Big Data Is Not Enough: People and Systems Are Needed to Benefit Health and Biomedicine

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Big Data is not enough

- Many use cases for Big Data
- Growing quantity of data available at decreasing cost
- Much demonstration of predictive ability; less so of value
- Many caveats for different types of biomedical data
- Effective solutions require people and systems

Many use cases for Big Data in medicine (Bates, 2014)

- High-cost patients – looking for ways to intervene early
- Readmissions – preventing
- Triage – appropriate level of care
- Decompensation – when patient's condition worsens
- Adverse events – awareness
- Treatment optimization – especially for diseases affecting multiple organ systems

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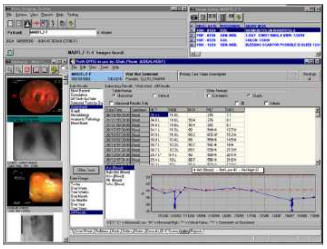
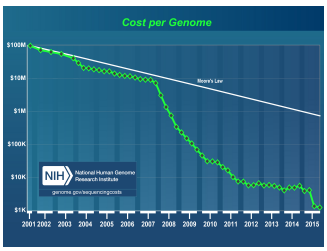
Growing quantity at increasingly lower cost of data

- Last half-decade has seen dramatic growth in adoption of electronic health record (EHR) by hospitals (96%) and physicians (83%) (DesRoches, 2015; Gold, 2016)
- Cost of genome sequencing has fallen faster than Moore's Law (NHGRI, 2016)
- Proliferation of other data sources
  - Imaging
  - Wearables
  - Web and social media





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Important data-related initiatives from US government

- Big Data to Knowledge (BD2K) (Bourne, 2015) – https://datascience.nih.gov
- Sync for Science (White, 2016) – http://syncfor.science
- Vital Directions for Health and Health Care (Dzau, 2016)
- Precision Medicine Initiative (Collins, 2015) – https://www.nih.gov/research-training/allofus-research-program
- Cancer Moonshot (Singer, 2016) – https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative
- 21st Century Cures (Kesselheim, 2017)

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Rationale

- Growing quantity and complexity of healthcare data through EHR capture, genomics, and other sources require more decision support (Stead, 2011)
- With shift of payment from "volume to value," healthcare organizations will need to manage information better to deliver better care (Horner, 2012; Burwell, 2015)
- New care delivery models (e.g., accountable care organizations) will require better access to data (e.g., health information exchange, HIE)
  - Halamka (2013): ACO = HIE + analytics

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Ever-growing number of studies demonstrating predictive ability

- Using EHR data to predict patients at risk for readmission (Amarasingham, 2010; Donzé, 2013; Gildersleeve, 2013; Hebert, 2014; Shadmi, 2015)
- Identifying patients who might be eligible for participation in clinical studies (Voorhees, 2012)
- Detecting postoperative complications (FitzHenry, 2013; Tien, 2015)
- Detecting potential delays in cancer diagnosis (Murphy, 2014)
- Predicting future patient costs (Charlson, 2014)

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Predictive studies (cont.)

- Optimizing primary care physician panel size (Rajkomar, 2016)
- Real-time alerting of mortality risk and prolonged hospitalization from EHR data (Khurana, 2016)
- Elucidating treatment pathways for common diseases (Hripcsak, 2016)
- NLP-based case-finding algorithm of HIE data increased detection of diabetes cases (Zheng, 2016)
- The list goes on and on …

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BUT, studies demonstrating improved patient outcomes are fewer

- Readmission tool applied with case management reduced readmissions (Gilbert, 2013)
- Bayesian network model embedded in EHR to predict hospital-acquired pressure ulcers led to tenfold reduction in ulcers and one-third reduction in intensive care unit length of stay (Cho, 2013)
- Readmission risk tool intervention reduced risk of readmission for patients with congestive heart failure but not those with acute myocardial infarction or pneumonia (Amarasingham, 2013)
- Use of EHR-based acuity score allowed intervention that reduced in-hospital mortality from 1.9% to 1.3% (Rothman, 2015)
- Tool to reduce delay in cancer diagnosis led to earlier diagnosis for colorectal and prostate cancer (Murphy, 2015)

