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**Public Participation in Health Care Decision-Making:
The Canadian Experience**

Linda Crelinsten

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in
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of
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ABSTRACT

Public Participation in Health Care Decision-Making: The Canadian Experience

Linda Crelinsten

Public participation in the policy process is being encouraged, is happening more frequently and is more valued. Nowhere is this trend more apparent than in the area of health care. Canadians are becoming more involved in the health care decision-making process. They are taking a more active role in decisions that affect their health and health services that are provided for them. Citizens have been invited by their provincial and federal governments to take part in the health policy process at many decision levels. They have been offered a seat at the decision-making table. This invitation raises an important issue. Is the public really permitted to take all the room that governments claim they are making available at the decision-making table? This thesis reviews the history of public participation in health care policy leading up to the adoption of the National Medical Care Insurance Act (Medicare) in 1968 to the present. It examines participation by citizens as individuals and as members of groups. Public involvement at the regional, provincial and federal levels is reviewed. This thesis identifies the variables, which impact on public participation. It examines and analyzes whether the public is able to participate in developing and implementing health policy in a valued and meaningful way. It demonstrates why public participation in health care decision-making is more successful in some situations than in others.

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INTRODUCTION

In Canada, there is an enormous amount of federal, provincial and municipal legislation concerning health care and health service delivery. Some legislation is specific to health care, while other legislation guarantees citizens rights that impact on health care. Canadians define their national identity through the principles of Medicare and more recently the Charter of Rights and Freedoms. Therefore, it should not be unexpected that in responding to health policy discussions, Canadians claim standing through the principles of Medicare and the Charter. Most Canadians consider health care to be a right. This becomes apparent whenever there is a hint that Medicare as we have come to know it might be modified in some way. At times it seems that our common bond as Canadians is what we consider to be our right to health care.

However, Canadians are becoming involved in ways other than just adding to the public outcry. Why are they more involved? They are voicing their interest and concerns about health care policy. Canadians are taking part in health care decision-making as individual patients, clients, citizens, consumers, stakeholders and users. They are members of health care professional associations and interest groups. They are serving as fund-raisers, volunteers, advocates, advisory committee members, and directors on institutional and regional boards. The public is not only contributing to the policy process at various levels but also demanding more accountability in the way that policy is being implemented. When Bill 120, the Act respecting health services and social services, was implemented it legislated that four members of the public be elected to serve on

institutional boards to represent the public. After running for election in 1992, I won a seat on the Board of Directors at a large acute care institution in Montreal. This experience contributed to my interest in public participation in health care policy. This paper will examine why Canadians are getting involved and how they are getting involved. It will speculate as to whether or not the public is having an impact on the health policy process and if so why, and if not, why not.

MEDICARE AND THE CANADIAN HEALTH CARE SYSTEM: A Brief History

Before examining public participation in the health policy process, it is necessary to understand how health services are delivered in Canada and to review the fundamental philosophy of Canada's health care system. "The British North America (BNA) Act 1867, established Canada as a nation, and provided for a division of powers between the federal and provincial governments. Section 92 states that provinces " may exclusively make laws in relation to ... the establishment, maintenance and management of hospitals, asylums, charities and eleemosynary institutions in and for the province, other than marine hospitals." The federal government has responsibilities in the areas of ensuring the quality of food and drugs and providing health services for the military, RCMP, federal prisoners, native Indians and the territories."¹ The division of powers did not change with the Canada Constitution Act of 1982. Each province had its own health care system before the federal government started to provide funding, and each provincial

¹ Anne Crichton, David Hsu and Stella Tsang, Canada's Health Care System: Its Funding and Organization. (Ottawa: Canadian Hospital Association Press, 1990), p.28.

system continues to be different although similarities do exist. However, Canada's health care system is decentralized. There are variations from province to province and the availability and delivery of health services within each province can be different.

Medicare, as we know it, has developed from a number of different programs that had been established federally and provincially, "In 1948 the National Health Grants Program offered to provide cost-shared financial support for health planning, public and mental health demonstration programs, professional training and most significantly hospital construction. By the late 1940s some provinces, Saskatchewan, British Columbia and Alberta had introduced their own hospital insurance schemes which were more expensive than first recognized. They needed federal support to meet the operating costs of hospitals. The federal Hospital Insurance and Diagnostic Services Act, 1957, provided for cost sharing of hospital operating expenses in the participating provinces. By 1961 all the provinces were participating in this cost-sharing program."²

Following the recommendations of the Royal Commission on Health Service (the Hall Commission) the National Medical Care Insurance Act (Medicare) was implemented in 1968. "This was the most thorough and complete survey of the health situation ever done in Canada up to that time, the Commission came out strongly in favour of a parallel shared-cost program to the Hospital Insurance program, a universal and government operated program for medical services."³ Saskatchewan's CCF (Co-operative

² Ibid., p.32

³ Maurice Leclair, "The Canadian Health Care System" in National Health Insurance: Can We Learn From Canada, S. Andreopoulos, ed., (New York: John Wiley & Sons, Inc., 1975), p.15.

Commonwealth Federation) government had already implemented a Medical Care Insurance Act in 1962. However, it took until 1971 before all provinces were fully participating. The provinces are responsible for the delivery of health services to their population. “By accepting federal financing for medicare services, provincial governments are bound by the conditions laid down in the Act.”⁴ This ensured that Ottawa was able to withhold any transfer payments from provinces that violated the conditions of the Canada Health Act. The Canadian Health Care Act ensures that, “no financial barrier should hinder access to health care and four basic conditions must be maintained: universality, comprehensive coverage, portability and non-profit public administration.”⁵ The provinces are required to adhere to these provisions of the Canada Health Act when implementing their own health care and services legislation. Even though it is the provinces’ responsibility to provide health services, the federal government still has a role to play in ensuring that health care is available to all Canadians and that the principles of Medicare are adhered to.

Funding for the system is made available in the form of transfer payments from the federal to the provincial governments. “The Medical Care Act provided that any province that had a medical care plan meeting the basic points would be eligible for the federal contribution. This was based on 50 percent of the national average per capita cost of the insured services of the national program times the average for the year of the

⁴ Sidney S. Lee, Quebec’s Health System: A Decade of Change, 1967-77. (Ottawa: The Institute of Public Administration of Canada, 1979), p.2.

⁵ Monique Bégin, Medicare Canada’s Right to Health. (Montreal: Optimum Publishing, 1987), p.25.

number of insured persons in the province.”⁶ Funding mechanisms for Medicare have changed over the years. By 1969 the federal government was concerned about open-ended cost sharing. Provincial governments had little incentive to monitor the management of services in relation to cost. The federal government set up a task force on the Cost of Health Services to examine how the funds were being used. However, it was not until 1977 that the Established Programs Financing Act was passed. The provinces were given block grants that were not related to hospital and medical costs, thereby allowing the provinces to allocate their health care dollars to other program areas. Federal funding under the Established Program Financing Act was suppose to grow at the same rate as the Gross National Product.

“The annual federal contribution consisted of a cash contribution (conditional on the province meeting certain federal criteria), and a transfer of personal and corporate income tax points(equalized as with other tax point transfers). In 1977-78, there was provision for an additional \$20. per capita to be paid as an incentive to develop extended health care services; this payment was also to be escalated annually by the average three year rate of growth in nominal GNP per capita. A five year review of EPF makes renegotiation of the terms possible. In the 1982 review limits were placed on the annual escalation of federal contributions.”⁷

By 1986 the Mulroney government lowered the growth formula to GNP minus 2 percent and by 1990 to GNP minus 3 percent. This can be seen as the beginning of the loss of ability that the federal government has in ensuring that the principles of Medicare are maintained by the provinces. If the federal government could no longer provide adequate funding how could the provinces continue to provide access to all of the health care

⁶ Ibid. Leclair, p.35.

⁷ Crichton, *ibid.*, p.34.

services they had in the past. This funding issue continues to provoke the same discussion today.

In 1984, the Canada Health Act was passed. It establish criteria and conditions that must be met before full payment would be made to the provinces with respect to insured health services and it extended health care services that were to be provided. A fifth criteria was added that had to be met by the provinces before full payment was to be made to them. It was accessibility. Accessibility was defined in the Canada Health Act as “reasonable access by insured persons to insured health services unprecluded or unimpeded, either directly or indirectly, by charges or other means.”⁸ This ensured that the provinces would no longer permit extra billing by physicians and allow hospitals to charge out-patients. However, the federal government does not have any power in establishing the way health services are planned or delivered. The Canada Health Act states “that the primary objective of Canadian health care policy is 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. The law does not require equal access and does not define what constitutes ‘reasonable access’”⁹

Transfer payments to the provinces have not kept up with the increasing cost of health care services provided by the provinces. “The current federal policy of reducing federal transfers and increasing provincial power is likely to have considerable long-term

⁸ Crichton, *ibid.*, p.35.

⁹ Raisa Deber et al. “The Public-Private Mix in Health Care” in Health Care Systems in Canada and Elsewhere (St. Foy: Editions MultiMondes, 1998), p.461.

impact. A weaker federal role is likely to further increase the gap among provinces in what they can afford, and may even call into question the ability of the poorer provinces to sustain existing programs.”¹⁰ This has added to public concern about possible modifications to Medicare and the possibility of a public/private mix.

There are provincial variations in how the transfer payments are used. However, the five criteria established by the Canada Health Act must be met. Yet, it is becoming increasingly more difficult for the federal government to uphold the criteria in the Act and the rights endorsed in the Charter of Rights and Freedoms. The influence that the federal government has is diminishing just as the transfer payments have diminished.

The rising cost of providing health services to their populations has placed provincial governments in a situation where they are looking at ways to control costs. There are many services that are not covered by Medicare. Most provinces leave drugs, dental services and nursing home care in private hands. A number of provinces have de-insured routine eye examinations.

The care in hospitals is very expensive. “Hospitals account for a large share of provincial health costs. Provinces have looked first to hospitals for cost savings. The provincial governments have encouraged institutions to release patients, arguing that many of them will be healthier and more independent if they are integrated into the

¹⁰ Ibid., p.477.

community.”¹¹ Because of this shift to home care, some provinces are covering the cost of services provided at home, such as, nursing care, social workers, therapists and homemakers. The cost of equipment in some situations may be covered as well. However, this is not consistent across Canada and not even consistent within each province. For example, there are some CLSCs in Quebec that will establish what is available to clients at home only after a means test.

In order to control the cost of physicians’ services, the provinces have introduced caps and clawbacks on physicians’ earnings. These vary from province to province. Different reimbursement mechanisms for physicians are continuing to be examined.

Provinces have also set limits on the number of students admitted annually to medical schools and the number of post-graduate training positions available in hospitals. “Recent policy moves have attempted to control physician numbers and distribution by such mechanisms as a national agreement to cut medical school enrolments by 10 percent, similar cuts to postgraduate training, tighter restrictions on allowing foreign-trained physicians (or even physicians trained in other provinces) to practice or bill fee for service, differential fees to encourage physicians to practice in underserved areas, and physicians resource plans.”¹² Cost containment has become an important issue when establishing health care policy. It has had an effect on human resources and the availability of health care services. In the past two years the government in Quebec

¹¹ Pat Armstrong, Hugh Armstrong, Jacqueline Choiniere, Take Care Warning Signals for Canada’s Health System. (Toronto: Garamond Press, 1994), p.22.

¹² Ibid. Deber., p.494.

offered early retirement packages to people working in the health care sector. This encouraged many well-trained nurses, doctors, physiotherapists and others to leave the system. The effects are still being felt.

Since 1985 almost every province has reviewed its health care system. Each province established priorities and set policy objectives for health care.

“The similarity of conclusions and recommendations among the provincial reviews is striking. Most concluded that society was devoting sufficient resources to the delivery of health care, but identified many inefficiencies and misplaced priorities. They listed many of the same pressures threatening the health care system, including an aging population, new technologies, the need for an increasing focus on quality of services, and the need for planning of human resources. Recommendations focused on redirecting the health care system towards greater emphasis on disease prevention and health promotion, towards community-based care, and towards greater accountability within the system.”¹³

Governments in Canada are addressing the need for cost containment and the recommendations of the various provincial reviews. This will require alliances being forged between, governments, health care providers and health care consumers. Many of the provincial reports had a number of recurring themes. These are:

1. Broadening the definition of health with the collaboration of multiple sectors.
2. Shifting emphasis from curing illness to promoting health and preventing disease.
3. Shifting focus to community-based rather than institutional-based care.
4. Providing more opportunity for individuals to participate with service providers in making decisions on health choices and health policies.

¹³ Health Policy Studies No.5, The Reform of Health Care Systems A Review of Seventeen OECD Countries. (Paris: Publications Service, OECD, 1994), p.114.

5. Devolution or decentralization of the provincial systems to some form of regional authorities.
6. Improved human resources planning, with particular emphasis on alternative methods for remuneration of physicians.
7. Enhanced efficiency in the management of services through the establishment of councils, coordinating bodies, and secretariats.
8. Increasing funds for health services research, especially in the areas of utilization, technology assessment, program/system evaluation, and information systems.¹⁴

Many of these issues impact directly on the individual, while others imply that the public's cooperation and participation will be needed in order to reach the objectives. Individual Canadians need to value the idea of health promotion and disease prevention. Therefore they must also see the need to broaden the determinants of health. Public participation is encouraged at many levels. The government is hoping that the individual will not only assume the responsibility of remaining healthy but also make informed decisions when he is not. In order to ensure that the goals of decentralization are met public participation is of the utmost importance. Members of the public are needed to serve on boards of institutions, councils and regions to ensure that the services provided meet the needs of the community and that resources are used efficiently. However, is the public really allowed to take all the room governments claim that they are making available at the decision-making table? In some situations the public is successful in having their voice heard while in others they are not. The rest of this paper will attempt

¹⁴ Sharmila Mhatre and Raisa Deber, "From Equal Access to Health Care to Equitable Access To Health: A Review of Canadian Provincial Health Commissions and Reports", International Journal of Health Services, Volume 22, Number 4, 1992, p.655.

to examine the successes, the problems and the limits of public participation in health care decision-making. First, I will establish how the role of the public has changed over the years since the debates leading up to the adoption of Medicare and how the problems with Medicare have been the impetus for change. Second, the changing nature of the doctor-patient relationship will be examined and the importance now placed on individual patient participation will be discussed. Third, the ways the public has become involved in the health care decision-making process and what are the factors that make them more effective in that process.

The Canadian citizen has been encouraged to become more participatory, we will discuss what that means and how it has affected the citizen as the patient and the citizen as the public participant. The effects that public participation has had on health care policy will be examined and evaluated.

CHAPTER I

Public Debate and the Canadian Health Care System: From Paternalism to Public Involvement

1. The Political Process and Public Participation

There is very little information documented about public participation or public input during the years that a publicly funded health insurance plan was being developed. There is also little information about the health concerns of Canadians. Monique Bégin states that,

the only public discussion on health had been fueled by a small booklet published in 1975 by the Federal Minister of Health Marc Lalonde, entitled, A New Perspective on the Health of Canadians". It talked about the need for new directions to improve the health of the population. It did not focus only on treatment, but also emphasized staying healthy and the importance of prevention and an improved lifestyle. Although the document was well received by those who advocated reform in the health care system, it attracted little attention and never reached a wide audience in the country.¹⁵

It expressed some of the main concerns that are still being addressed almost twenty-five years later. "There is the paradox of everyone agreeing to the importance of research and prevention, yet continuing to increase disproportionately the amount of money spent on treating existing illness. Public demand for treatment services assures these services of financial resources. No such public demand exists for research and preventive measures.

¹⁵ Ibid. Bégin., p.61.

As a result resources allocated for this purpose are generally insufficient.”¹⁶ These concerns still exist today. The public is constantly being encouraged by health care professionals and the government to adopt healthy lifestyles. Researchers are constantly calling for more money for research into the understanding, prevention and treatment of disease. However, when an individual or member of his family becomes ill they demand that every opportunity for recovery be made available to them. There is little wonder why the resource allocation decisions are so problematic.

The paternalistic approach of physicians did not encourage public debate about health care policy any more than it encouraged individuals to actively participate in their own health care decisions. Most physicians felt that they were doing what was right for their patients and society. In 1891 Dr. Alexander Reid, the founding dean of the Dalhousie Medical Faculty wrote a book entitled, Poverty Superseded: A New Political Economy for Canada.

“His book criticized unfettered capitalism and laid down the theoretical foundations for a benevolent government in which professionals would control the state apparatus. Inter-class conflict was to be reduced, competitive individualism would give way to expert management, and scientific principles would be applied to maximize the health and wealth of all citizens. This optimistic view of the state, allied with a strong belief in the social responsibility of professionals and experts, was eventually to gain widespread acceptance during the Progressive era in North American politics.”¹⁷

¹⁶ S. Andreopoulos, “The Health of Canadians” in S. Andreopoulos, ed., National Health Insurance: Can We Learn From Canada? (New York: John Wiley & Sons, Inc., 1975), p.4.

¹⁷ C. David Naylor, ed., Canadian Health Care and the State A Century of Evolution. (Montreal: McGill-Queen’s Press, 1992), p.5.

This idea, that the experts knew what the average citizen needed continued to influence health care policy for many years. In 1934 the Canadian Medical Association's Committee on Economics, "claimed that doctors naturally should try to shape health policy to their specifications: "(T)his is not a selfish motive because what is best for the medical profession must be best for the public".¹⁸ This perspective does not encourage or promote open discussion in health policy development.

During the years leading up to the implementation of National Health Insurance, first in Saskatchewan and then eventually across Canada there appears to be little public participation in the discussions. Yet public opinion polls conducted, found that a large majority of Canadians supported the notion of a publicly-funded health care insurance plan. There was no federal involvement in the provision of health insurance until the 1940s. One of the main reasons for this was the division of federal-provincial powers. Prime Minister MacKenzie King established a Royal Commission to examine Dominion-Provincial Relations that were impeding the establishing of social programs. In 1940, the Rowell-Sirois Report "sent conflicting signals. It concluded that two types of Social Insurance-Unemployment Insurance and contributory Old Age Pensions- are inherently of a national character, but Workman's Compensation and Health Insurance are not, and that in view of Canadian conditions, these can be financed and efficiently administered by the provinces. It was obvious that many of the provinces could not independently finance a health insurance program, and therefore federal financial

¹⁸ C. David Naylor, Private Practice, Public Payment Canadian Medicine and the Politics of Health Insurance 1911-1966. (Montreal: McGill-Queen's University Press, 1986), p.256.

contributions would be essential.”¹⁹ In 1945 a Dominion-Provincial Conference on Post-War Reconstruction, “the federal government presented a wide-ranging series of policy and program proposals, including social-security and health insurance. The conference collapsed because of the linking of federal financing to transfers of major tax fields from the provincial governments to the federal government, and the health insurance proposals were, for a decade, thrust into limbo.”²⁰ Yet, many Canadians after living through the Great Depression and World War II were well aware of the need for social welfare programs and health insurance. In a public opinion poll conducted in 1943, “75% of Canadians were favourable to a program of health insurance. Still hesitant, MacKenzie King compromised by appointing a Special Committee on Social Security of the House of Commons. This effectively stalled immediate legislative action on the matter. However, it set the stage for the first public debate on health insurance in Canada.”²¹ Like any other political debate groups lined up on both sides of the issue. The Canadian Medical Association (CMA) did not support a national health insurance plan for everyone. However, other health professionals (dentists, optometrists, pharmacists and nurses) favoured universal health insurance for all. “The medical lobby found allies in the health and business sectors. The Canadian Hospital Council, the Catholic Hospital Council, the Canadian Insurance Officers Association did not support a compulsory health insurance plan. During the same time that these hearings were taking place on health insurance, members of the business community and the pharmaceutical industry

¹⁹ Malcolm Taylor, Insuring National Health Care The Canadian Experience. (Chapel Hill: The University of North Carolina Press, 1990), p.15.

