



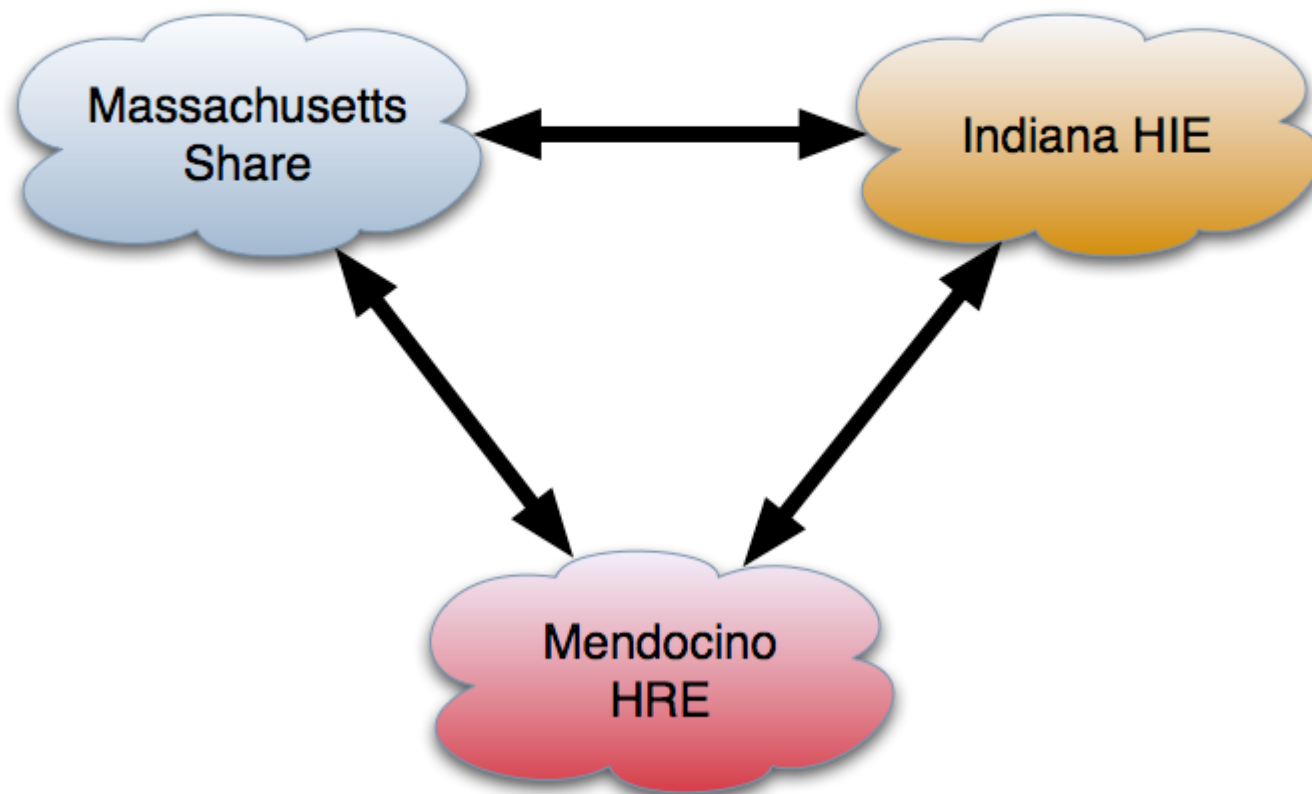
Personally Controlled Health Records and Public Health

Kenneth D. Mandl, MD, MPH
Children's Hospital Informatics Program
Harvard Medical School

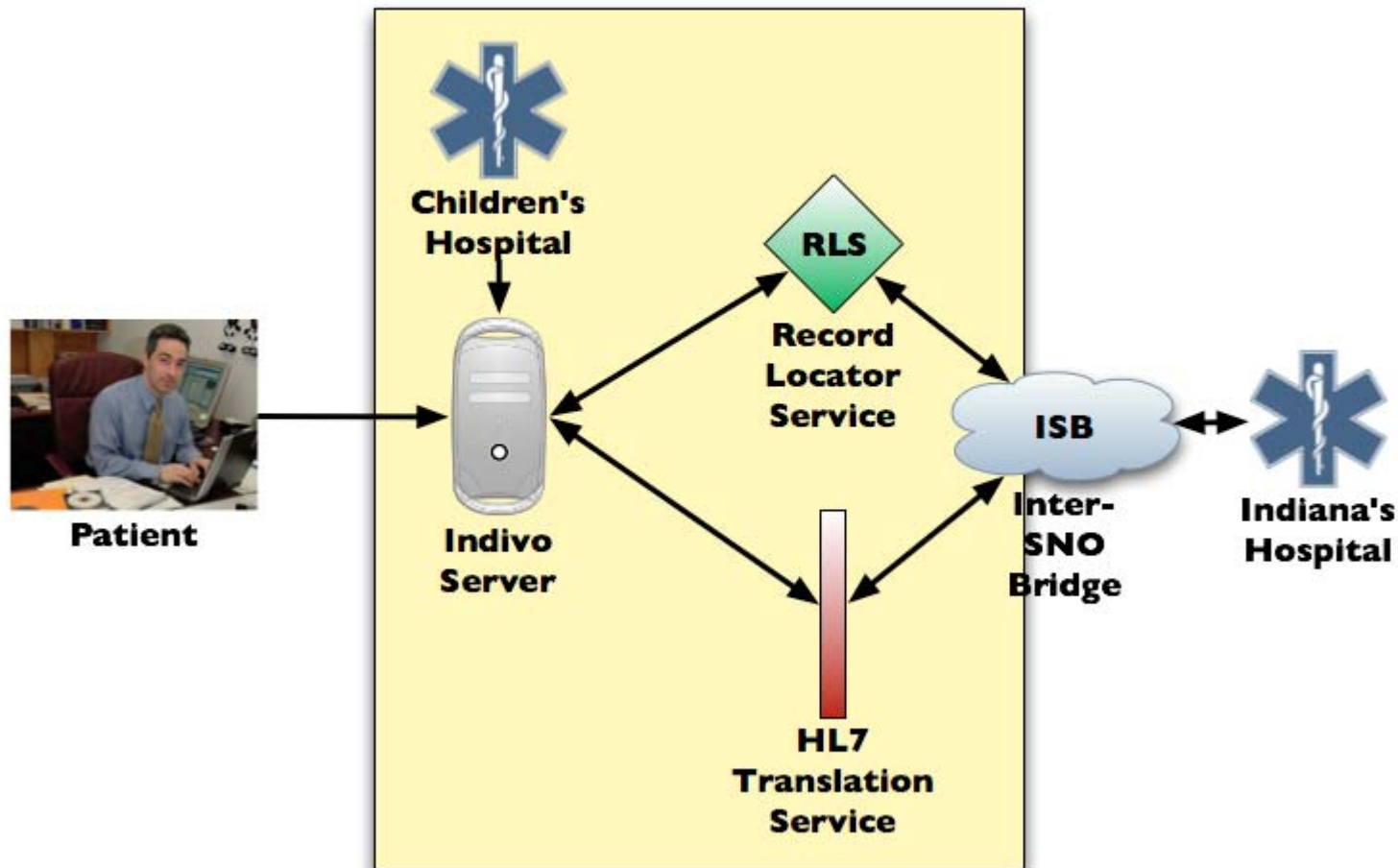
Public health challenges

- Surveillance
 - ✓ Clinical data are fragmented over sites of care and over time—NEED integration
- Communication
 - ✓ Few channels of communication between public health and individuals
 - ✓ Surveillance and action are often disconnected

