

New York Health Information Security and Privacy Collaboration (NY HISPC)

September 5, 2007

Agenda

- **Welcome and Introductions**
- **Background and Project Description**
- **Legal Context: Health Information Exchange**
- **Consent and Electronic HIE**
 - **RHIO and Provider Perspectives**
 - **Consumer Perspectives**
- **Review and Next Steps**



Background and Project Description: State Priorities and Agenda

Background

Overview of New York Landscape

■ Opportunity

- Rapidly expanding capacity for electronic health information exchanges through RHIOs

■ Challenge

- Current State and Federal laws governing health information exchange written in paper-based world and do not contemplate RHIOs

■ Goal of NY HISPC

- Create policy guidance governing the exchange of personally identifiable health information through RHIOs in NY that will support improvements in patient care while earning and maintaining patient trust

Background

Office of Health Information Technology Transformation (OHITT)

Mission

- Coordinate State health IT initiatives across public and private sectors

Funding

- \$106 million in 2007-8 for health IT implementation to support improvements in health care quality

Statewide Initiatives/Activities

- Strategic health IT implementation plan
- Health IT Coordinating Council
- Public-private advisory body (NYeC)
- HEAL NY Grants
- NYS DOH's Medicaid Health Information Exchange Pilot
- NYS' participation in NHIN implementation trials (pending approval)
- NY Health Information Security and Privacy Collaborative (HISPC)
- Health Information Technology Evaluation Collaborative (HITEC)

Background

New York e-Health Collaborative

Description

- Independent, public-private advisory body
- Diverse stakeholder membership

Activities

- Developing HIT and HIE policies and standards
- Evaluating and establishing accountability measures for NY's HIT strategy
- Convening, educating, and engaging key constituencies

NY HISPC Parts 1 and 2

Consent Considerations

NY HISPC Part 1 – Consent Recommendations

- General consent and notice of HIE allowable for general health information
- Specific consent required for all personal health information
 - Consent may be obtained either prior to loading data or at point of access
- **Short term:** Create universal consent form/process/language
- **Long term:** Create new law governing consent for disclosures for participants in RHIOs

NY HISPC Part 2 – Update on Consent

- DOH has made a policy determination that specific consent is required for all health information exchange conducted through a RHIO to earn public trust

NY HISPC Part 2: Background

Current Practices

- Diverse interpretations of State consent laws lead to multiple approaches to patient consent across RHIOs in NYS
- Consumer participation in patient consent practices vary across RHIOs
- Strong support within consumer advocacy community for existing state law protections that exceed HIPAA standards
- Little to no statewide dialogue has taken place on a standardized patient consent form and process for RHIOs

NY HISPC Part 2

Project Goals and Approach

- Project Goal: Implement trusted patient centered consent policies to protect privacy in an interoperable HIE environment
- Project Approach
 - Assess the current environment: what problems need solving?
 - Develop a sophisticated understanding of the options for solving those problems.
 - Develop consensus around the best options.
 - Implement new policies/laws.

Parameters and Focus

Starting Assumptions

1. Affirmative consent is necessary for the exchange of all health information through a RHIO.
 - Opinions vary about whether this is necessary under state law.
 - Conclusion based on belief by state officials that this is necessary public policy to earn patient trust and therefore, for the success of RHIOs.
2. New policies are necessary to provide clear rules in the marketplace for the benefit of consumers, providers and other RHIO stakeholders.
3. New policies should specifically govern HIE conducted among participants in RHIOs.
4. The policies must co-exist with HIPAA.
5. The policies may update, expand or strengthen state law.

Preliminary Findings

Key Issues

- How should RHIOs be defined?
- To what extent should consumers have the ability to direct what information is/is not included in the exchange?
 - Option 1: No filters – all in or all out.
 - Option 2: Filtering at provider level.
 - Option 3: Filtering at medical record level.
- What characteristics should a standardized consent process have?
 - What is necessary to ensure the information is clear and the consumer exercises informed consent?
 - In what format can consent be obtained – electronic, written, oral, implied?
 - Durability and revocation
- How should current administrative requirements be adapted to be meaningful in the new electronic environment?
- What are the parameters of consumers' right to access and control electronic personal health information?

