



2016 Non-Hospital Reporting Manual

Fourth Edition

Arkansas Central Cancer Registry

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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.)

Chapter 1

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
- 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) is to be used for those facilities annually reporting five (5) or less diagnosed or treated cancer cases. The form 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.

Note: The term "cancer" is used throughout this document to describe all reportable tumors as defined in this manual, means in situ (cancer/tumor that involves only the place which it began

and has not spread), or invasive cancers (tumor/cancer that grows in an uncontrolled manner and invades surrounding tissue and is capable of metastasizing).

Who Must Report

A. Health Care Providers Who Must Report

All health care providers who diagnose and/or treat cancer patients must report confirmed cases of cancer to the Arkansas Central Cancer Registry (ACCR). The types of providers listed below are included in this requirement.

- Hospitals
- Physicians
- Dentists
- Medical laboratories
- Freestanding radiation or medical oncology clinics
- Ambulatory outpatient surgical centers
- Nursing homes
- Other health care facilities, such as freestanding mammography or other radiology facilities, hospices, etc.

B. Determining Responsibility for Reporting

1. Physicians must report all required cancer cases that are not referred to a hospital for further diagnosis or treatment. This includes:
 - a. Patients who are clinically diagnosed and receive no further work-up or treatment
 - b. Patients who are newly diagnosed in the physician's own laboratory facility or by sending a specimen from the office to an outside laboratory, whether hospital or independent
 - c. Patients whose first course treatment is initiated in the physician's office or clinic. This includes cancer treatment by surgery, radiation, chemotherapy, immunotherapy, or hormones. *Exception:* If a hospital reports cases diagnosed and/or treated in a staff physician office, the physician need not duplicate this case to ACCR.
2. Dentists must report all required cancer cases that are not referred to a hospital for further diagnosis or treatment. This includes:
 - a. Patients who are diagnosed and/or treated by a dentist who performs a biopsy and/or receives a pathology report of a malignant diagnosis
 - b. Cases also reported by either hospital based or private/independent medical laboratories
3. Medical Laboratories: Hospital based laboratories and private or independent laboratories licensed in Arkansas must report all required cancer cases diagnosed in the lab for patients that are not referred to a hospital for further diagnosis and/or treatment. This includes:
 - a. Cases also reported by physician or dentist offices as described in paragraph 1b above

For hospital based laboratories these are "path only" cases that are reported by the hospital registry staff, but not necessarily included in the hospital registry.

4. Freestanding Radiation or Medical Oncology Clinics must report any patient initially diagnosed with a reportable cancer and/or when first course treatment is initiated at the non-hospital based facility. This includes cancer treatment by surgery, radiation, chemotherapy, immunotherapy, or hormones.
5. Surgery Centers: Freestanding surgery centers (independent centers not affiliated with any hospital) must report any patient undergoing a biopsy or other surgical procedure at the facility for a newly diagnosed reportable cancer. This includes cases reported by either a hospital based or private/independent medical laboratory as described in paragraph 3 above.

Surgery centers affiliated with a hospital must report any patient undergoing a biopsy or other surgical procedure at the facility for a newly diagnosed reportable cancer if the patient was not referred to the hospital for further diagnosis or treatment. This includes cases also reported by either hospital based or private/independent medical laboratories as described in paragraph 3 above.

6. Nursing Homes must report the following types of newly diagnosed reportable cancer cases:
 - a. Cases clinically diagnosed but not confirmed through biopsy, cytology, or other microscopic methods
 - b. Cases for whom the first course of treatment is initiated at the facility.
Treatment may include chemotherapy, immunotherapy, or hormone therapy.Nursing homes should identify all patients with a cancer diagnosis at the time of admission, even if diagnosed and treated prior to the admission. The facility should send copies of pertinent medical records relating to the diagnosis to ACCR.
7. Mammography or Other Radiology Facilities that provide screening, diagnostic, or therapeutic cancer services must report confirmed reportable cases of cancer.

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.”

Chapter 2

REQUIRED CASES

All confirmed cases of cancer that have been diagnosed or treated in Arkansas beginning January 1, 1996 or later must be reported to ACCR. This includes solid and hematopoietic malignancies. A clinical diagnosis or any case that is stated to be cancer by a recognized medical practitioner is reportable, even if there is no histologic or cytologic confirmation. Any cancer or malignancy listed on the death certificate is reportable.

