



**Cerebral Palsy**  
ALLIANCE

**CPQuest**  
COMMUNITY AND RESEARCHERS TOGETHER

# Community Involvement in Cerebral Palsy Research



A guide for people with cerebral palsy,  
their family members, carers, and advocates



### **Being involved is different from taking part in research.**

It is about being a member of the research team and bringing lived experience to the process. By working with researchers, you will improve research and therefore make a difference to the way research is used and progressed, and your treatment or care is provided in the future. Your involvement means the research is more relevant to your community.



“Combining my life experience with the researchers’ minds just makes sense to me. How can you help others when you do not know what it is like to live their life? What better people are there to guide research than those who live with the condition on a daily basis? We as parents and people with CP are experts in our own health condition and care needs, we know which issues are important and what will make the most difference in our lives.”

Shannon Clough, mum of Ethan and Hayley

### **CP Quest**

CP Quest is a collaborative initiative instigated in 2015 by a small group of parents of children with cerebral palsy (CP) and researchers from the Research Institute. It works as a mechanism to involve families and people with CP, in research activities so that lived experience can be incorporated in all research studies and major projects. Our small group has more than 80 volunteers today.

### **Why is community involvement in research important?**

When people with CP and their families get involved in research they work alongside researchers to make decisions about what research gets done, how it gets done and how the results are shared and applied in practice. We believe that community involvement improves CP research, and ultimately improves treatment and care for people living with CP.

### **What is the Cerebral Palsy Alliance Research Institute and Foundation?**

In 2005 Cerebral Palsy Alliance established a Research Foundation and a Research Institute to support and conduct Australian and international CP research.

Our Research Foundation supports the world’s best and brightest researchers to find ways to improve current interventions and search for ways to prevent and cure CP.

Our Research Institute is informed by our clients, their families and their advocates. Our research priorities were defined by the Delphi survey conducted by our research team in 2007, and in 2018 members of CP QUEST produced an updated list of research priorities.

## What's in this guide?

1. What is CP Quest?
2. What is a Research Partner, and how do I become one?
3. How will I be involved?
4. What will be my role?
5. What are the benefits of being involved?
6. What support can I expect?
7. Jargon buster
8. Where do I find out more?



## 1. What is CP Quest?

CP Quest is a group of people with CP, their families, carers, advocates, and researchers affiliated with Cerebral Palsy Alliance, who share a commitment to CP research.

### Our aims are:

- To integrate the experiences and expertise of people with CP and their families, across the different stages of research in all research projects
- To ensure high quality, relevant and valid research is conducted
- To give family members and individuals with CP the opportunity to share their ideas for future research with the Research Institute and Research Foundation
- To disseminate the results back to the community in easy-to-understand formats and in a timely manner

**Over the last few years our Research Partners have been involved in setting research priorities, training, strategy consultations, reference and advisory groups, and contributed at different levels in research projects and activities.**

[cerebralpalsy.org.au/our-research/get-involved-research/cp-quest/](https://cerebralpalsy.org.au/our-research/get-involved-research/cp-quest/)



## 2. What is a Research Partner?

A Research Partner is a person with lived experience of CP, family member, carer, advocate, or community member who volunteers their time and skills to work **in partnership** with a researcher or research team **to improve research**.

### How do I become a Research Partner?

Becoming a Research Partner is open to anyone who has a real interest and commitment to CP research, especially people who have CP or people who care for them and who wish to support and uphold the aims and objectives of this group. There is no limit on the number of Research Partners that can be in CP Quest. **You do not need to have any kind of qualification to be involved in research.** You may have skills from other parts of your life that will be valuable. However it is your knowledge and experience of CP that makes you the ideal Research Partner.

To join CP Quest, individuals must register as a Volunteer with CPA, complete a short online questionnaire (to gather contact details and information about specific skills sets and interests), and sign a code of conduct.

[https://www.surveymonkey.com/r/CP\\_QUEST\\_Partners](https://www.surveymonkey.com/r/CP_QUEST_Partners)

The level of commitment, frequency and type of involvement is subject to the availability and interests of each individual Research Partner. We invite Research Partners to get involved in projects through email, and they can then choose to accept or ignore the invitation.

**Research Partners can choose the activities they become involved with, how often and how much time they want to volunteer.**

If you are interested in being involved in a particular research project the researcher will then call a meeting to **discuss expectations and role**, commitment, expense reimbursement and/or honorarium with you. They will explain:

- The project that they are working on
- What will be expected
- How long the research project will be
- Frequency of meetings, and whether they will be in person or online
- What kind of support will be offered

You will be able to ask questions and decide if this is the project for you.