Stakeholder Meeting #1

Meeting Goal: Identify the Problem

- Establish a common understanding of key issues relating to patient consent and health information exchange as well as NY HISPC project goals
- Identify specific issues that need to be addressed when formulating new law/policy governing patient consent in the RHIO context



Background and Project Description: HISPC I and II

NY HISPC Part 1

Overview and Timeline

■ Process

- HHS Contract with Research Triangle Institute and National Governors Association for 18 month contract
- 34 States and territories selected
- Lead Agency in NYS: NYS DOH
 - Sub-Contractors: Manatt, Phelps & Phillips & Columbia University

■ Purpose

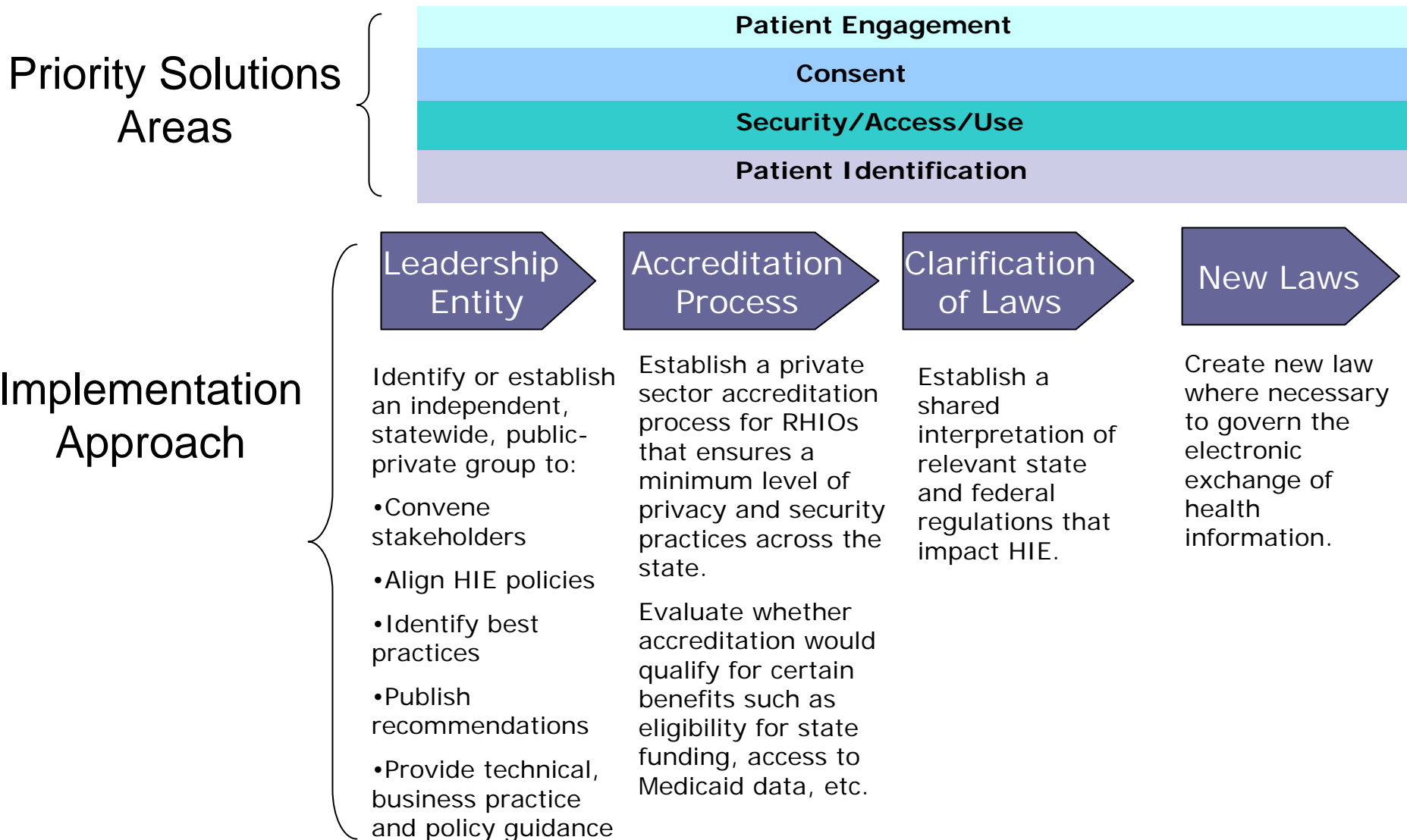
- Develop consensus-based solutions that support patient privacy and enable secure exchange of electronic health information
- Develop supporting plan to implement solutions

