What is a CTR?

CCR Knowledge Series

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Overview

- What is a CTR
- Cancer Registries & Process
- Knowledge base of a CTR
- What *IS* an Abstract
- What's *IN* an Abstract-
  - How do CTRs collect information
- Who Makes the Rules
  - Standard Setters
  - Coding Applications
- Patient Follow-up
  - Confidentiality
- Education Requirements
- Where do CTRs work
- Characteristics of a CTR

What is a CTR?

"Certified Tumor Registrar"

- We also collect data on reportable **benign tumors as well as cancer**
- We're most commonly referred to as "Cancer Registrars"

What is a CTR?

- CTRs are trained to collect data on all types of cancer diagnosed and/or treated within an institution, or other defined population.
- CTR's report the resulting cancer statistics to various health care agencies and state or national cancer registries.

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Responsibilities of Cancer Registrars

- Collect timely, accurate, and complete cancer data
- Develop expertise on all types of cancer
- Summarize patient's disease, from diagnosis to death in an "abstract"
- Provide support for cancer programs, and ensure compliance of reporting standards
- Collect cancer/tumor data from a variety of sources.
- Provide data for studies, create reports to illustrate data and report Cancer Statistics to various health care agencies.
- Some CTRs organize Cancer Conferences at (ACoS/CoC) hospitals

What is a Cancer Registry

- An Information system designed for cancer data
  - Collection
  - Storage
  - Management
  - Analysis
- A type of disease registry

NCRA "Introduction to the CANCER REGISTRY"

Purpose of a Cancer Registry

- Establish and maintain a cancer incidence reporting system
- Serve as an information resource for cancer research
- Provide information to assist public health officials and agencies

NCRA "Introduction to the CANCER REGISTRY"

Types of Cancer Registries

- **Hospital registries - Incidence-based**
  - Improvement of patient care
  - Professional education
  - Administrative information
  - Clinical research

NCRA "An Introduction to the Cancer Registry"

Types of Cancer Registries

- **State registries - Population-based**
  - Cancer prevention
  - Early detection
  - Determination of cancer rates and trends
  - Assess patterns of care and outcomes
  - Research
  - Evaluation of control efforts

NCRA "An Introduction to the Cancer Registry"

Cancer Registration Process

- A continual, systematic collection of data on the occurrence and characteristics of reportable malignancies and tumors.

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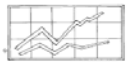
CTR Knowledge

CTR Required Knowledge Base

- Medical Terminology
- Anatomy and Physiology
- Cancer Disease Characteristics
- Understanding of Clinical Practice & Evidence based Guidelines
- Cancer Data Abstracting
- Cancer Staging Systems

CTR Required Knowledge Base

- Cancer Registry Procedures 
- Cancer Registry Database Management 
- Statistics and Epidemiology 

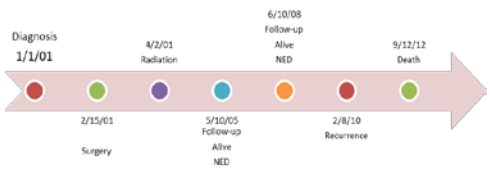
- Survival Analysis 
- Cancer Program Management* 

*Optional –Further Edu

What *IS* an Abstract?

The Cancer Registry Abstract

- "A record that contains information about each patient's tumor from the time of diagnosis and continuing through-out his or her life" *NCRA*



What Information is Collected "IN" an Abstract?

And how is it collected

What's "*In*" an Abstract

- **Patient Demographics**
  - Name
  - DOB
  - Address at Diagnosis
  - Gender, Race, Ethnicity
  - Marital status, Place of Birth
  - Insurance provider
  - Occupation

What's "*In*" an Abstract

Admission Information

- Date of first contact with facility
- Admission Dates –Inpatient/Outpatient
- Patient Referred from/Referred to
- Physicians & Specialists managing patient
- Class of Case
  - Analytic – diagnosed or treated for cancer at that facility; included in hospital data analysis
  - Non-analytic – seen for some other reason-no cancer dx or treatment provided by the facility; excluded from hospital data analysis

What's "*In*" an Abstract

- **Patient History & Comorbidities**
  - Physical findings, relevant presenting symptoms
  - Other conditions, disease which could effect treatment decisions or outcomes
    (Diabetes, COPD, heart disease, etc.)
  - Height, weight, tobacco & alcohol use
  - Patient family history and patient history of previous cancers

