

# CANCER REGISTRATION IN UTAH

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January 24, 2017



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HEALTH SCIENCES

# Overview of presentation

- Utah Cancer Registry
- Discuss public health surveillance and confidentiality
- Review elements of cancer registration
- Summarize uses of cancer registry data
- Summary

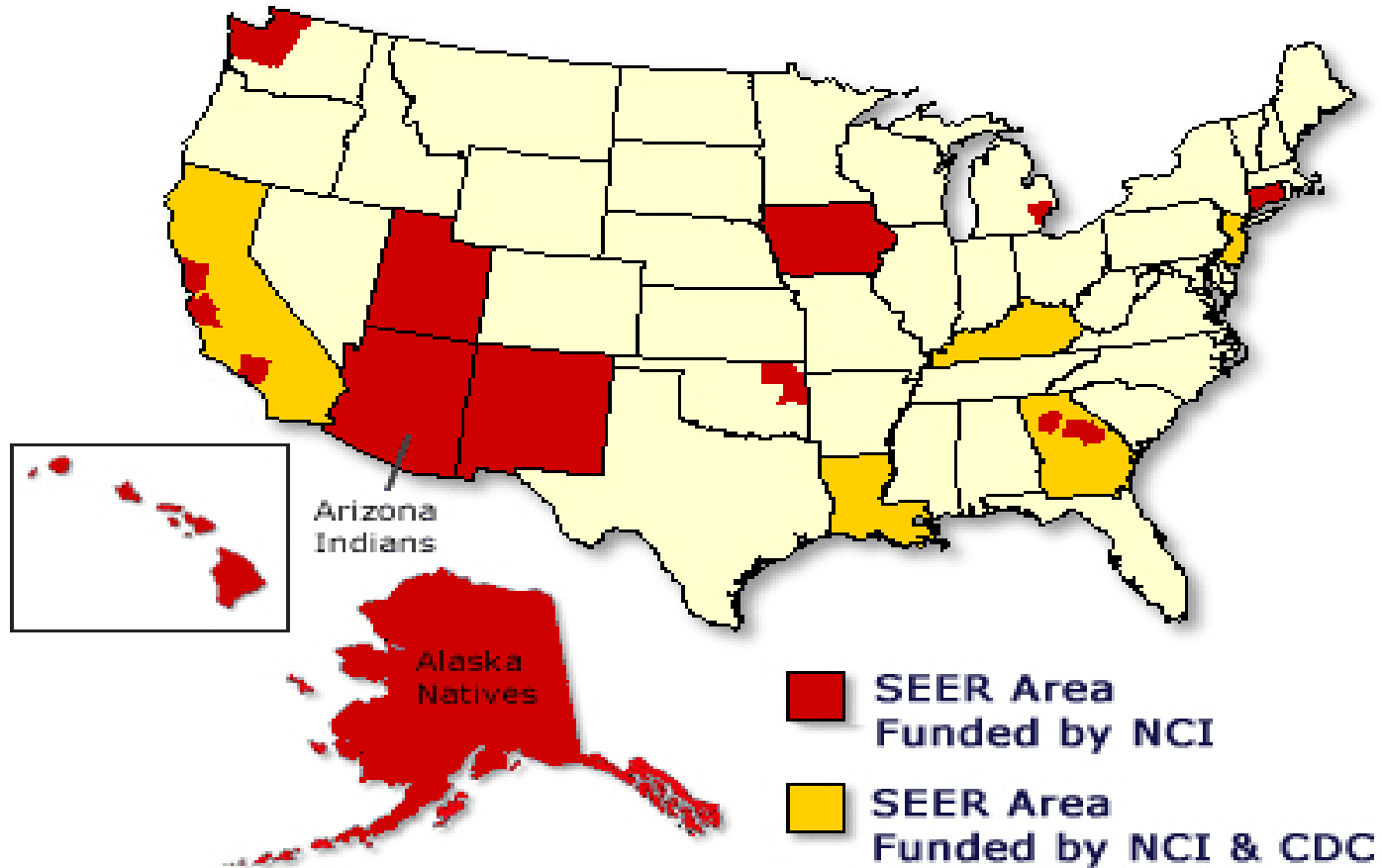


# Utah Cancer Registry

- Population-based
- Serving Utah since 1966
- Member of the National Cancer Institute's SEER Program since 1973
- Member of the North American Association of Cancer Registries since its inception in 1987
- UCR consistently graded amongst top SEER and NAACCR Registries since inception of grading systems



