



# Patient Choice and Data Sharing - an overview of HIE and HB1017

**Illinois Patient Consent Management Workshop**  
Wednesday, June 26<sup>th</sup>



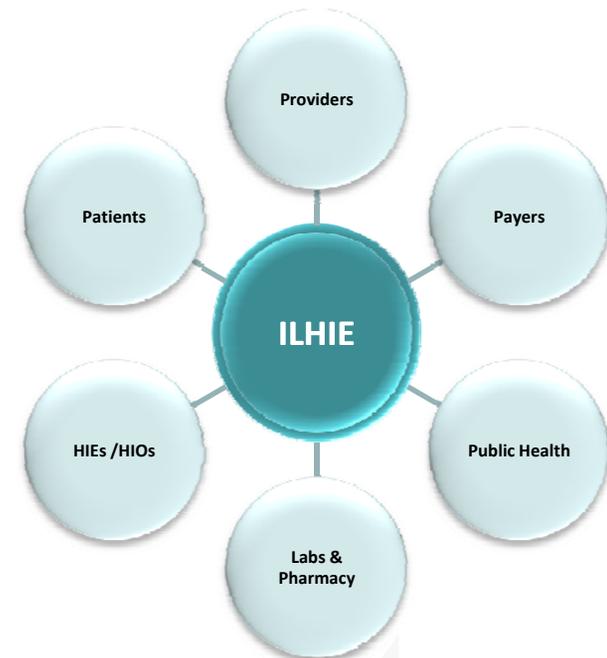
- I. Background
  - a. Technology: Recap of HIE; Methods of Electronic Exchange
  - b. Policy: ILHIE Authority Policies; Specially-protected PHI
  - c. Application of Policy to Technology: clinical data pathways; MHDDCA challenges
- II. HB1017 – amends MHDDCA (summer 2013)
  - a. Enactment
  - b. Overview
  - c. Care coordination; Patient choice; HIPPA Alignment
  - d. Participating HIEs
- III. ILHIE Authority Rulemaking
  - a. Deliberative Process
  - b. Workflow
  - c. Timeline



# Recap of Health Information Exchange



- **Goal:**
  - facilitate electronic flow of patient health records
    - ILHIE Act (20 ILCS 3860/10): “to promote and facilitate the sharing of health information among health care providers within Illinois and in other states”
- **Benefits:**
  - Improve patient health care quality and outcomes
  - Facilitate population health
  - Control healthcare costs



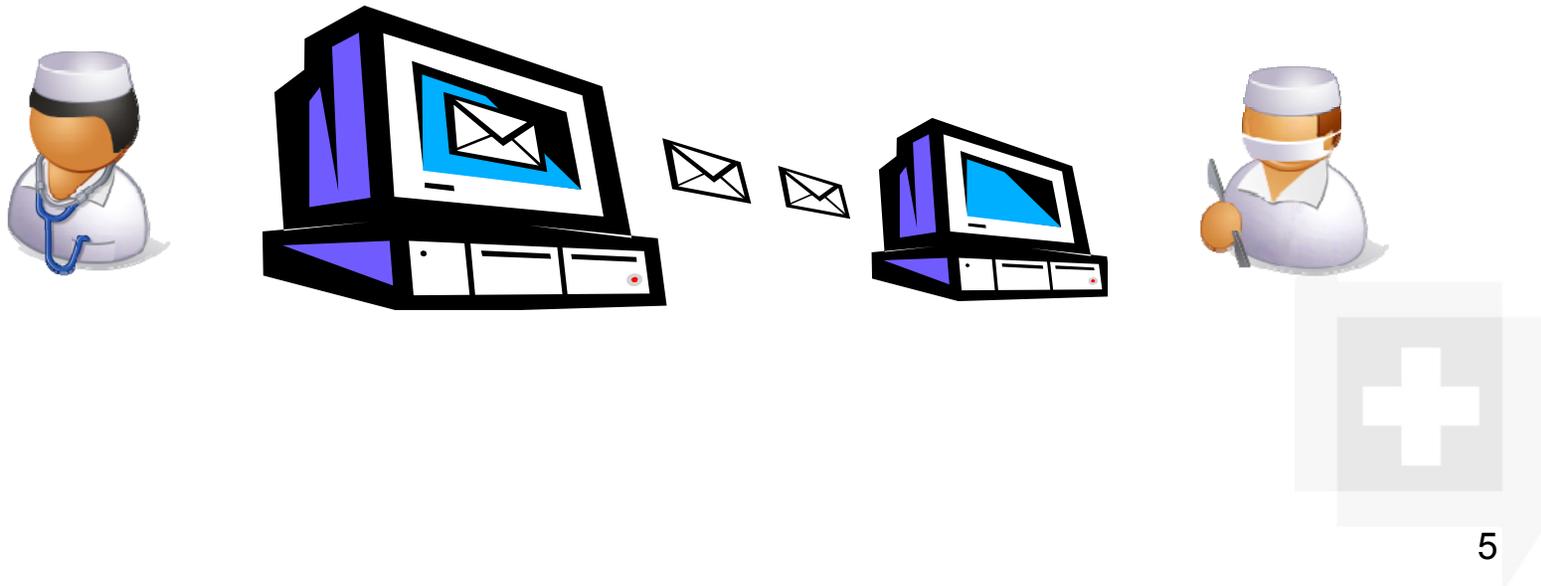
# Key Terms (EHR ≠ HIE)

- Protected Health Information (PHI) –
  - patient/ personal health data
- Electronic Health Record (EHR) –
  - a real-time electronic record of health-related information on an individual, and that can be created, managed and consulted by authorized clinicians across more than one health care organization
- Health Information Exchange (HIE) –
  - the electronic movement of health information among organizations



