Australian Cerebral Palsy Register Report 2023

BIRTH YEARS 1995-2016

Cerebral Palsy ALLIANCE RESEARCH INSTITUTE

CP Register

Piecing together the facts on cerebral palsy

Acknowledgements

The Australian Cerebral Palsy Register (ACPR) Group acknowledges the traditional owners and custodians of country throughout Australia and acknowledges their continuing connection to land, waters and community. We pay our respects to the people, the cultures and the elders past, present and emerging.

The 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 report trends of cerebral palsy (CP) in Australia, identify causal pathways and evaluate preventive strategies and management options for people with CP and their families.

The ACPR is hosted by the Cerebral Palsy Alliance Research Institute in Sydney, with ethical oversight by The University of Sydney Human Research Ethics Committee and the Aboriginal Health and Medical Research Council of New South Wales. The ACPR is funded by the Cerebral Palsy Alliance Research Foundation with generous support from Ignite Health Care.

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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;
- Adj A/Prof Hayley Smithers-Sheedy, Ms Emma Waight, Dr Shona Goldsmith and Dr Sarah McIntyre for developing, coordinating and writing this report;
- Mrs Renee Price for her work on the design and publishing of the report;
- Ms Tanya Martin for her beautiful artwork throughout the report; and
- Mr Paul Novak for the smooth running and maintenance of the ACPR infrastructure.

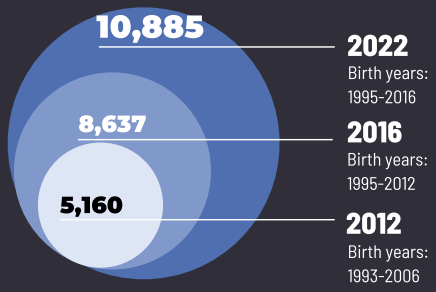
The ACPR exists as a result of a collaborative partnership between all the Australian state and territory CP registers, and the organisations which support each register.

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.

Members of the Australian Cerebral Palsy Register Group with colleagues from the Bangladesh Cerebral Palsy Register, the New Zealand Cerebral Palsy Register, the Sri Lankan Cerebral Palsy Register and the Surveillance of Cerebral Palsy in Europe.

Community summary

The Australian Cerebral Palsy Register is the largest single-country register of cerebral palsy (CP) in the world.



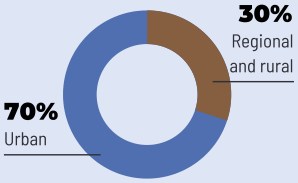
Since 1997-98, the rate of CP has declined from 2.5 to 1.5 per 1000 live births.

Provisional ACPR data indicates that this decline has been sustained through to 2015-16, equating broadly to a drop of **40%**.

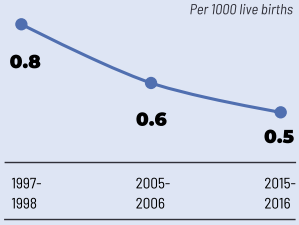
In 1997-98...
1 in 400
children in Australia were born with CP

In 2015-16...
1 in 700
children in Australia were born with CP

Three key findings from the ACPR:



Nearly a third of children with CP live in **regional, rural or remote Australia,** highlighting the need for high quality, accessible and culturally safe services.



The rate of children with CP who require assistive equipment for mobility is **declining.**

The majority of CP is caused by a brain injury during pregnancy and up to 28 days after birth **(prenatal and perinatal).**

However, **6%** of children have a recognised injury acquired after this period and before 2 years of age **(post-neonatal).**

Thank you to all the families and health professionals who so generously support the work of the Australian Cerebral Palsy Register.

Foreword

It is my pleasure to write this introduction to the 2023 Australian Cerebral Palsy Register (ACPR) report. It is a wonderful example of what can be achieved through partnerships and collaboration.

Data in this report show the rate of cerebral palsy in Australia is declining, while also presenting evidence of reduced severity, improved outcomes and overall enhanced quality of life for the one baby born every 20 hours with CP. Without the ACPR we would not be able to track and report these important trends and show so effectively the impact of new clinical interventions and improvements.

The fact that people with CP are living better lives than any time in history is a milestone to be celebrated.

We do not forget, however, the ongoing day-to-day challenges that remain for people with CP and their families. Nor the fact that the deficit-based approach so often adopted can cloud society's ability to see the individual, their capability, and their myriad contributions.

Rest assured that I understand CP is a unique, strong community. I also recognise that co-diagnoses are common, meaning tailored and targeted supports are required. The NDIS was created for this very reason.

The Government is working hard to get the NDIS back on track, starting with the independent NDIS Review which will recommend how to re-centre the system around the person – their choices, their control, their life.

We are working with people with lived experience to ensure the NDIS is sustainable, responsive and supportive and, crucially, puts people with disability back at the centre of the Scheme.

No longer should you or your loved one have to re-confirm that your child has CP at planning and review meetings, no longer should the nexus between the NDIS and the critical medical and therapeutic supports needed be a complex and stressful experience, no longer should you deal with a different person every time you interact with the agency, no longer should those critical early years feel so isolating and overwhelming.

To parents, carers, siblings, families, we see you and we hear you. We acknowledge your journey and your important role as a key partner in care.

The ACPR provides us with rich data from which to better understand CP and inform service planning. It sets a standard of best practice that would well serve all disability types and really speaks to the strength and advocacy of the CP community.

I offer my congratulations to every member of the ACPR Group on this report. Most importantly, thank you to all the families and individuals with cerebral palsy who so generously contributed to this research.

The Hon. Bill Shorten MP,

MINISTER FOR THE NDIS
AND GOVERNMENT SERVICES

Executive summary

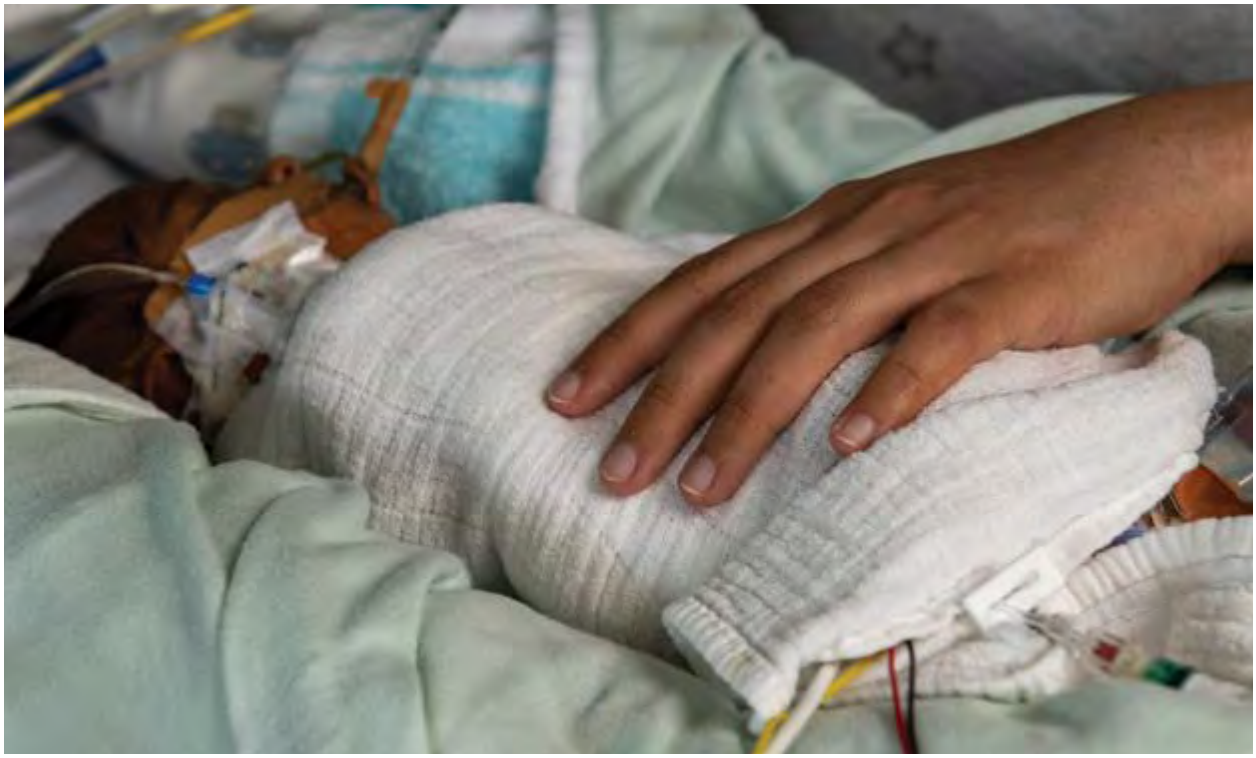
The Australian Cerebral Palsy Register (ACPR) was established in 2008 as a research database to facilitate the study of the distribution, frequency and severity of cerebral palsy (CP); the causes and determinants of CP; the effectiveness of prevention strategies and to help plan and evaluate services.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

This report comprises data provided in June 2022 for children with CP born between 1995 and 2016. Any notifications to state/territory registers after this date were not included in the report.

PART 1: ALL CP

In this birth cohort (1995-2016), there were a total of 10,855 records of children with CP reported from all states and territories of Australia.

- Prevalence of all CP declined from 2.4 (2.2, 2.6) per 1000 live births in 1997-98 to 1.5 (1.4, 1.6) in 2013-14 and provisional data indicates that this decline was sustained through to the 2015-16 birth years.
- This equates broadly to a drop from 1 in 400 children with CP born in Australia in 1997-98 to 1 in 700 children born with CP in 2015-16.
- Although the majority of children with CP live in major cities, 1 in 3 live in regional, remote or very remote Australia, highlighting the need for high quality, accessible and culturally safe services across Australia.



PART 2: PRENATALLY AND PERINATALLY ACQUIRED CP

Children included in this cohort (n=10,228, 94% of all CP) had a brain injury in the prenatal or perinatal period (i.e. during pregnancy and the first 28 completed days after birth).

- Prevalence of pre/perinatally acquired CP declined over this period (1995-96 to 2015-16)
  - across all maternal age groups
  - across all gestational age and birthweight groups
  - markedly for twins
  - for children who use assistive mobility devices (GMFCS III-V).
- The proportions of children with epilepsy or intellectual impairment decreased over these birth years.

PART 3: POST-NEONATALLY ACQUIRED CP

Children included in this cohort (n=627, 6% of all CP) had a recognised post-neonatal brain injury acquired more than 28 days after birth and before 2 years of age.

- Prevalence of post-neonatally acquired CP fluctuated over the reporting period with declines observed since 2007-08.
- The most common post-neonatal cause of CP was cerebrovascular accident (stroke), either spontaneous or associated with surgery or with cardiac complications.

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About cerebral palsy

Both internationally and in Australia, researchers working on CP registers draw on a range of references and perspectives when considering the definition of CP which best suits this work.[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 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

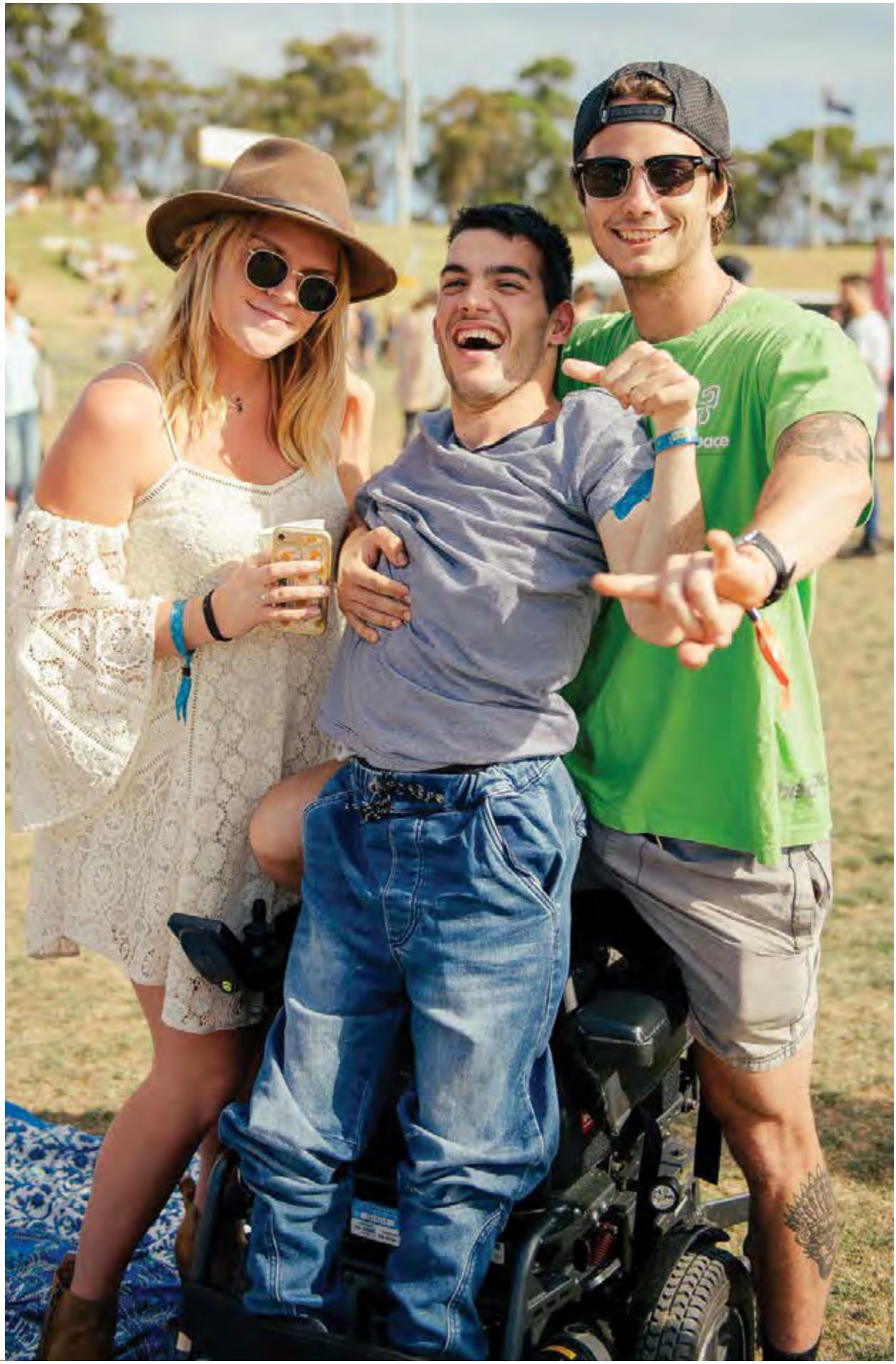
5) the interference, lesion, or abnormality originates in the immature brain[2]

For the majority of people with CP the entire causal pathway to brain injury is not completely 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 disorders of CP are classified into four main types: 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 problems with balance, depth perception and loss of coordination, so that movements are poorly organised 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 predominant hypotonic motor type.[9]

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

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.[16,17] A recent systematic review of data from CP register/surveillance systems and population-based prevalence studies determined an up-to-date birth prevalence estimate of CP in high-income countries at 1.6 per 1000 live births (95%CI 1.5, 1.7) with markedly higher prevalence in low-and-middle-income countries.[17]



What is the Australian Cerebral Palsy Register?

The Australian Cerebral Palsy Register (ACPR) is a database which includes 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:

Register	Register network	Custodian
Australian Capital Territory/New South Wales CP Registers Est 2005	Sarah McIntyre*, Hayley Smithers-Sheedy*, Shona Goldsmith*, Emma Waight, Georgina Henry, Iona Novak, Isabelle Balde, Nadia Badawi cpregister@cerebralpalsy.org.au	Cerebral Palsy Alliance Research Institute; The University of Sydney
Northern Territory Cerebral Palsy Register Est 2008	Fiona Kay* and Cassie Goldsworthy CP Register. THS@nt.gov.au	Northern Territory Government; Menzies
Queensland Cerebral Palsy Register Est 2006	Megan Auld* and Jacinta Quartermaine cpregister@cplqld.org.au	cpl choice • passion • life Choice, Passion, Life
The South Australian Cerebral Palsy Register Est 1998	Catherine Gibson*, Jennifer Hernandez and Heather Scott* cpregister@sa.gov.au	Government of South Australia; Women's & Children's Hospital Women's and Children's Health Network
Tasmanian Cerebral Palsy Register Est 2008	Clare Wiltshire, Nadine Davies*, Eliza Maloney* society@stgiles.org.au	St Giles; Tasmanian Health Service; Tasmanian Government St Giles and Tasmanian Department of Health
Victorian Cerebral Palsy Register Est 1986	Sue Reid*, Gina Hinwood, Angela Guzys, Dinah Reddihough, Christine Imms and Rod Hunt vic.cpregister@rch.org.au	murdoch children's research institute Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne
Western Australian Register of Developmental Anomalies - Cerebral Palsy Est 1977	Linda Watson*, Michele Hansen, Dylan Gration, Noula Gibson, Katherine Langdon, Jennie Slee and Eve Blair Linda.Watson@health.wa.gov.au	Western Australian Register of Developmental Anomalies Department of Health WA

*ACPR Research and Policy Group

	Children included in birth state/territory register on or after 1/1/2005	Adults included by birth state/territory register born prior to 01/1/2005
	1952	2170
	86	88
	1200	1083
	678	532
	118	99
	2011	4354
	1192	3443

For more details on state and territory CP registers including contact details, please see Appendix A.

The Australian Capital Territory, New South Wales and Australian CP Registers are funded by the Cerebral Palsy Alliance Research Foundation and Ignite Health Care. The Northern Territory CP Register is funded by Women, Children and Youth, Royal Darwin Hospital. The Queensland CP Register is funded by Choice, Passion, Life. The South Australian CP Register is funded by the Women's and Children's Health Network with additional support provided by Novita. The Tasmanian CP Register is supported by St Giles and the Tasmanian Department of Health. The Victorian CP Register received funding from the Cerebral Palsy Alliance Research Foundation, Lorenzo and Pamela Galli Medical Research Trust, the Victorian Department of Health and Human Services, and the Royal Children's Hospital Foundation, and infrastructure support was provided by the Victorian Government's Operational Infrastructure Support Program. The Western Australian Register of Developmental Anomalies - Cerebral Palsy is funded by Department of Health Western Australia.

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) reporting trends of CP

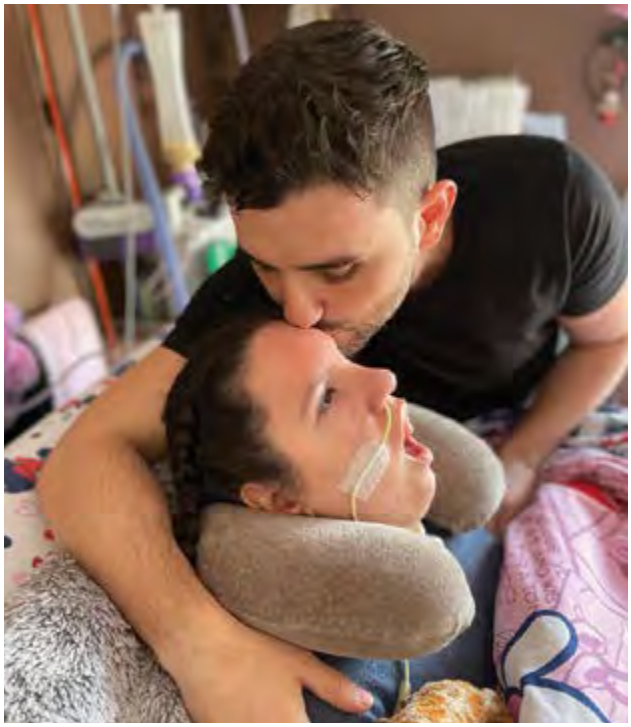
b) identifying interventions that effectively improve quality of life

c) identifying causal pathways to enable prevention

d) evaluating preventive strategies and

e) planning and evaluating services for children and adults with CP

The ACPR Research and Policy Group includes a representative from each state and territory CP register. This group meets regularly to improve the quality of and determine outputs for the ACPR. The group provides consultation to researchers who are seeking advice about accessing CP register data within Australia. For further information please contact: **cpregister@cerebralpalsy.org.au**



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.

Methods

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 and approved by The University of Sydney HREC, a National Health and Medical Research Council approved HREC. Projects involving the use of data stratified by Indigenous status are reviewed by the Aboriginal Health and Medical Research Council (EC00453) as well as state/territory Aboriginal and Torres Strait Islander HRECs as required.

The Cerebral Palsy Alliance Research Institute, The University of Sydney is the custodian organisation for the ACPR.

ACPR Community Aboriginal and Torres Strait Islander Reference Group

The 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 Tan Martin (Chair), Anne Masi, Sarah McIntyre, Leanne Diviney, Emma Stanton, Emma Waight, Linda Watson, Megan Auld, Gareth Baynam, Hayley Smithers-Sheedy, Sophie Marmont and Susan Woolfenden.

Cohort

The cohort of children with CP in this report were born between 1995 and 2016. In order to ensure that duplicate records were not included in the dataset, each state and territory group contributed only records of children born in their state and territory within this time frame. A de-duplication algorithm designed to highlight potential duplicates was also run as a further measure to avoid duplicate reporting.

Inclusion/exclusion criteria

In order to be included in the dataset, the criteria contained in the five definitional elements for CP must be fulfilled, as outlined earlier.[2] Contributing registers consider a registration to be confirmed when the individual reaches 5 years of age. In the event that new information becomes available, this may be updated which may involve inclusion or exclusion.

Denominator data

We are grateful to the Australian Institute of Health and Welfare for data from the National Perinatal Data Collection, the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM)[23] for providing access to data used for this project and for the assistance of the staff at Safer Care Victoria. The conclusions, findings, opinions and views or recommendations expressed in this report are strictly those of the authors. They do not necessarily reflect those of CCOPMM.

Reporting of numerator data

Ascertainment varies between states/territories, reflecting differences in both the time of establishment and the consent requirements of each register. Three states of Australia, South Australia, Victoria and Western Australia, have long established CP registers. CP registers that have been established more recently in Australian Capital Territory/New South Wales, Northern Territory, Queensland and Tasmania are also included in this report.

The calculation of birth prevalence in this report has used data drawn from the long-standing registers with the addition of Australian Capital Territory/New South Wales for birth years where ascertainment is considered complete/near complete. This addition now means nearly 80% of the Australian population is represented in birth prevalence results. Due to the disruptions to the work of the CP registers caused by the COVID-19 pandemic, the prevalence reported for the final birth period (2015-16) should be considered provisional.

Structure of this report

The results of this report have been divided into four sections: Part 1 reports on all CP as a whole, 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)[24], Part 3 refers to CP where a known post-neonatal cause (occurring more than 28 days after birth and before 2 years of age) has been identified and Part 4 provides information about the international network of CP register and surveillance programs.

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 projects including:

- Nation-wide research focussed on:
  - Trends in CP birth prevalence, disability severity and motor type in singletons (1995-2014)[21]
  - Headline estimates and trends for Aboriginal and Torres Strait Islander children living with cerebral palsy (Martin et al, manuscript under review)
  - Trends in prevalence of post-neonatally acquired CP (1973-2012)[22]
- Collaborative research with the Surveillance of Cerebral Palsy in Europe focussed on
  - Post-neonatally acquired CP (in process)
  - Risk of CP for children with cardiac anomalies (in process)
- Collaborative research with CP register and surveillance programs world-wide to report the global prevalence of CP[17] (see Section 4) and to map the aims and methodologies of register and surveillance programs to support collaboration (in process)
- Support and collaborate with other research groups internationally to establish new CP registers and to support research efforts stemming from these programs (see Section 4)
- Data linkage studies with state/ territory register partners
- Contribution of research and participation in the World CP Register and Surveillance Congress within the triennial International Alliance of Academics of Childhood Disability conference

Population proportions for the states and territories of Australia

A map showing the states and territories and the percentage of total population[18] has been provided below.

Australia has a total population of 26 million people,[19] with 310, 000 live births per year.[20] It is a large country with varying population densities and accessibility to services. See Residential Remoteness p22.

RESULTS

1

All children with cerebral palsy

Section 1 of this report includes all children with CP not differentiated by timing of brain injury.

Prevalence

Table 1. CP birth prevalence per 1000 live births (LB) and birth period (1995-2016)

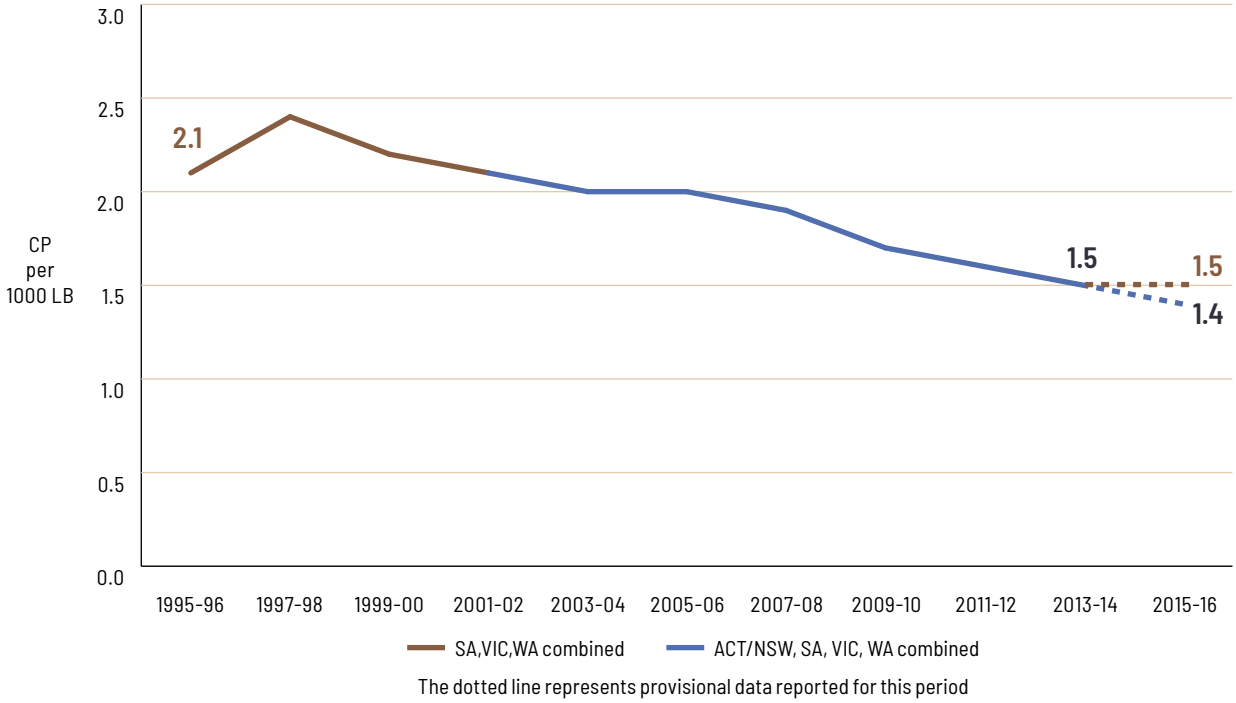
	1995-96	1997-98	1999-00	2001-02	2003-04	2005-06	2007-08	2009-10	2011-12	2013-14	2015-16*
SA, VIC and WA combined	**2.1** (1.9, 2.3)	**2.4** (2.2, 2.6)	**2.2** (2.1, 2.5)	**2.2** (2.0, 2.4)	**2.1** (1.9, 2.3)	**2.3** (2.1, 2.5)	**2.0** (1.8, 2.2)	**1.9** (1.7, 2.0)	**1.6** (1.4, 1.7)	**1.5** (1.4, 1.7)	**1.5*** (1.4, 1.6)
ACT/NSW, SA, VIC and WA combined				**2.1** (2.0, 2.2)	**2.0** (1.8, 2.1)	**2.0** (1.9, 2.2)	**1.9** (1.8, 2.0)	**1.7** (1.6, 1.9)	**1.6** (1.5, 1.7)	**1.5** (1.4, 1.6)	**1.4*** (1.3, 1.5)

*Provisional data

Table 2. Number of children with CP by state/territory of birth (1995-2016)

	All CP
	n
ACT/NSW	3490
NT	150
QLD	2012
SA	812
TAS	189
VIC	2659
WA	1543
TOTAL	**10,855 (100)**

Figure 1. CP birth prevalence overall by live births (LB) and birth period (1995-2016)



Prevalence of all CP declined from 2.4 (2.2, 2.6) per 1000 LB in 1997-98 to 1.5 (1.4, 1.6) in 2013-14. The prevalence for the final birth period should be considered provisional due to disruptions caused by the COVID-19 pandemic. The available data for this period does however suggest that the decline noted in 2013-14 has been sustained.

