



Children's Hospital
Informatics Program



Harvard
Medical School



Electronic Health Records: Platforms, Libraries, and Evidence

Kenneth D. Mandl, MD, MPH

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Children's Hospital Informatics Program
Children's Hospital Boston

Center for Biomedical Informatics
Harvard Medical School



*“We have lots of information technology.
We just don’t have any information.”*



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Libraries and the EHR

- ✓ Evidence delivery for Clinical Decision Making
 - ☞ Traditional evidence (the literature in journals)
 - ☞ Guidelines
- ✓ Knowledge resources
 - ☞ Consumer facing (Medline Plus)
 - ☞ Physician facing (Up to Date and beyond)
- ✓ Next Gen Knowledge Resources
 - ☞ Data to contextualize medical decisions
 - ☞ E.g., annotated gene variants
- ✓ Evidence about the HIT for HIT decision-makers (itdothealth)



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Primary literature



Meta analysis

The Cochrane Collaboration
Cochrane Reviews

Search Reviews
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Audio summaries | Evidence Aid summaries | Cochrane Methodology abstracts

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This database offers free access to the abstracts and, where available, the plain language summaries of all Cochrane systematic reviews. Links to the full-text versions are available on each page (see below for more information on access).

Search abstracts & summaries

Search Reviews

Advanced search

Browse abstracts & summaries

- **By topic** (according to Cochrane Review Groups)
- [Full list of reviews](#) (alphabetical list by title)
- [Full list of protocols](#) (alphabetical list by title)
- [Full list of registered titles](#) (alphabetical list by title)

By date and origin

- [New reviews only](#) (all new reviews from the current issue)
- [Updated reviews only](#) (all updated reviews from the current issue)
- [By date range](#)
- [By country of author](#)

Special collections

- [Audio summaries](#) of selected reviews (Podcasts from *The Cochrane Library*)
- [Evidence Aid summaries](#) (resources for natural disasters and other healthcare emergencies)
- [Cochrane Methodology abstracts](#)

Guidelines

The screenshot shows a web browser window displaying the 'mapofmedicine' website. The page title is 'Deep vein thrombosis - primary care'. The breadcrumb trail is 'Medicine / Haematology and haemostasis / Deep vein thrombosis'. A search bar is visible with the text '(e.g. asthma or "chest pain")'. The main content area features a flowchart for 'Suspected deep vein thrombosis (DVT)'. The flowchart starts with 'Suspected deep vein thrombosis (DVT)' and leads to 'Typical presentation', 'Clinical assessment', and 'Consider differential diagnosis'. From 'Consider differential diagnosis', the flowchart branches into three paths: 'Pregnancy', 'Recurrent DVT', and 'First DVT, not pregnant'. The 'Pregnancy' path leads to 'Refer urgently'. The 'Recurrent DVT' path leads to 'Refer urgently'. The 'First DVT, not pregnant' path leads to 'Determine pretest possibility', which then leads to 'Consider urgent referral' and finally 'Refer urgently'. A 'Key' button is located on the left side of the flowchart. On the right side, there is a sidebar for 'Suspected deep vein thrombosis (DVT)' with tabs for 'Quick info', 'Notes', and 'Add local info'. The 'Quick info' tab is active, showing a definition, incidence, and risk factors for DVT. The definition states: 'DVT is defined as a total or partial blockage by a blood clot of a deep vein in the legs - calf DVT affects the veins of the calf and proximal DVT affects veins above the knee'. The incidence is noted as 'the annual incidence of DVT is approximately 1/1000 people'. Risk factors include 'age', 'recent surgery', 'immobility including air travel', and 'past history of DVT'. A search button for the 'National Library for Health' is also present in the sidebar.

mapofmedicine® Institute for Innovation and Improvement NHS

Dr M. Stein | Profile | Admin report | Log out

Current view S-Devon | International | Other views

Deep vein thrombosis - primary care

Print page Feedback (3) Referral Letters Return Home

Medicine / Haematology and haemostasis / Deep vein thrombosis

Search: (e.g. asthma or "chest pain") Search

Key

Suspected deep vein thrombosis (DVT)

Typical presentation

Clinical assessment

Consider differential diagnosis

Pregnancy

Recurrent DVT

First DVT, not pregnant

Refer urgently

Refer urgently

Determine pretest possibility

Go to deep vein thrombosis - diagnosis

Consider urgent referral

Refer urgently

Suspected deep vein thrombosis (DVT)

Quick info Notes Add local info

Definition:

- DVT is defined as a total or partial blockage by a blood clot of a deep vein in the legs - calf DVT affects the veins of the calf and proximal DVT affects veins above the knee

Incidence:

- the annual incidence of DVT is approximately 1/1000 people

Risk factors include:

- age
- recent surgery
- immobility including air travel
- past history of DVT

Search National Library for Health

Done Internet

Live data

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

A E G I S

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

Map | Satellite | Hybrid

TEMPORAL | HISTORICAL

■ Aberration (99.9% Certainty)
 ■ Aberration (99% Certainty)
 ■ Normal
 Predicted Visits
 ■ Observed Visits

Done



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Use Case

A library wants to deliver one of these forms of evidence
INTO the clinician workflow



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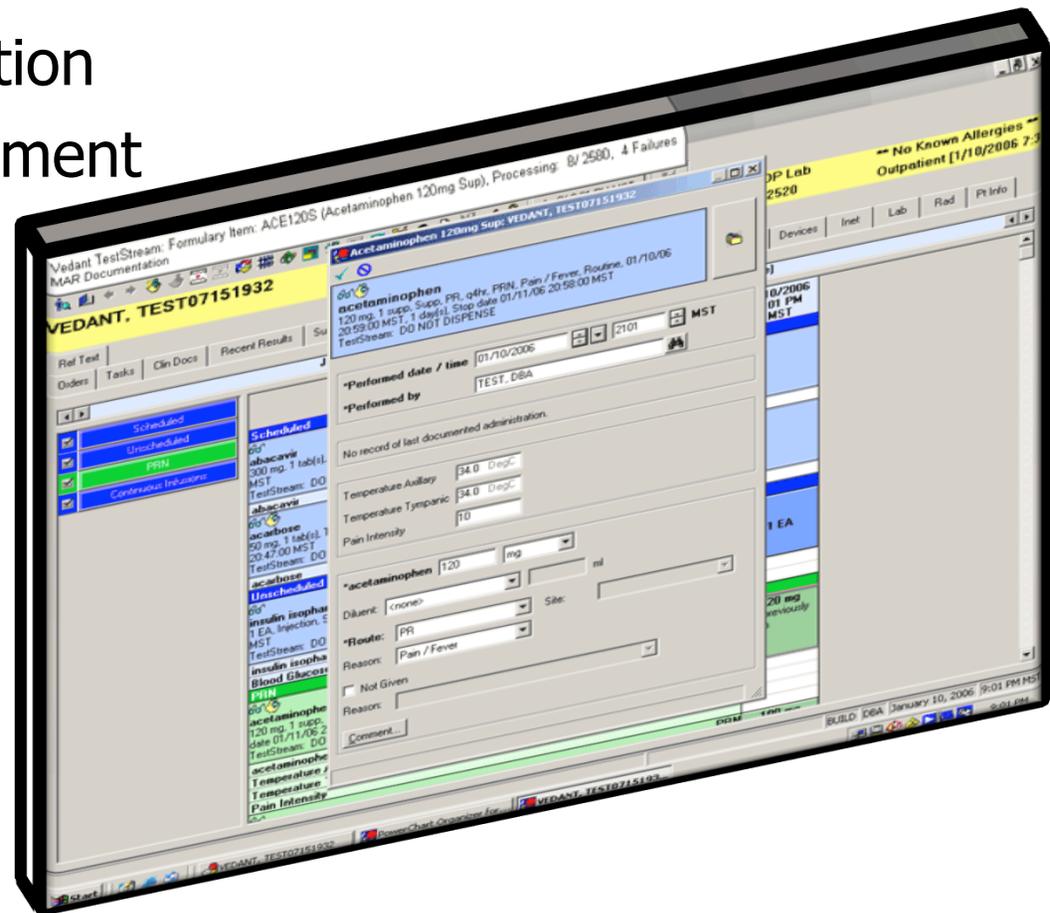


Healthcare Reform includes a \$48B investment in HIT



What's in an EMR?

- Documentation
- Billing
- Laboratory information
- Medication management
- ?Communication





David Blumenthal (ONC director)

- 2008—Only about 4% of primary care practices have full electronic health records
- 2009—Only about 1.5% of hospital have full electronic medical records



The right conclusion?

