

REPORT ON

THE HEALTH INFORMATION PROTECTION AMENDMENT REGULATIONS, 2010



**SASKATCHEWAN
INFORMATION AND PRIVACY COMMISSIONER**

MAY 3, 2010

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EXECUTIVE SUMMARY

The Saskatchewan Government has unveiled a new fundraising Regulation (Order in Council 187/2010) (the Regulation) to *The Health Information Protection Act* (HIPA)¹. This will empower regional health authorities (RHAs) in Saskatchewan to enter into agreements with fundraising foundations. These agreements can allow the RHAs to disclose to the foundations certain personal health information of patients who have recently received a health service in a hospital. The personal health information consists of three elements: (1) the name of the patient, (2) contact information for the patient and (3) the fact that the patient has recently received a health service in a hospital. In addition, it appears that the foundation will also learn which patients are frequently in hospital and those who are rarely in hospital by operation of the information transfer arrangement. This will be done without first obtaining the express consent of patients on an opt-in basis. Instead, patients have the right to opt-out of the program. If they opt-out then the foundation will be required to delete their name and information from the list of prospective donors.

The disclosure of personal health information to foundations is for a secondary purpose since it is unrelated to the diagnosis, treatment and care of the patient. The privacy ‘best practice’ for such a disclosure for a secondary purpose would be to obtain the express consent of the patient in advance of the disclosure. The experience with opt-out consent is that it is more likely that patients may not be aware of the disclosure of their personal health information to the foundations on a default basis and that they can only avoid this result by taking action to opt-out. In addition, details of the opt-out procedure may not be readily available to all patients in a timely way.

There was a public consultation in 2004 which resulted in negative feedback from the public and a public report from the Office of the Information and Privacy Commissioner (OIPC) that raised concerns with the opt-out nature of the proposed regulation. No public report was produced by Saskatchewan Health detailing the response to that public consultation invitation.

From 2004 to 2007 there were two additional consultations with the OIPC. It appeared that Saskatchewan Health would not proceed with that proposed regulation. In late 2009 and early 2010, Saskatchewan Health informally indicated to the OIPC that it would likely proceed with a fundraising regulation on the basis of opt-out. No draft regulation text was provided to the OIPC, however, since 2007 and there were no substantive discussions involving the Commissioner about the regulation from 2007 until this date.

¹ *The Health Information Protection Act*, S.S. 1999, c. H-0.021 (hereinafter HIPA).

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The OIPC has identified a number of difficulties with the Regulation. These include:

- Diminished patient confidence in the electronic health record;
- Risks associated with personal health information being shared with fundraising organizations that are not subject to any major privacy law (federal or provincial)² and for which there is no oversight by an independent Information and Privacy Commissioner or the Privacy Commissioner of Canada;
- Likelihood of pressure from other health related non-profit organizations for the ability to use personal health information for their fundraising efforts;
- Lack of capacity for health information staff in RHAs to manage the significant new work created by the Regulation without compromising their general work in administering the region's extensive HIPA responsibilities;
- Risk of the Saskatchewan Government being found to have violated the *Charter of Rights and Freedoms*³ and the privacy interests of Saskatchewan patients;
- Risk that Saskatchewan patients will react negatively to the disclosure of personal health information to the foundations and reduce their support for those foundations as a result; and,
- Risk that the additional complexity created by the Regulation will undermine progress to date towards the goal of ensuring all Saskatchewan health care workers have a comfortable understanding of what they can and cannot do with the personal health information of patients.

Most of these concerns and certainly the major concerns would be eliminated if the disclosure of the personal health information was on an opt-in basis rather than on an opt-out basis.

² Provincially, fundraising foundations do not appear to be subject to *The Freedom of Information and Protection of Privacy Act*, *The Local Authority Freedom of Information and Protection of Privacy Act*, or HIPA. They do appear to be subject to Saskatchewan's *The Privacy Act*. Foundations would not qualify as an organization for the purposes of the federal *Personal Information Protection and Electronics Document Act* (hereinafter PIPEDA).

³ *The Constitution Act, 1982*, S.C. 1982, c.11.

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BACKGROUND

In April 2010, the Minister of Health (the Minister) announced a new fundraising Regulation (Order in Council 187/2010) (the Regulation) under *The Health Information Protection Act*⁴ (HIPA). The Minister released a backgrounder entitled *Changes to Health Information Protection Regulations* as well as the *Health Information Protection Amendment Regulations: Fact Sheet*⁵ (Fact Sheet) by way of explanatory material. He also provided additional information in the Legislative Assembly (the Assembly) on April 12, 2010.

This Report to the Assembly provides my office's commentary on the Regulation.

This commentary is provided pursuant to my mandate that includes providing advice and commentary to the Assembly and to the Saskatchewan public. My mandate is particularized by sections 52 and 53 of HIPA as follows:

Privacy powers of commissioner

52 The commissioner may:

- (a) offer comment on the implications for personal health information of proposed legislative schemes or programs of trustees;
- (b) after hearing a trustee, recommend that the trustee:
 - (i) cease or modify a specified practice of collecting, using or disclosing information that contravenes this Act; and
 - (ii) destroy collections of personal health information collected in contravention of this Act;
- (c) in appropriate circumstances, comment on the collection of personal health information in a manner other than directly from the individual to whom it relates;
- (d) from time to time, carry out investigations with respect to personal health information in the custody or control of trustees to ensure compliance with this Act;
- (e) comment on the implications for protection of personal health information of any aspect of the collection, storage, use or transfer of personal health information.

General powers of commissioner

53 The commissioner may:

- (a) engage in or commission research into matters affecting the carrying out of the purposes of this Act;
- (b) conduct public education programs and provide information concerning this Act and the commissioner's role and activities;
- (c) receive representations concerning the operation of this Act.⁶

⁴ *Supra* note 1.

⁵ Government of Saskatchewan, *Health Information Protection Amendment Regulations: Fact Sheet* available online at <http://www.gov.sk.ca/news?newsId=15be15e7-585f-484a-be13-f202ff369355>.

⁶ *Supra* note 1, sections 52 and 53.

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The Regulation cannot be considered independent of the electronic health record (EHR). Indeed, HIPA was explicitly designed to enable and facilitate the creation and operation of an EHR for every individual in Saskatchewan. The Throne Speech of March 9, 1998 included the following announcement:

New technology is part of health care's future.

