, the date of first contact is the date the patient was physically first seen at the reporting facility.

• See the FORDS (Facility Oncology Registry Data Standards) or STORE (Standards for Oncology Registry Entry) manuals for further guidelines.

III.C.4.b.2. **Date of Diagnosis** – records the date of initial diagnosis by a physician for the tumor being reported.

- Use the first date of diagnosis whether clinically (imaging, labs, etc.) or pathologically established.
- If the physician states that in retrospect the patient had cancer at an earlier date, use the earlier date as the date of diagnosis.
- Refer to the list of ambiguous terms in Section III.D.3 for terms considered diagnostic of cancer.
- Use the date treatment was started as the date of diagnosis if the patient receives a first course of treatment before a diagnosis is documented.
- The date of death is the date of diagnosis for death certificate only (DCO) cases.
- If the year of diagnosis cannot be identified, it must be approximated. If you cannot estimate the diagnosis year, reach out to an ACR contact to see if this case has been reported by another facility.
- See the FORDS or STORE manuals for further guidelines.

III.C.4.b.3. **Primary Site** – also called topography, identifies the site where the tumor <u>originated</u>.

- Record the ICD-O-3 topography to the most specific site code as possible. Revisions were released on January 10, 2018. These need to be used before going to the ICD-O-3 book for codes.
- When a single tumor overlaps the boundaries of two or more subsites and the point of origin is not known, use subcategory 8.
- When applicable, use C76 codes for other and ill-defined sites codes, if applicable, instead of C80.9 unknown primary.
- Use subcategory 9 for multiple tumors that originate in different subsites of one organ.
- Follow the Summary of Principal Rules in ICD-O-3 (pages 20-40) and the current SEER Multiple Primary and Histology (MP/H) Coding Rules (for cases diagnosed 1-1-2007 to 12-31-2017) or Solid Tumor Rules (for cases diagnosed 1-1-2018 and later) to assign primary site for solid tumors.
- Follow the instructions in the Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and Database for assigning site for lymphomas, leukemia, and other hematopoietic neoplasms.

III.C.4.b.4. **Histology** – also called morphology, identifies the microscopic anatomy of cells.

- Use the MP/H Coding Rules (for cases diagnosed 1-1-2007 to 12-31-2017) and Solid Tumor Rules (for cases diagnosed 1-1-2018 and forward) when coding the histology for all reportable solid tumors.
- Record histology using the ICD-O-3 codes in the Numeric Lists/Morphology section (pages 69-104) and/or the Alphabetic Index

(pages 105-218). 2018 ICD-O3 Histology revisions were released on January 10, 2018. These need to be used before going to the ICD-O-3 book for codes

- Follow the Summary of Principal Rules outlined on pages 20-40 of the ICD-O-3.
- Review all pathology reports (include all addendums and outside pathology consult reports). Code the **final** pathologic diagnosis for solid tumors.
- Follow the instructions in the Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the Hematopoietic and Lymphoid Neoplasms Database for assigning histology for lymphomas, leukemia, and other hematopoietic neoplasms.
- The codes for cancer, NOS (8000) and carcinoma, NOS (8010) are <u>not</u> interchangeable. If the physician states carcinoma, then code 8010.
- See the STORE or FORDS manuals for further guidelines.

III.C.4.b.5. Behavior – Records the behavior of the tumor being reported. The fifth digit of the morphology (histology) code is the behavior code and describes whether tissue samples are benign (0), borderline (1), in situ (2), or invasive (3).

- Code 3 if any malignant invasion is present, no matter how limited.
- If the specimen is from a metastatic site, code the histology of the metastatic site and code 3 for behavior.
- Behaviors 0 (benign) and 1 (borderline) are reportable for intracranial and central nervous system (CNS) tumors beginning date of diagnosis January 1, 2004. Prior diagnosis years are not reportable.

Code	Label	Definition	
0	Benign	Benign	
1	Borderline	Uncertain whether benign or malignant Borderline malignancy Low malignant potential	

Uncertain malignant potential

• See *Appendix G* for a list of intracranial and CNS primary sites.

Code	Label	Definition
2	In situ & synonymous with in situ	Adenocarcinoma in an adenomatous polyp with no invasion of stalk Bowen disease (not reportable for (C44.x) Clark level 1 for melanoma (limited to epithelium) Comedocarcinoma, non-infiltrating (50.x) Confined to epithelium Hutchinson melanotic freckle, NOS (44.x) Intracystic, non-infiltrating (carcinoma) Intraepidermal, NOS (carcinoma) Involvement up to, but not including the basement membrane Lentigo maligna (C44.x) Lobular neoplasia (50.x) Lobular, non-infiltrating (C50.x) (carcinoma) Non-infiltrating (carcinoma) Non-infiltrating (carcinoma) Non-invasive (carcinoma only) No stromal invasion or involvement Papillary, non-infiltrating or intraductal (carcinoma) Precancerous melanosis (C44.x) Queyrat's erythroplasia (C60.x)
3	Invasive	Invasive or micro-invasive.

III.C.4.b.6. Grade – Describes the tumor's resemblance to normal tissue.

- Well differentiated (Grade 1) is the most like normal tissue, and undifferentiated (Grade 4) is the least like normal tissue.
- Grades 5-8 define particular cell lines for lymphomas and leukemia's.
- When there is no tissue diagnosis, it may be possible to establish grade through magnetic resonance imaging (MRI) or positron emission tomography (PET). When available, code grade based on the recorded findings from these imaging reports.
- Starting with cases diagnosed 1-1-2018 the grade field was expanded to Grade Clinical, Grade Pathological, and Grade Post Therapy.
- Use the Instructions for Coding Grade for 2014+ when coding grade for tumors diagnosed January 1, 2014, through 12-31-2017.
- Use the SSDI Grade & Coding Instructions for cases diagnosed 1-1-2108 and forward.
- For cases diagnosed before 2014, use the coding rules below.

Coding Grade/Differentiation on cases before 2014

Code	Label
1	Well differentiated: differentiated, NOS
2	Moderately differentiated; moderately well differentiated; intermediate differentiation
3	Poorly differentiated; dedifferentiated
4	Undifferentiated; anaplastic

Code	Label
5	T cell; T-precursor
6	B cell; pre-B; B-precursor
7	Null cell; non-T, non-B
8	NK (natural killer) cell (effective with diagnosis 1/1/95 and after)
9	Cell type not determined, not stated or not applicable; unknown primary; high grade dysplasia (adenocarcinoma in situ)

III.C.4.b.7. Tumor sequence - Indicates the sequence of malignant and nonmalignant neoplasms over the lifetime of the patient.

- Codes 00-59 and 99 indicate neoplasms of malignant (in situ or invasive) behavior (2 or 3)
- Codes 60-88 indicate neoplasms of non-malignant behavior (0 benign) to code benign brain and CNS neoplasms. See *Appendix G* for list of sites.
- Code 00 only if the patient has a single malignant primary. If the patient develops a subsequent in situ or invasive primary tumor, change the sequence number for the first tumor from 00 to 01, and sequence the subsequent tumors sequentially.
- Code 60 only if the patient has a single benign primary. If the patient develops a subsequent benign primary, change the code for the first tumor from 60 to 61, and assign codes to subsequent benign primaries sequentially.
- If two or more invasive or in situ neoplasms are diagnosed at the same time, assign the lowest sequence number to the diagnosis with the worst prognosis. If no difference in prognosis is evident, the decision is arbitrary.
- Any tumor in the patient's past must be taken into account when sequencing subsequent tumors. An example of this would be a first tumor which was diagnosed in 1994 (before ACR's reference year of 1996) and then the patient is diagnosed in 2010 with a new primary. The tumor diagnosed in 1994 would be sequence number 01 and the tumor diagnosed in 2010 would be 02, even though this first tumor did not need to be abstracted because it was diagnosed before the reference date. Make a note in the Text Remarks field that the sequence number 01 tumor was diagnosed in 1994.
- Do not reassign sequence numbers if one of those tumors becomes non-reportable later.
- Sequence numbers should be reassigned if the facility learns later of an unaccessioned tumor that affects the sequence.

III.C.4.b.8. Laterality – Identifies the side of a paired organ or the side of the body on which the reportable tumor originated. This applies to the primary site only. See *Appendix F* for a list of paired sites.

- Code laterality for all sites.
- Do not code metastatic sites as bilateral involvement.
- If both lungs have nodules or tumors and the lung of origin is not known, assign code 4.
- Where the right and left sides of a paired site are contiguous (come into contact) and the lesion is at the point of contact of the right and left sides, use code 5 = midline.
- In reference to the breast, midline refers to a tumor overlapping primary sites and is coded C50.8. Example: The midline of the right breast is coded 1 (right side laterality):

Code	Label	
0	Organ is not a paired site.	
1	Origin of primary is right.	
2	Origin of primary is left.	
3	Only one side involved, right or left origin not specific.	
4	Bilateral involvement at time of diagnosis, lateral origin unknown for a single primary; or both ovaries involved simultaneously, single histology; bilateral	
	retinoblastomas; bilateral Wilms tumors.	
5	Paired site; midline tumor	
9	Paired site, but no information concerning laterality	

III.C.4.b.9. Diagnostic Confirmation – Records the best method of diagnostic confirmation of the cancer being reported at any time in the patient's history. The rules for coding differ between solid tumors and hematopoietic and lymphoid neoplasms. Reference Section Two in either the STORE or FORDS manuals for instructions for coding solid tumors; use the SEER Hematopoietic & Lymphoid Coding Manual for instructions on coding hematopoietic or lymphoid tumors.

III.C.4.b.10. Stage of disease – Categories that describe how far a cancer has spread, usually at the time of diagnosis. See *Resources for Cancer Registrars* for additional information and links to manuals.

- Summary Stage 2018
- Summary Stage 2000
- AJCC TNM Stage

III.C.4.b.11. Size of tumor – records the largest dimension or diameter of the primary tumor in millimeters. To convert centimeters to millimeters, multiply the dimension by 10. Starting with cases diagnosed 1-1-2016, the fields have been changed to Tumor Size Clinical, Tumor Size Pathologic and Tumor Size Summary. See STORE or FORDS manuals for more information.

III.C.4.b.12. Number of Regional Lymph Nodes Examined and Positive

- Regional lymph nodes examined records the total number of regional lymph nodes that were removed and examined by the pathologist.
- Regional lymph nodes positive records the exact number of regional lymph nodes examined by the pathologist and found to contain metastases.

III.C.4.b.13. Site Specific Data Items (SSDI)

- Use for cases diagnosed on or after 1-1-2018. For cases diagnosed prior to this date, use Site Specific Factors (SSFs).
- See *Resources for Cancer Registrars* for the link for the manual.

III.C.4.c. Treatment Identifiers (First Course of Treatment):

Per the latest edition of the STORE manual: The first course of treatment includes all treatment methods documented in the treatment plan and administered to the patient before recurrence or disease progression. "Active surveillance or watchful waiting" is a form of planned treatment for some patients (such as prostate). "No therapy" is a treatment option that occurs if the patient, family or guardian refuses treatment, the patient dies before treatment starts, or the physician recommends no treatment be given. If the patient refuses all treatment, code "patient refused: (code 7 or 87) for all treatment modalities. *See the current STORE manual for further information. Link provided in the Resources for Cancer Registrars.*

III.C.4.d. Primary Care Physician

If known, the reporting facility must report the physician who is providing the primary management of the patient's cancer.

III.C.4.e. Text Fields are Required Fields

- Text is a required data field.
- All text fields should be completed with as much information regarding the tumor as possible. Text who, what, when, and where of a patient's cancer.
- Dates must be documented in the text even if there is a specific field for dates, such as date of surgery, date of biopsy, etc.
- Only include concise and precise information which is pertinent to the cancer and coded data fields.
- Text fields are used to justify all coded fields. There needs to be enough information included to be able to recode the case using only the text provided.
- The NAACCR List of Recommended Abbreviations for Abstractors is the only ACR approved abbreviations list to be used by all cancer registrars in Alaska. Having one recommended abbreviations list standardizes the abbreviations used by all reporting facilities. See *Appendix I* for the link to access the NAACCR abbreviations list.
- Text can also explain anomalies in codes, documents missing or unknown data, and fills in the holes in the abstract.
- If you code in the abstract that the patient is deceased, document in the "TEXT Remarks" field where you received that information. Be as specific as possible in case further research is required.
- See ACR Text Template for guidelines in entering text in Appendix J.

III.D. Case Eligibility

III.D.1. Determining What is Reportable

There are many guidelines a cancer registrar must follow to determine if a case is reportable. If you have any questions as to whether a specific case should be reported, contact an ACR representative for assistance.

III.D.2. Reportable vs. Non-reportable Cancer Cases

III.D.2.a. Reportable Cancer Cases:

- Malignant and/or in-situ tumor
- Benign brain and central nervous system (CNS) cases diagnosed on or after 1/1/2004 (*Appendix G*)
- Gastro-intestinal stromal tumors (GIST) and thymomas are frequently nonmalignant. However, they must be abstracted and assigned a *Behavior Code* of 3 if they are noted to have multiple foci, metastasis, or positive lymph nodes.
- Cases diagnosed within the last 10 years of the current diagnosis year. *Note:* This is a change from the previous requirement of the ACR reference date of January 1, 1996.
- Alaska resident and non-resident reportability:
 - Any person diagnosed with cancer in Alaska regardless of residency is reportable. ACR will transmit information for a non-resident to the state of residency via shared agreement with that state central registry.
 - Alaska resident diagnosed with cancer.
 - Non-resident of Alaska whether diagnosed in Alaska or another state who receives 1st course treatment in Alaska or who moves to Alaska during 1st course treatment. Report these only if there is information on which state the patient was diagnosed in and at least the year of diagnosis. If there is no information to validate, do not abstract the case and add the patient to the exclude list. ACR will transmit information for a non-resident to the state of residency via shared agreement with that state's central registry.
 - Contact an ACR representative for further inquiries.
- Cases where a confirmation of a cancer diagnosis is made by Pathology Only Class of Case 43. These are reportable.
- Cases diagnosed at autopsy Class of Case 38.
- Reportable by agreement cases: Registries may be requested to abstract tumors that are not required by the CoC (Commission on Cancer) for accredited cancer programs by ACR. ACR requires the following tumors to be abstracted and transmitted:
 - VIN III (Vulvar intraepithelial neoplasia, grade III, C51._)
 - VAIN III (Vaginal intraepithelial neoplasia, grade III C52._)
 - AIN III (Anal intraepithelial neoplasia, grade III C21.1)
- Primary polycythemia vera or essential thrombocythemia diagnosed on or after 1/1/2001. This does not include Polycythemia NOS or Thrombocytopenia.

