



## **PATIENTS' BILL OF RIGHTS – A COMPARATIVE OVERVIEW**

**Margaret Smith**  
**Law and Government Division**

**4 February 2002**

---

**PARLIAMENTARY RESEARCH BRANCH**  
**DIRECTION DE LA RECHERCHE PARLEMENTAIRE**

**The Parliamentary Research Branch of the Library of Parliament works exclusively for Parliament, conducting research and providing information for Committees and Members of the Senate and the House of Commons. This service is extended without partisan bias in such forms as Reports, Background Papers and Issue Reviews. Research Officers in the Branch are also available for personal consultation in their respective fields of expertise.**

**CE DOCUMENT EST AUSSI  
PUBLIÉ EN FRANÇAIS**

## TABLE OF CONTENTS

	<b>Page</b>
INTRODUCTION .....	1
RECENT INITIATIVES IN SIX COUNTRIES .....	2
A. Canada.....	2
1. Rights and Entitlements in Relation to Health Care – Federal Initiatives .....	2
a. Health Charter for Canadians.....	2
b. <i>Canada Health Act</i> .....	4
c. Patients’ Bill of Rights .....	5
1) Private Member’s Bill .....	5
2) Senate Committee Proposal.....	7
2. Rights and Entitlements in Relation to Health Care – Provincial Initiatives.....	7
a. Alberta.....	7
b. Ontario .....	8
c. Quebec.....	10
d. Nova Scotia.....	11
e. New Brunswick.....	13
3. Rights and Entitlements in Relation to Health Care – Policy Proposals .....	15
a. IRPP Task Force on Health Policy.....	15
B. New Zealand .....	17
1. The Code of Health and Disability Services Consumers’ Rights .....	18
2. The Health and Disability Commissioner.....	18
C. United Kingdom.....	19
D. Australia .....	22
E. United States.....	24
1. Federal Proposals.....	24
a. Presidential Initiatives.....	24
b. Congressional Initiatives.....	25
2. State Initiatives.....	27
a. Patients’ Rights in Relation to the Provision of Health Care.....	27
b. Patients’ Rights and Protections in Relation to Managed Care .....	29
F. Norway .....	30
CONCLUSION.....	31



CANADA

LIBRARY OF PARLIAMENT  
BIBLIOTHÈQUE DU PARLEMENT

## PATIENTS' BILL OF RIGHTS – A COMPARATIVE OVERVIEW

### INTRODUCTION

Concern about the state of the Canadian health care system tends to centre on its long-term sustainability. The focus is on rising costs, funding, human resource shortages, the use of technology, and primary care reform. Recently, the ambit of this concern has broadened to include an increasing interest in patients' rights which is being driven by a number of factors such as:

- evidence of long waiting times for diagnostic tests, treatment for certain diseases and conditions, and appointments with specialists;
- the growing numbers of educated and knowledgeable patients who are less willing to accept the status quo and are becoming more assertive in demanding information from health care providers;
- the increasing patient demand for a greater role in decisions affecting their care and treatment;
- the increasing complexity of the health care system; and
- the growing perception that patients need to be active health care “consumers.”

Canada is not alone in experiencing these developments. In an attempt to refocus the delivery of health care services to patients, countries such as New Zealand, the United Kingdom, Australia, the United States and Norway have seen the introduction of patients' bills of rights and responsibilities, or patients' charters, as they are sometimes called.<sup>(1)</sup> In some of these nations, patients' rights have the force of law; in others, they are statements of health policy. Regardless of the form they take, these initiatives have two goals: to empower patients by providing them with certain rights and entitlements as they interact with health care providers

---

(1) In the United Kingdom, the National Health Service (NHS) patients' guide (entitled *Your Guide to the NHS*) has replaced the Patients' Charter. This development is discussed in Section C.

and institutions; and to place the patient-health care provider relationship on a more equal footing. By outlining what is expected of health care providers, institutions and patients, they also serve as important guidelines for the delivery of health care services.

This paper discusses recent initiatives regarding the development and implementation of patients' bills of rights in Canada, New Zealand, the United Kingdom, Australia, the United States and Norway.

## **RECENT INITIATIVES IN SIX COUNTRIES**

### **A. Canada**

When discussing patients' rights in the context of the Canadian health care system, it is important to distinguish between "collective" rights and "individual" rights and entitlements.

- *Collective rights* are broad principles relating to the general societal obligation to make reasonable access to health care available for the entire population. What is reasonable in terms of the number and range of provided services depends on political, social and economic factors. Collective rights also relate to equal access to health care for all those living in a country or other geopolitical areas.
- *Individual rights and entitlements*, on the other hand, refer to the application of the health care system at the patient or consumer level; in other words, what individuals are entitled to and can expect at various stages of the health care system when they interact with health care providers and institutions. These rights include rights to information, privacy, confidentiality, and consent to treatment.

### **1. Rights and Entitlements in Relation to Health Care – Federal Initiatives**

#### **a. Health Charter for Canadians**

The 1964 Report of the Royal Commission on Health Services (Hall Commission) put forward a "Health Charter for Canadians."<sup>(2)</sup> This statement of collective

---

(2) Canada, Royal Commission on Health Services, Queen's Printer, 1964, Vol. 1, pp. 11-12.

entitlements was based on the assumption that the “achievement of the highest possible health standards for all people must become a primary objective of national policy....”<sup>(3)</sup>

The Charter states that this objective can be best achieved through a “comprehensive, universal Health Services Programme for the Canadian people” that would be:

- implemented according to Canada’s evolving constitutional arrangements;
- based on freedom of choice and on free and self-governing professions and institutions;
- financed through prepayment arrangements; and
- accomplished through the full cooperation of the general public, health professions, voluntary agencies, all political parties and levels of government.<sup>(4)</sup>

Certain principles – which were to become the basis upon which the federal government would contribute funding to provincial health care plans – were defined as follows:

- “*Comprehensive*”: “all health services, preventive diagnostic, curative, and rehabilitative that modern medical and other sciences can provide.”
- “*Universal*”: “adequate health services should be available to all Canadians wherever they reside and whatever their income, within limitations imposed by geographic factors.”<sup>(5)</sup>
- “*Health Services Programme*”: “legislative enactments and administrative arrangements to organize comprehensive universal health care including prepayment arrangements for financing personal health services introduced in stages.”<sup>(6)</sup>
- “*Freedom of Choice*”: a patient’s right to select a physician or dentist, and the right of the practitioner to accept or not to accept a patient except in emergency or on humanitarian grounds.<sup>(7)</sup>

---

(3) *Ibid.*, p. 11.

(4) *Ibid.*

(5) *Ibid.*

(6) The services would include: medical services; dental services for children, expectant mothers, and public assistance recipients; prescription drug services; optical services for children and public assistance recipients; prosthetic services; and home care services.

