

# Policy Matters



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**A Patients' Bill  
of Rights: A Cure  
for Canadians'  
Concerns About  
Medicare?**



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Policy Matters

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## Summary

Even though most Canadians are satisfied with the health care they receive, they are becoming increasingly concerned about access to and, in particular, waiting times for treatment. This concern is driving mounting dissatisfaction with publicly funded medicare and providing a platform for those who would like to see the introduction of two-tier medicine. Growing waiting times not only place a significant burden on those who must wait, but also undermine public confidence in the fairness and sustainability of the publicly funded health-care system.

In this paper, the authors explore the prospect of a patients' bill of rights addressing the public's concerns about waiting times, and argue that this kind of initiative could contribute to improving public confidence in medicare. They examine the experiences of a number of jurisdictions that have implemented patients' rights legislation, including Quebec, the United States, New Zealand, England, Spain, Sweden and Italy.

The paper first distinguishes between rights *in* health care and rights *to* health care. Rights *in* health care arise in the context of the delivery of health services by doctors, nurses and other professionals and include, for example, the right to give an informed consent. Rights *to* health care, on the other hand, address rights of patients vis-à-vis public and private insurers to have treatments funded and/or delivered in a timely fashion. This kind of right necessarily engages issues of management and funding of the health-care system.

Historically, patients' bills of rights have been directed at rights *in* health care. In Canada, the common law and codes of ethics already recognize certain rights *in* health care. According to the authors, however, realizing rights to access timely treatment requires looking beyond the clinical patient-provider relationship to examine decision-making throughout the health-care system.

Currently, citizens have two main avenues to get government decisions regarding rights *to* health care in Canada reviewed: through the Canadian Charter of Rights and Freedoms and through various administrative tribunals. However, both suffer serious limitations. The Charter can help to protect citizens against discriminatory decisions not to fund specific health-care treatments, but most rationing decisions made in the system are not so explicit. Rationing (or at least prioritization) occurs as health-care professionals, faced with limited resources, make choices between different health-care needs and different patients. The result can be long waiting lists and times for nonurgent and (more rarely) urgent needs. The establishment of administrative tribunals, as is the case in Ontario, to hear patients' challenges to explicit governmental decisions not to fund certain treatments presents the prospect, because of lower costs and a lower threshold for enti-

tlement to cross, of offering justice to more people than is possible through Charter litigation. But neither the ability to appeal to an administrative tribunal nor Charter litigation result in any systemic incentives for decision-makers to take seriously citizens' concerns regarding timeliness of care.

Drawing from the experiences of other countries, the authors find that there would be benefits in adopting a patients' bill of rights providing for rights *in* health care as has occurred in New Zealand. These benefits include the enumeration of patients' rights and responsibilities, an enforcement mechanism that is more accessible than either the general courts or professional colleges, and a centralized complaints system. However, the authors conclude that in order to respond to Canadians' concerns a bill of rights must also speak of rights *to* health care and, in particular, a right to timely treatment.

The authors caution that a patients' bill of rights alone cannot solve the problem of growing waiting times and that other system reforms must occur. They recommend the creation of an independent commissioner or ombudsperson charged with the task of investigating complaints in relation to access and timeliness in publicly funded medicare, but also access to privately financed services (private insurers, home care, prescription drugs, nursing homes, etc.). An independent commissioner or ombudsperson would be required to produce an annual public report on the degree to which health authorities and/or provincial ministries of health are achieving waiting list targets. Another (complementary) approach would be to give financial incentives to health authorities for better performance by allowing patients who have been waiting beyond the maximum guaranteed time the option of treatment in another city or another jurisdiction (as in the UK, Spain and Italy) or by allowing patients to choose their own hospital (as in Sweden).

A government determined to tackle waiting times in a public system should view a patients' bill of rights as one part of a package of reforms required. Failing to grapple with the problem of growing waiting times, the authors conclude, will have consequences, not only for individuals in need of care, but also for the political sustainability of medicare.

## Résumé

Si la plupart des Canadiens se disent généralement satisfaits des soins de santé qu'ils reçoivent, ils sont de plus en plus préoccupés de l'accès à ces soins et, surtout, des délais d'attente pour les traitements. Cette inquiétude suscite une insatisfaction grandissante à l'égard de notre système de santé et procure de solides arguments aux partisans d'un système à deux vitesses. Non seulement cette attente pèse-t-elle lourd sur les patients qui doivent ainsi attendre, mais elle mine en outre la confiance de la population envers l'équité et la pérennité du régime public de santé.

Aussi les auteures de ce document examinent-elles l'opportunité d'adopter une déclaration des droits des patients qui répondrait aux inquiétudes de la population quant aux délais d'attente, soutenant qu'une telle initiative pourrait contribuer à rétablir sa confiance dans le système de santé. Elles étudient l'expérience de juridictions ayant voté des lois pour protéger les droits des patients, au Québec, aux États-Unis, en Nouvelle-Zélande, en Angleterre, en Espagne, en Suède et en Italie.

Les auteures font tout d'abord une distinction entre les droits *en* santé et les droits *à* la santé. Dans le premier cas, ces droits portent sur les services fournis par les médecins, le personnel infirmier et autres spécialistes de la santé, par exemple le droit à un consentement informé. Dans le second cas, il s'agit du droit d'accessibilité aux soins en temps opportun et du droit d'obtenir de la part d'assureurs privés ou publics le financement nécessaire, ce qui soulève nécessairement des questions de gestion et de financement du système de santé.

Historiquement, les déclarations de droits des patients ont surtout porté sur les droits *en* santé. Au Canada, le droit commun et les codes de déontologie reconnaissent certains droits en la matière. Mais selon les auteures, l'octroi de droits à la santé réclame de dépasser la relation clinique patient-fournisseur pour analyser globalement les processus de décision au sein du système de santé.

Il existe au Canada deux principaux moyens d'évaluer les décisions gouvernementales touchant les droits à la santé : la Charte des droits et libertés et divers tribunaux administratifs. Tous deux ont cependant d'importantes limites. L'examen de la jurisprudence pertinente permet d'avancer que la Charte peut certes protéger les citoyens contre le refus discriminatoire de financer certains traitements, mais il reste que beaucoup sinon la majorité des décisions de rationnement ne sont jamais évaluées ou explicitées. Ces décisions sont souvent prises par des professionnels de la santé qui, faute de disposer des ressources nécessaires, sont amenés à privilégier certains soins et certains patients. Une pratique qui vient allonger les délais et listes d'attente pour les patients nécessitant des soins peu urgents mais aussi, quoique plus

rarement, des soins très urgents. Des tribunaux administratifs comme il en existe en Ontario, qui permettent de contester les refus gouvernementaux de financer certains traitements, offriraient à un plus grand nombre de patients de meilleures chances d'obtenir justice que le recours à la Charte, en raison notamment de coûts moindres et de conditions d'admissibilité plus souples. Mais cette possibilité d'en appeler devant un tribunal ou en vertu de la Charte n'a jusqu'ici incité aucun décideur à prendre vraiment au sérieux les inquiétudes des citoyens concernant la rapidité d'accès aux soins de santé.

Ayant analysé l'expérience d'autres pays, les auteures concluent que l'adoption d'une déclaration des droits des patients comportant des droits *en santé*, ainsi qu'on l'a fait en Nouvelle-Zélande, présenterait plusieurs avantages. Cela permettrait d'établir une définition claire de ces droits, en créant un mécanisme ayant force de loi plus accessible et plus légitime, et d'offrir un système de plaintes centralisé à point d'entrée unique. Toutefois, pour remédier aux inquiétudes des Canadiens relativement au temps d'attente, cette charte devra aussi inclure des droits à la santé, notamment un droit à des soins sans délais indus.

