

The Creation of a Tool to Measure Engagement in Patient-Oriented Research

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Appendix 1: Patient-Oriented Research Level of Engagement Tool (PORLET)

Overview

The SCPOR Patient-Oriented Research Level of Engagement Tool measures the degree to which a project meets the definition of patient-oriented research described by the [CIHR Strategy for Patient-Oriented Research \(SPOR\)](#).¹⁻³ The tool utilizes five criteria which have been adopted from SPOR published documents.^{2,3} These criteria are: *patients are partners, patient identified priorities, outcomes important to patients, team is multidisciplinary, and aims to integrate knowledge into practice*. Each of these criteria is rated on a scale from 1 to 5.

Instructions

- The tool scores each criteria on a continuum from 1 to 5. A score of 1 for each criteria suggests limited patient-oriented research criteria have been met within the project. A score of 5 for each criteria suggests all aspects of the project meet ideal patient-oriented research criteria, for instance: patients are activity involved in all aspects of the research project, the team has representation from research, health system and the patient community, and knowledge translations activities have been planned and approved by all members of the team.
- Each category should be assessed individually and then summed to provide a total score.
- A score of 1 indicates the lowest score possible and a score of 5 indicates the highest score possible in each category. The highest possible total score for a project is 25.

Definitions

Patient: The term patient is defined as either someone who has personal experience of a health issue, or their informal caregivers, including family and friends ([SPOR Patient Engagement Framework](#)).² The term patient may be replaced with client, family, resident, person with lived experience, community or community based organization.

Inform: To provide patients balanced and objective information to assist them in understanding the problem and potential solutions.

Consult: To obtain patients' feedback on the research project and decisions.

Involve: To work directly with patients throughout the process to ensure that their viewpoints are understood and considered.

Collaborate: To partner with patients in each aspect of the research project.

Empower: To place final decision making in the hands of the patients.

Note: Definitions for inform, consult, involve, collaborate and empower are adapted from the International Association for Public Participation (IAP2) [Public Participation Spectrum](#).⁴

References

- Canadian Institutes of Health Research (2017). *Strategy for Patient-Oriented Research*. Retrieved from <http://www.cihr-irsc.gc.ca/e/41204.html>
- Canadian Institutes of Health Research (2014). *SPOR Patient Engagement Framework*. Retrieved from <http://www.cihr-irsc.gc.ca/e/48413.html>
- Canadian Institutes of Health Research (2015). *SPOR Capacity Development Framework*. Retrieved from <http://www.cihr-irsc.gc.ca/e/49307.html>
- International Association for Public Participation (2015). *IAP2 Spectrum for Public Participation*. Retrieved from <http://iap2canada.ca/page-1020549>

Score Criteria	1	2	3	4	5	Criteria Score
Patients are Partners	Patients are named as team members and are informed about the research but do not have a role in any phase of the project.	Patients are named as team members who are consulted throughout the project.	Patients are named as team members who are involved throughout the project.	Patients are active partners who collaborate with team members throughout the research project.	Patients are equal partners who are empowered to make decisions throughout the research project.	
Patient Identified Priority	Patients do not identify the research priorities. Patients are informed about the research project.	Patients are consulted about the research priority.	Patients are involved in identifying the research priority.	Patients collaborate to identify the research priority with researchers, clinicians, stakeholders and the health system.	Patients identify the research priority to researchers, clinicians, stakeholders and the health system.	
Outcomes Important to Patients	Patients are not involved in identifying the research outcomes. Patients are informed about the research outcomes.	Patients are consulted about the research outcomes.	Patients are involved in identifying the research outcomes.	Patients collaborate to identify the research outcomes with researchers, clinicians, stakeholders and the health system.	Patients identify the research outcomes to researchers, clinicians, stakeholders and the health system.	
Team is Multi-disciplinary	Research team does not include relevant disciplines or stakeholders.	Research team includes relevant disciplines and stakeholders; however roles are unclear.	Research team includes relevant disciplines and stakeholders who have clear roles.	Research team includes relevant disciplines and stakeholders who have clear roles, but are not integrated throughout the project.	Research team includes relevant disciplines and stakeholders whose roles are clearly outlined and are integrated throughout the project.	
Aims to Integrate Knowledge into Practice	Patients and end-users do not have a role in the knowledge translation plan. They are informed about the plan.	Patients and end-users are consulted about the knowledge translation plan.	Patients and end-users are involved in the knowledge translation plan.	Patients and end-users collaborate on the knowledge translation plan.	Patients and end-users are creators and implementers of the knowledge translation plan.	
Total Score						0

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