Harvard Medical School

Countway Library of Medicine

PCHRI2006

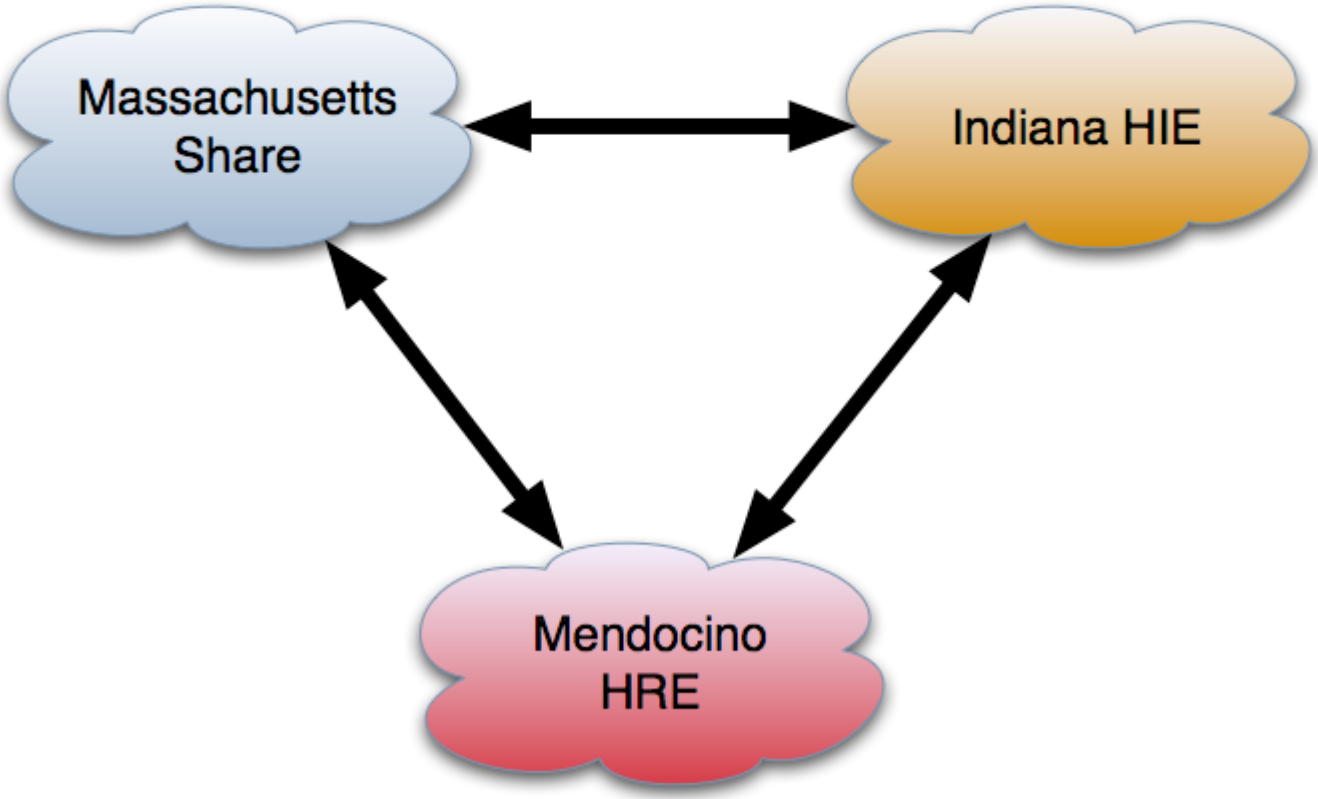
The Harvard Medical School Meeting on Personally Controlled Health Record Infrastructure

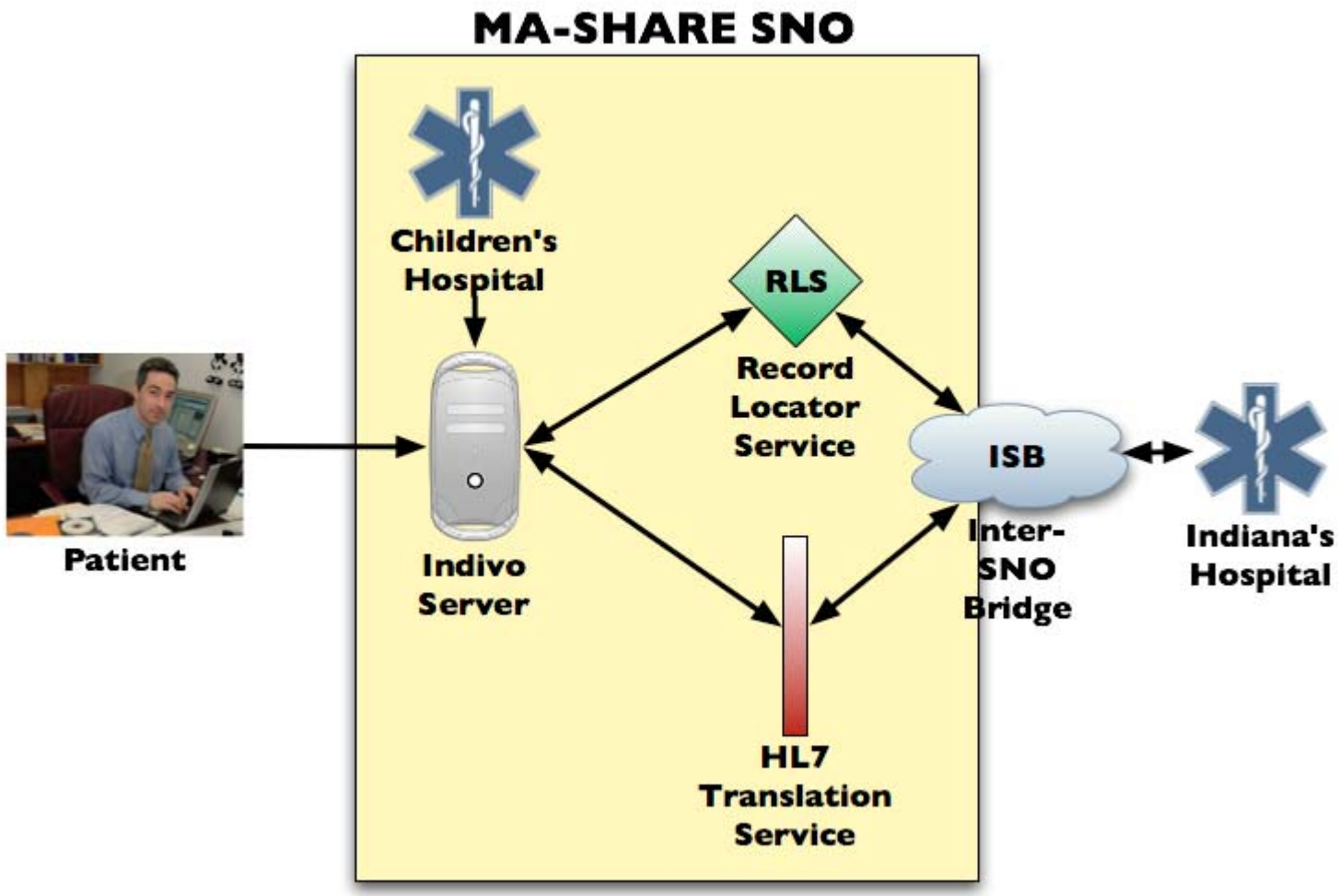
WWW.PCHRI2006.ORG

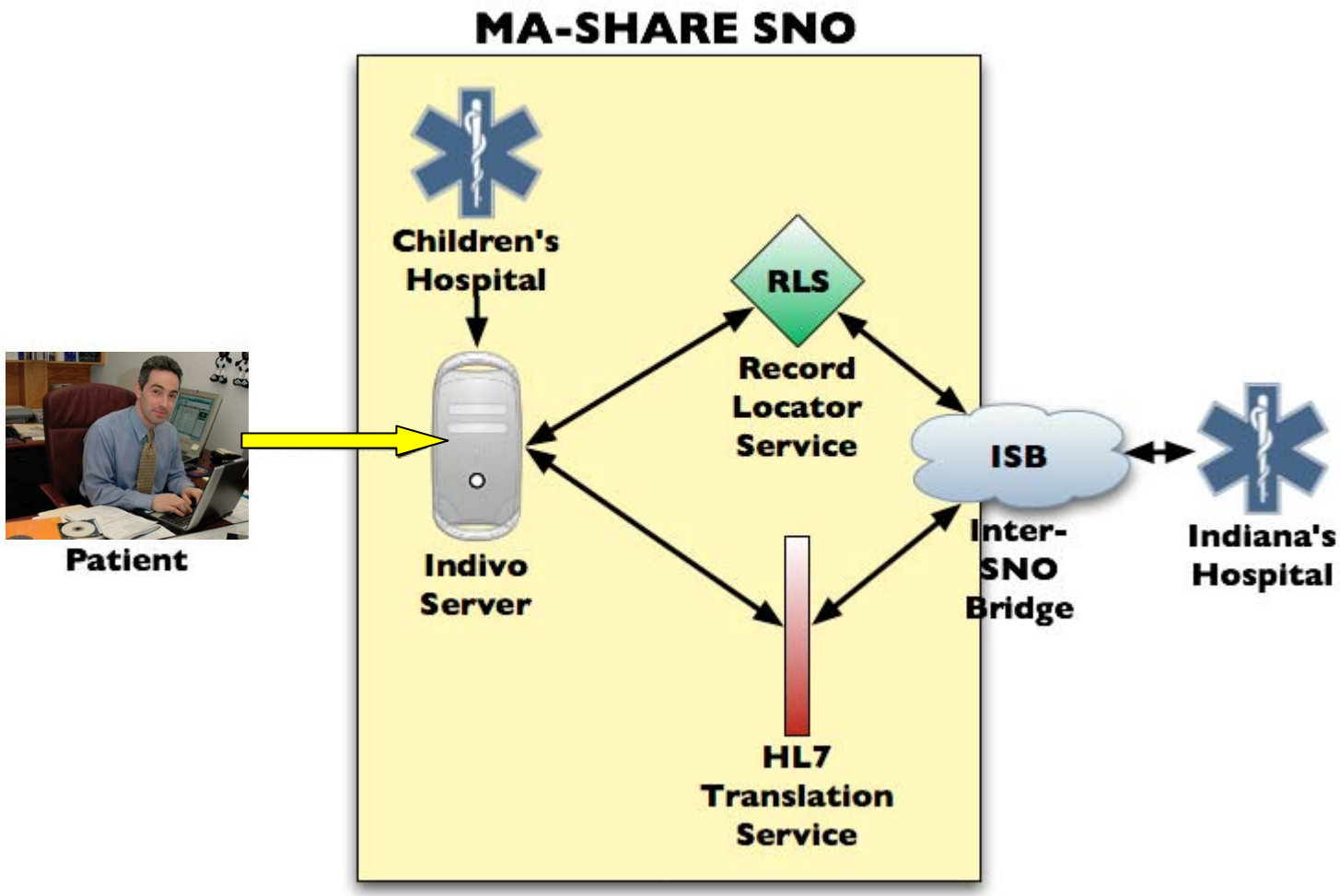
Models for PCHRI

Kenneth D. Mandl, MD, MPH

ONC-funded interregional architecture




MA-SHARE SNO
Children's Hospital
RLS
Record Locator Service
Patient
Indivo Server
ISB
Inter-SNO Bridge
Indiana's Hospital
HL7 Translation Service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HL7 Translation Service

