



Children's Hospital
Informatics Program



Harvard
Medical School

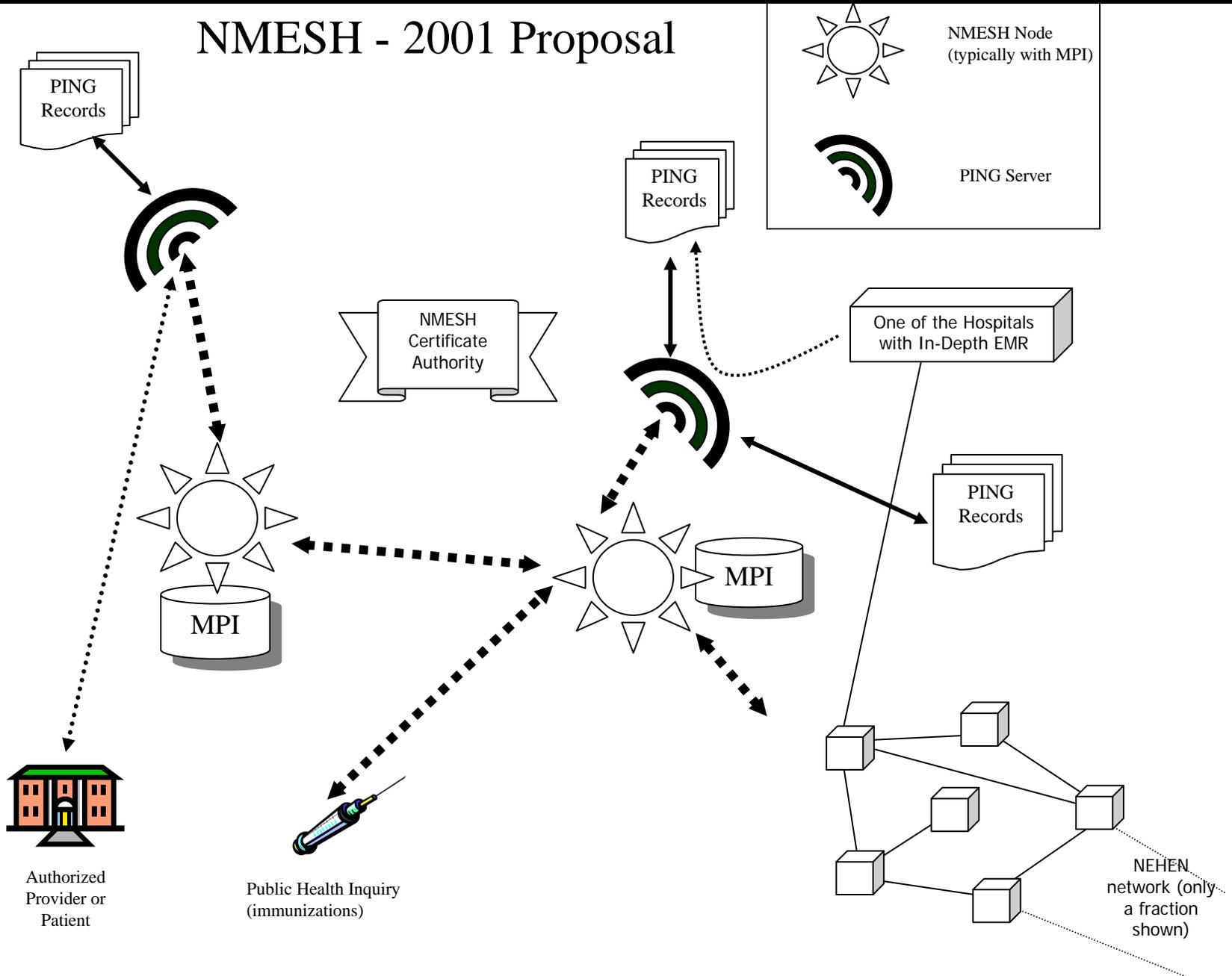
NMESH

The National Multi-Protocol Ensemble for Self-scaling Systems for Health

Final Report

Isaac 'Zak' Kohane, MD, PhD
Kenneth D. Mandl, MD, MPH

NMESH - 2001 Proposal





Components of the NMESH Proposal

- Goals
 - ✓ Feasible technically and sociologically
 - ✓ Scalable to the national scale
 - ✓ Robust and useful in disaster

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 - ✓ Shared Pathology Informatics Network (SPIN)
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 - ✎ Opensource, modular, disease surveillance system (NLM)



NMESH Process

- Technical and sociological adaptability
 - ✓ Inclusion of national leaders in standards (e.g., Halamka/HITSP)
- Making use of multiple available testbeds
 - ✓ ONC demos, RHIOs
- Independent evaluation team from Wisconsin

Evaluation foci and evidence

- *The biomedical and social value of the proposed application to the individuals served*
 - ✓ Commercial-grade, open source records integration approach that permits individual control over access
 - ✓ Cross-state records access & integration demonstration
- *Insight into the potential value of the application to public health*
 - ✓ AEGIS draws data on-demand from ED databases; can access information from Indivo folders
- *Insight into particular elements of the advanced network capabilities or the network specifications that are required for the support of the application*
 - ✓ SPIN search capacity to return every instance of a given entity with high precision and high recall
 - ✓ High performance testbed demonstrated access performance but not failure recovery



Current impacts

- 2007 ONC NHIN demonstrations
- Indivo rollouts
- Connecting for Health/Markle Foundation Common Framework
- Other Major SPIN implementations
 - ✓ NIH Clinical and Translational Science Awards
 - ✓ NCI Program
 - ✓ caBIG program
- HealthMap
- Gene Partnership Project

Current impacts

- 2007 ONC NHIN demonstrations and AHIC testimony
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1. Networked PCHRs
 2. P2P Surveillance System

Current impacts

- 2007 ONC NHIN demonstrations and AHRQ
 - **Indivo rollouts**
 - Connecting for Health/Markle Foundation
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 - HealthMap
 - Gene Partnership Project
- Children's Hospital Boston
 - MIT Medical
 - Harvard University
 - MassShare
 - Interoperation with MinuteClinic
 - Industrial Scaling (HP plus)

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"The SPIN network offered a way to build a network with a limited number of interfaces, but could use those interfaces in different ways for different kinds of reporting. As a result, we have been able to optimize our clinical reporting framework for that one purpose, while using SPIN to provide public health reporting among the same entities."

SPIN is the centerpiece of the informatics core of the Harvard CTSA application as well as regional and national scale efforts

Current impacts

demonstrations and AHIC testimony

- Individual rollouts
- Connecting for Health/Markle Foundation Common Framework
- Other Major SPIN implementations
 - ✓ NIH Clinical and Translational Science Awards
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- HealthMap
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Current impacts

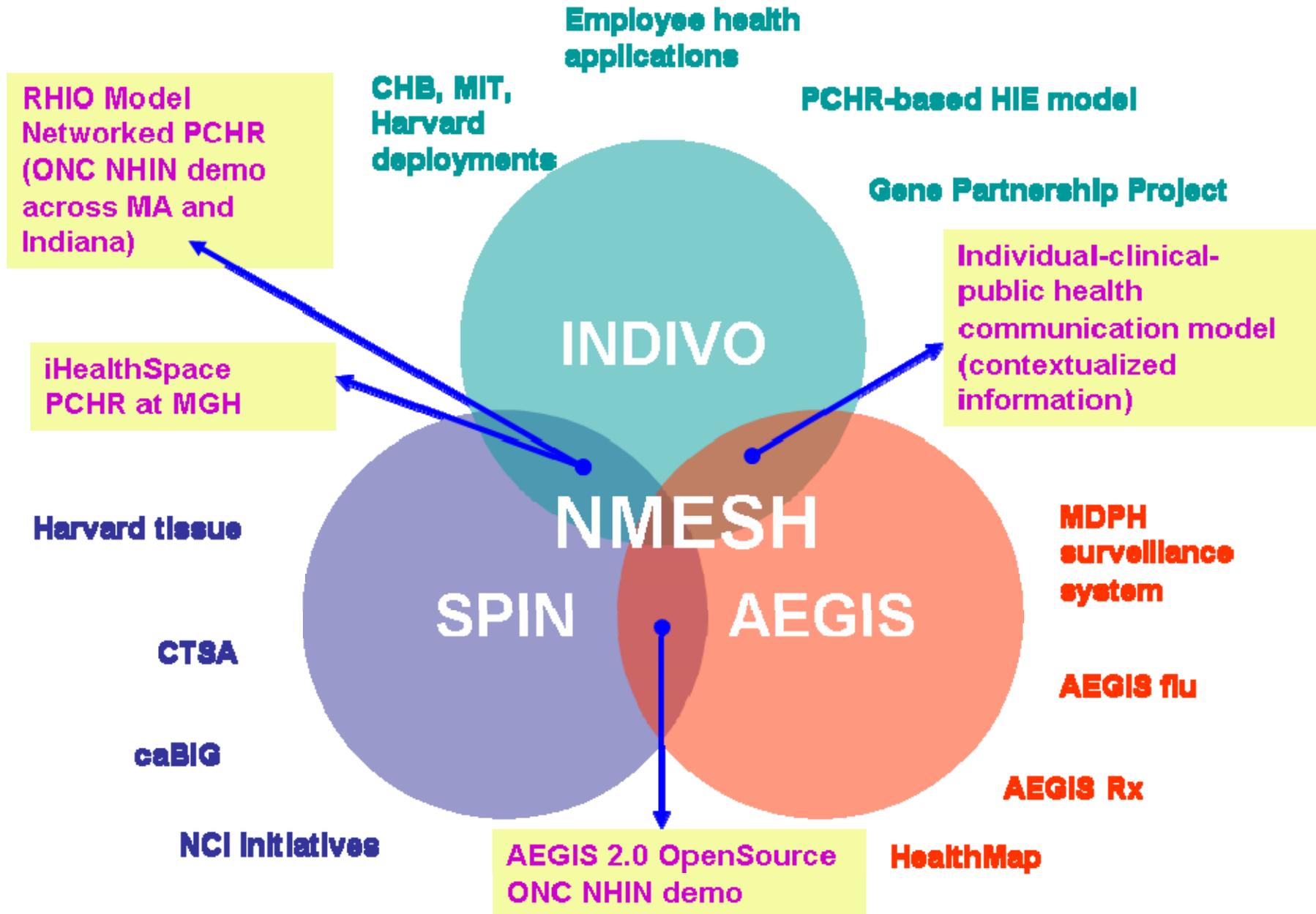
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- **HealthMap**
- Gene Partnership Project

The Healthmap project arose from the GIS focus within NMESH

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The Informed Cohort concept arises from the NMESH/Indivo projects





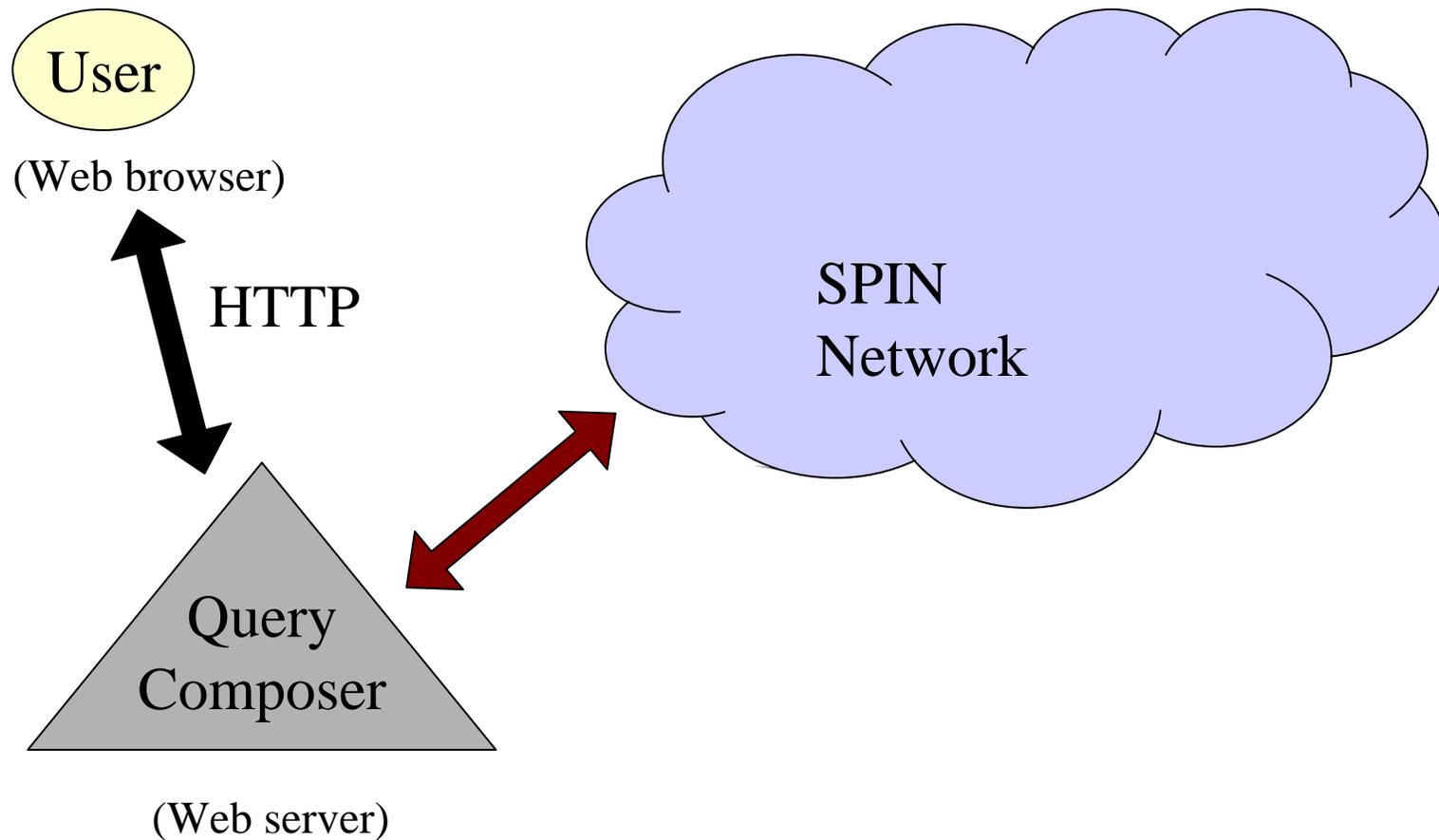
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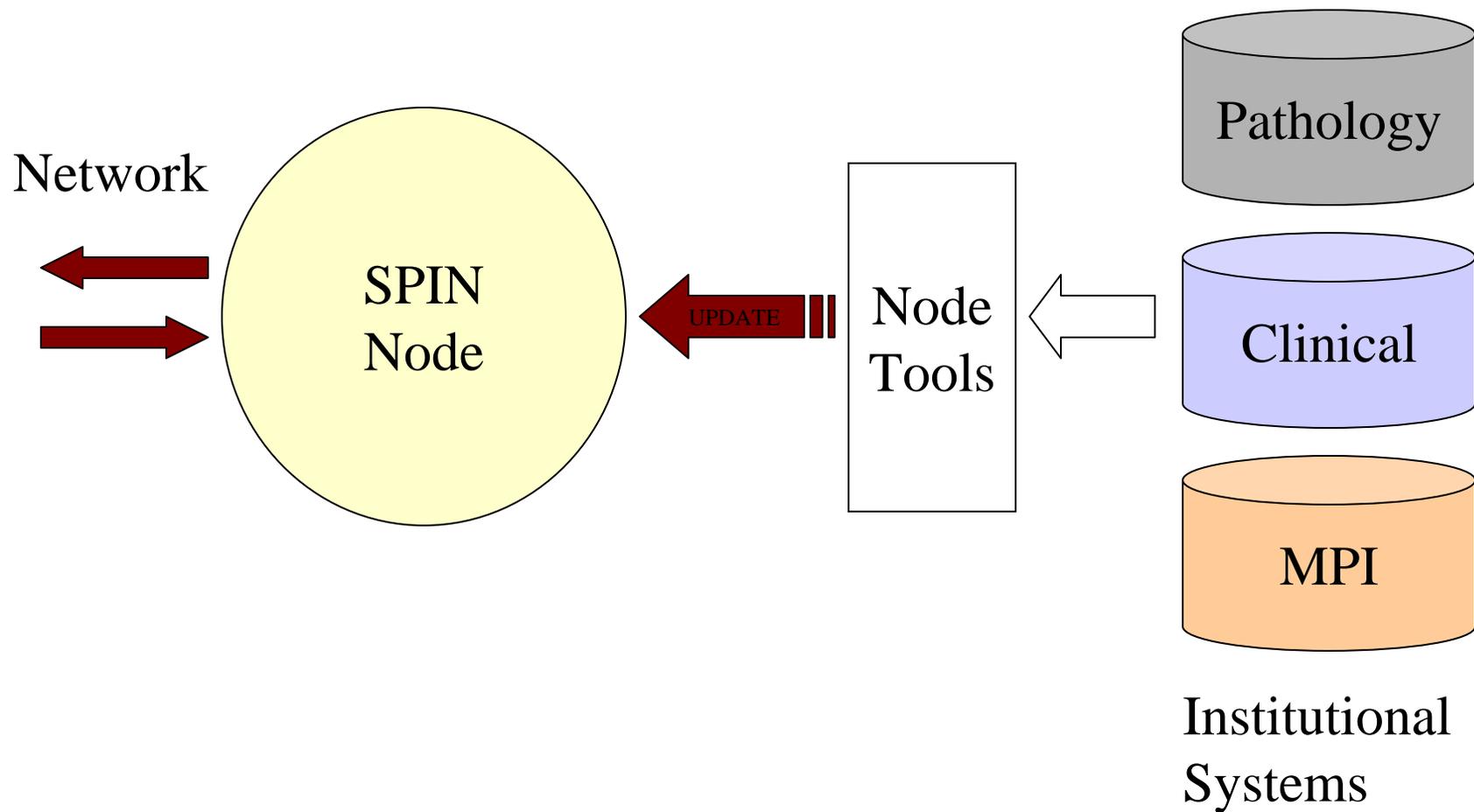
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Medical School

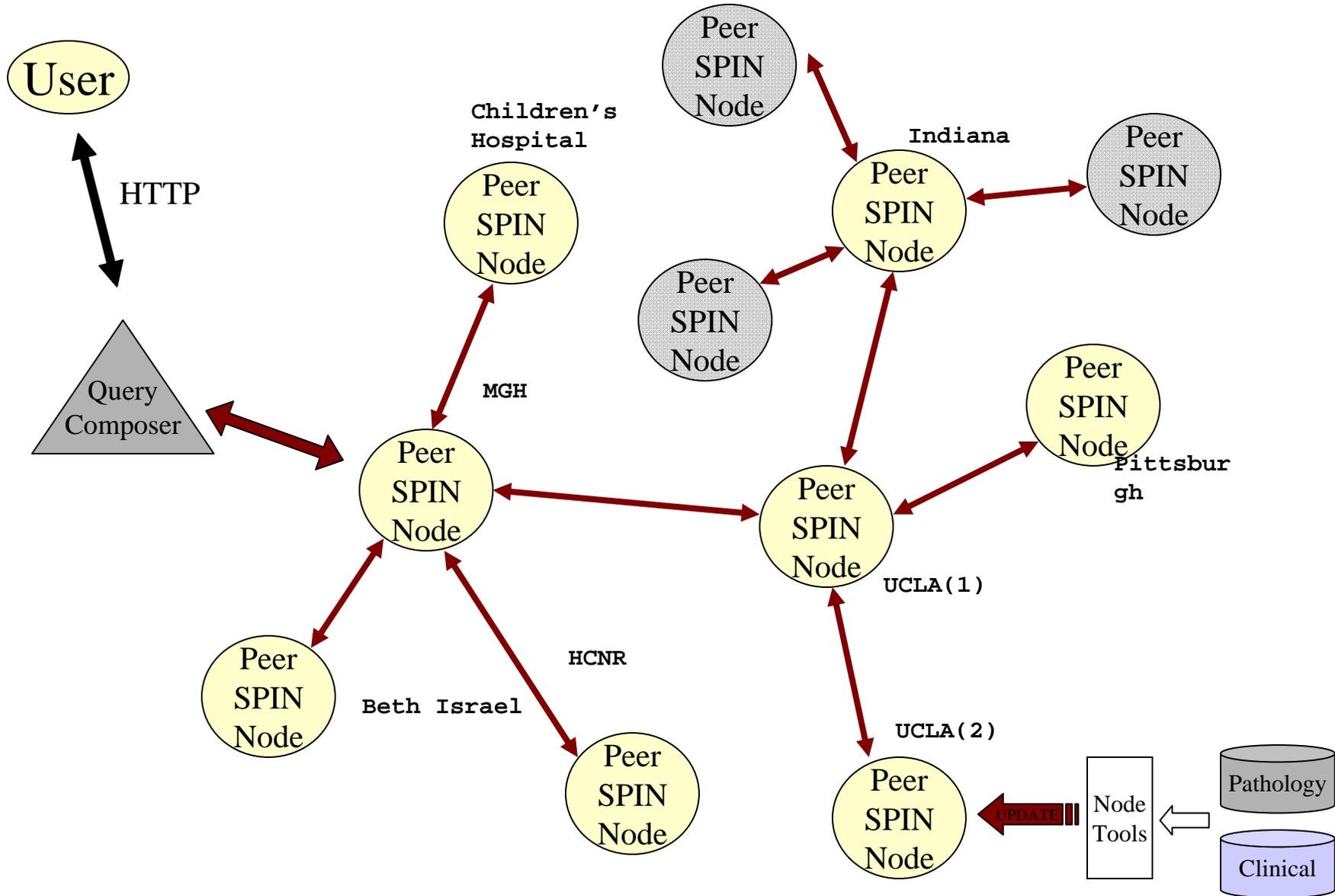
SPIN Overview

Birds-eye view of SPIN



Local view of institution







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Not Registered? [ENTER HERE](#) ▶

[REQUEST ACCOUNT](#) ▶

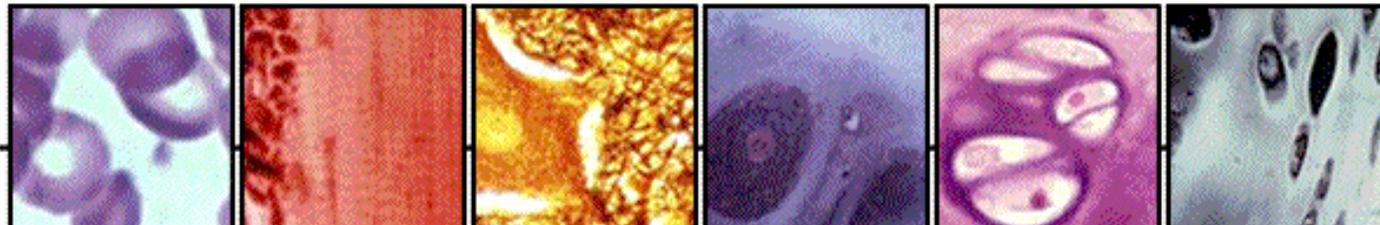
username:

password:

[REGISTERED USER LOGIN](#) ▶

National Institutes of Health
National Cancer Institute

Brigham & Women's Hospital
Beth Israel Deaconess Medical Center
Cedars-Sinai Medical Center
Children's Hospital
Dana-Farber Cancer Institute
Massachusetts General Hospital
Olive View Medical Center
UCLA Medical Center
VA Greater LA Healthcare System
University of Pittsburgh Medical Center



Shared *pathology* *informatics* *Network*

The objective of this initiative is to use state-of-the-art informatics techniques to establish an Internet-based virtual database that will allow investigators to locate appropriate human tissue specimens for their research.

The SPIN software will allow approved researchers access to data that describe archived tissue specimens across multiple institutions while still allowing those institutions to maintain local control of the data. The need for this capability has been fueled by the growing use of tissues, diagnostic specimens, and their related clinical data in modern biomedical research.

