

SURVEY REPORT

In preparation for the World CP Register Congress to be held on February the 19th 2009, as part of the International Cerebral Palsy Conference in Sydney, a survey was developed and sent to all the registers or surveillance groups known by the authors at this time (N=39). This document provides a summary of the Cerebral Palsy Register and Surveillance Survey forms completed. Hereafter in this document *surveillance programs* will refer to both ongoing CP Registers and time limited CP surveys. It is envisaged that this document will be updated regularly and made available on the Cerebral Palsy Institute website. For those wishing to change any details or submit information pertaining to their surveillance program, please e-mail: cpregister@tscnsw.org.au

The current report is intended as a reference document for all interested persons, most immediately those attending the World CP Register and Surveillance Congress.

Acknowledgment

There was a high response rate to the survey (66%) and special thanks are given to all the 26 participating programs listed below. A brief description of each of these groups and relevant contact details has been provided in the final sections of this document. If other groups would like to participate their data can be added to the electronically available document at any point.

AUSTRALIA

- New South Wales and Australian Capital Territory Cerebral Palsy Register
- Northern Territory Cerebral Palsy Register
- Queensland Cerebral Palsy Register
- The South Australian Cerebral Palsy Register
- Tasmanian Cerebral Palsy Register
- Victorian Cerebral Palsy Register
- Western Australia Cerebral Palsy Register

EUROPE

- National Danish Cerebral Palsy Register
- Registre des Handicaps de l'Enfant de la Haute-Garonne (France)
- Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP) (France)
- Southern Ireland Cerebral Palsy Register (SICPR)
- Central Italy Cerebral Palsy Register
- CP in Kaunas County (Lithuania)
- Norwegian Cerebral Palsy Registry

- Registro de Parálisis Cerebral de Madrid - DIMAS (Spain)
- Slovene National Cerebral Palsy Register
- The CP Register of Western Sweden
- CP UP (Sweden)

EUROPE - UNITED KINGDOM

- Cerebral Palsy Register for Scotland
- Mersey and Cheshire Cerebral Palsy Register
- North of England Collaborative Cerebral Palsy Survey
- Northern Ireland Cerebral Palsy Register (NICPR)
- 4Child, Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children

UNITED STATES OF AMERICA

- Autism and Developmental Disabilities Monitoring (ADDM) Network
- Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)
- Cerebral Palsy Registry (Chicago)

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1. Aims of Register and Surveillance Programs

There is considerable common ground in relation to the aims of all surveillance programmes. All listed multiple aims for their work, which can be described within the categories listed below. See Section 13 for further detail.

Prevention e.g. determining aetiology (multiple causal pathways to cerebral palsy)

Surveillance e.g. determining prevalence and time trends in cerebral palsy by severity

Resource for cerebral palsy research using registered cases as a source of subjects for aetiological or management research, to investigate the generalisability of research results generated from more limited samples of persons with CP, as a means of identifying CP as an outcome in long term follow up studies or using Register observations as a source of hypotheses concerning aetiology or management to be tested by further research – with registered cases forming a sampling frame.

Planning e.g. to assist with the development and planning of services.

Raise the profile of cerebral palsy e.g. increase community awareness amongst the community and professional groups

2. Data items collected

Data sheets itemising all variables recorded were received from 11 of the 26 surveillance programs and from two additional networks – the Australian Cerebral Palsy Register (ACPR) and Surveillance of Cerebral Palsy in Europe (SCPE). Please see Appendix 1 for the data items collected by each surveillance program.

In reviewing the information concerning which data items are collected it is clear that there is considerable common ground in relation to the manner in which information is collected.

Data items collected by all 13 programs listed in Appendix 1 were as follows:

- Date of birth
- Gender
- Mother's date of birth
- Number of fetuses
- Gestation
- Birthweight
- Diagnosis / motor type
- Epilepsy / seizures
- Gross Motor Function Classification System
- Intellectual function
- Post neonatal cause / timing

3. Data sources and methods of ascertainment

Survey respondents were asked to report on both sources of case data and methods of ascertainment. 25 of the 26 (96%) of surveillance groups who participated answered these questions. As can be seen in Table 1 below, register staff used a **variety of available records and networks to capture target data**.

46% of surveillance groups gained either **notification for later follow-up and / or direct registrations to their surveillance program from medical professionals** often these were paediatricians and neurologists, see Table 2.

Table 1 Data sources

Data sources	
<p>Health Staff Medical professionals including but not limited to: paediatricians, neonatologists, orthopaedic surgeons, neurologists, general practitioners Routine Child Health Surveillance Allied health staff – outpatient clinics Health visitors Disability service providers / specialist institutes for disabled children and adolescents</p> <p>Family Parents Self-reporting</p>	<p>Administrative records Diagnostic registers Morbidity data system Midwives notification system Birth register / certificates Death register / certificates Special school admissions lists Tax register Hospital in-patient records Hospital out-patient records Hospital databases in maternity and other hospitals</p> <p>Research partnerships Pre-term / low birth weight follow-up studies</p>

Table 2 Data sources

Method of Ascertainment	Number of groups reporting this method
Part of / following medical appt (paediatrician or neurologist)	12
Part of / following therapy consult (allied health)	4
Register staff accessing education-based records and school lists	4
Register staff accessing IP /OP lists, health / diagnostic registers	4
Register staff accessing death certificates / notifications	2
Parent registering following information from register staff / health professionals	2
Register staff contacting health practitioners by phone / mail	1
Registration after being contacted by register staff at a sign-up day	1
Registration as part of a programme provided / coordinated by the register	1
Record linkage with data bases / follow-up studies	1
Voluntary reports from paediatric hospital departments	1
Self-registration	1

NB: Almost all surveillance programs reported multiple methods of ascertainment.

4. Consent requirements

The consent requirements for collecting, recording and maintaining a data set varied across the different surveillance programs. The **majority had some combination of an informed consent requirement and specific legislation to allow the collection of data** from patient records or other data sources (Table 3). The challenge of informed consent procedures and capturing all cases within a register was noted as a topic for further discussion at the World Register Congress.

Almost all (92%) surveillance programs had provisions in place to be able to contact registered cases in relation to participating in future research activities.

