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## INTRODUCTION

The Web Plus Reporting Manual has been created to assist Pulmonary clinics in reporting cancer cases to the central cancer registry. This manual is to be used for cases diagnosed as of **January 1, 2007**.

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

In recent years there has been a shift toward outpatient diagnosis and treatment, which has caused cases not to be reported to the central registry. **This is an attempt to encourage and assist you in collecting and submitting data on all cancers.** Without this vital information the cancer burden on Arkansas residence will not 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 to review registry personnel.)

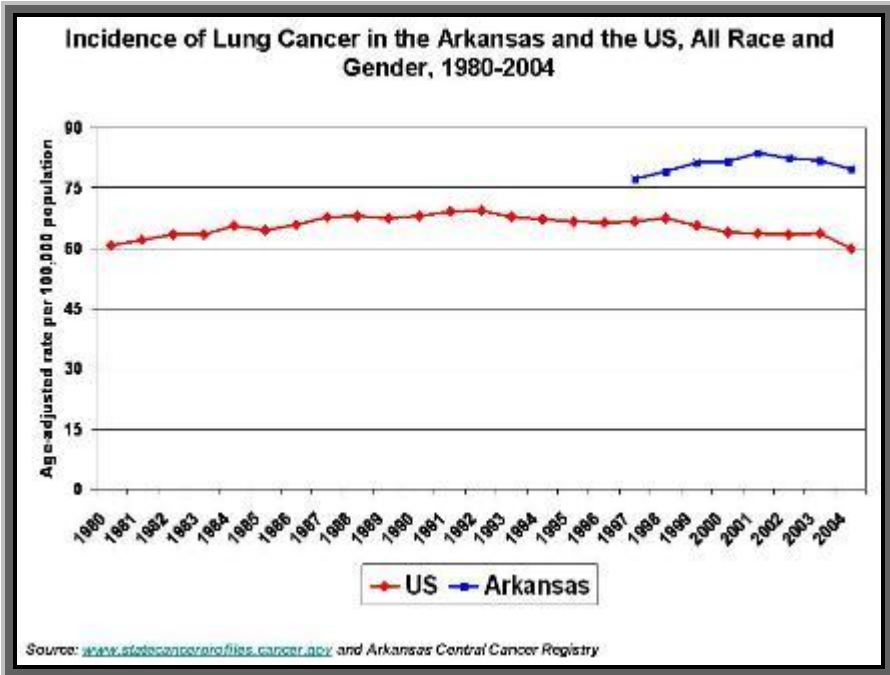
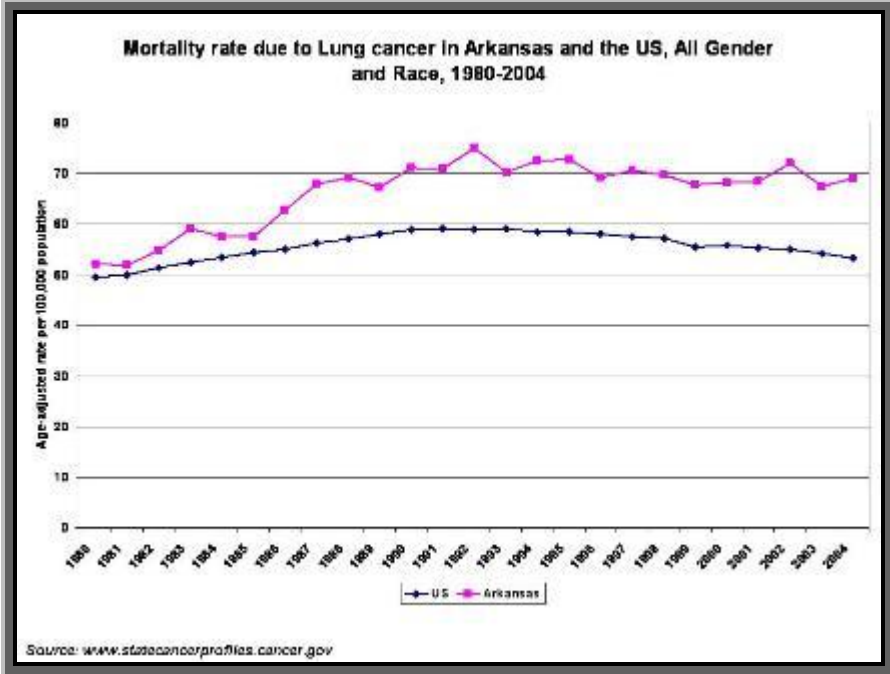
### **Statistics on/for Lung Cancer**

