



# Welcome to the AHRQ Medicaid and CHIP TA Webinar

## *Privacy and Security Open Community of Practice*

May 18, 2010, 3:00 – 4:30 p.m. Eastern

### **Facilitator:**

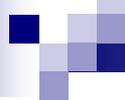
**Carolyn Turner**, Florida Agency for Healthcare Administration

### **Speakers:**

**Ellen Flink**, Director of Research in Patient Safety and Quality, New York State Department of Health

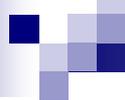
**Amy Zimmerman**, Chief, Health Information Technology, Rhode Island Department of Health

**Jocelyn Stein**, Strategic Planning Director, Minnesota Department of Human Services



# Agenda

- 3:00 – 3:10     **Welcome**  
*Carolyn Turner*, Florida Department of Healthcare Administration
- 3:10 – 3:30     **Presentation**  
*Ellen Flink*, Director of Research in Patient Safety and Quality, New York State Department of Health
- 3:30 – 3:40     **Presentation**  
*Amy Zimmerman*, Chief, Health Information Technology, Rhode Island Department of Health
- 3:40 – 3:50     **Presentation**  
*Jocelyn Stein*, Strategic Planning Director, Minnesota Department of Human Services
- 3:50 – 4:25     **Discussion/Ask the experts**
- 4:25 – 4:30     **Next Steps**



**AHRQ MEDICAID/CHIP OPEN COMMUNITY  
OF PRACTICE DISCUSSION  
MEDICAID'S POTENTIAL ROLES IN  
DEVELOPMENT AND ENFORCEMENT OF  
CONSENT POLICIES FOR HIE**

