

## Patient-Oriented Research

The Alberta SPOR SUPPORT Unit (AbSPORU) is using the CIHR's 2014 definition of patient-oriented research:

*“Patient-oriented research refers to a continuum of research that engages patients<sup>1</sup> as partners, focuses on patient-identified priorities, and aims to improve patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices”*

Further information can be found at: (<http://www.cihr-irsc.gc.ca/e/48413.html#a4>).

It is the aspiration of AbSPORU that over time, researchers in the province will conduct patient-oriented research which meets all components as outlined in the above CIHR definition. In the meantime, AbSPORU has operationalized the definition (below) to clarify the minimum requirements for a research project to be considered as patient-oriented. AbSPORU's operationalized definition of patient-oriented research includes at least one of the following:

### **1. Meaningfully engages patients as identified in the adapted IAP2 spectrum of engagement (see Figure 1) (at any one or more phases of the research process)**

Meaningful patient engagement refers to ACTIVE patient engagement that is mutually beneficial for all parties, across the research process. Examples include but are not limited to engagement in:

- Governance
- Identifying research topics to investigate
- Helping plan & organize a study
- Helping recruit participants & carry out the study
- Helping share the results with other patients/public

### **2. Focuses on patient-identified priorities.**

These may be identified through:

- Core Outcome Sets for clinical trials that have been developed with stakeholder involvement
- Focus groups
- James Lind Alliance approaches or adaptations of this approach\*
- Online priority setting activities

\* The James Lind Alliance brings patients, carers and clinicians together in Priority Setting Partnerships to identify and prioritise the top 10 uncertainties or 'unanswered questions' about the effects of the treatment that they agree are most important (<http://www.jla.nihr.ac.uk/>).

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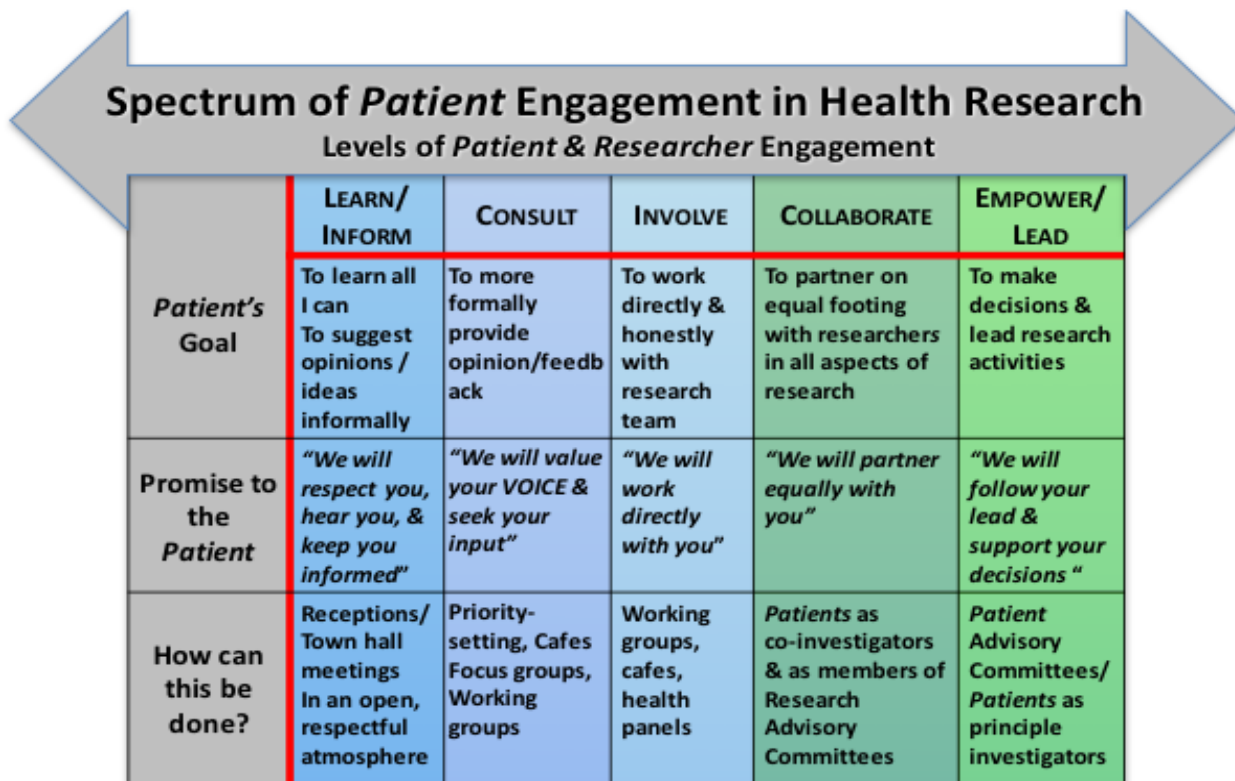
<sup>1</sup> an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends

**3. Aims to improve patient outcomes. Examples include, but are not limited to:**

- Patient Reported Outcome Measures (PROMS)
- Patient Reported Experience Measures (PREMS)
- Patient satisfaction measures
- Quality of life measures
- Management of symptoms and pain measures
- Potential clinical improvement measures
- Length of stay
- Cost effectiveness

We are using CIHR’s definition of knowledge translation as "a dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" (<http://www.cihr-irsc.gc.ca/e/29418.html#2>).

**Figure 1: Spectrum of patient and researcher engagement in research**



Adapted from IAP2 Spectrum of Engagement (2007) by Vandall-Walker (2016)