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Cancer Registry 101

Why, Who, What, Where, When and How of the Cancer Registry

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WHY?

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Why do registries exist?

Federal Law

Cancer Registries Amendment Act

Public Law 102-515

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Arkansas State Law

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.

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Arkansas State Law
cont…

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.

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Arkansas State Law
cont…

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.

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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 disease.

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ACCR Rules and Regulations
Cont..

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:**

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- Personal Information
  - Name
  - Address
  - Date of Birth
  - Place of Birth
  - Race and Spanish/Hispanic Origin
  - Sex
  - Social Security Number
  - County of Residence
  - Marital Status
  - Maiden Name, if applicable
  - Alias
  - Occupation History, if available
- Diagnosis
  - Class of case
  - Date of Diagnosis
  - Primary Site
  - Laterality
  - Histology
- Treatment
  - Diagnostic Confirmation
  - Grade
  - Staging (American Joint Committee for Cancer- AJCC)
  - Reporting identification of the facility or person reporting
- Summary of Treatment
  - Date first course started
  - Name of Physician
  - First course of treatment, i.e., surgery, radiation, chemotherapy, hormone therapy.
- Follow-up
- Recurrence

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Section IV. General Requirements Cont…

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

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

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

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ACCR Rules and Regulations
Cont..

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.

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ACCR Rules and Regulations
Cont..

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.

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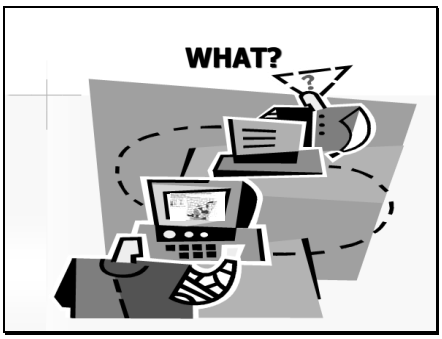

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What are the different types of registries or data sources?

- **Hospital registries** provide complex data for the evaluation of care within the *hospital*, and they are the primary source of data for state registries.
- **Population-based Registries** record and consolidate information from multiple reporting facilities within a *geographic area*
- **Central or state cancer registries** collect and consolidate data from both *hospital and population based registries, as well as physician's offices, pathology labs, radiation and chemotherapy treatment facilities.* All states have data sharing agreements in order to track patients that cross state boarders for diagnosis and treatment

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What diseases are reportable?

140.0 – 208.9	Malignant neoplasm's (solid tumors)
225.0 – 225.9	Benign neoplasm of brain and spinal cord neoplasm
227.3 – 227.4	Benign neoplasm of pituitary gland, pineal body, and other intracranial endocrine-related structures
230.0 – 234.9	Carcinoma in situ
237.0 – 237.9	Neoplasm of uncertain behavior [borderline] of endocrine glands and nervous system
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3)
238.6	Extramedullary plasmacytoma (9734/3)
238.71*	Essential thrombocythemia (9962/3)
238.72*	Low grade myelodysplastic syndrome lesions (includes 9980/3, 9982/3, 9985/3)

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What diseases are reportable? Cont…

- 238.71* Essential thrombocythemia (9962/3)
- 238.72* Low grade myelodysplastic syndrome lesions (includes 9980/3, 9982/3, 9985/3)
- 238.73* High grade myelodysplastic syndrome lesions (includes 9983/3)
- 238.74* Myelodysplastic syndrome with 5q deletion (9986/3)
- 238.75* Myelodysplastic syndrome, unspecified (9985/3)
- 238.76* Myelofibrosis with myeloid metaplasia (9961/3)
- 238.79* Other lymphatic and hematopoietic tissues (includes 9960/3, 9961/3, 9970/1, 9931/3)
- 273.2 Gamma heavy chain disease (9762/3); Franklin's disease (9762/3)
- 273.3 Waldenstrom's macroglobulinemia (9761/3)
- 288.3 Hypereosinophilic syndrome (9964/3)
- 289.83* Myelofibrosis (NOS) (9961/3)
- 795.06* Papanicolaou smear of cervix with cytologic evidence of malignancy *(without histologic confirmation) (positive Pap smear)*

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WHAT IS AN ABSTRACT?

- Abstract – An abstract is a list of required and critical data fields that include demographics, clinical presentation, diagnostic studies, staging information, treatment information, disease status and vital status of a patient diagnosed or treated with cancer.

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What is collected in an abstract?

A sample of an abstract includes:

- **Demographics**: name, DOB, SS#, address
- **Diagnosis**: site and type of cancer with date
- **Workup**: how cancer was found (scopes, x-rays, clinical presentation)
- **Staging**: how far the cancer progressed
- **Treatment**: all the modalities (surgery, chemo, etc) used to treat and hopefully cure the patient's cancer

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What do we use to identify cancer cases?

4 CASEFINDING METHODS

- PATHOLOGY REPORTS
- DISEASE INDEX
- DISCHARGE SUMMARY REVIEW
- DEATH CERTIFICATES

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What resources are available?

- Manuals
  - MP/H, Collaborative Staging Manual, ICD-0-3, FORDS
- Training
  - ACCR Staff
  - Outside CTRs/Data Reporters
  - Nationally
- Websites
  - NPCR, SEER, NAACCR, WHO, AJCC

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What software is available?

