



# ***Health Information Security and Privacy Collaboration (HISPC) National Conference***

## ***HISPC Contributions to Massachusetts HIE Privacy and Security Progress: Impact and Next Steps***

***March 5, 2009  
11:30 – 12:30  
Bethesda, MD***

***Diane L. Stone, MBA***

Health Information Security & Privacy  
**COLLABORATION**



# HISPC Contributions to Massachusetts HIE Privacy and Security Progress

- HISPC 2006
  - Privacy Landscape - Challenges to Interoperability
- HISPC 2007
  - Consent Decision Logic “Described”
- HISPC 2008
  - A Convergence of Priorities
    - Consent
    - Consumers
- Next Steps

# HISPC 2006 – Privacy Landscape - Examined and Challenges to HIE Interoperability

Process –

## Value Proposition for Massachusetts Stakeholders

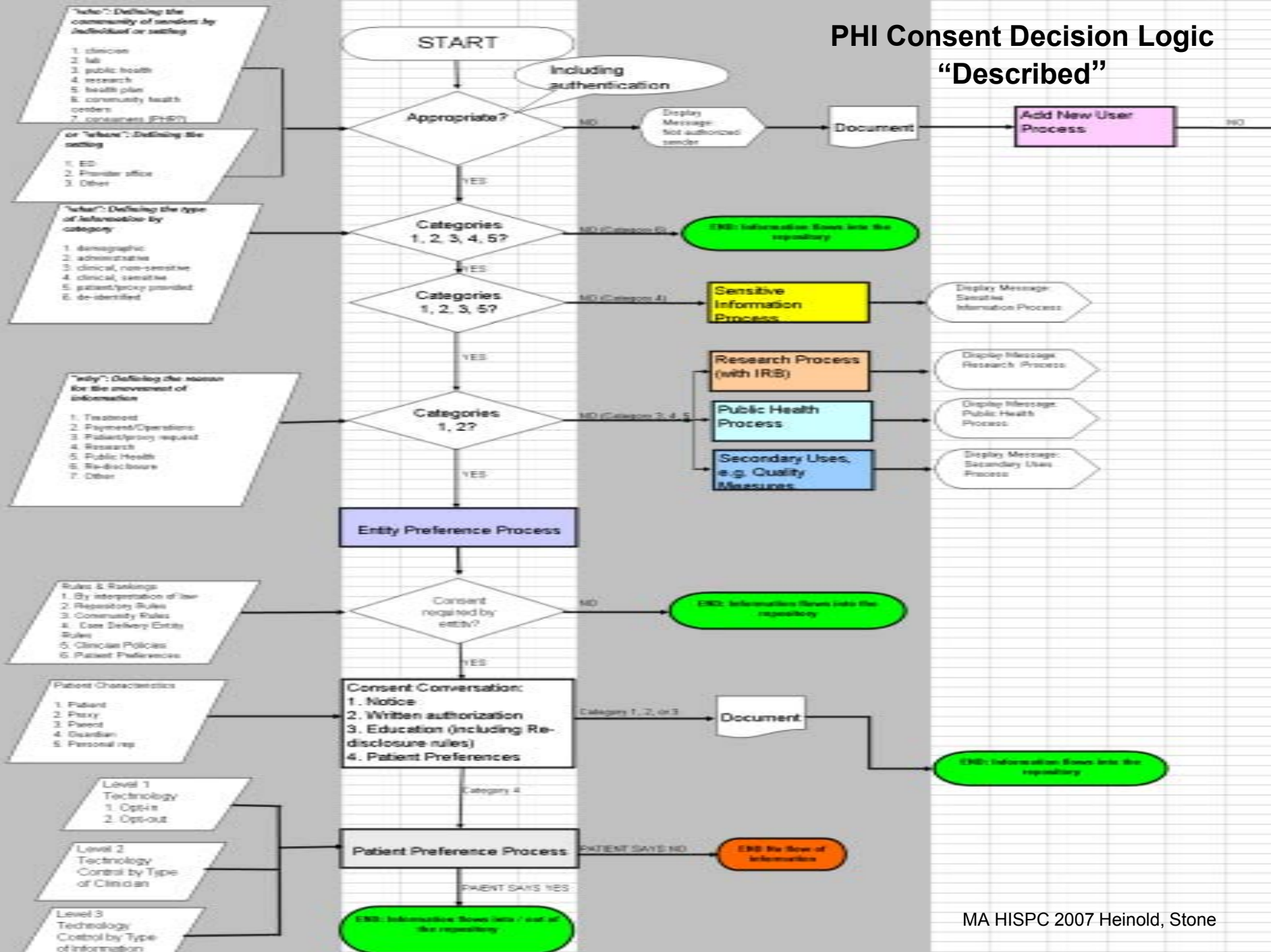
- Accomplished significant participation and commitment
- Brought recognition to complexity of MA laws and regulations
- Realization of variation in interpretation of laws
- Awareness of different policy & practice viewpoints
- Education about the challenges to interoperable HIE
- Concluded with next step focus on consent requirements and disclosure management

# HISPC 2007 - Confirmation of Complexity

## Opportunities to:

- Apply newly analyzed information
- Respond to growing realization that privacy, and specifically consent policies and practices, will impede interoperable HIE – long after technology has been developed
- Convene stakeholders to articulate varying positions on what comes first in a consent logic hierarchy
- Witness an epiphany as consensus converges on the consent management decision flow
- Develop *simple* graphic representation of consent process