Our health system will move into the information age with the continuing development of The Saskatchewan Health Information Network;

My government will introduce *The Health Information Protection Act* to safeguard all personal health information.⁷

The EHR was discussed in more detail in my Investigation Report H-2010-001.⁸

My respectful submission to the Assembly is that in considering the Regulation, there should be careful consideration of the impact such a regulation may have on the EHR being developed in this province and the degree to which Saskatchewan residents can feel comfortable that their personal health information will be adequately protected in this new system.

Since the initial iteration of the regulation was proposed in 2004, my position has consistently been that Saskatchewan Health⁹ should require express consent from patients **before** health trustees share any personal health information (including name, contact information and fact they have received a service in hospital) for fundraising purposes. That would represent a privacy 'best practice' and be the most appropriate resolution as far as this office is concerned. It would also be the approach most consistent with the preamble to HIPA:

WHEREAS the Legislative Assembly recognizes the following principles with respect to personal health information:

THAT personal health information is private and shall be dealt with in a manner that respects the continuing interests of the individuals to whom it relates;

THAT individuals provide personal health information with the expectation of confidentiality and personal privacy;

THAT trustees of personal health information shall protect the confidentiality of the information and the privacy of the individuals to whom it relates;

THAT the primary purpose of the collection, use and disclosure of personal health information is to benefit the individuals to whom it relates;

THAT, wherever possible, the collection, use and disclosure of personal health information shall occur with the consent of the individuals to whom it relates;

THAT personal health information is essential to the provision of health services;

⁷ Saskatchewan *Hansard*, March 9, 2010, p. 4.

⁸ Saskatchewan Information and Privacy Commissioner, Report H-2010-001 available online at <http://www.oipc.sk.ca/reviews.htm> at [88].

⁹ Saskatchewan Health may also be referred to as the Ministry of Health or the Ministry.

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THAT, wherever possible, personal health information shall be collected directly from the individual to whom it relates;
THAT personal health information shall be collected on a need-to-know basis;
THAT individuals shall be able to obtain access to records of their personal health information;
THAT the security, accuracy and integrity of personal health information shall be protected;
THAT trustees shall be accountable to individuals with respect to the collection, use, disclosure and exercise of custody and control of personal health information;
THAT trustees shall be open about policies and practices with respect to the collection, use and disclosure of personal health information¹⁰

I note that the preamble makes no mention of any responsibility to facilitate fundraising by hospital foundations nor was this identified as a purpose of the legislation either when it was debated in 1998 or when it became law on September 1, 2003.

The importance of prior express consent of the patient was summed up nicely by the MLA for Cannington on April 26, 1999 in the debate at Second Reading of Bill 29 – *The Health Information Protection Act* as follows:

Does this information belong to the government, does it belong to the doctors, or the medical practitioners that collected it, or does it belong to the patient? I would submit Mr. Speaker, that this information belongs to the patient because it's about them and their conditions. Therefore **if that information is going to be released to other parties not directly related to that patient's health and health services, that the information would have to be released only, Mr. Speaker, only with the consent of the patient involved.**¹¹ [emphasis added]

All provinces and territories, with the exception of Quebec and Saskatchewan, have approved the *Pan-Canadian Health Information Privacy and Confidentiality Framework* (the Framework). That includes the following provision 6.3:

A health information custodian shall not collect, use or disclose personal health information about an individual/trustee for the purpose of fundraising activities unless the individual expressly consents and the custodian collects, uses or discloses the information, as the case may be, subject to the prescribed requirements and restrictions, if any.¹² [emphasis added]

¹⁰ *Supra* note 1, preamble.

¹¹ *Supra* note 7, April 26, 1999, p. 764.

¹² Health Canada, *Pan-Canadian Health Information Privacy and Confidentiality Framework* (January 2005) available online at <http://www.hc-sc.gc.ca/hcs-sss/pubs/ehealth-esante/2005-pancanad-priv/index-eng.php>.

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A complementary provision is 6.4 that provides as follows:

A health information custodian/trustee shall not collect, use or disclose personal health information about an individual for the purpose of marketing anything unless the individual expressly consents and the custodian collects, uses or discloses the information, as the case may be, subject to the prescribed requirements and restrictions if any.¹³

Even though the Saskatchewan Government refused to formally approve the Framework, Saskatchewan Health has elected to reflect the principles of the Framework in the first three domain repositories it has created for the EHR in this province. This has been done presumably to ensure that the EHR constructed in Saskatchewan will allow the exchange of patient data with all other jurisdictions which have adopted the Framework.

In addition, I have consistently asserted that the reasons offered by Saskatchewan Health to justify the move to an opt-out model for the exclusive benefit of the hospital foundations are, in our view, demonstrably weak and vague; those reasons are also unsupported by any cogent evidence that the important function of fundraising is impaired or has been impaired by the requirement for patient consent or opt-in.

A further consideration is the Saskatchewan Government's adoption of *For Patients' Sake - Patient First Review Commissioner's Report to the Saskatchewan Minister of Health* (the Patient First Review Final Report) in late 2009. The thrust of that initiative appears to be that Saskatchewan will move towards a patient-centred health system. In his open letter to the Minister, Commissioner Tony Dagnone, stated:

The research findings make clear that those associated with health care must renew their commitment to putting the patient first. Patients ask that health care workers and their respective leadership see beyond their declared interests so that the interest of patients takes precedence at every care interaction, every future contract negotiation and every policy debate. Only in this way will we achieve a patient- and family-centred health system for Saskatchewan citizens. Similarly, government leaders and policy makers must keep the patient front and centre when policies, programs, and new models of care are designed and implemented.¹⁴

The change from opt-in consent to opt-out is inconsistent with the patient-centered approach since it takes power away from the patient and substitutes the discretion of the RHA to decide whether to disclose and how often to disclose personal health information to a foundation.

¹³ *Ibid.*

¹⁴ Saskatchewan Health, *For Patient's Sake: Patient First Review Commissioner's Report to the Saskatchewan Ministry of Health* available online at www.health.gov.sk.ca/patient-first-review p. iii.