Table 3 Consent requirements for data collection

Name of Register	Consent for Collection of Data	Contactable for future research?
NSW and ACT Cerebral Palsy Register	IC	Y
Northern Territory Cerebral Palsy Register	IC	Y
Queensland Cerebral Palsy Register	IC	Y
The South Australian Cerebral Palsy Register	M, IC, O	Y
Tasmanian Cerebral Palsy Register	IC	Y
Victorian Cerebral Palsy Register	L, IC	Yes (approx 80%)
Western Australia Cerebral Palsy Register	L	N
National Danish Cerebral Palsy Register	L	Y
Registre des Handicaps de l'Enfant de la Haute-Garonne	IC	Y
Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP)	L, O and family consent	Y
Southern Ireland Cerebral Palsy Register (SICPR)	IC	Y
Central Italy Cerebral Palsy Register	IC	Y
CP in Kaunas County Lithuania	IC	Y
Norwegian Cerebral Palsy Registry	IC	Y
Registro de Parálisis Cerebral de Madrid – DIMAS	L first phase IC for subsequent phases	Y if IC given
The CP Register of Western Sweden	L, IC, O	Y
CP UP	IC, O	Y
Cerebral Palsy Register for Scotland	IC	Y
Mersey and Cheshire Cerebral Palsy Register	IC	Y
North of England Collaborative Cerebral Palsy Survey	IC	Y
Northern Ireland Cerebral Palsy Register (NICPR)	O	Y
4Child, Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children	L	N (except cases where IC has been given)
Autism and Developmental Disabilities Monitoring (ADDM) Network	L	Y
Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)	L	Y
Cerebral Palsy Registry (Chicago)	IC, O	Y

ORANGE: Australia **BLUE:** Europe **GREEN:** Europe -United Kingdom of Great Britain and Northern Ireland
PLUM: United States of America

M Mandatory reporting, **IC** Registration after gaining individual consent, **L** Legislation allowing collection of data
O Other e.g. combination or alternative

5. Timing of data collection

The age at which data items are collected varied from 3 years to 12 years with some registers either collecting data or able to accept new data regarding a case on an on-going basis. Ascertainment of data was considered complete by most registers at or around 5 years of age.

Table 4 Timing of data collection

Name of register / surveillance group	Age/s data items Collected	Age ascertainment considered complete
NSW and ACT Cerebral Palsy Register	N/A	5 yrs
Northern Territory Cerebral Palsy Register	N/A when available.	N/A
Queensland Cerebral Palsy Register	At referral & 5 yrs	5 yrs
The South Australian Cerebral Palsy Register	From birth – no upper limited	5 yrs
Tasmanian Cerebral Palsy Register	Age of registration	On going
Victorian Cerebral Palsy Register	5 yrs, ongoing	5 yrs
Western Australia Cerebral Palsy Register	At first ascertainment (any age) & final update at age 5	At time of 5 yr old update for each birth year cohort.
National Danish Cerebral Palsy Register	5-6 yrs	4-5 years
Registre des Handicaps de l'Enfant de la Haute-Garonne	5, 8 & 12 yrs	12 yrs
Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP)	5 & 7 yrs	7 yrs
Southern Ireland Cerebral Palsy Register (SICPR)	5 yrs	10 yrs
Central Italy Cerebral Palsy Register	2 yrs+	5 yrs
CP in Kaunas County Lithuania	5-10 yrs	5-10 yrs
Norwegian Cerebral Palsy Registry	5+ yrs from 2007	5 years
Registro de Parálisis Cerebral de Madrid – DIMAS	5 yrs	5 yrs
The CP Register of Western Sweden	At minimum of 4 yrs of age	Not specified
CP UP	4-7 yrs	ASAP after 4 th Birthday
Cerebral Palsy Register for Scotland	At diagnosis, confirmed at 4 yrs	-
Mersey and Cheshire Cerebral Palsy Register	4-5 yrs	5 yrs
North of England Collaborative Cerebral Palsy Survey	5 yrs	5 yrs
Northern Ireland Cerebral Palsy Register (NICPR)	Up to approx 7 yrs	5 yrs
4Child, Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children	3yrs & 5 years	Usually 5 yrs
Autism and Developmental Disabilities Monitoring (ADDM) Network	Birth to age 8 yrs (retrospective record review)	Most recent evaluation must be at least 2 yrs and no older than 8 yrs.
Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)	Birth to age 8 yrs	8 yrs of age
Cerebral Palsy Registry (Chicago)	At Birth to 3 3-5, 6-12, and 13-18 years	8-10 years

6. Numbers observed in denominator population and registered cohorts

Table 5 Denominator and registration numbers

Name of Register	Approx Live Births per Year for Denominator Population	Number of cases you have registered for the birth year group 1988-92	Denominator data for the birth year group 1998-1992	Number of cases you have registered for the birth year group 1993-1998	Denominator data for the birth year group 1993-1998	Number of cases you have registered for the birth year group 1999-2003	Denominator data for the birth year group 1999-2003
NSW and ACT Cerebral Palsy Register	91000	138	-	305	537,864	366	449,805
Northern Territory Cerebral Palsy Register	3,700	-	-	-	3,600 average/year	-	3,700 average/year
QLD Cerebral Palsy Register	52,000	191 (1989 - 1993 birth years)	448 alive to 5 yrs (1989 - 1993 birth years)	277 (1994 - 1998 birth years)	470 alive to 5 yrs (1994 - 1998 birth years)	284	477 alive to 5 yrs
The South Australian Cerebral Palsy Register	18,644	-	-	Confirmed cases = 208 (Clinical assess at 5yrs of age) (Ascertained cases = 263)	11,5096 live births	1999-2002 Confirmed cases (Clinical assess at 5yrs of age) = 65 (Ascertained cases = 115)	1999-2002 = 71,343 live births
Tasmanian Cerebral Palsy Register	6,300	-	-	-	-	-	-
Victorian Cerebral Palsy Register	65,000	653	323,743	703	377,911	590	311,891
Western Australia Cerebral Palsy Register	25,000	1988-1992: 369 (5-yr group; avg 74/yr; excludes 78 born outside WA)	1988-1992 (5-yr group): Live births = 126,157, Neonatal survivors = 125598	1993-1998: 433 (6-yr group; avg 72/yr; excludes 93 born outside WA)	1993-1998 (6-yr group): Live births = 151,638, Neonatal survivors = 151158	316 (5-yr group; avg 63/yr; excludes 37 born outside WA; ascertainment incomplete for years after 1999, especially 2003).	1999-2003 (5-yr group): Live births = 124,486, Neonatal survivors = 124167

