POLICY DIALOGUE NO.7

Medically Necessary: What is it, and who decides?

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The Commission on the Future of Health Care in Canada, in partnership with select Canadian universities, hosted 12 televised policy dialogues on key health care issues. At each session, a moderator guided a panel of leading health care experts in a discussion focussing on a priority health issue for Canadians. These sessions were based on Issue/Survey Papers developed for the Commission by the Canadian Health Services Research Foundation. This report is a synopsis of one of these 12 policy dialogues.
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The Policy Dialogue opened with a brief video that described some of the current challenges in defining medically necessary:

At first glance, the term medically necessary seems relatively straightforward. Most people would interpret it to mean if you are sick, medically necessary is whatever it takes to make you better. And if you are in good health, then medically necessary is that which keeps you well. It is not quite that simple. Let’s look at it from the perspective of the Canada Health Act, the Act which sets the terms that the provinces must meet in order to receive funding for hospital and doctor services. In the Act, the term is used to identify the services that must be funded by provincial health insurance plans. It stipulates that to receive funding for health care, the provinces must pay for all hospital services that are medically necessary, as well as doctor services that are medically required.

The problem is that the Act neither defines what is medically necessary not provides a process for doing so. That is up to doctors to decide, though from time to time, a province may in fact delist certain services. So when a doctor decides that a service is medically necessary for a particular patient, it is fully funded by the government, and delivered according to the patient’s need and not on his ability to pay. If the service is considered unnecessary, then the patient must pay for it directly, not the provincial health plan. The concept is one that is based on need and not want.

As demands on our health system grow, the pressure is mounting for a precise definition of what is considered medically necessary. Such a definition would then provide the provinces with a clear understanding of the medical services they must provide. Easier said than done. It should come as no surprise that a variety of models and frameworks have been proposed for determining which patients should receive which services. For instance, there are many who feel that our understanding of what is medically necessary is too restricted because it is limited to services provided by doctors and hospitals. These people argue that the concept should be broadened to include a variety of factors that may have a positive impact on an individual’s health. And that is where the debate begins.

The discussion was focused on a background paper prepared for the Commission by the Canadian Health Services Research Foundation, entitled: Medically necessary: What is it and who decides? The paper proposed three courses of action which panelists then pursued in their presentations before discussion was opened up to all participants.
Course of action 1
The Canada Health Act should provide an explicit definition of what is medically necessary

Presentation by Daniel Weinstock:
This first option does not seem a viable means of defining what is medically necessary. We live in a pluralistic society in terms of our values and lifestyles, and this pluralism manifests itself significantly in the health care arena. Priorities in health care reflect cleavages in the values of citizens and these differences cannot be resolved by politicians, nor by medical experts. One way to arrive at a notion of health, and thereby a notion of medically necessary, appropriate for a pluralist society, is to bring all players together and democratize the debate on what is medically necessary, rather than assign the task to a particular closed group of experts, be they political or medical.

I really see two questions we will have to address in deciding our future in this regard. One is within the health care system and asks what is medically necessary and what, on the other hand, is medically accessory? The other, however, and this is where the need for open democratic debate comes in, is what place should health assume within the totality of budgetary requirements, such as education, technological, transportation and communications infrastructure, etc.

We know that if we were to respond to every need, health would consume every dollar of our total budget, and perhaps more. We must therefore make choices, and these choices will demand that we ask not just what is essential within health care but also how much of our total revenue we want to devote to health as opposed to other things. Once we have a democratically formulated answer to this question, we will need to face the painful but inevitable conclusion that we may not always be able to provide everything that is medically necessary. At that stage, we will no longer need the vocabulary put forth in the background document, which implies that everything medically necessary is entirely publicly funded. We will need to define even finer gradations within the medically necessary.

To come back to my first point about democratic debate, I am not saying that there is no place for experts in this public debate. I would recommend an ongoing institutionalized debate with a role for both experts and concerned citizens. The democratic debate would define the goals of the health care system; the experts would elucidate how to meet those goals as efficiently as possible.

Finally, the institutionalization of the democratic debate on this issue must be as impartial as possible, not by asking people to leave their differences at the door, but by involving all pertinent points of view and bringing all players to the table. It is also important that this debate be allowed room to evolve in step with our understanding of health, as well as advances in medical knowledge and technology.

Presentation by Dr Dominique Tessier:
This course of action lacks far too many essential elements at the decision-making level and smacks of a list of medically necessary services drawn up at the whim of system administrators. It also brings to a national level a question which I think must be increasingly addressed at a regional level.