- Juvenile astrocytoma, listed as 9421/1 in ICD-O-3, is required and should be recorded as 9421/3. See the latest edition of the STORE manual.
- Primary sites other than skin (C44.x) basal cell carcinoma (8090) and squamous cell carcinoma (8070); basal cell and squamous cell carcinomas of the skin are reportable if they arise at a mucocutaneous juncture or external genital site (will not have skin C44.x as the primary site topography code)
- Effective in 2015, code 8240/1 for Carcinoid tumor, NOS, of appendix (C18.1) becomes obsolete. Carcinoid tumors of the appendix must be coded to 8240/3. This is required and must be coded with a behavior 3. See the STORE manual.
- This list is not all inclusive, refer to the ICD-O-3 coding book.
- Contact an ACR representative if there are any questions.

III.D.2.b. Non-reportable Cancer Cases:

- Cases with a diagnosis year older than 10 years from the current diagnosis year. *Note:* This is a change from the previous cutoff of the ACR reference date of January 1, 1996.
- Alaska resident and non-resident non-reportability:
 - Non-resident of Alaska who was diagnosed and/or treated in another state but came to your facility for transient care (i.e., vacationing; to avoid interrupting a course of therapy initiated elsewhere) or non-cancer related care.
 - No exact or estimated date of diagnosis documented in the medical record. If there is a partial date of diagnosis known (year, year and month), then it is reportable. See STORE manual for guidelines on estimating Date of Diagnosis.
 - No information documented in the medical record to indicate active disease or establish history of. Check with an ACR representative for "history of" cases to see if it has been previously reported.
 - When information on the state of residency for a non-resident of Alaska, who was diagnosed and began treatment outside of Alaska but who has moved up to be with family and to continue treatment, is not available. Without the state of residency, data cannot be exchanged.
 - Contact an ACR representative for further questions.
- Records or slides seen in consultation only (i.e., no contact with the patient).
- Benign tumors, except brain and CNS tumors diagnosed on or after January 1, 2004. *NOTE:* ACR does not acknowledge high grade dysplasia of any site to be equivalent to in situ cancer and therefore should be considered benign for ACR reporting purposes. See Appendix G for a list of brain and CNS sites.
- In situ carcinoma of the cervix uteri (CIS), CIN III and PIN III of the prostate.
- Basal cell carcinoma, squamous cell carcinoma, and baso-squamous cell carcinoma of the skin (C44.x) are not reportable. If the primary site is other than skin, it is reportable.
- Secondary polycythemia and/or thrombocytopenia.
- Contact an ACR representative for any questions.

III.D.3. Diagnostic Language & Ambiguous Terms at Diagnosis

The diagnosis of cancer is made when a recognized medical practitioner states that the patient has cancer. As part of the registry casefinding processes, all diagnostic reports should be reviewed to confirm whether a case is required to be reported. If the terminology is ambiguous, use the following guidelines to determine whether a particular case should be included. Words or phrases that appear to be synonyms of these terms do not constitute a diagnosis such as "supposed" for "presumed" or "equal" for "comparable with". "Likely" alone does not constitute a diagnosis however "most likely" does. Use only the exact words on the lists. See the STORE manual Ambiguous Terms at Diagnosis; link provided in *Appendix A*.

The first and foremost resource for the registrar for questionable cases is the physician who diagnosed and/or staged the tumor. If the physician is not available, the medical record, and any other relevant reports, such as the pathology report, should be read carefully for the required information. The purpose of the ambiguous terminology listed below is to help registrars make consistent decisions with respect to reportability when no further information is available from any resource. When there is a clear statement of malignancy, the registrar should not refer to the list of ambiguous terms. Registrars should only rely on these terms when the situation is not clear, and the case cannot be discussed with the appropriate physician or pathologist. These terms must only be used "as references of last resort" in CoC accredited programs.

Genetic findings in the absence of pathologic or clinical evidence of reportable disease are indicative of risk only and do not constitute a diagnosis.

Ambiguous terms that constitute a cancer diagnosis:

Apparent(ly)	Favors	Probable
Appears	Malignant appearing	Suspect(ed)
Comparable with	Most likely	Suspicious (for)
Compatible with	Neoplasm*	Tumor*
Consistent with	Presumed	Typical of

*(beginning with 2004 diagnoses and only for brain and CNS sites C70.0-C72.9, C75.1-C75.3) additional terms for nonmalignant primary intracranial and central nervous system tumors only

<u>Exception</u>: If a cytology is identified only with an ambiguous term, do not interpret it as a diagnosis of cancer. Abstract the case only if a positive biopsy or a physician's clinical impression of cancer supports the cytology findings.

Example of Diagnostic Terms:

The inpatient discharge summary documents a chest x-ray *consistent with carcinoma* of the lung, right upper lobe. The patient refused further work-up or treatment. *Consistent with carcinoma is indicative of cancer*.

Ambiguous terms that do <u>not</u> constitute a cancer diagnosis without additional information:

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

Example of Non-diagnostic Terms:

The inpatient discharge summary documents a chest x-ray consistent with neoplasm of the right upper lobe of the lung. The patient refused further work-up or treatment. Consistent with **neoplasm** is not indicative of cancer. While "consistent with" can indicate involvement, "neoplasm" without specification of malignancy is not diagnostic except for non-malignant primary intracranial and central nervous system tumors.

If there is any question regarding tumor involvement, consult the attending physician or contact an ACR representative.

III.D.4. Class of Case

Class of Case reflects the facility's role in managing the cancer, whether the cancer is required to be reported by CoC or ACR and state law. *Class of Case* is divided into two groups:

 Analytic - those that are required by CoC and Alaska state law to be abstracted because of the facilities primary responsibility in managing the cancer case.
 Nonanalytic - those that are reported per state law or central registry request.

Class of Case 00-32, 38, 43 are reportable to ACR

Code Label 00 Initial diagnosis at the reporting facility AND all treatment or a decision not to treat was done elsewhere. Initial diagnosis at the reporting facility or in an office of a physician with 10 admitting privileges AND part or all of first course treatment or a decision not to treat was at the reporting facility, NOS. Initial diagnosis in an office of a physician with admitting privileges AND part of 11 first course treatment was done at the reporting facility. 12 Initial diagnosis in an office of a physician with admitting privileges AND all first course treatment or a decision not to treat was done at the reporting facility. 13 Initial diagnosis at the reporting facility AND part of first course treatment was done at the reporting facility; part of first course treatment was done elsewhere. Initial diagnosis at the reporting facility AND all first course treatment or a 14 decision not to treat was done at the reporting facility.

Analytic Class of Case, 00-14: Initial diagnosis at reporting facility or in a staff physician's office

Analytic Class of Case, 20-22: Initial diagnosis elsewhere

Code	Label	
20	Initial diagnosis elsewhere AND all or part of first course treatment was done at the	
	reporting facility, NOS.	
21	Initial diagnosis elsewhere AND part of first course treatment was done at the	
	reporting facility; part of first course treatment was done elsewhere.	
22	Initial diagnosis elsewhere AND all first course treatment or a decision not to treat	
	was done at the reporting facility.	

Class of Case not required by CoC to be abstracted, non-analytic. (May be required by Cancer Committee, state or regional registry, or other entity) 30-38: Patient appears in person at reporting facility

Code	Label
30	Initial diagnosis and all first course treatment elsewhere AND reporting facility
	participated in diagnostic workup (for example, consult only, treatment plan only,
	staging workup after initial diagnosis elsewhere)
31	Initial diagnosis and all first course treatment elsewhere AND reporting facility
	provided in-transit care; or hospital provided care that facilitated treatment
	elsewhere (for example, stent placement)
32	Diagnosis AND all first course treatment provided elsewhere AND patient presents
	at reporting facility with disease recurrence or persistence (active disease)
33	Diagnosis AND all first course treatment provided elsewhere AND patient presents
	at reporting facility with disease history only (disease not active) **ACR Note: Not
	Reportable
34	Type of case not required by CoC to be accessioned (for example, a benign colon
	tumor) AND initial diagnosis AND part or all of first course treatment by reporting
	facility. **ACR Note: Not Reportable
35	Case diagnosed before program's (ACR) Reference Date AND initial diagnosis
	AND all or part of first course treatment by reporting facility. **ACR Note: Not
	Reportable
36	Type of case not required by CoC to be accessioned (for example, a benign colon
	tumor) AND initial diagnosis elsewhere AND all or part of first course treatment
	by reporting facility. **ACR Note: Not Reportable
37	Case diagnosed before program's Reference Date (ACR) AND initial diagnosis
	else-where AND all or part of first course treatment by facility. **ACR Note: Not
	Reportable
38	Initial diagnosis established by autopsy at the reporting facility, cancer not
	suspected prior to death. **ACR Note: Reportable

Class of Case not required by CoC to be abstracted, non-analytic. (May be required by Cancer Committee, state or regional registry, or other entity) 40-99: Patient does not appear in person at reporting facility

Code	Label
40	Diagnosis AND all first course treatment given at a physician office or clinic.
41	Diagnosis and all first course treatment given in two or more different staff physician offices.
42	Non-staff physician or non-CoC accredited clinic or other facility, not part of reporting facility, accessioned by reporting facility for diagnosis and/or treatment by that entity (for example, hospital abstracts cases from an independent radiation facility)
43	Pathology or other lab specimens only ** <i>ACR Note: Pathology only, lab only, imaging only are reportable to ACR if the path, lab, and imaging diagnose cancer.</i>
49	Death Certificate only – DCO ** <i>ACR Note: these are reportable when determined to be missed cases during the death clearance process.</i>
99	Non-analytic case of unknown relationship to facility (not for use by CoC accredited cancer programs for analytic cases).

III.D.5. Resident vs. Non-resident

The patient's address at diagnosis is the patient's place of residence at the time of original diagnosis. The address at diagnosis is not updated if the patient moves after diagnosis. If the patient has more than one primary tumor, the address at diagnosis may be different for each primary depending on where the patient lived at the time of diagnosis. Per the U.S. Census Bureau residency is the place where a person lives and sleeps most of the time or the place that the person considers to be his or her usual home. See STORE manual, Patient Address and Residency Rules for more information. Refer to *Appendix C* for guidelines regarding the determination of residency for persons without apparent residences.

The current address initially is the patient's residence at the time the patient was first seen at the accessioning facility for this primary. The current address is updated if the patient moves.

Information on Alaska residents diagnosed and/or treated out-of-state will be obtained by ACR through established data exchange agreements (*case-sharing agreements*) with central registries in other states. ACR will collect cancer data on non-residents diagnosed in Alaska facilities. The information on each non-resident patient will be provided to the central registry in the state in which that patient resides, provided there is an established data exchange agreement with the central registry of that state.

III.D.6. First Course of Treatment vs. Subsequent Treatment

A reporting facility must provide ACR with the date and type of first course of treatment when available. This refers to any treatment that modifies, controls, removes, or destroys any or all malignancies including benign and borderline intracranial and CNS tumors.

As defined in the STORE manual, the first course of treatment includes all methods of treatment recorded in the treatment plan and administered to the patient before recurrence or

disease progression. "Active surveillance" is a form of planned treatment for some patients and is coded in the RX Summ-Treatment Status field. "No therapy" is a treatment option that occurs if the patient and/or family or guardian refuses recommended treatment, the patient dies before the start of treatment, or the physician recommends no treatment is to be given. If the patient refuses all treatment, code "patient refused" for all treatment modalities. First course of treatment includes all cancer-directed treatment planned by the physician(s) during or after the first diagnosis of cancer. Planned treatment may include multiple modes of therapy and may span intervals of a year or more.

If there is no treatment plan, established protocol or management guidelines, use the principle: "initial treatment must begin within four months of the date of initial diagnosis". All other cancer-directed therapy that begins within four months of the date of the initial treatment would be included as first course of treatment. Watchful waiting is considered first course treatment.

III.D.7 Lymphatic and Hematopoietic Disease

Refer to the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) Hematopoietic and Lymphoid Neoplasm Coding Manual and Database. Use this manual and database to abstract and code cases diagnosed January 1, 2010, and forward. Some information is available for cases diagnosed prior to 2010 to assist registrars in coding and making decision on multiple primaries. See *Appendix A* for link to the Hematopoietic and Lymphoid Database and Manual.

III.D.8. Primary vs. Secondary (Metastatic) Site

The primary site identifies the anatomical site where the cancer originated. This cancer is referred to as the primary tumor. A secondary or metastatic site identifies a distant part of the body to which the cancer has spread. Cancer identified at a secondary site is metastatic (i.e., it is not the primary tumor).

Accurate identification of a patient's primary tumor is essential for determination of the stage of disease and for successful use of the data for epidemiological studies. Therefore, when reporting a cancer case, it is important that the primary site, not a secondary (metastatic) site, be identified. Identify the primary site as documented by a physician and use the MPH coding rules (for cases diagnosed 1/1/2007-12/31/2017) or Solid Tumor Rules (for cases diagnosed 1/1/2018 and forward) for primary site coding.

If the only available information on the cancer pertains to metastatic involvement and the reporting facility cannot further define the origin of the primary, the case should be reported as follows:

- If no primary site is documented, code the primary site as unknown (C809).
- Use codes C76.0-C76.8 Other and ill-defined sites if applicable.

Example: A patient has a liver biopsy. The pathology report states, "metastatic adenocarcinoma". Unless more definitive information is available, this cancer case should be reported to ACR with the primary site listed as "unknown" and histology of adenocarcinoma.

When it is uncertain whether a lesion is a primary or secondary tumor or the primary site is unknown, query the primary physician, surgeon, pathologist or have the case presented at tumor board to try to obtain more definitive information about the tumor. If this is not possible, abstract the case as an unknown primary (C809) and document as much information in the text fields from the path report, operative report, History & Physical, radiology reports, treatment reports etc.

III.D.9. Recurring Cancers

Recurrence is the reappearance of disease that was thought to be cured or inactive (in remission). Recurrent cancer starts from the cancer cells that were not removed or destroyed by the original treatment.

Solid Tumor Rules 2018 General Instructions page 9 states: Use the Multiple Primary Rules as written to determine whether a subsequent tumor is a new primary or a recurrence. The **ONLY exceptions** are when a **pathologist compares slides** from the subsequent tumor to the "original" tumor and documents the subsequent tumor is a recurrence of the previous primary. Never code multiple primaries based only on a physician's statement of "recurrence" or "recurrent". If the pathologist compares the tissue from the present tumor to the original tissue and documents that it is a recurrence, add this to your exclusion list.

