

CONSULTING ON HEALTH POLICY IN CANADA

by Laurie Ham

Executive Summary

This report begins by outlining the legislative framework in which Canadian health and health care are situated. The formation of the *Canada Health Act* is briefly outlined to illustrate that: (1) the evolution of Medicare has been widely supported by citizens, indicative of the depth of citizen involvement and investment in national health care, (2) the evolution of the system has placed hospitals and physician services at the heart of Canada's health care system and, correspondingly, (3) the evolution of Medicare has firmly established specific stakeholders – most prominently, physician and hospital associations – as central to the policy development process. This has resulted in the effective involvement of prominent stakeholders and “experts” in policy development for health, while the role of citizens – as individuals, coalitions and/or organisations – has only recently become more clearly defined and understood.

In 1994, the federal government committed to examining the health system in the Speech from the Throne. The National Forum on Health (“the Forum”), a federal initiative with the mandate “to involve and inform Canadians and to advise the federal government on innovative ways to improve our health system and the health of Canada's people”, was the fulfilment of this commitment. The main body of this report details the role and activities of the Forum, presents policy outcomes and outlines its challenges and achievements.

This study highlights several unique aspects of the Forum. First, the Forum involved both citizens and stakeholders and made deliberate efforts to incorporate and balance the views of both. Second, the Forum structured its public consultation in two phases. The first phase involved an initial scoping of concerns and ideas that Canadians had regarding the present and future direction of health and health care issues, and the second phase allowed the Forum to “ground test” its directions before becoming recommendations. Finally, the Forum made use of public deliberation as a tool for citizen engagement. The Forum illustrated that Canadian citizens are able to constructively inform policy development when supported by accessible and timely information. This finding is important in light of the widely held belief that policy development within Canada's health sector is too complex to allow citizens to be effective participants.

In February 1997, the Forum presented its recommendations to the government just weeks before the Budget. A number of recommendations made by the Forum were immediately acted upon. For example, the federal government established a *Health Transition Fund* of \$CAD 150 million over a three-year period to be allocated to the provinces to help them launch pilot projects to investigate new and better approaches to health care delivery, including approaches to home care, Pharmacare and primary care reform. An additional \$CAD 50 million over a three-year period was put in place to launch a Canada Health Information System, and several programmes to improve the health and well-being of children were announced. Finally, the federal government guaranteed a minimum level of funding in cash transfer payments to the provinces in support of health, post-secondary education and social services/assistance. Because the Forum had involved citizens and stakeholders from the start, it could assure the government that policy directions rooted in the Forum's work would be widely supported.

The report concludes by highlighting promising directions regarding citizen involvement in policy development, both within and beyond the health sector. Three directions of particular importance are: (1) Health Canada's recent efforts to establish a strategic policy framework for public involvement, (2) the Government of Canada's current initiative to develop a policy for engaging Canadians, and (3) a renewed federal/provincial/territorial commitment to work in a collaborative manner in setting and achieving social policy objectives as expressed in the recent signing of the Social Union Framework Agreement. **The case study was submitted to the Secretariat in 1999 and covers events up to that date.**

Introduction

It is widely acknowledged that Canada's public system of health care, the country's "crowning social policy achievement," is in the midst of great change (Canadian Medical Association, 1998). The cost of Canada's health care system, approximately 9 per cent of Canada's GDP, is the country's largest expenditure of public money (Health Canada, 1999a). As is currently the case in many industrialised nations, citizens and governments are taking a careful look at the allocation of health care resources to ensure the efficacy and efficiency of every dollar spent.

Changing demographics and increased citizen expectations, among other factors, are placing new demands on Canada's health care system. Canada's population, although relatively young in comparison to other industrialised nations, is rapidly ageing. Because the elderly historically use hospitals and health care services at a higher rate than a younger population, this demographic change is feared to place particular pressure on health resources and is gaining increased attention from policy-makers.¹⁷ Also, citizen expectation of what Canadian health care dollars should cover is in a constant state of flux, most often pushing for broader and more inclusive coverage.

These changes are pulling the health care system in new directions at a time when resources for social expenditure are increasingly scarce. The early to mid-1990s was a period of government restraint during which provincial health expenditures – and federal transfers supporting these services – decreased in real terms. Although this has been partially redressed in recent federal budgets, citizens have questioned government commitment to health care throughout the 1990s. Canadian citizens share anxieties regarding the impact of decreased funding on the resilience of their health and health care system (Graves *et al.*, 1998).

This public concern has played a significant role in catalysing citizen and stakeholder interest in health care policy. In fact, Canadian citizens desire an increased voice in decision-making across many sectors – not only health. Recent polls indicate that 88 per cent of Canadians would feel better about government decisions if they knew that governments regularly sought informed input from average citizens, and 86 per cent say that the government should consult and engage citizens more (EKOS, 1998). A significant body of literature has emerged which speaks to an eroding relationship of trust between Canadian citizens and elected representatives and the larger "decline of deference" (O'Hara, 1998).¹⁸

Provincial and federal governments, facing difficult decisions regarding the allocation of scarce resources, are responding to citizen interest in policy development and actively engaging citizens and collaborating with stakeholders on a wider variety of issues than previously. Governments hope to more effectively meet the needs of a changing population, to do so more efficiently, and to encourage citizen ownership of ensuing policy directions (National Forum on Health 1997).

Purpose

The purpose of the present report, one part of Canada's contribution to the OECD's work on government-citizen relations, is to consider how the Government of Canada informs, consults with and engages citizens – as individuals and as organisations – in policy development in the health care sector. In doing so, this report:

- Discusses the federal experience with public involvement in health policy.
- Presents a recent national consultation process, *The National Forum on Health*.
- Highlights promising trends in public involvement within health policy and across the federal government as a whole.

Information for this report was gathered from: (1) interviews with government representatives, health policy professionals and groups representing particular illnesses, consumers, physicians, and nurses, and (2) current literature concerned with health policy.¹⁹

Canadian context

Institutions for Governance

Canada is a constitutional monarchy, a federal state, and a parliamentary democracy with two official languages (French and English) and two systems of law (civil and common law). The federal state brings together divergent political groups under a common government for common purposes, while allowing for the creation of separate local or regional governments to reflect the particular needs of each region. Thus Canadians are governed by a central, federal government – parliament – which is seated in Ottawa in the province of Ontario, as well as a legislature in each province. Municipal councils exist to govern at the level of the community, town and city. Canada includes ten provinces and, as of 1 April 1999, three territories.