- Need to use funding to push technology into practice
 - ✓ (\$40,000/doc)?
- Or that the technology has failed?

Are Doctors Luddites?



Has the promise of EMR been fulfilled?

Table. Frequencies of Reported Medication Ordering Errors and Error Risks Involving the CPOE System (n = 261 Respondents)

Error Type	Error Frequency During Past 3 Months, %					
	Never	Less Than Once a Week	About a Few Times a Week	About Once a Day	More Than Once per Day	Missing Response, %
Information Errors*						
Used CPOE to determine low dose for infrequently used medications	27.3	34.6	28.5	7.3	2.3	0.3
Used CPOE to determine the range of doses for infrequently used medications	18.5	40.4	27.3	10.8	3.1	0.3
Delayed for several hours canceling medication because of fragmented CPOE display	48.6	29.0	12.0	6.2	4.2	0.6
Observed a gap in antibiotic therapy because of unintended delay in reapproval of antibiotic	16.9	43.5	26.9	6.9	5.8	0.3
Human-Machine Interface Flaws†						
Not able to quickly tell which patients ordering for because of poor CPOE display	45.4	32.3	12.3	5.0	5.2	0.3
Been uncertain about patients' medications because of multiple CPOE displays	28.5	25.4	23.4	11.7	10.9	1.5
Delayed ordering because CPOE system down	16.3	45.0	33.1	8.8	4.6	0.3
Had difficulty specifying medications and problems ordering off-formulary medications	8.5	37.1	30.9	12.0	11.6	0.6

Abbreviation: CPOE, computerized physician order entry.

*Generated by fragmentation of data and failure to integrate the hospital's several computer and information systems.

†A reflection of machine rules that do not correspond to work organization or usual behaviors.

EMRs

- Very expensive
- Monolithic by design
- Tough to integrate into workflows
- Reduce productivity
- Difficult to customize or to integrate across systems
- Don't support information exchange
- Don't support communication

- Recently brought to light:
 - ✓ Hold harmless clauses
 - ✓ Gag orders
 - ✓ Congressional investigation



“I have no idea how you died. We don’t have access to your medical records.”

Disruptive Innovation

- What is it?
- Is it being prevented by:
 - ✓ Entrenched companies making products that are
 - ☞ Monolithic
 - ☞ Difficult to integrate
 - ☞ Complex and sprawling
 - ✓ Governmental protection?
- Will it happen anyway?



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The NEW ENGLAND
JOURNAL of MEDICINE

No Small Change for the Health Information Economy

Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., Ph.D.

The economic stimulus package signed by President Barack Obama on February 17 included a \$19 billion investment in health information technology. How can we best take advantage of this unprecedented opportunity to computerize health care and stimulate the health information economy while also stimulating the U.S. economy? A health care system adapting to the effects of an aging population, growing expenditures, and a diminishing primary care workforce needs the support

of a flexible information infrastructure that facilitates innovation in wellness, health care, and public health.

Flexibility is critical, since the system will have to function under new policies and in the service of new health care delivery mechanisms, and it will need to incorporate emerging information technologies on an ongoing basis. As we seek to design a system that will constantly evolve and encourage innovation, we can glean lessons from large-scale information-

technology successes in other fields. An essential first lesson is that ideally, system components should be not only interoperable but also substitutable.

The Apple iPhone, for example, uses a software platform with a published interface that allows software developers outside Apple to create applications; there are now nearly 10,000 applications that consumers can download and use with the common phone interface. The platform separates the system from the functional-



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Can we build EHR as an “iPhone-like” Platform

- There is a common application programming interface that enables
 - ✓ Software developers to build **SUSTITUTABLE** applications
 - ☞ Push innovation to the edges
 - ☞ Nimbly evolve functionality
 - ☞ Avoid vendor lock
 - ☞ Shrink switching costs



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Success of the iPhone platform

- 10,000→25,000→85,000 apps
- 2 Billion downloads
- 2800 medical apps

But what kind of platform(s)?

- Two major axes
 - ✓ Open vs. proprietary
 - ✓ Provider-centered vs. patient centered

- NB, the substitutable model is essential wherever you are on either of the above axes



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Federal CTO, HHS CTO, ONC

- Health internet
- Distributed innovation
- Consumer engagement
- PCHRs as first order members of the network

Consider this back-of-the envelope calculation

On a social networking site for people with diabetes:

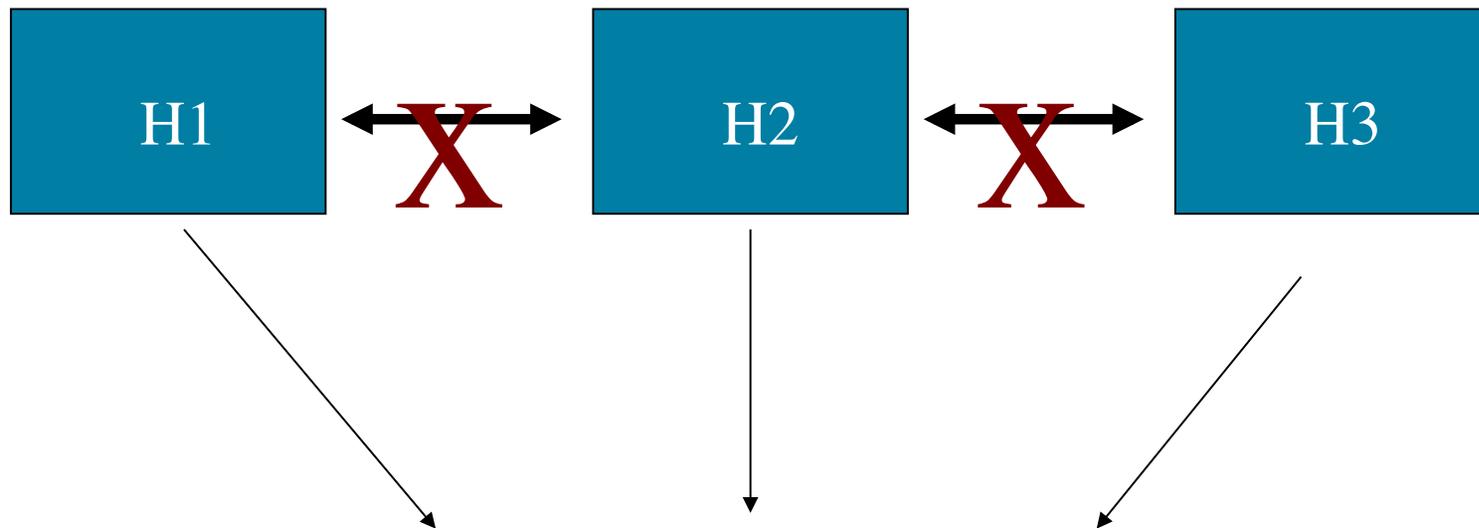
- Over one year, members in just 10 selected, geographically and demographically diverse states, spent approximately 54,000 hours online at the site.
- The average time onsite per member was just over 6 minutes per visit.
- At least half of these were returning members.
- Had we attempted to provide this much face-time in the traditional health care system, even assuming an unrealistically low reimbursement rate of \$100 per hour, the cost would have been \$5,400,000 dollars.