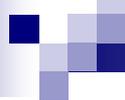
Ellen Flink, MBA

Director of Research in Patient Safety and Quality

New York State Department of Health

Office of Health Information Technology Transformation

May 18, 2010



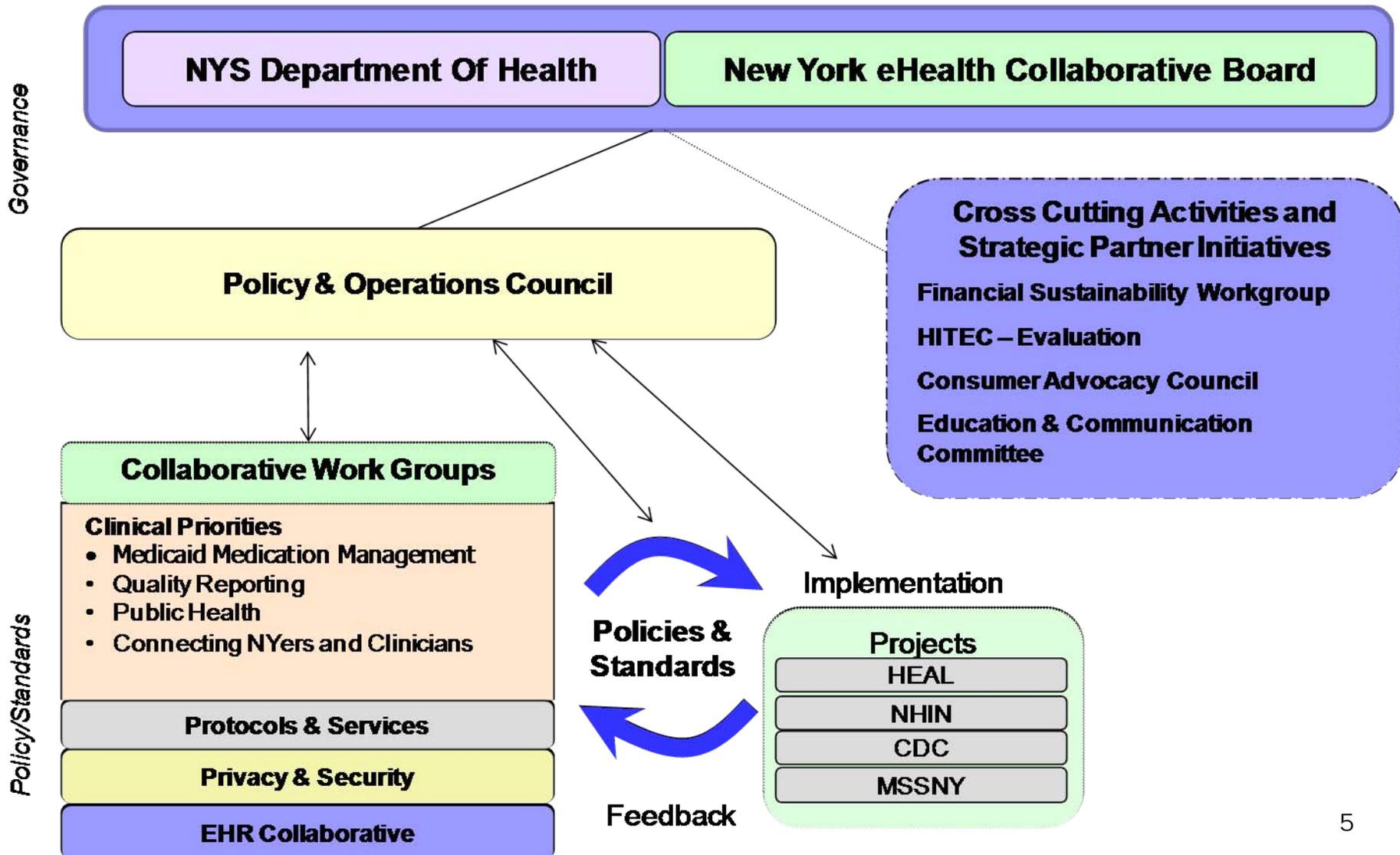
# Broad Goals for Health IT Strategy

Build health information infrastructure to support State health reform goals

- Support clinicians and consumers with information at point of care
- Advance care coordination
- Strengthen public health surveillance and response
- Enhance quality and outcome measures

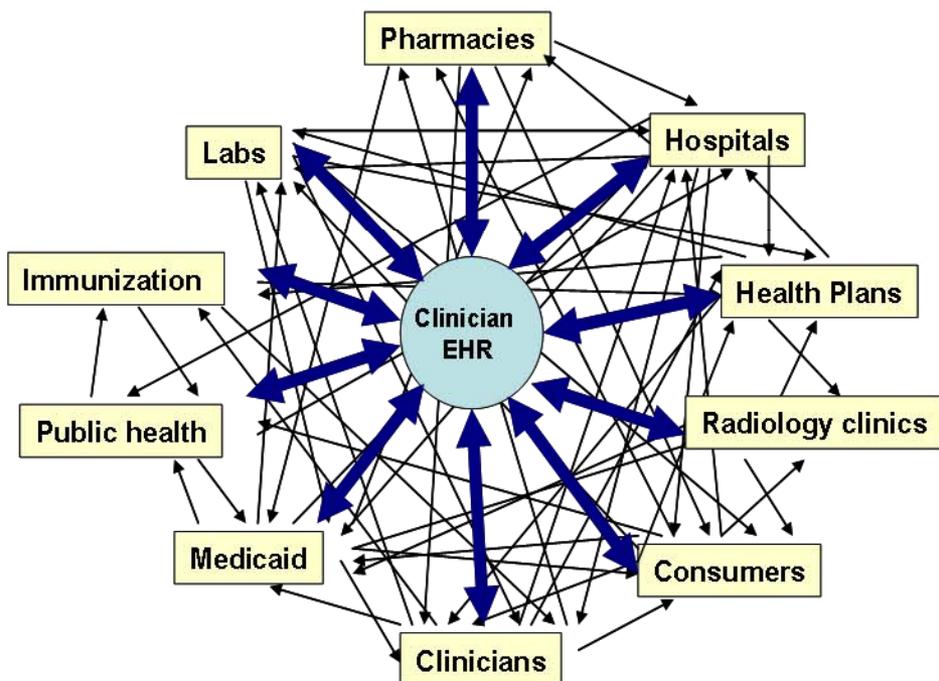
**Overall strategy is about systems change, not just health IT.**

