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# Patient/Family/Caregivers/Community (PFCC) Research Partnership

## Planning Guide for Researchers

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## Foreword

This planning guide was developed by a family member and researcher as part of the requirement for the **Family Engagement in Research Certificate of Completion Program run by McMaster University and Kids Brain Health Network**. This planning guide is to be used in conjunction with the infographic **“Engaging PFCCs as Partners in Research”** (see Appendix A).

## Purpose of the Planning Guide and Infographic

This document is a planning guide that accompanies the infographic titled **“Engaging PFCCs as Partners in Research.”** The planning guide contains more detailed information about the steps involved in research and how to engage partners in research (patients, families, caregivers, and community members - PFCC) and includes some additional information we were unable to fit into the infographic. Together, these documents provide researchers and PFCCs the steps necessary to establish a research partnership and to continue with the research partnership through each stage of the research process.

## What is Patient/Family/Caregiver/Community (PFCC) Research Partnership?

“Patient engagement is about meaningful collaboration. Patients become patient partners in the project and can be actively engaged in governance, priority setting, developing the research questions, and even performing certain parts of the research itself. This type of participation helps to ensure that the research being conducted is relevant and valuable to the patients that it affects. Patient partners can also collaborate with the research team to summarize or share the results with target audiences (especially other patients) and with policy makers or other decision makers who may apply the results in a health or community setting” (Patient engagement, 2018).

Although the definition provided above uses the term “patient,” research partnership can be with the patients themselves, family members or caregivers, or members of a community that has a research interest. Here we use the term patient, family, caregivers and community research partners as “PFCC.”

Most importantly, it has been demonstrated that successful partnerships in research are facilitated when there is a welcoming research environment for partners, there are shared goals, there is ongoing communication, the expectations of researchers and partners are

clear, there is adequate institutional support and policies for partnerships in research, there is an acknowledgement that patient partners bring a unique and valued perspective to research throughout all stages of the research journey, and there is mutual respect and trust (Black et al., 2018, Kirwan et al., 2017).

## Different Levels of Partnership Engagement: “Continuum of Engagement”

PFCCs can be involved in several levels in research (Figure 1; Bevans et al., 2014). PFCCs can assume a passive role in which individuals participate as research participants. When we speak of PFCC engagement, we are not referring to the passive role of research participation, rather we refer to PFCCs engaging in a more active role or partnership such as becoming part of the research team, as an equal team member, or being co-investigators on studies. Throughout this document and accompanying infographic, we have provided suggestions on how to engage PFCCs in research to take more of an *active* role. The strategies we have provided along the research journey suggest actionable steps that can be taken at each research juncture.

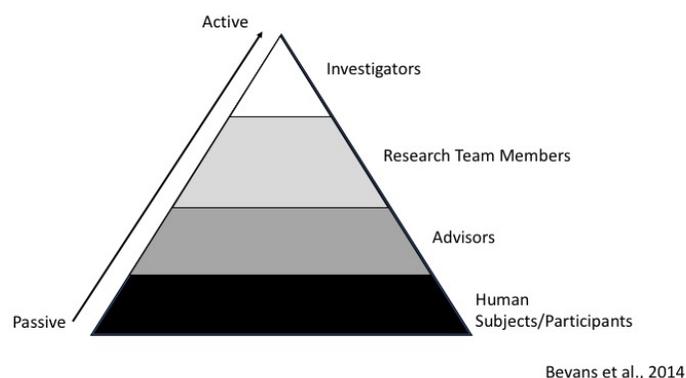


FIGURE 1. LEVELS OF ENGAGEMENT IN RESEARCH

Through a more active role, PFCC partners in research will begin to engage in activities that move far beyond the tokenistic contribution that may be inadvertently established through passive contribution.

## Roles of PFCC Partners

PFCCs can take on several roles when engaged as partners in research throughout each of the different stages of research (see Steps in the Research Process section on page 9). These roles are described in van Meeteren and Klem (2018) and we have outlined the roles below:

- Listener: The PFCC is *informed* about the research
- Co-Thinker: The PFCC is *asked* about their opinions
- Advisor: The PFCC *gives advice* (solicited or unsolicited) regarding the research
- Partner: The PFCC *works* in equal partnership with the researcher
- Director: The PFCC *takes initiative* and makes *final decisions* regarding the research project

Common ways for researchers and PFCC to hold meetings and to structure the partnership include (Sofolahan-Oladeinde et al., 2017):

- Patient forums/advisory groups
- In-person meetings
- Teleconferences
- Critique documents

Given the various roles that PFCC research partners can take on and the amount of time they invest in being a PFCC research partner, compensation should be discussed.