DANIEL NIGRIN

INDIVO PERSONALLY-CONTROLLED HEALTH RECORD

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

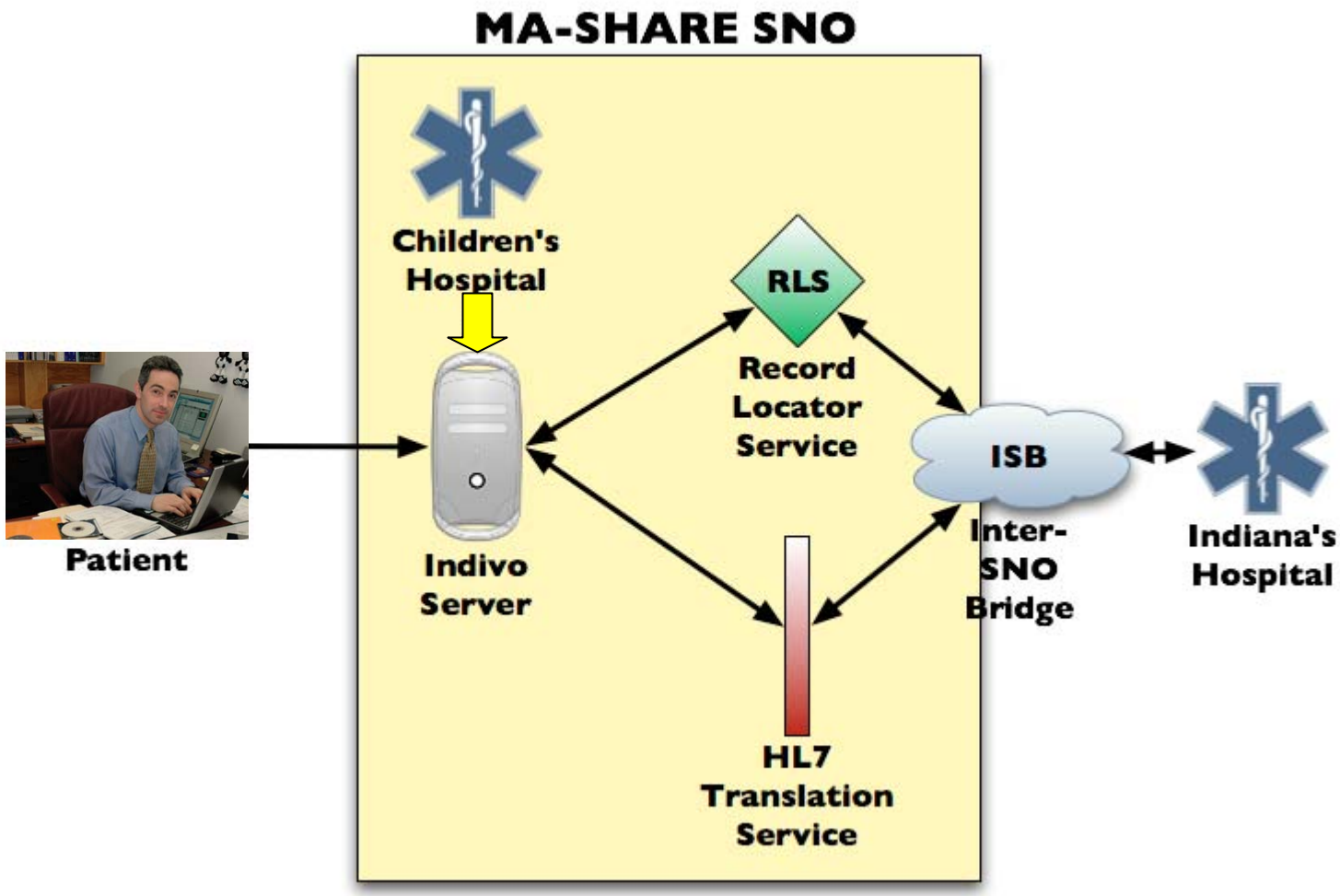
ROUTE
by mouth

FREQUENCY
once a day

DOCUMENT INFO
UPDATE HISTORY
ANNOTATIONS

ADD NEW ANNOTATION

Add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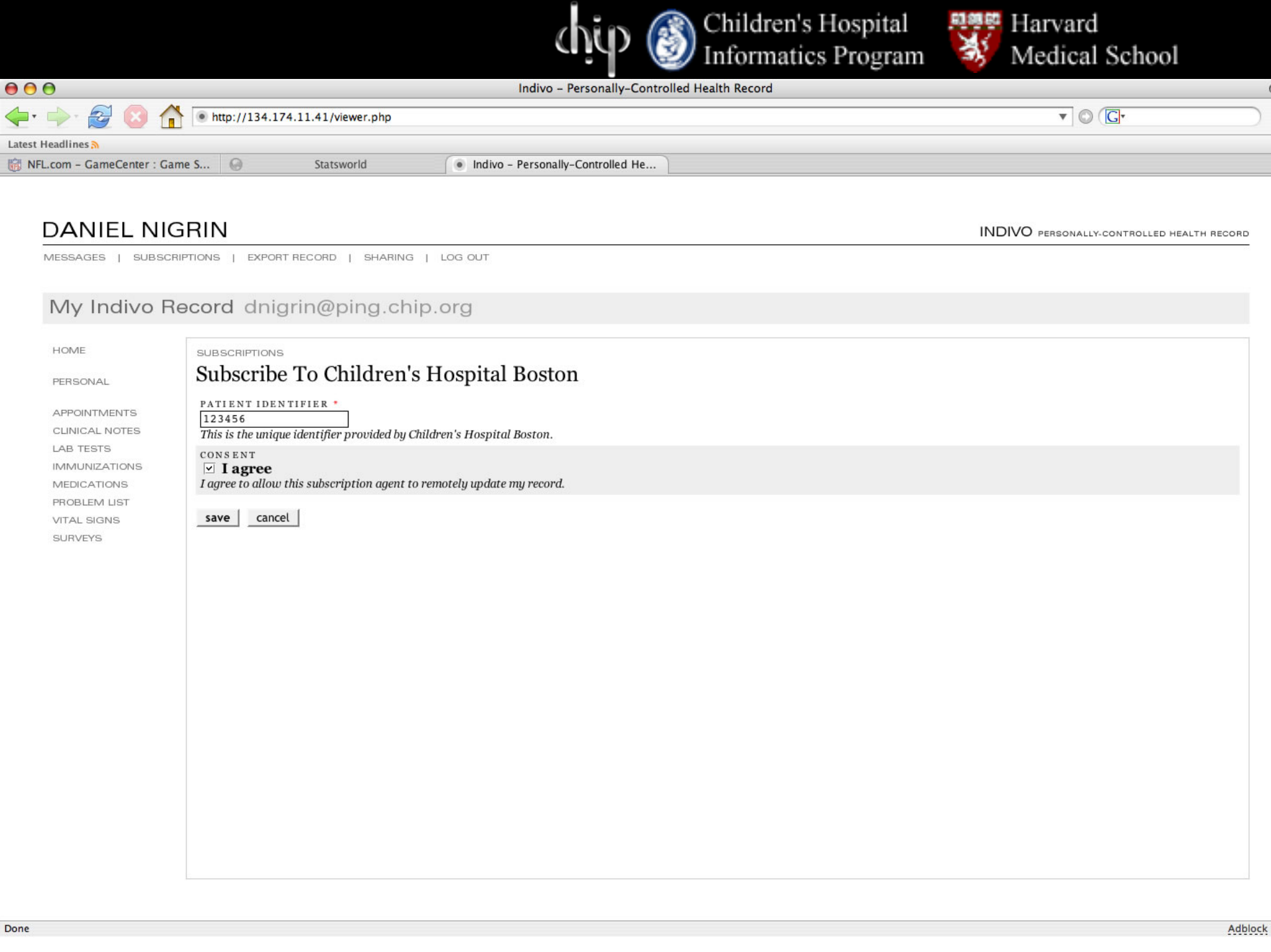
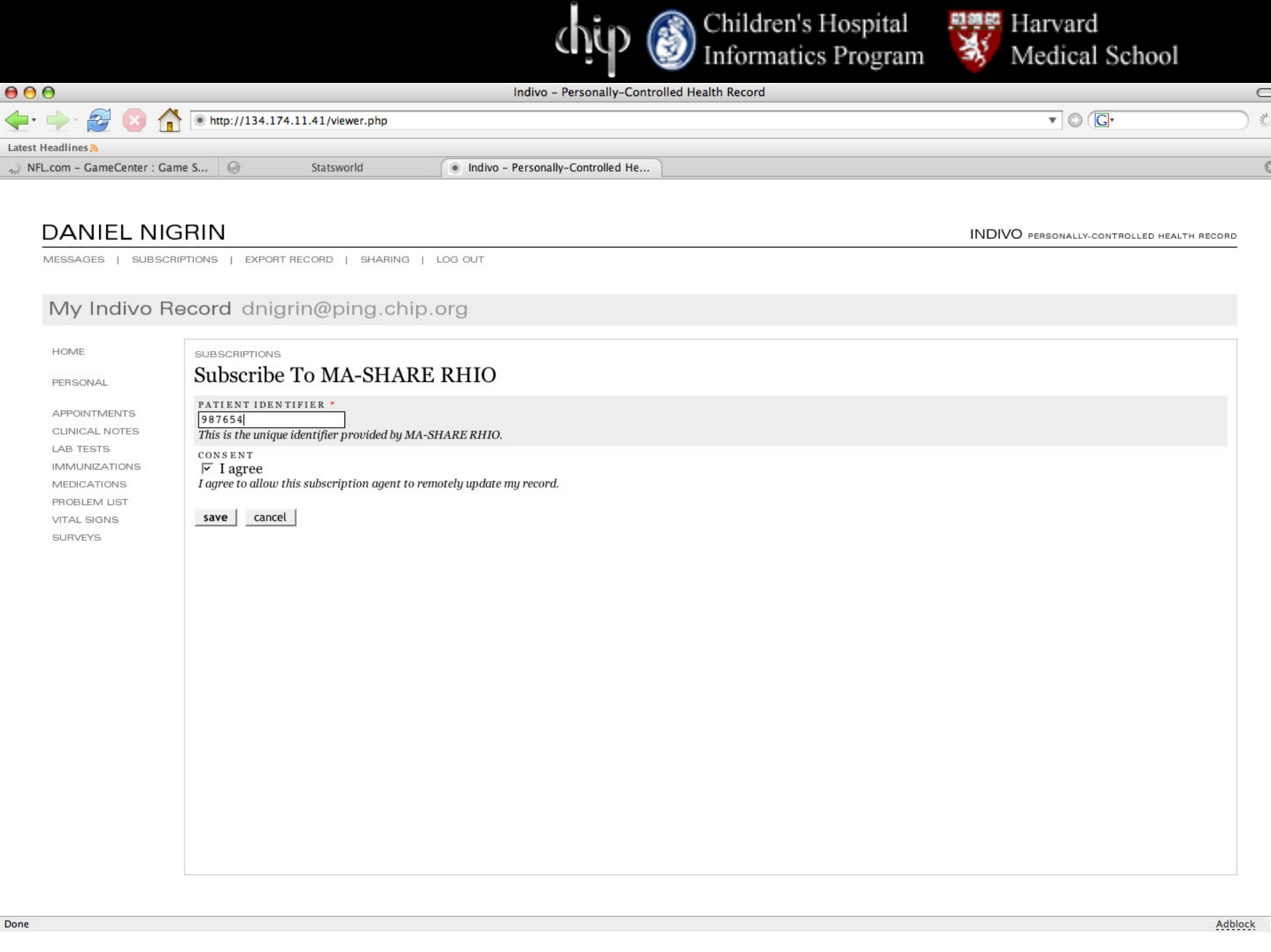

