

Engaging Patients in the Research Process



A toolkit for project leads

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This toolkit contains recommendations for engaging patient partners at the start of your research project. The purpose of this toolkit is to enable you, as a project lead, to enhance the collaborative experience within your team in the journey ahead.



Developing a patient engagement plan

Developing a patient engagement plan takes time. It is a shared and ongoing effort that is an iterative process. Answering the questions below will build a partnership with patients and set a clear way forward as you work together in patient-oriented research.

- **What aspects of your project will benefit most from the input of patient partners?**
- **What constraints/limitations do you face in this project?**
Being upfront about this aspect of your project will help manage expectations.
- **Why do you want to involve patients as partners in this research project?**
Both you and your patient partners should have the same clear understanding of why patients are being engaged.
- **What information (i.e., time commitment, expertise/skill sets) do patient partners need to be able to participate fully?**
How will you convey the required information to patient partners and ensure they understand it?
- **What is the best method to keep in touch after the project is completed?**
It is important to close the loop after engaging patients. Patient partners who gave up their time need to know how the information they provided was used, or why it was not used.

Tip: Explore what motivates patient partners

Members of the iCARE Patient Advisory Group felt strongly about raising awareness of type 2 diabetes. In partnership with researchers, they produced a video to dispel myths about type 2 diabetes. Both patient partners and researchers felt empowered by working on the production together.

- **What level(s) of engagement do you expect?**

INFORM: To provide the patient with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.

CONSULT: To obtain patient feedback on analysis, alternatives and/or decision.

INVOLVE: To work directly with the patient throughout the process to ensure that patient concerns and aspirations are consistently understood and considered.

COLLABORATE: To partner with the patient in each aspect of decision, including the development of alternatives and the identification of the preferred solution.

EMPOWER: To place final decision-making in the hands of the patient.

Note that the levels of engagement may vary for each patient partner or patient group. You may have more than one level of engagement within your project at a given time. For example, you may have groups of patients you want to *INFORM*, while the patient on your research team may be engaged at the *COLLABORATE* level. Level of engagement may also change over time.

- **What engagement methods will be used (e.g. patient on research team, patient advisory council, etc.)?**

- **Who will you involve in this research project?**

- **Who will your patient partners be?**

Consider the lived experience and skills of each of your project team members. Factors such as age group, sex, gender, geographical location, and cultural background may also be relevant.

Tip: Navigate the cultural context with people from the culture

Project 3.3A engaged an Elder early in the project to advise on Indigenous protocols and practices. He has been an integral member of the project team with his knowledge and wisdom.

- **What are the expected benefits to patients from being part of your research?**
- **How will patients be encouraged and supported to participate?**
- **How will patient engagement be leveraged?**
How will patient partners be involved in the different stages of the project: design, development, execution and evaluation?

Tip: Seek patient input on relevant outcomes and measures

Example: EMPATHY – Patients emphasized the importance of mental health screening in the selection of routine assessment tools for patient-reported outcome measures.

Tip: Ask what patient partners think about the proposed methodology

Example: Screen, Triage, Treat – The clinical trial design was modified to a more culturally appropriate model in response to input from Indigenous patient partners.

- **How will you evaluate patient engagement in this project?**
Evaluation should be considered from the perspective of patient partners as well as researchers. This will inform ongoing and future improvements in patient-oriented research but also allow the group to course-correct if need be. You may consider having regular reflections and review how the patient engagement activities in your project align with the guiding principles described in the SPOR Patient Engagement Framework:

INCLUSIVENESS: Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution, i.e. patients are bring their lives into this.

SUPPORT: Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training and education. Support also implies financial compensation for their involvement.

MUTUAL RESPECT: Researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge.

CO-BUILD: Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.

- **Who would be most appropriate to facilitate patient engagement within your research team and why?**

Tip: Keep in touch regularly in ways that work for your team members

Example: Self-management in CKD – A monthly project newsletter co-developed by researchers and the patient lead enhances communication by providing project updates for all team members.