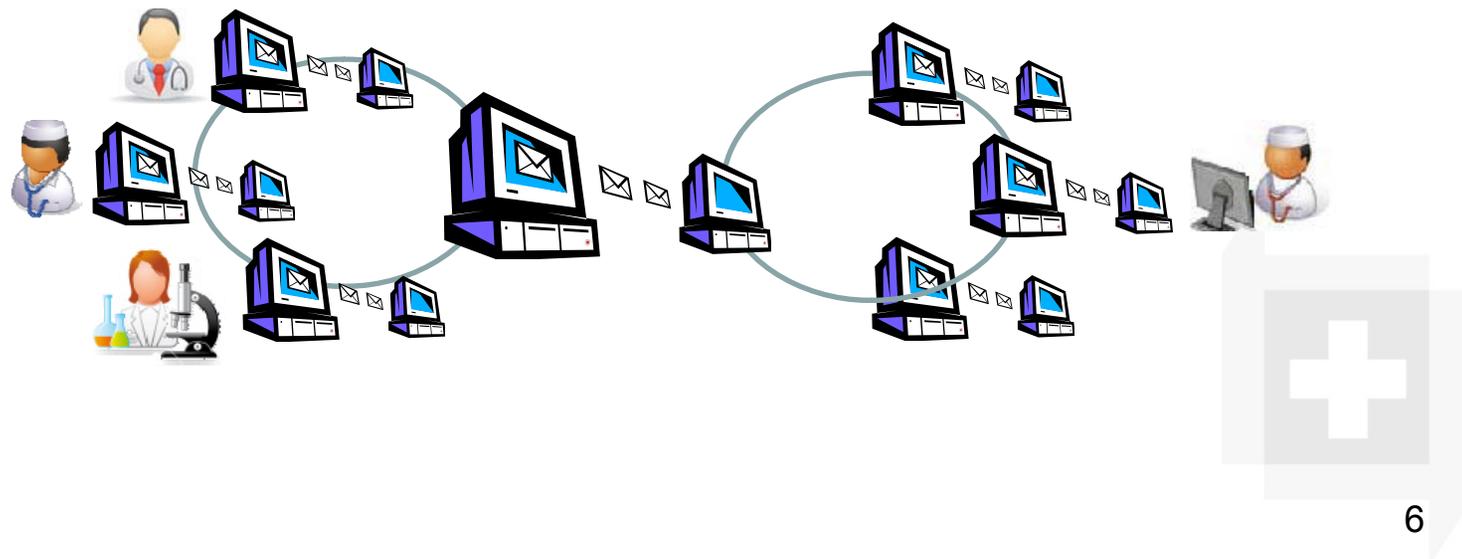
# Methods of Electronic Exchange (simplified; deployed in IL)

1. Direct/push/uni-directional – point to point transmission from data custodian to specific data recipient *≈ email with pdf attached*



# Methods of Electronic Exchange (simplified; deployed in IL)

2. Real-time/pull/query-response/bi-directional – data recipient requests data from HIE which provides data either deposited by data custodian in HIE repository (central storage model) or retrieved by HIE from data custodian's storage (federated storage model) ~=*Google search of databases*



# ILHIE Act: Protection of patient privacy & security



- “The Authority shall establish minimum standards for accessing the ILHIE to ensure that the appropriate **security and privacy protections** apply to health information, consistent with applicable federal and State standards and laws.”



- Dec. 1, 2011: Formation by ILHIE Authority Board of Data Security and Privacy Committee (DSPC)

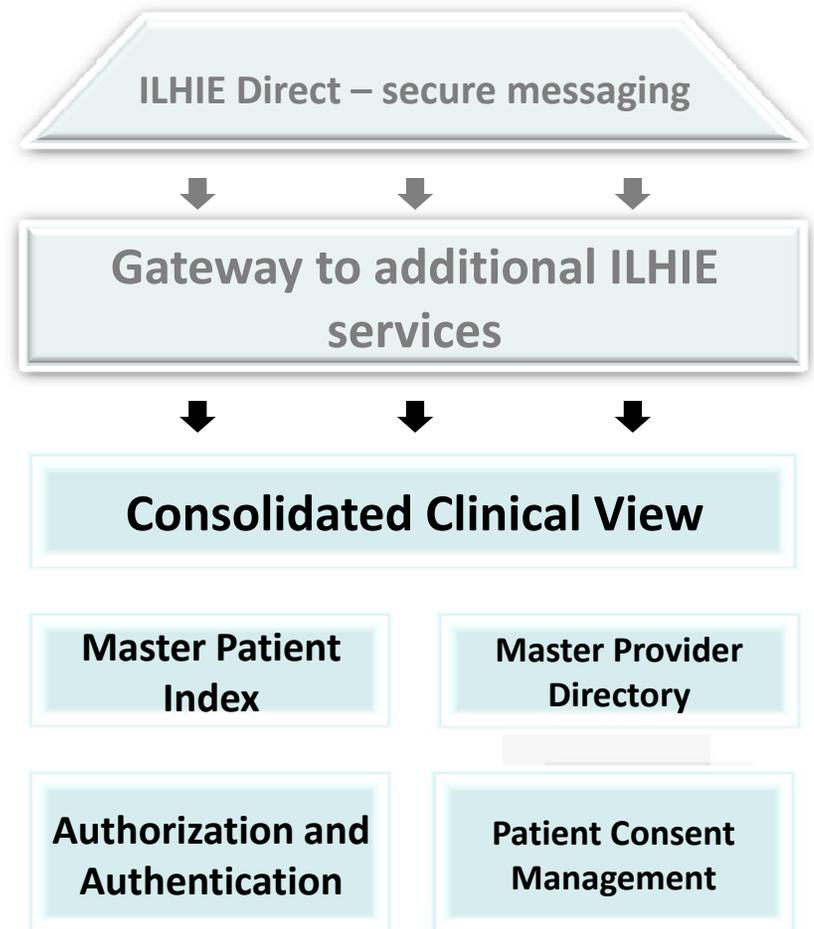
“The Committee’s role is to review, evaluate and recommend **ILHIE data privacy and security policies**, and to oversee the development of new ILHIE data privacy and security policy recommendations with appropriate collaboration with State of Illinois stakeholders, policy developers and implementers.”