chip
Children's Hospital
Informatics Program
Harvard
Medical School
Indivo – Personally-Controlled Health Record
http://134.174.11.41/viewer.php
Latest Headlines
NFL.com – GameCenter : Game S...
Statsworld
Indivo – Personally-Controlled He...
DANIEL NIGRIN
INDIVO PERSONALLY-CONTROLLED HEALTH RECORD
MESSAGES | SUBSCRIPTIONS | EXPORT RECORD | SHARING | LOG OUT
My Indivo Record dnigrin@ping.chip.org
HOME
PERSONAL
APPOINTMENTS
CLINICAL NOTES
LAB TESTS
IMMUNIZATIONS
MEDICATIONS
PROBLEM LIST
VITAL SIGNS
SURVEYS
SUBSCRIPTIONS
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.
save
cancel
Done
Adblock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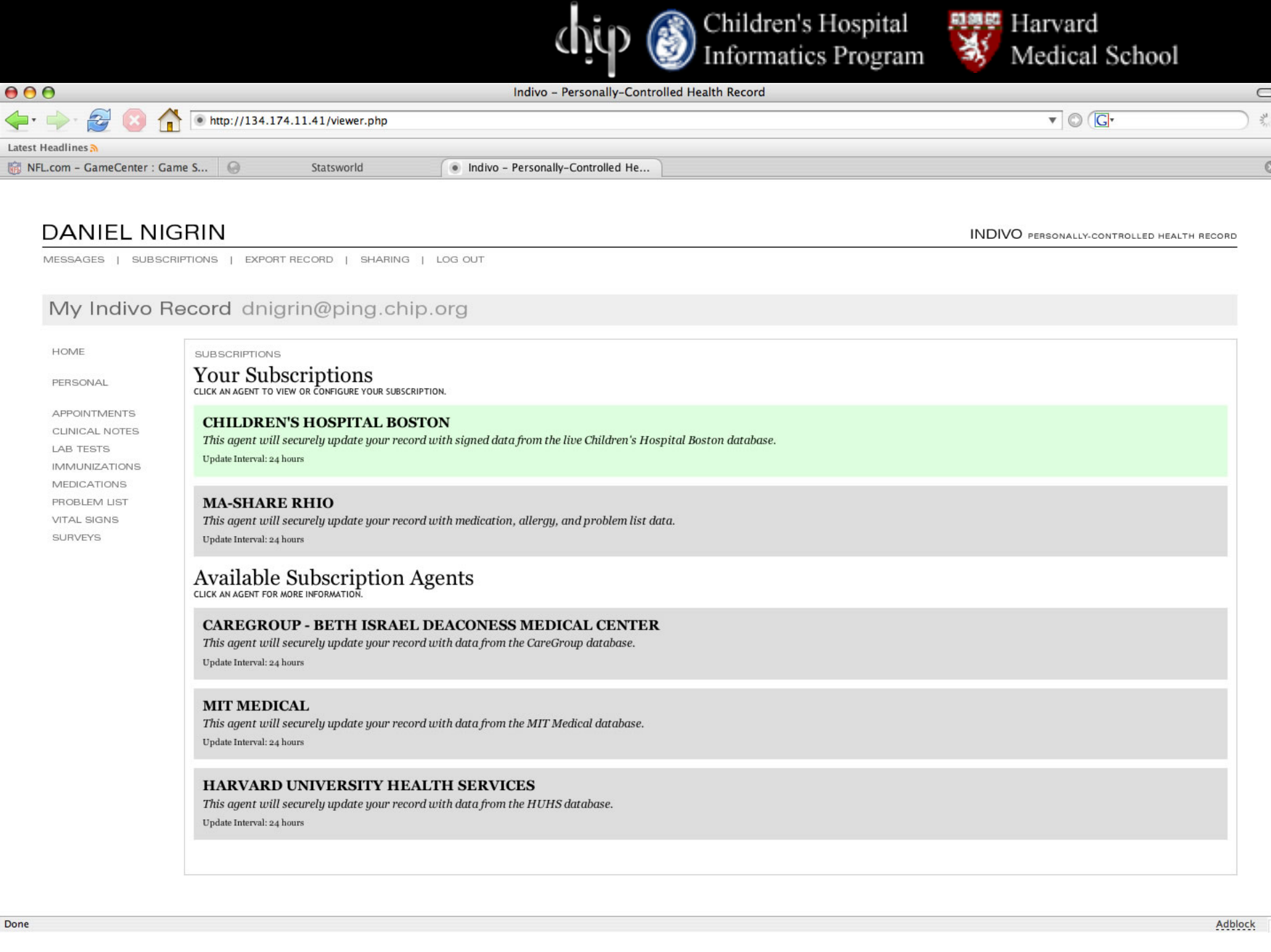
MEDICATIONS
PROBLEM LIST
VITAL SIGNS
SURVEYS
SUBSCRIPTIONS
Subscribe To MA-SHARE RHIO
PATIENT IDENTIFIER *
987654
This is the unique identifier provided by MA-SHARE RHIO.
CONSENT
I agree
I agree to allow this subscription agent to remotely update my record.
save
cancel
Done
Adblock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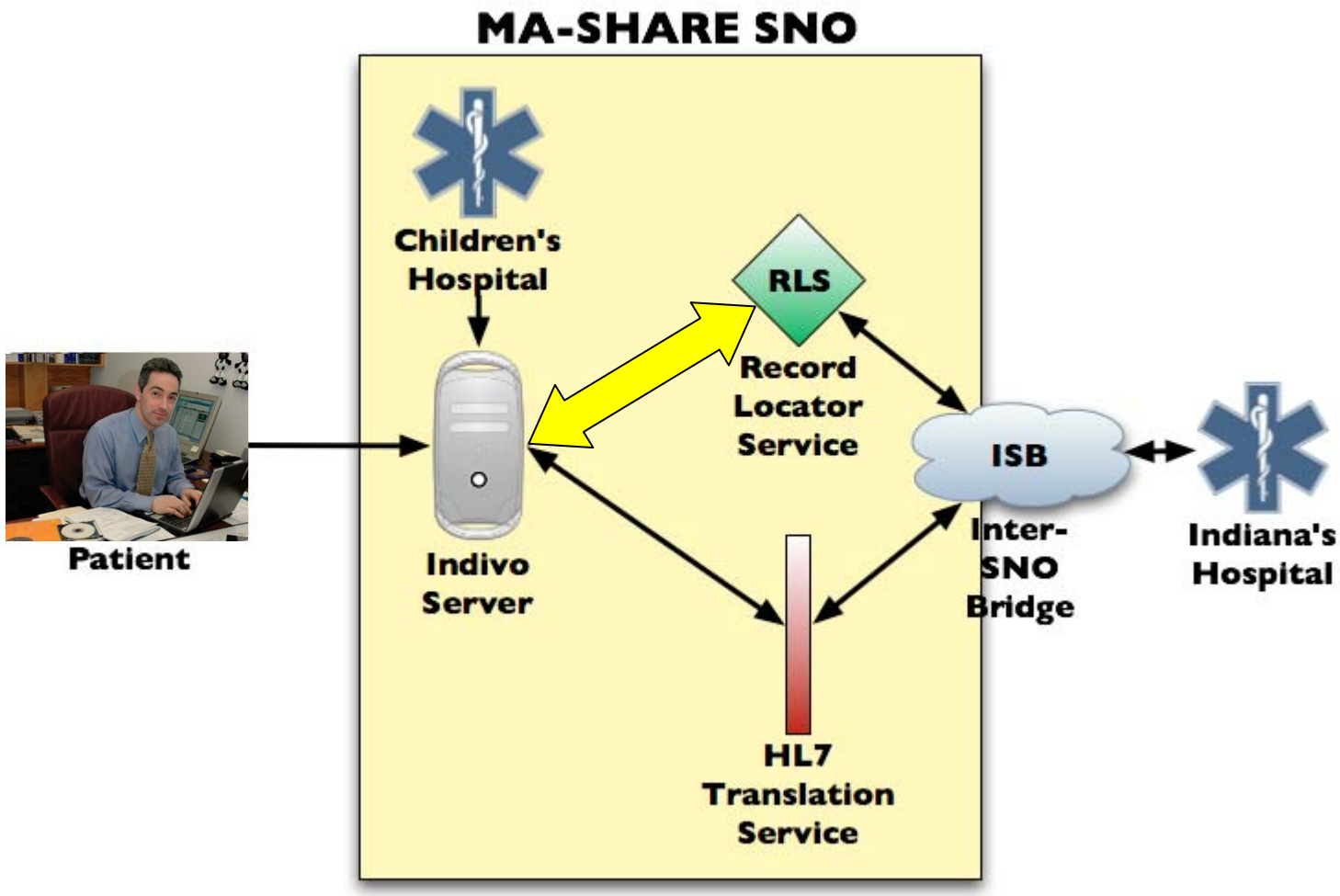
MEDICATIONS
PROBLEM LIST
VITAL SIGNS
SURVEYS
SUBSCRIPTIONS
Your Subscriptions
CLICK AN AGENT TO VIEW OR CONFIGURE YOUR SUBSCRIPTION.
CHILDREN'S HOSPITAL BOSTON
This agent will securely update your record with signed data from the live Children's Hospital Boston database.
Update Interval: 24 hours
MA-SHARE 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 HUHS database.
Update Interval: 24 hours
Done
Adblock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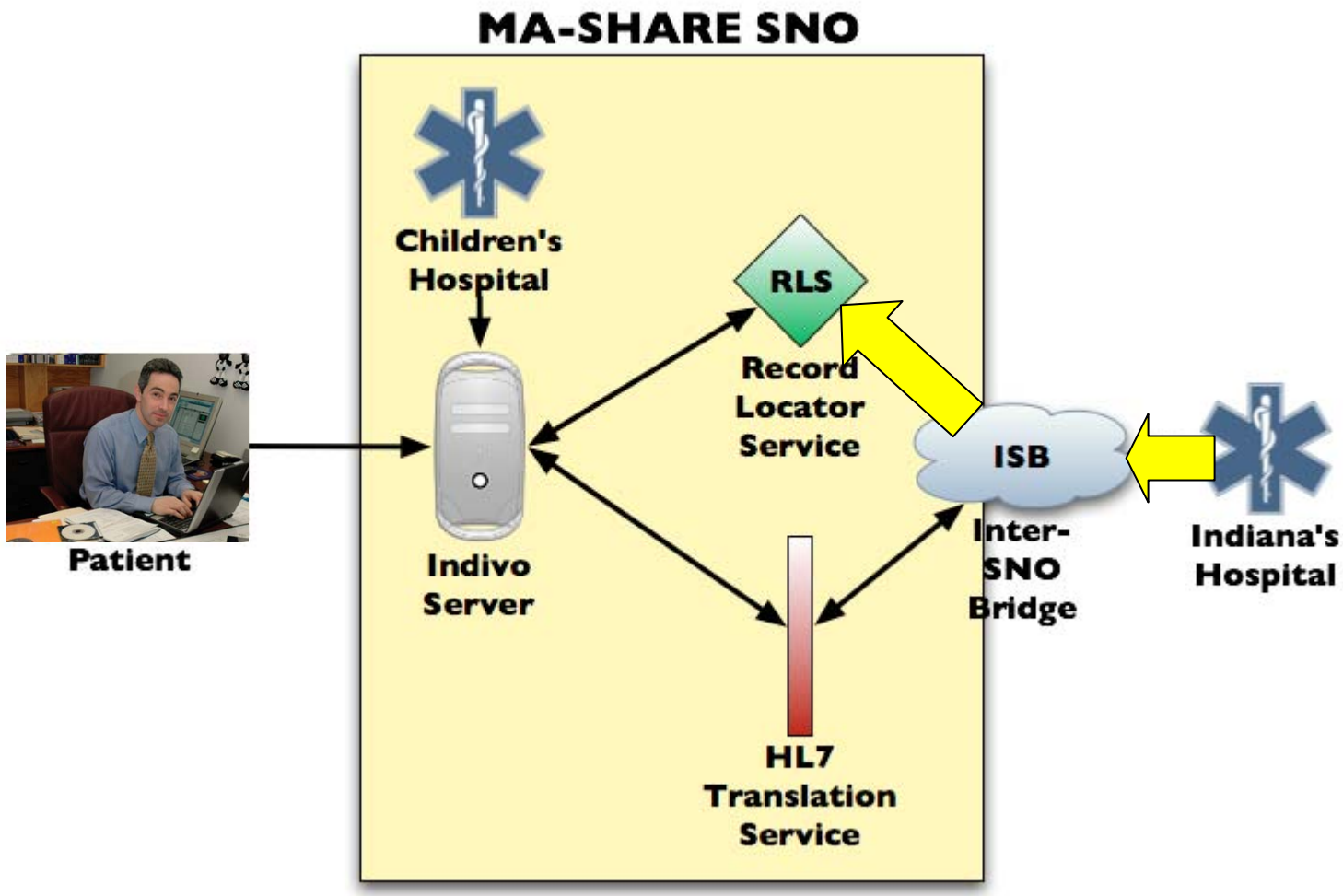
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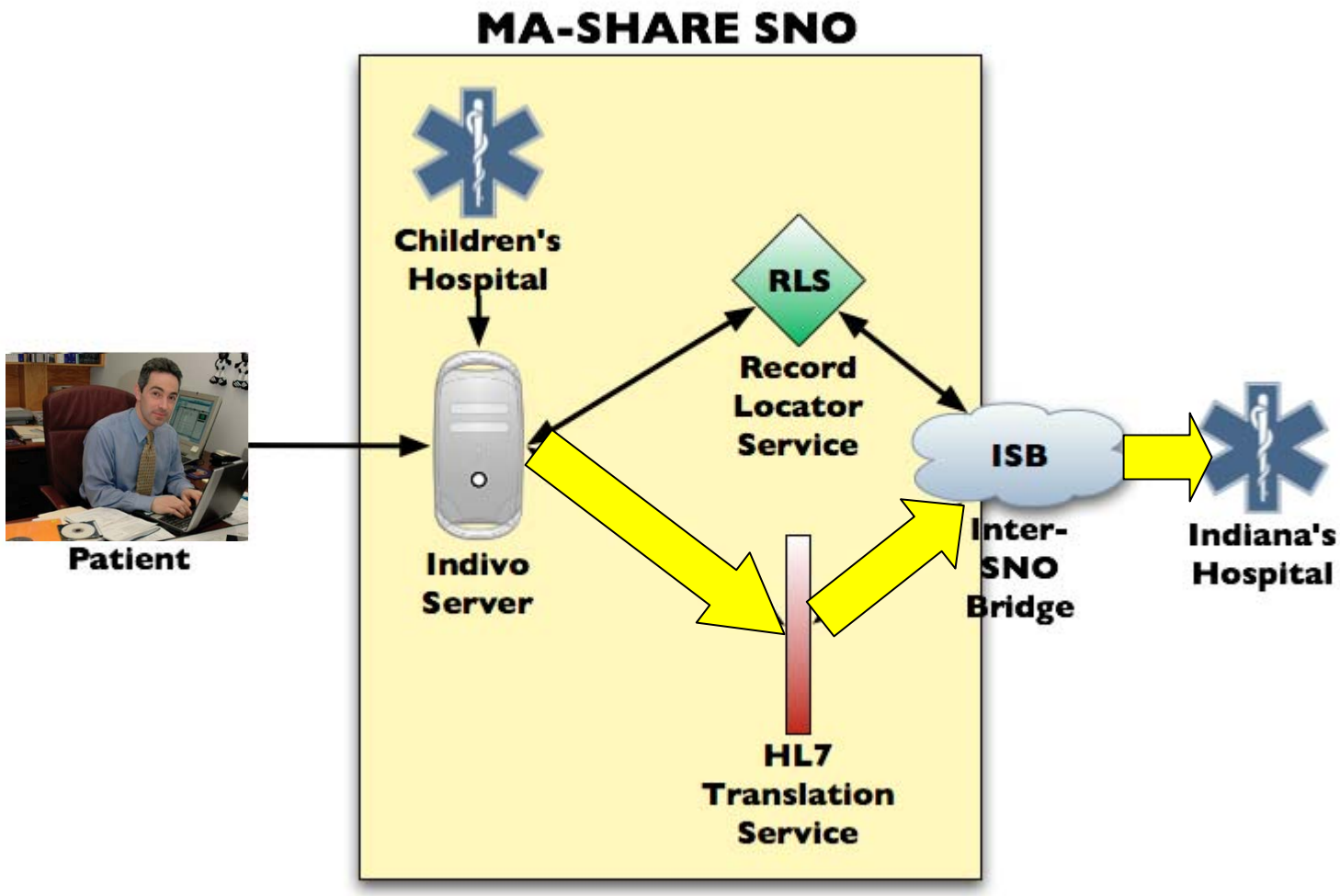
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Indivo Server
HL7 Translation Service