Les auteures y vont toutefois d'une mise en garde : une déclaration des droits des patients ne suffirait pas à tout régler et devrait donc s'accompagner d'autres réformes. Aussi recommandent-elles de confier à un commissaire ou un protecteur du citoyen indépendant la tâche d'enquêter sur les plaintes relatives aux problèmes d'accès et de délais soulevés tant par le régime public de santé que par les services privés (assureurs privés, soins à domicile, médicaments d'ordonnance, maisons de retraite, etc.). Il produirait aussi un rapport annuel sur les progrès accomplis en la matière par les autorités de santé ou les ministères provinciaux de la Santé. En complément, on pourrait envisager des incitations financières destinées à encourager les autorités de santé à mieux performer en termes de rapidité de traitement, en permettant par exemple à des patients en attente depuis plus longtemps que ne le prévoient les délais maximaux d'être traités dans une autre ville ou une autre région (comme c'est le cas en Angleterre, en Espagne et en Italie), ou de choisir leur propre hôpital (comme en Suède).

Tout gouvernement résolu à s'attaquer au problème des délais d'attente de son système de santé devrait considérer ce type de déclaration comme un élément clé d'un ensemble plus vaste de réformes. Faute de quoi, concluent les auteures, les Canadiens en quête de soins en souffriront tôt ou tard, tout comme la pérennité politique de ce système auquel nous tenons tant.

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A Patients' Bill of Rights: A Cure for Canadians' Concerns About Medicare?
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## Introduction

There is momentum for health reform in Canada. The Standing Senate Committee on Social Affairs, Science and Technology chaired by Senator Kirby released its "Final Report on the State of Health Care in Canada" in October 2002.<sup>1</sup> Canada's federal government has commissioned Roy Romanow, former premier of Saskatchewan, to report on the future of health care in Canada by the end of November 2002.<sup>2</sup> The Senate and Romanow reports follow closely after reports commissioned by the Alberta,<sup>3</sup> Saskatchewan<sup>4</sup> and Quebec<sup>5</sup> provincial governments. The reports to date call for varying but significant reform of medicare. The present federal Liberal government will need to act in response to these various recommendations or risk diminishing its stock of credibility as protector of publicly funded medicare. Politically the timing is crucial, being in a period prior to an election and with jostling for the leadership of the Liberal party under way. The new minister of health, Anne McLellan, has said that reform will be implemented within months of Romanow's report.<sup>6</sup> But what kind of reform will the federal government implement from the range of proposals presented in the Senate report and from the range of proposals that Roy Romanow will surely present?

One possibility for reform is to establish a national "patients' bill of rights." Indeed, five of the ten Canadian provinces have independently either implemented or are considering implementing a patients' bill of rights. Quebec, since 1991, has had legislation setting out patients' rights and has recently enacted new legislation that gives an ombudsman greater power to enforce those rights.<sup>7</sup> The Ontario government has promised that legislation will be introduced 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>8</sup> Legislation is currently under development.<sup>9</sup> The introduction of a patients' bill of rights has also been considered in Saskatchewan, New Brunswick<sup>10</sup> and Manitoba, and in September 2001 the Senate Committee put forward a patients' charter of rights as a reform option worthy of serious consideration at the national level.<sup>11</sup> A patients' bill of rights is obviously a popular reform proposal, but will 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 private options. This paper explores the prospects of a patients' bill of rights addressing Canadians' concerns about medicare and in so doing examines the experiences of jurisdictions that have implemented patients' rights legislation.

We begin by examining what Canadians' greatest concerns are with respect to medicare and argue that Canadians are primarily concerned about access to and, in particular, growing waiting times for treatment. We then explain the distinction

between rights *in* health care and rights *to* health care, the extent to which these different types of rights are protected in Canada and consider whether a patients' bill of rights could be a useful addition to protections already in place. We then turn to an examination of the experiences of Quebec, New Zealand, the United Kingdom, Spain, Sweden and Italy in protecting rights *in* and *to* health care through the medium of a patients' bill (or charter) of rights. Our particular focus is on those countries that have used a patients' bill of rights as a tool to address concerns about waiting lists and times.

## What Are Canadians' Concerns?

Canadians who use the health-care system are generally very satisfied with the care they receive, but they are extremely concerned about the growing waiting times for treatment.<sup>12</sup> A report released 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 health-care provider were frequently cited by those who experienced difficulty accessing care.*

The report went on to note that

*Among those waiting for specialized services, between 21.7 percent of those who waited for non-emergency surgery and 26.7 percent 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>13</sup>*

A number of policy analysts point out that there is little 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>14</sup> Some experts argue that "waiting" is not a problem worthy of concern in the absence of evidence that waiting longer periods of time for treatment will have an adverse impact on patients' health. Canadians remain unfazed by academic skepticism and are unpersuaded that

waiting times are not really a problem.<sup>15</sup> Canadians' concerns about waiting for care are fourfold:

1. Timeliness of treatment has the potential to have a significant impact on the chances of a successful cure or even of 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).
3. Delays in receiving care can result in private costs in terms of lost days of work, lost income and reduced productivity — costs which 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 in Ontario found cancer patients experience major psychological stress as a result of delays in diagnosis or treatment.<sup>16</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>17</sup>

The division between academic and public opinion on the impact of waiting for care rests at least in part on the importance each group attaches to linking treatment to measurable health-care outcomes. Many prominent health policy analysts in Canada support the concept of “evidence-based medicine.” Evidence-based medicine, grounded in health economics and health services research, argues that governments should only publicly fund health-care services that have a measurable impact on health-care outcomes.<sup>18</sup> Thus many health policy analysts will concede that timeliness is of relevance insofar as it impacts on the first of the concerns listed above of course (i.e., upon morbidity and mortality), but not necessarily the other three concerns. Citizens and patients, on the other hand, want to achieve positive health outcomes, but they 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. But timeliness is no less important to Canadians simply because its inherent value is more difficult to measure.

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

Given that access to and timeliness of treatment is the most important health-care issue for Canadians, will a patients' bill of rights effectively address this concern?

Let us first clarify 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 by doctors, nurses and other providers of health-care services. Secondly, there may be rights of access *to* health-care services, i.e., rights of patients vis-à-vis public and private insurers to have certain treatments funded and/or delivered in a timely fashion.<sup>19</sup> Historically, patients' bills of rights have protected rights *in* health care, i.e., the rights of patients vis-à-vis doctors, nurses and other health-care professionals. However, in order to address Canadians' key concerns about access and waiting times, a patients' bill of rights must recognize both rights *in* health care and rights *to* health care. That is, a patients' bill of rights needs to focus on both the clinical relationship (health-care providers and patients) and entitlement relationships (patients and/or citizens and health-care insurers, payers and/or managers, e.g., ministries of health, regional health authorities, community care centres, private insurers, etc.).

### **Rights *in* Health Care**

The common law recognizes certain rights *in* health care. These rights include the right to give informed consent,<sup>20</sup> to confidentiality,<sup>21</sup> to have access to one's own medical records<sup>22</sup> and to receive treatment that is provided with a reasonable degree of care.<sup>23</sup> Enforcement of these kinds of legal rights is discussed further below under "civil liability." Various professional colleges (e.g., the College of Physicians and Surgeons), 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 mirroring many common law rights, also often recognize rights *in* health care of a more intangible nature, e.g., that patients 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>24</sup> We discuss enforcement by professional colleges below under "self-regulation."

