



The New Zealand  
Cerebral Palsy  
Register

Te Rēhita a  
Hōkai Nukurangi  
Aotearoa

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**Kua tawhiti kē to haerenga mai,  
kia kore e haere tonu. He nui rawa  
o mahi, kia kore e mahi tonu.**

**You have come too far not to go  
further, you have done too much  
not to do more.** Sir James Hēnare

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Te Rēhita a Hōkai Nukurangi Aotearoa

The New Zealand Cerebral Palsy (NZCPR)

Governance and Standard Operating Policies (revised)

June 2022

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**Glossary:**

<i>(A) DHB</i>	<i>(Auckland) District Health Board (to be reviewed when the structure of the New Zealand Health Board has more clarity)</i>
<i>ACC</i>	<i>Accident Compensation Corporation (NZ)</i>
<i>CP</i>	<i>Cerebral Palsy</i>
<i>CPS</i>	<i>Cerebral Palsy Society</i>
<i>FMHSc</i>	<i>Faculty of Medicine and Health Science, University of Auckland</i>
<i>HDEC</i>	<i>Health and Disability Ethics Committee</i>
<i>IWI</i>	<i>A Māori community or people</i>
<i>MAPAS</i>	<i>Māori and Pacific Student Association</i>
<i>MRI</i>	<i>Magnetic Resonance Image</i>
<i>NGOs</i>	<i>Non-Government Organisations</i>
<i>NZCPR</i>	<i>New Zealand Cerebral Palsy Register</i>
<i>NZCYCN CP</i>	<i>New Zealand Child Youth Clinical Networks – Cerebral Palsy Network</i>
<i>NZDep13</i>	<i>New Zealand Deprivation Index (a measure of socioeconomic deprivation)</i>
<i>PIS/CF</i>	<i>Participant Information Sheet / Consent Form</i>
<i>TKHM</i>	<i>Te Kupenga Hauora Māori</i>
<i>TMR</i>	<i>Te Mana Raraunga</i>

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## 1. NZCPR Vision and Purpose Statement

CP is the most common cause of childhood physical disability in high income countries, occurring as a result of a non-progressive disturbance that occurred in the developing foetal or infant brain<sup>1</sup>. This injury results in a disorder in the development of movement and posture that causes activity limitation. The rates of CP have started to show a decline primarily in the prenatal/perinatal group due to increased awareness of CP and scientific advances that have improved clinical care<sup>2</sup>. Population based CP Registers are the best mechanism to measure birth prevalence, accurately track trends and determine health service requirements for people living with CP<sup>2</sup>.

**The New Zealand Cerebral Palsy Register's (NZCPR) vision is to be the source of accurate, consistent, relevant, and high-quality information to support positive health outcomes for all people in Aotearoa NZ with CP.**

The purpose of the NZCPR is to:

- To collect, analyse and report high-quality health data, for all people with CP
- To describe, monitor and advocate across the life course, for all people with CP
- To support high quality research that addresses the priorities of people with CP
- To identify inequities and understand priorities for people with CP in Aotearoa NZ
- To support Māori health equity for people with CP and their whanau

### 1.1 Principles and Values guiding NZCPR activities

Following the NZCPR's collaboration with Te Kupenga Hauora Māori (2020-2021), The NZCPR is committed to adopt and implement the following principles which guide our actions:

- Whanaungatanga – creating spaces that allow for good relationships with our participants, health professional members and stakeholders
- Manaakitanga – nurture partnerships and respect to ensure Māori can have ongoing contribution to the Registers activities and its transformation
- Kaitiakitanga - work with Māori and act in ways that protect Māori whānau with lived experience of CP, in particular the way in which the NZCPR ensures privacy; collects; analyses and reports on health data

The NZCPR activities are founded in the following values:

- To be centred around and be accountable to all people with CP and their whānau in Aotearoa NZ
- To prioritise an equity focused approach
- To commit and be accountable to Te Tiriti o Waitangi
- To be ethically responsible

## 1.2 NZCPR Goals to be achieved in the next 5 years

1. To advocate for central leadership from the Ministry of Health/Health NZ to set and support NZ health quality registers to attain registry standards
2. To maintain high ethical and professional standards, accountable to the ADHB; national health and disability ethical committees of NZ and our obligations for Te Tiriti o Waitangi.
3. To communicate register outcomes with all people with CP, whānau, clinicians, DHBs and Stakeholders (including NGO's) in Aotearoa NZ, by:
  - i. Annual reporting
  - ii. Relevant information resources and formats for all communication
4. To have a high quality\* dataset for at least 80% of the Register cohort by 2026  
(\* High quality = accurate, complete, reliable, relevant, and timely)
5. To have 85% participation on the Register across all ethnic groups for people with CP aged 0-21 years by 2026
6. To have meaningful partnerships with Māori (including mana whenua, Māori academics, health professionals, whānau and people with lived experience and interest in CP), aiming for co-governance across Register governance and advisory groups
7. To promote and support CP related research activities in Aotearoa NZ, with active participation in at least 3 research related projects annually
  - i. To have one of the research related activities to be directed to building and enabling Kaupapa Māori research capacity and capability by 2026

The NZCPR has set the following as priorities in order to achieve these goals:

### **Governance related:**

- To complete annual ethic reports and requirements for HDEC (National) and District Health Board (Locality) groups
- To have a timeline to incorporate Māori data sovereignty principles by 2026
- To redefine governance structure to enable:
  - Māori participation across all NZCPR Governance groups
  - Health Equity: for Māori, as tangata whenua of Aotearoa NZ and other populations in Aotearoa NZ, namely Pacific peoples, with known potential inequities
  - Lived Experience: people with lived experience of CP, whānau and people with CP

- Data Management: representation from across NZ of relevant health professionals in field of CP care; with inclusion of Academic, Statistical, Epidemiological and Ethical knowledge skill sets.
- To build networks across NZ health registries to promote information sharing and advocate for national guidance in setting Health Quality registry standards for Aotearoa NZ.

#### **Research and Data Quality related:**

- To be an active member of the NZCYCN CP network to help inform CP clinical practice, service delivery and promote research in Aotearoa NZ
- To increase the visibility of Register outcomes internationally and nationally, with participation and presentations at 2 relevant clinical conferences and workplaces annually
- To meet recommended international CP Register standards for CP prevalence reporting, with participation from 80% of CP population (5-21 years) in NZ by 2026
- To submit biennially research grant proposals to support CP research and Māori workforce development (summer studentships/RA/RF roles)
- Active promotion of Māori Summer studentships with the NZCPR (dependant on funding and appropriate supervision)

## **2. The NZCPR Governance Terms of Reference**

### **2.1 Governance Committee:**

#### **2.1.1 Structure**

Membership of the NZCPR Governance Group should comprise of individuals who have an interest and commitment to people with lived experience of cerebral palsy in Aotearoa NZ and be in keeping with the vision of the NZCPR. The Committee aspires for diverse representation from multiple health, cultural and community fields.