(7) *Ibid.*

**b. *Canada Health Act***

From the federal perspective, the primary objective of Canadian health care policy – to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers – is outlined in the *Canada Health Act*.<sup>(8)</sup> The fundamental collective principles underlying the Canadian health care system are set out in the five program criteria found in the Act. They are:

- public administration;
- comprehensiveness;
- universality;
- portability; and
- accessibility.<sup>(9)</sup>

“Public administration” ensures that the health care insurance plan of each province is administered and operated on a non-profit basis by a public authority that is responsible to the provincial government.

“Comprehensiveness” means that each provincial health insurance plan must cover all “insured health services,” provided by hospitals, medical practitioners or dentists or similar or additional services rendered by other health care practitioners where permitted. The term “insured health services” is defined by the Act to include medically necessary “hospital services,” medically required “physician services,” and “surgical-dental services” when performed in a hospital.

To satisfy the “universality” criterion, each provincial health insurance plan must cover all persons resident in a province.

“Portability” means that residents moving to another province must continue to be covered for insured services by the home province during a minimum waiting period (not longer than three months) imposed by the new province of residence for insurance coverage, and that residents are insured for services outside their province of residence if they are elsewhere in the country or outside Canada.

---

(8) R.S.C. c. C-6, section 3.

(9) *Ibid.*, section 7.

“Accessibility” means that insured health services should be provided on uniform terms and conditions and on a basis that does not impede or preclude reasonable access to those services.

In order to qualify for the full federal cash contribution for health care, provincial health insurance plans must satisfy these criteria and must not allow extra billing or user fees for insured services. When coupled with the prohibition on extra-billing and user fees, these five program criteria establish the principal collective right to health care in Canada – reasonable access to medically necessary hospital and physician services without charge anywhere in Canada.

### **c. Patients’ Bill of Rights**

#### **1) Private Member’s Bill**

Federal health care initiatives tend to focus on collective, system-wide principles and objectives rather than on the rights and expectations of individual users of the health care system. The absence of a federal focus on individual rights stems largely from the constitutional division of powers, which makes health care a provincial responsibility.

Recently, however, federal politicians have expressed increased interest in patients’ rights. Mr. Greg Thompson (New Brunswick Southwest) introduced a Private Member’s Bill – Bill C-261, An Act to establish the rights of patients in relation to health, treatment and records (Patients’ Bill of Rights) – in the House of Commons on 12 February 2001. This bill, if passed, would set out a number of rights with respect to the health care system as a whole as well as a series of personal rights for patients.<sup>(10)</sup>

In addition to outlining specific patients’ rights, the bill (clause 5) lists three health care responsibilities that patients would undertake:

- provide health professionals with full and accurate information relating to their health and the public health services they have received;
- cooperate with health professionals and to either follow their advice or indicate when they have not done so; and
- exercise due economy in using health services.

---

(10) Bill C-261, An Act to establish the rights of patients in relation to health, treatment and records, First Session, Thirty-seventh Parliament, 49-50 Elizabeth II, 2001.  
[http://www.parl.gc.ca/37/1/parlbus/chambus/house/bills/private/C-261/C-261\\_1/C-261\\_cover-E.html](http://www.parl.gc.ca/37/1/parlbus/chambus/house/bills/private/C-261/C-261_1/C-261_cover-E.html). This bill was originally introduced on 7 February 2000 as Bill C-417 but died on the *Order Paper* with the dissolution of Parliament for the 27 November 2000 federal election.



The rights pertaining to the public health care system found in clause 3 of the bill provide that all Canadians would have the right to “national collaboration between governments” to assure:

- (a) a good-quality, dependable and accessible national system of health care;
- (b) a system of health care that is transferable and generally uniform across Canada;
- (c) the minimum amount of overlap and duplication in public health services between different governments;
- (d) consistency in development of public health services between different governments resulting in consistency in the timing of development of services and innovation; and
- (e) regular consultation with the public about public health services in a forum that is public, open and gives a reasonable opportunity to present views to representatives of government, the House of Commons or a legislative assembly, and the medical profession.

Clause 4 of the bill outlines a substantial list of personal (individual) rights for users of the public health care system, including:

- (a) the right to be fully informed about one’s medical condition;
- (b) the right to be advised of the available treatment options;
- (c) the right to be involved in treatment decisions;
- (d) the right to information on the qualifications and experience of the health professionals from whom services are received;
- (e) the right to receive considerate, compassionate and respectful public health services;
- (f) the right to confidential communications with health professionals;
- (g) the right to have access to and copies of personal health records and to have them corrected, if necessary;
- (h) the right to have health records kept confidential and not used for any purpose other than public health services without written consent;
- (i) the right to designate a person to exercise rights on the patient’s behalf if the patient is not able to do so because of a physical or mental incapacity; and
- (j) the right to be informed of all rights and responsibilities under the bill and under other laws of Canada or a province with respect to public health services.

Recognizing that the provinces have primary responsibility for health care, the bill would enforce these rights through federal-provincial agreements and make full cash contributions to provinces under the *Federal Provincial Fiscal Arrangements Act* conditional upon the conclusion of federal-provincial agreements relating to patients’ rights.

## 2) Senate Committee Proposal

In its September 2001 issues and options document on the federal role in the Canadian health care system,<sup>(11)</sup> the Standing Senate Committee on Social Affairs, Science and Technology put forward a patients' bill of rights as an option to address the problem of timely access to health care services.

The Committee observed that adopting patients' bills of rights at the provincial level would accommodate differing provincial situations and might even inject an element of competition into health care delivery. At the same time, the Committee noted that because many Canadians would not want to see substantial discrepancies among provincial standards, the federal and provincial/territorial governments could participate in the development of minimum standards for timely access to health care that would serve as the basis for provincial patients' bills of rights.<sup>(12)</sup>

### 2. Rights and Entitlements in Relation to Health Care – Provincial Initiatives

In dealing with rights and entitlements to health care, provincial governments have adopted a range of approaches: Quebec has legislated certain entitlements; the current Ontario government has made a commitment to enact a patients' bill of rights; the Premier's Health Quality Council of New Brunswick has proposed a New Brunswick Health Charter of Rights and Responsibilities; and other provinces have set health care goals, objectives and expectations in planning and policy documents. Private Members' bills introduced in the Ontario and Alberta legislatures in the late 1990s also sought to enact a code of patients' rights and responsibilities.

A number of these initiatives are outlined below.

#### a. Alberta

A Private Member's bill – Bill 201, Alberta Patients' Bill of Rights – was introduced in the Alberta Legislative Assembly on 28 January 1998. The purpose of the bill was to:

---

(11) Standing Senate Committee on Social Affairs, Science and Technology, *The Health of Canadians – The Federal Role, Volume Four – Issues and Options*, September 2001.  
<http://www.parl.gc.ca/37/1/parlbus/commbus/senate/com-e/SOCI-E/rep-e/repintsep01-e.htm>

(12) *Ibid.*, p. 47.

- (a) ensure that patients were aware of their right to receive appropriate and timely care;
- (b) ensure that patients were treated with dignity and respect; and
- (c) promote and improve communication between patients and health care professionals.