The following statistics were provided by ACCR to the American Cancer Society Facts and Figures national publication. You can review the entire documentation at the American Cancer Society's web site: [www.cancer.org](http://www.cancer.org), then click on the Cancer Facts and Figures link to the left of the screen.

An estimated 213,380 new cases are expected in the US, accounting for about 15% of all cancer diagnoses. The incidence rate is declining significantly in men, from a high of 102 cases per 100,000 in 1984 to 78.5 in 2003. In women, the rate is approaching a plateau after a long period of increase.

An estimated 160,390 deaths, accounting for about 29% of all cancer deaths is expected in the US. Lung cancer accounts for the most cancer related deaths in both men and women. Death rates have continued to decline significantly in men from 1991-2003 by about 1.9% per year. Female lung cancer death rates are approaching a plateau.

**It is VITAL that your facilities data be included in the following statistics.** Some of the information pertaining to Arkansas is provided on the next page.



## **GENERAL INSTRUCTIONS**

The following information provides some basic rules regarding cancer reporting to the state central cancer registry.

All cancer cases diagnosed and/or treated for cancer in your facility, on or after January 1, 2007, must be reported to the ACCR.

For Pulmonary clinics this includes:

- ◆ Cases initially diagnosed at your facility and
- ◆ Cases treated at your facility only.

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

After the information has been recorded and reviewed for completeness and accuracy, please make a list of patients at your facility. Keeping a list of patients that have been reported to the ACCR may assist you 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

## **SUBMISSION GUIDELINES**

Web Plus is hosted on a secure web server that has a digital certificate installed; the communication between the client and the server is encrypted with Secure Socket Layer (SSL) Technology.

Web Plus is a web-based application used to collect cancer data securely over the public Internet. It is most suited for physicians' offices and other low volume reporting sources that do not have facility-based cancer registries.

Records are saved in a database at the hosting cancer registry and cases entered by one facility or office is not visible to other facilities. Data entered is validated by the CDC EDITS Engine running on a web survey. User display types and edit configurations are managed at the hosting facility.

## Requirements for Web Access

Web Plus requires Microsoft Internet Explorer version 5.0 or later or a Mozilla browser to operate the system fully. Although Web Plus works at 800 X 600 resolution, it can be best viewed at 1024 X 768 or higher resolution.

### Logging into Web Plus

To log into Web Plus, complete these steps:

1. Open your internet browser and type the following web address <https://dhhs.arkansas.gov/ACCR/logonen.aspx> It would be best to save the website to your favorites so that you will not have type it in each time you are entering data. To do this **click** on **Favorites** at the top of the page and **click** on **Add to Favorites** and give this web address a name you can remember.
2. Press **Enter**.  
**Result:** Either the network Password window or the Web Plus window opens.
  - If the Enter Network Password window opens, go to step 3.
  - If the Web Plus window opens, go to step 5.
3. Click within the User ID field to place your cursor there.
4. Type **demo** into each field and click **OK**.  
**Result:** The Web Plus log in page opens.
5. Type **901294** in the User ID field and **pulmonary** (**all lower case**) in the Password field.
6. Click **Log in**.  
**Result:** The Web Plus home page opens.
7. Click on the box labeled **New Abstract** and begin entering patient information.
8. Once all of the abstract information has been entered **Click** on the **Save** button down at the bottom left hand corner of the screen.
9. There will be a box come up over to the right informing you that the abstract passed all of the edits, **Click** on the **Yes** button and the abstract will be released to the Central Registry for our review.