The NZCPR Governance Committee Membership aims to include:

- i. Māori stakeholders
- ii. People with lived experience of CP and / or their whanau.
- iii. Representatives from relevant professional membership bodies and societies (Paediatric Society of NZ; NZ Orthopaedic Association; Perinatal Association of NZ; Australasian Faculty of Rehabilitation Medicine (NZ chapter)
- iv. Representatives from the CP Society of NZ
- v. Senior staff from the NZCPR Management Committee
- vi. The NZCPR Chair should typically be a senior and distinguished and independent clinician researcher

- vii. The presence of 50% of Governance committee members is required at a meeting to form a quorum
- viii. Formal minutes of meetings must be taken. Minutes will be distributed to members within 7 days of the meeting where possible. Members will have a further 7 days to comment on the draft minutes. If a member does not submit any comment by this time it will be assumed that the member is satisfied with the minutes as drafted

### 2.1.2 Purpose

- Provide strategic direction and oversight over all NZCPR activities
- To uphold and support the NZCPR's vision, purpose, aims, goals and priorities as outlined in NZCPR Operation Policy Chapter 1
- Provide advice on the NZCPR management, organisation, scope and funding
- Facilitate NZCPR to fulfil recommendations from the Māori Data Sovereignty audit (June 2022) see Appendix A.
- Provide support and regular review of all NZCPR policies, as determined by Management Committee
- Establish policies to address urgent issues of relevance, interest or significance, if required
- Participate in the development of NZCPR Research Priorities, with specific pro equity priority development
- To participate in review of applications for NZCPR research and data requests and / or to review publications arising from the NZCPR data, as requested by the Management Committee
- Formal minutes of meetings must be taken. Minutes will be distributed to members within 7 days of the meeting where possible. Members will have a further 7 days to comment on the draft minutes. If a member does not submit any comment by this time it will be assumed that the member is satisfied with the minutes as drafted

### 2.1.3 Member Obligations

- i. All members are required to sign the NZCPR Governance Committee Terms of Reference document (Appendix B)
- ii. Participate in twice yearly NZCPR Governance meetings (via ZOOM)
- iii. Provide guidance on NZCPR matters
- iv. Support and advocate for the work of the NZCPR
- v. Pre-read meeting documents as or if required
- vi. Assist the Management Committee, via email discussion, on an ad-hoc basis, between meetings if required
- vii. Maintain the confidentiality of the NZCPR business as advised by the Chair and not divulge the views expressed by individual members of the NZCPR to any person outside of the NZCPR or Governance group
- viii. Disclose conflicts of interest in their duties as a member of the Governance Committee  
Where relevant, Governance Committee members will:
  - Review NZCPR activities from a Māori perspective.
  - Support the Governance Committees knowledge and understanding when dealing with the collection and use of Māori data; Māori health related concepts, tikanga, incorporating Te Ao Māori values.
  - Play an active role in policy development to promote health equity for Māori peoples with CP.
  - Advocate and promote NZCPR core business amongst relevant professional body i.e., distribute annual reports or promote NZCPR membership and research
  - Review NZCPR activities from the perspective of people with CP and their families



The level of commitment and type of involvement will be on a case-by-case basis, subject to the availability and interests of individual member, particularly for those with lived experience

Where possible, the NZCPR Management Committee will endeavour to actively support Committee members to fulfil their role on the NZCPR Governance Committee, for example sharing Cerebral Palsy related professional development activities.

The role may provide compensation for costs of participating on a discretionary basis. NZ Government rate sum of \$360 per day plus half day prep is recommended for members that provide specialist knowledge and expertise especially in respect to supporting NZCPR Māori Data Governance Framework.

#### 2.1.4 Resignations, Termination

A Governance member term is for two years, where by new expression of interest will be sought or a new term negotiated with the chair.

- A member of Governance Committee may resign at any time by notifying the Chair in writing.
- The Chair of the Governance Committee may choose to remove a person from the committee if they decide it is not in the interests of the group, the Register or for the person to remain a member. If the Governance Committee intends to make such a decision, they must give the member written notice setting out the intended decision and the grounds on which it is based. These grounds include, though are not limited to:
  - The member failed to disclose a conflict of interest
  - The member failed to fulfil his/her obligations as Governance Committee member

#### 2.1.5 Review of the Terms of Reference

The terms of reference will be reviewed and updated as required:

Review Date	Outcome	Comment on revised/review details

## 2.2 Management Team (Administration team)

### 2.2.1 Purpose

- Responsible for managing day-to-day aspects of the NZCPR
- Responsible for administration, staffing and budget
- Ensure that the data collection and data quality processes function effectively and that issues arising are dealt with in a timely and effective manner
- Arrange timely and appropriate statistical analysis, reporting and publication of NZCPR data
- Review NZCPR data regularly and undertake necessary follow-up in accordance with policies ratified by the Governance Committee
- Report to the Governance Committee at regular intervals to ensure suitable resources are provided to facilitate action on policy-related issues
- Ensure compliance with requirements of ethics committees and all relevant legislation

- Provide reports and liaise as necessary with bodies providing funds to the NZCPR
- Check and verify all NZCPR Health Professional membership requests and manage jurisdiction allocation
- Inform jurisdiction members of any NZCPR Governance Committee and/or Australian CPR Policy and Research meeting outcomes and provide training/support for any changes that may arise as a result
- Liaise regularly with the Australian CP Register Group

### 2.2.2 Structure

- The Management Committee should convene at least monthly and have provision for the calling of extra ordinary meetings as required
- Minutes of these meetings should be taken
- Meetings should comprise of, a minimum of 2 individuals, including
  - i. The NZCPR staff involved in day to day operations of NZCPR
  - ii. At least 1 representative from Governance group – ie. Chair or person with lived experience
  - iii. Representation from Australian CP Register and/or website administrator, as required
  - iv. Administration support, as required

## 2.3 Advisory Group

### 2.3.1 Purpose

- Provide feedback to the management team on national / local issues related to ascertainment, data entry and data reporting

### 2.3.2 Structure:

- Frequency to be determined by the NZCPR Governance committee and can be done in an informal capacity so the NZCPR can adjust its activities to meet the needs of local areas
- Membership
  1. All NZCPR health professional members are invited to be represented on the advisory group
  2. Representation from Pacific and Māori Stakeholder Groups and/or Iwi
  3. Members of the public (parent of a child with CP or person with CP)

## 3. NZCPR relationship with priority relationships

### 3.1 Australian CP Register (ACPR) relationship

- The online data collection platform (also referred to as website in this document) is generously shared with the NZCPR by the Cerebral Palsy Alliance Research Institute in Australia. The NZCPR and ACPR are committed to collecting the same CP related minimum dataset. This is a cloud-based platform and is securely hosted by Macquarie Telecom Ltd Australia, meeting the security requirements of the NZ Department of Internal Affairs Cloud Risk Assessment undertaken in 2017. The specifics of the NZCPR data lifecycle are described in more detail under the Data Management in chapter 4.4. It is important to note that:
  - NZCPR data is not visible to or used by any Cerebral Palsy Alliance and Australian CP Register staff

- Paul Novak (Lead Website Developer) and Hayley Smithers-Sheedy (ACPR Lead and Research Fellow at the CP Alliance) have password protected access to the NZCPR platform, which is necessary for ongoing maintenance and addition of data fields to the website
- A Cerebral Palsy Alliance Research Institute and NZCPR working guidelines agreement (2015) provides a framework for the registry partnership (Appendix C). (Please note the Appendix can be opened digitally by double clicking on the front-page image).
- The NZCPR is viewed as a collaborative partner of the ACPR with shared common Register aims and as such participates in annual meetings, contributes to the NZ section of the bi-annual ACPR report (Appendix D 2018 example)

### **3.2 The Cerebral Palsy Society (CPS) relationship**

A signed Memorandum of Understanding exists between the NZCPR and Cerebral Palsy Society of NZ Inc (CPS), recognising that there is a shared common interest and jointly recognise key strategic initiatives in support of CP children and their families. The purpose is to develop a strategic alliance between the NZCPR and CPS with the objective of:

1. Improving health literacy through the interpretation and use of high-quality health information, improving decisions for health and well-being within the CP population
2. To agree a joint interim steering committee to oversee key appointments and to initiate the alliance project

In April 2022 the CPS funded a full time project manager for 18 months to implement the relationship and achieve the following goals over a 5-year time frame:

- Prioritised health information collection
- Acknowledgement of Maori data sovereignty
- Shared and targeted operational and leadership roles
- Research trial funding strategy aligned to interests of CPS members
- Shared communication strategy
- Refreshed governance structure

Review April 2024

### **3.3 The Cerebral Palsy Clinical Network (CPCN) relationship**

The CPCN is part of the New Zealand Child Youth Clinical Network. The NZCPR is a work stream within the CPCN and the NZCPR management team and clinical director are current members. The NZCPR is accountable to the CPCN by setting and reporting on key performance indicators and goals to be achieved within given time frames. These are regularly reviewed and updated according to the CPCN overarching directive.