[\[terms & conditions\]](#)



diagnosis ▼ ▲

Text: Code(s):

gender ▼ ▲

Female Male Transgender Unknown

age at specimen collection ▼ ▲

BETWEEN AND

topology ▼ ▲

date of specimen collection ▼ ▲

results format ▼ ▲

<p>search name: <input type="text"/></p> <p>search type: <input type="radio"/> CHIRPS Only <input checked="" type="radio"/> SPIN Network</p>	<p>statistics: <input type="text" value="bin on age"/></p> <p>detailed table fields: <input type="checkbox"/> Age at specimen collection <input type="checkbox"/> Date of specimen collection <input type="checkbox"/> Gender</p> <p>sort by <input type="text"/></p>
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clear search ▶



SEARCH

ADVANCED SEARCH

RESULTS

LOGIN

[home] [about]

Select ALL

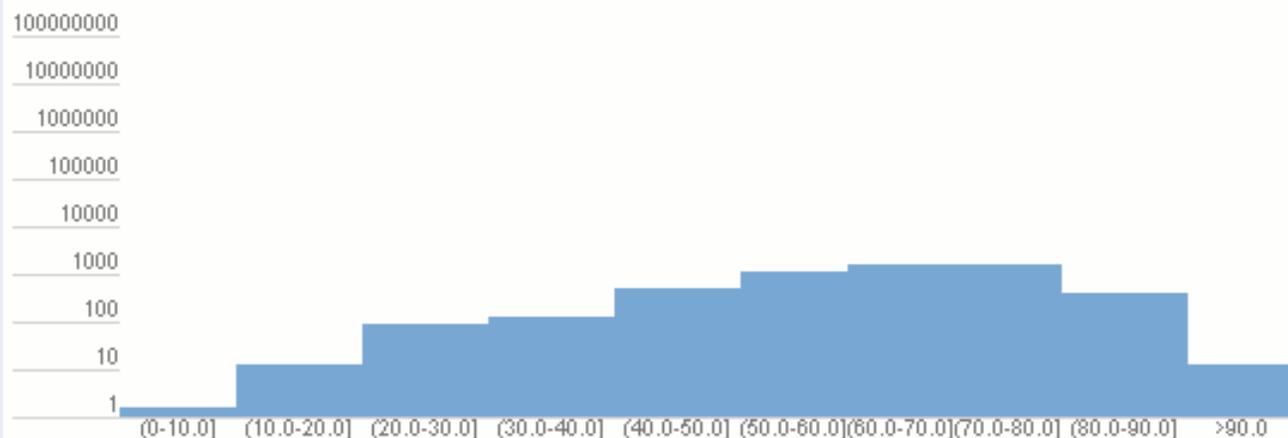
delete selected results

RESULTS SUBQUERY NODES Fetching.



name: records: 10247 nodes: 7 sent: 2004-05-27 23:49:36

age at sample collection



no value:	681
(0-10.0]:	3
(10.0-20.0]:	22
(20.0-30.0]:	99
(30.0-40.0]:	206
(40.0-50.0]:	761
(50.0-60.0]:	1797
(60.0-70.0]:	3105
(70.0-80.0]:	2894
(80.0-90.0]:	660
>90.0:	19

RESULTS SUBQUERY NODES



name: records: 0 nodes: 6 sent: 2004-05-27 23:48:55

RESULTS SUBQUERY NODES



name: detail records: 990 nodes: 7 sent: 2004-05-27 23:45:23

RESULTS SUBQUERY NODES



name: records: 0 nodes: 7 sent: 2004-05-27 23:43:57

delete selected results



SEARCH

ADVANCED SEARCH

RESULTS

LOGIN

[home] [about]

Select ALL

delete selected results

RESULTS

SUBQUERY

NODES

Fetching



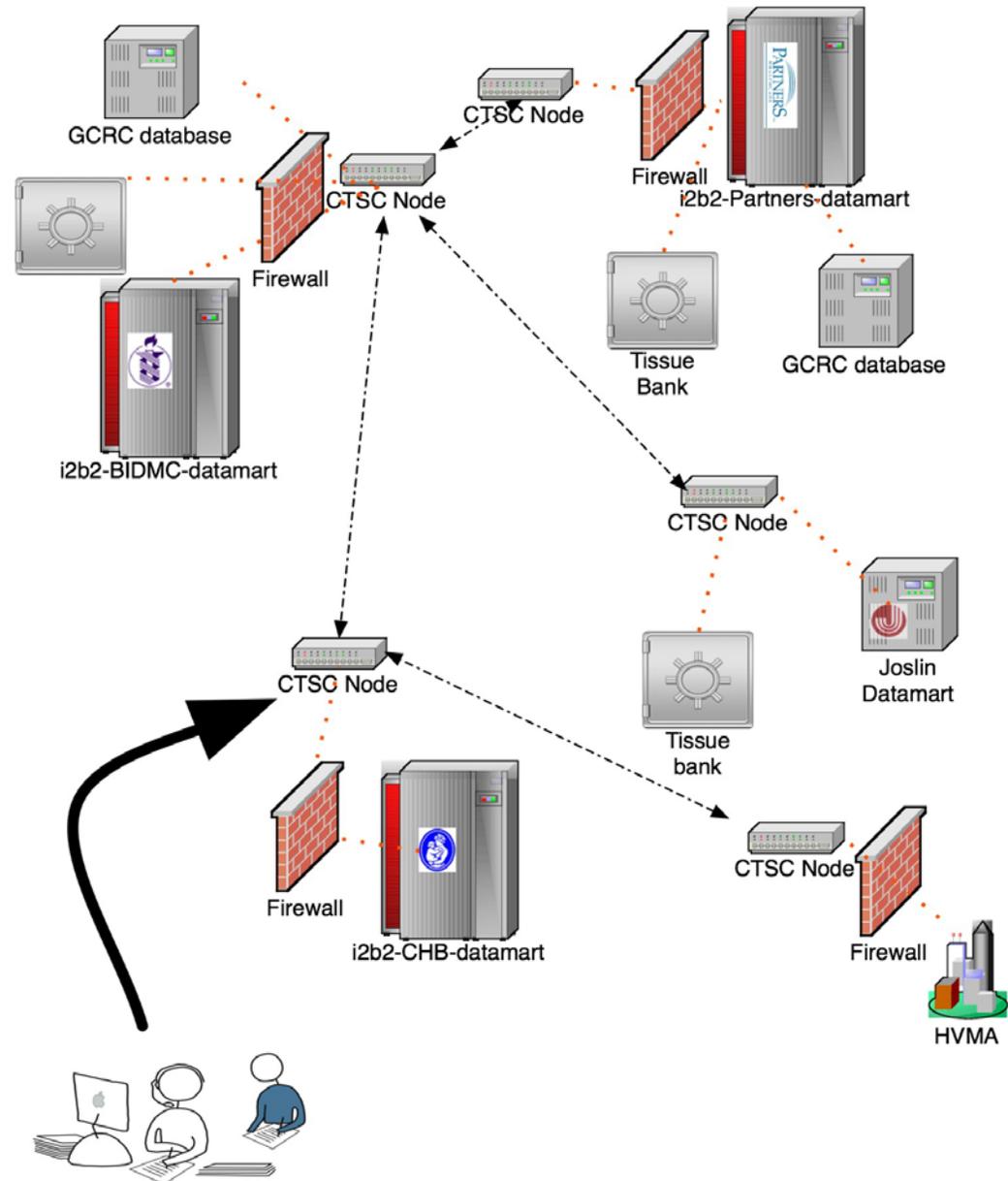
name: records: 990 nodes: 7 sent: 2004-05-27 23:32:25

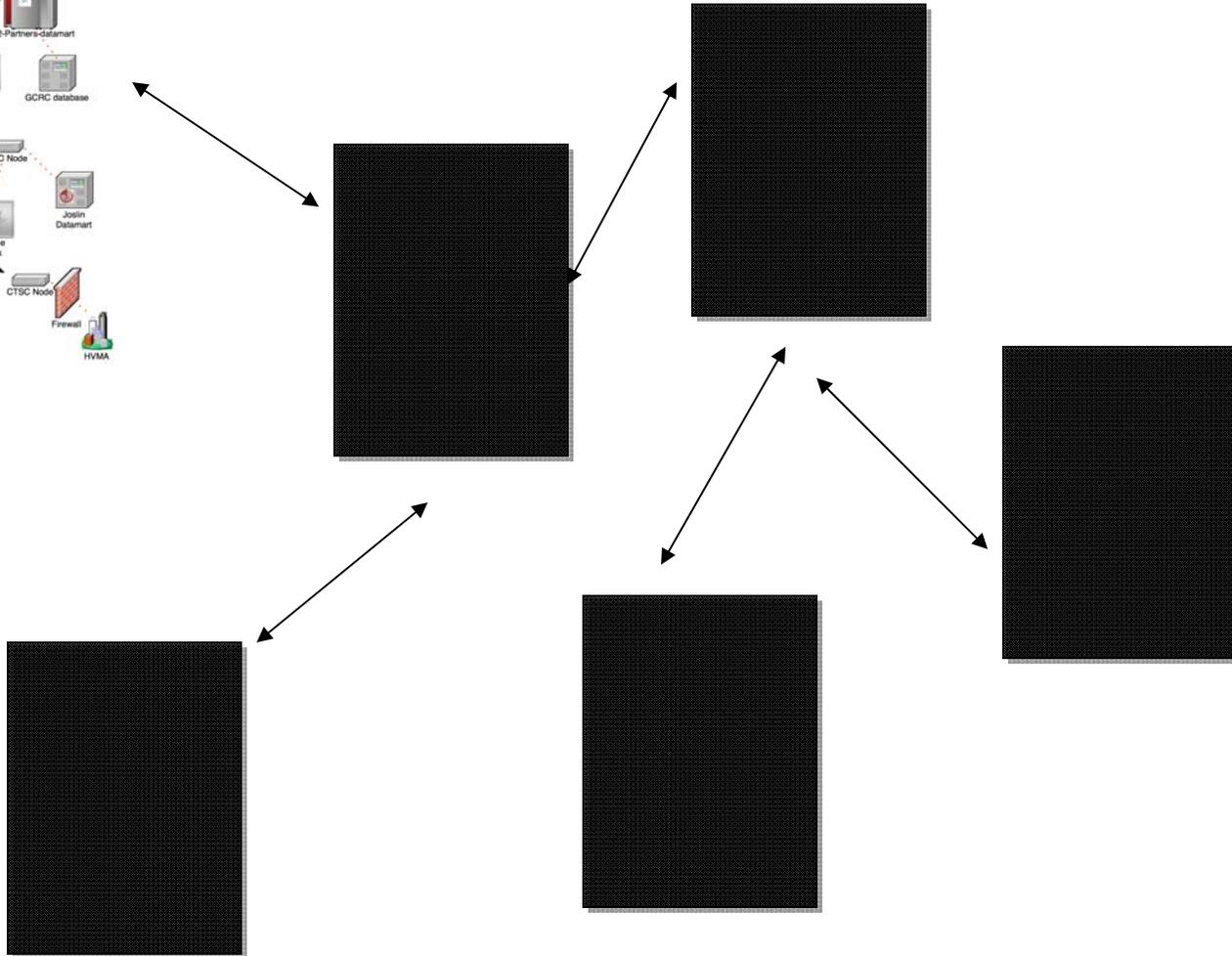
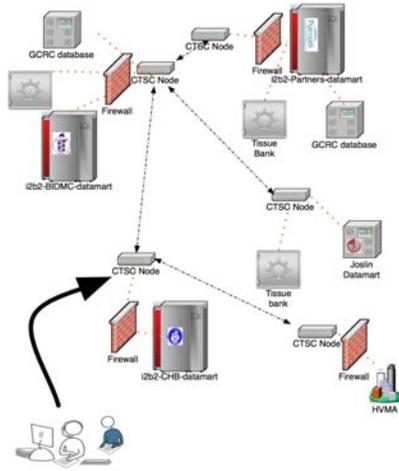
nodes that responded to your query:

- (1) CHIRPS - Beth Israel Deaconess Medical Center
- (1) CHIRPS - Brigham & Women's Hospital
- (1) CHIRPS - Children's Hospital Boston
- (1) CHIRPS - Massachusetts General Hospital
- (2) CHIRPS - University of California at Los Angeles Medical Center
- (1) Other - unidentifiable

delete selected results

HMS CTSA







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Indivo PCHR Overview

Personally Controlled Health Records

- A container to store and share your personal health information
- A “quicken for health care”
- A “health bank” account
- Provides a “virtual medical home” for patients

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)



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Boston

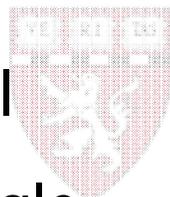


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100 invited participants including

CDC

Intel



Harvard
Medical
School



Harvard

NIH

Google

MIT

CMS

Microsoft

OSHU

VA

Intuit

U Wash

SSA

MinuteClinic

Wal-mart

BP

PCHRI2006

The Harvard Medical School Meeting on Personally
Controlled Health Record Infrastructure

WWW.PCHRI2006.ORG



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PCHRI2006

The Harvard Medical School Meeting on Personally
Controlled Health Record Infrastructure

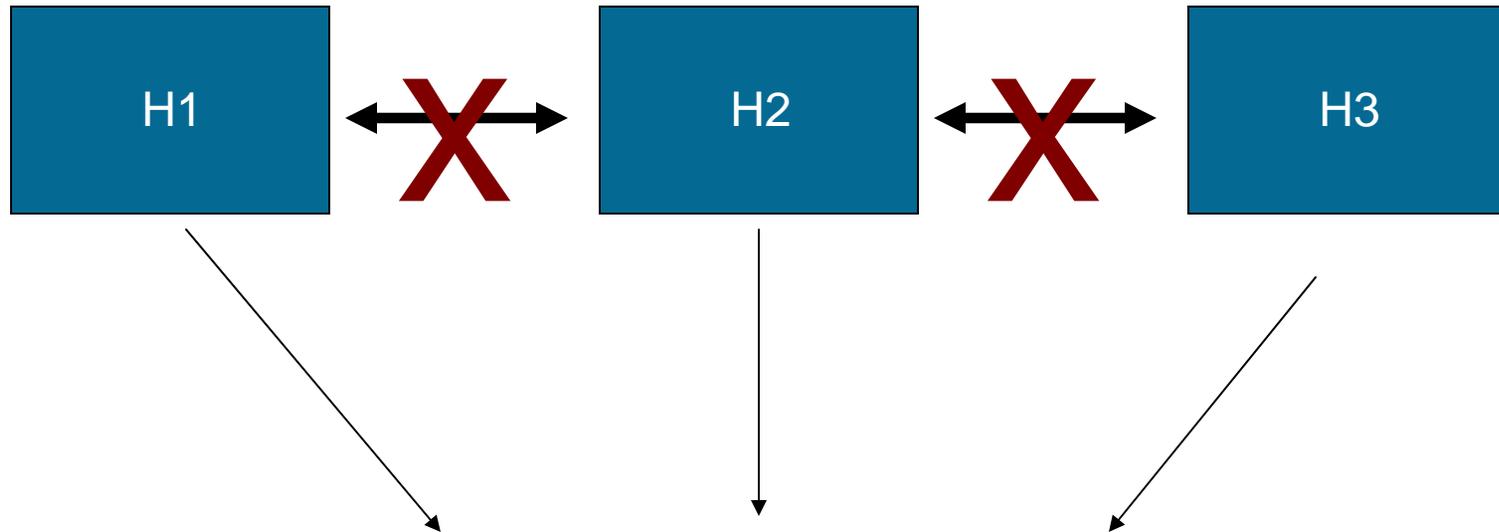
WWW.PCHRI2006.ORG

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



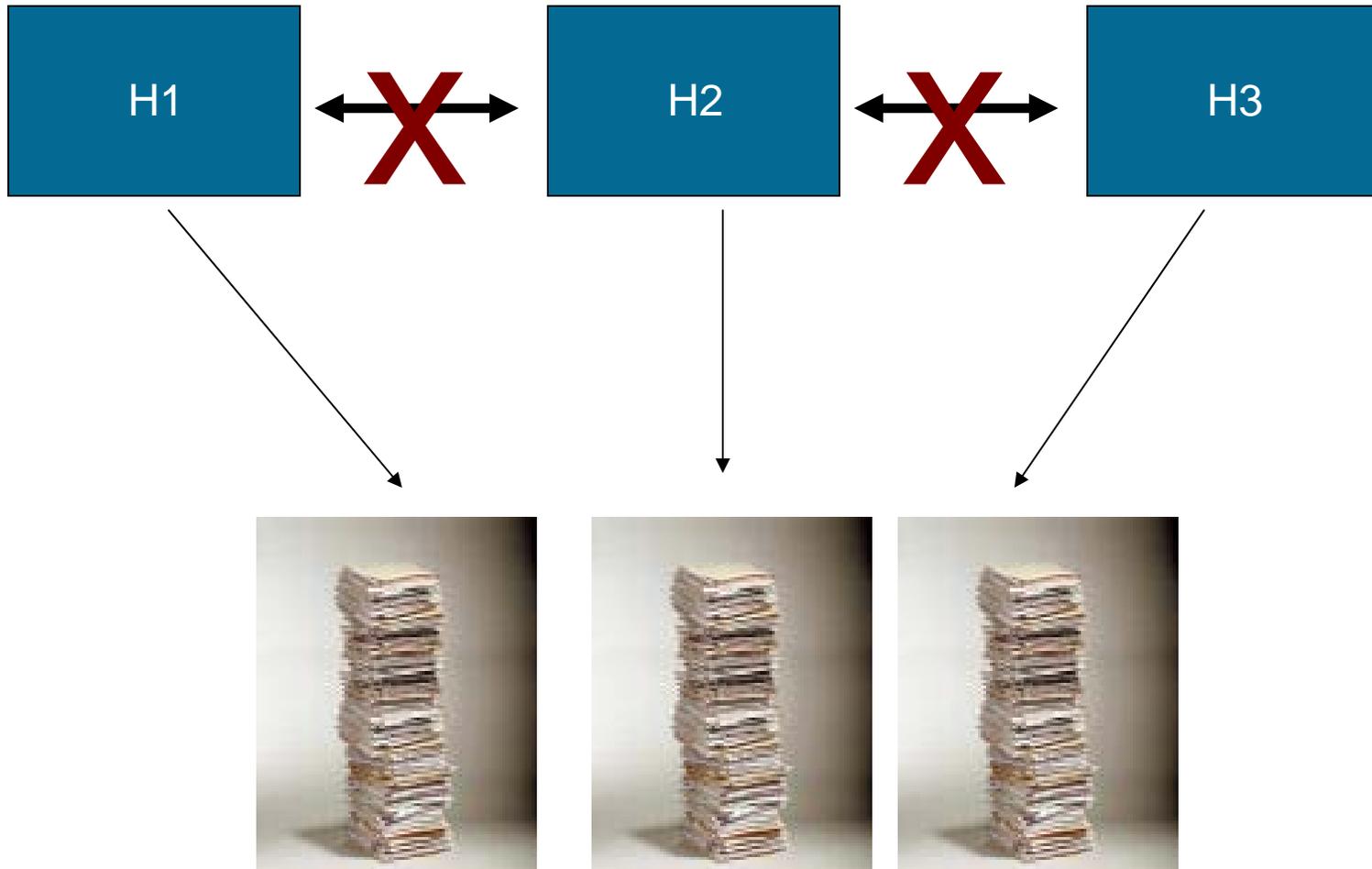
- Proprietary
- Perceived competition
- Privacy
- Health Insurance Portability and Accountability Act
- No dedicated resources to do so

The patient has rights to request the record

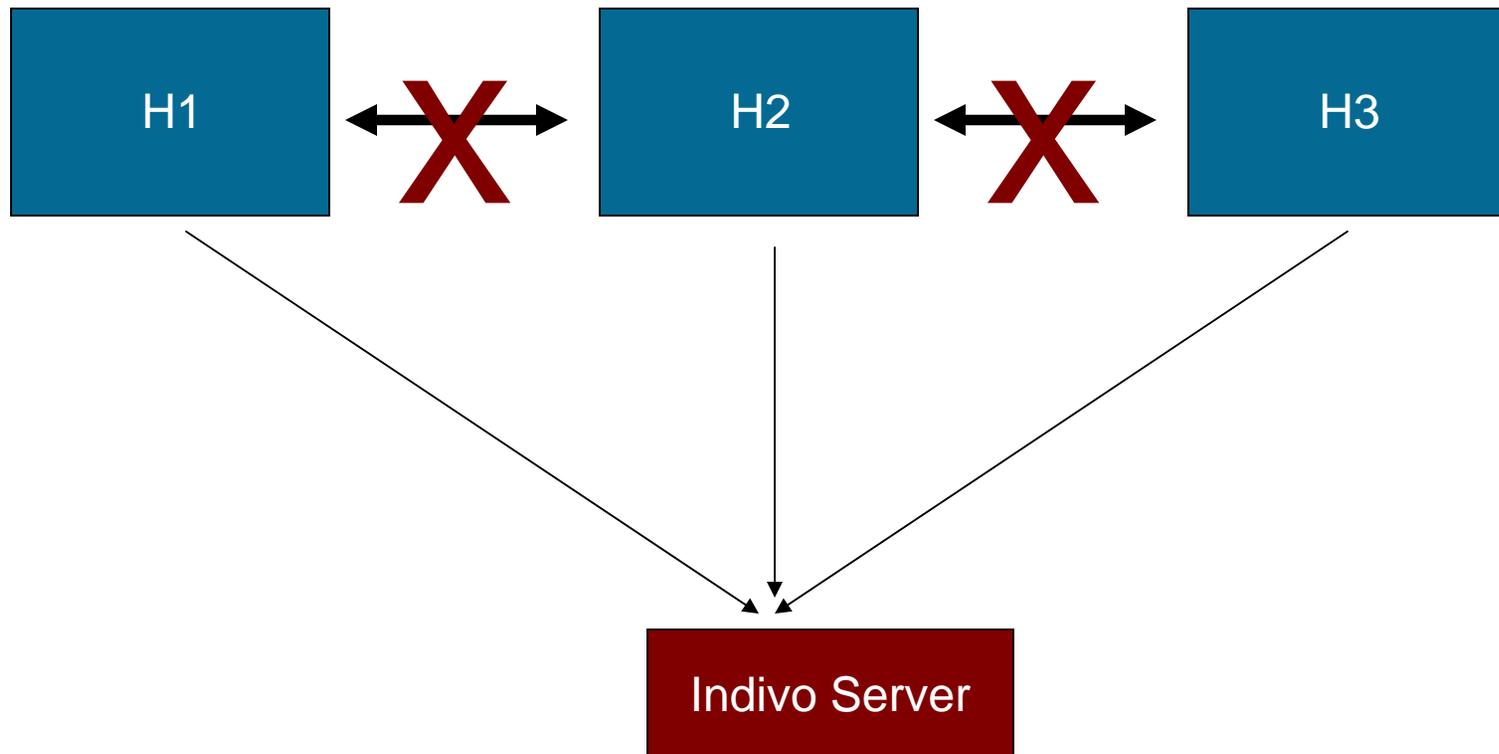


May I please have my record?

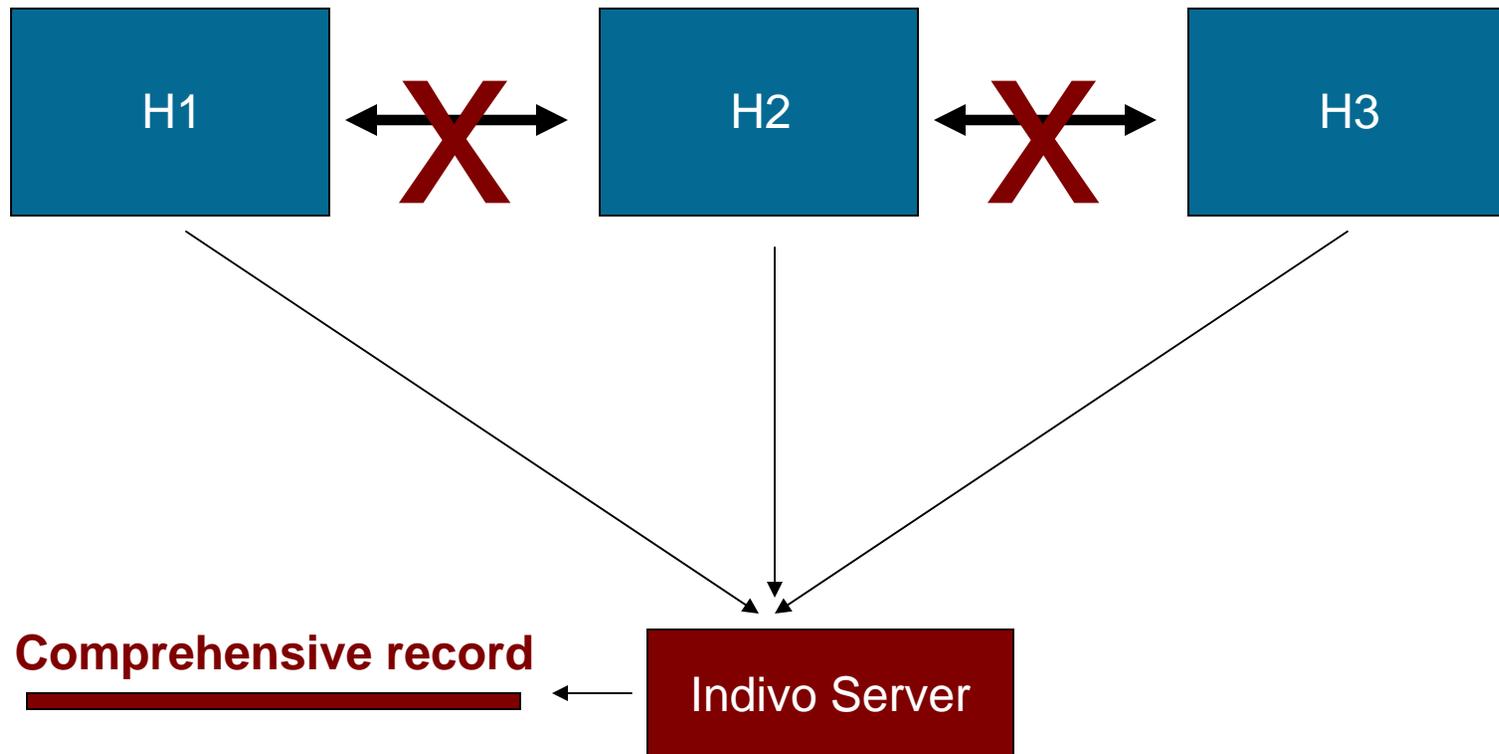
Currently . . .



