Operational Electronic Health Record Data for Comparative Effectiveness Research: Limitations and Challenges

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References


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Overview

• Opportunities
• Challenges
  – Early work
  – EHR data for quality assessment
  – EHR data for clinical research and comparative effectiveness research
  – Insights from health information exchange
• Future directions
Opportunities

• Many “secondary uses” or re-uses of electronic health record (EHR) data, including (Safran, 2007)
  – Personal health records (PHRs)
  – Clinical and translational research – generating hypotheses and facilitating research
  – Healthcare quality measurement and improvement
  – Health information exchange (HIE)
  – Public health surveillance for emerging threats

Opportunities (cont.)

• Facilitated by
  – Incentives for “meaningful use” of EHRs in the HITECH Act (Blumenthal, 2011; Blumenthal, 2011), aiming toward the “learning healthcare system” (Friedman, 2010)
  – Continued investment in Clinical and Translational Research Award (CTSA) program (Collins, 2011; Helfand, 2011)
  – Facilitation of comparative effectiveness research (CER) (Sox, 2009)
• Science is entering the era of “big data” (Hey, 2009), but there are some provocations about which to be concerned (Boyd, 2011)
Challenges

• Documentation is often what stands between clinical day and going home for dinner

• In other words, quality of data in EHR is often not the top priority for busy clinicians

• In addition, clinical records do not always tell a complete or accurate story, e.g., patients get care in many places or do not follow up

• What does the research show?

Early work focused on coded data

• Jollis, 1993 – for patients admitted for cardiac catheterization for suspected ischemic heart disease, claims data found lacking for important diagnostic and prognostic information
Coded data limitations (cont.)

- Many places for error in coding process (O’Malley, 2005)
- Claims data also have potential bias from incomplete data, although are plentiful and inexpensive (Schneeweiss, 2005)

Bulk of more recent work has focused on quality assessment

- Systematic review by Chan (2010) identified 35 studies assessing data quality for reliability and validity of quality measures from EHR data; categorized into three areas
  - Accuracy
  - Completeness
  - Variability
- (Cited previous systematic review on older systems by Thiru, 2003)
Continued research since Chan systematic review

- Kahn, 2010 – significant differences in rates of adverse drug events in a single institution’s EHR based on how calculated
- Benin, 2011 – measuring quality metrics using EHR data required substantial validation to ensure accuracy
- Parsons, 2012 – quality measures underestimated by use of only EHR data; impacted by variations in workflow and documentation practices

Some work has focused on quality of data for clinical research

- In Texas academic hospital, billing data alone only identified 22.7% and 52.2% respectively of patients with breast and endometrial cancer, increasing to 59.1% and 88.6% with a machine learning algorithm (Bernstam, 2010)
- At Columbia University, 48.9% of patients with ICD-9 code for pancreatic cancers did not have corresponding disease documentation in pathology reports, with many data elements incompletely documented (Botsis, 2010)
- Data from two medical centers in Minnesota were found to better predict Type 2 diabetes mellitus than from a single center (Wei, 2012)
- Alerting system to add 17 problems to patient problem lists accepted 41% of time (Wright, 2012)
Data “idiosyncracies” for clinical research from EHR data (Weiner, 2011)

- “Left censoring”: First instance of disease in record may not be when first manifested
- “Right censoring”: Data source may not cover long enough time interval
- Data might not be captured from other clinical (other hospitals or health systems) or non-clinical (OTC drugs) settings
- Bias in testing or treatment
- Institutional or personal variation in practice or documentation styles
- Inconsistent use of coding or standards

Much data is “locked” in narrative text reports (Hripcsak, 1995)

- Will natural language processing (NLP) help?
- State of the art and quantity of text increasing, but performance still imperfect (Stanfill, 2010)
  - How good is “good enough” for clinical research?
  - Possible uses interactively rather than unsupervised?
  - Research may guide improvement, e.g., challenge evaluations such as i2b2 (Uzuner, 2007-2010), TREC Medical Records Track (Voorhees, 2011), etc.
Additional insight is provided by studies of health information exchange

- Study of 3.7M patients in Massachusetts found 31% visited 2 or more hospitals over 5 years (57% of all visits) and 1% visited 5 or more hospitals (10% of all visits) (Bourgeois, 2010)
- Study of 2.8M emergency department (ED) patients in Indiana found 40% of patients had data at multiple institutions, with all 81 EDs sharing patients in common (Finnell, 2011)

Important not to forget the successes of discovery from the EHR

- Validation of genome-wide association studies (GWAS), many results from eMERGE, e.g.,
  - Red blood cell traits, built into a model, identified three of four previously identified loci (Kullo, 2010)
  - Combination of billing and clinical data predicted polymorphisms of a gene known to affect atrioventricular conduction (Denny, 2009)
- Designation of research cohort of patients with rheumatoid arthritis (Liao, 2010)
- Growing number of projects focused on advancing use of EHR data for clinical research
  - eMERGE (McCarty, 2010; Koh, 2011)
  - SharpN (Chute, 2011; Rea, 2012)
Future directions

• CTSA Taskforce on CER and Informatics
  – Task force for two CTSA Key Function Groups addressing this issue with EDM Forum

• What is needed?
  – Identification of best practices and development of guidelines for optimal data entry, structure, and extraction
  – Research agenda to identify and implement optimal approaches