### 3.4 Iwi and Māori Health Providers

The Māori Data Sovereignty audit (Appendix A) has identified that the NZCPR needs to establish relationships with Iwi to gain a mutual understanding of the benefits of the Register and how data could be used to advocacy purposes. As a longer-term goal, the NZCPR will look to building relationship with prominent Iwi within the Auckland area in the first instance within the next 3 years.

## 4. NZ Cerebral Palsy Register Standard Operational Procedures

### 4.1 NZCPR eligibility - Inclusion / exclusion criteria

- Inclusion criteria: People with a formal diagnosis of CP from a registered NZ medical professional are included in this project.
- Exclusion criteria: The Register will only keep health information about people with the formal description of cerebral palsy. People entered onto the register will be excluded from the register if, at the time of data entry it appears that the condition is progressive or the diagnosis of CP is in doubt
- The NZCPR accepts any definition of CP as long as it includes the following 5 key elements: CP is (1) a group of disorders i.e. it is an umbrella term; (2) it is permanent but not unchanging; (3) it involves a disorder of movement and/or posture and of motor function; (4) it is due to a non-progressive interference/lesion/abnormality; (5) this interference/lesion/abnormality arises in the developing brain<sup>3,4</sup>.
- Note: People entered into the Register when < 5 years of age will be contacted via email or post at 5yrs by the NZCPR management team to confirm diagnosis and that their health information is recorded on the Register

### 4.2 Membership

- The NZCPR has a range of 'membership' options (with a person with lived experience ; Parent of person with CP; Health Professional). This is to facilitate inputting data and communication between individuals and the NZCPR.
- Membership is completed online via the NZCPR website and individuals are required to provide basic demographic and contact details. On submission, they will be asked to create a secure password and answer to a security question (to be used in the event of a password reset). The username is then automatically generated, usually consisting of the individual's initial and surname. Individuals are then asked to select the option that best describes their membership request (parent; health professional; researcher etc)
- The NZCPR receives a notification of a new membership request via the NZCPR email address

#### 4.2.1 Parent / guardian or person with CP membership

- A parent/guardian or person with CP can create a secure username and password on the NZCPR website and progress to enter their own/child's data. By doing this it is assumed that consent to opt-in has been given.
- The NZCPR management team acknowledges that completion of the datasets requires a moderate level of health literacy and could be perceived as sensitive or "reliving a trauma" for the individual. As outlined in the Patient Information Sheet (PIS) the NZCPR management team are available to provide assistance with dataset completion or to listen to the individual if they have difficulty with the health information they are providing

- The NZCPR admin team are able to view the information as a “new” registration. The information provided is verified and approved using the clinical notes or contacting the nominated health professional using the details provided by the parent/person. The burden of dataset completion does not lie with individual and the preference is for the NZCPR management team to complete the datasets
- On completion of the datasets, the NZCPR management team will send a letter, via email or post, confirming that the registration is complete and thanking them for their participation (Appendix E)

#### 4.2.2 Health professional membership

- Any Health Professional (HP) in NZ can apply to become a member of the NZCPR by following the process described under 4.2 .
- Health professional membership requests are required to provide additional information regarding their area of work and their manager/team leader contact details. On receipt of the notification email, the NZCPR management verify professional and personal details by contacting the manager/ team leader given in the online membership application. In some instances, the individual may already be known to the NZCPR management team and this step is not necessary. Once the HP details have been verified, the NZCPR administration change the HP membership from “public user” to “health professional”, enabling the HP to enter datasets on behalf of their patient provided the consent guidelines (4.3.1) have been followed
- On completion of HP membership, the NZCPR management team will send an email to the HP confirming their HP status, username and a link to the webinar/ YouTube video on important information pertaining to NZCPR ascertainment and data entry (insert link when available)
- The NZCPR administration team is able to allocate a “jurisdiction” rule to a health professional member, provided a Jurisdiction Agreement with the NZCPR has been signed (Appendix F). A Jurisdiction member is usually a single clinician within a District Health Board (DHB) catchment area who, in agreement with their colleagues, has taken on the responsibility of overseeing ascertainment (including the consent process) and data entry on behalf of the NZCPR within their DHB. They are also able to view all registrations within their DHB

### 4.3 Ascertainment procedures

- Multiple sources will be used for recruitment of individuals onto the NZCPR. All methods aim to ensure individuals with CP and families are fully informed about the NZCPR and we minimise the time burden for individuals with CP and health professionals in participating in the NZCPR. The main examples of ascertainment methods are detailed below.

#### 4.3.1 Definition and process of opt-out consent

- Opt-out consent: Presuming that an individual, once fully informed, will be willing to be included on a Registry unless they lodge an objection (opt out) in a defined time. (From National Guidelines on Ethical Conduct [www.nhmrc.gov.au/guidelines/publications/e72](http://www.nhmrc.gov.au/guidelines/publications/e72) Accessed August 2016)
- Potential NZCPR participants must be provided with clear and easily interpreted information detailing:
  - i. The purpose of the NZCPR

- ii. That their identity and some specific clinical information will be retained in the NZCPR unless they contact the NZCPR to 'opt-out' within the defined time period of 4 weeks from being informed of the NZCPR details.
  - iii. How information contributed to the NZCPR will be used, including how data may be linked and shared
  - iv. That a decision not to participate in the NZCPR will incur no penalty, either financially or in respect to the care they will receive
  - v. How they may lodge a complaint through an independent complaints process
- A range of options are made available by which people can easily and freely notify the NZCPR should they not wish to participate in the register. These include telephone number with an answer service; web-based systems (opt-out form can be downloaded from the NZCPR website and emailed to the NZCPR), completing the section at the bottom of the PIS; contacting the NZCPR and requesting an opt-out form and self-addressed stamped envelope.
  - A period of four weeks should lapse, from time of the individual being informed about NZCPR details, before the NZCPR is able to assume consent for the NZCPR and complete the required datasets. The individuals can choose to opt-off the NZCPR at any point in the future i.e. beyond the 4 weeks, at which time their CP data would be removed.
  - If the NZCPR management team is required to provide families or individuals, they will check the residential address of the participant ensure that the correct PIS and Ascent forms relevant to each DHB are sent/emailed to the family/ individual. The age of the child must also be checked to ensure the correct Ascent form is sent/emailed where appropriate
  - The NZCPR has 2 PIS (Parent and person aged 16+) and 2 Ascent forms (7-11 years; 12-15 years) (Appendix for ADHB Parent PIS's)
  - Each letter or email that the NZCPR management team send must include the appropriate DHB PIS, Ascent forms, information flyer and cover letter

#### 4.3.2 Face to face

- The Health Professional is responsible for providing the parent / person with CP with information on the NZCPR, including the Patient Information Sheet and Patient Information Flyer (available to download from the NZCPR website)
- The parent / person with CP must be made aware that their information will be made entered onto the NZCPR in 4 weeks' time unless they advise otherwise by contacting the NZCPR as outlined in the Patient Information Sheet and Flyer
- If no contact has been made, the HP or NZCPR staff are then able to create a "new case" on the register and proceed with completing the datasets.

