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# Waiting for Health Care: What Role for a Patients' Bill of Rights?

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While Canadians are generally satisfied with the quality of the health care they receive, many are increasingly concerned about access to health care services and, in particular, about waiting times for treatment. These concerns have been fuelling the growing momentum for health care reform over the past few years. One of the reform possibilities currently being considered at both the federal and provincial level is a patients' bill of rights, which would confer certain rights on all users of the health care system.

In this article, the authors explore the merits of a patients' bill of rights and examine whether or not such a reform would address Canadians' concerns regarding the public health care system. The authors begin by highlighting Canadians' concerns about access to health care and discussing the perception that waiting times are increasing. They then explain the distinction between rights *in* and rights *to* health care and the extent to which these different rights can be protected in Canada. Finally, the authors present a detailed survey of the experiences of seven jurisdictions in implementing and enforcing a patients' bill of rights. In particular, the authors focus on those jurisdictions that have established the right to access health care services in a timely fashion and examine the mechanisms created to enforce this right. Drawing on the lessons from these jurisdictions, the authors conclude with suggestions regarding the potential models that could be used to guarantee patients' rights in Canada.

Si les Canadiens sont en général satisfaits de la qualité des soins de santé qu'ils reçoivent, plusieurs sont néanmoins de plus en plus préoccupés par l'accès à ces services et, en particulier, par les temps d'attente pour les traitements. Ces préoccupations nourrissent depuis quelques années un mouvement croissant en faveur d'une réforme du système de santé. L'un des projets de réforme présentement sous étude, tant au niveau fédéral que provincial, est la rédaction d'une charte des droits des patients qui conférerait certains droits à tous les usagers du réseau public de la santé.

Dans cet article, les auteures considèrent les mérites d'une charte des droits des patients et se demandent si une telle réforme répondrait aux attentes des Canadiens envers le réseau public de la santé. Les auteures commencent en soulignant les préoccupations des Canadiens quant à l'accès aux soins de santé et en discutant la perception selon laquelle les temps d'attente tendent à augmenter. Elles expliquent la distinction entre les droits *dans* les soins de santé et les droits *aux* soins de santé et dans quelle mesure ces différents droits peuvent être protégés au Canada. Enfin, les auteures proposent une revue détaillée de l'expérience de sept juridictions avec l'implantation et la mise en vigueur d'une charte des droits des patients. Les auteures portent une attention particulière aux juridictions où l'accès rapide aux soins de santé dans un délai raisonnable a été reconnu dans leurs chartes respectives des droits des patients et examinent les mécanismes créés pour faire observer ce droit. Les auteures terminent en suggérant, sur la base des leçons tirées des autres juridictions examinées, des modèles potentiels pouvant garantir les droits des patients au Canada.

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## Introduction

There is momentum for health care reform across Canada. At the federal level, the Standing Senate Committee on Social Affairs, Science and Technology, chaired by Senator Kirby, released its final report on the state of the health care system in Canada in October 2002.<sup>1</sup> This was followed by the final report of Roy Romanow's Commission on the Future of Health Care in Canada in November 2002.<sup>2</sup> The Kirby and Romanow reports followed closely upon the heels of reports commissioned by various provincial governments, including Alberta,<sup>3</sup> Saskatchewan,<sup>4</sup> New Brunswick,<sup>5</sup> and Quebec.<sup>6</sup> These reports call for varying but significant health care reform. But what kind of reform might governments implement from the range of options presented?

One possibility for reform is to establish a "patients' bill of rights", either nationally or on a province-by-province basis. We define a "patients' bill of rights" as legislation enumerating and consolidating those patients' rights that exist at common law as well as rights from other sources (e.g., duties that are described in medical codes of ethics). A patients' bill of rights would confer rights on users of all health care services (whether publicly funded or not, and whether provided by a regulated health professional or not) and place corresponding obligations on providers of those services. This bill of rights would provide, through an independent commissioner or ombudsperson, a process for patients who believe that their rights have been breached to make a complaint. The commissioner or ombudsperson would also have powers of investigation and enforcement.

Recently, a number of Canadian provinces have independently either implemented or are considering implementing a patients' bill of rights. Quebec, since 1991, has had

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<sup>1</sup> Canada, Standing Senate Committee on Social Affairs, Science and Technology, *The Health of Canadians—The Federal Role: Recommendations for Reform*, vol. 6 (Ottawa: Government of Canada, 2002) (Chair: Hon. Michael J.L. Kirby) [Kirby report].

<sup>2</sup> Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada* (Ottawa: Government of Canada, 2002) (Commissioner: Roy J. Romanow) [Romanow report].

<sup>3</sup> Alberta, Premier's Advisory Council on Health, *A Framework for Reform: Report of the Premier's Advisory Council on Health* (Edmonton: Government of Alberta, 2001) (Chair: Rt. Hon. Don Mazankowski). Alberta had earlier introduced patients' rights legislation: Bill 201, *Alberta Patients' Bill of Rights*, 2d Sess., 24th Leg., Alberta, 1998, was defeated on 4 February 1998.

<sup>4</sup> Saskatchewan, Commission on Medicare, *Caring for Medicare: Sustaining a Quality System* (Regina: Government of Saskatchewan, 2001) (Commissioner: Kenneth J. Fyke).

<sup>5</sup> New Brunswick, Premier's Health Quality Council, *Health Renewal: Report from the Premier's Health Quality Council* (Fredericton: Government of New Brunswick, 2002) (Chair: Michel C. Leger).

<sup>6</sup> Quebec, Commission of Study on Health and Social Services, *Emerging Solutions: Report and Recommendations* (Quebec City: Government of Quebec, 2001) (Chair: Michel Clair).

legislation setting out patients' rights<sup>7</sup> and has recently enacted new legislation that gives the ombudsperson greater power to enforce those rights.<sup>8</sup> In New Brunswick, the government recently introduced a bill that would establish a health charter of rights and responsibilities.<sup>9</sup> The previous Conservative government in Ontario promised legislation to protect "patients' rights to access health services, to complete information about their health, and to respect for their privacy, personal dignity and safety."<sup>10</sup> Legislation is under development<sup>11</sup> but had not yet been introduced at the time of writing and appears to have stalled under the new Liberal government in Ontario. The introduction of a patients' bill of rights has also been considered in Saskatchewan and Manitoba.<sup>12</sup>

At the federal level, the senate committee under Senator Kirby put forward a patients' guarantee vis-à-vis waiting times as a reform option worthy of serious consideration,<sup>13</sup> while Roy Romanow, in his report, recommended the establishment of a "Canadian Health Covenant" that would set out the responsibilities and entitlements of individual Canadians, health care providers, and governments.<sup>14</sup> The Kirby and Romanow reports were followed by the *First Ministers' Accord on Health Care Renewal* in February 2003.<sup>15</sup> The accord sets out an action plan for reform that states as its aim to ensure that "all Canadians have timely access to health services on the basis of need, not ability to pay, regardless of where they live or move in Canada," and that "the health care services available to Canadians are of high quality, effective,

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<sup>7</sup> *An Act respecting Health services and social services*, R.S.Q. c. S-4.2 [*Health Services Act*].

<sup>8</sup> *An Act respecting the Health and Social Services Ombudsman*, R.S.Q. c. P-31.1 [*Ombudsman Act*].

<sup>9</sup> Bill 60, *Health Charter of Rights and Responsibilities Act*, 5th Sess., 54th Leg., New Brunswick, 2003 (second reading 9 April 2003). The charter would give residents of New Brunswick the right: to timely access to health care services; to receive relevant health care information; to make informed health care decisions; to safe, comfortable, and considerate attention; and to the investigation of complaints. It would also place responsibilities on residents, including the responsibility to use health care services in a reasonable manner and to learn about and make health lifestyle choices. The charter would see the appointment of a Health and Wellness Advocate to, among other things, advise and assist individuals in the exercise of their rights and the performance of their responsibilities under the act.

<sup>10</sup> Hon. Hilary M. Weston, Lieutenant Governor of the Province of Ontario, "Speech from the Throne on the Opening of the First Session of the Thirty-Seventh Parliament of the Province of Ontario" (21 October 1999), online: Legislative Assembly of Ontario <[http://www.ontla.on.ca/hansard/house\\_debates/37\\_pari/session1/L002.htm](http://www.ontla.on.ca/hansard/house_debates/37_pari/session1/L002.htm)>.

<sup>11</sup> Telephone conversation with Kathie Clarke of the Ontario Ministry of Health and Long-Term Care (23 August 2002).

<sup>12</sup> See e.g. Manitoba Health, *Quality Health Care for Manitobans: The Action Plan for the New Millennium* (Winnipeg: Manitoba Health, 1999).

<sup>13</sup> Kirby report, *supra* note 1.

<sup>14</sup> Romanow report, *supra* note 2 at xxiv.

<sup>15</sup> Canada, *2003 First Ministers' Accord on Health Care Renewal* (5 February 2003), online: Canadian Intergovernmental Conference Secretariat <[http://www.scics.gc.ca/pdf/800039004\\_e.pdf](http://www.scics.gc.ca/pdf/800039004_e.pdf)>.

patient-centred and safe.”<sup>16</sup> While the accord does not mention a patients’ bill of rights, such a bill of rights could, if properly implemented, go some way toward ensuring that Canadians have access to timely and quality health care services, as required by the accord.

Although the idea of a patients’ bill of rights has been considered at both the federal and provincial level, there are obvious jurisdictional issues that arise in the context of a federal bill of rights, as the existing jurisprudence interprets the *Constitution Act, 1867*<sup>17</sup> in a manner that gives the provinces jurisdiction over most of the health care system. Nevertheless, it would be possible for the federal government to encourage, through financial incentives and disincentives, the province-by-province establishment of a patients’ bills of rights, which would have the benefit of ensuring that all Canadians have the same entitlements, from coast to coast. The use of the federal spending and taxing powers in this manner has been previously upheld by the courts. We do not purport here to provide an exhaustive determination of the feasibility of a federal bill of rights, nor do we reach any conclusions about whether it would be better to have a pan-Canadian bill of rights as opposed to differing provincial initiatives across the country. Our modest goals here are to explore whether the proposals for a patients’ bill of rights in Canada would address the concerns that Canadians currently have about their health care system and to highlight the lessons learned by other jurisdictions in implementing and enforcing a patients’ bill of rights.

A recent national survey found that Canadians are strongly supportive of the concept of a patients’ bill of rights.<sup>18</sup> Nine in ten Canadians indicated that they would support the appointment of an independent commissioner or ombudsperson to hear complaints about health care providers and health care services and make recommendations for actions to be taken.<sup>19</sup> A large majority (eighty-four per cent) of Canadians indicated that they would like to see the introduction of a bill of rights that sets out in one document the rights to which they are entitled as a patient.<sup>20</sup> When asked what rights they would like to see included in a patients’ bill of rights, the most common answers included the right to be treated with respect and dignity, the right to be fully informed about one’s medical condition and treatment, the right to give informed consent, and the right to receive care within a designated period of time.<sup>21</sup>

A patients’ bill of rights is obviously a popular reform proposal, but would it actually address Canadians’ concerns about medicare? If reform of publicly-funded medicare does not meet those concerns, the pressure for change will continue unabated and will, in our opinion, undoubtedly result in increased pressure for greater

<sup>16</sup> *Ibid.* at 1.

<sup>17</sup> (U.K.), 30 & 31 Vict., c. 3, reprinted in R.S.C. 1985, App. II, No. 5.

<sup>18</sup> IBM Business Consulting Services, *HealthInsider: Survey No. 8*, Fall/Winter 2002 (Toronto: IBM Business Consulting Services) [Survey No. 8].

<sup>19</sup> *Ibid.*

<sup>20</sup> *Ibid.*

<sup>21</sup> *Ibid.*

private options. We argue that Canadians are very concerned about access to health care services and, in particular, growing waiting times for treatment. This paper explores the prospects of a patients' bill of rights addressing concerns about waiting times and, in so doing, examines the experiences of jurisdictions that have implemented patients' rights legislation. Looking at the experiences of other jurisdictions provides a basis for examining the effectiveness of patients' bills of rights and potential models that would be appropriate for Canada.

We begin by examining Canadians' concerns with respect to medicare and argue that Canadians' concerns regarding timeliness in treatment (i.e., waiting times) must be taken seriously. We then explain the distinction between rights *in* health care and rights *to* health care and the extent to which these different types of rights are protected in Canada through the common law, self-regulation, and otherwise. We then turn to examine the experiences of Quebec, the United States, New Zealand, the United Kingdom, Spain, Sweden, and Italy in protecting rights in and to health care through the mechanism of a patients' bill (or charter) of rights. Our particular focus is upon those countries that have used a patients' bill of rights as a tool to address concerns about waiting lists and times.

## I. What Are Canadians' Concerns?

Canadians who use the health care system are generally very satisfied with the care they receive but extremely concerned about waiting times for treatment; many perceive waiting times to be getting longer.<sup>22</sup> A report released in mid-2002 by Statistics Canada noted the following:

An estimated 4.3 million Canadians reported difficulties accessing first contact services and approximately 1.4 million Canadians reported difficulties accessing specialized services such as specialist visits, non-emergency surgery (planned surgery, excluding dental surgery) and selected diagnostic tests (non-emergency MRIs, CT scans, or angiographies). While the type of barrier varied by time of day and service type, lengthy waits and problems contacting a

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<sup>22</sup> See e.g. PricewaterhouseCoopers, *HealthInsider: Survey No. 4*, Fall/Winter 2000 (Toronto: PricewaterhouseCoopers). The *HealthInsider* is a national syndicated survey of Canadians' opinions about health care. In this issue, it was reported that while "the majority (58%) [of Canadians] reported that the Canadian health care system was sound with few or minor changes needed ..." the remainder believe the health care system requires major changes (at 54). In *Survey No. 8*, *supra* note 20 at 57, *HealthInsider* reported that compared to five years ago, 62 per cent of respondents thought that the waiting time for medical services was either slightly or much longer, with about one-third indicating they had become much longer. See also Nadeem Esmail & Michael Walker, *Waiting Your Turn: Hospital Waiting Lists in Canada*, 13th ed. (Vancouver: Fraser Institute, 2003), online: Fraser Institute <<http://www.fraserinstitute.ca/shared/readmore.asp?sNav=pb&id=587>>. Note, however, that the Fraser Institute data has been criticized on a variety of methodological grounds—for instance, because it surveys individual physicians and thus is subject to recall bias, has a small response rate, and is limited by the use of different respondents yearly.

health care provider were frequently cited by those who experienced difficulty accessing care.<sup>23</sup>

The report went on to note that “[a]mong those waiting for specialized services, between 21.7 per cent of those who waited for non-emergency surgery and 26.7 per cent of those who waited for specialist visits indicated that their waiting time was unacceptable. They reported longer waits, between three and six times as long as those who reported that their waiting time was acceptable.”<sup>24</sup> A November 2002 national survey of Canadians found that forty-six per cent of Canadians think that the quality of health care has declined over the last five years; one of the top perceived reasons given for this decline, along with funding cutbacks and doctor and nurses shortages, was longer waiting times.<sup>25</sup> The same survey found that sixty-two per cent of Canadians thought that waiting times were longer compared to five years ago.<sup>26</sup>

A number of policy analysts point out that there is no evidence about the extent of the waiting time problem and argue that Canadians’ concerns are fuelled by an irresponsible media pursuing juicy human interest stories and by self-interested physician groups.<sup>27</sup> Yet Canadians remain unfazed by academic skepticism and unpersuaded that waiting times are not really a problem.<sup>28</sup> Canadians’ concerns about waiting for care are five-fold:

1. Timeliness of treatment has the potential to have a significant impact on the chances of a successful cure or even survival.
2. A patient waiting for treatment may experience pain and a significant decline in his or her quality of life (e.g., patients needing hip replacements).

