Texas Cancer Registry
Cancer Epidemiology and Surveillance Branch
Texas Department of State Health Services

Overview
Dwenda Smith, CTR
Trainer, Texas Cancer Registry
March 16, 2011
Who We Are

- The Texas Cancer Registry is a combination passive/active population-based surveillance system that collects, manages, analyzes, and disseminates Texas cancer incidence data.

- Done in accordance with the Texas Health and Safety Code, Chapter 82, Texas Cancer Incidence Reporting Act, established in 1979.

- One of 49 US state and territorial cancer registries that report cancer incidence data to and are funded by the Centers for Disease Control and Prevention (CDC), National Program of Cancer Registries (NPCR).

- Funded through the Centers for Disease Control, Department of State Health Services, and Cancer Prevention and Research Institute.
Who We Are

- **Vision**: A cancer-free Texas.

- **Mission**: To collect, maintain, and disseminate high quality cancer data that contribute towards cancer prevention and control, research, improving diagnoses, treatment, survival, and quality of life for all cancer patients.

- **Philosophy**: The TCR strives to:

  Maintain a high quality nationally certified statewide population-based cancer registry with complete, timely, and accurate data.

  Meet the data needs of Texans, including public health officials, healthcare practitioners, cancer researchers, health planners, advocacy groups, the public, and other local, state, and national entities.

  Make a significant contribution to the fight against cancer.
Who We Are

“Not everything that can be counted counts, and not everything that counts can be counted.”

—Albert Einstein
About Us

There are 51 full-time staff (46 DSHS, 5 contractors). 50% are CTRs.

In 2010, approximately 248,000 reports of cancer were received from over 500 cancer reporters located throughout the state.

99% of reporting is electronic.
What We Do

Major types of information collected:

- The occurrence of cancer
- The type, extent, and location of the cancer
- The type of initial treatment
- Key demographic information
- Patient vital status over time, and
- Cause of death
What We Do

Major sources of information:

- Hospitals
- Cancer treatment centers
- Clinical pathology laboratories
- Ambulatory surgery centers
- Supplemented by other sources of data, such as vital statistics
Texas Cancer Surveillance System
October 27, 2010

Legend:
- Green: Existing
- Yellow: Priority

*Scale: 1 being the most useful and 10 being the least useful.
Diagram based on CDC-NPCR-AERRO Scope Diagram.
What We Do

Serve a variety of customers at the local, state, and federal levels, including:

- Cancer researchers
- Academic institutions
- Health care providers
- Public health officials
- Other DSHS programs, state, and federal agencies
- Policy makers
- Advocacy groups, and
- The public
What We Do

Major activities include:

- Providing data for cancer research, cancer prevention and control planning, evaluation and educational programs.
  - Currently supporting 34 research studies, 20 of which are funded.
    - 50% are Texas researchers
  - 453 data requests, 386 from Texas customers (91%)
  - TCR data available on variety of state and national web sites.
What We Do

Major activities include:

- Providing data for cancer research, cancer prevention and control planning, evaluation and educational programs.
  - Limited use data sets available
  - Specialized data sets available upon request
  - In 2009, there were over 100 peer-reviewed journal articles published using TCR data.
What We Do

Major activities include:

- Investigating concerns of cancer excesses
  - Support 25-30 cancer cluster investigations per year conducted by Environmental Injury Epidemiology and Toxicology Unit

- Conducting epidemiologic studies
  - Impact of Race/Ethnicity on Cervical Cancer Survival

- Serving as a technical cancer data resource at the local and state levels, e.g.,
  - CERCIT, Breast Screening and Patient Navigation, Texas Breast Cancer Screening, Early Detection, Treatment and Outcomes Study, Texas Cancer Plan
Texas Cancer Registry

- Requested Citation: When Using Texas Cancer Registry Data
- Important Note: Change in Data for Rates
- TCR Data Release Policy: (doc, 61.5 KB)

