

What is In and Out of Medicare? Who Decides?

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Introduction

Five commissions in the last five years have investigated the future sustainability of Medicare in Canada: the Fyke Report in Saskatchewan, the Clair Report in Quebec, the Mazankowski Report from Alberta, the Kirby Report (produced for the Senate), and the Romanow Commission (appointed by the Prime Minister of Canada). Notwithstanding the different ideologies of the governments that commissioned them, all of their reports have confirmed certain fundamental principles of Canada's publicly-funded Medicare. For example, according to the Romanow Commission's final Report, all aspects of its review pointed to the "overriding conclusion that there is no need to abandon the principles or values underpinning Canada's health care system."ⁱ

The Canadian system rests on two bedrock principles. First, it is a system where access to important medical care is distributed on the basis of need, rather than ability to pay. Second, it is a system where services covered under Medicare are financed almost exclusively through general taxation revenues. Notwithstanding the endorsement of these key principles by multiple commissions, profound questions linger and will continue to linger long after the many volumes of commission reports have gathered dust. Specifically, these questions are:

- **What** health care services should be publicly funded?;
- **Who** decides what services should be publicly funded?; and
- What are the **processes** by which these decisions are made?

This issue is made more pressing by the acceptance of the First Ministers in the Health Accord of 2003 that the core of publicly-funded Medicare should expand beyond the traditional sectors of hospital and physician services and into home care and eventually into prescription drugs. As the *categories* of services that may receive full public funding broaden, it becomes even more crucial

to ask who decides what particular services within those categories should be publicly funded and what principles and processes guide those decisions?

With respect to the question of “what” services to fund, it is impossible to generalize across nations given different resource constraints and different values. A human rights approach, as epitomized in the Convention on Economic Social & Cultural Rights, is vital for determining a basic minimum of access to health care.ⁱⁱ However, as a country develops, it expands its medical care system beyond the “core” demanded by international human rights conventions to a much larger “core”; ambiguity prevails over what should be publicly funded or left to the private sector.

This ambiguity can be caused by an increased choice in health care delivery options due to technological or pharmaceutical advancements. How does one decide on which delivery option to choose? Is it a simple cost decision? For example, if a treatment costs \$150,000 with a 5% chance of success, should this be publicly funded? Or, if a new drug achieves the same health outcome at a price that is 20% above the existing drug on the market but has no side-effects; should this be publicly funded? In theory, of course, the choices or decisions made should be a function of information about the *relative* costs and health benefits, a function of the values we hold about achieving different health states and the values we have with regard to equality and fairness (in Canada, these values are part of the Constitution through the Charter of Rights and Freedoms), and a function of available resources. The process, however, is complicated even further by the simple economic truth that monies spent on one thing cannot be spent on another and thus trade-offs must always be made. For example, if the Ontario government spends an extra \$150,000 on health care then it cannot spend it on education, so what do Ontarians get for this money in health relative to education?

A Decision-Making Framework Grounded in the Canadian System

There have been numerous theoretical models put forward as templates for guiding decisions about what should and should not be publicly-funded both in Canada and internationally. However, while it is possible to speak in theory about how decisions should be made about what is in and out of publicly-funded Medicare it seems much more difficult to operationalize this in practice. The attempts to articulate the general principles that should drive decision-making about what is in and out of a publicly-funded basket both in Canada and internationally suffer from being too general, too abstract, and divorced from the complex details of any particular health care system. In particular, the existing models fail to take account of the political-economy of particular systems. Any system of decision-making filters the consideration of values, resources and information about costs and benefits through local structures and processes. As we discuss further below, in Canada, these structures and processes are characterized by accidents of history and long-held accommodations between governments and the medical profession, inflexible and inadequate regulations and law, and the interaction of different stakeholders and interest groups.

Thus before we can theorize about what processes and principles should be adopted it is important to understand how decisions are made now. This is in order to be able to ascertain and identify what principles and processes directly or indirectly currently drive decision-making and because the existing system will constrain what reforms are possible. Decision-making about what is in and out of Canadian Medicare is driven by the overarching normative framework that governs it, the *Canada Health Act*. The *Canada Health Act* provides that in exchange for federal funding, provinces need to ensure full public funding of “medically necessary” hospital services and “medically required” physician services. But the Act does not provide a definition of “medically necessary” and “medically required.” Nor, in turn, does provincial legislation. How, then, do provinces determine which particular services to fund?

We are part of a team of 10 interdisciplinary scholars who, through a three-year program of research, will explore how in Canada we decide what is in and out of the Medicare basket and to what extent it is possible to embrace a “better” set of principles and processes for decision-making. We start with the premise that in order to develop a better decision-making framework for what is in and out of Medicare it is crucial that we understand fully how our decisions are presently made. In general decision-making about what is in and out of publicly-funded Medicare reflects different silos of funding that support different sectors. Thus, as we will describe further below there are significantly different approaches to funding depending on whether we are dealing with physician services, hospital services, new technologies, pharmaceuticals, home-care etc. For example, what physician services are publicly-funded is largely a matter of negotiation between provincial governments and their respective medical associations. By comparison, which prescription drugs are included on provincial formularies involves a much more technocratic evaluation of the costs and benefits of the drugs. In this paper, we provide our research to date on how in Ontario decisions are made regarding what physician services are publicly-funded but will make references to other sectors by way of comparison. Subsequent research papers will address decision-making in other provinces and territories and expand to discuss other “categories” of care, in particular new technologies and drugs.