Compensation should constitute, at minimum, reimbursement for travel expenses, parking and childcare (if relevant). Further compensation (e.g., hourly wage) should be discussed openly and determined with the PFCC. The Change Foundation has established a tool for making decisions about compensating PFCC research partners:

<https://www.changefoundation.ca/patient-compensation-report/> ("Should money come into it?" 2019).

The Participation Matrix (see Table 1, including an example) can be completed as research activities are planned. Tasks for the research project (see Steps in the Research Process section on page 9 for various tasks that can be included here), PFCC research partners, and other members of the research team can be designated to the specific roles/tasks in the matrix. For more detailed information, please visit [www.participatiematrix.nl](http://www.participatiematrix.nl). (Note, this link brings you to the original, Dutch version of the Participation Matrix; we received a translated version through the McMaster University/Kids Brain Health Network Family Engagement in Research Certificate of Completion Course; van Meeteren & Klem, 2018).

TABLE 1. THE PARTICIPATION MATRIX ENABLES RESEARCHERS AND PFCCs TO DOCUMENT TASKS THAT WILL NEED TO BE COMPLETED THROUGHOUT THE RESEARCH JOURNEY AND THE INDIVIDUALS ON THE RESEARCH TEAM WHO WILL BE COMPLETING THE TASKS

			Role in project				
			Listener <i>Is informed</i>	Co-thinker <i>Is asked for opinion</i>	Advisor <i>Gives (asked or unsolicited) advice</i>	Partner <i>Works in equal partnership</i>	Director <i>Takes initiative, final decisions</i>
Stage of project	Preparation	e.g., Propose topic		e.g., Mary		e.g., Steve	
	Execution						
	Implementation						

## How to Find PFCCs as Partners in Research

Finding research partners can be challenging however Vat et al. (2017) provide some concrete strategies to recruit partners and discuss the platforms in which recruitment can take place. Partners for research could be recruited through social marketing methods (e.g., advertising on television, radio), community outreach (e.g., town hall meetings, connecting with community leaders), the health system (e.g., recruitment by health care staff or researchers) and partnering (e.g., collaborating with a group representing a specific perspective). Platforms that can be used to support recruitment include traditional means, (e.g., case by case basis), third-party (e.g., the use of a matching service) and directory models (e.g., online directory of patients interested in partnering in research and posting of research opportunities by researchers in which potential partners apply) (Vat et al., 2017). A variety of recruitment methods and platforms can be used alone or in combination depending on the research project.

Certain networks of PFCCs exist in which there are well-known influencers. These individuals could act as ambassadors for research projects and help with recruitment of PFCC research partners. Some of these individuals can be found online through social media groups or can be found serving as research partners on projects in the same research area (e.g., advocates, parent leaders). Some of these individuals maintain an online blog about research engagement and may hold Twitter accounts. A well-known influencer is Rachel Martens (<http://coffeeandresearch.blogspot.com/>, @RaeofSunshine79). Rachel organizes a Parents Partnering in Research Facebook Group and is a networker that can connect researchers with other influencers across disability groups, parent groups, institutions, and areas of interest. Through her website, and the websites of other influencers, you can connect with other influencers, parent leaders, advocates, etc. and can learn about connecting with PFCC research partners.

## Organizing the PFCC Research Partnership

There are several methods in which both researchers and research partners can begin forming a successful partnership. We have provided a brief outline of the steps that can be undertaken as a research partnership is being established in order to facilitate collaboration as the research journey is planned, implemented, and shared.

The set of items outlined below (Figure 2) help with establishing the research partnership and making decisions about what the research partnership will consist of.

It is important to appreciate that the PFCC may require some additional training to participate in research. For example, they may need to complete an online module (e.g., Fyreworks Partnership-Based Research Training, <https://fyeworkstraining.com>) or ethics tutorial (e.g., TCPS 2: Core tutorial, <https://tcps2core.ca/welcome>).

