The Learning Health System: Transforming Health Culture by Empowering Learning from Every Patient for Every Patient

Joshua C. Rubin, JD, MBA, MPH, MPP
University of Michigan and Learning Health Community
Monday, September 29, 2014
Farcus

by David Waisglass
Gordon Coulthart

100% PURE BEEF HAMBURGERS

"What conflict of interest?! I work here in my spare time."

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WAISGLASS/COUTHART

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Preliminary Acknowledgement

Some portions of this presentation were adapted from the work of my colleague, Dr. Charles P. Friedman.
Thank You AHIMA!
Thank You Meryl Bloomrosen!

The Learning Health System (LHS) and AHIMA’s Vision

“As the ‘Vision’ section of AHIMA’s website states, AHIMA aims to ‘lead the advancement and ethical use of quality health information to promote health and wellness worldwide.’ In many ways, the Learning Health System’s (LHS) overarching vision represents what can happen when diverse stakeholders connect and harmonize efforts at multiple levels to do just that.”
Everyone Will Be a Patient/Caregiver!
A Visit to the Doctor – What Would You Really Like to Hear?

- Certain, instant, painless, and free
- How about recommendations informed by the experiences of:
  - Every patient?
  - Patients like you?

Live better, together.
Many modern physician specialists like to think of their work as grounded in strong science. Yet 5 years ago, a group of cardiologists published their findings on the science underlying over 2700 practice recommendations issued by their specialty societies. Only 314 (or 11%) were based on ‘level A’ evidence, that is, evidence based on multiple well-done randomized trials. Nearly half of the recommendations were based solely on ‘expert opinion.’

According to Sloan-Kettering, only around 20 percent of the knowledge that human doctors use when diagnosing patients and deciding on treatments relies on trial-based evidence. It would take at least 160 hours of reading a week just to keep up with new medical knowledge as it’s published, let alone consider its relevance or apply it practically. Watson’s ability to absorb this information faster than any human should, in theory, fix a flaw in the current healthcare model. Wellpoint’s Samuel Nessbaum has claimed that, in tests, Watson’s successful diagnosis rate for lung cancer is 90 percent, compared to 50 percent for human doctors.
The LHS as a Vehicle for Democratizing Health: Some Guidance from JAMA, Circa 1906 (and from Harvard Business Review, Circa 2014)

**JAMA**: April 21, 1906, Vol XLVI, No. 16

**ARTICLE**

THE AUTOMOBILE FOR THE PHYSICIAN.

To no class is the development of the automobile of more importance than to physicians. How to reach their patients in the quickest, surest, easiest and cheapest manner is a practical problem to them. The doctor’s buggy is a familiar object in every hamlet, village, town and city, and is often looked for with an anxiety verging on impatience by rich and poor alike. In such cases the horse has always been too slow; nowadays it is always too slow, especially for the ambitious or busy doctor. As the horse has been superseded by electricity in street car transportation, so must the faithful old steed step aside for the automobile, either now or very soon.

This week we give the opinions of a large number of physicians who have had experience with the horseless vehicle. Our readers who were already in doubt whether or not to give up the

**Health Care Insights from Harvard Business Review**

Most hospitals are designed for the nineteenth century. Many doctors don’t know to share power. Most patients with complicated problems don’t receive coordinated care. It’s time for a revolution—led from within.

6/2014
Our Current “System” is a Non-Learning “System”

• Instead of being available for study, data from patients’ experiences reside in silos.

• Instead of being readily available to support decisions, best practice knowledge resides in journals where it sits for 17 years before it is widely adopted.

• Instead of studies being continuous, “studies” are separated from practice.

• Instead of being routine and inexpensive, the studies we do are cumbersome and cost-prohibitive.

• Instead of a “safety culture” valuing continuous improvement, we have a “blame” culture that hides the events we need to know about in order to learn from them.
The State of Today’s Non-Learning Non-Health Non-System

From *The Mentalist*:

• ...professionals who prescribe **drugs** they know little about

• to cure **diseases** they know even less about

• for **people** they know nothing about...

But that’s just pure fiction, right?
Learning about Drugs and Treatments?

Courtesy of Kenneth Mandl
Learning about Diseases?