Indigenous status

Table 3. Number and percentage of children with CP by child or maternal Indigenous status and state/territory of birth (1995-2016)

	Aboriginal n (%)^	Aboriginal and Torres Strait Islander n (%)^	Torres Strait Islander n (%)^	Non-Indigenous n (%)^	Total n	Unknown n (%)
ACT/NSW						
Pre/peri	167 (6.3)	◆ (0.1)	8(0.3)	2489 (93.4)	3265	599 (18.3)
PNN	11 (6.7)	0 (0.0)	◆ (0.6)	151 (92.7)	225	62 (27.3)
All	178 (6.3)	◆ (0.1)	9 (0.3)	2640 (93.3)	3490	661 (18.9)
NT						
Pre/peri	62 (49.2)	◆ (0.8)	0 (0.0)	63 (50.0)	129	3 (2.3)
PNN	13 (68.4)	0 (0.0)	◆ (5.3)	5 (26.3)	21	2 (9.5)
All	75 (51.7)	◆ (0.7)	◆ (0.7)	68 (46.9)	150	5 (3.3)
QLD						
Pre/peri	83(5.5)	11 (0.7)	13 (0.9)	1376 (92.8)	1919	436 (22.7)
PNN	11 (14.7)	0 (0.0)	◆ (1.3)	63 (84.0)	93	18 (19.4)
All	94 (6.0)	11 (0.7)	14 (0.9)	1439 (92.4)	2012	454 (22.6)
SA						
Pre/peri	32 (4.1)	0 (0.0)	0 (0.0)	748 (95.9)	780	0 (0.0)
PNN	◆ (9.1)	0 (0.0)	0 (0.0)	29 (90.9)	32	0 (0.0)
All	35 (4.3)	0 (0.0)	0 (0.0)	777 (95.7)	812	0 (0.0)
TAS						
Pre/peri	11 (7.1)	0 (0.0)	0 (0.0)	143 (92.9)	186	32 (17.2)
PNN	◆ (33.3)	0 (0.0)	0 (0.0)	◆ (66.7)	◆	0 (0.0)
All	12 (7.6)	0 (0.0)	0 (0.0)	145 (92.4)	189	32 (16.9)
VIC						
Pre/peri	64 (2.6)	◆ (0.0)	0 (0.0)	2427 (97.4)	2517	25 (1.0)
PNN	◆ (2.8)	0 (0.0)	◆ (0.7)	136 (96.5)	142	◆ (0.7)
All	68 (2.6)	◆ (0.0)	◆ (0.0)	2563 (97.3)	2659	26 (1.0)
WA						
Pre/peri	131 (9.2)	◆ (0.1)	◆ (0.1)	1298 (90.7)	1432	◆ (0.1)
PNN	23 (20.7)	0 (0.0)	0 (0.0)	88 (79.3)	111	0 (0.0)
All	154 (10.0)	◆ (0.1)	◆ (0.1)	1386 (89.9)	1543	◆ (0.6)
TOTAL						
Pre/peri	**550 (6.0)**	**16 (0.2)**	**22 (0.2)**	**8544 (93.6)**	**10,228**	**1096 (10.7)**
PNN	**66 (12.1)**	**0 (0.0)**	**◆ (0.7)**	**476 (97.2)**	**627**	**83 (13.2)**
All	**616 (6.4)**	**16 (0.2)**	**26 (0.3)**	**9020 (93.5)**	**10,855**	**1179 (13.2)**

◆ <5 children

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

Pre/peri: pre/perinatally acquired CP

PNN: post-neonatally acquired CP

All: total of both pre/perinatally and post-neonatally acquired CP

A Bird's-Eye View of Aboriginal inclusion and knowledge sharing within the Australian Cerebral Palsy Register
by Tan Martin

The Australian CP Register Group are working with Aboriginal researchers to continue to improve collection and completeness of this important data. For more information about trends of CP for Australian Aboriginal and Torres Strait Islander children and young adults, please see *A Birds-Eye View: Headline estimates and trends for Aboriginal and Torres Strait Islander children living with cerebral palsy*. This paper was led by Ms Tan Martin and is currently under review, expected to be published early 2023.

In Australia, 4.4% of babies are born to Aboriginal/and or Torres Strait Islander mothers.[25]

The proportion of Aboriginal and/or Torres Strait Islander children with CP varies considerably by state/territory. Whilst likely an underestimate, current ACPR data suggests Aboriginal and/or Torres Strait Islander children make up 6.8% of all children with CP.

Residential remoteness

Table 4. Number and percentage of children with CP by residential remoteness* at age 5 or time of birth

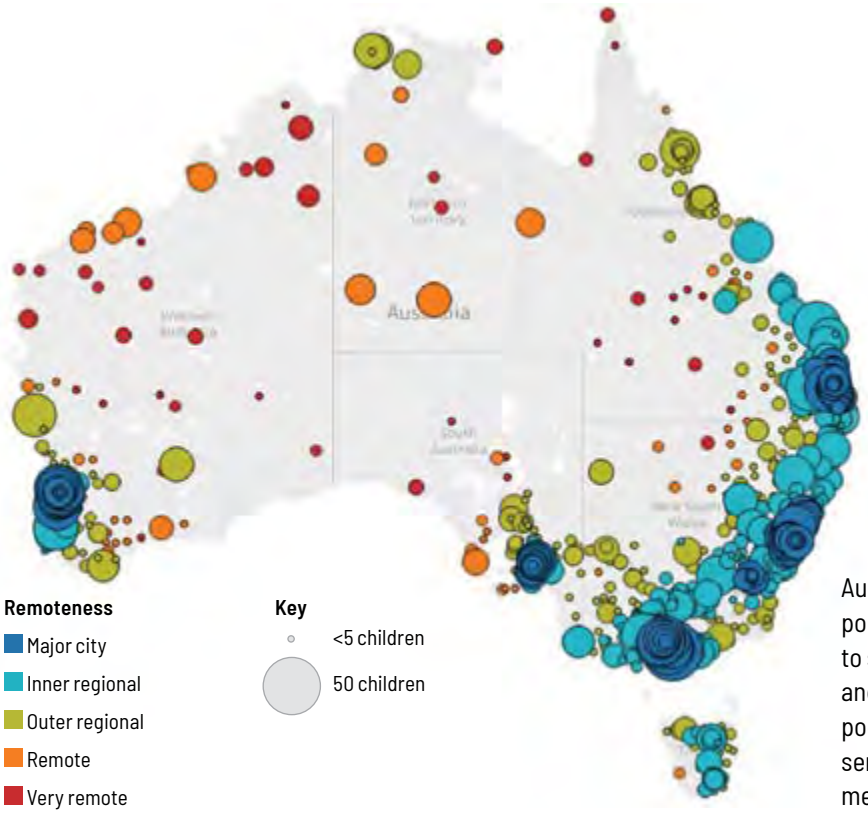
	Major city n (%)^	Inner regional n (%)^	Outer regional n (%)^	Remote n (%)^	Very remote n (%)^	Total n	Unknown n (%)
ACT/NSW	1736 (74.6)	456 (19.6)	121 (5.2)	8 (0.3)	◆ (0.2)	3490	1167 (33.4)
NT	6 (4.3)	0 (0.0)	79 (56.4)	46 (32.9)	9 (6.4)	150	10 (6.7)
QLD	987 (62.5)	344 (21.8)	200 (12.7)	28 (20.0)	20 (1.3)	2012	433 (21.5)
SA	576 (71.1)	105 (13.0)	88 (10.9)	34 (4.2)	7 (0.9)	812	◆ (0.2)
TAS	◆ (1.8)	135 (78.9)	31 (18.1)	◆ (1.2)	0 (0.0)	189	18 (9.5)
VIC	2024 (77.3)	503 (19.2)	92 (3.5)	◆ (0.0)	0 (0.0)	2659	39 (1.5)
WA	1137 (73.9)	117 (7.6)	137 (8.9)	81 (5.3)	67 (4.4)	1543	◆ (0.3)
TOTAL	**6467 (70.4)**	**1660 (18.1)**	**748 (8.1)**	**200 (2.1)**	**107 (1.2)**	**10,855**	**1673 (15.4)**

*Calculated by using Australian Statistical Geography Standard Remoteness Structure

◆ <5 children

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

Figure 2. Number of children with CP mapped by residential remoteness (1995-2016)

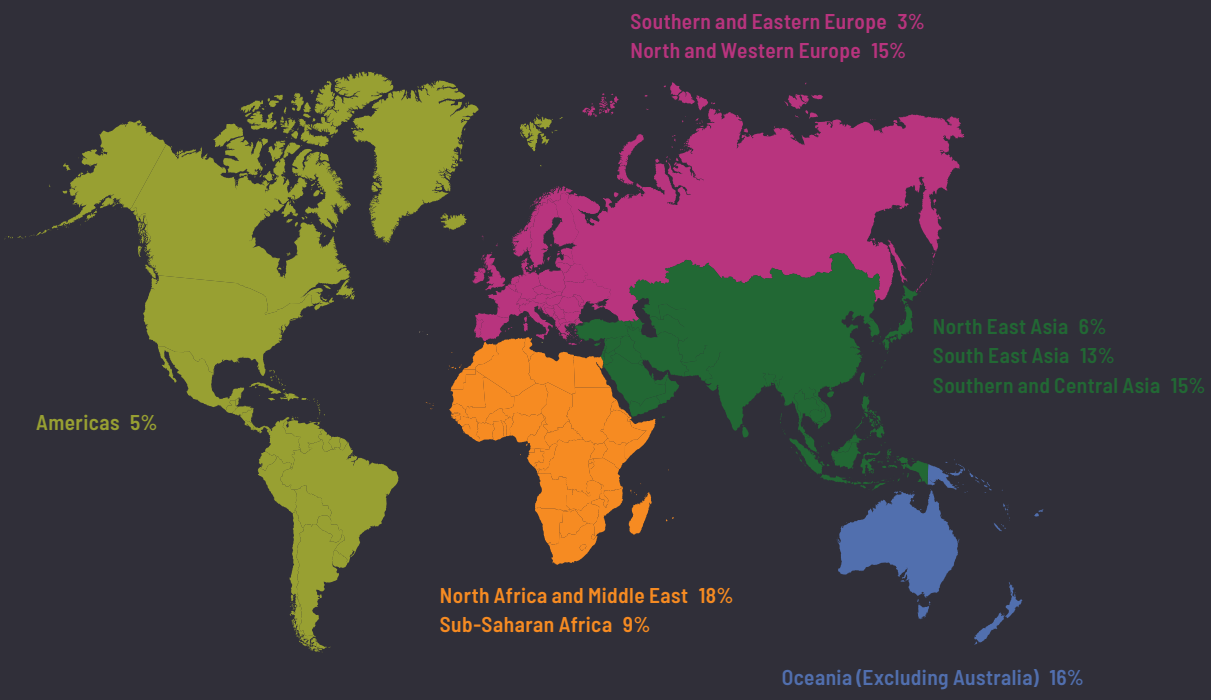


Australia is a large country with varying population densities and accessibility to services. Australians living in rural and remote Australia generally have poorer access to, and use of health services compared with those living in metropolitan areas.[26]

Whilst overall, the majority of children with CP live in major cities, almost 30% live in regional, remote or very remote Australia highlighting the need for high quality, accessible and culturally safe services across Australia.

Children with cerebral palsy born overseas

Figure 3: Percentage of children with CP born overseas included on state/territory CP registers, by region of birth (1995–2016)



A further n=160 children living in NSW/ACT, NT, TAS, QLD and WA were born overseas (location unknown to the CP registers)

An important group of children that are included on the state/territory CP registers were born overseas (1995-2016), n= 906. These children are not otherwise included in this report, however future research is currently being planned for this group.

The majority of children were born in North Africa and Middle East (18%), North and Western Europe (15%) and Oceania (16%).

RESULTS

2

Prenatally and perinatally acquired cerebral palsy

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

Prevalence

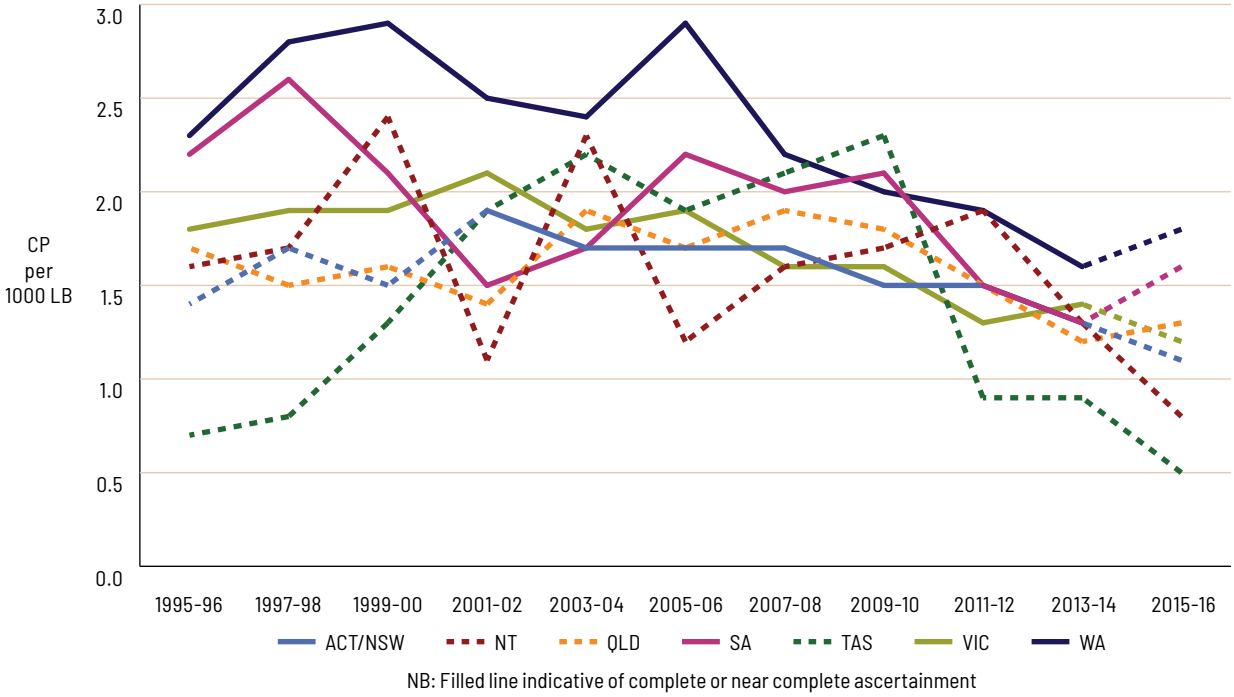
Table 5. CP birth prevalence per 1000 live births (LB) by state/territory of birth and birth period (1995-2016)

	1995-96	1997-98	1999-00	2001-02	2003-04	2005-06	2007-08	2009-10	2011-12	2013-14	2015-16
ACT/NSW											
CP	251	305	283	**337**	**308**	**333**	**343**	**308**	**304**	**263**	230
Rate LB	1.4	1.7	1.5	**1.9**	**1.7**	**1.7**	**1.7**	**1.5**	**1.5**	**1.3**	1.1
NT											
CP	11	12	17	8	16	9	12	13	15	10	6
Rate LB	1.6	1.7	2.4	1.1	2.3	1.2	1.6	1.7	1.9	1.3	0.8
QLD											
CP	160	145	158	134	193	184	227	218	186	152	162
Rate LB	1.7	1.5	1.6	1.4	1.9	1.7	1.9	1.8	1.5	1.2	1.3
SA											
CP	**83**	**95**	**76**	**53**	**58**	**79**	**79**	**82**	**60**	**53**	62
Rate LB	**2.2**	**2.6**	**2.1**	**1.5**	**1.7**	**2.2**	**2.0**	**2.1**	**1.5**	**1.3**	1.6
TAS											
CP	9	10	16	21	24	23	26	29	11	11	6
Rate LB	0.7	0.8	1.3	1.9	2.2	1.9	2.1	2.3	0.9	0.9	0.5
VIC											
CP	**224**	**236**	**234**	**260**	**233**	**251**	**226**	**228**	**201**	**219**	205
Rate LB	**1.8**	**1.9**	**1.9**	**2.1**	**1.8**	**1.9**	**1.6**	**1.6**	**1.3**	**1.4**	1.2
WA											
CP	**117**	**144**	**147**	**122**	**122**	**159**	**133**	**127**	**123**	**112**	126
Rate LB	**2.3**	**2.8**	**2.9**	**2.5**	**2.4**	**2.9**	**2.2**	**2.0**	**1.9**	**1.6**	1.8
TOTAL CP	**855**	**947**	**931**	**935**	**954**	**1038**	**1046**	**1005**	**900**	**820**	**797**
SA, VIC, WA combined											
Rate LB (95%CI)	**2.0 (1.8, 2.2)**	**2.2 (2.1, 2.5)**	**2.2 (2.0, 2.4)**	**2.1 (1.9, 2.3)**	**2.0 (1.8, 2.2)**	**2.2 (2.0, 2.4)**	**1.8 (1.6, 2.0)**	**1.8 (1.6, 1.9)**	**1.5 (1.3, 1.6)**	**1.4 (1.2, 1.5)**	**1.4* (1.3, 1.6)**
ACT/NSW, SA, VIC, WA combined											
Rate LB (95%CI)				**2.0 (1.8, 2.1)**	**1.8 (1.7, 2.0)**	**2.0 (1.8, 2.1)**	**1.8 (1.7, 1.9)**	**1.7 (1.6, 1.8)**	**1.5 (1.4, 1.6)**	**1.4 (1.3, 1.5)**	**1.3* (1.2, 1.4)**

*Provisional estimate

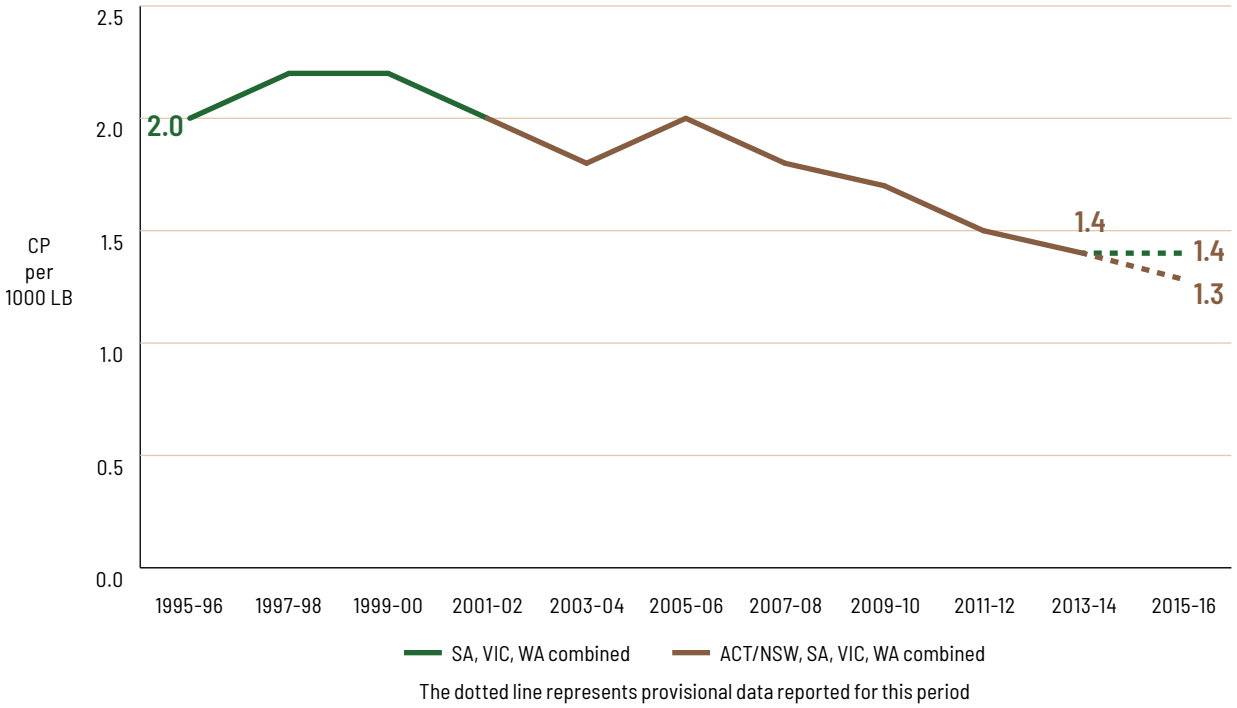
Black text indicative of complete or near complete ascertainment

Figure 4. CP birth prevalence per 1000 live births (LB) by state/territory of birth and birth period (1995-2016)



NB: Filled line indicative of complete or near complete ascertainment

Figure 5. CP birth prevalence per 1000 live births (LB) by combined state/territory of birth and birth period (1995-2016)



The dotted line represents provisional data reported for this period

Prevalence of prenatally and perinatally acquired CP declined from 2.2 (2.1, 2.5) in 1997-98 to 1.4 (1.3, 1.5) in 2013-14. The prevalence reported for the final birth period should be considered provisional due to disruptions caused by the COVID-19 pandemic. The available data does however suggest that the decline noted in 2013-14 has been sustained in 2015-16.

Timing of initial cerebral palsy description

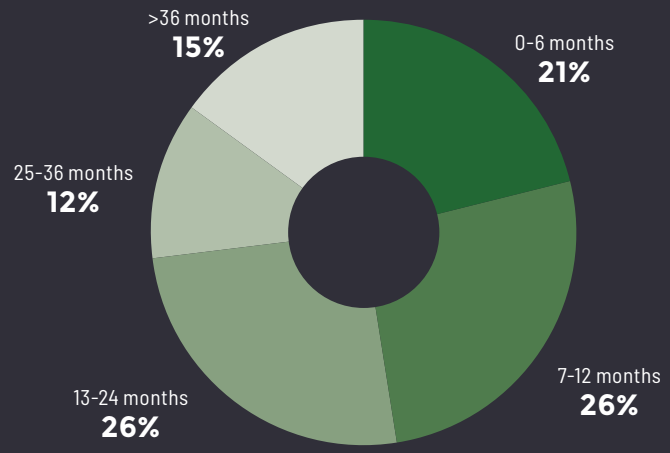
Table 6. Number and percentage of children with CP by timing of initial CP description and state/territory of birth (1995-2016)

	0-6 months n(%)^	7-12 months n(%)^	13-24 months n(%)^	25-36 months n(%)^	37-48 months n(%)^	49-60 months n(%)^	>60 months n(%)^	Total n	Unknown n(%)
ACT/NSW	516 (23.3)	549 (24.8)	619 (27.9)	234 (10.6)	124 (5.6)	62 (2.8)	113 (5.1)	3265	1048 (32.1)
NT	21 (20.8)	27 (26.7)	26 (25.7)	13 (12.9)	◆ (1.0)	7 (6.9)	6 (5.9)	129	28 (21.7)
QLD	310 (22.0)	340 (24.1)	403 (28.5)	156 (11.0)	71 (5.0)	58 (4.1)	74 (5.2)	1919	507 (26.4)
SA	148 (28.3)	140 (26.8)	137 (26.2)	47 (9.0)	31 (5.9)	◆ (0.8)	16 (3.1)	780	257 (32.9)
TAS	27 (17.3)	42 (26.9)	47 (30.1)	15 (9.6)	11 (7.1)	6 (3.8)	8 (5.1)	186	30 (16.1)
VIC	492 (23.3)	487 (23.0)	490 (23.2)	305 (14.4)	108 (5.1)	83 (3.9)	148 (7.0)	2517	404 (16.1)
WA	143 (10.8)	485 (36.6)	297 (22.4)	158 (11.9)	61 (4.6)	118 (8.9)	62 (4.7)	1432	108 (7.5)
TOTAL	**1657 (21.1)**	**2070 (26.4)**	**2019 (25.7)**	**928 (11.8)**	**407 (5.2)**	**338 (4.3)**	**427 (5.4)**	**10,228**	**2382 (23.3)**

◆< 5 children

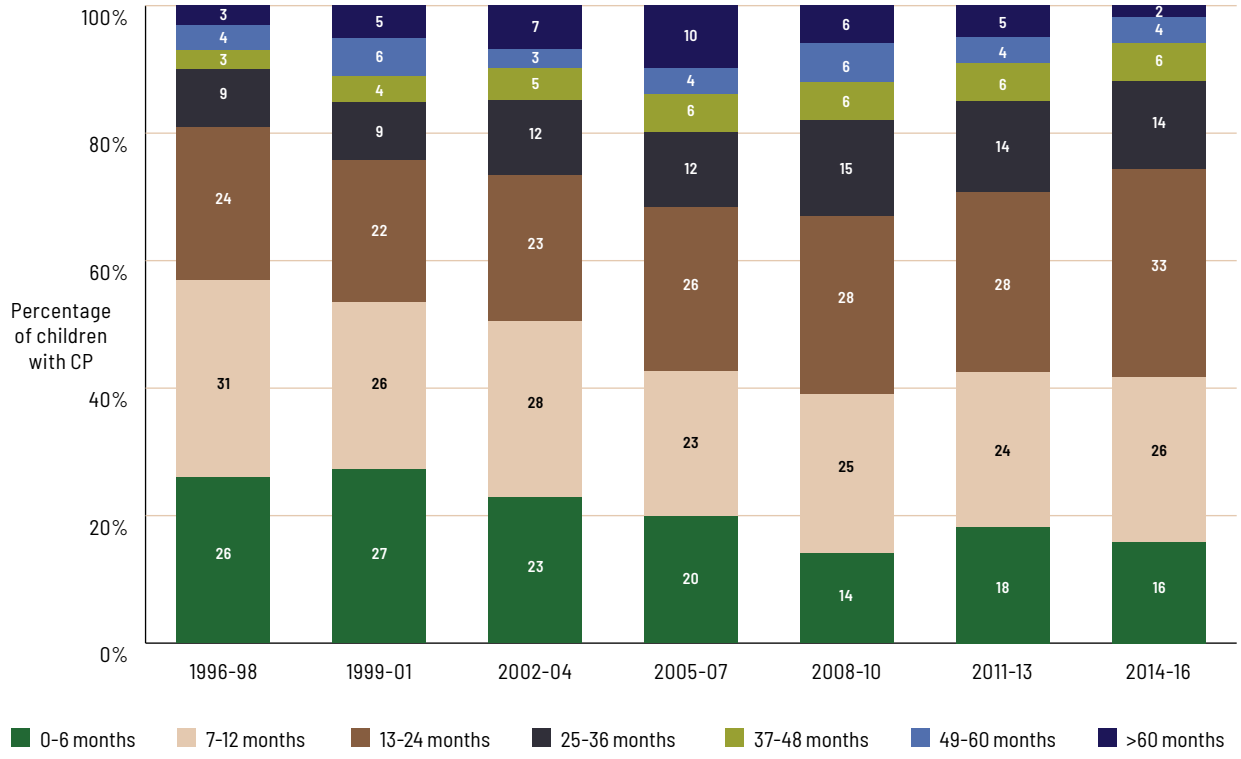
(%)^ calculated by **n/total n** minus **unknown n**; provided to allow state/territory comparisons

Figure 6. Percentage of children with CP by initial CP description interval (1995-2016)



Almost 50% of children born 1995-2016 were described as having CP in the first 12 months of life and almost three quarters by 2 years of age.

Figure 7. Percentage of children with CP by initial CP description interval and birth period (1996-2016)



Please note that there is considerable missing data for this variable. It is not always clear when a definitive diagnosis has been given to a family. The ACPR Group is committed to improving completeness of data for this variable over the coming years.