Decision-Making in Ontario

There are at least four bodies/institutions in Ontario involved in determining what physician services are included in the publicly-funded basket of services.

1. Physician Services Committee (a joint Ministry and Ontario Medical Association Committee)

2. Medical Registrars (salaried physicians within the Ministry of Health and Long Term Care (“MOHLTC”) that may determine claims for public funding)
3. The Health Services Appeal & Review Board
4. The Courts

We discuss each of these decision-making bodies.

1. Physician Services Committee

Long-held accommodations between the medical profession and Canadian governments are fundamental to Canadian Medicare. Not surprisingly then decision-making over what physician services are publicly funded is driven by the process of fee negotiations between the Ministry and the Ontario Medical Association (“OMA”), the latter being the bargaining agent for physicians in Ontarioⁱⁱⁱ. Negotiations between the OMA and the Ministry effectively determine the **range** of physician services publicly funded. By default these services are deemed “medically necessary”. Thus the phrase “medically necessary”^{iv} does not drive from an explicit application of principles but is rather determined by medical judgment as filtered through negotiations within the OMA and between the OMA and the Ministry and is a label applied *ex post*.

A key medium for the relationship between the OMA and the Ontario government is the Physician Services Committee (“PSC”). The PSC was created pursuant to an Agreement concluded in 1997 between the OMA and the Ministry and continues to operate pursuant to the 2000 Agreement. The PSC has 10 members: five members appointed by the OMA and five members appointed by the Ministry, and is chaired by a professional facilitator. In addition to being an important vehicle for governmental/professional relations, the PSC performs an important public role in reviewing utilization of services and recommending the de-listing of particular services in order to achieve certain financial targets.^v

What principles or values inform the PSC in deciding what physician services to publicly fund and which to delist? Both the 1997 Agreement and 2000 Agreement stipulate that the review and changes to the Schedule of Benefits is to be accomplished by a mix of “tightening” and “modernization.” Neither Agreement defines these terms.

Our research has revealed little evidence of a systematic approach to the de-listing process. However, there is evidence of increased attempts to incorporate evidence of cost-effectiveness into the decision-making process. For example, whereas in previous years a 1.5% increase was simply applied to all listed physician services, now various subcommittees try to identify more important services in terms of cost-effectiveness and devote more funds to these services and less to others. Even with this new development, the overall effect of the negotiation process seems to be to largely perpetuate the status quo. Fee increases are spread amongst existing services and there is little movement off the Schedule of Benefits of services covered, in other words it is extremely difficult for services to be delisted. Spending on new services and technologies must come from whatever is left over from the pie once increases for existing services have been made and the impetus for and recommendations for coverage of new treatments emerges from the OMA. The end result is little flexibility to allow the kind of trade-offs that cost-effectiveness analysis would seem to demand whereby new and more beneficial services or treatments replace older less beneficial services or treatments. This process contrasts sharply with processes used to determine whether or not to fund prescription drugs, where cost-effectiveness studies are heavily employed before a new drug is listed.¹ However, even with prescription drugs, much more effort is given to deciding which new drugs to add to the list than which drugs might be removed from the list. Nonetheless across two sectors which are surely both equally important we have two very different *approaches* to the use of technical evidence in decision-making, although the ultimate *impact* of these different approaches has yet to be measured.

Many of the PSC's decisions must involve more than technocratic assessment of the clinical benefits of a treatment. For example, delisting of particular services can have profound access effects on often very vulnerable groups (e.g. those with a hearing disability in the case of delisting of certain audiological services). Values are clearly important in listing and de-listing decisions. One important way of ensuring that a full scope of public values is canvassed is to provide a level playing field for participation by a wide range of groups and individuals. However, the respective roles for public participation and procedural fairness in the PSC process are minimal. Appendix A of the 1997 Agreement provides the only indication of procedural fairness: the PSC "is committed to giving appropriate opportunity to affected parties to provide timely input to the PSC before making recommendations to the Ministry and the OMA".

Different groups have, however, complained that they have had inadequate opportunity to make input into the decision-making process. Not surprisingly, most of these complaints come from groups of health care providers with a particular stake in the outcome. For example, the Ontario Association of Speech-Language Pathologists and Audiologists (OSLA) challenged the openness of the PSC decision-making process.^{vi} OSLA's concerns arose from a PSC recommendation to the Minister to de-list hearing aid evaluation and restrict coverage of diagnostic hearing tests. Essentially the de-listing affects audiologists who practiced on their own are now limited to working within a physician's office if they are to receive public funding for the provision of the diagnostic hearing tests.

OSLA's account of PSC decision-making is troubling even filtered through the lens of its own self-interest in the proceedings. Participation is limited to invitation by either the Ministry or the OMA. The membership of subcommittees whose recommendations are often extremely

influential is no more diverse than the PSC itself. Both the Ministry of Health and the OMA have agendas that may not necessarily elide with the public interest: the Ministry's agenda is presumably often one of restraining government increases in spending; and the OMA's agenda is presumably primarily that of ensuring the interests of its members through fee increases. Of course, the argument against greater public participation in this process is that sustainability would be threatened as government restrictions on spending increases may be harder to enforce. But this assumes public participation stirred into the mix of the present negotiation processes as opposed to first rethinking the accommodations reached between physicians and provincial governments. If the process of determining what is and out of Medicare could be unbuckled from determinations of what physician services to fund then it may be possible to establish a more rigorous and principled process, infused with public participation, that would allow relatively high benefit services and technologies to be in place of lower benefit services and technologies, already funded. It also assumes that greater public spending on health care is *politically* unsustainable whereas, arguably, with greater public participation in determining what is in and out of publicly-funded Medicare, there may be a greater appetite for tax levels necessary to sustain growth in publicly-funded Medicare.

