National Committee on Vital and Health Statistics

Subcommittee on Privacy, Confidentiality & Security

Personal Health Records

Tuesday, June 9, 2009

patientprivacyrights

“Anyone today who thinks the privacy issue has peaked is greatly mistaken…we are in the early stages of a sweeping change in attitudes that will fuel political battles and put once-routine business practices under the microscope.”

Forrester Research

an independent technology and market company that provides advice to global leaders in business and technology

What does ‘privacy’ mean?

- The *Hippocratic Oath* says “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.”

What does ‘privacy’ mean?

- The *NCVHS* (June 2006, Report to Sec. Leavitt) defined health information privacy as “an individual’s right to control the acquisition, uses, or disclosures of his or her identifiable health data”. (Definition originally from the IOM)

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

- 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)

Without Privacy, Quality Suffers

- The **entire health delivery system** is based upon the willingness of the individual to trust a health care practitioner sufficiently to disclose to the practitioner the most intimate details of his or her life.
- An assurance of privacy of health information is **necessary to secure effective, high quality health care.**

65 Fed. Reg. at 82,467.

Unintended consequences

Increases costs

- Delayed treatment

Decreases quality

- Suffering
- Deaths

Can’t get needed research

- People fear participation
- Absent, limited, or erroneous data

How to ensure privacy

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.

ADDENDUM

Texas Electronic Consent Components

Texas Electronic Consent Components (NDIIC)

- Consent = Required Field

Client Name

Client Number

Discloser

Activity Begin Date [ ] mm/dd/yyyy

Activity End Date [ ] mm/dd/yyyy

Release Expiration Date [ ] mm/dd/yyyy

Disclosee [None selected \/]

Other Disclosee [ ]

NOTE: Any item listed below may include information that reveals a client's HIV status.

Is it okay to release the following information? Action

- Screening/Intake ( )Yes ( ) No
- General assessment only ( )Yes ( ) No
- Medical assessment ( )Yes ( ) No
- Employment Assessment ( )Yes ( ) No
- Substance Abuse Assessment ( )Yes ( ) No
- Legal Assessment ( )Yes ( ) No
- Family/Social Assessment ( )Yes ( ) No
- Psychiatric Assessment ( )Yes ( ) No

- Diagnostic Impression ( )Yes ( ) No
- Clinician’s Assessment ( )Yes ( ) No
- Assessment Recommendations ( )Yes ( ) No
- Assessment Summary ( )Yes ( ) No
- Assessment Narrative ( )Yes ( ) No
- Wait List Recommendations ( )Yes ( ) No
- Lab Results ( )Yes ( ) No
- Treatment Plan(s) ( )Yes ( ) No
- Treatment Plan(s) Evaluations ( )Yes ( ) No
- Admission Reports ( )Yes ( ) No
- Procedures and Progress Notes ( )Yes ( ) No
- Clinician’s Notes ( )Yes ( ) No

- Client Progress Notes ( )Yes ( ) No
- Medications Records ( )Yes ( ) No
- Discharge Summary ( )Yes ( ) No
- Discharge Plans ( )Yes ( ) No
- Follow-up Reports ( )Yes ( ) No
- Compliance with Treatment Recommendations ( )Yes ( ) No
- Attendance ( )Yes ( ) No
- Prognosis ( )Yes ( ) No
- Referral Information ( )Yes ( ) No
- Referral follow-up ( )Yes ( ) No
- Program case ( )Yes ( ) No

- Program service ( )Yes ( ) No
- Client Interview ( )Yes ( ) No
- Authorization to Call Phone # ( )Yes ( ) No
- Authorization to Leave message ( )Yes ( ) No
- Residential Approval ( )Yes ( ) No
- Financial Eligibility ( )Yes ( ) No
- COSIG Voucher ( )Yes ( ) No
- ATR Voucher ( )Yes ( ) No
- ATR Services ( )Yes ( ) No
- Other Confidential Information (please specify) ( )Yes ( ) No

Other Information to Release

- Purpose for Releasing Information
- Comments

Signatures

I understand that my records are protected under the federal regulations governing Confidentiality of Alcohol and Drug Abuse Patient Records, 42 CFR part 2, and cannot be disclosed without my written consent unless otherwise provided for in the regulations. I understand this information will be used or disclosed solely for the purpose specified in the form. I also understand that I may revoke this consent at any time except to the extent that action has been taken in reliance on it, and that in any event this consent expires automatically as noted above.

