



Canadian Health Services Research **Foundation**  
**Fondation** canadienne de la recherche sur les services de santé

# **Building a Public Dialogue Framework for Defining the Medicare Basket**

June 2006

Thomas Rathwell  
Raisa Deber  
Nuala Kenny  
Lawrence Nestman  
Doreen Neville  
Patricia Conrad  
Eric Nauenberg  
Robert Thompson  
Thomas Ward

## **Funding Provided by:**

Canadian Health Services Research Foundation  
Canadian Institutes of Health Research  
Nova Scotia Health Research Foundation  
Newfoundland and Labrador Centre for Applied Health Research  
Ontario Ministry of Health and Long-Term Care

## Principal Investigator:

Dr. Thomas Rathwell  
Director & Professor  
School of Health Services Administration  
Dalhousie University  
5599 Fenwick Street  
Halifax, Nova Scotia, B3H 1R2  
Canada

Telephone: 1(902) 494-6579  
E-mail: [thomas.rathwell@dal.ca](mailto:thomas.rathwell@dal.ca)

This document is available on the Canadian Health Services Research Foundation web site ([www.chrsf.ca](http://www.chrsf.ca)).

For more information on the Canadian Health Services Research Foundation, contact the foundation at:

1565 Carling Avenue, Suite 700  
Ottawa, Ontario  
K1Z 8R1  
E-mail: [communications@chrsf.ca](mailto:communications@chrsf.ca)  
Telephone: 613-728-2238  
Fax: 613-728-3527

Ce document est disponible sur le site Web de la Fondation canadienne de la recherche sur les services de santé ([www.fcrss.ca](http://www.fcrss.ca)).

Pour obtenir de plus amples renseignements sur la Fondation canadienne de la recherche sur les services de santé, communiquez avec la Fondation :

1565, avenue Carling, bureau 700  
Ottawa (Ontario)  
K1Z 8R1  
Courriel : [communications@fcrss.ca](mailto:communications@fcrss.ca)  
Téléphone : 613-728-2238  
Télécopieur : 613-728-3527

# Building a Public Dialogue Framework for Defining the Medicare Basket

June 2006

Thomas Rathwell<sup>1</sup>  
Raisa Deber<sup>2</sup>  
Nuala Kenny<sup>3</sup>  
Lawrence Nestman<sup>4</sup>  
Doreen Neville<sup>5</sup>  
Patricia Conrad<sup>6</sup>  
Eric Nauenberg<sup>7</sup>  
Robert Thompson<sup>8</sup>  
Thomas Ward<sup>9</sup>

<sup>1</sup> Dalhousie University

<sup>2</sup> University of Toronto

<sup>3</sup> Dalhousie University

<sup>4</sup> Dalhousie University

<sup>5</sup> Memorial University of Newfoundland and Labrador

<sup>6</sup> Dalhousie University/University of Toronto/Canadian Health Services Research Foundation

<sup>7</sup> Ontario Ministry of Health and Long-Term Care

<sup>8</sup> Formerly Newfoundland and Labrador Department of Health

<sup>9</sup> Formerly Nova Scotia Department of Health

## Acknowledgements:

The assistance and contribution of Christine Joffres (senior researcher), Heather Chappell, Roger Chafe, Moses Batema, and Saleema Karim (research assistants) is gratefully acknowledged.

We are grateful particularly to the decision makers in both the public and private health sectors and community representatives who took time from their busy schedules to complete a detailed questionnaire/survey, participate in focus groups, and/or provide valuable comments on various aspects of the program of research.

## Table of Contents

Key Implications for Decision Makers .....	i
Executive Summary.....	ii
The Approach .....	1
<i>Objectives and Questions</i> .....	1
<i>Purpose</i> .....	2
<i>Conceptual Framework</i> .....	2
<i>Study Design</i> .....	5
The Results .....	5
<i>Project 1: Canadian Models</i> .....	5
<i>Project 2: International Models</i> .....	8
<i>Project 3: Private Sector Models</i> .....	9
<i>Project 4: Ethical Implications of Decision Frameworks</i> .....	11
<i>Project 5: Canadian Experiences with Public Participation in Healthcare</i> .....	13
<i>Public Dialogue Framework</i> .....	14
Lessons.....	17
References .....	19

## **Key Implications for Decision Makers**

- The debate about the basket of publicly funded healthcare services includes questions about both the content of policies and the processes to be followed in making such decisions.
- Governments must simultaneously pursue many, often contradictory, policy goals. For example, among the many goals of a healthcare system are to ensure that individuals receive access to high-quality “needed” services in a timely and efficient manner, without consuming so many resources to threaten the ability to pursue other societal priorities. Trade-offs are essential.
- Policy goals include elements of such “dominant ideas” as security, equity, efficiency, and liberty.
- In terms of content, the basket debate is, in large part, about equity. Nonetheless, many important goods are left for individuals to purchase individually.
- In terms of process, it is critical to determine when public involvement is required and for what purpose.
- Priority-setting exercises to date indicate there is much confusion regarding the goal/s or end-state/s desired.
- Countries that engaged in explicit prioritization for defining core services adopted one of the two following strategies. First is the “loose filter” method, whereby they relaxed the prioritization criteria and only rejected those services for which there was evidence of ineffectiveness, while continuing to fund publicly those for which there was no evidence. A second strategy was to grandfather all existing services and apply the prioritization criteria only to new services.
- There is little or no interface between governments and private health insurance carriers and/or benefit consultants. This lack of interface appears to result from disparities in value systems between the public and private sectors, a minimal understanding of the “other,” and mutual distrust.
- An ethical public dialogue framework can help clarify the issues under consideration, elucidate the principles and values that lie behind policy options, and help decision makers analyse the issues involved and their implications by facilitating understanding of the issues through multiple lenses. It also provides politicians and decision makers with an approach for the public justification of a particular course of action.
- The various methods of public involvement notwithstanding, experts continue to dominate prioritization efforts in these countries.
- The framework is an approach that outlines how best to involve citizens and other stakeholders in resource allocations, keeping in mind that different populations might prefer different forms of involvement; identifies the conditions for and how to foster meaningful debates on core services and/or resource allocations; provides guidance on how and when to move forward when consensus fails; and explores mechanisms through which the interests of hard-to-reach and disenfranchised groups can be identified.

