“Power to Patients”

Second Learning Health System Summit
Thursday, December 8, 2016

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It Couldn’t Be Done

BY EDGAR ALBERT GUEST

Somebody said that it couldn’t be done
But he with a chuckle replied
That “maybe it couldn’t,” but he would be one
Who wouldn’t say so till he’d tried.
So he buckled right in with the trace of a grin
On his face. If he worried he hid it.
He started to sing as he tackled the thing
That couldn’t be done, and he did it!

Somebody scoffed: “Oh, you’ll never do that;
At least no one ever has done it;”
But he took off his coat and he took off his hat
And the first thing we knew he’d begun it.
With a lift of his chin and a bit of a grin,
Without any doubting or quiddit,
He started to sing as he tackled the thing
That couldn’t be done, and he did it.

There are thousands to tell you it cannot be done,
There are thousands to prophesy failure,
There are thousands to point out to you one by one,
The dangers that wait to assail you.
But just buckle in with a bit of a grin,
Just take off your coat and go to it;
Just start in to sing as you tackle the thing
That “cannot be done,” and you’ll do it.
Keep Me Safe

“I had shoulder surgery [and] I knew I had an adverse event when I couldn’t move half my face following ...”

Read More

Please Help

“I have been trying to get my records from my former Pain Management [doctor] who moved out of my area ...”

Read More
Ben-Gurion
Your Life, Your Health

Sharing your digital health data could save your life

JOSEPH H. KANTER
“I want to commend Joe Kanter, the Kanter Family Foundation and the Agency for Healthcare Research and Quality for sponsoring this conference. The conference theme made me think of the popular 1960s slogan, ‘Power to the People.’ Given the importance of health care in our society today, I think you’ve captured the 2005 version of that with ‘Power to Patients.’”

William Novelli, Former CEO of AARP
Give Up Your Data to Cure Disease

By DAVID B. AGUS  FEB. 6, 2016
GREENBELT
1937


PRINCE GEORGE'S COUNTY HISTORICAL SOCIETY
“Just as the moon landing took 10 years to accomplish, framing the president’s health IT goal in a similar timeframe puts this effort into context... Joe, you’ve given us all a benchmark for persistence and vision. We’re living the life of Joe Kanter’s vision.”

Dr. David Brailer, The First National Coordinator for Health IT
Transforming Kanter's Vision

Joshua C. Rubin, MPH ‘04

Anyone familiar with the Johns Hopkins University Bloomberg School of Public Health knows the school's motto, “Saving Lives, Protecting Health—Millions at a Time.” Imagine if an information technology (IT) initiative could engage millions of ordinary people in doing just that, simply as a byproduct of living their lives and receiving healthcare services.

Many millennia ago, humankind invented writing, and that changed everything. A concept known as a Learning Health System (LHS) promises to do for healthcare no less than the invention of writing did for human civilization; to enable us to record and learn from our collective experiences so that future generations can pick up where previous ones leave off.
Joe's Jog Park Washington D.C.
“Power to Patients”
The Price of Freedom

Freedom Wall holds 4,048 gold stars. Each gold star represents one hundred American service personnel who died or remain missing in the war. The 405,399 American dead and missing from World War II are second only to the loss of more than 620,000 Americans during our Civil War.
“Anyone who says one man can’t make a difference hasn’t met Joe Kanter.”

Former Senate Majority Leader Bob Dole (R-KS)
“And that’s why I was so pleased that the Kanter Family Foundation and the current agency have teamed up to create the Health Legacy Partnership and to bring it to the stage it’s at today. I regard it as a continuation and hopefully a completion of the effort that I began so many years ago... This is so simple, so logical and so powerful in its implementation that it boggles the mind our society has not done this before now.”

Former Senate Majority Leader George Mitchell (D-ME)
Leadership Conference 2015

On March 13th we unified a diverse group of speakers who all share a common passion for the Learning Health System vision to discuss accomplishments and accelerate progress together in 2015.

Leadership Conference:
Unifying Accomplishments in the Learning Health System and Accelerating Progress
“Joe’s interest in this arena was stimulated by early work on shared decision-making. This pioneering work by Jack Wennberg and his colleagues was inspired by the radical idea that when there are two or more options, the penultimate decision-maker must be the patient.”

Dr. Carolyn Clancy, Director of AHRQ
Weaving Together
A HEALTHCARE Improvement Tapestry

LEARNING HEALTH SYSTEM BRINGS TOGETHER
HEALTH IT DATA STAKEHOLDERS TO SHARE
KNOWLEDGE AND IMPROVE HEALTH

By: Jonathan C. Babis, MD, MPH, MFP, and Charles P. Finkelman, MD
The Learning Health System (LHS)

“... one in which progress in 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 health care.” (IOM)
A Nationwide Learning Health System: A System of Health Learners Across Our Nation

- All-Inclusive
- Large Scale
- Decentralized
- Reciprocal

Governance
Engagement
Data Aggregation
Analysis
Dissemination

- Pharma
- Patient Groups
- Tech Industry
- Universities
- Government/Public Health
- Research Institutes
- Healthcare Delivery Networks
An (Unhealthy) Inconvenient Truth: “The Witching Hour”

By Joseph H. Kanter, For The Inquirer
POSTED: December 28, 2014

Even at the age of 91, I can write an opinion piece for this newspaper in about an hour. Data from respected institutions and researchers show that the following things occur in the U.S. during each hour.

Sixty-eight people die from heart disease, our number-one cause of mortality for more than 75 years.

Sixty-five succumb to cancer, our number two killer during the same decades.

Twenty-seven women are found to have breast cancer, and eighteen of them will get treatments that don’t work.
# LHS Core Values

## Core Values of the Learning Health System

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<td>3) Inclusiveness</td>
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<td>7) Governance</td>
<td>8) Leadership</td>
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<td>9) Scientific Integrity</td>
<td>10) Value</td>
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https://lillypad.lilly.com/entry.php?e=8284

www.LearningHealth.org
107 Endorsements of the LHS Core Values*
(As of 10/14/2016)

*To be included on the www.LearningHealth.org website.
Interoperability provides the underpinning infrastructure that is fundamental to enabling a learning health system.

Figure 2: A Learning Health System

**A Learning Health System:**

“...will improve the health of individuals and populations. The learning health system 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 learning health system is to efficiently and equitably serve the learning needs of all participants, as well as the overall public good.”

Taken from the *Learning Health Community’s Preamble*

**Scope**

The Roadmap is intended for health IT stakeholders who will build the infrastructure necessary for interoperability and for those who will use that infrastructure. This iteration of the Roadmap focuses primarily on actions that will enable a majority of individuals and providers across the care continuum to send, receive, find and use priority data domains.
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 healthcare professional, as a patient/caregiver, as a citizen, and in other roles.
“Let’s All Work Together to Give the Gift of Health...”