What's "*In*" an Abstract

- **Diagnostic Workup**
  - Imaging
  - Ultrasounds
  - Endoscopy
  - Biopsies
  - Tumor Markers
  - Labs/other





  - Must document
    - Dates, Procedures & Findings

What's "*In*" an Abstract

- **Tumor Information**
  - Date of Diagnosis
  - Type of Diagnostic Confirmation
  - Primary Site/Laterality
  - Histology Type/Behavior/Grade
  - Tumor size, or invasion within the organ or contiguous extension beyond
  - Prognostic Indicators
  - Extent of disease at diagnosis

What's "*In*" an Abstract

Stage of Disease at Diagnosis

- AJCC TNM Staging
  - Pretreatment-Clinical
  - Postsurgical-Pathologic
  - Neoadjuvant
- Collaborative Staging
  - Based on clinical and pathologic features combined
- SEER Summary Stage 2000
  - In situ, Local, Regional, Regional & Pos(+) LNs, Distant

✓ Each has different set of rules

What's "*In*" an Abstract

Treatment

- Surgery
  - Procedure, surgical margins
  - Lymph nodes examined
  - Surgical Observations
- Chemotherapy
  - Name of agents, doses, dates, Clinical trial info
- Radiation therapy
  - RT Modalities (External beam, brachytherapy, IMRT, etc)
  - Doses (cGy, etc)
  - Volume –Breast, or breast & lymph nodes, etc.

What's "*In*" an Abstract

Treatment

- Hormonal therapy
- Immunotherapy
- Other therapy
- Document agents, dates, contraindications, complications
  - Or patient refusal

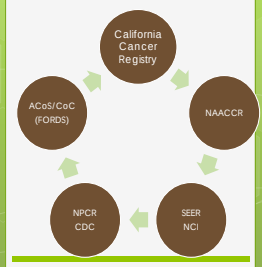
How We Collect Information

- Read medical record(s)
- From multiple sources & databases

May contact other physician offices, hospitals, pathology labs, oncology and radiation offices, surgery centers, etc.

- Information is collected and documented in both a textural narrative and "coded" using standardized coding applications.
- **The abstract is the basic foundation for all registry operations.**

Standard Setters



Organizations Who Govern Cancer Data Collection

- **National Program of Cancer Registries (NPCR) at the Center for Disease Control (CDC)**
  - Governs and supports registries is 45 states, the District of Columbia, and three territories, representing 96% of the U.S. population
- **Surveillance Epidemiology and End Results program (SEER) at the National Cancer Institute**
  - Source of cancer incidence and survival data from population-based cancer registries covering approximately 28% of the population
- **Together, CDC's NPCR and NCI's SEER collect data for the entire U.S.**

Organizations Who Govern Cancer Data Collection

- **North American Association of Central Cancer Registries (NAACCR)**
  - Develops and promotes uniform data standards for cancer registration, provides education and training, certifies population based registries, aggregates and publishes data from central registries.
- **California Cancer Registry (CCR)**
  - Sets rules for data collection requirements within California and follows coding structures and requirements from NPCR and NAACCR

Organizations Who Govern Cancer Data Collection

- **American College of Surgeons Commission on Cancer (ACoS/CoC)**
  - Created the first set of standardized data set items and developed coding rules.
    - Create patient care guidelines for cancer centers
    - For consistent patient cancer care
  - Participating hospitals must meet specific criteria
  - CTRs use CoC/FORDS coding rules for their hospitals
  - **CTRs must collect data to meet all requirements set by the various standard setting organizations**

Abstracting Coding Manuals & Applications

Coding Manuals & Applications

- CTR's must use various coding applications to code different portions of the abstract.
- These coding applications are necessary so data is entered accurately and just as important, **standardized** across all registries.

California Cancer Reporting System Standards Volume 1: Abstracting and Coding Procedures for Hospitals

- CCR's online abstracting resource for data collection in California.
- CA has different data collection requirements compared to other states.
- The CCR maintains and updates as needed based on Annual Data changes from SEER, FORDS, NAACCR and NPCR

Facility Oncology Registry Data Standards (FORDS)

- Registry standards/instructions for ACoS/CoC hospitals.
- Instructions direct
  - How to complete each field
  - Required case types
    - Code definitions
    - Additional data fields required for CoC hospitals.
- COC hospitals must incorporate the FORDs rules along with the CCR rules.

