The Georgia Cancer Registry –
A State’s Perspective

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GCCS is a surveillance research unit within the Department of Epidemiology of the Rollins School of Public Health.
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Georgia Center For Cancer Statistics
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EMORY SCHOOL OF PUBLIC HEALTH
Registry Structure

Georgia Center for Cancer Statistics

- Surveillance Activities
- National and International Training
- Research / Special Studies
GA Surveillance History

Atlanta SEER - 1975
GA Surveillance History

Atlanta SEER - 1975
Rural GA SEER - 1978
GA Surveillance History

Atlanta SEER - 1975
Rural GA SEER - 1978
GCCR (NPCR)- 1995
GA Surveillance History

Atlanta SEER - 1975
Rural GA SEER - 1978
GCCR (NPCR)- 1995
Greater GA SEER - 2010
Data Collection

Strength of U.S. Cancer Surveillance System

NAACCR Record Layout

(www.naaccr.org/StandardsandRegistryOperations/VolumeII.aspx)
## Data Collection

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Data Collection

Incidence

AND

Survival

Mortality Data from GA Vital Records
Data Collection (Incidence)

- **Sources of Data**
  - Medical records in:
    - Hospitals
    - Clinics
    - Pathology laboratories
    - Radiation therapy centers
    - Medical oncology centers
    - Nursing homes/hospices
    - Physician offices
  - Death certificates

- **Data Exchange**
  - Encrypted Electronic Submission in NAACR Format by Hospital Registrars
  - Encrypted Electronic Submission in NAACR Format by Contract Staff
  - Encrypted Electronic Submission in HL7 Format (Pathology)
  - Other: Paper Pathology, Short Records, Death Certificates, Registry Access to EMR, etc.
Data Collection (Survival)

• Sources of Data (primarily linkages)
  – Death Certificate Data (state and NDI)
  – Center for Medicare and Medicaid Services
  – Social Security Administration
  – Voter Records, Birth Records
  – Physicians
  – Hospitals
  – Others
Variables Collected and Reported
(Reference Handout)
State Cancer Registry Responsibility

- **Visual Editing**
  - Ensure text supports coded data

- **Case Consolidation**
  - Merge data on the same cancer from multiple sources to create the most complete record regarding diagnosis, staging and treatment

- **Data Editing**
  - Perform quality control of the submitted and consolidated data
Data Quality Control

• GA Edits for Reporting Sources
• SEER Edits
• NPCR Edits
• NAACCR Edits
• Audits (Case-finding and Re-abstraction)
• Extensive internal quality control reports
• Completeness evaluated by all Programs
Cautions in Data Use

• Timing of the Data Collection and Release
  – Approximate 2 year delay
  – (90% complete w/in 1 year)

• Under ascertainment of selected cancers
  – Diagnosed and treated in physicians offices only

• Identification & counting of cancers over time
  – ICD-O
  – Multiple Primary Rules

• Location of patients (address at diagnosis)
Data Access in Georgia

Legal authority for the Georgia Department of Community Health to collect health information is provided in Chapter 12 of the Official Code of Georgia. Official Code 31-12-1 empowers the Department to “…conduct studies, research, and training appropriate to the prevention of diseases….” Official Code 31-12-2 allows the Department to declare certain diseases and injuries to be reported in a manner and at such times as may be prescribed. Under this authority, information on persons with cancer is required to be reported to the Department or its designated agent.
Data Access in GA

- De-identified data available through SEER*Stat, the GCCS Website or the DCH (State’s) website
Data Access in Georgia

I. Studies involving direct patient contact
II. Studies not involving direct patient contact
   – Individual records for investigator to analyze
   – Linkage studies

Currently no cost with any approach
All require investigator institutional and State IRB approval plus signed Data Use Agreement
Data Access in Georgia

- Studies involving direct patient contact
  - Require physician notification if prospective
  - Left to the discretion of the IRB if retrospective
  - Initial patient contact must come from the registry

Time limiting step in data access is IRB approval