Australian Cerebral Palsy Register Report

2018

Cerebral Palsy ALLIANCE RESEARCH INSTITUTE

CP Register
Piecing together the facts on cerebral palsy

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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 preventive strategies and evaluate management options for those with CP and their families.

The ACPR is hosted by the Cerebral Palsy Alliance Research Institute in Sydney and funded by the Cerebral Palsy Alliance Research Foundation.

The ACPR Group acknowledges and thanks

- Mr Rob White CEO and Prof Nadia Badawi for their vision and commitment to the work of the ACPR;
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- Colonial First State for their generous support.

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 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 in uploading data, attending meetings, participating in working groups and writing this report.

Colonial First State
Global Asset Management

The Contributing Registers and Organisations

Australian Capital Territory and New South Wales Cerebral Palsy Registers – Cerebral Palsy Alliance, The 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 Children's Research Institute, Royal Children's Hospital, Melbourne

Western Australian Register of Developmental Anomalies – Cerebral Palsy – Department of Health Western Australia

Foreword

It is an honour to be invited to write some introductory words for the 2018 Australian Cerebral Palsy Register Report. At the outset I want to record my great admiration, respect and affection for the the Australian Cerebral Palsy Register (ACPR) and for all the inspiring organisations that support its important work.

My life has been enriched by enduring networks made through my mother's dedication to special education in the 1970s when she was a teacher of children with cerebral palsy. Across those years she made lifelong friendships with families that have been important and influential to me. Significant advances in every aspect of cerebral palsy have been made since. I have been grateful for the opportunity to observe many of these.

Results from this report clearly show that the rate of cerebral palsy is decreasing and so too is its severity. This is wonderful news and evidence of the effectiveness of committed researchers and clinicians working together across Australia.

I treasure the photo pictured showing Shannon Clough and her son Ethan with me at Admiralty House when I was Governor General. Sadly in the following year Ethan passed away. Shannon has not wavered in her commitment to cerebral palsy research since Ethan's death. I hold her in the highest esteem for her achievements as Chair of CP Quest – Community and Researchers Together. This group supports families and people with cerebral palsy to work together with researchers both to support current research and shape the future research agenda. For some years now, members of CP Quest have assisted with research projects, many of which rely on the cerebral palsy registers for data or as a mechanism for recruitment.

The ACPR itself, is a shining example of what can be achieved when groups from across the states and territories of Australia work together. This fantastic resource could not run without the support of the Cerebral Palsy Alliance and all those generous not for profit groups, health departments and research institutes that fund and house the state and territory registers.

This encouraging and uplifting report highlights the key aspects of cerebral palsy as a health and social

issue. Here, the ACPR Group reports on almost 9000 individuals from across Australia living with cerebral palsy. There are thousands more born before the ACPR began, with an estimated 37,000 individuals with cerebral palsy in our country. These individual people and their families are now navigating the National Disability Insurance Scheme which aims to support a better life for people with cerebral palsy and other significant permanent disabilities. This exciting program, still in its establishment phase, will one day I believe be considered one of our greatest national initiatives.

The work of the ACPR is watched by others across the globe. The ACPR Group shares both their infrastructure and their expertise with other groups wanting to set up their own registers. Remarkable work in New Zealand, Bangladesh and Sri Lanka is showcased here.

I offer my very warmest congratulations to every member of the ACPR Group and to their supporting organisations on this 2018 Report. Thank you to all the families and individuals with cerebral palsy who assist in the work of the cerebral palsy registers across Australia. This work is dedicated to them.

The Honourable Dame Quentin Bryce AD CVO

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 cerebral palsy (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 has been securely uploaded from each of the state and territory CP registers.

This is the fourth report of combined data from the ACPR Group. In section 4 of this report, we welcome the team from the recently established Sri Lankan CP Register. In this section we also include an update from the dedicated researchers working on the New Zealand and Bangladesh CP Registers. Each of these groups share the same minimum data set of the ACPR and its infrastructure. We are also pleased to welcome the establishment of a number of CP Registers in the region based in Singapore, Vietnam (Hanoi) and China (Henan Provincial Maternity and Infant Health Hospital). The ACPR Group looks forward to collaborating with these groups to undertake future research collaborations.

This 2018 report comprises data provided in August 2018 for the 1995-2012 birth years. Any notifications to state/territory registers after this date were not included in the report. There was a total of 8637 records of children with CP reported from all states and territories of Australia at this time. This included data provided by the three long-standing registers from South Australia (established in 1998), Victoria (1987) and Western Australia (1979) which have a long history of surveillance, stable methods and inclusion/exclusion criteria. In this report it can also be seen that the more recently established CP Registers in New South Wales/Australian Capital Territory, Queensland, Tasmania and the Northern Territory have made enormous gains in terms of the number of cases now ascertained.

In this birth cohort (1995-2012) there were 4064 children with CP registered with the three long-standing CP registers. The brain injury responsible for their CP is believed to have occurred during the prenatal or perinatal period of infant development for the majority (94%) of these children. The prevalence of CP for this group in the most recent reporting period (2010-2012) was 1.4 per 1000 live births (95%CI 1.3, 1.5).

The following key findings pertain to this cohort:

- The rate of pre/perinatally acquired CP declined from 2.1 (95%CI 2.0, 2.3) in 1995-1997 to 1.4 (1.3, 1.5) children per 1000 live births/neonatal survivors in the 2010-2012 period.
- The rate of CP per 1000 neonatal survivors for children born 20-27 weeks declined, 1995-2012.
- The rate of CP per 1000 live births for those born 37+ weeks declined, 2004-2012.
- The rates of twins born with CP declined (combined data SA and WA), 1995-2012.
- The rate of CP per 1000 neonatal survivors with moderate-severe gross motor function (Gross Motor Function Classifications System, levels III-V) declined, 1995-2012.
- The proportion of children with CP who *did not* have vision impairments, epilepsy and intellectual impairment increased, 1995-2012.

This CP cohort included 6% of children who had a recognised post-neonatal brain injury acquired more than 28 days after birth. In this group key findings for this reporting period (1995-2012) were as follows:

- The rate of post-neonatally acquired CP declined from 1.4 (95%CI 1.1, 1.9) in the 1995-1997 period to 0.8 (0.5, 1.1) children per 10,000 live births in the 2010-2012 period.
- There were proportionally more Aboriginal and Torres Strait Islander children and these children had more severe motor and other associated impairments compared with their non-Indigenous peers.
- The most common post-neonatal cause of CP was a cerebrovascular accident, either spontaneous, as a complication of surgery or associated with congenital cardiac anomalies.
- Severe associated impairments/disorders were proportionally more common amongst children with post-neonatally acquired CP compared to pre/perinatally acquired CP: blindness (10% v 4%), bilateral deafness (5% v 2%), non-verbal communication (32% vs 24%), moderate-severe intellectual impairment (28% vs 20%) and epilepsy (50% vs 30%).


WORLDWIDE

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About Cerebral Palsy

Both internationally and in Australia, CP registers draw on a range of references and perspectives when considering the definition of CP which best suits their purposes.[1] The ACPR has adopted the approach used by the Surveillance of Cerebral Palsy in Europe (SCPE),[2] allowing the use of any definition that includes the following five key elements common to the definitions published by Bax,[3] Rosenbaum[4] and Mutch.[5]

Cerebral palsy:

(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[2]

For the majority of individuals with CP the complete causal pathway to brain injury is not well understood. CP is associated with numerous antenatal and perinatal factors e.g., congenital infections, congenital anomalies, preterm birth, intrauterine growth restriction, neonatal encephalopathy and multiple pregnancy and with post-neonatal factors such as head trauma or cerebral infections.[6]

The motor impairments of CP are classified into four main subtypes: spastic, dyskinetic, ataxic and hypotonic. Individuals with spasticity may exhibit increased muscle tone, increased deep tendon reflexes, weakness and abnormal gait and posture.[7] Individuals with dyskinetic CP may have dystonic, athetoid or choreoathetoid movement patterns including involuntary, uncontrolled, recurring, occasionally stereotyped movements and fluctuating muscle tone.[8] 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.[8] A proportion of individuals with CP exhibit more than one motor type e.g. predominantly spasticity with dystonia, and a very small group have a hypotonic motor type.[9]

Among individuals with CP, the severity of the physical disability/gross motor impairment ranges from minimal to severe, and the complexity of the condition can be increased by the co-occurrence of associated impairments.[10, 11] The likelihood and severity of associated impairments increase with the severity of motor impairment.[12-15] Many individuals with CP will have more than one associated impairment, and their presence can complicate therapy, decrease quality of life for the individual and their family, and increase costs for both the family and society.[11]

Internationally, estimates of the prevalence of CP throughout the world vary depending on the method used to “count” cases, the percentage of the population ascertained and the selection criteria used.[16] Rates identified from on-going CP registers have ranged from 1.4 to 2.7/1000 live births whereas the range from cross-sectional surveys is 1.0 to 4.1/1000 live births.[11] The two largest data sets, the ACPR and the SCPE, and a recent meta-analysis of CP prevalence all report an overall birth prevalence of approximately 2.0/1000 live births.[16]

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.

State and Territory CP Registers

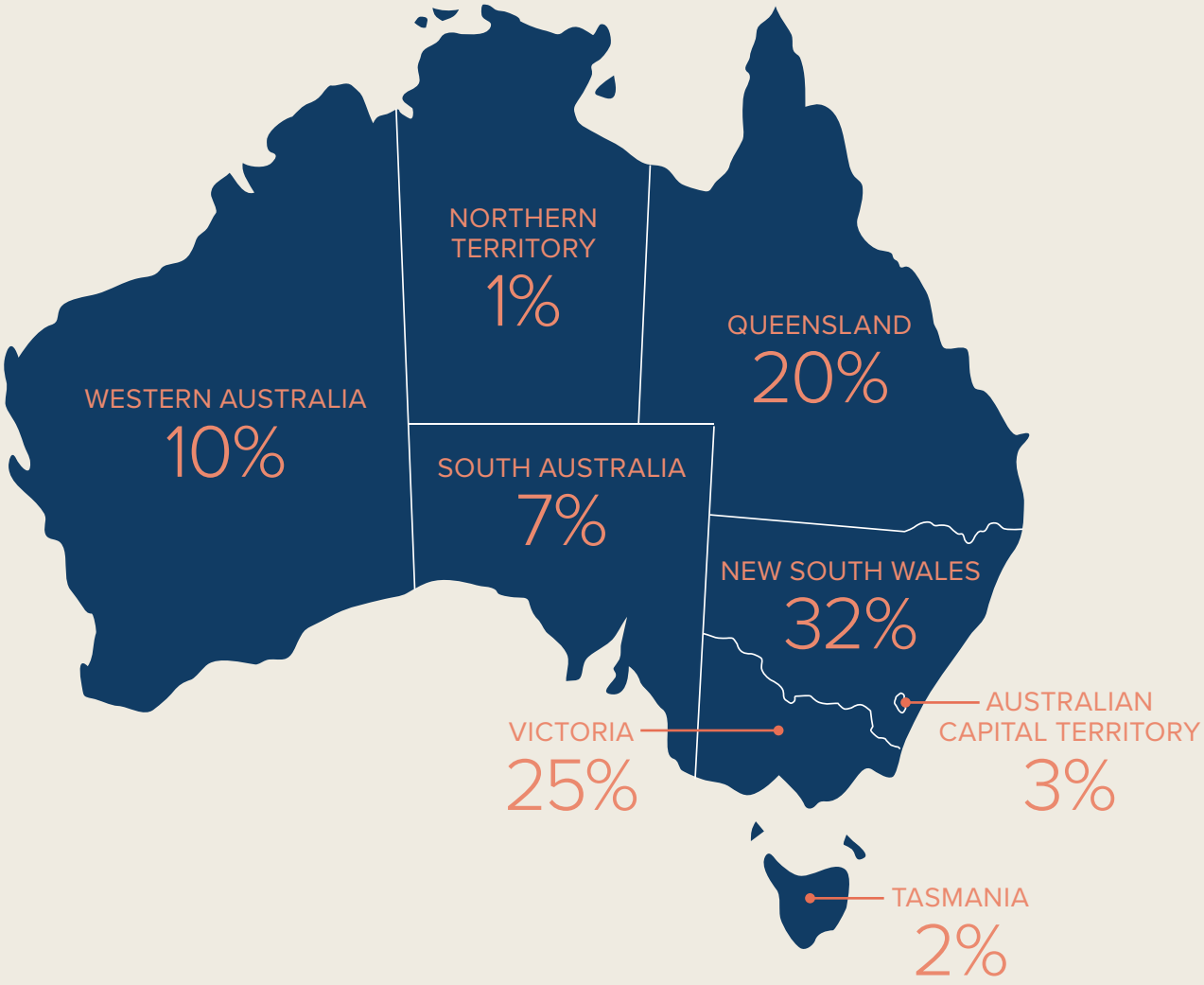
The ACPR exists as a result of collaborative partnerships between all Australian state and territory CP registers, and the organisations which support each register. The contributing registers and their organisations are as follows:

Cerebral Palsy Register	Custodian Organisation		Year that register was established	Children included in birth state/territory register born on/after 1/1/2001	Adults included by birth state/territory register born prior to 1/1/2001
Australian Capital Territory/ New South Wales CP Registers	Cerebral Palsy Alliance Research Institute	Cerebral Palsy ALLIANCE RESEARCH INSTITUTE	2005	2341	1542
Northern Territory CP Register	Centre for Disease Control	NORTHERN TERRITORY GOVERNMENT	2008	94	63
Queensland CP Register	CPL- Choice, Passion, Life	cpl choice • passion • life	2006	1212	676
South Australian CP Register	Women's and Children's Health Network		1998	605	386
Tasmanian CP Register	St Giles	stgiles	2008	134	48
Victorian CP Register	Murdoch Children's Research Institute @ Royal Children's Hospital, Melbourne	murdoch children's research institute	1986	2004	3707
Western Australian Register of Developmental Anomalies - CP	Department of Health WA		1977	1003	2415

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

Population Proportions for the States and Territories of Australia[19]

A map showing the states and territories and the percentage of total population has been provided below. Australia is a large country with varying population densities and accessibility to services. See Accessibility Remoteness Index (page 22). Australia has a total population of approximately 25 million people,[17] with 310,000 live births per year.[18]



Aims of the ACPR

The overarching vision for the ACPR is that the register should be used to assist in efforts to both reduce the incidence of CP and 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 and

d) evaluating preventive 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 about 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 is reviewed regularly by the Cerebral Palsy Alliance Human Research Ethics Committee, a National Health and Medical Research Council approved HREC (EC00402). Projects involving the use of data stratified by Indigenous status are reviewed by the Aboriginal Health and Medical Research Council (EC00453).

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

ACPR Community Aboriginal and Torres Strait Islander Reference Group

The recently established ACPR Community Aboriginal and Torres Strait Islander Reference Group (CARG) exists to provide expert guidance to the ACPR Research and Policy Group. One key role of the CARG is to increase community involvement in the use and reporting of ACPR data and research. Current members of the CARG include: Mick Adams, Leanne Diviney, Michael deLacy, Sophie Marmont, Tan Martin, Anne Masi, Sarah McIntyre, Marita Morgan, Natasha Murray, Hayley Smithers-Sheedy, Emma Waight, Linda Watson and Susan Woolfenden.

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:

- A collaborative research study with researchers from the Surveillance of Cerebral Palsy in Europe to investigate the contribution of higher multiple births to CP
- The Comprehensive CA-CP Study, a collaborative research study with researchers from the Surveillance of Cerebral Palsy in Europe and the European Surveillance of Congenital Anomalies (EUROCAT) to investigate the role of congenital anomalies in CP
- The support of other research groups internationally to establish new CP registers including the Bangladesh, New Zealand and Sri Lankan CP Registers (see Section 4)
- Completion of data linkages to support the evaluation of long-term outcome measures for the ACTOMGS04 trial
- Research to investigate opportunities for prevention and early detection of CP in Australian Aboriginal and Torres Strait Islander children through the examination of sociodemographic and clinical profiles
- The impact of social disadvantage on indicators of CP severity - an examination of the Australian CP Register
- Epidemiology of Cerebral Palsy: comparison of the European and Australian networks of CP registers
- Research to investigate CP trends in Australia (1995–2009)
- Contribution of papers and participation in the World CP Registers Congress, part of the 6th International Cerebral Palsy Conference, to be held in Anaheim USA in 2019

Methods

Cohort

The cohort selected for this report was born 1995-2012. In order to ensure that duplicate cases were not included in the dataset, each state and territory group contributed only cases that were born in their state or territory within this time frame. A de-duplication algorithm designed to highlight potential duplicates was run 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 for CP as outlined earlier.[2] Contributing registers consider cases to be confirmed when the individual reaches 5 years of age. In the event that new information becomes available, a case entry may be updated which may involve inclusion or exclusion.

Denominator Data

Data on live births and neonatal survivors for the years 1995-2012 (the denominator) was obtained from the Australian Institute of Health and Welfare. In some instances where missing data had been flagged, denominators were sourced from The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Report for Victoria.[20]

Reporting of Numerator Data

Case ascertainment varies between states, reflecting differences in both the time of establishment and the governance and consent requirements of each register. 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 New South Wales/Australian Capital Territory, 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 for some or all birth year groups. As such, the calculation of rates in this report has used data drawn from the long-standing CP registers with the addition of Queensland data at various points. To show the development of the newer CP registers, overall combined data is presented for the first time in Table 5. In regards to missing data, where more than 20% of data are missing or unknown, these data are reported in data tables only and are not included in calculations of combined data.

Results

The results of this report have been divided into four sections. Part 1 reports on all CP cases not differentiated by timing of brain injury, Part 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 Part 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.[21] 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. Part 4 provides information about the New Zealand, Bangladesh and Sri Lankan CP registers which share the ACPR minimum dataset and infrastructure.

1

All cerebral palsy

Prevalence

Table 1. Rate of pre/perinatally and post-neonatally acquired CP per live births (LB) by birth period, South Australia, Victoria and Western Australia combined (1995-2012)

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012
Pre/perinatally acquired CP per 1000 LB	2.1	2.1	2.0	2.0	1.8	1.4
Post-neonatally acquired CP *per 10,000 LB*	1.4	1.1	1.3	1.2	1.3	0.8
All CP per 1000 LB (95%CI)	2.2 (2.1, 2.4)	2.3 (2.1, 2.4)	2.2 (2.0, 2.3)	2.1 (2.0, 2.3)	1.9 (1.8, 2.0)	1.4 (1.3, 1.6)

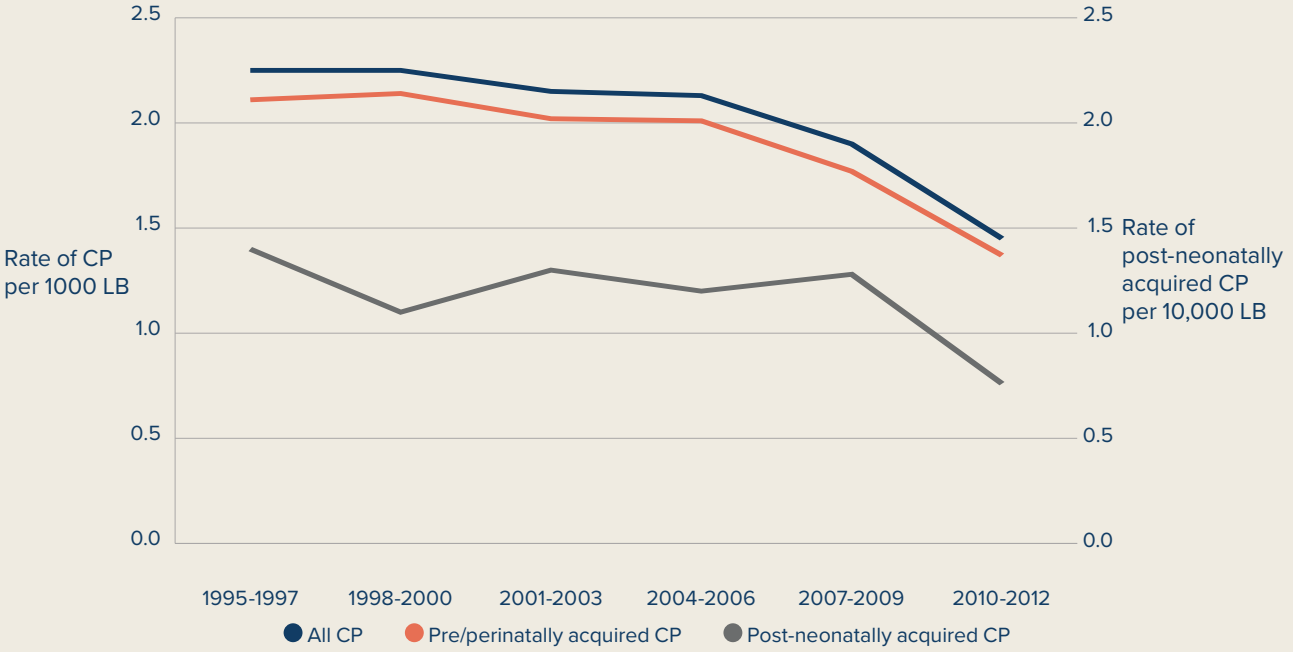
Note: Post-neonatally acquired CP rate is per 10,000 LB

Table 2. Pre/perinatally and post-neonatally acquired CP for each state/territory of birth, South Australia, Victoria and Western Australia combined (1995-2012)

	1995-2012				
	Live births (1995-2012) n	Pre/perinatally acquired CP n	Post-neonatally acquired CP n	TOTAL CP n	All CP cases Rate per 1000 live births
ACT/NSW	1714609	2648	158	**2806**	1.6
NT	66328	113	14	**127**	1.9
QLD	967774	1434	64	**1498**	1.5
SA*	338621	645	32	**677**	2.0
TAS	108747	142	0	**142**	1.3
VIC*	1200478++	2017	115	**2132**	1.8
WA*	494236	1165	90	**1255**	2.5
TOTAL	**4890793**	**8164**	**473**	**8637**	**1.8**
COMBINED*	**2033335**	**3827 (94%)**	**237 (6%)**	**4064**	**2.0 (95% CI 1.9, 2.1)**

++2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 1. Rates of all CP, pre/perinatally and post-neonatally acquired CP per live births (LB) by birth period, South Australia, Victoria and Western Australia combined (1995-2012)



Rates of pre/perinatal CP and post-neonatally acquired CP declined (1995-2012). The declining trend for pre/perinatal CP that was evident in the previous ACPR report (1993-2009) has continued. There was a marked decline in the rate of post-neonatally acquired CP in the most recent birth period (2010-2012).