Hospitals do not have a history of sharing information



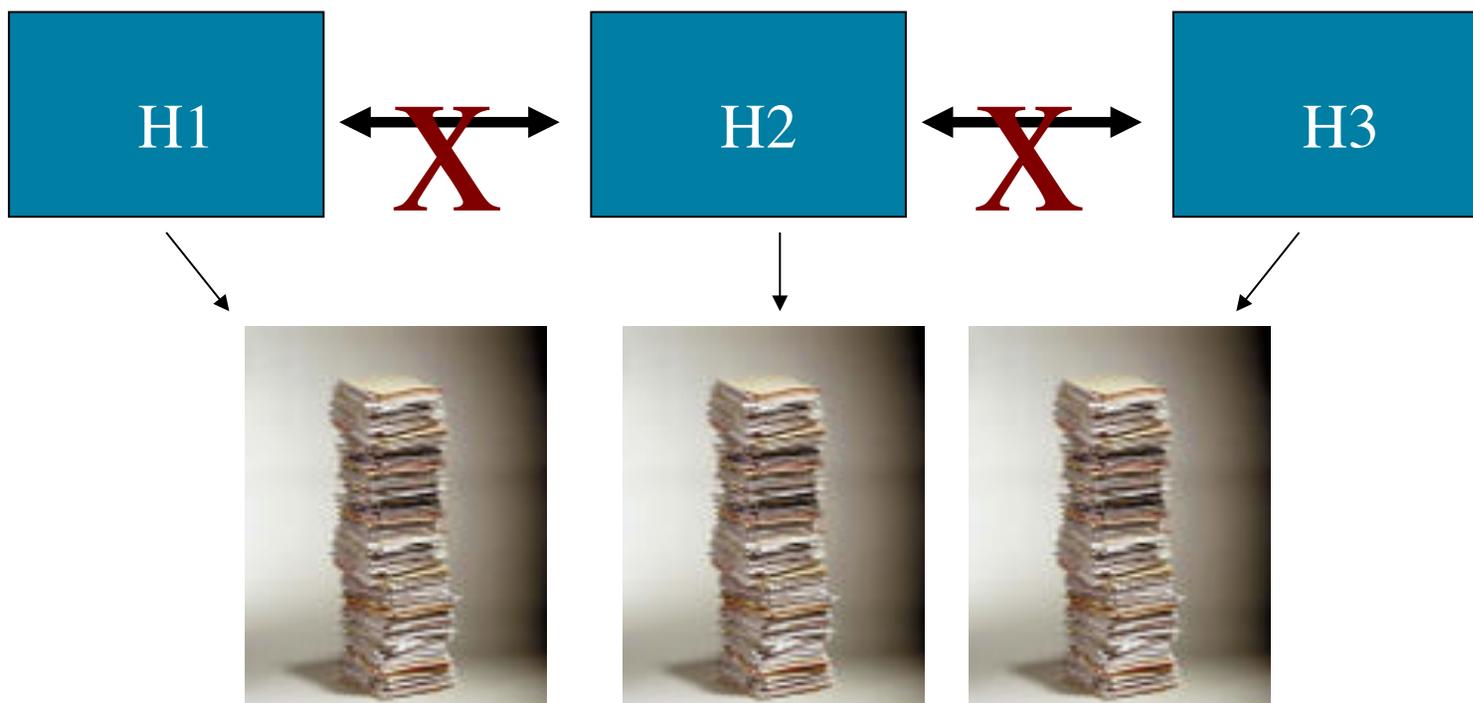
- Proprietary
- Perceived competition
- Privacy
- Health Insurance Portability and Accountability Act
- No dedicated resources to do so

**The patient has rights
to request the record**

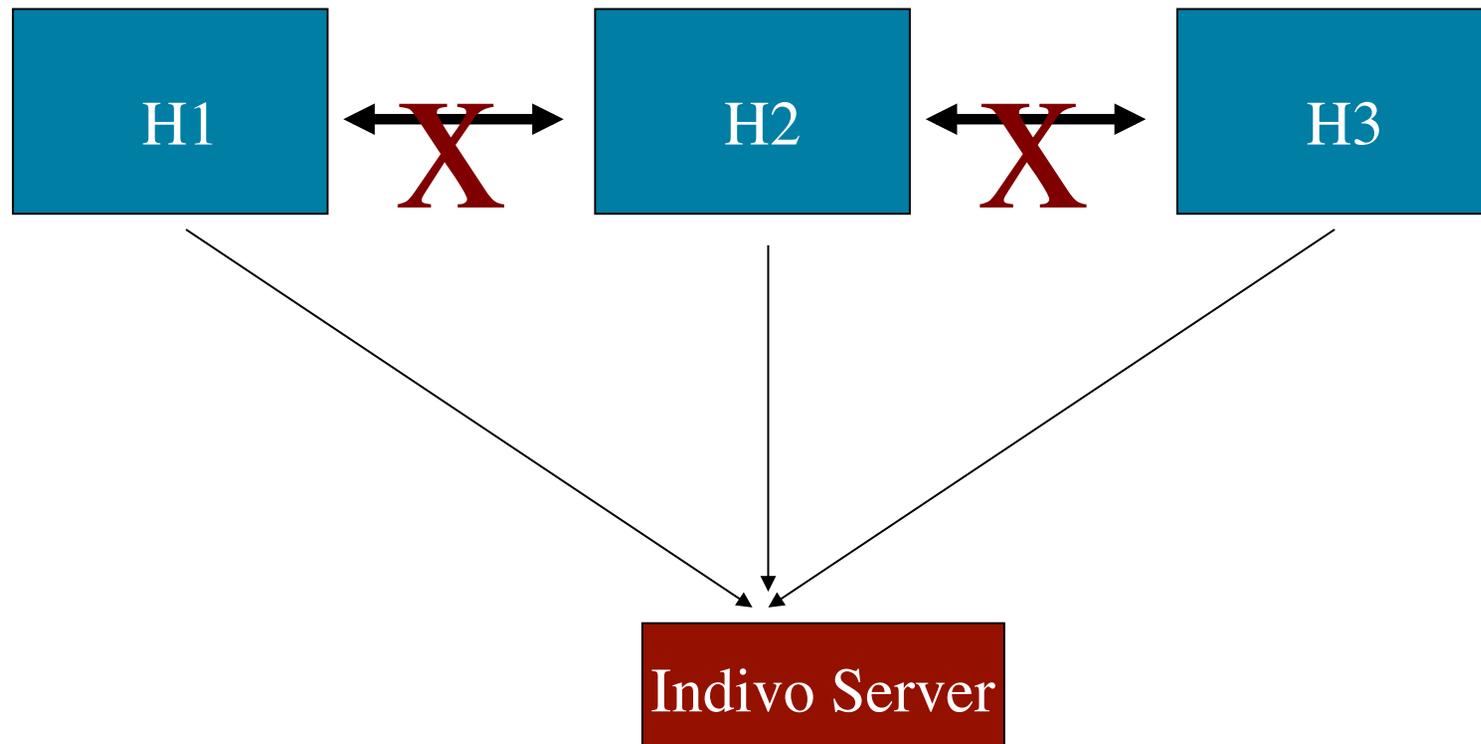


May I please have my record?

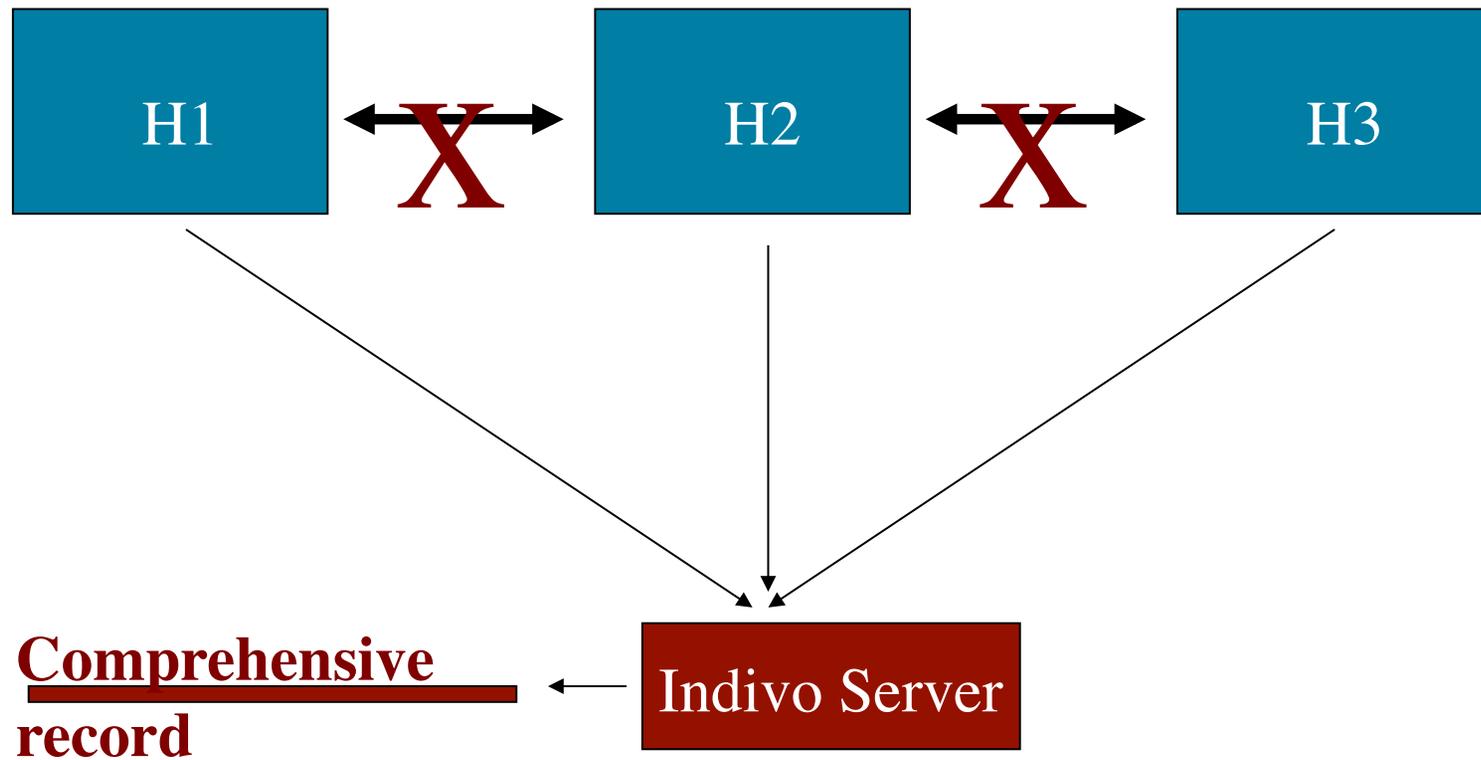
Currently . . .



