

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.

National Cancer Registrars Association

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

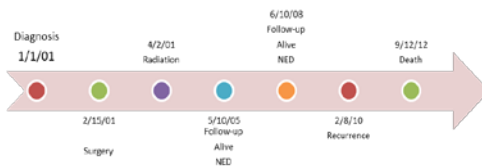


What IS an Abstract?



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 textual narrative and "coded" using standardized coding applications.
- The abstract is the basic foundation for all registry operations. 



Organizations Who Govern Cancer Data Collection

- National Program of Cancer Registries (NPCR) at the Center for Disease Control (CDC)**
 - Governs and supports registries in 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



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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

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



Collaborative Stage Data Collection System

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

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

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










Patient Follow-up



Patient Follow-Up

Follow-up Provides

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




Patient Follow-up Process

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




Confidentiality

The Cancer Registrar's Role




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.

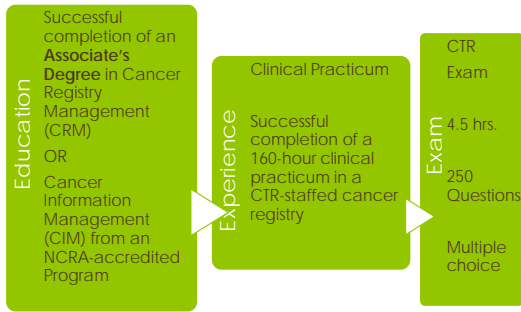


Confidentiality-A CTR's Role

- 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.

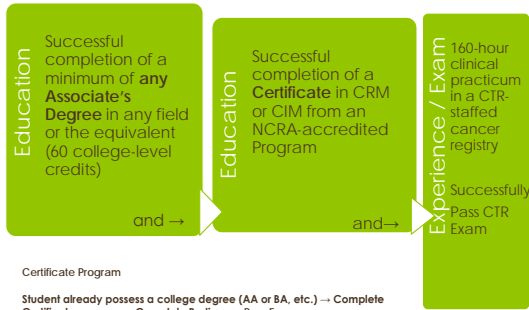


Eligibility Routes/ Route A - Path 1



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

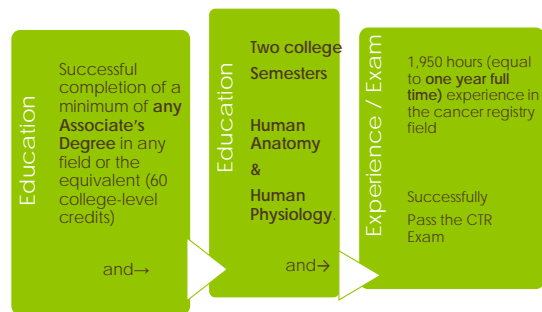
Eligibility Routes/ Route A - Path 2



Certificate Program

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



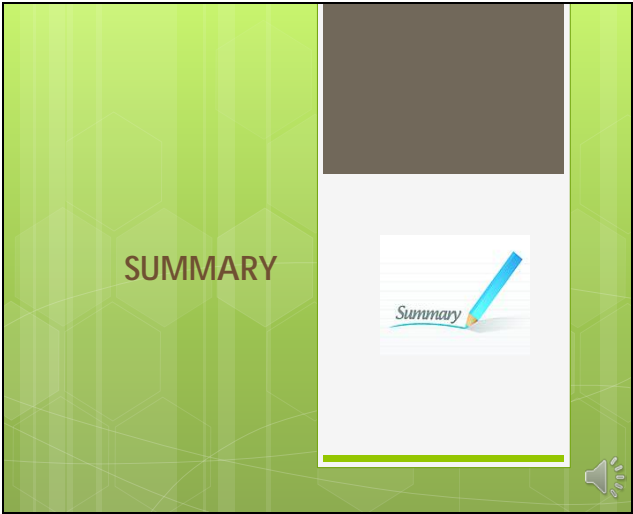
Where Do CTR's Work

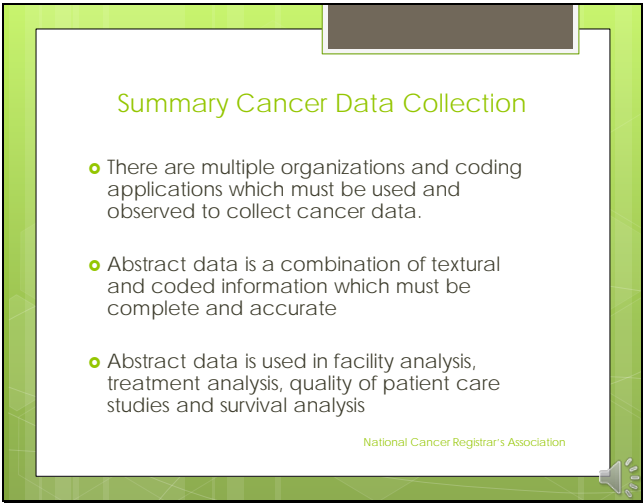


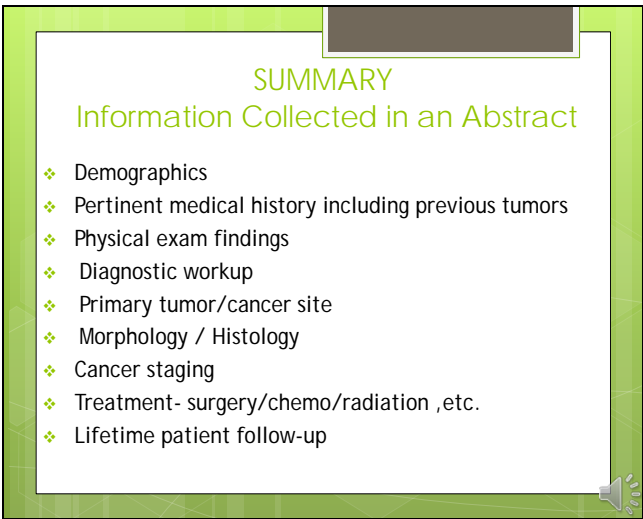
Where Do CTR's Work

- 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 - 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.



National Cancer Registrars Association

THANK YOU!



Acknowledgements

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