



Alaska Cancer Registry

Procedure Manual for Reporting Sources



Division of Public Health
Section of Chronic Disease Prevention & Health Promotion
May 2012

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:

The Alaska Cancer Registry (ACR)
Section of Chronic Disease Prevention & Health Promotion
Division of Public Health
Alaska Department of Health & Social Services
3601 C Street, Suite 722
Anchorage, AK 99503-5934

Phone: (907) 269-2020

Fax: (907) 561-1896

Web site: www.hss.state.ak.us/dph/chronic/cancer/registry.htm

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PART I INTRODUCTION

I.A. Cancer in Alaska

Cancer has been the leading cause of death in Alaska since 1993 and as such represents a significant public health concern for the residents of our 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 us about 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 that are screening, diagnosing or providing 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, Section of Chronic Disease Prevention and Health Promotion.

I.C. Mission of the Alaska Cancer Registry

The mission of ACR is to identify all reportable cancers in Alaska in order to provide information on the over-all burden, types, and changing patterns of cancer among residents of our State.

ACR collects information about the incidence of cancer, the types of cancers diagnosed and their location within the body, the extent of cancer at the time of diagnosis (disease stage), the kinds of treatment that patients receive and the mortality associated with this diagnosis. This information is cumulative over the lifespan of each Alaska resident who is diagnosed with cancer and it contributes to our 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 site at www.hss.state.ak.us/dph/chronic/cancer/registry.htm.

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

The Alaska Cancer Registry (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 North American Association of Central Cancer Registries (NAACCR) Standards for Cancer Registries, Volume III (2004).

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, or the physician, hospital or other health care provider involved in that patient’s care is confidential. Patient identification information (e.g., name, address, social security number), treating physician name or the hospital where treatment was administered are examples of confidential data. Information that characterizes the case load 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 6 cases in any one substrate.

II.D. Transmission of Confidential Data

ACR will routinely receive, and may periodically need to transmit, confidential data.

ACR hard copy data being transmitted by mail will be clearly marked “Confidential”. The transmitted information will be enclosed in an envelope marked “Confidential” for mailing and the envelope will include the senders name and return address. Certified mail with return receipt (for verification that transmission was received), overnight mail, or courier service will be employed for this transmission.

ACR hard copy data being transmitted by facsimile will also be clearly marked “Confidential”. The facsimile cover sheet will contain the following disclaimer: “This

transmission is intended only for the use of the individual or entity 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.” It is the responsibility of the ACR registrar transmitting the information to ensure that the facsimile 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 facsimile. During the notification call the registrar will verify that the FAX number being used for transmission is valid. The registrar will also telephone the intended recipient directly after transmission to verify that the transmission of the confidential data was successful.

Confidential data may be transmitted by telephone. It is the responsibility of the ACR registrar transmitting the information to ensure that the telephone transmission is being provided to the intended recipient.

Electronic files can be transmitted as an attachment using a facility’s internal secure email system. Electronic files from other central cancer registries can be retrieved by ACR from the registries’ FTP site, if such a mode of transfer is available. Otherwise, the registries can send electronic files to ACR through ACR’s Web Plus “File Uploader” function. The ACR Data Analyst will set up the central cancer registry with a user ID and password in Web Plus for this purpose.

Reporting facilities without secure email systems should contact ACR regarding a secure method of transmission. ACR no longer uses YouSendIt.

When ACR receives data from reporting sources electronically, the data are transferred to the network for inclusion into the source document archive files.

Electronic files can also be transmitted via CD. The CD should be clearly marked “Confidential” on the label and placed in a media mailer also marked “Confidential” for mailing. Certified mail with return receipt (for verification that transmission was received), overnight mail, or courier service will be employed for this transmission.

Hospitals, physicians, and other reporting facilities can implement their own internal procedures for transmitting confidential data to ACR.

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.

Variations in data exchange guidelines may exist between ACR and different states. 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 Program Manager for approval. The ACR Program Manager 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

Requests for confidential or identifying data (e.g., patient name, hospital and/or physician name) must include the following:

- Record-level data involving personal identifiers will not be released except by formal application and approval by the Section Chief and/or the Alaska Division of Public Health (DPH) Privacy Board, per the Section Chief's discretion.

Requests for confidential level data for research purposes must be approved by the Chronic Disease Prevention & Health Promotion Section Chief and/or the Alaska Division of Public Health (DPH) Privacy Board, per the Section Chief's discretion.

Requests meet the following ACR standards:

- Researcher must complete the Alaska Cancer Registry 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.
- Application will be reviewed and determination will be made whether ACR will provide data and what data will be released.
- ACR Research Agreement must be signed by the principal investigator.
- Any reports derived from confidential data need to be reviewed by the ACR Program Manager prior to publication or release to ensure that confidentiality has been maintained.

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:

1. Hospitals:

This includes general and specialized (e.g., psychiatric) facilities.

