Health Record Banks:
Creating a trusted, regulated industry to serve consumers, payers and providers

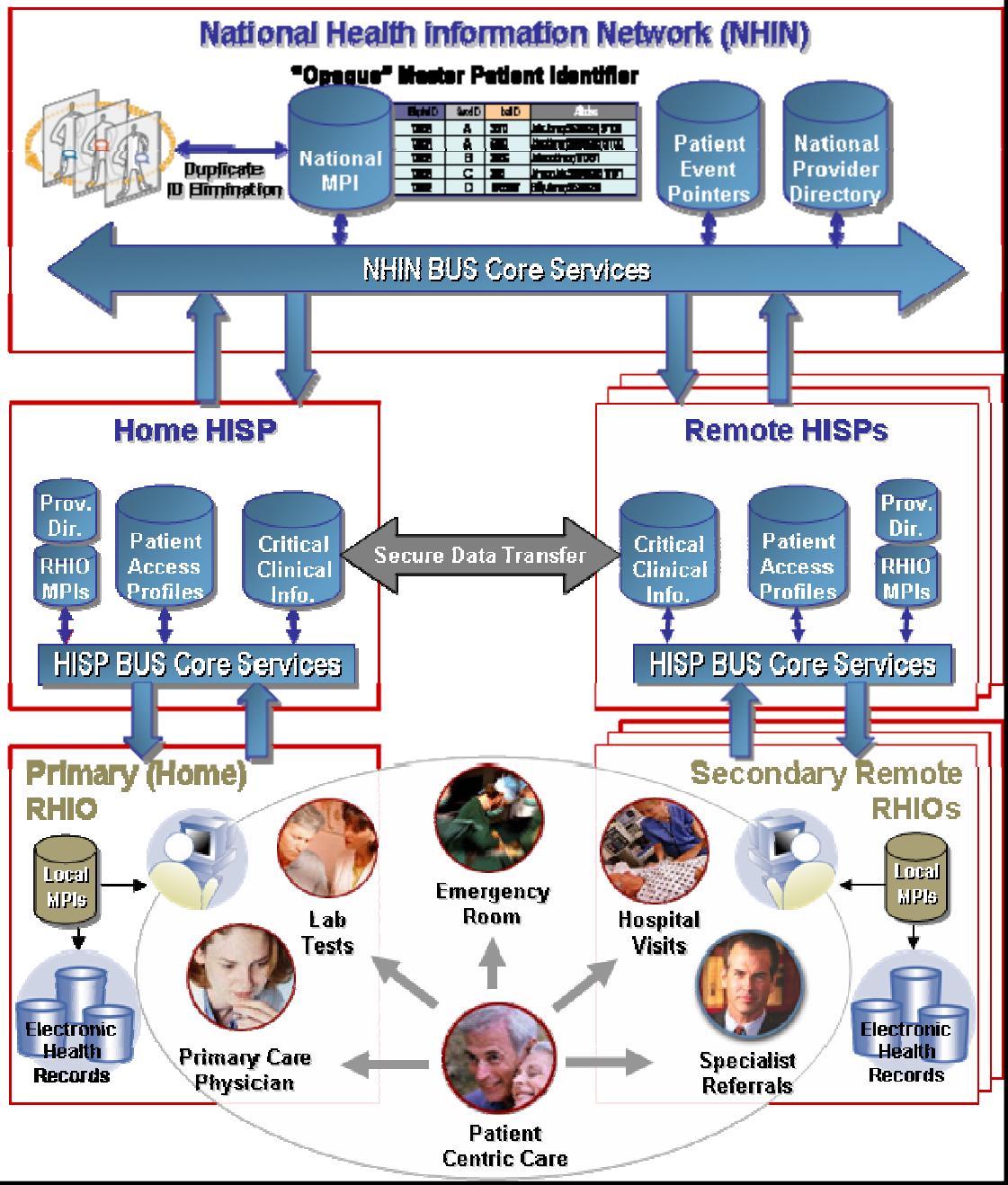
2005 Almaden Institute

IBM Research in Healthcare

Healthcare Information Infrastructure Needed

- Recognized international need
  - cost, quality, availability of care
- In U.S., government management not ideal
  - must stimulate private enterprise investment
  - leverage innovation, free market
  - elsewhere, government mandates healthcare infrastructure
- Control of medical costs essential
  - patients bearing more healthcare costs
  - growing number of bankruptcies