Name of Register	Approx Live Births per Year for Denominator Population	Number of cases you have registered for the birth year group 1992-1998	Denominator data for the birth year group 1992-1998	Number of cases you have registered for the birth year group 1993-1998	Denominator data for the birth year group 1993-1998	Number of cases you have registered for the birth year group 1999-2003	Denominator data for the birth year group 1999-2003
National Danish Cerebral Palsy Register	60,000	277	140,531	299	143,962	-	-
Registre des Handicaps de l'Enfant de la Haute-Garonne	13,000	110	58,837	111	75,058	-	-
Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP)	28,000	170	70,000	166	84,000	-	-
Southern Ireland Cerebral Palsy Register (SICPR)	8,500	69	7618.2 average live-births	107	7342.1 average live-births pa	71	7975.2 average live-births pa
Central Italy Cerebral Palsy Register	-	-	11,434	35	19,015	-	-
CP in Kaunas County Lithuania	6,082	124	54,553	117	49,660	-	-
Norwegian Cerebral Palsy Registry	60,000	-	-	294	-	103	-
Registro de Parálisis Cerebral de Madrid – DIMAS	10,500	-	-	69	36,105	-	-
The CP Register of Western Sweden	22,000-25,000	294	129,191 live births	289	143,163	1999-2002 192 children (2003 not yet investigated)	85,737 live births
CP UP	100,000	-	-	-	-	808	377111

Name of Register	Approx Live Births per Year for Denominator Population	Number of cases you have registered for the birth year group 1992-1998	Denominator data for the birth year group 1992-1998	Number of cases you have registered for the birth year group 1993-1998	Denominator data for the birth year group 1993-1998	Number of cases you have registered for the birth year group 1999-2003	Denominator data for the birth year group 1999-2003
Cerebral Palsy Register for Scotland	55,000	130 (1990 - 1992)		183		194	-
Mersey and Cheshire Cerebral Palsy Register	25,000	450	-	250	-	50	-
North of England Collaborative Cerebral Palsy Survey	30,000	290 the catchment area increased substantially from 1991 births	-	720	-	960	-
Northern Ireland Cerebral Palsy Register (NICPR)	24,000	301 (congenital cases born in the area only)	133,354 (livebirths)	337 (congenital cases born in the area only)	144,837 (livebirths)	245 (congenital cases born in the area only)	109,464 (livebirths)
4Child, Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children	36,000	(88-92) 418	(88-92) 180,194	(93-98) 370	(93-98) 207269	(99-2002) 154	(99-2002) 133,447
Autism and Developmental Disabilities Monitoring (ADDM) Network	114,897 (2002SY)	2002SY (1994 births) = 416 cases; 2004SY (1996 births) = 227 cases	2002SY census denominator = 114,897; 2004SY census denominator = 68,272	2006SY (1998 births) = data not yet available (surveillance year in progress)	2006SY census denominator = 142,338	-	-
Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)	Surveillance year (2004), US census 8-year-olds 45,478.	1996 SY (1988 births)= 133 cases; 2000 SY (1992 births) = 135 cases	1996 SY census denominator = 36,749; 2000 SY census denominator 43,593	1996 SY (1988 births)= 133 cases; 2000 SY (1992 births) = 135 cases	2002 SY census denominator = 44,299; 2004 SY census denominator= 45,478	-	-

7. Definition of cerebral palsy

Surveillance groups used one or more of the following published definitions listed or devised an alternative definition not referenced in their survey response.

Table 6 References cited for definitions of cerebral palsy

	Badawi et al (1998)	Bax MC (1964)	Bax et al (2005)	Mutch et al (1992)	Rosenbaum et al (2007)	SCPE Group (2000)	Surman et al (2008)
Australia	■	■	■	■		■	
Europe			■	■	■	■	
UK			■			■	■
USA					■		

Badawi N., Watson, L., Petterson, B., Blair E., Slee J., Haan E., Stanley F. (1998) What constitutes cerebral palsy? *Developmental Medicine and Child Neurology* 40: 520-527

Bax MC (1964): Terminology and classification of cerebral palsy. *Developmental Medicine and Child Neurology* 6:295-307

Bax M., Goldstein M., Rosenbaum P., Leviton A., Paneth N., Dan B., Jacobsson B., Damiano D. (2005) Proposed definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology* 47:571-576

Mutch L., Alberman E., Hagberg B., Kodama K., Perat MV (1992) Cerebral palsy epidemiology: where are we now and where are we going? *Developmental Medicine and Child Neurology* 34: 547-551

Rosenbaum L., Paneth N., Leviton A., Goldstein M., Bax M. (2007) The definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology* 49 (Suppl 109): 8-14

SCPE Collaborative Group. (2000) Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. *Developmental Medicine and Child Neurology* 42:816-24.

Surman G, Newdick H, King A, Gallagher M, Kurinczuk JJ. 4Child: Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children. Annual Report 2008, including data for births 1984 to 2002. Oxford: National Perinatal Epidemiology Unit. 2008. ISSN 1749-9674

8. Classification of cerebral palsy motor types and topography

Table 7 Spastic cerebral palsy - topographic classifications used

Topography:	Unilateral	Hemiplegia	Monoplegia	Bilateral	Diplegia	Tripelgia	Quadriplegia
REGION							
AUSTRALIA		■	■		■	■	■
EUROPE	■	▲		■	▲		▲
UK	■			■			
USA*	■			■			

- Almost all surveillance groups in this region reported use of this classification
- ▲ At least one surveillance group in this region reported use of this classification
- * Used by ADDM and MADDSP

Table 8 Other cerebral palsy motor types used

	Dyskinetic			Ataxic	Hypotonic	Unknown Unclassifiable	Misc
	Dyskinetic	Dyskinetic Athetoid	Dyskinetic Dystonic				
AUSTRALIA	▲	■	■	■	▲	▲	★
EUROPE	▲	■	■	■		■	◎
UK		■	■	■		■	
USA*		■	■	■	☀	■	☀

