AUSTRALIAN CEREBRAL PALSY REGISTER REPORT 2016

Cerebral Palsy ALLIANCE RESEARCH INSTITUTE

CP Register
Piecing together the facts on cerebral palsy

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Australian Cerebral Palsy Register Group and visiting scholars, March 2016

ACKNOWLEDGEMENTS

The Australian Cerebral Palsy Register (ACPR) Group sincerely thanks all the families and health professionals involved in this Australia wide effort. In these endeavours, we aim to collect the most accurate and complete data possible to monitor cerebral palsy (CP) in Australia, identify causal pathways, evaluate preventative strategies and evaluate management options for those with CP and their families.

The ACPR Group acknowledges and thanks:

- Mr Rob White CEO for his vision and commitment to the work of the ACPR;
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The staff at the Cerebral Palsy Alliance Research Institute would like to thank all members of the ACPR Policy Group for their expertise, time and commitment shown over the last twelve months while uploading data, attending meetings, participating in working groups and writing this report. The ACPR exists as a result of collaborative partnerships between all the Australian state and territory CP registers, and the organisations which support each register.

The contributing registers and their organisations are as follows:

- **Australian Capital Territory and New South Wales Cerebral Palsy Registers** – Cerebral Palsy Alliance, University of Sydney
- **Northern Territory Cerebral Palsy Register** – Centre for Disease Control
- **Queensland Cerebral Palsy Register** – CPL – Choice, Passion, Life and Queensland Department of Communities, Child Safety and Disability Services
- **South Australian Cerebral Palsy Register** – Women's and Children's Health Network
- **Tasmanian Cerebral Palsy Register** – St Giles
- **Victorian Cerebral Palsy Register** – Murdoch Childrens Research Institute, Royal Children's Hospital, Melbourne
- **Western Australian Register of Developmental Anomalies** – Cerebral Palsy – Department of Health WA

FOREWORD

I am honoured to write the foreword for the third report of the Australian Cerebral Palsy Register. Cerebral palsy is the most common cause of physical disability in early childhood, occurring in about two babies per 1000 live births. It is an umbrella term that encompasses a diverse group of disorders resulting from damage to the developing brain either during pregnancy or shortly after birth. Cerebral palsy is a non-progressive, but permanent condition that has lifelong consequences for individuals with cerebral palsy and their families.

Although some of the causes and risk factors for cerebral palsy are known, such as preterm birth and congenital anomalies, many are not. The relatively uncommon occurrence of cerebral palsy, its multiple presentations and diverse causal pathways, make it a complex condition to study and to target intervention. Furthermore, in order to monitor prevalence rates and evaluate prevention and treatment strategies, especially within different subgroups, it is necessary to study large populations of patients. Such challenges make registers a vital piece of the jigsaw in improving the health outcomes for those with cerebral palsy.

Australia has a proud history of cerebral palsy registries, with the first jurisdictional registry established by Fiona Stanley in Western Australia in 1975. Other registries followed in Australia, notably in Victoria and South Australia, with the national Australian Cerebral Palsy Register introduced in 2008. Cerebral palsy registries provide a number of important functions including monitoring trends, research, prevention, education and resource planning. They are used to provide accurate advice to patients, to improve care pathways, to prospectively identify patients eligible for clinical trials and to retrospectively analyse the effectiveness of interventions. Whether from a single cerebral palsy register or from a network of registries – such as the Australian Cerebral Palsy Register – the data are an excellent resource for informing health professionals, policy makers and those living with cerebral palsy. Indeed, the power of cerebral palsy register research is exemplified by the recent publication of a number of wide-ranging studies from the Australian cerebral palsy registries[1].

As information technology and methods for linking and transferring information between different data collections evolve, so too do the challenges and opportunities for cerebral palsy registries. The challenges relate to harmonising data between registries and considerations around sharing data. However, the opportunities far outweigh the challenges. Larger data sets with more cases and richer information on antecedents and long-term follow up of persons with cerebral palsy provide exciting possibilities for realising the full potential of cerebral palsy registries in the future. This so called 'big data' approach to research enables new questions to be tackled using large-scale data that span the biomedical, clinical, health services and public health domains. Such an approach facilitates specific subgroup analysis which is a necessity for our understanding of cerebral palsy.

I congratulate the Australian Cerebral Palsy Register on this excellent report. It represents a shared collaboration across the country reflecting the foresight of those in 2008 who developed the Australian Cerebral Palsy Register. I also wish to thank the many families, persons with cerebral palsy and health professionals who have made this report possible.

Associate Professor Georgina Chambers
Director, National Perinatal Epidemiology and Statistics Unit

EXECUTIVE SUMMARY

The Australian Cerebral Palsy Register (ACPR) was established in 2008 as a research database to facilitate the study of the distribution, frequency and severity of CP; the causes and determinants of CP; the effectiveness of prevention strategies and to help plan and evaluate services. The ACPR contains a deidentified copy of data that have been securely uploaded from each of the state and territory CP registers.

This is the third report of combined data from the ACPR Group. This year, the report contains a number of new analyses that have been made possible due to the availability of denominator data provided by our colleagues at the National Perinatal Epidemiology and Statistics Unit. This new data has provided opportunities for the ACPR Group to begin to explore rates and trends in the CP population over time. Another addition to this report is a new section describing the two recently established CP registers in Bangladesh and New Zealand that commenced active recruitment in 2015. These CP registers are affiliated with the ACPR and utilise the same infrastructure and minimum data set. The ACPR Group looks forward to continuing our collaboration with the talented researchers from these registers and to the inclusion of new data from these registers in future reports.

This 2016 report comprises data uploaded in October 2015 for the 1993-2009 birth years. Any children notified to state/territory registers after this date were not included in the report. This report contains a total of 7241 records of children with CP reported from all states and territories of Australia. This includes data provided by the three long-standing registers from South Australia (established in 1998), Victoria (1980) and Western Australia (1979) which have good ascertainment and are believed to have registered all eligible children in their respective jurisdictions. Data from these CP Registers have been selected for any calculations pertaining to rates of CP. Since the last report two of the more recently established CP registers, Queensland and the Northern Territory reached the minimum ACPR ascertainment requirement of 1.5 children with CP per 1000 live births excluding those with a known post-neonatal cause. Despite these excellent advances, the researchers from these registers report that they believe they remain under-ascertained.

In this birth cohort (1993-2009) there were 3892 children with CP registered on the three long-standing CP registers (South Australia, Victoria and Western Australia). This cerebral palsy cohort included 5.9% of children who had a recognised post-neonatal brain injury acquired more than 28 days after birth. The predominant post-neonatal cause of CP was cardiovascular accident either spontaneous, or associated with surgery or with cardiac complications.

For the remaining cohort (94.1%), the brain injury responsible for CP is believed to have occurred during the prenatal and perinatal period of infant development.

The following key findings pertain to this pre/perinatally acquired CP cohort:

- After a long period of stable prevalence at around 2-2.5/1000, the rate of CP per 1000 live births declined to 1.4-2.1/1000 in the 2007-2009 period, p22,23.
- Over the 1993-2009 period the rate of CP per 1000 live births reduced across all gestational age groups, p29.
- In contrast to the Australian population where 7.2% of live births in this period were born preterm (<37 weeks), 43% of children with CP were born preterm, p29.
- The decline in CP prevalence for children born at 20-27 weeks observed in the previous two triennia (2001-2003 and 2004-2006) did not continue in the most recent triennium (2007-2009) where a slight increase in rates of CP per 1000 live births was observed, p29.
- Amongst children born preterm, the rate of CP per 1000 neonatal survivors shows no shared trend across all jurisdictions, notably in the last triennium (2007-2009), p30,31.
- The declining rate of CP for children born as a twin or higher multiple has plateaued in this last triennium (2007-2009), p39.
- Males were found to be at higher risk of developing cerebral palsy. 57% of the cohort was male compared to 51% of the Australian population born during this period, p26.
- Rates of CP per 1000 live births have improved for all maternal age groups except for mothers <20 years which have remained stable over the 14 years reported, p28.


REAL MODE BRAND

INDEX

ABOUT CEREBRAL PALSY

Both internationally and in Australia, CP registers draw on a range of references and perspectives when considering the definition which best suits their purposes[2]. The ACPR has adopted the approach used by the Surveillance of Cerebral Palsy in Europe (SCPE)[3], allowing the use of any definition that includes the following five key elements common to the definitions published by Bax[4], Rosenbaum[5] and Mutch.[6]

CP:

(1) is an umbrella term for a group of disorders

(2) is a condition that is permanent but not unchanging

(3) involves a disorder of movement and/or posture and of motor function

(4) is due to a non-progressive interference, lesion or abnormality, and

(5) the interference, lesion or abnormality originates in the immature brain[3]

For the majority of individuals with CP the complete causal pathway to brain injury is not well understood. CP is associated with numerous perinatal factors, e.g., congenital infections, birth defects, preterm birth, intrauterine growth restriction, sentinel events and multiple pregnancy and with post-neonatal factors such as head trauma or cerebral infections[7].

The motor impairments of CP are classified into four main subtypes: spastic, dyskinetic, ataxic and hypotonic. Individuals with spasticity may exhibit increased deep tendon reflexes, weakness, abnormal gait and posture[8]. Individuals with dyskinetic CP may have dystonic, athetoid or choreathetoid movement patterns including involuntary, uncontrolled, recurring, occasionally stereotyped movements and fluctuating muscle tone[9]. Ataxic CP is characterised by problems with balance and depth perception and loss of coordination, so that movements are poorly organized in terms of force, rhythm and accuracy[9]. Hypotonic CP, where an individual has diminished muscle tone without other signs of motor impairment is the least common form of CP[10]. A proportion of individuals with CP exhibit mixed motor types, e.g., a predominantly spastic motor pattern with dyskinesia.

Among individuals with CP, the severity of the physical disability/gross motor impairment ranges from minimal to profound, and the complexity of the condition can be increased by the co-occurrence of associated impairments[11,12]. The likelihood and severity of associated impairments increase with the severity of motor impairment[13-16]. Many individuals with CP will have more than one associated impairment, and their presence can complicate therapy and decrease quality of life for the individual and their family, and increase costs for the family and to society[12].

Estimates of the prevalence of CP throughout the world vary depending on the methodology of "count", percentage ascertained and variations in selection criteria[17]. CP registers have identified rates ranging between 1.4-2.77/1000 live births; surveillance programs range between 2.1-3.6/1000 live births; and cross-sectional surveys range between 1.05 and 4.1/1000 live births[12]. The two largest data sets, the ACPR and the SCPE both have an overall birth prevalence of approximately 2/1000 live births and a recent meta-analysis reported 2.11/100 live births[17]. Although CP is found in all socioeconomic groups, since low birthweight is associated with low socio-economic status (SES) and CP is strongly associated with low birth weight, it can be anticipated that there would be an association between CP and low SES. However even in the normal birth weight ranges, rates of CP are 2.42/1000 live births for those in the lowest socio-economic groups, compared to 1.29/1000 for the most affluent groups[18,19].

For further information about the ACPR and a recent suite of papers from the ACPR Group please see, Smithers-Sheedy H, McIntyre S, Gibson C, Meehan E, Scott H, Goldsmith S, et al. A special supplement: findings from the Australian Cerebral Palsy Register, birth years 1993 to 2006. Dev Med Child Neurol. 2016;58 Suppl 2:5-10.

WHAT IS THE AUSTRALIAN CEREBRAL PALSY REGISTER?

The Australian Cerebral Palsy Register (ACPR) is an electronic database of data uploaded from the CP registers in each state and territory of Australia, from which individual identifiers have been removed and replaced by a unique code in order to ensure privacy of data.

The ACPR exists as a result of collaborative partnerships between all Australian state and territory CP registers, and the organisations which support each register. The contributing registers and their organisations are as follows:

- **Australian Capital Territory (ACT) and New South Wales Cerebral Palsy Register (NSW)**

  Cerebral Palsy Alliance Research Institute

- **Northern Territory (NT) Cerebral Palsy Register**

  Centre for Disease Control

- **Queensland (QLD) Cerebral Palsy Register**

  CPL - Choice, Passion, Life and Queensland Department of Communities, Child Safety and Disability Services

- **The South Australian (SA) Cerebral Palsy Register**

  Women's and Children's Health Network

- **Tasmanian (Tas) Cerebral Palsy Register**

  Cerebral Palsy Alliance and St Giles

- **Victorian (Vic) Cerebral Palsy Register**

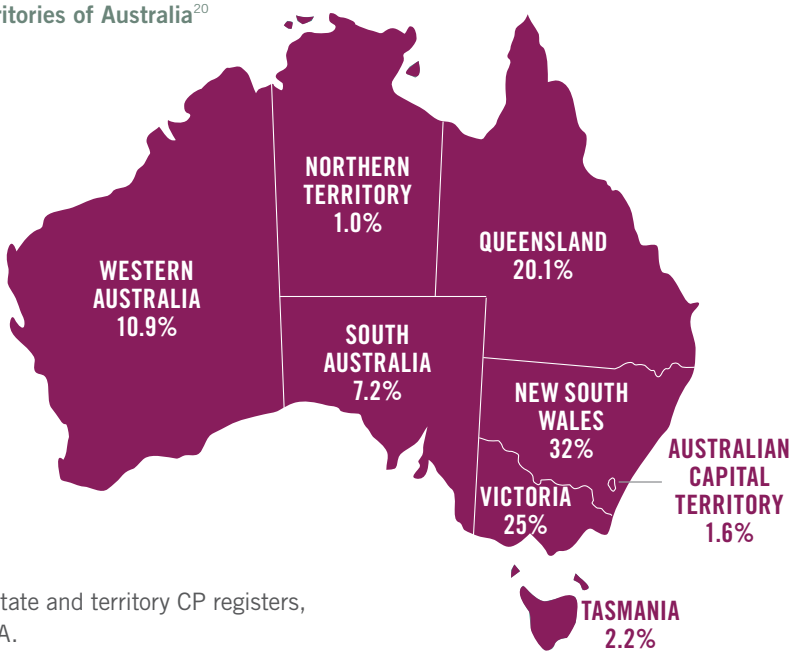
  Murdoch Childrens Research Institute, Royal Children's Hospital, Melbourne

- **Western Australian (WA) Register of Developmental Anomalies – Cerebral Palsy**

  Department of Health WA

A map showing the states and territories and the percentage of total population has been provided below. Australia has a total population of approximately 23.7 million people[20] with the bulk of the population living along the eastern seaboard.

Population proportions for the States and Territories of Australia[20]



For a more detailed description of each of the state and territory CP registers, including contact details, please see Appendix A.

AIMS OF THE ACPR

The overarching vision for the ACPR is that the register should be used to assist in efforts both to reduce the incidence of CP and significantly enhance the quality of life of those living with CP.

Specifically, the aim for the ACPR is to be a source of data that will support research relating to:

a) monitoring of CP

b) identifying interventions that effectively improve quality of life

c) identifying causal pathways to enable prevention

d) evaluating future preventative strategies.

The ACPR Research and Policy Group includes a representative from each state and territory CP register. This group is able to provide consultation to researchers who are seeking advice regarding CP research and accessing identified and non-identified CP register data within Australia. For further information please contact: **cpregister@cerebralpalsy.org.au**

Ethics

Contribution of data to the ACPR has been approved by the relevant Human Research Ethics Committee (HREC) overseeing each state and territory register. Additionally, both the management of ACPR data and the activities of, and work related to the ACPR are reviewed regularly by the Cerebral Palsy Alliance Human Research Ethics Committee (EC00402), a National Health and Medical Research Council approved HREC.

The Cerebral Palsy Alliance Research Institute, University of Sydney is the custodian organisation for the ACPR. Both the Research Institute and the ACPR are funded by Cerebral Palsy Alliance Research Foundation which is a wholly owned company of Cerebral Palsy Alliance.

Use of CP Register data

One of the important functions of both the state/territory and Australian CP registers is to act as a source of information about CP. Staff and researchers from CP registers respond to frequent enquiries from researchers, members of the public, university students, individuals with CP and their families, service providers and government agencies about CP, the epidemiology of CP in their geographic area and available services.

Current projects

In addition to their state and territory register responsibilities, ACPR Policy Group members have worked and continue to work with their national and international colleagues on a number of projects including:

- The contribution of papers and participation in the World CP Registers, Surveys and Networks Day, part of the 5th International Cerebral Palsy Conference, Sweden, 2016
- A collaborative research study with researchers from the Surveillance of Cerebral Palsy in Europe to investigate the contribution of higher multiple births to CP
- A collaborative research study with researchers from the Surveillance of Cerebral Palsy in Europe to further investigate the role of congenital anomalies as a risk factor for CP
- Completion of a data linkage to support the evaluation of long-term outcome measures for the ACTOMgSO4 trial
- A collaboration with researchers from the School of Medicine, Discipline of Pediatrics and Adolescent Health and the Marie Bashir Institute of Infectious Disease and Biosecurity, University of Sydney to investigate the prevalence of congenital cytomegalovirus amongst CP registrants
- The support of other research groups internationally to establish new CP registers including the Bangladesh Cerebral Palsy Register (BCPR) and the New Zealand Cerebral Palsy Register (NZCPR) see section 4
- Ongoing member/support of the Impact for CP network **https://impact.cerebralpalsy.org.au/** in relation to the Cerebral Palsy Register and Surveillance Research Cluster.

The work of CP registers in Australia has added to our understanding of CP and contributed significantly to research in this field. Please see Appendix C for a list of publications that have been generated by state and territory CP registers in Australia since the publication of the 2013 ACPR report.

METHODS

Cohort

The cohort selected for this report was born 1993-2009. In order to ensure that duplicate records were not included in the dataset, each state and territory group contributed only records of children that were born in their state or territory within this time frame. A de-duplication algorithm designed to highlight potential duplicates was run also as a further measure to avoid reporting duplications.

Inclusion/exclusion criteria

In order to be included in the dataset, a case must fulfil the criteria contained in the five definitional elements[3] as outlined earlier. Contributing registers consider a child's record to be confirmed / verified when the individual reaches 5 years of age. In the event that new information becomes available the child's record may be updated, which may involve inclusion or exclusion. Records of children who have been described by a suitably qualified health professional to have met the criteria for CP but who die prior to 5 years of age continue to be included in the registers.

Denominator data

Data on live births for the years 1993-2009 (the denominator) were obtained from the National Perinatal Epidemiology and Statistics Unit.

Reporting of numerator data

Case ascertainment varies between states and territories, reflecting differences in both the time of establishment and the governance and consent requirements of each register (see description of CP Registers in Appendix A). Three states of Australia - Western Australia, Victoria and South Australia have long established CP registers. These CP registers are believed to have registered all (or very nearly all) eligible persons and have been selected for any calculations pertaining to rates of CP. CP registers that have been established more recently in the Australian Capital Territory, New South Wales, Northern Territory, Queensland and Tasmania are also included in this report. The ascertainment rates of these registers are increasing rapidly; however, these groups are aware that they are currently under-ascertained. In regards to missing data, where more than 20% of data is missing or unknown, this data has been reported in data tables only and has not been included in calculations of combined data. Trends were analysed by χ^2 for trend (Epi Info 7, Centers for Disease Control and Prevention, Atlanta, GA, USA).

Results

The results of this report have been divided into four sections. Section 1 reports on all CP cases not differentiated by timing of brain injury, Section 2 refers to CP arising from an injury to the developing brain during the pre/perinatal period (throughout pregnancy and the first 28 completed days after birth) and Section 3 refers to CP where a known post-neonatal cause (occurring after 28 days of life and before 2 years of age) has been identified. The results have been presented in this format as the majority of pre/perinatal causes of CP are not well understood, whereas the likely proximal cause has been identified in post-neonatally acquired cases.

Section 4 is a new addition to the ACPR report which provides information regarding the New Zealand and Bangladesh CP Registers which share the ACPR minimum dataset and infrastructure.


RESULTS:
1 ALL CEREBRAL PALSY

ALL CHILDREN WITH CEREBRAL PALSY

Table 1. Pre/perinatally and post-neonatally acquired CP by state/territory of birth (1993-2009)

	Live births (1993-2009) n	Pre/perinatally acquired CP n	Post-neonatally acquired CP n	**TOTAL CP n**	Prevalence all CP Rate per 1000 live births
ACT	78697	104	13	**117**	1.5
NSW	1509760	1549	122	**1671**	1.1
NT	62643	96	18	**114**	1.8
QLD	862792	1255	53	**1308**	1.5
SA*	317536	609	29	**638**	2.0
TAS	104187	137	2	**139**	1.3
VIC*	1104389	1930	118	**2048**	1.9
WA*	448215	1123	83	**1206**	2.7
TOTAL	4488219	6803	438	**7241**	
COMBINED*	**1870140**	**3662 (94.1)**	**230 (5.9)**	**3892**	**2.1 (95%CI 2.0,2.2)**

NB: Whilst the ascertainment of registrations for CP in ACT, NT and QLD has increased rapidly to a total CP prevalence ≥1.5 per 1000 live births, these regions remain under-ascertained. As such the data from these regions has not been used in the calculation of combined rates.