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<sup>23</sup> Statistics Canada, “Key Findings” in *Access to Health Care Services in Canada, 2001*, online: Statistics Canada <<http://www.statcan.ca/english/freepub/82-575-XIE/findings.pdf>> [Statistics Canada, “Key Findings”].

<sup>24</sup> *Ibid.*

<sup>25</sup> *HealthInsider: Survey No. 8*, *supra* note 18.

<sup>26</sup> *Ibid.*

<sup>27</sup> See e.g. Steven Lewis *et al.*, “Ending Waiting-List Mismanagement: Principles and Practice”, *Commentary* (2000) 162 *CMAJ* 1297. For a discussion of the various factors that contribute to waiting lists, see S.E.D. Shortt, “Waiting for Medical Services in Ontario: Clarifying the Issues in a Period of Health Reform” (Discussion paper for the Atkinson Charitable Foundation, February 2000), online: University of Toronto <<http://www.utoronto.ca/hpme/dhr/pdf/Shortt.pdf>>.

<sup>28</sup> See e.g. Shelley Martin, “Almost 1 in 2 Canadians Says Health System Needs Major Surgery” (2001) 165 *CMAJ* 465. Martin reports that a survey carried out by PricewaterhouseCoopers found that 47 per cent of respondents said that the quality of health care had declined in the past five years, with just over one-fifth of the 47 per cent blaming longer waiting times. See also Rex Murphy, “What’s Your Prescription for Canada’s Health Care System?”, *Canadian Broadcasting Corporation* (Broadcast from Red Deer, Alberta on 13 February 2000), online: [CBC.ca <www.cbc.ca/checkup/features/red\\_deer.html>](http://www.cbc.ca/checkup/features/red_deer.html). It was reported that “[t]he waits for certain kinds of treatments are excruciating, anguishing, and in some sense a nullification of the boast that our health system is the best in the world.”

3. Delays in receiving care can result in private costs in terms of lost days of work, lost income, and reduced productivity—costs that do not have to be absorbed by provincial health ministries.
4. Patients waiting for treatment and their families and friends may experience great psychological stress. For example, a study of cancer patients in Ontario found that cancer patients experience major psychological stress as a result of delays in diagnosis or treatment.<sup>29</sup> The Statistics Canada report mentioned above found that one in five Canadians “who waited for specialized services indicated that waiting for care affected their lives. Most of these individuals reported that they experienced worry, stress and anxiety, pain or diminished health as a result of waiting for care.”<sup>30</sup>
5. Waiting lists are unfairly managed, and those with contacts (e.g., friends and relatives who work within the health care system) are able to jump the queue and have their needs met first or otherwise, they are able to purchase care in the US.

The division between academic and public opinion on the impact of waiting for care is due, at least in part, to the importance each group attaches to linking treatment to measurable health care outcomes. Most prominent health policy analysts in Canada support the concept of “evidence-based medicine”. Evidence-based medicine, grounded in health economics and health services research, posits that governments should only fund health care services that have a measurable impact on health care outcomes.<sup>31</sup> Many health policy analysts will therefore concede that timeliness is of relevance, but only insofar as it impacts on the first of the Canadian’s concerns (i.e., significantly affecting an individual’s health). Citizens and patients, on the other hand, want to achieve positive health *outcomes* but are also concerned with the *process* of care and how *long* it takes to have their needs addressed. Neither the process of care (e.g., being treated with respect) nor the speed with which care is supplied may be readily measurable in terms of health care outcomes.

In its 2002 report, Kirby’s senate committee recommended a health care guarantee where, for each type of major procedure or treatment, a maximum needs-based waiting time would be established and made public.<sup>32</sup> If this maximum time were exceeded, the insurer (the government) would pay for the patient to seek the

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<sup>29</sup> See Marko Simunovic *et al.*, “A Snapshot of Waiting Times for Cancer Surgery Provided by Surgeons Affiliated with Regional Cancer Centres in Ontario” (2001) 165 CMAJ 421.

<sup>30</sup> See Statistics Canada, “Key Findings”, *supra* note 23.

<sup>31</sup> See Robert G. Evans & G. L. Stoddart, “Producing Health, Consuming Health Care” in Robert G. Evans, Morris L. Barer & Theodore R. Marmor, eds., *Why Are Some People Healthy and Others Not?: The Determinants of Health of Populations* (New York: Aldine De Gruyter, 1994) 27 at 38. See also Douglas E. Angus *et al.*, *Sustainable Health Care for Canada: Synthesis Report* (Ottawa: Queen’s-University of Ottawa Economic Projects, 1995) for the argument that, as there is little evidence that many health care services have any impact on health, cutbacks in public spending can occur without impact on Canadians’ health.

<sup>32</sup> Kirby report, *supra* note 1 at 117.



procedure or treatment immediately in another jurisdiction, including, if necessary, another country (e.g., the United States). In his final report, Roy Romanow, on the other hand, did not favour the introduction of waiting time guarantees, stressing the difficulties that would ensue in determining what the appropriate guarantee should be and what the consequences would be if the health care system were unable to meet the time limits set in a guarantee.<sup>33</sup> Mr. Romanow suggested instead that efforts be directed to systematically gathering

information about health system performance that allows us to document where and why there are bottlenecks in the system so that we can target our prescriptive efforts. If the problem is a lack of doctors, hospital beds, or MRI capacity, then we should invest accordingly. Or if the problem is that we lack a centralized system for channelling patients to providers or institutions that have the smallest wait times, then let’s do that.<sup>34</sup>

The problem of waiting lists is not new, however, and governments and institutions have long had the option to follow Romanow’s recommendations for gathering better information about waiting lists and times and systematically addressing the problems—but they have not. We believe that this failure to act is due to insufficient direct incentives for decision-makers to rigorously address the problem of waiting lists, particularly as there is always the opportunity for provincial governments to blame the federal government’s underfunding for deficiencies in their health care systems. We discuss below the prospects for a waiting list guarantee as recommended by the senate committee to form part of a patients’ bill of rights and to address the present lack of incentives in the system that deal with waiting list and time issues.

## II. Rights *in* and Rights *to* Health Care

Given that access to, and timeliness in, treatment is a serious issue for Canadians, would a patients’ bill of rights effectively address this concern? Let us begin by clarifying what we mean by patients’ rights. There are two broad categories of patients’ rights. Firstly, rights *in* health care arise out of the clinical encounter, that is, the actual delivery of care by doctors, nurses, and other health care providers. Secondly, there may be rights *to* access health care services, such as the rights of patients vis-à-vis public and private insurers to have certain treatments funded and/or delivered in a timely fashion.<sup>35</sup> Historically, patients’ bills of rights have been directed at rights in health care, that is, directed at the rights of patients vis-à-vis doctors,

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<sup>33</sup> “The Romanow Report: One Year Later” *The Atkinson Letter* (November 2003) 1 at 5, online: The Atkinson Foundation <[http://www.atkinsonfoundation.ca/publications/11239\\_IPS\\_Atkinson\\_NL.pdf](http://www.atkinsonfoundation.ca/publications/11239_IPS_Atkinson_NL.pdf)>.

<sup>34</sup> *Ibid.*

<sup>35</sup> The history of the establishment of both rights “in” health care and rights “to” health care is discussed by Paul Starr, *The Social Transformation of American Medicine* (New York: Basic Books, 1982) at 388-93. In both the United States and Canada, rights “in” health care came about after rights “to” health care in the early 1970s.

nurses, and other professionals in a clinical encounter. In order to address Canadians' key concerns about their health care system, however, a patients' bill of rights ought to recognize both rights *in* health care and rights *to* health care. Specifically, a patients' bill of rights would need to focus on both the clinical relationship and entitlement relationships—those between patients/citizens and health care insurers, payers, and/or managers (e.g., ministries of health, regional health authorities, community care centres, private insurers, etc.)

### A. Rights in Health Care

In some areas, provinces have legislated specifically for patients' rights. In Ontario, for example, the *Long-Term Care Act, 1994* (which governs the provision of services to patients in the community) sets out a "bill of rights" for people receiving community services.<sup>36</sup> The rights include: the right to be dealt with in a courteous and respectful manner and to be free from mental, physical, and financial abuse by the service provider; to be dealt with by the service provider in a manner that respects an individual's dignity and privacy and that promotes an individual's autonomy; to give or refuse consent to the provision of any community service; and to raise concerns or recommend changes in connection with the community service provided to him or her and in connection with policies and decisions that affect his or her interests, to the service provider, government officials, or any other person, without fear of interference, coercion, discrimination, or reprisal.

The common law also recognizes certain rights *in* health care. These rights include the right to give informed consent,<sup>37</sup> to confidentiality,<sup>38</sup> to have access to one's own medical records,<sup>39</sup> and to receive treatment that is provided with a reasonable degree of care.<sup>40</sup> Enforcement of these kinds of legal rights is discussed

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<sup>36</sup> S.O. 1994, c. 26, s. 3.

<sup>37</sup> The common law provides that medical intervention may only be provided where the consent of the individual to be treated has been obtained: *Schloendorff v. New York Hospital*, 211 N.Y. 125, 105 N.E. 92 (N.Y.C.A. 1914); *Pratt v. Davis*, 118 Ill. App. 161 (1905); *Malette v. Shulman* (1990), 72 O.R. (2d) 417, 37 O.A.C. 281. The patient must be given the information that a reasonable or prudent person in the patient's circumstances would require in order to exercise a choice among feasible options that accord with his or her own wishes: *Reibl v. Hughes*, [1980] 2 S.C.R. 880, 114 D.L.R. (3d) 1.

<sup>38</sup> The common law places a duty on physicians to respect a patient's privacy and maintain information given in confidence: *McInerney v. MacDonald*, [1992] 2 S.C.R. 138, 93 D.L.R. (4th) 415.

<sup>39</sup> *Ibid.*

<sup>40</sup> In a medical negligence claim the plaintiff must prove that there was a duty of care, that the duty of care was breached, and that there was a causal link between the breach and the injury. This test has been stated as follows: "Every medical practitioner must bring to his task a reasonable degree of skill and knowledge and must exercise a reasonable degree of care. He is bound to exercise that degree of care and skill which could reasonably be expected of a normal, prudent practitioner of the same experience and standing ..." (*Critt v. Sylvester*, [1956] O.R. 132, 1 D.L.R. (2d) 502 at 508 (Ont. C.A.), *aff'd* [1956] S.C.R. 991, 5 D.L.R. (2d) 601). In certain jurisdictions, some of these rights are also recognized by statute. See e.g. the Ontario *Health Care Consent Act*, S.O. 1996, c. 2, Sch. A, which sets out the requirements for a valid consent.

below.<sup>41</sup> Apart from legal rights provided explicitly by statute and through the common law, various professional colleges (physicians, nurses, etc.), empowered by provincial legislation, establish codes of ethics and may discipline members of their respective professions who do not comply. Codes of ethics, in addition to recognizing many legal rights, also often recognize rights *in* health care of a more intangible nature, such as the right of a patient to be treated with respect and dignity. However, codes of ethics usually describe *duties* on the part of health professionals rather than *rights* accorded to patients.<sup>42</sup> We discuss enforcement by professional colleges further below.<sup>43</sup>

### 1. Self-Regulation

All provincial governments have granted self-regulatory status to the medical professions,<sup>44</sup> empowering them to control entry to the professions, to regulate quality, and to ensure that members adhere to standards of professional conduct.<sup>45</sup> This form of regulation is justified on the basis that health professionals are more likely to comply with standards and disciplinary procedures that are administered by their own qualified peers.<sup>46</sup> But self-regulation, as a form of regulation, is increasingly criticized for failing to protect the public from harm.<sup>47</sup> In recent years, there have been increasing reports of a “dramatic erosion in the public’s confidence in professional self-regulation.”<sup>48</sup> Self-regulating professions are more frequently accused of having a conflict of interest and “an inappropriate unwillingness to report or act upon the incompetent or unethical behavior of colleagues.”<sup>49</sup> Another criticism made of self-

<sup>41</sup> See Part II.A.2. (“Civil Liability”), below.

<sup>42</sup> See e.g. Canadian Medical Association, *Code of Ethics* (Ottawa: The Association, 1990).

<sup>43</sup> See Part II.A.1. (“Self-Regulation”), below.

<sup>44</sup> The regulation of occupations and professions is a provincial responsibility under subsection 92(13) of the *Constitution Act, 1867*, *supra* note 17.

<sup>45</sup> See, in Ontario, the *Regulated Health Professions Act, 1991*, S.O. 1991, c. 18.

<sup>46</sup> For a discussion of self-regulation, see Linette McNamara, Erin Nelson & Brent Windwick, “Regulation of Health Care Professionals” in Jocelyn Downie, Timothy Caulfield & Colleen M. Flood, eds., *Canadian Health Law and Policy*, 2d ed. (Markham: Butterworths, 2002) 55 at 73-80. For a discussion of different models of self-regulation, see Margot Priest, “The Privatization of Regulation: Five Models of Self-Regulation” (1997-98) 29 *Ottawa L. Rev.* 233.