## Executive Summary

### Context

Our program of research posits that the effort to determine the basket of publicly financed health services in Canada involves two basic components: the *policy content* of such decisions, and the appropriate *process* to be used in making them. We accordingly place strong focus on the potential contributions of a dialogue about the definitions of equity and its relationship to the efficiency, effectiveness, and overall sustainability of the health system. The framework presented in this report should assist decision makers to accomplish **two key objectives**: (i) to identify under what conditions and for what types of medicare decisions the engagement of the public is a worthwhile endeavour; and (ii) to design and evaluate the process of engaging the public in discussions around medicare coverage decisions.

The program of research undertook to (a) clarify different approaches which have been taken across jurisdictions and sectors towards defining the basket of publicly funded services; (b) place these approaches within a conceptual framework which creates a common language for discussion and highlights available policy options; and (c) test the framework's usefulness and acceptability for conducting a dialogue in Canada, with key stakeholders as senior decision makers and the community.

### Methods

The program of research utilized a qualitative research design in which a variety of methods are used to collect data. Embedded in the three stages around which the program of research was designed were a series of complementary “nested” projects which allowed the research team to triangulate sectors involved with the determination of services for collective funding decisions.

## **Results**

Generally, the experiences that we reviewed did attempt to identify criteria but were unclear about how to use them. Thus, although such concepts as human dignity, solidarity, justice, equity, need, severity, necessary care, effectiveness, efficiency, individual responsibility, value for money, and acceptability were all mentioned in the processes reviewed, it was rarely clear how these particular values or principles were chosen; how to rank or order the values when there is the inevitable conflict; and how to deal with competing or contradictory values.

The countries that attempted to engage in explicit prioritization for defining core services adopted one of the two following strategies. First, they relaxed the prioritization criteria and only rejected those services for which there was evidence of ineffectiveness, while continuing to fund publicly those for which there was no evidence. This is the “loose filter” method. A second strategy was to grandfather all existing services and apply the prioritization criteria only to new services. The partial retreat from explicitness in some countries may be explained by the challenges associated with priority-setting.

Our interviews with private insurers revealed that cost-shifting strategies have increased the burden of healthcare expenditures on employers and employees. The employers we interviewed accordingly are opposed to an expansion of private healthcare to the extent it leads to increased costs, decreased competitiveness, decreased profits, and stock market-related issues. As a result, employers have implemented varied cost containment strategies related to private healthcare baskets, which in turn have shifted costs to individuals.

Our surveys of decision-making/advisory bodies asked respondents to rate the importance of a series of factors in making their coverage decisions. As predicted by the conceptual framework, equity was given a high score. However, the pattern of responses revealed a strong focus on defining equity in terms of the characteristics of the item, with particular emphasis on clinical effectiveness, magnitude of benefit, fit with the mandate of the organization, and total cost. In contrast, most variables related to characteristics of the individual clustered on the relatively unimportant side of the scale, with only severity of symptoms of the illness or the illness itself even getting scores above the neutral point. Committees tend to be dominated by civil servants and health professionals; very few require public participation. Respondents were relatively satisfied with the effectiveness of the body, its process, and the outcomes/decisions but indicated considerable room for improvement. In addition, a mapping of where decisions were being made in four Canadian provinces found considerable differences across sub-sectors, reflecting the power of particular provider groups. It was noteworthy that physician services remained within silos; in contrast, hospital services were more frequently being traded off against other sub-sectors.

## **Implications**

It is not possible or even desirable to engage the public in every healthcare decision. Therefore, decision makers should think carefully about the issues in which they wish to engage the public and the structure of the public participation exercise. The framework should aid decision makers with the process.

## THE APPROACH

### Objectives and questions

Our program of research posits that the effort to determine the basket of publicly financed health services in Canada involves two basic components: the *policy content* of such decisions; and the appropriate *process* to be used in making them. We accordingly place strong focus on the potential contributions of a dialogue about the definitions of equity and its relationship to the efficiency, effectiveness, and overall sustainability of the health system. The framework presented in this report should assist decision makers to accomplish **two key objectives**:

(1) to identify under what conditions and for what types of medicare decisions the engagement of the public is a worthwhile endeavour; and (2) to design and evaluate the process of engaging the public in discussions around medicare coverage decisions.

*Why is this necessary?* Although the comprehensiveness condition of the Canada Health Act requires that all medically necessary hospital and physician services be publicly financed if provinces wish to receive full federal funding, it is silent on the issue of coverage for such rapidly growing out-of-hospital services as homecare, rehabilitation, and, in particular, outpatient pharmaceuticals. Even within the traditional hospital and physician sectors, provinces have the power to define the scope of “medically necessary” services, and considerable variation in access and comprehensiveness already exists across the country. The onslaught of new technologies (including advances in genetics) and increasing consumer demands is taxing the resources of the provincial healthcare systems, with little “evidence base” upon which to make informed decisions about coverage. Calls for the delineation of the boundaries of the publicly funded health system in Canada, often referred to as what should be included within the publicly funded “basket of services,” have grown accordingly.

In terms of the content, the conceptual framework begins with recognition that the basket debate is a debate about equity. In a free market, individuals are free to purchase whatever goods and services they wish and can afford; public funding thus asks the question which (if any) goods and services need be provided on an equitable basis, without regard of ability to pay. It then builds on the insights of Stone who identified a series of ways of viewing equity, which she grouped into three general categories: i) characteristics of the recipients; ii) characteristics of the items; and iii) characteristics of the process. In terms of process, it develops a framework to assist in determining where public involvement is appropriate and how best to structure it.

## **Purpose**

The program of research undertook to (a) clarify different approaches which have been taken across jurisdictions and sectors towards defining the basket of publicly funded services; (b) place these approaches within a conceptual framework which creates a common language for discussion and highlights available policy options; and (c) test the framework's usefulness and acceptability for conducting a dialogue in Canada, working with such key stakeholders as senior decision makers in the public, voluntary, and private sectors, and the community.