The combined data indicates that the brain injury responsible for CP primarily arises during the pre/perinatal period (94.1%). For a small group (5.9%) the brain injury occurred post-neonatally and before 2 years of age.

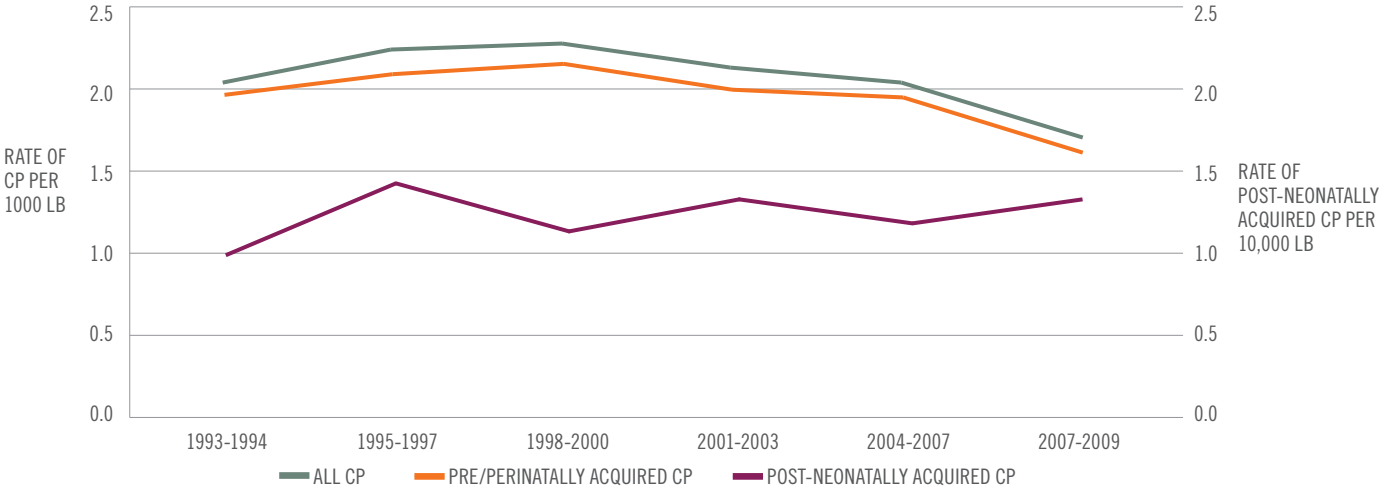
For this report of the Australian Cerebral Palsy Register, data pertaining to 7241 individuals with CP are reported. The total prevalence for CP is 2.1 per 1000 live births (95% CI 2.0, 2.2).

The rate of CP in Western Australia is considerably higher than that reported by other long-standing CP registers in Victoria and South Australia. The Western Australian CP Register has higher rates of ascertainment related at least in part to having a small population and centralised services in the state capital, Perth.

Table 2. Rate of pre/perinatally and post-neonatally acquired CP per live births (LB) and year of birth, South Australia, Victoria and Western Australia combined (1993-2009)

	1993-1994	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	1993-2009
Pre/perinatally acquired CP/1000 LB	2.0	2.1	2.1	2.0	1.9	1.6	2.0
Post-neonatally acquired CP/10,000 LB	1.0	1.4	1.1	1.3	1.2	1.3	1.2
All CP/1000 LB	2.1	2.2	2.3	2.1	2.1	1.8	2.1

Figure 1. Rate of CP per 1000 live births (LB) and year of birth, South Australia, Victoria and Western Australia combined (1993-2009)



INDIGENOUS STATUS OF MOTHER

Table 3. Number and percentage of children with CP by Indigenous status of mother and state/territory of birth (1993-2009)

	Aboriginal	Aboriginal and Torres Strait Islander	Torres Strait Islander	Non-indigenous	Total	Unknown
	n(%)^	n(%)^	n(%)^	n(%)^	n	n(%)
ACT						
Pre/peri	♦ (2.5)	0 (0.0)	0 (0.0)	79 (97.5)	**104**	23 (22.1)
PNN	♦ (10.0)	0 (0.0)	0 (0.0)	9 (90.0)	**13**	♦ (23.1)
NSW						
Pre/peri	71 (5.6)	♦ (0.2)	0 (0.0)	1186 (94.1)	**1549**	289 (18.7)
PNN	7 (7.4)	0 (0.0)	0 (0.0)	87 (92.6)	**123**	29 (23.6)
NT						
Pre/peri	52 (54.2)	0 (0.0)	0 (0.0)	44 (45.8)	**96**	0 (0.0)
PNN	14 (77.8)	♦ (5.6)	0 (0.0)	♦ (16.7)	**18**	0 (0.0)
QLD						
Pre/peri	49 (4.4)	8 (0.7)	8 (0.7)	1052 (94.2)	**1255**	138 (11.0)
PNN	♦ (6.3)	0 (0.0)	0 (0.0)	45 (93.8)	**53**	5 (9.4)
SA*						
Pre/peri	18 (3.0)	0 (0.0)	♦ (0.6)	585 (96.6)	**609**	♦ (0.7)
PNN	♦ (3.4)	0 (0.0)	0 (0.0)	28 (96.6)	**29**	0 (0.0)
TAS						
Pre/peri	5 (4.4)	0 (0.0)	0 (0.0)	108 (95.6)	**137**	24 (17.5)
PNN	0 (0.0)	0 (0.0)	0 (0.0)	♦ (100.0)	♦	0 (0.0)
VIC*						
Pre/peri	14 (0.8)	0 (0.0)	0 (0.0)	1823 (99.2)	**1930**	93 (4.8)
PNN	♦ (0.9)	0 (0.0)	0 (0.0)	115 (99.1)	**118**	♦ (1.7)
WA*						
Pre/peri	94 (8.4)	♦ (0.1)	0 (0.0)	1022 (91.5)	**1123**	6 (0.5)
PNN	18 (21.7)	0 (0.0)	0 (0.0)	65 (78.3)	**83**	0 (0.0)
TOTAL						
Pre/peri	**305**	**12**	**10**	**5899**	**6803**	**577**
PNN	**45**	♦	**0**	**354**	**438**	**39**
All CP	**350**	**13**	**10**	**6253**	**7241**	**616**
COMBINED*						
Pre/peri	**126 (3.5)**	**♦ (0.0)**	**♦ (0.1)**	**3430 (96.4)**	**3662**	**103 (2.8)**
PNN	**20 (8.8)**	**0 (0.0)**	**0 (0.0)**	**208(91.2)**	**230**	**♦ (0.9)**
All CP	**146 (3.9)**	**♦ (0.0)**	**♦ (0.1)**	**3638 (96.1)**	**3892**	**105 (2.7)**

♦< 5 cases

(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

Pre/peri CP: pre/perinatally acquired CP

PNN CP: post-neonatally acquired CP

Table 4. Number and frequency of children with CP per 1000 neonatal survivors (95% confidence interval) in 1996-2005 births by state/territory, and time of CP acquisition

	INDIGENOUS			NON-INDIGENOUS		
Location of Birth	Neonatal survivors	Pre/perinatal CP n: n/1000LB (95%CI)	Post-neonatal CP n: n/1000LB (95%CI)	Neonatal survivors	Pre/perinatal CP n: n/1000LB (95%CI)	Post-neonatal CP n: n/1000LB (95%CI)
NT	13036	33: **2.53 (1.69-3.39)**	6: **0.46 (0.1-0.82)**	22426	28: **1.25 (0.79-1.71)**	1: **0.045 (0-0.13)**
QLD	27748	53: 1.92 (1.41-2.44)	6: 0.22 (0.04-0.39)	464842	612: **1.32 (1.21 – 1.42)**	20: 0.043 (0.02-0.06)
WA	15721	52: 3.31 (2.41-4.21)	11: **0.70 (0.29-1.11)**	237364	608: 2.56 (2.36 – 2.76)	39: **0.16 (0.11-0.22)**
COMBINED*	**56505**	**138: 2.44 (2.03-2.85)**	**23: 0.41 (0.24 – 0.57)**	**724632**	**1248 1.72 (1.63 – 1.81)**	**60: 0.083 (0.06-0.10)**

Bold type denotes statistically significant ($p<0.05$) difference in proportion of live births (LB) affected by CP between Indigenous and non-Indigenous populations.

Table 5. Distribution of characteristics of impairments in 1996-2005 births in NT, QLD and WA for children subsequently described as having CP, by Indigenous status and time of CP acquisition

	PRE/PERINATAL CP			POST-NEONATAL CP		
Characteristic	Indigenous %	Non-Indigenous %	Relative risk (95%CI)	Indigenous %	Non-Indigenous %	Relative risk (95%CI)
Maximum n*	**138**	**1248**		**23**	**60**	
GMFCS I-II	54	57		52	53	
GMFCS III	9	17		4	9	
GMFCS IV-V	37	26	1.4 (1.0-2.0)	44	38	1.2 (0.5-2.8)
ID (IQ<70)	61	46	1.3 (0.9-1.9)	71	51	1.4 (0.6-3.1)
Epilepsy at 5y	44	30	1.5 (1.1 – 2.0)	38	39	1.0(0.4-2.5)
Some visual impairment	37	31		27	38	
Blind	11	5	2.4 (1.3 – 4.7)	18	6	3.3(0.7-16)
Some hearing impairment	22	8		18	2	
Deaf	4	2	1.6 (0.6 – 4.2)	9	5	1.7 (0.1-21)
Some speech impairment	36	36		50	55	
Non-verbal	30	23	1.3 (0.9 – 1.9)	40	27	1.5 (0.5-4.0)

*The maximum size of the denominator; missing data were excluded from denominators. 95% CI, 95% confidence intervals; GMFCS, Gross Motor Function Classification System; ID, intellectual disability.

Table 4 and 5 sourced from: Blair, E., Watson, L., O'Kearney, E. d'Antoine, H., deLacy, M. (2015) Comparing risks of cerebral palsy in births to Australian Indigenous and non-Indigenous. Dev Med Child Neurol. 2016;58 Suppl 2:36-42.

The combined data presented above were collated for a recent ACPR Group publication and provide the best available data on Indigenous status as a risk factor for CP. This data suggests that Indigenous children are at significantly increased risk of CP particularly post-neonatally acquired CP when compared with their Non-Indigenous peers.

For further information about Indigenous status as a risk factor for CP, please see Blair E, Watson L, O'Kearney E, D'Antoine H, Delacy MJ. Comparing risks of cerebral palsy in births between Australian Indigenous and non-Indigenous mothers. Dev Med Child Neurol. 2016;58 Suppl 2:36-42.

2 PRENATALLY OR PERINATALLY ACQUIRED CEREBRAL PALSY

SECTION 2 OF THIS REPORT REFERS TO CP ARISING FROM AN INJURY TO THE DEVELOPING BRAIN DURING THE PRENATAL/ PERINATAL PERIOD (THROUGHOUT PREGNANCY AND DURING THE FIRST 28 COMPLETED DAYS AFTER BIRTH).

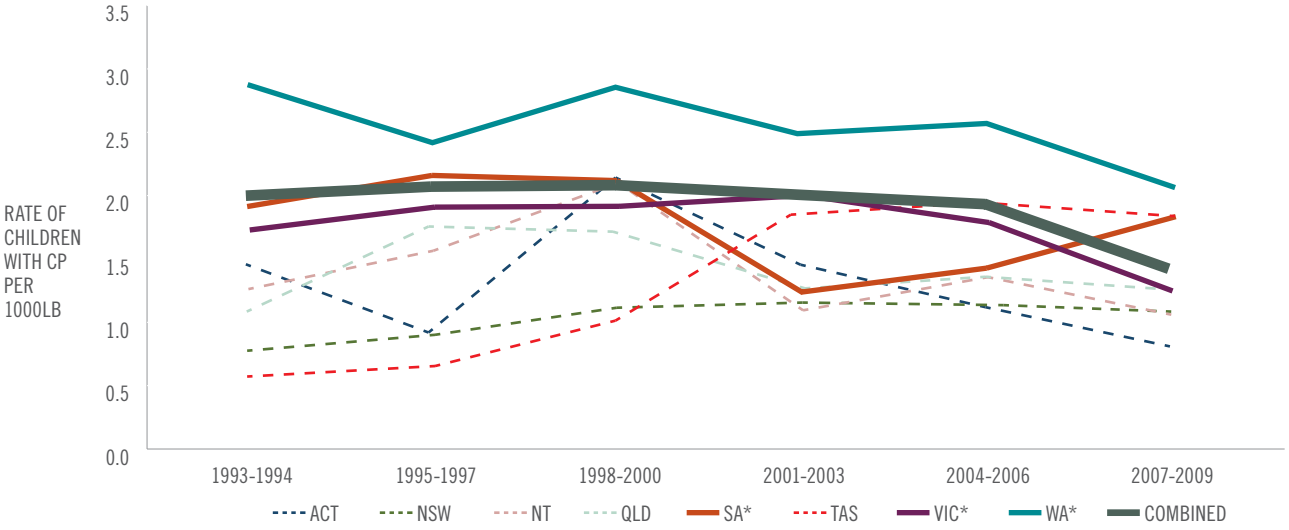
PREVALENCE

Birth prevalence of CP in this cohort is shown in Table 6 per 1000 live births and in Table 7 by 1000 neonatal survivors.

Table 6. Birth prevalence of CP by year and state/territory of birth, per 1000 live births (LB) (1993-2009)

	1993-1994	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	1993-2009
ACT							
Live Births (LB)	8875	13019	12300	12178	15369	16956	78697
CP Cases	14	12	27	20	18	13	104
CP cases/1000 LB	1.6	0.9	2.2	1.6	1.2	0.8	1.3
NSW							
Live Births (LB)	177331	261600	259035	257505	267314	286975	1509760
CP Cases	127	230	285	291	310	306	1549
CP cases/1000 LB	0.7	0.9	1.1	1.1	1.2	1.1	1.0
NT							
Live Births (LB)	7229	10916	10902	11336	10811	11449	62643
CP Cases	10	19	23	14	16	14	96
CP cases/1000 LB	1.4	1.7	2.1	1.2	1.5	1.2	1.5
QLD							
Live Births (LB)	93356	141218	140198	143791	161785	182444	862792
CP Cases	106	236	223	204	235	251	1255
CP cases/1000LB	1.1	1.7	1.6	1.4	1.5	1.4	1.5
SA*							
Live Births (LB)	39519	56986	54782	52917	54136	59196	317536
CP Cases	78	136	114	76	94	111	609
CP cases/1000 LB (95%CI)	2.0	2.4	2.1	1.4	1.7	1.9	1.9 (1.7,2.1)
TAS							
Live Births (LB)	13582	19275	18111	16779	17458	18982	104187
CP Cases	8	13	18	30	34	34	137
CP cases/1000 LB	0.6	0.7	1.0	1.8	1.9	1.8	1.3
VIC*							
Live Births (LB)	128660	187565	186272	187305	198353	216234	1104389
CP Cases	214	348	350	371	345	302	1930
CP cases/1000 LB (95%CI)	1.7	1.9	1.9	2.0	1.7	1.4	1.7 (1.7,1.9)
WA*							
Live Births (LB)	50447	75855	76137	73879	80578	91319	448215
CP Cases	139	185	216	182	210	191	1123
CP cases/1000 LB (95%CI)	2.8	2.4	2.8	2.5	2.6	2.1	2.5 (2.4,2.6)
COMBINED*							
Live Births (LB)	**218626**	**320406**	**317191**	**314101**	**333067**	**366749**	**1870140**
CP Cases	**431**	**669**	**680**	**629**	**649**	**604**	**3662**
CP cases/1000 LB (95%CI)	**2.0 (1.8,2.2)**	**2.1 (1.9,2.3)**	**2.1 (1.9,2.3)**	**2.0 (1.8,2.2)**	**1.9 (1.8,2.0)**	**1.6 (1.5,1.7)**	**2.0 (1.9,2.1)**
						TOTAL pre/perinatal CP:	**6803**

Figure 2. Birth cohort prevalence of CP per 1000 live births (LB) by state/territory and year of birth, in two and three year intervals (1993-2009)



After a long period of stable prevalence at around 2-2.5/1000, the rate of CP per 1000 live births declined to 1.4-2.1/1000 in the 2007-2009 period.

Table 7. Birth prevalence of CP per 1000 neonatal survivors (NNS) by state/territory of birth (1995 – 2009)

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	1995-2009
ACT & NSW						
NNS	273794	272988	269953	281766	302883	1401384
CP Cases	242	312	311	328	393	1586
CP cases/1000 NNS	0.9	1.1	1.2	1.2	1.3	1.1
NT						
NNS	10526	10100	10100*	10753	11404	52883
CP Cases	19	23	14	16	14	86
CP cases/1000 NNS	1.8	2.3	1.4	1.5	1.2	1.6
QLD						
NNS	142880	144619	147702	161180	181803	778184
CP Cases	236	223	204	235	251	1149
CP cases/1000 NNS	1.7	1.5	1.4	1.5	1.4	1.5
SA*						
NNS	56786	54641	52757	53986	59049	277219
CP Cases	136	114	76	94	111	531
CP cases/1000 NNS	2.4	2.1	1.4	1.7	1.9	1.9 (1.8, 2.1)
TAS						
NNS	19173	17895	16706	17387	18937	90098
CP Cases	13	18	30	34	34	129
CP cases/1000 NNS	0.7	1.0	1.8	2.0	1.8	1.4
VIC*						
NNS	186944	185419	186722	197671	197671#	954427
CP Cases	348	350	371	345	302	1716
CP cases/1000 NNS	1.9	1.9	2.0	1.7	1.5	1.8 (1.7,1.9)
WA*						
NNS	75555	75951	73700	80380	91125	396711
CP Cases	185	216	182	210	191	984
CP cases/1000 NNS	2.4	2.8	2.5	2.6	2.1	2.5 (1.9,3.1)
COMBINED*						
NNS	**319285**	**316011**	**313179**	**332037**	**347845**	**1628357**
CP Cases	**669**	**680**	**629**	**649**	**604**	**3231**
CP cases/1000 NNS	**2.1 (1.9,2.3)**	**2.2 (2.0,2.4)**	**2.0 (1.8,2.2)**	**2.0 (1.8,2.1)**	**1.7 (1.6,1.8)**	**2.0 (1.9,2.1)**

#Total NNS for previous triennium reported here as complete NNS data not available for this triennium

Analysis of the combined data demonstrated a significantly declining trend in the rate of CP per 1000 live births and neonatal survivors between 2001-2003 and 2007-2009 ($p < 0.05$). Data from Victoria and Western Australia show a striking reduction in the rate of CP in the final triennium 2007-2009.

