

Guidelines for Researchers to Access NZCPR Data

NZCPR Summary

The NZCPR is a confidential database of health information on people with cerebral palsy in NZ. Please contact us (email: nzcprregister@adhb.govt.nz) and see our websites and latest report for further information, including what data is collected:

- [NZCPR Website](#)
- [Starship Children's Hospital - Information about NZCPR](#)
- [NZCPR Report 2022](#)

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.

Helpful tips

Recruitment rates for projects that seek people with cerebral palsy to participate by completing a survey, participating in an interview or intervention, may vary. To optimise recruitment potential, it may be helpful to consider

- *Discussing your project with us in the planning stage*
- *Invitation to participate must be approved by the relevant ethics committee, but consider the following which we feel may improve participation rates:*
 - *If using an external form (e.g. a link for an interested participant to fill in contact details), keep the form to only 1 page if possible*
 - *Consider if the message can be communicated quickly, e.g. who is eligible and where to click*
 - *If offering koha, consider if it can be mentioned early in the invitation*

Role of NZCPR Governance Committee

The NZCPR Governance committee's research priorities is to utilise the NZCPR data to advocate and promote equitable health outcomes for all people living with CP in Aotearoa New Zealand across the lifespan ([Starship CP Research Page](#)). 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 invitations.



Process for NZCPR Data Access

1. Complete the NZCPR '[Access to the New Zealand Cerebral Palsy Register Request Form](#)'. Please email to nzcprregister@adhb.govt.nz
2. All applications must obtain / or be in the process of obtaining HDEC or relevant ethics committee approval
3. **All applications must complete the Te Toka Tumai Auckland Research Review process** and will be reviewed by the Te Toka Tumai Auckland Research Review Committee. Please see their website for the process details. <http://www.adhb.health.nz/health-professionals/research/approval-process/>
4. The NZCPR Governance committee will review all applications within a 7 working day timeframe
5. The decision letter will be sent via email
6. The NZCPR does not provide the researcher with any NZCPR participants' identifiable information. If your research proposal is for recruitment purposes and approved by the NZCPR Governance committee, the NZCPR administration team will be responsible for contacting the NZCPR participants, usually by email or post, that meet the inclusion criteria for the project. The NZCPR administration team will need the following documents from the researcher. The administration team will advise you on how many copies of each you will need to send to us:
 - i. Cover letter
 - ii. Participants information Sheet/s Flyer or invitation
7. If your study is related to data-linkage or use of NZCPR data and is approved by the NZCPR Governance Committee, the NZCPR administration team will prepare the data for you and remove any identifiable information before the data can be analysed by the researcher/s. Please refer to the [NZCPR Standard Operating Procedures](#) section 4.4.3.2 for more details on the NZCPR data management protocol and how the prepared data will stored and used.

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

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*



The New Zealand
Cerebral Palsy
Register

Te Rēhita a
Hōkai Nukurangi
Aotearoa



* Determined on a case-by-case basis