

Guidelines for Researchers to Access the NZ Cerebral Palsy Register (NZCPR)

The NZCPR is a confidential database of health information on people with cerebral palsy in NZ. Please contact us (Email: nzcpregister@adhb.govt.nz) and see our websites for further information: www.starship.org.nz/NZCPregister, and what data is collected: <https://nz.cpregister.com/>

i). Prior to starting your research

If you are planning to use the NZCPR database for your research project, **please contact us in your project planning stage**. This will ensure the NZCPR can provide the information you require for your project. If required, a quote can be provided for any financial costs the NZCPR might incur, depending on your project requirements.

ii). NZCPR Summary

Participants with cerebral palsy participate in our Registry through an 'opt-out' consent process. This means, we inform people with cerebral palsy about the NZCPR via face to face; letter /email or telephone and provide them with a Participant Information Sheet on the NZCPR. Participant's then have a 4-week period to inform us if they **do not** wish to participate on the NZCPR. If a participant does not opt-out then NZCPR team will add the participant to the NZCPR. As part of participating in the NZCPR, participants agree to be informed about relevant research, unless they inform us otherwise.

iii). Role of NZCPR Governance Committee

The NZCPR Governance committee aims to maintain and promote the NZCPR to improve quality of life for individuals with CP in NZ. As part of this, our role is to promote and encourage relevant research. The data held in the register is a significant data-set for NZ and the Governance Committee may wish to have oversight or be consulted on how it is reported and used. We are mindful of protecting the privacy and rights of our NZCPR participants and thus ensuring the research we inform participants on is ethically and scientifically sound and relevant to our participants. We also do not wish to overburden participants with research enquiries.

iv). Process for NZCPR Data Access

1. Complete the NZCPR 'Access to the New Zealand Cerebral Palsy Register Request Form'. Please email to nzcpregister@adhb.govt.nz
2. All applications must obtain / or be in the process of obtaining NZ HDEC approval
3. **All applications must complete the ADHB Research Review process** and will be reviewed by the ADHB Research Review Committee. Please see their website below for the process details. <http://www.adhb.health.nz/health-professionals/research/approval-process/>
4. The NZ Cerebral Palsy Register Governance committee will review all applications
5. Decision letter sent to researchers from NZCPR

6. Approval: NZCPR will send out the researchers Participants information Sheet to relevant families or NZCPR will provide researcher with relevant de-identified data

v). Criteria for Access to NZCPR Data:

- Significance of the proposal for people living in NZ with cerebral palsy
- The amount of previous research that has been accessed for a specific population
- Completed HDEC approval
- Completed ADHB Research Review approval

vi). Disclaimers:

1. The NZCPR Governance Committee will review the research proposal information provided. In this process every care will be taken to protect the privacy and intellectual property in relation to the project
2. A NZCPR Governance Committee member may be allocated to have oversight or a consultation role in the research project*
3. The NZCPR Governance Committee has the right to review findings and results of the study prior to publication*
4. There may be a cost associated with access to the NZCPR data for NZCPR management team support*

* Determined on a case-by-case basis