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# Surveillance of Cerebral Palsy in Europe

## *Development of the JRC-SCPE Central Database and Public Health Indicators*

Agnieszka Kinsner-Ovaskainen, Monica Lanzoni, Malika Delobel, Virginie Ehlinger, Catherine Arnaud, Simona Martin

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# Surveillance of Cerebral Palsy in Europe

## *Development of the JRC-SCPE Central Database and Public Health Indicators*

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# Contents

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# Abstract

The Surveillance of Cerebral Palsy in Europe (SCPE) network was established in 1998, bringing together professionals and researchers working in population-based registries of children with Cerebral Palsy (CP) across Europe. The aims of the network are to collect population data on CP to inform and improve understanding of the disease, to raise standards of care for children with CP, disseminate knowledge for patients, health care professionals and key stakeholders, and to provide a framework for collaborative research.

In 2016, to provide sustainability for this very important network, the SCPE Central Registry and European level coordination activities were transferred to the JRC and became part of the European Platform for Rare Diseases Registration. The SCPE Central Database is annually updated with new cases submitted by the SCPE Registries.

In line with the mission of the JRC for providing evidence-based policy support, and in order to extend the use of the SCPE Central database to public health relevant outputs, the JRC-SCPE Central Registry launched the initiative of developing public health indicators. The public health indicators have been developed by based on collaboration between the JRC and the University Hospital of Toulouse. The input for the calculations of these indicators is based on data included in the standard SCPE dataset and collected annually by the registries in the JRC-SCPE Central Database.

The current report describes the development of the JRC-SCPE Central Database after the transfer from the University of Grenoble, and the definition of a first set of key health indicators.

# 1 Introduction

Cerebral palsy (CP) is the leading cause of early-onset physical disability that has a lifelong impact for the individuals and their families. Its relatively uncommon occurrence, its various clinical patterns, the fact that causal pathways are still unknown in many cases, make it a complex condition to study and emphasize the need for studying populations of large size. Population-based registries and networks of registries play an important role in this, and allow to better understand the burden of the condition at population level, examine variations in clinical practice and access to care, raise standards of care for children with CP, provide information for education and resource planning, and disseminate knowledge to health professionals, policy makers, patients and families.

In the framework of implementing European Commission's strategy in the field of rare diseases, the Directorate-General Joint Research Centre (JRC) and the Directorate-General for Health and Food Safety (DG SANTE) signed in December 2013 the Administrative Arrangement (AA) on the 'Development and Maintenance of the European Platform on Rare Diseases Registration'. One objective of the AA was the transfer of the European-level coordination activities and the Central database of SCPE to the JRC.

SCPE is a network of population-based registries for the surveillance of cerebral palsy (CP) active since 1998. Currently it has 31 members in 23 EU/EFTA countries, out of which 23 members are actively providing data to the Central Registry (Fig. 1).

In order to offer a sustainable solution for the continuation of the SCPE activities, to secure the results of former work and to keep the network functioning, it was agreed that SCPE becomes part of the European Platform for Rare Diseases Registration being developed at the JRC, since the diseases/conditions it deals with belong to the category 'rare'.

The JRC-SCPE Central Registry is located in the Health in Society Unit (JRC.F.1, Ispra, Italy). The role of the Central Registry is to maintain and further develop the SCPE Central Database, securely manage the data from all registries, and analyse the data with respect to data quality. The Central Registry also supports and participates in the coordinating activities of the network, by maintaining regular contact with single registries and organisation of meetings (annual network meetings, Management Committee and various Working Groups). Moreover, the Central Registry has an important role in the dissemination of the network's results through

scientific reports and publication of relevant information on the JRC-SCPE website (currently under development).

