



The New Zealand
CEREBRAL PALSY
REGISTER.



The New Zealand Cerebral Palsy Registry

Report for Wellington Region
September 2021



Prof Sue Stott, Dr Anna Mackey and Alexandra Sorhage

New Zealand Cerebral Palsy Registry

Starship Child Health

September 2021

nzcpregister@adhb.govt.nz

Executive Summary

- There are 129 participants of all ages on the NZCPR from the wider Wellington region (CCDHB, HVDHB, Wairarapa DHB)
- This data report details **outcomes for the 0–21 year old population**
- 69% (n= 89) are ≤ 21 years, with a median age of 11 years
- 56% identify as NZ European; 20% as Māori
- 7 individuals (8%) are known to be under ACC coverage for CP

Birth history

- 57% born at term; 26% born very preterm (< 31 weeks)
- 58% born >2500g; 22% born < 1500g (very low birth weight)

Clinical

- 92% have a pre / perinatal cause for cerebral palsy
- 46% were given a CP diagnosis in the first 12 months of life
- CP motor type is Spastic Diplegia (31%); Hemiplegia (30%) and Quadriplegia (27%)
- 58% have independent mobility and function (GMFCS Level I and II)
- 29% have greater functional dependence (GMFCS IV and V)
- 65% have moderate to high level hand function (MACS Level I and II)

Comorbidities

- 26 individuals have or have had epilepsy (38%)
- 24 individuals have a Visual impairment
- 5 individuals have a Hearing impairment
- 18 individuals have a Speech impairment

How does this Wellington region data compare to other CP population datasets?

- We can use the [Australian Cerebral Palsy Registry](#) report for comparison:
Australian CP Registry data shows: 43% were born preterm (< 37 weeks); 50% of children receive a CP diagnosis in first 12 months; 40% have Spastic Hemiplegia/ Monoplegia, followed by Diplegia (36%) & Quadriplegia (24%); 62% function at GMFCS I and II; 12% GMFCS III and 26% GMFCS IV and V; 71% no epilepsy; 66% no visual impairment; 89% no hearing impairment; 63% no speech impairment.
- **This information shows that the Wellington Region dataset is comparable for key measures to an international population CP Registry dataset.**



Table of Contents

EXECUTIVE SUMMARY	1
DEMOGRAPHICS	3
Ethnicity Distribution	3
BIRTH INFORMATION	4
Gestational Age	4
Birth weight	4
Neonatal Intensive Care Unit (NICU) / Special Care Baby Unit (SCBU)	5
CLINICAL FINDINGS FOR WELLINGTON REGION COHORT (0-21 YEARS)	6
Timing of CP Cause	6
Time (Age) of First CP Description	6
Time of First CP Description varied by GMFCS	7
CP Type	7
Gross Motor Functional Classification System (GMFCS)	8
Manual Ability Classification (MACS)	9
Co Morbidities	10
Epilepsy	10
Visual Impairment	10
Hearing Impairment	10
Speech impairment	10
Note on Co morbidity Data Quality:	10
Additional information	11
Adult Population Summary for Wellington Region	11
Mortality	11
References and Links	12
Glossary	12
NZCPR MAIN DATASET FIELDS	13

Demographics

Total participants (0-21 years): 89

Gender: Male 67% (n=60); Female 33% (n=29)

Age Range: 1 - 21 years Average age 11 years (Figure 1)