**It is about finding the projects that need people like you, and roles that match your interests and experience.**

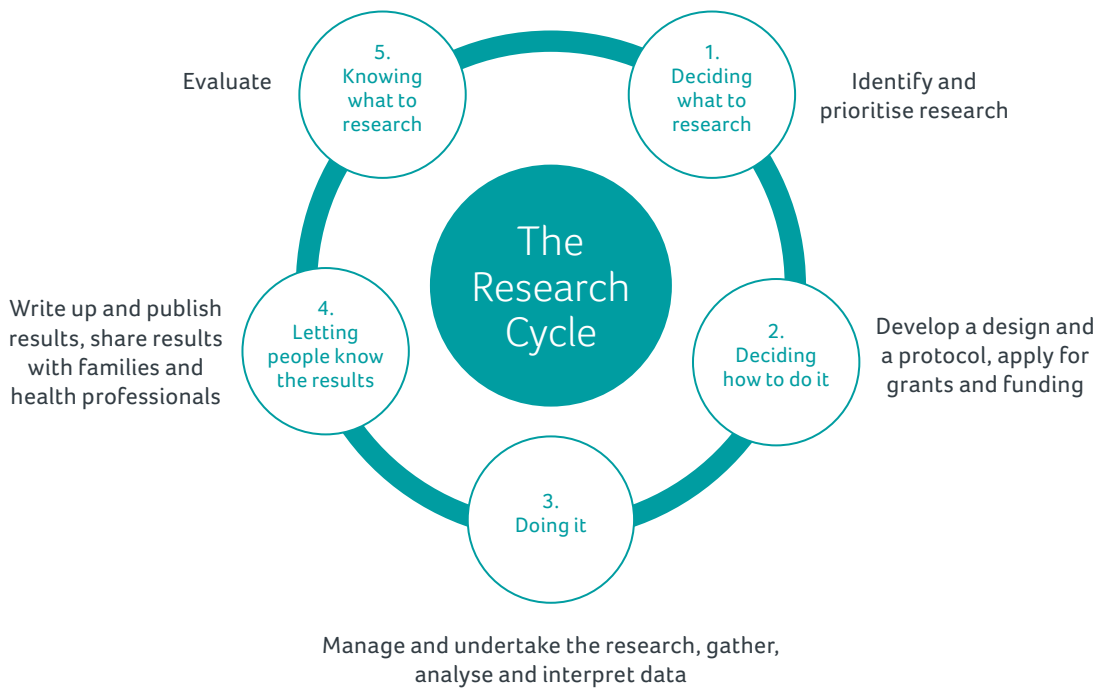


### 3. How will I be involved?

You can make a difference at any and every stage of research. Your contributions can help shape the thinking behind the research and the planning and delivery of the project.

You have a powerful voice that can influence others beyond the research team, including the people who take part in the research and the people who use the results. Sometimes involving Research Partners determines whether a project gets funded, whether it runs successfully and whether the results change practice.

Involvement can be at various **stages of the research** project and at **different levels**. You may be asked to participate in a project at any point (or all) of the research cycle\*.



Your knowledge from having experienced care and treatment for CP, or providing care for someone with CP, is of immense importance to researchers. By contributing your experience and views, you provide valuable expertise that would otherwise be missing.

**You will not be expected to have technical knowledge of how research works.** There are many different types of research looking at different topics and integrating the views of people from a variety of backgrounds can only improve the end result.

\*Telethon Kids Institute - An introduction to consumer and community involvement in health



## There are many **ways** or 'methods' to be involved in research:

- Share new ideas for research and develop priorities
- Make sure researchers work on the most important questions and outcomes for people with CP
- Assist in designing projects that make it easy for families to take part in research
- Identify how best to support people who take part in research, and make sure that any written materials are clear, easy to understand and include the most valuable information
- Help to collect the data and working with researchers to make sense of the results and share the results with people in the community

## Ways of being involved in CP Research

### You could write or comment on documents like:

- grant and ethics applications
- information sheets and consent forms
- pamphlets and brochures
- plain language summaries
- reports and documents about the dissemination of research results
- presentations to community groups

### Why?

If community members cannot understand the information contained in these documents, then it is likely a potential participant of the project will not understand them either. For example, the easier a consent form is to understand, the easier it is for someone to decide if they, or their child, wish to take part in the research project. Research Partners can also help to disseminate the results to ensure that the evidence of the research is more widely understood, applied, and changes to practice are made.