Indigenous status

Table 3. Number and percentage of children with CP by Indigenous status of mother for each state/territory of birth and Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

	Aboriginal	Aboriginal and Torres Strait Islander	Torres Strait Islander	Non-Indigenous	Total	Unknown
	n (%)^	n (%)^	n (%)^	n (%)^	n	n (%)
ACT/NSW						
Pre/peri CP	119 (6.3)	5 (<1.0)	♦ (<1.0)	1753 (93.3)	**2648**	769 (29.0)
PNN CP	6 (5.9)	♦ (1.0)	0 (0.0)	94 (93.1)	**158**	57 (36.1)
NT*						
Pre/peri CP	53 (47.7)	0 (0.0)	♦ (<1.0)	57 (51.4)	**113**	♦ (1.8)
PNN CP	10 (71.4)	♦ (7.1)	0 (0.0)	3 (21.4)	**14**	0 (0.0)
QLD*						
Pre/peri CP	66 (5.1)	13 (1.0)	9 (0.7)	1201 (93.2)	**1434**	145 (10.1)
PNN CP	7 (12.1)	0 (0.0)	0 (0.0)	51 (87.9)	**64**	6 (9.4)
SA*						
Pre/peri CP	23 (3.6)	0 (0.0)	♦ (<1.0)	617 (96.3)	**645**	♦ (<1.0)
PNN CP	♦ (6.3)	0 (0.0)	0 (0.0)	30 (93.8)	**32**	0 (0.0)
TAS*						
Pre/peri CP	12 (9.8)	0 (0.0)	0 (0.0)	111 (90.2)	**142**	19 (13.4)
PNN CP	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	**0**	0 (0.0)
VIC*						
Pre/peri CP	22 (1.1)	♦ (<1.0)	0 (0.0)	1896 (98.8)	**2017**	98 (4.9)
PNN CP	♦ (0.9)	0 (0.0)	0 (0.0)	111 (99.1)	**115**	♦ (2.6)
WA*						
Pre/peri CP	96 (8.2)	♦ (<1.0)	0 (0.0)	1067 (91.7)	**1165**	♦ (<1.0)
PNN CP	19 (21.1)	0 (0.0)	0 (0.0)	71 (78.9)	**90**	0 (0.0)
COMBINED*						
Pre/peri CP	**272 (5)**	**15 (<1)**	**11 (<1)**	**4949 (94)**	**5516**	**269 (5)**
PNN CP	**39 (13)**	**♦ (<1)**	**0 (0)**	**266 (87)**	**315**	**9 (3)**
All CP	**311 (6)**	**16 (<1)**	**11 (<1)**	**5215 (94)**	**5831**	**278 (5)**

♦ <5 cases
Pre/peri: pre/perinatally acquired CP
PNN: post-neonatally acquired CP
(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

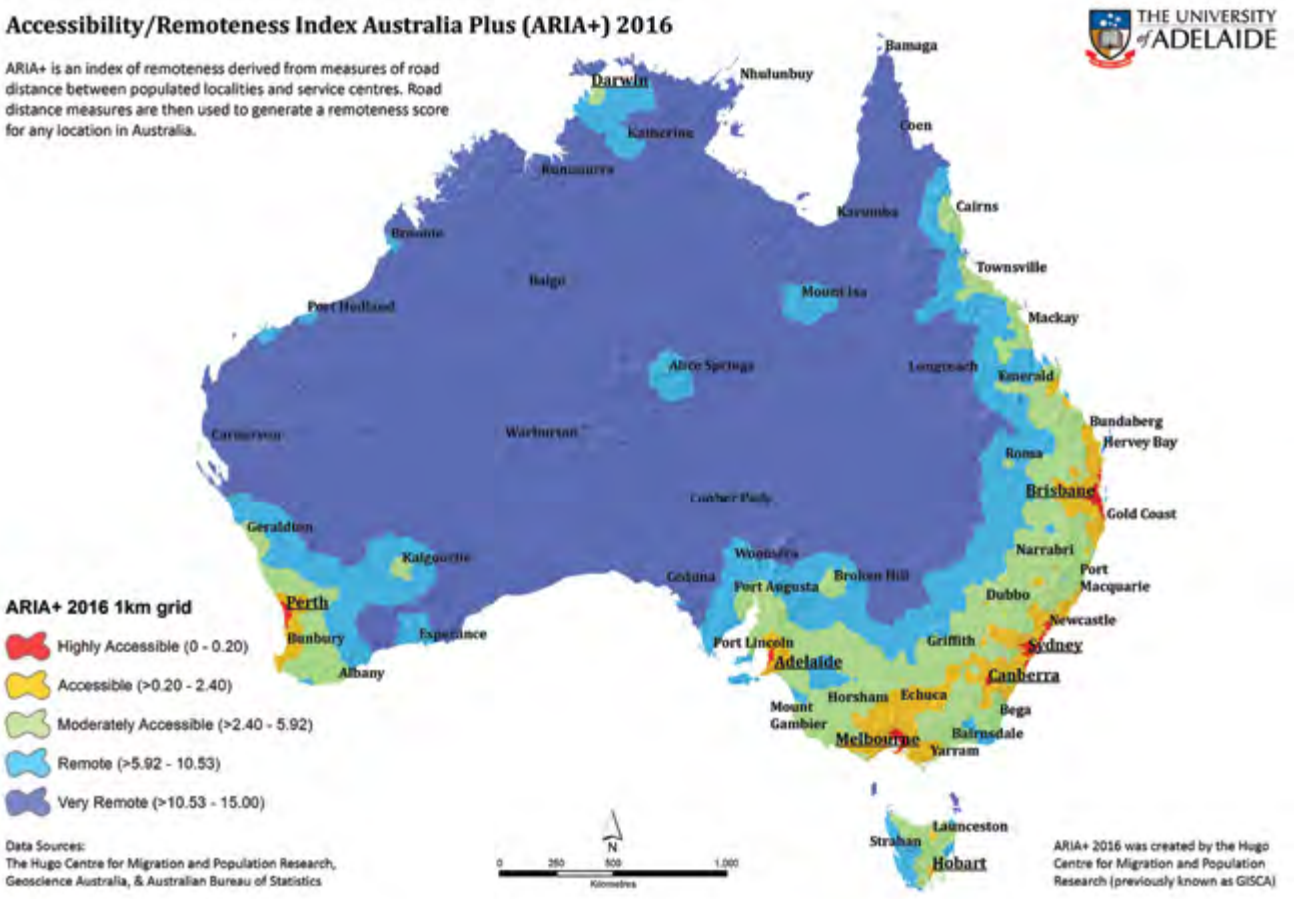
Table 4. Clinical characteristics of children with CP by Indigenous status and time of CP acquisition born Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

	Pre/perinatal CP		Post-neonatally acquired CP	
	Aboriginal and/ or Torres Strait Islander	Non-Indigenous	Aboriginal and/or Torres Strait Islander	Non-Indigenous
	n (%)	n (%)	n (%)	n (%)
Maximum n*	**282**	**4678**	**40**	**258**
GMFCS IV-V	87 (31.8)	1206 (25.8)	14 (35.0)	83 (32.7)
ID IQ <70	162 (60.4)	1974 (44.7)	23 (63.9)	144 (58.5)
Epilepsy⅄	120 (42.6)	1304 (28.2)	14 (37.8)	83 (32.2)
Visual impairment	87 (32.8)	1290 (29.2)	11 (31.4)	97 (39.3)
Blind	27 (10.2)	185 (4.2)	5 (14.2)	22 (8.9)
Hearing impairment	50 (19.3)	362 (8.1)	27 (75.0)	32 (13.1)
Deaf	9 (3.6)	107 (2.5)	◆ (6.3)	9 (3.8)
Speech impairment	110 (41.2)	1605 (36.4)	19 (54.3)	113 (45.6)
Non-verbal	83 (31.1)	1051 (23.8)	9 (25.7)	64 (25.8)

◆ <5 cases
*Maximum size of the denominator: missing data were excluded
⅄ Epilepsy is defined as two or more afebrile seizures before age 5 years; excluding neonatal seizures
ID: Intellectual Disability

Combined data indicated that 5.7% of children with CP were born to Indigenous mothers. In comparison, 3.9% of babies were born to Indigenous mothers in Australia in 2010.[22]

Investigating remoteness and access to services



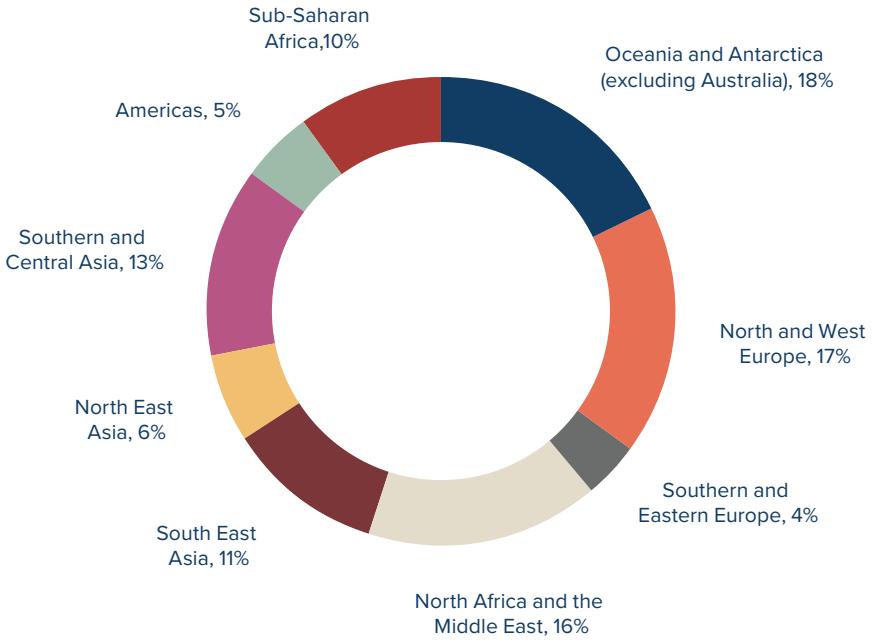
Australia is a large country with varying population densities and accessibility to services (see Accessibility Remoteness Index of Australia).[23] Australians living in rural and remote areas tend to have shorter lives and experience more disease and injury.[24] Individuals living in rural and remote areas have poorer access and lower use of health services compared with those living in metropolitan areas.[24]

Estimates from the Australian Bureau of Statistics (2011) note that around 20% of Aboriginal and Torres Strait Islander people live in remote (51,300 people) or very remote Australia (91,600 people) compared with <2% of the non-Indigenous population.

The ACPR Group is commencing a collaboration with Indigenous and non-Indigenous researchers and members of the ACPR's Community Aboriginal and Torres Strait Islander Reference Group to explore the question of residential remoteness, socioeconomic status and Indigenous status as risk factors for CP and associated co-morbidities.

Children with cerebral palsy born overseas

Figure 2: Percentage of children with CP born overseas included on state/territory CP registers by region of birth (1995–2012).[25]



A further n=46 children living in NSW/ACT and QLD were born overseas (location unknown to the CP registers)

A relatively small group of children on state/territory CP registers were born overseas 1995-2012 (n=706). Data on this group are not otherwise included in this report. The majority of children were born in Oceania (18%), North and Western Europe (17%) or North Africa and the Middle East (16%).

2

Prenatally or perinatally acquired cerebral palsy

Section 2 of this report refers to CP resulting from brain maldevelopment or insult during the prenatal/perinatal period (throughout pregnancy and during the first 28 completed days after birth).

Prevalence

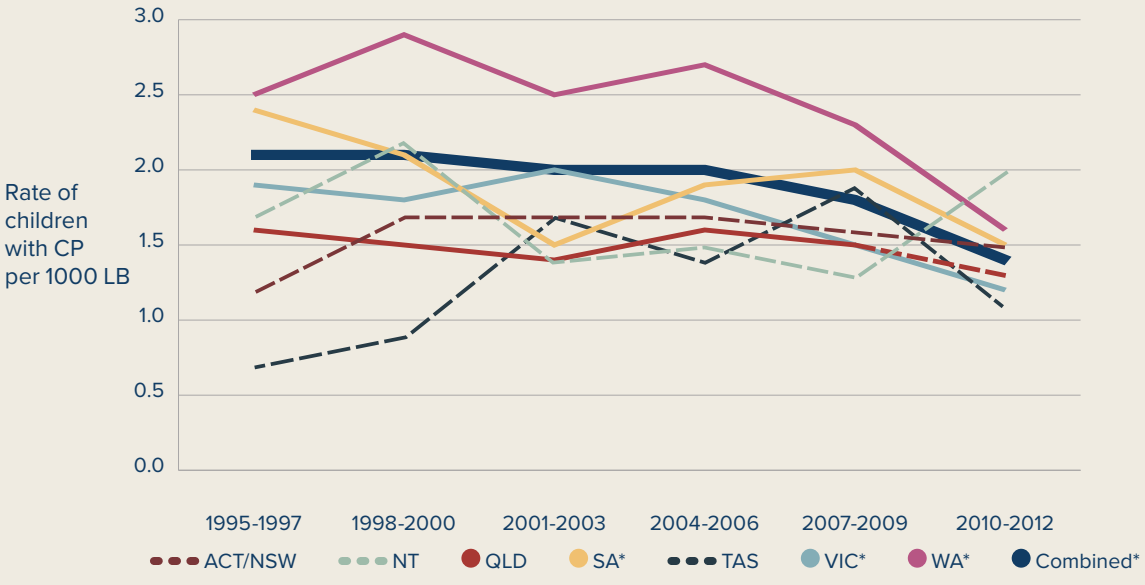
Table 5. Rate of CP per 1000 live births (LB) and neonatal survivors (NNS) for each state/territory of birth by birth period (1995-2012)

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012
ACT/NSW						
Live births (LB)	274511	273718	270769	282683	303930	308998
Neonatal Survivors (NNS)	273794	272988	269953	281766	302883	308122
CP Cases	321	453	452	486	479	457
CP cases/1000 LB	1.2	1.7	1.7	1.7	1.6	1.5
CP cases/1000 NNS	1.2	1.7	1.7	1.7	1.6	1.5
NT						
LB	10578	10684	11054	10811	11450	11751
NNS^	10526	10100	10100^	10753	11404	11700
CP Cases	18	24	16	16	15	24
CP cases/1000 LB	1.7	2.2	1.4	1.5	1.3	2.0
CP cases/1000 NNS	1.7	2.4	1.6	1.5	1.3	2.1
QLD						
LB	143481	145179	148253	161785	182444	186632
NNS	142880	144619	147702	161180	181803	186015
CP Cases	231	225	205	257	275	241
CP cases/1000 LB	1.6	1.5	1.4	1.6	1.5	1.3
CP cases/1000 NNS	1.6	1.6	1.4	1.6	1.5	1.3
SA						
LB	56986	54782	52917	54136	59196	60604
NNS	56786	54641	52757	53986	59049	60471
CP Cases	138	116	81	101	121	88
CP cases/1000 LB	2.4	2.1	1.5	1.9	2.0	1.5
CP cases/1000 NNS	2.4	2.1	1.5	1.9	2.0	1.5
TAS						
LB	19264	17963	16798	17459	18984	18279
NNS	19173	17895	16706	17387	18937	18222
CP Cases	14	16	29	25	37	21
CP cases/1000 LB	0.7	0.9	1.7	1.4	1.9	1.1
CP cases/1000 NNS	0.7	0.9	1.7	1.4	2.0	1.2
VIC						
LB	187596	186050	187389	198353	216234	224856
NNS++	186445	185391	186705	197661	214864	224188
CP Cases	350	344	373	350	321	279
CP cases/1000 LB	1.9	1.8	2.0	1.8	1.5	1.2
CP cases/1000 NNS	1.9	1.9	2.0	1.8	1.5	1.2
WA						
LB	75725	76128	73879	80578	91319	96607
NNS	75555	75951	73700	80380	91125	96429
CP Cases	187	218	182	217	206	155
CP cases/1000 LB	2.5	2.9	2.5	2.7	2.3	1.6
CP cases/1000 NNS	2.5	2.9	2.5	2.7	2.3	1.6

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012
TOTAL CP CASES	1259	1396	1338	1452	1454	1265
SA, VIC, WA and QLD COMBINED						
CP cases/1000 LB	2.0	2.0	1.8	1.9	1.7	-
ALL STATES AND TERRITORIES COMBINED						
CP cases/1000 LB	1.6	1.8	1.8	1.8	1.6	1.4
SA, VIC and WA COMBINED						
	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012
LB	320307	316960	314185	333067	366749	382067
NNS	318786	315983	313162	332027	365038	381088
CP Cases	675	678	636	668	648	522
CP cases/1000 LB (95%CI)	2.1 (2.0, 2.3)	2.1 (2.0, 2.3)	2.0 (1.9, 2.2)	2.0 (1.9, 2.2)	1.8 (1.6, 1.9)	1.4 (1.3, 1.5)
CP cases/1000 NNS(95%CI)	2.1 (2.0, 2.3)	2.1 (2.0, 2.3)	2.0 (1.9, 2.2)	2.0 (1.9, 2.2)	1.8 (1.6, 1.9)	1.4 (1.3, 1.5)

SA, VIC, WA and QLD COMBINED – QLD rates data have been included in this combined data as the QCPR is approaching complete ascertainment in all but the most recent triennium which has been excluded from this table
++2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports
^ NNS for previous triennium reported here as complete NNS data not available for this triennium

Figure 3. Rate of CP per 1000 live births (LB) for each state/territory of birth by birth period (1995-2012)



The combined (SA, VIC and WA) rate of CP per 1000 live births/neonatal survivors declined from 2.1 (95%CI 2.0, 2.3) in 1995-1997 to 1.4 (1.3, 1.5) in the 2010-2012 period.

Timing of initial cerebral palsy description

Table 6. Children with CP by timing of initial CP description for each state/territory of birth and Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

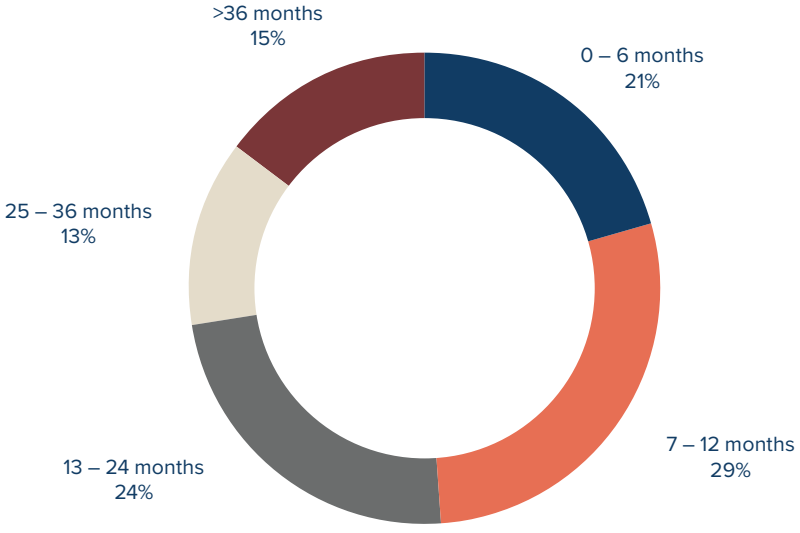
	0 – 6 months n (%)^	7 – 12 months n (%)^	13 – 24 months n (%)^	25 – 36 months n (%)^	37 – 48 months n (%)^	49 – 60 months n (%)^	Age 5 or later n (%)^	TOTAL CP n	Unknown n (%)
ACT/NSW	429 (23.5)	446 (24.4)	508 (27.8)	191 (10.4)	105 (5.7)	55 (3.0)	94 (5.1)	**2648**	820 (31.0)
NT	16 (19.3)	22 (26.5)	25 (30.1)	10 (12.0)	◆ (1.2)	5 (6.0)	◆ (4.8)	**113**	30 (26.5)
QLD*	267 (22.7)	285 (24.2)	326 (27.7)	132 (11.2)	54 (4.6)	52 (4.4)	62 (5.3)	**1434**	256 (17.9)
SA*	118 (27.7)	121 (28.4)	109 (25.6)	34 (8.0)	27 (6.3)	◆ (0.5)	15 (3.5)	**645**[&]	63 (12.9)
TAS*	18 (14.9)	36 (29.8)	35 (28.9)	12 (9.9)	8 (6.6)	◆ (3.3)	8 (6.6)	**142**	21 (14.8)
VIC*	411 (25.0)	419 (25.5)	343 (20.8)	254 (15.4)	74 (4.5)	59 (3.6)	86 (5.2)	**2017**	371 (18.4)
WA*	102 (9.5)	413 (38.5)	232 (21.6)	126 (11.7)	47 (4.4)	107 (10.0)	46 (4.3)	**1165**	92 (7.9)
TOTAL	**1361**	**1742**	**1578**	**759**	**316**	**284**	**315**	**8164**	**1653**
COMBINED*	**916 (21)**	**1274 (29)**	**1045 (24)**	**558 (13)**	**210 (5)**	**224 (5)**	**217 (5)**	**5403**	**803 (15)**

◆ < 5 cases

[&]SA total CP includes n=**156** that had not had their follow-up assessment at the time of data provision

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

Figure 4. Percentage of children with CP by initial CP description interval, Queensland, South Australia[&], Tasmania, Victoria and Western Australia combined (1995-2012)



[&]A further n=156 SA children had not had their follow-up assessment at the time of data provision

Combined data indicated that 50% of children in this cohort were described as having CP in the first year of life and almost three quarters by the age of 2 years. There was no discernible change in percentages of timing of CP description using these intervals over the reporting period (1995-2012).

Sex

Table 7. Number and percentage of children with CP by sex, for each state/territory of birth and all states/territories combined (1995-2012)

	Male n (%)	Female n (%)	TOTAL n
ACT/NSW*	1543 (58.3)	1105 (41.7)	**2648**
NT*	70 (61.9)	43 (38.1)	**113**
QLD*	816 (56.9)	618 (43.1)	**1434**
SA*	366 (56.7)	279 (43.3)	**645**
TAS*	82 (57.7)	60 (42.3)	**142**
VIC*	1166 (57.8)	851 (42.2)	**2017**
WA*	649 (55.7)	516 (44.3)	**1165**
TOTAL	4692	3472	8164
COMBINED*	**4692 (57)**	**3472 (43)**	**8164**

Combined data demonstrated that males were at higher risk of developing CP throughout the reporting period. 57.5% of the CP cohort was male compared to 49.5% of the Australian population.[26]

Table 8. Rate of CP per 1000 live births (LB) by sex and birth period, South Australia, Victoria and Western Australia combined (1995-2012)

Grouped year of birth		Male	Female	GENDER M/F ratio
1995-1997	**CP**	**377**	**298**	**1.3**
	Rate per 1000 LB (95%CI)	**2.3** (2.1, 2.5)	**1.9** (1.7, 2.1)	
1998-2000	**CP**	**381**	**298**	**1.3**
	Rate per 1000 LB (95%CI)	**2.3** (2.1, 2.6)	**1.9** (1.7, 2.1)	
2001-2003	**CP**	**356**	**279**	**1.3**
	Rate per 1000 LB (95%CI)	**2.2** (2.0, 2.5)	**1.8** (1.6, 2.0)	
2004-2006	**CP**	**407**	**261**	**1.6**
	Rate per 1000 LB (95%CI)	**2.4** (2.2, 2.6)	**1.6** (1.4, 1.8)	
2007-2009	**CP**	**353**	**295**	**1.2**
	Rate per 1000 LB (95%CI)	**1.9** (1.7, 2.1)	**1.7** (1.5, 1.9)	
2010-2012	**CP**	**307**	**215**	**1.4**
	Rate per 1000 LB (95%CI)	**1.6** (1.4, 1.7)	**1.2** (1.0, 1.3)	

2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Maternal age at time of delivery

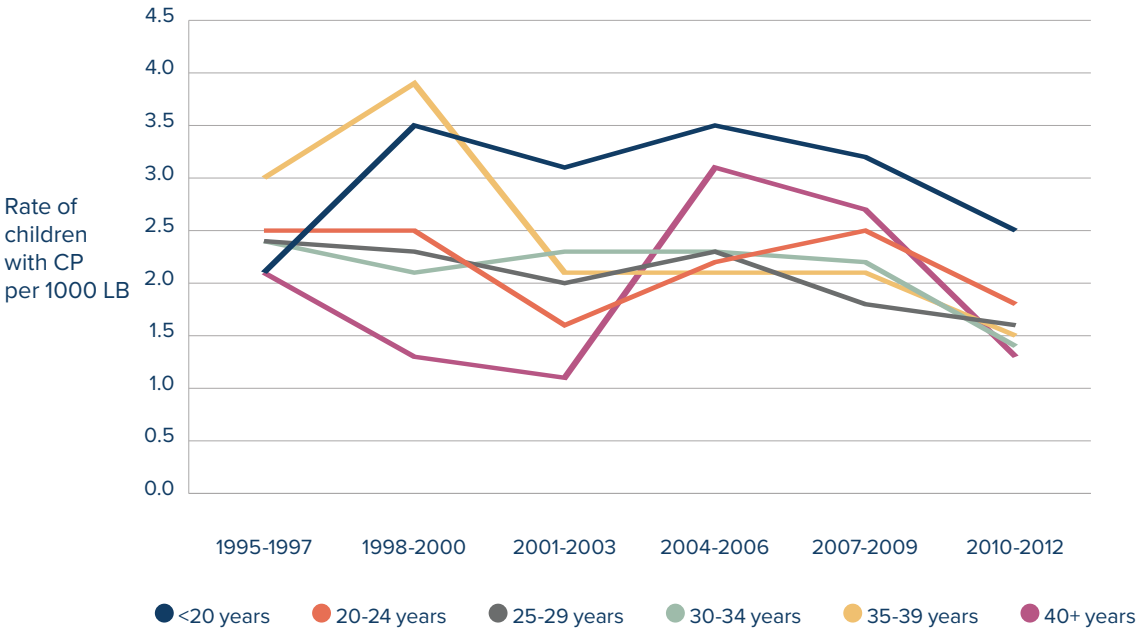
Table 9. Number and percentage of children with CP by maternal age (years) at delivery for each state/ territory of birth and Northern Territory, Queensland, South Australia, Tasmania and Western Australia combined (1995-2012)

	<20	20-24	25-29	30-34	35-39	40+	TOTAL	Unknown
	n (%)^	n (%)^	n (%)^	n (%)^	n (%)^	n (%)^	n	n (%)
ACT/NSW	84 (4.8)	268 (15.3)	445 (25.4)	540 (30.8)	330 (18.8)	86 (4.9)	**2648**	895 (33.8)
NT*	16 (15.1)	22 (20.8)	24 (22.6)	31 (29.2)	9 (8.5)	◆ (3.8)	**113**	7 (6.2)
QLD*	47 (4.1)	174 (15.1)	328 (28.5)	355 (30.9)	202 (17.6)	44 (3.8)	**1434**	284 (19.8)
SA*	43 (6.7)	121 (18.8)	176 (27.3)	189 (29.3)	104 (16.1)	12 (1.9)	**645**	0 (0.0)
TAS*	8 (6.1)	25 (19.1)	34 (26.0)	40 (30.5)	18 (13.7)	6 (4.6)	**142**	11 (7.7)
VIC	69 (4.4)	198 (12.6)	437 (27.9)	534 (34.1)	253 (16.1)	76 (4.9)	**2017**	450 (22.3)
WA*	85 (7.3)	174 (14.9)	330 (28.4)	351 (30.2)	188 (16.2)	36 (3.1)	**1165**	◆ (<1.0)
TOTAL	**352**	**982**	**1774**	**2040**	**1104**	**264**	**8164**	**1648**
COMBINED*	**199 (6)**	**516 (16)**	**892 (28)**	**966 (30)**	**521 (16)**	**102 (3)**	**3499**	**303 (9)**

◆ < 5 cases

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

Figure 5. Rate of children with CP per 1000 live births (LB) maternal age (years) at delivery per birth period, South Australia and Western Australia combined (1995-2012)



Combined data indicated that rates of CP per 1000 live births declined across all maternal age groups (2004-2012). Mothers <20 years continued to have the highest rate of CP.