■ Key Deliverables

- Final Reports available at www.health.state.ny.us/technology/nyhispc/

NY HISPC Part 1

Implementation Framework/Approach



NY HISPC Part 2

Goal, Process and Key Deliverables

- Goal: Implement trusted patient centered consent policies to protect privacy in an interoperable HIE environment
 - Phase I: Assessment and Consensus Building
 - Three stakeholder meetings
 - Inter-agency workgroup meeting
 - Engagement of neighboring states
 - Phase II: Recommendation and Legislative Proposal
 - Develop a white paper outlining the affirmative standardized consent form and process
 - Develop a legislative proposal to DOH for a new consent law governing electronic, interoperable health information exchange
 - Develop an operational plan for the new consent law
 - Phase III: Standardized Consent Form and Process and Education Plan Development
 - Develop a model standardized consent form and/or outline associated processes
 - Develop patient/consumer educational plan

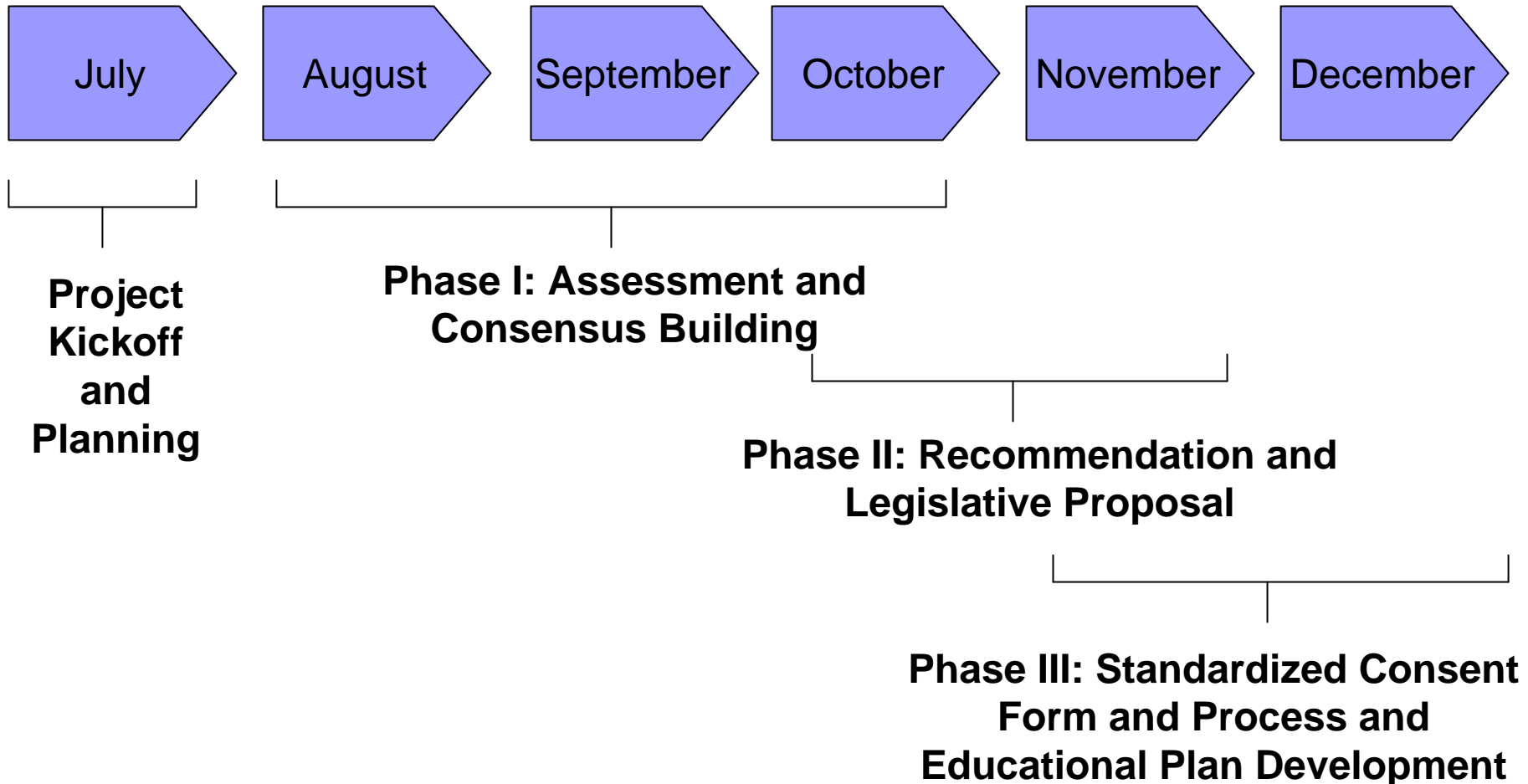