75 Years of Mortality in the United States, 1935–2010

Donna L. Hoyert, Ph.D.

Heart disease and cancer remained the 1st and 2nd leading causes of death, respectively, over the 75-year period.

Figure 2. Percentage of all deaths due to five leading causes of death by year. United States, 1935–2010

NOTE: 2010 data are preliminary.
Learning about Patients?
Learning from Patients?
Learning for Patients?

Chief Complaint: Preop evaluation

Preoperative Medical Evaluation

RUBIN, [...]
June 19, 2014

Mr. [...], Rubin is a [ ] year old [ ] lady seen through the kind courtesy of [ ] for preoperative evaluation prior to [ ] July 14.
A Non-Learning Healthcare *Culture*...

- Is not healthy?
- Is not caring?
- Is not systemic?
- Is not humane?
- Is not ethical?
- Is not sustainable?
“Unsustainable” – We Can’t Afford NOT to Do This!

“The price of doing the same old thing is far higher than the price of change.”
– Former President Bill Clinton
An (Unhealthy) Inconvenient Truth: One Hour...
The Impact of NOT Learning – If Our Healthcare System Were a Company...

- CEO – We spend way more than our peers and rank next to last on key indicators of being “high-functioning” (and we’re comparatively inefficient).
- CFO – We waste 30 cents of every dollar we spend (totaling $750 billion per year – larger than all but 18 countries’ GDPs); we hand 10 cents to criminals.
- CIO – We throw away 97% of the experience data needed to address our #2 killer (our #1 killer would give you a heart attack).
- CKO – We only use “level A” evidence 11% of the time; overall, only 20% of this “knowledge” utilized is evidence-based.
- Diversity – Not even close to representative...
- Customer Relations – Over 45% of our customers do not get the service (care) recommended; when they do get what is recommended, in certain cases, it works only 20%-30% of the time.
- Safety Officer – We used to believe preventable mistakes killed 98,000 consumers (patients in hospitals) per year, but new studies suggest that figure could be as high as 400,000.
- Quality Control – Quality improves at around 2% annually (*2 in 35 years).
- Mail Room – It takes about 17 years; lethally slow, falling 400+ years behind.
- PR – Infant mortality (compare with other nations).
- Human Resources – We have extraordinary people, but difficulty organizing and getting them the resources and information they need and desire.
- Child Care – Has a solution...
The Plight in Figures – Global Comparisons

Bloomberg Visual Data: Bloomberg Best (and Worst)

Most Efficient Health Care: Countries

<table>
<thead>
<tr>
<th>Rank</th>
<th>Country</th>
<th>Efficiency score</th>
<th>Life expectancy</th>
<th>Health-care cost as a percentage of GDP per capita</th>
<th>Health-care cost per capita</th>
</tr>
</thead>
<tbody>
<tr>
<td>44</td>
<td>Turkey</td>
<td>33.4</td>
<td>73.9</td>
<td>6.5</td>
<td>696</td>
</tr>
<tr>
<td>45</td>
<td>Iran</td>
<td>31.5</td>
<td>73.0</td>
<td>5.1</td>
<td>346</td>
</tr>
<tr>
<td>46</td>
<td>United States</td>
<td>30.8</td>
<td>78.6</td>
<td>17.2</td>
<td>8,609</td>
</tr>
<tr>
<td>47</td>
<td>Serbia</td>
<td>27.2</td>
<td>74.6</td>
<td>12.0</td>
<td>622</td>
</tr>
<tr>
<td>48</td>
<td>Brazil</td>
<td>17.4</td>
<td>73.4</td>
<td>9.9</td>
<td>1,121</td>
</tr>
</tbody>
</table>
A Health Equity Issue? 
A Civil Rights Issue?

We are pleased to distribute the following article by John Castellani, President and CEO of the Pharmaceutical Research and Manufacturers of America (PhRMA), that reinforces the value of increasing the recruitment of diverse populations into clinical trials.