- DSPC benefited from stakeholder engagement through public hearings and outreach (2012), culminating in Report adopted by Authority Board (9/19/2012)

# 5 Key Preliminary Findings & Recommendations: #1 (stages)



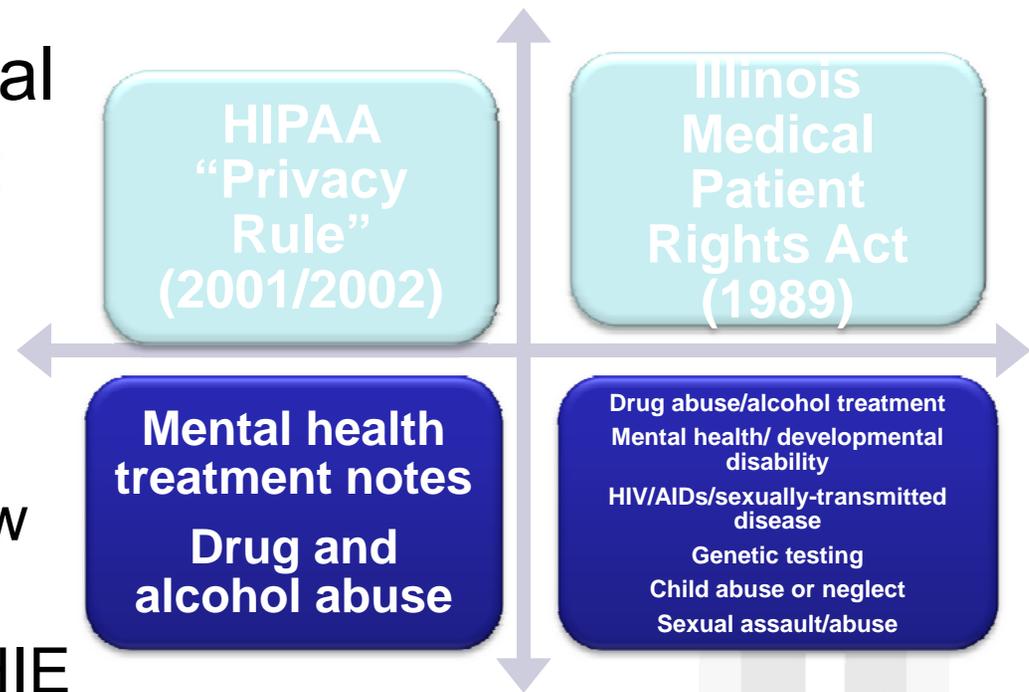
1. Multi-staged approach to implementation of ILHIE and the privacy & security policies which current technology enables



# 5 Key Preliminary Findings & Recommendations: #2 (laws)



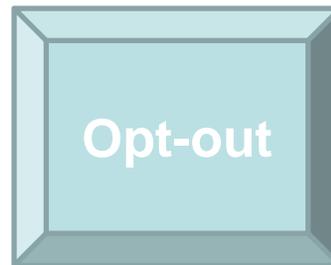
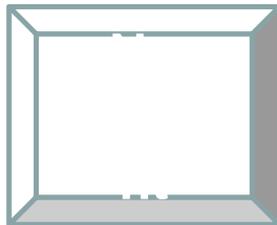
2. Harmonization of IL law with Federal law (e.g. HIPAA); amend IL laws
- Reduce IL law uncertainty
  - Look to Federal law leadership to facilitate national HIE inter-operability



## 5 Key Preliminary Findings & Recommendations: #3 (patient choice)

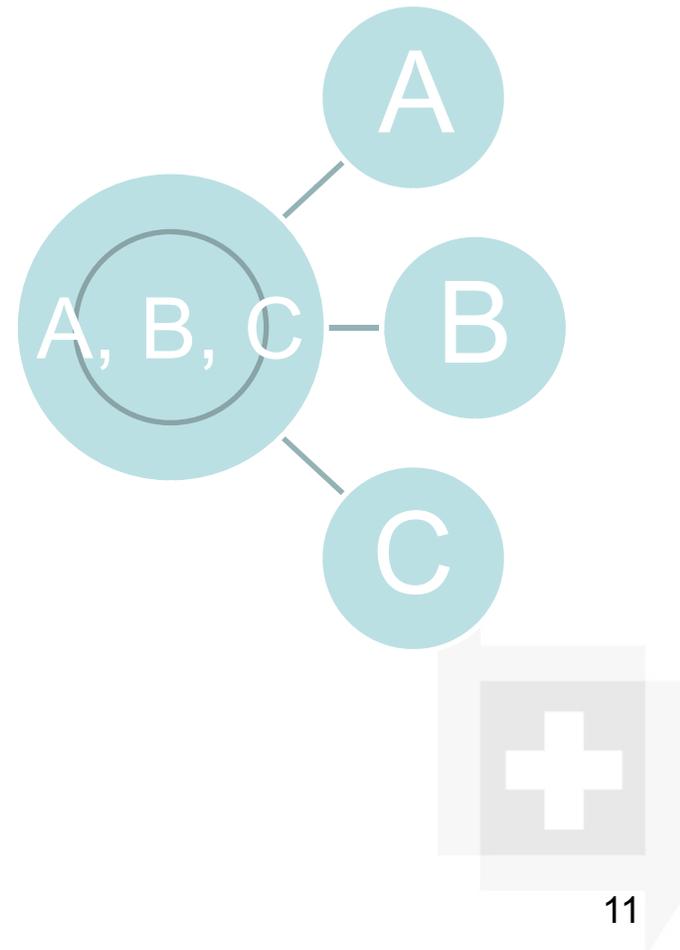


3. Encourage flow of PHI into HIE for HIE purposes, but provide patient privacy protection with patients being given “opt-out” choice for HIE participation



## 5 Key Preliminary Findings & Recommendations: #4 (granularity)

4. Since PHI segmentation is currently not technically practical, launch the ILHIE with an “all-data-in or all-data-out” patient choice, but as technology matures, introduce more granular patient choices for what PHI patients wish to share with whom