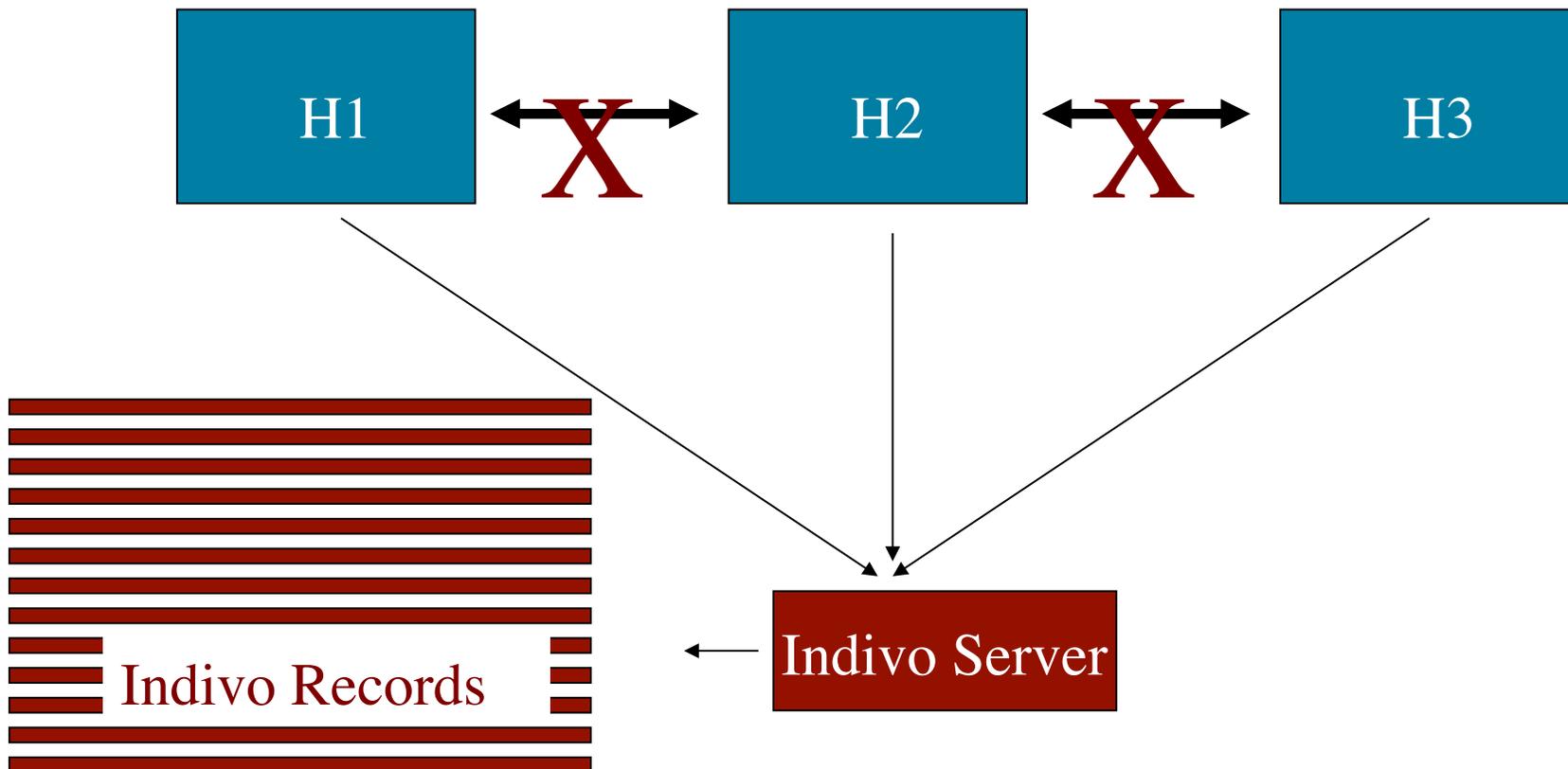
What if we gave patients a tool to request their records electronically?



And create a personal health record



**The collection of these records
is a population health database**



Our original statement on personal control

- 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



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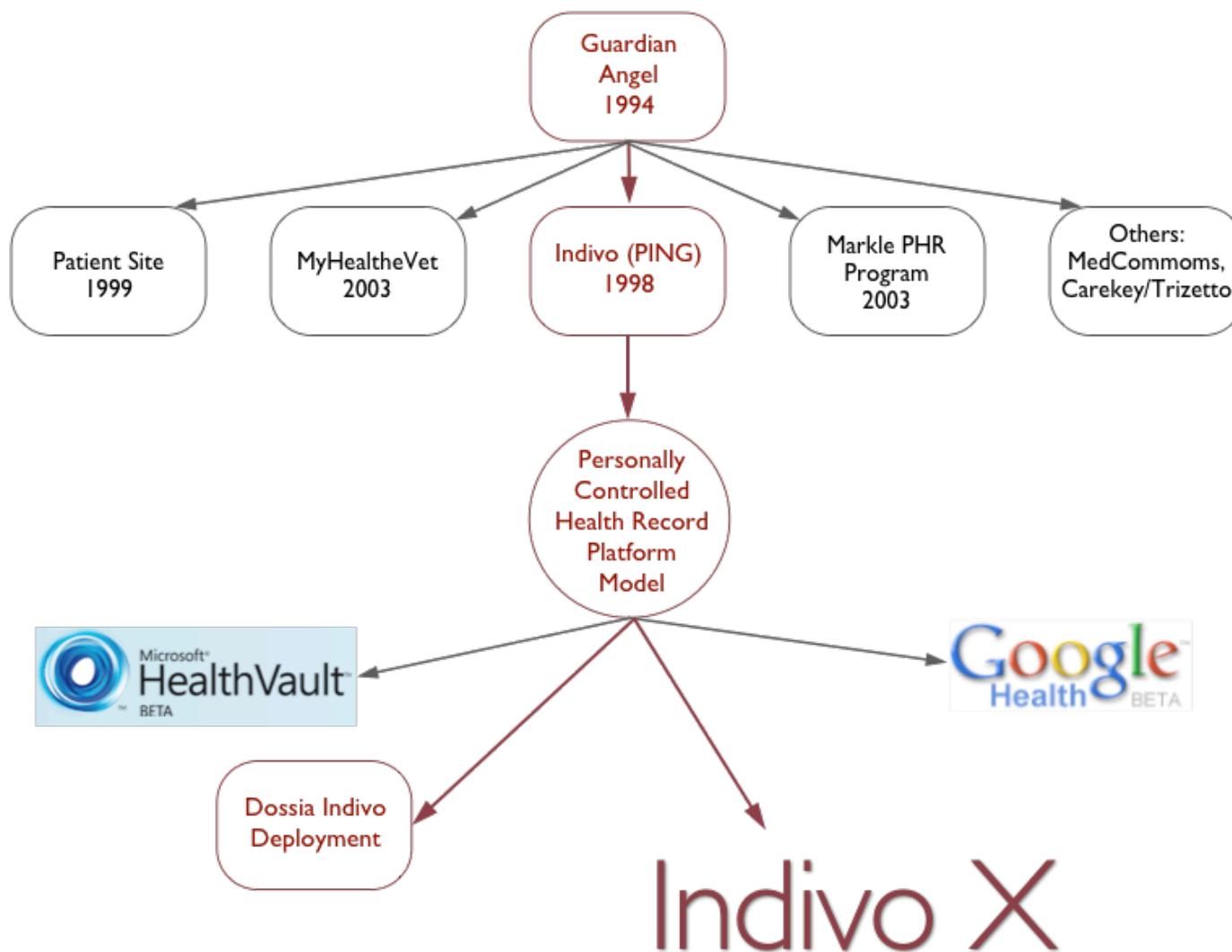