2. Medical Registrars

What does someone turn to in Ontario if a particular service or treatment is not listed in the provincial tariff schedule because it is de-listed; or it is new and has never been listed; or waiting times for covered services are too long in Ontario?

The first recourse of patients in Ontario is to appeal to the Ministry of Health and Long Term Care. In that case, our investigations indicate that a Medical Consultant may often play a pivotal part in the decision whether to deny or allow funding. Medical Consultants are salaried physicians employed with the Ministry (and indeed every province employs several Medical

Consultants). A Freedom of Information Act application revealed that the Medical Consultants from different provinces meet biannually through the auspices of the Interprovincial Health Insurance Agreements Coordinating Committee.^{vii} The transcript of one of the meetings obtained suggests that there may be pressure from province to province for particular provinces not to list new procedures and technologies because of pressures this creates in other provinces to fund treatments. Applications for access to more information about these meetings have been made, to date with no success. The Director of Access to Information at Health Canada has advised that, although there are relevant documents they will likely not be released to us as they fall within the exemption of information obtained "in confidence" from other governments the disclosure of which could be "injurious to federal-provincial consultations" (ss. 13 and 14).

Our research indicates that Medical Consultants are important decision-makers, deeply embedded within the provincial ministries. As part of our research we have identified and interviewed Medical Consultants in each province. Through this work we hope to reveal what values and principles drive their decisions on applications for public funding.

Interviews with the Medical Directors indicate three considerations that are weighed with respect to discussions in the inter-provincial meeting: 1. medical effectiveness of the treatment; 2. cost effectiveness; 3. and the approach of other provinces to the treatment. When asked to order the importance of these considerations most Medical Directors polled put either medical evidence or cross-provincial comparisons first, followed by economic considerations. This hierarchy suggests that Medical Directors are primarily concerned with discussing matters relevant to medical efficacy and cross-provincial uniformity than conducting any kind of cost-benefit analysis. When queried about whether the size of an affected subpopulation was a consideration, most Medical Directors interviewed reacted with some chagrin, suggesting that the threshold for funding is

medical necessity, and the relatively small size of an affected group is a more or less immaterial consideration.

Thus while the good news is that Medical Directors may have actualized the values of universality and portability into their decision-making processes the bad news is the more or less uniform agreement amongst Medical Directors about the relative unimportance of public opinion. Most Medical Directors seemed to indicate that they never considered public opinion directly. Reasons Medical Directors cited for avoiding this consideration involved concern at the public's lack of expertise in the medical aspects of these issues, including the concern that public opinion might be somewhat volatile, reflecting interest in a treatment because of its relative newness rather than with the weight of the medical evidence behind it.

There seems to be a deep sentiment that pervades government that it is better not to be explicit or transparent about how decisions are made regarding what to fund or not to fund. A spokesperson for former Health Minister Tony Clement is reported to have said that discussions regarding what is in and out of Medicare should remain behind closed doors: "Let's be frank, there will always be somebody saying, 'Don't do that,'" he says, referring to patients who will lobby to protect coverage of particular items.^{viii} Thus the fear is that if decisions are transparent then it will be harder to ration services and control costs.^{ix} In our work on Medical Consultants we have considered whether a lack of meaningful interaction with the public and a lack of transparency are satisfactory given the nature and content of the discussion that occurs at these inter-provincial meetings. We believe there is a strong argument for greater transparency, as opposed to more formal participatory processes, so that citizens, patients, and taxpayers can be assured of the basis upon which decisions are made or policy formulated and to provide a check to ensure that the principles followed in decision-making are those which reflect the larger public interest and values, as opposed to political or other interests.

3. The Health Services Appeal & Review Board

In most provinces the only recourse from a decision not to fund a particular treatment or service is to seek relief in the general courts, either through judicial review or through a Charter challenge. In a limited number of provinces (Ontario, Alberta, and British Columbia) there are administrative tribunals to which the citizens thereof can bring (on limited grounds) an application to review a decision not to publicly-fund a service or treatment. Ontario has the most active tribunal and a much larger mandate to review decision than the tribunals in Alberta and British Columbia, but, as we discuss below, its discretion is nonetheless still limited.

The Ontario Health Service Appeal and Review Board (the “Board”) was created by the Ministry of Health Appeal and Review Boards Act in December 1998 through the amalgamation of five predecessor tribunals. The Board is composed of at least twelve members, who are appointed by the Lieutenant-Governor in Council on the recommendation of the Minister of Health and Long Term Care.^x Members of the Board are appointed for 3 years and work on a part-time basis. The only stipulation in terms of membership is that no more than three members can be physicians and no member can be employed in the public service or otherwise by the Crown. Most of the members of the Board are lawyers, which as we discuss further below is problematic given that whilst some legal expertise is needed for determinations of what to publicly fund, there are other skill-sets that should be included. Most of the work of the Board involves conducting appeals from decisions made by the General Manager of the Ontario Health Insurance Plan (“OHIP”) under the Ontario Health Insurance Act^{xi} and its regulations.

