Privacy in the Era of EHRs

Restoring Patient and Doctor Freedom—by Protecting Privacy Rights

Twila Brase, RN, PHN,
President and Co-founder, CCHF
Building Health Surveillance Systems

- 1994 – Clinton Health Security Act
- 1996 – Health Insurance Portability and Accountability Act (HIPAA)
- 1999 – Healthcare Research and Quality Act of 1999 (HRQA)
- 2004 – Bush State of the Union Speech
- 2006 – Tax Relief and Health Care Act of 2006
- 2008 – Medicare Improvements for Patients & Providers Act (MIPPA)
- 2008 – Genetic Information Nondiscrimination Act of 2008 (GINA)
Congressional Action (continued)...

• 2009 – Health Info Tech. for Economic & Clinical Health Act (HITECH/ARRA)
• 2010 – Patient Protection and Affordable Care Act (ACA)
• 2015 – Medicare Access and CHIP Reauthorization Act (MACRA)
• 2016 – 21st Century Cures Act
• 2017 – The Consolidated Appropriations Act, 2017
• 2017 – Substance Use Disorder bill & Health Data Clearinghouse bill
HIPAA Does **NOT** Protect Privacy

- Patient consent not required for data sharing.
- HIPAA is a permissive rule
- Shalala: “age-old right to privacy in this new world of progress”
- 12 National Priority Purposes
- 2.2 million entities can access with permission from ‘covered entity’
- Plus...government access without consent
2.2 Million Entities – July 14, 2010 CMS Rule

<table>
<thead>
<tr>
<th>Health-Care Entity</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Business Associates* (conduct business on behalf of entities listed below)</td>
<td>1,500,000</td>
</tr>
<tr>
<td>Office of MDs, DOs, Mental Health Practitioners, Dentists, PT, OT, ST, Audiologists</td>
<td>419,286</td>
</tr>
<tr>
<td>Durable Medical Equipment Suppliers</td>
<td>107,567</td>
</tr>
<tr>
<td>Pharmacies</td>
<td>88,396</td>
</tr>
<tr>
<td>Nursing Facilities**</td>
<td>34,400</td>
</tr>
<tr>
<td>Home Health Service Covered Entities</td>
<td>15,329</td>
</tr>
<tr>
<td>Outpatient Care Centers***</td>
<td>13,902</td>
</tr>
<tr>
<td>Medical Diagnostic, and Imaging Service Covered Entities</td>
<td>7,879</td>
</tr>
<tr>
<td>Other Ambulatory Care Service Covered Entities (Ambulance and Other)</td>
<td>5,879</td>
</tr>
<tr>
<td>Hospitals (General Medical and Surgical, Psychiatric, Substance Abuse, Other Specialty)</td>
<td>4,060</td>
</tr>
<tr>
<td>Third Party Administrators Working on Behalf of Covered Health Plans</td>
<td>3,522</td>
</tr>
<tr>
<td>Health Insurance Carriers</td>
<td>1,045</td>
</tr>
<tr>
<td><strong>Total Entities and Business Associates</strong></td>
<td>2,201,325</td>
</tr>
</tbody>
</table>

* According to HHS, examples of business associates include third-party administrators or pharmacy benefit managers for health plans, claims processing or billing companies, transcription companies, and persons who perform legal, actuarial, accounting, management, or administrative services for covered entities and who require access to protected health information.
HIPAA - TPO Access

- **Treatment, Payment and Healthcare Operations** (§164.506)
- HIPAA permits access without consent for TPO
- Treatment — 62 words
- Payment — 64 words
- Health Care Operations — nearly **400 words**
- No accounting of disclosures required – unless state law preempts!
  (CFR §164.528)
HIPAA - Limited Data Set (LDS)

• For research, public health or health care operations

• Entirety of protected health information (PHI) minus 16 direct identifiers

• Included: city, state, ZIP, ages, DOB, DOD, Admin, Discharge, Service dates

• No authorization or consent required

• No accounting of disclosures required

• HHS: Data can be re-identified — Data use agreement (DUA) required
EHR/MU Mandate – ARRA 2009

• “Meaningful Use” – as defined by federal government

• Use government-certified HER (CEHRT) or lose it ($$$)

• “Government EHR”

• $30 billion in incentive payments (total $37B spent – Sen. Alexander 10/31/17 hearing)

• MACRA 2015 → Merit-Based Incentive Payments (MIPS)

• MACRA → Alternative Payment Models (APMs), including ACOs
MIPS – Performing to “Government Tune”

• He who pays the piper picks the tune.

• HHS regulators require data on:
  • “Quality”
  • “Resource Use”
  • “Clinical Practice Improvement Activities”
  • “ Meaningful Use” of “Certified” EHR Technology
Measuring Physician Performance - MIPS

What is the Merit-based Incentive Payment System?

Performance Categories

- Quality
- Cost
- Improvement Activities
- Advancing Care Information
Advancing Care Information - Scoring

The overall Advancing Care Information score would be made up of a base score, a performance score, and a bonus score for a maximum score of 100 percentage points.
ACI – Bonus for Surveillance Reporting

Advancing Care Information Bonus Score

for reporting on one or more of the following Public Health and Clinical Data Registry Reporting measures:

- Syndromic Surveillance Reporting (14 and 15)
- Specialized Registry Reporting (14)
- Electronic Case Reporting (15)
- Public Health Registry Reporting (15)
- Clinical Data Registry Reporting (15)

5% BONUS

for using CEHRT to report certain Improvement Activities

10% BONUS
ACOs – An APM Option

Tracking/Profiling Patients is Key:

“To be an ACO you need three things:

1. A common EHR
2. A robust data warehouse
3. A care coordination platform

If you don’t have those three elements, you are flying blind.”