Gestational age at delivery

Table 10. Number and percentage of children with CP by gestational age group (weeks) for each state/ territory of birth and all states/territories combined (1995-2012)

	20-27	28-31	32-36	≥37	TOTAL	Unknown
	n (%)^	n (%)^	n (%)^	n (%)^	n	n (%)^
ACT/NSW*	269 (12.2)	302 (13.7)	352 (15.9)	1284 (58.2)	**2648**	441 (16.7)
NT*	7 (6.4)	10 (9.1)	26 (23.6)	67 (60.9)	**113**	◆ (2.7)
QLD*	179 (13.5)	217 (16.4)	243 (18.3)	687 (51.8)	**1434**	108 (7.5)
SA*	94 (14.7)	103 (16.1)	108 (16.9)	334 (52.3)	**645**	6 (<1.0)
TAS*	15 (10.9)	19 (13.8)	24 (17.4)	80 (58.0)	**142**	◆ (2.8)
VIC*	243 (12.5)	286 (14.7)	303 (15.5)	1117 (57.3)	**2017**	68 (3.4)
WA*	121 (10.4)	146 (12.6)	188 (16.2)	707 (60.8)	**1165**	◆ (<1.0)
TOTAL	928	1083	1244	4276	8164	633
COMBINED*	**928 (12)**	**1083 (14)**	**1244 (17)**	**4276 (57)**	**8164**	**633 (8)**

◆ < 5 cases

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

Combined data indicated that 43% of CP births were preterm (<37 weeks gestation) over the reporting period (1995-2012). This is in contrast to the Australian population where ≃ 6-8% of live births during this period were preterm.[27, 28]

Table 11. Number and rate of children with CP born 20-27 weeks gestation per 1000 live births (LB) and neonatal survivors (NNS) by birth period, Queensland^, South Australia, Victoria and Western Australia (1995-2012)

Gestational age group	Year of birth		QLD^	SA	VIC	WA
20-27 weeks	1995-1997	CP	30	30	44	17
		Rate/LB (95%CI)	44.8 (31.6, 63.3)	101.4 (71.9, 141.0)	57.5 (43.1, 76.3)	54.1 (34.1, 85.0)
		Rate/NNS (95%CI)	88.8 (62.9, 123.9)	172.4 (123.5, 235.5)	98.7 (74.3, 129.9)	82.5 (52.2, 128.2)
	1998-2000	CP	35	20	46	26
		Rate/LB (95%CI)	49.9 (24.3, 52.1)	78.1 (51.1, 117.6)	55.6 (41.9, 73.3)	89.3 (61.7, 127.7)
		Rate/NNS (95%CI)	87.3 (42.6, 90.4)	117.7 (73.5, 166.3)	94.7 (71.7, 123.9)	133.3 (92.6, 188.2)
	2001-2003	CP	21	8	46	24
		Rate/LB (95%CI)	29.4 (19.3, 44.5)	30.4 (15.5, 58.9)	49.7 (37.4, 65.6)	81.4 (55.3, 118.2)
		Rate/NNS (95%CI)	51.7 (34.1, 77.8)	49.7 (25.4, 95.0)	90.6 (68.6, 118.7)	112.7 (76.9, 162.2)
	2004-2006	CP	38	7	36	21
		Rate/LB (95%CI)	45.6 (33.4, 61.9)	24.1 (11.7, 48.8)	37.0 (26.8, 50.8)	55.9 (36.8, 83.9)
		Rate/NNS (95%CI)	81 (59.6, 109.3)	35.5 (17.3, 71.5)	68.1 (49.6, 92.8)	79.5 (52.6, 118.5)
	2007-2009	CP	32	18	36	20
		Rate/LB (95%CI)	38.0 (27.0, 52.3)	65.5 (41.8, 101.1)	34.5 (25.0, 47.4)	49.9 (32.5, 75.8)
		Rate/NNS (95%CI)	66.4 (47.4, 92.2)	91.8 (58.9, 140.5)	61.7 (44.9, 84.3)	64.9 (42.4, 98.2)
	2010-2012	CP		11	35	13
		Rate/LB (95%CI)	-	36.8 (20.7, 64.7)	34.9 (25.2, 48.1)	36.2 (21.3, 61.0)
		Rate/NNS (95%CI)	-	50.0 (28.1, 87.3)	62.3 (45.1, 85.4)	45.8 (26.9, 76.7)

^QLD frequency and rates data have been included in this table as the QCPR is approaching complete ascertainment in all but the most recent triennium which has been excluded from this table
2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 6. Number and rate of children with CP born 20-27 weeks gestation per 1000 neonatal survivors (NNS) by birth period, South Australia, Victoria and Western Australia (1995-2012)

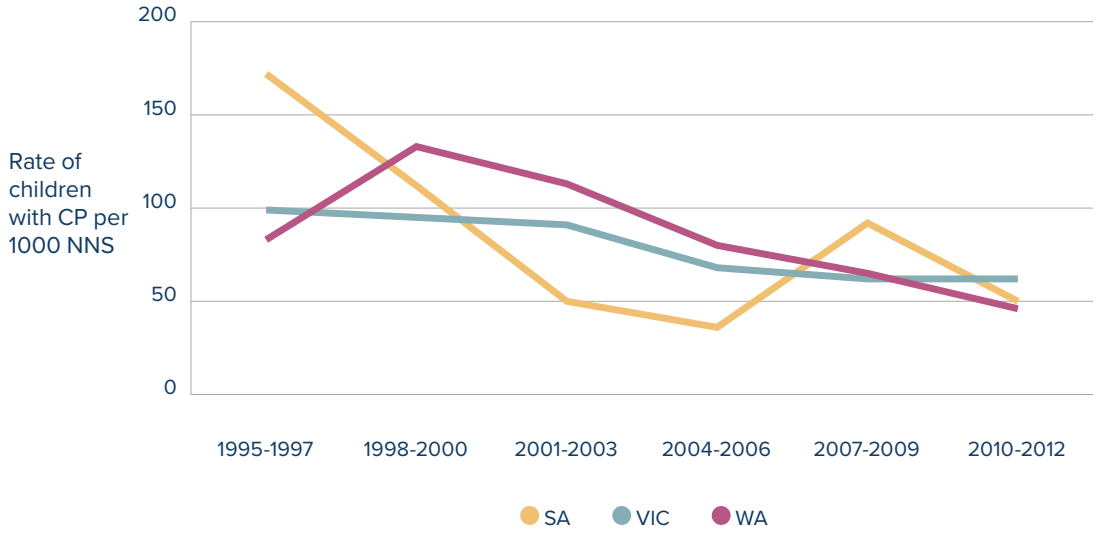


Table 12. Number and rate of children with CP born 28-31 weeks gestation per 1000 live births (LB) and neonatal survivors (NNS) by birth period, Queensland^, South Australia, Victoria and Western Australia (1995-2012)

Gestational age group	Year of birth		QLD^	SA	VIC	WA
28-31 weeks	1995-1997	CP	33	20	45	18
		Rate/LB (95%CI)	27.8 (20.9, 40.7)	45.2 (29.5, 68.9)	34.5 (25.9, 45.9)	35.4 (22.5, 55.3)
		Rate/NNS (95%CI)	29.2 (19.5, 38.6)	46.6 (30.4, 70.9)	36.1 (27.1, 48.0)	36.6 (23.3, 57.1)
	1998-2000	CP	39	27	52	27
		Rate/LB (95%CI)	31.7 (23.3, 43.1)	56.5 (39.1, 80.9)	39.2 (30.0, 51.0)	45.8 (31.6, 65.8)
		Rate/NNS (95%CI)	33.0 (24.2, 44.8)	58.2 (40.3, 83.3)	40.8 (31.3, 53.1)	46.7 (32.3, 67.1)
	2001-2003	CP	39	11	51	20
		Rate/LB (95%CI)	30.5 (22.4, 41.5)	24.7 (13.9, 43.7)	38.1 (29.1, 49.7)	37.9 (24.7, 57.8)
		Rate/NNS (95%CI)	31.5 (23.1, 42.8)	25.3 (14.2, 44.8)	39.2 (29.9, 51.2)	39.1 (25.5, 59.7)
	2004-2006	CP	26	16	44	21
		Rate/LB (95%CI)	19.0 (13.0, 27.7)	36.0 (22.3, 57.6)	31.6 (23.6, 42.1)	33.4 (22.0, 50.6)
		Rate/NNS (95%CI)	19.6 (13.4, 28.6)	36.4 (22.5, 58.2)	32.5 (24.3, 43.3)	33.9 (22.3, 51.2)
	2007-2009	CP	45	17	45	37
		Rate/LB (95%CI)	30.1 (22.6, 40.1)	35.6 (22.4, 56.3)	28.2 (21.2, 37.6)	51.9 (37.9, 70.7)
		Rate/NNS (95%CI)	31.0 (23.3, 41.3)	36.4 (22.9, 57.5)	29.0 (21.7, 38.6)	53.2 (38.9, 72.5)
	2010-2012	CP		12	49	23
		Rate/LB (95%CI)	-	24.9(14.3, 43.0)	33.6 (25.5, 44.1)	33.5 (22.4, 49.8)
		Rate/NNS (95%CI)	-	25.3 (14.5, 43.6)	34.3 (26.1, 45.1)	34.5 (23.1, 51.2)

^QLD frequency and rates data have been included in this table as the QCPR is approaching complete ascertainment in all but the most recent triennium which has been excluded from this table
2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 7. Number and rate of children with CP born 28-31 weeks gestation per 1000 neonatal survivors (NNS) by birth period, South Australia, Victoria and Western Australia (1995-2012)

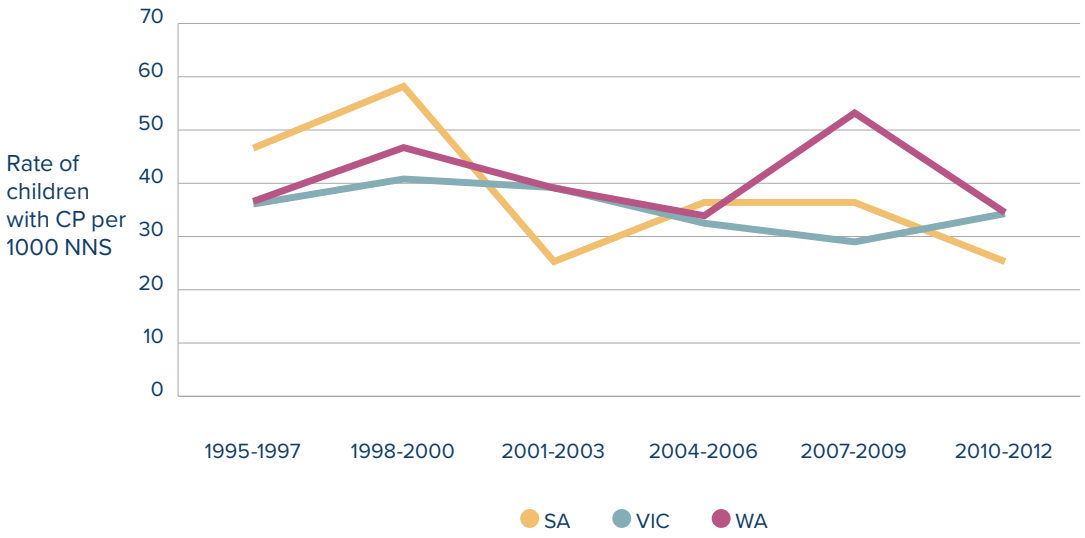


Table 13. Number and rate of children with CP born 32-36 weeks gestation per 1000 live births (LB) and neonatal survivors (NNS) by birth period, Queensland^, South Australia, Victoria and Western Australia (1995-2012)

Gestational age group	Year of birth		QLD^	SA	VIC	WA
32-36 weeks	1995-1997	CP	38	21	46	26
		Rate/LB (95%CI)	4.3 (3.2, 5.9)	6.1 (4.0, 9.2)	4.3 (3.2, 5.8)	6.1 (4.2, 8.9)
		Rate/NNS (95%CI)	4.4 (3.2, 6.0)	6.1 (4.0, 9.3)	4.4 (3.3, 5.8)	6.1 (4.2, 9.0)
	1998-2000	CP	35	24	39	27
		Rate/LB (95%CI)	3.9 (2.8, 5.4)	6.8 (4.6, 10.1)	3.5 (2.6, 4.8)	5.6 (3.9, 8.2)
		Rate/NNS (95%CI)	3.9 (2.8, 5.4)	6.8 (4.6, 10.1)	3.5 (2.6, 4.8)	5.6 (3.9, 8.2)
	2001-2003	CP	34	12	59	23
		Rate/LB (95%CI)	3.5 (2.5, 4.9)	3.5 (2.0, 6.1)	5.2 (4.0, 6.7)	4.7 (3.2, 7.1)
		Rate/NNS (95%CI)	3.5 (2.5, 4.9)	3.5 (2.0, 6.2)	5.2 (4.1, 6.7)	4.8 (3.2, 7.1)
	2004-2006	CP	44	14	53	49
		Rate/LB (95%CI)	3.9 (2.9, 5.2)	3.8 (2.3, 6.4)	4.3 (3.3, 5.6)	8.6 (6.5, 11.4)
		Rate/NNS (95%CI)	3.9 (2.9, 5.2)	3.8 (2.3, 6.4)	4.3 (3.3, 5.7)	8.7 (6.6, 11.4)
	2007-2009	CP	46	19	52	39
		Rate/LB (95%CI)	3.6 (2.7, 4.8)	4.7 (3.0, 7.3)	3.8 (2.9, 5.0)	6.2 (4.6, 8.5)
		Rate/NNS (95%CI)	3.7 (2.7, 4.9)	4.7 (3.0, 7.3)	3.8 (2.9, 5.0)	6.3 (4.6, 8.6)
	2010-2012	CP		18	54	24
		Rate/LB (95%CI)	-	4.0 (2.5, 6.4)	3.7 (2.8, 4.8)	3.5 (2.4, 5.2)
		Rate/NNS (95%CI)	-	4.0 (2.6, 6.4)	3.7 (2.9, 4.9)	3.5 (2.4, 5.2)

^QLD frequency and rates data have been included in this table as the QCPR is approaching complete ascertainment in all but the most recent triennium which has been excluded from this table
2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 8. Number and rate of children with CP born 32-36 weeks gestation per 1000 neonatal survivors (NNS) by birth period, South Australia, Victoria and Western Australia (1995-2012)

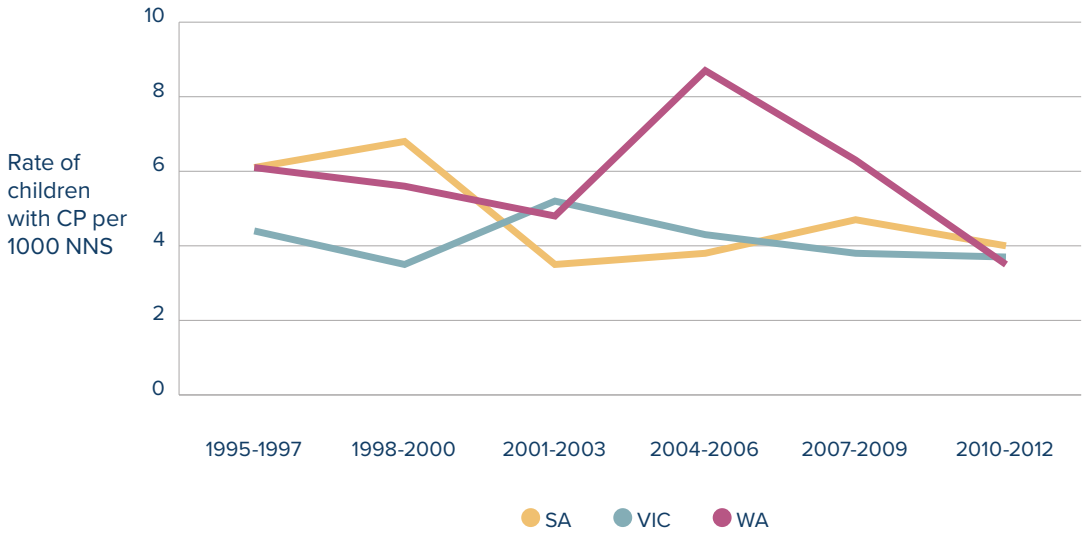


Table 14. Number and rate of children with CP born 37+ weeks gestation per 1000 live births (LB) and neonatal survivors (NNS) by birth period, Queensland^, South Australia, Victoria and Western Australia (1995-2012)

Gestational age group	Year of birth		QLD^	SA	VIC	WA
37+ weeks	1995-1997	CP	106	64	210	126
		Rate/LB (95%CI)	0.8 (0.7, 1.0)	1.2 (0.9, 1.5)	1.2 (1.1, 1.4)	1.8 (1.5, 2.1)
		Rate/NNS (95%CI)	0.8 (0.7, 1.0)	1.2 (1.0, 1.5)	1.2 (1.1, 1.4)	1.8 (1.5, 2.1)
	1998-2000	CP	98	44	197	139
		Rate/LB (95%CI)	0.7 (0.6, 0.9)	0.9 (0.6, 1.2)	1.1 (1.0, 1.3)	2.0 (1.7, 2.3)
		Rate/NNS (95%CI)	0.7 (0.6, 0.9)	0.9 (0.6, 1.2)	1.2 (1.0, 1.3)	2.0 (1.7, 2.3)
	2001-2003	CP	94	49	208	114
		Rate/LB (95%CI)	0.7 (0.6, 0.8)	1.0 (0.8, 1.3)	1.2 (1.0, 1.4)	1.7 (1.4, 2.0)
		Rate/NNS (95%CI)	0.7 (0.6, 0.8)	1.0 (0.8, 1.3)	1.2 (1.0, 1.3)	1.7 (1.4, 2.0)
	2004-2006	CP	133	63	206	126
		Rate/LB (95%CI)	0.9 (0.8, 1.1)	1.3 (0.8, 1.3)	1.1 (1.0, 1.3)	1.7 (1.4, 2.0)
		Rate/NNS (95%CI)	0.9 (0.8, 1.1)	1.3 (1.0, 1.6)	1.1 (1.0, 1.3)	1.7 (1.4, 2.0)
	2007-2009	CP	134	67	166	109
		Rate/LB (95%CI)	0.8 (0.7, 0.9)	1.2 (1.0, 1.6)	0.8 (0.7, 1.0)	1.3 (1.1, 1.6)
		Rate/NNS (95%CI)	0.8 (0.7, 0.9)	1.2 (1.0, 1.6)	0.8 (0.7, 1.0)	1.3 (1.1, 1.6)
	2010-2012	CP		47	130	93
		Rate/LB (95%CI)	-	0.8 (0.6, 1.1)	0.6 (0.5, 0.7)	1.0 (0.9, 1.3)
		Rate/NNS (95%CI)	-	0.8 (0.6, 1.1)	0.6 (0.5, 0.7)	1.0 (0.9, 1.3)

^QLD frequency and rates data have been included in this table as the QCPR is approaching complete ascertainment in all but the most recent triennium which has been excluded from this table
2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 9. Number and rate of children with CP born 37+ weeks gestation per 1000 neonatal survivors (NNS) by birth period, South Australia, Victoria and Western Australia (1995-2012)

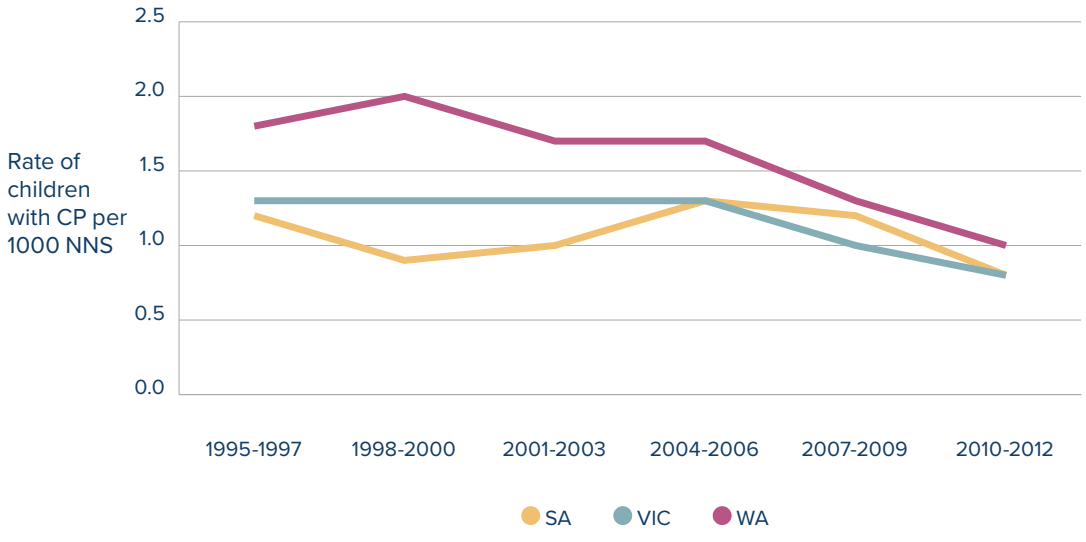
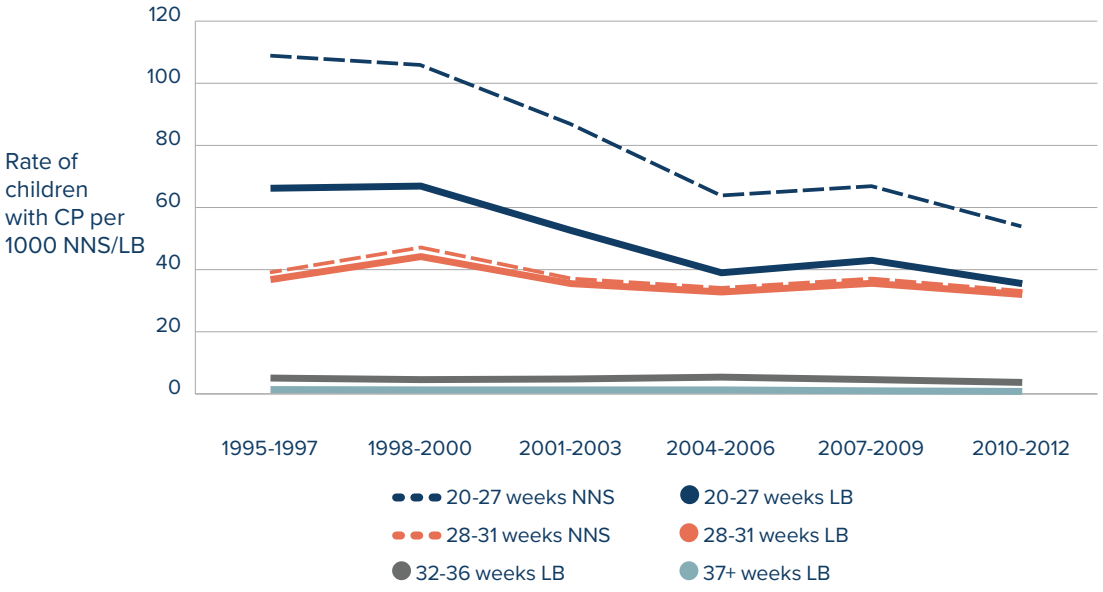


