



IBM Almaden Research Center

# Enabling the Healthcare Revolution



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## The Team

### Present



- Karen Brannon
- Alvin Cheung
- Sangeeta Doraiswamy
- Stefan Edlund
- Alexandre Evfimievski
- Joshua Hui
- Christopher Johnson
- Jerry Kiernan
- Karin Kailing
- Christine Robson
- Stefan Schoenauer
- Steve Watts

### Past

- Rakesh Agrawal
- Roberto Bayardo
- Kristen Lefevre
- Ralf Rantzau
- Ramakrishnan Srikant
- Raja Velu
- Yirong Xu



## Thesis

- The Healthcare Industry has been given its marching orders and is now consumed with computerizing its operations.
  
- As researchers, we must help this process by:
  - identifying the real problems,
  - filtering out bad solutions, and
  - working on emerging problems before they are recognized by healthcare practitioners



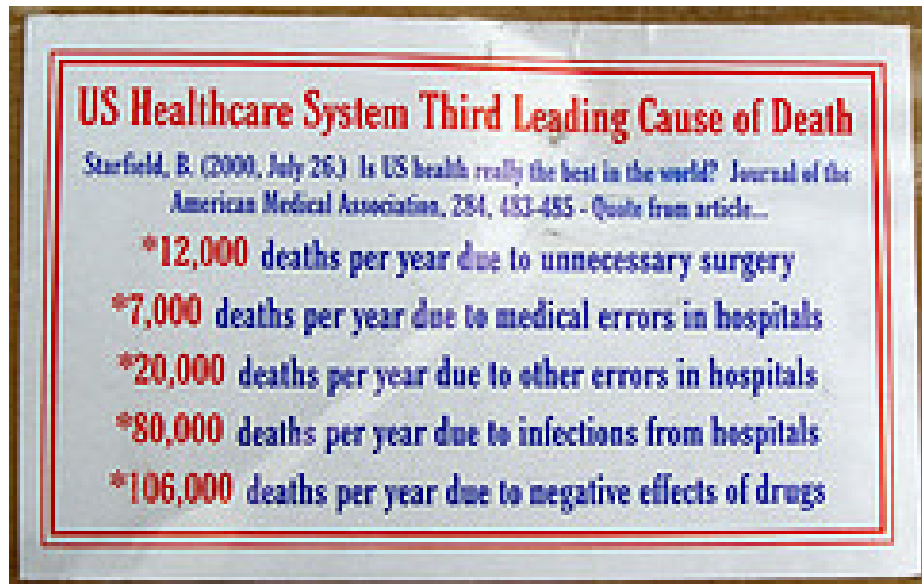
## Agenda

- The state of the sector
- Problems and Research Challenges.
- Call to Action

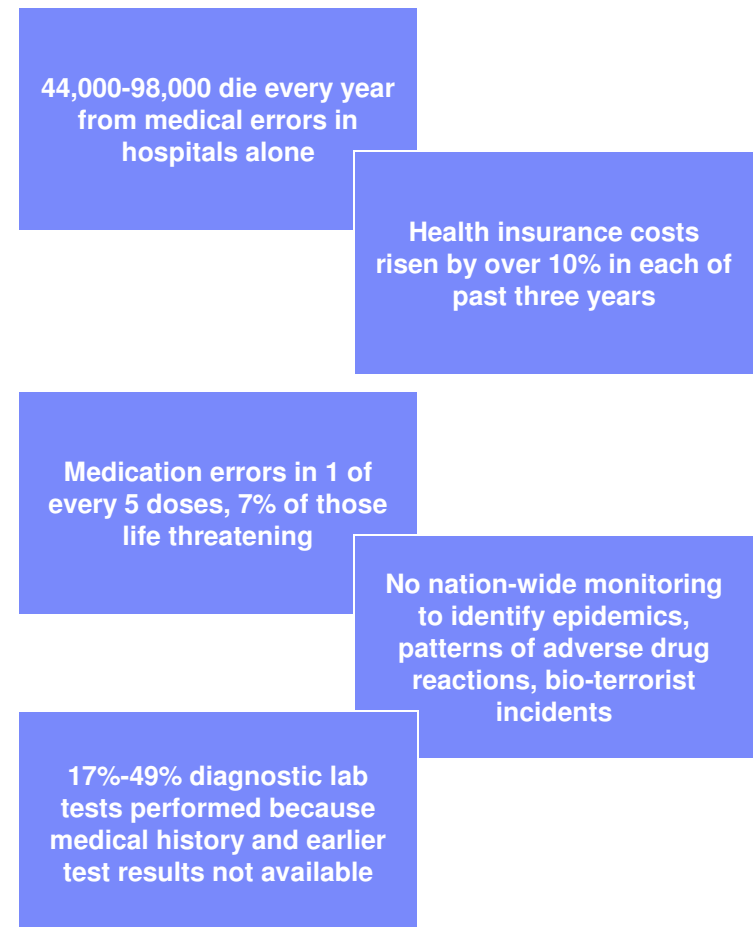


# US Healthcare System

## 2000



## 2004

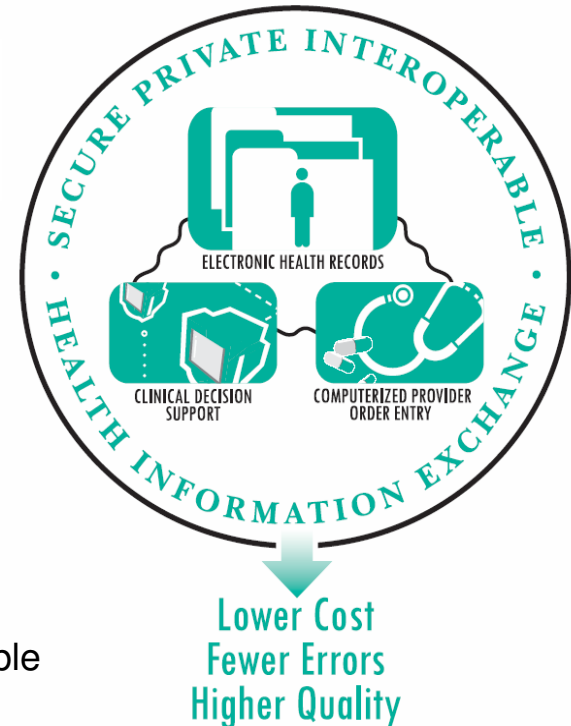


# Recommendations

**Revolutionizing Healthcare Through Information Technology**  
 President’s Information Technology Advisory Committee, June 04

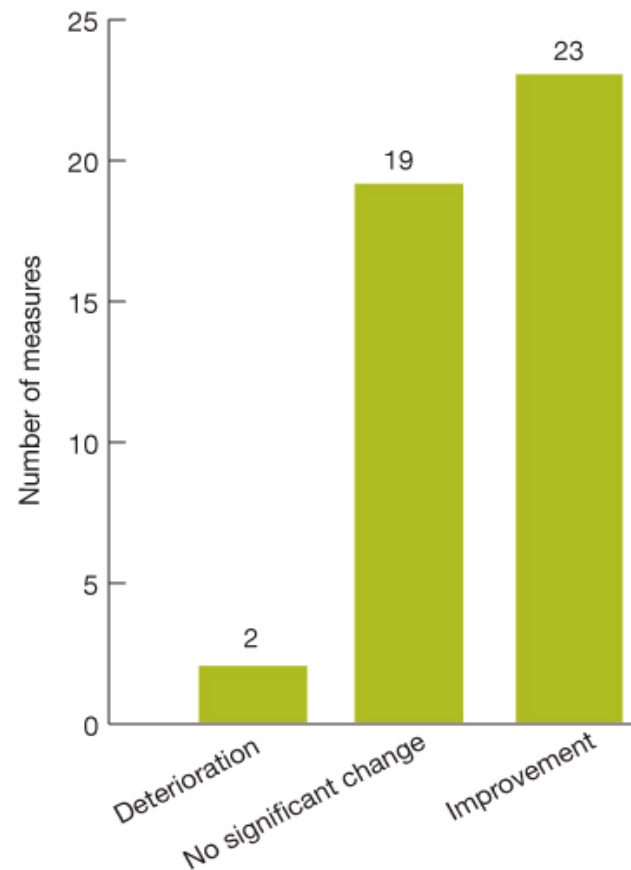
**The convergence of the following factors makes healthcare ripe for innovation:**

