Enhancing Cancer Registry Data for Comparative Effectiveness Research
An Introductory Webcast
Presented by the Florida Cancer Data System (FCDS) and the Florida Department of Health (DOH)
December 13, 2011

Discussion Outline

- Program Introduction
- Project Staff
- CER Data Collection
- CER Facility Survey
- Clarification of Reporting Roles
- Examples of Model Collaboration
What is Comparative Effectiveness Research?

- An approach to identify the best treatment procedures and strategies based on recorded patient outcomes
- Funded by the American Recovery and Reinvestment Act, the project provides a unique opportunity to expand current data collection for specific cancers
- The goal is to obtain detailed data to address questions targeting colorectal cancer, breast cancer, and chronic myeloid leukemia patients

Florida

- Department of Health application
  - 1 of 10 states funded
- Innovative design
  - Extensive utilization of electronic data streams
- Facilities should have little additional work apart from helping FCDS navigate the facilities and identify key personnel in select departments/offices

Key CER Personnel - Florida

**Florida Department of Health**
- Dr. Youjie Huang, Director of Cancer Reg. Ops. and CER PI
- Tara Hylton, Cancer Epidemiologist
- Jason Feldman, CER Project Coordinator

**FCDS**
- Dr. Jill MacKinnon, FCDS and CER Project Director
- Dr. Monique Hernandez, CER Project Manager
- Steve Peace, Manager for QC and Education
- Mike Thiry, Manager for Data Acquisition
Project Details

- Cases
  - Diagnosed in 2011 only
- Primary sites
  - Breast, Colorectal and CML
- Regions
  - Miami-Dade, Broward, Palm Beach, Orange and Hillsborough Counties
- Project Period:
  - December 2010 – September 2013

Targeted CER Questions

- Are colorectal cancer patients tested for KRAS and are the results used appropriately to determine treatment? What impact does KRAS testing have on 2-3 year survival among colorectal cancer patients?
- Are rectal cancer patients receiving radiotherapy and what is the timing of radiotherapy? Are disparities apparent in the appropriate neo-adjuvant use of radiotherapy among these patients?
- Are chronic myeloid leukemia (CML) patients being tested for the BCR-ABL2 gene and receiving appropriate treatment according to those results?
- Are women with breast cancer being tested appropriately for HER2, progesterone receptor (PR), and estrogen receptor (ER) status and treated appropriately?

Data Collection

- Planning since June 2010
- Innovative ideas for data gathering
  - Combination of electronic data streams hoping to minimize manual data collection
- Developed tools
  - Florida alone
  - All CER states collectively
The CER project requires comprehensive cancer data collection involving standard data items routinely collected by cancer registries, as well as additional non-standard data items. These additional data items are specific to the CER project and have not been previously collected through NPCR, SEER or COC nor have they been included in the Standard NAACCR Data Dictionary or in FORDS.

Non-Standard Data Items Categories:
- Socio-Economic Status
- Patient Work Up
- Chemotherapy
- Hormone Therapy
- Biological Response Modifiers
- Bio-Markers
- Comorbidities

Data Sources:
- Hospitals
- Physician offices
- Pathology laboratories
- RT/AS facilities
- AHCA discharge summaries
- Vital Statistics
- National Death Index
- Census
- Medical claims
- Medicare
- Medicaid

Active Data Collection

Passive Data Collection
CER Facility Survey

- A brief online survey has been developed to gather operational information about data collection specific to each facility.
- The survey can be accessed at the following site: https://www.surveymonkey.com/s/CER_Hospitals
- Information about survey participation was also sent by email to administrators and registry supervisors.

Facility Involvement

- FCDS has hired three experienced Certified Tumor Registrars to complete the data collection for this project.
- These CER CTRs are assigned to specified counties.
- Facilities should have little additional work apart from helping FCDS navigate the facilities and identify key personnel in select departments/offices.
- Prioritization of CER sites when possible.
- No effect on existing contracts with independent abstractors.

CER Outreach
Quality Control Coordinators

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<thead>
<tr>
<th>CER Outreach QC Coordinator</th>
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Data Sharing with Facilities

- Complete, specific first course treatment details
- Last date of contact
- Other?

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Clarification of Reporting Roles

- Florida Statute: 385.202 Statewide cancer registry states that:
  - Each licensed facility and each freestanding radiation therapy center shall report the diagnosis, stage of disease, medical history, laboratory data, tissue diagnosis, and radiation, surgical, or other methods of diagnosis or treatment for each cancer diagnosed or treated by the facility or center.

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Examples of Model Collaboration

- Navigational help needed to complete data collection
Contact Information

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Thank You. Questions????