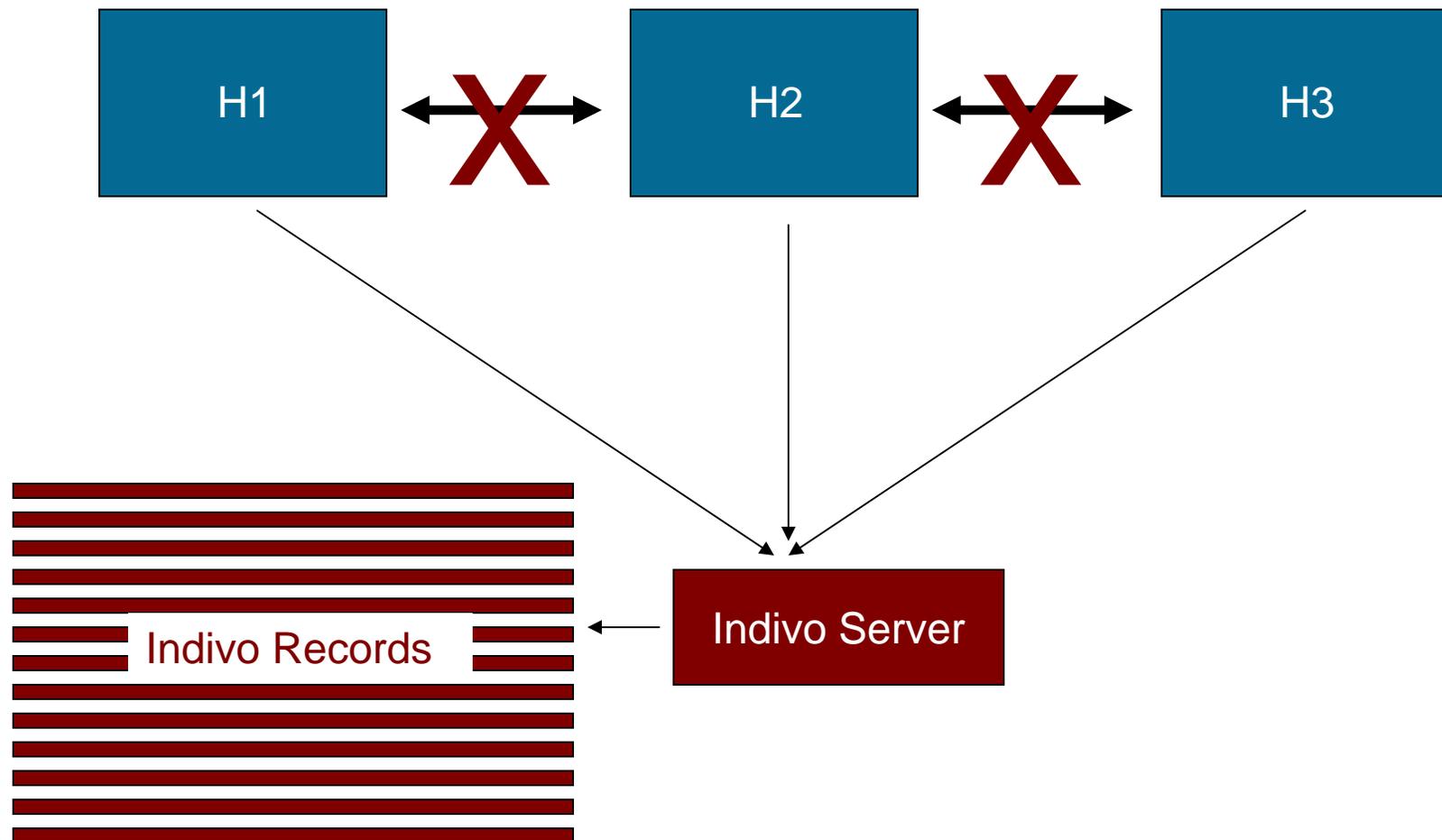
What if we gave patients a tool to request their records electronically?



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**



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AEGIS Population Health Monitoring Overview



https://server.aegis.chip.org - Home View - Mozilla Firefox

A E G I S



SELECT DATE

20	21	22	23	24	25	26	19
27	28	29	30	31	1	2	
3	4	5	6	7	8	9	
10	11	12	13	14	15	16	

SELECT HOSPITAL/SYNDROME

	MGH	AGH	ALL	MA	BEV	BIDMC	CHB
RESP	■■■						
GI							
RASH							
NEURO							
HEMOR							
ALL							
INJ							

SELECT ABBERRATION

Aberrations For Current Selection

■■■ MGH RESP ^S 9/7 [details](#) [export](#)

Other Aberrations

■■■ MGH RESP ^S 9/7 [details](#) [export](#)

■■■ MGH RESP ^S 9/6 [details](#) [export](#)

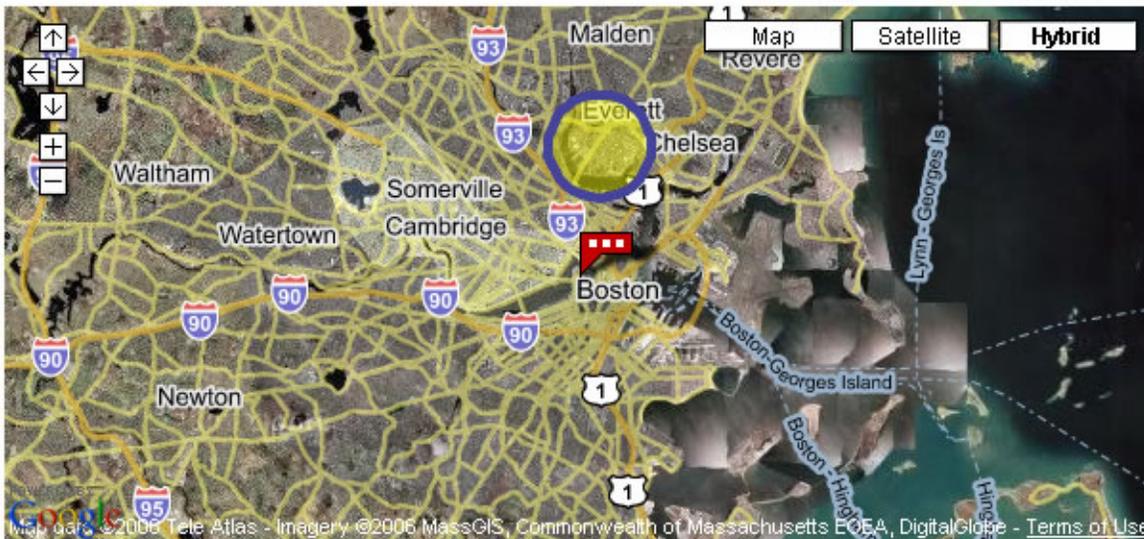
■■■ CHB RESP ^S 8/26 [details](#) [export](#)

--- SSHORE GI ^T 9/1 [details](#) [export](#)

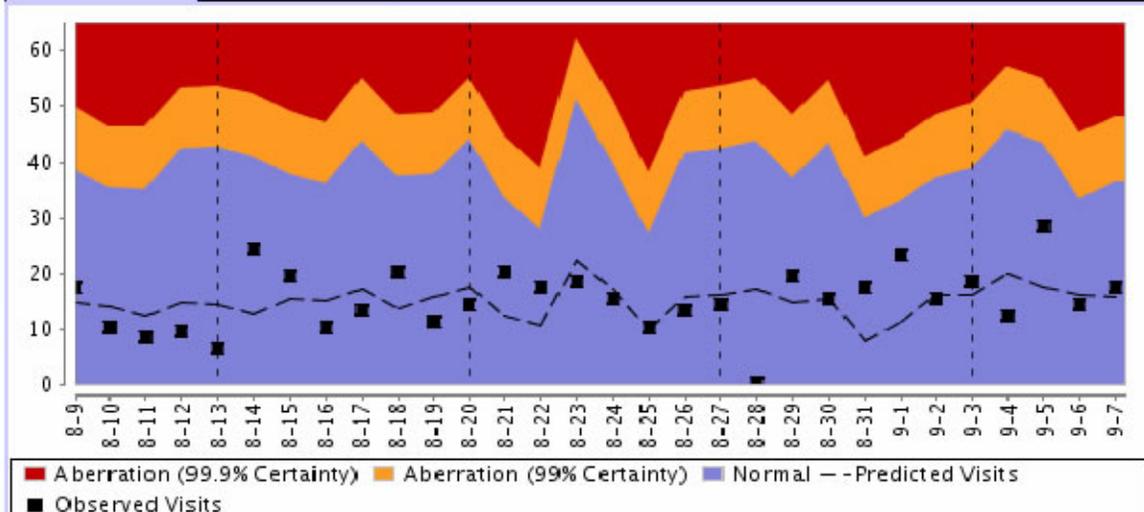
LEGEND

■	■	- Normal
---	---	- Aberration (99% Certainty)
■■■	■■■	- Aberration (99.9% Certainty)
□	□	- Result not yet available
	S/T	- Spatial/Temporal Aberration

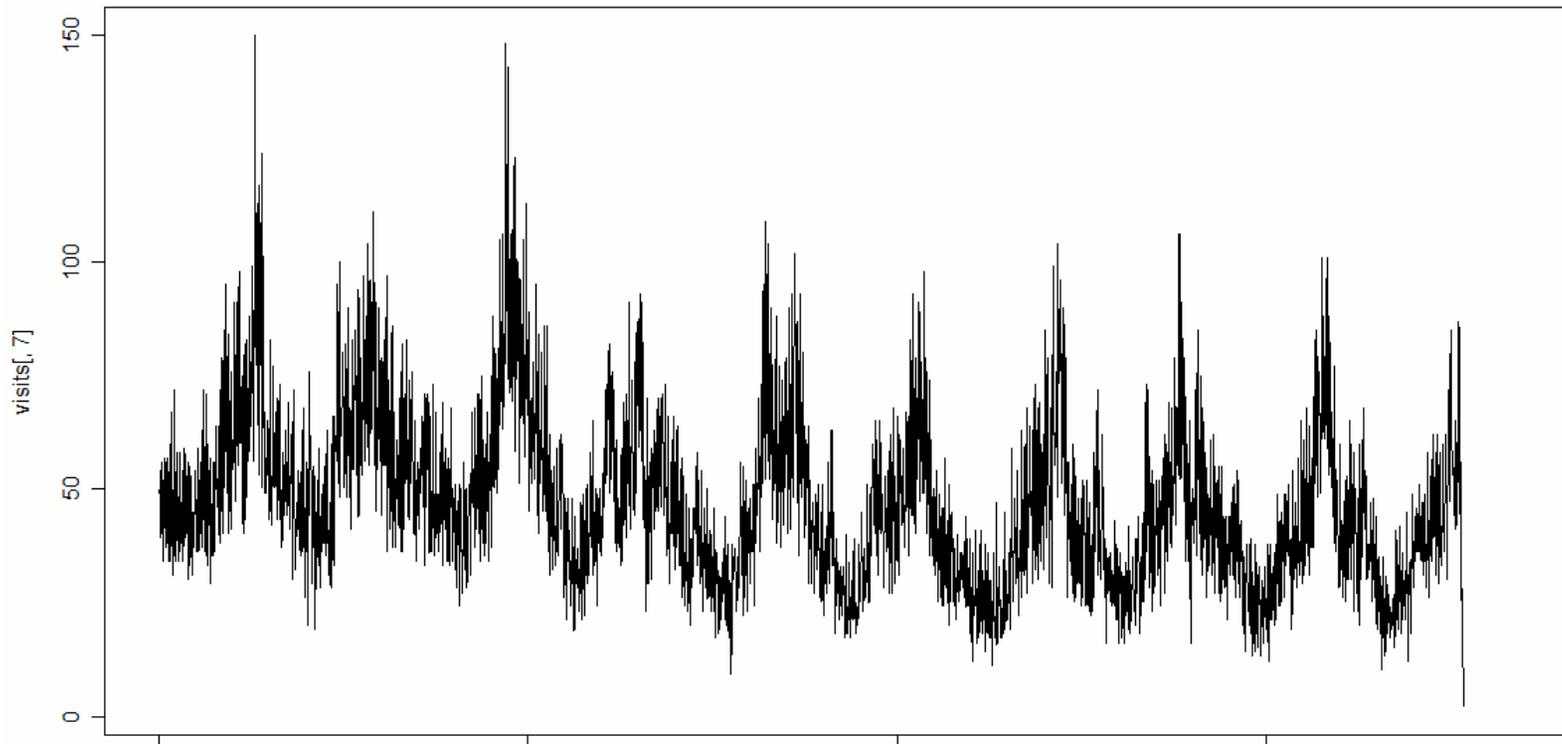
Help Logout



TEMPORAL HISTORICAL



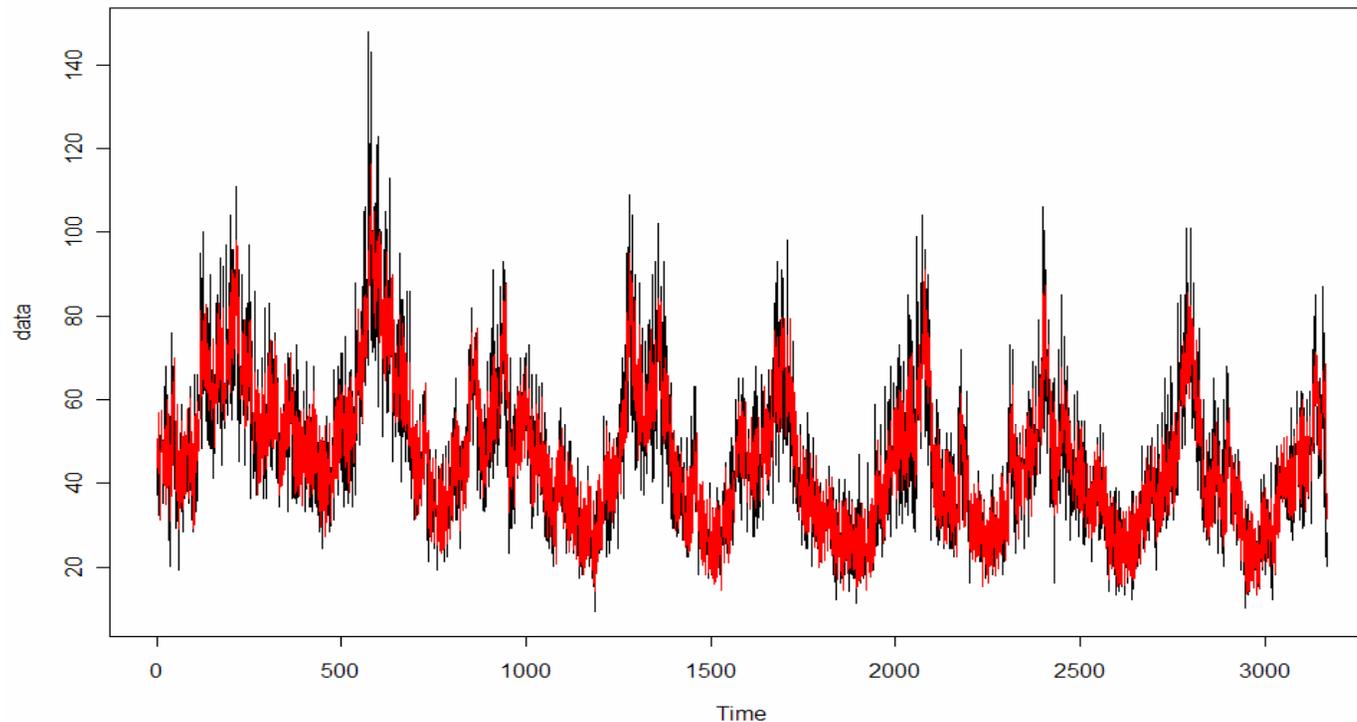
Observed data



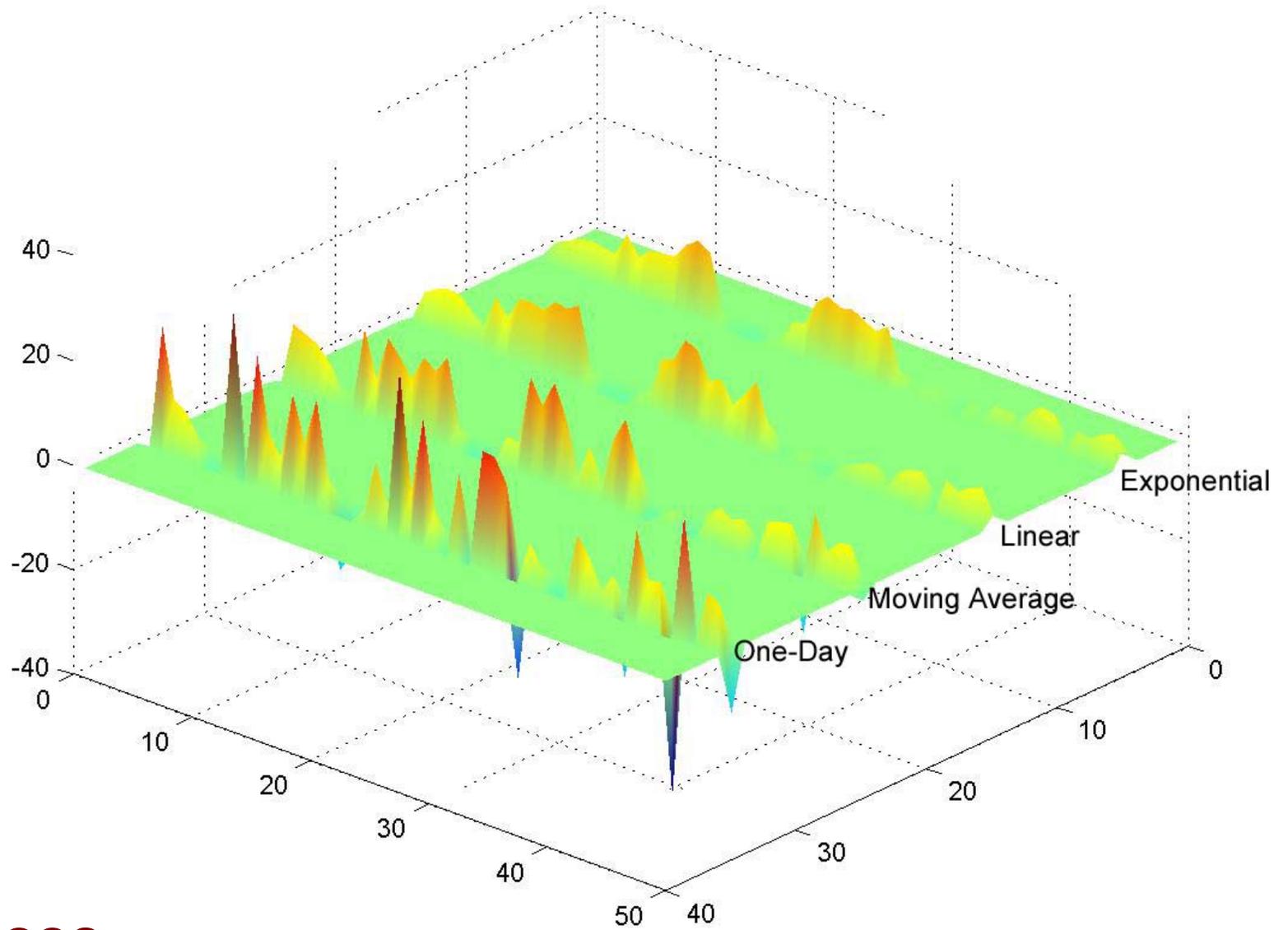
Daily counts of ED visits for respiratory syndromes from 1992 to 2002

The model forecast

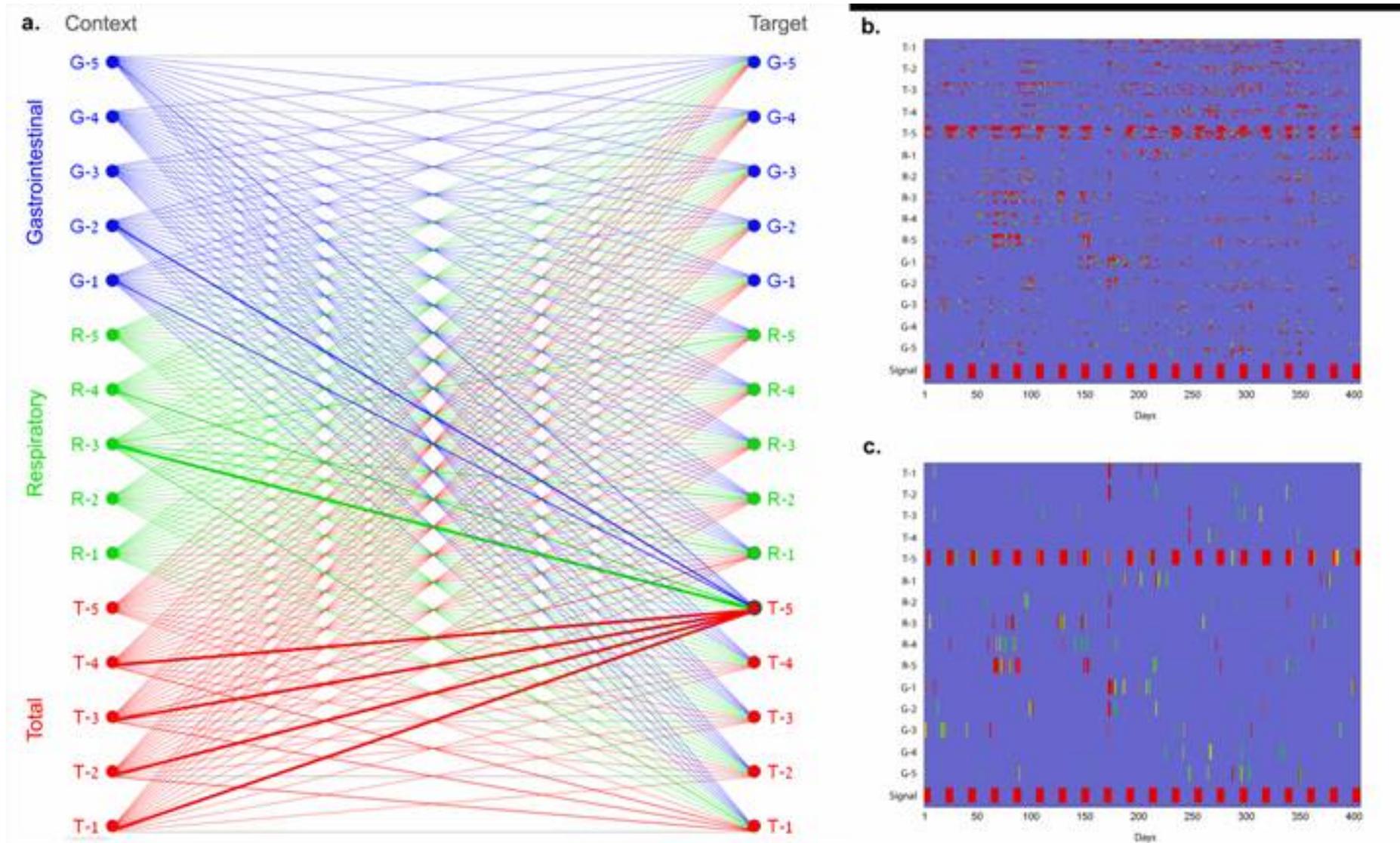
- Model with autoregressive components, seasonal trends, other trends, covariates