#### 4.3.3 Notification card

- The notification card (hardcopy or online) is to enable health professionals to easily inform the NZCPR team they have discussed the Register with a parent/person with CP and obtained their permission to be contacted by the NZCPR.
- The notification card can be completed via the website or manually using a pre-printed card and sent to the NZCPR administration team. The NZCPR administration team or jurisdiction holder (if available) are then able to pursue ascertainment following the guidelines

- It is desirable that the HP provide the parent/person with the PIS and information flyer, however the NZCPR management team will send the information to the family or person again if there is any uncertainty as to if this information has been provided by the HP
- The “date discussed” field on the notification card must be completed by the HP
- After 4 weeks, if no contact has been made by the parent/person, the NZCPR administration team will proceed with completing the datasets for the registrant
- In lieu of a notification card, The NZCPR management team will accept an email notification from a HP. In this instance the NZCPR management team will send the information to the family or person and manage the consent process. This is then considered to be the first step in starting the opt-out process and will be completed as described under section 4.3.1

#### 4.3.4 Ascertainment via contact with Multiple Service Providers

- Children with CP have complex health needs and access multiple health care providers and services. The NZCPR will work collaboratively with DHB, educational and community service providers to ensure their patients with CP receive NZCPR information and the registration process is followed according to the guidelines
- The letter/email accompanying the appropriate PIS’s and Ascent forms **must** include the name of the person or the service from which the patient’s details were obtained e.g *Dr \*\*\*\*\* from the Child Development Service at \*\*\*\*\* hospital has informed us you/ your child has cerebral palsy*
- This is then considered to be the first step in starting the opt-out process and will be completed as described under section 4.3.1.

#### 4.3.5 Ascertainment using the MoH National Minimum (hospital admissions) Dataset

The NZCPR has HDEC approval (13/NTA/130/AM11) to use identifiable information from the National Minimum (Hospital admissions) Dataset. The following ascertainment process must be undertaken in keeping with ethical obligations:

- On a bi-annual basis, the NZCPR will request from the Information Analyst (Analytical Services, Ministry of Health), via email ([data-enquiries@health.govt.nz](mailto:data-enquiries@health.govt.nz)), **all** hospital admissions coded for Cerebral Palsy (ICD10 G80-G83) for the preceding 2 years. This to include the person’s full name, DOB (to determine age and send out correct PIS’s and Ascent forms); full postal address, current DHB (to determine correct PIS’s and Ascent forms); prioritised ethnicity
  - HDEC approval letter (stored in L:\Groups\PAEDORTHO\CP Register\Ethics\HDEC Post Approval\Amendment \_11\_NMDS(ii)\Oct\_2018\_NMDS Approval) and HDEC form (L:\Groups\PAEDORTHO\CP Register\Ethics\HDEC Post Approval\Amendment \_11\_NMDS(ii)\May\_April\_2018\_Resubmission) must be sent with the request
- Once the data has been received from MoH, the NZCPR management team must undertake the following checks using the electronic medical record for the NHI. If there is no ability to check the NHI e.g., remote/ Citrix access isn’t available for the DHB, then the NHI is removed from the list and **NO** contact is to be made with the family or person.
  - Check the person is still alive. If the person is deceased not contact will be made
  - Check the residential address matches the information on the electronic record. If there is any uncertainty as to the current residential address, no contact is to be made

- Check the most recent or appropriate (e.g. Orthopaedic, Rehabilitation) clinic letter to ensure the person has a diagnosis of CP. If no CP is mentioned, then no contact is to be made with the person
- The letter accompanying the appropriate PIS's and Ascent forms for each DHB must state that their information was **obtained because they had a recent admission to hospital**. This is then considered to be the first step in starting the opt-out process and will be completed as described under section 4.3.1

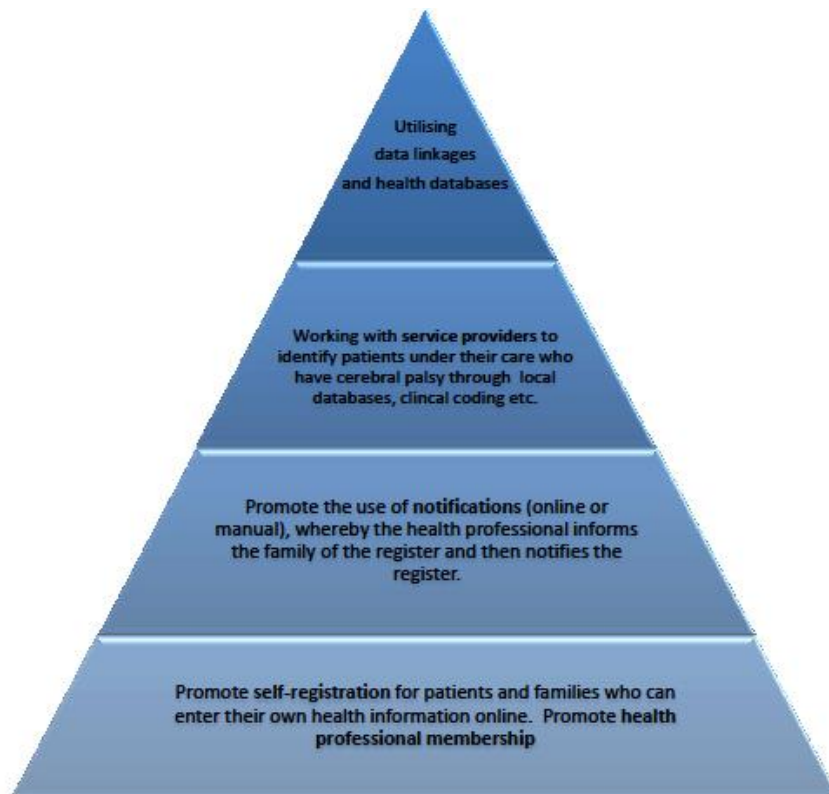


Figure 1: NZCPR methods for ascertainment preferences



## 4.4 Data Management

The NZCPR uses the NEAC guidelines for Life Cycle of Health Data (Figure 2) to guide data management

