



August 13, 2010

Mr. Fred Horne  
Co-chair, Minister's Advisory Committee on Health  
c/o Legislature Office  
#721 Legislature Annex  
9718 - 107 Street  
Edmonton, AB T5K 1E4

Dear Mr. Horne:

***RE: Health Law Institute's Submission on the Minister's Advisory Committee on Health Final Report***

The Health Law Institute would like to thank Mr. Horne and the current Advisory Committee for the opportunity to offer comments on specific aspects of the Minister's Advisory Committee on Health's (the MACH) Report, published January 20, 2010. This submission follows the oral presentation of Executive Director Tracey Bailey (delivered June 25<sup>th</sup>, 2010) and is intended to provide selected comments with particular focus on the principles discussed in the MACH Report, the proposed Patient Charter and ongoing consultation on issues arising out of the MACH Report.

We would be pleased to provide more comprehensive recommendations when more specific details about the Alberta Health Act become available.

**I. The Principles Discussed in the MACH Report**

***A. Keep Explicit Principles and Non-Hierarchical Scheme***

We would agree with the MACH that a set of clear principles is an important component of the contemplated Alberta Health Act. The explicit setting out of such principles enunciates the values Albertans might hope to see incorporated in our health care system, as well as assisting at times in the interpretation of the legislation. Many of the principles discussed at pages 10-15 of the MACH Report are laudable, consistent with the Canada Health Act and serve the purposes outlined above.

We also agree that these principles should not be arranged hierarchically. While a hierarchical scheme may well aid in issues of interpretation where there is conflict between principles, we would support a scheme of interpretation in this context where it is recognized that principles (and values) can conflict and that the best resolution of such

conflicts will involve a balancing of all of the enunciated goals. While compromise between conflicting principles may not always be easy, it is preferable in this context to resolving conflicts by subordinating one important principle to another.

### ***B. Add Stewardship as a Principle of the Alberta Health Act***

Health costs in Alberta have risen significantly in recent years. According to a 2002 Report prepared by the Premier's Advisory Council on Health, total health spending in Alberta increased from \$4.1 billion in 1991-92 to \$7.1 billion in 2001-2002<sup>1</sup>. In 2010, healthcare spending has risen to \$14.85 billion. Health & Wellness spending accounts for 39% of the Alberta government's total 2010-2011 expenditures.<sup>2</sup> Alberta's population is growing and, like the rest of Canada, is also aging. Demand for health services in this province is not likely to fall in the foreseeable future. Furthermore, technological advances in the health field mean that a continuous investment of resources will be needed to pursue state-of-the-art care.

It has been noted that Canada's system of universal healthcare is often expected to handle "unlimited demands with limited resources."<sup>3</sup> For this reason, the need to ensure health spending is sustainable has taken on greater importance in recent years. Alberta was the first Canadian province to officially recognize the importance of addressing sustainability of health spending.<sup>4</sup> The need for sustainable health spending has only increased in recent years.

Stewardship can be defined as "the careful and responsible management of something entrusted to one's care."<sup>5</sup> Given the nature of Alberta's healthcare system, as well as the larger role of the government to responsibly allocate resources (both to health and many other crucial areas), a principle recognizing stewardship is a necessary addition to the new *Alberta Health Act*. This principle is a recognition that the Alberta government is responsible for ensuring that the public health system, and other publicly funded services, remains viable into the future. While mention is made of the need for sustainability in the MACH report, it needs to be elevated to a distinct principle to balance off many of the other principles contained in the report.

Other principles already set out (timely and equitable access, fostering a culture of respect, remaining committed to public safety) are worthy aspirations and important for ensuring that Alberta's healthcare is of high quality. However, they cannot responsibly stand without a balancing principle given limited resources. To use two examples,

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<sup>1</sup> Margaret Smith, "Report of the Premier's Advisory Committee on Health (Alberta)", online: Canada Depository Services <[<http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb0133-e.htm#A.%C2%A0Sustainability\(txt\)>](http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb0133-e.htm#A.%C2%A0Sustainability(txt))>.

<sup>2</sup> "Health Coverage and Quick Facts", online: Alberta Health and Wellness <[<http://www.health.alberta.ca/newsroom/funding-quick-facts.html>](http://www.health.alberta.ca/newsroom/funding-quick-facts.html)>.

<sup>3</sup> Maxine Dumas Pion, "Shaking up Healthcare: Treatment Through a Collective Perspective" (2005) 10 *Canadian Family Physician* 943.

<sup>4</sup> Neil Stuart & Jim Adams, "The Sustainability of Canada's Healthcare System: A Framework for Advancing the Debate" (2007) 10 *Healthcare Quarterly* 96.