The ability to seek relief before an administrative tribunal rather than having to apply to the general courts offers the prospect of quicker, easier and cheaper recourse to justice. However, many who do appeal to the Board are disappointed to find that its discretion to review de-listing

or failure to list decisions is significantly constrained by the terms of the Act and the Regulations. For example, Section 24 of the relevant regulations lists medical services that are specifically excluded from OHIP coverage. These include services solely for the purposes of altering or restoring appearance (subsection 10), treatment for a medical condition that is generally considered experimental (subsection 17), *in vitro* fertilization, except in limited circumstances (subsection 23); reversal of sterilization (subsection 22); and the fitting and evaluation of hearing aids (subsection 27). These services are not insured services, and thus deemed not “medically necessary” under the Act. The Board has almost no discretion to reverse a decision not to publicly fund these services.

The Board does have some discretion with respect to access to out-of-country services. This occurs in two circumstances: when a citizen of Ontario requires unanticipated, emergency treatment while traveling, and/or when a citizen of Ontario secures pre-approval from the General Manager to obtain treatment that is unavailable, or unavailable without significant delay, in the province. Most of the Board’s discretion, and the most interesting decisions, revolve around the issue of pre-approved treatment. The relevant section states:^{xii}

- (i) Pre-Approved Treatment
 - (2) Services that are part of a treatment and that are rendered outside Canada at a hospital or health facility are prescribed as insured services if,
 - (a) the treatment is generally accepted in Ontario as appropriate for a person in the same medical circumstances as the insured person; and
 - (b) either,
 - i. that kind of treatment is not performed in Ontario by an identical or equivalent procedure; or

- ii. that kind of treatment is performed in Ontario but it is necessary that the insured person travel out of Canada to avoid a delay that would result in death or medically irreversible tissue damage.

In order to qualify for coverage an applicant must receive approval first from the General Manager of OHIP before leaving the country.^{xiii} We should also note that the total costs reimbursed are capped in a schedule and are significantly less than the actual costs incurred by most people who would travel to the US. It is usually when the General Manager denies approval under subs. 28.4(5) 2 that appeals with respect to the actual, substantive provisions of section 28.4 arise.

These issues tend to cluster around two sets of questions or issues:

1. Whether treatment is “generally accepted as appropriate” in Ontario for a person in the same medical circumstances as the appellant, and,
2. If so, whether it is a) available (“performed”) in the province; or, b) whether a delay in treatment would result in death or irreversible tissue damage.

Thus, in order to succeed in an appeal with respect to section 28.4, the Board must answer two, seemingly similar questions, first in the positive and then in the negative. The Board must first determine that the treatment is generally accepted in Ontario as acceptable for a patient in the same medical circumstances, and second it must then determine that the treatment is not performed in Ontario; either as an objective or practical matter. This presents a Catch-22 for most patients as the Board seems to use evidence that a particular treatment is *not* performed in Ontario to indicate that treatment is thus not generally accepted in Ontario. When the treatment in question is new it is of course not surprising that it is difficult to surmount the first part of the test.

The other main issue is what constitutes a sufficiently serious delay to merit seeking out-of-country health services. The statute is clear: the delay at issue must be such that to deny treatment any longer would result in death or medically irreversible tissue damage. In order for the Board to find that there has been a sufficiently significant delay, it generally requires evidence from a “physician who *practices in Ontario*”^{xiv} that delay *would*, and not *could*, result in death or medically significant irreversible tissue damage. Our review of the Board’s decisions indicates that this definition often frustrates appellants who bring appeals before the Board in hopes that it will be compassionate with respect to the psychological effects of delay, only to have the Board reiterate its limited jurisdiction.

Apart from the substantive issue that the Board’s discretion is constrained through the Act, there are also significant issues of access to the Board and transparency in decision-making. The Board’s judgments are not on-line and appointments must be made to view the judgments in Toronto – clearly, this has a disproportionate impact on anyone living outside of Toronto but particularly on applicants in Northern and remote areas. Moreover, the judgments are not indexed and one needs to know the name of the case in order to locate the decision.

As part of our research program, we have reviewed more than 1000 decisions rendered by the Board over the last 10 years. Our framework for review, in addition to calculating how frequently applicants succeed will analyze whether factors such as age, occupation, socio-economic status, presence of counsel etc. are linked to a successful outcome; on what grounds the Board is most likely to exercise discretion in favour of an applicant; to what extent applicants found on the various technical barriers (e.g. obtaining pre-approval prior to seeking out-of-country treatment); how the phrase “medically necessary” is used in the proceedings; to what

extent, if any, are public values taken into consideration; and what role is there for evidence of effectiveness and/or cost-effectiveness.

Through this analysis we hope to acquire a deep understanding of the factors that presently inform the Board's decision-making processes and make specific recommendations for reform of both the processes by which decisions are made; the composition of the tribunal (e.g. to better reflect the expertise required to make decisions about what to publicly fund); and reform of the framework legislation to better reflect the principles that should drive decision-making.

4. The Courts

There are two main mechanisms by which the courts play a role in determining what is in and out of Medicare: judicial review through general administrative law and through Charter challenges.