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PCHRs: the reference application

- Indivo
 - ✓ An open source PCHR
 - ✓ Developed with CDC and NIH funding
 - ✓ Built to public standards
 - ✓ Deployments:
 - ☞ Children's Hospital Boston
 - ☞ Massachusetts Institute of Technology
 - ☞ Dossia founding company employees (Walmart, AT&T, Intel . . .)
 - ☞ McMaster University affiliated sites
 - ☞ McGill University affiliated sites
 - ✓ New release, Indivo X, fall 2009





Indivo: The Open Source PCHR

MyChildren's | Children's Hospital Boston

USER GUARDIAN TESTING
[logout](#) | [manage account](#) | [help](#)

Health Records << MyChildren's Home

Health Records | Secure Messaging | Appointments | Demographics | Billing

Select Patient: Child Ten Testing

Child Ten Testing's Health Records

- » Bulletins
- » Account Preferences
- » Summary
- ▼ Health Profile
 - Problems
 - Medications
 - Allergies
 - ▼ Immunizations
 - » Current Immunizations
 - » Voided Immunizations
 - » Pediatric Chart
 - Equipment
 - Measurements
- Clinical Information
- Reports
- » Subscriptions
- » Export Records
- Sharing
- » Hidden Documents
- » Health Resources

IMMUNIZATIONS

Pediatric Chart

CLICK ANY IMMUNIZATION DATE FOR DETAILS.

Add immunization Get immunization forecast

Vaccine	Doses				
Hepatitis B	12-Apr-00	11-Jul-01			
Rotavirus					
Diphtheria, Tetanus, Pertussis	15-Nov-99	10-Jan-00	03-Mar-00	07-Feb-01	16-Jul-04
Diphtheria, Tetanus					
Tetanus and Diphtheria					
Haemophilus influenzae B	15-Nov-99	10-Jan-00	03-Mar-00	07-Feb-01	
Polio	15-Nov-99	10-Jan-00	09-Jun-00	11-Jul-01	
Measles, Mumps, Rubella	11-Sep-00				
Varicella	11-Sep-00				
Pneumococcal	11-Sep-00	07-Feb-01			
Hepatitis A					
Meningococcal					

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INDIVO™ PERSONALLY CONTROLLED HEALTH RECORD



Verbs of personal control: SUBSCRIBE

MyChildren's | Children's Hospital Boston

user: GUARDIAN TESTING
[logout](#) | [manage account](#) | [help](#)

Health Records << MyChildren's Home

Health Records | Secure Messaging | Appointments | Demographics | Billing

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- » Hidden Documents
- » Health Resources

DATA SUBSCRIPTIONS
Children's Hospital Boston

[Back to Subscriptions](#) | [Unsubscribe from this agent](#)

STATUS
Subscribed

ADMINISTRATOR CONTACT
<http://chextdev.tch.harvard.edu/mychildrens/contact>

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

UPDATE INTERVAL
24 hours

RECORD LAST UPDATED
8 Nov 2008 10:10 AM

TOTAL ADDED/UPDATED DOCUMENTS
39



Verbs of personal control: SHARE

MyChildren's | Children's Hospital Boston

user: GUARDIAN TESTING
[logout](#) | [manage account](#) | [help](#)

Health Records << MyChildren's Home

Health Records | Secure Messaging | Appointments | Demographics | Billing

Select Patient: Child Ten Testing

Child Ten Testing's Health Records

- » Bulletins
- » Account Preferences
- » Summary
- ▼ Health Profile
 - Problems
 - Medications
 - Allergies
 - ▼ Immunizations
 - » Current Immunizations
 - » Voided Immunizations
 - » Pediatric Chart
 - Equipment
 - Measurements
- Clinical Information
- Reports
- » Subscriptions
- » Export Records
- ▼ Sharing
 - ▼ My Records
 - » With Groups
 - » With Individuals
 - » Other People's Records
- » Hidden Documents
- » Health Resources

SHARING

Share My Health Data With Someone New

DOES THIS PERSON ALREADY HAVE AN INDIVO ID? *

Yes
 No / Not Sure

[continue](#) [cancel](#)



“This one allows release of your information to a sitcom”



Verbs of personal control: EXPORT

MyChildren's Children's Hospital Boston user: GUARDIAN TESTING
[logout](#) | [manage account](#) | [help](#)

Health Records << MyChildren's Home

Health Records | Secure Messaging | Appointments | Demographics | Billing

Select Patient: Child Ten Testing

Child Ten Testing's Health Records

- » Bulletins
- » Account Preferences
- » Summary
- ▼ Health Profile
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 - Medications
 - Allergies
 - ▼ Immunizations
 - » Current Immunizations
 - » Voided Immunizations
 - » Pediatric Chart
 - Equipment
 - Measurements
- Clinical Information
- Reports
- » Subscriptions
- » Export Records
- Sharing
- » Hidden Documents
- » Health Resources

EXPORT

Export Your Record

An export file may be used to transfer your personal health data to another system, or backup your data in another location. Click the "Export & Download" button. When the export has been generated, a browser notification will appear asking you to save the export to your computer.

Please Note: If you're an IE 7.0 user, you may have to click the "Export & Download" button twice to generate the exported file.

EXPORT FORMAT *

IndivoHealth

export & download

www.pchri2006.org and www.pchri2007.org

PCHRI2006

The Harvard Medical School Meeting on Personally
Controlled Health Record Infrastructure

PCHRI2007

The Harvard Medical School Meeting on Personally
Controlled Health Record Infrastructure

Copyrighted Material
 "Clayton Christensen has done it again, writing yet another book full of valuable insights . . .
The Innovator's Prescription might just mark the beginning of a new era in healthcare."
 —MICHAEL BLOOMBERG, Mayor, New York City

The Innovator's Prescription

A Disruptive Solution for Health Care



Clayton M. Christensen
 BESTSELLING AUTHOR OF *THE INNOVATOR'S DILEMMA*
 Jerome H. Grossman, M.D. & Jason Hwang, M.D.

"We cannot overstate how important PHRs are to the efficient functioning of a low-cost, high quality health-care system We think that the INDIVO system, or something like it is a good place to start."

