

Concerns about the privacy of Electronic Health Records

Patients and Health Care Providers...

Dr. Nicola (Nikki) T. Shaw

Research Chair, Health Informatics





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

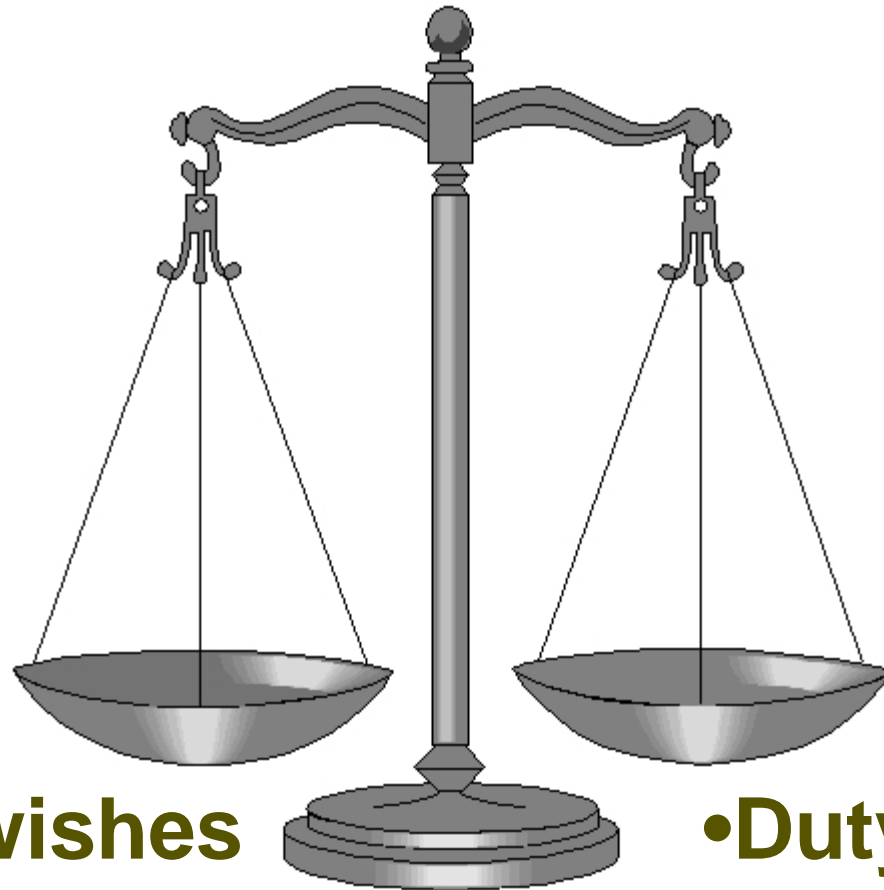
PART THREE



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?



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/>
- **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



Nicola.Shaw@albertahealthservices.ca or Nicola.Shaw@ualberta.ca