

ARKANSAS REGISTER

Transmittal Sheet

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Secretary of State
Mark Martin
State Capitol, Suite 026
Little Rock, Arkansas 72201-1094
(501) 682-3527
www.sos.arkansas.gov



For Office
Use Only:

Effective Date _____ Code Number _____

Name of Agency Board of Health

Department Department of Health/Center for Public Health Practice/Applied Epidemiology

Contact Theressia Mitchell E-mail Theressia.Mitchell@arkansas.gov Phone 501-661-2463

Statutory Authority for Promulgating Rules Ark. Code Ann. §§ 20-15-201 - 205

Rule Title: Rules Pertaining to the Arkansas Cancer Registry

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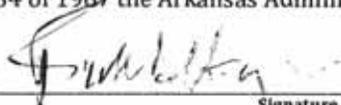
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Electronic Copy of Rule submitted under ACA 25-15-218 by:

<u>Robert Brech</u>	<u>robert.brech@arkansas.gov</u>	<u>1/27/2012</u>
Contact Person	E-mail Address	Date

CERTIFICATION OF AUTHORIZED OFFICER

I Hereby Certify That The Attached Rules Were Adopted
In Compliance with Act 434 of 1967 the Arkansas Administrative Procedures Act. (ACA 25-15-201 et. seq.)



Signature

501-661-2252 rick.hogan@arkansas.gov
Phone Number E-mail Address

General Counsel

Title

1/27/2012
Date

RULES PERTAINING TO THE ARKANSAS CANCER REGISTRY

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SECTION I. AUTHORITY

The following Rules Pertaining to the Arkansas Cancer Registry are duly adopted and promulgated by the Arkansas State Board of Health pursuant to the authority expressly conferred by the laws of the State of Arkansas, specifically Ark. Code Ann. §§ 20-15-201 - 205.

SECTION II. PURPOSE

The purpose of these rules and regulations is to clarify the cancer-reporting responsibilities of medical care professionals, hospitals, laboratories and institutions, pursuant to Arkansas law. In addition, it contains intervention for noncompliance, reinforces the confidentiality requirements, authorizes the exchange of cancer incidence data with other states and for the data to be made available to the public. In carrying out this mandate, The Arkansas Central Cancer Registry (“ACCR”) collaborates with the National Cancer Institute, the Centers for Disease Control and Prevention, medical research institutions, and national and international cancer surveillance programs designated by the ACCR, and public health agencies. The importance of cancer registration was reinforced by the passage of federal legislation in 1992 (Public Law 102-515) establishing the National Program of Cancer Registries, in which Arkansas participates.

SECTION III. DEFINITIONS

- A. “Benign neoplasms” means a benign tumor that does not grow in an unlimited, aggressive manner and does not invade surrounding tissues and does not metastasize .
- B. “Borderline tumor” means a neoplasm with many histologic criteria of malignancy, but future behavior is uncertain.

- C. “Cancer” means cellular abnormalities with widely variable courses, some grow rapidly, others grow slowly, others stop growing completely and some regress.
- D. “Casefinding” means a systematic process of locating cases eligible for inclusion in the cancer registry to include but not limited to pathology reports and disease indices.
- E. “Casefinding Audit” means a systematic process of reviewing facility based documents and information to ensure that all eligible/reportable cancer cases were identified, abstracted and reported by facilities to the ACCR.
- F. “Hospital Reporting Manual” means the manual containing guidelines and requirements to assist hospital registries in reporting cancer cases to the Arkansas Central Cancer Registry. The Hospital Reporting Manual is attached hereto as Appendix A.
- G. “In Situ (in place) cancer” means a cancer that involves only the place in which it began and that has not spread, or invaded and may regress.
- H. “Invasive cancer” means a tumor that grows in an uncontrolled manner and invades surrounding tissues and is capable of metastasizing.
- I. “New Primary” means a very basic definition is a first time diagnosed cancer. Multiple Primary and Histology Coding Rules must be applied to determine a new primary.
- J. “Non-Hospital Reporting Manual” means the manual containing requirements and guidelines to assist non-hospital facilities in reporting cancer cases to the Arkansas Central Cancer Registry. The Non-Hospital Reporting Manual is attached hereto as Appendix B.
- K. “Re-Abstracting (Quality Assurance) Audit” means a systematic process of reviewing specific data items and codes, to help ensure quality and accurate coding is being submitted by facilities to the ACCR.
- L. “Registry” means the system for the reporting, collection, and analysis of cancer cases by the Arkansas Department of Health.
- M. “Reporting” means the notification furnished to the Arkansas Department of Health of cases of in situ or invasive neoplasms of the human body, not including squamous cell and basal cell carcinoma of the skin.

SECTION IV. PARTICIPATION IN THE PROGRAM

- A. All licensed health care facilities and providers including, but not limited to: hospitals, pathology laboratories, health care practitioners, radiation treatment facilities, specialty clinics (ex. dermatology, oncology, urology clinics, etc.), surgery centers/clinics, and dental offices shall participate in the program.
- B. All participants shall designate specific staff member(s) to be responsible for reporting required cancer data and shall notify the ACCR of the name(s), title, work telephone number and e-mail address of the designated staff member(s).

SECTION V. CANCER CASE REPORTING

A. Reportable Cancer Cases

1. Any newly diagnosed in-situ or invasive cancer or reportable benign and borderline conditions as defined by the ACCR Hospital Manual (page 12) and Non-Hospital Reporting Manual (appendix F of the manual) is considered a reportable diagnosis. If a patient subsequently develops a new primary cancer, it shall be reported separately.

B. Format for reporting

1. The format for reporting, the required codes, and the standards for completeness and quality are defined in the ACCR Hospital and Non-Hospital Reporting Manuals. Text is required for specified variables and shall be adequate to permit quality assurance evaluation of coding decisions.

C. Data Items to be reported

1. The standardized report of cancer shall include as a minimum those data items required by the ACCR, a list of which is maintained in the ACCR Hospital and Non-Hospital reporting manuals. The report of cancer shall include the listed demographic, diagnostic, and treatment data as defined by the department.

D. Deadline for Reporting

1. Reporting shall occur no later than six months after the date of diagnosis of cancer.

E. Failure to Report

1. If a hospital, laboratory, facility or health care practitioner fails to provide the required information in the format or time specified by the ACCR or if the data are of unacceptable quality, personnel from the ACCR staff may enter the facility to abstract the information.

F. Quality Assurance

1. Staff members from the ACCR shall perform periodic quality assurance activities on all reporting facilities. These activities shall include:

a. Casefinding to ensure that all reportable cancer cases have been accessioned; and

b. Reabstracting the records of cancer patients to ensure accurate and complete coding of all data.

2. Reporting facilities shall assist the ACCR staff by providing the necessary casefinding documents, medical records and office space for conducting quality assurance activities.

3. In order to improve the quality of the data, the ACCR or their appointees shall offer training to reporting facility personnel if deemed necessary.

SECTION VI. CONFIDENTIALITY

A. All information reported to the ACCR shall be confidential and shall not be disclosed under any circumstances except:

1. To other state cancer registries or federal organizations with which the department has data sharing agreements that ensure confidentiality;
2. To department of health officials and its agents who are obligated to keep such information confidential; and
3. For approved cancer research under specific conditions where names and identities of the individuals are appropriately protected, and when such research is conducted for the purpose of cancer prevention, control and treatment.

B. Protection of Patient Identifying Information Obtained by Special Studies and Other Research Studies.

1. All identifying information such as records of interviews, questionnaires, reports, statements, notes and memoranda that are procured or prepared by employees or agents of the Arkansas Central Cancer Registry shall be used solely for statistical, scientific and medical research purposes and shall be held strictly confidential by the ACCR. This applies also to identifying information procured by any other person, agency, or organization, including public or private colleges and universities acting jointly with the ACCR in connection with special cancer studies and health research investigations.

SECTION VII. RELEASE OF DATA

A. Release of non-identifying information

1. To Federal Agencies: The ACCR is authorized to collaborate with the National Program of Cancer Registries (NPCR), the Centers for Disease Control and Prevention (CDC), and the National Cancer Institute (NCI) to provide cancer incidence statistics and participate in cancer studies.
2. To the Arkansas Department of Health: The ACCR shall work closely with the Arkansas Department of Health in investigating cancer-related issues and in evaluating programs. Because the ACCR data are an integral part of the Arkansas Department of Health cancer prevention and control programs, the use of registry data by public health officials shall be considered an in-house activity. Data required by the Arkansas Department of Health for responding to concerns expressed about threats to the public shall receive priority in determining the order of processing requests.
3. To the general public: Public reports published by the ACCR shall include aggregate, not patient identifying information or facility identifying information. Information that would potentially identify a cancer patient shall not be published.
4. To Others: The ACCR is authorized to collaborate with the North American Association of Central Cancer Registries (NAACCR) to provide cancer incidence statistics and participate in cancer studies.

B. Release of identifying information

1. Identifying information collected from any hospital, laboratory, facility or health care practitioner may be released to qualified persons for the purposes of cancer prevention, control and research, provided that each request for identifying information follows the established procedure outlined in the ACCR Policies and Procedures Manual and receives prior approval by the department and the Board of Health.

2. Data linkages with ACCR files shall be performed only by the ACCR staff, and the Registry may require the removal of identifiers to protect the identity of cases. The actual costs of the data linkage shall be borne by the researcher.

C. Interstate Exchange of Data

1. Because cancer patients may be diagnosed or receive treatment in another state, the ACCR is authorized to sign agreements with other states to acquire cancer data concerning Arkansas residents and, in return, to provide those states with data relating to their residents. Each signatory state shall agree in writing to keep all patient data confidential and privileged as defined in the contract for data exchange, a copy of which is included in the ACCR Policies and Procedures Manual.

SECTION VIII. VIOLATIONS AND PENALTIES

Every firm, person, or corporation who violates this rule may be assessed a civil penalty by the board. The penalty shall not exceed one thousand dollars (\$1,000) for each violation. Each day of a continuing violation may be deemed a separate violation for purposes of penalty assessments. However, no single fine levied by the Board shall exceed ten thousand dollars (\$10,000).

SECTION IX. EFFECTIVE DATE

The effective date of these Rules and Regulations shall be March 1, 2012.

SECTION X. SEVERABILITY

If any provision of these Rules and Regulations, or the application thereof to any person or circumstances is held invalid, such invalidity shall not affect other provisions or applications of these Rules and Regulations which can give effect without the invalid provisions or applications, and to this end the provisions hereto are declared to be severable.

SECTION XI. REPEAL

All Regulations and parts of Regulations in conflict herewith are hereby repealed.

CERTIFICATION

This is to certify that the foregoing Rules Pertaining to the Arkansas Cancer Registry adopted by the Arkansas State Board of Health at a regular session of said Board held in Little Rock, Arkansas on the 3rd day of November, 2011.



Paul Halverson, DrPH
Secretary
Arkansas State Board of Health

Appendix A



2010 Hospital Reporting Manual

Fourth Edition

Arkansas Central Cancer Registry

4815 West Markham Street
Little Rock, AR 72205

www.healthyarkansas.com/arkcancer/arkcancer.html

1-800-462-0599

501-661-2952

Fax (501) 661-2891



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PREFACE

The Arkansas Central Cancer Registry (ACCR) Hospital Reporting Manual has been created to assist hospital registries in reporting cancer cases to the central cancer registry. This is the fourth edition (2010) of this manual and it is being implemented to meet the requirements from the National Program of Cancer Registries (NPCR), the North American Association for Central Cancer Registries (NAACCR) and the Commission on Cancer (CoC) Facility Oncology Required Data Standards (FORDS). There are also clarifications and rules that are in place, in order to accurately complete abstraction of cancer cases. Implementation of this manual is to begin with cancer cases diagnosed as of January 1, 2010.

The Arkansas General Assembly originally established the Arkansas Central Cancer Registry (ACCR) in 1938. The registry only collected minimal data and was only for indigent patients who were referred to participating tumor clinics throughout the state of Arkansas. No funds were available from the state until 1945. By 1970, the data collected was computerized, but due to a state-funding crisis in 1979, The Arkansas Central Cancer Registry was eliminated.

In 1989, Arkansas again authorized a state cancer registry to be located at the Arkansas Department of Health, although funding was not available to staff the registry or collect the data. In 1992, The United States Congress passed the "Cancer Registries Amendment Act" (Public Law 102-515), which provided federal funding for state cancer registries. The law was carried out through efforts by the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. Funding for a cancer program in Arkansas began in 1994, when the first federal funds were awarded through the National Program for Cancer Registries (NPCR).

NPCR requires central registries to:

- ◆ Collect incidence data on all patients diagnosed and/or receiving first course of treatment in the registry's state, regardless of residency.
- ◆ Have legislation mandating the reporting of cancer cases by all facilities diagnosing and/or treating cancer
- ◆ Provide training for central registry staff, hospital registry and non-hospital reporting facility staff
- ◆ Collect information on cancer cases in a standard data format
- ◆ Produce pre-calculated data tables in an electronic data file or report, within 12 months of the end of the diagnostic year, 90% complete
- ◆ Produce pre-calculated data tables in an electronic data file or a report, within 24 months of the end of the diagnostic year, 95% complete
- ◆ Conduct case finding and re-abstrating audits to determine the completeness and quality of all cancer cases being submitted to the registry.

In 1994, the Arkansas Board of Health mandated cancer as a reportable disease in the State of Arkansas. The reference date for the Arkansas Central Cancer Registry is

January 1, 1996. This is the first time since 1979 that cancer data was collected in Arkansas.

The ACCR 1) collects data that are compliant with required NPCR data elements;
2) meets standard requirements designated by NPCR and NAACCR for incidence reporting;
3) assists in determining data quality; and
4) provide useful information, feedback and assistance to submitting facilities.

Data is submitted annually to NPCR and to NAACCR for registry certification and publication in Cancer in North America (CINA). Registries that submit data that meets established criteria of timeliness, accuracy and completeness are recognized annually as Silver or Gold Certified registries.

Without this data, our research and analytical studies cannot be accurate. The ACCR staff is available to assist with any questions and/or provide in-services to better prepare you for the process. (Refer to Appendix A to review registry personnel.)

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INTRODUCTION

ARKANSAS CANCER REPORTING REQUIREMENTS

Arkansas State reporting laws, NPCR standards, data quality and projected needs of the citizens of this state govern reporting requirements. This manual is for the intended use of hospital registries. The statutes also include facilities that provide diagnostic or therapeutic services, screening, patients diagnosed and/or treated as hospital in-patients, outpatients and in non-hospital facilities (e.g., pathology laboratories, ambulatory surgery centers, physician offices, freestanding treatment centers and long term care facilities) in an effort to become a true population-based central registry.

Hospitals are required to report all malignant, specific in-situ cancers and reportable benign brain and central nervous system tumors to the Arkansas Department of Health/Arkansas Central Cancer Registry. ACCR generally follows the rules of the following standard setters: Commission on Cancer, Facility Oncology Registry Data Standards (FORDS), and Surveillance Epidemiology and End Results (SEER) program of the National Cancer Institute. Data requirements are based on fields required by the National Program of Cancer Registries (NPCR) and the North American Association for Central Cancer Registries (NAACCR) recommendations for central cancer registries collecting incidence data, and some Arkansas specific fields.

ROLE OF HOSPITALS

The hospital cancer registry is the primary source for obtaining epidemiological information. A registry is responsible for providing a listing of cancer patients and pertinent information regarding their disease. A registry may be small or large, and the extent of submission of information is varied, depending on hospital size and the reporting methods for each facility. Some hospitals have had their own registries for years in accordance with ACoS requirements; while others have limited registries and in some cases, collection of cancer cases is provided by central registry staff.

ROLE OF ARKANSAS CENTRAL CANCER REGISTRY

The role of the Arkansas Central Cancer Registry (ACCR) is to gather information from hospitals and other sources to monitor the incidence of cancer in the state, to develop and evaluate cancer prevention and control through epidemiological research. The data is received in abstract form, electronically from hospitals that have on-site or contract registrars. ACCR regional abstractors or hospitals that serve as regional registries will obtain data from facilities that do not have registrars or where there is an annual caseload of 50 cases or less. The information is valuable in determining risk factors, environmental impacts, ethnic and social variations as well as effectiveness of state cancer control programs.

CONFIDENTIALITY

According to State Cancer Law (20-15-202) "Information accumulated and maintained in the Cancer Registry of Arkansas shall not be divulged except as statistical information which does not identify individuals and for purposes of such research as approved by the Arkansas State Board of Health". The rules and regulations also state " All information reported to the Department of Health shall be confidential and shall not be disclosed under any circumstances except (1) to other state cancer registries with which the Department of Health has agreements that insure confidentiality; (2) to other state health officials who are obligated to keep such information confidential; and (3) to approved cancer research centers under specific conditions where names and identities of the individuals are appropriately protected, and when such research is conducted for the purpose of cancer prevention, control and treatment.

ACCR staff is required to sign confidentiality agreements and follow confidentiality procedures as stated in the Arkansas Central Cancer Registry Policy and Procedure Manual. This also includes secure electronic access, fire resistant, locked file cabinets for confidential data, procedures for handling requests for data and policies for handling breaches of confidentiality.

HIPAA allows reporting of cancer cases to ACCR, because the registry is considered a public health authority. HIPAA allows facilities to report cancer incidence data to the registry in compliance with the current state statutes (20.15.201 – 20.15.205). Written informed consent is not required from the cancer patient, nor is a Business Associate Agreement required under HIPAA, but hospitals must document that reporting is occurring.

AUDITS

ACCR Quality Assurance Coordinator and/or Specialists conduct annual casefinding and quality assurance (re-abstracting) audits as required by NPCR. The purpose of these audits is to ensure that all reportable cases are being identified and reported to the Central Registry and that all information submitted to the registry is of good quality and accurately coded.

The audits are scheduled in advance to ensure the facilities adequate preparation time for the impending audit. After completion of audits, a report is provided to the facility cancer registry director and/or administrator, which summarize the percentage of case ascertainment or completeness and any suggestions that would help to improve the reporting process.

Casefinding audits are performed on inpatient and outpatient disease indices, pathology reports and other pertinent case finding documents such as: clinic sign-in logs, and surgery logs. These documents are reviewed and all reportable codes are compared to the facility information housed in the ACCR database. All cases that are not identified in the database will have to be reconciled by the registrar at the audited facility. The registrar will have a minimum of 30 days to complete the reconciliation process and return an updated list to ACCR with reasons why the identified cases were not abstracted or if the cases are reportable and were missed during the original abstracting period.

Cases that are reportable but were missed must be abstracted into their database and submitted to ACCR. All cases diagnosed before January 1, 1996 or cases not diagnosed or treated at the reporting facility are removed from the reconciliation log and a percentage is calculated at that time. A report is sent to the cancer registry supervisor and the administrator of the facility that summarizes the percentage of case ascertainment and provides suggestions to help improve the case ascertainment process.

Quality assurance or re-abstracting audits consists of an ACCR Quality Assurance Coordinator and/or Specialist re-abstracting specific fields selected by ACCR and are compared with the original data that has been submitted. Any discrepancies are documented and sent to the audited facility in a summary report. Exceptions are taken into consideration, (i.e. if a case has been merged/consolidated in the ACCR database and the audited facility did not have this information, which could indicate that the other procedures were done elsewhere and not available to the audited facility at the time the case was abstracted).

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GENERAL INSTRUCTIONS

The following information provides some basic rules regarding cancer reporting to the ACCR.

Hospital based registries are *required* by Arkansas statute (20.15.201 – 20.15.205) to abstract inpatient and outpatient cancer cases. Outpatient treatment is increasing and it is important to also collect cases from these facilities, to insure completeness of data collection.

All required data items should be *collected and reported* to ACCR. The list is based on the rules and regulations stated in the Arkansas statute, NPCR and NAACCR.

The ICD-O-3 coding scheme *must be used* for site and histology for cases diagnosed on or after January 1, 2001. The ICD-O-2 coding scheme must be used for cases diagnosed prior to January 1, 2001.

The SEER Summary Staging Manual – 2000 is to be used for cases *diagnosed* on or after January 1, 2001 to 2004. The SEER Summary Staging Guide, 1986 reprint, is to be used for cases diagnosed *prior* to January 1, 2001. For cases diagnosed after January 1, 2004 SEER Summary Staging is derived when using Collaborative Staging and Coding Instructions.

The AJCC Cancer Staging Manual – Sixth Edition is to be used for cases diagnosed on or after January 1, 2003. The Seventh Edition is to be used for cases diagnosed on or after January 1, 2010, it is an electronic manual accessed at the following website: <http://www.facs.org/cancer/coc/fords/fords2010.pdf>. TNM staging is derived when using Collaborative Staging and Coding Instructions for cases diagnosed on or after January 1, 2004.

The Collaborative Staging Manual and Coding Instruction – Version 1.04.00 is to be used for cases diagnosed on or after January 1, 2004. CSv2 Staging Manual and Coding Instruction is an electronic manual accessed at the following website: <http://cancerstaging.org/cstage/index.html> and is to be used for cases diagnosed on or after January 1, 2010.

Version 1.4 of the Hematopoietic DB and embedded Hematopoietic Manual are electronic and accessed at the following website: <http://seer.cancer.gov/tools/heme/index.html> to be used for cases diagnosed on or after January 1, 2010

Please stay abreast of revisions to manuals by periodic check of websites specific to provider of manual.

All cases diagnosed and/or treated for cancer in your facility on or after January 1, 1996, must be abstracted and reported to ACCR.

Completed cases should be submitted to the Central Registry within six months after date of initial diagnosis.

All pathology reports that are read by hospital pathology laboratories, but are not the responsibility of the hospital registry to abstract, should be forwarded to ACCR for further investigation. ACCR will be responsible for contacting the physicians on the pathology reports to obtain the information needed to include the case into the registry database.

All special data requests should be submitted on a data request form by accessing the online data request form at the following website: www.healthyarkansas.com/arkcancer/arkcancer.html or by phone at 1-800-651-3493, or 501-280-4830.

It is important that all reporting facilities submit data in a timely manner, to ensure the availability of data during the merging and de-duplication process. The requirements for data submissions are monthly reporting of cases.

All facilities submitting data electronically are required to perform EDITS on these cases to detect any errors that may exist in the data. Upon arrival to the central cancer registry, all files will undergo additional edit checks. If the file contains an unacceptable number of errors, it will be returned to the facility. A summary report of the errors is automatically sent to the facility with the rejected file. The facility will be given a maximum of 14 days to correct all errors and return the data file.

Changing Information

It is possible that after a case has been submitted to the ACCR, additional information added to the patient's chart would change specific data items. It is permissible to change any data item, including the primary site and histology. For changes made on five (5) or less cases, please call ACCR and report changes. For changes to more than five cases, make corrections to cases and resubmit via WebPlus, case can be included with next submission. If path report is amended, the amended report can be faxed to ACCR and changes will be made. For paper abstract form, complete the cancer form with the new information and write, "**AMENDED**" across the form in **red**.

Follow-up Information

Additional follow-up information is not required by ACCR on any case.

Non-Reportable File

All facilities are required to submit non-reportable cases to ACCR twice a year, January and October. These cases are to be documented and submitted electronically on an Excel spreadsheet. The following information should be included: Facility Name and Number, months/year being submitted, Patient Name, last and first, Social Security Number, Cancer Diagnosis (ICD-9 code), Cancer Site, Date of Birth, and Date of Diagnosis

CASE ELIGIBILITY

CASEFINDING TECHNIQUES

Cases can be identified via many sources. The pathology reports can provide cases diagnosed by histology, cytology, hematology, bone marrow or autopsy. Other sources are clinic admission logs, daily discharges, disease indices, inpatient and outpatient surgery logs, radiotherapy consults, treatment reports and logs, oncology clinic treatment reports and logs.

The pathology reports should *never* be the only source of casefinding, due to the fact that cases not diagnosed, only treated at your facility may not have a pathology report. Oncology clinic logs will be a good source in locating these cases. Cases not diagnosed histologically will be either confirmed by the physician in the patient's record or on the medical record disease index. A system should be established that would enable you to receive a copy of the disease index.

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ACCR REPORTABLE LIST ICD-9 Casefinding Codes for ICD-O-3 Reportable Diseases

The following ICD-9-CM list is intended to assist in reportable neoplasm casefinding activities. It should be used to identify potentially reportable tumors. Any reportable neoplasms diagnosed on or after January 1, 1996 should be reported to the Arkansas Central Cancer Registry

Reportable Neoplasms:

- ❖ Malignant neoplasms (exclusions noted below)
- ❖ Benign and borderline neoplasms of the central nervous system (Cases diagnosed on or after January 1, 2004)
- ❖ Carcinoma in-situ (exclusions noted below)
- ❖ Squamous intraepithelial neoplasia grade III of vulva (VIN), vagina (VAIN), and anus (AIN) beginning with 2001 cases
- ❖ Primary tumors that originate in a mucous membrane are reportable

140.0-208.9	Malignancies (primary and secondary)
203.1	Plasma cell leukemia (9733/3)
205.1	Chronic neutrophilic leukemia (9963/3)
225.0-225.9	Benign neoplasm of brain and spinal cord
227.3-227.4	Benign Pituitary gland and craniopharyngeal duct (pouch), pineal gland
230.0-231.9	Carcinoma in-situ of digestive organs and respiratory system
233.0-234.9	Carcinoma in-situ of breast and genitourinary system; other and unspecified sites
237.0-237.9	Neoplasms of uncertain behavior of endocrine glands and nervous system
237.70-237.72	Neurofibromatosis, unspecified, one, two vonRecklinghausen's Disease
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3), Extramedullary plasmacytoma (9734/3)
238.71-238.76	Essential thrombocythemia (9960/3-9962/3, 9985/3, 9986/3, 9987/3)
239.6-239.7	Neoplasms of uncertain nature brain, endocrine glands and other parts of nervous system
259.2	Carcinoid Syndrome
273.2	Gamma Heavy Chain Disease; Franklins Disease
273.3	Waldenstrom's macroglobulinemia
285.0	Sideroblastic Anemia (9982/3-9984)
288.3	Hypereosinophilic syndrome (9964/3)
289.83	Myelofibrosis (9961/3)
789.51	Malignant ascites
V58.0	Encounter or admission for radiotherapy
V58.1	Encounter for chemotherapy and immunotherapy

Neoplasms not required by ACCR:

Morphology Codes	Diagnosis/Terminology
8000-8004	Neoplasms, malignant, NOS of skin
8010/2	Carcinoma in-situ of cervix (CIS)
8010-8045	Epithelial carcinomas of the skin
8050-8084	Papillary and squamous cell carcinoma of skin
8077/2	Squamous Intraepithelial Neoplasia, grade III of cervix (CIN III)
8090-8110	Basal cell carcinoma of the skin
8148/2	Prostatic Intraepithelial Neoplasia

Revised 1/21/10

Ambiguous Terms that Constitute a Diagnosis

Apparent(ly)	Presumed
Appears	Probably
Comparable with	Suspect(ed)
Compatible with	Suspicious (for)
Consistent with	Tumor* (beginning with 2004 diagnoses and only for C70.0-C72.9, C75.1-C75.3)
Favors	Typical of
Malignant appearing Neoplasm* (beginning with 2004 diagnoses and only for C70.0-C72.9, C75.1-C75.3)	

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

Ambiguous Terms That Do Not Constitute a Diagnosis without additional information

The following terms **do not** indicate involvement of disease and should **not** be reported to the central cancer registry:

cannot be ruled out	possible	suggests
ruled out	potentially malignant	suggestive
equivocal	questionable	worrisome

Example: CT reveals a suspicious LUL mass. Bronchoscopy reveals a mass, “*worrisome* for malignant process”. Patient refuses any further workup or biopsy and discharged home. This is not a reportable case.

There are other ambiguous terms used with respect to tumor spread. Some may indicate tumor involvement or extension, while others are not considered to be

involvement. Refer to FORDS manual (pages 3 and 17) for a listing of those terms and additional information.

SEQUENCE NUMBER

- This number indicates the sequence of all reportable neoplasms over the lifetime of the patient. This data item is used to distinguish among cases having the same accession numbers, to select patients with only one primary tumor for certain follow-up studies, and to analyze factors involved in the development of multiple tumors. (See Coding Instructions/Patient Identification, Section 2 of the FORDS Manual).
- Codes 00-59 and 99 indicate reportable neoplasms of malignant or insitu behavior, (behavior equals 2 or 3).
- Codes 60-88 indicate neoplasms of non-malignant behavior (behavior equals 0 or 1)
- Code 00 only if the patient has a single malignant primary. If the patient develops a subsequent reportable primary tumor, change the code for the first tumor from “00” to “01”, and number subsequent tumors sequentially.
- Code only if the patient has a single non-malignant primary. If the patient develops a subsequent non-malignant primary, change the code for the first tumor from 60 to 61, and assign codes to subsequent non-malignant primaries sequentially.
- If two or more reportable neoplasms, malignant or in situ 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.
- If two or more non-malignant 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 which is reportable or reportable-by-agreement must be taken into account when sequencing subsequently accessioned tumors.
- Sequence numbers should be reassigned if the facility learns later of an unaccessioned tumor that would affect the sequence.