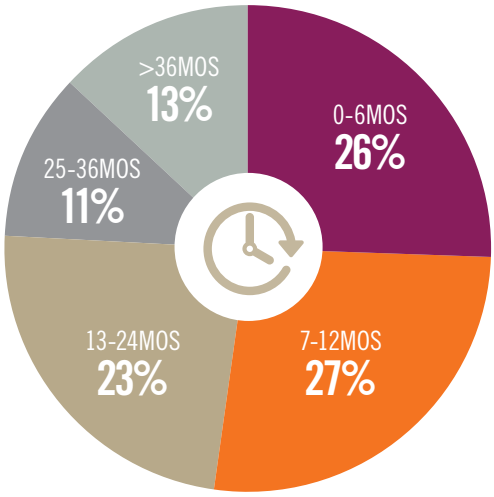
TIMING OF INITIAL CEREBRAL PALSY DESCRIPTION

Table 8. Children with CP by timing of initial CP description and state/territory of birth (1993-2009)

	0 – 6 months n(%)^	7 – 12 months n(%)^	13 – 24 months n(%)^	25 – 36 months n(%)^	37 – 48 months n(%)^	49 – 60 months n(%)^	Age 5 or later n(%)^	**TOTAL CP n**	Unknown n(%)
ACT*	30 (34.9)	21 (24.4)	22 (25.6)	5 (5.8)	♦ (4.7)	♦ (1.2)	♦ (3.5)	**104**	18 (17.3)
NSW*	437 (33.4)	280 (21.4)	329 (25.2)	126 (9.6)	53 (4.1)	35 (2.7)	47 (3.6)	**1549**	242 (15.6)
NT	17 (25.8)	12 (18.2)	18 (27.3)	8 (12.1)	♦ (1.5)	♦ (4.5)	7 (10.6)	**96**	30 (31.3)
QLD*	303 (29.1)	193 (18.5)	292 (28.0)	104 (10.0)	45 (4.3)	48 (4.6)	58 (5.6)	**1255**	212 (16.9)
SA*	125 (30.0)	119 (28.6)	103 (24.8)	31 (7.5)	23 (5.5)	♦ (1.0)	11 (2.6)	**609&**	24(3.9)
TAS	23 (21.7)	24 (22.6)	30 (28.3)	8 (7.5)	9 (8.5)	♦ (2.8)	9 (8.5)	**137**	31 (22.6)
VIC*	425 (26.8)	413 (26.1)	311 (19.6)	238 (15.0)	77 (4.9)	47 (3.0)	72 (4.5)	**1930**	347 (18.0)
WA*	80 (7.8)	429 (42.1)	224 (22.0)	109 (10.7)	48 (4.7)	130 (12.7)	0 (0.0)	**1123**	103 (9.2)
TOTAL	**1440**	**1491**	**1329**	**629**	**260**	**271**	**207**	**6803**	**1007**
COMBINED*	**1400 (25.7)**	**1455 (26.7)**	**1281 (23.5)**	**613 (11.2)**	**250 (4.6)**	**265 (4.9)**	**191 (3.5)**	**6570**	**946 (14.8)**

&South Australia Total CP includes n=169 that had not had their follow-up assessment at the time of data provision
(%)^ calculated by **n/total n** minus **unknown n** and SA n not assessed ; provided to allow state/territory comparisons
♦< 5 cases

Figure 3. Children with CP by timing of initial CP description, Australian Capital Territory, New South Wales, Queensland, South Australia&, Victoria and Western Australia combined (1993-2009)



&A further n=169 SA children had not had their follow-up assessment at the time of data provision

Combined data indicate that >50% of children in this cohort were described initially as having CP in the first year of life. >75% of this cohort were initially described as having CP by the age of 2 years.

SEX

Table 9. Number and percentage of children with CP by sex and state/territory of birth (1993-2009)

	Female n(%)	Male n(%)	TOTAL n
ACT*	39 (37.5)	65 (62.5)	**104**
NSW*	647 (41.8)	902 (58.2)	**1549**
NT*	34 (35.4)	62 (64.6)	**96**
QLD*	559 (44.5)	696 (55.5)	**1255**
SA*	258 (42.4)	351 (57.6)	**609**
TAS*	53 (38.7)	84 (61.3)	**137**
VIC*	827 (42.8)	1103 (57.2)	**1930**
WA*	505 (45.0)	618 (55.0)	**1123**
COMBINED*	**2922 (43.0)**	**3881 (57.0)**	**6803**

Figure 4. Percentage of children with CP by sex, all states and territories (1993-2009)

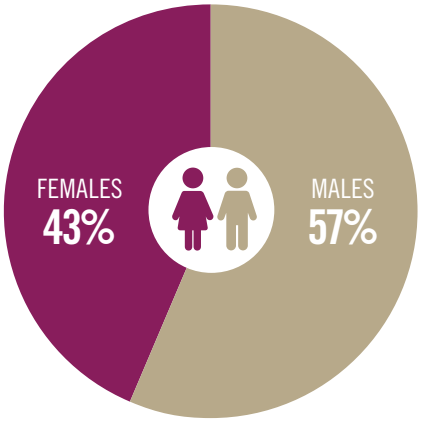


Table 10. CP birth prevalence per 1000 live births (LB) by sex, South Australia, Victoria and Western Australia (1995-2009)

Grouped year of birth		Males	Females	GENDER M/F ratio
1995-1997	CP	373	296	1.3
	Rate per 1000 LB	2.3	1.9	
	95% CI	2.1-2.5	1.7-2.1	
1998-2000	CP	379	302	1.3
	Rate per 1000 LB	2.3	2.0	
	95% CI	2.1-2.5	1.8-2.2	
2001-2003	CP	350	280	1.3
	Rate per 1000 LB	2.2	1.8	
	95% CI	2.0-2.4	1.6-2.0	
2004-2006	CP	399	253	1.6
	Rate per 1000 LB	2.3	1.6	
	95% CI	2.1-2.5	1.4-1.8	
2007-2009	CP	325	278	1.2
	Rate per 1000 LB	1.7	1.6	
	95% CI	1.5-1.9	1.4-1.8	

Combined data demonstrated that males are at a higher risk of developing cerebral palsy. 57% of the cohort was male compared to 51% of the Australian population born during this period[21].

For further information about associations of sex with specific subgroups of CP, please see Reid SM, Meehan E, Gibson CS, Scott H, Delacy MJ. Biological sex and the risk of CP in Victoria, Australia. Dev Med Child Neurol. 2016;58 Suppl 2:43-9.

MATERNAL AGE AT TIME OF DELIVERY

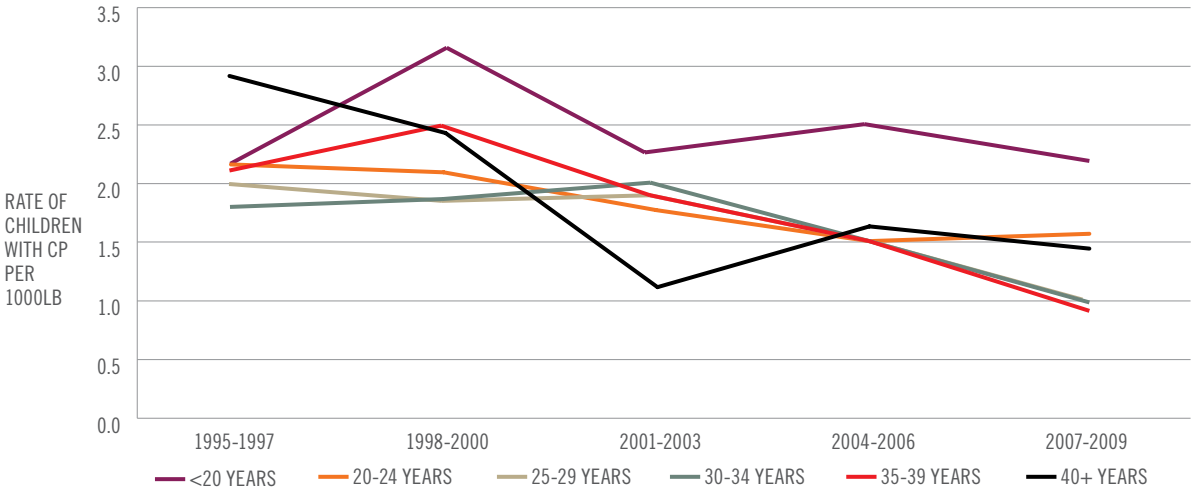
Table 11. Number and percentage of children with CP by maternal age (years) at delivery and state/territory of birth (1993-2009)

	<20 n(%)^	20-24 n(%)^	25-29 n(%)^	30-34 n(%)^	35-39 n(%)^	40+ n(%)^	**TOTAL n**	Unknown n(%)
ACT*	5 (5.4)	14 (15.1)	21 (22.6)	37 (39.8)	12 (12.9)	♦ (4.3)	**104**	11(10.6)
NSW*	65 (4.9)	212 (16.0)	343 (25.9)	419 (31.7)	234 (17.7)	49 (3.7)	**1549**	227(14.7)
NT*	19 (21.3)	20 (22.5)	21 (23.6)	17 (19.1)	9 (10.1)	♦ (3.4)	**96**	7(7.3)
QLD*	55 (5.5)	150 (14.9)	311 (31.0)	300 (29.9)	159 (15.8)	29 (2.9)	**1255**	251 (20.0)
SA*	33 (5.4)	120 (19.7)	167 (27.4)	187 (30.7)	92 (15.1)	10 (1.6)	**609**	0(0.0)
TAS*	8 (6.7)	22 (18.3)	33 (27.5)	37 (30.8)	13 (10.8)	7 (5.8)	**137**	17(12.4)
VIC*	72 (4.6)	206 (13.3)	439 (28.3)	540 (34.8)	235 (15.1)	61 (3.9)	**1930**	377(19.5)
WA*	85 (7.7)	181 (16.5)	317 (28.8)	319 (29.0)	169 (15.4)	29 (2.6)	**1123**	23(2.0)
COMBINED*	**342 (5.8)**	**925 (15.7)**	**1652 (28.0)**	**1856 (31.5)**	**923 (15.7)**	**192 (3.3)**	**6803**	**913(13.4)**

♦< 5 cases

(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

Figure 5. Children with CP per 1000 live births (LB), maternal age at delivery, South Australia, Victoria and Western Australia (1995-2009)



Rates of CP per 1000 live births have improved for all maternal age groups except for mothers <20 years which have remained stable over these 14 years.

GESTATIONAL AGE AT DELIVERY

Table 12. Number and percentage of children with CP by gestational age in weeks at delivery and state/territory of birth (1993-2009)

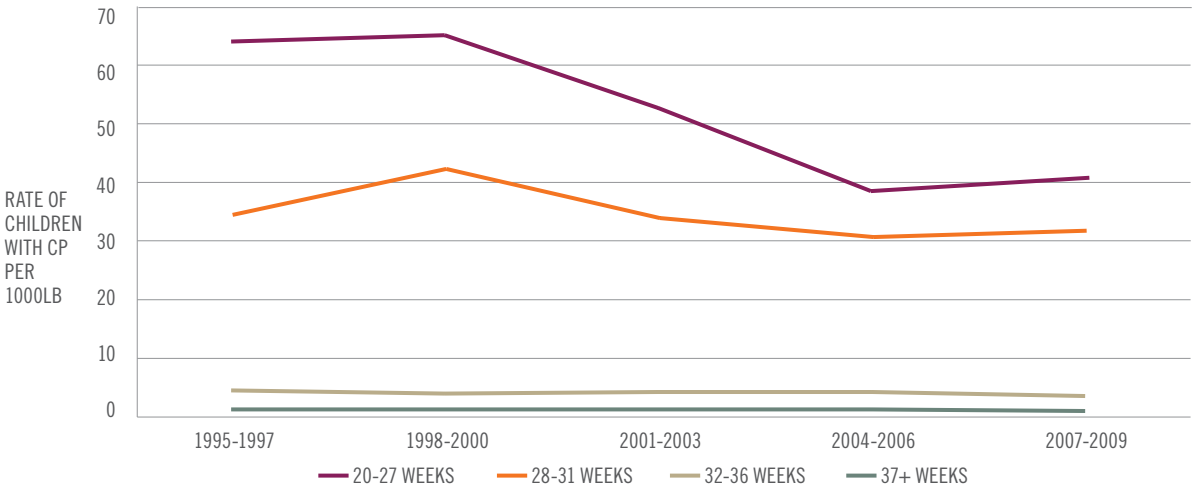
	20-27 n(%)^	28-31 n(%)^	32-36 n(%)^	≥37 n(%)^	**TOTAL n**	Unknown n(%)
ACT*	13 (13.1)	18 (18.2)	16 (16.2)	52 (52.5)	**104**	5 (4.8)
NSW*	206 (13.9)	195 (13.2)	227 (15.4)	849 (57.5)	**1549**	72 (4.6)
NT*	7 (7.7)	6 (6.6)	21 (23.1)	57 (62.6)	**96**	5 (5.2)
QLD*	165 (14.4)	184 (16.1)	201 (17.6)	595 (52.0)	**1255**	110 (8.8)
SA*	90 (14.9)	103 (17.0)	98 (16.2)	314 (51.9)	**609**	♦ (0.7)
TAS*	13 (10.1)	13 (10.1)	23 (17.8)	80 (62.0)	**137**	8 (5.8)
VIC*	238 (12.8)	260 (14.0)	267 (14.4)	1095 (58.9)	**1930**	70 (3.6)
WA*	124 (11.2)	138 (12.4)	177 (15.9)	673 (60.5)	**1123**	11 (1.0)
COMBINED*	**856 (13.1)**	**917 (14.1)**	**1030 (15.8)**	**3715 (57.0)**	**6803**	**285 (4.2)**

♦< 5 cases
(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

Table 13. Rate of children with CP per 1000 live births (LB), gestational age in weeks at delivery, South Australia, Victoria and Western Australia combined (1995-2009)

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009
20-27 weeks	65.5	66.2	50.5	39.0	40.9
28-31 weeks	36.4	45.1	35.0	31.6	32.7
32-36 weeks	5.2	4.7	4.8	4.9	4.1
37+ weeks	1.3	1.3	1.3	1.2	0.9

Figure 6. Children with CP per 1000 live births (LB), gestational age, South Australia, Victoria and Western Australia combined (1995-2009)



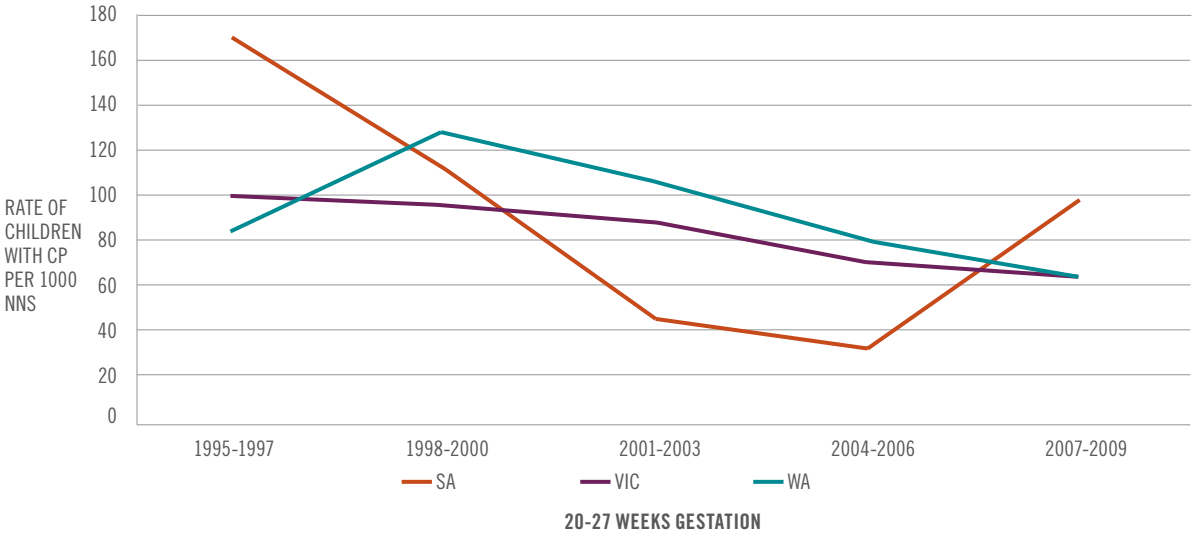
In this cohort the combined data indicate that 43% of CP births were preterm (< 37 weeks gestation). This is in contrast to the Australian population where 7.2% of live births were preterm[21]. The rate of CP per 1000 live births amongst the lower gestational age groups has risen slightly in the last triennium.

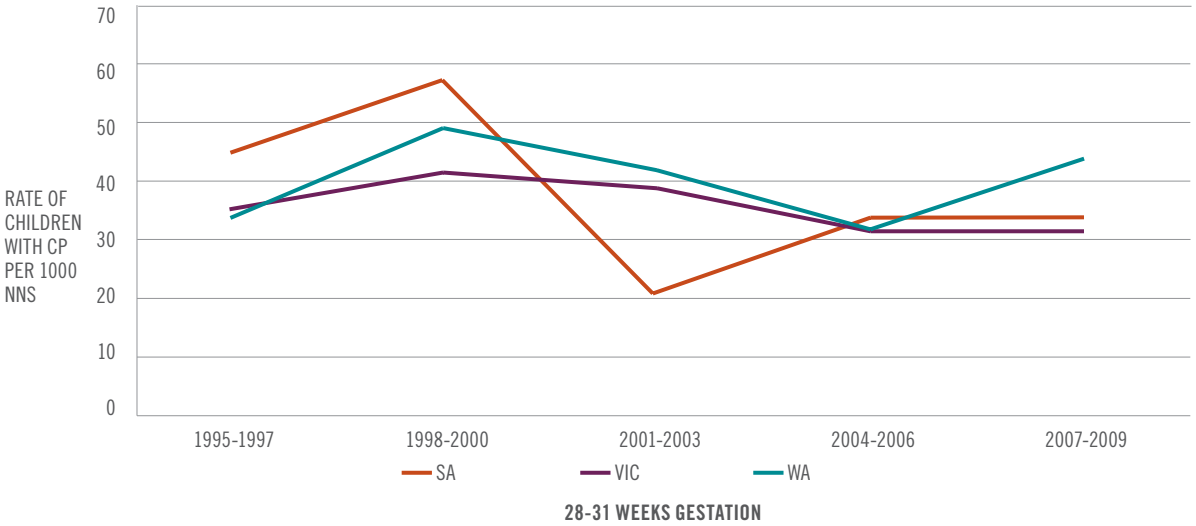
Table 14. Number and rate of children with CP born preterm per 1000 live births (LB) and neonatal survivors (NNS), by gestational age in weeks at delivery and state/territory of birth (1995-2009)