--Clayton Christensen
 Harvard Business School

2009

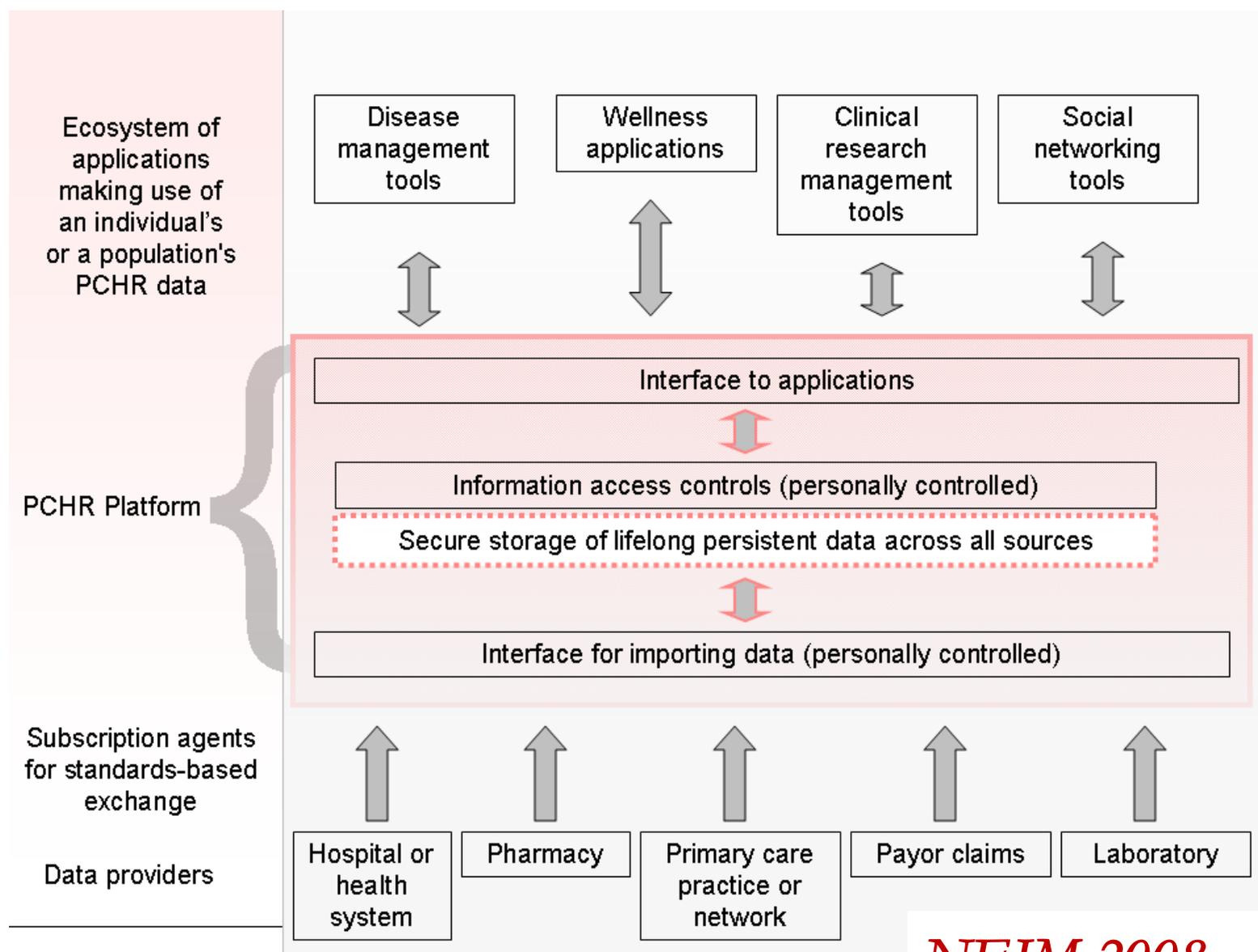


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NEJM 2008



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www.indivohealth.org

The screenshot shows a Mozilla Firefox browser window displaying the Indivo website. The browser title is "The Indivo Personally Controlled Health Record - Mozilla Firefox". The address bar shows "http://indivohealth.org/". The website header includes the "chip" logo and "Children's Hospital Informatics Program" text, along with logos for Children's Hospital, MIT, and HST. A navigation menu contains links for "INDIVO HOME", "RESEARCH & PUBLICATIONS", "INDIVO COLLABORATORS", "DEVELOPER COMMUNITY", and "TEAM & CONTACT INFO". The main content area features the "INDIVO™" logo and the tagline "THE PERSONALLY CONTROLLED HEALTH RECORD". A paragraph describes Indivo as the original PCHR system. A section titled "A platform for health-data innovation" lists features like secure storage and API access. A quote from Micky Tripathi is included. The right sidebar contains news items: "NEW INDIVO WEB SITE", "WAL-MART/DOSSIA LIVE WITH INDIVO", and "DOSSIA PARTNERS WITH CHILDREN'S HOSPITAL". A "More at our Blog" link with an RSS icon is also present.

The Indivo Personally Controlled Health Record - Mozilla Firefox

File Edit View History Bookmarks Tools Help

http://indivohealth.org/

chip Children's Hospital Informatics Program

INDIVO HOME RESEARCH & PUBLICATIONS INDIVO COLLABORATORS DEVELOPER COMMUNITY TEAM & CONTACT INFO

INDIVO™
THE PERSONALLY CONTROLLED HEALTH RECORD

Indivo is the original personally controlled health record (PCHR) system. A PCHR enables an individual to own and manage a complete, secure, digital copy of her health and wellness information. Indivo integrates health information across sites of care and over time. Indivo is free and open-source, uses open, unencumbered standards, and is actively deployed in diverse settings, in particular our own Children's Hospital Boston and the Dossia Consortium.

A platform for health-data innovation

Indivo is built to be extended and customized: users can connect their record to third-party applications that enhance the management and analysis of their health information. Indivo accelerates the development of these third-party applications by providing a core set of common features:

- secure storage, categorization and aggregation of health data.
- single sign-on and standards-based data-access delegation.
- a simple, open, web-based Application Programming Interface (API).
- unified user notification.

"If you ask me, Indivo is the most thoughtful and firmly grounded PHR project in the country, bar none."

MICKY TRIPATHI, PRESIDENT AND CEO OF THE MASSACHUSETTS EHEALTH COLLABORATIVE

NEW INDIVO WEB SITE
We've launched the new Indivo web site, reachable at indivohealth.org.

WAL-MART/DOSSIA LIVE WITH INDIVO
On September 30th, 2008, Wal-Mart went live with Personally Controlled Health Records through Dossia, powered by Indivo!

DOSSIA PARTNERS WITH CHILDREN'S HOSPITAL
On September 17th, 2007, the Children's Hospital Informatics Program and the Dossia Consortium announced ...

More at our Blog.



Microsoft HealthVault

Web health results

Learn about HealthVault | Learn about Devices | Web Application Directory | Device Directory | Personal

Health and fitness sites that connect with HealthVault

Be better connected

These sites use the data in your HealthVault record to help you take your health to the next level. They'll first show you the types of data they want to access and get your permission to do so. Once data's been added to your record, you can use it at other sites that use that data type—there's no need to enter it more than once.

Learn more about how HealthVault works

	<p>ActivePHR From ActiveHealth Management</p> <p>Simplify your life. Organize all your family's medical information - prescriptions, test results, immunizations and even family medical histories - with this easy-to-use online tool. Plus a patented monitoring system that alerts you about opportunities for improved care.</p>	<p>Learn more ></p> <p>Try now ></p>
	<p>Heart360 Cardiovascular Wellness Center From American Heart Association and American Stroke Association</p> <p>Welcome to Heart360! Use it to manage your blood pressure, blood glucose, cholesterol, weight, nutrition and physical activity, while receiving education and information specific to your condition.</p>	<p>Learn more ></p> <p>Try now ></p>
	<p>Heart Profilers From American Heart Association and Thomson Reuters</p> <p>The Heart Profilers are online treatment decision tools for heart patients, their families, and caregivers. The Heart Profilers deliver accurate, up-to-date and personalized treatment options based on clinical studies. Register now for your free, confidential, personalized report.</p>	<p>Learn more ></p> <p>Try now ></p>
	<p>Trial X From Applied Informatics, Inc.</p> <p>Trialx.org automatically matches participants to clinical trials based on their personal health information. Trialx.org uses an up-to-date database of 25,000+ trials approved by the US FDA.</p>	<p>Learn more ></p> <p>Try now ></p>
	<p>registeR4Health From CitiusTech</p> <p>registeR4Health is a simple tool that allows you to share registration information securely with your physician. It enables you to save time, eliminate registration errors and re-use information on your next visit. All registration information is securely stored in HealthVault.</p>	<p>Learn more ></p> <p>Try now ></p>
	<p>HealthCentral.com Health Tools From HealthCentral.com</p> <p>Part of The HealthCentral Network, Inc., HealthCentral.com is a collection of more than 35 consumer-focused, condition-specific health and wellness sites which provide in-depth medical information, tools and vibrant communities.</p>	<p>Learn more ></p> <p>Try now ></p>
	<p>Healthy Circles From Healthy Circles</p> <p>Healthy Circles is a free Personal Health Record (PHR) that allows for the storage and management of you and your loved one's health information. By way of a friendly interface, you can transform your data into interactive graphs and reports for use by you and your healthcare provider.</p>	<p>Learn more ></p> <p>Try now ></p>
	<p>Personal Health Record From LifeClinic.com</p> <p>The LifeClinic Personal Health Record allows individuals to record biometric readings and health information. Biometric readings are automatically inserted into your Personal Health Record when saved at a LifeClinic Health Station (automated blood pressure monitor) connected to the Internet.</p>	<p>Learn more ></p> <p>Try now ></p>

Take charge of your health today. [Create a Free HealthVault account >](#)



HealthVault in Action

See how you can manage your health—and that of your family—with HealthVault.