<sup>5</sup> *The Oxford English Dictionary*, 2<sup>nd</sup> ed., s.v. "stewardship."

achieving perfectly equitable care or timely access in all instances for all patients in all parts of the province would require an expenditure of far more resources than would likely be reasonably available. As a responsible steward, the Alberta government will need to place reasonable limits on these ideals to ensure continued financial viability. Including this principle will make it clear that while the needs of current users will be met to the greatest extent possible, the Alberta government cannot sacrifice long-term sustainability with only the short-term in mind. Instead, the system should strive to deliver high quality care to current users and ensure that quality care will be available to future generations of Albertans.

This principle could be worded as follows: “Recognize the need for accountable stewardship of healthcare resources.”

### ***C. “Person Centered” Care rather than “Family Centered” Care***

The principle intended to “put people and families at the centre of their health care” (p. 11) should be restructured. Rather than a principle dedicated to “family centered care”, the principle espoused should focus on “person-centered care”. While many Albertans will want family members or others close to them to be involved in decision-making, this will vary, as will the level of involvement wished for. The concept of family centered care assumes, inappropriately, that all Albertans will want such involvement. This will not be the case. If a patient does not desire family input into their healthcare decisions, such input should be neither sought nor encouraged. The concept of person-centered care is more flexible and appropriate as it encompasses whatever is important to the individual as part of the decision-making process – including the involvement of family members or other trusted individuals. It captures the inclusion of family in the process where that is desired; it also allows for a range of level of involvement.

At times, even in situations where an individual has expressed the initial desire to have family members involved, it may be necessary to reassess whether this is the continued wish of the individual, or whether it is in fact serving his or her best interests. Unfortunately, while family members are often an enormous source of support, they can also be a source of duress, coercion or other type of unwanted or harmful pressure on an individual. If severe enough, this pressure may lead to harm of the individual, including the potential violation of a person’s ability and right to make free and informed choices in relation to his or her own health. For these reasons, how much family involvement (if any) should be directed by a competent patient’s wishes whenever possible.

Furthermore, as currently drafted, the “core concepts” of patient and family centered care are written in such a fashion that it appears patient and family wishes receive similar, if not equal, weight. It is inaccurate to describe the decision-making process that most individuals will seek in this manner. Many people want support and/or help from family, whether to assist in understanding or retaining information presented, or ultimately in providing assistance to the person in reaching a decision. In some instances, individuals will wish to completely turn over the decision to a trusted family member or group. However, unless a person directs that this be the process, individuals have the right to

make decisions for themselves, though they may be very well supported in doing so. The voices of family should not be weighted equally to that of the individual, unless there has been a clear indication that that is the person's wish. Unless a patient lacks legal capacity, he or she is the final arbiter of decisions related to his or her own health.

Family background, personal factors, culture, religion and values often help to shape how an individual will want decisions to be made. It is crucial that our health care system understand this and adapt as necessary. However, it is not sufficient to assume that because an individual is from a particular culture or religious background, for example, that they share all of the associated beliefs and values. Again, the concept of person-centered care will allow for the delegation of decision-making to family members where appropriate in a given culture and where directed by the individual, but this will not be assumed to be the wishes of the individual as a starting point.

In terms of the sharing of a person's health information, current law must be kept in mind. While patients are undoubtedly entitled to timely, complete and accurate health information, family members are generally not entitled to the same information. While information may be shared where the individual wishes this to take place, or in other limited circumstances, one cannot assume that all persons will want his or her information shared openly with family members, even where they may be involved in assisting in decision-making. Indeed, there are many situations where healthcare providers are ethically and legally bound *not* to share information with families where the patient has not authorized such disclosure.

To reiterate, supporting family involvement where this is desired by an individual is a practice to be supported. However, this principle needs to be reworded to ensure family involvement does not trump free and informed decision making by patients. The principle should be that of "person-centered care".

#### ***D. Broaden "Person Centered Care" to Include Appropriate Shared Decision Making with Health Care Providers***

We would further recommend that the principle intended to "put people... at the centre of their health care" (p. 11) be framed to encompass shared decision-making with healthcare professionals where appropriate. While collaboration is discussed as a "core concept" on page 12, we would submit that it is appropriate to elevate the importance of such shared decision making. Often, health care providers will recommend that an individual receive particular health services. It is usually up to the individual in those circumstances to say whether they wish to follow those recommendations or not. However, we have seen growing circumstances where individuals are requesting or demanding access to health services. This is not always appropriate and health care providers must be part of the decision making process to determine what health services will be offered to individuals on a case by case basis. Many examples exist that could be cited. One area which has received much attention as of late is decision-making near or at the end-of-life where there may be ethical and/or practical disagreements between family members and health care providers. In some circumstances, the expertise of health care providers and their

input will be as important as that of the individual and/or his or her family. Situations like these must be captured by the principles surrounding decision-making.