<sup>47</sup> For example, over 300 submissions were submitted to the Ontario Ministry of Health and Long-Term Care during the course of a review of the *Regulated Health Professions Act*, *supra* note 45, by the Health Professions Regulatory Advisory Council in October 1999. A great number of the submissions expressed concern about the ability of regulated professions to protect the public from harm. As the extracts were viewed on an anonymous basis, it is not possible to give precise references for each submission; however, the extracts are on file with the authors.

<sup>48</sup> Timothy Stoltzfus Jost, “Oversight of the Quality of Medical Care: Regulation, Management, or the Market?” (1995) 37 *Ariz. L. Rev.* 825 at 835.

<sup>49</sup> Manitoba Law Reform Commission, *Discussion Paper: The Future of Occupational Regulation in Manitoba* (Winnipeg: Law Reform Commission, 1993) at 42. In Ontario, the Health Professions Appeal and Review Board (“HPARB”) deals with reviews of Complaints Committees’ decisions (such committees being established by the various professional colleges) under the *Regulated Health*

regulatory systems is that many patients do not know where to make complaints or about what they are entitled to complain.<sup>50</sup> Even when complaints are made, a recent survey shows that a large percentage of Canadians who had lodged a complaint against a health care provider were not satisfied with the attention it was given.<sup>51</sup>

A complex interaction of decisions goes into ensuring safety and the delivery of high quality care. Mistakes made by doctors or nurses are often only part of the problem. An important contributing factor is the quality of management within a system. The vital importance of management, in particular, reporting and communications systems has been demonstrated by high-profile tragedies, such as the deaths of twelve infants in the Winnipeg pediatric-cardiac program<sup>52</sup> and the deaths of twenty-nine children at the Bristol Royal Infirmary in the UK.<sup>53</sup> Quality of care is also

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*Professions Act*, supra note 47. The HPARB was established pursuant to the *Ministry of Health Appeal and Review Boards Act, 1998*, S.O. 1998, c.18, Sch. H, ss. 1-4. The HPARB does not investigate complaints, but will review whether an investigation by a Complaints Committee was adequate and whether the decision reached was reasonable. The HPARB has an entirely lay composition and its independent review of the decision-making process provides some comfort, but it is only useful to the extent that complaints are made in the first instance, and it does not fully address the issue of the public's lack of confidence in self-regulatory systems.

<sup>50</sup> A study carried out by PricewaterhouseCoopers in 1999 found that 38 per cent of people surveyed were "not at all certain" about where to launch a complaint regarding sexual misconduct by a health professional: PricewaterhouseCoopers, *Evaluation of the Effectiveness of the Health Professional Colleges' Complaints and Discipline Procedures with Respect to Professional Misconduct of a Sexual Nature and Status of the Colleges* (Toronto: PricewaterhouseCoopers, July 1999). A more recent national survey of Canadians by IBM Business Consulting Services found that when asked where they thought they could lodge a complaint about the health services they had received, almost four in ten Canadians said they did not know. *Survey No. 8*, supra note 18. This contrasts, for example, with the code of patients' rights in New Zealand, where the Health and Disability Commissioner has taken extensive action to advertise the code and the related complaints procedure, and to educate the public on how to make a complaint, including posters and brochures in doctors' waiting rooms and hospital waiting rooms as well as media advertising. The case of New Zealand is discussed below, in Part III.C.

<sup>51</sup> *Survey No. 8*, *ibid.*

<sup>52</sup> Associate Chief Judge Murray Sinclair, led a three-year inquest, from 1995 to 1998, into the deaths of 12 infant cardiac patients in Winnipeg. He found that the program was inadequately supervised; there was a quality-assurance and monitoring failure at the hospital; nurses' legitimate concerns were not taken seriously and the hospital did not provide an appropriate standard of care. "Sinclair ruled that 5 of the deaths at the Winnipeg Health Sciences Centre in 1994 involved some form of mismanagement, surgical error or misadventure, and were at least possibly preventable. He also ruled that another 3 infants might have lived had they been referred to a larger hospital for treatment, that 3 deaths could not be explained and that only 1 death had an acceptable explanation" (Barbara Sibbald, "Winnipeg Inquest Recommendation Could Leave Young MDs in Lurch, Expert Warns" (2001) 164 CMAJ 393 at 393).

<sup>53</sup> An inquiry into the deaths "concluded that a 'poisoned' atmosphere between managers, surgeons, anaesthetists and nurses led to a 'Greek tragedy' of events in which problems were neither identified nor resolved. The hospital's cardiac unit was described as a 'closed world' in which those who raised concerns were ignored and later threatened" (Felicity Morgan, "Children Perished in 'Culture of Secrecy'; Bristol Royal Infirmary Inquiry: Report Makes Nearly 200 Recommendations" *Western Mail* (19 July 2001) 5 at 5).

indirectly linked to resource allocation decisions made by Health Canada, provincial ministries of health, private insurers, and regional health authorities. Self-regulation does nothing to ensure the competence of these kinds of decision-makers, and the professional colleges only have the power to investigate the actions of individual members of their professions as opposed to the actions of hospitals, other institutions,<sup>54</sup> or health care funders and/or managers.

## 2. Civil Liability

The threat of medical malpractice litigation ostensibly provides incentives to health professionals to provide care of an adequate quality. The incentive structure, however, is far from perfect, given evidence that a great many incidences of malpractice go unchallenged in the courts. In the famous Harvard study in 1991,<sup>55</sup> the researchers reviewed medical records from over 30,000 hospital discharges and 3,500 malpractice claims in New York. The researchers found that there were 7.6 times as many injuries as there were claims. But it was the matching of specific claims to specific injuries in New York that threw the troubling relationship between malpractice claims and injuries into sharp relief: on the one hand, only two per cent of apparently negligent injuries resulted in claims, but on the other hand, only seventeen per cent of claims appeared to involve a negligent injury. These results have been replicated in other studies.<sup>56</sup> In other words, many legitimate claims are not made, and many of the claims made are not legitimate. Notwithstanding this evidence (albeit from the US), Canada's Prichard report in 1990 concluded that on balance, the threat of medical malpractice claims contributes to improving the quality of health care provided and reducing the frequency of avoidable health care injuries in Canada.<sup>57</sup> Prichard also stressed, however, that efforts must be made to increase and improve redress mechanisms, particularly complaint and discipline procedures.<sup>58</sup>

One in twenty-five Canadian physicians was named in a new legal action in 2000, and the number of malpractice cases proceeding to trial doubled between 1995 and 1999.<sup>59</sup> Ironically, the fact that litigation against physicians is on the increase is often

<sup>54</sup> This problem was identified by a number of the submissions to the Health Professions Regulatory Advisory Council. See *supra* note 47.

<sup>55</sup> A.R. Localio *et al.*, "Relation Between Malpractice Claims and Adverse Events Due to Negligence: Results of the Harvard Medical Practice Study III" (1991) 325 *New Eng. J. Med.* 245.

<sup>56</sup> See *e.g.* Eric J. Thomas *et al.*, "Incidence and Types of Adverse Events and Negligent Care in Utah and Colorado" (2000) 38 *Med Care* 261.

<sup>57</sup> J. Robert Prichard, *Liability and Compensation in Health Care: A Report to the Conference of Deputy Ministers of Health of the Federal/Provincial/Territorial Review on Liability and Compensation Issues in Health Care* (Toronto: University of Toronto Press, 1990) at 4.

<sup>58</sup> *Ibid.* at 24.

<sup>59</sup> See Susan Lightstone, "Class-Action Lawsuits Medicine's Newest Legal Headache" (2001) 165 *CMAJ* 622. This is not a new trend: between 1971 and 1990 the number of medical malpractice claims filed per 100 Canadian doctors increased from 0.55 to 1.7 (see Don Dewees, David Duff &

used as an argument that the present system is unsustainable and needs to be reformed—but this increase has to be put in context, since extrapolation from the US data suggests that the vast majority of patients do not pursue claims when they are the victim of negligent treatment. The reasons for this failure to litigate are numerous and include the time, stress, and costs involved, perceptions of the chances of success, discomfort with power imbalances, and failure to realize that a medical error has been made.<sup>60</sup> Apart from the fact that litigation only provides compensation to a very few patients, many have argued that the threat of litigation is not the best way to ensure high quality care and that a better system would allow physicians, nurses, and other health care professionals to disclose their errors without fear of legal reprisals.<sup>61</sup>

Physicians have, on occasion, tried to defend themselves against claims of malpractice by arguing that they had inadequate resources because of rationing decisions made by funders and managers. The courts are generally unsympathetic to such claims. For example, Justice Spencer in *Law Estate v. Simice* said “that if it comes to a choice between a physician’s responsibility to his or her individual patient and his or her responsibility to the medicare system overall, the former must take precedence in a case like this.”<sup>62</sup> In reality, however, physicians must make decisions that balance the needs of their own and other patients every day. The resources they have to work with and the efficiency of the systems in which they work undoubtedly influence the decisions and choices they make. But there has never been a successful tort action in Canada against a governmental authority regarding rationing decisions or incompetent management. This lack of success is largely due to the difficulties of launching a civil action against a government, since true policy decisions (as opposed to operational functions) are exempt from tort claims,<sup>63</sup> as well as to the difficulties in establishing causation (i.e., that on the balance of probabilities, one or more of the many decisions made *caused* the harm suffered by a patient).

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Michael J. Trebilcock, *Exploring the Domain of Accident Law: Taking the Facts Seriously* (New York: Oxford University Press, 1996) at 95-96.

<sup>60</sup> In a recent study of patients’ and physicians’ attitudes towards the disclosure of medical errors, a number of physicians said that fear of litigation limits what they tell patients about errors that have occurred: Thomas H. Gallagher *et al.*, “Patients’ and Physicians’ Attitudes Regarding the Disclosure of Medical Errors” (2003) 289 JAMA 1001. See also Michelle M. Mello & Troyen A. Brennan, “Deterrence of Medical Errors: Theory and Evidence for Malpractice Reform” (2002) 80 Tex. L. Rev. 1595.

<sup>61</sup> For an argument in favour of no-fault accident compensation, see Robert E. Astroff, “Show Me the Money!: Making the Case for No-Fault Medical Malpractice Insurance” (1997) 5:3 Health L. Rev. 9; *contra* Lewis N. Klar, “Tort and No-Fault” (1997) 5:3 Health L. Rev. 2.

<sup>62</sup> (1994), 21 C.C.L.T. (2d) 228 at 260, 17 B.C.L.R. (3d) 1 (B.C.S.C.).

<sup>63</sup> See *Brown v. British Columbia (Minister of Transportation and Highways)*, [1994] 1 S.C.R. 420, 89 B.C.L.R. (2d) 1; *Swinamer v. Nova Scotia (A.G.)*, [1994] 1 S.C.R. 445, 129 N.S.R. (2d) 321. See also Peter Hogg & Patrick J. Monahan, *Liability of the Crown*, 3d ed. (Toronto: Carswell, 2000) at 171.

### 3. Internal Complaints Mechanisms

A number of health care institutions have internal codes or bills of rights articulating the standard of services that patients can expect to receive. For example, the University Health Network in Toronto has a "Patient Bill of Rights and Responsibilities" that includes the right to be treated in a considerate and respectful manner that considers the patient's privacy and right to confidentiality.<sup>64</sup> In those provinces that have regionalized systems, some regional authorities have also articulated patients' rights (and responsibilities). In Saskatchewan, for example, the Saskatoon Health Region stipulates the rights of the client/patient, including the right to receive reasonable explanations about one's care; to agree to, or refuse, any procedure or medical treatment, except as specified by law; and to request a second medical opinion.<sup>65</sup>

A number of institutions and health regions also maintain an internal complaints mechanism to provide patients with an opportunity to express and resolve their concerns.<sup>66</sup> These are positive initiatives, helping to have patients' concerns dealt with promptly. As they are voluntary initiatives, however, there is variation in the nature of the rights granted and the level of enforcement. Furthermore, patients may view internal complaints mechanisms as lacking independence and impartiality. There is thus a strong argument for a supervisory appeal body to which a patient could turn if dissatisfied with how a health care institution has dealt with a complaint and for legislation establishing minimum standards and levels of enforcement to apply to all providers.

### 4. Conclusion: The Benefits of a Patients' Bill of Rights *in* Health Care?

Together, the various mechanisms discussed above make up a system of patient protection for rights *in* health care, but the system is not seamless and has a number of problems. Self-regulation increasingly is viewed as lacking sufficient independence and as being unresponsive to patients' needs. Civil litigation is costly, time-consuming, and arbitrary as to whom it punishes and compensates. Voluntary steps

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<sup>64</sup> University Health Network, "Patient Bill of Rights and Responsibilities", online: University Health Network <[http://www.uhn.ca/patient/patient\\_relations/rights\\_responsibilities.asp](http://www.uhn.ca/patient/patient_relations/rights_responsibilities.asp)>.

<sup>65</sup> Saskatoon Health Region, "Patient Advocate", online: Saskatoon Health Region <[http://www.saskatoonhealthregion.ca/your\\_health/patient\\_advocate.htm](http://www.saskatoonhealthregion.ca/your_health/patient_advocate.htm)>.

<sup>66</sup> See *e.g.* University Health Network, *supra* note 64, and Toronto's Mt. Sinai Hospital, online: Mt. Sinai Hospital <[www.mtsinai.on.ca](http://www.mtsinai.on.ca)>. Mt. Sinai Hospital, also in Toronto, maintains a Patient Relations Facilitator to resolve any problems. Patients are encouraged to address any questions or concerns directly with the people involved in their case, but if they feel that a matter requires further attention, they may contact the Patient Relations Facilitator. The Saskatoon Health Region has Client Representatives who are available to help ensure that patients are aware of their rights and options and use patients' feedback to recommend changes or improvements to enhance the quality of health services. See Saskatoon Health Region, *ibid.*

taken by institutions and/or health regions to address complaints, while laudable and indeed desirable, are piecemeal and lack the objectivity of independent review. A patients' bill of rights, monitored and enforced by an independent ombudsperson or commissioner, provides the prospect of addressing some of the problems of enforcing patients' rights *in* health care by offering relatively inexpensive, low-level, and independent resolution of disputes. As we discuss below, however, the concerns we have about our present system of protecting patients' rights *in* health care pale in comparison to the problems associated with the very few available avenues of recourse for ensuring patients' rights *to* access quality care in a timely fashion.

