Health Privacy: What Consumers Want

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Health Privacy Futures 2008
Realising the Opportunity

At a recent symposium on Privacy Law at the CyberLaw and Policy Centre of the University of New South Wales, Special Minister of State, Senator Faulkner said:
"Privacy is not about what we voluntarily - however unwisely, as others might see it - disclose of ourselves. Privacy is our right to make that decision for ourselves."

He went on:
"We can hardly be surprised that technological developments often seem to trade privacy for convenience, for profit, for uncensored, unregulated speech, or for efficiency in law enforcement. Too often, privacy is considered at the end of the process, when debate starts about how the technology will be used."

The one area that Senator Faulkner left out was one of the most important areas of concern for any person: our health and well-being. I imagine he would have agreed with its inclusion, though. This conference is a demonstration of how important it is. Most people expect their health information to be confidential, that is, between him or herself and their treating physician or medical team. We don't stop and think about the range of other people who have access to that information. Even so, we expect the same level of medical ethics to apply to anyone involved in making us well or seeing us through to our ultimate demise.

However, in today's technology dependent world, just as in finance, law enforcement, and communications, health information management is also changing. And there is some doubt as to whether or not the decisions being taken are done so with improved patient care outcomes in mind, and are based on a proper consideration of how health care providers use and access health information.

So what are consumer expectations in terms of Health Information management? And what actions can decision-makers take to meet those expectations?

Wants

Let's begin with the 'wants'. From a policy perspective, these areas are 'soft', that is, difficult to measure. Patient wants tend to be qualitative and contextual. They are the kinds of values that are recognised through individual experience and not hard numbers. But they are pretty straight forward.

I will focus on four of them:
Trust
Quality of Service
Transparency
Respect

This is a story from Craig, used with his permission:

Twelve months ago I had a routine procedure performed at XXX Hospital. It was a failure having permanent consequences for me. This is where the trouble began. I had trouble while under anaesthetic. The following day, BEFORE I had even spoken to my surgeon about what had gone wrong during the operation, I was visited by the anaesthetic registrar who was abusive and unprofessional. She reported to the entire public ward every single detail of my personal medical history, including private personal information and sensitive information that I did not want disclosed.

Angry, I requested all of my medical records from the numerous surgeries I had had at XXX Hospital to be investigated by a personal injury lawyer. I used the Freedom of information form provided and paid a fee. I DID NOT receive what I asked for and had to request this a number of times. I complained to the hospital's patient representative. The complaint was forwarded to the director of medical services. I received a number of idiotic replies stating that the "architecture" of the ward was responsible for my privacy breach and not the doctor who did it.

I further complained to the Health Care Complaints Commission and the state privacy commission. The Health Care Complaints Commission does not see an obvious breach of privacy as a concern and the matter was dismissed despite the fact that the privacy commissioner's office found the doctor to be in breach of several privacy principles. The privacy commission states that the hospital can a: choose to apologise or b; do nothing. Further more blood and urine tests obtained without my consent then went missing from the hospital and I got a letter from the managing director of the XX central XXX Health Service saying that they never existed, which is untrue. ...

Rest assured, if something goes wrong in a hospital your medical records, and the details that are NOT kept as official documents, will be made freely available to everyone except the patient. Once an accusation is made against a doctor or a hospital you get so buried in bureaucracy that you have no hope of resolution. There simply is no such thing as privacy in hospitals or in the medical profession whether it is electronic or otherwise." end his story

Dare I say there is much work to be done in XX hospital and XX Health Service before even more power is presented in terms of electronic records.

We don't have to accept all of Craig's conclusions, but we do have to agree that something's badly wrong here.

Trust

Trust is a keystone for positive health outcomes. Anxiety is the enemy. That includes trust in the decisions made about treatment, trust in the ability of the provider to deliver the treatment, and trust in the security of information divulged by patients to enable the diagnosis and treatment. This third area is critical because that information may be about illness or life style choices that could jeopardise other relationships should the information be accessed by, or indeed <u>given</u> to, those who aren't entitled to know it without patient consent. Where does trust intersect with the new Health Information Systems?

- Trust that the people delivering services know what they're doing. This includes the capability of the medical professionals and their supporting staff to <u>use</u> these new information collections <u>properly</u>. What training is being funded for this? What screening is being done so that staff are aware of their obligations?

- Trust that the technology is going to work. If GPs, specialists or Emergency departments are going to rely on these systems – one that has been continually described as a centralised collection of health records in an EHR – what is the backup plan when e-health data are NOT available?

