Caveats and Recommendations for Use of Operational Electronic Health Record Data for Research and Quality Measurement

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Outline

• Information-related problems and solutions in healthcare
• Opportunities for secondary use or re-use of clinical data for research and other purposes
• Caveats of operational clinical data
• Role of informatics research
Many problems in healthcare have information-related solutions

- Quality – not as good as it could be (McGlynn, 2003; Schoen, 2009; NCQA, 2010)
- Safety – errors cause morbidity and mortality; many preventable (Kohn, 2000; Classen, 2011; van den Bos, 2011; Smith 2012)
- Cost – rising costs not sustainable; US spends more but gets less (Angrisano, 2007; Brill, 2013)
- Inaccessible information – missing information frequent in primary care (Smith, 2005)

Growing evidence that information interventions are part of solution

- Systematic reviews (Chaudhry, 2006; Goldzweig, 2009; Buntin, 2011; Jones, 2014) have identified benefits in a variety of areas, although
  - Quality of many studies could be better
  - Large number of early studies came from a small number of “health IT leader” institutions

![Bar chart showing outcomes of study interventions](image)
What are the major challenges in getting where we want? (Hersh, 2004)

**Health Care Information Technology**
**Progress and Barriers**

- Cost
- Technical challenges
- Interoperability
- Privacy and confidentiality
- Workforce

The US has made substantial investment in health information technology (HIT)

"To improve the quality of our health care while lowering its cost, we will make the immediate investments necessary to ensure that within five years, all of America's medical records are computerized ... It just won't save billions of dollars and thousands of jobs – it will save lives by reducing the deadly but preventable medical errors that pervade our health care system."

January 5, 2009

Health Information Technology for Economic and Clinical Health (HITECH) Act of the American Recovery and Reinvestment Act (ARRA) (Blumenthal, 2011)
- Incentives for electronic health record (EHR) adoption by physicians and hospitals (up to $27B)
- Direct grants administered by federal agencies ($2B, including $118M for workforce development)
Which has led to significant EHR adoption in the US

Office-based physicians (Hsiao, 2014)

Emergency departments (Jamoom, 2015)

Outpatient departments (Jamoom, 2015)

Non-federal hospitals (Charles, 2014)

Providing opportunities for “secondary use” or “re-use” of clinical data

- (Safran, 2007; SHARPn, Rea, 2012)
- Using data to improve care delivery
- Healthcare quality measurement and improvement
- Clinical and translational research
- Public health surveillance
- Implementing the learning health system
Using data to improve healthcare

• With shift of payment from “volume to value,” healthcare organizations will need to manage information better to provide better care (Diamond, 2009; Horner, 2012)
• Predictive analytics is use of data to anticipate poor outcomes or increased resource use – applied by many to problem of early hospital re-admission (e.g., Gildersleeve, 2013; Amarasingham, 2013; Herbert, 2014)
• A requirement for “precision medicine” (IOM, 2011; Collins, 2015)
• Also can be used to measure quality of care delivered to make it more “accountable” (Hussey, 2013; Barkhuysen, 2014)

Clinical and translational research

• Many roles for clinical research informatics (Richesson, 2012)
  – Led in part by activities of NIH Clinical and Translational Science Award (CTSA) Program (Mackenzie, 2012)
• One of largest and most productive efforts has been eMERGE Network – connecting genotype-phenotype (Gottesman, 2013; Newton, 2013)
  – http://emerge.mc.vanderbilt.edu
  – Has used EHR data to identify genomic variants associated with various phenotypes (Denny, 2012; Denny, 2013)
Clinical and translational research (cont.)

- Other successes include replication of clinical studies, e.g.,
  - Randomized controlled trials (RCT)
    - Women’s Health Initiative (Tannen, 2007; Weiner, 2008)
    - Other cardiovascular diseases (Tannen, 2008; Tannen, 2009) and value of statin drugs in primary prevention of coronary heart disease (Danaei, 2011)
  - Observational studies
    - Metformin and reduced cancer mortality rate (Xu, 2014)
- Much potential for using propensity scores with observational studies as complement to RCTs
  - Often but not always obtain same results as RCTs (Dahabreh, 2014)

Caveats for the Use of Operational Electronic Health Record Data in Comparative Effectiveness Research