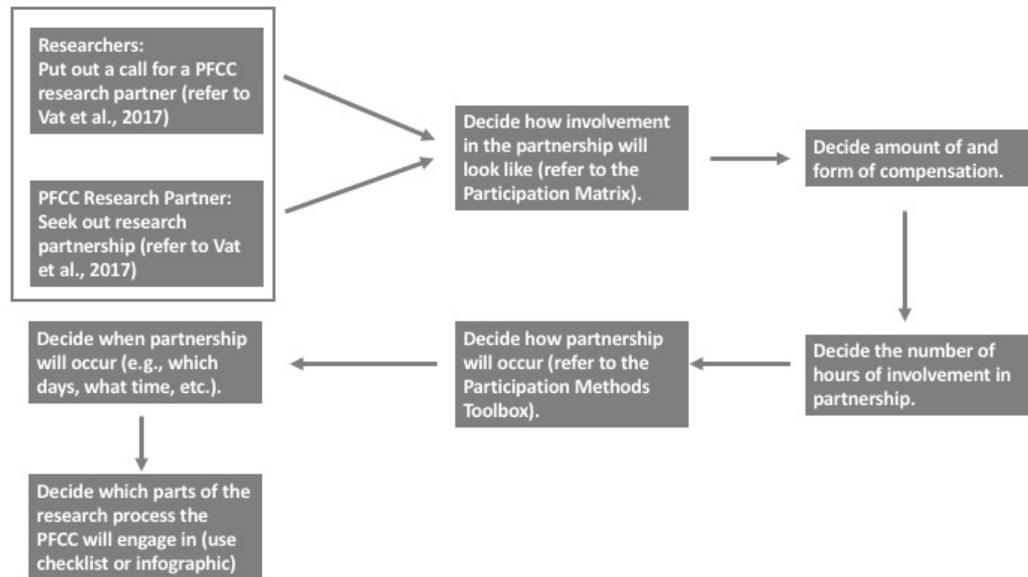


FIGURE 2. STEPS IN ESTABLISHING A RESEARCH PARTNERSHIP

Researchers may require additional training especially regarding lived experience related to the topic they are investigating. It would be useful for researchers to explore the blogs of the individuals shared in the “How to Find PFCCs as Partners in Research” section on page 6. Researchers can seek out and explore blogs, research literature, and network with online groups, directly related to their research topic. Taking a course such as the McMaster University/Kids Brain Health Network Family Engagement in Research Certificate of Completion Course and/or completing the Masterclass on the Conduct and Use of Patient-Oriented Research (offered through Ontario SPOR Support Unit (<https://surveys.mcmaster.ca/limesurvey/index.php/134321?lang=en>) is useful. Additionally, taking advantage of all resources provided in this document would be helpful.

The researcher should consider the use of a patient engagement evaluation tool to evaluate the level, quality, and feedback regarding PFCC engagement throughout the research process. The Patient and Public Engagement Evaluation Toolkit (2019) is a great resource to get started on putting together an evaluation tool: <https://ceppp.ca/en/our-projects/evaluation-toolkit/>

## Moving Forward: Steps in the Research Process

Now that several aspects of the research partnership have been established, it's time to work on the research project! Below are steps in the research process accompanied by tasks that can be done at each stage (Sofolahan-Oladeinde et al., 2017; "Ways community members can participate," n. d.; Mullins et al., 2012). Relevance to the particular project one is working on will need to be considered.

### 1. Topic Solicitation

- Identify topics that are important to PFCC
- Propose topics to be investigated
- Other: \_\_\_\_\_  
\_\_\_\_\_

### 2. Prioritization

- Solicit feedback: determine relevance of the research to PFCCs and public
- Assess the feasibility of PFCC involvement
- Identify barriers to continued PFCC participation
- Other: \_\_\_\_\_

### 3. Framing the Question

- Get approval of the study question from PFCC
- Ascertain question(s)' relevance and usefulness
- Assess "real-world" applicability
- Prioritize research questions
- Other: \_\_\_\_\_

### 4. Selection of Comparators and Outcomes

- Define and assess the relevance of outcomes from a PFCC perspective
- Get approval of the outcomes
- Other: \_\_\_\_\_

### 5. Creation of Conceptual Framework

- Get a reality check from PFCC
- Verify logic from PFCC
- Supplement with additional factors not documented in the literature
- Other: \_\_\_\_\_

### 6a. Research Ethics Submission

- Contribute to ethics application
- Review drafts of application
- Other: \_\_\_\_\_

6b. Funding Application Preparation

- Contribute to funding application
- Review drafts of application
- Provide letter of support
- Other: \_\_\_\_\_

6c. Recruit and Retain Participants

- Advise on the vocabulary used in the recruitment materials
- Use existing networks to advertise the study
- Provide support and information to participants about the specific study or on the experience of participating in research studies in general
- Other: \_\_\_\_\_

