

Track A, Day 2

Reducing Mistrust Through  
Education and Outreach



# Public Awareness of: Risks of Paper Charts & Benefits of Technology

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Rebecca Madison

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## Overview

- HISPC Findings
  - Common Misperceptions
  - Risks of Paper Charts
  - Benefits of Technology
- Alaska Differences
- Solutions



# Comparison



Paper-based Medical Practice	Intelligent Medical Practice...
Records are stored in paper folders and there is a delay of x.x minutes to 'pull' record	Records are electronically stored and instantly available when needed, eg when patient or MD calls
Workflow is dis-continuous, connectivity minimal	Workflow is continuous, with informational resources 'at hand' -- labs, pharmacy, hospital
Patients' access to information restricted	Patients are able to access health information on demand, schedule appointments, etc.
Communication with patients and others is synchronous only	Communication with patients and others is both synchronous and asynchronous
Patients never know performance level of medical care delivered	Performance and quality measures constantly generated, submitted, reported

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## Common Misperceptions

- Paper is more secure
- Horror stories from the news
- Lost or stolen electronic records



## Risks of Paper Charts

- Easily destroyed (fire, water, earth)
- Unable to retrieve
- Costly storage



## Benefits of Technology

- Duplicate copies
- Ease of distribution
- Tighter security
- Standard data sets
- Inexpensive storage

## Alaska Differences

- No roads
- No telephone lines
- Extreme weather



## Solutions

- Legal
- Standardized Policies & Procedures
- Participant Agreements
- Education and Communication



**THANK YOU**



## Reducing Mistrust and Confusion Among Patients

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HISPC National Meeting – March 6, 2007

Session 4A Educating Consumers About Risks &  
Rewards

California HISPC presenters:

Kathleen Delaney-Greenbaum, CalOHI

Kier Wallis, CalRHIO

HISPC – Health Information Security & Privacy Collaborative



## Changing Landscape

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- ❖ Costs and decision making shifting to consumer
  - Consumer-directed health plans, disease management, PHRs, etc.
- ❖ Patients are increasingly responsible, yet
  - Information does not reflect demographics, health risks, medical conditions

**Language and Context = Value**
- ❖ Patients want information on providers, health plans, care options



## Consumer Representation

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### Steering Committee

- Linda Ackerman, Privacy Activism
- Pam Dixon, World Privacy Forum
- Paul Smith, AARP
- Joanne McNabb, CA Department of Consumer Affairs

### Regional Stakeholder Meetings

- Beth Givens, Privacy Rights Clearinghouse
- Committee on the Shelterless
- Sandra Chapin, Consumer Federation of California
- Chris Hoofnagle, UC Berkley - Samuelson Center on Law Technology

Everyone is a consumer and patient!



## Consumer Perspectives

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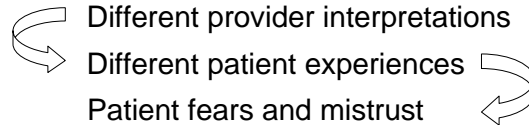
### ❖ Special populations highlighted concerns

- Public health
- Mental health
- Community clinics and health centers
- Public hospitals
- Medi-Cal
- State / Private industry
- Non-English speakers
- Migrant workers

## Patient Mistrust and Confusion

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- ❖ Patients do not have a basic understanding of HIPAA



- ❖ The foremost fears of patients are:
  - refusal or loss of health care benefits,
  - lost employment opportunities, and
  - misuse by businesses with financial interests

## Process Insights

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Consumers want...

- ❖ Iron clad security to minimize breaches
- ❖ The choice to share their PHI  
Opt-in vs. Opt-out
- ❖ Their health information electronically available
- ❖ To be empowered with information on providers, health plans and care options

## I AVR Experience

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❖ CA's realization that privacy and security precautions are **NOT** barriers to HIE, but rather a foundational imperative.

❖ The HISPC report timeline was driving faster than would allow for adequate research and surveys were prohibited.