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

File View Windows Help

Last Name	First Name	Middle Name
Nigrin	Daniel	

Street	City	State	Zip

Gender: M Birthdate: 11/19/1965 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	

Clinical Results:

Date	Description	Elapsed	Result		
20-Apr-06 08:58		-171 Days	Bl		
	Blood Glucose		23		
20-Apr-06 05:02		-171 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		279.0	mg/dL	
20-Apr-06 07:46		-172 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		252.0	mg/dL	
19-Apr-06 09:25		-172 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		207.0	mg/dL	
19-Apr-06 04:39		-172 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		201.0	mg/dL	
18-Apr-06 09:08		-173 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		141.0	mg/dL	
18-Apr-06 05:11		-173 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		251.0	mg/dL	
18-Apr-06 01:31		-173 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		163.0	mg/dL	
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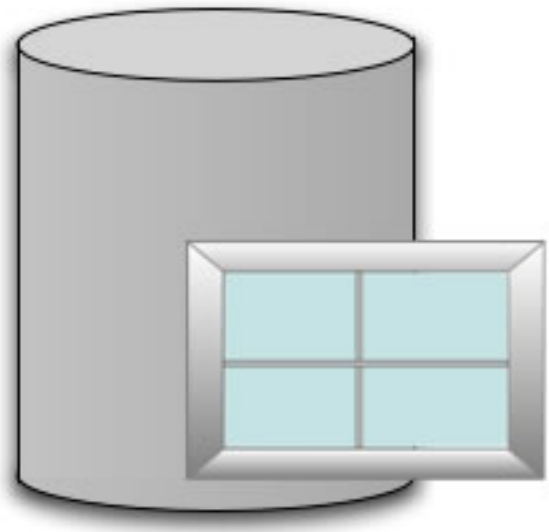
	Blood Glucose		240.0	mg/dL	
17-Apr-06 10:11		-174 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}
	Blood Glucose		220.0	mg/dL	
17-Apr-06 07:24		-174 Days	Blood Glucose		Nigrin, Daniel (dnigrin@ping.chip.org, Indivoatchildrensboston Indivoatchildrensboston Http://Org.Chip.Indivo.Installation) {a}