The bill would have provided patients with various rights, including the right to:

- receive health services without discrimination;
- have their personal and health information protected from disclosure;
- have access to their health information unless, in the opinion of a relevant health professional, the disclosure could result in immediate and grave harm to the patient's health or safety;
- refuse consent to any proposed treatment; and
- receive information relating to any proposed treatment and options.<sup>(13)</sup>

Bill 201 was defeated shortly after it was introduced.<sup>(14)</sup>

#### **b. Ontario**

The Ontario government has committed to introducing a patients' bill of rights and tying hospital funding to how well hospitals deliver health care services.<sup>(15)</sup> Prior to this commitment, at least three Private Members' bills to promote patients' rights had been introduced in the Ontario legislature over a three-year span.<sup>(16)</sup> The most recent of these – Bill 18, Health Care Accountability and the Patients' Bill of Rights Act, 1999 – which was introduced in April 1998, would have:

- codified the rights (as listed below) of residents of Ontario who receive health care;
- provided for the appointment of a Health Care Standards Commissioner who would promote understanding of and compliance with the Patients' Bill of Rights, participate in setting health care standards and developing a complaints procedure, monitor health care standards, and make recommendations to the Legislature for improvements to the laws and policies related to health care; and
- established whistleblower protection for health care providers.

The bill set out the following collective and individual rights:

---

(13) Legislative Assembly of Alberta, *Hansard*, 24th Legislature, 2nd Session, 28 January 1998.

(14) Bill 201 was defeated on 4 February 1998.

(15) Ontario, Ministry of Health and Long-Term Care, Ontario Budget 2000.

(16) Bill 41, Patients' Bill of Rights, 1996 (Mrs. Caplan); Bill 50, Health Care Accountability and Patients' Bill of Rights Act, 1998 (Mrs. Boyd); and Bill 18, Health Care Accountability and Patients' Bill of Rights Act, 1999 (Mrs. Boyd).

- the right to receive all necessary health care services in a health care system that:
  - a) is accessible, universal, comprehensive and publicly administered and funded,
  - b) offers freedom of choice,
  - c) provides timely treatment,
  - d) does not allow personal income to determine access to health care services, and
  - e) recognizes that every provider of health care services is a valued member of a multidisciplinary health care team;
- the right to give or refuse consent to the provision of health care services;
- the right to all information necessary to make fully informed health care choices, including information about who will provide particular services and their qualifications;
- the right to receive high-quality, publicly funded health care in the home and in the community as well as in health care facilities;
- the right to receive information about choices that promote good health as well as about measures that prevent illness and accident;
- the right to be dealt with by health care service providers,
  - a) with courtesy and respect,
  - b) in a manner that recognizes individual dignity and privacy and promotes individual autonomy,
  - c) in a manner that recognizes and responds to individual needs and preferences, including those based on ethnic, spiritual, linguistic, familial and cultural factors,
  - d) without mental, physical, sexual or financial abuse;
- the right to participate in any assessment of personal care requirements and in the development of plans for care;
- the right to make complaints, raise concerns, and recommend changes without fear of interference, coercion, discrimination or reprisal;
- the right to be informed of:
  - a) the laws, rules and policies affecting providers of health care services, and
  - b) the procedures for initiating complaints about providers of health care services;
- the right to confidentiality of health care records in accordance with the law.

None of the three bills has become law.

**c. Quebec**

Quebec's Act regarding health services and social services (*Loi sur les services de santé et les services sociaux*)<sup>(17)</sup> sets out entitlements with respect to health and social services.

Included among these are entitlements to:

- be informed of the existence of the health and social services resources available in the community and the conditions governing access to the services;
- receive health services in a continuous and personalized manner and which are scientifically, humanely and socially appropriate;
- choose the professional from whom or the institution from which health services are to be received;
- receive the care required when life or bodily integrity is endangered;
- be informed of the state of one's health and options for care prior to giving consent to care; and
- participate in decisions affecting one's care.<sup>(18)</sup>

It should be noted, however, that the Act limits the application of health and social services entitlements by tying them to structural and economic constraints. The entitlement to health services and to choose one's health care professional and institution must be exercised within the framework of the legislative and regulatory provisions relating to the organizational and operational structure of the institution and within the human, material and financial resources available to the institution.<sup>(19)</sup>

The Act also created a three-tier regime for dealing with complaints against health care facilities and providers. Complaints were to be made first to the relevant institution, then to the appropriate regional board and finally to the government-appointed Complaints Commissioner who examined complaints from persons who were dissatisfied with decisions made by regional boards.<sup>(20)</sup>

Bill 27, an Act respecting the Health and Social Services Ombudsman and amending various legislative provisions – which was introduced in May 2001 – replaces the Complaints Commissioner with a Health and Social Services Ombudsman (Health Services

---

(17) An Act Respecting Health Services and Social Services, 1991, R.S.Q. c. S-4.2.

(18) *Ibid.*, sections 4-10.

(19) *Ibid.*, section 13.

(20) *Ibid.*, section 56.

Ombudsman).<sup>(21)</sup> The Act streamlines the complaints procedure by creating a two-tier regime. In the first instance, local service quality commissioners and regional service quality commissioners examine complaints in relation to services and activities coming under their respective authorities. At the second tier, the Health Services Ombudsman hears appeals from complainants who are dissatisfied with decisions at the quality commissioner level.

The Act also gives the Health Services Ombudsman the power to intervene in circumstances where there are reasonable grounds to believe that a person or group of persons has been or may likely be adversely affected by an act or omission of an institution or a regional board.<sup>(22)</sup>

#### **d. Nova Scotia**

In Nova Scotia, the provincial government originally tasked the Provincial Health Council with developing a Patient's Bill of Rights. However, the Council produced a set of "Expectations for Health and Health Care in Nova Scotia" after concluding that a legislated patients' rights document "would pose innumerable legal problems that might take decades to resolve through the courts."<sup>(23)</sup>

The expectations fall into three broad categories: the attainment and maintenance of health for persons, families and communities; the development of health care and related services; and the provision of health care and related services. The latter two categories contain 10 expectations related to the development of the health care system and 21 expectations pertinent to the provision of health care.

The Expectations relating to the development of health care deal largely with what Nova Scotia residents should reasonably expect at the policy and system level. These include:

- a health care system that reflects their values;
- the development and delivery of service that reflects a commitment to the health, general well-being and dignity of all residents;

---

(21) Chapter 43, Statutes 2001, An Act respecting the Health and Social Services Ombudsman and amending various legislative provisions, Royal Assent, 11 December 2001, in force 1 January 2002, except for certain sections. <http://www.assnat.qc.ca/FRA/Publications/Projets-loi/etat-001.htm#et01f027>

(22) *Ibid.*, section 19.