- Almost all surveillance groups in this region reported use of this classification
- ▲ At least one surveillance group in this region reported use of this classification
- ☀ Cases with more than one but no predominant subtype were classified as spastic dyskinetic, spastic, ataxic, or dyskinetic ataxic; children with a previous diagnosis of hypotonic CP or CP not otherwise specified (NOS) plus generalized hypotonia were classified as hypotonic CP; and those with a documented diagnosis of CP but insufficient information to assign subtype were classified as CP NOS.
- ◎ Hagberg, Swedish Classification used in conjunction with SCPE. Functional classification also reported.
- ★ Functional classification reported.
- * Used by ADDM and MADDSP

9. Inclusion and exclusion criteria – part 1 Severity, hypotonia, age of survival and timing of injury

There was considerable variation across surveillance programs regarding criteria for a minimum age of survival for inclusion (from 1 year to 8 years). The majority (62%), of the 24 programs who responded to this question did not have severity criteria for inclusion as a case and most groups (92%) included postneonatally acquired cases. There was considerable variation across surveillance programs for this group with respect to the minimum age and maximum age at which the postneonatal brain damage could be acquired, see Table 9 below).

10. Inclusion and exclusion criteria – part 2 Chromosomal anomalies, genetic syndromes and metabolic diseases

There were 25 respondents to this section of the survey. These surveillance groups reported that they either did not have inclusion and exclusion criteria for cases that fell into this group (25%) or that they used one of two references to guide their decision as to inclusion or exclusion of these cases. Specifically, 29% of groups used that of Badawi et al (1998) and 46% referred to the Surveillance of cerebral palsy in Europe (2000).

Rett's Syndrome was highlighted by a number of respondents for special mention with many surveillance groups indicating that due to the progressive nature of the condition these cases would be excluded from their data set.

For those groups who did not refer specifically to either of the two references highlighted above, it was indicated that they either did not have criteria for identifying these cases or that if the definition for cerebral palsy was met then no exclusions were made.

Table 9 Inclusion and exclusion criteria

Name of register / surveillance group	Minimum age of survival for inclusion?	Severity criteria for inclusion?	Inclusion of postneonataly acquired cases to age?
NSW and ACT Cerebral Palsy Register	N	Y GMFCS 1	Y After first 28 days & by 5yrs.
Northern Territory Cerebral Palsy Register	N	N	Y -
QLD Cerebral Palsy Register	N	N	Y -
The South Australian Cerebral Palsy Register	N	N	Y -
Tasmanian Cerebral Palsy Register	N	N	Y 2 yrs
Victorian Cerebral Palsy Register	N	Y some level of motor impairment by 5 yrs	Y 2 yrs
Western Australia Cerebral Palsy Register	N	Y neurological signs even though function may not be impaired	Y After 28 days & by 5 years-
National Danish Cerebral Palsy Register	Y 1 yr	N	N
Registre des Handicaps de l'Enfant de la Haute-Garonne	Y 4 yrs	Y	Y 5 yrs
Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP)	Y 7 yrs	N	Y After 28 days by 7 years
Southern Ireland Cerebral Palsy Register (SICPR)	N	Y GMFCS 1	Y 2 yrs
Central Italy Cerebral Palsy Register	N	Y	Y
CP in Kaunas County Lithuania	N	Y GMFCS	Y 5 yrs
Norwegian Cerebral Palsy Registry	Y 1 yr	N	Y 2 yrs
Registro de Parálisis Cerebral de Madrid – DIMAS	Y 2 yrs	N	Y -
The CP Register of Western Sweden	Y 2 yrs	Y Fulfil criteria of CP	Y 2 yrs
CP UP	Y 2 yrs	Y Neurological signs and dysfunction	Y 2 yrs
Cerebral Palsy Register for Scotland	Y	N	Y After 27 days & by 2yrs
Mersey and Cheshire Cerebral Palsy Register	N	N	Y -
North of England Collaborative Cerebral Palsy Survey	N	N	Y 5 yrs
Northern Ireland Cerebral Palsy Register (NICPR)	Y 1 yr	N	Y After 28th day & by 5yrs
4Child, Four Counties Database of Cerebral Palsy, Vision Loss & Hearing Loss in Children	Y 1 yr	N	Y After first 28 days of life.
Autism and Developmental Disabilities Monitoring (ADDM) Network	Y 2 yrs	N	Y After first 28 days & by 8yrs
Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)	Y 8 yrs	N	Y -
Cerebral Palsy Registry (Chicago)	Y 2 yrs	N	Y -

11. Opportunities for research collaboration

The **majority (68%) of surveillance groups reported that they were already collaborating with other programs serving a different denominator group.**

Some respondents (44%) indicated that they had worked with other groups with the same denominator group as their own however this appeared to be less common.

The vast majority of respondents (96%) indicated that they would be **interested to consider further collaborative opportunities.**

Specifically, it was reported that collaboration would be useful in relation to research pertaining to questions where a larger sample size would be of particular benefit, for example

1. Epidemiological questions: such as the many causal pathways to cerebral palsy, cerebral palsy from consanguineous marriages, investigation of cerebral palsy in multiple births and
2. Post-neonatally acquired cerebral palsy from different causes.
3. Population-based health and
4. Social research questions such as understanding more about quality of life issues.

Larger sample sizes were noted to be essential due to the fact that for most research questions stratification of a cohort of registered cases is necessary (e.g. by cerebral palsy motor type and/or by gestational age); collaboration in this instance is often key to ensuring adequate numbers across strata.

In addition to collaborating to ensure appropriate numbers in strata, it was noted that collaboration provides a vehicle for sharing expertise and experience and was thought to be a cost and time efficient way to answer key questions in cerebral palsy research.

12. Items identified for discussion at the World Register Congress

Respondents to the survey stated they were keen to discuss with others the following questions and issues within the context of the World CP Register Congress:

Inclusion / exclusion criteria

- the sub-group of ataxic children
- age-limit for post-neonatally acquired brain injuries as CP cases
- the increasing identification of genetic syndromes, especially those that are slowly progressive, thus no longer meeting the criteria for CP, though historically they have been included (e.g., dopa-responsive dystonias, Retts, others).