### *Self-regulation*

Provincial governments have granted self-regulatory status to the medical professions<sup>25</sup> empowering them to control entry to the professions, regulate quality and ensure that members adhere to standards of professional conduct.<sup>26</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 peers.<sup>27</sup> But self-regulation, as a form of regulation, is increasingly criticized for failing to protect the public from harm.<sup>28</sup> In recent years, there has been a "dramatic erosion in the public's confidence in self-regulation."<sup>29</sup> Self-regulating professions are frequently challenged on the basis that they have a conflict of interest and "an inappropriate unwillingness to report or act upon the incompe-

tent or unethical behaviour of colleagues.”<sup>30</sup> Another criticism made of self-regulatory systems is that many patients do not know where to make complaints or what they are entitled to complain about.<sup>31</sup>

A complex interaction of decisions goes into ensuring safety and the delivery of high quality care. Mistakes made by individual 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 reporting and communications systems has been demonstrated by recent high-profile tragedies such as the deaths of 12 infants in the Winnipeg pediatric-cardiac program<sup>32</sup> and the deaths of 29 children at the Bristol Royal Infirmary in the UK.<sup>33</sup> Quality of care is also indirectly linked to resource allocation decisions made by insurers, payers and managers like Health Canada, provincial ministries of health, private insurers, regional health authorities, etc. Self-regulation does nothing to ensure the competence of these kinds of decision-makers, and the colleges have the power to investigate only the actions of individual members of their professions as opposed to the actions of hospitals or other institutions<sup>34</sup> or of health-care funders and/or managers.

#### *Civil liability*

The threat of medical malpractice litigation ostensibly provides a strong incentive to health professionals to provide care of an adequate quality. The Pritchard 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.<sup>35</sup> However, Pritchard also stressed that efforts must be made to increase and improve redress mechanisms, particularly complaints and discipline procedures.<sup>36</sup> One in 25 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>37</sup> But the fact that litigation against physicians is on the increase has to be put in context as the vast majority of patients do not pursue malpractice claims because of the time, stress and costs involved or because they do not know that a medical error has been made.<sup>38</sup> Apart from the fact that litigation provides compensation to only a very few patients, many have argued (notwithstanding the Pritchard report) 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 litigation.<sup>39</sup>

Physicians have tried to defend themselves against claims of malpractice by arguing they had inadequate resources because of rationing decisions made by funders and managers. Canadian courts are generally unsympathetic to such

claims. For example, J. 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>40</sup> But in reality each day physicians must make decisions that balance the needs of their own and other patients. The resources they have to work with and the efficiency of the systems they work within 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 is largely due to the difficulties of launching a civil action against a government as true policy decisions (as opposed to operational functions) are exempt from tort claims.<sup>41</sup> It is also due 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.

#### *Internal complaints mechanisms*

A number of health-care institutions have internal bills of rights codifying the standard of services that patients can expect to receive. For example, the Toronto General Hospital has a “Patient Bill of Rights and Responsibilities” that includes the right to be treated in a considerate and respectful manner.<sup>42</sup> A number of institutions also maintain an internal complaints mechanism to provide patients an opportunity to express and resolve their concerns.<sup>43</sup> These are positive initiatives, helping to ensure prompt treatment of patients’ concerns. However, as these are voluntary initiatives there is variation in the nature of the rights granted and the level of enforcement. Also, patients may view internal complaints mechanisms as lacking independence and impartiality. Thus there is a strong argument for a supervisory appeal body to which a patient can turn if dissatisfied with how a health-care institution has dealt with a complaint and for legislation that applies across all providers providing for minimum standards and levels of enforcement.

#### *Conclusion: The value added 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 clear problems. Self-regulation has been criticized for lacking sufficient independence and being unresponsive to patients’ needs. Civil litigation is costly, time-consuming and arbitrary as to whom it punishes and compensates. Voluntary steps taken by institutions to address complaints are piecemeal and lack the objectivity of independent review. A patients’ bill of rights, monitored and enforced by a specialist

patient ombudsman or commissioner, presents 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. However, as we discuss further below, the concerns we have about our present system of protecting patients' rights *in* health care pale relative to the very few avenues of recourse there are for ensuring patients' rights of access *to* quality care in a timely fashion.

### Rights to Health Care

Many Canadians are surprised to find there is in Canadian law no free-standing right to receive health care.<sup>44</sup> The *Canada Health Act* is an icon of Canadian citizenship, but in technical terms it only sets out conditions that provincial governments must comply with 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 obtain a review of a government decision regarding rights *to* health care. The first is the Canadian Charter of Rights and Freedoms. The most prominent recent cases are *Eldridge v. British Columbia (Attorney General)*,<sup>45</sup> *Cameron v. Nova Scotia (AG)*,<sup>46</sup> *Chaoulli c. Québec (Procureur général)*<sup>47</sup> and *Auton (Guardian ad litem of) v. British Columbia (Minister of Health)*.<sup>48</sup> The second route is through appeal to an administrative tribunal.

#### *Charter cases*

Generally, Charter cases involve challenges to a provincial government's refusal to publicly fund a particular treatment. In *Eldridge*, the Canadian Supreme Court held that the British Columbia government discriminated against deaf patients in refusing to fund sign-language interpreters in public hospitals. *Cameron* concerned the Nova Scotia government's decision not to fund a male infertility treatment. The Nova Scotia Court of Appeal ruled that the government had discriminated against the infertile but that this decision was saved by Section 1 of the Charter (a reasonable limit prescribed by law and demonstrably justified in a free and democratic society) because of the high cost of fertility treatments. Leave to appeal to the Supreme Court was denied.<sup>49</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. This decision was affirmed in the British Columbia Court of Appeal.<sup>50</sup>

Apart from Charter cases challenging a provincial government's failure to fund treatments, there is at least one case challenging restrictions on the existence of privately funded hospital and physician services.<sup>51</sup> *Chaoulli c. Québec*

(*Procureur général*)<sup>52</sup> involved a challenge to the Quebec government's prohibition on private health insurance for services covered by the public plan. The plaintiff wished to have private insurance to buy care that was ostensibly covered by the public plan but for which there were waiting lists. The 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 Section 7 rights of liberty and security of the person. However, after balancing the individual right to choose and access necessary health services against the collective goal of ensuring equal access to all, the Court found these violations to be in accordance with fundamental justice, and therefore not in violation of Section 7 of the Charter.

Thus 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 plaintiffs may become more successful in this regard. One could possibly 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 the means (interpretation services) to utilize health-care services that similarly situated patients without a hearing impairment were already entitled to. However, in *Auton* the British Columbia Supreme Court expressly rejected this means of limiting the precedent of *Eldridge*.<sup>53</sup> Notwithstanding this, the victories of a few patients are relatively modest and the expense and delay inherent in Charter litigation means that recourse to the Charter remains an unsatisfactory way to deal with most grievances and concerns citizens have regarding access to health care. Also, 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, the Charter can protect against explicit governmental decisions that openly deny or prevent access to a particular treatment, but most decisions are not so explicit and have an indirect effect on the availability of care.

#### *Administrative tribunals and judicial review*

In Ontario and British Columbia there are arms-length administrative tribunals that will hear claims by patients that provincial insurance plans should publicly fund particular treatments.<sup>54</sup> A high profile case in Ontario involved a successful claim to publicly fund a genetic test for the BRCA1 gene. The patient needed this test to determine whether she was genetically predisposed to breast cancer and so should take radical preventive measures.<sup>55</sup> Independent adminis-

trative tribunals like the Health Service Appeal and Review Board in Ontario provide an outlet for patients' concerns about the breadth of publicly funded schemes. Providing avenues of appeal to these kinds of administrative tribunals is a more efficient and fairer means of resolving disputes about what services should and should not be publicly funded *in general* than expensive and protracted Charter litigation.<sup>56</sup> Also, a patient may seek judicial review of an administrative tribunal's decision in the regular courts, either on the grounds that a fair process was not followed or that the decision was unreasonable in the circumstances.<sup>57</sup> The existence of an appeal route to an administrative tribunal need not open the floodgates for discontented patients to make claims. Of the 155 cases heard in Ontario in 2000, the Board upheld the patient's claim only 17 times.<sup>58</sup>

However, despite the advantages, establishing an administrative tribunal will not cure all the problems associated with civil litigation. To appear 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.

#### *Right 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 Ontario Health Services Appeal and Review Board will hear requests for out-of-country treatment where care is not available within a reasonable period of time. However, the delay must be such as to "result in death or medically significant irreversible tissue damage."<sup>59</sup> So in *extreme* cases, if a patient can demonstrate that failure to provide timely care is likely to put them in significant peril, he or she may be able to claim public funding for out-of-country treatment. However, this is a very narrow window of redress. Furthermore, there are currently independent administrative tribunals only in Ontario and British Columbia.