Our “Watson, come here I need you” moment

Personal information access point

- Tethered PHR

Tethered PHR

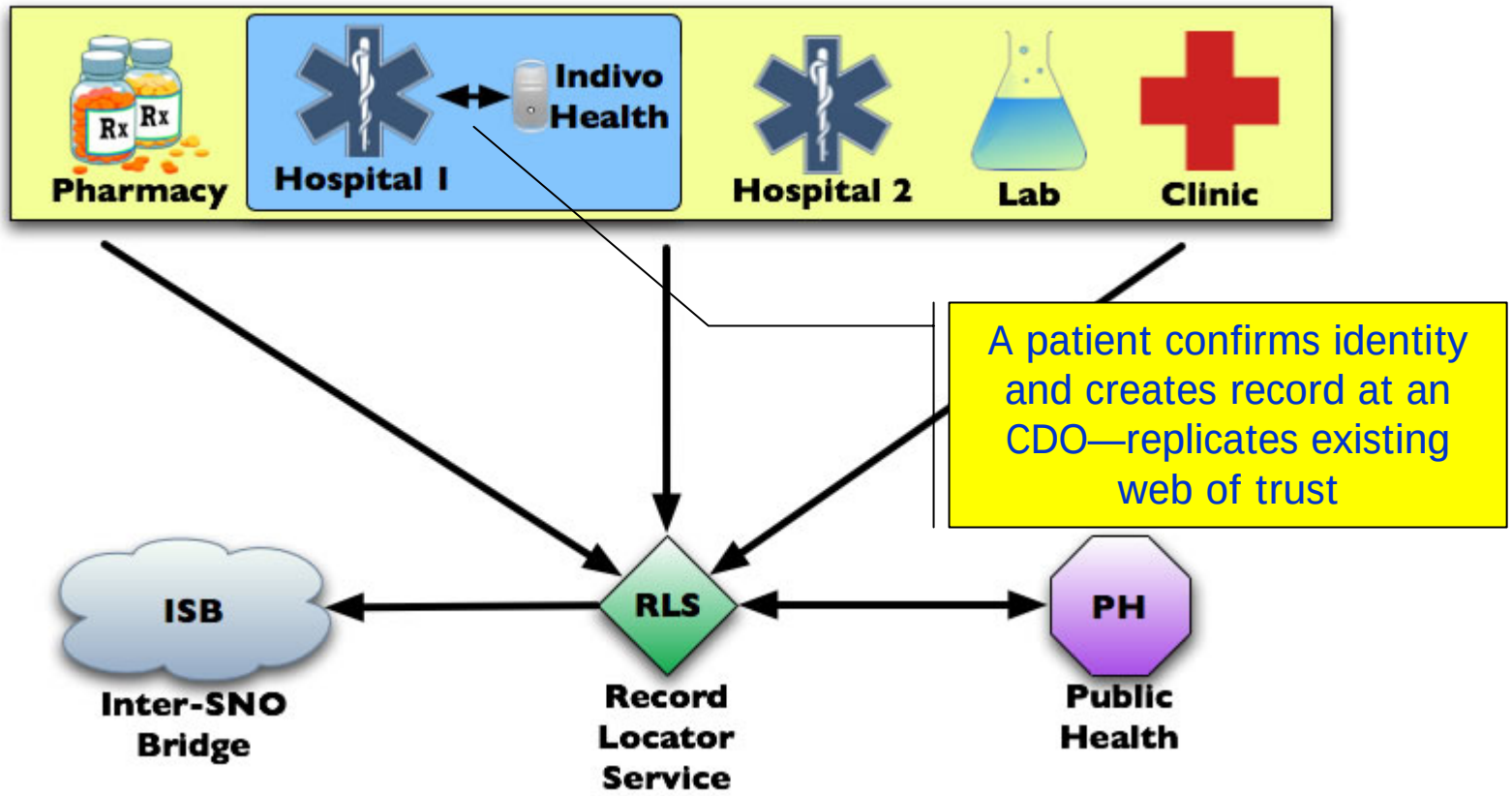


Window onto a single institutional database

Personal information access point

- Tethered PHR
- Personal NHIN gateway via CDO

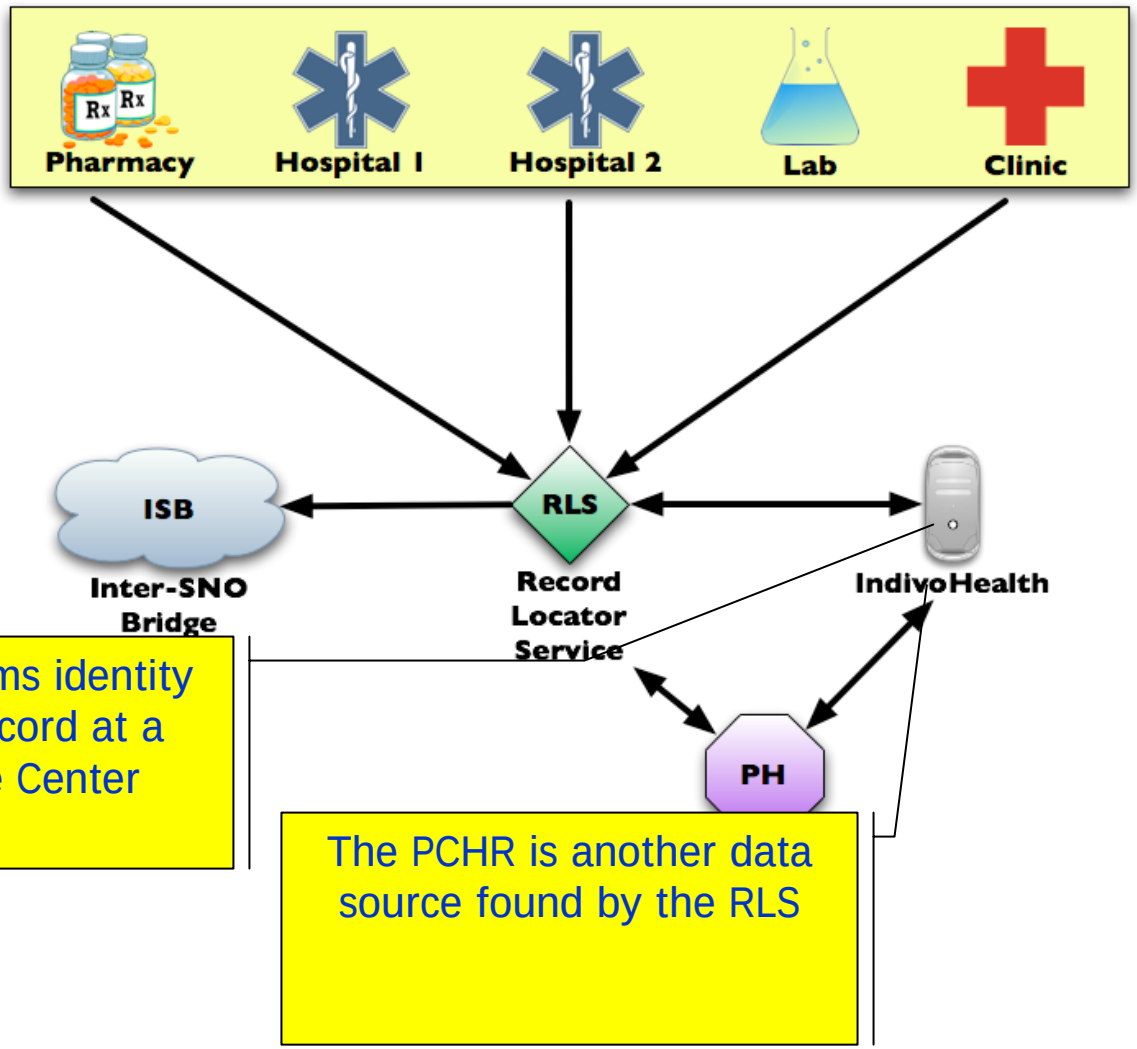
Personal NHIN gateway via CDO



Personal information access point

- Tethered PHR
- Personal NHIN gateway via CDO
- Personal NHIN via PCHR service

Personal NHIN gateway via PCHR service



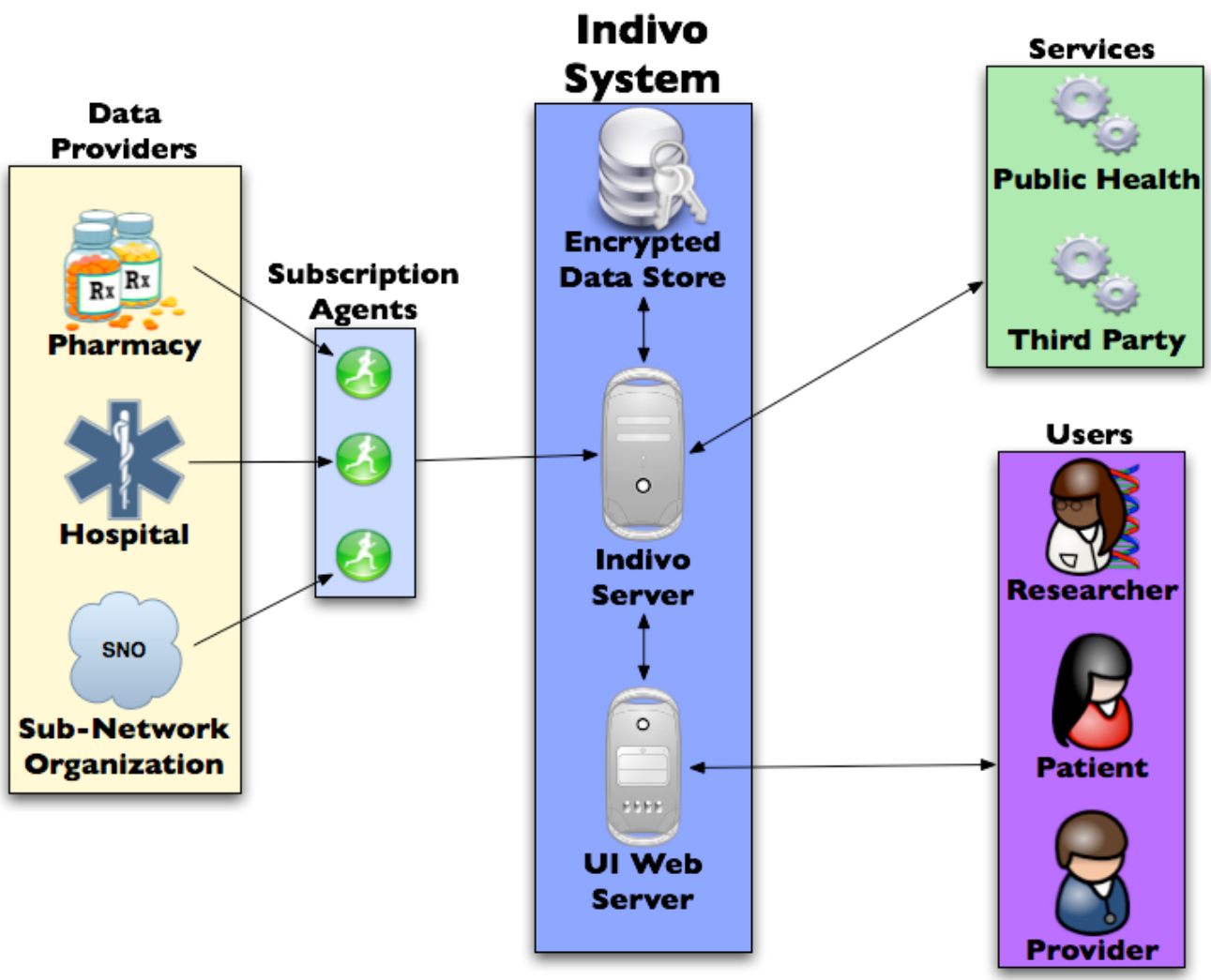
A patient confirms identity and creates record at a PCHR Service Center

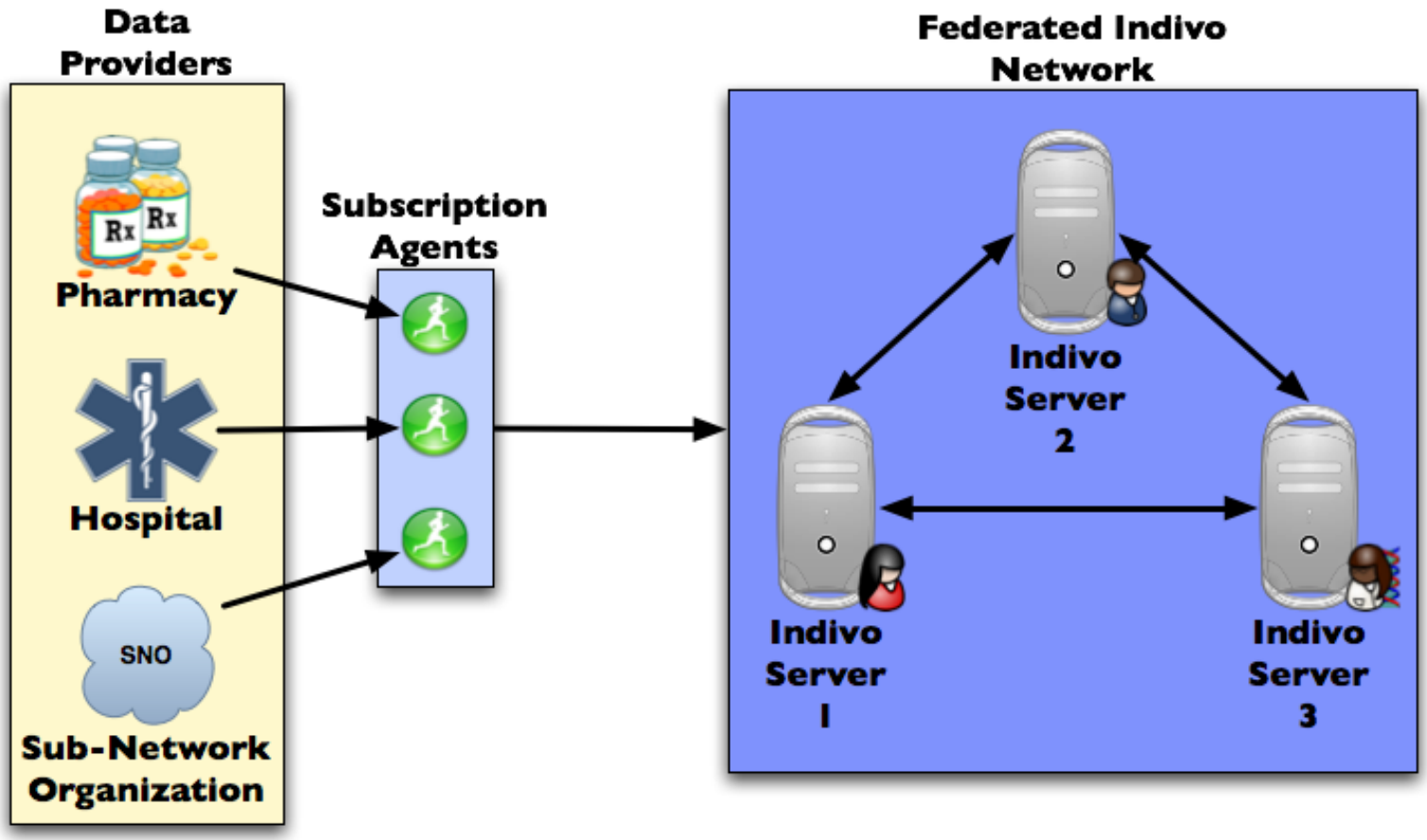
The PCHR is another data source found by the RLS

Personal information access point

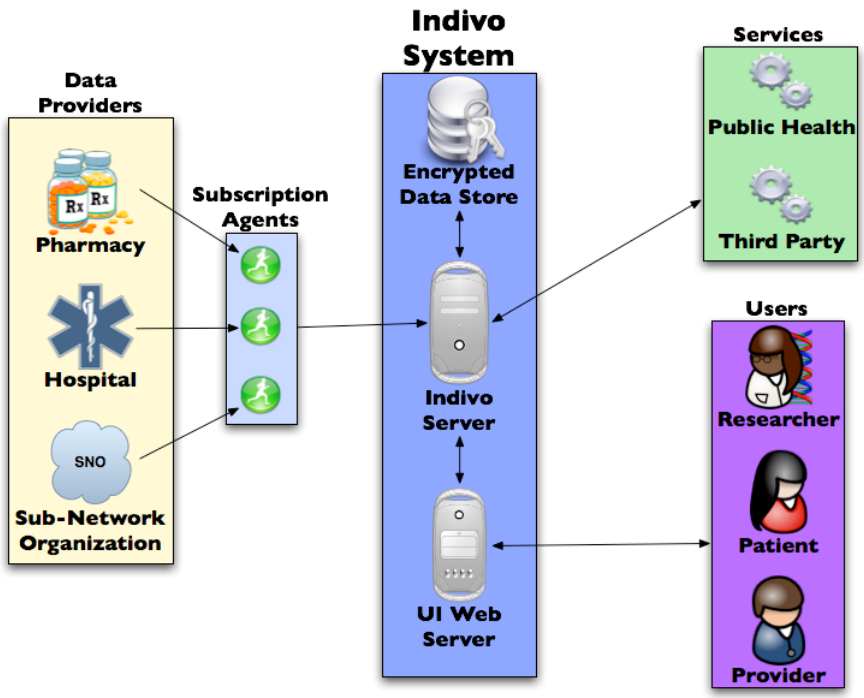
- Tethered PHR
- Personal NHIN gateway via CDO
- Personal NHIN gateway via PCHR service
- PCHR-centric (Aristotelian)

