Orientation to NAACCR and Cancer Surveillance

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Executive Director
NAACCR, Inc.
North American Association of Central Cancer Registries

- Collaborative umbrella organization for
  - cancer registries (all in US and Canada)
  - governmental agencies (NCI, CDC, PHAC)
  - professional associations (ACS, ACoS, AJCC, CAP, CPAC, NCRA)
  - individuals interested in enhancing the quality and use of cancer registry data.
Mission

• promotes uniform data standards for cancer registration;
• provides education and training;
• certifies population-based registries;
• aggregates and publishes data from central cancer registries;
• promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care
• to reduce the burden of cancer in North America.
Governance

• Governed by Board of Directors
  – Central registry directors, Sponsoring agency
• 9 full-time staff
• Most work done by committees of volunteers from member registries or organizations
• Funding through grants and contracts, mostly federal dollars
Cancer Surveillance

• Systematic collection of cancer incidence and related data in a defined population
  – Standard definitions (cancer, multiple primaries)
  – Standard codes
  – Standard application of rules

• Cancer Surveillance is most sophisticated and complete disease surveillance system in North America
National Cancer Surveillance Partners

• Centers for Disease Control and Prevention- National Program of Cancer Registries
• National Cancer Institute-SEER Program
• American Cancer Society
• American College of Surgeons
• National Cancer Registrars Association
Authority/Timelines

- Reportable disease in every state and province
- Cancer Registries Amendment Act
- Reportable within 6 months of diagnosis—usually longer
- Most data from (hospital) medical records -
  - If it is not in the medical record, it won’t be in a Registry
Types of Cancer Registries
Hospital or Cancer Center Registries

• Hospital or Cancer Center Registry
  – Collects data on patients seen at their facility only
  – Not population based
  – Skewed by location/demographics, medical specialties,
  – May be approved by American College of Surgeons (or not)
  – Not in every hospital
Types of Cancer Registries

Central Cancer Registries

- Collects data on all residents of an area (State, region, province)
- Is population based
- Not biased, and appropriate for research uses
- Compiles data from all sources
- Obtains information from other states
- Submissions come from hospitals and other sources
Data Basics

- Demographics: age, sex, race, ethnicity, residence at diagnosis (geo-coded), vital status
- Medical: primary site, laterality, morphology, stage, some tumor markers, co-morbidities
- Treatment: First course only
- Multiple primaries concurrent and over time
Data Collection

• Primary data source: abstracted information from hospital medical record
  – 5,000 CTRs
• Other sources: Electronic pathology data, independent laboratories, physicians, free-standing surgi-centers, radiation clinics, discharge data etc....
• Death certificates
Data Processing in a Central Registry

- Matching
- Consolidation
- Visual Review and Verification
- Editing
- Linking (Vital status, IHS, etc.)
- De-duplicating
- Merging cases from out of state
- Submission to national partners
NAACCR Certification Criteria

- Completeness of case ascertainment
  - 95% for gold
  - 90% for silver
- Passing EDITS and inter-record EDITS
  - 100% for gold
  - 97% for silver
- Percent DCO cases
  - <=3% for gold
  - <=5% for silver
Certification Continued

• Timeliness
  – Within 23 months
• Rate of duplicate cases
  – <=1/1,000 for gold
  – <=2/1,000 for silver
• Missing data field
  – Sex, age, county
    • <=2% for gold
    • <=3% for silver
  – Race
    • <=3% for gold
    • <=5% for silver
2010 Canada and U.S. Certification
National Data Sets

• No Centralized Registry
• National Cancer Data Base-
  – Data submitted from ACoS approved facilities only
  – No identifiers used, de-duplication by algorithm
  – Not population based
  – From bigger cancer centers
  – Cannot identify individuals for follow-up or interview
US Databases

• SEER/NCI
  – Since 1973, high quality, 26% of US pop., state and metro areas, some special populations, follow up and survival data

• CDC/National Program of Cancer Registries
  – Since 1995, nearly all states (excludes some SEER states), broader coverage, shorter time period, less rigorous standards
### Aggregate Data Availability

<table>
<thead>
<tr>
<th>Source</th>
<th>Years Covered</th>
<th>US Population Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEER</td>
<td>1975 – 2008 (33 years)</td>
<td>10%</td>
</tr>
<tr>
<td>United States Cancer Statistics (NCI, CDC, NAACCR)</td>
<td>1998 – 2007 (10 years)</td>
<td>84%</td>
</tr>
<tr>
<td>United States Cancer Statistics (NCI, CDC, NAACCR)</td>
<td>2003 – 2007 (5 years)</td>
<td>97%</td>
</tr>
<tr>
<td>United States Cancer Statistics (NCI, CDC, NAACCR)</td>
<td>2004 – 2006 (3 years)</td>
<td>100%</td>
</tr>
</tbody>
</table>
NAACCR Data Set

- Includes SEER, NPCR, and Canadian Registries
- Since 1995
- 97% of US population
- Certification Standards used in publications and standardized data sets
- Web-based applications available
- Research data bases available to members
NAACCR’s Role in Research (External)

• Provide opportunities for external groups to work with Registries
• Town Hall Meetings
  – In-person Meetings
• Facilitate IRB approvals
• Facilitate collaboration among Registries
  – Newsletter
  – Presentations
For Consideration

• Residence information
  – No residential history
  – Exposure/latency problems
  – Migration issues

• Data may be available for recent time periods only

• Geocoding to different standards, differing degrees of certainty

• Confidentiality and Multiple IRBs
Questions?