

Speaking Notes for Presentation to Prairie  
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“Health Information Privacy and  
Effective Health Policy-making and  
Healthcare Delivery”

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## I. Introduction

- Personal health information is one of the most, if not the most , sensitive areas of public concern about the potential loss of privacy.
  
- Risks of inappropriate disclosure of sensitive personal health information are different from financial disclosures because the harm is personal, not financial.
  
- Healthcare privacy is also different because of the wide range of potential users on many different levels, spanning the public and the private sector and operating under different privacy laws.
  
- Personal health information is not only used immediately for care purposes, it is also collected and used for research, policy planning, fraud investigation and safety/quality assurance purposes.
  
- A number of trends in the healthcare field enlarge the privacy concerns, such as:
  - increasingly team-based and networked approaches to delivery,
  - new channels of delivery, such as telehealth, walk-in clinics, health portals, etc.

- an increasing focus on chronic diseases and life-long care which means maintaining health information for long periods;
  - the emergence and gradual spread of the electronic health record (EHR) not as a singular record but rather as an amalgam of information from many sources,
  - evolving technology which both supports information security but also makes the data more complex and comprehensive.
- The E-Health movement is a work in progress and the decision-makers are making extravagant claims on what it will deliver:
- improved access and service;
  - service integration;
  - eliminating redundancy and increasing efficiency;
  - greater patient safety;
  - giving patients more control.
- According to the Ontario Health Council, 32,000 patients in that province are made worse each year by the lack of EHRs.
- Canadians are reporting greater personal experience with EHRs. In a recent Health Canada survey 1/3 of respondents reported first hand experience with electronic health records.

- The same survey identified some interesting trends:
  - growing awareness of privacy laws (51% up from 39%),
  - belief that EHRs protect health information better than paper systems,
  - belief that an electronic healthcare system would be more accessible, efficient and effective than a paper based system.
  
- Canadians' concerns about EHRs included: access for malicious purposes (45%), use for unauthorized purposes (42%) and breakdown of security (37%).
  
- To increase their comfort level in reliance upon EHRs, Canadians want audit trails, penalties for unauthorized access, the right to be informed about breaches, access to and the right to correct their own health records and clear privacy policies.
  
- Such survey findings have to be interpreted with caution. While Canadians are worried in a general, vague way about privacy in the health field, most citizens are ill informed about existing laws, regulations, policies, procedures and practices.
  
- Apart from privacy pundits like those in the room today (the present speaker

excluded), it is not clear how much ordinary Canadians value their privacy in practice compared to the answers they give to pollsters. I do not have Canadian data but a 2006 survey in the USA found that only 7 percent of Americans cared enough about privacy to change their behaviour in the marketplace. I recall a debate on the National Advisory Council to Statistics Canada (on which I serve) in which a vice president of a bank declared “we have no privacy, get over it!”

- Also, there is not a strong advocacy community around privacy concerns, as there is, for example, around the public’s right to know. The relative absence of such advocacy groups becomes important as I move now to examine the necessity for balancing and trade offs between personal privacy and effective healthcare policy-making and service delivery.

## II Effective Healthcare vs. Privacy

- The issues involved with combining privacy with more accessible, efficient and effective healthcare are usually formulated in polarized terms.
- Commentators cite the paradox that Canadians insist on accessible, cost-effective, safe, quality healthcare, but they also insist on strict privacy for

their personal health information. Logically, it seems that both ends of this “teeter-totter” cannot be up at the same time.

- The usual response to this dilemma is to call for a balanced approach. Balance is one of those “feel good”, happy words which everyone can endorse. In the case of healthcare and privacy, balance implies that authorities will gather only the right amount and the right type of information, they will ensure that it is distributed only to the right locations at the right time, they will guarantee that it is secure and used only for authorized purposes, and in all cases there will be informed, active or deemed consent from patients to share sensitive information about their health status within the so-called “circle of care.”
- Designing privacy considerations into policies and practices in advance and taking advantage of technological opportunities to enhance security for information will supposedly allow us to create a “win-win” situation, rather than an ‘either-or’ situation involving unnecessary trade offs.
- Reporting and disclosure will allow for honest dialogues about mistakes and adverse events. Gathering of information on outcomes will enable patients and families to have access to relevant information about the performance of institutions and individual providers.