NHIN Conceptual Data Architecture



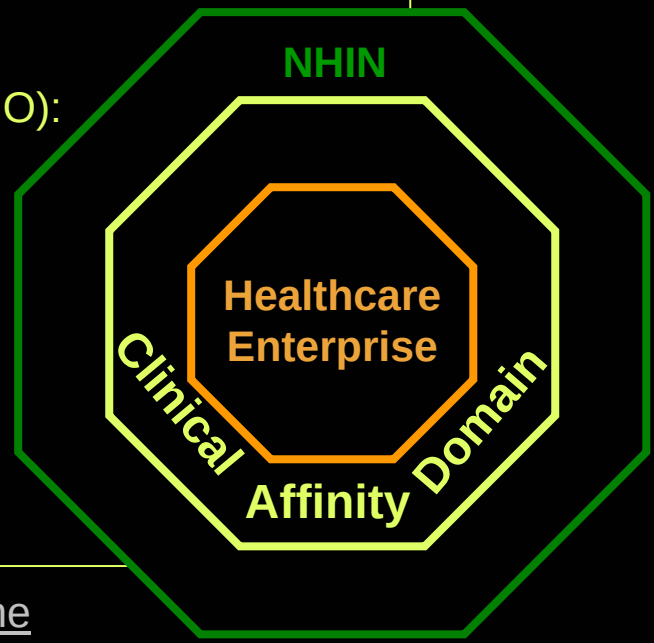
IBM Healthcare Information Infrastructure

- Develop and implement technologies to enable
  - cross-institutional and longitudinal EHRs
  - management and sharing of EHRs
  - distributed heterogeneous environment
  - with messaging that adheres to privacy, security

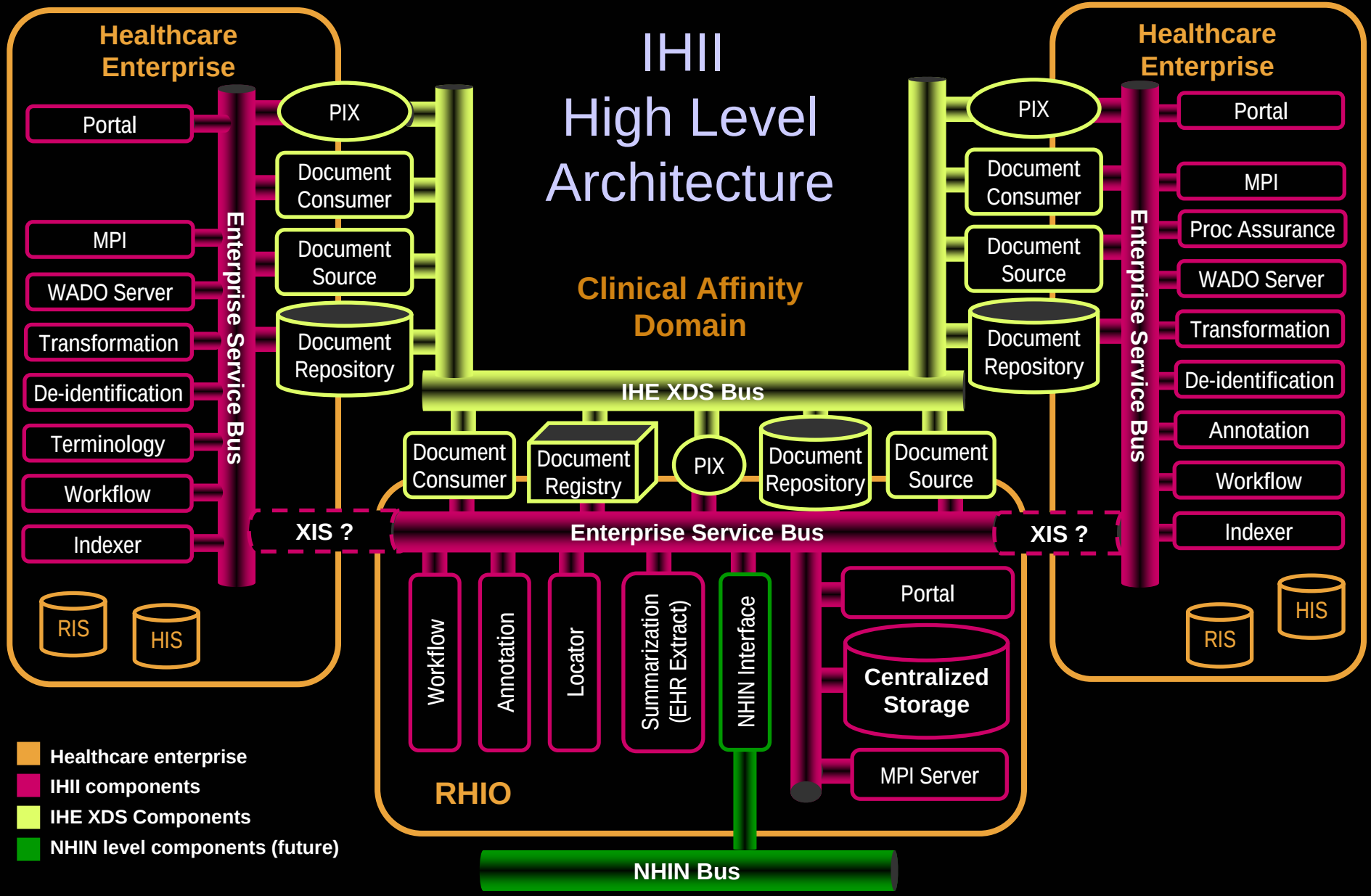
- Clear and concise demonstration
  - healthcare workers concerned with individual care
  - Regional Healthcare Information Organizations (RHIOs)
  - State and Federal customers responsible for public health