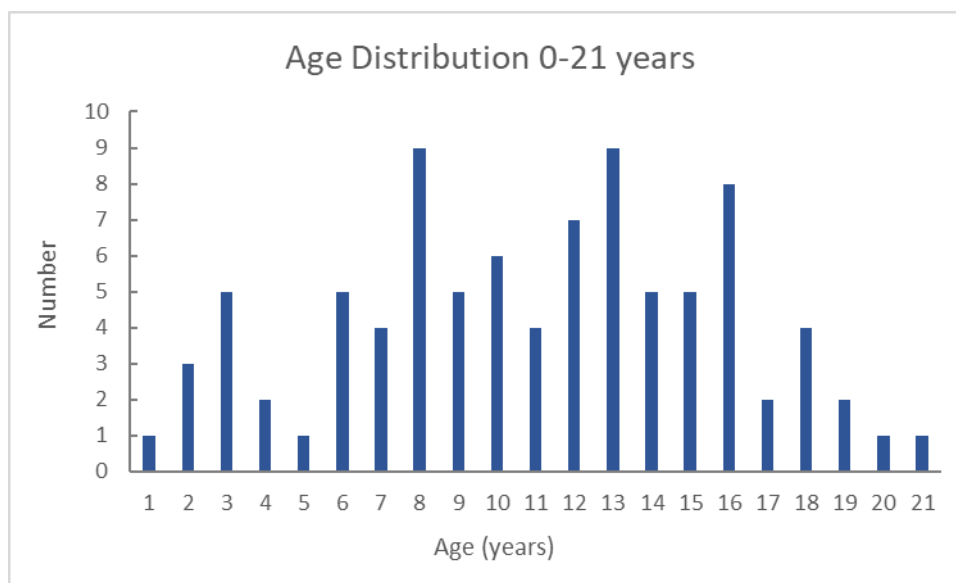


Figure 1: Age distribution for Wellington Region cohort on the NZCPR

Ethnicity Distribution

Table I: Wellington Region Ethnicity Distribution on NZCPR (Count and %)

Ethnicity	CCDHB	HVDHB	WRDHB	Total	
	Count	Count	Count	Count	%
NZ Euro	41	6	3	50	56%
NZ Māori	9	8	1	18	20%
Other	3	2	1	6	7%
Indian	3	1	1	5	6%
Chinese	2	1	0	3	3%
MELAA	1	1	0	2	2%
Other Euro	1	0	1	2	2%
Samoan	1	1	0	2	2%
Cook Isld	1	0	0	1	1%
Total	62	20	7	89	100%

MELAA = Middle Eastern Latin America African

Birth Information

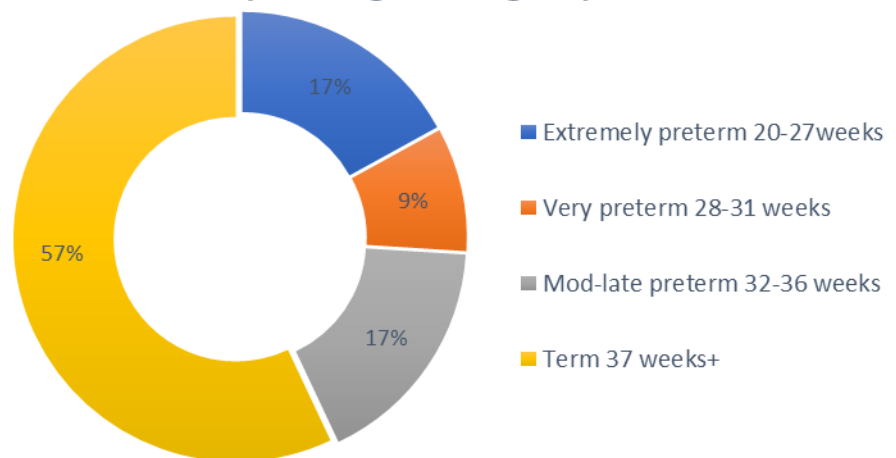
Gestational Age

Table II: Gestational Age of Wellington Region cohort on NZCPR

Gestational Age	Count	(%)
Extremely preterm 20-27weeks	13	17
Very preterm 28-31 weeks	7	9
Mod-late preterm 32-36 weeks	13	17
Term 37 weeks+	43	57
Grand Total	76	100