### ***E. Continue to Encourage Equitable Access***

The “equitable access” principle is key to our health care system and it is encouraging to see access for vulnerable populations (including, but not limited to, the homeless, the impoverished, the disabled and those coping with mental health issues) singled out in the discussion on key principles. Access to health services should be based on need, and not on the ability to lobby. The new structure should be established to support this key ideal of our health care system. Indeed, many of the groups noted above require access to health services but face numerous barriers to making their voice heard. They are often not the groups most able to lobby for a change in the allocation of resources to the health services they require. We applaud the MACH for recognizing the need to protect vulnerable Albertans and would encourage the committee to keep the needs of such groups in mind when designing this new *Act*.

## **II. Patient Charters**

### ***A. Background: Patient Charters***

While the actual significance of adopting a Patient Charter may be debatable, we believe that some important lessons can be learned from experiences both within and outside Canada. What follows is a survey of similar developments within Canada as well as a brief review and discussion of one of the more controversial Charters in recent years.

#### ***1. Canada’s Experience with a Patient Charter***

Seven Canadian Provinces have introduced, attempted to introduce, or considered introducing a patients’ Charter or bill of rights. Canada’s federal government also had a private members bill (C-261) introduced in 2001, which, if passed, would have set out patient rights similar to those discussed in the MACH report, as well as several patient responsibilities (including the responsibility to exercise due economy in one’s use of public health services).<sup>6</sup> This Bill did not contain specific enforcement mechanisms, but required the Minister to consult with the provinces on how these rights and responsibilities could be most effectively fostered. This Bill did not proceed beyond first reading.

Manitoba and Saskatchewan have both stated their intention to implement a Patient Charter, but appear to have not yet taken formal steps to do so.

Alberta itself had a private members bill tabled in 1998 (Bill 201) which would have contained the rights being proposed in the MACH report.<sup>7</sup> For enforcement, this bill

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<sup>6</sup> Bill C-261, *An Act to establish the rights of patients in relation to health, treatment and records*, 1<sup>st</sup> Sess. 37<sup>th</sup> Parl., 2001.

<sup>7</sup> Bill 201, *Alberta Patients’ Bill of Rights*, 2<sup>nd</sup> sess., 24<sup>th</sup> leg., Alberta 1998.

simply required that the Minister of Health would ensure adequate mechanisms existed to protect the patient rights contained. Failure to protect these rights could result in legal challenge. This bill was defeated shortly after its introduction.

Past Ontario governments have sought to introduce a Patient Charter, but its attempts have been defeated three times. The rights in the most recent attempt (Bill 50) would have included rights very similar to those contained in the MACH Report.<sup>8</sup> Unlike Alberta, however, Bill 50 would have called for the appointment of a Health Care Standards Commissioner who would be responsible for promoting compliance with the Patients' Bill of Rights, participating in setting health care standards and developing a complaints procedure. Like its predecessors, Bill 50 was defeated shortly after its introduction.

New Brunswick's Premier's Health Quality Council completed a report in 2002 recommending the adoption of a Patient Charter. New Brunswick responded by tabling Bill 60 the following year. The rights and responsibilities contained in that bill were substantially similar to those in the MACH report, though with somewhat more detailed explanation.<sup>9</sup> The Bill would have appointed a Health and Wellness Advocate who would have promoted knowledge of and compliance with the legislation and would be responsible for resolving complaints. Interestingly, the Health and Wellness advocate would be allowed to refuse a complaint, however, if it was "more appropriately dealt with by another existing complaints mechanism or by judicial proceedings."<sup>10</sup> This Bill reached second reading but was never passed.

Nova Scotia considered legislating a patient Bill of Rights, but upon examination by its Provincial Health Council, ultimately elected to produce a non-binding set of expectations. The Provincial Health Council agreed that a legally enforceable Patient Charter "would pose innumerable legal problems that might take decades to resolve through the courts."<sup>11</sup> Instead of a Patient Charter, the Nova Scotia Provincial Health Council produced a document entitled "Expectations for Health and Health Care in Nova Scotia."<sup>12</sup> Most of the "rights" contained in this document resemble those proposed in the MACH report. One unusual addition is the expectation that the government will seek, if appropriate, "widespread public input into major changes to the healthcare system." There is also an expectation that patients will "[receive] a full explanation, in advance, for any charges for services not covered by the provincial health care plan." Not surprisingly, this document appears to contain no formal enforcement mechanisms.

Quebec is the only province to have produced legislation containing the rough equivalent of a Patient Charter. In 1991, Quebec passed *An Act Respecting Health Services and*

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<sup>8</sup> Bill 50, *Health Care Accountability and Patients' Bill of Rights Act, 1998*, 36<sup>th</sup> leg., 2<sup>nd</sup> sess., Ontario, 1999.

<sup>9</sup> Bill 50, *Healthcare Charter of Rights and Responsibilities Act*, 5<sup>th</sup> sess., 54<sup>th</sup> leg., New Brunswick, 2003.