In 1867, The Constitution Act (formerly known as The British North America Act) established Canada as a federal state and divided the power to make laws between the federal and provincial levels of government.²⁰ Health care is defined as a provincial responsibility and provincial governments are, therefore, responsible for the primary delivery of physician and hospital services. Other key elements of the health system for which the provinces/territories are responsible include home care, long-term care, rehabilitation, and pharmaceutical programmes (Provincial/Territorial Ministers of Health, 1997).

The federal government has always played a central role in providing resources for health and health care. Through a variety of cost-sharing arrangements, the federal government has been able to ensure uniformity of health care coverage among provinces (Maslove, 1998). Provincial receipt of federal transfer payments is contingent upon the provinces meeting certain minimum standards of comprehensive coverage, accessibility of services, universality, portability and public administration. These five criteria defined in the Canada Health Act are considered the “pillars” of Canada’s health care system.

From the late 1950s, with the inception of national health insurance in Canada, to the late 1970s, the federal government reimbursed each province 50 cents on every dollar spent in the areas of hospital and medical care insurance. After renegotiating with the provinces, the federal government moved from the “cost-sharing” approach to a “block funding” formula which lasted almost 20 years (1977/78 to 1995/96). In the 1995 budget, the federal government announced the creation of the Canadian Health and Social Transfer (CHST). The CHST collapsed health, post-secondary education, and social assistance all into one cash transfer, giving the provinces greater flexibility to allocate funds where they see fit. At the time the CHST was established, there was also a significant decrease – more than \$CAN 7 billion – in federal funds transferred to the provinces.

Since 1995, there has been much written on the implications of the CHST for health care. When the CHST was introduced, it was the subject of considerable hostility and criticism from groups working within the fields of health care, education and social assistance (Maslove, 1998). Many groups made their concerns known in their submissions to the House of Commons Standing Committee on Finance during the course of public hearings in 1995.²¹ Most of these groups felt the CHST marked the demise of the federal government’s ability to ensure that the principles of the Canada Health Act are met (Steinhauer, 1995); others suggested it will have little impact on health care (Hurley *et al.*, 1995). Suffice to say, however, that the federal government’s level of funding of health care is largely seen – by citizens, stakeholders and provincial decision-makers alike – to be a signal of their commitment to health care and the principles embodied in the Canada Health Act.

Table 13 illustrates that Canadian health care is being delivered in increasingly diverse settings. Hospital expenditures declined from 39.3 per cent of total health expenditures in 1990 to 33.4 per cent in 1998, while public home care expenditures increased from 2.2 to 4 per cent of public health spending. Spending on drugs has also increased. These changes have taken place during a period of fiscal restraint. Between 1990 and 1994, public health spending rose from \$CAD 1 643 to 1 808 per person. However, in real per capita terms, funding for public health has declined since 1994.

Table 13. Fact and figures about Canada's health system (in Canadian dollars)

	1990	1994	1998
Total health expenditures as share of GDP (%)	9	9.6	9.1
Per capita total health expenditures	\$2 203	\$2 508	\$2 613
Public health expenditures (in billion dollars)	\$45.7	\$52.9	\$55.8
Per capita public health expenditures	\$1 643	\$1 808	\$1 821
Total health expenditures by use of funds (share of total in %)			
Hospitals	39.3	36.2	33.4
Home care ²²	2.2	3.1	4.0
Physicians	15.1	14.6	14.4
Drugs	11.3	12.7	14.0

Source: Health Canada, 1999.

The Social Union Framework Agreement

Throughout the 1900s, federal-provincial agreements have granted the provinces more power in the areas of social and economic policy. These agreements grow from long-standing and unresolved debates between the federal and provincial governments concerning the permanency of each government, where the majority of law-making power should fall, and whether or not Canada's federation should be highly centralised or decentralised. Canada's current Prime Minister advocates a "flexible federalism," which is able to accommodate provinces which have "distinctly different value orientations" (Lassey *et al.* 1997). While some provinces prefer strong federal involvement, others prefer greater provincial autonomy.

In the early 1990s, it became increasingly apparent that tensions between different levels of government might stall action on shared social priorities and threaten to erode already established social programmes. In February 1999, however, a new spirit of collaboration was ushered in when federal, provincial and territorial governments (with the exception of Quebec) signed the Social Union Framework Agreement (SUFA), an intergovernmental agreement "based on mutual respect between orders of government and a willingness to work more closely together to meet the needs of Canadians" (Intergovernmental Affairs, 1999). SUFA acknowledges that citizens have an important role to play in shaping their society. Among other commitments, within SUFA, governments agree to:

- Respect the principles of Medicare: comprehensiveness, universality, portability, non-profit public administration and accessibility.
- Work in partnership with individuals, families, communities, voluntary organisations, business and labour, and ensure appropriate opportunities for Canadians to have meaningful input into social policies and programmes.

Voluntary and non-governmental organisations have always played a central role in creating and strengthening the social fabric of Canada. Recent surveys indicate that Canada's 31 million citizens volunteer over 900 million hours annually, creating a diverse and textured voluntary sector. In 1996, there were 74 918 charities registered in Canada and it is further estimated that more than 100 000 organisations not registered as charities exist (Canadian Centre for Philanthropy, 1997). Many of these organisations focus on health promotion, health care delivery and other health care issues. For example, in 1996, there were 3 180 organisations supporting medical research and public health; 5 238 organisations categorised as "community benefit" (for example, Meals on Wheels and Humane Societies); and 10 317 public foundations and social service organisations focusing on children, family and the disabled, welfare and services, international assistance and relief.

However, over the last decade, challenges facing the voluntary sector have been heightened by economic restructuring, the rethinking of government services, and changes in the demographics of the Canadian population. A key limitation to voluntary sector involvement in policy development is the legal requirement which states that non-profit organisations must limit their advocacy work to 20 per cent or less of their budget to retain their charitable status. This legal constraint works as a financial

disincentive for organisations to become more involved in advocacy work and “in general, weakens the consumers’ opportunity to push for change” (Kushner and Rachlis, 1997). Indeed, many organisations that focus on advocacy work find themselves without the financial or human resources to engage in policy debates in any substantive way or track policy development processes as they become protracted.

