

Can a Patients' Bill of Rights Address Concerns About Waiting Lists?

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Introduction

Growing concern among Canadians about access to timely health care services of a high quality has provided the impetus for several provinces to consider introducing a patients' bill of rights. Québec, since 1991, has had legislation setting out patients' rights and is currently considering a new Bill that will give an Ombudsman greater power to enforce those rights.¹ 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."² Legislation looks likely to be introduced in early 2002. The introduction of a patients' bill of rights has also been considered in Saskatchewan, New Brunswick and Manitoba and in September 2001 the Senate Special Committee on Medicare put forward a patients' charter of rights as a reform option worthy of serious consideration at a national level.³ Here, we address the prospect of a patients' bill of rights addressing Canadians' concerns about their health care system and, in particular, consider whether a patients' bill of rights can address Canadians' concerns about waiting lists. To answer this question we draw from the experience of jurisdictions that have implemented patients' rights legislation.

¹ Bill 27, An Act Respecting the Health and Social Services Ombudsman and Amending Various Legislative Provisions, National Assembly 2nd sess., 36th Leg., Québec, 2001, online: <http://www.assnat.qc.ca/eng/publications/Projets-loi/publics/01-a027.htm>.

² Speech from the Throne, Address of the Honourable Hillary M. Weston, Lieutenant Governor of the Province of Ontario on the Opening of the First Session of the Thirty-Seventh Parliament of the Province of Ontario (21 October 1999), online: www.premier.gov.on.ca/english/library/thronespeech_Oct2199.htm (date accessed: 23 November 2000). See also Government of Ontario, Press Release, "2000 Ontario Budget – Balanced Budgets, Brighter Futures" (2 May 2000), online: www.newswire.ca/government/ontario/english/releases/May2000/02/c0848.html (date accessed: 23 November 2000).

³ See the Standing Senate Committee on Social Affairs, Science and Technology, "The Health of Canadians – The Federal Role, Volume Four – Issues and Options" (September 2001), on-line: <http://www.parl.ca.ca/37/1/parlbus/commbus/senate/com-e/SOCI-E/rep-e/reprintssep01-e.htm>.

What are Canadians concerned about?

Canadians are greatly concerned about the quality of publicly funded health care and in particular about the length of time waiting for care.⁴ There is disagreement amongst experts as to the true extent of the waiting list problem and how seriously the problem should be taken,⁵ but regardless of this scholarly fracas Canadians are very concerned about the length of waiting lists and the consequent difficulties of accessing timely care.⁶ This is hardly surprising as timeliness of treatment has the potential to have a significant impact on the chances of a successful cure or even of survival. Also the period spent waiting for treatment may be a period within which a patient experiences a significant decline in his/her quality of life (e.g., patients needing hip replacements). 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. Perhaps of the greatest importance for most people is that delays in treatment can cause great psychological stress, both for patients and their family and friends. For example, a recent study of cancer patients in Ontario found cancer patients experience major psychological stress as a result of delays in diagnosis or treatment.⁷ Why then does medicare seem unable to respond to patients' and citizens' concerns regarding access to timely care?

⁴ PriceWaterhouse Coopers, HealthInsider, Survey Number Five, Spring/Summer 2001, p. 25 reports that 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 S. Martin, “Almost 1 in 2 Canadians says health system needs major surgery” (2001) CMAJ 165(4) at 465.

⁵ In 1999, 0.7 percent of Canada’s population was on a waiting list – which is significantly lower than the percentage of the populations waiting in the UK and New Zealand – see C.H. Tuohy, C.M. Flood & M. Stabile, “How Does Private Finance Affect Public Health Care Systems: Marshalling the Evidence from OECD Nations” (Working Paper, University of Toronto, 1 June 2001). However, according to M. Walker & G. Wilson, *Waiting Your Turn: Hospital Waiting Lists in Canada* 11/e (Vancouver: Fraser Institute, 2001), online: http://www.fraserinstitute.ca/publications/critical_issues/2001/wyt/index.html the length of waiting is increasing. They report that “waiting time for surgical and other therapeutic treatments grew significantly in 2000-01. Total waiting time between referral from a general practitioner and treatment, averaged across all 12 specialties and 10 provinces surveyed, rose from 13.1 weeks in 1999 to 16.2 weeks in 2000-01. This nationwide deterioration reflects waiting-time increases in eight provinces, while concealing decreases in waiting times in Saskatchewan and Newfoundland.” The Fraser Institute data has been criticized, however, on a variety of methodological grounds not the least of which because it surveys individual physicians and thus is subject to recall bias, hampered by a small response rate, and limited by the use of different respondents yearly.

⁶ See for example Martin, *supra* note 4. Martin reports that a survey carried out by Pricewaterhouse Coopers 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 CBC, Cross Country Checkup – from Red Deer, Alberta (13 February 2000), online: www.radio.cbc.ca/programs/. 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”.

⁷ M. Simunovic, A. Gagliardi, D. McCready *et al.*, “A snapshot of waiting times for cancer surgery provided by surgeons affiliated with regional cancer centres in Ontario” (2001) CMAJ 165(4) at 421-5.

Although this is an oversimplification, it seems that the primary goal of provincial governments in governing their respective health care systems has been to control growth in public spending on health care whilst not adversely affecting health care outcomes (e.g. mortality and morbidity rates). The focus on health care outcomes has its origins in what is known as the “evidence-based medicine” movement. Evidence-based medicine, grounded in health economics and health services research, argues we should only publicly fund health care services when they have a measurable impact on health care outcomes.⁸

Of course citizens and patients want to achieve positive health *outcomes* they also are (unsurprisingly) concerned about 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 this does not, in our opinion, negate their importance. Our present system does not ensure the accountability of decision-makers in the publicly-funded health care system to the citizens they represent, thus allowing citizens' genuine concerns about process and timeliness to remain unaddressed.⁹ Should and could a patients' bill of rights help to improve the accountability of decision-makers in the publicly funded system and, in particular, address concerns about waiting lists?

Why a patients' bill of rights?

What do we mean when we talk about patients' rights? In this article we suggest that patients' rights fall into two different categories. Firstly, rights in health care arise out of the patient-provider relationship, that is, the actual delivery of health care services. Secondly, there is a question as to whether there should be rights to access health care services.¹⁰ In this article, we argue that to address what are Canadians' key concerns about their health care system, a patients' bill of rights ought to recognize both rights *in*

⁸ R.G. Evans & G.L. Stoddart, “Producing Health, Consuming Health Care” in R.G. Evans, M.L. Barer & T.R. Marmor, *Why are Some People Healthy and Other Not?: The Determinants of Health of Populations* (New York: Aldine De Gruyter, 1994) 27 at 38. See also D.E. Angus *et al.*, *Sustainable Health Care for Canada, Synthesis Report* (University of Ottawa: Ottawa, 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.