NY HISPC Part 2

NY Collaborative Workgroup Participation

1. Standard Policies: Interstate Data Exchange Policy Collaborative
 - Consent/authorization from the patient for use and disclosure
 - Consent/authorization for use/disclosure provided by the data source
2. Communications Collaborative
 - Determining core message
 - Training and dissemination messages

NY HISPC Part 2

Timeline for Key Deliverables



NY HISPC Part 2

Stakeholder Meeting Participants and Dates

Invited Participants

- Agency Officials
- Consumer Advocates
- Elected Officials
- Industry Representatives
- Payers
- Providers
- RHIOs

Dates

- September 5th (NYC)
- October 1st (Albany)
- October 24th (NYC)

NY HISPC Part 2

Stakeholder Meetings: Goals and Proposed Outcomes

■ Meeting 1

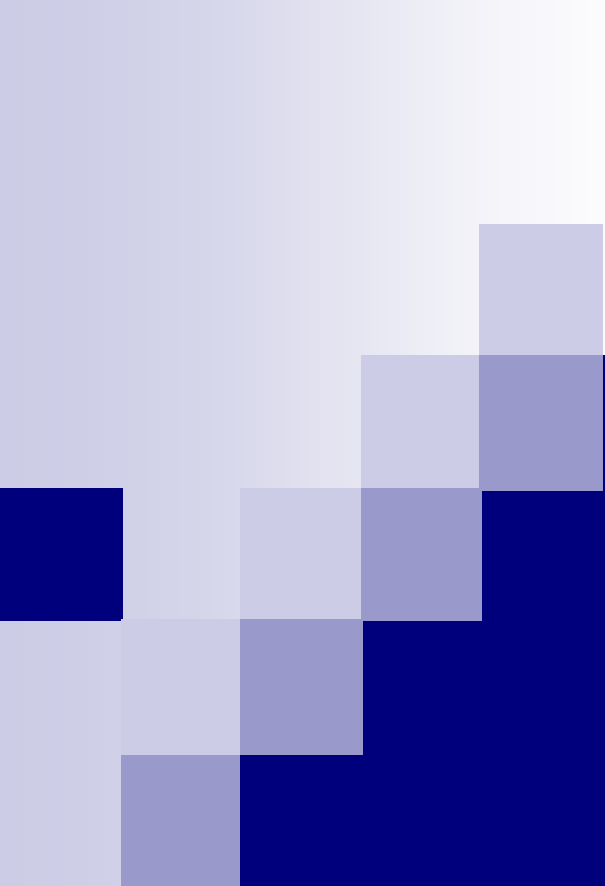
- Establish a common understanding of the key issues and project goals.
- Identify specific issues that need to be addressed when formulating new law/policy governing consumer consent in the RHIO context.

