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A Submission on Bill 32

THE PERSONAL HEALTH INFORMATION AMENDMENT ACT

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INTRODUCTION

The Manitoba Institute for Patient Safety (MIPS) is pleased to provide the following commentary and indicate its general support for Bill 32. Amendments to the Personal Health Information Act that contribute to patients and families being able to take their rightful place in advocating for themselves and their family members are welcomed. The amendments also continue to protect the privacy of personal health information of patients which is of paramount concern.

There is world wide recognition that involving patients and families in care, often referred to as "patient or patient and family centered care", is essential to improve patient safety. A key element of this care relationship is information exchange. Mechanisms such as amendments in Bill 32 that improve the ability for consumer/healthcare provider partnerships are important and will support a safer, higher quality health care system serving all Manitobans.

This submission will be divided into three parts. First, we will provide a brief description of the Institute for those who may not be fully aware of our mandate and current work with patients and families. Secondly, we will provide a brief discussion of the importance of patient and family involvement and the relevance to Bill 32. Thirdly, we will highlight sections of the Bill in terms of the balance between protection of privacy of personal health information, and access to personal health information to support patients and families as partners in the care team.

I. MANITOBA INSTITUTE FOR PATIENT SAFETY

The Manitoba Institute for Patient Safety was recommended in 2003 by a representative committee of key stakeholders in the health field chaired by Dr. John Wade, former Dean of Medicine at the University of Manitoba. In May 2004 the Minister of Health announced that the government had agreed to the creation of the Institute and announced the composition of the first board of directors.

The Institute is a not-for-profit corporation with a mandate to undertake activities, to stimulate and coordinate the efforts of others and to provide independent and objective advice to all parts of the health care system in support of minimizing preventable injuries to patients. MIPS is governed by a twelve member board of directors, five appointed Minister of Health and seven elected by Member Organizations, of which we have 30. Our current Board Chair is Mr. Reg Toews.

There are many dedicated individuals and organizations currently addressing different aspects of patient safety. However, preventable events causing harm to patients are still too frequent in the healthcare system.

The system involves multiple organizations and health care providers, difficult problems of coordination and integration of service delivery, the interaction between technology and human factors, entrenched professional cultures which fear open discussion of adverse events and limits to our knowledge of how best to ensure safe, quality healthcare. The Institute was established to address the complicated issues of patient safety from a system-wide approach and to promote improvements in all parts of the system.

Our predominant style of operation is collaboration and partnership with others. We work with member organizations as well as many other groups that we work with on key, province wide initiatives.

A significant achievement in 2007-2008 was the establishment of the Institute's Patient Advisory Committee. The Committee was created in Spring 2007 to provide a voice for patients and family members who have an interest in patient safety, experiences and opinions about provisions of quality healthcare, and safety in the health care system – positive and negative – and an interest in working collaboratively with MIPS to promote patient safety in healthcare settings.

Members joined the Committee because they have had involvement with the healthcare system as patients and family members, and some of those experiences have been far less than satisfactory. However, members want to be able to use what they have learned from those experiences -as hard as some of them have been – to ensure that other patients and families can benefit from the improvements in care. Further detail on the Committee's work will be outlined in section three.

Included in our package is a copy of the most recent annual report which outlines the Institute's accomplishments and information on our health literacy initiative "It's Safe to Ask. We would be pleased to answer any questions you might have in relation to those initiatives.

II. <u>BILL 32 AND THE BROADER PATIENT SAFETY AGENDA</u>

Our comments on Bill 32 are in the context of supporting patient and family-centered care. Patient and family-centered care is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among health care patients, families and providers.[1] Partnering with patients and families – not only involving them in decisions about their care, but also gaining the benefits of their help and insights to better plan and deliver care, leads to better outcomes and increased satisfaction for patients and health care providers.[2]

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[1] Institute for Family-Centered Care. <u>Advancing the Practice of Patient and Family Centered Care. How to Get Started</u>. Bethesda, Maryland, 2008.
[2] Ibid

Patient and family involvement is the essence of patient and family-centered care. "Families, however they are defined, are essential to patients' health and well-being and are allies for quality and safety within the healthcare system. Family members are more than surrogates to be called on when the patient is unable to make decisions on their behalf. They are essential members of the care continuum and care-giving team".[3] Core concepts of this care model are dignity and respect, participation, collaboration, and, important to Bill 32, information sharing.