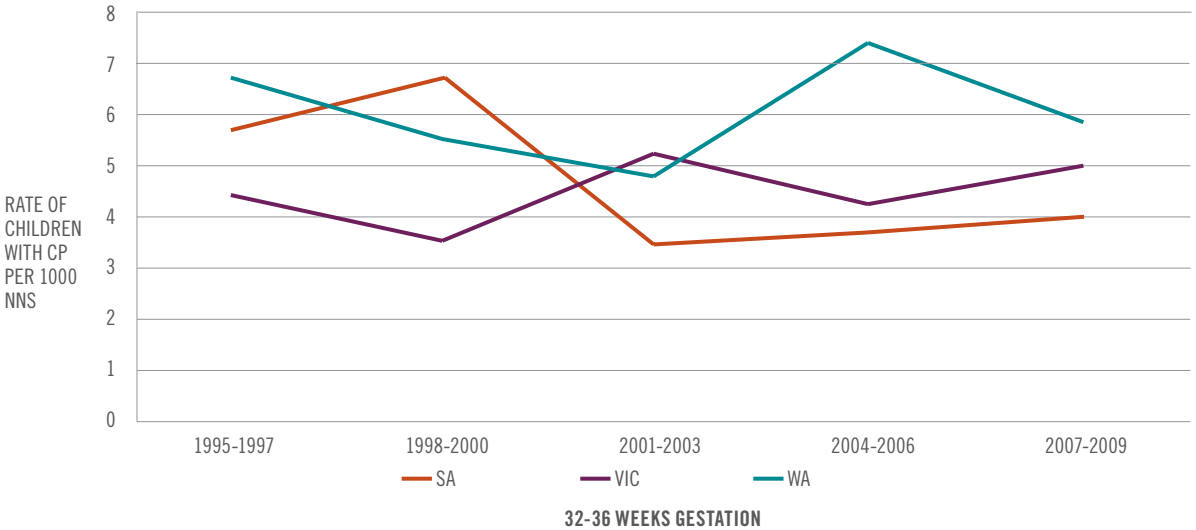
Gestational age group	Year of birth		SA	VIC	WA
20-27 weeks	**1995-1997**	**CP**	**29**	**44**	**17**
		Rate/LB (95%CI)	**98.0** (62.3 – 133.7)	**57.5** (40.5 - 74.5)	**54.1** (28.4 - 79.8)
		Rate/NNS (95%CI)	**166.7** (106.0 – 227.4)	**98.7** (69.5 - 127.9)	**82.5** (43.3 - 121.7)
	1998-2000	**CP**	**20**	**46**	**25**
		Rate/LB (95%CI)	**78.1** (43.9 – 112.3)	**55.6** (39.5 - 71.7)	**85.9** (52.2 – 119.6)
		Rate/NNS (95%CI)	**111.7** (62.7 – 160.7)	**94.7** (67.3 - 122.1)	**128.2** (77.9 – 178.5)
	2001-2003	**CP**	**7**	**45**	**23**
		Rate/LB (95%CI)	**26.6** (6.9 – 46.3)	**48.6** (34.4 – 62.8)	**55.9** (33.1 – 78.7)
		Rate/NNS (95%CI)	**43.5** (11.3 – 75.7)	**88.6** (62.7 – 114.5)	**108.0** (63.9 – 152.1)
	2004-2006	**CP**	**7**	**36**	**21**
		Rate/LB (95%CI)	**24.1** (6.2 – 42.0)	**37.0** (24.9 – 49.1)	**55.9** (32.0 – 79.8)
		Rate/NNS (95%CI)	**35.5** (9.2 – 61.8)	**68.0** (45.8 – 90.3)	**79.5** (45.5 – 113.6)
	2007-2009	**CP**	**18**	**33**	**19**
		Rate/LB (95%CI)	**65.5** (35.2 – 95.8)	**31.8** (21.0 – 42.6)	**47.4** (26.1 – 68.7)
		Rate/NNS(95%CI)	**91.8** (49.4 – 134.3)	**62.4** (41.1 – 83.7)*	**61.69** (34.0 – 89.4)
28-31 weeks	**1995-1997**	**CP**	**20**	**45**	**17**
		Rate/LB (95%CI)	**45.2** (25.4 – 65.0)	**34.5** (24.4 – 44.6)	**33.5** (17.6 – 49.4)
		Rate/NNS (95%CI)	**46.6** (26.2 – 67.0)	**36.1** (25.6 – 46.6)	**34.6** (18.2 – 51.0)
	1998-2000	**CP**	**27**	**53**	**28**
		Rate/LB (95%CI)	**56.5** (35.2 – 77.8)	**39.9** (29.2 – 50.6)	**47.5** (29.9 – 65.1)
		Rate/NNS (95%CI)	**58.2** (36.2 – 80.2)	**41.6** (30.4 – 52.8)	**48.4** (30.5 – 66.3)
	2001-2003	**CP**	**9**	**51**	**21**
		Rate/LB (95%CI)	**20.2** (7.0 - 33.4)	**38.1** (27.6 – 48.6)	**39.8** (22.8 – 56.8)
		Rate/NNS (95%CI)	**20.7** (7.2 – 34.2)	**39.2** (28.4 – 50.0)	**41.1** (23.5 – 58.7)
	2004-2006	**CP**	**15**	**43**	**20**
		Rate/LB (95%CI)	**33.7** (16.6 – 50.8)	**30.9** (21.7 – 40.1)	**31.8** (17.9 – 45.7)
		Rate/NNS (95%CI)	**34.1** (16.8 – 51.4)	**31.8** (22.3 – 41.3)	**32.3** (18.1 – 46.5)
	2007-2009	**CP**	**16**	**43**	**32**
		Rate/LB (95%CI)	**33.5** (17.1 - 49.9)	**27.0** (18.9 – 35.1)	**44.9** (29.3 – 60.5)
		Rate/NNS (95%CI)	**34.3** (17.5 – 51.1)	**31.8** (18.9-35.1)*	**46.0** (30.1 – 61.9)
32-36 weeks	**1995-1997**	**CP**	**20**	**46**	**29**
		Rate/LB (95%CI)	**5.8** (3.3 - 8.3)	**4.3** (3.1 – 5.5)	**6.8** (4.3 – 9.3)
		Rate/NNS(95%CI)	**5.8** (3.3 – 8.3)	**4.4** (3.1 – 5.7)	**6.8** (4.3 – 9.3)
	1998-2000	**CP**	**24**	**40**	**27**
		Rate/LB (95%CI)	**6.8** (4.1 – 9.5)	**3.6** (3.1 – 5.5)	**5.6** (4.3 – 9.3)
		Rate/NNS (95%CI)	**6.8** (4.1 – 9.5)	**3.6** (3.1 – 5.7)	**5.6** (4.3 – 9.3)
	2001-2003	**CP**	**12**	**60**	**23**
		Rate/LB (95%CI)	**3.5** (1.5 – 5.5)	**5.3** (4.0 -6.6)	**4.7** (3.5 – 7.7)
		Rate/NNS (95%CI)	**3.5** (1.5 – 5.5)	**5.3** (4.0 -6.6)	**4.8** (3.5 – 7.7)
	2004-2006	**CP**	**14**	**51**	**42**
		Rate/LB (95%CI)	**3.8** (1.8 - 5.8)	**4.1** (3.0 - 5.2)	**7.4** (5.2 - 9.6)
		Rate/NNS (95%CI)	**3.8** (1.8 - 5.8)	**4.2** (3.1 - 5.4)	**7.4** (5.2 – 9.6)
	2007-2009	**CP**	**16**	**46**	**36**
		Rate/LB (95%CI)	**3.9** (2.0 – 5.8)	**3.3** (2.3 – 4.3)	**5.8** (3.9 – 7.7)
		Rate/NNS (95%CI)	**4.0** (2.0 – 6.0)	**5.0** (3.6 – 6.4)*	**5.8** (3.9 – 7.7)

*Total NNS for previous triennium used here in calculation of rates as complete NNS data not available for this triennium

Figure 7. Rate of children with CP born preterm per 1000 neonatal survivors (NNS) by gestational age in weeks at delivery and state/territory of birth (1995-2009)







Amongst children born preterm, the rate of CP per 1000 neonatal survivors shows no shared trend across all jurisdictions, notably in the last triennium (2007-2009).

BIRTH WEIGHT

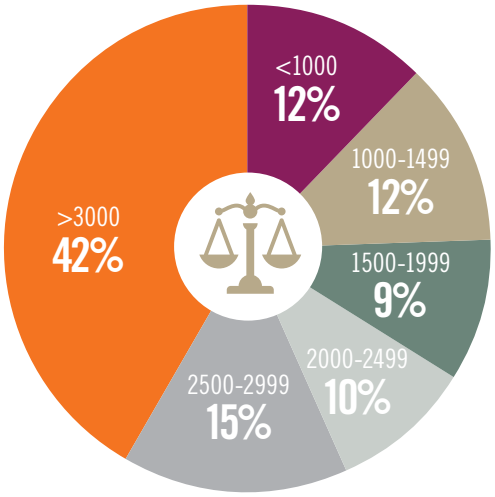
Table 15. Number and percentage of children with CP by birth weight in grams and state/territory of birth (1993-2009)

	<1000 n(%)^	1000-1499 n(%)^	1500-1999 n(%)^	2000-2499 n(%)^	2500-2999 n(%)^	3000-3499 n(%)^	3500-3999 n(%)^	4000+ n(%)^	**TOTAL n**	Unknown n(%)
ACT*	11 (11.6)	15 (15.8)	9 (9.5)	6 (6.3)	13 (13.7)	23 (24.2)	14(14.7)	♦ (4.2)	**104**	9 (8.7)
NSW*	182 (13.0)	176 (12.6)	112 (8.0)	146 (10.4)	195 (13.9)	290 (20.7)	219 (15.6)	82 (5.8)	**1549**	147 (9.5)
NT*	7 (7.9)	♦ (3.4)	9 (10.1)	9 (10.1)	12 (13.5)	31 (34.8)	15 (16.9)	♦ (3.4)	**96**	7 (7.3)
QLD*	143 (13.1)	146 (13.4)	108 (9.9)	119 (10.9)	148 (13.6)	209 (19.2)	153 (14.0)	63 (5.8)	**1255**	166 (13.2)
SA*	87 (14.4)	79 (13.1)	64 (10.6)	52 (8.6)	81 (13.4)	122 (20.2)	77 (12.7)	43 (7.1)	**609**	♦ (0.7)
TAS*	8 (7.0)	12 (10.5)	11 (9.6)	♦ (3.5)	22 (19.3)	38 (33.3)	11 (9.6)	8 (7.0)	**137**	23 (16.8)
VIC*	221 (12.7)	204 (11.7)	175 (10.1)	155 (8.9)	267 (15.3)	342 (19.7)	262 (15.1)	114 (6.6)	**1930**	190 (9.8)
WA*	107 (10.0)	121 (11.3)	96 (9.0)	95 (8.9)	190 (17.8)	256 (24.0)	142 (13.3)	61 (5.7)	**1123**	55 (4.9)
COMBINED*	**766 (12.4)**	**756 (12.2)**	**584 (9.4)**	**586 (9.4)**	**928 (15.0)**	**1311 (21.1)**	**893 (14.4)**	**378 (6.1)**	**6803**	**601 (8.8)**

♦ < 5 cases

(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

Figure 8. Percentage of children with CP by birth weight in grams, for all states/territories (1993-2009)



Low birth weight is defined as <2500g, very low birth weight <1500g and extremely low birth weight <1000g[22]. Combined data show that 43% of children with CP were born at low birth weight compared to 6% of the Australian population; 25% were born with very low birth weight compared to 1%, 12% had an extremely low birth weight compared with 0.4% of the Australian population[21].

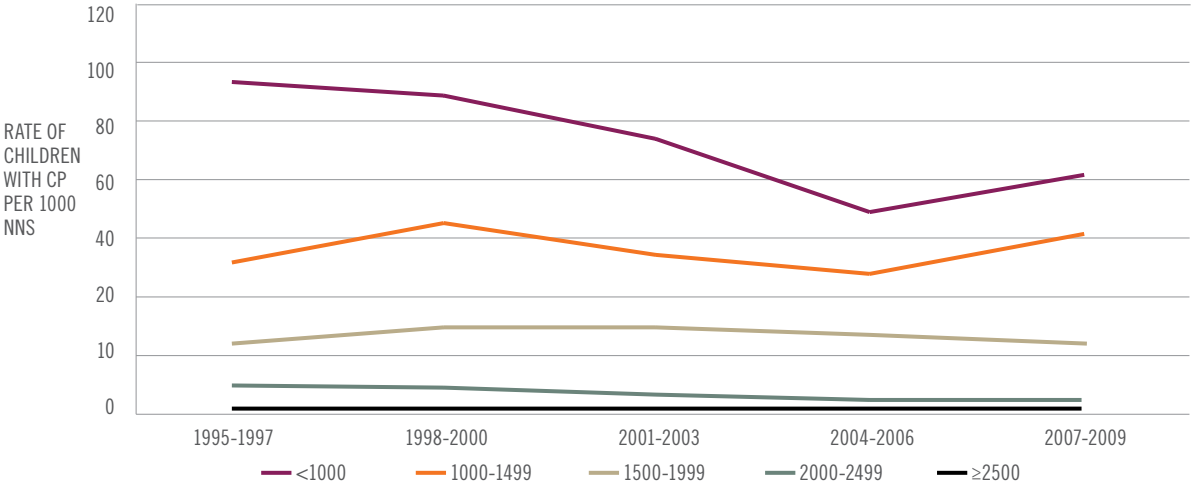
Table 16. Number and rate of children with CP by 1000 neonatal survivors (NNS), birth weight in grams and state/territory of birth (1995-2009)

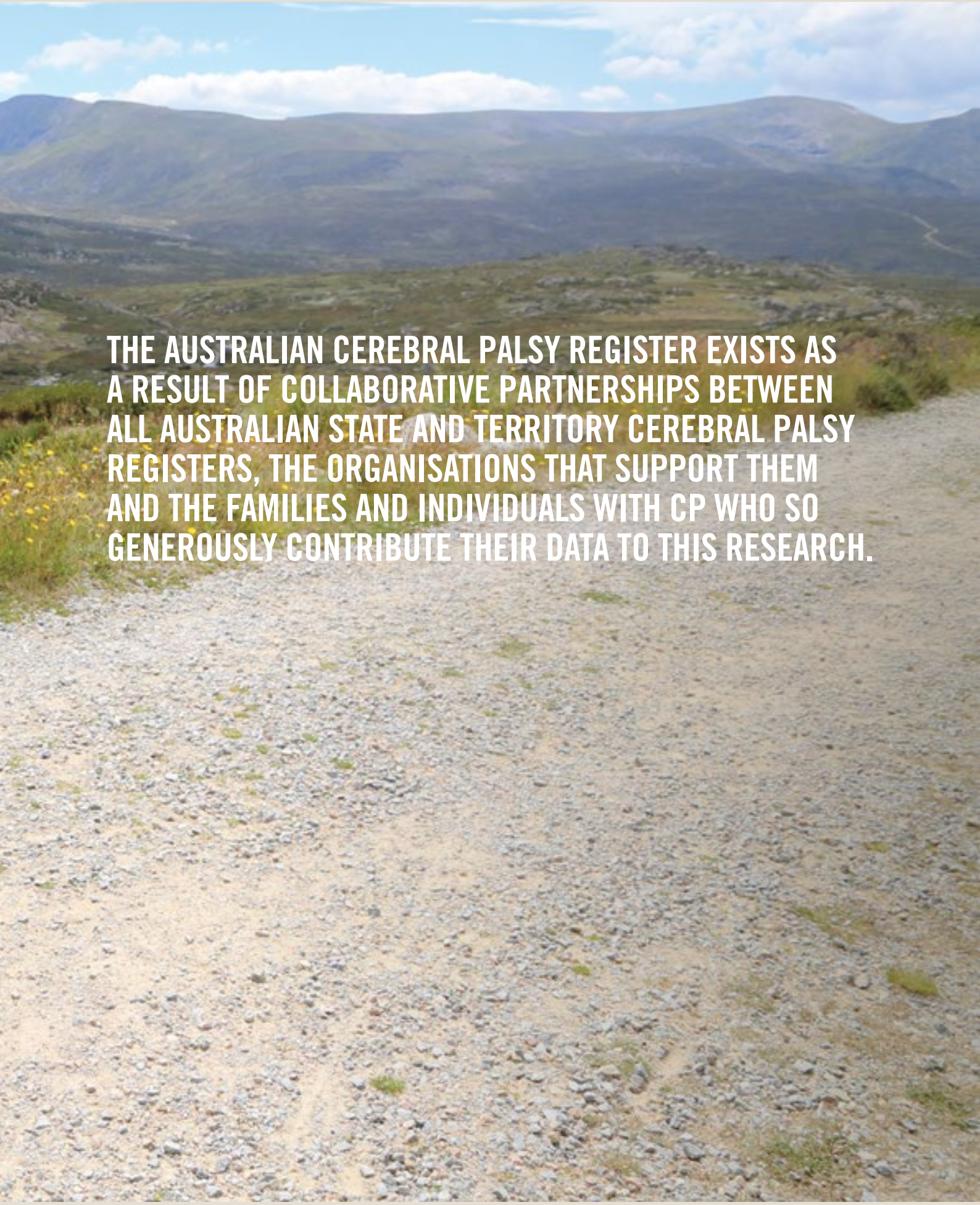
		SA			VIC			WA		
Birth weight	Birth years	n	NNS	Rate/1000 NNS (95%CI)	n	NNS	Rate/1000 NNS (95%CI)	n	NNS	Rate/1000NNS (95%CI)
<500	1995-1997	-	♦	-	♦	8	**125.0** (-120.0 – 370.0)	-	6	-
	1998-2000	♦	10	**100.0** (-96.0 – 296.0)	-	16	-	♦	8	**125.0** (-120 – 370)
	2001-2003	-	6	-	♦	21	**190.5** (3.8 – 377.1)	-	5	-
	2004-2006	-	9	-	-	13	-	-	9	-
	2007-2009	-	11	-	-	13*	-	♦	13	**76.9** (-73.8 – 227.7)
500-999	1995-1997	27	198	**136.4** (84.9 – 187.8)	46	496	**92.7** (65.9 – 119.5)	16	214	**74.8** (38.1 – 111.4)
	1998-2000	19	188	**101.1** (55.6 – 146.5)	41	512	**80.1** (55.6 – 104.6)	25	217	**115.2** (70.0 – 160.4)
	2001-2003	8	174	**46.0** (14.1 – 77.8)	43	535	**80.4** (56.4 – 104.4)	19	201	**94.5** (52.0 – 137.0)
	2004-2006	5	178	**28.1** (3.5 – 52.7)	28	543	**51.6** (32.5 – 70.7)	17	275	**61.8** (32.4 – 91.2)
	2007-2009	17	187	**90.9** (47.7 – 134.1)	30	543*	**55.2** (35.5 – 75.0)	16	292	**54.8** (27.9 – 81.6)
1000-1499	1995-1997	15	325	**46.2** (22.8 – 69.5)	29	951	**30.5** (19.4 – 41.6)	17	444	**38.3** (20.1 – 56.5)
	1998-2000	20	348	**57.5** (32.3 – 82.7)	43	1061	**40.5** (28.4 – 52.6)	19	438	**43.4** (23.9 – 62.9)
	2001-2003	6	322	**18.6** (3.7 – 33.5)	40	1079	**37.1** (25.6 – 48.6)	22	404	**54.5** (31.7 – 77.2)
	2004-2006	12	360	**33.3** (14.4 – 52.2)	37	1119	**33.1** (22.4 – 43.7)	14	462	**30.3** (14.4 – 46.2)
	2007-2009	14	357	**39.2** (18.7 – 59.8)	30	1119*	**26.8** (17.2 – 36.4)	25	525	**47.6** (29.0 – 66.3)
1500-1999	1995-1997	9	731	**12.3** (4.3 – 20.4)	29	2166	**13.4** (8.5 – 18.3)	13	897	**14.5** (6.6 – 22.4)
	1998-2000	18	709	**25.4** (13.7 – 37.1)	31	2328	**13.3** (8.6 – 18.0)	13	886	**14.7** (6.7 – 22.6)
	2001-2003	7	660	**10.6** (2.7 – 18.5)	42	2344	**17.9** (12.5 – 23.3)	13	930	**14.0** (6.4 – 21.6)
	2004-2006	9	712	**12.6** (4.4 – 20.9)	29	2437	**11.9** (7.6 – 16.2)	28	1062	**26.4** (16.6 – 36.1)
	2007-2009	11	766	**14.4** (5.9 – 22.8)	28	2437*	**11.5** (7.2 – 15.7)	20	1173	**17.1** (9.6 – 24.5)
2000-2499	1995-1997	11	2303	**4.8** (2.0 – 7.6)	33	7094	**4.7** (3.1 – 6.2)	22	2957	**7.4** (4.3 – 10.5)
	1998-2000	11	2196	**5.0** (2.0 – 8.0)	29	7326	**4.0** (2.5 – 5.4)	18	3080	**5.8** (3.1 – 8.5)
	2001-2003	8	2135	**3.7** (1.2 – 6.3)	28	7466	**3.8** (2.4 – 5.1)	11	3050	**3.6** (1.5 – 5.7)
	2004-2006	10	2240	**4.5** (1.7 – 7.2)	21	7998	**2.6** (1.5 – 3.7)	14	3294	**4.3** (2.0 – 6.5)
	2007-2009	8	2424	**3.3** (1.0 – 5.6)	21	7998*	**2.6** (1.5 – 3.7)	18	3549	**5.1** (2.7 – 7.4)
2500+	1995-1997	71	53227	**1.3** (1.0 – 1.6)	201	183243	**1.1** (0.9 – 1.2)	117	71037	**1.6** (1.3 – 1.9)
	1998-2000	44	51189	**0.9** (0.6 – 1.1)	183	176198	**1.0** (0.9 – 1.2)	139	71318	**1.9** (1.6 – 2.3)
	2001-2003	47	49459	**1.0** (0.7 – 1.2)	192	174158	**1.1** (1.0 – 1.3)	109	69106	**1.6** (1.3 – 1.9)
	2004-2006	58	50487	**1.1** (0.9 – 1.4)	181	175263	**1.0** (0.9 – 1.2)	118	75278	**1.6** (1.3 – 1.9)
	2007-2009	61	55300	**1.1** (0.8 – 1.4)	110	175263*	**0.6** (0.5 – 0.8)	84	85573	**1.0** (0.8 – 1.2)
Unknown		♦			185			55		

♦<5 cases

*Total NNS for previous triennium used here in calculation of rates as complete NNS data not available for this triennium

Figure 9. Rate of children with CP per 1000 neonatal survivors (NNS), by birth weight in grams, South Australia, Victoria and Western Australia combined (1995 -2009)





THE AUSTRALIAN CEREBRAL PALSY REGISTER EXISTS AS A RESULT OF COLLABORATIVE PARTNERSHIPS BETWEEN ALL AUSTRALIAN STATE AND TERRITORY CEREBRAL PALSY REGISTERS, THE ORGANISATIONS THAT SUPPORT THEM AND THE FAMILIES AND INDIVIDUALS WITH CP WHO SO GENEROUSLY CONTRIBUTE THEIR DATA TO THIS RESEARCH.