Operational clinical data may be (Medical Care, 2013):
- Inaccurate
- Incomplete
- Transformed in ways that undermine meaning
- Unrecoverable for research
- Of unknown provenance
- Of insufficient granularity
- Incompatible with research protocols
Caveats of clinical data

• Documentation not always a top priority for busy clinicians (de Lusignan, 2005)
• Not every diagnosis is recorded at every visit; absence of evidence is not always evidence of absence, an example of a concern known by statisticians as censoring (Zhang, 2010)
• Makes seemingly simple tasks such as identifying diabetic patients challenging (Miller, 2004; Wei, 2013; Richesson, 2013)

“Idiosyncrasies” of clinical data (Hersh, 2013)

• “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
Overcoming the caveats: recommendations for EHR data use

- (Hersh, 2013)
- Assessing and using data
- Adaptation of “best evidence” approaches to use of operational data
- Need for standards and interoperability
- Appropriate use of informatics expertise

A big challenge is interoperable data
Challenges to EHRs have spurred focus on interoperability

- Office of National Coordinator for Health IT (ONC) developing interoperability road map for 10-year path forward (Galvez, 2014)
- Emerging approaches include
  - RESTful architectures for efficient client-server interaction
  - OAuth2 for Internet-based security
  - Standard application programming interface (API) for query/retrieval of data
    - Need for both documents and discrete data
    - Emerging standard is Fast Health Interoperability Resources (FHIR)

Also need to develop clinical data research networks

- Established
  - HMO Research Network – facilitates clinical research
    - [www.hmoresearchnetwork.org](http://www.hmoresearchnetwork.org)
  - FDA Mini-Sentinel Network – safety surveillance
    - [www.mini-sentinel.org](http://www.mini-sentinel.org)
- New
  - PCORnet – [www.pcornet.org](http://www.pcornet.org)
    - Clinical data research networks (CDRNs) – 11 networks aggregating data on >1M patients each
      - (Fleurence, 2014; Collins, 2014; and other papers in JAMIA special issue)
    - Common Data Model for subset of data
Critical role for informatics research

• Many areas of need, e.g.,
  – Data standards and interoperability
  – Data science
  – People and organizational issues
  – Information retrieval and text mining
• Currently funded by many different entities
  – NLM – basic research in informatics, especially clinical informatics
  – Other NIH institutes – tend to focus on bioinformatics
  – AHRQ and PCORI – applied clinical informatics

An instance of research: cohort discovery

• Adapting information retrieval techniques to medical records
• Use case somewhat different from usual information retrieval: want to retrieve records and data within them to identify patients who might be candidates for clinical studies
• Another goal: working with large quantity of data, i.e., not few hundred documents typical to natural language processing studies
Challenges for informatics research with medical records

- Has always been easier with knowledge-based content than patient-specific data due to a variety of reasons
  - Privacy issues
  - Task issues
- Facilitated with development of large-scale, de-identified data set from University of Pittsburgh Medical Center (UPMC)
- Part of Text Retrieval Conference (TREC), an annual challenge evaluation sponsored by National Institute for Standards and Technology (NIST) (Voorhees, 2005)
- Medical Records Track launched in 2011, repeated in 2012 (Voorhees, 2012)
Some issues for test collection

• De-identified to remove protected health information (PHI), e.g., age number → range
• De-identification precludes linkage of same patient across different visits (encounters)
• UPMC only authorized use for TREC 2011 and TREC 2012 but nothing else, including any other research (unless approved by UPMC)

Easy and hard topics

• Easiest – best median bpref
  – 105: Patients with dementia
  – 132: Patients admitted for surgery of the cervical spine for fusion or discectomy
• Hardest – worst best bpref and worst median bpref
  – 108: Patients treated for vascular claudication surgically
  – 124: Patients who present to the hospital with episodes of acute loss of vision secondary to glaucoma
• Large differences between best and median bpref
  – 125: Patients co-infected with Hepatitis C and HIV
  – 103: Hospitalized patients treated for methicillin-resistant Staphylococcus aureus (MRSA) endocarditis
  – 111: Patients with chronic back pain who receive an intraspinal pain-medicine pump
Failure analysis for 2011 topics  
(Edinger, 2012)