6d. Data Collection

- Participate in a trial run of the study to assess the preparedness of the staff and to be able to explain the experience to participants
- Participate in data collection (e.g., read study questions, administer interviews), including potentially obtaining consent from participants
- Collect feedback
- Identify obstacles as the study progresses
- Provide solutions to obstacles faced during study progress
- Screening of participants (if applicable for a study)
- Explaining the study
- Other: \_\_\_\_\_

6e. Data Analysis

- Contribute a unique perspective on the interpretation of data
- Give feedback on potentially counterintuitive results
- Identify how results relate to lived experience
- Place results in a real-world context
- Helping with data analysis and/or coding of data (might need to receive training for this)
- Data entry
- Other: \_\_\_\_\_

6f. Translation

- Interpret results to be meaningful
- Document which results are easy or difficult to understand
- Indicate which results are counterintuitive
- Other: \_\_\_\_\_

7. Dissemination

- Present the patient perspective at conferences
- Present in non-traditional settings to reach new audience(s)
- Invite researchers to present at patient advocacy organizations

- Co-publish in non-academic materials
- Participate in the publication committee
- Facilitate engagement of other patients
- Help other patients to understand findings
- Other: \_\_\_\_\_

#### 8. Dissemination Plan

- Identify the partnership approach (organizations, public)
- Identify organizations that should be aware of the study and track its progress
- Plan how to engage interest of opinion leads (TV, print radio)
- Identify non-traditional models of dissemination
- Develop a public-friendly version of results
- Other: \_\_\_\_\_

#### Other

- Answer questions from researchers
- Evaluate the success of patient engagement by surveys (or other means) at the start, middle, and end of the project (and/or at additional time points)
- Getting feedback from other PFCC members on any parts of the research process
- Other: \_\_\_\_\_

## Additional Tools and Resources

**The following online resources may be helpful when planning PFCC engagement.**

\*for longer links, copy and paste the entire link into your web browser if it does not work

### **Resource: Cultivating Research and Progress (Resources Directory)**

*Produced by:* Centre of Excellence on Partnership with Patients and the Public

*Link:* <https://ceppp.ca/en/resources/>

### **Resource: Patient and public engagement (Evaluation Toolkit)**

*Produced by:* Centre of Excellence on Partnership with Patients and the Public

*Link:* <https://ceppp.ca/en/our-projects/evaluation-toolkit/>

### **Resource: Tools for partnering with patients in health research**

*Produced by:* Patients Canada – Make your experience count

*Link:* <https://patientscanada.ca>

### **Resource: Patient Engagement Workbook for Researchers**

*Produced by:* HIPxChange

*Link:* <https://www.hipxchange.org/HCSRNEngagementWorkbook>

### **Resource: A Toolbox for Creating Sustainable Partnerships with Patients and Families in Research**

*Produced by:* Institute for Patient- and Family-Centred Care

*Link:* <http://ipfcc.org/bestpractices/sustainable-partnerships/index.html>

### **Resource: Strategy for Patient-Oriented Research**

*Produced by:* Canadian Institutes of Health Research

*Link:* <http://www.cihr-irsc.gc.ca/e/45851.html>

### **Resource: Patient Engagement: Tools & Resources**

*Produced by:* St. Michael's Inspired Care. Inspiring Science.

*Link:* <http://stmichaelshospitalresearch.ca/patient-engagement-resource/>

**Resource: Patient Engagement Tools & Resources**

*Produced by:* Can-SOLVE CKD Network

*Link:* <https://www.cansolveckd.ca/patient-engagement/>

**Resource: Patient Recruitment**

*Produced by:* Patient Engagement Resource Centre

*Link:* <https://www.patientengagement-phcresearch.com/framework-1>

**Resource: SPOR Patient Engagement Platform Helps Public Make a Difference in Health Research**

*Produced by:* BeTheCure.ca

*Link:* <https://bethecure.ca/research/>

**Resource: Lessons from Changing CARE: The Discovery Phase of Experience-Based Co-Design**

*Produced by:* The Change Foundation

*Link:* <https://www.changefoundation.ca/category/patient-engagement/>

## Acknowledgements

We would like to thank our classmates from the Family Engagement in Research Certificate of Completion Course for their inspiring discussion and ideas during the Winter 2019 course. We are immensely grateful for the guidance, knowledge, and feedback provided by the teaching assistant, course coordinator and course instructors: Crystal Shannon, Andrea Cross, Connie Putterman, and Donna Thomson. Thank you to Kids Brain Health Network and McMaster University for making our participation in this course possible.

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## Appendix A

The “Engaging PFCCs as Partners in Research” infographic:

