

# The Learning Health Community and the Essential Standards to Enable Learning (ESTEL) Initiative

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*Strength through Collaboration*

## *Healthcare*

- Quality healthcare
- Informed decisions
- Personalized medicine
- Patient safety and privacy
- Public health
- Improved therapies
- Efficiencies/reduced costs

*Information from healthcare  
(private, aggregated)  
to enable research*

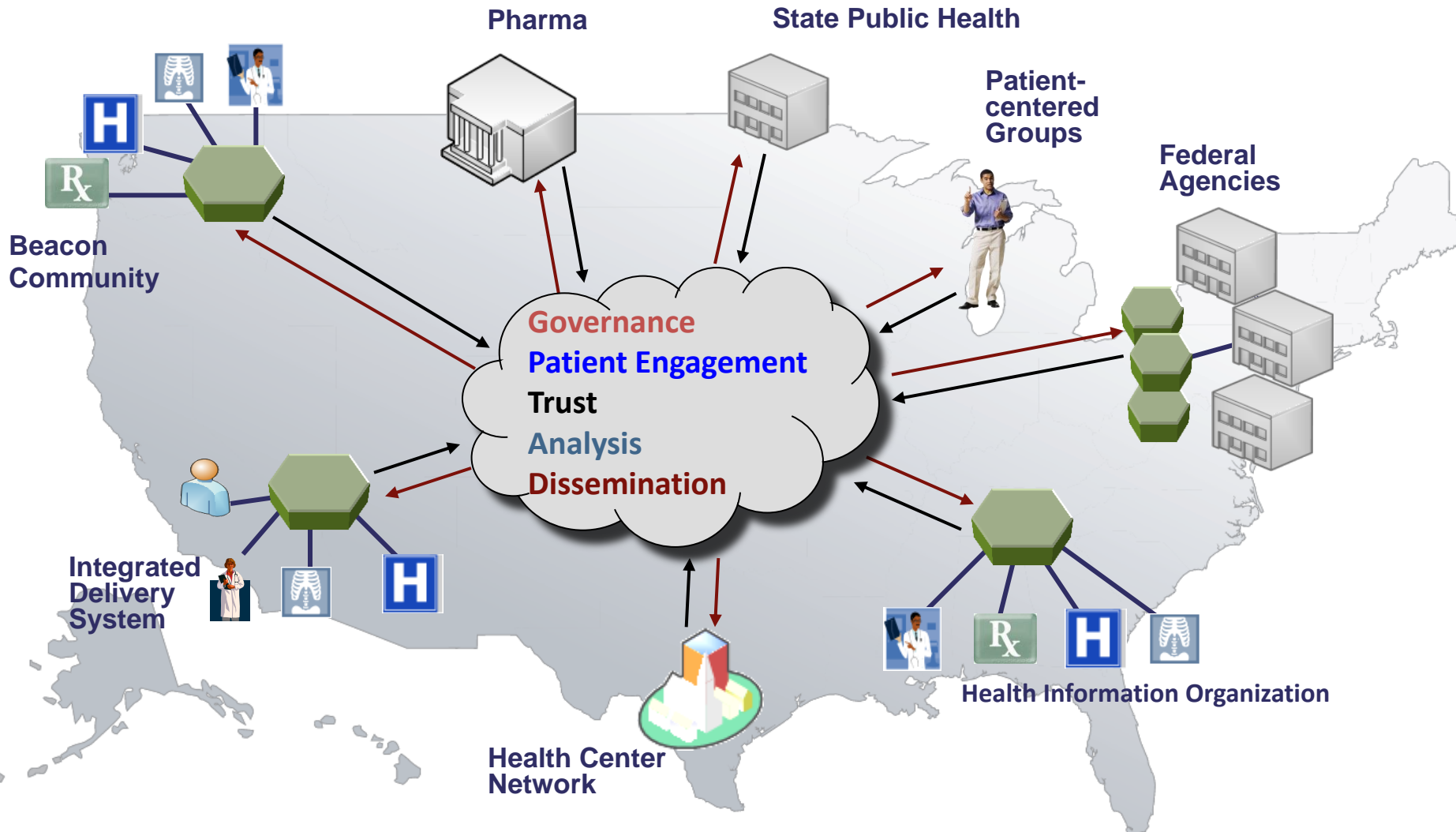


## *Research*

- Discovery of new therapies
- Understanding diseases
- Testing/comparing therapies (CER)
- Assessing efficacy
- Monitoring safety
- Understanding responses (genomics, biomarkers)
- Public health/quality evaluations
- Post-marketing surveillance

*Research findings  
to inform  
healthcare  
decisions*

# A National-Scale Learning Health System



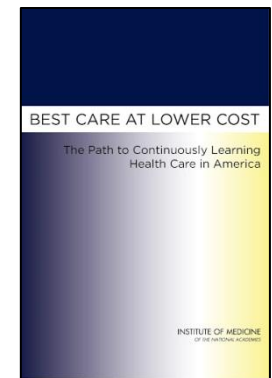
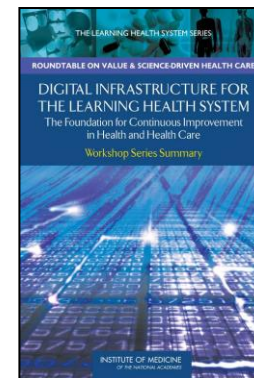
Source: Dr. C. P. Friedman