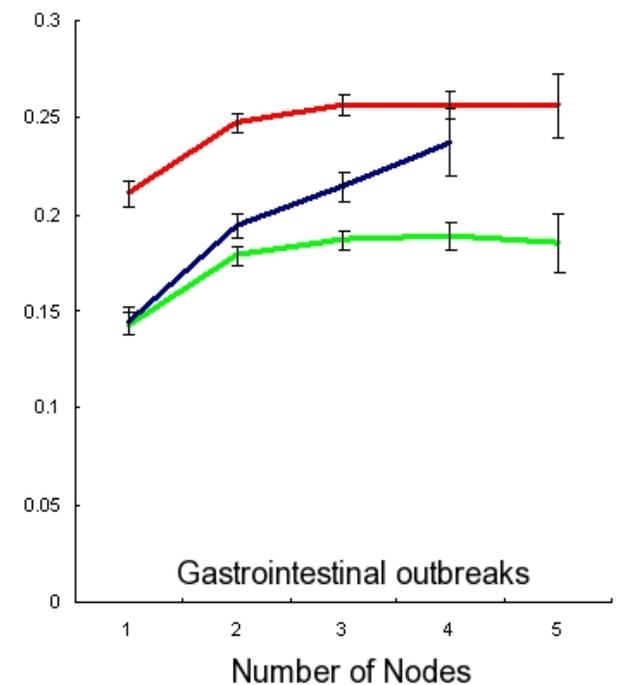
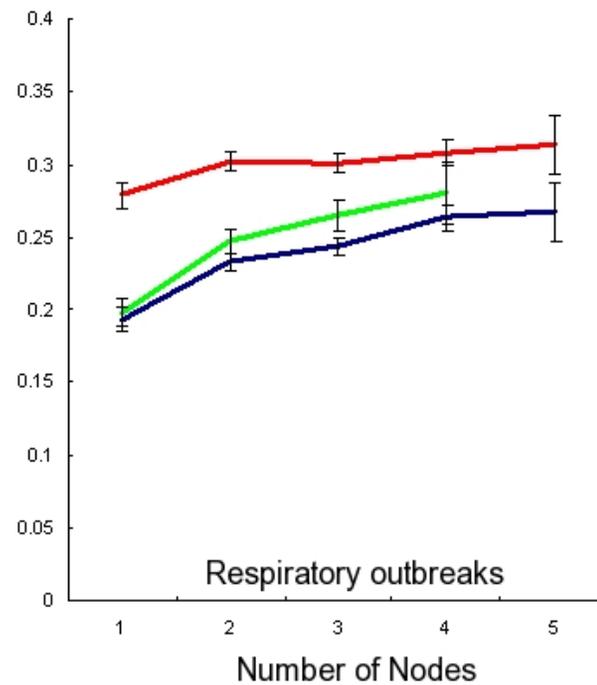
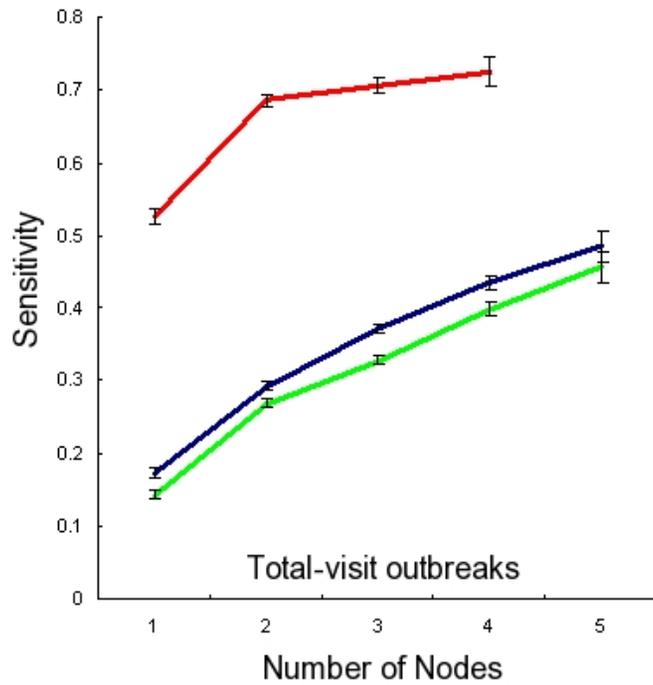


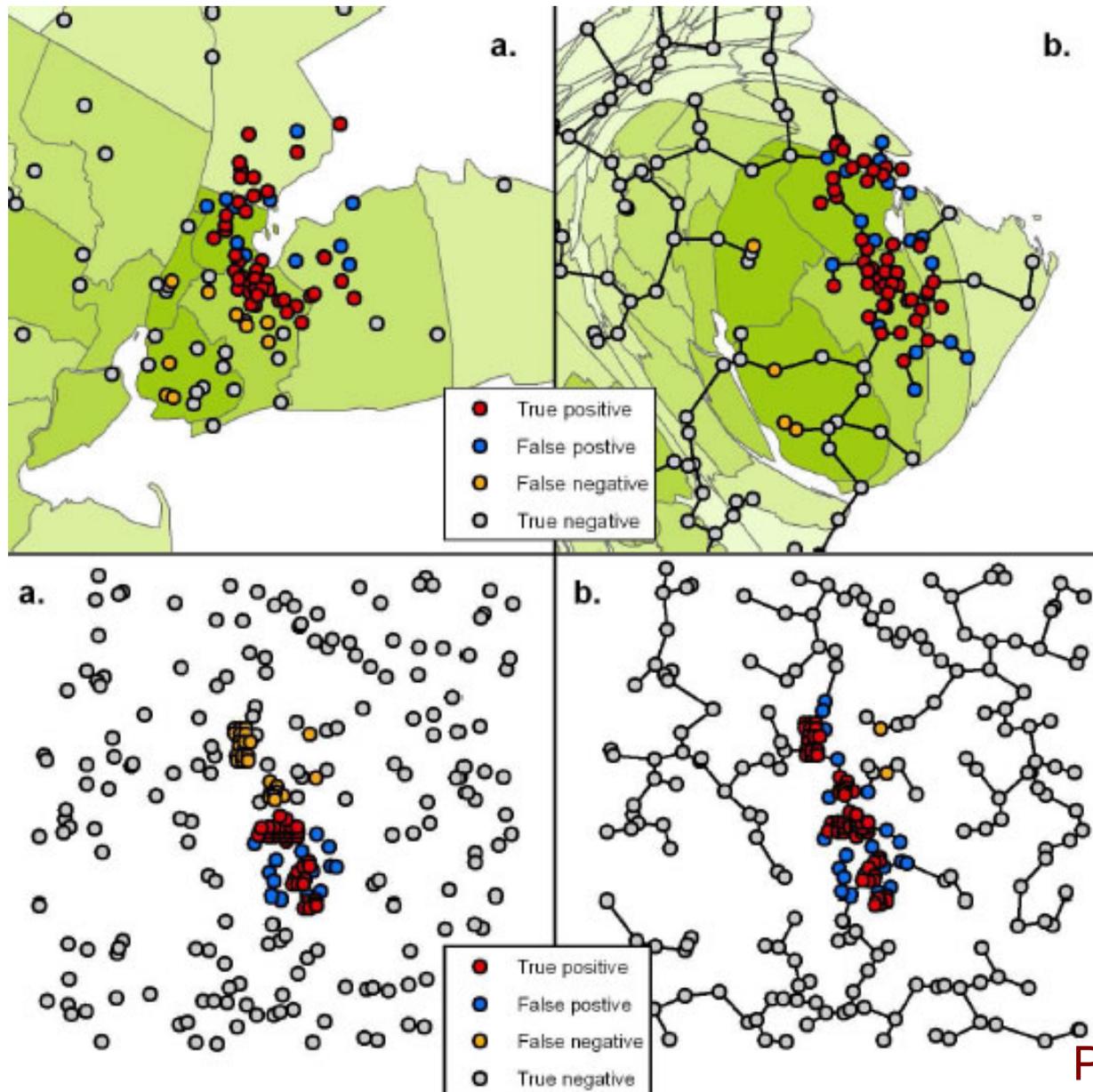
Reis 2003



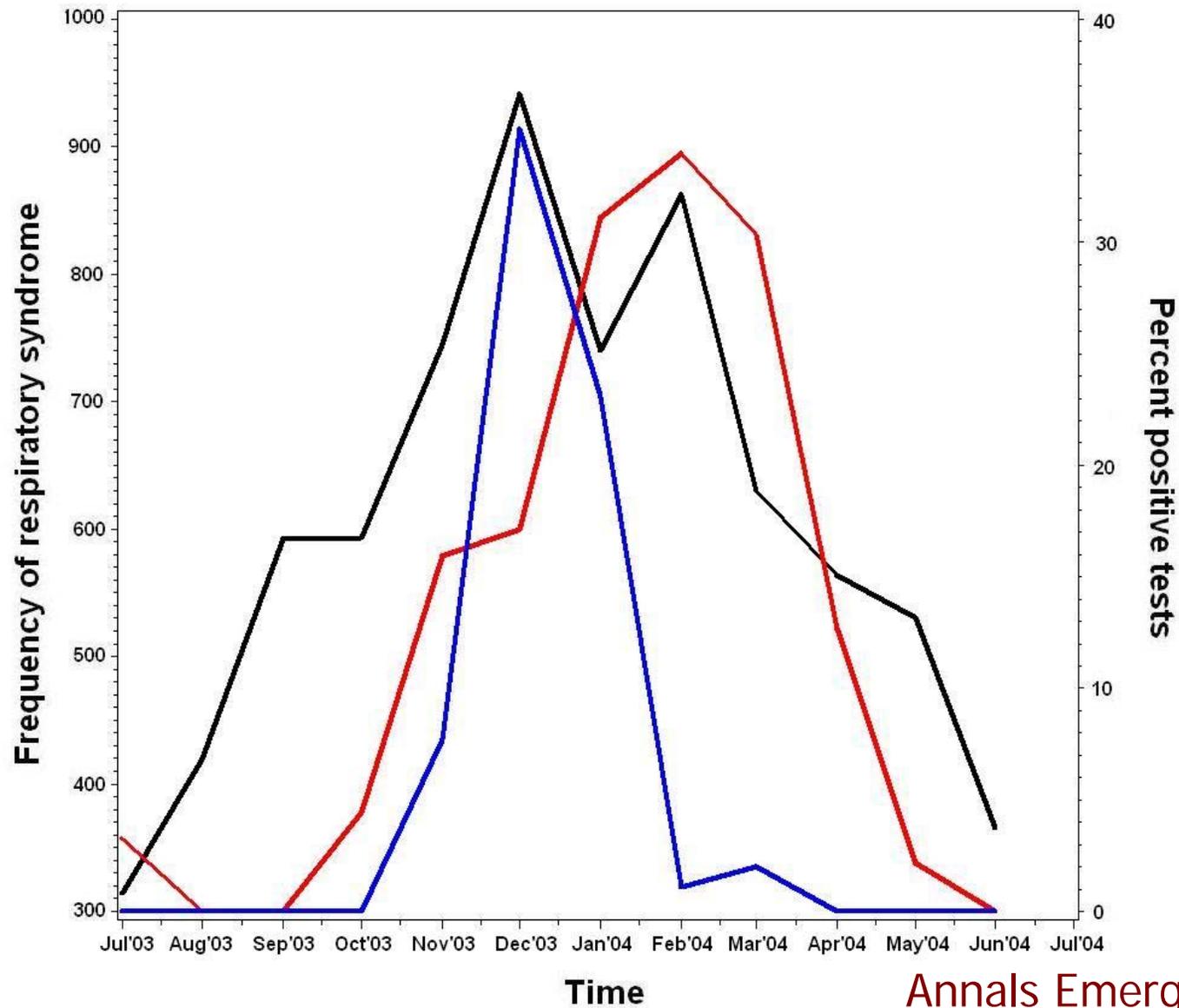
PNAS 2003







Biological validation



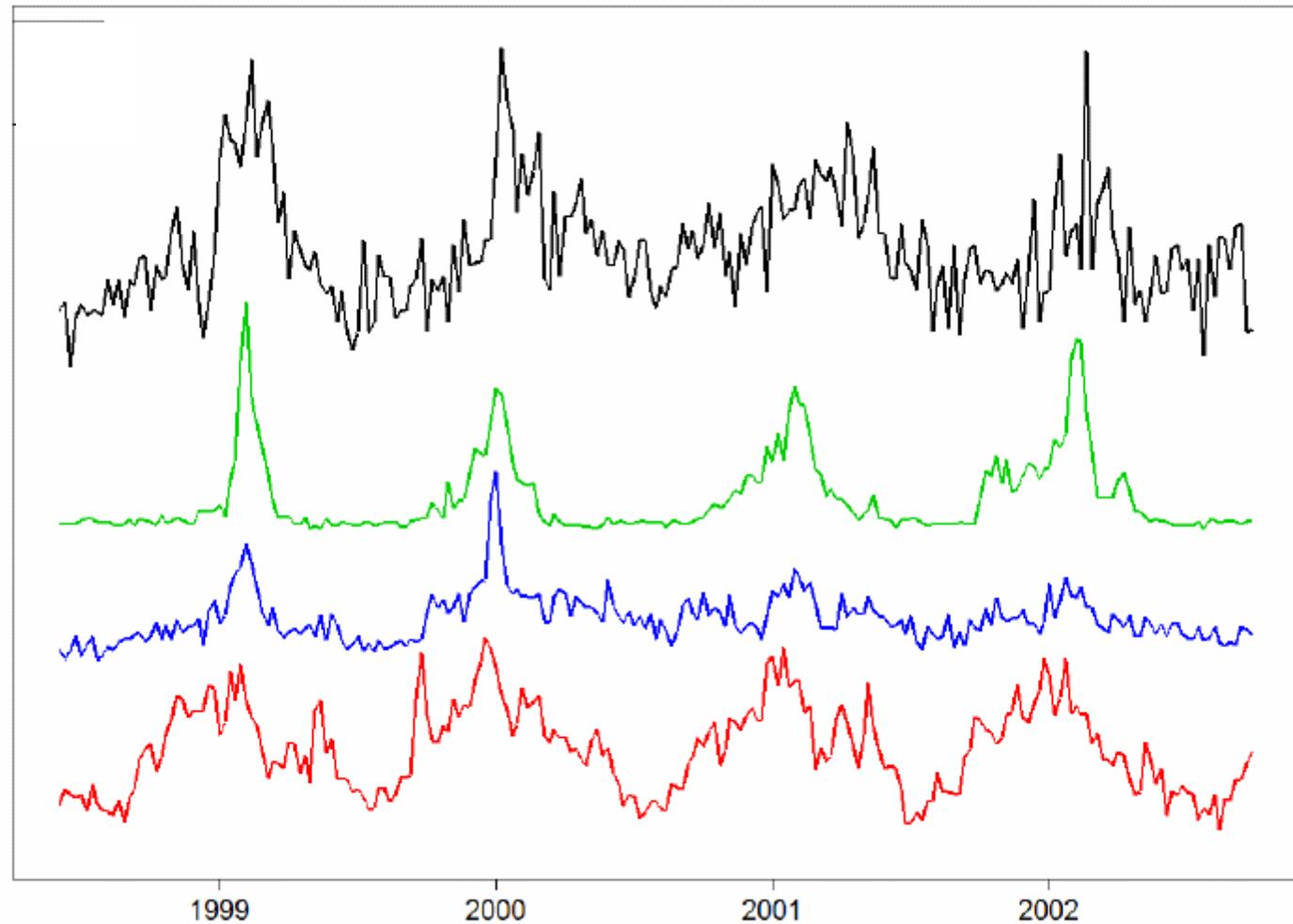
Age differences

**Pneumonia/
Influenza
Mortality
(CDC)**

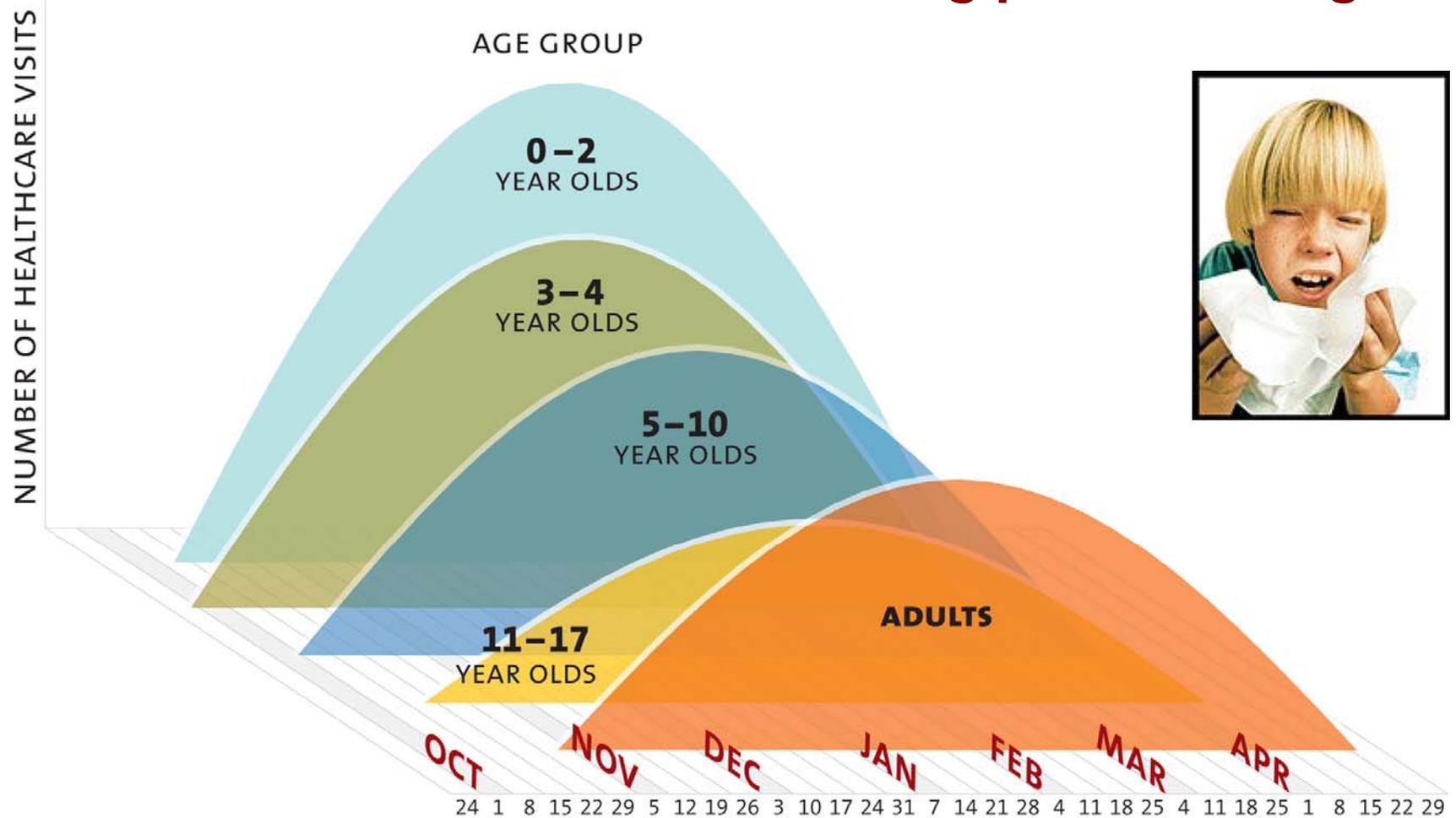
**Influenza
like illness
(CDC)**

Adult ED

Pediatric ED



Defining pediatric targets



EDITORIAL DESK

Influenza Vaccine for Children

(NYT) 261 words

Published: February 25, 2006

The nation's top advisers on vaccine policy have taken a wise if timid step in recommending that all children from 2 to 5 years old be vaccinated against influenza every year, along with their parents, siblings and caregivers. This

The nation's top advisers on vaccine policy have taken a wise if timid step in recommending that all children from 2 to 5 years old be vaccinated against influenza every year, along with their parents, siblings and caregivers.

Any mother or father can endorse the wisdom of vaccinating young children -- not just to protect the youngsters, but also to prevent them from infecting the rest of the household with bugs picked up at preschools or on neighborhood play dates. Expanding vaccinations for children could help, at least in a small way, to reduce the burden of influenza in the community.

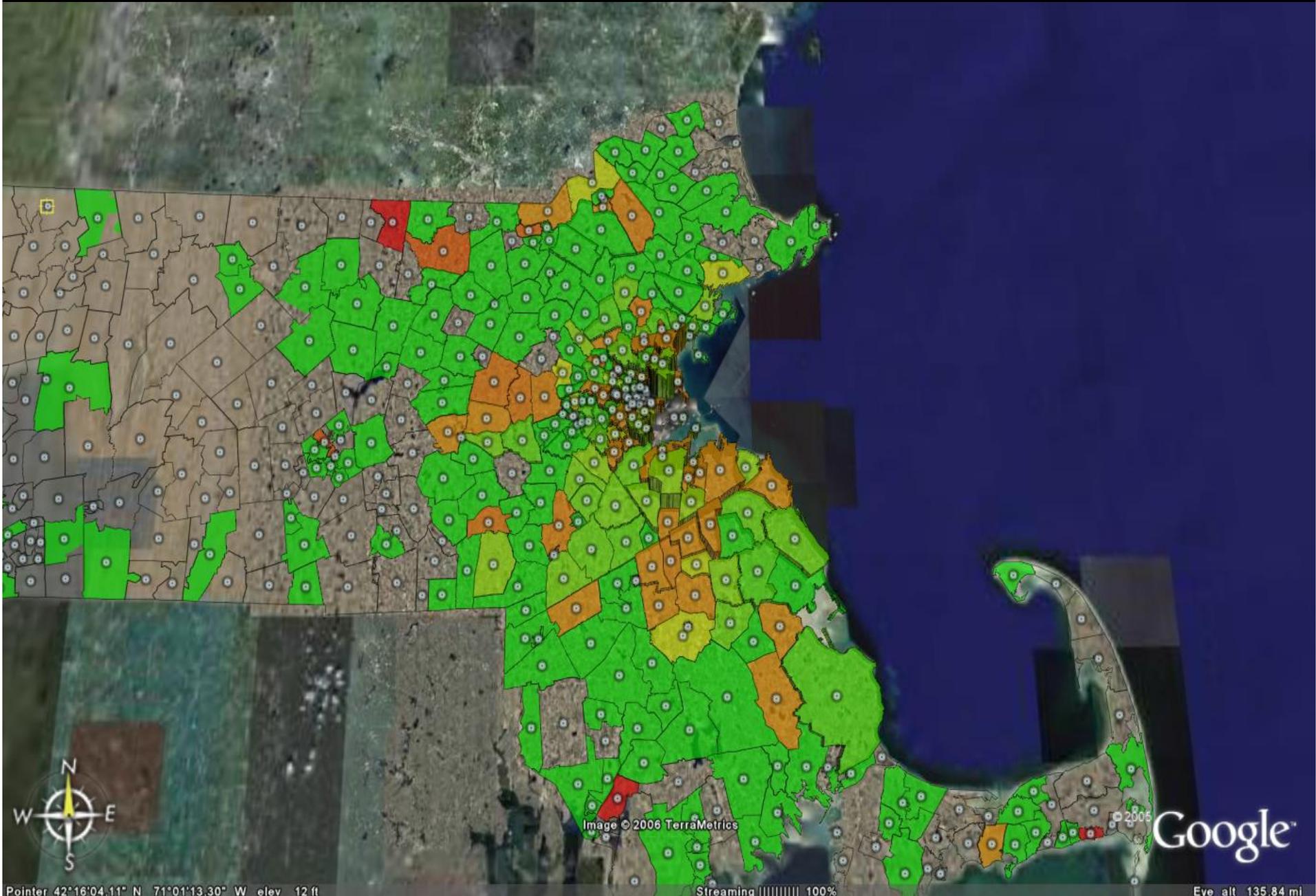
Our only qualm is to wonder whether even more children should be vaccinated to protect us all from the flu bugs circulating in elementary, middle and high schools. The advisory committee seems to have limited its recommendation at least in part because of concerns that the troubled vaccine industry may not be able to meet a much higher demand. But in the long run, it would make sense to ramp up production capacity and vaccinate virtually everyone as a prelude to preparing for mass vaccinations should an influenza pandemic strike.