## **B. Rights to Health Care**

Many Canadians are surprised to find out that there is no free standing right in Canadian law *to* receive health care.<sup>67</sup> The *Canada Health Act*<sup>68</sup> is an icon of Canadian citizenship, but in technical terms, it only sets out conditions with which provincial governments must comply in order to receive federal funding assistance. Nonetheless, the ten provincial governments have established universal health insurance programs. Having done so, these governments expose themselves to legal duties in terms of how they administer their respective public programs. There are two main routes to having government decisions regarding rights to health care reviewed. The first route requires invoking the Charter. The most prominent recent cases are *Eldridge v. British Columbia (A.G.)*,<sup>69</sup> *Cameron v. Nova Scotia (A.G.)*,<sup>70</sup> *Chaoulli c. Québec (P.G.)*,<sup>71</sup> and *Auton v. British Columbia (Minister of Health)*.<sup>72</sup> The second route is through judicial review of administrative decisions.

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<sup>67</sup> Section 7 of the *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act, 1982* (U.K.), 1982, c. 11, has been invoked to claim a right to health care. Canadian courts have not ruled definitively on the issue; it appears unlikely, however, that they will interpret the right to life protected by section 7 as including a positive right to health care. See Canadian Bar Association, *What's Law Got to Do with It?: Health Care Reform in Canada* (Ottawa: The Canadian Bar Association, 1994) at 19-26.

<sup>68</sup> R.S.C. 1985, c. C-6.

<sup>69</sup> [1997] 3 S.C.R. 624, 38 B.C.L.R. (3d) 1 [*Eldridge*].

<sup>70</sup> (1999), 204 N.S.R. (2d) 1, 177 D.L.R. (4th) 611 (N.S.C.A.) [*Cameron*].

<sup>71</sup> [2000] R.J.Q. 786, [2000] J.Q. No. 479 (QL) (Sup. Ct.) [*Chaoulli*], aff'd [2003] J.Q. no 4 036 (QL) (C.A.).

<sup>72</sup> (2000), 78 B.C.L.R. (3d) 55, 2000 BCSC 1142 [*Auton*]. Note that leave to appeal to the Supreme Court of Canada has been granted to the plaintiff in *Auton* and that the appeal was heard on 9 June 2004: see *infra* note 77. A number of provinces have submitted notices of intervention respecting the constitutional questions to be decided in the appeal, namely, Alberta, Saskatchewan, Newfoundland, Quebec, Ontario, Manitoba, and New Brunswick. The constitutional questions concern whether the definitions of "benefits" and "health care practitioners" in section I of the *Medicare Protection Act*, R.S.B.C. 1996, c. 286, and ss. 17-29 of the *Medical and Health Care Services Regulation*, B.C. Reg. 426/97, infringe sections 7 and 15(1) of the Charter by failing to include services for autistic children based on applied behavioural analysis.



## 1. Charter Cases

Generally, Charter cases involve challenges to a provincial government's refusal to publicly fund a particular treatment. In *Eldridge*, the Supreme Court of Canada held that the British Columbia government discriminated against deaf patients in refusing to fund sign language interpreters in public hospitals.<sup>73</sup> *Cameron* concerned the Nova Scotia government's decision not to fund male infertility treatments. The Nova Scotia Court of Appeal ruled that the government had discriminated against the infertile plaintiff but that this decision was saved under section 1 of the Charter (that is, as a reasonable limit prescribed by law and demonstrably justified in a free and democratic society) because of the high cost of fertility treatments.<sup>74</sup> Leave to appeal to the Supreme Court was denied.<sup>75</sup> In *Auton*, the British Columbia Supreme Court held that the British Columbia government discriminated against autistic children by refusing to fund certain treatments and that this action was not saved by section 1 of the Charter.<sup>76</sup> This decision was affirmed by the British Columbia Court of Appeal but is being appealed to the Supreme Court of Canada.<sup>77</sup>

Apart from Charter cases challenging a provincial government's failure to publicly fund treatments, there is at least one case challenging restrictions on private financing for treatment in private hospitals and for physician services.<sup>78</sup> *Chaoulli* involved a challenge to the Quebec government's prohibition on private health insurance for services covered by the public plan.<sup>79</sup> The plaintiff physician (Mr. Chaoulli) and his patient (Mr. Zelotis) wished to provide and receive private medical services of the kind ostensibly covered by the public plan but for which there were waiting lists. They argued that patients have a constitutional right to pay privately for certain services, such as hip surgery. The Quebec Superior Court agreed that there were serious gaps and deficiencies in Quebec's health care system and found that the prohibitions against private insurance did violate the plaintiff's rights of liberty and security of the person as guaranteed by section 7 of the Charter. After balancing the individual's right to choose and access necessary health care services against the collective goal of ensuring equal access to all, however, the court found these violations to be in accordance with fundamental justice, and thus not in violation of section 1 of the Charter. At the Quebec Court of Appeal, Justice Delisle found that

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<sup>73</sup> *Eldridge*, *supra* note 69.

<sup>74</sup> *Cameron*, *supra* note 70.

<sup>75</sup> Leave to appeal to the Supreme Court denied 29 June 2000 without reasons: [2000] 1 S.C.R. viii, [1999] S.C.C.A. No. 531 (QL).

<sup>76</sup> *Auton*, *supra* note 72.

<sup>77</sup> *Auton v. British Columbia* (2002), 220 D.L.R. (4th) 411, 2002 BCCA 538, leave to appeal to S.C.C. granted [2003] 1 S.C.R. vi, [2002] S.C.C.A. No. 510 (QL).

<sup>78</sup> Canada is unique among developed countries in effectively restricting the development of a two-tier system that would allow those with private resources or insurance to purchase quicker or better care in the private sector. For a complete discussion, see Colleen M. Flood & Tom Archibald, "The Illegality of Private Health Care in Canada" (2001) 164 CMAJ 825.

<sup>79</sup> *Chaoulli*, *supra* note 71.

section 7 was not breached at all, as the right to enter into contracts for private insurance is an economic right that is not protected by section 7. Moreover, to be successful in a section 7 claim, an applicant must demonstrate an actual or imminent breach of his or her right, and in this case, the appellant's right was not at risk. Justice Brossard concurred with Justice Delisle, finding that neither life, liberty, nor security of the person was jeopardized and, moreover, that elimination of the right to enter into a private insurance contract, as provided for in Quebec legislation, is an economic right, which, in itself and isolated from its potential consequences, is not fundamental to one's life. By comparison, Justice Forget found that there was a breach of section 7, but like Justice Piche of the Superior Court, found that the breach of section 7 was in accordance with the principles of fundamental justice. Leave to appeal this case to the Supreme Court was granted and the case was heard on 8 June 2004.<sup>80</sup>

Although, historically, patients have had difficulty in persuading courts that the Charter should operate to afford rights to health care, there are hints from both *Auton* and *Eldridge* that future litigants will be more successful. One could limit the precedent of *Eldridge* with an argument that the hearing impaired plaintiffs were not asking for any *new* health care good or service, but for the *means* (interpretation services) to utilize medical services to which all similarly situated patients without a hearing impairment were entitled. But in *Auton*, the British Columbia Supreme Court expressly rejected this means of limiting the precedent of *Eldridge*. Nevertheless, the relatively modest victories of a few patients and the expense and delay inherent in Charter litigation mean that recourse to the Charter remains an unsatisfactory way to deal with *most* grievances and concerns regarding access to health care. Moreover, although the Charter can, in certain circumstances, address explicit rationing decisions by governments (for example, failing to fund a particular service or delisting a particular service), it has far less capacity to challenge the multitude of resource allocation decisions made in the health care system every day. In other words, while the Charter can protect against explicit governmental decisions that openly deny or prevent access to a particular treatment, most decisions are not explicit and have only an indirect effect on the availability of care.

## 2. Administrative Tribunals and Judicial Review

In Ontario, there is an arm's-length administrative tribunal that will hear patients' claims that the provincial insurance plan should fund particular treatments.<sup>81</sup> A high profile case recently heard by the tribunal involved a successful claim to publicly fund

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<sup>80</sup> [2003] 1 S.C.R. vii, [2002] S.C.C.A. No. 280 (QL).

<sup>81</sup> The Health Services Appeal and Review Board (*Ministry of Health Appeal and Review Boards Act, 1998*, *supra* note 49) in Ontario is an independent quasi-judicial tribunal that conducts hearings pursuant to a number of statutes, including the *Health Insurance Act*, R.S.O. 1990, c. H.6. Appeals may be brought under the *Health Insurance Act* against a refusal by the General Manager of the Ontario Health Insurance Plan to pay for health care services.

a genetic test for the BRCA1 gene.<sup>82</sup> The patient needed this test to determine whether she was genetically predisposed to breast cancer and thus whether she needed to take radical preventive measures (indeed the genetic test ultimately revealed that she did not carry the gene and the double mastectomy was not called for). Independent administrative tribunals, like the Health Services Appeal and Review Board in Ontario, can provide an outlet for patients’ concerns about the breadth of publicly funded schemes. Providing avenues of appeal to an administrative tribunal about what services should and should not be publicly funded has the distinct advantage over expensive and protracted Charter litigation that many more people will be able to have their cases (and concerns) heard.<sup>83</sup> Additionally, the existence of an administrative appeal does not preclude a patient from seeking judicial review in the regular courts on the grounds that a fair process was not followed or that the decision was unreasonable in the circumstances.<sup>84</sup> Moreover, the existence of an appeal route to an administrative tribunal need not open the floodgates for discontented patients to make claims; much will depend on how the grounds for appeal are framed. Of the 155 cases heard in 2000, the Ontario Health Services Appeal and Review Board only upheld a patient’s claim seventeen times.<sup>85</sup>

Despite its advantages, however, establishing an administrative tribunal will not cure all of the problems associated with civil litigation. Appearing before a tribunal still requires a patient to make a challenge in a relatively adversarial environment and to muster both time and resources (both of which are in short supply in a period of ill health). Moreover, these administrative mechanisms do not result in any systemic incentives for decision-makers to take seriously citizens’ concerns regarding timeliness of care.

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<sup>82</sup> See Carolyn Abraham, “Tenacious Woman Scores Medical Victory” *The Globe and Mail* (27 August 1999) A1.

<sup>83</sup> There is always, of course, a role for a Charter challenge as a safety net in addition to any administrative means of review. The Ontario Health Services Review and Appeal Board considers that it has jurisdiction to consider Charter challenges. On 6 September 2001, it released its decision in *L.H. v. The General Manager* (A.G. Ontario, intervener) (Board file S.6492), on a motion brought by the Ontario Health Insurance Plan asking the board to rule upon its jurisdiction to consider the constitutional validity of a schedule to the *Health Insurance Act*, *supra* note 81. The board concluded that it does have Charter jurisdiction. Indeed, the board had already been of that opinion. Under its *Rules of Practice and Procedure* (adopted 22 September 2000), there was provision under Rule 11 for bringing notice of a constitutional question to the board. A court will, however, review the board’s decision on a Charter matter if it is not correct, whereas it may be deferential on other decisions and not overturn the decision so long as it is reasonable. Subsection 6(3) of the *Ministry of Health Appeal and Review Boards Act, 1998*, as am. by *Government Efficiency Act, 2002*, S.O. 2002, c. 18, Sch. I, s. 16, now provides that the board “shall not inquire into or make a decision concerning the constitutional validity of a provision of an Act or a regulation.”

<sup>84</sup> How much deference a court will accord to an administrative tribunal depends on the facts of each case; the standard of review can range from a standard of correctness (the least deferential) through reasonableness simpliciter to patent unreasonableness (the most deferential).

<sup>85</sup> Review of the Health Services Appeal and Review Board files, 26 October 2001, by a student at the Faculty of Law, University of Toronto.

### 3. Rights to Timely Treatment?

We have yet to see a Charter case on the right of a patient to access publicly funded health care in a timely fashion. The *Chaoulli* case mentioned above will, for the first time, raise the question, albeit indirectly, of whether Canadians have a right to timely treatment and if instances of failure to treat in a timely fashion are justified, given the larger redistributive agenda of publicly funded medicare. *Chaoulli* will also have to address whether or not a right to purchase private insurance and avoid waiting should trump the goal of universal one-tier health insurance.<sup>86</sup>

A world away from Charter challenges before the Supreme Court is administrative review by tribunals like the Ontario Health Services Appeal and Review Board, which hears requests for out-of-country treatment where care is not available in a timely way. The delay must, however, be said to “result in death or medically significant irreversible tissue damage.”<sup>87</sup> So in *extreme* cases, if a patient can demonstrate that failure to provide timely care is likely to put him or her in significant peril, he or she may be able to claim public funding for out-of-country treatment. This situation is a very narrow window of redress, however, and Ontario is currently the only province with an independent administrative tribunal empowered with this jurisdiction.<sup>88</sup>

General administrative law may also, in extreme cases, provide a remedy to patients who have had to wait too long for treatment. To our knowledge, the first Canadian example of this is the Quebec Superior Court case of *Stein v. Québec (Régie de l'Assurance-maladie)*.<sup>89</sup> In that case, Mr. Stein's doctors warned him that his life was in danger and that he should be operated on as soon as possible but no later than four to eight weeks from the date of detection of cancerous lesions in his liver. He waited for three and a half months for a surgery date, and at the end of this period, a date had not been set. Using his own money, Mr. Stein went to New York to buy the treatment he needed and then sought to challenge the Quebec Health Insurance Board

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<sup>86</sup> While we support waiting time guarantees (see below), the goal should be, in our view, to improve the quality of the publicly funded health care system, not to privatize. One of us has expressed elsewhere her opposition to the Charter Challenges in the *Chaoulli* case. See Colleen M. Flood, Comment, “Two-tier Medicine Isn't the Answer” *The National Post* (21 June 2004) 10. See *contra* Margaret Sommerville, Comment, “Getting Past the Myth of Medicare” *The National Post* (21 June 2004) 10.

<sup>87</sup> See R.R.O. 1990, Reg. 552, s. 28.4(2)(b)(ii) [R.R.O. 1990].