Coding

- what is the best system for coding syndromes/disorders that covers the range of conditions that need to be recorded? It has been suggested that in some instances ICD10 and POSSUM are inadequate - is the McKusick numbering system a possibility (see OMIM - Online Mendelian Inheritance in Man: <http://www.ncbi.nlm.nih.gov/omim/>)?

Trends

- general decline in rate over all birthweight groups
- an increase rate in term and dyskinetic cp
- an increase in rate of unilateral cp cases

Funding and management of registers

- consent and funding
- running registers with explicit, individual consent
- stable funding

Australia

New South Wales and Australian Capital Territory Cerebral Palsy Registers

The Cerebral Palsy Institute, a wholly owned subsidiary of The Spastic of New South Wales

Commenced: 2005

Target population:

Individuals who have acquired cerebral palsy before age 5 years who were born or currently live in New South Wales or the Australian Capital Territory

Sarah McIntyre
Cerebral Palsy Institute
321 Mona Vale Road
Terrey Hills
NSW
2084
Australia
smcintyre@tscnsw.org.au
02 9479 7272

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 preventative strategies and assist in planning services for children and adults who have cerebral palsy. These goals represent the aims of the NSW and ACT CP Register and are aligned with this register's partnership with the Australian Cerebral Palsy Register.

Northern Territory Cerebral Palsy Register

Department of Health and Families

Commenced: 2008

Target population:

All individuals who have Cerebral Palsy, who born in, or live in, the Northern Territory

Carmen Ewens
Royal Darwin Hospital
Rocklands Dr
PO Box41326 Casuarina, 0811
Tiwi
NT
0810
Australia
carmen.ewens@nt.gov.au
08 89228338

Purpose:

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

Queensland Cerebral Palsy Register
Cerebral Palsy League of Queensland

Commenced: 2006

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

Michael deLacy
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Australia
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07 33588002

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

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

Women's & Children's Hospital Children, Youth and Women's Health Service
(Government of South Australia)

Commenced: 1998

Target population: Children with cerebral palsy, acquired cerebral palsy such as children who have sustained a head injury, near drowning, complications of inborn errors of metabolism and cerebrovascular accidents.

Heather Scott
Children's Youth and Women's Health Service
72 King William Road
North Adelaide
Adelaide
SA
5006
Australia
cywhs.sabdr@cywhs.sa.gov.au
(08) 81617368

Purpose:
To determine and monitor the prevalence of cerebral palsy in South Australia. To gather information about affected children that may provide clues to the causes of cerebral palsy. To document the severity and range of disabilities experienced by children with cerebral palsy. To use the information collected to plan facilities for affected children. To act as a source of information about cerebral palsy, for both families and the community. To improve community and professional awareness of cerebral palsy, including its causes and outcomes. To provide a resource for research into cerebral palsy. To contribute to mortality and morbidity studies of cerebral palsy.

Tasmanian Cerebral Palsy Register
Menzies Research Institute

Commenced: 2008

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

Julie Bunyard
Menzies Research Institute
Private Bag 23
Hobart
Tasmania
7001
Australia
tascpregister@menzies.utas.edu.au
03 62264717

Purpose:
The Tasmanian Cerebral Palsy Register collects information about people living in Tasmania with cerebral palsy. The Register is important in enabling us to know how many people are living in Tasmania with CP, in which areas they live, and whether there are any changing trends in the incidence or severity of CP. The Register also aims to facilitate research into the causes, prevention and treatment of CP.

The Victorian Cerebral Palsy Register
Murdoch Childrens Research Institute /
Royal Children's Hospital, Melbourne

Commenced: 1986

Target population:
Individuals with cerebral palsy born since 1970.

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

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

Western Australian Cerebral Palsy Register

Telethon Institute for Child Health Research

Commenced: 1977

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

Telethon Institute for Child Health Research

PO Box 855

West Perth

WA

6872

Australia

linda@icmr.uwa.edu.au

(08) 9489 7766

Purpose:

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

Europe

Denmark

National Danish Cerebral Palsy Register
National Institute of Public Health, Øster
Farimagsgade 5,2 1399, Copenhagen

Commenced: 1965

Peter Uldall
Rigshospitalet Ped Clinic 5004
Blegdamsvej
Copenhagen
2100
Denmark
pu@rh.dk
+4535455096

Target population:
CP-children only -medical history is coded
as well at age 5 years

Monitoring birthrate of CP in Denmark and
exploring into aetiology, long term follow-up
on social aspects and monitoring intervention
during first 5 years of life

France

Registre des Handicaps de l'Enfant de la Haute-Garonne Child Disabilities Register of Haute-Garonne

Institut National de la Santé et de la Recherche Médicale / National Institute of Health and Medical Research Institut National de Veille Sanitaire / National Institute of Health Surveillance

Commenced: 1999

Target population:

We record children with at least one severe disability among: motor impairments (including Cerebral Palsy), Visual and Hearing Impairments, Intellectual disabilities, Psychiatric disorders (autism and pervasive developmental disorders). The population covered by the register is the Haute-Garonne County.

Catherine Arnaud
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INSERM U 558,
37 Allées Jules Guesde
Toulouse
31073
France
carnaud@cict.fr
05 67 77 12 86

Purpose:

Our aims are: -to monitor prevalence rates of severe childhood disabilities over time. We then record children with at least one of the following impairments: motor impairments (including cerebral palsy), severe visual and hearing impairments, severe intellectual disabilities, psychiatric disorders (autism and pervasive developmental disorders) -to describe other disabilities and medical conditions associated with the main impairment and autonomy of the child -to study factors associated with these disabilities, especially perinatal factors -to describe care, assistance and schooling of these children.

Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP) (Register of childhood disabilities and perinatal survey).

Non governmental organisation. Funded by local authorities from 3 counties. Affiliated to Grenoble University (TheMAS-TIMC research team).

Commenced: 1992 (children born 1984)

Target population:

Children with severe motor deficiency, including all children with cerebral palsy Children with severe intellectual impairment (defined by IQ<50) Children with severe visual impairment children with severe hearing impairment Children with severe psychiatric disorders, including autism and psychosis.