## **Conceptual Framework**

As Stone (1) suggests, there are “values of community life that give rise to controversy over particular issues: equity, efficiency, security, and liberty. These values are motherhood values: everyone is for them when they are stated abstractly, but the fight begins as soon as we ask what people mean by them.” She goes on to define them as:

- equity — “treating likes alike;”
- efficiency — “getting the most output for a given input;”
- security — “satisfaction of minimum human needs;” and
- liberty — “do as you wish as long as you do not harm others.”

Furthermore, Stone notes that each of these goals can have multiple claims made in their name. For example, equity can be variously defined in terms of the items, recipients, or processes. In addition, these goals often conflict with one another.

We conclude that the debate about the basket of services is a debate about equity. Among the many goals of a healthcare system are security — that is, ensuring individuals receive access to high-quality “needed” services in a timely and efficient manner — and efficiency — ensuring this is done with the minimum resources needed to accomplish this goal (and that resources are not wasted and so diverted from other valued uses). However, the goal of liberty would also suggest minimal coercion. Thus, by themselves, these goals would not mandate public financing, since many individuals would be able to purchase many of the services needed to meet security goals from their own resources, much as they purchase food or housing. The rationale for public financing of at least some portion of services thus begins with some concept of equity — the belief it is unacceptable for certain people to be denied certain services because of their inability to pay. Note that equity has many meanings, as we explore below. In particular, it is not equivalent to equality; equality is defined in terms of uniformity, whereas equity is defined in terms of “fairness.” The conceptual framework for the research builds on the insights of Stone (1), who argues that “behind every policy issue lurks a contest over

conflicting, though equally plausible, conceptions of the same abstract goal or value\_\_ [T]he first task of the political analyst is to reveal and clarify the underlying value disputes so that people can see where they differ and move toward some reconciliation” (p.12). Stone identified eight separate approaches for analysing equity, which in turn can be grouped into three general categories: i) characteristics of the recipients; ii) characteristics of the items; and iii) characteristics of the process.

*Issues relating to definition of recipients:* A number of issues arise. If likes are to be treated alike, then how does one define like? What is the definition of membership in each group (class of recipients)? To what extent can those who are not alike be treated differently? Indeed, what sorts of factors can legitimately be considered in determining such groups?

Recipients can be defined differently for different purposes. For publicly financed coverage under the Canada Health Act, individuals must fit the definition of “insured persons,” which is further defined as follows (2): “insured persons” refers to a resident of a province other than (a) a member of the Canadian Forces; (b) a member of the Royal Canadian Mounted Police who is appointed to a rank therein; (c) a person serving a term of imprisonment in a penitentiary; or (d) a resident of the province who has not completed such minimum period of residence or waiting period, not exceeding three months, as may be required by the province for eligibility for or entitlement to insured health services (p.4). Other programs may define recipients in terms of clinical/disease status (such as drug programs for people with HIV/AIDS), age (such as programs for children), cause of injury (for example, workers’ compensation), geographic location (for example, programs mounted by regional health authorities), employment status (such as private employer-based insurance), ethno-racial group (for example, programs offered by/to particular community groups, such as First Nations), or income. The appropriateness and acceptability of various definitions clearly requires examination.

*Issues relating to definition of items:* Similarly, how should an item be determined? Should items be considered in isolation, or as part of a larger bundle? Should the value be considered in absolute terms or in terms of the value of an item to a particular individual?

The Canada Health Act defines “insured services” but leaves considerable discretion — they are defined as medically required services (with no guidance as to how this is determined or by whom), as long as they are delivered by medical practitioners (that is, physicians) or in hospitals. This approach does not clarify which individuals will receive particular services (for example, who would have priority to receive an organ). It also leaves room for two different approaches

depending upon the way in which care is financed. The incentives for providing services funded on a fee-for-service basis (including many physician services) thus differ from the incentives for providing services incorporated within global budgets (3). Indeed, global budgets can be an incentive to individual providers to implicitly ration the number (and distribution) of even insured health services through “bedside rationing by physicians” (4).

There is an extensive literature internationally on the rationale for and results of efforts to define which services would be publicly funded, including analyses of explicit rationing efforts in Oregon (5) and New Zealand (6) and de-listing experiences in Britain (7). However, while the National Forum on Health (8) called for significant expansion of publicly funded health services to include homecare and pharmacare, more recent proposals (5, 12) have included the suggestion that we at least examine the possibility of explicitly defining what services should be publicly funded. It must be recognized that public financing cannot be examined in a vacuum; many policy options see public financing as either supplementary or complementary to privately financed care. Indeed, a survey by Gamble et al. reveals considerable disagreement across stakeholders about what items should be universally funded (4). As such, it becomes essential to view definitions of the basket within the context of what will be paid for at all, whether by government, by another third-party payer (workers’ compensation, private insurance, charity), or by the individual and/or his/her family.

Caulfield et al. (9) have developed one such approach — the Four Screen Model — designed to clarify which items should be paid for publicly. The model begins with a pre-screen, to determine if the service is ethically acceptable. If the service fails the pre-screen, it need not be further evaluated. The model relies upon expert advice for the first two screens, with allowance for “conditional passes” where evidence is incomplete. Screen 1 — effectiveness (does it work?) — requires expert input. Screen 2 — *appropriateness* (how much will it benefit particular potential recipients?) — also requires expert information, tailored to the individual potential recipient (and hence operationally often applied by front-line providers). The next two screens incorporate public input, as consumer and as citizen. Screen 3 — *informed consent* (does the recipient really want the service, given the risks and benefits?) — requires dialogue between potential patient and provider. The fourth screen then explicitly addresses the issue of whether the public should pay for that service. A number of criteria are suggested, including the need to collect better evidence to deal with uncertainties arising at screens 1 and 2, the desire to provide services in the most efficient manner possible, and the ethical question about whether we, as a society, are willing to let people get priced out of the market for the service. If the answer is no, Caulfield et al. (9) suggest the service should be included in the basket of

publicly financed healthcare services. If the answer is yes, then a market-driven private financing option can be made available for persons wishing to access this service.