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, and diagnostic imaging centers
- Free-standing pathology or diagnostic laboratories
- Physicians
- Home health agencies
- Hospices
- Nursing homes and intermediate care facilities

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

- Class 00 = Cases initially diagnosed at the reporting facility but all treatment or no treatment decision made elsewhere.
- Class 10 = Cases initially diagnosed and treated at the reporting facility or physicians office.
- Class 20 = Cases initially diagnosed elsewhere and treatment taking place at the reporting facility or physician office.
- Class 30 = Cases initially diagnosed and treatment started at another facility and is being followed by another physician or clinic. This would include consult only, staging workup after initial diagnosis elsewhere.
- Class 40 = Diagnosis AND all first course treatment given at a physician office or clinic.
- Class 43 = Pathology or lab reports only.
- Class 49 = Death Certificate only

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 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. Reference Date

Only new cancer cases diagnosed on or after the reference date of January 1, 1996, will be collected by ACR.

III.C.2. Data Items Collected by ACR

Each primary site of cancer will be collected separately. Any subsequent diagnosis or treatment of cancer in another primary site should be collected as a separate case. 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.

A reporting facility must provide ACR with all pertinent information available on each patient diagnosed and/or treated for cancer relevant 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 important that each reporting facility provide all information available to assist ACR in obtaining a complete record. In addition to these items, a reporting facility should provide ACR with any supporting text to substantiate tumor diagnosis, staging, histology and treatment.

ACR realizes that a reporting source may have limited information to report for some of their patients. Since ACR will be able to merge 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.

A reporting facility is required to provide ACR the following:

Patient Identifiers:

- Patient's full name
- Patient's maiden name (and/or alias)
- Patient's date of birth
- Patient's sex
- Patient's race and ethnicity
- Patient's social security number
- Patient's residence at time of diagnosis or first contact (street, city, state, zip code)
- Payer at diagnosis (no insurance, self pay, insurance type, etc.)

- Patient's tobacco history, divided into four categories:
 - Cigarette smoking
 - Smoking tobacco products other than cigarettes (e.g., pipes, cigars, kreteks/flavored products)
 - Smokeless tobacco products (e.g., chewing tobacco, snuff, iqmik)
 - Tobacco, NOS
- Total years tobacco use
- Height at diagnosis
- Weight at diagnosis

Cancer Identifiers:

- Date of first contact
- Date of diagnosis
- Primary site
- Histology
- Behavior
- Tumor grade
- Tumor sequence
- Laterality (i.e., if paired organ)
- Method of diagnostic confirmation
- Stage of disease at diagnosis (i.e., summary stage)
- Size of tumor
- Number of lymph nodes examined and positive
- All collaborative stage (CS) fields, including site-specific factors (SSF), are required when information is available in the medical record

Treatment Identifiers:

- Date of surgery or other treatment plans
- Surgical primary site (type of surgery performed)
- Lymph node surgery, i.e. removed or aspirated
- Surgery to other sites, other than primary cancer site
- Chemo, hormone, BRM, transplant or other treatments
- Regional radiation treatment/modality

Primary Care Physician

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

Text Fields

- All text fields should be completed.
- Text fields are used to justify all coded fields.

III.C.3. 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 case ascertainment or casefinding is an integral step for ensuring that all eligible cases are identified and reported. Appendix C provides a sample process that may be used for casefinding purposes.

III.D. Case Eligibility

III.D.1. Determining what is reportable

There are many guidelines a cancer registry must follow to know whether a case is reportable and that it is described correctly. If there is any question whether a case is reportable, contact ACR for assistance.

III.D.2. Diagnostic Language

The diagnosis of cancer is made when a recognized medical practitioner states that the patient has cancer. These guidelines for interpretation of ambiguous terminology are adapted from *Facility Oncology Registry Data Standards (FORDS)*, revised 2011, p. 3-4.

Terms that constitute a cancer diagnosis:

Apparently	Most likely
Appears	Presumed
Comparable with	Probable
Consistent with	Suspect(ed)
Compatible with	Suspicious (for)
Favors	Typical of
Malignant appearing	

Tumor or neoplasm – beginning with 2004 diagnoses and only for brain and CNS sites (C70.0-C72.9, C75.1-C75.3)

Exception: If a cytology report states “suspicious”, do not interpret it as a diagnosis of cancer. Abstract the case only if a positive biopsy or a physician’s clinical impression of cancer supports the cytology.

Terms that do not constitute a cancer diagnosis:

Cannot be ruled out	Worrisome
Equivocal	Questionable
Suggests	Rule out
Possible	Reaching
Potentially malignant	Bordering on
Likely	

If there is any question regarding tumor involvement, consult the attending physician or call your ACR representative

III.D.3. Resident vs. Non-resident

A resident is a person reporting an Alaska address at the time of diagnosis. As the U.S. Census Bureau states, residency is “the place where [a person] lives and sleeps most of the time or the place what the person considers to be his or her usual home.” Refer to Appendix A for guidelines regarding the determination of residency for persons without apparent residences.