CONSENT OPTIONS

Consent in HIPA provides any trustee with 3 different options:

- (1) express consent or opt-in (highest standard),
- (2) implied consent with a right to opt-out (a national standard for purposes of the EHR), and
- (3) no consent or in section 27(2) described as “deemed consent” (lowest standard).

Except for three limited circumstances where express consent is required by statute [sections 18.1(3)(b)(i), 27(5)(b) and 29(1) of HIPA], trustees must determine, in accordance with their ethical codes and standards and the circumstances and urgency of the health service, which option is most appropriate. In a number of scenarios in an emergency room or ICU, no consent may be the most appropriate option. In the treatment of a chronic condition such as diabetic patient where the patient must play a large role in his/her own treatment plan, express consent would be more appropriate. Given the prejudice that attaches to the use of personal health information for employment purposes, express consent should always be required for section 26(3) of HIPA as well.

The best practice is to consider consent in terms of cascading thresholds. Start by considering the highest standard and the one most consistent with a patient-centered system which would be express consent. Only if express consent would not be appropriate in the particular circumstances should the trustee then consider whether implied consent would be appropriate. In the event that implied consent would not be appropriate in the circumstances, then the trustee should consider deemed consent or no consent. Trustees should be mindful that deemed consent completely disempowers the patient and is the hardest form of consent to reconcile with a patient-centered health care system except for limited circumstances. These limited circumstances would normally be urgency, an unconscious patient, or an imminent risk to the health or safety of a patient. Deemed consent should never be invoked casually or as a default approach to dealing with patients and their wishes.

The basic structure of HIPA, similar to that of the stand-alone health information laws in Manitoba, Alberta and Ontario and the not yet in force laws in New Brunswick and Newfoundland, is that there is easy sharing of patient’s personal health information among health care workers who need that information to provide diagnosis, treatment and care for the patient. There is, however, a kind of protective wall around that therapeutic context and any disclosure of personal health information outside of the therapeutic context requires either consent or legal authorization. Generally, exceptions to the consent requirement are limited and specific. This is seen as critically important to ensure that patients have confidence that they will have a measure of control over any use or disclosure of their personal health information for any secondary purpose (any purpose unrelated to the diagnosis, treatment or care of that patient). The numerous opinion surveys undertaken by Canada Health Infoway, Health Canada and the Privacy Commissioner of Canada reveal strong support for the facilitated sharing of patient

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personal health information in the therapeutic context but serious concern on the part of patients with non-consented disclosure for secondary purposes.¹⁵

ANALYSIS OF THE CASE FOR OPT-OUT

Consider the various arguments put forward to support the Regulation:

1) Patients have historically been contacted to ask for donations.

This argument ignores the reason for the enactment of HIPA. HIPA was developed explicitly to enable and to facilitate the EHR for each man, woman and child living in Saskatchewan. The very enactment of HIPA signalled major changes in the way that personal health information would thereafter be collected, used and disclosed. HIPA in numerous ways changed any number of health information practices. It is apparent from materials produced by Saskatchewan Health and the regulatory colleges leading up to the September 1, 2003 proclamation of HIPA, or shortly thereafter, that it would not be business as usual. HIPA created new rules around consent, new requirements for transparency, policies and procedures, explicit limiting disclosure rules and a ‘need-to-know’ requirement for all collection, use and disclosure transactions. There were new restrictive rules that severely limit when the health services number (HSN) for residents can be required or used. There was provision for independent oversight by an independent Information and Privacy Commissioner appointed by the Assembly. All of this signalled a new awareness of the risks that attach to EHRs that could potentially be viewed and used by many thousands of health care workers. This represented a radically different threat than the improper viewing by a rogue healthcare worker of personal health information in paper patient files physically located in the family physician’s clinic.

The Fact Sheet includes an interesting statement that:

Many Saskatchewan health regions, affiliated hospitals and approved fundraising foundations traditionally had access to contact information of hospital patients, for inclusion in fundraising campaigns. The practice has not been allowed under regulations that came into effect July 2005, two years after the proclamation of *The Health Information Protection Act* (HIPA).¹⁶

My view is that such a claim is inaccurate and not supported in law. The prohibition against the former practice of disclosing personal health information to foundations would have been effected by the proclamation of HIPA on September 1, 2003. This would have been a full two years before Saskatchewan Health indicates it became unlawful. HIPA outlaws disclosure of personal health information, including the name, contact information and the fact of a recent hospital service, to any non-trustee unless there is consent or specific statutory authority for such

¹⁵ Survey available at <http://www.infoway-inforoute.ca/>. Those survey results appear to be consistent with results of a public consultation undertaken by the Government of Saskatchewan in 1998: *Consultation Paper on Protection of Personal Health Information*.

¹⁶ *Supra* note 5.

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a disclosure. I can find no such authority in HIPA. In any event, if Saskatchewan Health's assertion is correct, there would have been no reason to propose a regulation based on opt-out when it undertook its 2004 public consultation. I might add that in the three consultations between 2004 and 2007 dealing with disclosure of personal health information for fundraising purposes that involved my office, there was never any acknowledgement or advice from Saskatchewan Health that the foundations had been routinely receiving personal health information subsequent to September 1, 2003. Given the statement in the Fact Sheet, it would be appropriate for Saskatchewan Health to clarify precisely what, if any, personal health information was disclosed to hospital foundations by any Saskatchewan trustees in the period September 1, 2003 to July 2005.

The new stand-alone health information laws developed in Manitoba (1997), Alberta (2001), Saskatchewan (2003) and Ontario (2004) all, to a greater or lesser extent, reflected the work and recommendations from the federal Advisory Council on Health Infostructure (Advisory Council).

In the 2000 publication of the Advisory Council, *Canada Health Infoway: Paths to Better Health: Final Report*, it was stated:

Patient-based health records are fundamental to provincial and territorial health infostructures. However, they have the potential for serious violations of privacy. The Council believes that, with particular care, **electronic health records can actually enhance privacy protection**, improve patient care, enable telehealth, **empower citizens through greater control of their own health records** and serve as the foundation for an ever-improving information and evidence-based health system.