Sex

Table 7. Number and percentage of children with CP by sex and state/territory of birth (1995-2016)

	Male n (%)	Female n (%)	TOTAL n
ACT/NSW	1891 (57.9)	1374 (42.1)	3265
NT	78 (60.5)	51 (39.5)	129
QLD	1093 (57.0)	826 (43.0)	1919
SA	451 (57.8)	329 (42.2)	780
TAS	112 (60.2)	74 (39.8)	186
VIC	1464 (58.2)	1053 (41.8)	2517
WA	801 (55.9)	631 (44.1)	1432
TOTAL	**5890 (57.6)**	**4338 (42.4)**	**10,228**

Figure 8. Percentage of children with CP by sex (1995-2012)

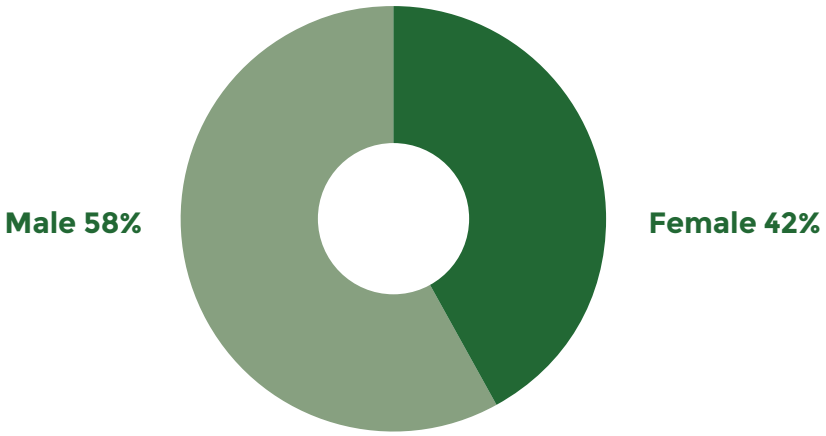
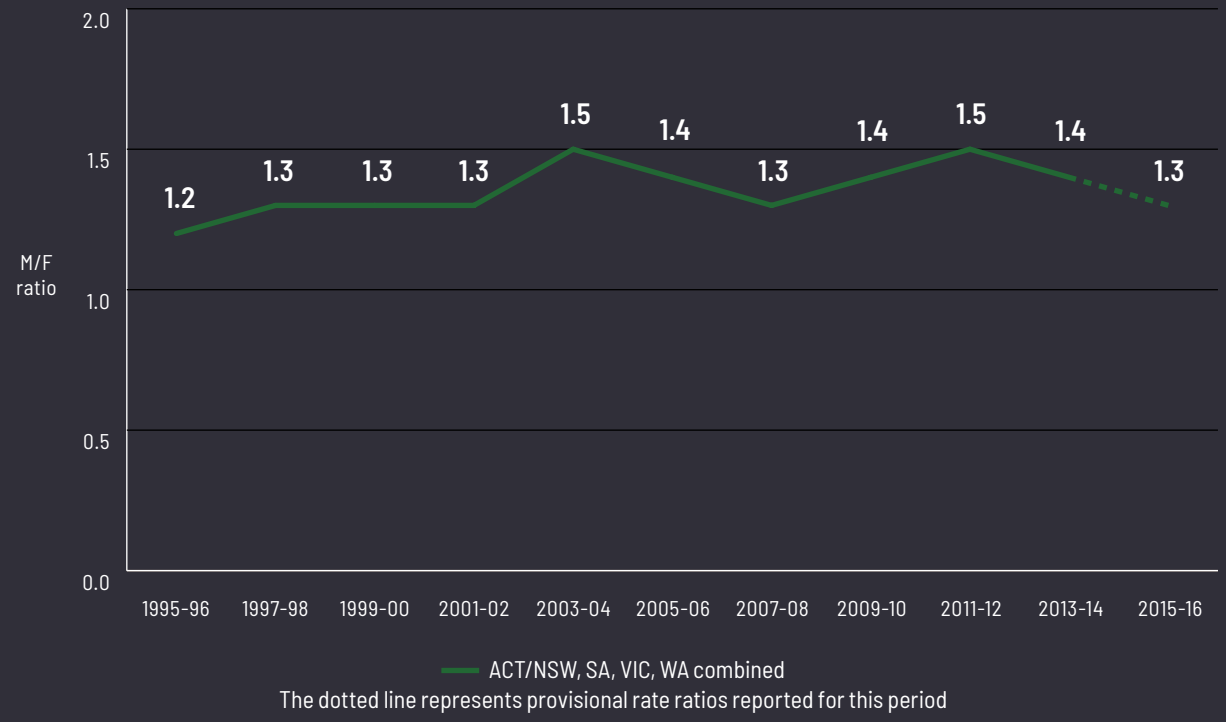


Figure 9. CP male/female sex ratio by birth period (1995-2016)



The dotted line represents provisional rate ratios reported for this period

Males are at higher risk of CP. 58% of this cohort was male compared with 51% of the Australian population.[25]

Maternal age at time of delivery

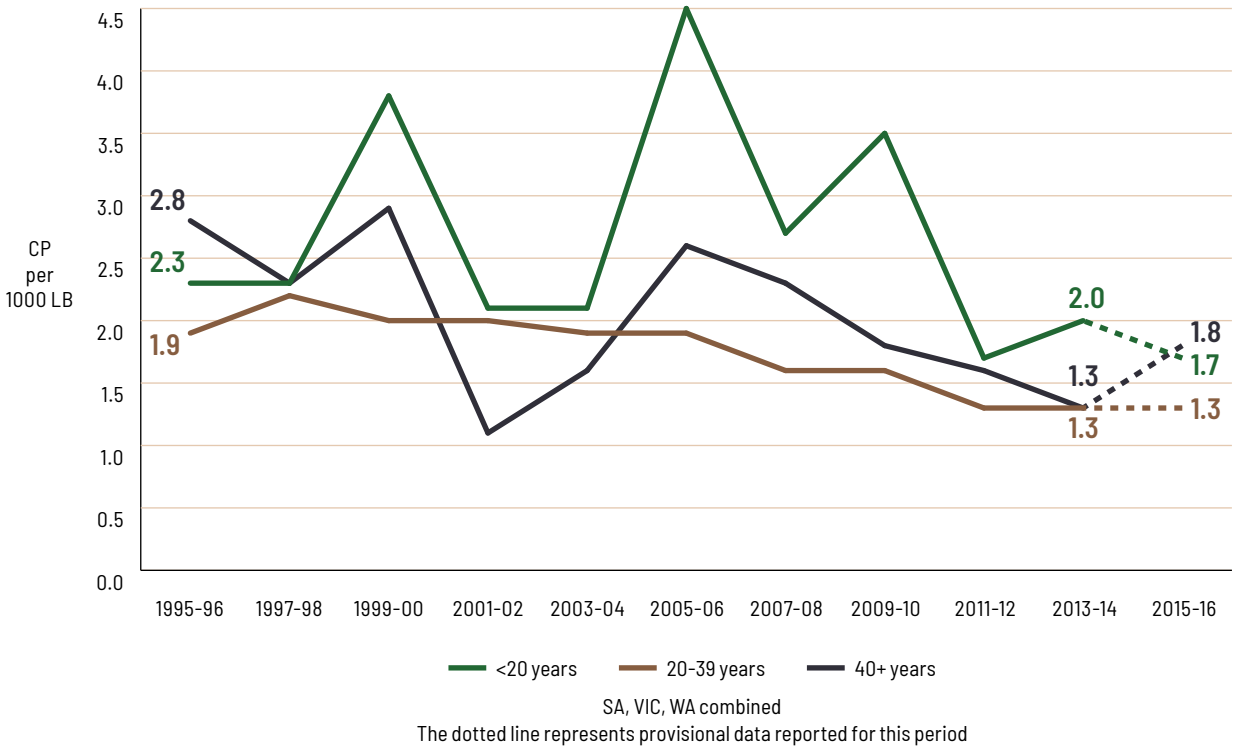
Table 8. Number and percentage of children with CP by maternal age (years) at delivery and state/territory of birth

	<20 n (%)^	20-24 n (%)^	25-29 n (%)^	30-34 n (%)^	35-39 n (%)^	40+ n (%)^	Total n	Unknown n (%)
ACT/NSW	93 (4.9)	281 (14.8)	500 (26.3)	602 (31.7)	331 (17.4)	94 (4.9)	3265	1364 (41.8)
NT	18 (15.1)	23 (19.3)	25 (21.0)	35 (29.4)	12 (10.1)	6 (5.0)	129	10 (7.8)
QLD	51 (3.7)	203 (14.8)	400 (29.2)	425 (31.0)	240 (17.5)	52 (3.8)	1919	548 (28.6)
SA	47 (6.0)	140 (17.9)	214 (27.4)	235 (30.1)	126 (16.2)	18 (2.3)	780	0 (0.0)
TAS	12 (7.1)	34 (20.2)	42 (25.0)	47 (28.0)	26 (15.5)	7 (4.2)	186	18 (9.7)
VIC	98 (4.3)	274 (12.1)	617 (27.2)	758 (33.4)	415 (18.3)	108 (4.8)	2517	247 (9.8)
WA	92 (6.4)	217 (15.2)	416 (29.1)	421 (29.4)	238 (16.6)	47 (3.3)	1432	◆ (0.1)
TOTAL	**411 (5.1)**	**1172 (14.6)**	**2214 (27.5)**	**2523 (31.4)**	**1388 (17.3)**	**332 (4.1)**	**10,228**	**2188 (21.4)**

◆< 5 children

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

Figure 10. CP birth prevalence per 1000 live births (LB) by maternal age (years) at delivery and birth period (1995-2016)



SA, VIC, WA combined

The dotted line represents provisional data reported for this period

Prevalence of CP declined across all maternal age groups. Fluctuations in prevalence of teenage births and births of mothers 40+ years likely reflect the relatively small numbers included in these groups across the 22-year period.

Gestational age at delivery

Table 9. Number and percentage of children with CP by gestational age group (weeks) and state/territory of birth (1995-2016)

	<28 n (%)^	28-31 n (%)^	32-36 n (%)^	37+ n (%)^	Total n	Unknown n (%)
ACT/NSW	304 (11.5)	366 (13.9)	439 (16.6)	1531 (58.0)	3265	625 (19.1)
NT	9 (7.1)	12 (9.5)	27 (21.4)	78 (61.9)	129	◆ (2.3)
QLD	213 (13.3)	266 (16.6)	301 (18.8)	822 (51.3)	1919	317 (16.5)
SA	108 (13.9)	129 (16.5)	131 (16.8)	412 (52.8)	780	0 (0.0)
TAS	17 (9.5)	24 (13.4)	33 (18.4)	105 (58.7)	186	7 (3.8)
VIC	298 (12.1)	345 (14.0)	388 (15.7)	1434 (58.2)	2517	52 (2.1)
WA	145 (10.1)	169 (11.8)	249 (17.4)	867 (60.6)	1432	◆ (0.1)
TOTAL	**1094 (11.9)**	**1311 (14.2)**	**1568 (17.0)**	**5249 (56.9)**	**10,228**	**1006 (9.8)**

◆< 5 children

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

43% of children with CP were born preterm (<37 weeks) during this reporting period. This is in contrast to the Australian population where 8.5% of live births during the period were preterm.[25]

Table 10. Number and CP birth prevalence, children born <28 weeks' gestation per 1000 live births (LB) and neonatal survivors (NNS) by birth state/territory and birth period (1995-2016)

Gestational age group	Year of birth		ACT/NSW	SA	VIC	WA
<28 weeks	**1995-96**	**CP**	**33**	**16**	**31**	**11**
		Rate/LB (95%CI)	51.3 (36.8, 71.2)	80.8 (50.4, 127.2)	61.0 (43.3, 85.3)	53.1 (29.9, 92.6)
		Rate/NNS (95%CI)	88.7 (63.9, 122.0)	141.6 (89.1, 217.7)	108.0 (77.1, 149.2)	85.9 (48.7, 147.3)
	1997-98	**CP**	**40**	**26**	**28**	**17**
		Rate/LB (95%CI)	58.7 (43.4, 79.0)	153.8 (107.2, 215.9)	54.1 (37.3, 77.0)	81.3 (51.4, 126.4)
		Rate/NNS (95%CI)	99.3 (73.7, 132.3)	232.1 (163.6, 318.4)	90.3 (63.2, 127.4)	114.1 (72.5, 175.1)
	1999-00	**CP**	**31**	**8**	**32**	**16**
		Rate/LB (95%CI)	40.5 (28.7, 56.9)	43.2 (22.1, 83.0)	56.4 (40.3, 78.6)	84.7 (52.8, 133.1)
		Rate/NNS (95%CI)	71.8 (51.0, 100.1)	62.5 (32.0, 118.5)	95.5 (68.5, 131.7)	129.0 (81.0, 199.4)
	2001-02	**CP**	**34**	**◆**	**31**	**13**
		Rate/LB (95%CI)	45.6 (32.8, 63.0)	16.0 (5.4, 45.9)	52.9 (37.5, 74.1)	64.0 (37.8, 106.5)
		Rate/NNS (95%CI)	84.3 (60.8, 115.3)	27.0 (9.2, 76.5)	95.7 (68.2, 132.6)	92.2 (54.7, 151.4)
	2003-04	**CP**	**29**	**5**	**26**	**17**
		Rate/LB (95%CI)	40.7 (28.5, 57.8)	28.9 (12.4, 65.9)	41.5 (28.5, 60.2)	81.3 (51.4, 126.4)
		Rate/NNS (95%CI)	74.7 (52.5, 105.3)	43.9 (18.9, 98.6)	75.6 (52.1, 108.4)	109.7 (69.6, 168.6)
	2005-06	**CP**	**38**	**7**	**28**	**15**
		Rate/LB (95%CI)	50.1 (36.7, 68.1)	36.3 (17.7, 73.0)	40.8 (28.4, 58.4)	57.9 (35.4, 93.3)
		Rate/NNS (95%CI)	95.7 (70.5, 128.7)	52.6 (24.7, 104.7)	76.1 (53.2, 107.8)	83.3 (51.1, 132.9)
	2007-08	**CP**	**29**	**10**	**26**	**13**
		Rate/LB (95%CI)	34.0 (23.8, 48.4)	52.1 (28.5, 93.2)	36.7 (25.2, 53.3)	52.8 (31.1, 88.3)
		Rate/NNS (95%CI)	62.4 (44.0, 88.5)	74.6 (41.0, 131.9)	64.8 (44.6, 93.3)	67.7 (40.0, 112.4)
	2009-10	**CP**	**24**	**14**	**31**	**15**
		Rate/LB (95%CI)	29.0 (19.6, 42.8)	74.1 (44.6, 120.5)	46.1 (32.6, 64.6)	52.8 (32.3, 85.3)
		Rate/NNS (95%CI)	53.5 (36.2, 78.3)	96.6 (58.4, 155.5)	83.8 (59.7, 116.5)	69.8 (42.7, 111.9)
	2011-12	**CP**	**19**	**5**	**20**	**6**
		Rate/LB (95%CI)	23.0 (14.8, 35.7)	25.8 (11.1, 58.9)	30.5 (19.9, 46.7)	26.1 (12.0, 55.7)
		Rate/NNS (95%CI)	41.5 (26.7, 63.9)	36.2 (15.6, 82.0)	54.8 (35.7, 83.1)	32.4 (14.9, 68.9)
	2013-14	**CP**	**14**	**5**	**24**	**11**
		Rate/LB (95%CI)	17.7 (10.6, 19.5)	27.2 (11.7, 62.0)	32.5 (21.9, 47.9)	46.6 (26.2, 81.5)
		Rate/NNS (95%CI)	29.7 (17.7, 49.2)	37.9 (16.3, 85.6)	58.3 (39.5, 85.2)	59.1 (33.3, 102.8)
	2015-16	**CP**	**13**	**9**	**21**	**11**
		Rate/LB (95%CI)	16.2 (9.5, 27.5)	48.6 (25.8, 89.9)	31.2 (20.5, 47.2)	43.5 (24.4, 81.5)
		Rate/NNS (95%CI)	27.3 (16.0, 46.1)	63.4 (33.7, 116.6)	49.2 (32.4, 74.0)	57.6 (32.5, 100.2)

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

Black text indicative of complete or near complete ascertainment

Figure 11. CP birth prevalence, children born <28 weeks' gestation per 1000 neonatal survivors (NNS) by birth state/territory and birth period (1995-2016)

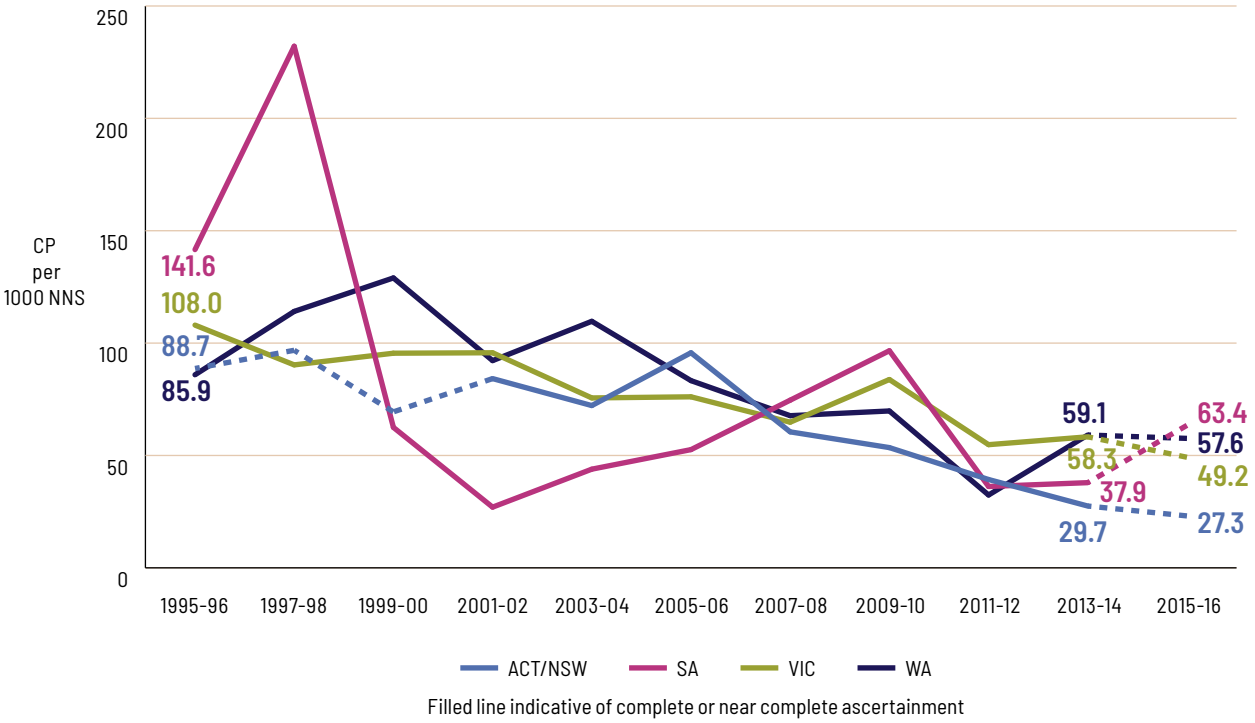


Figure 12. CP birth prevalence, children born <28 weeks' gestation per 1000 live births (LB) and neonatal survivors (NNS) by combined state/territory and birth period (1995-2016)

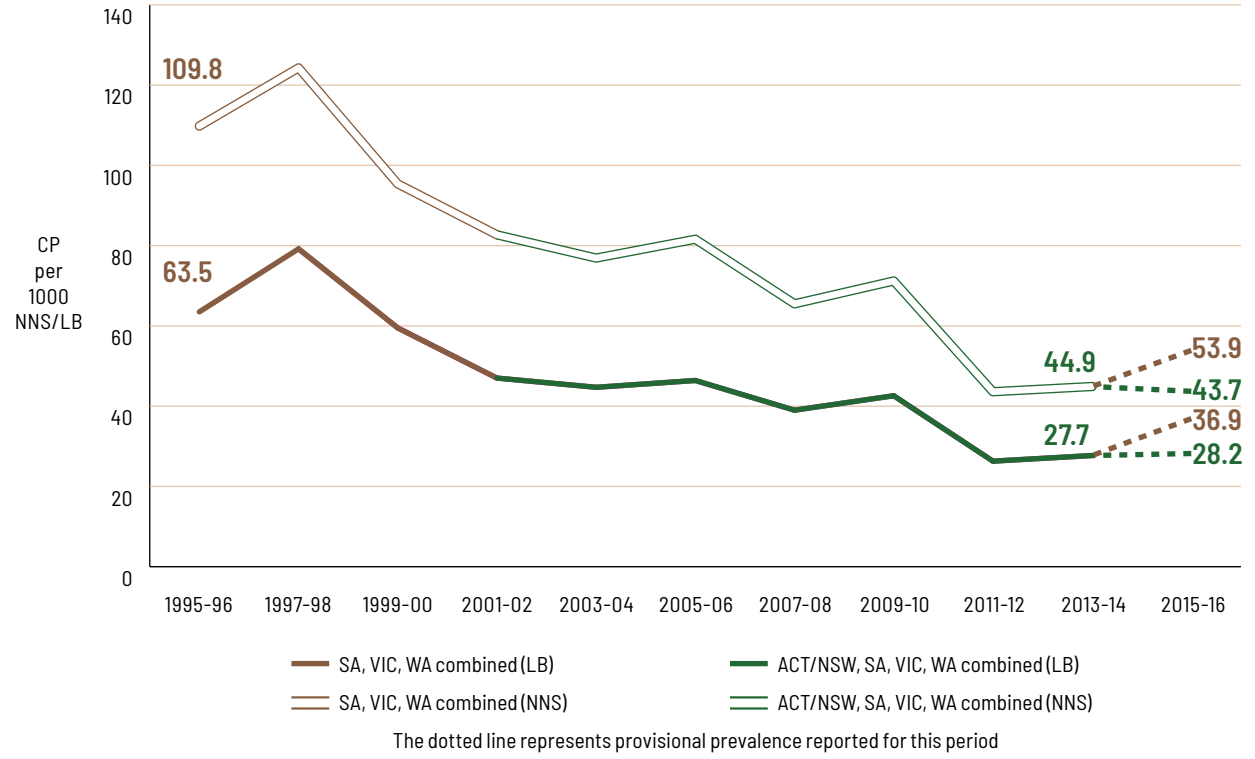


Table 11. Number and CP prevalence, children born 28-31 weeks' gestation per 1000 live births (LB) by state/territory and birth period (1995-2016)

Gestational age group	Year of birth		ACT/NSW	SA	VIC	WA
28-31 weeks	**1995-96**	**CP**	**28**	**19**	**33**	**6**
		Rate/LB (95%CI)	25.6 (17.7, 36.7)	63.8 (41.2, 97.4)	38.4 (27.5, 53.5)	18.9 (8.7, 40.7)
	1997-98	**CP**	**34**	**12**	**28**	**21**
		Rate/LB (95%CI)	28.8 (20.7, 40.0)	41.1 (23.7, 70.4)	30.9 (21.4, 44.3)	54.7 (36.0, 82.2)
	1999-00	**CP**	**24**	**19**	**37**	**18**
		Rate/LB (95%CI)	19.2 (12.9, 28.4)	57.6 (37.2, 88.2)	42.7 (31.2, 58.3)	45.3 (28.9, 70.5)
	2001-02	**CP**	**32**	**5**	**39**	**13**
		Rate/LB (95%CI)	25.0 (17.7, 35.0)	16.9 (7.3, 39.1)	42.3 (31.1, 57.3)	36.9 (21.7, 62.2)
	2003-04	**CP**	**33**	**8**	**26**	**15**
		Rate/LB (95%CI)	26.0 (18.5, 36.2)	28.8 (14.7, 55.7)	31.0 (21.1, 45.0)	39.7 (24.2, 64.4)
	2005-06	**CP**	**44**	**15**	**29**	**14**
		Rate/LB (95%CI)	32.8 (24.5, 43.7)	46.9 (28.6, 75.9)	29.8 (20.9, 42.5)	32.9 (19.7, 54.4)
	2007-08	**CP**	**38**	**16**	**31**	**27**
		Rate/LB (95%CI)	28.5 (20.8, 38.8)	53.0 (32.9, 84.3)	30.1 (21.3, 42.4)	56.0 (38.8, 80.3)
	2009-10	**CP**	**43**	**10**	**44**	**19**
		Rate/LB (95%CI)	32.6 (24.3, 43.7)	30.6 (16.7, 55.4)	39.0 (29.2, 52.0)	43.1 (27.8, 66.3)
	2011-12	**CP**	**41**	**5**	**32**	**15**
		Rate/LB (95%CI)	29.8 (22.0, 40.2)	15.2 (6.5, 35.1)	31.0 (22.1, 43.5)	31.5 (19.2, 51.3)
	2013-14	**CP**	**24**	**9**	**25**	**16**
		Rate/LB (95%CI)	17.7 (11.9, 26.2)	26.9 (14.2, 50.3)	21.8 (14.8, 31.9)	32.1 (19.9, 51.5)
	2015-16	**CP**	**25**	**11**	**21**	**5**
		Rate/LB (95%CI)	19.3 (13.1, 28.3)	34.3 (19.2, 60.3)	19.4 (12.7, 29.4)	10.4 (4.4, 24.1)

Black text indicative of complete or near complete ascertainment

Figure 13. CP birth prevalence, children born 28-31 weeks' gestation per 1000 live births (LB) by birth state/territory and birth period (1995-2016)

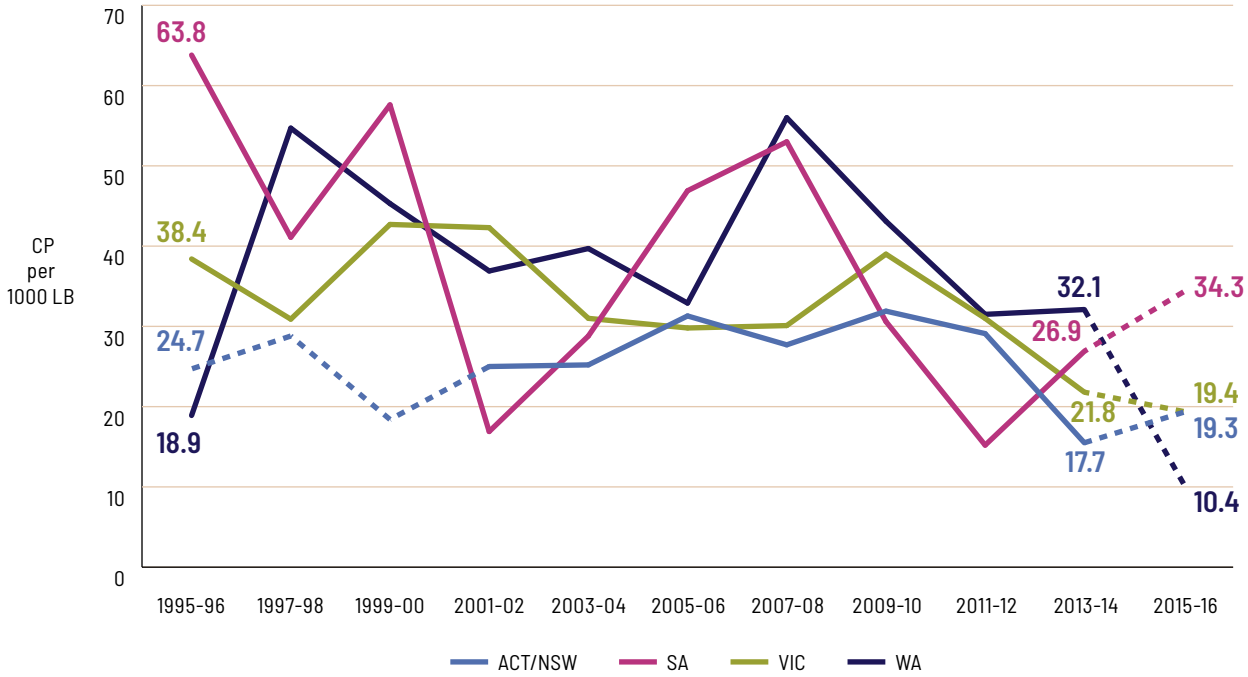


Figure 14. CP birth prevalence, children born 28-31 weeks' gestation per 1000 live births (LB) by combined birth state/territory and birth period (1995-2016)

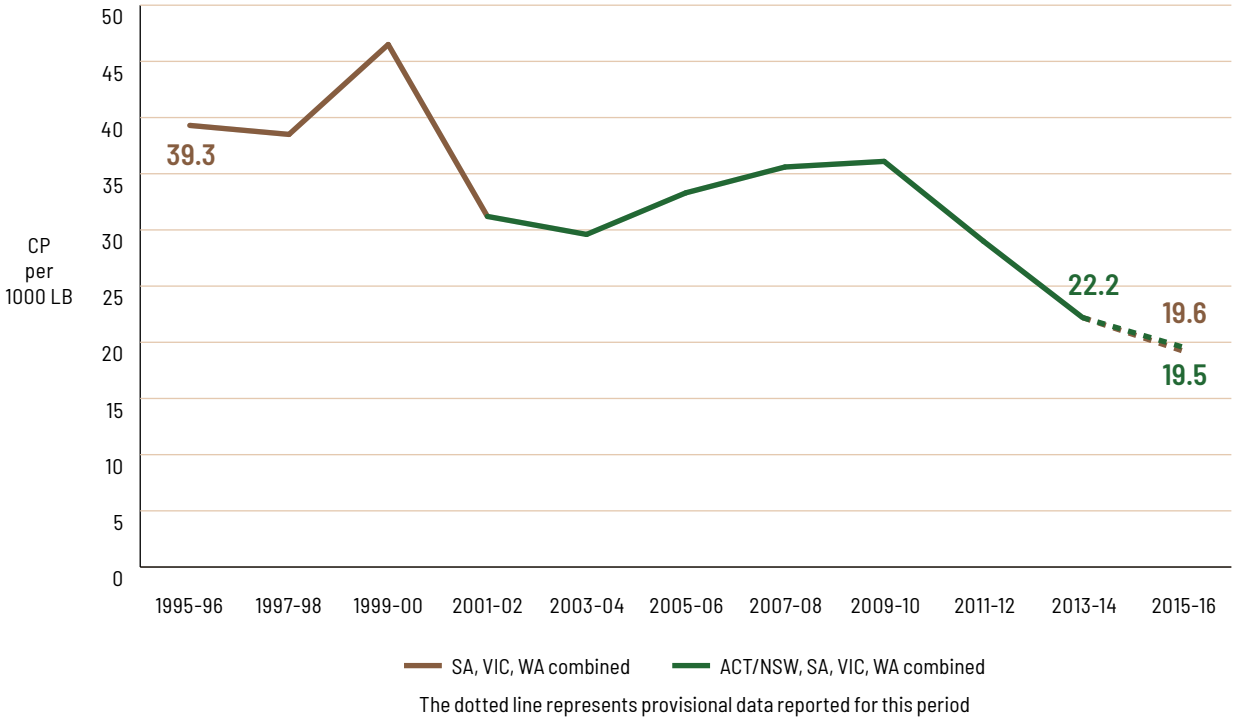


Table 12. Number and CP birth prevalence, children born 32-36 weeks' gestation per 1000 live births (LB) by birth state/territory and birth period (1995-2016)

