

**National Committee on Vital and Health Statistics  
Subcommittee on Privacy and Confidentiality**

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**Overview of INPC Privacy Structure**

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Presented – April 17, 2007



# Agenda

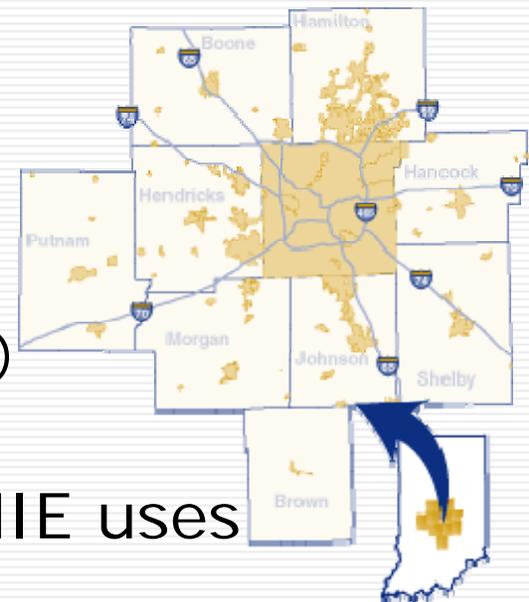
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- Overview of INPC
  - Region Statistics
  - Logical Infrastructure
  - Uses of Data
  - Legal Structure
  - Self-Imposed Privacy & Security Constraints
  - Patient Requests for Restrictions
- Difficulties in Implementing Restrictions



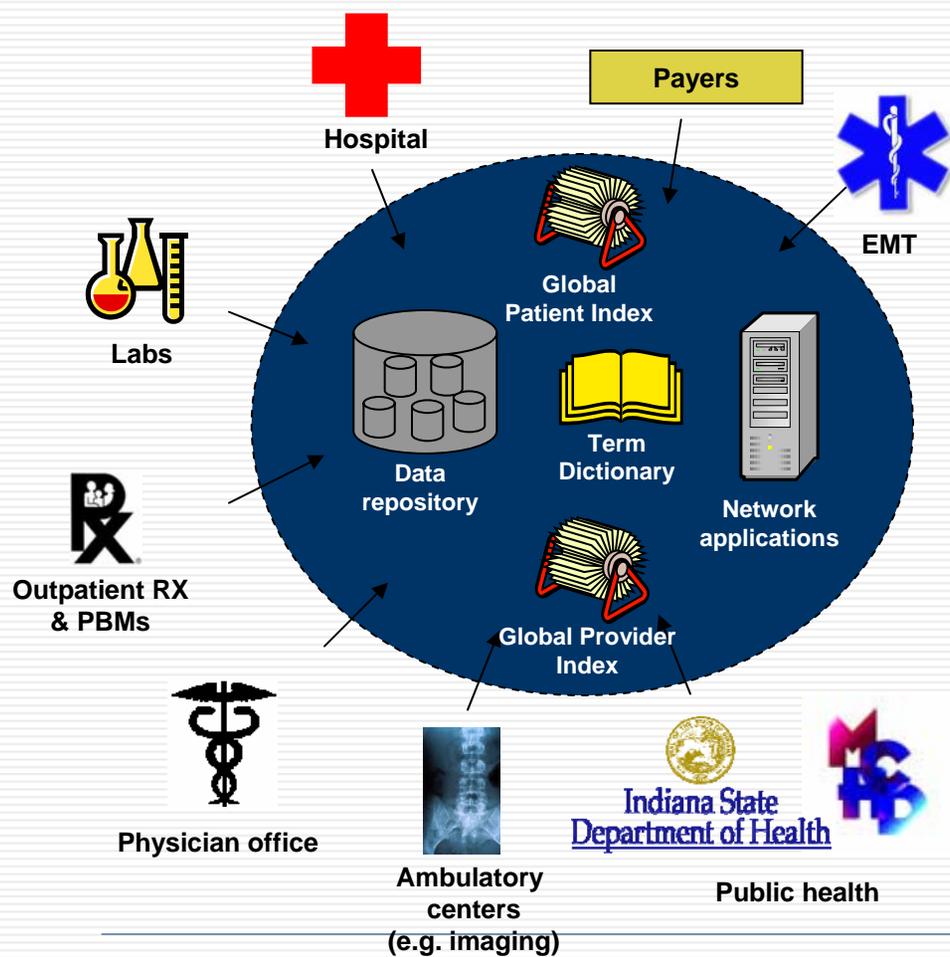
# Indiana Network for Patient Care

- INPC is a virtual health information exchange
- Formed in 1997
- INPC covers central Indiana which has 1.6MM people (25% of state)
- Mantra: reuse of data for:
  - Treatment
  - Research
  - Public Health
  - Healthcare Operations (e.g., quality)
- No financial data in INPC
- Indiana state laws favorable to HIE uses