- **What roles will patient partners play in your research?**

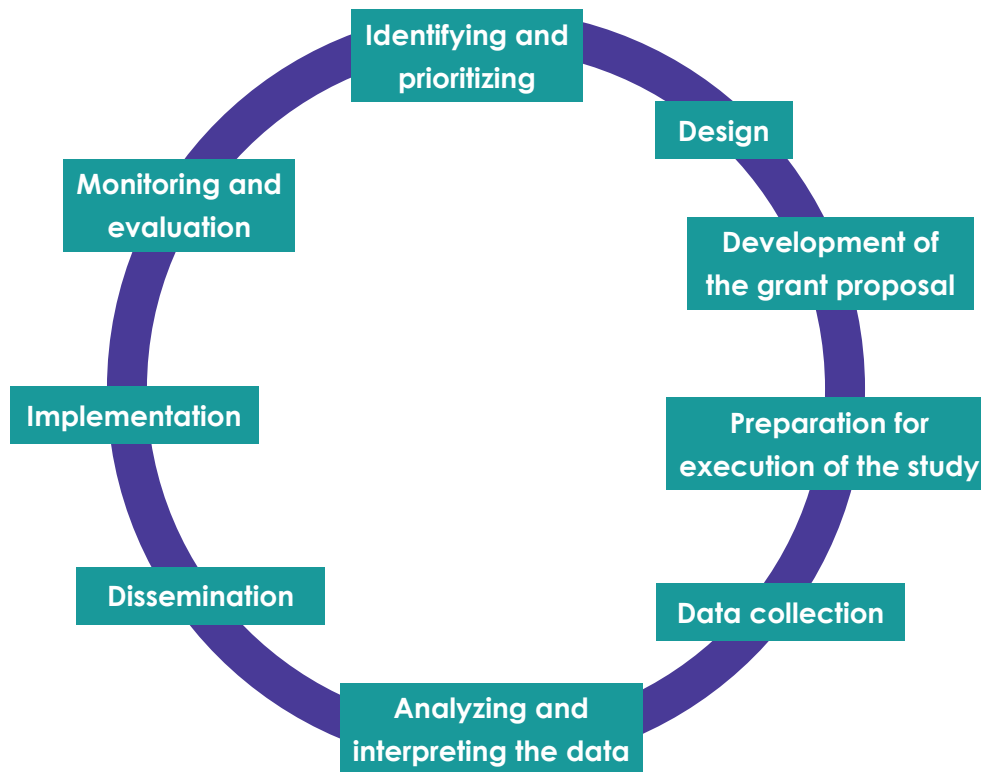
A list of possible roles for patients in health research is available on page 7 to guide planning and discussion with your patient partners.

Tip: Explore the expertise of patient partners and how they may contribute beyond their lived experience with an illness

Example: Living donor kidney transplantation – The patient lead used her expertise in community engagement to organize a workshop and patient focus groups in order to identify new opportunities for improving access and quality of living kidney donation.

Roles for Patients in Research

The figure below illustrates the research process/life cycle followed by a list that describes possible roles patient partners may take part in research at the various stages. Note that the list is not exhaustive. Specific role(s) that a patient partner could play in a research project are to be discerned with the project lead and research team on an ongoing basis. This reference only serves as a guide to start the conversation.



[Source: Izabela Szelest, Research Facilitator, College of Medicine, University of Saskatchewan]

Identifying and prioritizing

- Through community representation and organizations help inform research priorities
- Be consulted about research topics and priorities important to them
- Collaborate and co-develop with researchers and other key groups topics for research

Design

- Inform the design of the research study
- Clarify the research question and affirm its importance
- Ensure the methods selected are appropriate for patients
- Co-develop patient recruitment strategy
- Review and comment on proposed questionnaires and data collection methods

Development of the grant proposal

- Help to ensure that the research proposed and chosen methods are ethical
- Inform areas where patients and the public could be involved
- Define outcome measures
- Advise on the appropriateness of the lay summary
- Raise awareness about costs of involvement, expenses and prompt researchers to cost for involvement
- Become co-applicants

Preparation for execution of the study

- Assist with writing patient information and consent forms
- Review ethics and operational approval applications prior to submission
- Aid in designing the detailed protocol
- Produce research updates that are patient friendly

Data collection

- Drafting/revising study materials and protocols
- Assisting with the recruitment of study participants
- Assist with conducting interviews and surveys

Analyzing and interpreting data

- Assist the research team in developing themes from data
- Be consulted to determine if they understand and interpret data the same way as the research team
- Develop more approachable methods to help interpret the data

Dissemination

- Advise on different avenues for disseminating the results
- Author/co-author manuscripts, newsletters and other appropriate information outlets
- Jointly present the findings with researchers
- Write information for local patient groups/hospitals, etc.
- Assist in getting results/findings published on charities/voluntary organization websites
- Help distribute results within their informal network
- Produce summaries of findings

Implementation

- Increase the likelihood that results of research are implemented by adding validity to the findings
- Develop patient information for new services/interventions within hospitals, clinics, etc.

Monitoring and evaluation

- Have continued involvement with the study to maintain focus and address issues as they arise
- Collaborate with researchers to evaluate the research process
- Reflect on their role and what they have learned

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The content of this document was drawn from the patient engagement references noted above as well as experience of the working group tasked to prepare this document. If you have other tips that may help improve this document, please feel free to forward them to us at info@can-solveckd.ca.