

Engaging PFCCs* as Partners in Research

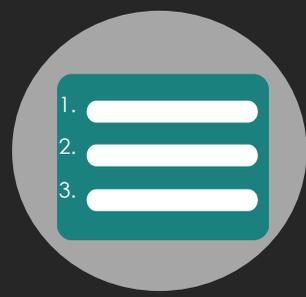
*Partners can include patients, family, caregivers, and/or community members (PFCC)

TOPIC SOLICITATION



- ✓ Identify topics important to PFCC
- ✓ Propose topics

PRIORITIZATION



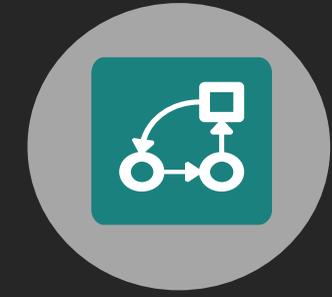
- ✓ Solicit feedback from PFCC
- ✓ Prioritize research questions

FRAMING THE RESEARCH QUESTION



- ✓ Get approval of study question(s) re: relevance, usefulness, "real-world" applicability

SELECTION OF COMPARATORS AND OUTCOMES



- ✓ Define outcomes and assess relevance of outcomes from a PFCC perspective
- ✓ Get approval of outcomes

DISSEMINATION



- ✓ Present PFCC's perspective at conferences
- ✓ Present in non-traditional settings
- ✓ Co-publish
- ✓ Lay summaries



- ✓ Contribute and review draft documents
- ✓ Provide insight; network for recruitment
- ✓ Provide letters of support

CREATION OF CONCEPTUAL FRAMEWORK



- ✓ Get feedback from PFCC
- ✓ Verify logic from PFCC
- ✓ Supplement with additional factors not documented in the literature