# Patient Partners' Role in Research

For a respectful and mutual partnership, communication between researchers and patient partners should be open and honest

#### **Research Stages**

### The Role for Patient Partners

#1 Pre-planning



### Joining the Project Team

- · Intro to whole team with charter, roles, bios, pictures and meeting
- Understand the project: topic, develop or refine the research question, current stage
- Timelines for meetings, tasks, project duration
- Expenses & compensation: travel, parking, honoraria
- Understanding basic research language and terms: CIHR Jargon Buster: http://www.cihr-irsc.gc.ca/e/48952.html
- Understand the ethical requirements TCPS 2: Core Online tutorial for researchers detailing ethical conduct regardless of methods or area of study. https://tcps2core.ca/welcome

#2 Preparatory



#### Finalizing the Project Plan

Finalize the research question, study design and protocol; complete funding applications

- Review proposal drafts, with specific contributions to sections on patient engagement, timeline, budget and knowledge transfer
- Ensure that outcomes and measures reflect lived experience
- Help develop scripts and participant communication materials (consent form, emails, information letters)
- Advice to help recruitment strategies

#3 Execution



# **During the Study**

Preparing for study start; recruitment, collect and analyze data

- Suggestions for improving recruitment, network with patient groups
- Patient perspective on study results

#4 Knowledge Translation



## **Sharing the Study Results**

Communicate research findings

- Help coordinate dissemination plan
- Develop public-friendly versions of results
- · Advise on use of social media
- Co-publish in a variety of formats (Journals, blogs, newsletters)
- Co-present results (webinar, conferences)







