

## Cerebral Palsy Alliance Human Research Ethics Committee (HREC)

### **Policy for: Cerebral Palsy Alliance Human Research Ethics Committee**

Cerebral Palsy Alliance Human Research Ethics Committee (EC00402) is a **registered** National Health and Medical Research Council (NHMRC) Human Research Ethics Committee (HREC) in NSW / ACT. The scope of the HREC to review ethics applications is **limited within their registered status, i.e., not a lead HREC**. The demographics of the potential participants and other details of proposed projects may preclude the Cerebral Palsy Alliance HREC from reviewing an application for ethics approval.

**Please note:** the focus of the Cerebral Palsy Alliance HREC is to review applications that involve the **recruitment of CPA Clients or CPA Staff as participants**, and the involvement of **CPA Sites and other CPA resources** to conduct the project.

Please review the following to identify the appropriateness of submitting an application for CPA HREC review.

**Identify the appropriate lead HREC to provide *primary* ethics approval for your project.** The lead HREC is typically located at a university or hospital or at CPA (for CPA staff). If a university, hospital or CPA are not appropriate, the administering institution that funded projects should provide the lead HREC processes.

**Identify if there is a need for *secondary* ethics approval through CPA HREC.** Does your proposal involve recruiting / accessing:

CPA Clients	<b>If yes:</b> submit application to CPA HREC.  If your project has been submitted to a lead HREC using the NEAF, you can submit that same NEAF and a <b>letter/email from a relevant Cerebral Palsy Alliance manager confirming their approval for CPA involvement in the project.</b>
CPA Staff	
CPA Sites or resources	
NSW/ACT CP Register	<b>If yes:</b> Contact the data custodian to seek a letter of support regarding support from the NSW/ACT CP Register e.g. as a means of recruitment to your research project or to request summary/ non-identifiable data. Submit application to CPA HREC including the letter of support. <b>To access non-identifiable data, an application for an ethics waiver or low risk application may be appropriate.</b>
NSW/ACT CP Check-Up™	

**If your project involves the Australian Cerebral Palsy Register web-based platform provided by Cerebral Palsy Alliance** please ensure you have contacted the data custodian [cpregister@cerebralpalsy.org.au](mailto:cpregister@cerebralpalsy.org.au) for advice and contact details for the relevant Australian state or territory HREC process.

Ethical approval for conduct of a research study or recruitment involving **CPA affiliated international CP registries** should be sought from the relevant data custodian and HREC at that international site. The location of employment of the Principal Investigator and data collection sites should also guide the decision as to the choice of most appropriate HREC or Institutional Review Board (IRB).

**Next Step: Review the Approval process to conduct research at Cerebral Palsy Alliance.**

[https://research.cerebralpalsy.org.au/wp-content/uploads/sites/3/2015/09/Research\\_Ethics\\_Flowchart\\_030915.pdf](https://research.cerebralpalsy.org.au/wp-content/uploads/sites/3/2015/09/Research_Ethics_Flowchart_030915.pdf)

For further info: <https://research.cerebralpalsy.org.au/our-work/ethics/>