Sylvie Rey
RHEOP
23, av Albert 1er de Belgique
Grenoble
Isère
38000
France
syrey.rheop@orange.fr
0033 457582657

Purpose:

1) Surveillance of severe childhood neuro-sensorial deficiencies: monitoring their rates and their relationship with adverse perinatal events 2) Develop research studies either on aetiology and prevention of the deficiency or on caring and participation of children with deficiency 3) extend surveillance to other childhood disabilities, e.g. children with mild mental retardation

Ireland

Southern Ireland Cerebral Palsy Register (SICPR)

Enable Ireland

Commenced: 1966

Target population:
Children with cerebral palsy

Alan Lyons
Enable Ireland
Ballintemple
Cork
Ireland
alyons@enableireland.ie
00353 (0)21 461 6854

Purpose:
In collaboration with SCPE, epidemiological functions such as determining prevalence rates, aetiology, etc. - from a clinical perspective, to develop population-based services such as secondary impairment prevention programmes - locally, and in collaboration with other registers nationally and internationally, to participate in population-based health and social research (good example is SPARCLE study)

Italy

Central Italy Cerebral Palsy Register

Commenced: 1988

Target population:
Children with cerebral palsy

Maria Giulia Torrioli
Policlinico Gemelli di Roma
Largo Agostino Gemelli 1
Rome
Italy
00100
mgtorrioli@rm.unicatt.it
0039336654363

Purpose:
Determining rates and aetiology.

Lithuania

CP in Kaunas County

Kaunas Child Development Clinic

Commenced: 2002

Target population:
Children with CP.

Audrone Prasauskiene
Kaunas Child Development Clinic
Lopselio st. 10
Kaunas
47180
Lithuania
prasauskiene.a@takas.lt
370 698 40936

Purpose:

To determine prevalence of CP in Kaunas County, to find out main aetiological factors and to give recommendations for organizing intervention activities.

Norway

Norwegian Cerebral Palsy Registry

Helse Sør Øst

Commenced: 2001

Target population:
Children with cerebral palsy.

Guro L. Andersen
Habiliteringssenteret
Postbox 2168
Welhavensvei 14-16
Tønsberg
3103
Norway
guro.andersen@siv.no

Purpose:

Determining rates, aetiology, follow perinatal care in Norway; follow treatment and follow-up of children with CP in Norway.

Spain

Registro de Parálisis Cerebral de Madrid - DIMAS (Discapacidad en la Infancia Madrid)

Madrid Health Service (Hosp Univ 12 Octub - SERMAS)

Commenced: 2004

Target population:
Children with cerebral palsy.

Javier De La Cruz
Servicio Madrileño de Salud (SERMAS)
Hospital Universitario 12 de Octubre
Unidad de Investigación - Ed. Materno-Infantil (P-2) Madrid
Madrid
28041
Madrid
jdacruz@h12o.es
+34 913 808 672

Purpose:
Determining rates - platform for research (clinical epidemiology & health services research).

Slovenia

Slovene National Cerebral Palsy Register

University Medical Centre Ljubljana

Commenced: 1976

Target population:
Children / persons with cerebral palsy.

Milivoj Velickovic Perat
University Medical Centre Ljubljana
Vrazov trg 1
Ljubljana
SI-1525
Slovenia
milivoj.velickovic@mf.uni-lj.si
+386-1-5229200

Purpose:
Epidemiology of cerebral palsy in Slovenia.

Sweden

The CP Register of Western Sweden
Sahlgrenska University Hospital, Göteborg

Commenced: 1971

Target population:
Children with cerebral palsy.

Kate Himmelmann
The Regional Rehabilitation Center for
Children and Adolescents, The Queen
Silvia Children's Hospital
Box 210 62
Göteborg
SE 418 04
Sweden
kate.himmelmann@vgregion.se
+46 31 502623

Purpose:
The aim is to monitor prevalence and
aetiology of cerebral palsy as well as gross
and fine motor function and accompanying
impairments in the population of western
Sweden.

**CPUP - Swedish National Health Care
Quality Programme for Prevention of
Hip Dislocation and Severe
Contractures in Cerebral Palsy**
Swedish National Competence Centre for
Musculoskeletal Disorders www.nko.se
and SALAR Swedish Association of Local
Authorities and Regions www.skl.se
Commenced: 2005

Target population:
Children with cerebral palsy and children
with signs of CP / probable CP. Children
not fulfilling CP criteria after fourth birthday
excluded.

Lena Westbom
Children's Hospital
Lund University Hospital
LUND
SE-221 85
Sweden
lana.westbom@med.lu.se
+46 46 178268 or 171000

Purpose:
Secondary intervention. The main goal of
the programme is to prevent hip
dislocation and severe contractures. Other
aims of the programme are to describe the
course of functioning and development in
CP, to evaluate treatment methods and
increase cooperation between health care
professionals.

Europe :

United Kingdom of Great Britain and Northern Ireland

Cerebral Palsy Register for Scotland
Napier University

Commenced: 2003

Target population:
Children with cerebral palsy born after the 1st of January 1990.

Abbi Green
CPRS
Merchiston Campus
Napier University
Edinburgh
EH7 5QF
Scotland, UK
a.green@napier.ac.uk
0131 455 2454

Purpose:
To investigate the epidemiology of CP. To monitor CP trends in Scotland. To carry out research. To assist with the development and planning of services. work into CP related issues.

Mersey and Cheshire Cerebral Palsy Register
University of Liverpool

Commenced: 1980

Target population:
Children with cerebral palsy.

Mary Jane Platt
University of Liverpool
Whelan Building
Division of Public Health
Liverpool
L69 3GB
UK
mjplatt@liv.ac.uk
44 151 794 5580

Purpose:
The objectives of the register are as follows: To monitor population trends in the prevalence of cerebral palsy within the counties of Merseyside and Cheshire. To assess the year of birth cohort effect on life expectancy of people affected by cerebral palsy born in Merseyside and Cheshire. To determine whether the severity of functional disability in cerebral palsy is changing within Merseyside and Cheshire

North of England Collaborative Cerebral Palsy Survey

Regional Maternity Survey Office

Commenced: 1960 births (retrospective),
1991 (prospective)

Target population:
Children with cerebral palsy.

