

# New Zealand Cerebral Palsy (NZCPR) Standard Operating Policies and Guidelines

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## 1.0 Purpose and Aims of the NZ Cerebral Palsy Register

The register is a secure, confidential database of clinical information about all people in New Zealand with Cerebral Palsy (CP). Information will include birth details; clinical information about CP and how it affects physical functioning. The NZ CP Register (NZCPR) has been set up in collaboration with the Australian CP Register. Every three years the NZCPR will contribute de-identified details to the Australian CP Register for reporting purposes.

CP is the most common cause of physical disability in childhood. There is no known cure and the rates of CP have remained unchanged despite recent advances in medicine. Most CP occurs as a result of factors prior to birth, for 80% of people with CP the cause is poorly understood. Understanding the causal pathways to CP is important as it provides scope for new opportunities for prevention of CP and for reducing the severity of motor impairments. CP Register data can also be used for the evaluation of new interventions and determining health service requirements for people living with CP.

If everyone in NZ with CP contributes data, we will be able to: Know how many people have CP in NZ and how this affects them; Begin to improve health and education planning in NZ for people with CP; Promote research that can assess intervention and prevention strategies; Allow us to compare our practice across geographical regions in New Zealand and internationally.

### Specific vision and aims:

Vision: To enhance the quality of life for people in NZ with CP

Aims:

- i. To improve our understanding of CP (Prevalence; Impact of condition at all levels)
- ii. To evaluate our clinical practice (Surveillance; Preventative; Service Quality and Planning)
- iii. To identify and address any potential disparities
- iv. To facilitate research

## 2.0 The NZ Cerebral Palsy Register (NZCPR) Governance Terms of Reference

### 2.1 Governance Committee:

#### 2.1.1 Purpose

- Provide strategic direction and oversight over all Registry's activities, including that of the management committee
- Provide scheduled review of the aims of the NZCPR
- Evaluate the progress of the NZCPR in meeting these aims
- Establish policies to address issues of clinical interest or significance that may arise.
- Facilitate policy support for issues identified by the Advisory Committee
- Provide advice on the NZCPR management, organisation, scope, development and funding
- Monitor the NZCPR's data quality management processes and reporting
- Develop and monitor policies for access to data and responses to quality of care issues
- Review and advise on output and reports published from the NZCPR team
- Provide advice on the collection and interpretation of data

- Review all applications for research and data requests for identified or identifiable data
- Review publications arising from the NZCPR data
- Review and advise on communication strategy, including communication with consumers

### 2.1.2 Structure

- The Governance Committee should meet more than once annually and have provision for the calling of extra ordinary meetings as required in order to review applications to access the NZCPR dataset and urgent issues as advised by the administration team
- Membership should comprise of relevant individuals interested in the management of people with cerebral palsy in NZ, ensuring a diversified representation from multiple health and community fields. Membership should include:
  - i. Representations from relevant health societies (Paediatric Society of NZ; NZ Orthopaedic Association; Perinatal Association of NZ; Australasian Faculty of Rehabilitation Medicine (NZ chapter)
  - ii. Representations from consumer groups - CP Society of NZ; Individual with CP; Parent and Family member of individuals with CP
  - iii. Maori Health representation
  - iv. Representation from the funding body
  - v. Senior staff from the Management Committee
- The Chair of the Steering Committee should typically be a senior and distinguished and independent clinician researcher
- The term of appointment for members who are not register staff is 2-4 years and the term limit for membership is 10 years.
- The presence of 50% of Governance committee members is required at a meeting to form a quorum
- 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

The Governance Committee will:

- Provide guidance on NZCPR matters including not limited to those raised by the NZCPR and Advisory Group
- Support and advocate for the work of the NZCPR
- Pre-read meeting documents as required
- Assist the Chair, on an ad-hoc basis, between meetings if required
- 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
- Disclose conflicts of interest in their duties as a member of the Governance Committee

### 2.1.4 Resignations, Termination

- 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 Cerebral Palsy Alliance 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 Group (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
- Membership should comprise of
  - i. Two clinical specialists (currently an NZROT research officer and NZRPT physiotherapy practitioner)
  - ii. Representation from Australian CP Register and/or website administrator
  - iii. Administration support, as required