# Statewide Public-Private Partnership & Collaboration Process

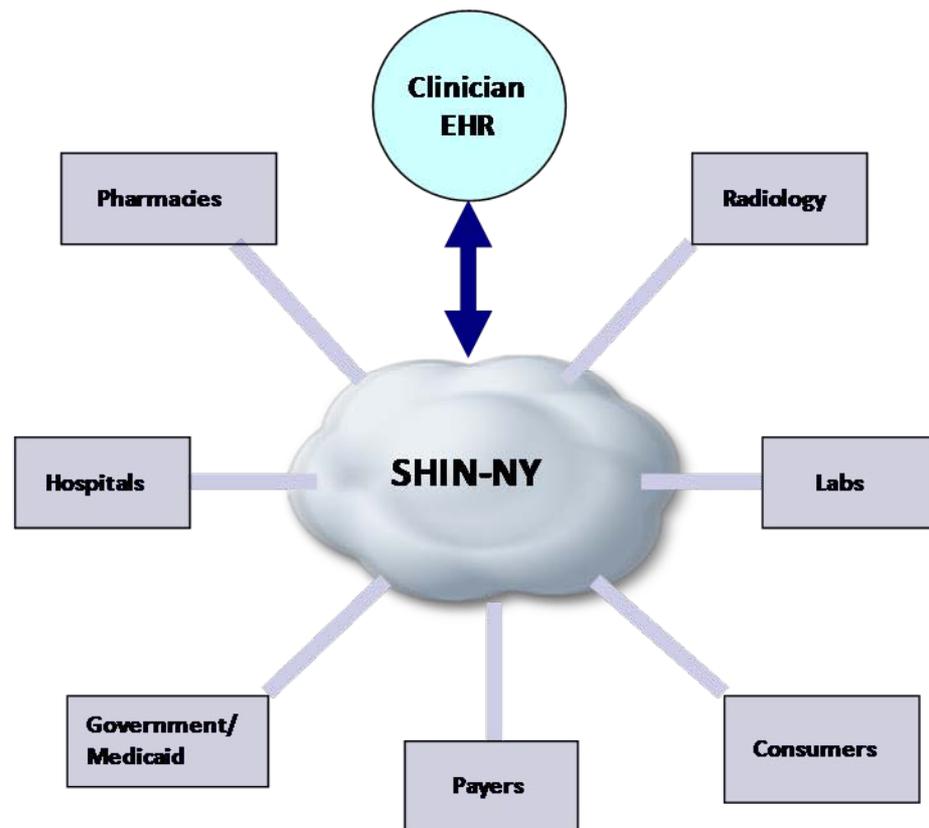


# Vision for New York's Health Information Infrastructure

Costly, High Risk and non-Interoperable EHRs



Interoperable EHRs





# Alignment of Federal and State Policies and Funding

- Incentives for meaningful use of health IT—Medicare and Medicaid move into more significant roles
- Standards for HIE and HIT—new certification standards and processes
- Funding for HIE implementation—build on current State efforts
- Role of NHIN

**Major governance and implementation issues still TBD at federal level.**

**We will need to adapt NYS strategy but we can also lead by example.**



# Patient-Centered State Medicaid HIT/HIE Plan for New York

- Support HIT adoption and clinical practice workflow reengineering.
- Incentivize meaningful use of EHR technology.
- Improve quality of care delivery by supporting the patient-centered medical home model.