- Trust that the information we share is not going to be abused: Wider access to electronically held records comes with new dangers. There is real potential that through pushing one wrong number on a keyboard, information will be sent to inappropriate places. In a 2008 US survey of 1000 adults, 62% said they were not too confident or not at all confident that electronic health records would remain confidential. Just last week, the transportability and potential for loss of data on 10 USB memory sticks was a problem in six Hong Kong hospitals where the identity numbers and regular medical records of 10,000 patients were lost. What safeguards are being considered to mitigate that possibility here? What governance systems are in place so that the consequences for those who mess up [that's a technical term] are high enough to deter poor or unethical, if not illegal, behaviours? http://www.ihealthbeat.org/Data-Points/2008/Are-You-Confident-That-Electronic-Health-Records-Will-Remain-Private.aspx ; http://www.thestandard.com.hk/news_detail.asp?pp_cat=11&art_id=65526&sid=18808278&con_type=1&d_str=20080507&sear_year=2008

- Trust that the goal posts are not going to shift once a program is promoted. The situation in NSW with Health*elink*, begun in 2006, is an example where trust was broken. Originally promoted as opt-in, the opposite actually occurred, then boasting that xx thousands of people were enrolled. If those examples of 'trials' continue – where opt-in doesn't really mean opt-in at all – involving groups in the community who have what might be termed softer or more reticent voices, such as the elderly and children in this case – then trust is already out the window. And now, the NSW government has announced a roll-out of Electronic Medical Records without publishing the results of the evaluation of the trials. http://www.privacy.org.au/Campaigns/E_Health_Record/HealthElink.html ; http://www.emr.health.nsw.gov.au/

Quality of Service

The key outcomes of health service is restoration of health or a comforted departure. Most people interact with health services when we or our family members are sick or injured and need professional treatment. To that end, three points are of concern with regard to health information collection and use:

- Accuracy of information: If a decision is going to be taken with regard to a treatment option, particularly in emergency situations, patients need to be assured that the best information available is being used. This is one of the key arguments given in support of EHR systems by those proposing them. However, can we be sure that what is in the EHR is up to date, complete, correct to this particular moment, and unbiased? Is the current central storage model going to achieve those levels of quality? Are there other approaches, such as 'just in time' federated information retrieval systems, that would provide better accuracy of information?

- Quality of the doctor or carer: We have heard a few sad stories lately of how the health system has failed patients, usually women, due to clinician error, and in some high profile cases, malpractice. Will the health information systems also provide more information to the consumer about the people treating us? What are their track records? What are their qualifications? What is their most recent training activity in relation to the treatment they are going to provide? What is the track record of this particular hospital? Will e-health systems provide a quality of service record to the patient for better choices about who is treating them?

- Quality of management of tax-payer money: One of the buzz words in health circles over the last 10 years or so is evidence based decision making. As a taxpayer who will foot the bill for these systems, where is the evidence that the investment is going to result in better health care outcomes? Is there any besides xx thousands of people having enroled?

Transparency

In order to make informed choices, to make an informed consent decision, either for participation in ehealth processes or treatment, the consenting person needs all the relevant information, good and bad. And I don't think that is being done. Not out of malice, but because the systems aren't well enough understood and because most technology decisions are based on 'selling' technological solutions by those with different agendas than patient care. This is why those with the responsibility to purchase and design MUST put the patient/doctor in the centre of the planning and development process. As an aside, I'd like to meet the person who made the determination that it was 'all right' to use full body scans in airports!

- Don't just tell us what high minded goals (policy) you are trying to achieve - give us the details of what you are doing (practice). Few people will disagree with "we want to improve health care". What they will worry about is "We are going to put all your health records into a big database so your doctor can see your complete medical records. And by the way, anyone in a hospital or doctor's practice can also get at them."

- What are the benefits of participation in an e-health system for the patient and the doctor? What is being gained through the trade-off?

- What are the negatives – the side effects and risks – of participation? It can't all be rosy. Nothing in technology or ANY system is risk free. Has that question even been asked? Is it being included in the literature of the trials being conducted now? Or is it all gloss of how wonderful these projects are? Too much spin and not enough realism?

- Be clear what health information is. It is easy to say that an individual's health records should be stored in digital form, but what is the extent of these records? Should an individual's health record contain information about who performed all the services that individual has accessed? As an example, when an individual has an operation, should the name of every health professional and manager involved also be stored? When we have scripts filled, should the name of every person working at the pharmacy at that time be recorded? If not, why not?

- Similarly, are there different implications to the patient with regard to what is defined as health or medical information? In a current article in Nature magazine, a debate is underway about the personalized genome and how to manage that information. Fairfax newspapers reported on Saturday that a Sydney company will be providing personal genetic analysis soon. It is already happening in Melbourne to determine ‘athletic’ ability, whatever that means. Will the genome of an individual be stored in the medical record? Or will it be quarantined? Where is our equivalent to the US Genetic Information Nondiscrimination Act of 2008 before our genomic information is defined as part of our health record? http://www.nature.com/nature/journal/v456/n7218/full/456034a.html ; http://www.nature.com/nature/journal/v456/n7218/full/456001a.html ; http://www.theage.com.au/national/letting-my-gene-genies-out-of-the-bag-20081107-

5k7w.html

- Who are the people who will see the collected health information? What can they do with it?
- If they do the wrong thing, how can the problems be rectified? Who is carrying the can? To whom do I complain? What are the penalties? Will it be fixed?