Figure 2:
Gestational Age (%)
for Wellington
Region cohort on
NZCPR

Gestational Age Distribution (%) on NZCPR (Wellington Region)

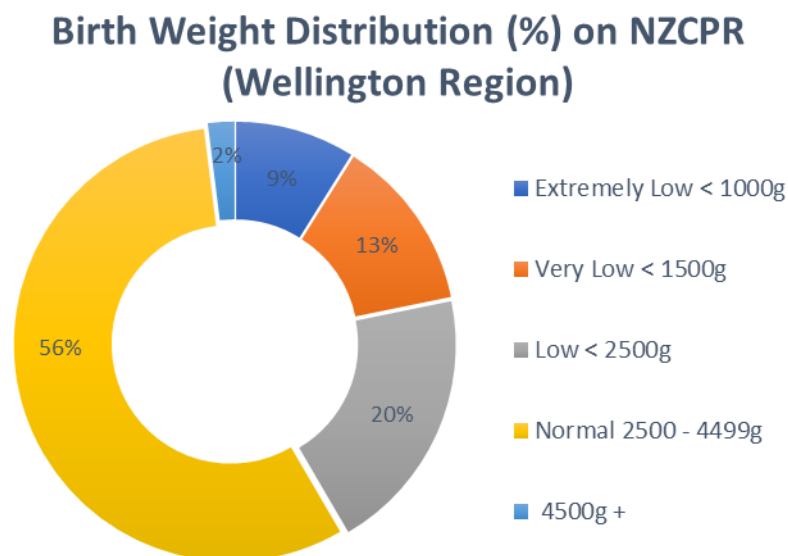


Birth weight

Table III: Birth Weight (g) distribution for Wellington Region cohort on NZCPR

Birth Weight	Count	(%)
Extremely Low <1000g	4	9
Very Low < 1500g	6	13
Low < 2500g	9	20
Normal 2500 - 4499g	26	56
4500g +	1	2
Grand Total	46	100

Figure 3: Birth Weight categories (%) for Wellington Region cohort on NZCPR



Neonatal Intensive Care Unit (NICU) / Special Care Baby Unit (SCBU)

- 43% (n=38) spent time in NICU and / or SCBU unit following birth
- Remaining 57% (n=51) either did not spend time in NICU / SCBU unit /or it is unknown from the medical records (i.e., not documented or unable to see birth records).

For the NICU/ SCBU sub cohort (n=38):

- 61% were **born preterm** (< 37 weeks)
- 51% had **< 2500g birth weight** (24% Low; 16% Very Low and 11% Extremely Low BW)
- 39% received a **CP diagnosis** by 12 months (compared to 24% of non NICU/SCBU cohort)
- Spastic diplegia was the most common **CP type distribution** (37%).
- 66% have a **GMFCS I-II distribution** (compared to 53% of the non NICU/SCBU cohort)

Clinical findings for Wellington Region cohort (0-21 years)

Timing of CP Cause

Table IV: Timing of Cause of Cerebral Palsy for Wellington Region cohort

Timing Of CP Cause	Count	(%)
Pre/Peri-natal	77	92
Post Neonatal	4	5
Uncertain Time of Cause	3	3
Total	84	100

(Note: Excluding Missing Data n=5)

- 7 individuals (8%) are known to be under ACC for the cause of their CP.

Time (Age) of First CP Description

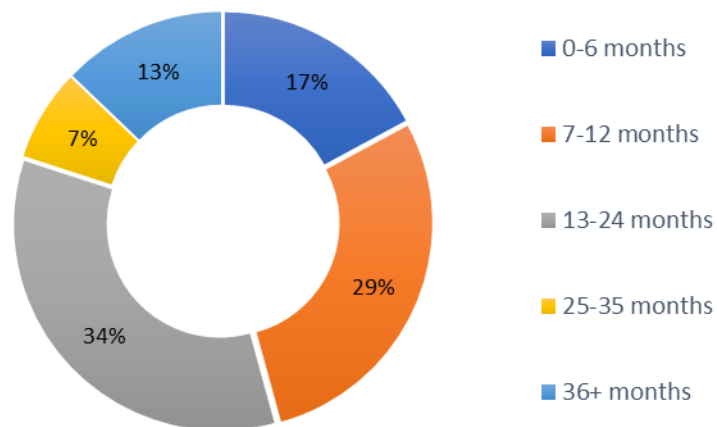
Average age of first CP description was: 19.5 months of age (Range: 1 year to 12 years old)