<table>
<thead>
<tr>
<th>Reasons for Incorrect Retrieval</th>
<th>Number of Visits</th>
<th>Number of Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visits Judged Not Relevant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Topic terms mentioned as future possibility</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>Topic symptoms/condition/procedure done in the past</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td>All topic criteria present but not in the time/sequence specified by the topic description</td>
<td>19</td>
<td>6</td>
</tr>
<tr>
<td>Most, but not all, required topic criteria present</td>
<td>17</td>
<td>8</td>
</tr>
<tr>
<td>Topic terms denied or ruled out</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Notes contain very similar term confused with topic term</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Non-relevant reference in record to topic terms</td>
<td>37</td>
<td>18</td>
</tr>
<tr>
<td>Topic terms not present—unclear why record was ranked highly</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Topic present—record is relevant—disagree with expert judgment</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>Visits Judged Relevant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Topic not present—record is not relevant—disagree with expert judgment</td>
<td>44</td>
<td>21</td>
</tr>
<tr>
<td>Topic present in record but overlooked in search</td>
<td>103</td>
<td>27</td>
</tr>
<tr>
<td>Visit notes used a synonym or lexical variant for topic terms</td>
<td>22</td>
<td>10</td>
</tr>
<tr>
<td>Topic terms not named in notes and must be inferred</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Topic terms present in diagnosis list but not visit notes</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Results for 2012

<table>
<thead>
<tr>
<th>Run</th>
<th>mfNDCG</th>
<th>mfAP</th>
<th>P(10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NLM/MSmar1*</td>
<td>0.680</td>
<td>0.366</td>
<td>0.749</td>
</tr>
<tr>
<td>uducUM</td>
<td>0.578</td>
<td>0.286</td>
<td>0.592</td>
</tr>
<tr>
<td>unnamed2</td>
<td>0.547</td>
<td>0.275</td>
<td>0.557</td>
</tr>
<tr>
<td>oshuMaahboud*</td>
<td>0.520</td>
<td>0.250</td>
<td>0.611</td>
</tr>
<tr>
<td>atpeq1</td>
<td>0.521</td>
<td>0.224</td>
<td>0.519</td>
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<tr>
<td>UDhafMed123</td>
<td>0.517</td>
<td>0.236</td>
<td>0.528</td>
</tr>
<tr>
<td>ucmdTr/McontrQEd</td>
<td>0.509</td>
<td>0.231</td>
<td>0.553</td>
</tr>
<tr>
<td>NCITAUBC4</td>
<td>0.487</td>
<td>0.206</td>
<td>0.517</td>
</tr>
</tbody>
</table>

Per-topic scores for mfNDCG computed over all runs.
What approaches did (and did not) work?

- Best results in 2011 and 2012 obtained from NLM group (Demner-Fushman, 2011)
  - Top results from manually constructed queries using Essie domain-specific search engine (Ide, 2007)
  - Other automated processes fared less well, e.g., creation of PICO frames, negation, term expansion, etc.
- Best automated results in 2011 obtained by Cengage (King, 2011)
  - Filtered by age, race, gender, admission status; terms expanded by UMLS Metathesaurus
- Benefits of approaches commonly successful in IR provided small or inconsistent value
  - Document focusing, term expansion, etc.

Continued work – Mayo Clinic-OHSU collaboration

Led by:
- Hongfang Liu – Mayo
- Stephen Wu – OHSU

EMR text

Chief complaint: severe cough and fever, Cough started 2 days ago, expectoration.

Chronic obstructive pulmonary disease

Text query

NLP (cTAKES)

Severe Cough

Lung Disease

Pneumonia

Chronic Disease

Chief of Staff

content field:
C0010200 C0015967

Layered Language Index

text field:

severe cough and fever annotations:

content field:
C0010200 C0015967
Conclusions

- There are plentiful opportunities for secondary use or re-use of clinical data
- We must be cognizant of caveats of using operational clinical data
- We must implement best practices for using such data
- We need consensus on approaches to standards and interoperability
- Research to discover best methods and useful results is critical

For more information

- Bill Hersh
  - http://www.billhersh.info
- Informatics Professor blog
  - http://informaticsprofessor.blogspot.com
- OHSU Department of Medical Informatics & Clinical Epidemiology (DMICE)
  - http://www.ohsu.edu/informatics
  - http://www.youtube.com/watch?v=T-74duDDywU
  - http://oninformatics.com
- What is Biomedical and Health Informatics?
  - http://www.billhersh.info/whatis
- Office of the National Coordinator for Health IT (ONC)
  - http://healthit.hhs.gov
- American Medical Informatics Association (AMIA)
  - http://www.amia.org
- National Library of Medicine (NLM)