### You could buddy up with a researcher to:

- provide links between the researcher, other community members, organisations and/or the research funder
- provide insight into unexpected or unexplained research findings
- disseminate the research or reports to the community

### You could be a member of the research team to:

- provide input into the development of the study brainstorm solutions to potential problems
- carry out interviews with participants or other community members
- help analyse results and interpret findings
- evaluate consent procedure and develop the participant information sheet

### You could be a member of a Reference group and:

- provide advice throughout a project or particular stage of a project
- participate in active discussions around a particular area of research
- receive information about a study or its findings
- provide input into the development of priorities for future research projects



## 4. What will be my role?

Depending on the timing when you get involved, you are likely to be asked to share your thoughts and views on the researchers' ideas and plans for their research.

You might do this in a number of ways, for example by:

- attending meetings with researchers
- joining a group of people, carers and representatives attached to a research organisation or a specific project
- becoming a member of a research team
- commenting on written documents via email
- joining a group to advise on a specific project

Some meetings may be in person. Some may be held over the phone or online meeting platforms like Zoom or Teams. **You will be able to work in a way that suits you best, choosing roles that match your interests, experience, and skills.**

Over time, you may want to take your involvement further. You might want to get involved in actually doing the research and helping researchers to make sense of the findings. You might want to get involved in:

- training researchers in community involvement
- presenting research results at conferences and workshops
- writing articles for newsletters and social media
- contributing to articles written by researchers



**You can do as much or as little as you want and can always say 'no' if what is being asked of you feels too much.**

You can go as far as you want in developing your skills and experience as a Research Partner, working on small or large projects, for only a few weeks or over a few years. There are a range of opportunities that are open to you.





## Examples of CP research areas that you can be involved in:

- Identifying causes of CP and new avenues for prevention
- Monitoring and reporting on trends of CP
- Developing novel techniques to prevent and minimise brain damage, for example stem cell therapy
- Developing new therapies for early intervention and new processes for early detection
- Developing new technologies to improve mobility and communication
- Designing programs to improve function, participation and quality of life
- Reporting on the impact of CP to support awareness and advocacy

## Examples of involvement opportunities:

### Completed involvement projects and activities

#### ☆ **Results of Genetic Causes of CP - Plain language summary**

CP Quest Research Partners assisted in producing a one page easy to read summary of the results of a study looking at genetic causes of CP.

#### ☆ **The NSW/ACT CP Register Advisory Committee** consists of researchers, Research Partners, staff, and health professionals. It comes together twice a year to:

- provide advice at a strategic level
- advise on participation activities for projects
- enhance research through community and lived experience perspective
- give input into the methodology, recruitment, project report and dissemination strategy
- receive updates

#### ☆ **In 2018, Research Partners of CP QUEST produced an updated list of research priorities:**

- improving daily living,
- interventions,
- community engagement,
- prevention and early detection of CP,
- causal pathways

The Research Foundation grants program introduced targeted calls for research to address priority areas. [https://cerebralpalsy.org.au/wp-content/uploads/2021/03/CP-Quest-research-priorities\\_amended.pdf](https://cerebralpalsy.org.au/wp-content/uploads/2021/03/CP-Quest-research-priorities_amended.pdf)





## 5. What are the benefits of being involved?\*

People who have been involved in research say that the experience has been more rewarding and more enjoyable than they ever expected. It has given them:

- a new challenge and a sense of value
- new knowledge about how research works and the latest findings
- new skills as well as opportunities to use existing skills, for example research skills, computer skills, experience working in a team and document writing skills
- increased confidence and higher self-esteem by developing new skills
- a different way to think about their condition
- the opportunity to meet new people and share experiences
- a voice that influences processes that affect people's health or healthcare
- knowledge of, and insights into their condition
- the inner satisfaction of knowing that they are contributing to research and giving back to the community

People who get involved in research have different reasons for wanting to do it. Some people have had a difficult experience and appreciate being able to do something positive with it. Others have had very good experiences, and see their involvement as an opportunity to 'give something back'. For most people, it's about **wanting to make a difference** so that in the future, care will be better for the people who come after them.

\*INVOLVE - NIHR Public Information Pack - A quick guide



## 6. What support can I expect?

Before you get involved in a research project, or when you join a group, you may be offered training about involvement and about research.

The aim of training is to help you understand the research world a bit better so that you can understand how your contributions add value. But **you'll probably learn the most from actually doing it** – 'learning on the job' and your skills, understanding and confidence will greatly increase over time.

Depending on your background and experience, you may find some forms of support more helpful than others. As with anything else in life, you will learn how to 'do involvement' in a

number of ways. You'll read about it and you'll **learn from other partners**.