General administrative law may also, in extreme cases, provide a remedy to patients who have had to wait too long for treatment. The first example of this that we know of in Canada is the Quebec Superior Court case of *Stein v. Québec (Régie de l'Assurance-maladie)*.<sup>60</sup> In this case Mr. Stein's doctors warned his life was in danger and 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 obtain the treatment he needed and then sought to challenge the Quebec Health

Insurance Board's refusal to pay for his treatment. He was successful on the grounds that, given the facts of the case, the Board's decision not to pay for the treatment was patently unreasonable.

Thus 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). Even in provinces that have established tribunals to hear such claims, the window of appeal is very narrow (e.g., in Ontario the delay must be said to have caused "medically significant irreversible tissue damage or death"). Many times patients will be in a situation where there are significant risks (and severe psychological stress) in waiting for treatment, but it will be difficult to show conclusively that waiting will put the patient in extreme peril. Moreover, requiring a patient to initiate and make out a case in this regard when they are unwell and in need of care imposes a very high barrier to claims being made. Mr. Stein was fortunate enough to be able to pay out-of-pocket for the care he needed in New York and then subsequently seek reimbursement. Not all patients are so fortunate. Moreover, 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 seriously citizens' concerns regarding timeliness of care.

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 plays 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 patients in Ontario with some medical conditions are more likely to die if they are admitted to hospital on a weekend rather than a weekday. The reasons given for this phenomenon are lower staffing levels in acute care hospitals on weekends as well as higher numbers of staff who are less experienced, managed by fewer supervisors and covering for more absent staff.<sup>61</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 15 months for elective surgeries whereas in most cities children could expect to wait less than 10 weeks.<sup>62</sup> These problems are not addressed by establishing and enforcing rights *in* health care and reviewing physician decision-making, but could be addressed by putting in place rights *to* access timely health care. Thus there are strong arguments to consider introducing a patients' bill of rights that incorporates some guarantee or commitment on the part of provincial governments to ensure timely access to services for Canadians.

## Lessons from Different Jurisdictions

In this section we examine the experiences of jurisdictions implementing patients' bills of rights, particularly focusing on those jurisdictions where rights have been established *to* access health-care services in a timely fashion. The jurisdictions we will examine are Quebec, New Zealand, the UK, the US, Sweden, Spain and Italy.

### Quebec, Canada

In Quebec, users' rights *in* and *to* health care are set out in legislation put in place in 1991.<sup>63</sup> This legislation established the Complaints Commissioner who oversees enforcement of patients' rights and to whom appeals may be made with respect to determination of complaints by regional boards. New legislation, which came into force in January 2002, replaces the Complaints Commissioner with the Health and Social Services Ombudsman (the Ombudsman), who has greater power to enforce patients' rights.<sup>64</sup>

The new Act gives the Ombudsman power, in certain circumstances,<sup>65</sup> to intervene directly 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 person working for such a body.<sup>66</sup> The Ombudsman has the general power to "by any appropriate means" see that users are respected and their rights<sup>67</sup> enforced. The Ombudsman's main function is the examination of complaints by users. He or she also has the function of ensuring that institutions and regional boards handle the complaints addressed to them in conformity with the procedures set out in the Act. The Act aims to speed up the handling of user complaints by establishing an examination process comprising two levels instead of three.<sup>68</sup>

The Act provides for important procedural changes in enforcing patients' rights in Quebec, but it does not change the content of patients' rights. The 1991 legislation provides for rights *in* health care, such as the right of a patient to give consent to treatment and to participate in any decision affecting his or her state of health or welfare. The Act also includes rights *to* health care. Section 7 provides that "every 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." There is, however, no right to receive timely treatment. 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>69</sup>

In sum, the Quebec system provides for patients to make complaints to health-care institutions and regional boards<sup>70</sup> for the resolution of those complaints and for appeal to an independent body, but does not provide for any rights to access timely health care treatments. The success of the legislation will depend in large measure on how vigorous the new Ombudsman is in enforcement. The extent to which the Ombudsman will be proactive may be tied to the degree of independence he or she has from government. Concerns have been expressed about the fact that the Ombudsman is answerable to the minister of health and social services and not to the National Assembly.<sup>71</sup>

### The 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 accessing needed health care. These measures do not seek to expand the numbers of people covered by private insurance (approximately 16.3 percent of US citizens, mainly the working poor, have no health insurance<sup>72</sup>), but rather comprise 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>73</sup> as well as by patients' bills of rights in a number of states.<sup>74</sup> In 1996 the US federal government enacted the *Health Insurance Portability and Accountability Act*.<sup>75</sup> This Act does not tackle the problem of the uninsured in the system but makes some attempt to restrict insurers, employers and managed-care plans from dropping coverage for people once they become in need of expensive health-care services. More recently, the US House of Representatives<sup>76</sup> and the US Senate have respectively passed bills providing for a bill of patients' rights.<sup>77</sup> 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>78</sup> Both bills enable patients to appeal decisions of a managed-care plan to an independent review board.<sup>79</sup> Both bills also overcome, in significantly different degrees, the limitations of the *Employee Retirement Income Security Act* (ERISA), a Byzantine piece of federal legislation that is viewed as a significant impediment to patients suing managed-care plans in state courts.<sup>80</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 outright deny a treatment on the basis of cost but will frame the decision as a medical one.<sup>81</sup> Implicit rationing is more difficult to detect and regulate than explicit rationing; nonetheless, some attempts are made. For example, 48 of the 50 states prohibit the use of “gag clauses” where managed-care plans prohibit doctors from discussing with patients treatments their plan does not cover, attempted referrals that the plan has refused, and the terms of financial incentives doctors receive.<sup>82</sup> Similarly, both the Senate and House bills would prohibit gag clauses.<sup>83</sup>

In addition, there is a patchwork of federally mandated and state-initiated consumer assistance programs across the 50 states.<sup>84</sup> State-initiated programs fall into two main categories: Medicaid ombudsman programs (for the poor) and general health-care ombudsman programs (that serve people with private insurance).<sup>85</sup> These programs have three main functions: investigating and resolving consumer complaints, education about consumers’ health-care rights and providing feedback to policymakers on how to improve the performance of the health-care system.

What can Canada glean from the US experience? The US system is sharply distinguishable from the Canadian system because of its failure to guarantee all citizens access to health care and its significantly greater reliance on private insurance and private financing. Moreover, for well-insured Americans there does not seem to be a problem with waiting lists and times. Despite these obvious differences, the US experience with regulation of private insurers and managed-care companies warrants examination when considering how to regulate entitlements and access to timely treatment within the Canadian public insurance model. 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>86</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 15 percent of the recent rise in health-care costs.<sup>87</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 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, as management and budgetary responsibility (and thus the task of realizing patients' rights) for health insurance programs primarily rests with the ten provinces.

### New Zealand

The growth of a patients' rights movement in New Zealand began in force in 1987 when it was revealed that an estimated 30 women<sup>88</sup> with cervical carcinoma in situ died as a result of the failure to provide appropriate treatment at an Auckland hospital. These women had, without their consent, been enrolled in a research trial that 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 this maltreatment went unchecked. As a result of the Committee's report,<sup>89</sup> Parliament in 1994 passed the *Health and Disability Commissioner Act*. The goal of this legislation is to protect the rights of "consumers"<sup>90</sup> of health and disability services by providing an accessible, independent and consumer-friendly complaints mechanism.<sup>91</sup> To this end, a Code of Health and Disability Consumers' Rights (the Code) was enacted in 1996 as a regulation under the Act.

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;
- the right to complain; and
- rights in respect of teaching or research.

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 consumers' rights and investigating alleged breaches of the Code.