Information on Alaska residents diagnosed and/or treated out-of-state will be obtained by ACR through established data exchange agreements (*casesharing 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.4. Reportable vs. Non-reportable Cancer Cases

Reportable cancer cases:

- Malignant and/or In Situ tumors
- Benign brain and CNS cases diagnosed on or after 1/1/04 (refer to FORDS, 2011, p. 3)
- Cases diagnosed on or after the ACR reference date of January 1, 1996
- Cases where the patient being seen has active disease (i.e., clinical evidence of cancer), even if the medical visit is for a condition other than cancer
- Cases where the patient is receiving any kind of first course cancer treatment in your facility. This includes outpatient services for any kind of first course cancer treatment (i.e., radiation therapy, chemotherapy, surgery, etc.).
- Cancer patients who are diagnosed by a facility out of state but return to have therapy initiated or continued in Alaska
- Cases where a confirmation of a cancer diagnosis is made by Pathology Only
- Cases diagnosed at autopsy
- Cancer cases newly diagnosed in the State of Alaska, regardless of residency
- Basal cell and squamous cell carcinomas of the skin are reportable if they arise at a mucocutaneous juncture or external genital site. Mucocutaneous sites include the lips, eyes, nostril, anus, artificial ostomy sites, and genital sites including vagina, clitoris, vulva, prepuce, penis, scrotum, and perineum.
- Reportable by agreement cases to ACR are VIN III, VAIN III, AIN III (prior to 1/1/12)
- Primary Polycythemia (vera) and Essential thrombocythemia diagnosed on or after 1/1/01

Non-reportable cancer cases:

- Cases diagnosed prior to the ACR reference date of January 1, 1996
- Records or slides seen in consultation only (i.e., no contact with the patient)
- Cancer patients who are traveling or vacationing in the area and visit a facility to receive transient care (i.e., to avoid interrupting a course of therapy initiated elsewhere)
- Benign tumors, except brain and CNS tumors diagnosed on or after January 1, 2004
- VIN III, VAIN III, AIN III (after 1/1/12)
- PIN III of the prostate, carcinoma in-situ of the cervix uteri (CIS, CIN III)
- Basal, squamous and baso-squamous cell carcinomas of the skin (with exceptions as noted above)
- Secondary polycythemia and/or thrombocytopenia

III.D.5. First Course of Treatment vs. Subsequent Treatment

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

As defined in FORDS, 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. If treatment is not documented, any treatment one year after diagnosis is considered 2nd course treatment and is not reported.

Under circumstances where there is no treatment after the first diagnosis of cancer, “no treatment” will be considered the first course of treatment.

III.E. Multiple Primary and Histology (MPH)

This section applies to cancers diagnosed on or after January 1, 2007 and later. A patient may have many lesions that are associated with one tumor or one site (one primary cancer), or different tumors that develop independently in multiple sites (multiple primary cancers). Operational rules are necessary to prevent “under” or “over” reporting of cancer to ACR. References for this section are in the SEER Multiple Primary and Histology Coding Rules, 2007 (updated 9/27/2011), NAACCR Data Standards, Vol. II, Ver. 12,

Chap. 3, and FORDS 2011, preface and p. 114-117. Please note; if you are unsure if a cancer is a new primary, recurrence or a multiple primary call your ACR representative for assistance.

III.E.1. Single Primaries

A single lesion of one histology type is considered one primary even if the lesion crosses site boundaries. For example, an ovarian tumor that involves the fallopian tube, or a kidney tumor that involves the ureter is a single primary.

Multiple Tumors reported as one primary:

- Simultaneous multiple lesions with the same histology in the same site are a single primary. If one lesion is in-situ (behavior code 2) and another invasive (behavior code 3), this is considered to be a single invasive primary.
- Tumor(s) with the same histology that recurs at the same site as an earlier malignancy would be:
 - The same primary tumor if diagnosed within two months of the original diagnosis or if it followed an in-situ tumor within 60 days.
 - A new primary if the tumor followed an in-situ tumor by greater than 60 days.

Paired Organs:

- Each side of a paired organ is a separate site. Therefore, tumors arising in both sides simultaneously would be considered two separate primaries unless a physician states otherwise (e.g., there is one primary that metastasized). Refer to FORDS 2011 manual, pages 9 and 10 or see Appendix E, laterality and paired organs.
- Adenocarcinoma in a Colon Polyp:
 - Simultaneous lesions and polyps in one segment of the colon are a single primary,
 - Polyps may be present in more than one segment of the colon. If the diagnosis reads “adenocarcinoma in multiple polyps”, it is one primary cancer with site code: colon, NOS - C18.9.