Thanks again for your time and cooperation.

## REPORTABILITY

All facilities are required to report cancer cases to the ACCR. The following requirements are listed below:

### **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 (Chemo, hormonal, immunotherapy, etc)
- d. Surgery is performed inside of your institution
- e. No treatment is given (supportive care, watchful waiting or "observation" only). This includes palliative treatment.

### **What information is required?**

Any details related to the **diagnosis, treatment and staging of this cancer**. We need any information you have, even if the data items are unable to be completed. Providing the name of the physician or hospital in which the patient was diagnosed or treated, will enable us to retrieve more accurate information. This information may be found in the facility history and physical, discharge summaries, pathology reports, etc. Please include the date of death.

## CONFIDENTIALITY AND HIPAA

The ACCR has policies and procedures that address patient confidentiality. It is also stated in the state law Section 20-15-203. Confidentiality and Section V. Confidentiality in the "Rules and Regulations", states that "all information exposed to the Arkansas Department of Health & Human Services (ADHHS) shall be confidential and shall not be disclosed under any circumstances except (1) to other state cancer registries with which ADHHS 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." No identifiable information will be released in any data from the central registry.

The Arkansas Central Cancer Registry has an online query system that allows the public to retrieve data on all cancer sites that are collected. It can be sorted by county, sex, and race. The data is also used to develop county fact sheets that include the top cancer sites for each county, county population, risks factors for cancer, local physicians and resources. The web based query system can be accessed at <http://cancer-rates.info/>.

There are numerous data requests made for the data that is submitted to the central registry. The information provided assists in receiving state and federally funded programs that provides information on early detection and encourages regular medical exams. It could also provide mammograms or other cancer related screenings at little or no cost to the patient.

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.”

## **DATA ENTRY FIELDS WITH DESCRIPTIONS**

### **REPORTING FACILITY IDENTIFICATION**

Each facility will be assigned a specific identification number. The information entered in this area is used to identify the facility that is reporting the cancer case. Please record full name of the facility. If there is only one physician practicing, record the name of the physician in this area.

### **ABTRACTOR**

The person who has been assigned to abstract the cancer cases will record their initials in this field.

### **PATIENT DEMOGRAPHICS**

#### **PATIENT NAME (CRITICAL FIELD)**

- ◆ 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

#### **SOCIAL SECURITY NUMBER (CRITICAL FIELD)**

Record the patient's Social Security number, if known. Do not record the spouse's number. Use **9s** if number is unknown. Enter explanation for no number in Remarks Text field. No dashes are necessary.

#### **ADDRESS AT DIAGNOSIS (CRITICAL FIELD)**

Please record the patient's address at the time of diagnosis. In other words, record the address where the patient lived when diagnosed with cancer.

#### **CITY AT DIAGNOSIS (CRITICAL FIELD)**

Please record the patient's city at the time of diagnosis. In other words, record the city where the patient lived when diagnosed with cancer.

#### **STATE AT DIAGNOSIS (CRITICAL FIELD)**

Please record the patient's state at the time of diagnosis. In other words, record the state where the patient lived when diagnosed with cancer.

### **ZIP CODE AT DIAGNOSIS (CRITICAL FIELD)**

Please record the patient's zip code at the time of diagnosis. In other words, record the zip code where the patient lived when diagnosed with cancer.

### **COUNTY AT DIAGNOSIS**

Please record the patient's county at the time of diagnosis. In other words, record the county where the patient lived when diagnosed with cancer. Available county codes can be selected from the drop down box.

### **TOBACCO HISTORY (CRITICAL FIELD)**

Record the current status of tobacco use. Tobacco history includes the use of cigarettes, cigars and chewing tobacco. Available codes can be selected from the drop down box.