# Registries Funded by SEER



# SEER Funded Registries

- Gold Standard Registries in the US
- Population based – Entire State of Utah
- Submit two error free data tapes – November-February
- Submit annual reports containing milestones, current publications using UCR data, etc.
- Graded on specific quality indicators



# SEER Data Quality Profile Report for November 2013 Submission

0000001526 - SEER Utah

	Numerator	Denominator	Percent	Goal
<b>For Cases Diagnosed in 2011</b>				
Unknown/Il-Defined Site	125	10,928	1.14	< 2.5%
Unknown Laterality	83	4,780	1.74	< 6.0%
Unknown/Invalid Census Tract	0	10,982	0.00	< 2.0%
Death Certificate Only	54	10,982	0.49	< 1.5% and > 0.0%
Non-Specific Histology	203	10,928	1.86	< 2.5%
<b>Completeness Estimate (Last 10 Dx Yrs used, if available)</b>				
Total	10,525	10,647	98.85	>= 98.0% in November 2013
Invasive	9,566	9,642	99.21	
In situ	959	1,005	95.42	
<b>For Cases Diagnosed 1995-2011</b>				
Unknown Cause of Death	328	45,560	0.72	< 2.5%
<b>For Cases Diagnosed 1995-2010 and Followed into 2011</b>				
<b>Percent Followed (Invasive):</b>				
Age < 20	2,160	2,306	93.67	>= 90+, >= 80**
Age 20-64	48,012	49,593	96.81	>= 90+, >= 80**
Age 65+	48,993	49,345	99.29	>= 95+, >= 90**
All Ages	99,165	101,244	97.95	
Percent Followed (In situ)	7,678	8,080	95.02	>= 90+, >= 80**
<b>For Cases Diagnosed 1995-2010 and Followed into 2012</b>				
<b>Percent Followed (Invasive):</b>				
Age < 20	2,064	2,306	89.51	
Age 20-64	47,467	49,593	95.71	
Age 65+	48,809	49,345	98.91	
All Ages	98,340	101,244	97.13	
Percent Followed (In situ)	7,530	8,080	93.19	

# North American Association of Central Cancer Registries

- Develops and promotes uniform data standards for cancer registration;
- Provides education and training;
- Certifies population-based registries;
- Aggregates and publishes data from central cancer registries;
- Promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.



# NAACCR QUALITY AWARDS

## Certification Levels

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### NAACCR Gold Certification



Cancer registries that meet the Gold Standard for Registry Certification have achieved the highest NAACCR standard for complete, accurate, and timely data to calculate standard incidence statistics for the year reviewed. The assessment is repeated annually and the recognition only pertains to a single year of data. To achieve Gold Certification, the data from a cancer registry must meet all of the following criteria:

- ▶ Case ascertainment has achieved 95% or higher completeness.
- ▶ A death certificate is the only source for identification of fewer than 3% of reported cancer cases.
- ▶ Fewer than 0.1% duplicate case reports are in the file.
- ▶ All data variables used to create incidence statistics by cancer type, sex, race, age, and county are 100% error-free.
- ▶ Less than 2% of the case reports in the file are missing meaningful information on age, sex, and county.
- ▶ Less than 3% of the cases in the file are missing meaningful information on race (US only).
- ▶ The file is submitted to NAACCR for evaluation within 23 months of the close of the diagnosis year under review.

### NAACCR Silver Certification



Cancer registries that meet the Silver Standard for Registry Certification have achieved a high standard for complete, accurate, and timely data for calculating standard incidence statistics for the year reviewed. The assessment is repeated annually and the recognition only pertains to a single year of data. To achieve Silver Certification, the data from a registry must meet all of the following criteria:

- ▶ Case ascertainment has achieved 90% or higher completeness.
- ▶ A death certificate is the only source for identification of fewer than 5% of reported cancer cases.
- ▶ Fewer than 0.2% duplicate case reports are in the file.
- ▶ All data variables used to create incidence statistics by cancer type, sex, race, age, and county are 97% error-free.
- ▶ Less than 3% of the case reports in the file are missing meaningful information on age, sex, and county.
- ▶ Less than 5% of the cases in the file are missing meaningful information on race (US only).
- ▶ The file is submitted to NAACCR for evaluation within 23 months of the close of the diagnosis year under review.