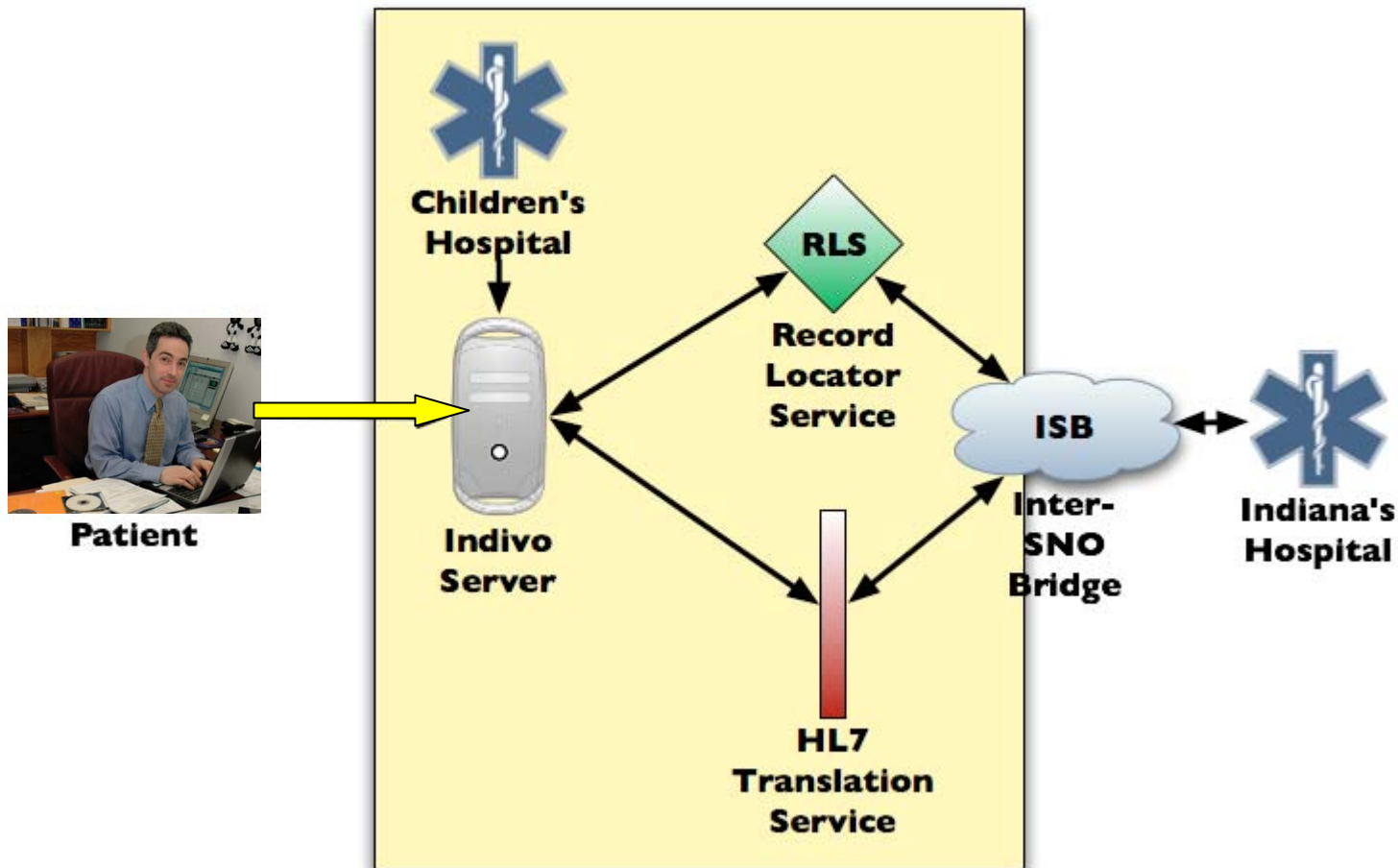
ONC-funded interregional architecture



MA-SHARE SNO



MA-SHARE SNO





DANIEL NIGRIN

INDIVO PERSONALLY-CONTROLLED HEALTH RECORD

MESSAGES | SUBSCRIPTIONS | EXPORT RECORD | SHARING | LOG OUT

My Indivo Record dnigrin@ping.chip.org

HOME

PERSONAL

- CONTACT INFO
- OTHER CONTACTS
- INSURANCE

APPOINTMENTS

CLINICAL NOTES

LAB TESTS

IMMUNIZATIONS

MEDICATIONS

PROBLEM LIST

VITAL SIGNS

SURVEYS

MEDICATIONS

Medication Detail

[Back to Medications](#)

[Edit This Document](#)

MEDICATION NAME

Tapazole (prescription)

DOSE

5 mg

ROUTE

by mouth

FREQUENCY

once a day

DOCUMENT INFO

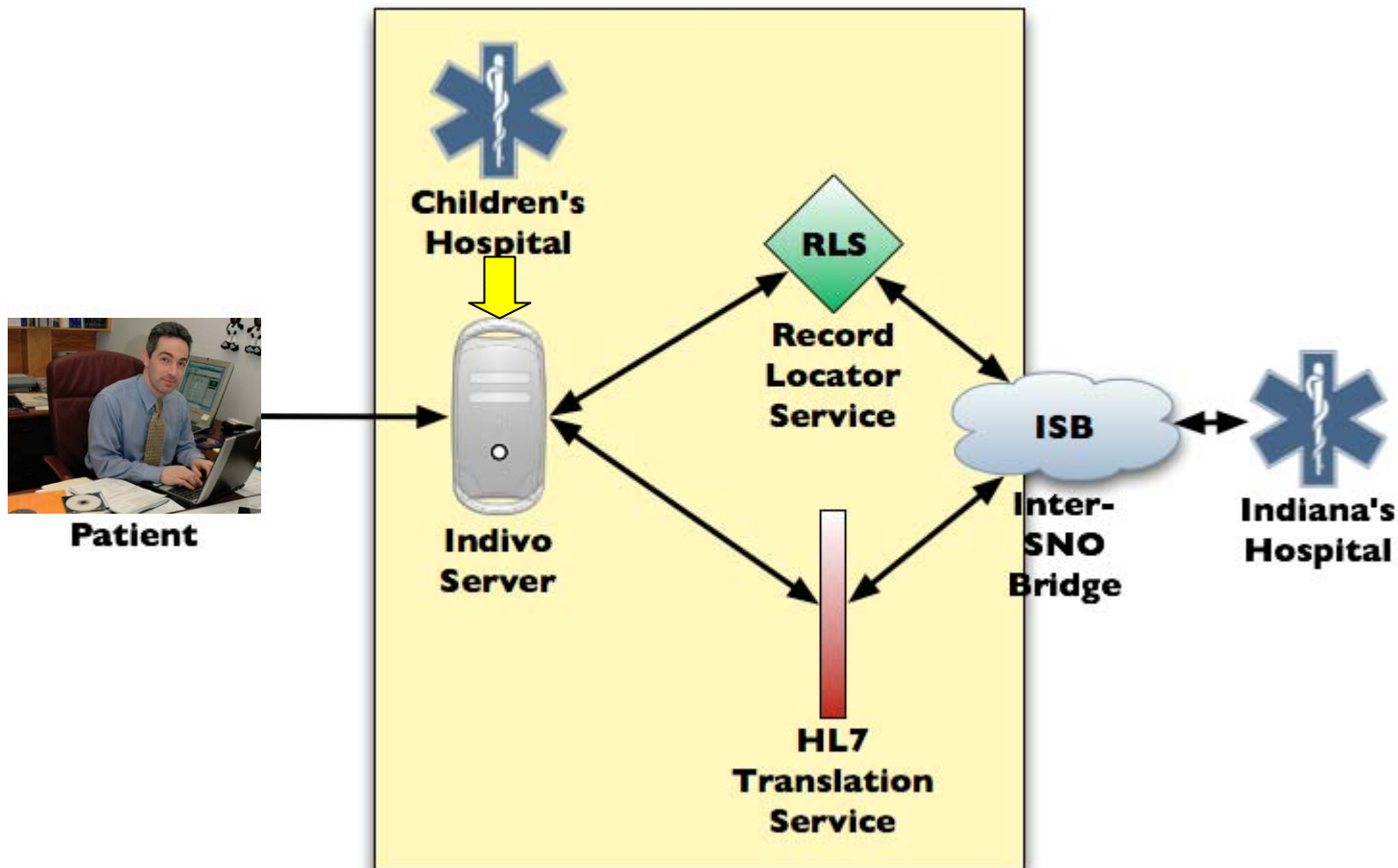
UPDATE HISTORY

ANNOTATIONS

ADD NEW ANNOTATION

Add

MA-SHARE SNO





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- SURVEYS

SUBSCRIPTIONS

Subscribe To Children's Hospital Boston

PATIENT IDENTIFIER *

This is the unique identifier provided by Children's Hospital Boston.

CONSENT
 I agree
I agree to allow this subscription agent to remotely update my record.



Indivo - Personally-Controlled Health Record

http://134.174.11.41/viewer.php

Latest Headlines

NFL.com - GameCenter : Game S... | Statsworld | Indivo - Personally-Controlled He...

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SUBSCRIPTIONS

Subscribe To MA-SHARE RHIO

PATIENT IDENTIFIER *

This is the unique identifier provided by MA-SHARE RHIO.

CONSENT
 I agree
I agree to allow this subscription agent to remotely update my record.



DANIEL NIGRIN

INDIVO PERSONALLY-CONTROLLED HEALTH RECORD

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SUBSCRIPTIONS

Your Subscriptions

CLICK AN AGENT TO VIEW OR CONFIGURE YOUR SUBSCRIPTION.

CHILDREN'S HOSPITAL BOSTON

This agent will securely update your record with signed data from the live Children's Hospital Boston database.

Update Interval: 24 hours

MA-SHARE RHIO

This agent will securely update your record with medication, allergy, and problem list data.

Update Interval: 24 hours

Available Subscription Agents

CLICK AN AGENT FOR MORE INFORMATION.

CAREGROUP - BETH ISRAEL DEACONESS MEDICAL CENTER

This agent will securely update your record with data from the CareGroup database.

Update Interval: 24 hours

MIT MEDICAL

This agent will securely update your record with data from the MIT Medical database.

