Te Rēhita a Hōkai Nukurangi Aotearoa Rīpoata 2022

The New Zealand Cerebral Palsy Register Report 2022

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 Henare
>
> *Whakataukī gifted to the NZCPR from Hon. Peeni Henare (2021)* (Ngāti Hine; Ngāpuhi) Member of NZ Parliament for Tāmaki Makaurau.

Forward

Amy Hogan, Researcher and Member Support Advisor, Cerebral Palsy Society of New Zealand

The New Zealand Cerebral Palsy Register is a vital clinical and community resource. Accurate and comprehensive population data provides the foundation for meaningful intervention, engagement, and advocacy. Cerebral palsy is a complex condition involving many different elements. A register provides an effective way to measure these elements and target change such as recent work overseas, lowering the rates of premature labour, and maternal infection. The New Zealand register brings our CP work in line with international standards and strengthens both community outreach and meaningful clinical practice. A sustained register benefits individuals with CP, their whānau, their advocacy community, and clinicians. Incorporating the Te Reo Māori term and its translation, '*Hōkai Nukurangi*: to achieve what is important to you' embodies what the register is working to create. Through developing an understanding of who we are, who the community is, and what we need both now and in the future.

Professor Sue Stott, Chair of New Zealand Cerebral Palsy Cerebral Palsy Register (NZCPR)

The concept for a NZ CP Register started 10 years ago, when we first heard about the progress gained from international CP Registers; from Australia, with information on timing and causal pathways of CP ; and from Europe, evidence on population hip surveillance resulting in reduction in hip dislocations for children with CP. Initial barriers on how to clearly define and classify CP in medical terminology had also been overcome with increasing use and understanding in NZ of tools such as the Gross Motor Functional Classification System. The Starship Foundation was pivotal in providing start-up funding in 2015 and this allowed the establishment of a Register that now has over 1400 individuals on it. Since then, the Paediatric Society of NZ CP Clinical Network has been established and we have developed closer ties with the CP community. We are also grateful for the support we have had from people and families with CP in NZ. The value of the NZ Register will continue to increase over time as more people with CP participate. We are now working with the CP Society of NZ to ensure that data collected are meaningful to individuals with CP and that information is obtained that can be readily used by health and disability services to advocate for equity and meaningful change. The NZ CP Register look forward to continuing the on-going relationship with both Paediatric Society of NZ CP Clinical Network and CP Society of NZ and working with other stakeholders to advocate for people with CP living in NZ.

Executive Summary

Overview

1,416

Individuals with CP on the NZCPR living in NZ

77% of participants are in the paediatric age range (birth period 2001 – 2016)

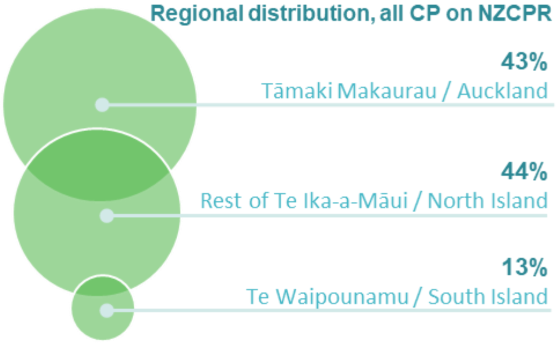
14% of individuals on the NZCPR were born overseas

13% have ACC Coverage for their CP

The NZCPR represents over half (55%) of the estimated CP population (5-21 years age group) for Aotearoa NZ

Demographics

Regional distribution, all CP on NZCPR

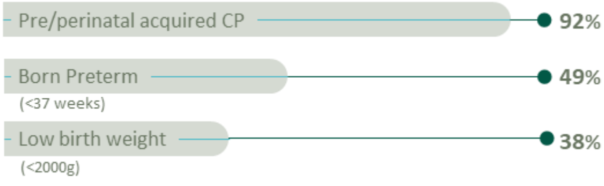


Prioritised ethnicity on NZCPR

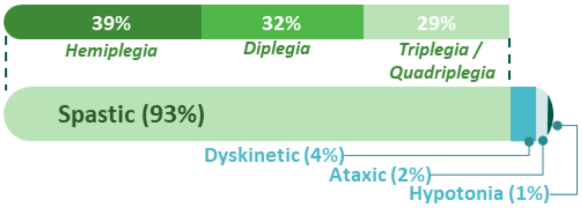
46% Of the CP population are living in the most deprived geographical regions in NZ,* with a greater representation for Māori individuals compared to non-Māori

**Based on the NZ Deprivation Index*

Clinical Descriptions



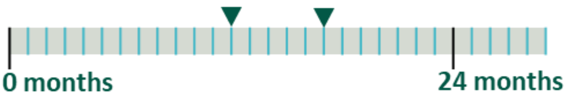
Motor Types

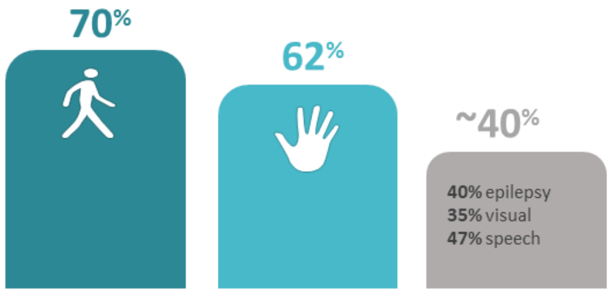


Time of first CP Description for pre/perinatal acquired CP

39% receive a CP diagnosis by 12 months

median age of CP diagnosis 17 months





40% epilepsy
35% visual
47% speech

70% use walking as the main form of mobility (GMFCS I - III)

62% have difficulty using their hands in everyday tasks (MACS II -V)

~40% of people with CP have an associated condition

Future

The NZCPR aims:

- to increase engagement of all people living with CP
- to inform stakeholders on health indicators for CP
- to advocate for equity in health outcomes.

Ngā Mihi Nui -Thank you

All regions in NZ are represented in the NZCPR and we grateful for the support from all local health regions across NZ

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Contact Details

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Home: https://starship.org.nz/health-professionals/cerebral-palsy-research/
Registration: https://nz.cpregister.com/

Abbreviations

ACC	Accident Compensation Corporation
ACPR	Australian Cerebral Palsy Register
AoNZ	Aotearoa New Zealand
CP	Cerebral Palsy
CFCS	Communication Functional Classification System
EDACS	Eating and Drinking Classification System
GMFCS	Gross Motor Functional Classification System
LB	Live Births
MACS	Manual Ability Classification System
MRI	Magnetic Resonance Imaging
NZCPR	New Zealand Cerebral Palsy Register

Hōkai Nukurangi – Cerebral Palsy

The New Zealand Cerebral Palsy Register
Te Rēhita a Hōkai Nukurangi Aotearoa

Hōkai Nukurangi

New strength-based Te Reo term for 'Cerebral Palsy'

Hōkai Nukurangi – to achieve what is important to you

Whether traversing (hōkai) the earth (nuku) in body or traversing the sky (rangi) in mind and spirit, a person adapts to different environments, utilising the means and abilities that are appropriate to them.

...One of the exercises I was given in my training within te ao Māori was to observe birds and how they adapted in different environments. Flying in different wind currents, at different heights in the sky, a seagull walking in sand, the kākāriki on the forest floor, the pūkeko in the swamp and many others.

The kaupapa was simple. Observe the natural adaptation of the birds to the environment and, with time and patience, hopefully learn to be as adaptable as the birds are. This is the essence of 'Hōkai Nukurangi'.

In my discussions with Māori / Non-Māori people and whānau with cerebral palsy, this was the most prominent, consistent, important theme, that each individual and each individual whānau had different wants, needs and goals that they desired out of a good, happy life. This new term expresses that concept.

Term kindly Developed by **Keri Opai**

The New Zealand Cerebral Palsy Register

Cerebral palsy (CP) is a term used to describe a physical condition that affects muscle control and movements across the body. It is the most common physical disability in childhood and a lifelong permanent condition. Cerebral palsy is caused by an insult to the brain in early development.

The NZ Cerebral Palsy Register: Te Rēhita a Hōkai Nukurangi Aotearoa is working to better understand the impacts of CP for people in Aotearoa NZ.
Scan QR for the website: https://nz.cpregister.com/
Email: nzcpregister@adhb.govt.nz

Background

The New Zealand Cerebral Palsy Register (NZCPR) was established in 2015 and is a coordinated data collection system (confidential database) of relevant health information for all people with Cerebral Palsy (CP) in Aotearoa New Zealand (Aotearoa NZ). The NZCPR operates with National Ethical approval (HDEC 13/NTA/130) (and additional Locality District Health Board approvals) and is based at Starship Child Health, Te Toka Tumai, Auckland, New Zealand. The NZCPR is affiliated to the Australian Cerebral Palsy Register, with collection of a similar minimum dataset [1, 2]. People with CP in Aotearoa NZ live valued and fulfilling lives and the vision of the NZCPR is to be the source of 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 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 whānau / families

The NZCPR is committed to Te Tiriti o Waitangi / Treaty of Waitangi and ensuring the following principles guide our actions and activities:

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

The NZCPR, as the kaitiaki or protectors of the health information, respect the privacy and dignity of each individual. We acknowledge that the data summary presented in the report is a high-level descriptive view of CP in Aotearoa NZ and does not reflect the impact of CP on an individual and their whānau / families in day-to-day life.