⁹ See C.M. Flood, *International Health Care Reform: A Legal, Economic and Political Analysis* (London: Routledge, 2000) at Chapter 4.

¹⁰ This division into rights *to* health care and rights *in* health care was articulated by P. Starr. He notes that in the United States in the early 1970s, the movement to establish a right to health care was followed by a movement to establish rights in health care: P. Starr, *The Social Transformation of American Medicine* (New York: Basic Books, 1982) at 388-93. In a subsequent article, Annas makes reference to Starr and utilizes the distinction between rights to health care and rights in health care: G.J. Annas, “A National Bill of Patients' Rights” (1998) *New Eng. Jnl. Of Med.* 338 (10) at 695.

health care, and rights *to* health care. We interpret the latter as including the right to access health care of an adequate quality and delivered within an acceptable time frame. That is, a patients' bill of rights needs to focus on both the patient/provider relationship as well as relationships between patients/citizens and health care funders and/or managers.

Rights *in* health care

Certain rights *in* health care are recognized at common law, for example, the right to give informed consent¹¹, to confidentiality¹², to have access to one's own medical records¹³, and to receive treatment that is provided with a reasonable degree of care.¹⁴ In certain jurisdictions some of these rights are also recognized by statute.¹⁵ Codes of ethics, in addition to recognizing many legal rights also often recognize rights *in* health care of a more intangible nature e.g., the right to be treated with respect and dignity. However, codes of ethics usually describe such concepts in terms of *duties* on the part of health professionals rather than *rights* accorded to patients.¹⁶ A variety of mechanisms serve to enforce both duties on the part of health care professionals and rights *in* health care in Canada. In this section we briefly discuss these mechanisms and critique their capacity to protect patients.

Self-regulation: Provincial governments have granted self-regulatory power to the medical professions¹⁷ empowering them to control entry to the professions, regulate technical quality, and ensure that members adhere to standards of professional conduct.¹⁸ Arguably, the prospect of being disciplined by peers assists in promoting compliance

¹¹ The common law provides that medical intervention may only be provided where the consent of the individual to be treated has been obtained: *Schloendorff v. New York Hospital*, 211 N.Y. 125, 105 N.E. 2d 92 (N.Y.C.A. 1914); *Pratt v. Davis*, 118 Ill. App. (1905); *Malette v. Shulman* (1990), 72 O.R. (2d) 417 (C.A.). 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), 114 D.L.R. (3d) 1 (S.C.C.).

¹² The common law places a duty on physicians to respect a patient's privacy and maintain information given in confidence: *McInerney v. MacDonald* [1992] 2 S.C.R. 138 [hereinafter *McInerney*].

¹³ *McInerney*, *ibid.*

¹⁴ 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), 1 D.L.R. 502 (Ont. C.A.) at 508; *affd* [1956] S.C.R. 991.

¹⁵ See, for example, in Ontario, the Health Care Consent Act, S.O. 1996, c. 2 Sch. A which sets out the requirements for a valid consent.

¹⁶ See, for example, the Code of Ethics of the Canadian Medical Association, online: <http://www.cma.ca/inside/policybase/1996/10-15.htm>.

¹⁷ The regulation of occupations and professions is a provincial responsibility under s. 92(13) of the Constitution Act, 1867 (U.K.), 30 & 31 Vict., c. 3, reprinted in R.S.C. 1985, App II, No. 5.

¹⁸ See, in Ontario, the Regulated Health Professions Act R.S.O. 1990, C.I.3.

with standards and reduces errors in adjudication.¹⁹ However, self-regulatory systems have come under increasing criticism as failing to protect the public from harm²⁰ and there has been a “dramatic erosion in the public’s confidence in self-regulation.”²¹ Self-regulating professions are now more likely to be viewed as having a conflict of interest and “an inappropriate unwillingness to report or act upon the incompetent or unethical behaviour of colleagues.”²² Another downfall of self-regulatory systems is that reportedly many people do not know where to make complaints or what they are entitled to complain about.²³

Various safety failures within hospitals, for example the sad case of the Winnipeg pediatric-cardiac program, highlights the importance of reporting systems and communications within hospitals and other institutions. Moreover, concerns about funding cutbacks, reductions in the numbers of hospitals and hospital beds, failure to fund new technologies and drugs, incorrect predictions of manpower needs etc. have drawn attention to the direct and indirect effects on both quality and safety flowing from the decisions of funders and/or managers. Presently, self-regulatory bodies do not deal with these kinds of concerns and only have the power to investigate the actions of individual members of their professions as opposed to the actions of hospitals or other institutions²⁴ or of health care funders and/or managers.

¹⁹ For a discussion of self-regulation, see L. McNamara & E. Nelson, “Regulation of Health Care Professionals” in J. Downie, T. Caulfield, eds., *Canadian Health Law and Policy* (Toronto: Butterworths, 1999) at 51-78. For a discussion of different models of self-regulation see M. Priest, “The Privatization of Regulation: Five Models of Self-Regulation” (1997-98) 29 *Ottawa L. Rev.* 233.

²⁰ See, for example, anonymous submissions in respect of the Regulated Health Professions Act, October 1999. The Regulated Health Professions Act is currently under review by the Regulated Health Professions Council (RHPC). The RHPC received over 300 submissions from the public 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.

²¹ T. Stoltzfus, “Overview of the Quality of Medical Care: Regulation, Management, or the Market” (1995) *Arizona Law Review* 825 at 835.

²² Manitoba Law Reform Commission, *Discussion Paper: The Future of Occupational Regulation in Manitoba* (Winnipeg: Law Reform Commission, 1993) at 42. In Ontario, the Health Professions Appeal and Review Board (HPARB) deals with reviews of Complaints Committees’ decisions (such committees being established by the various professional Colleges) under the Regulated Health Professions Act. The HPARB was established pursuant to the Ministry of Health Appeal & Review Boards Act, 1998, S.O. 1998, c.18, Schedule H., ss1-4 and performs duties assigned to it under the Regulated Health Professions Act, 1991, R.S.O., 1990, C.I.3, 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.

²³ A study carried out by Pricewaterhouse Coopers in 1999 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. Pricewaterhouse Coopers, “Evaluation of the Effectiveness of the Health Professional Colleges’ Complaints and Discipline Procedures with Respect to Professional Misconduct of a Sexual Nature and Status of the Colleges” (Toronto: Pricewaterhouse Coopers, July 1999).

²⁴ This problem was identified by a number of the submissions to the RHPC. *Supra* note 20.