(23) Nova Scotia, Provincial Health Council, "Expectations for Health and Health Care in Nova Scotia," 18 May 2000. <http://www.healthcouncil.ns.ca/rights.htm>

- access to health care and related services and supports, including: primary care, acute care, long-term care and home care as well as emergency, palliative, rehabilitative and preventive services;
- the development and delivery of service guided by the best available qualitative, quantitative and experiential evidence;
- support for individual and community efforts to enhance the health and well-being of residents;
- eradication of intersectoral and other barriers to ensure better health and health care;
- equitable allocation of resources;
- adequate funding for, and wise management of, services that have an impact on health;
- continued Government commitment to the spirit of the *Canada Health Act* and *Nova Scotia's Health Goals* (1992); and
- widespread public input into major proposed changes to the health care system.<sup>(24)</sup>

The Expectations for the provision of health care services, on the other hand, outline what individual residents should reasonably expect in relation to their personal health care. These include:

- providing services that respect values, culture, language, religion, ethnicity and individual ability;
- being treated with respect, dignity and consideration;
- paying attention to the individual's views, preferences, observations and problems regarding all aspects of care;
- providing care in a manner that is free from abuse, neglect and prejudice;
- providing care based primarily on individual need;
- receiving safe, competent and ethical care by qualified providers;
- knowing the names, qualifications and professional roles of the health care providers;
- providing health care and related services with reasonable accommodation for the geographic distribution of the population;
- being cared for in a clean, safe and healthy environment;
- receiving understandable information about one's health care;
- participating fully in all decisions related to one's health care, either directly or where circumstances dictate, through the use of an appropriate proxy or Advance Directive;
- participating in arrangements for discharge;

---

(24) *Ibid.*

- honouring requests for the withdrawal of treatment or the refusal of care except where otherwise prescribed by law;
- honouring refusals to participate in research or educational activities;
- being informed of the relevant risks, benefits and reasonably foreseeable consequences of any proposed intervention together with the risks and potential consequences of refusing care;
- being adequately informed of the rules, regulations, policies and limits associated with the provision of health care and related services;
- receiving a full explanation, in advance, for any charges for services not covered by the provincial health care plan;
- being assured of privacy;
- observing confidentiality unless disclosure is authorized by law;
- receiving an explanation of the requirements for disclosure of confidential information; and
- having reasonable and timely access to and copies of personal health care records as well as the right to request changes to the records.<sup>(25)</sup>

#### **e. New Brunswick**

In its January 2002 report,<sup>(26)</sup> the New Brunswick Premier's Health Quality Council outlined a New Brunswick Health Charter of Rights and Responsibilities, the purpose of which is to set out what New Brunswick residents can expect from the health care system and health care professionals. The Charter, which sets out a number of specific rights and responsibilities at three levels – the individual, the health professional, and the health care system – addresses five broad classes of rights:

- access to health services;
- the making of one's own decisions;
- good communication and information;
- personal consideration and respect; and
- the addressing of issues and complaints.<sup>(27)</sup>

---

(25) *Ibid.*

(26) New Brunswick Premier's Health Quality Council, *Health Renewal: Report from the Premier's Health Quality Council*, January 2002. [http://www.gov.nb.ca/op\\_cpm/e-phqc.pdf](http://www.gov.nb.ca/op_cpm/e-phqc.pdf)

(27) The proposed Charter is outlined on pages 91-95 of the Report from the Premier's Health Quality Council.



The rights encompassed under “access to health services” include the right to:

- receive publicly funded health services on the basis of need, rather than ability to pay, lifestyle or any other factor;
- have access to primary care in one’s local area;
- receive health services from a family physician or collaborative practice team;
- have equitable access to health services;
- obtain a second opinion;
- have continuity of care;
- receive health services that respond to individual needs and preferences;
- receive services in the official language of choice; and
- ensure wheelchair accessibility.

Responsibilities outlined under access to services include both individual and health system responsibilities. The former include the responsibility to:

- learn how to access health services;
- use services appropriately and wisely; and
- live a healthy lifestyle.

The corresponding health system responsibilities include the responsibility to:

- respond to patients’ needs in a timely manner based on established standards;
- provide information about treatment and services;
- provide a seamless continuum of care;
- deliver services effectively and efficiently without compromising quality;
- spend public funds prudently and wisely;
- provide a clear policy about health care professionals reporting concerns about risks for patients;
- provide a safe working environment;
- respect health care personnel; and
- ensure wheelchair accessibility.

The rights under “the making of one’s own decisions” deal with issues such as being informed, refusing treatment, choosing treatment, participating in research, and receiving

information about the qualifications and experience of health professionals. The health system's responsibilities under this category centre on providing information about treatments and procedures and their implications as well as respecting health care decisions.

“Good communications and information” covers rights to an explanation of proposed treatments and risks, access to health records, information about new treatment advances, and information on health services. Patients have a corresponding responsibility to ask questions, follow instructions, understand their treatment plan, and request information.

Rights under “personal consideration and respect” focus on providing a clean and safe care environment, being treated with dignity and respect, and protecting privacy. The Charter also stresses that patients have a responsibility to collaborate with health care personnel and to be courteous and respectful.

Finally, the proposed Charter outlines rights to complain along with a corresponding responsibility on the health system to provide mechanisms to address complaints.

The Premier's Health Quality Council did not address whether the Charter should be entrenched in legislation, noting, however, that it was up to the government to decide whether the Charter should be legislated or made part of public policy.

In order to facilitate the rights outlined in the proposed Charter, the Council recommended the creation of an advocate system composed of Health System Advocates to facilitate access and communications. Regional Advocates would be created in each regional health authority along with one Provincial Advocate who would deal with province-wide policy and communications issues. The Health System Advocate system would also address patients' concerns and complaints of a defined scope.<sup>(28)</sup>

### **3. Rights and Entitlements in Relation to Health Care – Policy Proposals**

#### **a. IRPP Task Force on Health Policy**

In 2000, the Institute for Research on Public Policy<sup>(29)</sup> (IRPP) Task Force on Health Policy released a series of recommendations to Canada's first ministers on reforming Canada's health care system. Among the recommendations was a suggestion for increasing the

---

(28) *Ibid.*, p. 85.

(29) The IRPP is an independent, national non-profit public policy research organization founded in 1972.

accountability of health organizations through mechanisms such as Patients' Charters and a Health Care Ombudsperson.<sup>(30)</sup>

The IRPP Task Force suggested that Patients' Charters should be adopted at the provincial level to permit patient entitlements to be adapted to the particular circumstances of each province. In the beginning, charters would focus on a short list of items and not include broad statements dealing with all personal health services.<sup>(31)</sup> Under the IRPP proposal, health organizations would issue a statement of "patient rights, expectations and responsibilities with regard to the appropriateness, quality and timeliness of care"<sup>(32)</sup> and report annually on how hospitals and other health care providers were meeting these entitlements. The overriding view was that Patients' Charters would result in improved health care services.

The Task Force argued that an effective Patients' Charter must be built on the following premises:

- a change in health services organizations;
- a selective focus on quality of services;
- a determination to commit incremental resources; and
- an effective appeals process.<sup>(33)</sup>

The Task Force saw a number of benefits from creating Patients' Charters. First, they would "refocus the delivery of health care services on the patient and on the quality of these services in each and every community."<sup>(34)</sup> An emphasis on outcomes would result in a shift in decision-making to a regionally managed system that could be adapted to meet the needs of particular regions and patients. Second, because they are directed to individual entitlements, Patients' Charters would focus the measurement of quality on individual contacts with the system rather than on aggregate numbers.<sup>(35)</sup> Third, Charters would compel governments to

---

(30) The Institute for Research on Public Policy, IRPP Task Force on Health Policy Recommendations to First Ministers, 2000, p. 22. <http://www.irpp.org>

(31) *Ibid.*, p. 27.