## 2.3 Advisory Group

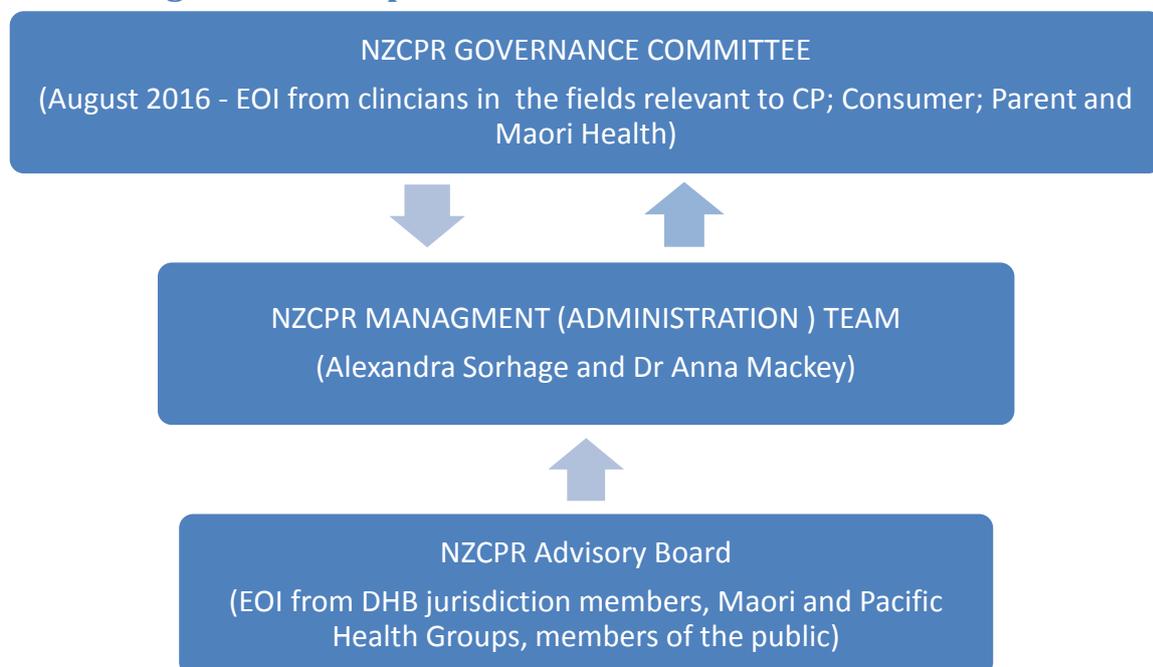
### 2.3.1 Purpose

- 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
- Membership
  1. All NZCPR jurisdiction members are invited to be represented on the advisory group
  2. Representation from Pacific and Maori Health Support Groups
  3. Members of the public (parent of a child with CP or person with CP)

## 2.4 Diagrammatic depiction of NZCPR Governance structure



## 3.0 Australian CP Register (ACPR) relationship

- A Cerebral Palsy Alliance Research Institute and NZCPR working guidelines agreement (2015) provides a framework for the registry partnership (See Appendix A). This is due to be updated in 2019/2020 and the NZCPR will submit this new or any future agreement along with the yearly HDEC Progress Report. (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 and it is regarded as an independent contributor of CP data to the Australian CP register
- The ACPR and NZCPR share common aims for using the data of the register (monitoring CP; effective intervention; casual pathways and prevention)

- The NZCPR collect data on an independent website using the ACPR platform. The ACPR custodian is an administrator of the NZCPR and is able to access the data in the event of the management team not being available
- The NZCPR will contribute de-identified data to the ACPR on a three yearly basis for reporting purposes

## 4.0 NZ Cerebral Palsy Register Operational guidelines

### 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 records about people with the formal description of cerebral palsy. People entered onto the register will be excluded from the register if their diagnosis changes from the diagnosis of cerebral palsy.
- 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. Reference: Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Dev Med Child Neurol* 2000; 42: 816-24
- The (free to access) publication by the ACPR members (2014) details the precise NZCPR inclusion and exclusion criteria: *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
- Note: People entered into the Register when < 5 years of age will be contacted at 5yrs by the NZCPR staff to confirm diagnosis and information on the Register

### 4.2 Membership

- The NZCPR has a range of ‘membership’ options on the NZCPR website (Individual with CP; Parent of person with CP; Health Professional). This is to facilitate inputting data and communication between individuals and the NZCPR.
- Membership is completed online and NZCPR administration team verifies all individuals before membership is approved.

