

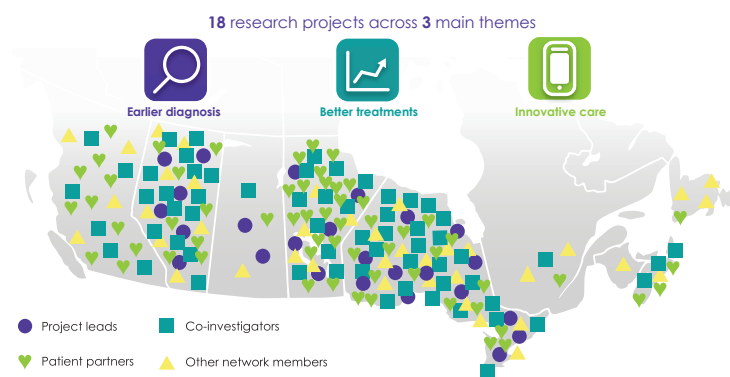
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Background

Can-SOLVE CKD

Can-SOLVE CKD is a pan-Canadian network seeking solutions and innovations that will transform kidney health in Canada through 18 patient-centered projects spanning basic science, clinical and population health research.



Research Operations Committee

The Research Operations Committee (ROC) performs annual peer-review on all projects to evaluate and provide guidance for successful implementation of the research program. The ROC reports to the Steering Committee. Membership includes patient and Indigenous partners, experts of research methodology and clinical research. We aim to describe the Patient-Oriented Research (POR) Collaborative Peer-Review Model employed by ROC and facilitators that enable patient partners to participate as equal and contributing voices in the process.

Methods

Review Process

A review package includes a progress update by the project team, Knowledge Users and Knowledge Translation Committee review feedback, POR Training log, patient engagement check-in calls and survey report. The format involves the assignment of a researcher as a primary reviewer, focusing on scientific methods, a patient partner as a secondary reviewer, focusing on patient engagement, and a reader, who contributes to the discussion. Each reviewer completes an evaluation checklist and attends a session to reach consensus on recommendations which are then collated on a letter back to the project team. Network supports may be dispatched to facilitate recommendations. Major concerns require project teams to address and respond to ROC with possible interim reporting.

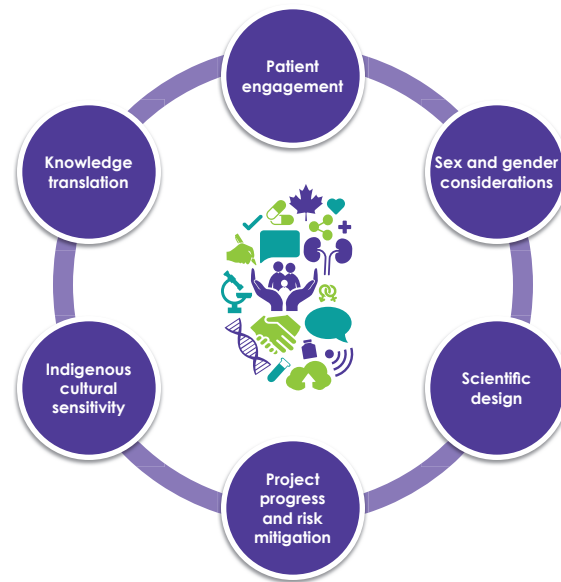
Pre-requisites for being an effective patient partner reviewer:

- Must be comfortable with themselves and not afraid to voice opinions
- Must be motivated and interested in the work

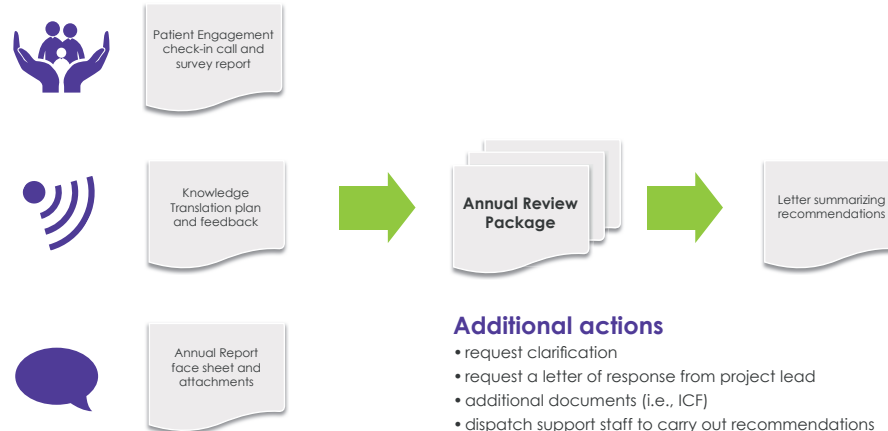
An environment that cultivates progressive engagement includes:

- Respectful and inclusive facilitation at meetings
- A forum for peer support to share learning
- Provide the opportunity to learn on the job

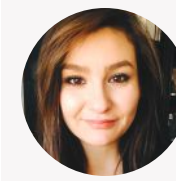
Elements of the review



The review process



Patients as equal partners



"The Research Operations Committee was very intimidating at the beginning but the committee is so supportive I never felt incompetent or 'less than'. It helped me to realize that I have so much knowledge to contribute on patient engagement and I feel my input is really valued and makes a difference for the research teams. I love that it gives me a greater understanding of the research projects and overall the experience has been really positive."

Chantel Large, ROC Member & Indigenous Peoples' Engagement and Research Council Member

"To be a member of the ROC is not only an amazing learning opportunity but also having the ability to input, from a patient perspective, into the research projects is incredibly fulfilling. The Committee has allowed me to gain a far better understanding of 'health research' including such challenges as Research Ethics Board approvals and multi-centre funding requirements. I believe patient engagement is critical in Patient Oriented Research. As a patient partner on the committee, I have had the opportunity to provide meaningful input into each of the research projects."

David Hillier, ROC Member & Patient Council Executive



"As a researcher, it is common to participate in review processes whereby we attempt to constructively improve the quality of research projects. ROC was a distinctly different and enriching experience for me because it embraces two major values: research projects must be constructed towards benefit for patients, and (II) each aspect of review and advice must be generated in true partnership with patients and patient partners. These values brought me to the coal face of 'social responsibility in research' in a unique way that had a major positive impact. I feel great appreciation for the opportunity to focus my efforts and to have engaged with fellow researchers and patients this way."

Norman Rosenblum, Past ROC Chair & CIHR INMD Scientific Director

Conclusions

The Collaborative Peer-Review Model ensures accountability of POR principles encouraging research outputs to have high impact in healthcare. This can be considered and adapted for other organizations for patient partners to have a prominent role in monitoring and governance of POR.

Acknowledgments

This work is funded by the Canadian Institutes of Health Research through the Strategy for Patient-Oriented Research.