A cancer may occur at the same site where a previous cancer with a different histology had been diagnosed. Even though this is in the same site, it is reported as a new cancer case. See Solid Tumor Rules for diagnosis year 2018 and forward, 2007 MP/H for diagnosis 2017 and prior to code multiple histologies and timing rules for each site.

III.E. How to Report

III.E.1. Metriq Reporting Hospitals: The hospital CTR will perform casefinding procedures to identify all reportable cancer cases, abstract each case in their hospital database, and transmit to ACR monthly. Supporting text is required to be included in the abstracts to verify histology, staging, etc. Support documentation is not required as abstracts would be completed or overseen by a CTR.

III.E.2. Web Plus Reporting Hospitals: The hospital staff will perform casefinding procedures (*Appendix E*) to identify all reportable cancer cases. Hospital staff will abstract each case identified using ACR's Web Plus system. Web Plus is a web-based abstracting computer program available at no cost to the hospital, and no software is required to be installed for its use. It is available over a secure Internet connection, and access is controlled through ACR's assignment of user IDs and passwords. Supporting text is required to be included in the abstracts to verify coded information (histology, staging, etc.) Copies of the medical records (support documentation) are required for abstract completion and quality assurance of reported data. Documentation may be submitted to ACR through Web Plus, DSM, hospital secure email, fax, or mail.

Support documentation includes the following:

History & Physical Consultation reports Discharge summary Operative report Pathology reports Imaging reports Laboratory reports Radiation, chemo, hormone, etc. Any other reports that have tumor information ACR offers training to new staff assigned to complete cancer reporting for their facility. Contact the ACR Data Analyst, Julie Cleaton, for Web Plus log in and training at <u>julie.cleaton@alaska.gov</u> or call 907-269-8047. Contact the ACR Education and Training Coordinator or call 907-269-8071 for reportability and registrar training.

III.E.3. Contract CTR Reporting Hospitals: The hospital will contract with a Certified Tumor Registrar (CTR) to perform active casefinding and abstracting procedures. Cases can be abstracted using ACR's Web Plus system. Supporting text is required to be included in the abstracts to verify coded information (histology, staging, etc.). No supporting documentation is required to be submitted to ACR since a CTR would be completing the abstracts.

Contact the ACR Data Analyst for Web Plus log in and training at <u>julie.cleaton@alaska.gov</u> or call 907-269-8047.

III.E.4. Pathology Laboratories

Pathology laboratories should submit data electronically to ACR. Cases can be transmitted in HL7 NAACCR record layout specifically developed for pathology laboratory reporting. See the NAACCR document, "Standards for Cancer Registries, Volume V, Pathology Laboratory Electronic Reporting" for record layout details. Alternatively, cases can be abstracted using Web Plus. Contact the ACR Data Analyst, Julie Cleaton, for Web Plus log in at julie.cleaton@alaska.gov or call 907-269-8047.

III.E.5. Physicians

ACR requires reporting from physicians in private and group practice who diagnose and/or treat patients with cancer.

Physician practices reporting more than 25 cases per year are strongly encouraged to report electronically using the HL7-CDA CDC record layout which was specifically developed for physician reporting for the "Meaningful Use" Medicare and Medicaid incentive program. See the CDC document, "Implementation Guide for Ambulatory healthcare Provider Reporting to Central Cancer Registries HL7 Clinical Document Architecture (CDA), Release 1.1 March 2014" for record layout details. Otherwise, they can report electronically using ACR's Web Plus system. Contact the ACR Data Analyst, Julie Cleaton, for Web Plus log in at julie.cleaton@alaska.gov or call 907-269-8047.

If there are extenuating circumstances that prevent electronic reporting approved by ACR management, then physicians can report using the "ACR Cancer Reporting Form for Health Care Providers" (*Appendix D*). Both Web Plus and reporting form submissions should include copies of supporting documentation specific to the cancer (physical examination reports, x-rays/scans, scopes, laboratory tests, operative reports, pathology reports, radiation therapy reports, diagnostic radiology reports).

III.E.6. Submitting Data to ACR

Data on reportable cancer cases may be transmitted to ACR using the various secure methods as defined in section II.D. Electronic files should be in the current NAACCR record layout.

III.F. Death Clearance

Death clearance is the process of matching registered deaths each year against the reported cases in the ACR database to see if the cancer cause of death for each person had been reported to ACR. If not, death clearance follow back is performed to identify potentially missed cases.

The ACR registrar designated to perform death clearance will send a follow back Excel spreadsheet to each hospital consisting of a list of names to be researched against the hospital database. The hospital registrar should identify and document on the spreadsheet persons who were seen at the facility and whether there is a diagnosis of cancer in the medical records. Upon completion of the research, the reconciled follow back spreadsheet should be submitted to ACR through Web Plus, DSM, or hospital secure email. Any cases determined to be missed are to be abstracted as a missed incidence case and submitted to ACR, allowing the case to be removed from death clearance only (DCO) status. After research, the case could be found as non-reportable because it does not meet reporting criteria or remain as a DCO case if the only information available is from the death certificate. For these two outcomes, no abstract is submitted by the hospital.

For the death clearance follow-back process to be complete, both of the following conditions must be met:

- 1. All potential incidence cases must be resolved as a missed incidence case, a DCO case, or excluded as not-reportable based on registry reporting requirements.
- 2. All cases determined to be a missed incidence case or DCO case must be entered into the registry database.

Death Clearance is performed annually on deaths which occurred two years back from the current year. ACR begins the process in April and concludes the process by the end of September. Death Clearance is a case finding process for ACR to ensure that all cancer cases are reported in the state of Alaska.

III.G. What Happens After Reporting

When cancer cases are received in the ACR office, they are recorded in a submission log. Electronic submissions are transferred to a secure data server pending quality control review and uploaded into the central registry database. Hardcopy submissions are hand-entered into the central registry database and then stored in a locked file cabinet.

III.G.1 Quality Control (QC) of Submitted Abstracts

ACR performs visual quality control (QC) on abstracts submitted by all reporting facilities. This process entails comparing the codes entered in all the required fields to the text entered in the text fields for accuracy and completeness of data.

III.G.2. Tracking Quality of Data via Hospital Feedback

To improve data quality, ACR will send feedback to CTR hospitals and those facilities who submit medium or large hospital abstracts in Web Plus for education and training purposes.

- ACR registrars compare the coded fields to the information entered in the text fields in the abstract.
- If there is a discrepancy, the ACR registrar will change the codes according to the text entered in the text fields.
- The ACR registrars report the change to the hospital via the hospital feedback report.
- The hospital feedback report is an Excel spreadsheet created by the designated ACR registrar for that hospital.
- The hospital feedback will be sent out quarterly via Web Plus.
- The hospital will have 1 month to refute any changes made.
- After two months, the abstract is closed to changes unless new information is submitted by the hospital.

III.G.3. Tracking Completeness of Data:

- ACR utilizes the annual MDI Audits and Death Clearance to track completeness of data for the National Data Quality Standard for the November Call for Data.
- Each ACR registrar will communicate with their designated hospitals for the status of their reporting as warranted.

III.G.4. Tracking Timeliness of Data:

Abstracts are required to be submitted to ACR within six months from date of diagnosis or date of 1st contact (Alaska Administrative Code, 7 AAC 27.011)

III.G.5 Re-Abstracting Audit

NPCR Standard for Re-abstracting audits states: at least once every five years a combination of casefinding and re-abstracting audits from a sampling of source documents are conducted for each hospital-based reporting facility and may include external audits by CDC or SEER.

A re-abstracting audit compares submitted data to source documents to validate the accuracy and validity of the data.

The purpose of a re-abstracting audit is to:

- Identify discrepancies in the interpretation of the information in the medical records and/or abstracting and coding rules.
- Help identify missing information to determine if the information was truly not available or missed by the hospital registrar.
- Look for patterns in incorrect coding of data which would provide opportunities for training and standardize the interpretation and abstracting among data collectors.
- Help identify the need for modification of ACR and hospital registry processes and procedures.

ACR has established the following guidelines for conducting the re-abstracting audits:

- Hospital based registries which report more than 50 cases per year qualify for the reabstracting audit.
- Due to software and other challenges, military hospitals will not undergo reabstracting audits.
- The re-abstracting audit will be performed on the current plus one year data. A minimum of five and not more than 10 items will be chosen to be re-abstracted. (This will be determined by the ACR registrars prior to the audit.)
- 10% of the reported cases not to exceed 15 cases will be re-abstracted.
- Only cases in which the patient was diagnosed and treated at the hospital will be reabstracted.

Further information will be sent to the hospital registrars when the re-abstracting audit is scheduled for each hospital.

For assistance or any questions, call the Alaska Cancer Registry at (907) 269-0995. Registry staff is available Monday through Friday, 8:00 AM - 5:00 PM except holidays.

APPENDIX A: REQUIRED CANCER REPORTING MANUALS BY STANDARD SETTER

American College of Surgeons, Commission on Cancer, National Cancer Database <u>https://www.facs.org/quality-programs/cancer/ncdb/call-for-data</u>

1. Standards for Oncology Registry Entry (STORE) Manual.

Use for cases diagnosed January 1, 2018 forward. https://www.facs.org/~/media/files/quality%20programs/cancer/ncdb/store_manual_2 018.ashx

Read Foreword, Preface, and Section One: Case Eligibility and Overview of Coding Principles (pgs. 1-44)

2. Facility Oncology Registry Data Standards (FORDS).

Use for cases diagnosed January 1, 2002 to December 31, 2017. Reference the version of FORDS depending on the year of diagnosis: <u>https://www.facs.org/quality-programs/cancer/ncdb/call-for-data/fordsolder</u> Read Section One: Case Eligibility and Overview of Coding Principles prior to using manual

Section Two: Instructions for Coding provides reference for coding fields in the abstract

Appendix B: Site-Specific Surgery Codes – use to code surgeries; having a printed copy for reference may help when abstracting

American Joint Commission on Cancer (AJCC) https://cancerstaging.org

1. Cancer Staging Manual, 8th Edition.

For cases diagnosed from 1/1/2018 and forward.

The 3rd Printing of the 8th Edition AJCC Cancer Staging Manual has been updated since the initial release of the manual and is only available for print purchase at this time.

Read Chapters 1 and 2 for general instructions and the Rules for Classification in each site chapter prior to assigning stage

ACR and NPCR will not require AJCC TNM 8th Edition staging to be assigned for cases diagnosed in 2018 and 2019 for all hospitals. Please reference individual registry requirements to ensure adequate data fields are completed prior to submission Small and medium hospitals abstracting through Web Plus will not be required to assign AJCC TNM Stage if the registrar is not a CTR (Certified Tumor Registrar). All staging information regarding tumor size, lymph node involvement and metastasis should be entered in the text fields and support documentation must be sent to ACR to allow for abstract completion

2. Cancer Staging Manual, 7th Edition.

For cases diagnosed January 1, 2010 to December 31, 2017. <u>https://cancerstaging.org/references-tools/deskreferences/Pages/default.aspx</u> Read Chapter 1, Purposes and Principles of Cancer Staging for general guidelines Read Rules for Classification in each site chapter before assigning stage Small and medium hospitals abstracting through Web Plus will not be required to assign AJCC TNM Stage if the registrar is not a CTR. All staging information regarding tumor size, lymph node involvement and metastasis should be entered in the text fields and support documentation must be sent to ACR to allow for abstract completion

3. Collaborative Staging Manual and Coding Instructions, Version 02.05. Use for cases diagnosed January 1, 2010 to December 31, 2017.

https://cancerstaging.org/cstage/schema/Pages/version0205.aspx

- On the website, click on Coding Instructions; there will be a link to download CS Coding Instructions v02.05. Read general rules and instructions.
- Access the Site Specific CS schemas by clicking on the Schema header tab. The sites are listed in natural order but can be sorted to alphabetical order by clicking on the appropriate page tab.

Read the notes at the top of the page for coding the CS fields for each site There are also notes of discontinued Site Specific Factors in many of the schemas that are no longer required; follow the rules to code for "not collected."

For cases diagnosed 01/01/2004 through 12/31/2015, the following fields are required:

CS Tumor Size CS Extension CS Tumor Size/Ext/Eval CS Lymph Nodes CS Lymph Nodes Eval CS Mets at DX CS Mets at DX – Bone, Brain, Liver, Lung CS Mets Eval CS Site Specific Factors 1-25^{*} (*required through 12/31/2017)

For cases diagnosed 01/01/2016 through 01/01/2017, the following fields are required:
Tumor Size SummaryTumor Size SummaryMets at DX-LiverMets at DX-BoneMets at DX-LungMets at DX-BrainMets at DX-OtherMets at DX-Distant LNMets at DX-Other

For cases diagnosed 01/01/2018 and forward, Site Specific Data Items (SSDIs) replace Site Specific Factors (SSFs). See NAACCR information on next page.

Collaborative Stage (CS) Version Guideline

Version #	Date Started	Date Ended
010400	1/1/2008	12/31/2009
020200	1/1/2010	12/31/2010
020302	1/1/2011	12/31/2011
020440	1/1/2012	12/31/2013
020550	1/1/2014	12/31/2015

CS Version Input Current – enter the current version 020550

CS Version Input Original – enter the version # for the year of diagnosis

CS Version Derived – enter the current version 020550 for cases diagnosed through 12/31/2015. This field will no longer be required for cases diagnosed 1/1/2016 and forward.

North American Association of Central Cancer Registries (NAACCR)

https://www.naaccr.org

- Grade Coding Instructions and Tables
 <u>https://www.naaccr.org/SSDI/Grade-Manual.pdf</u>
 Effective for use with cases diagnosed 01/01/2018 and forward
 Read all introductory information prior to using the site-specific grading tables (pgs. 7-30)
- 2. National Interstate Data Exchange Agreement https://www.naaccr.org/national-interstate-data-exchange-agreement/
- 3. Pathology Laboratory Electronic Reporting, Volume V https://www.naaccr.org/pathology-laboratory-electronic-reporting/

4. Site-Specific Data Item (SSDI) Manual

https://www.naaccr.org/SSDI/SSDI-Manual.pdf?v=1527608547 Required for all cases starting with tumor diagnosed January 1, 2018 and forward. Before using the SSDI Manual, it is important to review the introductory materials and general instructions carefully. Although the majority of data items that are collected as SSDIs were previously collected as SSFs, the format of the data items and allowable values have changed substantially.

