



# SC Central Cancer Registry

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Healthy People. **Healthy Communities.**

# Objectives

- Overview of SCCCR data collection
- Uses for the data
- Strengths/Limitations
- How to access data

# SC Central Cancer Registry

- Law passed in 1996 -SC Central Cancer Registry Act (reference date Jan. 1, 1996)
- All SC healthcare providers must report newly diagnosed cancer cases to DHEC
- Includes hospitals, path labs, freestanding treatment facilities, physicians who diagnose/treat cancer pts.
  - Example: Dermatologists, urologists, med oncologists
- Non-covered entity under HIPAA privacy rule
- Currently - 18 years of data housed in SCCCR

## state cancer registries

designed to... (from CDC NPCR website <https://www.cdc.gov/cancer/npcr/about.htm> )

- monitor cancer trends over time
- show cancer patterns in various populations & identify high-risk groups
- guide planning & evaluation of
  - cancer control programs
  - progress towards health objectives
- help set priorities for allocating health research
- advance clinical, epidemiological, and health services research
- provide information for a national database of cancer incidence

## state cancer registries

collect information about the occurrence of cancer (incidence) including  
- *but not limited to* - information related to...

- cancer diagnosis
  - type & location of cancer: primary site, histology, behavior, laterality
  - extent of cancer at diagnosis: stage, grade, tumor size, metastasis
  - first course of treatment: surgery, radiation, chemotherapy, etc.
- demographics: age, race, ethnicity, sex
- personal identifiers: name, SSN, date of birth, address (at Dx & current)
- hundreds of other variables to describe the cancer & treatment



# South Carolina Cancer Incidence Data



**Are the data credible to assess SC Communities?**

Data are Graded Annually:

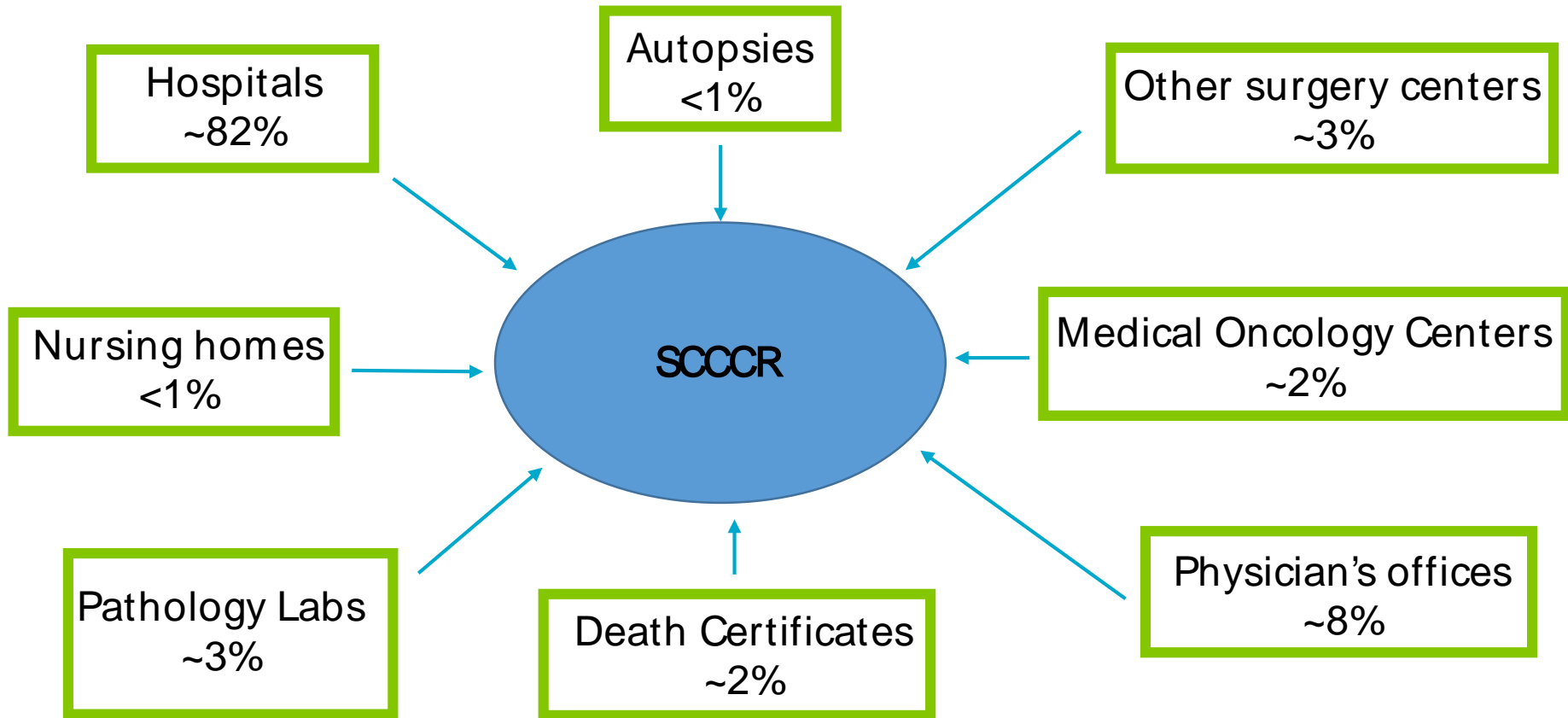
North American Association of Central Cancer Registries (NAACCR)  
CDC National Program of Cancer Registries (NPCR)