²⁰ Malcolm Taylor, *Ibid.*, p.15.

²¹ Antonia Maioni. Parting at the Crossroads The Emergence of Health Insurance in the United States and Canada. Princeton:Princeton University Press, 1998), p. 68.

were involved in promoting anti-CCF campaigns that attacked the party's socialistic platform."²² However, the issue was so central to the CCF party platform, that in 1944 when Tommy Douglas became premier of Saskatchewan he also took on the health portfolio as minister of health.

The CCF kept health care on the political agenda. The farm movement and labour movement supported a universal national health insurance plan. Both of these groups supported the CCF's social reform policies. The Canadian Congress of Labour and the Canadian Federation of Agriculture were strongly in favour of a universal compulsory national health insurance plan. It is interesting to note that the two organized groups, which held the most supportive and vocal position on universal health care represented a particular social segment of society and not an interest group. They were the people who were well aware of the financial impact that illness and/or accidents can have on individuals and their families.

In 1948 Prime Minister MacKenzie King announced the National Health Grants Program. "These grants were a welcome source of new funds for the provinces. They were to ensure the most effective use of other grants, to plan the extension of hospital accommodation, and to plan for the proper organization of hospital and medical insurance. One of the spin-off effects was that the meetings of provincial health officials held periodically in Ottawa to review annual expenditures and new proposals provided opportunities to compare ideas, report solutions to mutual problems, and exchange plans

²² Ibid., p.70-71.

for new projects on a scale never before known. The grants program thus had a catalytic effect on nationwide health services planning and development, not anticipated when it was launched.”²³

When Prime Minister St. Laurent came to power in 1953,

“he retreated from postwar promises of health reform by emphasizing provincial responsibility in health. Paul Martin, the Minister for National Health and Welfare, was well aware that provincial leaders, organized labour, and the CCF were increasingly restless with the limits of the health grants program. He warned that federal commitment was necessary to keep alive the faith of Canadians in the health and social reform promises of the Liberal party.”²⁴

However, a national health insurance plan was built by adding bits and pieces of coverage at a time. In 1957 the Hospital Insurance and Diagnostic Services Act was passed unanimously by the four political parties then represented in the House of Commons. During the 1950s the Canadian Medical Association continued to reject a publicly funded national health insurance plan. Their allies from the 1940s were joined by the Canadian Chamber of Commerce and the Canadian Pharmaceutical Manufacturers Association. However, organized labour continued to give strong support to a national health plan. “In 1956 the Trade and Labour Congress and the Canadian Congress of Labour merged to form the Canadian Labour Congress. The CLC platform emphasized health reform as “the No. 1 aim” of the new organization.”²⁵ The public debate about a universal, publicly funded health care insurance scheme was divided along socio-

²³ Malcolm Taylor, *Ibid.*, p.82.

²⁴ Maioni, *ibid.*, p.94-95.

²⁵ Maioni, *ibid.*, p.100.

economic lines. The farmers and workers on one side and the medical association and business interests on the other, while the majority of Canadians participated through the opinion polls.

In a Gallup poll that was conducted in April 1956, that asked, “Would you favour, or oppose, a government operated plan whereby any hospital expenses you incurred would be paid for out of taxes-even if it meant higher taxes? “Sixty two percent of Canadian responded positively. By September this margin had grown to seventy-two percent.”²⁶ Public pressure, as well as, continued pressure from the labour movement undoubtedly had some influence in assuring the passage of the Hospital Insurance and Diagnostic Services Act. However, it was the Conservative government of Prime Minister John Diefenbaker that implemented the legislation. “One unanticipated outcome of the national program was that with the federal contribution to Saskatchewan, relieving it of 45 percent of its expenditures on their provincial hospital insurance plan, the Saskatchewan government decided to introduce its long-promised and long-delayed medical insurance program.”²⁷ The Saskatchewan health insurance plan went into effect on July 1, 1962. The doctors in that province went on strike for three weeks. The media coverage across Canada was very critical of the physicians

In 1961 Prime Minister Diefenbaker appointed Justice Emmett Hall to chair the Royal Commission on Health Services. After hearing hundreds of submissions

²⁶ Maioni, *ibid.*, p.102.

²⁷ Maioni, *ibid.*, p.100.

and holding public hearings the Hall Report recommended a government sponsored, comprehensive, universal health insurance plan. The Canadian Medical Association and its allies criticized the Report. The insurance and pharmaceutical industry were concerned about the damaging effects it would have on business and the Chamber of Commerce felt it increase government expenditures.

After the 1965 federal election the Liberals formed a minority government. They were dependent on NDP support. "As soon as Parliament reconvened in 1966, the NDP pressured the government to introduce legislation. The NDP would not support any watered-down version of the bill. The medical insurance proposals had become "politically potent; no one could be seen as opposed". This was evident at the bill's final passage, by a vote of 177 to 2. The starting date of the plan was to be July 1, 1968."²⁸

It took until 1971 until all of the provinces were fully participating in Medicare. The vote in the House of Commons in 1968 would lead one to believe that there was immense support for a universal health care program. However, it had been a long hard struggle. The agricultural movement, the labour movement and many public opinion polls later finally encouraged the politicians that the majority of Canadian citizens were in favour of Medicare. In her book Parting at the Crossroads The Emergence of Health Insurance in the United States and Canada, Antonia Maioni stresses the importance of the third party system and the active role the CCF and the NDP played in the debate. Their

²⁸ Malcolm Taylor, *ibid.*, p.95.

continued presence in the debate kept the need for a publicly funded national health insurance plan on the political agenda. “Even though it was regionally based, the CCF-NDP exerted an important influence in the national health insurance debate because of its pivotal position as the third party of the Left in a political system dominated by a centre party. The third party was able to articulate and sustain the demand for universal and comprehensive government-financed insurance by providing an effective public counterweight to the opposition of the medical lobby in setting the public debate on the health insurance issue.”²⁹ There is no doubt that the presence of the third party was important but far more important was the party’s position on social democratic policies. There is a fourth and fifth party sitting in the House of Commons today who never could have been relied upon to support a publicly funded health insurance plan. These parties often appear to be promoting regional issues rather than social ones.

Three provinces tried to obtain concessions, Alberta, Ontario and Quebec, all for different reasons. Physicians in Quebec went on strike and were legislated back to work. Since its implementation, it has not always been easy to insure Medicare as it was first envisioned. Changes in the transfer of payment schemes to the provinces and decreased funding have put the federal government in a precarious position to be the defender of the five principles endorsed in the 1984 Canada Health Act.

Over the years public participation in the debate has also changed. Leading up to the national implementation of a health insurance program, organized labour and

²⁹ Maioni, *ibid.*, p.162.

agricultural movements, as well as politicians with a socialist view participated vociferously in the debate. While the public's voice was heard mainly in their response in polls conducted by the federal government. This continues to be an important element in the process to date. "In a 1993 Gallup poll, 96 percent of Canadians preferred Canada's health care system to the one in the United States. The same survey also showed the public confidence in the quality of care our system delivers is also on the rise-89 percent rated it good or excellent, up from 71 percent in 1991."³⁰

In Quebec, the Castonguay Commission Report in the 1970 had recommended public participation as a major component of future health reform. At the time there was a growing movement toward public participation in all aspects of government. In 1976, a conference was held in Quebec to review initiatives that were undertaken by the government that had been proposed in the report. At this conference, Jean Rochon felt that they had been unrealistic about the level of participation that had been expected. The people who had ended up participating were those who were militant about a particular issue or those who had already been participating in the system. Claude Forget questioned whether participation had been a "genuine objective". He felt that the true purpose was not to give consumers a voice, but to let them think that they had a role in the health system. Forget felt that the professionals, even though the public had attained a measure of power within the system, would continue to remain the predominant group. Nicole Martin, economic advisor to the Castonguay Commission and Director of Health

³⁰ Michael Rachlis, Carol Kushner, Strong Medicine How to Save Canada's Health Care System. (Toronto: Harper Collins Publishers Ltd., 1994), p.9.

Services Planning, in the Ministry of Social Affairs in Quebec in 1976, reported that public participation had never been successful at the hospital level or the CLSC level. However, she was encouraged by the fact that the hospitals and their administrators were openly discussing their budgets. Jean-Yves Rivard, an economist and expert consultant in hospital administration to the Commission argued that they had over-estimated the ability of the people, who were involved, to adapt to the proposed changes. Claude Forget felt that the boards of directors seemed to view themselves as consulting groups rather than administrative groups. He did not have much confidence in their problem-solving ability. Many of the participants at the conference felt that the role of the hospital administration and the role of the board member needed clearer definitions of tasks and powers. One of the problems had been that not enough effort had been put into educating the board members. However, Claude Castonguay and Claude Forget both acknowledged that despite the fact that public participation on the boards created conflict, change was occurring and there was more cross-fertilization of ideas and more interaction among the different groups.³¹ One of the major themes that continues to reoccur when discussing public participation in health care decision-making both then and now is the need to educate the public about their role in the different processes and in particular, the parameters of that role.

When discussing ways that the Canadian experience in developing Medicare may have been improved, one of the recurring suggestions is that the role of the Canadian

³¹ The main themes discussed and a list of the participants at this Conference is reported on in Sidney S. Lee, Quebec's Health System: A Decade of Change, 1967-77. (Ottawa: The Institute of Public Administration of Canada, 1979), p.33-47.

public should have been more active. In writing about the Canadian health care system in 1975 Maurice Leclair, Deputy Minister of Health and Welfare Canada, in 1975 writes, “(M)ore participation in decision-making by those affected by the decision such as the providers of health insurance and the consumers would have prevented many problems. While the universal programs have resolved some of the major problems, the advent of universal hospital and medical insurance has made the public and the politicians more aware of the deficiencies in the health care system. The consumer has become much more militant and vociferous in their demands and the providers are finding out that in all these matters, it is usually the general population which has the last word.”³² It is unrealistic to expect that most of the problems that occur with the implementation of any new policy can be worked out beforehand. Particularly, in the area of health care in Canada, which is impacted on by federal legislation, provincial legislation, federal and provincial funding and affects the public and a number of professional associations and various institutions. The role of the public in health care decision-making is a very complex and varied one. At times Canadians seem preoccupied with their role as consumers and at other times come out strongly in support of the five principles of the Canada Health Act which benefits all of society.

However, Monique Bégin noted that the role of the public and the political process itself was of extreme value in assuring that the principles of Medicare were maintained. Leading up to the passage of the Canada Health Act in 1984, the law which prevented extra billing by physicians and the use of user fees by some institutions,

³² M.Leclair, *ibid.*, p.89.

Monique Bégin developed a strategy to ensure that there would be political and public support for her legislation. “She and her staff worked tirelessly with national and provincial coalitions to garner public support for the proposed law. She commissioned an opinion poll to demonstrate to her cabinet colleagues that she had grass-roots support. After winning their approval, her department published a white paper, *Preserving Universal Medicare*, and distributed it strategically, so that requests for additional copies soon flooded the department. She tackled opposition from medical associations and most of the provinces by hosting a series of community forums that gave the “repressed structural interests” – especially the nurses and consumers – a real voice in the debate. It paid off. The House of Commons unanimously passed this landmark legislation.”³³

Federal legislation, which continues to protect Medicare, will need not only the will of the public, but also, the political will of the party in power and a continuing, strong commitment by the Federal Minister of Health. Even though the public is better organized and the media at times helps to get the attention of the politicians whenever the dismantling of Medicare is discussed, it will continue to take a strong commitment on the part of the federal government. Particularly, if federal funding continues to decrease, the provinces can make a stronger argument about the lack of commitment by the federal government. It makes it easier to start dismantling a program when another group can share the political blame.

In 1984, prior to the passage of the Canada Health Act, which reaffirmed the federal government’s commitment to Medicare, there was a loud public outcry. Interest in

³³ Rachlis and Kushner, *ibid.*, p.309.

the issues was not only brought to the public's attention by Monique Bégin but also by a number of major stakeholders. Some groups formed a coalition to present their positions to the government. "One of the major groups was the Health Action Lobby - HEAL. It was a coalition of seven major health organizations- the CMA, the Canadian Nurses Association, Canadian Public Health Association, Long-Term Care Association, Canadian Psychological Association, and the Canadian Consumer Association. HEAL was one of the first groups to offer recommendations to governments on the substance and process for preserving the Medicare system. The significance of seven organization, with competing interests, coming together and speaking with one voice on the future of the health care system was not lost on the federal government."³⁴ Health care issues and Medicare are very much on the minds of the public. The public is becoming more involved as individuals and as members of groups. The provincial governments have been encouraging public participation in many ways and groups have been encouraging their members to voice their opinions.

In the past few years the constitutional discussions have made the public more aware of not only issues in the Constitution but also the Charter of Rights. During one of the constitutional discussions the idea of entrenching the five principles of the Canada Health Act in a social charter was being considered. Canadians value their health care system, yet what do they consider their responsibility to protect it? As valued as Medicare appears to be now, "there was no major outcry for Medicare on the part of the

³⁴ Amelia Armit, "Review and Forecast of Federal-Provincial Relations", in Health Care Innovation, Impact and Challenge, S. Mathwin Davis ed., (Kingston: School of Policy Studies/School of Public Administration, Queen's University, 1992), p.31.

Canadian populace in the mid-1960s.”³⁵ However, the role of the public has changed in the public policy arena and particularly in health care.

In June 1985, the Minister of Health, Jake Epp sent a letter to his provincial counterparts affirming the federal objective to uphold the principles of the Canada Health Act. This letter, from a policy implementation perspective, served also as a signal for the bureaucracy to adopt a consensual conciliatory versus adversarial approach to the resolution of issues under the CHA and its regulation. A year later the federal government released a *Framework on Health Promotion: Achieving Health for All*, which became a seminal influence to current national health promotion strategies.³⁶

This reaffirmation of the Canada Health Act and the promotion of health for all by the federal government came at a time when fiscal arrangements for the funding of health care were being changed. Decreased funding to the provinces was putting pressure on them to change their health care delivery to the public. The provinces were put in a position to maintain the principles of Medicare and promote health for all citizens with less funding. The onus for health care was on the provinces and on individuals who were made more aware of the preventive aspects of health care by the federal government’s paper on health promotion. In some ways this called on Canadians to become more involved in their own health care decision-making and for the provinces to find innovative ways to make resource allocation decisions, which they have attempted to do by encouraging more public participation. Armit comments that “policy innovations in health care were the by-products of intensive, often complex federal-provincial relations. In the 1990s there has been a lot of talk about reforming the health-care system, not only

³⁵ Malcolm Taylor, Health Insurance and Canadian Public Policy: The Seven Decisions that created the Canadian Health Insurance System. (Montreal: McGill – Queen’s University Press, 1978), p.367.

³⁶ Amelita Armit, “Review and Forecast of Federal-Provincial Relations”, in Health Care Innovation, Impact and Challenge, S. Mathwin Davis ed., (Kingston: School of Policy Studies, Queen’s University, 1992.), p.30.

in response to fiscal conditions, but also in response to the growing public understanding of the need for a health system focused on “wellness” and the broad determinants of health.”³⁷ Governments are asking the public to not only participate in the policy arena but also to take more responsibility for their own “wellness”. The public is far more aware of the importance of lifestyle in relation to the benefits to health than ever before.

2. Why More Public Participation Now?

At least two major reasons have played a role in bringing about increased public involvement in health care decision-making. The first one results from a combination of two factors: fiscal restraint and consumerism. Neo-conservative ideology and a weak economy in the 1980s had an impact on health reform. Declining tax dollars and decreased transfer payments left the provinces looking for innovative ways to manage their health care budgets. In an effort to allocate scarce resources in a more efficient, effective and responsive manner, the management of health care services was decentralized and moved closer to the populations they served. Every province, except Ontario, has introduced regional structures for the planning and delivery of health services. Canadians have also become more distrusting of their governments and the role the politicians and the public service play in the policy process. This and increased consumerism in health care have sparked more of a demand for accountability by the public of politicians and civil servants. This has encouraged reform in the public service,

³⁷ Ibid., Armit, p.31.

as they learn to work with a more demanding, often more knowledgeable public.

“Changing perceptions about health care, along with the rise of consumerism, and the demand for greater accountability in the use of public health care resources are propelling governments and consumers toward even broader “citizen as expert” participation in difficult health care choices.”³⁸ The second reason, which has contributed to more public participation in health care decision-making, is that Canadians are more aware of their rights. The entrenchment of the Charter of Rights and Freedoms in the Constitution was the catalyst for Canadians to show more of an interest in “rights”. Also the unraveling of the medical model in health care and the evolution of the doctor-patient relationship has not only enabled more active participation in individual decision-making, but also, in public forums. Let us look at these two reasons in turn.

Consumer Awareness and Accountability

The rise of consumerism in the 1960s encouraged the average individual to play more of a participatory role alongside business and government. Consumer preferences, expectations and protection became important issues.

“The role of consumers in policy selection has been increased by the weight given by governments to opinion polls and by the extensive public consultation which is now almost a routine part of policy development. The consumer era brought a dispersion of power, a situation in which everyone has some power but no one has a great deal of it.

³⁸ Dianne Macfarlane, “Citizen Participation in the Reform of Health Care Policy: A Case Example”, in Healthcare Management Forum, Volume 9, No. 2 Summer, 1996, p.32.

This dispersal of power provided an opportunity for everyone to affect events. Openness replaced secrecy, and simple processes became complex. The major winners were the communities and the organized users/consumers/citizens. The losers were those groups and persons who historically have been the advisers to governments. In health care the major losers were the physicians and hospitals."³⁹

Consumerism by its nature increased public participation and the importance given to consumers by government. Consumer expectations in health care continue to rise. Advanced technology and new miracles promised by the pharmaceutical industry have contributed to the average citizen feeling that anything is possible in health care. Dr. Gail Silber-Wells in a 1987 report commented that,

“consumers expect to be partners and to share in the planning and decision-making process of the health care system. They are also broadening and re-defining their role as both providers and self-care agents through their own efforts in maintaining individual health or treating certain unhealthy conditions. The public is evolving a health role. Accordingly, behavioral changes associated with heightened personal responsibility in chronic disease management involve a shift from the passive sick role to the more active empowered role.”⁴⁰

Individuals are taking more responsibility for promotion and prevention in their own health care issues. Information about low fat diets, exercise programs, stop smoking programs and medical screening tests for certain conditions have enabled the average citizen to be more pro-active in health maintenance.

³⁹ Ralph Sutherland and Jane Fulton, Spending Smarter and Spending Less Policies and Partnerships for Health Care in Canada. (Ottawa: Canadian Hospital Association Press, 1994), p.19.

⁴⁰ Gail Silber-Wells, Changing Priorities for Canada's Health Care System, Executive Brief Series (Ottawa: Canadian Hospital Association, 1987), p.8.

The increased awareness and expectations of Canadians as consumers have led them to become more skeptical of their government and lack trust in the politicians that represent them. There has been an increased demand for accountability by the public. David Zussman argued: "Citizens are not participating less in political life; they are participating more. It appears that their interest in politics is negatively related to their confidence in public institutions. As a result, citizens throughout these advanced industrial states are increasingly inclined to turn to unconventional forms of political action in order to satisfy their need for involvement."⁴¹ However, Zussman notes that the increased knowledge and sophistication of the public also has led to the emergence of a less compliant public.