IHII Organizational Granularity

- Healthcare Enterprise: May refer to a broad variety of healthcare facilities, such as private practice, nursing home, ambulatory clinic, acute care in-patient facility, etc
- Clinical Affinity Domain: A group of healthcare enterprises that have agreed to work together using a common set of policies and share a common infrastructure
  - Regional Healthcare Information Organization (RHIO): Organization that provides the IT facilities for implementing the centralized services provided by the clinical affinity domain
- National Health Information Network (NHIN): The NHIN level ties multiple Affinity Domains



Integrating the Healthcare Enterprise, www.himss.org/ihe



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Current Health Information Infrastructure

- Current health information infrastructure is:
  - static
  - not focused on the evolution of healthcare
  - a physician-centered, industrial model
  - approach to data sharing similar to hoarding
- Current approach to consumers is:
  - process-centric
  - not conducive to creating demand-centered behavior
  - not focused on information liquidity, value creation

Financial Industry Analogy

- Transformation of Financial Systems and Markets
  - paper based to highly reliable electronic methods
  - Increased sense of trust and security
  - reliability of transactions

- Insights
  - principles
  - structures
  - mechanisms
  - experiences
  - managing systemic shocks

Financial Industry Emergence

- Financial banks used to:
  - be small, isolated, with limited exchanges
  - be goldsmiths, storage centers, money transporters
  - issue currency, keep own reserves
- Multiple systems address different, specific needs
  - state, federal, community banks
  - mutual funds, mortgage providers, brokers, etc.
- Resilient system
  - decentralized with ownership at edges
- Regulation provides for
  - beneficial interests of intermediaries and consumers
  - continual evolution and innovation at quickening pace
  - extremely high reliability, confidence, trust, privacy

Banking Customers Very Willing to Pay

- Very high levels of trust
- Fast
- Securely, privately
- Huge volumes
- Everywhere and at any time
- Extremely high accuracy
- With rapidly changing financial instruments
- With the ***true*** version of multiple conflicting records
- With risks analyzed and mitigated
- At extremely efficient prices