Obstacles to the more effective involvement of voluntary organisations have begun to be addressed by the federal government. Furthering the important work of the Voluntary Sector Roundtable,²³ Joint Tables were convened in May 1999 to address three issues: building a new relationship, strengthening capacity, and improving the regulatory framework. Each table was composed of senior government officials and voluntary sector leaders, and the process was structured to ensure shared decision-making and ownership. A report, representing the culmination of the Joint Table discussions, *Working Together: A Government of Canada/Voluntary Sector Joint Initiative*, was released in September, 1999, and will form the basis for further discussion and an implementation plan (Voluntary Sector Task Force 1999).

The health care sector

Medicare was not born overnight. Nor was it the outcome of calm, reasoned discussions. Its history is fraught with false starts, difficult and sometimes acrimonious federal/provincial relations, and numerous confrontations between governments and health care providers and suppliers

(National Forum on Health 1997)

Growing from a citizen-based and supported movement, hospital insurance was founded in Saskatchewan in 1947. Several more provinces soon followed, and the National Health Grants programme, which offered matching grants to provinces for hospital construction, was approved at the federal level in 1948 (Lassey *et al.*, 1997). By 1961, provincial hospital insurance had been made available in all provinces and a nationwide insurance standard was firmly established. Finally, the *National Medical Care Insurance Act* (which is known as Medicare) was enacted in 1966 and initiated in 1968. The programme provided 50 per cent federal matching for provincial insurance and required universal coverage, comprehensive services, portability, public management and reasonable access to services. All ten provinces had established Medicare by 1971 and “the legislation creating this program was among the most widely supported parliamentary decisions ever undertaken in Canada” (*ibid.*).

The *Canada Health Act* was passed in 1984. It consolidated, amended and replaced several of the separate laws that had been developed over the previous two decades and provided for additional federal monitoring, including limitations on user fees and extra billing by physicians. Box 39 (below) outlines the principles of the *Canada Health Act* (1984), while Box 40 outlines the primary features of Canada’s health care system.

It is beyond the scope of this report to provide a detailed account of the formation of Canada’s health care system. However, this short history highlights that:

- The evolution of Medicare was widely supported by citizens, indicative of the depth of citizen involvement and investment in national health care – an investment that continues today.
- The evolution of the system – occurring over a period of decades – placed hospitals and physician services at the heart of Canada’s health care system. Health policy analysts cite this as a primary reason for Canada’s escalating health care costs. They argue that the provision of health at the level of community and household and via health care professionals and providers other than doctors would be a more efficient use of resources.
- Correspondingly, the evolution of Medicare has firmly established specific stakeholders – most prominently, physician and hospital associations – as central to the policy development process. This has resulted in the effective involvement of prominent stakeholders and “experts” in policy development for health, while the role of citizens – as individuals, coalitions and/or organisations – has only recently become more clearly defined and understood.

Box 39. Principles of the *Canada Health Act*

Under the *Canada Health Act*, the following five criteria or principles must be met for a province to receive its full federal transfer payment.

- **Universality** – The provincial health insurance plan must cover 100 per cent of eligible residents on uniform terms and conditions.
- **Comprehensiveness** – All medically necessary services provided by hospitals and physicians must be covered.
- **Accessibility** – The plan must provide reasonable access to insured services with no user fees.
- **Portability** – Residents are entitled to coverage when they move to another province within Canada or when they travel within Canada or, on a limited basis, abroad.
- **Public Administration** – The plan must be administered and operated on a non-profit basis by a public authority accountable to the provincial government.

Source: Health Canada, 1999a.

Box 40. Primary Features of the Canadian Health Care System

Hospital and physician services are covered by provincial health insurance – without significant co-payments at the point of service after a deductible amount.

The provincial health plan is the only payer for medically necessary hospital and medical services. Funds are derived from personal, sales and corporate taxes. Seventy-five percent of all health care costs are paid from public sources. Private insurance is not allowed for basic services.

Citizens are free to choose their doctor and hospital.

Physician practices are largely private and independent, with a fee-for-service payment system based on rates negotiated by physician organisations and provincial governments. A standard billing form is used by all physicians.

Hospitals are largely public and non-profit, with financing based on an annual global budget. Virtually all major surgery and high-technology diagnostic tests are provided in hospitals, with only a few recent exceptions.

Essentially all high-technology available in other advanced countries is also accessible in Canada. However a provincial planning process limits the distribution of high-cost technologies, such as CT scans and MRIs, to regional hospitals.

Source: Lassey *et al.*, 1997.

Public involvement in the Health Care Sector

Stakeholders in health

Traditionally, decision-making in health care has relied heavily on medical expertise. However, as Canada's health care system transforms, difficult power shifts must be accommodated between "traditional" stakeholders and relatively new sources of input for policy development, including citizens and community-based groups. Current reforms are refocusing the health care system towards "primary care, health promotion, home care, and community-based services" (Lassey *et al.*, 1997). In such a system, physicians play a less influential role and policy-makers, nurses, and public health professionals who deal with the causes of good health might become more influential, and community centres cornerstones of health delivery (Janigan, 1995).

Further, the input of citizens as individuals is increasingly being sought as governments recognise that the current decisions being made about health care are not only technical in nature, and therefore

in the realm of experts, but value-laden and could be informed effectively by citizens' views and priorities.

Some of the more prominent stakeholder organisations in Canada's health care sector include:

- *Associations*: including The Canadian Healthcare Association (formerly the Canadian Hospital Association) which represents the nation's hospitals; The Canadian Medical Association which represents most physicians and works towards quality improvement, improved co-ordination/communication with other provider groups and organisations; The Canadian Association for Quality Health Care which serves as a forum for health professionals and provider organisations to consider quality improvement issues; The Canadian Public Health Association which is composed of health professionals from over 25 health disciplines and is active in conducting and supporting health and social programmes both nationally and internationally; the Canadian Nurses Association which represents professional nurses; and the Canadian Pharmacists Association which is the national organisation of pharmacists committed to providing leadership for the profession of pharmacy.
- *Accrediting Bodies*: including The Canadian Council on Services Accreditation, which is responsible for the accreditation of health care organisations, professional colleges, and Canadian medical practitioners.
- *Organisations associated with specific illnesses*: including the Canadian Cancer Society, the Heart and Stroke Foundation, and Canadian AIDS Society, which attempt to shape the medical research agenda through policy interventions.
- *Coalitions of non-governmental organisations*: including the Health Action Lobby (HEAL) which is a coalition of national organisations dedicated to protecting and strengthening Canada's health care system.²⁴ HEAL is a diverse group of approximately 30 organisations, including professional associations (several whom are mentioned above), consumer organisations (Consumers Association of Canada) and groups associated with specific illnesses.

