Bridging the Disconnect between Healthcare Providers and Information Technologists

Privacy and Security

The Patient's Perspective

April 9, 2010

Claremont Graduate University

Who said this?

- “Medical records would belong to patients. Clinicians, rather than patients, would need to have permission to gain access to them.”
- *“Individuals have the right to control – and must have the ability to control – who can access their personal health information. All health information technology should be deployed to improve individual health, not to protect the status quo of proprietary claims to data.”*

Citations

- **Don Berwick MD, nominee to lead CMS**: *What 'Patient-Centered' Should Mean: Confessions Of An Extremist***,** *A seasoned clinician and expert fears the loss of his humanity if he should become a patient.* in *Health Affairs* 28, no. 4 (2009): w555–w565 (published online 19 May 2009; 10.1377/hlthaff.28.4.w555)

- **Newt Gingrich**, **Former Speaker of the House**, testimony March 15, 2006 before the House Subcommittee on the Federal Workforce and Agency Organization

2 Key reference articles

- *What 'Patient-Centered' Should Mean: Confessions Of An Extremist***,** *A seasoned clinician and expert fears the loss of his humanity if he should become a patient.* In *Health Affairs* 28, no. 4 (2009): w555–w565 (published online 19 May 2009; 10.1377/hlthaff.28.4.w555) by Don Berwick.

- Improve Privacy in Research by Eliminating Informed Consent? IOM Report Misses the Mark. In The Journal of Law, Medicine & Ethics, Volume 37, Issue 3 (p 507-512) by *Mark A. Rothstein.*

US has no definition of ‘privacy’

What does ‘privacy’ mean?

Privacy means control over personal information.

Without control, you have no privacy.

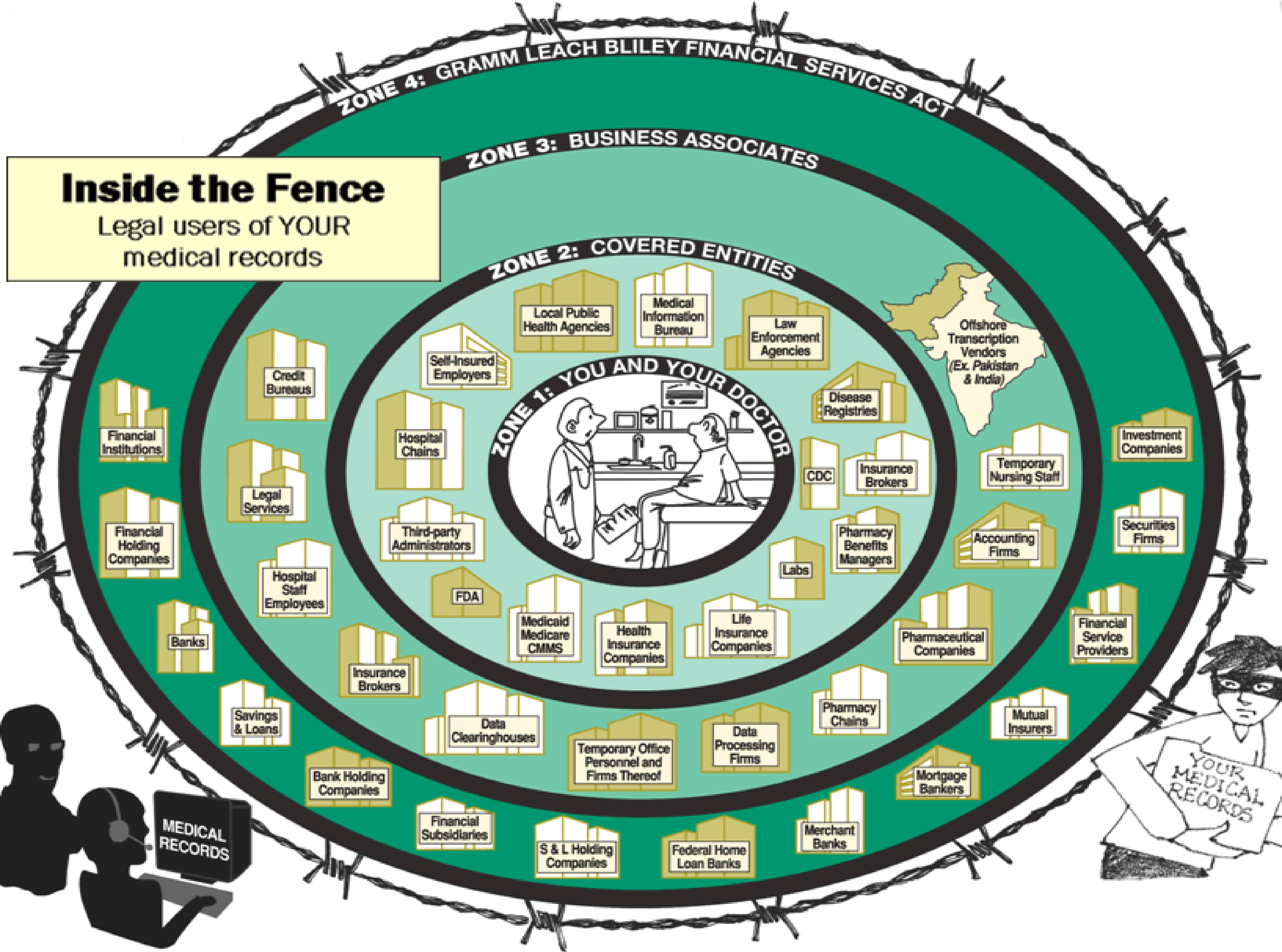
Americans have no control over personal health data

HIPAA eliminated consent

1996	Congress passed HIPAA, but did not pass a federal medical privacy statute, so the Dept. of Health and Human Services (HHS) was required to develop regulations that specified patients’ rights to health privacy.	*“… the Secretary of Health and Human Services shall submit to [Congress]…**detailed recommendations on standards with respect to the privacy of individually identifiable health information.”***
2001	President Bush implemented the HHS HIPAA “Privacy Rule” which recognized the “right of consent”.	*“….a covered health care provider **must obtain the individual’s consent,** in accordance with this section, prior to using or disclosing protected health information to carry out treatment, payment, or health care operations.”*
2002	HHS amended the HIPAA “Privacy Rule”, eliminating the “right of consent”.	*“The **consent provisions…are replaced** with a new provision…that provides regulatory permission for covered entities to use and disclose protected health information for treatment, payment, healthcare operations.”*

Inside the Fence

Legal users of YOUR medical records



Consequences:

- **JOB LOSS/ denial of promotions**
  - health data is used to discriminate
- **Millions AVOID needed treatment**
- Bad data/ no data = poor quality of research
  - people avoid participation, lie, omit
- Insurance and credit discrimination

HIT designed for mining and selling PHI without consent will not be trusted and fail

American Employers Discriminate

- **35% of Fortune 500 companies admit to using medical records for hiring and promotions**

65 Fed. Reg. 82,467

Wal-Mart Memo Suggests Ways to Cut Employee Benefit Costs

“Redesign benefits and other aspects of the Associate experience, such as job design, to attract a healthier, more productive workforce.”