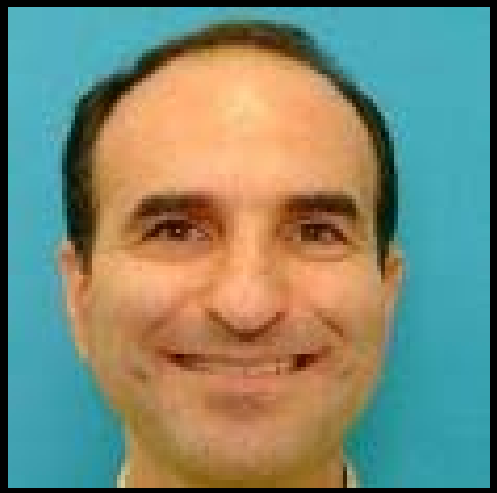
Beneficial Role of Health Record Banks (HRBs)

- Creating a trusted, regulated industry to:
  - serve consumers, payers, and providers
  - enable individual rights of ownership
    - security, access, confidentiality, privileges
    - providing beneficial interest to intermediaries
  - provide ready access to health information
  - serve local, state, federal needs

- Likely will evolve from current players:
  - insurance companies, hospitals, employers, government, financial institutions, etc.

- Will require government legislation and regulation

With Special Recognition to Amnon Shabo



A Global Economic-Medico-Legal Model for the Sustainability of Longitudinal Electronic Health Records

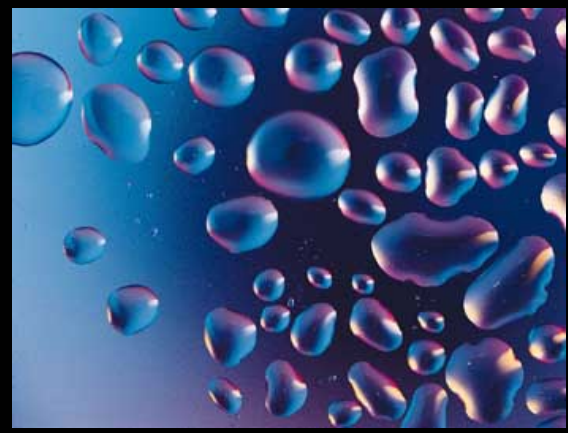
Amnon Shabo (Shvo)
IBM Research Lab in Haifa

Abstract

This paper presents a vision of sustaining lifetime Electronic Health Records (EHRs) based on a comprehensive socio-economic-medico-legal model. According to an ISO definition proposal, an EHR is "a longitudinal collection of personal health information concerning a single individual, entered or accepted by healthcare providers, and stored electronically. The information is organized primarily to support continuing, efficient and quality healthcare and is stored and transmitted securely." A natural extension of this definition could lead to a lifetime EHR – an invaluable information entity with the potential for increasing patient safety and quality of care. The challenge is how to compile and sustain a coherent EHR across the lifetime of an individual. This proposal states that lifetime EHRs should be sustained by new players in the healthcare arena, who will function as Independent Health Record Banks (IHRBs). These multiple competing organizations would be established following preemptive legislation and should be regulated by that legislation. They should also be independent in the sense that they are neither owned by healthcare providers nor by health insurer/payers or government agencies. The fundamental principle of the new legislation is that the medico-legal copies of all individual's records are stored in these banks and healthcare providers will no longer serve as the legal record keepers. This revolutionary constellation brings two main benefits to providers as well as to consumers: (1) Providers will be able to cut the costs of long term record keeping, which is mandatory according to current laws and (2) They will be able to provide better care based on the availability of a lifelong health record of their new patient. This model is not centered on any of the current players in the field. It is not government-centric, as it does not suggest having national repositories of the citizen EHRs. Additionally, it is not provider-centric, as it suggests moving the records created by the providers to an objective custody. This model is not even consumer-centric, as it does not suggest letting patients own and maintain copies of their records. Thus, this model is non-centric in its essence – it is focused on the objective and independent service of sustaining individual EHRs, much like financial banks are perceived with regard to certain financial assets.

