

## **The Pain in Cerebral Palsy Special Interest Group Terms of Reference**

### **Introduction and Purpose**

Current research indicates that 3 out of 4 individuals living with cerebral palsy experience pain across their lifetime. The pain experience varies depending on several factors including a person's mobility status, age, motor type and other comorbidities as well as psychosocial factors. The Pain in Cerebral Palsy Special Interest Group (SIG) brings together individuals from across Australasia and beyond with an interest in progressing the research and consequent clinical management of pain in people with cerebral palsy. Our members come from different health profession and research backgrounds as well as the lived experience of cerebral palsy. The purpose of the Pain SIG is to share information, drive research and support each other to improve the outcomes for people with cerebral palsy who have pain.

### **Membership and structure**

The Pain SIG will have one chair and one secretary, selected from the membership group. The group will consist of:

1. health professionals, researchers and clinician-researchers working in cerebral palsy and other childhood onset disability fields.
2. people with the lived experience of cerebral palsy and other childhood onset disabilities.

Group members will be strongly encouraged to be members of the Australasian Academy of Cerebral Palsy and Developmental Medicine; however, this is not mandatory.

There is currently no limit on the number of people within the group.

### **Roles and Responsibilities**

Members of the Pain SIG are expected to:

1. attend online meetings, or send apologies when attendance is not possible.
2. actively participate and contribute to meetings, processes and tasks of the group
3. present ideas from their areas of expertise and provide feedback on issues and priorities.
4. Contribute the research ideas and participate where appropriate.
5. provide timely responses to requests for information and advice from other members.
6. report back regularly to their own and related organisations if appropriate.
7. Contribute to open and respectful discussion.
8. Share power equally between members.
9. Maintain privacy and confidentiality.

### **Becoming a Pain SIG member**

There is no formal process for becoming members providing people meet the membership criteria. The Pain SIG section on the AusACPDM website displays representatives from the SIG who can be contacted for further information (<https://www.ausacpdm.org.au/education/ausacpdm-pain-research-special-interest-group/>). People interested in joining the SIG are encouraged to contact one of those members.

### **Meetings and communication**

SIG meetings will be held approximately every 2-3 months. Meeting will be online via Zoom or Teams and will last for one hour. Meeting agendas will be emailed to the group prior to each meeting and minutes recorded and distributed within one week of the meeting. The Chair, or a delegate, will facilitate the meetings and the secretary, or a delegate, will record minutes and distribute to group members. A representative from the Pain SIG will report on the group's activities at the AusACPDM Annual General Meeting and updates provided in newsletters as required.

### **Research Authorship**

Active involvement in research and publications/presentations of results by members of the group are actively encouraged. Each project arising from the special interest group will have explicit agreements about potential authorship at the beginning of the project.

Presentations and publications discussed in detail within the full group should acknowledge the group's contribution. It is suggested that this be at the level of an "Acknowledgment" in the paper/presentation.

**Date:** 27 February 2025. To be updated in 2027.