### **ALCOHOL HISTORY**

Record the current status of alcohol use. This includes any information given about past alcohol use. Available codes for this field can be selected from the drop down box.

### **FAMILY HISTORY**

Record the family history for the cancer type, which is currently being abstracted. Select Yes, if there are other family members with the same cancer as being abstracted. Available codes for this field can be selected from the drop down box.

### **RACE (CRITICAL FIELD)**

Record the patient's race in this field. Available codes for this field can be selected from the drop down box.

### **HISPANIC ORIGIN**

Record the patient's Spanish/Hispanic origin in this field:

- 1 Mexican (includes Chicano)
- 2 Puerto Rican
- 3 Cuban
- 4 South or Central American (Brazil)
- 5 Other specified Spanish/Hispanic origin (includes European)
- 6 Spanish, Hispanic, Latino, NOS; Evidence other than surname or maiden name that person is Hispanic
- 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).

9 Unknown whether Spanish or not

### **BIRTH DATE (CRITICAL FIELD)**

Complete the patient's birth date, record the month in the first two spaces, the day in the next two spaces, and the four-digit birth year in the last four spaces. (No slashes necessary)

If the month and day of birth are unknown, but the year is known, Put 99 for the month and day. Example if you only know patient was born in 1937, 99/99/1937.

If the year of birth is unknown, estimate 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.

\*"9" or "99" is used by cancer registries to indicate unknown information.

### **SEX (CRITICAL FIELD)**

Record the person's gender. Available codes for this field can be selected from the drop down box.

- 1 Male
- 2 Female
- 3 Other, (Hermaphrodite)
- 4 Transsexual
- 9 Unknown

### **PRIMARY PAYER**

Record the type of insurance the patient has at the time of diagnosis and/or treatment. Available codes for this field can be selected from the drop down box.

### **USUAL OCCUPATION TEXT**

Record the patient's usual occupation (i.e., the kind of work performed during most of the patient's working life before diagnosis of this tumor). Do **not** record "retired." If usual occupation is not available or is unknown, record the patient's current or most recent occupation, or any available occupation.

## **USUAL INDUSTRY TEXT**

Record the primary type of activity carried on by the business/industry at the location where the patient was employed for the most number of years before diagnosis of this tumor. Be sure to distinguish among “manufacturing,” “wholesale,” “retail,” and “service” components of an industry that performs more than one of these components. If you know the type of industry in which the patient is employed, record the industry type, ex: agriculture. If you only know the name of the industry, record it in this field.

|                              |
|------------------------------|
| <b>CANCER IDENTIFICATION</b> |
|------------------------------|

## **DATE OF FIRST CONTACT**

Record the date of first contact with the reporting facility for the diagnosis and/or treatment of the tumor. The date may represent the date of an outpatient visit for a biopsy, x-ray, scan or laboratory test. Format: MMDDYYYY (No slashes necessary)

## **DATE OF DIAGNOSIS (CRITICAL FIELD)**

Record the date of initial diagnosis by a recognized medical practitioner for the tumor being reported whether clinically or microscopically confirmed. Format: MMDDYYYY (No slashes necessary)

## **AGE AT DIAGNOSIS**

Click on the calculator icon to the left of the field to calculate patient’s age at the time of diagnosis. The patient’s complete date of birth and the date of diagnosis must be entered before this function can be performed.

## **PRIMARY SITE (CRITICAL FIELD)**

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 try to document the site of origin as specific as possible. Click on the magnifying glass to the left of the field and enter skin in the search box, if you are unable to determine which area the cancer has arose, record Lung, Nos (C34.9).

## **PRIMARY SITE TEXT (CRITICAL FIELD)**

Document the primary site information in the text field. (Max. 40 characters available)

## **HISTOLOGY TYPE (CRITICAL FIELD)**

Histology refers to the study of tissue and cells on the microscopic level. These are the abnormal cells seen by a pathologist. The pathology report will include a complete description of the tissue's appearance. They are grouped according to their appearance.