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Pointer 42°16'04.11" N 71°01'13.30" W elev 12 ft

Streaming ||||| 100%

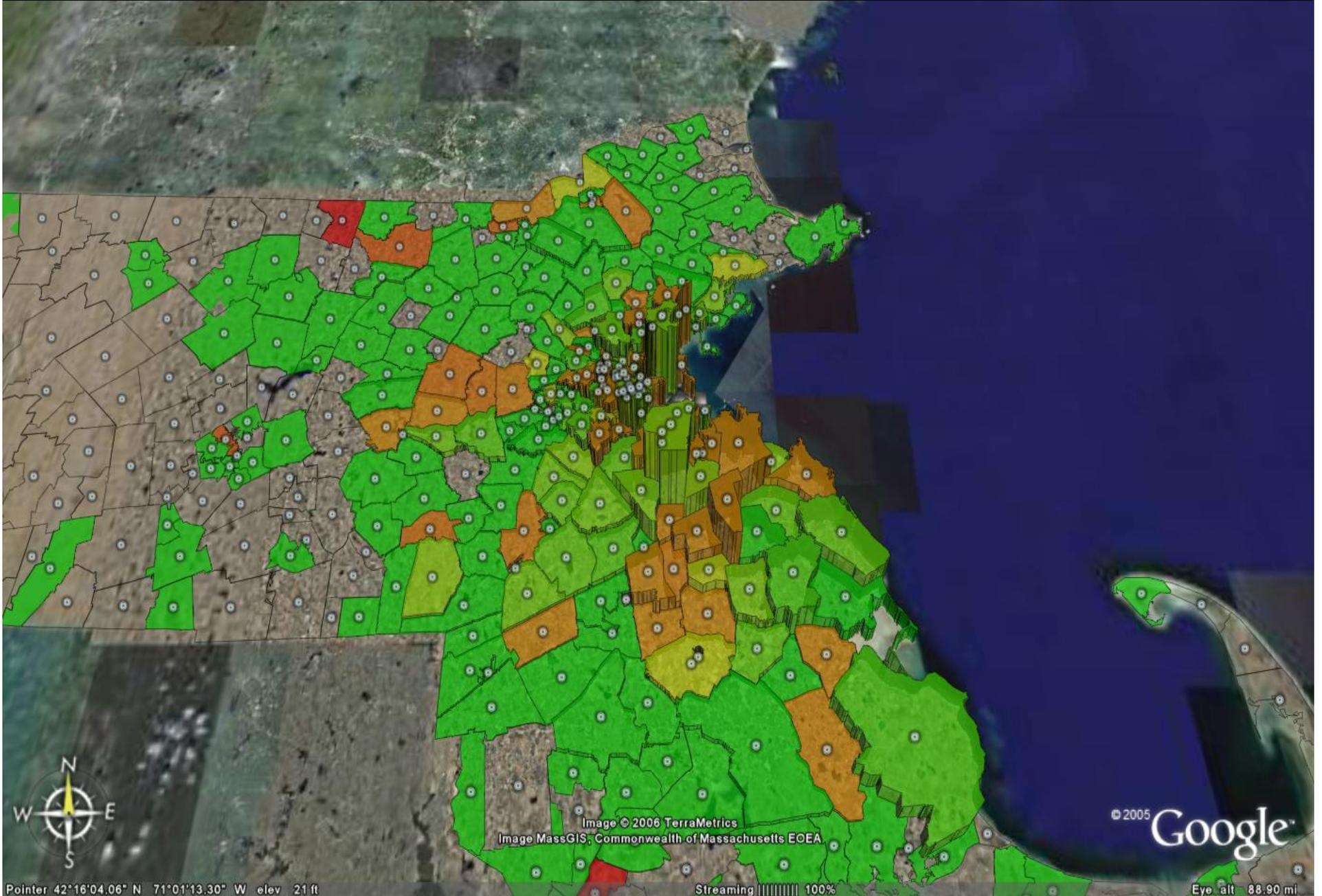
Eye alt 135.84 mi



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Streaming ||| 100%

Eye alt 88.90 mi



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Image © 2006 TerraMetrics
Image MassGIS, Commonwealth of Massachusetts EOEAA

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Pointer 42°16'04.05" N 71°01'13.30" W elev 21 ft

Streaming ||||| 100%

Eye alt 65.41 mi



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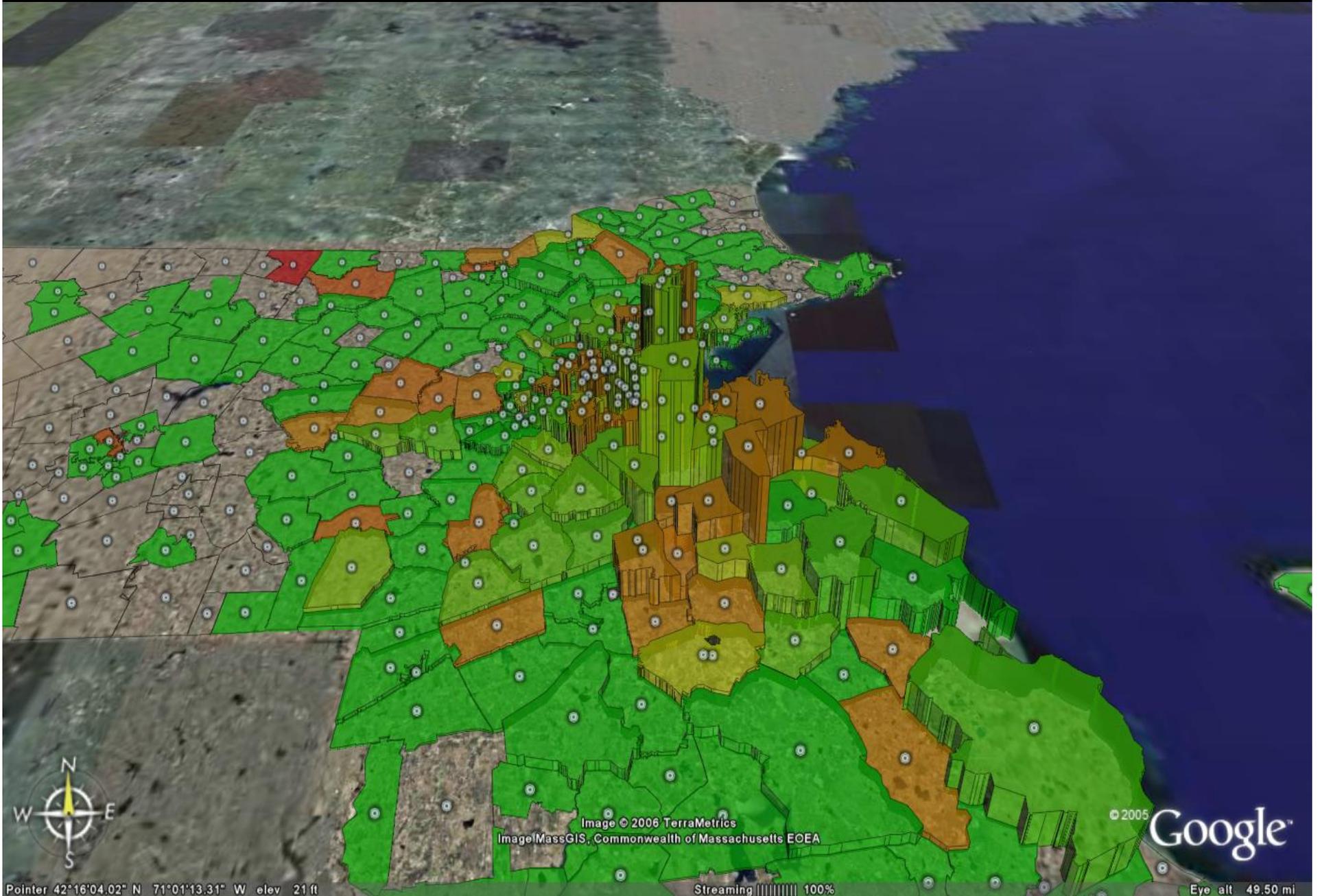


Image © 2006 TerraMetrics
Image/MassGIS, Commonwealth of Massachusetts EOEA

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Pointer 42°16'04.02" N 71°01'13.31" W elev 21 ft

Streaming ||||| 100%

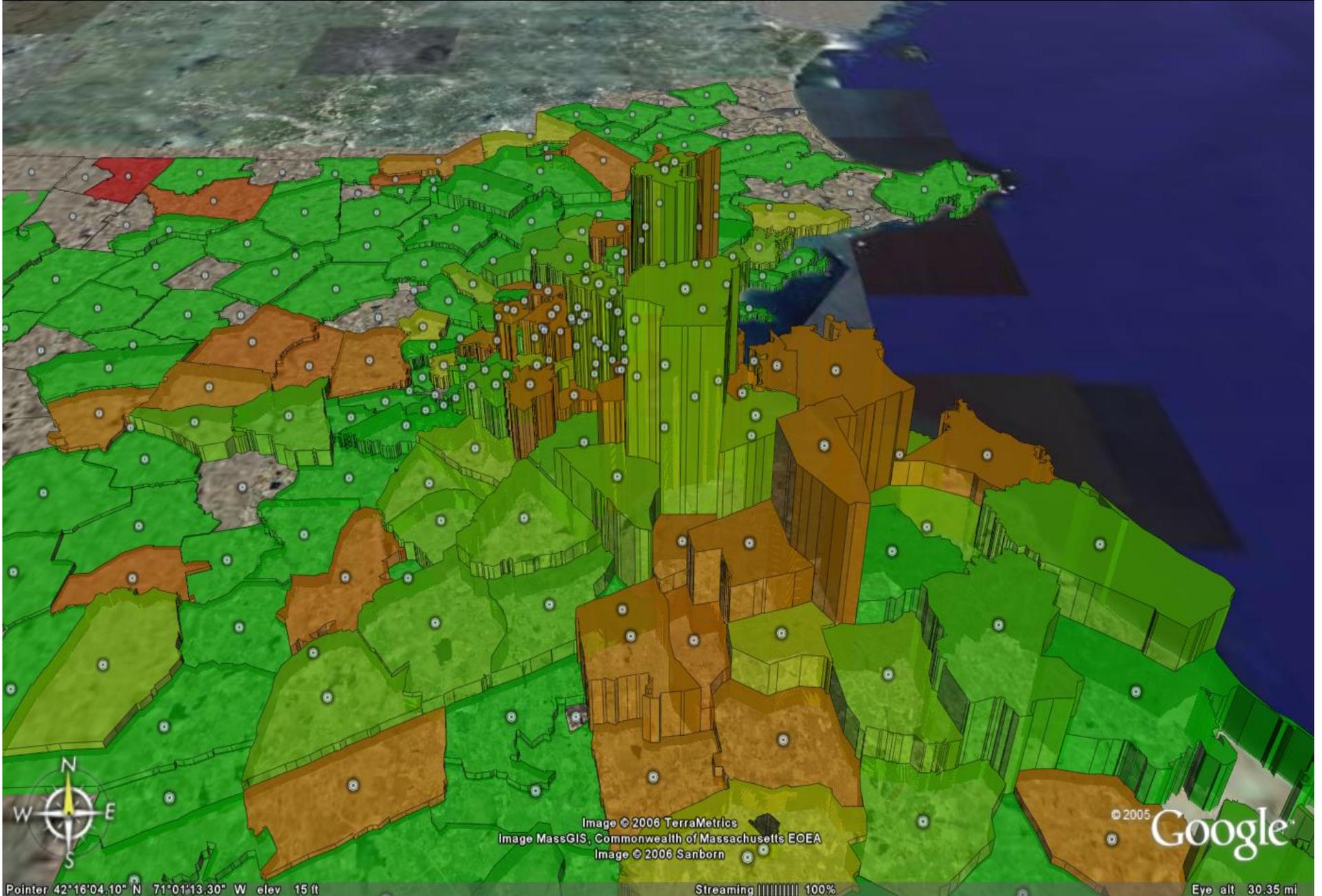
Eye alt 49.50 mi



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Pointer 42°16'04.10" N 71°01'13.30" W elev 15 ft

Image © 2006 TerraMetrics
Image MassGIS, Commonwealth of Massachusetts EOE
Image © 2006 Sanborn

Streaming ||||| 100%

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Eye alt 30.35 mi



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Image © 2006 TerraMetrics
Image MassGIS, Commonwealth of Massachusetts EOEA

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Pointer 42°16'03.90" N 70°59'26.66" W elev 6 ft

Streaming ||||| 100%

Eye alt 18.27 mi



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Pointer 42°16'03.90" N 70°59'26.66" W elev 6 ft

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Image MassGIS, Commonwealth of Massachusetts EOE

Streaming ||||| 100%

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Eye alt 18.27 mi

HealthMap

Global disease alert map

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Harvard-MIT Division of Health Sciences & Technology
Language: [English](#) | [Español](#) | [About](#)

Feeds

- ProMED Mail
- World Health Organization
- EuroSurveillance
- Google News
- ProMED Español
- Google News Español

Diseases, last 30 days

- Select: [all](#), [none](#) [info](#)
- Foot and Mouth (893)
 - Influenza (101)
 - Avian Influenza (98)
 - Legionnaires' (64)
 - E. coli (63)
 - Other Animal Disease (52)
 - Dengue Fever (49)
 - Cholera (48)
 - Marburg Fever (42)
 - Not Yet Classified (36)
 - Swine Fever (33)

Alerts by country

- Zoom to country:
- [United Kingdom \(924\)](#)
 - [United States \(174\)](#)
 - [Australia \(105\)](#)
 - [India \(60\)](#)
 - [Spain \(58\)](#)
 - [Canada \(44\)](#)
 - [Uganda \(41\)](#)
 - [China \(32\)](#)
 - [Indonesia \(29\)](#)
 - [Japan \(24\)](#)

Latest alerts

- [Betting agency losses mount due to equine flu outbreak - Radio New Zealand](#)
- [\[Cholera\] Mueren 70 personas en India por epidemia de cólera - La Jornada ...](#)
- [Australian equine influenza outbreak worries southern industry - The Southland ...](#)
- [PRO/EDR> Influenza activity, southern hemisphere](#)
- [Ill-timed outbreak breeds concern - Melbourne Herald Sun](#)
- [Owners shift blame for Equine flu](#)

Zoom to: [N. America](#) [S. America](#) [Europe](#) [Africa](#) [Mideast](#) [Asia](#) [Australia](#) [World](#)

[Full Screen](#)

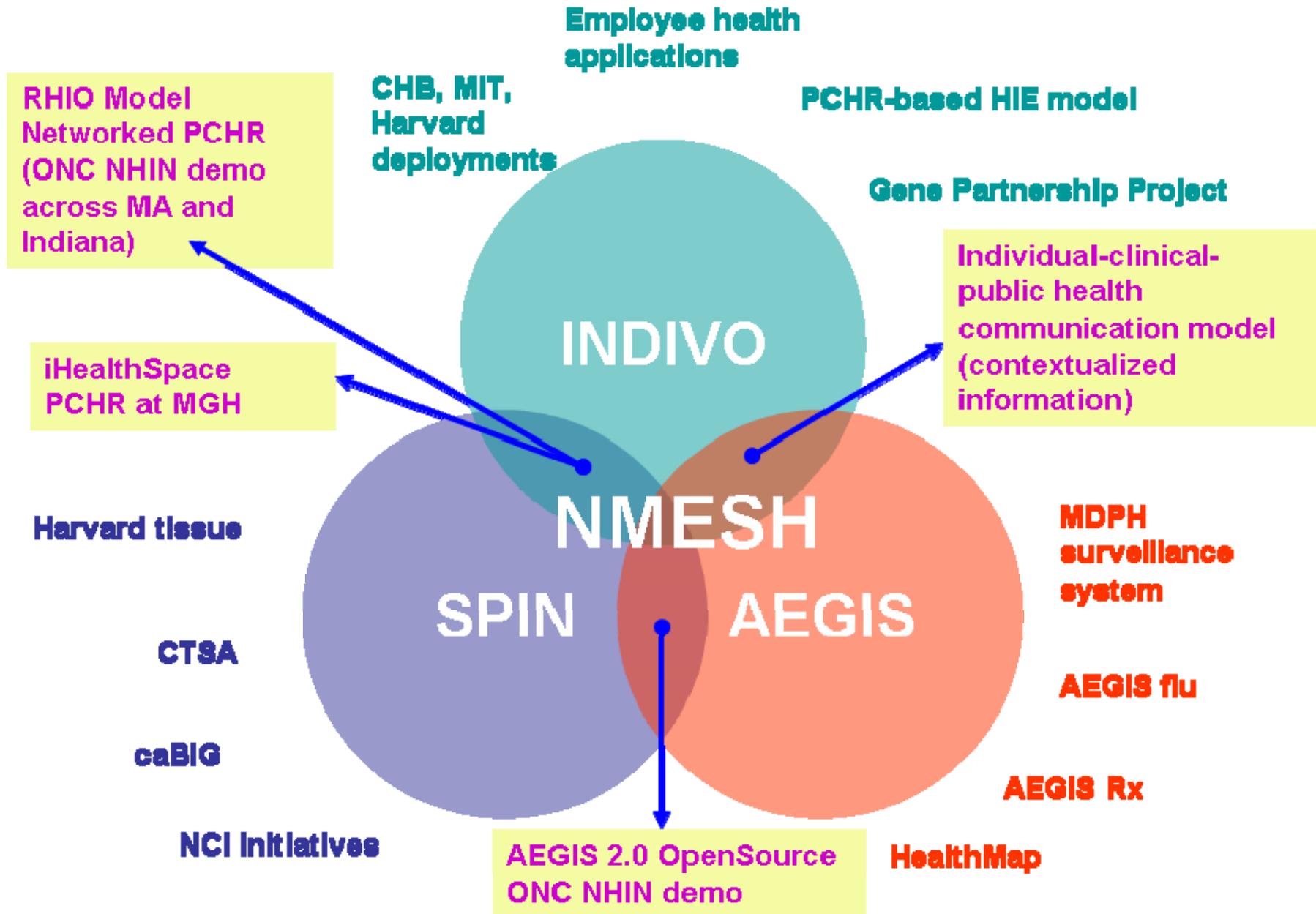


POWERED BY Google
Date range: 28 Jul - 26 Aug
[Map controls]

Country level | Province or local level | Heat Index: Low High [More info...](#)

Last update: 26 Aug 2007 17:07 | Next update: 26 Aug 2007 18:07

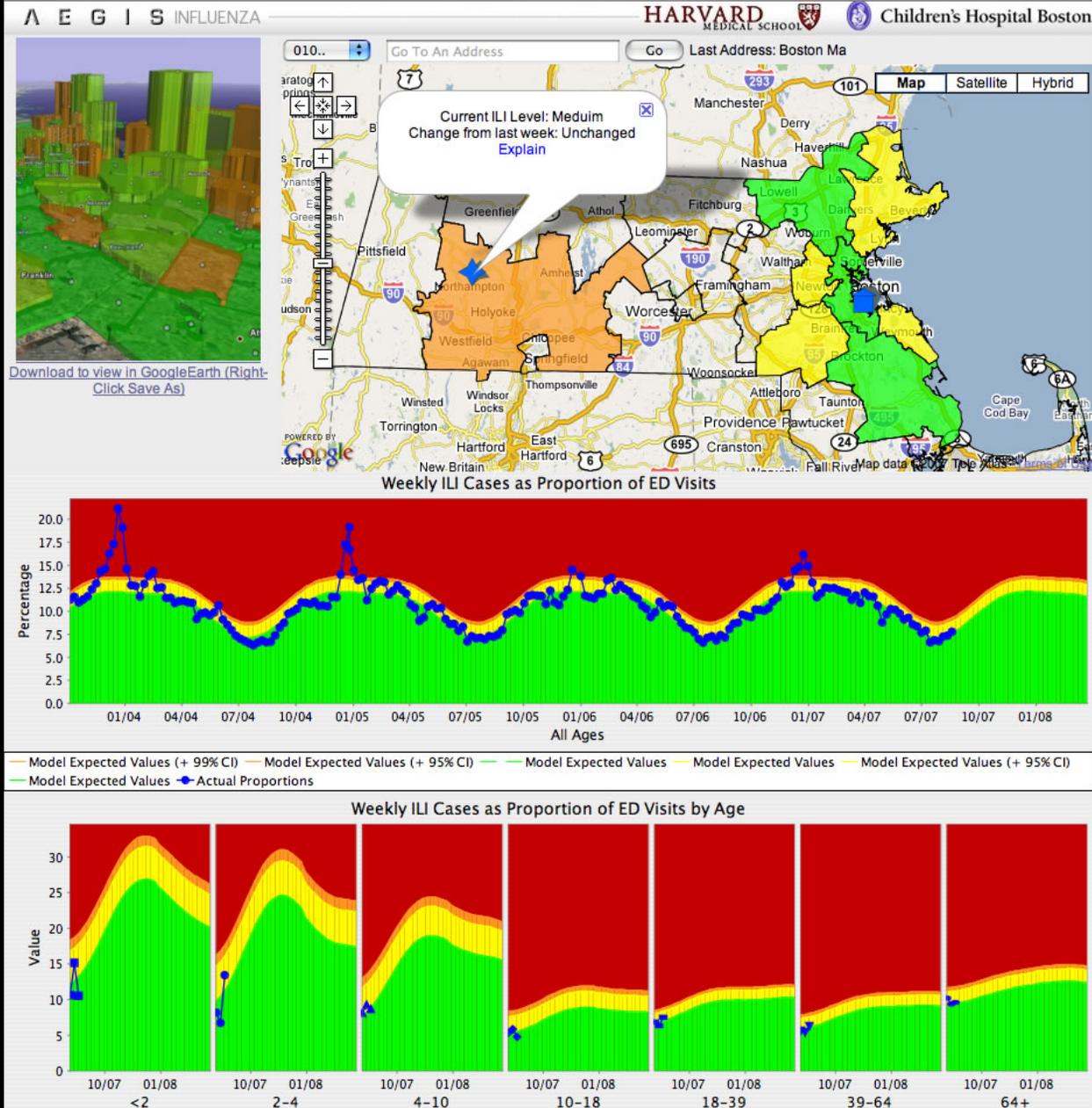
Enter your email address to sign up for our low-volume announcements list:

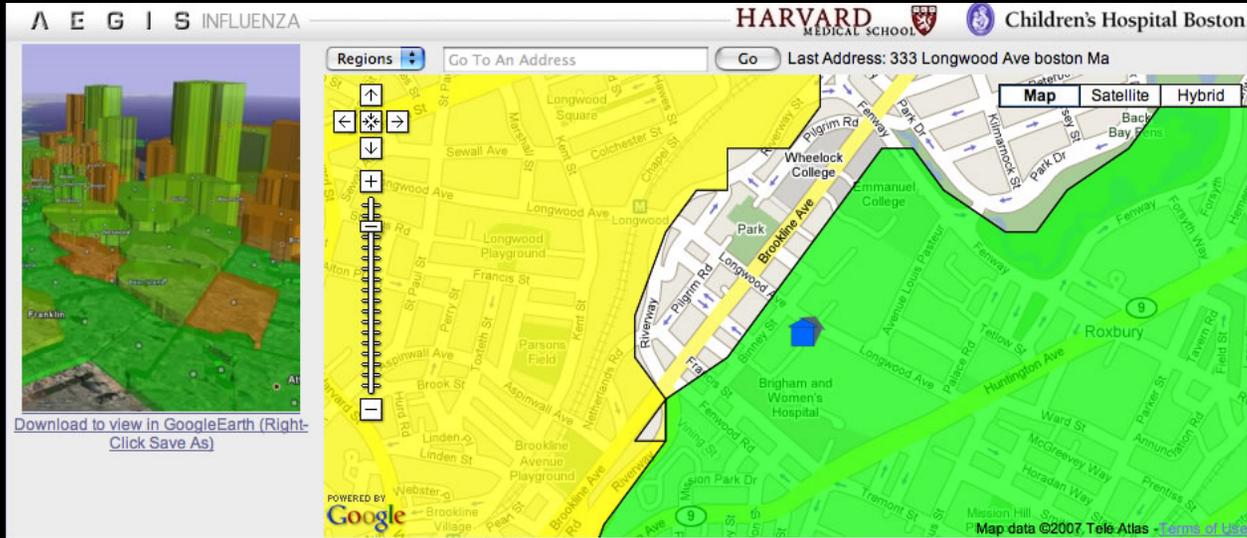




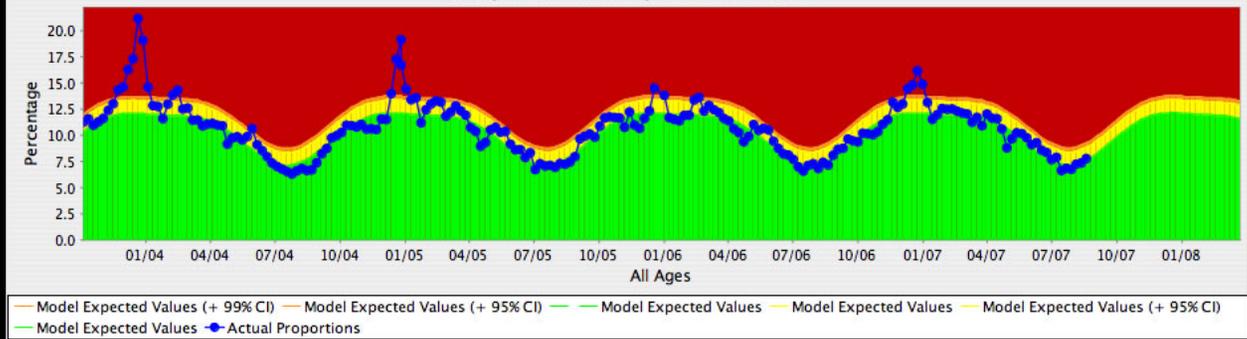
NMESH Integrative Products

1. Contextualized Risk
2. Self-scaling NHIN-biosurveillance example
3. Networked PCHR

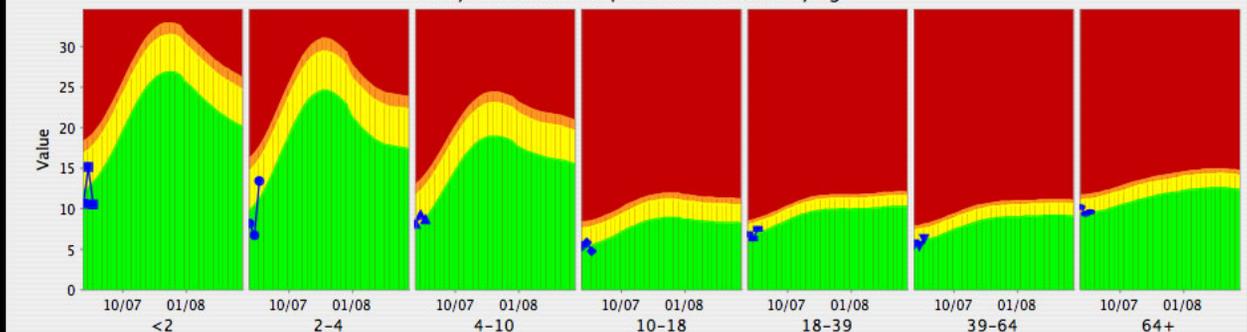




Weekly ILI Cases as Proportion of ED Visits



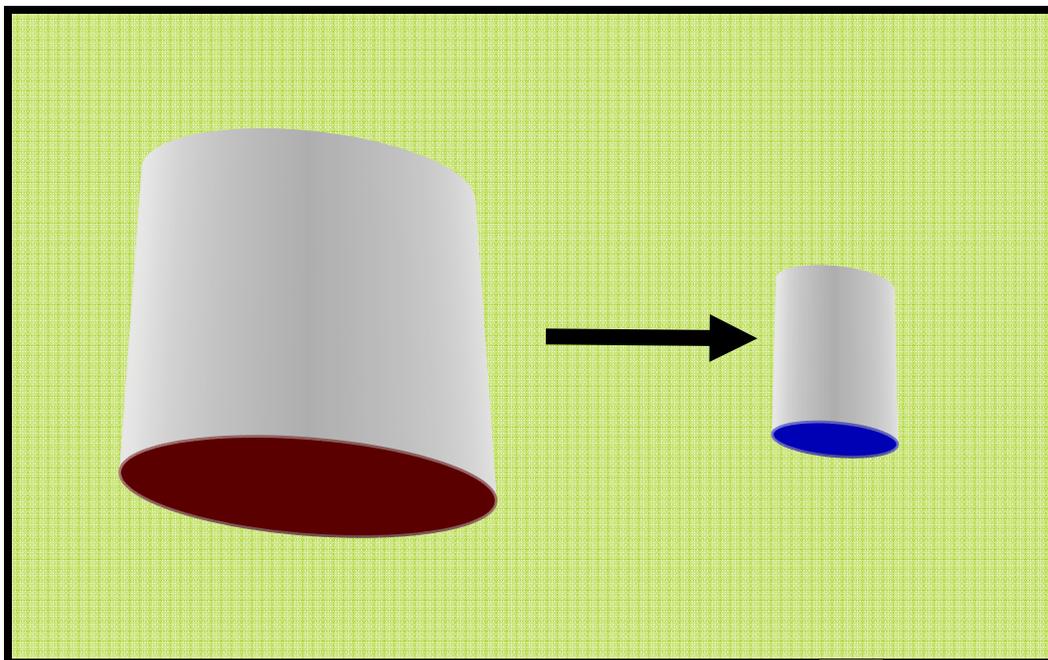
Weekly ILI Cases as Proportion of ED Visits by Age

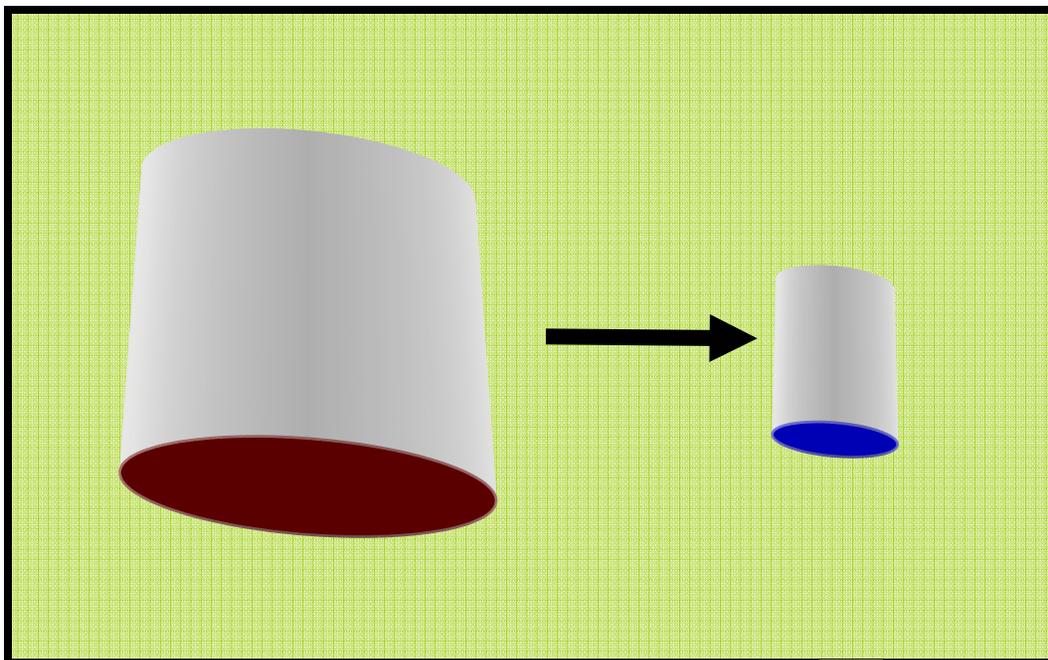


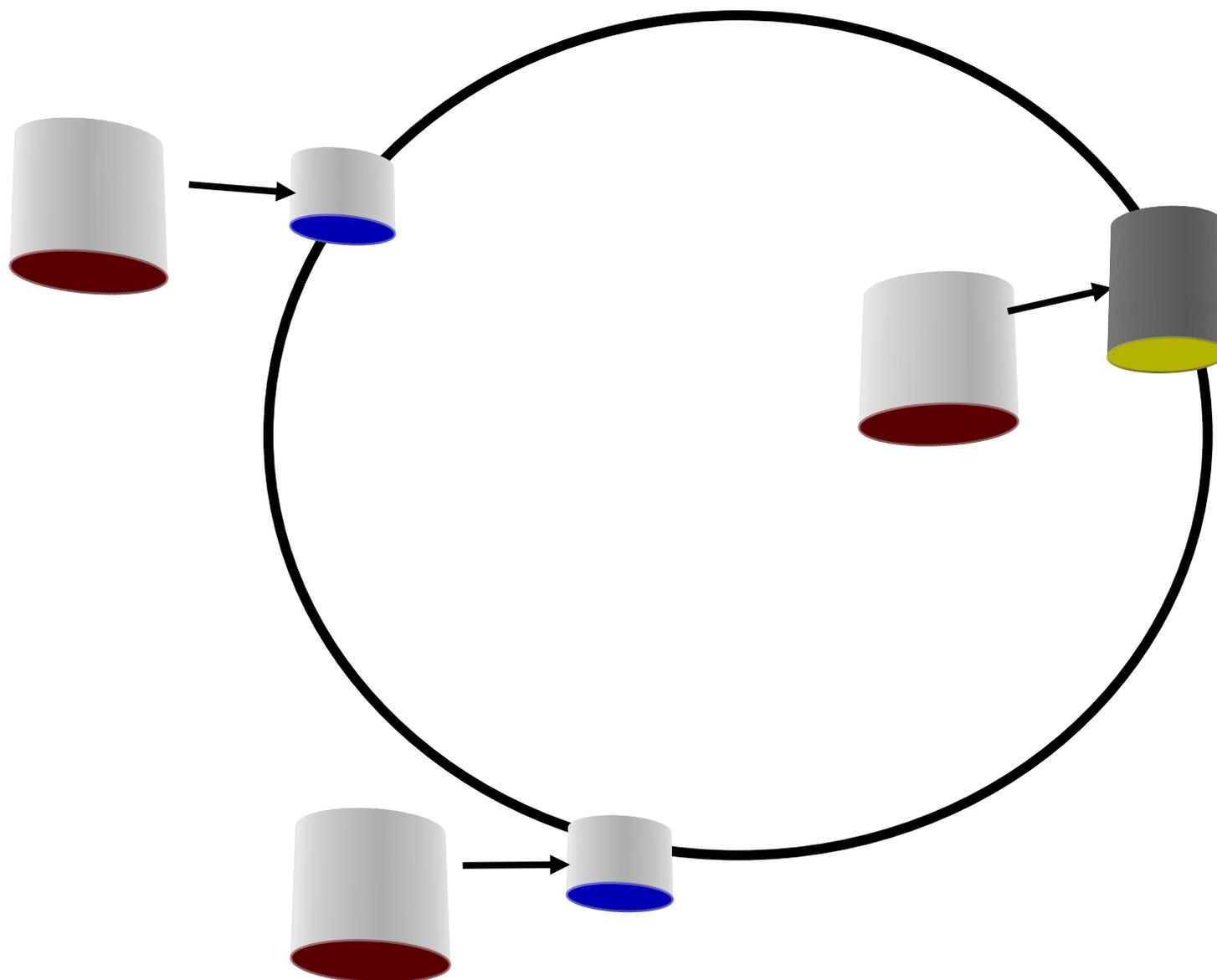


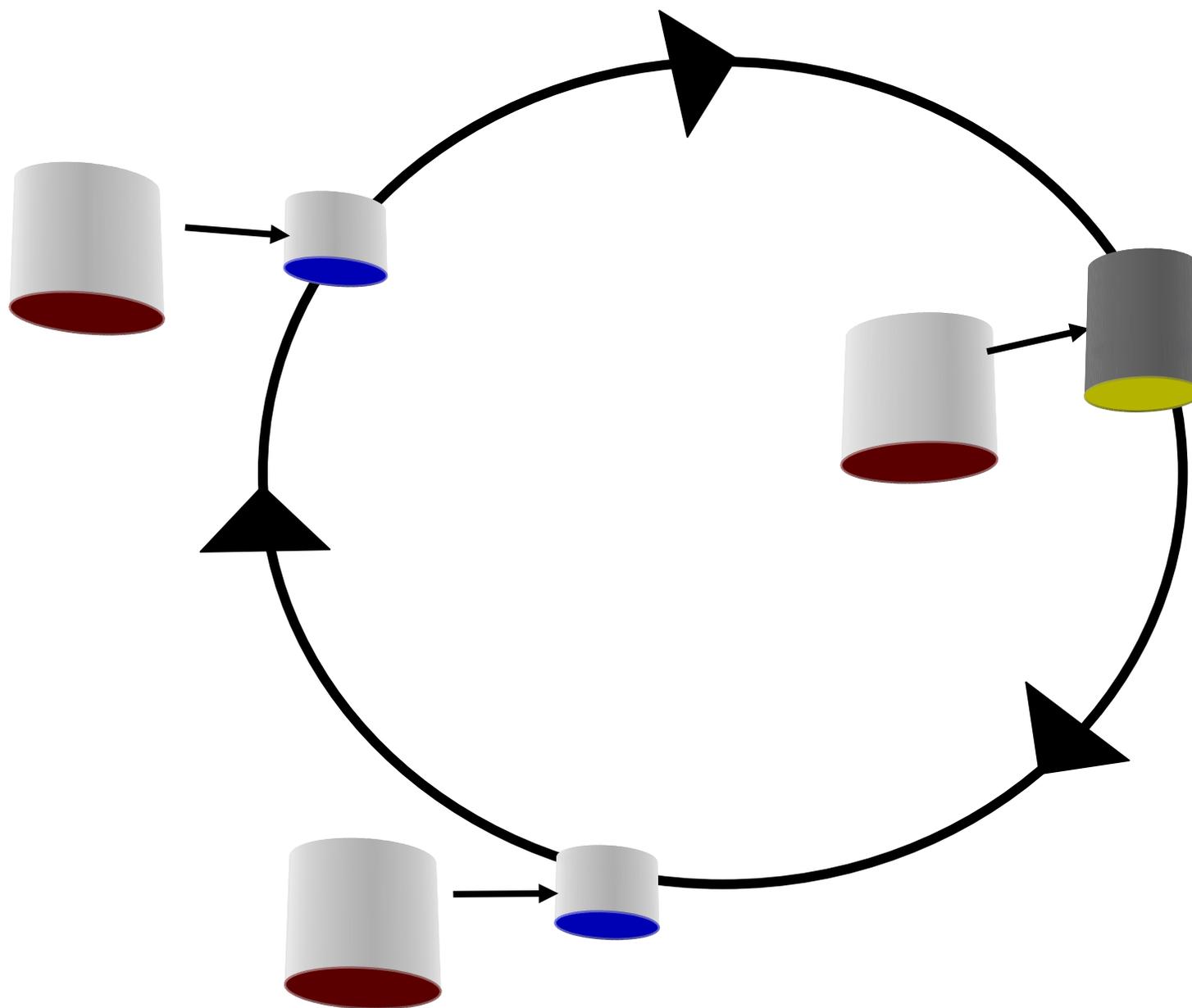
Approach to National Health Information Network

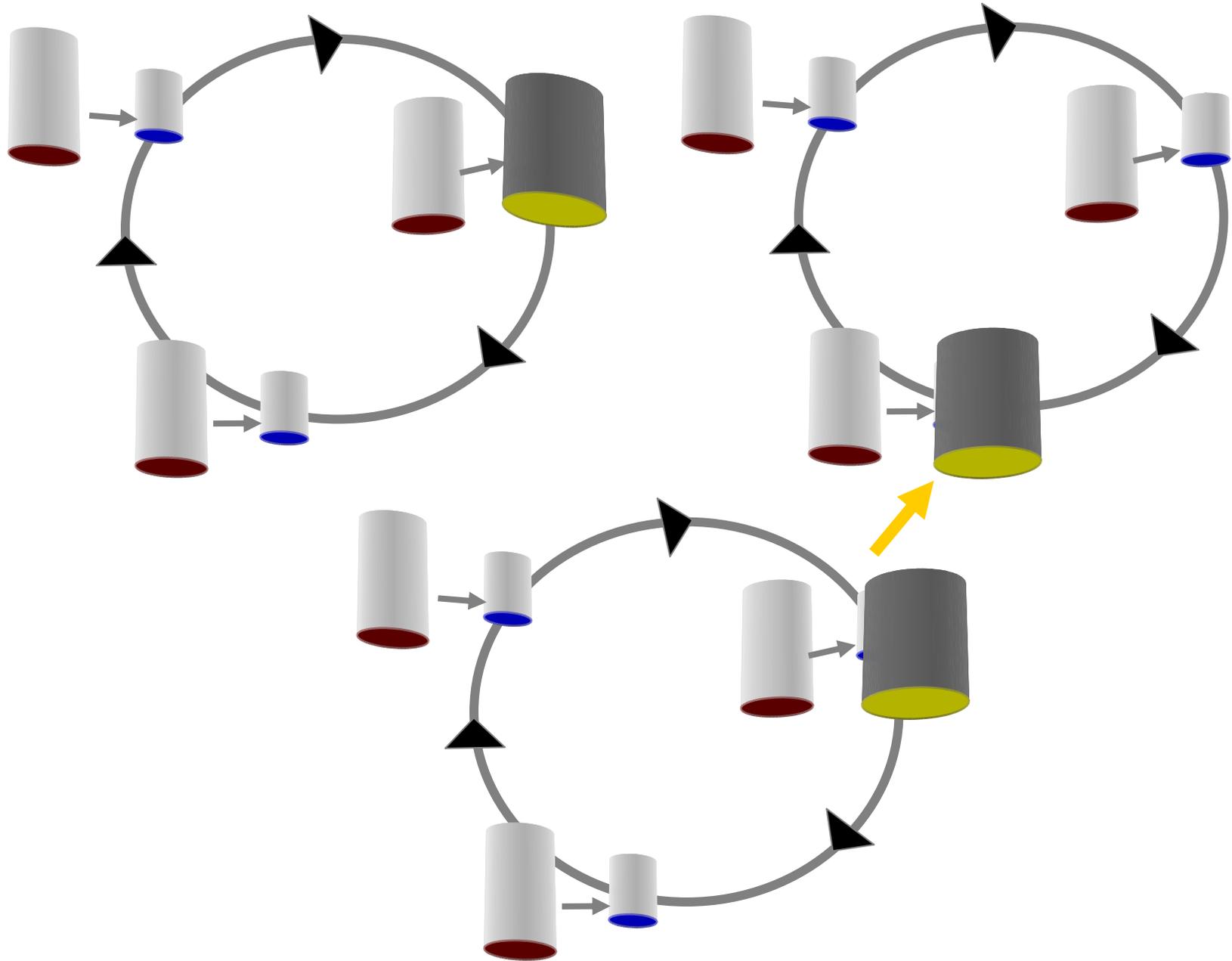
- Self-scaling architecture--encourage voluntary regional collaborations that coalesce to form a nationwide network.
 - ✓ distributed approach
 - ✓ enable strong institutional autonomy
 - ✓ transparency to ensure patient trust
 - ✓ variable levels of identifiable information
 - ✓ variable access levels of access

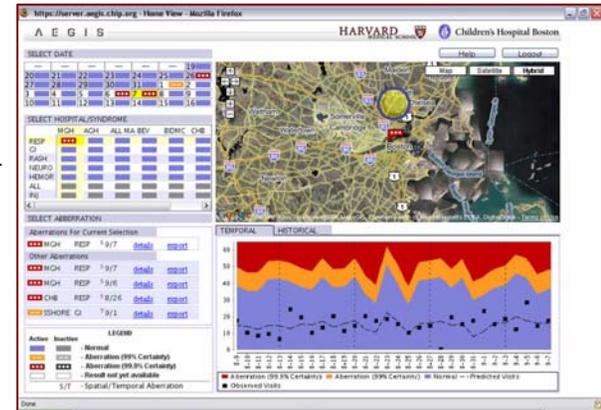
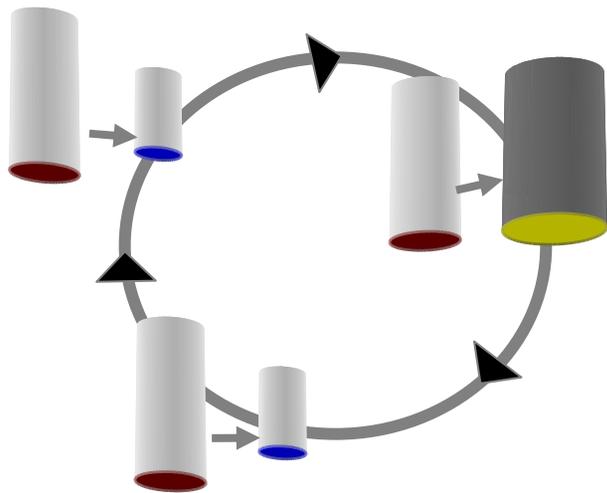
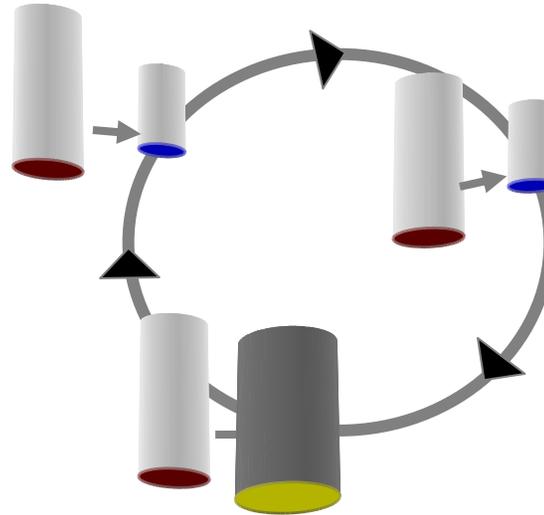
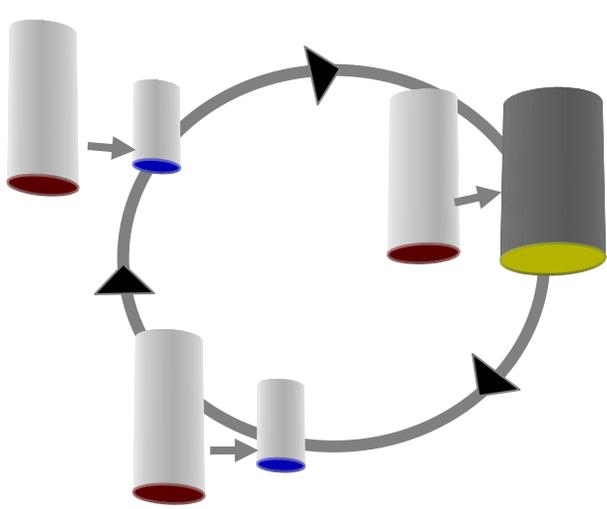