“The team is also considering additional initiatives to support this objective, including: all jobs to include some physical activity (e.g., all cashiers do some cart gathering).”   October 26, 2005

The New York Times

HHS citations: harms from lack of privacy

Harms from lack of Privacy

- HHS estimated that **586,000** Americans did not seek earlier cancer treatment due to privacy concerns.
- HHS estimated that **2,000,000** Americans did not seek treatment for mental illness due to privacy concerns.
- **Millions** of young Americans suffering from sexually transmitted diseases do not seek treatment due to privacy concerns.

65 Fed. Reg. at 82,777

Harms from lack of Privacy

The California Health Care Foundation found that **1 in 8** Americans have put their health at risk *because of privacy concerns*:

- Avoid seeing their regular doctor
- Ask doctor to alter diagnosis
- Pay for a test out-of-pocket
- Avoid tests

Harms from lack of Privacy

Employers Discriminate

35% of Fortune 500 companies admit to using medical records for hiring and promotions

65 Fed. Reg. 82,467. *(BEFORE the amended HIPAA Privacy Rule)*

Harms from lack of Privacy

- The Rand Corporation found that 150,000 soldiers suffering from PTSD do not seek treatment because of privacy concerns
- The lack of privacy contributes to the highest rate of suicide among active duty soldiers in 30 years

“Invisible Wounds of War”, the RAND Corp., p. 436, (2008)

NIH: harms from lack of privacy

"It's pretty clear that the public is afraid of taking advantage of genetic testing," said Dr. Francis S. Collins, director of the National Human Genome Research Institute at the National Institutes of Health.

"If that continues, the future of medicine that we would all like to see happen stands the chance of being dead on arrival."

Studies/polls/focus groups on consumers’ expectations of control over PHI for clinical uses and research

10 Million Americans Want Privacy

The bipartisan Coalition for Patient Privacy, 2010

AIDS Action
American Association of People with Disabilities
American Association of Practicing Psychiatrists
American Chiropractic Association
American Civil Liberties Union
American Conservative Union
American Psychoanalytic Association
Association of American Physicians and Surgeons
Bazelon Center for Mental Health Law
Bob Barr (former Congressman R-GA)
Citizens for Health
Citizen Outreach Project
Clinical Social Work Association
Consumer Action
Consumers for Health Care Choices
Cyber Privacy Project
Doctors for Open Government
Ethics in Government Group
Fairfax County Privacy Council
Family Research Council
Free Congress Foundation
Georgians for Open Government
Gun Owners of America
Health Administration Responsibility Project, Inc.
Just Health
Multiracial Activist
Microsoft Corporation Inc.
National Center for Transgender Equality
The National Center for Mental Health Prof. & Consumers
National Whistleblower Center
National Workrights Institute
Natural Solutions Foundation
New Grady Coalition
Pain Relief Network
Patient Privacy Rights Foundation
Privacy Activism
Privacy Rights Now Coalition
Private Citizen, Inc.
Republican Liberty Caucus
Student Health Integrity Project
TexPIRG
Thoughtful House Center for Autism
Tolven, Inc.
Tradition, Family, Property, Inc.
Universata, Inc.
U.S. Bill of Rights Foundation
You Take Control, Inc.

AHRQ: 2009
20 focus groups

- A majority want to “own” their health data, and to decide what goes into and who has access to their medical records (AHRQ p. 6).

- There was near universal agreement in all focus groups that if medical data are to be stored electronically, health care consumers should have some say in how those data are shared and used. (AHRQ p.29)

- A majority believe their medical data is “no one else’s business” and should not be shared without their permission. This belief was expressed not necessarily because they want to prevent some specific use of data but as a matter of principle. (AHRQ p. 18)

- Participants overwhelmingly want to be able to communicate directly with their providers with respect to how their PHI is handled, including with whom it may be shared and for what purposes. Most believe they should automatically be granted the right to correct misinformation (AHRQ p.33)

- In fact, in the AHRQ Report they learned there was no support for the establishment of general rules that apply to all health care consumers. Participants thought that health care consumers should be able to exert control over their own health information **individually, rather than collectively**.

  (AHRQ p. 29)

AHRQ Publication No. 09-0081-EF "Final Report: Consumer Engagement in Developing Electronic Health Information Systems" Prepared by: Westat, (July 2009)

http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_1248_888520_0_0_18/09-0081-EF.pdf

NPR/Kaiser/Harvard 2009 Poll

The Public and the Health Care Delivery System

59% are NOT confident that if their medical records and PHI were stored electronically and shared online, that those records would remain confidential

NPR/Kaiser/Harvard 2009 Poll

76% believe it likely that an unauthorized person would get access to their medical records if the US adopts a system where medical records are kept electronically and shared online.

http://www.kff.org/kaiserpolls/upload/7888.pdf

Research on Consent and NBS Programs

From Public Health Genomics

Westin/Harris Survey for the Institute of Medicine

Results of a National Survey
Commissioned by the Institute of
Medicine Committee on
“Health Research and the Privacy of
Health Information: The HIPAA Privacy
Rule”
Original Report - November 2007; Revised and expanded - March 2008

IOM Survey: People Won’t Participate in Research Without Privacy

by Dr. Alan F. Westin

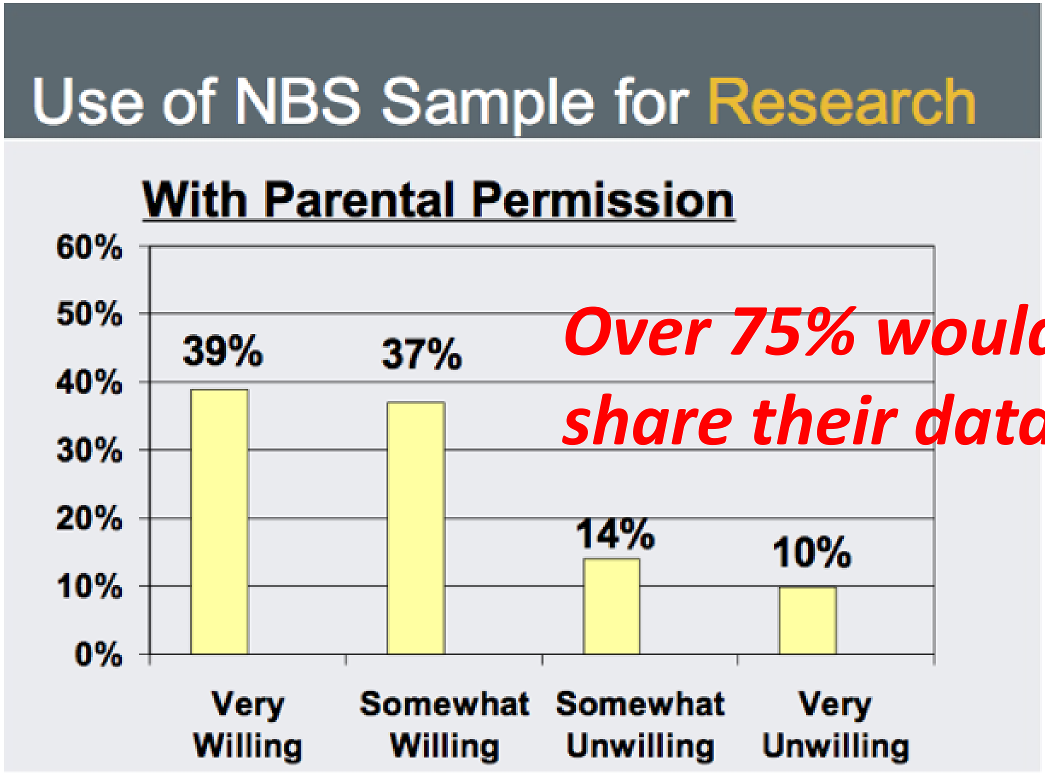
- Only 1% agreed that researchers would be free to use personal medical and health information without consent
- Only 19% agreed that personal medical and health information could be used as long as the study “never revealed my personal identity” and it was supervised by an Institutional Review Board.

