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

A Checklist for Researchers

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Table of Contents

Foreword

This checklist 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 checklist is to be used in conjunction with the infographic "**Engaging PFCCs as Partners in Research**" and can also be used with the **Planning Guide for Researchers**.

Moving Forward: Steps in the Research Process

After establishing several aspects of the research partnership, 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)
☐ Identity 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: _____
☐ Other: _____
☐ Other: _____
☐ Other: _____
☐ Other: _____

Acknowledgements

References

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