

5

things to know about patient-oriented research (POR) in Canada

Nicole Doria¹ and Emily Faulkner¹



Maritime SPOR SUPPORT Unit, Nova Scotia Health Authority, Halifax, NS, Canada

1 To bridge the gap between research and practice, Canada launched a Strategy for Patient-Oriented Research (SPOR).¹

SPOR is intended to improve health outcomes, enhance patients' health care experiences, and sustain the Canadian health care system. The strategy outlines a collaborative process to identify patient priorities and ensure the delivery of high quality and cost-effective health care.

2 In the context of SPOR, patients should be involved as partners in all phases of research.

Patients must be meaningfully involved in the preparatory, execution, and translational phases of research as co-leaders in a process of co-learning.² Patients should not be invited to participate after a project has started.^{2,3}

3 Tokenistic engagement is a barrier to achieving meaningful POR.

Tokenism occurs when patients are involved as a symbolic effort.³ To achieve genuine engagement, researchers and physicians should: improve stakeholder diversity, use terminology that everyone can understand, show the results and decision-making process to patient partners, engage in reciprocal learning, and promote the patient voice as equal.³

4 Training patient-partners is an effective way to improve research outcomes.

Patient partner roles and expectations should be communicated in the preparatory phase of POR.^{2,3} Role-specific training should be customized to each patients' individual circumstance and level of health literacy to avoid poor research outcomes.^{4,5} Lack of appropriate training can contribute to unfamiliarity with processes, expectations and language of research.³

5 The advancement of POR is impeded by inconsistent language and unclear terminology.^{2,4}

Commonly used terms such as patient, patient engagement, and patient-oriented are often used inconsistently. It is important that clear and established language is being used as POR becomes more established and well-utilized.

References:

1. Canadian Institutes of Health Research. Canada's strategy for patient-oriented research: Improving health outcomes through evidence-informed care. Ottawa, Ontario; 2011.
2. Shippee N, Domecq G, Prutsky Lopez G, Wang Z, Elraiyah T, Nabhan M, Brito J, et al. Patient and service user engagement in research: A systematic review and synthesized framework. *Health Expectations*. 2015; 18(5): 1151-1166.
3. Hahn D, Hoffmann A, Felzien M, LeMaster J, Xu J, Fagnan L. Tokenism in patient engagement. *Family Practice*. 2017; 34(3): 290-295.
4. Prey J, Woollen J, Wilcox L, Sackeim A, Hripcsak G, Bakken S, et al. Patient engagement in the inpatient setting: A systematic review. *Journal of the American Medical Informatics Association*. 2014; 21(4): 742-750.
5. Kirwan J, de Wit M, Frank L, Haywood K, Salek S, Brace-McDonnell S, et al. Emerging Guidelines for Patient Engagement in Research. *Value in Health*. 2017; 20(3): 481-486.