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 Périmat 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)
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

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

### Table 2  Data sources

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

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

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

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

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

Cerebral Palsy

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

<table>
<thead>
<tr>
<th>Name of Register</th>
<th>Approx Live Births per Year for Denominator Population</th>
<th>Number of cases you have registered for the birth year group 1988-1992</th>
<th>Denominator data for the birth year group 1998-1992</th>
<th>Number of cases you have registered for the birth year group 1993-1998</th>
<th>Denominator data for the birth year group 1993-1998</th>
<th>Number of cases you have registered for the birth year group 1999-2003</th>
<th>Denominator data for the birth year group 1999-2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW and ACT Cerebral Palsy Register</td>
<td>91000</td>
<td>138</td>
<td>-</td>
<td>305</td>
<td>366</td>
<td>449,805</td>
<td></td>
</tr>
<tr>
<td>Northern Territory Cerebral Palsy Register</td>
<td>3,700</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3,600 average/year</td>
<td>-</td>
<td>3,700 average/year</td>
</tr>
<tr>
<td>The South Australian Cerebral Palsy Register</td>
<td>18,644</td>
<td>-</td>
<td>-</td>
<td>Confirmed cases = 208 (Clinical assess at 5yrs of age) (Ascertained cases = 263)</td>
<td>11,5096 live births</td>
<td>1999-2002 Confirmed cases (Clinical assess at 5yrs of age) = 65 (Ascertained cases = 115)</td>
<td>1999-2002 = 71,343 live births</td>
</tr>
<tr>
<td>Tasmanian Cerebral Palsy Register</td>
<td>6, 300</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Victorian Cerebral Palsy Register</td>
<td>65,000</td>
<td>653</td>
<td>323,743</td>
<td>703</td>
<td>377,911</td>
<td>590</td>
<td>311,891</td>
</tr>
<tr>
<td>Name of Register</td>
<td>Approx Live Births per Year for Denominator Population</td>
<td>Number of cases you have registered for the birth year group 1988-1992</td>
<td>Denominator data for the birth year group 1988-1992</td>
<td>Number of cases you have registered for the birth year group 1993-1998</td>
<td>Denominator data for the birth year group 1993-1998</td>
<td>Number of cases you have registered for the birth year group 1999-2003</td>
<td>Denominator data for the birth year group 1999-2003</td>
</tr>
<tr>
<td>-----------------</td>
<td>--------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
</tr>
<tr>
<td>National Danish Cerebral Palsy Register</td>
<td>60,000</td>
<td>277</td>
<td>140,531</td>
<td>299</td>
<td>143,962</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Registre des Handicaps de l'Enfant de la Haute-Garonne</td>
<td>13,000</td>
<td>110</td>
<td>58,837</td>
<td>111</td>
<td>75,058</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Registre des Handicaps de l'Enfant et Observatoire Périmatal de l'Isère et des deux Savoies (RHEOP)</td>
<td>28,000</td>
<td>170</td>
<td>70,000</td>
<td>166</td>
<td>84,000</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Southern Ireland Cerebral Palsy Register (SICPR)</td>
<td>8,500</td>
<td>69</td>
<td>7618.2 average live-births</td>
<td>107</td>
<td>7342.1 average live-births pa</td>
<td>71</td>
<td>7975.2 average live-births pa</td>
</tr>
<tr>
<td>Central Italy Cerebral Palsy Register</td>
<td>-</td>
<td>-</td>
<td>11,434</td>
<td>35</td>
<td>19,015</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CP in Kaunas County Lithuania</td>
<td>6,082</td>
<td>124</td>
<td>54,553</td>
<td>117</td>
<td>49,660</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Norwegian Cerebral Palsy Registry</td>
<td>60,000</td>
<td>-</td>
<td>-</td>
<td>294</td>
<td>-</td>
<td>103</td>
<td>-</td>
</tr>
<tr>
<td>Registro de Parálisis Cerebral de Madrid – DIMAS</td>
<td>10,500</td>
<td>-</td>
<td>-</td>
<td>69</td>
<td>36,105</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The CP Register of Western Sweden</td>
<td>22,000-25,000</td>
<td>294</td>
<td>129,191 live births</td>
<td>289</td>
<td>143,163</td>
<td>1999-2002 192 children (2003 not yet investigated)</td>
<td>85,737 live births</td>
</tr>
<tr>
<td>CP UP</td>
<td>100,000</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>808</td>
<td>377111</td>
</tr>
<tr>
<td>Name of Register</td>
<td>Approx Live Births per Year for Denominator Population</td>
<td>Number of cases you have registered for the birth year group 1988-1992</td>
<td>Denominator data for the birth year group 1988-1992</td>
<td>Number of cases you have registered for the birth year group 1993-1998</td>
<td>Denominator data for the birth year group 1993-1998</td>
<td>Number of cases you have registered for the birth year group 1999-2003</td>
<td>Denominator data for the birth year group 1999-2003</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>-----------------------------------------------------</td>
<td>------------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
<td>------------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
<td>------------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Cerebral Palsy Register for Scotland</td>
<td>55,000</td>
<td>130 (1990 - 1992)</td>
<td>183</td>
<td>194</td>
<td>-</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Mersey and Cheshire Cerebral Palsy Register</td>
<td>25,000</td>
<td>450</td>
<td>-</td>
<td>250</td>
<td>-</td>
<td>50</td>
<td>-</td>
</tr>
<tr>
<td>North of England Collaborative Cerebral Palsy Survey</td>
<td>30,000</td>
<td>290 (the catchment area increased substantially from 1991 births)</td>
<td>-</td>
<td>720</td>
<td>-</td>
<td>960</td>
<td>-</td>
</tr>
<tr>
<td>Northern Ireland Cerebral Palsy Register (NICPR)</td>
<td>24,000</td>
<td>301 (congenital cases born in the area only)</td>
<td>133,354 (livebirths)</td>
<td>337 (congenital cases born in the area only)</td>
<td>144,837 (livebirths)</td>
<td>245 (congenital cases born in the area only)</td>
<td>109,464 (livebirths)</td>
</tr>
</tbody>
</table>