PCHR-centric (Aristotelian)




Data Providers
Pharmacy
Hospital
SNO
Sub-Network Organization
Subscription Agents
Federated Indivo Network
Indivo Server 2
Indivo Server 1
Indivo Server 3

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

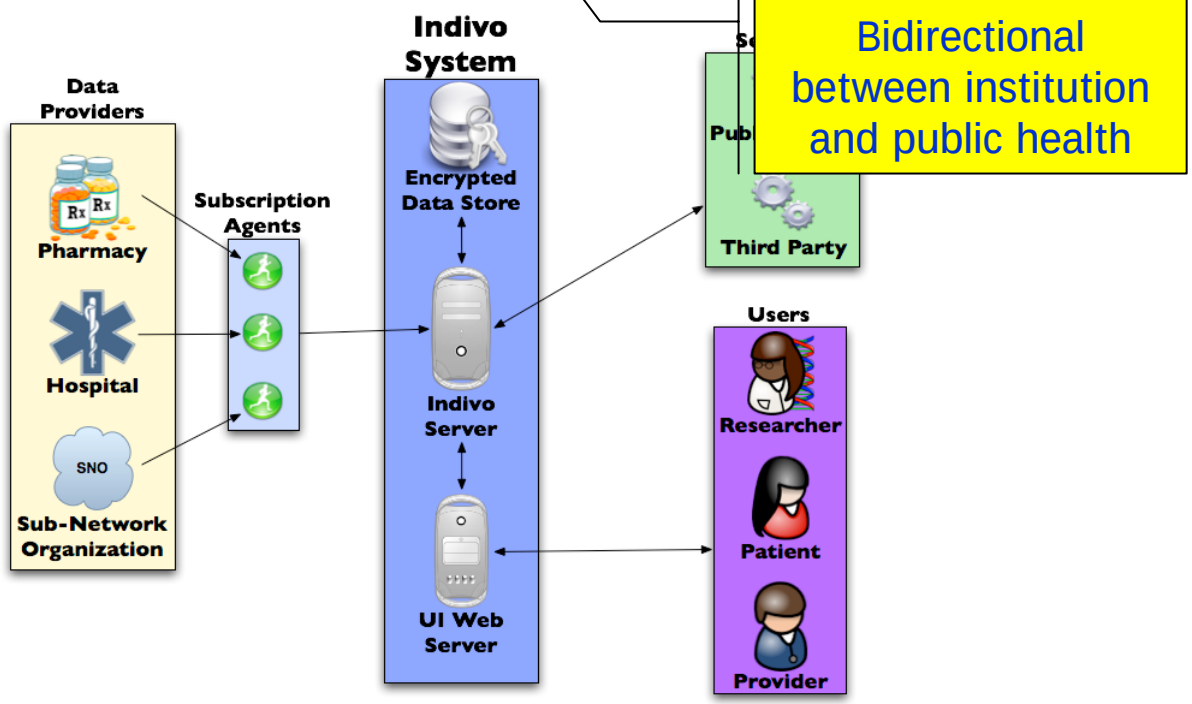


- "De-identified data"
- Mandatory reporting in public health
- Surveillance

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

Bidirectional between institution and public health

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



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**

A score card

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

Even in a RHIO-enabled world

- Privacy
  - ✓ April 2006 ACLU letter to Congress
  - ✓ Moving toward a system of opt in and opt out
  - ✓ Danger is a massive opt out or failure to opt in
- Personal control allows HIPAA compliant sharing of medical data for public health and research

