patientprivacyrights

Do Patients Have a Right to Health Information Privacy?

Why You Should Care

Why privacy?

2,400 years of
consensus on privacy
reflected in law and ethics

Definition of privacy

Hippocrates

“Whatsoever I shall see or hear of the lives of men or women which is not fitting to be spoken, I will keep inviolably secret.”

The Code of Fair Information Practices (1974)

“There must be a way for a person to prevent information about the person that was obtained for one purpose from being used or made available for other purposes without the person's consent.”

NCVHS

“An individual’s right to control the acquisition, uses, or disclosures of his or her identifiable health data”

June 2006, Report to Sec. Leavitt

What does ‘privacy’ mean?

Legal definition: ‘privacy’ means control over personal information

No control = no privacy

HHS and Congress have not defined ‘privacy’

Constitutional rights to privacy

“In fact, *the constitutionally protected right to privacy of highly personal information is so well established that no reasonable person could be unaware of it.*”

Sterling v. Borough of Minersville, 232 F.3d 190, 198 (3rd Cir. 2000).

"*The right to be let alone is the most comprehensive of rights and the right most valued by civilized men.*

To protect that right, every unjustifiable intrusion by the government upon the privacy of the individual, whatever the means employed, must be deemed a violation of the [Constitution].*”*

Olmstead v. United States, 277 U.S. 438, 478, 48 S.Ct. 564, 572 (1928) (Brandeis dissent)

Ethics, privileges, common law

The ethical codes of all the health professions require informed consent before use or disclosures of personal health information.

"Since the time of Hippocrates physicians have pledged to maintain the secrecy of information they learn about their patients, disclosing information only with the authorization or the patient or when necessary to protect an overriding public interest, such as public health.

***Comparable provisions are now contained in the codes of ethics of virtually all health professionals*."**

Report to HHS, NCVHS (June 22, 2006)

Research ethics

In medical research on human subjects, considerations related to the well- being of the human subject should take precedence over the needs and interests of society.

Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patients information, and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject.

World Medical Association Declaration of Helsinki June 1964

Privileges

A physician-patient privilege is recognized in laws of 43 states and the District of Columbia.

The State of Health Privacy, Health Privacy Project (2000)

A psychotherapist-patient privilege is recognized in the laws of all 50 states and the District of Columbia.

Jaffee v. Redmond, 116 S. Ct. 1923, 1929 (1996)

Common Law

All 50 states and the District of Columbia recognize in tort law a common law or statutory right to privacy of personal information.

HHS finding 65 Fed. Reg. at 82,464

Ten states have a right to privacy expressly recognized in their state constitutions.

