Enhancing Cancer Registries for Comparative Effectiveness Research: A CDC/NPCR Approach

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Overview

ICF was awarded this project as a primary contractor for the Centers for Disease Control and Prevention (CDC) through funding from the American Recovery and Reinvestment Act of 2009 (ARRA). The purpose of the project is to establish Specialized Cancer Registries by enhancing data collected through a subset of NPCR-funded central cancer registries for Patient-Centered Health Research (also called Comparative Effectiveness Research or CER). Outcomes will include a dataset to be used for comparative effectiveness and other research. Activities performed under the project include:

- Additional data collection
- Training and methodological development
- Expansion of electronic reporting
- Pilot testing of innovative public health applications for cancer registries, with the goal of developing sustainable methods to enhance cancer registry data

Targeted CER Questions

Project activities will permit a more detailed evaluation of the four initial CER questions identified by CDC along with the Agency for Healthcare Research and Quality and CDC Office of Genomics. These questions are:

- 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 are they receiving appropriate treatment according to those results?
- Are women with breast cancer being tested appropriately for HER2, progesterone receptor, and estrogen receptor (ER) status and being treated appropriately?

Activities Being Performed by CDC

CDC staff members are active participants in this project. For example, CDC will:

- Provide dataset with area-based demographic characteristics for use by registries for linkage
- Provide data dictionary of definitions, codes, and structure for new data items
- Provide edit sets for ensuring data completeness and validity
- Develop Data Submission Specifications which will include descriptions of all variables to be submitted; for what diagnosis years; and the dates of submission
- Provide technical guidance on best practices for data collection and data linkage
- Review and comment on ICF and central registry protocols and reports
- Provide access to and support of NPCR software (Abstract Plus, eMaRC Plus, Link Plus and Web Plus) as needed by registries; CDC will update the Registry Plus products with the additional data items and edits required for CER
- Provide input and technical assistance to registries, including site visits to evaluate progress

Activities Being Performed by Specialized Cancer Registries

Participating Specialized Cancer Registries are performing a series of tasks with specific benchmarks:

- Data collection, including collecting required NPCR Cancer Surveillance System data for cases diagnosed in year 2011 and new data items for CER data collection, including the following:
  - Cancer staging
  - Data on biomarkers
  - Race/ethnicity, place of birth
  - Co-morbid conditions
  - Smoking history
  - Height, weight, occupation, vital status
  - Detailed information on systemic treatment regimen/drugs
    - Dose planned and received
- Expanded and sustainable data data-linkage activities
- Increased electronic laboratory reporting for improved data quality, completeness, and timeliness, including reporting from non-hospital sources, and e-reporting from clinical and pathology laboratories
- Enhanced education and training efforts

Overall CER Project Timeline

2010
- Call for State proposals
- Review and selection of specialized cancer registries
- Establish subcontracts

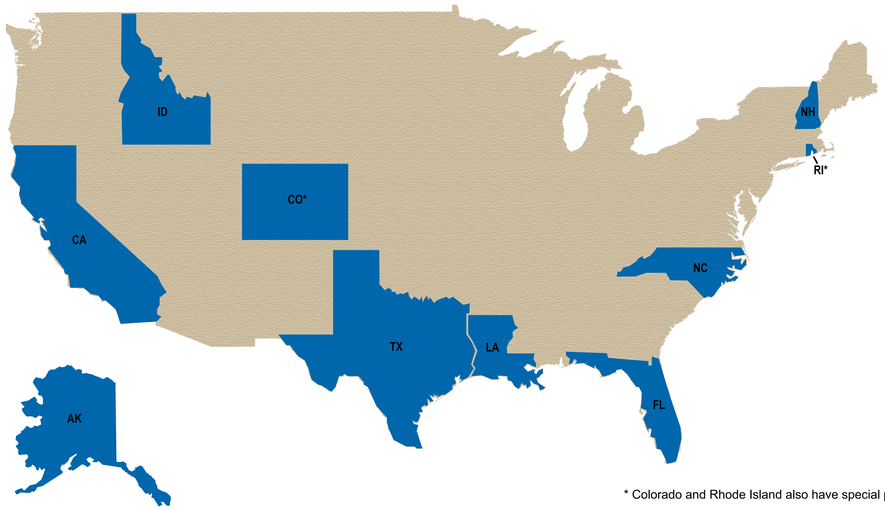
2011
- Develop protocols and methodologies for new data elements
- Training of data collectors
- Collect data
- Identify, recruit, and implement electronic reporting in laboratories and facilities
- Share best practices across registries

2012
- Perform data linkages
- Continue implementation of electronic reporting
- Develop IT infrastructure for data transmission and quality control
- Continue collecting data
- Submit pilot data in November 2012

2013
- Submit data in January 2013
- Prepare project/dataset documentation
- Create dataset for submission to RDC
- Final report of activities and outcomes

Selected Specialized Cancer Registries in Core CER Project

Through an open and competitive process, 10 NPCR central cancer registries were selected to participate in the Core CER Project as Specialized Cancer Registries. These registries represent a diverse group of NPCR-funded central cancer registries in terms of registry type, caseload, capacity and experience, geographic distribution, and underlying population. See the map below for their distribution.



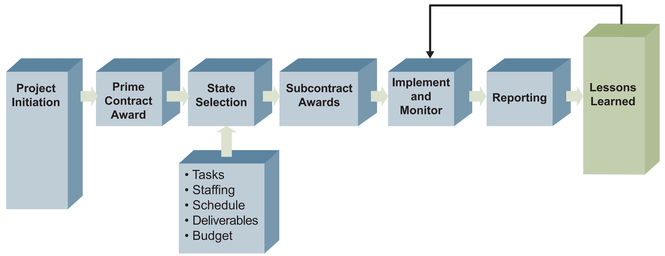
* Colorado and Rhode Island also have special projects.

Activities Being Performed by ICF

As CDC's primary contractor for the CER project, ICF provides contract administration and technical assistance support for the funded Specialized Cancer Registries:

- **Contract Administration**
  - Establishing a mutually agreeable subcontract with each funded state
  - Identifying, in collaboration with CDC, appropriate performance criteria for subcontracts
  - Monitoring cancer registry compliance with all CDC requirements
  - Managing the submission of quarterly ARRA reports
- **Technical Assistance**
  - Supporting cancer registries in the identification, recruitment, and implementation of electronic reporting by laboratories and EHRs
  - Provide necessary data utilities to facilitate the data submission; these utilities may include, but are not limited to, data extraction, editing, conversion, and recoding programs
  - Facilitating the sharing of best practices across registries and developing standard protocols for activities performed by multiple registries
  - Providing the IT infrastructure necessary to facilitate data transmission, quality control, and processing
  - Consulting on data linkage and methodology development

CER Management Process



CER Comparative Effectiveness Research CDC·NPCR SPECIALIZED REGISTRY

For more information about the project, please contact:

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