Malignant or in situ

Code	Definition
00	One malignant or in situ primary only in the patient's lifetime
01	First or two or more independent malignant or in situ primaries
02	Second of two or more independent malignant or in situ primaries
...	(Actual sequence of this malignant or in situ primary)
59	Fifty-nine or more independent malignant or in situ primaries
99	Unspecified malignant or in situ sequence number or unknown

Non-Malignant Primaries

Code	Definition
60	Only one non-malignant primary
61	First of two or more independent non-malignant primaries
62	Second of two or more independent non-malignant primaries
...	(Actual sequence of this nonmalignant primary)
87	Twenty-seven of twenty-seven independent non-malignant primaries
88	Unspecified number of independent nonmalignant primaries

Examples:

Code	Reason
00	A patient with no history of previous cancer is diagnosed with insitu breast carcinoma June 13, 2003
01	The sequence number is changed when the patient with breast carcinoma diagnosed on June 13, 2003, is diagnosed with subsequent skin melanoma on August 30, 2003.
02	The sequence number is assigned to a skin melanoma diagnosed on August 30, 2003, following a breast carcinoma diagnosed on June 13, 2003.
04	A nursing home patient is admitted to a hospital for first course surgery for a colon Adenocarcinoma. The patient had three previous primary cancers the registry is requires to accession, but was not seen at this facility. No sequence numbers 01, 02, or 03 are entered for this patient.
60	The sequence number assigned to a benign brain tumor diagnosed on November 1, 2005, following a breast carcinoma diagnosed on June 13, 2003 and a skin melanoma diagnosed on August 30, 2003.
63	Myeloproliferative disease (9975/1) is diagnosed by the facility in 2003 and accessioned as sequence 60. A benign brain tumor was diagnosed and treated elsewhere in 2002; patient comes to the facility with a second independent benign brain tumor in 2004. Unaccessioned earlier brain tumor is counted as Sequence 61, myeloproliferative disease is resequenced to 62, and second benign brain tumor is sequence 63

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PATIENT ADDRESS AND RESIDENCY RULES

The patient's *address at diagnosis* is the place of residence at the time of original diagnosis. *It does not change* if the patient moves. If the patient has multiple primary tumors, the address at diagnosis *may be different for subsequent primaries*.

The *current address* 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. If the patient has more than one primary tumor, the current address should be the same for each primary.

Normally a residence is the home named by the patient. Legal status and citizenship *are not* factors in residency decisions. Rules of residency are identical to or comparable with the rules of the Census Bureau's definition, "the place where he or she lives and sleeps most of the time or the place the person considers being his or her usual home." Vital statistics rules may differ from Census rules. **"Do not record the residence from the death certificate."** Review each case carefully.

Rules for Persons with Ambiguous 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 the patient was staying when the cancer was diagnosed. This could be a shelter or a diagnosing facility.

Persons away at school: College students are residents of the school area. Boarding school students below the college level are residents of their parents' homes.

Persons away in Institutions: The Census Bureau states, "Persons under formally authorized, supervised care or custody," are residents of the institution. This includes the following:

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 Affairs (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 families. Military personnel may use the installation address or the surrounding community's address.

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PATIENT IDENTIFICATION INFORMATION

NAME SUFFIX

This field identifies any suffix associated with the patient's name

Do not punctuate

LAST NAME

This field identifies the last name of the patient.

Blanks, spaces, hyphens, and apostrophes are allowed. Do not punctuate.

FIRST NAME

Record the patient's first name. Do not use punctuation.

MIDDLE NAME

Record middle name, the middle initial can be used if full middle name is not available. Do not use punctuation.

MAIDEN NAME

Record the maiden name of married female patients. If the patient has no maiden name or the information is not available, leave blank.

ALIAS

Many patients use a name different from their given name.

If the patient uses an alias for the first name, record only the first name alias.

If a patient uses an alias for the last name, record the last name alias.

If a patient uses an alias for the first and last name, record both the last name and first name alias.

PATIENT ADDRESS AT DIAGNOSIS (NUMBER AND STREET)

This field identifies the patient's address (number and street) at the time of diagnosis. The address is part of the patient's demographic data and has multiple uses. It indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Record the number and street address or the rural mailing address of the patient's usual residence at the time the cancer was diagnosed or treated.

The address should be fully spelled out with standardized use of abbreviations and punctuations. If no street address is known, record "UNKNOWN". **DO NOT LEAVE BLANK.**

Punctuation is normally limited to periods. Avoid use of the pound sign (#) whenever possible to designate address units. The preferred notation is as follows: 102 MAIN STREET, APT 101. If a pound sign is used, there must be a space between the pound sign and the secondary number (i.e., 425 FLOWER BLVD # 72).

If the patient has multiple tumors, the address may be different for subsequent primaries.

Do not update this item if the patient's address changes.

See "Residency Rules" for further instructions in Section One of FORDS for further instructions

ADDRESS AT DIAGNOSIS – SUPPLEMENTAL

Record the additional address at diagnosis information such as the name of nursing home or apartment complex.

CITY/TOWN AT DIAGNOSIS (CITY OR TOWN)

Record the city or town in which the patient resides at the time of cancer diagnosis. The city or town is part of the patient's demographic data and has multiple uses. It indicates referral patterns and allows for the analysis of cancer clusters or environmental studies. If the city is unknown, record "UNKNOWN". **DO NOT LEAVE BLANK.**

If the patient resides in a rural area, record the name of the city or town used in his or her mailing address

If the patient has multiple malignancies, the city or town may be different for subsequent primaries.

Do not update this data item if the patient's city/town or residence changes.

STATE AT DIAGNOSIS

Record the U. S. postal service two-letter state abbreviation for the state of residence at cancer diagnosis. Use the two-letter abbreviation for patients whose residence at diagnosis was a Canadian province.

If the patient has multiple tumors, the state of residence may be different for subsequent primaries

Do not update this data item if the patient's state of residence changes.

Code	Definition
IL	If the state in which the patient resides at the time of diagnosis and treatment is Illinois, then use the USPS code for the state of Illinois
XX	Resident of a country other than the U. S. (including its territories, commonwealths or possessions) or Canada and the country is known .
YY	Resident of a country other than the U. S. (including its territories, commonwealths, or possessions) or Canada and the country is unknown
US	Resident of U. S., NOS (including territories, commonwealths, or possessions); Canada, NOS; the state is unknown
CN	Resident of Canada and the providence is unknown
ZZ	Residence unknown

Note: See list of common abbreviations in Appendix G or refer to Zip Code directory on the Internet at <http://pe.usps.gov/cptm/ftp/pubs/pub28/pub23.pdf>

ZIP CODE AT DIAGNOSIS

Record the 9-digit U.S. extended postal code, do no record hyphens. When not available record the 5-digit postal code followed by four blanks

Record M6G2588_ _ _ the 6-character Canadian postal code followed by three blanks

Record 88888_ _ _ _ or 88888888 if the patient is a resident of a country other than Canada, United States or U. S. possessions and zip code is unknown.

Record 99999_ _ _ _ or 99999999 if the patient is a resident of Canada, United States, or U. S. possessions but the zip code is unknown, or residence is unknown.

COUNTY AT DIAGNOSIS

Identifies the county of the patient's residence at the time the reportable tumor is diagnosed. This data item may be used for epidemiological purposes. An example would be, to measure the cancer burden in a particular geographic area.

For U.S. residents, use codes issued by the Federal Information Processing Standards (FIPS) publication, **Counties and Equivalent Entities of the United States, Its Possessions, and Associated areas**. This publication can be accessed on the Internet at <http://www.epa.gov/>

If the patient has multiple tumors, the county codes may be different for each tumor.

Code 001-997 Counties at diagnosis, valid FIPS codes

Code 998, if the patient does not reside in Arkansas or county code unknown

Code 999, if county of residence at diagnosis is unknown.

Do not update this data item if the patient's county of residence changes

ADDRESS CURRENT – NUMBER AND STREET

This field should be completed only if the current address is different than the Address at Diagnosis

ADDRESS CURRENT – SUPPLEMENTAL

- Record number and street address at which the patient currently resides. Standard abbreviations may be used. If no street address is available, record **“UNKNOWN”**.
- Do not record temporary address
- Use the school address for college students
- Children in boarding schools (below college) are considered residents of their parents' home.
- Use the address where the transient or homeless person resided at the time of the cancer diagnosis, i.e., shelter or diagnosing facility.

CITY/TOWN CURRENT

- Record city or town of the current residence
- Standard abbreviations are acceptable
- If the city is not available, record **“UNKOWN”**.

STATE CURRENT

Record the U.S postal service two-letter state abbreviation for the state of current residence. **See Appendix K.**

Use “**XX**” resident of country other than U.S. (including its territories, commonwealths or possessions), or Canada **and country known**.

Use “**YY**” for residents of country other than U.S. (including its territories, commonwealths, or possessions) or Canada and **country unknown**.

Use “**US**” Resident of the U.S. (including its territories, commonwealths, or possessions) and the state is **unknown**

Use “**CN**” Resident of Canada and the providence is **unknown**

Use “**ZZ**” for residence unknown.

ZIP CODE CURRENT

Record the 5-digit zip code and the 4-digit extension (if known) for the patient’s address at diagnosis.

Record “888888888” if the patient is a resident of a country other than Canada, United States or U. S. possessions and zip code is unknown.

Record “999999999” if the patient is a resident of Canada, United States, or U. S. possessions but the zip code is unknown or residence is unknown.

BIRTH DATE

Complete the patient’s birth date, recording the month first, the day next, and the four-digit birth year last.

If the month and day of birth are unknown, but the year is known, record as *99/99/1921.

If the year of birth is unknown, calculate the year.

EXAMPLE: The history and physical states that the patient is 75 years old at the time he is admitted into your facility, January 15, 2002; there is no birth date documented; record the date of birth as *99/99/1927.

Please see FORDS 2010 Section Two: Coding Instructions – page 61 & 62
Date of Birth and Date of Birth Flag

SOCIAL SECURITY NUMBER

Record the patient's Social Security number, if known, record without dashes. **Do not record the spouse's number.** Social Security numbers that end with "B" or "D" record as 999999999, the patient receives benefits under the spouse's number and this is the spouse's SSN. Use **9s** also if patient does not have a SSN or if SSN is not available.

BIRTH PLACE

Record the place where the person was born (state or country), use the most specific code from SEER Geocodes, *standards for Cancer Registries Volume II: Data Standards and Data Dictionary*. **See Appendix K**

Use 000-750 SEER Geocode

Use **998** for unknown birthplace outside of the United States no other details

Use **999** for unknown birthplace

DO NOT LEAVE THIS FIELD BLANK.

ALCOHOL HISTORY

Code the patient's current or past usage of alcoholic beverages, such as wine or beer.

- 0 – No history of alcohol usage
- 1 – Current use of alcohol (this includes social usage)
- 2 – Past history of alcohol usage, no current usage
- 9 – Unknown (if no information is available)

TOBACCO HISTORY

Code the patient's current or past usage of tobacco products

- 0 – Never smoked
- 1 – Cigarette smoker, current
- 2 – Cigar/pipe smoker, current
- 3 – Snuff, chew, smokeless tobacco, current
- 4 – Combination use, current (Smokes and chews or dips)
- 5 – Previous tobacco usage
- 9 – Unknown (if no information is available)

RACE (1-5)

Record the race of the patient. This field allows calculation of race specific incidence rates. Record the multi-racial patients using the following table:

Code	Definition	Code	Definition
01	White	20	Micronesian, NOS
02	Afro/American	21	Chamorro
03	American Indian, Aleutian, Eskimo (includes South and Central American Indians)	22	Guamanian, NOS
04	Chinese	25	Polynesian, NOS
05	Japanese	26	Tahitian
06	Filipino	27	Samoan
07	Hawaiian	28	Tongan
08	Korean	30	Melanesian, NOS
09	Asian Indian, Pakistani	31	Fiji Islander
10	Vietnamese	32	New Guinean
11	Laotian	96	Other Asian-Asian, NOS, Oriental, NOS
12	Hmong	97	Pacific Islander, NOS
13	Kampuchean (Cambodian)	98	Other
14	Thai	99	Unknown

If only one race is reported for the person, use code “88” for remaining race fields (Race 2-Race 5)

If Race 1 is “99”, Unknown, Race 2-Race 5 must also be “99”.

This field is used to code the primary race of the person and is to be used in conjunction with “Spanish/Hispanic Origin”. Additional races reported by the person should be coded in Race 2 – Race 5.

Mexican, Puerto Rican or Cuban origins are coded as white.

Race 1 identifies the primary race of the person and will be the field used to compare race data on cases diagnosed prior to January 1, 2000.

If a person’s race is recorded as a combination of white and any other race, code to the appropriate other race in this field and code white in the next race field.

If a person’s race is recorded as a combination of Hawaiian and any other race(s), code the person’s primary race as Hawaiian and code the other races in Race 2-Race 5 as appropriate.

When the race is recorded as “Oriental”, “Mongolian”, or “Asian”, and the place of birth is recorded as China, Japan, the Philippines, or another Asian nation, code the race based on the birthplace information. Ex. The person’s race is recorded as “Asian” and the place of birth is recorded as “Japan”, code race as 05.

If the case is diagnosed prior to 1/1/2000, Race 2-Race 5 must be blank, UNLESS the patient has more than one primary with at least one primary diagnosed 1/1/2000.

If Race 2 is blank, Race 3 – Race 5 must also be blank.

SPANISH/HISPANIC ORIGIN

Code the patient’s Spanish/Hispanic origin.

- 0 – Non-Spanish, Non-Hispanic
- 1 – Mexican (includes Chicano)
- 2 – Puerto Rican
- 3 – Cuban
- 4 – South or Central American (Brazil)
- 5 – Other specified Spanish/Hispanic origin (includes European; excludes Dominican Republic)
- 6 – Spanish Hispanic, Latino, NOS; Evidence other than surname or maiden name that the person is Hispanic, but cannot be assigned to any category of 1-5
- 7 – Spanish surname only (Only evidence of the person’s Hispanic origin is surname or maiden name – no evidence verifying that the person is not Hispanic)
- 8 – Dominican Republic (for use with patient who were diagnosed with cancer on January 1, 2005 or later)
- 9 – Unknown whether Spanish/Hispanic or not stated in patient record

SEX

Code the patient’s sex

- 1 - Male
- 2- Female
- 3 - Other (hermaphrodite)
- 4 - Transsexual
- 9 – Not stated in patient record, Unknown

OCCUPATION TEXT

This data item is applicable for patients 14 years or older at the time of diagnosis and is reported as text.

Record the patient's usual occupation before the cancer diagnosis.

If the patient had several jobs over a lifetime, record the occupation engaged in for the longest period of time, if known.

If the patient is retired and the occupation is unknown, **DO NOT RECORD RETIRED**, record **UNKNOWN**.

If the patient was a housewife/househusband and never worked outside of the home, record "homemaker", "housewife" or "househusband".

Record "unknown" if no information is available. **DO NOT LEAVE BLANK**.

INDUSTRY TEXT

This data item is applicable for patients 14 years or older at the time of cancer diagnosis.

Record the primary type of business activity performed by the company where the patient was employed for the most number of years.

Distinguish whether the industry is involved in manufacturing, wholesale, retail or service.

If the primary activity is unknown, record the name of the company and city or town. The central registry may be able to determine the business activity performed.

Record "unknown" if no information is available. **DO NOT LEAVE BLANK**.

If the patient is retired and the type of industry is unknown, **DO NOT RECORD RETIRED**, record **UNKNOWN** in this field.

Primary Payer at Diagnosis

This identifies the patient's primary payer/insurance carrier at the time of initial diagnosis and/or treatment.

- 01 – Not insured – Patient has no insurance and is declared a charity write-off
- 02 – Not insured, self-pay – Patient is responsible for charges
- 10 – Insurance, NOS – Type insurance unknown
- 20 – Private Insurance, Managed Care, HMO or PPO
- 21 – Private insurance: Fee-for-Service
- 31 – Medicaid
- 35 – Medicaid administered through a Managed Care Plan
- 60 – Medicare without supplement, Medicare NOS
- 61 – Medicare with supplement, NOS
- 62 – Medicare administered through a Managed Care plan
- 63 – Medicare with private supplement
- 64 – Medicare with Medicaid eligibility
- 65 – TRICARE
- 66 – Military
- 67 – Veterans Affairs
- 68 – Indian/Public Health Service
- 99 – Insurance status unknown

DATE OF FIRST CONTACT

- Record the date (month, day, and four digit year) of the first inpatient or outpatient encounter at this facility for diagnosis of and/or treatment for this primary cancer. This may be the date of an outpatient visit for a biopsy, x-ray, scan or lab test. If autopsy only, record the date of death.
- If exact date is unknown, the date may be estimated using available information
- Beginning 2010, the way dates are transmitted has changed. In order that registry data can be interoperable with other data sources. The interoperable form is CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date. *Date of First Contact Flag: FORDS Section Two Coding Instructions – pg 104*

Example: Patient comes into your facility for a CT scan of the pelvis and abdomen on 8/21/2001. Report reads “Large mass at the hepatic flexure consistent with carcinoma.” Patient returns for a colonoscopy and biopsy of lesion, which reveals mucinous Adenocarcinoma. Date of first contact will be 8/21/2001 (date of the CT scan). Information is limited to description “spring”, 2003; date of first contact is April 2003

CLASS OF CASE

This data element is designed to separate the reporting registry's cancer cases into **analytic** and **nonanalytic** categories. The code structure for this item is revised in 2010. ACCR requires Class of Case 00, 10,11,12,13, 14, 20, 21, and 22.

DEFINITIONS:

Analytic Classes of Case

- 00 – Initial diagnosis at the reporting facility AND all treatment or a decision not to treat was done elsewhere
- 10 - Initial diagnosis at the reporting facility or in a staff physician's office AND part or all of first course treatment or a decision not to treat was at the reporting facility, NOS
- 11 – Initial diagnosis in staff physician's office AND part of first course treatment was done at the reporting facility
- 12 – Initial diagnosis in staff physician's office 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
- 14 – Initial diagnosis at the reporting facility AND all first course treatment or a decision not to treat was done at the reporting facility
- 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
- 22 – Initial diagnosis elsewhere AND all first course treatment was done at the reporting facility

Non-analytic Classes of Cases

- 30 – Initial diagnosis and all first course treatment elsewhere AND reporting facility
- 31 – Initial diagnosis and all first course treatment elsewhere AND reporting facility provided in-transit care
- 32 – Diagnosis AND all first course treatment provided elsewhere AND patient presents at reporting facility with disease recurrence or persistence
- 33 – Diagnosis AND all first course treatment provided elsewhere AND patient presents at reporting facility with disease history only
- 35 – Case diagnosed before program's Reference Date AND initial diagnosis AND all or part of first course treatment by reporting facility
- 37 – Case diagnosed before program's Reference Date AND initial diagnosis elsewhere AND all or part of first course treatment by facility

- 38 – Initial diagnosis established by autopsy at the reporting facility, cancer not suspected prior to death
- 40 – Diagnosis AND all first course treatment given at the same staff physician's office
- 41 – Diagnosis and all first course treatment given in two or more different staff physician offices
- 42 – Non-staff physician or other facility not part of reporting facility, accessioned by reporting facility for diagnosis and/or treatment by that entity (ex: hospital abstracts cases from an independent radiation facility)
- 43 – Pathology or other lab specimens only
- 49 – Death certificate only
- 99 – Non-analytic case of unknown relationship to facility

REPORTING SOURCE

Code the source of documents used to abstract the majority of information on the tumor being reported. This may not be the source of original case finding (for example, if a case is identified through a path lab report review and all source documents used to abstract the case are from the physician's office, code this item 4). This data item is used by the central cancer registry to assist in the measurement of case reporting from all facilities:

- 1 Hospital inpatient, hospital outpatient, clinic
- 2. Radiation Treatment Centers or Medical Oncology Centers (hospital- affiliated or independent)
- 3 Laboratory only (hospital-affiliated or independent)
- 4 Physician office/private medial practitioners (LMD)
- 5 Nursing home, convalescent home, convalescent hospital, hospice
- 6 Autopsies only
- 7 Death certificate only
- 8. Other hospital outpatient units/surgery centers

NPI -PRIMARY SURGEON

This identifies the physician who performed the most definitive surgical procedure.

Record the 10-digit NPI for the physician who performed the most definitive surgical procedure

If the patient did not have surgery, NPI for the primary surgeon is unknown or not available. The physician who performed the surgical procedure was not a surgeon (general practitioner), leave code blank

ATTENDING PHYSICIAN (MANAGING PHYSICIAN)

The managing physician is the doctor responsible for the overall management and care of the patient during the diagnosis and treatment of the reported cancer.

Use the Medicare UPIN physician numbers or NPI number.

If managing physician is unknown, leave field blank

FOLLOWING PHYSICIAN (FOLLOW-UP PHYSICIAN)

The following physician assumes responsibility for the patient's current medical care.

Follow-up letters requesting information about the patient's cancer and cancer status will be directed to this physician

Use the Medicare UPIN physician numbers or NPI number.

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CANCER IDENTIFICATION

PRIMARY SITE

The primary site is defined as the organ or site in which the cancer originated or began. A metastatic site indicates that the primary (originating) tumor has spread from the original site to other areas in the body. Cancer registries only code the primary site in this field, using the ICD-0-2 (cases diagnosed prior to January 1, 2001) or ICD-0-3 (cases diagnosed on or after January 1, 2001) manual to determine the correct site code, use current ***SEER Multiple Primary and Histology Coding Rules*** to assign site for solid tumors. Follow the instructions in ***Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and Hematopoietic and Lymphoid Neoplasms Database*** for assigning site for lymphomas, leukemia and other hematopoietic neoplasms. Indications of metastatic sites are used in the registry for identifying the extent of the patient's disease and for staging purposes.

It is preferable to identify the exact location of the primary (originating) tumor, whenever possible. The most specific location of a tumor should be coded. If the specific sub-site of an organ cannot be determined, use the NOS (not otherwise specified) category for that organ or region. The registrar should use all documents available in the medical record to determine the most specific site code, including the pathology reports, scans, X-rays, MRIs, etc.

Use subcategory 9 for multiple tumors that originate in different subsites of one organ.

EXAMPLE: A patient is diagnosed by CT scan with mass in head of pancreas consistent with carcinoma, code to C25.0 instead of C25.9, pancreas NOS.

When a primary site is overlapping into one or more sub-sites, code the **.8** (overlapping lesion code). Overlapping applies to sites that are contiguous (adjacent) to one another.

EXAMPLE: Overlapping lesion of oropharynx. Code overlapping lesion when a large tumor involves both the lateral wall of the oropharynx (C10.2) and the posterior wall of the oropharynx (C10.3) and the point of origin is not stated.

Stomach (sub-site as identified). An extranodal lymphoma of the stomach is coded C16._ (sub-site as identified).

Lymphomas originating in the lymph nodes are coded C77. _

If the primary site is documented as an “unknown primary”, use code **C80.9**.

HISTOLOGIC TYPE/BEHAVIOR ICD-0-3 (Cases diagnosed on or after January 1, 2001)

Histologic type refers to the **classification** of malignancy described in the pathology or cytology report. Refer to the ICD-0-3 manual to select the correct histologic code. The first three digits of the histology code will indicate the cancer cell type. Use the current **Multiple Primary and Histology Coding Rules** when coding the histology for all reportable tumors. These rules are effective for cases diagnosed January 1, 2007 or later. Code the **final** pathologic diagnosis for solid tumors.

EXCEPTION: If the final diagnosis is “Not Otherwise Specified” (carcinomas, NOS, melanoma, NOS, then code the histology from the microscopic description or comment if it identifies a more specific histology type.

For lymphomas, leukemias and other hematopoietic tumors, follow the instructions in **Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the Hematopoietic and Lymphoid Neoplasms Database**

BEHAVIOR CODE

The behavior code occupies the 5th space (digit) of the histologic code. This component of the histologic code indicates the way in which the neoplasm will act or behave – malignant (3) or non-malignant (2). Only neoplasms with the behavior code of **0 (benign), 1 (borderline), 2 (in situ) or 3 (invasive)** are to be reported to the central cancer registry. ACCR only requires primary sites to be collected and submitted. If the pathology report describes the cancer as metastatic, the registrar should be alerted that

the primary site is not described on this report and must take steps to identify the primary site with a behavior code of **3**. **The hospital registry does not utilize behavior codes of 6 or 9.**

The following terms are synonymous with (behavior code 2) in-situ cancers:

- Adenocarcinoma in a adenomatous polyp with no invasion of stalk
- Clark's level 1 for melanoma (limited to epithelium)
- Comedocarcinoma, non-infiltrating (C50. *)
- Confined to epithelium
- Hutchinson's melanotic freckle, NOS (C44. *)
- Intracystic, non infiltrating
- Intraductal
- Intraepidermal, NOS
- Intraepithelial, NOS
- Involvement up to but nor including the basement membrane
- Lentigo maligna (C44. *)
- Lobular neoplasia
- Lobular, noninfiltrating (C50. *)
- Noninfiltrating
- Noninvasive
- No stromal involvement
- Papillary, noninfiltrating or intraductal
- Pre-cancerous melanosis (C44. *)
- Queyrat's erythroplasia (C60. *)

Behavior code is coded as **malignant (3)** if there is documentation of any invasion present.

EXAMPLE: Pathology report of the cervix reads: "squamous cell carcinoma insitu (8070/2) with microinvasion of squamous cell carcinoma (8070/3). This case should be coded to the invasive behavior **8070/3**.

MULTIPLE PRIMARIES

For all cases diagnosed on or after January 1, 2007, please refer to the ***Multiple Primary and Histology Coding Rules*** to determine whether the case is a single primary or multiple primaries, revised April 30, 2008 and released May 6, 2008.

For lymphomas, leukemia and other hematopoietic tumors, follow the instructions in ***Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual and the Hematopoietic and Lymphoid Neoplasms Database***

TIMING

Please refer to Multiple Primary and Histology Coding Rules, site-specific for appropriate timing rules.

REVISING THE ORIGINAL DIAGNOSIS

Data are gathered from multiple sources using the most recent and complete information available. Over time, the patient's records may contain new information such as tests, scans and consults. Change the primary site, laterality, histology and stage as the information becomes more complete. If the primary site is changed, it may also be necessary to revise site-specific staging and treatment codes. **There is no time limit for making revisions that give better information about original diagnosis or stage.** However, the abstractor must carefully review the additional document/information, multiple primary rules and notice timeframes especially if staging information is updated. Most cases that require revision are unknown primaries.

EXAMPLE:

The institution clinically diagnoses a patient with carcinomatosis. The registry enters the case as an unknown primary (C80.9), carcinoma, NOS (8010/3), stage of disease unknown. Nine months later, a paracentesis shows serous cystadenocarcinoma. The physician says that the patient has an ovarian primary. Change the primary to ovary (C56.9), histology to serous cystadenocarcinoma (8441/3), and diagnostic confirmation to positive cytology study, no positive histology (2). If enough information is available, change the stage from unknown to the appropriate staging.

GRADE OR DIFFERENTIATION

This code occupies the 6th position of the histologic code. This number describes the grade or differentiation characteristics of the cancer. In most cases, the pathology report is the source for this description.

- Code grade according to instructions in ICD-0-3 (cases diagnosed on or after January 1, 2001).
- Code the grade as stated in the **FINAL** pathologic diagnosis. If the grade is **NOT** stated in the final pathologic diagnosis, use the information from the microscopic description or comments
- If a pathology report describes a neoplasm with two different grades, code to the highest grade reported even if the highest grade is a focus
- **EXAMPLE:** Pathology report reads, infiltrating ductal carcinoma, moderately differentiated, Code 8500/**33**. Grade **3** takes precedence over moderately differentiated Grade **2**.
- Code the grade/differentiation from the primary tumor, not from metastatic sites
- If the primary site is unknown, code grade/differentiation as 9 (unknown).

- Code the grade for in situ lesions if the information is available. If the lesion is both invasive and in situ, code only the invasive portion. If the invasive component grade is unknown, then code 9
- Do not use grading terms such as low, high or intermediate grade for lymphomas as a basis for differentiation. These terms are categories in the Working Formulation of Lymphoma Diagnoses and do not relate to Grade/differentiation.
- Codes 5-8 define T-cell or B-cell origin for leukemia and lymphomas. T-cell, B-cell or null cell classification have precedence over grading or differentiation.
- If no grade is given for astrocytomas, code 9 (unknown).
- If no grade is given for glioblastoma multiforme, code 9 (unknown)
- If grade Path system and Grade Path value are coded, Grade/Differentiation must not be 9.

The codes used for grade are:

CODE	GRADE/CELL	DESCRIPTION
1	Grade I,1,i	Well Differentiated, differentiated, NOS
2	Grade II,2,ii,I/III or 1/3	Moderately Differentiated, moderately well; intermediate differentiated
3	Grade III,3,iii,II/III or 2/3	Poorly differentiated
4	Grade IV,4,iv,III/III or 3/3	Undifferentiated, anaplastic
For Lymphomas and Leukemias		
5	T-cell	T-cell, T-precursor, lymphomas & leukemias
6	B-cell	B-cell, Pre-B, B-precursor, lymphomas & leukemias
7	Null cell	Leukemias only, Null cell, Non T – Non B
8	NK cell	Natural Killer cell, lymphomas & leukemias
For all Histologies		
9	Grade/diff unknown	Grade/cell type not determined, not stated, not applicable

GRADE PATH SYSTEM

This indicates whether a two, three or four grade system was used in the pathology report. **Please see FORDS section two, pg 114 for further instructions**

GRADE PATH VALUE

Describes the grade assigned according to the grading system in *Grade Path System*. This item records the numeric grade reported in the pathology report, it supplements but does not replace *Grade/Differentiation*. **Please see FORDS, section two, pg 115 for further instructions**

DIAGNOSTIC CONFIRMATION

Information for this field records the best method of how the reported cancer was diagnosed at any time in the patient's history.

The data item represents a hierarchical coding scheme with **code 1** taking precedence.

If any time during the patient's cancer experience, a more definitive diagnostic method is performed and confirms a malignancy; this data item should be changed to reflect that confirmation.

Example: Patient is diagnosed on 2/10/07, by CT scan with probable lung cancer with no further workup. Diagnostic confirmation is coded to radiology (**7**). Later in March of 2007, the patient undergoes a bronchoscopy in which biopsies confirm squamous cell carcinoma. The diagnostic confirmation code is changed to reflect the positive histology (**1**).