The federal Minister of Health should work with his provincial and territorial counterparts to improve patient care through the creation of provincial and territorial person-based, electronic health record systems. **These systems would make accessible on a need-to-know basis and under the control of patients – all relevant information about their past medical histories.**

As one means of protecting patients' privacy, Minister should ensure that legislative safeguards are in place against the use of personal identifiers in health for purposes outside the health field. Also critical will be measures to improve the security of health records by taking advantage of modern technologies such as encryption, authentication and the electronic logging of all accesses made to a personal record.¹⁷ [emphasis added]

¹⁷ Advisory Council on Health Infostructure, *Canada Health Infoway: Paths to Better Health: Final Report* available online at <http://www.hc-sc.gc.ca/hcs-sss/pubs/ehealth-esante/1999-paths-voies-fin/index-eng.php>, p. 9.

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The Advisory Council also considered “secondary uses” of personal health information and the extent to which that should be allowed. Secondary use would be for a use other than diagnosis, treatment and care for the patient (i.e. research, use for health system planning, fundraising, etc). On this score the Advisory Council was clear:

Such [health information] **legislation should prohibit all secondary commercial use of personal health information** and set clear limits on access and use of health information by third parties outside the health care system. It should contain provisions regulating secondary uses of non-identifiable health information, taking into account the range of potential identifiability of such information. Finally, it should prohibit the use of personal identifiers in health for other purposes.¹⁸ [emphasis added]

In *A Conceptual Privacy Impact Assessment (PIA) on Canada’s Health Record Solution*, it is stated that:

Express consent is generally required for the use or disclosure of personal health information for purposes outside the ‘circle of care’ (i.e. to insurers, employers, marketers) that are not otherwise permitted by law.¹⁹ [emphasis added]

Also in the same document:

Consent is the means by which individuals may exercise control over their personal health information. **The right of patients to permit or restrict access to their personal health information is becoming increasingly important as public awareness of both privacy and EHRs continue to increase.**²⁰ [emphasis added]

2) The information to be disclosed to the health foundations is not ‘personal health information’ but merely contact information.

It has been suggested that the information that would go to foundations would somehow not be ‘personal health information’. This is clearly inaccurate. Personal health information is defined broadly in section 2(m) of HIPA as follows:

2(m) **“personal health information” means**, with respect to an individual, whether living or deceased:

- (i) information with respect to the physical or mental health of the individual;
- (ii) information with respect to any health service provided to the individual;

¹⁸ *Ibid.*, p. 11.

¹⁹ Canada Health Infoway, *A Conceptual Privacy Impact Assessment (PIA) on Canada’s Health Record Solution* available online at http://www2.infoway-inforoute.ca/Documents/CHI_625_PIA_rj13.pdf, p. 53.

²⁰ *Ibid.*, p. 53.

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(iii) information with respect to the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of the individual;

(iv) information that is collected:

(A) in the course of providing health services to the individual; or

(B) incidentally to the provision of health services to the individual; or

(v) registration information;²¹ [emphasis added]

Registration information that is subsumed in the definition of personal health information is defined by section 2(q) of HIPA as follows:

2(q) “registration information” means information about an individual that is collected for the purpose of registering the individual for the provision of health services, and includes the individual’s HSN and any other number assigned to the individual as part of a system of unique identifying numbers that is prescribed in the Regulations;²²

Also, in the EHR:

“all clinical data and data in the chart registry [including name, and address] will be uniformly classified as personal health information, all of which is extremely sensitive,”²³ [emphasis added]

It is problematic to subdivide personal health information in section 2(m) of HIPA into a new category of ‘client information’ and a new category of ‘other personal health information’ as is done by the Regulation. HIPA already provides for ‘registration information’ that is a sub-category of personal health information. There is also ‘de-identified information’ defined in HIPA. In the course of our HIPA oversight work we have encountered, not infrequently, confusion over what is and is not personal health information. Often we have encountered an assumption that personal health information is only diagnostic, treatment and care information. Our office has worked diligently over the last six years to promote awareness that even the name of a patient and their contact information is captured by the definition of personal health information. In addition, with all privacy laws, compliance is highest when those subject to such laws have a comfortable understanding of what is permitted and what is prohibited. To the extent that such laws are made more complicated and less accessible to workers and the public, then compliance tends to decrease. This is one of the reasons why in such instruments as the Framework, the definition of personal health information is very broad and there has been a consistent effort to avoid subdividing that personal health information into multiple types and subgroups of personal health information.

²¹ *Supra* note 1, section 2(m).

²² *Supra* note 1, section 2(q).

²³ *Supra* note 19, p. 57.

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To compound the confusion, in the Saskatchewan Health document – *Changes to Health Information Protection Regulations*, Saskatchewan Health introduces yet another term – “medical information”. This is not defined in the document but apparently would exclude some of what is defined as “registration information” and therefore “personal health information”. This is also not a term used in HIPA or in the existing HIPA regulations or in the Framework document.

In any event, it is not just the name and address for the patient that will be disclosed by the RHA to the foundation, but also another key item of personal health information which is the fact that the named individual has recently been discharged from a hospital in Saskatchewan.

Furthermore, for the dialysis patient or the patient with a chronic disease, since they frequently go to the hospital for treatment, they will presumably be on many lists provided by the RHA to a foundation over the course of a year. That clearly will be information that reveals personal health information of the individual, namely that they have a health condition that warrants frequent hospital treatments. In a fundraising context, these patients would presumably be ‘high-value targets’.

3) Patient lists are the best way to raise funds for hospitals and other health facilities.

When considering the proposition, initial questions that come to mind might be:

- What research or studies is this proposition based on?
- Why would this be more successful than soliciting donations from every adult in Saskatchewan?
- Is it obvious that grateful patients and family members will be more motivated to donate to their local hospital or hospital foundation than all potential patients living in any Saskatchewan community?

I respectfully submit that the sole determinant, however, must not be what works best from the perspective of fundraisers. Fundraisers in the healthcare sector as well as all other areas of charitable giving must adapt to the risks of identity theft, inappropriate disclosures of sensitive personal health information, new privacy invasive technologies, powerful search engines and the risks they pose to individual privacy. I have consistently urged that any new regulations that permit non-consented disclosure of personal health information should be carefully evaluated against a new test – will this disclosure bolster or undermine patient confidence in the EHR?

As noted earlier, the name, address and fact of a recent attendance at a hospital for service qualifies as personal health information for all purposes of HIPA. Accordingly, it is subject to the same legal protection as diagnostic, treatment and care information for any patient.