#### 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 his or her own data. By doing this it is assumed that consent to opt-in has been given.
- 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

#### 4.2.2 Health professional membership

- Any Health Professional (HP) can apply to become a member of the NZCPR by creating a secure username and password. This will enable the HP to enter data on behalf of their patient with CP, once they have been fully informed on the NZCPR
- The NZCPR admin team are alerted, by email, of a new HP membership request and verify professional and personal details by contacting the manager/ team leader given in the

online membership application. Once the HP details have been verified, the NZCPR administration change the HP membership from “public user” to “health professional”, enabling data input following the ascertainment guidelines

- 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. (See Appendix B for Jurisdiction agreement)

### 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 1 month 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.

#### 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 one month's 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
- The "date discussed" field on the notification card must be completed by the HP
- After 1 month, if no contact has been made by the parent/person, the NZCPR administration team will proceed with completing the datasets for the registrant
- At any time, if an opt-out form is received, the existing record can be silenced

#### 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
- In accordance with the opt-out process, once a parent or person with CP has been informed about the NZCPR, if after a one month no contact has been made by the parent/person, the NZCPR administration team will proceed with completing the datasets for the registrant.

#### 4.3.5 Ascertainment via Linking Databases

- No data linkages can be made to obtain any NZCPR related data. Linkages to any existing databases for purposes of NZCPR ascertainment will require separate and additional NZ HDEC review and approval (post approval form amendment)
- Any research driven requests for the NZCPR data linkage require separate NZ HDEC approval and review by the NZCPR Governance Committee
- For NZCPR ascertainment purposes: to minimise the risk of informing patients who have died, moved residence or do not have cerebral palsy as a final diagnosis, it is imperative that the NZCPR be able to access the patients demographic information and latest clinic letter via the electronic health record (refer to NMDS feasibility study Appendix E). The NZCPR does not retain any information pertaining to this "check". The purpose of the "check" is to minimize the risk of contacting i)a family of a deceased person ii)a person who has CP but who is not eligible for NZCPR registration as they do not reside in NZ iii) a person does not have a diagnosis of CP even if this may have been considered at some point and therefore

captured by the NMDS. If the person with CP identified from the NMDS is eligible for NZCPR membership, they will be informed of the register via post; inclusive of the PIS, information flyer and cover letter. This will be considered as the first step in starting the opt-out process and will be completed as described under section 4.3.1

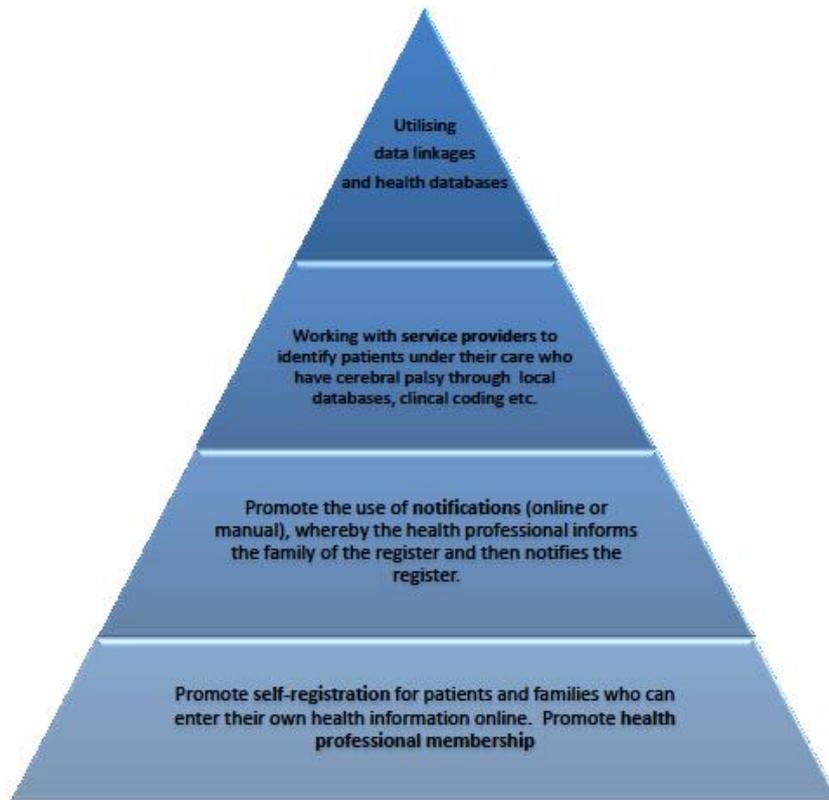


Figure 1: NZCPR methods for ascertainment preferences

#### 4.4 Data Entry

- The NZCPR administration team are responsible for checking and verifying **all** of the information for each case entered onto the register
- 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