When Asked, Consumers Support Use of Their Data

"How willing are you to have your child's blood sample (from newborn screening) used for future research studies, with (or without) your permission?"

Four choices were:

- ***Very willing***
- ***Somewhat willing***
- ***Somewhat unwilling***
- ***Very unwilling***



Use of NBS Sample for Research

With Parental Permission

Over 75% would share their data!

CASE WESTERN RESERVE UNIVERSITY

Source: Dr. Aaron Goldenberg (Case Western Reserve), *Public Health Genomics*, July 9, 2009 (as reported at Genetic Alliance Conference on Newborn Screening, December 2009).

~~When~~ If Asked, Consumers Support Use of Their Data

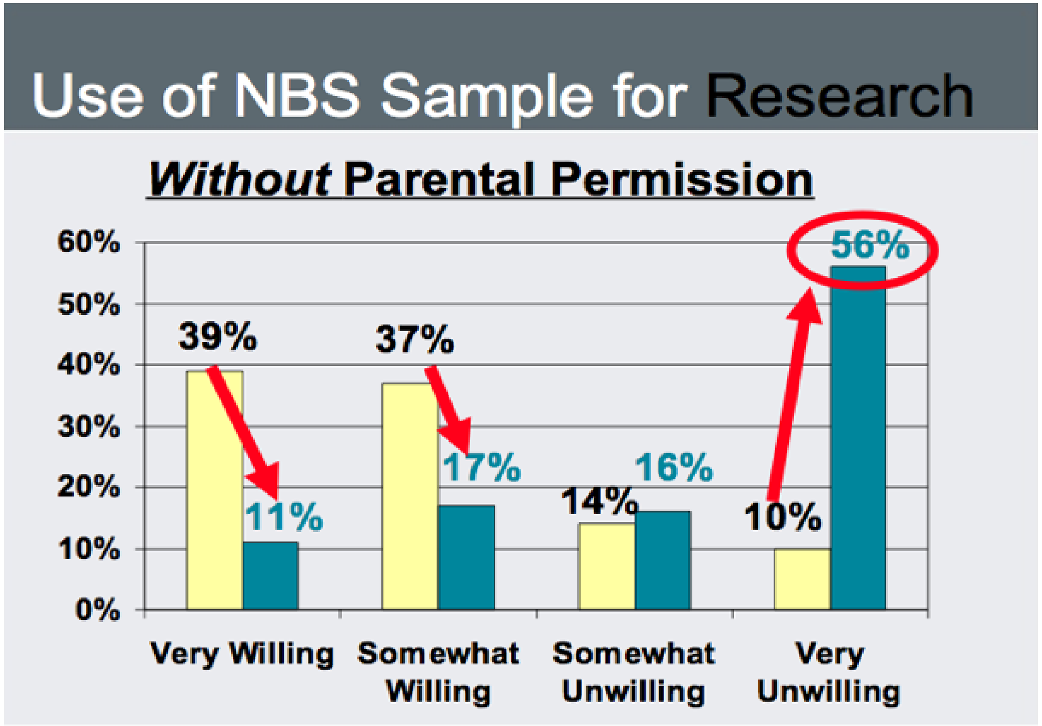
"How willing are you to have your child's blood sample (from newborn screening) used for future research studies, with (or without) your permission?"

WITHOUT CONSENT Only 28% were OK with research use

and 72% were NOT OK with research

Four choices were:

- ***Very willing***
- ***Somewhat willing***
- ***Somewhat unwilling***
- ***Very unwilling***



CASE WESTERN RESERVE UNIVERSITY

Source: Dr. Aaron Goldenberg (Case Western Reserve), *Public Health Genomics*, July 9, 2009 (as reported at Genetic Alliance Conference on Newborn Screening, December 2009).

Privacy Rights in Federal and State Law

ARRA—historic new privacy rights

Old rights under HIPAA:

- Providers may offer consent (Original HIPAA Privacy Rule), so patients can restrict disclosures---not addressed
- Psychotherapy Notes require consent to disclose---not addressed

New rights:

- Ban on sales of PHI (Protected Health Information)---2010
- Segmentation---delayed
- Audit trails x 3 years---2011 or later
- Breach notice---2010
- Encryption
- Patient can prevent disclosures of PHI for 'payment and healthcare operations' if pays out-of-pocket--not addressed
- Consent Technologies---2014 or later

Solutions:

Meet demand for privacy
via
privacy-enhancing
technologies

Do Not Disclose

Register on the National Do Not Disclose List

Let Congress know that you want a Do Not Disclose list.

Do you want:

- To choose who can see and use your personal information, from prescriptions to DNA?
- To protect your children's health information, so it won't be used against them in the future for jobs or credit?
- To get a clear explanation of how your information will be used before you decide to share it?

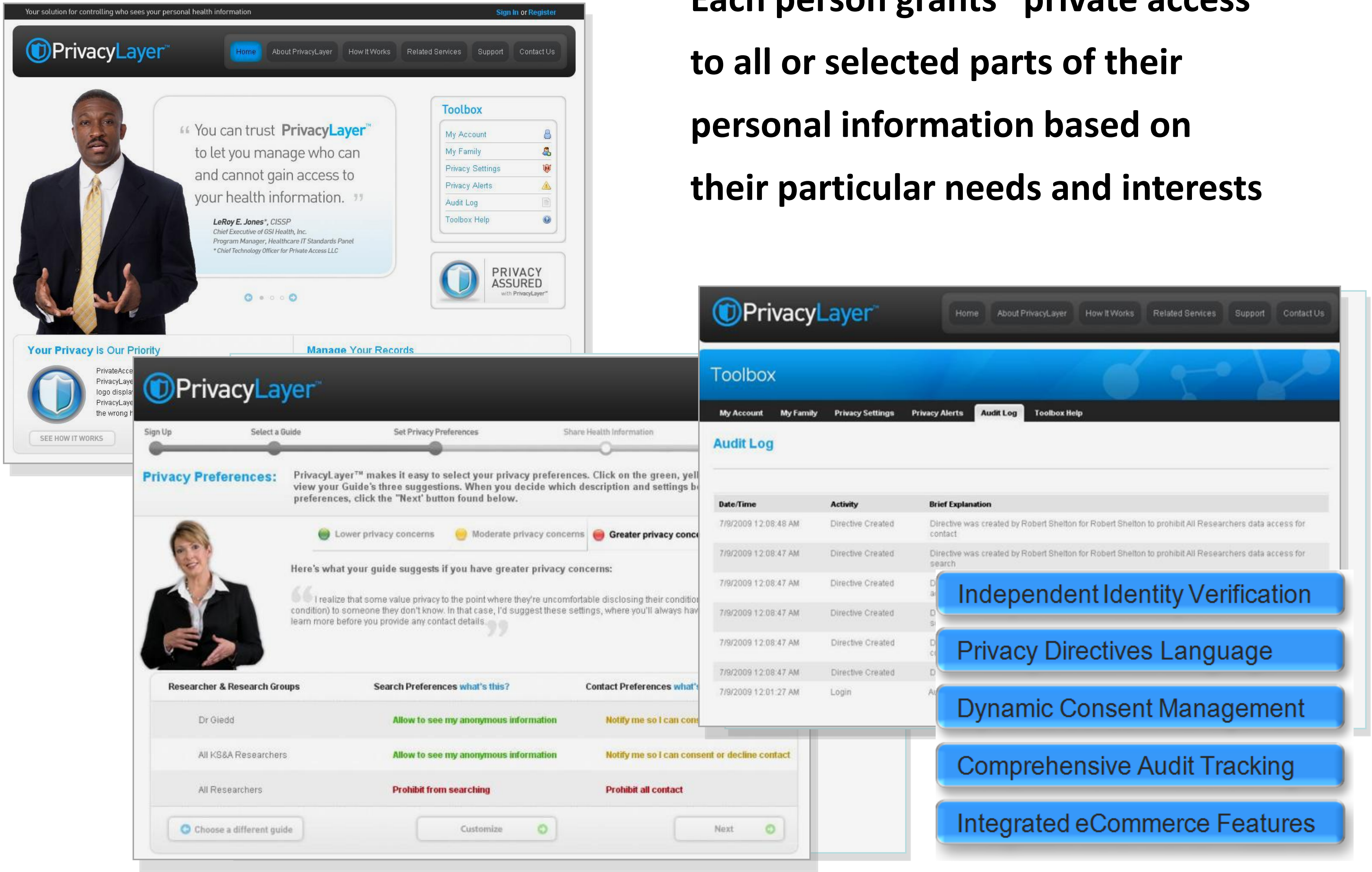
Then sign up to support the "*Do Not Disclose*" campaign!