Table 15. Rate of children with CP per 1000 live births (LB) and neonatal survivors (NNS) by gestational age group (weeks) and birth period, South Australia, Victoria and Western Australia combined (1995-2012)

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012
20-27 weeks						
Rate LB	**66.2**	**66.9**	**52.6**	**39.0**	**43.0**	**35.5**
(95%CI)	(54.2, 80.6)	(54.9, 81.4)	(42.3, 65.1)	(30.7, 49.5)	(34.4, 53.7)	(27.6, 45.5)
Rate NNS	**110.2**	**107.0**	**88.4**	**64.6**	**68.1**	**55.3**
(95%CI)	(90.6, 133.4)	(88.0, 129.4)	(71.4, 109.0)	(50.9, 81.7)	(54.6, 84.6)	(43.1, 70.7)
28-31 weeks						
Rate/LB	**36.8**	**44.2**	**35.5**	**32.8**	**35.6**	**32.0**
(95%CI)	(29.8, 45.4)	(36.7, 53.2)	(28.7, 43.8)	(26.5, 40.6)	(29.3, 43.1)	(25.9, 39.4)
Rate/NNS	**38.3**	**45.8**	**36.5**	**33.6**	**36.5**	**32.7**
(95%CI)	(31.0, 47.3)	(38.0, 55.1)	(29.5, 45.1)	(27.1, 41.5)	(30.0, 44.2)	(26.5, 40.3)
32-36 weeks						
Rate/LB	**5.1**	**4.6**	**4.8**	**5.4**	**4.6**	**3.7**
(95%CI)	(4.1, 6.2)	(3.8, 5.7)	(3.9, 5.9)	(4.5, 6.4)	(3.8, 5.5)	(3.0, 4.5)
Rate/NNS	**5.1**	**4.7**	**4.8**	**5.4**	**4.6**	**3.7**
(95%CI)	(4.2, 6.3)	(3.8, 5.7)	(3.9, 5.9)	(4.5, 6.5)	(3.8, 5.5)	(3.1, 4.5)
37+ weeks						
Rate/LB	**1.3**	**1.3**	**1.3**	**1.3**	**1.0**	**0.8**
(95%CI)	(1.2, 1.5)	(1.2, 1.4)	(1.2, 1.4)	(1.2, 1.4)	(0.9, 1.1)	(0.7, 0.9)
Rate/NNS	**1.3**	**1.3**	**1.3**	**1.3**	**1.0**	**0.8**
(95%CI)	(1.2, 1.5)	(1.2, 1.4)	(1.2, 1.4)	(1.2, 1.4)	(0.9, 1.1)	(0.7, 0.9)

2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 10. Rate of children with CP per 1000 live births (LB) and neonatal survivors (NNS), by gestational age group and birth period, South Australia, Victoria and Western Australia combined (1995-2012)



Combined data indicated that the rate of CP per 1000 live births for the largest group, those born 37+ weeks, declined between 2004 and 2012. The rate of CP per 1000 NNS for children born 20-27 weeks has also shown a steady decline between 1995 and 2012.

Birth weight

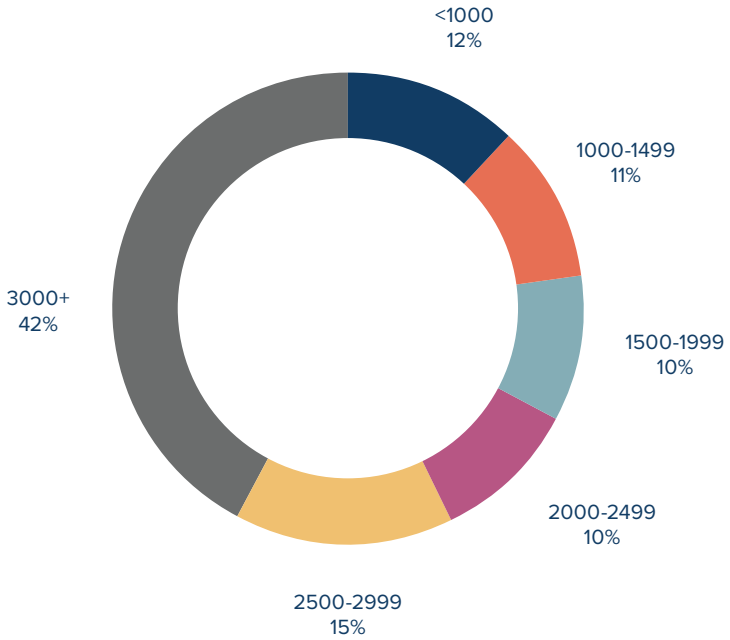
Table 16. Number and percentage of children with CP by birth weight group (grams) for each state/territory of birth and Northern Territory, Queensland, Tasmania, Victoria and Western Australia combined (1995-2012)

	<1000	1000-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	TOTAL	Unknown
	n (%)^	n (%)^	n (%)^	n (%)^	n (%)^	n (%)^	n (%)^	n (%)^	n	n (%)
ACT/NSW	231 (11.8)	235 (12.0)	185 (9.4)	197 (10.1)	280 (14.3)	417 (21.3)	296 (15.1)	118 (6.0)	2648	689 (26.0)
NT*	6 (5.6)	8 (7.4)	8 (7.4)	14 (13.0)	16 (14.8)	34 (31.5)	17 (15.7)	5 (4.6)	113	5 (4.4)
QLD*	161 (12.8)	162 (12.9)	127 (10.1)	150 (11.9)	178 (14.1)	240 (19.1)	167 (13.3)	74 (5.9)	1434	175 (12.2)
SA*	90 (14.0)	77 (12.0)	66 (10.3)	60 (9.4)	83 (12.9)	132 (20.6)	87 (13.6)	46 (7.2)	645	◆ (<1.0)
TAS*	11 (8.4)	16 (12.2)	12 (9.2)	7 (5.3)	27 (20.6)	33 (25.2)	14 (10.7)	11 (8.4)	142	11 (7.7)
VIC*	236 (13.2)	203 (11.3)	193 (10.8)	170 (9.5)	267 (14.9)	351 (19.6)	270 (15.1)	101 (5.6)	2017	226 (11.2)
WA*	112 (9.6)	110 (9.5)	107 (9.2)	108 (9.3)	203 (17.5)	292 (25.2)	167 (14.4)	62(5.3)	1165	◆ (<1.0)
TOTAL	**847**	**811**	**698**	**706**	**1054**	**1499**	**1018**	**417**	**8164**	**1114**
COMBINED*	**616 (12)**	**576 (11)**	**513 (10)**	**509 (10)**	**774 (15)**	**1082 (21)**	**722 (14)**	**299 (6)**	**5516**	**425 (8)**

◆< 5 cases

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

Figure 11. Percentage of children with CP by birth weight group (grams), Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)



Low birth weight is defined as <2500g, very low birth weight <1500g and extremely low birth weight <1000g. Combined data showed that 43% of children with CP were born with low birth weight compared to 6.2% of the Australian population; 23% were born with a very low birth weight compared to 1% and 12% had an extremely low birth weight compared to 0.4% of the Australian population.[27]

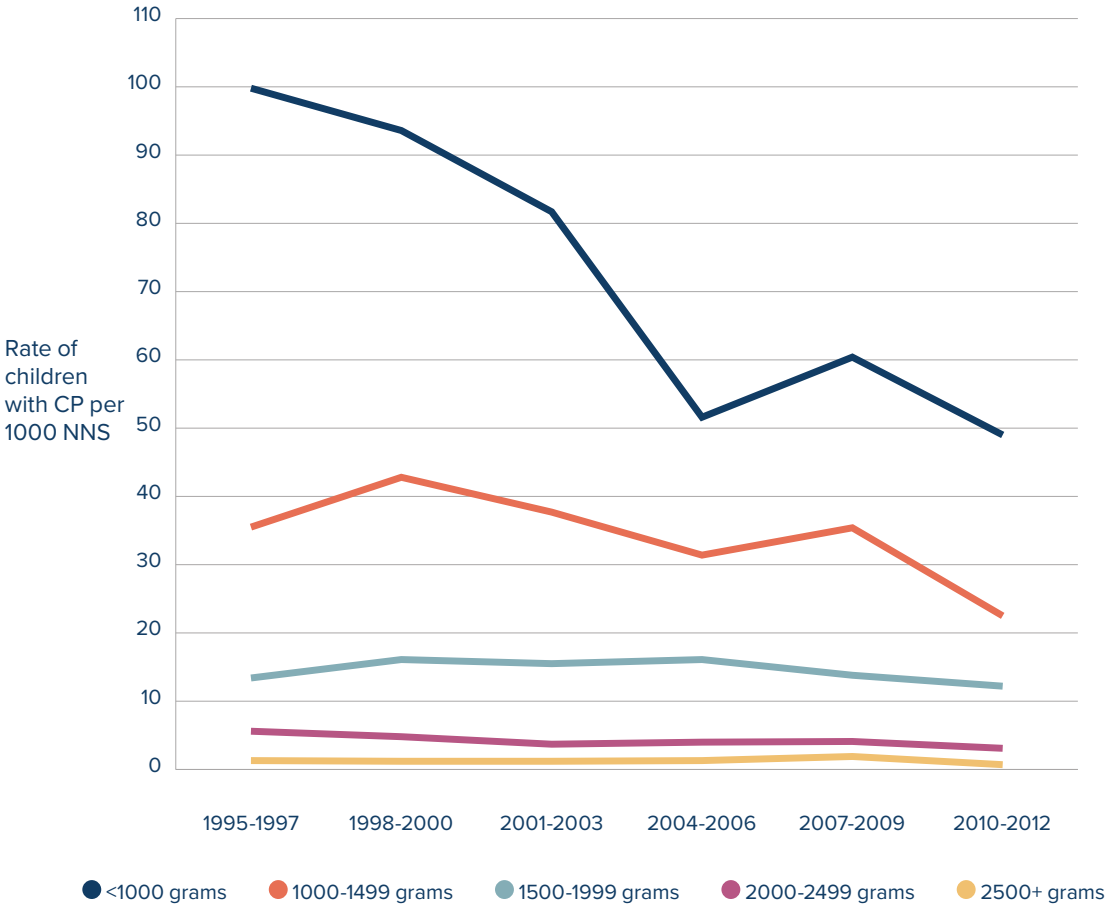
Table 17. Number and rate of children with CP by 1000 neonatal survivors (NNS) by birth weight group (grams) and birth period, Queensland^, South Australia, Victoria and Western Australia (1995-2012)

		QLD^			SA		
Birth weight	Birth years	n	NNS	Rate/1000 NNS (95%CI)	n	NNS	Rate/1000 NNS (95%CI)
<500 grams	1995-97	◆	◆	-	-	◆	-
	1998-00	◆	9	**333.3** (120.6, 645.8)	◆	10	**100.0** (17.9, 404.2)
	2001-03	◆	6	**166.7** (30.1, 563.5)	-	6	-
	2004-06	-	10	-	-	9	-
	2007-09	-	-	-	-	11	-
	2010-12				◆	8	**125.0** (22.4, 470.9)
500-999 grams	1995-97	26	363	**71.6** (49.3,102.9)	28	198	**141.4** (99.7, 196.8)
	1998-00	32	428	**74.8** (53.5, 103.6)	19	188	**101.1** (65.7, 152.4)
	2001-03	31	390	**79.5** (56.6, 110.6)	10	174	**57.5** (31.5, 102.5)
	2004-06	33	463	**71.3** (51.2, 98.4)	5	178	**28.1** (12.1, 64.1)
	2007-09	21	487	**43.1** (28.4, 65.0)	17	187	**90.9** (57.5, 140.8)
	2010-12				9	218	**41.3** (21.9, 76.6)
1000-1499 grams	1995-97	26	858	**30.3** (20.8, 44.0)	15	325	**46.2** (28.2, 74.7)
	1998-00	29	859	**33.8** (23.6, 48.1)	20	348	**57.5** (37.5, 87.1)
	2001-03	27	954	**28.3** (19.5, 40.9)	7	322	**21.7** (10.6, 44.2)
	2004-06	24	995	**24.1** (16.3, 35.6)	13	360	**36.1** (21.2, 60.8)
	2007-09	32	1092	**29.3** (20.8, 41.1)	15	357	**42.0** (25.6, 68.2)
	2010-12				7	352	**19.9** (9.7, 40.5)
1500-1999 grams	1995-97	17	1898	**9.0** (5.6, 14.3)	9	731	**12.3** (6.5, 23.2)
	1998-00	16	1896	**8.4** (5.2, 13.7)	18	709	**25.4** (16.1, 39.8)
	2001-03	23	1939	**11.9** (7.9, 17.7)	7	660	**10.6** (5.1, 21.7)
	2004-06	17	2228	**7.6** (4.8, 12.2)	9	712	**12.6** (6.7, 23.8)
	2007-09	33	2371	**13.9** (9.9, 19.5)	13	766	**17.0** (9.9, 28.8)
	2010-12				10	867	**11.5** (6.3, 21.1)
2000-2499 grams	1995-97	23	5400	**4.3** (2.8, 6.4)	12	2303	**5.2** (3.0, 9.1)
	1998-00	20	5610	**3.6** (2.3, 5.5)	11	2196	**5.0** (2.8, 8.9)
	2001-03	16	5935	**2.7** (1.7, 4.4)	8	2135	**3.7** (1.9, 7.4)
	2004-06	31	6678	**4.6** (3.3, 6.6)	10	2240	**4.5** (2.4, 8.2)
	2007-09	26	7232	**3.6** (2.5, 3.3)	10	2424	**4.1** (2.2, 7.6)
	2010-12				9	2682	**3.4** (1.8, 6.4)
2500+ grams	1995-97	104	134345	**0.8** (0.6-0.9)	71	53227	**1.3** (1.1, 1.7)
	1998-00	97	135805	**0.7** (0.6-0.9)	46	51189	**0.9** (0.7, 1.2)
	2001-03	92	138467	**0.7** (0.5-0.8)	49	49459	**1.0** (0.7, 1.3)
	2004-06	124	150787	**0.8** (0.7-1.0)	64	50487	**1.3** (1.0,1.6)
	2007-09	124	170594	**0.7** (0.6-0.9)	66	55300	**1.2** (0.9, 1.5)
	2010-12				52	56341	**0.9** (0.7, 1.2)

◆< 5 cases
^Queensland frequency and rates data have been included in this table as the QCPR is approaching complete ascertainment in all but the most recent triennium which has been excluded from this table
++2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

VIC			WA		
n	NNS[++]	Rate/1000 NNS (95%CI)	n	NNS	Rate/1000 NNS (95%CI)
◆	8	**125.0** (22.4, 470.9)	-	6	-
◆	16	**62.5** (11.1, 283.3)	◆	8	**125.0** (22.4, 470.9)
5	21	**238.1** (106.3, 450.9)	-	5	-
-	13	-	-	9	-
-	42	-	◆	13	**76.9** (13.7, 333.1)
◆	72	**41.7** (14.3, 115.5)	-	8	-
46	496	**92.7** (70.3, 121.5)	17	214	**79.4** (50.2, 123.5)
41	512	**80.1** (59.6, 106.8)	26	217	**119.8** (83.1, 169.8)
43	535	**80.4** (60.2, 106.5)	19	201	**94.5** (61.4, 142.9)
30	543	**55.2** (39.0, 77.8)	18	275	**65.5** (41.8, 101.1)
33	597	**55.3** (39.6, 76.6)	18	292	**61.6** (39.3, 95.3)
33	592	**55.7** (40.0, 77.3)	12	286	**42.0** (24.2, 71.9)
30	951	**31.5** (22.2, 44.7)	16	444	**36.0** (22.3, 57.7)
41	1061	**38.6** (28.6, 52.0)	18	438	**41.1** (26.2, 64.0)
39	1079	**36.1** (26.6, 49.0)	22	404	**54.5** (36.2, 81.1)
34	1119	**30.4** (21.8, 42.2)	14	462	**30.3** (18.1, 50.2)
31	1206	**25.7** (18.2, 36.3)	28	525	**53.3** (37.2, 76.0)
28	1243	**22.5** (15.6, 32.4)	12	497	**24.1** (13.9, 41.7)
29	2166	**13.4** (9.3, 19.2)	13	897	**14.5** (8.5, 24.6)
32	2328	**13.7** (9.8, 19.3)	13	886	**14.7** (8.6, 24.9)
41	2344	**17.5** (12.9, 23.6)	13	930	**14.0** (8.2, 23.8)
28	2437	**11.5** (8.0, 16.6)	31	1062	**29.2** (20.6, 41.1)
30	2782	**10.8** (7.6, 15.4)	22	1173	**18.8** (12.4, 28.2)
33	2779	**11.9** (8.5, 16.6)	15	1120	**13.4** (8.1, 22.0)
34	7094	**4.8** (3.4, 6.7)	23	2957	**7.8** (5.2, 11.6)
32	7326	**4.4** (3.1, 6.2)	18	3080	**5.8** (3.7, 9.2)
28	7466	**3.8** (2.6, 5.4)	11	3050	**3.6** (2.0, 6.4)
24	7998	**3.0** (2.0, 4.5)	20	3294	**6.1** (3.9, 9.4)
27	8330	**3.2** (2.2, 4.7)	22	3549	**6.2** (4.1, 9.4)
25	8784	**2.8** (1.9, 4.2)	13	3837	**3.4** (2.0, 5.8)
203	183243	**1.1** (1.0, 1.3)	118	71037	**1.7** (1.4, 2.0)
176	176198	**1.0** (0.9, 1.2)	143	71318	**2.0** (1.7, 2.4)
193	174158	**1.1** (1.0, 1.3)	116	69106	**1.7** (1.4, 2.0)
186	175263	**1.1** (0.9, 1.2)	134	75278	**1.8** (1.5, 2.1)
120	200332	**0.6** (4.9, 7.1)	114	85573	**1.3** (1.1, 1.6)
111	210330	**0.5** (0.4, 0.6)	100	90680	**1.1** (0.9, 1.3)

Figure 12. Rate of children with CP per 1000 neonatal survivors (NNS), by birth weight group (grams) and birth period, South Australia, Victoria and Western Australia combined (1995-2012)



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 18. Number and percentage of children with CP by birth plurality for each state/territory of birth and Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

Birth plurality	Singletons n (%)^	Twins n (%)^	Higher multiples n (%)^	TOTAL n	Unknown n (%)
ACT/NSW	1787 (87.3)	241 (11.8)	20 (1.0)	**2648**	600 (22.7)
NT*	99 (94.3)	6 (5.7)	0 (0.0)	**113**	8 (7.1)
QLD*	1096 (85.4)	173 (13.5)	15 (1.2)	**1434**	150 (10.5)
SA*	576 (89.3)	66 (10.2)	3 (0.5)	**645**	0 (0.0)
TAS*	116 (84.1)	18 (13.0)	4 (2.9)	**142**	◆ (2.8)
VIC*	1694 (87.8)	217 (11.2)	19 (1.0)	**2017**	87 (4.3)
WA*	1044 (89.6)	112 (9.6)	9 (0.8)	**1165**	0 (0.0)
TOTAL	6412	833	70	8164	849
COMBINED*	**4625 (88)**	**592 (11)**	**50 (1)**	**5516**	**249 (5)**

◆< 5 cases

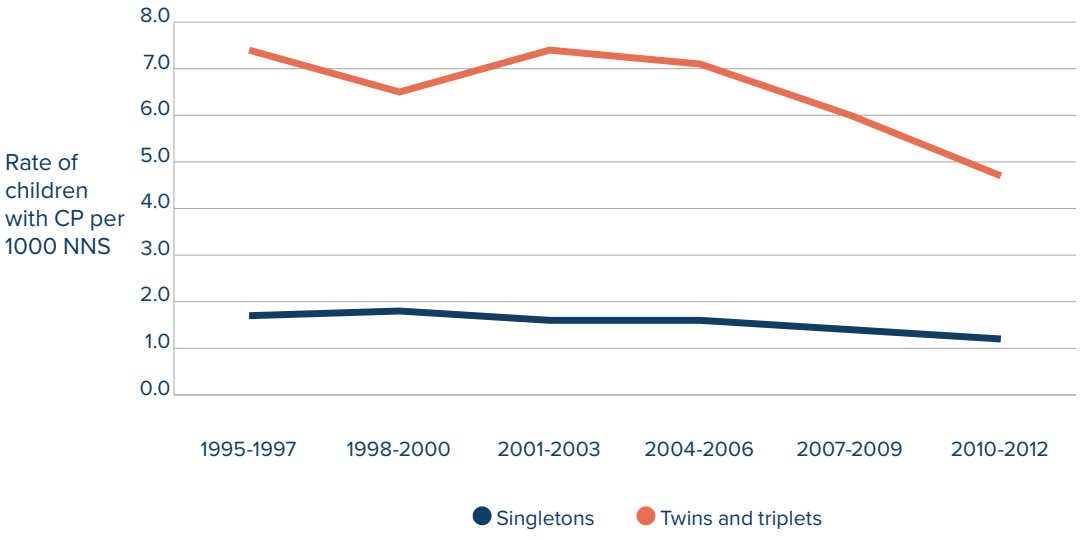
(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

Table 19. Rate of children with CP per 1000 neonatal survivors (NNS) by plurality and birth period, South Australia, Victoria and Western Australia combined (1995-2012)

	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012
Singletons						
CP n	595	605	546	568	546	454
NNS	309955	306161	302794	320862	354116	369699
Rate/1000 NNS (95%CI)	**1.9** (1.8, 2.1)	**2.0** (1.8, 2.1)	**1.8** (1.7, 2.0)	**1.8** (1.6, 1.9)	**1.5** (1.4, 1.7)	**1.2** (1.1, 1.3)
Twins and triplets						
CP n	76	67	76	81	71	53
NNS	9303	9842	10370	11167	11463	11374
Rate/1000 NNS (95%CI)	**8.2** (6.5, 10.2)	**6.8** (5.4, 8.6)	**7.3** (5.8, 9.0)	**7.3** (5.8, 9.0)	**6.2** (4.9, 7.8)	**4.7** (3.6, 6.1)

2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 13. Rate of children with CP per 1000 neonatal survivors (NNS) by plurality and birth period, South Australia, Victoria and Western Australia combined (1995-2012)



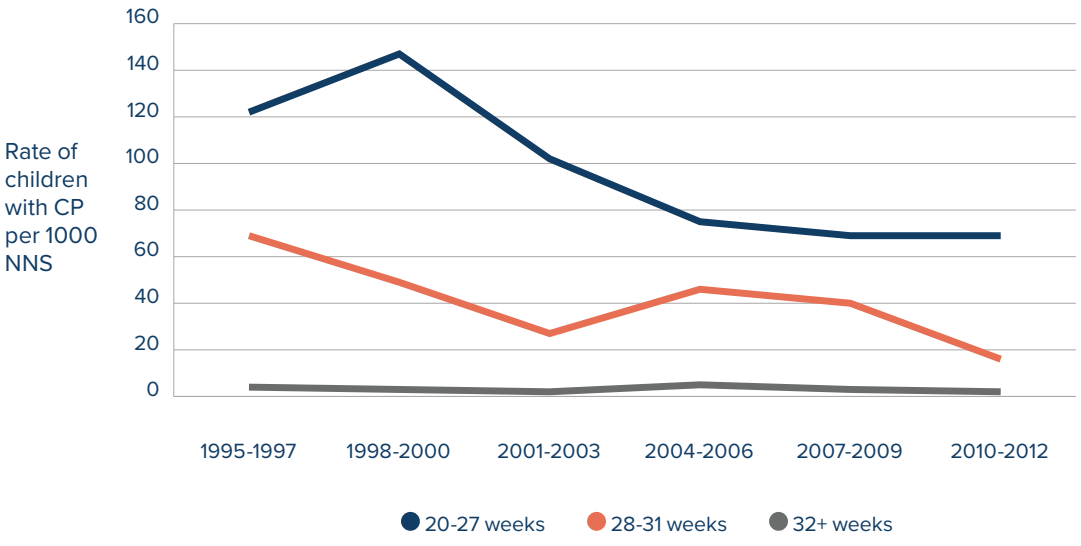
The rate of CP per 1000 NNS amongst twins and triplets declined (2004-2012).

