Developing an Information-Sharing Portal for Comparative Effectiveness Research: An ICF Approach

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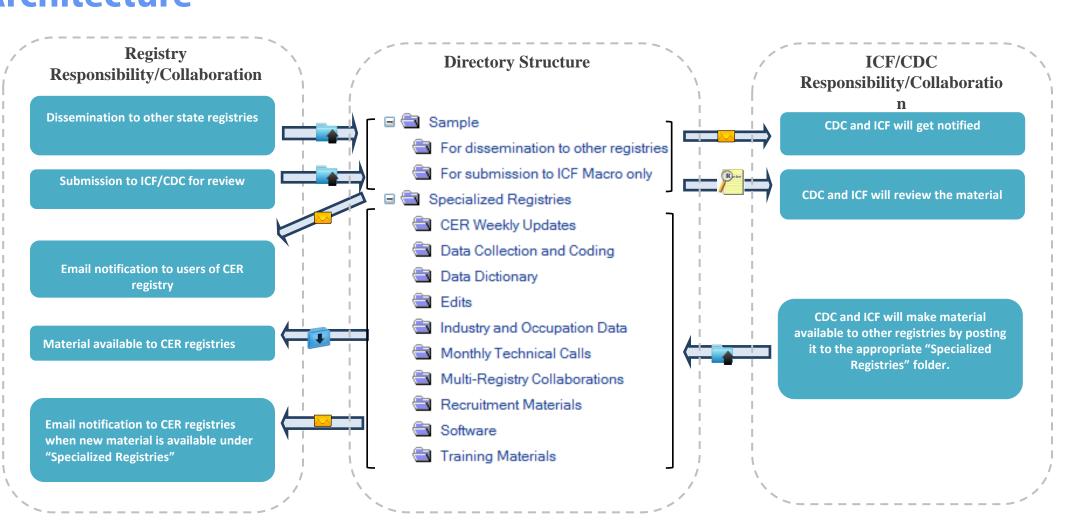**ICF International, Fairfax, VA**

Background of CER Project

- American Recovery and Reinvestment Act (ARRA) funded activities to enhance cancer registry data collection for Comparative Effectiveness Research (CER).
- CER data infrastructure activities include enhancing (1) distributed data networks, (2) longitudinal linked Electronic Health Record (EHR) databases and (3) patient registries.
- Provide an opportunity for central cancer registries to collect data to address targeted CER questions.
- NPCR-CER funding established Specialized Cancer Registries through a subset of NPCR-funded central cancer registries for Patient-Centered Health Research.
- The special projects were selected to develop methods for innovative uses of cancer registries and cancer registry data to improve health outcomes among cancer patients. CCR identified activities and mechanisms where cancer registry data would be used to support the enhancement of clinical outcomes and facilitate the establishment of formal relationships.
- Outcomes 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

CER Information Sharing Portal – How?

- The CER Information Sharing portal has been structured to allow different levels of access:
  - CDC – "Management" access that allows dissemination of training materials and central guidance controlled by key CDC project team staff.
  - CER Registries – Registry-specific, secure folders allow CDC to provide secure and private information exchange with participating registries.
  - Methods are available to facilitate knowledge and information exchange across the registries, helping to resolve issues faced across the project.
  - ICF – Administrative, tracking and notification functionality allows ICF project staff to provide technical assistance and support the CER registries in timely manner.
- The portal provides management and tracking for support requests so that generic technical questions later become FAQ s and are available to all CER registries under the same portal.
- The centralized portal for registered users have access to the dashboard that displays an event calendar and important notifications.