<sup>10</sup> *Ibid*, s. 8 (2)(d).

<sup>11</sup> Nova Scotia, Provincial Health Council, *Expectations for Health and Health Care in Nova Scotia*, 18 May 2000.

<sup>12</sup> Nova Scotia, Provincial Health Council, [\*Expectations for Health and Health Care in Nova Scotia\*](#) (18 May 2000).

*Social Services*.<sup>13</sup> The rights protected in this *Act* are partially similar though somewhat more limited than those in the MACH report. The legislated rights include:

- The right to be informed of the existence of the health and social services resources available in the community and the conditions governing access to the services;
- The right to receive health services in a continuous and personalized manner, and which are scientifically, humanely and socially appropriate;
- The right to choose the professional from whom or the institution from which health services are to be received;
- The right to receive the care required when life or bodily integrity is endangered;
- The right to be informed of the state of one's health and options for care prior to giving consent to care; and
- The right to participate in decisions affecting one's care.

While the right to choose the professional from whom care is to be received could be regarded as potentially significant, these rights are tied to economic and structural constraints. Section 13 of this *Act* specifically states that

“The right to health services and social services and the right to choose a professional and an institution as provided in sections 5 and 6 shall be exercised within the framework of the legislative and regulatory provisions relating to the organizational and operational structure of the institution and within the limits of the human, material and financial resources at its disposal.”

Originally a complaints commissioner was appointed under this legislation to deal with complaints pertaining to these rights. Subsequently, however, Quebec enacted new legislation appointing a Health and Social Services Ombudsman.<sup>14</sup> The Ombudsman, unlike their predecessor, has the right to directly intervene if they feel that a person or group of people is likely to have their rights threatened by institutional actions/omissions by health regions or institutions. The Ombudsman is responsible for ensuring that institutions and regional boards comply with complaint procedures specified in the *Act*. While complaints are still heard by institutions and regional health boards, the ombudsman is intended to supervise and regulate the complaints procedure in place. The Ombudsman oversees (through institutional and regional complaint boards) approximately 150-250 complaints per year.<sup>15</sup>

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<sup>13</sup> *An Act Respecting Health Services and Social Services*, 1991, R.S.Q. 1991, c. S-4.2 at ss. 4 to 13.

<sup>14</sup> Bill 27, *An Act Respecting the Health and Social Services Ombudsman and Amending Various Legislative Provisions*, 1<sup>st</sup> Sess., 36<sup>th</sup> Leg., Quebec, 2001.

<sup>15</sup> Quebec Health and Social Services Ombudsman, *Annual Complaints Reports*, online: Health and Social Services Ombudsman <<http://www.agencesante09.gouv.qc.ca>>.

In summary, only one Canadian province has crafted legislation creating a functional Patient Charter (Quebec). One other has created a non-binding set of expectations without any new enforcement mechanisms (Nova Scotia). However, legislating specific rights in a Patient Charter is hardly a necessary step for improving complaint resolution procedures. Indeed, a legislated Patient Charter or parallel enforcement mechanism may actually add complexity if overlapping dispute resolution processes are created (as will be discussed shortly).

## 2. Background: The United Kingdom's Experience with a Patient Charter

A number of other nations, including New Zealand, Australia, Spain, Norway, and parts of the United States, have crafted Patient Charters.

The United Kingdom's experience, however, deserves particular attention for two reasons. First, unlike other Patient Charters we have reviewed, the UK's 1992 *Patient Charter*<sup>16</sup> included a number of specific expectations along with a variety of more common aspirational statements. These more specific expectations included the following:

- readmission within one month if surgery is cancelled on the scheduled day for non-medical reasons;
- a maximum waiting period of 13 weeks for a non-urgent outpatient appointment in 90% of cases;
- patient at outpatient clinics to be seen within 30 minutes of his or her scheduled appointment time;
- a maximum wait of two hours for a hospital bed after admission to hospital through an emergency department;
- immediate assessment of patients arriving at an accident and emergency department;
- waiting times for an ambulance not to exceed 14 minutes in urban areas, 19 minutes in rural areas.

Second, the English *Charter* was criticized in a particularly scathing manner following its inception. In particular, the *Charter* was characterized as a vague hodgepodge of aspirations and service goals.<sup>17</sup> The same report concluded that the document was of very

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<sup>16</sup> *Patient's Charter*, NHS Patients Standard Care Committee (Mar 1992-Sept 1993).