— Dan Moriarity, chief information officer of Atrius Health
Coercive Consents – Essentia Health—Pg 1
GENERAL CONSENT AND AUTHORIZATION

I certify that I am the patient/family member named above and that I have read and understand the contents of this document.

I hereby authorize Essentia Health to share health information about me with my physician, Essentia Health or other health organization, government program, and other persons who are authorized to receive it as specified in law.

I hereby authorize Essentia Health to disclose health information to anyone whom you have identified as a family member, personal representative, or other person to whom you want Essentia Health to disclose your health information.

I understand that I have the right to receive a copy of this authorization upon request.

I understand that I may revoke this authorization at any time by notifying Essentia Health in writing. The patient's release will be revoked only for the data identified on the date of revocation.

Essentia Health

October 1, 2023

Signature: [Patient Name]

Date: [Current Date]
Is This Consent?

Essentia Health respects your right to privacy. Under the following conditions your health information will only be released with your consent:

K. I authorize Essentia Health to release my medical records to, and as needed, to discuss my care with my doctors, other healthcare providers, and anyone else Essentia Health either believes to be involved in, or who may participate in my care, treatment, case management and/or discharge planning. This includes source documents (such as x-rays). I authorize Essentia Health to electronically release my protected health information to other healthcare providers involved in my care and treatment and who share electronic medical record systems with Essentia Health. This includes information related to the diagnosis and treatment of mental illness, alcohol or drug use, sexually transmitted diseases (STDs), HIV test results, developmental disabilities and genetic testing results.
Patients Can Refuse to Sign HIPAA

4. Know What You are Signing.

The law requires your doctor, hospital, or other health care provider to ask for written proof that you received the Notice of Privacy Practices, or what they might call an “acknowledgement of receipt.” The law does not require you to sign the acknowledgement form.

If you choose not to sign, your provider must keep a record that they did not get your signature, but they still have to treat you.

If you choose to sign, you have not given up any of your rights or agreed to any special uses of your health records. You are just stating you got the Notice.

To learn more, visit www.hhs.gov/ocr/privacy/.
Genetic Intrusions

• **Newborn Dried Blood Spots (“Baby DNA”)**
  • Taken as part of State’s newborn (genetic) screening program
  • 15-18 states store 2+ years to indefinitely
  • States collect store, use, analyze, conduct research, disseminate
  • Only 28% of parents approve use for research without consent (2009 study)

• **Federal “Common Rule”** – authorizes bedside research and requires no consent for research on deidentified specimens

• **Preserving Employee Wellness Programs Act (proposed)**
“Information Commons” for Research

• 21st Century Cures Act
• Creates an Information Commons
• Requires sharing by researchers into a common pool
• Permits access by all researchers regardless of training/motives
• Creates a “global pediatric clinical study network”
Public Health Surveillance

“Electronic case reporting (eCR) is the automated electronic generation and transmission of reports of potential cases of reportable conditions from the electronic health record to state and local public health authorities for review and action. eCR can allow state and local health departments to conduct real-time surveillance without burdening health care providers.”

Government “Tapping” Into EHRs

Centers for Disease Control and Prevention (CDC):

“is focusing on efforts to improve data collection capabilities by accessing information buried in EHRs and utilizing cloud-based applications.”

—“CDC Plans to Improve Public Health Data Collection by Moving to the Cloud and Accessing EHRs”

National Health Data System - HHS Plan 2010:
https://www.healthit.gov/sites/default/files/nhin-architecture-overview-draft-20100421-1.pdf
Americans Want Medical Privacy

• 1% willing to allow researcher access without consent – Harris 2008

• 15% taking steps to protect own medical privacy in 1999 (before EHR/MU)

• *All of Us* – the Precision Medicine Initiative (PMI)
  • 20-30% of 4,000 refuse consent for EHR access *(Politico, 10/25/17)*

• 2000 Gallup survey:
  • 78% - medical records should be confidential
  • 93% - no researcher access to genetic information without consent
  • 92% - oppose government access without their permission
  • 67% - oppose researcher access to medical records without consent
Constitutional Right to Privacy

Fourth Amendment:

The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no Warrants shall issue, but upon probable cause, supported by Oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized.
“The makers of our Constitution...conferred, as against the Government, the right to be left alone—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 Fourth Amendment.”
Divulge Data—or Protect Privacy & Control?

“Whatever, in connection with my professional practice or not, in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret.”

— Hippocratic Oath (c. 400 BC)
Action Steps to Restore Privacy

• Protect from Government & Corporate Controllers

• **Limited List of Action Steps:**
  
  • Add consent requirements to all health care legislation – States/Congress
  
  • End EHR/MIPS/APM mandates – *Congress*
  
  • Refuse the government EHR
  
  • Refuse to comply with MIPS/APMs/PQRS
Action Steps Continued...

• Inform patients about EHR controls, health surveillance
• Refuse to report data/release records without express patient consent
• Refuse to hook up to “the grid”
• No HIE/eHealth Exchange without SEPARATE opt-in patient consent
• Prohibit and do not use coercive (consolidated) consent forms
• Refuse to conduct bedside research
• Freedom from Third-Party Payment
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Doctor

FUTURE

Patient

Patient

Patient

Doctor

Hospital

Insurer

(back to the future)
Coming Soon!
BIG BROTHER
IN THE
EXAM ROOM
The Dangerous Truth about
Electronic Health Records

TWILA BRASE, RN, PHN
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