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I would encourage the Assembly to consider the impact of the Regulation on Saskatchewan patients. One might expect that many patients will feel uncomfortable once they learn that their personal health information is being routinely disclosed by the RHA to a foundation. There may be a danger of a backlash from those patients which may negatively impact the foundation's reputation in the community. Our office has heard from a number of patients who have expressed dissatisfaction with the Regulation and who have declared that they will no longer contribute to the foundation in their community.

There is also a question about the sense of vulnerability of many patients when they learn of the non-consented disclosure of their personal health information to foundations. Our office has received complaints from citizens who learned that their personal health information had been disclosed by the hospital, in which they recently received service, to a foundation. In fact, the letter to one former patient was signed by the head of surgery in the hospital. This is troublesome for several reasons. Would a patient receiving such a letter be concerned that their future care might be compromised if he or she elects not to make a contribution to the foundation or if they do not make a sufficiently large contribution?

HIPA came into force September 1, 2003. It is acknowledged in the explanation of the proposed regulation that HIPA does not currently permit disclosure of personal health information without express consent of the individual. I would hope that all RHAs have not been disclosing personal health information of patients to the foundations for the last six and one-half years without express consent of those patients.

I have not seen any evidence that this has been so difficult, costly or inconvenient that it warrants permitting disclosure of personal health information to bodies that are not directly involved in providing diagnosis, treatment or care to that patients.

4) How much of an impact has the express consent requirement had on fundraising?

A quick glance at the publications of the major health foundations in Saskatchewan suggests that Saskatchewan residents continue to support their hospitals generously in spite of the requirement for the last six and one-half years of express consent.

In this case, not only has there been no cogent evidence of the injury to Saskatchewan's major foundations but a perusal of the Annual Reports for the major foundations in Regina and Saskatoon demonstrate that despite the prohibition against non-consented disclosure of personal health information from RHAs to the foundations, those same foundations have enjoyed impressive success in fundraising year over year.

In 2008, the Hospitals of Regina Foundation reported revenue of \$5.5 million from charitable giving and \$3.5 million from charitable gaming. That is a remarkable increase from 2005 when the same organization received \$5 million in charitable giving and only \$1 million in charitable gaming.

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In Saskatoon, the 2008-2009 Annual Report for the Royal University Hospital Foundation states:

We are pleased to report that in 2008-2009, \$10,836,672 was raised through donations, bequests, events, gaming and other revenues. At the same time, \$10,008,200 was granted to Saskatoon Health Region programs at RUH. Due to the impact of the world economic downturn, net realized returns on our investment portfolio were negative at -2.87% for the past year. However, over the five years previous to the current year, our rate of return has been 3.47%. Our Board of Directors “fund management strategy” is prudent financial management and committed to protecting the value of our endowed and non-endowed funds. We remain diligent in our policy of providing accountable and transparent stewardship over the long-term growth of donor funds.²⁴

The foundation’s website also includes the following statement in regard to their 25th anniversary:

We celebrate the future. We are pleased to report that with regard to fundraising dollars, this past year was our most successful to date: we raised and received \$4.83 million in combined donations, net proceeds from events and lotteries, and investment income. This encouraging number reflects the RUH Foundation’s growing strength, as well as our community’s growing support for our vision of “creating excellence in and impacting health care by raising funds to anticipate and respond to needs for research, education and patient-care” – both today and in the future.²⁵

The evidence suggests that our major Saskatchewan health foundations have been very successful in their fundraising efforts since HIPA came into force September 1, 2003. They have done this operating on the basis of express consent or opt-in by patients. Therefore, on what basis can it be said that there is now some extraordinary need to abandon the privacy best practice of opt-in by patients and substitute the discretion of RHAs for the decision of patients? I have not found any evidence that would justify this change.

5) The requirement to obtain express consent would not be as effective.

A key question is:

- Why does the Regulation provide for opt-out consent rather than express consent?

²⁴ Royal University Hospital Foundation, *2008-2009 Annual Report*, available online at http://www.ruhf.org/annual_report.php, p.2.

²⁵ Royal University Hospital Foundation, *Royal University Hospital Foundation Celebrates 25th Anniversary*, available online at <http://www.ruhf.org/>.

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The purpose of disclosing personal health information (name, address and recent hospital service) is for a secondary purpose (i.e. a purpose unrelated to the diagnosis, treatment or care of a patient).

The Privacy Commissioner of Canada has outlined under the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA)²⁶ a commonly accepted four criteria test to apply in the context of disclosure for any secondary purpose:

1. The personal information must be clearly non-sensitive in nature and context.
2. The information-sharing situation must be limited and well-defined as to the nature of the personal information to be used or disclosed and the extent of the intended use or disclosure.
3. The organization's purposes must be limited and well-defined, stated in a reasonably clear and understandable manner, and brought to the individual's attention at the time the personal information is collected.
4. The organization must establish a convenient procedure for easily, inexpensively, and immediately opting out of, or withdrawing consent to, secondary purposes and must notify the individual of this procedure at the time the personal information is collected.²⁷

In applying that four-part test to the Regulation in question, it appears that Saskatchewan Health intends to address 2, 3 and 4, although we must reserve judgment until we see the toolkit being prepared by Saskatchewan Health for that purpose. The fundamental problem however, is posed by the first element. The fact that an individual has been in hospital is sensitive and prejudicial information that is close to the biographical core of the individual. When one considers the context, namely the developing EHR and the potential exposure of any patient's personal health information to thousands of health sector workers, it is very difficult to imagine that one could reasonably conclude this information was "clearly non-sensitive" within the meaning of the four-part test above. In these circumstances, opt-out would not be appropriate in this specific case applying the four-part test developed by the Privacy Commissioner of Canada for the purposes of PIPEDA.

²⁶ *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c.5 as amended.

²⁷ Privacy Commissioner of Canada, *Leading by Example: Key Developments in the First Seven Years of the Personal Information and Electronic Documents Act (PIPEDA)* available online at: http://www.priv.gc.ca/information/pub/lbe_080523_e.pdf, p. 52.