<sup>88</sup> British Columbia and Alberta also have tribunals that hear requests for out-of-country treatments but these tribunals are not independent in the sense that government officials save on them. Alberta's Out-of-Country Health Services Committee (established by s. 28.01(1) of the *Alberta Health Care Insurance Regulation*, Alta. Reg. 216/81) reviews, evaluates, and makes decisions pertaining to funding applications for the costs associated with medical, hospital, and/or oral surgical services received out of the country. There is also an Appeal Panel, established by s. 28.05(1) of Alta. Reg. 216/81. Members of both the committee and appeal panel are appointed by the Minister of Health and Wellness.

<sup>89</sup> [1999] R.J.Q. 2416, [1999] Q.J. No. 2724 (QL).

officials’ refusal to pay for his treatment. The court indicated that it should apply the most deferential standard of review to the board’s decision, namely, patent unreasonableness. Even on that very deferential standard, however, the board’s decision was overturned.

As can be observed from the preceding discussion, patients who have concerns about accessing timely care have only very limited forms of redress before the courts: demonstrating that a decision not to publicly fund out-of-country treatment was patently unreasonable or, in Ontario, that the waiting time would have caused “death or medically significant irreversible tissue damage.”<sup>90</sup> In many cases, patients will be in a situation where there are significant risks (and severe psychological stress) in waiting for treatment, but where it is difficult to show conclusively that waiting will put the patient in extreme peril. Moreover, requiring patients to initiate and make out cases in this regard, when they are unwell and in need of care, imposes a very high barrier to claims being made. Mr. Stein was able to pay the out-of-pocket expenses for the care he needed in New York and then subsequently seek reimbursement. Most patients will not be so fortunate. Finally, the fact that the law provides such limited means of redress even in extreme cases does little to inculcate systemic incentives for decision-makers to take citizens’ concerns regarding timeliness of care seriously.

Realizing rights to access timely treatment requires us to look beyond the clinical patient-provider relationship and examine decision-making throughout the entire health care system. The management and funding of the health care system play a crucial part in determining whether patients’ needs are met and services are provided in a timely fashion. For example, a recent study published in the *New England Journal of Medicine* found that Ontario patients with certain medical conditions were more likely to die when they were admitted to hospital on a weekend rather than a weekday. The reasons given for this phenomenon were lower staffing levels in acute care hospitals on weekends, as well as higher numbers of staff who were less experienced, managed by fewer supervisors, and covering for more absent staff.<sup>91</sup> In Saskatoon, the city’s only pediatric general surgeon has recently expressed his concerns that an improper allocation of resources is resulting in Saskatoon children waiting fifteen months for elective surgeries, whereas in most cities, children could expect to wait less than ten weeks.<sup>92</sup> These problems, we submit, cannot be addressed by establishing and enforcing rights *in* health care and reviewing physician decision-making. Rather, what is required is the establishment of rights to access timely health care in the public sector.

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<sup>90</sup> R.R.O. 1990, *supra* note 87.

<sup>91</sup> See Chaim M. Bell & Donald A. Redelmeier, “Mortality Among Patients Admitted to Hospitals on Weekends as Compared with Weekdays” (2001) 345 *New Eng. J. Med.* 663.

<sup>92</sup> See Jason Warick, “Saskatoon Kids Wait for Surgery” *The Leader Post* (18 September 2001) A4.

### III. Lessons from Different Jurisdictions

We now turn to an examination of the experiences of different jurisdictions in implementing a patients' bill of rights, particularly focusing on those jurisdictions where rights have been established to access health care services in a timely fashion. The jurisdictions we consider are Quebec, the US, New Zealand, the UK, Spain, Sweden, and Italy. Comparing the experiences of jurisdictions that have implemented patients' rights legislation allows us to identify the key features of a scheme that would most effectively achieve recognition and enforcement of patients' rights, including the right to access health care in a timely manner.

#### A. Quebec, Canada

In the province of Quebec, users' rights *in* and *to* health care are set out in legislation put in place in 1991.<sup>93</sup> This legislation established the Complaints Commissioner to oversee the enforcement of patients' rights and to whom appeals could be made from decisions rendered by regional boards regarding patients' complaints.<sup>94</sup> New legislation, which came into force between January and April 2002, replaced the commissioner with a Health and Social Services Ombudsman ("the Ombudsman") with greater powers to enforce patients' rights.<sup>95</sup>

The new act gives the Ombudsman power, in certain circumstances, to directly intervene if there are reasonable grounds to believe that the rights of a natural person or a group of natural persons have been, or may likely be, adversely affected by an act or omission, including that of any institution or regional board, or of any person working for such a body.<sup>96</sup> The Ombudsman has the general power to see to it, "by any appropriate means", that users are respected and that their rights are enforced.<sup>97</sup> The Ombudsman's main function is the examination of complaints by users regarding the health services or social services the user received, ought to have received, is receiving, or requires. When a complaint relates to a physician, dentist, or pharmacist, however, the complaint is not heard by the Ombudsman but through an alternative procedure involving a medical examiner designated by the board of directors of the

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<sup>93</sup> See *Health Services Act*, *supra* note 7, ss. 4-16.

<sup>94</sup> *Ibid.*

<sup>95</sup> See *Ombudsman Act*, *supra* note 8.

<sup>96</sup> The Ombudsman may intervene if, in his or her opinion,

recourse to the process provided for in [the relevant legislation] would likely be compromised, serve no purpose or be illusory, either owing to possible reprisals against the person or group of persons concerned, the special vulnerability or abandonment of the targeted clientele, or in any other case which, in the opinion of the Ombudsman, warrants an immediate intervention of the Ombudsman, especially where problems may interfere with the well-being of users and the recognition and enforcement of their rights (*ibid.*, s. 20).

<sup>97</sup> *Ibid.*, s. 7.

institution, facility, or centre where the patient was treated.<sup>98</sup> The Ombudsman also has the responsibility of ensuring that institutions and regional boards handle the complaints addressed to them in conformity with the procedures set out in the act.<sup>99</sup> The 2002 amendments also aim to speed up the handling of user complaints by establishing an examination process that consists of only two levels instead of three.<sup>100</sup>

While the 2002 amendments in the *Ombudsman Act* provide for important procedural changes in enforcing patients' rights in Quebec, they do not significantly change the content of patients' rights. The *Health Services Act* specifies that health services and social services should be offered "with continuity and in a personalized and safe manner," and that they should be "scientifically, humanly and socially appropriate."<sup>101</sup> That act provides for rights in health care, such as the right to give consent to treatment and to participate in any decision affecting one's state of health or welfare. Users' rights also include some limited rights to health care. Section 7 provides that "[e]very person whose life or bodily integrity is endangered is entitled to receive the care required by his condition. Every institution shall, where requested, ensure that such care is provided."<sup>102</sup> There is, however, no specific right to receive timely treatment. Moreover, section 13 of the act also leaves open the prospect of providers, institutions, and boards defending inadequate treatment by arguing that such inadequacies were due to limited resources.<sup>103</sup>

In sum, the Quebec system is worthy of examination, as it provides an accessible forum in which patients can make complaints to health care institutions and regional boards.<sup>104</sup> With recent amendments, the system is now less complex than that first introduced in 1991 and provides an opportunity to resolve both specific users' complaints and more systemic concerns, as well as a mechanism for appeal to an independent body. The success of the legislation will depend in large measure on how vigorous the new Ombudsman enforces it. The extent to which the Ombudsman will

<sup>98</sup> See *Health Services Act*, *supra* note 7, s. 42.

<sup>99</sup> See *Ombudsman Act*, *supra* note 8, s. 7.

<sup>100</sup> The 1991 legislation provided for a three-tier complaint procedure that required complaints to be made to institutions, then to regional boards, and finally to the Complaints Commissioner. To achieve a two-tier complaint procedure, the new act provides for the appointment of regional service quality commissioners and local service quality commissioners who are to exercise the first level of jurisdiction over complaints regarding services or activities coming under their authority. The Ombudsman constitutes the second and final level. See generally *Health Services Act*, *supra* note 7, ss. 29-40, 60-72; *Ombudsman Act*, *ibid.*, s. 8.

<sup>101</sup> *Health Services Act*, *ibid.*, s. 4.

<sup>102</sup> *Ibid.*, s. 7.

<sup>103</sup> Section 13, *ibid.*, provides that "[t]he 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" [emphasis added].

<sup>104</sup> Section 60, *ibid.*, sets out the circumstances in which a complaint may be addressed directly to the regional service quality commissioner of a regional board.

be proactive may in turn be tied to the degree of independence he or she has from government. Concern has been expressed that the position of Health and Social Services Ombudsman is not as independent as it could be, given that the Ombudsman remains answerable to the Minister of Health and Social Services and not to the National Assembly.<sup>105</sup> The legislation is also limited by the fact that the complaints process only applies to public institutions (or to those partly publicly financed) and not to private facilities and, as mentioned above, that it does not provide any specific right to timely treatment.<sup>106</sup>

## B. United States

Over the last decade, the US has been swept by a managed care revolution. Private insurance companies now manage the delivery of care by physicians and control costs through direct and indirect mechanisms and incentives. In response to grave concerns about the limits placed on care by managed care companies, there has been a flurry of federal and state legislation aimed at protecting those with insurance from limitations on access to, and diminishment in, quality of health care. These measures do not generally seek to expand the number of people covered by private insurance (approximately 16.3 per cent of US citizens, mainly the working poor, have no health insurance<sup>107</sup>), but rather constitute a set of consumer rights protecting those who already have private insurance or government-sponsored insurance.

*Explicit* rationing by managed care plans regarding the scope of coverage, duration of benefits, premiums, and choice of providers is regulated—mostly at the state level—by legislative minimum standards,<sup>108</sup> as well as by “patients’ bills of rights” in a number of states.<sup>109</sup> In 1996, the US federal government enacted the *Health Insurance Portability and Accountability Act*.<sup>110</sup> This act does not tackle the problem of the uninsured in the system, but does make some attempt to prevent

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<sup>105</sup> See Québec Ombudsman, Press Release, “Bill on the Health and Social Services Ombudsman: The Québec Ombudsman Issues Her Recommendations” (8 June 2001), online: Québec Ombudsman <<http://www.ombuds.gouv.qc.ca/en/publications/communiqué/010608.asp>>.

<sup>106</sup> See *Health Services Act*, *supra* note 7, s. 95.

<sup>107</sup> See OECD, *OECD Health Data 2001: A Comparative Analysis of 30 Countries*, CD-ROM (Paris: OECD, 2001) at Table 146.

<sup>108</sup> Much of the legislation that speaks to patients’ rights to access services only applies to existing enrollees’ ability to access services covered by their private health insurance plan.

<sup>109</sup> Four states that have specifically enacted patients’ bills of rights are Massachusetts, Vermont, New Jersey, and West Virginia. The Massachusetts and Vermont legislation is not restricted to managed care; however, the New Jersey and West Virginia bills of rights are typical of the many other managed care laws that exist in over forty states and seek to regulate the managed care industry. Some states have patients’ bills of rights that only target specific areas of the health care sector, as opposed to dealing with the rights of those enrolled in managed care plans, such as home care (e.g., New Hampshire).

<sup>110</sup> *Health Insurance Portability and Accountability Act of 1996*, Pub. L. No. 104-191, 110 Stat. 1936.



insurers, employers, and managed care plans from dropping coverage for people once they begin to need expensive health care services. In 2001, the US House of Representatives<sup>111</sup> and the US Senate,<sup>112</sup> respectively, introduced bills providing for a patients’ bill of rights. Both bills provide national standards of entitlements for those with existing health insurance ensuring, for example, access to specialists, government-sponsored clinical trials, and emergency services,<sup>113</sup> and both also enable patients to appeal the decisions of a managed care plan to an independent review board.<sup>114</sup> The two bills also overcome, to significantly different degrees, the limitations of the *Employee Retirement Income Security Act of 1974*,<sup>115</sup> a Byzantine piece of federal legislation that has been interpreted by the courts as preventing patients from suing managed care plans in state courts with respect to decisions concerning eligibility for treatment.<sup>116</sup>

Managed care plans may give financial and other incentives to doctors and health care professionals to contain costs. In such a situation, *implicit* rationing may occur: the physician will not deny a treatment explicitly on the basis of cost but will frame the decision as a medical one.<sup>117</sup> Implicit rationing is more difficult to detect and regulate than explicit rationing; nonetheless, some attempts are made. For example, a few states prohibit the use of “gag clauses”, whereby managed care plans disallow doctors from discussing with patients treatments that the plan does not cover, attempted referrals that the plan has refused, and the terms of the financial incentives

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<sup>111</sup> U.S., Bill H.R. 2563, *Bipartisan Patient Protection Act*, 107th Cong., 2001 (second reading on 6 September 2001) [*House Bill*].

<sup>112</sup> U.S., Bill S. 1052, *Bipartisan Patient Protection Act*, 107th Cong., 2001 (as passed by the Senate on 29 June 2001) [*Senate Bill*]. Both bills failed to become law before the end of the 107th congressional session. To date, they have not been reintroduced.

<sup>113</sup> See Title I, Subtitle B in both the *House Bill*, *supra* note 111, and the *Senate Bill*, *supra* note 112. See especially section 114 (Timely access to specialists), section 119 (Coverage for individuals participating in approved clinical trials), and section 113 (Access to emergency care).

<sup>114</sup> See *ibid.*, ss. 101-105. Title IV amends the *Employee Retirement Income Security Act of 1974*, 29 U.S.C. §1001 (1990) [*ERISA*].

<sup>115</sup> *ERISA*, *ibid.*

<sup>116</sup> See *e.g.* *Pegram v. Herdrich*, 530 U.S. 211 (2000) and *Marks v. Waters*, WL 1154113 (4th Cir. 2003), where the plaintiff’s claim concerning eligibility was pre-empted by the *ERISA*. It is with respect to the *ERISA* that the *House Bill* differs significantly from the *Senate Bill*. The *House Bill* places significant limits on patients’ capacity to sue managed care plans in state courts. First, damage claims for pain and suffering are limited to \$1.5 million (*House Bill*, *supra* note 111, s. 402), compared to the \$5 million cap in the *Senate Bill* (*supra* note 112, s. 402). Second, punitive damages are limited to \$1.5 million (*House Bill*, *supra* note 111, s. 402). Finally, the *House Bill* would make any suit in a state court subject to special federal standards, including a higher standard of proof requiring the plaintiff to overcome a “presumption (rebuttable by clear and convincing evidence) that the designated decisionmaker exercised ordinary care in making such determination” (*House Bill*, *supra* note 111, s. 402 would amend the *ERISA* to include subparagraph 502(n)(1)(B)).