# Patient-Centered State Medicaid HIT/HIE Plan for New York (cont'd)

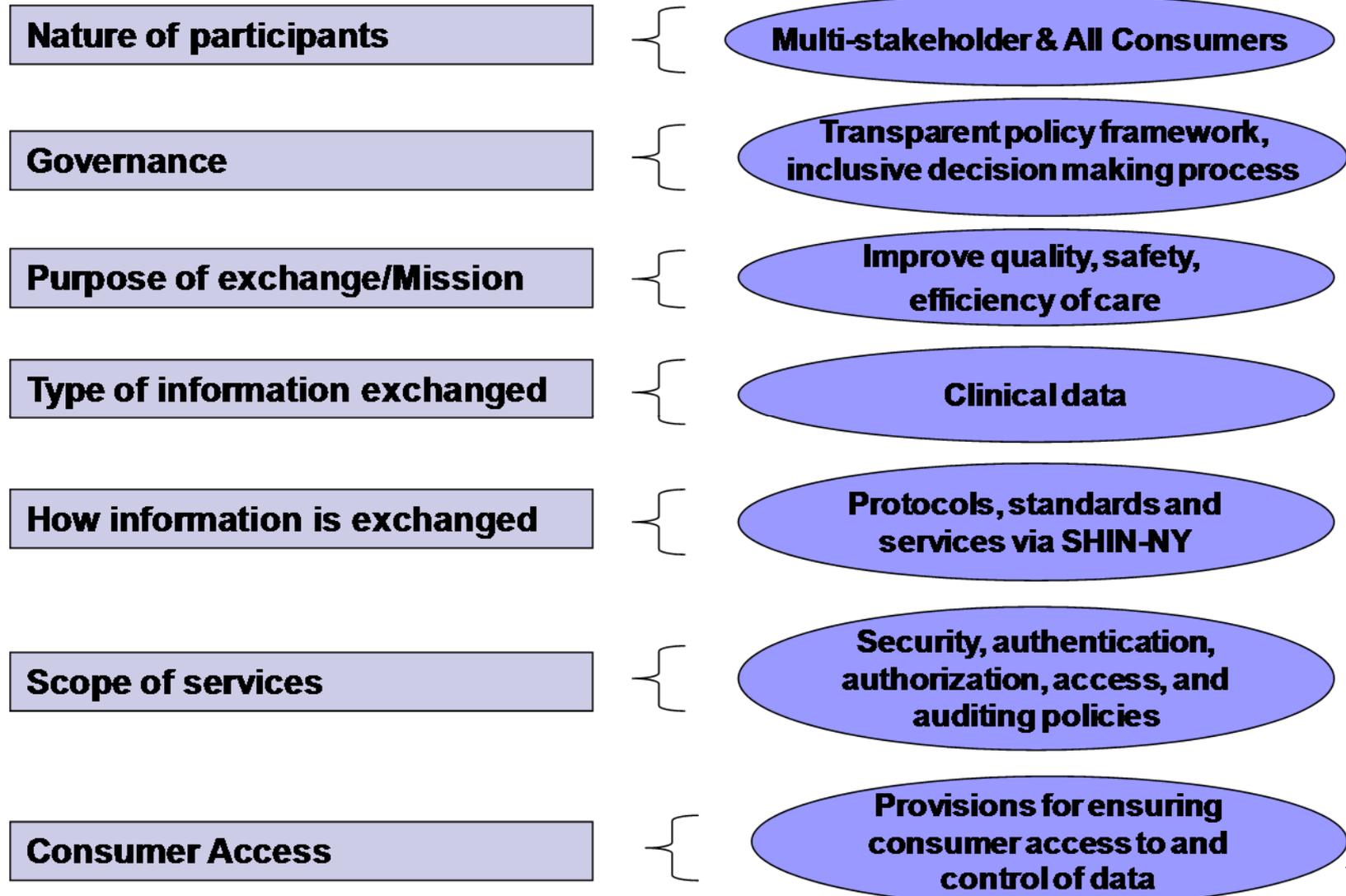
- Improve patient safety by incentivizing e-prescribing.
- Promote improvements in quality of care as documented by clinically based electronically reported quality metrics.
- Improve care coordination via use of clinical data distributed through interoperable HIE utilizing NY Medicaid's HIE/MITA enterprise architecture.

