

**Patient Partnership Council for
De-Implementing Low Value Care**

TERMS OF REFERENCE

Vision

Building partnership among patients, the public and the Choosing Wisely Canada innovative Clinical Trial (CWC-iCT) research team to advise and guide research involving patients.

Purpose

The group aims to provide advice relating to the development of research questions, the design, delivery and evaluation of the research projects, as well as dissemination of the results, thereby ensuring the patient voice is present throughout the project. The group was formally established in October 2018 by the CWC-iCT Steering Committee.

Roles and responsibilities

The primary role of Patient Partners is to ensure the public and patient perspective is included in every stage of the research project. The group is composed of Patient Partners from Ontario (ON), Alberta (AB) and Newfoundland and Labrador (NL), and all members sit on the CWC-iCT Steering Committee.

The Patient Partners:

- provide insights in understanding patient/public perspectives, as well as prioritizing research questions.
- provide advice on designing the research project and outcome selection.
- provide views on the plans for design, implementation and evaluation of applied interventions.
- provide support in recruiting processes for additional patient advisors for the project.
- participate and contribute in in-person and telephone meetings to provide specific insights based on their experiences (or that of people they represent) in relation to a specific illness or condition, or health service.
- review documents related to the research project to provide patients/public points of view*.
- review documents to be shared with the general public and offer suggestions for revisions*.
- provide guidance and advice throughout all phases of the project.
- contribute to dissemination of the results of the project by reviewing strategies and materials.
- provide feedback and recommendations for further work (e.g., consultation on patient-centered interventions, consensus on barriers and facilitators to implementing interventions, consultation on any documents directed toward the patients/public. This is not an exclusive list. Items may develop as the research project progresses).

*Overall, it is anticipated that the Patient Partner role will entail on average 20 hours per month combined among all Patient Partners. This includes time related to email and telephone meetings and reviewing materials. However, this may vary depending on the stage of the project.

Accountability and reporting

The Patient Partnership Council is an autonomous group which works closely with other groups within the research project. The Patient Partners report their activities to the CWC-iCT Steering Committee.

Ways of working

The members virtually meet quarterly, and face-to-face once a year at an annual meeting. Based on the project phase, the group members may be required to communicate more frequently via email or virtual meeting. Members of the group will receive the meetings' agendas or related documents by email in advance, with enough notice to provide comments and feedback (minimum one week). Members will be invited to attend provincial team meetings as their time allows. Members may be contacted between the meetings for their advice/comments as needed. Subgroups may be formed to work on specific issues which may convene separate meetings. Members are reminded that the shared documents are not intended to be circulated beyond the group and are subject to terms of confidentiality and copyright.

Decision Making

Consensus decision making is preferred. Where consensus cannot be reached, voting can be conducted to progress decision making.

Membership

Membership of the group is open to individuals who have an interest in engaging with research as a Patient Partner. Two to three members will represent each of the provinces (ON, AB, NL). The group membership lasts for the duration of the study. The group members can terminate their membership at any point, by emailing the Patient Engagement Coordinator (Stefanie Linklater), their regional lead (AB - Dr. Shannon Ruzycski; ON – Dr. Kyle Kirkham; NL – Dr. Amanda Hall) or the project's National Research Lead (Dr. Andrea Patey).

Expectations

- Timely responses to email correspondences, and efforts to participate at in-person and virtual meetings.
- Respecting diversity and different opinions.
- Working collaboratively with other team members, as well as the Steering Committee.
- Respecting and maintaining confidentiality.
- Working understanding of the harms of overuse and low value care.
- Having a generalized commitment to the improvement and sustainability of the health care system.

Levels of Engagement

- Each provincial coordinator will generate a Patient Engagement Plan for the ongoing work in their province. Each Patient Partner will be asked to indicate their preferred level of engagement for each task. More details about Patient Engagement Plans can be found here:

<https://pubmed.ncbi.nlm.nih.gov/34953028/>

Etchegary H, Pike A, Patey AM, Gionet E, Johnston B, Goold S, Francis V, Grimshaw J, Hall

A; De-Implementing Wisely Research Group. Operationalizing a patient engagement plan for health research: Sharing a codesigned planning template from a national clinical trial. Health Expect. 2022 Apr;25(2):697-711. doi: 10.1111/hex.13417.

Key requirements

- Attending a screening interview.
- Signing the confidentiality agreement*.
- Signing the Terms of Reference acknowledgement (attached to this document).
- Completing training as required.

*Only applies to the members who are not involved primarily through CWC or Strategy for Patient-Oriented Research (SPOR) and need to sign a confidentiality agreement with the Ottawa Hospital Research Institute.

Payment

Patient Partners will be remunerated and supported for their time spent contributing to this research project. This support includes providing safe environments which promote honest interactions, cultural competence, training, and education, as well as financial compensation. For more details on how the members will be compensated for their contribution, please see the document “Patient partner appreciation policy”.

Reviewing

The group will review and update its Terms of Reference annually.

**Patient Partnership Council for
De-Implementing Low Value Care: Research Program of CWC-IRN
TERMS OF REFERENCE ACKNOWLEDGEMENT**

I have read the terms of reference, and I understand compliance with it, is a condition of working with the Patient Partnership Council and that failure to comply may result in a discontinuation of my involvement.

Print Name Here

Date

Signature