

**Submission to the Ministry of Consumer and Business Services**

**RESPONSE TO THE DRAFT ONTARIO  
PRIVACY OF PERSONAL ACT**

**From: Association for Healthcare Philanthropy (AHP) Canada**  
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## Executive Summary

Attached is a response to the draft legislation on the draft Ontario *Privacy of Personal Information Act* prepared by the Association for Healthcare Philanthropy. Our national organization includes 200 individuals who raise funds for virtually every hospital in the Province of Ontario.

Legislative initiatives dealing with privacy and protection of health information have a direct impact upon our members and their ability to assist and advance the fundraising activities of the institutions they serve. Increasingly, fundraising initiatives are critical in supporting our hospitals to facilitate the massive restructuring mandated by the provincial government. This restructuring is intended to promote better coordination of care and to enhance and sustain quality health care in the Ontario health system.

According to the Ontario Hospital Association, the capital cost required to redevelop and restructure provincial hospitals ranges anywhere from six to seven billion dollars. To date, the Ministry of Health has designated only \$2.4 billion.

As currently written, the proposed privacy rules under the draft Ontario *Privacy of Personal Information Act* – while well intentioned – could hinder the capability of hospitals and their fundraising arms to support the provincial government’s health care reforms. Fundraising is a crucial component to health reform in Ontario.

The legislation should acknowledge and address the unique role of the charitable sector and the unique needs that charities have in their funding requirements.

Central to these efforts are grateful patients, and the ability of hospital fundraisers to reach out to these patients and their families in the hope they will provide a gift. Once established, hospitals need the ability to cultivate and maintain these relationships, and in most cases donors appreciate this relationship.

## **General Recommendations**

1. We believe that all provisions affecting the privacy of personal health information for healthcare fundraising purposes be spelled out in legislation and not be left to regulations drafted at a later date.
2. We believe that first contact with a patient should be allowed to be a solicitation that also includes an ability on the part of the individual to opt-out. We further believe that this first contact should be made no sooner than 30 days after discharge and not 60 days as proposed by the legislation.
3. We believe the legislation should recognize that donating is a voluntary act which implies consent to future contact. This recognition would allow charities to maintain relationships with donors, providing that opportunities to opt-out or decline future contact is offered on a regular basis.

## **The Association for Healthcare Philanthropy**

The Association for Healthcare Philanthropy is an international organization of health care fundraising executives and health care institutions dedicated to the advancement of health care through philanthropy. AHP Canada's mission is to be the primary source of philanthropic expertise in Canadian health care, building on partnerships with AHP International and other partners. Our membership totals 350 fundraising professionals across Canada, with 200 of these active and fundraising for hospitals in Ontario.

AHP does not generally respond to provincial legislative initiatives, however, we have consistently responded to privacy initiatives in the area of health care. We consider this a fundamental issue for our membership and for the hospitals they represent.

We commend the Ontario government for its legislative proposal and for its specific emphasis in ensuring that protections are in place for personal health information. This legislation is critical for patients, providers and institutions to protect the privacy of personal information to which data custodians are entrusted and to inspire public confidence in the information management practices of healthcare fundraisers.

We are committed to supporting the adoption of health privacy legislation for the province of Ontario, and would request to be included in consultations and questions on the re-drafting of this important legislative initiative.

## **Philanthropy and Health Care in Ontario**

Philanthropy has become a vital component of the health care system in Ontario. As fiscal challenges for health services increase, so does the need for alternate sources of funding. To augment fundraising for our hospitals, it is critical that the public and private sectors work in tandem.

The Ontario government is in the midst of implementing a massive redesign of its hospital structure. Arguably, not since the inception of Medicare in the late '60s, has change occurred on such a grand scale in the provincial health system.

Philanthropy is the lynchpin to enabling this change to occur in a seamless and smooth fashion. Ministry of Health funding formulas for approved capital projects cap the government share at a range of 50% to 70% per project cost. Consequently, communities and their hospitals, must make up the difference in project costs of anywhere from 30% to 50%.