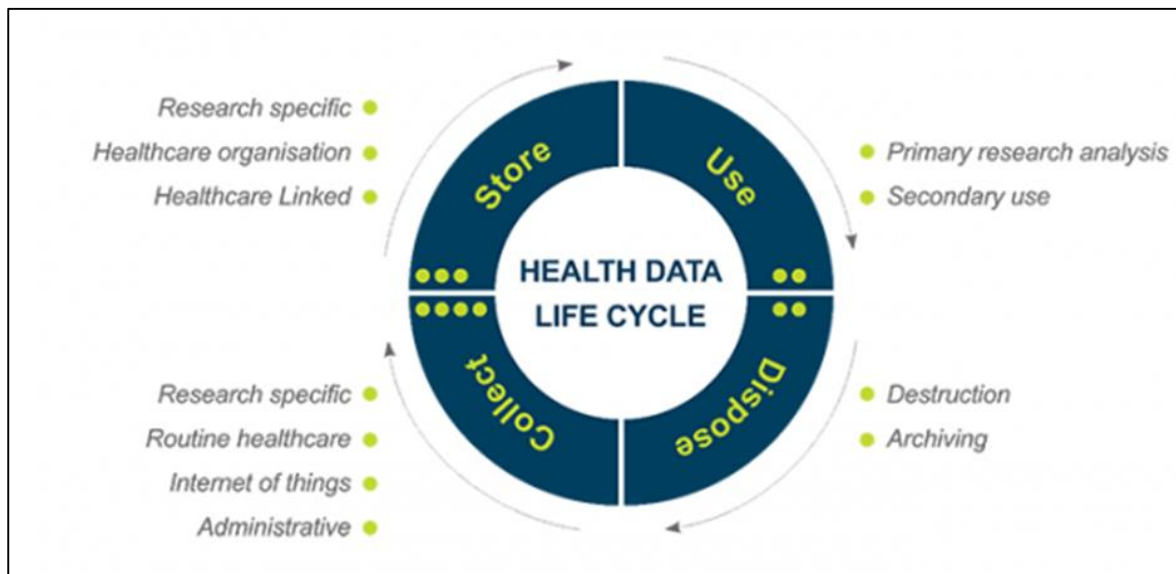


Figure 2: [NEAC Health Data Life Cycle](#)

### 4.4.1 Māori Data Definition

Māori data refers to data produced by Māori or that is about Māori and the environments Māori have relationships with. Māori Data includes but is not limited to:

- Data from organisations and businesses
- Data about Māori that is used to describe or compare Māori collectives
- Data about Te Ao Māori that emerges from research.

#### 4.4.1.2 Establishing a Māori Data Governance Framework

To strengthen Māori Data Provisions, the NZCPR aims to work towards establishing a Māori Data Governance Framework with oversight from Māori Governance Committee member/s.

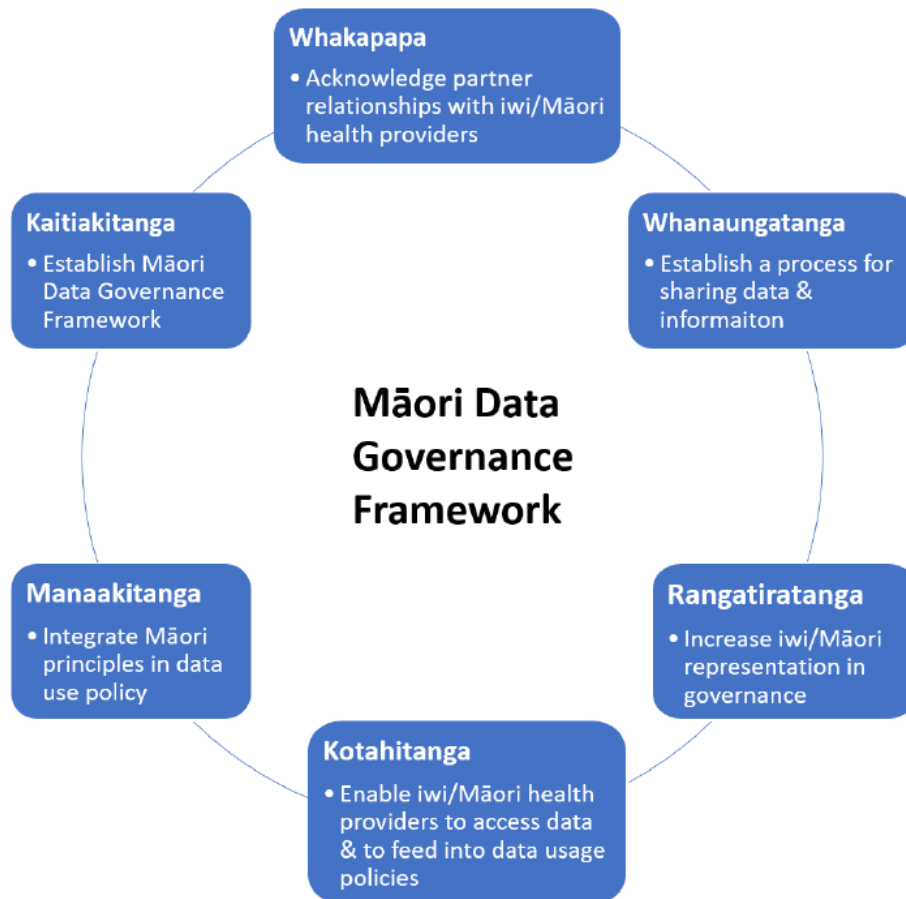


Figure 3: Māori Data Governance Framework

#### 4.4.2 Data Collection

- The NZCPR administration team are responsible for checking and verifying **all** of the information for each case entered onto the register, irrespective of its origin
- Clinical Information must be accessed according to each individual DHB's research policies and procedures (e.g. ADHB requires an email with the NHI of each person to be sent to clinical records requesting access to the Concerto and 3M for that NHI)
- Information can be collected and datasets are verified in the following way:
  - Searching through clinical notes
  - Contacting the nominated health care professional for more information
  - Contacting the parents/ person with CP for more information, usually pertaining to personal, birth and classification details
- Verification at aged 5 is done to confirm the clinical details and is required before any case is approved\*
- An approved case is then eligible for statistical analysis and reporting
- A minimum of 80% of completed datasets for each case is required in order to be eligible for reporting purposes
- Jurisdiction members are able to verify and approve information for cases registered in their DHB

- NZCPR management participate in regular (every 2 months) ACPR Microsoft Teams meetings to discuss quality of data collection for minimum datasets and case reports

#### 4.4.2.1 Minimum dataset

The same minimum dataset is collected by the ACPR and will be used when the NZCPR contributes a report to the ACPR bi-annual report.

- Demographic Data:
  - First, Middle and Last Name
  - Date of Birth
  - Gender
  - Residential Details at Time of Birth (DHB if born in NZ or Country of Birth)
  - Current Residential Address
  - Email address (preferable way of contacting participants)
- Birth Details:
  - Mother's age at time of birth
  - Mother's previous history of live births/ still births/ miscarriages
  - Birth order and plurality
  - Birth weight
  - Gestational age
  - Level of care required at the time of birth and time spent in neonatal unit if applicable
  - Birth defect
- Timing and Cause of CP
  - Timing and cause (pre/perinatal or postnatal)
  - Known pre/perinatal or postnatal cause
  - MRI or Cranial Ultrasound results < 2years of age (as classified by SCPE<sup>5</sup>)
  - MRI >2 years (as classified by Himmelman et al <sup>6</sup>)
- Clinical Details
  - Initial Description of CP: Age, Type and GMFCS
  - Description of CP at age 5: Predominate Type, Secondary Type
  - Functional Classifications: GMFCS (essential); MACS, CFCS, EDACS (desirable)
  - Associated Impairments: Intellectual, Speech, Visual, Hearing, Epilepsy, Known Syndrome (POSSUM code)
- Mortality: The NZCPR has HDEC approval (insert #) to retrospectively link to MoH mortality data. The NZCPR management team will extract all NZCPR NHI in Excel format and send this to the Ministry of Health business analyst. This can be done in the same method and at the same time (biannual) as the NMDS linkage described under 4.3.5. The NZCPR management team will then update the online registration to reflect **date of death**. No future contact is to be made with the participant's family following their death
  - Cause of death ICD codes: This information can be obtained from the Mortality Collection database. There is a charge to access this data and it is not up-to date (in 2021 only data up to 2017 was available). At present the NZCPR is opting not to complete these datasets