Gestational age group	Year of birth		ACT/NSW	SA	VIC	WA
32-36 weeks	**1995-96**	**CP**	**21**	**13**	**30**	**15**
		Rate/LB (95%CI)	2.2 (1.4, 3.4)	5.5 (3.2, 9.4)	4.2 (2.9, 6.0)	5.2 (3.2, 8.6)
	1997-98	**CP**	**26**	**17**	**29**	**18**
		Rate/LB (95%CI)	2.6 (1.8, 3.8)	7.4 (4.6, 11.9)	4.1 (2.9, 5.9)	6.0 (3.8, 9.5)
	1999-00	**CP**	**48**	**16**	**26**	**20**
		Rate/LB (95%CI)	4.6 (3.4, 6.0)	6.8 (4.2, 11.0)	3.5 (2.4, 5.1)	6.3 (4.1, 9.6)
	2001-02	**CP**	**40**	**11**	**43**	**16**
		Rate/LB (95%CI)	3.9 (2.9, 5.3)	4.9 (2.7, 8.8)	5.7 (4.3, 7.7)	4.9 (3.0, 8.0)
	2003-04	**CP**	**48**	**7**	**38**	**23**
		Rate/LB (95%CI)	4.7 (3.5, 6.2)	2.9 (1.4, 6.0)	4.9 (3.6, 6.7)	6.8 (4.5, 10.2)
	2005-06	**CP**	**41**	**9**	**37**	**35**
		Rate/LB (95%CI)	3.6 (2.7, 4.9)	3.7 (1.9, 7.0)	4.4 (3.2, 6.1)	9.0 (6.4, 12.4)
	2007-08	**CP**	**48**	**10**	**36**	**23**
		Rate/LB (95%CI)	4.0 (3.0, 5.3)	3.8 (2.0, 6.9)	3.9 (2.8, 5.4)	5.6 (3.7, 8.3)
	2009-10	**CP**	**40**	**19**	**39**	**24**
		Rate/LB (95%CI)	3.3 (2.4, 4.5)	6.7 (4.3, 10.5)	4.2 (3.1, 5.7)	5.6 (3.8, 8.3)
	2011-12	**CP**	**44**	**9**	**38**	**23**
		Rate/LB (95%CI)	3.5 (2.6, 4.6)	2.9 (1.6, 5.6)	3.9 (2.8, 5.3)	4.9 (3.3, 7.4)
	2013-14	**CP**	**48**	**11**	**40**	**26**
		Rate/LB (95%CI)	3.7 (2.8, 4.9)	3.5 (2.0, 6.3)	3.8 (2.8, 5.2)	5.0 (3.4, 7.4)
	2015-16	**CP**	**35**	**9**	**32**	**26**
		Rate/LB (95%CI)	2.7 (2.0, 3.8)	2.9 (1.5, 5.5)	2.9 (2.1, 4.1)	5.1 (3.5, 7.4)

Black text indicative of complete or near complete ascertainment

Figure 15. CP birth prevalence, children born 32-36 weeks' gestation per 1000 live births (LB) by birth state/territory and birth period (1995-2016)

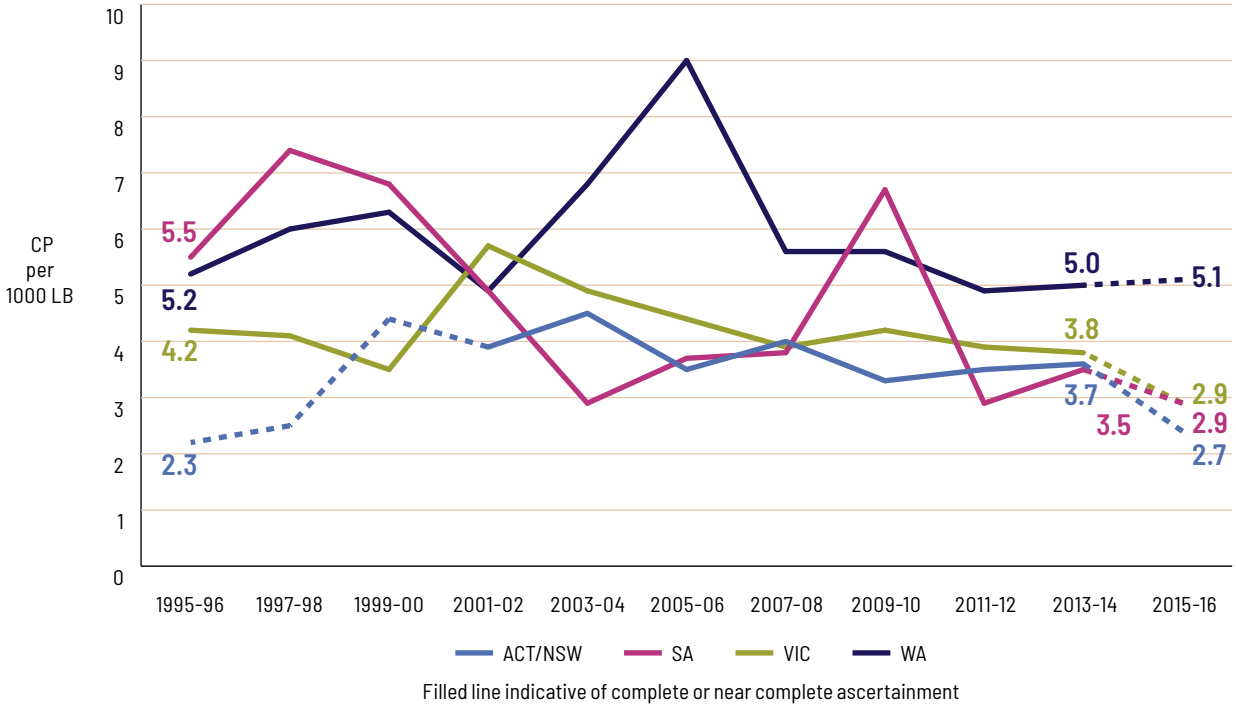


Figure 16. CP birth prevalence, children born 32-36 weeks' gestation per 1000 live births (LB) by combined birth state/territory and birth period (1995-2016)

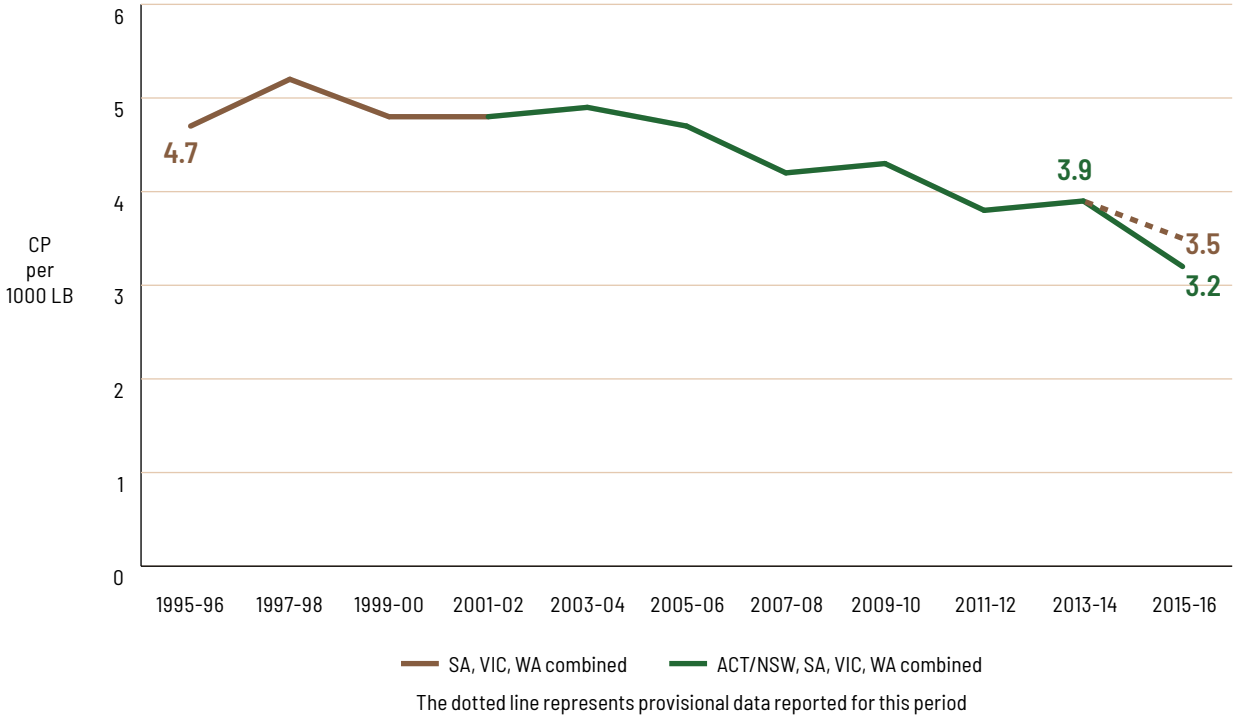


Table 13. Number and CP birth prevalence, children born 37+ weeks' gestation per 1000 live births (LB) by birth state/territory and birth period (1995-2016)

Gestational age group	Year of birth		ACT/NSW	SA	VIC	WA
37+ weeks	**1995-96**	**CP**	**86**	**35**	**128**	**84**
		Rate/LB (95%CI)	0.5 (0.4, 0.6)	1.0 (0.7, 1.4)	1.1 (0.9, 1.3)	1.8 (1.4, 2.2)
	1997-98	**CP**	**131**	**40**	**146**	**88**
		Rate/LB (95%CI)	0.8 (0.6, 0.9)	1.2 (0.8, 1.5)	1.3 (1.1, 1.5)	1.9 (1.5, 2.3)
	1999-00	**CP**	**132**	**33**	**134**	**93**
		Rate/LB (95%CI)	0.8 (0.6, 0.9)	1.0 (0,7, 1.4)	1.2 (1.0, 1.4)	2.0 (1.6, 2.4)
	2001-02	**CP**	**161**	**34**	**142**	**80**
		Rate/LB (95%CI)	1.0 (0.8, 1.1)	1.0 (0.7, 1.5)	1.2 (1.0, 1.4)	1.8 (1.4, 2.2)
	2003-04	**CP**	**136**	**38**	**139**	**67**
		Rate/LB (95%CI)	0.8 (0.7, 0.9)	1.2 (0.8, 1.6)	1.2 (1.0, 1.4)	1.5 (1.1, 1.8)
	2005-06	**CP**	**155**	**48**	**154**	**95**
		Rate/LB (95%CI)	0.9 (0.7, 1.0)	1.4 (1.1, 1.8)	1.2 (1.0, 1.4)	1.9 (1.5, 2.3)
	2007-08	**CP**	**179**	**43**	**128**	**70**
		Rate/LB (95%CI)	1.0 (0.8, 1.1)	1.2 (0.9, 1.6)	1.0 (0.8, 1.1)	1.3 (1.0, 1.6)
	2009-10	**CP**	**162**	**39**	**111**	**69**
		Rate/LB (95%CI)	0.9 (0.7, 1.0)	1.1 (0.8, 1.5)	0.8 (0.7, 1,0)	1.2 (0.9, 1.5)
	2011-12	**CP**	**152**	**41**	**102**	**79**
		Rate/LB (95%CI)	0.8 (0.7, 0.9)	1.1 (0.8, 1.5)	0.7 (0.6, 0.9)	1.3 (1.0, 1.6)
	2013-14	**CP**	**137**	**28**	**126**	**59**
		Rate/LB (95%CI)	0.7 (0.6, 0.8)	0.8 (0.5, 1.1)	0.9 (0.7, 1.0)	0.9 (0.7, 1.2)
	2015-16	**CP**	**100**	**33**	**124**	**83**
		Rate/LB (95%CI)	0.5 (0.4, 0.6)	0.9 (0.6, 1.2)	0.8 (0.7, 1.0)	1.3 (1.0, 1.6)

Black text indicative of complete or near complete ascertainment

Figure 17. CP birth prevalence, children born 37+ weeks' gestation per 1000 live births (LB) by birth state/territory and birth period (1995-2016)

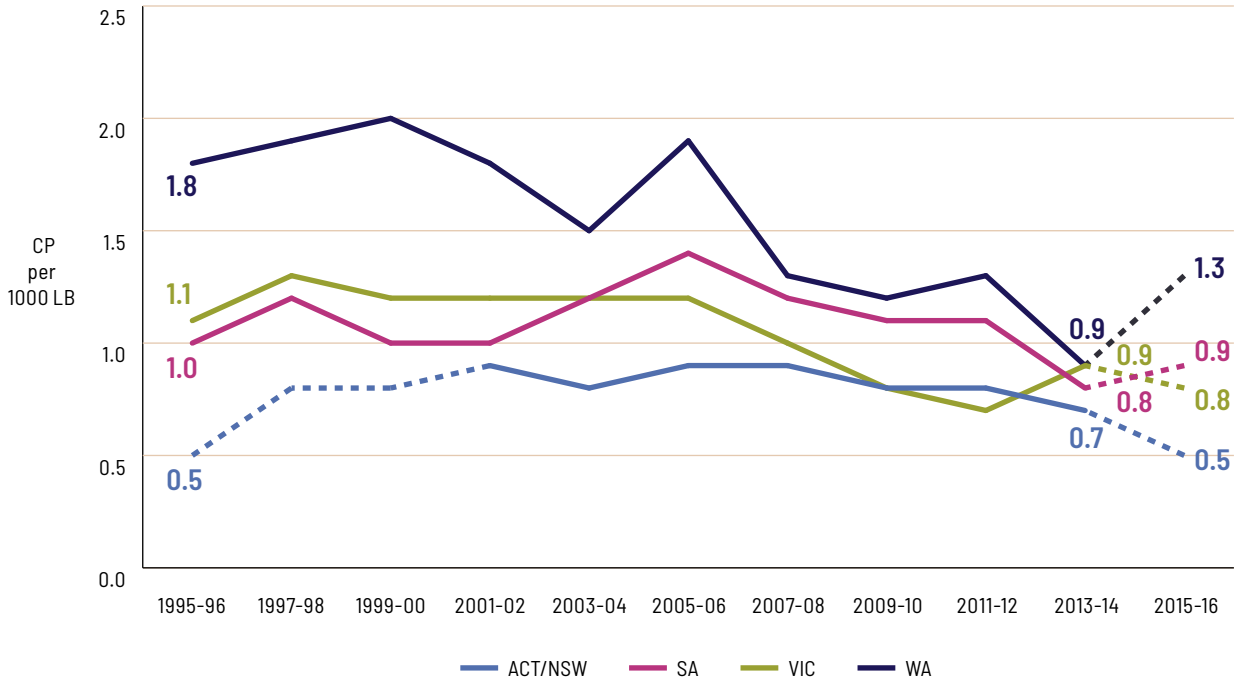
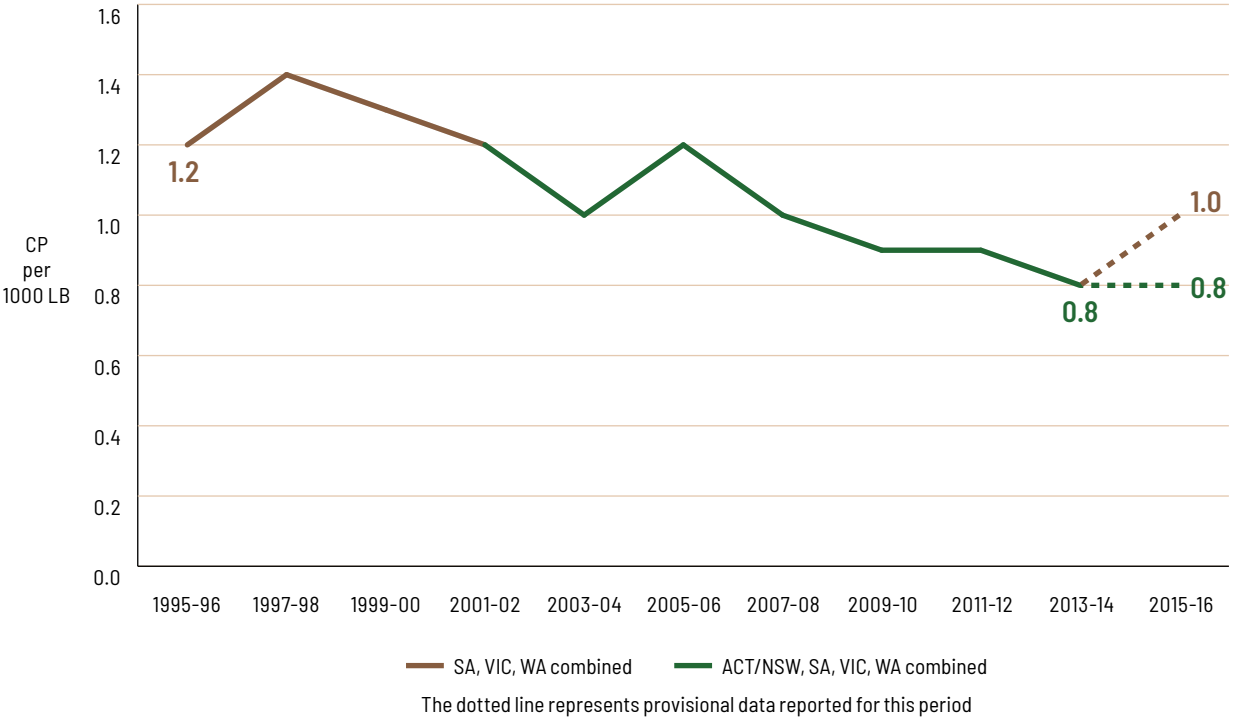


Figure 18. CP birth prevalence, children born 37+ weeks' gestation per 1000 live births (LB) by combined birth state/territory and birth period (1995-2016)



Birth weight

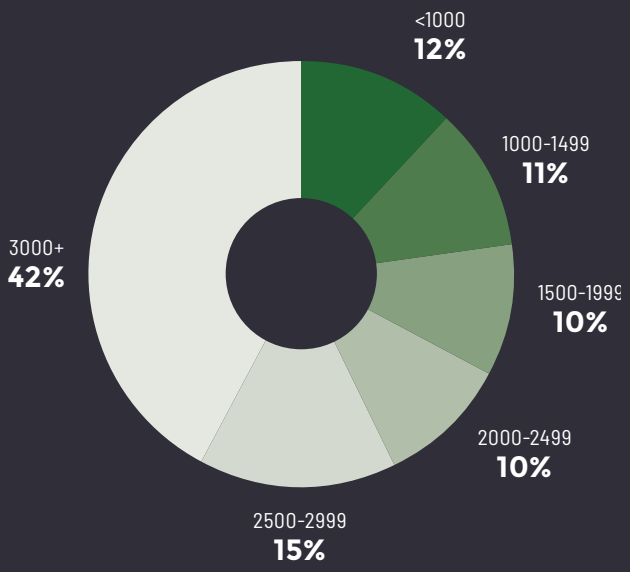
Table 14. Number and percentage of children with CP by birthweight group (grams) and state/territory of birth (1995-2016)

	<1000 n (%)^	1000-1499 n (%)^	1500-1999 n (%)^	2000-2499 n (%)^
ACT/NSW	250 (11.0)	273 (12.0)	219 (9.6)	231 (10.1)
NT	9 (7.3)	9 (7.3)	9 (7.3)	15 12.2)
QLD	188 (12.5)	194 (12.9)	163 (10.8)	173 (11.5)
SA	108 (13.8)	91 (11.7)	79 (10.1)	74 (9.5)
TAS	12 (7.2)	21 (12.6)	15 (9.0)	11 (6.6)
VIC	286 (12.4)	258 (11.2)	249 (10.8)	222 (9.6)
WA	133 (9.3)	130 (9.1)	124 (8.7)	138 (9.6)
TOTAL	**986 (11.5)**	**976 (11.4)**	**858 (10.0)**	**864 (10.1)**

◆< 5 children

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

Figure 19. Percentage of children with CP by birth weight group (grams) (1995-2012)

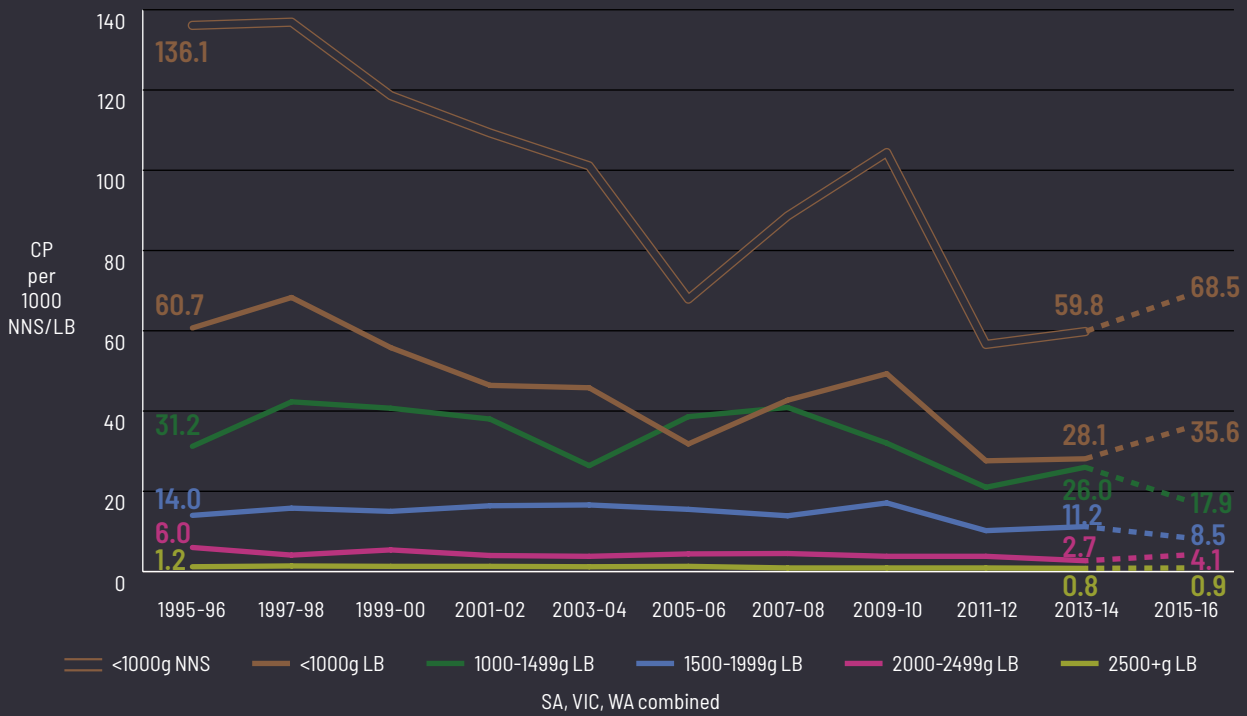


43% of children with CP were born with low birth weight compared to 6.5% of the Australian population; 22% were born with a very low birth weight compared to 1% and 11% had an extremely low birth weight compared to 0.5% of the Australian population.[25]

Low birth weight is defined as <2500g, very low birth weight <1500g and extremely low birth weight <1000g.

2500-2999 n (%)^	3000-3499 n (%)^	3500-3999 n (%)^	4000+ n (%)^	Total n	Unknown n (%)
332 (14.6)	494 (21.7)	340 (14.9)	138 (6.1)	3265	988 (30.3)
20 (16.3)	38 (30.9)	18 (14.6)	5 (4.1)	129	6 (4.7)
214 (14.2)	293 (19.4)	192 (12.7)	90 (6.0)	1919	412 (21.5)
107 (13.7)	161 (20.6)	105 (13.5)	55 (7.1)	780	0 (0.0)
32 (19.2)	46 (27.5)	17 (10.2)	13 (7.8)	186	19 (10.2)
359 (15.6)	456 (19.8)	335 (14.6)	137 (6.0)	2517	215 (8.5)
255 (17.8)	357 (24.9)	213 (14.9)	81 (5.7)	1432	◆ (0.1)
1319 (15.4)	**1845 (21.5)**	**1220 (14.2)**	**519 (6.0)**	**10,228**	**1641 (16.0)**

Figure 20. CP birth prevalence per 1000 live births (LB) and neonatal survivors (NNS) by birth weight group (grams) and birth period (1995-2016)



SA, VIC, WA combined

The dotted line represents provisional data reported for this period

Prevalence of CP declined overall across all birthweight groups. Provisional data suggests that between 2011-12 and 2015-16 prevalence increased amongst children born <1000g.

Plurality

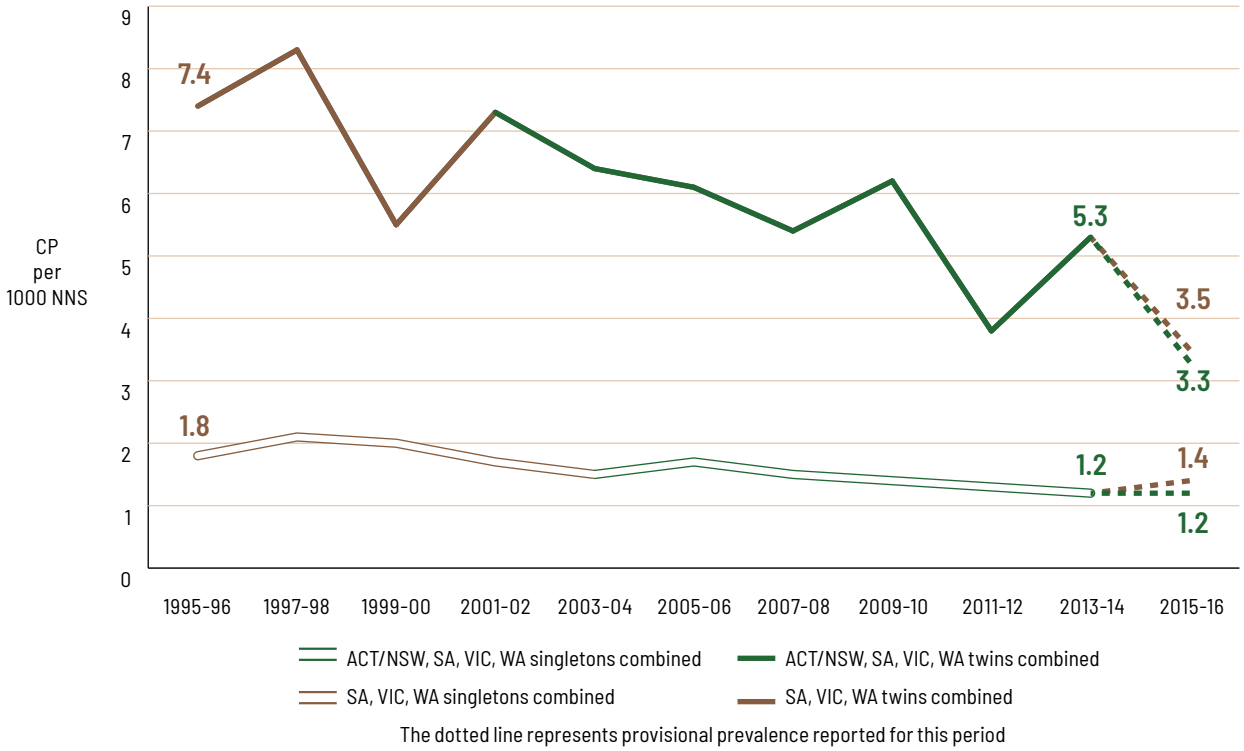
Table 15. Number and percentage of children with CP by birth plurality and state/territory of birth (1995-2016)

	Singletons n (%)^	Twins n (%)^	Higher order multiples n (%)^	Total n	Unknown n (%)
ACT/NSW	2415 (88.0)	306 (11.1)	24 (0.9)	3265	520 (15.9)
NT	106 (92.2)	9 (7.8)	0 (0.0)	129	14 (10.9)
QLD	1297 (85.2)	211 (13.9)	15 (1.0)	1919	396 (20.6)
SA	704 (90.2)	72 (9.2)	◆ (0.5)	780	0 (0.0)
TAS	153 (86.4)	19 (10.7)	5 (2.8)	186	9 (4.8)
VIC	2209 (88.7)	261 (10.5)	21 (0.8)	2517	26 (1.0)
WA	1291 (90.2)	132 (9.2)	9 (0.6)	1432	0 (0.0)
TOTAL	**8175 (88.3)**	**1010 (10.9)**	**78 (0.8)**	**10,228**	**965 (9.4)**

◆< 5 children

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

Figure 21. CP birth prevalence per 1000 neonatal survivors (NNS) by plurality and birth period (1995-2016)



The prevalence of CP declined amongst both singletons and twins.