In general, success in applications for judicial review of decisions not to fund medical treatments is rare and the courts are deferential to governmental decision-making in determining what is and is not publicly funded. Courts demonstrate their deference to the existing processes for determining what is in and out of Medicare, by reviewing decisions on the standard of "patent unreasonableness." This is the most deferential standard of review possible in administrative law, with the other possibilities being "reasonableness simpliciter" and "correctness" (the latter being the least deferential). For example, the only successful judicial review claim before the courts with regard to waiting times has been *Stein v. Quebec (Regie de l'Assurance-maladie)*.^{xv} In this case Mr. Stein waited months for surgery, even though his doctors warned his life was in danger if he was not operated on within four to eight weeks. He was successful before the Quebec Superior Court in overturning the Quebec health insurance board officials' refusal to pay for his treatment in a New York hospital on the grounds that, given the facts of the case, the decision was patently unreasonable. Thus the court was prepared to be very deferential to the Board's

decision-making; however, even allowing for this very high standard of deference the court felt compelled to overturn the Board's decision. Thus the courts will check the *rationality* of decisions about what is in and out of Medicare, but will generally not hold the government or other institutions to any higher standard.

As another example of the court's deferential stance towards the decision-making processes is the 2001 case of *Shulman v. College of Audiologists and Speech Language Pathologists of Ontario*. In that case, the College of Audiologists and Speech Language Pathologists of Ontario (CASLPO) was unsuccessful in its application to review a decision to delist audiology services not provided under the direct supervision of a physician. The Ontario Superior Court of Justice (Pardu J.) held that Government's concern that it not pay for medically unnecessary diagnostic hearing tests is a legitimate one and further warned that a court should be cautious about characterizing structural changes to OHIP which do not shut out vulnerable persons as discriminatory, given the institutional impediments to design of a healthcare system by the judiciary. The applicants also failed in their Charter challenge.

Interestingly, notwithstanding that this case was not successful it has in the view of some in the Ministry of Health significantly chilled the prospects for further delisting to occur. The OMA Tariff Committee, which makes recommendations for delisting, does not wish to rise the ire of audiologists and one suspects they welcome having the excuse not to explore for further services to de-list and thus risk raising the ire of particular constituencies within the OMA, e.g. family doctors etc. So there is the prospect that the mere threat of judicial review, and the political heat that accompanies a judicial challenge, even an unsuccessful one, helps to perpetuate the status quo and reinforces rigidities in the system.

On the other hand, whilst the fear of judicial review may perpetuate the status quo in terms of what is covered, a Charter challenge offers the potential of bringing Canadian values into the decision-making process, albeit ex post. To date the courts have not found that Canadian citizens have positive right to publicly-funded health care under s. 7 of the Charter, which guarantees life, liberty, and security of the person. However, once a government elects to provide some publicly-funded health services, then it must do so in compliance with the Constitution, including s. 15 of the Charter. Section 15 provides:

15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Even if discrimination is found under s. 15 (1) it may be “saved” by s. 1 of the Charter which provides that “the *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.” Thus a government may defend a finding that a particular policy or decision is discriminatory by pointing to the principles and processes that were followed in making a decision and how although the needs of those discriminated against were considered there were other countervailing needs or considerations that outweighed these concerns.

Section 15 has been used to overturn a decision by a BC hospital not to fund interpretation services for hearing-impaired patients, on the grounds that this decision discriminated against these patients who could not access and communicate with health care providers as other non-hearing impaired patients could. It has also been used recently to overturn a decision of the BC provincial government not to fund a relatively controversial therapy for autistic children (this is being appealed to the Supreme Court). There are many issues that are raised by the court’s

review on Charter grounds of decisions not to publicly fund treatments. The first point to note is that this is a one-way street and does nothing to counter the difficulty of delisting treatments and may exacerbate the existing reluctance of decision-makers to formally delist treatments that relatively are of less benefit. On the other hand, given that the Charter as part of the Constitution is as clear a statement of agreed public values as one is likely to find, the role that the courts play a critical role in checking governmental decision-making, decisions which increasingly based on cost-effectiveness analysis or desire to restrain government spending, may discriminate against marginalized and vulnerable groups. To eliminate then the prospect of successful Charter challenges and to ensure decision-making that respects public values, Charter issues should be taken into account at the time decisions are made to list or delist.

Discussion

Our discussion will focus on four themes: the extent to which our present system is designed to focus on outputs rather than inputs; the role of physicians and other interest groups in impeding and enabling reform; a consideration of the role for public values and public participation in decision-making; and finally a consideration of the role for law and legal institutions.

i. Focus on Outputs Rather Inputs

What then is the result of the layers of decision-making and the processes we have described? We hypothesize that the cumulative effect of the processes is a form of stagnation and maintenance of the status quo, i.e. services are rarely delisted thus limiting the possibility of new services being added to the range of services that are publicly funded. There are few systematic reviews of older technologies and treatments to determine whether they remain cost effective. Further, there is enormous resistance to changing the range and types of services that we publicly fund, primarily by individuals with vested interest in maintaining public funding for certain procedures. Also governments and medical associations are wary of being exposed to either

judicial review or Charter challenge, even when the courts have indicated that they will be extremely deferential to decision-making in this regard and even given the relatively low number of successful Charter challenges. The net result is that newer treatments and technologies are looked at with a much more sceptical eye and are more frequently scrutinized for cost-effectiveness. New drugs must not only prove cost effectiveness, but must also prove that they outperform existing drugs on the market if they are more expensive. New home care services must wait for additional funding before they replace existing in-hospital care. New hospital technologies are frequently delayed due to cost alone until long after they have diffused in other medical markets.

