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

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1

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

2

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)

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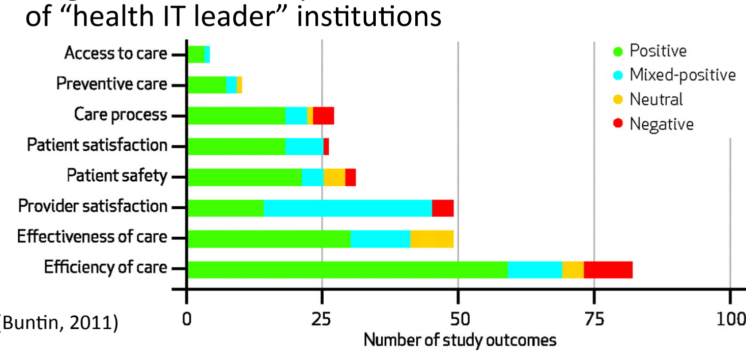
Growing evidence that information interventions are part of solution

- 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



(Buntin, 2011)

What are the major challenges in getting where we want? (Hersh, 2004)

Health Care Information Technology
Progress and Barriers

William Hersh, MD

IN THE 3 DECADES SINCE THE TERM "MEDICAL INFORMATics" was first used, individuals working at the intersection of information technology (IT) and medicine have developed and evaluated computer applications aim-

in this issue of *JAMA*, Slack demonstrates the value that patient-physician e-mail can have in improving patient care, and also catalogs the incomplete but encouraging underlying evidence.[11] As with many applications of IT, the technology can improve the existing situation but also empower clinicians and patients to think more fundamentally about how inno-

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

care IT.[8,9] It is no exaggeration to declare that the years ahead portend the "decade of health information technology."[10]

Informatics is poised to have a major impact in patient-clinician communication. In the Clinical Crossroads article

See also p 2255.

ment. The rest goes to those who typically do not pay for

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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)

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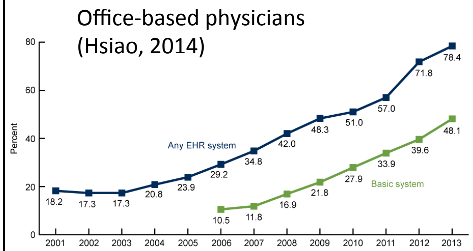
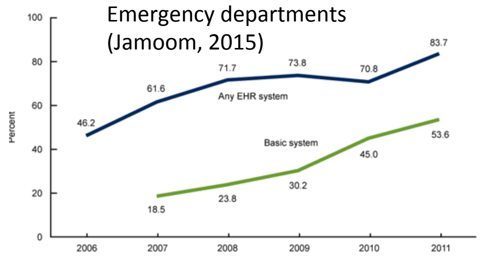
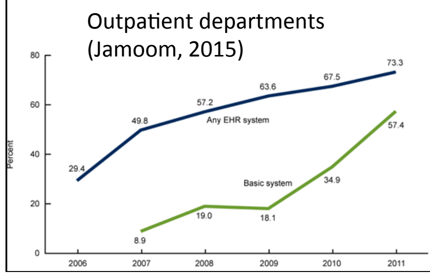
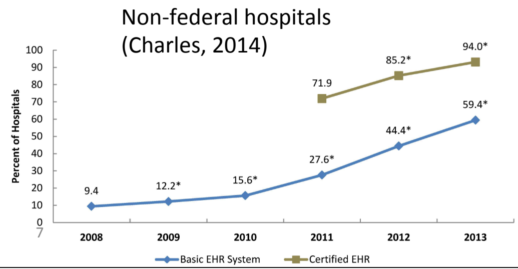
Which has led to significant EHR adoption in the US









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

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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)

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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)

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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