"Cerebral Palsy Institute"
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

<table>
<thead>
<tr>
<th></th>
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<th></th>
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<th></th>
<th></th>
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<tr>
<td><strong>Australia</strong></td>
<td>■</td>
<td>■</td>
<td>■</td>
<td>■</td>
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</tr>
<tr>
<td><strong>Europe</strong></td>
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<td>■</td>
<td>■</td>
<td>■</td>
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<td>■</td>
<td>■</td>
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<tr>
<td><strong>UK</strong></td>
<td>■</td>
<td></td>
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<td>■</td>
<td>■</td>
</tr>
<tr>
<td><strong>USA</strong></td>
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<td>■</td>
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<td>■</td>
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</tr>
</tbody>
</table>


### 8. Classification of cerebral palsy motor types and topography

#### Table 7: Spastic cerebral palsy - topographic classifications used

<table>
<thead>
<tr>
<th>Topography:</th>
<th>Unilateral</th>
<th>Hemiplegia</th>
<th>Monoplegia</th>
<th>Bilateral</th>
<th>Diplegia</th>
<th>Tripelgia</th>
<th>Quadriplegia</th>
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</thead>
<tbody>
<tr>
<td>REGION</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>AUSTRALIA</td>
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<td>EUROPE</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- ▲ 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

<table>
<thead>
<tr>
<th>Dyskinetic</th>
<th>Ataxic</th>
<th>Hypotonic</th>
<th>Unknown</th>
<th>Unclassifiable</th>
<th>Misc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyskinetic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyskinetic Athetoid</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyskinetic Dystonic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>REGION</th>
<th>Dyskinetic</th>
<th>Ataxic</th>
<th>Hypotonic</th>
<th>Unknown</th>
<th>Unclassifiable</th>
<th>Misc</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td></td>
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<td>EUROPE</td>
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<tr>
<td>UK</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- ▲ 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