We have significant concerns about this approach. At a minimum, the principle of “necessity” must embrace the requirement of effectiveness (i.e. the treatment must provide a reasonable chance of achieving a particular health state (recovery, alleviation of pain, etc). Yet studies in evidence-based medicine in the developed world demonstrate little or no evidence of effectiveness for up to 30-40% of health care services that physicians recommend.^{xvi} In any event our present decision-making process is not consistent with principles of cost-effectiveness, as evidenced by the fact that we have a system that fully funds routine annual general check-ups despite the consensus of expert medical panels since 1979 that they have little effect on the detection of disease, but does not fund life-saving drugs like, for example, insulin for all Canadians.

Much of the reluctance to fund new technologies comes from the fact that they are relatively untested and usually quite expensive. In a system that has no formal mechanism to remove an expensive and ineffective technology, it is quite understandable that policy makers would be reluctant to introduce new treatments. However, many of these treatments may indeed be cost-effective and superior to existing treatment. Enhancing the flexibility to fund new treatments of relatively

greater benefit and replace older treatments, would allow us to improve the health care available to Canadians and dispel the long-standing criticism that our system lags behind other developed countries in technology adoption.

A useful schematic diagram for thinking about health care technologies has been suggested by David Cutler (2003). The diagram, reproduced in Figure 1, shows a dichotomy of technologies into high and low cost along the Y axis, and into high and low effectiveness along the X axis. The most successful technologies will be those that are both highly effective, and low cost, represented by the bottom right box. However, some technologies will be highly effective and expensive, and successful health care systems will also adopt these technologies (the upper right hand corner) if the benefits exceed the costs. Unfortunately, many technologies fall into neither of these categories, but rather into the left hand side of the box representing relatively ineffective technologies. Systematic review of existing technologies would allow our system to remove those technologies that over time do not show themselves to belong on the right hand side. Cutler also argues that many innovative and costly technologies may require more time to demonstrate cost effectiveness. While universal systems such as those in Canada may need to exercise more caution when adopting new technology than health care insurers in a more private setting, flexibility in technology adoption coupled with rigorous review (and removal) processes might broaden the number of cost effective and beneficial technologies available to Canadians. There are barriers to making this transition, but the question must be asked as to why we do not allocate resources to more high benefit procedures? The likely answer is that under the current framework, once a technology is adopted, it is here for good (at least until it becomes obsolete).

ii. Political Accountability/History and Interest Groups

We are seeking in our research to renew the basis of long-held accommodations between governments and the medical profession and could be the basis for a new deal that would

increasingly reward physicians for performance rather than throughputs and inputs. Partly the problem here is a lack of incentives and the need to align incentives. Can we reward physicians for the improvements in health outcomes they achieve? What is the appropriate level (patient/practice/ region) to measure physician outcomes?

Also what do we do about conflicts of interest if we open up the range of services that should be publicly funded? For example, if we acknowledge that sometimes an MRI scan is medically necessary and sometimes it is not, and if physicians have the discretion to make that determination, then how do we make sure that the same physician will not have a conflict of interest in sending a patient for a private MRI?

We plan to explore through this research program whether new accommodations can be reached with physicians so that it is possible to unbuckle determinations of remuneration for physicians from decisions about what is in and out of Medicare. We are also exploring whether it is possible to allow for a sorting of services across the spectrum of public/private financing and to cut through the sectoral boundaries that have historically characterized Canada's system (full public funding for hospital and physician services; mixed funding for prescriptions and home care) given the conflicts of interests that may arise for physicians to whom the responsibility will likely fall to determine whether a particular health need is one that falls in or out of the publicly-funded basket.

iii. Public Values and Public Participation in Decision-Making

Although evidence is important, so are values.^{xvii} Indeed there may not be good evidence for the kinds of care that citizens value – e.g., caring services and palliative care are difficult to measure in terms of health outcomes as are traditional healing practices and treatments. Also difficult to measure is the extent to which patients are treated with respect and dignity and in accordance

with their culture. The importance of values is increasingly recognized as is the idea that citizens need a voice in governance structures and are no longer content to assume that governments or physicians sufficiently represent the public interest in these matters.^{xviii} However, public participation is presently given little weight in decision-making regarding what to fund publicly. While communication and participation is considered “essential” in determining access to services at the clinical level, between doctors and their patients^{xix}, it is virtually non-existent between the state and its citizens in determining the same issues at the policy level.^{xx} As one participant in the consultation process told the Romanow Commission, “Our system lacks communication, lacks clear accountability”.^{xxi} For example, as discussed above, what physician services are funded by Canadian governments is largely determined by tariff or fee negotiations between provincial governments and medical associations and the decision-making does not involve any form of public participation nor is it transparent and open for public review.