Architecture

Main Features and Functions

Home/Event Announcement

Upon login, the home page contains announcements of newly uploaded content as well as upcoming events and meeting dates.
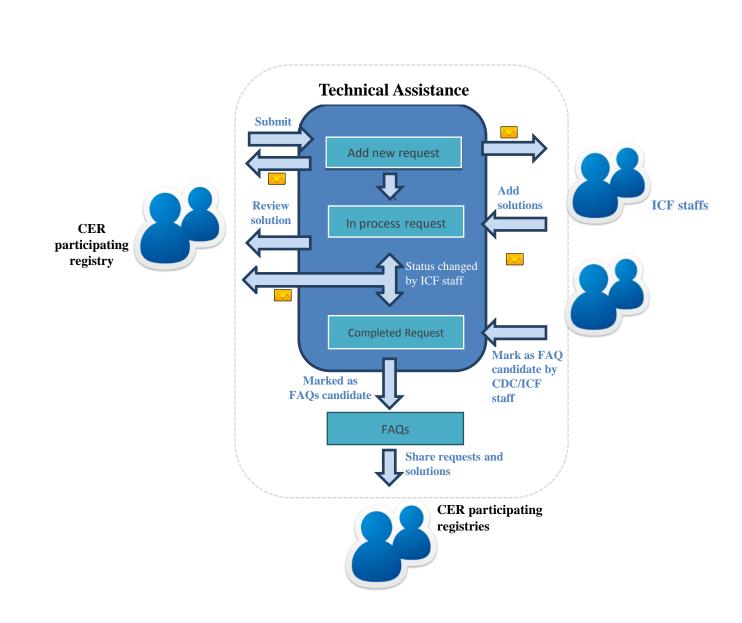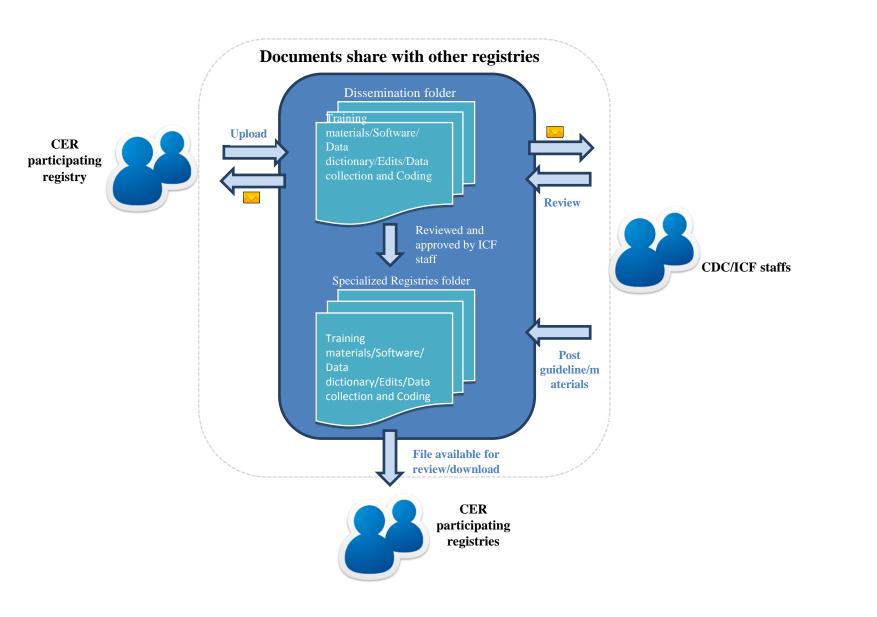

Technical Assistance

The CER participating registries submit technical assistance requests which are then reviewed by CDC and ICF staff. CDC and ICF then add the solution to the pending request for the registry to review. If CDC or ICF believe the request to be very useful, the request is then tagged as an FAQ candidate, which is then passed on to the FAQ page in order to quickly and easily share the information with other CER participating registries.
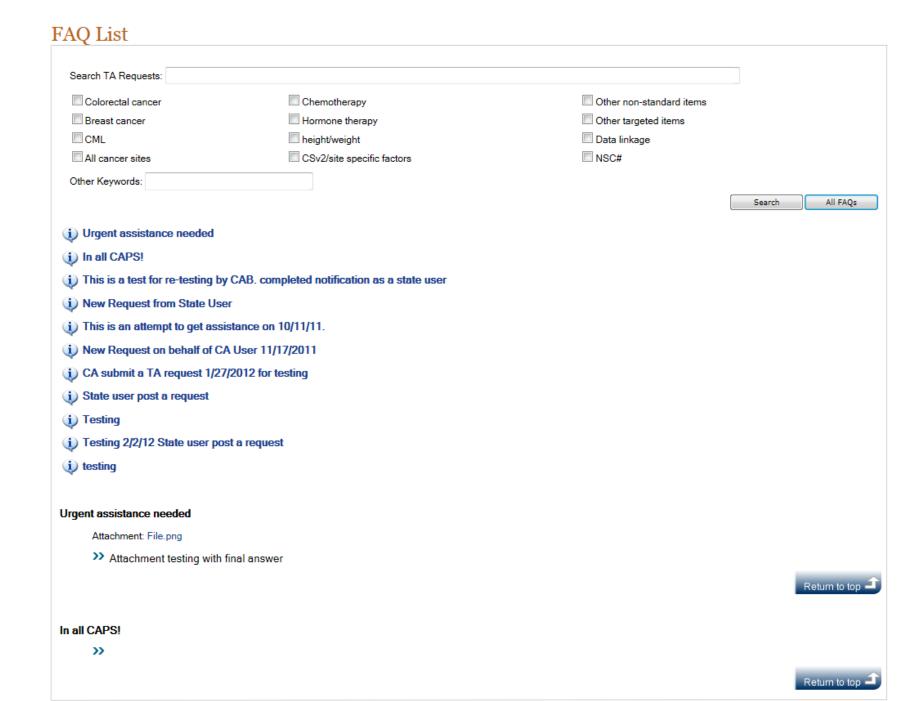