The Underlying Condition: Increasing Diversity in Clinical Trials

By John Castellani - February 20, 2014

Opinion: African-Americans, at 12 percent of the population, comprise only 5 percent of clinical-trial participants; the numbers for Hispanics are 16 percent and 1 percent. It's time for that inequity to change, PhRMA's CEO says.
The old industry model of prescribing drugs for a large patient population with mixed results is due for a change, said Taurel, who served as CEO of Lilly from 1998 until March of this year. Patients are too often disappointed with their treatment, he said, and with good reason. Efficacy rates of medicines prescribed for some of the most common illnesses average around 50 percent.

That means some are more effective than 50 percent, but some are far less. Drugs for reducing cholesterol, for instance, work about 80 percent of the time, Taurel said, while many cancer drugs are only 20 percent effective.

“There will always be some trial and error in the practice of medicine, but certainly we can do better than 50/50.”
Adoption of new practices years after discovery

A. Balas, Institute of Medicine, 2001

Table II. Landmark Clinical Trials and Current Rate of Use for Selected Procedures

<table>
<thead>
<tr>
<th>Clinical Procedure</th>
<th>Landmark Trial</th>
<th>Current Rate of Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammography</td>
<td>1982 [13]</td>
<td>70.4% [8]</td>
</tr>
<tr>
<td>Fecal occult blood test</td>
<td>1986 [16]</td>
<td>17% [17]</td>
</tr>
<tr>
<td>Diabetic foot care</td>
<td>1993 [18]</td>
<td>20% [19]</td>
</tr>
</tbody>
</table>

Flu vaccine, year 32: 55% doing it, 45% still not
Beta blockers, year 18: 62% doing it, 38% still not
Cholesterol, year 16: 65% doing it, 35% still not
Diabetic foot care, year 7: 20% doing it, 80% still not

Slide Courtesy of “e-Patient Dave” deBronkart
To Err is Human... But Could We do a Better Job of Learning from Our Mistakes?

Deaths by medical mistakes hit records

Published on Healthcare IT News (http://www.healthcareitnews.com)

Deaths by medical mistakes hit records

Posted on Jul 18, 2014
By Erin McCann, Associate Editor

It’s a chilling reality – one often overlooked in annual mortality statistics: Preventable medical errors persist as the No. 3 killer in the U.S. – third only to heart disease and cancer – claiming the lives of some 400,000 people each year. At a Senate hearing Thursday, patient safety officials put their best ideas forward on how to solve the crisis, with IT often at the center of discussions.

Hearing members, who spoke before the Subcommittee on Primary Health and Aging, not only underscored the devastating loss of human life – more than 1,000 people each day – but also called attention to the fact that these medical errors cost the nation a colossal $1 trillion each year.

“The tragedy that we’re talking about here (is) deaths taking place that should not be taking place,” said subcommittee Chair Sen. Bernie Sanders, I-Vt., in his opening remarks.

[See also: EHR adverse events data cause for alarm]

Among those speaking was Ashish Jha, MD, professor of health policy and management at Harvard School of Public Health, who referenced the Institute of Medicine’s 1999 report To Err is Human, which estimated some 100,000 Americans die each year from preventable adverse events.

“When they first came out with that number, it was so staggeringly large, that most people were wondering, ‘could that possibly be right?’” said Jha.

Some 15 years later, the evidence is glaring. “The IOM probably got it wrong,” he said. “It was clearly an underestimate of the toll of human suffering that goes on from preventable medical errors.”
This Situation Really is Criminal...

Health-care fraud in America
That’s where the money is

How to hand over $272 billion a year to criminals
May 31st 2014 | From the print edition

In America the scale of medical embezzlement is extraordinary. According to Donald Berwick, the ex-boss of Medicare and Medicaid (the public health schemes for the old and poor), America lost between $82 billion and $272 billion in 2011 to medical fraud and abuse (see article). The higher figure is 10% of medical spending and a whopping 1.7% of GDP—as if robbers had made off with the entire output of Tennessee or nearly twice the budget of Britain’s National Health Service (NHS).
Conserving (Real-World) Human Experience and Democratizing Health: A Patient Activist’s Questions...

“What if your data did not have to die in dusty paper files and unconnected electronic silos? What if many private institutions, non-profit organizations, research centers, government entities and individual patients decided to share data? What if we could do this over a span of years creating an ever larger data set? That data set could be accessed by the many in a timely fashion that will enable both the individual and the organization to make informed health decisions.”

