A Study on Breast Cancer Patients Using Florida Cancer Registry Data Linked with Hospital Electronic Medical Records

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**Project Period:** 09/30/10 – 09/29/12  
**Grant Number:** R24 HS19658-01  
**Data Description:** [http://dx.doi.org/10.3886/ICPSR34544.v1](http://dx.doi.org/10.3886/ICPSR34544.v1)

**Infrastructure Description**

The Florida Department of Health collaborated with the Florida Agency for Health Care Administration to link the Florida Cancer Data System (FCDS) with hospital electronic medical records (EMRs) of a large, urban hospital system. This linkage allowed the FCDS to capture cancer diagnosis and treatment data more quickly and flexibly than was possible with traditional methods of cancer reporting, and the expanded data capacity provided invaluable potential for comparative effectiveness research on cancer treatments.

**Specific Aims**

Establish a real-time linkage between the FCDS, the statewide cancer registry, and hospital EMR systems to extract data and enhance the medical information available for approximately 10% of the statewide annual cancer incidence records. Using data obtained from this linkage allows the FCDS to capture “end-results” data, which will result in robust data sets for outcomes research.

**Pilot Study**

The pilot used the enhanced, linked dataset to compare the impact of various medical treatments on disease outcomes for complex breast cancer patients, controlling for patients’ characteristics, cancer characteristics, and comorbidities.

Hospital staff transferred 12,804 tumor records from patient EMRs to the FCDS for matching with 11,506 breast cancer patients. These EMR provided detailed data on patient treatments received, health histories, pathology records, and clinician’s notes, and was processed in a flat file format that the registry could receive and interpret.

**Infrastructure Goal**

Link cancer registry data with electronic medical record (EMR) data for cancer patients to enhance medical information available for comparative effectiveness research.

**Data Sources**

Cancer diagnosis and treatment data from the EMRs of a large, urban hospital system.  
Florida Cancer Registry Data

**Data Access**

Data contain confidential information that can directly identify a patient. Reporting facility data also are included. Therefore, to obtain these data, researchers must follow the Florida Cancer Data System (FCDS) data-sharing agreement process, as outlined on the FCDS data sharing request, found at: [http://fcds.med.miami.edu/inc/datarequest.shtml](http://fcds.med.miami.edu/inc/datarequest.shtml).

**Strategies Addressed from the HHS Strategic Framework on Multiple Chronic Conditions**

1.D. Implement and effectively use HIT  
4.B. Understand the epidemiology of MCCs  
4.C. Increase clinical research  
4.D. Address health disparities
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Results indicated that incorporating cancer data from EMRs is feasible if hospital leadership make it a priority and dedicate staff with data linkage expertise. Data linkage policies and procedures are needed to address patient confidentiality concerns. Such policies and procedures should: (1) address how to protect patient confidentiality and define the legal obligation for reporting data; (2) define the ownership of data; (3) establish compatibility of data systems within hospital networks and the state cancer registry; and (4) ensure secure means of data transmission through data sharing agreements.

Publications (as of September 2013)

(Additional publications currently in preparation).

Posters and Presentations


Updated 9/2013