Sign Up Today!

TELL–A–FRIEND

Consent Solutions So Far for Research Biobanks

Each person grants "private access" to all or selected parts of their personal information based on their particular needs and interests



Your solution for controlling who sees your personal health information

Sign In or Register

"You can trust PrivacyLayer™ to let you manage who can and cannot gain access to your health information."

LeRoy E. Jones, CISSP*
Chief Executive of GSI Health, Inc.
Program Manager, Healthcare IT Standards Panel
** Chief Technology Officer for Private Access LLC*

Your Privacy is Our Priority

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Manage Your Records

Privacy Preferences: PrivacyLayer™ makes it easy to select your privacy preferences. Click on the green, yell
view your Guide's three suggestions. When you decide which description and settings b
preferences, click the "Next' button found below.

Here's what your guide suggests if you have greater privacy concerns:

"I realize that some value privacy to the point where they're uncomfortable disclosing their conditio
condition) to someone they don't know. In that case, I'd suggest these settings, where you'll always hav
learn more before you provide any contact details."

Researcher & Research Groups	Search Preferences what's this?	Contact Preferences what's
Dr Giedd	Allow to see my anonymous information	Notify me so I can cons
All KS&A Researchers	Allow to see my anonymous information	Notify me so I can consent or decline contact
All Researchers	Prohibit from searching	Prohibit all contact

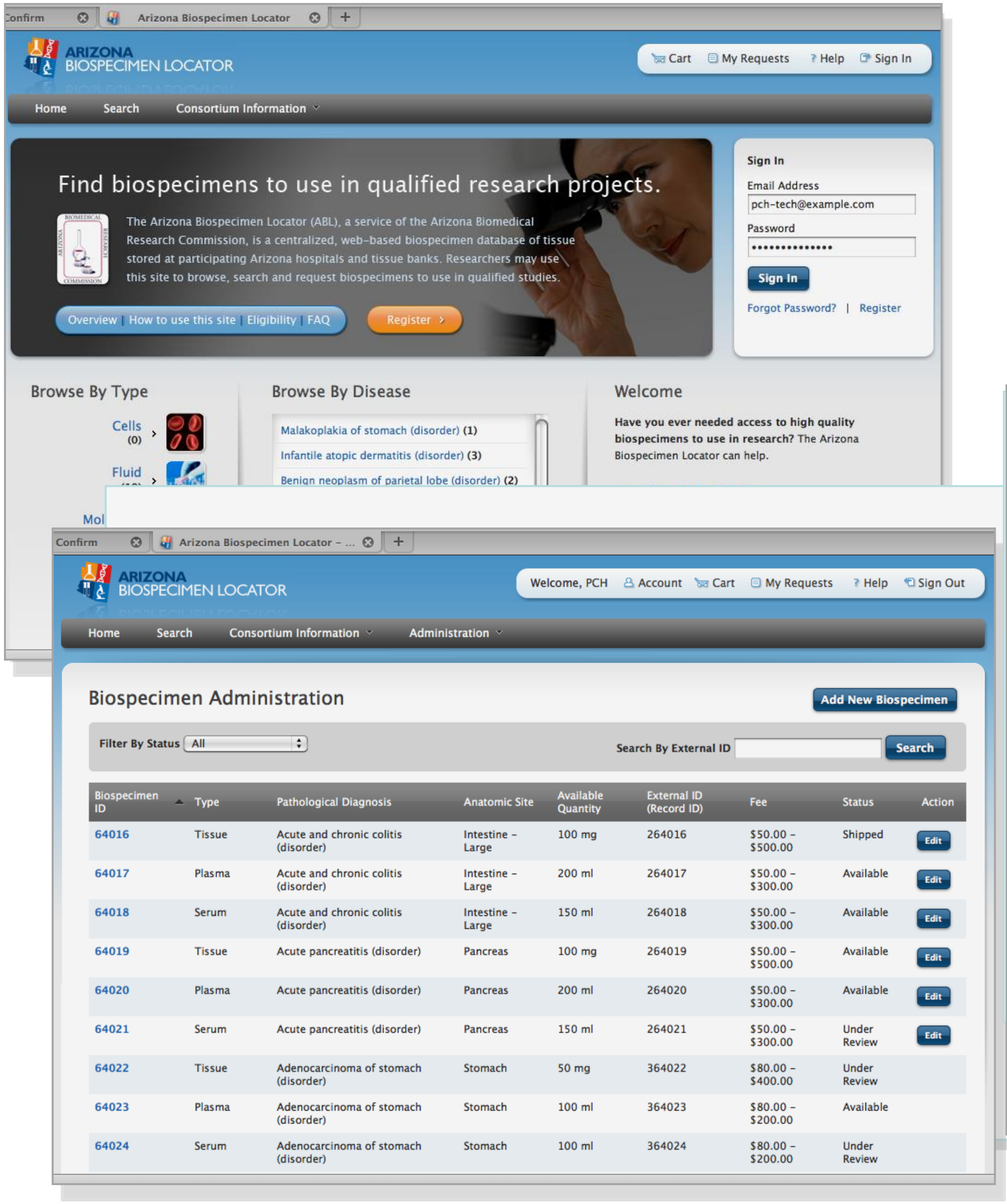
Audit Log

Date/Time	Activity	Brief Explanation
7/9/2009 12:08:48 AM	Directive Created	Directive was created by Robert Shelton for Robert Shelton to prohibit All Researchers data access for contact
7/9/2009 12:08:47 AM	Directive Created	Directive was created by Robert Shelton for Robert Shelton to prohibit All Researchers data access for search
7/9/2009 12:08:47 AM	Directive Created	D a
7/9/2009 12:08:47 AM	Directive Created	D s
7/9/2009 12:08:47 AM	Directive Created	D c
7/9/2009 12:08:47 AM	Directive Created	D
7/9/2009 12:01:27 AM	Login	A

- Independent Identity Verification
- Privacy Directives Language
- Dynamic Consent Management
- Comprehensive Audit Tracking
- Integrated eCommerce Features

ABRC Biospecimen Locator Service

… consent can be integrated into cutting-edge applications such as services for locating biospecimens for use in qualified research projects



Find biospecimens to use in qualified research projects.