– Regina Holliday at the Learning Health System Summit, 2012
Electronically Capturing and Conserving Human Experience...

GOVERNMENT HEALTH IT
Published on Government Health IT (http://www.govhealthit.com)

EHR incentive payments climb toward $24 billion
By Diana Manns, Senior Editor
The Centers for Medicare & Medicaid Services have paid out $23.7 billion in electronic health record incentives under the meaningful use program through last month — up from $22.9 billion in April, according to Elizabhet Myers, policy and outreach lead at the CMS Office of eHealth Standards and Services at the June 10 monthly Health IT Policy committee meeting.
The Broader Context...

IT in People’s Lives Today
The “Demand” and the Technology
(Gartner and Others)

- 50% of U.S. 21 year olds have created Web content
- Average American teenager sends 2,282 SMS text messages per month
- 70% of U.S. 4 year olds have used a computer
- Facebook – Over 500 million “friends”
- The Nielsen Company survey: almost 1/3 of mobile phone users use a smartphone and Hispanics, Asian/Pacific Islanders and African Americans have highest smartphone adoption rates
- Your smartphone is one million times cheaper, one thousand times more powerful, and one hundred thousand times smaller than MIT’s 1965 computer
- Over 31 billion Google searches performed last month, up tenfold from three years ago
- More video uploaded to YouTube in the last two months than if ABC, CBS, and NBC had been airing content 24/7 since 1948
- Wikipedia, now a decade old, averages 4,300 new articles per day
- Over 350,000 apps for iPhone alone in Apple’s App Store
- Ray Kurzweil: building > pocket > blood cell in 25 years

Source: Forrester’s June 24, 2005, “The Seeds Of The Next Big Thing” report
Note: This graph contains data that projects future IT investments from 2005 to 2024.
“Learning How to Learn”
(and Breaking Down Barriers to Continuous Learning...)

Patient/Consumer Engagement  Clinical Care and Quality Improvement

Public/Population Health  Research

Learning
The LHS Vision: Ripples of Health and Their Synergistic Fusion into Currents of Transformation

Each time a man stands up for an ideal, or acts to improve the lot of others, or strikes out against injustice, he sends forth a tiny ripple of hope... and crossing each other from a million different centers of energy and daring those ripples build a current that can sweep down the mightiest walls of oppression and resistance.

(Robert Kennedy)
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 ongoing study.
- This happens routinely and inexpensively, and almost invisibly.
- All of this is part of the culture.
A National-Scale Health System That Learns A System of Health Learners Across Our Nation
Personal Computing and the “Intergalactic Network”, 1962

“... An electronic commons open to all: ‘the main and essential medium of informational interaction for governments, institutions, corporations, and individuals.’”

Preamble to the LHS Core Values, 2012

• The national-scale, person-centered, continuous and rapid learning health system (LHS) will improve the health of individuals and populations. The LHS will accomplish this by generating information and knowledge from data captured and updated over time – as an ongoing and natural by-product of contributions by individuals, care delivery systems, public health programs, and clinical research – and sharing and disseminating what is learned in timely and actionable forms that directly enable individuals, clinicians, and public health entities to separately and collaboratively make informed health decisions…

• The proximal goal of the LHS is to efficiently and equitably serve the learning needs of all participants, as well as the overall public good…

• Ultimately recognizing that better health for all is a global imperative, the LHS aspires to embrace strategic approaches that facilitate harmonization with other nations in pursuit of a global system, as well as within the United States.
The LHS Continuous Learning Environment

• 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”
The LHS as One Reusable Infrastructure that Supports...

- Research  
  - Clinical  
  - Comparative effectiveness  
  - Translational
- Public Health  
  - Surveillance  
  - Situational awareness
- Quality Improvement  
  - Health process and outcomes research  
  - Best practice dissemination
- Consumer Engagement  
  - Knowledge-driven decision making
How to Learn: “Virtuous Cycles” of Study, Learning, and Improvement

A Problem of Interest

- Decision to Study
- Take Action
- Customized Feedback to Decision-Makers
- Interpret Results
- Analyze Data
- Assemble Experience Data
How to Learn *Routinely*: A Single Platform Supporting Multiple Simultaneous “Virtuous Cycles”
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.
Table: Characteristics of a Continuously Learning Health Care System