On the other hand, the role of governments is evolving. Fiscal constraints and an increasingly demanding public are encouraging government to examine the ways they are performing.

Many governments are searching for alternatives to the traditional bureaucratic model of public administration. These alternatives must be capable of delivering better service at lower cost, in a manner that responds more quickly to changing needs and opportunities. Better service is being demanded both by a public that is increasingly concerned by the impact of the quality of public services on its welfare and convenience and by governments that are coming to recognize the impact that public demand can have on national economic performance."⁴²

⁴¹ David Zussman "Do citizens trust their government?" in Canadian Public Administration, Volume 40, No.2 (Summer), p.235.

⁴² J. David Wright, Special Operating Agencies Autonomy, Accountability and Performance. The Canadian Centre for Management Development. (Ottawa: Minister of Supply and Services Canada, 1995), p.3.

Much has been done in the past decade to bring health care policy and delivery of health care services closer to the community. Most provinces have attempted to do this through decentralization. It was felt that by taking the authority from a centralized agency and bringing it closer to the community would result in increased citizen participation in health care decision-making and responsiveness to local needs. In Canada's highly decentralized system of health care delivery, initiatives must be taken at the local level to ensure that the system meets the needs of the citizens it serves and is accountable to them. There have been efforts made by various institutions to measure quality of services by the use of performance-oriented measurements and quality management principles. Many Canadian hospitals do patient satisfaction surveys in various departments. Michael Barzelay noted, "the most relevant information and evidence for judging how well a provider fulfills the main purpose of providing a service are users' evaluations of service quality and value."⁴³

A more active democratic approach with increased public participation poses problems for both the government and public administration. The federal and provincial governments have also been selective about which issues they encourage public debate. "The unveiling of the Canada Health and Social Transfer in the February 1995 budget came on the heels of an extensive Social Security Review consultation process, yet no hint or discussion of the new transfer had been part of the parliamentary hearings."⁴⁴

⁴³ Michael Barzelay, Breaking Through Bureaucracy: A New Vision for Managing in Government. (Berkeley: University of California Press, 1992), p.110.

⁴⁴ Katherine Graham and Susan Philips, "Citizen Engagement: Beyond the Customer Revolution", in Canadian Public Administration, Volume 40, No. 2 (Summer), p.262.

The provincial governments of both Quebec and Ontario have downloaded the cost for a number of services to the municipalities. These decisions were made with no input from the public or from the municipalities. As much as governments have stated that they are encouraging public discussion and participation, they remain selective about which issues and particularly in areas of budget and transfer payments.

This is very much the case in health care decision-making. The federal government decides the amount of the transfer payment to the provinces and each province in turn decides how much will be allocated to health care. The provinces then provide a budgeted amount to a regional board, who then allocates money to individual hospitals and community clinics. Despite the possibility of pre-budget consultations at the federal level meaningful citizen input does not occur. The health service delivered to the citizen is far removed from initial budgetary process.

Fiscal restraint has placed increased pressure on the public service to do more with less. Gregory Albo also points out that there are two other reasons why there is pressure on the public sector to change. One factor is that “(D)emocracy is above all about popular rule, equality, and active citizenship; yet the public sector is organized in a hierarchical, quasi-military chain of control, rules, and regulations for the distribution of public goods and services. This dual structure is rife with contradictions, and increasingly incompatible with an educated citizenry.” The second factor includes the re-conception of citizenship. Albo feels that “popular movements tend to emphasize a notion of ‘democratic citizenship’ in the sense of equal entitlement to the consumption of collective

goods and services, and the right of participation and control over the planning, administration, and distribution of these same goods and services.”⁴⁵ Economic pressures and public discontent have been the catalyst for change in the public sector. Part of the reason for the economic woes of Medicare is that “public entitlement” that Albo speaks about. Increasing demand by the public is adding to the strain on the health care system.

As Leslie Seidle put it: “(T)he Canadian federal government seems to have suffered particularly from citizen disaffection: when asked in 1992 whether they believe the federal/national government serves the public interest, respondents in the United States, France and Germany expressed a higher level of approval than those in Canada.”⁴⁶ The Canadian Public Service has responded to the call for change. A task force was established to examine among other issues, service to the public. There have been attempts made to make the public service more customer-oriented and responsive to the needs of the public.

The changing role of government has had a major effect on the delivery of public services and therefore on the public service sector. Leslie Seidle points out that there are three reasons for taking steps to improve service delivery. “They are: to respond to the expectations of citizens who, it has been shown, are increasingly dissatisfied with public sector performance; to foster efficiency and economy; and to provide information that

⁴⁵ Gregory Albo, “Democratic Citizenship and the Future of Public Management”, in Gregory Albo, D. Langille and L. Panitch eds., *A Different Kind of State? Popular Power and Democratic Administration*. (Toronto: Oxford University Press, 1993), p.18-19.

⁴⁶ F. Leslie Seidle, *Rethinking the delivery of public services to Citizens*. (Montreal: The Research Institute for Public Policy, 1995), p.12.

may be useful in evaluating and revising public policies and programs.”⁴⁷ In Canada, the public administration sector has responded to the need for change by adopting some concepts from the private sector. In the public sector citizens and members of the public are often now referred to as customers, clients, consumers and stakeholders. Reform has taken place in most western democracies. As Gilles Bouchard noted:

“(E)n 1987, l’Organisation de coopération et de développement économique (OCDE) publie L’administration au service du public, un petit livre dans lequel l’organisme international passe en revue les relations entre l’administration publique et la population. Dès le départ, on précise que l’on désignera la population desservie par la terme client. On privilégie ce terme pour diverses raisons, entre autres parce qu’il englobe non seulement les individus mais aussi les organisations don’t les entreprises, et parce que, comparé à des termes plus neutres comme “usager” ou “utilisateur”, il évoque une attitude plus active et plus exigeante à l’égard du secteur public. Ce que l’on ne dit pas, c’est que le choix du terme client reflète aussi la résurgence du libéralisme économique et la prééminence de l’entreprise privée sur l’administration publique.”⁴⁸

Changing the terminology not only implies participation on a more equal level, but also a responsibility to participate in public policy and service delivery. Whether that participation means taking part in the decision-making or providing feedback to improve services, the changing nature of public administration is being encouraged to work in partnership with the public.

⁴⁷ F. Leslie Seidle, *Rethinking the delivery of public services to Citizens*. (Montreal: The Research Institute for Public Policy, 1995), p.7.

⁴⁸ Gilles Bouchard, “De citoyen à client: plus qu’un changement de vocabulaire” in Politique et Societes, no.29, 15 annee, printemps 1996, p.145.

The Impact of the Charter

Much of the discourse about health care policy and service delivery concentrates on being client-focused and customer-service oriented. This not only implies that the citizen has a more participatory role but also has the *right* to efficient and effective services. This poses a problem in public service delivery particularly in the area of health care. Perhaps efficiency is not necessarily a primary goal of health care. Nor is effectiveness always the first goal of a patient or a family who might want everything done to prolong the life of a family member. The public plays a different role at different times in health care decision-making. This often depends on which role the individual finds himself in at any given time. A member of a hospital board or advisory council representing the public may be convinced that efficiency and effectiveness are important goals to be met when discussing health care services for their community. However, an individual, who is trying to make an informed health care decision for himself or a member of his family, may not necessarily put a great deal of emphasis on evidence based information. The concern shifts to what the citizen considers to be his individual right.

There has also been more emphasis put on individual responsibility for health by the government. “The Health Charter for Canadians in 1964 and the Lalonde Report in 1974 stressed the importance of lifestyle. The Evans Report repeated this call for individuals to take responsibility in 1987.”⁴⁹ In the previously mentioned document

⁴⁹ Chrichton, Hsu and Tsang, *ibid.*, p.242.

entitled *Achieving Health for All: A Framework for Health Promotion*, Health and Welfare Canada outlined three challenges that impact on the level of responsibility that the government expects of the individual with respect to health promotion. These are: reducing inequities, in view of the fact that health status is directly related to economic status; increasing the prevention effort, mainly by changing life-styles; and enhancing people's capacity to cope with chronic conditions, disabilities, and mental health problems. The document also elaborated on the strategies needed for health promotion. These are: fostering public participation; strengthening community health services; and coordinating healthy public policy.⁵⁰ Both the provincial governments and the federal government are encouraging increased public participation at the individual level and the community level. Individuals are being encouraged to assume responsibility for their own health care decisions and communities are being encouraged to take part in the service delivery and allocation of resource decisions. The challenge of governments to reduce health care costs has widened the circle of decision-makers, the public has been given a key role to play.

Over the past decade the provinces have sponsored a series of commissions, task forces, and public forums directed at reforming the system. What is significant about these provincial reports is the consistency in the message across jurisdictions and in relation to reports in the 1970s. The reports emphasize the following themes: containing costs, increasing the effectiveness and efficiency of health care, enhancing the responsiveness and accountability of the system through decentralized decision-making, and facilitating citizen participation.⁵¹

⁵⁰ Malcolm Taylor, *Insuring National Health Care The Canadian Experience*, (Chapel Hill: The University of North Carolina Press, 1990), p.209.

⁵¹ John Church and Paul Baker, "Regionalization of Health Services in Canada: A Critical Perspective," in *International Journal of Health Services*, Volume 28, Number 3, 1998, p.469.

Another major reason for increased public interest in health care decision-making is the role that The Charter of Rights and Freedoms has played in the policy arena. In Canada, citizens consider access to a publicly funded health care system to be a right. The Charter is having an effect on public policy in Canada. It is unlikely that resource allocation decisions in health care will escape the effect the Charter is having on public policy decisions and individual health care decisions.

The Charter is being used by advocacy groups to promote their interests and by individuals who are concerned that their rights are being jeopardized. The courts are also playing a role in the health care policy process. Competing individual rights, individual versus community rights and allocation of health care resources may place demands on the system that will have to be addressed. Various courts across the country from the provincial level to the Supreme Court level are being drawn into the policy process. The public servants are also well aware of the role the Charter plays in the policy process. Some senior public administrators feel that if the principles of the Charter were respected during the development of the policy the courts would be called upon less frequently and the legislation would better reflect Canadian values. John Tait, Senior Advisor to the Privy Council Office and former Deputy Minister of Justice, comments

“I believe that in the early stages of policy development, we should focus most on the purposes, principles and values that underlie Charter rights and freedoms and leave strictly legal considerations to a latter stage. Working with the Charter increases the government’s ability to maintain the lead on policy issues, establish the right balance between courts and government, and to reflect, reaffirm and interpret Canadian values.”⁵²

⁵² John C. Tait and Mel Cappe, Perspectives on Public Policy. (Ottawa: Minister of Supply and Services Canada, 1995), p.16-17.

This is an important innovation on the part of public administration as the attitude of the courts in Canada has changed since the Charter of Rights was adopted in 1982.

“Canadian courts used to exhibit extreme deference toward the elected arms of government. They regarded it as less intrusive to tell the government that it could not pass a particular law or pursue a specific line of action than to tell it what law should be enacted or what line of action should be taken. They also showed considerable reluctance to order conduct which would require detailed or long-lasting supervision. The Charter has now given judges a constitutional mandate to do what they were previously reluctant to do, however, and the first few years of Charter litigation have clearly demonstrated that judges are taking this responsibility seriously. Due deference is still paid to democratic decision-making, but where political decisions contravene constitutional rights, the courts are no longer reluctant to award appropriate remedies.”⁵³

Rights discourse has become more prevalent in Canadian society. In his book Waiting for Coraf: A Critique of Law and Rights, Allan Hutchinson states, “not only has the Charter taken discrete issues out of the political forums of democratic debate and into the legal arenas of judicial pronouncements, but the whole ethos of rights-talk has saturated Canadian politics and society.”⁵⁴ Even though there has been a heightened awareness of rights in the health care field, most citizens do not realize the extent to which their rights exist. Once the discussion goes beyond the right of access to health care services, most people do not realize the implication this has on health care policy. In Quebec, Bill 120 is the perfect example of the emphasis that has been given to users’ rights. Our society has empowered and continues to empower citizens to be autonomous

⁵³ Dale Gibson, The Law Of The Charter: General Principles. (Toronto: The Carswell Company Limited, 1986), p.199.

⁵⁴ Allan C. Hutchinson, Waiting for Coraf: A Critique of Law and Rights. (Toronto: University of Toronto Press, 1995), p.24.

decision-makers with respect to their health care. Health care issues are continuing to challenge governments, policy-makers and courts everywhere. Economic, political and ethical dilemmas posed by advanced technology, scarce resources and an ever demanding public, who are becoming increasingly more aware of their rights are encouraging governments to bring more parties into the planning process. “Our deficit of democracy has become acute at the very time that Canada is in the midst of constructing a “new social union” – a redefinition of the rights, roles and responsibilities between citizens and governments, among governments of the federation, and between markets and society. Restoring trust in government and building a new social union necessitate putting citizens, not merely customers, at the heart of the practice of public administration. The Charter entrenched individual rights and provided a reference point for the emerging philosophy of individual responsibility taking.⁵⁵ This is particularly true in the area of health care policy. A more well thought out alliance between the government, citizens and health care experts could well make the process more democratic and keep decisions from being made predominantly in the courts. This would encourage treating health care, not only an individual right, but as a social good. Most provincial governments in the task forces and open forums that they have conducted in the past decade have recommended more public participation. In June 1992, the health and finance ministers met for the first time in 25 years, there was an open and frank exchange of perspectives on the fiscal context and the steps taken by governments to manage the health care system within this context. The consensus among the ministers of health supported by the ministers of

⁵⁵Katherine Graham and Susan Philips, “Citizen Engagement: Beyond the Customer Revolution”, in Canadian Public Administration, Volume 40, No. 2 (Summer), p.256.

finance was the need to launch a nation-wide strategy to inform Canadians about their roles and responsibilities in respect of receiving the most appropriate health care services. The need for broader citizen involvement was seen as a key aspect in re-orienting the health care system.⁵⁶ In Jean Chretien's National Forum on Health public participation was seen as a necessity and was made an important recommendation.

The consumerism of the sixties made the average consumer more aware of his influence in the market place and the policy arena. The public plays more of a role in what products and services they want made available to them. This has spilled over into the area of health care. When the new technology or drug has not been effective the public then wants to be made aware of the alternative or complimentary therapies that are available to them. The effects of consumerism and the heightened awareness of individual rights have had an impact on individual choices that are made in health care. The public is seeking information to make choices and decisions about treatment options. The paternalism that once was the hallmark of the doctor-patient relationship is less apparent and continues to evolve. The doctrine of informed consent has better enabled individual patients to be partners in the decision-making process.

Michael Yeo, an ethicist in the Department of Ethics, Canadian Medical Association, makes a strong argument that parallels can be drawn for supporting both individual and community participation in health care decision-making. He notes that medical decisions are value decisions. On an individual level it is ownership of the

⁵⁶ Amelia Amit *ibid.*, p.33.

decision that is part of the patient's autonomy or right to self-determination. That is the fundamental value upon which the doctrine of informed consent stands. He states that the theoretical justification for public participation is based on public participation as community consent. Resource allocation decisions are value decisions and belong by right to the public, the ultimate users of health care who must bear the benefits and burdens of these decisions just like the individual patient. Both the public and the individual have lost confidence in the traditional surrogate arrangements in which health care decisions are being made. Therefore there has been more active participation by individuals in their health care decisions and by the public in policy making.⁵⁷ We will now examine how Canadians are participating in their own individual decision-making and in public decision-making with regard to health care.

⁵⁷ Michael Yeo examines the ethics of public participation in his article titled, "Ethics of Public Participation" in Efficiency vs. Equality: Health Reform in Canada, Michael Stingl and Donna Wilson, editors. (Halifax: Fernwood Publishing Co. Ltd., 1996), p.44-45.

CHAPTER II

Reconfiguring the Patient-Doctor Relationship: The Challenges of Health Care Democratization

In its Code of Ethics, the Canadian Medical Association states: provide your patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of your ability; make every reasonable effort to communicate with your patients in such a way that information exchanged is understood; respect the right of a competent patient to accept or reject any medical care recommended.⁵⁸ The patient – doctor relationship is evolving as more of a partnership. The democratization of health care presents new challenges. Patients are becoming more active in their own treatment decisions and are also being more pro-active in areas of prevention and health promotion. It is important to examine the ways the public is participating more on an individual level as it has affected their relationships with health care professionals and health care institutions. Policy has been changed at the micro and macro level to deal with the increased interest and awareness of individual citizens in participating in their own health care decisions. In an address to the fifteenth annual meeting of the Society for Medical Decision Making, in 1994 Dr. Hilary Llewellyn-Thomas stated, “(T)here are scientific, clinical, political and ethical reasons for studying patients’ decisions about their health care. The effects of patient consumerism on the doctor-patient relationship, the development of clinical guidelines, and the current debate about the allocation of scarce health care dollars are generating intense interest in how

⁵⁸ Code of Ethics, (The Canadian Medical Association, Ottawa, 1996)

patients make decisions.”⁵⁹ I will examine the impact that legislation and jurisprudence has had on the doctor-patient relationship and how the evolution of that role has encouraged more individual citizen participation in health care decisions. Quebec’s Bill 120 will be reviewed to demonstrate the rights and obligations that citizens have acquired in the health care arena.

1. The Patient-Doctor Relationship and the Rights of the Patient

It is important to examine the basis of the doctor-patient relationship and how that has evolved allowing the individual patient to become more autonomous. In their book A Theory of Human Need, Len Doyal and Ian Gough make sound arguments for the reasons they see the two basic human needs of all persons, in all cultures, as being physical health and autonomy. They claim that “since physical health and autonomy are the preconditions for any individual action in any culture, they constitute the most basic human needs – those which must be satisfied to some degree before actors can effectively participate in their form of life to achieve any other valued goals.”⁶⁰ In Canadian society, health care is a human need and a human right. Health care policy often has a major effect on the individual and society.

⁵⁹ Hiliary Llewellyn-Thomas, “Patients’ Health Care Decision Making: A Framework of Descriptive and Experimental Investigations”, a Presidential Address at the fifteenth annual meeting of the Society for Medical Decision Making, October 1994, Cleveland, Ohio.

⁶⁰ Len Doyal and Ian Gough, A Theory of Human Need, (New York: The Guilford Press, 1991), p.54.

When discussing health care it is important to remember that both moral rights and legal rights play a major role. In liberal democratic societies the individual and his freedom and rights are basic to the society. Legislation, both federal and provincial acknowledges the autonomy of the individual and guarantees definite rights within the system. To appreciate the magnitude these rights have in health care it is worthwhile to examine the libertarian concept of the person, the doctor-patient relationship and the expanding role the patient (or user) is playing in the decision-making process.

In health care there are often no clear boundaries between the individual's moral rights and legal rights. The rights and responsibilities or obligations of the health care professionals also have the same clouding of boundaries between the legal and the moral. Moral and legal rights are based on the concepts of the individual, autonomy and justice. The theory of distributive justice also plays a role in the delivery of health care. The concept of the autonomy of the individual is based on the principle referred to as the 'principle for the respect for persons'. By this is meant:

“(H)umans act morally and have a capacity for rational choice, they possess value independently of any special circumstances conferring value, and because all human beings and only human beings have such unconditional value, it is inappropriate to treat them as if they had merely the conditional value possessed by natural objects and animals. When discussing the Principles of Autonomy it implies that individuals should be allowed to be self-determining agents, making their own choices when their own interests are at stake. They should be free of external control and in control of his or her own affairs.”⁶¹

⁶¹ Tom Beauchamp and Leroy Walters, Contemporary Issues in Bioethics, second edition. (California: Wadsworth Publishing Inc., 1982), p.26-27.