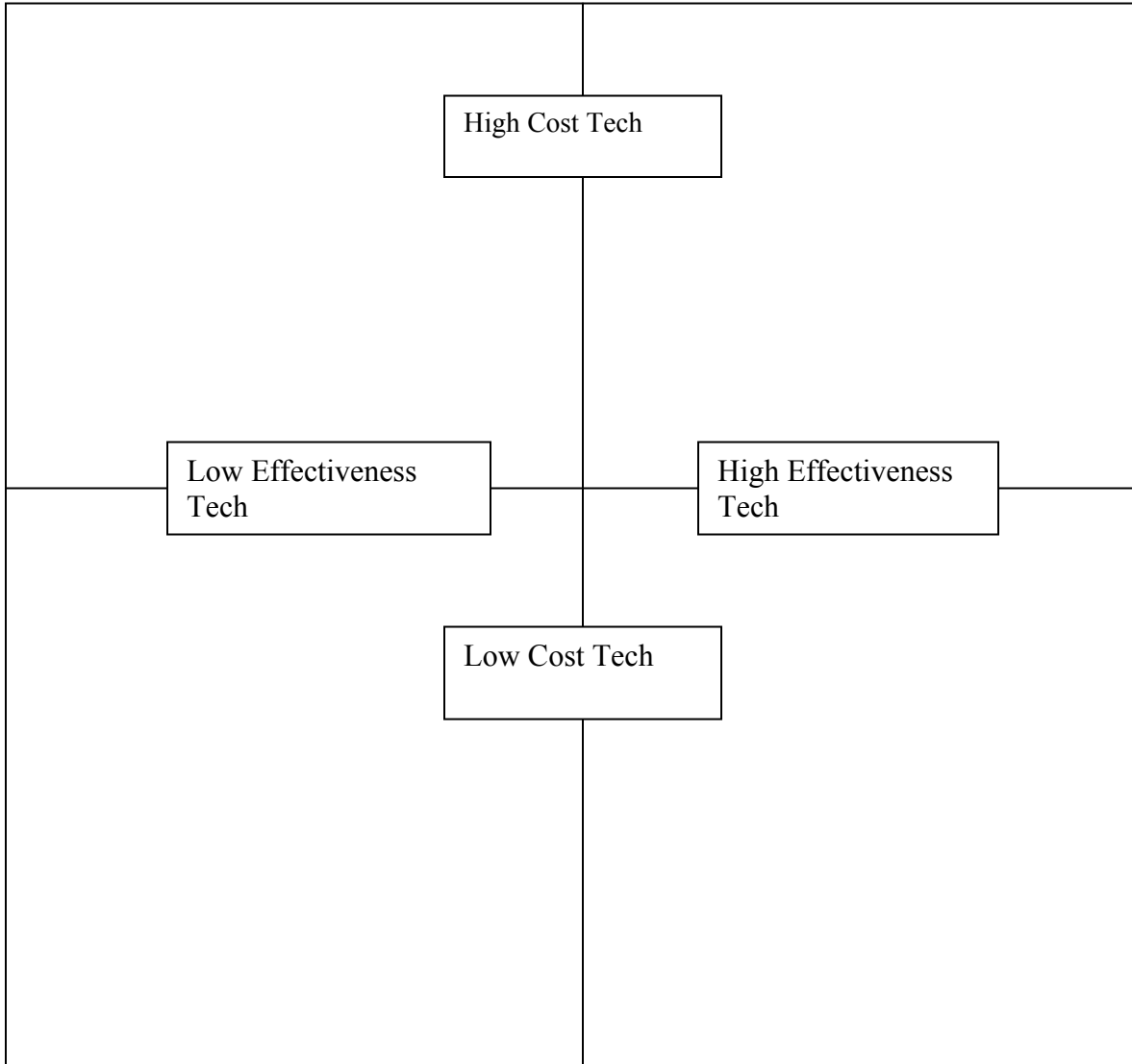
At what point, given the historical and political complexities inherent in Medicare, could (and should) the public be involved? What role could public values have in determining what services are publicly funded and which are left to the private sector? What, in particular, is the role of legal institutions (e.g. national legislation enshrining rights to health care) in shaping and reinforcing values? Also as we try to move beyond care that we have been conditioned to accept in the past and the predominance of physicians and hospitals in our health care system, how do we deal with the fact that we value this kind of care even though there may be no evidence that much of it is effective? There are already entrenched expectations and public values; we do not have a clean slate with which to work. We must recognise that values are not developed in a vacuum, but are shaped by existing institutions.

The Role of Law and Legal Institutions

Law and legal institutions can be both barriers and facilitators to an equitable and efficient health care system. For example, in Canada, the *Canada Health Act*^{xxii} (the “CHA”) gives primacy to hospital and physician services. Although the Act has protected Canadians well through the years it has skewed public resources towards hospital and physician services rather than community care, home care, public health, preventative care, drugs and new technologies. Thus while law can be a powerful force, entrenching values and protecting entitlements, it can also result in inflexibility and present barriers to reform if it fails to keep pace with changing technology, expectations, and health care needs.^{xxiii}

As part of our project we are exploring what should be the legal framework for entitlements to health care? Can legal rights be framed to ensure that the rights are meaningful through changing circumstances? In other words, is it possible to create robust rights that ensure equitable access to care and that keep pace with changing technology, expectations and resources? Also what role should and can the law play in providing redress to dissatisfied citizens and patients? We believe that the existing legal framework is inappropriate, inaccessible and ineffective and that changes need to be made to facilitate redress and challenge on the part of patients and citizens unsatisfied with decisions about the scope of Medicare. This is not simply because of concerns vis-à-vis fairness for individual claimants but as a check to keep the process of decision-making both rigorous and principled. Specifically, appeal mechanisms such as exist in Ontario through the Health Services Appeal and Review Board should be available in all provinces, so that patients and citizens do not have to rely on access to the general courts alone to provide a check on decision-making. Also review should be done on a principled basis, such principles articulated in provincial legislation, including analysis of relative cost-effectiveness, a commitment to funding new relatively beneficial treatments and delisting older and less beneficial treatments, and consideration of fundamental Canadian values, such as the equality provisions of the Charter.