Surveillance, Epidemiology, and End Results (SEER) <u>https://seer.cancer.gov/</u>

- 2018 Solid Tumor Coding Rules. Use for cases diagnosed January 1, 2018 and later. <u>https://seer.cancer.gov/tools/solidtumor/</u> Read Preface and General Instructions (pgs. 3-14) prior to using manual Use to determine the number of primaries to abstract and the histology codes to use for each primary
- 2007 Multiple Primary and Histology (MP/H) Coding Rules, revised November 2010. Effective for cases diagnosed January 1, 2007 to December 31, 2017. <u>https://seer.cancer.gov/tools/mphrules/</u> Read Preface and Multiple Primary & Histology Rules General Instructions (pgs. 5-14) prior to use for each primary Use to determine the number of primaries to abstract and the histology codes to use for each primary

3. Hematopoietic and Lymphoid Neoplasm Database.

May be used for any/all hematopoietic or lymphoid neoplasms by year of effective date

https://seer.cancer.gov/tools/heme/

https://seer.cancer.gov/tools/heme/Hematopoietic_Instructions_and_Rules.pdf Read the introductory information (pgs. 8-40) prior to using manual The online database has the option to calculate for multiple primaries. This should be used secondary and when prompted to do so in the manual

- 4. Instructions for Coding Grade for 2014+ <u>https://seer.cancer.gov/tools/grade/grade-2014-coding-instructions.pdf</u> Effective for use with cases diagnosed 01/01/2014 through 12/31/2017
- 5. SEER Program Coding and Staging Manual 2016: Section V Stage of Disease at Diagnosis

https://seer.cancer.gov/archive/manuals/2016/SPCSM_2016_SectionV.pdf Use to determine Tumor Size Summary and Mets at Dx fields.

6. <u>SEER Rx</u> – Interactive Antineoplastic Drugs Database. May be used to help code any non-surgical treatments

https://seer.cancer.gov/tools/seerrx/

Provides a searchable database; lists Generic and brand names of drugs, the type of treatment (category), the primary site(s) treated, and whether to code Clicking on search results opens more information on each drug or regimen

7. Summary Staging Manual 2018.

Effective for cases diagnosed January 1, 2018 and forward. <u>https://seer.cancer.gov/tools/ssm/</u> Read the General Coding Instructions section (pgs. 4-29) prior to using manual

8. Summary Staging Manual 2000.

Effective for cases diagnosed January 1, 2001 to December 31, 2017. <u>https://seer.cancer.gov/tools/ssm/ssm2000/</u> Read the introductory information for coding guidelines (pgs. 2-15) prior to use

World Health Organization (WHO) https://www.who.int/

- Use to code topography (primary site)
- Use to code morphology (histology)
- 1. International Classification of Diseases for Oncology, 3rd Edition, 2nd Revision (ICD-O-3.2).

Recommended for use on cases starting January 1, 2020 and forward. <u>http://www.iacr.com.fr/index.php?option=com_content&view=category&layout=blog&id=100&Itemid=577</u>

2. International Classification of Diseases for Oncology, 3rd Edition, 1st Revision (ICD-O-3.1).

For use on cases diagnosed January 1, 2009 to December 31, 2019. <u>http://www.iacr.com.fr/index.php?option=com_content&view=category&layout=blog&id=100&Itemid=577</u>

Read sections 1-4 (pgs. 1-30) for information regarding the history, structure, and coding principles within this manual.

- 3. International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3). For use on cases through December 31, 2008. <u>http://www.iacr.com.fr/index.php?option=com_content&view=category&layout=blog&id=100&Itemid=577</u>
- International Classification of Diseases, 10th Edition, Clinical Modification (ICD-10-CM)
 Effective October 1, 2015.
- 5. International Classification of Diseases, 9th Edition, Clinical Modification (ICD-9-CM)

Effective until 09/30/2015.

Required Cancer Reporting Manuals by Standard Setter

A, Fritz and Associates, LLC Manual versions based on diagnosis year

International Classification of Diseases for Oncology - ICD-O-3

- First edition 1976 1991
- Second edition 1992 2000
- Third edition 2001 present

American Joint Committee on Cancer (AJCC) TNM Staging System

- Second edition 1983 (breast only) 1988
- Third edition 1989 1992 (all sites)
- Fourth edition 1993 1997
- Fifth edition 1998 2002
- Sixth edition 2003 2009
- Seventh edition 2010 2017
- Eighth edition 2018 present

Summary Staging

•	Summary Staging Guide	1977 - 2000
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- SEER Summary Staging Manual 2000 2001 2017
- SEER Summary Staging Manual 2018 2017 present

Collaborative Stage Data Collection System

- Version 1.00 2004
- Version 1.01 2004
- Version 1.02 2005
- Version 1.03 2007
- Version 1.04 2008
- Version 2.00 2010
- Version 2.03.00 2011
- Version 2.04.00 2012
- Version 2.05 2014

Solid Tumor Rules	2018 – present
Multiple Primaries and Histology Coding Rules	2007 - 2017
STORE – Standards for Oncology Registry Entry	2018 – present
FORDS – Facility Oncology Registry Data Standards	2003 - 2017
ROADS – Registry Operations and Data Standards Manual	1996 - 2002

APPENDIX B: LOCAL, STATE, AND NATIONAL TRAINING FOR CANCER REGISTRARS

- 1. NAACCR Webinars monthly. ACR purchases the NAACCR Webinar Series each year to provide training and education to hospital registrars that report cancer cases to ACR. Webinars are posted to ACR's FLccSC learning management system.
- 2. ACR Newsletter sent quarterly via email.
- 3. TRAK (Tumor Registrars of Alaska) Educational Conference registrar conference held in Anchorage.
- 4. NCRA (National Cancer Registrars Association) Educational Conference annual.
 - See the NCRA website for Conference dates and locations. <u>https://www.ncra-usa.org/</u>
 - NCRA Center for Cancer Registry Education (must be a NCRA member) <u>http://www.cancerregistryeducation.org/</u>
- 5. <u>Cancer Registry Management Principles & Practices for Hospitals and</u> <u>Central Registries, Third Edition</u>
 - Composed of 42 chapters, which are organized into six sections: Planning and Design of Registries, Informatics, Operations, Uses of Registry Data, Standard Setters, and Professional Organizations, and Central and Other Registries.

6. North American Association of Central Cancer Registries (NAACCR)

- Monthly webinars are purchased by ACR. Recorded versions of the webinars will be available in the ACR FLccSC portal when it has been established in the spring of 2020.
- The NAACCR Webinars are to provide education and training to cancer registrars who abstract and report cancer cases to ACR.
- Per Jim Hofferkamp, NAACCR: We do have a standing policy that central registries can re-distribute the webinars to registries that report to them and to the registry staff. They should not redistribute to anyone that is not a member of their staff or does not report to the central registry. Some state registries purchase the webinar series through the state association. That way anyone that is a member of the state association can have access to the recordings.

7. <u>SEER (Surveillance, Epidemiology, and End Results Program)</u>

<u>https://seer.cancer.gov/registrars/</u> For Cancer Registrars: Information for cancer registrars

• SEER Program Coding and Staging Manual

- Appendix A County Codes
- Appendix B Country and State Codes
- Appendix C Site Specific Coding Modules
 - A list of all the sites comes up.
 - Click on a site and you will see MP/H coding rules, CS Staging Scheme, and Surgery Codes
 - SEER surgery codes sometimes have better explanations of the surgeries, so I print a copy to put with the FORDS Appendix B – Site Specific Surgery codes for each site.
- Other Manuals
 - o SEER Summary Stage 2000 and Summary Stage 2018
- <u>Training</u>
 - Cancer Registrar Training the following resources are available for cancer registrars.
 - Hematopoietic & Lymphoid Neoplasms Online Training
 - Multiple Primary and Histology Coding Rules Training
 - SEER*Educate
 - SEER Self Instructional Manuals for Tumor Registrars
 - SEER's Training Web Site Web-based training modules for cancer registrars. These are self-paced training modules.

APPENDIX C: RULES FOR PERSONS WITHOUT APPARENT RESIDENCES

<u>Persons with More Than One Residence</u> (summer and winter homes): Use the address the patient specifies if a usual residence is not apparent.

<u>**Persons with No Usual Residence**</u> (transients, homeless): Use the address of the place they were staying when the cancer was diagnosed. This could be a shelter or the diagnosing facility.

Persons Away at School: College students are residents of the school area. Boarding school children below college level are residents of their parents' home. (<u>Note</u>: This rule does not apply when determining eligibility for receipt of the Alaska Permanent Fund Dividend).

<u>**Persons in Institutions:**</u> The Census Bureau states "Persons under formally authorized, supervised care or custody" are residents of the institution. This includes:

- Incarcerated persons
- Persons in nursing, convalescent, and rest homes
- Persons in homes, schools, hospitals, or wards for the physically disabled, mentally challenged or mentally ill
- Long-term residents of other hospitals, such as Veterans Administration (VA) hospitals

<u>Persons in the Armed Forces and on Maritime Ships:</u> Members of the armed forces are residents of the installation area. Use the stated address for military personnel and their family. Military personnel may use the installation address or the surrounding community's address.

The Census Bureau has detailed residency rules for Navy personnel, Coast Guard, and maritime ships. Refer to Census Bureau publications for the detailed rules.

APPENDIX D: GUIDELINES FOR COMPLETING CANCER REPORTING FORMS

It is preferred that submitters of cancer data use Web Plus Internet reporting. Electronic data entry is preferred; however, if a provider does not have the capacity to report electronically, paper submission is accepted. All forms are located on the ACR web site and can be printed off at your location or saved to your computer:

http://dhss.alaska.gov/dph/Chronic/Documents/Cancer/assets/ProviderCancerForm.pdf

Supporting Text/Documentation

While the information supplied will vary depending on the nature of the reporting source (i.e., physician vs. hospital), it is important that each reporting source provides all the information it can on each reportable cancer case. When available, the reporting source should provide any additional supporting documentation that helps substantiate the information recorded on this form. This includes pathology, surgery, x-ray, and other laboratory reports.

REPORTING SOURCES:

All hospitals, physicians, surgeons, and other health care facilities and practitioners (e.g., laboratories, clinics, outpatient surgery centers, nursing homes) screening, diagnosing, or providing treatment for cancer patients in the State of Alaska are considered reporting sources.

REPORTING TIMEFRAME:

Alaska law requires the Reporting Source to submit a case report within six months of the date of diagnosis or within six months of the patient's first visit after diagnosis of a reportable cancer.

WHICH CANCERS ARE REPORTABLE?

See Section III.D.

THE CANCER REPORTING FORM:

For each reportable cancer diagnosed and/or treated at your office or facility, submit a Cancer Reporting Form containing healthcare provider identification, patient identification and demographics, cancer identification, diagnostic information, and treatment information. A section concerning family history of cancer and smoking history is also included. A separate Cancer Reporting Form must be completed for each primary tumor. *Example: Two Cancer Reporting Forms would be required for a patient diagnosed with a primary adenocarcinoma of the lung and Burkitt's lymphoma*.

COMPLETING THE CANCER REPORTING FORM:

Please type or clearly print the information requested for each item. While most items are self-explanatory, the following instructions may be useful:

Reporting Health Care Provider (Name, Address & Phone #)

Record the name, address and phone number of your office or facility.

Form Completed by (Name)

Record the name of the person completing the report form.

Date Form Completed

Record the MM/DD/YY the report form was completed.

Name of Provider or Facility Patient Referred to

Record the name and address of the physician or facility to whom you referred the patient.

Patient's Name (Last, First, Middle, Maiden, or Aliases)

Record the full name of the patient.

Patient's Address at Diagnosis (Street, City, State, Zip Code)

Record the permanent home address at the time of diagnosis, **not** a temporary relocation for treatment. Street address takes priority over post office box number.

Social Security Number

Record the patient's social security number. Do not record the spouse's number.

Date of Birth

Record the patient's birth date in MM/DD/YY format.

Marital Status (Check one)

Check the most appropriate category for the patient's marital status.

Race (Check one)

Check the most appropriate category for the patient's race. If "American Indian/AK Native", indicate tribe if available. When "Other" category is checked, be as specific as possible.

Ethnic Type (Check one)

Check the most appropriate category for the patient's ethnic type. If "Hispanic" category is checked, be as specific as possible.

Sex (Check one)

Check the appropriate category for the patient's sex.

Date of Diagnosis

Record, in MM/DD/YY format, the date of first diagnosis of this cancer by any recognized medical practitioner.

Date of First Contact

Record, in MM/DD/YY format, the date the patient was first seen at your office or facility with a reportable cancer.

Date of Last Contact

Record, in MM/DD/YY format, the date the patient was last seen at or contacted by your office or facility.

Diagnosing Facility/Office

Record the place of first diagnosis of this cancer by any recognized medical practitioner.

Primary Site

Record the site of origin of the cancer. It is important to identify the **primary** site and **not** a metastatic site. If the primary site cannot be determined, enter "Unknown".

Histologic Cell Type

Record the histology. Example: small-cell carcinoma, adenocarcinoma, etc.

Tumor Grade

Record the tumor grade, if known. Example: undifferentiated.

Paired Organ/Laterality (Check one)

Check the appropriate category for the organ involved. *Example: For colon, check "not applicable" because the colon is not a paired organ.*

Diagnostic Confirmation (Check one)

Check the most reliable method used in diagnosing this cancer.

Tumor Size (mm)

Record the size of the patient's tumor, when applicable. *Example: For leukemia, tumor size is* **not** applicable.

Stage of Disease at Diagnosis (Check one)

Stage of Disease at Diagnosis (i.e., the "stage" of the cancer) is limited to all information available **within four months** of diagnosis. **Remember:** The stage of disease indicates how far the cancer has spread **at the time of diagnosis**. Check the most appropriate stage category.

In Situ: Not progressed through the basement membrane of the organ involved (non-invasive tumor).

Localized: Limited to the site of origin; progression through the basement membrane, but not beyond the walls of the organ involved.

Regional, Direct Extension: Tumor invades adjacent organs or tissues only.

Regional, Lymph Nodes: Tumor involvement of regional nodes only.

<u>Regional, Direct Extension and Lymph Nodes</u>: Tumor invades both adjacent organs and regional lymph nodes.

<u>Regional, NOS</u>: Not otherwise specified (i.e., the stage is "regional", but invasion of adjacent organs and/or lymph node involvement is not specified).

<u>Distant</u>: Direct extension beyond adjacent organs or tissues or metastases to distant site(s) or distant lymph nodes (e.g., spread through the

Unstaged: No information is available to determine the stage of disease.

<u>First Course of Treatment</u> (i.e., treatment that modifies, controls, removes, or destroys cancer tissue) - Check all categories that apply for the planned first course of treatment only. If "Other" category is checked, please specify.