The background document describes services as being unevenly available between provinces and regions within provinces. That seems entirely appropriate and perhaps even desirable if the needs of that community are being met. We could not possible provide large,
multidisciplinary teams for HIV/AIDS care in remote parts of the country, while these are absolutely necessary in our major urban centres. That does not mean people with HIV in other areas should not receive care, but it will be offered in different forms because needs are not the same all over.

Likewise, even if we describe health care services as being relatively equal in each province, we find that respect for the diversity of populations in each region is not always the same. In some areas, people may find it difficult to obtain care because of their sexual orientation, their culture, their religious or cultural beliefs. When we start looking at drawing up a list of medically necessary services, we absolutely must take into consideration the diversity of the populations we serve. And we need to ensure that our definitions are flexible enough to allow us to care for that particular individual who really needs a service that may be considered optional or discretionary for others.

We talk a lot about returns on investment or cost savings when we discuss medically necessary care, but there is something odious about that language when one is standing before a patient who needs care.

Lists are getting a lot of attention these days, but we also need to address the question of waits for services. People are free to go out and purchase services considered not medically necessary. Why should they not have the same option for services that are not medically urgent, but that would be covered once they became urgent. I am not suggesting we open the floodgates to private care completely, but I think this question must be introduced into the debate about what is medically necessary.

**Panel and audience discussion:**
Dr. Morin pointed to the Oregon experience of list-making, which he considered generally successful, but which, he felt, displayed just how difficult the exercise was. Many panelists felt that the exercise of defining these terms within a legislative text, by government, would focus on cost issues to the exclusion of patient well-being. Repeatedly, panelists emphasized the need not to lose sight of patient needs, with some stating that this must come ahead of cost considerations in treatment coverage decisions.

“It will be necessary to establish close links between ills, words and funding for the whole system.” - Dr Audet-Lapointe

A few panelists openly stated that Quebec must be involved in this discussion, because health care is subject to a federal law. As General De Gaulle stated: those who are absent are wrong: we need to participate in the discussion to get some of our ideas across, because Quebec is not going to be in a different situation tomorrow morning.
Course of action #2
A group of health care experts should decide what treatments or services are medically necessary

Presentation by Dr Paul Barré:
I have been in practice for almost 30 years and have never experienced private practice, but rather have lived the medical insurance and hospital insurance system. It works fairly well, and is much less expensive and bureaucratic than that of our neighbours in the US, which spends an enormous amount on health care administration, something we should avoid in Canada. Here in Canada, medical care is available to all, our life expectancy has risen, neonatal mortality has dropped, hospitalizations are shorter, except for chronic care.

We have made tremendous progress. New medications make a great difference in the quality of life of our patients, new technology such as MRI has facilitated diagnosis, and in surgery, techniques such as laparoscopy have shortened hospital stays and recovery times. We can do much more today than was possible 30 years ago, so it is not surprising that the cost of the system has gone up. However, I think that investing in health is a very good investment. We also face a number of challenges. We lack personnel, we lack equipment, we lack long term care facilities. Our hospitals are badly maintained, as an outbreak of mushrooms in our operating rooms recently exemplified.

We need to include doctors much more, not just in drawing up lists of insured services, but in the administration of health care. We could put together an expert committee, but it will find that most services offered through our health care system are medically necessary. We could even add a few. We already have any number of expert committees, mostly non-governmental bodies at the provincial and federal level. We have elaborated clinical practice guidelines in any number of areas and the expertise is already there. What our federal officials could do is fund more clinical research that will help us decide on treatment courses. The NIH in the US has funded clinical trials in breast cancer and dialysis, for example, to identify the best treatment options.

Finally, we need to respect regional and provincial differences and give local players more say. Manitoba is facing a diabetes epidemic among its native population. We should concentrate decision making powers in the areas where they can do the most good, whether that is in the provincial arena, the hospital or the universities.

Presentation by Dr Audet-Lapointe:
A recent Fraser Institute report placed Canada 18th worldwide in access to MRI, with a waiting time of seven months. We do not have a perfect system. However, people say that once they do get to hospital, they are treated well. The problems are getting there in the first place, and follow-up after discharge.

I agree that Quebec needs to be present and involved in these discussions because otherwise, someone else will be making decisions for us. The day when Quebec has full jurisdiction over its affairs, we can consider not participating in decision-making processes like this one tonight.

