

## How Patient-Oriented is Your Research?

### Background

#### What is the purpose of this document?

The following questions can help identify the extent to which a proposed research project might be patient-oriented. Consideration of these questions can guide the selection of options of additional supports that could be offered by the BC SUPPORT Unit for the project. Additionally, working through these questions can help identify areas or ideas that might not have been considered or included in the initial research plan.

The BC SUPPORT Unit can help researchers walk through these questions and support researchers to facilitate planning of a patient-oriented research (POR) project.

#### What do we mean by ‘Patient’?

We use the term ‘patient’ as an overarching term that includes individuals with personal or lived experience of a health issue and informal caregivers, including family and friends ([Strategy for Patient Oriented Research](#)).

### Questions to guide discussion and planning

The defining characteristics of POR are provided in bold below. Following each characteristic is a relevant question and key information to inform subsequent discussion.

#### **POR: Engages patients as partners**

*Q1: Are there, or is there a plan, to engage patient partners on the research team?*

Please note that having a patient ‘partner’ on the research team does not include the intention to recruit patients, families or caregivers to participate in the research study itself as research subjects for the purpose of data collection (research done ‘on’ patients)



### Engaging patients as research partners does include:

- Having designated patients as *partners / collaborators / co-creators* on the research team for the purpose of making research-related decisions (research done ‘with’ patients).
- Patient partners can potentially be engaged at any or all stages of the research cycle. Patient partnership should be considered in the initial stages of planning for the project. The level and type of patient engagement can vary across the stages of research. The IAP2 levels of involvement in public participation provides a helpful framework for understanding how patient partners might be engaged in research. [See the IAP2 Public Participation Spectrum diagram.](#)

### **POR: Focuses on patient-identified priorities**

*Q2: Can you demonstrate that your research idea or focus is a priority for patients?*

### **This could include:**

- *Synthesized evidence from the literature (from others) and / or with members of the research team as contributors to the existing evidence, indicating that patients have identified this line of research as a priority.*
- Identification and / or validation of this research idea as a priority from your previous work with patients at a *consultation level*. Some examples of patient consultation methods used to gather patient priorities include interviews, surveys, focus / discussion groups, public sessions, workshops.
- Identification and / or validation of this research idea as a priority from your previous work with patients at a *collaborative or lead level*. Some examples of patient collaboration or leadership methods used to gather patient priorities include participatory research design, patient-directed strategies such as World cafés, Delphi Methods and patient governance / advisory groups.



**POR: Aims to improve health outcomes that are important and matter to patients.**

*Q3: Can you demonstrate that you are measuring outcomes that matter or are important to patients?*

This is not just the intention to conduct patient-centered outcomes research ([definition](#)) or the use of patient-reported outcome measures (PROMs, PREMs) in the research project.

**This could include:**

- *Synthesized evidence from the literature* (from others) and / or with patient partners on the research team as contributors to the existing evidence, indicating that patients have identified that the outcomes measures in this research matter or are important to them.
- Identification and / or validation of this research idea as a priority from previous work with patients at a *consultation level* (see examples above) that identify that the outcomes are important or meaningful.
- Identification and / or validation of this research idea as a priority from previous work with patients at a *collaborative or lead level* (see examples above) that identify that the outcomes matter or are priorities.

**POR: Has a multi-disciplinary team working in partnership with ALL relevant stakeholders, including patients.**

*Q4: Can you demonstrate that you have identified and included all relevant stakeholders as research partners on the research team?*

This does not include end-of-research knowledge transfer / translation plans in which you have identified groups or organizations that should be targeted for dissemination of the research findings. Rather, a multi-disciplinary POR research team should have research team members from all stakeholder groups likely to be impacted by or involved with conducting the research, as well as, supporting the uptake of the research findings. Stakeholder engagement should begin at the outset of the research planning through to implementation and evaluation of impact. Noting that all stakeholder partners do not need to be involved to the same degree throughout the research project.



**POR stakeholders MUST include:**

- Patients, family members or caregivers

**POR stakeholders SHOULD include:**

- Health system decision-makers (i.e. Individuals working within the health system who make decisions about health care service delivery and management).
- Health care providers / clinicians (i.e. Individuals working within the health system who provide health care to patients).

**POR stakeholders COULD include (where appropriate):**

- Health payer / policy makers
- Health technology / industry partners

**POR: Aims to co-create and apply knowledge to improve healthcare practices, systems and policies.**

*Q5: Can you identify a clear and direct link for how this research could be used in the near term to support health practice, system or policy change?*

The Canadian Medical Association Journal (CMAJ) has defined themselves as a “[home for patient-oriented research](#)”. CMAJ recently published a supplemental issue dedicated to POR from researchers working in Ontario ([November 07, 2018; Volume 190, Issue Suppl](#)). This issue offers some examples of POR across the spectrum of health care practice, systems and policy.

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