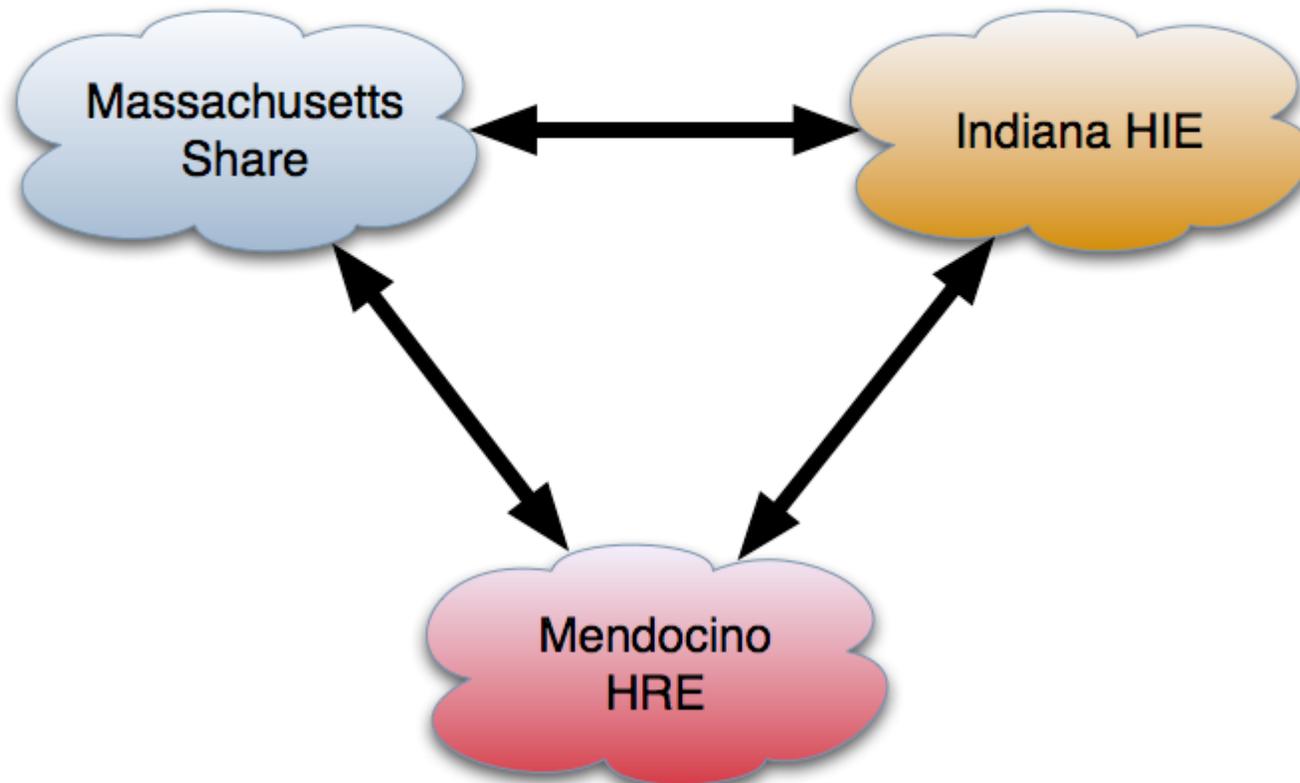


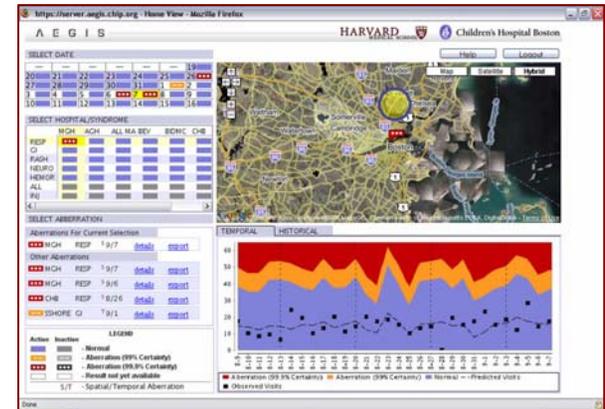
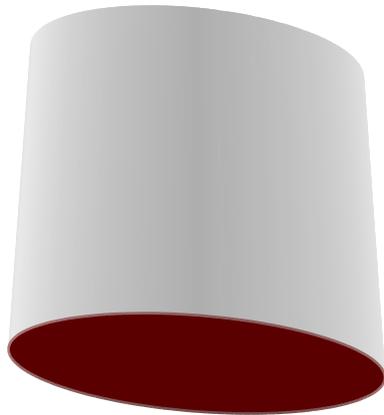




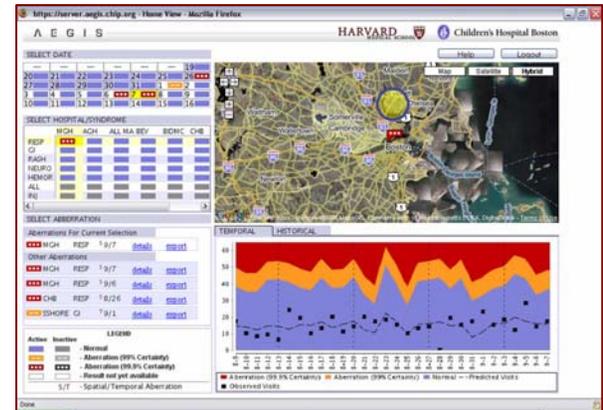
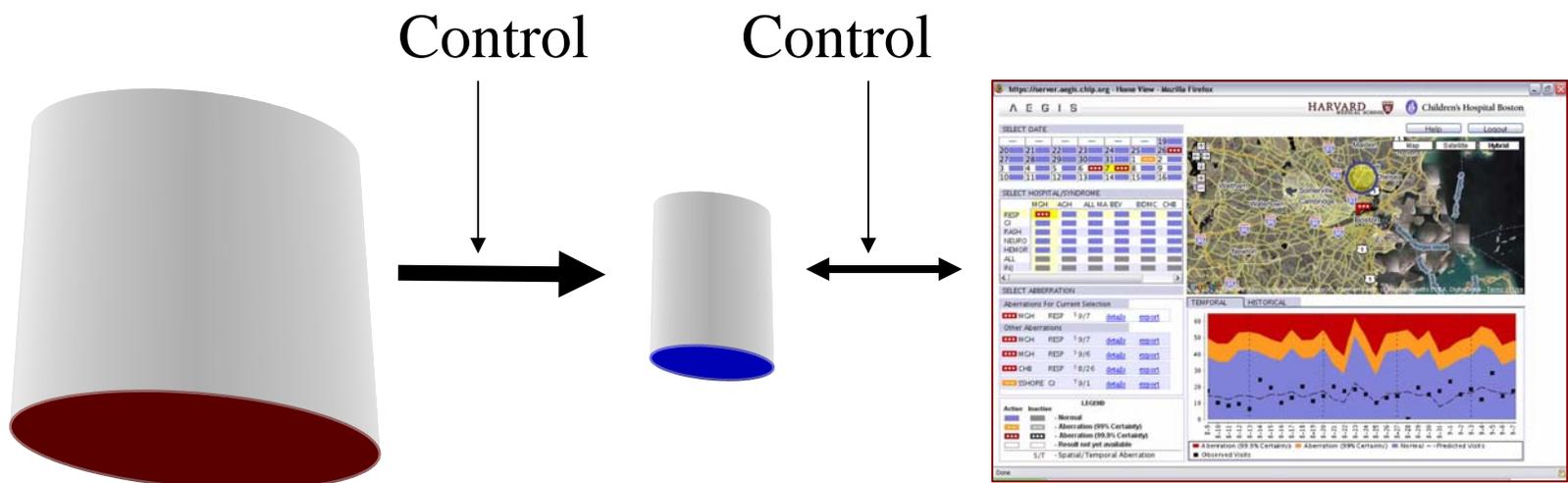


Linked regions—in practice

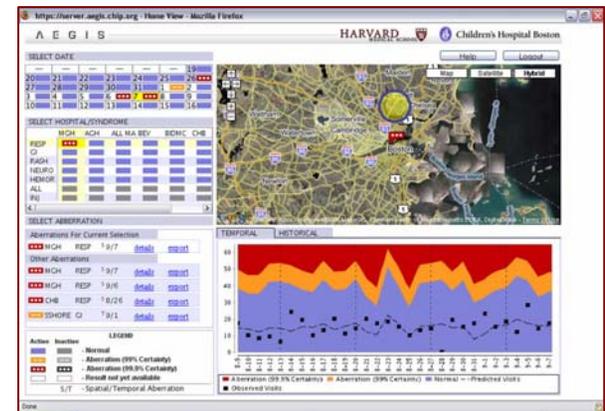
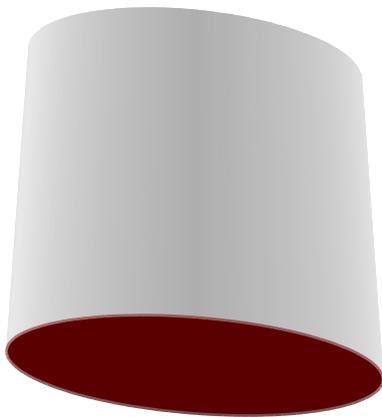




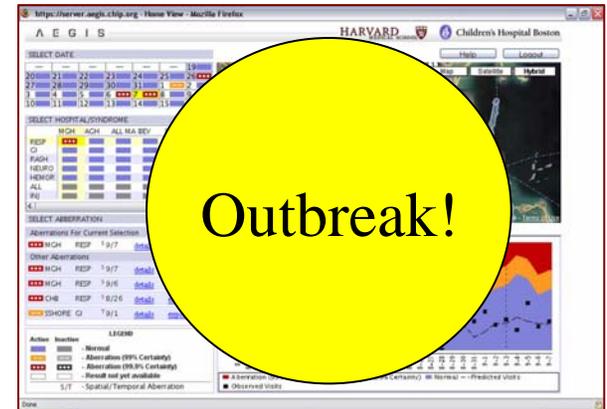
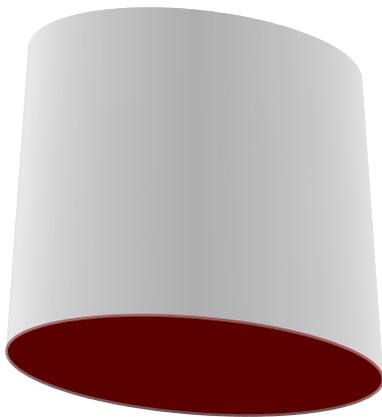
JAMIA 2007



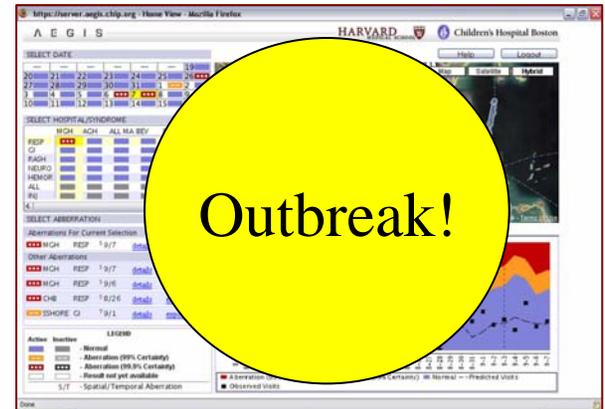
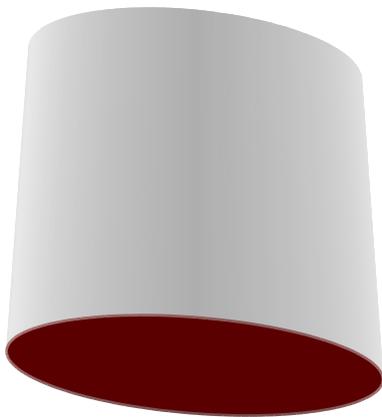
Anonymized data



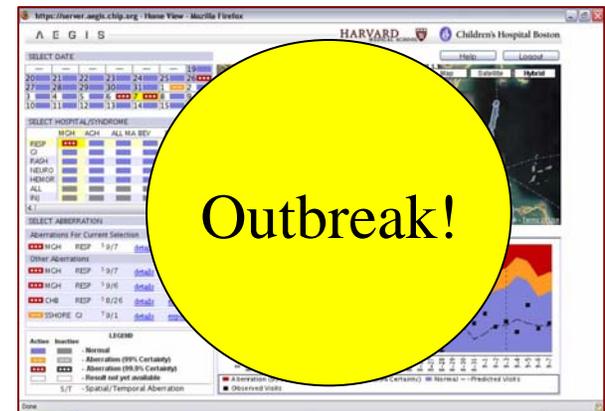
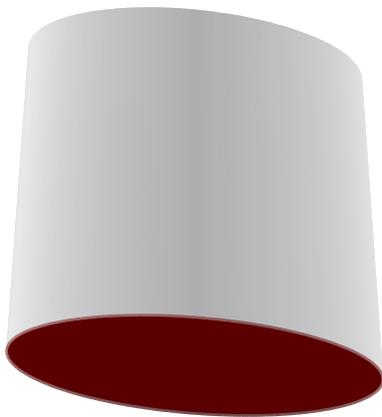
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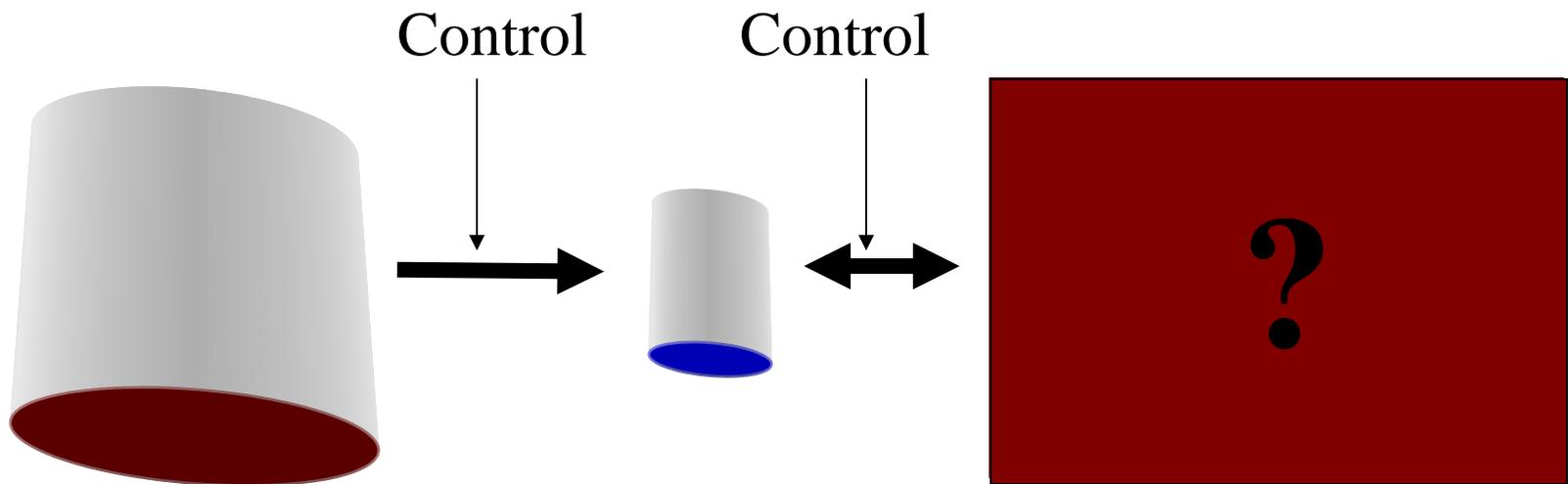


Query under public health authority



Return appropriate data
(based on prior agreement)





Editorial ■

Lessons Learned from the Shared Pathology Informatics Network (SPIN): A Scalable Network for Translational Research and Public Health

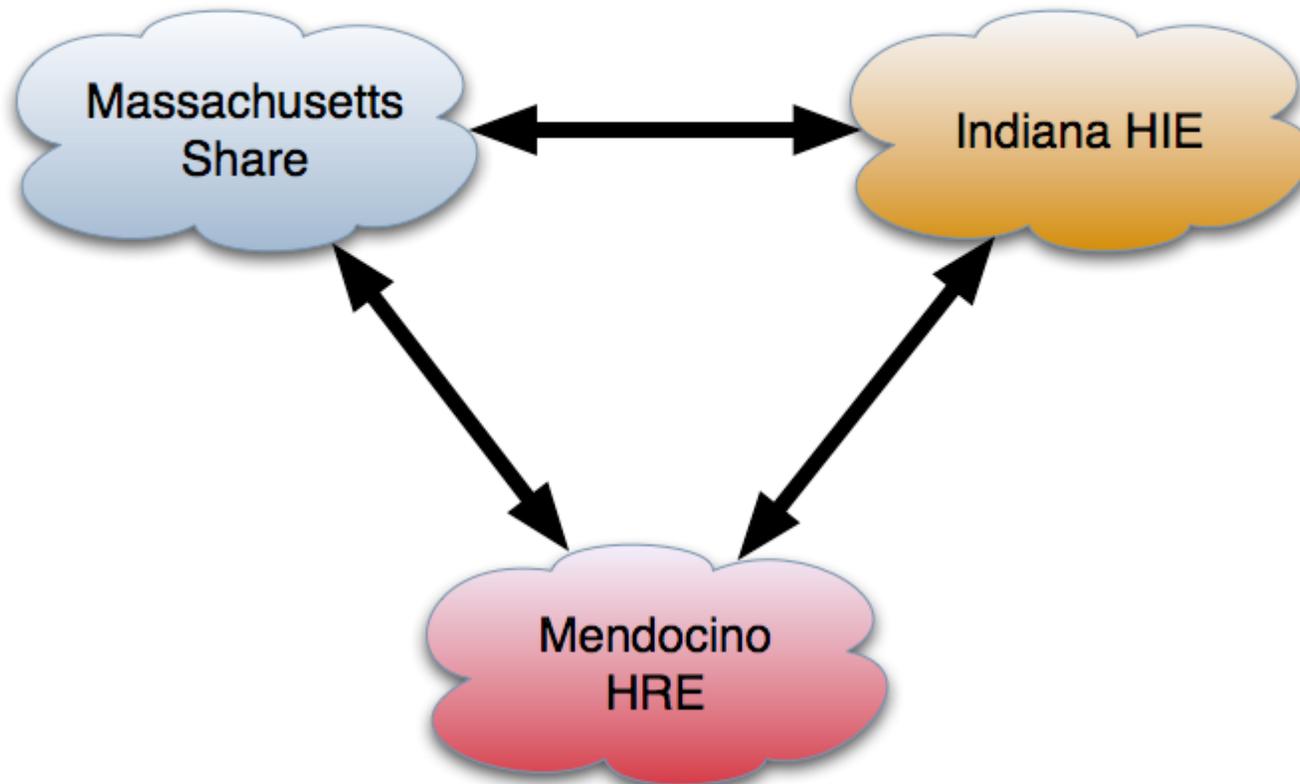
MICHAEL J. BECICH, MD, PhD

■ *J Am Med Inform Assoc.* 2007;14:534–535. DOI 10.1197/jamia.M2477.

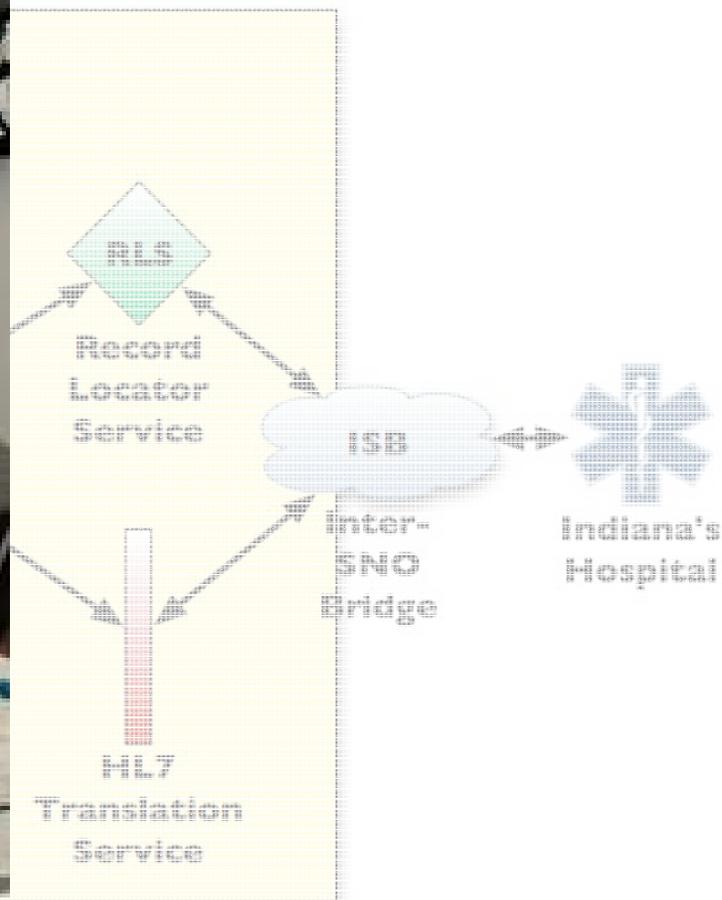
The article by McMurry et al. in the current issue of JAMIA describes an innovative architecture to support National

ing agreements . . .”¹ This work includes successful development, integration, and support for de-identification

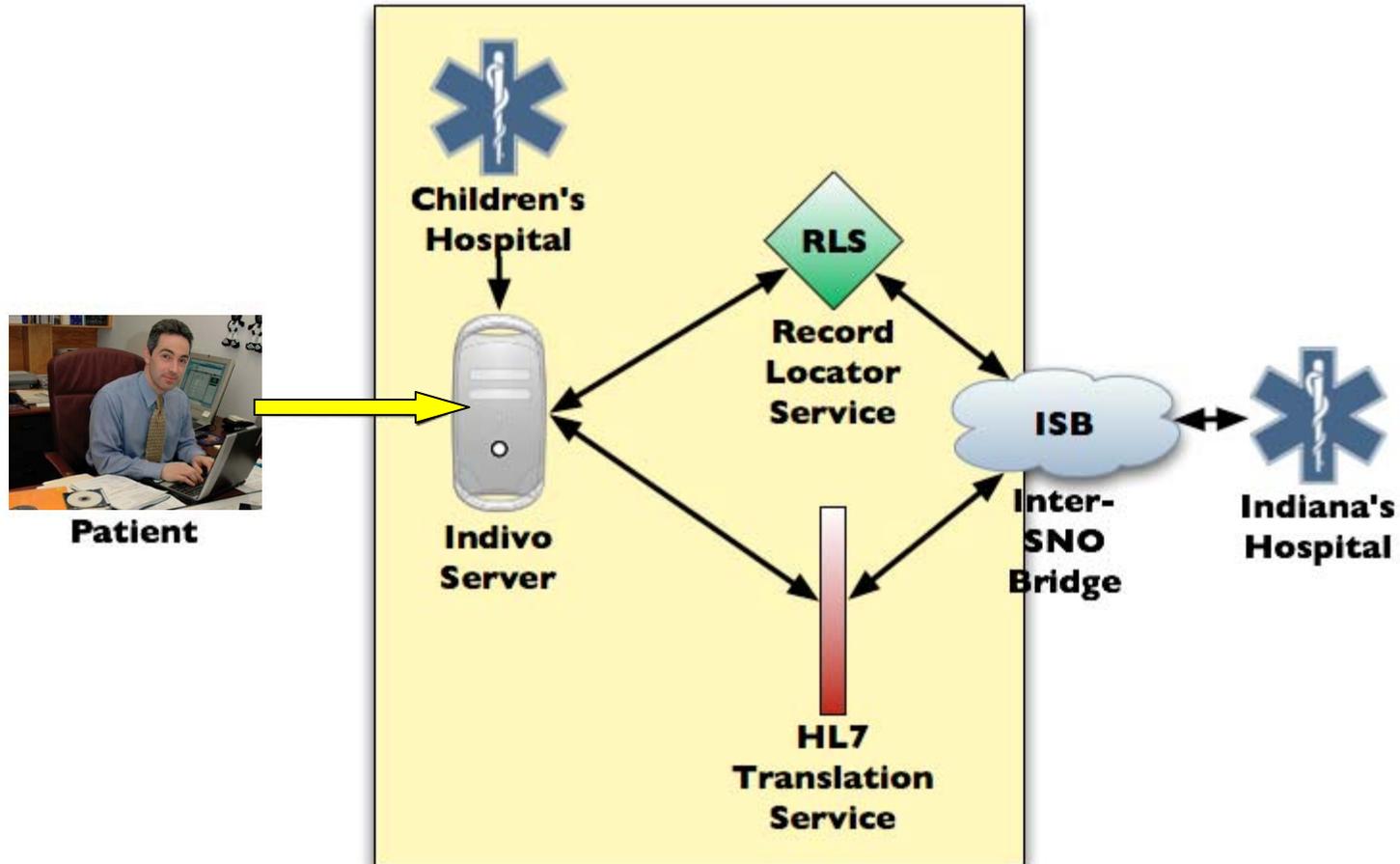
ONC-funded interregional architecture



MA SHARE SNO



MA-SHARE SNO





DANIEL NIGRIN

INDIVO PERSONALLY-CONTROLLED HEALTH RECORD

MESSAGES | SUBSCRIPTIONS | EXPORT RECORD | SHARING | LOG OUT

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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