Document Sharing

Each state registry can upload documents to the Dissemination folder within their own registry, to share with other registries. CDC and ICF staff then review the documents from the Dissemination folder and move them to the appropriate Specialized Registry folder, allowing other states to then review and download the files of their choosing.
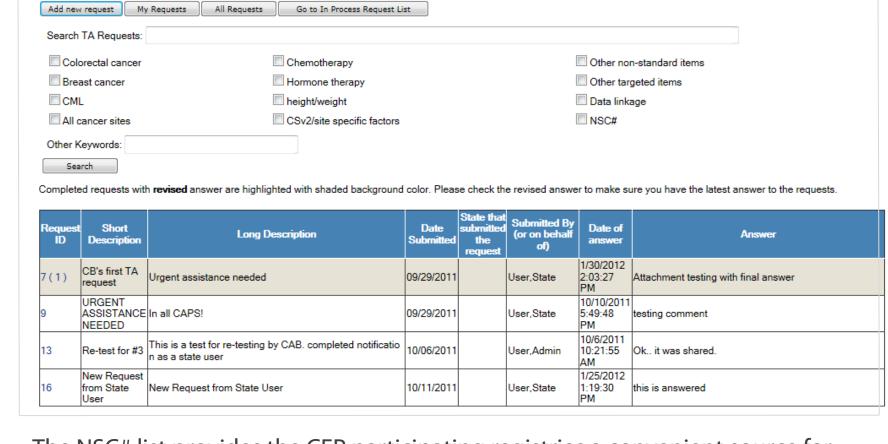

Collaboration

If the technical assistance request was chosen by CDC or ICF to be an FAQ candidate, the request is then added to the FAQ listing. The CER participating registries can then access the list to find solutions to other registry's questions and solutions. The FAQ listing has search functionality built in to allow the user to easily find a solution.

Request Monitoring

The Completed Technical Assistance Request List assists CDC and ICF in keeping track of which registries are submitting requests, when the requests were received and completed and what the provided solution was. Completed requests are available for viewing by other participating registries.

The NSC# list provides the CER participating registries a convenient source for up-to-date drug information. Participating registries can opt to receive email notifications when there are new files added.
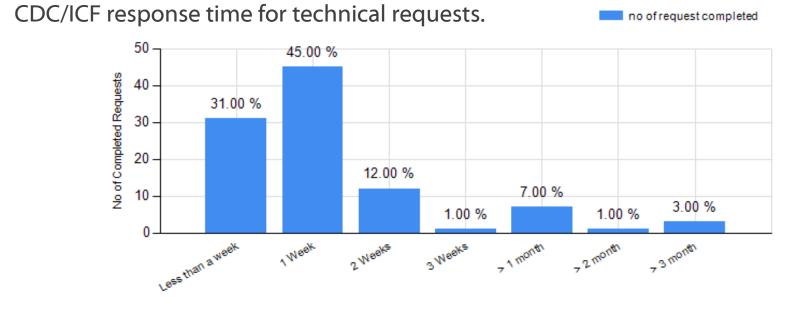

Management Reporting

Most downloaded files from top 7 Directories by 04/30/2013

The aim of the Information Sharing Portal is to have the information in one location, for rapid sharing. The chart below illustrates how used the portal is.

Directory Name	No of time files downloaded
Training Materials	1257
Data Dictionary	469
Edits	441
Monthly Technical Calls	299
Data Collection and Coding	265
Industry and Occupation Data	67
CER Weekly Updates	66

Technical Assistance Request by 4/30/2013

To facilitate effective collaboration between the participating registries, technical requests are addressed quickly. The chart below illustrates the CDC/ICF response time for technical requests.

CER Information Sharing Portal – Why?

- CDC's Comparative Effectiveness Research (CER) project required developing a sustainable method for rapid data collection and the expansion of data items collected through linkages and electronic reporting, to develop new capacity for innovative public health applications of cancer registries, and to develop datasets for researchers to address CER-related research questions.
- Participating CER cancer registries with specialized projects required a platform to communicate, collaborate and receive technical assistance in timely manner. CER registries also required confidentiality of material they share with CDC and ICF. A centralized information-sharing portal was created by ICF to facilitate collaboration of training materials and other project-relevant information among all participating CER cancer registries.
- A dashboard was implemented to provide a platform to share important information, notifications and a calendar for upcoming meetings and events. This allows CDC to easily share weekly updates, information on special projects and monthly technical call discussions.
- The portal allows ICF to maintain operational support to manage the pilot Data Submission and Data Quality Reviews from the 10 state specialized registries. The portal also houses the technical support, technical assistance requests tracking and communications in one central location.

Benefits

- For states, the CER information sharing portal serves as an integrated platform for collaboration, information sharing and technical assistance.
  - Provides states a central point to look for various types of resources to enhance the data collection for comparative effectiveness research, such as weekly project updates, guidelines and manuals for data collection and coding, data dictionaries and edits metafiles, software tools, training materials, etc.
  - Offers states the ability to easily submit inquiries and technical assistance requests for rapid support.
  - Serves as a convenient platform for states participating CER projects to collaborate with each other and share resources such as training documents and other information.
- For CDC and ICF, the CER information sharing portal provides a convenient tool for project monitoring and management as well as information dissemination.
  - Streamlines the process for handing technical assistance requests improve response time.
  - Allows CDC and ICF to efficiently disseminate information and guidelines to participating states.
  - Allows CDC and ICF to closely monitor portal usage and track task progress so that constant improvement can be achieved.
- The CER information sharing portal is very easy to customize for many other uses.

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