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)

Children's Hospital Informatics Program — Harvard Medical School

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

AEGIS — HARVARD MEDICAL SCHOOL — Children's Hospital Boston

Help | Logout

SELECT DATE

—	—	—	—	—	—	19
20	21	22	23	24	25	26
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

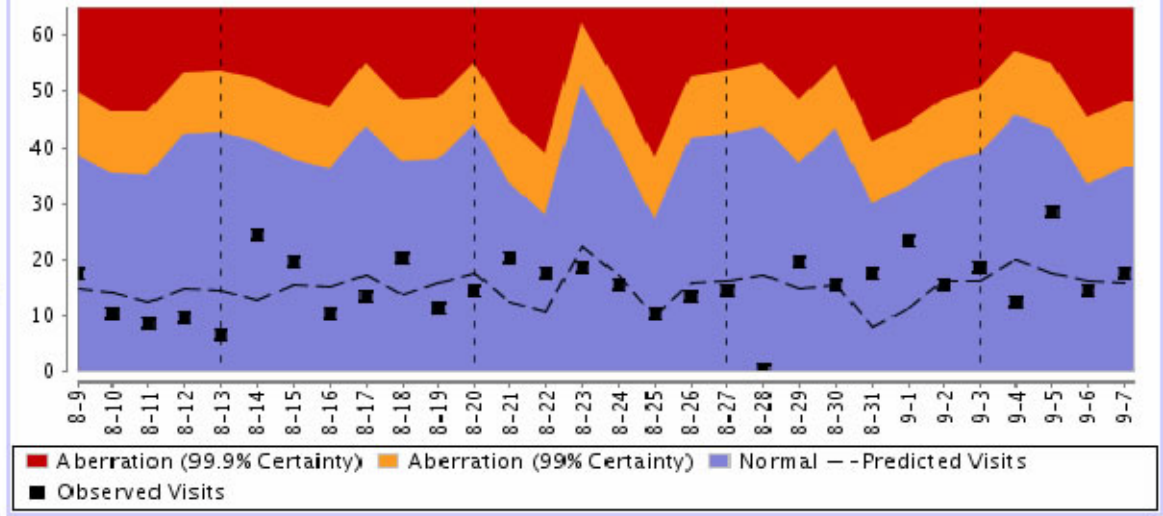
Other Aberrations

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

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

TEMPORAL | HISTORICAL



Flipside of completeness is fragmentation

- Ironically, the technology to integrate is itself fragmenting
- At this moment in time, fragmentation of PCHR's themselves—many many offerings.
  - ✓ Health insurance plans
  - ✓ Employers
  - ✓ Hospitals
  - ✓ Primary care practices
  - ✓ Independent models

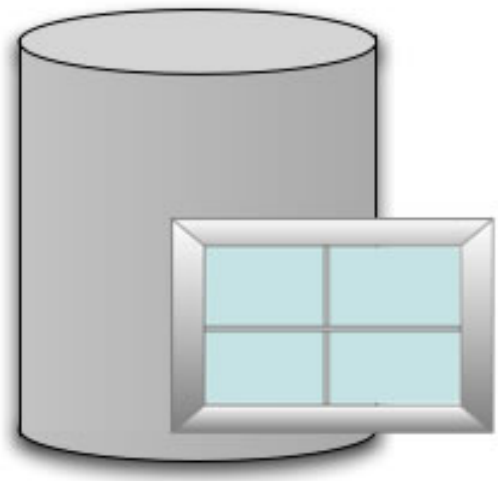
Tethered PHR

- Identity management—by CDO
- Patient information access—website at each site of care
- Data aggregation—none

Score:

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

Context specific



Personal NHIN gateway via CDO

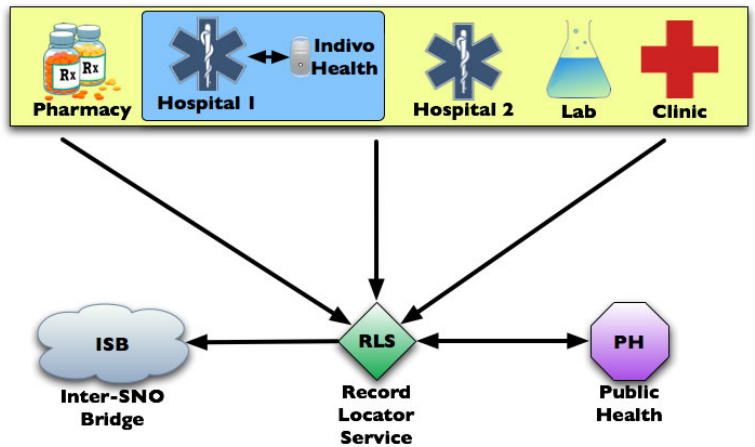
- Identity management—by CDO
- Patient information access—via PCHR website
- Data aggregation—by coordinating entity

Score:

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

Dependent on rate of SNO development. Hospital 2 has to trust Hospital 1

Would be 3 except for opt out



Personal NHIN gateway PCHR Service

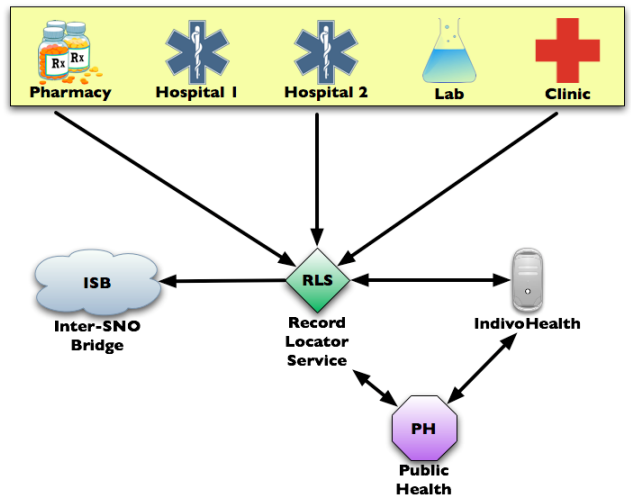
- Identity management—by PCHR service
- Patient information access—via PCHR website
- Data aggregation—by coordinating entity

Score:

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

Dependent on rate of SNO development

Would be 3 except for opt out

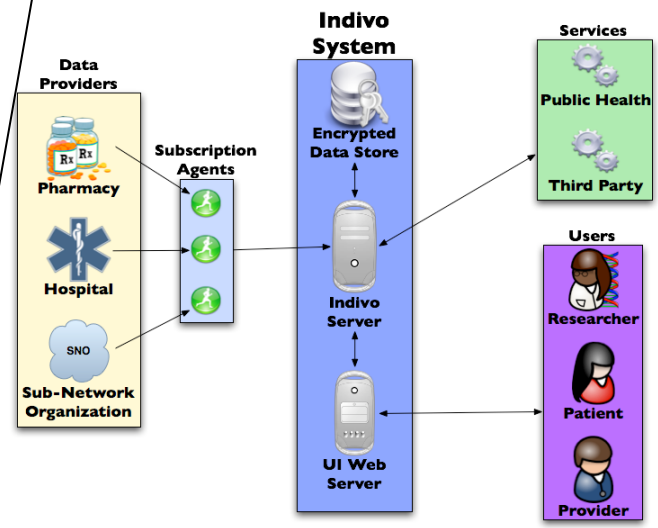


PCHR-centric (Aristotelian)