Mixed or Multiple Histology:

A single lesion with mixed histology types can be one primary with a combination histology code or multiple primary. It would be best to call your ACR representative to assist you in this determination.

Lymphatic and Hematopoietic Disease:

If the physician clearly states that a Hematopoietic diagnosis is a new primary, use that information and document it in text. If there is no clear information, use the SEER table “Definitions of Single and Subsequent Primaries for Hematologic Malignancies” to determine multiple primaries.

This can be downloaded from the web site: seer.cancer.gov/icd-o-3, or call your ACR representative to assist you.

III.E.2. Multiple Primaries

- Multiple lesions with the same histology occurring in different sites are separate primaries, unless a physician says they are metastatic. Tumors in sites with ICD-O-3 topography codes that are different at the second, third or fourth character are multiple primaries.
- Multiple lesions with different histologies in a single site are separate primaries, whether they occur simultaneously or at different times, reference MPH coding rules, September 2011 update, or call your ACR representative.
- Multiple lesions with different histologies occurring in different sites are separate primaries, unless a physician says otherwise.
- General rules of thumb for MPH reporting:
 - If the tumor has both invasive and in-situ components, report the most invasive histology.
 - If an invasive tumor follows an in-situ tumor in the same site by more than 60 days, report as a new primary.
 - If it's impossible to determine if there is a single, mixed, or undetermined histology, report as a single tumor with the most invasive histology.

MPH Reporting Chart

Site	Histology	Time after 1 st dx date	Report as
Head/neck	Single/mix/undetermined	5 years	New Primary
Colon	Single/mixed/undetermined	1 year	New Primary
Lung	Each single/mixed histology	3 years	New Primary
Skin	Each melanoma occurrence	60 days	New Primary
Breast	Single/mixed/undetermined	5 years	New Primary
Renal pelvis/Bladder	Single/mixed/undetermined	3 years	New Primary
All other sites	Single/mixed/undetermined	1 year	New Primary
Brain/CNS	Benign/borderline	None	New Primary*
Brain/CNS	Malignant	**	**

**Contact ACR for assistance. Timing is not used to determine multiple primaries for benign and borderline intracranial and CNS tumors.*

***Refer to MPH manual p.255-256, rule M1 - M10.*

A lesion diagnosed after a remission from an earlier malignancy at the same site and having the same histology is not a recurrence unless a pathologist specifically states that it is recurrent by comparing the histology of the new cancer to the original cancer (refer to MPH chart above for guidance)

III.E.3. 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.

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:

- Identify the primary site as documented by a physician and use the MPH coding rules for primary site coding.
- If no primary site is documented, code the primary site as unknown (C809).

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 primary or secondary, report the case and ACR will consult with their Medical Advisor to make this determination. Please supply as much information about the cancer as possible (e.g., path and radiology reports, surgery, and H&P summaries).

III.E.4. Recurring Cancers

Recurrence is the reappearance of disease that was thought to be cured or inactive (in remission). When a lesion is diagnosed within two months of remission from an earlier malignancy diagnosed at the same site and having the same histology it is considered a recurrence. This recurrence starts from cancer cells that were removed or killed by the original therapy. These cases are not collected by ACR but MUST be placed on your exclusion list (refer to Appendix C). A cancer may occur at the same site where a previous cancer had been diagnosed that has a *different* histology than the earlier cancer. Even though this is in the same site, it is reportable as a new cancer case.

*Example: A patient has a lumpectomy in January 1996, for an infiltrating ductal carcinoma (8500/3). In March 1996, the physician biopsies the same quadrant of the same breast and pathologic examination confirms infiltrating ductal carcinoma. This is a **recurrence** of the original tumor.*

III.F. How to Report

III.F.1. Hospitals with Registries

Hospitals with computerized registries will be required to submit data abstracted by trained tumor registrars. The preferred method of data submission is electronic transmission over the Internet or on electronic media (CD). Supporting text is required to be included to verify diagnosis, histology, staging, etc.

III.F.2. Hospitals without Registries

Hospitals that currently do not have cancer registries are still required to comply with the six-month reporting requirement for submitting information regarding individuals diagnosed with cancer and/or treated at their facilities. Cases are to be submitted electronically using one of the following two options:

Option #1: The hospital staff perform casefinding procedures (refer to Appendix C) 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 histology, staging, etc. Copies of pathology reports and any reports pertaining to the cancer (physical exam, radiology, treatment summaries, consults, admit & discharge documents, etc.) need to be faxed or mailed to ACR as supporting documentation for quality assurance of reported data.

Option #2: 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 histology, staging, etc. No supporting documentation would need to be submitted to ACR since a CTR would be completing the abstracts.

III.F.3. Pathology Laboratories

Pathology laboratories should submit data electronically to ACR. Cases can be abstracted into Web Plus. Alternately, cases can be transmitted in the "pipe-delimited" NAACCR record layout specifically developed for pathology laboratory reporting. See the NAACCR document, "Standards for Cancer Registries, Volume V, Pathology Laboratory Electronic Reporting" for details of the record layout.