The Code is limited as there is no right to receive treatment or to receive timely treatment.<sup>92</sup> Moreover, clause 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 clause 3 of the Code “takes into account factors such as a consumer’s clinical circumstances and a provider’s resource constraints.”<sup>93</sup> Although it is surely correct not to hold a provider to account where there are inadequate resources, this raises the question of who 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 a consumer’s relationship with a health-care provider. It does not provide citizens with rights vis-à-vis public-sector decision-makers, and the Commissioner, directly investigate the actions of District Health Boards. The Health and Disability Commissioner does, however, have the power to investigate and report on “generic systems issues,”<sup>94</sup> which indirectly provides some means of review of public-sector decision-makers.

Although New Zealand’s Code of Rights is limited to primarily protecting rights *in* health care, in this regard 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 in complaints (88 percent increase between 1980 and 1990; a 43 percent increase between 1996 and 2001<sup>95</sup>) against doctors since the Commissioner’s office was founded. 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 procedures. The legislation emphasizes resolution of complaints, and this means that few complaints are ultimately referred for disciplinary hearings.<sup>96</sup>

### United Kingdom

The United Kingdom’s Health Services Ombudsman may investigate complaints from a person who “has sustained injustice or hardship” as a consequence of “a failure in a service provided by a health service body, a failure of such a body to provide a service which it was a function of the body to provide, or maladministration connected with any other action taken by or on behalf of such a body.”<sup>97</sup> In 1996 the Ombudsman’s authority was extended to hear complaints regarding all aspects of publicly funded health-care services and complaints regarding the clinical judgement of physicians, nurses and other clinical professionals.<sup>98</sup> The Ombudsman may now also investigate the actions of private health providers.

The relevant legislation expressly provides that the Ombudsman is unable to question the merits of a decision taken by a body in the course of exercising any discretion vested in that body except in the case of maladministration.<sup>99</sup> This provision would seem to restrict the Ombudsman’s capacity to question resource allocation decisions and systemic issues causing growing waiting times and lists.

Indeed, the Ombudsman in her 2000-2001 annual report noted that she had received several complaints about long waiting times, but found "the allocation of resources is a matter for the NHS [National Health Service] and local managers, and not for me." But she did go on to note that she is not completely without some power to deal with issues of waiting lists and times: "However, I may criticize trusts which have not taken explicit and open decisions about resource allocation, have not well-supported criteria for urgent access to services; or have no mechanisms for re-assessing individuals' needs for the service."<sup>100</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 Patients' Charter. The Charter, first introduced in 1992, set out national standards regarding what patients in the public system could *expect* in terms of access and treatment (as opposed to being enforceable rights). At the regional level, health authorities and NHS trusts (which manage the public hospitals) were encouraged to negotiate even higher standards, and every year health authorities published a report on each hospital's performance against Charter standards. A revised Patients' Charter, introduced on April 1, 1995,<sup>101</sup> provided that patients were "to be guaranteed [hospital] admission for treatment for a specific date within two years," subsequently reduced to eighteen months and then to a target of twelve months for some procedures. In addition to rights the Charter also set out nine standards, including respect for privacy, dignity and religious beliefs, and specific guarantees with respect to waiting times, e.g., a guarantee of being seen within thirty minutes in an outpatient clinic.

The New Labour reforms of December 1997 proposed to improve the Patients' Charter to "tell people about the standards of treatment and care they can expect of the NHS. It will also explain patients' responsibilities."<sup>102</sup> As of April 1, 2001, an NHS Guide has replaced the Charter in England, but the Patients' 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>103</sup> The new Guide has been criticized for being too vague about what patients can expect and for failing to explicitly state patients' rights to, for example, the right to a free yearly health check if over 75 years old.<sup>104</sup> As with the Charter that preceded it, the Guide provides for patients to make complaints but *does not create legally enforceable rights*. However, the new Guide does 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 28 days. If a hospital fails to comply it must pay for the treatment at a time and in a hospital chosen by the patient.<sup>105</sup>

Have the guarantees and statements made in the 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>106</sup> The number of individuals waiting for elective procedures fell by 2.9 percent in the period December 1994 to March 1995, at which point there were 1,040,161 people on waiting lists. Approximately the same number of people were on waiting lists at September 30, 1995.<sup>107</sup> The number of people waiting for more than 12 months for elective procedures on September 30, 1995 was 27,900, a reduction of 55 percent since September 1994, when there were 62,300.<sup>108</sup> Through 1997 waiting lists started to increase again, with 1,207,500 waiting at the end of September 1997 (an increase of 1.5 percent over the previous quarter) and with the number of people waiting for more than 12 months increasing by 24 percent.<sup>109</sup> The numbers waiting had slightly declined by January 31, 1999, with 1,159,400 people waiting and with the number of people waiting more than twelve months dropping to 54,600.<sup>110</sup>

But the mere fact that there is some evidence that the numbers of people waiting declined does not reveal very much. It has now become clear that waiting lists are not as important an indicator as waiting times and that governments should focus on the latter.<sup>111</sup> Moreover, 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 waves of health-care reform have been implemented in the UK. As a result we cannot conclusively determine whether reductions in the growth in waiting times and lists are a short-term phenomenon and will simply rise again at the same pace; whether improvements have been due to improved efficiency and management within the system; or whether improvements have been due to increased resources being invested in the system. There was also some evidence that reductions in waiting times were at the cost of promptly treating those with acute needs, which indicates the need to be very cautious in the use of incentives to change decision-making behaviour.<sup>112</sup> Despite these caveats, one can say that the evidence from the UK in the late 1980s and 1990s was that waiting times declined in response to a combination of infusions of public funding and mechanisms to change incentives within the public sector.<sup>113</sup> The inclusion of statements and guarantees in a Patients' Charter and now in a Patients' Guide do not confer rights 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 Patients' Charter could be viewed as symbolizing a commitment by UK governments 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 combination of methods used to change behaviour must be carefully calibrated so as not to simply cause other problems in the system, e.g., shifting resources away from treating those with acute needs to those who have waited too long for elective surgery.

### Spain

In the UK, guarantees regarding waiting times cannot be enforced by individual patients. By comparison, in the Navarra region of Spain, guarantees regarding waiting times are enshrined in legislation.

Over the last seven years in Spain, three out of eight regional health authorities that have adopted policies designed to reduce the length of waiting lists have shown better waiting list and/or time indicators and patient satisfaction.<sup>114</sup> According to Tony Ramirez-Arellano (Health Advisor to the Cabinet of the Spanish Prime Minister) the average waiting time for surgery (in days) declined from 135 in 1996 to 68 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 increased to 166,583 in 2001.<sup>115</sup> The Spanish waiting list initiative incorporated four different types of measures. These were: 1) validating information systems regarding the numbers 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 overtime in public hospitals; and 4) requiring that if a hospital is unable to meet a waiting time target, the regional health government will pay for the patient to access care in the private sector.

The greatest reduction in waiting times occurred in the Navarra Health Service, which incorporated waiting standards into its regional legislation.<sup>116</sup> The legislation in Navarra provides for a maximum waiting time of 180 days for elective surgery treatments.<sup>117</sup> A central unit is charged with assessing the situation of each patient on the waiting list.<sup>118</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. Where this occurs, the regional government in question pays all costs,

including the transport and living expenses of both patient and companion. Following the success in Navarra, the regional government of Andalusia is taking steps to incorporate guarantees of maximum waiting times in its patients' rights legislation.<sup>119</sup>

Thus it seems that the Spanish initiatives have met with much success; but it is not possible to extrapolate from this experience alone and conclude that such an initiative would necessarily work in other jurisdictions. For example, Spain's success 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.

