Learning Health: Foundations, Future, and Provocations

Erich Huang, MD, PhD and Shelley Rusincovitch, MMCi

Monday, September 11, 2017, 9:15–10:00 AM
In this session, the presenters will discuss the foundations and context of learning health systems, including background and relevance to interoperability, evidence generation, bridging of healthcare and research, systems-level improvement, population health, and levels of scale from local to national.

They will also pose ten provocative questions about learning health and future potential intended to fuel thought, engagement, and creativity from the attendees.
Disclosures

• Erich Huang:
  – Founder, kelaHealth (Startup)
  – Founder, Stratus Medicine (Startup)

• Shelley Rusincovitch has no disclosures to report
Today’s outline

• Foundations of Learning Health
• What Can Learning Health Learn from Data Science?
• Provocations
• Discussion
Foundations of Learning Health
The Institute of Medicine's Roundtable on Value & Science-Driven Health Care has been convened to help transform the way evidence on clinical effectiveness is generated and used to improve health and health care. We seek the development of a learning health system that is designed to generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care.

**Vision:** Our vision is for a healthcare system that draws on the best evidence to provide the care most appropriate to each patient, emphasizes prevention and health promotion, delivers the most value, adds to learning throughout the delivery of care, and leads to improvements in the nation's health.
Landscape

- LHS is responsive to new capabilities and rapidly-evolving capacity
  - EHR adoption (accelerated by Meaningful Use)
  - Potential benefit from repurposing data
  - Recognizing where healthcare lags behind state of the art in other industries
Scale

- National
- Networks
- Cross-institutional
- Regional
- Local
- Hyper-local
**LHS = “Network of networks that connects islands of expertise”**

**Current Initiatives Leading to an LHS Capability Include:**

- CRN Cancer Research Network
- THE PRECISION MEDICINE INITIATIVE
- NCIN National Cancer Intelligence Network
- pcori Patient-Centered Outcomes Research Institute
- NIH National Cancer Institute Genomic Data Commons
- IBM The Impact of IBM's Watson on Healthcare
- MILLIONS OF WOMEN WITH POLYCYSTIC OVARIAN SYNDROME ARE GOING UNDIAGNOSED, UNTREATED, UNSUPPORTED. THIS MUST CHANGE!
- Transform Health Project
The Core Values Underlying a National-Scale, Person-Centered, Continuous-Learning Health System (LHS)

1. Person-Focused
2. Privacy
3. Inclusiveness
4. Transparency
5. Accessibility
6. Adaptability
7. Governance
8. Cooperative and Participatory Leadership
9. Scientific Integrity
10. Value
PCORnet®: the National Patient-Centered Clinical Research Network

An innovative initiative funded by the Patient-Centered Outcomes Research Institute (PCORI), PCORnet is a large, highly representative, national patient-centered clinical research network.

Our **vision** is to support a learning U.S. healthcare system and to enable **large-scale clinical research** conducted with **enhanced quality and efficiency**.

Our **mission** is to enable people to make informed healthcare decisions by efficiently conducting clinical research relevant to their needs.
Resulting in a national evidence system with unparalleled research readiness

PCORnet represents:
~122 million patients
who have had a medical encounter in the past 5 years

*some individuals may have visited more than one Network Partner and would be counted more than once

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Creating a purpose-driven learning and improving health system: The Johns Hopkins Medicine quality and safety experience

Peter J. Pronovost | Simon C. Mathews | Christopher G. Chute | Antony Rosen

Abstract

Health care has often relied on independent silos of medical research to drive progress and innovation. However, this approach does not adequately address the complexities and opportunities within the modern health care environment. We posit that creating a learning and improving health system that is purpose-driven will ultimately lead the next transformation in health care. We share the experience within Johns Hopkins Medicine that established a learning and improving health system in quality and safety. The system is built around a clear and compelling patient-centered purpose and leverages a fractal framework that provides horizontal links for peer learning and vertical links for accountability. It dismantles traditional research and clinical silos and combines basic and applied research with health system operations. As a result, the system aligns the goals and strengths of a diverse set of stakeholders including clinicians, patients, researchers, and administrators toward a common goal.

