What is Biomedical and Health Informatics? (2)

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Terms related to medical/clinical records

- *Electronic health record* (EHR) – patient's health record in digital form
  - Has mostly supplanted electronic medical record (EMR)
- *Meaningful use* – program of incentives for EHR adoption in US requiring that they be used in ways that achieve healthcare goals
- *Personal health record* (PHR) – personally controlled health record
- *Health information exchange* (HIE) – exchange of health information across traditional business and other boundaries (a verb)
  - Organization managing HIE used to be called a *Regional Health Information Organization* (RHIO), now called an HIE (a noun)

Many are extolling virtues of BMHI in healthcare and related areas

- Most prominent discussion has focused on improving healthcare through improved quality, safety, and efficiency
- However, there are many challenges
  - Mixing IT with clinical workflow has been difficult
  - Some HIT has been deleterious
  - Financial benefits of IT do not always accrue to those who pay
  - Larger problems in healthcare organization and financing make any type of change difficult

Informatics is also essential for modern biomedical research

- Embodied in the National Institutes of Health (NIH) Roadmap to accelerate biomedical research discovery (http://commonfund.nih.gov)
  - "Today's biomedical researcher routinely generates … billions of bytes of data. … What researchers need are computer programs and other tools to evaluate, combine, and visualize these data. In some cases, these tools will greatly benefit from the awesome strength of supercomputers or the combined power of many smaller machines in a coordinated way but, in other cases, these tools will be used on modern personal computers and workstations."
- Also permeates priorities of NIH Director (Collins, 2010)
  - High-throughput technologies
  - Translational research
  - Supporting healthcare reform
  - Global health
  - Empowering the research community

Informatics terms for biomedical research

- *Translational research* – classically, the translation of basic research into clinical applicability ("bench to bedside"), but also from controlled settings to community and population (Woolf, 2008)
  - Increasing recognition that research findings must "translate" into clinical care more quickly and efficiently, leading to US government investment in *clinical and translational research* through the NIH Clinical & Translational Science Award (CTSA) program (Leshner, 2013)
  - *Translational bioinformatics* – bioinformatics applied to health-related problems (Kann, 2013)
- *Precision medicine* (IOM, 2011; Collins, 2015) – clinical care tailored to an individual's characteristics, including their genome
  - Previously called *personalized medicine* (Schleidgen, 2013)
- *Clinical research informatics* (CRI) is area of informatics applied to clinical research (Richesson, 2012)
  - Difference between information technology (IT) and informatics very evident in this domain (Bernstam, 2009)

We cannot ignore the essential role of the consumer/patient/citizen

- Original Strategic Framework of the Office of the National Coordinator for Health IT (ONC) called for IT to facilitate "consumer-centric, information-rich" healthcare (Brailer, 2004)
- Some advocate that the PHR be at the center of the discussion concerning health records (Krist, 2011)
  - Many issues related to flow of information and responsibility for it
- *e-Patients* – Internet-enabled patients
  - Originated with self-help leader, Dr. Tom Ferguson (2007)
  - Best known is e-Patient Dave, who found a great deal of incorrect information in his medical record in Boston teaching hospital and publicized it widely (Wangsness, 2009)
  - Further elucidated in book from Stanford Medicine X (Chu, 2012)

A final perspective of informatics

- Data ➔ Information ➔ Knowledge
  - Used in many fields but introduced in informatics by Blum (1984)
- Data are the raw material collected and stored
- Information gives meaning and organization to the data
- Knowledge provides understanding and applicability to new situations
- Some add wisdom, as knowing how to apply knowledge (Rowley, 2007)

Informatics is increasingly becoming a "data science"

- EHR (and probably all informatics) work changing from "implementation" to "analytics" (Hersh, 2012)
- Data science is the "sexiest job of the 21st century?" (Davenport, 2012)
- Growing importance of role for *analytics* in healthcare (Adams, 2011; O'Reilly, 2012; Hersh, 2014)
  - But we must use caution to make sure that clinical data is complete, correct, and otherwise sound (the role of informatics?) (Hersh, 2013)

We have entered the era of "Big Data"

- Four "V's" of Big Data: volume, velocity, variety, and variability (NIST, 2015)
- Leading to a new paradigm of science (Hey, 2009)?
  - Making the scientific method obsolete, i.e., no need for experimentation any more? (Anderson, 2007)
  - Not really; many caveats for research use of clinical data (Hersh, 2013)
- Other concerns about data science and Big Data
  - "Provocations" to studying data (Boyd, 2011)
    - Bigger is not necessarily better
    - We study what we can answer
    - Not all data is available or accessible
  - Haven't many fields been doing this already, e.g., statistics (Donoho, 2015)?

Is medicine/health really an information science?

- Many studies over the years, even from pre-computer era, found physicians spend great deal of time with information
- For outpatient physicians
  - Physicians in a general medicine clinic found to spend 37.8% of time charting, 5.3% consulting, 1.7% in other activities, and remaining 55.2% of time with patients (Mamlin, 1973)
  - 14-39% of work took place outside the exam room (Gilchrist, 2005; Gottschalk, 2005)
  - Work related to patient when physician not present consumed 15-23% of work day (Gottschalk, 2005; Farber, 2007; Chen, 2010)

Time studies in hospital and emergency departments

- Time studies of hospital (Ammenwerth, 2009; Tipping, 2010; Kim, 2010; Tipping, 2010; Yousefi, 2011; Victores, 2014) and emergency (Chisholm, 2011) physicians show physicians spent about
  - 15-38% of their time in direct patient care
  - 50-67% of their time in indirect patient care, divided between reviewing results, performing documentation, and engaging in communication

Even more work with data and information more recently

- Studies in era of widespread EHR adoption
  - Interns spent about 40% of time spent interacting with computers (Block, 2013)
  - About 60% of internists reported "loss" of around 48 minutes per day due to EHR usage (McDonald, 2014)
  - Residents in an academic teaching hospital found to spend 50% of time with computers vs. 10% time directly with patients (Mamykina, 2016)
  - Physicians found to spend two hours of time doing EHR and desk time for every hour of direct patient time, plus an additional 1-2 hours per night (Sinsky, 2016)
  - Two studies of primary care physicians found spending 50% (Tai-Seale, 2017) and 60% (Arndt, 2017) of workday with EHR and other desktop medicine tasks
- These studies don't answer what is right amount of time (Hersh, 2017)

Information chaos and complexity

- Physician performance and safety impacted by "information chaos" (Beasley, 2011)
- Epidemiology and all of healthcare system are "complex adaptive systems" where small changes can be unpredictable and lead to new states of equilibrium (Pearce, 2006)