- Software Vendors
  - Oncolog
  - Precise
  - ERS
- Registry Plus
  - Web Plus
  - Created by CDC
  - Free

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What software does the Central Registry use?

- CancerCore
  Created by Chris Fisher, Systems Programmer

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What happens to the case after it is submitted?

Quality Assurance Activities

- Patient de-duplication
- Case consolidation
  - Extensive review of coding rules
  - Maintain list of common errors

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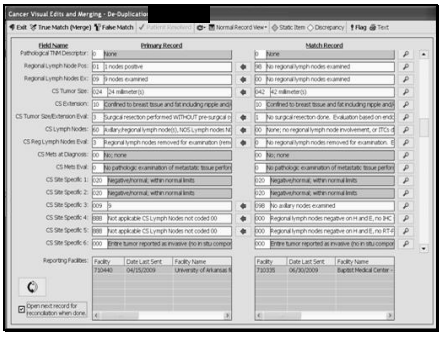

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CS Extension

Code	Description
00	In situ: noninfiltrating; intraepithelial Intraductal WITHOUT infiltration Lobular neoplasia
05	Paget Disease of nipple (WITHOUT underlying tumor)
07	Paget Disease of nipple (WITHOUT underlying invasive carcinoma pathologically)
10	Confined to breast tissue and fat including nipple and/or areola Localized, NOS
20	Invasion of subcutaneous tissue Local infiltration of dermal lymphatics adjacent to pr...
30	Attached or fixation to pectoral muscle(s) or underlying tissue Deep fixation Invasion...
40	Invasion of (or fixation to): Chest wall Intercostal or serratus anterior muscle(s)...
51	Extensive skin involvement, including: Satellite nodule(s) in skin of primary breast Ulc...
52	Any of the following conditions described as involving more than 50% of the breast ...
61	(40) + (51)
62	(40) + (52)
71	Diagnosis of inflammatory carcinoma WITH a clinical description of inflammation, ery...
72	OBSOLETE - Description: Diagnosis of inflammatory WITH a clinical diagnosis of infla...
73	Diagnosis of inflammatory carcinoma WITH a clinical description of inflammation, ery...

(*) Code Range Description Select Cancel

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What does this mean for Registries in the state?

- New Procedure
- Training

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What other activities are performed in the Central Registry?

Quality Assurance Activities

- Audits
  - Casefinding
  - Text
  - Re-Abstracting

  Data Fields – Not a formal process;
- Data Edits

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What are expectations for audits?

- Preparation
- Schedule Adjustments
- Time, Time, Time

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What other activities are performed using the data

- Data Utilization Activities
- Research
- Publications – Arkansas Cancer Facts and Figures
- External Data Linkage

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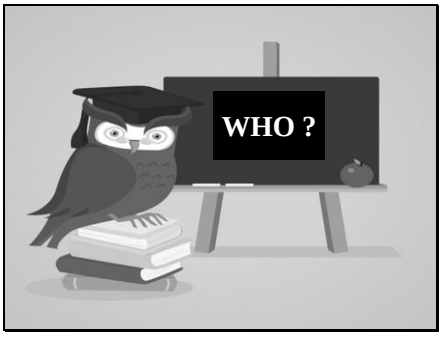

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Who should do the abstracting?

- Certified Tumor Registrars (CTRs)
  - Permanent position(s)
  - Contract position(s)
  - Outsourcing company
- Data Reporters
  - Do not have CTR credential
  - Key in minimal text data to be compliant with the law

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Who uses our data?

- Citizens
- Epidemiologist
- Researchers
- Doctors
- Administrators
- American Cancer Society
- NCI
- Policy Makers

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Who are the standard setters?

- National Program of Cancer Registries (NPCR)
- National Association of Central Cancer Registries (NAACCR)
- Surveillance, Epidemiology and End Results (SEER)
- Commission on Cancer (COC)

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WHERE ?

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Where can you find cancer data or comparison data?

- Reports – Arkansas Cancer Facts and Figures
- American Cancer Society
- Journal articles
- Cancer in North America
- National Cancer Data Base
- The SEER Public Use File and SEER*Stat
- United States Cancer Statistics
- Data Requests - State Registry database
  http://cancer-rates.info/ar/

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Where to focus attention?

- Data Quality and Completeness
- Data Utilization
- Registry Image

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WHEN ?

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When to submit abstracted cases?

- All Hospitals - Monthly Submissions
- Facilities – Monthly or Quarterly
- Physician Offices – Case by case

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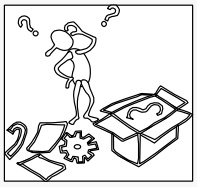
HOW ?



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How to submit abstracted cases

- Web-Plus
  - Secure on-line web based application needed to import abstracts

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HOW ARE WE CERTIFIED?

North American Association of Central Cancer Registries – NAACCR

GOLD!!

- Case ascertainment - 97.5% (>95%)
- Completeness of information recorded (age at diagnosis, sex, race, state/county) - 0.0-0.9% (≤ 3%)
- Death certificate only cases - 2.4% (≤3%)
- Duplicate primary cases - 0.8 per 1000 (≤1)
- Passing EDITS - 100% (100%)
- Timeliness - 23 months

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Acknowledgements

Arkansas Central Cancer Registry is in association with the Arkansas Department of Health and is funded by CDC/NPCR