- Probable emergence of standards as standard healthcare infrastructure;
- Current healthcare crisis in the United States and public pressure for affordable, quality healthcare;
- U.S. government encouragement and guidance regarding development of an interoperable electronic health records system; and
- Development of technological and clinical standards to enable the exchange of healthcare information.



**Ending the Document Game**  
 – Connecting and Transforming Your healthcare Through Information Technology  
 President’s Commission on Systemic Interoperability, August 2005

# National Healthcare Quality Report (NHQR) 2005

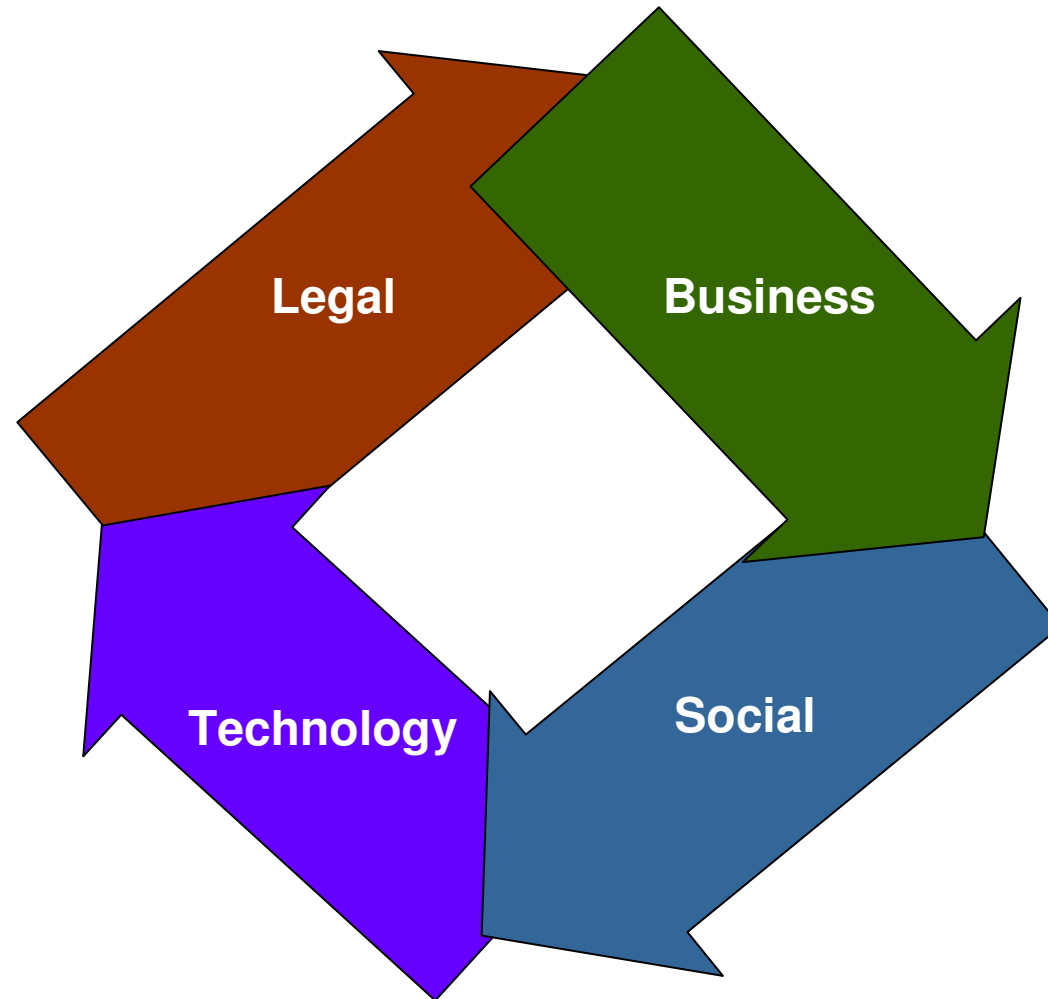


Health Care Quality Is  
Improving, but More  
Remains To Be Done

Number of NHQR core measures showing significant improvement, no significant change, or deterioration over multiple years (n=44)

<http://www.qualitytools.ahrq.gov/qualityreport/2005/browse/browse.aspx>

# Healthcare Ecosystem



## HEALTHCARE - BUSINESS

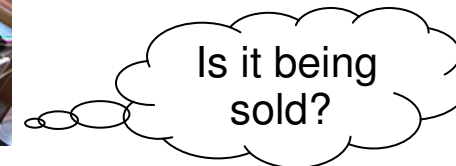
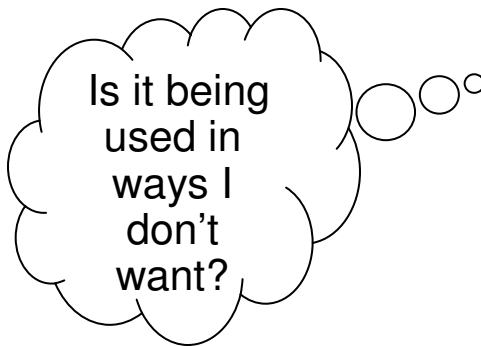


- *Concern 1:* What is the economic model for enabling Health Banks?
- *Concern 2:* What is the incentive/insurance model for Patient-Centric Networks?
- *Concern 3:* What is the business case for a system of RHIOs?
- *Concern 4:* Who assumes liability? What the value of a contract violation in an electronic system?



# HEALTHCARE - SOCIAL

- Privacy !!!
- Privacy !!!!!
- Privacy !!!!!!!!!!!!!



## HEALTHCARE - LEGAL

- *Concern 1: Synergy with Technology Advances*
- *Concern 2: Consistency of Law*
- *Concern 3: Enforcement of Legislation*
- *Concern 4: Notification and Consent*