(32) *Ibid.*, p. 22.

(33) *Ibid.*, p. 27.

(34) *Ibid.*, p. 26.

(35) *Ibid.*, p. 27.

allocate greater resources to the health care system in order to live up to the entitlements provided.<sup>(36)</sup>

To overcome barriers imposed by the expense of the litigation, and scepticism about the effectiveness of such charters, the Task Force suggested that an administrative appeals process be established at local and provincial levels, through an official such as an ombudsperson who would monitor the system's adherence to the principles of Medicare and the patients' entitlements under provincial charters.<sup>(37)</sup>

## **B. New Zealand**

New Zealand has legislated rights for consumers of health and disability services in a Code of Health and Disability Services Consumers' Rights, created in 1996 as a regulation under the *Health and Disability Commissioner Act 1994*.<sup>(38)</sup> The impetus for the passage of the Act came from two factors: the widespread view at the time that the law was inadequate to protect consumers of health and disability services; and public concern about the imbalance in power and knowledge between health care professionals and health care consumers. This was documented by a commission of inquiry established by the New Zealand government to investigate allegations relating to inadequate treatment of cervical cancer in an Auckland hospital.<sup>(39)</sup>

The Act's purpose is "to promote and protect the rights of health consumers and disability services consumers, and, to that end, to facilitate the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights" (s. 6). The aim is to achieve this objective through: the Code of Health and Disability Services Consumers' Rights; the appointment of a Health and Disability Commissioner to investigate complaints against persons or bodies who providing health care or disability services; and the education of health care providers and consumers.

---

(36) *Ibid.*, p. 28.

(37) *Ibid.*

(38) Statutes 1994, No. 88.

(39) S. Cartwright, *The Report of the Cervical Cancer Inquiry*, 1998.

## 1. The Code of Health and Disability Services Consumers' Rights

The Code of Health and Disability Services Consumers' Rights<sup>(40)</sup> sets out ten rights relating to the patient-health care provider relationship. These are:

- 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;<sup>(41)</sup>
- 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 have support persons present;
- the right to accept or refuse participation in teaching or research; and
- the right to complain.

The Code also outlines compliance requirements for health care providers. Where the rights cannot be met, the onus is on the provider to establish that it was reasonable in the circumstances not to have done so.

## 2. The Health and Disability Commissioner

The Health and Disability Commissioner appointed under the Act has far-reaching powers. The Commissioner, whose initial task was to prepare a draft Code, has ongoing responsibility to review the Code in accordance with the Act. Other responsibilities include promoting the rights of health and disability services consumers, investigating alleged breaches of the Code,<sup>(42)</sup> and making recommendations for resolving breaches. The

---

(40) New Zealand, The Code of Health and Disability Services Consumers' Rights, <http://www.hdc.org.nz/about/claus1.html>

(41) One of the features of the right to have services that comply with legal, professional, ethical and other relevant standards is that it allows the standards of professional and other bodies to be enforced through the Code by the Health and Disability Commissioner.

(42) Under section 14(1)(e) of the Act, the Commissioner can investigate, on complaint or on the Commissioner's own initiative, any action that is or appears to be in breach of the Code.

Commissioner can also advise the minister responsible for the Act and report on the need for action to protect the rights of health consumers and disability services consumers.<sup>(43)</sup>

The Commissioner has the authority to refer a matter under investigation to the Director of Proceedings, an independent statutory officer under the Act, who can hold proceedings regarding a complaint. Generally, proceedings can be brought before the Complaints Review Tribunal and various health professional disciplinary bodies.

The Complaints Review Tribunal has the authority to issue consumer remedies including:

- a declaration that the action of the provider is in breach of the Code;
- an order restraining the provider from continuing or repeating the breach, or from engaging in, or causing or permitting others to engage in, conduct of the same kind as that constituting the breach;
- damages;
- an order that the provider perform any specified acts with a view to redressing any loss or damage suffered by the consumer as a result of the breach; and
- any other relief the Tribunal thinks fit.<sup>(44)</sup>

The Act also provides for advocates to assist consumers in resolving their complaints or concerns directly with health and disability service providers. Advocates neither investigate nor make decisions on whether the Code has been breached. They also perform an educational function by promoting awareness of the Code and the Act to consumers and providers. Advocacy services operate independently of the Commissioner, health care providers and disability services providers, but the Commissioner can issue guidelines for the operation of such services.<sup>(45)</sup>

### **C. United Kingdom**

The United Kingdom (UK) introduced a patients' bill of rights in 1992 when the National Health Service (NHS) Patient's Charter<sup>(46)</sup> was implemented to improve the quality of

---

(43) *Health and Disability Commissioner Act 1994*, s. 14.

(44) *Ibid.*, section 54.

(45) *Ibid.*, section 30.

(46) National Health Service, Patient's Charter.

care delivered to patients. Complaints about the NHS had been rising steadily, patients were experiencing long waiting periods for medical services, and concerns were being voiced about the quality of care and the manner in which patients were being treated.

The NHS Patient's Charter<sup>(47)</sup> was composed of individual rights and service standards (known as expectations). The rights comprised core principles such as access to health care, the receiving of information to make informed choices about medical care, and included the right to:

- receive health care on the basis of clinical need, not on ability to pay, lifestyle or any other factor;
- be registered with a General Practitioner (GP), change GPs easily and quickly, and have a medical checkup;
- be prescribed appropriate drugs and medicines, and have free medicines if the patient is within certain age categories;
- obtain emergency medical treatment at any time;
- be referred to an acceptable specialist and obtain a second opinion;
- choose whether to take part in medical research or medical student training;
- have a clear explanation of any proposed treatment, the risks involved and the alternatives;
- have access to personal health records;
- have complaints about NHS services investigated; and
- receive detailed information on local health services including quality standards and waiting times.

The Charter standards (expectations) were more specific and sought to address concerns about the quality of health care services and waiting times for certain procedures. These standards included:

- readmission within one month if surgery was cancelled on the scheduled day for non-medical reasons;
- a maximum waiting period of 13 weeks for a non-urgent outpatient appointment in 90% of cases;
- patients at outpatient clinics being seen within 30 minutes of their scheduled appointment time;

---

(47) England, Scotland, Wales and Northern Ireland have separate charters. The information in this paper is drawn from the charter for England.

- a maximum wait of two hours for a hospital bed after admission to hospital through an emergency department;
- immediate assessment of patients arriving at an accident and emergency department;
- waiting times for an ambulance not to exceed 14 minutes in urban areas, 19 minutes in rural areas;
- clean, safe hospitals with clear signs;
- pre-discharge arrangements for necessary post-hospital care;
- provision of a clear explanation of a hospital's food, nutrition and health policy as well as catering services and standards; and
- respect for privacy, dignity, and religious and cultural beliefs.