#### 4.4.2.2 NZCPR unique datasets

The NZCPR has unique datasets that is collected as follows:

- NHI
- NZ Ethnicity (Statistics New Zealand Level 2 collection). This is primarily obtained from the electronic medical record and where possible, prioritised ethnicity for Māori is used
- Deprivation Index (NZDep)
- Iwi (when this is linked to NHI and visible in the electronic health record or as determined by Iwi partners). As per the Māori Data Sovereignty audit, it is recommended that the NZCPR check Iwi affiliations with participants, where possible and contact details are available, a member of the management team will confirm Iwi affiliations with a new registrant
- Current District Health Board
- Specialist Service making the initial diagnosis
- Timing of first hip X-ray (for hip surveillance)
- Covered by ACC

#### 4.4.2.3 Auditing of data entry

- On the 1<sup>st</sup> July biannually, the NZCPR management team will perform an audit on data entry for approved registrations. This will be done by:
  - Extracting all “approved” registrations from the NZCPR website in Microsoft Excel format
  - Using the Excel Randomise Tool to select random NHI’s (aiming for 3 NHI’s for each person to audit)
  - Two NZCPR staff (members of management team, with clinical note access) will audit 3 NHI’s, matching the datasets on the website against the electronic medical records for the NHI for completeness and accuracy
  - The audit outcome tool (Appendix G) must be completed (with no identifiable information included) and saved in the audit folder on the CP Register secure L: drive
  - Results of the audit can be included in the year appropriate HDEC progress report

#### 4.4.2.4 Opportunity to opt-off at age 16

- When a child on the register reaches the age of 16 years, the NZCPR administration team contact the child and the parent/ caregiver by sending a letter (the most up-to-date address sourced from the medical records) and the child will be given the opportunity to opt-off having their health information stored on the register, based on the assumption of capacity. If the child does not have capacity to make decisions about their health information collection, the representative appearing to be acting on his/her behalf or in the best interest of the child will be able to determine if their health information is retained on the register ([NZ Health Information Privacy Code 1994](#)).
- Prior to making contact with the parent, the NHI number of the child should be checked against the address and details held in the electronic health record to ensure that the child is still living

#### 4.4.2.5 Age 5 verification \*

- If information is collected on the NZCPR before a child's 5<sup>th</sup> birthday the NZCPR team will reconfirm the clinical information at 5 years of age, through contact with the participant, health professional or medical notes.
- At present, age 5 verification is completed by the administration team or jurisdiction member
- Verification can be done by locating the letter/s from the last clinical assessment/s in the year that the child turned 5. Alternatively, the nominated health care professional can be contacted to verify the clinical information
- Once the clinical information is completed on the register, the case can be approved

#### 4.4.2.6 Opting out after registration is complete

At any time, the parent/ person with CP can contact the NZCPR to opt-out of the research clause as outlined in the PIS. If the NZCPR receives a request to opt-out, the administrator will immediately "silence" the record. By silencing a record, the data is no longer visible and cannot be used for analysis or reporting purposes, both locally and for the ACPR report. The NZCPR will no longer make any contact with the person/ family. Where possible, a letter or email will be sent to the person or family to acknowledge their wishes and advise them that their information has been "silenced" on the Register.

### 4.4.3 Data Storage

#### 4.2.3.1 Data Security

- Health data for all NZCPR participants is stored directly on a cloud based service hosted by Macquarie Telecommunications (Australia). Macquarie Telecom is a Level 1 Service Provider that:
  - Fully meets the requirements the of the Payments Card Industry Data Security Standard as stated in Privasec issued Attestation of Compliance (AoC) and Report on Compliance (RoC) dated 23rd November 2016
  - The Intellicentre Data Halls have an established tamper-resistant and tamper-evident barrier to meet the requirements of the SCEC and an appropriate access control and intrusion detection capability are complimentary to the security of the area
  - Provision of Cloud and Managed Hosting solutions including network infrastructure and secure data centre facilities for Government and Enterprise customers as identified in the Statement of Applicability ISO27001:2013 20161025.xls.
    - Certificate No: ISM20044 (Issued January 2017, expiry 8 February 2020)
  - All data in transit uses industry standard 2048 Bit SSL **encryption** and key size is 2048 bit to ensure confidentiality of the data. Data is not encrypted at rest.
  - Two types of **audit** are to be performed annually as part of the annual security audit of the CP Register:
    - i. Audit of the security plan and the procedures that are developed to support the plan

- ii. Audit the protective mechanisms employed with respect to the level of security that they provide and are expected to provide in the future, and that the mechanisms correctly and effectively support the appropriate policies
- **Key Compromise and Recovery:** If the keys are compromised or suspected of being compromised the following compromise-recovery plan is to be put into effect:
  - i. The following parties, which represents all those required to complete the recovery actions, to be informed as soon as possible
    - a. Hayley Smithers-Sheedy, Research Fellow, CP Research Institute
    - b. Paul Novak, Lead Developer – CP Register, Contractor
    - c. Nick Culpitt, Information Technology Manager, Cerebral Palsy Alliance
    - d. Paul Novak or H Hayley Smithers-Sheedy to immediately inform the NZCPR management team of the compromise
  - ii. Paul Novak, Leader Developer is to perform the following Recovery actions for all effected keys
    - a. The application should be taken offline for a maintenance period
    - b. Existing keys are to be revoked
    - c. Key revocation to be confirmed with certificate authority
  - iii. The keys are to be regenerated and new certificates issued by the chosen certificate authority.
  - iv. All information that may be compromised as a result of the incident is to be identified and reported to Cerebral Palsy Alliance Research Institute Ethics Committee for further action
  - v. Paul Novak and/or Hayley Smithers-Sheedy are to immediately inform the NZCPR management team of the compromise. The NZCPR team are to bring this to the attention of the ADHB CIO and inform participants and HDEC of the implications and course of action taken
- When required, the NZCPR management team are responsible for extracting data from the NZCPR platform. Extraction uses Microsoft Excel™. Worksheets are saved onto the secure ADHB L: Drive (CP Register folder). This folder is password protected and only accessible by the NZCPR management team and stored securely as per ADHB Health Alliance security and firewall protocols.

#### 4.4.4 Data Usage

Data released from the NZCPR will be in **de-identified** format for:

- Biannual Australian CP Register Report: NZ specific chapter for reporting
- NZCPR produced publications, annual reports
- DHB specific reports
- Researchers, on application with appropriate ethical consent

Data released from the NZCPR will be in identifiable form (using NHI) for: pre-identified DHB contacts across NZ, to allow for regional service provision

#### **4.4.4.1 NZCPR use of its own data**

When there are sufficient national registrations to determine prevalence (is this 1.5 /1000 live births), the NZCPR would be in a position to contribute to the bi-annual ACPR report. Reporting would follow the same format as the ACPR.

The NZCPR will produce an annual report on its progress in relation to ascertainment and population description and/or prevalence.

- i. Every effort will be made to make reports and research publications (that have used the NZCPR data) available to view on the NZCPR and/or Starship website; via the CPS and NZCPR social media platforms
- ii. The NZCPR will send out an annual newsletter with relevant information and progress to all participants (preference is via email)

#### **4.4.4.2 DHB specific reporting (to be reviewed when new NZHB structure becomes clearer)**

Once individual DHB's have sufficient ascertainment (70% of expected CP population <19 years as calculated using estimates from MoH DHB population profiles) the NZCPR management team is able to produce a formal report, using de-identified data, and share this with Jurisdiction, HP members and clinicians. The NZCPR can also present the findings from the report in a more formal "training or in-service" setting at the request of the individual services.