Other stakeholders in health policy, although not focused on health care specifically, include the many groups whose work focuses on the broader determinants of health, such as homelessness, poverty and unemployment. Canadian groups such as the National Anti-Poverty Organisation and the Canadian Labour Congress address health issues in the context of their other priorities.

Complexity and policy development

Is policy development within Canada's health sector too complex to allow citizens to be effective participants? This belief is embodied by some researchers and decision-makers who suggest that health care is of limited interest to most individuals until they become patients or "consumers" of health care. Lomas (1996) states:

The average citizen (as opposed to the self interested patient or provider or manager) has so far shown little interest in contributing [to dialogue surrounding health care] and rarely has the requisite skills for most of the tasks asked of him or her.

This point of view is contested by evidence that suggests that citizens hesitate to get involved in policy development because of the obstacles to doing so and the perceived lack of legitimacy of some consultation processes, rather than their own complacency or disinterest (Kushner and Rachlis, 1998). Many Canadian examples exist of effective citizen interventions and government initiatives that have influenced policy, including:

- The efforts of breast cancer survivors to network, lobby and influence public policy at the National Breast Cancer Forum in Montreal in November 1993.
- The formation of the Seniors Citizens' Consumer Alliance for Long Term Care Reform in Ontario in the early 1990s, which resulted in new legislation being introduced which closely mirrored advice put forward by the Alliance.²⁵

- The *National Forum on Health*, a national consultation process which deliberately and effectively created space for both stakeholders and citizens and found that citizens were able to constructively inform policy development when supported by accessible and timely information.

Challenges to public involvement

There are a number of key challenges to effectively involving the public in policy development. They include:

- Balancing the viewpoints of “experts” – for example, physicians and policy analysts – with those of citizens and patients. This is especially challenging given the centrality of medical expertise to health policy development and the complexity of the subject matter.
- Differentiating between “concentrated” interest (those who have a direct stake in how well the health care system operates, including patients, physicians, etc.) and “diffuse” interests (citizenry at large whose considerations involve competing public priorities, including tax cuts and economic growth).
- Ensuring that citizen and consumer groups are accountable to their constituencies and membership and ensuring that there are mechanisms in place to ensure this accountability.²⁶
- Capturing the diversity of Canada’s size, demographics, economic activities and ethnicity – particularly challenging in a national consultation.
- Making space for citizens to be involved in consultations as civic-minded individuals rather than only as members of an organisation or stakeholder group.
- Ensuring that consultation processes, when necessary, will have credibility and relevance for different levels of government.

In the following section, the National Forum on Health is presented in detail to illustrate how the federal government approached and often met the challenges outlined above. Following the account of the Forum, policy outcomes are presented, challenges are revisited, and achievements of the Forum are highlighted.

The National Forum On Health

In 1994, the federal government committed to extensive dialogue surrounding health and health care in the Speech from the Throne.²⁷ The National Forum on Health was the fulfilment of this commitment. Launched by the Prime Minister in October 1994, the Forum’s mandate “was to involve and inform Canadians and to advise the federal government on innovative ways to improve our health system and the health of Canada’s people” (Governor General of Canada, 1994). The mandate dictated that the Forum work to engage Canadians in dialogue.

Canadians were ready to be involved. As previously highlighted, in 1994, public concern about the federal government’s commitment to Medicare was at an all-time high. Fuelling this concern was a growing voice for various forms of privately administered health care facilities and services. Although the federal government stated repeatedly that they were absolutely and unequivocally committed to the principles of Medicare, their actions spoke differently.

Although the Forum completed its work in early 1997, it had many important outcomes that continue to impact policy development within the health sector. The following factors made the Forum particularly unique:

- The Forum approached its work in two phases. During the first phase, Forum members gathered input from citizens and stakeholders to shape the Forum’s work. The second phase involved the Forum checking back to ensure that what they put forward as recommendations correctly reflected citizen and stakeholder views and priorities.
- The Forum provided space for both citizens and stakeholders to provide input. In fact, in the second phase of the process, citizens and stakeholders were brought together at the same conferences. This allowed areas of divergence as well as common ground to be discovered and

clarified. Further, this allowed the Forum to assure decision-makers that their recommendations enjoyed widespread support from a diverse audience, and action growing from these recommendations would be supported.

- The Forum used a deliberative process. Deliberation, unlike debate, encourages reflection and learning, promotes collaboration and a focus on common ground, and allows new options to emerge. While polling gets at “top of mind” answers, deliberation allows citizens to work with the complexities, constraints and trade-offs facing health decision-makers today.

Background

The Prime Minister was the Chair of the Forum, and the Federal Minister of Health its Vice Chair. The provinces were initially very cautious of the Forum. As the primary providers of health care, many provinces felt that a national consultation process would unduly raise citizen expectations in a time of reduced federal and provincial spending for health. The credibility and usefulness of the Forum was immediately at stake; many felt that without the main providers of health care – the provinces – on board, it was questionable what the Forum could actually accomplish. Other critics felt that the dialogue was only a “smoke screen for [the] Finance Minister[’s] steady erosion of Ottawa’s contribution to health care costs” (Gray, 1994). Eventually, the provinces decided to take on observer status *vis-à-vis* the Forum’s activities.

Despite this, the federal government moved ahead with the Forum. Twenty-four individuals were chosen to make up its main body, and an arms-length Secretariat was established in Health Canada to support the Forum’s work. The Forum included economists, health policy analysts, physicians, health care providers, lawyers, academics, business people, and community activists. These individuals were all held in high esteem, and their collective credibility silenced much of the anti-Forum sentiment in the initial months of their tenure (McGregor, 1995). Forum members made it very clear from the start that they didn’t see themselves as “mouthpieces for stakeholders” (Gray, 1994). Their credibility as a group was further enhanced as they confirmed that they engaged in the process as individuals and as volunteers.

Representatives from the provinces were invited to attend all aspects of the Forum’s process and three official representatives did so on a regular basis. In turn, they reported back to their provincial counterparts. All publications, information and discussions throughout the Forum’s tenure were made available to the provincial governments. Several officials from the Forum Secretariat as well as the Ministry of Health also made deliberate efforts to communicate with provincial ministries throughout the duration of the Forum.

