A Rapid-Learning Health System

A Behavioral Science-Economics-Public Policy Perspective

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Perspectives

• #1. A learning society
• #2. Paradigms
• #3. Revolutionary technologies
• #4. Economics of information
• #5. Systems studies
• #6. Innovation & diffusion
#1. A Learning Society

- The generation and application of new, useful knowledge has been the key driver of economic growth & progress, since at least the Industrial Revolution.

- Many elements of modern societies influence learning, e.g. federal R&D support, research universities, high-tech industries, education, venture capital & competitive economic system, science & science-based professions, engineering, IT, Internet/WWW, intellectual property & patents, tax policies.

- There are many unresolved research questions, and large variations among countries and across sectors, in policies and practices.

- Overall, US performance is mixed, particularly in health, education, economic growth where government has a large role. Learning how to create better learning systems from Big Data would have many benefits.
Healthcare Needs Rapid Learning

- Learning problems contribute to many areas of poor performance
  - High and rising costs, wide variations in practice, poor quality, knowledge errors (Vioxx, food pyramid, hormone replacement therapy), long lags in adopting better practices, large gaps in clinical evidence base (comparative effectiveness, pregnant women, children, seniors with multiple chronic illnesses), falling research productivity, reliance on long, expensive RCT methods, out-of-date diagnostic taxonomy & wide heterogeneity of response to therapies, slow 40-year progress in war on cancer, federal budget deficits, lack of information on questions of importance to patients, emergency preparedness

- NRC report proposes new national learning system to revolutionize research, clinical care, and public health. (Francis Collins: 20-30M patient learning network). Latest issue of Science on cancer genetics data learning sees “a medical renaissance” and “a medical enlightenment”.
2. Paradigms

- Most scientific research occurs within intellectual paradigms that shape – and focus (limit) - scientific disciplines, research questions, institutions and careers – and ideas about how to most quickly and reliably advance scientific knowledge. Scientific revolutions are fueled by new paradigms. **The adoption of new intellectual paradigms is slow, resisted, and profoundly psychological & sociological**

- **The medical research paradigm-system differs from (lags?) other areas of modern science**
  - Medical research emphasizes RCTs. Highly productive sciences combine experiments, observational data, and predictive models. The goal is the predictive model (E=MC squared). Predictive models for biology and medicine are under-developed.
  - The rate of scientific advances varies greatly among areas. The fastest advances come from using experiments to definitively test multiple theories. Biological sciences and research are theory poor; many RCTs produce limited information.
  - Medical research has been a “data poor” environment. Most research projects require timely, expensive collection of unique datasets.
  - Emphasis on R01s (individual researcher-initiated projects) vs national laboratories (DOE), research networks, focused projects (DARPA)
Paradigms

• The genetics revolution, IT-EHRs, the problems of a slow-learning health system, and leaders are starting to influence government agency thinking about new research paradigms, resources, and methods
  – Kaiser-VA-Geisinger-HMORN; FDA mini-Sentinel, National Center for Accelerating Translational Science, HCS Collaboratory, bio-banks, many new databases, registries, and research networks, PCORI and CER, BD2K

• Is it possible to learn much faster? What new ideas, research questions, and methods would be needed? *Once all influences on health are “in the computer” the rate of scientific progress shifts to how smart we are about using computers*
#3. Revolutionary Technologies

- The largest benefits come from revolutionary technologies, e.g. steam engine, electricity, telephone, automobiles, personal computers, Internet/WWW, microscope, DNA sequencing. They are high impact, disruptive – and hard to predict.

- Health sector learning now has the opportunities and challenges of five revolutions at the same time:
  - IT & computers – electronic health records, research registries, decision-support
  - Genetics – precision diagnostics, targeted therapies and prevention
  - WWW/Internet – ability to share information, learning networks, MOOCs
  - Consumer movement – informed patients
  - Smart technologies and Apps

- This will need new visions, new ideas, open minds, creative thinking – and a lot of learning!
A New Learning System

• A key concept is *in silico* research to complement *in vitro* and *in vivo*. The potential to design and pre-populate large computerized databases, with millions of patient records that can provide useful research in minutes or days vs 7+ years. e.g. mini-Sentinel (125m patients/24 hours); TASTE CER study in organized learning systems (90% cost reduction)

• **Major changes in RL system:**
  – number and type of patients studied, kinds & amounts of data (<6% in RCTs & selective→tens of millions, clinically rich, longitudinal data, representative populations in real-world settings)
  – who does research & where (small academic community→organized delivery systems, crowd sourcing), RO1’s→national laboratories & DARPA initiatives; physician specialty societies
  – number of researchers and others able to use data, how research is done & results adopted
  – number of studies, speed, expense, more and different questions
  – log-on to world’s evidence base, with smart software support!
#4. Economics of Information

- Many kinds of information are not a standard (physically limited, controllable) economic good. Most economists would agree that basic science research and other kinds of scientific data are “public goods” to be government-supported.

- The “economics of the commons” for data-sharing is very strong (10 institutions contribute 100 patient records for a 1,000 patient registry, each gain 900 records (9:1 return)).

- The federal government must have a key role in data policy & data resources for a learning health care system (NIH, FDA, CDC, CMS, ONC-EHRs).
#5. Systems Studies

- Systems theory is one of the most widely used and powerful intellectual perspectives for natural and social sciences

- Recent developments study living organisms (and social institutions) as complex, adaptive, evolving systems - often with surprising emergent properties - that exist within eco-systems of other complex, adaptive, evolving systems

- An important aspect of the discussions about a learning healthcare system is that they go beyond “big data” to envision a “learning system”. **We need to build a new research field, with public-private collaboration, for how to design & evolve learning systems, for a learning society**

- The “use cases” are structured for systems thinking – what would we want a learning system to do?, what are its elements?, relationships?, processes?, performance metrics? what are the key research questions?
#6. Innovation & Diffusion

THE LATEST RESEARCH SHOWS THAT WE REALLY SHOULD DO SOMETHING WITH ALL THIS RESEARCH.
Innovation & Diffusion

• Learning systems deal with human beings and human institutions, with their own ideas, psychologies, capabilities and limitations, resources, environments, incentives and agendas

• Can we replace the classic “S” curve with a “J” curve, i.e. “go viral” with new learning, using the Internet/WWW, social media and other new tools?

• The $10 B CMS Innovation Center adds potential “demand pull” to learning through supply-wide diffusion. Aligning learning, doing good and doing well may be a promising strategy.
Conclusion

“How much faster can we learn?” is now, and in exciting, new ways, a question to which new answers can evolve in healthcare and elsewhere.