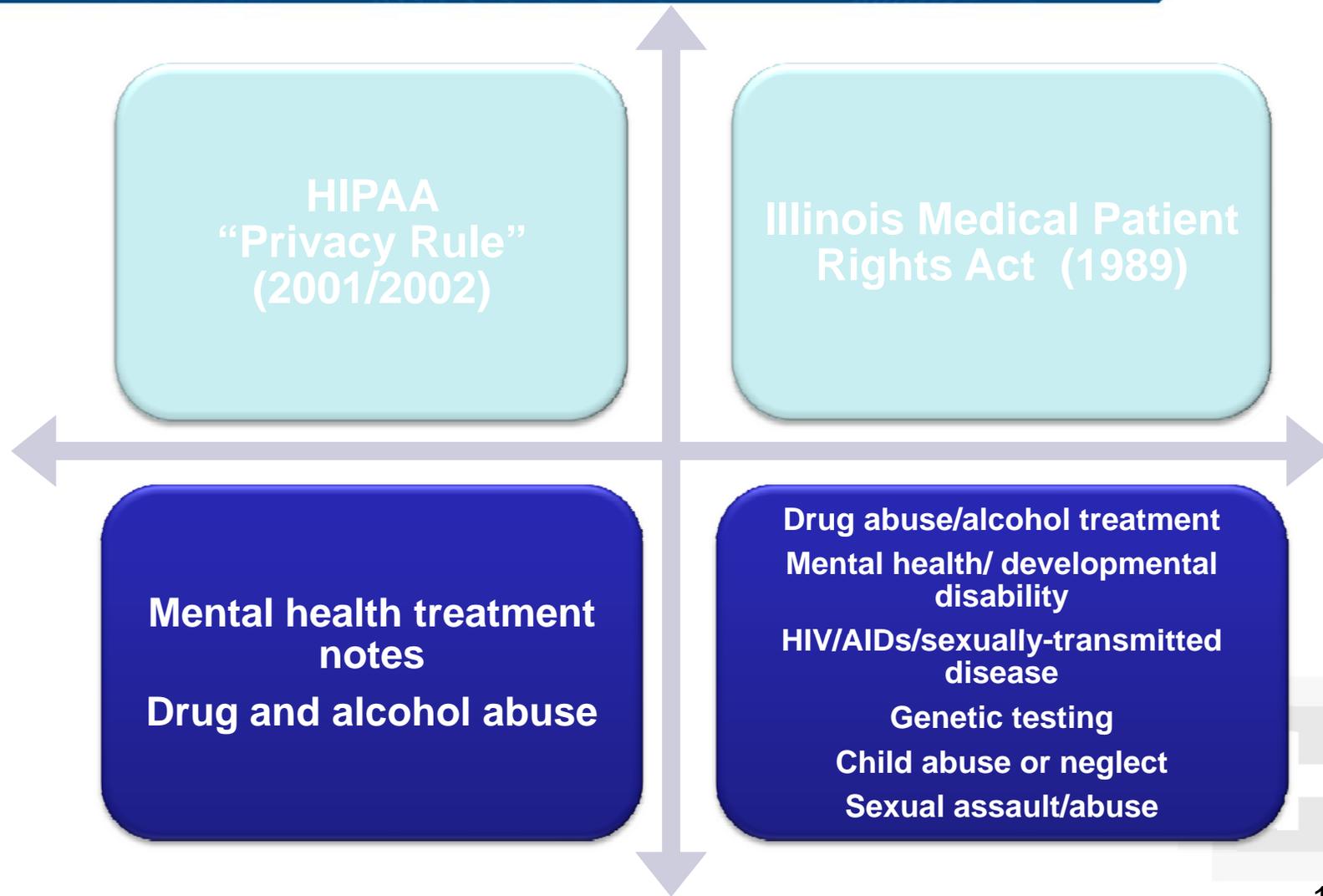
## 5 Key Preliminary Findings & Recommendations: #5 (trust)