- This is the prevailing model which guides policy making in the field of healthcare privacy. It implies we can strike just the right balance so as to optimize the achievement of all values and interests involved. In practice, however, it is more realistic to suggest that the balance being sought will, of necessity, involve trade offs.

- I would argue that it is impossible to fully and adequately resolve the tensions between effective healthcare and privacy in the abstract and apart from actual real life situations. The alternative is to proceed on a pragmatic case-by-case basis. This involves the risk that the tensions will be resolved in one direction. Most likely the push for more effective, efficient and safer healthcare will, over time, incrementally “crowd out” privacy concerns. The benefits to the public from gathering and sharing personal health information are generally assumed to outweigh the costs of some marginal loss of privacy.

- In the search for coherent and consistent approaches to finding the right balance, governments seem to be following two policy paths. First, there are seeking to make the two broad sets of concerns (efficiency/effectiveness/safety and privacy/disclosure and accountability)

compatible, complementary and even mutually reinforcing.

- At present, public policy with respect to handling health information is going in diverse, contradictory directions. There is an insistence on gathering more information to provide safer, seamless, high quality care. There is a recognized need for more information on outcomes. There is a need for a measure of confidentiality to enable honest dialogues when something goes wrong. There is the public's recognition that health professionals do not have a monopoly on knowledge and cannot achieve perfection in their practices. This leads to calls for greater transparency and accountability. Calls for disclosure have to be reconciled with privacy concerns and existing privacy laws have often fallen behind the times. Treating all of these public policy issues in isolation from one another ignores the interdependencies among them. Secondly, they are seeking to mitigate the tensions involved with detailed guidelines for implementation. This second option may be inherently unstable given the complex and dynamic nature of healthcare policy and services and the difficulty of foreseeing the prescribing in advance for the diverse situations which will arise.
- A further complication is the fact that the healthcare system is multi-tiered, it involves both public and private components, multiple domains of care

and a complex web of federal and provincial privacy laws. Four provinces

- Alberta, Manitoba, Ontario and Saskatchewan- have passed health-specific privacy laws.

- To think realistically about reconciling privacy and effective healthcare we need to move beyond simple dichotomies.

- For example, we need to distinguish different types of information (individual identifiable, individual, non-identifying and aggregate information), different methods of collection (through the care process, through administrative processes through research) and the different purposes and uses (to promote safety/quality, to support policy development, for legal purposes.)

- In the time available and with my limited knowledge, I cannot presume to talk about all parts of the healthcare system. Accordingly, I have chosen to focus on the crucial aspect of patient safety and the efforts to reduce the number of adverse events which cause harm to patients.

### III The Case of Patient Safety

- In the patient safety fields, the debates have revolved around finding an appropriate balance in the operation of three information-handling process. The three processes are reporting, disclosure and informing.
  
- Reporting refers to the mandatory or voluntary provision of information about adverse events to peer review bodies such as critical incident committees, mortality and morbidity committees and to professional health regulatory bodies.
  
- In a growing number of provinces including Manitoba, there is a mandatory, legal requirement to report adverse events causing serious harm to patients.
  
- Disclosure refers to the provision of information to patient and families. In the past, when adverse events occurred there was a reluctance on the part of care providers and care institutions to provide much information. Again, in a growing number of provinces this has become a legal requirement. Some provinces, such as B.C. and Manitoba, have also passed Apology Acts which allow providers to “say sorry” without increasing their exposure to malpractice suits and other legal actions.