In a recent study, the ACPR Group reported declines in CP birth prevalence of singletons (1995-2014). These declines were evident across all gestational age groups along with declines in birth prevalence of moderate-severe disability for children with CP born <28 and 37+ weeks.[21]

Due to the small frequency of triplets and quadruplets, it is difficult to study CP in these sub-groups. The ACPR Group and Surveillance of Cerebral Palsy Europe recently collaborated to pool de-identified data to examine risk and trends in prevalence of CP amongst higher order multiple births. The subsequent paper reported that the prevalence of CP among twins significantly declined in Europe and Australia; triplets and quadruplets had an increased risk of CP compared to twins due to their higher risk of preterm birth.[27]

Congenital anomalies

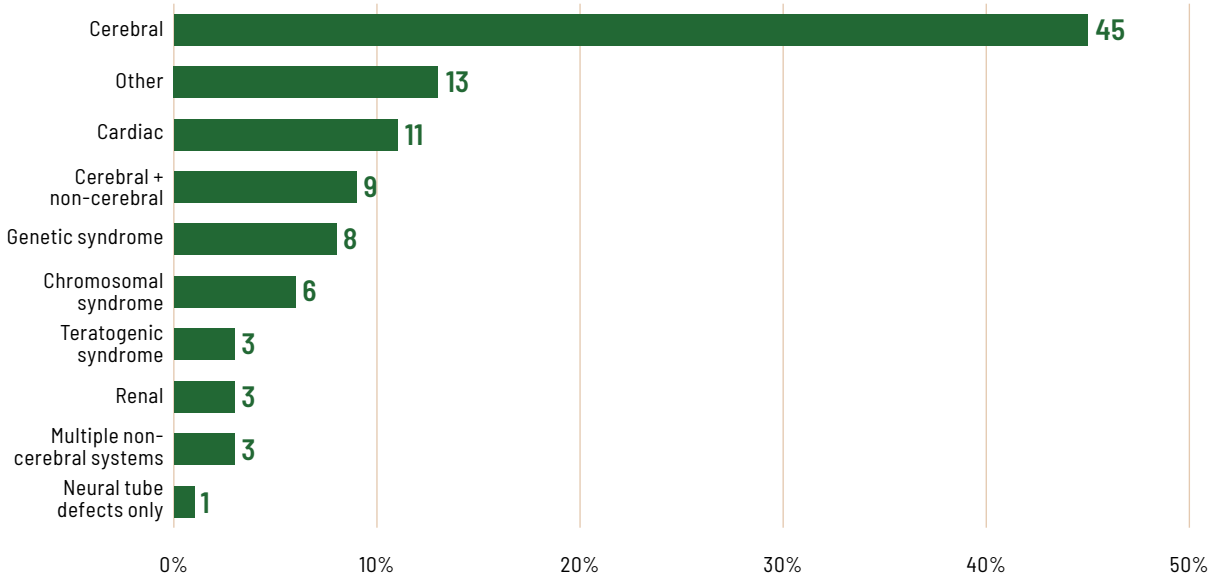
The ACPR is undertaking a suite of collaborative research projects focused on congenital anomalies, known as the *Comprehensive investigation of congenital anomalies in cerebral palsy (Comprehensive CA-CP Study)*.[28] In partnership with the Surveillance of Cerebral Palsy in Europe (SCPE) and EUROCAT, this data linkage study pooled data from CP and congenital anomaly registers in nine regions of Australia (South Australia, Victoria and Western Australia) and Europe, for children born 1991-2009. The dataset created is the largest of its kind to date, which is enabling better understanding of the co-occurrence of congenital anomalies, which are often individually rare conditions, in children with CP.

22.8%
(95% CI 21.9, 23.8)

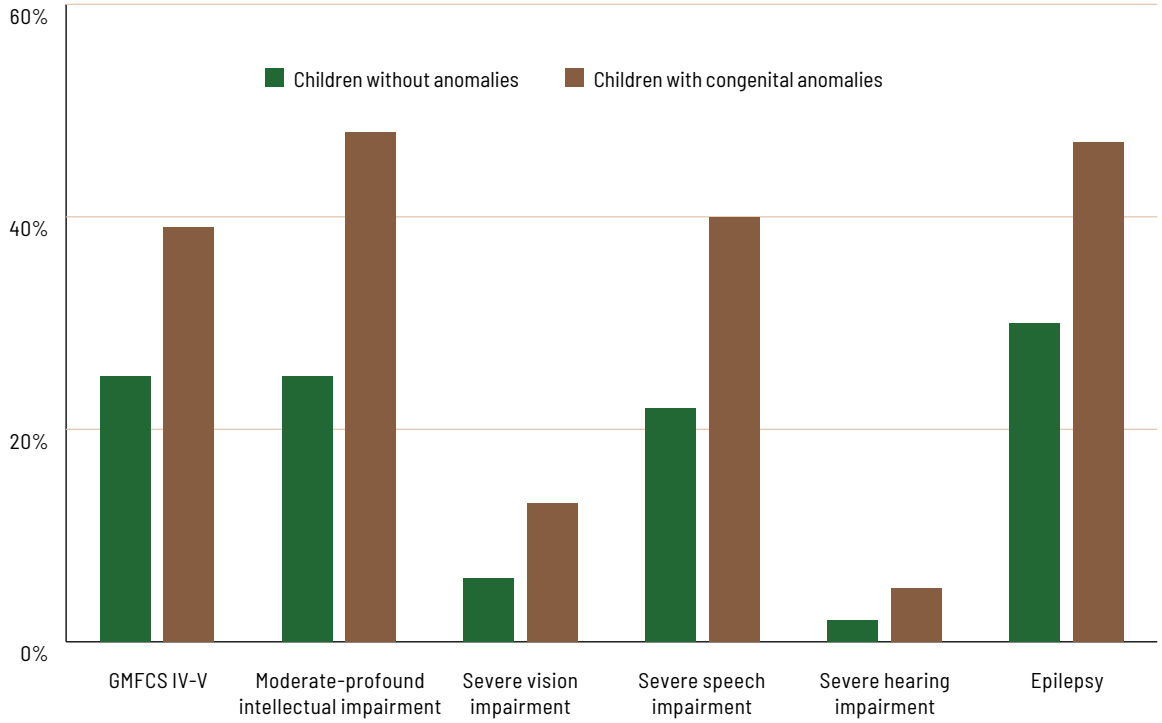
The Comprehensive CA-CP Study found that major congenital anomalies are present in 22.8% (95% CI 21.9, 23.8) of children with pre/perinatally acquired CP.[29]

Children with congenital anomalies were classified by type and aetiology of congenital anomalies. The largest group of children (45.2%) had isolated cerebral anomalies, with another 8.6% having both cerebral and non-cerebral anomalies. For 1 in 6 children, their congenital anomaly was associated with a chromosomal/genetic (13.6%) or teratogenic syndrome (3.0%).

Classification of children with major congenital anomalies, Europe and Australia 1991-2009



Clinical profile for children with and without major congenital anomalies, Europe and Australia 1991-2009



Overall, children with major congenital anomalies had a more severe clinical profile than children without anomalies, particularly in children with cerebral, chromosomal/genetic or teratogenic syndromes.

The prevalence of specific congenital anomalies, by body system (cerebral, cardiac etc) and by individual anomaly has been published.[29]

Motor type and topography

Table 16. Number and percentage of children with CP by predominant motor type and spastic topography and state/territory of birth (1995-2016)

	Spastic n (%)^	*Unilateral spastic CP*	*Bilateral spastic CP*	
		Hemiplegia/monoplegia n (%)	*Spastic diplegia n (%)*	*Spastic triplegia n (%)*
ACT/NSW	2532 (81.2)	*1097 (43.3)*	*803 (31.7)*	*38 (1.5)*
NT	82 (79.6)	*33 (40.2)*	*23 (28.0)*	*0 (0.0)*
QLD	1283 (85.6)	*472 (36.8)*	*508 (39.6)*	*22 (1.7)*
SA	723 (93.3)	*322 (44.5)*	*248 (34.3)*	*14 (1.9)*
TAS	143 (88.8)	*48 (33.6)*	*72 (50.3)*	◆ *(2.8)*
VIC	2067 (83.6)	*859 (41.6)*	*671 (32.5)*	*59 (2.9)*
WA	1160 (81.1)	*437 (37.7)*	*555 (47.8)*	*17 (2.5)*
TOTAL	**7990 (83.6)**	***3268 (40.9)***	***2880 (36.0)***	***154 (1.9)***

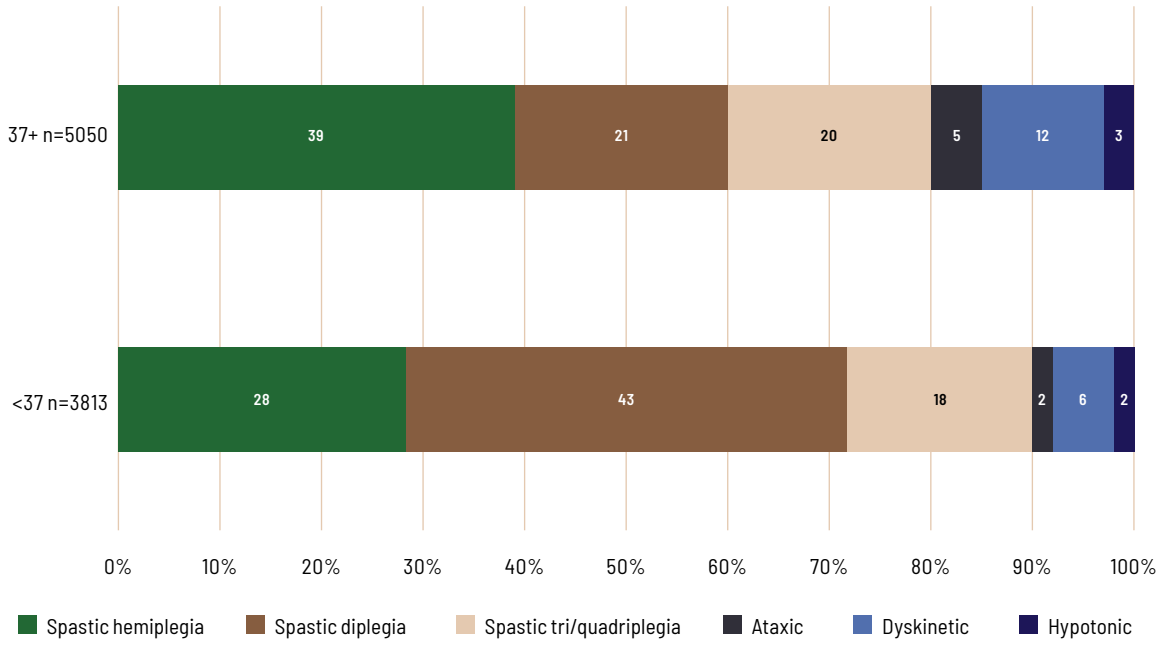
◆< 5 children

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

Spastic hemiplegia is the most common topographical pattern of spasticity, however if diplegia, triplegia and quadriplegia are grouped as bilateral spastic CP this group would be predominant.

	Ataxic n (%)^	Dyskinetic n (%)^	Hypotonic n (%)^	Total n	Unknown n (%)
Spastic quadriplegia n (%)					
594 (23.5)	158 (5.1)	356 (11.4)	72 (2.3)	3265	147 (4.5)
26 (31.7)	6 (5.8)	10 (9.7)	5 (4.9)	129	26 (20.2)
281 (21.9)	54 (3.6)	113 (7.5)	49 (3.3)	1919	420 (21.9)
139 (19.2)	23 (3.0)	23 (3.0)	6 (0.8)	780	5 (0.6)
19 (13.3)	6 (3.7)	12 (7.5)	0 (0.0)	186	25 (13.4)
478 (23.1)	62 (2.5)	229 (9.3)	114 (4.6)	2517	45 (1.8)
151 (13.0)	87 (6.1)	161 (11.3)	23 (1.6)	1432	◆ (0.1)
1688 (21.1)	**396 (4.1)**	**904 (9.5)**	**269 (2.8)**	**10,228**	**669 (6.5)**

Figure 22. Percentage of children with CP by predominant motor subtype and spastic topography and gestational age group (weeks) (1995-2016)



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

Figure 23. Percentage of children by spastic subtype and gestational age group (weeks) (1995-2016)

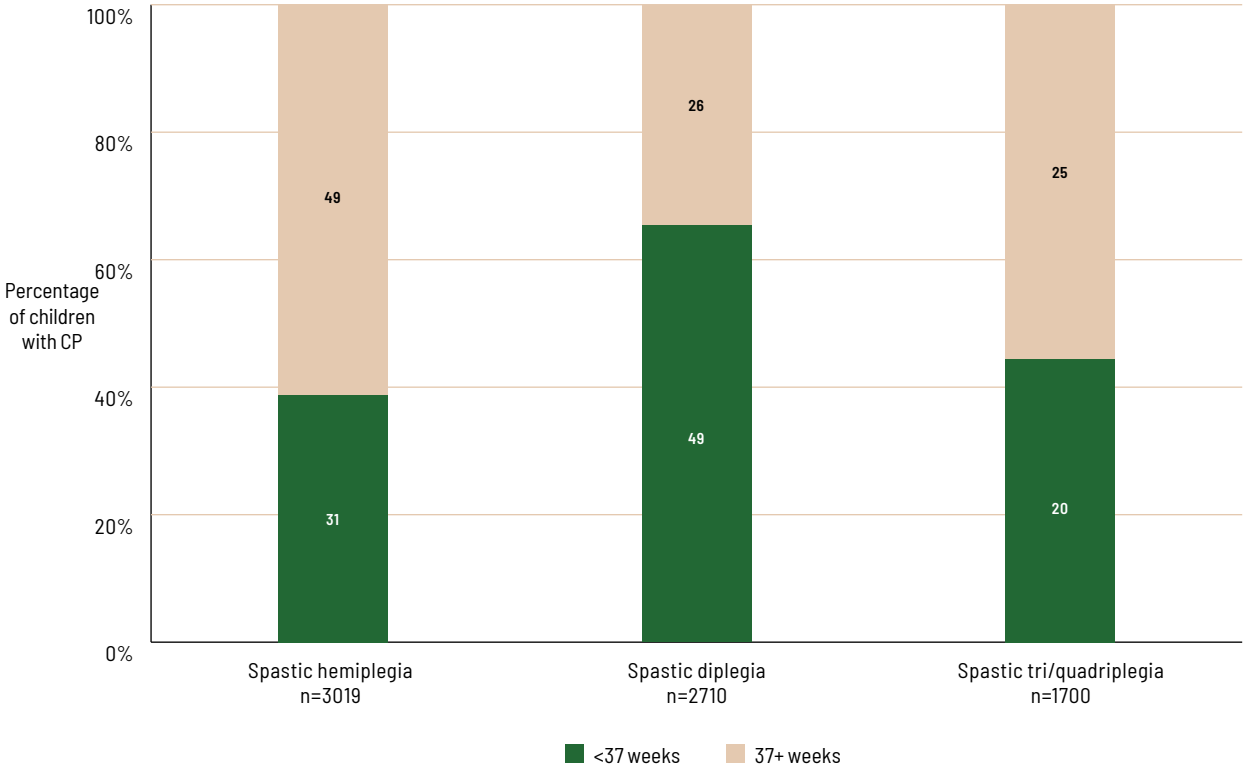
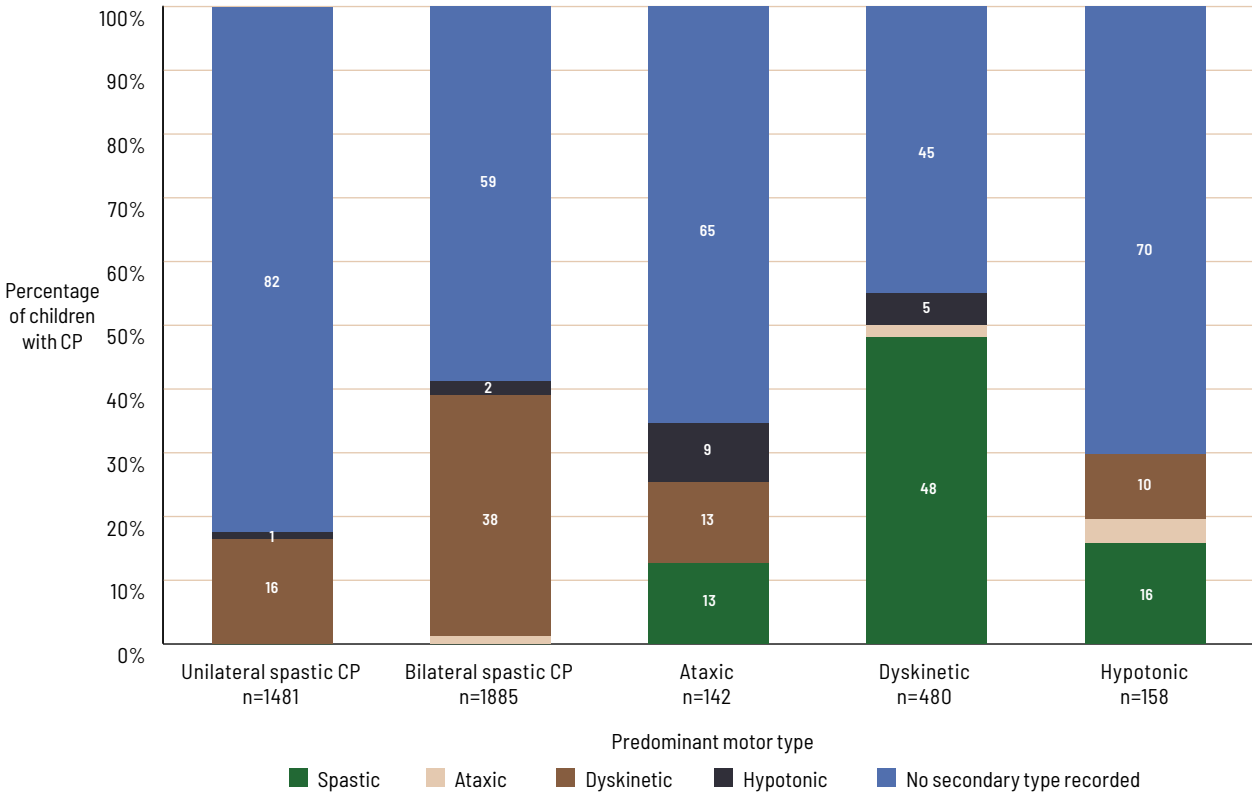


Figure 24. Percentage of children with CP by predominant subtype and secondary type (2007-2016)



**The 2007-2016 cohort was used for this figure, as secondary motor type data is more readily available for children in these more recent birth years
NB 'Dyskinetic cerebral palsy' includes both dystonic and athetoid/choreoathetoid CP

Data from this period illustrates that amongst children with unilateral spasticity, 16% also had dyskinesia. Amongst children with bilateral spasticity almost 40% had dyskinesia. In children described with a predominant motor type of dyskinesia, almost half also had spasticity.

The figures above are likely an underestimate of secondary or co-occurring motor types. The CP Registers have historically collected data pertaining to predominant CP motor type, however with data on secondary motor type becoming increasingly available it is hoped that ascertainment for this variable will continue to improve. In recent years many states in Australia have adopted the *Cerebral Palsy Description Form* (Appendix B) and the ACPR Group hopes this will further support data collection of co-occurring motor types.

Gross motor function

Table 17. Number and percentage of children with CP by Gross Motor Function Classification System[30] group and state/territory of birth (1995-2016)

	GMFCS I-II n (%)^	GMFCS III n (%)^	GMFCS IV-V n (%)^	Total n	Unknown n (%)
ACT/NSW	1937 (64.1)	316 (10.4)	771 (25.5)	3265	241 (7.4)
NT	67 (62.0)	10 (9.3)	31 (28.7)	129	21 (16.3)
QLD	878 (57.8)	217 (14.3)	423 (27.9)	1919	401 (20.9)
SA	396 (65.5)	80 (13.2)	129 (21.3)	780	175 (22.3)
TAS	112 (70.9)	12 (7.6)	34 (21.5)	186	28 (15.1)
VIC	1584 (63.5)	251 (10.1)	658 (26.4)	2517	24 (1.0)
WA	928 (64.8)	171 (11.9)	333 (23.3)	1432	0 (0.0)
TOTAL	**5902 (63.2)**	**1057 (11.3)**	**2379 (25.5)**	**10,228**	**890 (8.7)**

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

Figure 25. Percentage of children with CP by Gross Motor Function Classification System group (1995-2016)

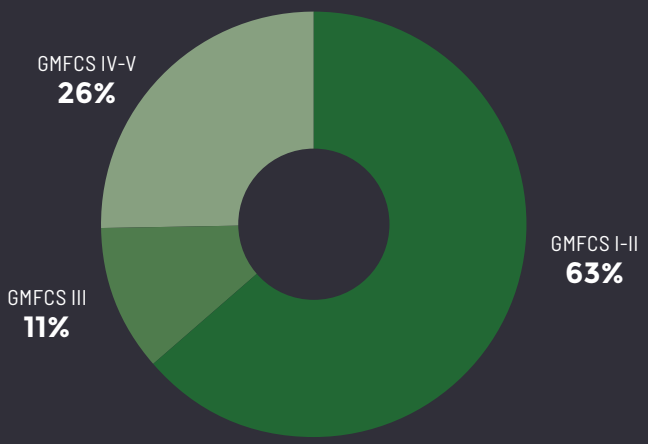


Figure 26. Percentage of children with CP by Gross Motor Function Classification System[30] group and predominant motor type (1995-2016)

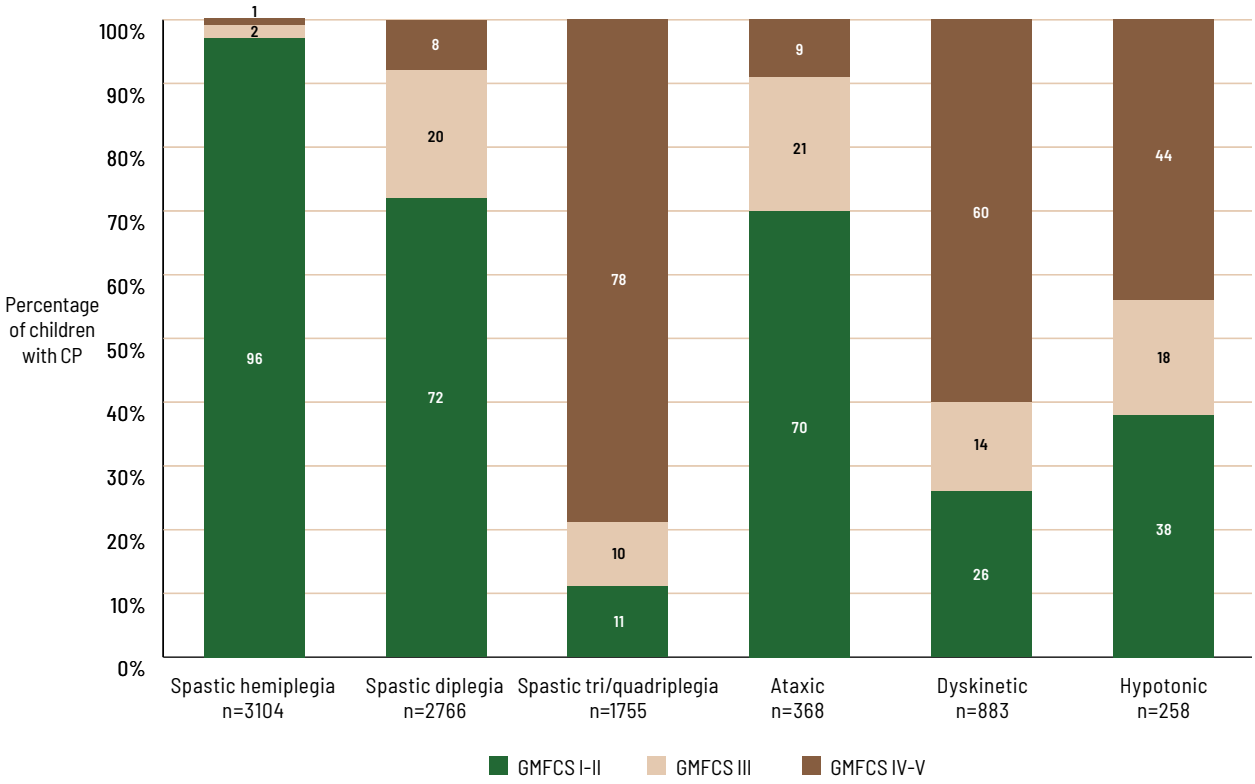


Figure 27. Percentage of children with CP by Gross Motor Function Classification System[30] category and birth period (1996-2016)

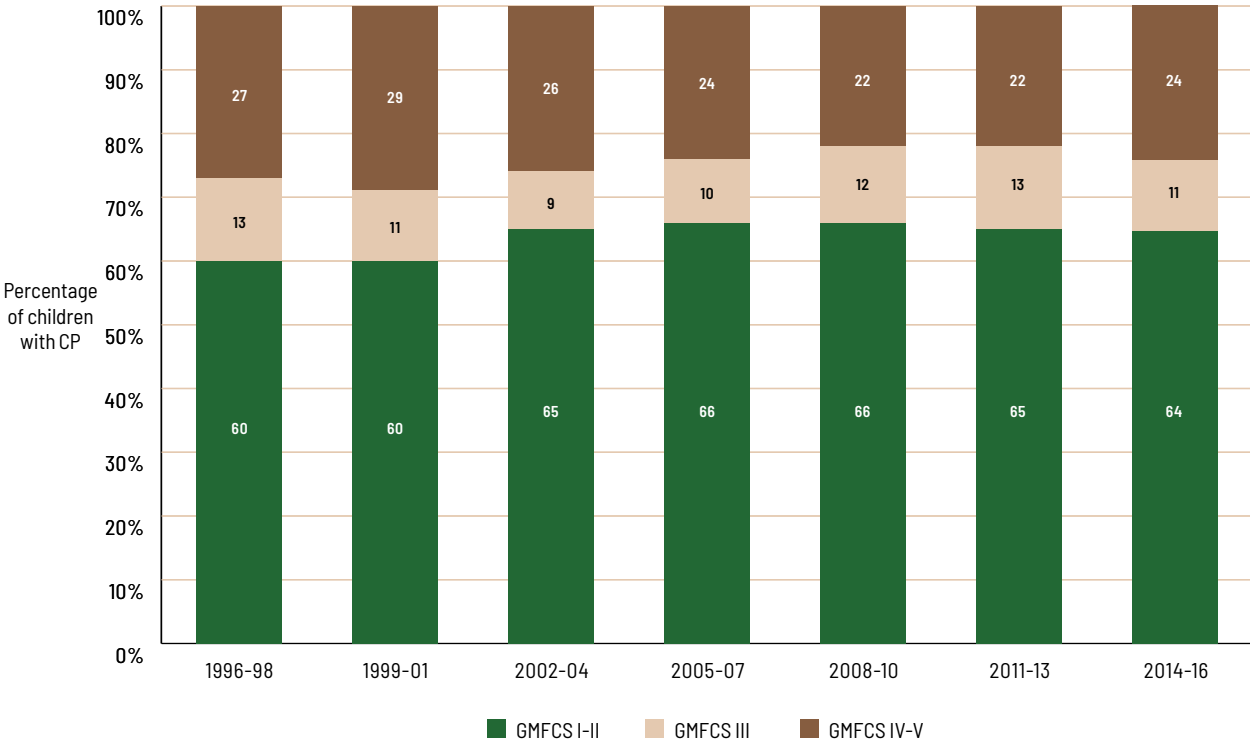
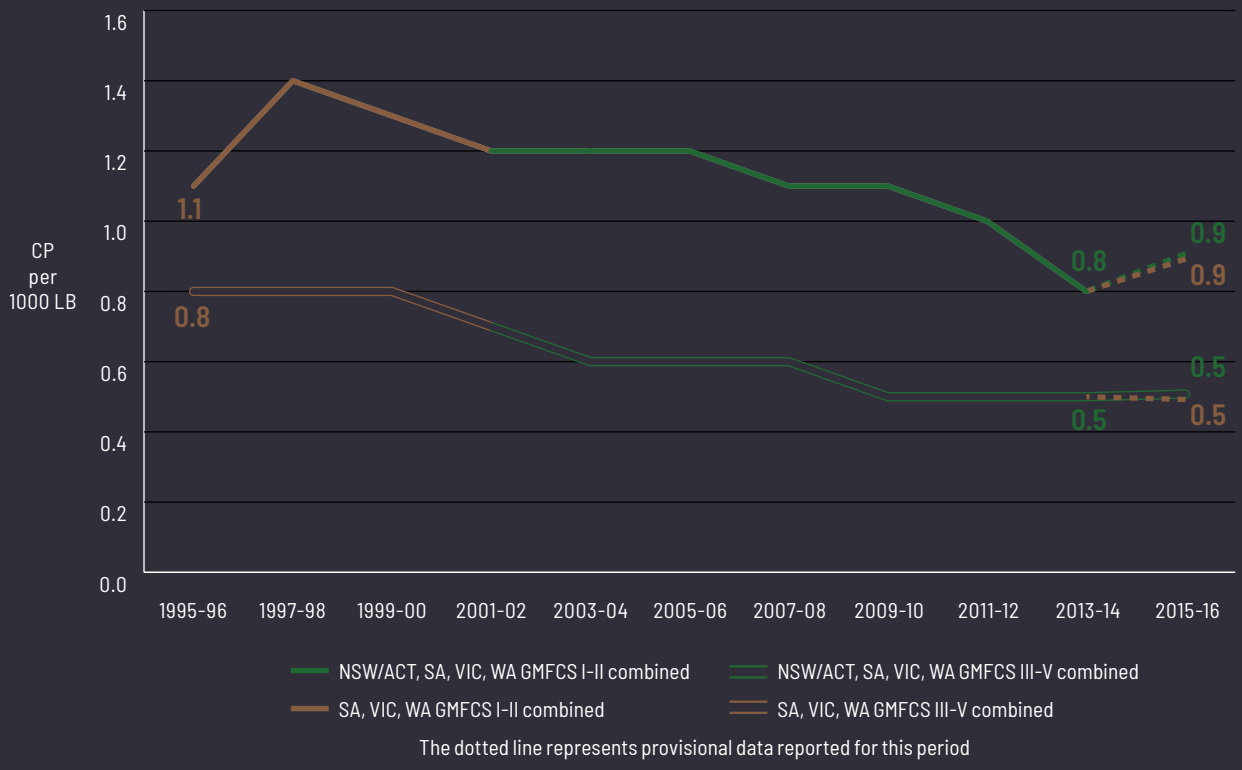


Figure 28. CP birth prevalence per 1000 live births (LB) by Gross Motor Function Classification System[30] category per 1000 live births (LB)(1995-2016)



The prevalence of CP for children described as GMFCS III-V declined from 0.8 (1999-00) to around 0.5 per 1000 LB in 2007-08 where it has remained relatively stable.