*Issues relating to definition of process:* Process is important because people are more willing to accept unequal results if the process is considered fair. Stone (1) contends that process is important because in society, distributions of services are “carried out by real people, taking real actions, not by invisible hands\_ the processes of distribution create or destroy things of value (such as loyalty, community spirit or jobs) apart from the things that they explicitly distribute” (p52). A number of issues arise when considering process. For example, who should make these decisions? Decision-making can be placed within government (national, provincial, or local), within regional health authorities or similar sector-specific bodies (such as Ontario’s community care access centres, which allocate homecare services), within provider organizations (for example, hospitals or physicians deciding how to use their resources), or even at the individual level (such as medical savings accounts). Decisions about which services should be provided through public funds could use a variety of processes, ranging from competition, through to lottery, first-come-first-served, or voting.

### **Study Design**

The program of research utilized a qualitative research design in which a variety of methods are used to collect data. Embedded in the three stages around which the program of research is designed are five “nested” projects which are complementary and provide triangulation of sectors involved with the determination of services for collective funding decisions (that is, publicly insured, publicly funded but not universally insured programs including pharmacare or homecare). In addition, the projects employed comparative triangulation since the scope of the projects includes provincial, national, and international perspectives. Triangulation in this context refers to the process of applying a number of different approaches to the research questions to enhance the validity of the information obtained and to reduce inherent bias.

## **THE RESULTS**

**Project 1: Canadian Models** [led by Raisa Deber] reviewed current approaches taken in Canada to defining the basket of publicly funded services in different sectors and different jurisdictions. The project was disaggregated into three components: *(i) macro-level decisions about which service categories will be given public financing; (ii) meso-level decisions about how resources will be allocated within a program; and (iii) micro-level decisions about how resources will be allocated within a service category.*

One component involved a survey which was distributed and completed between March 1, 2004 and March 11, 2005 to decision-making/advisory bodies involved in making decisions about “who gets what” for nine specified sub-sectors [see Appendix One for the survey instrument]. Responses were received from 44 bodies in the provinces of Ontario (18), Newfoundland and Labrador (9), Nova Scotia (7), British Columbia (4), Alberta (4), Manitoba (1), and Saskatchewan (1). To preserve anonymity, results are reported in aggregate form.

These bodies were involved in making decisions/giving advice about the following sub-sectors (many were involved with multiple sub-sectors): physician services (48 percent); out-of-province benefits (21 percent); drug benefits (25 percent); assistive devices (21 percent); public health (39 percent); homecare (46 percent); hospital services (36 percent); diagnostic testing (39 percent); and long-term care (34 percent), as well as a number of other services, including ambulance, community relations, health promotion, mental services, and placement services for disabled populations (23 percent).

Several questions attempted to determine the relative importance of characteristics of the items and the recipients. All were scored on a Likert scale of 1-5, where 1 = not at all important and 5 = very important. The following tables give sample size, mean, and standard deviation for each potential factor.

The first question asked about the characteristics of individuals who might receive an item (Table 1):  
*“There are a number of factors which might be used in making decisions about “who gets what.” When your decision-making body makes its decisions, how important are each of the following factors about the categories of the people who might receive the goods/services?”*

**Table 1**

<b>Factors</b>	<b>N</b>	<b>Mean</b>	<b>Std Dev</b>
Geographical location (e.g., the region they live in)	44	2.85	1.5
How disease/disability was acquired (e.g., workplace, auto)	44	1.72	1.2
Age	44	2.35	1.4
Income	44	1.83	1.3
Insurance coverage	44	1.77	1.1
Severity of symptoms	44	3.23	1.5
Severity of illness (e.g., if it is life-threatening)	44	3.45	1.7
Total costs already incurred by that individual (e.g., cap on total costs)	44	2.03	1.2
Other factors	44	1.67	1.3

Although all of these factors ranged from 1 to 5, most items related to characteristics of the individual clustered on the relatively unimportant side of the scale, with only the severity of symptoms of the illness and the severity of the illness (whether it is life-threatening) getting scores above the neutral point. **Equity**, in short, appears to make our respondents unwilling to single out some individuals as more deserving than others.

The next question looked at a series of potential characteristics of the item (Table 2):

*“There are a number of factors which might be used in making decisions about which goods/services to provide. When your decision-making body makes its decisions, how important are each of the following factors about the items themselves?”*

**Table 2**

<b>Factors</b>	<b>N</b>	<b>Mean</b>	<b>Std Dev</b>
<b>Clinical</b> , Demonstrated effectiveness	43	4.43	0.82
<b>Clinical</b> , Magnitude of benefit, if successful	43	4.08	1.03
<b>Clinical</b> , Probability of benefit	43	3.69	1.15
<b>Clinical</b> , Morbidity/side effects compared to alternatives	43	3.63	1.20
<b>Clinical</b> , Number likely to receive good/service	43	3.42	1.25
<b>Clinical</b> , Ability to target those more likely to benefit, “number needed to treat”	43	3.44	1.25
<b>Clinical</b> , Cost-effectiveness	43	3.90	0.92
<i>Clinical, Other</i>	43	1.16	0.75
<b>Financial</b> , Total cost	43	4.07	1.07
<b>Financial</b> , Revenue-generating potential	43	1.71	1.03
<b>Financial</b> , Net cost to funding body	43	3.66	1.10
<b>Financial</b> , Source of payment	43	2.49	1.40
<b>Financial</b> , Type of payment	43	2.44	1.40
<i>Financial, Other</i>	43	1.35	1.11
<b>Organizational Impact</b> , Need for additional specialized personnel/staffing	43	3.76	1.21
<b>Organizational Impact</b> , Need for more space/infrastructure	43	3.48	1.40
<b>Organizational Impact</b> , Demand from patients	43	3.52	1.07
<b>Organizational Impact</b> , Demand from providers	43	3.43	0.98
<b>Organizational Impact</b> , Controversy/media attention	43	3.08	1.25
<i>Organizational Impact, Other</i>	43	1.22	0.85
<b>Managerial</b> , Availability of similar services elsewhere	43	3.53	1.17
<b>Managerial</b> , Fit with mandate of organization	43	4.20	0.87
<b>Managerial</b> , Fit with current services offered by organization	43	4.06	0.89
<b>Managerial</b> , Coverage decisions in other jurisdictions/organizations	43	3.44	1.05
<i>Managerial, Other</i>	43	1.07	0.46
<b>Ethical Principles</b> , Equity	43	4.03	1.04
<b>Ethical Principles</b> , Compassion	43	3.62	1.03
<b>Ethical Principles</b> , Comprehensiveness	43	3.85	0.95
<i>Ethical Principles, Other</i>	43	1.31	1.00

In contrast, the specific clinical, financial, organizational impact, managerial, and ethical factors clustered on the important side of the scale (above 3). However, certain financial factors such as the revenue-generating potential of the items, source of payment (public, private, or out-of-pocket), and the type of payment (global budget or fee for service) scored below the neutral point of 2.5 and were therefore considered unimportant.