This report will describe the number, demographic, and clinical details of people with CP currently on the NZCPR. We acknowledge that:

- The paediatric population (Birth Period 2001-2016) has been the priority population for ascertainment for the initial period of operation of the NZCPR. Note: The report will also provide an overview of data for both the older and younger age groups.

- The NZCPR is currently unable to report birth prevalence as it is still under ascertained. We calculate prevalence currently to identify what proportion of children in NZ are on the register, to guide us with ascertainment strategies.

Potential Value of NZCPR

Health Registers have been shown to improve health outcomes internationally through population-based reporting, with the ability to monitor key markers over time, facilitate the development of standardized care pathways, and enable implementation of preventative strategies for earlier detection of secondary health issues [3-5]. As the NZCPR continues to build greater participation, it will have potential to inform on key outcomes of interest, including equity and health services. We value the ongoing guidance from people with lived experience of CP and in particular the Cerebral Palsy Society of New Zealand to help us achieve this.

The NZCPR can used the combined power of collated health information on people with CP in Aotearoa NZ:

- To help stakeholders to advocate and understand what living with CP means for different groups
- To guide health planning and ensure all people with CP can access the right health services when they are needed
- To learn about what works in preventing and improving health for all people with CP in Aotearoa NZ
- To share important information to people with CP and their whānau / families
- To promote research about CP

About Cerebral Palsy

CP is a lifelong condition. It is described as the most common cause of childhood physical disability in high income countries, occurring due to a non-progressive disturbance (injury / insult) in the developing foetal or infant brain [6, 7]. This injury results in a disorder in the development of movement and posture that can cause activity limitation. Multiple and varied neurologic events in early life can lead to the clinical picture defined as CP. While the neurologic injury or insult is static, the developmental consequences are profound for the person and their whānau / families, with potential for secondary impairments across multiple body systems across the lifespan.

The rates of CP encouragingly now show a decline in many high income countries (from 2.1 to 1.6 peryu 1000 live births)[8] potentially impacted by improved clinical care in the pre / perinatal period. Population based CP Registers are the best mechanism to measure birth prevalence, accurately track trends and determine health service requirements [9, 10].

Description of Cerebral Palsy

For the majority of people with CP, a pathway of events that leads to the brain disturbance occurs predominantly in the Pre or Perinatal period, (in utero or up to the first 28 days of life[1]). In this report it is described as Pre / Perinatal acquired CP.

A brain disturbance that occurs after 28 days of age until 2 years of age, is known as post-neonatal (PNN) acquired CP. The timing of the cause / causes of CP can also be unknown.

Identification on the potential timing of a cause of CP is often further informed by findings from a cranial MRI. Cranial MRI information is not available for this current NZCPR report. Prior to 2021, the NZCPR did not classify the cranial MRI reports for individuals. Since 2021, the NZCPR has begun using a standardized MRI Classification System, in keeping with Australian and European CP Registers[11]. Future NZCPR reports will be able to provide more in-depth details on this outcome.

Terminology

CP can be described in medical terminology by the parts of the body affected, the type of movement disorder and the functional abilities of the individual and examples of each have been used in this report, with explanations described below.

Movement	Type	Definition	General Descriptions
Spastic / Spasticity		Increased muscle tightness or stiffness and associated weakness	
	Monoplegia / Hemiplegia	Affecting one limb or one side of the body (arm, trunk, leg)	Unilateral Cerebral Palsy
	Diplegia	Predominantly affecting lower limbs	Bilateral Cerebral Palsy
	Triplegia / Quadriplegia	Affecting three or all four limbs	
Dyskinetic	Dystonia	Sustained or intermittent muscle contractions causing twisting or repetitive movement	
	Athetosis	Uncontrolled, slow, “stormy”, writhing movements	
Ataxic		Shaky movements, affects a person’s balance and coordination	

From the Australian CP Alliance website: https://cerebralpalsy.org.au/about-conditions/cerebral-palsy/#1534292840469-5ffb8d03-90d3

Functional Ability

The Gross Motor Functional Classification System (GMFCS) is frequently referred to in medical terminology to classify an individuals’ functional abilities [12]. The classification is from Level I to Level V, with GMFCS I / II indicating independent walking mobility, GMFCS III use of a walking device, GMFCS IV / V wheeled mobility used. Similar classification systems for Manual Ability (MACS), Communication (CFCS) and Eating and Drinking (EDACS) are also included in the report [13-15].

Methodology

NZCPR Operation Process

The NZCPR has an informed consent with opt out, participation process, with NZ Health and Disability Ethics Committee approval (HDEC 13/NTA/130). The NZCPR collects a similar minimum dataset to the Australian Cerebral Palsy Register. The NZCPR dataset includes information on Demographics, Birth History and Clinical information relevant to CP.

There are multiple methods for participation on the NZCPR, including self-registration and being informed via relevant health service providers, further details are available in the NZCPR Operating Policy document (https://nz.cpregister.com/Public/AboutUs). The NZCPR confirms CP diagnosis via a clinical note review at age 5 years. Individuals can join the Register at any age.

Definition of cerebral palsy

The NZCPR working definition for CP inclusion on the Register states that cerebral palsy:

- is an umbrella term for a group of disorders which are permanent but not unchanging,
- impacts movement, posture, or motor function
- is due to a non-progressive injury to the developing brain

Reference: Smithers-Sheedy et al, (2014) *[7]* and Surveillance of CP in Europe group[16]

Data extraction and linkage

For this report NZCPR data was first extracted in November 2021. De-identified data linkage for NZ Social Deprivation information (NZDep13)* and Prioritized Ethnicity for this cohort was obtained from NZ Ministry of Health (16/11/2021) (https://www.health.govt.nz/nz-health-statistics/data-references/code-tables/common-code-tables/ethnicity-code-tables Last accessed July 2022) . Cleaning of the dataset and completion of relevant data fields was completed by 1st May 2022, when the final data extraction was done for the descriptive analysis for the report.

*Social Deprivation

The NZ Deprivation Index (NZDep 13) is an area-based measure of socioeconomic deprivation in New Zealand [17] . It measures the level of deprivation for people in each small geographical area. It is based on nine Census variables. It is calculated as Decile 1 to 10 and converted to 5 Quintiles. Quintile 1 represents the least deprived geographical areas to Quintile 5 the most deprived areas. The National Health Index for each individual on the NZCPR was sent to the Ministry of Health (NZ) to obtain a de- identified (anonymous) NZDep Index quintile. The impact of the social determinants of health on long term health outcomes are known for other health conditions and included in this report to further describe the impact of CP for individuals and whānau / families.

Denominator data

The average number of live births over the 2001-2016 birth period is: 59,675. This data was obtained from Stats Infoshare NZ site (https://infoshare.stats.govt.nz/ Last accessed May 2022). Additional live birth data with birth weight and gestational categories was obtained via Ministry of Health (NZ).

Analysis

The NZCPR is currently unable to report birth prevalence as it is still under ascertained (see Figure 1). We can calculate prevalence to identify what proportion of children in NZ are on the register, to guide us with ascertainment strategies. The prevalence calculation is determined using the number of confirmed cases of CP for a birth period on the NZCPR and the number of live births for matching stated birth period.

Descriptive analysis has been completed using (n) and percentage (%) as stated by each Table and Figure. For key outcomes, descriptive analysis has been included for the total relevant population and by priority ethnicity groupings, Māori, and non-Māori.

Chapter 1: Participation on the NZCPR

This chapter includes information on the current number of people participating (or ascertained) on the NZCPR (Figure 1). Table 1 shows the preliminary rates of CP by the number of live births, for those born in Aotearoa NZ during birth period 1995 -2016. This information has been calculated to help track our ascertainment progress and is not a report on prevalence of CP in Aotearoa NZ.