Allan Colver
Newcastle University
Regional Maternity Survey Office
25 Claremont Place
Newcastle
NE61 6LH
UK
allan.colver@ncl.ac.uk
44 191 2196672

Purpose:
Epidemiology Research Service Planning.
Now beginning to be involved in quality of
care.

Northern Ireland Cerebral Palsy Register (NICPR)

Queen's University Belfast

Commenced: 1991

Target population:
Children with early onset cerebral palsy
(sustained sometime before, during or
within the first 28 days of life following
birth) and children with late onset cerebral
palsy (sustained sometime after the 28th
day of life following birth but on or before
their 5th birthday).

Dr Jackie Parkes
Queen's University Belfast
Room 1.36, Mulhouse Building
ICS, Grosvenor Road
Belfast
BT12 6BJ
Northern Ireland
j.parkes@qub.ac.uk
028 9063 5045

Purpose:
To provide a systematic approach to the
surveillance of the Northern Irish
population in determining the prevalence
and changes in prevalence, severity and
prevailing risk factors in relation to children
and young people with cerebral palsy; - to
act as a sampling frame for further
research into aetiology, health services
research and clinical care.

**4Child, Four Counties Database of
Cerebral Palsy, Vision Loss and
Hearing Loss in Children**

National Perinatal Epidemiology Unit

Commenced: 1984

Target population:

Children with cerebral palsy and / or vision
loss and / or sensorineural hearing loss.

Geraldine Surman
National Perinatal Epidemiology Unit
University of Oxford
Headington
Oxford
OX3 7LF
UK

geraldine.surman@npeu.ox.ac.uk

+44 (0) 1865 289724

Purpose:

1. To monitor the prevalence of cerebral palsy, vision loss and hearing loss in children from 1984 onwards in the four counties of Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire 2. To provide a research platform and support research and audit initiatives using 4Child data 3. To develop links with other researchers and collaborate in research within the UK, Europe and with other centres around the world.

United States of America

Autism and Developmental Disabilities Monitoring (ADDM) Network

Centers for Disease Control and Prevention (CDC)

Commenced: 2002

Target population:

The ADDM Network targets 8-year-old children born in a birth year that corresponds to the surveillance year (SY) being monitored; who have CP and/or another developmental disability -- autism spectrum disorders (all sites); intellectual disability, hearing loss, vision impairment (GA only).

Marshalyn Yeargin-Allsopp
Centers for Disease Control and Prevention
1600 Clifton Road
MS E-86
Atlanta
GA
30333
USA
mxy1@cdc.gov
404-498-3842

Purpose:

The aims of the ADDM Network are fourfold: 1) To provide regular and systematic monitoring of prevalence of selected developmental disabilities (DDs), including cerebral palsy, according to demographic factors such as age, sex, race/ethnicity and to examine temporal trends in the prevalence of the conditions; 2) To assess the possible relationships between selected maternal and child characteristics noted on birth certificates and the occurrence of the selected DDs; 3) To examine the social, emotional, medical and educational consequences of DDs ; and 4) To provide a framework for initiating special studies of children with the selected DDs through establishment of a large case series of such children.

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

Centers for Disease Control and Prevention (CDC)

Commenced: 1991

Target population:

MADDSP currently targets 8-year-old children in a birth year that corresponds to the surveillance year being monitored; who have cerebral palsy and/or another developmental disability -- intellectual disability, hearing loss, vision impairment or autism spectrum disorder; whose parent(s) or legal guardian(s) reside in the five-county metropolitan Atlanta, Georgia area of the US at some time during the surveillance year of interest.. (For surveillance years 1991-1996, monitoring was conducted on children 3-10 years-of-age.)

Marshalyn Yeargin-Allsopp
Centers for Disease Control and Prevention
1600 Clifton Road
MS E-86
Atlanta
GA
30333
USA
mxy1@cdc.gov
404-498-3842

Purpose:

The aims of MADDSP are fourfold: 1) To provide regular and systematic monitoring of prevalence of selected developmental disabilities (DDs), including cerebral palsy, according to demographic factors such as age, sex, race/ethnicity and to examine temporal trends in the prevalence of the conditions; 2) To assess the possible relationships between selected maternal and child characteristics noted on birth certificates and the occurrence of the selected DDs; 3) To examine the social, emotional, medical and educational consequences of DDs ; and 4) To provide a framework for initiating special studies of children with the selected DDs through establishment of a large case series of such children.

Cerebral Palsy Registry

Northwestern University Feinberg School of
Medicine Department of Physical Therapy
and Human Movement Sciences and
Rehabilitation Institute of Chicago and
University of Chicago Comer Children's
Hospital and Kennedy Research Center on
Neurodevelopmental Disabilities

Commenced: 2006

Target population:
Children with cerebral palsy ages birth to 18
years

Donna S. Hurley PT, DPT
Northwestern University
645 North Michigan Avenue
Suite 1100
Chicago
Illinois
60611
USA
d-hurley@northwestern.edu
312-503-3342

Purpose:

1. To establish a secure registry of children with cerebral palsy in the Chicago Metropolitan Area.
2. To connect researchers with families and children interested in participation in intervention and research studies.
3. To gather and assimilate surveillance data on children with cerebral palsy

14. List of publications pertaining to surveillance data / register output as submitted by survey respondents

References from all respondents have been collated and placed in alphabetical order as follows:

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16. Appendix

Key for Appendix Table 1

- Australian Cerebral Palsy Register (ACPR) a collaboration of 7 cerebral palsy registers from each State and Territory of Australia
- New South Wales and ACT Cerebral Palsy Register (NCPR)
- Victorian Cerebral Palsy Register (VCPR) and
- Western Australia Cerebral Palsy Register (WCPR)
- Surveillance of Cerebral Palsy in Europe (SCPE), a collaborative network of 24 cerebral palsy registers and surveys in 14 centres in 8 countries across Europe
- Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des deux Savoies (RHEOP)
- Norwegian Cerebral Palsy Register (CPRN),
- CP Register of Western Sweden (WS)
- CPUP* (Sweden) Please note that in addition to the items listed in this table CPUP collect a range of data items as part of a national follow-up program e.g. - GMFCS E&R, The Functional Mobility Scale (FMS)(version 2), Mod Ashworth (Bohannon and Smith 1987) GMFM, PEDI, MACS, Modified classification of the House, Thumb in palm
- Mersey and Cheshire Cerebral Palsy Register (MCCPR),
- North of England Collaborative Cerebral Palsy Survey (NECCPS)
- ADDM Autism and Developmental Disabilities Monitoring Network (ADDM)
- ** Disability rates and severity rates are used by RHEOP and refer to a % by the regional "disability" commission and to describe a deficiency / deficiencies e.g. motor, intellectual, sensorial, or psychiatric