There are some innovative models to involve patients and families in care. One excellent example is the Planetree Care Partners Program. This model was developed by Angelica Thieriot, herself a patient in 1978 during an episode of a life threatening illness followed by experiences with family members requiring hospitalization.

"Relegated to distant family waiting areas and the limbo of not knowing what was happening to loved ones, she found the family experience to be as depersonalized and terrifying as her experience as a patient. Motivated to action by these events, and by her vision for a more healing hospital experience for patients and families, Thieriot founded Planetree as a non-profit organization in 1978. Taking its name from the sycamore, or planetree, under which Hypocrites taught his students, the organization dedicated itself to radically changing the way health care was delivered."[4]

In the Planetree Model, patients identify a family member or friend who will be their primary care giver or support person as part of the pre-admission work-up. Care partners are identified by name in the chart and given buttons or nametags making it easy for hospital staff to identify them. They participate to whatever extent they and the patient wish, but are encouraged to assist with care and enhance communication with the health care team. Care partners are also supported in various ways. For example, they may be served meals, stay in room 24 hrs/day, receive discounted parking, etc. They are advised to speak up and to challenge any thing that doesn't seem right. The program includes volunteer partners for those who are alone. [5]

Efforts to incorporate patients' voices in improving healthcare quality and patient safety, including their wishes concerning how their loved ones will be involved, are underway worldwide. One of the goals of the Institutes' Patient Advisory Committee is to gain better access to personal health information for patient advocates. The amendments to Bill 32 are, therefore, timely. The Committee is developing information on "advocating for your health". This includes advocating for oneself, as well as how to ask for help from a trusted person.

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[3] Ibid, page 6.
[4] Frampton, S.Gilpin, L., Charmel, L. (eds) Putting Patients First. John Wiley and Sons. 2003. Page 1.
[5] Planetree Alliance www.planetree.org/

The word “advocate” may be substituted with the terms identified in Bill 32 of “a close personal relationship, trusted friends, and family”. The patient advocate is someone who is the patient’s promoter, campaigner and champion, and who will speak on their behalf. Some people need advocates because they are unable or uncomfortable expressing their feelings, opinions, and expectations for their own care. They may be afraid to speak out. They may have difficulty understanding what is happening to them in healthcare settings. They may be too ill to speak for themselves. All of us, particularly those who have been in hospital, can relate to complicated, confusing, stressful, and sometimes frightening healthcare situations. These situations may put the patient, who does not have an advocate or spokesperson, at a disadvantage for getting the best care they need.

The Patient Advisory Committee has outlined times when patients may wish to have an advocate or someone who will support them and believe in them. Areas that an advocate might address that involves information exchange include:

- Getting information and answers,
- Asking specific questions,
- Clarifying options for doctors, referrals, diagnostic tests, procedures, and treatments,
- Understanding test results,
- Making treatment decisions, and
- Ensuring that the patients’ wishes are followed if and when they are not able to do that for themselves.

All of these potential areas of responsibility for an advocate are dependent on information exchange within the circle of care. Communication and information are critical to the ability of the care team, including patients and families, to function effectively. Legislation affecting access to and disclosure of personal health information is critical to how successful the care team will function, and ultimately, to quality and safe care.

III. BILL 32: A STEP IN THE RIGHT DIRECTION TO WELCOMING PARTNERS IN CARE

Bill 32 must promote a balance between protection of privacy of personal health information, and access to personal health information (defined in the Act as recorded information) to support patients and families as partners in the care team.