<table>
<thead>
<tr>
<th>TABLE: Characteristics of a Continuously Learning Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Science and Informatics</strong></td>
</tr>
<tr>
<td>• <strong>Real-time access to knowledge</strong>—A learning health care system continuously and reliably captures, curates, and delivers the best available evidence to guide, support, tailor, and improve clinical decision making and care safety and quality.</td>
</tr>
<tr>
<td>• <strong>Digital capture of the care experience</strong>—A learning health care system captures the care experience on digital platforms for real-time generation and application of knowledge for care improvement.</td>
</tr>
<tr>
<td><strong>Patient-Clinician Relationships</strong></td>
</tr>
<tr>
<td>• <strong>Engaged, empowered patients</strong>—A learning health care system is anchored on patient needs and perspectives and promotes the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team.</td>
</tr>
<tr>
<td><strong>Incentives</strong></td>
</tr>
<tr>
<td>• <strong>Incentives aligned for value</strong>—In a learning health care system, incentives are actively aligned to encourage continuous improvement, identify and reduce waste, and reward high-value care.</td>
</tr>
<tr>
<td>• <strong>Full transparency</strong>—A learning health care system systematically monitors the safety, quality, processes, prices, costs, and outcomes of care, and makes information available for care improvement and informed choices and decision making by clinicians, patients, and their families.</td>
</tr>
<tr>
<td><strong>Culture</strong></td>
</tr>
<tr>
<td>• <strong>Leadership-instilled culture of learning</strong>—A learning health care system is stewarded by leadership committed to a culture of teamwork, collaboration, and adaptability in support of continuous learning as a core aim.</td>
</tr>
<tr>
<td>• <strong>Supportive system competencies</strong>—In a learning health care system, complex care operations and processes are constantly refined through ongoing team training and skill building, systems analysis and information development, and creation of the feedback loops for continuous learning and system improvement.</td>
</tr>
</tbody>
</table>
Some LHS Use Cases...

science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and healthcare.” Understanding the transformative potential of a system that optimizes every participant’s ability to learn from the ever-increasing amount of digitally captured health data, patient activist Regina Holliday in 2012 described a key component of the LHS vision by asking, “What if your data did not have to die in dusty paper files and unconnected electronic silos? What if many private institutions, non-profit organizations, research centers, government entities and individual patients decided to share data? What if we could do this over a span of years creating an ever-larger data set? That data set could be accessed by the many in a timely fashion that will enable both the individual and the organization to make informed health decisions.”

LHS Use Cases Illustrate Transformative Potential
The LHS will, as a single infrastructure producing cycles of learning and continuous improvement on many scales, serve the learning needs of all stakeholders—empowering them to take actions informed by this timely-generated knowledge, and bringing about transformative change.

Several sample use cases serve to illuminate the potential of an LHS:

- When a patient faces a difficult medical decision, in collaboration with clinicians, the patient will be able to base that decision on the real world experiences of similar patients. Such informed decision-making is rendered possible precisely because the data describing those experiences do not die in paper files or electronic silos and remains available as a learning resource for others.
- A stakeholder interested in post-market surveillance of a new drug will be able to rapidly detect safety signals and recognize the imperative to modify personalized dosage algorithms. This detection will come directly from electronic health record (EHR) data captured as a byproduct of care delivery, as well as other sources. In turn, modified clinical decision support rules based on these personalized dosage algorithms can be rapidly created and fed into EHR systems.
- During an epidemic public health stakeholders will be able to receive near real-time reports of new cases. Rapid analysis based on this quick, systematic reporting will enable clinicians to be alerted as the disease spreads to new geographic areas.
- Multiple and diverse stakeholders with shared interests in developing innovative solutions to address important health and healthcare challenges will be empowered to utilize the same infrastructure that enables the previously described use cases to also serve as a foundation upon which to develop and iteratively refine as-yet unimagined innovations aimed at realizing transformative impacts.