The Forum was initially given \$CAD 12 million and four years in which to fulfil its mandate and report back to the Prime Minister. Immediately, the Secretariat and Forum members began to work at defining overall objectives and establishing broad parameters for dialogue. Four main themes emerged from this preliminary stage of work which guided all subsequent investigations of the Forum. The areas, indicative of the breadth and depth of the Forum’s mandate, were:

- *Values*: The Values working group sought to understand the values and principles that Canadians hold about health care, so that the system continues to reflect and respond to these values.
- *Striking the balance*: This group considered how to allocate limited resources within the health sector, and between the health sector and other sectors of the economy.
- *Determinants of health*: The Determinants of Health working group considered what actions must be taken to allow Canadians to continue to enjoy a long life and possibly increase their health status.
- *Evidence-based decision making*: The Evidence-Based Decision Making group considered how individuals, practitioners and policy makers can have access to and utilise the best available evidence in making decisions.

The Forum began its own work with a review of the previous 20 years’ experience in health policy analysis, including the findings of Royal Commissions and Task Forces across the country. They also

commissioned more than 40 academic papers from experts in various fields and examined health expenditures and outcomes in Canada and in other jurisdictions (Ferderber, 1998).

Engaging Canadians

The overall structure of the Forum emphasised multiple avenues of input and knowledge. One of these avenues was the extensive citizen engagement exercise that ran parallel to the Forum's own investigations and research work. The consultation effort was structured so that it was able to inform the Forum's work throughout the process, rather than just being "tacked on" at the end. The Forum decided to consult individual Canadians, voluntary organisations and stakeholders.

Early in the Forum's process, several decisions were made around the structure of the consultation. First, it would use a study circle approach involving a nine-hour time commitment for each participant. Study circles are a policy-making and consultative tool that differs from both focus groups and standard polling in that they rest on the premise that citizens have a responsibility to become informed on an issue, as well as a right to comment on it (Democracy Education Network, 1994). Study circles allow citizens to become involved in a policy process to a depth beyond that afforded by more traditional consultation; which may be important with complex policy issues such as health. The circles provide for a structured, facilitated and in-depth deliberation that encourages participants to consider each other's viewpoints in a non-confrontational manner (Ferderber *et al.*, 1997). The Forum called their study circles "discussion groups".

The Forum also decided that the consultation would be divided into two phases. The first was an initial scoping of concerns and ideas that Canadians had regarding the present and future direction of health and health care issues; the second phase would "ground test" the directions of the Forum before these directions were concretised into recommendations. The purposes of these two phases were as follows:

Phase I:

- To engage Canadians in a dialogue on health and health care and on the changes and improvements needed at the national level.
- To examine issues as they relate to the health of Canadians.

Phase II:

- To seek views on the Forum's proposed directions and options.
- To solicit advice on approaches to implementation.

Phase I: Identifying key issues

Between November 1995 and April 1996, discussion groups were held in 34 different communities. Interested individuals were asked to register in advance of the discussion groups and commit approximately nine hours of their time, usually over two to three sessions. A private firm was contracted to organise the consultation and endeavoured to work with local community groups to set up the discussion groups. These were preceded by the broad distribution of the consultation document, *Let's Talk*. The consultation document formed the basis for dialogue in the discussion groups, and could also be completed by individuals who were not taking part in the discussion groups. Over 1 000 copies of the consultation document were returned. The consultation document contained data, information and some preliminary analysis, all organised under the four broad themes initially outlined by the Forum. As such, the consultation document was an educational tool which provided timely, objective and accessible information to support informed dialogue on health, both in the discussion groups and across the country.

During the discussion groups, people were eager to bring up local and regional issues, that fell outside the mandate of the Forum. Talk of local hospital closures, regional funding issues and the

ongoing *Inquiry into the Blood System in Canada* (the *Krever Inquiry*), 1994 to 1997, were never far from mind. Forum members were also encouraged to attend the community meetings and many did so. Their presence at the discussion groups was often greatly appreciated by participants who felt more assured that their comments would be taken up in the development of the Forum's report.

By the end of the first phase, 71 discussion groups had been expertly facilitated and 1 300 Canadians had been involved. Although the Forum made a sincere commitment to capturing the diversity of Canada's size, demographics, economic activities and ethnicity, it was challenging to engage the "average" Canadian in discussion groups. Several stakeholders contacted believed that the study circles were dominated by those with a direct stake in health care (physicians, patients, care-givers) rather than those with more diffuse interests. Other stakeholders felt that the Forum very successfully engaged Canadians from all avenues of society.

The Forum also deliberately engaged a variety of communities that might otherwise experience barriers to participating, including homeless men, street children, new Canadians, low-income mothers, senior citizens and First Nations (aboriginal populations). The latter involved working with community leaders and band members as well as the translation of the consultation document into Inuktituk.

Key stakeholders were also involved. In April 1996, a conference in Toronto brought together representatives of local, regional, provincial and national organisations with a specific interest in health and health care. More than 200 people attended the conference and, while there, participated in professionally facilitated groups to discuss the Forum's four key issues. These were how to:

- Allocate and organise resources in health and health care.
- Move from research to action on the determinants of health.
- Encourage evidence-based analysis and research in decision-making about health and health care.
- Identify the values Canadians hold about health and health care and ensure that these values influence decisions.

The conference marked the end of the first phase of consultations. Following this, the Forum distributed a report on their dialogue with Canadians. The report highlighted what they had heard in the discussion groups. Comments included:

- Broad support for a publicly funded national health care system in accordance with the principles of the Canada Health Act.
- Divergent opinions on how the system should be financed and whether non-essential services could be accommodated on a private basis within a public system.
- Endorsement of new models of health care which might focus on wellness promotion and illness prevention, home care support and community health centres.
- Recognition that the health of people is influenced by economic factors such as the availability of employment, adequate income, education and sufficient local resources.
- Concern regarding the accessibility and accuracy of diagnostic and treatment health information (National Forum on Health, 1996a).

Phase II: Feedback on proposed directions and options

From the beginning of the first phase, the Forum was committed to revisiting each of the 71 discussion groups to present what had been formulated as broad directions before any recommendations were made to the government. However, between the first and second phase of consultations, the federal government requested that the Forum complete its work by December 1996 in order for its timing to better correspond with the demands of the budget and election cycles, thus shortening their mandate by approximately one year.