5. Adopt measures to build provider and patient trust in the ILHIE



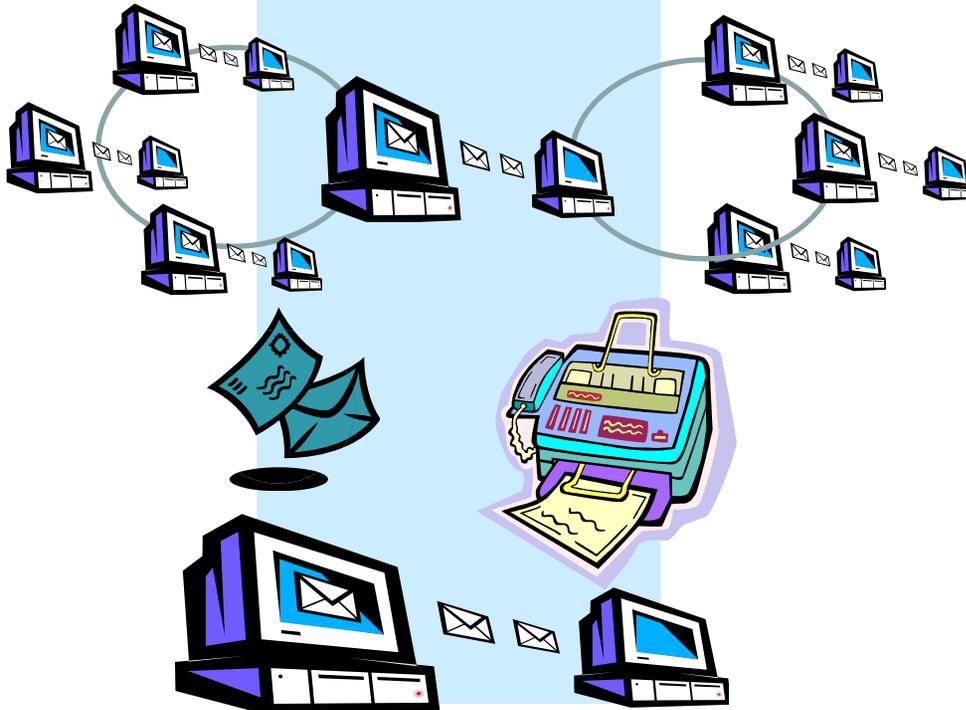
# Specially-protected PHI



# Clinical data pathways - choices

Provider choice  
determines available  
pathways

Provider



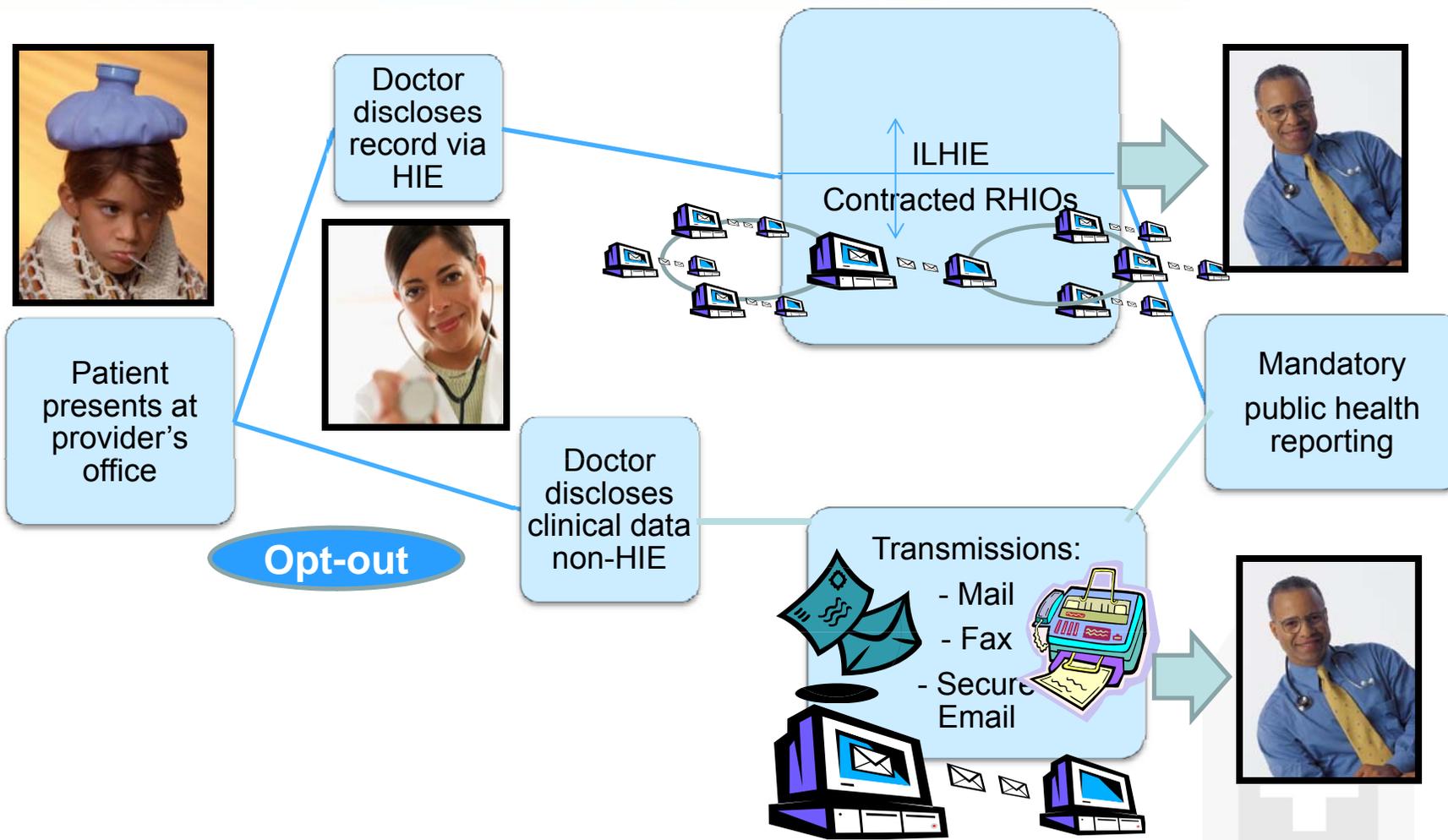
Patient choice  
directs HIE data  
flow