In order for a person to make decisions as an autonomous individual about their own health, they not only must be free from external control and in control of their own affairs but they must also possess the information to make relevant choices. “Autonomous action can be analyzed in terms of normal choosers who act intentionally, with understanding and without controlling influences that determine the action.”⁶²

The concept of distributive justice is considered to be “the proper distribution of social benefits and burdens. Egalitarian theories of justice emphasize equal access to primary goods; Marxist theories emphasize need; libertarian theories emphasize rights to social and economic liberty; and utilitarian theories emphasize a mixed use of such criteria so that public and private utility are maximized.”⁶³ These concepts form the basis of much of the further discussion of patients’ rights and the importance of individual participation in health care decision-making.

In conjunction with these rights, there are obligations on the part of the physicians which must be considered. One of the principles basic to medical ethics is ‘primum non nocere ---- above all do no harm’. This has been further broadened to principles of beneficence and nonmaleficence. These include the four following elements: “one ought not to inflict evil or harm, one ought to prevent evil or harm, one ought to remove evil or harm, and one ought to do or promote good.”⁶⁴ These principles are relevant when

⁶² Tom Beauchamp and James Childress, Principles of Biomedical Ethics, third edition. (New York: Oxford University press, 1989), p.69.

⁶³ Beauchamp and Walters, *ibid.*, p.31.

⁶⁴ Beauchamp and Walters, *ibid.*, p.28.

discussing the doctor-patient relationship as it exists within the health care delivery system in Canada.

There has been a gradual shift in the dynamics of the doctor-patient relationship. This relationship was previously based on the principles of paternalism. The doctor was seen as the “all-knowing” physician who knew what was best for each individual for whom he cared, as a father knows what is best for his children. Some moral philosophers define paternalism as “the limitation of a person’s liberty of action or liberty of information justified by reasons referring exclusively to the welfare or needs of the person whose liberty is limited.”⁶⁵ Despite the fact that all health professionals may still frequently find themselves in paternalistic roles, whether they should continue to assume the role is questionable.

The doctor-patient relationship is now seen by some as a contractual relationship and as a fiduciary relationship by others. However, no matter what one chooses to call the relationship it is important to realize that the doctor-patient relationship is governed by moral and legal principles. There are a number of imbalances built into this relationship which make it difficult to always insure the autonomy and allow the self-determination of the individual. The main obstacle is the asymmetry of information. It is difficult enough for physicians to keep up with the rapidly changing world in medicine, it is impossible to expect that patients should be fully aware of their medical options. Therefore, it is the duty of the doctor as the patient’s agent, to provide the patient with information that will

⁶⁵ Beauchamp and Walters, *ibid.*, p.38.

enable her to take a more active role in the decision-making process, to remain autonomous and maintain self-determination.

There are pros and cons to looking at the doctor-patient relationship in terms of a contractual relationship and a fiduciary relationship. However, most health care professionals consider it to be a fiduciary relationship. When examining the relationship in terms of a contract, there is implied a business like approach with which most patients and physicians would not be comfortable. "Thinking of the doctor-patient relationship as a contract seems to establish only minimal expectations from the physician and the patient. The physician will deal with the technical values; the patient will deal with the social and personal values. In reality things are much more complex than this in health care."⁶⁶ Most patients and doctors consider their relationship to be a fiduciary one with all that that implies. "A fiduciary model rests on treating the whole person. The reason is that the values of the patient must also be part of the dialogue about medical treatment."⁶⁷ A fiduciary relationship implies that there is a certain level of trust, loyalty and confidentiality that might better promote discussion and participation on the part of the patient. The contractual model has been widely criticized as being unrealistic and encouraging 'minimalist' thinking rather than a richer physician-patient relationship. The ideal seems to be shared decision-making with contributions by both patient and physician. "Patients bring to the relationship their personal moral values or life-style preferences about which they could be expected to know more than the physician could

⁶⁶ E. Pellegrino and D. Thomasma, For the Patient's Good The Restoration of Beneficence in Health Care. (New York: Oxford University Press, 1988), p.52.

⁶⁷ E. Pellegrino and D. Thomasma, *ibid.*, p.53.

and the physicians bring their expertise about the technical aspects of diagnosis and management.”⁶⁸

The importance of informed consent in the doctor-patient relationship has had a major impact on the level of participation by individuals in their health care decision-making. “The primary function of informed consent is protecting and enabling individual and autonomous choice. An informed consent occurs if a patient or research subject with substantive understanding and in substantial absence of control by others intentionally authorizes a professional to do something. Legal, philosophical, regulatory, medical and psychological literature have all tended to favour the following elements as the analytical components of informed consent: disclosure, understanding, voluntariness, competence and consent.”⁶⁹ Patients must be given adequate information so that they are capable of assessing the risks of what the doctor is recommending as therapeutic. In Quebec, for example, the requirement for consent to a treatment or procedure is demanded by law in the Civil Code and by Bill 120. The legal doctrine of informed consent is also entrenched within the Physicians’ Code of Ethics.

The extent to which individuals must be informed and the importance that society places on that concept can be fully appreciated by examining the jurisprudence related to the doctrine of informed consent. Two interesting cases which show the extent of the legal interpretation and the emphasis placed on individual autonomy and self-

⁶⁸ Raisa Deber, “Physicians in health care management: The patient-physician partnership: changing roles and the desire for information”, in The Canadian Medical Association Journal, 1994; 151 (2), p.172.

⁶⁹ Beauchamp and Childress, *ibid.*, p.75-76.

determination are *Reibl v Hughes*, 1980, and *Currie v Blundell*, 1992. In the case of *Currie v Blundell*, a twenty-five year old woman, Jean Currie underwent cardiac surgery and suffered a massive hemorrhage. Due to the extent of loss of blood, the woman became hypotensive (low blood pressure) and infarcted her spinal artery. She was left with a handicap evaluated at 30%, a partial paralysis of her lower limbs. This young woman sued Dr. Blundell and was awarded damages on the grounds that not only had she not been informed of this risk but also she had not been informed that a surgical resident would be doing a major part of the surgery.⁷⁰ This court case brought to the attention of hospital administrators and doctors that they should not automatically assume that just because patients are in a teaching hospital that they are aware that the medical residents often perform procedures. It also reaffirmed the fact that patients must be fully informed.

In the case of *Reibl v Hughes*, Mr. Reibl sought the advice of his physician concerning his headaches. The physician informed Mr. Reibl that his hypertension (high blood pressure) was the probable cause of his headaches. However, he could not find any other underlying cause, so referred him to a neurosurgeon. Mr. Reibl was diagnosed as having a narrowing of the left carotid artery (an artery leading to the brain). The narrowing of the artery however is not the cause of the hypertension. The neurosurgeon informed Mr. Reibl that there was a 10% chance of having a stroke each year that he lived with this condition. The neurosurgeon, Dr. Hughes suggested that the patient have surgery to correct this condition. The patient agreed to have this surgery, suffered a massive stroke, which paralyzed the right side of his body. The failure of proper

⁷⁰ *Currie v Blundell*, Cour Superieure du Quebec, R.J.Q., 1992, p.764-777.

disclosure both pro and con became very material to this case. The defendant, Dr. Hughes did not inform the patient about the 10% chance of having a stroke during the procedure or the 4% chance of dying. The doctor also did not make it clear that the operation would not cure his headaches. Even though it can be established that medical evidence demonstrates the reasonableness of a recommended operation, it does not assume that a reasonable person in the patient's position would necessarily agree to the procedure. Even if proper disclosure had been made of all the material risks, there is a possibility that a reasonable person would have refused the surgery at that particular time. Relevant to this issue was whether a reasonable person in Mr. Reibl's position would have declined the surgery at this time. He was within one and a half years of his retirement, when he would be able to earn full pension benefits, if he had continued his job. It was felt by the court, that a reasonable person in the plaintiff's position would have opted against the surgery at this particular time, especially if he had been informed of all the potential risks. This was the judgement of the Ontario Court of Appeal. The defendant appealed to the Supreme Court of Canada which upheld the decision, "that had there been proper disclosure of attendant risks, a reasonable person in the plaintiff's position would, on a balance of probabilities, have opted against the surgery rather than undergoing it at that time."⁷¹ The decisions handed down in these two court cases may be viewed as society re-affirming the importance of the individual receiving full information in order to participate in his own medical decisions in partnership with the physician. The standard today is not what a reasonable physician would do in the same circumstances, but what a reasonable patient would do in the same circumstances.

⁷¹ Reibl v Hughes, The Dominion Law Reports, October 7, 1980.

Along with this right is there a duty on the part of the patient to become informed. This may be asked also in relation to individuals representing the public while making health care decisions for the community. This will be discussed in detail when examining public decision-making. It is the physician's duty obviously to do the informing yet, should patients be required to have a certain base line knowledge so that they can ask relevant questions? When one reads the legislation and some of the jurisprudence the onus is definitely on the physician. He must not only pass on the information but also insure that the patient understands it. "The patient's understanding of the information required to be given to him under the doctrine of "informed consent" is necessary for a legally valid consent, this appears to be more and more accepted."⁷²

"Investigators have also concluded that encouraging patients to take a more active role in their care may indeed pay off in improved outcomes. Patients who are actively involved in care may have a better functional capacity and perceive themselves as healthier than those not actively involved. They may also have more effective relationships with their physicians."⁷³ It is important for individual patients to become involved in their own health care decisions prior to needing the treatment or the surgery. It is beneficial for patients to ask questions and acquire information about health promotion and disease prevention. Raisa Deber notes that for patients to take an active role in decision-making they will need clarification of the following: "the available alternatives; the potential outcomes of each alternative; the costs, risks and benefits of

⁷² M. Somerville, Consent to Medical Care Protection of Life Series. A Study Paper prepared for the Law Reform Commission of Canada. (Minister of Supply and Services, 1980), p.15.

⁷³ Raisa Deber, *ibid.*, p.173.

each alternative; and the values of each potential outcome. Clinicians have a key role in ensuring that such information is available and understandable and in supporting patients in making informed and wise choices".⁷⁴ It is unlikely that most physicians have the time available to review every situation as thoroughly as Deber suggests. I have recently heard of physicians answering their own recently seen patients' questions by email. There has been information made available to patients with benign prostatic hyperplasia, who must choose between a watch and wait strategy or surgery. This program on interactive videodisc is being developed by a US non-profit group, the Foundation for Informed Medical Decision-Making. This is a very beneficial way for individuals to get information at their own speed. Individuals are taking more responsibility for getting information. However, it is important that the government insure that the information is not product oriented but disease oriented. If pharmaceutical or medical technology companies start distributing information directly to patients this will not be beneficial to patients or to their communities. If an individual seeks more information about health care issues for himself or to bring to a group, that information must be unbiased. It must offer alternatives from which to choose. It is the best interest of individuals and the community that people participate in health care decision-making pro-actively. Many Canadians are doing so as they become more aware of fitness, diet and 'well-being'. This is the ideal time to have an active exchange with health care professionals and become informed, not when they find themselves lying on a stretcher in the Emergency Room.

⁷⁴ Raisa Deber, "Physicians in health care management: The patient-physician partnership:decisionmaking, problem solving and the desire to participate", in The Canadian Medical Association Journal, 1994; 151 (4), p.427.

However, it is very difficult to get individuals interested in health matters unless they have a potential or actual health problem.

2. A Case Study: Bill 120 in Quebec

However, by increasing patients' knowledge, whether that has occurred as a discussion in obtaining an informed consent or through an informal chat during an annual check-up, they are better able to participate in other health care forums. Legislation in some provinces has provided for patients to become involved in the decision-making in the institutions where they are receiving services. It is obvious that a better informed patient is a valuable participant on such a committee. The Quebec case brings to light the evolving nature of the patient's/citizen's input in health care decision-making. Quebec is interesting because it has developed legislation that is far more forward thinking with reference to the reorganization of health care and social services than any other province. It also has attempted to decentralize health care service delivery more than any other province. Professor Andre-Pierre Contandriopoulos, Director of the Department of Health Administration at the University of Montreal, stated in a recent interview for *Le Devoir*, "Quebec is already a step ahead of the rest of the planet. Quebec is a society characterized by its suppleness, its ability to change things absolutely radically in an extraordinary short time without experiencing a revolution."⁷⁵ Duncan Sinclair, Dean of the Faculty of Medicine at Queen's University, stated "our colleagues in Quebec have a

⁷⁵ Louis Lafrance, "Health System on the mend. Researcher refuses simple diagnosis of sweeping changes under way in health sector thanks to Minister Rochon", in *LeDevoir*, February 9, 1998. Translation provided by Articles and analyses on the internet, www.mri.gouv.qc.ca.

long record of leading us all in innovative ways of managing the health-care system from a public policy perspective. La belle province recognized before the rest of us that health care is a public good and the health-care system is, in effect, a public utility.”⁷⁶ Health policy in Quebec is innovative and forward thinking.

The mainstay of Quebec’s legislation on the question of patient involvement in health care decisions is Bill 120. Passed in 1991, it was designed to place the citizen at the centre of the health care system, the citizen as decision-maker and the citizen as consumer. It is interesting, before looking at how the individual is being encouraged to participate, to first examine the basis of the framework for Bill 120. Bill 120 states in Article 3. For the application of this Act, the following guidelines shall guide the management and provision of health services and social services:

- (1) the person requiring services is the reason for the very existence of these services;
- (2) respect for the user and recognition of his rights and freedoms must inspire every act performed in this regard;
- (3) the user must be treated, in every intervention, with courtesy, fairness and understanding, and with respect for his dignity, autonomy and needs;
- (4) the user as far as possible, play an active role in the care and services which concern him;
- (5) the user must be encouraged, through the provision of adequate information, to use services in a judicious.

⁷⁶ Duncan Sinclair, “Introduction”, in Health Care Innovation, Impact and Challenge, S. Mathwin Davis ed., (Kingston: School of Policy Studies/School of Public Administration, Queen’s University, 1992), p.3.

Articles 8, 9, and 10 pertain to the legal requirement of informed consent and the right of the user to participate in the decision-making.

8. Before giving his consent to care concerning him, every user of health services and social services is entitled to be informed of his state of health and welfare and to be acquainted with the various options open to him and the risks and consequences generally associated with each option.
9. No person may be made to undergo care of any nature, whether for examination, specimen taking, treatment or any other intervention, except with his consent.
10. Every user is entitled to participate in any decision affecting his state of health or welfare.⁷⁷

Many of the same rights exist in other provinces however, it is interesting that in Quebec they are re-affirmed in legislation that expands on health and social services delivery.

This legislation also encourages the users of institutions to get involved on users' committees. The functions and responsibilities of these committees are clearly established in the Bill. Article 212 states that the functions of the users' committee are:

- (1) to inform users of their rights and obligations;
- (2) to foster the improvement of the living conditions of the users and to assess the degree of satisfaction of users with regard to the services obtained from the institution;
- (3) to defend the common rights and interests of users;

⁷⁷ Bill 120 An Act respecting health services and social services and amending various legislation, Quebec Official Publisher, 1991, p.7-8.

(4) to accompany and assist a user on request, in any action he undertakes, including the filing of a complaint.⁷⁸

These are just some of the statements in the legislation about users' committees and their functions. However, it is evident that the Quebec government is not only encouraging people to get involved in the institutions where they seek medical services but also encouraging them to monitor their experiences there. In this manner it is hopeful that patients will become better able to promote and protect their rights in the system, while becoming aware of the inherent problems in the institution. Since two members of the users' committee are legislated to be on the board of the institution this ensures their participation in the decision-making process. This hopefully is proving to be particularly beneficial to the entire community the institution serves, because these board members have first hand experience with the institution. They become aware of the institution's strengths and weaknesses. This is a positive step in the right direction in an attempt to balance individual rights with community interests. These patients, as members of a user's committee and institutional boards, will be in a position to comment on the services that are available to the rest of the community and hopefully provide the hospital or CLSC or long-term care facility with feedback to improve, add or change the services that are offered. Knowledge and experience that patients acquire while interacting with health care professionals and institutions benefit not only themselves but also the entire community an institution serves.

⁷⁸ Bill 120 *ibid.*, p.60.

On December 7, 1999 the Patients' Committee of the Royal Victoria Hospital sent a letter to Premier Bouchard with copies to Pauline Marois, Minister of Health and Social Services, Jacques Leonard, President of the Treasury Board the Deputy Minister of Health, Michele Manquin-Ethier among others. The letter stated:

"As members of the Patients' Committee of the Royal Victoria Hospital we are writing to bring to your attention a very serious concern. Our committee has a clear mandate under the terms of the Quebec Health and Social Services Act (L.Q. 1991c.42 article 212) according to which we are required "...to foster the improvement of the quality of the living conditions of users and assess the degree of satisfaction of users with regard to the services obtained from the institution." In addition, our mandate states that the committee is expected to "...defend the common rights and interests of users before the institution or any competent authority." It is because of our intent to honour the terms of the mandate that we seek to call your attention to the following urgent matter.

Chronic overcrowding in the emergency ward of the Royal Victoria Hospital is causing great stress for patients and the situation has deteriorated to the point where we believe that urgent, remedial action must be taken and permanent, long-term solutions found. For example, during a recent five-day period in November 1999 there were approximately thirty-nine patients on stretchers in the corridors. This places an unbearable burden upon both patients and personnel. Indeed, the situation is so critical that on November 12 the evening shift nurses walked off the job to protest a situation that was, in their professional opinion, downright dangerous.

We draw your attention to the fact that The Canadian Medical Association has recommended guidelines for emergency room care, guidelines which neither the Royal Victoria Hospital nor any other hospital in Montreal is presently able to meet. For example, the CMA suggests that for acute care cases the nurse to patient ratio should be 1:3. In reality, the ratio is often 1:5 or 1:6. Despite such trying conditions the staff continues to provide excellent care thanks to their dedicated professionalism and often heroic efforts. However, this is not a situation that can be sustained for very long without exacting a huge toll with potentially tragic outcomes."⁷⁹

⁷⁹ Letter written to The Honourable Lucien Bouchard, by the Patients' Committee of the Royal Victoria Hospital, Montreal, December 7, 1999.

This letter from this patients' committee demonstrates how important it is for individual patients to get involved and effect the process of change. Not only was it important for them to know their rights but also to act upon those rights and obligations, and hopefully improve health care services for the community.

Health care accreditation has become an important fact of life for most Canadian health care institutions. "When accreditation started in 1919, standards were a matter for the hospitals alone to decide. Now reports and recommendations by the surveyors are sent to funding authorities for information. In the last decade, mental, rehabilitation and long-term institutions have also sought accreditation."⁸⁰ The Canadian Council on Health Services Accreditation visits hospitals and other health care institutions across the country. This is often a very extensive look at the institution. Health care institutions are accredited for either a two or three year period. The role of the patient in this process has been given increased importance over the years. It is stated in the Standards for Acute Care Organizations, in Article 7.4 that: "Surveyors will also interview selected clients/patients, families and, if possible, client/patient advocates. The purpose of the interview is to understand the client/patient and family perspective of the care process. Each surveyor involved in the assessment of a care group will interview 2-3 clients/patients and/or their families. Both the organization and the surveyors will participate in the selection of suitable individuals. In addition, surveyors may, during the course of the survey, informally interact with a number of clients/patients and families."⁸¹

⁸⁰ Crichton Hsu and Tsang, *ibid.*, p.91-94.