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In *A Conceptual Privacy Impact Assessment (PIA) on Canada's Health Record Solution*, it is stated that:

The determination of “authorized purposes” must be managed on a jurisdictional basis, in compliance with applicable legal and ethical requirements as well as privacy best practices, to instill[sic] confidence in the public that their personal health information will not be collected for unreasonable purposes (e.g. marketing, insurance eligibility, employment, etc.) without their express consent.²⁸
[emphasis added]

Why would express consent not be as effective? What are we measuring when we speak of effectiveness? If effectiveness refers to a large number of citizens committed to supporting their health care system through donations in addition to their taxes, surely a high degree of public confidence in the health care system and hospital foundations would contribute to that goal. In my view, that would be enhanced by requiring express consent before disclosure of personal health information to foundations.

It can perhaps be argued that, at the end of the day, the most important consideration is the degree to which individuals have a comfortable understanding of what will happen to their most sensitive and prejudicial information – their personal health information. To the extent that individuals are empowered through express consent, a high degree of confidence is actively promoted. As we move towards EHRs, this becomes increasingly important. If Saskatchewan residents feel that they have little control over what happens to their personal health information and to whom that information is disclosed for purposes not related to their diagnosis, treatment and care, they are likely to become more suspicious and wary of EHRs.

6) The requirement of express consent would add administrative cost to the process.

It is not clear how express consent would add significant administrative cost to the process. Anyone entering hospital is routinely required to provide a considerable amount of information including registration information, information about next of kin, whether they wish to be contacted by spiritual counsellors, etc. Express consent could be easily dealt with at the same time.

Indeed, it would appear that seeking express consent at the time the patient is admitted to hospital would be much simpler and presumably much less expensive than managing the complexity that attaches to the kind of opt-out process contemplated by the Regulation.

This could be done as simply as offering a check-off box on a registration form for any patient. If the patient declines to check the box, nothing further need be done. There would of course need to be compliance with the notice requirements of sections 9 and 10 of HIPA. If the patient agrees that his name and address can be disclosed to the foundation, then it is a simple administrative matter for the RHA to forward that information to the foundation. It would be a

²⁸ *Supra* note 19, p. 65.

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relatively simple matter for admissions staff to have a policy about not seeking consent from evidently vulnerable or incapacitated patients and to be trained accordingly.

In contrast, the proposed opt-out procedure is much more complicated and time intensive. It will require careful tracking of patients and their discharge date. It will mean receiving opt-out notices at the RHA that must be transmitted to the foundation and sharing of those notices between the two bodies. It will also mean frequent checking of lists over time. Unlike the alternative one off opt-in procedure, a good deal of paperwork and administrative time will no doubt be consumed in meeting all of the technical requirements of the Regulation.

It is not at all clear that the Saskatchewan RHAs currently have the capacity to properly and efficiently manage an opt-out system as contemplated by the Regulation. That, in turn, increases the risk that all procedures and rules will not be followed scrupulously and consistently.

ADDITIONAL CONSIDERATIONS

There are three further considerations that warrant attention:

1) No privacy law for fundraising foundations in Saskatchewan

As I have commented in past Annual Reports, there are significant gaps in privacy protection in Saskatchewan. One gap is that, unlike British Columbia and Alberta, non-profit organizations are not subject to any of the major federal or provincial privacy laws.²⁹ As well, given the interpretation of PIPEDA by the Privacy Commissioner of Canada, these same foundations escape scrutiny by the federal Privacy Commissioner³⁰. In the result, a Saskatchewan patient who is concerned that a foundation has improperly collected, used or disclosed their personal health information or who is denied access to their information in the custody of the foundation, cannot utilize statutory remedies such as HIPA or PIPEDA.

Presumably, those foundations will be required to enter into contracts by means of which the RHAs may purport to retain control over the personal health information of patients that is transferred under the Regulation to the foundation. Unfortunately, our office does not have the resources to be able to effectively monitor or audit these agreements. To a large extent, it will be necessary for the RHAs to monitor these contractual arrangements. I have not seen the form of contract contemplated by Saskatchewan Health but the contracts will need to clearly identify whether the activity of the foundations is a “use” or “disclosure” within the meaning of HIPA.

²⁹ *Supra* note 2.

³⁰ For more information, see the following resources from the Office of the Privacy Commissioner of Canada: *The Application of the Personal Information Protection and Electronic Documents Act to Charitable and Non-Profit Organizations* available online at http://www.priv.gc.ca/fs-fi/02_05_d_19_e.cfm; *Commissioner's Findings - PIPEDA Case Summary #2006-345: Private school not covered by PIPEDA (July 5, 2006)* available online at http://www.priv.gc.ca/cf-dc/2006/345_20060705_e.cfm; *Commissioner's Findings - PIPEDA Case Summary #2005-309: Daycare denied parent access to his personal information - April 18, 2005* available online at http://www.priv.gc.ca/cf-dc/2005/309_20050418_e.cfm

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There should also be a comprehensive audit program to ensure no use or disclosure contrary to the agreement.

It is also interesting that the Regulation specifically describes the transfer of personal health information from the RHA to the foundations as a disclosure. In a privacy context disclosure means that the RHA usually surrenders control of the personal health information that is transferred. Alternatively, if the RHA retains control, the transaction is a use. It is important that Saskatchewan Health reveals precisely how the approved contracts are structured so the public and our office can understand which provisions in HIPA will be engaged.

I am concerned that the transfer of this personal health information from trustees to foundations will put the information at greater risk and undermine public confidence. I note that the very fact that the foundations appear to have been lobbying for the move from express consent to a form of opt-out may reflect a lack of familiarity with and commitment to the foundations of privacy law.

It is likely that the opt-out contemplated by the Regulation will often occur after the transfer of personal health information from the trustee to the foundation. There is no guarantee that the foundation will immediately destroy the information that is the subject of an opt-out and purge it from its databases.

2) *Charter of Rights and Freedoms*

In Canada, our Supreme Court has determined that all Canadians enjoy a right of privacy in circumstances where they have a reasonable expectation of privacy in terms of information about themselves. I suggest that Canadians have a reasonable expectation that when they enter a hospital for surgery or other treatment that they should have a measure of control over who, aside from health care providers, can get that information for purposes unrelated to their diagnosis, treatment or care. The right of privacy is not codified in the *Charter of Rights and Freedoms*³¹ (the Charter) but is included in two sections: Section 8 (unreasonable search and seizure) and Section 7 (life, liberty and security – rights that can only be denied someone in accordance with the principles of fundamental justice).