# NY HISPC Phase II Goals

- Advance health information exchange through the development and implementation of a standardized consent process for RHIOs in NYS
  - Ensure that consumer consent is informed and knowing.
  - Provide clarity and ensure consistency in consent process.
  - Give RHIOs standing to address patient consent on behalf of physicians, providers, and New Yorkers.
  - Enable incentives and protections to encourage participation.

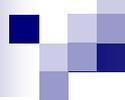
# Analytic Framework

## RHIO – Core Components



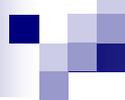
# Consent Policy Components

- Scope of HIE activities governed
- RHIO definition
- Uses of information
- At what point consent is obtained
- Where and by whom consent may be obtained
- Provider participation in HIE
- Sensitive information
- Standardized consent process
- Durability and revocability
- Consumer engagement
- Audit and transparency
- RHIO-to-RHIO transfers



# Key Principles of Consent Policies and Procedures

- Facilitate consumer choice and address consumer concerns about privacy.
- Promote exchange of information to improve the quality and efficiency of care.
- Provide RHIOs operational flexibility to implement consent policies and procedures.
- Develop policies that are practical for providers.
- Make policies simple and clear with concrete rationale.



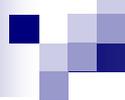
# Consent is part of a larger policy framework

- RHIOs have responsibility for ensuring privacy and security of information collected and exchanged
  - Access and use policies
  - Authentication of identity
  - Authorization for access
  - Consumer and provider identification
  - Transmission security
  - Data integrity
  - Audit trails for clinicians and consumers
  - Administrative and physical security
  - Enforcement and protections

# Interoperability “Rules of the Road” Adopted by NYS

- Consent for access to information
  - No consent for uploading or converting data
  - All PHI included
  - Consumer choice on which providers have access
  - Medicaid program supports consent policy
- Data content standards and specifications for clinical use cases incorporated in health IT applications
- Network communication protocols to replace “one-off” proprietary interfaces
- System security and trust includes role based access, authentication of users, audit capabilities

**Successful implementation of health IT requires common policies and enforceable agreements.**



# Role of Consumers and Patient Groups in the Process

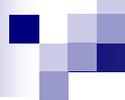
- Education and outreach
- Engagement
- Evaluation

# Goals

- Educate and inform consumers to cultivate an aware and engaged population.
- Convey the big picture of benefits and risks associated with ehealth (including privacy)—and why it matters to the individual consumer.
- Create a range of materials appropriate for general and point-of-care settings.
- Leverage RHIOs and other community stakeholders, to adapt and disseminate information that is culturally and linguistically appropriate based on the diversity of their individual communities.
- Create templates that are customizable for different audiences.
- Measure success.

# Materials Developed

- eHealth brochure—translated into 14 languages
- Visual ads—emergency and convenience versions
- Radio spots—emergency and convenience versions
- Video—adapted from Oregon’s video
- Web site—[www.ehealth4ny.org](http://www.ehealth4ny.org)
- Model consent form—translated into 14 languages
- Train-the-trainer slide deck
- FAQs about consent and privacy
- Two reports based on our experiences/lessons learned about developing consent policy and educating the public about it



# A Few Key General Lessons

- An inclusive process takes time.
- No one deliverable can fit all needs: need different kinds of media and customizable templates.
- Direct consumer testing is essential.
- It's hard to find a balance on extent of detail (and it varies by medium).
- There are limits on lowering literacy levels—especially for the consent form.