These projects must go forward, so important reforms can be implemented. The overall price tag for hospital redevelopments and restructuring is extremely steep. According to the Ontario Hospital Association the capital price tag for overall hospital restructuring is between \$6 billion to \$7 billion (*Putting Patients First: 2002 Budget Priorities, March 4, 2002*). To date, the Ministry of Health has committed \$2.4 billion in capital against these project costs.

Suffice to say, the demands upon hospital fundraisers will be significant. At the same time, the proposals for privacy legislation may hamper the efforts of hospital foundations to achieve much needed fundraising targets.

We are not advocating that a reduction in health privacy at the expense of fundraising. However, we believe that legislation should not be constructed in a manner that places unnecessary roadblocks in the way of philanthropic efforts that are desperately needed to pave the way for health system reform.

We are also active nationally in underscoring the value of philanthropy and have responded to the Commission on the Future of Health Care in Canada and will be meeting with the Commissioner in April. The Commission on the Future of Health Care in Canada has had numerous presentations emphasizing the significant role that philanthropy performs in sustaining a universal health care system.

Philanthropy's influence in the health care system goes well beyond equipment, bricks and mortar. In the teaching hospitals, partnerships have flourished with the various Faculties of Health Sciences. Other funds are at work in community hospitals providing seed money for new programs and community outreach. Increasingly, there are requests to support research infrastructure at a time when we should be supporting the work of scientists and clinicians.

Communications from the development offices and related foundations of our health care institutions seek to both educate the community and generate resources. Through health care development programs, the community is afforded a viable partnership into the health care system. More importantly, we believe that understanding leads to commitment from our communities to the ongoing support of our valued health care system.

A key aspect of our fundraising efforts, are our grateful patient programs. These programs reach out to those who have had a positive interaction with their local hospital. Surveys conducted in 1992 and 2000 further illustrate the importance of grateful patients to fundraising programs across Ontario. In a survey of hospital donors conducted in 1992 by the then Hamilton Civic Hospitals Foundation, 80% of donors identified themselves as either a grateful patient or a family member of a grateful patient. This survey was repeated in 2000 at the North York General Hospital and 82% of responding donors identified themselves as former patients or immediate family of former patients. In preparation for this response, a recent survey of ten Ontario hospitals indicated that approximately \$3 million was raised from half a million grateful patients. Contacts with these 500,000 patients resulted in a mere 75 complaints!

Clearly grateful patients are at the heart of health care philanthropy.

## **Philanthropic Facts**

- Virtually every health care institution in the province of Ontario is currently contacting patients as a primary source of new donors.
- The hospital system is dependent on philanthropy to fund a significant portion of an estimated \$6 - \$7 billion capital expansion.
- There is a historical and traditional interest in communities for individuals to be able to contribute and support charitable programs associated with their communities. Hospitals and Foundations respect this privilege and greatly value the privacy of personal information to which they are entrusted.
- Grateful patients and their families create the single largest pool of health care supporters.
- Barriers to relationship development will be greatly detrimental to the philanthropic sector, resulting in significant and increased administrative costs, a greater cost per dollar raised and lower net funding to health care programs.
- Successful philanthropic programs are donor centred. This means that charities seek to develop long-term, meaningful relationships with their supporters. True philanthropy is not transaction based. It is relationship based.
- Fundraising organizations benefit from relevant and reliable first hand information that is shared between fundraisers and their volunteers and information provided directly by the existing or prospective donor.
- Every fundraising organization requires the ability to expand its list of supporters by approaching new prospects. The range of personal information available in the public domain varies considerably, from telephone book to Internet web based services and public libraries. Foundations require access to this information to support their abilities to expand lists of potential prospects.

AHP members in Ontario have access to limited personal information and consistently respect the confidentiality of that information through the AHP Statement of Professional Standards and its companion Donor Bill of Rights.