William R. Hersh, MD, Mark G. Weiner, MD,† Peter J. Embi, MD, MS,‡ Judith R. Logan, MD, MS,* Philip R.O. Payne, PhD,‡ Elmer V. Bernstam, MD, MSE,§ Harold P. Lehmann, MD, PhD,|| George Hripcsak, MD, MS,¶ Timothy H. Hartzog, MD, MS,# James J. Cimino, MD,** and Joel H. Saltz, MD, PhD††*

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

(*Med Care* 2013;00: 000–000)

Health Information Technology (ONC) through the Strategic Health IT Advanced Research Projects (SHARP) Program,

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)

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"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

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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

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

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Altmetric 6

Abstract

There is an increasing amount of clinical data in operational electronic health record (EHR) systems. Such data provide substantial opportunities for their re-use for many purposes, including comparative effectiveness research (CER). In a previous paper, we

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A big challenge is interoperable data

INFORMATICS PROFESSOR

THIS BLOG MAINTAINS THE THOUGHTS ON VARIOUS TOPICS RELATED TO BIOMEDICAL AND HEALTH INFORMATICS BY DR. WILLIAM HERSH, PROFESSOR AND CHAIR, DEPARTMENT OF MEDICAL INFORMATICS & CLINICAL EPIDEMIOLOGY, OREGON HEALTH & SCIENCE UNIVERSITY.

WEDNESDAY, MAY 15, 2013

Universal EHR? No. Universal Data Access? Yes.

A recent blog posting calls for a "universal EMR" for the entire healthcare system. The author prov laments how lack of access to the c impedes optimal clinical care. I wo clinical research, and public health well.

However, I do not agree that a "uni this problem. Instead, I would adv

WILLIAM HERSH

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SATURDAY, SEPTEMBER 6, 2014

Unscrambling Eggs and the Need for Comprehensive Data Standards and Interoperability

Two local informatics-related happenings recently provided teac moments demonstrating why a comprehensive approach to stan and interoperability is so critical for realizing the value of health Fortunately, the Office of the National Coordinator for Health IT (ONC) has prioritized interoperability among its activities movir forward, and other emerging work on standards provides hope t problems I will described that occurred locally (and I know occu

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FRIDAY, FEBRUARY 6, 2015

The Conundrum of Structured vs. Unstructured Data

As in all complex endeavors, the push for a healthcare system underpinned by structured and interoperable electronic health record (EHR) data has turned out to be more complicated than we might have anticipated when acceleration of EHR adoption was begun about a decade ago. This does not mean that anyone was right or wrong; it just shows the inherent complexities of trying to solve the real problems that motivate data-related problems in healthcare. These healthcare problems have been well-documented over the past couple decades by

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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) – http://wiki.hl7.org/index.php?title=FHIR_for_Clinical_Users

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Also need to develop clinical data research networks

- Established
  - HMO Research Network – facilitates clinical research
    - www.hmoresearchnetwork.org
  - FDA Mini-Sentinel Network – safety surveillance
    - www.mini-sentinel.org
- New
  - PCORnet – 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

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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

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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

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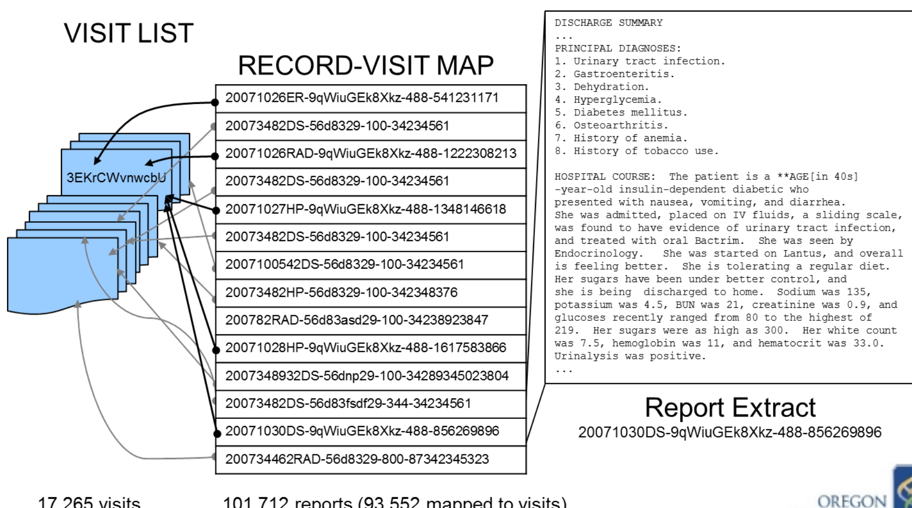
Challenges for informatics research with medical records