### Sweden

According to Blomqvist, in Sweden the right of all residents to all "necessary" health care is part of national legislation.<sup>120</sup> In 1992, the "Patient Choice and Care Guarantees" (PCCG) was introduced. The PCCG reform was directed specifically at hospital care and provided that patients requiring surgery or other hospital treatment would have the right to freely choose the hospital in which they would receive treatment (in the expectation that patients would choose hospitals with the shortest waiting lists). In addition, the PCCG specified that money would follow the patient. Consequently, if a patient elected to receive care in a hospital other than the one to which he or she was originally assigned, a specified sum of money would be transferred from the budget of the latter to that of the former. As a result Blomqvist notes there has been substantial reduction in waiting times for important kinds of elective surgery, to the point where, by the end of 1993, waiting lists "ceased to be a political issue."<sup>121</sup> More recently, maximum waiting time guarantees have been introduced for consultations with primary care doctors and specialists. Blomqvist notes that the guarantees specify the maximum waiting time before a person will be seen by a doctor in primary care (eight days, although of course patients are seen by other personnel, such as a nurse, before that) or to see a specialist (three months).

The Swedish experience is of particular interest as the rights granted to patients were not in regard to any specific maximum waiting times but rather the right to freely choose a hospital. In Canada, there are no provincial restrictions on which hospitals a patient can be treated in. However, in Canada hospitals are "block funded," i.e., they receive a lump sum largely independent of how many patients they treat or services they provide. It would be a radical departure in the Canadian context to move away from block-funding hospitals and for funds to follow patients, thus providing an incentive for hospitals to compete for patients by reducing waiting times. Undoubtedly, such a proposal would have conse-

quences for long-term planning, financial stability and prioritization of resources within hospitals. Thus the Swedish approach to waiting lists cannot be recommended without close study, but what evidence there is suggests it is worthy of consideration.

### Italy

Article 32 of the Italian Constitution provides that “the Republic protects health as a fundamental right of the individual and as a concern of the collectivity and guarantees free care to the indigent.” 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>122</sup> For example, the 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>123</sup> Hence patients cannot be refused access to “necessary” care, even if this is available only in a private facility.<sup>124</sup> Accordingly, in the past Italian patients frequently travelled outside their local health authority, abroad, or visited a private provider in order to obtain services that were not available locally. France reports that although the use of providers outside the local health authority or region has always had to be authorized, the tendency in the past was for this to be done automatically and often on a retroactive basis.<sup>125</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 or, if necessary, to a private provider. However, since the late 1980s, the courts have begun to recognize that due to fiscal constraints the National Health Service (SSN) might have to be selective in the kinds of care it provides. In 1989 the central authorities tightened up the ability of patients to go abroad. A list of pathologies was drawn up for which authorization may be granted. This list specifies the maximum waiting times beyond which patients are entitled to go abroad. Legislation requires referral committees 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.

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 do not have much evidence about how costly this initiative is. Only 2.4 percent of Italians seeking diagnoses in 2001 experienced delays of greater than 60 days, and only 1.2 percent waited longer than 60 days to be examined by a specialist.<sup>126</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>127</sup>

## Conclusion

What would be the benefit of passing a patients' bill of rights in Canada, whether at the provincial or federal level?

The experiences of New Zealand 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. It would allow for the enumeration of patients' rights in one comprehensive piece of legislation, and it would provide an enforcement mechanism (by means of an independent commissioner or ombudsperson) that would be more accessible than the courts and viewed as more legitimate (being independent) than the professional colleges. It would also provide oversight of alternative health-care providers who are currently not subject to regulation and/or professional self-regulation; provide a centralized complaints system with just one entry point (as opposed to, for example, the existence of 23 colleges in Ontario, which causes confusion as to which college a complaint should be made to); allow investigation of practice settings such as hospitals and systems complaints which are not attributable to a sole identifiable professional; promote low level resolution of complaints; 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 rather 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 will depend on a strong commitment of resources<sup>128</sup> and the independence of the office.

There are many positive contributions a patients' bill of rights could make in improving a patient's rights *in* health care and in the interactions between health-care providers and patients. However, this alone would not address what has become a key concern of Canadians: timely access. Patients and citizens have very few avenues of recourse vis-a-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. Failing to address in a systemic way the issue of timeliness has consequences not only for those individuals in need of care, but also for the political sustainability of Canada's much cherished medicare program.<sup>129</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 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 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 lists and times will grow and waiting lists may be unfairly administered.

One of the goals of our paper 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 United Kingdom, Spain, Sweden and Italy are worthy of consideration. 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 (a charter) and following through with system 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 system to achieve those targets. In one region in Spain, residents have rights to treatment within maximum waiting times enshrined in law, and if the waiting time is exceeded the health authority must pay for their treatment in another region or jurisdiction. In Sweden, residents have the right to choose any hospital they wish for treatment and "money follows the patient," thus providing strong financial incentives to hospitals to keep waiting times down. Have these initiatives been successful? Although there is some evidence that they have, particularly from Spain and Sweden, it is virtually impossible to conclude with certainty whether successes are attributable to the establishment of a patients' charter or bill of rights or to other factors. Efforts at reducing waiting times and lists often occur simultaneously with other 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 possible due to the particular nature of local supply conditions (e.g., surplus hospital capacity); or whether improvements have been due to improved efficiency and management within the system or due to the infusion of increased resources into the system. However, it is apparent that a patients' bill of rights can be part of a package of initiatives designed to reduce waiting times 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 go some way toward repairing public confidence in medicare. The inclusion of statements and guarantees of waiting times and lists in the Patients' Charter has been used by UK governments to symbolize a commitment to respond to patients' concerns regarding timeliness. In providing for a right to timely care, the goal is to reorient the system partially towards the justified concerns of Canadians and to impose some measure of accountability on the part of funders and/or managers for the delivery of timely care. A Canadian statement of patients' rights could set out maximum waiting times for different types of treatment, e.g., six months for nonurgent elective surgery like hip operations. Physicians would still triage patients on the basis of the acuity of their condition, but patients would have the security of knowing that they will not have to wait longer than the maximum waiting time.

It is clear that a statement of rights alone cannot cure medicare. Thus what else is required to achieve maximum waiting time targets? We envisage an independent commissioner or ombudsperson charged with the task of investigating complaints in relation to access and timeliness. With respect to timeliness, the goal need not necessarily be to give redress to individual patients but at a minimum to provide for an independent audit with annual public reporting on the degree to which health authorities and/or provincial ministries of health are achieving waiting list targets. The annual exposure of this kind of information to the light of public scrutiny should provide some incentive for decision-makers to strive to reduce overall waiting times. The US system amply demonstrates that access problems can also occur within a *privately* financed system. In our opinion a patient ombudsman should monitor not only access (and waiting times) in publicly funded medicare, but also access to privately financed services (private insurers, home care, prescription drugs, nursing homes etc.).

Another approach to waiting times, coming out of the experiences in Spain, Italy and the UK, is to give patients who have been waiting beyond the maximum waiting time the option to have the necessary surgery performed in another city or another jurisdiction (another province or in the US) and have the cost paid for by the relevant hospital or health authority or from the provincial budget. Yet another approach from Sweden is to allow patients to choose their own hospital and to pay those hospitals that service more patients additional fees, thus promoting competition between hospitals in reducing waiting times. These kinds of reforms have strong appeal as they provide clear financial incentives for performance. However, incentives are often slippery and unpredictable, and strong financial incentives should not be lightly employed without closely considering the possible down-stream consequences. There is some evidence from the UK that the

initial employment of these kinds of incentives resulted in resources being shifted from one sector (out-patients) to another (elective surgery), with the result that waiting times improved in one area and worsened in another.<sup>130</sup>

Having said that governments need to be cautious in the use of strong financial incentives, we can also point out that lessons learned in the UK could assist Canadian policy-makers to calibrate financial incentives, predict and monitor likely sources of tension (e.g., inappropriate resource shifting) and set appropriate waiting list targets. There are dangers with tinkering with incentives and there is a risk that unforeseen consequences may come to pass, but there are also considerable dangers in governments not directly tackling and being seen to be tackling Canadians' concerns about waiting times.