Civil liability: The threat of medical malpractice suits arguably provides a strong incentive to health professionals to provide care of an adequate quality. Reportedly, one in 25 physicians in Canada was named in a new legal action in 2000 and the number of malpractice cases proceeding to trial doubled between 1995 and 1999.²⁵ Despite these increased figures, the relatively high costs, time involved, and stress of litigation deter many people from pursuing potential civil claims.²⁶ Thus the incidence of malpractice is much higher than the cases that are litigated indicate, resulting in arbitrariness in whom is punished and compensated. Many patients have no desire to spend their time and resources pursuing litigation and would be satisfied with an acknowledgement of wrongdoing, an apology, and assurances that it will not happen again. In a 1990 report, Pritchard 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.²⁷ However, Pritchard also recommended that efforts be made to increase the availability of mechanisms of redress and accountability including complaints and discipline procedures.²⁸

Occasionally health care professionals have raised as a defense to a claim of malpractice that they had inadequate resources because of decisions made by funders and managers. The courts are generally unsympathetic to such claims. For example, Spencer J. 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.”²⁹ With respect, this is an idealistic view of the physician/patient encounter and, of course, not all beneficial treatments can be supplied to all patients and everyday physicians must make decisions that balance the needs of individual patients with the needs of their own and other patients. The extent to which physicians’ decisions are made more difficult, and the choices more tragic, is undoubtedly affected by the resources they have to work with which are the result of decisions made by those who fund and manage medicare. Just as physicians have not been successful so far in using limited resources as a defense to a medical malpractice

²⁵ S. Lightstone, “Class-action lawsuits medicine’s newest legal headache” (2001) CMAJ 165(5) at 622. This is not a new trend -- between 1971 and 1990 the number of medical malpractice claims filed per 100 Canadian doctors increased from 0.55 to 1.7 – M.J. Trebilcock, D. Dewes & D. Duff, *Exploring the Domain of Accident Law: Taking the Facts Seriously* (New York: Oxford University Press, 1996) at 96.

²⁶ In a 1990 report, Pritchard noted that “medical malpractice litigation is among the most complex, time consuming and demanding kinds of personal injury litigation ... when account is taken of all the legal fees, the costs of the court system, and the time and energy of everyone concerned with the litigation, in excess of 50 percent of all the money spent on malpractice goes to the expenses of litigation and not to the injured patients for the purposes of compensation”. J.R.S. Pritchard, *Liability and Compensation in Health Care (A Report to the Conference of Deputy Ministers of Health of the Federal/Provincial/Territorial Review on Liability and Compensation Issues in Health Care)* (Toronto: University of Toronto Press, 1990) at 4.

²⁷ Pritchard, *ibid.* at 2.

²⁸ *Ibid.* at 24.

²⁹ *Law Estate v. Simice*[1994] 21 C.C.L.T. (2d) 228 at 260.

claim, neither have decisions made by governments, funders and managers been the subject of tort actions on the part of patients. This is due to the difficulties of launching a civil action against a government as true policy decisions (as opposed to operational functions) are exempt from tortious claims³⁰ and in 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 codes or bills of rights articulating 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, which considers the patient's privacy and right to confidentiality.³¹ A number of institutions also maintain an internal complaints mechanism to provide patients an opportunity to express and resolve their concerns.³² These are positive initiatives, helping to have patients' concerns dealt with promptly. However, as these are voluntary initiatives and there is variation in the nature of the rights granted and the level of enforcement, there is arguably still a need for legislation that applies across all providers providing for minimum standards and levels of enforcement. Also patients may view internal complaints mechanisms as lacking independence and impartiality which speaks at least to the need for a supervisory appeal body to which a patient can turn if dissatisfied with how a health care institution has dealt with a complaint.

Conclusion: 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 some clear disadvantages. Self-regulation (rightly or wrongly) tends to be viewed as lacking sufficient independence and 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 may be viewed as piece-meal initiatives, lacking independence. A patients' bill of rights, monitored and enforced by a Patient Ombudsman, offers 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. Looking at patients' rights *to* access quality care in a timely fashion we see that physicians can be

³⁰ *Brown v. B.C.* [1994] 1 S.C.R. 420; *Swinamer v. N.S.* [1994] 1 S.C.R. 445. See also P. Hogg & P.J. Monahan, *Liability of the Crown* 3/e (Toronto: Carswell, 2000) at 161-171.

³¹ See Toronto General Hospital, online: [www.uhn.ca/patients and visitors/relation/rights.html](http://www.uhn.ca/patients_and_visitors/relation/rights.html) (date accessed: 3 September 2001).

³² See for example, the Toronto General Hospital, online: [www.uhn.ca/patients and visitors/relation/rights.html](http://www.uhn.ca/patients_and_visitors/relation/rights.html) (date accessed: 3 September 2001); and Toronto's Mt. Sinai Hospital, online: www.mtsinai.on.ca (date accessed: 3 September 2001). 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.

subject to litigation claims in their role as the gatekeepers to the publicly funded system and in the decisions they make in triaging the needs of different patients. However, as discussed further below, patients and physicians have very few avenues of recourse against the funders and managers of the system, whose various decisions may sharply constrained the choices of physicians in treating patients. Thus the concerns we have about our present system of protecting patients' rights *in* health care pales relative to the very few avenues of recourse there are for ensuring patients' rights *to* access quality care in a timely fashion.

Rights to health care

There is no specific law granting Canadians a free-standing right *to* receive health care.³³ Nonetheless there are government programs in place providing publicly funded health care and once a government has taken it upon itself to provide publicly funded health care to some or all members of its citizenry, then the law imposes some duties in terms of how these programs are administered. For example, recent years have seen a number of challenges under the Canadian Charter of Rights and Freedoms to rationing decisions in these publicly funded programs. Under the Charter the most prominent recent cases are *Eldridge v. British Columbia (Attorney General)*³⁴, *Cameron v. Nova Scotia (AG)*³⁵, *Chaoulli c. Québec (Procureure generale)*³⁶ and *Auton (Guardian ad litem of) v. British Columbia (Minister of Health)*³⁷.

In *Eldridge*, the Canadian Supreme Court held that British Columbia provincial government's decision not to fund sign-language interpreters in hospitals as part of its public health insurance plan discriminated against deaf patients. It was successfully argued that this was because in the absence of interpretation services, deaf people would not be able to access publicly funded hospital services, as other Canadian citizens are able to (communication being essential to the doctor/patient relationship). *Cameron* concerned the Nova Scotia government's decision not to fund a male infertility treatment. The Nova Scotia Court of Appeal ruled that while the government's decision did discriminate against infertile persons, the high cost of the treatment meant that it was justified under section 1 (a reasonable limit prescribed by law and demonstrably justified in a free and democratic society). Leave to appeal to the Supreme Court was denied.³⁸ In

³³ 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 the Canadian Bar Association Task Force Report *What's Law Got To Do With It? Health Care Reform in Canada* (Ottawa: The Canadian Bar Association, 1994).