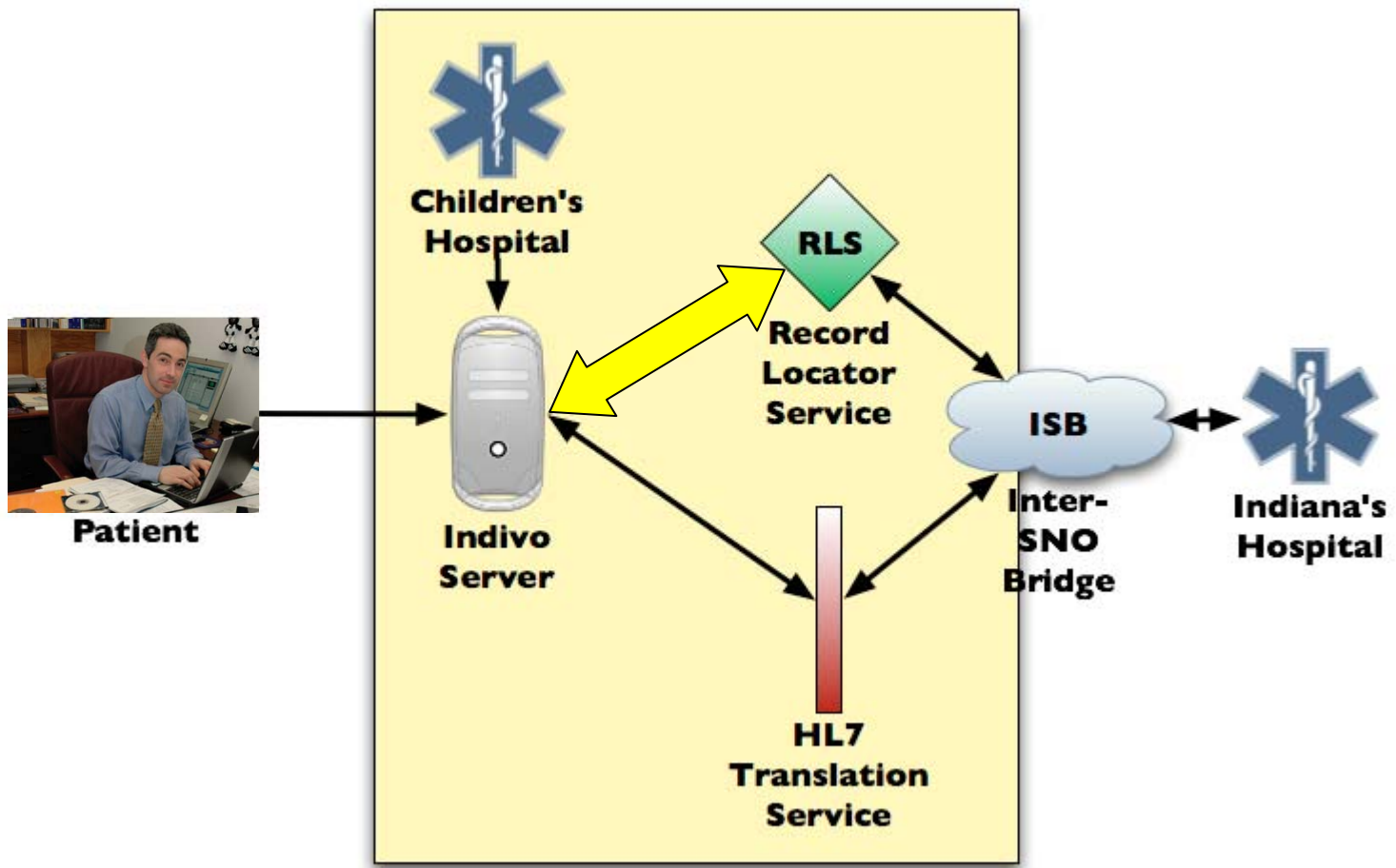
Update Interval: 24 hours

HARVARD UNIVERSITY HEALTH SERVICES

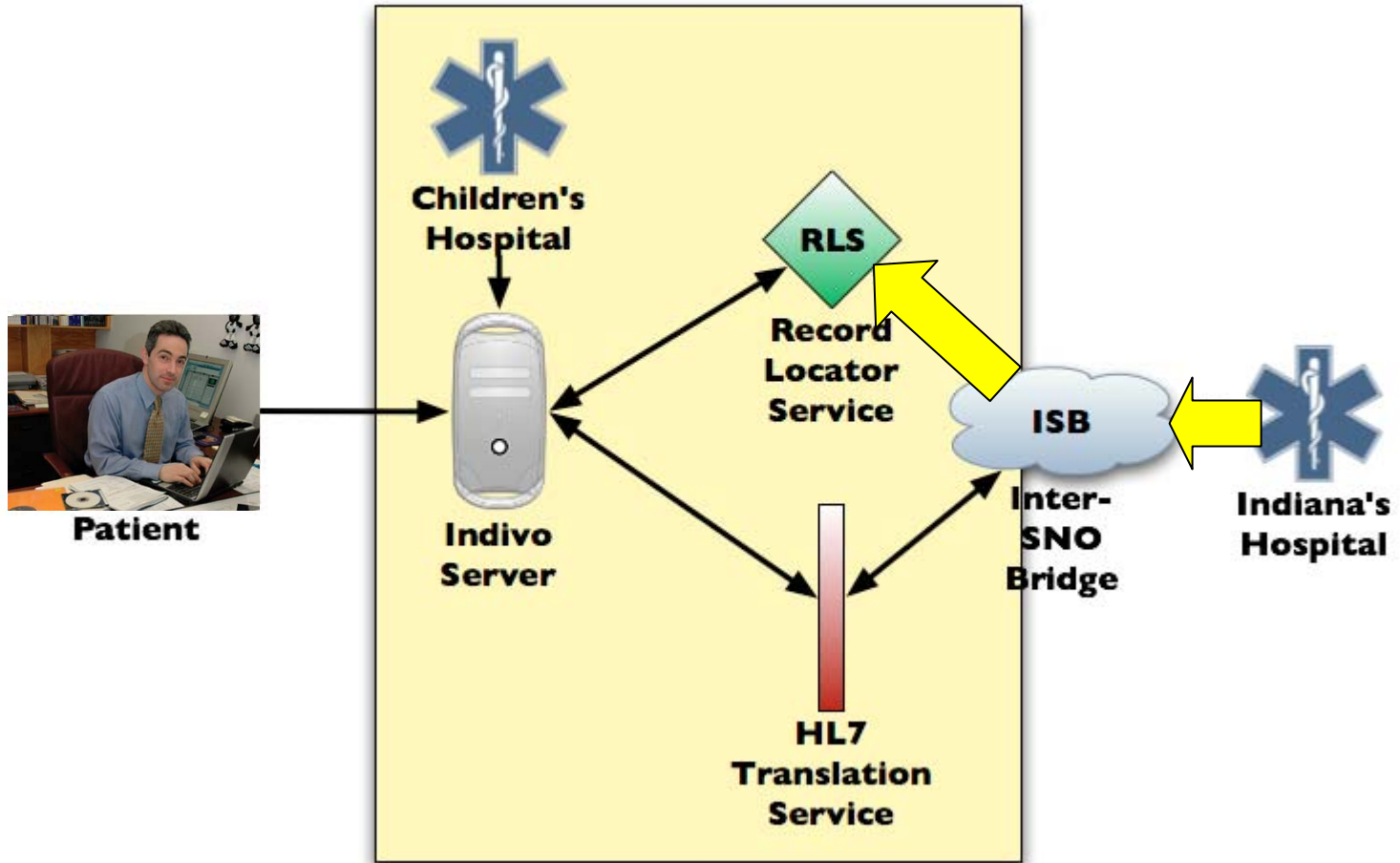
This agent will securely update your record with data from the HUSHS database.

