

This checklist will help build authentic partnerships & enhance collaboration among study teams with patient partners, clinicians and scientists

A novel checklist to promote collaborative stakeholder partnerships in pediatric research

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Background: Engaging patients and families to inform research priorities and guide pediatric health research can improve the relevance, quality, and validity of all stages of clinical research. Despite this, patient partners continue to voice concerns regarding their input and providing meaningful contributions as research team members.

Description: During the McMaster University, CanChild, Kids Brain Health Network Family Engagement in Research Certificate of Completion Course, researchers and parents of children with complex medical conditions were paired to create tools to enhance family engagement in pediatric research. The resulting infographic is divided into four general research stages: 1) pre-planning; 2) preparatory; 3) execution; and 4) knowledge translation. At each stage, we highlight considerations for the patient partner by listing a series of questions they and the research lead should discuss.



Significance: This easily accessible infographic provides a general guide for patient partners to have meaningful discussions with all research team members. This checklist can promote a valued partnership versus the traditional consultative model of engagement.


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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
<p>#1 Pre-planning</p> 	<p>What Should I Know?</p> <ul style="list-style-type: none"> • 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?
<p>#2 Preparatory</p> 	<p>How Can I Help?</p> <p>Finalize the research question, study design and protocol; complete funding applications</p> <ul style="list-style-type: none"> • 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?
<p>#3 Execution</p> 	<p>What Comes Next?</p> <p>Preparing for study start; recruitment, collect and analyze data</p> <ul style="list-style-type: none"> • 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?
<p>#4 Knowledge Translation</p> 	<p>How Can We Share Our Results?</p> <p>Communicate research findings</p> <ul style="list-style-type: none"> • 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.cihr-irsc.gc.ca/e/49232.html>



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