# New York Resources

- [Ehealth4ny.org](http://Ehealth4ny.org)
- [nyehealth.org](http://nyehealth.org)
- [nyhealth.gov/technology](http://nyhealth.gov/technology)



# Contact Information

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[www.health.state.ny.us/technology/](http://www.health.state.ny.us/technology/)



# **AUTHORIZATION APPROACH FOR RHODE ISLAND'S STATEWIDE HIE**

Amy Zimmerman, MPH

Rhode Island Department of Health

# Context

- Department of Health received contract with AHRQ to develop Rhode Island's HIE
- Initially share laboratory and medication history to create integrated longitudinal patient record, other data types to be added over time
- Subcontract to Rhode Island Quality Institute (local nonprofit) for governance
- Rhode Island Quality Institute form (RIQI), formally designated as the State's RHIO in 2008 via RFP process; and is state-designated entity for ARRA
- RIQI will be fully operating all aspects of current care (policies, customer service, and technology) by July 2010

# Governance

- Governance = RIQI committee structure
  - Steering committee
  - Consumers
  - Physicians
  - Policy and legal State leaders
  - Technical group (initial data submitters)
    - Hospitals
    - Laboratory chain
    - Department of Health laboratory
    - Others

# RI HIE Authorization Model

Authorization Model: Requires two levels

- Opt in to participate (Enroll): All or nothing
  - No data can leave its source unless patient has opted in
  - All information from all participating data submitting partners is sent to/through the HIE
- Authorize providers to view the following:
  - Patients control which providers can access their data
  - At a minimum, patients who have enrolled have agreed to have their information be available for viewing in unanticipated situations (emergency, covering providers, etc) and will be notified at the time by the provider, or, if needed later, by the RHIO

# Influences (1)

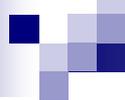
- Availability of health information from multiple sources:
  - Enhances the value of the HIE...
  - ...but also makes an HIE different from electronic records systems currently in use by hospitals, physicians, etc.
  - Greater perceived risk of security breaches or unauthorized access to data by employers, insurers, others—people need informed choice

# Influences (2)

- Existing Rhode Island law
  - RIGL 5-37.3 governs health care confidentiality in general—permits disclosure without prior authorization for coordination of care, emergency, other.
  - Other State laws prohibit disclosure of information to without prior authorization, even if for coordination of care:
    - RIGL 23-11, Sexually Transmitted Diseases
    - Similar issue with 42 CFR, Part 2
  - Authorizing disclosure to the HIE and to providers to view the HIE allows one policy for all data types.

# Influences (3)

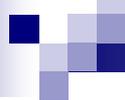
- Uncertainty about nature of disclosure to an HIE
  - Is encrypted data submission to a RHIO-operated HIE considered disclosure?
  - What is the nature of a RHIO?
    - Can disclosure to a RHIO-operated HIE occur without prior authorization because it is a health care provider or business associate that receives information for operations or coordination of care?
    - Can all health information be disclosed to the RHIO because all is potentially “minimum necessary”?
    - How will the RHIO use identifiable and de-identified information?



# RI Stakeholder Environment

The diverse stakeholders that have participated in the HIE process have determined that

- Consumers are concerned about the confidentiality of their medical data.
- Safeguards are necessary to protect consumer information and provider participants in the HIE.
- Codifying these safeguards in statute ensures long-term protection of consumer information and privacy.
- Community support was strong.



# currentcare's Legislative History

## **RI Health Information Exchange Act of 2008** (passed June 2008)

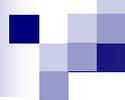
- Intended to establish safeguards and confidentiality protections for currentcare; in order to improve the quality, safety, and value of health care.
- RIQI developed legislation and obtained sponsors; not submitted by State government.
- Successfully passed with minor revisions due to broad community input and consensus-development process.
- Is stricter than provisions in HIPAA, does not allow access, release, or disclosure of confidential health care information through the HIE without patient authorization or pursuant to the act.