These documents have been attached as a supplement to this brief. AHP would welcome the opportunity to discuss them, in addition to any recommendations or information contained in this submission, in greater detail with the ministry.

## Comments of Legislative Proposals

While our policies and practices strongly support privacy protection, the proposed legislation is likely to create serious barriers to our activities. As a general concern, Section 26 of the proposed Bill requires consent to fundraising activities “except as provided in the regulations”. We cannot support this approach. It is essential that the rules that affect our ability to raise funds from our former patients be clearly established in the legislation.

Hospitals and their foundations are separate corporations. As “health information custodians” under the proposed law, hospitals will have legal obligations before personal information is disclosed to their affiliated foundations. As recipients of the information, special protective rules will apply to the foundations. In both situations, the law must be made clear. This is not the case in the draft.

We recognize that in the past, some foundations have collected not only names, addresses, telephone numbers and discharge dates from hospitals, but also names of physicians and in some cases, the nature of the service received. Statistics demonstrate that targeted fundraising efforts are more successful when, for example, the appeal will benefit a service area which has been of direct benefit to the person that is being approached.

Under the proposed legislation, patients’ names and contact information qualifies as “personal information”. Is it also “personal health information”? The response to this question could be important because some provisions, such as sections 13 – 18 addressing incapacity, only apply to personal health information. We do not believe that name and address data constitutes personal health information. If it is not considered as personal health information, then we must ensure that somehow the substitute decision making rules apply to support the role that families play in fundraising.

The legislation states that consent will be the rule for obtaining personal health information. Although conceptually sound, there are significant practical problems with this approach. For example, a number of elements that must be satisfied for a valid consent are set out in the draft legislation.

The person giving consent must be mentally capable. While there is a presumption of capacity, there are elaborate procedures for determining capacity where it may be in issue, with *notice* and “due process” review rights, and an extensive prioritized list of substitute-decision makers to make the decision based on the person’s “wishes, values and beliefs”. We can understand the need for the foregoing measures where medical treatment is proposed. However, we cannot see its application in our circumstances.

When is the hospital at risk in disclosing the information and the foundation in collecting and using it? While “implied” consent may apply to the hospital, it does not apply to its foundation (s.8(1)1). The concept of implied consent to medical care may be well established. It is not so transparent in the case of the disclosure of information. Even if a person is aware of the reasonably obvious purposes to be made of their information, can one necessarily assume that they know the implications of such disclosures so as to imply a fully informed consent? We are recommending a non patient specific information and opt-out process which would make the disclosure and use of name and address information “reasonably obvious” for the purposes of implied consent.

The provisions regarding withdrawal of consent are somewhat confusing, particularly in view of the list of exceptions in section 12(1) and its inclusion in the definition of “informed consent” in section 8(4)(c).

It seems truly impractical to apply these somewhat confusing provisions to the disclosure of basic personal information for the purpose of determining whether former patients wish to support hospital fundraising efforts.

On the matter of the 60-day minimum for notifying a former patient, the proposed regulation is unclear whether the obligation rests with the hospital or with the foundation to initiate contact. If this is the hospital’s responsibility, it will place a significant burden on hospital resources that are already stressed. If the responsibility rests with the foundation, is the hospital permitted to provide it with basic name and address information without consent? Can initial contact with former patients serve as a solicitation that also offers such persons the ability to opt-out of future solicitations or must they receive an opt-out form only? Must this communication be in writing or can former patients be contacted by other methods, such as by telephone or e-mail?

## Recommendations for Change

It should be noted that in some types of care such as pediatric, chronic and /or long term care, that it is a parent or guardian of a minor and/or a family member or care decision maker who are approached for support. Throughout our recommendations, when we use patient, it is extended to any of the above as appropriate.