Vision

Table 18. Number and percentage of children with CP by vision status at 5 years (1995-2016)

	No impairment n (%)^	Some impairment n (%)^	Functionally blind n (%)^	Total n	Unknown n (%)
ACT/NSW	1460 (59.3)	890 (36.1)	112 (4.5)	3265	803 (24.6)
NT	66 (56.9)	40 (34.5)	10 (8.6)	129	13 (10.1)
QLD	907 (60.1)	542 (35.9)	60 (4.0)	1919	410 (21.4)
SA	339 (64.6)	164 (31.2)	22 (4.2)	780	255 (32.7)
TAS	111 (68.1)	48 (29.4)	◆ (2.5)	186	23 (12.4)
VIC	1540 (66.3)	690 (29.7)	94 (4.0)	2517	193 (7.7)
WA	971 (69.8)	346 (24.9)	74 (5.3)	1432	41 (2.9)
TOTAL	**5394 (63.5)**	**2720 (32.0)**	**376 (4.4)**	**10,228**	**1738 (17.0)**

◆< 5 children

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

Figure 29. Percentage of children with CP by vision status and birth period (1996 -2016)

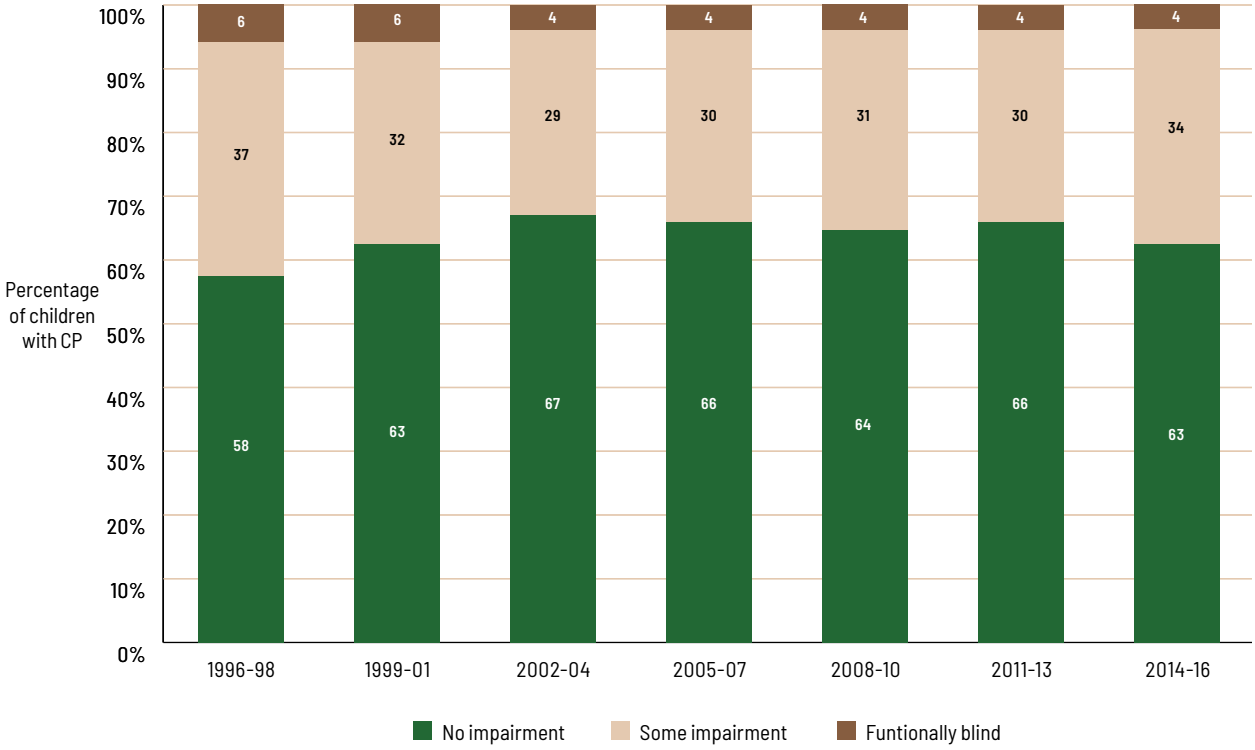


Table 19. Number and percentage of children with CP by presence/absence of strabismus at 5 years (1995-2016)

	No strabismus n (%)^	Strabismus n (%)^	Total n	Unknown n (%)
ACT/NSW	1090 (75.4)	356 (24.6)	3265	1819 (55.7)
NT	52 (76.5)	16 (23.5)	129	61 (47.3)
QLD	887 (65.2)	474 (34.8)	1919	558 (29.1)
SA	307 (62.1)	187 (37.9)	780	286 (36.6)
TAS	94 (79.0)	25 (21.0)	186	67 (36.0)
VIC	1500 (69.8)	648 (30.2)	2517	369 (14.7)
WA	942 (71.7)	371 (28.3)	1432	119 (8.3)
TOTAL	**4872 (70.1)**	**2077 (29.9)**	**10,228**	**3279 (32.1)**

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

Hearing

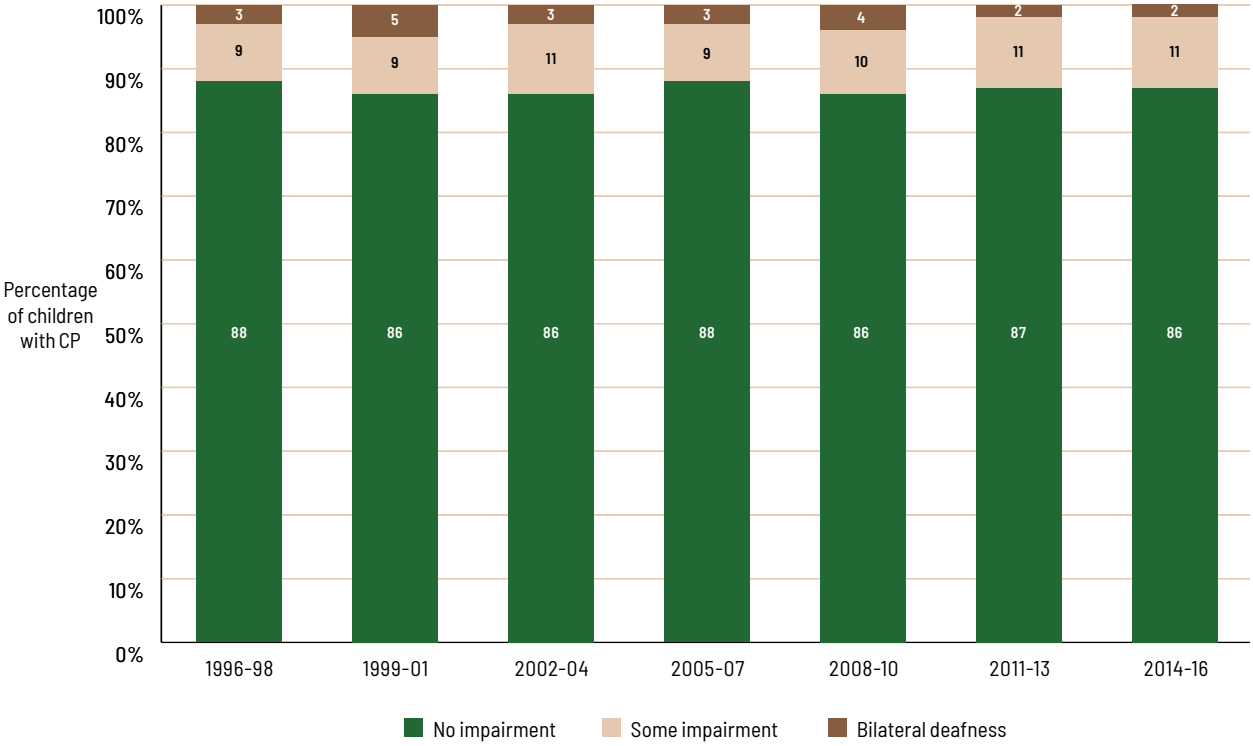
Table 20. Number and percentage of children with CP at 5 years by hearing status (1995-2016)

	No impairment n (%)^	Some impairment n (%)^	Bilateral deafness n (%)^	Total n	Unknown n (%)
ACT/NSW	2095 (85.2)	249 (10.1)	116 (4.7)	3265	805 (24.7)
NT	88 (75.9)	24 (20.7)	◆ (3.4)	129	13 (10.1)
QLD	1357 (88.6)	143 (9.3)	31 (2.0)	1919	388 (20.2)
SA	499 (95.2)	16 (3.1)	9 (1.7)	780	256 (32.8)
TAS	148 (89.2)	16 (9.6)	2 (1.2)	186	20 (10.8)
VIC	1994 (85.3)	268 (11.5)	77 (3.3)	2517	178 (7.1)
WA	1248 (90.4)	108 (7.8)	25 (1.8)	1432	51 (3.6)
TOTAL	**7429 (87.2)**	**824 (9.7)**	**264 (3.1)**	**10,228**	**1711 (16.7)**

◆< 5 children

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

Figure 30. Percentage of children with CP by hearing status and birth period (1996-2016)



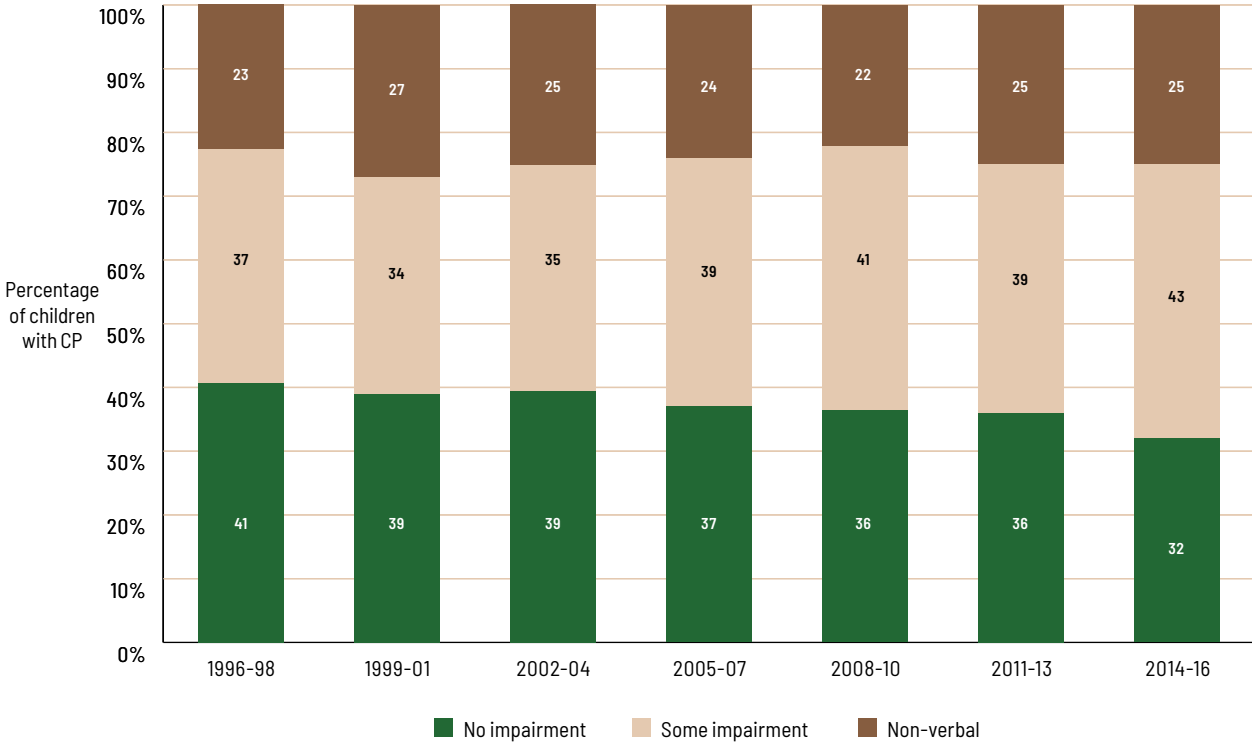
Speech

Table 21. Number and percentage of children with CP by speech status at 5 years (1995-2016)

	No impairment n (%)^	Some impairment n (%)^	Non-verbal n (%)^	Total n	Unknown n (%)
ACT/NSW	931 (35.4)	1054 (40.1)	642 (24.4)	3265	638 (19.5)
NT	38 (33.0)	42 (36.5)	35 (30.4)	129	14 (10.9)
QLD	590 (38.8)	582 (38.3)	348 (22.9)	1919	399 (20.8)
SA	250 (47.7)	206 (39.3)	68 (13.0)	780	256 (32.8)
TAS	78 (45.6)	74 (43.3)	19 (11.1)	186	15 (8.1)
VIC	870 (37.0)	845 (35.9)	639 (27.1)	2517	163 (6.5)
WA	495 (36.0)	507 (36.8)	374 (27.2)	1432	56 (3.9)
TOTAL	**3252 (37.4)**	**3310 (38.2)**	**2125 (24.5)**	**10,228**	**1541 (15.1)**

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

Figure 31. Percentage of children with CP by speech status and birth period (1996-2016)



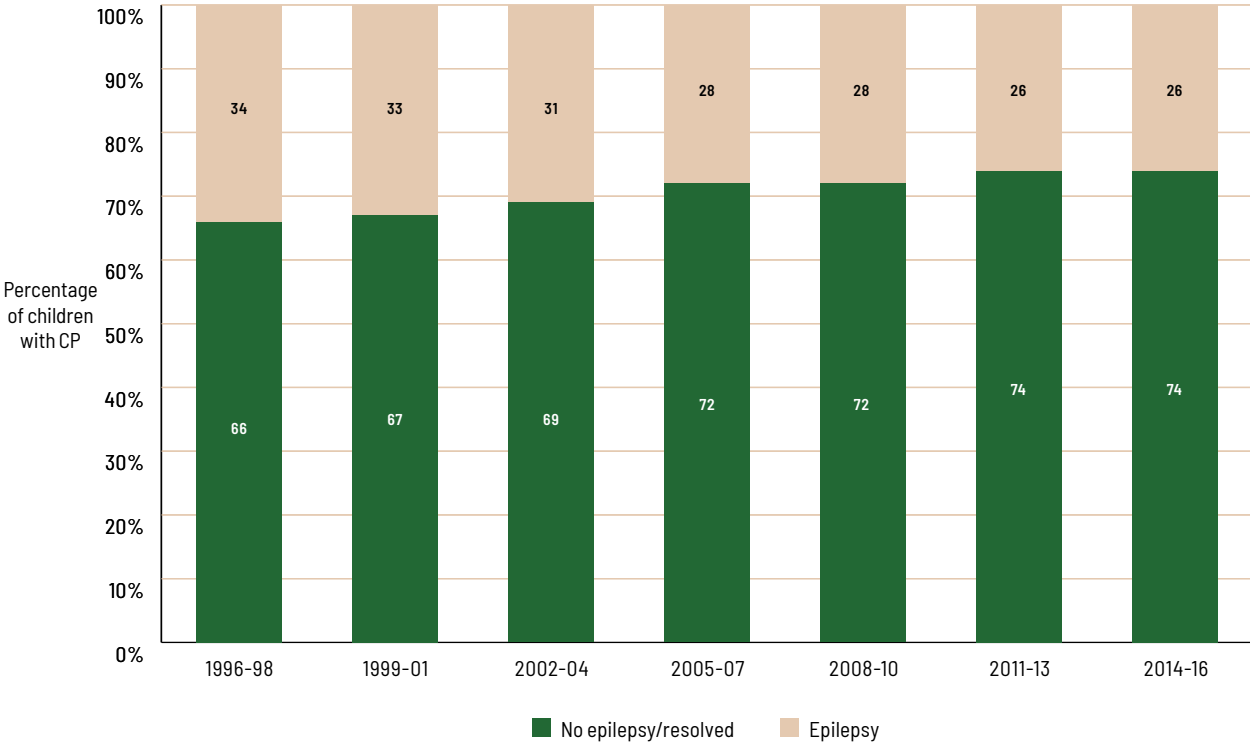
Epilepsy

Table 22. Number and percentage of children with CP by presence/absence of epilepsy at 5 years (1995-2016)

	No epilepsy n (%)^	Resolved# n (%)^	Epilepsy⅄ n (%)^	Total n	Unknown n (%)
ACT/NSW	1642 (64.8)	133 (5.2)	760 (30.0)	3265	730 (22.4)
NT	72 (59.0)	5 (4.1)	45 (36.9)	129	7 (5.4)
QLD	1074 (68.6)	62 (4.0)	429 (27.4)	1919	354 (18.4)
SA	386 (72.8)	30 (5.7)	114 (21.5)	780	250 (32.0)
TAS	122 (69.7)	6 (3.4)	47 (26.9)	186	11 (5.9)
VIC	1582 (64.5)	51 (2.1)	821 (33.5)	2517	63 (2.5)
WA	966 (68.8)	20 (1.4)	419 (29.8)	1432	27 (1.9)
TOTAL	**5844 (66.5)**	**307 (3.5)**	**2635 (30.0)**	**10,228**	**1442 (14.1)**

(%)^ 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 32. Percentage of children with CP by presence of epilepsy (1996-2016)

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Intellect

Table 23. Number and percentage of children with CP by intellect status (1995-2016)

	No impairment n (%)^	Impaired, level unknown n (%)^	Mild impairment n (%)^	Moderate to severe impairment n (%)^	Total n	Unknown n (%)
ACT/NSW	1183 (45.6)	441 (17.0)	288 (11.1)	681 (26.3)	3265	672 (20.6)
NT	56 (49.1)	28 (24.6)	8 (7.0)	22 (19.3)	129	15 (11.6)
QLD	777 (52.5)	248 (16.8)	140 (9.5)	315 (21.3)	1919	439 (22.9)
SA	361 (68.8)	38 (7.2)	67 (12.8)	59 (11.2)	780	255 (32.6)
TAS	83 (50.0)	25 (15.1)	24 (14.5)	34 (20.5)	186	20 (10.8)
VIC	1100 (48.2)	499 (21.8)	305 (13.4)	380 (16.6)	2517	233 (9.3)
WA	817 (57.5)	185 (13.0)	121 (8.5)	299 (21.0)	1432	10 (0.7)
TOTAL	**4377 (51.0)**	**1464 (17.0)**	**953 (11.1)**	**1790 (20.9)**	**10,228**	**1644 (16.1)**

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

Figure 33. Percentage of children with CP by intellect status (1995-2016)

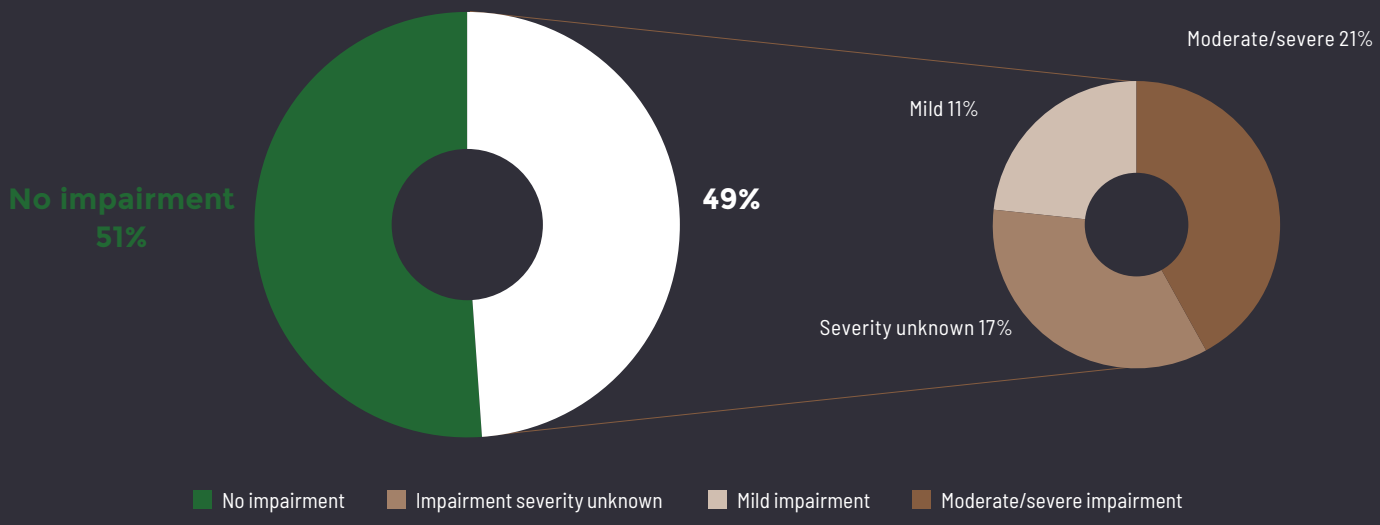
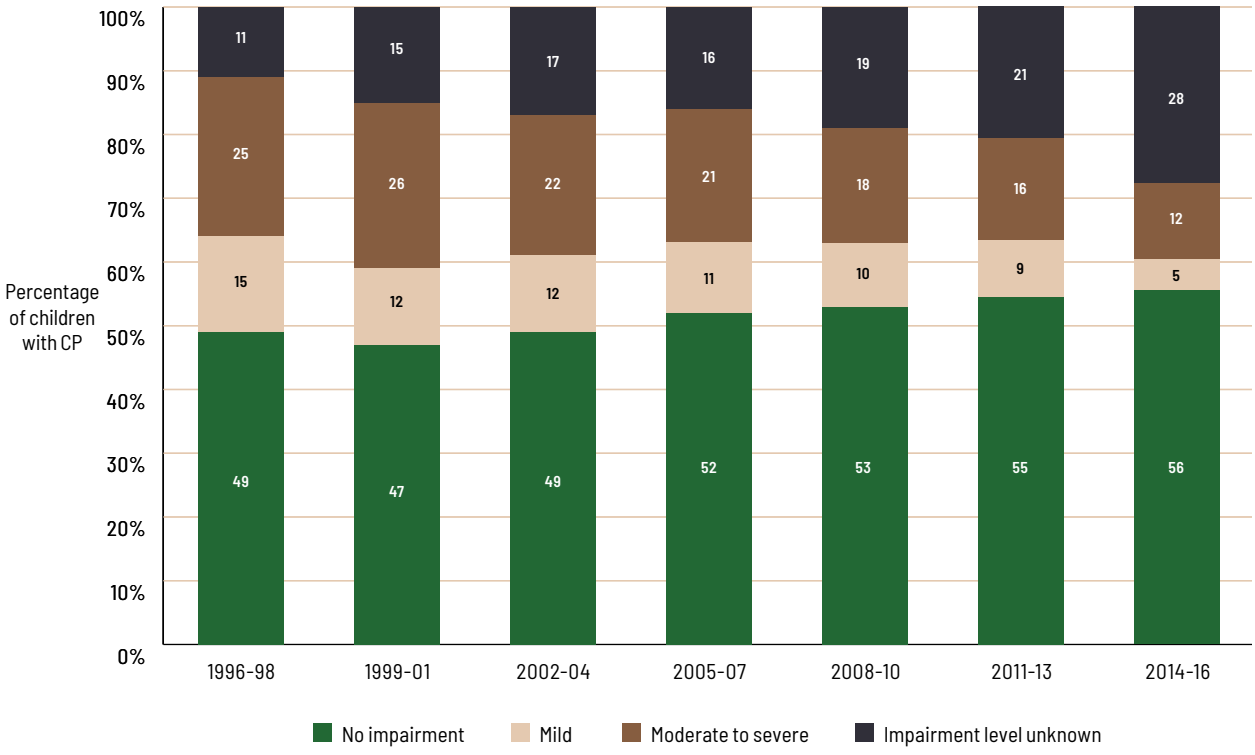


Figure 34. Percentage of children with CP by level of intellectual impairment and birth period (1996-2016)



While associated impairments are common for children with CP, in data from recent birth years >60% of children did not have a visual impairment, >85% had no hearing impairment, >70% communicated verbally, >70% did not have epilepsy and >55% did not have an intellectual impairment.

The proportions of children who **did not** have epilepsy or intellectual impairment increased during this reporting period.

RESULTS

3

Post-neonatally acquired cerebral palsy

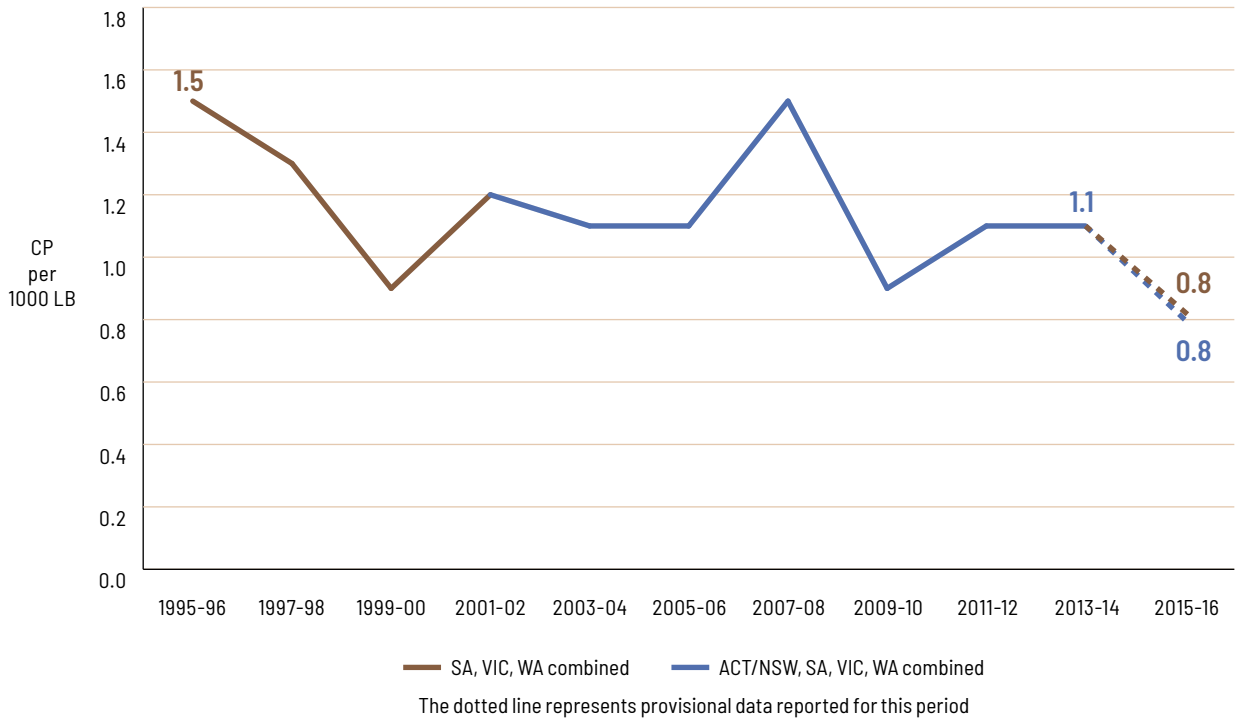
Section 3 of this report refers to CP resulting from a recognised post-neonatal brain injury acquired more than 28 days after birth and before 2 years of age.