Update Interval: 24 hours

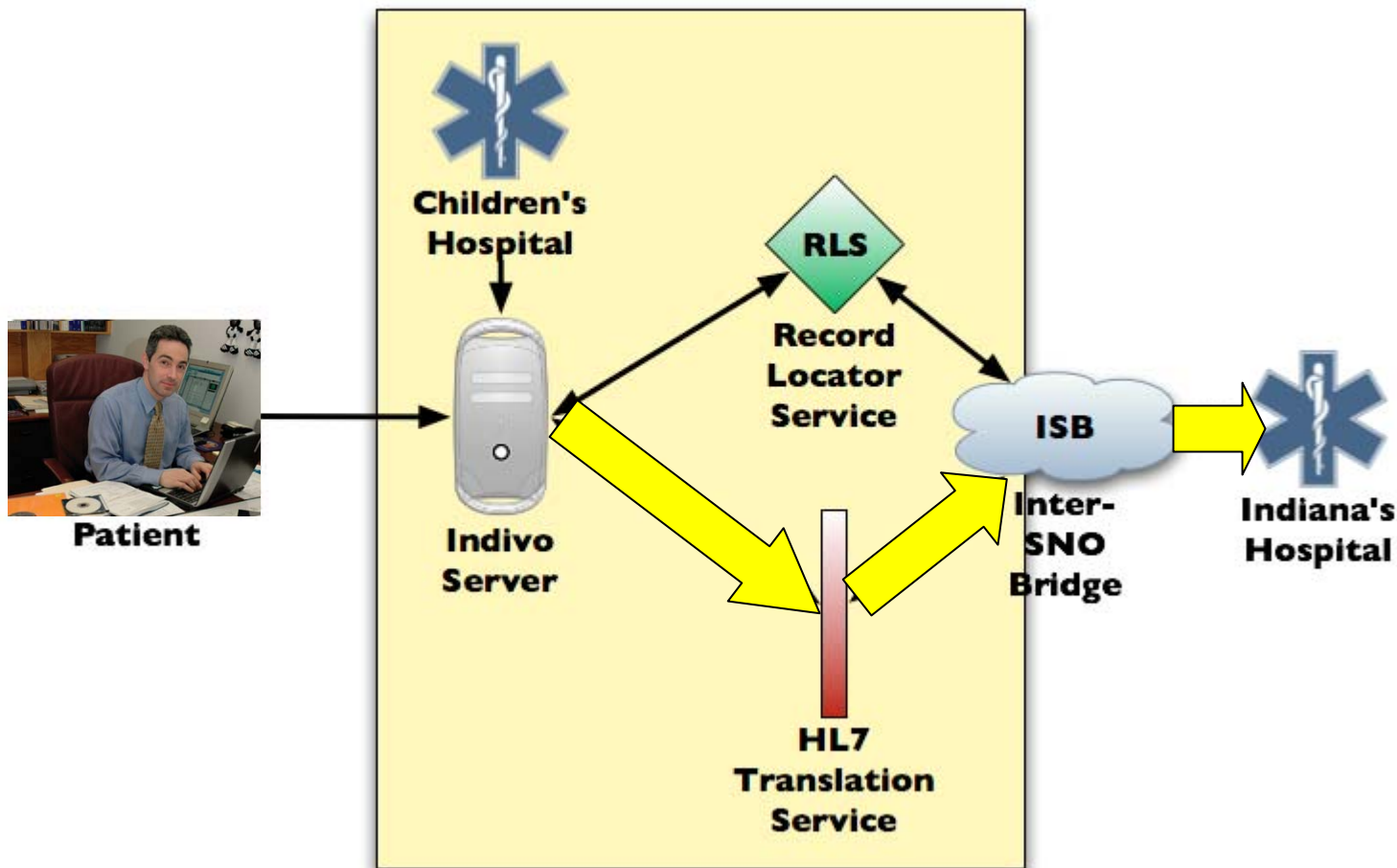
MA-SHARE SNO



MA-SHARE SNO



MA-SHARE SNO







Connecting for Health - USER, GUEST - [Nigrin, Daniel]

File View Windows Help

Last Name
 First Name
 Middle Name
 Street
 City
 State
 Zip
 Gender
 Birthdate
 SSN
 MRN
 Institution

Red fields are required. Advanced Querying

Nigrin, Daniel IndivoAtChildrensBoston IndivoAtChildrensBoston http://org.chip.indivo.installation : dnigrin@ping.chip.org Age: 41 Years (user: USER, GUEST)

Query Parameters:
 NAME: Nigrin, Daniel
 SEX: M
 DOB: 19-Nov-65

Medication Dispensing History:

Medication	Dosage	Last Filled Date
Tapazole	5 : mg	

Our "Watson, come here I need you" moment

Clinical Results:

Date	Description	Elapsed	Re
20-Apr-06 08:58	Blood Glucose	-171 Days	23
20-Apr-06 05:02	Blood Glucose	-171 Days	279.0 mg/dL
20-Apr-06 07:46	Blood Glucose	-172 Days	252.0 mg/dL
19-Apr-06 09:25	Blood Glucose	-172 Days	207.0 mg/dL
19-Apr-06 04:39	Blood Glucose	-172 Days	201.0 mg/dL
18-Apr-06 09:08	Blood Glucose	-173 Days	141.0 mg/dL
18-Apr-06 05:11	Blood Glucose	-173 Days	251.0 mg/dL
18-Apr-06 01:31	Blood Glucose	-173 Days	163.0 mg/dL
18-Apr-06 06:24	Blood Glucose	-174 Days	240.0 mg/dL
17-Apr-06 10:11	Blood Glucose	-174 Days	220.0 mg/dL
17-Apr-06 07:24	Blood Glucose	-174 Days	

Challenges

- Bias
 - ✓ For surveillance or communication, want a large and comprehensive denominator
- Participation—danger of opt out if
 - ✓ Concerns over privacy
 - ✓ Lack of control
 - ✓ Lack of trust
 - ✓ April 2006 ACLU letter to Congress
- De-identification of data is limiting

In this week's NEJM

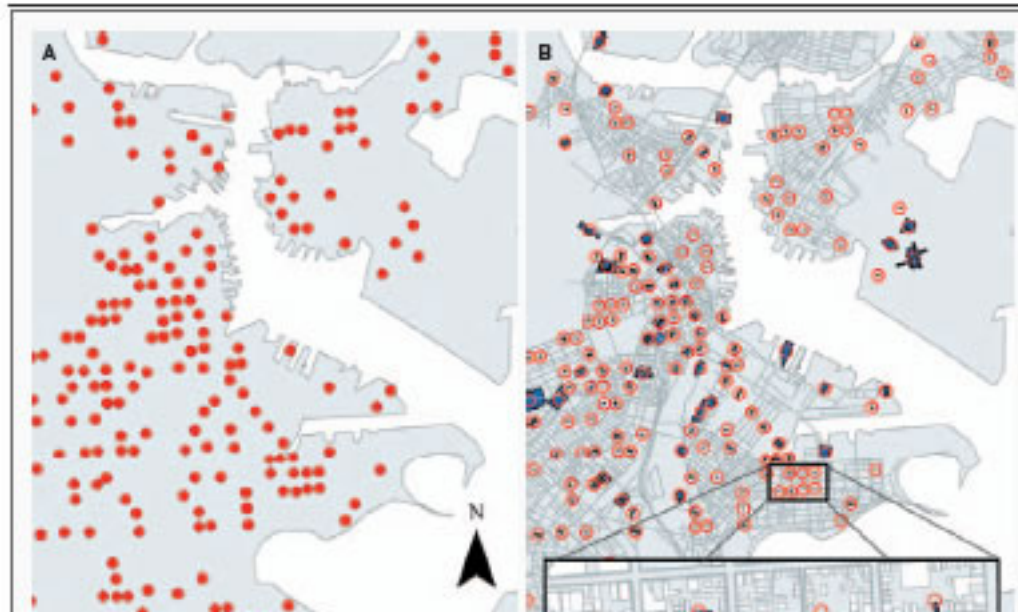
CORRESPONDENCE

No Place to Hide — Reverse Identification of Patients from Published Maps

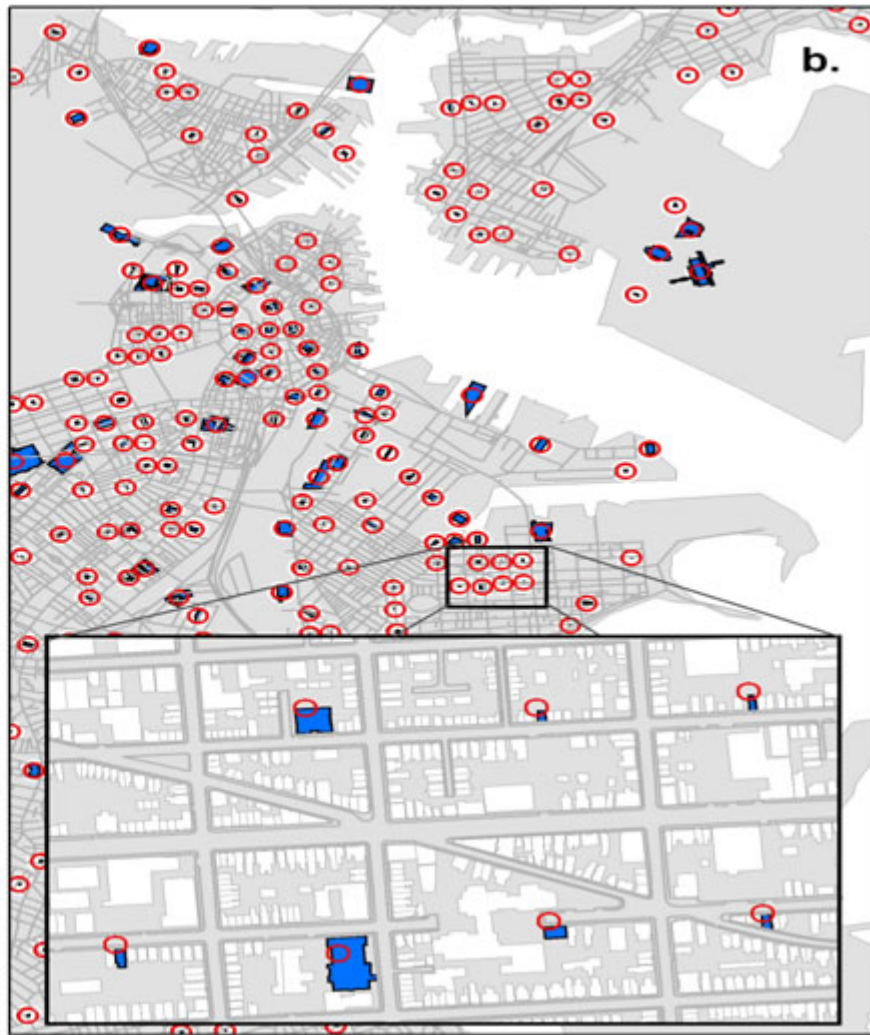
TO THE EDITOR: The mapping of health data is now widespread in both academic research and public health practice.¹ Although the notion that location influences the risk of disease dates back to the mapping of yellow fever and cholera in the 1800s, research that integrates maps with human health is an emerging field based on the widespread availability of geographic information system (GIS) software.² Such systems have broad applicability, and their use has been fueled by the availability of increased computing power, user-

friendly software, and large geographic databases. The number of publications that use GIS data for health research has grown by about 26% per year, four times the rate of increase in the number of articles on human health in general.² Patients' addresses are mapped to identify patterns, correlates, and predictors of disease. These maps are then published electronically and in print.³

Using keyword searches for the terms "geographic" and "map" in the figure legends of articles in five major medical journals published



Re-identified



Brownstein, Cassa, Mandl. NEJM 2006

Even in a RHIO enabled world

The NEW ENGLAND JOURNAL of MEDICINE

SOUNDING BOARD

Health-Information Altruists — A Potentially Critical Resource

Isaac S. Kohane, M.D., Ph.D., and Russ B. Altman, M.D., Ph.D.