PLURALITY

Table 17. Number and percentage of children with CP by birth plurality and state/territory of birth (1993-2009)

Birth plurality	Singletons	Twins	Higher order multiples	**TOTAL**	Unknown
	n(%)^	n(%)^	n(%)^	**n**	n(%)
ACT*	81 (84.4)	15 (15.6)	0 (0.0)	**104**	8 (7.7)
NSW*	1225 (88.5)	143 (10.3)	16 (1.2)	**1549**	165 (10.7)
NT*	85 (95.5)	♦ (4.5)	0 (0.0)	**96**	7 (7.3)
QLD*	967 (86.0)	138 (12.3)	19 (1.7)	**1255**	131 (10.4)
SA*	539 (88.5)	69 (11.3)	♦ (0.2)	**609**	0 (0.0)
TAS*	110 (85.9)	15 (11.7)	♦ (2.3)	**137**	9 (6.6)
VIC*	1601 (87.1)	214 (11.6)	24 (1.3)	**1930**	91 (4.7)
WA*	987 (89.6)	106 (9.6)	8 (0.7)	**1123**	22 (2.0)
COMBINED*	**5595 (87.8)**	**704 (11.1)**	**71 (1.1)**	**6803**	**433 (6.4)**

♦ < 5 cases

(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

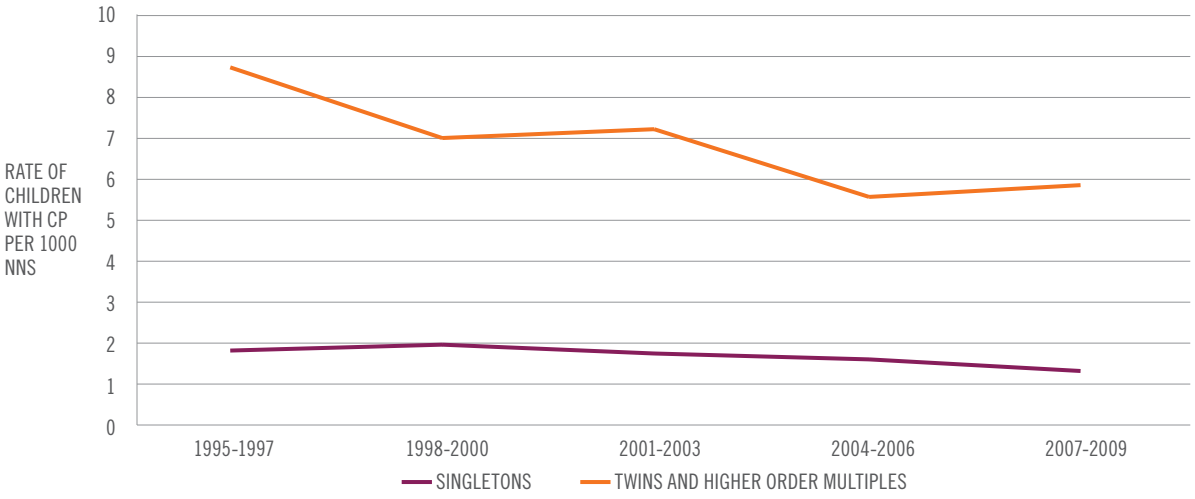
Combined data indicates that 12.2% of children with CP were from a multiple birth compared to 3.1% of all births in Australia[21].

Table 18. Rate of children with CP per 1000 neonatal survivors (NNS), by plurality, South Australia, Victoria and Western Australia combined (1995-2009)

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009
Singletons					
CP n	591	601	535	544	487
NNS	309955	306161	302794	320862	336519*
Rate/1000 NNS	1.9	2.0	1.8	1.7	1.4
95%CI	1.7 – 2.1	1.8 – 2.2	1.7 – 2.1	1.6 – 1.8	1.3 – 1.5
Twins and higher order multiples					
CP n	81	70	75	64	67
NNS	9330	9850	10385	11175	11322*
Rate/1000 NNS	8.7	7.1	7.2	5.7	5.9
95%CI	6.8 – 10.6	5.4 – 8.7	5.6 – 8.9	4.2 – 7.0	4.5 – 7.3

*Total Victorian NNS for previous triennium reported here as complete NNS data not available for this triennium

Figure 10. Rate of children with CP per 1000 neonatal survivors (NNS) by plurality South Australia, Victoria and Western Australia combined (1995-2009)



Due to the small frequency of higher order multiple births, it is difficult to study CP in this sub-group of children. The ACPR is currently undertaking a collaborative research study with researchers from the Surveillance of Cerebral Palsy in Europe to pool de-identified data to examine the risk of CP amongst higher order multiple births.

PREDOMINANT MOTOR TYPE

Table 19. Number and percentage of children with CP by predominant motor type *(with spastic topography)* and state/territory of birth (1993-2009)

	Spastic n(%)^	*Hemiplegia*	*Diplegia*	*Triplegia*	*Quadriplegia*	Ataxic n(%)^	Dyskinetic n(%)^	Hypotonic n(%)^	**TOTAL n**	Unknown n(%)
ACT*	81 (88.0)	*35 (43.2)*	*23 (28.4)*	*0 (0.0)*	*23 (28.4)*	♦ (2.2)	7 (7.6)	♦ (2.2)	**104**	12 (11.5)
NSW*	1156 (83.8)	*481 (41.6)*	*318 (27.5)*	*22 (1.9)*	*335 (29.0)*	75 (5.4)	90 (6.5)	58 (4.2)	**1549**	170 (11.0)
NT*	71 (78.9)	*29 (40.8)*	*20 (28.2)*	*0 (0.0)*	*22 (31.0)*	5 (5.6)	10 (11.1)	4 (4.4)	**96**	6 (6.3)
QLD*	996 (86.9)	*346 (34.7)*	*417 (41.9)*	*16 (1.6)*	*217 (21.8)*	49 (4.3)	66 (5.8)	35 (3.1)	**1255**	109 (8.7)
SA*	564 (93.4)	*228 (40.4)*	*197 (34.9)*	*15 (2.7)*	*124 (22.0)*	19 (3.1)	18 (3.0)	♦ (0.5)	**609**	5 (0.8)
TAS	74 (88.1)	*24 (32.4)*	*31 (41.9)*	♦ *(5.4)*	*15 (20.3)*	♦ (4.8)	6 (7.1)	0 (0.0)	**137**	53 (38.7)
VIC*	1643 (86.7)	*653 (39.7)*	*554 (33.7)*	*43 (2.6)*	*393 (23.9)*	73 (3.9)	116 (6.1)	64 (3.4)	**1930**	34 (1.8)
WA*	922 (82.1)	*353 (38.3)*	*430 (46.6)*	*24 (2.6)*	*115 (12.5)*	81 (7.2)	97 (8.6)	23 (2.0)	**1123**	0 (0.0)
TOTAL	**5507**	***2149***	***1990***	***124***	***1244***	**308**	**410**	**189**	**6803**	**389**
COMBINED*	**5433 (85.8)**	***2125 (39.1)***	***1959 (36.1)***	***120 (2.2)***	***1229 (22.6)***	**304 (4.8)**	**404 (6.4)**	**189 (3.0)**	**6666**	**336 (5.0)**

♦< 5 cases

(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

NB: 'Dyskinetic cerebral palsy' includes both dystonic and athetoid/choreoathetoid CP

Combined data indicates that spasticity was the predominant motor type of CP (85.8%). South Australia had a lower proportion of dyskinesia as the predominant motor type. The ACPR is endeavouring to determine whether these differences are aetiological.

Combined data indicates that hemiplegia (including monoplegia) is the most common topographical pattern of spasticity. However, if diplegia, triplegia and quadriplegia are grouped as bilateral spastic CP[3] this group was predominant.

There is considerable variability in the proportions of hypotonic CP across jurisdictions (0.5%-4.4%). The ACPR Group is working with clinicians and researchers to consider the inclusion and exclusion criteria for hypotonic CP. The Surveillance of Cerebral Palsy in Europe do not include hypotonia as a sole motor type of CP. If cases of hypotonic CP were removed from combined ACPR data, there would be no difference in the reported rates.


HILLS

Figure 11. Number and percentage of children with CP by predominant motor type and gestational age group in weeks, Australian Capital Territory, New South Wales, Northern Territory, Queensland, South Australia, Victoria and Western Australia combined (1993-2009)

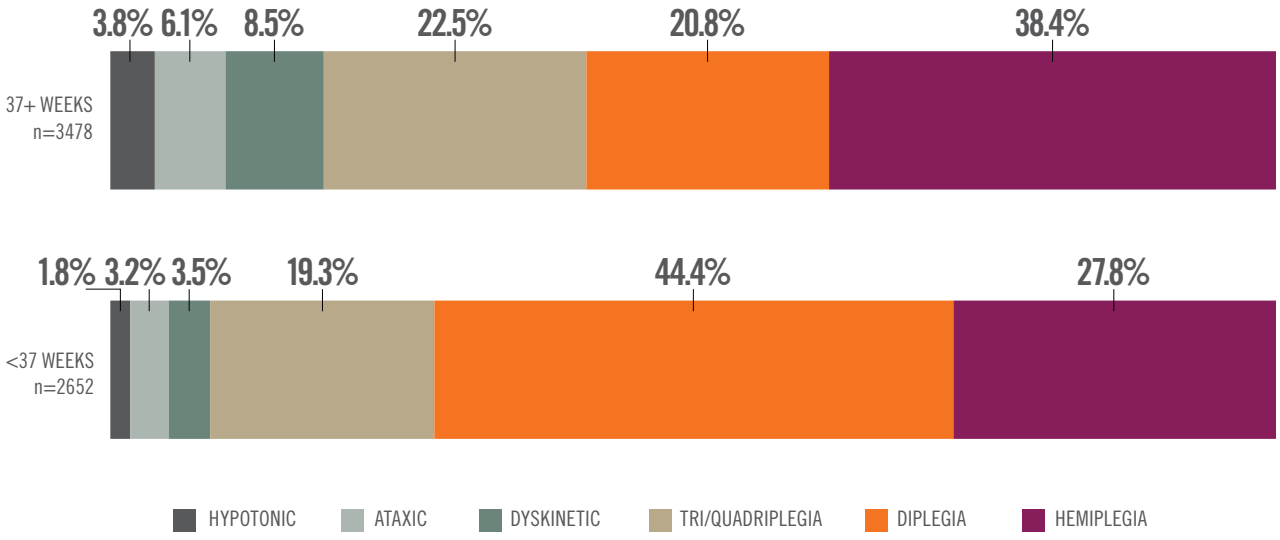
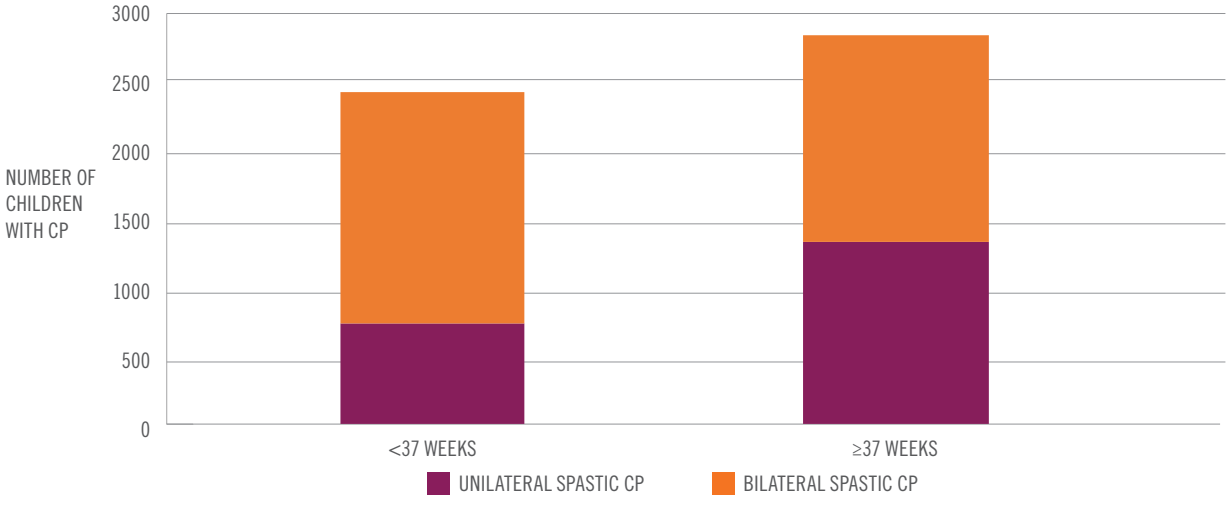


Figure 12. Number of children with CP by predominant spastic subtype (unilateral or bilateral) and gestational age in weeks, Australian Capital Territory, New South Wales, Northern Territory, Queensland, South Australia, Victoria and Western Australia combined (1993-2009)



For information about the Australian Spasticity Assessment Scale, please see Love S, Gibson N, Smith N, Bear N, Blair E. Interobserver reliability of the Australian Spasticity Assessment Scale (ASAS). Dev Med Child Neurol. 2016;58 Suppl 2:18-24.

Figure 13. Number and percentage of children with CP by predominant and secondary motor type, South Australia, Victoria and Western Australia combined (2007-2009*)

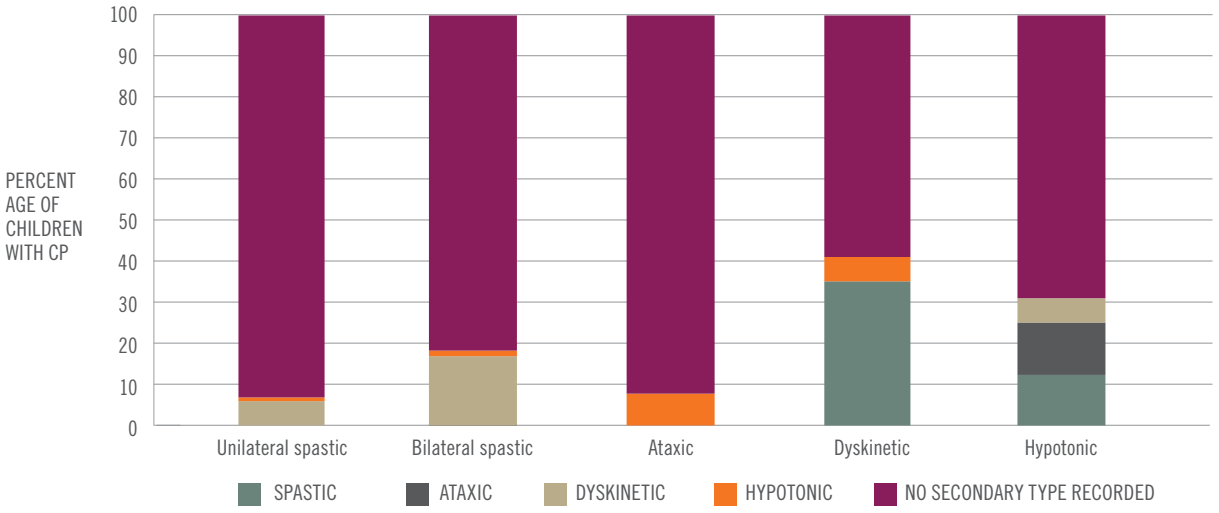
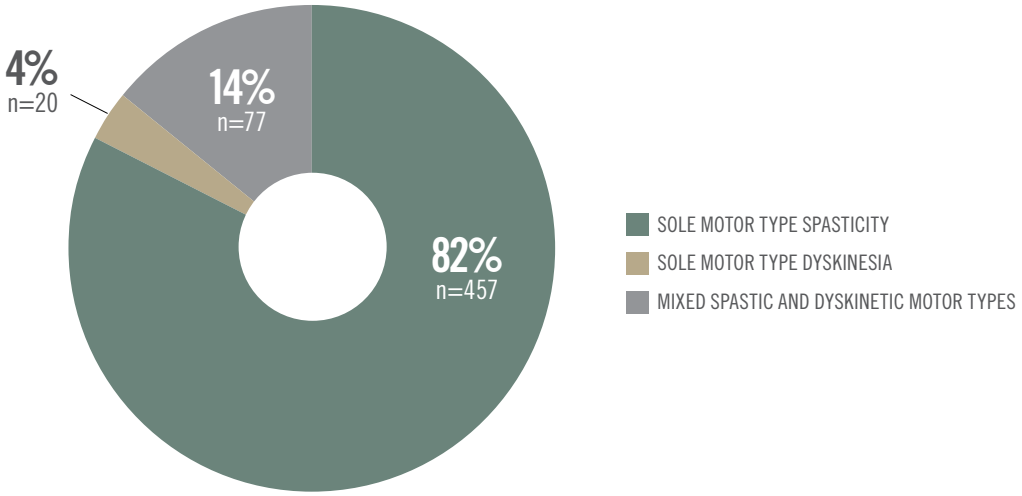


Figure 14. Number and percentage of children with CP by sole motor type (spastic or dyskinetic) and mixed motor type (spastic and dyskinetic), South Australia, Victoria and Western Australia combined (2007-2009*)



*The 2007-2009 cohort was used for these figures, as this most recent triennium has the most complete available data from the CP registers at this time.
NB: 'Dyskinetic cerebral palsy' includes both dystonic and athetoid/choreoathetoid CP.

Combined data suggests that amongst children who have a predominant spastic or dyskinetic motor type a minimum of 14% have a mixed motor type of both spastic and dyskinetic CP. The CP registers have historically focussed on collection of data pertaining to the predominant motor type so this figure is likely to be an underestimate. In recent years many states in Australia have adopted the Cerebral Palsy Description Form (see Appendix B) and the ACPR Group hopes this will assist with accurate data collection of mixed motor types.

GROSS MOTOR FUNCTION

Table 20. Number and percentage of children with CP by Gross Motor Function Classification System[24] levels (GMFCS) and state/territory of birth (1993-2009)

	I n(%)^	II n(%)^	III n(%)^	IV n(%)^	V n(%)^	**Total** **n**	Unknown n(%)
ACT*	34 (36.2)	19 (20.2)	13 (13.8)	15 (16.0)	13 (13.8)	**104**	10 (9.6)
NSW*	528 (37.2)	299 (21.0)	164 (11.5)	192 (13.5)	238 (16.7)	**1549**	128 (8.3)
NT*	38 (40.4)	21 (22.3)	7 (7.4)	7 (7.4)	21 (22.3)	**96**	♦ (2.1)
QLD*	340 (29.3)	304 (26.2)	167 (14.4)	181 (15.6)	169 (14.6)	**1255**	94 (7.5)
SA*	193 (44.0)	90 (20.5)	55 (12.5)	46 (10.5)	55 (12.5)	**609**[&]	♦ (0.2)
TAS	29 (42.0)	12 (17.4)	8 (11.6)	8 (11.6)	12 (17.4)	**137**	68 (49.6)
VIC*	656 (35.4)	493 (26.6)	193 (10.4)	232 (12.5)	279 (15.1)	**1930**	77 (4.0)
WA	252 (47.0)	93 (17.4)	55 (10.3)	59 (11.0)	77 (14.4)	**1123**	587 (52.3)
TOTAL	**2070**	**1331**	**662**	**740**	**864**	**6803**	**967**
COMBINED*	**1789 (35.3)**	**1226 (24.2)**	**599 (11.8)**	**673 (13.3)**	**775 (15.3)**	**5543**	**312 (5.8)**

♦< 5 cases

[&]South Australia Total CP includes n=169 that had not had their follow-up assessment at the time of data provision

(%)^ calculated by **n/total n** minus **unknown n** and SA n not assessed; provided to allow state/territory comparisons

Combined data from South Australia and Victoria indicates that at the age of 5 years the predominant levels of gross motor function are GMFCS I and II (59.2%). More than half the children with CP are able to walk indoors and on level surfaces outdoors at age 5 years without needing an assistive mobility device.