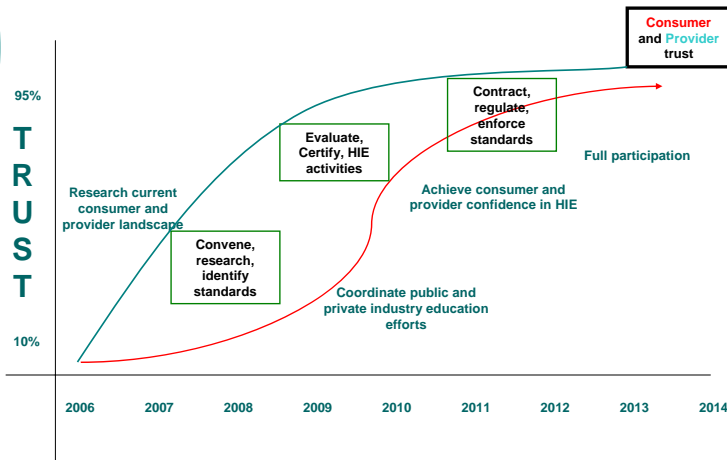


## I AVR and I ASR Findings

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Establish a group specific to privacy and security to develop:	
Infrastructure	<b>Privacy and Security Oversight Board</b> -oversee resolution of HIE privacy and security issues
Technology	<b>Technology Committee</b> - identify security standards
Law and Liability	<b>Legal Committee</b> - identify privacy and security laws issues that affect HIE
Rights & Responsibilities	<b>Operational Procedures Committee</b> - develop standard privacy guidelines & procedures
Levels of knowledge	<b>Guidance &amp; Education Committee</b> - improve patient education about their rights & records
Lack of trust	Resolve through collaboration activities

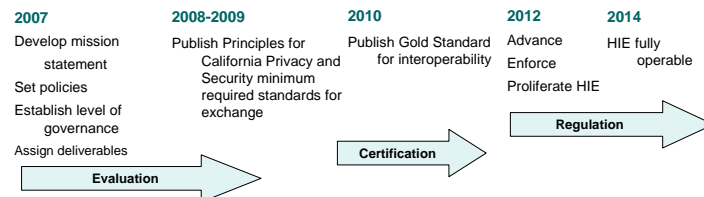
## Consumer and Provider Trust



## Privacy & Security Advisory Board

### CA to address privacy and security issues

- ❖ CA's relationship to federal regulatory agencies and other states
- ❖ The Board's role, scope, and coordination with other initiatives and groups
- ❖ Continue as a public-private partnership to standardize, implement, and enforce privacy and security standards for HIE in CA



## Guidance & Education Committee

- Advance HIE without inhibiting public participation
- Develop consumer messages about HIE
- Develop industry appropriate education efforts to precede standards rollout

### 2007-2008

**Research** current level of public knowledge

**Grassroots** work with privacy advocates

**Conduct** a consumer survey to quantify perspectives (i.e. Markle work)

### 2009

**Develop** curriculum on

1. Patient rights and responsibilities
2. Benefits of HIE

### 2010

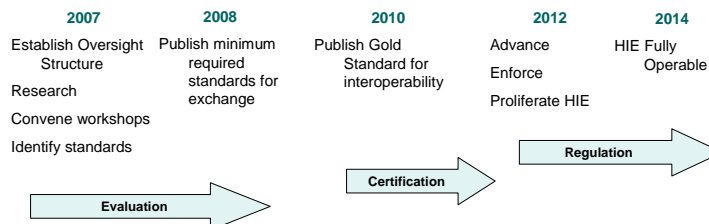
**Conduct** foundational education

1. Patient rights & responsibilities
2. Benefits of HIE
3. FAQs document

## Next Steps

### Moving forward from current project:

- **Establish Infrastructure:** Participation, membership, and authority
- Continue privacy and security efforts in CA
- Convene appropriate stakeholders
- Determine funding mechanism





## Contact Information

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# RTI HISPC National Meeting

## March 5 – 6, 2007

### HIPAA EDUCATION

Why the Confusion?  
What Can We Do About It?

William J. O'Byrne, JD  
Coordinator, NJ e-HIT  
NJ-HISPC Project Leader

## WHY THE CONFUSION?

### WHO SAID HIPAA HAD TO BE INTEROPERABLE? Especially Privacy?

- We forgot to explain HIPAA to the small providers!
- Some misinterpretation is intentional!
- Each covered entity has it's own interpretation based on it's own needs.
- Old habits are hard to break!

## Perspectives from New Jersey

- HINT = NJ Health Information Electronic Data Interchange Technology Act
- HISPC and NPI Groups
  - Same committed individuals and business entities
- Clearinghouse Certification
- All HIPAA Requirements part of EHRs / RHIOs
  - Necessary for interoperability-everything is related

## Perspectives from New Jersey

- HINT
  - Framework for state government, payers, providers, clearinghouses, third party vendors, and third party administrators (TPAs) to meet and discuss and resolve interoperability issues
  - Develop administrative rules based on industry consensus
    - Implementation guides
    - Based on federal standards, state law, broad industry consensus
  - Unified business model for HIPAA, EHR, and RHIOs
  - NJ DOBI is the state agency that administers HINT