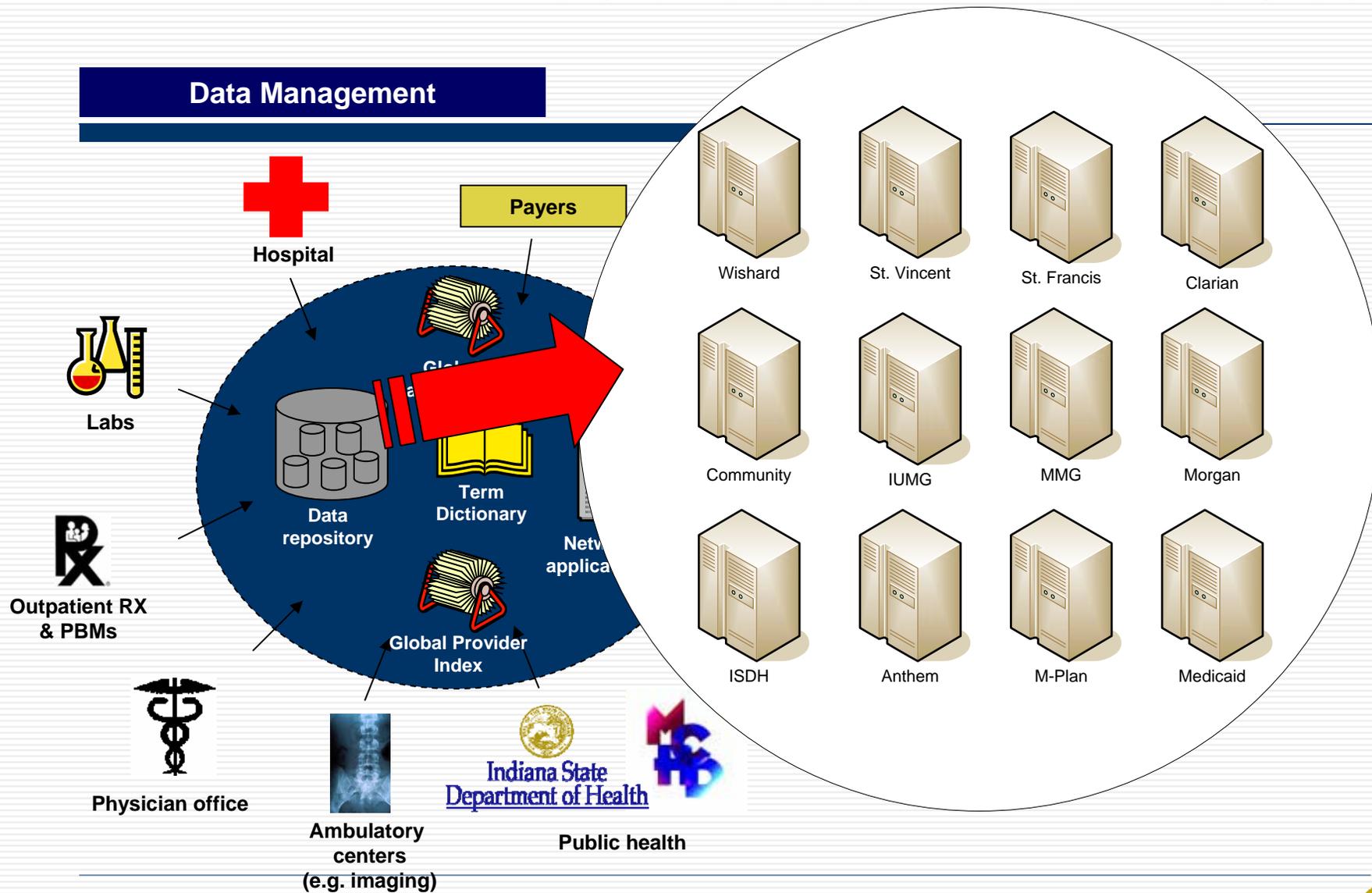


# Mantra: *Data Reuse*

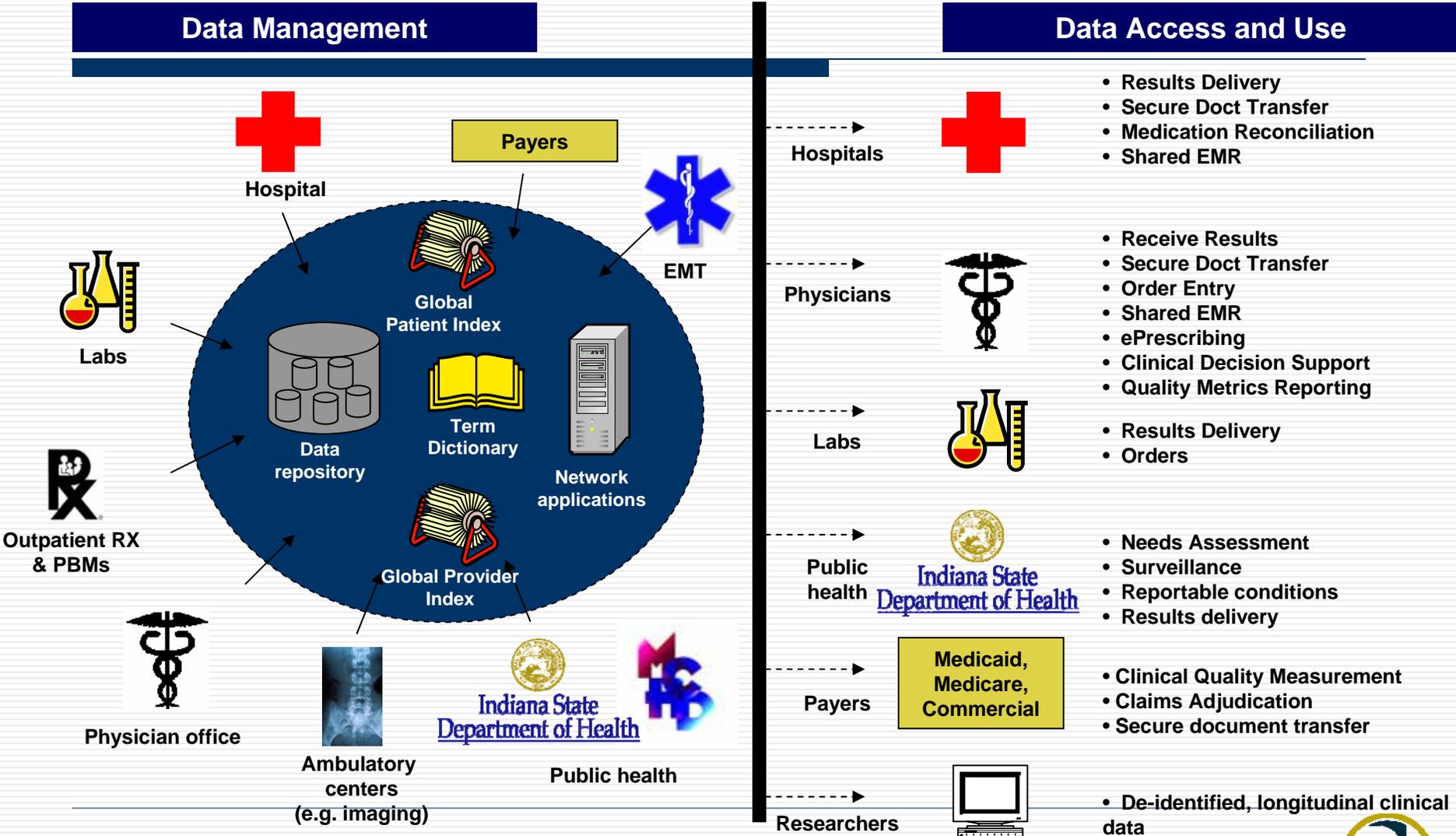
## Data Management



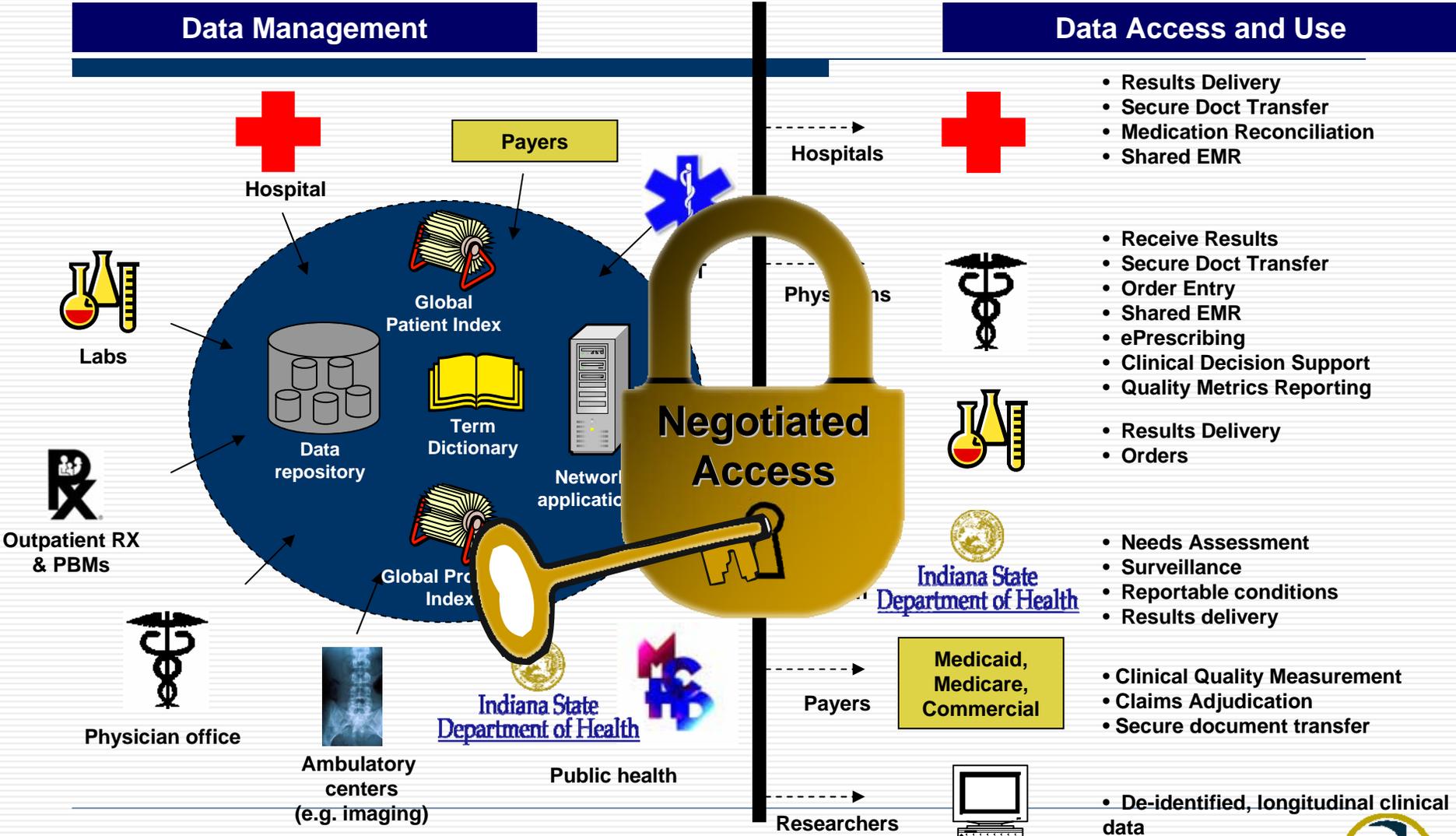
# Federated Data Model



# Mantra: *Data Reuse*



# Mantra: *Data Reuse*



# Indiana Network for Patient Care

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- Statistics:



- > 95 data feeds coming in
- > 900,000,000 records
- Data on > 3,000,000 patients
- Receive > 5,000,000 messages per month
- > 10 terabytes of data

# Legal Structure

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- Regenstrief (administrator of INPC) is a business associate of the covered entities that provide data to INPC for several purposes:
  - De-identifying data for research
  - Transmitting reportable diseases to public health authorities
  - Disclosing to providers for treatment
  - Aggregating data for quality reporting
- Regenstrief is merely the custodian



# Privacy & Security Constraints

- INPC participants mutually agree on how access occurs
- Access for treatment must be based on some evidence that the patient is under treatment of that provider at that time