Table V: Timing of first Cerebral Palsy Description

Time (Age) of first CP Description	Count	(%)
0-6 months	12	17
7-12 months	20	29
13-24 months	24	34
25-35 months	5	7
36+ months	9	13
Grand Total	70	100

Timing of First CP Description (Wellington Region)

Figure 4: Time of first CP Description (%) for Wellington Region on NZCPR



Time of First CP Description varied by GMFCS

- 40% of GMFCS I and II and 44% GMFCS III children had a CP diagnosis by 12 months
- 58% of GMFCS IV and V had a CP diagnosis by 12 months of age

CP Type

Table VI: CP topographical description for Wellington Region cohort on NZCPR

CP Type	Count	(%)
Spastic - Mono/ Hemiplegia	27	30
Spastic - Quadriplegia	24	27
Spastic - Diplegia	28	31
Dyskinetic	8	9
Ataxic	1	1
Unknown	1	1
Total	88	100

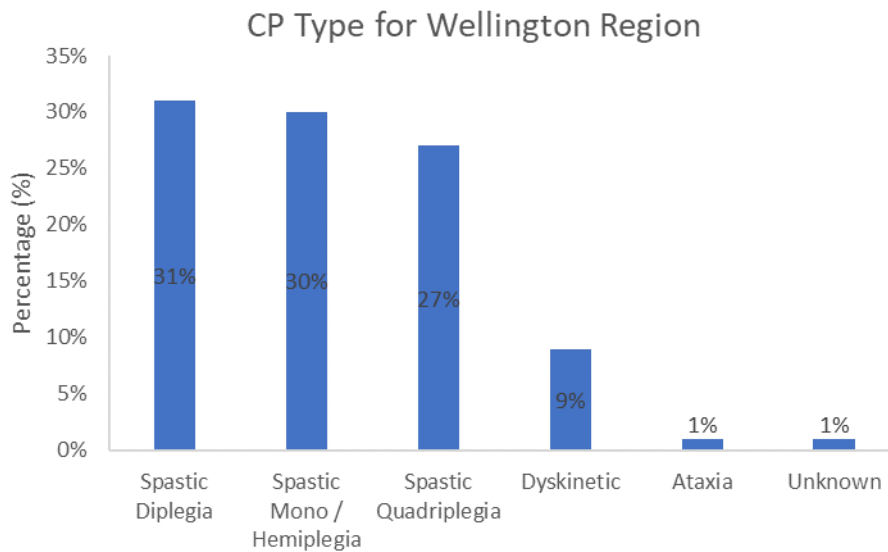


Figure 5: Topographical classification of CP for Wellington Region cohort

Gross Motor Functional Classification System (GMFCS)

Table VII: Functional Ability Classification (GMFCS) for Wellington Region cohort on NZCPR

GMFCS	Count	(%)
Level I	42	47
Level II	10	11
Level III	11	12
Level IV	18	20
Level V	8	9
Grand Total	89	100

Figure 6: Functional Ability using GMFCS (%) for the Wellington Region cohort on NZCPR

