

CP QUEST COMMUNITY AND RESEARCHERS TOGETHER

TERMS OF REFERENCE WORKING ARRANGEMENTS FOR CP QUEST

The Cerebral Palsy Alliance (CPA) Research Institute is dedicated to conducting cerebral palsy (CP) research with the aim of preventing, treating and curing CP. As the eventual beneficiaries of CP research, the views and experiences of families are integral to all aspects of CP research. To achieve this, CP QUEST has been established to collaborate with the Research Institute.

Purpose

- To integrate the experiences of people with CP and their families, along the lifespan into research activities
- To have people with CP, families and researchers work in partnerships based on understanding, respect and shared commitment to research that will improve the lives of people with CP and their families
- Ensure high quality, relevant and valid research is conducted through the Research Institute
- To create a mechanism where family members and individuals with CP can share their ideas for future research with the Research Institute and Research Foundation.

Responsibilities & Roles

- The level of commitment and type of involvement will be on a case-by-case basis, subject to the availability and interests of individual members.
- Lead the development of a research agenda which is informed by people with CP and their families.
- Provide the perspective of people with CP and families to research projects e.g.

a) In preparatory phases of research: identify issues to consider when developing a new piece of research; research design development; contribute to grant writing

b) Study design and procedures: Review parent information sheet and consent forms and other forms of communication (e.g. flyers, mail outs); identify relevant outcomes; investigate feasibility of completing desired assessment/data gathering processes; testing surveys, outcome measures etc.

c) Recruitment: identify barriers to recruitment for research studies; use networks to inform potential participants; identify novel and relevant means of informing families and people with CP about studies (e.g. podcasts, YouTube etc.); model support for projects e.g. podcasts, newsletters

d) Completing the research: Facilitate focus groups; interview or support participants while they complete questionnaires

e) Interpret results of studies through discussions with researchers about the meaning of findings

f) Drive the uptake of evidence into practice, dissemination of findings, knowledge translation; user friendly language summaries; develop means of dissemination, report back to their networks; co-present results of research in workshops/conferences/families and people with cerebral palsy groups.

Membership

- CP QUEST will be open to anyone who has a real interest and commitment to CP research, particularly those people who have CP or family members of people with CP, and who wish to support and uphold the aims and objectives of this group. We specifically encourage people with: a) links to established community groups to consult and represent; b) an ability to reflect broader interests and needs of people with CP
- There is no limit on the number of people who are part of the CP QUEST. Interested people can register as a volunteer with CPA at any point in time.
- Two family members, or people with CP, plus at least one researcher will jointly Co-Chair CP Quest
- Members may be offered an honorarium for participating in research activities where available and applicable
- One meeting will be held each year for members of CP QUEST, all other communication will be through email
- CP Quest will report back to CPA regarding issues addressed during the meeting, and throughout the year