<sup>117</sup> See Sara Rosenbaum, David M. Frankford & Brad Moore, “Who Should Determine When Health Care Is Medically Necessary?” (1999) 340 *New Eng. J. Med.* 229.

that doctors receive.<sup>118</sup> Similarly, both the *Senate Bill* and the *House Bill*, providing for a federal patients' bill of rights, prohibit gag clauses.<sup>119</sup>

In addition to the proposed patients' bills of rights, there is a patchwork of federally mandated and state-initiated consumer assistance programs across the fifty states.<sup>120</sup> State-initiated programs fall into two main categories: Medicaid ombudsperson programs for those of the poor that the state has determined qualify for Medicaid and general health care ombudsperson programs, which serve people with private insurance.<sup>121</sup> These programs have three main functions: investigating and resolving consumer complaints; educating the public about consumers' health care rights; and providing feedback to policy-makers on how to improve the performance of the health care system.

The US system is sharply distinguishable from the Canadian system because of the former's failure to guarantee all citizens access to health care and its significantly greater reliance on private insurance and out-of-pocket payments. Moreover, well-insured Americans do not appear to suffer long waiting times and lists. Nonetheless, there are lessons for Canada from the US experience, particularly when considering regulation of entitlements and access to timely treatment. One insight from the US experience is the possibility that governments are more willing to regulate the private sector (e.g., managed care plans) than they are to bind public sector management.<sup>122</sup> Public choice theory would predict that governments are more willing to regulate when the costs incurred are not borne by the government itself. For example, a recent report prepared by PricewaterhouseCoopers for the American Association of Health Plans found that government mandates and regulations were responsible for fifteen per cent of the recent rise in health care costs.<sup>123</sup> In the Canadian context, this may mean that we are more likely to see the development and enforcement of patients' rights when governments have devolved budgetary responsibilities to other institutions (e.g., regional health authorities and hospitals) and can demand of these

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<sup>118</sup> Robert L. Schwartz, "How Law and Regulation Shape Managed Care" in David A. Bennahum, ed., *Managed Care: Financial, Legal, and Ethical Issues* (Cleveland: Pilgrim Press, 1999) 21 at 31.

<sup>119</sup> See sections 131-35 in both the *House Bill*, *supra* note 111, and the *Senate Bill*, *supra* note 112.

<sup>120</sup> See Families USA, *Consumer Health Assistance Programs: Report on a National Survey* (June 2001) at 2-6, online: Families USA <<http://www.familiesusa.org/site/DocServer/survey.pdf?docID=750>>.

<sup>121</sup> *Ibid.* at 5-6. Federal law requires that all states offer at least three specific types of consumer health insurance programs: long-term care ombudsperson programs, protection and advocacy programs for persons with disabilities, and state health insurance assistance programs for Medicare beneficiaries (those over 65) (*ibid.* at 2-3).

<sup>122</sup> Of course, another explanation for the amount of patient rights' legislation in the US relative to the Canadian context is that there is simply a much greater need for such regulation because for-profit insurers are more likely to subject patient interests to their own corporate interests.

<sup>123</sup> See Robin Toner & Sheryl Gay Stolberg, "Decade After Health Care Crisis, Soaring Costs Bring New Strains" *New York Times* (11 August 2002) 1.1. See also PricewaterhouseCoopers, "The Factors Fuelling Rising Healthcare Costs" (April 2002) at 4, online: American Association of Health Plans <<http://www.aahp.org/InternalLinks/PwCFinalReport.pdf>>.

institutions that patients’ rights be upheld. It may also mean that the federal government will look favourably upon any proposals for a patients’ bill of rights, since the management and budgetary responsibility for health insurance programs (and thus the task of realizing patients’ rights) rests primarily with the ten provinces.

### C. New Zealand

The growth of a patients’ rights movement in New Zealand began in earnest in 1987 when it was revealed that an estimated thirty women with cervical carcinoma in situ died as a result of the failure to appropriately treat women at an Auckland hospital.<sup>124</sup> These women had, without their consent, been enrolled in a research trial, which entailed withholding conventional treatment to see how the disease progressed. A committee of inquiry was established to report on what factors had resulted in a climate where such maltreatment could go unchecked. As a result of the committee’s report,<sup>125</sup> the New Zealand Parliament introduced new legislation in 1994.<sup>126</sup> The goal of the *Health and Disability Commissioner Act* is to protect the rights of “consumers”<sup>127</sup> of health and disability services by providing an accessible, independent, and consumer friendly complaints mechanism.<sup>128</sup> To this end, a *Code of Health and Disability Consumers’ Rights* was enacted as a regulation under the act in 1996.<sup>129</sup>

The *Code* provides for ten general rights: the right to be treated with respect; the right to freedom from discrimination, coercion, harassment, and exploitation; the right to dignity and independence; the right to services of an appropriate standard; the right to effective communication; the right to be fully informed; the right to make an informed choice and give informed consent; the right to support; rights in respect of

<sup>124</sup> This estimate comes from the “Brief of Evidence from Sandra Coney, Under the Health and Disability Services Act 1993, in the Matter of the Ministerial Inquiry into the Under-reporting of Cervical Cancer Abnormalities” at 6, online: Gisborne Cervical Screening Inquiry <<http://www.csi.org.nz/proceedings/coney.pdf>>.

<sup>125</sup> See Silvia Cartwright, *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women’s Hospital and into Other Related Matters* (Auckland: Government Printing Office, 1988); N.Z., *Hansard*, Introduction of Health Commissioner Bill, 4 September 1990 (Rt. Hon. Helen Clark).

<sup>126</sup> *Health and Disability Commissioner Act 1994* (N.Z.), 1994/88.

<sup>127</sup> Discourse about patients’ rights in Canada tends to use the term “patient”. The New Zealand legislation, however, uses the term “consumer”, which conveys a wider meaning, as it encompasses people who are not patients in the strict sense of the word, but who also have rights (e.g., a person picking up a prescription from a pharmacy). In this article, we only use the term “consumer” when discussing the New Zealand legislation.

<sup>128</sup> Note that New Zealand has a no-fault accident compensation scheme that bars common law claims for damages for personal injury. Arguably, because consumers in New Zealand lack the common law’s protection in respect of medical negligence, the protection of rights by an independent commissioner takes on a heightened importance.

<sup>129</sup> *Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996* (N.Z.), 1996/78 [Code].

teaching or research; and the right to complain. A number of these rights were already recognized to some extent at common law and in professional codes of ethics. Under the *Code*, the rights are applicable to *all* health and disability service providers, including alternative providers such as naturopaths and homeopaths, whether working in the public or private sector. A Health and Disability Commissioner is charged with promoting the rights of consumers and investigating alleged breaches of the *Code*.<sup>130</sup>

The *Code* is limited, as there is no right to receive treatment, nor to receive timely treatment.<sup>131</sup> Moreover, section 3 provides that there is no breach of the *Code* if a provider has taken “reasonable actions in the circumstances to give effect to the rights, and comply with the duties” in the *Code*. The current Health and Disability Commissioner has written that section 3 of the *Code* “takes into account factors such as a consumer’s clinical circumstances and a provider’s resource constraints.”<sup>132</sup> Although it is surely correct not to hold a provider to account where the failure to treat is due to inadequate resources, the commissioner’s statement raises the question of who, in these circumstances, should be held to account. In this regard, it is important to note that the *Code* frames rights in the context of the clinical encounter and the “consumer’s” relationship with a health care provider. It does not provide citizens with rights vis-à-vis public sector decision-makers, nor can the commissioner directly investigate the actions of district health boards, which are responsible for funding most health care services and managing the hospitals within their region. The commissioner does, however, have the power to investigate and report on “generic systems issues”,<sup>133</sup> which indirectly provides some means of review of managerial and funding decisions.

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<sup>130</sup> The commissioner’s options on finding a breach of the *Code*, *ibid.*, include the making of reports and recommendations to the provider, the health professional body, the minister of health, or any other person the commissioner thinks fit. Recommendations to providers vary from case to case, but may include a written apology to the consumer; reimbursing the consumer’s costs; undertaking specific training; and implementing and reviewing systems to prevent further breaches. Where recommendations are made, the commissioner follows up and monitors implementation. The commissioner may also refer the matter to the Director of Proceedings, who may bring disciplinary and/or other proceedings (*Health and Disability Commissioner Act*, *supra* note 126, ss. 35-49).

<sup>131</sup> The right to services of an appropriate standard, set out in section 2 of the *Code*, *supra* note 129, includes the right of every consumer to have services provided: with reasonable care and skill; that comply with legal, professional, ethical, and other relevant standards; in a manner consistent with his or her needs; that minimize the potential harm to, and optimize the quality of life of, that consumer. Every consumer also has the right to co-operation among providers to ensure quality and continuity of services.

<sup>132</sup> Ron Paterson, “Patients’ Rights in New Zealand: Lessons for Ontario?” (Paper presented at the Second Annual Health Law Day, Faculty of Law, University of Toronto, 12 October 2001), online: Institute for Research on Public Policy <<http://www.irpp.org/events/archive/oct01/paterson.pdf>>.

<sup>133</sup> In commenting on the commissioner’s power to investigate generic systems issues, Tipping J. in *Nicholls v. Health and Disability Commissioner*, [1997] N.Z.A.R. 351 at paras. 16-17, [1997] NZAR LEXIS 18 (H.C.) noted,

Although New Zealand's *Code* is limited primarily to protecting rights in health care (as opposed to right to health care), it appears to be serving both patients and health care professionals well. Patients now have a greater knowledge of what their rights in health care are, and are finding it easier to make complaints. Ron Paterson, the current Health and Disability Commissioner reported, for example, a dramatic increase of forty-three per cent in complaints against doctors between the founding of the commissioner's office in 1996 and 2001.<sup>134</sup> Although this might seem problematic for physicians, the other side of the coin is that there has been a dramatic decline in the number of physicians facing disciplinary charges since 1996. Because the commissioner is the gatekeeper to professional discipline, and as the commissioner emphasizes settlement of complaints, few complaints are ultimately referred to disciplinary hearings.<sup>135</sup>

#### D. United Kingdom

The United Kingdom's Health Service Ombudsman ("the Ombudsman") may investigate complaints from a person who "has sustained injustice or hardship" as a consequence of "(a) a failure in a service provided by a health service body, (b) a failure of such a body to provide a service which it was a function of the body to provide, or (c) maladministration connected with any other action taken by or on behalf of such a body."<sup>136</sup> In 1996, the Ombudsman's authority was extended to include complaints regarding all aspects of publicly funded health care services, as

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There was some debate as to how far the Commissioner could go into what were described as policy or management areas. The simple answer in my view is that the Commissioner may investigate any conduct of a health care provider which (a) can reasonably be described as a policy or practice; and (b) is or appears to be in breach of the Code. Power of investigation is not open-ended in the sense that the subject matter must fulfil the definition of the word "action" and must also be such that it is or appears to be in breach of the Code but, subject to those limitations, the power of investigation is not otherwise circumscribed. It is neither possible nor desirable for the Court to go any further than that, much less attempt to provide abstract examples of what would or would not be within the Commissioner's powers of investigation. One thing however can be said. Because of the fact that the word "action" includes any policy or practice, the Commissioner is not limited to investigating single or discrete incidents or happenings. She can investigate anything within the definition of "action" so long as it is or appears to her to be in breach of the Code.

<sup>134</sup> Ron Paterson, "The Patients' Complaints System in New Zealand" (2002) 21:3 Health Aff. 70.

<sup>135</sup> See *ibid.* The commissioner is the gatekeeper to professional discipline, because under the legislation, all complaints made to professional registration bodies must be referred to the commissioner. This includes all complaints about doctors, nurses, dentists, pharmacists, et cetera. Once referred to the commissioner, no disciplinary action can be taken by the professional body until the commissioner or the Director of Proceedings (who, on referral from the commissioner, may bring disciplinary and/or other proceedings against the health care provider) has dealt with the matter and decided to take no further action. Only at this point can the professional body take up the matter itself (*Health and Disability Commissioner Act, supra* note 126, ss. 38-39).

<sup>136</sup> *Health Service Commissioners Act 1993* (U.K.), 1993, c. 46, s. 3 [*HSCA*].

well as complaints regarding the clinical judgment of physicians, nurses, and other clinical professionals.<sup>137</sup> The Ombudsman may now also investigate the actions of providers in the private sector.

The relevant legislation expressly provides that the Ombudsman is unable to question the merits of a decision made by an administrative body in the course of exercising any discretion vested in that body, except in the case of maladministration.<sup>138</sup> This provision restricts the Ombudsman's capacity to question resource allocation decisions and systemic issues causing growing waiting times and lists. Indeed, in her 2000-2001 annual report the Health Service Ombudsman for England<sup>139</sup> noted that she had received several complaints about long waiting times and asserted that "[t]he allocation of resources is a matter for the [National Health Service] and local managers, and not for me."<sup>140</sup> But she did go on to note that she is not completely incapable of dealing with issues of waiting lists and times: "However, I may criticise trusts which have not taken explicit and open decisions about resource allocation; have no well-supported criteria for urgent access to services; or have no mechanism for re-assessing individuals' needs for the service."<sup>141</sup>

UK governments have tried to tackle the problem of long waiting lists and times, and one method has been to include statements setting out maximum waiting times in a Patient's Charter. First introduced in 1991, the charter set out national standards of service regarding what patients in the public system could *expect* in terms of access and treatment (i.e., the charter did not grant enforceable rights *per se*). At the regional level, health authorities and National Health Service trusts (which manage the public hospitals) were encouraged to negotiate even higher standards, and health authorities published an annual report each year measuring every hospital's performance against charter standards. A revised Patient's Charter, introduced on 1 April 1995, expressly stated how long patients should expect to have to wait for various services.<sup>142</sup> In

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<sup>137</sup> See the *Health Service Commissioners (Amendment) Act 1996* (U.K.), 1996, c. 5.