Table 20. Rates of twin born children with CP per 1000 neonatal survivors (NNS) by gestational age group (weeks) and birth period, South Australia and Western Australia combined (1995-2012)

Twins	1995-1997	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012
20-27 weeks						
CP n	11	11	9	7	7	8
NNS	90	74	88	93	101	116
Rate/1000 NNS (95%CI)	122.2 (69.9, 205.7)	148.6 (85.1, 246.9)	102.3 (54.7, 183.1)	75.3 (36.9, 147.3)	69.3 (34.0, 136.2)	69.0 (35.4, 130.2)
28-31 weeks						
CP n	14	13	7	12	12	5
NNS	204	265	263	263	301	318
Rate/1000 NNS (95%CI)	68.6 (41.3, 111.9)	49.1 (28.9, 82.1)	26.6 (13.0, 53.9)	45.6 (26.3, 78.0)	39.9 (23.0, 68.4)	15.7 (6.7, 36.3)
32+ weeks						
CP n	12	9	6	19	10	6
NNS	3422	3506	3703	3652	3785	3955
Rate/1000 NNS (95%CI)	3.5 (2.0, 6.1)	2.6 (1.4, 4.9)	1.6 (0.7, 3.5)	5.2 (3.3, 8.1)	2.6 (1.4, 4.9)	1.5 (0.7, 3.3)

VIC data excluded from this graph due to missing denominator data

Figure 14. Rates of twin born children with CP per 1000 neonatal survivors (NNS) by gestational age group (weeks) and birth period, South Australia and Western Australia combined (1995-2012)



VIC data excluded from this graph due to missing denominator data

Combined data (SA and WA) indicated a reduction in rates of twin born children with CP (1995-2012) at the same time as the number of neonatal survivors increased.[29]

Due to the small frequency of triplets and quadruplets, it is difficult to study CP in this sub-group of higher order multiple births. 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.

Congenital anomalies

Table 21. Number and percentage of identified congenital anomalies amongst children with CP for each state/territory of birth and Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

	No known congenital anomaly n (%)^	One or more congenital anomalies n (%)^	Total n	Unknown n (%)
ACT/NSW	1271 (71.7)	502 (28.3)	**2648**	875 (33.0)
NT	58 (76.3)	18 (23.7)	**113**	37 (32.7)
QLD*	913 (71.7)	361 (28.3)	**1434**	160 (11.2)
SA#*	392 (60.8)	253 (39.2)	**645**	0 (0.0)
TAS*	116 (93.5)	8 (6.5)	**142**	18 (12.7)
VIC*	1508 (77.3)	442 (22.7)	**2017**	67 (3.3)
WA*	760 (65.5)	400 (34.5)	**1165**	5 (<1.0)
TOTAL	5018	1984	8164	1162
COMBINED*	**3689 (72)**	**1464 (28)**	5403	**250 (5)**

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.

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

Combined data indicated that the proportion of children with CP with reported congenital anomalies was 28%. Researchers from the ACPR Group are now investigating congenital anomalies in CP in collaboration with the Surveillance of Cerebral Palsy in Europe and EUROCAT. This large study is exploring the co-occurrence of congenital anomalies and CP. The *Comprehensive investigation of congenital anomalies in cerebral palsy (The Comprehensive CA-CP Study)*[30] has linked data between CP and congenital anomaly registers in regions of Europe and Australia in order to create the large dataset required to explore these heterogeneous conditions.

Motor type and topography

Table 22. Number and percentage of children with CP by predominant motor type at 5 years for each state/territory of birth and all states/territories combined (1995-2012)

	Spastic	*Hemiplegia/ Monoplegia*	*Diplegia*	*Triplegia/ Quadriplegia*	Ataxic	Dyskinetic	Hypotonic	TOTAL	Unknown
	n (%)^				n (%)^	n (%)^	n (%)^	n	n (%)
ACT/NSW*	1968 (82.3)	*853 (43.3)*	*578 (29.4)*	*537 (27.3)*	112 (4.7)	192 (8.0)	118 (4.9)	**2648**	258 (9.7)
NT*	80 (81.6)	*31 (38.8)*	*24 (30.0)*	*25 (31.3)*	5 (5.1)	9 (9.2)	◆ (4.1)	**113**	15 (13.3)
QLD*	1135 (86.5)	*407 (35.9)*	*463 (40.8)*	*265 (23.3)*	52 (4.0)	86 (6.6)	39 (3.0)	**1434**	122 (8.5)
SA*	593 (92.9)	*260 (43.8)*	*202 (34.1)*	*131 (22.1)*	21 (3.3)	19 (3.0)	5 (0.8)	**645**	7 (1.1)
TAS*	117 (88.0)	*39 (33.3)*	*56 (47.9)*	*22 (18.8)*	◆ (3.0)	12 (9.0)	0 (0.0)	**142**	9 (6.3)
VIC*	1690 (85.7)	*694 (41.1)*	*554 (32.8)*	*442 (26.2)*	62 (3.1)	147 (7.5)	74 (3.8)	**2017**	44 (2.2)
WA*	969 (83.2)	*362 (37.4)*	*468 (48.3)*	*139 (14.3)*	75 (6.4)	102 (8.8)	19 (1.6)	**1165**	0 (0.0)
TOTAL	6552	*2646*	*2345*	*1561*	331	567	259	8164	455
COMBINED	**6552 (85)**	***2646 (40)***	***2345 (36)***	***1561 (24)***	**331 (4)**	**567 (7)**	**259 (3)**	**8164**	**455 (6)**

◆ < 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 cerebral palsy

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

Figure 15. Percentage of children with CP by predominant motor subtype and gestational age group (weeks) all states/territories combined (1995-2012)

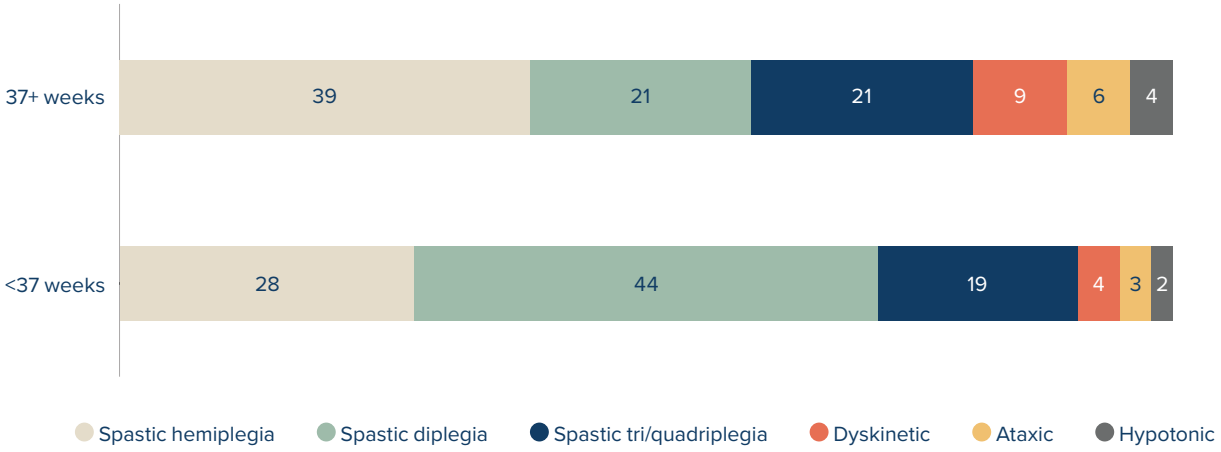


Figure 16. Number of children with CP by predominant spastic subtype (unilateral or bilateral) and gestational age group (weeks) all states/territories combined (1995-2012)

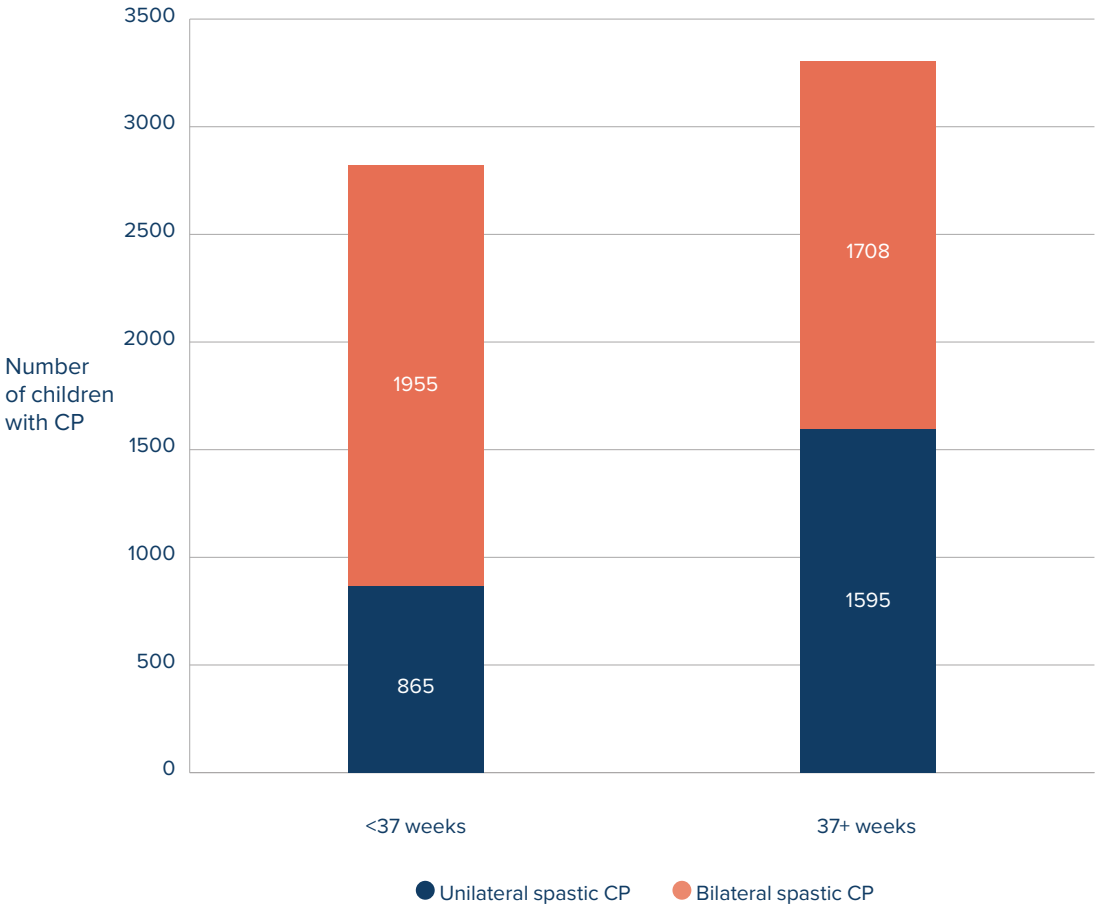
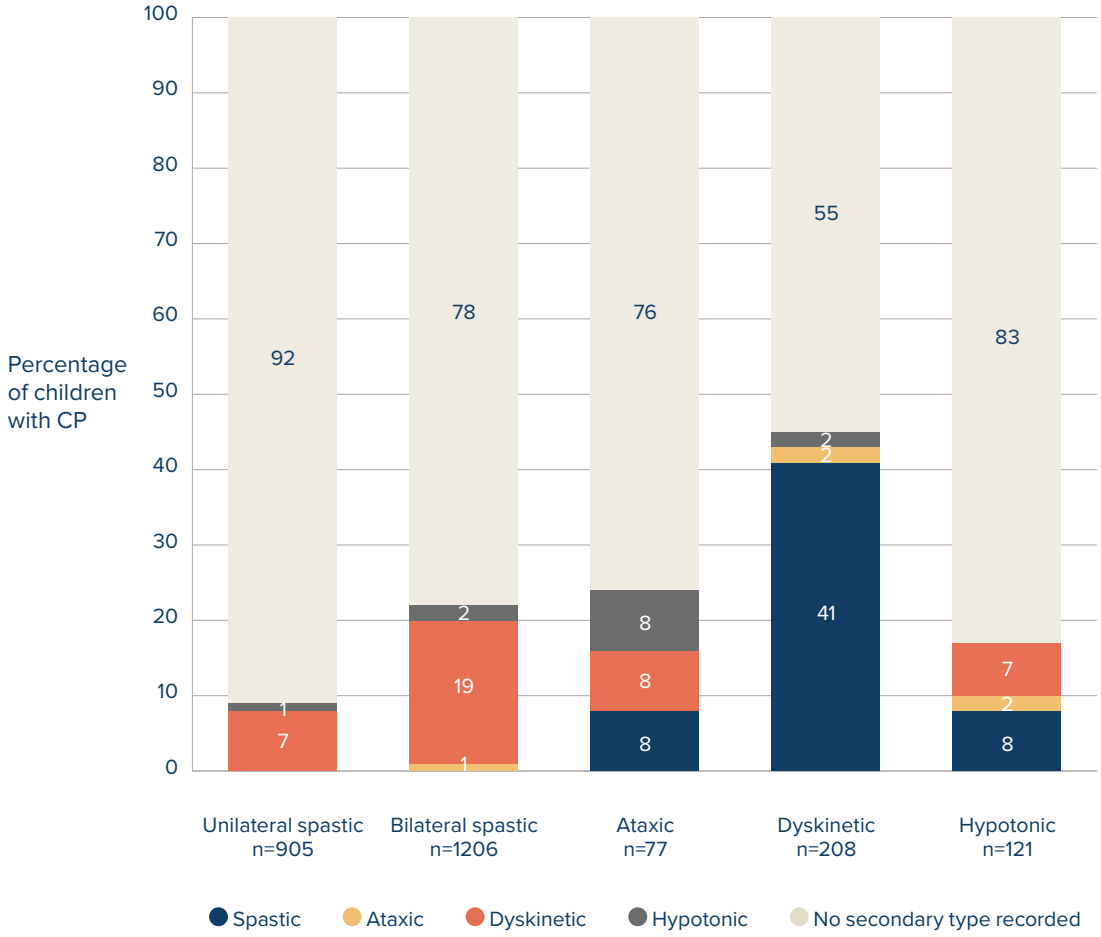


Figure 17. Number and percentage of children with CP by predominant and secondary motor type at 5 years, all states/territories combined (2007-2012)*



*The 2007-2012 cohort was used for this figure, as these more recent triennia have the most complete available data (for secondary motor type) from the CP registers at this time.
NB: 'Dyskinetic cerebral palsy' includes both dystonic and athetoid/choreoathetoid CP.

Combined data (2007-2012) suggested that amongst children with unilateral spasticity, 7% also had dyskinesia. Amongst children with bilateral spasticity, almost 20% also had dyskinesia (Figure 17). In children described with a predominant motor type of dyskinesia, 41% were also identified with spasticity.

The CP registers have historically focussed on collection of data pertaining to the predominant motor type, so these figures pertaining to secondary or co-occurring motor types are 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 motor types.

Gross motor function

Table 23. Number and percentage of children with CP by Gross Motor Function Classification System[31] groups (levels I-II, III, IV-V) at 5 years for each state/territory of birth and all states/territories combined (1995-2012)

	I-II n (%)^	III n (%)^	IV-V n (%)^	Total n	Unknown n (%)
ACT/NSW*	1510 (62.6)	263 (10.9)	641 (26.6)	**2648**	234 (8.8)
NT*	64 (62.7)	10 (9.8)	28 (27.5)	**113**	11 (9.7)
QLD*	752 (56.5)	187 (14.1)	391 (29.4)	**1434**	104 (7.3)
SA*	301 (66.3)	56 (12.3)	97 (21.4)	**645**[&]	35 (7.2)
TAS*	86 (64.7)	13 (9.8)	34 (25.6)	**142**	9 (6.3)
VIC*	1224 (63.2)	192 (9.9)	522 (26.9)	**2017**	79 (3.9)
WA*	762 (65.4)	145 (12.4)	258 (22.1)	**1165**	0 (0.0)
TOTAL	4699	866	1971	8164	472
COMBINED*	4699 (62)	866 (11)	1971 (26)	8164	472 (6)

[&]SA total CP includes n=**156** that had not had their follow-up assessment at the time of data provision
(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

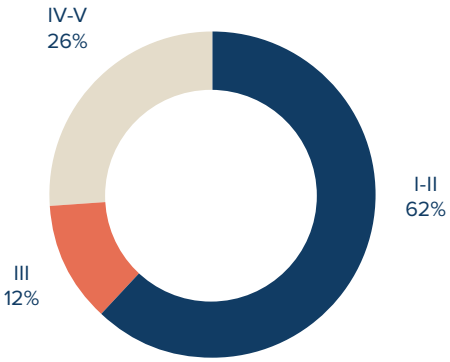


Figure 18. Percentage of children with CP by Gross Motor Function Classification System[31] groups (levels I-II, III, IV-V), predominant motor type at 5 years and birth period, all states/territories combined (1995-2012)

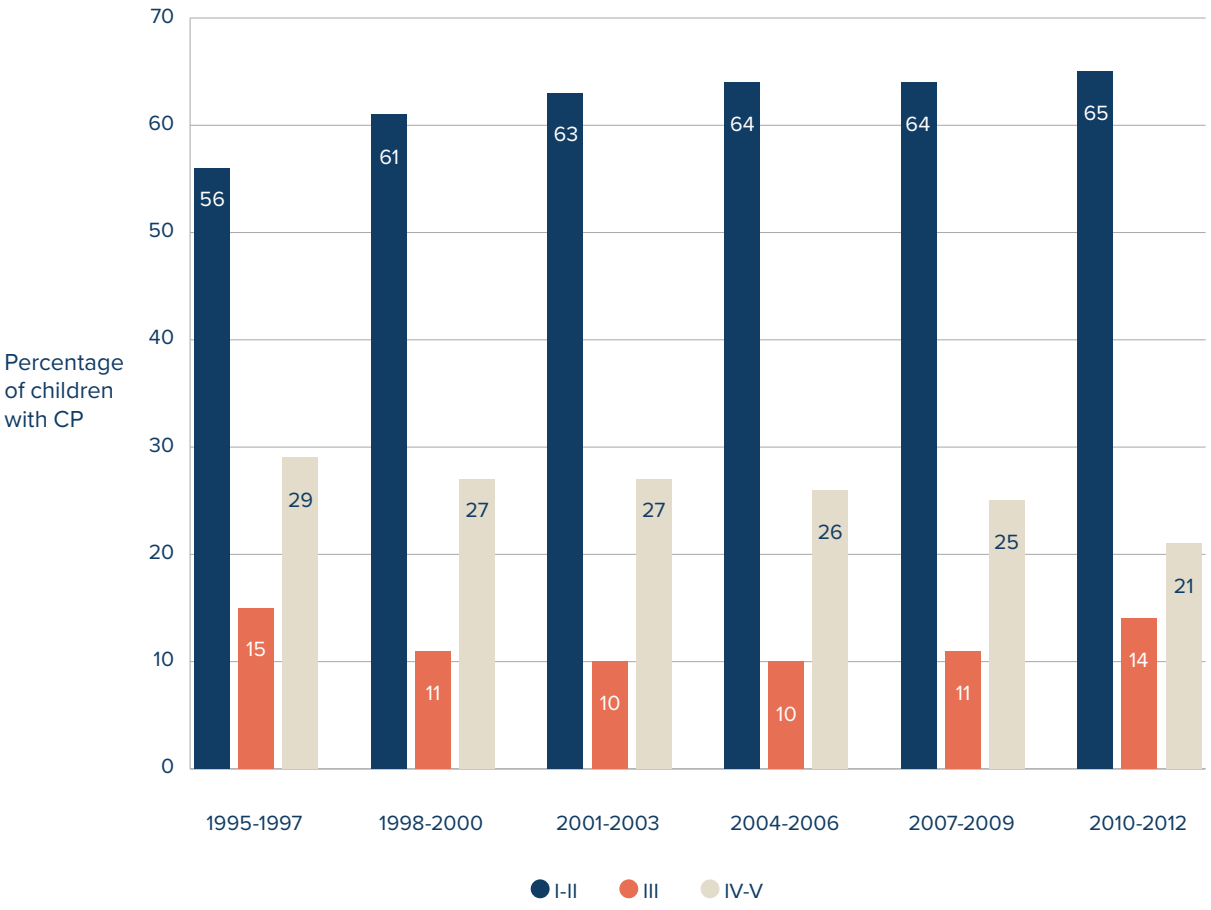
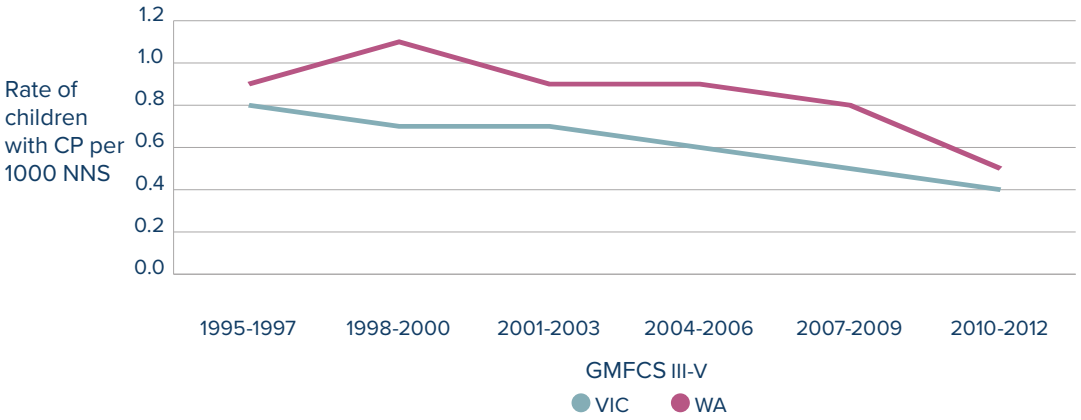


Table 24. Number and rate of children with CP per 1000 neonatal survivors (NNS) by Gross Motor Function Classification System[31] groups (Levels I-II, III-V) at 5 years and birth period, Queensland^, Victoria and Western Australia (1995-2012)

	Birth years	NNS	GMFCS I-II		GMFCS III-V	
			CP	Rate/1000 NNS (95%CI)	CP	Rate/1000 NNS (95%CI)
QLD^	1995-1997	142880	111	**0.8** (0.6, 0.9)	106	**0.7** (0.6, 0.9)
	1998-2000	144619	115	**0.8** (0.7, 1.0)	99	**0.7** (0.6, 0.8)
	2001-2003	147702	99	**0.7** (0.6, 0.8)	92	**0.6** (0.5, 0.8)
	2004-2006	161180	135	**0.8** (0.8, 1.1)	90	**0.6** (0.5, 0.7)
	2007-2009	181803	164	**0.9** (0.8, 1.1)	98	**0.5** (0.4, 0.7)
	2010-2012	-	-		-	
VIC	**1995-1997**	186445	190	**1.0** (0.9, 1.2)	141	**0.8** (0.6, 0.9)
	1998-2000	185391	209	**1.1** (1.0, 1.3)	129	**0.7** (0.6, 0.8)
	2001-2003	186705	239	**1.3** (1.1, 1.5)	130	**0.7** (0.6, 0.8)
	2004-2006	197661	220	**1.1** (1.0, 1.3)	123	**0.6** (0.5, 0.7)
	2007-2009++	214864	207	**1.0** (0.8, 1.1)	107	**0.5** (0.4, 0.6)
	2010-2012++	224188	159	**0.7** (0.6, 0.8)	84	**0.4** (0.3, 0.5)
WA	**1995-1997**	75555	118	**1.6** (1.3, 1.9)	69	**0.9** (0.7, 1.2)
	1998-2000	75951	136	**1.8** (1.5, 2.1)	83	**1.1** (0.9, 1.4)
	2001-2003	73700	117	**1.6** (1.3, 1.9)	64	**0.9** (0.7, 1.1)
	2004-2006	80380	145	**1.8** (1.5, 2.1)	72	**0.9** (0.7, 1.1)
	2007-2009	91125	136	**1.5** (1.3, 1.8)	70	**0.8** (0.6, 1.0)
	2010-2012	96429	110	**1.1** (0.9, 1.4)	45	**0.5** (0.3, 0.6)

^Queensland frequency and rates data have been included in this table as the QCPR is approaching complete ascertainment in all but the most recent triennium which has been excluded from this table
2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 19. Rate of children with CP per 1000 neonatal survivors (NNS) by Gross Motor Function Classification System[31] group (level III-V) at 5 years and birth period, Victoria and Western Australia (1995-2012)



2007-2012 denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

The rate of children with CP per 1000 NNS described with GMFCS III-V declined (1995-2012).