# Confidentiality

## ***Rationale for cancer surveillance:***

- Benefits derived from cancer surveillance justify the collection of private and confidential information

## ***Registry must:***

- Protect the privacy of data subjects
- Ensure that information is used to benefit the public



# Confidentiality

## *Concepts...*

### **Data subjects**

- Patient
- Institution
- Physician

### **Types of confidential information**

- Specific items that identify a data subject
- Combinations of non-specific items that may identify a data subject



# Confidentiality

- UCR takes confidentiality very seriously
- Identifiable data never given without permission from patient
- Researchers requests must be approved by IRB, ARC
- After approval, patients called by UCR staff for approval to give researchers their name



Statistics and other information regarding the burden of cancer are made possible by Cancer Surveillance. Timely and effective use of such information in the war against cancer



# Public Health Surveillance

## *Reportable Diseases*

Reportable Diseases are

- *Considered a risk to the public health*
- *Monitored to assist in prevention and control*

The Director of the Utah Department of Health is authorized to designate the list of Reportable Diseases in Utah



# Public Health Surveillance

## *Cancer is a Reportable Disease in Utah*

- Cancer Reporting Rule (R384-100)
- All cases of cancer diagnosed or treated in the state of Utah must be reported to the Utah Department of Health
- Letter of agreement between the University of Utah and the Utah Department of Health designates Utah Cancer Registry as the official repository for such information
- Exempt from HIPAA
- Cancer surveillance is best achieved through cooperation, not coercion



# A crude chronology of cancer

Screening

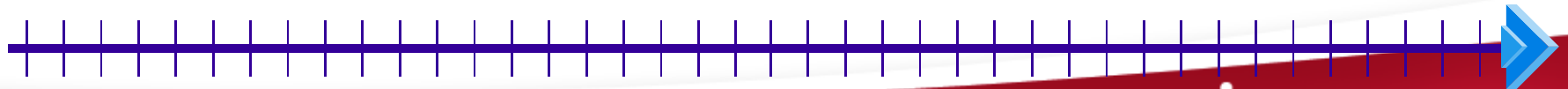
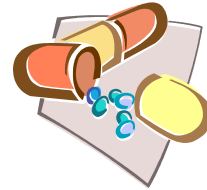
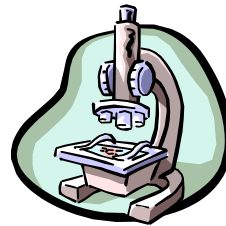
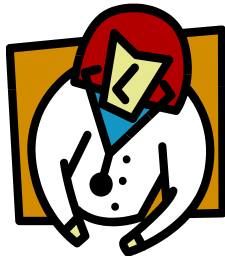
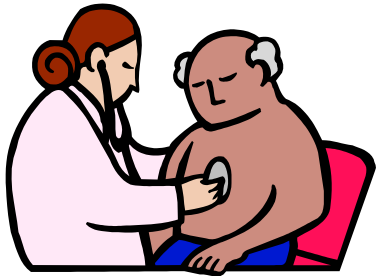
Symptoms

Clinical examination

Diagnosis

Treatment

Outcome



*Time*



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# Steps in cancer registration

## *Case finding*

- Identify cancer cases
- Common sources:

*Pathology reports*

*Hospitals and clinics*

*Radiation/Oncology diagnosis and*

*Private physician offices*

*Extended care facilities*

*Vital records*



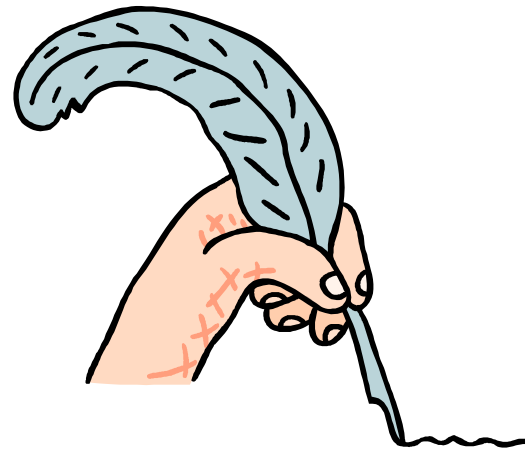


# Steps in cancer registration

## *Abstracting*

*Transcribe/summarize relevant information from...*

- Health care provider notes in medical record
- Pathology reports
- Laboratory reports
- Other sources



# Steps in cancer registration

## *Combining information*

- Many patients are seen at more than one facility
- Information from multiple sources must be combined into a single record
- Resolve discrepancies
- Avoid duplicate entries for same patient



# Steps in cancer registration

## *Coding*

- Summarize cancer characteristics in standard format
- Rules established by professional organizations
  - Surveillance, Epidemiology, & End Results (SEER) Program*
  - North American Association of Central Cancer Registries*
  - National Cancer Registrars Association*
  - American College of Surgeons*
  - World Health Organization*
  - Centers for Disease Control and Prevention*