Newer studies of outcomes

- Use of predictive report based on NLP tool reduced time in discharge planning meetings and 30-day all-cause mortality although not cost or readmissions (Evans, 2016)
- Development and use of a universal data architecture at Geisinger has led to successes in (Erskine, 2016)
  - Closing loop on appropriate treatment and lack of follow-up
  - Early detection and treatment of sepsis
  - Monitoring and control of surgery costs and outcomes
- In cohort of children with cerebral palsy, implementation of a learning health system led to (Lowes, 2016)
  - 43% reduced hospital days
  - 30% reduction in emergency department visits
  - 210% reduction in healthcare costs

Some challenges for analytical use of clinical (EHR) data

- Data quality and accuracy is not a top priority for busy clinicians (de Lusignan, 2005)
- Data quantity can be overwhelming – average pediatric ICU patient generates 1348 information items per 24 hours (Manor-Shulman, 2008)
- Patients get care at different institutions (Bourgeois, 2010; Finnell, 2011)
- Much data is "locked" in text (Hripcsak, 2012)
- EHRs of academic medical centers not easy to combine for aggregation (Broberg, 2015)

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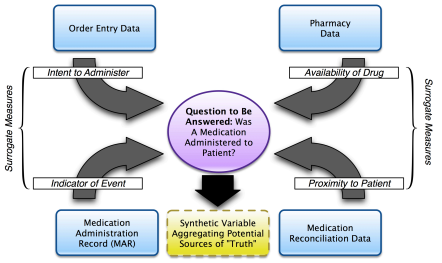
Caveats for use of operational EHR data (Hersh, 2013) – may be

- Inaccurate
- Incomplete
- Transformed in ways that undermine meaning
- Unrecoverable
- Of unknown provenance
- Of insufficient granularity
- Incompatible with research protocols



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Many "idiosyncrasies" of clinical data (Hersh, 2013)

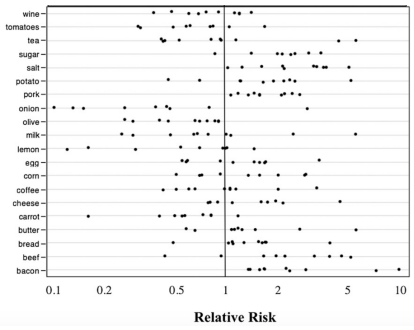
- "Left censoring" – First instance of disease in record may not be when first manifested
- "Right censoring" – Data source may not cover long enough time interval
- Data might not be captured from other clinical (other hospitals or health systems) or non-clinical (OTC drugs) settings
- Bias in testing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

Information from scientific publications can also be problematic

- Science, driven by experimentation, is the best source of truth, but just because something is written in a journal article does not mean it is true
  - Winner's curse (Ioannidis, 2005; Young, 2008) leads to publication bias (Dwan, 2013)
  - Reproducibility (Begley, 2012; Science, 2015; Begley, 2015; Baker, 2016)
  - Clinical trials may not be representative of patient populations (Weng, 2014; Prieto-Centurion, 2014; Geifman, 2016)
  - Use of surrogate endpoints may distort efficacy (Kim, 2015)
  - Reversal (Ioannidis, 2005; Prasad, 2013; Prasad, 2015)
  - Erroneous information in reference materials (Randhawa, 2015)
  - Outright fraud not infrequent (RetractionWatch.com), may be driven by predatory publishing (Haug, 2013; Moher, 2016)

Results can be misleading, conflicting, or hyped

- Observational studies can mislead us, e.g., Women's Health Initiative (JAMA, 2002)
- Observational studies do not discern cause and effect, e.g., diet and cancer (Schoenfeld, 2013)
- Hype about new technologies not yet fully assessed, e.g., IBM Watson – much promise but much hype (Hersh, 2013; Hersh, 2016; Schank, 2016)



Biomedical researchers are not necessarily good software engineers

- Many scientific researchers write code but are not always well-versed in best practices of testing and error detection (Merali, 2010)
- Scientists have history of relying on incorrect data or models (Sainani, 2011)
- They may also not be good about selection of best software packages for their work (Joppa, 2013)
- 3000 of 40,000 studies using fMRI may have false-positive results due to faulty algorithms and bugs (Eklund, 2016)