# PHI Consent Decision Logic "Described"



# HISPC 2008 - Convergence of Priorities: Consent and Consumers

## 2 HISPC Projects in Massachusetts

- **Multi-State Interstate Disclosure and Patient Consent Requirements Collaborative**
  - Identified & documented 11 states' privacy laws for PHI disclosure
  - Analyzed and displayed their variations and commonalities
  - Recommended next steps to reconcile different approaches to enable interstate HIE
- **Multi-State Consumer Education and Engagement Collaborative**
  - Focused on the unmet needs to communicate and build trust with consumers
  - Emphasized development of multiple media to provide understandable descriptions, definitions, situations, questions and answers around use and disclosure of PHI

# Multi-State Interstate Disclosure and Patient Consent Requirements

## Situation #1:

- For the Non Emergency Treatment Scenario where patient data is in one state and required for treatment in another

## Results:

- From a relational matrix of 11 PHI sources and 17 PHI types, 187 questions asked Yes or No\* to requiring consent to release PHI
- Massachusetts state law requires consent for PHI disclosure in 108 of these instances
- Consent required consistently across all sources of PHI for release of:
  - Diagnosis for HIV/AIDS
  - Genetic testing
  - HIV test results
  - Mental health records
  - Substance abuse, and
  - Medications used for HIV/AIDS
- Without exception, consent required if PHI is held by an inpatient or outpatient mental health facility

# Multi-State Interstate Disclosure and Patient Consent Requirements

## Situation # 2

- For the Emergency Treatment Scenario where patient data is in one state and required for treatment in another

## Results:

- From a relational matrix of 11 PHI sources and 17 PHI types, 187 questions asked Yes or No\* to requiring consent to release PHI
- Massachusetts state law requires consent for PHI disclosure in 89 of these instances
- Consent required consistently across all sources of PHI for release of:
  - Diagnosis for HIV/AIDS
  - Genetic testing
  - HIV test results
  - Mental health records
  - Substance abuse
  - Medications used for HIV/AIDS
- Consent required in most instances if PHI is held by a psychiatrist, other outpatient facility, or a commercial payer

# Multi-State Interstate Disclosure and Patient Consent Requirements

## Situation # 3

- Can a state Public Health agency release population collected PHI to a provider in another state for treatment purposes

## Results:

- From a matrix of 7 PHI sources and 18 PHI types, 77 questions asked Yes or No\* to requiring consent to release PHI from a state's public health agency to another state's provider
- Massachusetts state law requires consent for PHI disclosure in 44 of these instances
- Consent required consistently across all types of PHI except from Hospitals Admission records and Hospital discharge summary sources

# Results Sample compared to Other 10 States

**Legend**  
 Is consent required?  
 No  
 Sometimes  
 Unclear or N/A  
 Yes

## Scenario 1 - Treatment (Non-Emergency)

	Hospital	Physicians
Medication History	Green Green Green Green Green Green Red Red	Green Green Green Green Green Yellow Grey Red Red
Lab Tests	Green Green Green Green Green Yellow Red Red	Green Green Green Green Green Yellow Yellow Red Red
HIV: Test Results *	Green Green Green Yellow Red Red Red Red	Green Green Yellow Grey Red Red Red Red
Other STDs *	Green Green Green Green Grey Red Red Red	Green Green Yellow Grey Red Red Red Red
Mental Health Records *	Green Yellow Yellow Grey Red Red Red Red	Green Yellow Yellow Grey Red Red Red Red
Substance Abuse	Green Green Green Grey Red Red Red Red	Green Green Green Grey Red Red Red Red
Genetic *	Green Green Green Green Yellow Red Red Red	Green Green Green Yellow Grey Red Red Red

MA requires consent \*

## Results – Massachusetts Compared to other 10 States

- Wide spectrum of state law approaches to when PHI can be disclosed without consent



Note that reference to “the fewest” and “the most” requirements may not reflect the level of restrictions placed on disclosure, but rather may simply reveal a level of completeness or complexity in terms of a state’s laws and how they are structured

# Multi State Consumer Education & Engagement Collaborative

Statement of the Problem – Consumers want to know that their PHI is safe from unwanted use and disclosure.

## Today:

- The use and sharing of PHI is largely based on consumer trust
- Collaborative sought to improve trust
- **How?**
  - By increasing awareness and understanding of privacy and security challenges, requirements, and patient rights
- **Strategy?**
  - Multi-modal educational approaches, targeted audiences, and literacy and language considerations.

# Multi State Consumer Education & Engagement Collaborative Massachusetts Specific Projects

Developed a set of resources that focus on *behavioral and sensitive health information.*

A multi-modal approach was used including a:

- Self-directed tutorial
- FAQs
- Legal Inventory & Consumer/Provider Information Sheets
- Video Documentary
- PHR Inventory and Consumer Guidelines

These tools were literacy controlled and reviewed by MA legal experts.

## Next Steps – To Address Interstate Variation in Consent Laws

- Should we raise the level of privacy protection nationwide to match the most restrictive states, or should we adopt the rules of the least restrictive states to enhance HIE?
- Align state laws with HIPAA categories of use, with different rules for treatment, for payment and for health care operations?
- Develop better tools to help providers and consumers deal with complex privacy laws
  - Online legal resources
  - Consent management software

# MA HISPC Multi-State Project Direction

*Consent Collaborative*

**Co- Chair**

**Diane L. Stone MBA**

[dstone@mahealthdata.org](mailto:dstone@mahealthdata.org)

[diane.stone1@comcast.net](mailto:diane.stone1@comcast.net)

(781) 789-4685

*Consumer Education and Engagement Collaborative*

**Director**

**Jerilyn W. Heinold MPH**

[jheinold@mahealthdata.org](mailto:jheinold@mahealthdata.org)

[Jheinold@comcast.net](mailto:Jheinold@comcast.net)

(617) 771-6689



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