III.F.4. Physicians

ACR requires reporting from physicians in private and group practice who diagnose and/or treat patients with cancer. Physicians must report their cancer cases, except for cases directly referred to or previously admitted to an Alaska hospital or other Alaska facility providing diagnostic or therapeutic services. Physicians and/or staff are strongly encouraged to report electronically using ACR's Web Plus system. If there are extenuating circumstances that prevent

electronic reporting, then physicians can report using the “ACR Cancer Reporting Form for Health Care Providers” (Appendix B). Both Web Plus and reporting form submissions should include paper 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.F.5. 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. above. Electronic files should be in the current NAACCR record layout.

III.G. What Happens After Reporting

When cancer case reports 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 upload into the central registry database. Hardcopy submissions are hand-entered into the central registry database and then stored in a locked, fireproof file cabinet. Reporting facilities will be notified in writing that their data submission was received.

For assistance or any questions, call the Alaska Cancer Registry at (907) 269-2020. Registry staff are available Monday through Friday, 8:00 AM - 5:00 PM.

REFERENCES

Abstracting and Coding Guide for the Hematopoietic Diseases, NIH Publication No. 05-5146, May 2002 (use for cases diagnosed before 1/1/2010).

www.seer.cancer.gov/registrars

Hematopoietic Database version 1.6.2, updated 10/20/2010 (use for cases diagnosed after 1/1/2010).

www.seer.cancer.gov/registrars

Collaborative Staging Manual and Coding Instructions, Version 020200 (use for cases diagnosed after 1/1/2010).

www.cancerstaging.org/cstage/manuals/coding0202.html

Collaborative Staging Manual and Coding Instructions, Version 010400 (use for cases diagnosed before 1/1/2010).

www.cancerstaging.org/cstage/manuals/archives.html

Facility Oncology Registry Data Standards Manual, 2007, revised for 2011 (use for cases diagnosed after 1/1/2007).

www.facs.org/cancer/coc/fordsmanual.html

International Classification of Diseases, 9th Revision, Clinical Modification, 4th Edition.

www.cdc.gov/nchs/about/major/dvs/icd9des.htm

International Classification of Diseases for Oncology, 3rd Edition, World Health Organization Geneva, 2000.

books.google.com/books?id=2FVdGxRhs0IC

Manual for Staging of Cancer, American Joint Committee on Cancer, J. B. Lippincott, Philadelphia, 7th Edition (use for cases diagnosed after 1/1/2010).

www.cancerstaging.org/products/ajccproducts.html#Publications

Manual for Staging of Cancer, American Joint Committee on Cancer, J. B. Lippincott, Philadelphia, 6th Edition (use for cases diagnosed before 1/1/2010).

www.cancerstaging.org/products/ajccproducts.html#Publications

Multiple Primary and Histology Coding Rules, 2007, revised November 2010.

www.seer.cancer.gov/tools/mphrules/download.html

North American Association of Central Cancer Registries, Standards for Cancer Registries, Volume II.

<http://www.naaccr.org/StandardsandRegistryOperations/VolumeII.aspx>

A significant selection of reference materials dealing with all aspects of cancer registries have been published in recent years. For information on publications available please contact the ACR office at (907) 269-2020.

Appendix A

Rules for Persons Without Apparent Residences

RULES FOR PERSONS WITHOUT APPARENT RESIDENCES

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

Persons With No Usual Residence (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. (Note: This rule does not apply when determining eligibility for receipt of the Alaska Permanent Fund Dividend).

Persons in Institutions: 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 retarded or mentally ill
- Long-term residents of other hospitals, such as Veterans Administration (VA) hospitals

Persons in the Armed Forces and on Maritime Ships: 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 Naval personnel, Coast Guard, and maritime ships. Refer to Census Bureau publications for the detailed rules.

Appendix B

Guidelines for Completing Cancer Reporting Forms

GUIDELINES FOR COMPLETING CANCER REPORTING FORMS

It is preferred that submitters of cancer data use Web Plus Internet reporting. If the health care provider is not able to report electronically, a paper submission will be accepted. All forms are located on the ACR web site and can be printed off at your location or saved to your computer: www.hss.state.ak.us/dph/chronic/cancer/registry.htm

REPORTING SOURCES:

All hospitals, physicians, surgeons, and other health care facilities and practitioners (e.g., laboratories, clinics, 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 of the reportable cancer. If the cancer diagnosis was made **prior to** the patient being seen by the Reporting Source, the reporting timeframe is within six months from the patient's first visit to that Reporting Source following the cancer diagnosis.

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 (if any).

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.

Guidelines for Reporting Cancer Cases

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.

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 two 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.

Regional, Direct Extension and Lymph Nodes- Tumor invades both adjacent organs and regional lymph nodes.