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.

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

*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.

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 within 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.

Cases that are NOT Required or Reportable

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.
- In-situ of the cervix (CIS) or cervical intraepithelial neoplasia (CIN III)
- Prostatic intraepithelial neoplasia, grade III (PIN III)

Chapter 3

REPORTING GUIDELINES

When to Report

Cases must be reported to ACCR no later than six (6) months after the date of diagnosis or the date you first saw the patient for this cancer, whichever is earlier.

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:

Arkansas Central Cancer Registry
4815 West Markham Street, Slot 7
Little Rock, AR 72205
Attn: John Guire, CTR
Quality Assurance Coordinator

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 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.

Chapter 4

INSTRUCTIONS FOR REPORTING CANCER DATA

Reporting Facility Identification

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

Instructions for coding:

1. WebPlus users- refer to WebPlus manual
2. Paper Form- record full name and address of the facility, telephone number, and fax number, name and e-mail address of contact person. The contact number is the one responsible for completing the form.

Patient Identification

1. 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.

2. Address:

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

3. Gender:

Circle the appropriate gender for the patient

4. 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.

5. 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.

6. Phone Number:

Patient's resident number or contact phone number

7. Occupation:

Occupation at the time of diagnosis, if known

8. Race and Hispanic Origin:

Use the following to record race

Codes	Description	Codes	Description
01	White, Caucasian	20	Micronesian, NOS
02	Black, African-American	21	Chamorro/Chamorro
03	American Indian, Aleutian, Eskimo	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
10	Vietnamese	31	Fiji Islander
11	Laotian	32	New Guinean
12	Hmong	96	Other Asian, including Asian, NOS and Oriental, NOS
13	Kampuchean (Cambodian)	97	Pacific Islander, NOS
14	Thai	98	Other
15	Asian Indian or Pakistani, NOS	99	Unknown
16	Asian Indian		
17	Pakistani		

- 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)

9. Primary Payer:

Circle the one application applicable 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 vs. 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)

Cancer Identification

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 1:00 o'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. Please be as specific as possible when recording primary site.

- Report (1) for right or (2) for left.

Paired Sites:

Adrenal Gland

Parotid gland

Testis

Bones

Tonsil

Kidney

Breast

Renal pelvis

Lung

Connective Tissue

Sinus

Skin

Eye

Ovary

- Report 0 if the organ is a non-paired site or if the primary is unknown
- Report 3 if the only one side is involved but right/left is not specified
- Report 4 if there is bilateral involvement, but side of origin is unknown.
- Report 4 if there is bilateral involvement, but stated to be a single primary
- Report 5 if the tumor is midline for a paired site
- Report 9 if the organ is paired but there is no information on laterality

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:

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.

20. Behavior:

“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

21. 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

22. Lymph Nodes Positive and Removed:

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

23. Preoperative Tumor Markers:

Refers to prognostic indicators of cancer for certain sites

24. 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

Distant metastasis: widely disseminated; tumor has spread from primary site to remote areas of the body, through the blood stream or lymph system

Unstaged, 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 T1N0M0 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.

Treatment Information

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).

25. First Course of 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.

26. 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.

27. Types of 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.

28. Diagnostic or Surgical Procedure(s):

Record cancer-directed surgical procedures or diagnostic procedures.

Examples: Incisional biopsy of (site), lumpectomy, polypectomy, wide resection or excision

29. Date(s) Procedures:

Record the date each procedure was performed.

30. Cancer Therapy Drugs:

List any drug given to the patient for the purpose of modifying, controlling, removing, or destroying cancer tissue. Do not list drugs given for palliation (relief of pain or symptoms) only.

Examples of chemotherapy: 5-FU, Cytosol, Taxol

Examples of hormone therapy: Tamoxifen, Lupron, Prednisone is coded only when administered in combination with chemotherapy such as MOPP

Examples of immunotherapy drugs: Interferon, Herceptin, Perjeta, Levamisole

31. 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

32. 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.