- 1 The Standing Senate Committee on Social Affairs, Science and Technology (2002).
- 2 Online: <http://www.healthcarecommission.ca>
- 3 Alberta had earlier introduced patients' rights legislation. This bill, Alberta Patients' Bill of Rights, was defeated on February 4, 1998.
- 4 Government of Saskatchewan (2001).
- 5 Quebec Ministry of Health, Commission on Medicare (2001c).
- 6 Arnold (2002).
- 7 Quebec (2001a).
- 8 Weston (1999). See also Ontario (2000).
- 9 Telephone conversation with Kathie Clarke, Ministry of Health and Long Term Care, August 23, 2002.
- 10 Commission on the Future of Health Care in Canada (2002). A discussion paper notes that New Brunswick is the first jurisdiction in Canada to consider a formal charter, which is still being drafted. While affirming people's right to medically needed care, the charter also reminds them of a duty to "live a healthy lifestyle." It gives no standards or wait-time guarantees, and neither the rights nor the responsibilities it outlines are legally enforceable. Instead, advocates will monitor the use of the charter and handle complaints. To give effect to the charter commitments, reforms to New Brunswick's system are also planned. See also: *Health Renewal: Report from the Premier's Health Quality Council*.
- 11 Standing Senate Committee on Social Affairs, Science and Technology (2001).
- 12 PricewaterhouseCoopers (2001), p. 25. While "58% of Canadians feel that few or minor changes are required, the remainder believe the health-care system requires major changes" and that "looking to the future, more than one-third of Canadians believed it very likely they would have to wait a long time to receive non-emergency care. Only 12% felt it would be very unlikely." See also Walker and Wilson (2001). Note, however, that the Fraser Institute data has been criticized on a variety of methodological grounds, e.g., 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.
- 13 Sanmartin et al. (2002).
- 14 For example, see Lewis et al. (2000). For a discussion of the various factors that contribute to waiting lists see Shortt (2000).
- 15 See, for example, Martin (2001), p. 465. Martin reports that a survey carried out by PricewaterhouseCoopers found that 47 percent of respondents said the quality of health care has declined in the past five years with 22 percent blaming longer waiting times. See also Canadian Broadcasting Corporation, Cross Country Checkup (2000). It was reported that "the 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."
- 16 Simunovic et al. (2001), pp. 421-425.
- 17 Sanmartin et al. (2002).
- 18 Evans and Stoddart (1994), p. 38. See also Angus et al. (1995) for the argument that as there is little evidence that many health-care services have any impact on health, cut-backs in public spending can occur without impact on Canadians' health.
- 19 Starr (1982), pp. 388-393. Paul Starr first noted the differences between rights *in* health care and rights *to* health care. See also Annas (1998), p. 695.
- 20 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 [1990]*; *Pratt v. Davis [1905]*; *Malette v. Shulman [1990]*. 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].
- 21 The common law places a duty on physicians to respect a patient's privacy and maintain information given in confidence: *McInerney v. MacDonald* [1992].
- 22 *McInerney v. MacDonald* [1992].
- 23 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...": *Critis v. Sylvester* [1956]. In certain jurisdictions some of these rights are also recognized by statute. See for example Ontario (1996), which sets out the requirements for a valid consent.
- 24 See for example, the Code of Ethics of the Canadian Medical Association.
- 25 The regulation of occupations and professions is a provincial responsibility under s. 92(13) of the Constitution Act, 1867 (U.K.).
- 26 See Ontario (1990).
- 27 For a discussion of self-regulation, see McNamara et al. (2002). For a discussion of different models of self-regulation see Priest (1997-1998), p. 233.
- 28 See for example, anonymous submissions in respect of the (Ontario, 1990a) Regulated Health Professions Act. This Act is currently under review by the Regulated Health Professions Council (RHPC), which received over 300 submissions in October 1999. A great number of the submissions expressed concern at 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 author.
- 29 Stoltzfus (1995), p. 835.
- 30 Manitoba Law Reform Commission (1993), p. 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 (Ontario, 1990a) Regulated Health Professions Act. The HPARB was established pursuant to the *Ministry of Health Appeal & Review Boards Act* (Ontario 1998) (Schedule H., ss1-4) and performs duties assigned to it under the *Regulated Health Professions Act* (1990) (s.18-26). 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 does not fully address the issue of the public's lack of confidence in self-regulatory systems.
- 31 PricewaterhouseCoopers (1999). A 1999 study found that 38 percent of people surveyed were "not at all certain" about where to launch a complaint regarding sexual misconduct by a health professional.
- 32 Associate Chief Judge Murray Sinclair led a three-year inquest (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 moni-

- toring 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 five 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 three infants might have lived had they been referred to a larger hospital for treatment, that three deaths could not be explained and that only one death had an acceptable explanation": Sibbald (2001), p. 393.
- 33 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." See Morgan (2001).
- 34 This problem was identified by a number of the submissions to the Regulated Health Professions Council.
- 35 Pritchard (1990), p. 2.
- 36 Pritchard (1990), p. 24.
- 37 Lightstone (2001), p. 622. This is not a new trend. Between 1971 and 1990 the number of medical malpractice claims filed per 100 Canadian doctors increased to 1.7 from 0.55. See Trebilcock et al. (1996), p. 96.
- 38 The famous "Harvard Study" on malpractice found that only one in eight incidents of medical malpractice ever resulted in a legal claim by an injured patient. See Brennan et al. (1991).
- 39 For an argument in favour of no-fault accident compensation, see Astroff (1996); against, see Klar (1997).
- 40 *Law Estate v. Simice* [1994].
- 41 *Brown v. B.C.* [1994]; *Swinamer v. N.S.* [1994]; see also Hogg and Monahan (2000), p. 171.
- 42 See <http://www.uhn.ca/patientsandvisitors/patient.html>
- 43 See for example, the Toronto General Hospital, <http://www.uhn.ca> and Toronto's Mt. Sinai Hospital, [www.mtsinai.on.ca](http://www.mtsinai.on.ca) Mt. Sinai Hospital 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.
- 44 The Canadian Charter of Rights and Freedoms has been invoked to claim a right to health care pursuant to Section 7 (the right to life). Canadian courts have not ruled definitively on the issue; however, it appears unlikely that they will interpret Section 7 as including a positive right to health care. See Canadian Bar Association (1994).
- 45 *Eldridge v. British Columbia (Attorney General)* [1997].
- 46 *Cameron v. Nova Scotia (AG)* [1999].
- 47 *Chaoulli c. Québec (Procureur général)* [2000]; per Piche, J., this judgment is available only in French.
- 48 *Auton (Guardian ad litem of) v. British Columbia (Minister of Health)* [2000].
- 49 Denied June 29, 2000, without reasons, [1999] S.C.C.A. N. 531.
- 50 *Auton v. British Columbia* [2002].
- 51 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 Flood and Archibald (2001).
- 52 *Chaoulli c. Québec (Procureur général)* [2000].
- 53 The Court of Appeal did not expressly address this point.
- 54 For example, the Ontario Health Services Appeal and Review Board

- (HSARB) (Ministry of Health Appeal and Review Boards Act) is an independent quasi-judicial tribunal that conducts hearings pursuant to a number of statutes including the Health Insurance Act. Appeals may be brought under the *Health Insurance Act* against a refusal by the General Manager of OHIP to pay for health-care services.
- 55 Abraham (2000).
- 56 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 Review and Appeal Board considers that it has jurisdiction to consider Charter challenges. On September 6, 2001, it released its decision in *L.H. v. The General Manager, The Ontario Health Insurance Plan* (AG Ontario, intervener) (Board file S.6492), on a motion brought by OHIP asking the Board to rule upon its jurisdiction to consider the constitutional validity of a schedule to the Health Insurance Act. 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 September 22, 2000), there was provision under Rule 11 for bringing notices of constitutional questions to the Board.
- 57 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), thorough reasonableness, simpliciter to patent unreasonableness (the most deferential).
- 58 Review of the Health Services Appeal and Review Board files on October 26, 2001.
- 59 *Ontario Health Insurance Act* (Ontario 1990b), s. 28.4, et seq.
- 60 *Stein v. Québec (Regie de l'Assurance-maladie)* [1999].
- 61 Bell and Redelmeier (2001), p. 663.
- 62 "Lack of Doctors Means Children Must Wait for Surgery" (2001).
- 63 Quebec (1991) ss. 4 to 13.
- 64 Quebec (2001a).
- 65 The Ombudsman may intervene if, in his or her opinion, "recourse to the process provided for in [the Act] 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.": Quebec (2001a) s.19.
- 66 Quebec (2001a) s.20.
- 67 As defined in Title II, Part I of Quebec (1991).
- 68 The 1991 legislation provided for a three-tier complaint procedure requiring complaints to be made to institutions, then to regional boards, then 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.
- 69 Section 13 provides that "the right to health services and social services and the right to choose a professional and an institution as provided in sections 5 and 6 shall be exercised within the framework of the legislative and regulatory provisions relating to the organizational and operational structure of the institution *and within the limits of the human, material and financial resources at its disposal* [emphasis added]." (Quebec, 1991)