GMFCS Distribution for Wellington Region

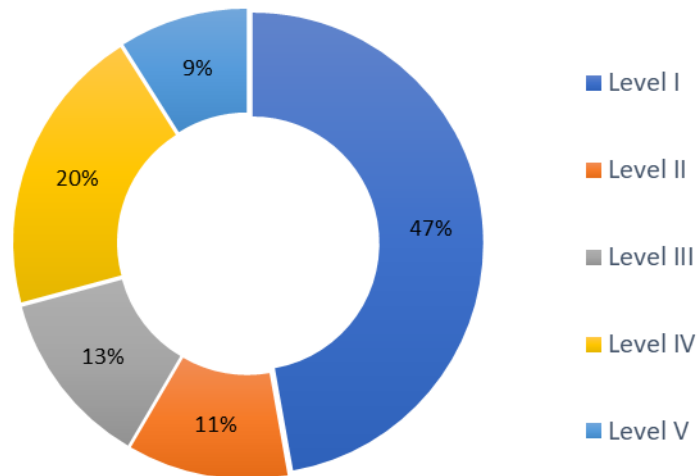
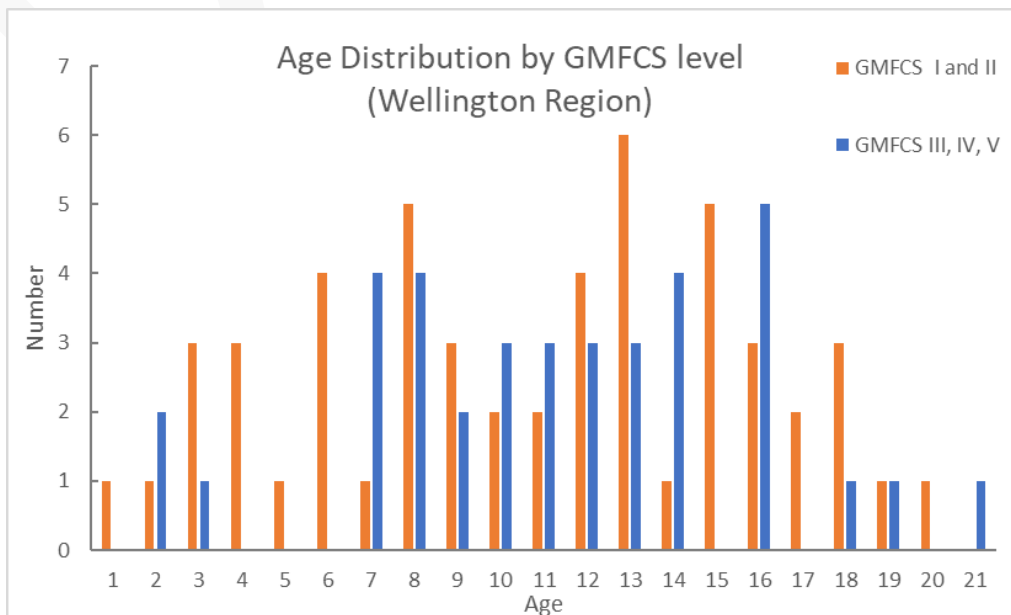


Figure 7: Age Distribution by Functional Ability (GMFCS) for Wellington Region



Manual Ability Classification (MACS)

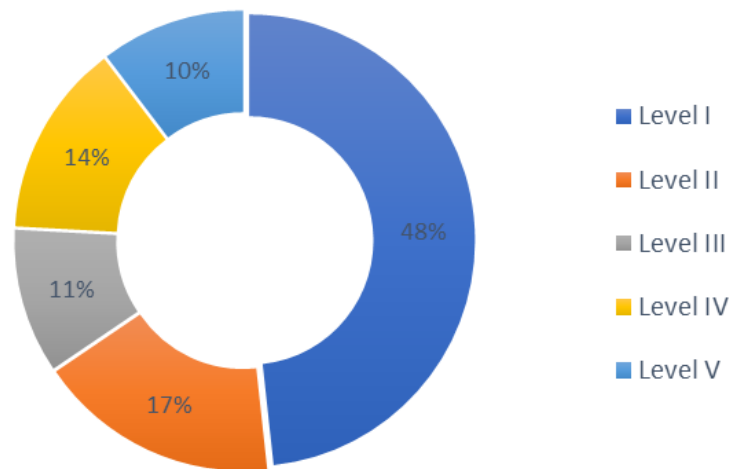
Note: Data found for only 29/89 individuals (33%)