Date Therapy Initiated (if known)

Record the date that treatment was first initiated, if known.

Did the Patient Go Out-of-State for Therapy?

Indicate if the patient went out-of-state for therapy and specify the state.

Family History of Cancer (Check)

Check the appropriate category to indicate family history of cancer.

Smoking History (Check)

Check the most appropriate category to indicate the patient's smoking history. Indicate the total number of years the patient has smoked and the number of packs smoker per day.

ACR CANCER REPORTING FORM FOR HEALTH CARE PROVIDERS

Instructions: Complete this form on each patient diagnosed with and/or treated for a reportable cancer. A separate form must be completed for each primary tumor.

REPORTING HEALTH CARE PRO	VIDER		Т	elephone:	
FORM COMBLETED BY AL-				Fax: DATE COMPI	EPED
FORM COMPLETED BY (Name)				DATE COMPL	ETED
NAME OF PROVIDER OR FACILI	TY PATIENT REFI	ERRED TO (IF A)	NY) (i.e., Oncology, Rad	liation Oncologist, Su	irgeon)
PATIENT'S NAME (Last)	(First)	(Middle)	(Maiden or Aliase	s)	
PATIENT'S ADDRESS AT DIAGNO	OSIS (Street, City, Sta	ate, Zip Code)			
SOC, SEC, #	DATE OF BIR	TH MARI	TAL STATUS (Chec	k one)	
			ingle D Married	Separated	
	MMDDY	•	Divorced D Widowed	I Unknown	
RACE (Check one)		ETHNIC TYPE	(Check one)		SEX (Check one)
White Black		Non-Hispanic			(Check one)
	Pacific Islander			pecify)	Male
Other Unknown	(specify)		141	<u></u>	Female
DATE OF DIAGNOSIS DATE OF	FIRST CONTACT	DATE OF LAST	CONTACT DIA	GNOSING FACI	LITY/OFFICE:
PRIMARY SITE	0011	M M D			
HISTOLOGIC CELL TYPE			TUMOR	GRADE	
PAIRED ORGAN/LATERALITY (C		p. 🗆 Right 🗆 L	eft 🗆 Both 🗆 Side	e not specified	Unknown
DIAGNOSTIC CONFIRMATION (C	· · · · · · · · · · · · · · · · · · ·	_	_		
	gy Micro-c		•	Direct Visualizati	on
Clinical diagnosis only Radiog TUMOR SIZE (mm) STAGE OF	DISEASE AT DIA	marker study		Unknown	
			gional, Direct Extensi	on & Lymph Node	e 🗆 Distant
	Regional, Lymph		gional, NOS	on ee Eympir rood	
FIRST COURSE OF TREATMENT		3		ncer tissue)	
(Check all that apply): None					ve only
Excisional E	Biopsy 🛛 Laser surg	jery 🗆	Cryosurgery	□ Surgery	, NOS
Radiation	Chemothe	гару 🗆	Hormone therapy	Immun	otherapy
Other (speci	fy):				
DATE THERAPY INITIATED (if known):					
DID THE PATIENT GO OUT-OF-STATE FOR THERAPY: Yes No IF YES, WHICH STATE:					
Fam. Hist. of Cancer (Check): None Sibling Parent Grandparent Aunt/Uncle Spouse Child Unk.					
Smoking History (Check): Tot, Yrs. Smoking Packs/Day					
□ Non-smoker □ Smoker □ Cig	ar/pipe Chew/sr	uff 🗌 Quit 🗌			-
Note: Please submit supporting to				elpra oparativa. H	L&D) to varify

<u>Note</u>: Please submit supporting text/documentation (e.g., pathology reports/radiology findings/pre-operative H&P), to verify diagnosis, staging, histology, treatment, etc. Please mail this form and documentation to: Alaska Cancer Registry, Department of Health and Social Services, Division of Public Health, Section of Chronic Disease Prevention and Health Promotion, 3601 C St. Suite 722, Anchorage, AK 99503-5934. If you have any questions, please contact ACR at (907) 269-2020 or (888) 933-7874; Fax: (907) 561-1896. Thank you for your cooperation.

APPENDIX E: CASEFINDING

Casefinding is a term generally applied to a hospital setting but can be used in physician practices as well. It is a system for identifying every cancer case seen by a facility whether for screening, diagnosis, or treatment. Although exact procedures might vary from hospital to hospital, they ordinarily involve careful monitoring of the records kept by the services and departments. There are two methods of casefinding: ACTIVE and PASSIVE.

Active casefinding is performed by registry personnel who screen the source documents themselves. This method is usually done in hospitals where the registry has a Certified Tumor Registrar (CTR) or a designated cancer reporter. Passive casefinding is when other departments notify the registrar of potentially reportable cases. In all situations, all potential cases found by Medical Disease Index (MDI) review or pathology review must be reconciled and reported to ACR. The following are sources that may be useful in casefinding within your organization.

Medical Disease Index (MDI)

Disease index and daily discharges. Certain ICD-9-CM (before October 1, 2015) and ICD-10-CM (after October 1, 2015) codes used by medical records departments for discharge diagnosis identify neoplasms that may be reportable to ACR. Case finding procedures should include a periodic review of the medical records with the following ICD-9 and ICD-10 codes and then the subsequent determination of reportability prior to sending to ACR. These lists can also be found on the SEER Website: https://seer.cancer.gov/tools/casefinding/

Code	Description
140.9-199.1	Malignant Neoplasms (excluding 173.0-173.9, other malignant neoplasm of the
	skin)
200.0-208.9	Malignant Neoplasms of Lymphatic and Hematopoietic Tissue
209.0-209.3	Neuroendocrine Tumors (effective 1/1/2009)
225.0-225.9	Benign Neoplasms of brain and other parts of nervous system
227.3	Benign Neoplasms of pituitary gland and craniopharyngeal duct
227.4	Benign Neoplasm of pineal gland, pineal body
230.0-234.9	Carcinoma In-situ (excluding 233.1, carcinoma in-situ of the cervix uteri and excluding 232, carcinoma in-situ of the skin)
238.4	Polycythemia vera (histology 9950)
238.7	Lymphoproliferative/Myelodysplastic Syndrome Disease
273.3	Waldenstrom's Macroglobulinemia
288.1	Hemophagocytic syndrome (histology 9751 & 9754)

ICD-9-CM Case Finding Codes (use before October 1, 2015)

ICD-10-CM Case Finding Codes (use from October 1, 2015 to present)

Code	Description	
C00 C43, C4A.	Malignant neoplasms (excluding category C44), stated or presumed to	
-, C45 ,C96	be primary (of specified site) and certain specified histologies	
C4A	Merkel cell carcinoma	
C44.00-C44.99	Basal cell carcinoma and Squamous cell carcinoma of the skin C44.x	
	are not reportable.	
C44.00, C44.09	Unspecified/other malignant neoplasm of skin of lip	
C44.10-, C44.19-	Unspecified/other malignant neoplasm of skin of eyelid	
C44.20-, C44.29-	Unspec/other malignant neoplasm skin of ear and external auricular canal	
C44.30-, C44.39-	Unspec/other malignant neoplasm of skin of other/unspecified parts of face	
C44.40, C44.49	Unspecified/other malignant neoplasm of skin of scalp & neck	
C44.50-, C44.59-	Unspecified/other malignant neoplasm of skin of trunk	
C44.60-, C44.69-	Unspec/other malignant neoplasm of skin of upper limb, incl. shoulder	
C44.70-, C44.79-	Unspec/other malignant neoplasm of skin of lower limb, including hip	
C44.80, C44.89	Unspec/other malignant neoplasm of skin of overlapping sites of skin	
C44.90, C44.99	Unspec/other malignant neoplasm of skin of unspecified sites of skin	
D00-D03, D05,	In-situ neoplasms Note: Carcinoma in situ of the cervix D06(CIN III-8077/2);	
D07-D09	Prostatic Intraepithelial Carcinoma D07.5(PIN III-8148/2) and D04 carcinoma in-situ of the skin are not reportable	
D18.02	Hemangioma of intracranial structures and any site	
D18.1	Lymphangioma, any site Note: Includes Lymphangiomas of Brain, Other parts of nervous system and endocrine glands, which are reportable	
D32	Benign neoplasm of meninges (cerebral, spinal, and unspecified)	
D33	Benign neoplasm of brain and other parts of central nervous system	
D35.2 - D35.4	Benign neoplasm of pituitary gland, craniopharyngeal duct and pineal gland	
D42, D43	Neoplasm of uncertain or unknown behavior of meninges, brain, CNS	
D44.3 - D44.5	Neoplasm of uncertain or unknown behavior of pituitary gland, craniopharyngeal duct and pineal gland	
D45	Polycythemia vera (9950/3) ICD-10-CM Coding instruction note: Excludes familial polycythemia (C75.0), secondary polycythemia (D75.1)	
D46	Myelodysplastic syndromes (9980, 9982, 9983, 9985, 9986, 9989, 9991, 9992)	
D47.1	Chronic myeloproliferative disease (9963/3, 9975/3) <i>ICD-10-CM Coding instruction note: Excludes the following:</i> <i>Atypical chronic myeloid leukemia BCR/ABL-negative (C92.2_)</i> <i>Chronic myeloid leukemia BCR/ABL-positive (C92.1_)</i> <i>Myelofibrosis & Secondary myelofibrosis (D75.81)</i> <i>Myelophthisic anemia & Myelophthisis (D61.82)</i>	

Code	Description
D47.3	Essential (hemorrhagic) thrombocythemia (9962/3)
	Includes: Essential thrombocytosis, idiopathic hemorrhagic
	thrombocythemia
D47.4	Osteomyelofibrosis (9961/3)
	Includes: Chronic idiopathic myelofibrosis
	Myelofibrosis (idiopathic) (with myeloid metaplasia)
	Myelosclerosis (megakaryocytic) with myeloid metaplasia)
	Secondary myelofibrosis in myeloproliferative disease
D47.Z-	Neoplasm of uncertain behavior of lymphoid, hematopoietic, and
	related tissue, unspecified (9960/3, 9970/1, 9971/3, 9931/3)
D47.9	Neoplasm of uncertain behavior of lymphoid, hematopoietic, and
	related tissue, unspecified (9970/1, 9931/3)
D49.6, D49.7	Neoplasm of unspecified behavior of brain, endocrine glands, and other
	CNS
R85.614	Cytologic evidence of malignancy on smear of anus
R87.614	Cytologic evidence of malignancy on smear of cervix
R87.624	Cytologic evidence of malignancy on smear of vagina

Note: Pilocytic/juvenile astrocytoma M-9421 moved from behavior /3 (malignant) to /1 (borderline malignancy) in ICD-O-3. However, SEER registries will CONTINUE to report these cases and code behavior as /3 (malignant).

Pathology Reports. These include cytology, tumor markers, and autopsy reports. Since pathologic studies are done for most patients suspected of having cancer, reviewing pathology reports for casefinding new reportable cases. Positive pathology reports should provide information on the primary site, histology, and stage of disease of the cancer.

Lab/Imaging ONLY reports. Some facilities will see cancer patients that were diagnosed and treated elsewhere. They may enter the facility only for follow-up lab work (PSA) or radiology studies (CT scan). These cases should be reported if the lab test and imaging report diagnose cancer however check with your ACR contact to see if the case has been reported by another facility before you abstract the case. If the case has been reported, add this patient to your exclusion list and do not abstract.

<u>Exclusion – Non-Reportable List.</u> The Alaska Cancer Registry requires each facility to maintain an Exclusion List. These are cases that are not required to be reported by cancer standard setters and/or Alaska Cancer Registry.

- Cases that can be placed on your exclusion list are those stated as non-reportable in Section III.D.2.b.
- The Data elements to be recorded are as follows:
 - o patient's last name
 - patient's first name
 - date of birth
 - medical record number
 - o social security number
 - site, the ICD-9 or ICD-10 code

- date of diagnosis or date of 1st contact
- primary physician
- \circ reason for exclusion
- o date case was added or last updated
- The exclusion list should be an MS Excel spreadsheet.
- Each facility should have <u>one</u> exclusion list, in which new cases are added each year. You should not have an exclusion list for each year.
- Should be in alphabetical order by the patient's last name.
- Enter the patient's date of birth in the same format. ACR recommends using yyyymmdd format with no / or in between the numbers. However, if you use another format such as mmddyyyy, be consistent throughout your exclusion list. Using various formats for the date of birth creates problems for electronically matching date of birth.
- <u>Date Added or Updated Column</u>: The month and year the case was added to the exclusion list or the reason the exclusion was updated, should be entered in a column on the list. This helps ACR for future MDI audit reviews in determining timing rules for multiple primaries.
- Each patient should be entered once on the exclusion list unless the exclusion is for a different tumor site. Each tumor site that is to be excluded should be entered on a separate line.
- As of September 20, 2013, ACR no longer accepts non-reportable cases from facilities. It is the responsibility of the reporting facility to list non-reportable cases on their exclusion list.
- Maintaining an accurate and complete exclusion list will be beneficial to each cancer registrar during the annual MDI Review Audit. ACR compares the MDI and the exclusion list both electronically and manually for matched sites. If the reason for exclusion is valid, the case is deleted from the reconciliation list and the cancer registrar will not have to research the case again.
- The Exclusion list must be submitted along with your MDI to ACR when you are going through MDI casefinding audit review process.
- See the example of an Exclusion List at the end of *Appendix E*.

Example Exclusion List

Last Name	First Name	Middle Name	Suffix	Sex	Medical Record Number	Social Security Number	Birth Date	Site/ICD-10 Site Code	Diagnosis Year	Reason for Exclusion	Case Added or Last Updated
COTTON	JOE	EYE	SR	Μ	K12345	123456789	19220601 YYYYMMDD	LUNG UPPER LEFT LOBE	2016	TOURIST VISITING FAIRBANKS FM CALIF W/LUNG CA	4/2017

Please include as many verifying identifiers as possible for your facility: Date of birth, middle initials, medical record numbers and/or social security numbers are helpful for identifying whether we have the right patient.