Microscopic Confirmation

- 1 – Positive histology
- 2 – Positive cytology, no positive histology
- 4 – Positive microscopic confirmation, method not specified

Not Microscopically Confirmed

- 5 – Positive laboratory test/marker study
- 6 – Direct visualization without microscopic confirmation
- 7 – Radiography and other imaging techniques without microscopic confirmation
- 8 – Clinical diagnosis only (other than 5, 6, or 7)

Confirmation Unknown

- 9 – Unknown whether or not microscopically confirm

Diagnostic Confirmation Explanation:

CODES	DEFINITIONS
1	Tissue specimens from biopsy, frozen section, surgery, autopsy, or dilation and curettage. Bone marrow biopsy and bone marrow aspiration.
2	Microscopic examination of cells removed from a neoplasm. Fine-needle aspiration (FNA). Cytology includes smears from the sputum, cervix, vagina, bronchial brushings and washings , tracheal washings, Prostatic secretions , breast secretions, gastric fluids, spinal fluid, peritoneal fluid, pleural fluid and urinary sediment – includes paraffin-block specimens from concentrate spinal, pleural, or peritoneal fluid
4	Case is reported as microscopically confirmed, but no information is available about the method (histology, cytology)
5	Diagnosis based on certain laboratory tests or marker studies clinically diagnostic (abnormal

	electrophoretic spike for multiple myeloma or Waldenstrom's macroglobulemia, alpha - fetoprotein for liver cancer). Elevated PSA is nondiagnostic of cancer. If the <u>physician</u> uses the PSA as a basis for diagnosing prostate cancer with no other workup, record as code 5.
6	Diagnosis made at surgical exploration or by endoscopy – no positive histology or cytology – Autopsy only case (information from gross autopsy report)
7	Malignancy reported by the physician from an imaging technique report only, includes ultrasound, computerized (axial) tomography (CT or CAT) and magnetic resonance imaging (MRI) – no positive histology or cytology
8	Diagnosed by clinical methods not mentioned above – no positive histology or cytology. Reported by the <u>physician</u> in the medical record.
9	Statement of malignancy was reported in the medical record– method of confirmation is unknown

Instructions for Coding Hematopoietic or Lymphoid Tumors (9590-9992)

- There is no priority hierarchy for coding *Diagnostic Confirmation* for hematopoietic and lymphoid tumors. See the *Hematopoietic Database* for information on the definitive diagnostic confirmation for specific types of tumors.
- Code 1 when the microscopic diagnosis is based on tissue specimens from biopsy, frozen section, surgery, or autopsy or bone marrow specimens from aspiration or biopsy.
- For leukemia only, code 1 when the diagnosis is based only on the complete blood count (CBC), white blood count (WBC) or peripheral blood smear. Do not use code 1 if the diagnosis was based on immunophenotyping or genetic testing using tissue, bone marrow or blood.
- Assign code 3 when there is a histology positive for cancer AND positive immunophenotyping and/or genetic testing results. Do not use code 3 for neoplasms diagnosed prior to January 1, 2010.

- 1 – Positive histology
- 2 – Positive cytology
- 3 – Positive histology PLUS positive immunophenotyping AND positive genetic studies
- 4 – Positive microscopic confirmation, method not specified
- 5 – Positive laboratory test/maker study
- 6 – Direct visualization without microscopic confirmation
- 7 – Radiographic and other imaging techniques without microscopic confirmation
- 8 – Clinical diagnosis only, other than 5, 6 or 7
- 9 – Unknown whether or not microscopically confirmed

Code	Definition
------	------------

1	Histologic confirmation (tissue microscopically examined)
2	Cytologic confirmation (no tissue microscopically examined; fluid cells microscopically examined).
3	Histologic is positive for cancer, and there are also positive immunophenotyping and/or genetic test results. Example: bone marrow exam is positive for acute myeloid leukemia (9861/3) Genetic testing shows AML with inv(16)(p13.1q22) (9871/3).
4	Microscopic confirmation is all that is known, unknown if the cells were from histology or cytology.
5	A clinical diagnosis of cancer is based on laboratory tests/maker studies which are clinically diagnostic for cancer
6	The tumor was visualized during a surgical or endoscopic procedure only with no tissue resected for microscopic examination
7	The malignancy was reported by the physician from an imaging technique report only
8	The malignancy was reported by the physician in the medical record
9	A statement of malignancy was reported in the medical record, but there is no statement of how the cancer was diagnosed.

AMBIGUOUS TERMINOLOGY DIAGNOSIS

Identifies cases for which an ambiguous term is the most definitive word or phrase used to establish a cancer diagnosis.

Please apply the instructions in the current version of *Multiple Primary Histology and Coding Rules* to code this item

DATE OF CONCLUSIVE DIAGNOSIS

Record the date when a conclusive cancer diagnosis (based on definitive statement of malignancy) is made 60 days or more following an initial diagnosis that was based only on ambiguous terminology.

- Record the date a conclusive diagnosis was made based on a definitive statement of malignancy more than 60 days after the date of initial diagnosis. Update the histology code if it is different.
- Apply the instructions in the current version of *Multiple Primary Histology and Coding Rules* to code this item
- Leave blank for cases diagnosed prior to January 1, 2007
- Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable.

MULTIPLICITY COUNTER

This record the number of tumors (Multiplicity) reported as a single primary

- This data item does not apply to metastatic tumors.
- Apply the instructions in the current version of *Multiple Primary Histology and Coding Rules* to code this item
- Use 88 for leukemia, lymphoma, immunoproliferative disease, Kaposi sarcoma and unknown primaries
- Leave blank for cases diagnosed on or before December 31, 2006

Codes

01 One tumor only

02 Two tumors present

03 Three tumors present

...

...

88 Information on multiple tumors not collected/not applicable for this site

99 Multiple tumors present, unknown how many; unknown if multiple tumors

DATE OF MULTIPLE TUMORS

This identifies the date the patient is diagnosed with multiple or subsequent reportable tumor(s) reported as a single primary. Multiple tumors must have the same histologic group as the original tumor and must be located in the same organ or primary site as the original tumor, using the primary site and histology coding rules.

- Record the date the patient is diagnosed with synchronous multiple tumors abstracted as a single primary
- Record the *Date of Initial Diagnosis* as the *Date of Multiple Tumors* when multiple tumors are abstracted and reported as a single primary at the time of initial diagnosis.
- Apply the instructions in the current version of *Multiple Primary Histology and Coding Rules* to code this item
- Do not assign a date for leukemia, lymphoma, immunoproliferative disease
- Leave blank for cases diagnosed prior to January 1, 2007
- Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable

TYPE OF MULTIPLE TUMORS REPORTED AS ONE PRIMARY

This identifies cases with multiple tumors that are abstracted as a single primary using the multiple primary rules in terms of the mix of histologic behaviors represented.

- The data item does not apply to metastatic tumors
- Apply the instructions in the current version of *Multiple Primary Histology and Coding Rules* to code this item
- Leave blank for cases diagnosed on or before December 31, 2006

LATERALITY

Laterality refers to a **paired (right or left)** organ. The following codes are used to complete this data item:

Code	Definition
0	Organ is not considered to be 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 specified
4	Bilateral involvement, side of origin unknown, stated to be single primary, <ul style="list-style-type: none"> ❖ Both ovaries simultaneously involved with a single histology ❖ Bilateral retinoblastomas ❖ Bilateral Wilms' tumors
5	Paired site: midline tumor
9	Paired site, but no information concerning laterality

Laterality is applicable to the following major heading sites and the subsequent sub-sites:

SITE	ICD-0 CODE	SITE	ICD-0 CODE
Parotid	C07.9	Skin of external ear	C44.2
Submandibular gland	C08.0	Skin-other unspecified parts of the face (if midline use 9)	C44.3
Sublingual gland	C08.1	Skin of trunk – code 9 if midline	C44.5
Tonsillar fossa	C09.0	Skin of upper limb & shoulder	C44.6
Tonsillar pillar	C09.1	Skin of lower limb & hip	C44.7
Overlapping lesion of tonsil	C09.8	Peripheral nerves & autonomic nervous system, upper limb & shoulder	C47.1
Tonsil, NOS	C09.9	Peripheral nerves & autonomic nervous system of lower limb & hip	C47.2
Nasal cavity – excludes nasal cartilage & nasal septum	C30.0	Connective, subcutaneous, & other soft tissues-upper limb & shoulder	C49.1
Middle ear	C30.1	Connective, subcutaneous, & other soft tissues, lower limb & hip	C49.2
Maxillary sinus	C31.0	Breast	C50.0 – C50.9
Frontal sinus	C31.2	Ovary	C56.9
Main bronchus – excluding carina	C340	Fallopian tube	C57.0
Lung	C34.1-C34.9	Testis, undescended, descended, nos	C62.0 –C62.9
Pleura, Nos	C38.4	Epididymis	C63.0
Long bone-upper limb & scapula	C40.0	Spermatic cord	C63.1
Short bone, upper limb	C40.1	Kidney, nos	C64.9
Long bone, lower limb	C40.2	Renal pelvis	C65.9
Short bone, lower limb	C40.3	Ureter	C66.9
Rib & clavicle-excludes sternum	C41.3	Eye & lacrimal gland	C69.0-C69.9
Pelvic bones-excludes	C41.4	Adrenal gland	C74.0-C74.9

sacrum, coccyx, & symphysis pubis			
Skin of eyelid	C44.1	Carotid body	C75.4
Skin of external ear	C44.2	Cerebral meninges, NOS	C70.0
Skin of other & unspecified parts of face	C44.3	Cerebrum	C71.0
Skin of trunk	C44.5	Frontal lobe	C71.1
Skin of upper limb & shoulder	C44.6	Temporal lobe	C71.2
Skin of lower limb & hip	C44.7	Parietal lobe	C71.3
Occipital lobe	C71.4	Olfactory nerve	C72.2
Optic nerve	C72.3	Acoustic nerve	C72.4
Cranial nerve	C72.5		

Codes C70.0 – C72.5 exclude cases diagnosed prior to 2004, should only be coded as paired organ site for cases diagnosed 1/1/04 and after

STAGING SCHEMES

There are three staging schemes used on an abstract, according to dates of diagnosis.

General Summary Stage at diagnosis – SEER Summary Stage

SEER Summary Stage 2000

These schemes are used for cases diagnosed on or after January 1, 2001; use Summary Staging Manual 2000.

SEER Summary Stage 1977

This scheme is used for cases diagnosed prior to January 1, 2001; use the Summary Staging Guide 1986 reprint

AJCC Stage (TNM) – clinical, pathologic, other, and pediatric
(For cases diagnosed before January 1, 2004)

Please refer to the appropriate staging manual for cases diagnosed prior to January 1, 2004

Collaborative Staging will be used for cases diagnosed on or after January 1, 2004.

Collaborative Staging Version 2 (CSv2) will be used for cases diagnosed on or after January 1, 2010

The Collaborative Staging System schemas consist of the data fields necessary to derive T, N, M, and Stage Group according to the sixth and seventh editions of the AJCC Staging Manual; Summary Stage 1977, and SEER Summary Stage 2000.

- Collaborative Staging is collected on all cases diagnosed on or after January 1, 2004 regardless of whether they are microscopically confirmed.
- Collaborative Staging is collected on all sites/histologies.
- All schemas apply to all histologies unless otherwise noted.

REFER TO THE APPROPRIATE MANUAL WHEN STAGING. NEVER RELY ON YOUR MEMORY.

DATE OF SURGICAL DIAGNOSTIC AND STAGING PROCEDURE

Records the date on which the surgical diagnostic and/or staging procedure was performed.

- Record the date that surgical diagnostic and/or staging procedure was performed at this or any facility
- Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable.

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DATE OF FIRST COURSE OF TREATMENT

- Record the earliest date on which treatment (surgery, radiation, systemic or other therapy) of the patient began whether administered at the reporting hospital or at another facility.
- If active surveillance or watchful waiting is selected as the first course of treatment, record the date this decision is made.
- In case of non-treatment in which a physician decides not to treat a patient or a patient's family or guardian declines all treatment, record the date this decision was made
- Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable

Examples:

A pt has a core biopsy on 2/12/04 and subsequently undergoes an excisional biopsy on 2/14/04	February14, 2004
A pt begins receiving preoperative radiation elsewhere on April 21, 2005 and subsequent surgical therapy at this facility on June 2, 2005	April 21, 2005

DATE OF FIRST THERAPY FLAG

This flag explains why there is no appropriate value in the corresponding date field, *Date of First Course of Treatment*. **Refer to FORDS Section two, Coding Instructions pg 212 for instructions to code this item**

DATE OF FIRST SURGICAL PROCEDURE: Formerly called Date of Cancer-directed Surgery.

Records the earliest date on which any first course surgical procedure was performed.

Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable

RX DATE –SURGERY FLAG

This flag explains why there is no appropriate value in the corresponding date field, *Date of First Surgical procedure*

Refer to FORDS Manual, Section Two: Coding Instructions, pg 216 for further instructions

DATE OF MOST DEFINITIVE SURGICAL RESECTION OF PRIMARY SITE

Records the date of the most definitive surgical procedure(s) performed to the primary site as part of the first course of treatment.

Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable

RX DATE MOST DEFINITIVE SURGERY FLAG

This flag explains why there is no appropriate value in the corresponding date field, *Date of Most Definitive Surgical Resection of the Primary Site*. **Refer to FORDS Section two, Coding Instructions pg 219 for instructions to code this item**

SURGICAL PROCEDURE OF PRIMARY SITE

Records the surgical procedure(s) performed to the primary site

- Site-specific codes for this data item are found in Appendix B of FORDS manual. Use the operative and pathology reports to determine the proper code(s) for surgical procedure(s).
- If registry software allows only one procedure to be collected, document the most invasive surgical procedure for the primary site.
- If registry software allows for multiple procedures to be recorded, this item refers to the most invasive surgical procedure of the primary site.
- For codes 00 through 79, the response positions are hierarchical. Last-listed responses take precedence over responses written above. Code 98 takes precedence over code 00. Use codes 80 and 90 only if more precise information about the surgery is not available.
- Excisional biopsies that remove the entire tumor and/or leave only microscopic margins are to be coded in this item.
- Surgery to remove regional tissue or organs is coded in this item only if the tissue/organs are removed in continuity with the primary site, except where noted in Appendix B.
- If a previous surgical procedure to remove a portion of the primary site is followed by surgery to remove the remainder of the primary site, then code the total or final results
- If the procedure coded in this item was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record this surgery in the item *Palliative Care*

SURGERY CODE DESCRIPTION

Code	Label	Definition
00	None	No surgical procedure or primary site, Diagnosed at autopsy.
10-19	Site-specific codes; tumor destruction	Tumor destruction, no pathologic specimen produced. Refer to Appendix B for the correct site-specific code for the procedure
20-80	Site-specific codes; resection	Refer to Appendix B for the correct site-specific code for the procedure
90	Surgery, NOS	A surgical procedure to the primary site was done, but no information on the type of surgical procedure is provided
98	Site-specific codes; special	Special code. Refer to Appendix B for the correct site-specific code for the procedure
99	Unknown	Patient record does not state whether a surgical procedure of the primary site was performed and no information is available. Death certificate only.

SCOPE OF REGIONAL LYMPH NODE SURGERY

This field identifies the removal, biopsy or aspiration of regional lymph node(s) at the time of the surgery of primary site or during a separate event.

There is no minimum number of lymph nodes removed in order to record this field. If only one lymph node was removed, code using the range of 1-5.

- The scope of regional lymph node surgery is collected for each surgical event even if the surgery of the primary site was not performed.
- Codes 0-7 are hierarchical. If only one procedure can be recorded, code the procedure that is numerically higher.
- Code 9 for primaries of the meninges, brain, spinal cord, cranial nerves, and other parts of the central nervous system (C70.0-C70.9, C71.0-C71.9, C72.0-C72.9); for lymphomas (M-9590-9596, 9650-9719, 9727-9729) for a lymph node site (C77.0-C77.9); for unknown and ill-defined primaries (C76.0-C76.8, C80.9) or for hematopoietic, reticuloendothelial, immunoproliferative, or myeloproliferative disease (C42.0, C42.1, C42.3, C42.4 or M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)
- Do not record distant lymph node removal in this field. Code in *Surgical Procedure/Other Site*.
- Refer to current *AJCC Cancer Staging Manual* for site-specific identification of regional lymph nodes.
- If the procedure coded in this item was provided to prolong patient's life for by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record this surgery in the item *Palliative Care*

REGIONAL LYMPH NODE CODING DEFINITIONS

Code	Label	Definition
0	None	No regional lymph node surgery. No lymph nodes found in the pathologic specimen. Diagnosed at autopsy
1	Biopsy or aspiration of regional lymph node, NOS	Biopsy or aspiration of regional lymph node(s) regardless of the extent of involvement of disease.
2	Sentinel lymph node biopsy	Biopsy of the first lymph node or nodes that drain a defined area of tissue within the body. Sentinel node(s) are identified by the injection of a dye or radio label at the site of the primary
3	Number of regional nodes removed, unknown or not stated; regional lymph nodes removed, NOS	Sampling or dissection of regional lymph node(s) and the number of nodes removed is unknown or not stated. The procedure is not specified as sentinel node biopsy.
4	1-3 regional lymph nodes removed	Sampling or dissection of regional lymph node(s) fewer than four lymph nodes found in the specimen. The procedure is not specified as sentinel node biopsy
5	4 or more regional lymph nodes removed	Sampling or dissection of regional lymph nodes with at least four lymph nodes found in the specimen as sentinel node biopsy.
6	Sentinel node biopsy and code 3, 4, or 5 at same time, or timing not stated	Code 2 was performed in a single surgical event with code 3, 4, or 5. Or, code 2 and 3, 4, or 5 was performed, but timing was not stated in patient record.
7	Sentinel node biopsy and code 3, 4, or 5 at different times	Code 2 was followed in a subsequent surgical event by procedures coded as 3, 4, or 5.
9	Unknown or not applicable	It is unknown whether regional lymph node surgery was performed; death certificate only; for lymphomas with a

		lymph node primary site; unknown or ill defined primary; or for hematopoietic reticuloendothelial, immunoproliferative, or myeloproliferative disease.
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SURGICAL PROCEDURE/OTHER SITE

Record the surgical removal of *distant lymph nodes* or other tissue(s)/organ(s) beyond the primary site.

- Assign the highest numbered code that describes the surgical resection or distant lymph node(s) and/or regional/distant tissue or organs.
- Incidental removal of tissue or organs is not a “Surgical Procedure/Other Site.”
- Surgical Procedure/Other Site is collected for each surgical even if surgery of the primary site was not performed

SURGICAL PROCEDURE/OTHER SITE DEFINITIONS

Code	Label	Definition
0	None	No surgical procedure of non-primary site was performed. Diagnosed at autopsy.
1	Non-primary surgical procedure performed	Non-primary surgical resection of other site(s), unknown if regional or distant
2	Non-primary surgical procedure to other regional sites	Resection of regional site
3	Non-primary surgical procedure to <i>distant lymph nodes</i>	Resection of distant lymph node(s).
4	Non-primary surgical procedure to distant site	Resection of distant site
5	Combination of codes	Any combination of surgical procedures 2, 3, or 4
9	Unknown	Unknown whether any surgical procedure of non-primary site is performed. Death certificate only.

SURGICAL MARGINS OF THE PRIMARY SITE

Records the final status of the surgical margins after resection of the primary tumor.

- Code the margin status as it appears in the pathology report after the resection of the primary tumor.
- Microscopic involvement is not visible to the eye and is usually documented in the final diagnosis or microscopic portion of the pathology report.
- Macroscopic is visible to the eye and is documented in the operative report or the gross portion of the pathology report.

- Codes 0-3 are hierarchical; if two codes describe the margin status, use the numerically higher code.
- If the pathology report makes no mention of margins, code 9
- For lymphomas (M-9590-9597, 9650-9719, 9724-9738) with a lymph node primary site (C77.0-C77.9), code 9.

Example: Patient has Excisional biopsy with involved margins. Later has a modified radical mastectomy with clear margins. Code the margin status after the mastectomy, 0-All margins grossly and microscopically negative.

SURGICAL MARGINS DEFINITIONS

Code	Label	Definition
0	No residual tumor	All margins grossly & microscopically negative
1	Residual tumor, NOS	Involvement indicated but not otherwise specified
2	Microscopic residual tumor	Residual tumor identified microscopically, is not visible to the naked eye
3	Macroscopic residual tumor	Gross tumor of the primary site which is visible to the naked eye
7	Margins not evaluable	Cannot be assessed (indeterminate)
8	No primary site surgery	No surgical procedure of the primary site, Diagnosed at autopsy
9	Unknown or not applicable	Unknown whether a surgical procedure to the primary site was performed; death certificate only; for lymphomas with a lymph node primary site; unknown or ill-defined primary; or hematopoietic, reticuloendothelial, immunoproliferative, or myeloproliferative disease.

DATE RADIATION STARTED

Record the date radiation therapy began that is part of first course treatment. The RX date – **Radiation Flag** explains why there is no appropriate value in the corresponding date field. **Location of Radiation Treatment** identifies the location of the facility where radiation therapy was administered during the first course of treatment. **Radiation Treatment Volume** identifies the volume or anatomic target of the most clinically significant regional radiation therapy delivered to the patient during the first course of treatment. **Regional Treatment Modality**, records the dominant modality of radiation therapy used to deliver the most clinically significant regional dose to the area of interest during the first course of therapy. **Regional Dose**, records the dominant or most clinically significant total dose of regional radiation therapy delivered to the patient during the first course of treatment. The unit of measure is centiGray (cGy). **Boost Treatment Modality**, records the dominant modality of radiation therapy used to deliver the most clinically significant boost dose to the primary volume of interest during the first course of treatment. **Date Radiation Ended**, the date on which the patient completes or receives the last radiation treatment at any facility. **Radiation Date Ended Flag**, This flag explains why there is no appropriate value in the corresponding date field, *Date Radiation Ended*. Refer to **FORDS Section Two, Coding Instructions for complete instructions**

RADIATION TEXT

Record the type of radiation being received in this field.

RADIATION/SURGERY SEQUENCE

Records the sequencing of radiation and surgical procedures given as part of the first course of treatment

0	No radiation therapy and/or surgical procedures	No radiation therapy given or unknown if radiation therapy given; no scope of regional lymph node surgery; no surgery to other regional sites, distant site or distant lymph nodes or unknown whether surgery given.
2	Radiation therapy before surgery	Radiation given before surgery to primary site
3	Radiation therapy after surgery	Radiation therapy given after surgery to primary site
4	Radiation therapy both before and after surgery	Radiation given before and after any surgery to primary site
5	Intraoperative radiation therapy	Intraoperative therapy given during surgery to primary site
6	Intraoperative radiation therapy with other therapy administered before or after surgery	Intraoperative radiation therapy given during surgery to primary site
9	Sequence unknown	Administration of radiation therapy and surgery to primary site

Refer to FORDS Section Two, Coding Instructions for complete instructions

DATE CHEMOTHERAPY STARTED

Record the date initiation of chemotherapy that is part of the first course of treatment..

RX Date-Chemo Flag, This flag explains why there is no appropriate value in the corresponding date field, *Date Chemotherapy Started*.

CHEMOTHERAPY

00	None, Chemotherapy was not part of the planned first course therapy, Diagnosed at autopsy
01	Chemotherapy administered as first course therapy, but the type and number of agents is not documented in patient record
02	Single-agent chemotherapy administered as first course therapy
03	Multiagent chemotherapy administered as first course therapy
82	Chemotherapy was not recommended/administered because it was contraindicated due to patient risk factor
85	Chemotherapy was not administered because patient died prior to planned

	or recommended therapy
86	Chemo was not administered. It was recommended by patient's physician but was not administered as part of first course therapy. No reason stated in patient record
87	Chemo not administered. Recommended by physician. Patient refused
88	Chemo was recommended, unknown if administered
99	Unknown if chemo recommended or administered, not in patient record. Death certificate only

Refer to the SEER *Rx Interactive Drug Database (<http://www.seer.cancer.gov/>) for a list of chemotherapeutic agents.

Refer to FORDS Section Two, Coding Instructions for complete instructions

CHEMOTHERAPY TEXT

Record the chemotherapy agents being administered to the patient in this field.

HORMONAL THERAPY

Records the type of hormone therapy administered as first course treatment at this and all other facilities. This therapy is defined as any agent (drug) and/or procedure that affect cancer tissue by changing the hormonal balance of the patient. Included are hormones, antihormones and steroids, as well as endocrine surgery. It is not usually used as a curative measure.

00	None, hormone therapy was not part of the planned first course therapy. Diagnosed at autopsy.
01	Hormone therapy administered as first course therapy
82	Hormone therapy not recommended/administered, contraindicated due to patient risk factors
85	Hormone therapy not administered, patient died prior to
86	Hormone therapy not administered, recommended by patient's physician, not administered as part of first course. No reason in patient record
87	Hormone therapy not administered, recommended, patient refused
88	Hormone therapy recommended, unknown if administered
99	Unknown if hormonal agent recommended or administered. Death certificate only

Refer to the SEER *Rx Interactive Drug Database (<http://www.seer.cancer.gov/>) for a list of hormonal agents.

DATE HORMONAL THERAPY STARTED

Record the date the hormonal therapy started. **RX Date-Hormone Flag**, this flag explains why there is no appropriate value in the corresponding date field, *Date Hormone Therapy Started*.

Refer to FORDS Section Two, Coding Instructions for complete instructions

HORMONAL TEXT

Record the hormonal agent(s) being administered to the patient in this field.

IMMUNOTHERAPY

Records the type of Immunotherapy administered as first course treatment in this or any other facilities. Immunotherapy consists of biological or chemical agents that alter the immune system or change the host's response to the tumor cells.

00	None, immunotherapy was not part of first course therapy. Diagnosed at autopsy
01	Immunotherapy administered at first course therapy
82	Immunotherapy not recommend/administered because contraindicated due to patient risk factors
85	Immunotherapy not administered, patient died prior
86	Immunotherapy not administered, recommended by patient's physician but not administered as part of first course, no reason in patient record
87	Immunotherapy not administered, recommended, patient refused
88	Immunotherapy recommended, unknown if administered
99	Unknown whether an immunotherapeutic agent(s) was recommended or administered, not in patient record. Death certificate only

Refer to the SEER *Rx Interactive Drug Database (<http://www.seer.cancer.gov/>) for a list of hormonal agents.

DATE IMMUNOTHERAPY STARTED

Record the date of initiation of immunotherapy or a biologic response modifier (BRM) that is part of the first course of treatment. **RX Date-BRM Flag**, this flag explains why there is no appropriate value in the corresponding date field, *Date Immunotherapy Started*.

Refer to FORDS Section Two, Coding Instructions for complete instructions

IMMUNOTHERAPY TEXT

Record the type of BRM being administered to the patient in this field.

HEMATOLOGIC TRANSPLANT AND ENDOCRINE PROCEDURES

Identifies systemic therapeutic procedures administered as part of the first course of treatment at this and all other facilities. This field allows for the coding of treatment that involve the alteration of the immune system or change the patient's response to tumor cells but does not involve the administration of antineoplastic agents.

- Bone marrow transplants should be coded as autologous (bone marrow from patient) or allogeneic (bone marrow donated from family member). Syngeneic transplants (marrow from identical twin) are coded as allogeneic.

00	No transplant procedure or endocrine therapy was administered as part of first course therapy
10	A bone marrow transplant procedure was administered, but the type was not specified
11	Bone marrow transplant-autologous (stem cell transplant or boost)
12	Bone marrow transplant-allogeneic
20	Stem cell harvest and infusion. Umbilical cord stem cell transplant
30	Endocrine surgery and/or endocrine radiation therapy
40	Combination of codes 30 and 10, 11, 12 or 20
82	Hematologic transplant and/or endocrine surgery/radiation was not recommended, contraindicated due to patient risk factors
85	Hematologic transplant and/or endocrine surgery/radiation not administered patient died prior to
86	Hematologic transplant and/or endocrine surgery/radiation not administered, recommend by physician, not administered as part of first course therapy
87	Hematologic transplant and/or endocrine surgery/radiation was not administered, recommended, treatment refused by patient
88	Hematologic transplant and/or endocrine surgery/radiation was recommended, but unknown if administered
99	Unknown whether hematologic transplant and/or endocrine surgery/radiation was recommend, not in patient record. Death certificate only

Refer to FORDS Section Two, Coding Instructions for complete instructions

PALLIATIVE PROCEDURE

Identifies any care provided in an effort to palliate or alleviate symptoms. Palliative care is performed to relieve symptoms and may include surgery, radiation therapy, systemic therapy and/or other pain management therapy.

0	No palliative care provided. Diagnosed at autopsy
1	Surgery to alleviate symptoms, but no attempt to diagnose, stage, or treat the primary tumor is made
2	Radiation therapy to alleviate symptoms, but no attempt to diagnose, stage, or treat the primary tumor is made
3	Chemotherapy, hormone therapy or other systemic drugs to alleviate symptoms, but no attempt to diagnose, stage, or treat the primary tumor
4	Patient received or was referred to pain management therapy
5	Any combination of codes 1, 2, and/or 3 without code 4
6	Any combination of codes 1, 2, and/or 3 with code 4
7	Palliative care was performed or referred, but no information on type

	available. Palliative care provided but does not fit the descriptions for codes 1-6
9	Unknown if palliative care was performed; not stated in patient record

EXAMPLE:

A patient is diagnosed with Stage IV prostate cancer. His only symptoms are painful bony metastases in his right hip and lower spine. XRT is given to those areas.

Refer to FORDS Section Two, Coding Instructions for complete instructions

RECURRENCE

Recurrence indicates the return of the cancer after a period of remission or after the patient has experienced a period of documented disease-free intermission. Use this field for **first recurrence only**.

TYPE OF FIRST RECURRENCE

- Code 00 – 70 are hierarchical. Record the highest-numbered applicable response.
- Use codes “06, 16, 17, 26, 27, 36, or 46 “for tumors that are originally diagnosed as in situ. **Do not use these codes for any other tumors.**
- Codes 00, 88, or 99 may apply to any tumor.
- Codes 51-59 apply only if all first occurrences were in a single category. There may be multiple metastases (or “seeding”) within the distant location.
- Code **00** for leukemias that are in remission. If the patient relapses, then code recurrence status as **59**.
- If the patient has more than one primary and the physician does not state which cancer has recurred, code the recurrent disease to each tumor and at a later date if the recurrent primary is identified, revise the codes appropriately.