The histology can be obtained from the pathology report. ***If there wasn't a pathological diagnostic procedure done, and the physician states specific type of cancer, code this type.***

Click on the magnifying glass and enter the histology name into the search box. Example: enter adenocarcinoma in the search box click on search and select the appropriate code. In this example the appropriate code would be 8140.

## **HISTOLOGY TEXT (CRITICAL FIELD)**

Document the histology information in the text field. (Max. 40 characters available)

## **GRADE**

The Histologic Grade is a qualitative assessment of the differentiation of the tumor expressed as the extent to which a tumor resembles the normal tissue at that site. Select a Grade from the drop down box.

- Grade 1 Well Differentiated
- Grade 2 Moderately Differentiated
- Grade 3 Poorly Differentiated
- Grade 4 Undifferentiated, Anaplastic
- Grade 5 T Cell; T-precursor
- Grade 6 B cell; pre-B;B-precursor
- Grade 7 Null Cell; non T-non B
- Grade 9 Unknown, Not Determined

## **PATHOLOGY TEXT (CRITICAL FIELD)**

Please provide Primary Site, Histology and other pathology report information on this patient. This is a key field for the central registry to be able to complete the abstract. (Max 250 characters available) please abbreviate if necessary.

|                                 |
|---------------------------------|
| <b>STAGE/PROGNOSTIC FACTORS</b> |
|---------------------------------|

### **COLLABORATIVE STAGE TUMOR SIZE (CS TUMOR SIZE)**

Record the largest dimension or diameter of the primary tumor. It should always be recorded in millimeters. To convert centimeters to millimeters, multiply the dimension by 10. If the tumor size is given in tenths of millimeters, round down if between .1 and .4 mm, and round up if between .5 and .9 mm.

### **COLLABORATIVE STAGE EXTENSION (CS EXTENT OF DISEASE)**

This field identifies growth (extension) of the primary tumor within the organ of origin or its direct extension into neighboring organs. The extension of the tumor is documented in the pathology report. Once you **click** on the **magnifying glass icon** there will be a box open to the right of the screen, scroll down past the grey colored notes to see the appropriate code selection for this field.

### **COLLABORATIVE TUMOR SIZE/EXTENSION EVALUATION (HOW EVALUATED)**

This field records the codes for “CS Tumor Size” and “CS Extension” based on the diagnostic methods employed. It describes the methods used to diagnose the primary cancer. Once you **click** on the **magnifying glass icon** there will be a box open to the right of the screen, please select the appropriate code for this field.

### **COLLABORATIVE STAGE METS AT DIAGNOSIS (CS DISTANT METS AT DX)**

This field identifies the distant site(s) of metastatic involvement at time of diagnosis. In other words, when the patient was diagnosed, tumor had already spread indirectly (through vascular or lymph channels) to a site remote from the primary tumor. Once you **click** on the **magnifying glass icon** there will be a box open to the right of the screen, please select the appropriate code for this field.

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| <b>TREATMENT – 1<sup>ST</sup> COURSE</b> |
|--|

### **DATE OF SURGERY**

Record the date that surgery was performed at your facility. **This includes any excisions, biopsies, and other procedures.** Format: MMDDYYYY (No slashes necessary)

### **SURGICAL PROCEDURE (CRITICAL FIELD)**

Please provide information that pertains to any procedure that removes a specimen and is read by a pathologist. (Max 250 characters available) please abbreviate if necessary.

## **FOLLOW UP/VITAL STATUS**

### **DATE OF LAST CONTACT**

Record the last date that the patient was in your facility after diagnosis and treatment. If the patient has expired, record the date of death. Format: MMDDYYYY (No slashes necessary)

### **VITAL STATUS**

Record the vital status of the patient. **Click** on the drop down box to select the appropriate code for this field.

- 0 Dead
- 1 Alive

### **CANCER STATUS**

Record the presence or absence of clinical evidence of the patient's malignant or non-malignant tumor. **Click** on the drop down box to select the appropriate code for this field.