Vision

Table 25. Number and percentage of children with CP by vision status at 5 years for each state/territory of birth and Northern Territory, South Australia, Queensland, Tasmania, Victoria and Western Australia combined (1995-2012)

	No impairment n (%)^	Some visual impairment n (%)^	Functionally blind n (%)^	TOTAL n	Unknown n (%)
ACT/NSW	1218 (60.2)	713 (35.3)	91 (4.5)	**2648**	626 (23.6)
NT*	60 (56.6)	37 (34.9)	9 (8.5)	**113**	7 (6.2)
QLD*	743 (59.4)	451 (36.1)	56 (4.5)	**1434**	184 (12.8)
SA*	279 (65.2)	134 (31.3)	15 (3.5)	**645**[&]	61 (12.5)
TAS*	86 (66.7)	39 (30.2)	◆ (3.1)	**142**	13 (9.2)
VIC*	1223 (69.0)	483 (27.3)	66 (3.7)	**2017**	245 (12.1)
WA*	800 (70.8)	270 (23.9)	60 (5.3)	**1165**	35 (3.0)
TOTAL	4409	2127	301	8164	1171
COMBINED*	3191 (66)	1414(29)	210 (4)	5516	545 (10)

◆ < 5 cases

[&]SA total CP includes n=**156** that had not had their follow-up assessment at the time of data provision

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

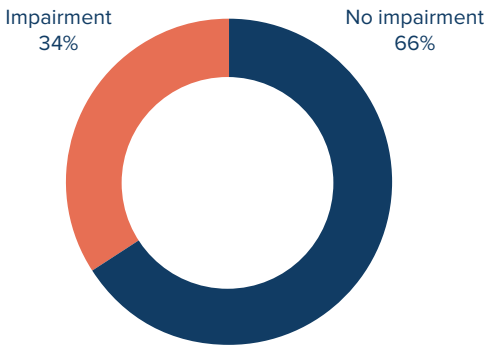


Figure 20. Percentage of children with CP by vision status at 5 years and birth period, Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

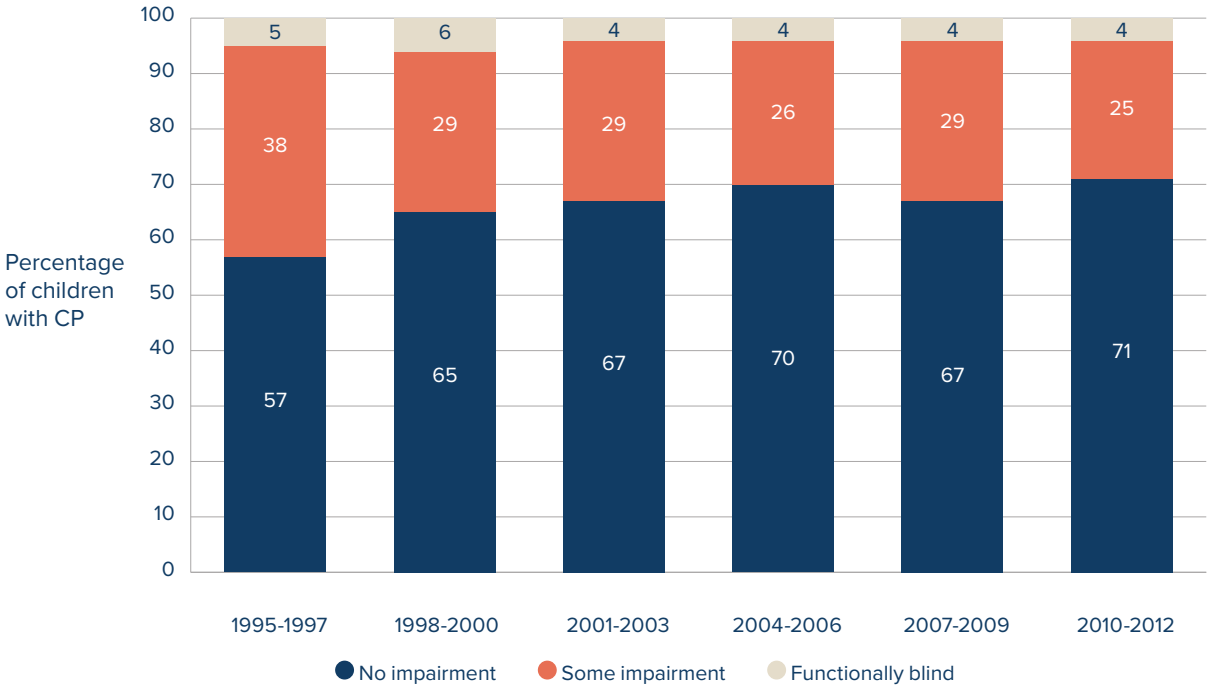


Table 26. Number and percentage of children with CP by presence/absence of strabismus at 5 years and birth period for each state/territory of birth and South Australia and Western Australia combined (1995-2012)

	No strabismus	Strabismus	TOTAL	Unknown
	n (%)^	n (%)^	n	n (%)
ACT/NSW	906 (78.4)	249 (21.6)	**2648**	1493 (56.4)
NT	44 (77.2)	13 (22.8)	**113**	56 (49.6)
QLD	734 (64.8)	399 (35.2)	**1434**	301 (21.0)
SA*	255 (61.9)	157 (38.1)	**645**[&]	77 (15.7)
TAS	76 (79.2)	20 (20.8)	**142**	46 (32.4)
VIC	968 (71.0)	395 (29.0)	**2017**	654 (32.4)
WA*	760 (72.0)	295 (28.0)	**1165**	110 (9.4)
TOTAL	**3743**	**1528**	**8164**	**2737**
COMBINED*	**1015 (69)**	**452 (31)**	**1810**	**187 (11)**

[&]SA cases total including a further n=156 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

Hearing

Table 27. Number and percentage of children with CP at 5 years by hearing status for each state/territory of birth and Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

	No impairment n (%)^	Some impairment n (%)^	Bilateral deafness n (%)^	Total n	Unknown n (%)
ACT/NSW	1701 (83.5)	226 (11.1)	109 (5.4)	**2648**	612 (23.1)
NT*	78 (75.7)	21 (20.4)	◆ (3.9)	**113**	10 (8.8)
QLD*	1126 (88.2)	125 (9.8)	26 (2.0)	**1434**	157 (10.9)
SA*	413 (95.2)	14 (3.2)	7 (1.6)	**645**[&]	55 (11.2)
TAS*	116 (86.6)	15 (11.2)	◆ (2.2)	**142**	8 (5.6)
VIC*	1531 (86.6)	180 (10.2)	57 (3.2)	**2017**	249 (12.3)
WA*	1027 (91.7)	72 (6.4)	21 (1.9)	**1165**	45 (3.9)
TOTAL	5992	653	227	8164	1136
COMBINED*	**4291 (89)**	**427 (9)**	**118 (2)**	**5516**	**524 (10)**

◆ < 5 cases

[&]SA total CP includes n=**156** that had not had their follow-up assessment at the time of data provision

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

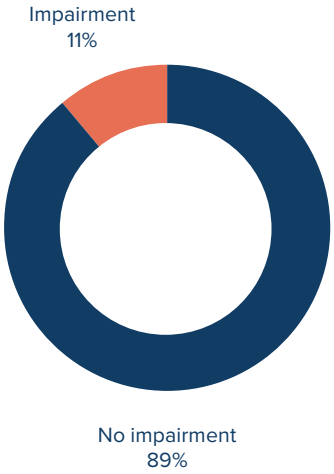
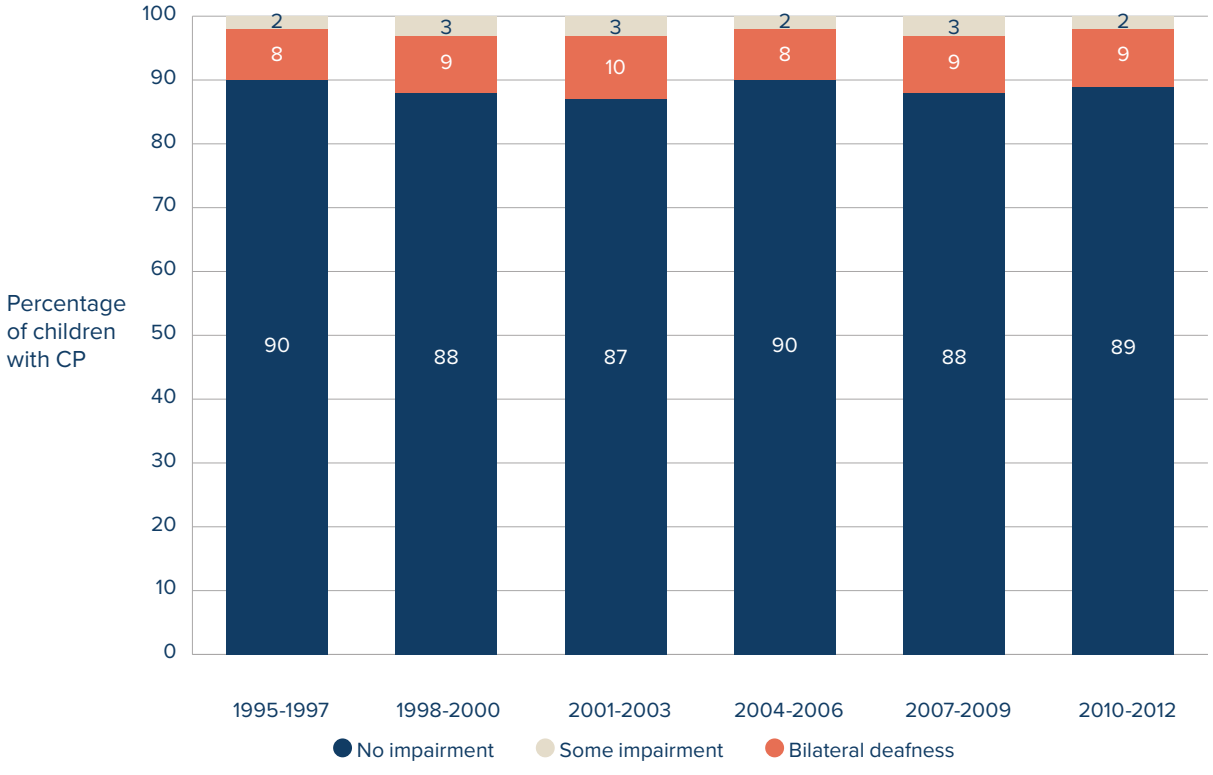


Figure 21. Percentage of children with CP by hearing status at 5 years and birth period, Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)



Speech

Table 28. Number and percentage of children with CP by speech status at 5 years for each state/territory of birth and all states/territories combined (1995-2012)

	No impairment n (%)^	Some impairment n (%)^	Non-verbal n (%)^	Total n	Unknown n (%)
ACT/NSW*	710 (32.9)	926 (42.9)	523 (24.2)	**2648**	489 (18.5)
NT*	34 (32.1)	40 (37.7)	32 (30.2)	**113**	7 (6.2)
QLD*	508 (39.5)	474 (36.8)	305 (23.7)	**1434**	147 (10.3)
SA*	203 (46.5)	177 (40.5)	57 (13.0)	**645**[&]	52 (10.6)
TAS*	68 (50.7)	52 (38.8)	14 (10.4)	**142**	8 (5.6)
VIC*	658 (37.8)	608 (34.9)	475 (27.3)	**2017**	276 (13.7)
WA*	420 (37.7)	408 (36.6)	287 (25.7)	**1165**	50 (4.3)
TOTAL	2601	2685	1693	8164	1029
COMBINED*	2601 (37)	2685 (38)	1693 (24)	8164	1029 (13)

[&]SA total CP includes n=**156** that had not had their follow-up assessment at the time of data provision
(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

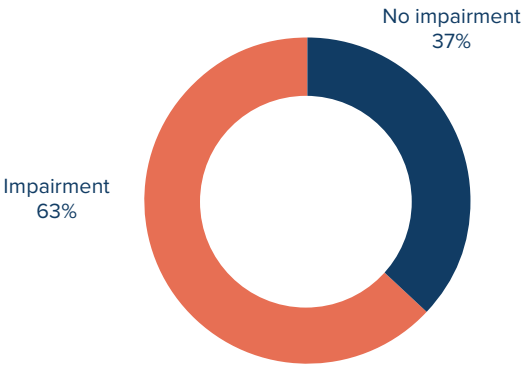
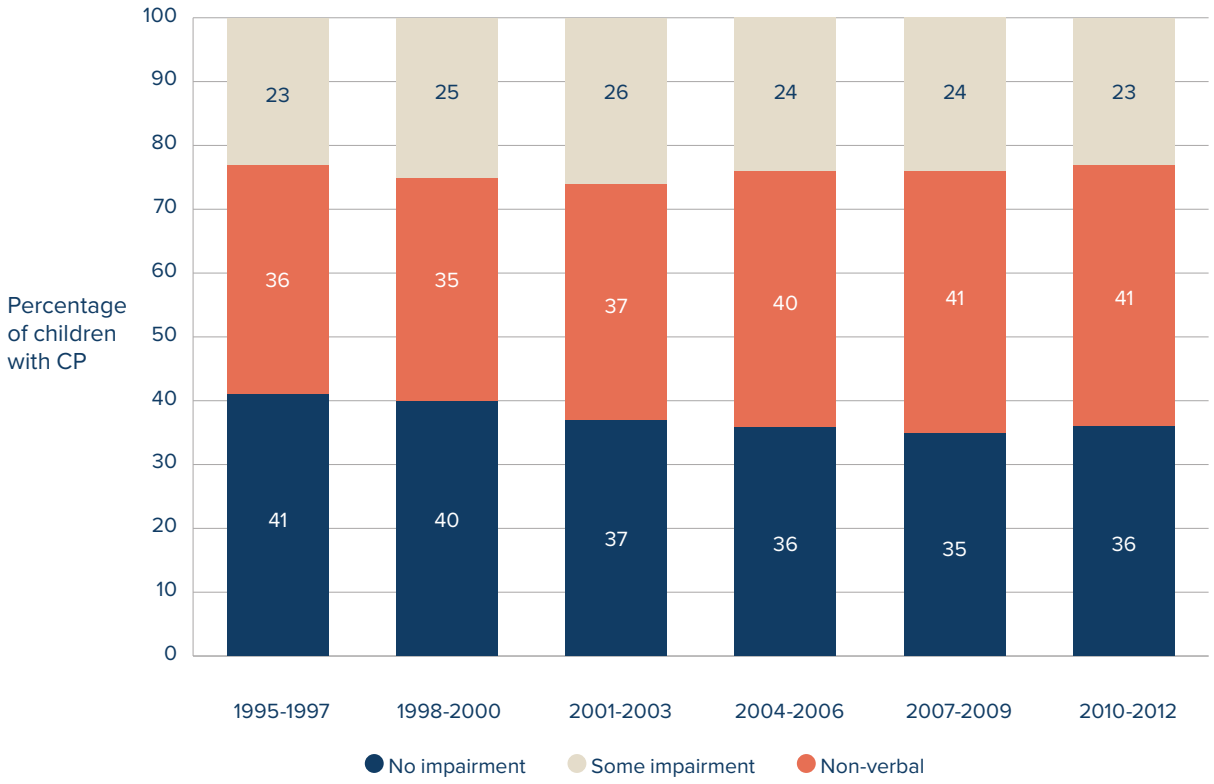


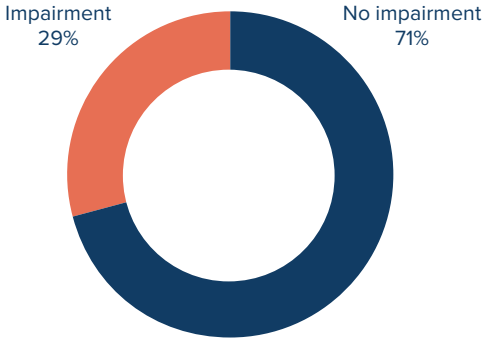
Figure 22. Percentage of children with CP by speech status at 5 years and birth period, Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)



Epilepsy

Table 29. Number and percentage of children with CP by presence/absence of epilepsy at 5 years for each state/territory of birth and Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

	No epilepsy n (%)^	Resolved# n (%)^	Epilepsy⅄ n (%)^	Total n	Unknown n (%)
ACT/NSW	1344 (64.9)	100 (4.8)	626 (30.2)	**2648**	578 (21.8)
NT*	64 (59.3)	◆ (2.8)	41 (38.0)	**113**	5 (4.4)
QLD*	886 (67.3)	53 (4.0)	377 (28.6)	**1434**	118 (8.2)
SA*	324 (73.8)	26 (5.9)	89 (20.3)	**645**[&]	50 (10.2)
TAS*	98 (70.0)	6 (4.3)	36 (25.7)	**142**	◆ (1.4)
VIC*	1290 (67.6)	45 (2.4)	573 (30.0)	**2017**	109 (5.4)
WA*	791 (69.3)	11 (1.0)	339 (29.7)	**1165**	24 (2.1)
TOTAL	4797	244	2081	8164	886
COMBINED*	3453 (68)	144 (3)	1455 (29)	5516	308 (6)



◆ < 5 cases

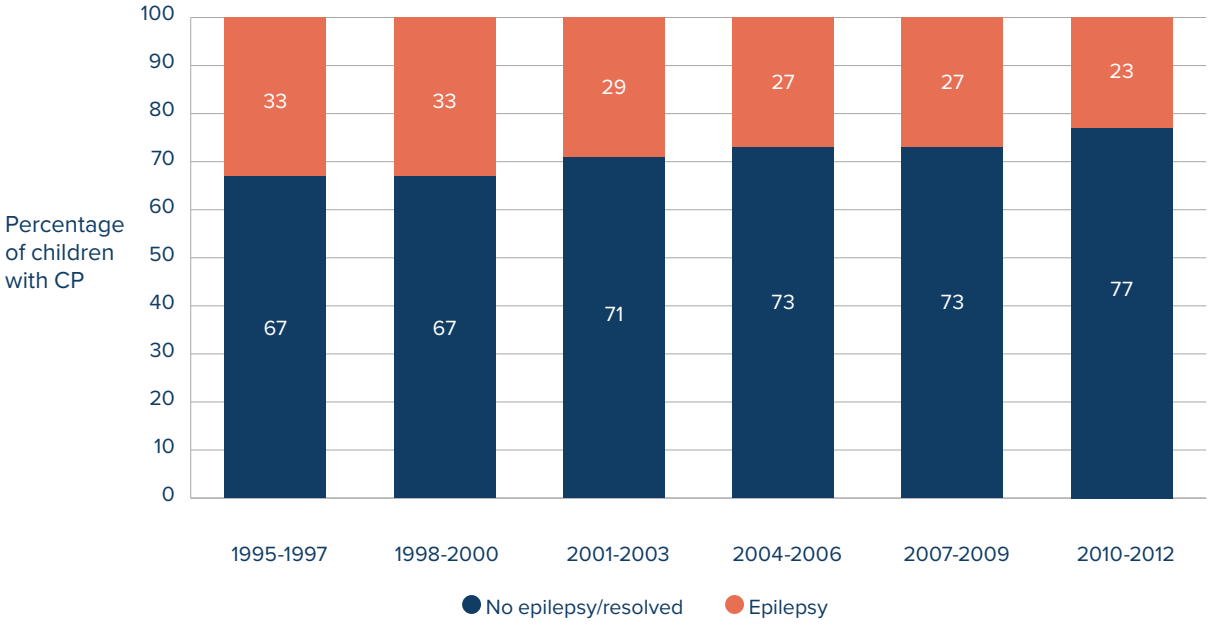
[&]SA total CP includes n=**156** that had not had their follow-up assessment at the time of data provision

(%)^ calculated by **n/total n** minus **unknown n**; 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; excluding neonatal seizures

Figure 23. Percentage of children with CP by presence/absence of epilepsy at 5 years and birth period, Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)



Intellect

Table 30. Number and percentage of children with CP by intellect status at 5 years for each state/territory of birth and Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

	No impairment	Impairment, severity unknown	Mild impairment	Moderate – severe impairment	TOTAL	Unknown
	n (%)^	n (%)^	n (%)^	n (%)^	n	n (%)
ACT/NSW	924 (44.1)	390 (18.6)	250 (11.9)	531 (25.3)	**2648**	553 (20.9)
NT*	50 (47.7)	26 (24.8)	8 (7.6)	21 (20.0)	**113**	8 (7.6)
QLD*	658 (52.0)	197 (15.6)	126 (10.0)	283 (22.4)	**1434**	170 (11.9)
SA*	302 (69.1)	31 (7.1)	54 (12.4)	50 (11.4)	**645**[&]	52 (10.6)
TAS*	72 (56.9)	20 (15.3)	15 (11.5)	24 (18.3)	**142**	11 (7.7)
VIC*	865 (50.0)	362 (20.9)	196 (11.3)	307 (17.7)	**2017**	287 (14.2)
WA*	671 (58.4)	118 (10.3)	104 (9.1)	256 (22.3)	**1165**	16 (1.4)
TOTAL	**3542**	**1144**	**753**	**1472**	**8164**	**1097**
COMBINED*	**2618 (54)**	**754 (16)**	**503 (10)**	**941 (19)**	**5516**	**544 (10)**

[&]SA total CP includes n=**156** that had not had their follow-up assessment at the time of data provision
(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

Figure 24. Percentage of children with CP by intellect status at 5 years, Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)

