

LETTERS

Against patient involvement in clinical research

In a recent editorial,¹ Kirsten Patrick propounds the view that patient involvement should be an essential component of clinical research. “Patients and their caregivers must be involved in decision-making at *all* steps in the research process, from design to choice of primary and secondary outcomes ...” As an example of failure to do this, she cites a study² that found that incentive payments to primary care physicians for providing care to patients with multiple chronic conditions did not have a significant impact on patients’ primary care contacts, continuity of care or management costs. Patrick criticizes the paper for the fact that “the outcomes were almost certainly not patient-relevant.” Surely that is a bit much. Why would this study, which was based on administrative data, need to refer to patients? In what way would it be improved by doing so? And, if the potential saving of millions of dollars to the health care system is not “patient-relevant,” what is? These pronouncements would not merit comment if they did not come from the deputy editor of the journal, who concludes her editorial with the warning that, “As we appraise research that is submitted to the journal, we will consider

carefully methods used to involve public and patient representatives in design and implementation.” In other words, if you want to get published in *CMAJ*, make sure you list the names of representatives of the public and of patients among your authors or at least in your methods section. You will have to make up your own mind who representatives of the public are. Must they be elected? What distinguishes a regular author from a representative of the public?

I suggest that those who hold the incredible power to accept or reject our research submissions should leave the authors to decide how the research should be carried out, and judge the study solely on its quality.

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References

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2. Lavergne MR, Law MR, Peterson S, et al. A population-based analysis of incentive payments to primary care physicians for the care of patients with complex disease. *CMAJ* 2016;188:E375-83.

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