<sup>17</sup> Greg Dyke, *The New NHS Charter – A Different Approach*, Report on the new NHS Charter, December 1998, online  
<[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4106095.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4106095.pdf)>.

little practical utility.<sup>18</sup> In order to meet the standards associated with the *Charter*, it was alleged that English hospitals focused excessively on admission times and quality measurement rather than an actual improvement of patient outcomes.<sup>19</sup> Data exists suggesting that the specific expectations created (but not fulfilled) by the *Charter* actually contributed to conflicts, and even violence, between patients and healthcare providers.<sup>20</sup>

Finally, the English *Charter* was criticized for containing no clear and effective method of complaint resolution.<sup>21</sup> The UK's *Patient Charter* was revised in 1995 and 1997, and was ultimately repealed in 2001. The document that ostensibly replaced it is called *Your Guide to the NHS*. This document discusses what patients can expect during their encounters with public health staff, and sets out general expectations for patients and the health system. Notably changed are the expectations regarding wait times. For instance, rather than setting out a specific maximum wait time for hospital admission, the new guide provides very general guidelines. For example, it reads: "If you then need to be admitted into hospital from the accident and emergency department, you will be placed in a bed as soon as possible. This should happen within two hours of the decision to admit you."<sup>22</sup> This guide appears to have been incorporated into the NHS' website where timelines are stated more as general goals rather than specific expectations.<sup>23</sup> Ironically, the new guide has also been criticized as being too vague and failing to state what patients' rights are at all.<sup>24</sup>

### 3. Summary

In summary, our estimation is that a Patient Charter may provide little positive impact, may create unnecessary complexity, and could even produce unintended negative consequences. For this reason, we would urge caution in considering whether to go ahead or not with the creation of a Patient Charter at all.

### ***B. Considerations for an Alberta Patient Charter***

If the committee continues to explore the possibility of creating a Patient Charter, or decides that a Patient Charter is appropriate, we have several considerations that we feel should be borne in mind.

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<sup>18</sup> *Ibid.*

<sup>19</sup> *Ibid.*; Melanie H Wilson Silver, "Patients' rights in England and the United States of America: The Patient's Charter and the New Jersey Patient Bill of Rights: a comparison" (1997) 23 *BMJ: Journal of Medical Ethics* 213.

<sup>20</sup> M.G. Jenkins et al., "Violence and verbal abuse against staff in accident and emergency departments: a survey of consultants in the UK and the Republic of Ireland" (1998) 15 *Emergency Medicine Journal* 262; H. Burnaby-Atkins, "Seven days on the casualty frontline" *Evening Standard* (27 January 1998) 8.

<sup>21</sup> Silver, *supra* note 19.

<sup>22</sup> *Your Guide to the NHS* (2001), online: <<http://www.nnuh.nhs.uk/docs%5Cleaflets%5C36.pdf>>.

<sup>23</sup> National Health Services website, "NHS Services", online: NHS <<http://www.nhs.uk/NHSEngland/AboutNHSservices/Pages/NHSServices.aspx>>.

<sup>24</sup> Colleen Flood & Tracey Epps, "A Patients' Bill of Rights: A Cure for Canadians' Concerns About Medicare?" (2002) 3 *IRPP Policy Matters* 1.

## *1. Be Clear as to the Intended Purpose of an Alberta Patient Charter*

The MACH report talks about building trust, and establishing a shared understanding of rights and responsibilities as the rationale behind the creation of a Patient Charter. If the decision is made to consult further and/or establish an Alberta Charter, a key issue to consider prior to its design is the intended role that a Charter, if drafted, should play here.

Is the intention to educate and inform Albertans, both users and providers of health services? As such, should it be limited to a set of aspirational statements and avoid the creation of legally enforceable rights? Generally speaking, almost all the Patient Charters we reviewed consisted of statements meant to encourage positive behavior and educate patients about already existing rights.

Is the intention to provide further legal and ethical support for existing rights? Is it meant to create new rights? If the Charter is rights-based, is there an intention to establish a new disputes resolution structure? To rely on already existing routes for resolution of complaints? Or to streamline existing processes?

The goals of such a Charter are crucial to keep in mind as they will affect everything from whether to enshrine the Charter in legislation, to language used within the document, to resources to be allocated to support any rights and/or dispute resolution mechanisms. Depending on the content of a future charter and whether it is legally enforceable, we might strongly recommend setting out its purpose explicitly in a preamble

## *2. Avoid the Creation of Legally Enforceable Rights if a Patient Charter is Developed*

We recommend the MACH avoid creating legally enforceable rights if a Patient Charter is ultimately drafted; the reasons are set out in the following four sections.

### a. Setting out of rights unnecessary if they exist elsewhere

Most of the rights referenced in the MACH report (page 25) already exist, set out in legislation, case law, and/or policy documents. For example, a patient's right to confidentiality and the right to seek access to one's own health information are protected by the *Health Information Act*<sup>25</sup>, in addition to law developed by our courts<sup>26</sup>. Similarly, the right to be fully informed about medical treatment and services is a basic element of Canadian medical law.<sup>27</sup> As such, there would appear to be little, if any, need to give such rights the force of law in a Patient Charter. One valid reason to set out existing rights and/or other aspirations would be to educate and inform Albertans. This is worthy of consideration. However, we view the duplication of existing rights as unnecessary and

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<sup>25</sup> R.S.A. 2000, c. H-5.