“Gold Certified” and a “Registry of Distinction” for data completeness, timeliness, and quality (97.2% complete Case Ascertainment)

80% of the cases are collected by hospital cancer registries (CTRs) and reported electronically, we collect remaining 20% from small hospitals, pathology labs, freestanding treatment centers, and physician offices – case information comes from pt. medical record. Extensive national standards in place for all data collection

**Answer is Yes!**

## Where do the data come from ?

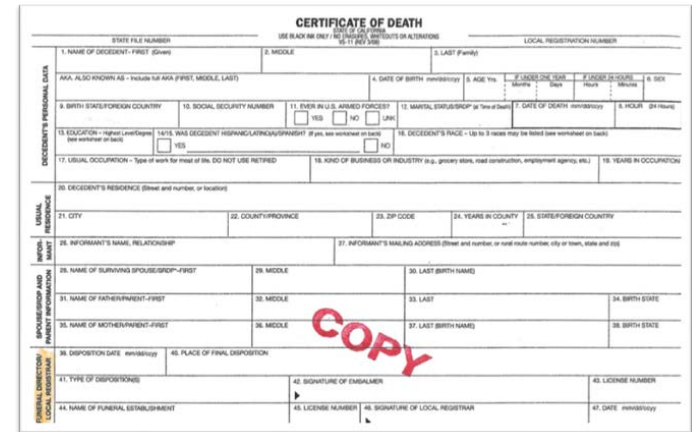


# South Carolina Cancer Mortality Data

ALL deaths are systematically reported to DHEC Vital Records by state law - Cancer deaths are pulled for SCCCR analysis

Any cancer deaths identified that have not been reported as an incident case are followed back to clinical source to determine date of diagnosis and confirm the cancer and add to the registry as a 'missed case' (process is called Death Clearance)

So, the death data are reliable to evaluate SC communities



The image shows a 'CERTIFICATE OF DEATH' form from the South Carolina Department of Health and Environmental Control. The form is divided into several sections: DECEASED'S PERSONAL DATA, DECEASED'S RESIDENCE, DECEASED'S MARRIAGE AND SPONSORSHIP AND BURIAL INFORMATION, and DECEASED'S FUNERAL INFORMATION. A large red 'COPY' stamp is overlaid on the bottom right portion of the form. The form includes fields for name, date of birth, social security number, education, occupation, residence, and funeral arrangements.