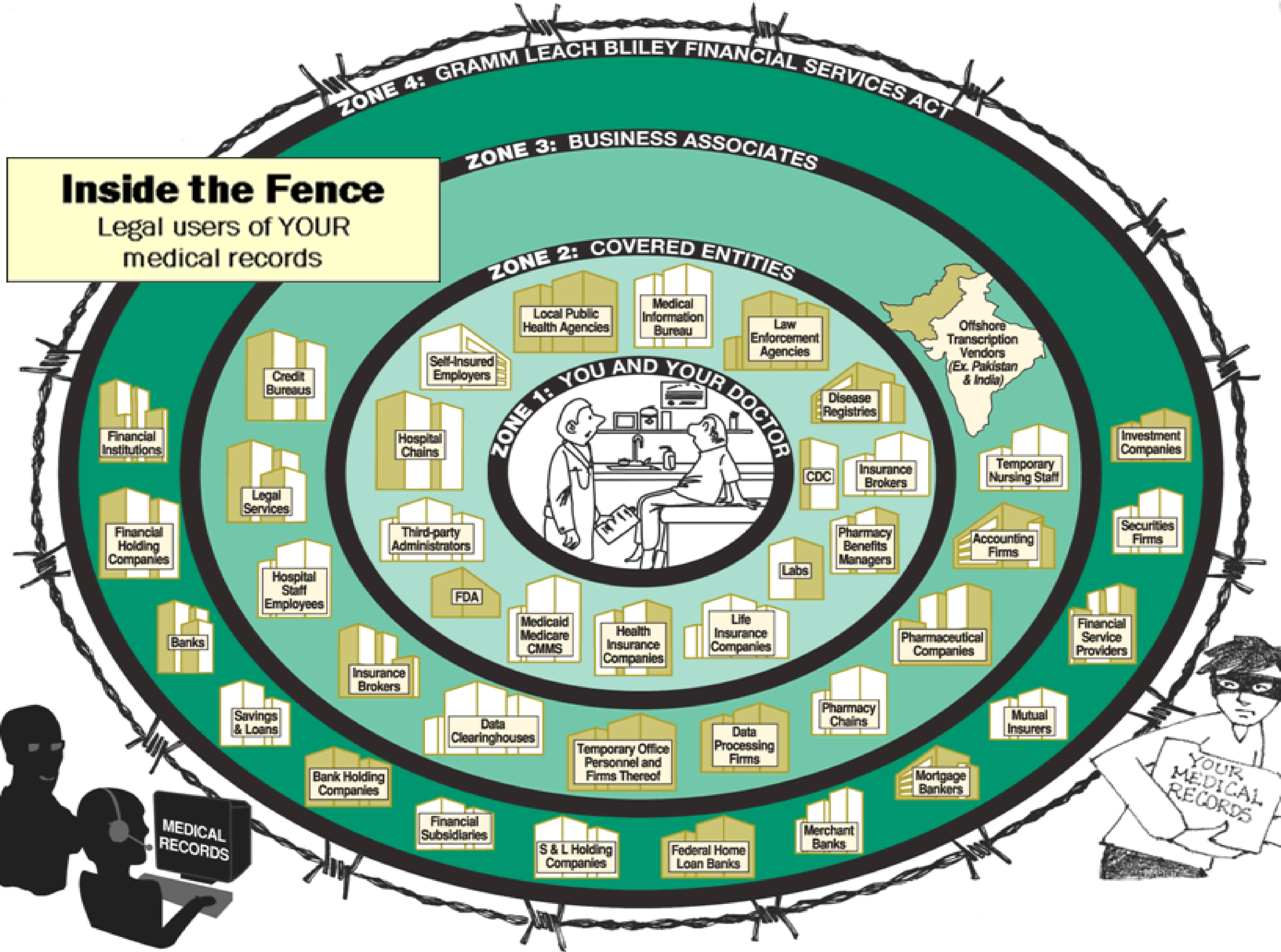
HHS ‘deregulated’ Americans’ rights to health privacy in 2002