<sup>26</sup> *Halls v. Mitchell*, [1928] S.C.R. 125; *McInerny v. McDonald*, [1992] 2 S.C.R. 138.

<sup>27</sup> *Reibl v. Hughes*, [1980] 2 S.C.R. 880; *Hopp v. Lepp*, [1980] 2 S.C.R. 192; Ellen I. Picard & Gerald Robertson, *Legal Liability of Doctors and Hospitals in Canada* (Toronto: Carswell, 2007).

cumbersome, particularly at a time when the province is considering the consolidation of key health related legislation.

b. Patient expectations may increase; greater trust in and effectiveness of the system may not

As was the case in the United Kingdom, described above, a Patient Charter that contains rights may create or elevate patient expectations. If such expectations are set out and met, this could indeed lead to greater trust in the health care system, a stated goal in the MACH Report. However, if such expectations cannot be fulfilled, as a result of constrained resources or otherwise, the result will likely be considerable frustration and a loss of trust in the system.

In addition, health care service providers may devote an inordinate amount of resources and energy to explicit expectations established to the detriment of other needs that are not set out in the Charter. Hospitals and service providers may devote considerable attention to meeting the explicit expectations regardless of whether that equates to improved quality of patient care for an individual or group of persons, and potentially at the expense of other important services that are not so explicitly included.

Finally, the creation of new rights or expectations may also have unintended negative consequences. Using timelines for care as an example, legally enforceable timelines may detrimentally impact a balanced delivery of services, and have providers overly focused on these goals which may or may not lead to improved patient outcomes. While practice guidelines about timeliness of admission or treatment may be appropriate in many instances, including these as part of an enforceable Patient Charter is likely to have negative consequences. We submit that a Patient Charter is not the most appropriate forum for such detailed guidelines to be espoused.

c. A legally enforceable Patient Charter may lead to increased litigation and/or complaints

A legally enforceable Patient Charter may lead to increased litigation and/or complaints. This may or may not be a positive development. It is important for Albertans to have mechanisms to file complaints about, or seek resolution of a dispute with, the health care system and/or health service providers. Education and increased awareness of available resources for people are to be encouraged. Effective mechanisms for filing a complaint and resolving disputes should be an integral part of the system. This includes the avenue of litigation for individuals who have been negligently injured, where compensation is required and/or would be of assistance to them to pay for costs of future care and so on. Many routes for such disputes currently exist, including professional regulatory bodies, complaints officers, ombudsmen, and legal counsel.

However, prior to creating a Patient Charter, an analysis of whether that may create an increased demand for the use of complaints mechanisms, to what extent, and whether that would be a positive or potentially negative consequence is worthy of a cost-benefit

analysis given our health care system's limited resources. A substantial increase in the use of such systems may draw resources away from the provision of care itself without a sufficient corresponding benefit.

There are commentaries suggesting that a rights-focused Patient Charter will lead to a climate of increased complaints, confrontation between health care providers and patients, and a more litigious approach to healthcare.<sup>28</sup> Instead of depicting the public health system as an arena where competing objectives must be balanced to maximize public benefit, Patient Charters may encourage the maximum pursuit of individual rights regardless of the strain placed on publicly stewarded resources.

It has been suggested that a Patient Charter is designed to lead to an increase in complaints by setting patient expectations and encouraging patients to take action if such expectations are not fulfilled.<sup>29</sup> While a study actually correlating an increased number of complaints directly to a Patient Charter has not been completed, British anecdotal evidence suggests that their 1992 Patient Charter *contributed* to confrontations between staff and patients due to frustrated expectations, though, as noted, this was not based on an empirical study. In particular, there was no specific examination of whether the global "complaint rate" increased as a result of the Patient Charter.<sup>30</sup> Other authors suggest that a Patient Charter, if nothing else, has the potential to focus patient attention on lodging a complaint if a specific expectation is frustrated.<sup>31</sup> It is speculative to say without a study on point, but it may be logical to assume that a Patient Charter may help appraise some patients of rights that they were unaware they had or inform such patients of the complaint mechanisms in place. Informed patients may be more likely to question their care or seek to make formal complaints if they feel their rights under the Charter have been violated. In short, if expectations are set and a complaint mechanism is given increased visibility, more complaints may come in. This may be viewed as a positive or negative development.