In the event that there should be a future challenge to the proposed Regulation on the basis that it violates the right of privacy, guaranteed by sections 7 and 8 of the Charter, the province would presumably attempt to rely on section 1 of the Charter which provides as follows:

1. The Canadian *Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.³²

³¹ *Supra* note 3.

³² *Supra* note 3, section 1.

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To succeed in invoking section 1, the province would have to show two things:

- (a) The objective which the Regulation responsible for a limit on a Charter right or freedom is designed to serve must be of sufficient importance to warrant overriding a constitutionally protected right or freedom, and
- (b) the party invoking this section must show that the means chosen are reasonable and demonstrably justified. This is sometimes called the proportionality test. The three components of this proportionality test are:
 - 1) The Regulation must be carefully designed to achieve the balance in question i.e. it must not be arbitrary, unfair or based on irrational considerations but must be rationally connected with the objective.
 - 2) The Regulation must impair as little as possible the right or freedom in question.
 - 3) The Regulation must be proportional to the objective.

My view is that it will be difficult for Saskatchewan to establish that the Regulation is rationally connected with the ostensible objective(s) of HIPA. No evidence has been provided to establish that “rational connection”. I also question how a court could be persuaded that the impairment is as minimal as possible or how it could be viewed proportional to the ostensible objective.

A 2007 Ontario Superior Court of Justice decision may also have implications for the Regulation in our province. The decision in Cheskes v. Ontario (Attorney General) was considering amendments to Ontario’s *Vital Statistics Act* in regard to adoption records and access to those records. Key to the decision was a determination that a fundamental right to privacy guaranteed by the Charter (section 7) had been infringed and that the legislation could not be sustained after a section 1 analysis.

Relying on R. v. O’Connor, the Justice declared that the disclosure of birth and adoption records under the new amendments “constitutes an invasion of the dignity and self-worth of each of the individual applicants, and their right to privacy as an essential aspect of their right to liberty in a free and democratic society has been violated.”³³ Consequently, the applicants’ right to liberty in a free and democratic society had been violated.

In his judgment, Belobaba J. stated that:

[87] The case law is clear that the liberty interest protected by s. 7 of *the Charter* includes more than freedom from physical restraint. The liberty interest also protects the rights of citizens to make fundamental life choices without interference from the state. Or, to put it in the language used by the Supreme Court in *Malmo-Levine*, the right to liberty in s. 7 includes the “*right to an irreducible sphere of personal autonomy wherein individuals*

³³ R. v. O’Connor [1995] 4 S.C.R. 411 (S.C.C.).

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may make inherently private choices free from state interference. The only caveat is that the decisions being made must be fundamentally or inherently personal such that, “by their very nature, they implicate basic choices going to the core of what it means to enjoy individual dignity and independence.”

...

[90] The Attorney-General submits that the ‘fundamentally personal decision’ line of cases does not apply because here the private information is under the control of a government ministry. Strictly speaking, the decision whether or not to release the identifying information is the government’s, not the applicants’. I accept this distinction but I am more persuaded by the following two points – the first point was made by a Supreme Court judge and the second by an expert on adoption. First, that all information about a person is in a fundamental way her own, for her to communicate or retain for herself as she sees fit, and second, that the facts surrounding an individual’s adoption belong to that person regardless of where and how that information is stored. Furthermore, to say that the information is in the “control” of a government ministry begs the very question that’s before me. The applicants argue that though the government possesses their identifying information and could physically transfer it to any party, s. 7 of the Charter protects their ability to choose where the government may make such a transfer. I can see no reason why the government’s collection of personal information permits it to intrude on fundamental personal choices that would otherwise fall within the ambit of the liberty interest.³⁴

The judge determined that the following qualifies as a principle of fundamental justice under section 7:

Where an individual has a reasonable expectation of privacy in personal and confidential information, that information may not be disclosed to third parties without his or her consent.³⁵

Interestingly, the judge also determined that this was not a case where the court had to balance competing Charter-protected rights because the right to access confidential information as claimed by searching adoptees and birth parents is not a Charter-protected right. This observation is significant since the Regulation also appears to create a collision between a Charter protected right of privacy and a non-right based argument built on the convenience of the foundations.

In its section 1 analysis, the judge concluded that the government’s rationale involved a pressing and substantial objective and also that there was a rational connection with the impugned provisions and the legislative objectives. The legislation failed however the third element, minimal impairment. A similar outcome may flow from the Regulation in question.

³⁴ Cheskes v. Ontario (Attorney General) [2007] 87 O.R. (3d) 581.

³⁵ *Ibid.*, at [107].

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The Ontario government had asserted that the adoption disclosure provisions in the new law are “carefully tailored” and do not unreasonably overshoot their purposes. The judge found otherwise. In fact, the judge stated that “[c]ontrary to the submission of the Attorney General, the disclosure provisions in the new law have not been ‘carefully tailored’. The applicants’ rights under s. 7 have been completely eradicated.”³⁶

The Cheskes decision was subsequently considered by the Ontario Superior Court of Justice in John Doe v. Ontario [2007] O.J. No. 3889 and quoted with approval. The Ontario Court of Appeal also considered the Cheskes decision in Ontario v. Marchand, [2007] O.J. No. 4440. The Ontario Court of Appeal noted that there had been no appeal from Cheskes.

I suggest that the test of proportionality is an excellent public policy approach Saskatchewan Health should follow when considering this new opt-out procedure which allows personal health information to be disclosed to foundations without express consent.

3) Treatment of Fundraising in other Jurisdictions

As noted earlier, the provinces that have an operating stand-alone health information law are Manitoba, Alberta, Saskatchewan and Ontario.

Alberta has prohibited the use or disclosure of personal health information for fundraising purposes. Alberta’s *Health Information Act* provides as follows:

107(2) No person shall knowingly ...

(f) use individually identifying health information to market any service for a commercial purpose or to solicit money unless the individual who is the subject of the health information has specifically consented to its use for that purpose.³⁷

The penalty for this offence is a fine of not more than \$50,000.

This Alberta provision is consistent with a key recommendation in the *Canada Health Infoway: Paths to Better Health: Final Report* as follows:

5.1 In harmonizing and strengthening the protection of personal health information across jurisdictions, governments should ensure that their privacy legislation for health embodies the following mechanisms and principles:...