International Classification of Disease for Oncology (ICD-O-3)

- Primary site (Topography)
- Histology (cell type)
- Behavior (benign, in situ, invasive)
- Grade(tumor cell differentiation)
- Example
  - Central breast = C50.1
  - Poorly differentiated infiltrating ductal carcinoma = 85003/3

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Multiple Primary and Coding Histology Rules

- Consistent and Standardized coding to…
  - Determine number of primary sites
    - Two or more tumors in same primary site
  - Designation of combination histology
    - Two or more histologies in same tumor
- 9 Site Specific Rule sets for
  lung, breast, colon, melanoma of the skin, head and neck, kidney, renal pelvis/ureter/bladder, and malignant brain cancers.
- Separate rules for malignant solid tumors in all other sites

Hematopoietic Database

- Hematopoietic and lymphoid neoplasms
  - Leukemia
  - Lymphoma
  - Blood disorders
- Accurate reporting
  - One primary or two primaries
  - Histology coding

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American Joint Committee on Cancer (AJCC) Staging Manual

- TNM tumor staging
  - Tumor
  - Nodes
  - Metastasis
  - Each cancer site has its own rules
  - No Staging schema for Brain, CNS and hematopoietic and Lymphoid neoplasms.

Collaborative Stage Data Collection System

- Tumor size
  - Tumor extension and evaluation
- Lymph nodes and evaluation
  - Number examined
  - Number positive
- Distant metastasis and evaluation
- Site-specific factors 1-25

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Surveillance, Epidemiology & End Results (SEER) Summary Stage 2000

- Categorizes how far tumor has spread
  - Insitu
  - Localized
  - Regional
  - Regional with LNs
  - Distant
- Applicable to **All** malignant primary sites

Patient Follow-up

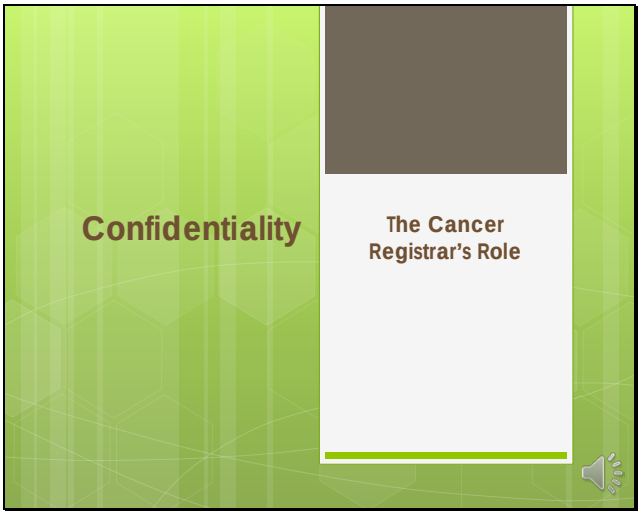
Patient Follow-Up

Follow-up Provides

- Patient current address 
- Other contacts for patient 
- Update on current managing physicians 
- Patient Vital Status 
- Current cancer status 
  - Free of cancer
    - Recurrent disease
- Additional treatment(s) 
- New type of cancer 

Patient Follow-up Process

- Performed annually on every patient
  - Yearly or Monthly patient list generated
    - Follow-up list compared to various sources
      - Hospital admissions
      - Outpatient and clinic encounters
- Physician or Patient phone calls or letters
- Other hospital registries or facility contacts
- If needed, contact made with patient designated family or friends
- Search Obituaries and State death indices



Confidentiality & Cancer Registry

- Cancer data is highly confidential with laws & rules which regulate its use.
- Cancer registries must submit data for state and national reporting per established laws.
- HIPAA allows cancer registries to share and exchange information with other hospitals, registries or physicians diagnosing or treating a shared patient.

Confidentiality-A CTR's Role

- Data is Encrypted when it's sent outside the registry
- Registrars strip identifying information before releasing data to researchers
- Protect patient identifiers in Cancer Conferences, studies and the annual follow-up process.