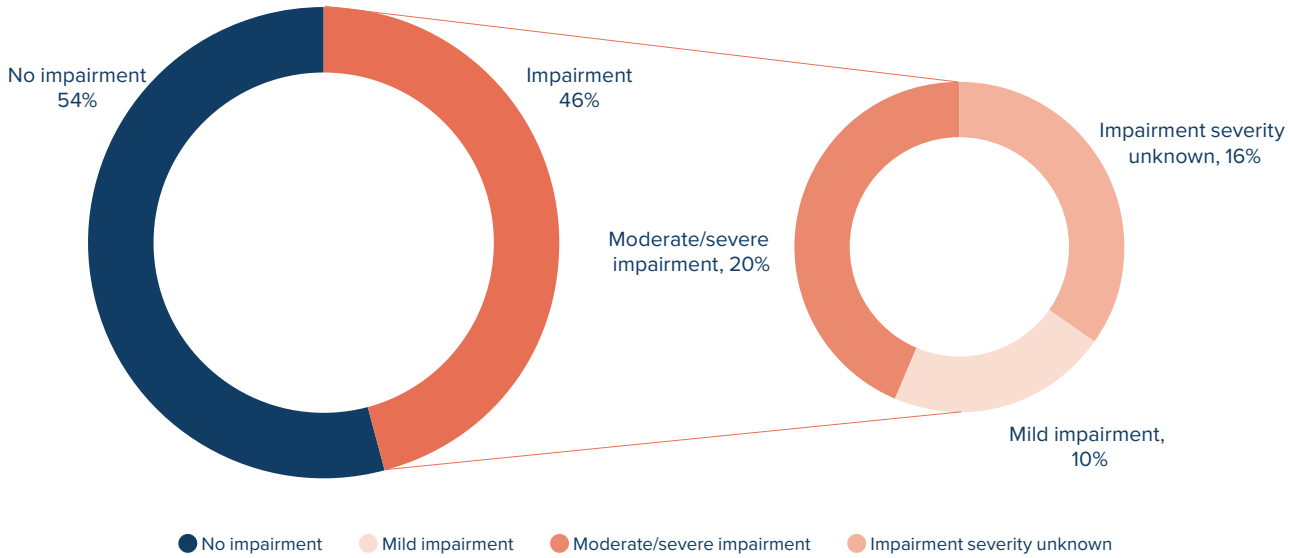
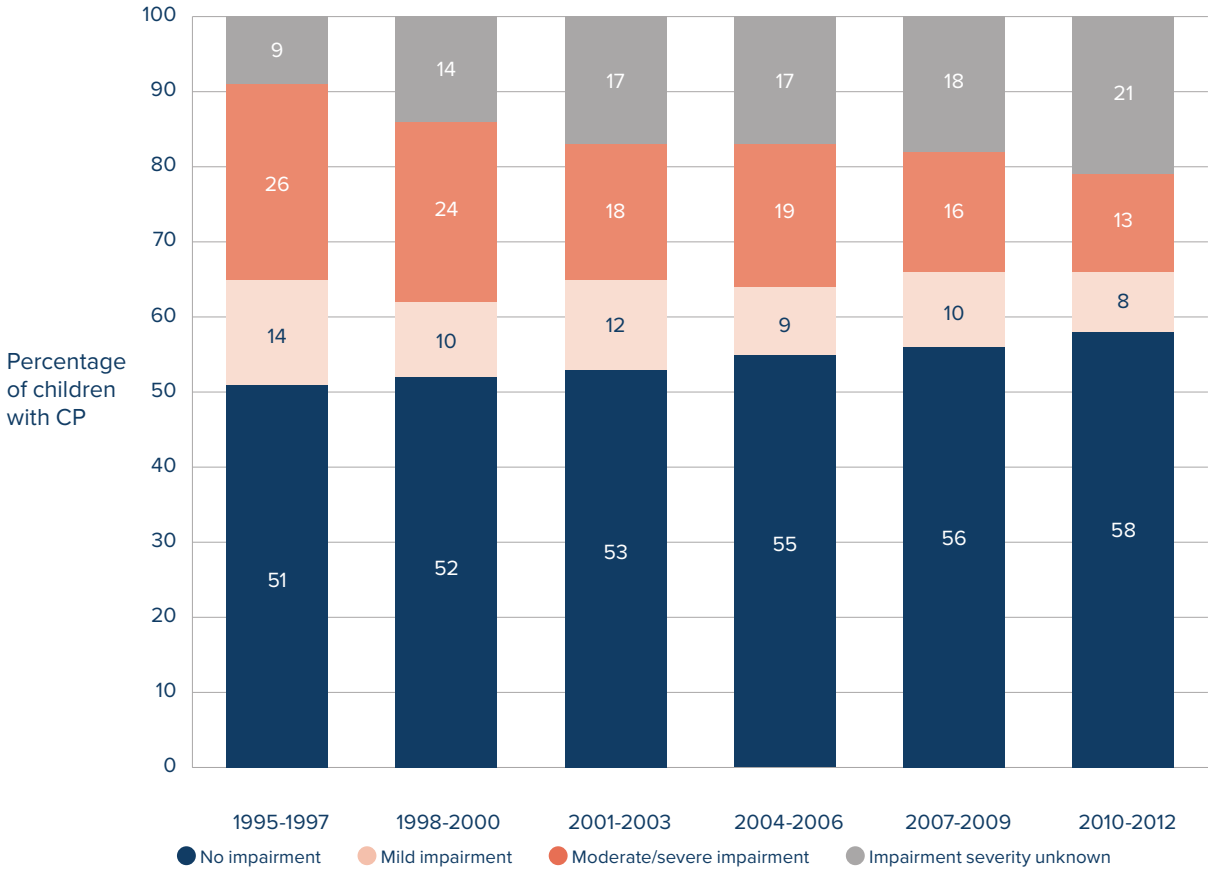


Figure 25. Percentage of children with CP by intellect status at 5 years and birth period, Northern Territory, Queensland, South Australia, Tasmania, Victoria and Western Australia combined (1995-2012)



Combined data indicated that associated impairments were common for children with CP during the reporting period (1995-2012). At the age of five years, almost 35% had a vision impairment, 11% had a hearing impairment, >60% had a speech impairment, almost 30% had epilepsy and >50% had an intellectual impairment.

The proportion of children with CP who **did not** have have a vision impairment, epilepsy and intellectual impairment increased over this period (1995-2012).

3

Post-neonatally acquired cerebral palsy

Section 3 of this report refers to CP resulting from a recognised post-neonatal brain injury acquired more than 28 days after birth

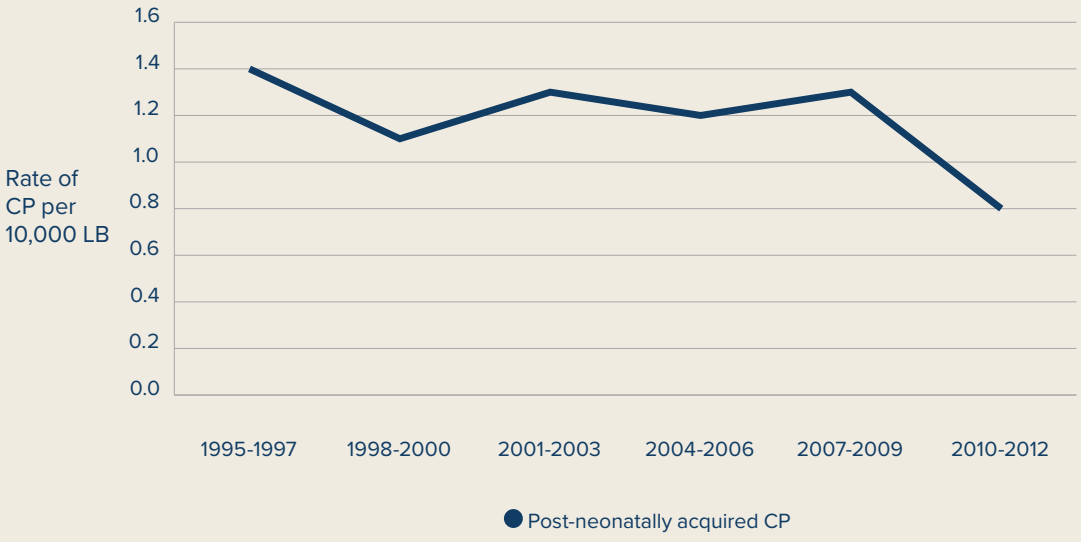
Prevalence

Table 31. Number and rate of children with post-neonatally (PNN) acquired CP per 10,000 live births (LB) for each state/territory of birth and South Australia, Victoria and Western Australia combined (1995-2012)

	PNN acquired CP cases	Percentage of all CP cases	Live births	Rate of PNN cases per 10,000 LB (95% CI)
ACT/NSW	158	5.6	1714609	**0.9** (0.8, 1.1)
NT	14	11.0	66328	**2.1** (1.3, 3.5)
QLD	64	4.3	967774	**0.7** (0.5, 0.8)
SA*	32	4.7	338621	**0.9** (0.7, 1.3)
TAS	0	0.0	108747	**0.0**
VIC*	115	5.4	1200478	**1.0** (0.8, 1.1)
WA*	90	7.2	494236	**1.8** (1.5, 2.2)
TOTAL	**473**	**5.5**	**4890793**	**1.0 (0.9, 1.1)**
COMBINED*	**237**	**5.8**	**2033335**	**1.2 (1.0, 1.3)**

2007-2012 Denominator data for VIC sourced from: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity Annual Reports

Figure 26. Rate of children with post-neonatally acquired CP per 10,000 live births (LB) by birth period, South Australia, Victoria and Western Australia combined (1995-2012)



Combined data indicated the overall prevalence for post-neonatally acquired CP (1995-2012) was 1.2 per 10,000 live births. Combined data indicated that rates of post-neonatally acquired CP declined (2007-2012). The rate observed in the last triennium - 0.8 per 10,000 live births (2010-2012) - is the lowest recorded rate to date.

Post-neonatal cause

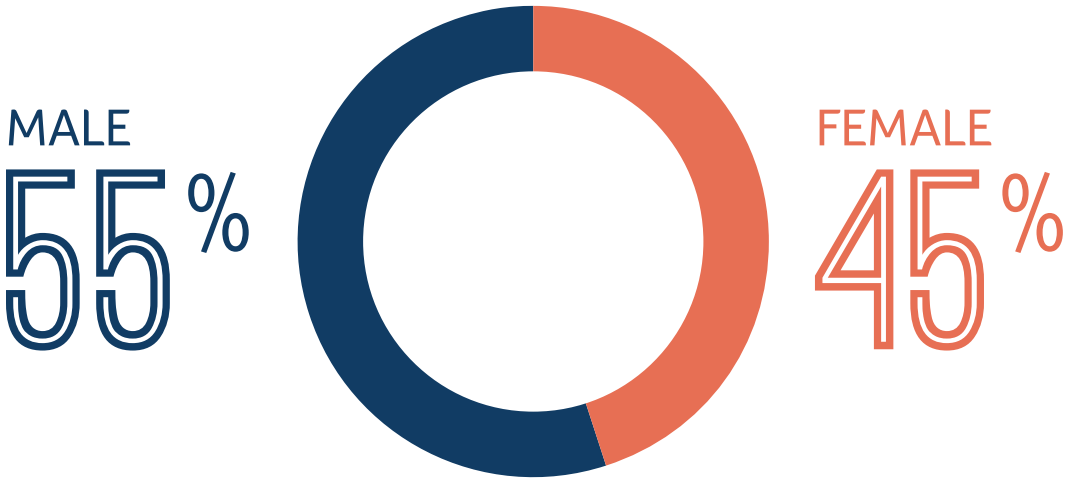
Table 32. Number and percentage of children with CP by identified post-neonatal cause of CP and all state/territories combined (1995-2012)

Post-neonatal cause	All states and territories n (%)
Viral/bacterial infection unspecified	119 (25.2)
Cerebrovascular accident (CVA) associated with surgery CVA associated with cardiac complications CVA spontaneous/other	48 (10.1) 18 (3.8) 93 (19.7)
Fall	15 (3.2)
Non-accidental injury	58 (12.3)
Other head injury	18 (3.8)
Near drowning	16 (3.4)
Apparent life threatening event	13 (2.7)
Post-seizure	23 (4.9)
Peri-operative hypoxia	10 (2.1)
Motor vehicle accident	10 (2.1)
Other post-neonatal event	32 (6.8)
TOTAL	473

The most common post-neonatal cause of CP was cerebrovascular accident either spontaneous, or associated with surgery or with cardiac complications.

Sex

Figure 27. Percentage of children with post-neonatally acquired CP by sex, all states/territories combined (1995-2012)



Combined data demonstrated that males were at higher risk of post-neonatally acquired CP throughout the reporting period (1995-2012). Here, 55% of the CP cohort were male, compared to 49.5% of the population.[26]

Motor type and topography

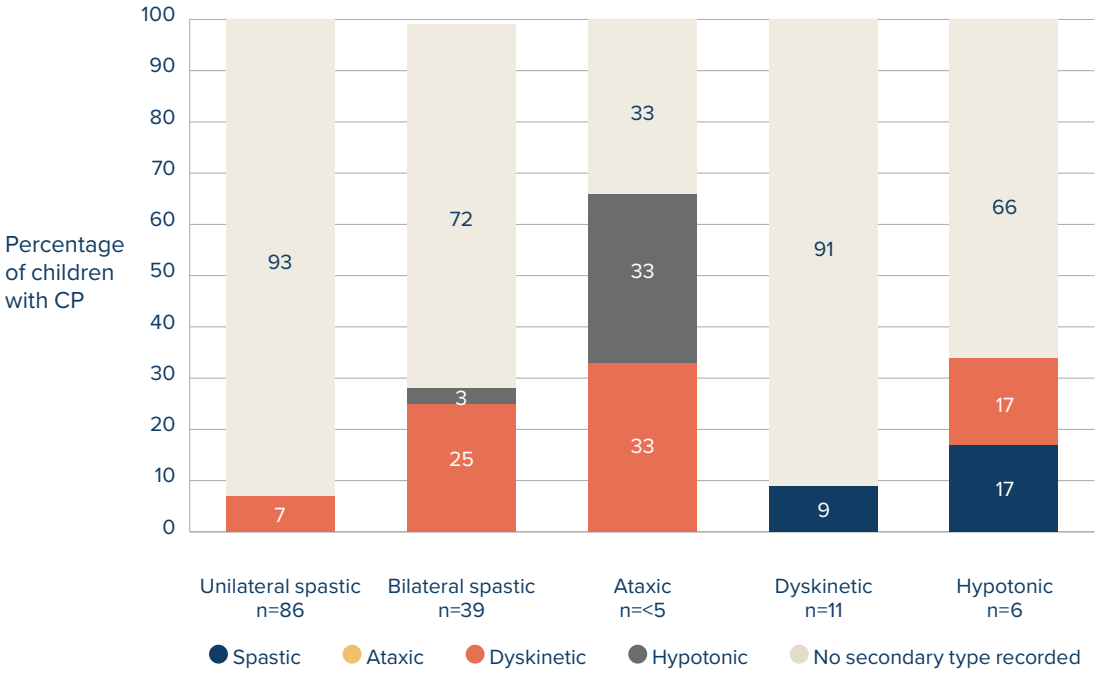
Table 33. Number and percentage of children with post-neonatally acquired CP by predominant motor type and spastic topography at 5 years, South Australia, Victoria and Western Australia combined (1995-2012)

	Spastic	*Hemiplegia/ Monoplegia*	*Diplegia*	*Tri/ Quadriplegia*	Ataxic	Dyskinetic	Hypotonic	TOTAL	Unknown
	n (%)^	*n (%)*	*n (%)*	*n (%)*	n (%)^	n (%)^	n (%)^	n	n (%)
VIC, SA and WA	218 (92.4)	*130 (59.6)*	*21 (9.6)*	*67 (30.7)*	◆ (1.7)	9 (3.8)	5 (2.1)	**237**	◆ (<1.0)

◆ < 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 cerebral palsy

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

Figure 28. Percentage of children with post-neonatally acquired CP by predominant motor type and secondary motor type at 5 years, all states/territories combined (2007-2012)*



*Only data 2007-2012 was used for this figure, as these most recent triennia had the most complete available data from the CP registers at this time.
NB: 'Dyskinetic cerebral palsy' includes both dystonic and athetoid/choreoathetoid cerebral palsy.

Combined data (2007-2012) suggested that amongst children with bilateral spasticity 25% also had dyskinesia (Figure 28). The CP registers have historically focussed on collection of data pertaining to the predominant motor type so these figures are likely to be an underestimate. In recent years many states/territories of Australia have adopted the Cerebral Palsy Description Form (see Appendix B) and the ACPR Group hopes this will assist with accurate data collection of motor types.


City

Vision, hearing, speech, intellect and epilepsy

Table 34. Number and percentage of children with post-neonatally acquired CP by vision, hearing, speech, intellect and epilepsy status at 5 years, all states/territories combined (1995-2012)

	No impairment n (%)^	Some impairment n (%)^	Severe impairment@ n (%)^	TOTAL n	Unknown n (%)^
Vision	211 (50.7)	162 (38.9)	43 (10.3)	**473**	57 (12.1)
Hearing	336 (84.0)	46 (11.5)	18 (4.5)	**473**	73 (15.4)
Speech	103 (24.4)	185 (43.8)	134 (31.8)	**473**	51 (10.8)
Intellect	114 (27.3)	185 (44.4)	118 (28.3)	**473**	56 (11.8)
	No epilepsy n (%)^	**Resolved# n (%)^**	**Epilepsy⅄ n (%)^**		
Epilepsy	184 (41.9)	35 (8.0)	220 (50.1)	**473**	34 (7.2)

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

Combined data showed that many children with CP had associated comorbidities.

Severe associated impairments/disorders were proportionally more common amongst children with post-neonatally acquired CP compared to pre/perinatally acquired CP: blindness (10% v 4%), bilateral deafness (5% v 2%), non-verbal communication (32% vs 24%), moderate-severe intellectual impairment (28% vs 20%) and epilepsy (50% vs 30%).

4

Affiliated cerebral palsy registers

Bangladesh Cerebral Palsy Register

The **Bangladesh Cerebral Palsy Register (BCPR)** project commenced in January 2015 in collaboration with CSF Global, Bangladesh, The University of Sydney and Cerebral Palsy Alliance, Australia.

Investigators

Gulam Khandaker, Mohammad Muhit, Tasneem Karim, Hayley Smithers-Sheedy, Israt Jahan, Manik Chandra Das, Mahmudul Hassan Al Imam, Iona Novak and Nadia Badawi

Aims

To establish a platform for a national CP register in Bangladesh and to:

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

Findings to date

Since January 2015, a total of 1388 children with CP have been registered into the BCPR. Among them, 824 were from a population-based surveillance in Shahzadpur subdistrict of Bangladesh with a known denominator available from the Bangladesh Population and Housing Census data. The observed prevalence of CP was 3.4 per 1000 children (95% confidence interval 3.2–3.7), resulting in an estimated 233 514 children (95% CI 219 778–254 118) with CP in Bangladesh.

The mean age of the 1388 children on the BCPR was 7.9 years and 39.1% were female. 218 (15.8%) were born preterm. 856 (61.7%) had intrapartum related respiratory depression (IPR NRD) and 538 (38.8%) of all children experienced early feeding difficulty. 1006 (72.5%) were delivered at home; among them 592 (58.8%) had IPR NRD. Although the timing of CP was unknown for 383 (27.6%), nearly two thirds of the children (n=889, 64.0%) had a history suggestive of pre and perinatal cause of CP.

The mean age at initial diagnosis of CP was 5.6 years. The majority of the children (n=1075, 77.4%) had a predominant motor type of spastic CP; 339 (24.4%) with spastic hemiplegia/monoplegia, 205 (14.8%) with spastic diplegia, 128 (9.2%) had spastic triplegia and 403 (29.0%) spastic quadriplegia. The remaining children had a dyskinesia (n=85, 6.1%), ataxia (n=6, 0.4%) and hypotonia (n=167, 12.0%). 978 (70.4%) were described with Gross Motor Function Classification System (GMFCS) Level III-V of which only 27 (2.8%) received any assistive device. In total, 856 (61.7%) had not received rehabilitation and only 205 (14.8%) were attending any school. 1056 (76.1%) children had at least one associated impairment; speech: 970 (69.9%), intellectual: 513 (37.0%), epilepsy: 321 (23.1%), visual: 138 (9.9%), and hearing: 148 (10.7%).

Ongoing research projects

- Bangladesh Cerebral Palsy Register (BCPR): scaling up and sustaining the first population-based CP register from a low and middle-income country
- Health related quality of life of children with CP in rural Bangladesh (Bangladesh CPQoL study)
- Feasibility study on early diagnosis of CP in low resource rural settings by General Movement assessment
- Outcome assessment of community-based parent-led early intervention for children with CP in a rural sub-district of Bangladesh
- Community based management of epilepsy for children with CP in a northern sub-district of Bangladesh
- Establishing an assistive device centre for children with CP in rural Bangladesh
- Eye care for children with disabilities in rural Bangladesh

BCPR

TARGET POPULATION:

All people with cerebral palsy
<18 years residing in Bangladesh

CONTACT DETAILS:

CSF Global

WEBSITE:

bangladesh.cpregister.com

EMAIL:

Tasneem.karim@health.nsw.gov.au

PHONE NUMBER:

61 431 959 050
88 01717 095905

ETHICS COMMITTEE REFERENCE NUMBER:

BMRC/NREC/2013-2016/1267, southasia-irb-2014-l-01 and NHMRC HREC: EC00402: 2015-03-02

Services

- **Early Intervention and Rehabilitation Centres:** CSF "Shishu Shorgo" (Children's Heaven) Early Intervention and Rehabilitation Centres are staffed by trained physiotherapists and community therapists to provide early intervention services to children with CP. Currently there are five operational centres in Bangladesh. The goal of this transition program for children with CP and their families is to increase the child's participation in their family, school and community.
- **Parent Self-Help Groups:** Parent support and education are provided through engagement of the caregivers of children with CP in all elements of the transition program. The community therapists involve the parents in services like group therapy and community follow-up by providing family centred-care, keeping the caregiver informed about the child's progress and providing recommendations. These steps help empower caregivers to advocate for and facilitate their child's participation at their home, community, school and vocation. Caregivers are also able to form support networks with other caregivers of children with CP through this program.
- **Inclusive Education:** Throughout the transition program, centre staff provide the child and family follow-up in the community. One of the goals of this community follow-up is to facilitate the transition process by supporting the child's local school to enable their admission to school and participation in school activities.
- **Wheelchair Distribution:** 664 custom-built wheelchairs designed, manufactured and funded by Wheelchair for Kids, Australia and transported with the generosity of Cerebral Palsy Alliance, Australia have been distributed among children from the BCPR cohort.
- **Assistive Devices Centre:** CSF Global has established a wheelchair manufacturing facility in the BCPR surveillance site to cater to the unmet need for assistive devices identified through the BCPR study with support from Cerebral Palsy Alliance and *tna solution*, Australia. The production unit currently has the capacity to produce 50 wheelchairs per month.
- **Construction of Ramps:** Wheelchair ramps have been constructed with funding from the Rotary Club of Turramurra, Australia across the surveillance area to ensure wheelchair accessibility at homes and schools.

Advocacy

- The key informant's method (KIM) is a novel approach for community engagement and identification of children with disability, including CP, from communities. It involves training local volunteers, referred to as key informants (KIs), who reside in the community. The study implementation team (CSF Global; www.csf-global.org) has trained over 25000 KIs nationally and has an extensive network of KIs in the surveillance area. The KIs play a vital role in community mobilization, advocacy and generation of awareness regarding disability inclusive development.
- World Cerebral Palsy Day 2017 was observed in collaboration with key partners in the form of a photo exhibition in Dhaka, Bangladesh. Over 40 portraits were displayed for three days alongside locally produced assistive devices. The exhibition witnessed hundreds of visitors and significant contributions were received primarily as purchase of portraits and sponsoring of assistive devices, and drew significant media attention.
- A National Dissemination Workshop On Eye Care for Children with Disability in Rural Bangladesh was held on 18 March 2018 in Dhaka, Bangladesh. This event was part of a USAID Child Blindness Program funded project titled 'Eye Care for Disabled Children' conducted in the BCPR surveillance area with the view of presenting key findings and sharing learning experiences from the study with key stakeholders such as national and international NGOs, policy makers and prominent media personnel. Its aim here to initiate advocacy for disability inclusive development and highlight the importance of an inclusive healthcare system to truly ensure health for all, including children with disability in rural communities.

Publications

Khandaker G, Muhit M, Karim T, Smithers-Sheedy H, Novak I, Jones C, Badawi N. The Epidemiology of Cerebral Palsy (CP) in Bangladesh: findings from the first population-based register of children with CP in a low and middle-income country. *Developmental Medicine & Child Neurology.* 2018. *[in press]*

May P, Smithers-Sheedy H, Muhit M, Cumming R, Jones C, Booy R, Badawi N, Khandaker G. Immunisation status of children with cerebral palsy in rural Bangladesh: results from the Bangladesh Cerebral Palsy Register. *Infectious Disorders - Drug Targets.* 2018. *[in press]*

Khan A, Ashher F, Karim T, Nawar A, Jahan I, Muhit M, Dey A, Beard F, Khandaker G, Maternal immunization status of children with cerebral palsy in rural Bangladesh. *Infectious Disorders - Drug Targets.* 2018. *[in press]*

Power R, King C, Muhit M, Heanoy E, Galea C, Jones C, Badawi N, Khandaker G. Health-related quality of life of children and adolescents with cerebral palsy in low-and middle-income countries: a systematic review. *Developmental Medicine & Child Neurology.* 2018 May;60(5):469-79.

Jahan I, Muhit M, Karim T, Smithers-Sheedy H, Novak I, Jones C, Badawi N, Khandaker G. What makes children with cerebral palsy vulnerable to malnutrition? Findings from the Bangladesh cerebral palsy register (BCPR). *Disability and Rehabilitation.* 2018 Apr 13:1-8.

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 to develop a national cerebral palsy (CP) register with surveillance of children for CP. *BMC Neurology.* 2015 Dec;15(1):173.