Deregulating 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



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

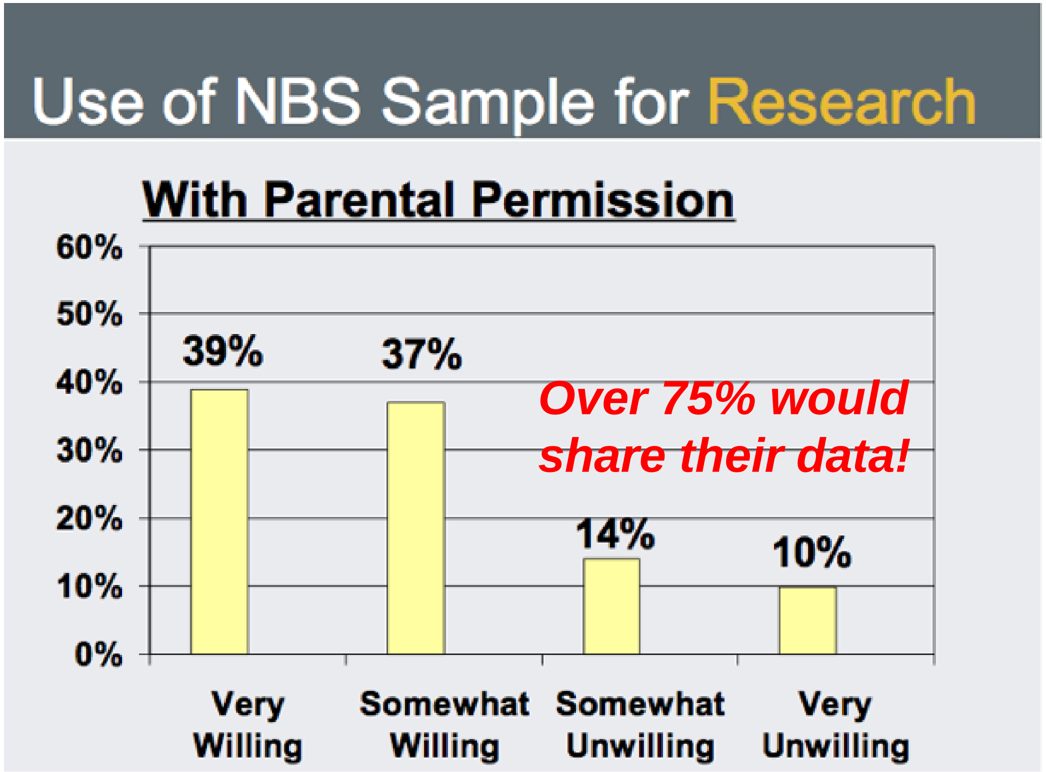
From Public Health Genomics

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

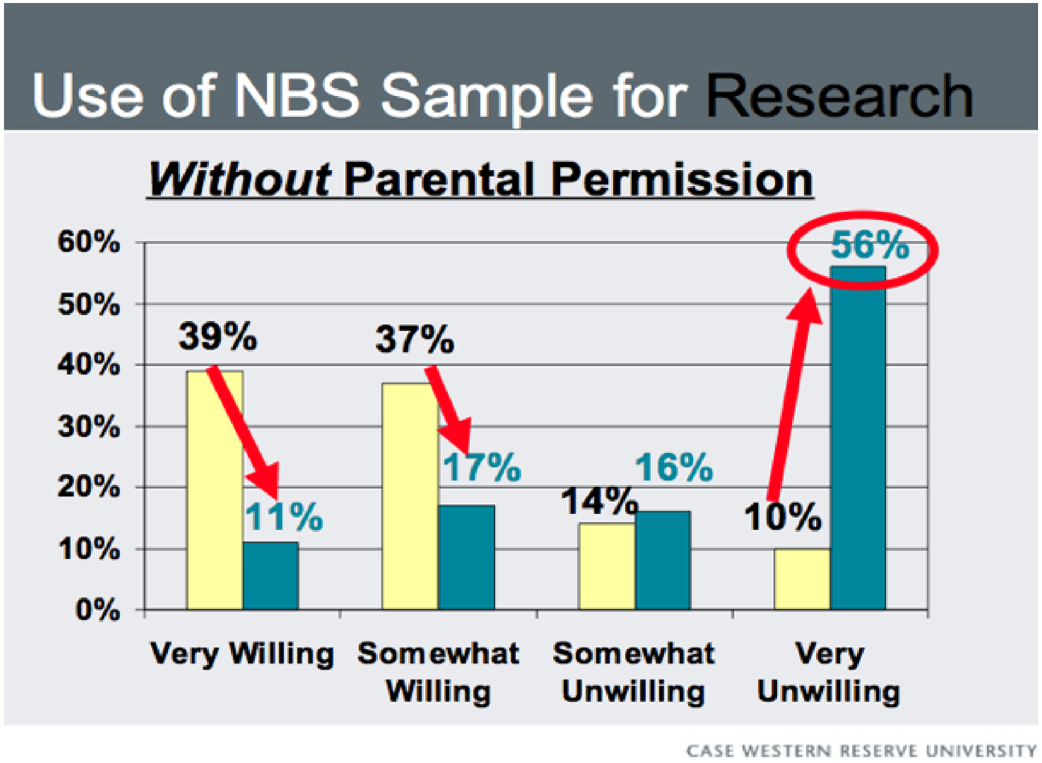
Source: Dr. Aaron Goldenberg (Case Western Reserve), *Public Health Genomics*, July 9, 2009 (as reported at Genetic Alliance Conference on Newborn Screening, December 2009).

When ~~Asked~~ If, 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***



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

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

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 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

- 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."

Deborah C. Peel, MD

Founder and Chair

(O) 512-732-0033

dpeelmd@patientprivacyrights.org

www.patientprivacyrights.org

patientprivacyrights