You can also ask the researcher, or **contact us** for help at any time - [cpquest@cerebralpalsy.org.au](mailto:cpquest@cerebralpalsy.org.au), a dedicated staff member may be able to support your involvement.

**CP Quest is committed to supporting families, community members and researchers to gain the confidence and knowledge to work together effectively.** Community involvement **training** is organised by CP Quest for researchers and

Research Partners once a year either face to face or online and takes just a few hours. Two CP Quest Research Partners have been trained along with two researchers to co-deliver training sessions to CP Quest partners in the future.

In the mean time we highly recommend the free online training from Telethon Kids Institute:

**An introduction to consumer and community involvement in health research**



## 7. Jargon buster

**Advisory group** - The group that helps to develop, support, advise and monitor the project. The group often includes people who use services, carers, researchers, Research Partners and other health and social care professionals, who can provide relevant advice.

**Advocate** - A person who speaks or writes in support or defence of a person, or cause.

**Carer** - A carer is a relative, friend or partner who provides a substantial amount of care to another person on a regular basis, but not necessarily through living with them.

**Code of conduct** - A code of conduct is a set of rules outlining the norms, rules, and responsibilities or proper practices of an individual party or an organisation. A policy to lay out the organisation's principles, standards, and the moral and ethical expectations that employees, volunteers and third parties are held to as they interact with the organisation.

**Data** - Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others, for example in reports, graphs or diagrams.

**Disseminate** - Dissemination refers to the process of sharing research findings with stakeholders and wider audiences, and is essential for uptake and use of research findings. It can be done by publishing project findings in peer reviewed journals and publications, presenting at national conferences and meetings of professional associations. Lay summaries can be used to present research findings to community groups.

**Grant** - Research grants are given to enable researchers to carry out a particular piece of research. They might amount to millions of dollars for a major study about genetics for example, or a few hundred dollars for a local study about people's experience of using a particular service. Usually, in order to get research grants, researchers have to write a research proposal and receive a positive peer review.

**Honorarium** - An honorarium is a payment made to bestow recognition to a person for his or her services in a volunteer capacity or for services for which fees are not traditionally required.

**Involvement** - Involvement in research refers to active involvement between people who use services, carers and researchers, rather than the use of people as participants in research (or as research 'subjects'). Many people describe involvement as doing research with or by people who use services rather than to, about or for them.

**Lived experience** - Personal knowledge about the world gained through direct, first-hand experience rather than through representations constructed by other people.

**Participant** - A participant is someone who takes part in a research project. Sometimes research participants are referred to as research 'subjects'.

**Participant information** - Researchers must provide a participant information leaflet to everyone they invite to take part in a research study to ensure people can make an informed decision about this. The leaflet explains what taking part will involve and should include details about: why the research is being done, how long it will last, what methods will be used and the possible risks and benefits, etc.

**Protocol** - A protocol is the plan for a piece of research. It usually includes information about: what question the research is asking and its importance/relevance, the background and context of the research, including what other research has been done before, how many people will be involved, who can take part, the research method, what will happen to the results and how they will be publicised. A protocol describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research ethics committee for approval.

**Reference group** - A group of people that influences the decisions and opinions of a person or group that advises an organisation on a particular subject or a group to which a person or another group is compared when you are studying the effects of something.

**Research** - The term research means different things to different people, but is essentially about finding out new knowledge that could lead to changes to treatments, policies or care.

**Researcher** - Researchers are the people who do the research. They may do research for a living, and be based in a university, hospital or other institution, and/or they may be a service user or carer.

**Research Partner** - The term Research Partner is used to describe people who get actively involved in research, to the extent that they are seen by their 'professional' colleagues as a partner, rather than someone who might be consulted occasionally. Partnership suggests that researchers and service users/carers have a relationship that involves mutual respect and equality.



## 8. Where do I find out more?

**WAHTN** - Involving Consumers in Health and Medical Research: A practical handbook for organisations, researchers, consumers and funders

**Health Consumers NSW** - Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective

**Telethon Kids Institute**

**WAHTN**

**NHMRC**

**INVOLVE UK**

**ACTA**

**Health Consumers NSW**

This guide has been produced in partnership with volunteers and Research Partners of CP Quest. Resources have been adapted and collated from other organisations and groups including INVOLVE UK, ACTA, Telethon Kids Institute and WAHTN.

**For more information,  
please get in touch:**



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Visit **[cerebralpalsy.org.au/our-research/get-involved-research/cp-quest/](https://cerebralpalsy.org.au/our-research/get-involved-research/cp-quest/)**



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