Disclosure

I am the chair of the Interim Steering Committee of the Learning Health Community, a grassroots not-for-profit organization.
I believe that people are naturally drawn to ideas that reflect imagination and vision.

By the end of this talk, I hope to convince you that pursuit of a learning health system makes good sense for the nation, for individual states, and for all health care delivery systems.

And maybe even that ‘Big Data’ is subsumed by the learning health system concept and vision.
Today’s Menu

• The state of nation’s health macro-system (very briefly)

• Learning, the Learning Health System (LHS), and ‘Big Data’

• Lessons from other ‘Big’ efforts

• Widespread calls for the LHS and nationwide progress
In One Figure...
In Words

• Spending 18% of GDP on health, which is unsustainable
  – 25% of which is “wasted”

• ~45th in infant mortality. Japan and Sweden have a rate 40% of ours.

• “To Err is Human” Study: ~100,000 deaths per year due to medical error. No improvement since then.

• Among five highly developed nations, the U.S. is last or next-to-last on five indicators of a “high functioning” health system
A Non-Learning System: We Can’t Detect “Safety Signals” (This graph could only be made in retrospect.)
Today’s Menu

• The state of nation’s health macro-system (very briefly)

• Learning, the Learning Health System (LHS), and ‘Big Data’

• Lessons from other ‘Big’ efforts

• Widespread calls for the LHS and nationwide progress
So…

Macro problems need system solutions.
The Institute of Medicine

Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care

Best Care at Lower Cost: The Path to Continuously Learning Health Care in America
Ultra Big Data: A National-Scale Learning Health System (LHS)
A Health System That Can Learn

• Every patient’s experience is available for study

• Best practice knowledge is immediately available to support decisions

• Improvement is continuous through routine ongoing study

• This happens routinely and inexpensively, and almost invisibly

• All of this is part of the culture
A Learning System *Routinely* Enables:

- **Pursuit of Best and Safer Care at Lower Cost:** Communities of interest discover what interventions are most cost-effective and are supported in implementing them.

- **Enhanced Public Health:** During an epidemic, new cases are reported directly from EHRs, the spread of the disease is predicted, and clinicians are alerted.

- **Consumer Empowerment:** Patients facing difficult medical decisions discover the experiences of other patients like them.
How To Learn: “Virtuous Cycles” of Study, Learning and Improvement

A Problem of Interest

- Assemble Experience Data
- Analyze Data
- Interpret Results
- Customized Feedback to Decision-Makers
- Take Action
- Decision to Study
Example of A Virtuous Learning Cycle

Reducing Falls in Nursing Homes

- **Assemble Data:**
  - How do we prevent falls?
  - What is the fall rate?

- **Take Action:**
  - Change Current Practice: In whole or part...

- **Interpret Results:**
  - Are the results credible?
  - What advice should be given?

- **Provide Feedback:**
  - Based on your current practice, you might want to consider...

- **Analyze Data:**
  - What practices associate with lower fall rates?

- **Decision to study falls**
Example of a ‘Big Data’ Rapid Learning Cycle

Interpret Results:
Are the results credible?
What advice should be given?

Take Action: Change
Current Practice:
In whole or part...

Provide Feedback:
Based on your current practice, you might want to consider...

Take Action: Change
Current Practice:
In whole or part...

Decision to study XXX

Assemble Data:
What is the incidence of XXX?
And characteristics of pts with the disease.

Analyze Data:
Has anything changed?

National Surveillance for XXX
How to Learn *Routinely*: A Single Platform Supporting Multiple Simultaneous “Virtuous Cycles”

Different Problems

Slower Cycle

Rapid Cycle

PLATFORM
Why a Platform?

If you needed to do 20 loads of wash in one day, where would you go: a laundromat or 20 different neighbors’ houses???

• Without a platform:
  – Every virtuous cycle is a “one off”, requiring its own agreements, technology, staffing, analytics, dissemination mechanisms
  – No economy of scale: The 10^{th} cycle costs as much as the first.

• With a platform:
  – All cycles are floated by the infrastructure
  – The 10^{th} cycle costs a small fraction of the first
The Environment of a Learning System

- Many virtuous cycles ongoing concurrently.
- Study and continuous improvement are the norm.
- Current best practice knowledge routinely available to clinicians and patients

“Learn from every patient”

“17 years to 17 months to 17 weeks to 17 days to 17 hours”
Learning Systems Can Exist at Any Level of Scale

- The scale of the system = the scope of the platform
- Local, state, national, global
The LHS and Big Data

• Virtuous cycles can use ‘Big Data’ techniques (but don’t have to)
• The current obsession with ‘Big Data’ emphasizes the data collection and analysis part of the loop, but largely ignores the feedback side
• IMHO, the Learning Health System is bigger than ‘Big Data’
Today’s Menu

• The state of nation’s health macro-system (very briefly)

• Learning, the Learning Health System (LHS), and ‘Big Data’

• Lessons from other ‘Big’ efforts

• Widespread calls for the LHS and nationwide progress
The LHS Can’t be Framed Purely as a Technical Problem
History Lesson: the Panama Canal

The French built the Suez Canal as a ditch in the desert.