Health Information Liquidity Benefits All

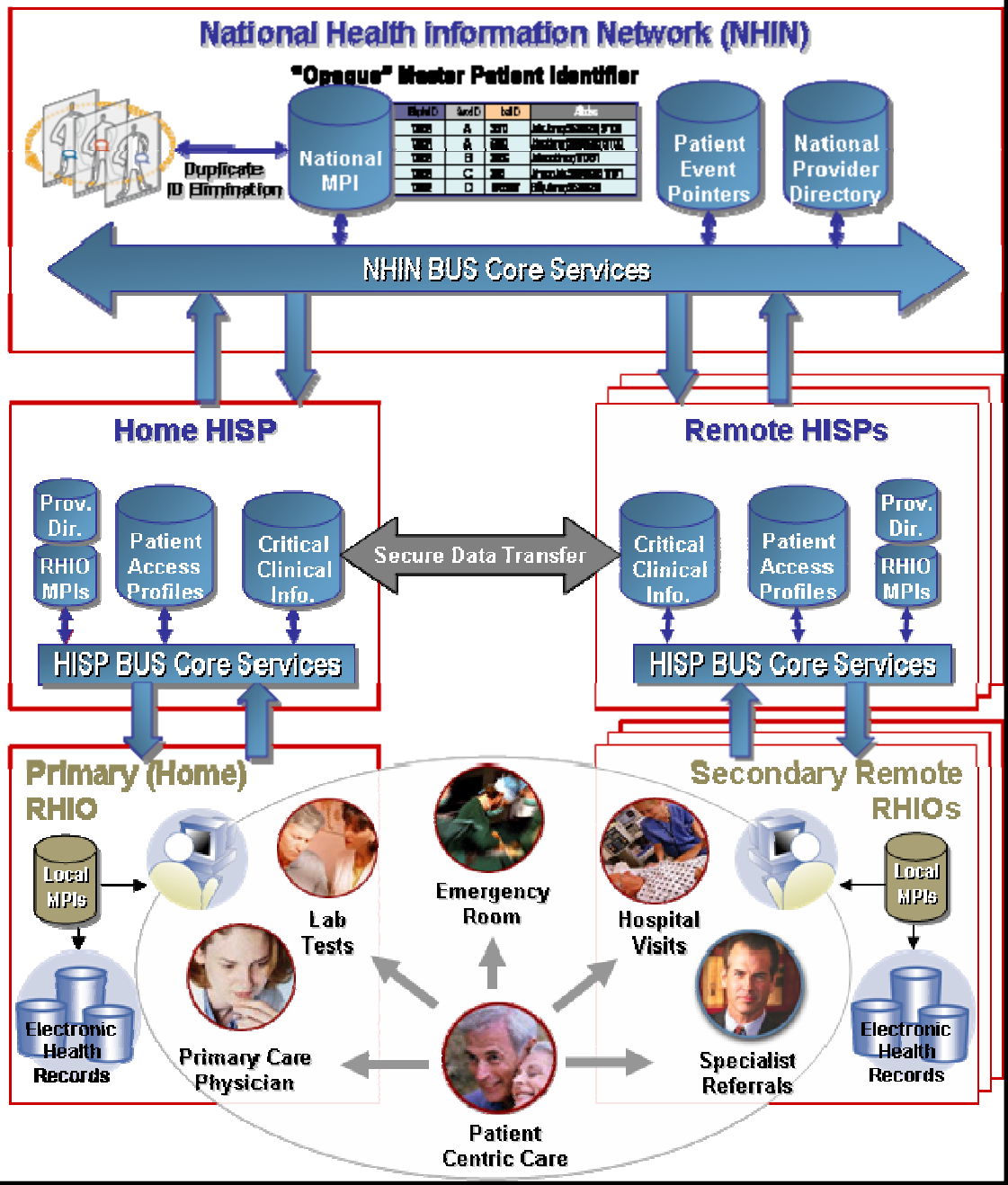
- Consumers
  - individuals, citizens
- Employers
- Insurers/payers
- Physicians
- Pharmacies
- Life sciences companies
- Interest groups
- Health systems
  - public health, hospitals, nursing homes, labs



Liquid Assets Require Organized Markets

- Banking as model for consumer behavior
- Who are likely buyers?
  - insurers
  - pharmaceutical companies
  - advertisers
- Who are likely sellers?
  - individuals
  - hospitals, doctors
  - insurers
- How do we ensure?
  - integrity, privacy, security

NHIN Conceptual Data Architecture



Prospective Benefits of HRBs

- Improve health care, safety, reduce errors, costs
- Robust information management
  - interoperable, agnostic
  - integrate with public health infrastructure
- Serve interests of all parties

- Emergence of intermediaries, infomediaries
- Evolve interactions among current health actors
- Influence coordination costs
- What are *unintended* consequences of perturbing current health information dynamics?