Web Query Tool*
- Selectable Texas Cancer Incidence & Mortality Rates & Maps

Estimates of Cancer Cases and Deaths
- Expected Cases and Deaths

Selected Cancer Data Tables
- Childhood Cancer in Texas
- Top 10 Cancer Sites in Texas (xls, 26 KB)
- Incidence & Mortality Data for Texas

Selected Cancer Fact Sheets
- Texas (pdf, 32.6 KB)
  by County,
  by Health Service Region

Estimated Number of Persons Living with Cancer
- Estimated Cancer Prevalence

Research Data Files and Data Linkage
- Data files and linkage

*Important Note: The Web Query Tool link will take you to an external website. External links to other sites are intended to be informational and reference only. The Texas Cancer Registry makes no warranty as to the accuracy, completeness, or usefulness of any information at those locations.
What We Do

- Serving as a technical cancer data resource on national cancer registry scientific, standards, and operations committees:
  - NPCR-CDC Scientific and National Death Index Linkage Work Groups
  - North American Association of Central Cancer Registries (NAACCR) Board
  - NAACCR Data Use and Research Survival Work Group
  - NAACCR Scientific Editorial Board
  - NAACCR Data Standards and Evaluation Committee
  - NAACCR Registry Operations Committees
    - Data Items and Standards, Education, Automated Tumor Linkage, Electronic Pathology Reporting, Death Clearance
Program Distinctions and Recent Accomplishments

- One of the largest population-based registries in North America
- Bringing North American Association of Central Cancer Registries Annual Meeting to Austin, 2013
- Awarded $1.5 million over the next 3 years as 1 of 10 CDC Specialized Comparative Effectiveness Research (CER) Registries
  - Focusing on treatment effectiveness and patient outcomes
- Collaboration between the National Program of Central Cancer Registries and Office of Genomics at the Centers for Disease Control and Prevention, Agency for Health Research and Quality
Additional Data Collection

- Capture additional or higher quality data
  - Cancer staging
  - Treatment
    - focus specifically on colorectal and breast cancers, chronic myeloid leukemia
  - Biomarkers
  - Co-morbid conditions
  - Smoking history
  - Height, weight, occupation, vital status
  - Census tract or block characteristics
    - poverty, education, availability of healthcare professionals
  - Linkage with the Breast and Cervical Cancer Early Detection Program, National Death Index, Medicare and Medicaid Claims Data
Future of CER and the TCR

- Learn from experience
  - Costs and resources involved
  - Improving quality, quantity, availability, access, use of data

- Sustainability
  - Data linkages
  - Electronic reporting, use of electronic pathology and medical records

- Transfer of knowledge and experience in the registry community
  - Mentoring with other NPCR registries

- Benefit from ongoing partnerships with academic centers/researchers (CERCIT)
  - Filling critical knowledge gaps with new data sets, studies, training, data dissemination, special reports
History of Cancer Registration

- **1913** - Cancer Campaign Committee of the American College of Surgeons, Chicago

- **1932** - Connecticut State Cancer Registry

- **1932** - Yale-New Haven Hospital – first approved hospital cancer registry

- **1979** – Texas Cancer Registry established in Texas statute, funding eliminated in 1987, re-established in 1989
## Types of Cancer Registries

- **Central**
- **Geographical area- SEER**
- **Hospital**
  - May be approved by the American College of Surgeons Commission on Cancer
  - Specialty-Pediatric Cancers, Brain tumors
Who Are Cancer Registrars?