Patient

Participates  
in HIE

Opts-out  
of HIE

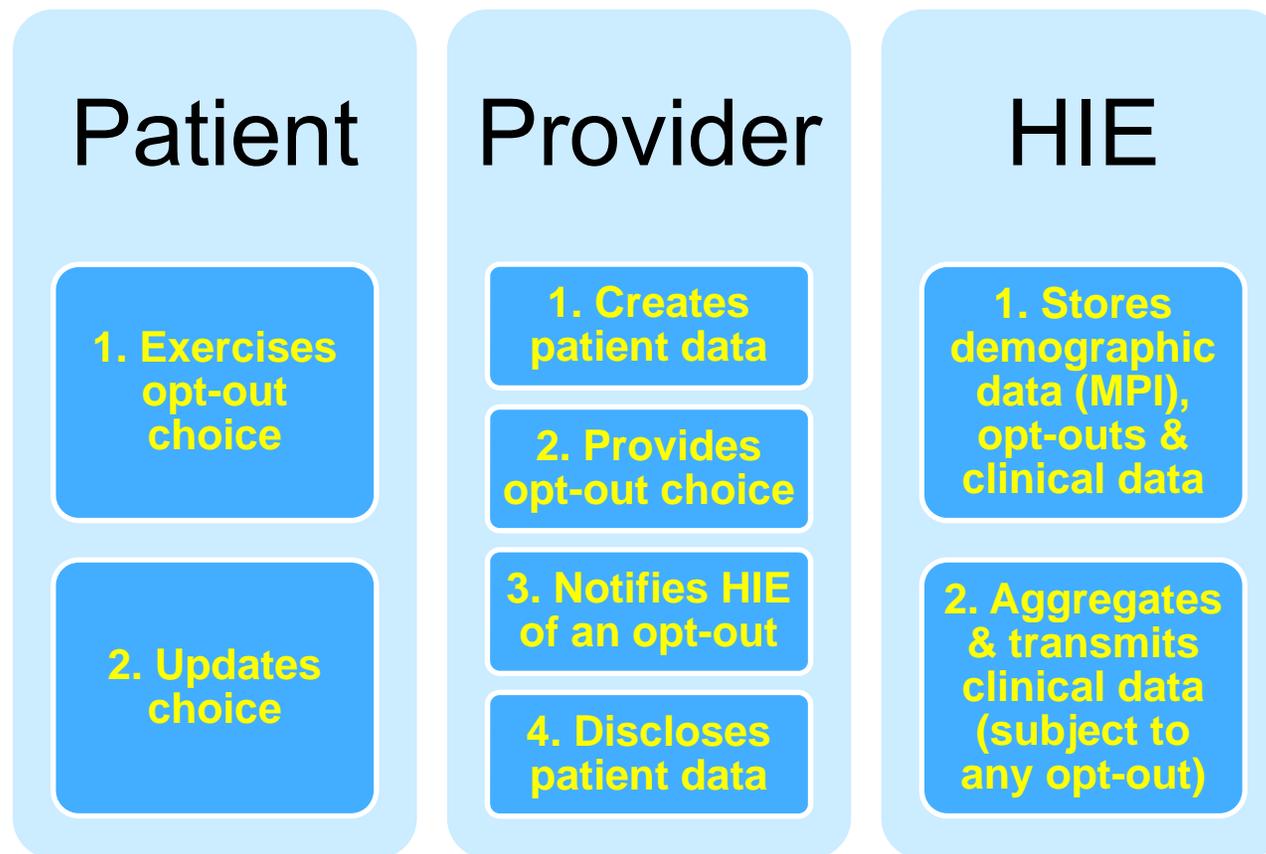
# Clinical data pathways – data flow



# HIE pathway opt-out: 3 Essential Parties



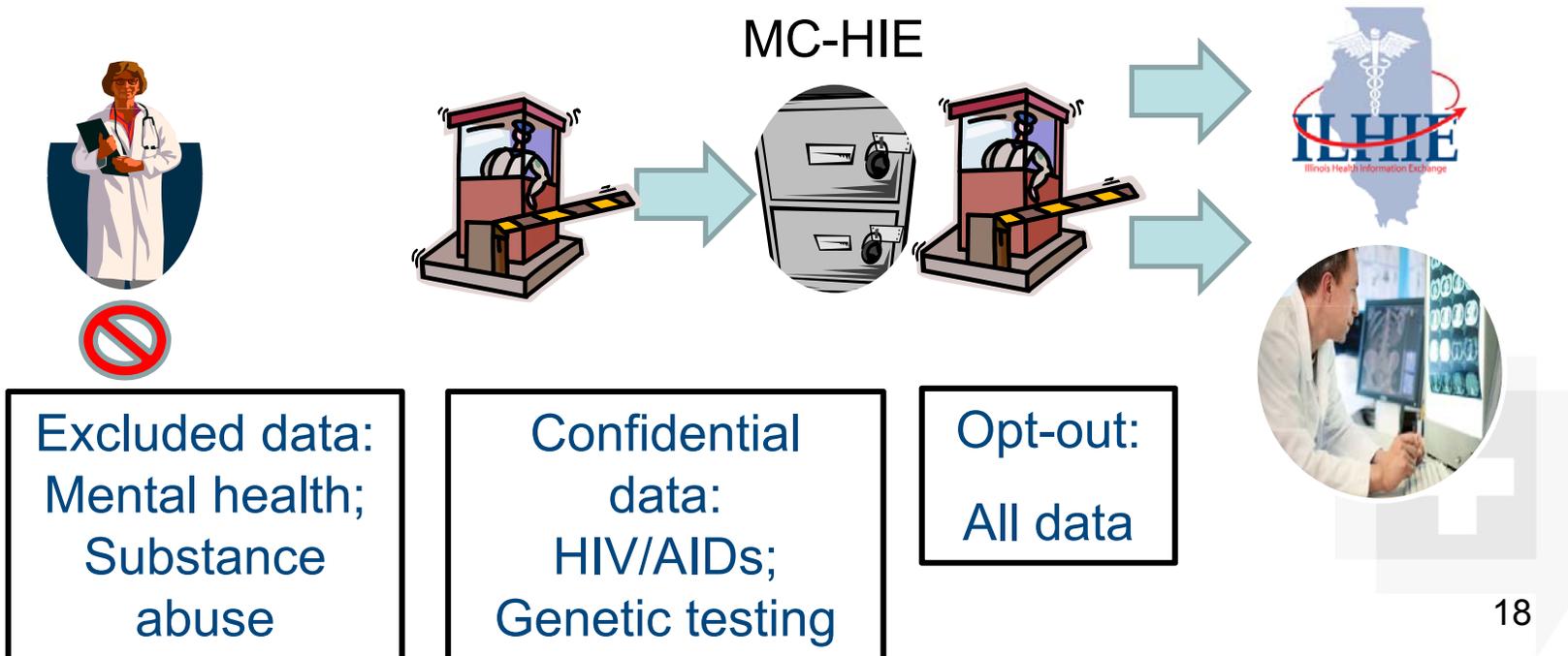
Each party has specific responsibilities



- Illinois Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/)
  - Vintage
    - Created prior to federal HIPAA (1996-2002)
    - Created prior to multi-party info sharing for care coordination
    - Created prior to electronic record exchange
  - Requires patient consent for disclosure of “record”, with few exceptions
  - “**Blanket consent** to the disclosure of unspecified information shall not be valid. **Advance consent** may be valid only if the nature of the information to be disclosed is specified in detail and the duration of the consent is indicated.” (Sec. 5c)
    - “**Blanket consent**” and “**advance consent**” are undefined

# Exclusion of mental health data from HIE ...

- For HIE which collects and stores patient data for later release to future data recipients, it is difficult, if not impossible, at time of data's creation to obtain qualifying patient consent
- MetroChicago HIE policy: HIE participants not to submit patient mental health records



... = Exclusion of mental health patients from HIE



- MetroChicago HIE policy: participants not to submit patient mental health records
  - Implementation: difficult to sequester just mental health data; entire patient record excluded
  - Consequence: mental health patients denied benefits of HIE, even if they should desire HIE
  - Implication: impacts patient data available through ILHIE
  - Implication: impacts State's Medicaid program



# Solution: HB1017 enactment



- 10 endorsing organizations
  - Community Behavioral Healthcare Association of Illinois (CBHA); Illinois Academy of Family Physicians (IAFP); Illinois Alcoholism and Drug Dependence Association (IADDA); Illinois Association of Rehabilitation Facilities (IARF); Illinois College of Emergency Physicians (ICEP); Illinois Hospital Association (IHA); Illinois Primary Health Care Association (IPHCA); Illinois Psychiatric Society (IPS); Illinois State Medical Society (ISMS); National Association of Social Workers (NASW) – Illinois Chapter
- 10 legislative sponsors
  - Rep. Sara Feigenholtz; Rep. Al Riley; Rep. David R. Leitch; Rep. Elaine Nekritz; Rep. Elgie R. Sims, Jr. ; Rep. Camille Y. Lilly; Sen. Heather Steans; Sen. Don Harmon; Sen. Dave Syverson; Sen. Mattie Hunter
- March 8, 2013: Passed in House (115-0)
- May 23, 2013: Passed in Senate, with amendment (57-0)
- May 28, 2013: House concurs amended version (117-0)
- **August 28, 2013: becomes law 90 days after enactment (unless vetoed by Governor)**