Should there be more sharing of scientific data? Yes, but …

- Came to fore with ICMJE guidelines (Taichman, 2016) and NEJM "research parasites" editorial (Longo, 2016)
  - Pro: fairness to funders (taxpayers) and subjects (patients)
  - Con: researchers who carried out the heavy work need period of embargo and protection from misuse of their data (ICIFTDS, 2016); costs of curating and organizing 27K clinical trials per year; amount of actual use modest (Strom, 2016)
- Informatics issues: need for attention to standards (Kush, 2014); workflows, patient engagement (Tennenbaum, 2016)

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Other concerns

- Boyd (2012) – critical questions for Big Data
  - Big Data changes the definition of knowledge
  - Claims to objectivity and accuracy are misleading
  - Bigger data are not always better data
  - Taken out of context, Big Data loses its meaning
  - Just because it is accessible does not make it ethical
  - Limited access to Big Data creates new digital divides
- Fung (2014) – Big Data is OCCAM
  - **O**bservational
  - Lacking **C**ontrols
  - Seemingly **C**omplete
  - **A**dapted
  - **M**erged
- Big Data not neutral; reflects our values and priorities (Richards, 2014; Barocas, 2015)

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Big Data requires more than the data; also takes people

- Data scientists – the "sexiest profession of the 21st century" (Davenport, 2012)
- McKinsey (Manyika, 2011) – need in US in all industries (not just healthcare) for
  - 140,000-190,000 individuals who have "deep analytical talent"
  - 1.5 million "data-savvy managers needed to take full advantage of big data"
- Similar analysis by IDC (2014) of need for 180,000 with "deep" talent and 5-fold around with skills in data management and interpretation

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Big Data also requires systems

- Infrastructure (Amarasingham, 2014)
  - Stakeholder engagement
  - Human subjects research protection
  - Protection of patient privacy
  - Data assurance and quality
  - Interoperability of health information systems
  - Transparency
  - Sustainability
- New models of thinking and training users of data (Krumholz, 2014)

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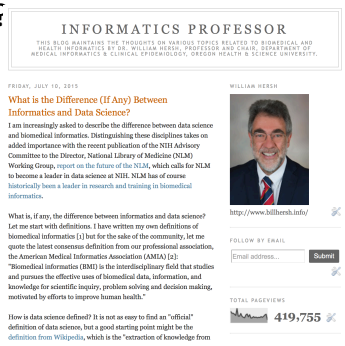
Some axes to grind

- Is data science really new or different?
  - Statisticians (Donoho, 2016) and informaticians (Hersh, 2015) have been doing some of this for a long time
- Will Big Data transform medicine?
  - In some areas, but need more demonstration of value than ability to predict
- How can we optimize its use?
  - Research focused on its applications and their outcomes
  - Don't oversell it, especially to clinicians



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.

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What is the Difference (If Any) Between Informatics and Data Science?

I am increasingly asked to describe the difference between data science and biomedical informatics. Distinguishing these disciplines takes on added importance with the recent publication of the NIH Advisory Committee to the Director, National Library of Medicine (NLM) Working Group, report on the future of the NLM, which calls for NLM to become a leader in data science at NIH. NLM has of course historically been a leader in research and training in biomedical informatics.

What is, if any, the difference between informatics and data science? Let me start with definitions. I have written my own definitions of biomedical informatics [1] but for the sake of the community, let me quote the latest consensus definition from our professional association, the American Medical Informatics Association (AMIA) [2]: "Biomedical informatics (BMI) is the interdisciplinary field that studies and pursues the effective uses of biomedical data, information, and knowledge for scientific inquiry, problem solving and decision making, motivated by efforts to improve human health."

How is data science defined? It is not as easy to find an "official" definition of data science, but a good starting point might be the definition from Wikipedia, which is the "extraction of knowledge from

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Much promise for Big Data in Health and Biomedicine, but need

- Other aspects of informatics
  - Robust EHRs and other clinical data sources
  - Standards and interoperability
  - Health information exchange
  - Usability of clinical systems
- Improved completeness and quality of data
- Research demonstrating how best applied to improve health and outcomes
- Human expertise and systems to apply and disseminate