Table 21. Number and rate of children with CP per 1000 neonatal survivors (NNS), by Gross Motor Function Classification System (GMFCS) category (I-II or III-V), South Australia and Victoria (1995-2009)

			GMFCS I-II		GMFCS III-V	
	Birth years	NNS	CP	Rate/1000 NNS	CP	Rate/1000 NNS
SA[&]	1995-1997	56786	82	1.4	31	0.5
	1998-2000	54641	51	0.9	31	0.6
	2001-2003	52757	35	0.7	23	0.4
	2004-2006	53986	49	0.9	25	0.5
	2007-2009	59049	42	0.7	39	0.7
VIC	1995-1997	186944	188	1.0	141	0.8
	1998-2000	185419	216	1.2	128	0.7
	2001-2003	186722	233	1.2	135	0.7
	2004-2006	197671	218	1.1	119	0.6
	2007-2009	197671*	186	0.9	105	0.5

*Total Victorian NNS for previous triennium reported here as complete NNS data not available for this triennium
[&]A further n=169 SA children had not had their follow-up assessment at the time of data provision

Figure 15. Rate of children with CP per 1000 neonatal survivors (NNS), by Gross Motor Function Classification System (GMFCS) category (I-II or III-V), South Australia and Victoria (1995-2009)

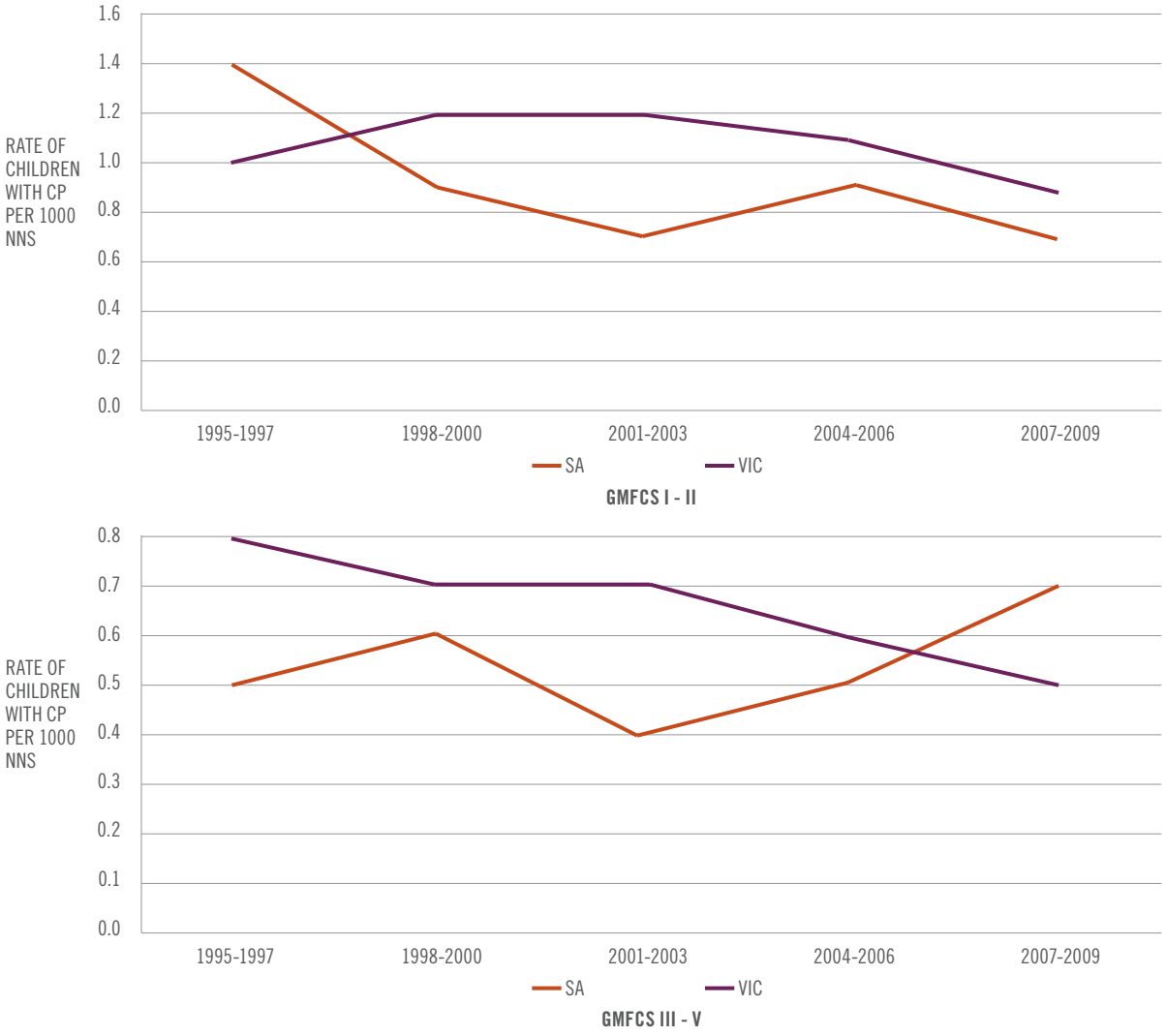
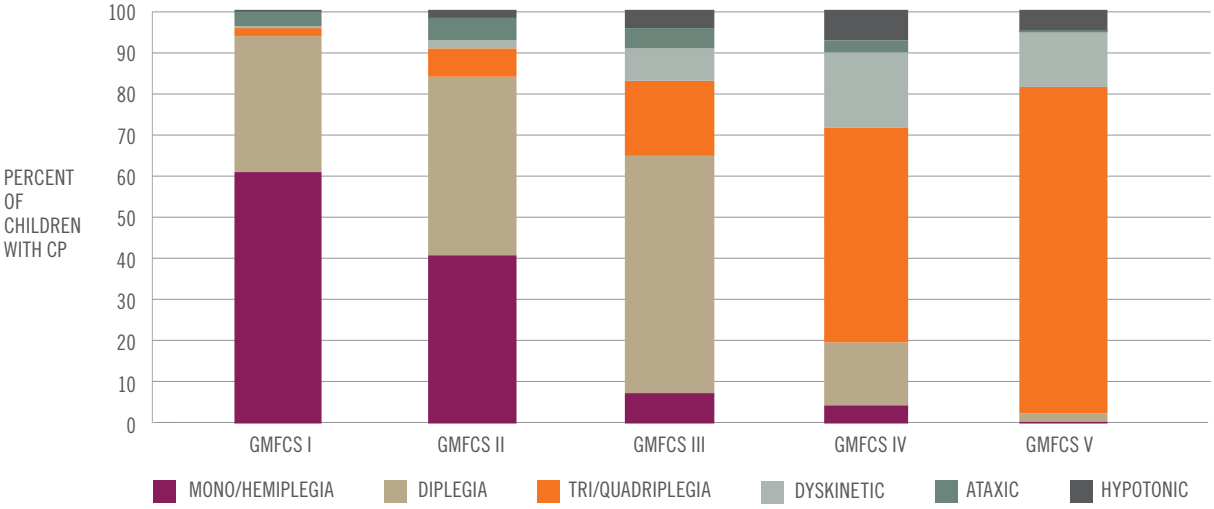


Figure 16. Percentage of children with CP by Gross Motor Function Classification System (GMFCS) level and predominant motor type at 5 years, South Australia and Victoria combined (1993-2009)



CONGENITAL ANOMALIES

Table 22. Number and percentage of identified congenital anomalies amongst children with CP by state/territory of birth (1993-2009)

	No known congenital anomaly n(%)^	One or more congenital anomalies n(%)^	**Total**	Unknown n(%)
ACT*	75 (82.4)	16 (17.6)	**104**	13 (12.5)
NSW*	1027 (78.5)	281 (21.5)	**1549**	241 (15.6)
NT	44 (73.3)	16 (26.7)	**96**	36 (37.5)
QLD*	819 (72.9)	304 (27.1)	**1255**	132 (10.5)
SA*#	365 (59.9)	244 (40.1)	**609**	0 (0.0)
TAS	97 (96.0)	♦ (4.0)	**137**	36 (26.3)
VIC*	1506 (78.5)	413 (21.5)	**1930**	11 (0.6)
WA*	856 (76.2)	267(23.8)	**1123**	0 (0.0)
TOTAL	**4789**	**1545**	**6803**	**469**
COMBINED*	**4648 (75.3)**	**1525 (24.7)**	**6570**	**397 (6.0)**

♦< 5 cases

(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

The SA CP Register is directly linked to SA Birth Defects Register – this figure therefore represents a more likely proportion of children with CP who have a congenital anomaly.

The proportions of children with CP with reported congenital anomalies range from 21.8% to 40.1% in the three long-standing CP registers.

Researchers from the ACPR Group are now investigating this risk factor through a collaboration between the Surveillance of Cerebral Palsy Europe and EUROCAT. This large study will explore the co-occurrence of congenital anomalies and CP. *"The Comprehensive CA-CP Study"* will link data between CP and congenital anomaly registers in regions of Europe and Australia and subsequently pool data to create a sufficiently large dataset to explore these heterogeneous conditions.

For further information about congenital anomalies as a risk factor for CP, please see McIntyre S, Blair E, Goldsmith S, Badawi N, Gibson C, Scott H, et al. Congenital anomalies in cerebral palsy: where to from here? Dev Med Child Neurol. 2016;58 Suppl 2:71-5.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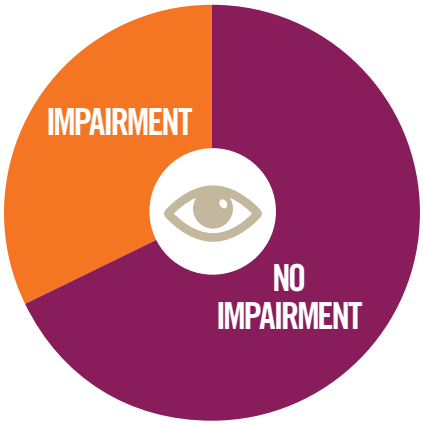
ASSOCIATED IMPAIRMENTS

Vision

Table 23. Number and percentage of children with CP by vision status and state/territory of birth (1993-2009)

	No impairment n(%)^	Some impairment n(%)^	Functionally blind n(%)^	TOTAL n	Unknown n(%)
ACT*	54 (62.8)	29 (33.7)	♦ (3.5)	**104**	18 (17.3)
NSW*	817 (62.8)	435 (33.4)	49 (3.8)	**1549**	248 (16.0)
NT*	46 (51.1)	35 (38.9)	9 (10.0)	**96**	6 (6.3)
QLD*	618 (57.0)	415 (38.3)	51 (4.7)	**1255**	171 (13.6)
SA*	260 (61.3)	148 (34.9)	16 (3.8)	**609**[&]	16 (3.6)
TAS*	79 (69.9)	32 (28.3)	2 (1.8)	**137**	24 (17.5)
VIC*	1197 (68.8)	474 (27.2)	70 (4.0)	**1930**	189 (9.8)
WA*	756 (69.3)	273 (25.0)	62 (5.7)	**1123**	32 (2.8)
COMBINED*	**3827 (64.5)**	**1841 (31.0)**	**262 (4.4)**	**6803**	**704 (10.6)**



♦< 5 cases

[&]South Australia CP Total includes n=169 that had not had their follow-up assessment at the time of data provision

(%)^ calculated by **n/total n** minus **unknown n and SA n not assessed**; provided to allow state/territory comparisons

Table 24. Number and percentage of children with CP by presence/absence of strabismus and state/territory of birth (1993-2009)

	No strabismus n(%)^	Strabismus n(%)^	TOTAL n	Unknown n(%)
ACT	48 (84.2)	9 (15.8)	**104**	47 (45.2)
NSW	739 (82.8)	154 (17.2)	**1549**	656 (42.3)
NT	36 (73.5)	13 (26.5)	**96**	47 (49.0)
QLD	665 (66.4)	336 (33.6)	**1255**	254 (20.2)
SA*	236 (57.3)	176 (42.7)	**609**[&]	28 (6.4)
TAS	70 (82.4)	15 (17.6)	**137**	52 (38.0)
VIC	938 (73.6)	336 (26.4)	**1930**	656 (34.0)
WA*	739 (72.2)	284 (27.8)	**1123**	100 (8.9)
TOTAL	**3471**	**1323**	**6803**	**1840**
COMBINED*	**975 (67.9)**	**460 (32.1)**	**1732**	**128 (8.2)**

♦< 5 cases

[&]South Australia CP Total includes n=169 that had not had their follow-up assessment at the time of data provision

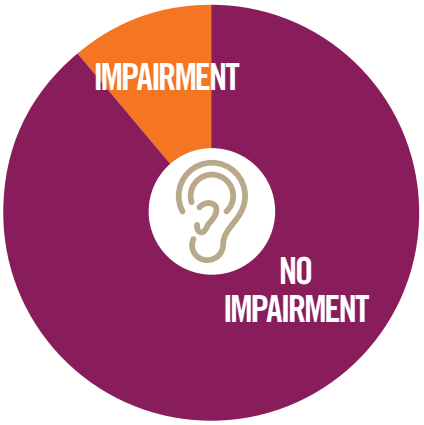
(%)^ calculated by **n/total n** minus **unknown n and SA n not assessed**; provided to allow state/territory comparisons

For further information about strabismus amongst children with CP, please see Blair E, Smithers-Sheedy H. Strabismus, a preventable barrier to social participation: a short report. Dev Med Child Neurol. 2016;58 Suppl 2:57-9.

Hearing

Table 25. Number and percentage of children with CP by hearing status and state/territory of birth (1993-2009)

	No impairment n(%)^	Some impairment n(%)^	Bilateral deafness n(%)^	**TOTAL n**	Unknown n(%)
ACT*	80 (87.0)	10 (10.9)	♦ (2.2)	**104**	12 (11.5)
NSW*	1188 (86.8)	115 (8.4)	66 (4.8)	**1549**	180 (11.6)
NT*	64 (73.6)	20 (23.0)	♦ (3.4)	**96**	9 (9.4)
QLD*	989 (88.2)	107 (9.5)	25 (2.2)	**1255**	134 (10.7)
SA*	409 (94.5)	17 (3.9)	7 (1.6)	**609**[&]	7 (1.6)
TAS*	111 (95.7)	5 (4.3)	0 (0.0)	**137**	21 (15.3)
VIC*	1503 (86.5)	181 (10.4)	53 (3.1)	**1930**	193 (10.0)
WA*	998 (92.2)	63 (5.8)	21 (1.9)	**1123**	41 (3.7)
COMBINED*	**5342 (88.5)**	**518 (8.6)**	**177 (2.9)**	**6803**	**597 (9.9)**



♦< 5 cases

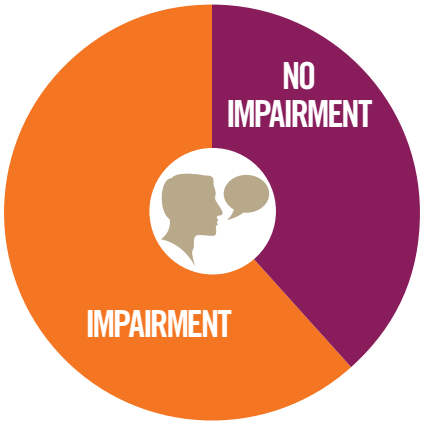
[&]South Australia CP Total includes n=169 that had not had their follow-up assessment at the time of data provision

(%)^ calculated by **n/total n** minus **unknown n and SA n not assessed**; provided to allow state/territory comparisons

Speech

Table 26. Number and percentage of children with CP by speech status and state/territory of birth (1993-2009)

	No impairment n(%)^	Some impairment n(%)^	Non-verbal n(%)^	**TOTAL n**	Unknown n(%)
ACT*	38 (40.4)	36 (38.3)	20 (21.3)	**104**	10 (9.6)
NSW*	465 (33.1)	612 (43.6)	328 (23.3)	**1549**	144 (9.3)
NT*	30 (33.3)	30 (33.3)	30 (33.3)	**96**	6 (6.3)
QLD*	460 (40.4)	406 (35.6)	273 (24.0)	**1255**	116 (9.2)
SA*	194 (44.5)	185 (42.4)	57 (13.1)	**609**[&]	♦ (0.9)
TAS*	60 (51.3)	46 (39.3)	11 (9.4)	**137**	20 (14.6)
VIC*	683 (39.6)	564 (32.7)	476 (27.6)	**1930**	207 (10.7)
WA*	411 (38.3)	392 (36.6)	269 (25.1)	**1123**	51 (4.5)
COMBINED*	**2341 (38.5)**	**2271 (37.4)**	**1464 (24.1)**	**6803**	**558 (8.4)**



♦< 5 cases

[&]South Australia CP Total includes n=169 that had not had their follow-up assessment at the time of data provision

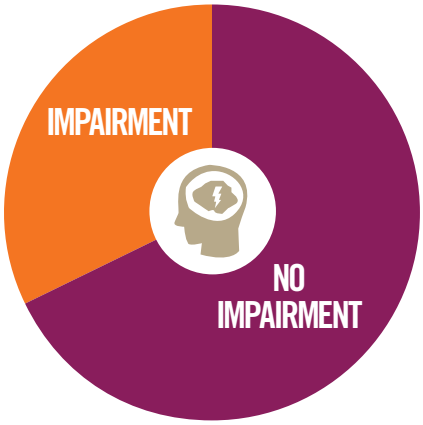
(%)^ calculated by **n/total n** minus **unknown n and SA n not assessed**; provided to allow state/territory comparisons

For further information about associated impairments amongst children with CP, please see Delacy MJ, Reid SM. Profile of associated impairments at age 5 years in Australia by cerebral palsy subtype and Gross Motor Function Classification System level for birth years 1996 to 2005. Dev Med Child Neurol. 2016;58 Suppl 2:50-6.

Epilepsy

Table 27. Number and percentage of children with CP by presence/absence of epilepsy^ and state/territory of birth (1993-2009)

	No epilepsy n(%)^	Resolved# n(%)^	Epilepsy^ n(%)^	TOTAL n	Unknown n(%)
ACT*	68 (72.3)	♦ (4.3)	22 (23.4)	**104**	10 (9.6)
NSW*	955 (68.3)	71 (5.1)	372 (26.6)	**1549**	151 (9.7)
NT*	49 (53.3)	♦ (2.2)	41 (44.6)	**96**	♦ (4.2)
QLD*	740 (64.6)	46 (4.0)	359 (31.4)	**1255**	110 (8.8)
SA*	317 (74.2)	23 (5.4)	87 (20.4)	**609&**	13 (3.0)
TAS*	85 (68.0)	8 (6.4)	32 (25.6)	**137**	12 (8.8)
VIC*	1268 (68.1)	37 (2.0)	557 (29.9)	**1930**	68 (3.5)
WA*	755 (68.7)	15 (1.4)	329 (29.9)	**1123**	24 (2.1)
COMBINED*	**4237 (67.9)**	**206 (3.3)**	**1799 (28.8)**	**6803**	**392 (5.9)**



♦< 5 cases

&South Australia CP Total includes n=169 that had not had their follow-up assessment at the time of data provision

(%)^ calculated by **n/total n** minus **unknown n and SA n not assessed**; provided to allow state/territory comparisons

Resolved # = Resolved by 5 years of age (seizure free for two or more years without medication)

^Epilepsy is defined as two or more afebrile seizures before age 5 years; does not include neonatal seizures.