This request required the Forum and Secretariat to remodel the latter stages of the Forum's work. Given the new timeline involved, it would now be impossible to revisit the discussion groups that were

engaged in Phase I, yet Forum members were committed to testing their strategic directions with citizens. This second consultation phase was reshaped to include a phone survey and two regional conferences in Vancouver and Montreal.

Conference participants were drawn from both the public discussion groups and the stakeholder groups. Approximately 200 people attended each conference. Taking into consideration input from the public discussion groups, previous conferences, meetings with experts, commissioned academic papers, letters and briefs, the Forum prepared a background document, *Advancing the Dialogue on Health and Health Care* which outlined the Forum's thinking in three broad areas: preserving the system while doing things differently, transforming into action knowledge about what makes people healthy, and using better evidence for better decisions (National Forum on Health, 1996b). This document was distributed to all conference participants. Individuals who could not attend the conferences were invited to respond to a telephone questionnaire.

The Vancouver and Montreal conferences were unique in that they brought together more than 200 citizens and stakeholders at each meeting. There was no explicit weighting of public and professional views and the conferences served to give a general sense of where members of the two groups agreed or disagreed with the interpretations and views of the Forum members.

In addition to the conferences and telephone questionnaires, 500 randomly selected members of the public were also invited to participate in a telephone survey for the purposes of comparison. This all happened within a six week period in the fall of 1996.

Both the conferences and phone interviews verified that *Advancing the Dialogue on Health and Health Care* did a good job of capturing and responding to the concerns, opinions and suggestions of Canadians as provided in Phase I. While there was strong support on proposed directions for change, there was less support for the proposed methods to implement these directions. Conference participants offered useful alternatives and discussion at the conferences further informed the Forum's crafting of their final report (Ferderber *et al.*, 1997).

Forum members also reviewed the findings of the consultation and found a strong degree of consensus between the views of the public and stakeholders in both phases of consultation. Further, consultation participants expressed a high degree of satisfaction with the Forum's consultation process; approximately 75 per cent of the questionnaire respondents were satisfied with the opportunity to express their views during the Forum's process of consultation (Ferderber *et al.*, 1997).

Outcomes

On 4 February 1997, the Forum presented its findings to the Prime Minister. The two-volume report, *Canada Health Action: Building on the Legacy*, was well received by citizens, practitioners, and administrators alike. Everyone who had participated in the process – from stakeholders to citizens – could see themselves in the report and, in turn, the Forum was able to assure decision-makers that initiatives growing from Forum recommendations would enjoy widespread citizen and stakeholder support and buy-in.

The Report's release date, just two weeks before the 1997 Federal Budget, allowed the federal government to respond to Canadians by speaking to some of the Forum's key recommendations in the Budget. Further, the report landed on politicians' desks at the end of their mandate, which is a politically opportune time. It should be noted, however, that the shortening of the consultative process and the subsequent decision to not revisit discussion groups meant that citizens were not engaged at the level they initially believed they would be. This did not appear problematic; efforts of the Forum secretariat to "check in" and report back via the conferences and phone interviews appeared to have fulfilled citizens' expectations of the process.

Forum recommendations

General findings

The Forum's final report, *Canada Health Action: Building on the Legacy*, presented key recommendations for change. The Forum found that the Canadian health care system was fundamentally sound and

advocated that its core characteristics remain unchanged. Forum members believed that first-dollar coverage (i.e. no user fees) for medically necessary services financed through general taxation ensures that Canadians receive medical attention when they need it and avoids the duplication, overlap and inefficiencies of a system made up of hundreds of private plans. Instead, the current system of 12 interlocking medical insurance plans reduces administrative costs and provides more consistency and bargaining power in dealing with health care providers and the health care industry. The Forum strongly stated that the profit motive has no place in Canadian health care; it is “both inconsistent with a view of health as a public good and moreover leads to high administrative costs and inequities in access and quality” (National Forum on Health, 1997).

In 1997, when the report was released, the Forum estimated that Canadians were spending \$CAD 72 billion annually, or \$CAD 2 500 per capita on health care – one of the most expensive health care systems in the world. The Forum stated that there was already enough money in the health care system and any perceived “crisis” was not due to reduced funding. Citing unexplained Canada-wide variations in rates of surgical procedures, hospital days being used by those who do not require acute care, and the inappropriate use of drugs – to name only three examples – the Forum pointed out that resources could be used more efficiently within the system, thus improving the system with little change in funding levels. In its recommendations, the Forum remained aware of the fact that the report was being tabled in an environment that was very concerned with reducing the country’s deficit.

Priority One: Preserving our health care system by doing things differently

The Forum recommended that Canada’s health care system be preserved by doing things differently. The “single payer” model with public funding for medically necessary services, the five principles of the Canada Health Act, and strong federal/provincial collaboration and partnership should all be preserved. What did the Forum say should be done differently?

First, they recommended that the reduction in federal-provincial transfer payments be halted and a floor established below which the transfer payment would not sink. This would give the provinces some certainty and stability in funding arrangements, as well as ensure that the federal government could still enforce the principles of the Canada Health Act.

Secondly, the Forum recommended the expansion of coverage for medically necessary drugs and home care. Currently in Canada, pharmaceuticals are provided at no charge while a patient is in a hospital; however, once he or she is discharged, these costs are out-of-pocket expenses. The Forum noted that the cost of drugs was the most quickly increasing cost in health care – Canadians spend nearly as much on drugs as they do on physicians’ services – and concluded that there could be cost savings and better access to medically necessary services for Canadians if pharmaceuticals were brought under the coverage of Medicare (see Table 13). To achieve this, the Forum recommended establishing a national drug information system as well as undertaking careful studies to analyse the best way to control costs while integrating existing private insurance plans and provincial Pharmacare (which provide varying levels of coverage) plans into a publicly administered system.

Similar recommendations were made regarding home care. Home care involves caring for post-acute, chronic care and palliative care patients at home; a system that can be cost-effective and less stressful for the patient if the proper support mechanisms are in place. Again, like drugs, many services are offered in a hospital and long-term care settings, but have to be paid for out of the patient’s pocket when the patient is discharged. The Forum recommended that these out-of-hospital services be made an integrated part of publicly funded health services; thus the maxim, “fund the care, not the provider or the site.”²⁸

Thirdly, the Forum recommended that primary care – the first point of contact between a patient and the health care system – be carefully examined and reformed. The Forum did not put forward any particular model, but suggested that any reform of primary care include the following key elements: (1) realignment of funding to the patients, not services; and (2) a remuneration method that is not based on the volume of services provided by physicians but promotes a continuum of preventive and treatment services and the use of multidisciplinary teams.

