



IBM Almaden Research Center

Moving Toward a Consumer-Driven Electronic Health Records Infrastructure

Intelligent Information Systems
IBM Almaden Research Center

View of the Future of Health Care

- **Consumers will exert increasing control over their health care**
 - Increased patient financial responsibility
 - High deductible insurance plans, health savings accounts
 - Increased transparency of cost and quality
 - Market demand for cost transparency and quality metrics, HHS developing standards
 - Increased patient involvement in care
 - Self-monitoring, automated data collection, knowledge of treatment options
- **Wealth of available data will transform medical care and research**
 - Automated data collection and electronic storage
 - Pervasive monitoring devices, biosensors, large volumes of electronic data
 - Secure exchange and analysis capabilities
 - Sharing and analysis of encrypted, randomized, and anonymized data
 - Data-driven exploration and discovery
 - Enhance creativity, hypothesis generation, testing - data mining, OLAP, eScience
 - Enhanced clinical decision support
 - Useful data access and health analytics at point-of-care

Supporting Trends

■ Medical

- More patient involvement in records mgmt, payment, treatment decisions
- Increase in specialty services, telemedicine, walk-in clinics, low cost providers
- Investments in biotechnology, growth of clinical genomics and systems biology
- Pervasive monitoring devices, EDC, statistical analysis, profiling diagnostics

■ Technological

- Online patient access, higher bandwidth, proliferation of wireless technologies
- Small and inexpensive personal devices, increased storage and computation
- Automated data capture, RFID and sensor networks, bio-sensors

■ Legal

- Data protection laws in United States, Europe, Japan, Canada, Australia
- FDA regs regarding electronic records; state and federal drug pedigree laws
- Federal rules regarding preservation and discovery of electronic records

Components of Technical Vision

**Patient-Centric
Disclosure and Use
Policies**

**Full Accountability
for Information
Activity**

**Secure Management
of Distributed
Health Information**

**Novel Methods of
De-identifying
Health Information**

**Personalized and
Exploratory Health
Data Analytics**

Overview of Components

1. Patient Centric Disclosure and Use Policies

- Empower patients to refine and personalize disclosure and use policies
- Enforce policies across enterprises and resolve policy conflicts
- Support fine-grained policy modifications for various data types

2. Full Accountability for Information Activity

- Enable systems to track access, modification, and disclosure of all PHI
- Provide enhanced query capability to investigate various information activity
- Develop methods to analyze and classify audit logs to support transparency*

3. Secure Management of Distributed Health Information

- Provide encryption and authentication controls for personal storage devices
- Enable policy-based selective sharing of PHRs on mobile devices
- Ensure legitimate access, secure transmission of patient data over Internet

* Idea proposed by Jerry Kiernan.

Overview of Components

4. Novel Methods of De-Identifying Health Data

- Anonymization techniques that combine encryption with generalization *
- De-identification of non-relational data, such as documents and images
- Explore de-identification of genetic data

5. Personalized and Exploratory Data Analytics

- Analytics based on individual characteristics to inform patient decisions
- Enhance creativity and scientific discovery through data-driven exploration
- Privacy-preserving mining of autonomous distributed data sources

* Idea proposed by Sasha Evfimievski.