Aggregated Data for Disease Management

- Population identification processes
- Evidence-based practice guidelines
- Collaborative practice models
  - physician and support-service providers
- Patient self-management education
  - primary prevention, behavior modification programs, compliance/surveillance
- Process & outcomes measurement, evaluation, management
- Routine reporting/feedback loop
  - communication with patient, physician, health plan and ancillary providers, and practice profiling

Improved Pharmaceutical R&D

- Increased flow, exchange of information for researchers
  - clinical genomics
  - adverse event reporting
- Improved patient recruitment
  - Leukemia Society
- Ability to identify potential side effects, adverse events
  - large cohort trials expensive, difficult to manage
  - millions of data points, including negative data
  - addresses limitations of blogs, news groups, affinity groups
    - e.g. is total memory loss in patients associated with statins?

Public Health and HRBs

- Information about financial flows and exchanges
  - identify geographic or demographic areas of need
    - identify patterns of illiquid care?
    - healthcare equivalent of digital divide
  - used to create financial instruments
  - used to identify fraud or illegal behavior
- Identify larger scale patterns of public health issues
  - continual monitoring of health information to identify threats early
  - real-time epidemiological data to train, refine models
    - including negative data
- *"It's war games for infectious diseases," said Dr. Donald S. Burke, a professor at the Johns Hopkins public health school. "You use complex simulations to ask a series of what-if questions."*

Spatiotemporal Epidemiological Modeler

alphaWorks > Java technology >

Spatiotemporal Epidemiological Modeler

A tool for spatiotemporal modeling of infectious agents across the United States.

Date Posted: April 21, 2005

Overview | Requirements | Download | FAQs | Forum | Reviews

What is the Spatiotemporal Epidemiological Modeler?

The Spatiotemporal Epidemiological Modeler (STEM) tool is designed to help sci
create and use spatial and temporal models of emerging infectious diseases. T
understanding, and potentially preventing, the spread such diseases.

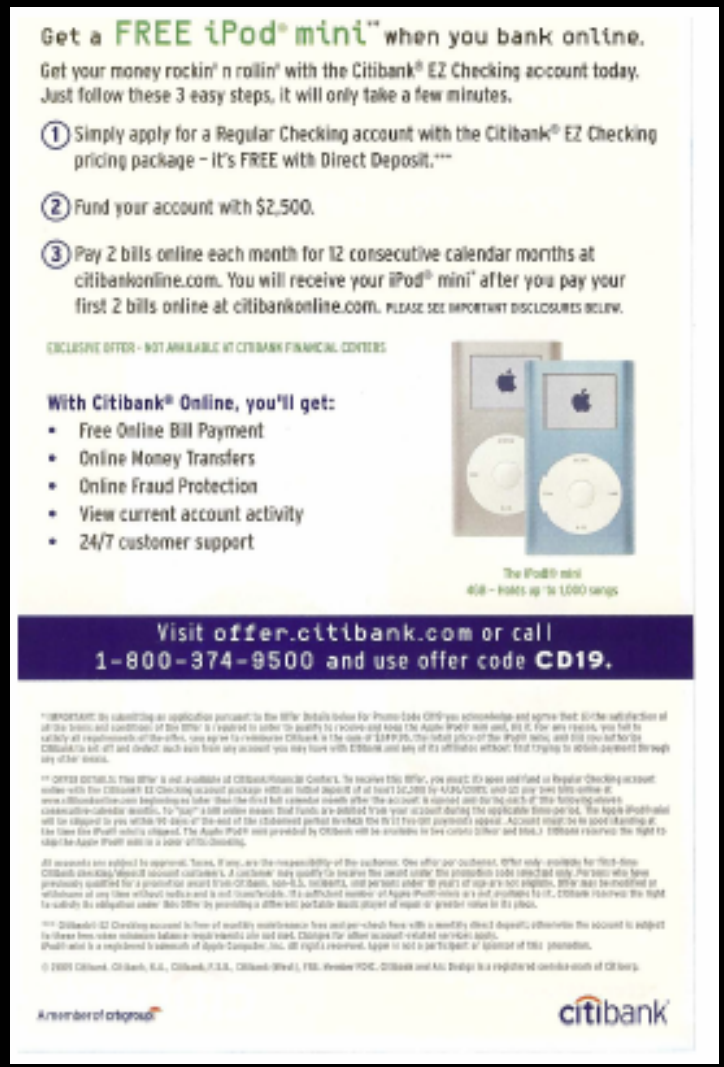
Policymakers responsible for creating strategies to contain diseases and preve
understanding of disease dynamics and the likely outcomes of preventative ac
connected world with extremely efficient global transportation links, the vector
complex. STEM facilitates the development of advanced mathematical models,
involving multiple populations (species) and interactions between diseases, an
epidemiology