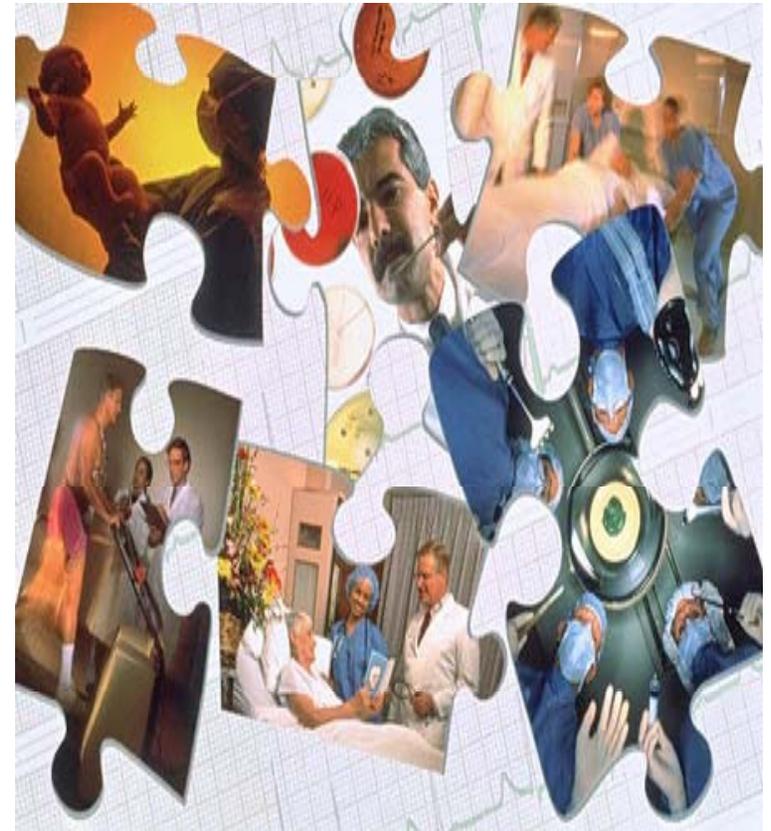
# HB1017 Overview: Modernizing the MHDDCA



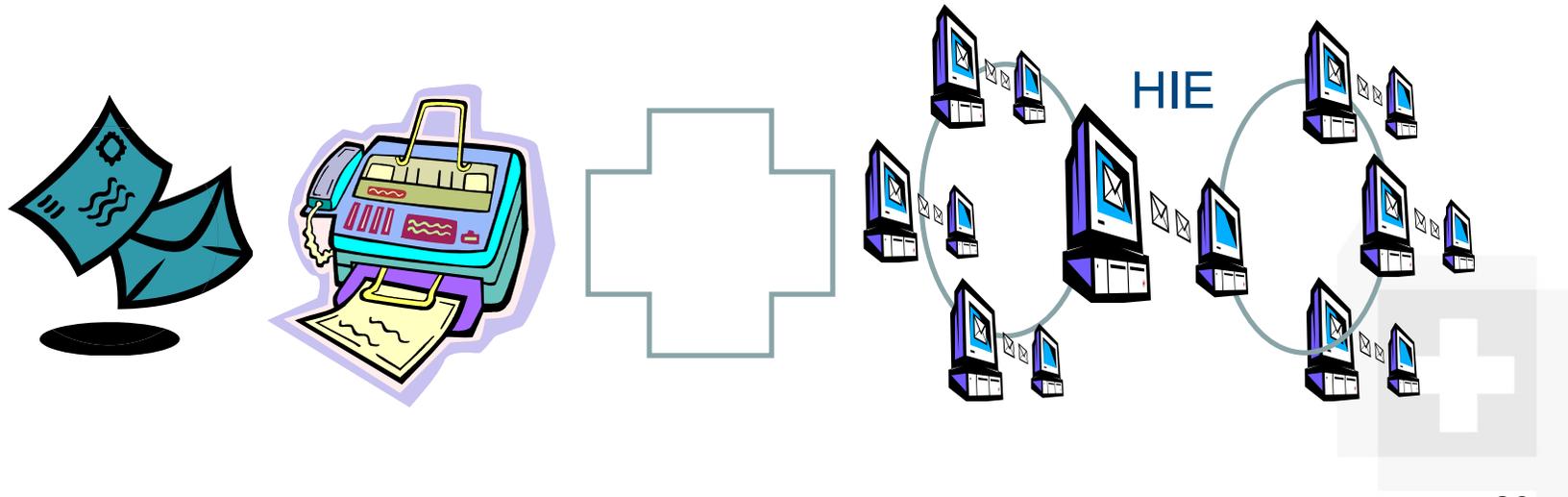
- Care coordination
  - ❑ Clarify existing exceptions for “treatment” to include “care coordination” ( § § 9.0, 9.2)
  - ❑ Recognize the role and responsibilities of the ILHIE to facilitate secure data exchange for the improvement of patient care
  
- Patient choice (HIE exception)
  - ❑ Add new consent approach (opt-out) for records exchanged through an HIE ( § § 9.5, 9.6)
  - ❑ Review annually the feasibility of adopting new technologies that allow for greater patient choice
  - ❑ Standardize how patient consent is managed by HIEs
  
- HIPAA alignment
  - ❑ Adopt HIPAA definitions for agents (“business associates”) and “de-identified” data ( § § 9.8, 9.11)

## Care coordination

- Currently, **therapists** allowed to disclose patient mental health data for treatment without patient consent ( § 9.0)
- Currently, **State agencies** allowed to disclose patient mental health data for treatment without patient consent ( § 9.2)
- Both exceptions clarified to include “**care coordination**”, and allow disclosures by and among “**integrated health systems**” and members of “**interdisciplinary team**”



- New Approach. HB1017 fundamentally proposes a different set of patient consent rules to apply to the electronic exchange of a medical record through a health information exchange. (new “HIE exception”, sec. 9.5)
- Continuation of existing rules. Existing MHDDCA continues to apply to existing (non-HIE) methods of disclosure (e.g. facsimile; mail)



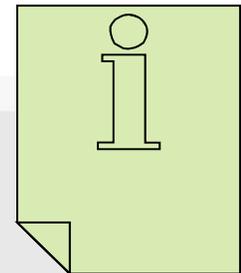
## Patient Choice: Opt-out

- Patient Opt-Out. The bill sets out the policy principle that patients are to enjoy an “opt-out” choice regarding the disclosure of their medical record by a health information exchange. (new Sec. 9.6)
- Delegation of Rulemaking. As the health information exchange environment is dynamic and evolving, the bill delegates the preparation of implementing rules to the ILHIE Authority, an administrative agency of the State created in 2010. (new Sec. 9.6)