³⁴ [1997] 3 SCR 624. (S.C.C.).

³⁵ (1999) 177 DLR (4th) 611 (N.S.C.A.).

³⁶ [2000] J.Q. No. 470 (QL) (C.S.Q.) per Piche J. This judgment is only available in French.

³⁷ [2000] B.D.J. No. 1547, 2000 BCSB, 1142.

³⁸ Leave to appeal to the Supreme Court denied 29 June 2000 without reasons, [1999] S.C.C.A. No. 531.

a more recent case, *Auton*, the British Columbia provincial government had failed to fund a treatment for autistic children. The plaintiffs were successful in their argument before the British Columbia Supreme Court that as a consequence of the government's failure there had been a breach of their section 15 rights to equal protection and benefit of the law.

In a 1999 case, *Chaoulli c. Québec (Procureure generale)*³⁹ the plaintiff challenged the Québec government's prohibition on private health insurance for services that are covered by the public plan. The plaintiff wished to have private insurance to buy care that was meant to be covered by the public plan but for which there were waiting lists. The court noted that there were serious gaps and deficiencies in Québec'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 thus not in violation of section 7 of the Charter.

These Charter cases suggest that while plaintiffs have historically had difficulty in persuading Courts that the Charter should operate to afford rights *to* health care, things may be changing. In *Eldridge* the hearing-impaired plaintiffs were successful but arguably they 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 entitled to. However, in *Auton* the British Columbia Supreme Court rejected this means of limiting the precedent of *Eldridge*. Thus there are hints from both *Auton* and *Eldridge* that plaintiffs may become more successful in Charter claims for rights *to* health care. However, 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 accessing health care due to. Also although the Charter can, in certain circumstances, address explicit rationing decisions on the part of government, for example, failing to fund a particular service or delisting a particular service, it is far less adept at ensuring that the multitude of resource allocation decisions made in the health care system accord with Charter values.

In Ontario and British Columbia there are arms-length administrative tribunals in place to deal with claims that provincial insurance plans should publicly fund particular treatments.⁴⁰ A high profile case in Ontario involved a successful claim before the

³⁹ *Supra* note 36.

⁴⁰ For example, the Health Services Appeal and Review Board (HSARB) (Ministry of Health Appeal and Review Boards Act, 1998, S.O. 1998, c. 18) in Ontario is an independent quasi-judicial tribunal that conducts hearings pursuant to a number of statutes including the Health Insurance Act, R.S.O. 1990, c.H.7.

Health Services Appeal and Review Board that the provincial government should fund the BRCA1 genetic test a claimant required to determine whether she had a predisposition to breast cancer.⁴¹ These kinds of independent administrative tribunals provide an outlet for patients' concerns about the breadth of publicly funded schemes and arguably are a much more efficient and fairer mechanism for resolution of these kind of disputes *in general* than expensive and protracted Charter litigation. There is always, of course, a role for a Charter challenge as a safety-net in addition to any administrative means of review.⁴² However, these appeal routes do not appear to be widely known and still require that patients muster their time and resources (both of which are in short supply in a period of ill-health) to make a challenge in a relatively adversarial environment. Moreover, these administrative mechanisms do not result in any systematic incentives for decision-makers to take seriously citizens' concerns regarding timeliness of care.

A right to timely health care?

As noted, a key concern of Canadians is increasing waiting lists and times. 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 in a timely way. However, the delay must be said to "result in death or medically significant irreversible tissue damage."⁴³ Thus, in extreme cases in Ontario where 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 and there are currently only independent administrative tribunals in Ontario and British Columbia. With regard to a general appeal to the courts for access to timely care, the only recognition to date has been by the Québec Superior Court in *Stein v. Québec (Regie de l'Assurance-maladie)*⁴⁴. 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

Appeals may be brought under the Health Insurance Act against a refusal by the General Manager of OHIP to pay for health care services.

⁴¹ C. Abraham, "Tenacious Woman Scores Medical Victory" *The [Toronto] Globe and Mail* (27 August 2000) at A1.

⁴² 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. A court will, however, review the Board's decision on a Charter matter if it is not correct whereas it may be deferential on other decisions and not overturn the decision so long as it is reasonable. (Cuddy Chicks)

⁴³ See *Health Insurance Act*, General, R.S.O. 1990, Reg. 552, s. 28.4, et seq.

⁴⁴ [1999] QJ No. 2724

three and a half months for a surgery date and at the end of this period a date had not been set. Consequently Mr. Stein went to New York to obtain the treatment he needed and then sought to challenge the Québec health insurance board officials' refusal to pay for his treatment. He was successful on the grounds that, given the facts of the case, the 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 an administrative decision-maker was patently unreasonable in deciding not to publicly fund out-of-country treatment) and, in Ontario, before an administrative tribunal (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. In the case of Mr. Stein he was fortunate enough to be able to pay out-of-pocket for the care he needed in New York and then seek reimbursement. Many patients will not be 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.

Although 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, this alone would not address what has become a key concern of Canadians, timely access. The failure 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. Thus failing to address in a systematic way the issue of timeliness has consequences not only for those individuals in need of care but for the political sustainability of Canada's much cherished medicare program. Ensuring equitable access cannot be achieved by simply stating that everyone has a right to publicly funded care as that right is hollow without also speaking to issues of quality and timeliness. Ought not a person who has been assessed in need of a particular service have a right to receive that service in a reasonably timely manner? Should there not be a right to receive treatment in an emergency room within a certain number of hours, or the right to receive an operation or therapy for non-emergency services within a certain number of months following diagnosis?

Rights to access timely care engages relationships beyond the immediate patient-provider relationship and engages decision-makers 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 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 phenomena 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.⁴⁵ 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 for 15 months for elective surgeries whereas in most cities children could expect to wait less than 10 weeks.⁴⁶ These problems are not addressed by establishing and enforcing rights *in* health care and reviewing physician decision-making but potentially may be addressed by putting in place rights *to* access timely health care.

Thus we believe there are strong arguments for considering the introduction of 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. This would place an obligation on the governments to ensure that the health care system responds to the needs of Canadians and thus increase public accountability. The implementation of such a guarantee or commitment is not without precedent as we discuss below.

