Concerns about the privacy of Electronic Health Records

*Patients and Health Care Providers...*

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Overview

1. To provide the background for this exploratory study
2. To provide an overview of the current literature concerning privacy & EHRs
3. To raise an ethical question for discussion & thought
PART ONE

Background...
EHR uptake in Canada remains slow

• Are privacy concerns holding back uptake?
  – Major breaches of private patient health information
    • Lost laptops (non-conformant with policies)
  – 9 million Americans believe that their health information has been lost or stolen
  – American physicians have so little trust in the US government that they would retire rather than adopt government EHRs
PART TWO

Current literature...
Structured review

• May-June 2008
• PubMed, EMBASE, CINAHL, Cochrane, iEEE, CMA CPG, Patient Safety Resource
• English language only, EHR specific, no date limitations, original research only

• Privacy vs. security or confidentiality
  – Privacy – “The desire to control or limit access to one’s personal health information.”
21 Articles

- 9 USA, 5 UK, 2 New Zealand, 1 Ireland, 1 Canada, 1 Norway, 1 Denmark, 1 Oman
- 14 quantitative, 7 qualitative
- 6 addresses privacy & EHRs as their main objective
- 14 patient concerns, 5 provider concerns, 1 both patient & provider
- 1 study included providers other than physicians & nurses
General concerns

- Majority of patients have no concerns
- All studies – subset of patients who have serious concerns
- About half of all providers believe that EHRs increase risks to patient confidentiality
- All groups concerned with unauthorized access (hackers, insurance companies etc)
  - Stigma associated with mental health issues; commercial use of data; exploitation & blackmail
Sharing information in an EHR

• Patients don’t want their entire record shared
• Limitations required
  – No clarity on what these should be aside from sexual & mental health
• No consensus on which providers should be able to access what information in what circumstances
  – Patients tended to want more restrictions than providers
Lack of trust - Custodians

• 3 studies
  – 1 study:
    • majority of patients had a high level of trust
  – 2 studies:
    • patients felt that their information was not being adequately protected

• Highest trust in health care providers
• Lowest trust in researchers!!
In summary...

- Patients much less concerned than their providers about privacy & the EHR
- Patients who have experienced stigmatization much more concerned than the “worried well”
- Concerns may lead to a lack of disclosure by patient to providers hindering care
- Lack of clear consensus on who should have access and how that access should be managed
Caveat

• Limited research
• Lack of generalizability between countries
  – Legislative differences
  – Relationship between patient & payer
• No study focused on whether or not providers felt they have the skills needed to manage privacy & the EHR
• Security, privacy & confidentiality
  – Muddled & confused terms
PART THREE

An ethical dilemma…
Balancing the scales...

- Patient’s wishes
- Duty of care
Patients

Not as concerned as providers...
Sexual & Mental Health

• Do patients even care about their information anymore?
Is it likely that I have HIV?

• On 7/18 of this year I had unprotected sex (I realize this was a mistake, if you're going to answer my question please avoid the lecture). It wasn't planned, and I asked the boy afterward if he has any diseases. He said no, but of course I cannot know this for sure. I went in to be tested a couple days after, but the doctor said that an HIV test wouldn't be valid until about 3 months later and any other disease wouldn't show up for a couple weeks either. So I'm going back in about a week to be tested, and then again once three months is up for an HIV test. In the meantime, I'm terrified.

• I went traveling to Guatemala for 2 weeks and while I was there I came down with the flu (fever, etc) and then later had a bad case of diarrhea. Those things may be from traveling. Now that I'm home, though, I'm still having some diarrhea, I had a fever yesterday, my lymph nodes are swollen/sore, I've had a loss of appetite, my body has been achy, and I've been itchy with slight little rashes. I looked up symptoms of early HIV infection, and all of those things are listed.

• So, should I be worried? Or should I hope that these things are just from traveling?

http://answers.yahoo.com/question/index?qid=20090812012025AArZUef
HIV Awareness Campaign

- http://www.posornot.com/posornot
- Michael, 38
- Jennifer, 31
- Et al....
  - Pictures posted; Basic background information; Details about how they became infected and how they’re dealing with being HIV+
Mental Health

http://www.chovil.com/

The Experience of Schizophrenia

Ian Chovil's Homepage
Intimate Health Details

• [http://shlookshlies.blogspot.com/](http://shlookshlies.blogspot.com/)

• Ulcerative Colitis
  – Experiences with the illness, surgery, without a colon etc etc…

• Rural BC
  – Small plane ride & woman’s experiences with fertility issues
Providers

Greater concern & professional obligation…
Hippocratic Oath

“What I may see or hear in the course of 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.”
Do we, as professionals, have a duty to protect patients even from themselves?
Review

• Lack of uptake of EHRs in Canada
  – ? Privacy concerns
• Literature review
  – Limited evidence & no real consensus
    • Patients less concerned than providers for the most part
• What is our obligation as professionals?
Thank you

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