## LEGAL – Synergy with Technology

A balance can be struck between Law and Technology such that each influences better development of tools to support the other.

### EXAMPLE

- PITAC reports names low-cost, minimal impact auditing as a key component for a 21<sup>st</sup> Century Healthcare Network (2004). However, technology that solved that exact problem (HDB Compliance Auditing) existed in 2003.
- Lots of medical ontologies exist (Technology requirement), yet no standardised clinical vocabulary (Emerging Legal Imperative).

*Christopher Johnson, Rakesh Agrawal, "Intersections of Law and Technology in Balancing Privacy Rights with Free Information Flow", Proceedings of the Fourth IASTED International Conference on Law and Technology, Cambridge, Massachusetts, USA, October 2006.*



# LEGAL – Consistency of Laws



*On trying to follow the rules at present...*

“You could actually run your self ragged thinking about all the inconsistencies”

- **Cynthia L. Hahn**, Administrator, Research Compliance, Research Privacy Officer,  
The Feinstein Institute for Medical Research, 350 Community Drive, Manhasset, NY 11030

## Example

- Federal and state definitions of a human subject (for clinical research) :
  - Feds (45CFR46.102.f): "Human subject means a living individual about..."*
  - NY State (Article 24A, section 2441):"Human subject" shall mean any individual..."*
- Federal Law overrides in case of doubt but if the State Law conflicts; many extenuating circumstances may be allowed according to weight
- NSLIJ (North Shore-Long Island Jewish) Health System extrapolates that in NY research regulations apply to both the living and the deceased.