⁸¹ Standards for Acute Care Organizations A Client-centred Approach 1995, (Ottawa: Canadian Council on Health Services Accreditation, 1995), p.23.

This further establishes the importance that is placed on the individual and his participation in all aspects of the health delivery system. It is no longer just the institutions, professionals or governments establishing the standards and the process of measurement, but citizens, who through their use of the system, have gained a knowledge and experience that is being valued for assessment and future planning.

Bill 120 clearly establishes a framework for patients' complaints. Article 29 states that every institution shall establish a procedure for the examination of filed by users. Article 30 states that the institution must publish the complaint examination procedure and inform each user of the existence of the publication and a means of obtaining a copy thereof.⁸² This facet of the legislation goes hand in hand with the requirement by the government, for each institution to establish a Code of Ethics. According to Article 233 a Code of Ethics must be established of which all employees must be made aware as well as all patients. This document must set out the rights of the users and the practices and conduct expected, with respect to the users, from the employees, the trainees, including medical residents, and all practicing professionals in the institution.⁸³ This will not only serve to protect patients' rights when they are in hospital but also makes them more aware of their rights, particularly at a time when they feel the most vulnerable. The Act also states that the Code of Ethics must be made available to every user who is an in-patient in the institution.

⁸² Bill 120, *ibid.*, p.12.

⁸³ Bill 120, *ibid.*, p.68.

It is important to point out however, that complaints filed are about the services in the institution and not about medical acts. It is also stipulated in the Act that if a user disagrees with the conclusions of the complaint sent to him by the senior management of the institution, he can file the complaint with the Regional Board. The senior management of the Regional Board will then examine the complaint. However, any complaints about medical acts are submitted to the Council of Physicians, Dentists and Pharmacists of that institution. The professional to whom the complaint is referred must examine it and review the chart of that user then, submit in writing, a report to senior management.

It is worth noting that Article 15 of Bill 120 states that English-speaking persons are entitled to receive health services and social services in English. This shows a commitment on the part of the government to ensure minority rights in the area of health care service delivery. It is interesting that language rights are clearly stipulated in an act which deals with health and social services.

Another right which Bill 120 bestows on the user of the health care system in Quebec and one which has been affirmed by the Supreme Court in other provinces is access to the medical chart. In Quebec, the user (anyone over the age of fourteen) is to be given access to their medical records. If this access is denied on the advice of a physician, then the patient must be notified. "It can be denied if it is felt that communication of the record would likely be seriously prejudicial to the user's health."⁸⁴ However, this lack of

⁸⁴ Bill 120, *ibid.*, p.9.

access is encouraged to be only temporary and the Act clearly states what a person's recourse is should he be denied access. Article 27 states, "A user to whom an institution refuses access to his record or to information contained therein may, by way of a motion, apply to a judge of the Superior Court or the court of Quebec or to the Commission d'accès à l'information for a review of the decision of the institution."⁸⁵ Articles 25 and 26 deal with the situation when a user requests information from his record from an institution. The institution is not only obliged to give him the information but must also provide a health care professional to help him understand the information. Quebec seems to be ahead of other provinces with this legislation. In a court case in New Brunswick in 1992, a patient, Margaret MacDonald, requested all the information in her records from Dr. Elizabeth McInerney. The physician gave the patient only the information from her record with which she (the physician) was involved. She refused to give any of the information from the record which had been acquired by previous consultants. The patient won the right to have access to her medical records in the New Brunswick Court of Appeal. The doctor appealed to the Supreme Court. Two judges in the New Brunswick Court of Appeal noted that "there is no legislation in New Brunswick regulating a patient's access to his/her medical records and commented that a noticeable trend has developed favouring an individual's access to personal information."⁸⁶ The decision of the Supreme Court was that "the lower court quite properly held that the respondent was entitled to copies of documentation in her medical chart."⁸⁷

⁸⁵ Bill 120, *ibid.*, p.12.

⁸⁶ *McInerney v MacDonald*, Supreme Court Review, 1992, p.143.

⁸⁷ *Ibid.*, p.159.

In this decision by the Supreme Court, Justice LaForest brings up some interesting points about patients' access to their own recorded medical information and the reasons why he feels this is becoming an important issue in the delivery of health care services. He feels that since medical records are shared with insurance companies, employers, researchers and government payers, the patient should know the contents. Also the practice of medicine has become highly specialized and patients are often no longer treated by a family doctor who has their records in one place. People themselves have become very mobile and they might be better served if they had copies of their own records, which were easily accessible to give new physicians with whom they might have to consult.

One of the concerns that has been expressed about allowing easy access of patients to their own records is that physicians may tend to be very careful in what they write, and may not be as frank in their observations, or as detailed in their recording, as they would if they knew that access was more limited. This in turn would make the medical record less meaningful than it was meant to be. This type of legislation which encourages the user to become more pro-active in their own health care also establishes obligations on the part of the user to be knowledgeable about his medical condition and keep the information that might be needed for his further treatment available.

Legislation exists in Quebec and other provinces which ensures the right of a patient to also refuse treatment. In Quebec this is established not only in Bill 120 but also in the Civil Code. A patient's right of refusal of treatment was challenged in court with

the Nancy B. case on January 6, 1992. The plaintiff, Nancy B. asked the court for an order that the defendant hospital, the Hotel Dieu de Quebec and Dr. Daniele Marceau and Hotel Dieu medical staff and officials not administer any treatment without her consent. Also that at her request they cease treatment presently being given. Nancy B. suffered from Guillain-Barre Syndrome (a disease causing ascending motor paralysis). In a statement made by the judge deciding the case, he quoted section 19.1 of the Civil code which states, "that no person may be made to undergo care of any nature, whether for examination, specimen taking, removal of tissue or any other act, except with his consent." He then continued that the logical corollary of the doctrine of informed consent is that the patient has the right not to consent, that is the right to refuse treatment and to ask that it cease where it has already begun."⁸⁸ The judgement handed down, "permits Dr. Daniele Marceau, the plaintiff's attending physician to STOP the respiratory support treatment being given the latter, when she so desires; her consent must however be checked once again before any act in this regard is done; permits Dr. Daniele Marceau to request from the defendant hospital, the Hotel Dieu of Quebec, the necessary circumstances such as these, so that everything can take place in a manner respecting the dignity of the plaintiff."⁸⁹

When examining recent jurisprudence and the current trends in health care, in Quebec and elsewhere in Canada, there is a definite complementarity of thought. Both legislation and judicial review are clearly stating and upholding the rights of the health

⁸⁸ Nancy B. v Hopital Hotel Dieu, Quebec Superior Court, The Dominion Law Review, January 6, 1992, p.389-390.

⁸⁹ Ibid., p.395.

services users. In the deliberations about this case the judge refers to Judge Gonthier's comments in a similar case which state, "Policy-based limits are almost always the product of a balancing of individual autonomy and some larger societal interest. That balancing may be better performed in the light of actual situations, rather than in the abstract, as Parliament would be compelled to do."⁹⁰ This is of interest because there is legislation in place which gives people the right to have treatment or not to have treatment yet, there are still members of the judiciary who feel that these situations should be examined in a case by case situation. These types of statements could possibly lead to doctors requesting judicial review before they would be willing to listen to the patient particularly in controversial areas. One would hope that the 'balancing' to be done would be done on a careful case by case basis by health care professionals, who know the dynamics of the situation, have a good relationship with the patient and have support of legislation. It is hoped that the patient's right to autonomy and self-determination would not often have to be decided in court.

3. Obligations: The Flip Side of Patients' Rights

Interestingly, although legislation like Bill 120 has extended the reach of patients and users of medical services with regard to decisions that immediately affect them, they also underscore the obligations patients should feel toward the public health system. By empowering the citizen in Quebec, the government is encouraging a more responsible patient to interact with the health care professionals and a more knowledgeable user to

⁹⁰ Ibid., p.393.

use the health care services wisely. Users' rights are being ensured by making them more aware of their rights through information and through the requirement to participate by not only using the health care system but by monitoring it. As active participants in the system, citizens will become more aware of the dichotomy that exists between the funding of the system and the right of access to the system. In Quebec this legislation has encouraged an increased level of participation of patients where they seek treatment. The doctor-patient relationship has changed but so too has the relationship with other health care professionals and the institutions. Patients are being asked to actively participate in the policy process in their institutions. Standards of care have been set in the institutions and the public is being asked to help monitor those standards and then perhaps make changes in light of budget constraint or human resource issues. It is, as the legislation in Quebec points out, the responsibility of the institution to make sure that patients are made aware of codes of ethics and complaint procedure, but it is up to the individual to help measure the care given with the standard of care stated. When asked to sit on a users' committee in an institution should not most patients feel an obligation to do so? If he does agree, is it then not another obligation to become knowledgeable about the issues? The state is encouraging citizens to have a sense of ownership not only for their own health but also for the health care system.

A number of suggestions have been made that would make the individual patient more aware of the cost of health care in Canada. "One suggestion was to require the signature of the patient on every bill or chit submitted by the doctor to the provincial plans. The purpose of this process was two-fold: first to stop doctors from charging for

services not performed; and secondly to make patients more aware of the cost of the encounter at point of service. This has been implemented in at least one region with minimal effect. Another suggestion was to send every citizen who has received health services in the past three to six months an itemized statement listing all the costs paid by the Medicare plan on their behalf. Alberta currently does this and continues to be as frustrated about costs as all the other provinces.”⁹¹ Whether either of these measures would make patients more fiscally responsible is debatable. Policing your physician is not a very comfortable place for a patient. Knowing what they cost the system may be interesting for some patients, but if they feel that their health care needs have been attended to and they are feeling better, they will probably be of the opinion that the money was well spent.

Governments in Canada have increased the public’s awareness of health care rights and encouraged the promotion and protection of those rights at a time when advanced technology and an aging population are increasing the demands on an already diminished pool of resources. Whether or not new health care reforms may promote a greater sense of community or increased individualism is still not clear. Hopefully the value that Canadians place on their system of universal health care will ensure that what is accomplished is done for the greater societal good while still promoting and protecting the individual rights of all citizens. Will users and providers stop making unreasonable demands on the system so that a certain level of health care can be maintained for the

⁹¹ William V. Weiss, Healthcare Conflicting Opinions, Tough Decisions. (Toronto: New Canada Publications, 1992), p.75.

entire population. If individuals are not able to help redefine goals for the community, then governments may have to redefine the objectives of the health care delivery system. It has been shown that once individuals are placed in situations that require that difficult medical decisions be made the majority of people want everything possible to be done regardless of age or condition. Individual health care decisions are often so difficult to make particularly when a life is at stake, providers as well as patients tend to lean on the side of doing more than less. It is also difficult for health care professionals to think about balancing the rights of the individual with what is best for the greater good of society, when in individual situations they are there to benefit the patient. Health care institutions are always trying to educate the health care professionals that work there about the cost benefit of various procedures, tests and treatments. However, the health care professionals know that their duty is first to the patient.

“Physicians must reassert their commitment to individual patients: a commitment that must be seen by patients as taking precedence over any obligation to society as a whole. If the patient feels that the physician is making decisions while prioritizing what has been called distributive justice, all basis for trust in that physician will be jeopardized. We believe that understanding this is of great importance to the physician, to the medical profession, and especially to policy-makers. The healer and the advocate for the individual cannot be separated.”⁹²

⁹² Richard Cruess and Sylvia Cruess, “The Impact of Health Policy on Clinical Decisions and the Doctor-Patient Relationship”, in Do We Care? Renewing Canada’s Commitment To Health Margaret Somerville, ed., (Montreal: McGill-Queen’s University Press, 1999), p.32.

4. A Fragile Balance, Be That As It May

Many health care professionals feel strongly that life should be maintained at all cost. In a 1990 case in Saskatchewan, where parents refused to allow their nine-month old son, who was born with biliary atresia (malformation of the liver drainage system), to have a liver transplant. They made a fully informed, considered decision to withhold consent for a liver transplant. They were concerned about the suffering this young child would endure during this major operation and the side effects of the immuno-suppressive drugs that he would need for the rest of his life. The parents were very concerned that these drugs would make the child highly susceptible to infectious diseases and not allow him to have any semblance of a normal childhood. Physicians in the case attempted to have the child made a ward of the court because they felt that the parents were not making a correct decision. Judge David Arnot of the Saskatchewan provincial court stated: “the decision to partake in this high-tech medical procedure is not purely a medical question. There are other components in the equation. There is a practical, emotional, social, and psychological component both for the child and the parents. There is a quality of life issue for the child. The physicians and the Minister of Social Services have focused only on the medical component of the case. Therefore the application made to request a temporary committal of the child to the care and protection of the Ministry was denied.”⁹³ Medical decisions are rarely made in isolation of other factors. Patients, families and health care professionals have a difficult time deciding when enough

⁹³ *The Minister of Social Services v Francois and Leslie Paulette, The Provincial Court for Saskatchewan*, April 20, 1990.

resources have been used and when heroic measures are no longer in the best interest of any of the individuals involved. Charles Taylor has stated that,

“the modern notion of dignity of the person is essentially that of an agent, who can affect his own condition. Citizen dignity involves the notion of citizen capacity. One model focuses on individual rights and equal treatment, as well as a government performance which takes account of the citizen’s preferences. Citizen capacity consists mainly in the power to retrieve these rights and ensure equal treatment, as well as to influence the effective decisionmakers. This retrieval may take place largely through the courts, in systems with a body of entrenched rights. But it will also be effected through representative institutions. The ideal is not ‘ruling and being ruled in turn’, but having clout.”⁹⁴

Present day health care legislation does enable citizen capacity by giving the user the power to retrieve his rights and ensure his equal treatment. There is also the ability not only to influence the decision-makers but also to be a decision-maker for the community.

In Canada, it appears that in the area of health care policy we have the perfect mix. It encourages the system to focus on the individual and maintaining his rights, while promoting the health care of the community. However, there are a number of dilemmas that occur, both theoretically and practically. There are competing individual interests, as well as, individual versus community interests that require that difficult choices be made. As individuals, we might possibly interpret that according to the Canada Health Act and various other provincial legislation, we have a legal right to health care, but we should examine our moral right to all health care. The interpretation of legal and moral rights are not the same, and perhaps, particularly in light of health care, it should become important

⁹⁴ Nancy Rosenblum, ed., Liberalism and the Moral Life. (Cambridge: Harvard University press, 1989), p.178-179.

to take both into consideration when taking part in the decision-making process. As a society we may have to focus on what aspects of health care we have a right to. Our right to health care may have to be examined in relation to our needs and not necessarily to our expectations and wants. A balance may have to be struck between our individual rights and individual needs in health care with our societal rights and our societal needs to health care. Recent trends in health care policy have enabled the individual to be his own decision-maker, as well as a decision-maker for the community. Are we up to the challenge?

CHAPTER III

Public Participation in Community Health Care Decision-making: The Parameters of Participation

Despite all of the problems with health care delivery in Canada, that are constantly referred to by the media, Canadians still have and value one of the fairest and comprehensive health care delivery systems in the world. However, advanced technology, an aging population, diminishing resources and an increasingly demanding, more knowledgeable public are making it difficult for governments to develop health care policy in isolation. Many Canadians feel that their concerns are not adequately represented by their elected members in government. All of the hype about waiting lists in the media and the call for the government to do something may lead to the rationing of some health care services or the privatization of other health care services. The public is being encouraged to take part in the policy process. One of the most important areas where they should definitely get involved is health care.

There has been a democratization of health care in the past decade. There are two definitions of democracy which are applicable to health care and demonstrate why public involvement is necessary to ensure that the health care policy reflects the needs of the citizens. The first definition is "The set of relations and institutions which permit the citizenry to control their own lives."⁹⁵ Sartori states that "democracy results from, and is

⁹⁵ V. Navarro "Workers' and community participation and democratic control in Cuba", in International Journal of Health Services, 1980;10, p.198.

shaped by, the interaction between its ideals and its reality, the pull of an ought and the resistance of an is.”⁹⁶ This further emphasizes the fact that health care policy must be developed in the framework of rationalization and the making of difficult choices. In order to facilitate the democratization of health care systems, Robin Watts suggests that the following characteristics of democracy be implemented and enhanced. These are: responsibility to others as well as self; equality of opportunity to realize potential; emphasis on collective rights; participation in decision-making; placement of responsibility for decision-making as close as possible to those affected; public debate; and protection against abuse of power (e.g. professional control of knowledge).⁹⁷ This appears to be much of what the provincial governments are attempting to do as they try to encourage the public to become informed and responsible about their own health care decisions, and get involved in the decisions that will affect their communities. Nine of the provincial governments have instituted measures to decentralize health care. They hoped to increase accountability, encourage more public participation and bring the decision-making closer to the community being affected.

How does the Canadian public get involved in health care decision-making? They do so in any variety of ways. They become members of advisory committees, members of local or regional health councils, members on institutional or regional boards of directors or they join interest groups. They also form groups or individually make presentations to local committees, provincial committees, federal parliamentary committees, or Senate

⁹⁶ G. Sartori, The Theory of Democracy Revisited. (Chatham, N.J.: Chatham House, 1987), p.8.

⁹⁷ Robin Watts, “Democratization of Health Care: Challenge for Nurses”, in Advanced Nursing Science, 1990;12(2), p.39.

hearings on such issues as organ and tissue donation and transplantation, euthanasia and reproductive technology.

It is important to examine the role of the public in the policy process. What is public participation? Is the way the public participates related to how they see their role in the system? Who represents the Canadian public? When the public participates in the health policy process, does that ensure that the “public interest” is represented? The Canadian government is encouraging citizen engagement in the policy arena. How is that being achieved?

1. Public Participation: What does it mean?

It is extremely important for Canadians to get involved in the health care policy process. Health care policy has a direct effect on the individual and the community. Health care policy is also concerned with vulnerable individuals and groups, such as the frail elderly and the mentally ill. This adds a strong altruistic component to the requirement of being a participant, who must sometimes diminish the instinct of self-interest. Economic restraint has been the catalyst for health care reform. It is imperative that the public participate in this reform movement. In its final report the National Forum on Health stated that, “our research revealed an interaction of strong vested interests and powerful values (pride, equality, compassion, national identity) which provides the capacity for rigorous debate in the future. At a time when other traditional values have

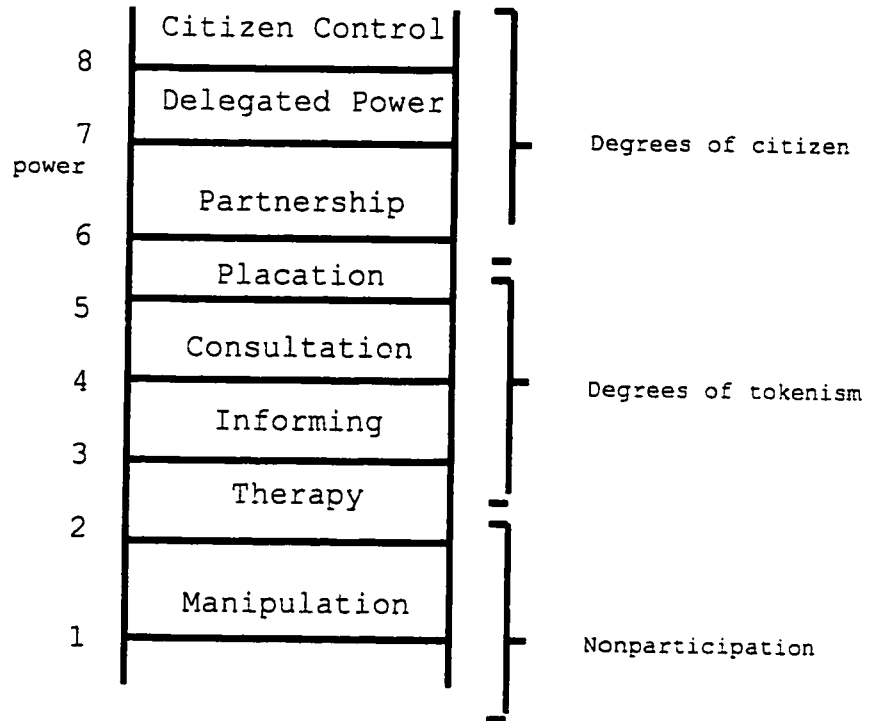
been placed under demonstrable stress, health and health care have increased in importance and prominence as a shared and common value.”⁹⁸

What makes public participation effective in health care policy? In order for the delegate who is appointed or elected to participate effectively in the health care policy process at the institutional, local or regional level they must know and be accountable to the group that they represent. Their participation must be valued by both the group they represent and by the other members of the council or board where they are participating. They must also be knowledgeable about the issues. If they are not they must be willing to take the time to become more informed. “Participation has meant everything from sharing power or complete citizen control of the decision-making process to no redistribution of power and the public’s being “educated” or “consulted with”. Others consider it to be, any legitimate involvement by the public in the health care planning processes, whether the goal be information exchange or shared decision-making.”⁹⁹ There are a number of different frameworks for public participation that are suggested in the literature. It is worthwhile to review some of these.