We agree that persons must have the opportunity to be excluded from solicitation. The solicitation of gifts in grateful patient programs is a sensitive issue. Any direct request of a patient, during his or her stay in the hospital, to exclude him or herself from a solicitation list is an emotionally charged proposition. Asking patients at any time during their stay or at discharge to sign a waiver permitting the hospital to solicit them for a gift creates an ethical dilemma. An individual who is ill, weak, frightened or all three, when confronted with a request to let his or her name be used for fundraising, is put in a very difficult situation. The patient may not be prepared to make a fair decision. The situation may strain the fragile caregiver/patient relationship.

Hospitals have different discharge processes to respond to varied types of care (for example, emergency visits, outpatient services, inpatient services, etc). As such, it would be difficult for hospitals to achieve a consistent, corporate process for obtaining patient consent for fundraising upon discharge or release.

The requirement to obtain patient consent during the care process also means that care providers would be obligated to discuss fundraising issues with patients, rather than using trained fundraising professionals or hospital business staff. Care providers may object to soliciting patient consent for this purpose, and they may feel that they already have enough information to communicate to patients regarding instructions for follow-up care, pain management, post-procedure medications, etc.

For the above reasons discharge is no more appropriate than admission to solicit patient consent for fundraising since both the admission and discharge processes involve health management and “treatment” issues.

A non patient specific opt-out approach to obtaining patient consent for fundraising purposes should be considered. Notification regarding a patient’s right to opt-out of a grateful patient solicitation program can be done through communications that would include, but not be limited to:

- Poster signage in high traffic patient areas such as emergency, admitting, lobbies and waiting areas;
- Printed text in hospital-based patient information materials and on websites; and,
- Availability of “opt-out” information and return envelope in admitting areas and waiting rooms.

A consistent message format should be used in hospitals to inform patients that their personal non-health information may be used by the hospital to communicate with them in the future to fundraise or solicit their opinion.

A hospital, or its affiliated foundation, could conduct its actual solicitation to patients no sooner than 30 days after either the discharge of an in-patient or the release of an out-patient (as opposed to 60 days in the proposed regulation). The rationale for a 30-day cycle relates to current health care practices that focus on shorter lengths of stay and the prevalence of ambulatory care service delivery.

This first solicitation should include a clear and direct opportunity for the individual to have their name removed from hospital/foundation solicitation programs. Thus, the opportunity could be offered while keeping the field open to telephone, e-mail or other forms of first contact.

As for existing donors however, we strongly believe that these relations fully meet the test of implied consent and we should continue to provide the opportunity for them to opt-out of the process of solicitation on a regular basis. Most health care fundraisers are using this practice already – for example, in telephone fundraising programs individuals are provided the opportunity to decline a call.

We strongly believe that donors will support this solution because of their increasing requests for foundations to be accountable for a reasonable cost per dollar raised and stewardship for their gifts. Indeed, it has been made clear by the Canadian public, that in addition to providing a tax receipt for their donation, a reputable fundraising organization is expected to be accountable to the public by maintaining a history of the donor’s relationship with fundraising organizations. Donors expect that fundraising organizations will be aware of their record/history of gift contributions to provide recognition of support over time and reports on the outcome of the use of their gifts. This expectation addresses the historical nature of a relationship rather than a transaction between the donor and the organization.

## **Contents of a Suggested Legislative Framework**

We have taken the liberty of preparing a structure for provisions that we believe could form the basis for appropriate legislation with regard to fundraising activities.

First, there should be a prohibition on using or disclosing personal name and address information for the purpose of fundraising activities unless the person consents through a non-patient specific, opt-out consent process at any point in the care delivery cycle.

Second, there should be an obligation to provide notices in appropriate forms and languages, about the facilities' fundraising activities and the manner by which persons can refuse fundraising solicitation or requests.

Third, as an exception to the need for consent, where the person has not opted-out, at least thirty days following the person's discharge from a facility, program or service, the person could be notified about fundraising activities and would be told that if the person does not wish to be contacted again, they may opt-out in a clearly explained manner. If the person then chooses to opt-out, their name and contact information must be designated as such in all central files and mailing lists.