Lessons from Other Jurisdictions

In this section we will look at a number of jurisdictions that have implemented a Patients' Bill of Rights with a particular focus on where rights have been established to access health care services in a timely fashion. The jurisdictions we will examine are Québec, New Zealand, the UK, the US, Sweden and Spain.

Québec

In Québec, users' rights *in* and *to* health care are set out in legislation put in place in 1991.⁴⁷ The office of Complaints Commissioner was established pursuant to this legislation and has oversight over the enforcement of patients' rights, acting as an appeals level in respect of complaints made to regional boards.⁴⁸ Bill 27, introduced in May 2001, makes provision for this office to be replaced by that of the Health and Social Services Ombudsman (the Ombudsman) with greater power to enforce patients' rights. The Complaints Commissioner does not have powers of direct intervention and he or she is restricted to examination of complaints upon appeal. Bill 27 proposes to give the Ombudsman power to directly intervene if he or she has reasonable grounds to believe

⁴⁵ C.M. Bell & D.A. Redelmeier, "Mortality Among Patients Admitted to Hospitals on Weekends as Compared with Weekdays" (2001) *New England Jnl of Med.* 345(9) at 663-668.

⁴⁶ See "Lack of Doctors Means Children Must Wait for Surgery", *The LeaderPost* (19 September 2001).

⁴⁷ An Act Respecting Health Services and Social Services, 1991, R.S.Q. 1991, c. S-4.2 at ss. 4 to 13.

⁴⁸ *Ibid.* at ???

that a person or a group of persons has been or may likely be adversely affected by an act or omission, including that of any institution or regional board.⁴⁹ However, the Ombudsman may only 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 attitude of resignation of the targeted clientele, or in any other case envisaged in the intervention procedure established by the Ombudsman under section 21... which 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.⁵⁰

It is proposed that the Ombudsman have the general power to “by any appropriate means” ensure that users are respected and their rights enforced. It is also proposed that the Ombudsman be charged with ensuring that the complaints processes in institutions and regional boards conform with the law (Bill 27 defines the minimum content of the complaint examination procedure that must be established by every institution and regional board.)

Bill 27 also aims to speed up the handling of user complaints by establishing an examination process comprising two levels instead of three (the current legislation presently requires complaints to be made to institutions, then to regional boards, then to the Complaints Commissioner). To achieve this, it requires 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.

Bill 27 provides for important procedural changes in enforcing patients’ rights in Québec but there is no proposal to change the content of the rights as established in 1991. The 1991 legislation provides for rights *in* health care such as the right to give consent to treatment and to participate in any decision affecting his or her state of health or welfare. Users’ rights also include 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”. The legislation does not, however, provide any specific guarantees or rights to timely receipt of services. Moreover, the legislation provides in section 13 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

⁴⁹ Bill 27, *supra* note 1 at s. 19.

⁵⁰ *Ibid.*

structure of the institution *and within the limits of the human, material and financial resources at its disposal.*” (emphasis added).

Thus the Québec system provides the opportunity to make complaints about services received and to appeal to an independent body. Québec has also taken some important steps towards enhancing the accountability of hospitals and regional health care boards⁵¹ by requiring that they be subject to a complaints procedure which, if assent is given to Bill 27, will be overseen by an Ombudsman. Section 13 of the Act does seem to leave open the prospect of providers, institutions and boards claiming limited resources in defense to any complaint by a patient. However, perhaps there is the hopeful prospect that a proactive Health and Social Services Ombudsman will not simply accept a simple claim of limited resources and will instead require principled justifications for resource allocation decisions within the budget received and over time encourage the development of transparent criteria. However, the extent to which the Ombudsman will be proactive may be tied to the degree of independence he/she has from government and concerns have been expressed about the fact that the Health and Social Services Ombudsman will still remain answerable to the Minister of Health and Social Services and not to the National Assembly.⁵² More specifically, neither the present legislation nor the proposed Bill provide for any specific right to timely treatment or puts in place specific incentives to achieve waiting time targets.

The United States

Over the course of the last ten years there has been a managed care revolution in the US in which private insurance companies through direct and indirect mechanisms and incentives now control costs and manage the delivery of care by physicians. In response to this revolution there has been a flurry of federal and state legislation aimed at protecting those with insurance from limitations on access to and diminishment in quality of health care. These measures do not generally seek to expand the numbers of people covered by private insurance (approximately 14 percent of US citizens, mainly the working poor, have no health insurance) 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

⁵¹ *Ibid.* at s. 58. Section 58 sets out the circumstances in which a complaint may be addressed directly to a regional board.

⁵² See Québec Ombudsman, “Press Release: Bill on the Health and Social Services Ombudsman: the Québec Ombudsman issues her recommendations”, June 8, 2001, online: <http://www.ombuds.gouv.qc.ca/en/publications/communique/010608.htm>.

legislative minimum standards⁵³ as well as by “Patients’ Bills of Rights” in a number of states.⁵⁴ In 1996 the US federal government enacted the Health Insurance Portability and Accountability Act.⁵⁵ This Act does not tackle the problem of the uninsured in the system but does address public concerns over insurers, employers, and managed care plans dropping coverage for people once they become in need of expensive health care services. More recently, the US House of Representatives⁵⁶ and the US Senate have passed Bills providing for a Bill of Patients’ Rights.⁵⁷ 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.⁵⁸ Both Bills also enable patients to appeal decisions of a managed care plan to an independent review board⁵⁹ and both also overtake, to varying extent, the limitations of ERISA, enabling patients to sue health care plans in state courts.⁶⁰

⁵³ Much of the legislation that speaks to patients’ rights to access services only applies to existing enrollees’ ability to access services covered by their private health insurance plan. Over forty states have these kind of patient protection laws, often enacted as a number of measures over a number of years, rather than one single and comprehensive patients’ rights package. These laws most commonly deal with access issues, standards for utilization management activity implemented by the health plan as a means of cost containment and health promotion, and grievance procedures. Also common are provisions prohibiting a health plan from restricting communication with patients concerning treatment options, addressing access to emergency services, freedom of choice, disclosure of plan information and prompt payment.

⁵⁴ Four states that have specifically enacted “patients’ bills of rights” are Massachusetts, New Jersey and West Virginia. The Massachusetts and Vermont legislation is not restricted to managed care, however, the New Jersey and West Virginia bills of rights are typical of the many other managed care laws that exist in over forty states and seek to regulate the managed care industry. Some states have patients’ bills of rights that only target specific areas of the health care sector, as opposed to dealing with the rights of those enrolled in managed care plans e.g., home care (New Hampshire); long term care (Alabama, Arkansas, California, Colorado, Connecticut, Florida, Hawaii, Illinois, Kansas, Kentucky, Massachusetts, Maryland, Maine, Michigan, Minnesota, Missouri, Montana, North Carolina, Nebraska, Nevada, New Mexico, New York, Ohio, Oregon, Pennsylvania, South Carolina, Texas, and Vermont); and mental health.