[Watch Now!](#)



New! Smart health solutions

We did the research and rounded up some handy applications and devices to help you achieve your most common goals:

- Lose or maintain weight
- Get fit, stay fit
- Manage high blood pressure
- Organize family health info
- Prepare for emergency

[See all solutions >](#)



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SURVEILLANCE MODEL

Distribute



I want to see:

Data Set/Category

Remove

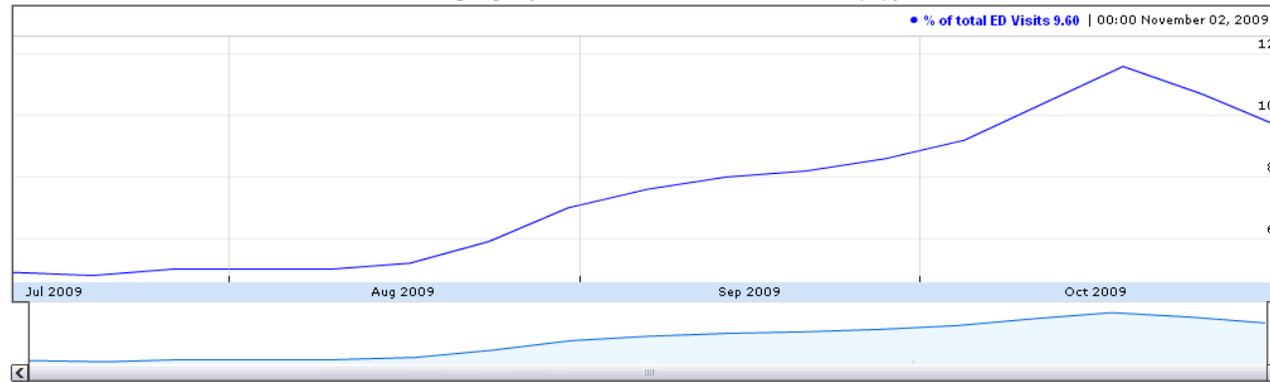
Advanced Tools

Fever (broad) All Ages x

Show:

Percent of Emergency Department Visits For Influenza-Like Illness (ILI) per Week

% of total ED Visits



Data Smoothing:

smooth
by 3 weeks

mean: 7.45 median: 7.6 standard deviation: -47.76

Dataset: Fever (broad)
Category: All Ages

2009-11-02 to 2009-11-09



Distribute



I want to see:

Data Set/Category

Remove

Advanced Tools

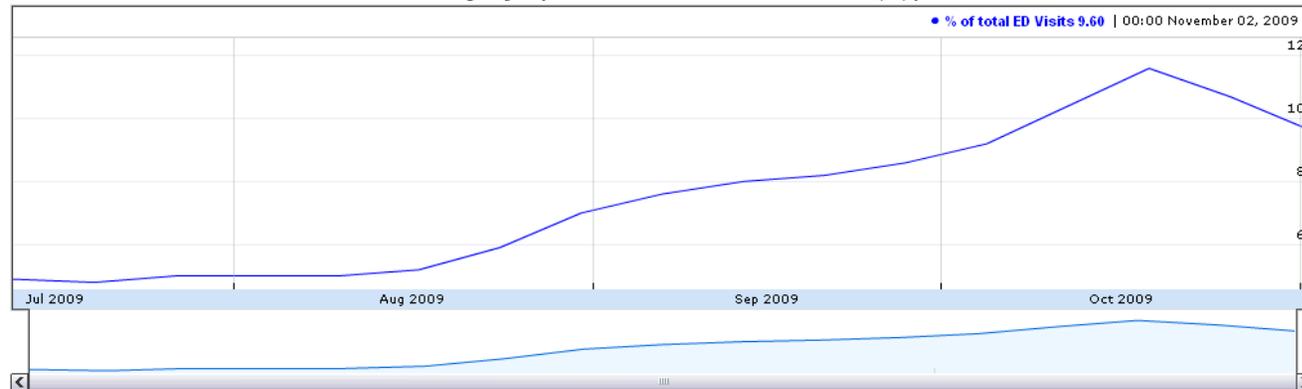
Fever (broad) All Ages x

Show:

% of total ED Visits

Percent of Emergency Department Visits For Influenza-Like Illness (ILI) per Week

• % of total ED Visits 9.60 | 00:00 November 02, 2009



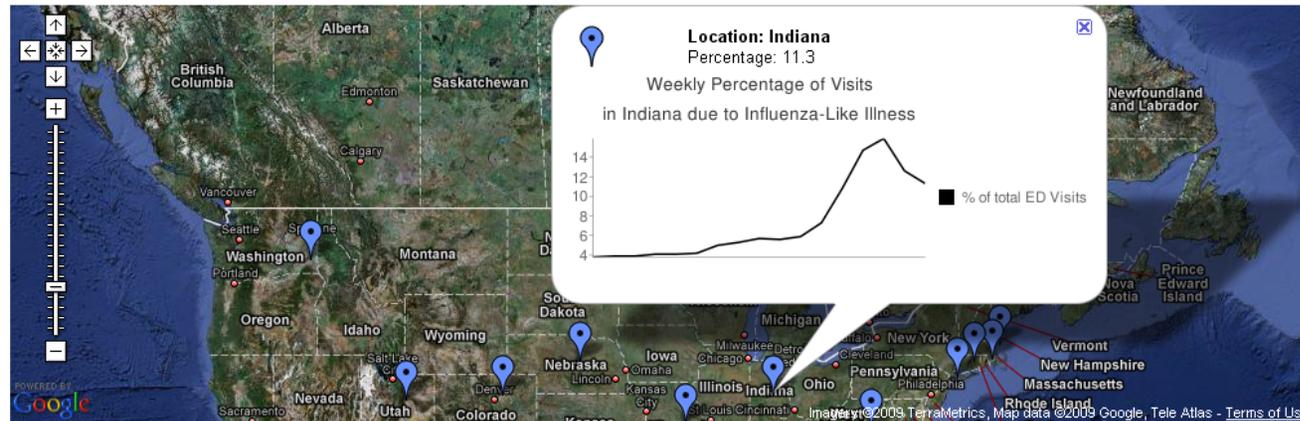
Data Smoothing:

smooth
by 3 weeks

mean: 7.45 median: 7.6 standard deviation: -47.76

Dataset: Fever (broad)
Category: All Ages

2009-11-02 to 2009-11-09





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CONSENTED surveillance



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, efficacious, and safe. The Human Genome Project showed us that among humans, DNA sequences are 99.9 percent similar, but the remaining 0.1 percent, in the context of environmental and epigenetic factors, produces the entirety of genetic variability within the human population. How can we use

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 cross-sectional studies.²

CAUSE FOR CONCERN:
NO PERFECT ANONYMITY

When they agree to participate in research studies,

2006

High potential for information altruism

- ✓ Surveyed experienced PCHR users about willingness to share information from record for population health and public health
 - ☞ 34% users “**very agreeable**”
 - ☞ 35% “**moderately agreeable**”
 - ☞ 21% “**somewhat agreeable**” to sharing for population health monitoring
 - ☞ After more than one year of exposure to a pilot system, ONLY 9% report they are “**not agreeable**” to sharing



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THE CLINICAL AND TRANSLATIONAL RESEARCH MODEL



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PCHR vendors and users create large accessible populations for public health study and intervention



The NEW ENGLAND
JOURNAL of MEDICINE

Tectonic Shifts in the Health Information Economy

Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., Ph.D.

In a recent shift in the health information landscape, large corporations are seeking an integral and transformative role in the management of health care information. The mechanism by which this transformation is likely to take place is through the creation of computer platforms that will enable patients to manage health data in personally controlled health records (PCHRs). Two types of large corporations are involved. Technology companies such as Google and Microsoft see

at one hospital, a visit to an emergency department at another hospital, and test results at a laboratory. She logs into her hosted PCHR at a secure Web site. Since she has established subscriptions to automatic updates from each of these clinical entities, her PCHR is current with copies of those data.

The PCHR enables the patient to authorize access to information (views or even copies of the record) to others, including clinical providers,

New England Journal of Medicine, April 2008

TrialX Enabling Patients to Find New Treatments.

Sign Up as Patient | Sign Up as Investigator | Sign in

- Home
- Take a Tour
- Patients
- Investigators
- Community
- Help

1. Search for clinical trials by entering or importing your health information

The screenshot shows the TrialX search interface. At the top, it says "Start Here! All services are FREE! Your data are kept completely secure and confidential." Below this, there are two main search methods: "Search Trials By Condition or Treatment" and "Get Matching Trials based on your Personal Health Record". The first method has input fields for "Enter conditions" (with an example: diabetes, breast cancer) and "Enter treatments" (with an example: glutamine, infrared therapy). A "Find Clinical Trials" button is below. The second method involves linking to a HealthVault account. A "Recent Searches" list includes "parkinson's disease", "postoperative pain", "measles", "high cholesterol", and "child". A "TrialX Facts" box lists statistics: "14,000+ ongoing clinical trials approved by the US FDA", "8000+ clinical trial investigators", and "3000+ and counting participants matched to clinical trials". A dropdown menu is open over the "Enter conditions" field, showing a list of suggestions for "breast cancer", including "breast cancer", "breast carcinoma", "breast cancer carcinoma", "breast neoplasm", "breast tumor", "breast neopl", "breast cancer stage iv", "breast cancer metastatic", "breast carcinoma stage iv", and "breast feeding".