Why the LHS is Urgently Needed
Single-purpose initiatives aimed at learning from real world experiences of patients captured as a byproduct of care delivery illustrate the potential impact of such learning when it is made routine and empowered to occur at a large scale. According to the National Cancer Institute (NCI), since the 1970s significant portions—presently around 4,000 children in NCI-sponsored trials alone—of the approximately 10,000 children per year diagnosed with cancer have entered clinical trials. With such a high rate of participation and large data field to study, the United States has been able to greatly improve and tailor treatments and survival rates for childhood cancers. Treatment has improved dramatically.

The American Childhood Cancer Organization has found that in 1977, five-year survival rates hovered around 50 percent. By
Democratizing (Public) Health: Empowering Millions to Participate...
The LHS as a Fractal

- At every level of scale, it looks pretty much the same
- Local, state, regional, national, global
- A system of like sub-systems
LHS Fever: Words
“The meaningful use space is almost endless in the ways we need to use it today, whether for public health, disaster or improving populations, but also to create a learning system, one that is able to enhance the knowledge base so that nobody gets left behind... By 2024, we are very hopeful that’s the kind of environment we’re going to have.” – National Coordinator Karen DeSalvo, 4/10/2014
Connecting Health and Care for the Nation: 
A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure

10-Year Agenda: The Learning Health System

By year 10, the nation’s health IT infrastructure will support better health for all through a more connected health care system and active individual health management. Information sharing will be improved at all levels of public health, and research will better generate evidence that is delivered to the point of care. Advanced, more functional technical tools will enable innovation and broader uses of health information to further support health research and public health.
LHS Fever in Action

- Learning “islands”
- Data federations and networks
- Grant programs
A Grassroots Movement Anchored in the LHS Core Values

• Person-Focused
• Privacy
• Inclusiveness
• Transparency
• Accessibility
• Adaptability
• Governance
• Cooperative and Participatory Leadership
• Scientific Integrity
• Value

http://www.LearningHealth.org/
For more information, please contact:
Bridget Stratton
Public Relations
312-233-1097
bridget.stratton@ahima.org

AHIMA Endorses Learning Health System’s Core Values

Supports national collaborative effort to share quality data, information to improve patient health

CHICAGO – June 16, 2014 – The American Health Information Management Association (AHIMA) announces its endorsement of the core values of a learning health system (LHS) that supports an effort to share secure, high-quality data to improve patient health.

The LHS concept represents a transformative vision of data, information, and knowledge sharing to empower all stakeholders to routinely engage in virtuous cycles of continuous learning and improvement.
January 22, 2013

Dear Colleague:

I am writing to invite you and your organization to support healthcare transformation by joining a multi-stakeholder movement to develop a national learning health system (LHS).

The learning health system (LHS) will support the transformation of American healthcare to which we are all committed, enabling us to learn more rapidly from the tremendous amounts of digitally stored health information—to help individuals make better-informed care decisions, to improve patient care, and to support public health and biomedical research.

A collaborative, grassroots approach to building a national learning health system is growing out of the May 2012 LHS Summit sponsored by the Joseph H. Kanter Family Foundation. At the Summit, over 80 organizations spanning the health sector worked together to develop a set of LHS Core Values (attached). I am proud that Geisinger is one of the 36 organizations that have formally endorsed the Core Values and is a active member of the Learning Health Community (http://www.learninghealth.org) that has grown out of it.

Please review the attached Core Values and consider endorsing them using the attached endorsement template. Endorsing these Core Values will make an important statement and link your organization with a growing network of like-minded organizations. (Your endorsement does not commit your organization to support the Learning Health Community in any way.)

Additional information can be found in the attached article, the reports from the Institute of Medicine (IOM) reports listed below, and the Federal Health IT Strategic Plan, also listed below. Please direct specific questions about the Learning Health Community and the endorsement process to Josh Rubin, Executive Director of the Joseph H. Kanter Family Foundation, at Josh@JoshRubin.com.

Sincerely,

Glenn D. Steele, Jr., MD, PhD
President & Chief Executive Officer

Attachments

WWW.GEISINGER.ORG
62 Endorsements of the LHS Core Values*
(As of 6/25/2014)
Brief Overview of the Learning Health Community

• Vision
  – The Learning Health Community ("Community") aims to mobilize and empower multiple and diverse stakeholders to collaboratively realize a national-scale (and ultimately global), person-centered, continuous and rapid learning health system (LHS). The vision for the LHS is embodied in the consensus LHS Core Values dated July 20, 2012; these Core Values will guide and underpin the development of the LHS.