The Charter stressed the importance of GPs establishing their own practice charters and for hospitals to set local standards for waiting times.

In June 1997, the UK Department of Health commissioned a study to review the existing Patient's Charter and develop proposals for a new NHS Charter. Overall, the study gave the Charter very low marks. Describing it as a "disconnected ragbag of so-called service rights and aspirations," the study concluded that the Charter was of limited usefulness.<sup>(48)</sup>

The Charter was criticized on a number of fronts, from the manner in which it was drawn up and implemented to its content. It was described as a top-down initiative which staff saw as a "political" document designed to assuage mounting complaints about health care services. NHS staff believed the Charter engendered a blame culture by giving patients rights without obligations.

Critics argued that the Charter encouraged cheating to comply with admission standards. By measuring the process by which patients travelled through the system rather than the clinical outcome or the quality of the care prescribed, all the targets could be met but patients could still be dissatisfied with their level of treatment and care.<sup>(49)</sup>

Despite these criticisms, however, the study found that one of the most important impacts of the Charter was the more consumerist culture it injected into the British health care system.

---

(48) Greg Dyke, *The New NHS Charter – A Different Approach*, Report on the new NHS Charter, December 1998.

(49) *Ibid.*, pp. 10-11.



In the end, the study concluded that the NHS would not benefit from the imposition of another national charter and proposed instead that local charters be developed in trusts, primary care groups and other community health services dealing directly with patients.<sup>(50)</sup> It did not, however, recommend a complete abandonment of national standards, and suggested a national framework containing some minimum national standards that could be included in local charters.

In 2001, the Patient's Charter was replaced by a new NHS document, *Your Guide to the NHS*.<sup>(51)</sup> The Guide sets out what patients can expect from the NHS in relation to current and future waiting times for certain kinds of treatment, ambulance arrivals, treatment in hospital emergency departments, and appointments with a GP or a nurse practitioner. For example, by 2004, patients should not have to wait more than four hours in an accident and emergency department from arrival to admission, transfer and discharge. The Guide also provides a care guarantee when a patient's operation is cancelled on the day of surgery for non-clinical reasons. In this case, the hospital is required to provide another surgery date within 28 days or pay for treatment in a hospital of the patient's choice.

The UK government has also put forward a plan for a Patient Advocacy and Liaison Service under which patient advocates will act as independent facilitators to: (a) handle patients' complaints about service; and (b) guide patients through the complaints process.

An independent Health Service Ombudsman investigates complaints about the NHS.<sup>(52)</sup> The type of complaints examined include those relating to: poor service or failure to provide a service; allegations that staff did not follow proper procedures or were rude; and complaints about the care received from doctors, nurses and other health professionals.

#### **D. Australia**

The Australian commonwealth government provides financial assistance to the States and Territories for public hospitals and other health services conditional upon the latter entering into agreements (Australian Health Care Agreements). States and Territories must

---

(50) *Ibid.*, p. 16.

(51) United Kingdom, National Health Service, *Your Guide to the NHS*. <http://www.nhs.uk/nhsguide/> Patient's Charters continue to apply in Wales, Scotland and Northern Ireland.

(52) Additional information about the Health Service Ombudsman can be found at <http://www.ombudsman.org.uk/>

agree to develop a Charter giving residents various types of information, including the provision of health services, the process for making complaints, and how the complaints will be heard. As a result, States and Territories have developed Public Patients' Hospital Charters<sup>(53)</sup> that include a number of rights, including the right to:

- receive free public hospital services as a public patient;
- be treated on the basis of health needs, regardless of financial or health insurance status;
- have access to public hospital services, regardless of place of residence;
- be treated with respect, compassion and consideration of privacy, taking into account the patient's background, needs and wishes;
- participate fully in health care decisions including admission, discharge and arrangements for continuing care;
- receive a clear explanation of proposed treatment including risks and alternatives, before agreeing to the treatment;
- seek a second medical opinion;
- give informed consent (except in exceptional circumstances) before a procedure is carried out, including consent to participation in undergraduate health professional teaching or medical research;
- withdraw consent or refuse further treatment;
- have access to personal medical records;
- be assured that personal information will be kept confidential, unless otherwise provided by law;
- have interpreter services when necessary; and
- complain about health care and be advised of the procedure for expressing concerns.

Australia has also developed a Private Patients' Hospital Charter which sets out guidelines relating to private patients in a public hospital, a private hospital or a day hospital facility and what such patients can expect from doctors, hospitals and health insurance funds.

---

(53) Examples include the Northern Territory Public Hospital Charter and the South Australia Charter for Public Health System Consumers.

## **E. United States**

Over the past decade, managed health care through organizations – commonly known as health maintenance organizations (HMOs) – proliferated in the United States as employers and governments sought to contain rising health insurance costs.<sup>(54)</sup> In their quest to contain costs, managed care organizations have garnered numerous criticisms and complaints. For example, HMOs have been routinely accused of improperly denying coverage or delaying care. As well, surveys have reported patient problems such as difficulty seeing physicians, the refusal to make referrals to specialists, restricted coverage for emergency services, limits on the length of hospital stays and delays, and denial of payment on the grounds that procedures are not medically necessary. In some cases, these actions have resulted in health problems and significant financial costs for patients.

In fact, there have been so many complaints and criticisms that governments have felt it necessary to enact laws guaranteeing patients' rights in managed care situations. State governments were first off the mark in enacting patients' rights statutes to deal with the managed care industry. Also, a variety of patients' rights bills have been put before the House of Representatives and the Senate; to date, however, none has become law.

A number of these initiatives are discussed below.

### **1. Federal Proposals**

#### **a. Presidential Initiatives**

In 1997, President Clinton created the Advisory Commission on Consumer Protection and Quality of the Health Care Industry and charged it with developing a patients' bill of rights. Later that year, the Advisory Commission issued the Patients' Bill of Rights and Responsibilities, which set out seven categories of rights and one set of responsibilities:<sup>(55)</sup>

- the right to information;<sup>(56)</sup>
- the right to choose one's health care providers, including access to qualified specialists;

---

(54) Jill A. Marsteller and Randall R. Bovbjerg, "Federalism and Patient Protection: Changing Roles for State and Federal Government," August 1999, Urban Institute, p. 3.  
<http://newfederalism.urban.org/html/occa28.html>

(55) U.S. Department of Health and Human Services, HSS Fact Sheet, *The Patients' Bill of Rights in Medicare and Medicaid*, 12 April 1999. <http://www.hhs.gov/news/press/1999pres/990412.html>

(56) Patients have the right to receive accurate, easily understood information to assist them in making informed decisions about their health plans, facilities and professionals.

- the right to access to emergency services;<sup>(57)</sup>
- the right to participate in health care decisions;
- the right to care without discrimination;<sup>(58)</sup>
- the right to privacy;
- the right to speedy complaint resolution;<sup>(59)</sup> and
- the responsibility to maintain good health.