The following table illustrates the correct codes for the type of **first recurrence**:

Code	Definition
00	Patient became disease-free after treatment and has not had a recurrence.
04	In situ recurrence of an invasive tumor
06	In situ recurrence of an in situ tumor
10	Local recurrence, and there is insufficient information available to code 13-17. Local recurrence includes confined to the remnant of the organ of origin, to the organ of origin, to the anastomosis, or to scar tissue where the organ previously existed.
13	Local recurrence of an invasive tumor
14	Trocar recurrence of an invasive tumor. Includes recurrence in the trocar path or entrance site following prior surgery.
15	Both local and trocar recurrence of an invasive tumor (both 13 and 14)

16	Local recurrence of an in situ tumor, NOS
17	Both local and trocar recurrence of an in situ tumor.
20	Regional recurrence, and there is insufficient information available to code to 21-27.
21	Recurrence of an invasive tumor in adjacent tissue or organ(s) only.
22	Recurrence of an invasive tumor in regional lymph nodes only.
25	Recurrence of an invasive tumor in adjacent tissue or organ(s) and in regional lymph nodes (both 21 and 22 at the same time)
26	Regional recurrence of an insitu tumor, NOS.
27	Recurrence of an in situ tumor in adjacent tissue or organ(s) and in regional lymph nodes at the same time.
30	Both regional recurrence of an invasive tumor in adjacent tissue or organ(s) and/or regional lymph nodes (20-25) and local and/or trocar recurrence (10, 13, 14, or 15)
36	Both regional recurrence of an in situ tumor in adjacent tissue or organ(s) and/or regional lymph nodes (26-27) and local and/or trocar recurrence (16 or 17).
40	Distant recurrence, and there is insufficient information available to code to 46-62.
46	Distant recurrence of an insitu tumor.
51	Distant recurrence of an invasive tumor in the peritoneum only. Peritoneum includes peritoneal surfaces of all structures within the abdominal cavity and/or positive ascitic fluid.
52	Distant recurrence of an invasive tumor in the lung only. Lung includes the visceral pleura.
53	Distant recurrence of an invasive tumor in the pleura only. Pleura include the pleural surface of all structures within the thoracic cavity and/or positive pleural fluid.
54	Distant recurrence of an invasive tumor in liver only.
55	Distant recurrence of an invasive tumor in bone only. This includes bones other than primary site.
56	Distant recurrence of an invasive tumor in the CNS only. This includes the brain and the spinal cord, but not the external eye.
57	Distant recurrence of an invasive tumor in the skin only. This includes skin other than the primary site.
58	Distant recurrence of an invasive tumor in lymph node only. Refer to the staging scheme for a description of lymph nodes that are distant for a particular site.
59	Distant systemic recurrence of an invasive tumor only. This includes leukemia, bone marrow metastasis, carcinomatosis, and generalized disease.
60	Distant recurrence of an invasive tumor in a single distant site (51-58) and local, trocar and/or regional recurrence (10-15, 20-25, or 30)
62	Distant recurrence of an invasive tumor in multiple sites (recurrences that can be coded to more than one category 51-59)
70	Since diagnosis, patient has never been disease-free. This includes cases with distant metastasis at diagnosis, systemic disease, unknown primary or minimal disease that was not treated.
88	Disease has recurred, but the type of recurrence is unknown.
99	It is unknown whether the disease has recurred or if the patient was ever disease-free.

DATE OF FIRST RECURRENCE

- Code the month, day and the year that a physician states that the patient has had a recurrence from the current cancer.
- If the exact date is unknown, estimate at least the recurrence year that may be found in documented information. Estimation is preferred instead of an unknown date.
- If the only time stated is spring, summer, fall or winter, estimated these dates as April, July or October and December or January respectively.
- Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable

RECURRENCE DATE-1ST FLAG

This flag explains why there is no appropriate value in the corresponding date field, *Date of First Recurrence*

Refer to FORDS Section Two, Coding Instructions for complete instructions

LAST DATE OF CONTACT/DATE OF DEATH

- Record the date which the patient was known to be alive or date of death
- If a patient has multiple primaries, all records should have the same date of last contact
- As of January 2, 2006, CoC does not require class 00 cases to be followed
- Beginning in 2010, the way dates are transmitted has changed. The interoperable form of transmits CCYYMMDD form, where blank spaces are used for unknown trailing portions of the date or where a date is not applicable

DATE OF LAST CONTACT FLAG

This flag explains why there is no appropriate value in the corresponding date field, *Date of Last Contact or Death*

VITAL STATUS

Record the patient's vital status using the following codes:

- 0-Dead
- 1-Alive

CANCER STATUS

Records the presence or absence of clinical evidence of patient's malignant or non-malignant tumors as of the *Date of Last Contact or Death*.

- 1 – No evidence of this cancer
- 2 – Evidence of this cancer
- 9 – Unknown whether this cancer is present; not stated in patient record

TEXT FIELDS

Text fields provide ACCR with the written documentation and descriptions of abstracted data necessary to perform accurate quality control and case evaluation. Text also completes the case completeness procedure when the patient has been seen by more than one facility. Record the appropriate information needed that will substantiate the abstracted data.

Please refer to Minimum Text Requirements, General and by Site on ACCR website for specifics

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APPENDIX A ACCR STAFF RESOURCES

Theressia Mitchell, RHIT, CTR
Program Director
Arkansas Central Cancer Registry
800-462-0599, ext 2952 or (501) 661-2463
Theressia.mitchell@arkansas.gov

Vince Teglia
Assistant Director
Arkansas Central Cancer Registry
(501)-661-2952 Fax 501-661-2891
Vincent.teglia@arkansas.gov

Wanda Rhodes, RHIT, CTR
Quality Assurance Coordinator
800-462-0599, ext 2089 or (501) 661-2089
wanda.rhodes@arkansas.gov

Education/Training

Melissa Riddle, RHIT, CTR
Education/Training Coordinator
800-462-0599, ext 2141 or (501) 661-2141
Melissa.riddle@arkansas.gov

QA Specialists

Sue Ann Caudell, CTR
Death Clearance Specialist
800-462-0599 ext4129 or (501) 280-4129
Sue.caudell@arkansas.gov

Maria Bohn
Pathology Intake Specialist
800-462-0599 ext 4826 or (501) 280-4826
Maria.bohn@arkansas.gov

Regional Abstractors

Amy Greer, BA, CTR
Central Region Abstractor
800-462-0599, ext 2841 or (501) 661-2841
amy.greer@arkansas.gov

Cynthia Gulley, CTR
Data Consolidation Specialist
Northeast Regional Abstractor
870-368-5453
cynthia.gulley@arkansas.gov

Laura Pickering, CTR
State Abstractor
800-462-0599, ext 2069 or (501) 661-2069
Laura.pickering@arkansas.gov

Technical Support Personnel

Chris Fisher, BA
Systems Programmer
800-462-0599, ext 2320 or (501) 661-2320
christopher.fisher@arkansas.gov

Carol Middleton
Budget Coordinator
800-462-0599, ext 4105 or 501-280-4105
carol.middleton@arkansas.gov

Johnnie Jackson
Administrative Coordinator
800-462-0599, ext. 2960 or (501) 661-2960
johnnie.jackson@arkansas.gov

Arkansas Central Cancer Registry Mailing Address
4815 West Markham Street
Little Rock, AR 72205

To access the cancer registry's website visit to:
www.healthyarkansas.com/arkcancer/arkcancer.html

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Appendix B

State Law

Subchapter 2 – Cancer

20-15-201. Reporting requirements.

The Arkansas Department of Health shall accumulate such data concerning cancer in Arkansas and its residents as is deemed appropriate for the purpose of describing the frequency of cancer, furnishing reports to health professionals and the public, and for planning and evaluating cancer prevention and control programs. Such data shall be collected under the authority of regulations promulgated by the Arkansas State Board of Health.

20-15-202. State Cancer Plan.

A task force consisting of public and private entities will be established by the Director of the Department of Health to assist the department to develop a strategic plan for a coordinated, comprehensive, statewide network of cancer resources, services, and programs.

20-15-203. Confidentiality.

Information accumulated and maintained in the Cancer Registry of Arkansas shall not be divulged except as statistical information which does not identify individuals and for purposes of such research as approved by the Arkansas State Board of Health.

20-15-204. Agreements with other states.

The Arkansas Department of Health is hereby authorized to enter into agreement with other states and federal organizations authorized to exchange registry data. Such agreements shall prohibit divulging information to entities without prior approval of the Arkansas State Department of Health.

20-15-205. Gifts, grants, and donations.

The Department of Health is authorized to receive gifts, grants, and donations for the purpose of this subchapter.

ACCR Rules and Regulations

Section I. Authority

The following rules and regulations pertaining to Arkansas Cancer Registry are duly adopted and promulgated by the Arkansas State Board of Health pursuant to the authority expressly conferred by the laws of the State of Arkansas.

Section II. Purpose

Since cancer is one of the leading causes of death in Arkansas it is essential that the specific information concerning this group of disease be collected, analyzed and reported. All Arkansans will benefit from the epidemiological surveillance of this group of diseases.

Section III. Definitions

Registry. Means the system for the reporting, collection, and analysis of cancer cases by the Arkansas Department of Health.

Reporting. Means the notification furnished to the Arkansas Department of Health of cases of in situ or invasive neoplasms of the human body, not including squamous cell and basal cell carcinoma of the skin.

Section IV. General Requirements

Each hospital or other medical facility providing screening, diagnostic or therapeutic service, physicians, including surgeons, and all other health care practitioners or their designees shall report the following information concerning each case.

Personal Information.

Name.

Address.

Date of Birth.

Place of Birth.

Race and Spanish/Hispanic Origin.

Sex.

Social Security Number

County of Residence

Marital Status.

Maiden Name, if applicable.

Alias.

Occupation History, if available.

Diagnosis.

Class of case.

Date of Diagnosis.

Primary Site.

Laterality.

Histology.

Treatment.

Grade.

Diagnostic Confirmation.

Staging (American Joint Committee for Cancer – AJCC).

Reporting identification of the facility or person reporting.

Summary of Treatment

Date first course started.

Name of Physician.

First course of treatment, i.e., surgery, radiation, chemotherapy, hormone therapy.

Follow-Up.

Recurrence.

In order to insure the accuracy and completeness of the cancer registry within the Department of Health, staff and agents shall be permitted access to records of hospitals, other medical facilities, physicians (including surgeons), nursing homes and other individuals or agencies providing services wherein records concerning patients in which cases of cancer are identified are located.

All reporting shall be made on forms or in an acceptable manner in accordance with directives of the Department of Health. All cancer cases shall be reported within six months after the date of discharge or diagnosis is made or within six months after a cancer case is known, even if diagnosed elsewhere. Where appropriate cancer data will be in the format recognized by the American Association of Central Cancer Registries.

Each hospital licensed by the Department of Health shall designate a person who shall be responsible for accurate and timely reporting pursuant to this rule. Such hospital shall also adopt a policy which ensures the designation of such person and the hospital's reporting to the Registry.

Section V. Confidentiality

All information reported to the Department of Health shall be confidential and shall not be disclosed under any circumstances except (1) to other state cancer registries with which the Department of Health has agreements that insure confidentiality; (2) to other state health officials who are obligated to keep such information confidential; and (3) to approved cancer research centers under specific conditions where names and identities of the individuals are appropriately protected, and when such research is conducted for the purpose of cancer prevention, control and treatment.

Section VI. Severability

If any provision of these rules and regulations, or the application thereof to any person or circumstances is held invalid, such invalidity shall not affect other provisions or applications of these rules and regulations which can give effect without the invalid provisions or applications, and to this end the provisions hereto are declared to be severable.

Section VII. Repeal

All regulations and parts of regulations in conflict herewith are hereby repealed.

APPENDIX C

Cancer Registries Amendment Act

Public Law 102-515

102d Congress

An Act

Entitled the "Cancer Registries Amendment Act".

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

SECTION 1. SHORT TITLE.

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

SEC. 2. FINDINGS AND PURPOSE.

- a. Findings.-Congress finds that-
 1. cancer control efforts, including prevention and early detection, are best addressed locally by State health departments that can identify unique needs;
 2. cancer control programs and existing statewide population-based cancer registries have identified cancer incidence and cancer mortality rates that indicate the burden of cancer for Americans is substantial and varies widely by geographic location and by ethnicity;
 3. statewide cancer incidence and cancer mortality data, can be used to identify cancer trends, patterns, and variation for directing cancer control intervention;
 4. the American Association of Central Cancer Registries (AACCR) cites that of the 50 States, approximately 38 have established cancer registries, many are not statewide and 10 have no cancer registry; and
 5. AACCR also cites that of the 50 States, 39 collect data on less than 100 percent of their population, and less than half have adequate resources for insuring minimum standards for quality and for completeness of case information.
- b. Purpose.-It is the purpose of this Act to establish a national program of cancer registries.

SEC. 3. NATIONAL PROGRAM OF CANCER REGISTRIES.

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

"Part M-National Program of Cancer Registries

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

- a. "In general.-The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State's cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), data concerning-
 1. "demographic information about each case of cancer;
 2. "information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;
 3. "administrative information, including date of diagnosis and source of information;
 4. "pathological data characterizing the cancer, including the cancer site, stage of disease (pursuant to Staging Guide), incidence, and type of treatment; and
 5. "other elements determined appropriate by the Secretary.
- b. "Matching Funds.-
 1. "In General.-The Secretary may make a grant under subsection (a) only if the State, or the academic or nonprofit private organization designated by the State to operate the cancer registry of the State, involving agrees, with respect to the costs of the program, to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs or \$1 for every \$3 of Federal funds provided in the grant.
 2. "Determination Of Amount of Non-Federal Contribution; Maintenance of Effort.-
 - A. "Non-Federal contributions required in paragraph (1) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, may not be included in determining the amount of such non-Federal contributions.
 - B. "With respect to a State in which the purpose described in subsection (a) is to be carried out, the Secretary, in making a determination of the amount of non-Federal contributions provided under paragraph (1), may include only such contributions as are in excess of the amount of such contributions made by the State toward the collection of data on cancer for the fiscal year preceding the first year for which a grant under subsection (a) is made with respect to the State. The Secretary may decrease the amount of non-Federal contributions that otherwise would have been required by this subsection in those cases in which the State can demonstrate that decreasing such amount is appropriate because of financial hardship.
- c. "Eligibility for Grants.-
 1. "In General.-No grant shall be made by the Secretary under subsection (a) unless an application has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such a manner, and be accompanied by such information, as the Secretary may specify. No such application may be approved unless it contains assurances that the applicant will use the funds provided only for the purposes specified in the approved application

and in accordance with the requirements of this section, that the application will establish such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement and accounting of Federal funds paid to the applicant under subsection (a) of this section, and that the applicant will comply with the peer review requirements under sections 491 and 492.

2. "Assurances.-Each applicant, prior to receiving Federal funds under subsection (a), shall provide assurances satisfactory to the Secretary that the applicant will-
 - A. "provide for the establishment of a registry in accordance with subsection (a);
 - B. "comply with appropriate standards of completeness, timeliness, and quality of population-based cancer registry data;
 - C. "provide for the annual publication of reports of cancer data under subsection (a); and
 - D. "provide for the authorization under State law of the statewide cancer registry, including promulgation of regulations providing-
 - i. "a means to assure the complete reporting of cancer cases (as defined in subsection (a)) to the statewide cancer registry by hospitals or other facilities or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;
 - ii. "a means to assure the complete reporting of cancer cases (as defined in subsection (a)) to the statewide cancer registry by physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;
 - iii. "a means for the statewide cancer registry to access all records of physicians and surgeons, hospitals, individuals, or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;
 - iv. "for the reporting of cancer case data to the statewide cancer registry in such a format, with such data elements, and in accordance with such standards of quality timeliness and completeness, as may be established by the Secretary;
 - v. "for the protection of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;
 - vi. "for a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research;

- vii. "for the authorization or the conduct, by the statewide cancer registry or other persons and organizations, of studies utilizing statewide cancer registry data, including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and
 - viii. "for protection for individuals complying with the law, including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.
- d. "Relationship to Certain Programs.-
 - 1. "In General.-This section may not be construed to act as a replacement for or diminishment of the program carried out by the Director of the National Cancer Institute and designated by such Director as the Surveillance, Epidemiology, and End Results Program (SEER).
 - 2. "Supplanting of Activities.-In area where both such programs exist, the Secretary shall ensure that SEER support is not supplanted and that any additional activities are consistent with the guidelines provided for in subsection (c)(2) (C) and (D) and are appropriately coordinated with the existing SEER program.
 - 3. "Transfer of Responsibility.-The Secretary may not transfer administration responsibility for such SEER program from such Director.
 - 4. "Coordination.-To encourage the greatest possible efficiency and effectiveness of Federally supported efforts with respect to the activities described in this subsection, the Secretary shall take steps to assure the appropriate coordination of programs supported under this part with existing Federally supported cancer registry programs.
- e. "Requirement Regarding Certain Study on Breast Cancer.-In the case of a grant under subsection (a) to any State specified in section 399K(b), the Secretary may establish such conditions regarding the receipt of the grant as the Secretary determines are necessary to facilitate the collection of data for the study carried out under section 399C.

"SEC. 399I. PLANNING GRANTS REGARDING REGISTRIES.

- a. In General.-
 - 1. "States.-The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States for the purpose of developing plans that meet the assurances required by the Secretary under section 399B(c)(2).
 - 2. "Other Entities.-For the purpose described in paragraph (1), the Secretary may make grants to public entities other than States and to nonprofit private entities. Such a grant may be made to an entity only if the State in which the purpose is to be carried out has certified that the State approves the entity as qualified to carry out the purpose.
- b. "Application.-The Secretary may make a grant under subsection (a) only if an application for the grant is submitted to the Secretary, the application contains the certification

required in subsection (a)(2) (if the application is for a grant under such subsection), and the application is in such form, is made in such a manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

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

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

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

- a. "In General.-Subject to subsections (c) and (d), the Secretary, acting through the Director of the National Cancer Institute, shall conduct a study for the purpose of determining the factors contributing to the fact that the breast cancer mortality rates in other States.
- b. "Relevant States.-The States referred to in subsection (a) are Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Vermont, and the District of Columbia.
- c. "Cooperation of State.-The Secretary may conduct the study required in subsection (a) in a State only if the State agrees to cooperate with the Secretary in the conduct of the study, including providing information from any registry operated by the State pursuant to section 399H(a).
- d. "Planning, Commencement, and Duration.-The Secretary shall, during each of the fiscal years 1993 and 1994, develop a plan for conducting the study required in subsection (a). The study shall be initiated by the Secretary not later than fiscal year 1994, and the collection of data under the study may continue through fiscal year 1998.
- e. "Report.-Not later than September 30, 1999, the Secretary shall complete the study required in subsection (a) and submit to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Labor and Human Resources of the Senate, a report describing the findings and recommendations made as a result of the study.

"SEC. 399L. AUTHORIZATION OF APPROPRIATIONS.

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

- b. "Breast Cancer Study.-Of the amounts appropriated for the National Cancer Institute under subpart 1 of part C of title IV for any fiscal year in which the study required in section 399K is being carried out, the Secretary shall expend not less than \$1,000,000 for the study."

Approved October 24, 1992.

Authorization extended through 19

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APPENDIX D

HIPAA ACT

§ 164.512 Uses and disclosures for which consent, an authorization, or opportunity to agree or object is not required.

A covered entity may use or disclose protected health information without the written consent or authorization of the individual as described in §§ 164.506 and 164.508, respectively, or the opportunity for the individual to agree or object as described in § 164.510, in the situations covered by this section, subject to the applicable requirements of this section. When the covered entity is required by this section to inform the individual of, or when the individual may agree to, a use or disclosure permitted by this section, the covered entity's information and the individual's agreement may be given orally.

(a) Standard: uses and disclosures required by law.

(1) A covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.

(2) A covered entity must meet the requirements described in paragraph (c), (e), or (f) of this section for uses or disclosures required by law.

(b) Standard: uses and disclosures for public health activities.

(1) Permitted disclosures. A covered entity may disclose protected health information for the public health activities and purposes described in this paragraph to:

(i) A public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions; or, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority;

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APPENDIX E

ACCR REPORTABLE LIST ICD-9 Casefinding Codes for ICD-O-3 Reportable Diseases

The following ICD-9-CM list is intended to assist in reportable neoplasm casefinding activities. It should be used to identify potentially reportable tumors. Any reportable neoplasms diagnosed on or after January 1, 1996 should be reported to the Arkansas Central Cancer Registry

Reportable Neoplasms:

- ❖ Malignant neoplasms (exclusions noted below)
- ❖ Benign and borderline neoplasms of the central nervous system (Cases diagnosed on or after January 1, 2004)
- ❖ Carcinoma in-situ (exclusions noted below)
- ❖ Squamous intraepithelial neoplasia grade III of vulva (VIN), vagina (VAIN), and anus (AIN) beginning with 2001 cases
- ❖ Primary tumors that originate in a mucous membrane are reportable

140.0-208.10	Malignancies (primary and secondary)
203.2	Plasma cell leukemia (9733/3)
205.2	Chronic neutrophilic leukemia (9963/3)
225.0-225.9	Benign neoplasm of brain and spinal cord
227.3-227.4	Benign Pituitary gland and craniopharyngeal duct (pouch), pineal gland
230.0-231.9	Carcinoma in-situ of digestive organs and respiratory system
233.0-234.9	Carcinoma in-situ of breast and genitourinary system; other and unspecified sites
237.0-237.9	Neoplasms of uncertain behavior of endocrine glands and Nervous system
237.70-237.72	Neurofibromatosis, unspecified, one, two vonRecklinghausen's Disease
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3), Extramedullary plasmacytoma (9734/3)
238.71-238.76	Essential thrombocythemia (9960/3-9962/3, 9985/3, 9986/3, 9987/3)
239.6-239.7	Neoplasms of uncertain nature brain, endocrine glands and other parts of nervous system
259.2	Carcinoid Syndrome
273.2	Gamma Heavy Chain Disease; Franklins Disease
273.3	Waldenstrom's macroglobulinemia
285.0	Sideroblastic Anemia (9982/3-9984)
288.3	Hypereosinophilic syndrome (9964/3)
289.83	Myelofibrosis (9961/3)
789.51	Malignant ascites

V58.0	Encounter or admission for radiotherapy
V58.1	Encounter for chemotherapy and immunotherapy

Neoplasms not required by ACCR:

Morphology Codes	Diagnosis/Terminology
8000-8004	Neoplasms, malignant, NOS of skin
8010/2	Carcinoma in-situ of cervix (CIS)
8010-8045	Epithelial carcinomas of the skin
8050-8084	Papillary and squamous cell carcinoma of skin
8077/2	Squamous Intraepithelial Neoplasia, grade III of cervix (CIN III)
8090-8110	Basal cell carcinoma of the skin
8148/2	Prostatic Intraepithelial Neoplasia

Revised 1/21/10

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APPENDIX F

MEDICAL ABBREVIATION LIST

Abbreviations which are acceptable to use when abstracting cases are listed below. For abbreviated names of Antineoplastic Drugs see *SEER Program Self-Instructional Manual for Tumor Registrars, Book 8, Third Edition* or *SEER Rx website*

Abdomen	ABD	Cervical Intraepithelial Neoplasia	CIN
Abdominal Perineal	AP	Cervix	CX
Acid Phosphatase	ACID PHOS	Cesium	CS
Acquired Immunodeficiency Syndrome	AIDS	Chemotherapy	CHEMO
Acute Granulocytic Leukemia	AGL	Chest X-ray	CXR
Acute Lymphocytic Leukemia	ALL	Chief Complaint	CC
Acute Myelogenous Leukemia	AML	Chronic Granulocytic Leukemia	CGL
Adenocarcinoma	ADENOCA	Chronic Lymphocytic Leukemia	CLL
Adjacent	ADJ	Chronic Myeloid Leukemia	CML
Admission, Admit	ADM	Clear	CLR
Alcohol	ETOH	Common Bile Duct	CBD
Alkaline Phosphatase	ALK PHOS	Complete Blood Count	CBC
Alpha-fetoprotein	AFP	Computerized Axila Tomography Scan	CT, CAT
Also known as	AKA	Consistent With	C/W
Ambulatory	AMB	Continue	CONT
Anaplastic	ANAP	Cystoscopy	CYSTO
Anterior	ANT	Cytology	CYTO
Anteroposterior	AP	Date of Birth	DOB
Approximately	APPROX	Death Clearance Only	DCO
Arteriovenous	AV	Decreased	DECR (<)
Aspiration	ASP	Dermatology	DERM
Auscultation & Percussion	A & P	Diagnosis	DX
Autopsy	AUT	Diameter	DIA
Axillary	AX	Differentiated	DIFF
Bacillus Calmette-Guerin	BCG	Dilation & Curettage	D & C
Barium	BA	Discharge	DIS, DISC
Barium Enema	BE	Discontinued	DC
Benign Prostatic Hypertrophy/hyperplasia	BPH	Disease	DZ, DIS
Bilateral	BIL	Doctor	DR, MD
Bilateral Salpingo-oophorectomy	BSO	Ears, Nose, & Throat	ENT
Biological Response Modifier	BRM	Emergency Room	ER
Biopsy	BX	Enlarged	ENL
Blood Urea Nitrogen	BUN	Esophagogastroduodenoscopy	EGD
Bone Marrow	BM	Estrogen Receptor	ER
Bone Scan	BSC	Evaluation	EVAL
Calcium	CA	Examination	EXAM
Carcinoembryonic Antigen	CEA	Examination under anesthesia	EUA
Carcinoma	CA	Excision	EXC
Carcinoma In Situ	CIS	Exploratory Laparotomy	EXP LAP
CAT Scan	CT	Extend, Extension	EXT
Centimeter	CM	External	EXT
Central Nervous System	CNS	Extremity	EXT

Cerebrospinal Fluid	CSF	Eyes, ears, nose, & throat	EENT
Family History	FH	Midclavicular line	MCL
Floor of mouth	FOM	Middle lobe	ML
Follow-up	FU	Millimeter	MM
Frozen Section	FS	Minimum	MIN
Gastroenterostomy	GE	Moderate	MOD
Gastrointestinal	GI	Moderately Differentiated	MD, MOD DIFF
Grade	GR	Modified Radical Mastectomy	MRM
Gynecology	GYN	Nausea & Vomiting	N & V
Head, Eyes, Ears, Nose, & Throat	HEENT	Negative	NEG (or -)
Hematocrit	HCT	Neurology	NEURO
Hemoglobin	HGB	No evidence of disease	NED
History	HX	Normal	NL
History & Physical	H & P	No significant findings	NSF
History of	HO	Not applicable	NA
History of Present Illness	HPI	Not otherwise specified	NOS
Hormone	HORM	Not recorded	NR
Hospital	HOSP	Obstructed (ing, ion)	OBST
Human Chorionic Gonadotropin	HCG	Operating Room	OR
Human Immunodeficiency Virus	HIV	Operative report	OP report
Hysterectomy	HYST	Outpatient	OP
Immunoglobulin	IG	Packs per day	PPD
Includes, including	INCL	Palpated	PALP
Increase	INCR (or>)	Papanicolaou Smear	PAP
Infiltrating	INFILT	Papillary	PAP
Inpatient	IP	Past Medical History	PMH
Intravenous	IV	Pathology	PATH
Intravenous Pyelogram	IVP	Patient	PT
Kidneys, Ureter, Bladder	KUB	Percutaneous	PERC
Laparotomy	LAP	Physical Examination	PE
Lateral	LAT	Platelets	PLT
Left	L, LT	Poorly differentiated	PD, POOR DIFF
Left Costal Margin	LCM	Positive	POS (or +)
Left lower extremity	LLE	Positron Emission Tomography	PET
Left lower lobe	LLL	Possible	POSS
Left lower quadrant	LLQ	Posterior	POST
Left upper extremity	LUE	Posteroanterior	PA
Left upper lobe	LUL	Postoperative	PO, POSTOP
Left upper quadrant	LUQ	Preoperative	PREOP
Liver, kidney, spleen, (bladder)	LKS(B)	Present Illness	PI
Lower extremity	LE	Prior to admission	PTA
Lower inner quadrant	LIQ	Probable	PROB
Lower outer quadrant	LOQ	Progesterone receptor	PR
Lumbar puncture	LP	Pulmonary	PULM
Lumbosacral	LS	Radiation	RAD
Lymph Node(s)	LN, LNs, LNS	Radiation absorbed dose	RAD
Macroscopic	MACRO	Radiation therapy	RT
Magnetic Resonance Imaging	MRI	Radical	RAD
Malignant	MALIG, MAL	Radium	RA
Mastectomy	MAST	Red blood cells	RBC
Maxillary	MAX	Resection	RESEC
Medicine	MED	Respiratory	RESPIR
Metastatic, Metastases	MET, METS	Review of systems	ROS

Microscopic	MICRO	Right	R, RT
Right costal margin	RCM	Transurethral Resection	TUR
Right lower extremity	RLE	Transurethral Resection Bladder	TURB
Right lower lobe	RLL	Transurethral Resection Prostate	TURP
Right lower quadrant	RLQ	Treatment	RX, TX
Right middle lobe	RML	Undifferentiated	UNDIFF
Right upper extremity	RUE	Upper extremity	UE
Right upper lobe	RUL	Upper gastrointestinal	UGI
Right upper quadrant	RUQ	Upper inner quadrant	UIQ
Rule out	RO, R/O	Upper outer quadrant	UOQ
Salpingo-oophorectomy	SO	Vagina, Vaginal	VAG
Shortness of breath	SOB	Vaginal Hysterectomy	VAG HYST
Specimen	SPEC	Vaginal intraepithelial neoplasia	VAIN
Small	SM, SML	Vascular	VASC
Small bowel	SB, SML BWL	Vulvar intraepithelial neoplasia	VIN
Squamous	SQ, SQUAM	Well differentiated	WD, WELL DIFF
Squamous Cell Carcinoma	SCC	White blood cells	WBC
Status post	S/P	With	W/ or C
Surgery, Surgical	SURG	Within normal limits	WNL
Symptoms	SX	Without	W/O
Total Abdominal Hysterectomy + Bilateral Salpingo-oophorectomy	TAH-BSO	Work-up	W/U
Total Vaginal Hysterectomy	TVH	X-ray	XR
Transitional Cell Carcinoma	TCC	Year	YR

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APPENDIX G

Official United States Postal Service Abbreviations

State/Possession	Abbreviation
ALABAMA	AL
ALASKA	AK
AMERICAN SAMOA	AS
ARIZONA	AZ
ARKANSAS	AR
CALIFORNIA	CA
COLORADO	CO
CONNECTICUT	CT
DELAWARE	DE
DISTRICT OF COLUMBIA	DC
FEDERATED STATES OF MICRONESIA	FM
FLORIDA	FL
GEORGIA	GA
GUAM	GU
HAWAII	HI
IDAHO	ID
ILLINOIS	IL
INDIANA	IN
IOWA	IA
KANSAS	KS
KENTUCKY	KY
LOUISIANA	LA
MAINE	ME
MARSHALL ISLANDS	MH
MARYLAND	MD
MASSACHUSETTS	MA
MICHIGAN	MI
MINNESOTA	MN
MISSISSIPPI	MS
MISSOURI	MO
MONTANA	MT
NEBRASKA	NE
NEVADA	NV
NEW HAMPSHIRE	NH
NEW JERSEY	NJ
NEW MEXICO	NM
NEW YORK	NY
NORTH CAROLINA	NC
NORTH DAKOTA	ND

NORTHERN MARIANA ISLANDS	MP
OHIO	OH
OKLAHOMA	OK
OREGON	OR
PALAU	PW
PENNSYLVANIA	PA
PUERTO RICO	PR
RHODE ISLAND	RI
SOUTH CAROLINA	SC
SOUTH DAKOTA	SD
TENNESSEE	TN
TEXAS	TX
UTAH	UT
VERMONT	VT
VIRGIN ISLANDS	VI
VIRGINIA	VA
WASHINGTON	WA
WEST VIRGINIA	WV
WISCONSIN	WI
WYOMING	WY

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APPENDIX H

Surgery – Cancer Treatment

Surgery is the oldest form of cancer treatment. It also has a key role in diagnosing cancer and finding out how far it has spread (staging). Advances in surgical techniques have allowed surgeons to successfully operate on a growing number of patients. Today, less invasive operations often can be done to remove tumors while saving as much normal tissue and function as possible.

