

Checklist for Patient Partners in Research

Patient refers to individuals with lived experience of a health issue, including family members and other informal caregivers*

Research Stages

Considerations for Patient Partners

#1 Pre-planning



What Should I Know?

- Who are the team members?
- What are the roles & responsibilities?
- How will I be expected to participate?
- How much time will I need to spend on the project?
- Am I being reimbursed and/or compensated?
- How much research knowledge do I need?
- What am I comfortable/capable of contributing?



#2 Preparatory



How Can I Help?

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

- How does my lived experience inform the research question and study objectives?
- How does my lived experience inform the outcome measures used?
- How can I help choose the measurement tools so they are user-friendly?
- Can I ensure that study documents use participant-friendly language?
- Can I give any advice on how best to recruit?
- How can I assist with funding applications?



#3 Execution



What Comes Next?

Preparing for study start; recruitment, collect and analyze data

- What advice can I give to improve study recruitment?
- What are the best ways to collect data?
- Can I give advice to overcome any barriers?
- How can my lived experience inform results after data analysis?



#4 Knowledge Translation



How Can We Share Our Results?

Communicate research findings

- Can I write a lay summary of the study results?
- How and with who do we share the results?
- Can I share the results with my own networks and communities?
- Will I be asked to present the results (webinar, conferences)?



This represents that all your questions and concerns have been addressed and you are comfortable transitioning to the next stage

*<http://www.cihir-irsc.gc.ca/e/49232.html>

Created by: Kristina McGuire & Heather Shearer as part of the McMaster University/Kids Brain Health Network Family Engagement in Research Certificate of Completion Program