<table>
<thead>
<tr>
<th>Name of register / surveillance group</th>
<th>Minimum age of survival for inclusion?</th>
<th>Severity criteria for inclusion?</th>
<th>Inclusion of postneonatally acquired cases to age?</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW and ACT Cerebral Palsy Register</td>
<td>N</td>
<td>Y</td>
<td>Y After first 28 days &amp; by 5yrs.</td>
</tr>
<tr>
<td>Northern Territory Cerebral Palsy Register</td>
<td>N</td>
<td>N</td>
<td>-</td>
</tr>
<tr>
<td>QLD Cerebral Palsy Register</td>
<td>N</td>
<td>N</td>
<td>-</td>
</tr>
<tr>
<td>The South Australian Cerebral Palsy Register</td>
<td>N</td>
<td>N</td>
<td>-</td>
</tr>
<tr>
<td>Tasmanian Cerebral Palsy Register</td>
<td>N</td>
<td>N</td>
<td>Y 2 yrs</td>
</tr>
<tr>
<td>Victorian Cerebral Palsy Register</td>
<td>N</td>
<td>Y</td>
<td>Y 2 yrs</td>
</tr>
<tr>
<td>Western Australia Cerebral Palsy Register</td>
<td>N</td>
<td>Y</td>
<td>Y After 28 days &amp; by 5 years-</td>
</tr>
<tr>
<td>National Danish Cerebral Palsy Register</td>
<td>Y</td>
<td>1 yr</td>
<td>N</td>
</tr>
<tr>
<td>Registre des Handicaps de l’Enfant de la Haute-Garonne</td>
<td>Y</td>
<td>4 yrs</td>
<td>Y 5 yrs</td>
</tr>
<tr>
<td>Registre des Handicaps de l’Enfant et Observatoire Périnatal de l’Isère et des deux Savoies (RHEOP)</td>
<td>Y</td>
<td>7 yrs</td>
<td>Y After 28 days by 7 years</td>
</tr>
<tr>
<td>Southern Ireland Cerebral Palsy Register (SICPR)</td>
<td>N</td>
<td>Y</td>
<td>GMFCS 1 N</td>
</tr>
<tr>
<td>Central Italy Cerebral Palsy Register</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>CP in Kaunas County Lithuania</td>
<td>N</td>
<td>Y</td>
<td>GMFCS Y 5 yrs</td>
</tr>
<tr>
<td>Norwegian Cerebral Palsy Registry</td>
<td>Y</td>
<td>1 yr</td>
<td>N</td>
</tr>
<tr>
<td>Registro de Parálisis Cerebral de Madrid – DIMAS</td>
<td>Y</td>
<td>2 yrs</td>
<td>N</td>
</tr>
<tr>
<td>The CP Register of Western Sweden</td>
<td>Y</td>
<td>Y Fulfill criteria of CP</td>
<td>Y 2 yrs</td>
</tr>
<tr>
<td>CP UP</td>
<td>Y</td>
<td>Y Neurological signs and dysfunction</td>
<td>Y 2 yrs</td>
</tr>
<tr>
<td>Cerebral Palsy Register for Scotland</td>
<td>Y</td>
<td>N</td>
<td>Y After 27 days &amp; by 2yrs</td>
</tr>
<tr>
<td>Mersey and Cheshire Cerebral Palsy Register</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>North of England Collaborative Cerebral Palsy Survey</td>
<td>N</td>
<td>N</td>
<td>Y 5 yrs</td>
</tr>
<tr>
<td>Northern Ireland Cerebral Palsy Register (NICPR)</td>
<td>Y</td>
<td>1 yr</td>
<td>N</td>
</tr>
<tr>
<td>4Child, Four Counties Database of Cerebral Palsy, Vision Loss &amp; Hearing Loss in Children</td>
<td>Y</td>
<td>1 yr</td>
<td>Y After first 28 days of life.</td>
</tr>
<tr>
<td>Autism and Developmental Disabilities Monitoring (ADDM) Network</td>
<td>Y</td>
<td>2 yrs</td>
<td>N</td>
</tr>
<tr>
<td>Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)</td>
<td>Y</td>
<td>8 yrs</td>
<td>N</td>
</tr>
<tr>
<td>Cerebral Palsy Registry (Chicago)</td>
<td>Y</td>
<td>2 yrs</td>
<td>N</td>
</tr>
</tbody>
</table>
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  
QCPR  
PO Box 386  
Fortitude Valley  
Brisbane  
Qld  
4006  
Australia  
mdelacy@cplqld.org.au  
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@ichr.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, 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
Institut National de la Santé et de la Recherche Médicale (INSERM)
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).