- 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)

Test collection



(Courtesy, Ellen Voorhees, NIST)

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

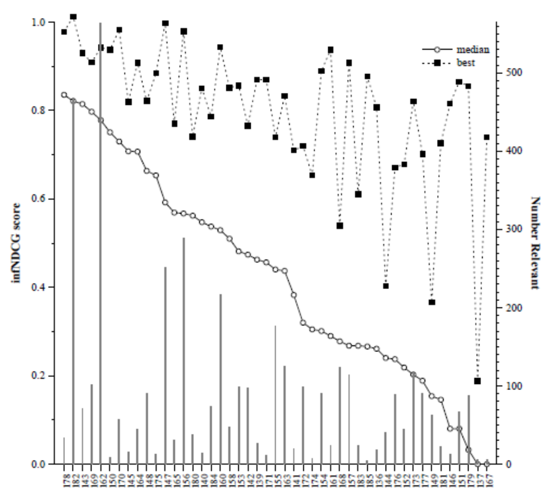
- Easiest – best median bpref
  - 105: Patients with dementia
  - 132: Patients admitted for surgery of the cervical spine for fusion or discectomy
- Hardest – worst best bpref and worst median bpref
  - 108: Patients treated for vascular claudication surgically
  - 124: Patients who present to the hospital 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)

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

Results for 2012

Run	infNDCG	infAP	P(10)
NLMManual*	0.680	0.366	0.749
udelSUM	0.578	0.286	0.592
sennamed2	0.547	0.275	0.557
ohsuManBool*	0.526	0.250	0.611
atigeo1	0.524	0.224	0.519
UDinfoMed123	0.517	0.236	0.528
uogTrMConQRd	0.509	0.231	0.553
NICTAUBC4	0.487	0.216	0.517



Per-topic scores for infNDCG 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.

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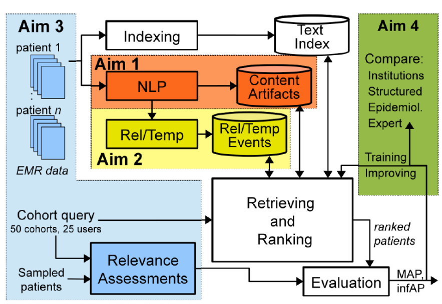
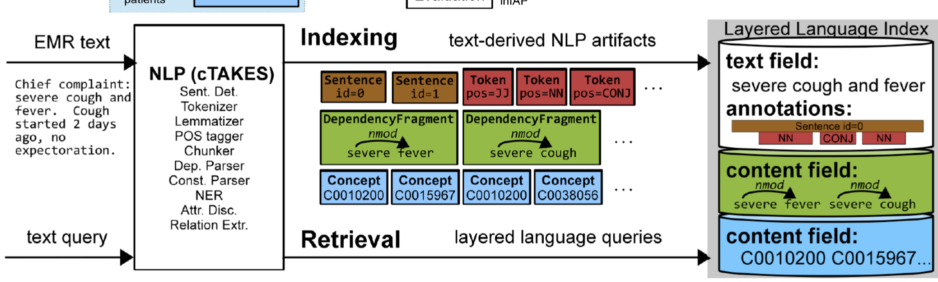
Continued work – Mayo Clinic-OHSU collaboration



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



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

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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-74duDDvwU
  - 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)
  - http://www.nlm.nih.gov

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