Table VIII: Upper Limb Ability using MACS for Wellington Region

MACS	Count	(%)
Level I	14	48
Level II	5	17
Level III	3	10
Level IV	4	14
Level V	3	10
Total	29	100

Figure 8:
Manual
Ability
Classification
System (%)
for the
Wellington
Region
cohort on
the NZCPR

Manual Ability Distribution (Wellington Region)



Co Morbidities

Epilepsy

- 26 individuals have or have had epilepsy, approximately 38 % of the cohort.
- Note: Epilepsy status was unknown for 21 individuals.

Visual Impairment

- 24 individuals have some form of visual impairment, with n = 3 of those documented as 'functionally blind'.
- Note: Visual ability was unknown for n = 35 individuals

Hearing Impairment

- 5 individuals have a hearing impairment, with n = 2 having bilateral deafness.
- Note: Hearing ability was unknown for n = 43 individuals

Speech impairment

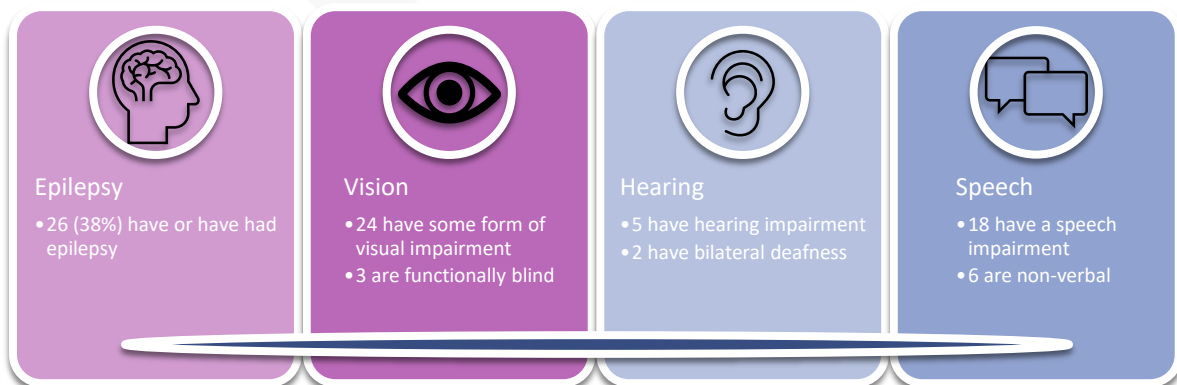
- 18 individuals have some form of speech impairment, with n = 6 of those 'non-verbal'.
- Note: Speech ability was unknown for n = 47 individuals

Note on Co morbidity Data Quality:

- Co morbidity classification codes on the NZCPR are historically quite broad and difficult to determine from medical records.
- The NZCPR is now also collecting standardized international measures to assist with obtaining more accurate information, these include:
 - **Communication Functional Classification System (CFCS)**
 - **Eating and Drinking Ability Classification System (EDACS)**
 - **Visual Function Classification System (VFCS)**
- More information on these tools is available at:

<https://www.starship.org.nz/guidelines/classification-systems-for-cerebral-palsy/>

Co Morbidities Summary for Wellington Region



- *For nearly half of individuals the presence of co morbidities is not well documented*

Additional information

- These datasets shown have been chosen for clinical relevance, data quality and high numbers in the dataset.
- The main NZ Cerebral Palsy Registry datasets are on the final page, if there are further data you are interested in, please let us know.
- Data quality and completion is dependent on what is available within the medical records.
- The NZCPR has capability to obtain the NZ Social Deprivation Index data and / or Prioritized Ethnicity data from the Ministry of Health for this cohort

How many children with CP would we expect to see in the Wellington Region?