■ Meeting 2

- Set out priority issues to be addressed through project.
- Develop common understanding of various options for resolving the issues and the pros/cons of each.
- Seek to identify emerging points of consensus on solutions.

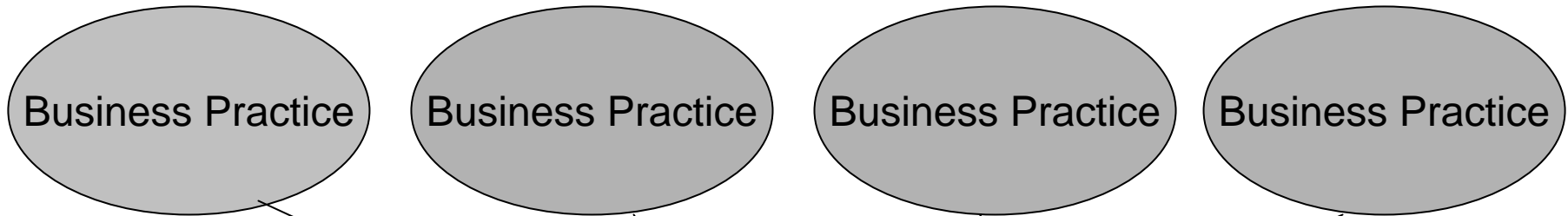
■ Meeting 3

- Present proposed recommendations.
- Seek feedback and consensus.



Emerging Issues Under Current Law Related to Health Information Exchange

Business Practices: Determine how and to what extent privacy and security requirements are implemented in the exchange of health information.



State Law:
Preempts HIPAA where more stringent and not in conflict

HIPAA:
Provides the floor for legal requirements

Some of the Issues and Challenges for RHIOs

- Disclosure with consent
- Emergency treatment
- Fear of private law suits

State Laws on Health Information Exchange
Patient Consent Options

	Implied	Affirmative
General	<p>Patient receives HIPAA privacy notice, which informs patient of right to restrict disclosures made for treatment and certain other purposes. If patient does not request restriction, consent is implied. No signed patient consent is obtained.</p>	<p>Patient signs consent form generally authorizing disclosures for treatment and/or other purposes. Consent does not expressly reference RHIO.</p>
RHIO-Specific	<p>Patient receives notice specifically describing RHIO and informing patient of right to opt out. If patient does not opt out, consent is implied. No signed patient consent is obtained.</p>	<p>Patient signs consent form specifically authorizing disclosures to and/or through the RHIO for treatment and/or other purposes.</p>

What Does “Specific” Mean?

- How does the consent specify the recipients of the information?
 - Does the consent need to provide the names of the RHIO participants?
- How does the consent specify the purpose of the disclosure?
 - Should the consent be for purposes other than providing the patient with medical treatment?
 - If so, how does the consent specify the purpose (e.g., a disclosure for the purpose of the recipient conducting quality improvement activities)?

Creating a Durable Consent

- How do you provide a way for patients to know who the RHIO participants are now and in the future?
- How do you give patients a way to revoke consent after they give it?

Unified Consent Form

- Can a single form provides consent to disclose all medical records and claims data, including specially protected information, for use in HIE?
- Such a form would be under jurisdiction of DOH, OMH, OMRDD, OASAS, OAG and SID.
- DOH has agreed to be part of a multi-State effort to seek clarification from SAMHSA to determine whether a form like this could be used to disclose substance abuse information.

Emergency Treatment

- If a patient who is in need of immediate medical attention is unconscious or otherwise unable to consent, a provider may treat the condition under the emergency doctrine, and it is not necessary for the provider to obtain a court order before providing treatment (PHL § 2805-2(d)).
- In the current paper-based world, emergency providers may also obtain information about the patient without consent in order to provide emergency treatment.
- With eHIE, more information may be available to emergency treatment providers.