The Institute believes that efforts to improve access to recorded information by patients and families (according to the wishes of the patient) will have a positive impact on patient care and patient safety. The following outlines specific comments on selected key amendments to the Personal Health Information Act as well as additional observations regarding the introduction of the legislation.

Consent (Division 2.1 Consent, Section 19)

In the context of sharing recorded information by providers to families, the new provision will continue to respect the rights of patients to determine to whom they wish to share personal health information, as well as clarifying how consent is to be gained (either express or implied). The Institute supports provisions which clarify health care providers' roles and responsibilities with regard to sharing personal health information.

A challenge for trustees is determining the appropriateness of disclosure of personal health information in circumstances where the patient has not provided written authorization (Section 60 (2)). There can be circumstances where the patient has the capacity to exercise their rights as outlined in the Act but is not able to do so. This could be, for example, an elderly parent who may have confusion because of their immediate episode of illness or due to the effects of their medication. Although the Act does have provisions for disclosure of personal health information without consent, (23(1)), in practice, this hinges on the health care provider having full understanding of their responsibility to disclose in the circumstances as outlined in the Act. It is also important that health care providers understand that PHIA principally addresses the question of access to records, not access to thoughts and conversations. The Institute believes that sharing of pertinent clinical information is integral to good clinical care.

Ideally, the consideration of a having a person to access personal health information in the role of advocate has been made well in advance of the care episode. This includes a decision to have an advocate, what assistance they might want from their advocate, and an outline of their wishes in writing. This is particularly important prior to hospitalization, as it can help minimize misunderstandings between all parties who may have an interest in the patient's well-being.

The Patient Advisory Committee is addressing this issue in their current work, and will be suggesting that people have a letter that names an advocate or support person. The letter should define the role that the person would like the advocate to play in their healthcare, even if the person can communicate for themselves. For example, the person may give an advocate the rights to: access medical records; be fully informed about the person's healthcare; or be involved in decision making about their care. People should bring copies of this letter to give to healthcare providers and ask that the letter be put in the patient's medical file. This process will assist trustees under the Personal Health Information Act in confirming a substitute decision maker and gaining expressed consent, including situations where the patient is able to communicate for themselves. However, it is likely that this form of communication will be used in situations of elective admission to hospital as consumers may not carry the letter with them.

Another proactive measure is to have space on the admission form to hospital and personal care homes. This space would trigger the admitting professional to ask if the patient/resident gives permission to the trustee to disclose personal health information and to whom. This measure would ensure patients know their rights to assign an advocate and also clarify for the trustee the patient's wishes for disclosure of personal health information.

In the future, consideration should be given to the revision of the health care directive as a way to consolidate information for trustees on the patient's choices regarding an advocate.

Information about Current Care and Timely Disclosure (23 (1.1))

In current episodes of care, patients, families and advocates need comprehensive and timely information. Healthcare processes occur within a complex, busy and sometimes fragmented system, and there are circumstances where wait times for information are reasonable, such as for results from complex tests. However, when information on the current record of care is available, it should be shared in a timely manner with patients and families/advocates. The Institute supports a change to the proposed amendment that would require hospitals and personal care homes to respond to requests for access to personal health information from patients/advocates (as legally defined) regarding the current record of care within 24 hours. The exception is circumstances that fall under the Mental Health Act where the Director of the facility may need to make a judgment about potential harm to the patient or family member if the information is read directly. Access within 24 hours would be the start of the process of sharing information. The Winnipeg Regional Health Authority has instituted this as standard practice for any admitted in-hospital patient (or his/her legal representative).

Regarding review of the information with the patient/advocate, medical charts can be complex and the medical language difficult to understand. It is possible that there may not be a qualified health care provider available within 24 hours who is familiar with the patient's care plan and is able to review the record with the patient/advocate. Therefore, it is recommended that a requirement be added to the current section 7(2) on this issue. The amendment would require that upon the patient's/advocate's request, the trustee must provide an explanation of the accessed medical record by a qualified healthcare professional within 48 hours of the original request for information.