Figure 1. Ascertainment of the NZCPR over first seven years

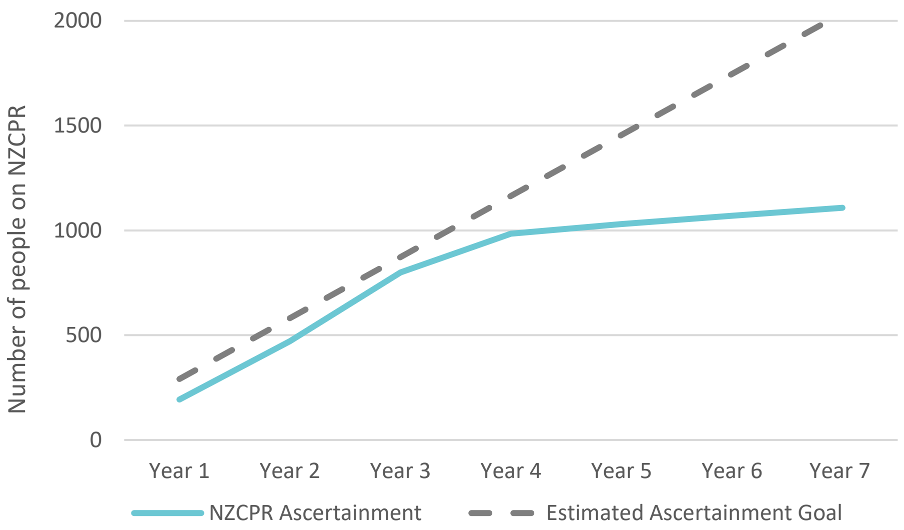


Figure 1. shows NZCPR participation for the 5 – 21 year old age group (paediatric population). The grey dashed line of estimated ascertainment represents an expected population, based on a CP prevalence of 2 per 1000 live births. From this assumption, the NZCPR currently has participation from 55% of the estimated CP paediatric population. Year 1 to 4 represents large retrospective ascertainment of children onto the NZCPR, with Year 5 to 7 representing a shift towards prospective ascertainment of new CP onto the NZCPR.

An estimated total CP population in Aotearoa NZ can be determined using a CP prevalence rate (2 per 1000 live births, LB) and an average NZ live birth rate of 60 000 per year. This information indicates potentially up to 120 new people with CP each year, with a total population of people with CP in Aotearoa NZ of approximately 10 000.

Table 1. Number (n) of people with CP on NZCPR per Live Births (LB) for birth period 1995-2016

	1995-96	1997-98	1999-00	2001-02	2003-04	2005-06	2007-08	2009-10	2011-12	2013-14	2015-16
Number of Live Births (LB) in NZ	114,954	112,953	113,655	109,821	114,210	116,937	128,385	126,438	122,583	115,962	120,468
(n) Pre / Perinatal acquired CP on NZCPR	25	40	57	77	102	103	145	130	108	113	67
Pre & Perinatal acquired CP per 1000 LB	**0.22**	**0.35**	**0.50**	**0.70**	**0.89**	**0.88**	**1.13**	**1.03**	**0.88**	**0.97**	**0.56**
(n) Post-neonatal acquired CP on NZCPR	<5	<5	<5	9	7	9	14	20	12	9	<5
Post-neonatal acquired CP per 10, 000 LB	**0.2**	**0.1**	**0.4**	**0.8**	**0.6**	**0.8**	**1.1**	**1.6**	**1.0**	**0.8**	**0.2**
All CP on NZCPR per 1000 LB	**0.2**	**0.4**	**0.5**	**0.8**	**1.0**	**1.0**	**1.2**	**1.2**	**1.0**	**1.1**	**0.6**

Includes all people with CP currently on the NZCPR in birth period 1995-2016.
Excludes all individuals born outside of New Zealand

Number of children with CP on NZCPR (Birth Period 2001-2016)

Table 2. Number (n) of children with CP on NZCPR per Live Births for birth period 2001-2016 by ethnicity groups

	Live Births 2001-16	Pre & Perinatal acquired CP	Post Neonatal acquired CP	Total CP	All CP / 1000 Live Births
	n	*n*	*n*	*n*	*n*
Māori	271,617	235	42	277	1.02
Non-Māori	683,187	610	40	650	0.95
All	954,804	845	82	927	0.97

Excludes all individuals born outside of New Zealand

Figure 2. Comparison of current NZCPR rates of children with CP per live births (LB) for birth period 2001-2016 to the Australian CP Register outcomes (2020 Report)

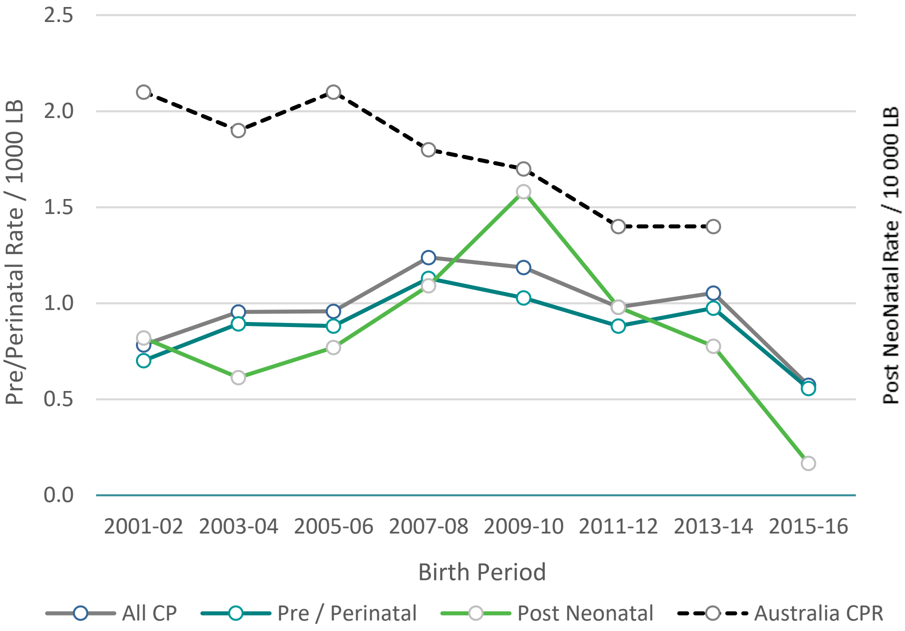


Figure 2. includes CP population prevalence data (Black dashed line) from the Australian Cerebral Palsy Register (Australian CPR) 2020 report, for reference purposes[2]. The information on the rate of CP per live births for Aotearoa NZ is lower due to the incomplete CP population ascertainment currently for the NZCPR.

Chapter 2: Summary of All CP on NZCPR (All Birth Years)

Overview

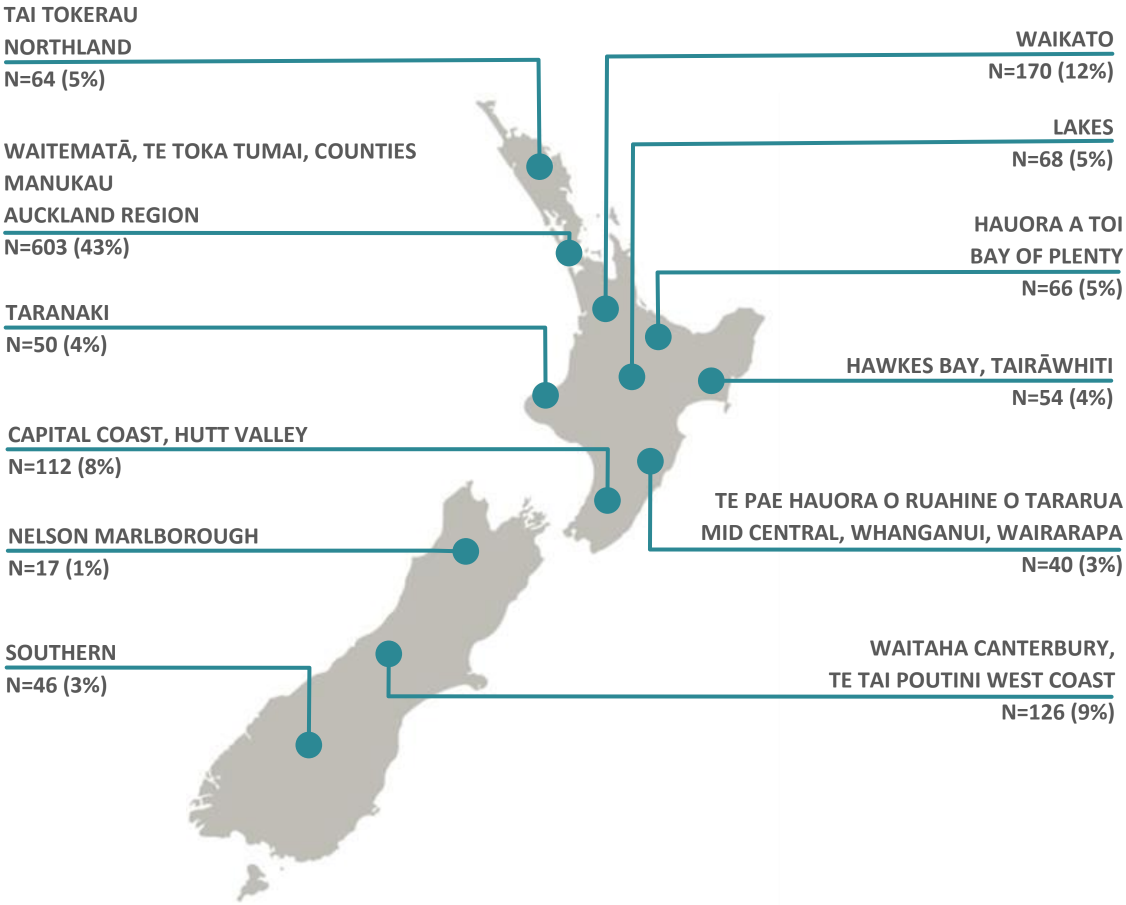
There are 1416 participants with CP on the NZCPR from birth years 1945 to 2021, currently living in Aotearoa NZ. A total of 77% were born in birth period 2001-2016; 18% were born 2000-1945; 5% born after 2016. A summary for all the CP population on NZCPR is shown below.