The Arizona Biospecimen Locator (ABL), a service of the Arizona Biomedical Research Commission, is a centralized, web-based biospecimen database of tissue stored at participating Arizona hospitals and tissue banks. Researchers may use this site to browse, search and request biospecimens to use in qualified studies.

Sign In

Email Address: pch-tech@example.com

Password: ••••••••••••••

Sign In

Forgot Password? | Register

- Malakoplakia of stomach (disorder) (1)
- Infantile atopic dermatitis (disorder) (3)
- Benign neoplasm of parietal lobe (disorder) (2)

Welcome

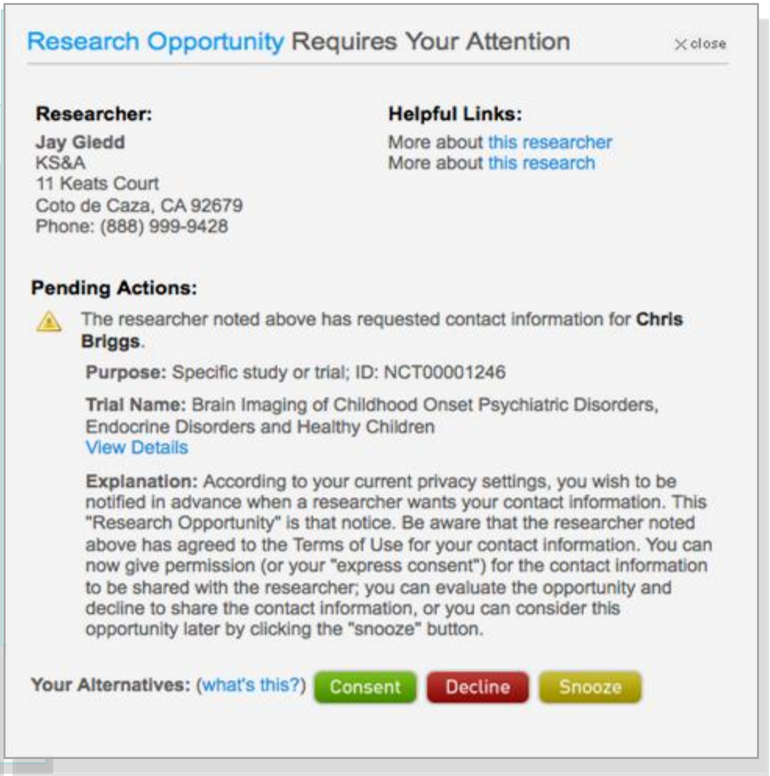
Have you ever needed access to high quality biospecimens to use in research? The Arizona Biospecimen Locator can help.

Biospecimen Administration

Filter By Status: All

Search By External ID

Biospecimen ID	Type	Pathological Diagnosis	Anatomic Site	Available Quantity	External ID (Record ID)	Fee	Status	Action
64016	Tissue	Acute and chronic colitis (disorder)	Intestine - Large	100 mg	264016	\$50.00 - \$500.00	Shipped	Edit
64017	Plasma	Acute and chronic colitis (disorder)	Intestine - Large	200 ml	264017	\$50.00 - \$300.00	Available	Edit
64018	Serum	Acute and chronic colitis (disorder)	Intestine - Large	150 ml	264018	\$50.00 - \$300.00	Available	Edit
64019	Tissue	Acute pancreatitis (disorder)	Pancreas	100 mg	264019	\$50.00 - \$500.00	Available	Edit
64020	Plasma	Acute pancreatitis (disorder)	Pancreas	200 ml	264020	\$50.00 - \$300.00	Available	Edit
64021	Serum	Acute pancreatitis (disorder)	Pancreas	150 ml	264021	\$50.00 - \$300.00	Under Review	Edit
64022	Tissue	Adenocarcinoma of stomach (disorder)	Stomach	50 mg	364022	\$80.00 - \$400.00	Under Review	
64023	Plasma	Adenocarcinoma of stomach (disorder)	Stomach	100 ml	364023	\$80.00 - \$200.00	Available	
64024	Serum	Adenocarcinoma of stomach (disorder)	Stomach	100 ml	364024	\$80.00 - \$200.00	Under Review	



Research Opportunity Requires Your Attention

Researcher:
Jay Giedd
KS&A
11 Keats Court
Coto de Caza, CA 92679
Phone: (888) 999-9428

Helpful Links:
More about this researcher
More about this research

Pending Actions:

⚠ The researcher noted above has requested contact information for **Chris Briggs**.

Purpose: Specific study or trial; ID: NCT00001246

Trial Name: Brain Imaging of Childhood Onset Psychiatric Disorders, Endocrine Disorders and Healthy Children
View Details

Explanation: According to your current privacy settings, you wish to be notified in advance when a researcher wants your contact information. This "Research Opportunity" is that notice. Be aware that the researcher noted above has agreed to the Terms of Use for your contact information. You can now give permission (or your "express consent") for the contact information to be shared with the researcher; you can evaluate the opportunity and decline to share the contact information, or you can consider this opportunity later by clicking the "snooze" button.

Your Alternatives: (what's this?)

Pfizer And Private Access to Develop Online Community for Clinical Research

Wednesday, August 19, 2009

Pfizer and Private Access have begun a collaborative partnership into the world of online communities.

According to the press release, Private Access allows patients to control to whom, and for what purposes, they grant access to see all or selected portions of their personal health information. By granting “private access” only to researchers focused on the conditions that interest them, patients can be more quickly and precisely matched to appropriate clinical trials while simultaneously protecting their confidential personal health information.

http://epharmasummit.blogspot.com/2009/08/pfizer-and-private-access-to develop.html

Open Source Consent Solutions

1. Adapt/use the National Data Infrastructure Improvement Consortium (NDIIC) open source electronic consent module as the minimum standard for consent tools in PHRs and for all HIT

2. Require the strong privacy protections in 43 CFR Part 2 be extended to cover all personal health information (PHI), wherever it is held.

Audit trails based on authentication

Mar 01, 2010

Imprivata's New Product Helps Hospitals Proactively Investigate and Audit Access to Patient Health Information

PrivacyAlert^{TM} Quickly Detects Snooping and Identity Theft of Medical Records

Imprivata PrivacyAlert quickly detects snooping, identity theft and general inappropriate access of medical records through its automated pattern recognition, which delivers alerts on more than 100 patient privacy scenarios. Users can deploy automated and scalable privacy monitoring policies that assist in investigating and reporting on patient data privacy breaches.

Imprivata PrivacyAlert enables information security officers and privacy officers to deploy automated and scalable privacy monitoring solutions that assist them in investigating and reporting on patient data privacy breaches.