To facilitate ease of reading colour coding has been used:

ORANGE: Australia **BLUE:** Europe **GREEN:** United Kingdom of Great Britain and Northern Ireland **PLUM:** United States of America

Appendix Table 1

Data collected

Items collected by all 11 programs are indicated in bold CAPITALS

	ACPR	NCPR	VCPR	WCPR	SCPE	RHEOP	CPRN	WS	CPUP*	MCCPR	NECCPS	ADDM	MADDSP
1. Child Information													
DOB													
GENDER													
Aboriginal/Indigenous status													
Ethnicity													
2. Parent information & maternal history													
Main caregiver – who eg. parent, relative, stepmother, adoptive mother													
MOTHER'S DATE of BIRTH													
Mother's height													
Indigenous status of parents													
Number of previous live births to mother													
Number of previous stillbirths to mother													
Number of previous miscarriages to mother													
Education level/occupation of parents													
Birth country of parents													
3. Information regarding pregnancy & neonatal period													
Assistance with conception													
Estimated due date by ultrasound & dates													
Early bleeding <13 weeks or 13-24 weeks													
Antepartum haemorrhage													
Placental abruption													
Placenta praevia													

	ACPR	NCPR	VCPR	WCPR	SCPE	RHEOP	CPRN	WS	CPUP*	MCCPR	NECCPS	ADDM	MADDSP
Possibility of IUGR													
Pregnancy induced hypertension													
Pre-eclampsia													
Chorioamnionitis													
Other maternal sepsis													
Maternal diabetes													
Thyroid problem													
Premature rupture of membranes													
Imminent miscarriage or preterm labour													
Rh- or ABO- immunisation													
Acute illness or disease in mother during pregnancy or delivery													
Other antenatal complication													
Signs of intrauterine asphyxia													
Indicators of fetal distress e.g. CTG, meconium													
Uterine rupture													
Other intrapartum problems including cord prolapse													
NUMBER OF FETUSES													
Order of birth if one of multiple births													
Other babies of multiple birth – birthweight, congenital anomaly, other													
GESTATIONAL AGE													
Evidence of vanished fetus or fetus papyraceous													
Place of delivery													
Onset of labour (spontaneous, induced, CS)													
Presentation at delivery (cephalic, breech, ventouse, other)													

	ACPR	NCPR	VCPR	WCPR	SCPE	RHEOP	CPRN	WS	CPUP*	MCCPR	NECCPS	ADDM	MADDSP
Delivery mode													
Placental infarction													
Time in each stage of labour													
BIRTHWEIGHT													
Head circumference at birth													
Weight/duration of gestation (standard growth curves)													
Birth length													
APGAR													
Time to establish respiration													
NICU													
Ventilation													
Resuscitation – heart massage													
Resuscitation – buffer treatment													
Resuscitation – fetal cord pH and base deficit													
Drugs given eg. surfactant / steroids													
Meningitis in neonatal period													
Perinatal hypoxia													
Perinatal apnoea													
Perinatal acidosis													
Perinatal cardiac arrest													
Intracranial haemorrhage													
Neonatal hypoxia													
Other neonatal factors/diagnoses (including rhesus incompatibility ¹ , jaundice ² , exchange transfusion ³)				1, 2 only									
Hydrocephalus													
Infection/s													
Necrotising enterocolitis													
Brain malformation													

	ACPR	NCPR	VCPR	WCPR	SCPE	RHEOP	CPRN	WS	CPUP*	MCCPR	NECCPS	ADDM	MADDSP
4. Diagnostic information & classification													
DIAGNOSIS/MOTOR TYPE													
Age/date at diagnosis													
Height													
Weight													
Aetiology of main deficiency if known													
Neonatal Seizures													
EPILEPSY/SEIZURES													
Encephalopathy													
Syndromes / congenital malformations													
Other diagnoses													
GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM													
Walking function													
Sitting ability													
Upper limb function													
Bimanual Fine Motor Function Scale													
Manual Ability Classification System													
Hand function													
Vision													
Hearing													
IQ													
INTELLECTUAL FUNCTION													
Current hydrocephalus													
Interaction with child													
Severity criteria*													
Disability rate*													
Feeding difficulties													

	ACPR	NCPR	VCPR	WCPR	SCPE	RHEOP	CPRN	WS	CPUP*	MCCPR	NECCPS	ADDM	MADDSP
Communication – understanding & expression													
Use of graphic communication aids													
Use of gesture / sign													
POSTNEONATAL CAUSE/TIMING													
5. Diagnostic testing / scans													
MRI													
CAT scan													
Cranial ultrasound in neonatal period													
Placentation – placental history													
6. Surgery / intervention													
Gastrostomy													
Fundoplication													
Saliva surgery													
Rhizotomy													
Orthopaedic surgery													
Drug treatment for spasticity – baclofen ¹ , botulinum toxin ² , intrathecal baclofen ³													
Surgery													
Drug treatment for epilepsy													
Oxygen required after hospital													

	ACPR	NCPR	VCPR	WCPR	SCPE	RHEOP	CPRN	WS	CPUP*	MCCPR	NECCPS	ADDM	MADDSP
7. Other													
Lifestyle assessment questionnaire													
Schooling													
Date and cause of death													
Paediatrician/health professionals													
Family history													

17. List of authors for referencing purposes

Smithers-Sheedy, H, McIntyre, S, Watson, L, Yeargin-Allsop, M, Blair, E, Cans, C, Report of the international survey of cerebral palsy registers and surveillance systems, 2009

