

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

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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/datasetrequest.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)

Hernandez M, Voti L, Feldman J, Tannenbaum S, Scharber W, MacKinnon J, Lee D, Huang Y. Cancer registry enrichment via linkage with hospital-based electronic medical records: a pilot investigation. *Journal of Registry Management*. 2013; 40(1): 37-44.

(Additional publications currently in preparation).

Posters and Presentations

Xiao H, Tan F, Feldman J, Huang Y. Survival of women with triple negative breast cancer in Florida. Presentation at: American Public Health Association; 2013 Nov 2-6; Boston, MA.

Feldman J, Huang Y, Hernandez MN, Leonidas G, Koniaris LG, Xiao H. Linking hospital EMR and cancer registry data to compare breast cancer treatment and patient-centered outcomes. Oral presentation at: the Council for State and Territorial Epidemiologists Annual Conference; 2013 Jun 9-13; Pasadena, CA.

Feldman J, Huang Y, Hernandez MN. Policies, practices and partnerships for collaborative data sharing. Oral presentation at: the Council for State and Territorial Epidemiologists Annual Conference; 2013 Jun 9-13; Pasadena, CA.

Huang Y, Feldman J, Hernandez MN, Mackinnon JA. Collecting cancer registry data through linking hospital electronic medical records. Oral presentation at: the Council for State and Territorial Epidemiologists Annual Conference; 2013 Jun 9-13; Pasadena, CA.

Feldman JD, Adams-Thames AX, Tan F, Huang Y, Hylton T, Xiao H. Bouncing balls: Investigating drivers of hospital readmissions with hospital and cancer registry data. Oral presentation at: Thinking Big: The Future of Cancer Surveillance. North American Association of Central Cancer Registries Annual Conference; 2013 Jun 8-14; Austin, TX.

Feldman JD, Hernandez MN, Mackinnon JA, Huang Y, Tan F, Lee D, Hylton T, Adams-Thames AX. Establishing data linkage policies for administrative records and hospital records – lessons from Florida. Poster presentation at: Thinking Big: The Future of Cancer Surveillance. North American Association of Central Cancer Registries Annual Conference; 2013 Jun 8-14; Austin, TX.

Xiao H, Tan F, Huang Y, Feldman J, Koniaris L, Gummadi S, Ali AA, Adunlin GB. Impact of BMI on breast cancer prognosis in patient-centered research: A Florida Pilot Study. Oral presentation at: Thinking Big: The Future of Cancer Surveillance. North American Association of Central Cancer Registries Annual Conference; 2013 Jun 8-14; Austin, TX.

Xiao H, Tan F, Huang Y, Feldman J, Koniaris L, Gummadi S, Ali AA, Adunlin GB. Impact of body mass index on prognosis for breast cancer patients. Poster presentation at: International Society for Pharmacoeconomics and Outcomes Research 18th Annual International Meeting; 2013 May 18-22; New Orleans, LA.

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Xiao H, Tan F, Huang Y, Feldman J, Koniaris L, Gummadi S, Ali AA, Adunlin GB. Impact of hormone receptor status and Her2 on survival of triple negative breast cancer patients. Poster presentation at: International Society for Pharmacoeconomics and Outcomes Research 18th Annual International Meeting; 2013 May 18-22; New Orleans, LA.

Hernandez M, MacKinnon J, Huang Y, Feldman J, Scharber W, Hylton T, Adams A, Davis A, Fulewider B. Hospital EMR transmission to a central cancer registry for enhanced research and registry validation. Poster presented at: Leveraging Knowledge and Action to Improve Health Care Quality. 6th Annual Conference of the Agency for Healthcare Research and Quality; 2012 Sept 9–12; Bethesda, MD.

Herndandez M, Mackinnon J, Feldman J, Huang Y, Scharber W, Hylton T, Adams-Thames A. Hospital EMR transmission to a central cancer registry for enhanced research and registry validation. Poster presented at: CDC National Cancer Conference; 2012 Aug 21–23; Washington, DC.

Herndandez M, Mackinnon J, Huang Y, Feldman J, Scharber W, Hylton T, Adams-Thames A. Capturing EMR data for cancer care research and validation of registry data: A Florida case study. Paper presented at: Building Bridges for Cancer Surveillance: 25 Years of Progress. Annual Conference of the North American Association of Central Cancer Registries; 2012 June 5–7; Portland, OR.