Note: Upon request from an individual DHB's, a DHB summary can be completed by the NZCPR, even if 70% ascertainment not yet achieved, i.e. for a funding application or business case development

The Working agreement between the NZCPR and DHB jurisdiction holders stipulates that the NZCPR Governance Committee reviews individual requests from DHB's for teaching, presentation or publication purposes

#### **4.4.4.3 Using the NZCPR for research purposes**

The NZCPR will publish, via the Starship and NZCPR websites, research priorities for the forthcoming two years. Equity focussed research that aims to identify and eliminate inequities for Māori and Pasifika children and people with CP will always be a focus and preference will be given to research that supports this priority

- i) All applications to make use of or access NZCPR data for research purposes should be directed to the NZCPR Governance Committee (Appendix H). Application forms are made available to download from the NZCPR website and collated by the administration team to present at the Governance Committee meetings at the bi-annual meeting or via email and decisions will be minuted or collated if via email. All applications must be endorsed by the relevant Institutional Ethics Committee and the applicant must be aware of and compliant with national and institutional ethic processes and procedures.
  - Relevant documents that must be submitted with the application include Ethics approved Protocol, Data Management Protocol, Patient Information and Ascent forms (if applicable) and other forms relevant to the study e.g., Questionnaires

- If the study includes equity focussed research, the NZCPR requires demonstration of consultation with or inclusion of Māori or Pacifica investigators on the research team
  - All applications will have to complete the ADHB locality approval process through the ADHB Research Office. The application is made through the online Auckland Health and Research Committee (AHREC) portal.. The Research Office will verify with the NZCPR Governance Committee that the NZCPR have capacity and in principal support the research project prior to locality assessment being approved. The NZCPR reserves the right to decline an application based on staffing capacity.
- ii. Depending on the type of research project (e.g. secondary use of NZCPR data), a member of the NZCPR Governance Committee may be required to be on the researcher’s investigators team and a named author on any publications that result from the study
  - iii. The NZCPR reserves the right to charge for the time required for NZCPR management staff to prepare data for a research study (POA)
  - iv. Applicants will be advised in writing as to the outcome of the application and procedures on accessing the register

#### **4.4.5 Data Disposal**

Health Data is stored on the NZCPR cloud-based platform indefinitely or until the register ceases to exist, in which case all health information will be erased and participants informed.

NZCPR extracted data form the cloud-based platform and stored on the ADHB L: Drive will be stored for 10 years from the date of extraction.

Review date: September 2023



## 6. References:

- 1) Reddihough D. Cerebral palsy in childhood. Aust Fam Physician. 2011 Apr;40(4):192-6. PMID: 21597527
  - 2) Badawi, N., McIntyre, S. and Hunt, R.W. (2021), Perinatal care with a view to preventing cerebral palsy. Dev Med Child Neurol, 63: 156-161. <https://doi.org/10.1111/dmcn.14754>
  - 3) Surveillance of Cerebral Palsy in Europe. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE). Dev Med Child Neurol. 2000 Dec;42(12):816-24. doi: 10.1017/s0012162200001511. PMID: 11132255.
  - 4) Smithers-Sheedy H, Badawi N, Blair E, Cans C, Himmelmann K, Krägeloh-Mann I, McIntyre S, Slee J, Uldall P, Watson L, Wilson M. What constitutes cerebral palsy in the twenty-first century? Dev Med Child Neurol. 2014 Apr;56(4):323-8. doi: 10.1111/dmcn.12262. Epub 2013 Sep 20. PMID: 24111874.
  - 5) Neonatal neuroimaging classification system. <https://eu-rd-platform.jrc.ec.europa.eu/sites/default/files/SCPE%20Scientific%20report%201998-2018.pdf>
  - 6) Himmelmann et al (2016) MRI classification system (MRICS) for children with cerebral palsy: development, reliability, and recommendations Dev Med Ch Neurol 2016, 59 (1) 57-64
- National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015). The National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee. Commonwealth of Australia, Canberra.  
[www.nhmrc.gov.au/guidelines/publications/e72](http://www.nhmrc.gov.au/guidelines/publications/e72)
- Operating Principles and Technical Standards for Australian Clinical Quality Registries. Nov 2008 Australian Commission on Safety and Quality in Health Care.  
<http://www.safetyandquality.gov.au/our-work/information-strategy/clinical-quality-registries/>

## Appendix A: Te Kotahi Institute Review of Māori Data Sovereignty within the GSOPs of the New Zealand Cerebral Palsy Register



Māori DSov - NZ  
Cerebral Palsy Regis

## **Appendix B: NZCPR Term of Reference Agreement with Governance Committee Member**

**The New Zealand Cerebral Palsy Register (NZCPR) Governance Committee**

Te Rēhita a Hōkai Nukurangi Aotearoa

**Expression of Interest (2022)**

*The NZCPR is calling for Expressions of Interest to join the NZCPR Governance Committee.*

*We are particularly seeking people to help provide oversight from the lived experience of Cerebral Palsy in Aotearoa NZ and on Māori Data and Hauora.*

*Please read Terms of Reference below for the position details and contact Alexandra Sorhage, for further details: [nzcprregister@adhb.govt.nz](mailto:nzcprregister@adhb.govt.nz)*

*Ngā mihi nui*

*Prof Susan Stott, Alexandra Sorhage, Dr Anna Mackey*



**The New Zealand Cerebral Palsy Register**

**Te Rēhita a Hōkai Nukurangi Aotearoa**

**NZCPR Governance Committee Terms of Reference (June 2022)**

**The New Zealand Cerebral Palsy Register’s (NZCPR) vision is to be the source of high-quality information to support positive health outcomes for all people in Aotearoa NZ with CP.**

<b>Background</b>	<p>The NZCPR is a confidential database of relevant health information collected with consent from people with cerebral palsy living in Aotearoa NZ. It was established in 2015 and currently operates from the Paediatric Orthopaedic service, Starship Children’s Health, ADHB.</p> <p align="center"><a href="https://starship.org.nz/health-professionals/cerebral-palsy-research/">https://starship.org.nz/health-professionals/cerebral-palsy-research/</a></p> <p>Membership of the NZCPR Governance Group should comprise of individuals who have an interest and commitment to people with lived experience of cerebral palsy in Aotearoa NZ and be in keeping with the vision of the NZCPR. The Committee aspires for diverse representation from multiple health, cultural and community fields.</p>
<b>Membership</b>	<p>The NZCPR Governance Committee Membership aims to include:</p> <ul style="list-style-type: none"> <li>i. Māori stakeholders</li> <li>ii. People with lived experience of CP and / or their whānau.</li> <li>iii. Representatives from relevant health professional groups (Paediatric Society of NZ; NZ Orthopaedic Association; Perinatal Association of NZ; Australasian Faculty of Rehabilitation Medicine (NZ chapter)</li> <li>iv. Representatives from the CP Society of NZ</li> </ul>



## **Appendix C: Contract with Australian CP Register**

### **The Cerebral Palsy Institute (CPI) and NZ CP Register Agreement (NZCPR)**

**&**

### **Working Guidelines 2015**

# Appendix D: Australian Cerebral Palsy Register Report (2018)

ResearchGate

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/323070725>

## Australian Cerebral Palsy Register Report, 2018

Technical Report · December 2018

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**Hayley Smithers-Sheedy**  
Cerebral Palsy Alliance  
70 PUBLICATIONS 1,031 CITATIONS

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Cerebral Palsy Alliance  
94 PUBLICATIONS 4,033 CITATIONS

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The University of Sydney  
30 PUBLICATIONS 2,140 CITATIONS

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Some of the authors of this publication are also working on these related projects:



**Congenital CMV and CP in Australia** [View project](#)



**Adolescents with cerebral palsy in rural Bangladesh: Health-related quality of life, mental health and sexual and reproductive health** [View project](#)

All content following this page was uploaded by [Hayley Smithers-Sheedy](#) on 12 December 2018.

