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Patients know about pharmacare: let's listen to them on Bill C-64

Patient groups' involvement should be built into the program, not just a one-time pre-consultation.



The workforce crisis in Canadian health care received a sliver of good news in April when more med school grads signed up to train in family medicine than last year. Patients welcomed this as a step in the right direction, but it doesn't solve the chronic shortage of physicians, nurses, and personal support workers, and will only potentially make a difference over years.

We say the same of our proposed national pharmacare program.

Bill C-64 lays out groundwork for the first phase of a universal pharmacare program with potential to build a better framework. It would start a process to ensure Canadians have universal access to medicines, not just services of doctors, hospitals, and labs. Ours is the only country with a publicly funded healthcare system that does not have universal coverage for prescription drugs.

But for those managing a chronic or complex disease, what does a better framework look like? Will meeting the medication needs of the wider population lead to more basic coverage of fewer drugs? What about difficult-to-treat diseases? Anything that has the potential to change how medications are covered will be met with keen scrutiny by the patients who need them most.

That's why the Best Medicines Coalition presented recommendations to the Standing Committee of Health. The coalition represents some 30 patient organizations, from Parkinson's, arthritis, hemophilia and blindness to cancers and other complicated and rare diseases. It aims to ensure all patients have access to the medication they need and that patients are meaningful participants in the development and oversight of pharmacare policy.

The Coalition's recommendations sought to bring transparency and accessibility to this bill. We were heard but not heeded — yet. This is a missed opportunity. Patients must be included from the start, because if we get this wrong, nothing changes: Canadians will lack access to the drugs they need. They won't get better.

One in ten Canadians with chronic conditions ended up in overcrowded emergency departments because their conditions worsened when they couldn't afford their prescriptions, according to a [Leger poll](#) commissioned in February by the Heart and Stroke Foundation and the Canadian Cancer Society.

Yes, most Canadians are covered by some 100,000 private drug insurance plans and the more than 100 public ones, but that's not the whole picture. The [federal 2019 pharmacare report](#) found 7.5 million Canadians weren't sufficiently covered by their drug insurance. A much smaller group were completely uninsured.

If you live in Canada, you should have access to the medication you need. Which drugs will be covered is important, but as crucial is how Canada's Drug Agency recommends them, and the timeline for these decisions.

Patient groups were consulted on how a drug gets added to the proposed national formulary as part of a research initiative. But their involvement should be built into the program, not just a one-time pre-consultation.

The Best Medicines Coalition recommended having patient interests represented on two new fronts: a chief patient officer (CPO) at Health Canada and a patient ombudsman who reports directly to Parliament.

The CPO would work from within the organization, supported by an advisory committee with diverse patient representation. It should be someone with lived experience whose role gives them authority to ensure patient expertise is recognized and used to drive reform and ongoing work.

The patient ombudsman would work outside the organization reporting directly to parliament. Besides reporting any failures to uphold the Act and regulations, this ombudsman would also assess barriers and concerns as expressed by patients when it comes to accessing medications.

It's not enough for a government to say it wants universal access to medication. Bill C-64 should speak to the role patients must take in improving equitable access to medication. Patients are here. They know what it takes to make pharmacare better. Listening to patients and adopting these recommendations will be a step in the right direction.

John Adams is board chair of the Best Medicines Coalition, and CEO and co-founder of Canadian PKU & Allied Dis-orders, with lived experience as an anemia, cancer, and cardiac patient and as a care-giver. Linda Wilhelm lives with rheumatoid arthritis and is a past board chair of the Best Medicines Coalition, and co-founder and president of the Canadian Arthritis Patient Alliance.