Surgery offers the greatest chance for cure for many types of cancer, especially those that have not spread to other parts of the body. Most people with cancer will have some type of surgery.

Why is surgery used for cancer?

Surgery can be done for many reasons. Some types of surgery are very minor and may be called procedures, while others are much bigger operations. The more common types of cancer surgeries are reviewed here.

Preventive (prophylactic) surgery

Preventive surgery is done to remove body tissue that is likely to become cancerous (malignant), even though there are no signs of cancer at the time of the surgery. For example, pre-cancerous polyps may be removed from the colon.

Sometimes preventive surgery is used to remove an entire organ when a person has an inherited condition that puts them at a much higher risk for having cancer some day. For example, some women with a strong family history of breast cancer are found to have a change (mutation) in their DNA in a breast cancer gene (BRCA1 or BRCA2). Because their risk of getting breast cancer is high, these women may want to consider prophylactic mastectomy (the breasts are removed before cancer is found).

Diagnostic surgery

This type of surgery is used to get a tissue sample to tell whether or not cancer is present or to tell what type of cancer it is. The diagnosis of cancer is often made by looking at the cells under a microscope. Many methods are used to get a sample of cells from a suspicious-looking area. These are described in the section, "Surgery to diagnose and stage cancer."

Staging surgery

Staging surgery is done to find out how much cancer there is and how far it has spread. While the physical exam and the results of lab and imaging tests can help figure out the clinical stage of the cancer, the *surgical stage* (also called the *pathologic stage*) is usually a more exact measure of how far the cancer has spread.

Examples of surgical procedures commonly used to stage cancers, such as laparotomy and laparoscopy, are described in the section, "Surgery to diagnose and stage cancer."

Curative surgery

Curative surgery is done when a tumor appears to be confined to one area, and it is likely that all of the tumor can be removed. Curative surgery can be the main treatment for the cancer. It may be used alone or along with chemotherapy or radiation therapy, which can be given before or after the operation.

Sometimes radiation therapy is actually used during an operation. This is called *intraoperative* radiation therapy.

Debulking (cytoreductive) surgery

Debulking surgery is done to remove some, but not all, of the tumor. It is done when removing the entire tumor would cause too much damage to an organ or near-by tissues. In these cases, the doctor may remove as much of the tumor as possible and then try to treat what's left with radiation therapy or chemotherapy. Debulking surgery is commonly used for advanced cancer of the ovary.

Palliative surgery

This type of surgery is used to treat complications of advanced cancer. It is not intended to cure the cancer. Palliative surgery can also be used to correct a problem that is causing discomfort or disability. For example, some cancers in the abdomen may grow large enough to block off (obstruct) the intestine. If this happens, surgery can be used to remove the blockage. Palliative surgery may also be used to treat pain when the pain is hard to control by other means.

Supportive surgery

Supportive surgery is used to help with other types of treatment. For example, a vascular access device such as a port-a-cath can be surgically placed into a large vein. The port can then be used to give treatments or draw blood for testing, instead of having needles put in the arms.

Restorative (reconstructive) surgery

This type of surgery is used to change the way a person looks after major cancer surgery or to restore the function of an organ or body part after surgery. Examples include breast reconstruction after mastectomy or the use of tissue flaps, bone grafts, or prosthetic (metal or plastic) materials after surgery for oral cavity cancers. For more information on these types of reconstructive surgery, please see the American Cancer Society documents [Breast Reconstruction after Mastectomy](#) and [Oral Cavity and Oropharyngeal Cancer](#).

Surgery to diagnose and stage cancer

A biopsy is a procedure done to remove a tissue sample so that it can be looked at under a microscope. Some biopsies may need to be done in surgery, but many types of biopsies involve removing tumor samples through a thin needle or an endoscope (a flexible lighted tube). Biopsies are often done by surgeons, but they can be done by other doctors, too. Some of the more common ways to do a biopsy are reviewed here.

Fine needle aspiration biopsy

Fine needle aspiration (FNA) uses a very thin needle attached to a syringe to pull out a small amount of tissue from a tumor. If the tumor can't be felt near the surface of the body, the needle can be guided into the tumor by looking at it with an imaging method such as an ultrasound (US) or CT (computed tomography) scan.

The main advantage of FNA is that no surgical incision (cutting through the skin) is needed. A drawback is that in some cases the needle can't take out enough tissue for a definite diagnosis. A more invasive

type of biopsy may then be needed.

Core needle biopsy

This type of biopsy uses a slightly larger needle to take out some of the tissue. A core biopsy can be aspirated (removed) with a needle if the tumor can be felt at the surface. Core biopsies can also be guided by imaging methods if the tumor is too deep to be felt.

The advantage of core biopsy is that it usually collects enough tissue to find out whether or not the tumor is cancer.

Excisional or incisional biopsy

For these biopsies a surgeon cuts through the skin to remove the entire tumor (excisional biopsy) or a small part of the tumor (incisional biopsy). They can often be done with local or regional anesthesia. This means numbing medicine is used just in the area where the biopsy will be done. If the tumor is inside the chest or abdomen, general anesthesia (drugs that put you into a deep sleep) may be needed.

Endoscopy

This procedure uses a thin, flexible tube with a viewing lens or a video camera and a fiber optic light on the end. If a video camera is used, it is connected to a television screen. This allows the doctor to clearly see any tumors in the area. Endoscopes can be passed through natural body openings to look at areas of concern in places such as the following:

- throat (pharyngoscopy)
- voice box (laryngoscopy)
- esophagus (esophagoscopy)
- stomach (gastroscopy)
- small intestine (duodenoscopy)
- colon (colonoscopy or sigmoidoscopy)
- bladder (cystoscopy)
- respiratory tract -- windpipe, bronchi, and lungs (bronchoscopy)

Some of the advantages of endoscopy are:

- The doctor can look right at the tumor and get a good idea of where it is and how big it is.
- A biopsy can be taken through the scope to find out if the tumor is cancer.
- An open surgical incision or general anesthesia is usually not needed.

Local numbing medicines are needed before some types of endoscopy. Medicines may also be given to make you sleepy.

Ultrasonography

Ultrasound devices can be attached to the end of some endoscopes. This allows doctors to look at the

layers of the esophagus (swallowing tube), bronchus (main breathing tube), and parts of the large intestine (bowel). Nearby lymph nodes can be seen, too. Using the ultrasound pictures to guide it, a needle can be placed through the endoscope and cells can be collected from lymph nodes that do not look normal.

Laparoscopy, thoracoscopy, or mediastinoscopy

Laparoscopy is much like endoscopy, but a small incision is made in the skin of the abdomen (belly). A thin tube called a laparoscope is then put through the incision and into the abdomen to look for possible areas of cancer that can be biopsied. When this type of procedure is done to look inside the chest it is called a *thoracoscopy* or *mediastinoscopy*.

Open surgical exploration (laparotomy, thoracotomy, or mediastinotomy)

When less invasive tests do not give enough information about a suspicious area in the abdomen, a laparotomy may be needed. In this procedure, a surgeon makes an incision, usually from the bottom of the sternum (breastbone) down to the lower part of the abdomen (belly), which allows him to look directly at the area in question. The location and size of the tumor and the surrounding areas can be seen and biopsies can be taken, if needed. Because this is a major surgical procedure, general anesthesia (medicines that put you in a deep sleep) is needed. An operation much like this can be done to open and look inside the chest. It is called a thoracotomy.

If lymph nodes near the trachea are swollen, a mediastinotomy is done. General anesthesia (medicines that put you in a deep sleep) is used for this procedure. A special scope (mediastinoscope) is put in the body through a small incision above the top of the sternum (breastbone) and biopsies are collected from the areas of concern.

Special surgery techniques

When most people think of surgery, they picture a doctor using a scalpel and other surgical instruments to remove, repair, or replace parts of the body affected by disease. But newer techniques, using different types of instruments, have expanded the concept of what surgery is. Some of these newer techniques are described below.

Laser surgery

A laser is a highly focused and powerful beam of light energy which can be used for very precise surgical work, such as repairing a damaged retina in the eye. It can also be used to cut through tissue (instead of using a scalpel) or to vaporize (burn and destroy) cancers of the cervix, larynx (voice box), liver, rectum, or skin.

Some surgeries can be made less invasive by using laser light. For example, with fiber optics the light can be directed inside the body without having to make a large incision.

Lasers are also used in a type of surgery called *photoablation* or *photocoagulation*. This means lasers are used to destroy tissue or to seal tissues or vessels. This type of surgery is often used to relieve symptoms, such as when large tumors block the windpipe or esophagus, causing problems with breathing or eating.

Cryosurgery

Cryosurgery involves the use of a liquid nitrogen spray or a very cold probe to freeze and kill abnormal cells. This technique is sometimes used to treat pre-cancerous conditions, such as those affecting the

cervix. Cryosurgery is also being studied as a treatment for some cancers, such as those of the prostate.

Electrosurgery

High-frequency electrical current can be used to destroy cells. It is used for some cancers of the skin and mouth.

Mohs surgery

Mohs micrographic surgery, also called microscopically controlled surgery, is a technique to remove certain skin cancers by shaving off one thin layer at a time. After each layer is removed, a specially trained dermatologist (skin doctor) or a pathologist (doctor who specializes in diagnosing and classifying diseases by lab tests) looks at the tissue layer under a microscope. When all the cells look normal under the microscope, the surgeon stops removing layers of tissue.

This technique is used when the extent of the cancer is not known or when as much healthy tissue as possible needs to be preserved (as in cancers around the eye). It is done under local anesthesia by a specially trained surgeon.

Chemosurgery is an older name for this surgery and refers to certain chemicals put on the tissue before it is removed. Mohs surgery does not involve use of cancer chemotherapy drugs.

Laparoscopic surgery

A laparoscope is a long, narrow, flexible tube placed through a small incision (cut) to look inside the body. It is sometimes used to take biopsy samples. In recent years, doctors have found that by creating some small holes and using special instruments, the laparoscope can be used to perform surgery without making a large incision. This can help reduce blood loss during surgery and pain afterwards. It can also shorten hospital stays. Laparoscopic surgery is commonly used today to remove gallbladders and to repair hernias.

The role of laparoscopic surgery in cancer treatment is not yet clear. Doctors are now studying whether it is safe and effective to use laparoscopic surgeries for many cancers of the bladder, colon, prostate, and kidney, among others. It may prove to be as safe and effective as standard surgery while being less invasive. Some studies have hinted at this being the case. But larger, long-term studies still need to be completed.

Thorascopic surgery

A thoracoscope is a narrow, rigid tube with a camera connected at one end that can be placed through a small incision (cut) into the chest after the lung is collapsed. This allows the doctor to see inside the entire chest. Any areas of concern on the lining of the chest wall can be biopsied, fluid can be drained, and small tumors on the surface of the lung can be removed with small stapling devices. This less-invasive approach has also been used to remove parts (lobes) of the lung that contain cancer. Studies have shown that for early stage lung cancer, results are much like removing part of the lung by doing an open thoracotomy (incision in the side of the chest).

Other forms of surgery

Newer ways to remove or destroy cancer tumors are always being explored. Some methods are beginning to blur the lines between what we commonly think of as "surgery" and other forms of treatment. Researchers are testing many new techniques, using things such as high intensity focused ultrasound (HIFU); microwaves or radio waves (radiofrequency ablation, or RFA); or even magnets in an attempt to

get rid of unwanted tissue. While promising, these techniques are still largely experimental.

As doctors learn how to better control the energy waves used in radiation therapy, some newer radiation techniques that are almost as effective as surgery have been found. By using radiation sources from different angles, *stereotactic radiation therapy* delivers a large precise radiation dose to a small tumor area. The doses are so exact that the term *stereotactic surgery* is sometimes used, even though no incision (cut) is actually made. In fact, the machines used to deliver this treatment have names like Gamma Knife and Cyber Knife, although no actual knife is involved. The most common site being treated with this technique is the brain, but it is also being used in head, neck, lung, and spine tumors. Researchers are looking for ways to use it to treat other types of cancer, too.

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APPENDIX I

GLOSSARY OF TREATMENT TERMS

GLOSSARY OF TREATMENT TERMS (referenced from the training manual prepared by the American College of Surgeons Commission on Cancer)

Abdominal-perineal resection: Surgical procedure used in the treatment of colorectal Cancer that requires a combined approach through the abdomen and the perineum. Complications include ureteral injury, urinary dysfunction, urinary tract infections, sexual dysfunction, perineal and abdominal wound infections, and stomal complications.

Adjuvant therapy: A therapy that aids another, such as chemotherapy, after surgery.

Allogeneic bone marrow transplantation: Transplanting bone marrow from one person to another person who is of the same tissue type.

Amputation: The removal of a limb or another appendage or outgrowth of the body.

Antioncogenes: Genes having the ability to regulate growth and inhibit carcinogenesis.

Antrectomy: Excision of the antrum.

Autologous bone marrow transplantation: Transplanting the patient's own bone marrow after ablative treatment.

BCG: Bacille Calmette Guerin vaccine, a tuberculosis vaccine, containing living, avirulent, bone-strain tubercle bacilli. It is administered by a special technique using a multiple puncture disk and is used immunotherapy for the treatment of cancer, particularly malignant melanoma and bladder cancer.

Bilobectomy: Removal of two lobes.

Billroth I: Pylorotomy with end-to-end anastomosis of the upper portion of the stomach to the duodenum.

Billroth II: Partial gastric resection with closure of duodenal stump and gastrojejunostomy.

Biopsy: Removal and examination, usually microscopic, of tissue from the living body. Biopsies are done to determine whether a tumor is malignant benign.

Excisional: The entire lesion is removed by surgical cutting

Incisional: Biopsy of a selected portion of a lesion

Needle aspiration: Biopsy in which tissue is obtained by application by suction through a needle attached to a syringe

Punch: A type of incisional biopsy

Shave: A type of incisional biopsy since the tumor is rarely totally removed

Brachytherapy: Radiation from a source placed within the body or a body cavity.

Cecetomy: Excision of the cecum.

Cecocolostomy: Surgical anastomosis of the ileum to the cecum.

Cervicectomy: Excision of the cervix utero.

Cholecystectomy: Excision of the gallbladder.

Cholecystojejunostomy: Surgical anastomosis of the gallbladder and jejunum.

Colectomy: Excision of the colon or a portion of it.

Colony-stimulating factor (CSF): Soluble protein factors that stimulate division and maturation of bone marrow stem cells. All CSFs are named a function of the cell most responsive to the factor (e.g., granulocyte colony-stimulating factor or GCSF).

Coloproctectomy: Surgical removal of the colon and rectum.

Colposcopy: The process of examining the vagina and cervix by means of a speculum and a magnifying lens; procedure used for the early detection of malignant changes on the cervix/vagina cuff.

Conization: The removal of a “cone” of tissue, as a partial excision of the cervix. This can be done with a scalpel or electrocautery; the scapel technique preserves the histologic elements of the tissue better.

Continent urinary reservoir (Continent ileal reservoir): Also called the “kock pouch”; a surgical procedure which provides an intra-abdominal pouch that stores urine and has two nipples valves that maintain continence and prevent ureteral reflux.

Craniotomy: Any surgical operation on the cranium.

Cryoprostatectomy: Destruction of the prostate by the application of extreme cold.

Cryosurgery: The destruction of tissue by application of extreme cold.

Cystectomy: Excision of the urinary bladder or a part of it.

Debulking: Surgery to reduce tumor to aggregates of 2 cm. Or less; improves the response to postoperative chemotherapy.

Duodenostomy: Surgical formation of a permanent opening into the duodenum.

Endoscopic retrograde cholangiopancreatogram (ERCP): A procedure consisting of a combination of retrograde cholangiography and transhepatic cholangiography used to visualize all portions of the biliary tree.

Enterectomy: An excision of a portion of the intestine.

Esophagectomy: An excision of a portion of the esophagus.

Esophagocoloplasty: An excision of a portion of the esophagus and its replacement by a segment of the colon.

Esophageoenterostomy: An excision of the esophagus and the stomach.

Esophagoscopy: Direct visual examination of the esophagus with an esophagoscope.

Fulguration: Destruction of living tissue by electric sparks generated by a high frequency current.

Gastrectomy: Excision of all (total) or a portion (partial or subtotal) of the stomach.

Glossectomy: Excision of all or a portion of the tongue.

Gray: The S1 (Systeme International d'Unites) unit of absorbed radiation dose, defined as the transfer of 1 joule of energy per Kg of absorbing material. 1 Gray = 100 rads.

Hartmann's operation: Resection of a portion of the colon, with the proximal end of the colon brought out as a colostomy and the distal stump or rectum being closed.

Hemicolectomy: Excision of approximately half of the colon.

Hepatectomy: Excision of all or a portion of the liver.

Hysterectomy: Surgical removal of the uterus.

Abdominal: performed through the abdominal wall

Modified radical (type2): removal of the uterus a portion of the parametrium

Radical or Wertheim procedure (type3): removal of the uterus and excision of the pelvic lymph nodes with wide lateral excision of the parametrical and paravaginal supporting structure

Simple (type 1): removal of the uterus

Subtotal: the cervix is left in place

Total (pan): the uterus and cervix are completely excised

Vaginal: performed through the vagina

Ileal conduit: A surgical procedure that uses a segment of the ileum for the diversion of urinary flow from the ureters.

Ileocolectomy: Excision of the ileum and part of the colon.

Ileocolostomy: Surgical anastomosis of the ileum to the colon.

Immunotherapy: Passive immunization of an individual by administration of performed antibodies actively produced in another individual (serum or gamma globulins). The term has also come to include the use of immunopotentiators, replacement of immunocompetent tissue (bone marrow), and infusion of specially-treated white blood cells.

Intensification therapy (also called reintensification therapy): This therapy has been proposed to prevent the return of the leukemic cell population. After one year of sustained, complete remission, the person undergoes the same intensive induction therapy as in the initial treatment period. The objective is bone marrow depression. After recovery of the bone marrow depression, the person continues on maintenance therapy for another year.

Interferon: Natural glycoprotein released by cells invaded by viruses or certain infectious agents; acts as a stimulant to noninfected cells, causing them to synthesize another protein with antiviral capabilities. Interferons are divided into these subsets, with each originating from a different cell and having distinctive chemical and biologic properties:

Alpha: produced by leukocytes in response to a viral infection

Beta: produced by fibroblasts in response to a viral infection

Gamma: produced by lymphoid cells in culture that is stimulated by a mitogen

Interleukin-2: Glycoprotein produced by helper T-cells that is an essential factor in the growth of T-cells and seems to induce the production of interferon. It is used as an anti-cancer drug in the treatment of a wide variety of solid tumors.

Intrathecal chemotherapy: Cytotoxic drugs injected into the cerebrospinal fluid (CSF), thus bypassing the blood-brain barrier.

Intravesical chemotherapy: Chemotherapy administered via a Foley catheter for the treatment of bladder cancer. The Foley is then usually clamped for a period of time and then emptied. This procedure delivers a high local concentration to the tumor area. Patients receiving this therapy require life-long cystoscopic surveillance for recurrent disease.

Jejunostomy: Surgical creation of a permanent opening between the jejunum and the surface of the abdominal wall.

Laminectomy: Excision of the lamina.

Laryngectomy: Partial or total removal of the larynx.

Laryngopharyngectomy: Excision of the larynx and pharynx.

LEEP: Loop Electrosurgical Excision Procedure uses an electrical current passed through a thin wire to loop to act as a knife to excise tissue.

Limp perfusion: Used in the treatment of malignant melanoma, where certain chemotherapeutic drugs (usually L-phenylalanine and DTIC) are instilled into the affected extremity by arterial perfusion. A pump system counteracts the normal arterial pressure, permitting a steady state of infusion, allowing the drugs to have the greatest effect at the disease site, usually performed after surgical removal of the bulk of the tumor mass.

Lingulectomy: Excision of the lingual of the left lung.

Lumpectomy: (tylectomy) Excision of only the local lesion in carcinoma of the breast.

Lymphadenectomy: Excision of one or more lymph nodes.

Lymphangiography: The film produced by lymphangiography, which is an x-ray of the lymphatic channels after introduction of a contrast medium.

Mandibulectomy: Excision of the mandible.

Mastectomy: Surgical removal of breast tissue.

Extended radical: Supraradical mastectomy; surgical removal of the internal mammary chain of lymph nodes, the entire involved breast, the underlying chest muscle, and the lymph nodes in the axilla.

Halstead radical: surgical en bloc removal of the entire involved breast, the underlying chest muscles, and the lymph nodes in the axilla.

Modified radical: surgical removal of the entire involved breast and many lymph nodes in the axilla. The underlying chest muscles are removed in part or are left in after removal of axillary lymph nodes.

Partial: removal of the tumor along with varying amounts of surrounding normal tissue (also called segmental, tylectomy, or quadrantectomy).

Simple (total): surgical removal of the entire involved breast with or without the underlying chest muscles, and axillary lymph node dissection is not done.

Subcutaneous: excision of the breast tissue with preservation of overlying skin, nipple, and areola.

Neck dissection: Excision of lymph nodes in neck area.

Modified radical neck: the same lymph nodes are removed as in a radical neck dissection; however one or more non-lymphatic structures are preserved

Radical neck dissection: includes the removal of all ipsilateral cervical lymph node groups (i.e., lymph nodes from levels I through V or submental, submandibular, cranial jugular, medical jugular, caudal jugular, dorsal cervical nodes along the accessory nerve and supraclavicular) and removal of the spinal accessory nerve, internal jugular vein and sternocleidomastoid muscle.

Selective neck dissection: preserves one or more lymph node groups routinely removed in a radical neck dissection

Nephrectomy: Surgical removal of a kidney and usually Gerota's fascia, perinephric fat; renal vein, and appropriate lymph nodes.

Nephroureterectomy: Removal of the kidney and ureter.

Omentectomy: Excision of all or part of the omentum.

Ommaya Reservoir: This device is a subcutaneous cerebrospinal fluid (CSF) reservoir that is implanted surgically under the scalp and provides access to the CSF through a burr hole in the scalp. Drugs are injected into the reservoir with a syringe, and the domed reservoir is then depressed manually to mix the drug within the CSF. This device eliminates the need for multiple lumbar punctures in the repeated administration of intrathecal chemotherapy.

Oophorectomy: Excision of one or both ovaries; also called ovariectomy.

Orchiectomy: Surgical removal of one or both testis.

Pancreatectomy: Excision of the pancreas.

Pancreaticoduodenostomy: Anastomosis of the pancreatic duct to a different site on the duodenum.

Pancreaticogastrostomy: Anastomosis of the pancreatic duct to the stomach.

Pancreaticojejunostomy: Anastomosis of the pancreatic duct to the jejunum.

Pancreaticoduodenectomy: Excision of the head of the pancreas and the adjacent portion of the duodenum.

Parotidectomy: Excision of a parotid gland.

Pelvic exenteration: Surgical removal of all reproductive organs and adjacent tissue.

Anterior: includes the bladder, distal ureters and genital organs with their ligamentous attachments and pelvic lymph nodes

Extended: includes pelvic blood vessels or bony pelvis

Posterior: includes the rectum and rectosigmoid with ligamentous attachments and pelvic lymph nodes

Total: includes removal of all pelvic contents and pelvic lymph nodes. A radical hysterectomy, pelvic lymph node dissection, removal of the bladder, distal ureters and genital organs with their ligamentous attachments.

Pharyngectomy: Excision of part of the pharynx.

Pharyngolaryngotomy: Excision of the pharynx and larynx.

Photodynamic therapy: A photosensitizing drug is exposed to specific wavelengths of light in the presence of oxygen.

Pneumonectomy: Excision of lung tissue.

Lobectomy: excision of a single lobe

Partial: excision of less than the entire lung

Total: excision of the entire lung

Proctectomy: Excision of the rectum.

Proctectomy: Excision of the rectum and lower colon.

Prostatectomy: Excision of the prostate.

Quadrantectomy: Removal of one-fourth of the tissue.

Rectosigmoidectomy: Excision of the rectosigmoid colon; also called a proctosigmoidectomy.

Salpingo-oophorectomy: Excision of the fallopian tube and ovary.

Sigmoidectomy: Excision of the sigmoid colon.

Sigmoidoscopy: Direct examination of the interior of the sigmoid colon.

Splenectomy: Excision of the spleen.

Stereotactic surgery: A surgical technique used in neurology in which precise localization of the target tissue is possible through use of three-dimensional coordinates, also known as stereotaxis surgery.

Thermal ablation: Destruction of tissue with heat.

Thyroidectomy: Excision of the thyroid gland.

Subtotal: more than two-thirds of the gland is removed

Total: the entire gland is removed

Total abdominal hysterectomy with bilateral salpingectomy and oophorectomy (TAHBSO): Total removal of the uterus and the cervix performed through the abdominal wall rather than the vagina route, in addition, the fallopian tubes and the ovaries are removed bilaterally.

Trachelectomy: Excision of the uterine cervix.

Transurethral resection of prostate (TURP): Removal of a portion of the prostate gland by means of an instrument passed through the urethra. This procedure removes only enlarged prostatic tissue, as in benign prostatic hypertrophy. Normal prostatic tissue and the outer capsule are left intact.

Tylectomy: Lumpectomy.

Ureterosigmoidostomy: A surgically-created anastomosis of one or both ureters to the sigmoid colon. In this form of diversion of urinary flow, there is no need for an appliance because the urine flows into the colon which acts as a kind of reservoir.

Vulvectomy: Excision of the vulva.

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Appendix J

Cancer Abstracting Tips

Start by reading the H & P to find the signs and symptoms associated with the illness, details of any workup that has already been performed for this malignancy, past history of other malignancies and smoking history. Review all scopes, surgeries, histology & cytology reports, pertinent labs, x-rays, scans, ultrasounds, MRIs etc. to aid in determining the primary site as well as to identify the extent of disease for staging. Review the discharge summary and use as a guide but follow coding rules and principles to ensure proper primary site, histology, behavior & grade codes are assigned. Some cases will be a clinical diagnosis made by the physician based on lab, x-ray etc. findings and may never be confirmed by biopsy.

1. PRIMARY SITE

Use the ICD-0 code manual to assign the correct code. Follow all general rules as well as site-specific rules in Multiple Primary and Histology Coding Manual to determine how many primaries/abstracts. Use all information available in the medical record to determine the site-try to be specific and code to the subsite if documentation is available.

2. HISTOLOGY/BEHAVIOR/GRADE

Use the correct ICD-0 code manual to assign the codes. All pathology and cytology reports for the case should be reviewed to determine the most accurate histology term.

Refer to and follow all general as well as site-specific rules in Multiple Primary and Histology Coding Manual to determine correct histology.

Be certain of the behavior code-in situ (2) or invasive (3). Review the in situ terms often and become familiar with them. If even a **tiny focus** of invasion is documented on the path report the case is no longer considered in situ but invasive.

Always code the highest grade/differentiation when two are given.

3. DIAGNOSTIC CONFIRMATION

Determine if the case was confirmed microscopically or **not** microscopically.

Positive **histology** specimen (tissue from biopsy, surgery, autopsy, D&C and bone marrow biopsy/aspiration, peripheral blood smear) always takes precedence over positive **cytology**.

4. DATE OF DIAGNOSIS

Date of diagnosis refers to the first diagnosis of this cancer by ANY RECOGNIZED MEDICAL PRACTITIONER. This is often a clinical diagnosis and may never be confirmed histologically. Even if confirmed histologically later, the original diagnosis date remains the same. (The diagnosis date is changed only if upon documented medical and/or pathological review of a previous condition the patient is deemed to have had cancer at an **earlier** date- the date of diagnosis is then backdated to reflect the findings.) If diagnosis date is not documented, if at all possible, estimation of a date is preferable to recording unknown in this field. Keep in mind cases can be diagnosed o outpatient studies such as x-rays, scans, mammogram, MRI,

ultrasound, etc.- the date of diagnosis would be the date of the study even if they were admitted and had histologic confirmation at a later date.

5. **TREATMENT**

First course of therapy is all treatment planned at initial diagnosis- sometimes this may take up to a year or more; treatment means cancer directed therapy that modifies, controls, removes or destroys primary or metastatic cancer tissue; if the cancer progresses during treatment and the treatment plan is changed it is no longer first course of therapy- it becomes subsequent therapy; if the patient becomes disease free and then has a recurrence the treatment is always considered subsequent therapy.