Intellectual impairment

Table 28. Number and percentage of children with CP by level of intellectual impairment and state/territory of birth (1993-2009)

	No impairment n(%)^	Unconfirmed probably borderline or no impairment n(%)^	Unconfirmed probably greater than borderline impairment n(%)^	Mild impairment n(%)^	Moderate –severe impairment n(%)^	TOTAL n	Unknown n(%)
ACT*	36 (41.4)	11 (12.6)	17 (19.5)	9 (10.3)	14 (16.1)	**104**	17 (16.3)
NSW*	480 (35.1)	153 (11.2)	210 (15.4)	172 (12.6)	353 (25.8)	**1549**	181 (11.7)
NT*	39 (41.9)	♦ (4.3)	20 (21.5)	8 (8.6)	22 (23.7)	**96**	♦ (3.1)
QLD*	432 (38.4)	130 (11.5)	174 (15.5)	121 (10.7)	269 (23.9)	**1255**	129 (10.3)
SA*	259 (59.5)	27 (6.2)	33 (7.6)	54 (12.4)	62 (14.3)	**609&**	5 (1.1)
TAS*	62 (54.4)	8 (7.0)	8 (7.0)	15 (13.2)	21 (18.4)	**137**	23 (16.8)
VIC*	510 (29.8)	376 (22.0)	303 (17.7)	189 (11.0)	334 (19.5)	**1930**	218 (11.3)
WA*	651 (58.0)	10 (0.9)	113 (10.1)	97 (8.6)	251 (22.4)	**1123**	♦ (0.1)
COMBINED*	**2469 (40.8)**	**719 (11.9)**	**878 (14.5)**	**665 (11.0)**	**1326 (21.9)**	**6803**	**577 (8.7)**

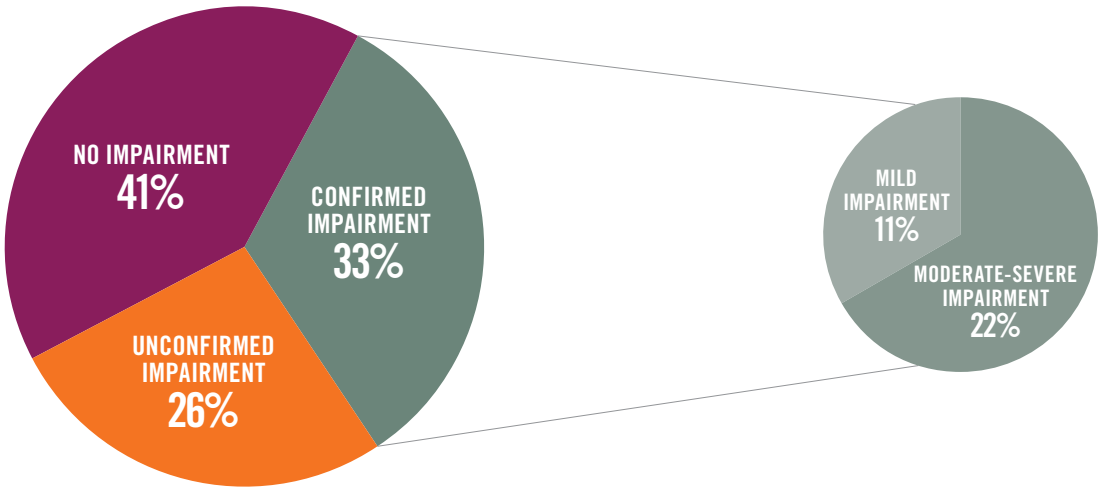
♦< 5 cases

&South Australia CP Total includes n=169 that had not had their follow-up assessment at the time of data provision

(%)^ calculated by **n/total n** minus **unknown n and SA n not assessed**; provided to allow state/territory comparisons

For further information about associated impairments amongst children with CP, please see Delacy MJ, Reid SM. Profile of associated impairments at age 5 years in Australia by cerebral palsy subtype and Gross Motor Function Classification System level for birth years 1996 to 2005. Dev Med Child Neurol. 2016;58 Suppl 2:50-6.

Figure 17. Percentage of children with CP by level of intellectual impairment, all state/territories combined (1993-2009)



Combined data indicates that associated impairments were common for children with CP. At the age of five: 28.8% had epilepsy; >50% had an intellectual impairment; >60% had a speech impairment; >30% had a vision impairment and >10% had a hearing impairment.

3 POST-NEONATALLY ACQUIRED CEREBRAL PALSY


THE VERY
HUNGRY
CATERPILLAR

PREVALENCE

Prevalence of CP where there is an identified post-neonatal cause

Table 29. Number and rate of children with post-neonatally acquired (PNN) CP per 10,000 live births (LB) and state/ territory of birth (1993-2009)

	PNN acquired CP	Percentage of all CP	LB	Rate of children with PNN CP per 10,000 LB
ACT	13	11.1	78697	1.7
NSW	122	7.4	1509760	0.8
NT	18	14.8	62643	2.7
QLD	53	4.1	862792	0.6
SA*	29	4.5	317536	**0.9 (95% CI 0.6, 1.2)**
TAS	♦	1.4	104187	0.2
VIC*	118	5.8	1104389	**1.1 (95%CI 0.9, 1.3)**
WA*	83	6.9	448215	**1.9 (65% CI 1.5, 2.5)**
TOTAL	438	6.0	4488219	1.0
COMBINED*	**230**	**6.0**	**1870140**	**1.2 (95% CI 1.0,1.4)**

♦< 5 cases

POST-NEONATAL CAUSE

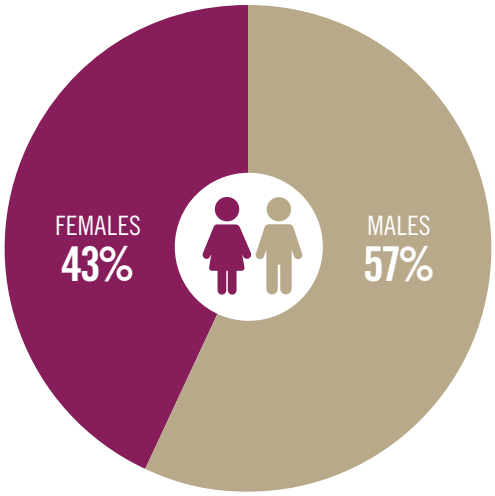
Table 30. Number and percentage of children with CP by identified post-neonatal cause of CP, South Australia, Victoria and Western Australia (1993-2009)

POST-NEONATAL CAUSE	CP n(%)
Viral/bacterial infection unspecified	60 (26.1)
Cerebrovascular accident associated with surgery	15 (6.5)
Cerebrovascular accident associated with cardiac complications	12 (5.2)
Spontaneous/other cerebrovascular accident	41 (17.8)
Fall	7 (3.0)
Non-accidental injury	29 (12.6)
Other head injury	♦ (1.7)
Near drowning	6 (2.6)
Apparent life threatening event	7 (3.0)
Post-seizure	10 (4.3)
Peri-operative hypoxia	5 (2.2)
Other post-natal event	25 (10.9)
Motor vehicle accident	9 (3.9)
TOTAL	**230**

Combined data indicates the prevalence for post-neonatally acquired CP to be 1.2 per 10,000 live births. The predominant post-neonatal cause of CP was cardiovascular accident being either spontaneous, associated with surgery or with cardiac complications.

SEX

Figure 18. Number and percentage of children with post-neonatally acquired (PNN) CP by sex, all states/territories (1993-2009)



Combined data demonstrates that males are at a higher risk of post-neonatally acquired CP. 57% of the cohort of children with CP due to post-neonatal causes were male, compared to 51% of the Australian population[21].

MATERNAL AGE AT TIME OF DELIVERY

Table 31. Number and percentage of children with post-neontally acquired CP by maternal age at delivery, all state/ territories combined (1993-2009)

	<20 n(%)^	20-24 n(%)^	25-29 n(%)^	30-34 n(%)^	35-39 n(%)^	40+ n(%)^	**TOTAL n**	Unknown n(%)
All states / territories	41 (10.9)	86 (22.8)	91 (24.1)	102 (27.1)	48 (12.7)	9 (2.4)	**438**	61 (13.9)

(%)^ calculated by **n/total n** minus **unknown n**

PREDOMINANT MOTOR TYPE AND TOPOGRAPHY

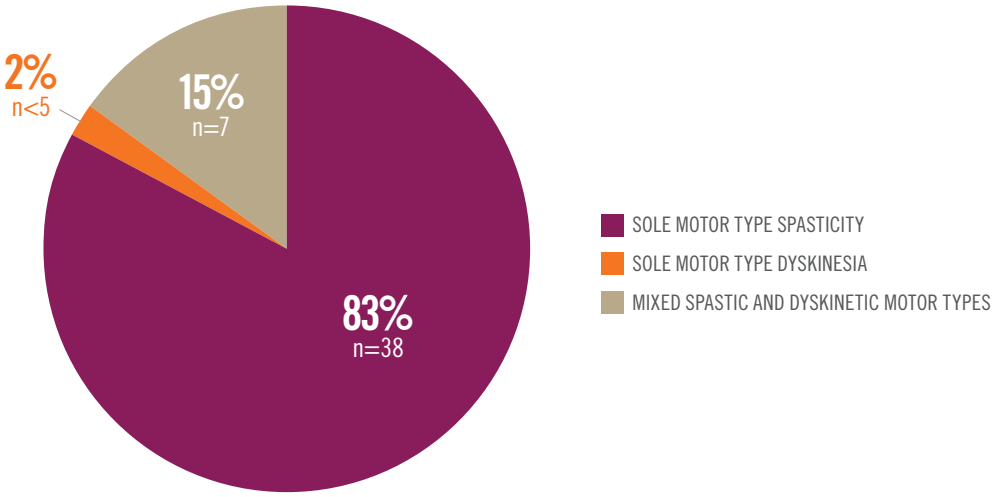
Table 32. Number and percentage of children with post-neonatally acquired (PNN) CP by predominant motor type and spastic topography, South Australia, Victoria and Western Australia combined (1993-2009)

	Spastic	*Hemiplegia*	*Diplegia*	*Tri / Quad riplegia*	Ataxic	Dyskinetic	Hypotonic	**TOTAL**	Unknown
	n(%)^	*n(%)*	*n(%)*	*n(%)*	n(%)^	n(%)^	n(%)^	**n**	n(%)
South Australia, Victoria and Western Australia combined	372 (89.9)	*193 (51.9)*	*41 (11.0)*	*138 (37.1)*	17 (4.1)	16 (3.9)	9 (2.2)	**438**	24 (5.5)

(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons
NB: 'Dyskinetic cerebral palsy' includes both dystonic and athetoid/choreoathetoid CP

Combined data indicates that spasticity was the most predominant motor type of CP (89.9%) and hemiplegia (including monoplegia) or unilateral spastic CP (52%) the most common topographical pattern of spasticity.

Figure 19. Number and percentage of children with post-neonatally acquired CP by sole motor type (spastic or dyskinetic) and mixed motor type (spastic and dyskinetic), South Australia, Victoria and Western Australia combined (2007-2009*)



*Only data 2007-2009 were used for these figures, as this most recent triennium has the most complete available data from the CP registers at this time.
NB: 'Dyskinetic cerebral palsy' includes both dystonic and athetoid/choreoathetoid CP

Combined data suggests that amongst children who have a predominant spastic or dyskinetic motor type, a minimum of 15% have a mixed motor type of both spastic and dyskinetic CP. The CP registers have historically focussed on collection of data pertaining to the predominant motor type and so this figure is likely to be an underestimate. In recent years many states in Australia have adopted the Cerebral Palsy Description Form (see Appendix B) and the ACPR Group hopes this will assist with accurate data collection of mixed motor types.

ASSOCIATED IMPAIRMENTS

Table 33. Number and percentage of children with post-neonatally acquired CP by associated impairment status, all states/territories combined (1993-2009)

Associated Impairment	No impairment n(%)^	Some impairment n(%)^	Severe impairment{} n(%)^	**TOTAL**	Unknown n(%)
Vision	212 (53.5)	141 (35.6)	43 (10.9)	**438**	42 (9.6)
Hearing	338 (84.5)	43 (10.8)	19 (4.8)	**438**	38 (8.7)
Speech	107 (26.3)	165 (40.5)	135 (33.2)	**438**	31 (7.1)
Intellectual impairment	113 (28.0)	171 (42.4)	119 (29.5)	**438**	35 (8.0)
	No epilepsy n(%)^	Resolved# n(%)^	Epilepsy^ n(%)^	**TOTAL**	Unknown n(%)
Epilepsy	188 (44.2)	37 (8.7)	200 (47.1)	**438**	13 (3.0)

(%)^ calculated by **n/total n** minus **unknown n**

{} Severe impairments: vision (functional blindness), hearing (bilateral deafness), speech (non-verbal communication), intellectual impairment (moderate to severe impairment)

Resolved # = Resolved by 5 years of age (seizure free for two or more years without medication)

^Epilepsy is defined as two or more afebrile seizures before age 5 years; does not included neonatal seizures.

Combined data show that associated impairments were common for children with CP. At the age of five: almost 50% had epilepsy; >70% had an intellectual impairment; >70% had a speech impairment; >40% had a vision impairment and >15% had a hearing impairment.

4 AFFILIATED CEREBRAL PALSY REGISTERS

THIS SECTION HIGHLIGHTS THE WORK OF CP REGISTERS WHICH ARE UTILISING THE ACPR INFRASTRUCTURE AND SHARE THE SAME MINIMUM DATA AS THE ACPR. IN THE FUTURE AS THESE CP REGISTERS BECOME MORE ESTABLISHED IT IS PLANNED THAT OPPORTUNITIES FOR SHARED RESEARCH AND REPORTING BETWEEN THE ACPR AND THESE NEW CP REGISTERS WILL BE POSSIBLE.

NZCPR

TARGET POPULATION:
All people with cerebral palsy residing in New Zealand

CONTACT DETAILS:
Paediatric Orthopaedics, Starship Children's Hospital, Park Road, Auckland, New Zealand

WEBSITE: https://nz.cpregister.com/

EMAIL: nzcpregister@adhb.govt.nz

PHONE NUMBER: +64(0)93074949 ext 21898

ETHICS COMMITTEE REFERENCE NUMBER: 13/NTA/130

Professor Susan Stott, Ms Alexandra Sorhage, Dr Anna Mackey

Thanks to a never ending supply of patience, perseverance and passion from Professor Sue Stott and Dr Anna Mackey, the New Zealand Cerebral Palsy Register began active recruitment in April 2015. It would also not have been possible without the financial support from the Starship Foundation's fifth annual Friends of Starship Diamonds & Stars Tea Party in 2014 fundraiser and contributions from the Cerebral Palsy Society and Allergan.

The Past

To assist with establishing the aims and potential benefits of having a New Zealand register, a survey was sent to relevant health professionals in 2012 asking, "What do people want to gain from a New Zealand register?". Together with the publication of a poster presentation at the 2012 International Cerebral Palsy Conference in Pisa[1] the aims of the register were established:

- Improve understanding of CP: prevalence, impact of the condition, service planning
- Evaluate clinical practice: surveillance, preventative practice, service quality
- Identify / address any potential disparities
- Facilitate research: causes, prevention and clinical practice

The Present

A dedicated team of a research officer and an honorary research associate working part-time have spent the last eight months publishing marketing material through written and web based avenues, establishing systems and processes to manage recruitment and ethical obligations, and generally promoting the NZCPR at every available opportunity. To date we have almost 100 registrants and we are looking forward to sharing our de-identified data with Australia in 18 months' time.

The Future

Exciting developments and plans for 2016 include the formation of a NZCPR Governance Committee, our very own New Zealand website going "live" and putting together a robust "opt-off" ethics proposal for Health and Disability Ethics Committee approval which we feel will assist with increasing the number of registrations. The focus will be on assisting individual District Health Boards with outstanding locality ethics to obtain approval and to continue assisting local paediatric teams with recruitment to ensure that there is national representation of the CP population on the register.

Reference: (1) Mackey, A H., O'Callaghan, M., & Stott, N S. (2012) Development of a cerebral palsy population register: case study in New Zealand. Proceedings of 4th International Cerebral Palsy conference, Pisa, Italy, p.243.

THE BANGLADESH CEREBRAL PALSY REGISTER

The Bangladesh Cerebral Palsy Register project commenced in January 2015. This project is a collaboration with CSF Global, Bangladesh, the University of Sydney and Cerebral Palsy Alliance, Australia.

Investigators:

Dr Gulam Khandaker: gulam.khandaker@health.nsw.gov.au

Dr Hayley Smithers-Sheedy, Dr Tasneem Karim, Prof Iona Novak, Prof Robert Booy, Prof Cheryl Jones, Ms Eamin Zahan Heanoy, Prof Nadia Badawi and Prof Mohammad Muhit

Aims:

To establish a platform for a national CP register in Bangladesh using Australian CP Register (ACPR) infrastructure and to

- Determine the prevalence of CP in Bangladesh
- Determine the aetiology to identify preventable causes
- Systematically assess severity & associated impairments
- Complete a needs assessment & develop a framework for service delivery

Findings to date:

Since January 2015, 710 children with CP have been recruited to the register giving an overall unadjusted CP prevalence of 3.1 per 1,000 children (95% CI 2.9 – 3.3). After adjusting for the missed cases (77.5% ascertainment of all physically impaired cases by Key Informant Method compared with door-to-door survey) our estimated prevalence of CP in the Shahjadpur sub-district of Bangladesh is 4.0 per 1,000 children (95% CI 3.7 – 4.2).

Our interim analysis of 662 children with CP (recruited by March 2016) has shown that the majority (n=492, 74.3%) have spastic CP; 153 (23.1%) with spastic quadriplegia. GMFCS classification showed 289 (43.7%) with GMFCS IV-V. Many children had associated impairments; intellectual disability 331 (50.0%), epilepsy 210 (31.7%), visual 136 (20.5%), hearing 78 (11.8%) and speech impairment 444 (67.1%).

The majority (72.7%) of children were delivered at home (68.6% by Traditional Birth Attendant) and 15.5% were born pre-term (7.7% extreme pre-term). 29.3% of all children with CP experienced neonatal seizures and early feeding difficulty, most likely due to severe neonatal encephalopathy (NE). Over half of the children (n=353, 53.4%) had a history suggestive of pre and perinatal cause of CP mainly intrapartum-related neonatal respiratory depression and infections and in another 40.3% (n=267) the timing of CP was unknown. Among those children 207 (31.3%) never received any rehabilitative services and only 25 (3.8) received an assistive device as part of their rehabilitation. Only 109 (16.5%) were attending any school.

BCPR

TARGET POPULATION:
All people with cerebral palsy <18 years residing in Bangladesh

CONTACT DETAILS:
CSF Global, Bangladesh

WEBSITE: bangladesh.cpregister.com

EMAIL: tkarim@csf-global.org

PHONE NUMBER: +88 01819245060

ETHICS COMMITTEE REFERENCE NUMBER: BMRC/NREC/2013-2016/1267, southasia-irb-2014-I-01 and NHMRC HREC: EC00402: 2015-03-02

Collaboration with Wheelchairs for Kids

The Bangladesh CP Register project has provided the opportunity to develop a partnership with Wheelchairs for Kids and Rotary Club of Turramurra. This has allowed the distribution of 332 wheelchairs across Shahjadpur to date and installation of 50 wheelchair accessible ramps at the houses and schools of the children with CP registered in the BCPR. Transportation of those wheelchairs from Australia was supported by tna Solutions. This initiative has provided wheeled mobility to children with CP, making an enormous difference to the daily lives of both the children and their families.

World Cerebral Palsy Day

Families and children with CP celebrated World CP Day in 2015. Events such as this create a sense of community for children with CP and their families. World CP Day provided opportunity for families to come together and has been an important initiative to raise awareness of CP and to reduce some of the cultural stigma attached to disability.

Current research projects

The BCPR is a key source of recruitment for a variety of current research projects including but not limited to:

- CP oral health study - Factors affecting dental caries experience among children and adolescents with CP in rural Bangladesh
- Bangladesh CP Quality of Life study - Health related quality of life of adolescents with CP in rural Bangladesh and the psychological wellbeing of their primary caregivers
- Early diagnosis of CP - General Movement Assessment (GMA) and early diagnosis of CP at community level

Publications and conference presentations

Khandaker G, Smithers-Sheedy H, Islam J, Alam M, Jung J, Novak I, Booy R, Jones C. Bangladesh Cerebral Palsy Register (BCPR): a pilot study to develop a national cerebral palsy (CP) register with surveillance of children for CP. BMC neurology. 2015;15:173.

Khandaker G, Smithers-Sheedy H, Islam J, Alam M, Jung J, Novak I, Booy R, Jones C, Badawi N, Muhit M. Bangladesh Cerebral Palsy Register (BCPR): a pilot study towards developing a national cerebral palsy (CP) register and surveillance of children with CP. 28th EACD Annual Meeting - Stockholm, 1-4 June 2016 [Poster]

Jung J, Muhit M, Smithers-Sheedy H, Islam J, Novak I, Booy R, Jones C, Badawi N, Khandaker G. Nutritional status of children with Cerebral Palsy (CP) in rural Bangladesh: preliminary results from Bangladesh Cerebral Palsy Register (BCPR) pilot study. 28th EACD Annual Meeting - Stockholm, 1-4 June 2016 [Oral]

Akhter R, Hassan N, Martin F, Muhit M, Rahman R, Smithers-Sheedy H, Jones C, Badawi N, Khandaker G. Factors Affecting Dental Caries Among Bangladeshi Children With Cerebral Palsy. 94th General Session & Exhibition of the IADR in Seoul, Republic of Korea on 21st June 2016 [Poster].

Khandaker G, Smithers-Sheedy H, Shahama S, Huda A, Novak I, Booy R, Jones C, Badawi N, Muhit M. Bangladesh Cerebral Palsy Register (BCPR): developing a cerebral palsy (CP) register and surveillance of children with CP in a typical low-and middle-income country. 70th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) will take place September 20-24, 2016 in Hollywood, Florida [Oral].