Gender Distribution (%)

Note: Indeterminate gender ≤1 %

Regional Distribution

Figure 3. Regional Distribution across Aotearoa NZ of all CP on the NZCPR



Socioeconomic Deprivation Distribution (NZDep13) all CP on NZCPR

The NZDep13 is an area-based measure of socioeconomic deprivation in New Zealand[17]. It measures the level of deprivation for people in each small geographical area. It is based on nine Census variables. It is calculated as Decile 1 to 10 and converted to 5 Quintiles. **Quintile 1 represents the least deprived geographical areas to Quintile 5 the most deprived areas.**

Figure 4. Current domicile Quintiles distribution for All CP on NZCPR

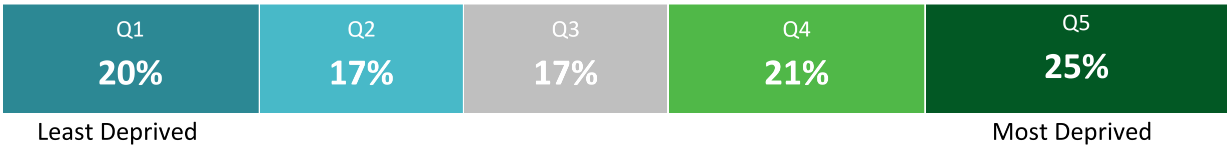
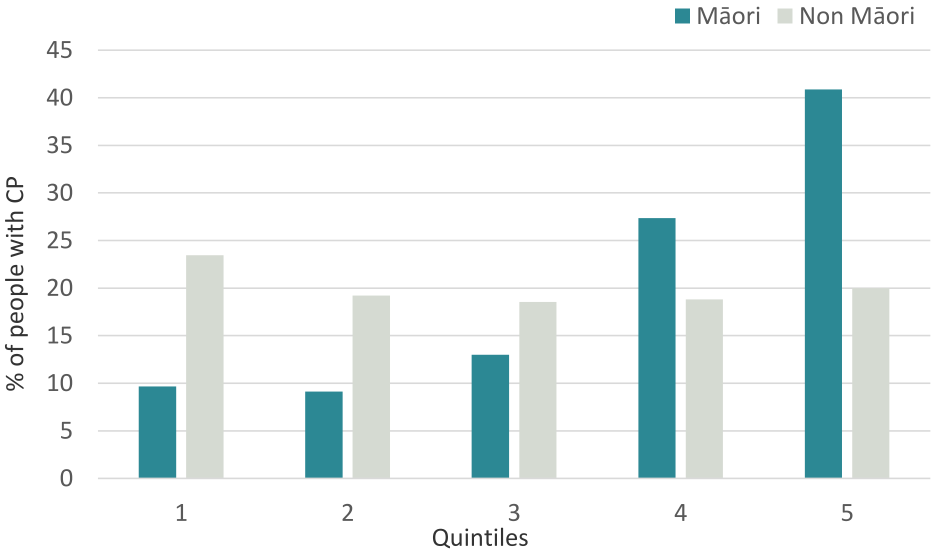


Figure 5. Percentage (%) of people with CP on NZCPR living in each domicile Quintile by Ethnicity groups



Ethnicity

Table 3. Prioritised Ethnicity Distribution of all people with CP currently on NZCPR

Description	*n* (%)	Description	*n* (%)
NZ European	633 (45)	African	15 (≤ 1)
NZ Māori	362 (26)	Middle Eastern	14 (≤ 1)
Indian	68 (5)	Fijian	11 (≤ 1)
Other European	66 (5)	European - not further defined	10 (≤ 1)
Samoan	61 (4)	Niuean	8 (≤ 1)
Chinese	32 (2)	Latin American / Hispanic	7 (≤ 1)
Tongan	29 (2)	Other Pacific Island	≤ 5 (≤ 1)
Cook Islands Māori	25 (2)	Asian not further defined	≤ 5 (≤ 1)
Other Asian	25 (2)	Tokelauan	≤ 5 (≤ 1)
Southeast Asian	17 (≤ 1)		
Total (Excluding Unknown)		1395	
Unknown		*21*	

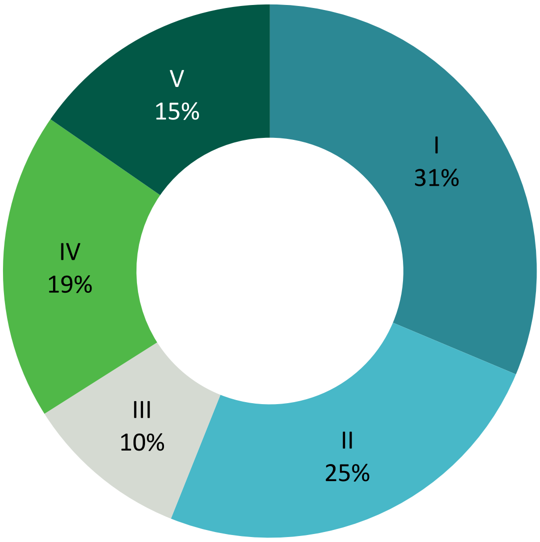
Reference: Level 2 Ministry of Health Ethnicity Description

https://www.health.govt.nz/nz-health-statistics/data-references/code-tables/common-code-tables/ethnicity-code-tables

Functional Ability of all people with CP currently on NZCPR

Gross Motor Classification System (GMFCS) is used to represent functional ability for all people with CP on the NZCPR. Level I, II are equivalent to independent mobility without a walking aid; Level III, walking with a walking aid and Level IV, V represents individuals using predominantly wheeled mobility.

Figure 6. GMFCS Distribution (%) for all people with CP on NZCPR



Chapter 3: Paediatric Pre / Perinatal acquired CP on NZCPR (Birth period 2001-2016)

Overview

At the time of reporting there were a total n=1088 paediatric cases of CP on the NZCPR, of which n = 953 (92%) have an identified pre / perinatal acquired CP; n = 88 (8%) are post-neonatal acquired. N = 47 missing or unknown time of cause. Note: Information from individuals who are now deceased are excluded from this analysis and discussed further in Chapter 9.

Pre / Perinatal Acquired CP

For the Pre / Perinatal acquired CP (n = 953), a total of n= 832 were born in Aotearoa NZ and data is used from this group for all Birth and Diagnosis related descriptions. The complete cohort of (n=953) is used for all clinical descriptions.

Gender

MALE 58% **FEMALE 42%**

Note: Indeterminate gender <1 %

Timing of CP description

The median age of first CP Description is 17 months.

Table 4. Number (n) and Percentage (%) of children with CP on NZCPR by timing of initial CP description and ethnicity groups (Birth Period 2001-2016)

	Age							Total	*Unknown*
	0-6 months	7-12 months	13-24 months	25-36 months	37-48 months	49-60 months	Age 5<	Excluding Unknown	
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n*	*n*
Māori	23 (13)	46 (27)	56 (32)	30 (17)	8 (5)	≤ 5 (2)	6 (3)	173	58
Non-Māori	51 (11)	134 (28)	158 (33)	62 (13)	29 (6)	20 (4)	25 (5)	479	122
All	74 (11)	180 (28)	214 (33)	92 (14)	37 (6)	24 (4)	31 (5)	652	180

Figure 7. Pie chart of percentage (%) distribution of Timing of first CP Description

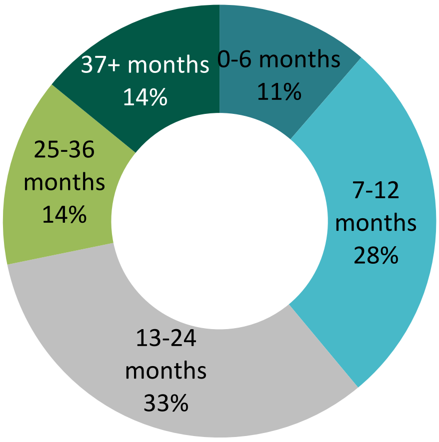


Table 5. Number (n) and Percentage (%) of children with CP on NZCPR by timing of initial CP description across Birth Years 2001-2016