- 1. If there is a history of a cancer, the initial diagnosis year is helpful in determining multiple primaries or deletion from the MDI
- 2. The reason for exclusion is a brief explanation on WHY your facility should not have to report this case. In some cases, that reason may not be sufficient, and the central registry can then work with the facility registrar on negotiating the reportability; however, the more information we have, the better we can sort through the exclusion and draft a proper reconciliation list.
- 3. Your exclusion list should be in alphabetical order, regardless of diagnosis year. This list should be *perpetual* and should not have new worksheets for new MDI years. If a patient shows up over the course of 2 to 3 years for follow up on the same cancer that was reported previously, they should not be listed 2 or 3 times on the exclusion list. This makes sorting through the list a little more difficult and more time consuming at the central registry level.
- 4. The last column should be updated each time you cross the patient. This will ensure no duplicates are posted when they show up on successive MDI lists. The only time a patient should truly be listed more than once is if they have multiple primaries that have previously been reported; your reason for exclusion should then match what you found for the current MDI and then the date of update changed in the last column

APPENDIX F: SPECIFIC TISSUES WITH ILL-DEFINED SITES, LATERALITY AND PAIRED ORGAN SITES

If any of the following histologies appears only with an ill-defined site description such as abdominal or arm in the record, code the primary site to the tissue in which such tumors arise rather than the ill-defined region (C76._)

Histology	Description	Code to this Site		
8720-8790	Melanoma	C44, skin		
8800-8811, 8813-8830, 8840-8921, 9040-9044	Sarcoma except periosteal fibrosarcoma and dermatofibrosarcoma	C49, Connective, Subcutaneous and Other Soft Tissue		
8990-8991	Mesenchymoma	C49, Connective, Subcutaneous and Other Soft Tissue		
9120-9170	Blood vessel tumors, lymphatic vessel tumors	C49, Connective, Subcutaneous and Other Soft Tissue		
9580-9582	Granular cell tumor and alveolar soft part sarcoma	C49, Connective, Subcutaneous and Other Soft Tissue		
9240-9252	Mesenchymal chondrosarcoma and giant cell tumors	C40, C41 for Bone and Cartilage; C49, Connective, Subcutaneous and Other Soft Tissue		
8940-8941	Mixed tumor, salivary gland type	C07 for Parotid Gland; C08 for Other and Unspecified Major Salivary Glands		

Laterality and Paired Organs

Laterality must be recorded for the following paired organs as 1-5 or 9. Organs that are not paired, for which you have not recorded right or left laterality, are coded 0. This code is new for 2010, and it may be used retrospectively for cases diagnosed prior to 2010. *Note: Although it is appropriate to code a laterality for a site that is not listed as paired per FORDS 2016 & STORE, ACR will continue to perform quality control and auditing per NAACCR data standards, coding 0 for non-paired sites.* For cases 2021 and forward C44.4 has laterality.

Paired Organ Sites

Site	Description	
C07.9	Parotid gland	
C08.0	Submandibular gland	
C08.1	Sublingual gland	
C09.0	Tonsillar fossa	
C09.1	Tonsillar pillar	
C09.8	Overlapping lesion of tonsil	
C09.9	Tonsil, NOS	
C30.0	Nasal cavity (excluding nasal cartilage and nasal septum)	
C30.1	Middle ear	
C31.0	Maxillary sinus	
C31.2	Frontal sinus	
C34.0	Main bronchus (excluding carina)	
C34.1–C34.9	Lung	
C38.4	Pleura	
C40.0	Long bones of upper limb and scapula	
C40.1	Short bones of upper limb	
C40.2	Long bones of lower limb	
C40.3	Short bones of lower limb	
C41.3	Rib and clavicle (excluding sternum)	
C41.4	Pelvic bones (excluding sacrum, coccyx, and symphysis pubis)	
C44.1	Skin of eyelid	
C44.2	Skin of external ear	
C44.3	Skin of other and unspecified parts of face	
C44.4	Skin of scalp and neck	
C44.5	Skin of trunk	
C44.6	Skin of upper limb and shoulder	
C44.7	Skin of lower limb and hip	
C47.1	Peripheral nerves and autonomic nervous system of upper limb and shoulder	
C47.2	Peripheral nerves and autonomic nervous system of lower limb and hip	
C49.1	Connective, subcutaneous, and other soft tissues of upper limb and shoulder	
C49.2	Connective, subcutaneous, and other soft tissues of lower limb and hip	
C50.0–C50.9	Breast	
C56.9	Ovary	
C57.0	Fallopian tube	
C62.0–C62.9	Testis	
C63.0	Epididymis	
C63.1	Spermatic cord	
C64.9	Kidney, NOS	
C65.9	Renal pelvis	
C66.9	Ureter	
С69.0–С69.9	Eye and lacrimal gland	

Site	Description	
C70.0	Cerebral meninges, NOS (excluding diagnoses prior to 2004)	
C71.0	Cerebrum (excluding diagnoses prior to 2004)	
C71.1	Frontal lobe (excluding diagnoses prior to 2004)	
C71.2	Temporal lobe (excluding diagnoses prior to 2004)	
C71.3	Parietal lobe (excluding diagnoses prior to 2004)	
C71.4	Occipital lobe (excluding diagnoses prior to 2004)	
C72.2	Olfactory nerve (excluding diagnoses prior to 2004)	
C72.3	Optic nerve (excluding diagnoses prior to 2004)	
C72.4	Acoustic nerve (excluding diagnoses prior to 2004)	
C72.5	Cranial nerve, NOS (excluding diagnoses prior to 2004)	
С74.0-С74.9	Adrenal gland	
C75.4	Carotid body	

APPENDIX G: PRIMARY SITE CODES FOR NON-MALIGNANT PRIMARY INTRACRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS

Non-Malignant primary intracranial and central nervous system tumors with a behavior code of 0 (benign) or 1 (benign/borderline) are reportable regardless of histology. (This table is from the NAACCR Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary)

Meninges:

- C70.0 Cerebral meninges
- C70.1 Spinal meninges
- C70.9 Meninges, NOS

Brain:

- C71.0 Cerebrum
- C71.1 Frontal lobe
- C71.2 Temporal lobe
- C71.3 Parietal lobe
- C71.4 Occipital lobe
- C71.5 Ventricle, NOS
- C71.6 Cerebellum, NOS
- C71.7 Brain stem
- C71.8 Overlapping lesion of brain
- C71.9 Brain, NOS

Spinal Cord, Cranial Nerves, and Other Parts of the Central Nervous System

- C72.0 Spinal cord
- C72.1 Cauda equine
- C72.2 Olfactory nerve
- C72.3 Optic nerve
- C72.4 Acoustic nerve
- C72.5 Cranial nerve, NOS
- C72.8 Overlapping lesion of brain and central nervous system
- C72.9 Nervous system, NOS

Other Endocrine Glands and Related Structures

- C75.1 Pituitary gland
- C75.2 Craniopharyngeal duct
- C75.3 Pineal gland

APPENDIX H: IN SITU TERMS, LYMPH NODES, AND ADDITIONAL CODING TIPS

IN SITU TERMS

- Adenocarcinoma in adenomatous polyp with no stalk invasion
- Behavior code 2
- Bowen's disease
- CIN III (carcinoma in situ of the cervix or may equal dysplasia) Not reportable
- Clark's level I (melanoma)
- Confined to epithelium
- DCIS = ductal carcinoma in situ
- Hutchinson's melanotic freckle (melanoma)
- Intracystic, non-infiltrating
- Intraductal
- Intra-epidermal
- Intra-epithelial
- Intrasquamous
- Involvement up to but not including the basement membrane
- Lentigo maligna (melanoma)
- Lobular neoplasia (breast)
- Non-infiltrating
- Non-invasive
- No stromal invasion
- Precancerous melanosis (melanoma)
- Preinvasive
- Queyrat's erythroplasia (penis)
- Stage 0 (TNM stage group for many sites)
- Tis (staging T=Tumor) in situ

Source: April Fritz Principles of Oncology Training Program and Multiple Primary and Histology Coding Rules.

Lymph Nodes

Terms meaning Lymph Node (LN) involvement for solid tumors for the purposes of CS coding:

- Fixed
- Matted
- Mass in the hilum, mediastinum, retroperitoneum, and /or mesentery

These would be considered clinical involvement only where there is an additional comment by the physician that the nodes are suspicious for malignancy or involvement or when the physician's TNM staging indicates cN1 or higher.

- Palpable
- Enlarged
- Visible swelling
- Shotty
- Lymphadenopathy

Code as involvement for lung primaries only.

- Adenopathy
- Enlargement
- Mass in the hilum or mediastinum

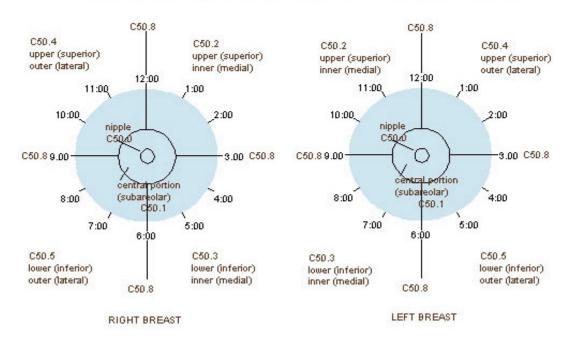
For lymphomas, any positive mention of LN indicates involvement of those lymph nodes.

Regional LNs are not palpable for inaccessible LN sites:

- Bladder
- Colon
- Kidney
- Prostate
- Esophagus
- Stomach
- Lung
- Liver
- Corpus uteri
- Ovary

This information is from the Collaborative Stage Data Collection System Part I Section I "Coding Involvement of Regional and Distant Lymph Nodes pages 23-24 (Version 02.04)

Quadrants of the Breast



"Clock" Positions, Quadrants and ICD-O Codes of the Breast

This diagram is from the SEER Training Modules (http://training.seer.cancer.gov)

Breast Primary Site Codes

Terms and Descriptive Language	Site Term and Code
Areolar	Nipple C500
Nipple	
Paget disease without underlying tumor	
Note: Paget with underlying tumor is coded to the	
quadrant of breast in which the underlying tumor is	
located.	
Above nipple	Central portion of breast C501
Area extending 1 cm around areolar complex	
Behind the nipple	
Below the nipple	
Beneath the nipple	
Central portion of breast	
Cephalad to nipple	
Infra-areolar	
Lower central	
Next to areola, NOS	
Next to nipple	
Retroareolar	
Subareolar	
Under the nipple	
Underneath the nipple	

Superior innerUpper inner quadrant of breast C50Superior medialUpper inner quadrant (UIQ)Upper medialLower inner quadrant of breast C50Inferior innerLower inner quadrant of breast C50Superior lateralUpper outer quadrant of breast C50Superior outerUpper outer quadrant (UOQ)Inferior lateralLower outer quadrant of breast C50Upper outer quadrant (UOQ)Inferior lateralLower outer quadrant (LOQ)Lower outer quadrant of breast C50Inferior outerLower outer quadrant of breast C50Lower outer quadrant (LOQ)Axillary tail of breastAxillary tail of breastAxillary tail of breast C506Tail of SpenceOverlapping lesion of breast C50812:00 o'clockOverlapping lesion of breast C5083:00 o'clockOverlapping lesion of breast C5089:00 o'clockOverlapping lesion of breast C508Inner breast, NOSInner breast, NOSLower breast, NOSLateral breast, NOSLower breast, NOSMedial breast, NOSMedial breast, NOSMidline breast, NOS	03 04
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Lower breast, NOS Medial breast, NOS Midline breast, NOS	
Medial breast, NOS Midline breast, NOS	
Midline breast, NOS	
Octor I was to NOC	
Outer breast, NOS	
Overlapping lesion of breast	
Superior breast, NOS	
Upper breast, NOS	
³ / ₄ or more of breast involved with tumor Breast, NOS C509	
Diffuse (tumor size 998) Note: Used for:	
Entire breast • Non-contiguous multiple tumo	ors in
Inflammatory without palpable mass different quadrants/subsites of	
Multiple tumors in different subsites (quadrants) breast OR	f same
within the same breast • Unk/unable to identify in which	f same
quadrant/subsite the tumor is	
Outpatient biopsy with no qua	ch
identified. Patient lost to follo	ch located (ex:
Inflammatory carcinoma, diff	ch located (ex: udrant
	ch located (ex: idrant w-up.)

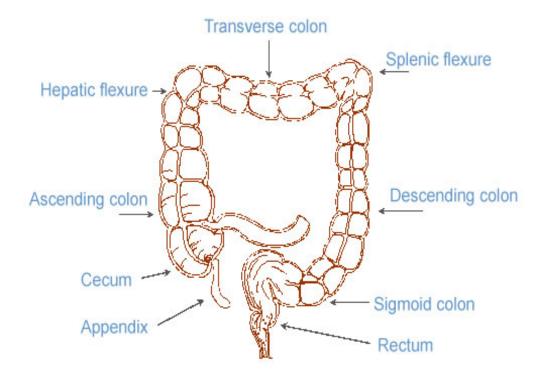
Source: Solid Tumor Rules 2018 Manual

Lung Primary Site Codes

Terminology	Which side of lung	Site Term and Code
Bronchus intermedius Carina Hilus of lung Perihilar	Right and Left sides	Mainstem bronchus C340 Note: Bronchus intermedius is the portion of the right mainstem bronchus between the upper lobar bronchus and the origin of the middle and lower lobar bronchi
Lingula of lung	Left side	Upper lobe C341
Apex Apex of lung Lung apex Pancoast tumor Superior lobar bronchus Upper lobe bronchi	Right and Left sides	Upper lobe C341
Middle lobe Middle lobe bronchi	Right side	Middle lobe C342
Base of lung Lower lobar bronchus Lower lobe Lower lobe bronchi Lower lobe segmental bronchi	Right and Left sides	Lower lobe C343
Overlapping lesion of lung	Right and Left sides	Overlapping lesion of lung C348 Note: One lesion/tumor which overlaps two or more lobes
Bronchus, NOS Bronchogenic Extending up to the hilum Extending down to the hilar region Lung, NOS Pulmonary, NOS Suprahilar, NOS	Right and Left sides	 Lung, NOS C349 Note: Includes: Multiple tumors in different lobes of ipsilateral lung OR Multiple tumors in ipsilateral lung: unk if same lobe or different lobe OR Tumor in bronchus, unk if mainstem or lobar bronchus OR Tumor present, unk which lobe
Lobar bronchi, NOS Lobar bronchus, NOS	Right and Left sides	Code the lobe in which the lobar bronchus tumor is present C34_ Note: When lobe of origin is not documented/unknown, code to lung, NOS C349.

