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

CDC: Christie Eheman, PhD • Dave Butterworth, MPA • Frances Micheaud, CTR • Linda Mulvihill, RHT, CTR • Castine Verrill, MS, CTR • Joan Phillips, CTR

CDC Contractor: Jen Wike, MBA, MPH

ICF: Kevin Zhang, PhD • Syvella J. Kirby, PMP • Aliza Fink, PhD

Overview

ICF was awarded this project as a primary contractor to 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 collection through a subset of NCI-funded central cancer registries for Patient-Centered Comparative Effectiveness research. This is being done to allow for comparative effectiveness research and other activities, and the project is planned to be just under four years of full support.

Project activities include the following:

- Activities Being Performed by ICF
- Activities Being Performed by CDC
- Targeted CER Questions
- Initial Data Collection
- Enhanced Data Collection
- Data Submission
- Data Transmission
- Data Processing
- Data Quality Control
- Data Linkage
- Final Report

Activities Being Performed by ICF

- Provide necessary data utilities to facilitate the data submission; these utilities may include, but are not limited to, data extraction, editing, validation, and data transmission.
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- Develop protocols and methodologies for new data elements.
- Provide technical guidance on best practices for data collection and data linkage.
- Provide necessary data utilities to facilitate the data submission; these utilities may include, but are not limited to, data extraction, editing, validation, and data transmission.
- Facilitating the sharing of best practices across registries and developing standard protocols for activities performed by multiple registries.

Activities Being Performed by CDC

- 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 CDC data collection, including the following:
  - Cancer staging
  - Race/ethnicity
  - Residence
  - Marital status
  - Occupation
  - Smoking history
  - Height, weight
  - Blood pressure
  - Underlying cause of death
  - EHR
  - ED
  - Global position system (GPS)
  - Temperature
  - Blood tests
  - Radiation therapy
  - Chemotherapy
  - Additional education and training efforts

Activities Being Performed by Specialized Cancer Registries

- Providing edit sets for ensuring data completeness and validity.
- Developing data linkage strategies.
- Establishing and maintaining data repositories.
- Sharing best practices.
- Providing technical assistance to registries.
- Developing and implementing data transmission and processing.
- Developing and implementing data quality control.
- Developing and implementing data linkage protocols.

Targeted CER Questions

- Are breast cancer patients being treated appropriately for HER2 status and patient characteristics?
- Are colorectal cancer patients tested for KRAS and used in clinical decision making?
- Are chronic myeloid leukemia (CML) patients being treated for the BCR-ABL1 gene and are they receiving appropriate treatment according to their risk?
- Are women with breast cancer being tested appropriately for HER2, progesterone receptor, and estrogen receptor (ER) status and patient characteristics?
- Are rectal cancer patients receiving radiotherapy and what is the timing of radiotherapy? Are disparities apparent in the appropriate use of radiotherapy?

Initial Data Collection

- Initial data collection included:
  - Cancer staging
  - Race/ethnicity
  - Residence
  - Marital status
  - Occupation
  - Smoking history
  - Height, weight
  - Blood pressure
  - Underlying cause of death
  - EHR
  - ED
  - Global position system (GPS)
  - Temperature
  - Blood tests
  - Radiation therapy
  - Chemotherapy
  - Additional education and training efforts

Enhanced Data Collection

- Enhanced data collection includes:
  - Additional data collection to enhance cancer registry data items for CER data collection, including the following:
    - Cancer staging
    - Race/ethnicity
    - Residence
    - Marital status
    - Occupation
    - Smoking history
    - Height, weight
    - Blood pressure
    - Underlying cause of death
    - EHR
    - ED
    - Global position system (GPS)
    - Temperature
    - Blood tests
    - Radiation therapy
    - Chemotherapy
    - Additional education and training efforts

Data Submission

- Data submission includes:
  - Submitting data to RDC in November 2012

Data Transmission

- Data transmission includes:
  - Final report of activities and outcomes

Data Processing

- Data processing includes:
  - Establishing and maintaining data repositories.
  - Sharing best practices.
  - Providing technical assistance to registries.
  - Developing and implementing data transmission and processing.
  - Developing and implementing data quality control.

Data Quality Control

- Data quality control includes:
  - Providing edit sets for ensuring data completeness and validity.
  - Developing data linkage strategies.
  - Establishing and maintaining data repositories.
  - Sharing best practices.
  - Providing technical assistance to registries.
  - Developing and implementing data transmission and processing.
  - Developing and implementing data quality control.

Data Linkage

- Data linkage includes:
  - Establishing and maintaining data repositories.
  - Sharing best practices.
  - Providing technical assistance to registries.
  - Developing and implementing data transmission and processing.
  - Developing and implementing data quality control.

Final Report

- Final report includes:
  - Submitting data to RDC in November 2012
  - Final report of activities and outcomes

CER Management Process

For more information about the project, please contact:

Dave Butterworth, MPH • Project Manager • (770) 488-1930 • DButterworth@cdc.gov
Christie Eheman, PhD • Senior Chair • (770) 488-0610 • CEheman@cdc.gov
Frances Micheaud, CTR • Deputy Senior Chair • (770) 488-4578 • FMicheaud@cdc.gov

Syvella J. Kirby, PMP • ICF Project Manager • (404) 882-2013 • skirby@icf.com
Kevin Zhang, PhD • ICF Project Director • (919) 467-8708 • kzhang@icf.com

Selected Specialized Cancer Registries in Core CER Project

Through an open and competitive process, 16 NPCR-funded 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 cancer registries in terms of registry type, caseload, capacity, and experience, geographic distribution, and underlying populations. See the map below for their distribution.