33. 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
RULES PERTAINING TO THE ARKANSAS CANCER REGISTRY
Table of Contents

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, and 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.

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

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For more information regarding:

- General administrative issues

CONTACT:

Director
800-482-5850, Ext 2463 (501) 661-2463

For more information regarding:

- Studies or reports
- Special data request

CONTACT:

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Technical Support Personnel

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Arkansas Central Cancer Registry Mailing Address
4815 West Markham Street, slot 7
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 (FAQ)

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.

1. C.F.R 164.501
2. C.F.R 164.512
3. C.F.R 160.103

5. Will private practice physicians be permitted to continue to provide follow-up information to hospital cancer registries without patient consent?

Yes. Although private practice physicians are health providers, and thus covered under the provisions of the HIPAA privacy regulations,² 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 an entity likely to be viewed as public health authority¹ 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	Suspect	Fixation, fixed	Suspicious
Induration	To		

Terms That Do Not Constitute Tumor Involvement/Extension

The following terms are **NOT** interpreted as tumor involvement

Approaching	Questionable	Equivocal	Suggests
Possible	Very close to		

Appendix F

ACCR REPORTABLE LIST

The following ICD-10-CM list is intended to assist in reportable neoplasm casefinding activities. It should be used to identify potentially reportable tumors. Any reportable neoplasm diagnosed on or after January 1, 1996 should be reported to the Arkansas Central Cancer Registry.

Effective dates **October 1, 2015 – September 30, 2016**

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)
- Carcinoid, NOS (excluding appendix, unless stated to be malignant)
- Pilocytic/juvenile astrocytoma is listed as 9421/1 in ICD-0-3, is reportable and should be coded to 9421/3
- 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 and include the following: Lip, Anus, Labia, Clitoris, Scrotum, Vulva, Vagina, Prepuce and Penis

Code	Definition
C00._ - C96._	Malignancies (primary and secondary)
D00._ - D09._	In Situ neoplasms; CIS cervix/CIN3- 8077/2 and Prostatic Intraepithelial Carcinoma/PIN- 8148/2 are NOT reportable
D18.02	Hemangioma of intracranial structures and any site
D18.1	Lymphomangioma Note: includes only lymphomangioma of brain, other parts of nervous system and endocrine gland
D32._	Benign neoplasm of meninges (cerebral, spinal, and unspecified)
D33._	Benign neoplasm of brain and other parts CNS
D35.2 – D35.4	Benign pituitary gland and craniopharyngeal duct, pineal gland
D42._, D43._	Neoplasms of uncertain behavior meninges, brain, CNS
D44.3 – D44.5	Neoplasm of uncertain or unknown behavior Pituitary gland and craniopharyngeal duct (pouch), pineal gland
D45	Polycythemia Vera (9950/3)
D46._	Myelodysplastic Syndromes
D47.1	Chronic Myeloproliferative disease
D47.3	Essential thrombocythemia
D47.4	Osteomyelofibrosis
D47.7	Other specified neoplasms of uncertain/unknown behavior of lymphoid, hematopoietic
D47.Z_	Other neoplasms of uncertain behavior of lymphoid, hematopoietic tissue
D47.9	Neoplasm of uncertain behavior of lymphoid, hematopoietic and related tissue
D49.6, D49.7	Neoplasms of uncertain behavior of brain, endocrine glands, and other CNS
D72.1	Eosinophilia, reportable diagnosis: Hypereosinophilic syndrome

E34.0	Carcinoid Syndrome
R18.0	Malignant Ascites
Z51.0	Encounter or admission for radiotherapy
Z51.1	Encounter or admission 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
8010-8045	Epithelial carcinomas of skin
8050-8084	Papillary and Squamous cell carcinoma of skin
8077/2	Squamous Intraepithelial Neoplasia, grade 3 of cervix (CINIII)
8090-8110	Basal cell carcinoma of skin
8148/2	Prostatic Intraepithelial Neoplasia (PIN)

Borderline cystadenomas M-8442, 8451, 8462, 8472, 8473, of the ovaries which moved from /3 to /1 are **NOT** collected as of 1/1/2001

The following terms are synonymous with in situ disease (Behavior code 2):

Adenocarcinoma in an adenomatous polyp with no invasion of stalk

Clark's level I melanoma or limited to epithelium

Noninfiltrating comedocarcinoma, confined to epithelium

Hutchison's melanotic freckle NOS, intracystic-noninfiltrating, intraductal, intraepithelium NOS, intraepidermal NOS (involvement up to but not Including basement membrane.)