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Appendix K

GEOCODES

Alphabetical List

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250	America, Central
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300	America, South
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245	Antilles, NOS
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365	Argentina
087	Arizona
071	Arkansas
611	Armenia (Turkey)
633	Armenia (U.S.S.R.)
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680 Asia, East

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611 Asia Minor, NOS

610 Asia, Near-East

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620 Asian-Arab countries

634 Asian Republics of the
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109 Atlantic/Caribbean area, other
U.S. possessions

100 Atlantic/Caribbean area, U.S.
possessions

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711 Australia New Guinea

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457 Belarus

541 Belgian Congo

433 Belgium

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246 Bermuda

456 Bessarabia

643 Bhutan

539 Bioko (Fernando Poo)

452 Bohemia

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540 St. Helena
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 629 Saudi Arabia
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 581 Somalia
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 545 South Africa, Republic of
 545 South Africa, Union of
 300 South America
 380 South American Islands
 026 South Carolina
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 695 South Korea
 020 South Mid-Atlantic States
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 499 Southern Europe, NOS
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 443 Spain
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 673 Sumatra
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Appendix L

Effective Dates for Registry

These are the official dates of implementation for various coding references; remember that your registry may have varied from these dates.

<p>STAGING AND CODING</p> <p><i>International Classification of Diseases for Oncology</i></p> <p>First edition.....1976-1991</p> <p>Second edition^U.....1992-2000</p> <p>Third edition.....2001-</p> <p>American Joint Committee of Cancer TNM Staging System</p> <p>Second edition.....1983 (breast only**) – 1988</p> <p>Third edition.....1989-1992 (all sites***)</p> <p>Fourth edition.....1993-1997</p> <p>Fifth edition^U.....1998-2002</p> <p>Sixth edition.....2003-2009</p> <p>Seventh edition.....2010-</p> <p>SEER Extent of Disease Manual</p> <p>First edition.....1988-1991</p> <p>Second edition.....1992-1997</p> <p>Third edition^U.....1998-</p> <p>Summary Staging</p> <p><i>Summary Staging Guide</i>.....1977-2000</p> <p>SEER Summary Staging Manual 2000^U.....2001-</p> <p>Collaborative Staging System.....2004† -2009</p> <p>Collaborative Staging Version 2.....2010-</p> <p>Multiple Primary and Histology Coding Rules...2007-</p>	<p>CANCER PROGRAM STANDARDS</p> <p><i>Cancer Program Manual 1986</i>.....1986-1990</p> <p><i>Cancer Program Manual 1991</i>.....1991-1995</p> <p>Cancer Program Standards (Volume I).....1996-2003 (June)‡</p> <p>Revised Cancer Program Standards (Volume I)..... July 2003‡ -</p> <p>Data Collection</p> <p><i>Data Acquisition Manual</i>.....1988-1994</p> <p>1st revision 10/89</p> <p>2nd revision 10/90</p> <p><i>Data Acquisition Manual, revised</i>.....1994-1995</p> <p>Registry Operations and Data Standards (ROADS Manual).....1996-2002</p> <p>2-digit surgery codes.....1988-1997</p> <p>“New” surgery codes^U.....1998-2002</p> <p><i>Facility Oncology Registry Data Standards (FORDS)^U</i>.....2003-</p> <p>SEER Program Manual</p> <p>First edition.....1988-1991</p> <p>Second edition.....1992-1997</p> <p>Third edition^U.....1998-2003†</p> <p>Third edition revision 1 (Treatment codes only)^U.....2003-</p> <p>SEER Self-instructional Manuals for Cancer Registrars, Book 8: Antineoplastic Agents, Third edition^U.....1993-</p>
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* Effective with cases diagnosed on or after January 1 of the initial stated year and ending with cases diagnosed on December 31 of the closing year

** TNM staging of breast cancer was required as of 1982, prior to the second edition

*** The commission of Cancer urged implementation of TNM staging of all sites as of 1989 but did not require it until 1991.

† SEER permits treatment codes for cases diagnosed in 2003 to be submitted in either Third edition or Third Edition Revision 1 format. Contact SEER or your SEER central registry for further information.

‡ Proposed date as of 01/2003

^U Updated pages/errata were released after publication. Contact the publishing organization’s Web site for a copy.

Health Care Facilities – Cancer Registry Contacts

APPENDIX M

<u>AHEC</u> 300 E. 6 th Street – Texarkana, AR 71854 Fax: (870) 779-6045		
Christy Dabbs		
Donna Marlar	(870) 779-6084	marlardonnaj@uams.edu
Dianne Ketchum-Supervisor	(870) 779-6084 or (870) 779-6027	Ketchumdianne@uams.edu
William McIntire, Admin-AHEC		

<u>Arkansas Methodist Hospital</u> 900 Kingshighway - Paragould, AR 72450 Fax: (870) 239-7110		
Linda Northen, RHIT	(870) 239-7065	linda.northen@arkansasmethodist.org
Tracy Trieu-Supervisor	(870) 239-7323	Tracy.trieu@arkansasmethodist.org

<u>Arkansas Tech University</u> Wilson Hall - Russellville, AR 72801 Fax: (501) 964-9504		
Chris Merle	(501) 968-0364	Hicm@atvum.atu.edu

<u>Ashley Co. Medical</u> P.O. Box 400 – 1015 Unity Road – Crossett, AR 71635 – Fax: (870) 364-1404		
Kayla Hill-Supervisor	(870) 364-1242	Kayla.hill@acmconline.org

Baptist Health (LR, NLR, Arkadelphia, Heber Springs, Stuttgart)

9601 Interstate 630, Exit 7 – Little Rock, AR 72205

Erin Propst Doug Weeks Kelly Savoy – Director Medical Rec	(501) 202-2084	Kelly.Savoy@baptist-health.org
Vacant- Supervisor		
Kathy Blundell	(903) 306-0864 (home) & (903) 490-4445 (cell) Please call home # first.	Katherine.Stinson@baptist-health.org
Susan Paxton	(903) 832-7137 (home) (903) 280-1024 (cell) Please call home # first.	spaxton@windstream.net susan.paxton@baptist-health.org

Baptist (Forrest City)

1601 Newcastle – Forrest City, AR 72335 - Fax: (870) 261-0440

Penny Davis-Supervisor	(870) 261-0439	Penny_Davis@chs.net
------------------------	----------------	--

Barnes Jewish

3120 Prestwick Circle- Jonesboro, AR 72401

Tammy Newman, CTR	(870) 972-0281	newantammy1@yahoo.com
-------------------	----------------	--

Baxter Regional

624 Hospital Drive – Mountain Home, AR 72653- Fax: Fax (870) 425-2074(her home)

Ron Peterson, CEO Cathy Hamel, Nursing officer over registry		chamel@baxterregional.org
---	--	--

Karyn Cramer- Fax (870) 425-2074	(870) 706-0519	kcramer@baxterregional.org
---	----------------	--

<u>Bradley Medical</u>		
Warren, AR 71671 – Fax: (870) 226-4323		
Virginia Ulrich-Supervisor	(870) 226-4324	vulrich@bcmed.org

<u>CARTI</u>		
P.O. Box 55050 – Markham and University – Little Rock, AR 72215 – Fax: (501) 663-1746		
Beth Coleman CEO-Jan Berford1	(501) 296-3403	bcoleman@carti.com
Dana Ray	(501) 296-3404	dray@carti.com
Donna Laster	(501) 296-3408 (501) 663-0503 (Fax)	dlaster@carti.com
Melody Knight	(501) 296-3433	mknight@carti.com
Cora Whittemore Dan Summers-Supervisor	(501) 296-3402	whittemore@carti.com dsummers@carti.com

<u>Chambers Medical Hospital</u>		
Hwy 10 E. Detroit Street – Danville, AR 72833		
Nita Andrews	(479) 495-6273 (479) 495-6347 (Fax)	nitaandrews@chambers.com
Mary Ann Daves Amber Bottoms-Supervisor	(479) 495-6258 (479) 495-6299 (Fax)	amberbottoms@chambershospital.com

<u>Chicot Memorial</u>		
P.O. Box 512-2729 Hwy. 65 & 82 – Lake Village, AR 71653 – Fax: (870) 265-9309		
Sharon Walker – HIM Director	(870) 265-5351 Ext 316	walkers@chicotmemorial.com
Bonnie Bush-Supervisor	(870) 265-5351 Ext: 324	bushb@chicotmemorial.com

Columbia Medical Park Hospital

2001 S. Main – Hope, AR 71801 – Fax: (870) 722-7131

Lanelle Bell-Dir. Med. Records

(870) 722-2446

lbell@shiloh-corp.com

Community Medical Center IZARD Co.

P.O. Box 438 – 103 Grasse Street – Calico Rock, AR 72519

Mindy Woods, RHIA (870)-297-3726 Fax (870)-297-4161

mindywoods75@yahoo.com

Kim Skidmore-Supervisor

kim.skidmore@cmcofic.org

Conway Regional

2302 College Avenue – Conway, AR 72032 – Fax: (501) 450-2103

Wendy Wiley (Director)

(501) 450-2132

wwiley@conwayregional.org

(501) 513-5590

Bettye Belleton, CTR, BA

(501) 213-5988 – cell
(501) 961-1731 – home

belletonbettyej@uams.edu

Mary ‘Cissy’ Carrigan, CTR

(501) 213-5986 –cell
(501) 833-6023 -home

carriganmaryc@uams.edu

Crittenden Memorial Hospital

P.O. Box 2248 – 200 Tyler Street – West Memphis, AR 72303

Lisa Bailey-Supervisor

870-735-1500

Lisa_bailey@cmhwm.org

Cross Ridge Community Hospital

P.O. Box 590 – Wynne, AR 72396 – Fax: (870) 208-2104

Penny Chappell-Supervisor

(870) 238-3300 x 2146

pchappell@sbrmc.org

Dallas County Medical Center

201 Clifton Street – Fordyce, AR 71742 –Fax: (870) 352-7129

Frances Hartman-Supervisor

(870) 352-3159

fhartman@dallascountymedicalcenter.com

Dardanelle Hospital (River Valley Med Ctr)

P.O. Box 578-200 N. 3rd – Dardanelle, AR 72834 – Fax: (479) 229-6166

Tonya Mays-Supervisor

(479) 229-6124

tonya.mays@dardanellehospital.com

Delta Memorial

300 E. Pickens Street – Dumas, AR 71639 – Fax: (870) 382-8153

Jenny Guthrie

(870) 382-8245
Fax# (870) 382-8153

medrec@deltamem.org

DeQueen Regional Medical Center

1306 West Collin Raye Drive DeQueen, AR 71832 – Fax: (870) 642-7797

Shirley Clardy-Supervisor

(870) 642-7572

No E-mail

Dewitt City Hospital

C/O Medical Records

P.O. Box 32 – 1641 Whitehead Drive – Dewitt, AR 72042 – Fax: (870) 946-4344

Ellen Dillion

(870) 946-3571 x 259

edillion@centurytel.net

Charlotte Hackney-Supervisor

(870) 233-2159

chackney@centurytel.net

Drew Memorial

778 Scogin Drive – Monticello, AR 71655 – Fax: (870) 460-3521

Rhonda Brown – Director Med.Rec.

(870) 460-3532

rbrown@drewmemorial.org

First Care Family Doctors, West

775 E. Douglas – Prairie Grove, AR 72753 – Fax: (479) 846-5056

Sandra Beckcom

(479) 846-5005

Five Rivers Medical Center

2801 Medical Center Drive – Pochahontas, AR 72455 – Fax: (870) 892-6286

Lona Dorman-Supervisor

(870) 892-6240

ldorman@FRMCAR.com

Fulton County Hospital

P.O. Box 517 – 679 N. Main – Salem, AR 72576 – Fax: 870-895-2717

Nancy Cole-Supervisor

870-895-2691

njcole@fultoncountyhospital.org

Garland County Community College

101 College Drive – Hot Springs, AR 71913 – Fax: (501) 760-4183

Susan Wallace

(501) 760-4293

swallace@admin.gccc.cc.ar.us

Valerie Bond

(501) 760-4294

vbond@admin.gccc.cc.ar.us

Great Rivers Medical Center***

1520 N. Division – Blytheville, AR 72315 – Fax: (870) 838-7487

Ron Rasdon

(870) 838-7227

Debra Walker-Supervisor

Dwalker2@allianceimaging.com

Michelle King-HIM Director

(870) 838-7168

Jim Richardson-CEO

Harris Hospital

1205 McLain – Newport, AR 72112 – Fax: 870-512-3484

Shelia Drake-Supervisor

(870) 512-3052

Shelia_drake@chs.net

Healthpark Hospital

1636 Higdon Ferry Road – Hot Springs, AR 71973 – Fax: (501) 520-3706

Jamie Chapman-Supervisor

(501) 520-2026

jchapman@healthparkhospital.com

Gail Avi

Administrator – Doug Parker

Helena Regional Medical

P.O. Box 788 – 1801 Martin Luther King Drive – Helena, AR 72342 – Fax: (870) 816-3690

Jackie Scott Carol Parham-Supervisor	(870) 816-3681	mailto:shantadean@chs.net carolparham@chs.net
---	----------------	---

Highland Oncology

22 West Colt Square – Fayetteville, AR 72703

NARTI	(479) 361-5847	
-------	----------------	--

Hope Cancer Resources (formerly NARTI)

5835 W. Sunset – Springdale, AR 72762 – Fax: (479) 361-9104

Pat Overton	(479) 361-5847 Ext 16	pat.overton@hopecancerresources.org
Bill Heburn-Interim CEO		
Sherry Tuck Sandy Prince-Supervisor	(479) 361-5847 Ext 19	sherry.tuck@hopecancerresources.org sprince@narti.org

Hospice Angels

3801 Camden Road, Chapel Village, Suite 12, Pine Bluff AR 71603 – Fax: (870) 534-4884

Susan Padgett	(870) 534-4847	padgetthospice@cablelynx.com
Vanessa Jensen	(870) 534-4847	vanessa.hospice@cablelynx.com

Hot Spring County Medical

1001 Schneider Drive – Malvern, AR 72104 – Fax: (501) 332-7309

Debby Hunt-Supervisor	(501) 332-7380	dhunt@hscmc.org
-----------------------	----------------	--

Hot Springs Medical Group***

Heritage Physicians Group

#1 Mercy Lane #101 – Hot Springs, AR 71913

Christine	(501) 627-1800	501-609-2253
-----------	----------------	--------------

Howard County Memorial Hospital

8th & Leslie – P.O. Box 381 – Nashville, AR 71852

Carolyn Williams-Supervisor

870-845-4400

carolynw@howardmemorial.com

Elekta

Charlette Bellefeuille
3208 Bugle Drive –
Pine Bluff, AR 71603

(870) 879-3651
(fax) 870-879-3671

cbellefeuille@elekta.com

Kathy Dunaway
304 Wilburn Heights
Central City, AR 72914

1-479-434-4286

kathy_dunaway@yahoo.com
kdunaway@elekta.com

Jane Phillip Medical Center***

3500 SE Frank Phillips Blvd. – Bartlesville, OK 74006 – Fax: (918) 331-1718

Melanie Lucas

(918) 331-1633

MLucas@JPMC.org

Jefferson Regional Medical Center

1515 W. 42nd Street – Pine Bluff, AR 71601 – Fax: (870) 541-7938

Loreene Hale

(870) 541-7306

Loreene.Hale@jrmc.org

Nancy Beyer, HIM Mgr-Supervisor

(870) 541-8689

beyern@jrmc.org

Administrator – Morie Mehyou

John L. McClellan Memorial Hospital (LR VA)

4300 West 7th Street – Little Rock, AR 72205 - Fax: (501) 257-6915

Glynis White	(501) 257-6914	glynis.white@va.gov
Jennifer Fielding	(501) 257-6912	Jennifer.fielding@va.gov
Debra Reed	(501)-257-6913	Debra.Reed2@va.gov
Michael P. Winn, Director Marie Lisko-Supervisor	(501) 257-6816	marie.lisko@va.gov

Johnson County Regional Hospital

P.O. Box 738 – 1100 E. Poplar – Clarksville, AR 72830 – Fax: (479) 754-5349

Connie Young-Supervisor	(479) 754-5315	medrec2@arkansas.net
-------------------------	----------------	--

Lawrence Memorial

P.O. Box 839 – 1309 W. Main – Walnut Ridge, AR 72476 – Fax: (870) 886-5534

Darlene Johann, RHIT-Supervisor	(870) 886-1243	djohann@lawrencehealth.net
---------------------------------	----------------	--

Little River Memorial Hospital

451 West Locke Street-Ashdown, AR 71822 - Fax: (870) 898-4172

Kayla Chandler -Supervisor	(870) 898-5011 Ex. 3147	Records.rlmh@sbcglobal.net
----------------------------	-------------------------	--

Little Rock Air Force Base

314th MDG/SGSAL

Tiffany Rhodes	(501) 987-7464	
----------------	----------------	--

Magnolia Hospital

P.O. Box 629 – Magnolia, AR 71754 Fax: 870-235-3223

Melissa Rogers	870-235-3420	
----------------	--------------	--

McGehee – Desha County Hospital

P.O. Box 351 – 900 S. Third – McGehee, AR 71654 – Fax: (870) 222-5846

Kay Jones-Supervisor

(870) 222-2136

kjones@mcgeeehospital.org

Medical Center of South Arkansas

700 W. Grove Street – El Dorado, AR 71730 – Fax: (870) 863-2002

Barbara Murchison

(870) 863-2020

barbara.murchison@triadhospitals.com

Jeanette Worth

(870) 864-3575

Jeanette.worth@triadhospitals.com

Sandra Miller-Supervisor

sandra.miller@triadhospitals.com

Mena Medical

311 N. Morrow – Mena, AR 71953 – Fax: (479) 394-4577

Connie Hernandez-Supervisor

(479) 394-6100 x 2356

Connie.may@menaregional.com

Mercy Hospital – Turner Hospital

801 W. River – Ozark, AR 72949 – Fax: (501) 667-4791

Krista Poole

(479) 314-6621

krista.pool@.mercy.net

Mercy Hospital of Scott County

P.O. Box 2230 – Hwy. 71 & 80 – Waldron, AR 72958 – Fax: (479) 637-3523

Krista Poole

(479) 314-6621

krista.pool@.mercy.net

Millard Henry Clinic of Russellville

101 Skyline Drive – Russellville, AR 72801 – Fax: (479) 968-3988

Libby Caston-Supervisor

(479) 968-2345

(Russellville)

(479) 968 3336

(Danville)

Libby.caston@saintmarysregional.com or
caston@hotmail.com

National Park Medical

1910 Malvern Avenue – Hot Springs, AR 71901 – Fax: (501) 321-9948

Beth Loveday	(501) 620-2721	Elizabeth.loveday@NPMCHS.com
Tonya Clark –Supervisor-HIM Dir. Jerry Mabry-CEO	(501)-620-2527	tonya.clark@capellahealth.com

NEA Baptist Memorial Hospital

3024 Stadium Boulevard – Jonesboro, AR 72401 – Fax: (870) 972-7024

Pat Williams	(870) 972-7490	Pat.williams@bmhcc.org
Paul Betz – Administrator Cynthia Teague-Supervisor		cynthia.teague@bmhcc.org

North Arkansas Regional Medical

620 N. Main – Harrison, AR 72601 – Fax: (870) 414-4949

Claudia Brigham-Supv.Med. Records		cbrigham2002@yahoo.com
Tracy Curtis	870-414-4262	Tracy.Curtis@narmc.com
Tim Hill	870-414-5155	

North Logan Mercy

500 E. Academy – Paris, AR 72855 – Fax: (479) 963-6155

Marilyn Frazier	(479) 314-6266	
Shelly Caldwell	(479) 314-6267	
Krista Poole	(479) 314-6621	krista.pool@.mercy.net

North Metro Medical Center(Formerly Rebsamen)

1400 Braden Street – Box 159 – Jacksonville, AR 72076 – Fax: (501) 982-3055

Joyce Scallish-Supervisor Mike Schimming-CEO	(501) 985-7490	Jscallish@northmetromed.com
---	----------------	--

Ouachita County Medical

P.O. Box 797 – 638 California Street – Camden, AR 71701 – Fax: (870) 836-1460

Sharon Veith-Supervisor	(870) 836-1386	sveith@ouachitamedcenter.com
-------------------------	----------------	--

Ozark Health Medical Center

P.O. Box 206 – Clinton, AR 72031 – Fax: (501) 745-9479

Sheila Smith-Supervisor	(501) 745-9481	sheila.smith@myozarkhealth.com
-------------------------	----------------	--

Petit Jean Home Health

1401 East Broadway – Morrilton, AR 72110

Lydia Hoyt	(800) 337-2599	lhoyt@stvincenthealth.com
------------	----------------	--

Piggott Community Hospital

1206 Gordon Duckworth Drive – Piggott, AR 72464 – Fax: (870) 598-3240

Janet Watson-Supervisor	(870) 598-3881 x 731	janwatson@centurytel.net
-------------------------	----------------------	--

Pike County Memorial Hospital

315 East 13th Street – Murfreesboro, AR 71958- Fax: (870) 285-3305

Kay Wadley-Supervisor	903-293-0609	dwadley@paperlessimagingplus.com
-----------------------	--------------	--

Registry Partner's Inc.

706 Hillview Street – Texarkana, TX 75501 – Fax: (972) 692-6867

Crystal McDaniel, CTR	(903) 276-2532	cmcdaniel@cableone.net
-----------------------	----------------	--

Carla Edwards	(903) 244-0976	Edwards.carla@yahoo.com
---------------	----------------	--

Saline Memorial

#1 Medical Park Drive – Benton, AR 72015 – Fax: (501) 776-6078

Cindy Bullock-Supervisor	(501) 776-6079	cbullock@scmc.com
--------------------------	----------------	--

Debra Adams	(501) 776-6000	deb.adams@salinememorial.org
-------------	----------------	--

St. Anthony's Medical

4 Hospital Drive – Morrilton, AR 72110 – Fax: (501) 977-2422

Molly Fisher

501-977-2300

mfisher@stvincenthealth.com

St. Bernard's Regional – Cancer Treatment Center

225 E. Jackson #45 – Jonesboro, AR 72401 – Fax: (870) 972-1610

Beverly Harralson-Supervisor

(870) 919-5083

bharralson@sbrmc.org

Sarah Fink

(870) 972-4168

sfink@sbrmc.org

(update phone 9/7/2009 from her e-mail)

St. Edwards Mercy Medical

P.O. Box 17000 – 7301 Rogers – Fort Smith, AR 72917 Fax: (479) 452-0474

Diana Wilson. RHIA,CTR – CR Supv.

(479) 314-6621

Diana.wilson@.mercy.net

Marilyn Frazier HIM Dir.

(479) 314-6266

Roberta Adams

(479) 314-6266

St. Joseph's – Mercy Cancer Center

1455 Higdon Ferry Road, Suite C – Hot Springs, AR 71913 – Fax: (501) 622-2363

Kathy Webber, CTR

(501) 622-2129

Kathy.Webber@mercy.net

Sandra Blanton

(501) 622-1965

Sandra.Blanton@mercy.net

Kay McHughs, Operation Mgr- Supv.

Kay.Mchughs@mercy.net

Vicky Sanders, Executive Director

Tim Johnsen

Philip Ruth-Director of Medical

Imaging and Radiation Therapy

St. Mary's Regional Medical

C/O Medical Records – 1808 W. Main – Russellville, AR 72801 – Fax: (479) 964-9488

Anita Schwander-Supervisor

(479) 967-0719

Anitta.schwander@saintmarysregional.com

Paula Page

479-964-9110

Wendell Vanes, CFO

479-968-2841

St. Vincent's Medical Center

#2 St. Vincent Circle – Little Rock, AR 72205 – Fax: (501) 552-4308

Erin Holloway-Supervisor	501-552-3639	EHolloway@stvincenthealth.com
David Hall, MD	501-552-3000	
Tamika Savage	(501) 552-3636	TamikaSavage@catholichealth.net

Senior Specialties Hospice

1310 West Main, Suite A – Russellville, AR 72801 – Fax: (501) 587-5969

Latricia James	(501) 967-9300	
Dianna McGuire	(501) 967-9300 or (501) 443-4301 x 5739	

South Mississippi County Regional Medical Center (Closed 2009)

P.O. Box 607 – Osceola, AR 72370 – Fax: (870) 563-7148

Faith Reeves, RHIT	(870) 563-7169	Faith.reeves@smcregional.com
--------------------	----------------	--

Southwest Hospital (Closed July 15th, 2008)

11401 Interstate 30 – Little Rock, AR 72209 – Fax: (501) 801-3000

Nancy Byers	(501) 455-7184	
-------------	----------------	--

Sparks Health System

P.O.Box 247 – Fort Smith, AR 72902-0247 – Fax: (479) 709-7423

Darlene Williams	(479) 709-7458 or (888) 788-5295	dawillia@sparks.org
Joycien Owens	(479) 709-7421	jowens@sparks.org
Kathleen Ridenour-Supervisor D. Melody Trimble-CEO	479-709-1919	kridenou@sparks.org

Stone County Medical

P.O. Box 510 – Hwy. 14 E. – Mountain View, AR 72560 – Fax: (870) 269-8884

Leslie Harris	See White River Medical Center for contact info for Leslie Harris.	
Robert Wright	870-868-1945	

Stuttgart Regional (owned by Baptist)

P.O. Box 1905 – N. Buerkle Road – Stuttgart, AR 72160 – Fax: (870) 672-6860

	(870) 673-3511 x 361	
--	----------------------	--

The Surgical Clinic of Central Arkansas

9500 Kanis Road #501 – Little Rock, AR 72031

Karen Smith-Supervisor	501-227-9080	ksmith@surgicalclinicofCA.com
------------------------	--------------	--

UAMS/Cancer Registry

4301 West Markham, Slot 733 – Little Rock, AR 72205-7199 – Fax: (501) 686-8519

Carlene Akins	501-213-9028	Cakins@uams.edu
Bettye Belleton, CTR, BA	(501) 213-5988 – cell (501) 961-1731 – home -	belletonbettyej@uams.edu
Dr. Peter Emanuel – Director		
Lois J. Williams-Raynor, RHIA, CPC Supervisor	(501) 213-5989 – cell (501) 982-6143 – home -	williamsraynorloisj@uams.edu -also her fax #
Mary “Cissy” Carrigan, CTR	(501) 213-5986 – cell (501) 833-6023 – home	carriganmaryc@uams.edu
Linda Erkman, CTR	(501) 213-5984 – cell (501) 723-4031 home	erkmanlindag@uams.edu
Sheryl Peters	(501) 213-5985 – cell (501) 353-1366 – home	peterssherylb@uams.edu

UAMS/HIM Program

4301 West Markham, Slot 733 – Little Rock, AR 72205-7199 – Fax: (501) 686-8519

Kathy Trawick, Ed. D.

(501) 686-8613

TrawickKathyC@uams.edu

Karen K. Smith, RHIA, Instructor

(501) 686-7790

kksmith@uams.edu

VA Medical Center

Veterans Health Care System of the Ozarks

1100 North College – Fayetteville, AR 72703 – Fax: (479) 587-5829

Cheryl McNeil, CTR

(479) 443-4301 x 5739

Cheryl.mcneil1@va.gov

Dr. Robert Levy

Dr. John Henley, Chief of Staff

robert.levy@va.gov

Revised 12/21/10

[Return to Table of Contents](#)

Appendix B



Arkansas Central Cancer Registry

4815 West Markham Street

Little Rock, AR 72205

<http://www.healthy.arkansas.com/arkcancer/arkcancer.html>

1-800-462-0599

501-661-2952

Fax (501) 661-2891

2010 Non Hospital Reporting Manual

Third Edition – Revised



Our Mission...

The mission of the Arkansas Central Cancer Registry is to serve the public by collecting, analyzing, researching and disseminating quality cancer data to help describe the burden of cancer, so evidence-based cancer prevention and control programs can be implemented to reduce cancer incidence and mortality in Arkansas.

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INTRODUCTION

The Arkansas Central Cancer Registry (ACCR) Non-hospital Reporting Manual has been created to assist non-hospital facilities in reporting cancer cases to the Arkansas Central Cancer Registry. Implementation of this edition of the manual is to begin with cancer cases diagnosed January 1, 2010 and after.

The Arkansas General Assembly originally established the Arkansas Central Cancer Registry in 1938. The registry only collected minimal data and was only for indigent patients who were referred to participating tumor clinics throughout the state of Arkansas. No funds were available from the state until 1945. By 1970, the data collected was computerized, but due to a state-funding crisis in 1979, The Arkansas Central Cancer Registry was eliminated.

In 1989, Arkansas again authorized a state cancer registry to be located at the Arkansas Department of Health, although funding was not available to staff the registry or collect the data. In 1992, The United States Congress passed the "Cancer Registries Amendment Act" (Public Law 102-515), which provided federal funding for state cancer registries. The law was carried out through efforts by the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. Funding for a cancer program in Arkansas began in 1994, when the first federal funds were awarded through the National Program for Cancer Registries (NPCR). Also in that year, the Arkansas Board of Health mandated cancer as a reportable disease in the State of Arkansas. The reference date for ACCR is January 1, 1996, first time cancer cases were collected since 1979.

NPCR requires central registries to:

- ◆ Collect incidence data on residents of Arkansas,
- ◆ Have legislation mandating the reporting of cancer cases by all facilities that diagnose and/or treat cancer,
- ◆ Provide training for state personnel, hospital registry and non-hospital reporting facility staff,
- ◆ Follow a standard data set when collecting cancer cases and data must be submitted in the current version of NAACCR file format.
- ◆ Publish an annual report within 24 months of the end of the diagnostic year,
- ◆ Conduct case finding and quality assurance audits to determine the completeness and quality of all cancer cases being submitted to the registry.

With the shift towards outpatient diagnosis and treatment of cancer cases it is vitally important to have those cases reported to the central registry. Some of the cases that are in this category are prostate, malignant melanoma and bladder cancers. This is an attempt to encourage and assist medical facilities in collecting and submitting this data. Without this data, our research and studies cannot be accurate. The ACCR staff is available to assist with any questions and/or provide in-services to better prepare you for the process. (Refer to [Appendix B](#) contact information for registry personnel.)