The quality and safety infrastructure at our institution draws its inspiration from the idea of a fractal—an elegant structure in nature, such as a fern, containing identical shape and varying size structures, providing horizontal links for peer learning and vertical links for accountability. While there is a hierarchical organizational structure for quality and safety, its foundation is based on the integration of smaller units that are similar in structure (composition of faculty/staff), process (use of similar tools), and approach (using a common framework to address issues).
Intent

LHS exists as a concept to address challenges
• Close the gap with evidence applications
• Improve quality
• Create continuous systems
• Reduce barriers between research and practice
• Population health: reaching beyond one patient at a time
• Respect the engagement and autonomy of patients and caregivers
• Recognize the challenges in clinical practice and difficulties in implementation
• Create a system-level appreciation and synergy
Making better choices about health and health care requires the best possible evidence. Unfortunately, decisions made today in this system are not supported by evidence derived from randomized or well-designed observational studies as rich, diverse sources of evidence are widely available for research tools continue to grow in cation, the research and health care now have the opportunity to ently generate the scientific to support improved decision making, and health care.

high-quality, data-driven evidence from the importance of qualitative information as a source of knowledge for informing and will entail substantial changes to the culture of clinical research, interactions between providers and patients, and the ways in which health systems, clinicians, and patients work together with the clinical research community to create a new environment for generating and using evidence in practice. In this article, we propose a set of core principles for data collaboration and system organizational design that we believe will further enable research efforts by both the private sector and government agencies (see box). Although these principles represent high-level articulations of concepts that are not new, their distillation will help to focus collaboration across federal agencies and with the private sector, thereby achieving synergies that will enable the more rapid development of an effective system.
Methods

• LHS draws upon existing knowledge and components, but seeks to apply efficiently and at scale.
  – Competencies
  – Learning from technology and data science
Domains:
1. Systems Science
2. Research Questions and Standards of Scientific Evidence
3. Research Methods
4. Informatics
5. Ethics of Research and Implementation in Health Systems
6. Improvement and Implementation Science
7. Engagement, Leadership, and Research Management

What Can Learning Health Learn from Data Science?
Improving Patient Care by Capturing Computerized data:

A glimpse into the creation of The Duke Databank for Cardiovascular Disease
COST CONSTRAINTS
IMPLEMENTATION
DATA-DRIVEN

MONEYBALL
IN THEATERS SEPTEMBER 23
Inpatient Admissions 63,312
Outpatient Visits 1,280,514
Surgeries/Endoscopies 85,248
ER visits 66,860
Hospital Labs 5,428,178
Necessary but not sufficient
... IT’S STILL EARLY IN THE EVOLUTION...
< 1 pound
“5 Tool Player”
“Catcher with a bad elbow converted to 1st baseman”
AN ACADEMIC HEALTH SYSTEM THAT LEARNS
Novel Platform

Compute Stack

Data Stack

Application Stack

Output

Academic Glory
DATA
SCIENCE

INTEGRATED APPLICATIONS

SERVICE

SERVICE
DATA SCIENCE

INTEGRATED APPLICATIONS

SERVICE

Output

Application Stack

Data Stack

Compute Stack

Novel Platform

HARDENING

SERVICE

Output

Application Stack

Data Stack

Compute Stack

Novel Platform
Knowledge among computer scientists about how to think of and approach the analysis of data is limited, just as the knowledge of computing environments by statisticians is limited. A merger of the knowledge bases would produce a powerful force for innovation.

—Bill Cleveland on *Data Science* (2001)
8 — “Therefore its name is called Babel, because there the Lord confused the language of all the earth; and from there the Lord scattered them abroad over the face of all the earth.”
BTW: MUMPS/Cache isn’t even a blip
Data Scientist: The Sexiest Job of the 21st Century

by Thomas H. Davenport and D.J. Patil

FROM THE OCTOBER 2012 ISSUE
“Well Frank, now that you've discovered that I was correct about patient monitoring, what are you going to do with all this expensive computer equipment we bought you”.

I looked at those steely blue eyes and said that I needed his help. He recommended that I learn some medicine, so that I would be better prepared to support doctors in what they did, instead of what they said they did.”

—Frank Starmer
DevOps and Continuous Integration

How containers and DevOps transformed Duke University's IT department

When Duke started looking into taming its VM sprawl, it became obvious that not just its infrastructure but its entire culture would need to change.

Image by: opensource.com

Provocations
First Provocations (with thanks to Ed Hammond)

1. Can learning healthcare exist with only a single patient?
2. Can we achieve learning health without first understanding the clinical setting?
3. Are we any good at understanding a healthy state?
4. What does learning health not encompass?
5. Do we have the necessary standards available to achieve true comparability of data?
Second Provocations (with thanks to Ed Hammond)

6. Why is learning health any different from any other initiative?
7. If you only write a paper about it, how does it count as learning health?
8. Are tomorrow’s quality measures going to be adequate to measure learning health?
9. Is the current state of technology ready for learning health?
10. Is learning health ready to insert itself into a torrent of change and rapid evolution?
“What we do is fall in love with words. But instead we should be thinking: **What do we want to accomplish?**”

—Ed Hammond
Continuing the conversation

Visit the website for the Duke Center for Health Data Science:
https://healthdatascience.duke.edu

Download these slides on GitHub:
https://github.com/rusincovitch/portfolio

Tweet at us:
@erichhuang and @rusincovitch

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