- Client Signature mm/dd/yyyy
- Parent, Guardian, or Other Representative Signature When Required mm/dd/yyyy
- Staff Signature mm/dd/yyyy

This information has been disclosed to you from records protected by federal confidentiality rules (42 CFR part 2). The federal rules prohibit you from making any further disclosure unless further disclosure is expressly permitted by the written consent of the person to whom it pertains or as otherwise permitted by 42 CFR part 2. A general authorization for the release of medical or other information is NOT sufficient for this purpose. The Federal rules restrict any use of the information to criminally investigate or prosecute any alcohol or drug abuse patient.

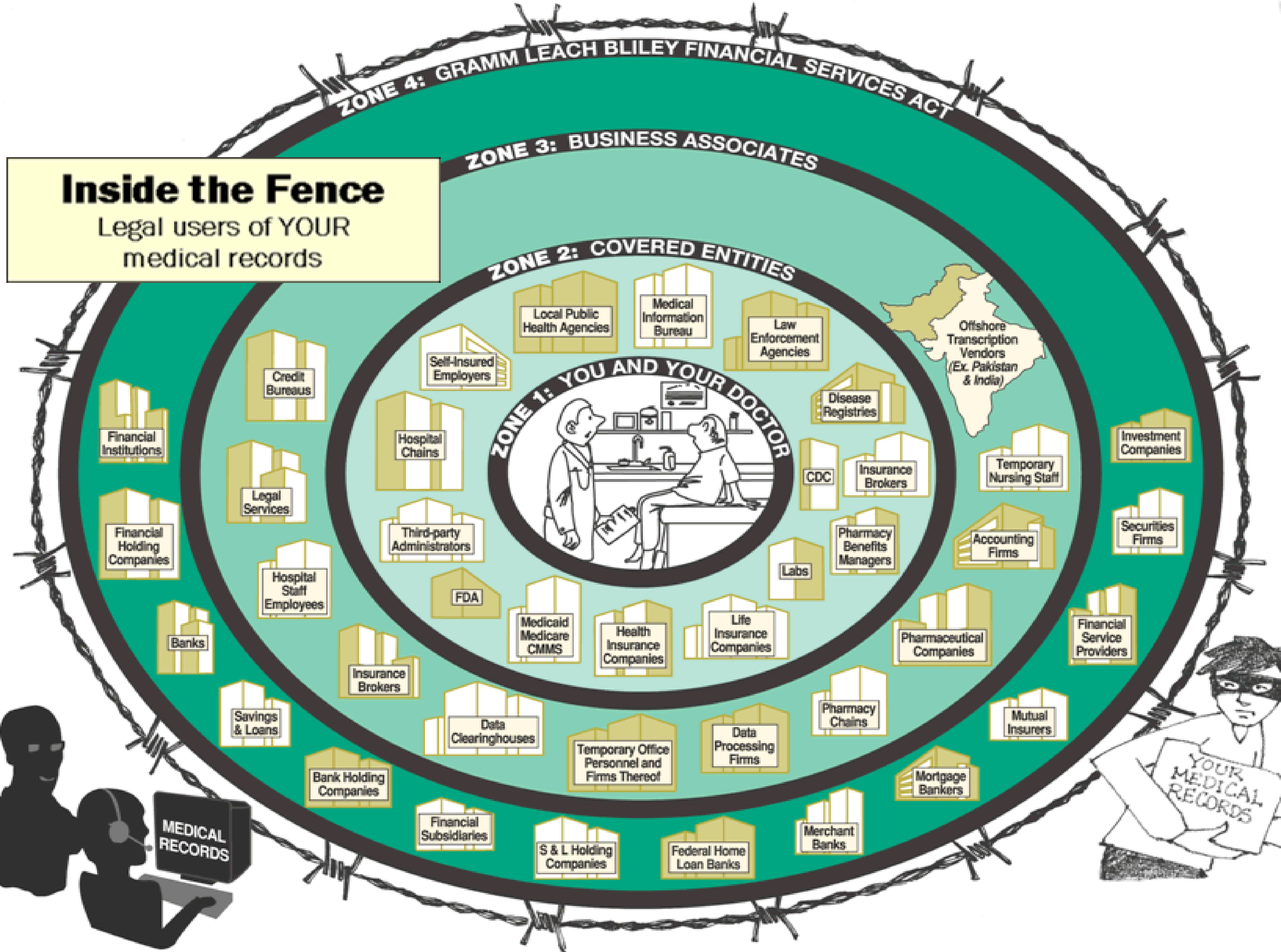
Why HIPAA is not enough to protect privacy

Elimination of 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



Progress with Privacy
Patient Privacy Rights

www.patientprivacyrights.org

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