## Perspectives from New Jersey

### New Jersey HISPC and HIPAA

- NJ DOBI named by Gov. Corzine to be the project manager for the NJ HISPC project
  - NJ HISPC united a widespread group of committed individuals and business entities
- NJ DOBI has drafted administrative rules, including
  - Payment of medical claims
  - Creation of private and secure EHRs
- NJ DOBI sees all interoperability issues as related and intertwined
  - HIPAA is very much part of EHR
  - HIPAA is one part HISPC and necessary for interoperable HIE in New Jersey

## Perspectives from New Jersey

- NJ-HISPC sees HIPAA confusion as a major barrier to interoperability
- NJ-HISPC sees HIPAA education as a necessary foundation building block for interoperability

# WHAT CAN NJ DO ABOUT IT?

## NJ-HISPC Education Project

[next three slides taken from the NJ-HISPC Interim Implementation Planning Report]

- Engage all state agencies and educational institutions that write, develop and present training, education and certificate programs.
- The Department of Labor and Force Development, the Human Resource Development Institute, state and county colleges, private technological educational vendors should all be enlisted in the effort to create and write course specific classes on the following subjects that should offer specialized certificates and credentialing in the following subjects related to EHR networks:
  - 1) Interoperability
  - 2) HIT, EDI and EHR Workflows
  - 3) Federal and State privacy and security Law, guidelines and standards.
  - 4) HIPAA Security and Privacy Requirements, without all the misperception and misunderstanding

# WHAT CAN NJ DO ABOUT IT?

## NJ-HISPC Education Project

- Specific Topics for Education Programs:
  - • Notice of Privacy Practices
  - • Consent
  - • Authorization
  - • Minimum Necessary
  - • De-identification
  - • Law Enforcement
  - • Employer/employee and PHI
  - • Workers compensation/ disability and the ADA

# WHAT CAN NJ DO ABOUT IT?

## NJ-HISPC Education Project

- Specific Forms of Education:
  - • Face-to-face training
  - • Community forums
  - • Classroom and continuing education credits
  - • Town Hall forums
  - • Teleconferences
  - • Webex presentations and conferences
  - • Newsletters
  - • Posting news and alerts to websites and portals
  - • Brochures
  - • Mass media

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# RTI HISPC National Meeting

## March 5 – 6, 2007

### HIPAA EDUCATION

Why the Confusion?  
What Can We Do About It?

Susan A. Miller, JD  
MA-HISPC, and NJ-HISPC

## WHY THE CONFUSION?

### Lack of Knowledge

Small providers still do not have sufficient knowledge of HIPAA  
privacy never mind any other HIPAA rule

### Misunderstanding

Covered entities of all sizes misunderstand some provisions of  
HIPAA

### Differing Interpretations

Covered entities interpret HIPAA differently for all kinds of  
reasons, governance, internal rules, impact of state law

## Perspectives from Multiple States

- The VWG and LWG in both Massachusetts [MA] and New Jersey [NJ] identified understanding the HIPAA regulations as a major barrier to interoperability
- Quickly understood that HIPAA education is necessary

## Perspectives from Multiple States

- In the VWG and SWG stages MA and NJ recognized HIPAA issues were complicated by state law and regulations, specifically
  - Patient consent and
  - Sensitive clinical information
- Also, quickly determined education needed in state law and regulations as well

## Perspectives from Multiple States

- At the VWG and SWG stages MA and NJ talked to their stakeholders about their HIPAA practices and state law practices
- Both MA and NJ designed two phases to HIPAA and state laws and regulations education:
  - Collect the laws and regulations in one place, and write English translations of the laws and regulations
  - Teach / create education tools

## Perspectives from Multiple States

- Both MA and NJ have addressed both HIPAA and state laws and regulations education in SWG interim reports, and IPWG interim reports
- Both states have discovered that without HIPAA and state laws and regulations understanding, then there will be no consensus interpretation and no ability to translate into technical requirements
  - In other words, this is as much a barrier to interoperability as proprietary technology

## Perspectives from Multiple States

- GOOD NEWS:
- Both MA and NJ have HIPAA preemption reports previously developed
  - NJ is updating it's preemption report during the HISPC project period
  - MA plans to update it's preemption study as a first step during it's implementation project

## WHAT CAN WE DO ABOUT IT?

- Both MA and NJ have written into their IPWG interim report and are beginning now three levels of work to prepare for HIPAA education:
  - 1) Comprehensive review of state laws and regulations
  - 2) Updating the preemption reports
  - 3) Collecting best practices from stakeholders
- All will be needed before translation into English and development of training tools and products

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