Lentigo maligna, lobular neoplasia, lobular-noninfiltrating, noninvasive, no stromal involvement, papillary noninfiltrating or intraductal

Vaginal intraepithelial neoplasia Grade III or VAIN III

Vulvar intraepithelial neoplasia Grade III or VIN III

Anal intraepithelial neoplasia Grade III or AIN III

- **If any invasion is present, no matter how limited cases must be coded to invasive behavior**
- **If other benign or borderline diseases are required to be collected by your hospital cancer committee or other appointed officials, they are not required to be reported to ACCR.**

For cases diagnosed **before October 1, 2015** use the ICD-9-CM Reportable List found at:

<http://www.healthy.arkansas.gov/programsServices/healthStatistics/CancerRegistry/Pages/Registrars.aspx>

Appendix G

PATIENT REPORTING FORM

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: _____

Patient Name:

<i>Last</i>	<i>First</i>	<i>Middle</i>
-------------	--------------	---------------

Address:

<i>Street</i>	<i>City</i>	<i>State</i>	<i>Zip Code</i>
---------------	-------------	--------------	-----------------

Gender: *Male* *Female*

DOB: (mm/dd/yyyy) _____ Social Security # _____

Phone number: () _____ - _____

Occupation: _____

Race: **white** **Af. Am.** **Hispanic Other (please specify)** _____

Primary Payer (circle one):

com/private **Medicare w/supple** **Medicare w/o supple** **Medicaid**
Self pay **Not insured** **Unknown**

Tobacco Use: **yes** **no** **past** **unk**

Alcohol Use: **yes** **no** **past** **unk**

Family Hx of cancer: **yes** **No** **Unk**

Is this a new cancer or a recurrence of a previously diagnosed cancer? (Check one) **New** **Recurrence**

Procedures Performed: (If you attach pathology report, leave this section blank)

Biopsy: _____ FNA: _____ BM Asp: _____ Date of Procedure: _____

Surgical Procedure Type: _____ Date of Procedure: _____

Primary Cancer site: _____ Diagnosis Date: _____

Paired Organ (left/right/bilateral): _____

Tumor Size: _____

Histology (cell type): _____

Grade(circle one): **well** **moderate** **poorly differentiated**

Lymph nodes removed (# positive / # removed): _____ / _____

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) _____ / _____ / _____

Staging procedures: (attach copies of reports)

Date: _____ MRI ___ Date: _____ EGD ___ Date: _____
Positive Negative Unknown Positive Negative Unknown Positive Negative Unknown

Colonoscopy ___ Date: _____ Bone Scan ___ Date: _____ Mammogram ___ Date: _____
Positive Negative Unknown Positive Negative Unknown Positive Negative Unknown

CT Scan Chest ___ Date: _____ CT Abd/Pelvis ___ Date: _____
Positive Negative Unknown Positive Negative Unknown

Radiograph (Other): _____ Date: _____
Positive Negative Unknown

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)
other, generalized, carcinomatosis, disseminated, not specified, unknown

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**): _____

Physician Responsible for Ongoing Therapy/Care: _____

Date last contact: _____

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: 12/02/12

Instructions for Patient Reporting Form

1. Patient Name: Full name of patient. Note any aliases or nicknames.
2. Patient's Home Address: Residence at the time of diagnosis, if unknown put current address.
3. Gender: Please Circle the appropriate gender for the patient.
4. Date of Birth: Record patient's date of birth including month, day, and year.
5. Social Security Number: Social security number of patient. Do not use spouse's social security number.
6. Phone Number: Patient's residence
7. Occupation: Occupation at the time of diagnosis, if known.
8. Race: Record specific race of patient
9. 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: John Guire, CTR
4815 W. Markham, Slot #7
Little Rock, AR. 72205
Phone: (501) 280-4826 Fax: (501) 661-2891

Revised: 12/28/10

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