APPENDIX A

Information and contact details of the contributing State and Territory CP Registers

Name	Date of Establishment	Custodian Organisation	Type of Consent Required	Contactable for Future Research
NSW and ACT Cerebral Palsy Register	2005	Cerebral Palsy Alliance	IC	Yes
Northern Territory Cerebral Palsy Register	2008	Centre for Disease Control	IC	Yes
Queensland Cerebral Palsy Register	2006	CPL - Choice, Passion, Life and Queensland Department of Communities, Child Safety and Disability Services	IC	90%
South Australian Cerebral Palsy Register	1998	Women's and Children's Health Network	L, IC	Yes
Tasmanian Cerebral Palsy Register	2008	St Giles in collaboration with Cerebral Palsy Alliance	IC	Yes
Victorian Cerebral Palsy Register	1986	Murdoch Childrens Research Institute, Royal Children's Hospital, Melbourne	E, IC,O	Yes (Approximately 80%)
Western Australian Register of Developmental Anomalies - Cerebral Palsy	1977	Department of Health WA	E, O	No

IC Registration after gaining individual consent, **L** Legislation allowing collection of data, **E** Ethics approval to collect data without informed consent, **O** Other e.g. combination or alternative

New South Wales and Australian Capital Territory Cerebral Palsy Registers

Cerebral Palsy Alliance Research Institute, University of Sydney

Target population:
Individuals who have acquired CP before age 5 years who were born or currently live in New South Wales or the Australian Capital Territory.

Dr Sarah McIntyre
Cerebral Palsy Alliance Research Institute
187 Allambie Rd
Allambie Heights NSW 2100
Australia
smcintyre@cerebralpalsy.org.au
(02) 9479 7200

Purpose:
The main aims of the CP Register are to monitor incidence and prevalence of CP, gain further understanding about the causes of CP, evaluate preventative strategies and assist in planning services for children and adults who have CP. These goals represent the aims of the NSW and ACT CP Register and are aligned with this register's partnership with the Australian Cerebral Palsy Register.

We are moving into an era where prevention of secondary impairments has become a particularly high priority for the NSW CP Register and CP Alliance due to the resounding success of a follow-up program for CP, called CPUP, which was initiated in Sweden in 1994 and the establishment of the Australian Hip Surveillance Guidelines. These programs have reduced the incidence of hip dislocation, pain, scoliosis and contractures amongst children with CP. An extension to the CP Register, called CP Check-Up™ has been built and now provides a platform for collection of surveillance data in NSW / ACT.

For further information, please contact lead Research Project Officer Petra Karlsson at cpregister@cerebralpalsy.org.au

Northern Territory Cerebral Palsy Register

Department of Health and Families

Target population:
All individuals who have CP, who were born in, or live in the Northern Territory.

Rebecca Jarman and Dr Keith Edwards
Centre for Disease Control
Building 4, Royal Darwin Hospital
NT 0811
Australia
cpregister@nt.gov.au
(08) 8922 8044

Purpose:
The main aims of the CP Register are to determine the prevalence, location and functional status of people in the Northern Territory who have CP. This information is used to assist in the planning, development and provision of services, and to support research into CP.

Queensland Cerebral Palsy Register

CPL - Choice, Passion, Life and Queensland Department of Communities, Child Safety and Disability Services

Target population:
All people were born in or receive services in Queensland who have CP.

Michael deLacy
QCPR
PO Box 386
Fortitude Valley
Brisbane QLD 4006
Australia
mdelacy@cpl.org.au
(07) 3358 8122

Purpose:
Determine the number, locations and general abilities of the population of people with CP in QLD for use by government, non-government agencies and people with CP in service planning. Provide a population resource for intervention trials. Contribute to investigations into causes and prevention of CP.

The South Australian Cerebral Palsy Register
(part of the South Australian Birth Defects Register)

Women's and Children's Health Network

Target population:
All children who live in or were born in South Australia who have been diagnosed with CP, including post-neonatally acquired CP up to 2 years of age.

Dr Catherine Gibson and Heather Scott
Women's and Children's Health Network
72 King William Road
North Adelaide
Adelaide SA 5006
Australia
sabdr@health.sa.gov.au
(08) 8161 7368

Purpose:
The main aims of the South Australian Cerebral Palsy Register are to determine and monitor the prevalence of CP in South Australia; gather information about affected children that may provide clues to the causes of CP; document the severity and range of disabilities experienced by children with CP; use the information collected to plan facilities for affected children; act as a source of information about CP for both families and the community; improve community and professional awareness of CP including its causes and outcomes; provide a resource for research into CP and contribute to mortality and morbidity studies of CP.

Tasmanian Cerebral Palsy Register

St Giles

Target population:
The Register only collects information on CP. The main focus is on young children, but accepts registrations from all Tasmanians with CP.

Madeline Rowell, Kirsty Bartlett-Clark, Dr Eliza Maloney
St Giles
PO Box 416
Launceston TAS 7250
Australia
society@stgiles.org.au
(03) 6345 7333

Purpose:
To monitor how many people are living with CP in Tasmania, in which areas they live and whether there are any changing trends in the incidence or severity of CP in the state. The register also aims to facilitate research into the causes, prevention and treatment of CP.

Victorian Cerebral Palsy Register

Murdoch Childrens Research Institute / Royal Children's Hospital, Melbourne

Target population:
Individuals with CP born since 1970

Dr Sue Reid
Murdoch Childrens Research Institute
Royal Children's Hospital
Flemington Road
Parkville VIC 3052
Australia
sue.reid@mcri.edu.au
(03) 9345 4807

Purpose:
To determine the frequency and describe the characteristics of CP in Victoria, to enable research into aetiology and to select cohorts for intervention and other studies.

Western Australian Register of Developmental Anomalies - Cerebral Palsy

Target population:
All individuals from birth-year 1956 who have CP acquired before age 5 years and were born or currently live in WA.

Linda Watson
WARDA
King Edward Memorial Hospital
PO Box 314
Subiaco WA 6904
Australia
Linda.Watson@health.wa.gov.au
(08) 9340 2768
0403 806 932
http://www.kemh.health.wa.gov.au/services/register_developmental_anomalies/

Purpose:
(1) To monitor trends in the CPs and identify areas of concern for future investigation (2) To conduct population based epidemiological studies of the various CP subgroups, particularly to elucidate causes (3) To evaluate changes in antenatal, obstetric and neonatal care in relation to CP as an index of neurological outcome (4) To identify CP as an outcome in other study populations (5) To aid in the planning of services for individuals with CP by providing distribution of CP in WA by age, severity, geographical area, etc to service organisations (6) To contribute WA CP data to the Australian Cerebral Palsy Register.

CP Description Form and Australian Spasticity Assessment Scale[23]

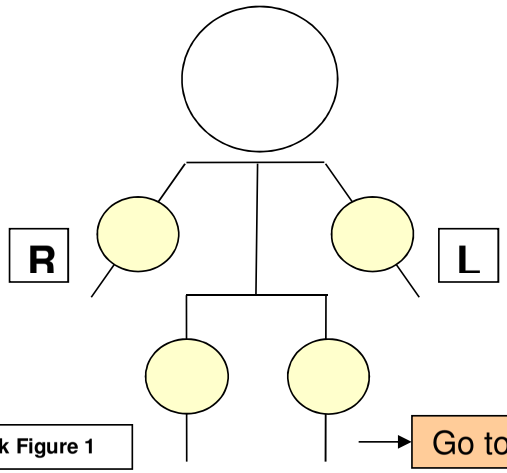
CEREBRAL PALSY DESCRIPTION FORM Part I: MOTOR IMPAIRMENTS

Child's name: _____ Please attach sticky label if available _____ DOB: _____ Examining clinician: _____ Date: _____

1. Is there spasticity in one or more limbs?

Please tick Yes / No boxes as appropriate

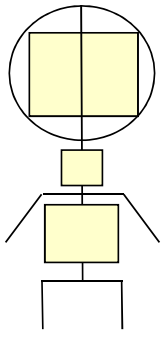
Yes ☐ No ☐



Stick Figure 1

Go to **2**

2. Describe face/ neck/trunk tone



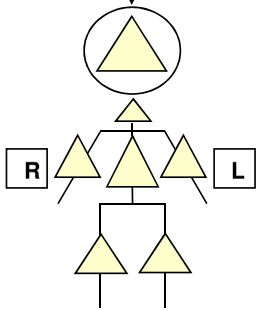
Stick Figure 2

Go to **3**

3. Is muscle tone varying?

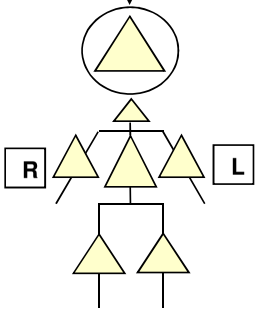
Yes ☐ No ☐

Dystonia



Stick Figure 3a

Athetosis and/or Chorea



Stick Figure 3b

Go to **4**

4. Is ataxia present?

Yes ☐ No ☐

Is there generalised hypotonia with increased reflexes?

Yes ☐ No ☐

Please number tone/ movement abnormalities present in this child in order of predominance (1 = most predominant or only abnormality)

- ☐ Spasticity
- ☐ Dystonia
- ☐ Athetosis
- ☐ Chorea
- ☐ Ataxia
- ☐ Generalised Hypotonia

Instructions for completing Stick figures 1 and 2 above:

Limb muscle tone: ○

Enter: Highest Australian Spasticity Assessment Scale score in that limb (PTO for scoring criteria)

Face/neck/trunk muscle tone: □

Enter: ↓ = Hypotonic
↑ = Hypertonic
↕ = Fluctuating
N = Normal

Instructions for completing Stick figures 3a and 3b above:

Please tick triangles where signs are present.

Please describe CP type and severity in words as you would write in the medical record: _____

_____

_____ Form designed for the Australian Cerebral Palsy Register: April 2013

PTO

Please explain this form to parents if there is interest and opportunity. It will be useful to retain a copy for your records. Please forward to the address overleaf.

Australian Spasticity Assessment Scale (ASAS)
Love SC, Gibson N, Blair E

0 No catch on rapid passive movement (RPM) (no spasticity).

1 Catch on RPM followed by release. There is no resistance to RPM throughout rest of range.

2 Catch occurs in second half of available range (after halfway point) during RPM and is followed by resistance throughout remaining range.

3 Catch occurs in first half of available range (up to and including the halfway point) during RPM and is followed by resistance throughout remaining range.

4 When attempting RPM, the body part appears fixed but moves on slow passive movement.

NB Contractures do not need to be recorded on this form.

Part II: FUNCTION AND ASSOCIATED IMPAIRMENTS

Please indicate Gross Motor Function Classification System E&R level (Palisano et al, 2007):

GMFCS: Level I ☐ Level II ☐ Level III ☐ Level IV ☐ Level V ☐

Please indicate Manual Ability Classification System level (Eliasson et al, 2006):

MACS: Level I ☐ Level II ☐ Level III ☐ Level IV ☐ Level V ☐

Please indicate associated impairments present in this child:

Intellectual:
☐ Normal
IQ / DQ or severity range _____
Method of assessment / Date assessed _____
Comments _____

Epilepsy:
☐ None
Previously, but now resolved _____
Seizure type(s) if current _____
Age at onset _____

Visual:
☐ Normal
Some impairment _____
Bilateral blindness _____
Strabismus _____
Uncertain _____

Hearing:
☐ Normal
Some impairment _____
Bilateral deafness _____
Uncertain _____

Speech:
☐ Normal
Some impairment _____
Non-verbal _____
Uncertain _____

Swallowing:
☐ Normal
Modifications required (eg, special spoon, food thickening) _____
Non-oral feeding _____
Uncertain _____

Please forward to: **Western Australian Register of Developmental Anomalies - CP**
King Edward Memorial Hospital, PO Box 134, Subiaco WA 6904

PTO

For further information about the Australian Spasticity Assessment Scale please see Love S, Gibson N, Smith N, Bear N, Blair E. Interobserver reliability of the Australian Spasticity Assessment Scale (ASAS). Dev Med Child Neurol. 2016;58 Suppl 2:18-24.

APPENDIX C

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APPENDIX D

Minimum data set at time of data provision

State submitting data
Numeric code representing state/territory submitting data

CP number
Unique identifier from state/territory CP register

Date of birth
Year of birth

Sex
Single digit: 1 male, 2 female, 9 unknown

Postcode of mother's address at time of birth
Four digit: postcode

Postcode of case address at 5 years
Four digit: postcode

Postcode of case at latest known address
Four digit: postcode

Mother's date of birth
Eight digit: (dd-mm-yy)

Mother's age at time of delivery
Two digit: (years)

Mother's indigenous status
Single digit: 1 Aboriginal but not Torres Strait Islander origin, 2 Torres Strait Islander but not Aboriginal origin, 3 Aboriginal and Torres Strait Islander origin, 4 Neither Aboriginal nor Torres Strait Islander origin, 9 not stated

Mother's country of birth
Four digit: Standard Australian Classification of Countries (SACC) (ABS Catalogue No. 1269.0).

Mother's occupation at time of, or prior to pregnancy
Single digit: Major group, Australian Standard Classification of Occupations, Second Edition, 1997 (ABS Catalogue No. 1220.0).

Father's occupation at time of birth
Single digit: Major group, Australian Standard Classification of Occupations, Second Edition, 1997 (ABS Catalogue No. 1220.0).

Mother's highest level academic qualification at time of delivery
Single digit: 0 none, 1 primary, 2 incomplete secondary, 3 complete secondary, 4 secondary NOS, 5 apprenticeship/ trade qualifications, 6 incomplete tertiary, 7 complete tertiary or higher, 8 tertiary NOS, 9 not stated

Mother's highest level academic qualification at time of birth of child
Single digit: 0 none, 1 primary, 2 incomplete secondary, 3 complete secondary, 4 secondary NOS, 5 apprenticeship/ trade qualifications, 6 incomplete tertiary, 7 complete tertiary or higher, 8 tertiary NOS, 9 not stated

Age at which motor disorder first described as CP by clinician (not corrected for preterm birth)
Single digit: 0, 0–6 months, 1, 7-12 months, 2, 13-24 months (during second year), 3, 25-36 months (during third year), 4, 37-48 months (during fourth year), 5, 49-60 months (during fifth year), 6, Age 5 or later, 9, not stated

Predominant type of CP at age 5 years
Single digit: 0 spastic monoplegia, 1 spastic hemiplegia, 2 spastic diplegia, 3 spastic triplegia, 4 spastic quadriplegia, 5 ataxia, 6 dyskinetic CP, mainly athetoid, 7 dyskinetic CP, mainly dystonic , 8 hypotonic CP, 9 not stated

Limb(s) affected in monoplegia and hemiplegia or limbs most affected in other spastic CP types, as the predominant CP type at age 5 years
Single digit: 1 right upper limb, 2 right lower limb, 3 right side – upper and lower limbs, 4 left upper limb, 5 left lower limb, 6 left side – upper and lower limbs, 9 unknown

Secondary type of CP at age 5 years
Single digit: 0 spastic monoplegia, 1 spastic hemiplegia, 2 spastic diplegia, 3 spastic triplegia, 4 spastic quadriplegia, 5 ataxia, 6 dyskinetic CP, mainly athetoid, 7 dyskinetic CP, mainly dystonic , 8 hypotonic CP, 9 not stated

Limb(s) affected in monoplegia and hemiplegia or limbs most affected in other spastic CP types, as the secondary CP type at age 5 years
Single digit: 1 right upper limb, 2 right lower limb, 3 right side – upper and lower limbs, 4 left upper limb, 5 left lower limb, 6 left side – upper and lower limbs, 9 unknown

Gross Motor Function Classification System (GMFCS) level at age 5 years
Single digit: 1 level 1, 2 level 2, 3 level 3, 4 level 4, 5 level 5, 9 Unknown

Manual Ability Classification System (MACS) level age 5 years
Single digit: 1 level 1, 2 level 2, 3 level 3, 4 level 4, 5 level 5, 9 Unknown

Postneonatal timing of brain injury that caused CP
Single digit: 0 No postneonatal cause, 1 Postneonatal cause (after 28 days and before age 2 years), 2 neonatal injury in an undisputedly normal infant, 9 uncertain whether postneonatal cause or not

Attributed cause of CP if known with certainty
Two digit: Pre/perinatal causal factors: 01 genetic/ chromosomal, 02 intrauterine CMV infection, 03 other intrauterine TORCH infection, 08 other prenatal cause. Postneonatal causes: 21 dehydration due to gastroenteritis, 22 other bacterial infection, 23 other viral infection, 28 infection nos, 31 CVA associated with surgery, 32 CVA associated with cardiac complications (not during/post surgery), 38 CVA spontaneous / other CVA, 41 MVA –

passenger in vehicle, 42 MVA – Pedestrian, 43 fall, 44 non-accidental, 48 other head injury / nos,51 near drowning, 52 apparent life-threatening event, 54 post-seizure, 55 peri-operative hypoxia, 58 other postneonatal event

Associated syndrome co-existing with motor disability or syndrome having a motor component that meets the definition of CP
Four digit: Possum codes www.possum.net.au

Congenital anomalies
Two digit: Birth defects codes categorised by ICD10 major headings: 01 no birth defect, 02 nervous system, 03 urogenital, 04 musculoskeletal, 05 cardiovascular, 06 gastrointestinal, 07 chromosomal, 08 respiratory, 09 metabolic, 10 haematological/ immune

Epilepsy at age 5 years
Single digit: 0 none, 1 resolved by age 5 years (seizure free for two or more years without medication), 2 epilepsy, 9 unknown. NB: epilepsy defined as two or more afebrile seizures before age 5 years; does not include neonatal seizures.

Intellectual impairment at age 5 years
Single digit: 0 normal (IQ > 70 or so described), 2 mild impairment (IQ 50-69 or so described), 3 moderate impairment (IQ 35-49 or so described), 4 severe impairment (IQ < 35 or so described), 5 probably greater than borderline impairment, severity uncertain, 6 probably borderline or no impairment, 9 intellectual ability unknown

Vision impairment at age 5 years
Single digit: 0 no impairment, 2 some visual impairment (wears glasses), 3 functionally blind (may have light perception, ability to see colour differences, see shadows but unable to use), 9 visual status unknown

Strabismus at age 5 years
Single digit: 0 no strabismus, 2 strabismus, 9 strabismus status unknown

Hearing at age 5 years
Single digit: 0 no impairment, 2 some impairment (includes conductive loss), 3 bilateral deafness, 9 hearing status unknown

Speech impairment at age 5 years
Single digit: 0 no impairment, 2 some impairment, 3 non-verbal, 9 speech status unknown

Place of birth
Single digit: 1 hospital, 2 birth centre, attached to hospital, 3 birth centre, free standing, 4 home birth, planned, 5 home birth, unplanned, 6 born before arrival at hospital, 7 born outside home or hospital without medical assistance, 8 other, 9 not stated

State/territory of birth
Numeric code representing state/territory submitting data

Level of care facility of hospital of birth
Single digit: 1 home / hospital without neonatal intensive care unit or special care nursery, 2 hospital with special care nursery, 3 hospital with neonatal intensive care unit, 9 not stated

Length of stay in neonatal intensive care unit (days)
Three digit: Number of days, 000 not admitted to higher level care, 888 admitted to higher level care than general ward, length of stay unknown, 999 not stated

Assisted conception used in this pregnancy
Single digit: 0 unassisted conception, 1 fertility drugs only, 2 artificial insemination, 3 IVF, 4 ICSI, 5 GIFT, 6 other assisted conception, 7 assisted conception, type u/k, 9 unknown / no information

Number of mother's previous births of 20 weeks or more, excluding co-multiples of case
Single digit: 1 singleton, 2 twins, 3 triplets, 4 quadruplets, 5 quintuplets, 6 sextuplets, 8 other, 9 unknown

Plurality of birth
Single digit: 1 singleton, 2 twins, 3 triplets, 4 quadruplets, 5 quintuplets, 6 sextuplets, 8 other, 9 unknown

Birth order
Single digit: 1 singleton or first of a multiple birth, 2 second of a multiple birth, 3 third of a multiple birth, 4 fourth of a multiple birth, 5 fifth of a multiple birth, 6 sixth of a multiple birth, 8 other, 9 unknown

Birth weight (grams)
Four digit: birth weight grams

Gestational age (completed weeks)
Two digit: completed weeks

MRI 1 completed after neonatal period (28 days) and prior to 2 years of age
Single digit: 0 no, 1 MRI normal, 2 MRI abnormal, 9 unknown

MRI 2 completed after 2 years of age
Single digit: 0 no, 1 MRI normal, 2 MRI abnormal, 9 unknown

Date of death
Eight digit: dd-mm-yyyy, 01-01-1901 unknown, 02-02-1902 not applicable

Death cause
ICD10 alpha-numeric code

Post mortem carried out
Single digit: 0 no, 1 yes, 9 unknown

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