Selected conference presentations

Jahan I, Karim T, Das MC, Muhit M, McIntyre S, Smithers-Sheedy H, Badawi N, Khandaker G. Mortality among children with cerebral palsy (CP) in rural Bangladesh: results from a population-based surveillance study. 72nd Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), 9-13 October 2018, Cincinnati, Ohio [Oral Presentation].

Power R, Muhit M, Heanoy E, Karim T, Jones C, Badawi N, Akhter R, Khandaker G. Health related quality of life (HRQoL) of adolescents with Cerebral Palsy (CP) in rural Bangladesh. 9th Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference, 21-24 March 2018, Auckland, New Zealand [Oral presentation].

Khandaker G, Karim T, Smithers-Sheedy H, Novak I, Jones C, Badawi N, Muhit M. Epidemiology of Cerebral Palsy (CP) in Bangladesh: findings from the first general population-based register in a low and middle-income country. 9th Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference, 21-24 March 2018, Auckland, New Zealand [Oral presentation].

Jahan I, Muhit M, Karim T, Smithers-Sheedy H, Novak I, Jones C, Badawi N, Khandaker G. What makes children with cerebral palsy vulnerable to malnutrition? 9th Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference, 21-24 March 2018, Auckland, New Zealand [Oral presentation].

Khandaker G, Karim T, Muhit M, Smithers-Sheedy H, Novak I, Booy R, Jones C, Badawi N. The Epidemiology of Cerebral Palsy (CP) in Bangladesh: findings from the first general population-based register of children with CP in a low and middle-income country. 9th Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference, 21-24 March 2018, Auckland, New Zealand [Oral presentation].

Khandaker G, Muhit M, Smithers-Sheedy H, Karim T, Novak I, Badawi N. Prevalence and causes of cerebral palsy (CP) among children in rural Bangladesh – results from the Bangladesh CP Register (BCPR). 29th European Academy of Childhood Disability Conference, 17-20 May 2017, Amsterdam, The Netherlands [Poster].

Karim T, Smithers-Sheedy H, Novak I, Jones C, Badawi N, Muhit M, Khandaker G. Rehabilitation status of children with cerebral palsy in rural Bangladesh - Findings from the Bangladesh Cerebral Palsy Register (BCPR) study. 29th European Academy of Childhood Disability Conference, 17-20 May 2017, Amsterdam, The Netherlands [Oral presentation].

Khandaker G, Muhit M, Smithers-Sheedy H, Karim T, Novak I Badawi N. The burden of cerebral palsy (CP) among children in rural Bangladesh – results from the Bangladesh CP Register (BCPR) study. 71st Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), 13-16 September 2017, Montreal, Canada [Oral presentation].

Karim T, Khandaker G, Smithers-Sheedy H, Novak I, Jones C, Badawi N, Muhit M. Associated impairments among children with cerebral palsy in rural Bangladesh: findings from the Bangladesh Cerebral Palsy Register (BCPR). 71st Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), 13-16 September 2017, Montreal, Canada [Oral Presentation].

Karim T, Smithers-Sheedy H, Novak I, Jones C, Badawi N, Muhit M, Khandaker G. Health inequity in children with cerebral palsy (CP) - Comparing Bangladesh CP register (BCPR) data with National Population and Housing Census. 71st Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), 13-16 September 2017, Montreal, Canada [Poster].

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 presentation].

New Zealand Cerebral Palsy Register

Investigators

Professor Susan Stott, Dr Anna Mackey and Ms Alexandra Sorhage

Aims

The NZCPR has been in operation for three years, with an opt-off consent process since late 2016. The aims are to increase our understanding of CP in New Zealand to assist service planning, clinical decision making, advocacy for people with CP and to facilitate research. The NZCPR is currently funded through Starship Foundation support and based within the Paediatric Orthopaedic service at Starship Children's Hospital, Auckland, with a full-time Research Officer.

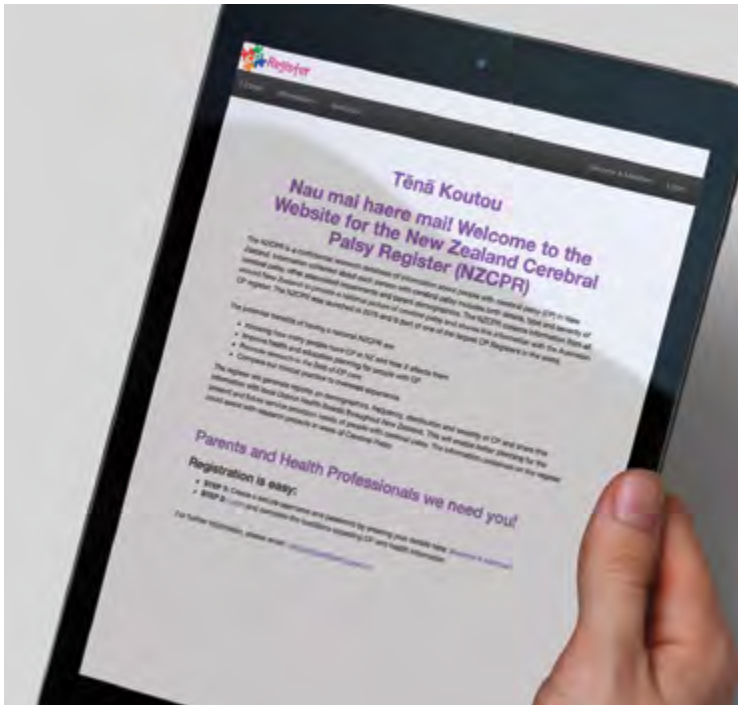
Research and other activities

The key governance and management activities have included i) the formation of a national Governance committee (2016), with key stakeholder and clinical representation ii) development of a formal NZCPR Research policy iii) development of a NZ specific IT platform and website and iv) maintaining ongoing ethical requirements for ascertainment across New Zealand. Multiple ascertainment methods continue to be investigated, including targeted linkage to existing health datasets in New Zealand.

Interim outcomes from the NZCPR: As of July 2018, the NZCPR has 910 registrations from birth years 1945 - 2016 (Age range 0-73 years, median age 12 years, with 86% (n=782) between 0-19 years). Regional distribution remains Auckland-centric, with 58% from the Auckland metro region. Currently, clinical datasets are still incomplete compared to demographic data. Functional distribution (n=479) by Gross Motor Functional Classification System, Levels I-V is 27%, 27%, 14%, 19%, 14% respectively. Gestational age (n=361) showed 53% had premature birth (<36 weeks). Low birth weight (< 1500g) is present in 27% of the cohort (n=289). Time of documented diagnosis of CP (n=283) averaged 23 months, with 13% documented in the first 6 months; 26% at 7-12months; 35% from 13-24 months and 26% >24 months.

The NZCPR has been active in national and international presentations [1, 2] and is currently using the early outcomes to guide future research proposals. Data ascertainment, regional engagement, completed datasets and data quality remain the NZCPR priorities. We greatly appreciate the ongoing support and expertise of the Australian Cerebral Palsy Register network.

1. Mackey AH, Sorhage A, Wilson N, Stott NS. Ethnic and regional diversity of the New Zealand Cerebral Palsy Register. Paediatric Society of NZ conference, Christchurch Nov, 2017.
2. Mackey AH, Sorhage A, Wilson N, Stott NS. Ethnic diversity of the New Zealand Cerebral Palsy Register. Australasian Academy of Cerebral Palsy & Developmental Medicine conference. Developmental Medicine & Child Neurology, March 2018, 60 (S1) 1-79.



The NZCPR team and colleagues at AusACPDM conference, Auckland March 2018. (From Left-Right: Prof Sue Stott, Dr Anna Mackey, Dr Nichola Wilson, Dr Sian Williams and Ms Alexandra Sorhage)

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 9307 4949 ext 21898

ETHICS COMMITTEE REFERENCE NUMBER:

13/NTA/130

Sri Lankan Cerebral Palsy Register

Investigators

Dr Samanmali Sumanasena Kularatne, Mr Gopi Kitnsamy, Dr Hayley Smithers-Sheedy, Prof Nilanthi de Silva, Mrs Thilini Madushika, Dr Nimisha Muttiah, A/Prof Gulam Khandaker, Dr Dimuthu Wijesekara, Dr Pyara Ratanayake, Dr Jithangi Wanigasinghe, Dr Monika de Silva, Dr Jayatri Jogoda, Dr Shyamani Hettiarachchi, Dr Thilini Rodrigo, Dr James Rice, Prof Cheryl Jones, Dr Sarah McIntyre, Mrs Shona Goldsmith, Prof MA Muhit and Mrs B. T. N. Adikari

Aims

- To establish a secure web-based Sri Lankan CP Register (SLCPR) for hospital and community based surveillance of CP in Sri Lanka
- To utilise SLCPR data to describe:
  - demographic features
  - CP prevalence
  - timing of brain injury (pre/perinatal or post-neonatally acquired)
  - aetiology of CP
  - clinical profile
  - use and access to rehabilitation services for children with CP

Research and other activities

Work commenced on the Sri Lankan CP Register in March 2017. Since this time we have gained approval for this work through the Sri Lankan Ministry of Health and have obtained ethics approvals through the Faculty of Medicine at the University of Kelaniya. The SLCPR minimum dataset and registration forms have been finalised and the new SLCPR website has been launched: http://srilanka.cpregister.com. Data collection has now commenced at the hospital surveillance sites.

The CP Lanka organisation has started the community midwives training program in Trincomalee & Batticaloa (Eastern Province) and also in Killinochchi (Northern Province). To date 120 midwives have participated in the Eastern province and another 50 in the North. CP Lanka has also organized training programs for Special Educational Needs (SEN) teachers in the Eastern, Western and Northern provinces. A Special Paediatric Wheelchair distribution camp was organized in Batticaloa (East) in April 2018 and 85 children and their families attended. 58 children from the Western province have received wheelchairs in 2018.

Investigators from the hospital and community based Sri Lankan CP Register programs.

SLCPR

TARGET POPULATION:

All people with cerebral palsy in the Western (community and hospital surveillance) and Eastern Province (community surveillance) of Sri Lanka

CONTACT DETAILS:

University of Kelaniya and CP Lanka Foundation

WEBSITE:

http://srilanka.cpregister.com

EMAIL:

htmadushika@gmail.com

ETHICS COMMITTEE REFERENCE NUMBER:

Faculty of Medicine, University of Kelaniya, study number P/105/03/2017, National Health Research Council Reference Number - ETR/E/NHRC/MISC/2017, Ethics Review Committee of Colombo South Teaching Hospital, application number - AA/03/2018

Appendix A

New South Wales and Australian Capital Territory Cerebral Palsy Register

The Cerebral Palsy Alliance Research Institute, a wholly owned subsidiary of Cerebral Palsy Alliance

Target population:

Individuals who have CP acquired before 2 years of age who were born or currently live in New South Wales or the Australian Capital Territory

Dr Sarah McIntyre

Brain and Mind Centre, University of Sydney
88 Mallett St
Camperdown NSW 2050 Australia

smcintyre@cerebralpalsy.org.au

61 2 9975 8928

Purpose:

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

An extension to the CP Register, called CP Check-Up™ now provides a platform for the ongoing collection of surveillance data focussed on the prevention of secondary impairments in children living with CP in NSW/ACT. For further information please contact lead Dr Petra Karlsson at **cpregister@cerebralpalsy.org.au**.

NSW/ACT CP Register now includes an opt-off consent policy throughout Cerebral Palsy Alliance and the NSW Children's Hospitals. This particularly successful partnership is thanks to our hospital investigators: Dr Simon Paget, Dr Kirsty Stewart and Ms Karen Bau (SCHN Westmead), Dr Maria Kyriagis and Ms Kerry Hanns (SCHN Randwick), Dr Heather Burnett (Kaleidoscope John Hunter Children's Hospital), Mrs Nicole Gerrand (Hunter New England Local Health District).

An advisory group has also been developed to provide strategic guidance, thanks to: Prof Nadia Badawi, Ms Isabelle Balde, Ms Leanne Diviney, Miss Natasha Garrity, Mrs Shona Goldsmith, Ms Kerry Hanns, Dr Petra Karlsson, Ms Sophie Marmont, Dr Tan Martin, Dr Sarah McIntyre, Prof Natasha Nassar, Ms Katarina Ostojic, Dr Simon Paget, Dr Michael Peek, Dr Ingrid Rieger, Dr Hayley Smithers-Sheedy, Ms Anna te Velde, Ms Emma Waight and Dr Sue Woolfendon.

Cerebral Palsy
ALLIANCE

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

Ms Natasha Murray and Dr Catherine Boyd

Centre for Disease Control
Building 4, Royal Darwin Hospital
NT 0811 Australia

natasha.murray@nt.gov.au

61 8 8922 8044

Purpose:

The main aims of the CP register are to determine the number, location and abilities of people in the Northern Territory who have CP; also to use this information to assist in the planning, development and provision of services, and to provide a resource for research into CP.

Queensland Cerebral Palsy Register

CPL - Choice, Passion, Life

Target population:

All people were born in or receive services in Queensland who have CP

Mr Michael deLacy

Queensland Cerebral Palsy Register
PO Box 386
Fortitude Valley
Brisbane
QLD 4006 Australia

mdelacy@cplqld.org.au

61 7 3358 8122

Purpose:

(1) To 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.

(2) To provide a population resource for intervention trials.

(3) To contribute to investigations into causes and prevention of CP.

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 Ms Heather Scott

Women's and Children's Health Network
72 King William Road
North Adelaide
Adelaide
SA 5006 Australia

cpregister@sa.gov.au

61 8 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 cerebral palsy, document the severity and range of disabilities experienced by children with cerebral palsy, use the information collected to plan facilities for affected children, act as a source of information about cerebral palsy for both families and the community, improve community and professional awareness of cerebral palsy including its causes and outcomes, provide a resource for research into CP and contribute to mortality and morbidity studies of cerebral palsy

Tasmanian Cerebral Palsy Register

St Giles

Target population:

The Register only collects information on cerebral palsy. The main focus is on young children, but accepts registrations from all Tasmanians with cerebral palsy.

Ms Kirsty Bartlett-Clark, Dr Eliza Maloney, Ms Amy Cochrane and Ms Jacinta Hickey

St Giles
PO Box 45,
New Town
Tasmania
TAS 7008 Australia

society@stgiles.org.au

61 3 6238 1888

Purpose:

To monitor how many people are living in Tasmania with cerebral palsy, 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 Children's Research Institute at The Royal Children's Hospital, Melbourne

Target population:

Individuals with CP born since 1970

Dr Sue Reid

Developmental Disability and Rehabilitation Research

Murdoch Children's Research Institute
50 Flemington Road
Parkville
VIC 3052 Australia

sue.reid@mcri.edu.au

61 3 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

Ms Linda Watson

Western Australian Register of Developmental Anomalies – CP

King Edward Memorial Hospital
PO Box 314
Subiaco
WA 6904 Australia

linda.watson@health.wa.gov.au

61 8 9340 2768
61 403 806 932
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 distributions of CP in WA (for example by age, severity, geographical area) to service organisations

(6) To contribute WA CP data to the Australian Cerebral Palsy Register.

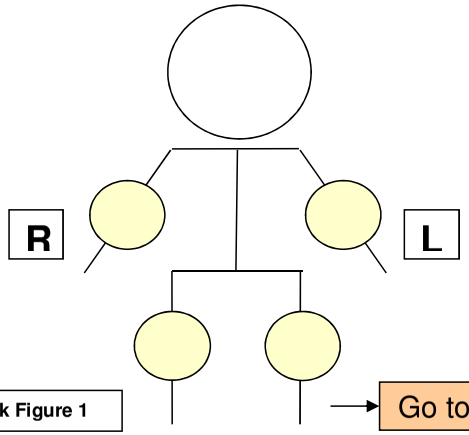
CEREBRAL PALSY DESCRIPTION FORM Part I: MOTOR IMPAIRMENTS

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

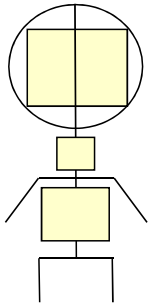
Yes ☐ No ☐



Stick Figure 1

Go to **2**

2. Describe face/ neck/trunk tone



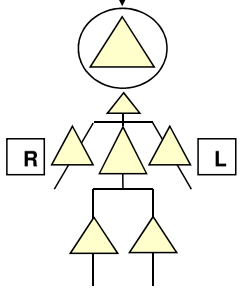
Stick Figure 2

Go to **3**

3. Is muscle tone varying?

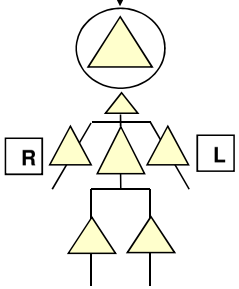
Yes ☐ No ☐

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 ☐

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 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

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.

Footnote: https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/communicable%20diseases/PDF/Cerebral_Palsy_Description_Form_WARDA_website.pdf

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

Appendix C

Projects supported by state/territory cerebral palsy registers through data provision or recruitment (2017-2018)

New South Wales/Australian Capital Territory Cerebral Palsy Register

- Family perceptions about genomics research in CP, bio-banking and international data sharing; Ms Yana Wilson, Cerebral Palsy Alliance Research Institute, The University of Sydney
- Gene discovery in cerebral palsy; Dr Michael Kruer, Phoenix Children's Hospital, USA
- Parenting Acceptance and Commitment Therapy (PACT): innovative, online support for families of children with cerebral palsy; Dr Koa Whittingham, The University of Queensland
- The Friends Project; Dr Sarah McIntyre, Cerebral Palsy Alliance Research Institute, The University of Sydney
- Experiences of caregivers in feeding their child with CP; Dr Christine Taylor, Western Sydney University
- Early life parechovirus infection neurodevelopment at 3+ years (ELPIN-3); Prof Cheryl Jones, The Children's Hospital at Westmead
- Survey on visual abilities in children with cerebral palsy; Belinda Deramore Denver, Australian Catholic University
- REACH: Randomised trial of Rehabilitation very EArly in Congenital Hemiplegia; Dr Cathy Morgan, Cerebral Palsy Alliance Research Institute, The University of Sydney
- GAME: Goals Activity Motor Enrichment; Dr Cathy Morgan, Cerebral Palsy Alliance Research Institute, The University of Sydney
- Orthoses (splints) for the wrist and hand; Dr Margaret Wallen, Australian Catholic University
- The mechanisms of behaviour problems in children and adolescents with cerebral palsy; Mr Xun Li, The University of Sydney
- Stem Cell Reference Group; Dr Megan Finch-Edmondson, Cerebral Palsy Alliance Research Institute, The University of Sydney
- Can we predict cerebral palsy at birth?; A/Prof Jeffrey Craig, Murdoch Children's Research Institute
- Effective engagement of children and young people with cerebral palsy as partners in research; Dr Margaret Wallen, Australian Catholic University
- Family partnership in CP research: identifying engagement strategies; Dr Margaret Wallen, Australian Catholic University
- Chronic pain in cerebral palsy: a prevalence study and randomised controlled trial of biofeedback mediated relaxation for the management of chronic pain in children and adolescents with cerebral palsy via the BrightHearts app; Ms Katarina Ostojic, KidsRehab, The Children's Hospital at Westmead
- Seamless journeys to work; Dr Lisa Stafford, Queensland University of Technology; University of Queensland
- Intensive Early Adaptive Therapy (I-EAT) to improve feeding and swallowing: a clinical trial for infants at risk of cerebral palsy; Ms Amanda Spirit-Jones, Cerebral Palsy Alliance, The University of Sydney
- The effects of LSVT LOUD® on drooling (swallowing and speech); Ms Michelle McInerney, Australian Catholic University

Queensland Cerebral Palsy Register

- Testing novel measures of community function and participation in adults with cerebral palsy (CP); Professor Stewart Trost, Queensland University of Technology
- Identifying Red Flags for Feeding Difficulties and Nutritional Status in Children and Young People with Cerebral Palsy; Dr Kristie Bell, The University of Queensland and Lady Cilento Children's Hospital
- Enhancing neuromuscular control of the ankle through targeted motor training in cerebral palsy; Ms Shari O'Brien, The University of Queensland

Victorian Cerebral Palsy Register

- Improving our understanding of MRI patterns, structure-function relationships and causal pathways in cerebral palsy; Dr Sue Reid, Murdoch Children's Research Institute

- Characterising quality of life for children with intellectual disability; Dr Jenny Downs, Telethon Kids Institute
- Extent to which antenatal screening can predict cerebral palsy; Dr Monique Peris, University of Melbourne
- Cognitive and behavioural outcomes in adolescents with cerebral palsy; Dr Robyn Stargatt, LaTrobe University
- Bed time stories: An exploratory study of sleep disturbance for children with CP and their parents; Ms Sacha Petersen, Royal Children's Hospital, Melbourne
- Successfully negotiating life challenges: Learnings from adults with cerebral palsy; Prof Christine Imms, Australian Catholic University
- The epilepsies in cerebral palsy; Dr Monica Cooper, Royal Children's Hospital, Melbourne
- Can we predict the type of motor disorder of children with CP from their gait pattern, or its variability?; Dr Morgan Sangeux, Murdoch Children's Research Institute
- Developing a version of the CP QOL-Child for clinical settings; Ms Elena Swift, University of Melbourne
- Minimising Impairment Trial: a multicentre randomised controlled trial of upper limb orthoses for children with cerebral palsy; Prof Christine Imms, Australian Catholic University
- Validation of a clinical checklist for the early identification of respiratory disease in children and young people with cerebral palsy; Dr Marie Blackmore, Ability Centre / Sue Reid, Murdoch Children's Research Institute
- Infant Wrist Hand Orthosis Trial (iWHOTrial): a multicentre randomised controlled trial of wrist hand orthoses for young children with cerebral palsy; Prof Christine Imms, Australian Catholic University
- An inclusive dance program for children with disabilities; Prof Nicole Rinehart, Deakin University
- The long term impact of saliva control surgery; Prof Dinah Reddihough, Royal Children's Hospital, Melbourne
- Children and young people with CP as partners in research; Dr Margaret Wallen, Australian Catholic University
- FitSkills: a community-university partnership to increase exercise participation among youth with disability; Prof Nora Shields, LaTrobe University
- ALLPlay: Understanding benefits and barriers for children of all abilities to participate in community sport; Prof Nicole Rinehart, Deakin University
- Dance and children with disability: experiences of dance schools, dance teachers, parents and children; Dr Tamara May, Deakin University
- Development and initial validation of an assessment of visual ability for children with cerebral palsy – Survey on visual abilities in children with cerebral palsy; Ms Belinda Deramore Denver, Australian Catholic University
- Anxiety in children with cerebral palsy; Dr Giuliana Antolovich, Royal Children's Hospital, Melbourne
- Daily Living Transactions; Understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy; Ms Robyn Heesh, Royal Children's Hospital, Melbourne
- Surveillance of hip displacement in Victorian children with cerebral palsy: parent and carer perspectives of the barriers and facilitators to engaging with hip surveillance; Prof Dinah Reddihough, Royal Children's Hospital, Melbourne
- Investigating the needs, gaps and barriers to mental health care for mothers of children with a disability; Dr Kim-Michelle Gilson, University of Melbourne
- Gene discovery in cerebral palsy; Dr Michael Kruer, Barrow Neurological Institute / Prof David Amor, Murdoch Children's Research Institute
- Can we predict cerebral palsy at birth? A/Prof Jeff Craig, Murdoch Children's Research Institute

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

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 I, 2 level II, 3 level III, 4 level IV, 5 level V, 9 unknown

Manual Ability Classification System (MACS) level age 5 years

Single digit: 1 level I, 2 level II, 3 level III, 4 level IV, 5 level V, 9 unknown

Post-neonatal timing of brain injury that caused CP

Single digit: 0 No post-neonatal cause, 1 Post-neonatal cause (after 28 days and before age 2 years), 2 neonatal injury in an undisputedly normal infant, 9 uncertain whether post-neonatal 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. Post-neonatal 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 post-neonatal 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, OMIM, ICD10 or Orphanet

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 unknown, 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

References

1. Goldsmith S, McIntyre S, Smithers-Sheedy H, Blair E, Cans C, Watson L, et al. on behalf of the Australian Cerebral Palsy Register Group. An International Survey of Cerebral Palsy Registers and Surveillance Systems. *Dev Med Child Neurol.* 2016;58(Suppl 2):11-7.
2. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE). *Dev Med Child Neurol.* 2000;42(12):816-24.
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