Sherry Arnstein has developed a model of participation. It is referred to as Arnstein’s Ladder of Citizen Participation. The levels of participation and their explanation follow.

⁹⁸ Canada Health Action: Building on the Legacy, Synthesis Reports and Issues Papers, (Volume II of the Final Report) (Ottawa:National Forum on Health), p.5.

⁹⁹ Gail MacKean and Wilfreda Thurston, “A Canadian Model of Public Participation in Health Care Planning and Decision Making”, in Efficiency vs Equality: Health Reform In Canada Michael Stingl and Donna Wilson eds., (Halifax: Fernwood Publishing Co. Ltd., 1996), p.55.



The bottom rungs of the ladder are (1) Manipulation and (2) Therapy. These two levels describe levels of “non-participation” that have been contrived by some to substitute for genuine participation. Their real objective is not to enable people to participate in planning but to enable power holders to “educate” or “cure” the participants. Rungs (3) Informing and (4) Consultation progress to levels of “tokenism” that allow the have-nots to hear and have a voice. When they are proffered by power-holders as the total extent of participation, citizens may indeed hear and be heard. But under these conditions they lack the power to ensure that their views will be heeded by the powerful. When participation is restricted to these levels, there is no follow through, no “muscle”, hence no assurance of changing the status quo. Rung (5) Placation, is simply a higher level of

tokenism because the ground rules allow have-nots to advise, but retain for the power holders the continued right to decide. Further up the ladder are levels of citizen power with increasing degrees of decision-making clout. Citizens can enter into a (6) Partnership that enables them to negotiate and engage in trade-offs with traditional power holders. At the topmost rungs (7) Delegated Power and (8) Citizen Control “have not” citizens obtain the majority of decision-making seats, or full managerial power. This ladder helps to illustrate the point that so many have missed – that there are significant gradations of citizen participation.”¹⁰⁰ This model was developed in the 1960s in the United States and used in urban renewal programs. If this model was emulated by the Canadian public to set goals for their level of participation, it would pose obligations on the part of the government and the citizens to achieve the topmost rungs. The public would have to become far more informed about the issues. It would also require representatives of the public to become aware of the concerns and opinions of the group that they represent. Is this possible in all areas of health care policy development and implementation? It is not likely and may not even be desirable by the public on every issue. Certainly, the upper most rungs should be the goal set for the level of participation of the individual citizen in the doctor-patient relationship. However, in other situations perhaps the level of participation achieved might be lower and yet acceptable to the group being represented. Perhaps the best policy process would include a cross-fertilization of

¹⁰⁰ Sherry R. Arnstein, “A Ladder of Citizen Participation”, in Journal of American Institute of Planners (July, 1969), p.217.

ideas, “expert” opinion with public values and concerns, and no one group having “control”.

MacKean and Thurston contend that there are five social factors that determine how far up the ladder of participation the public will be able to climb in any given situation. These are: the context of public participation, the characteristics and support of public participants, the characteristics of change, the goals and objectives of public participation and the characteristics of participatory techniques. The authors feel that the health care sector does not provide a social climate which encourages public participation. This has occurred because of the traditional view of the patient as compliant, willing and passive. However, they feel that if an institution has had a history of supporting and involving the public then they will respond to increased public participation in decision-making. They note that public participants need particular skills, experience and knowledge to maximize their impact on the health care organization. They also need a mandate from the users or the community that they are drawn from. Next, they examine the characteristics of change and note that decentralization of the system opens up more opportunities for public input, as the decision making becomes closer to the community. The authors have developed six goals of public participation that coincide with the top six rungs of Arnstein’s ladder: informing the public, consultation with the public, the public acting in an advisory capacity, decision-making in partnership with the public, delegated power through decision-making to the public, and public control. They review a number of participatory techniques that are used to meet the broad goals that they outlined. These are:

Informing: hold agency information meetings, develop printed materials, establish information repositories;

Consultation: hold neighbourhood or public hearings, hold focus groups, hold workshops;

Advising: establish advisory committees, review boards or task forces;

Partnership: establish review boards, regulatory boards, planning committees, coalitions with members of the public and the powerholders;

Delegated Power: establish semi-autonomous community health boards, councils or coalitions;

Citizen Control: establish autonomous community health boards, councils or coalitions.¹⁰¹ This comprehensive model of participation is a helpful framework to use when examining the various ways citizens do get involved in the health care policy process. It does not negate any form of participation but does suggest factors that would make it more effective. It also stresses the importance that not all policy situations need one group to be totally dominant. The public's input to the decision-making process can change and shape the "balance of power" between the experts and the policy-makers. This framework also shows the need for the public participants to become educated and informed about the issues and the health care delivery system. In order for the public to participate effectively it takes commitment on the part of the individual citizen, the institution and the government. Without that support public participation will not be validated.

¹⁰¹ MacKean and Thurston, *ibid.*, p. 55-67. A complete review of their model of participation is discussed and they provide a case study to demonstrate their points.

Julia Abelson and Jonathan Lomas from the Centre for Health Economics and Policy Analysis, McMaster University have developed a systematic approach to involving the public in community decision-making. They developed their approach by analyzing the health care restructuring process that occurred between 1994 and 1996 in three Ontario communities. They note that the first step in any public participation exercise is to identify the objectives for involving the public. They note that “framing participation in a power-sharing context, as Arnstein’s normative depiction does, is as much about the goals of participation, as the activities involved. A simpler way of characterizing the public’s role is to ask whether the intent is to give members of the public a “voice” or a “choice” in the decision-making process. Giving them “voice” is synonymous with consultation exercises where the public’s input is advisory. In contrast, giving the public “choice” means its role is decisive and it takes responsibility for the final decision(s). The general public, at least in Ontario, seems largely content to have voice while leaving the final choice to others. The presentation and dissemination of information is the principal vehicle used to both encourage public participation and elicit informed input.¹⁰² Their systematic approach to facilitate public input to community decision-making involves identifying:

- . the objective and context of participation;
- . which publics are to be selected for participation and how will they be selected;
- . what information will be presented and how;
- . how the public will be asked to participate over what time period; and

¹⁰² Julia Abelson and Jonathan Lomas, “In Search of Informed Input: A Systematic Approach to Involving the Public in Community Decision Making”, in Healthcare Management Forum (Winter, 1996), Volume 9, No. 4, p.48-49.

. what input the public will be asked to provide.

Being clear about the objectives for involving the public at the outset, and paying careful attention to the compatibility of different elements in the process, are two important considerations.¹⁰³ The authors describe all of the elements to be considered in the process of encouraging public participation, yet note that there is “no magic formula” for involving the public. In some instances perhaps having a voice is enough while in others having a choice is more important. This may depend on how close the decision taken will affect the participants. They also note that the context within which the community is being asked to participate drives other elements of the process. By context they mean, is the public participation taking place for forward planning or crisis management? The other factors which influence public participation are: selection of the representative of the public; the participation timeline; the participation medium i.e. meetings, telephone interviews; the information available; and the content i.e. assumed resource constraint, technical vs. non-technical.¹⁰⁴

In reviewing the three previous frameworks for participation it becomes obvious that the level of participation will be different depending on the issue. There are times when it appears more appropriate that the public be contributing equally with the experts and other times when they are participating as consultants or bringing one more point of

¹⁰³ Abelson and Lomas, *ibid.*, p. 51.

¹⁰⁴ This comprehensive approach to all of the elements that affect public participation are described in the article which resulted from their study of health care system restructuring in three Ontario communities. The study was done using interviews, document review and newspaper content analysis. Abelson and Lomas, “In Search of Informed Input: A Systematic Approach to Involving the Public in Community Decision Making”, in Healthcare Management Froum, Volume 9, No.4, (Winter, 1996), p.48-52.

view to the discussion. Often the members of the public bring ethics, social values, and personal experience, as well as, some common sense to the technical discussion.

2. Who is the Public?

When examining community participation and public participation, who is considered the community? In some areas in Canada the population is homogeneous, while in others, there is a great deal of ethnic, cultural and religious diversity in a fairly small area. A community has been defined as: “a group of people living in the same area and sharing the same basic values and organization; a group of people sharing the same basic interests at any given time; or a group of people targeted for interventions by a service provider, indicating a common need for things such as maternal health or accident prevention.”¹⁰⁵ However Labonte points out that, “not all neighbours have the same interests, and affinity (shared values, concerns) is an equally important aspect of community. Communities cannot be defined demographically – a common error committed by health planners. Community exists when individuals with a shared affinity, and perhaps a shared geography, organize.”¹⁰⁶ The public is being asked to participate in many different ways in many different areas of health policy. Individuals, as well as, communities are being asked to take part in health prevention and promotion projects.

¹⁰⁵ W. Bichman, S.B.Rifkin, M.Shrestha, “Toward Measurement of Community Participation” in World Health Forum, 1989; 10(3/4) p.467-472.

¹⁰⁶ R. Labonte, “Health Promotion: from concepts to strategies”, Healthcare Management Forum, 1988;1, p.24-25.

Canadians are being asked to get involved in various aspects of health care policy. As citizens we have many rights, this is particularly obvious in the area of health care. What is our obligation as citizens? Why has public participation become so important in the area of health care policy?

The Canadian government is encouraging citizen engagement. In their paper titled, *Talking with Canadians: Citizen Engagement and the Social Union*, prepared for the Canadian Council for Social Development, the authors examine the Canadian experience with citizen engagement. They note some key issues which are important to all public policy, but are relevant particularly to health care policy.

“In this complex policy environment, the federal and provincial governments face exceedingly difficult choices concerning how to balance social policy responsibilities and public expectations with new fiscal realities and delicate political relationships within the federation. It is increasingly suggested that the complexity of the task of resolving the many problems now facing society is beyond the capacity of governments alone to address. The goal of better public policy will be better served through a more integrated and holistic approach than in the past, one that combines the efforts of governments and those outside government ---- including citizens.”¹⁰⁷

Who participates and how to encourage participation are major issues to address? Public participation should encourage the development of policy that is more appropriate and responsive to community needs, provide the opportunity for an exchange of ideas and create a more democratic society. Hopefully, by enabling the public to become involved they will be more accepting of the final product, particularly if all of the ideas and options have been discussed openly and there has been a true exchange of information

¹⁰⁷ Frances Abele, K. Graham, A.Ker, A. Maioni and S.Philips, Talking with Canadians: Citizen Engagement and the Social Union. (Ottawa: Canadian Council on Social Development, 1998), p.9.

and opinion. “Better public policy requires better public participation processes. Involving stakeholders at the beginning of policy development helps to distribute and promote ownership and commitment. This is essential, considering resource constraints, fiscal pressures and the complexity of issues.”¹⁰⁸ There are a number of ways that the public has participated in the past. Participation has become so important in the area of health care, that some provincial governments are actively seeking and selecting participants for advisory councils and boards of institutions and regions and some, like Quebec and Saskatchewan and British Columbia have legislated a place on the boards for public representatives.

In the past decade, the terms used to describe the citizen have changed. At times this has been done to change perceptions and imply a different, evolving more responsible and equal role in a relationship. This has occurred at many levels of the policy process. Citizens are referred to as taxpayers, stakeholders, clients, customers and consumers. Much of this is a result of the private influence on public management and the need to show that these citizens were valued and listened to. The ‘changed’ terminology in the area of health care was first introduced to emphasize the fact that the relationship between the individual, formerly known as the patient, was now considered an equal and contributing member of the health care team. The individual had rights but also obligations to take an active part in the decision-making process surrounding his own treatment. What’s in a name? Does a change in terminology automatically determine

¹⁰⁸ Peter Sterne, Public consultation Guide: Changing the Relationship Between Government and Canadians. (Ottawa: Canadian Centre for Management Development, 1997), p.2.

the way that person will behave or the way others will interact with him. In a public forum does the citizen, taxpayer or stakeholder get involved in the same way as the patient, client or consumer? Often how people choose to refer to themselves has an effect on the way they choose to carry out a role and to take part in the policy process. By the same token, the term that the institution or government uses may affect the role that the individual will play and how valued their contribution will be to the process. "It is a symptom of the crisis of citizenship in the 1980s that most political rhetoric, whether of the left or the right, addresses the electorate not as citizens but as taxpayers or consumers."¹⁰⁹ Is the use of this terminology appropriate when trying to engage the public in the policy process or at another more micro level trying to encourage them to monitor and improve health services? Leslie Seidle notes that,

"the use of the terms client, customer, consumer do not fully capture the nature of the interaction that occurs when a public sector employee serves someone who is among other things a taxpayer, a voter or a member of one or more voluntary organizations with an interest in public policy.The term "customer" is particularly unsatisfactory in the sense that the user of a public service, unlike the exigent shopper, often cannot choose another provider. Another advantage of the expression "citizen" is that it ought to remind us that those who receive services from the public sector also have responsibilities: for example... to cooperate with those charged with assessing levels of satisfaction and identifying improvements respecting the substance of public policy and measures for its delivery. A leading Australian scholar, Anna Yeatman has described the relationship between service deliverer and recipient as one of "coproduction", in which "the delivery of the service depends on the intelligent judgement and responsible commitment of both parties."¹¹⁰

¹⁰⁹ Michael Ignatieff, "The Myth of Citizenship", in Queen's Quarterly, Volume 94 No. 4 (Winter, 1987) p.981.

¹¹⁰ F. Leslie Seidle, Rethinking the delivery of public services to Citizens.(Montreal: Institute for Research on Public Policy, 1995) p.9-10.

These statements are extremely relevant to health care service delivery and health care policy.

The terms such as consumer or customer are not appropriate to health care in Canada, although many would disagree. The terms patient and citizen are far more useful in that they capture the roles at both the micro and macro levels. It also implies that rights, obligations and responsibilities exist. Bob Rae makes an important distinction between consumers and citizens with respect to health care. “We are all sometimes consumers of the health care system and when we are, the evidence suggests that we act in our own interest as energetically as possible. We are strong advocates on behalf of ourselves, our children our families and our communities. As consumers, we drive the health care system, continually forcing improvement and demanding better quality. As citizens, we make choices based on a broader sense of what the public interest and good are. The more public these processes become, the better off we all are. Politicians would be very happy to devolve responsibility for choices to citizens at a local level, because they want to share difficult decisions. Consumers may say “We need this now,” but citizens are needed to say, “Okay, but then we have to choose between this and that.”¹¹¹ Difficult choices have been made and will continue to have to be made. One of the main reasons that all levels of government are encouraging more public participation is that increasingly scarce resources mean difficult decisions have to be made. In examining the institutional boards which have been put in place in Quebec, with two members from the

¹¹¹ Bob Rae, “Health Policy in the Consumer Era” in Do We Care? Renewing Canada’s Commitment to Health (Montreal: McGill-Queen’s University Press, 1999), p.90.

users' committee and four members representing the public, one would hope that the balance that Bob Rae suggests is necessary might be achieved.

John Ralston Saul, in his discussion about Health Canada's recent document titled "Shared Responsibility, Shared Vision", notes that, "partners and other stakeholders are invited to join in the discussion". He comments that, "there is no suggestion anywhere in the document that health care is something that actually belongs to the citizens. Rather, it belongs to the stakeholders. The whole notion of stakeholder is based on a corporatist dictate that the only time citizens can claim a seat at the table is when they are interested parties. Not by virtue of being a disinterested citizen, but by virtue of being an interested party engaged in interest mediation. At every level the debate has been reduced to deciding what roles various stakeholders should play. At this level the citizen is reduced to consumer."¹¹² Future decisions about public policy can not be driven by a consumerist approach. This is true not only in the area of health care but also about education, the environment and industrial policy as well. There are many ethical implications that should be part of public policy debates. These are not often brought to the table by the customer or stakeholder. Timothy Caulfield, a professor of law at the University of Alberta, cautions about taking a consumer approach when developing policy that relates to new biotechnology.

"What we are hearing is the rhetoric of consumer empowerment and consumer choice, which stresses the maintenance of consumer confidence and national competitive advantage. These are all important issues, but they do not encourage an ethical basis for health policy. Given the clinical

¹¹² John Ralston Saul, "Health Care at the end of the Twentieth Century: Confusing Symptoms for Systems", in Do We Care? Renewing Canada's Commitment to Health. (Montreal: McGill-Queen's University Press, 1999), p.16.

potential of biotechnologies and the billions of dollars at stake, industry and government do not want to get bogged down in health ethics discourse. However, while the market's invisible hand may be an ideal guide for market efficiency and even technological innovation, developing meaningful ethical health policy demands something more. Ethical health care policies result from community involvement and sometimes require placing public good above individual desires."¹¹³

New medical technology and drug therapy have caused the cost of health care to soar in the past decade. The appropriate use of these therapies will have to be decided. Neither in our role as patients or citizens will we be able to make those decisions alone but we should certainly have a say in policies that are developed around their use. It is our right as patients and citizens to participate. Involvement leads to a broader understanding of all of the issues, medical, ethical and economic. This will benefit the citizens as well as the government.

Some associations have decided that the presence of a lay person on their board would benefit their association and the community. However, they have had a difficult time identifying "who" or "what" is a lay person. The Royal College of Physicians and Surgeons of Canada and the National Council on Ethics of Human Research have established that they feel that the presence of a lay person would bring an added perspective to their deliberations. A tri-council policy statement involving the Medical Research Council of Canada, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council of Canada recommended in "Article 1.3 (d) that the Research Ethics Boards (REB) consist of at

¹¹³ Timothy Caulfield, "Tensions in Ethics Policy: The Consumer vs the Citizen", in Do We Care? Renewing Canada's Commitment to Health. (Montreal: McGill Queen's University, 1999), p.119-120.

least one member that has no affiliation with the institution, but is recruited from the community served by the institution. The community member requirement is essential to help broaden the perspective and value base of the REB beyond the institution, and thus advances dialogue with, and accountability to, local communities.¹¹⁴ Each of these associations is having a hard time finding a representative from the community, someone who does not represent an interest group or a business group. They are looking for a lay person who represents the public's interests. This is a recurring theme when examining the issue of public participation. Who represents the public? Who is best able to represent the "public interest"? The public interest changes from one situation to another, which also makes it more difficult to identify someone who is able to speak to all of the issues while representing the majority of the public. Add to this equation the need to find a representative who is articulate, informed about the issues and has the confidence to actively participate in the discussions with the physicians, researchers and academics.