Ability to set and focus investigation criteria on employee, patient or combination of both.
Out-of-the-box support for all leading healthcare applications including Eclipsys,
GE Centricity Enterprise, MEDITECH Magic, Siemens Invision and others.

http://www.marketwire.com/press-release/Imprivatas-New-Product-Helps-Hospitals-Proactively-Investigate-Audit-Access-Patient-1123908.htm

Deborah C. Peel, MD

Founder and Chair

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www.patientprivacyrights.org

patientprivacyrights

HIT systems and products:

EHRs, PHRs,

e-prescribing, etc, etc

Data mining by federal and corporate design

- Weak Security
- No privacy
- Secondary Use

No trusted seal-of-approval for privacy and security (yet)

Weak Security

- Easy to hack
- Strong 2-factor authentication not required
- Data encryption at rest not required
- Loss/theft of mobile devices
- No role-based access, i.e., no consumer access controls (hacking from the inside)
  - Example: in an 8-hospital system all 33,000 employees can access every patient record

2010: # of Breaches through March

Medical/Healthcare

Totals for Category:

- **# of Breaches: 44**
- **# of Records: 132,089**
- **% of Breaches: 22.9**
- **% of Records: 2.1%**

All Categories

Totals for All Categories :

- **# of Breaches: 192**
- **# of Records: 6,739,583**
- **% of Breaches: 100.0**
- **% of Records: 100.0%**

2009 Data Breaches – Paper vs. Electronic Summary

Totals for Electronic records:
# of Breaches: 369
# of Records: 222,286,837
# of Health records: 11,279,390
% of Breaches: 74.1
% of Records: 99.9

Totals for Paper records:
# of Breaches: 129
# of Records: 190,206
% of Breaches: 25.9
% of Records: .01

BUT **in more than 52% of the breaches publicly reported, NO statement of the number of records exposed is given.** Therefore, it is *unknown* how many total records may have been exposed due to breaches in 2009.

2009 - type of breach

2,532,674+	Data on the Move
21,780+	Subcontractors
8,501,878+	Hacking
3,317+	Accidental Exposure
13,871+	Insider Theft
245,698+	Unknown Attributes (type not reported)

Identity Theft Resource Center

http://www.idtheftcenter.org/index.html

Electronic medical records at risk of being hacked, report warns

CIO news

By Linda Tucci, Senior News Writer
19 Sep 2007 | SearchCIO.com

The electronic health record systems that automate the digitized medical histories of U.S. patients are severely at risk of being hacked, a new report has claimed.

"There was not one system we could not penetrate and gain control of data," said eHVRP board member Daniel S. Nutkis. "These systems were not any worse than banking systems. But the banking systems have elaborate security mechanisms sitting on top of them."

The eHVRP report is based on a 15-month study of more than 850 provider organizations.

NIH Data Breaches

- **Barton health records stolen and he's ticked**

  Dallas Morning News, April 3, 2008, by **Todd J. Gillman**

  Rep. Joe Barton revealed Thursday that he is one [of the 3,000+] heart patients whose medical records were on an unencrypted laptop stolen from a National Institutes of Health researcher.

- ***New York Times* Editorial re: NIH Breach,** March 26, 2008

  "There should be a federal law imposing strict privacy safeguards on all government and private entities handling medical data. Congress should pass a bill like the Trust Act, introduced by Representative Edward Markey, a Democrat of Massachusetts, imposing mandatory encryption requirements and deadlines for notifying patients when their privacy is breached. As the N.I.H. has shown, medical privacy is too important to be left up to the medical profession."

Georgia Patients' Records Exposed on Web for Weeks

The New York Times, April 11, 2008, by Brenda Goodman

- A company hired by the State of Georgia to administer health benefits for low-income patients is sending letters to notify **tens of thousands of residents** that their **private records were exposed on the Internet for nearly seven weeks** before the error was caught and corrected, a company spokeswoman said on Thursday.

- **The records of as many as 71,000 adults and children enrolled in the Medicaid or PeachCare for Kids** programs **were inadvertently posted on Feb. 12**, said Amy Knapp, a spokeswoman for the company, WellCare Health Plans Inc., whose headquarters are in Tampa, Fla.

COMPUTERWORLD

Portable Storage Devices Pose IT Security Risk

How much damage can a memory stick or iPod do?
Plenty, say users and Analysts

March 27, 2006 (Computerworld) -- **Baptist Memorial Health Care Corp. in Memphis, TN**

- ***users found it difficult to copy significant amounts of data to floppy disks, and the company "did not allow CD writers"***
- ***users turned to "the USB flash drive, with enormous capacity and zero installation***
- ***only about 10% of companies have any policies dealing with removable storage devices***

http://www.computerworld.com/action/article.do?command=viewArticleBasic&taxonomyName=management&articleId=109911&taxonomyId=14&intsrc=kc_feat

No privacy

- Over 4 million ‘covered entities’, including providers, self-insured employers, data warehouses, etc, can access protected health information for treatment, payment, and healthcare operations
- Millions more ‘business associates’ can use data without consent
- Audit trails NOT required for all uses and disclosures

Secondary Use/Sale

- The business model for many HIT software/systems is selling data
- Major academic hospitals sell patient data
- Insurers sell data
- All prescriptions are data mined and sold
- PH data on every American is sold

Healthcare IT News

Practice Fusion expands, shows signs of rapid growth

By Diana Manos, Senior Editor
12/31/07

Practice Fusion subsidizes its free EMRs by selling de-identified data to insurance groups, clinical researchers and pharmaceutical companies.

*Howard said he does not expect data-sharing will be a concern to physicians who use Practice Fusion's EMRs. **"Every healthcare vendor is selling data."***

EMR vendor sells patient data to for-profit genetics research firm

Healthcare IT News, 3/20/2008 by Richard Pizzi

- “Perlegen Sciences, Inc., a company exploring the clinical application of genetic research, plans to collaborate with an undisclosed electronic medical records vendor to identify and develop genetic markers that predict how patients are likely to respond to specific medical treatments.

- Under the terms of the agreement, **Perlegen**, based in Mountain View, Calif. , **will have exclusive access to the EMR vendor's database of U.S. records for the purpose of assessing and selecting patients** from whom appropriate genetic samples could be collected.”

In August, 2006, a large insurer, with plans in all 50 states, announced the creation of a new business unit to aggregate and sell the claims and health records of 79 million enrollees:

The Medical Director said that the intended use of the database is to “service the big employers that pay the bills and want to pay smaller bills for health insurance.”

He was “very enthralled about the ability to help multi-state employers fix their healthcare costs.” During the one and one-half years that the plan had been building the database, he had “never heard about privacy concerns.”