CTR Education Requirements

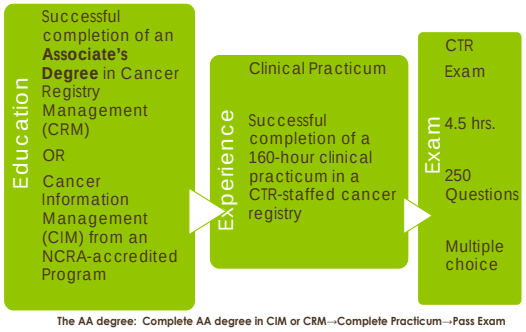
CTR Education & Certification Requirements

- In the past CTRs were trained primarily on the job.
- Today many formal education programs exist
- Certification exam offered twice annually

CTR Education & Certification Requirements

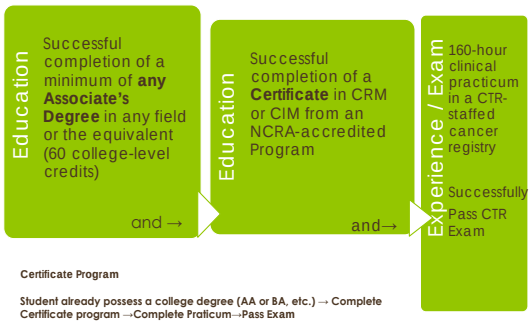
- Multiple eligibility route/options available
- Minimum requirement AA degree plus Eligibility requirements to take exam

Eligibility Routes/ Route A - Path 1



The AA degree: Complete AA degree in CIM or CRM→Complete Practicum→Pass Exam

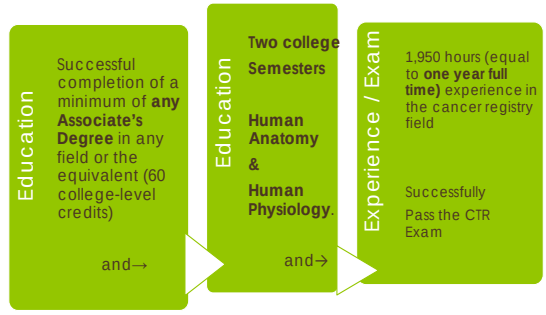
Eligibility Routes/ Route A - Path 2



Certificate Program

Student already possess a college degree (AA or BA, etc.) → Complete Certificate program →Complete Praticum→Pass Exam

Eligibility Routes / Route B



AA degree → take A&P →Work Full Time x 1 year in a cancer registry → Pass Exam

Maintaining your CTR

- Requires completion of 20 cancer related education CEs every 24 months
- National Cancer Registrar's Association
  - The NCRA is the national organization who manages credentialing, offers education, lobby's and supports the cancer registry profession.

Where Do CTR's Work

Where Do CTR's Work

- **Most Cancer Registrars work for hospitals**
- Radiation or Medical Oncology Centers
- State Central or Regional registries
- Standard Setting Organizations SEER, NAACCR, NPCR, the CoC, or AJCC
- Government Agencies
- Research & Pharmaceutical Companies
- Cancer Registry Software Vendors
- Cancer Registry Consulting and Contracting Firms
- Self Employed Contractors

SUMMARY

Summary Cancer Data Collection

- There are multiple organizations and coding applications which must be used and observed to collect cancer data.
- Abstract data is a combination of textural and coded information which must be complete and accurate
- Abstract data is used in facility analysis, treatment analysis, quality of patient care studies and survival analysis

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SUMMARY
Information Collected in an Abstract

- Demographics
- Pertinent medical history including previous tumors
- Physical exam findings
- Diagnostic workup
- Primary tumor/cancer site
- Morphology / Histology
- Cancer staging
- Treatment- surgery/chemo/radiation ,etc.
- Lifetime patient follow-up

Summary - Cancer Abstract

- The cancer registry process is a continual, systematic collection of data on the occurrence and characteristics of reportable malignancies and tumors.

- **"**A record that contains information about each patient's tumor from the time of diagnosis and continuing through-out his or her life" *NCRA*

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CTR Credential

- Demonstrates a requisite medical and scientific knowledge base and professional competence needed for cancer data collection

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Characteristics of a CTR

- ✓ **Dedicated**
- ✓ **Enthusiastic**
- ✓ **Self-motivated**
- ✓ **Detail-oriented**
- ✓ **Have medical and scientific knowledge**
- ✓ **Enjoy working behind the scenes**
- ✓ **Greatest satisfaction is contributing to the knowledge of cancer to improve patient care.**

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What is a CTR?

- CTR's are data management experts who collect tumor & cancer data from a variety of sources treated within an institution or other defined population and report the resulting cancer statistics to various health care agencies.
- CTRs bridge the information gap by capturing a complete summary of a patient's disease from diagnosis to death.

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THANK YOU!

Acknowledgements

- National Cancer Registrars Association
  - **"An Introduction to the Cancer Registry"**