They tried to build the Panama Canal the same way, and failed. They didn’t have the right perspective on the problem.
The Socio-Technical Approach that Built the Panama Canal
Today’s Menu

• The state of nation’s health macro-system (very briefly)

• Learning, the Learning Health System (LHS), and ‘Big Data’

• Lessons from other ‘Big’ efforts

• Widespread calls for the LHS and nationwide progress
Elements of Learning Systems are Assembling

The best proof that something can be done is someone already doing it:

1. Words: calls and reports
2. Digital data
3. “Learning Islands”
4. Data federations and networks
5. Grant programs
6. A grassroots coalition of the willing
7. A science of learning systems
...U.S. health care needs to adopt new work methods, outlined in the Institute of Medicine’s vision for a learning health system... Such methods would enable clinicians and health care managers to more rapidly improve value by continuously examining current clinical workflows, management tools from other service industries, burgeoning databases, and advances in applied sciences (especially health psychology and information, communication, and materials technologies). They could then use the insights gained to design and test innovations for better fulfilling patients’ health goals with less spending and rapidly scaling successful innovations.
The 2011 Federal Health IT Strategic Plan

Goal I: Achieve Adoption and Information Exchange through Meaningful Use of Health IT

Goal II: Improve Care, Improve Population Health, and Reduce Health Care Costs through the Use of Health IT

Goal III: Inspire Confidence and Trust in Health IT

Goal IV: Empower Individuals with Health IT to Improve their Health and the Health Care System

Goal V: Achieve Rapid Learning and Technological Advancement

Better Technology → Better Information → Transform Health Care
Progress: Health Data are Increasingly in Digital Form

Figure 1. Percentage of office-based physicians with EHR systems: United States, 2001–2013

NOTES: EHR is electronic health record. “Any EHR system” is a medical or health record system that is either all or partially electronic (excluding systems solely for billing). Data for 2001–2007 are from in-person National Ambulatory Medical Care Survey (NAMCS) interviews. Data for 2008–2010 are from combined files (in-person NAMCS and mail survey). Estimates for 2011–2013 data are based on the mail survey only. Estimates for a basic system prior to 2006 could not be computed because some items were not collected in the survey. Data include nonfederal, office-based physicians and exclude radiologists, anesthesiologists, and pathologists.

SOURCE: CDC/NCHS, National Ambulatory Medical Care Survey and National Ambulatory Medical Care Survey, Electronic Health Records Survey.
Progress: Learning “Islands”

- Organizations that have become Learning Health Systems at their level of scale.
- But don’t routinely connect with other islands.
Progress: Inter-organizational Data Federations and Networks
Progress: Grant Programs

- NIH “Big Data to Knowledge”
- PCORI Research Networks
- NSF Smart and Connected Health
Progress: Grassroots Movement

- National “Summit” convened in May 2012 to envision LHS as set of shared beliefs
- A Dumbarton Oaks conference for the LHS
- ~70 organizations represented at the National Press Club
- Resulted in 10 consensus Core Values
- 61 organizations have formally endorsed
- Giving rise to a Learning Health Community
61 Endorsements of the LHS Core Values* (As of 6/17/2014)

*To be included on a Learning Health Community public website that will list all organizations that have endorsed the LHS Core Values.
LHS Research Challenges Workshop: April 2013

- A national workshop to explore the research challenges inherent in achieving a high functioning LHS
- Computer science to epidemiology to economics
- 45 invited participants plus Federal liaisons
- Report (“Toward a Science of Learning Systems”) at healthinformatics.umich.edu/lhs/nsfworkshop
Workshop Findings at Two Levels

1. What we were asked to do: the research questions that must be addressed to meet LHS system level requirements
   - 106 questions organized into four categories and 19 sub-categories

2. Something transcendent: A vision of a science of cyber-social ecosystems necessary to address these questions (and achieve the LHS)
In Sum

• The nation’s health macro-system needs help

• The Learning Health System (LHS), the ultimate ‘Big Data’ system, can help

• It’s important to view it as a social-technical system

• Elements of a national LHS are assembling
Thanks & Write to Me

cpfried@umich.edu