I will look at the medically necessary question from many different perspectives: the citizen in need of health care, the citizen wondering where their tax dollars are going, and the physician with a long career with the University of Montreal and Notre Dame Hospital, in cancer care, administration and the establishment of the Fondation québècoise du cancer. What I have
found in my dealings with the system is a tremendous lack of accountability among institutions and governments, which often undertake projects that are entirely disconnected from reality and often go over budget, for which they are not held accountable. As a surgeon in an operating room where the nurses hide the staples costing $3.50 a dozen, hearing that government is cutting health care spending by several million makes you wonder. When we have to tell someone they have breast or prostate cancer, and then try to convince them that waiting 10 to 12 weeks for treatment will not affect their outcome, we have to wonder.

Secondly, the bureaucratisation of the health care system has led to a profound disaffection among health care professionals. There was a time when people were proud to be a graduate of the nursing school, to be affiliated with this hospital or that university. Over the past 30 years, we have systematically demolished much of that legacy, much of that pride in belonging. Today, people in health care view their work as a job, not a career or a vocation.

Third, the patient has been forgotten by the system. When we arrive in the operating room in the morning and the nurse says: “Sorry but I only have five spots in intensive care and there are eight priority cases; you’ll have to choose.” How do we respond? Which person are we going to choose? The patient is not considered. When we speak with experts and officials, these things are invisible, and yet they have pushed doctors and others who care directly for patients outside of the decisions.

We have to expand the idea of expert beyond the number of degrees someone has. A patient who is suffering, in pain and waiting, that is an expert. The nurse caring for too many patients in hospital is an expert. And we need to bring people together to find consensus on what range of health care our society can pay for.

Panel Discussion:
There was a lot of support for broadening our concept of expertise before delegating any major decisions to expert committees. It would especially have to include patients and those directly involved in their care. The notion of an expert committee with this range of expertise, and the idea of allowing the work to become an ongoing process, increased support for this second course of action. What it would not do, panelists felt, was eliminate the need for societal debate over how much of our resources we want to devote to health care.

*The first person to decide that care is medically necessary is the patient, when he or she goes to see a doctor in the first place. We also decide whether or not we are going to follow through with a proposed treatment.* -- Lucie Chauvette

Some felt that we had expert committees in place who were already drawing up guidelines for appropriate care in specific areas, and that government could be most valuable in supporting clinical research that helped identify the best treatments in given areas.

Dr. Tessier drew the paradox that services deemed not medically necessary may be more accessible (for those who can pay) than services deemed medically necessary that would only be available through the public system. He also warned that we must be cautious about letting majority population rule health care priorities. I just returned from Guyana, where they decided to stop providing HIV tests, a move the population approves of because it lowers incidence numbers and removes the stigma that an HIV diagnosis came along with.

Panelists considered it of utmost importance that patients and those closest to them be well represented in defining what is medically necessary. Parliamentarians were not trusted to have enough of a grasp of the front-line realities to make these decisions. Dr. Tessier also raised
the concern that doctors were growing increasingly uncomfortable in a work environment that limited their option in providing care. They needed to be much more closely involved in decisions.

“The more we are going to involve them in this decision making, together with their patients, the better our chances are of boosting the morale of our troops and rekindling the flame at the practice level.” - Dr Tessier

Including patients as experts on such committees was a priority for most participants. Examples of Quebec groups that take patient input seriously, such as the Programme québécois de lutte contre le cancer or la stratégie canadienne de lutte contre le cancer or the initiative canadienne sur le cancer du sein were considered to place the patient first and could be used as models for different kinds of consultation. Panelists pointed to existing ethics committees as examples of involving patients in expert deliberations. Audience participant Martine Isabelle Forêt had a different view of them: The ethics committees you describe do not, for the most part, include patient representatives. I have been working in Geneva recently, where they do have patients on their ethics committees. Because the research involves psychiatric disorders and aging, these representatives are either crazy or elderly. Despite everyone’s best intentions, their voices are not heard in the debate, their views are discounted and their opinions disqualified. But because they are physically present, the committee sits with a clear conscience. Many concurred that the main challenge was to get citizens’ and patients’ voices heard and respected in the decision-making process.
Course of action #3
The benefit to an individual’s health should be used to decide what is medically necessary

Presentation by David Page:
I will address this issue from a patient perspective. My domain is hemophilia, a chronic disease which has received a lot of attention in recent years because of the contamination of the blood supply. These unfortunate events, however, saw the formation of strong partnerships between doctors and patients to decide what treatment is really necessary.

I would however like to talk about another disease, Syndrome X. It is a serious condition that requires care if I am to continue to enjoy life, work and avoid death. These treatments are medically necessary. I must see specialists regularly, sometimes often. But we live in a rich country and I think I have the right to see a specialist right away before my condition gets worse.