Liability and Fear of Private Law Suits

- Assume a consent form and process is approved by all relevant State and federal agencies.
- Private law suits are still a possibility, and the courts make the final determination of how the law ought to be interpreted.

New Legislation

- There will continue to be uncertainty under current law.
- A new law could make it easier for RHIOs to move forward.



Consent and Electronic HIE: RHIO and Provider Perspectives

Stakeholder Meeting #1

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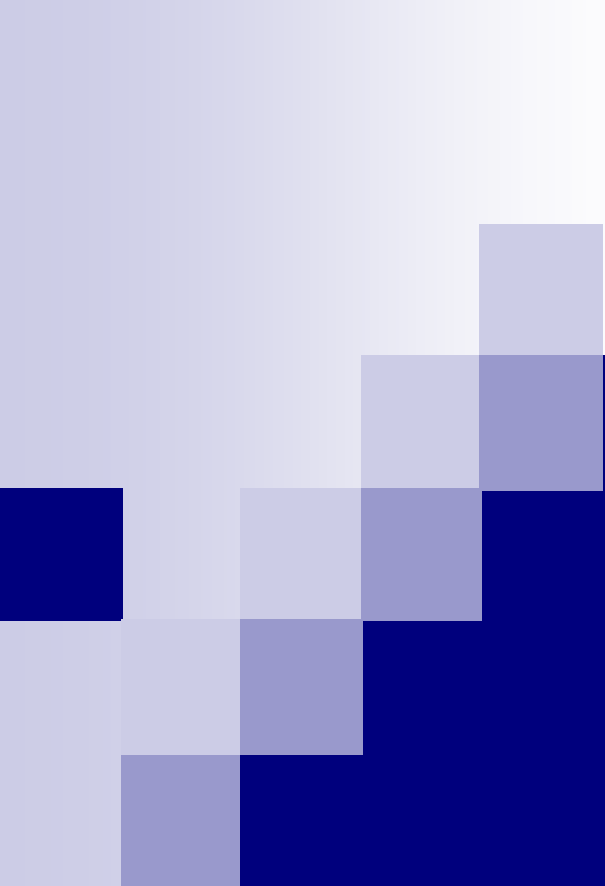
Consent and Electronic HIE: RHIO and Provider Perspectives

- Rachel Block, NYeC (Moderator)
- Barbara Radin, Bronx RHIO
- Laura E. Rosas, NYC DOHMH
- Patricia Hale, ARCHIE
- Tom Check, Visiting Nurse Service of NY

Panel Discussion

RHIOs and Providers

- What is the purpose of the exchange?
- What information is being exchanged?
- Who are the key parties involved?
- What are the anticipated benefits of the exchange to patients, providers and other stakeholders?
- What role do consumers have in the planning and operation of the exchange?
- What is your consent model and approach?
- What are your main challenges (current and future) related to consumer engagement and consent?



Consent and Electronic HIE: Consumer Perspectives

Consent and Electronic HIE: Consumer Perspectives

- Janlori Goldman, Health Privacy Project
 - What do consumers want?
 - What are the key issues for consumers with electronic HIE?
 - How are consumers being engaged in setting policy at the project, state and national level?

- Arthur Levin, Center for Medical Consumers
 - Why should consumers care?
 - What does this mean for quality?
 - What will it take to make this work for consumers?

- Anita Marton, Legal Action Center
 - What does this mean for consumer privacy?
 - What are the key legal and policy considerations for consumers in New York?



Next Steps

Next Steps

- Meeting 2: October 1st (Albany)
 - Set out priority issues to be addressed through project.
 - Develop common understanding of various options for resolving the issues and the pros/cons of each.
 - Seek to identify emerging points of consensus on solutions.
- Meeting 3: October 24th (NYC)
 - Present proposed recommendations.
 - Seek feedback and consensus.