In terms of process, committees tend to be dominated by civil servants and health professionals; very few require public participation. Respondents were relatively satisfied with the effectiveness of the body, its process, and the outcomes/decisions (all scoring slightly above the neutral point with scores about 3.5 on a 5-point scale) but indicated considerable room for improvement.

A second component involved a mapping of where decisions were being made in four Canadian provinces found considerable differences across sub-sectors, reflecting the power of particular provider groups. It was noteworthy that physician services remained within silos; in contrast, hospital services were more frequently being traded off against other sub-sectors. Full results are included in the master's thesis of H. Chappell (10).

**Project 2: International models** [led by Thomas Rathwell and Christine Joffres] undertook a thorough review and critique of the international literature on the topic of defining the boundaries of a publicly insured health system in selected industrialized countries. The focus is on prioritization in publicly financed healthcare systems and reviews the experience of a sample of countries that have engaged in priority-setting in order to define core public services (Norway, the Netherlands, New Zealand, Sweden, and the U.S./Oregon).

Implicit prioritization prevails in most in countries and has traditionally been characterized by an avoidance of explicit choices, a lack of clarity about the strategies used to choose between healthcare services or programs, and failure to make publicly accountable statements about the rationale for decisions, thus leading to a lack of awareness among the public that prioritization is actually occurring (9,11,12). However, public awareness of growing waiting lists, increasing demands for new services, the need to contain costs, and well-publicized “tragic” cases have highlighted the ethical and practical challenges of prioritization and made implicit strategies less appealing (13).

Prioritization approaches in the countries reviewed had several purposes. They were generally intended to guide future purchasing decisions at the political and/or planning levels. They were also designed to define a core of healthcare services to be publicly funded and accessible. These

services were defined with reference to various principles, including need, evaluation of the value of the services under consideration, appropriateness of services, and/or some element of effectiveness linked to a specific clinical context. A variety of stakeholders was involved in the development of prioritization models, including lay citizens, experts (such as clinicians, economists), administrators, and politicians. The influence of stakeholders was rarely explicit, with the exception of New Zealand, where stakeholder involvement led to the identification of six priority services areas — children’s health; mental health; integrated community care; emergency ambulance services; rehabilitation; and hospice care — and where stakeholders continue to be involved in prioritization. In some cases, such as in the Netherlands, the resulting prioritization models generated a great deal of public and/or professional resistance. The models also suggest an inherent dilemma as to the meaning and operationalization of participation. For example, in many models, while the “public” was consulted regarding a number of issues related to the development of prioritization models, little was said (or done) to ensure ongoing involvement of a broad range of stakeholders in the actual prioritization decisions, with perhaps the exception of New Zealand and Sweden. The activities undertaken in New Zealand, Sweden, the Netherlands, and Norway were quite “democratic” as citizens were represented on the commissions, although in a different sense than what the “public involvement” convention requires. The various methods of public involvement notwithstanding, experts continue to dominate prioritization efforts in these countries.

Ultimately, the countries examined that attempted to engage in explicit prioritization for defining core services adopted one of the two following strategies. Sometimes, they relaxed the prioritization criteria and only rejected those services for which there was evidence of ineffectiveness, while continuing to fund publicly those for which there was no evidence. This is the “loose filter” recommended by Deber et al. (14,15). A second strategy was to grandfather all existing services and apply the prioritization criteria only to new services (16). The partial retreat from explicitness in some countries may be explained by the challenges associated with priority-setting.

**Project 3: Private Sector Models** [led by Lawrence Nestman and Christine Joffres] solicited and critiqued information gathered from private sector insurance companies in Canada, Europe, and the U.S. regarding the processes they undertake to decide upon a basket of services offered under their insurance plans.

Data were collected via face-to-face interviews or focus groups in Alberta, Ontario, Quebec, and Nova Scotia. An interview guide was developed and reviewed by key informants and tested for

face and content validity. The interview guide included two types of questions: those that ensured specific issues related to private healthcare baskets were systematically explored with each respondent; and those that facilitated the generation of spontaneous information and allowed interviewers to pursue information in whatever direction seemed most appropriate. Questions were about the decision-making criteria influencing the design of health plans, the roles of insurers and employers with regard to employees' benefits packages, cost containment strategies, and the interface between the public and private baskets of healthcare.

Participants were selected purposefully with specific attention to relevance (that is, the participants' professional experiences were relevant to the research questions) and diversity (that is, inclusion of participants with diverse backgrounds, such as for profit and not-for-profit, insurance companies, and consulting firms). Informants included 12 large organization employers, 26 CEOs and executive personnel from the seven biggest private health insurance companies, and 24 key people from international benefit consulting firms.

There is little or no interface between governments and private health insurance carriers and/or benefit consultants. This lack of interface appears to result from disparities in value systems between the public and private sectors, a minimal understanding of the "other," and mutual distrust. Private health insurance carriers repeatedly expressed they would like to be advised of, if not consulted, approximately six months in advance of any services being de-listed from the list of publicly funded healthcare services.

Increased public healthcare expenditures have led to varied cost-shifting strategies (from public to private sector), delays (in adding new services to the list of publicly funded services), inter- and intra-provincial erosion of equity, and an erosion of the comprehensiveness of publicly funded healthcare packages. For example, over the years, governments have reduced the coverage of, restricted the eligibility to, or eliminated previously publicly funded services, including rehabilitative and chiropractic services, assistive devices, eye and dental care, home support, mental services, out-of-province coverage, and out-patient pharmaceuticals. This was particularly noticeable in the less affluent provinces (Nova Scotia, Newfoundland and Labrador, New Brunswick, and Prince Edward Island). In some provinces, governments have become the second payer of services traditionally covered by the province (such as specific dental services in Nova Scotia). This erosion has led to a decreased access to specific services (particularly in poorer provinces), increased waiting for specific services, queue jumping, and a mushrooming of private clinics for diagnostic services, eye care, and more recently hip and knee surgery.