⁵⁵ Health Insurance Portability and Accountability Act (HIPAA) (PL, 104-191 August 21, 1996, 110 Stat 1936 (HR3103) § 301).

⁵⁶ Bipartisan Patient Protection Act (Placed on the Calendar in the Senate) HR 2563PCS.

⁵⁷ 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.

⁵⁸ HR 2563 PCS: 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.

⁵⁹ In general, Title 1 – Improving Managed Care, ss. 101-105. In particular, s. 104, which amends ERISA to include s. 503 C.

⁶⁰ 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)).

Where managed care plans give incentives to health care professionals to contain costs, *implicit* rationing may occur.⁶¹ This rationing is more difficult to regulate than explicit rationing, although regulatory measures have been proposed and adopted in an attempt to ensure a proper balance between medical necessity and cost factors. For example, 48 of the 50 states prohibit the use of "gag clauses" which is where managed care plans require that doctors not discuss matters such as treatments the plan does not cover, attempted referrals that the plan has refused, and financial incentives under which doctors deliver care.⁶² Similarly, both the Senate and House Bills providing for a Federal Patients' Bill of Rights prohibit gag clauses.⁶³ At the state level, there are also a number of federally mandated and state-initiated consumer assistance programs (which include ombudsman programs and other consumer health assistance programs.)⁶⁴ These programs have three main functions: investigating and resolving consumer complaints; educating the relevant public about consumers' health care rights; and providing feedback to policymakers and others with a view to improving the performance of the health care system. By federal law, all states offer at least three specific types of consumer health assistance 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). State initiated programs fall into two main categories: Medicaid ombudsman programs (for those of the poor that the state has determined qualify for Medicaid) and general health care ombudsman programs (that serve people with private insurance).

New Zealand

New Zealand has accorded rights to consumers⁶⁵ of health and disability services by way of a statutory Code of Health and Disability Services Consumer Rights (the Code) which was prescribed as a regulation pursuant to the Health and Disability Commissioner Act 1994 (the Act).⁶⁶ The Act was introduced following the report of a committee of inquiry set up by the government to investigate allegations concerning a failure to adequately

⁶¹ S. Rosenbaum *et al.*, "Who Should Determine When Health Care is Medically Necessary?" (1999) *New Eng. Jnl. of Med.* 340(3) at 229.

⁶² S. Schwartz, "How Law and Regulation Shape Managed Care" in D. Bennahum *ed.*, *Managed Care: Financial, Legal and Ethical Issues* (Cleveland: Pilgrim Press, 1999).

⁶³ 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".

⁶⁴ See a report of a national survey carried out by Families USA (a national, non-profit, consumer advocate network): Families USA, "Consumer Health Assistance Programs: Report on a National Survey" (Families USA, Washington DC: June 2001), online: <http://www.familiesusa.org/media/pdf/survey.pdf>.

⁶⁵ Discourse about rights in (or to) health care in Canada tends to use the term "patient". However, the New Zealand legislation uses the term "consumer". The term "consumer" 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 only use the term "consumer" when discussing the New Zealand legislation.

⁶⁶ The Health and Disability Commissioner Act 1994.

treat cervical cancer at an Auckland hospital.⁶⁷ The Act aimed to fill perceived gaps in the existing system by providing an accessible, independent and ‘consumer friendly’ complaints mechanism.⁶⁸

The ten rights provided for in the Code are couched in very general terms: the right to be treated with respect; the right to freedom from discrimination, coercion, harassment, and exploitation; the right to dignity and independence; the right to services of an appropriate standard; the right to effective communication; the right to be fully informed; the right to make an informed choice and give informed consent; the right to support; rights in respect of teaching or research and the right to complain. Many of these rights were already recognized to some extent at common law and in professional codes of ethics. Under the Code, they are applicable to *all* health and disability service providers, including alternative providers such as naturopaths and homeopaths. A Health and Disability Commissioner is charged with promoting the rights of consumers and investigating alleged breaches of the Code.

The New Zealand Code of Rights is limited in a number of important respects. First, the Act does not provide a right *to* receive health care nor are there any specific statements of rights and expectations with respect to waiting lists and waiting times. The code frames rights in the context of “consumers” relationships with health care providers and not in the context of relationships with the funders and/or managers of the health care system. Within limits, the Health and Disability Commissioner does have the power to investigate and report on “generic systems issues”.⁶⁹ However, the New Zealand Code of Rights

⁶⁷ See New Zealand, House of Representatives, 4 September 1990 (Rt. Hon Helen Clark), online: http://www.rangi.knowledge-basket.co.nz/hansard/han/text/1990/09/04_112.html (date accessed: 4 November 2000).

⁶⁸ 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.

⁶⁹ In commenting on the Commissioner’s power to investigate generic systems issues, Tipping J. in *Nicholls v Health and Disability Commissioner* [1997] NZAR 351 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.”

contains no specific right to receive timely care⁷⁰, nor are the actions of health care decisions-makers in district health boards directly open to investigation by the Commissioner. Moreover, clause 3 of the Code provides that there will not be a breach if a provider can show that they have taken “reasonable actions in the circumstances to give effect to the rights, and comply with the duties” in the Code. Thus, if a district health board cuts health spending with the result that a hospital provides services of a substandard quality to a particular patient, the hospital will not be held in breach of 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.”⁷¹ This certainly seems fair enough from the provider’s perspective and in these circumstances one would have to rely upon the Commissioner to release a report on his/her own initiative explaining how resource allocation decisions had contributed to the failure to provide services of an adequate quality.

United Kingdom

A UK “Patients’ Charter” was first introduced in 1992. The Charter set out national standards regarding what patients could *expect* (as opposed to being enforceable rights) in terms of access and treatment from the publicly-financed system. 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 publish an annual report on each hospital's performance against Charter standards. The Patients' Charter, introduced on 1 April 1995, expressly stated how long patients should expect to have to wait for various services.⁷² 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 also in relation to waiting times, such as a guarantee of being seen within thirty minutes in an outpatient clinic.

⁷⁰ 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 minimises the potential harm to, and optimises the quality of life of, that consumer; and; every consumer has the right to co-operation among providers to ensure quality and continuity of services.

⁷¹ R. Paterson, “Patients Rights in New Zealand: Lessons for Ontario”, paper presented at the Faculty of Law, University of Toronto, 2nd Annual Health Law Day, 12 October 2001.