In 1998, President Clinton directed the following bodies – the federal Department of Health and Human Services as well as the departments of Labor, Defense and Veterans’ Affairs and the Office of Personnel Management – to bring their health programs, including Medicare and Medicaid, into compliance with the consumer protections proposed in the Commission’s bill by the end of 1999.

#### **b. Congressional Initiatives**

The U.S. Congress has been debating patients’ rights issues since the mid-1990s. In the 106<sup>th</sup> Congress, the Senate and the House of Representatives each passed a bill on this subject: the Bipartisan Consensus Managed Care Improvement Act of 1999 (the Norwood-Dingell Bill, H.R. 2723)<sup>(60)</sup> passed the House of Representatives in October 1999; and Bill S. 1344 passed the Senate in July 1999. However, Congress was unable to reconcile the differences between the two bills.

---

(57) Health plans should pay for emergency services when a patient has: symptoms that a “prudent layperson” would reasonably expect to place the patient’s health in serious jeopardy; serious impairment to bodily functions; or serious dysfunction of any bodily organ or part.

(58) Patients have the right to considerate, respectful care and must not be discriminated against in the marketing or enrolment or in the provision of health care services based on race, ethnicity, national origin, religion, sex, age, current or anticipated mental or physical disability, sexual orientation, genetic information, or source of payment.

(59) Patients have the right to a fair and efficient process for resolving differences with their health plans, health care providers and health care institutions, which includes an independent system of external review.

(60) H.R. 2723 was folded into a health “tax and access” bill (H.R. 2990) and passed the House of Representatives as part of H.R. 2990.

The 107<sup>th</sup> Congress has also seen patients' rights proposals. In June 2001, the Senate passed Bill S. 1052, the *Bipartisan Patient Protection Act*,<sup>(61)</sup> while the House of Representatives passed a patients' rights bill, H.R. 2563, in August of the same year.<sup>(62)</sup>

The bills have important similarities. Under both bills:

- health plans would have to reveal to enrollees how they operate;
- health plans would have to allow enrollees to see specialists outside each plan's network when the network does not include the required physician;
- health plans would be required to pay for emergency care provided to enrollees who reasonably believed that they needed immediate medical attention;
- enrollees who were receiving ongoing treatment would be able to continue to be cared for by their health care provider for a limited period of time after the provider had left a plan's provider network;
- health plans would be required to establish internal processes to review coverage denials and other decisions.<sup>(63)</sup>

However, there are also notable differences between the two bills. One key difference relates to the structure of an independent system to review challenges to health care plan decisions. Most states have established an independent review process to review decisions unfavourable to health plan enrollees. H.R. 2563 would have federal review procedures override state review processes while S. 1052 would establish minimum federal standards, but allow states to have their own review programs.<sup>(64)</sup>

Another, and perhaps the most contentious, difference relates to the extent of permissible litigation by enrollees against their health plans. Both bills include provisions that would allow enrollees to sue their health plans, but there are significant differences in the scope of the liability provisions. S. 1052 would allow suits to proceed in state courts under state laws for denial of benefits or quality-of-care issues and in federal court for other matters. H.R. 2563 would also allow suits in state courts but under stricter federal rules relating to burden of proof

---

(61) Bill S. 1052 was sponsored by Senators McCain (R-Arizona), Kennedy (D-Massachusetts) and Edwards (D-North Carolina). <http://thomas.loc.gov/cgi-bin/query/D?c107:4:./temp/~c107QYzfNt::>

(62) Bill H.R. 2563 was sponsored by Representatives Ganske (R-Iowa), Dingell (D-Michigan) and Norwood (R-Georgia). <http://thomas.loc.gov/cgi-bin/query/D?c107:3:./temp/~c107QYzfNt::>

(63) Stephanie Lewis, *A Guide to the Federal Patients' Bill of Rights Debate*, prepared for The Kaiser Family Foundation, August 2001, p. 4. <http://www.kff.org/content/2001/3179/DebatePaper.pdf>

(64) *Ibid.*, p. 6.

and damages.<sup>(65)</sup> The bills also differ on the amount of damages that an enrollee could recover. The Senate bill would allow for the recovery of economic damages (lost wages and medical expenses) and non-economic damages (pain and suffering) without limitation and up to US\$5 million in punitive damages in federal suits where it was established that the health plan's actions were in flagrant violation of an enrollee's rights and a proximate cause of the enrollee's injury or death. H.R. 2563, on the other hand, would allow for the recovery of economic damages but would cap non-economic damages at US\$1,500,000 and would allow punitive damages up to US\$1,500,000 in limited circumstances.<sup>(66)</sup>

Although passed in 2001, these bills have not yet proceeded to a conference committee for reconciliation. However, patients' rights are expected to be back on the legislative agenda in 2002.

## **2. State Initiatives**

State governments were enacting patients' rights laws well before legislation was placed before Congress. At the state level, two forms of statutes predominate – laws that give patients certain rights in relation to the provision of health care (particularly hospital services), and laws that provide protections for patients in managed care situations.

### **a. Patients' Rights in Relation to the Provision of Health Care**

Florida's *Patient's Bill of Rights and Responsibilities*<sup>(67)</sup> is a representative sample of state laws that establish patients' rights in relation to the provision of health care services. The Florida law requires health care providers and health care facilities to recognize patients' rights in the course of medical care. It also requires patients to respect the health care provider's or health care facility's right to expect certain behaviour on the part of patients. Under the law, a patient has the right to:

- be treated with courtesy and respect;
- have their privacy protected;

---

(65) *Ibid.*, p. 7.

(66) *Ibid.*, pp. 8-9.

(67) Florida Statutes, Title XXIX, Chapter 381.026.  
[http://www.leg.state.fl.us/statutes/index.cfm?App\\_mode=Display\\_Statute&Search\\_String=&URL=Ch0381/SEC026.HTM&Title=->2001->Ch0381->Section%20026](http://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=Ch0381/SEC026.HTM&Title=->2001->Ch0381->Section%20026)

- receive a prompt and reasonable response to questions and requests;
- know who is providing medical services and who is responsible for his or her care;
- know what patient support services are available, including interpreter services;
- know the rules and regulations applying to patient conduct;
- receive information about diagnosis, planned course of treatment, alternatives, risks and prognosis;
- refuse any treatment, except as otherwise provided by law;
- be given full information and necessary counselling on the availability of financial resources for patient care;
- receive a reasonable estimate of the charges for medical care prior to treatment;
- have impartial access to medical treatment or accommodations, regardless of race, national origin, religion, physical handicap, or source of payment;
- receive treatment for any emergency medical condition that will deteriorate from failure to provide treatment;
- have access to any medical treatment that is, in the judgement of the patient and his or her health care practitioner, in the patient's best interests;
- know if medical treatment is for purposes of experimental research and to consent to or refuse to participate in such research; and
- express grievances about any violation of the patient's rights.