Birth Years	0-6 months	7-12 months	13-24 months	25-36 months	37+ months	Total Excluding Unknown
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n*
2001-02	7 (15)	15 (32)	11 (23)	2 (4)	12 (26)	47
2003-04	7 (10)	18 (26)	24 (35)	10 (14)	10 (14)	69
2005-06	8 (11)	23 (33)	17 (24)	9 (13)	13 (19)	70
2007-08	10 (9)	31 (28)	41 (37)	14 (13)	14 (13)	110
2009-10	14 (14)	22 (21)	38 (37)	15 (15)	14 (14)	103
2011-12	6 (6)	22 (23)	36 (38)	18 (19)	12 (13)	94
2013-14	10 (10)	34 (34)	28 (28)	14 (14)	14 (14)	100
2015-16	9 (16)	15 (27)	19 (34)	10 (18)	3 (5)	56

Figure 8. Proportion (%) of children with CP by Time of first CP Description categories over Birth Period 2001-2016

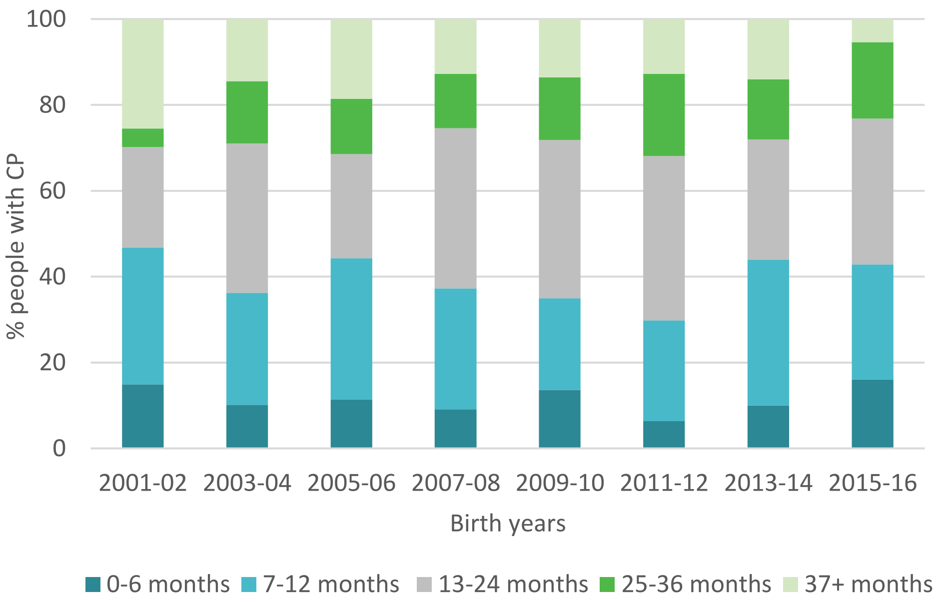


Figure 8 indicates a consistent pattern in the timing of first CP description over time, with approximately 40% receiving a CP description in first 12 months and 75% of infants by 24 months of age.

Gestational age (GA) at delivery

Table 6. Number (n) and Percentage (%) of children with CP on NZCPR by gestational age group (weeks) and ethnicity groups (Birth years 2001-2016)

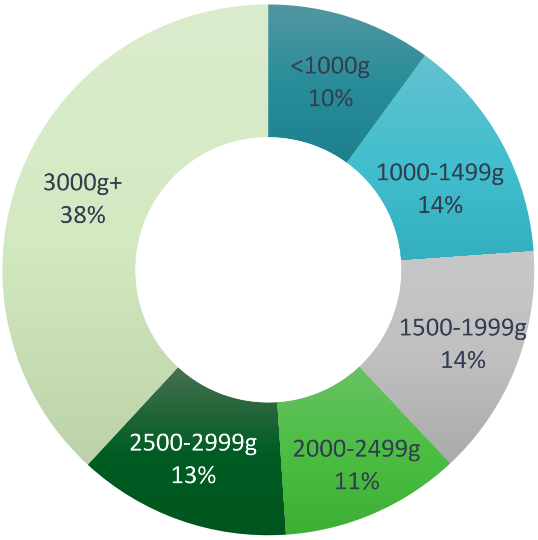
	Gestational Age (weeks)					
	20-27	28-31	32-36	≥37	Total	*Unknown*
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n*	*n*
Māori	24 (12)	26 (13)	34 (17)	122 (59)	206	29
Non-Māori	67 (12)	101 (18)	125 (22)	278 (49)	571	39
All	91 (12)	127 (16)	159 (20)	400 (51)	777	68

Birth weight

Table 7. Number and Percentage (%) of children with CP on NZCPR by birth weight in grams (g) and ethnicity groups (Birth years 2001 -2016)

	Birth Weight (grams)								Total Excluding Unknown	*Unknown*
	<1000g	1000-1499g	1500-1999g	2000-2499g	2500-2999g	3000-3499g	3500-3999g	4000+g		
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n*	*n*
Māori	20 (11)	20 (11)	26 (15)	15 (9)	24 (14)	37 (21)	21 (12)	11 (6)	174	*61*
Non-Māori	46 (9)	71 (15)	67 (14)	57 (12)	61 (13)	108 (22)	48 (10)	28 (6)	486	*124*
All	66 (10)	91 (14)	93 (14)	72 (11)	85 (13)	145(22)	69 (10)	39 (6)	660	*185*

Figure 9. Pie chart percentage (%) of children with CP on NZCPR by birth weight in grams (g), 2001-2016



Plurality

Table 8. Number (n) and Percentage (%) of children with CP on NZCPR by plurality (Birth Years 2001-2016)

Singletons	**Twins**	**Higher multiples**	**Total** Excluding Unknown	***Unknown***
***n* (%)**	***n* (%)**	***n* (%)**	**n**	**n**
601 (84)	80 (12)	10 (1)	691	*154*

Congenital anomalies

Data on congenital anomalies was available for approximately half of the Pre / Perinatal acquired CP cohort (n=465), with 65% having no congenital anomaly reported and 35% having at least one congenital anomaly. The most common anomalies were Cardiovascular (12%) and Brain (12%) anomalies.

Figure 10. Type of Congenital Anomalies for pre / perinatal acquired CP on NZCPR (Birth Years 2001-2016) in percentage (%)

Miscellaneous includes 2% of Urogenital, Other, Musculoskeletal, 1% of Gastrointestinal, Respiratory, Nervous System, Dysmorphic and Metabolic anomalies.

Motor type and topography

Table 9. Number (n) and Percentage (%) of children with CP on NZCPR by predominant motor type at age 5 years (Birth Years 2001-2016)

	Movement Type							**Total** Excluding Unknown	***Unknown***
	Spastic								
	All spastic	***Hemiplegia/ Monoplegia***	***Diplegia***	***Triplegia/ Quadriplegia***	**Ataxic**	**Dyskinetic**	**Hypotonia**		
	***n* (%)**	*n (%)*	*n (%)*	*n (%)*	***n* (%)**	***n* (%)**	***n* (%)**	***n***	***n***
Māori	204 (90)	*91 (45)*	*51 (25)*	*62 (30)*	3 (1)	16 (7)	4 (2)	227	9
Non-Māori	629 (94)	*234 (37)*	*212 (34)*	*183 (29)*	15 (2)	22 (3)	6 (1)	672	43
All	834 (93)	*325 (39)*	*264 (32)*	*245 (29)*	18 (2)	38 (4)	10 (1)	900	*53*

Note: Ethnicity unknown for n=1

Figure 11. Bar graph Percentage (%) of children with CP on NZCPR by motor type and gestational age groups (37+ weeks and <37 weeks)