The public is being compelled to participate in the health care policy arena. This is occurring at different levels of the policy process and in different contexts. In some situations members of the public are being elected to boards and at others they are being appointed. Canadian citizens are also joining voluntary associations and interest groups in order to promote and educate the public about particular health related topics. In each situation the requirements for effective participation are different and the expectations of

¹¹⁴ Tri-council Policy Statement, Ethical Conduct for Research Involving Humans. (Ottawa: Medical Research Council of Canada, 1998), p.1.4.

the public representative are varied. Are representatives of the public up to the challenge of making health care decisions for the community?

CHAPTER IV

Public Participation: What are the Venues?

In the past decade attempts have been made in health care to balance the influence of the payer, the provider, the community and the patient. This has placed more responsibility on the part of individuals to participate and governments to facilitate that participation. Public participation has been more effective in some situations and not in others. Where and why the public participates affects the way the public participates.

1. Provincial Health Care Reform: The Need for More Public Participation

The federal and provincial governments have initiated processes that have encouraged and enabled public participation in the reforms to their health care systems.

“The main vehicle for reform has been a change in the governance structure through devolution of authority for decision-making from the provincial governments to regional, district or local bodies. Most reform proposals have involved widespread calls for increased citizen, public or community participation as an instrument for achieving the objectives or as an objective in itself. One of the stated purposes for establishing community-based structures is to give individuals decision-making authority. Full participation is often equated with citizen control over decision-making.”¹¹⁵

What are the various ways that the provincial governments have enabled public participation?

¹¹⁵ J. Abelson, J. Lomas, J. Eyles, S. Birchard G. Veenstra, “Does the Community Want Devolved Authority? Results of Deliberate in Ontario” in Canadian Medical Association Journal, August 15, 1995;153(4), p.403.

In every province, except Ontario, the provincial governments have introduced regional structures that have placed the locus for authority and accountability for health care services closer to the populations they serve. All of the provincial reports, which were the results of the forums, task forces and commission that were held in the past decade, emphasized the same themes. They were: “containing costs, increasing the efficiency and effectiveness of health care, enhancing the responsiveness and accountability of the system through decentralized decision-making, and facilitating citizen participation.”¹¹⁶ In Quebec, for example, two reports were produced as a result of the Rochon Commission. *Improving Health and Well-Being in Quebec*, in 1989 and *A Reform Centred on the Citizen* in 1990. These resulted in legislation, Bill 120, which provided for regional boards and the representation on those boards, as well as institutional boards.

“Some of the provinces have introduced two tiers, an upper regional tier and a local tier of devolved governance; others have introduced only a regional tier. Broadly speaking, the provinces can be divided into two groups on the basis of maturity of their implementation. Of the 5 provinces in which authorities are more established, Quebec, New Brunswick, Saskatchewan and Prince Edward Island started implementation before 1994, and Alberta implemented its authorities so rapidly that the tasks being performed by the boards reflect greater maturity. Of the 4 provinces in which authorities are immature, Newfoundland, Nova Scotia, and British Columbia have complete initial implementation, and Manitoba has started it. Devolved authorities are granted their powers from 3 sources. The provincial government gives them legitimacy by formally devolving powers to plan and to allocate provincial funds. From local health care providers and institutions they acquire to procure management rights to reorganize and reform service delivery. From the local and regional population have come their

¹¹⁶ John Church and Paul Barker, “Regionalization of Health Services in Canada: A Critical Perspective”, in *International Journal of Health Services*, Volume 28, Number 3, 1998, p.469.

credibility and mandate to represent the citizens' needs, wants and preferences."¹¹⁷

Many of these board members are appointed by the province, but in Saskatchewan, Quebec, British Columbia and Alberta some of the members are elected. It is hoped that these regional structures will facilitate coordination and planning of health care services.

The Saskatchewan report titled, *Working Together Toward Wellness A Saskatchewan Vision for Health*, states

“to achieve a community-based model for health services, the Department of Health requests that communities join together to create health districts with a population of approximately 12,000 people. Each district will have a single board for a full range of health services. Initially the home care, long-term care and acute care and ambulance services will be most directly affected. However, the districts will be responsible for planning all health services. The legislation titled *An Act respecting Health Districts*, article 7 states the residents of a health district shall elect eight members to the health district board.”¹¹⁸

In Quebec some members of the regional board, as well as community organizations and hospitals are also elected. “The elected members of the board of directors of the regional boards must live in the territory covered by the board, be at least 18 years of age and derive no income from a network establishment, the board itself, the Department, the Regie de l'assurance maladie du Quebec or a community or private organization providing health care and social services. The elected members of the board of directors must first belong to the electoral college of that regional board.”¹¹⁹ These

¹¹⁷ Jonathan Lomas, John Woods and Gerry Veenstra, “Devolving authority for health care in Canada's provinces: An introduction to the issues”, in Canadian Medical Association Journal, February 1, 1997;156(3) p.372-374.

¹¹⁸ Saskatchewan. *Working Together Toward Wellness: A Saskatchewan Vision for Health*, “A Health District Development Guide”, Regina, 1992, p.2, and *An Act respecting Health Districts*, p.5.

¹¹⁹ Quebec, “Improving Health and Well-Being in Quebec”, April 1989. Gouvernement du Quebec, *Ministere de la Sante and des Services sociaux*, p.103.

boards in cooperation with the establishments and community organizations in their territory are responsible for planning and coordinating health and social services; and for the allocation of budgets to the establishments and community organizations. They are also responsible for the evaluation of the regions overall budgetary performance. Quebec also passed legislation that required that at least 4 members of the boards of institutions to be elected to represent the public. Citizens have been given the opportunity to have input into the decision-making process in the institutions in their communities. In Chapter 3, Article 132 states,

The board of directors of an institution which operates a hospital shall be composed of the following persons, who shall be members of the board as and when they are elected or appointed:

- (1) four persons elected by the population at a public meeting;
- (2) where applicable, two persons elected by members of the users' committee of the institution;

Article 170 states, the board of directors shall manage the affairs and exercise the powers of the institution.

Article 171 states, the board of directors shall establish priorities and orientations for the institution and see they are observed.¹²⁰

Through this legislation the Quebec government not only gave rights to individual users but also to the community. It appears that by the process of representative democracy the government wants the community to set policy in response to their own needs. The institutional boards are responsible for the planning and provision of services and monitoring of budgets within the hospital, while the regional boards are responsible for the same things at the next level. In the institutions the board members are not responsible for the micro-management of the institution but take part in the broader

¹²⁰ Bill 120, *ibid.*, p.45.

decision-making process which sets the priorities, according to the needs of the community it serves. If citizens feel properly represented perhaps there will be less focus on competing interests and rights. It seems that public institutions with input from members of the public would promote the interests of the community while still being able to focus on the health rights of the individual user. One can be hopeful that this type of “hands-on” involvement might establish a better moral framework for decision-making than only focusing completely on individual rights. If citizens, who are elected to represent the public, can sit side-by-side the health care professionals and administrators and contribute to the policy process at an institutional and regional level, hopefully, the values, priorities and preferences of the community will be reflected. As previously noted, there is a problem deciding who represents the community. Another major stumbling block occurs when trying to identify to whom is this representative accountable. In a recent interview the Auditor-General of British Columbia commented that appointment to the boards and councils had been based on gender, ethnicity and regional concerns rather than expertise, and he also expressed concern about the boards’ lack of accountability.¹²¹ In his review of the new provincial reforms, Jonathan Lomas has found that many appointees are not sociodemographically representative of the communities they are representing. It is doubtful that these board members reflect the views of the community they represent. The public feels that an election adds a certain amount of legitimacy to the process. However, there has been some concern expressed that elected members usually represent particular interest groups. In a survey conducted

¹²¹ Lynn Haley, “Regionalization: Closer to Home or Farther from Care?” The Medical Post, November 23, 1999, p.35.

by health care policy experts at McMaster University, the results showed “that 50% of the members of the boards of the devolved authorities felt constrained by their provincial governments.”¹²²

Another characteristic that is common to many of the provincial reforms is “the desire to evaluate the types of outcomes that are produced by the health services”.¹²³ This information will then provide the basis for future resource allocation. The government is also promoting the concept of evidence-based medicine and is calling on the health care professionals to do studies that produce this information in order to further plan health service delivery. The provincial governments are hoping that the increased participation of the public and citizens’ interactions with the experts will produce responsible, responsive health care policy.

In some regions of the country there is a void in the newly created system. In British Columbia, for example, where 60% of the health care budget is administered by 11 regional boards and 34 community health councils there are only 8 functioning medical advisory councils. As was noted earlier in this paper Maurice Leclair, a former deputy minister of health had expressed the opinion that the problems with Medicare may have been avoided if the health care participants, the providers and the consumers had participated in the decision-making. Health care policy decisions should not be taken at any level without input from many sources representing as many of the opinions as

¹²² Jonathan Lomas, *ibid.*, p.819.

¹²³ Church and Barker, *ibid.*, p.472.

possible. If one group does not participate in the decision-making process then they will be less likely to buy into the decision taken, especially physicians. “Regionalization of health care in British Columbia is so unpopular among physicians it is driving some to ignore or circumvent provincial regulations.”¹²⁴ Many physicians felt that money was being wasted to create new administrative positions to run these regional boards. As we have seen the development of health care policy is becoming more complex. It requires getting consensus on the issues and not leaving a particular opinion unaddressed.

Citizens are also being asked to serve on advisory committees that examine a particular issue in their community. In one particular case, the Minister of Health of Alberta requested that two public representatives be included on a working group whose mandate it was to review the findings of a report that had made recommendations concerning the regional restructuring of the acute care hospitals in Calgary. Four groups were formed to examine the issues, however public participation was suggested for only one group, the working group that was to review the closure of a pediatric hospital in Calgary. In order to do this it was suggested that pediatric services be incorporated into one of the adult acute care institutions. The two members representing the public were also members of the parent advisory committee of the Alberta Children’s Hospital. The two public participants commented that “the pressure to view issues from this second perspective was sometimes very intense, and the experience was one of the most stressful that they had undergone.”¹²⁵ When representing the public the situation becomes far more

¹²⁴ Pat Rich, “B.C. docs largely ignoring regional health boards”, in The Medical Post, July 20, 1999, p.41.

¹²⁵ MacKean and Thurston *ibid.*, p.64-67.

difficult to put in terms of positive or negative impacts, or failures and successes. As was discussed, there are many factors which affect the level of public participation in decision-making. As the framework suggested by both Abelson and Lomas, and Thurston and MacKean points out one of the first things to consider is the context in which the public is being asked to participate. For example, in the case mentioned by MacKean and Thurston two public representatives were asked to join the committee at the last minute. In the whole restructuring process four committees had been formed. The only one that had any public participation was the one that had received the most media attention and the one deliberating about the most politically contentious issue, to move pediatric services to an adult acute care institution. In this situation the two representatives ended up submitting a minority report to accompany the working group report. "Although they had agreed to most of the report, they were unable to support the conclusions with respect to the effect on quality of care of a move to another site."¹²⁶ If the public is being asked to get involved with issues as a means "of putting out a fire" or as a public relations exercise, this cannot be considered participation. However, if the public is participating on an ongoing basis as a member of a health council or district board his presence is validated by the provincial legislation and he is expected to have a role in the planning process.

A member of a board or council, who is representing the public, can only be effective in the decision-making process if he is knowledgeable about the issues. This information is often made available through the administrators in the institutional or regional structure. Often the public representative can only be as informed as much as the

¹²⁶ MacKean and Thurston, *ibid.*, p.67.

institution wants him to be. Knowledge and information are necessary first steps to ensure that public participation is valued and will lead to empowerment for the community. Yet these members may feel as though they are in a conflict if the board's objective is efficiency and they are concerned about continuing to provide a needed service to the community. One of the main reasons for regionalization was to ensure the efficient and effective use of resources. Some of the main reasons for public participation were empowerment and self-determination of the community. There are a number of conflicting issues to be addressed while hoping to promote public participation in developing health care policy.

2. Citizen Participation: One Individual's Experience

As a board member I participated in a number of projects where I felt that there was a place for a public voice. In one instance, I was mandated by the Board to be their representative to examine issues brought to the Board's attention by members of the executive of the union, that represented the kitchen and housekeeping staff. The union was having difficulty working with the contracted management firm that was hired to manage these two services. The union felt that adequate funds had not been allocated to keep the hospital clean. After meeting with 38 employees and members of the management company and union executive, I filed my report with the Board. Some changes were made to improve the working conditions, old equipment was replaced and job descriptions were more clearly defined. When the contract was up with the management firm it was agreed that the next one would go to tender. Issues like this one

can not only affect the cleanliness of the hospital but also the hospital morale. This in turn has an effect on the patients and families. I was given the responsibility of serving as chairman of the hospital's Quality of Care and Services Committee. The hospital had a strong commitment to continuous quality improvement and monitored many of the activities that when on in the institution. This committee was mandated:

“to monitor the quality management programs of the hospital that integrate various elements contributing to quality but not limited to, quality assurance, risk management, patient satisfaction, safety and security; to evaluate performance indicators to ensure they reflect the quality of patient services; to receive regular reports on quality management programs from all medical, clinical, support and administrative departments and services; and to review significant incidents to ensure that department/service action plans are designed and implemented to address these incidents.”¹²⁷

We reviewed such issues as the evaluation of the impact of day surgery, the services available in the Geriatric Day Hospital and educational programs available to dialysis patients among many others. These were some of the services that had been reorganized in an attempt to deal with the “virage ambulatoire”. The hospital was developing mechanisms to improve efficiency and adapt to the system. It was important that these services as well as others be monitored in order to ensure that the patients continued to receive the appropriate services.

¹²⁷ The Quality of Care and Services Committee, Royal Victoria Hospital, 1992.

3. The Public: Members of Interest Groups and Volunteer Associations

There are many individuals in Canada who also participate and hope to influence the health policy process by becoming members of public interest groups. They often join these groups because they feel strongly about a particular cause or they, or a member of their family, has been affected by a specific disease. These groups have their own objectives and health policy agenda. These groups hope: to educate the public about a particular disease; to raise awareness not only about the disease but also about the needs of those who suffer from it; to lobby the government to allocate more resources for treatment, services and research. There have been some very powerful groups who have had a great deal of success in being heard and being given more resources. The public and the government is much more aware of the needs of people who are HIV positive and who have breast cancer than they are of many other disease related groups in Canadian society.

“A “public” interest group is defined as a group whose members act together to influence public policy in order to promote their common interest and whose objective is to benefit people beyond their own membership. In contrast to economic or business associations, their intentions are not centred upon providing direct economic benefit to their members. Membership is voluntary and relatively open such that anyone may join the group.”¹²⁸ Some of these interest groups have been very powerful lobbyists and

¹²⁸ Susan D. Phillips, “How Ottawa Blends: Shifting Government Relationships with Interest Groups” in How Ottawa Spends The Politics of Fragmentation 1991-92. Frances Abele ed., p.215.

changed the way the public and the government sees them. The breast cancer lobby has become more vocal over the past few years. Sharon Batt in her book, The Politics of Breast Cancer Patient No More states, “We have much to learn from AIDS activists. We must educate ourselves about the disease, about the amount of money that is spent on it, and about the policies that govern where that money goes. We must ask why the cause of breast cancer is still not known after all these years. We must voice our anger about the thousands of women who die each year of breast cancer.”¹²⁹

Many of the health related interest groups have had an influence on health care policy both nationally and provincially. They have made presentations to the Royal Commission on New Reproductive Technology, the Senate Special Committee on Euthanasia and Assisted Suicide, and the Standing Committee on Health, Organ and Tissue Donation and Transplantation as well as many others in the past decade. “In the politics of the 1990s, interest groups are placing increased pressure on Ottawa to blend their demands into the policy process. The federal government is not just a passive recipient of interest group demands. Rather, government departments shape the opportunities for certain groups – and not others – to participate in the policy-making process by creating mechanisms for public consultation. In addition, the federal government has a long-standing practice of providing funding to public interest groups so they may organize their constituencies and represent their concerns.”¹³⁰ Often these interest groups can help inform policy by their expertise. Other voluntary agencies, which

¹²⁹ Sharon Batt, The Politics of Breast Cancer Patient No More (Charlottetown: gynergy books, 1994), p.27.

¹³⁰ Susan D. Phillips, *ibid.*, p.184.

rally around specific illnesses, have had a major impact through public awareness and fund raising. Individuals with diabetes or other chronic illnesses often are very knowledgeable about the disease and information related to it. Some of these groups have identified the resources to develop information and education packages that present their cause to government as well as the public. "For many voluntary agencies, power and role are as great as the fervor and size of their supporters, which can be considerable, as demonstrated by the success with which the Alzheimer's society and the advocates for the physically disabled changed public and government perceptions, policies and spending.¹³¹ Members of these groups have a very strong commitment to their cause. However, there are other groups that are not as well funded or organized and have a much more difficult time being heard at the policy level. These groups serve many roles in health care policy debates.

4. The Public as Consultants, Partners and Educators

Some of these social sector organizations form partnerships with government and improve services to a particular segment of society. This enables them to have input into the development of or make changes to public policy. For example, "in 1992, one such group in New Brunswick had developed a project to demonstrate the effectiveness of enhanced community and health services to support seniors in their homes; and to test a model of assessment to determine eligibility for community long-term care and nursing

¹³¹ Ralph Sutherland and Jane Fulton, Spending Smarter and Spending Less Policies and Partnerships for Health Care in Canada. (Ottawa: The Health Group, 1994), p.78.

home services. In 1993 the project became a program, and by early 1994 it had been extended to the entire province.”¹³² These social organizations promote public participation often at a level very close to the community. Their volunteers are well aware of many of the issues and are extremely valuable when reviewing health service delivery.

Some of these agencies, at times, work closely with the government. For example, the Quebec Palliative Care Association was contracted by the Minister of Health and Social Services to do a needs assessment in the area of palliative care in Quebec. They have been conducting written surveys as well as holding focus groups. They will then make recommendations to the government concerning the needs of patients in need of end-of-life care. When the public (citizens which include health care professionals, volunteers patients and families) gets involved there should be more opportunity to develop patient-centred approaches to health care policy. Often these kinds of associations are more in touch with the issues than any institution as they get a broad perspective from their membership and allied health professionals.

“Parliament is becoming a more important target for interest groups. Although some MPs may subscribe to the argument that Parliament has been “captured” by interest groups, the more prevalent view is that interest groups make a useful

¹³² F. Leslie Seidle, Rethinking the delivery of public services to Citizens, *ibid.*,p.149-151.

contribution by providing information, proposing policies and providing reaction as to whether legislation and regulations will be workable.”¹³³

Health care professional associations have an obligation and a responsibility to lobby the government. The Canadian Medical Association, the Canadian Nurses’ Association and others have advocacy as one of their mandates. They should be addressing the social issues as well as the health care issues as they are often so closely linked. It is necessary for them to participate as groups but also as individuals in the policy process.

Many members of the public either individually or represented by a group have made presentations to committees who have recently reviewed some of the controversial issues in health care policy. The Royal Commission on New Reproductive Technologies heard public submissions from 1990-1992. During that time they “sampled the views of 40,000 Canadians.”¹³⁴ The final report called for federal legislative action as one of its major recommendations. The prohibitions reflect Canadians’ views.