- Informing refers to the provision of information to the public about the performance of healthcare institutions, including their track records of fatal or serious adverse events.
- Examples of informing are the publication on-line of physician profiles and of hospital report cards.
- There are three main purposes behind the informing function: (1) to provide a basis for better informed use of the healthcare system; (2) to promote transparency and greater external accountability and (3) to provide an incentive for learning and improvement.
- Recent legislative changes were meant to overcome a culture of silence and to promote a more honest dialogue about why unwanted, untoward events causing harm to patients occur.
- To overcome the reluctance to discuss adverse events, Saskatchewan and Manitoba led the way in entrenching the principle of “qualified privilege” into law. Under the Evidence Act of those two provinces, the proceedings of critical incident committees which investigate adverse events are given

some protection against disclosure in legal proceedings of various kinds.

- I am not a lawyer, but as I understand the principle of qualified privilege it is meant to offer confidentiality protection only to the extent necessary to ensure that safety and quality assurance activities are not hindered by the reasonable fear of health professionals that disclosure will have unreasonable, adverse professional consequences. Please note the use of the “reasonableness” test in the formulation of the concept.
  
- Some health professionals have claimed a right to professional privacy. Up to a point, their professional lives should not be a completely open book. However, they are granted delegated authority to regulate themselves and they are paid from the public purse, so it is appropriate to place limits on their professional (not personal) privacy.
  
- Sensitivity to the privacy, legal and reputational concerns of health professionals (mainly physicals) and healthcare institutions have led both Saskatchewan and Manitoba to limit the sharing of information about adverse events. The reports from critical incident investigations at the institutional level are communicated to the regional health authorities and to

the provincial departments of health. This information is made available to the public only in an aggregated form. It does not involve reporting by procedure and by institution. Reporting on a more “fine grained” basis, it is feared, would lead to non-reporting, defensiveness or incomplete reporting because individual and institutional reputations would be affected. More detailed information could also compromise the privacy of patients and families, especially when small communities are involved.

#### IV Conclusions

- Canadians are concerned about health privacy. They are less deferential towards health professionals. They are better educated and have access to more information about health problems and health issues via the internet. They are more insistent on their right to know and have pushed for proactive disclosure by such means as physician profiles, hospital report cards, data bases on outcomes, more transparent and open regulatory processes and so on.
  
- It is not all members of the public, however, who are part of the “patient rights” movement. The more vulnerable segments of Canadian society - the poor, Aboriginals, new Canadians, the elderly - tend to be less able to

protect their rights, including their right to privacy. In many respects, concern to protect one's privacy is a middle and upper class cultural norm. For marginal groups, loss of privacy is seen as the price to be paid for gaining access to healthcare and/or they are intimidated by the superior (professional) - subordinate (patient) relationships which exist in the field.

-It is estimated (Canadian Council on Learning, Health Literacy in Canada, 2008) that 60% of adult Canadians do not have the necessary knowledge and skills to manage their health and healthcare. Health literacy involves “the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across a life course.” (Canadian Public Health Association, A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy, 2008). Interacting with the health system alone is risky for many Canadians and upholding people's rights to safe care as well as personal privacy requires more intermediary and advocacy groups

- We need to look at more face-to-face and expeditious ways to help patients cope with a grotesquely complicated healthcare system. Patient representatives within institutions help up to a point, but such offices are

often low profile and their leaders are seen as employees, not advocates.

- Among the provinces, only Quebec has a specialized health ombudsman. In other provinces, the general ombudsman's jurisdiction usually extends to the health sector. However, the visibility and capacity of general ombudsman in the health field is limited. In some cases, like Manitoba, the ombudsman also looks after privacy concerns. I favour the development of health ombudsman across the provinces.
- My final observation takes me back to the notion of trade offs introduced at the beginning of these remarks.
- Efficiency, effectiveness and safety concerns should not always, everywhere and automatically trump privacy concerns. This is in danger of happening because there is not a "privacy lobby" of any significant size and political clout. A growing number of citizens see privacy as a lost value - something they are willing to forsake in return for better health policy and quality service.
- The leaders in this room today have a responsibility to uphold the privacy cause and to ensure that the trade offs do not all move in one direction.

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