One of the key ideas behind sequencing the human genome was the promise of “personalized medicine.” The idea was that genetic information could be used to make health care more precise, effica-

the National Human Genome Research Institute, has called for large cohorts (at least 200,000 subjects) to be assembled simply to achieve the necessary sample sizes to overcome the problems of

BMJ

- A PCHR stored all of an individual's medical history in a container with:
 - ✓ patient control
 - ✓ interoperability
 - ✓ open standards

Information in practice

Public standards and patients' control: how to keep
electronic medical records accessible but private

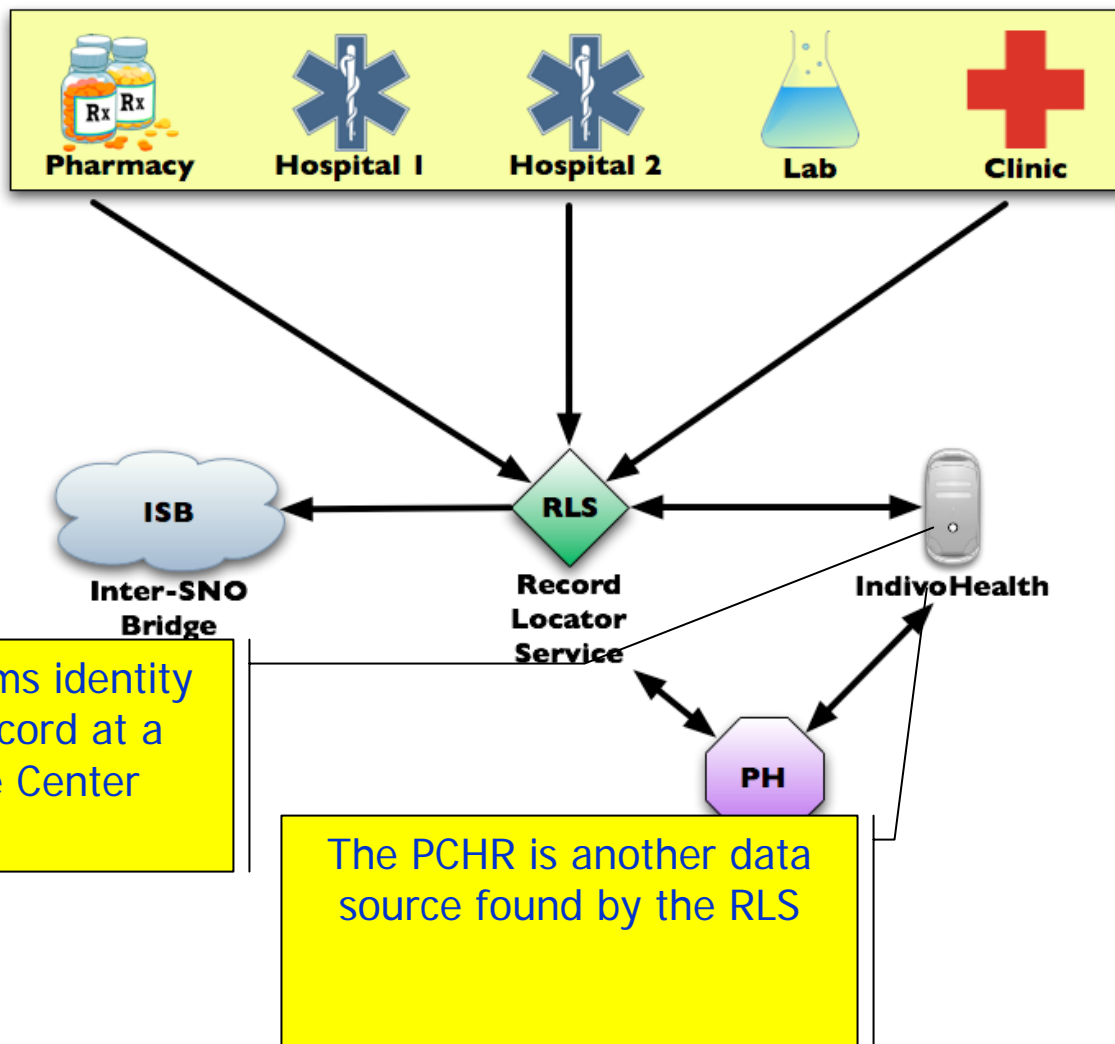
Kenneth D Mandl, Peter Szolovits, Isaac S Kohane

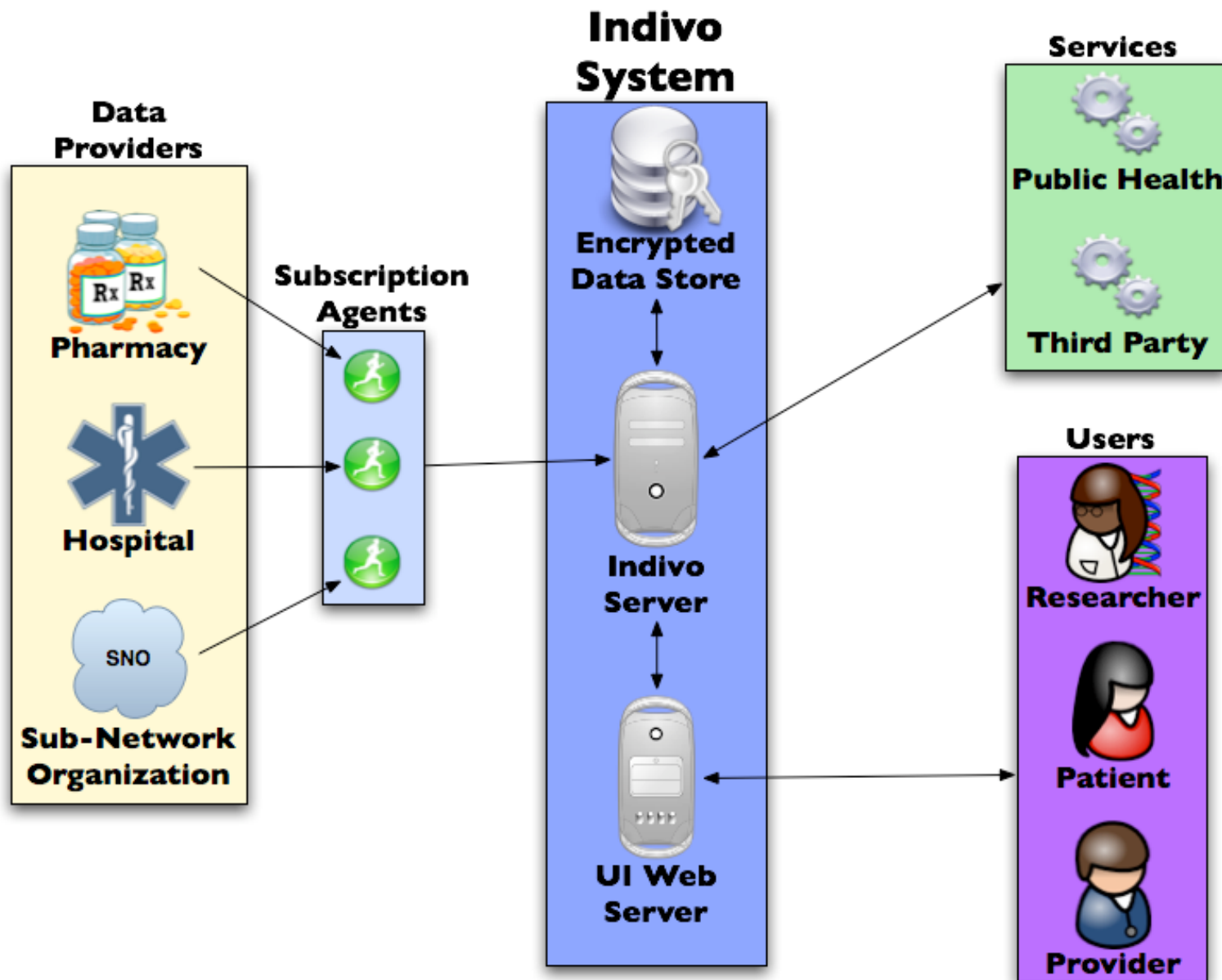
BMJ 2001;322:283-7

Patient role

- Patients can
 - ✓ access the record
 - ✓ grant access to others
 - ☞ specific to their role
 - ☞ of selected portions of the record
 - ✓ store their record in a location of their choice
 - ✓ annotate in the record (but not delete)