Figure 1: Cost and Effectiveness Dichotomy



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ⁱ Canada, Final Report of the Commission on the Future of Health Care in Canada (Ottawa: Library of Parliament, 2002) (Chair: Roy Romanow) at 45 (hereafter, “Romanow Report”). Available online at http://www.hc-sc.gc.ca/english/pdf/romanow/pdfs/HCC_Final_Report.pdf.

ⁱⁱThe Convention on Economic, Social and Cultural Rights (CESCR) Committee considerably developed the normative content of the right to health in Article 12 of the Convention as well as the nature of state obligations. For a discussion, see Audrey Chapman, *Health Care Reform: A Human Rights Approach* (Georgetown University Press, 1994) and Brigit C.A. Toebes, *The Right to Health as a Human Right in International Law* (Antwerp: Intersentia, 1999).

ⁱⁱⁱ Pursuant to s. 3 of the *Health Care Accessibility Act*, R.S.O. 1990 c. H.3, the Ministry may enter into agreements with the OMA "to provide for methods of negotiating and determining the amounts payable under the [Ontario Health Insurance] Plan in respect of the rendering of insured services to insured persons.

^{iv} Find use of “medically necessary” in CHA and cite Abelson et al “Four meanings”.

^v Pursuant to the 1997 agreement the MOHLTC and the OMA agreed to various initiatives designed to lessen the impact of utilization growth including an annual cap of 1.5% on increases in funding for medical services. The revised 2000 Agreement provided for a 1.95% increase in all fees listed in the schedule of benefits effective April 2000. For each of the remaining three years of the agreement, the PSC could recommend either an across-the-board increase of 2% in all fees, or it could target certain services for larger increases (and maintain the status quo or even decrease fees for other services) within a general cap of 2% for total funding of the listed services on the Schedule of Benefits (with increases being effective on April 1 of each year).

^{vi} Ontario Association of Speech-Language Pathologists and Audiologists (OSLA), “Unheeded Advice: Consumers Pay the Price” (February 2002) online: <[http://www.osla.on.ca/pdf/Unheeded%20Advice%20Feb%202002%20re%20PSC%20Recommendations PDF.pdf](http://www.osla.on.ca/pdf/Unheeded%20Advice%20Feb%202002%20re%20PSC%20Recommendations%20PDF.pdf)> (date accessed: 4 March 2003).

^{vii} Its predecessor was the Federal-Provincial/Territorial Coordinating Committee on Reciprocal Billing”.

^{viii} V. Lu “More Cuts Coming to Medical procedures” *The Toronto Star* (2 February 2002)

^{ix} Discussion about setting substantial limits on Medicare’s benefit package could actually increase costs, because legislators and health ministers are placed in the position of confronting public pressures. See J. Oberlander, T. Marmor, and L. Jacobs, “Rationing medical care: rhetoric and reality in the Oregon Health Plan” *CMAJ* 2001;164(11):1583-7

^x Pursuant to section 7(1) of the Review Boards Act

^{xi} Cite Act.

^{xii} Cite section.

^{xiii} Section 28.4(5) of the Regulation.

^{xiv} Emphasis added.

^{xv} [1999] QJ No. 2724.

^{xvi} See G.L. Stoddart, M.L. Barer, R.G. Evans & V. Bhatia, *Why Not User Charges? The Real Issues — A Discussion Paper* (Ontario: The Premier’s Council on Health, Well-being and Social Justice, 1993) at 6.

^{xvii} For a discussion, see John M. Eisenberg, “Globalize the Evidence, Localize the Decision: Evidence-based Medicine and International Diversity” (2002) 21: 3 *Health Affairs* 166-168.

^{xviii} Roy Romanow, The Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada*. Final Report, November 2002.

^{xix} As LaForest J. commented in *Eldridge v. British Columbia (A.G.)*, the fact that “adequate communication is essential to proper medical care is surely so incontrovertible that the Court could, if necessary, take judicial notice of it” ((A.G.) [1997] 3 S.C.R. 624 at para 70, hereafter, “*Eldridge*”). Because communication between doctor and patient is so important at this level of decision-making, the law intervenes to protect it and encourage it a range of different ways, including the doctrine of informed consent and duties of confidentiality, contained in professional code of ethics, principles of tort law and equity (particularly, fiduciary duties).

^{xx} We are grateful to Caroline Pitfield for making this point.

^{xxi} Romanow Report, *supra* note i at 63.

^{xxii} Citation.

^{xxiii} *Strengthening the Foundations: Securing the Modernity of the Canada Health Act* (with Sujit Choudhry)
http://www.healthcarecommission.ca/Suite247/Common/GetMedia_WO.asp?MediaID=946&Filename=13_Flood_E.pdf. This report will be included in a book published by the University of Toronto Press.

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