Employers are opposed to an expansion of private healthcare as it leads to increased costs, decreased competitiveness, decreased profits, and stock market-related issues. As a result, employers have implemented varied cost-containment strategies related to private healthcare baskets including:

- changes in overall plan design (such as defined contributions plans versus defined benefits plans);
- changes in overall plan design (such as defined contributions plans versus defined benefits plans);
- changes in benefits package design (such as annual caps for specific services);
- implementation of new delivery mechanisms (such as pre-approval/authorization of specific services or drugs);
- changes in plan funding/contributions (such as collective purchasing);
- benefits cuts (such as for massage therapy);
- enhanced communication with employees to become better consumers;
- development of incentives for employees to go to low-cost providers;
- elimination or reduction of future retiree benefits coverage; and
- development of workplace wellness programs.

**Project 4: Ethical Implications of Decision Frameworks and Processes** focused on developing an analytical framework incorporating ethical models and approaches to public participation. The project [led by Nuala Kenny] focused on defining and describing key ethical issues in building a public dialogue to determine what services and programs ought to be delivered by universal, publicly funded healthcare. An outline of theoretical issues requiring exploration was developed including:

1) understanding public policy as a moral/ethical endeavour and a citizen issue; and 2) practical issues in creating a public dialogue: a) definitions of dialogue and forms of public participation; b) clarifying the goals of the dialogue; c) space for the dialogue; d) language and form of the dialogue and the role of evidence; e) the problem of representation; f) the influence of elites, advocacy, and special interest groups; g) consensus, compromise, and decision-making; and h) evaluation.

From exploration of these issues, we conclude that an ethical analysis of public policy should include an assessment of the ends or goals of the policy, the process by which the decision is made, and the explicit criteria utilized in the decisions. An ethical framework for public dialogue would include attention to the values inherent in each of these three elements.

We reviewed a set of international priority-setting exercises as well as extensive literature on Canadian public participation in health decisions. We found that there is much confusion regarding the goals of the projects and of public participation itself. Some processes were focused on improving the health of the public; others were focused on managing healthcare costs; others were aimed explicitly at the identification of those services and programs that “deserved” public funding. Without clarity regarding the goal/s, meaningful priority-setting becomes very difficult.

The development of an ethical public dialogue framework requires identification of a process which encompasses fairness, inclusion, participation, transparency, reasonableness, and public accountability. An ethical process for determining priorities for the use of public resources is crucially important “in cases where there is a range of viewpoints about the right and the good, or in cases where ‘tragic choices’ must be made collectively, as in cases of priority setting or rationing” (17). Such a process ought to ensure that efforts are made to get input from all the potential stakeholders affected by healthcare resource allocation, including hard-to-reach and/or disenfranchised groups; all deliberations should be publicly accessible, visible, and genuine; and the resulting decisions should be publicly available and be subject to appeal and revision in response to legitimate concerns. Attention must be given to the proper balance between professionals and the public in the process. The complex issue of the role of empirical evidence and its understanding by the public participants is an essential element of any priority-setting exercise. Any process to determine societal priorities must include an element of public accountability. Additionally, a transparent process requires that those participating in the priority-setting debates be given adequate background information; consequences of priority-setting options be clearly outlined; and the rationale, consequences, and trade-offs of decisions be made widely public.

Finally, an ethical framework for priority-setting requires identification and explication of the criteria (substantive values) which are or ought to be utilized in making the decision/s. The experiences we reviewed identified various criteria. Some criteria were clearly ethical/normative, whereas others were more technical. Explicit ethical concepts such as human dignity, solidarity, justice, equity, need, severity, necessary care, effectiveness, efficiency, individual responsibility, value for money, and acceptability were mentioned frequently. It was not always clear how the particular values or principles were chosen (except perhaps in the cases of New Zealand and Norway) or ranked when there is the inevitable conflict and how to deal with competing or contradictory values. To be fair, Sweden had a very clear rank order of their principles, and Norway stated explicitly that they had to be balanced, thus the reasons for emphasizing fair

process and accountability. These countries notwithstanding, there was a general failure of the projects reviewed to develop a formal ethical framework. From these reviews it is clear that more work on clarification of the values at stake in public involvement in health priority-setting is needed if explicit priority-setting is to achieve its potential.

**Project 5: Canadian Experiences with Public Participation in Healthcare** [led by Doreen Neville and Roger Chafe] was a literature review designed to complement the findings from the other four projects. Together, they provided the raw material for the development of the framework (outlined below) to assist decision makers in better engaging the public in healthcare decisions.

The federal and provincial governments have long recognized the importance of public participation in healthcare, as illustrated by the conclusions of a wide variety of reports on the healthcare system dating from the early 1970s. Thus there have been numerous attempts over the years at all levels of the healthcare system to engage the public in healthcare decisions.

A review of the academic literature since 1980 on Canadian experiences of public participation in healthcare governance was undertaken. Articles included in the review were those that discussed actual experiences of public participation in healthcare governance in Canada. Articles which examined Canadian public participation the areas of health research, health promotion, compliance with treatment regimes, and patient-physician relations were largely excluded from the review. However, when the public's involvement in these areas extended to the management of budgets and other aspects of program governance, they were included in the review. Articles about research on public participation, theoretical analysis, or expert opinion on how to improve public participation also were included. Altogether, some 76 articles published between 1980 and 2005 met the selection criteria.

One product of the review is an annotated bibliography (Appendix Two). The annotations focus on outlining the main points in the article, describe the type of public participation exercise undertaken, and identify the main findings and/or lessons learned. Where appropriate, the original abstract of the article is provided. Some of the key factors arising from the review are:

- there is little experience in Canada with large priority-setting exercises for medical services;
- there is considerable evidence of public involvement in priority-setting at the regional or program level;

- involvement of the public is uneven and skewed, so that extra measures need to be in place to ensure the participation of marginalized groups; and
- there are costs associated with public participation for all parties, whether the institution or the individual.