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
jdlcruz@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
lena.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
mplatt@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).

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.

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

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.)

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.

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
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:


- Blair E, Stanley FJ. When can spastic cerebral palsy be prevented? The generation of causal hypotheses by multivariate analysis of a case-control study. *Paediatric and Perinatal Epidemiology* 1993; 7: 272-301.


- Colver AF. The benefits of a population register of cerebral palsy. Indian Paediatrics. 2003:40:639-644
- Colver AF, Sethu T. The term diplegia should be abandoned. Archives of Disease in Childhood 2003:88:286-290


Garne E, Dolk H, Krägeloh-Mann I, Holst Ravn S, Cans C; SCPE Collaborative Group Cerebral palsy and congenital malformations Eur J Paediatr Neurol. 2007 Sep 17 [Epub ahead of print]


Gibson CS, MacLennan AH, Hague WM, Rudzki Z, Sharpe P, Chan A, Dekker GA. MTHFR C677T and Factor V Leiden thrombophilic polymorphisms are risk factors for...
cerebral palsy. Australian Society for Medical Research Conference, SA Branch, Adelaide Australia 2004 (oral presentation).


- Gibson CS, Goldwater PN, MacLennan AH, Haan EA, Priest K, Dekker GA. Fetal exposure to herpesviruses may be associated with pregnancy-induced hypertensive disorders and preterm birth in a Caucasian population. BJOG 2008; 115: 492-500.


- Glinianaia SV, Pharoah PO, Wright C, Rankin JM; Northern Region Perinatal Mortality Survey Steering Group. Fetal or infant death in twin pregnancy: neuro-developmental consequence for the survivor. Archives of Disease in Childhood, Fetal and Neonatal Edition 2002;86:F9-F15


- Jarvis S, Holloway J, Hey E. An increase in cerebral palsy in babies of normal birthweight. Archives of Disease in Childhood 1985:60:1113-21
- Jessen EC, Colver AF, Mackie PC, Jarvis SN Development and validation of a tool to measure the impact of childhood disabilities on the lives of children and their families.. Child: care, health and development. 2003:29:21-34


- McConachie H, Colver AF, Forsyth RJ, Jarvis SN, Parkinson KN. Participation of disabled children: how should it be characterised and measured? Disability and Rehabilitation 2006, 28(18):1157-1164


- Michelsen SI. Nyt forskningsprojekt om de sociale konsekvenser af cerebral parese. Spastikeren 4, 2001


Stanley FJ. The use of a register in assessing the level of handicap in the community: The WA Cerebral Palsy Register. Community Health Studies 1982; 6: 135-143.


15. Additional references

### 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 Périscolaire 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

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## 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
- Possibility of IUGR
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<th>Condition</th>
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<td>Indicators of fetal distress e.g. CTG, meconium</td>
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<td>Resuscitation – fetal cord pH and base deficit</td>
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### Communication – understanding & expression

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Use of graphic communication aids

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Use of gesture / sign

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### POSTNEONATAL CAUSE/TIMING

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### 5. Diagnostic testing / scans

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- MRI
- CAT scan
- Cranial ultrasound in neonatal period
- Placentation – placental history

### 6. Surgery / intervention

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- Gastrostomy
- Fundoplication
- Saliva surgery
- Rhizotomy
- Orthopaedic surgery
- Drug treatment for spasticity – baclofen¹, botulinum toxin², intrathecal baclofen³
- Surgery
- Drug treatment for epilepsy
- Oxygen required after hospital

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17. List of authors for referencing purposes