# Uses for our data

- Patient contact studies
- Epidemiologic research: ex. case control studies
- Data linkages for research studies
- Statewide cancer control planning and intervention
- “Suspected” cancer cluster statistical assessments
- Health care policy and decision making
- National Cancer Data Sets

# Types of Data Release

- Aggregate and Confidential Data Release
- Protocol for Release of Confidential SCCCR Data  
<http://www.scdhec.gov/Health/DiseasesandConditions/Cancer/CancerStatisticsReports/DataRelease/>
- All requests for confidential data release must come to SCCCR with IRB approval

# Aggregate data

- Plan for grant proposals, policy development and proposed changes, and program assessment
- Assessment of excess cancer occurrence and deaths for SC communities (Community Cancer Assessments) due to cancer concerns
- State Cancer Plan objectives, baseline data, and evaluation
- State Cancer Profiles Website, ACS Cancer Facts & Figures, CINA, Cancer in 5 Continents (CI5), NPCR National Data Set

SCAN (<http://scangis.dhec.sc.gov/scan/>)

# Data Linkage Studies, Example

- World Trade Center Health Registry
  - WTCHR was established to evaluate and monitor the long-term health consequences of those affected by the world trade center disaster on September 11, 2001.
  - Includes rescue/recovery workers and persons who worked, lived or attended school in lower Manhattan
  - To study the WTC-related exposures associated with cancer incidence and to see if there is evidence of excess cancer incidence among WTCHR registrants.

# Patient Contact Studies, Example

- Osteosarcoma Surveillance Study – Post Marketing Research (req. by FDA)
  - RTI (Research Triangle Institute) is contracted by the pharm company Eli Lilly to systematically monitor Forteo (a drug used to treat osteoporosis) exposure in osteosarcoma patients and to study the prevalence and medical factors of osteosarcoma in adults ages 40 and older.
  - Quarterly release of newly diagnosed osteosarcoma patients from SCCCR, to RTI for their Osteosarcoma Surveillance Study, to determine if any incident osteosarcoma cases have a history of Forteo treatment and to collect additional patient information and data related to other exposures.

# Epidemiologic Research, Example

- Utilization of radiotherapy for H&N cancer as first course treatment
  - This study conducted by MUSC medical student analyzed the rate of utilization, the timeliness (after diagnosis), and the total package time of indicated radiotherapy to determine if these factors impact overall survival.
  - Used distance to nearest oncology center to assess disparities

# SCCCR Data Strengths

- Statewide Population-based Cancer Incidence Database with 18 years of data
- Consistently awarded high levels of excellence by NAACCR and CDC as 'gold or silver certified' since 1997
- All data that are critical for measuring completeness of incidence at state/county/race/sex levels are examined in the certification process, so there are minimal 'missing' data variables

# SCCCR Data Limitations

- Currently 1996-2013 data available (2014 soon) -  
*24-month lag time to complete data collection, processing, case consolidation, de-duplication, death clearance, and quality control of cases, so that incidence is of high quality and counted correctly; this is the national standard for cancer data. National discussions about 'real-time reporting' of cancer cases to expedite data use*
- Lack of some popular research variables – comorbidities; smoking and alcohol history, etc.



# Obtaining access to data

- SCCCR data application with on-line instructions and helpful hints for researchers
- <http://www.scdhec.gov/Health/DiseasesandConditions/Cancer/CancerStatisticsReports/DataRelease/>
- DHEC IRB application
- Data Use Agreement
- Fees (if applicable)

# Ways to Expedite Timeline

- Read all documents in full
- Submit draft data application (ask only for data variables that are justified in protocol)
- Review edits with SCCCR staff, then submit final app
- Review by Cancer Control Advisory Committee – Surveillance Subcommittee (CCACSS) – if required
- Once approved , sent to DHEC IRB

**In total, 4-6 weeks for less complex requests. Longer for those requiring CCACSS review, or linkages**



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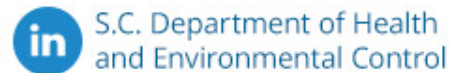
# CONTACT US

[www.scdhec.gov](http://www.scdhec.gov)

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## Stay Connected

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# **HEALTH DATA SYMPOSIUM**

**Break**

**Resume at 10:50**