There are many treatments available for Syndrome X, according to my doctor. Some good, others less good, some new, some old, some inexpensive, some very expensive, some with side effects, others without, some that have passed through rigourous clinical trials, others which are still considered experimental. So what am I going to receive? Obviously I want the treatment that provides the best chance of continuing to enjoy life. And I want something proven, I do not want to be a guinea pig. That is what I tell my doctor. But I worry when I see how busy he is that he may not be up to date on the science of this particular condition. He assures me that no, he has been in touch with a group of colleagues who have been tracking old and new medicines and have established practice guidelines for Syndrome X. They succeeded in quickly getting the treatments that offer the best chance of survival approved and these are now considered medically necessary and are reimburse by our health care system.

It turns out that the treatment for syndrome X is very expensive. Not only that, but for reasons that are not quite clear, is available only in limited quantities. It is promising enough that everybody wants to try it, those with syndrome Y, Z and more. But the doctor reassures me again that mechanisms have been put in place to ensure that people like me with Syndrome X, take priority, while those with other syndromes may receive it -- if there is any left -- on a research basis.

I had to wonder what my doctor would have done had he not been in touch with this expert group. How could he have decided by himself whether I should receive it? More difficult, how could he have weighed the benefits I could gain from it against the benefits some other patients could derive. How could such a system be fair?

It may happen that a service is deemed medically unnecessary, or that its cost cannot be justified. But that has to be a decision society takes after public deliberations and after considering various options. When a person is sick, they must have access to the best treatments that can benefit them, without delay, and the choice of treatment must consider individual response to treatment. The choice of treatments must be based on the best scientific evidence and on the assurance from competent objective experts that we are not wasting our resources.

Presentation by Anne Katy:
I have suffered from chronic pain since 1995. I will call it disease “Y”. I am treated by doctors at the Montreal General Hospital Pain Clinic, by family doctors and by specialists. Treatment at the Pain Clinic has permitted me to feel a little less pain, but also to live with the pain and understand it better. The pain is still bad enough that I can only work part time, but it is better.

This year, someone suggested that I join a psychology group, which was not covered by the
RAMQ. However, I did manage to pay for the program, and it helped enormously to develop psychological tools to live more normally with the pain. This is what allowed me to return to work part time and every day I use what I learned in the program to keep the pain under control.

This type of treatment is beneficial and necessary when coupled with medical care to accelerate the patient’s progress. These too should be covered by our health care system without regard for the patient’s financial situation.

Panel and audience discussion:
A number of audience participants and panelists expressed the view that the health system was underfunded, and that defining medically necessary with a view to cutting services was the wrong way to go. There was some suspicion that the whole medically necessary discussion was a way to open up the system to more private participation as services were defined out of the public realm. Some panelists had nothing against the idea of a parallel private system that would provide both medically necessary and medically accessory services. Others felt there were already too many inequities in our health system, with different people having to find different ways of meeting their health needs.

The most regrettable fact is that these steps to remove services from our public basket of services has been undertaken as a bureaucratic process, without involving citizens and stakeholders. What I am saying now is let us add the democratic debate to the process before we go any further -- David Weinstock

Participants agreed that it would be difficult to integrate measures of how a therapy or service improved someone’s life into a definition of medically necessary. However, the litmus test of Can you look a patient in the eye and tell them this treatment is not available, and was considered critical by several panelists.

“I think those are decisions that we should be able to make while looking calmly at someone who is potentially affected by what we decide.” - Audience participant

As a result, patients and system users must be much more involved in the decision-making process about what services will be considered medically necessary. Some also felt that a system should provide guidelines, but be flexible enough to allow us to treat those who do not fit into the general rules.

Conclusions:
While neither the first option of mandating government to define medically necessary, nor the second option of mandating an independent expert committee to do so met with much approval among panelists and other participants, the bias was definitely in favour of the second. Approval for this type of committee increased significantly when “expert” was taken to include the expertise of patients and when provisions included healthy representation by those closely involved in patient care. Drawing up such a list could not be a simple cost cutting exercise and had to be done with concern for patient needs. As well, the discussion pointed much more toward a perpetual process, whereby a commission would be mandated to continuously examine and
review what was medically necessary in light of evolving technology, understanding and needs.

Panelists pointed to a number of existing bodies charged with assessing the benefits of health technologies. Their main problem was underfunding, and some questioned whether this would not be the fate of a new body as well. Other panelists felt that while one large commission may be able to sketch the broad lines of a list, many smaller commissions in each specialized area would be needed to really fill in the details.

The overarching feeling was that decisions about what is medically necessary have been made in a closed bureaucratic process for long enough and that it was time to bring some democratic deliberation to bear. The lack of societal consensus on the fundamental question of what our health care system hopes to achieve was seen as a major stumbling block in the work of defining medically necessary.