⁷² The Charter notes that patients can expect to be seen immediately in Accident and Emergency Departments, 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 – *NHS Waiting Times Good Practice Guide* (Leeds: NHS Executive, May 1996) at 2.

The UK's Health Services Commissioner was empowered to investigate a complaint from a person who "has sustained injustice or hardship" as a consequence of "a failure in a service provided by a health care service body, a failure of such a body to provide a service, which it was a function of the body to provide, or maladministration in connection with any other action taken by or on behalf of such a body".⁷³ The scope of the Commissioner's authority was extended in 1996 to allow her or him to hear complaints regarding all aspects of publicly-funded health care services and to hear complaints regarding the clinical judgements of doctors, nurses, and other clinical professionals.⁷⁴ The list of bodies subject to investigation has also been extended to include private providers. However, the Act continues to expressly provide that the Commissioner 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.⁷⁵ 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.⁷⁶

The New Labour Reforms of December 1997 proposed to expand and enrich the Patient's Charter to "tell people about the standards of treatment and care they can expect of the NHS. It will also explain patients' responsibilities".⁷⁷ The Charter has now been replaced by a NHS "Guide", which purports to set out patients' rights and responsibilities and, purportedly, highlights the standards and services people can expect from the NHS.⁷⁸ As with the Charter that preceded it, the Guide provides for patients to make complaints but does not create legally enforceable rights that did not already exist. However, the new Guide has been criticized for being too vague about what patients can expect of the government and failing to explicitly state patients' rights to, for example, a free yearly health check if over 75 years old.⁷⁹ Instead, within the Guide, the government promises that the NHS will, for example, "respond to different needs of different populations" and "work continuously to improve quality services and minimize errors". The new Guide does provide, however, 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.

⁷³ The Health Services Commissioners Act (UK), 1993, c. 46, s.3.

⁷⁴ See the Health Services Commissioners (Amendment) Act (UK), 1996, c. 5.

⁷⁵ The Health Services Commissioners Act (UK), 1993, c. 46, s.3(4) and s.3(5).

⁷⁶ For a discussion of these cases see J.H. Tingle, "The Allocation Of Healthcare Resources In The National Health Service In England: Professional And Legal Issues" (1993) 2 *Annals Of Health Law* 195. More recently, see *R. v. Cambridge Health Authority, ex parte B* [1995] 2 All ER 129 (CA) at 130, where it was noted "(the judiciary)...was not in a position to decide on the correctness of the difficult and agonizing judgements 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."

⁷⁷ Department of Health, "The New NHS: Modern Dependable, A White Paper", CM 3807 (London, 8 December 1997), section 4.20 online:

<http://www.official-documents.co.uk/document/doh/newnhs/contents.htm>.

⁷⁸ Department of Health, News Release, "Your Guide to the NHS Launched", <http://www.doh.gov.uk>.

⁷⁹ See S. Crompton "Are We Losing Our Rights as Patients?", *The Times* (17 July 2001) at 12.

If it does not the hospital will have to pay for the treatment at a time and hospital chosen by the patient.

Did the guarantees regarding waiting times have any impact? As one of us has noted elsewhere, the UK internal market had some early success in reducing the problem of growing waiting lists.⁸⁰ 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 was 1,040,161 people on waiting lists and approximately the same number of people were on waiting lists at 30 September 1995.⁸¹ The number of people waiting for more than 12 months for elective procedures on 30 September 1995 was 27,900 -- a reduction of 55 percent since September 1994, when there were 62,300.⁸² How much of this improvement is due to the improved efficiency of the system as opposed to additional government expenditures is unclear. Through 1997 waiting lists started to increase once again with 1,207,500 waiting at the end of September 1997 (an increase of 1.5 percent over the previous quarter) and with the number of people waiting for more than 12 months increasing by 24 percent.⁸³ The numbers waiting had slightly declined by 31 January 1999 with 1,159,400 people waiting and with the number of people waiting more than twelve months dropping to 54,600.⁸⁴ However, now there has been growth in the waiting list to get on the waiting list! How this works is that patients are not put on waiting lists for particular treatments until they are seen by a specialist to confirm that that they do in fact need the treatment and should be on the waiting list. There were 468,000 people on waiting lists to see specialists at the end of 1998.⁸⁵ Thus the evidence from the UK from the waiting list initiative in the early 1980s and 1990s was that waiting times declined in response to combination of infusions of public funding and mechanisms to change incentives within the public sector so that improvements in timeliness were rewarded.⁸⁶

⁸⁰ See Flood, *supra* note 9 at Chapter 3.

⁸¹ A. Harrison, ed., King's Fund Policy Institute, "Health Care UK 1994/95: An Annual Review Of Health Care Policy" (Bristol: J.W. Arrowsmith Limited, 1995) at 38 (Table 13). There were 1,040,152 people on waiting lists at 30 September 1995 -- 9 less than at March 1995 -- Department of Health, News Release 96/1, "Hospital Waiting List Statistics Published" (1 January 1996).

⁸² Department of Health, *ibid.* T. Besley, J. Hall & I. Preston, "Private Health Insurance and the State of the NHS, (Commentary No. 52)" (London: The Institute for Fiscal Studies, 1996) at Figure 3, similarly show a significant decline in the percentage of the population on long-term waiting lists after 1990.

⁸³ J. Snell, "Action Team Appointed to Tackle Rising Waiting Lists", (20 November 1997) Health Services Journal 4, as quoted by W. Bartlett, "Regulation, Trust and Incentives: Contractual Relations and Performance in the NHS Quasi-Market", (Paper prepared for the conference Institutions, Markets and (Economic) Performance: Deregulation and its Consequences, Utrecht University, December 11-12, 1997).

⁸⁴ Department of Health, Press Notice 1999/0119, "Statistical Press Notice - NHS Waiting List Activity Figures 31 January 1999", (2 March 1999), online: <http://www.coi.gov.uk/coi/depts/GDH/coi2565f.ok> (date accessed: 1 April 1999).

⁸⁵ See S. Lyall, "Britain's Prescription for Health Care: Take A Seat", *The New York Times* (19 April 1999) p. 3.