I. GENERAL INSTRUCTIONS

The following information provides some basic rules regarding cancer reporting to the Arkansas Central Cancer Registry.

The cancer reporting law applies to all medical facilities, including outpatient surgery clinics, hospices, nursing homes, outpatient clinics, etc.

All cancer cases diagnosed and/or treated for cancer in your facility, on or after January 1, 1996, must be reported to the ACCR. For skilled nursing homes (not intermediate or residential care facilities) and hospices this includes:

- ◆ Cases initially diagnosed while residing in your facility;
- ◆ Cases diagnosed with cancer and/or treated for a recurrence while residing in your facility; and

The completed case should be submitted to the central registry quarterly for skilled nursing homes and hospices.

For ambulatory surgery centers, freestanding cancer clinics, etc.. , this includes

- ◆ Cases initially diagnosed at your facility;
- ◆ Cases treated at your facility only, without having any treatment performed at a hospital; and
- ◆ Cases that have pathology performed at the treating facility (ex: dermatology clinics).

The completed case should be submitted to the central registry monthly for ambulatory surgery centers, freestanding cancer clinics, treatment centers and physician's offices.

The recommended reporting method is electronic reporting using WebPlus. WebPlus is free software offered to all medical facilities reporting cases to the Arkansas Central Cancer Registry.

The paper reporting form ([Appendix G](#)) requires information on data items related to the patient and cancer being reported. There may be times when the medical record does not have all of the appropriate information to assist in coding these fields. If there is insufficient information to complete all of the items on the form, *complete the form with as much information as possible*. The name of the attending physician and the hospital in which the patient may have been admitted should be *included* on the patient form so that the facility can be contacted if more information is needed. **If information cannot be found, please document by writing “unknown” or “information not available”, rather than leaving the fields blank.**

Pertinent portions of the patient's chart (i.e. history and physical, operative summary, pathology report) can be submitted to the registry for our review. You will *not* be responsible for contacting physicians for any information on cancer cases. There are instructions for completing the patient information form, (**Appendix H**). These instructions will help you understand the information that is being collected.

A. SUBMISSION GUIDELINES

1. WebPlus, using a secure electronic web-based browser
2. Paper form, type or handwritten using the required reporting forms (**Used only for facilities reporting five (5) or less cases per year**).

Changing Information

It is possible that after a case has been submitted to the ACCR additional information added to the patient's chart would change specific data items. It is permissible to change any data item, including the primary site and histology. For changes made on five (5) or less cases, please call ACCR and report changes. For changes to more than five cases, make corrections to cases and resubmit via WebPlus, case can be included with next submission. If path report is amended, the amended report can be faxed to ACCR and changes will be made. For paper abstract form, complete the cancer form with the new information and write, "**AMENDED**" across the form in **red**.

Follow-up Information

Additional follow-up information is not required by ACCR on any case.

Patient List

A list of patients submitted to ACCR via WebPlus can be made available to all submitting facility.

For cases submitted using paper forms; after the information has been recorded and reviewed for completeness and accuracy, please make a list of patient cases submitted. Keeping a list of patients that have been reported to the ACCR may assist in the future to verify that the patient has been reported. This list should include:

- a. Patient Name
- b. Social security number
- c. Date of birth
- d. Date of diagnosis
- e. Primary site
- f. Date case was submitted to the ACCR

Submit all forms and information in “confidential” envelope to:

Maria Bohn
Arkansas Central Cancer Registry
4815 West Markham, Slot 7
Little Rock, AR 72205

B. REPORTABILITY

All facilities reporting more than five (5) cases per year are required to report cancer cases electronically to the ACCR. The following requirements are listed below:

1. **Patients diagnosed and/or treated at your facility (physician's office, freestanding clinics and ambulatory surgery centers, etc)**
 - a. Diagnosis might be clinical (X-rays, CT scans, clinical exam, etc)
 - b. Diagnosis might be pathological (biopsy, cytology, bone marrow, etc)
 - c. Treatment given inside your institution (chemotherapy, radiation, hormonal, immunotherapy, etc)
 - d. Surgery is performed inside of your institution (TURP, lumpectomy, etc)
 - e. No treatment is given (supportive care or "observation" only). This includes palliative treatment.

2. **Long term facilities (skilled nursing homes and hospices)**
 - a. Any patient diagnosed with cancer prior to admission in your facility and undergoing cancer directed treatment.
 - b. Any patient diagnosed with cancer, but is being treated at your facility for other reasons (hip fracture, dementia, etc)
 - c. Any patient with a history of cancer who has been without disease for several months or several years, who is diagnosed and/or treated for recurrence of the original cancer.

Deaths should be reported as they occur. This will ensure all necessary data is included on the patient information form before the medical record has been removed and placed in storage.

What information is required?

Any details related to the **diagnosis, treatment and staging of this cancer**. Any information providing the name of the physician or hospital where the patient was treated will enable the retrieval of more accurate information. This information may be found any or all of the following documents: History and Physical, Discharge Summaries, Pathology Reports, etc. Please include the date of death if the patient dies before the case is submitted to the ACCR.

C. CONFIDENTIALITY AND HIPAA

All ACCR staff is required to sign confidentiality agreements and follow all ACCR policies and procedures that address patient confidentiality. The state law Section 20-15-203, “Rules and Regulations”, states that “all information reported to the Arkansas Department of Health shall be confidential and shall not be disclosed under any circumstances except (1) to other state cancer registries with which the Department of Health has agreements that insure confidentiality; (2) to department of health officials and its agent who are obligated to keep such information confidential; and (3) to approved cancer research centers under specific conditions where names and identities of the individuals are appropriately protected, and when such research is conducted for the purpose of cancer prevention, control and treatment.

The Arkansas Central Cancer Registry’s annual incidence report is electronic via the ACCR online query system at <http://www.cancer-rates.info>. Reports obtained from this site are age-adjusted invasive cancer incidence rates by county and region. Reports can further be defined with details by age, sex, race and year; as well as the top ten cancers in the state. Data requests that cannot be fulfilled via the online query system are referred to the ACCR epidemiologist ([Appendix B](#) for contact information and ACCR website address).

Based on HIPAA privacy regulations, the ACCR is a “public health authority, authorized by law to collect and receive such information for the purpose of preventing and controlling disease, injury and disability, including ... reporting of disease ... and the conduct of public health surveillance...” [C.F.R. 164.512 (b)(1)(i)(2001)] This makes it possible for any facility that is eligible to report cancer to the central registry (i.e. hospital, hospice, etc) without obtaining an individual informed consent.

For more information, see [Appendix C](#), “Frequently Asked Questions and Answers about the HIPAA Regarding Cancer Reporting.”

D. REPORTABLE TERMINOLOGY

There are certain ambiguous terms used by cancer registries to help determine if this case should/should not be reported to the central registry. The following terms indicate involvement of disease and **should** be reported to the central registry:

- | | |
|-------------------|--|
| ◆ Apparent(ly) | Presumed |
| ◆ Appears | Probably |
| ◆ Comparable with | Suspect(ed) |
| ◆ compatible with | Suspicious (for) |
| ◆ consistent with | Tumor* (beginning with 2004 diagnoses and only for C70.0-C72.9, C75.1-C75.3) |
| ◆ most likely | Typical of |
| ◆ probable | Favors |
| ◆ suspect | Malignant appearing |
| ◆ suspicious | |

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

Example: CT of the pelvis shows mass in right kidney **consistent with** renal cell carcinoma. No other workup was done and due to patient's other medical conditions, no treatment will be performed. This case **should** be reported to the central registry.

If it is unclear whether a case should be reported or not, complete the patient information form with an explanation of the uncertainty of this case or call ACCR toll free number (800) 482-5850, ext. 2089 for assistance.

CASES NOT REQUIRED TO BE REPORTED

There are certain cases that **do not** have to be reported to the central registry. They are as follows:

- ◆ Patients who are admitted into your facility and treated for a recurrence of cancer, but were diagnosed before January 1, 1996.
- ◆ Basal or squamous cell carcinomas of the skin.
- ◆ Insitu of the cervix (CIS) or cervical intraepithelial neoplasia (CIN III)
- ◆ Prostatic intraepithelial neoplasia, grade III (PIN III)

REPORTING DEATHS

Death information is important in completing cancer data in the registry database. Here are some important tips to help in reporting death cases:

- ◆ If there is information about the death of a patient, it should be reported at the time the cancer is being reported.
- ◆ Cancer or a history of cancer can be reported at patient's death. The primary cause of death may or may not be related to the cancer diagnosis. These cases are reviewed based on the information that is coded on the death certificate. If deaths are reported as they occur, it can eliminate or greatly decrease the number of requests for death information from the central registry.
- ◆ Deaths can be submitted using same methods as reporting cancer cases. Make sure a date of diagnosis is documented, if available. If the exact diagnosis date is unknown but you know the approximate date diagnosed, please give that.

DEATH CLEARANCE PROCESS

Death clearance is a process in which death certificates with cancer as the cause of death is matched with cancer patients in the registry database. Cancer may or may not be the cause of death for some of the patients that are in the database. Death certificates that do not match with the registry database and have a cause of death as cancer are followed to determine the eligibility of the cases identified.

CANCER REPORTING FORMS

Instructions for entering cases using WebPlus are included in the WebPlus manual that will be given to each WebPlus user facility during the training period.

There are instructions on the back of the paper cancer reporting form that serve as a quick reference to assist in accurate completion of the form. **If there is any information that cannot be located to complete a certain data field, record "unknown" or "Information not available, rather than leave the data field blank.**

REPORTING FACILITY IDENTIFICATION

The information entered in this area is used to identify the facility that is reporting the cancer case.

Instructions in WebPlus manual for WebPlus users

Paper Form: Record full name and address of the facility, telephone number, fax number, name and e-mail address of contact person. The contact person is the one responsible for completing the form.

A. PATIENT IDENTIFICATION INFORMATION

01. PATIENT NAME

- ◆ Record the patient's last name, then first name, followed by the middle name. Record middle initial if full middle name is not available.
- ◆ Titles such as MD or Jr., may be recorded after the last name
- ◆ Hyphenated last names are acceptable
- ◆ Record any nicknames, aliases, or maiden names listed in parenthesis.

02. ADDRESS

Record the patient's address when patient was diagnosed with cancer. If address is unknown, record where the patient is currently living.

03. GENDER

Circle the appropriate gender for the patient

04. BIRTH DATE

Complete the patient's birth date, recording the four-digit year, two-digit month and the two-digit date last.

If the month and day of birth are unknown, but the year is known, record as *1937/99/99.

EXAMPLE: The history and physical states that the patient is 71 years old at the time he is admitted into your facility, January 15, 2008; there is no birth date documented; record the date of birth as *1937/99/99. **9" or "99" is used by cancer registries to indicate unknown information.

05. SOCIAL SECURITY NUMBER

Record the patient's Social Security number, if known. Do not record the spouse's number. Use **9s** if unknown and **0s** if no social security number.

06. PHONE NUMBER

Patient's resident number or contact phone number

07. OCCUPATION

Occupation at the time of diagnosis, if known

08. RACE AND HISPANIC ORIGIN

Use the following to record race

Codes		Codes	
01	White	21	Chamorroan
02	Black	22	Guamanian, NOS
03	American Indian, Aleutian, or Eskimo	25	Polynesian, NOS
04	Chinese	26	Tahitian
05	Japanese	27	Samoan
06	Filipino	28	Tongan
07	Hawaiian	30	Melanesian, NOS
08	Korean	31	Fiji Islander
09	Asian Indian, Pakistani	32	New Guinean
10	Vietnamese	88	No further race documented
11	Laotian	96	Other Asian, including Asian, NOS and Oriental, NOS
12	Hmong	97	Pacific Islander, NOS
13	Kampuchean (including Khmer and Cambodian	98	Other
14	Thai	99	Unknown
15	Micronesia, NOS		

- ◆ White includes Mexican, Puerto Rican, Cuban, and all other Caucasians.
- ◆ African-American includes Black.
- ◆ A combination of White and African-American is coded to African-American.

HISPANIC ORIGIN

Indicate if the patient is of Spanish/Hispanic origin.

- ◆ Mexican (includes Chicano)
- ◆ Puerto Rican
- ◆ Cuban
- ◆ South or Central American (Brazil)
- ◆ Other specified Spanish/Hispanic origin (includes European)
- ◆ Spanish, Hispanic, Latino, NOS; Evidence other than surname or maiden name the person is Hispanic
- ◆ Spanish surname only (Only evidence of the person's Hispanic origin is surname or maiden name – no evidence verifying that the person is not Hispanic)

09. PRIMARY PAYER

Circle the one application at the time of initial diagnosis and/or treatment. (See Appendix C for explanation of insurance types).

10. TOBACCO HISTORY

Circle current, former, none or unknown. Tobacco history includes the use of cigarettes, cigars, chewing tobacco, and snuff

11. ALCOHOL HISTORY

Circle current, former, none or unknown, this includes social usage

12. FAMILY HISTORY

Circle one, is there history of any cancer in the family

13. NEW VERSUS RECURRENCE

The first thing that should be established about the patient's cancer is whether it is a new cancer or one that has been previously diagnosed and treated before the patient is seen at your facility (recurrence). Look for statements made in the history and physical, progress report, etc., such as "this is a newly-diagnosed cancer" or "this cancer was diagnosed 10 years ago. The physician may offer no information about the diagnosis. If so, record "unknown".

14. PROCEDURE PERFORMED

Record the type of procedure that was performed to diagnose the patient's cancer (Ex: CT scan, positive laboratory test)

B. CANCER IDENTIFICATION INFORMATION

15. PRIMARY CANCER

The primary site is the organ or site where the cancer is located or originated. A patient's disease may spread (metastasize) or be active in several areas of the body, but the **original site** is the one that should be recorded.

Please be as specific as possible when describing sites. "Upper Lobe of Lung" would be preferable to "Lung". If the term in the medical record is general, (e.g. breast) that is acceptable

Breast cancer is recorded in different ways. The quadrant may not be specified (Upper outer quadrant), but the position where the cancer is in recorded as 1o'clock, etc. Record this in this field.

Some primary sites may not be identified, but the patient is confirmed to have cancer. Record this site as an "**unknown primary**".

Lymphomas are generally located in lymph nodes, but it can be found in an organ (stomach, intestine, etc). If you are unable to determine where the disease began, record "**Lymphoma, NOS**".

Leukemia and other diseases of the blood (myeloproliferative disorders, myelodysplastic syndromes, anemia, etc) are systemic (involving the whole body) and originate in the bone marrow, record "**not applicable**" (N/A) in this field.

16. DATE OF DIAGNOSIS

Record the year, month and day this cancer was **originally** diagnosed by a medical practitioner. If this is a recurrence of a previously diagnosed cancer, the date is still the date the cancer was **first** diagnosed. Though it may be more difficult to find an exact diagnosis date for a recurrence, follow the rules as for a newly diagnosed cancer.

- ◆ If the month or year of diagnosis is not documented, estimate as close as possible instead of recording **unknown**.
- ◆ If only the time of year, spring, fall, or winter of the year is documented, use April, July, October, or December (also for end of the year) and January for beginning of the year.
- ◆ No information is available for date, record **unknown**.

17. PAIRED ORGANS (LATERALITY)

Laterality refers to one side of a paired organ (breast, lung, kidney, etc). If the information is available, record which side is involved. See list below.

PRIMARY SITES – LATERALITY

This list includes the most frequently diagnosed primary sites. Please be as specific as possible when recording primary site. **Bold terms (red) indicate sites that should be coded for laterality (right or left).**

Adrenal Gland	Gallbladder	Palate (soft or hard)	Submandibular gland
Anus	Glottis		Supraglottis
Appendix	Gum	Pancreas	Testis
Ascending colon	Heart	Parotid gland	Thymus
Bladder	Hepatic Flexure of colon	Penis	Thyroid gland
Bone marrow	Hypopharynx	Pharynx	Tongue
Bones (specific)	Ileum	Prostate	Tonsil
Body area, leg	Jejunum	Pyriform sinus	Trachea
Arm, etc)	Kidney	Rectosigmoid Junction	Transverse colon
Brain	Larynx	Rectum	Unknown
Breast	Lip	Renal pelvis	Urethra
Cecum	Liver	Retroperitoneum	Uterus (corpus uteri)
Cervix (cervix Uteri)	Lung	Salivary gland	Vagina
Colon	Lymph nodes (specific region, axillary, groin, etc. or organ)	Sigmoid colon	Vulva
Connective Tissue (specific body area, leg, arm, etc.)	Mediastinum	Sinus	
Descending colon	Mouth	Skin	
Duodenum	Nasal cavity	Small intestine	
Epiglottis	Nasopharynx	Spinal cord	
Esophagus	Oropharynx	Spleen	
Eye	Ovary	Splenic flexure of colon	
		Stomach	

18. TUMOR SIZE

Record the size of the tumor **before** treatment. The tumor size information may be found on the imaging scans (CT, MRI), operative report and pathology report.

19. HISTOLOGY TYPE and behavior

Histology refers to cell type; this information can be found on the pathology report. It describes the type of cancer cells (adenocarcinoma, squamous, etc.). The pathology report will include a complete description of the tissue appearance.

“Behavior” describes the way a neoplasm acts or behaves. Tumors are considered to be malignant or benign. If they are benign, they are non cancerous and not to be reported to the central cancer registry with the exception of benign tumors of the brain and central nervous system. (In the ICD-O coding manual benign tumors will have the number “0 or 1” at the end of the histology code (ex: 9530/1).

Cancers that have to be reported to the central registry are either **in situ** or **malignant**. These will have codes “2” and “3” at the end of the histology codes in the ICD-O coding manual. In situ tumors are at their earliest stages (precancerous) and are not life threatening. Malignant tumors have cells that are cancerous and potentially life threatening. There are hundreds of terms classifying histologies. Here are some major ones:

List of Common Histologies Indicating Malignancy

- Chronic myeloproliferative disease, NOS
- Essential thrombocythemia
- Chronic neutrophilic leukemia
- Hypereosinophilic leukemia
- Adenocarcinoma
- Astrocytoma (brain)
- Carcinoma
- Glioma (brain)
- Hodgkin lymphoma (many more specific terms are used)
- Infiltrating ductal (breast)
- Intraductal carcinoma (breast)
- Large cell carcinoma
- Leukemia (acute, chronic, etc)
- Melanoma
- Mucinous cystadenocarcinoma or adenocarcinoma
- Multiple myeloma
- Myelodysplastic syndromes
- Non-Hodgkin lymphoma (many more specific terms are used)
- Non-small cell carcinoma
- Papillary transitional cell carcinoma (urinary organs)
- Polycythemia Vera
- Refractory anemia
- Sarcoma (soft tissue)
- Small cell carcinoma
- Squamous cell carcinoma
- Transitional cell carcinoma (urinary organs)

List of Common Terms Synonymous with In Situ Histologies

- Bowen’s disease
- Hutchinson’s melanotic freckle, NOS
- Intraductal
- Intraepithelial, NOS
- Lentigo maligna
- Non-invasive
- Non-infiltrating

20. GRADE OR DIFFERENTIATION

Describes how much or how little a tumor resembles the normal tissue from which it arose.

This can usually be found on the pathology report. It is the 6th digit code for histologic grading and differentiation. Codes are as follow:

Code		
1	Grade 1	Well differentiated Differentiated, NOS
2	Grade II	Moderately differentiated Moderately well differentiated Intermediate differentiation
3	Grade III	Poorly differentiated
4	Grade IV	Undifferentiated Anaplastic
9		Grade or differentiation not determined, not stated or not applicable

21. LYMPH NODES POSITIVE AND REMOVED

Refers to number of lymph nodes positive for cancer and how many lymph nodes were removed.

22. PREOPERATIVE TUMOR MARKERS

Refers to prognostic indicators of cancer for certain sites

23. STAGE OF DISEASE AT DIAGNOSIS

Cancer staging describes the extent of disease or how far the disease has spread in the patient's body. This information determines treatment recommendations as well as prognosis of the patient.

A cancer may be described as local, regional or advanced. Record the stage that is mentioned by the physician in the patient's medical record. If the physician states localized, record "localized". If there is no stage mentioned, record "unknown" or "no information in chart". Below is table that will assist you in determining stage.

DESCRIPTION
in situ; precancerous
localized; tumor confined to organ of origin; no evidence of spread beyond the primary site
regional by direct extension; tumor extends directly beyond the primary site surrounding (regional) organs or tissues
regional to lymph nodes; tumor extends beyond the organ of origin (primary site) into the regional lymph nodes
regional by direct extension and to lymph nodes; tumor extends beyond primary site by direct extension, into regional lymph nodes AND adjacent tissues

stant metastasis; widely disseminated; tumor has spread from primary site to remote areas of the body, through the blood stream or lymph system
staged; unknown; unspecified – use for unknown primaries and those cases where adequate staging information is NOT available

If a physician states the patient has “Stage I” disease, record “Stage I” in the stage field. The physician may also state that the patient has a T1NOMO disease; this is the TNM staging system. Record the TNM as stated in the patient’s record in the stage field.

Familiarity with different staging systems is recommended.

C. TREATMENT

Treatment or therapy for cancer should modify, control, remove or destroy cancer tissue (cancer directed treatment). Therapy can be used to treat cancer tissue in primary or metastatic site(s).

24. FIRST COURSE THERAPY

The first course therapy should include all cancer-directed treatments described in the initial treatment plan and delivered to the patient. Treatment may begin at one facility and continues at another or delivered within another facility.

There are times when treatment has been *refused, comorbid conditions may affect the patient’s quality of life and treatment is not recommended, or the patient is under observation or watchful waiting*. This is considered first course therapy. Record “no treatment” in the treatment field and the date that no treatment is decided in the treatment date field. If the physician uses a “*wait and see approach*”, this is termed as “*observation only*”; record “*observation only*” in the treatment field and record the date that the “*observation only*” was determined.

TREATMENT FOR RECURRENCE

If a patient has a disease-free period of several months or several years and the cancer returns to the same region of the original cancer or to regional or distant sites, it is considered a recurrence. If the cancer returns while residing at a facility, the case is to be reported to the ACCR by that facility with indications that this is **not** a new cancer. The diagnosis date should be the date of the **ORIGINAL** diagnosis. The remainder of the information will pertain to the treatment of the recurrence.

TYPES OF TUMOR-DIRECTED TREATMENT

Record all known cancer-directed therapy administered to patient at the facility or another facility. The complete cancer directed treatment is important when calculating survival rates and other issues regarding patient mortality.

Record all treatment considered to be chemotherapy, radiation, hormonal, immunotherapy or palliative care, documenting the type of treatment that was given in the treatment field. If it is unknown whether the patient received treatment, record “**unknown**” or “**information not available**”. Do not leave any spaces blank.

SURGERY

Record the type of surgical procedure(s) performed on the patient from the operative report. The pathology report may also have the type of surgical procedure(s).

RADIATION THERAPY

Record the type and date the radiation therapy was received by the patient. Below are some types of radiation therapy given:

- ◆ Beam Radiation – Includes x-ray, cobalt, linear accelerator, stereotactic radiosurgery, such as gamma knife and proton beam.
- ◆ Radioactive implants – often used for prostate cancer.
- ◆ Radioisotopes – such as iodine-131 or phosphorus-32, given orally, or by intravenous injection (often used for bone pain).

CHEMOTHERAPY, HORMONAL THERAPY, IMMUNOTHERAPY

Record any drug given to treat the patient's cancer. Some drugs may be given alone and some are given with a combination of other drugs (CHOP, ABVD, VAD, etc). It is okay to record the abbreviations.

Hormonal treatments are drugs such as Tamoxifen for breast cancer, Lupron (treatment for prostate cancer).

Immunotherapy treatment includes bone marrow transplants, interferon, BCG. Patients in long-term care facilities will not be eligible for these treatments.

PALLIATIVE CARE

For many patients, cancer directed treatment may not be an option. In these patients, medications may be used to provide relief from symptoms, for pain control, or to limit side effects from other medications.

OTHER CANCER-DIRECTED THERAPY

Sometimes patients chose to have alternative treatments for their cancer, uncommon methods and drugs. Record the information regarding these treatments if documented.

Treatment Dates

If it proves difficult to determine dates for treatments use the following to assist you in completing these fields. It is preferable to estimate the date of a treatment than to leave it blank.

- ◆ Record the four-digit year, month and day in which cancer directed treatment was given.
- ◆ If the exact date of treatment is unknown, it is best to estimate the date, using the information that is currently available.
- ◆ Record “**NONE**” when no treatment is given and “**UNKNOWN**” when it is unknown if treatment was given.

25. PHYSICIAN

Record the physician who is responsible for managing the treatment of the patient; this can include primary care physicians and specialty physicians such as urologist, dermatologists, etc. Names and all contact information should be included. This allows the ACCR staff to contact the physician if more information is needed

26. DATE OF LAST CONTACT/DEATH

If the patient is still living, record the date that you are completing the form. If the patient has transferred to another facility, record the date of transfer. If the patient died and the date of death is known, record the date of death.

27. PATIENT STATUS

Refers to last known condition of the patient. The patient was alive with/without cancer, patient alive, cancer status unknown, patient deceased with/without cancer, patient deceased and cancer status unknown.

APPENDIX A

State Law

Subchapter 2 – Cancer

20-15-201. Reporting requirements.

The Arkansas Department of Health shall accumulate such data concerning cancer in Arkansas and its residents as is deemed appropriate for the purpose of describing the frequency of cancer, furnishing reports to health professionals and the public, and for planning and evaluating cancer prevention and control programs. Such data shall be collected under the authority of regulations promulgated by the Arkansas State Board of Health.

20-15-202. State Cancer Plan.

A task force consisting of public and private entities will be established by the Director of the Department of Health to assist the department to develop a strategic plan for a coordinated, comprehensive, statewide network of cancer resources, services, and programs.

20-15-203. Confidentiality.

Information accumulated and maintained in the Cancer Registry of Arkansas shall not be divulged except as statistical information which does not identify individuals and for purposes of such research as approved by the Arkansas State Board of Health.

20-15-204. Agreements with other states.

The Arkansas Department of Health is hereby authorized to enter into agreement with other states and federal organizations authorized to exchange registry data. Such agreements shall prohibit divulging information to entities without prior approval of the Arkansas State Department of Health.

20-15-205. Gifts, grants, and donations.

The Department of Health is authorized to receive gifts, grants, and donations for the purpose of this subchapter.

ACCR Rules and Regulations

Section I. Authority

The following rules and regulations pertaining to Arkansas Cancer Registry are duly adopted and promulgated by the Arkansas State Board of Health pursuant to the authority expressly conferred by the laws of the State of Arkansas.

Section II. Purpose

Since cancer is one of the leading causes of death in Arkansas it is essential that the specific information concerning this group of disease be collected, analyzed and reported. All Arkansans will benefit from the epidemiological surveillance of this group of diseases.

Section III. Definitions

- A. Registry. Means the system for the reporting, collection, and analysis of cancer cases by the Arkansas Department of Health.
- B. Reporting. Means the notification furnished to the Arkansas Department of Health of cases of in situ or invasive neoplasms of the human body, not including squamous cell and basal cell carcinoma of the skin.

Section IV. General Requirements

- A. Each hospital or other medical facility providing screening, diagnostic or therapeutic service, physicians, including surgeons, and all other health care practitioners or their designees shall report the following information concerning each case.
 - 1. Personal Information.
 - a. Name.
 - b. Address.
 - c. Date of Birth.
 - d. Place of Birth.
 - e. Race and Spanish/Hispanic Origin.
 - f. Sex.
 - g. Social Security Number

- h. County of Residence
 - i. Marital Status.
 - j. Maiden Name, if applicable.
 - k. Alias.
 - l. Occupation History, if available.
2. Diagnosis.
- a. Class of case.
 - b. Date of Diagnosis.
 - c. Primary Site.
 - d. Laterality.
 - e. Histology.
3. Treatment.
- a. Grade.
 - b. Diagnostic Confirmation.
 - c. Staging (American Joint Committee for Cancer – AJCC).
 - d. Reporting identification of the facility or person reporting.
4. Summary of Treatment
- a. Date first course started.
 - b. Name of Physician.
 - c. First course of treatment, i.e., surgery, radiation, chemotherapy, hormone therapy.
5. Follow-Up.
6. Recurrence.

B. In order to insure the accuracy and completeness of the cancer registry within the Department of Health, staff and agents shall be permitted access to records of hospitals, other medical facilities, physicians (including surgeons), nursing homes and other individuals or agencies providing services wherein records concerning patients in which cases of cancer are identified are located.

C. All reporting shall be made on forms or in an acceptable manner in accordance with directives of the Department of Health. All cancer cases shall be reported within six months

after the date of discharge or diagnosis is made or within six months after a cancer case is known, even if diagnosed elsewhere. Where appropriate cancer data will be in the format recognized by the American Association of Central Cancer Registries.

- D. Each hospital licensed by the Department of Health shall designate a person who shall be responsible for accurate and timely reporting pursuant to this rule. Such hospital shall also adopt a policy which ensures the designation of such person and the hospital's reporting to the Registry.

Section V. Confidentiality

All information reported to the Department of Health shall be confidential and shall not be disclosed under any circumstances except (1) to other state cancer registries with which the Department of Health has agreements that insure confidentiality; (2) to other state health officials who are obligated to keep such information confidential; and (3) to approved cancer research centers under specific conditions where names and identities of the individuals are appropriately protected, and when such research is conducted for the purpose of cancer prevention, control and treatment.

Section VI. Severability

If any provision of these rules and regulations, or the application thereof to any person or circumstances is held invalid, such invalidity shall not affect other provisions or applications of these rules and regulations which can give effect without the invalid provisions or applications, and to this end the provisions hereto are declared to be severable.

Section VII. Repeal

All regulations and parts of regulations in conflict herewith are hereby repealed.

