

Patients as Partners in Research

# Planning Guidelines

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## Planning Guidelines

### Purpose

These Guidelines are for us, as patient/caregiver partners on a research team. They are to help us prepare for the initial discussions with the research team and to help guide our early discussions with the principal investigator (PI) for the project.

As a patient/caregiver partner on a research team, we have a role in planning the project even if the project is quite well defined when we are brought on board. These Guidelines are for the initial conversation or meeting with our PI and team indicating subjects to be covered.

### What I Should Already Know

#### PROJECT LIFECYCLE AND PRACTICALS

- Is the project still in the application process or is it funded and underway
- How long is the project
- Where is the PI located and where is the team
- Who are on the team
- What is the commitment of time and effort I need to make
- Is there separate funding for patient/caregiver partners

### Understanding the Project

In order to help define the role we, as patient partners, will play, it is necessary to understand the project and where the project is in its lifecycle.

#### GOAL OF THE RESEARCH

- Is the goal set in stone? Do I understand it?
- Is the goal valid from the patient perspective? Can the goal be changed if need be?
- What is the value of the research goal to patients?
- We need to discuss and validate the goals of the research with other patient/caregiver partners
- Might also be helpful to re-word the goals in easy to understand terms

#### RESEARCH APPROACH AND METHODOLOGY

- Methodology – does it make sense from the patient perspective? Interviews, surveys, admin data?
- Use of patients as subjects – give feedback from my patient or caregiver perspective; are the subjects going to receive the project results and plans for implementation or dissemination?
- Analysis – what role can I play? Can I review the draft and ask questions?

#### DISSEMINATION OF RESULTS

- Is there a plan to let the public know about this? Should there be?
- What roles can I play? As co-presenter at conferences? Talking to the press?

### Patient/Caregiver Partner Role

Our role is to help form and support the partnership as well as participate as partners. Patient partnership is often a new experience for researchers. We can provide some guidance to our team about how to proceed with the partnership and how to orient and support us and our fellow patient/caregiver partners.

## Patients as Partners in Research: Planning Guidelines

For example:

- Number of Patient/Caregiver Partners: We have found it is important to have a minimum of 2 other patients/caregiver partners on the team, preferably geographically close and acquainted with the topic area. We are patients and caregivers and can't always maintain our commitment so if there is more than one of us, there is a stronger chance of continuity.
- Defining the Role: We should discuss our role within this specific research project together with the PI:
  - Should we attend all team meetings – discuss – there may be some that are inappropriate for patients to attend
  - Review the elements of the project to see what role we should play
- Patient Panel as an Optional Addition: For some projects, we may as a team feel a panel of patients has a role. We can help define that role and the additional administration and support it requires.
- Defining Support: Who is my main point of contact throughout this process. Who do I email or call if I have a question about logistics and can I also talk to this person about any concerns I have as a patient partner?
- Confirm any decisions in a document (Partnership Plan) so we can refer to it throughout the project and everyone is clear on our role. We all should have copies of this document.

### ORIENTATION

- We can help interview prospective fellow patient partners and find out their concerns and perceptions
- We can help plan how we would like to be oriented to the project and the team, for example:
  - Bios and pictures of all team members with their project roles - including patient partners
  - Stages and timelines of the project with an idea of what we are to do and when
  - Initial team meeting and a discussion about the partnership so everyone understands each others' roles.

### MEETINGS

- We can help determine what materials we need in advance; and if we need a briefing prior to meeting
- We can help figure out how best to meet with us:
  - For in person meetings, check if there are accessibility issues or if any of us have fatigue due to illness that may impose some requirements
  - Make sure that we all know how to connect in to phone/online meetings or webinars
- Meeting costs – we should know how this will be covered

### RECRUITMENT

- We should not be tasked with recruiting patients as subjects and probably not with recruiting any patients for a panel either; we could however, offer to interview candidates

As patient/caregiver partners, we have a unique opportunity to make sure that the goal of improving the health of Canadians remains at the forefront of any research we are involved in. We can also help make partnering with us easy and productive for our researchers.