• Mission and Approach
  – The Community’s mission is to galvanize a national grassroots movement in which multiple and diverse stakeholders work together to transform healthcare and health by collaboratively realizing the LHS vision. It will enable and catalyze positive steps toward achieving this vision.
  – Members of the Community are bonded together by their shared determination to realize the LHS and their common belief in the Core Values that serve to underpin it.

• Initiatives
  – Consistent with the emergent characteristics of the LHS itself and the grassroots approach of the Community, major steps toward realizing the LHS vision are accomplished through self-organizing, multi-stakeholder, collaborative initiatives. Each initiative is hosted by a trusted neutral convener.

http://www.LearningHealth.org/
The Learning Health Community:
Interim Steering Committee Members

- Holt Anderson, North Carolina Healthcare Information and Communications Alliance, Inc.
- Kate Berry, National eHealth Collaborative
- Jeffrey Brown, Harvard Pilgrim Health Care Institute
- Harry Cayton, Professional Standards Authority for Health and Social Care UK
- Charles Friedman, University of Michigan (Interim Chair)
- Claudia Grossmann, Institute of Medicine
- Robert Kolodner, ViTel Net and Open Health Tools
- Rebecca Kush, Clinical Data Interchange Standards Consortium (Ex Officio)
- Allen Lichter, American Society of Clinical Oncology
- Janet Marchibroda, Bipartisan Policy Center
- Frank Rockhold, GlaxoSmithKline
- Joshua Rubin, University of Michigan
- Jonathan Silverstein, NorthShore University HealthSystem
- Richard Tannen, University of Pennsylvania
- James Walker, Siemens Healthcare

http://www.LearningHealth.org/
Example of the CDISC-Convened Essential Standards to Enable Learning (ESTEL) Initiative

- ESTEL charter, “just enough” standardization
  - A self-organizing Learning Health Community initiative
- Hosted meetings to date
  - Hosts and diverse participants
  - Webinars and conference calls
- Some outcomes and work in progress
  - Continuous refinement of scope of work
  - Collaborative development of use cases
  - “Hourglass model” consensus
  - Participants, metadata, data model
  - Identification of next steps
Launching the NCHICA-Hosted LHS Governance Initiative...
The LHS Cannot be Framed as a Purely Technical Challenge
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 transcendental:* a vision of a science of learning systems necessary to address these questions (and achieve the LHS)
The LHS Vision: Potential Far-Reaching Transformative Impacts...

- Impacts of the LHS on the health of individuals, communities, and populations (and the fiscal health of the system itself)
- Impacts of the infrastructure created – empowering continuous learning, improvement, and innovation
- Impacts from the multi-stakeholder collaborative community (communities) of interest, social capital, and movement catalyzed
- Impacts of the new cross-disciplinary science of learning systems/cyber-social ecosystems in innovatively addressing societal challenges beyond the health domain
Let’s Achieve Our Shared LHS Vision Together!

While the fusion of great ideas, insights, and interests from seemingly divergent disciplines and multiple and diverse stakeholders can be more challenging than fission (splitting apart), it is also far more powerful. The community, anchored in the LHS Core Values, is actively working to inspire and catalyze the grassroots collaboration required to harmonize the great work taking shape into the LHS vision that can deliver on its promise to transform healthcare.

The Learning Health Community recognizes that LHS will be a foundation for continuous improvement in healthcare that touches the lives and health of current and future generations across the US and around the world—but only if healthcare stakeholders achieve it together. Like any grassroots endeavor, the Learning Health Community and the initiatives it spawns will become what the members of this community make it into.

To help give shape to the LHS, the authors of this article encourage your active participation and invite you to contact them to become engaged in the movement.
“Let’s all work together to give the gift of health to our children and our nation.”

- Envisioning the future; what is right?

- How do we all work collaboratively to realize this vision?

- Why is doing so (together) urgent?
Two Questions to Consider*

1. What can a LHS do for me?
2. What can I do for a LHS?

*In your role as a health information management professional, as a patient/caregiver, as a citizen, and in other roles.
“Together We Will!”

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

– Margaret Mead
Questions?

Thank You!

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