## Legal – Consistency of Laws (2)



- State laws are great examples of competing regulations

45CFR46.102.f seeks to promote research through privacy, but....

*In effect, it reads that a de-identified human being is not a human being, and thus the patient has no rights over the data*

–Source: Cynthia L. Hahn

- Message:

*In cases of the complexity of conflicting and interacting rules and sometimes authorities, with diverse and evolving metadata, different weights, constantly changing with time and geography and application domain, a simple “hard wired” rules set seems unlikely to be a long term viable solution*

- Barry Robson, Chief Scientific Officer, Healthcare and Life Sciences Global Innovation Unit, IBM

## Legal – Enforcement

- Major US Healthcare Legislation is HIPAA
- Security and privacy rules became effective since 2003
- Progress
  - Enforcement remains slow, with no expectation of substantial change
  - Almost 20,000 HIPAA complaints. More than 73% closed. More than 250 complaints referred to DOJ for criminal investigation

*“Our first approach to dealing with any complaint is to work for voluntary compliance. So far it's worked out pretty well.”*

**- Office of Civil Rights Head**

- Current State
  - Privacy litigation is increasing. However, not based Healthcare-specific legislation.



# Legal – Notification and Consent

**WE HAVE  
BEEN  
NOTIFIED**

## Notification

- California SB1386 set a precedent for notification laws.

*All Californian residents must be notified of a data breach if their data was stored in an unencrypted form and even if there is no proof of damage to the resident*

- Similar notification laws are in the process of being passed in the other states. The constraints and exceptions on each vary.
- Possible room for exploitation.

## Consent

- OECD Principles advocate patient consent during information collection on information use and processing.
- American legislation addresses only information use



## HEALTHCARE - TECHNOLOGY

1. **Modeling** – capturing the environment.
2. **Standardization** – enabling application sharing.
3. **Storage** – efficient models, media and formats.
4. **Security and Privacy** – protecting patients and businesses.
5. **Data Analytics** – deriving insight from medical content.
6. **Interoperability** – allowing systems communication.
7. **Remote systems** – moving towards home-based care.
8. **Services Science** – delivering new models of healthcare delivery.



## TECHNOLOGY - MODELING

***Build a system that closely matches the healthcare environment and that healthcare stakeholders will use***



- Do not just apply cool technology.
- Study practitioners to develop systems that match their workflow.
- Create Intuitive user interfaces and devices.
- The Extra step: Automate tedious tasks.
- Validate your model and deployment.

## HEALTHCARE - STANDARDIZATION

- Lots of work on Healthcare standards (HL7, CDA, etc.)
- However, disturbing trend – the need to standardize/resolve between versions of standards.
- There is a need to develop a Healthcare Industry Data Model, possibly geared towards various fields
- Lots of architectural alternatives and no study of the trade-offs of these alternates; also need for definition of integration paths of research technology into these architectures.



## HEALTHCARE - STORAGE

- Standard EMR/EHR/PHR format
- Availability and Reliability
  - Secure from data loss, contamination, leakage
- Cost-effective Record Keeping
  - Reliable enforcement of retention, migration, replication, and duplicate detection methods should enable cost-effective storage
- Centralized vs. Decentralized
  - Explore various storage approaches for EHR infrastructure
- Life Cycle Management – Enforce data management policies



## HEALTHCARE – SECURITY and PRIVACY (1)

- Policy Specification
  - Design for Healthcare
  - Policy Coverage
- Fine-grained disclosure controls
  - Cell-level policy enforcement over sensitive patient data
  - Control access of centralized data from diverse locations
- Portable disclosure policies (sticky policies)
  - Ensure data is protected in accordance with policy after transfer