# Steps in cancer registration

## *Editing*

- Check for errors and inconsistencies
- Standard algorithms available



# Steps in cancer registration

## *Follow-up*

- Determine vital status of patient
- Key to accurate survival statistics
- Sources:

*Hospital/clinic medical records*

*Electronic Public Databases - SSA, CMS*

*Vital records*

*Other State Cancer Registries*

*Physician Offices*

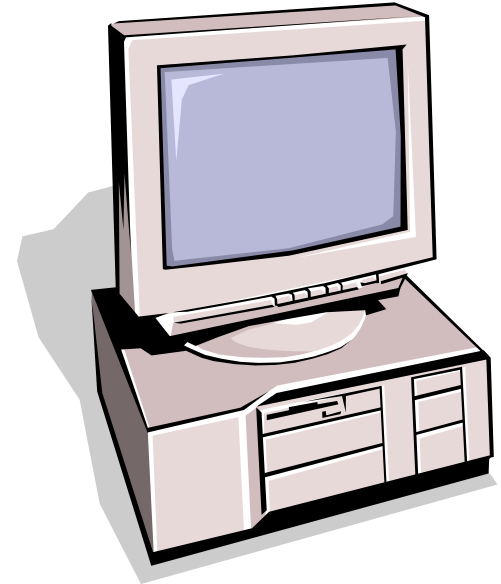
*Patient contact*



# Steps in cancer registration

## *Database management*

- Data entry
- Checking for duplicates
- Edits
- Updates
- Facilitate data collection
- Facilitate follow-up
- Extract and summarize data for reports



# Types of information

## *Patient characteristics*

### Patient identifying information

- Name, including maiden name and aliases
- Social security number
- Birth date
- Place of residence

### Uses:

- Combining information
- Follow-up
- Patient contact



# Types of information

## *Characteristics of the cancer*

### Primary-specific information

- Histology
- Primary cancer site
- Date of diagnosis
- Stage of disease at diagnosis



### Uses:

- Classification by primary site/type
- Time trend analyses
- Characterizing extent of disease





# Types of information

## *Cancer directed therapy*

### Primary-specific therapy

- Treatment modality
  - Surgery*
  - Radiation*
  - Chemotherapy*
  - Hormones*
  - Other*
- Date of initial therapy
- Facility where treated

### Used for:

- Characterizing patterns of care



# Types of information

## *Health care providers*

### Including:

- Physicians

*Follow-up physician*

*Surgeon*

*Oncologist*

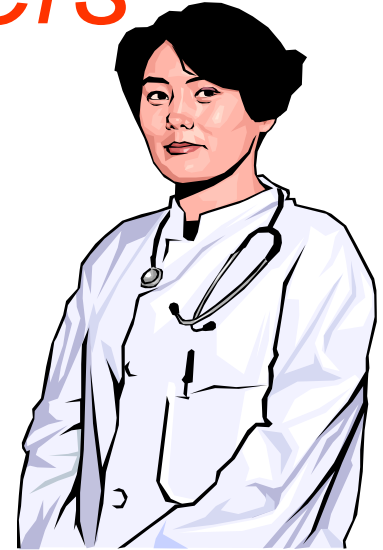
*Radiation oncologist*

*Other*

- Hospitals and other health care facilities

### Uses:

- Follow-up
- Patient contact



# Types of information

## *Patient vital status*

### Vital status

- Alive or deceased
- Date of last information
- Cause of death, if deceased

### Uses:

- Follow-up
- Survival



# Uses of Cancer Registry Data

- Utilized for cancer surveillance and research.
- Public health policy, planning, and cancer prevention
- Cancer control efforts at the local, state, and national levels.
- Contribute to the publically available SEER, NAACCR, and UDOH interactive cancer statistic databases.
- Support epidemiological research into the cause, prevention and treatment of cancer
- Assist with local cancer investigations



# Publications using Registry Data

- Included in NCI's Annual Report to the Nation on Cancer
- National and international publications –NAACCR and International Agency for Research on cancer (IARC)
- UDOH publications
- Numerous scientific publications
- List of publications:

<http://ucr.utah.edu/research/publications/index.htm>



# Summary

- Cancer surveillance – complex
- Strict regulations what to collect, when to collect,  
how to collect information
- Confidentiality at UCR is of utmost importance
- Use UCR data – assured using complete and accurate data
- Steps in cancer registration
- Types of information collected
- How UCR data is utilized



# *Thanks*

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