### **The Public Dialogue Framework**

This component of the study was led by Doreen Neville and Roger Chafe. Following a review of both the academic literature regarding public engagement exercises in Canada, the U.S., and Europe and the findings from the five projects in Phase 1, several key points emerged which helped shape the development of the framework document. These include:

- Within the context of the Canadian healthcare system, medicare coverage decisions are made by different levels of government and numerous groups of decision makers.
- Medicare coverage decisions encompass a wide range of topics, but can be categorized broadly as decisions to increase, redirect, or reduce resources directed to components of the publicly funded health insurance system. Examples include decisions regarding whether to cover the latest pharmaceuticals, new medical procedures, or expanded homecare services; direct more resources to the prevention of public health programs; or remove services from coverage (de-listing).
- Medicare is first and foremost a publicly funded program and the public has a legitimate and useful role to play in determining what the program should and should not deliver.
- To date, the approach to public participation in healthcare decision-making in Canada and elsewhere has been neither systematic nor consistent; and concerns have been expressed about the degree to which *meaningful* public participation occurs during consultation exercises.

The decision was reached that the framework should assist decision makers to accomplish **two key objectives:** (i) to identify under what conditions and for what types of medicare decisions the engagement of the public is a worthwhile endeavour; and (ii) to design and evaluate the process of engaging the public in discussions around medicare coverage decisions.

The framework document (Appendix Three) is presented in two main sections. The first part of the framework provides a synopsis of some of the key issues which need to be considered in developing public participation exercises around medicare coverage and how these issues impact the design of a public engagement exercise. This synopsis is not meant to be an

exhaustive account of all the possible issues which may arise, but rather an overview of the important points which should be considered in order to develop a viable, meaningful public participation exercise. Topics addressed include:

- **Decision-making considerations:** the need for hard choices, the choice between explicit and implicit decision-making approaches, level of coverage decisions required, decisions regarding who gets what; and
- **Issues which Arise in Designing a Public Participation Exercise:** what is public participation in decision-making, what are the goals of public participation in decision-making, what do we want public input on, what level of public involvement is appropriate, who is the public, how do we handle the diversity of views which will be expressed, should we involve the private sector industry, how do we structure the exercise, and what are the major costs involved?.

The second part of the framework is arranged around the three phases of any public engagement exercise: (i) setting goals; (ii) structuring the process; and (iii) reporting and evaluating success. The steps involved in each phase are presented in Table 3 and briefly discussed below.

**Table 3**  
**A Framework for Involving the Public in Medicare Coverage Decisions**

<b>Phase 1: Establish the Goals</b>	<b>Phase2: Structure the Exercise</b>	<b>Phase 3: Evaluate The Exercise and Communicate Results</b>
<ul style="list-style-type: none"> <li>■ Step 1: Identify the Decision Question</li> <li>■ Step 2: Identify the Rationale for Involving the Public</li> <li>■ Step 3: Confirm/Revisit the Decision to Engage in the Public Participation Exercise</li> </ul>	<ul style="list-style-type: none"> <li>■ Step 4: Specify the Task the Public Will be Asked to Undertake</li> <li>■ Step 5: Confirm the Desired Level Of Public Involvement</li> <li>■ Step 6: Determine the Timing of the Public Participation Exercise within the Decision-Making Process</li> <li>■ Step 7: Select the Participants</li> <li>■ Step 8: Finalize the Structure of the Public Engagement Exercise</li> </ul>	<ul style="list-style-type: none"> <li>■ Step 9: Evaluate the Participation Exercise</li> <li>■ Step 10: Disseminate the Findings</li> </ul>

In Phase 1 (setting goals) the focus is on identifying the decision which must be made and clarifying the rationale for involving the public in the decision-making process. *The framework provides a series of screening questions at the end of Phase 1 which can help decision makers*

*confirm or revisit their intention to proceed with a public participation exercise at this time and for this question.*

In Phase 2 (structuring the public engagement exercise) the focus shifts to the logistics of designing the exercise, such as specifying the task the public will be asked to undertake, confirming the desired level of public involvement, determining the timing of the engagement exercise within the decision-making cycle, selecting the participants, and finalizing the design of the exercise. *The framework provides a checklist that the decision maker can use at the end of this phase to determine if the public participation exercise has been adequately designed.*

Phase 3 (evaluating the process and communicating results) outlines the major questions which should be addressed in an evaluation of the exercise and approaches to dissemination of the findings once the exercise is completed.

### ***Preliminary Testing of the Framework***

The framework was circulated for preliminary feedback to several representatives of decision-making organizations and consumer/community groups. Several approaches were utilized:

- Guidelines for conducting focus groups with decision makers were developed. Focus groups with decision makers were held in St. John's and Halifax.
- Decision makers in Ontario were sent a copy of the framework document (as well as background information) and asked to provide feedback regarding its utility and suggestions regarding how it could be revised to be more helpful to decision makers.
- Guidelines for conducting focus groups with community groups were also developed. Focus groups with community representatives were held in St. John's and Halifax.

See Appendix Four for a more extensive summary of the feedback received from each group: decision makers and community representatives.

Thus the framework is an approach that outlines how best to involve citizens and other stakeholders in resource allocations, keeping in mind that different populations might prefer different forms of involvement; identifies the conditions for and how to foster meaningful debates on core services and/or resource allocations; provides guidance on how and when to move forward when consensus fails; and explores mechanisms through which the interests of hard-to-reach and disenfranchised groups can be identified.

The research team is in the process of revising the framework document to incorporate the

feedback received to date. Additional testing of the framework with both decision makers and community representatives is required.

## **LESSONS AND IMPLICATIONS**

Our review confirms that prioritization is not amenable to fixed or technical formulas, and that the operationalization of current priority-setting criteria (such as need, efficiency) remains challenging. Additionally, prioritization cannot be isolated from the complexities and realities of healthcare systems. As noted earlier, prioritization decisions are made at different levels: national/federal; state/provincial/or equivalent; district health authority/city council/or equivalent; hospital (hospital management and hospital departments); and at the general practitioner and specialist levels, all of which may differ in their perspectives to priority-setting. Additionally, within each of these levels, different cultures have been identified: the administrative culture, the treatment culture, and the care culture (18,19). These three cultures can lead to different approaches to priority-setting issues. For example, administrators may support shorter hospitalization times given that this would allow treating more patients and decreasing waiting times. Clinicians are less concerned by decreasing waiting lists than by attending to the health needs of each one of their patients. Concretely, this means that clinicians will only release patients when their illness/disease has been effectively treated. For care providers, patients may be released only when they feel safe being discharged and/or have a social network able to provide care to patients outside of the hospital. While the dividing line between the three cultures may not be as clear as articulated here, it does exist and it does affect prioritization decisions.