- Online access to clinical data on a patient in the hospital is limited by:
  - Time
  - Location
  - User



# Patient Requests

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- Provider has relationship with the patient
- Provider has its privacy policy
- Provider decides what data to send to INPC
- Provider makes decision on whether to grant patient request



# Patient Requests

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- INPC agreement says any patient inquiries would be referred to the provider
- INPC participant would not agree to amendment or restriction without consulting Regenstrief to see if technically feasible
- Any amendments must be electronic
- Most providers do not allow restrictions



# Patient Requests – Our Experience

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- INPC began in 1997 – pre-HIPAA, so consent was required
  - < 0.5% did not consent
  - Of that small %, 70% came from one clerk
- Post-HIPAA, INPC participants no longer require consent
  - Only 2 patients have requested a restriction
- What happens? Patient data is not shared between institutions at all (all or nothing)



# Difficulties in Implementing Restrictions

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- Hypothetical restrictions:
  - By test result (e.g., HIV)
  - By medication
- Relevance to patient care
  - Treatment regimen options
  - ADEs, complications, additional procedures, pain, death
  - Adds cost to patient and employer/payer (out of pocket \$ and lost workdays)



# Difficulties in Implementing Restrictions

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- Restrictions on data negatively impact:
  - Patient care
  - Research
    - Limits the value of the data
    - May result in incorrect conclusions
  - Healthcare operations (e.g., quality)
  - Public health (e.g., syndromic surveillance)
  - Cost (of system, to administer, to participate)
  - Liability (of participants, of HIE)
  - Ability to use past data
  - Ability to detect fraud and abuse



# Difficulties in Implementing Restrictions

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- Balance the rights of the individual with the benefit to the whole population



**Thank you**

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Questions?

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