

Drug bill an attempt at democracy

Since Ontarians pay for drug funding, they should have a say in choosing which drugs are important, *by Doug Martin and Andreas Laupacis*

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George Smitherman, Ontario's minister of health and long-term care, is championing Bill 102, the Transparent Drug System for Patients Act, 2006. He hopes the act will help ensure that "patients will be involved in priority-setting and in the drug-funding decision-making."

This is a laudable goal. It won't be easy to implement, but it's definitely worth a try.

It is laudable for at least three reasons.

First, drug costs are rocketing — they are the leading driver of rising health-care costs.

Even when effective drugs make other health services unnecessary, drugs are still expensive. Decisions about drug funding are crucial to the sustainability of the system, and so are deserving of careful attention.

Second, because we generally do not fund ineffective drugs, the drugs under review are both effective and costly. This dynamic means decisions about drug funding are highly complex and value laden. For example: When should we fund drugs that provide a small benefit for many people vs. drugs that provide a large benefit to only a few?

When should we fund extremely expensive drugs that only provide a small benefit? When should we fund drugs for children vs. drugs for seniors? Reasonable people may disagree about which values to emphasize in these decisions.

Third, important goals of public policy-making, such as drug funding decisions, are legitimacy and fairness. Our health system is funded by public money — that is, OUR money — and it exists to serve patients and potential patients, that is, US. Legitimate decisions may only be made with OUR input; fair decision-making requires mechanisms for including US.

A recent Leger poll found only 36 per cent of Canadians believe policy-making by our government reflects the will of the people. Bill 102 may help redress this significant democratic deficit.

However, though the goal of public involvement in drug funding decisions is laudable, it will not be easy to achieve for a number of reasons.

Bureaucrats and their political masters who make funding decisions are very protective of their tradition of cabinet secrecy, witnessed by the fact that Ontario still doesn't publicly indicate the reasons for its drug-funding decisions. (To its credit, the national Common Drug Review posts the rationale for its decisions on its web site.)

The politicians who oversee the system are elected to represent, and in some instances inform, the will of the people.

However, they too often seek to evade blame for complex and controversial decisions by leaving the judgment in the hands of bureaucrats and experts, and keeping the rationale for those decisions secret.

The drug companies also have a long history of vigorously defending secrecy. They demand that Health Canada (which decides what drugs can be sold in Canada) and the public drug plans (which decide which drugs will be paid from the public purse) keep confidential the information that pharmaceutical companies have submitted to them.

But, let us assume for a moment that democracy-in-action triumphs here in Canada, and politicians, bureaucrats, experts and drug companies are willing to involve patients in making drug funding decisions. How can this goal be achieved?

There are two ways of involving patients and the public: consultation and shared decision-making.

Many techniques of consultation have been tried in many jurisdictions — for example, small advisory councils and large-scale surveys — and each technique has strengths and weaknesses and are worth trying in Ontario.

However, the enduring problem with consultation is that patients' and public viewpoints are too easily ignored by "experts" when the actual decisions are made. International experience shows that patients quickly recognize when this happens, refuse to participate and become even more disillusioned about their governments.

The only way to ensure true patient and public engagement with health policy-making is shared decision-making. Currently, decisions about drug funding are made by committees of bureaucrats and technical experts.

It is not difficult to invite patients to sit on these committees and share the decision making responsibility. We fully support Bill 102's intent to add patients to the Committee to Evaluate Drugs.

When this happens, the difficult part will be for those who have traditionally held authority to begin to recognize that the traditional values that have driven decision-making may change.

When different people are involved, different viewpoints — different values — will emerge. Fairness requires that those values conflicts be acknowledged and resolved openly and honestly.

Cancer Care Ontario (CCO) recognized this a decade ago when it formed a committee to make funding decisions for new and expensive anti-cancer drugs.

The committee included bureaucrats, scientists, physicians *and* cancer patients *and* members of the public.

And they figured out not only how to talk to each other meaningfully, but also how to resolve their value conflicts fairly, and make decisions that were sensible for the cancer system.

In the last two years, the decision-making responsibility has been shifted to the Drug Therapeutics and Quality Committee of the Ontario Ministry of Health and Long-Term Care where, unfortunately, patients and public representatives are not included.

Ultimately, democratic participation is both a responsibility and a privilege that so many others around the world are denied.

Canadians who have that privilege, who want to shape these important decisions, must accept the responsibility of thinking about what is best for all Canadians, not merely their own corner of the health-care world. Shared decision-making means shared responsibility.

If patients are to become involved in priority setting, they must recognize that sometimes we must say "No." Single-minded self-interest is unhelpful and unwelcome.

Concern about the understandable self-interest of patient and disease advocacy groups is why the Common Drug Review plans to prohibit patient advocates from being among the representatives of "the public" or "citizens" that will join its decision-making committee in the fall.

We applaud Smitherman's plans to involve patients in priority-setting decisions related to drugs in Ontario. We agree that the time to eliminate the democratic deficit in decision-making related to drugs is now.

We hope that all involved will overcome the difficulties we have mentioned and that in a few years we will see this successful initiative spread to other priority-setting exercises within public policy.

Is anyone interested in talking about how much we should spend on education vs. health care?

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