Source: Solid Tumor Rules 2018 Manual

Anatomy of Colon and Rectum



This diagram is from the SEER Training Modules (http://training.seer.cancer.gov)

(TT1

Splenic Flexure

Hepatic Flexure

Transverse

Ascending

Cecum

(These are approximate measurements)		
Location	Measurement	
Anus	0-4 cm	
Rectum	4-16 cm	
Rectosigmoid	15-17 cm	
Sigmoid	17-57 cm	
Descending	57-82 cm	

82 cm

132 cm

150 cm

82-132 cm

132-147 cm

Colonoscopy Measurements from Anal Verge

Site Term and Code	Synonyms
Bladder, anterior wall C673	
Bladder, dome C671	Roof
	Vault
	Vertex
Bladder, lateral wall C672	Lateral to ureteral orifice
	Left wall
	Right wall
	Sidewall
Bladder neck C675	Internal urethral orifice
	Vesical neck
Bladder, NOS C679	Lateral posterior wall (no hyphen)
Bladder, overlapping lesion C678	Fundus
	Lateral-posterior wall (hyphen)
Bladder, posterior wall C674	
Bladder, trigone C670	Base of bladder
	Below interureteric crest
	Below interureteric field
	Below interureteric ridge
	Floor of bladder
Bladder, Urachus C677	Mid umbilical ligament
Bladder, ureteric orifice C676	Just above ureteric orifice
Overlapping lesion of urinary organs	
C688	
Paraurethral gland C681	
Renal pelvis C659	Pelvis of kidney
	Pelviureteric junction
	Renal calyces
	Renal calyx
Ureter C669	
Urethra C680	Cowper gland
	Prostatic utricle
	Urethral gland
Urinary system, NOS C689	
Source, Solid Tumor Dulog 2019 Monue	•

Renal Pelvis, Ureter, Bladder and Other Urinary Primary Site Codes

Source: Solid Tumor Rules 2018 Manual

Bladder Coding Tips NAACCR Webinar

Definite statements of non-invasion for papillary transitional cell carcinomas include:

- Noninfiltrating
- Noninvasive
- No evidence of invasion
- No extension into lamina propria
- No stromal invasion
- No extension into underlying supporting tissue
- Negative lamina propria and superficial muscle
- Negative muscle and (subepithelial) connective tissue
- No infiltrative behavior/component

Inferred descriptions of noninvasion for papillary transitional cell carcinomas include:

- No involvement of muscularis propria and no mention of subepithelium/submucosa
- No statement of invasion (microscopic description present)
- (Underlying) Tissue insufficient to judge depth of invasion
- No invasion of bladder wall
- No involvement of muscularis propria
- Benign deeper tissue
- Microscopic description problematic (noninvasion versus superficial invasion)
- Frond surfaced by transitional cell
- No mural infiltration
- No evidence of invasion (no sampled stroma)
- Confined to mucosa

TURBT (Transurethral resection of the bladder tumor)

- Coded as a surgical procedure and the FORDS and STORE Appendix B Site-Specific Surgery Code is 27 (Excisional biopsy)
- A TURBT with fulguration is coded as surgery code 22.
- Code CS Tumor Size/Ext Eval as 1 No surgical resection done. Per note at top which states TURBT is clinical and is recorded as 1. (*Cases diagnosed prior to 2016*)
- TURBT meets clinical classification and not pathological classification for AJCC TNM Stage assignment.

APPENDIX I: NAACCR RECOMMENDED ABBREVIATIONS FOR ABSTRACTORS

The link will take you to the NAACCR Data Dictionary. The NAACCR Recommended Abbreviations for Abstractors is Appendix G of that document.

http://datadictionary.naaccr.org/?c=17

APPENDIX J: ACR TEXTING TEMPLATE

DIAGNOSTIC FIELDS

Field Name	Texting Instructions
Physical Exam	Record the dates of the patient's physical exam, age, sex, and all findings about the presence or absence of neoplasm, particularly the location of the primary tumor, its size, the extent to which it has spread, and involvement of lymph nodes. <i>Remember: the PE documents exactly what the physician sees, feels, hears, and</i> <i>even smells in relation to the specific cancer!</i> EXAMPLE: 7/18/2010: 68yo white FE w/ ecchymosis LOQ Lt breast w/ some firmness in area no distinct mass; no other masses, skin change, nipple discharge, inversion, or axillary adenopathy; IMP: CA Lt breast
X-Rays/Scans	 When recording X-Rays or Scans, enter dates, name of hospital or physician (if done in office), name of test, and pertinent positive and negative results of X-rays, computerized axial tomography (CT), magnetic resonance imaging (MRI), echosonography, and other imaging. If a metastatic series is reported, record the results of each study in the series. Enter a description of the primary tumor, including size, location, and whether or not multi-focal. Text any pertinent information about the tumor from the <u>Findings</u> and the <u>Impression.</u> EXAMPLE: 6/15/2010 FMH screen MMG: 1cm equally dense irregular density Lt breast 5:00; 6/22/2010 AK Regional U/S: no cyst or solid mass seen Lt breast; 6/22/2010 Prov MMG: 0.8cm mass indistinct margins Lt breast 5:00; 6/26/2010 FMH CXR: neg. *Enter "none" if no X-rays or scans were performed*
Scopes	Record dates, name of hospital or physician (if done in office), name of procedure, and positive and negative findings of laryngoscopies, sigmoidoscopies, mediastinoscopies, colonoscopies, bronchoscopies, cystoscopies, and other endoscopic procedures. Include mention of biopsies, washings, and other procedures performed during the examinations, but enter their results in the Pathology section. Record size of an observed lesion, if given. EXAMPLE: 08/08/2011 FMH Cysto: golf-ball size bladder tumor Rt side of bladder close to trigone area, unable to identify ureteral orifice <i>*Enter "none" if no endoscopic examination was performed*</i>

Field Name	Texting Instructions
Lab Tests / Tumor Markers	 Enter dates, name of hospital or physician (if done in office), name of test, and results of lab tests or procedures used in establishing the diagnoses of neoplasms or metastases, such as serum protein electrophoresis for multiple myeloma or Waldenstrom's macroglobulinemia, serum alpha fetoprotein (AFP) for liver cancer, BRCA1/BRCA2 for breast, molecular profiling techniques (oncotype DX and MammaPrint), complete blood count (CBC), CEA and other tumor marker studies. Document the date, test type, value, and interpretation (elevated, borderline, or normal) of any pertinent tumor markers or lab tests in the lab text field. Some Tumor Markers: Breast: estrogen receptor (ER), progesterone receptor (PR), HER2 Neu over-expression. ex: ER/PR neg, HER2 (IHC=3+, pos; FISH=pos) Prostate: prostatic-specific antigen (PSA) Melanoma: mitotic rate, an estimate of the growth rate Colon and Rectum: KRAS
Operative findings/ Procedures	 (High; nl <2.5) *Enter "none" if no labs were performed* Record dates, name of hospital or physician (if done in office), name of procedure, and relevant findings of diagnostic surgical procedures, such as biopsies, dilation, and curettage (D & C), and laparotomy. Record tumor size, any statements about observed nodes, even if they are not involved, extent to which tumor has or has not spread beyond primary site, and any residual tumor tissue to include margin status. <i>Remember: operative findings are the observation of the surgeon –what the surgeon actually sees or feels when the patient is opened and explored</i>! EXAMPLE: 11/20/11 FMH Laparoscopic segmental ileocecal resection: FINDINGS: 4 suspicious lesions in Lt lobe of liver; one lesion near edge of Lt lobe of liver; no lesion seen on Rt lobe. IMP-Rt colon ca; metastatic colon ca to Lt liver lobe. *Enter "none" if no operative findings were performed*

Field Name	Texting Instructions
Pathology Text	 Record pertinent findings both positive and negative, in a concise and uniform manner. Record positive findings before negative findings. If additional space is needed, continue the pathology text in the Staging Text field. Record findings in the following suggested format: Specimen date (date specimen was removed from the patient) Pathology report number Primary cancer site/tissue specimen source Histology /behavior/grade (include all modifying adjectives, such as predominantly, with the features of, with foci of, elements of) Extent of disease within and beyond the primary site Tumor size (record only the greatest dimension of the tumor) Status of margins Lymph node involvement: number positive, number examined, name of lymph node chain if stated. Records as: # LNs positive/ # LNs examined (2+/4 Axillary LNs) Other tissue (s) / organ (s) Include any comments or reports from outside consultants EXAMPLE: 11/3/11 (S11-0507) Ileocecum: mod diff adenoca cecum infiltrating muscularis propria into adj fibroadipose tissue; TS: 5.7cm; Prox/dist margins neg; 21+/21 pericolic LNs; Liver bx: (+)
Primary Site	 It is essential to identify the original (primary) site of a tumor rather than a metastatic (secondary) site. Identify the primary site by careful scrutiny of all reports in the patient's medical record. Where information in the record is conflicting, statements in the pathology report generally take precedence over other statements If the record does not provide a clear answer, ask the patient's physician If the only information available is the secondary site, then it should be reported using the following rules: NOS: use NOS (not otherwise specified) subcategory when a sub site or tissue of an organ is not specifically listed in ICD-O-3. Do not use NOS if a more descriptive term is available Codes C76.0 – C76.8: Use these codes for diagnosis referring to regions and ill-defined sites of the body, such as "head", "thorax", "abdomen", "pelvis", "upper limb", and "lower limb". Code C80.9: Use this code when the primary site is not known and the only information available is the metastatic or secondary site.

DIAGNOSTIC REPORT DATA ITEMS

Field Name	Texting Instructions
Histology Behavior	In coding histology, use all pathology reports regarding the tumor. The specimen taken from a resection is usually the most representative, unless all the cancerous material was removed during a biopsy. An AJCC staging form may also be used if it is signed by a physician Other diagnostic procedures or the final clinical diagnosis may be used as the basis for coding histology only if no pathology report is available.
Staging	The text field must contain a description that has been entered by the abstractor independently from the codes. Use the most definitive text you have.

Field Name	Taxting Instructions
Field Name	Texting Instructions
Surgery Text	Record surgical procedures in chronological order including the name of the facility. If more than three surgical procedures are performed on a patient, the earliest and the most definitive surgery must be included.
	 Record data in the following order: Date each surgical procedure performed Record each procedure-excisional bx, wide excision, total organ removal, etc. DO NOT record aspiration biopsies or incisional biopsies here Facility where each procedure was performed Name of each surgical procedure (read the entire op-report, don't just copy the name of the procedure) EXAMPLE: 11/20/11 AK Regional: Laparosc segm ileocecal resect *Enter "none" if no surgery was performed*
Radiation	The name or chemical symbol and method of administration of any radiation
Therapy	 therapy that is directed toward tumor tissue or given prophylactically must be documented in the text field. Do not include radiation for hormonal effect, such as irradiation of non-cancerous endocrine glands. Do not include irradiation of the male breast to prevent gynecomastia. Record the following information in this order: Treatment start and stop dates Where treatment was given (facility) Other treatment information (i.e., pt discontinued after 3 months, etc.) Treatment summary: Treatment volume Regional treatment modality Boost treatment modality Reason for no radiation if radiation treatment would be expected Radiation sequence with surgery EXAMPLE: 10/8/11 – 12/13/11 FMH Rt neck, SCLAV fossa, pre+post auricular, occipital LNs: 3600 cGy in 20 fractions, 6MV photons; 900 cGy in 5 fractions Rt neck scar+tumor bed region, 9MEV. Total: 4500 cGy

TREATMENT REPORT DATA ITEMS

Field Name	Texting Instructions
Chemotherapy	Chemotherapy includes the use of any chemical to attack or treat cancer tissue, unless the chemical achieves its effect through change of the hormone balance or by affecting the patient's immune system. In coding consider only the agent, not the method of administering it, although the method of administration may be recorded. Chemotherapy typically is administered orally, intravenously, or intracavitary, and sometimes topically or by isolated limb perfusion. The drugs are frequently given in combinations that are referred to by acronyms or protocols. DO NOT record the protocol numbers alone. Two or more single agents given at separate times during the first course of cancer directed therapy are considered to be a <u>combination regimen</u> . Record the following information in this order: • Treatment start date in chronological order • Agents • Reason for no treatment if chemotherapy would be expected SEER*Rx is the downloadable, interactive antineoplastic drug database that replaces SEER Self-Instructional Manual Book 8, Antineoplastic Drugs. The software can be downloaded from the <u>SEER*Rx Web Site</u> . Example: 8/16/11-9/30/11 CHOP * <i>Enter "none" if no chemotherapy was given</i> *
Hormone Therapy	Report the administration of hormones, anti-hormones, or steroids to attack cancer tissue by changing the patient's hormone balance. Record surgery performed for hormonal effect (such as castration) and radiation for hormonal effect for breast and prostate cancers only. When steroids are combined with chemotherapy, record their use, in addition to reporting the chemotherapy in the chemotherapy section. Record the following information in this order: • Treatment start date in chronological order • Agents • Reason for no treatment if hormone therapy would be expected SEER*Rx is the downloadable, interactive antineoplastic drug database that replaces SEER Self-Instructional Manual Book 8, Antineoplastic Drugs. The software can be downloaded from the <u>SEER*Rx Web Site</u> . *Enter "none" if no hormone treatment was given*
Immunotherapy	 *Enter "none" if no hormone treatment was given* Immunotherapy/Biological response modifier therapy (BRM) is a generic term covering everything done to the immune system to alter it or change the host response to a cancer (defense mechanism). Record the following information in this order: Treatment start date in chronological order Agents SEER*Rx is the downloadable, interactive antineoplastic drug database that replaces SEER Self-Instructional Manual Book 8, Antineoplastic Drugs. The software can be downloaded from the <u>SEER*Rx Web Site</u>. *Enter "none" if no immunotherapy was given*

Field Name	Texting Instructions
Other Treatment	 Record definitive, cancer-directed treatment that cannot be assigned to any other category, for example: Hyperbaric oxygen (as adjunct to definitive treatment). Hyperthermia (given alone or in combination with chemotherapy, as in isolated heated limb perfusion for melanoma). Cancer vaccines are still in the experimental phase. Currently, clinical trials use cancer vaccines for brain, breast, colon, kidney, lung, melanoma, and ovary. Any experimental drug that cannot be classified elsewhere. Double blind clinical trial information where the type of agent administered is unknown and/or there is any use of a placebo. However, after the code is broken, report the treatment under the appropriate category (a correction record should be submitted when the data are available). Unorthodox and unproven treatment, such as laetrile or krebiozen. For Newly Reportable Hematopoietic Diseases (NRHD) only, specify in the Remarks field and use code 1 "Other Therapy" for the following: Transfusions/Plasmapheresis Phlebotomy/Blood Removal Supportive Care Aspirin Observation

Field Name Texting Instructions Text area for manual documentation of the facility, physician office, city, state, Place of Diagnosis or country where the diagnosis was made. Usual Enter any available information about the kind of work performed (e.g., Occupation television repairman, chemistry teacher, bookkeeper, construction worker), up to 100 characters associated with the longest held occupation. Avoid the use of abbreviations where possible. If an occupation is recorded in the chart without mention of its being the • longest held, indicate this with an asterisk next to the entry (e.g., insurance salesman*). If the patient is not employed, try to determine the longest held • occupation. Do not enter a term such as "homemaker," "student," "retired," "unemployed" or "disabled" unless no other information can be obtained. If no information is available, enter "NR" (not recorded). Do not leave this field blank. Please refer to http://www.cdc.gov/niosh/docs/2011-173/ **Usual Industry** Enter any available information about the industry associated with the longest held occupation (e.g., automotive repair, junior high school, trucking, house construction), up to 100 characters. If the chart identifies the employer's name but does not describe the industry, enter the employer's name (and city if available). If only an abbreviation is given for the industry or employer (e.g., PERS, USD, or FDIC), record it even if it's meaning is not known. However, avoid the use of abbreviations where possible. If no information is available, enter "NR" (not recorded). Do not leave this field blank. Please refer to http://www.cdc.gov/niosh/docs/2011-173/ Remarks Textual information that does not fit into its designated field can be recorded in the Remarks area. Record other pertinent information for which there is no designated field. CER data recorded here. Items to record: • CER fields: height, weight, tobacco use and types of tobacco used i.e., cigarettes/chew/dip/snuff Patient history of previous cancer Sequence (i.e., this 2012 case is a sequence 01 (changed from 00) Patients transferred to another facility: where/physician name

DEMOGRAPHICS

Works Cited:

Alaska Cancer Registry. April Fritz, BA, RHIT, CTR. <u>The Cancer Registry Casebook: Volume II</u>. 2011. California Cancer Registry System Standards Volume I. <u>Abstracting and Coding Procedures for Hospitals</u>. http://www.ccrcal.org/DSQC_Pubs/V1_2013_Online_Manual/index.htm. <u>FORDS (Facility Oncology Registry Data Standards)</u>. 2012.