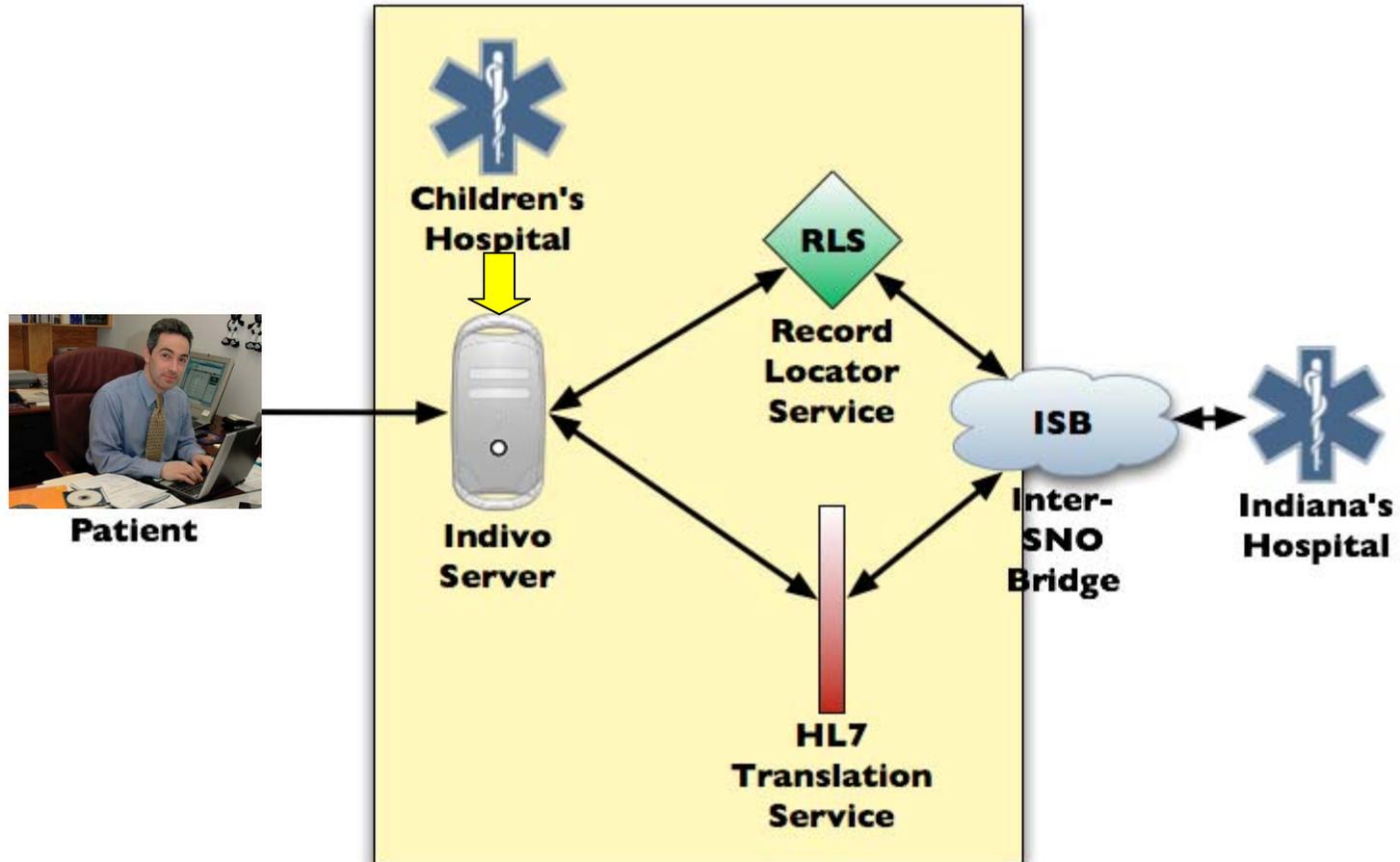
UPDATE HISTORY

ANNOTATIONS

ADD NEW ANNOTATION

[Add](#)

MA-SHARE SNO





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Subscribe To Children's Hospital Boston

PATIENT IDENTIFIER *

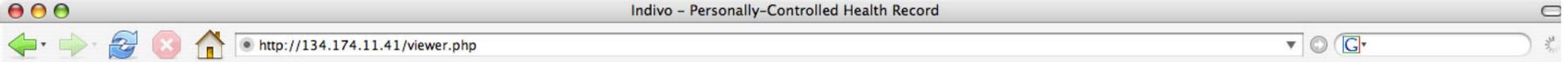
123456

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.



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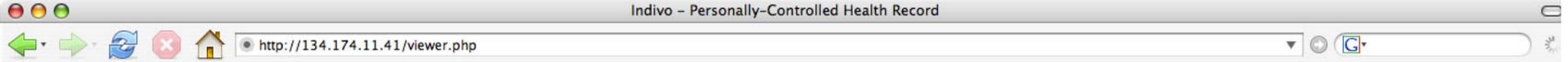
987654

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

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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.

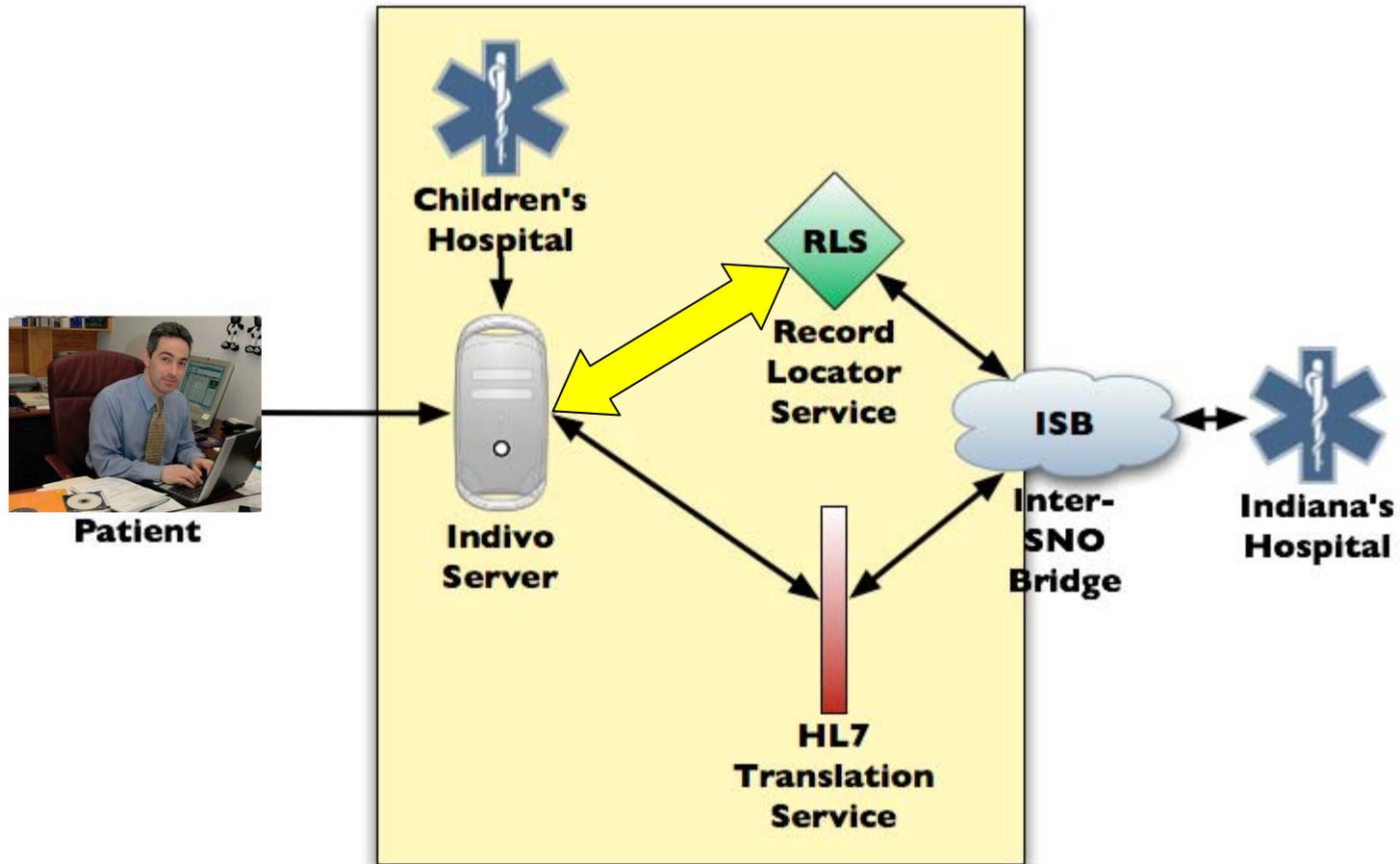
Update Interval: 24 hours

HARVARD UNIVERSITY HEALTH SERVICES

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

Update Interval: 24 hours

MA-SHARE SNO



chip



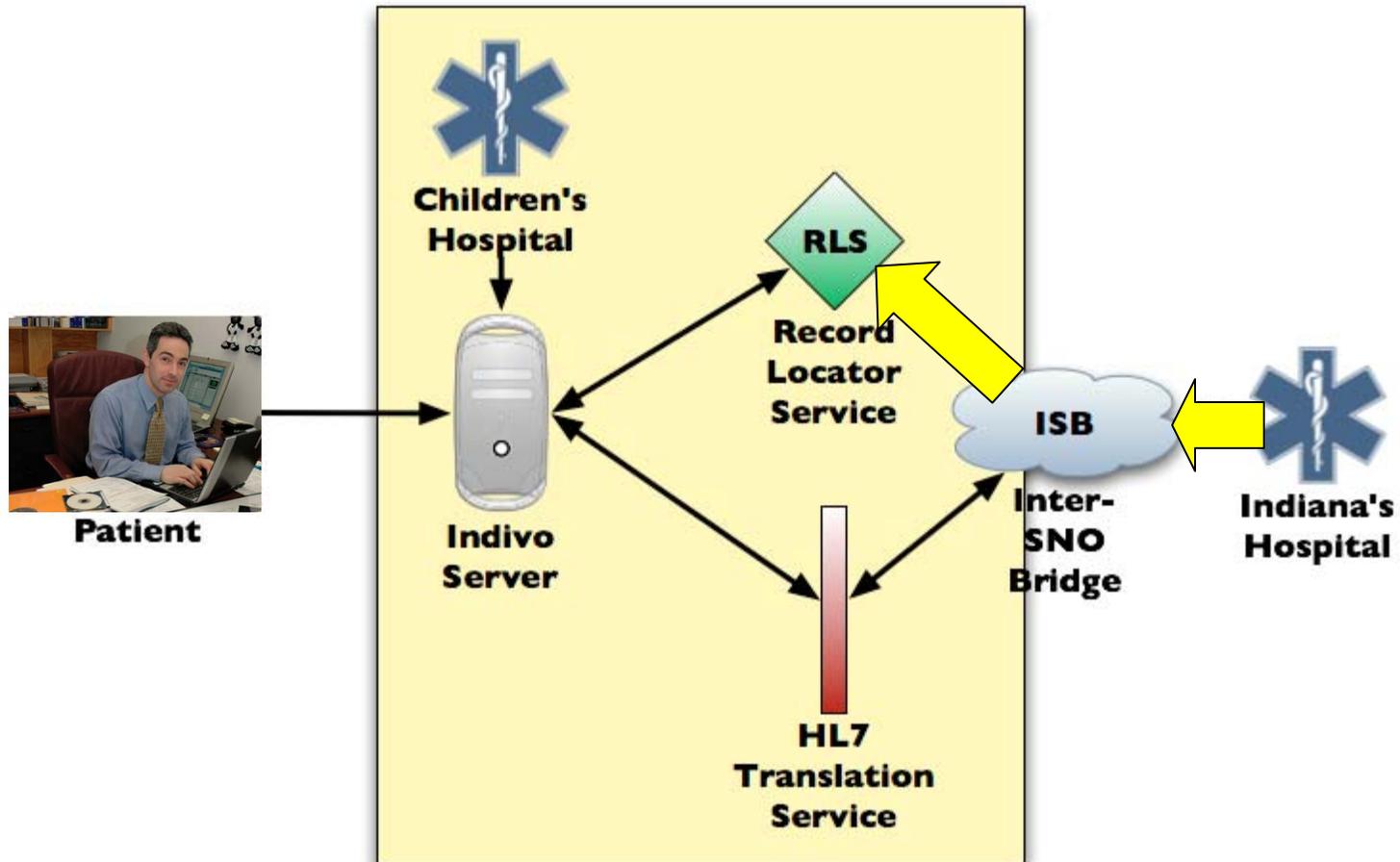
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Informatics Program



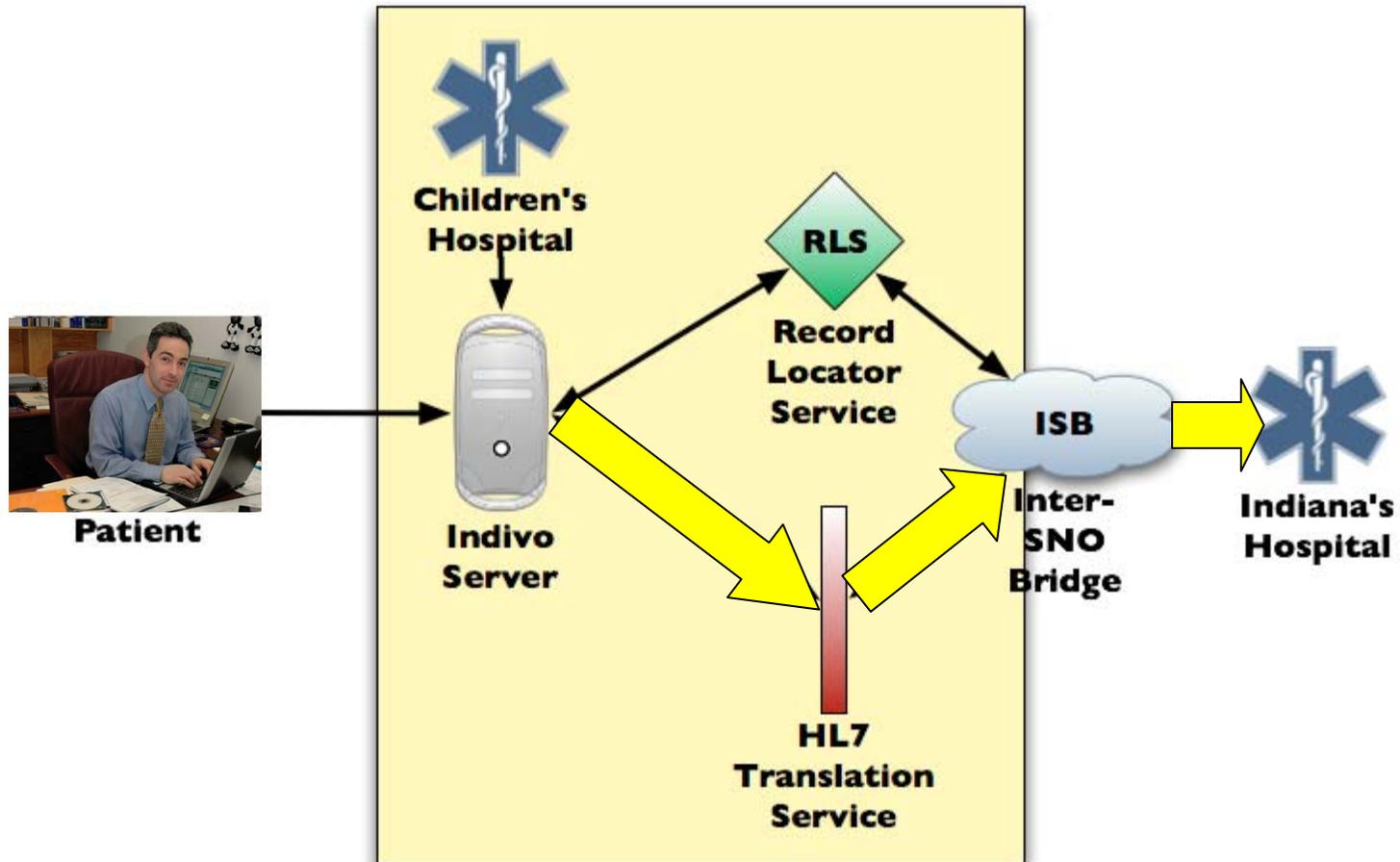
Harvard
Medical School



MA-SHARE SNO



MA-SHARE SNO





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Informatics Program



Harvard
Medical School





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

Red fields are required. Advanced Querying

Nigrin, Daniel Indiv At Childrens Boston Indiv At Childrens Boston http://org.chip.indiv installation : dnigrin@ping.chip.org Age: 41 Years (user: USER, GUEST)

Query Parameters:

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

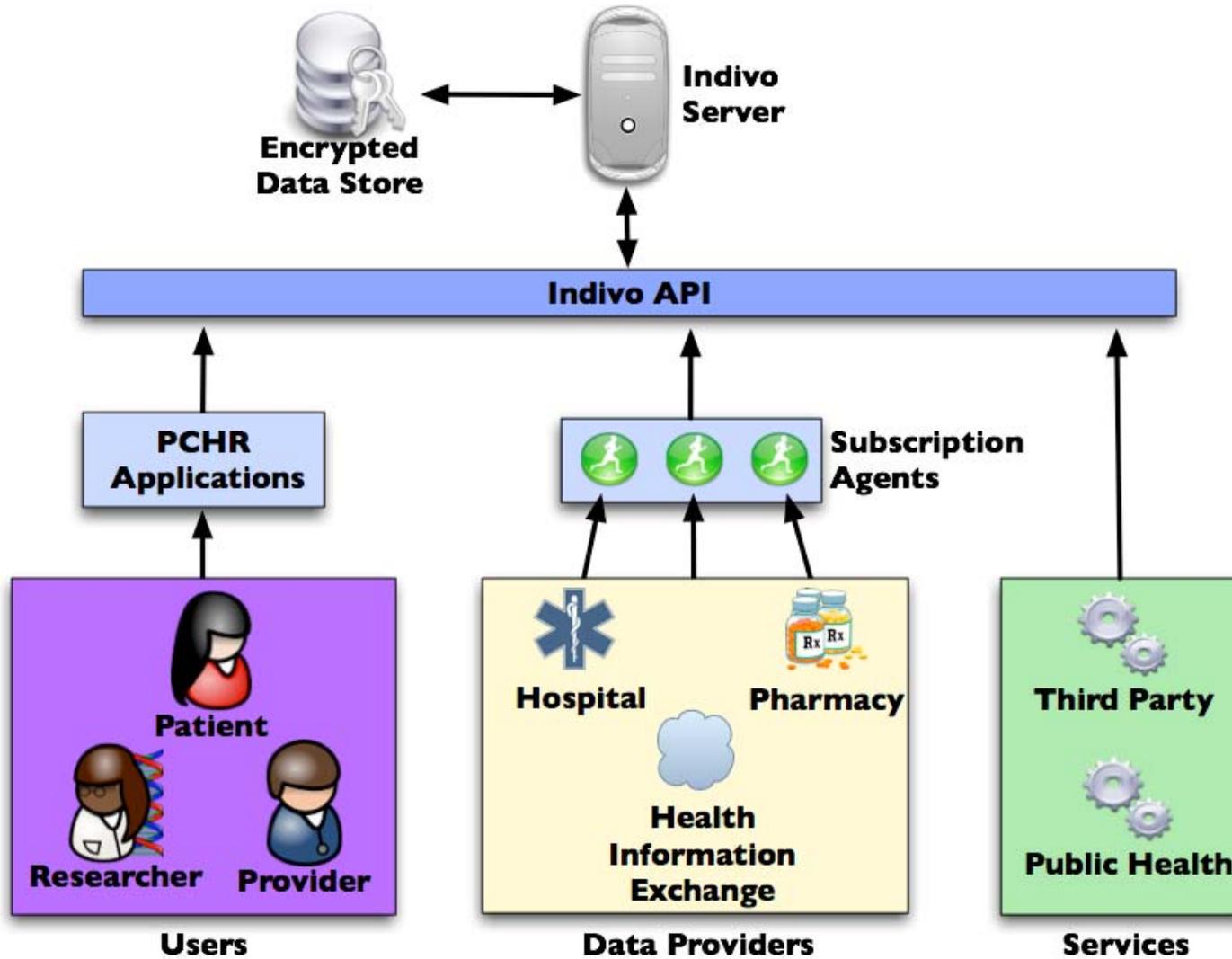
Medication Dispensing History:

Medication	Dosage	Last Filled Date
Tapazole	5 : mg	

Clinical Results:

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

Our "Watson, come here I need you" moment



Informed Cohort

Kohane et al,
Science, 2007

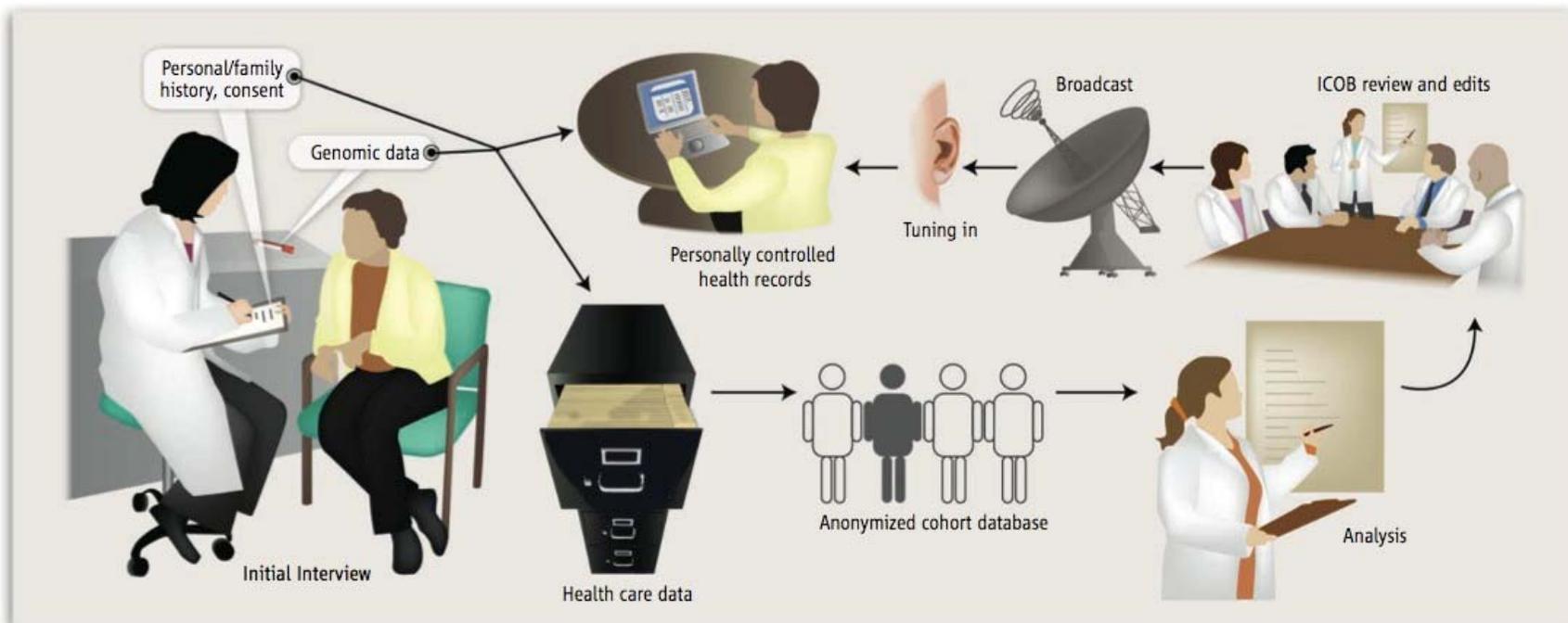
POLICYFORUM

MEDICINE

Reestablishing the Researcher-Patient Compact

Isaac S. Kohane,^{1,2,3*} Kenneth D. Mandl,^{1,2,3} Patrick L. Taylor,^{2,4} Ingrid A. Holm,^{2,5}
Daniel J. Nigrin,^{1,2,3} Louis M. Kunkel^{2,5,6}

Well-intentioned regulations protecting privacy are denying important information to patient subjects. Advances in information technology mean that a better approach to clinical research is possible.





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Summary of Products

- <http://www.indivohealth.org/>
- <http://aegis.chip.org/>



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Harvard
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Summary

- Goals
 - ✓ Feasible technically and sociologically



Children's Hospital
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Harvard
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Summary

- Goals
 - ✓ Feasible technically and sociologically
 - ✓ Scalable to the national scale



Summary

- Goals
 - ✓ Feasible technically and sociologically
 - ✓ Scalable to the national scale
 - ✓ Robust and useful in disaster