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

Distant- Direct extension beyond adjacent organs or tissues or metastases to distant site(s) or distant lymph nodes (e.g., spread through the circulatory or lymphatic system to parts that are remote from the primary tumor).

Note: Leukemias, multiple myeloma, reticulendotheliosis and Letter-Siwe's Disease are **always** staged as "Distant" because of their systemic nature.

Guidelines for Reporting Cancer Cases

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

First Course of Treatment (i.e., treatment that modifies, controls, removes or destroys cancer tissue)

Check all categories that apply. If “Other” category is checked, please specify. (Note: This is for the planned first course of treatment only).

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.

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.

CUTANEOUS MALIGNANT MELANOMA FORM

This form was designed for use by Dermatologist but can be used by any provider that removes suspected skin cancers in the office or clinic. Squamous cell carcinoma and basal cell carcinoma of the skin are not reportable but all occurrences of melanoma are reportable.

This form is available on the ACR web site, www.hss.state.ak.us/dph/chronic/cancer/registry.htm under “Forms”. It can be filled out on line or saved to your computer for future use. The form is self-explanatory and should be sent to ACR with pathology supporting data.

WHERE TO MAIL COMPLETED FORMS:

Alaska Cancer Registry
Section of Chronic Disease Prevention & Health Promotion
Alaska Department of Health and Social Services
3601 C Street, Suite 722
Anchorage, AK 99503-5934

QUESTIONS: Call (907) 269-2020
Fax (907) 561-1896

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 PROVIDER		Telephone:																																					
		Fax:																																					
FORM COMPLETED BY (Name)		DATE COMPLETED																																					
NAME OF PROVIDER OR FACILITY PATIENT REFERRED TO (IF ANY) (i.e., Oncology, Radiation Oncologist, Surgeon)																																							
PATIENT'S NAME (Last) (First) (Middle) (Maiden or Aliases)																																							
PATIENT'S ADDRESS AT DIAGNOSIS (Street, City, State, Zip Code)																																							
SOC. SEC. #	DATE OF BIRTH <table style="width:100%; text-align: center;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td>M</td><td>M</td><td>D</td><td>D</td><td>Y</td><td>Y</td> </tr> </table>							M	M	D	D	Y	Y	MARITAL STATUS (Check one) <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Unknown																									
M	M	D	D	Y	Y																																		
RACE (Check one) <input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Am. Indian/AK Native <input type="checkbox"/> Asian/Pacific Islander <input type="checkbox"/> Other _____ (specify) <input type="checkbox"/> Unknown		ETHNIC TYPE (Check one) <input type="checkbox"/> Non-Hispanic <input type="checkbox"/> Hispanic _____ (specify) <input type="checkbox"/> Unknown																																					
		SEX (Check one) <input type="checkbox"/> Male <input type="checkbox"/> Female																																					
DATE OF DIAGNOSIS <table style="width:100%; text-align: center;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td>M</td><td>M</td><td>D</td><td>D</td><td>Y</td><td>Y</td> </tr> </table>							M	M	D	D	Y	Y	DATE OF FIRST CONTACT <table style="width:100%; text-align: center;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td>M</td><td>M</td><td>D</td><td>D</td><td>Y</td><td>Y</td> </tr> </table>							M	M	D	D	Y	Y	DATE OF LAST CONTACT <table style="width:100%; text-align: center;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td>M</td><td>M</td><td>D</td><td>D</td><td>Y</td><td>Y</td> </tr> </table>							M	M	D	D	Y	Y	DIAGNOSING FACILITY/OFFICE:
M	M	D	D	Y	Y																																		
M	M	D	D	Y	Y																																		
M	M	D	D	Y	Y																																		
PRIMARY SITE																																							
HISTOLOGIC CELL TYPE		TUMOR GRADE																																					
PAIRED ORGAN/LATERALITY (Check one): <input type="checkbox"/> Not app. <input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> Both <input type="checkbox"/> Side not specified <input type="checkbox"/> Unknown																																							
DIAGNOSTIC CONFIRMATION (Check one) <input type="checkbox"/> Histology <input type="checkbox"/> Cytology <input type="checkbox"/> Micro-confirmed (method not specified) <input type="checkbox"/> Direct Visualization <input type="checkbox"/> Clinical diagnosis only <input type="checkbox"/> Radiography <input type="checkbox"/> Lab test/marker study <input type="checkbox"/> Unknown																																							
TUMOR SIZE (mm)	STAGE OF DISEASE AT DIAGNOSIS (Check one) <input type="checkbox"/> In Situ <input type="checkbox"/> Regional, Direct Extension <input type="checkbox"/> Regional, Direct Extension & Lymph Node <input type="checkbox"/> Distant <input type="checkbox"/> Local <input type="checkbox"/> Regional, Lymph Node <input type="checkbox"/> Regional, NOS <input type="checkbox"/> Unstaged																																						
FIRST COURSE OF TREATMENT (i.e., treatment that modifies, controls, removes or destroys cancer tissue) (Check all that apply): <input type="checkbox"/> None <input type="checkbox"/> Patient refused treatment <input type="checkbox"/> Diagnostic procedure only <input type="checkbox"/> Palliative only <input type="checkbox"/> Excisional Biopsy <input type="checkbox"/> Laser surgery <input type="checkbox"/> Cryosurgery <input type="checkbox"/> Surgery, NOS <input type="checkbox"/> Radiation <input type="checkbox"/> Chemotherapy <input type="checkbox"/> Hormone therapy <input type="checkbox"/> Immunotherapy <input type="checkbox"/> Other (specify): _____																																							
DATE THERAPY INITIATED (if known): _____																																							
DID THE PATIENT GO OUT-OF-STATE FOR THERAPY: <input type="checkbox"/> Yes <input type="checkbox"/> No IF YES, WHICH STATE: _____																																							
Fam. Hist. of Cancer (Check): <input type="checkbox"/> None <input type="checkbox"/> Sibling <input type="checkbox"/> Parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Aunt/Uncle <input type="checkbox"/> Spouse <input type="checkbox"/> Child <input type="checkbox"/> Unk.																																							
Smoking History (Check): <input type="checkbox"/> Non-smoker <input type="checkbox"/> Smoker <input type="checkbox"/> Cigar/pipe <input type="checkbox"/> Chew/snuff <input type="checkbox"/> Quit <input type="checkbox"/> Unknown		Tot. Yrs. Smoking	Packs/Day																																				