⁸⁶ See C. Ham, *Health Policy in Britain: the Politics and Organization of the National Health Service* 3/e (London: Macmillan, 1992) at 71; R. Klein, *The New Politics of the NHS* 3/e (London: Longmans, 1995)

Spain

Spain affords an example of the use of legislation to specify guarantees of maximum waiting times. Over the last seven years, three out of eight Regional Health Authorities that adopted policies designed to reduce the length of waiting lists have shown “better waiting list/time indicators and patient satisfaction.”⁸⁷ The average waiting time for surgery (in days) declined from 135 days in 1996 to 68 days in 2001; the number of patients waiting more than 6 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 has increased again to 166,583 in 2001.⁸⁸ The Spanish waiting list initiative incorporated four different types of measures to meet its objectives of reducing waiting lists and times. The measures were 1) validating information systems regarding the numbers waiting; 2) providing incentives to organization 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 that the Regional Health Authority/hospital pay for the patient to access the care in the private sector. In addition, it is reported that the greatest reduction in waiting times occurred in the Navarra Regional Health Authority, which incorporated waiting standards into its regional legislation.⁸⁹ Following this success, the regional government of Andalusia is taking steps to incorporate guarantees of maximum waiting times in its patient rights regulation.⁹⁰

Sweden

According to Blomqvist, in Sweden, the right for all residents to all “necessary” health care is part of national legislation.⁹¹ In 1992, the “patient choice and care guarantees” (henceforth 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 have been substantial

at 237; B.H. Hamilton & R. E. Bramley-Harker, “The Impact of NHS Reforms on Queues and Surgical Outcomes in England: Evidence from Hip Fracture Patients,” *The Economic Journal* at 109, 457, 437-462.

⁸⁷ T. Ramirez-Arellano (Health Advisor for the Cabinet of the Spanish Prime Minister) International Health Economics Association Conference, York University, 22-25 July 2001.

⁸⁸ *Ibid.*

⁸⁹ *Ibid.*

⁹⁰ Email from T. Ramirez-Arellano, 5 September 2001.

⁹¹ Å. Blomqvist, “International Health Care Models: Sweden” (Background paper prepared for the Standing Senate Committee on Social Affairs, Science and Technology), March 2001.

reduction in waiting times for important kinds of elective surgery, to the point where, by the end of 1993, waiting lists had “ceased to be a political issue”.⁹² More recently, maximum waiting time guarantees have been introduced for consultations with primary care doctors and specialists. Blomqvist notes that the guarantee specifies 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).

Conclusion

A number of jurisdictions have passed various versions of Patients’ Bills of Rights in order to respond in a tangible way to mounting concern in publicly funded systems about the quality, timeliness and accessibility of care. However, these initiatives usually speak to enforce patients’ rights *in* health care vis-à-vis health care professionals and do not speak to ensuring the accountability of the variety of funders and managers who make resource allocation decisions that impose constraints on health care providers.

There would be value to Canadians in a patients’ bill of rights designed to promote an understanding and better enforcement of rights *in* health care. In terms of the patient provider relationship, it would make it easier for patients to exercise rights in their dealings with health care providers. It has the potential to do so by enumerating patients’ rights in one comprehensive piece of legislation and providing an enforcement mechanism (by means of a Commissioner or Ombudsperson) that would be both more accessible and viewed as more legitimate (being independent). It would also provide the following benefits: the ability to address services provided by 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 for complaints (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 consumers and providers. A patients’ bill of rights should emphasize education of both providers and consumers so that it does not become simply a complaints mechanism but a positive instrument by which to actively promote and encourage protection of rights *in* health care. Of course as with any such initiative, its success will depend on a commitment of resources so as to make the legislation work and gain credibility with both patients and health care providers alike.⁹³

⁹² M. I. Harrison & J. Calltorp, “The re-orientation of market-oriented reforms in Swedish health care” (2000) *Health Policy* 50 at 219-40 as quoted by A. Blomqvist, *ibid.* at 14.

⁹³ The IRPP Task Force on Health Policy noted the importance of overcoming the inherent scepticism of most people regarding public statements of good intentions. It also noted that if a Bill of Rights is going to help, it is important that there is a substantial commitment of resources to service delivery and to

However, to the extent that a patients' bill of rights only speaks to rights *in* health care it would overlook a key concern of Canadians, namely ensuring access *to* timely care. Ensuring equitable access cannot be achieved by simply stating that everyone has a right to publicly funded care as that right is hollow without also speaking to issues of quality and timeliness. Ought not a person who has been assessed in need of a particular service have a right to receive that service in a reasonably timely manner? Should there not be a right to receive treatment in an emergency room within a certain number of hours, or the right to receive an operation or therapy for non-emergency services within a certain number of months following diagnosis? Patients and physicians have very few avenues of recourse against the funders and managers of the system, whose various decisions may sharply constrain physicians' choices in treating patients. 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. Thus the concerns we have about our present system of protecting patients' rights *in* health care pales relative to the very few avenues of recourse there are for ensuring patients' rights *to* access quality care in a timely fashion.

In Canada, we have not seen many initiatives on the part of provincial governments aimed at protecting citizens from unfair or ill-conceived resource allocation decisions resulting in a deterioration in the quality and timeliness of care. As in other publicly funded countries, everyone has insurance coverage for a core range of services (hospital and physician services in Canada). But 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, 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 publicly funded systems that seek to ensure access on the basis of need and not ability to pay. That being said if there are no incentives within a publicly funded system to ensure that there are standards regarding waiting lists and times, then the evidence tends to suggest that waiting lists will only ever continue to grow. This not only places a significant burden on those who must wait but undermines citizen confidence in the fairness and sustainability of the publicly funded health care system.

We envisage that a bill of rights in Ontario would therefore include not only rights *in* health care, but would also include rights *to* health care. It could do the latter by setting rights in terms of guaranteed maximum waiting times. A Commissioner or Ombudsperson could be charged with the task of investigating complaints in relation to access and timeliness and reporting annually as to progress in meeting the targets set.

What is a “reasonable” waiting time will depend on the severity of the condition, the total level of resources available to the health care system and societal values [and will need to be reviewed on a regular basis]. Thus, for example, it may be reasonable to say in Ontario that patients should expect to wait no more than a year for non-urgent elective surgery like hip operations. It will still be up to physicians to triage patients on the basis of the acuity of their condition but in general no patient should expect to have to wait, for example, for more than a year. By providing for a right to timely care the goal is to reorient the system partially towards the justified concerns of patients and to impose some measure of accountability on the part of funders/managers for ensuring the delivery of timely care.

An important question is how a right to timely treatment should be enforced. One possibility is not to give any particular redress to individual patients but to provide for an independent audit with public annual reporting on the degree to which health authorities/provincial ministries of health are achieving waiting list targets. The annual exposure of this kind of information to the sunlight of public scrutiny should provide some incentive for decision-makers to strive to reduce overall waiting times. Another stronger possibility, coming out of the experiences in Spain and Sweden and following proposals in the UK, is to allow individuals who have been waiting beyond the maximum guaranteed time the option to have the necessary surgery performed in another city or indeed another jurisdiction (another province or in the US) and the cost of this, including all travel and accommodation, to be paid for by the Health Authority or from the provincial budget.