Prevalence

Table 24. Number and birth prevalence of children with post-neonatally (PNN) acquired CP per 10,000 live births (LB) by state/territory of birth (1995-2016)

	Children with PNN acquired CP n	Percentage of all children with CP %	PNN CP per 10,000 live births (95% CI)
ACT/NSW	225	6.5	1.1
NT	21	14	2.8
QLD	93	4.6	0.8
SA	32	4.1	0.8
TAS	◆	1.6	0.2
VIC	142	5.3	0.9
WA	111	7.2	1.8
TOTAL	**627**	**5.8**	**1.0 (0.9, 1.1)**

Figure 35. Prevalence of post-neonatally acquired CP per 10,000 live births (LB) (1995-2016)



Whilst rates fluctuated over these 22 years, the decline observed between 2007-08 and 2013-14 appears to have been sustained.

Post-neonatal cause

Table 25. Number and percentage of children with CP by identified post-neonatal cause of CP (1995-2016)

Post-neonatal cause	All states and territories n (%)
Cerebrovascular accident*	164 (26.2)
Viral/bacterial infection	143 (22.8)
Non-accidental injury	83 (13.2)
Other head injury	24 (3.8)
Post-seizure	24 (3.8)
Fall	23 (3.7)
Motor vehicle accident	22 (3.5)
Near drowning	19 (3.0)
Apparent life-threatening event	18 (2.9)
Peri-operative hypoxia	9 (1.4)
Other post-neonatal event	98 (15.6)
TOTAL	**627**

*Cerebrovascular accident associated with surgery/ cardiac complications or spontaneous

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

An ACPR study focusing on post-neonatally acquired CP in Australia was published in 2022. The aim of this paper was to describe post-neonatally acquired CP in terms of prevalence, clinical characteristics and sociodemographic profile.

Overall, there was a statistically significant decline in post-neonatally acquired CP between 1973 and 2012 (long term trends). Cerebrovascular accidents were the most common cause of post-neonatally acquired CP, a shift from historic findings reporting infection as the most common cause. This suggests historic and current health intervention programmes (e.g. vaccinations) have been somewhat successful. However, children born to teenage mothers, children born to Aboriginal and Torres Strait Islander mothers and children born in remote areas were over-represented in this cohort, suggesting more specific preventive measures and supports are required for these priority groups.[22]

Sex

Figure 36. Percentage of children with post-neonatally acquired CP by sex (1995-2016)

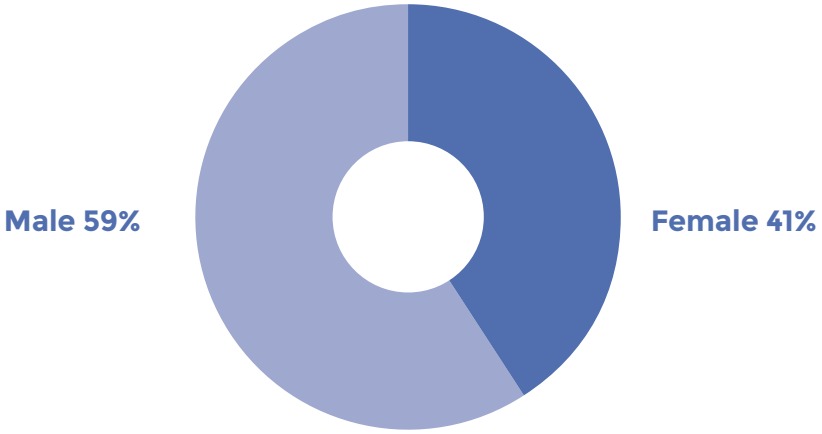
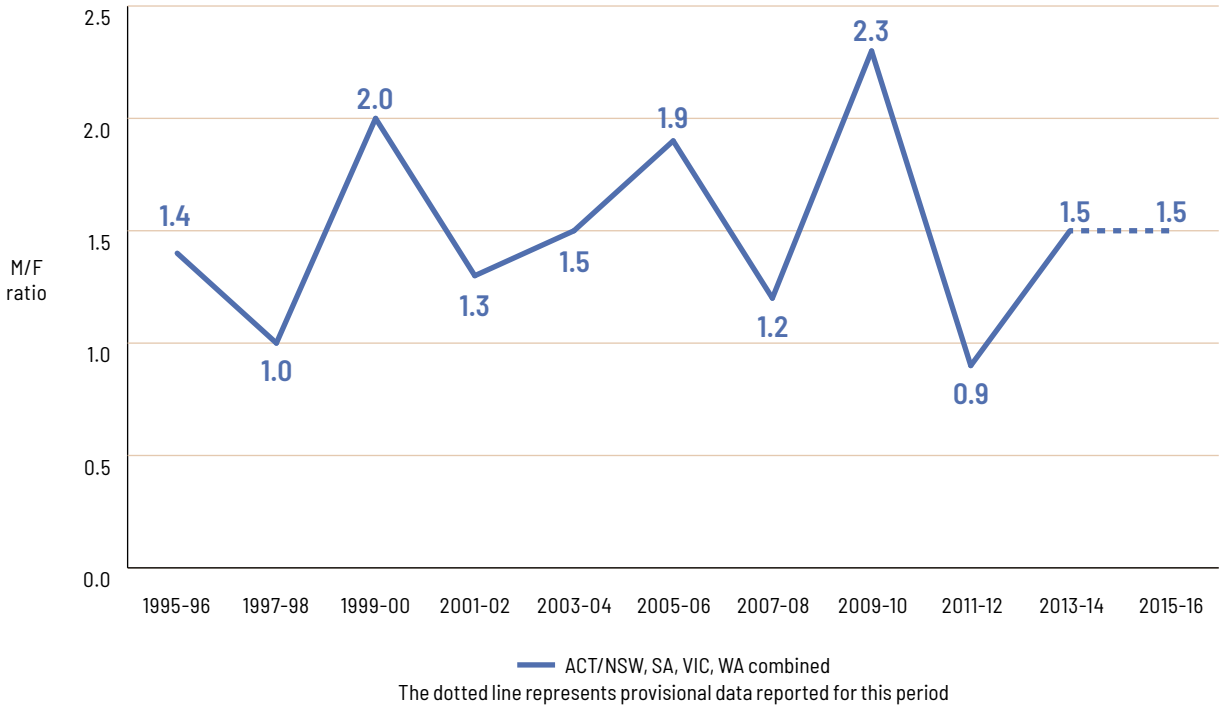


Figure 37. CP by male/female sex ratio and birth period



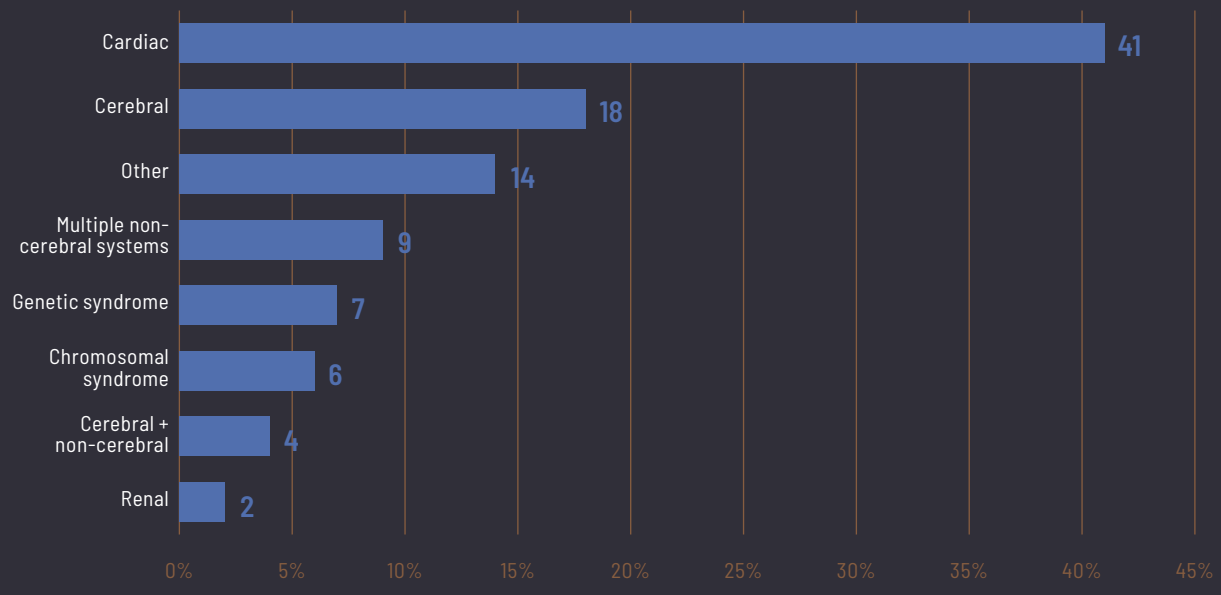
Congenital anomalies

Given the relatively small number of children with post-neonatally acquired CP, the collaborative *Comprehensive CA-CP Study* was particularly important for understanding congenital anomalies in this group. Major congenital anomalies were identified in over one in four children with post-neonatally acquired CP (25.6%; 95% CI 21.7, 29.9)[31]

26%
(95% CI 22, 30)

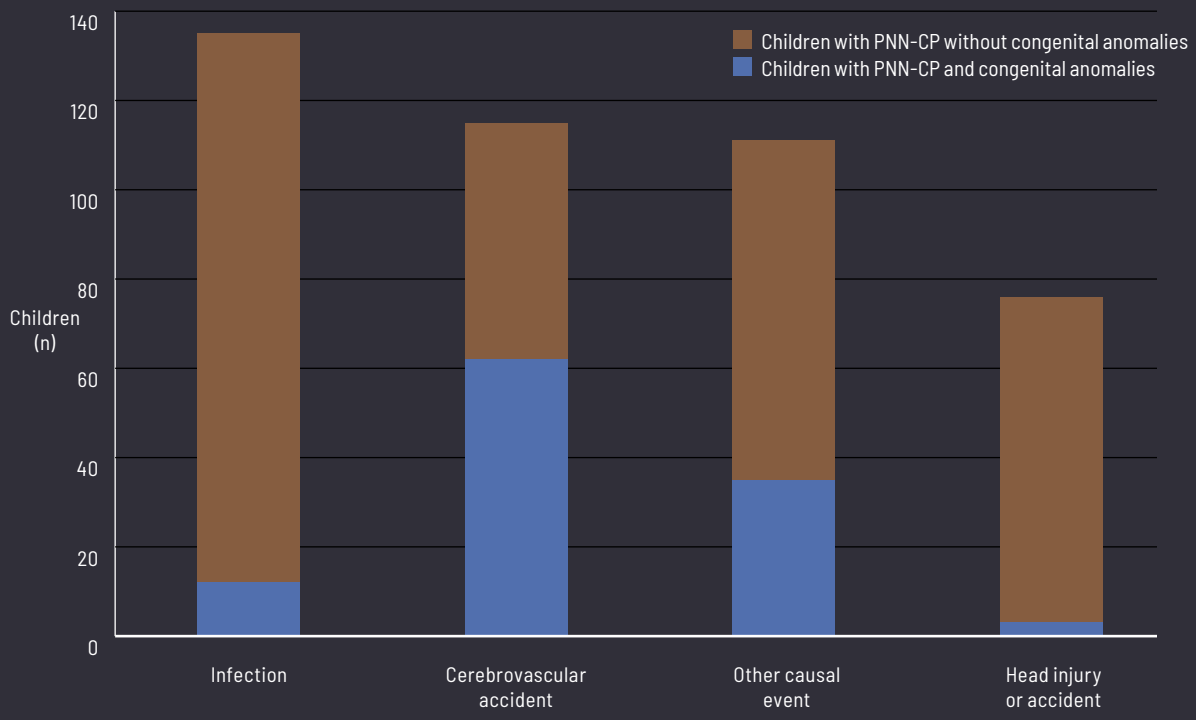
Using the classification by type and aetiology of congenital anomalies, the largest group of children (40.8%) had isolated cardiac anomalies, and severe cardiac defects were common.

Classification of children with major congenital anomalies, Europe and Australia 1991-2009



Severe clinical outcomes were common in children with post-neonatal CP, with or without major congenital anomalies.

Causes of post-neonatally acquired cerebral palsy (PNN-CP) in children with and without congenital anomalies, Europe and Australia 1991-2009



In 77% of children with congenital anomalies, the anomaly was deemed 'likely associated' with their cause of CP.

The presence of congenital anomalies by known cause of post-neonatal CP and the prevalence of specific congenital anomalies, by body system (cerebral, cardiac etc) and by individual anomaly has been published.[31]

Motor type and topography

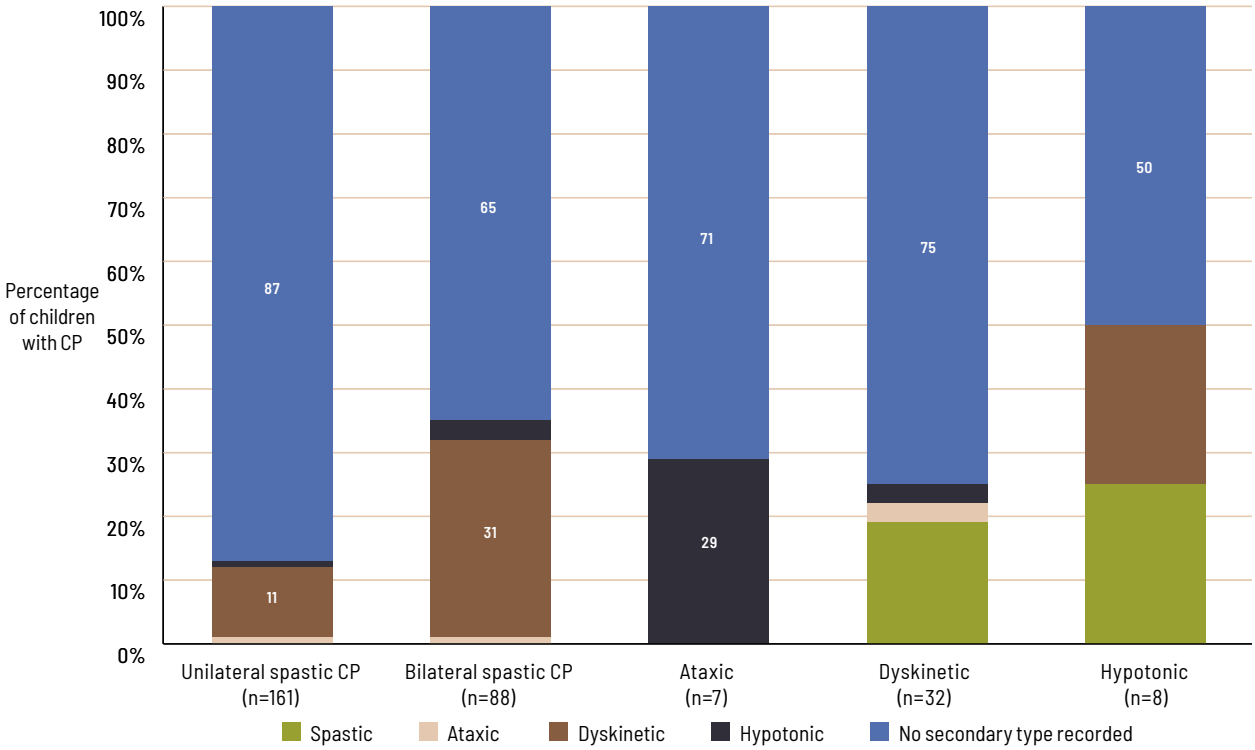
Table 26. Number and percentage of children with post-neonatally acquired CP by predominant motor type and spastic topography at 5 years

	Spastic n (%)^	*Unilateral spastic CP*		*Bilateral spastic CP*	Ataxic n (%)^	Dyskinetic n (%)^	Hypotonic n (%)^	Total n	Unknown n (%)
		Hemiplegia/monoplegia n (%)	*Diplegia n (%)*	*Tri/ Quadriplegia n (%)*					
All states and territories	517 (87.1)	*297 (57.5)*	*52 (10.0)*	*168 (32.4)*	15 (2.5)	49 (8.2)	13 (2.2)	628	33 (5.3)

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

Spasticity was the most common predominant motor type, with unilateral spastic CP (hemiplegia, including monoplegia) the most common topographical pattern of spasticity.

Figure 38. Percentage of children with post-neonatally acquired CP by sole motor type and secondary motor type at 5 years (2007-2016)*



*The 2007-2016 cohort was used for this figure, as secondary motor type data is more readily available for children in these more recent birth years
NB: 'Dyskinetic cerebral palsy' includes both dystonic and athetoid cerebral palsy

Gross motor function

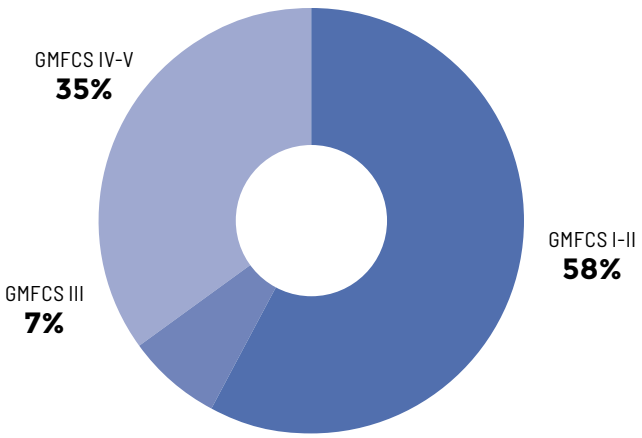
Table 27. Number and percentage of children with post-neonatally acquired CP by GMFCS[30] at 5 years

	GMFCS I-II n (%)^	GMFCS III n (%)^	GMFCS IV-V n (%)^	Total n	Unknown n (%)
ACT/NSW	112 (60.2)	11 (5.9)	63 (33.9)	225	39 (17.3)
NT	10 (66.7)	0 (0.0)	5 (33.3)	21	6 (28.6)
QLD	39 (48.1)	8 (9.9)	34 (42.0)	93	12 (12.9)
SA	21 (75.0)	0 (0.0)	7 (25.0)	32	4 (12.5)
TAS	0 (0.0)	◆ (66.7)	◆ (33.3)	◆	0 (0.0)
VIC	82 (58.6)	8 (5.7)	50 (35.7)	142	◆ (1.4)
WA	65 (58.6)	10 (9.0)	36 (32.4)	111	0 (0.0)
TOTAL	**329 (58.3)**	**39 (6.9)**	**196 (34.8)**	**627**	**63 (10.0)**

◆< 5 children

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

Figure 39. Percentage of children with post-neonatally acquired CP by Gross Motor Function Classification Group (1995-2016)



Vision, hearing, speech, intellect and epilepsy

Table 28. Number and percentage of children with post-neonatally acquired CP by vision, hearing, speech, intellect and epilepsy status at 5 years (1995-2016)

	No impairment n (%)^	Some impairment n (%)^	Severe impairment@ n (%)^	Total n	Unknown n (%)
Vision	246 (47.8)	210 (40.8)	59 (11.4)	627	112 (17.9)
Hearing	419 (84.3)	58 (11.7)	20 (4.0)	627	130 (20.7)
Speech	122 (23.6)	222 (42.9)	173 (33.5)	627	110 (17.5)
Intellect	172 (33.6)	194 (37.9)	146 (28.5)	627	115 (18.3)
	No epilepsy n (%)^	Resolved# n (%)^	Epilepsy✦ n (%)^		
Epilepsy	218 (40.6)	53 (9.9)	266 (49.5)	627	90 (14.4)

(%)^ 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), Intellect (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.

Severe associated impairments/ disorders were proportionally more common amongst children with post-neonatally acquired CP compared to pre/perinatally acquired CP: blindness (11% v 4%), bilateral deafness (4% v 3%), non-verbal communication (33% v 24%) moderate-severe intellectual impairment (28% v 21%) and epilepsy (50% v 30%).

RESULTS

4

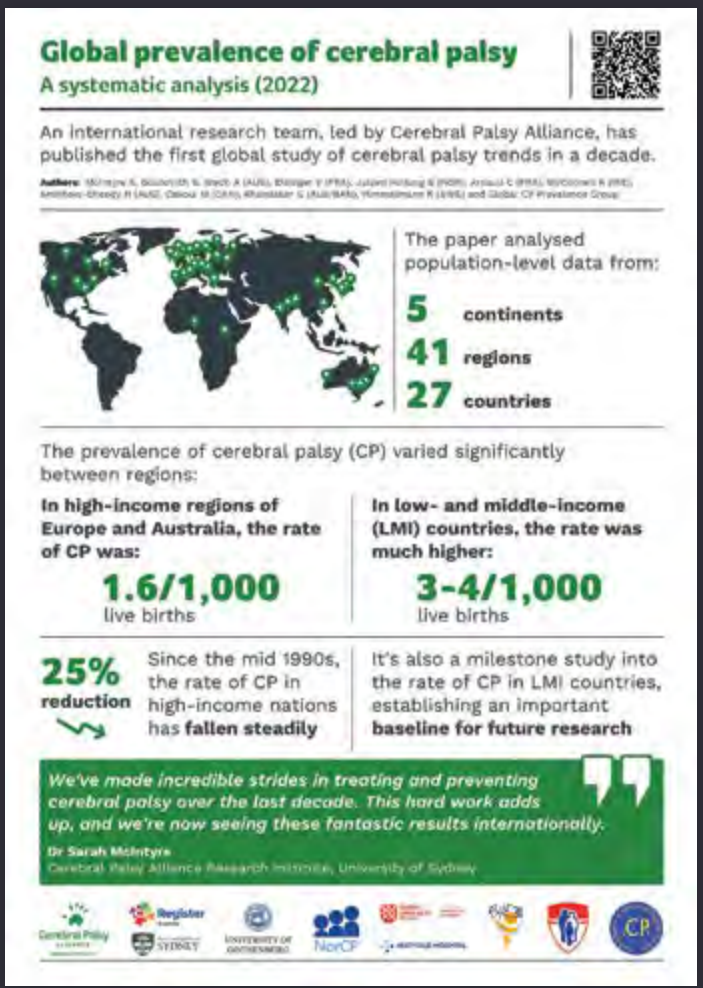
Global collaboration

A spotlight on register and surveillance programs across the world.

Over the last decade the number of new CP register and surveillance programs internationally has rapidly increased. Major CP register and surveillance networks include the Australian Cerebral Palsy Register, the Surveillance of Cerebral Palsy in Europe and the Global Low- and Middle-Income Country Cerebral Palsy Register.

In preparation for the World CP Register and Surveillance Congress in 2022, a survey of CP register and surveillance programs internationally was completed. This survey has captured core information on the aims and methodologies of register and surveillance programs internationally. The results of this survey are currently being synthesised by members of the ACPR Group and study collaborators. The final paper will provide an update of previous work completed in 2016[1] and will be published and available in 2023.

There are strong research links across CP register and surveillance programs internationally, resulting in collaborative research including a recent paper exploring the global prevalence of CP.[17] This research identified a declining trend in prenatally and perinatally acquired CP birth prevalence in high-income countries (HICs). Whilst the authors acknowledged that it is not yet possible to measure trends in CP prevalence in Low- and Middle-Income Countries (LMICs), current estimates suggest prevalence is markedly higher than in HICs.



CP registers/surveillance programs in the Asia-Pacific

The ACPR Group has been privileged to work with researchers across the region to support the development and establishment of new CP registers. Support provided ranges from general encouragement and advice to collaboration on new research.

The ACPR Group has the pleasure of regularly liaising with our colleagues and friends 'across the ditch' in New Zealand. **The New Zealand CP Register** was established in 2015 and has a vision to be the source of relevant and high-quality information to support positive health outcomes for all people in Aotearoa New Zealand with CP. We recommend to you the first NZCPR Report which was published earlier this year and provides an overview of the excellent work being conducted by the NZCPR team.

2017 saw the establishment of the **Singapore CP Registry**. This program aims to improve the overall understanding of CP in Singapore and to assist in planning of services and resources for people with CP. This register is an exciting new resource for both epidemiological and clinical research.[25]

Many LMICs have both high population density and high prevalence of CP compared with HICs, however until relatively recently there has been little data available to understand CP in these settings. It has been exciting to see the establishment of multiple registers across the region including **Bangladesh**,[32–37] **China**,[38] **Indonesia**,[39,40] **Nepal**,[41,42] **Sri Lanka**,[43] and **Vietnam**.[44] The programs and research outputs associated with these registers have been extraordinary and are a credit to the committed teams leading and working on them. Importantly the establishment of the Global Low- and Middle-Income Country Cerebral Palsy Register has brought together CP data from across LMICs to report on key issues.

The Global Low-and Middle-Income Country Cerebral Palsy Register

The Global Low-and Middle-Income Country Cerebral Palsy Register (GLM CPR) is a multi-country network of established and emerging CP registers in LMICs. The CP registers affiliated with the GLM CPR collect and collate information about the epidemiology of CP in LMICs using a standard harmonized protocol. Since establishment in 2018, the network has grown exponentially.

Currently 11 LMIC based CP registers are affiliated with the GLM CPR and the platform has ongoing collaborations to expand the network in the future.

To date, data from the CP registers affiliated with the GLM CPR has been utilized in 5 PhD projects and 2 Masters projects.

List of countries contributing data to the GLM CPR:	Countries with emerging CP registers:
Bangladesh	Vietnam
Indonesia	Malawi
Nepal	Mexico
Ghana	Vanuatu
Suriname	Sudan
Argentina	







Currently 11 LMIC based CP registers are affiliated with the GLM CPR and the platform has ongoing collaborations to expand the network in the future.

Key achievements

To date the CP registers affiliated with the GLM CPR have collectively published 30 papers in high impact peer reviewed journals. Of these papers, four published combined data from multiple CP registers.

Key publications include:

- Epidemiology of cerebral palsy in low-and middle-income countries: preliminary findings from an international multi-centre cerebral palsy register[45]
- Predictors of rehabilitation service utilisation among children with cerebral palsy (CP) in low-and middle-income countries (LMIC): findings from the global LMIC CP register[46]
- Epidemiology of malnutrition among children with cerebral palsy in low-and middle-income countries: findings from the Global LMIC CP register[47]
- Novel weight estimation equation for children with cerebral palsy in low-resource settings: validation in a population-based cohort[48]

Appendices

Appendix A

Australian Capital Territory and New South Wales Cerebral Palsy Register

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

Sarah McIntyre and Shona Goldsmith

Cerebral Palsy Alliance Research Institute,
Brain and Mind Centre, The University of Sydney
88 Mallett St Camperdown
NSW 2050 Australia

cpregister@cerebralpalsy.org.au

61 2 9975 8000

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.

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, Prof Russell Dale, Dr Richard Webster, Dr Kavitha Kothur and Ms Karen Bau (SCHN Westmead), Dr Maria Kyriagis and Ms Kerry Hanns (SCHN Randwick), Dr Heather Burnett (Kaleidoscope John Hunter Children's Hospital), Dr Nicole Gerrand (Hunter New England Local Health District).

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

https://cerebralpalsy.org.au/our-research/get-involved-research/cp-register/

Northern Territory Cerebral Palsy Register

Women, Children & Youth division, Top End Health Service

Target population:

All individuals who have CP, who were born in, or live in the Northern Territory

Fiona Kay and Cassie Goldsworthy

Women, Child and Youth division
Top End Health Service
Department of Health
Floor 5, Royal Darwin Hospital main building.
Rocklands Drive, Tiwi
NT 0810 Australia

CPRegister.THS@nt.gov.au

61 8 8922 8885

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.

https://nt.gov.au/wellbeing/health-conditions-treatments/cerebral-palsy-register

Queensland Cerebral Palsy Register

CPL - Choice, Passion, Life

Target population:

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

Purpose:

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; to provide a population resource for intervention trials and to contribute to investigations into causes and prevention of CP.

http://www.qcpr.org.au/

Megan Auld

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

mauld@cpl.org.au

61 7 3358 8143

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

Catherine Gibson and Heather Scott

Women's and Children's Health Network
72 King William Road
North 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.

https://www.wch.sa.gov.au/professionals/registers/cerebral-palsy-register

Tasmanian Cerebral Palsy Register

St Giles and the Tasmanian Health Service Department

Target population:

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

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 Tasmania. The register also aims to facilitate research into the causes, prevention and treatment of CP.