# Form and content of patient “opt-out” and “meaningful disclosure”

- Patient to be offered “**opt-out**” after “**meaningful disclosure**”
- *The Authority shall through appropriate rules, standards, or contractual obligations ... give consideration to*
  - ❑ *the **format and content of the meaningful disclosure***
  - ❑ *and the availability to recipients of **information regarding an HIE and the [opt-out] rights** of recipients*
- *These rules, standards, or contractual obligations shall provide for **written notice** of a recipient's right to opt-out which directs the recipient to a health information exchange **website** containing*
  - ❖ *(i) an **explanation of the purposes** of the health information exchange;*
  - ❖ *and (ii) audio, visual, and written instructions on **how to opt out** of participation in whole or in part to the extent possible.*

A light blue rounded rectangle containing the text "info@HIE.org" in yellow.

# Data segmentation technology annual review criteria



The ... Authority shall also give **annual consideration** ...

[to] the extent to which **relevant health information technologies**

- ① ❖ **reasonably available** to therapists and HIEs in this State
- ② ❖ **reasonably enable the effective segmentation of specific information** within a recipient's electronics medical record
- ③ ❖ and reasonably enable the **effective exclusion** of specific information from disclosure by an HIE to third parties,
- ④ ❖ as well as the availability of **sufficient authoritative clinical guidance** to enable the **practical application** of such technologies to effect recipient disclosure preferences.

... the Authority Board shall consider information provided by affected persons or organizations regarding

- ⑤ ❖ the **feasibility**,
- ⑥ ❖ **availability**,
- ⑦ ❖ **cost**,
- ⑧ ❖ **reliability**, and
- ⑨ ❖ **interoperability**

of any technology or process under consideration by the Board.



## ➤ HIPAA “business associate” concept (sec. 9.8)

- ❑ = agent of a health care provider (“covered entity”) subject to a number of requirements to safeguard the privacy and security of patient data
- ❑ Providers and HIEs customarily utilize external IT specialists to provide various IT services.
- ❑ HB1017 adopts the federal HIPAA “business associate” concept and thereby imposes upon such agents the privacy and security obligations of federal HIPAA.

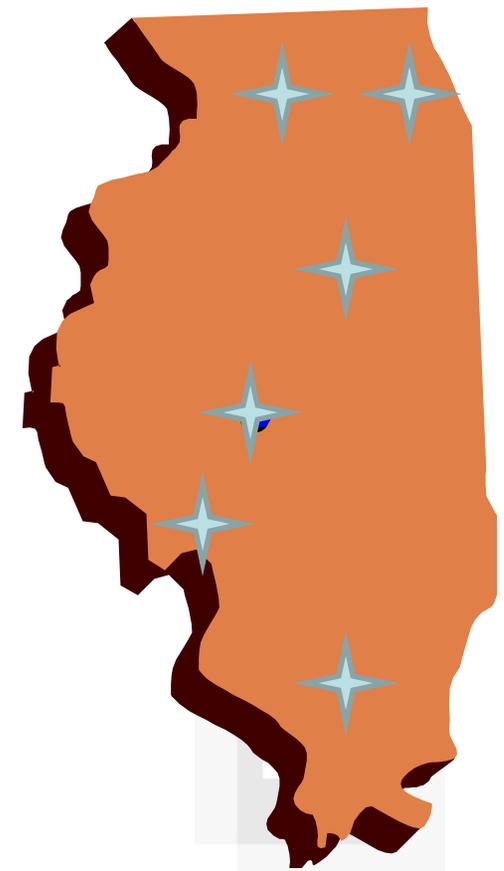
## ➤ HIPAA “de-identification” & “limited data set” (sec. 9. 11)

- ❑ = removal of elements of a patient’s record to conceal patient’s identity for data to be submitted to public health and quality oversight authorities, or to conduct medical research
- ❑ HB1017 adopts the federal HIPAA “de-identification” safeguards for those occasions when providers and HIEs provide patient data to their “business associates” for such data element removal

# Participating HIEs



- Illinois Health Information Exchange [State-wide]
- Central Illinois Health Information Exchange [Peoria]
- Illinois Health Exchange Partners, LLC [Metro East St. Louis]
- Lincoln Land Health Information Exchange, LLC [Springfield]
- MetroChicago HIE [Chicago]
- Northern Illinois Health Information Exchange [Rockford]
- Southern Illinois Health Information Exchange [Carbondale]
- TriRivers Health Information Technology, LLC [Rockford]



# Delegation to ILHIE Authority



- HB1017 delegates responsibility to the ILHIE Authority for more detailed implementation rules of
  1. patient “opt-out”,
  2. meaningful disclosure, and
  3. data segmentation technology review
  
- ILHIE Authority is:
  - ❑ An administrative agency of the State (ILHIE Act, 20 ILCS 3860/)
  - ❑ Accountable to Governor, General Assembly and judicial process
  - ❑ Charged with protection of patient privacy and security through the establishment of standards and requirements for the use of health information and the requirements for participation in the ILHIE
  - ❑ Must follow formal rulemaking process, including public notices and opportunity for public comment. Prior to publication of a proposed rule, the ILHIE Authority will seek input from organizations that could potentially be impacted.

# ILHIE Authority Deliberative Process



**ILHIE Authority Workgroups & Advisory Committees; Stakeholders**

recommendations; testimony



**ILHIE Authority Data Security & Privacy Committee**

recommendations



**ILHIE Authority Board**

Policy reflected in: standards,

rules,

contractual obligations



**JCAR; Secretary of State**

Formal Rulemaking

# ILHIE Deliberative Timeline



- **July/Aug 2013** – Work Groups deliberate & formulate policy recommendations
- **Mid-Sept/Oct 2013** – Recommendations to ILHIE Authority Data Security & Privacy Committee (DSPC)
- **Nov 13, 2013** – DSPC Recommendation to the ILHIE Authority Board for Board adoption
- **Nov/Dec 2013** – Publication of First Notice of Rulemaking
- **2014** – Rulemaking lasts no less than 90 days, no more than 365

Questions ?



IL HIE: [www.hie.illinois.gov](http://www.hie.illinois.gov)

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