We trust that the foregoing will be of assistance. While we strongly endorse the need to protect the privacy of our patients and foster the development and implementation of clear policies in this regard, we also must underscore the need to ensure that our ongoing efforts to support our health care system are not jeopardized by unworkable laws.

**ASSOCIATION FOR HEALTHCARE PHILANTHROPY**  
**STATEMENT OF PROFESSIONAL STANDARDS AND CONDUCT**

Association for Healthcare Philanthropy members represent to the public, by personal example and conduct, both their employer and their profession. They have, therefore, a duty to faithfully adhere to the highest standards and conduct in:

1. Their promotion of the merits of their institutions and of excellence in health care generally, providing community leadership in co-operation with health, educational, cultural, and other organizations;
2. Their words and actions, embodying respect for truth, honesty, fairness, free inquiry, and the opinions of others, treating all with equality and dignity;
3. Their respect for all individuals without regard to race, colour, sex, creed, ethical or national identity, handicap or age;
4. Their commitment to strive to increase professional and personal skills for improved service to their donors and institutions, to encourage and actively participate in career development for themselves and others whose roles include support for resource development functions, and to share freely their knowledge and experience with others as appropriate;
5. Their continuing effort and energy to pursue new ideas and modifications to improve conditions for, and benefits to, donors and their institution;
6. Their avoidance of activities that might damage the reputation of any donor, their institution, any other resource development professional or the profession as a whole, or themselves, and to give full credit for the ideas, words or images originated by others;
7. Their respect for the rights of privacy of others and the confidentiality of information gained in the pursuit of their professional duties;
8. Their acceptance of a compensation method freely agreed upon and based on their institution's usual and customary compensation guidelines, which have been established and approved for general institutional use while always remembering that:
  - (a) Any compensation agreement should fully reflect the standards of professional conduct; and
  - (b) Antitrust laws in the United States prohibit limitation on compensation methods. (Not applicable in Canada)
9. Their respect for the law and professional ethics as a standard of personal conduct, with full adherence to the policies and procedures of their institution;
10. Their pledge to adhere to this Statement of Professional Standards and Conduct, and to encourage others to join them in observance of its guidelines.

**A DONOR BILL OF RIGHTS**

Philanthropy is based on voluntary action for the common good. It is a tradition of giving and sharing that is primary to the quality of life. To assure that philanthropy merits the respect and trust of the general public, and that donors and prospective donors can have full confidence in the not-for-profit organizations and causes they are asked to support, we declare that all donors have these rights:

- I. To be informed of the organization's mission, of the way the organization intends to use donated resources, and of its capacity to use donations effectively for their intended purposes.
- II. To be informed of the identity of those serving on the organization's governing board, and to expect the board to exercise prudent judgement in its stewardship responsibilities
- III. To have access to the organizations' most recent financial statements.
- IV. To be assured their gifts will be used for the purposes for which they were given.
- V. To receive appropriate acknowledgement and recognition.
- VI. To be assured that information about their donations is handled with respect and with confidentiality to the extent provided by law.
- VII. To expect that all relationships with individuals representing organizations of interest to the donor will be professional in nature.
- VIII. To be informed whether those seeking donations are volunteers, employees of the organization or hired solicitors.
- IX. To have the opportunity for their names to be deleted from mailing lists that an organization may intend to share.
- X. To feel free to ask questions when making a donation and to receive prompt, truthful and forthright answers.

**Developed by:** American Association of Fund Raising Counsel (AAFRC)  
Association of Fundraising Professionals (AFP)  
Association for Healthcare Philanthropy (AHP)  
Council for Advancement and Support of Education (CASE)

**Endorsed by:** Independent Sector  
(in formation) National Catholic Development Conference (NCDC)  
National Committee on Planned Giving (NCPG)  
National Council for Resource Development (NCRD)  
United Way of America