Nadine Davies

St Giles
PO Box 45,
New Town
TAS 7008 Australia

society@stgiles.org.au

61 3 6238 1888

Clare Wiltshire and Eliza Maloney

Tasmanian Paediatric Rehabilitation Service,
Royal Hobart Hospital,
Women's and Children's Services
Level 3, 48 Liverpool Street
Hobart
TAS 7001 Australia

clare.wiltshire@ths.tas.gov.au

0439 375397

Victorian Cerebral Palsy Register

Murdoch Children's Research Institute at The Royal Children's Hospital, Melbourne

Target population:

Individuals with CP born since 1970

Sue Reid

Developmental Disability
and Rehabilitation Research
Murdoch Children's Research Institute
50 Flemington Road
Parkville
VIC 3052 Australia

sue.reid@mcri.edu.au

Purpose:

To monitor the frequency, life expectancy, and characteristics of CP in Victoria, to enable research into aetiology and to select cohorts for intervention and other studies.

https://www.mcri.edu.au/research/projects/victorian-cerebral-palsy-register

Western Australian Register of Developmental Anomalies – Cerebral Palsy

Western Australian Department of Health

Target population:

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

Linda Watson and Michèle Hansen

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 6458 2768

61 403 806 932

Purpose:

To monitor trends in the CPs and identify areas of concern for future investigation; to conduct population based epidemiological studies of the various CP subgroups, particularly to elucidate causes; to evaluate changes in antenatal, obstetric and neonatal care in relation to CP as an index of neurological outcome; to identify CP as an outcome in other study populations; 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 and to contribute WA CP data to the Australian Cerebral Palsy Register.

https://www.wnhs.health.wa.gov.au/Our-services/Service-directory/WARDA

Appendix B

CP Description Form and Australian Spasticity Assessment Scale

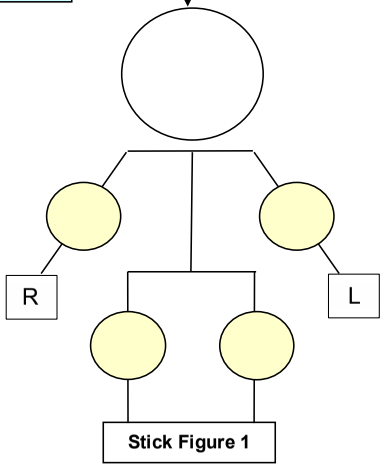
CEREBRAL PALSY DESCRIPTION FORM Part I: MOTOR IMPAIRMENTS

Child's name: Please attach sticky label if available DOB: Place of birth (State, Country):
Examining clinician: Date:

1. Is there spasticity in one or more limbs?

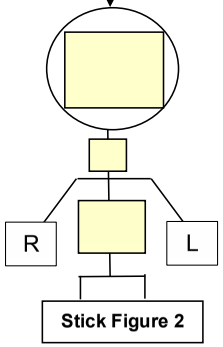
Please tick all Yes/No boxes as appropriate

Yes No



Stick Figure 1

2. Describe face/ neck/trunk tone

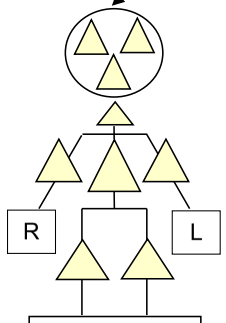


Stick Figure 2

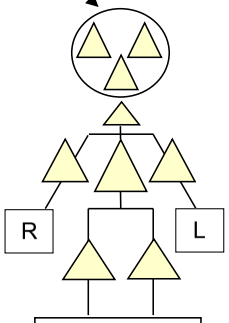
3. Is muscle tone varying?

Yes No

Dystonia Choreoathetosis



Stick Figure 3a



Stick Figure 3b

4. Is ataxia present?

Yes No

Is there generalised hypotonia with increased reflexes?

Yes No

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

- ☐ Spasticity
- ☐ Dystonia
- ☐ Choreoathetosis
- ☐ Ataxia
- ☐ Generalised hypotonia

Stick Figure 1: Australian Spasticity Assessment Scale (ASAS)

Enter: Highest spasticity score

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 & 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.

Stick Figure 2 Instructions:

Face/Neck/Trunk muscle tone:

Enter ↓ = Hypotonia
↑ = Hypertonia
↕ = Fluctuating
N = Normal

Stick Figures 3a and 3b Instructions:

Tick triangles where signs are present or score (PTO)

Please explain this form to families if there is interest and opportunity. Describe CP motor type and topography as you would write in the medical record:

Was the Hypertonia Assessment Tool (HAT) used to identify spasticity and/or dystonia?
Yes ☐ No ☐

Please indicate how spasticity was quantified in Stick Figure 1:
Australian Spasticity Assessment Scale (ASAS) ☐ Other (please specify):_____
Not used ☐

Please indicate how dyskinesia was quantified in Stick Figures 3a and 3b:
Barry Albright Dystonia Scale (BADS) ☐ Dyskinesia Impairment Scale (DIS) ☐
Other (please specify):_____ Not used ☐

Part II: FUNCTION AND ASSOCIATED IMPAIRMENTS

Please complete as many clinical details as possible

Gross Motor Function Classification System E&R

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

Functional Mobility Scale (FMS)

5m: _____ **50m:**_____ **500m:**_____

Manual Ability Classification System

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

Communication Function Classification System

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

Eating and Drinking Ability Classification System

EDACS: Level I ☐ Level II ☐ Level III ☐ Level IV ☐ Level V ☐
Independent ☐ Requires assistance ☐ Totally dependent ☐

Intellectual impairment:

None ☐ Probably none ☐ Probably some ☐
Mild ☐ Moderate ☐ Severe ☐
Not tested ☐ IQ score if tested:_____

Viking Speech Scale

☐ **I** (Speech not affected by motor disorder)
☐ **II** (Speech imprecise, usually understandable to unfamiliar listeners)
☐ **III** (Speech unclear, not usually understandable to unfamiliar listeners out of context)
☐ **IV** (no understandable speech)

Briefly describe presence or absence of associated impairments

Epilepsy:
None ☐ Previously, but now resolved: ☐
Yes, seizure type(s):_____ Age at onset: _____

Vision:
Normal ☐ Some impairment: ☐ Bilateral blindness: ☐ Strabismus: ☐ Uncertain: ☐

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

Other diagnoses:
None ☐ Mental health:_____
Developmental disorder (e.g. ASD, ADHD):_____
Other_____

Form designed by: Sarah Love, Noula Gibson, Eve Blair, Linda Watson (April 2013) for the Australian Cerebral Palsy Register, Version IV 2020 modified by: original authors, Kids Rehab, Children's Hospital Westmead and Cerebral Palsy Alliance.

Appendix C

Projects supported by state/territory cerebral palsy registers (2019-2022)

Australian Capital Territory and New South Wales Cerebral Palsy Register

- Exploring the relationship between clinical and sociodemographic factors and outpatient health service access and utilisation in children with cerebral palsy; Dr Simon Paget; Children's Hospital at Westmead and The University of Sydney.
- Epidemiology of congenital heart defects in NSW children and impact on health, health service utilisation, health costs and educational attainment; Prof Natasha Nassar; The University of Sydney.
- Generating evidence for a strong foundation in the early years: using population health data for translational child health, healthcare and policy; Prof Natasha Nassar; Children's Hospital at Westmead and The University of Sydney.
- Joining the dots – linking neonatal abstinence syndrome (NAS) to the future; Prof Ju Lee Oei; The Royal Hospital for Women.
- Brain-Computer Interfaces and Eye-Gaze technology for Standardized Testing; Dr Petra Karlsson; Cerebral Palsy Alliance, The University of Sydney.
- "HABIT-iLE" Hand Arm Bimanual Intensive Training including Lower Extremity training for children with bilateral cerebral palsy; Dr Ashleigh Hines; Cerebral Palsy Alliance, The University of Sydney.
- Understanding emotions and cerebral palsy; Adj A/Prof Hayley Smithers-Sheedy; Cerebral Palsy Alliance, The University of Sydney.
- Livable Bathrooms – Washbasins in Public Accessible Bathrooms; Kim Anderson; University of New South Wales.
- Breaking the limits; Aaron Millernad; Western Sydney University.
- Body Composition of Adults with Cerebral Palsy; Jennifer Fleeton; The University of Sydney.
- Sharing your experiences of overseas stem cell treatment for cerebral palsy; Dr Madison Paton; Cerebral Palsy Alliance, The University of Sydney.
- The MUGgLE study: Muscle growth in typically developing children and children with cerebral palsy; Prof Rob Herbert; NEURA.
- A qualitative study: the lived experience, impact on daily living and management of pain in children and adolescents with cerebral palsy; Dr Katarina Ostojic; The University of Sydney, Sydney Children's Hospital Network.
- An explorative study investigating swallowing and mealtime experiences of young adults with cerebral palsy; Loren Apokourastos, The University of Sydney.
- Participate CP - Helping kids with cerebral palsy to be more physically active through doing sports and leisure; Prof Iona Novak; Cerebral Palsy Alliance, The University of Sydney.
- Epilepsy in children with cerebral palsy: defining prevalence and clinical/ radiological risk factors; Dr Kavitha Kothur, The Children's Hospital at Westmead.
- Financial costs for families and people living with cerebral palsy in Australia; Claire Galea; Cerebral Palsy Alliance, The University of Sydney.
- A valuation study to develop a Cerebral Palsy specific preference-based measure; Mina Bahramour; Griffith University.
- The mental health and well-being of children with neurodevelopmental conditions or rare genetic disorders during the COVID-19 pandemic: A survey of parents; Dr Anne Masi and Prof Valsamma Eapen; University of New South Wales.

- Theoretical treatments for spasticity management in cerebral palsy; Tawanwart Thipayawat; The University of Sydney.
- Your opinion: Neural stem cell therapy for cerebral palsy; Madeleine Smith; Monash University.
- Novel wearable augmented and alternative communication solution for people with complex communication needs; Dr Petra Karlsson; Cerebral Palsy Alliance, The University of Sydney.
- Perspectives of parents of children with cerebral palsy who have had spinal surgery: A qualitative study; Dr Margaret Wallen; Australian Catholic University.
- Does Rapid Syllable Transition Treatment (ReST) improve speech for children with cerebral palsy and makes it easier for them to take part in daily conversations; Johanna Korkalainen; The University of Sydney.
- Barriers to Strength Training for Adults with Cerebral Palsy; Jerusha Mather; Victoria University.
- Mindfulness and Cerebral Palsy; Adj A/Prof Hayley Smithers-Sheedy; Cerebral Palsy Alliance, The University of Sydney.
- Informing Knowledge Translation for Selective Dorsal Rhizotomy; Dr Simon Paget; Children's Hospital at Westmead.
- Neuro-cCMV: determining the contribution of congenital CMV infection to brain malformations and white matter disorders; Prof Richard Leventer; Royal Children's Hospital and Murdoch Children's Research Institute.
- EPIC-CP (Equity Pathways and Integrated Care in Cerebral Palsy) Co-designing equity pathways for CP; Dr Katarina Ostojic; University of New South Wales.
- Exploring Young Adulthood: Experiences and Perceptions of participation for those with cerebral palsy; Jacqueline Ding; Murdoch Children's Research Institute.
- Cultural and linguistic diversity in children with complex communication needs; Natalie Skinner; Macquarie University.
- Developing a preference-based wellbeing index: the Disability Wellbeing Index (DWI); Dr Kim Bulkeley; The University of Sydney.
- Cerebral palsy and the compulsory schooling experience: a post-school narrative enquiry; Shandele Pascoe; University of Newcastle.

Queensland Cerebral Palsy Register

- The Functional Communication Classification System (FCCS) reliability and validity for children with cerebral palsy aged 2 to 4 years. Ms Katy Caynes; The University of Queensland.
- Participation of primary school aged children with cerebral palsy and relationships with communication function. Ms Katy Caynes; The University of Queensland.
- Clinimetric evaluation of the Portable examination of Lower Limb for young people and children - Neurological (PeLLycaN) for use in children and young people with Cerebral Palsy. Ms Ramona Clarke; Griffith University.
- Financial costs for families and people living with cerebral palsy in Australia. Ms Claire Galea; The University of Sydney.
- Understanding the Physical and Mental Health, and Participation of Young People with CP. Prof Christine Imms; MCRI.
- iWHOT: Infant Wrist Hand Orthoses Trial (iWHOT): A multicentre RCT of rigid upper limb orthoses for children with cerebral palsy with embedded economic analysis. Prof Christine Imms; MCRI.

- A new version of the Kids-BESTest: validation and app development. A/Prof Leanne Johnston; The University of Queensland.
- Getting ready for school: A state-wide study investigating the service expectations and choices of families with children with CP. A/Prof Leanne Johnston; The University of Queensland.
- Muscle tone and functional performance in children. A/Prof Leanne Johnston; The University of Queensland.
- Neural Stem Cell Therapy for Cerebral Palsy: Acceptability in the Cerebral Palsy Community. Dr Madison Paton; Cerebral Palsy Alliance Research Institute, The University of Sydney.
- KeE (Key-eLearning-Early Diagnosis): A randomised controlled trial of adaptive eLearning and virtual patient simulation for early diagnosis of cerebral palsy. Prof Iona Novak; Cerebral Palsy Alliance Research Institute, The University of Sydney.
- Participation of young people with cerebral palsy. Ms Jacinta Quartermaine; The University of Queensland & CPL.
- Participation experiences of young people with cerebral palsy. Ms Jacinta Quartermaine; The University of Queensland & CPL.
- Mindfulness Based Intervention for Adults with CP with Anxiety and/or Emotion Regulation Difficulties. Adj A/Prof Hayley Smithers-Sheedy; The University of Sydney.

Victorian Cerebral Palsy Register

- Strengthening School Communities – Student Voice; Dr Ana Mantilla, Monash University
- Increasing physical activity among young adults with disability; Prof Nora Shields, Latrobe University.
- Hip surveillance for Victorian children with cerebral palsy: Evaluation of knowledge translation impact; Dr Kate Willoughby, The Royal Children's Hospital, Melbourne.
- Mindfulness Based Intervention for Adults with Cerebral Palsy with Anxiety and/or Emotion Regulation Difficulties; Adj A/Prof Hayley Smithers-Sheedy, Cerebral Palsy Alliance, The University of Sydney.
- Victorian CP Hip Surveillance Network; Tim Marshall, Murdoch Children's Research Institute.
- Neural Stem Cell Therapy for Cerebral Palsy: Acceptability in the Cerebral Palsy Community; Dr Madison Paton, Cerebral Palsy Alliance, The University of Sydney
- Musculoskeletal pathology classification; Prof Kerr Graham, The Royal Children's Hospital, University of Melbourne.
- Quantifying dyskinesia in children with cerebral palsy; Dr Melissa Louey, University of Melbourne.
- Financial costs for families and people living with cerebral palsy in Australia; Dr Claire Galea, Cerebral Palsy Alliance, The University of Sydney.
- Prophylactic Antibiotics to Prevent Chest Infections in Children with Neurological Impairment (PARROT) Trial; Prof Dinah Reddihough, The Royal Children's Hospital, Melbourne.
- iWHOTrial: A multicentre randomised controlled trial of rigid wrist hand orthoses for young children with cerebral palsy; Prof Christine Imms, The University of Melbourne.
- Understanding the needs and perspectives of people with CP and their families; Prof Christine Imms, University of Melbourne.
- Global prevalence of cerebral palsy: A systematic analysis; Dr Sarah McIntyre, Cerebral Palsy Alliance, The University of Sydney.
- Fitskills- a community-university partnership to increase exercise participation among youth with disability; Prof Nora Shields, Latrobe University.

- Social outcomes of school leavers with cerebral palsy in Victoria; Prof Christine Imms, University of Melbourne.
- Lived Experience of Overseas Stem Cell Treatment for Cerebral Palsy; Dr Madison Paton, Cerebral Palsy Alliance, The University of Sydney.
- Temporal trends, clinical characteristics, risk factors and causes of post-neonatally acquired cerebral palsy in Australia 1960-2012; Emma Waight, Cerebral Palsy Alliance, The University of Sydney.
- Temporal trends, clinical characteristics and risk factors of pre/perinatally acquired cerebral palsy in Australia 1995-2012; Dr Sarah McIntyre, Cerebral Palsy Alliance, The University of Sydney.
- Parents' beliefs and attitudes surrounding the cause of cerebral palsy and the potential genetic nature to this cause; Prof David Amor, University of Melbourne
- Understanding emotions and cerebral palsy; Adj A/Prof Hayley Smithers-Sheedy, Cerebral Palsy Alliance, The University of Sydney.
- Identifying opportunities for prevention of cerebral palsy and improved outcomes in Australian Aboriginal and Torres Strait Islander children through the examination of sociodemographic and clinical profiles; Prof Sue Woolfenden, Cerebral Palsy Alliance, The University of Sydney.
- Gene discovery in cerebral palsy; Prof Michael Kruer/Prof David Amor, University of Melbourne.
- Finding genes for rare conditions that run in families (Accelerated Gene Identification Project); Prof David Amor, The University of Melbourne.
- KeE (Key-eLearning-Early Diagnosis): A randomised controlled trial of adaptive eLearning and virtual patient simulation for early diagnosis of cerebral palsy; Prof Iona Novak, Cerebral Palsy Alliance, The University of Sydney.
- Temporal trends, clinical characteristics, risk factors and causes of postneonatally acquired cerebral palsy in Australia 1960-2014
- Cerebral Palsy and co-occurring conditions in Victorian children of immigrant and refugee backgrounds; Dr Ifrah Abdullahi; Murdoch Children's Research Institute.
- Patterns of health service utilisation in adolescents and young adults with cerebral palsy aged 10-30 years: a data linkage study; Prof Dinah Reddihough, The Royal Children's Hospital, Melbourne, Australia.
- Is access to SDR equitable in Australia? Dr Simon Paget, Children's Hospital at Westmead and The University of Sydney
- Accessing the suitability of the EQ-5D-Y for children and adolescents with intellectual disability; A/Prof Jenny Downs, Telethon Kids, WA.
- Neuro cCMV: determining the contribution of congenital CMV infection to brain malformations and white matter disorders; Prof Rick Leventer, The Royal Children's Hospital, Melbourne.
- Survival in cerebral palsy in Victoria; Dr Sue Reid, Murdoch Children's Research Institute.
- CPCHILD to CHU9D: a unique mapping algorithm for use in economic analyses of interventions for children with cerebral palsy; Dr Kate Willoughby, The Royal Children's Hospital, Melbourne.

Western Australian Register of Developmental Anomalies – Cerebral Palsy

- Mental health disorders among individuals with craniofacial anomalies in Western Australia – A population-based retrospective data linkage study; Prof Linda Slack-Smith, University of Western Australia.
- Developmental disability in the family: The impact for siblings in Western Australia; Dr Emma Glasson, Telethon Kids Institute, Perth.

- Temporal trends, clinical characteristics, risk factors and causes of postneonatally acquired cerebral palsy in Australia 1960-2014; Emma Waight, Cerebral Palsy Alliance, The University of Sydney.
- Global prevalence of cerebral palsy: A systematic analysis; Dr Sarah McIntyre, Cerebral Palsy Alliance, The University of Sydney.
- Declining trends in prevalence and severity of singleton children with prenatally or perinatally acquired cerebral palsy in Australia, births 1995-2014; Adj A/Prof Hayley Smithers-Sheedy, Cerebral Palsy Alliance, The University of Sydney.
- Impact of having a child with developmental disabilities on siblings; Caitlyn Gray, Telethon Kids Institute, Perth.
- Characterising the epidemiology of RSV and other respiratory infections through record linkage: clinical burden, outcomes, risk factors and impacts of interventions; Dr Hannah Moore, Telethon Kids Institute, Perth.
- Western Australian Child Development Atlas; Dr Megan Bell, Telethon Kids Institute, Perth.
- Modelling linked population data to understand and improve long-term outcomes for children of incarcerated mothers to reduce social and economic impacts; Dr Megan Bell, Telethon Kids Institute, Perth.
- Obstetric, sociodemographic, and environmental risks of adverse perinatal and early childhood outcomes in Australia; Dr Gizachew Tessema, Curtin University, Perth.
- Monitoring the impact of the Western Australian Preterm Birth Prevention Initiative on preterm births; Prof John Newnham, University of Western Australia.
- Exposure to family and domestic violence is associated with increased childhood hospitalisations; Dr Carol Orr, Telethon Kids Institute, Perth.
- Developmental Disability among Aboriginal Children in Western Australia; Dr Alison Gibberd, University of Melbourne.
- The utilisation and safety of prescription drugs of dependence in pregnancy; Dr Erin Kelty, University of Western Australia.
- Indigenous Child Removals Western Australia (I-CaRe WA); Prof Sandra Eades, University of Melbourne.
- Survival with CP into the sixth decade in WA; Eve Blair, Telethon Kids Institute, Perth.

Appendix D

ACPR minimum data set at time of data provision

Please note that this list does not include all variables collected by state/territory CP registers – only those submitted to the ACPR

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

1: male, 2: female, 9: unknown

Indigenous status

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

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

dd-mm-yyyy

Mother's age at time of delivery

age (years)

Mother's Indigenous status

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

ISO 3166 Alpha-2 ISO codes

Mother's occupation at time of, or prior to pregnancy

major group: Australian Standard Classification of Occupations (ABS Catalogue No 1220.0)

Mother's highest level of academic qualification at time of delivery

0: none, 1: primary, 2: incomplete secondary, 3: complete secondary, 4: Secondary NOS, 5: apprenticeship/ trade qualification, 6: incomplete tertiary, 7: complete tertiary or higher, 8: tertiary NOS, 9: not stated

Father's occupation at time of birth

major group: Australian Standard Classification of Occupations (ABS Catalogue No 1220.0)

Father's highest level of academic qualification at time of delivery

0: none, 1: primary, 2: incomplete secondary, 3: complete secondary, 4: Secondary NOS, 5: apprenticeship/ trade qualification, 6: incomplete tertiary, 7: complete tertiary or higher, 8: tertiary NOS, 9: not stated

State of birth

numeric code representing state/territory

Place of birth

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

Level of care facility of hospital of birth

1: home/hospital without neonatal intensive care unit or special care nursery, 2: hospital with special care nursery, 3: hospital with neonatal care unit, 9: not stated

State of neonatal service

numeric code representing state/territory

Length of stay in neonatal intensive care unit

number of days in neonatal intensive care unit, 000: not admitted to neonatal intensive care unit, 888: admitted to neonatal intensive care unit, 999: not stated

Length of stay in higher level care than general ward

number of days in higher level care, 000: not admitted to higher level care, 888: admitted to higher level care, 999: not stated

Classification of neonatal MRI/ultrasound (NNICS)

as per SCPE's NNICS.

Neonatal MRI/ultrasound, involvement of posterior limb of the internal capsule at term (not myelinated)

0: no, 2: yes, 9: not stated

Source of neonatal MRI/ultrasound used for classification

1: MRI/US, 2: MRI/US report, 3: other summary report, 4: other source (describe), 9: not stated

MRI completed after neonatal period, MRI classification system (MRICS)

as per SCPE's MRICS

Source of MRI used for classification

1: MRI, 2: MRI report, 3: other summary report, 4: other source (describe), 9: not stated

Assisted conception

0: no, 1: yes, ovulation stimulation / fertility drugs only, 2: yes, artificial insemination 3: yes, in vitro fertilisation, 4: yes, intracytoplasmic sperm injection, 5: yes, gamete intrafallopian transfer, 6: other (please specify), 7: yes, unknown, 8: not stated

Live births to mother

total number of mother's births prior to the birth of this child with CP.

Still births

total number of mother's births that resulted in fetal death at or after 20 weeks of pregnancy, prior to the birth of this child with CP

Birth plurality

1: singleton, 2: twins, 3: triplets, 4: quadruplets, 5: quintuplets, 6: sextuplets, 8: other, 9: not stated

Birth order

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, 8: other, 9: not stated

Twin to twin transfusion

2: yes

Co-fetal death of a multiple ≥ 20 weeks

2: yes

Birthweight

Birthweight (grams)

Gestational age

Gestational age (completed weeks)

Timing of brain injury

0: pre/perinatal (up to 28 days of life), 1: post-neonatal (after 28 days of life and before 2 years of age), 2: neonatal injury in a previously healthy infant, 9: not stated

Pre/perinatal factors of aetiological relevance:

Genetic chromosomal cause

2: yes

In utero cytomegalovirus

2: yes

Other intrauterine (TORCH) infection

2: yes

Other pre/perinatal cause

2: yes (please specify)

Congenital anomaly (1-10)

1: no birth defect, 2: nervous system, 3: urogenital, 4: musculoskeletal, 5: cardiovascular, 6: gastrointestinal, 7: chromosomal, 8: respiratory, 9: metabolic, 10: haematological or immune, 11: other

Single congenital anomalies EUROCAT classification variable

0: none, 1: chromosomal/genetic syndrome with cerebral, 2: chromosomal/genetic syndrome: without cerebral, 3: teratogenic syndrome: with cerebral, 4: teratogenic syndrome: without cerebral, 5: isolated system: cerebral, 6: isolated system: cardiac, 7: isolated system: other, 8: multiple systems: with cerebral, 9: multiple systems without cerebral, 10: minor only, 99: not stated

Congenital anomaly syndrome ICD

syndrome with congenital anomaly (code ICD9BPA or ICD10BPA)

Congenital anomaly syndrome Orphanet

syndrome with congenital anomaly, Orphanet

Congenital anomaly syndrome text

syndrome with congenital anomaly text description

Congenital anomaly code 2-9 ICD

congenital anomaly code (ICD9BPA or ICD10BPA)

Congenital anomaly 2-9 Orphanet

congenital anomaly orphanet code

Congenital anomaly 2-9 text

congenital anomaly text

Post-neonatal cause

Infection

21: dehydration due to gastroenteritis, 22: other bacterial infection, 23: other viral infection, 28: infection NOS,

Cerebrovascular accident

31: associated with surgery, 32: associated with cardiac complications (not during/post surgery), 38: spontaneous/other CVA

Head injury

40: motor vehicle accident – non-specified, 41: motor vehicle accident – passenger in vehicle, 42: motor vehicle accident – pedestrian, 43: fall, 44: non-accidental, 48: Other head injury NOS

Other causal events

51: near drowning, 52: apparent life-threatening event, 53: post-immunisation, 54: post-seizure, 55: peri-operative hypoxia, 59: other post-neonatal event

Age at which motor disorder first described as CP by clinician (not correct for preterm birth)

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: 5 years+, 9: not stated

Predominant type of CP at age 5 years

1: spastic mono/hemiplegia, 2: spastic diplegia (no limb selection required), 3: spastic triplegia (code most involved upper limb), 4: spastic quadriplegia (no limb selection required), 5: ataxia (no limb selection required), 6: dyskinetic CP, mainly athetoid, 7: dyskinetic CP, mainly dystonic, 8: hypotonic, 9: not stated

Predominant topography at age 5 years

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, 7: both sides upper limbs (dyskinetic types only), 8: both siders lower limbs (dyskinetic types only) 9: both sides upper and lower limbs (dyskinetic types only), 99: not stated

Secondary type of CP at age 5 years

1: spastic mono/hemiplegia, 2: spastic diplegia (no limb selection required), 3: spastic triplegia (code most involved upper limb), 4: spastic quadriplegia (no limb selection required), 5: ataxia (no limb selection required), 6: dyskinetic CP, mainly athetoid, 7: dyskinetic CP, mainly dystonic, 8: hypotonic, 9: not stated

Secondary topography at age 5 years

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, 7: both sides upper limbs (dyskinetic types only), 8: both siders lower limbs (dyskinetic types only) 9: both sides upper and lower limbs (dyskinetic types only), 99: not stated

Gross Motor Function Classification System (GMFCS) level at age 5 years

1: level I, 2: level II, 3: level III, 4: level IV, 5: level V, 9: not stated

Manual Ability Classification System (MACS) level at age 5 years

1: level I, 2: level II, 3: level III, 4: level IV, 5: level V, 9: not stated

Viking level at 4 years+

1: level I, 2: level II, 3: level III, 4: level IV, 9: not stated

Eating and Drinking Ability Classification System (EDACS) level at 3 years+

1: level I, 2: level II, 3: level III, 4: level IV, 5: level V, 9: not stated

EDACS level of assistance at 3 years+

0: independent, 1: requires assistance, 2: totally dependent, 9: not stated

Epilepsy at 5 years

0: none, 1: resolved by age 5 years (seizure free for two or more years without medication), 2: epilepsy, 9: not stated

Intellectual impairment at age 5 years

0: normal (IQ>70 or so described), 2: mild impairments (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: not stated

Vision at age 5 years

0: no impairment, 2: some visual impairment, 3: functionally blind (may have light perception, ability to see colour differences, sees shadows but unable to use), 9: not stated

Strabismus at age 5 years

0: no strabismus, 2: strabismus, 9: not stated

Hearing at age 5 years

0: no impairment, 2: some impairment (includes conductive loss), 3: bilateral deafness, 9: not stated

Speech impairment at age 5 years

0: no impairment, 2: some impairment, 3: non-verbal, 9: not stated.

Date of death

dd-mm-yyyy

Death cause

ICD10 code

Post-mortem carried out

0: no, 1: yes, 9: not stated

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Contact details

Australian Cerebral Palsy Register

E: cpregister@cerebralpalsy.org.au
W: cpregister.com

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