The Forum recommended that the federal government establish a \$CAD 50 million/year transition fund to support innovation in the directions outlined above. The fund would fund pilot projects, disseminate results and promote implementation of the best models.

Priority Two: Transforming our knowledge about health into action

The Forum acknowledged that there is much more to health than only health care, and made a number of recommendations to improve the health of Canadians at a broader level. The Forum recommended:

- A broad, integrated child and family strategy consisting of both programmes and income support.
- Collaboration among the federal government, the private sector, and existing foundations to strengthen community action.
- An Aboriginal Health Institute to help Aboriginal communities find solutions to their health problems and take action.
- Explicit acknowledgement of the health and social impact of economic policies, and action to help individuals who are trying to enter the workforce.

Priority Three: Using better evidence to make better decisions

Trends such as the growing focus on population health and its determinants, greater fiscal pressures, new information and knowledge created by research and advances in technology, and the health and health care reform movement, are demanding better decision-making. Evidence-based decision-making is the systematic application of the best available evidence in the evaluation of options for decision-making in clinical, management and policy settings. To foster an environment of evidence-based decision-making, the Forum recommended that:

- A nationwide health information system be established which would bring together a standardised set of longitudinal data on health status, determinants of health and health system performance, and would ensure patient privacy and confidentiality.
- A comprehensive research agenda be established to advance the knowledge base and produce high-quality content for the health information system. This would involve undertaking a strategic overview of the current state of health-related knowledge, identifying the best mechanisms for promoting analysis, synthesis, translation and dissemination and uptake of existing data, and ensuring that funding for research is balanced between basic clinical research and non-medical determinants of health.

Mere weeks after the Forum presented its final report, the federal government presented its 1997 Budget. A number of recommendations made by the Forum were immediately acted upon. The federal government established a *Health Transition Fund* of \$CAD 150 million over a three-year period to be allocated to the provinces to help them launch pilot projects to investigate new and better approaches to health care delivery, including approaches to home care, Pharmacare and primary care reform. An additional \$CAD 50 million over a three-year period was put in place to launch a Canada Health Information System and several programmes to improve the health and well-being of children were announced. Finally, a cash floor was placed on the CHST (the transfer of funding to the provinces from the federal government in support of health, post-secondary education and social services/assistance) of \$CAD 11 billion, below which the cash component of the transfer would not fall. This cash component was raised to \$CAD 12.5 billion later that year, as recommended by the Forum. This assured the provinces that they would have predictable and stable funding.

Current directions for health

Almost three years have passed since the Forum tabled its final report. It is clear that citizen input shaped the Forum's final report. But did the Forum's report have any impact on policy? The true

effectiveness of the Forum rests in whether its recommendations for change were used to inform policy development and catalyse changes to the health care system.

Many initiatives rooted in the work of the Forum are being realised today. For example, an Aboriginal Health Institute and Canadian Health Information Network have both been established. In November of 1999, legislation was announced to create the Canadian Institutes of Health Research, an institute which will be responsible for organising, co-ordinating and funding health research at the federal level and furthering evidence-based decision-making.

Forum recommendations falling under their first priority, *Preserving our health care system by doing things differently*, were the most politically delicate to put forward. These recommendations, touching on home care, Pharmacare and primary care reform, have direct implications for provincial actions in the areas of health and health care delivery, as well as implications for several powerful stakeholder groups, including physicians, hospitals and the private insurance industry. Further, there is widespread concern about the potential cost of insured home care and pharmaceutical programmes. Because of these factors, there are divergent perspectives on home care and Pharmacare; some characterise movement in these areas as painstakingly slow, while other stakeholders state that Medicare must be strengthened and stabilised before there is an expansion of coverage to include home care and Pharmacare (Canadian Medical Association, 1998).

There has been some movement on these initiatives, however. In early 1998, three national, invitational conferences were held which considered national approaches to Pharmacare, Home Care and Health Info-Structure, respectively. The federal Minister of Health and a provincial counterpart hosted the conferences, funded by the Health Transition Fund. Each conference shared the common objective of fostering dialogue among stakeholders on the complex issues associated with each initiative. Therefore, dialogue has begun on each of these issues but no national plans for Pharmacare or home care have been put in place yet.

Challenges and achievements of the National Forum on Health

- *Balancing viewpoints*: The Forum's work emphasised multiple avenues of input and knowledge. Stakeholder conferences, expert reports, citizen discussion groups and academic papers all fed into the work of the Forum. One of the Forum's major challenges was to produce an accepted set of recommendations from this variety of experience, background and input. The explicit weighting of viewpoints was up to the Forum members in the crafting of their final report, and although regional conferences in 1996 assured the Forum that they had captured and reflected input from citizens, experts and stakeholders, there were still groups who felt that they had not been given sufficient "air time" throughout the Forum's work. Whether this is inevitable in policy development processes or avoidable remains unanswered.
- *Representation in discussion groups*: Capturing the diversity of Canada's population is particularly challenging. Several groups contacted reported that the discussion groups were dominated by those with an immediate stake in health care, such as physicians or recent patients. Others did not share this point of view and felt, largely through efforts to work with local organisations grounded in local communities, the Forum reached the "average" Canadian. This remains a challenge central to all consultation processes, particularly those of national scope and characterised by such diverse stakeholders.
- *Government and citizen commitment*: Prime Ministerial, Ministerial and senior departmental support was vital to the Forum's credibility and legitimacy. Further, the Forum illustrated that Canadians are willing to commit a considerable amount of time to policy-relevant discussions that are of meaning and value to them.
- *Adequate time and resources*: Effective consultation requires adequate time and resources, both human and financial. Because the highest levels of the federal government were committed to the Forum's work, the process was well resourced and supported by a secretariat of more than twenty individuals. The budget and human resources required reflected the breadth, depth and

complexity of the subject matter under investigation as well as the geographic vastness and diversity of Canada itself.