The special Senate Committee on Euthanasia and Assisted Suicide “received thousands of letters and detailed briefs from concerned people and professionals. The Report is an initial step in the long process ahead for Canadians

¹³³ F. Leslie Seidle, “Interest Advocacy through Parliamentary Channels: Representation and Accommodation”, in equity & community the charter, interest advocacy and representation, F. Leslie Seidle ed., (Montreal: The Institute for Research on Public Policy, 1993), p.214.

¹³⁴ New Reproductive and Genetic Technologies Setting Boundaries, Enhancing Health (Ottawa: Minister of Services and Supply, 1996), p.25.

attempting to find solutions to the problems it raises. The manner in which we, as a society, respond to these problems will have a significant impact on the lives of all Canadians and will reflect on Canadian Society as a whole for many years to come.”¹³⁵ These comments are particularly interesting because some of the recommendations made are directly related to health care policy development. One set of recommendations revolved around the issues of palliative care: the need to make it a top priority in the restructuring of the health care system, the need to develop and implement national guidelines and standards, and that research in the areas of pain and symptom relief be expanded and improved. Another recommendation addressed the issues of pain control and sedation practices. Some of the recommendations were: to expand and improve the education and training of health care professionals with respect to pain control, and to develop guidelines and standards for the provision of treatment for the purpose of alleviating suffering where that may shorten life. The committee recommended that the prohibition against euthanasia continue.

Both of these reports made recommendations based on the opinions of thousands of Canadians and both of these reports have implications for health policy. There are a number of ways to prevent some of the causes of infertility, it will be up to the public to decide if it is a reasonable use of resources to educate the public about prevention. In order to offer patients an alternative to euthanasia we must be able to offer them good palliative care which will provide patients with pain and symptom relief. This

¹³⁵ Proceedings of the Senate Special Committee on Euthanasia and Assisted Suicide, (Ottawa: Canada Communication Group – Publishing, May 31, 1995), p. 2.

will require more resources as they are not many well developed palliative care programs in Canada. However, once the public has encouraged the government to adopt specific recommendations what is the responsibility of the government and of Canadians to demand some follow-up on these recommendations. If we as a society have identified a need then do we not have a responsibility to develop health care policy to address the situation or to at least establish a timeline or a framework where responsive public policy can be addressed.

One of the most interesting public consultation processes that has taken place recently is the Standing Committee on Health's study of the state of organ and tissue donation in Canada. It held two months of public hearings, where it heard from over 100 individuals and received numerous written briefs from other individuals and organizations. The presentations were made by people interested in and involved with tissue and organ transplantation. The mandate of this committee is very interesting. The terms of reference proposed for the study were:

.To consult, analyze and make recommendations regarding the state of organ and tissue donation in Canada;

. To consult broadly with stakeholders, including, but not limited to, provinces, transplant centres, medical personnel, patients, families, organ and tissue retrieval organizations and international experts;

. To consider the appropriate role for the federal government in the development of national safety, outcome and process standards for organ and tissue donations, as well

as in the promoting of public and professional awareness and knowledge regarding organ and tissue donation, procurement and transplantation; and

.To consider the legislative and regulatory regimes governing organ and tissue donation in other countries.¹³⁶

This committee made eighteen extensive recommendations. However, what is interesting is the terms of reference. The stakeholders identified included medical personnel, patients and families and the promotion of public and professional awareness regarding organ and tissue donation. This shows that even before the process began the Minister of Health was well aware that donation of organs would require public involvement. The importance of specifically noting that patients and families should be included in the process suggests some understanding of the role that these people play in the decision-making process not only for themselves but for many others. Unlike the other two public consultation processes previously mentioned this is much closer to the individual, the family and the community. The value of the role of the patient is obvious in the consultation process and the value of the role that the public will play in the improvement of organ availability is also noted. Canadians are taking more responsibility for their own health.

The government, with some help from interest groups and some health care professionals' associations, is doing its part to educate the public about health promotion

¹³⁶ Organ and Tissue Donation and Transplantation: A Canadian Approach, Report to the Standing Committee on Health. (Ottawa: Publications Service, 1999), p.1

and disease prevention. Stop smoking campaigns, the value of wearing bicycle helmets and child safety practices have enabled individuals to see appreciate the value for themselves and the public. People are very aware of the benefits of exercise and a health diet. Activities run by the Advanced Coronary Treatment Foundation (ACT), which is a national non-profit organization funded by a number of companies from the pharmaceutical industry, inform the public about pre-hospital emergency issues. Their members have worked towards the mandatory implementation of CPR training in schools in the Ottawa Carleton area which has now been extended to other communities. They have also been a keen supporter of paramedics in a number of Ontario cities and have developed a program to educate the public on how to recognize symptoms of a possible impending heart attack and when to seek medical care. People are educating themselves and helping to educate the public. Often people are more compelled to get involved when they feel that they can have a positive impact. There are many voluntary associations that provide an opportunity for the public to get involved and participate in health care decisions that might benefit their community.

There has been increased public participation in all aspects of health care decision-making in the past decade. In some areas we have made more strides than others. There are a number of areas where research needs to be done on the effectiveness of public participation. Policy analysts have identified factors that enhance the public's role in health care decision-making. However, there is still a great deal of work to be done in examining other issues such as whether increased public participation better

addresses the needs of the community and whether it makes the system more accountable.

CONCLUSION

Increased public participation in health care has promoted the health of individuals and the population. The role of the public in health care decision-making is continuing to evolve. However, the role of the individual in his own health care choices has reached a much higher level of influence than the public participation in choices for the community. As more and more individuals feel empowered and knowledgeable the influence of public participation should be increased. Yet we have to ensure that by encouraging public participation in all levels of policy making that the public voice is not the only one heard. A balance must be achieved in developing frameworks of public participation, not all situations should give the same weight to the public voice. It is important to remember that the public voice changes depending on the issue and the context of participation. A good way to understand this is to review an individual situation where more of a balance would have best suited the occasion. Perhaps it is a good lesson to remember when evaluating how much public participation is appropriate for the health care policy being developed.

Dr. Franz Ingelfinger expressed the problem very clearly. "After years of treating patients with gastroesophageal problems, the doctor found himself a victim of glandular cancer astride the gastroesophageal junction. He received numerous and conflicting opinions regarding proposed treatment. He began to wish for someone who would dominate, who would, in a paternalistic manner, assume some responsibility for

his care.”¹³⁷ If someone with this much relevant knowledge feels distressed about making a decision on his own for himself how would a lay person feel in the same situation or in a situation where he is being asked to make a decision for a community. Granted, many of the decisions that are made at a local or regional level are not life and death but they do affect health care services that are valued by some group. The increased focus on autonomy and self-determination of the individual has made the doctor-patient relationship a more participatory one. The increased role given to the public in health care decisions for the community has made the process more democratic. However, neither situation should be without a preliminary discussion on the expected role of each party. Often, just as in any other decision-making situation there is place for some leadership. In a recent study on the role patients wish to play in treatment decision-making, the researchers found that “genuine informed choice is not simple to achieve. It requires modification of the relationship between patient and provider and recognition of the ability of patients to participate in making choices that affect their lives. It does not, however, require abandonment of the recognition that providers have expertise that is highly valued by their patients.”¹³⁸

The medical model is being replaced in health care by a more “holistic” approach. Many physicians and nurses are aware that the spiritual, psychological, social and physical all contribute to the well-being of the patient. Abele, Graham and others in their discussion about citizen engagement talk about the “holistic” approach to policy

¹³⁷ Janet Storch, *Patients' Rights*, (Toronto: McGraw-Hill Ryerson, Ltd., 1982), p.24.

¹³⁸ Raisa Deber, Nancy Kraetschmer, Jane Irvine, “What role do Patients Wish to Play in Treatment Decision Making”, in “The Archives of Internal Medicine”, Volume 156, July 8, 1996, p.1420.

development, this is particularly relevant to health care policy. It has been suggested by some that the Human Genome project will enable individuals to know their entire genetic make-up and then could have surgery and other treatments prophylactically. This kind of individualism cannot be encouraged or even tolerated in society. It has been shown that people with more education and more personal resources are often the most demanding when it comes to health care. They want more information, they ask more questions and they want more treatment options. Health care policy must be developed with the whole of society in mind, its shared values and concerns. Health care policy must be developed using a “holistic” approach.

In all of the provinces, the district and regional councils/boards are responsible for the allocation of the resources. However, the provincial governments decide how much money is allocated to health care to each region. Some experts in health care policy note that this is the best way to ensure cost-containment. If regional authorities were given the responsibility to decide how much money should be allocated to health services in their communities, there is concern that they would respond to increased pressure from their constituencies to provide more resources. Presently, they are being expected to respond to community needs without being given any further resources. These public participants are taking part in the decision-making process, yet they are not being given much latitude in being able to respond to community needs.

Many of these new governance structures were adopted at the same time budgetary restrictions and new ways of delivering health care services were put in place.

For example, in Quebec the virage ambulatoire was to be implemented in order to deinstitutionalize health care. This occurred before the CLSCs had been allocated enough resources and had enough time to plan the appropriate services. The hospital personnel were not ready for the extensive discharge planning that was required to allow patients to go home that quickly. In many areas the hospitals had not been accustomed to working closely with the CLSCs to plan patient care. This put added pressure for decision-making on the boards of both the CLSCs and the hospitals. Many of these new members representing the public did not come into the system when it was functioning at its best. Change was occurring rapidly often before all of the appropriate structures were in place. "In Alberta, regional boards were expected, within 90 days of their appointment, to come up with business plans based on annual budget reductions of more than 5%. This made it clear that expenditure reduction was the preoccupation."¹³⁹

In Saskatchewan fifty-two hospitals were closed before home care and First Responders programs could be put in place. The elections to the new health boards did not even take place until the new restructuring had been completed. This had the most impact on rural communities. "The communities felt disenfranchised from the centralized government and felt there was not consumer participation and a devolution of responsibility to the local level. The actions of the government suggest not a new vision in health policy for Saskatchewan but simply an exercise to reduce expenditure."¹⁴⁰ The

¹³⁹ Jonathan Lomas, "Devolving authority for health care in Canada's provinces: Emerging issues and prospects", in Canadian Medical Association Journal, March 15, 1997;156(6), p.821.

¹⁴⁰ Amanda James, "Closing rural hospitals in rural Saskatchewan: on the road to wellness?" in Social Science and Medicine, 49 (1999), p.1032.

situations were similar in all of the provinces. Provincial legislation established frameworks for public participation but in many instances only after major restructuring had taken place. Regional boards have also not been given any control or influence concerning the amount of money allocated to their regions. It begs the question why public participation now? Were the provincial governments looking for ways for the public to share the blame?

In an article in The Globe and Mail dated August 16, 1997 the writer comments that from 1995 to 1996 public funding for medicine dropped by \$262 million, while at the same time private spending rose by \$1.2 billion. This money was used mainly for dentists' fees, eyeglasses, private rooms in hospital and drugs. Therefore, the author concludes that Medicare is not falling apart. However, there is no mention of home care services. People are going home earlier after surgery, medications are being given intravenously at home and dressings are being changed by home care nurses. If there are not enough community resources available, private funding has surely been financing more of those services in the past three or four years. The financial burden on the individual is increasing. The public representatives on the new governing bodies are taking part in the decision-making about how to allocate the resources available but what if there are not enough resources being allocated. What appears to have developed in some of these new governing bodies is shared power in the decision-making but not at the first instance. Much of the decision-making is taking place in reaction to what has already occurred.

The need for information in order for public participation to be effective cannot be stressed enough. Hospital boards, district councils and regional boards need to provide public members with the opportunity for a formal orientation process. Information should be given to members both orally and in writing. Administrators and health care professionals should be available to answer questions and clarify issues. Public participation can only be effective if public representatives come to the discussion informed.

One of the main problems that has been recognized is the fact that these boards are being asked to make decision without the necessary information. In some situations the information is not even available to the administrators. "There are a lack of adequate mechanisms in place to gather the information, assess the need and evaluate the cost and effect and disseminate the results."¹⁴¹ Much of the information that is needed to efficiently and effectively plan allocation of resources is only starting to be collected. For example, when planning for home care services, it is important for regional or district boards to know not only the number of people in the area, but also those people, who only have one or two possible family caregivers in the same area.

In the past, it was felt that the medical community discouraged public participation because they proposed that most of the information needed for decision-making was too complicated. Today it is not just the medical information that is complicated but the various delivery systems that work between institutions and

¹⁴¹ Church and Barker, *ibid.*, p.477.

community centres and between community centres and other health service providers. Often it seems that long term planning has been done in an ad hoc fashion. There are many cancer patients who are now having to go to the United States for radiation therapy. This is the result of not one decision but many. The provincial governments were not fully aware of the projections of the number of new cancer patients or chose to ignore them; the regional boards did not allocate resources for the radiation therapy equipment and the government in Quebec while limiting enrollment to medical schools and residency training programs offered early retirement packages to health care professionals. The public has been asked to participate in health care policy development in interesting times. Understanding the integration and coordination of health care service delivery, while being constantly made aware of the need for rationalization, makes the task of being the representative of the public a difficult one.

Many of the decisions that are being made by members who represent the public are being made on a cost effective basis and not always consciously. At a recent meeting of a hospital committee, which consisted of public members , health care administrators and professionals, the benefit of using care maps for hip replacement patients was being discussed. Care maps are standardized treatment which are modeled after widely accepted guidelines to ensure optimal use of resources. Not all disease situations can be adequately managed within the constraints of a care map. They do not take into account unexpected variability that is common in health care. The presentation given by the head nurse in orthopedics was impressive and the patients seemingly did well. Members of the committee wanted to know why care maps cannot be used in all treatment planning.

These were the same people who were intended to bring the “other” opinion to the discussion. People like to make decisions using clear guidelines and a solid framework however, the members representing the public were intended to bring the notion of citizen preferences, values and benefits to the discussion. On the other hand it is difficult to be a member of a governing body that is responsible for planning health care policy at any level without any understanding of how the system works, or how the hospital works or about medicine in general. The terminology used, the complex human resources issues, the different unions involved do not contribute to making the task an easy one. It also can be unnerving to take part in a discussion with a number of other people who all have experience in the health care area and the majority of whom have ten to fourteen years of post-secondary education and training. It often takes a strong personality and a belief in the value of presenting a particular point of view. Members who represent the public must be cautious not to automatically align themselves with the health care professionals and administrators, and not to make cost containment the basis for all of their decisions.

One of the main concerns that has been expressed about increased regionalization is the inability to set standards of care that are adhered to at least across each province. This will become much more difficult to establish and monitor if each district or region sets their own standards dependent on the amount of resources allocated to a particular situation. This is occurring at a time when performance indicators and evidence-based practice are the watchwords of the day. The standards should be based on absolute values

and not resource allocation. This is the information that the public needs to know to participate fully in the policy arena.

There has been a great deal of discussion as to whether the public is better represented by appointed boards or elected boards. One would automatically assume that the answer would be elected boards, that might be true, but not for the reasons one might expect. There are a number of rules surrounding the election of members to represent the public on hospital boards in Quebec, for example. However, as an elected member it is difficult in a large metropolitan area to identify the group you represent. You really do not have an identifiable group to whom you are accountable. This is probably quite different in a smaller community or in a rural setting. Representation of a particular point of view is more easily attained in a homogeneous community but in larger centres it proves more difficult. One of the reasons that elected members may prove to represent the public better is that they chose to run for election and make the commitment in terms of time and interest.

Now that the reforms encouraging public participation are a few years old there appears to be a certain level of apathy that has infiltrated the system. Perhaps the idea of sharing the blame with the government instead of the responsibility has become more evident. The Health Minister in Saskatchewan has suggested that the system of elections should be reviewed and possibly ended. In the recent health board elections, "Saskatoon was the only district with more than one candidate in every ward, and Regina had only

one ward with more than one candidate and only 636 people voted in that election.”¹⁴² Quebec has also seen very much the same thing happen. There has been a lower voter turnout in the past two elections and a fewer number of candidates. “In Montreal, only 17,000 people, or 1.2 percent of eligible voters cast their ballots to elect community members to the boards of directors of 45 health centres.”¹⁴³ The majority of the public have begun to feel that even with public participation many of the decisions about health care have already been taken. The main issues that interest people are what health care services are available. They feel that not much is being done about overcrowded emergency wards and long waits for surgery. The number of candidates that ran in the last election was down from 507 in 1996 to 373 in 1999. If this situation truly reflects what the public thinks about the importance of public participation in health care decision-making it is a sad comment on our society. Some of the provincial governments had expressed concern that these new boards might start advocating for more resources for their communities. There appears to be little possibility of that happening.

In Quebec, in the last two elections there has been at least one instance where issues other than health care were the focus of the election. In the first election in 1992 the Orthodox Jewish community sent bus-loads of its members to vote in the election being held at the Sir Mortimer Davis, Jewish General Hospital. This was to ensure that policy decisions taken within the hospital would continue to reflect Jewish religious law. In the election recently held this past November Howard Galganov ran for election to the

¹⁴² “Disinterest prompts system review”, in The Medical Post, November 2, 1999, p.2.

¹⁴³ Nicolas Van Praet “Voter apathy hits new low”, in The Gazette, November 17, 1999, p.A4.

Lakeshore Hospital board and won. People automatically expected him to focus on linguistic rights in health care policy. The health care system across Canada needs people to represent the public and not a particular interest or group. These are not the parameters that reflect health care outcomes. Representation is needed to ensure that there is continued access to health care resources that reflect the needs of the community.

Some of the most interesting opportunities for citizens to have a “voice” in health care policy are available by belonging to an interest group or voluntary association. There is probably much more of a sense of accomplishment in raising money, educating and informing the public and advocating on behalf of a particular vulnerable group in society. The citizens who do get involved in these groups often feel a strong sense of commitment. They themselves or family members or friends have had the disease that reflects the group or association to which they belong. These citizens often feel responsible and accountable to the group. They encourage research and advocate on behalf of this particular segment of the population. Many of these groups will take part in the various consultation processes that are held by the governments or write letters or circulate petitions on behalf of their group. Their level of participation often depends on how organized they are and the resources available to them. As Leslie Seidle has pointed out, these groups will probably continue to gain more of an influence as the federal government continues to restructure.

Support for a publicly funded universal health insurance plan had come from the CCF party and the labour and agricultural movements. These groups represented the

varied social concerns of the majority of the Canadian public. Despite the possibilities for increased public participation in health care decision-making and input into health care policy there appears to be a lack of interest on the part of the public. People tend to get involved in health care issues only if they have been affected in some way. As a society we still continue to spend most of our health care dollars on the treatment of disease. Yet we are well aware of the benefits of good prenatal and childhood care and nutrition and the opportunity it offers in preventing many medical conditions in later years. Who will speak to the greater good of society if we all wait until we have a specific reason to participate. "The preliminary results from a study underway in Quebec on the Health Cities Network reveal that the primary actors in the healthy cities projects are professionals rather than the local citizens. These evaluations suggest that "concentrated interests" are more likely to participate than are "diffuse interests"; providers remain more likely to participate than consumers, and special interest groups with immediate needs more likely than the general public."¹⁴⁴ In order to ensure that health care policy reflects the needs and concerns of the population it serves participation in the process is needed by all of the groups that it affects. Health care decisions are not going to get any easier in the future. An aging population, advances in technology and an ever more informed public are going to continue placing increased demands on the system. We as a society have to decide how those decisions will best reflect our values and priorities. Public participation in health care decision-making has to be informed, encouraged, facilitated, representative and valued.

¹⁴⁴ Sharmila Mhatre and Raisa Deber, *ibid.*, p.664.

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