Note: 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.



ACR Cancer Reporting Form – Cutaneous Malignant Melanoma

Please mail this form to: Alaska Cancer Registry, Dept 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

Patient Information

Last Name: _____ First Name: _____ MI: _____

Home Phone: _____ SSN: _____ Date of Birth: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Occupation: _____

- Race:** African American **Ethnicity:** Hispanic **Marital Status:** Married
Mark all that apply American Indian/Alaskan Native Non-Hispanic Single
 Asian Divorced
 Native Hawaiian/ Pacific Islander Widowed
 White
 Other

Cancer Information

Date of Diagnosis: _____ Primary Site: _____

Laterality: RT LT

- Histology:** Amelanotic melanoma Mucosal-lentiginous melanoma
 Amelanotic, desmoplastic melanoma Neutropic melanoma
 Acral lentiginous melanoma Nodular melanoma
 Balloon cell melanoma Pre-cancerous melanosis
 Epitheloid cell melanoma Regressing melanoma
 Hutchinson melanotic freckle Spindle cell melanoma
 Lentigo maligna melanoma Superficial spreading melanoma
 Malignant blue nevus Melanoma, type not determined
 Minimal deviation (nevoid) melanoma Other: specify: _____
 Amelanotic melanoma _____

Depth of Invasion: _____ mm Clark's level: I II III IV

- Stage of Disease:** In-situ **Surgery/Treatment**
 Localized Excisional biopsy/excision
 Regional, direct extension Wide excision
 Regional, nodes Re-excision
 Distant Wide re-excision
 Unknown Other: _____

Other Treatment: Yes No

Type: _____ **Date Last Seen:** _____

Date: _____ **Cancer Status:** Evidence No evidence

Facility: _____

Practitioner Information

Practitioner name: _____ Patient referred from: _____

Patient referred to: _____ Date completed: _____

Appendix C

Procedure for Case Ascertainment / Casefinding

Procedure for Case Ascertainment / Casefinding

Casefinding is a term generally applied to a hospital setting but can be used in large 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 involves registry personnel in retrieving all source documents. This method is usually done in hospitals where the registry has a Certified Tumor Registrar (CTR). Passive 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 maybe useful in casefinding within your organization.

- Medical Disease Index (MDI). Disease index and daily discharges. Certain ICD-9-CM 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 codes and then the subsequent determination of reportability prior to sending to ACR.

140.0-199.1	Malignant Neoplasms <i>(excluding 173.0-173.9, other malignant neoplasm of the skin)</i>
200.0-208.9	Malignant Neoplasms of Lymphatic and Hematopoietic Tissue
209.0-209.3	Neuroendocrine Tumors (eff 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 <i>(excluding 233.1, carcinoma in-situ of the cervix uteri and excluding 232, carcinoma in-situ of the skin)</i>
238.4	Polycythemia vera (histology 9950)
238.7	Lymphoproliferative/ Myelodysplastic Syndrome Disease
273.3	Waldenstrom's Macroglobulinemia
288.4	Hemophagocytic syndrome (histology 9751 & 9754)

- Laboratory reports - These include pathology, cytology, tumor markers, and autopsy reports. Since pathologic studies are done for most patients suspected of having cancer, reviewing or obtaining copies of reports with positive or indicative diagnoses can find the majority of reportable cases. Positive pathology reports will provide information on the primary site, histology and stage of disease of the cancer. All of this information is important in the abstracting process. Pathology may have its own coding system for identifying neoplasms other than ICD-9 codes.