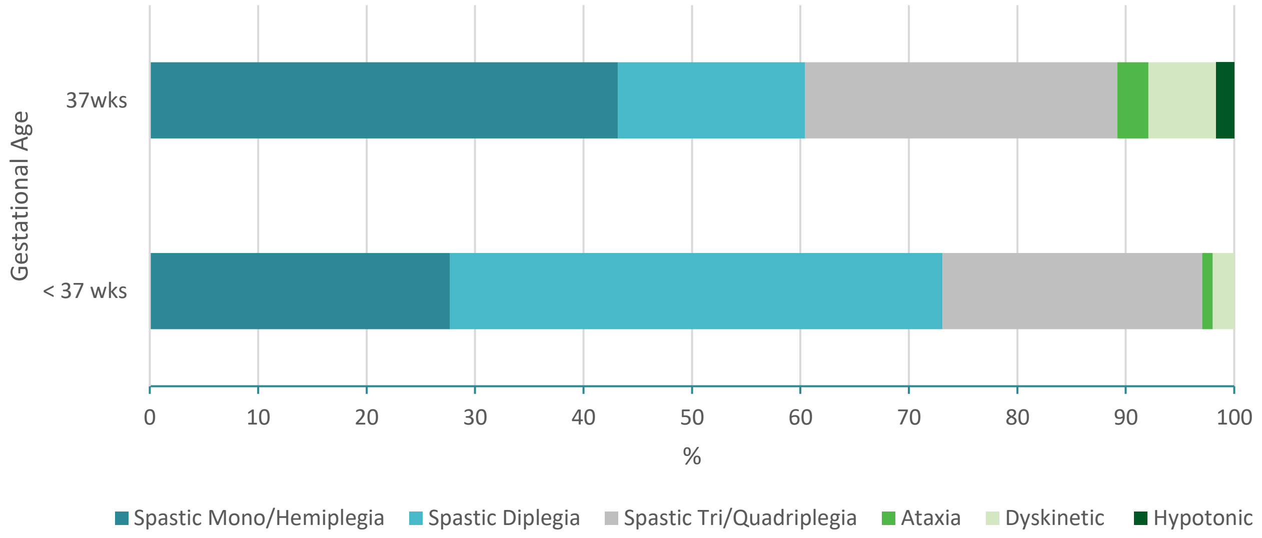
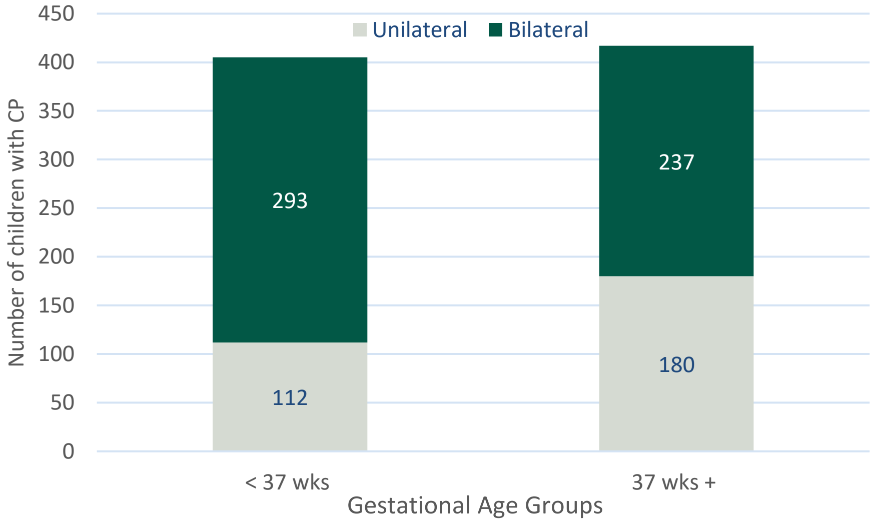


Figure 12. Stacked bar graph of number of children with CP on NZCPR by unilateral or bilateral motor type and gestational age group (37+ weeks and <37 weeks)



Gross Motor Functional Classification System (GMFCS)

Table 10. Number (n) and Percentage (%) of children with CP on NZCPR by GMFCS and ethnicity groups

	GMFCS			Total Excluding Unknown	Unknown
	I-II	III	IV-V		
	n (%)	*n* (%)	*n* (%)	*n*	*n*
Māori	135 (59)	16 (7)	79 (34)	230	6
Non-Māori	426 (62)	72 (10)	194 (28)	692	23
All	563 (60)	88 (10)	273 (30)	924	29

Figure 13. Pie Chart percentage (%) distribution of children with CP on NZCPR by GMFCS

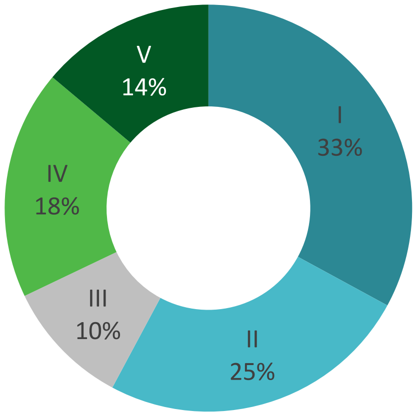
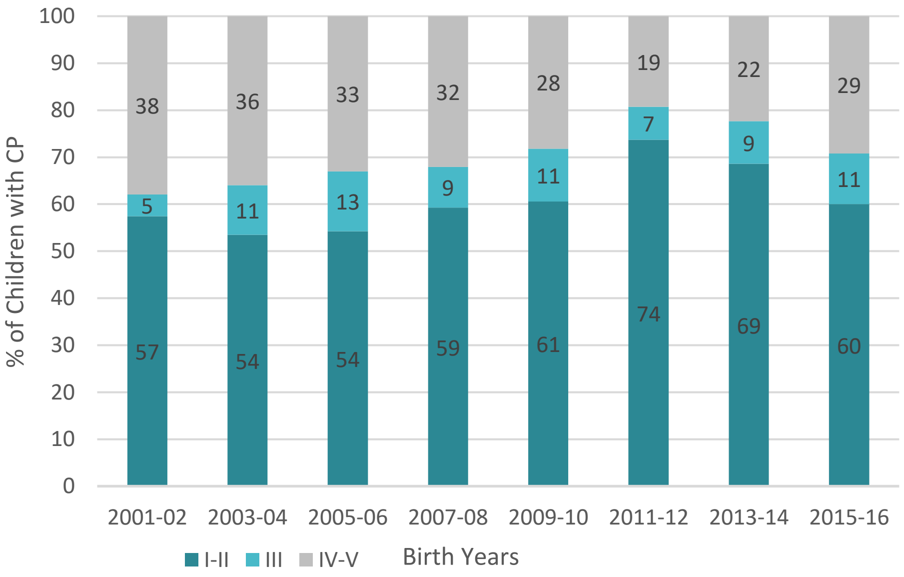


Figure 14. Stacked bar graph of percentage (%) of children with CP on NZCPR by GMFCS groups for birth years 2001-2016



Associated Conditions

Table 11. Number (n) and Percentage (%) of children with CP on NZCPR with associated conditions

	No Impairment	Some Impairment	Significant impairment
	n (%)	*n (%)*	*n (%)*
Vision	391 (55)	261 (36)	65 (9)
Hearing	606 (87)	66 (9)	28 (4)
Speech	347 (53)	166 (25)	145 (22)
Intellect	337 (47)	170 (24)	206 (29)
	No Epilepsy	**Resolved by Age 5**	**Epilepsy**
	n **(%)**	***n*** **(%)**	***n*** **(%)**
Epilepsy	476 (59)	50 (6)	277 (34)

Vision: Some = Wears glasses; Significant = Functionally blind.
Hearing: Some = Conductive Hearing Loss; Significant = Bilateral deafness.
Speech: Significant = Non-Verbal; Intellect: Significant = Moderate to Severe
Note: Intellect information is obtained from medical record documentation and not necessarily from formal testing

Additional CP Functional Classifications: MACS, CFCS, EDACS

Additional standardized CP Classifications include Manual Ability Classification System (MACS); Communication Functional Classification System (CFCS); Eating and Drinking Classification System (EDACS).

Table 12. Number (n) and Percentage (%) of children with CP on NZCPR using CP Functional Classifications

Level	MACS	CFCS	EDACS
	n **(%)**	***n*** **(%)**	***n*** **(%)**
I	185 (38)	244 (65)	95 (54)
II	175 (36)	39 (10)	5 (3)
III	40 (8)	28 (7)	7 (4)
IV	51 (10)	46 (12)	10 (6)
V	35 (7)	21 (5)	59 (34)

Manual Ability Classification System (MACS); Communication Functional Classification System (CFCS); Eating and Drinking Classification System (EDACS). Level I is representative of minimal impairment to Level V representative of more significant impairment, for each classification.

Chapter 4: Paediatric Post-neonatal acquired CP (Birth period: 2001-2016)

Overview

There are 88 participants on the NZCPR with a post-neonatal (PNN) acquired cause of CP in the birth period 2001-2016

Gender Distribution Post-neonatal acquired CP

Ethnicity PNN

Table 13. Number (n) and percentage (%) of prioritised Ethnicity distribution for post-neonatal acquired CP on NZCPR

Ethnicity	*n* (%)
NZ Māori	40 (45)
NZ European	27 (31)
Samoan	6 (7)
Other Euro	≤5 (2)
Cook Islands Māori	≤5 (≤1)
Tongan	≤5 (≤1)
South East Asia	≤5 (≤1)
Chinese	≤5 (≤1)
Indian	≤5 (≤1)
Other Asian	≤5 (≤1)
Middle Eastern	≤5 (≤1)
African	≤5 (≤1)

Causes of PNN acquired CP

Table 14. Number (n) and Percentage (%) of children with CP on the NZCPR by cause of post-neonatal acquired CP and ethnicity groups.