- Estimates of prevalence are still challenging, as a Registry we are working to better monitor where people are born, to help determine prevalence based on the yearly live birth rate and neonatal survivor rate for a particular region.
- CCDHB, HVDHB, Wairarapa DHB serves a total population of 320,640. (CCDHB), 156,790. (HVDHB), 48,480. (Wairarapa DHB) in 2020/2021. **Approx. Total: 320,845.**
See [Capital & Coast DHB | Ministry of Health NZ](#)
- Approximately 24 % of the total population is reported as between **0-19 years** (approx. 80,000. individuals).
- Therefore, a gross estimate based on a range of CP prevalence¹ of between 1 -2/1000 would have a **predicted range of children (0-19 years) with CP for Wellington Region of 80-160.**

Adult Population Summary for Wellington Region

- There are 40 individuals 22 years and over, age range (22 -79 years)
- 40% Male; 60% Female
- Ethnicity distribution: 58% NZ European; 18% Māori; 10% Samoan; 8% Other; 5% MELAA; 3% Indian
- GMFCS data available for n=18: Categories: GMFCS III n = 3 (17%); GMFCS IV n = 4 (22%); GMFCS V n = 11 (61%)

Mortality

There are 8 recorded deaths within the Wellington Region cohort, n = 2 were less than 21 years of age and the remaining n = 6 over 21 years. Currently these numbers are included in the above analysis.

References and Links

1. Galea C, McIntyre S, Smithers-Sheedy H, Reid SM, Gibson C, Delacy M, Watson L, Goldsmith S, Badawi N, Blair E; Australian Cerebral Palsy Register Group. Cerebral palsy trends in Australia (1995-2009): a population-based observational study. *Dev Med Child Neurol*. 2019 Feb;61(2):186-193. doi: 10.1111/dmcn.14011. Epub 2018 Sep 6. PMID: 30187914
- [Report-of-the-Australian-Cerebral-Palsy-Register-Birth-Years-1995-2012.pdf \(cpreregister.com\)](#)
 - [Capital & Coast DHB | Ministry of Health NZ](#)
 - <https://www.starship.org.nz/guidelines/classification-systems-for-cerebral-palsy/>
 - <https://www.starship.org.nz/health-professionals/cerebral-palsy-research/>

Glossary

CP	Cerebral Palsy
CCDHB	Capital Coast District Health Board
GMFCS	Gross Motor Functional Classification System
HVDHB	Hutt Valley District Health Board
MACS	Manual Ability Classification System
MELAA	Middle Eastern Latin America African
NICU	Neonatal Intensive Care Unit
NZCPR	New Zealand Cerebral Palsy Register
SCBU	Special Care Baby Unit
WRDHB	Wairarapa District Health Board

NZCPR Main Dataset Fields

Demographic	CaseID
	NHI
	Gender
	CP Ethnicity Code
	Age
	Birth Date
	DHB
	Region
Birth	NICU / SCBU
	NICU Length Of Stay
	Gestational Age
	Birth Weight Grams
	Birth Plurality Code
	Birth Order Code
	Birth Complications Code
	Birth Defect Code
Clinical	Time of 1st_CP Diagnosis
	Specialist Service Make Diagnosis
	CP Type
	Timing Of Cause
	Prenatal Cause Code
	Post Neonatal Cause Code
	GMFCS Initial
	GMFCS Age5
	MACS
	EDACS
	CFCS
Comorbidities	Epilepsy
	Intellectual Impairment Code
	Visual Impairment Code
	Strabismus Code
	Hearing Impairment Code
	Speech Impairment Code
Surveillance	Cranial MRI
	Time 1st Hip Xray
Admin	Record Status Code
	Created On
	ACC
	Is Silent
	Still Alive Code
	Comments