<sup>138</sup> *HSCA*, *supra* note 136, ss. 3(4)-(5). This provision is consistent with case law reflecting a general reluctance on the part of the courts to intervene in the rationing and allocation decisions made by government authorities and providers within the UK's publicly funded health care system. For a discussion of these cases, see John H. Tingle, "The Allocation of Healthcare Resources in the National Health Service in England: Professional and Legal Issues" (1993) 2 *Annals Health L.* 195. See also *R. v. Cambridge Health Authority*, [1995] 2 All E.R. 129 (C.A.) at 130 where it was noted that the judiciary "was not in a position to decide on the correctness of the difficult and agonising judgments which had to be made by health authorities as to how a limited budget was best allocated to the maximum advantage of the maximum number of patients ..."

<sup>139</sup> Note that there is a Health Service Ombudsman for each of England, Scotland, and Wales.

<sup>140</sup> The Health Service Ombudsman for England, *Annual Report 2001-02* at 9, online: <<http://www.ombudsman.org.uk/hsc/document/har02/ar02.pdf>>.

<sup>141</sup> *Ibid.*

<sup>142</sup> The charter noted that patients could expect to be seen immediately in Accident and Emergency Departments, within 18 months for in-patient or day case services, within 12 months for coronary artery bypass grafts and associated procedures, and within 26 weeks for a first consultant outpatient

addition to setting out the rights of patients, the charter also set out the standards of service that patients could expect to receive, including respect for privacy, dignity, and religious beliefs, as well as specific guarantees with respect to waiting times (e.g., a guarantee of being seen within thirty minutes of one’s specific appointment time in an outpatient clinic).<sup>143</sup>

The New Labour’s reforms of December 1997 proposed to improve the Patient’s Charter to “tell people about the standards of treatment and care they can expect of the NHS. It will also explain patients’ responsibilities.”<sup>144</sup> As of 1 April 2001, a new document—*Your Guide to the NHS*—replaced the charter in England,<sup>145</sup> but the Patient’s Charter still applies in Wales, Scotland, and Northern Ireland. The *Guide* sets out patients’ rights and responsibilities and highlights the standards and services people can expect from the NHS.<sup>146</sup> The new *Guide* has been criticized for being too vague about what patients can expect and failing to explicitly state patients’ rights to, for example, a free yearly health check if over seventy-five years of age.<sup>147</sup> As with the charter that preceded it, the *Guide* allows patients to make complaints but does not create legally enforceable rights. The new *Guide* does, however, provide a specific commitment with regard to waiting times and states that from 2002, if an operation is cancelled on the day of surgery for non-clinical reasons, the hospital will have to offer another date within the next twenty-eight days. If a hospital fails to comply, it must pay for the treatment at the time and hospital chosen by the patient.<sup>148</sup>

Have the guarantees and statements made in the Patient’s Charter and *Guide* regarding waiting times had any impact on reducing waiting times and lists in the UK? As one of us has noted elsewhere, the UK Conservative government of the day had some success in the mid-1990s in its attempt to stem growing waiting lists.<sup>149</sup>

appointment, with 90 per cent of patients being seen within 13 weeks. See National Health Service, *NHS Waiting Times Good Practice Guide, January 1996* (Leeds: NHS Executive, 1996) at 2.

<sup>143</sup> See U.K., Department of Health, *The Patient’s Charter and You—A Charter for England* (1996), online: Press for Change <<http://www.pfc.org/uk/medical/pchrt-e1.htm#charter>>.

<sup>144</sup> U.K., Department of Health, *The New NHS: Modern, Dependable* (A White Paper presented to Parliament by the Secretary of State for Health by Command of Her Majesty) (London: The Stationery Office, 1997) at § 4.20.

<sup>145</sup> National Health Service, *Your Guide to the NHS*, online: National Health Service <[http://www.nhs.uk/nhsguide/nhs\\_guide.pdf](http://www.nhs.uk/nhsguide/nhs_guide.pdf)> [*Guide*].

<sup>146</sup> See U.K., Department of Health, Press Release, “‘Your Guide to the NHS’ Launched” (Ref. No. 2001/0055) (26 January 2001), online: Department of Health <[http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT\\_ID=4009925&chk=sRmmFB](http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4009925&chk=sRmmFB)>.

<sup>147</sup> See Simon Crompton, “Are We Losing Our Rights as Patients?” *The Times* (17 July 2001).

<sup>148</sup> See *Guide, supra* note 145 at 31. The *Guide* also provides that outpatients should expect to wait no more than 26 weeks; patients can expect to be seen within 30 minutes of their appointment at an outpatient clinic; in-patients should expect to wait no more than 18 months; a patient referred urgently with suspected cancer will be seen within two weeks; and, beginning in 2003 for all patients, suspected angina patients will be assessed in a specialist chest pain clinic within two weeks (see *Guide, ibid.* at 27).

<sup>149</sup> See Colleen M. Flood, *International Health Care Reform: A Legal, Economic and Political Analysis* (London: Routledge, 2000) at 100-101. The number of individuals waiting for elective

Nevertheless, how much of this improvement is due to the increased efficiency of the system, as opposed to additional government spending, is unclear. Moreover, the mere fact that there is evidence indicating that the number of people waiting has declined does not reveal whether the amount of time that people have to wait has decreased. Additionally, it is very difficult to disentangle cause and effect and to assess whether there have been any real reductions in waiting lists and times. Efforts at reducing waiting times and lists have occurred at the same time as implementations of wave after wave of health care reform. As a result, we cannot conclusively determine whether reductions in the growth of waiting times and lists are a short-term phenomenon and whether improvements have been due to improved management and productivity or to increased resources being pumped into the system. There was also some evidence that reductions in waiting times for elective surgeries came at the cost of promptly treating those with acute needs, which would highlight the importance of using caution when relying on incentives to change decision-making behaviour.<sup>150</sup> Nonetheless, the evidence from the UK in the late 1980s and 1990s was that waiting times did decline in response to a combination of infusions of public funding and changes to the incentive structure within the public sector so as to reward improvements in timeliness.<sup>151</sup>

The inclusion of statements and guarantees in a Patient's Charter and now in a *Guide* do not, in general, confer enforceable rights for patients, but rather are used as performance benchmarks for decision-makers in the public system. To some extent, the inclusion of statements and guarantees of waiting times and lists in the Patient's

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procedures fell by 2.9 per cent in the period from December 1994 to March 1995, when there were 1,040,161 people on waiting lists. See Anthony Harrison, ed., *Health Care UK 1994/95: An Annual Review of Health Care Policy* (Bristol: King's Fund Policy Institute, 1995) at 38. Approximately the same number of people (1,040,152) were on waiting lists on 30 September 1995. The number of people waiting for more than 12 months for elective procedures on 30 September 1995 was 27,900—a reduction of 55 per cent since September 1994, when there were 62,300. See U.K., Department of Health, News Release, "Hospital Waiting List Statistics Published" (Ref. No. 96/1) (4 January 1996); Timothy Besley, John Hall & Ian Preston (*Private Health Insurance and the State of the NHS* (London: The Institute for Fiscal Studies, 1996) at 9), similarly show a significant decline in the percentage of the population on long-term waiting lists after 1990. Through 1997, waiting lists started to increase once again with 1,207,500 waiting at the end of September 1997 (an increase of 1.5 per cent over the previous quarter), with the number of people waiting for more than 12 months increasing by 24 per cent. See Janet Snell, "Action Team Appointed to Tackle Rising Waiting Lists" *Health Service Journal* (20 November 1997) 4. The numbers waiting had slightly declined by 31 January 1999 with 1,159,400 people waiting, with the number of people waiting more than 12 months dropping to 54,600. See U.K., Department of Health, Statistical Press Notice, "NHS Waiting List Figures, 31 January 1999" (Ref. No. 1999/0119) (2 March 1999), online: Department of Health <<http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesLibrary/fs/en>>.

<sup>150</sup> See Lewis *et al.*, *supra* note 27.

<sup>151</sup> See Christopher Ham, *Health Policy in Britain: The Politics and Organisation of the National Health Service*, 3d ed. (London: Macmillan, 1992) at 71; Rudolf Klein, *The New Politics of the National Health Service*, 3d ed. (London: Longman, 1995) at 237; Barton H. Hamilton & Robert Edward Bramley-Harker, "The Impact of the NHS Reforms on Queues and Surgical Outcomes in England: Evidence from Hip Fracture Patients" (1999) 109 *The Econ. J.* 437.



Charter has been used by UK governments to symbolize a commitment to respond to patients’ concerns regarding timeliness. If a government has the will to reduce waiting times and lists, then it can do so through some combination of resource investment, use of financial incentives, and improvements in efficiency. But the US experience clearly indicates that the combination of methods used to change behaviour must be carefully calibrated so as not to create other problems in the system, such as the shifting of resources away from the treatment of those with acute needs to the treatment of those who have waited too long for elective surgery.

### E. Spain

While in the UK, guarantees regarding waiting times are not enforceable by individual patients, guarantees regarding waiting time are enshrined in legislation in the Navarra region of Spain.<sup>152</sup> Over the last eight years, three of the eight Spanish regional health authorities that have adopted policies designed to reduce the length of waiting lists have shown better waiting list time indicators and patient satisfaction.<sup>153</sup> According to Toni Ramirez-Arellano (Health Advisor of the Cabinet of the Spanish Prime Minister), the average waiting time for surgery declined from 135 days in 1996 to sixty-eight days in 2001; the number of patients waiting more than six months declined from 49,842 in 1996 to 5,155 in 2001; and the total number of patients waiting for surgery declined from 190,000 in 1995 to 132,221 in 1998 but had increased again to 166,583 in 2001.<sup>154</sup> The Spanish waiting list initiative incorporated four different types of measures to meet its objectives of reducing waiting lists and times. The measures were: (1) validating information systems regarding the number of patients waiting; (2) providing incentives to organizations to meet both expenditure targets and waiting time targets; (3) adding temporary additional capacity through contracting out to private hospitals and paying overtime in public hospitals; and (4) requiring the regional government to pay for a patient’s care in the private sector if a public hospital in its region is unable to meet the waiting time target. The greatest reduction in waiting times occurred in the Navarra Regional health service, which had incorporated waiting standards into its regional legislation.<sup>155</sup>

The legislation in Navarra provides for a maximum waiting time of 180 days for elective surgery treatments.<sup>156</sup> A central unit is charged with assessing the situation of

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<sup>152</sup> See Toni Ramirez-Arellano, “Surgical Waiting List Initiative: INSALUD (Spain), 1996-2001” (Plenary presentation to the International Health Economics Association, July 2001) [unpublished] [Ramirez-Arellano, “Initiative”]; E-mail correspondence from Toni Ramirez-Arellano to Colleen M. Flood (5 September 2001) [Ramirez-Arellano, E-mail].

<sup>153</sup> See Ramirez-Arellano, “Initiative”, *ibid.*

<sup>154</sup> *Ibid.*

<sup>155</sup> See *ibid.*; Ramirez-Arellano, E-mail, *supra* note 152.

<sup>156</sup> Elective surgery treatments account for approximately 90 per cent of all non-urgent treatments affected by the waiting list problem (see Ramirez-Arellano, E-mail, *ibid.*).

each patient on the waiting list.<sup>157</sup> If it is foreseen that the hospital of reference within the patient's local region will be unable to meet the waiting time guarantee, the patient must be sent to another public hospital. If no public hospital can satisfy the waiting time guarantee, the patient has the right to choose a private hospital or a public/private hospital outside the area governed by the regional health service in order to obtain the required treatment. When this occurs, the regional government in question pays for all costs, including the transportation and living expenses of both the patient and a companion. Following the success in Navarra, the regional government of Andalusia is taking steps to incorporate guarantees of maximum waiting times into its patients' rights legislation.<sup>158</sup>

While it would seem that the Spanish initiatives have been very successful, it is not possible to extrapolate from this experience alone to conclude that such an initiative would necessarily work in other jurisdictions. For example, the fact that Spain has succeeded in reducing waiting lists may be due to surplus capacity in the hospital sector (public and private), so that financial incentives to reduce waiting lists can be acted upon readily. Further research is required into the Spanish initiative on waiting lists to see whether it would be possible for a system without such high levels of hospital capacity to realize the same gains using waiting list guarantees and associated financial penalties and incentives.

## **F. Sweden**

In Sweden, the right of each resident to all "necessary" health care is part of national legislation.<sup>159</sup> In 1992, the Patient Choice and Care Guarantee ("PCCG") reforms were introduced. The PCCG reforms were directed specifically at hospital care and provided patients requiring surgery or other hospital treatment the right to choose freely the hospital in which they would receive treatment. The assumption behind this initiative was that patients would choose the hospital with the shortest waiting times. "[M]oney was to follow the patient," so that if a patient elected to receive care in a hospital other than the one to which he or she had originally been assigned, a specified sum of money would be transferred from the budget of the latter to that of the former.<sup>160</sup> As a result, Blomqvist notes, there has been a substantial reduction in waiting times for important kinds of elective surgery, to the point where,

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<sup>157</sup> An "Official Register of Surgical Demand" is kept, and waiting time commences when a doctor signs a form for surgical treatment and the patient accepts the same with his or her signature. The patient's copy is regarded as a "guarantee" for the patient that he or she will get treatment within the next six months (see *ibid.*).

<sup>158</sup> See *ibid.*

<sup>159</sup> See Åke Blomqvist, "International Health Care Models: Sweden" (Background paper prepared for the Standing Senate Committee on Social Affairs, Science and Technology, March 2001).

<sup>160</sup> Michael I. Harrison & Johan Calltorp, "The Reorientation of Market-Oriented Reforms in Swedish Health-Care" (2000) 50 *Health Pol'y* 219 at 222.

by the end of 1993, waiting lists “ceased to be a political issue”.<sup>161</sup> More recently, maximum waiting time guarantees have been introduced for consultations with primary care doctors and specialists. Blomqvist notes that the guarantees specify eight days as the maximum waiting time before a person will be seen by a doctor in primary care (although patients may be seen by other personnel, such as a nurse, before that), and three months as the maximum waiting time to see a specialist.<sup>162</sup>

The Swedish experience is of particular interest, as the rights initially granted to patients were not in regard to any specific maximum waiting times, but rather concerned the right to freely choose a hospital. In Canada, there are no provincial restrictions on which hospitals a patient can be treated in. Nevertheless, it would be a radical departure in the Canadian context to move away from block-funding hospitals (whereby hospitals receive a set amount per year largely regardless of their productivity levels) to allow public funds to follow patients. If the financial incentives were changed then hospitals would be rewarded for competing for patients by reducing waiting times. Undoubtedly, such a proposal would impact long-term planning, financial stability, and prioritization of resources within hospitals, and there are risks. In addition, significant geographic barriers exist in that some Canadians do not have a choice of hospitals within a reasonable distance. Thus, the Swedish approach to waiting lists cannot be recommended without further study, although what evidence there is suggests that it is worthy of consideration.

