Patient and Family Engagement in Clinical Trials: How, When, and Why

Collaborate to prioritize relevant research questions

Provide input on what to measure and how to measure it

Assess feasibility of trial and participation

Recommend appropriate compensation



Find, retain, and support trial participants

Craft documents that are clear, concise and easily understood

> Facilitate open communication with participants

Planing he frial Meaningful,

feasibility Analyzing Results Greater reach and impact

Doing the Trial useful results Increased





Collaborate on when, how, and where to share results

Write up plain language summaries

Present results (e.g., at patient



Establish meaningful changes for patients and families

Identify how results relate to lived experience & place results in realworld context



and/or academic conferences)







Resources and references: CTO Participant Experience Toolkit; Bagley et al. 2016; Crocker et al. 2018; Manafo et al. 2018

This resource was created as part of the McMaster University, CanChild, and Kids Brain Health Network Family Engagement in Research Certificate of Completion Program. Copyright © 2021 (B. Bedir, N. Butcher, L. Mendonza, A. Walker). All Rights Reserved.