http://www.alphaworks.ibm.com/tech/stem

Planning to Mitigate Shocks to System

- What happens to data when…
  - doctor's office closes, goes out of business, or hospital closes?
  - data center crashes?
  - RHIO becomes insolvent?
- Need to have mechanisms, regulations in place to ensure shock can be absorbed
  - best done in larger market, not smaller
- Local shocks, acute and chronic
  - significant price changes, consumer purchasing power
- Massive, immediate demand due to disaster
  - natural disasters: tsunami, earthquake, epidemic
- Proactive management of shocks with increased awareness
  - community "health value"

Incentives to Consumers



Data Mining – Hippocratic Database Technologies

GOAL

Create a new generation of information systems that protect the privacy, security, and ownership of data while not impeding the flow of information.

Private and Secure Data Management

Active Enforcement
Database-level enforcement of disclosure policies and patient preferences

Privacy Preserving Data Mining
Preserves privacy at the individual level, while still building accurate data mining models at the aggregate level

Tracking of Data Access and Disclosure

Compliance Auditing
Determine whether data has been disclosed in violation of specified policies

Database Watermarking
Tracks origin of leaked data by tracing hidden bit pattern embedded in the data

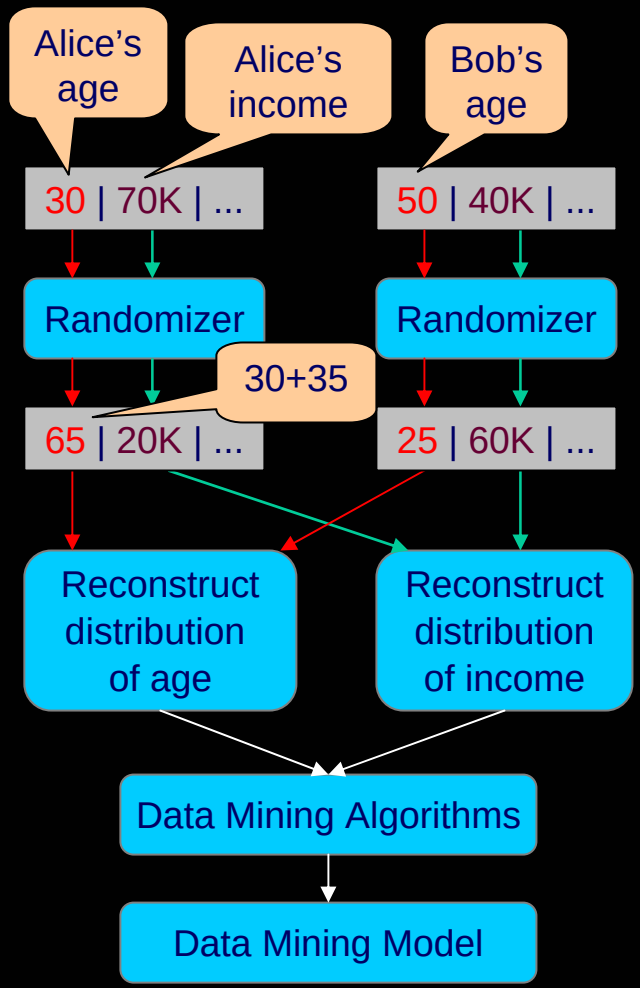
Secure Information Sharing

Sovereign Information Integration
Selective, minimal sharing across autonomous data sources, without trusted third party

Optimal *k*-anonymization
De-identifies records in a way that maintains truthful data but is not prone to data linkage attacks

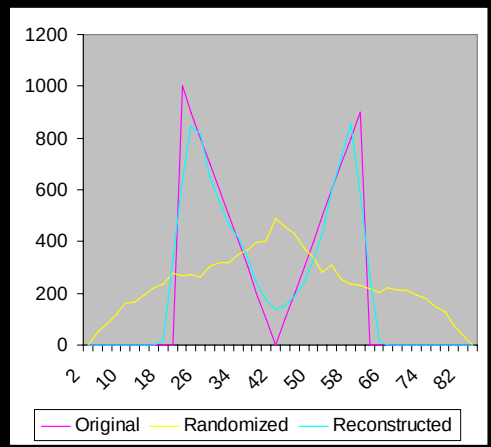
Intelligent Information Systems Group – Rakesh Agrawal

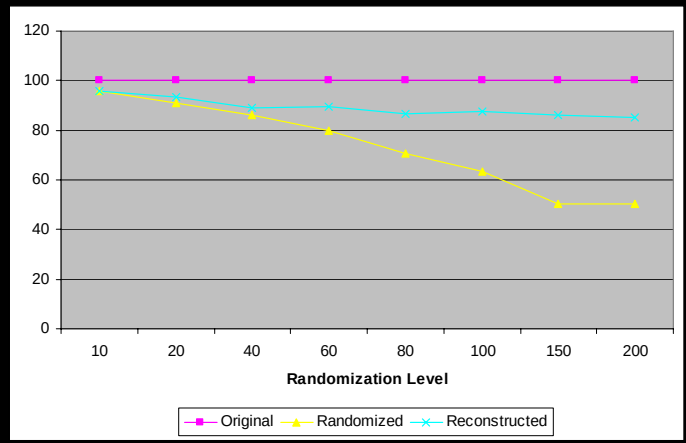
HDB Privacy Preserving Data Mining



Sigmod 00, KDD02, Sigmod 05(?)

- Insight: Preserve privacy at the individual level, while still building accurate data mining models at the aggregate level.
- Add random noise to individual values to protect privacy.
- EM algorithm to estimate original distribution of values given randomized values + randomization function.
- Algorithms for building classification models and discovering association rules on top of privacy-preserved data with only small loss of accuracy.





HDB Sovereign Information Integration (SII)

- **Separate databases due to statutory, competitive, or security reasons.**
  - **Selective, minimal sharing on need-to-know basis.**
- **Example: Among those who took a particular drug, how many had adverse reaction and their DNA contains a specific sequence?**
  - **Researchers must not learn anything beyond counts.**
- **Algorithms for computing joins and join counts while revealing minimal additional information.**

Sigmod 03, Sigmod 04, DIVO 04

Minimal Necessary Sharing

R	
a	
u	
v	
x	

S	
b	
u	
v	
y	

R ⋈ S

- R must not know that S has b & y
- S must not know that R has a & x

R ⋈ S

u
v

Count (R ⋈ S)

- R & S do not learn anything except that the result is 2.

Questions

- Answering financial questions:
  - what is our GDP?
  - what is our deficit/surplus?
  - how much money is in circulation?
  - how do we compare with the EU, Brazil, Japan, China, etc.?

- Answering health questions:
  - what is our nation's Health Value?
  - what is our surplus/deficit?
  - what are the trends, rates of change?
  - what is our nation's Health Output?

Possible Research Next Steps

- To model health information dynamics
  - social, environmental, technological, economic
  - map a blueprint for linkages across the global landscape
- Interoperable healthcare information infrastructure
- Model Architecture on financial systems
  - leverage tremendous experience in financial models
  - employ agent-based models
    - informed by real-world data, local context
    - enable adaptive representations of dynamic systems
    - study interacting agents and agent cluster
- Rapidly test new models at scale