- 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

BMJ

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

The NEW ENGLAND JOURNAL of MEDICINE

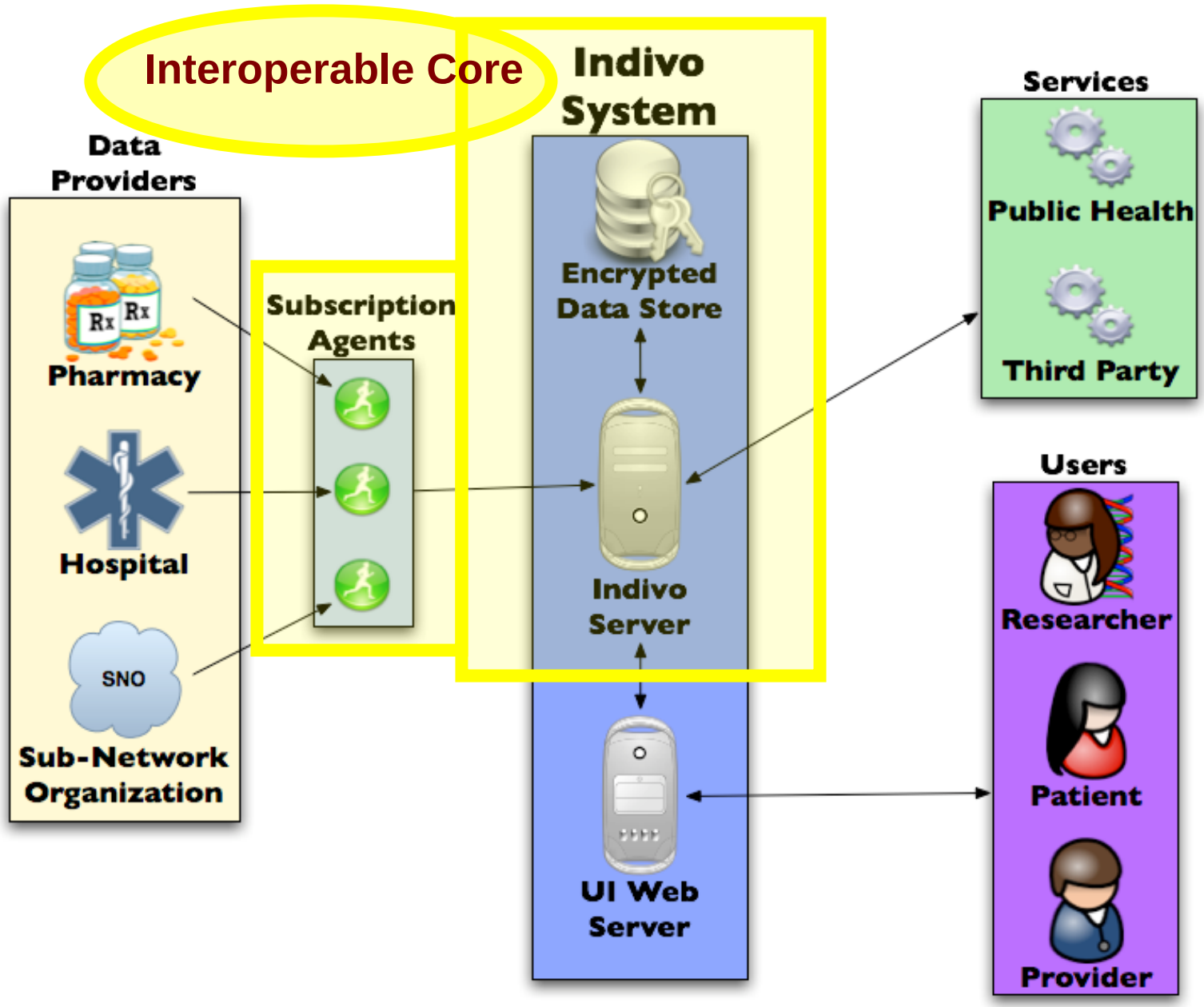
SOUNDING BOARD

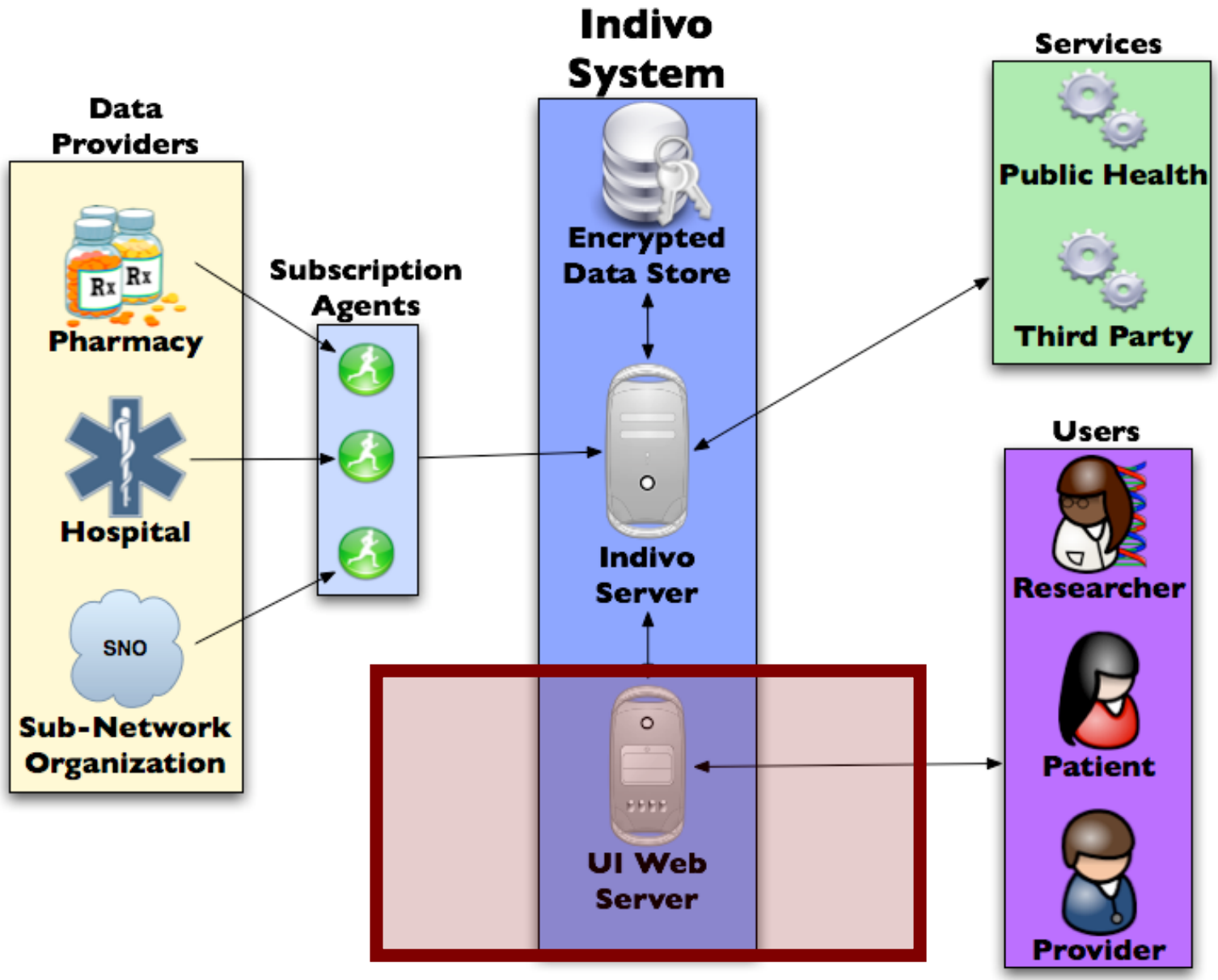
Health-Information Altruists — A Potentially Critical Resource

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


Interoperable Core
Indivo System
Data Providers
Pharmacy
Hospital
SNO
Sub-Network Organization
Subscription Agents
Encrypted Data Store
Indivo Server
UI Web Server
Services
Public Health
Third Party
Users
Researcher
Patient
Provider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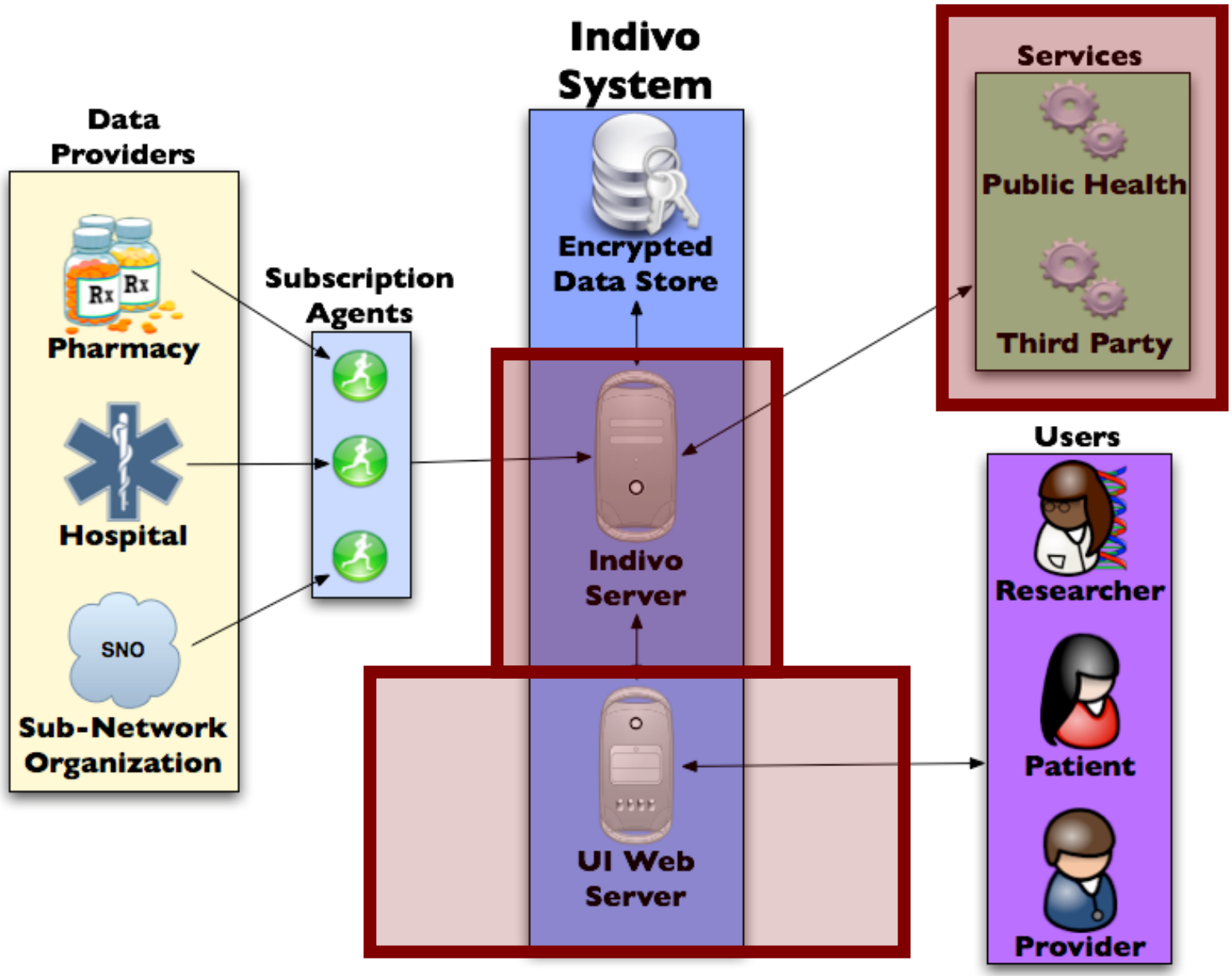
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Third Party
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Patient
Provider

chip Children's Hospital Informatics Program Harvard Medical School

The NEW ENGLAND JOURNAL of MEDICINE

Perspective

AUGUST 31, 2006

Primary Care — Will It Survive?

Thomas Bodenheimer, M.D.

The American College of Physicians recently warned that "primary care, the backbone of the nation's health care system, is at grave risk of collapse."[1] And indeed, primary care is facing a confluence of factors that could spell disaster. Patients are increasingly dissatisfied with their care and with the difficulty of expressing frustration that the knowledge and skills they are expected to master exceed the limits of human capability, making das that cause patients dissatisfaction simultaneously breed frustration in physicians.

Contributing to this frustration is the growing set of demands placed on primary care. The preventive services that a physician either ought to provide because there is evidence of their efficacy or might provide because of the

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