2. Match yourself to clinical trials using our unique decision engine

Your Health Condition:	Clinical Trials				Match Score
breast cancer e.g. Diabetes or Breast Cancer	Age = 55	Gender = female	Condition = breast cancer	State = NY	How does it work?
Your Location:	A Study of Effectiveness of Trast...	✔	✔	✔	Excellent Match(7/7) Contact Investigator



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The New York Times
Friday, May 9, 2008

Health

WORLD U.S. N.Y. / REGION BUSINESS TECHNOLOGY SCIENCE HEALTH SPORTS OP
RESEARCH FITNESS & NUTRITION MONEY & POLICY

Well

Tara Parker-Pope on Health

[Back to front page »](#)

April 18, 2008, 11:11 am

Can We Trust Google With Our Medical Records?



THE WALL STREET JOURNAL

ews Today's Newspaper My Online Journal Multimedia & Online Extras M

HEALTH BLOG

WSJ's blog on health and the business of health.

Blog Search:

< Heartbeat Genes Could Provide Alternativ[...] -- PREVIOUS | [SEE ALL POSTS FROM THIS BLOG](#) | NEXT >

April 17, 2008, 8:56 am

Can Microsoft and Google Protect Our Health Records?

Posted by Sarah Rubenstein

Microsoft and Google are good at a lot of stuff. But will they be good at safeguarding patients' private health information? And what happens if they mess up?

Both technology giants have unveiled online personal health records that patients can use to store what could be treasure troves of data — for the patients as well as everyone from clinical researchers to marketers. (Microsoft's has launched.) But a critique in this week's issue of the *New England Journal of Medicine* points out that the two companies aren't "covered entities" under the major federal law, HIPAA, that has patient-privacy protections. Translation: They don't have to follow it.



"Unless this changes, a group of researchers may emerge

U.S. News & World Report

Friday, May 9, 2008

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Patient-Controlled Health Records Could Change Future of Research

Used wisely, they may spur discoveries, but some warn privacy needs regulation

Posted 4/16/08

WEDNESDAY, April 16 (HealthDay News) -- Increasing patient control of health records could dramatically change how medical research is conducted, say Children's Hospital Boston researchers.



In a Sounding Board article in the April 17 issue of the *New England Journal of Medicine*, the researchers noted that the shift to personally controlled health records (PCHRs) will give patients and doctors easier access to records during clinical care and will also have a major impact on the conduct of biomedical research.

The New York Times

Business

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MEDIA & ADVERTISING WORLD BUSINESS SMALL BUSINESS YOUR MONEY DEALBOOK MARKETS RESEARCH

Warning on Storage of Health Records

By STEVE LOHR
Published: April 17, 2008

In an [article in The New England Journal of Medicine](#), two leading researchers warn that the entry of big companies like [Microsoft](#) and [Google](#) into the field of personal health records could drastically alter the practice of clinical research and raise new challenges to the privacy of patient records.

The authors, Dr. Kenneth D. Mandl and Dr. Isaac S. Kohane, are longtime proponents of the benefits of electronic patient records to improve care and help individuals make smarter health decisions.

But their concern, stated in the article published Wednesday and in an interview, is that the medical profession and policy makers have not begun to grapple with the implications of companies like Microsoft and Google becoming the hosts for vast stores of patient information.



- **Genes**
- **Environment**
 - **Microbiome**
- **Phenotype**
- **Healthcare**

NEED LARGE N
NEED data capture
at home and in
clinics

Linking Clinical Care to Research via the PHR Platform : The Informed Cohort

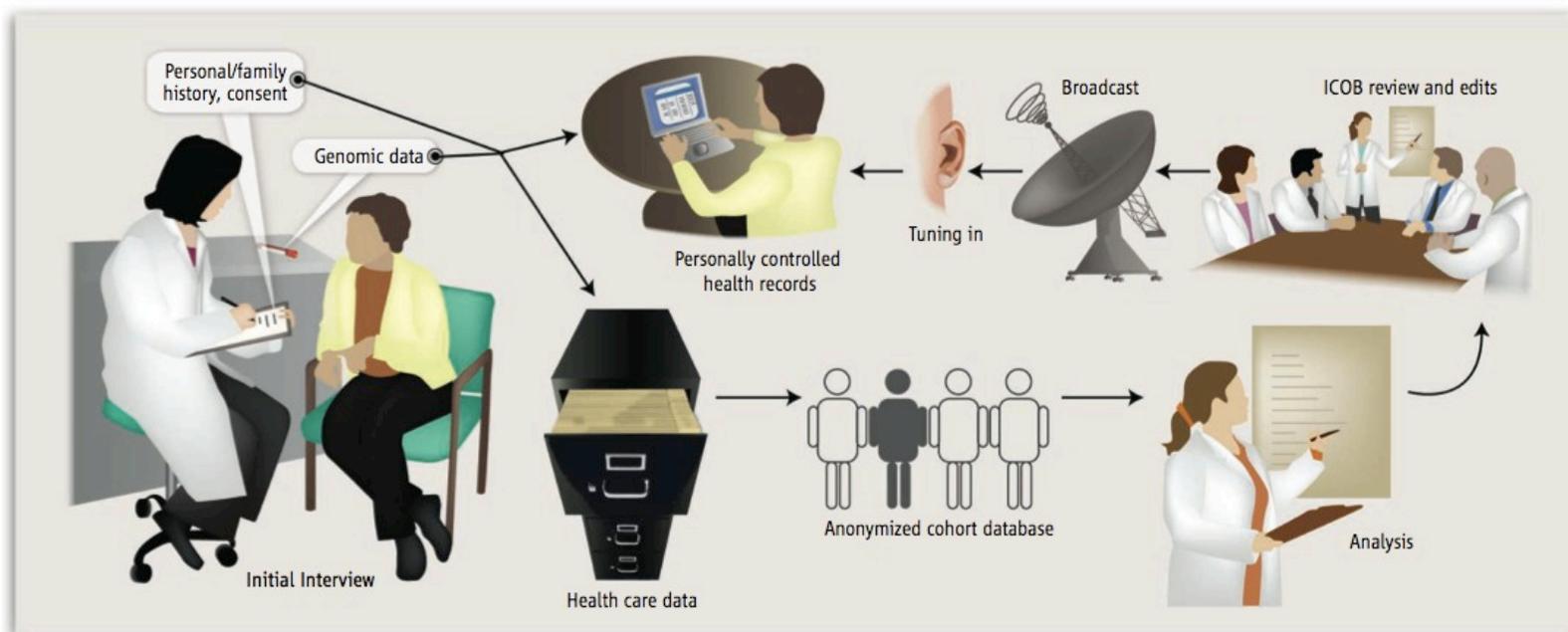
POLICYFORUM

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.



Science, 2007

Limitations on PCHRs

- Slow adoption
- Few clinical data systems yet export to PCHRs
- Constraints on consumers' perceived value (apps not yet there)
- Regulatory flaws, e.g., CLIA
- Consent issues are complex
 - ✓ Terms of use is not consent
 - ✓ Family consent



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An important barrier: consent and permissions for pediatric pop. is complex

Journal of the American Medical Informatics Association Volume 15 Number 6 November / December 2008

737

Viewpoint Paper ■

Whose Personal Control? Creating Private, Personally Controlled Health Records for Pediatric and Adolescent Patients

FABIENNE C. BOURGEOIS, MD, MPH, PATRICK L. TAYLOR, JD, S. JEAN EMANS, MD,
DANIEL J. NICRIN, MD, MS, KENNETH D. MANDL, MD, MPH

Abstract Personally controlled health records (PCHRs) enable patients to store, manage, and share their own health data, and promise unprecedented consumer access to medical information. To deploy a PCHR in the pediatric population requires crafting of access and security policies, tailored to a record that is not only under patient control, but one that may also be accessed by parents, guardians, and third-party entities. Such hybrid control of health information requires careful consideration of both the PCHR vendor's access policies, as well as institutional policies regulating data feeds to the PCHR, to ensure that the privacy and confidentiality of each user is preserved. Such policies must ensure compliance with legal mandates to prevent unintended disclosures and must preserve the complex interactions of the patient-provider relationship. Informed by our own operational involvement in the implementation of the Indivo PCHR, we provide a framework for understanding and addressing the challenges posed by child, adolescent, and family access to PCHRs.

■ J Am Med Inform Assoc. 2008;15:737-743. DOI 10.1197/jamia.M2865.

Journal of the American Medical Informatics Association, 2008



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Next challenges

- Myth of personal control
- What flows across the API
- How data hungry are the applications?
- Can we make this interesting to patients/consumers?



“Whoa—way too much information!”



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