## HEALTHCARE – SECURITY and PRIVACY (2)



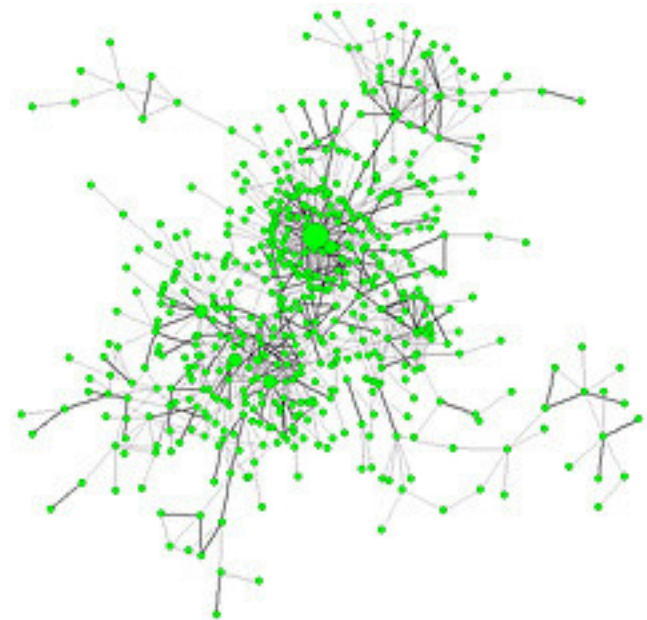
- Auditing / Data Access Tracking
  - Cost-effective methods of auditing for patients, physicians, hospitals
  - Identify who accessed information and appropriateness of access
- Trust Hierarchy and Authentication
  - Means for verifying the identities of those accessing and altering data

## HEALTHCARE – SECURITY and PRIVACY (3)

- Re-identification
  - Resolving the need to de-identify and re-identify?
- Notification
  - Enabling Technology?
- Consent
  - Is there a formal model?
  - Any guarantees?

## HEALTHCARE – DATA ANALYTICS

- Clinical Decision Intelligence
- Clinical Genomics
- Disease Surveillance
- Systems Biology
- Operational Efficiencies



# HEALTHCARE - INTEROPERABILITY

- Information sharing
  - Methods of sharing EHRs among various sovereign systems, applications, and organizations
  - Tools for developing standard technical and clinical vocabularies
- Data Pointillism
  - Unambiguous linking of patient data from multiple sources (without universal patient ID)
- Data Integration
  - Integrate information in various modalities from a variety of sources to identify trends and gather research data
  - Ensure completeness of individual EHRs



## HEALTHCARE – REMOTE SYSTEMS

- **RFID / sensor networks** - assist in tracking persons and equipment
- **Pervasive technologies** - bio-sensing devices, Monitoring devices
- **After-effects** - Architectural implications of health information stored on personal devices



## TECHNOLOGY – SERVICES SCIENCE

- **70% Solution** - provides the opportunity to research how to create solutions that are 70% complete, in that they generically meet most of the requirements of many of the clients but require some customization through service engagements.
- **Vetting and Refinement of Services Research Tools** - For example, the component business model for healthcare can help decipher how a Healthcare installation would affect a provider's business, and where there would be gaps, duplications and overextensions of application functionality.



## SUMMARY

- The Healthcare sector is in dire of help.
- Fruitful ground for research.
- We have an opportunity to better society.
- We need to make sure that our work is relevant and a key component in enabling the 21<sup>st</sup> Century Healthcare Revolution.

## CALL TO ACTION



- Pick a VERY, VERY hard, but well-defined problem.
- Find Healthcare domain enterprise (i.e. a Healthcare entity).
- Leverage your skill-set to create an immediately applicable solution.
- Do great, objective work.
- Gather requirements for future research, iterate.



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**THE END**

More Information:

<http://www.almaden.ibm.com/software/disciplines/iis/>

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