APPENDIX B

RESOURCES/ADDITIONAL FORMS

ACCR STAFF RESOURCES

For more information regarding:

- Installation of WebPlus software
- Completing cancer reporting forms
- Forms or reprints of ACCR materials
- Scheduling in-service

CONTACT:

Vincent Teglia

Assistant Director

800-482-5850, ext 2952 or (501) 661-2952

Fax (501) 661-2891

vincent.tegria@arkansas.gov

For more information regarding:

- ◆ General administrative issues

CONTACT:

Theressia Mitchell, CTR, RHIT

Director

800-482-5850, ext 2463 or (501) 661-2463

theressia.mitchell@arkansas.gov

For more information regarding:

- ◆ Studies or reports
- ◆ Special data requests

CONTACT:

Abby Holt, MPH, MLIS

Epidemiologist

800-482-5850 ext 4830 or (501) 280-4830

Abby.holt@arkansas.gov

QA Specialists

Sue Ann Caudell, CTR
Death Clearance Specialist
800-482-5850 ext4129 or (501) 280-4129
Sue.caudell@arkansas.gov

Maria Bohn
Pathology Intake Specialist
800-482-5850 ext 4826 or (501) 280-4826
Maria.bohn@arkansas.gov

Regional Abstractors

Cynthia Gulley, CTR
Data Consolidation Specialist
Northeast Regional Abstractor
870-368-5453
cynthia.gulley@arkansas.gov

Sharon Deramus, CTR, LPN
WebPlus Reviewer
479-253-6027
Sharon.deramus@arkansas.gov

Technical Support Personnel

Chris Fisher, BA
Systems Programmer
800-, 482-5850 ext 2320 or (501) 661-2320
christopher.fisher@arkansas.gov

Geray Pickle
Budget Coordinator
501-671-1489
geray.pickle@arkansas.gov

Johnnie Jackson
Administrative Coordinator
800-482-5850, ext. 2960 or (501) 661-2960
johnnie.jackson@arkansas.gov

Arkansas Central Cancer Registry Mailing Address
4815 West Markham Street
Little Rock, AR 72205

To access the cancer registry's website visit:

<http://www.healthy.arkansas.gov/programsServices/healthStatistics/CancerRegistry/Pages/default.aspx>

To access the online query system:

<http://www.cancer-rates.info/ar/index.php>

APPENDIX C

FREQUENTLY ASKED QUESTIONS AND ANSWERS REGARDING CANCER REPORTING

1. When did Health Insurance Portability and Accountability Act (HIPAA) become effective?

President Bush approved the regulations on April 12, 2001.

The official effective date of the regulations was April 14, 2001. Covered entities, including hospital and physicians, had two (2) years to comply (by April 14, 2003), except for small health plans which were effective April 14, 2004.

2. What is a 'Public Health Authority' under HIPAA?

Under HIPAA, a 'Public Health Authority' refers to "an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors of persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate."¹ "...Such agencies are authorized by law to collect or receive such information for the purposes of preventing or controlling disease injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions."² ***Central cancer registries and hospital cancer registries if required to report cancer cases are considered public health authorities because state laws mandate their duties.***

3. What is a 'Covered Entity' under HIPAA?

A 'Covered Entity' is a health care plan, a healthcare clearinghouse, or a health care provider who transmits any health information in electronic form for financial and administrative transactions. A 'health care provider' is "a provider of medical or health services, and any other person who furnishes, bills or is paid for health care in the normal course of business."³

4. What if a patient does not want follow-up information to be collected?

State-mandated cancer reporting typically does not require patient informed consent nor can individuals elect to be removed from reporting. In a state, which allows the collection of follow-up cancer data for public health purposes, it can be collected regardless of consent from a patient.

5. Will private practice physicians be permitted to continue to provide follow-up information to hospital cancer registries without patient consent?

¹ C.F.R. 164.501

² C.F.R. 164.512

³ C.F.R. 160.103

Yes. Although private practice physicians are health providers, and thus covered under the provisions of the HIPAA privacy regulations², there are several reasons why they can continue to provide follow-up information to hospital cancer registries without patient consent. First, the hospital cancer registry is likely to be viewed as public health authority¹ because it is an entity acting under a grant of authority from or contract with a State, tribal, or local public health agency to provide for public health surveillance.¹

The HIPAA regulations specify that covered entities may use or disclose protected health information without the written consent or authorization of the individual...under specific circumstances. These include disclosures for public health activities and purposes to public health authorities authorized by law to collect or receive such information for the purpose of preventing or controlling disease or conduct public health surveillance.³

As public health authorities, hospital cancer registries are exempt from the HIPAA regulations and may continue to seek public health data from providers the same as before the HIPAA regulations were finalized. DHHS did not attempt to interfere with state and local public health matters such as cancer surveillance through the implementation of these regulations.

Second, even if some hospital cancer registries are not public health authorities (because they are not associated with a state or local public health agency to work on public health matters), physicians may still have to provide follow-up information. HIPAA regulation Sec. 164-512(a) specifically states that: a covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.

Thus, where a hospital cancer registry is required by state or local law to collect cancer data, physicians must follow the follow-up requirements of the registry to the exclusions of HIPAA privacy protections.

Finally, the consent requirement for disclosures under the HIPAA regulations does not limit the types of disclosures allowed. Provided a patient consents to the use or disclosure of his or her health data to a hospital cancer registry as part of the broader consent language, regularly sharing data between physicians and hospital cancer registries is permissible. In future cases, patient consents may specifically reference the sharing of data with all hospital cancer registries. For existing cases, written patient consent may also suffice for the purpose of authorizing these exchanges.

¹ 45 C.F.R. § 164.501 (2001).

² 45 C.F.R. 160.103

³ 45 C.F.R. 164.512

6. How does HIPAA impact the data collection of non-reportable/benign diseases (i.e. benign brain, CIN III, Co-morbid conditions)?

HIPAA does not obstruct any state law that supports or mandates the reporting of such cases.

7. Are private practice physicians still required to report new cancer cases?

Yes, in compliance with state reporting regulations. The central cancer registry has a reportable list that identifies which cancers are reportable, and all reportable cancers should be reported, as required by state law.

8. Is there specific legal documentation that supports the requirement to release cancer patient information to any agency?

Individual state laws and regulations document cancer reporting requirements. Central registries should be able to provide copies of their state's law(s) and regulations(s) upon request.

9. What, if any, are the consequences of not cooperating with state cancer registry requests for new cancer case information?

HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes. Penalties for failing to comply with state reporting are specified in the state law and often consist of significant fines.

10. Doesn't HIPAA nullify the state law for reporting cancer cases to Central Cancer Registry?

No. Public health reporting under the authority of state law is specifically exempted from HIPAA rules.

11. Once HIPAA is in place, will pathology labs be able to continue to send new cancer case information to the state cancer registry?

Yes. Public health reporting under the authority of state law is specifically exempted from HIPAA rules.

12. Since HIPAA, is federal, will it override the state laws?

No. HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes.

13. If the government-authorized public health entity is not located in the same state as the covered entity, is it still ok under HIPAA to provide the data?

Yes. In fact, the definition of a 'public health entity' was broadened in the section "Uses and Disclosures for Public Health Activities", which states specifically "...We broaden the scope of allowable disclosures ...by allowing covered entities to disclose protected health information not only to U.S. public health authorities but also, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority."^{1,2}

¹ F.R. p.82525

² 45 C.F.R. 164.512

APPENDIX D

PRIMARY PAYER CODES

CODES	DEFINITION	
01	Not Insured	Patient has no insurance and declared a charity write-off
02	Not insured, self-pay	Patient has no insurance and is declared responsible for charges
10	Insurance, NOS	Type of insurance unknown or other than the types listed in codes 20, 20, 31, 35, 60-68
20	Private Insurance Managed Care, HMO, or PPO	An organized system of prepaid care for a group of enrollees usually within a defined geographic area. Generally formed as one of four types: a group model, an independent physician association (IPA), a network, or a staff model. "Gate-keeper model" is another term for describing this type of insurance
21	Private Insurance: Fee-for-Service	An insurance plan that does not have negotiated fee structure with the participating hospital. Type of insurance plan not coded as 20.
31	Medicaid	State government administered insurance for persons who are uninsured, below the poverty level, or covered under entitlement programs.
35	Medicaid-Administered through a Managed Care plan	Patient is enrolled in Medicaid through a Managed-Care program (e.g. HMO or PPO). The managed care plan pays for all incurred costs.
60	Medicare without supplement, Medicare, NOS	Federal government funded insurance for persons who are 62 years of age or older, or are chronically disabled (social security insurance eligible). Not described in codes 61, 62, or 63.
61	Medicare with supplement, NOS	Patient has Medicare and another type of unspecified insurance to pay costs not covered by Medicare.
62	Medicare-Administered through a Managed Care plan	Patient is enrolled in Medicare through a Managed Care plan (e.g. HMO or PPO). The Managed Care plan pays for all incurred costs.
63	Medicare with private supplement	Patient has Medicare and private insurance to pay costs not covered by Medicare.

64	Medicare with Medicaid eligibility	Federal government Medicare insurance with State Medicaid administered supplement.
65	TRICARE	Department of Defense program providing supplementary civilian- sector hospital and medical services beyond a military treatment facility to military dependents, retirees, and their dependents. Formally CHAMPUS (Civilian Health and Medical Program of the Uniformed Services).
66	Military	Military personnel or their dependents who are treated at a military facility.
67	Veterans Affairs	Veterans who are treated in Veterans Affairs facilities
68	Indian/Public Health Service	Patient who receives care at an Indian Health Service facility or at another facility, and the medical costs are reimbursed by the Indian Health Service.
99	Insurance status unknown	It is unknown from the patient's medical record whether or not the patient is insured.

APPENDIX E

AMBIGUOUS TERMINOLOGY

DIAGNOSIS

Terms That Constitute A Diagnosis

For the purpose of determining reportable cases, interpret the following as a diagnosis of cancer.

- | | |
|-------------------|-----------------|
| • Apparent(ly) | Favor(s) |
| • Appears to | Presumed |
| • Compatible with | Probable |
| • Consistent with | Suspect |
| • Most likely | Suspicious(for) |

Example: The inpatient discharge summary documents that the patient had a chest x-ray **consistent with** a carcinoma of the right upper lobe. The patient refused further work-up or treatment.

Do not interpret cytology without pathology confirmation as a diagnosis of cancer.

Terms That **Do Not** Constitute A Diagnosis

Do not interpret the following as a diagnosis of malignancy. **Do not** include patients who have a diagnosis consisting of these terms:

- | | |
|----------------|-------------|
| • Equivocal | • Suggests |
| • Possible | • Worrisome |
| • Questionable | |

Example: Final diagnosis is reported as **possible** carcinoma of the breast.

STAGING

Terms that Constitute Tumor Involvement/Extension

In the absence of cytologic or histologic confirmation, interpret the following terms as evidence of tumor involvement. The description may be taken from the clinical, operative, or pathologic documentation.

- | | |
|-------------------|------------|
| • Adherent | • Into |
| • Apparent | • Onto |
| • Compatible with | • Out onto |
| • Consistent with | • Probable |

- Encroaching upon
- Fixation, fixed
- Induration
- Suspect
- Suspicious
 - To

Terms That **Do Not** Constitute Tumor Involvement/Extension

The following terms are **NOT** interpreted as tumor involvement

- Approaching
- Equivocal
- Possible
- Questionable
 - Suggests
 - Very close to

APPENDIX F

ACCR REPORTABLE LIST ICD-9 Casefinding Codes for ICD-O-3 Reportable Diseases

The following ICD-9-CM list is intended to assist in reportable neoplasm casefinding activities. It should be used to identify potentially reportable tumors. Any reportable neoplasms diagnosed on or after January 1, 1996 should be reported to the Arkansas Central Cancer Registry

Reportable Neoplasms:

- ❖ Malignant neoplasms (exclusions noted below)
- ❖ Benign and borderline neoplasms of the central nervous system (Cases diagnosed on or after January 1, 2004)
- ❖ Carcinoma in-situ (exclusions noted below)
- ❖ Squamous intraepithelial neoplasia grade III of vulva (VIN), vagina (VAIN), and anus (AIN) beginning with 2001 cases
- ❖ Primary tumors that originate in a mucous membrane are reportable

140.0-208.9	Malignancies (primary and secondary)
203.1	Plasma cell leukemia (9733/3)
205.1	Chronic neutrophilic leukemia (9963/3)
225.0-225.9	Benign neoplasm of brain and spinal cord
227.3-227.4	Benign Pituitary gland and craniopharyngeal duct (pouch), pineal gland
230.0-231.9	Carcinoma in-situ of digestive organs and respiratory system
233.0-234.9	Carcinoma in-situ of breast and genitourinary system; other and unspecified sites
237.0-237.9	Neoplasms of uncertain behavior of endocrine glands and Nervous system
237.70-237.72	Neurofibromatosis, unspecified, one, two vonRecklinghausen's Disease
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmocytoma (9731/3), Extramedullary plasmacytoma (9734/3)
238.71-238.76	Essential thrombocythemia (9960/3-9962/3, 9985/3, 9986/3, 9987/3)
239.6-239.7	Neoplasms of uncertain nature brain, endocrine glands and other parts of nervous system
259.2	Carcinoid Syndrome

273.2	Gamma Heavy Chain Disease; Franklins Disease
273.3	Waldenstrom's macroglobulinemia
285.0	Sideroblastic Anemia (9982/3-9984)
288.3	Hypereosinophilic syndrome (9964/3)
289.83	Myelofibrosis (9961/3)
789.51	Malignant ascites
V58.0	Encounter or admission for radiotherapy
V58.1	Encounter for chemotherapy and immunotherapy

Neoplasms not required by ACCR:

Morphology Codes	Diagnosis/Terminology
8000-8004	Neoplasms, malignant, NOS of skin
8010/2	Carcinoma in-situ of cervix (CIS)
8010-8045	Epithelial carcinomas of the skin
8050-8084	Papillary and squamous cell carcinoma of skin
8077/2	Squamous Intraepithelial Neoplasia, grade III of cervix (CIN III)
8090-8110	Basal cell carcinoma of the skin
8148/2	Prostatic Intraepithelial Neoplasia

Revised 1/21/10

APPENDIX G

Form should only be used by facilities reporting 5 or less cases annually

**Arkansas Central Cancer Registry / Arkansas Department of Health
Patient Reporting Form**

Reporting Facility Name: _____ **Person completing Form:** _____

1. Name: _____
Last First Middle

3. Address: _____

Street City State Zipcode 3. Gender: *Male Female*

4. DOB: (mm/dd/yyyy) _____ 5. Social Security # _____ 6. Phone number: () _____ - _____

7. Occupation: _____ 8. Race: **white Af. Am. Hispanic Other (please specify)** _____

9. Primary Payer (circle one): *com/private Medicare w/supple Medicare w/o supple Medicaid Self pay Not insured Unknown*

10. Tobacco Use: *yes no past unk* 11. Alcohol Use: *yes no past unk* 12. Family Hx of cancer: *yes No Unk*

13. Is this a new cancer or a recurrence of a previously diagnosed cancer? (**Check one**) *New Recurrence* _____

14. Procedures Performed: (**If you attach pathology report, leave this section blank**)

Biopsy: _____ FNA: _____ BM Asp: _____ Date of Procedure: _____

Surgical Procedure Type: _____ Date of Procedure: _____

15. Primary Cancer site: _____ 16. Diagnosis Date: _____ 17. Paired Organ (left/right/bilateral): _____

18. Tumor Size: _____ 19. Histology (cell type): _____

20. Grade(circle one): **well, moderate or poorly differentiated** 21. Lymph nodes removed (# positive / # removed): _____

22. Pre op Tumor Markers (**circle one and add value**) Prostate (PSA/PAP) _____ Breast (ERA/PRA) _____ / _____
Liver (AFP) _____ Colon (CEA) _____ Ovary (CA-125) _____ Testis (AFP/hCG) _____ / _____ / _____

23: Staging procedures: (attach copies of reports)

Date: _____ MRI ___ Date: _____ EGD ___ Date: _____
Negative Unknown Positive Negative Unknown Positive Negative Unknown

Colonoscopy ___ Date: _____ Bone Scan ___ Date: _____ Mammogram ___ Date: _____
Negative Unknown Positive Negative Unknown Positive Negative Unknown

CT Scan Chest ___ Date: _____ CT Abd/Pelvis ___ Date: _____ Radiograph (Other): ___ Date: _____
Negative Unknown Positive Negative Unknown positive Negative Unknown

24. Distant metastasis _____ *Use these codes for distant metastasis*
0 - none, 1 - peritoneum, 2 - lung, 3 - Pleura, 4 - liver, 5 - bone, 6 - central nervous system, 7 - skin, 8 - lymph nodes (distant)
generalized, carcinomatosis, disseminated, not specified, unknown

25. Has the patient had any of the following treatments? Where performed? _____

Chemotherapy: Yes/No Start Date: _____ Agent(s): _____

Hormone Treatment: Yes/No Start Date: _____ Type: _____

Radiation Therapy: Yes/No Start Date: _____ Stop Date: _____

Radiation Modality (circle one): External beam / Photons / Electrons / stereotactic / Gamma Knife / Brachytherapy / Combination / Unknown

Radiation Dose (cGY): _____ Radiation Boost Dose (cGY) : _____

Other Treatment (please specify): _____

26. Physician Responsible for Ongoing Therapy/Care: _____ 27. Date last contact: _____

28. Patient Status (circle one) : Alive, free of cancer Alive, evidence of cancer Alive, cancer status unknown
Deceased, free of cancer Deceased, evidence of cancer Deceased, cancer status unknown

Rev: 03/24/08

Appendix H

Instructions for Patient Reporting Form

01. Patient Name: Full name of patient. Note any aliases or nicknames.
02. Patient's Home Address: Residence at the time of diagnosis, if unknown put current address.
03. Gender: Please Circle the appropriate gender for the patient.
04. Date of Birth: Record patient's date of birth including month, day, and year.
05. Social Security Number: Social security number of patient. Do not use spouse's social security number.
06. Phone Number: Patient's residence
07. Occupation: Occupation at the time of diagnosis, if known.
08. Race: Record specific race of patient
09. Primary Payer: Circle one
10. Tobacco Use: Circle one
11. Alcohol Use: Circle one
12. Family history of cancer: Circle one
13. New or Recurrence: If this is the first time the patient has been diagnosed with this cancer, circle new. If this is a recurrence of previously diagnosed cancer, circle recurrence.
14. Procedures Performed: Document the type of procedure that was performed to diagnose the patient's cancer. Record the date of the procedure.
15. Primary Cancer site: Record the cancer based on location of cancer (i.e. breast, colon, etc.)
16. Record the Date of Diagnosis
17. Paired Organ: If site is a paired organ, record which side, (ex: right lung, right breast)
18. Record the tumor size
19. Histology (cell type): This information may be found on the pathology report. Histology describes the type of cancer cell (adenocarcinoma, Squamous, etc.)
20. Grade: Circle one. This can be found on the path report.
21. Lymph nodes removed: Record # positive / # removed: Ex: 3/10
22. Pre Op Tumor Markers: Circle one and add value
23. Staging procedures: attach copies of reports, if available.
24. Distant metastasis: If cancer has spread to other sites beyond the primary site, record the site to which it has spread.
25. Treatment: Document the type of treatment the patient received. Include the procedure name and the place the procedure was performed.

26. Physician responsible for ongoing therapy/care: Document the physician that is responsible for managing the treatment of the patient. Include address and telephone number. This can include primary care physicians and specialty physicians such as urologist, dermatologist, etc.
27. Date last contact: Record the last time the patient was seen by your facility.
28. Patient status: Document the last known status of the patient.

Please return to:

AR Department of Health / ACCR
ATTN: Maria Bohn
4815 W. Markham, Slot #7
Little Rock, AR. 72205
Phone: (501) 280-4826 Fax: (501) 661-2891

Revised: 12/28/10

(Manual – Rev 2/18/09;6/16/10)

FINANCIAL IMPACT STATEMENT

PLEASE ANSWER ALL QUESTIONS COMPLETELY

DEPARTMENT Department of Health
DIVISION Center for Public Health Practice/Cancer Registry
PERSON COMPLETING THIS STATEMENT Theressia Mitchell
TELEPHONE NO. 501-661-2463 **FAX NO.** 501-661-2891 **EMAIL:** theressia.mitchell@arkansas.gov

To comply with Act 1104 of 1995, please complete the following Financial Impact Statement and file two copies with the questionnaire and proposed rules.

SHORT TITLE OF THIS RULE Arkansas Cancer Registry Rules and Regulations

1. Does this proposed, amended, or repealed rule have a financial impact? Yes No
2. Does this proposed, amended, or repealed rule affect small businesses? Yes No
If yes, please attach a copy of the economic impact statement required to be filed with the Arkansas Economic Development Commission under Arkansas Code § 25-15-301 et seq.

3. If you believe that the development of a financial impact statement is so speculative as to be cost prohibited, please explain.

4. If the purpose of this rule is to implement a federal rule or regulation, please give the incremental cost for implementing the rule. Please indicate if the cost provided is the cost of the program.

<u>Current Fiscal Year</u>	<u>Next Fiscal Year</u>
General Revenue _____	General Revenue _____
Federal Funds _____	Federal Funds _____
Cash Funds _____	Cash Funds _____
Special Revenue _____	Special Revenue _____
Other (Identify) _____	Other (Identify) _____
Total _____	Total _____

5. What is the total estimated cost by fiscal year to any party subject to the proposed, amended, or repealed rule? Identify the party subject to the proposed rule and explain how they are affected.

<u>Current Fiscal Year</u>	<u>Next Fiscal Year</u>
\$ _____	\$ _____

6. What is the total estimated cost by fiscal year to the agency to implement this rule? Is this the cost of the program or grant? Please explain.

<u>Current Fiscal Year</u>	<u>Next Fiscal Year</u>
\$ <u>10,000</u>	\$ <u>2,000</u>

Print and Mail rules to all affected facilities. Follow-up next fiscal year

Economic Impact Statement Of Proposed Rules or Regulations

EO 05-04: Regulatory Flexibility

Department Department of Health Division Cancer Registry
Contact Person Theressia Mitchell Date _____
Contact Phone 501-661-2463 Email Theressia.Mitchell@arkansas.gov
Title of Subject: Arkansas Cancer Registry Rules and Regulation Changes

Benefits of the Proposed Rule or Regulation

- 1. Explain the need for the proposed change(s). Did any complaints motivate you to pursue regulatory action? If so, please explain the nature of such complaints.**
 - ❖ The original rules pertaining to Arkansas Cancer Registry were adopted and approved by Arkansas State Board of Health in 1994. Because of advancement in medicine and evolvement of medical practices, an update to the language and definitions would better clarify the rules.
- 2. What are the top three benefits of the proposed rule or regulation?**
 - ❖ Clarification on who is responsible for reporting cancer diagnoses to ACCR
 - ❖ Clarification on what cancer diagnoses should be reported
 - ❖ Assurance of confidentiality of patients' private information
- 3. What, in your estimation, would be the consequence of taking no action, thereby maintaining the status quo?**
 - ❖ Cases not being reported are missing from state database system, obscuring the true burden of cancer for the state. This data is used to help produce statistics for such programs as Breast and Cervical, Prostate Cancer Foundation, and HIV/AIDS. This data is also shared with such state entities as Arkansas Center for Health Improvement (ACHI).
 - ❖ Certification of the registry is in jeopardy; Arkansas's data will not be used in certain research projects, such as Geographical Association of Agriculture and Pancreatic Cancer, this project is exploring an association between residence in agriculture areas and the incidence of pancreatic cancer. Pediatric brain Tumor Incidence, this study is comparing cancer incidence of Central Brain Tumor Registry of United States (CBTRUS) and the International Classification of Childhood Cancer. This project is using incidence data on all cases (at any age) of non-malignant (benign or borderline) and malignant primary brain tumors from US cancer registries that are included in Cancer in North America (CINA). If we are not certified our data is not included in CINA.
 - ❖ A continued costly effort on the part of state Cancer Registry staff to maintain continuous contact with medical professionals regarding non-compliant issues as well as continue case ascertainment from facilities that are non-compliant.
 - ❖ Many Quality Assurance Activities for Cancer Registry are incomplete.
 - ❖ The cancer registry cannot be fully used for what it was designed, which includes the monitoring of cancer trends over time, determining cancer patterns in various populations, helping to guide the planning and evaluation of cancer control programs (determine whether prevention, screening and treatment efforts are making a

difference), help set priorities for allocating health resources as well as advance clinical, epidemiologic and health services research.

4. **Describe market-based alternatives or voluntary standards that were considered in place of the proposed regulation and state the reason(s) for not selecting those alternatives.**
 - ❖ Previous methods used to inform health care professionals of the reportability of certain cancers are as follows: Letters, providing educational materials, journal articles, and Cancer Registry staff presenting registry data to medical professionals in educational conferences, electronic mail, and facsimile.
 - ❖ Number of facilities in database that should report is approximately 880, not all are reporting; of the ones that are reporting, 154 facilities reporting cases late 100% of the time, 53 report cases late 75-99% of the time, 16 reports late 25-49% of the time. The number of total cases reported late is 11,600, 57% of cases are late every year.

Impact of Proposed Rule or Regulation

5. **Estimate the cost to state government of collecting information, completing paperwork, filing, recordkeeping, auditing and inspecting associated with this new rule or regulation.**
 - ❖ Casefinding hours, Case ascertainment, abstracting time as well as travel time, and abstracting time for State Cancer Registry abstractors results in an approximate cost of \$378 per case. This is expected to decline once the proposed amendments are implemented.
6. **What types of small businesses will be required to comply with the proposed rule or regulation? Please estimate the number of small businesses affected.**
 - ❖ All healthcare facilities that diagnose and/or treat patients with cancer. This could potentially affect approximately 800 small facilities.
7. **Does the proposed regulation create barriers to entry? If so, please describe those barriers and why those barriers are necessary.**
 - ❖ No
8. **Explain the additional requirements with which small business owners will have to comply and estimate the costs associated with compliance.**
 - ❖ The cost of data collection should not be appreciably greater than what is currently required. However, there will be a cost to those entities currently not complying. The amendments to this rule clarify who must comply.
9. **State whether the proposed regulation contains different requirements for different sized entities, and explain why this is, or is not, necessary.**
 - ❖ The requirements are the same for all entities.
10. **Describe your understanding of the ability of small business owners to implement changes required by the proposed regulation.**
 - ❖ With initial guidance and training from the ADH/ACCR, and a willingness on the part of the facilities to comply with these rules and regulations, the process of implementing these changes are very manageable.
11. **How does this rule or regulation compare to similar rules and regulations in other states or the federal government?**
 - ❖ All surrounding states have comparable rules and regulations
 - ❖ Louisiana – Louisiana Tumor Registry Law 1299.82 - The “President” (Louisiana State University) shall establish in the office of the president a statewide registry program

for reporting cancer cases. If the facility fails to report in a format prescribed by the president, the president may enter the facility, obtain the information, and report it in the appropriate format. In these cases, the facility shall reimburse the president for the cost of obtaining and reporting the information.

- ❖ Missouri – Title 19-Department of Health CSR 70-21.010; Missouri Revised statutes, Chapter 192 Department of Health and Senior Services, Section 192.657. Reporting of Cancer Cases. This rule establishes a method of mandatory reporting of all cancer cases of inpatient and outpatients in order to conduct cancer incidence surveillance and epidemiologic studies and to facilitate development, implementation and evaluation of cancer prevention and control measures in Missouri. Violation of any provisions of sections 192.650 to 192.657 shall be an infraction.
- ❖ Mississippi – 41-91-1 – Mississippi cancer Registry Act, Law 1993; establish and maintain central cancer registry. Any person or entity who fails to provide the information required to be provided to the cancer registry or who misuses the information provided to the cancer registry shall be subject to a civil penalty of Fifty Dollars (\$50.00) for each such failure or misuse.
- ❖ Oklahoma – Cancer Registry Statue Title 63 Public Health and Safety 63 OS 1-551 – The state Commissioner of Health shall establish and maintain an up-to-date tumor registry to ensure an accurate and continuing source of data concerning such cancerous, precancerous and tumorous diseases. Any order issued pursuant to this section shall state with specificity the nature of the violation. Any penalty assessed in the order shall not exceed Ten Thousand Dollars (\$10,000.00) per day of noncompliance with the order. In assessing such a penalty, the Department shall consider the seriousness of the violation and any efforts to comply with applicable requirements.
- ❖ Tennessee – TCA 4-5-202 - All hospitals, laboratories, facilities and health care practitioners shall report data concerning Tennessee patients who are diagnosed and/or treated for cancer. If any hospital, laboratory, facility or health care practitioner fails to provide the required data in format specified by the department or if the data are of unacceptable quality, the Commissioner or the Commissioner's authorized representative may enter the facility to casefind and abstract the information. The facility shall reimburse the department for the actual cost of casefinding, abstracting, coding and editing, a maximum of fifty (\$50.00) per case.
- ❖ Texas – Texas Cancer Incidence Reporting Act, Section 82.005 – The cancer registry must be a central data bank of accurate, precise and current information. The cancer registry must include a record of the cases of cancer that occur in the state; and information concerning cancer cases as the board considers necessary and appropriate for the recognition, prevention, cure or control of cancer. Section 82.008 (f) - A health care facility, clinical laboratory or health care practitioner that knowingly or in bad faith fails to furnish data as required by this chapter shall reimburse the department or its authorized representative for the costs of accessing and reporting the data. The costs reimbursed under this subsection must be reasonable, based on the actual costs incurred by the department or by its authorized representative in the collection of data and may include salary and travel expenses. The department may assess a late fee on an account that is 60 days or more overdue. The late fee may not exceed one and one-half percent of the total amount due to the late account for each month or portion of a month the account is not paid in full.

❖ Public Law 102-515 102d Congress – October 24, 1992

12. Provide a summary of the input your agency has received from small businesses or small business advocates about the proposed rule or regulation.

- ❖ Responses received: Six telephone calls, 2 electronic mails, one paper postal mail and one facsimile response. Five respondents were asking how they could become compliant with reporting, from those three wanted to be trained to use the free software and report cases. One hospital responded by hiring an additional person in the cancer registry. Two respondents made comments opposing many sections of the proposed changes. One respondent opposed the entire document.