While an increased number of complaints will lead to greater utilization (and therefore associated expense) of complaints mechanisms, such an increase does not necessarily

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<sup>28</sup> Stephen Eisenstein, "The Chartered Patient and the Damaged Doctor" (1996) 313 *British Medical Journal* 1268; "BMA Scotland Responds to consultation on a proposed Patient Rights Bill" (2009) online: British Medical Association <[http://www.bma.org.uk/healthcare\\_policy/responses\\_consultations/ScotPatientRights.jsp?page=1](http://www.bma.org.uk/healthcare_policy/responses_consultations/ScotPatientRights.jsp?page=1)>; Central Alberta Council on Aging "Protect Health Act" (open submission in response to MACH Report) *Red Deer Advocate* 20 July 2010, online: Red Deer Advocate <[http://www.albertalocalnews.com/reddeeradvocate/opinion/Protect\\_health\\_act\\_98833959.html](http://www.albertalocalnews.com/reddeeradvocate/opinion/Protect_health_act_98833959.html)>.

<sup>29</sup> G. Bryce, "Complaints- and how to deal with them" (1998) 15 *Journal of Accident and Emergency Medicine* 63.

<sup>30</sup> Mark Jenkins *et al.*, "Violence and verbal abuse against staff in accident and emergency departments: a survey of consultants in the UK and Ireland" (1998) 15 *Journal of Accident and Emergency Medicine* 262; J.C. Saines, "Violence and Aggression in the A & E: Recommendations for action" (1999) 7 *Accident and Emergency Nursing* 8; "Patients Charter Blamed for Attacks on NHS Staff" *BBC News* 28 October 1998, online: BBC <<http://news.bbc.co.uk/2/hi/health/202942.stm>>. Note that the Patient Charter at the time of these reports contained specific wait time expectations. Note further that both studies also blamed alcohol abuse and greater societal aggression for these conflicts.

<sup>31</sup> Fedelma Winkler, "Complaints by Patients" (1993) 306 *British Medical Journal* 472;

correlate with an increase in litigation. We have reviewed a relatively large amount of scholarly literature on this subject, but have yet to find a study that links the creation of a Patient Charter with such an increase. Authors likewise suggest that patients often seek recourse in litigation only after the regular complaints procedure fails to produce satisfaction<sup>32</sup> and that an effective complaint system could actually reduce instances of litigation.<sup>33</sup>

However, it would not be accurate to suggest that a Patient Charter will *not* lead to an increase in litigation just because such an increase has not been established in other jurisdictions. This appears to be an unknown due to the lack of reliable research on the issue. Whether or not such an increase occurs may depend in large measure on the nature of the rights provided by the Charter. Nearly all of the rights discussed at page 25 of the MACH report, as mentioned earlier, are highly general and already enforceable through other sources. However, should the Patient Charter create new rights, this may well fuel new litigation in the province. For example, the MACH report suggests that a Patient Charter may ensure “an equitable allocation of resources.” If this principle is included, depending upon how it was drafted, this could be seen as creating a new and potentially enforceable right.

In summary, there is little evidence regarding how a Patient Charter may impact the rate of litigation. At best, there is some evidence that Patient Charters *may* encourage additional complaints or at least make the formal complaints process more visible.

d. If citizen responsibilities are included at all, they should not affect the provision of health services

Our organization would caution the committee about including specific citizen responsibilities as part of a Patient Charter, though other Charters have included them.<sup>34</sup> If it is clear that such statements are aspirational only, and failure to comply will not lead to negative repercussions on individuals, perhaps certain statements may be worthwhile to educate as to good stewardship on the user side of the system. However, there are a number of potential pitfalls with the inclusion of some statements, particularly if stated as “responsibilities”. We will briefly touch on a few of these.

Even if no formal “penalties” are established for failing to meet such responsibilities, we would suggest that they do not accord with the rights Albertans do have to access appropriate health services. While certain scarce resources are appropriately allocated in part based upon health and/or lifestyle, in many instances these would be inappropriate bases to refuse care.

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<sup>32</sup> Margaret Prior, “The case for the orthopedic nurse expert” (1997) 1 *Journal of Orthopedic Nursing* 67.

<sup>33</sup> Joan M. Gilmour, *Patient Safety, Medical Error and Tort Law: An International Comparison: Final Report* (2006), online: Osgoode Hall Law School <[http://osgoode.yorku.ca/osgmedia.nsf/0/094676DE3FAD06A5852572330059253C/\\$FILE/FinalReport\\_Full.pdf](http://osgoode.yorku.ca/osgmedia.nsf/0/094676DE3FAD06A5852572330059253C/$FILE/FinalReport_Full.pdf)>.

<sup>34</sup> For example, Florida’s *Patient’s Bill of Rights and Responsibilities*, Fla. Stat. §381.026 (1999).

There is the potential, as well, if listed as such for individuals to delay seeking assessment and/or care in an attempt to be good stewards, leading to a serious (an potentially more expensive) provision of services when they do seek them out. It is also worrisome that health care providers may use these, inappropriately, to refuse to take on new patients or refuse to continue care for individuals who are not “living up to his or her responsibilities”.