Personal NHIN gateway via PCHR service



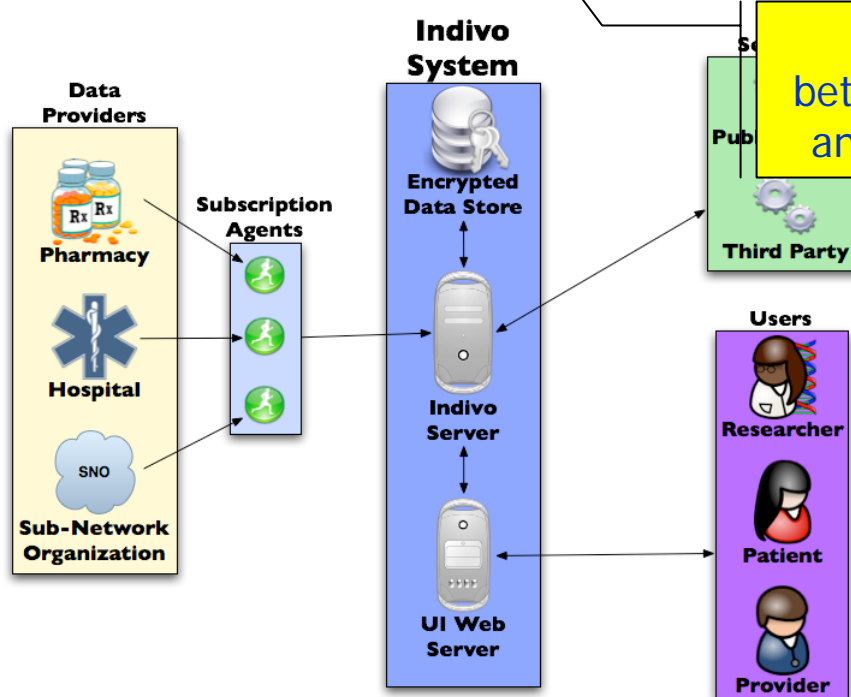


- “De-identified data”
- Mandatory reporting in public health
- Surveillance

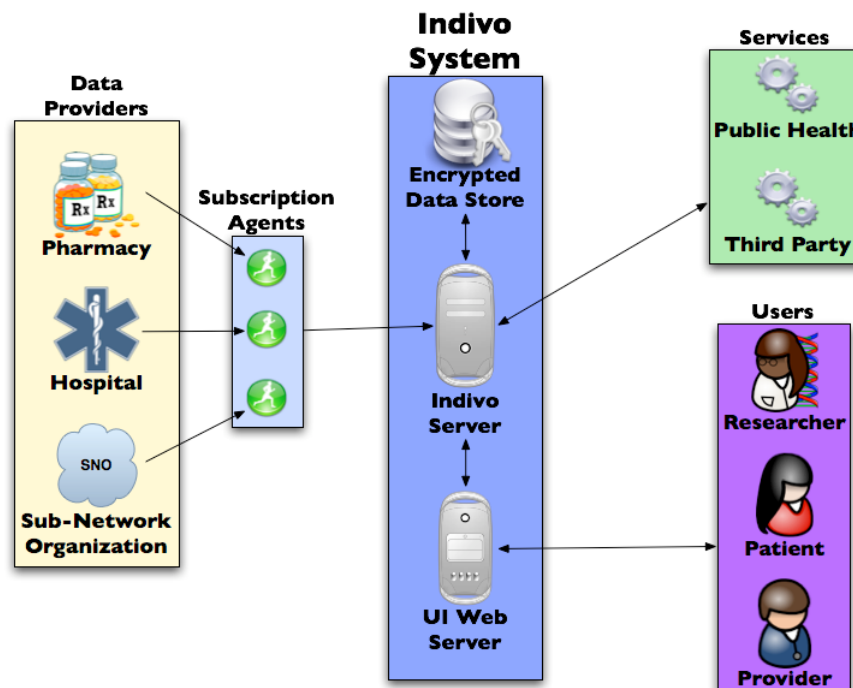
Sweeney 87% rule- don't we want to go beyond aggregated counts?

Public acceptance and the danger of opt out (or failure to opt in)

Bidirectional between institution and public health



- The main reason not to subscribe to the Aristotelian model is because you do NOT believe that patients should control all information flow.

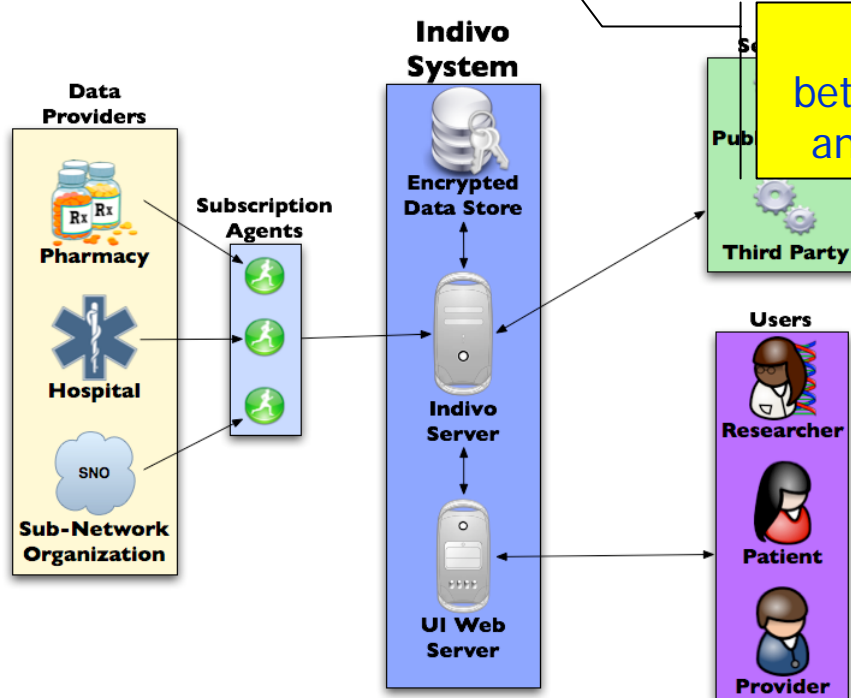


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Personal NHIN gateway PCHR Service

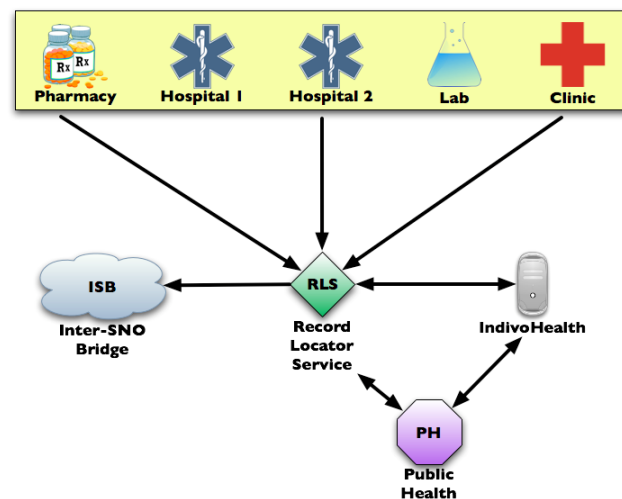
- Identity management—by PCHR service
- Patient information access—via PCHR website
- Data aggregation—by coordinating entity

Score :

1. Personal control 
2. Public Health/research   
3. Completeness 

Dependent on rate of SNO development

Would be 3 except for opt out



PCHR-centric (Aristotelian)

- Identity management—by PCHR service
- Patient information access—via PCHR website
- Data aggregation—by PCHR service

Score :

1. Personal control



2. Public Health/research

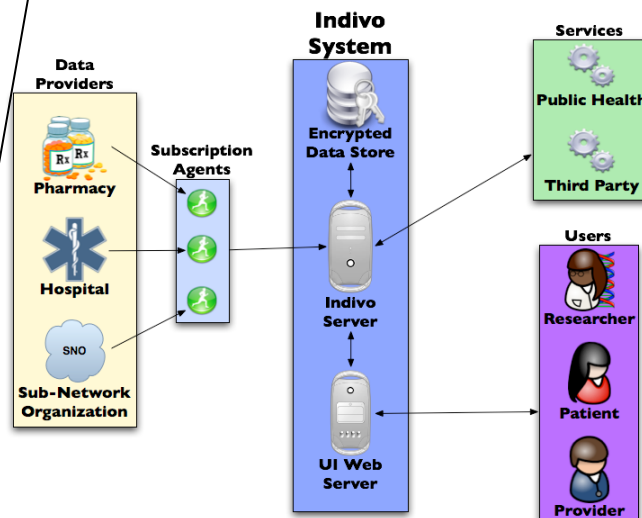


3. Completeness



It may be much faster to hook up individuals to their CDOs than to convince CDO's to share data in a SNO