- *Deliberative processes work*: A deliberative process, when well structured, professionally facilitated and supported with factual and easily understood information, works to create a dialogue. Dialogue differs from debate; dialogue encourages reflection and learning, promotes a focus on common ground and collaboration, and allows new ideas to emerge. Most discussion group participants were prepared for the discussions and felt comfortable to modify their views as the discussions continued. Many participants left the process with a greater capacity to analyse and make more informed decisions about policy issues than they had upon entering the process. In this sense, deliberation leads to greater civic literacy. Equally important is that participants felt ownership for the Forum's proposed directions and, as such, realised that they had a role to play in implementing the directions and ensuring the government took action.
- *Ensuring outcomes are embraced by multiple governments*: Initially, the Forum struggled with a lack of provincial involvement. This was of particular importance because the provinces are responsible for the delivery of health care, and recommendations from the national consultation were sure to have implications for provincial operations. The provinces were rightly nervous about raising citizens' expectations in a time of decreased social expenditure. However, even if it may not be possible to have all levels of government involved, the Forum did demonstrate that both informal and formal lines of communication and a commitment to transparency can build trust and keep all players informed.
- *Forum members engaged as individuals and volunteers*: Discussions in Canada of health and health care policy can be highly politicised. The Chair of the Forum's Steering Committee stated "We're a group of people interested in national issues, not a federal government agency... there is an intense desire among us to keep the Forum non-political, but obviously we need a grasp of the political context" (as quoted in Gray, 1994). Because Forum members engaged as individuals and volunteers, rather than representatives of stakeholder groups, they were credible with citizens, government officials and many stakeholders.

Given these challenges and achievements, it can be clearly stated that the Forum did fulfil its mandate. Not only did the Forum present "actionable" recommendations that many stakeholders and citizens were able to endorse, it successfully heightened the level of dialogue surrounding health and health care issues across Canada.

Promising Directions

A number of promising directions regarding citizen involvement in policy development can be identified. Three of particular importance include: (1) Health Canada's recent efforts to establish a strategic policy framework for public involvement, (2) the Government of Canada's current work on a policy for engaging Canadians, and (3) a renewed federal/provincial/territorial commitment to work in a collaborative manner in setting and achieving social policy objectives.

Health Canada: Developing a strategic policy for public involvement

Since 1998, Health Canada has been actively developing a strategic "*Corporate Framework and Guidelines for Public Involvement*". In doing so, Health Canada is striving to become a more "people-focused" department and has committed to ensure public input into processes which affect the policy development and programme delivery of Health Canada; achieve accountability, better decision-making and increased public understanding; and assume that interested and affected parties may want to be involved in an issue and informed of its progress (Health Canada, 1999b).

While the strategic framework is still in its developmental phase, the increased commitment of Health Canada to public involvement, transparency and accountability was repeatedly cited as a promising direction by stakeholders in the current research – yet whether this translates to an increased transparency in policy development remains to be seen.

Government of Canada: A policy for engaging Canadians

The Privy Council Office, in collaboration with all federal departments and agencies, is currently developing a *Federal Policy Statement and Guidelines on Engaging Canadians*. This policy statement will replace the existing federal consultation guidelines (1992). The purpose of the policy is to affirm the government's commitment to public consultation, to define general guiding principles and practices for the effective engagement of citizens in government decision-making, and to outline roles and responsibilities in supporting a consultative culture in the federal government.

The federal government commitment is intended to result in: policies and programmes that are responsive to public priorities, needs and concerns; well-informed, sound and broadly accepted decisions; accountability to decision-makers and the public; ongoing improvement of federal consultation processes; and increased confidence in federal institutions.

Federal/Provincial/Territorial Collaboration: A renewed commitment

The Governments of Canada have a number of mechanisms in place to ensure that social policy objectives pursued at different levels of government are not working at cross purposes. Conferences of federal-provincial-territorial ministers occur at least annually, and more regularly at the level of deputy minister or assistant deputy minister.

In September 1999, the Annual Conference of Federal-Provincial-Territorial Ministers of Health resulted in a firm commitment to joint action and collaboration on a number of key health issues, including commitments to maintain a financially sustainable, publicly funded health care system; collaborate on health and human resource planning; collaborate on work on population health approaches to improve the health of Canadians; and promote the development and effective use of information technologies.

The provincial Minister of Health and Social Services, Prince Edward Island, stated of the meeting, "in addition to jurisdictional duties, Ministers also have a clear responsibility to work together to meet the health needs of all Canadians." The Federal Minister of Health stated that the, "federal, provincial and territorial ministers made real progress here on a broad range of health issues... we will continue working together to ensure that all Canadians have access to high quality health care and that they have the information they require to make well-informed decisions to promote their own health and well-being" (Canadian Intergovernmental Conference Secretariat, 1999). These comments, specific to the health sector, reflect the broader commitment to collaboration as expressed in the recent signing of the Social Union Framework Agreement.

Conclusions

These emergent trends are timely as the Federal Budget delivered on 16 February 1999 included a five-year plan to increase funding to the health care system. In 1998-1999, the total CHST transfer to the provinces was \$CAD 26.3 billion (\$CAD 12.5 billion in cash and \$CAD 13.8 billion in tax point transfers). The 1999 Budget committed an additional \$CAD 11.5 billion in CHST cash over the five year period of 1999-2000 to 2003-2004. This represents a substantial investment in health care, although the cash component of \$CAD 15 billion for 2001-2002 and subsequent years is less than the \$18.5 billion in cash transfers prior to the introduction of the CHST in 1996-97. Most popular with the provinces was the announcement that an initial \$CAD 3.5 billion would be allocated to the provinces on an equal per capita basis over a maximum of three years, and each province would have full flexibility to spend the money at the rate of their choice.

Although this increased money is welcomed by all levels of government and by citizens, it must be noted that the Forum did conclude that Canadians were spending enough money on health care, and that the problems that exist are not caused by insufficient funds. However, when discussing expenditures, the Forum always spoke of the mixture of public and private spending. Therefore, when the Forum recommended that the public system be broadened to include home care and drugs, it was

actually calling for increased public spending, therefore allowing decreased private spending. It remains to be seen if the “fix” the health care system needs is a financial or a structural one.

Regardless, all signs point to increased collaboration between governments, the voluntary sector, stakeholders and citizens, both in the health care sector and across the federal government. This can only lead to more informed policy dialogue and decisions and represents a positive trend in government-citizen relations in Canada.

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