APPENDIX K: GLOSSARY OF TERMS

<u>ABSTRACT</u>: A summary of patient information that contains pertinent data about the tumor and its management from the time of diagnosis until the time the patient expires.

ACCESSION NUMBER: Provides a unique identifier for the patient consisting of the year in which the patient was first seen at the reporting facility and the consecutive order in which the patient was abstracted.

ACoS: The American College of Surgeons.

ADJUVANT THERAPY: Treatment modality, such as chemo or radiation given after surgery with the intent to destroy micrometastases.

AJCC: The American Joint Committee on Cancer.

<u>AMBIGUOUS TERMINOLOGY</u>: a list of commonly used descriptive terms, used by cancer registrars that may or may not indicate tumor involvement.

<u>ANALYTIC:</u> a category of class of case that indicates that the cancer was initially diagnosed and/or treated at a specific healthcare facility and is eligible for inclusion in that registry's statistical reports of treatment efficacy and survival.

<u>BEHAVIOR CODE</u>: Records the behavior of the tumor being reported. The fifth digit of the morphology code is the behavior code. Is used by pathologists to describe whether tissue samples are benign (0), borderline (1), in situ (2), or invasive (3).

<u>CANCER DIRECTED</u>: treatment which modifies, controls, removes, or destroys cancer cell or tissue planned by the physician(s) listed in the treatment plan

<u>CHEMOTHERAPY</u>: Cancer therapy that achieves its antitumor effect through the use of antineoplastic drugs that inhibit the reproduction of cancer cells by interfering with DNA synthesis and mitosis.

<u>CLASS OF CASE</u>: Reflects the facility's role in managing the cancer. Divides cases into two groups, analytic cases (codes 00-22) and nonanalytic cases (codes 30-49 and 99).

<u>CLINICAL STAGING</u>: Includes any information obtained about the extent of cancer before initiation of definitive treatment (surgery, systemic or radiation therapy, active surveillance, or palliative care) or within four months after the date of diagnosis, whichever is shorter, as long as the cancer has not progressed. <u>**CoC**</u>: Commission on Cancer. Organization that sets standards for cancer care in hospitals, established in 1922 by the American College of Surgeons (ACoS).

<u>COMORBIDITIES AND COMPLICATIONS</u>: Preexisting medical conditions, factors influencing health status, and/or complications during the patient's hospital stay for the treatment of this cancer using ICD-9-CM.

<u>COMPLETENESS</u>: the comprehensiveness of the data set collected, the specification of code values (as opposed to blank and unknown code values), and the avoidance of omissions; assurance that all cases in a specific population have been included in the disease registry.

<u>CONTIGUOUS</u>: directly adjacent; continuously adjoining; without lapse or intervening space.

<u>CS</u>: Collaborative Stage Data Collection System. Cancer staging system designed to derive the extent of disease at the time of diagnosis based on a complex computer algorithm bases on tumor size, extension of the primary tumor, lymph node involvement, and metastases.

<u>CYTOLOGY</u>: the microscopic review of cells in body fluids obtained from aspirations, washings, scrapings, and smears; usually a function of the pathology department

DATE OF FIRST CONTACT: The date of the facility's first inpatient or outpatient contact with the patient for diagnosis or treatment of the cancer.

DEATH CLEARANCE: The process of linking death certificates from a state's vital statistics office with registry records to obtain death data for previously registered cancer cases.

DEATH CERTIFICATE ONLY (DCO): a case that has been reported to a central registry through the state's vital statistics office based on a cancer diagnosis on the death certificate. These are cases that remain after follow-back procedures have been completed.

DIFFERENTIATION: how much or how little a tumor resembles the normal tissue from which it arose; also called grade. Differentiation is often categorized as well differentiated (closely resembling normal cells), moderately differentiated, poorly differentiated or undifferentiated (having no resemblance to normal cells; anaplastic).

<u>DIRECT EXTENSION</u>: Contiguous growth of the tumor from the primary site into an adjacent organ or surrounding tissue.

DISEASE PROGRESSION: Further direct extension, regional node involvement, or distant metastasis known to have developed after the diagnosis was established.

ENDOCRINE THERAPY: Cancer therapy that achieves its antitumor effect through the use of radiation or surgical procedures that suppress the naturally occurring hormonal activity of the patient (when the cancer occurs at another site) and, therefore, alter or affect the long-term control of the cancer's growth.

FIRST COURSE OF TREATMENT: medical care that is planned or given at the time of initial diagnosis. All cancer-directed treatment (modifies, controls, removes, or destroys cancer cell or tissue) planned by the physician(s) listed in the treatment plan. If no treatment was planned, first course treatment is within the first **4** months of the date of initial diagnosis. See STORE manual.

FIRST COURSE SURGERY: the most definitive type of surgical treatment the patient received from any facility and when it was performed.

FOLLOW-BACK: reviewing a patient's medical history to ascertain whether a case reported first by a death certificate ever had that cancer diagnosed at any other source while the patient was alive. Also, the process of requesting more information from physicians, hospitals, or other healthcare providers for cancer death non-matches from the death clearance process.

<u>**GRADE</u>**: How much or how little a tumor resembles the normal tissue from which it arose; the aggressiveness of a tumor. Also called differentiation.</u>

<u>HEMATOPOIETIC</u>: Pertaining to tissues that generate blood components, such as the blood, marrow, and stem cells.

<u>HISTOLOGY</u>: The type of cells that comprise the primary cancer. Also called morphology in the ICD-O-3 book.

HORMONE THERAPY: Cancer therapy that achieves its antitumor effect through changes in hormonal balance. This type of therapy includes the administration of hormones, agents acting via hormonal mechanisms, antihormones, and steroids.

ILL-DEFINED SITE: A cancer that originated in an area of the body that cannot be precisely described or coded to a single organ such as upper limb, thorax, pelvis, etc.

IMMUNOTHERAPY: Treatment that boosts, directs, or restores the body's normal immune system and enhances the body's own ability to fight the cancer. Also called biological response modifier therapy (BRM).

IN SITU: A tumor confined to the organ of origin without invasion.

LATERALITY: Identifies the side of a paired organ or the side of the body on which the reportable tumor originated. This applies to the primary site only.

<u>METASTATIC LESION</u>: A secondary (metastatic) lesion that results from the dissemination of tumor cells from the primary site to a more distant part of the body.

NON-CANCER DIRECTED: procedures that do not attempt to modify, control, remove, or destroy cancer tissue.

<u>NON-RESIDENT</u>: A non-resident is a person reporting an address outside of Alaska at the time of diagnosis.

PALLIATIVE: intended to relieve symptoms or make the patient more comfortable; action taken to maximize the well-being of patients who cannot be cured. Considered non-cancer directed treatment.

PATHOLOGIC STAGING: Includes any information obtained about the extent of cancer through completion of definitive surgery as part of first course treatment or identified within 4 months after the date of diagnosis, whichever is longer, as long as there is no systemic or radiation therapy initiated or there is no disease progression.

PATHOLOGY REPORT: the written description of the microscopic examination of a tissue. The gross description reports the physical characteristics of the tissue: size, color, and abnormalities visible with the unaided eye. The microscopic description reports the cellular characteristics aided by the use of a microscope; what cells are involved, the behavior, and the aggressiveness or grade of any abnormality. The final diagnosis is a summary of the findings and indicates the pathologist's impression of what was found in concise terms.

POST THERAPY STAGING: (post-neoadjuvant therapy staging) includes any information obtained about the extent of cancer after completion of neoadjuvant therapy followed by surgery, and the time frame should be such that the post neoadjuvant surgery and staging occur within a time frame that accommodates disease specific circumstances. This stage classification is designated as ypTNM.

PRIMARY SITE: The site (i.e., location in the body) where the original lesion (i.e., primary cancer) was identified. Also called topography in the ICD-O-3 book.

QUALITY CONTROL: Program to assure the quality of the data collected. The rigor and comprehensiveness of a registry's quality management program is another important and defining characteristic. A variety of methodologic alternatives can be selected including staffing decisions, sampling methods, hospital feedback, reabstracting studies, recoding audits, benchmarks used, computer edits, visual edits, and death certificate only methods.

<u>RADIATION THERAPY</u>: cancer-directed treatment by radioactivity that kills cells by damaging DNA, thereby affecting the ability of the cell to divide.

<u>RECURRENCE</u>: The return or reappearance of a cancer after a disease-free interval or remission. Per the General Instructions in the Multiple Primary and Histology Manual and the Solid Tumor Rules, "**Do not use** a physician's statement to decide whether the patient has a recurrence of a previous cancer or a new primary. Use the multiple primary rules as written **unless a pathologist compares** the present tumor to the **original tumor** and states that this tumor is a recurrence of cancer from the previous primary".

<u>REFERENCE DATE</u>: The reference date is the date after which all reportable cancer cases will be included in the registry. January 1, 1996, is the reference date for ACR.

<u>REGIONAL LYMPH NODES</u>: those lymph nodes that are the first level of lymphatic drainage from an organ and can usually be removed as part of the cancer-directed treatment.

REPORTABLE BY AGREEMENT CASES: Registries may be requested to abstract tumors that are not required by the CoC (Commission on Cancer) for accredited cancer programs by ACR. ACR requires the following tumors to be abstracted and transmitted:

- VIN III (Vulvar intraepithelial neoplasia, grade III, C51._)
- VAIN III (Vaginal intraepithelial neoplasia, grade III C52_)
- AIN III (Anal intraepithelial neoplasia, grade III C21.1)

<u>REPORTABLE CANCERS</u>: Reportable cancers include all carcinoma in-situ and invasive neoplasms excluding in situ carcinoma of the cervix uteri (CIS), CIN III and PIN III of the prostate, *basal cell carcinoma of the skin and *squamous cell carcinoma of the skin (***unless** these conditions arise at a mucocutaneous juncture or external genital site).

<u>REPORTING SOURCE</u>: All hospitals, physicians, surgeons, and other health care providers (e.g., laboratories, clinics, nursing homes) diagnosing or providing treatment for patients with reportable cancers in the State of Alaska are considered Reporting Sources.

RESIDENT: A resident is a person reporting an Alaska address at the time of diagnosis.

SCOPE OF LYMPH NODE SURGERY: describes the removal, biopsy, or aspiration of regional lymph nodes at the time of surgery of the primary site or during a separate surgical event.

SECONDARY DIAGNOSIS: Preexisting medical conditions, factors influencing health status, and/or complications during the patient's hospital stay for the treatment of this cancer using ICD-10-CM values.

SEQUENCE NUMBER: Indicates the sequence of malignant and nonmalignant neoplasms over the lifetime of the patient.

STAGE OF DISEASE: The stage that best summarizes the extent of disease (i.e., in-situ, localized, regional, or distant). This may be expressed by AJCC TNM staging, Summary Staging and/or Collaborative Stage. . Stage of disease indicates how far the cancer has spread. This process classifies the tumor to its degree of differentiation, its potential for responding to therapy and to the patient's prognosis.

<u>STAGING</u>: The process of classifying a tumor with respect to its degree of differentiation, it's potential for responding to therapy, and to the patient's prognosis.

<u>SUMMARY DATA</u>: Data that are grouped by age, sex or geographic area and displayed so that individual patients, physicians, or institutions cannot be identified.

<u>SURGICAL PROCEDURE OTHER SITE:</u> records the surgical removal of distant lymph nodes or other tissue(s) or organ(s) removed beyond the primary site. This information is useful in evaluating the extent of metastatic involvement.

SURGICAL PROCEDURE OF PRIMARY SITE: is a site specific item that describes the most invasive extent of local tumor destruction or surgical resection of the primary site and of surrounding tissues or organs that are removed in continuity with the primary site tumor.

SUSPENSE: a list of identified potential reportable cases that have not been abstracted; a list of cases that have been ascertained but not yet completed.

<u>SYSTEMIC THERAPY</u>: Includes the treatment modalities captured by the item's chemotherapy, hormone therapy, immunotherapy, endocrine therapy, and hematologic transplants.

<u>TIMING OF DATA COLLECTION</u>: Information gathered through completion of surgery (ies) in first course or all information available within four months of the date of diagnosis in the absence of disease progression, whichever is longer.

TNM CLASSIFICATION: A method of classifying malignant tumors with respect to primary tumor ("T"), involvement of regional lymph nodes ("N"), and presence or absence of metastases ("M").

VISUAL REVIEW: the process of editing an abstract by visually comparing data fields; a supplementary quality control procedure to computerize edit checking.

Some of the definitions are from the Cancer Registry Management Principles & Practices for Hospitals and Central Registries, 2011, Third Edition, Kendall Hunt Publishing Company, pages 471-508.