Moving Toward a Consumer-Driven Electronic Health Records Infrastructure
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.