The Act continues to allow a 30 day timeframe for response to requests for access to personal health information "in any other case" other than section (6(1 b)) for healthcare being currently provided. There are instances where patients/advocates need information from their records (for example, those with an unconfirmed diagnosis and unstable condition who are seeking a second opinion or seeking care outside of the province) and the 30 day time frame is too long.

Therefore, it is recommended that this timeframe be re-examined with the possibility of reducing it to, for example, seven days.

Substitute Decision Makers (60(2))

Section 60(2) identifies substitute decision makers that can exercise the rights of the individual under the act when the individual lacks the capacity to do so. The expansion of the Act to include family members and trusted friends is critical to patient/family-centered care and support. The Institute supports this amendment.

Public Education

Bill 32 is one step toward welcoming patients, families and trusted friends to be partners in care. However, action should be directed toward health care providers and the leadership of health care agencies to ensure a clear understanding of the aims of the Personal Health Information Act from the perspective of patient/family-centered care. Care providers need to be educated about the differences between access, trustee use and disclosure. Too often have we heard the challenges faced by family members in getting the information they need in order to advocate on behalf of their loved ones. We believe that this relates to the way in which the Personal Health Information Act has been interpreted in practice. The time to debate what information can be shared with whom and when, is not during a crisis with a loved one. This only adds to an already stressful situation and detracts from the essence of patient-family centered care.

The public also needs to be educated and reminded in their episodes of care about:

- Their rights
  - To appoint and authorize in writing a family member or trusted friend to access personal health information on their behalf,
  - To protection of personal health information,
  - To correct errors in these records, and
- Resources available and how to locate them.

The Institute's Patient Advisory Committee acknowledges this need for public awareness and is formulating plans to address this area in their work on advocacy.

Ideally, education is ongoing and becomes part of the health care conversation in all health care settings.

Health Literacy

As mentioned above, in order for patients and families to play a role in the health care system they must know what their rights are to access to information and where to go for help. And, as part of educating patients and families to be involved in their own care, they need to be directed to resources that explain their rights and how to exercise these rights.

An important reminder is that we must bridge the divide between the legislation as written and the legislation as understood by patients, families and care providers. This divide requires that the legislation be "translated" into plain language. Patient rights to appoint and authorize a family member or trusted friend to access personal health information and to protect their personal health information must be described in a way that people can understand and act on the information.

The health system demands high levels of literacy in order to access services, use material, and follow health related advice. Hundreds of studies over several years have demonstrated that requirements for literacy skills to understand health related material far exceed those of the majority of people.[6] Health literacy is a dimension of literacy pertaining to "the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course."[7]

It is estimated that approximately 60% of adult Canadians/Manitobans do not have the necessary skills to manage their health and their healthcare[8] Health literacy also affects overall health. Canadians with the lowest health-literacy skills have been found to be more than two and one half times as likely to be in fair or poor health as those with the highest skill levels.[9]

Examples of the impact of low health literacy skills on patient safety include:

- difficulty providing informed consent,
- not understanding directions on medicine labels,
- difficulty calculating timing to take medicine, and
- not understanding discharge instructions.

Health literacy is a major challenge that will take concerted efforts to address. The Institute's initiative "It's Safe to Ask" is a health literacy initiative that promotes clear communication as a basis for providing patients and families with the information they need in health care situations. These same principles should be

[6] Canadian Council on Learning. Health Literacy in Canada. Initial Results. 2007
[7] Canadian Public Health Association. A Vision for a Health Literate Canada. Report of the Expert Panel on Health Literacy. 2008, page 11.
[8] Canadian Council on Learning. Health Literacy in Canada. 2008, page 20.
[9] Ibid.

applied to all educational efforts to assist the public and health care providers in understanding personal health information legislation.

Summary

Amendments to the Personal Health Information Act will contribute to what is a necessary transformation in the culture of health care. These amendments welcome patients, families and trusted friends as partners in care. For this reason, the Institute supports the bill with the recommendations noted.