Respect

Of all the consumer desires, this is one of the most difficult to effect because it is an attitude, a mindset. I recall the abusive doctor in Craig's story. The stereotype is that health professionals expect respect because of their knowledge and professional standing. Equally, patients who come to these professionals are due respect – for their choices, their own knowledge of their own circumstances, and their dignity as individuals whose lives are really at stake in the transaction. That includes respectful handling of their health information.

These four expectations – Trust, Quality, Transparency and Respect – are important because if you ignore these things, or under-value them, you're not just letting human beings down - you're designing systems to fail. People *within* the system will dislike it and will compromise the design as they try to make it more acceptable to patients.

Action

Let's turn our attention to what should be done in health information developments to address these expectations:

Involve
Inform and Educate
Listen and Respond
Honour Wishes

Involve More of Those Who Have Most At Stake.

1. Stop thinking the value of health information systems is efficiency for government departments and research, and put the patient/doctor – the receiver and deliverer of the services – in the centre of the decision making process. Involve MORE consumers and doctors in the process than bureaucrats, consultants and IT staff. The processes and information flows need to be tested with real users of health services and those who deliver them. Even the federal health minister is in favour: "it's now widely accepted that consumers should have a central role as the users and beneficiaries of healthcare - and, ultimately the ones who pay for it". http://www.australianit.news.com.au/story/0,24897,24535256-5013046,00.html
2. Involve a range of individuals with different health needs. Illness, injury, chronic, acute, movement, intellectual level, language, life stage, age, culture – make your own list. The systems developed must cater for any or all people, not just white, middle class, pick your age group, pick your health status. I believe the challenge you all face in developing a system that is fair, functional and beneficial to anyone who wants to get involved and believes they would benefit is the most difficult aspect of all this. Only when representatives

of these groups are involved to test your assumptions will the optimum design be realised.

3. Make health records owned by the individual and require that a record be kept of everyone who looks at them, adds to them or changes them. Privacy would then be at the heart of the system and would be dealt with as a fundamental requirement, not bolted on as an afterthought as Minister Faulkner described.

Inform and Educate

1. The more information, the better. Again Minister Roxon: "Comparable data on quality of care, adverse events or infection rates for superbugs will allow consumers to legitimately distinguish between effective and less effective healthcare providers, and allow them to make informed decisions."

2. Inform at the right time. People who are anxious about their illness and future are not always in the right frame of mind to make complex decisions. Stress does that to people. Doctors and supporting medical staff should be the ones to do this over time.

3. Inform in reasonable chunks, not all at once.

4. Inform patients of exactly how their e-data will be used. Who will read it? Will it be used for secondary purposes? What conditions will apply to data access and use? Will it be made available to insurance companies or employers? What body or organisation will mind the records and provide access? Will one's podiatrist see that one has suffered depression in the past? Will they be advised each time a medico has access to their EHR, like a bank statement?

5. Don't assume they understood the first time the information was given. Don't assume they can read or heard what was said.

6. Provide examples, both good and not so good, so that the person is truly informed in order to decide whether or not to give consent.

Listen and Respond

1. Be open minded. Listen to comments and questions without pre-judging just because a system design decision has already been made on paper. Before the system is built and procedures written in stone, use that involvement I mentioned earlier and revise. Trials should be just that: experiments. Too many times recently, I've participated in projects where the program implementations are out of order, with no beta testing at all, just roll-out. The result is wasted money, wasted time, mistakes, and gun-shy participants.

2. Listen to each person as an individual, not just once, but at every encounter. Their personal situations must be considered in the context of different levels of sensitivity with regard to patient information as well as their health status at any particular point in time.

Honour Their Wishes

1. Provide alternatives for participation within the handling of health information. Change takes time. The point is to provide for improved health, not fill in a blank, not fulfill a data

subject quota for research projects. It should be a negotiation between the patient and their doctors as to what information should be captured, and accessible to whom and when.

2. Realise that patients have relationships that are beyond the one they have with their doctor. They are balancing a whole life, not just an ill or injured period in their lives. Provision must be made to allow the individual to make determinations with regard to who gets to know what.

What I have attempted to do today is move away from the policy and technology, and shift the discussion to the values that most of us can relate to as caring human beings who respect one another.

If you are someone making decisions about health information privacy policy and practice, I will leave you with one request. As you encounter a fork in the road where one path leads to a risky approach to greater collection, storage, and access of health information without assured and demonstrated benefit to the patients involved, and the other path leads to a less efficient yet safer and lesser collection, storage and access, picture in your mind –

your mother or father, your spouse, or your children – someone in your world who is important to you, and ask yourself:

which is the better option?

which carries the most respect for that person in your life and his or her individual dignity as a human being?

which will make and keep them well?