We would also note that several of the potential “responsibilities” noted in the MACH Report are problematic in themselves.

For instance, while encouraging a healthy lifestyle is sensible and crucial for fostering preventative care, we would note that making a patient specifically responsible for their lifestyle (or punishing lifestyle choices) may not be compatible with universal healthcare. Positive and healthy choices are important, but an inclusive and universally available system must not be perceived as punishing Albertans who have made particular choices.

Ascertaining whether a citizen is adequately protecting their own health is all but impossible. All Albertans, regardless of how health conscious they may be, make some unhealthy or unwise choices. What kind or what extent of unhealthy choices are acceptable under this principle? What level of health knowledge should be ascribed to the average Albertan? Does it matter if medical consensus about the healthiness of a choice does not exist? What about behaviours like the consumption of coffee, red wine, and chocolate, which have both positive and negative health effects?

Likewise, suggesting that Albertans have the responsibility to “learn how to better access health services” and “use services appropriately and wisely” may be particularly unfair to many, including those suffering from chronic conditions or who have limited command of the English language and a lack of familiarity with how Alberta’s healthcare system operates (as is the case with some recent immigrants). Similarly, how would one assess whether an individual has unreasonably overreacted to symptoms and used health services in such a way that was not fully responsible. Should people be criticized, even informally, for simply not knowing how a complex system operates or occasionally overreacting to existing symptoms? Should people be discouraged from seeking health services because their actions *might not* be appropriate or completely responsible? We would suggest that part of the role of the health care providers is to guide patients on a case-by-case basis as to what is appropriate in his or her circumstances. In many instances, it may be difficult, if not impossible, for individuals to make that call.

Some patient responsibilities may conflict with established legal rights. For instance, the MACH Report considers the inclusion of the responsibility to “[Follow] an agreed-upon care plan” and “[follow] instructions.” Patients have the long recognized legal right to refuse consent to treatment and, indeed, there may be situations where a patient may have legitimate reasons for electing not to pursue a recommended course of treatment or instruction. The right to refuse treatment and to seek alternative opinions and treatment have long been recognized and supported, yet seem inconsistent with these new responsibilities under the Patient Charter.

Given the importance Albertans and Canadians attach to universally available healthcare, it may not be appropriate to include responsibilities in a Patient Charter. While many of the aspirations are laudable, including them as citizen responsibilities is not appropriate. In addition to conflicting with popular understandings of the healthcare system, some of the responsibilities listed are hopelessly vague and would be of no practical value.

### *3. Examine Existing Complaints and Dispute Resolution Mechanisms*

It may be timely to examine existing complaints and/or dispute resolution mechanisms in Alberta and to ask whether or not they are serving Albertans well, or whether streamlined, or perhaps new mechanisms would be worthwhile to establish. Discussing the possible creation of a Charter raises this as in some instances new frameworks have, to some extent, been created in other jurisdictions. At first glance, it would appear to be of little value to set up a parallel complaint resolution mechanism for the Patient Charter if rights are established, and breaches of those existing rights already have working enforcement mechanisms. Mere duplication of mechanisms would be an unwise expenditure of resources. For example, a patient that is concerned about a violation of their confidentiality or an unjustified failure to disclose information can seek assistance and redress through Alberta's Information and Privacy Commissioner. Patients who have complaints about their access to publicly funded healthcare or their treatment at an Alberta hospital can pursue a complaint with an individual hospital's complaint review body or the Alberta Ombudsman. Albertans who feel that they have been the subject of discrimination have a range of human rights remedies under human rights legislation. Such aggrieved persons could also, if a complaint relates to a specific healthcare provider, file a grievance with the appropriate regulatory association or professional college. And, as previously discussed, litigation is an appropriate option in some circumstances.

However, it may be the case that certain measures may be implemented to improve this process, both for individuals and the system itself. This does not, however, need to be done through a Patient Charter.

### *4. Conclusion on the Patient Charter*

We submit that, in deciding whether to proceed with the development of a Patient Charter, the committee must carefully weigh whether the benefits of a Charter will outweigh its possible negative effects and potential costs. If the committee finds that continuing to develop a Charter is appropriate, we believe that it is important to draft the document with a clear purpose in mind. We also suggest that making a Patient Charter legally enforceable may be problematic. Finally, we would encourage the committee to use this opportunity to review existing dispute resolution procedures.

### **III. Ongoing Public Consultation**

The Health Law Institute supports facilitating public engagement in the planning and drafting stages of this legislation. Broad public and stakeholder consultation will help produce an *Act* that ultimately reflects the desires, concerns and interests of Albertans. We applaud the committee's actions to date in this regard.

Thank you again for giving us the opportunity to provide submissions. We would be pleased to answer any questions, address any comments or provide further submissions if it would assist the committee in any way.

Yours Truly,

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