- 1 No Evidence of this cancer
- 2 Evidence of this cancer
- 9 Unknown, indeterminate

### **REPORTING PHYSICIAN**

Record the physician that is reporting the case. **Click** on the **magnifying glass icon** there will be a box open to the right of the screen, please select the appropriate physician UPIN number from the codes listed.

## **TEXT FIELDS**

\*\* If there is no information available enter N/A. These fields will be used by the ACCR to complete additional information on this case. Please provide as much information as possible so that we have a quality abstract.

### **PHYSICAL EXAM**

Please provide history and physical information on this patient. (Max. 200 characters available) please abbreviate if necessary.

### **X-RAY / SCANS**

Please provide x-ray and scan information on this patient. ( Max 250 characters available), please abbreviate if necessary.

### **LAB RESULTS**

Any peripheral blood, cytology, Nuclear Medicine Red Plasma Volume Studies, Bone Marrow, Flow Cytometry, IHC and other test results. (Max 250 characters available)

### **REMARKS TEXT**

Please provide any additional information on the patient such as smoking history, family history, other physicians involved in the care for this patient, LDH test results, and if patient has expired. (Max 350 characters available) please abbreviate if necessary

## **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 neoplasm's 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. Social Security Number

f. County of Residence

B.

1. Diagnosis.

- a. Class of case.
- b. Date of Diagnosis.
- c. Primary Site.
- d. Laterality.
- e. Histology.

2. Treatment.

- a. Grade.
- b. Diagnostic Confirmation.
- c. Staging (American Joint Committee for Cancer – AJCC).
- d. Reporting identification of the facility or person reporting.

3. Summary of Treatment

- a. Date first course started.
- b. Name of Physician.
- c. First course of treatment, i.e., surgery, radiation, chemotherapy, hormone therapy.

4. Follow-Up.

5. Recurrence.

C. 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.

D. 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.

- E. 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 scheduling an in-service:

CONTACT:

Michael Castera, CTR  
Quality Assurance Specialist/IT Liaison  
Office: (501) 661-2069  
Fax: (501) 661-2891  
[michael.castera@arkansas.gov](mailto:michael.castera@arkansas.gov)

For more information regarding:

- ◆ Studies or reports
- ◆ Special data requests
- ◆ General administrative issues

CONTACT:

Gigi White, RHIT, CTR  
Program Director of the Arkansas Central Cancer Registry  
Arkansas Department of Health  
501-661-2463  
501-661-2891 - fax  
[glynis.white@arkansas.gov](mailto:glynis.white@arkansas.gov)

To access the cancer registry's website go to:

[www.healthyarkansas.com/arkcancer/arkcancer.html](http://www.healthyarkansas.com/arkcancer/arkcancer.html)

## APPENDIX C

### FREQUENTLY ASKED QUESTIONS AND ANSWERS REGARDING CANCER REPORTING

#### 1. When does 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, have two (2) years to comply (by April 14, 2003), except for small health plans which have until April 14, 2004 to comply.

#### 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."<sup>1</sup> "...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."<sup>2</sup> ***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."<sup>3</sup>

#### 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?

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<sup>1</sup> C.F.R. 164.501

<sup>2</sup> C.F.R. 164.512

<sup>3</sup> C.F.R. 160.103

Yes. Although private practice physicians are health providers, and thus covered under the provisions of the HIPAA privacy regulations<sup>2</sup>, 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 authority<sup>1</sup> 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.<sup>1</sup>

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.<sup>3</sup>

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

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<sup>1</sup> 45 C.F.R. § 164.501 (2001).

<sup>2</sup> 45 C.F.R. 160.103

<sup>3</sup> 45 C.F.R. 164.512

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.

**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."<sup>1,2</sup>

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<sup>1</sup> F.R. p.82525

<sup>2</sup> 45 C.F.R. 164.512