Post-neonatal causes of CP	Māori	Non-Māori	All
	n (%)	*n (%)*	*n (%)*
Infection (Viral / Bacterial/ Unspecified)	12 (30)	14 (30)	26 (30)
CVA associated	7 (18)	12 (26)	19 (22)
Head Injury - Non-Accidental / Abusive Head Trauma	12 (30)	≤5 (11)	17 (20)
Near SIDS	≤5 (8)	≤5 (11)	8 (9)
Apparent Life-Threatening event	≤5 (≤5)	≤5 (9)	6 (7)
Post seizure	≤5 (≤5)	≤5 (9)	6 (7)
Other not specified	≤5 (≤5)	0 (0)	≤5 (≤5)
Head Injury - Fall	0 (0)	≤5 (≤5)	≤5 (≤5)

CVA = Cardiovascular Accident; SIDS = Sudden Infant Death Syndrome

Motor Type and Functional Ability of PNN acquired CP

Figure 15. Percentage (%) of post-neonatal acquired CP on NZCPR by predominant Motor Type

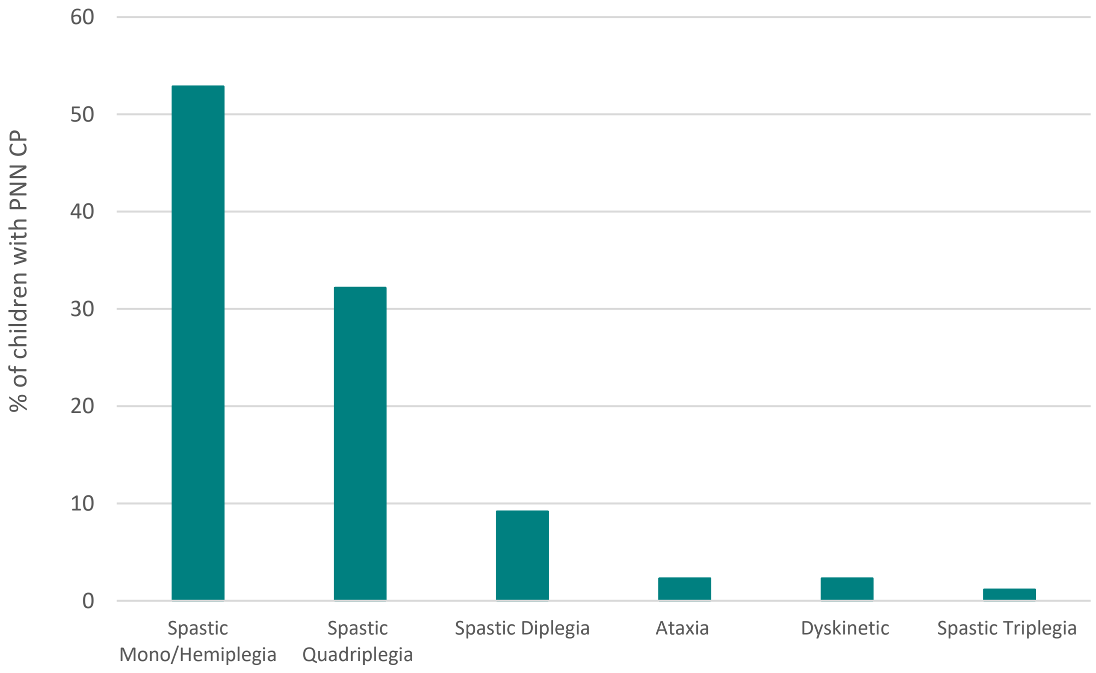


Table 15. Number (n) and percentage (%) of children with PNN acquired CP on NZCPR by Gross Motor Functional ability (GMFCS) and ethnicity groups.

GMFCS	Māori	Non-Māori	All
	n (%)	*n* (%)	*n* (%)
I	11 (28)	11 (23)	22 (25)
II	7 (18)	21 (44)	28 (32)
III	≤5 (10)	≤5 (6)	7 (8)
IV	8 (21)	7 (15)	15 (17)
V	9 (23)	6 (13)	15 (17)

Associated Conditions for PNN acquired CP on NZCPR

Table 16. Number (n) and Percentage (%) of children with PNN Acquired CP on NZCPR with associated conditions

	No Impairment	Some Impairment	Significant Impairment
	n (%)	*n* (%)	*n* (%)
Vision	32 (40)	23 (29)	25 (31)
Hearing	55 (81)	7 (10)	6 (9)
Speech	25 (34)	23 (31)	26 (35)
Intellect	11 (14)	25 (32)	43 (54)
	No Epilepsy	**Resolved by Age 5**	**Epilepsy**
	n (%)	*n* (%)	*n* (%)
Epilepsy	28 (32)	13 (15)	47 (53)

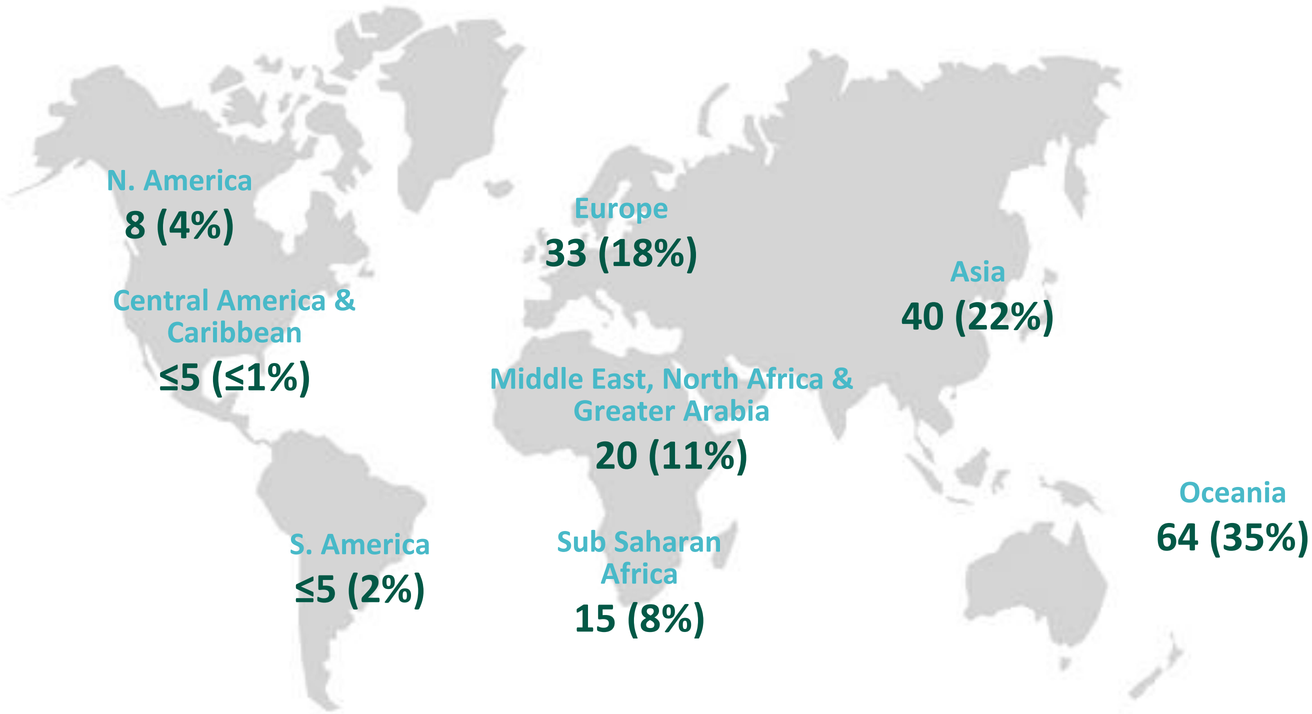
Vision: Some = Wears glasses; Significant = Functionally blind
Hearing: Some = Conductive Hearing Loss; Significant = Bilateral deafness
Speech: Significant = Non-Verbal; Intellect: Significant = Moderate to Severe
Note: Intellect information is interpreted from medical records and not from formal testing

Chapter 5: Children with CP on NZCPR born overseas

Overview

There are n = 195 people with CP currently living in Aotearoa NZ who were born overseas, a total of 14% of NZCPR cohort. *This includes all CP Types, All Birth years.*

Figure 16. Distribution of birth location for individuals on NZCPR born overseas



Total *n*=184, unknown *n*=11

Chapter 6: Adults with CP on NZCPR

The NZCPR has information from 256 adults with CP (those born before 2001), combining both the pre / perinatal acquired CP (95%, n=224) and post-neonatal acquired CP (5%, n=11) datasets. The birth year range is from 2000 to 1945. Information from 12 individuals who are now deceased are excluded from data analysis below.