# currentcare's Legislative History

## RI Health Information Exchange Act of 2008, continued

- Patients voluntarily choose to enroll in the HIE.
- Providers voluntarily choose to participate in the HIE.
- The RHIO will administer and operate the HIE.
- An HIE advisory commission will be created to provide recommendations to the Dept of Health, in consultation with the RHIO, regarding uses of confidential health care information.
- Health information may be accessed and released only if authorized by patient, except in an emergency, for public health purposes, and for administration by the RHIO.
- Patient can withdraw authorization at any time.
- HIE is not subject to subpoena unless a court order has been obtained.
- HIE is subject to certain security provisions.
- Civil and criminal penalties for violations (up to \$10,000 per violation if intentional).
- Department of Health to write rules and regulations.



# currentcare's Legislative History

## **RI Health Information Exchange Act of 2008, continued**

### **Patient Rights:**

- Ability to see who accessed their information
- Ability to obtain a copy of their information in the HIE
- To be notified in the event of a breach that may lead to identity theft or other injury
- To terminate participation at any time
- To request an amendment of their information through their provider

# Implementation Considerations (1)

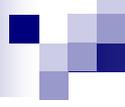
- Authorization to participate in the HIE assumes an “enrollment” process
  - Want to use “trusted source” (like health care provider) to enroll participants in the HIE.
  - Does benefit accrue to providers/others who are asked to enroll people?
  - How much information is required upon enrollment to ensure accurate matching with clinical records?  
To verify identity?
- Requires slow build-up of data in the HIE, and no historical data

# Implementation Considerations (2)

- Authorization to participate in the HIE requires a feasible and affordable technical solution—which stakeholders should shoulder the costs?
  - 1) Data-submitting organizations record HIE participation status; disclose only subset of records to HIE.
  - 2) Data-submitting organizations send automatic message to HIE with demographic data only; get message back confirming enrollment; disclose clinical information only when demographic data match with an enrolled HIE participant.
  - 3) Data-submitting organizations disclose all demographic and clinical information to the HIE automatically; HIE destroys any information that does not match with an enrolled HIE participant.
- Number of transactions between data submitters and HIE has implications for performance of HIE.

# Implementation Considerations (3)

- Authorization to providers
  - At what level can the HIE manage access restrictions? At the institutional or individual level?
  - How much information is needed to ensure that intended provider is granted authorization?
  - When does authorization to view occur? Can authorization be granted in real time?
  - How does a patient verify identity to demonstrate that he/she has right to authorize providers?



# Challenges:

- Consumer education and communication
- Authorization form: simple, understandable
- Enrollment
- Alignment of enrollment, use of data-submitting partners, and treating providers
- Provider education



**Amy Zimmerman**

**Director's Office**

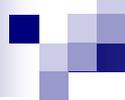
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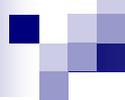


# Open Q&A



# Discussion Questions

- What are some best practices for developing patient consent policy for HIE? Are they applicable to Medicaid as well as HIOs?
- What special considerations relate to Medicaid social services and case worker access to records in an HIE (either controlled by an HIO or by Medicaid)?
- What special concerns are involved in the use of Medicaid claims data in HIE?



# More Discussion Questions

- What are some best practices for developing patient consent policy for HIE? Are they applicable to Medicaid as well as HIOs?
- What special considerations relate to Medicaid social services and case worker access to records in an HIE (either controlled by an HIO or by Medicaid)?
- What special concerns are involved in the use of Medicaid claims data in HIE?

# Next Steps

- Next Community of Practice meeting:
  - Proposed date: July 19, 2010
  - Next meeting topic?
    - Suggestions?
  - If you would like to join the Privacy and Security Community of Practice, please e-mail [sajohnson@rti.org](mailto:sajohnson@rti.org)