Personal health information is for sale

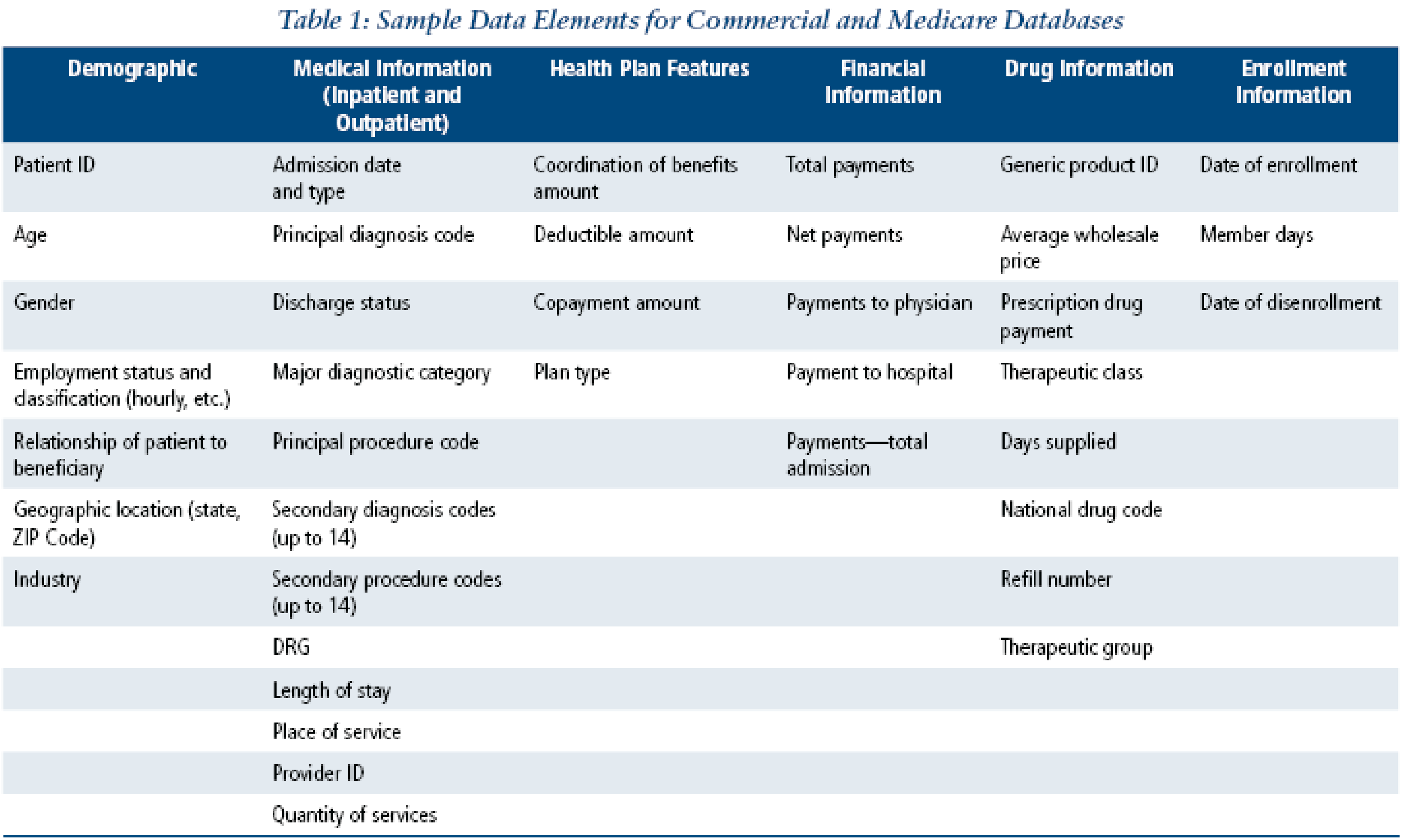


Table 1: Sample Data Elements for Commercial and Medicare Databases

Demographic	Medical Information (Inpatient and Outpatient)	Health Plan Features	Financial Information	Drug Information	Enrollment Information
Patient ID	Admission date and type	Coordination of benefits amount	Total payments	Generic product ID	Date of enrollment
Age	Principal diagnosis code	Deductible amount	Net payments	Average wholesale price	Member days
Gender	Discharge status	Copayment amount	Payments to physician	Prescription drug payment	Date of disenrollment
Employment status and classification (hourly, etc.)	Major diagnostic category	Plan type	Payment to hospital	Therapeutic class	
Relationship of patient to beneficiary	Principal procedure code		Payments—total admission	Days supplied	
Geographic location (state, ZIP Code)	Secondary diagnosis codes (up to 14)			National drug code	
Industry	Secondary procedure codes (up to 14)			Refill number	
	DRG			Therapeutic group	
	Length of stay				
	Place of service				
	Provider ID				
	Quantity of services				

Medicare and Medicaid data is for sale

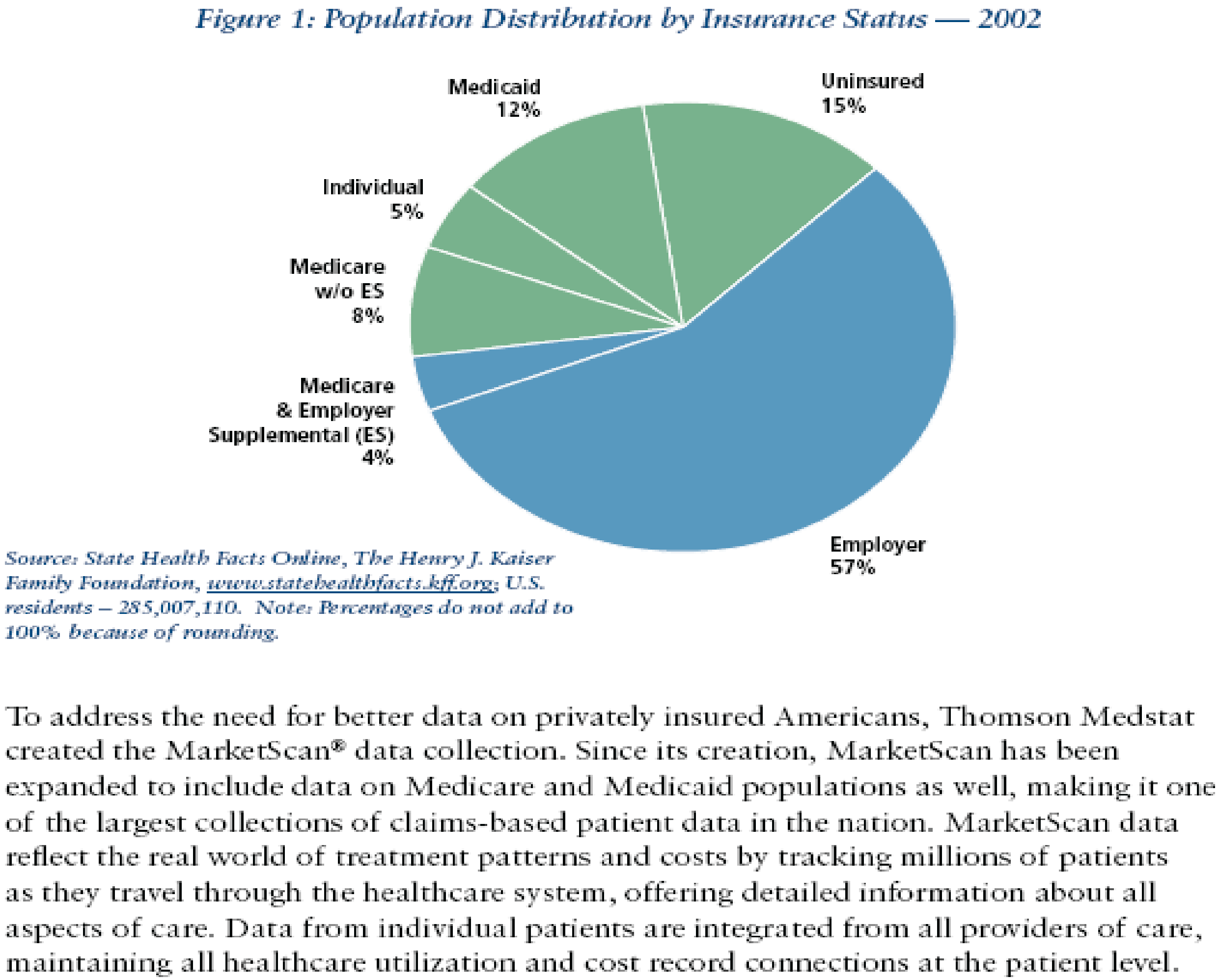


Figure 1: Population Distribution by Insurance Status — 2002

Source: State Health Facts Online, The Henry J. Kaiser Family Foundation, www.statehealthfacts.kff.org; U.S. residents – 285,007,110. Note: Percentages do not add to 100% because of rounding.