Gender distribution for adults with CP on NZCPR

MALE 48% **FEMALE 50%**

Note: indeterminate gender <5 (<1%)

Table 17. Number (n) and percentage (%) of prioritised Ethnicity distribution for adults with CP on NZCPR

Ethnicity	*n* (%)
NZ European	123 (53)
NZ Māori	53 (23)
Samoan	16 (7)
Indian	14 (6)
Cook Island Māori	10 (4)
Other European	8 (3)
Tongan	6 (3)
Other Asian	≤5 (≤1)
Chinese	≤5 (≤1)
Middle Eastern	≤5 (≤1)
African	≤5 (≤1)
European - not further defined	≤5 (≤1)
Niuean	≤5 (≤1)
Tokelauan	≤5 (≤1)
Fijian	≤5 (≤1)
Other Pacific Island	≤5 (≤1)
Southeast Asian	≤5 (≤1)
Latin American / Hispanic	≤5 (≤1)

Figure 17. Bar graph of percentage (%) of Adults with CP on NZCPR by predominant Motor Type

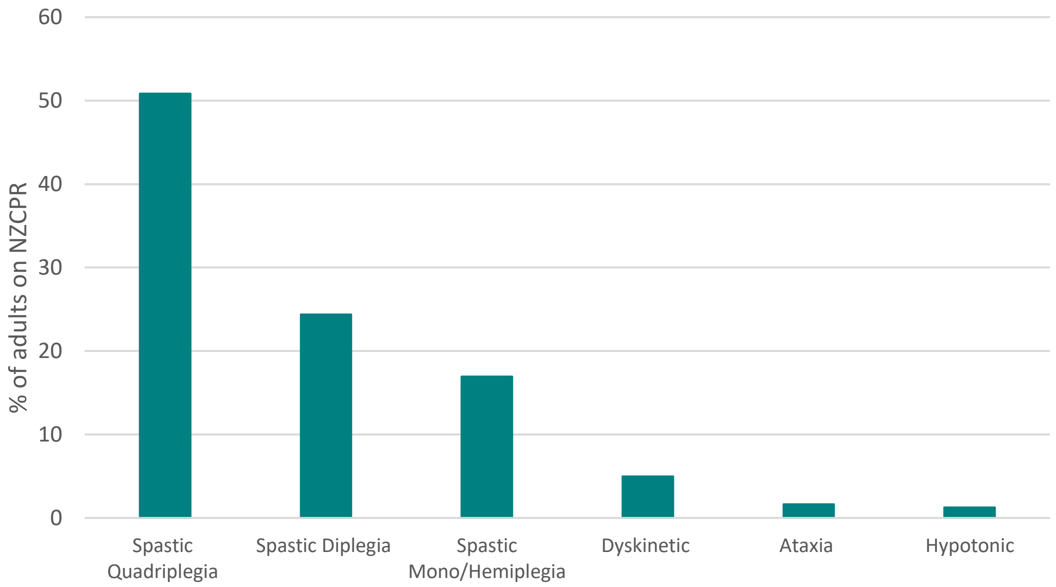
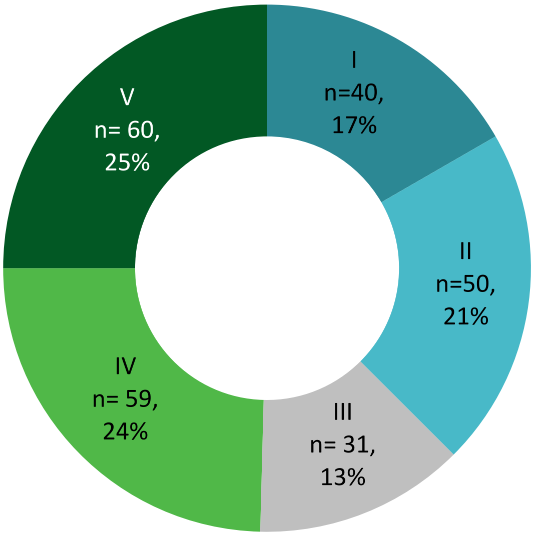


Figure 19. Number (n) and Percentage (%) of Functional Ability (GMFCS) distribution for Adults with CP on NZCPR



Percentage values excluding unknowns (n=16).

Chapter 7: Under 5 years of age

Overview:

- There are currently 72 individuals on the NZCPR from birth period 2017-2022.
- Gender distribution: n= 41 Male; n=31 Female. There are n=61 identified as due to a pre / perinatal acquired CP, with n=3 as post-neonatal acquired CP and the remaining (n= 8) unknown, at this stage.
- Prioritised ethnicity distribution is 43% NZ European and 32% NZ Māori, with representations of ≤ 10% for Chinese and ≤ 5% for Other European, Tongan, Latin American, Indian, Samoan, Tokelauan and Fijian ethnicities.
- Functional ability, as classified by the GMFCS is known for n=56 individuals, with 61% GMFCS I/II; 11% GMFCS III and 29% GMFCS IV/V.

Chapter 8: Accident Compensation Corporation (ACC)

In Aotearoa NZ there is a no-fault coverage scheme for accidental injury, known as Accident Compensation Corporation (ACC) (https://www.acc.co.nz/ Last Accessed July 2022). Some people with CP have ACC coverage due to the cause of their CP. Tables 20-23 details the ACC coverage status for people with CP on the NZCPR at time of reporting.

Table 18. Number (n) and percentage (%) of people with CP on NZCPR by ACC coverage status and ethnicity groups

People with CP	ACC Coverage Status			Total Excluding Unknowns
	No	Yes	Under Review	
	n (%)	*n* (%)	(%)	*n*
All	765 (86)	115 (13)	(1)	887
Māori	211 (83)	39 (15)	(2)	254
Non-Māori	552 (88)	75 (12)	(<1)	630

Includes pre/perinatal and post-neonatal acquired CP; those individuals still alive and born in Aotearoa NZ.

Table 19. Number (n) and percentage (%) of people with pre / perinatal acquired CP on NZCPR by ACC coverage status and ethnicity groups

Pre / Perinatal acquired CP	ACC Coverage Status			Total Excluding Unknowns
	No	Yes	Under Review	
	n (%)	*n* (%)	(%)	*n*
All	579 (90)	62 (10)	(<1)	644
Māori	157 (89)	17 (10)	(1)	176
Non-Māori	422 (90)	45 (10)	(<1)	468

Table 20. Number and percentage (%) of people with post-neonatal acquired CP by ACC coverage status and ethnicity groups

Post-neonatal acquired CP	ACC Coverage Status			Total Excluding Unknowns
	No	Yes	Under Review	
	n (%)	*n* (%)	*n*	*n*
All	43 (54)	36 (46)	0	79
Māori	22 (55)	18 (45)	0	40
Non-Māori	21 (54)	18 (46)	0	39

Table 23: Gross Motor Functional Classification System (GMFCS) distribution for all people on NZCPR by ACC Coverage for CP

ACC Coverage	**GMFCS**					**Total Excluding Unknowns**	**Unknowns**
	I	**II**	**III**	**IV**	**V**		
	***n* (%)**	***n* (%)**	***n* (%)**	***n* (%)**	***n* (%)**	***n***	***n***
Yes	16 (15)	17 (15)	18 (16)	28 (25)	31 (28)	115	5
No	251 (35)	177 (24)	70 (10)	127 (17)	101 (14)	726	47

Table 23 indicates that individuals with ACC coverage for their CP have greater Gross Motor functional severity, with 53% of people with ACC coverage using wheeled mobility (GMFCS IV/V) compared to 31% GMFCS IV/V for people without ACC coverage for their CP.

Chapter 9: Individuals who are now deceased

Overview

- There are 32 individuals who had been registered on the NZCPR who are now deceased (17 Male; 15 Female).
- Prioritised ethnicity identification for this group includes 11% NZ European, 11% NZ Māori and ≤ 5% for Samoan; South-East Asian; European not further defined; Cook Island Māori, Tongan and Fijian ethnicities.
- Functional ability, as classified by the GMFCS was known for 24 of these individuals, with GMFCS I-II n=1; GMFCS III n=0; GMFCS IV-V n=23.
- Age at time of death was between 3 to 77 years, with a median of 16 years of age. The cause of death was not available currently for these individuals.

Chapter 10: Future Recommendations

Overview

The NZCPR aims to be guided in its future data collection and reporting priorities by its key stakeholders, which include people with lived experience of CP, Māori, and relevant health professionals. The NZCPR has begun to establish better connections with these stakeholders, including:

- In 2021, the NZCPR signed a Memorandum of Understanding with the Cerebral Palsy Society of NZ, to work together to achieve the advocacy goals of people with lived experience of CP in Aotearoa NZ.
- The NZCPR completed a Māori Data Sovereignty audit through Te Kotahi Research Institute, University of Waikato in 2021 and will be working to address key recommendations from this audit. These included increasing Māori governance roles within the NZCPR; collection of Māori participant's iwi affiliations and continuation of relationship building with Māori health providers, iwi and stakeholders with the NZCPR.
- The NZCPR is a member of the Paediatric Society of NZ Cerebral Palsy Clinical Network Governance Committee, which aims to use NZCPR data to better monitor outcomes of interest over time for the CP population in Aotearoa NZ.
- The NZCPR has an updated Operation Policy (See: https://nz.cpregister.com) which includes NZCPR visions and goals for next 5 years.

Data Recommendations

The NZCPR continues to work towards increasing participation of all people with CP in Aotearoa NZ, to better understand CP population prevalence and to monitor health outcomes over time. Current data priorities for the NZCPR include:

- Ensuring ascertainment of Māori and other priority populations to allow ongoing equity review
- Classifying cranial MRI using the MRI Classification System, to better inform on the timing of cause of CP
- Consideration for future ethical approval for data linkage to the NZ Birth Defects Dataset to address limitations in congenital anomalies data, as currently information not easily available in medical records.
- Promotion to health professionals to increase use and documentation in medical records of standardized terminology relating to CP, including GMFCS, MACS, CFCS and EDACS. This information allows better understanding of the CP population and enables easier use for advocacy by people with lived experience of CP

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