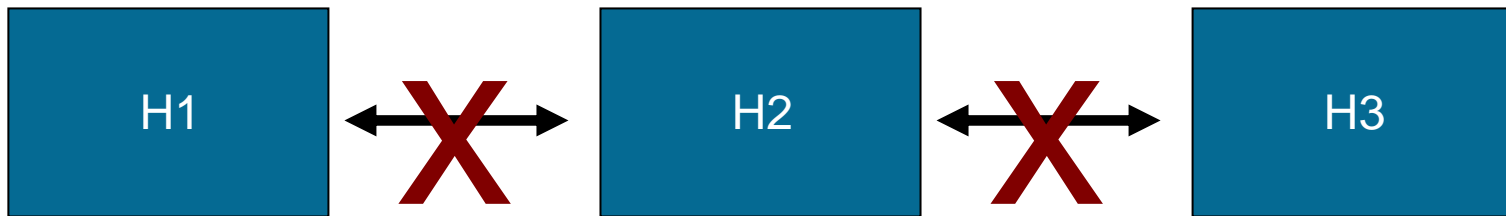
Here non participation is a factor





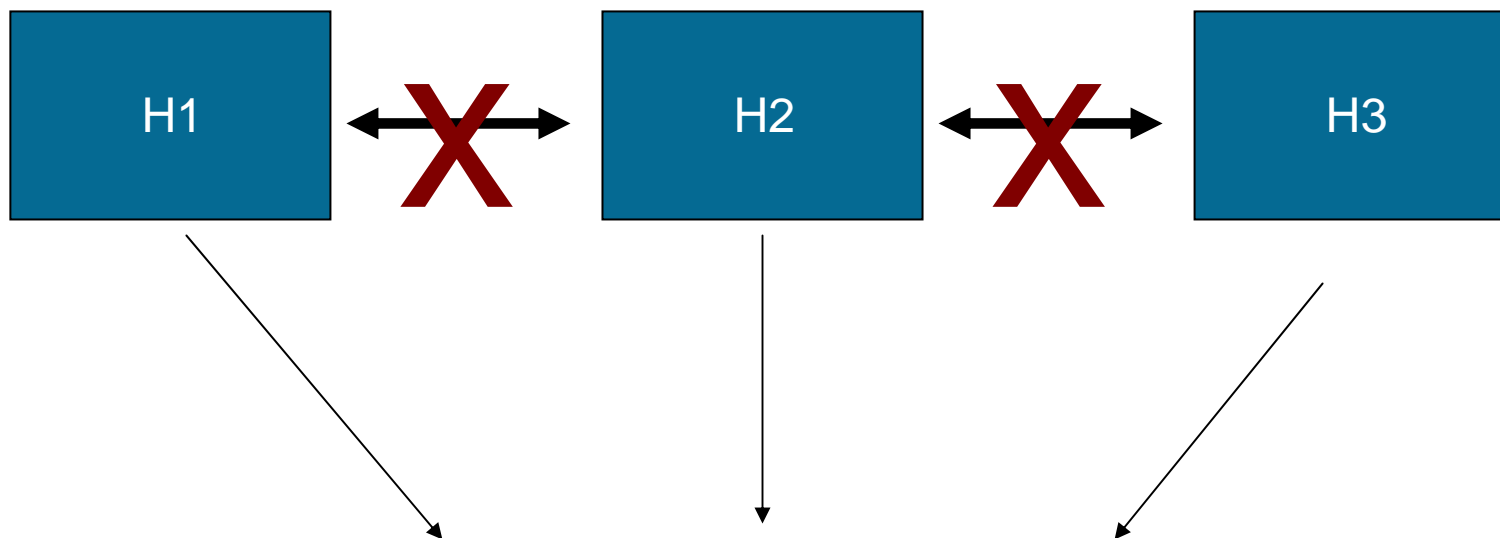
**Will all hospitals share
information in a RHIO?
The jury is out.**

Potential RHIO pitfall: hospitals do not have a history of sharing information



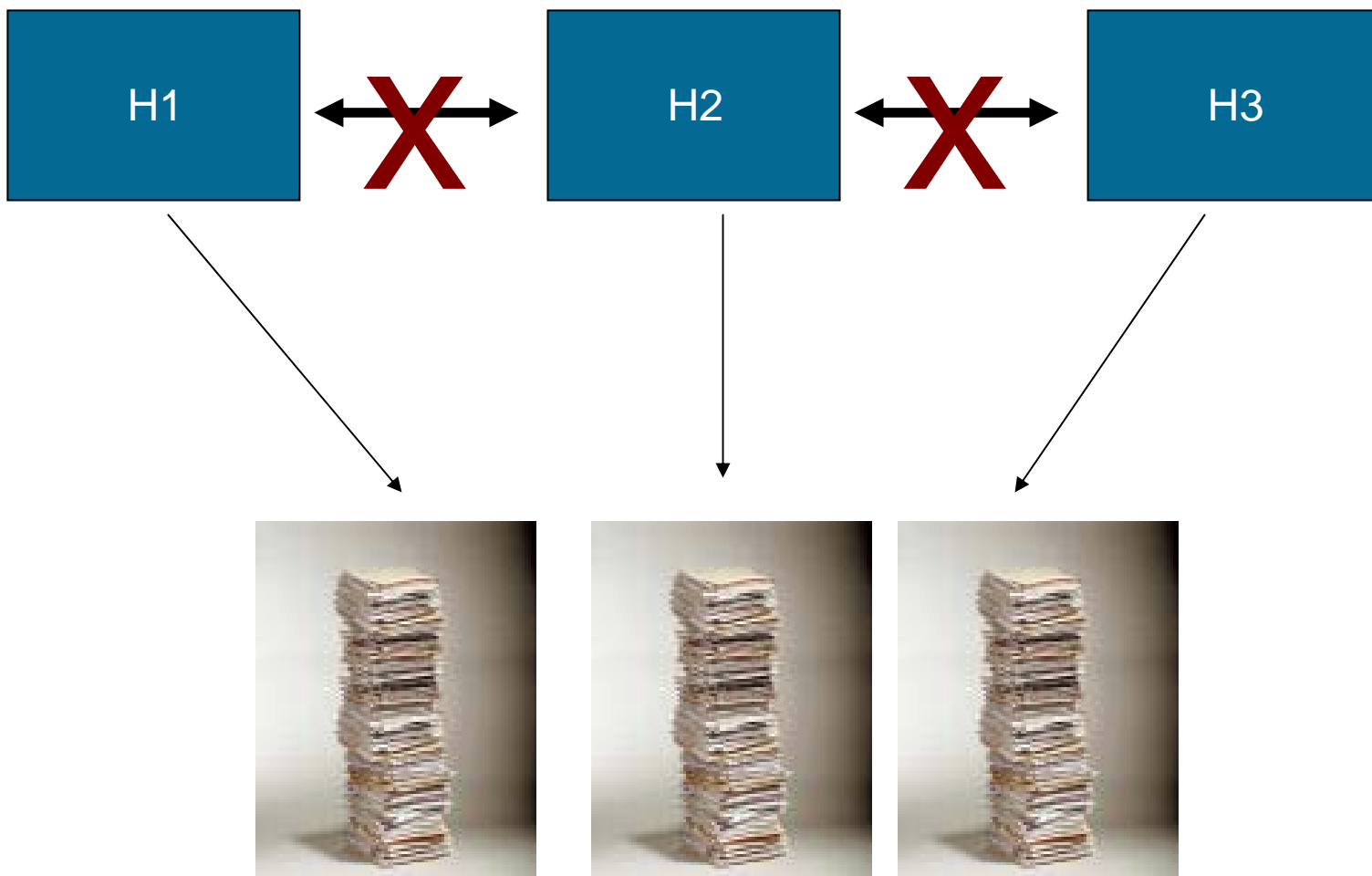
- Proprietary
- Perceived competition
- Privacy
- Health Insurance Portability and Accountability Act
- No dedicated resources to do so

The patient has rights to request the record

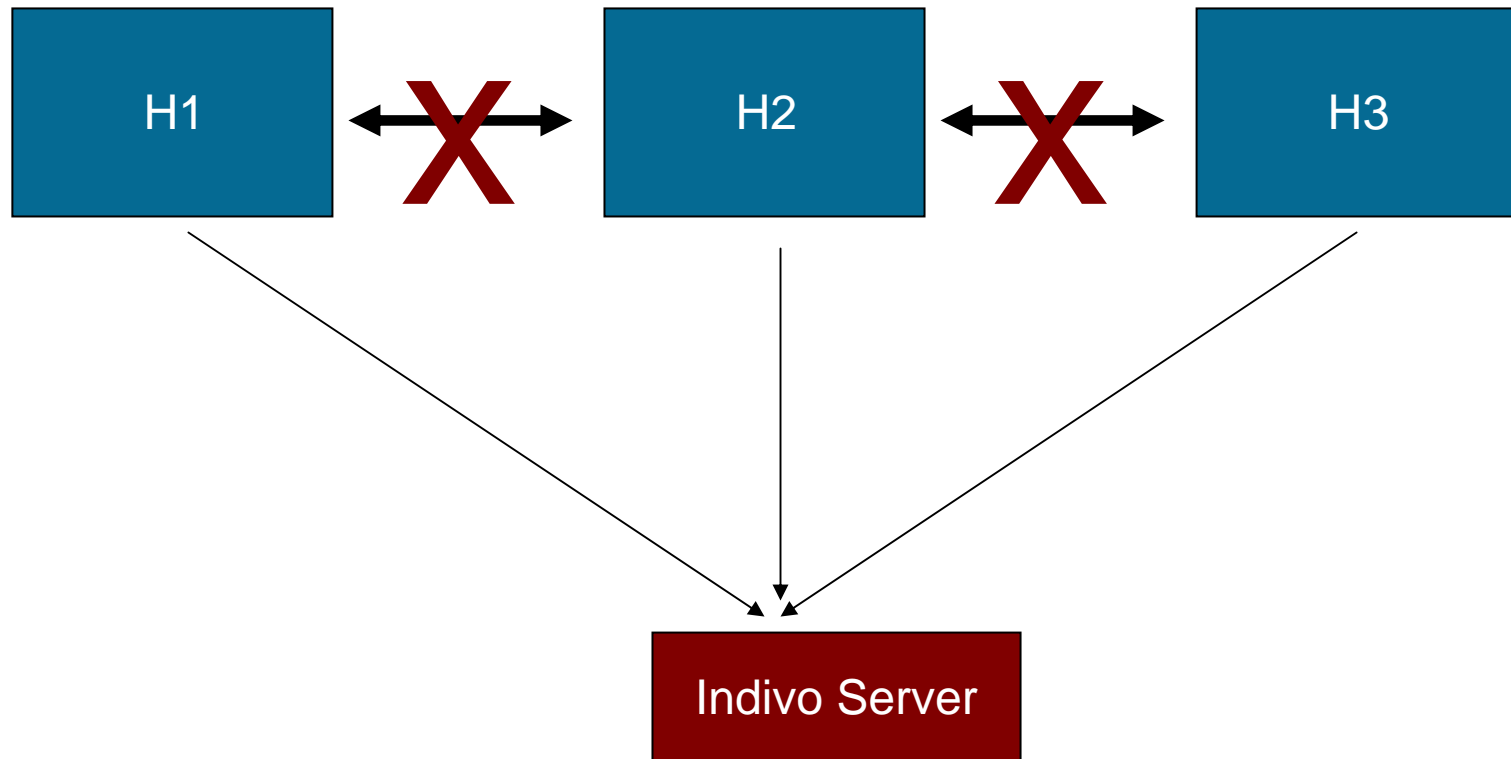


May I please have my record?