Our surveys of decision-making/advisory bodies involved with making decisions about any or all of specified sub-sectors asked respondents to rate the importance of a series of factors in making their coverage decisions, on a Likert scale from 1 = not at all important to 5 = very important. As predicted by the conceptual framework, equity was given a high score (4.03). However, the pattern of responses revealed a strong focus on defining equity in terms of the characteristics of the item, with particular emphasis on clinical effectiveness, magnitude of benefit, fit with the mandate of the organization, and total cost. In contrast, most variables related to characteristics of the individual clustered on the relatively unimportant side of the scale, with only severity of symptoms of the illness and severity of the illness even getting scores above the neutral point. Committees tend to be dominated by civil servants and health professionals; very few require public participation. Respondents were relatively satisfied with the effectiveness of the body, its process, and the outcomes/decisions (all scoring slightly above the neutral point with scores about 3.5 on a 5-point scale) but indicated considerable room for

improvement. In addition, a mapping of where decisions were being made in four Canadian provinces found considerable differences across sub-sectors, reflecting the power of particular provider groups. It was noteworthy that physician services remained within silos; in contrast, hospital services were more frequently being traded off against other sub-sectors

Our analysis reinforces what others have already pointed out (16,20-22). There is a continuous need for further research and additional information on varied issues, including the health status of populations (distribution of disease, disability, and risk factors); the needs amenable to healthcare interventions; the relative degrees of need in different populations; the relative effectiveness and cost-effectiveness of various services; optimum material for decision-making for prioritization; priority-setting tools (tools for analysis and decision-making); priority-setting options and their trade-offs; awareness and communication strategies to educate citizens about difficult questions and democratic values; as well as in meaningful ways to involve the different stakeholders.

However, our analysis also suggests the need for an ethical framework that would guide prioritization decisions. An ethical framework can assist in clarifying the issues under consideration, elucidate the principles and values that lie behind policy options, and assist decision makers in the analysis of the issues involved and their implications by facilitating understanding of the issues through multiple lenses. It also provides politicians and decision makers with an approach for the public justification of a particular course of action.

## REFERENCES

1. Stone, D. *Policy Paradox: The Art of Political Decision Making*. New York: WW Norton & Company, 1997.
2. Government of Canada. *Canada Health Act*. Ottawa: Government of Canada, 1985
3. Robinson JC. Theory and practice in the design of physician payment incentives. *Milbank Q.*, 79(2):149-177, 2001.
4. Deber R, Gamble B. “What’s in, what’s out”: Stakeholders’ views about the boundaries of Medicare. *Healthcare Quarterly*, 7(4), suppl 2-10. 2004.
5. Brannigan M. Oregon’s experiment. In D. Seedhouse ed. *Reforming Health Care: The philosophy and practice of international health reform*. Chicester: Wiley, 1995
6. Howden-Chapman P, Ashton T. Public purchasing and private priorities for healthcare in New Zealand. *Health Policy*, 54:27-43, 2000
7. Hunter DJ. *Desperately Seeking Solutions*. New York: Addison-Wesley Longman, 1997
8. National Forum on Health. *Canada Health Action: Building on the Legacy: The Final Report of the National Forum on Health*. V.1 Ottawa: National Forum on Health, 1997
9. Caulfield, Tim A; Burgess, Michael M; Williams-Jones, Bryn; Baily, Mary Ann; Chadwick, Ruth; Cho, Mildred; Deber, Raisa; Fleising, Usher; Flood, Colleen; Friedman, Jan; Lank, Rhoda; Owen, Terrance; Sproule, John. Providing genetic testing through the private sector - a view from Canada. *Isuma*, 2(3):1-10, 2001.
10. Heather Chappell, “Provincial Structures for Resource Allocation Decision-making Health Care: A case study of four provinces in Canada.” MSc, U of Toronto, Department of Health Policy, Management and Evaluation, 2005.
11. Coast, J, Donovan J, Frankel S. *Priority setting: the health care debate*. New York; John Wiley & Sons, 1996

12. Calabreis G & Bobbitt P. *Tragic Choices: The conflicts society confronts in the allocation of tragically scarce resources*. New York: WW Norton & Company, 1978.
13. Ham C. *Health Care Reform: Learning from International Experience*. Buckingham: Open University Press, 1997.
14. Deber R, Narine I, Baranek P, Sharpe N, Zlotnik-Shaul R, Coyte P, Pink G, Williams P. *The public-private mix in health care. Report to the National Forum on Health by the University of Toronto, Department of Health Administration, 1997.*
15. Deber R, Ross E, Catz M. *Comprehensiveness in health care. Report to the HEAL. University of Toronto, Department of Health Administration, 1994.*
16. Hurley J, Cosby J, Giacomini M, Hutchison B. *Making resource allocation decisions in the health care sector: A review of some recent proposals. Regionalization Research Centre. Saskatoon Saskatchewan, Occasional Paper No. 4, 2000.*
17. Kenny N, Giacomini M. *Wanted: A new ethics field for health policy analysis. Health Care Analysis, 13(4):247-250, 2005.*
18. Danish Council of Ethics. *Priority-setting in the Health Services. Denmark, Danish Parliament. 1997.*
19. Eriksen H, Ulrichsen H. *Three cultures in the hospital sector, nursing administration and medical column. Copenhagen: Handelshojskolens Forlag, 1991.*
20. Ashton T, Cummings J, Devlin N. *Priority-setting in New Zealand: translating principles into practice. J Health Serv Res Policy, 5(3):170-5, 2000.*
21. Maynard A, Bloor K. *Our certain fate: rationing in health care. London: Office of Health Economics, 1998.*
22. Rachlis M, Kushner C. *Strong medicine: How to save Canada's health care system. Toronto: Harper Collins, 1994.*