- 70 Section 58 of the AC sets out the circumstances in which a complaint may be addressed directly to a regional board. Quebec (2001a)
- 71 Quebec (2001b).
- 72 OECD Health Data 2001(cd rom) Table 146.
- 73 Much of the legislation that speaks to patients' rights to access services applies only to existing enrollees' ability to access services covered by their private health insurance plan.
- 74 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 target only specific areas of the health-care sector, as opposed to dealing with the rights of those enrolled in managed-care plans, e.g., home care (New Hampshire).
- 75 United States (1996).
- 76 *Bipartisan Patient Protection Act* (Placed on the Calendar in the Senate) HR2563PCS. Passed by the House of Representatives on August 2, 2001.
- 77 The bill passed by the Republican House of Representatives varies in some important respects from that passed by the Democratic US Senate so that difficult negotiations are ahead as representatives try to broker a deal that will meet the approval of the Senate, the House and the President.
- 78 HR2563PCS: in general, Subtitle B. In particular, s. 114: timely access to specialists; s. 119: coverage for individuals participating in approved clinical trials; s. 113: access to emergency care.
- 79 In general, Title 1, Improving Managed Care, ss. 101-105. In particular, s. 104, which amends ERISA to include s. 503 C.
- 80 It is in the latter that the bill passed by the House of Representatives differs significantly from the Senate bill. The House bill places the following kinds of limits on patients' capacity to sue managed-care plans in state courts: damage claims for pain and suffering limited to \$1.5 million (s. 402 of HR2563PCS) compared to the \$5 million cap in the Senate bill (S. 402 of S. 1052 PP) and punitive damages to \$1.5 million (s. 402 of HR2563PCS); any suit in a state court would be 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 decision-maker exercised ordinary care in making such determination" (s. 401 of HR2563 PCS would amend ERISA to include s. 502(n)(1)(B)).
- 81 Rosenbaum et al. (1999), p. 229.
- 82 Schwartz (1999).
- 83 In HR2563, the relevant sections are 131-135, under subtitle D: "Protecting the Doctor-Patient Relationship." In S. 1052PP, s.131-135, under subtitle D: "Protecting the Doctor-Patient Relationship."
- 84 See the report by Families USA (2001), a national, non-profit, consumer advocate network.
- 85 Federal law requires that all states offer at least three specific types of consumer health insurance programs: long-term care ombudsman programs, protection and advocacy programs for persons with disabilities, and state health insurance assistance programs for Medicare beneficiaries (those over 65).
- 86 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.

- 87 Noted by Toner and Stolberg (2002). See Chart 4 in PricewaterhouseCoopers (2002), p. 4.
- 88 This estimate comes from Coney (1993), p. 6.
- 89 See Cartwright (1988). See also New Zealand, House of Representatives, September 4, 1990, (Rt. Hon. Helen Clark). Hansard, online: <http://rangi.knowledge-basket.co.nz/hansard/han/text/1990/09/04-chron.html>.
- 90 Discourse about patients' rights in Canada tends to use the term "patient." However, the New Zealand legislation 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, for example, a person picking up a prescription from a pharmacy. In this article we use the term "consumer" only when discussing the New Zealand legislation.
- 91 Note that New Zealand has a no-fault accident compensation scheme that bars common law claims for damages for personal injury. It is arguable that 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 heightened importance.
- 92 Section 4 provides that every consumer has the right 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 minimizes the potential harm to, and optimises the quality of life of, that consumer; and every consumer has the right to cooperation among providers to ensure quality and continuity of services.
- 93 Paterson (2001).
- 94 In commenting on the Commissioner's power to investigate generic systems issues, J. Tipping in *Nicholls v. Health and Disability Commissioner* [1997] noted "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."
- 95 Paterson (2002), p. 77.
- 96 Paterson (2002), p. 77.
- 97 United Kingdom (1993), c. 46, s.3.
- 98 United Kingdom (1996a), c. 5.
- 99 United Kingdom (1993), c. 46, s.3(4) and s.3(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 Tingle (1993). See also *R. v. Cambridge Health Authority* [1995], p. 130, where it was noted "(the judiciary)...was not in a position to decide on

- the correctness of the difficult and agonizing 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.”
- 100 Health Service Ombudsman for England (2002), p. 9.
- 101 The Charter notes that patients can expect to be seen immediately in Accident and Emergency Department, to be seen within 18 months for inpatient or day case services, within 12 months for coronary revascularisations and associated procedures, and within 26 weeks for a first consultant outpatient appointment with 90 percent of patients being seen within 13 weeks: National Health Service (1996), p. 2.
- 102 National Health Service (1997), at section 4.20.
- 103 United Kingdom (1996b)
- 104 See Crompton (2001).
- 105 The NHS 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; inpatients should expect to wait no more than 18 months; a patient referred urgently with suspected cancer will be seen within 2 weeks; and (from 2003) suspected angina patients will be assessed in a specialist chest pain clinic within two weeks.
- 106 See Flood (2000), ch. 3.
- 107 Harrison (1995), p. 38. There were 1,040,152 people on waiting lists at September 30, 1995 — nine less than at March 1995. See Also United Kingdom (1996b).
- 108 United Kingdom (1996b). See also Besley and Preston (1996): figure 3 similarly shows a significant decline in the percentage of the population on long-term waiting lists after 1990.
- 109 Snell (1997).
- 110 United Kingdom (1999).
- 111 For a discussion, see Harrison (2000), pp. 52-60.
- 112 For a discussion, see Lewis et al. (2000), pp. 297-300.
- 113 Ham (1992) p. 71; Klein (1995), p. 237; Hamilton and Bramley-Harker (1999) pp. 437-462.
- 114 Ramirez-Arellano (2001).
- 115 Ramirez-Arellano (2001).
- 116 Ramirez-Arellano (2001).
- 117 Elective surgery treatments account for approximately 90 percent of all non-urgent treatments affected by the waiting list problem. Personal communication with T. Ramirez-Arellano, September 5, 2001.
- 118 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/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. Personal communication with T. Ramirez-Arellano, September 5, 2001.
- 119 Personal communication with T. Ramirez-Arellano, September 5, 2001.
- 120 Blomqvist (2001).
- 121 Harrison and Calltorp (2000), pp. 219-240, as quoted by Blomqvist (2001), p. 14.
- 122 France (1997), p.22. See also, France (1999), pp. 39-55.
- 123 Sentence 992, 1988.
- 124 Sentence 992, 1988.
- 125 Sentence 992, 1988.
- 126 ISTAT (2002), p. 39.
- 127 ISTAT (2002), p. 39.
- 128 IRPP Task Force on Health Policy (2000), p. 27. It noted the importance of overcoming the inherent skepticism of most people regarding public statements of good intentions. It also noted that if a bill of rights is going to help, it is important that there be a substantial commitment of resources to service delivery and to implement processes.

- 129 For an elaboration of this argument, see Flood and Choudhry (2002).
- 130 For a discussion, see Harrison (2000), pp. 52-60.

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