Toward Complete & Sustainable Learning Systems

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Disclosure

I am the chair of the Interim Steering Committee of the Learning Health Community, a grassroots not-for-profit organization.
How I Got Here

- **2009-2011**: Encountered the LHS as ONC’s Chief Science Officer and engaged with IOM
- **2011-2012**: Organized LHS National Summit, which spawned a national grass-roots Community
- **2013**: Organized NSF workshop on LHS research challenges
- **Now**: Chair of first academic department of LHS
Main Points

Goal from Lynn’s presentation:

To learn as quickly as possible about the best medical care for each person—and to deliver it.

• This requires support of complete learning cycles
  – Without complete cycles we cannot improve

• This requires a scalable infrastructure (platform)
  – Without a platform there will be chaos
A Health System That Can Learn

• Every patient’s characteristics and experience are available for study

• Best practice knowledge is immediately available to support decisions

• Improvement is continuous through ongoing study

• This happens routinely, economically and almost invisibly

• All of this is part of the culture
Complete “Virtuous Cycles” of Study and Improvement

A Problem of Interest

- Decision to Study
- Assemble Relevant Data
- Analyze Data
- Deliver Tailored Message
- Take Action to Change Practice
- Interpret Results
- Complete the cycle

Deliver Tailored Message
Take Action to Change Practice
Decision to Study
A Problem of Interest
Interpret Results
Analyze Data
Assemble Relevant Data
Decision to Study

Importance of Complete Cycles

• Lynn’s expressed goal of delivering best care after learning what it is

• Jason report: November, 2014

The learning health system needs to be “closed loop” to ensure a continuous and transparent cycle of research, analysis, development, and adoption of improvements relevant to health and wellness and to the delivery of health care.
But Instead of Doing This...

A Problem of Interest

- Decision to Study
  - Take Action to Change Practice
  - Deliver Tailored Message
  - Interpret Results

- Analyze Data
- Assemble Relevant Data

- Deliver Tailored Message
- Take Action to Change Practice
- Decision to Study

- Interpret Results
- Analyze Data
- Assemble Relevant Data

[Diagram depicting a cycle involving problem of interest, decision to study, analysis of data, and delivery of tailored message.]
We Seem to be Doing This

A Problem of Interest

1. Assemble Relevant Data
2. Analyze Data
3. Interpret Results
4. Take Action to Change Practice
5. Deliver Tailored Message
6. Decision to Study
7. Journals?
What I’m Observing

• Belief that if we get the data and analytics side right, everything else will fall into place
  – But we know that’s not true

• “Big Data to Knowledge”
  – And then what?

• PopMedNet (basis of PCORNet) does not support the feedback “red” side of a complete cycle
Use cases, all “open loop”:

- Pragmatic clinical trial design
- Observational studies
- Single study private network
- Pragmatic clinical trial follow up
- Reuse of research data
My Pitch…

- To meet Lynn’s goal, delivery systems & research networks must run many **complete** learning cycles simultaneously, each addressing a different problem

- Also, need an **infrastructure** that makes learning effective, sustainable, and routine--with economy of scale

- Enter the platform…
How to Learn *Routinely*: A Single Platform Supports Multiple Simultaneous “Virtuous Cycles”

Different Problems

Rapid Cycle

Slower Cycle

PLATFORM
In Other Words…

- Without a platform, each learning cycle develops its own, sub-optimal methods for learning; no economy of scale

- With a platform, all cycles share & benefit from a common infrastructure; costs are distributed
Components of the Complete Platform

- Technology and policy for making knowledge persistent and sharable
- Technology for aggregating and analyzing data
- Policies governing access to data
- Mechanisms for tailoring messages to decision makers
- Mechanisms for capturing changed practice
- Mechanisms for communities of interest to form
- Interpret Results
  - Deliver Tailored Message
  - Take Action to Change Practice
  - Decision to Study
  - Assemble Relevant Data
  - Analyze Data
  - A Problem of Interest
Components of the Complete Platform

- Technology and policy for making knowledge persistent and sharable
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A Platform, Built Right

- Will scale to embrace genomic data
- Will have sharable, interchangeable components: “build once, use many”
- I urge the genomic community to demand attention to complete learning cycles and the “platform” approach
What is My Department Doing?

• Viewing the LHS as a research challenge
• Trying to balance out current efforts with focus on the “feedback” side
  – Partnering with PopMedNet
• Building reusable and scalable platform components
• Would be delighted to partner with the genomics community
So It’s Up to Us and the Stakes are High

Is it?

Or

And is it?

Or
Thanks & Write to Me

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