Privacy and Confidentiality: Where have we been? Where are we going?

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HIPPOCRATES

HIP PPOCRATIC Oath
400 B.C.

“What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about.”

HIPAA
2003 A.D

Responses to HIPAA

• Researchers:
  – I can no longer do clinical research
  – These regulations are killing me
  – What were they thinking?
• Patients:
  – It is still the status quo – I don’t see any more protection
  – What were they thinking?

So what are the facts?

• Balance between individual rights and public good
• Individuals’ desire to have their information treated with respect and confidentiality
• Researchers’ desire to be able to access info
Doctors need patient’s full disclosure

- Optimal medical care requires honest and open communication between patients and physicians
- Patients who withhold information – or give incorrect information may receive inferior medical care
  - How often do you floss?

Patients demand privacy protection

- Patients trust that their information stops with their doctor
  - Not if your doctor uses the elevator!!!
- Patients often do not understand how their information is used in their care
  - Why do so many people handle my information?

FACT?:

**My information stops with my Doctor......right?**

Medical Marketing Service advertises a database available...that includes the names of 4.3 million people with allergies; 923,000 with bladder control, problems; and 380,000 who suffer from clinical depression (www.mmlists.com)
The 13-year-old daughter of a hospital employee took a list of patients’ names and phone numbers from the hospital when visiting her mother at work. As a joke, she contacted patients and told them that they had been diagnosed with HIV. Wash.Post March 1, 1995, p A17

FACT?:

**Computer technology provides excellent privacy protection**

Eli Lilly inadvertently revealed over 600 patient e-mail addresses of those receiving reminders to take their Prozac (NYT, Jan 19, 2002, p. C3)

About 400 pages of detailed psychological records concerning visits and diagnoses of at least 62 children were accidentally posed on the University of Montana website (LA Times, Nov. 7, 2001, p. A1)

A doctor’s laptop was stolen at a medical conference. The computer contained the names and medical histories of his patients. (Wash Post, Nov. 5, 2000, p. A1)

Fact:

**Patients want us to use their data**

Mayo Clinic – 96% of 214,000 patients agreed to have their medical records accessible for research


Fact:

**Patients want us to use their data**

Equifax-Harris Consumer Privacy Survey – 1996 – 1,005 adults

- 60% willing to provide criminal records (60%) vs 40% willing to provide medical records
- Use of medical info for research – assuming consent not feasible AND info would be kept confidential
  - 31% - NEVER ACCEPTABLE
  - 38% - somewhat acceptable
  - 18% - OK
Fact: Patients want us to use their data
106 patients in doctors’ offices
Opt-in or opt-out preference for consent:
28 (26%) – satisfied with passive notification and ability to opt-out at any time
78 (74%) – wanted opportunity to provide consent first
What should be in the consent?
57% wanted specific information
BMJ 2003;326:373

Fact: Patients want us to use their data
602 persons with serious genetic or other chronic medical condition asked:
“Medical researchers should be able to get my medical records without my permission if it will help them to do research that will advance medical knowledge.”
• 31.1% agree
• 13.6% neutral
• 55.4% disagree
J. Law,Med&Ethics 2003;31:429-33

Need for TRUST
• System of privacy protections
• Review of all research
• Shadenfreude
• The simple lure of titillating information

SCHADENFREUDE
SHAD-n-froy-duh
A malicious satisfaction in the misfortunes of others

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The GLOBE
May 3, 2004
• Single issue literature review
• Exempt research
Kelly Ripa’s son had to be treated by a plastic surgeon after gnashing his head at school…the wound needed stitches…three on the outside and four on the inside.

Actor Robert Pastorelli’s autopsy disclosed a bombshell revelation…missing organs – indicating that he may have been secretly suffering from an incurable disease…” “…liver destroying Hepatitis B…and incurable Crohn’s disease

Supported by photocopies of the autopsy and toxicology reports

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The GLOBE
May 3, 2004

• Weird Al’s parents die from carbon monoxide poisoning
• John Lennon’s father had cancer
• Monaco’s Princess Caroline once suffered from alopecia
• Nia Vardalos “started undergoing fertility treatments.”
• Queen Latifah “looks like she’s put on about 20 pounds…”
FACTS

Maintaining confidentiality is difficult.
Maintaining the public’s trust may be even more difficult.