# Big Innovation – From Big Data to Big Change: The Learning Health System

## Some Use Cases: How the LHS Transforms Health...

- For patients and caregivers (Joe Kanter)
- For clinicians
- For researchers
- For surveillance, safety, and quality leaders
- For public health professionals
- For other healthcare stakeholders

## The National-Scale Learning Health System

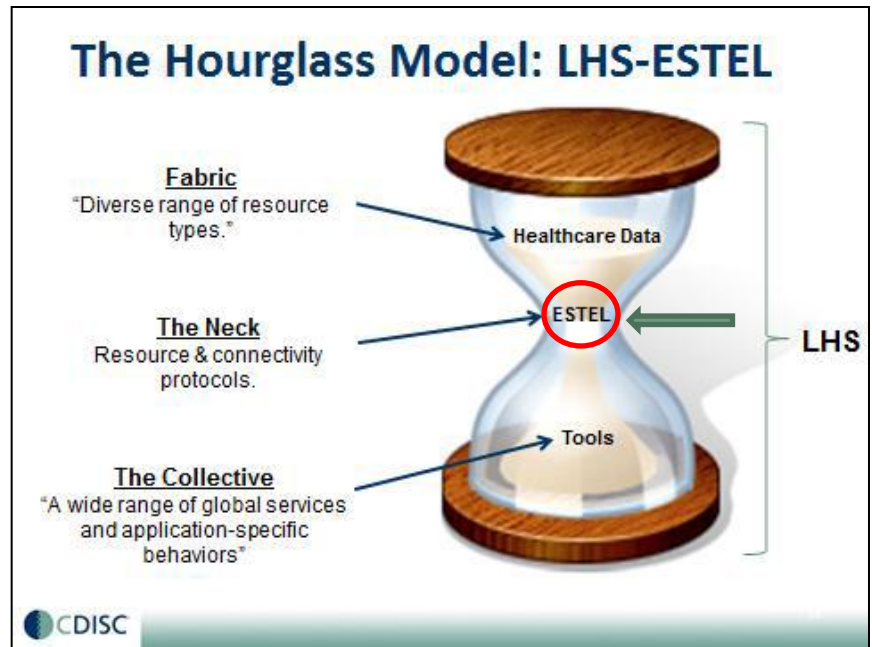
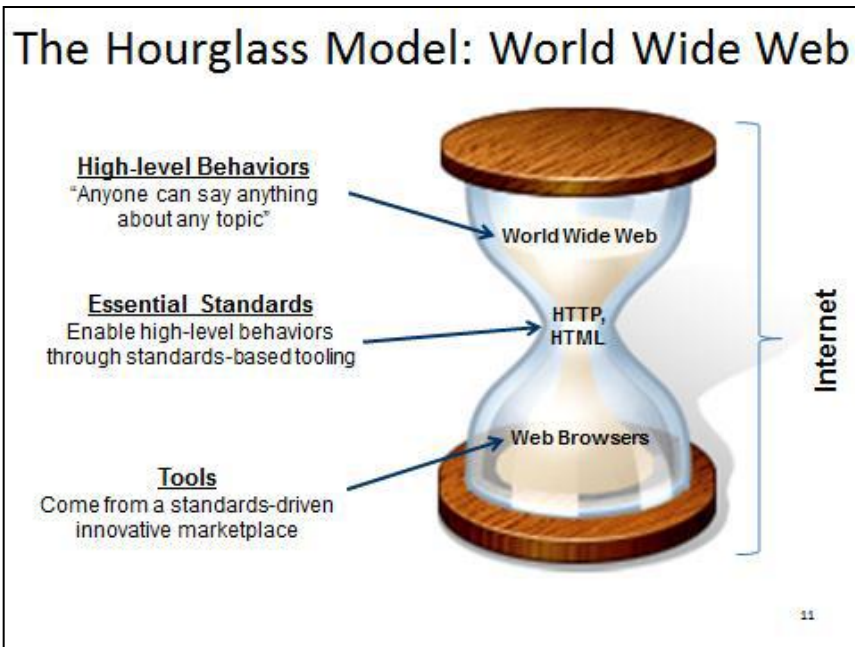


# Essential Standards to Enable Learning (ESTEL) Initiative

- ESTEL Charter: “Just Enough” Standardization
  - A self-organizing Learning Health Community initiative
- ESTEL Activities to Date
  - CDISC/TMA, IOM, Duke hosted Feb, July, Sept F2F meetings
  - Diverse participants
  - Webinars and conference calls
- Outcomes and Work in Progress
  - Continuous refinement of scope of work
  - Collaborative development of use cases
  - “Hourglass model” consensus
  - Participants, metadata, data model



# The “Hourglass Model” and ESTEL



*DRAFT*



**The Clinical Data Interchange Standards Consortium (CDISC):** a global, open, multi-disciplinary, vendor-neutral, non-profit standards developing organization (SDO), a 501c3

***The CDISC Mission:*** *Develop and support global, platform-independent data standards that enable information system interoperability to improve medical research and related areas of healthcare*

***The CDISC Vision:*** *Informing patient care and safety through higher quality medical research.*

*Strength through Collaboration*