To address the need for better data on privately insured Americans, Thomson Medstat created the MarketScan® data collection. Since its creation, MarketScan has been expanded to include data on Medicare and Medicaid populations as well, making it one of the largest collections of claims-based patient data in the nation. MarketScan data reflect the real world of treatment patterns and costs by tracking millions of patients as they travel through the healthcare system, offering detailed information about all aspects of care. Data from individual patients are integrated from all providers of care, maintaining all healthcare utilization and cost record connections at the patient level.

All 55,000 American pharmacies are data mined daily

- **Nex2, Inc. (Sold to United Healthcare in 2002):**

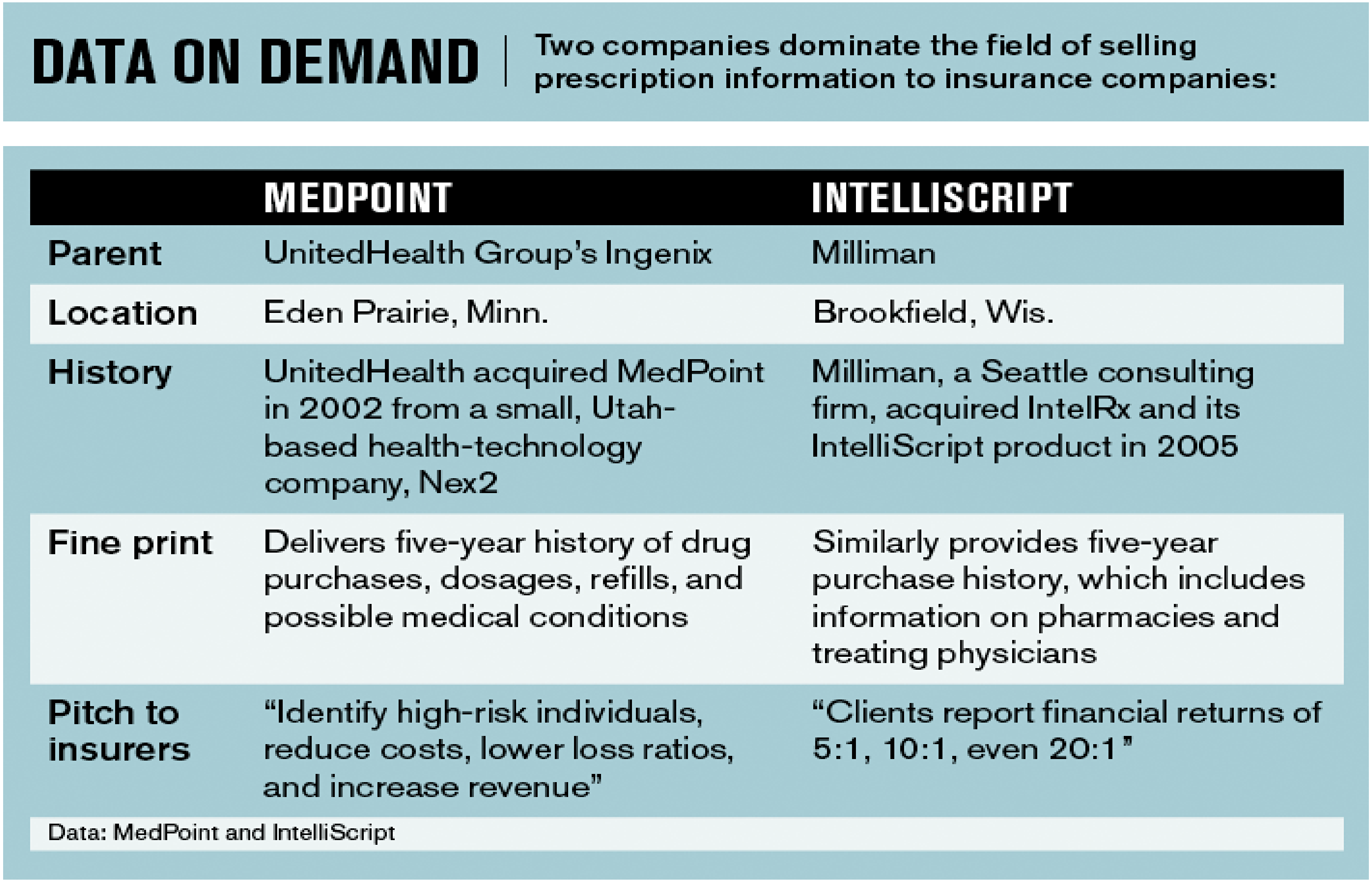
  In stealth-mode, Nex2 built what are arguably the largest, near-realtime drug history databases in the world, with over 200 million Americans' five-year running drug histories online (over 12 TB total). The databases are updated every 24 hours by every retail pharmacy in America via the PBMs... [these] prescription profiles acting as a powerful surrogate for the medical record itself.

- All of this is HIPAA compliant because the insurance company always has the release, signed by the individual applicant. United Healthcare's ***Ingenix unit now runs these massive virtual database operations, still in stealth-mode, for obvious reasons.***

Businessweek July 23, 2008:

"They Know What's in Your Medicine Cabinet, How insurance companies dig up applicants' prescriptions—and use them to deny coverage"

http://www.businessweek.com/magazine/content/08_31/b4094000643943.htm?chan=magazine+channel_in+depth



DATA ON DEMAND

Two companies dominate the field of selling prescription information to insurance companies:

	MEDPOINT	INTELLISCRIPT
Parent	UnitedHealth Group's Ingenix	Milliman
Location	Eden Prairie, Minn.	Brookfield, Wis.
History	UnitedHealth acquired MedPoint in 2002 from a small, Utah-based health-technology company, Nex2	Milliman, a Seattle consulting firm, acquired IntelRx and its IntelliScript product in 2005
Fine print	Delivers five-year history of drug purchases, dosages, refills, and possible medical conditions	Similarly provides five-year purchase history, which includes information on pharmacies and treating physicians
Pitch to insurers	"Identify high-risk individuals, reduce costs, lower loss ratios, and increase revenue"	"Clients report financial returns of 5:1, 10:1, even 20:1"

Data: MedPoint and IntelliScript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“It’s pretty clear that the public is afraid of taking advantage of genetic testing,” said Dr. Francis S. Collins, director of the National Human Genome Research Institute at the National Institutes of Health.

“If that continues, the future of medicine that we would all like to see happen stands the chance of being dead on arrival.”

The New York Times

Insurance Fears Lead Many to Shun DNA Tests

By AMY HARMON
Published: February 24, 2008

Katherine Anderson, seen in a checkup last week, developed a blood clot last year partly due to an undiagnosed genetic condition.