- Lab ONLY reports. Some facilities will be seeing cancer patients that were diagnosed and being treated elsewhere. They may enter the facility only for follow up lab work (PSA) or radiology studies (CT scan). Facilities who see patients for lab only testing and they are not the holder of the patients record need to report those cases on an electronic exclusion list stating specifically why the patient was not reported to ACR and the name of the attending physician who ordered the tests.
- Exclusion List. For the purposes of reporting to ACR, the definition of an excluded case is one that is not required by COC, State of Alaska law, or determined by the ACR Cancer Program Manager to be reported to ACR. Cases that can be placed on your exclusion list are those stated as non-reportable in Section III.D.4. The exclusion list is set up by each facility in an Excel spreadsheet format. The data elements to be recorded are as follows: medical record number, social security number, last name, first name, middle initial, sex, birth date, behavior, site, the ICD-9 site code that prompted the research of this case, date of 1st contact (date the ICD-9 site code you are researching first appeared in your casefinding), primary physician, and reason for exclusion. A blank exclusion list spreadsheet can be obtained by calling ACR. It is very important to keep this exclusion list up-to-date by adding to the list when casefinding and/or by updating the date of 1st contact if the ICD-9 code on the list reappears for the same patient at a later date than first entered. The Exclusion list must be submitted along with your MDI to ACR when you are going through state casefinding review or can be submitted throughout the year when arranged with ACR.
- Outpatient records - Chemotherapy and radiation therapy reports and logs. Patients seen by a facility for continuation of a treatment plan regardless of where the diagnosis was made is required to report to ACR.
- Surgery reports - Operative and endoscopic reports and logs. Reports with positive or indicative diagnoses supplement pathology reports. They often provide information on involvement of organs or tissues that may not have been resected and assist in the appropriate staging of the case.
- Radiation therapy reports - Radiation therapy log and treatment summaries can provide information on first course of treatment and/or identify cases not admitted.
- Diagnostic radiology reports - Radiology logs, including logs of scans (e.g., CT scan, MRI, chest film, mammogram, bone scan, ultrasonic scan). Reports with positive or indicative diagnoses provide pertinent information about the primary tumor, stage of disease, and lymph node involvement.

Appendix D

Laterality and Paired Organ Sites

Laterality and Paired Organ Sites

Laterality (NAACCR Item #410) 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.

Paired Organ Sites

ICD-0-3	Site
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
C44.5	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

ICD-0-3	Site
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
C69.0 – C69.9	Eye and lacrimal gland
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)
C74.0 – C74.9	Adrenal gland
C75.4	Carotid body

Source: Fords, 2011, pages 9-10

Appendix E

Glossary of Terms

GLOSSARY OF TERMS

ABSTRACT: 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.

AJCC: The American Joint Committee on Cancer.

AJCC, 7th Ed. Cancer Staging Manual: current staging manual for all healthcare providers.

ACoS: The American College of Surgeons.

CoC: Commission on Cancer.

CS: Collaborative Staging.

DIAGNOSTIC LANGUAGE: The diagnosis of cancer is made when a recognized medical practitioner states that it is cancer. Refer to *Guidelines for Interpretation of Ambiguous Terminology* (Adapted from American College of Surgeons [ACoS], Commission on Cancer, *Facility Oncology Registry Data Standards* (FORDS), revised 2011, p 3-4, in the text of this procedure manual.

FIRST COURSE OF TREATMENT: All cancer-directed treatment planned by the physician(s) listed in the treatment plan. If no treatment plan, within the first 4 months of the date of initial diagnosis (exception - 2 months for leukemia). SEE 2011 FORDS PG 19-20, and 201

GRADE: The degree to which a cancer cell resembles the normal cell from which it came.

HISTOLOGY: The type of cells that comprise the primary cancer.

LATERALITY: Laterality refers to tumor involvement in a paired organ (i.e., right, left or bilateral involvement).

METASTATIC LESION: 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-RESIDENT: A non-resident is a person reporting an address outside of Alaska at the time of diagnosis.

PRIMARY SITE: The site (i.e., location in the body) where the original lesion (i.e., primary cancer) was identified.

RECURRENCE: The return or reappearance of a cancer after a disease-free interval or remission.

REFERENCE DATE: 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.

REPORTABLE CANCERS: Reportable cancers include all carcinoma in-situ and invasive neoplasms excluding carcinoma in-situ of the cervix uteri, *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).

REPORTABLE LIST: The Reportable List refers to the list of Reportable Cancers. The *International Classification of Diseases, 9th Revision, Clinical Modification, 4th ed.* (ICD-9) is the reference source used by ACR to establish the Reportable List.

REPORTING SOURCE: 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.

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.

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

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

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").