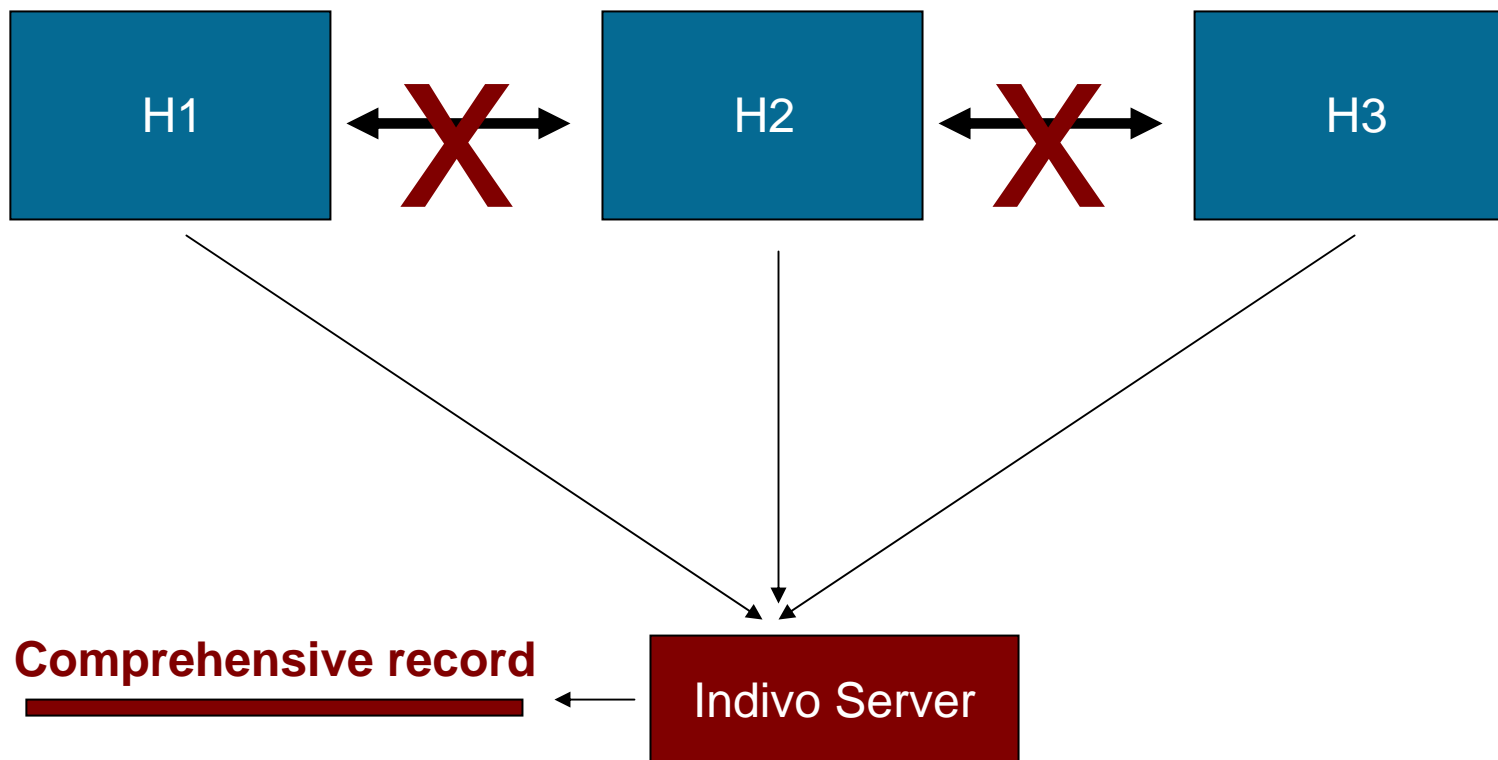
Currently . . .



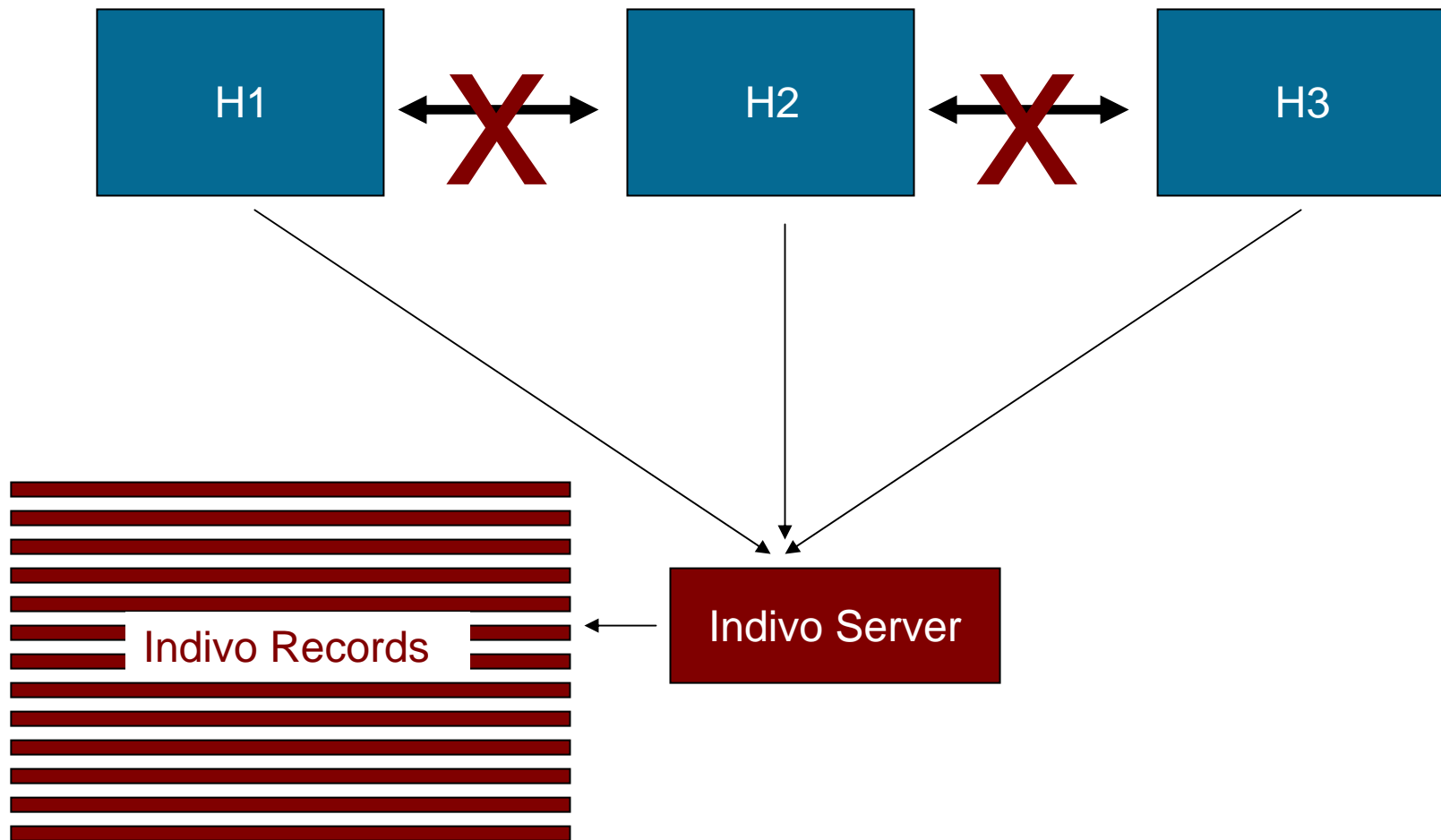
What if we gave patients a tool to request their records electronically?



And create a personal health record



The collection of these records is the population health database



Rely on individual rights

- Confront privacy head on by exercising individual rights to information
- **The patient is the integrator of his/her own medical record**

Main technical goals

- Enable a *single* point of access for patients to their PCHR, effectively making a virtual medical home
- Allow patients to control data flows through a RHIO
- Establish a line of communication with patients

PCHR

- Creates an integrated record
- Defacto virtual medical home

Communication

