

CLyDRN Annual General Meeting

Patient Engagement Evaluation

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Objectives

- To ensure we're "all on the same page" re: expectations for patient engagement
- To guide scientists' and patients' engagement in collaborative discussion to come up with feasible studies that meet patient expectations
- Address concerns from CIHR's Lyme Oversight Committee feedback re: CLyDRN's second report
- Present the GRIPP2-SF for consideration to document patient involvement

Patient Engagement

Beliefs include:

- The fact that we are in the midst of a paradigm shift, actively involving patients, family and community members in PCAC and various research processes
- We can work together through active collaboration and building consensus



CIHR: Strategy for Patient- Oriented Research (SPOR) Patient Engagement Framework

https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Patient-oriented research is ultimately aimed at achieving benefits that matter to patients:

- Improved health
- Improved access to the health care system
- The right treatment at the right time
- Being an active and informed partner in health care
- Quality of life that is tied to patient-oriented outcomes
- Make a contribution to improving the cost effectiveness of the health care system

The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, leads to better results.

The patient perspective is integrated into every step of the research process including developing research questions, defining research objectives, collecting data and evaluating results.



SPOR Patient Engagement Framework

Evaluation of Patient Engagement in SPOR

https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Desired Outcomes of Patient Engagement:

- Inclusive mechanisms and processes are created
- Respectful collaboration is established amongst patients, researchers and health care providers
- The experiential knowledge of patients is valued as evidence as part of the research process
- Research is informed and codirected by patients
- Common goal of timely implementation of quality research



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Successful patient engagement includes the following:

- i. **Inclusive Mechanisms and Processes:** Patient involvement at all levels is a desired aspiration that also means shared leadership and decision-making processes in which patients are co-building with researchers, practitioners and other decision-makers in collaborative research teams. There is also opportunity for peer to peer recruitment and engagement. (Patient-led research is supported).
- ii. **Multi-Way Capacity Building:** This ensures that the capacities of patients, researchers, and health care providers are being developed in order to work effectively together. There is support for creating safe environments that promote honest interactions, cultural competence, training and education.
- iii. **Multi-Way Communication and Collaboration:** A safe environment of mutual respect is fostered and is characterized by honest conversations that inform and involve people.
- iv. **Experiential Knowledge Valued as Evidence:** Experiential knowledge of patients, families and caregivers is mobilized and translated.
- v. **Patient-Informed and Directed Research:** Research approaches engage patients in collaborative methods and the research is inclusive of a range of patients. Recognition is given to a diversity of patients' needs and expectations through a range of roles.
- vi. **A Shared Sense of Purpose:** All participants work together towards the goal of timely improvements to the quality of research driven by patient-oriented outcomes. Mechanisms are in place for a continuous feedback loop in which the results of patient-oriented research are communicated back to patients.

GRIPP2-SF

Guidance for Reporting Involvement of Patients and the Public (GRIPP2)

International guidance for reporting of patient and public involvement in health and social care research

Section and topic	Item	Reported on page No
1: Aim	Report the aim of PPI in the study	
2: Methods	Provide a clear description of the methods used for PPI in the study	
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	

Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research *BMJ* 2017; 358 :j3453 doi:10.1136/bmj.j3453

<https://www.bmj.com/content/358/bmj.j3453>

GRIPP2 Rationale and Implementation

- Supports SPOR Patient Engagement Framework
 - A transparent way to document early involvement or co-design efforts and other desired outcomes of patient and community engagement
- Documents the extent of patient and community involvement throughout the network
 - Can be compared across pillars, and over time
- A pilot of the adoption of GRIPP2 reporting guidelines can be an example of patient-scientist collaboration
 - PCAC can advise scientists on wording, and format, and support consistency of reporting across the network.

A decorative graphic consisting of several concentric, overlapping curved bands. The left side features blue bands, and the right side features green bands. The bands are semi-transparent and have a slight gradient, creating a sense of depth and movement.

Thank you!

Discussion

CIHR's oversight committee's comments

- Re: the need for an evaluation framework: “The Oversight Committee requests a revised response to Section 1.2 of the document, with a focus on the plans to address the concerns raised, in particular the issues raised around patient engagement.”
- “The oversight committee expressed concern over the continued challenges of patient engagement and the retention of patient partners in leadership roles. The committee would like to see a clear path forward for meaningful engagement and retention of patient partners addressed in the third year of activities. “