### G. Italy

Article 32 of the Italian Constitution provides that the Republic of Italy protects health as a fundamental right of the individual and as a concern of the collectivity, and guarantees free care to the indigent.<sup>163</sup> George France notes that over the years, the courts have increasingly interpreted this provision as giving a right to health care to all residents.<sup>164</sup> For example, the Italian Constitutional Court found in 1988 that since the right to health is “primary and fundamental”, patients have the right to “full and complete protection”.<sup>165</sup> Hence, patients cannot be refused access to “necessary” care, even if this is only available in a private facility.<sup>166</sup> Accordingly, patients have

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<sup>161</sup> Blomqvist, *supra* note 159, citing Harrison & Calltorp, *supra* note 160 at 223.

<sup>162</sup> Blomqvist, *ibid.*

<sup>163</sup> *Costituzione della Repubblica Italiana*, 1947, art. 32: “La Repubblica tutela la salute come fondamentale diritto dell’individuo e interesse della collettività, e garantisce cure gratuite agli indigenti.”

<sup>164</sup> George France, “Cross-Border Flows of Italian Patients Within the European Union: An International Trade Approach” (1997) 7:3 (Supp.) *Eur. J. Pub. Health* 18. See also George France, “The Changing Nature of the Right to Health Care in Italy” in André den Exter & Herbert Hermans, eds., *The Right to Health Care in Several European Countries* (The Hague: Kluwer Law International, 1999) 39 [France, “Changing Nature”].

<sup>165</sup> Corte costituzionale, Sentenza n. 992 (1988), online: Consulta Online <<http://www.giurcost.org/decisioni/1988/0992s-88.html>>. See also France, “Changing Nature”, *ibid.* at 46.

<sup>166</sup> See *ibid.*

frequently travelled outside their local health authority, abroad, or gone to a private provider in order to obtain services that were not available locally.

George France reports that although the use of providers outside the local health authority or region has always required authorization, the tendency in the past was for this to be done automatically and often on a retroactive basis.<sup>167</sup> The non-availability of a particular service in a particular area was considered a valid reason for a patient to get authorization to go to another area, and if necessary, to a private provider. Since the early 1990s, however, the courts have begun to recognize that due to fiscal constraints, the Italian National Health Service (Servizio Sanitario Nazionale or "SSN") might have to be selective in the kinds of care it provides.<sup>168</sup> In 1989, the central authorities restricted the ability of patients to go abroad for treatment. A list of pathologies was drawn up for which authorization could be granted. This list specifies the maximum waiting times beyond which patients are entitled to go abroad. Legislation requires a referral committee made up of doctors to establish whether the patient can obtain the necessary care within a reasonable time from a domestic provider. If this is not possible, the committee determines where the patient can best obtain the care in question abroad, and the SSN pays for the costs incurred.<sup>169</sup>

There is very little evidence from Italy regarding the consequences of its approach to waiting lists. It would seem that waiting times and lists are not a significant problem, but we have little evidence about the cost of this initiative. Only 2.4 per cent of Italians seeking diagnoses in 2001 experienced delays of greater than sixty days, and only 1.2 per cent waited longer than sixty days to be examined by a specialist.<sup>170</sup> Unfortunately, those subjected to the longest waits tended to be the elderly and people of the lowest levels of education, with the indigent also experiencing delays before being seen by specialists.<sup>171</sup> The government attributes these problems to organizational inefficiencies and inequities.<sup>172</sup>

## Conclusion

What would be the benefit of the passage of a patients' bill of rights in Canada, be it at the federal level, or more likely, the provincial level? The experiences from New Zealand, Quebec, and several US states that have consumer assistance programs suggest that there are significant benefits to be had in a patients' bill of rights that addresses rights *in* health care. Such a code would allow for the enumeration of patients' rights in one comprehensive piece of legislation and would provide an

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<sup>167</sup> Personal communication between the authors and George France.

<sup>168</sup> See France, "Changing Nature", *supra* note 164 at 48.

<sup>169</sup> See *ibid.*

<sup>170</sup> See National Institute of Statistics, *Annual Report 2001: Synthesis—Diversity in the Differences* at 39, online: Istat <<http://www.istat.it/English/RAinglese.pdf>>.

<sup>171</sup> See *ibid.*

<sup>172</sup> See *ibid.*

enforcement mechanism (by means of an independent commissioner or ombudsperson) that would be both more accessible<sup>173</sup> and viewed as more legitimate and independent than that available through self-regulating professional bodies. A patients' bill of rights would also: provide oversight of alternative health care providers who are currently not subject to regulation and/or professional self-regulation; provide (if the New Zealand model was followed) a centralized complaints system with just one entry point (as opposed to, for example, the existence of twenty-three professional colleges in Ontario, which causes confusion regarding to which college a complaint should be made);<sup>174</sup> allow investigation of practice settings, such as hospitals, and of systemic complaints that are not attributable to a sole identifiable professional; promote low-level resolution of complaints; provide remedies;<sup>175</sup> and facilitate ongoing education of both patients and health care providers.

A patients' bill of rights should emphasize education so that it does not become simply a complaints mechanism, but a positive instrument by which the protection of rights *in* health care can be promoted. Of course, as with any such initiative, its successful implementation and credibility would depend on adequate resources<sup>176</sup> and the independence of the office of the ombudsman or commissioner. Some may argue that establishing a commissioner or ombudsperson runs the risk of establishing a bureaucratic entity that will detract funding from front line patient care. We believe, however, that the amount required to establish an enforcement body would be more than compensated by the potential benefits, including, as we discuss below, incentives to increase efficiencies within the health care system.

There are thus many positive contributions a patients' bill of rights could make in improving patients' rights *in* health care and in the interactions between health care providers and patients. A patients' bill of rights alone, however, would not address what has become a key concern of Canadians: timely access to health care services. Canadians who receive treatment are, on the whole, very satisfied with the clinical encounter, but Canadians remain very concerned about access and especially waiting times for treatment, and it is this concern that is driving mounting dissatisfaction with

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<sup>173</sup> The New Zealand model is valuable in this regard for its success in streamlining the complaints system and its efforts at educating the public so that they know their rights and where to complain if they think that those rights have been breached.

<sup>174</sup> Of course, Canadians would remain free to bring a legal claim in the courts.

<sup>175</sup> Remedies might include making recommendations to the provider, the health professional body, or others that a written apology be provided to the patient; that the patient's costs (where applicable) be reimbursed; that they undertake specific training; and that systems be reviewed or implemented to prevent further breaches.

<sup>176</sup> The Institute for Research on Public Policy's Task Force on Health Policy noted the importance of overcoming "the inherent scepticism of most people regarding public statements of good intentions." It also noted that if a bill of rights is going to help, "it will require a very substantial commitment of resources to service delivery and to implementation processes" (IRRP Task Force on Health Policy, *Recommendations to First Ministers* (Montreal: The Institute for Research on Public Policy, 2000) at 27).

publicly funded medicare. Patients and citizens have very few avenues of recourse vis-à-vis the funders and managers in the public health care system, whose cumulative decision-making determines waiting times. The perceived inability of the publicly funded health care system to ensure timely access to care has also become a platform for those who would like to see the introduction of two-tier medicine.<sup>177</sup> Failing to address in a systematic way the issue of timeliness has consequences not only for those individuals in need of care, but for the political sustainability of Canada's much cherished medicare program.<sup>178</sup> Equitable access cannot be achieved by simply stating that everyone has a right to access publicly funded care, as that right is hollow without also speaking to the issues of quality and timeliness.

To be clear, we are not advocating the elimination of waiting times for treatment. It would be extremely inefficient to run a system at a capacity that could meet all health needs the moment they arise (hospitals would be often empty, hospital beds would be unused or used by people who do not really need to be there, and health care professionals would be underutilized, all at great expense). Consequently some form of prioritization of health care needs and thus queuing or waiting is, somewhat ironically, a necessary characteristic of an efficient system. That being said, if there are no incentives within a publicly funded system to maintain standards regarding waiting lists and times, the evidence tends to suggest that waiting times will grow and that waiting lists may be unfairly administered. This not only places a significant burden on those who must wait, but undermines public confidence in the fairness and sustainability of the publicly funded health care system.

One of the goals of this article has been to consider whether it would be feasible to include a right to timely treatment and specific guarantees regarding waiting times in a patients' bill of rights. Such initiatives are not without precedent, and the experiences of the UK, Spain, Sweden, and Italy are worthy of consideration in this regard. Each of these countries has tackled growing waiting times and lists, either by setting out rights to timely treatment in legislation or by setting out expectations in a public document and following through with systematic changes designed to realize those targets. In England, patients are told what they can expect in terms of waiting times, and financial incentives are used to encourage managers within the public system to achieve those targets. In one region of Spain, residents have rights to treatment within maximum waiting times enshrined in law, and if the waiting time is exceeded, then the local health authority must pay for their treatment in another region or jurisdiction. In Sweden, residents have the right to choose any hospital they

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<sup>177</sup> See e.g. Susan Pinker, "Why Does Such a Big Issue Rest on the Shoulders of Two Citizens? FP Asks After Losing Private Medicine Battle" (2000) 162 CMAJ 1348.

<sup>178</sup> For an elaboration of this argument, see The Commission on the Future of Health Care in Canada, "Strengthening the Foundations: Modernizing the Canada Health Act" (Discussion Paper No. 13, August 2002), online: University of Toronto <<http://www.news.utoronto.ca/misc/FloodChourhry.pdf>>.

wish for treatment, and “money follows the patient”, which provides strong financial incentives to hospitals to keep waiting times down.

Have these initiatives been successful? Although there is some evidence to indicate that they have, particularly from Spain and Sweden, it is virtually impossible to conclude with certainty whether the observed successes are attributable to the establishment of a patients' bill of rights or to other factors. Efforts at reducing waiting time and lists often occur simultaneously with other system reforms and changes in the level of health care funding. We cannot conclusively determine whether reductions in the growth in waiting times and lists are simply a short-term blip; whether reductions have been achieved due to the particular nature of local supply conditions (e.g., surplus hospital capacity); or whether improvements are attributable to improved efficiency and management or the infusion of increased resources into the system. What is apparent, however, is that a patients' bill of rights can be a meaningful part of a package of initiatives to be undertaken by a government determined to tackle growing waiting times in the public system.

At a minimum, any Canadian government evaluating the merits of a patients' bill of rights should at least consider including not only rights *in* health care but also rights *to* health care. A patients' bill of rights that provides for both types of rights would also, and probably most importantly, go some way toward restoring public confidence in medicare. The inclusion of statements and guarantees of waiting times and list in the NHS Patient's Charter, for example, symbolized the UK government's commitment to respond to patients' concerns regarding timeliness. In providing for a right to timely care, the goal would be to reorient the system partially toward the justified concerns of Canadians and to impose some measure of accountability on the part of funders and/or managers for ensuring the delivery of timely care. A patients' bill of rights could set out generous *maximum* waiting times for different types of treatment (e.g., six weeks for oncology services or six months for non-urgent elective surgery, such as hip operations). The maximum time determined would obviously need to be done on the basis of the best scientific evidence available about the extent to which it is safe to allow patients to wait. Physicians would still triage patients on the basis of the acuity of their condition, but patients would have the security of knowing that they would not have to wait longer than the maximum waiting time.

It is clear, however, that a patients' bill of rights alone cannot cure all that ails medicare, and a key question is what other system reforms would be required to achieve the waiting time targets articulated in a patients' bill of rights. We envisage an independent commissioner or ombudsperson that would be charged with the task of investigating complaints in relation to access and timeliness. With respect to timeliness, unlike the rights *in* health care (such as the right to be treated with respect), the goal would not be to give redress to individual patients, but to provide for an independent audit with annual public reporting on the degree to which health authorities/provincial ministries of health are achieving waiting list targets. The annual exposure of this kind of information to the sunlight of public scrutiny should provide further incentive for decision-makers to strive to reduce overall waiting times.

The US system amply demonstrates the many access problems that can arise within a privately financed system. In our opinion, a patient ombudsperson should monitor access and waiting times in publicly funded medicare, as well as access to privately financed services (private insurers, home care, prescription drugs, nursing homes, etc.).

Another approach to addressing the issue of waiting times, coming out of the experiences in Spain, Italy, and the UK, would be to give patients who have been waiting beyond the maximum guaranteed time the option to have the necessary surgery performed in another city or jurisdiction at the expense of the relevant hospital or health authority unable to meet the waiting time target. Yet another approach from Sweden would be to allow patients to choose their own hospital and to pay those hospitals who treat more patients additional fees, thereby promoting competition between hospitals to reduce waiting times. These reforms have strong appeal, as they provide clear financial incentives for performance. As the use of financial incentives can be problematic, however, they should not be lightly employed without closely considering their possible downstream consequences. In particular, there is evidence from the UK that the initial employment of these kinds of incentives resulted in resources being shifted from one sector (outpatients) to another (elective surgery), with the result that waiting times improved in one area and worsened in another.<sup>179</sup> Having said that governments need to exercise caution in using strong financial incentives, we must point out, of course, that while the present system is already replete with financial incentives, none of them direct decision-makers to take waiting times seriously. Moreover, we can also point out that lessons learned in the UK could assist Canadian policy-makers in calibrating financial incentives, predicting and monitoring likely sources of tension (e.g., inappropriate resource shifting), and setting appropriate waiting list targets. Thus, although there are dangers in tinkering with incentives and a risk that unforeseen consequences might come to pass, there are also considerable dangers in governments not directly tackling, and not being seen to tackle, Canadians' concerns about timely access to treatment.

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<sup>179</sup> See Anthony Harrison, "The War on Waiting" in John Appleby & Anthony Harrison, eds., *Health Care UK Winter 2000: The King's Fund Review of Health Policy* (London: King's Fund Policy Institute, 2000) 52.