

## LETTERS

### For patient involvement in clinical research

Dr. Patrick's call for greater patient involvement in research and a focus on patient-focused outcomes is timely and critical, and I applaud *CMAJ* for taking this important position.<sup>1</sup>

As a public health physician, the involvement of key stakeholders in planning, research, and evaluation of policies and programs has long been well understood — even if it faces deployment challenges in practice. Community-based participatory research represents one such model.<sup>2</sup> Ultimately, members of our communities will bear the benefits and burdens of public policy. Thus, understanding potential effects as part of planning and monitoring for outcomes, both intended and unintended, is critical to ensuring that, put simply, we got it right — and if not, see what needs to change.

The private sector has had similar philosophies in seeking consumer testing and input. Even things as simple as apples are subject to testing.<sup>3</sup> Business models are highly dependent on not just coming up with a product that looks good in practice, but one that is sought after, with tangible impacts, that a consumer might consider purchasing. Many companies would argue that to ignore the consumer in the development of their value proposition is foolhardy.

The parallel concept is that patient involvement is essential in planning and conducting health care research — be it around assessing treatments, experiences, or systems change — to ensure outcomes are relevant to those who matter — the patients accessing care.

Critics will argue that any other number of measures can act as a proxy for

improved outcomes, such as cost-savings or decreased wait times. Such measures do not allow us to understand the direct impacts on population- and individual-level health outcomes. To truly appreciate what health outcomes impact quality and quantity of life, you have to ask the people who are living with the outcomes of the intervention in question.

Critics will also argue that it's difficult to identify who represents the voice of the patient. That is, however, a specious argument: just because something is difficult that does not mean it shouldn't be attempted. Again, to take an example from the private sector — if a company isn't hearing from the right voices, it will figure it out quickly when things start to go awry.

Canadian academics and practitioners produce much research, and every day new programs, policies and interventions are ripe for investigation. Given the high stakes, the medical community has a responsibility to ensure that any planning and evaluation is informed by the people who live with the outcomes.

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**Competing interests:** None declared.