At the same time, the law also outlines certain patient responsibilities, including responsibility for:

- giving health care providers accurate and complete information about their health;
- reporting unexpected changes in their condition;
- indicating whether they understand a contemplated course of action;
- following the treatment plan recommended by the health care provider;
- keeping appointments and notifying the health care provider or health care facility if unable to do so;
- assuring prompt payment of medical bills; and
- following health care facility rules and regulations affecting patient care and conduct.

## **b. Patients' Rights and Protections in Relation to Managed Care**

Patients' rights laws in relation to managed care differ across U.S. states; however, a number of common themes run through these initiatives. Typically, patients' rights initiatives deal with at least some of the following issues: disclosure of information about medical coverage to enrollees; mandated coverage of emergency services; utilization of review/external review relating to the medical necessity of a procedure; continuity of care; access to specialists; physician incentives; protection of the doctor-patient relationship; and health care plan liability. These themes are outlined in more detail below.<sup>(68)</sup>

- *Consumer Information:* Most states require HMOs to provide basic information about their benefits and services to current and potential enrollees in the plan. Failure to do so could result in fines and penalties.
- *Timely Service and Patient Access to Care:* Most states require HMOs to ensure that plan enrollees have timely access to benefits.
- *Specialists as Primary Care Physicians:* Many state laws allow plan enrollees to name a specialist as their primary care doctor, particularly obstetricians/gynecologists.
- *Utilization Review:* A number of state laws give plan enrollees the right to discuss an unfavourable preliminary coverage decision with an HMO medical director who has the authority to review and change or reverse the decision.
- *Point of Service Provisions:* Many states require HMOs to offer a point of service option or product in their plans that permit plan enrollees willing to pay higher out-of-pocket costs to receive partial coverage in relation to services obtained from health care providers outside their plan.
- *Continuity of Care:* State provisions mandating continuity of care require an HMO to provide enrollees with the opportunity to continue to obtain services covered by the HMO plan for a defined period of time (usually 90 days) from a health care provider who no longer participates in the HMO's network.
- *Ability to Choose and Change Health Care Providers:* Some laws require HMOs to allow enrollees to choose their health care provider from any of the HMO's participating providers and to change providers.
- *Privacy of Medical Records:* State legislation provides for patient access to, and the confidentiality of, medical records.
- *Access to Emergency Services:* Many state laws require HMOs to allow enrollees to seek medical services at an emergency room without prior authorization from the HMO.

---

(68) The themes listed have been summarized from: Douglas A. Hastings, "Patient Rights meet Managed Care: Understanding the Underlying Conflicts," reprinted from *Journal of Health Law*, 1999, pp. 4-7, [http://www.ebglaw.com/article\\_20.html](http://www.ebglaw.com/article_20.html).



- *Physician Incentive Plans*: A number of states regulate “incentive plans” between HMOs and health care providers. State laws typically provide that HMOs cannot use financial incentive programs to compensate health care providers for requesting or providing less than medically necessary and appropriate care. Where incentives are permitted, HMOs may be required to disclose them to enrollees.
- *Health Care Plan Liability*: A number of state laws allow enrollees to sue HMOs in relation to decisions that directly affect their health; some permit litigation in connection with disputes over plan coverage.<sup>(69)</sup>

## F. Norway

In addition to the kinds of individual rights typically included within the scope of patients’ rights, Norway has enacted patients’ rights legislation through *The Patients’ Rights Act*.<sup>(70)</sup> The Act includes various rights, including the right to choice of hospital, the right to treatment, and the right to get an evaluation from a specialist within 30 days after receiving a referral from a general practitioner.

The Act also sets out rights to:

- receive emergency medical care;
- participate in decisions relating to patient care;
- receive information;
- be assured that a patient’s medical information will be kept confidential;
- give consent to treatment;
- have access to medical records; and
- complain.

A “patient ombud” is established to safeguard patients’ rights and interests in relation to health services.<sup>(71)</sup>

---

(69) For an overview of state liability laws, see the paper entitled *Key Characteristics of State Managed Care Organization Liability Laws: Current Status and Experience*, August 2001, prepared by Patricia Butler for The Henry J. Kaiser Family Foundation.  
<http://www.kff.org/content/2001/3155/MCOREport.pdf>

(70) *The Patients’ Rights Act*, Act of 2 July 1999, no. 63 relating to Patients’ Rights,  
[http://odin.dep.no/hd/engelsk/news/new\\_public/030071-200002/index-dok000-b-n-a.html](http://odin.dep.no/hd/engelsk/news/new_public/030071-200002/index-dok000-b-n-a.html)

(71) World Health Organization, European Observatory on Health Care Systems, *Health Systems in Transition: Norway*, 2000. <http://www.who.dk/document/e68950.pdf> This document gives a detailed overview of the health care system in Norway.

## CONCLUSION

A number of countries have developed patients' bills of rights. In some nations, patients' rights have been legislated; in others, they have been promulgated in charters as non-binding policy documents. These initiatives often provide for collective rights such as equal access to health care as well as individual rights that pertain to the relationship between patients and health care providers or institutions. Examples of individual rights include: giving consent to treatment, participating in health care decisions, receiving information about treatment options and medical procedures, being assured of privacy and confidentiality, receiving dignified and respectful patient treatment, and having a complaint investigation and resolution process.

A 2001 paper<sup>(72)</sup> notes that a patients' bill of rights designed to promote understanding and better enforcement of rights in health care services would improve patients' ability to deal with health care providers. However, the authors point out that such a bill of rights would not address concerns about access to timely care. They envisage an Ontario bill of rights that would include both rights to health care by establishing guaranteed maximum waiting times for health care services along with a Commissioner or Ombudsperson to investigate complaints about access and timeliness as well as rights when receiving health care services.<sup>(73)</sup>

The concept of a patients' bill of rights is less well developed in Canada than in a number of other countries. Only since the late 1990s have proposals to create such bills in this country been discussed. To date, the majority of Canadian proposals for patients' bills of rights focus on certain collective and individual rights in relation to the provision of health care services, but have not included waiting time guarantees. One of the most detailed of these initiatives is the proposal put forward in January 2002 by the New Brunswick Premier's Health Quality Council which sets out a number of specific rights and responsibilities at three levels – the individual, the health professional, and the health care system – and addresses five broad classes of rights. At the federal level, the Private Member's bill, Bill C-261, outlines a series of collective and individual patients' rights as well as patients' responsibilities; the bill proposes to develop these rights through federal-provincial agreements and by making full cash contributions

---

(72) Colleen Flood and Tracey Epps, "Can a Patients' Bill of Rights Address Concerns About Waiting Lists?" Draft Working Paper, Health Law Group, Faculty of Law, University of Toronto, 9 October 2001. <http://www.irpp.org/events/archive/oct01/flood.pdf>

(73) *Ibid.*, p. 23.

to provinces under the *Federal Provincial Fiscal Arrangements Act* conditional upon the conclusion of federal-provincial agreements relating to patients' rights.

Patients' bills of rights may well be part of the future landscape of the Canadian health care system. Whether developed through legislation or as statements of government policy, they can serve as an important tool for recognizing patients' rights, defining health care objectives, and emphasizing the complementary nature of the rights and responsibilities of patients and health care providers.