- Certified Tumor Registrars (CTR)
- Coders
- Health Information Management (HIM) Directors
- Transcriptionists
- Other staff designated to identify and report cancer data to the state
The Necessary Tools

- 2010 Texas Cancer Reporting Handbook
- Collaborative Stage Data Collection System Coding Instructions, (CSv-2) version 2.02.00.
- 2010 Hematopoietic and Lymphoid Neoplasm Case Reportability and Coding Manual
- 2010 Seer Program Manual
- 2007 Multiple Primary Histology and Coding Rules
The Cancer Registrar

- Develops a casefinding process for accurate case ascertainment
- Identifies casefinding sources
- Arranges access to these sources
- Reviews Disease Indexes monthly
- Reviews TCR Facility data reports
The Cancer Registrar

- Reviews TCR non-reportable list
- Identifies reportable cancers using list of reportable ICD-9 CM codes
- Maintains a list of non-reportable cancers
- Submits cancer data within six - nine months
- Runs numerous edits and resolves errors
- Conducts data quality studies and audits
Coding with ICD-O-3

International Classification of Diseases for Oncology

Third Edition

Editors
April Fritz
Constance Percy
Andrew Jack
Kangarathnam Shanmugaratnam
Leslie Sabin
D. Max Parvin
Sharon Whealn

World Health Organization
Geneva

Copyrighted Material
Differences Between ICD-O and ICD-9 or 10

- There are basic differences with ICD-O.
- The topography code describes the behavior of the neoplasm (malignant, benign, in situ, or uncertain whether malignant or benign).
- A specific range of codes identifies each of these types of behavior.
Differences Between ICD-O and ICD-9 or 10

- Very few histological types are identified in ICD-9 or 10
- For example, there is no way in ICD-9 or 10 to distinguish between an adenocarcinoma of the lung and a squamous cell of the lung: both would be coded to C34.9
Differences Between ICD-O and ICD-9 or 10

- ICD-O uses only one set of four characters for topography; so for example, the topography code (C34.9 for lung) remains the same for all neoplasms of that site.

- The behavior code incorporated in the 5th digit in the morphology field, identifies whether the neoplasm is malignant, benign, and so forth.
<table>
<thead>
<tr>
<th>Topography</th>
<th>Morphology</th>
<th>Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>C34.9</td>
<td>M-8010/3</td>
<td>Malignant neoplasm of the lung, such as carcinoma</td>
</tr>
<tr>
<td>C34.9</td>
<td>M-9061/6</td>
<td>Metastatic neoplasm of the lung, such as metastatic seminoma of the testis</td>
</tr>
<tr>
<td>C34.9</td>
<td>M-8070/2</td>
<td>In situ neoplasm of the lung, such as squamous cell carcinoma in situ</td>
</tr>
<tr>
<td>C34.9</td>
<td>M-8140/0</td>
<td>Benign neoplasm of the lung, such as adenoma</td>
</tr>
<tr>
<td>C34.9</td>
<td>M-8240/1</td>
<td>Uncertain behavior neoplasm of the lung, such as carcinoid of uncertain behavior</td>
</tr>
</tbody>
</table>
Quality Assurance

- TCR implements an extensive series of quality assurance procedures which consist of both internal and external processes to ensure reliability, completeness, consistency and comparability of TCR data.

- TCR data are evaluated as fit for use on an annual basis by the Centers for Disease Control and Prevention and the North American Association of Central Cancer Registries.
Internal QA Processes

- Submission review
  - Cases submitted electronically

- TCR data upload system checks all submitted abstracts for errors
  - Possible duplicate submissions
  - Invalid codes

- TCR staff review & resolve records with edit errors
External QA Processes

- Facility Training
- Casefinding Data Quality Audits
  - When a facility submits all cases for any given year
- Re-abstracting Data Quality Audits
  - Compare previous record to re-abstracted record
- Death Clearance
  - Electronically match TCR cases to Vital Statistics death records to identify missed cases
- Annual Calls for Data (certification process)
“Oh, if only it were so simple.”

© The New Yorker Collection 1987 Bernard Schoenbaum from cartoonbank.com. All rights reserved.
For more information on Texas cancer data or to make a request, contact:

Texas Cancer Registry
Texas Department of State Health Services
1100 W. 49th Street
Austin, Texas 78756
Mailing address: PO Box 149347, Austin, Tx 78714-9347
(512) 458-7523 –or- (800) 252-8059

Visit us on the Web:
http://www.dshs.state.tx.us/tcr