#### 4.4.1 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 on Concerto to ensure that the child is still living

#### 4.4.2 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

### 4.5 Data Collected

- The core data set of health information collected for the NZ CP Register is in line with the core data set requirements for the Australian CP Register, to enable contribution of de-identified data every three years.
- In addition NZ specific information is to be collected including NHI; NZ ethnicity data; District Health Board location; ACC details. See Appendix C

### 4.6 Data Management

- For the on-going maintenance of the New Zealand Cerebral Palsy Register (NZCPR) data we have a protocol to review if any participants who we are informing about the NZCPR or already on the NZCPR have died. This information ensures we avoid sending information out to bereaved families. In addition it allows for improved accuracy on our future reporting of prevalence of cerebral palsy in New Zealand.
- One-off retrospective review of existing NZCPR participants: Ministry of Health business analyst to review our NZCPR participant NHI list with the Ministry of Health NHI dataset and inform us if any deaths and date of death have been registered from our participant list
- Prospective maintenance: Quarterly review from ADHB information analysts to compare our NHI participant list with newly registered deaths data. Note: the DHB is informed twice monthly by the Ministry of Health of any new deaths registered.
- Cause of death ICD codes: This information can be obtained from the Mortality database. This retrospective information becomes available on a yearly basis from the Ministry of Health. The NZCPR would inform the Mortality database of the registered deaths on our

NZCPR and receive details on ICD codes cause of death and whether a post mortem was completed.

- Date of death, coding for primary and secondary cause of death and whether or not a most mortem was carried out is recorded on the register. Data will be retained and used for reporting purposes. Extra care (through thorough cleaning of data) is taken to ensure the individual or family will not be contacted by the register e.g. invitations to participate in research projects.

#### 4.7 Data Usage

- The Working agreement between the NZCPR and DHB jurisdiction holders stipulates that the NZCPR Governance Committee reviews individual requests from DHB to teaching, presentation or publication purposes
- All applications to make use of or access NZCPR data for research purposes should be directed to the NZCPR Governance Committee (Appendix F)
  - i. 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
  - ii. All applications will have to complete the ADHB locality approval process through the ADHB Research Office. Link to the application forms are made available on the website and on the NZCPR application forms. 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
  - iii. Data access and reporting policies for the register should be made available to persons wishing to use register data
  - iv. Application forms will be 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
  - v. Applicants will be advised in writing as to the outcome of the application and procedures on accessing the register
- 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.
- Every effort will be made to make reports and research publications (that have used the NZCPR data) available to view on the NZCPR website

#### 4.8 Data Security

- Data is held on a secured website (via the Australian CP Register), with the server hosted in a security vault. Identifiable data is held behind 2 firewalls separated by an electronic demilitarised zone. All electronic transactions follow e-security transmission protocols; with access to data and functionality restricted via passwords. Any identifiable data stored in NZ will be on a secure, password protected District Health Board server.

- Regular audit of data security will be completed by ADHB IT services
- Cloud Risk Assessment Tool and Privacy Impact Assessment documents completed and submitted October 2017 (this supersedes previous exemption certificate). CRAT and PIA approved by the Manager for Health Informatics (ADHB) and Chief Information Security Officer (Health Alliance). No further assessment or on-going review is required unless there are changes to the cloud hosting provider (Appendix D).

#### 4.8.1 Use & Disclosure

- Data released from the NZCPR will be in **de-identified** format for:
  - Australian CP Register for reporting every three years
  - NZCPR produced publications or annual 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
  - Researchers to inform (consented) participants of studies - Contact details only given

## 5.0 References:

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: Contract with Australian CP Register**

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

**&**

### **Working Guidelines 2015**

# **Appendix B: 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

| <b>NZCPR member</b> | <b>Jurisdiction member</b> |
|---------------------|----------------------------|
|                     | DHB:                       |
| Name:               | Name:                      |
| Signature:          | Signature:                 |
| Date:               | Date:                      |

## Appendix C: Data Collection Form



NZCPR\_dataset  
form\_12Sept2018.pdf

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## Appendix D: Cloud Risk Assessment Tool (completed and approved)



Copy of  
Cloud-Risk-Assessme



Privacy Impact  
Assessment and Fran

## Appendix E: NMDS feasibility study summary



Summary\_APRIL201  
8\_NMDS\_.pdf

## Appendix F: NZCPR Research Policy



Guidelines\_NZCPR  
Access for ResearcheData



Access to NZCPR  
Request Form\_\