(g) provisions prohibiting all secondary commercial use of personal health information;³⁸

³⁶ *Ibid.*, at [153].

³⁷ *Health Information Act*, R.S.A. 2000, c. H-5, section 107(2).

³⁸ *Supra* note 17, p. 5-4.

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Manitoba's government is apparently considering changing its legislation to accommodate an opt-out system for fundraising by hospital foundations. We do not know the outcome of those deliberations and cannot assume that the province will follow Saskatchewan's change in law.

In the proposed Manitoba regulation, which has no Saskatchewan counterpart, a trustee must not disclose if the trustee is a hospital and the reason for the patient's admission would reasonably be considered to be sensitive personal health information. This at least acknowledges the fact that a hospital admission can be prejudicial. Given that prejudice and sensitivity can be very subjective on the part of the patient, this kind of determination, being left to a trustee, is very unsatisfactory. It would be much simpler and safer to assume that any hospital visit may be prejudicial and sensitive in the view of the patient. To accommodate that reality, it would make more sense to adopt an opt-in consent model.

Ontario's *Personal Health Information Protection Act, 2004* provides for disclosure of personal health information by custodians (equivalent to trustees in Saskatchewan) and a right for patients to opt-out. It is important to note, however, that Ontario embarked on a very ambitious and apparently effective communications and training plan when its law was proclaimed. In addition, Ontario institutions have operated under a robust public sector access and privacy regime since 1988. That may distinguish to a significant extent the Ontario provision in operation from the opt-out system that will prevail in Saskatchewan.

In New Brunswick, the *Personal Health Information Privacy and Access Act* (S.N.B. 2009, c. P-7.05) has been passed by the Legislative Assembly but has not yet been proclaimed. In section 19(1)(b) express consent is required from the patient before their personal health information can be disclosed by a custodian to a "a person for the purpose of fundraising activities".

In Newfoundland and Labrador, the *Personal Health Information Act* (S.N. 2008, c. P-7.01) is not yet in force. It requires consent from the patient before personal health information can be disclosed by a custodian to a non-custodian for a non-health related purpose unless required or permitted by law. Disclosure to a fundraising foundation by a custodian of the name, contact information and the fact that the patient had recently received services in an acute care hospital would require prior consent of the patient.

SPECIFIC COMMENTARY ON THE REGULATION

I wonder how we can expect the same degree of vigilance to be devoted to the protection of personal health information once we have subdivided 'personal health information' in section 2(m) of HIPA into 'client information' and 'other personal health information'. Our office has encountered confusion over whether registration information which includes name and address, warrants the same kind of protection afforded diagnostic, treatment and care information. In our view, the answer must be affirmative.

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The ‘client information’ definition in the Regulation misses the most important element, namely that this named individual at this identified address **received a hospital service** within the last reporting period. This third element of information is effectively communicated by the patient’s name on the list of eligible clients.

I note that ‘affiliate’ is also a designated trustee for purposes of the Regulation. The experience of this office is that affiliates generally may not be at the same state of HIPA compliance as the RHAs. This would be another area of weakness in terms of privacy protection and this new opportunity to disclose personal health information for affiliates who may not be well equipped to meet all HIPA standards.

Section 7.1(3) of the Regulation is inadequate since it fails to require the RHA to disclose to the patient at the point of service detailed information about the automatic transfer of personal health information to the foundation. This notice should include identification of the three elements of information: name, address and the provision of recent hospital services. Reference to the opt-out is only part of the notice that must be provided to the patient.

I don’t understand how the disclosure will operate with respect to chronic disease patients or dialysis patients, etc. who are regular attendees at a hospital for treatment and care. Presumably, from a fundraising perspective, these patients would be high value targets and they will presumably show up on many client lists provided over the course of say a year from the RHA to the foundation. How will these chronic disease or repeat patients be protected from repetitive solicitations for funds given they will be a particularly vulnerable population to begin with?

The new section 7.1(7) of the Regulation does not acknowledge that the most significant element of personal health information is the fact the individual on the ‘client list’ was recently a patient at an acute care facility in Saskatchewan. That element is embedded in the act of disclosing the client or target list to the foundation.

Who will designate the archive for purposes of section 7.1(8) of the Regulation? Presumably, the information on patients must be returned to the region or destroyed under the region’s supervision. It should not be up to the foundation to be dealing with any archive.

There is no reference to how many times or how frequently patients can be contacted by the foundation soliciting funds. There is no limitation in the Regulation as to how often patients can or will be solicited for funds.

The penalties and offence provisions in HIPA do not clearly apply to foundations yet they are also not subject to the penalties and offence provisions in PIPEDA. This is a troubling gap that warrants immediate attention.

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CONCLUSION

I respectfully submit that it is very difficult to reconcile the Regulation with the Saskatchewan Government's commitment to a patient-centered health care system. To eliminate the current opt-in consent process and substitute the health region's judgment for that of the patient appears to contradict the adoption of the Patient First Review Final Report.

I accept that fundraising by hospital and health region foundations is an important and valuable activity in the province. Nonetheless, I urge the Assembly to consider the potential negative impact an opt-out may have including the following:

- Diminished patient confidence in the electronic health record;
- Risks associated with personal health information being shared with fundraising organizations that are not subject to any major privacy law (federal or provincial) and for which there is no oversight by an independent Information and Privacy Commissioner or the Privacy Commissioner of Canada;
- Likelihood of pressure from other health related non-profit organizations for the ability to use personal health information for their fundraising efforts;
- Lack of capacity for health information staff in regional health authorities (RHAs) to manage the significant new work created by the Regulation without compromising their general work in administering the RHAs extensive HIPA responsibilities;
- Risk of Saskatchewan Government being found to have violated the *Charter of Rights and Freedoms* and the privacy interests of Saskatchewan patients;
- Risk that Saskatchewan patients will react negatively to the disclosure of personal health information to the foundations and reduce their support for those foundations as a result; and,
- Risk that the additional complexity created by the Regulation will undermine progress to date towards the goal of ensuring all Saskatchewan health care workers have a comfortable understanding of what they can and cannot do with the personal health information of patients.

Respectfully submitted,

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Saskatchewan Information and Privacy Commissioner