

# 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>

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# 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
<p>#1 Pre-planning</p> 	<h2>Joining the Project Team</h2> <ul style="list-style-type: none"><li>• Intro to whole team with charter, roles, bios, pictures and meeting</li><li>• Understand the project: topic, develop or refine the research question, current stage</li><li>• Timelines for meetings, tasks, project duration</li><li>• Expenses &amp; compensation: travel, parking, honoraria</li> <li>• Understanding basic research language and terms: CIHR Jargon Buster: <a href="http://www.cihr-irsc.gc.ca/e/48952.html">http://www.cihr-irsc.gc.ca/e/48952.html</a></li> <li>• Understand the ethical requirements - TCPS 2: Core – Online tutorial for researchers detailing ethical conduct regardless of methods or area of study. <a href="https://tcps2core.ca/welcome">https://tcps2core.ca/welcome</a></li></ul>
<p>#2 Preparatory</p> 	<h2>Finalizing the Project Plan</h2> <p>Finalize the research question, study design and protocol; complete funding applications</p> <ul style="list-style-type: none"><li>• Review proposal drafts, with specific contributions to sections on patient engagement, timeline, budget and knowledge transfer</li><li>• Ensure that outcomes and measures reflect lived experience</li><li>• Help develop scripts and participant communication materials (consent form, emails, information letters)</li><li>• Advice to help recruitment strategies</li></ul>
<p>#3 Execution</p> 	<h2>During the Study</h2> <p>Preparing for study start; recruitment, collect and analyze data</p> <ul style="list-style-type: none"><li>• Suggestions for improving recruitment, network with patient groups</li><li>• Patient perspective on study results</li></ul>
<p>#4 Knowledge Translation</p> 	<h2>Sharing the Study Results</h2> <p>Communicate research findings</p> <ul style="list-style-type: none"><li>• Help coordinate dissemination plan</li><li>• Develop public-friendly versions of results</li><li>• Advise on use of social media</li><li>• Co-publish in a variety of formats (Journals, blogs, newsletters)</li><li>• Co-present results (webinar, conferences)</li></ul>



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