The user has requested enhancement of the downloaded file.





## **Appendix E: Acknowledgement Letter for Self-Registration**

New Zealand Cerebral Palsy Register  
Paediatric Orthopaedics  
Starship Children's Health  
Private Bag 92 024,  
Auckland 1142  
EMAIL: [nzcpregister@adhb.govt.nz](mailto:nzcpregister@adhb.govt.nz)  
[www.starship.org.nz/NZCPregister](http://www.starship.org.nz/NZCPregister)

Parent / caregiver for XXXXX  
Address

Email: (optional)

Date

Dear Parent / Caregiver,

Thank you for taking the time to register your child on the NZ Cerebral Palsy Register.

We can now work with you and your local health professionals to help fill in the information collected for the Register. I have enclosed our latest Participant Information Sheet and the form of the information collected for the Register.

(Optional) If you can let us know a **name of a local health professional** we can make contact with to begin completing the information required.

Thank you very much for your support in helping us have a better understanding of Cerebral Palsy in New Zealand.

Kind Regards

On behalf of The New Zealand Cerebral Palsy Register





# Appendix F: The New Zealand Cerebral Palsy Register (NZCPR) and Health Professional (HP) Member Agreement

## Working Guidelines 2016

### **Background**

The NZCPR is an electronic database of identifiable (NHI) data. The NZCPR is a collaborative partner of the Australian Cerebral Palsy Register (ACPR) and is regarded as an independent contributor of CP data to the ACPR. The NZCPR remains the custodian of all the data contained within its own register. NZCPR de-identified data is shared with ACPR.

The NZCPR administration team are responsible for verifying and validating **all** entries on the register. Once a registration has been approved, the information contained within the entry cannot be modified unless directed by the administrator. The NZCPR encourages any health professional to become a member of the NZCPR by creating a login/ password on the NZCPR website, which will enable the health professional to enter registrations on behalf of their patients if written consent is in place.

The NZCPR administration team is able to allocate a “jurisdiction” rule to a health professional member. This is usually a single clinician within a District Health Board (DHB) catchment area who, in agreement with their colleagues, has taken on the responsibility of overseeing ascertainment (including the consent process) and data entry on behalf of the NZCPR within their DHB.

### **Agreement**

The jurisdiction holder is the custodian for the data held on the NZCPR for their DHB. The jurisdiction holder is accountable to the NZCPR. The jurisdiction holder agrees to:

- Ensure compliance with Health and Disability Ethics Committee and DHB locality requirements pertaining to privacy so that CP data is used responsibly and respectfully and privacy is safeguarded
- Whilst written consent is a requirement, to ensure consent forms are stored securely and made accessible to the NZCPR if required
- Upload the minimum dataset onto the NZCPR as determined by the ACPR
- Advise the NZCPR of any technical/ IT issues arising from inputting data
- To consult with the NZCPR before any reports or data is used for teaching, presentation or publication purposes
- All applications to make use of or access NZCPR data should be directed to the NZCPR Governance Committee
- To keep local health professionals, consumer groups and interested parties informed of NZCPR progress or changes if appropriate

- To contribute to the NZCPR Advisory Board in the form of bi-annual meetings and emails as appropriate/ urgent matters

The NZCPR agrees to:

- Inform jurisdiction members of any NZCPR Governance Committee and ACPR Policy and Research meeting outcomes and provide training/ support for any changes that may arise as a result
- Invite jurisdiction members to participate as a representative on the NZCPR Advisory Board (refer to Appendix ? attached)
- Provide technical assistance and resolve technical issues arising from using the NZCPR website

NZCPR member	Jurisdiction member
	DHB:
Name:	Name:
Signature:	Signature:
Date:	Date:

## Appendix G: Parent Patient Information Sheet (ADHB)

Participant Information Sheet			
Study title:	<b>The New Zealand Cerebral Palsy Register Te Rēhita a Hōkai Nukurangi Aotearoa</b>		
Locality:	New Zealand	Ethics committee ref.:	<b>13/NTA/130</b>
Lead investigator:	Professor Susan Stott	Contact phone number:	09 3074949 Ext 21898

### **What is Te Rēhita a Hōkai Nukurangi Aotearoa or the NZ Cerebral Palsy Register?**

The Register collects information about your child and their hōkai nukurangi or cerebral palsy (CP) as well as information about other people with CP in Aotearoa New Zealand. The information that is collected is confidential to the Register.

### **Why do we need the NZ Cerebral Palsy Register?**

We know that CP is the most common cause of physical disability for children in Aotearoa New Zealand. We currently do not know how many people in Aotearoa New Zealand have CP and how CP affects people's everyday lives. The more people who join the Register, the more information we will have about people with CP in Aotearoa NZ. This information can help to seek further funding as well as guide and improve health services and future treatments for people with CP.

### **What are the aims of the NZ Cerebral Palsy Register?**

The aim of the Register is to collect health information about:

- How many people have CP in Aotearoa New Zealand?
- How CP affects Māori and how are health outcomes for Māori with CP different from other groups?
- What can be changed to improve the future for people with CP and their whānau/families?

### **What are the benefits of the NZ Cerebral Palsy Register?**

The Register is able to combine all the health information on people with CP in Aotearoa NZ, to help health services and disability groups to:

- Understand what living with CP means for different groups (such as Māori or people living in different parts of the country)
- Guide health planning staff, to make sure all people with CP can access the right health services when they are needed
- Promote research about CP so we can learn about what works in preventing and improving health for all people with CP in Aotearoa New Zealand
- Share important information with you and your whānau.

### **Who are the health professionals who run the Register?**

The Register is based at Starship Children's Health, Auckland, led by Professor Susan Stott, Paediatric Orthopaedic Surgeon together with a team of health professionals from each DHB region in Aotearoa New Zealand. The Register team also includes Dr Anna Mackey and Alexandra Sorhage who are both based at Starship Hospital and work part-time for the Register. The Register team works closely with many health professionals from across all parts of the country.

## Appendix H: Researchers Access to NZCPR Data Request Form



### Access to the New Zealand Cerebral Palsy Register Data Request Form

#### Section A: General Summary

Date:

Full Project Title:

	Person/s submitting	Position	Place of work/ contact details
1			
2			
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1. Are you requesting the NZCPR assistance with (tick which is applicable):

Assistance with CP recruitment for research purposes

Specific details of request (Number of participants; GMFCS; Time frame etc):

Access to data/ data linkages for reporting / research purposes

Specific details of request (Number of participants; GMFCS; Time frame etc):

\*Note: A financial fee may be charged for clinical / administrative time for large data recruitment projects and /or preparing data for data linkages.

2. Briefly describe this project (in lay terms) including the potential benefits for people with Cerebral Palsy in NZ: (up to 200 words)

#### Section B: Proposed Research

We require information on the following areas listed below.

Note: You can just attach a PDF copy of your HDEC ethics application.

- *Background / Justification*
- *Aims / Hypotheses*
- *Research Design*
- *Statistical analysis*
- *Endpoints / Analysis / Dissemination*
- *Responsiveness to Maori*
- *Project funding*

Access to NZCPR Request Form\_v2.  
Updated July 2017

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