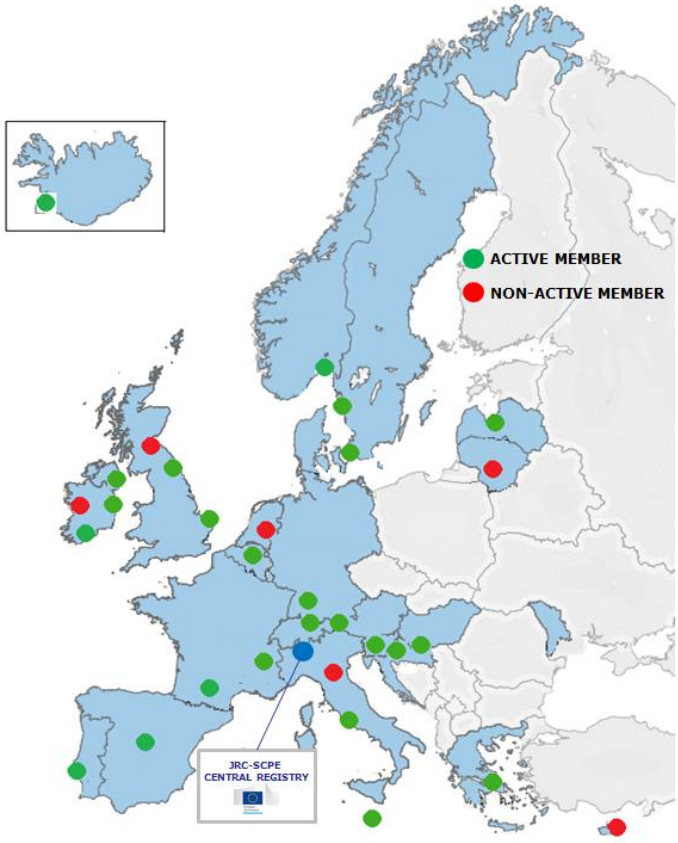


**Figure 1.** Map of the SCPE network, including active [•] and past [•] member registries and the JRC-SCPE Central Registry.

SCPE promotes quality and harmonization of CP definition/description. The SCPE Central Database is the collection of anonymised data submitted by SCPE Registry members in a standardised way, checked and validated by the Central Registry. The SCPE Central Database was transferred to the JRC in 2016 and SCPE member registries submit annually new cases to the JRC-SCPE Central Registry. The database contains about 20.000 cases of children with CP, covering the live-birth period 1976-2008.

Using the data collected in the JRC-SCPE Central Database, the network develops collaborative epidemiological and clinical research about CP, disseminates knowledge for patients, health care professionals and key stakeholders, develops best practice in monitoring trends in CP and raises standards of equitable care for people with CP. All this improves outcomes for individuals with CP.

Until now SCPE network concentrated mainly on its epidemiological and clinical research. However, the SCPE Database is also a valuable resource that can potentially

provide evidence-based information to policy makers to facilitate provision of appropriate, accessible, cost-effective care management programmes aimed to improve the quality of life for children and young people with CP and for their caregivers.

Public health indicators are increasingly developed for many conditions to inform planning, action and reporting, and overall serve as a basis for policy-making to improve the health at the population level. They are at the intersection of health policy issues and routinely collected datasets. They must be monitored on a systematic basis, regularly reported, using a consistent set of data that reflects the whole scope of the condition, and over time thus identifying any trend. Consistent with this, the public health indicators may assist in determining what the research priorities are.

The current report describes conceptual definition of a first set of public health indicators that have been developed based on collaboration between the JRC and the University Hospital of Toulouse. The input for the calculations of these indicators will be based on data included in the standard SCPE dataset and collected annually by the registries in the JRC-SCPE Central Database.

The SCPE public health indicators are intended to be useful descriptive tools for a better understanding of the condition, for monitoring the heath of the population of children with CP, and for addressing their main determinants. They are designed to show differences between registries that could reflect the complex interactions between social and economic factors, the physical environment, the access to care and individual behaviours and living conditions. These indicators are the first step to invite actions for implementing programs and service deliveries for improvement of the children's condition and life when growing and aging.

# 2 The evolution of the JRC-SCPE Central Database

The added value of the SCPE network of registries comes from the pooling of standardised data into the Central Database to perform monitoring and research activities. The operation of the Central Database includes all activities aimed at strengthening the value and quality of the database. This comprises, among other functions, maintaining the database, updating it annually with data submissions from registries, and extending the network of data providers.

The SCPE Central Database has been transferred from the Centre in Grenoble to the JRC in December 2016. In 2016 the JRC-SCPE Central Registry performed several activities to enable full functionality of Central Database at JRC, including the formalisation of the collaboration agreement with all registries, set-up of the secure JRC-SCPE IT infrastructure and notification to the Data Protection Officer.

## 2.1 Management of the Central Database

The Central Database was transferred from the Centre in Grenoble in an Ms Access file format containing data collected from the registries and variables derived from them. At the moment of the transfer, the database contained 17.372 cases collected since 1998 (until the birth year 2006), as well as the denominators for all active registries.

After the transfer of the Central Database the JRC-SCPE Central Registry contacted all registries of the network in order to check that all the data were present and in line with the local datasets. In April 2017 a general update of the different types of denominators used for the analysis of the data was also performed. Not all the registries are able to collect locally all the type of denominators, while it is possible for the registries that have a national coverage (Table 1).

**Table 1.** Percentage of SCPE active registries (18) which have the different types of denominators.

| Denominator type | % of SCPE active registries |
|---|---|
| Total births | 100% |
| Delivery mode | 50% |
| Delivery mode (by birth weight) | 44% |
| Delivery mode (by gestational age) | 44% |
| Place of birth | 72% |
| Maternal age and parity | 94% |
| Neonatal death (by birth weight) | 67% |
| Neonatal death (by gestational age) | 67% |
| Neonatal death Multiple (by birth weight) | 56% |
| Neonatal death Multiple (by gestational age) | 56% |
| Livebirth (by birth weight) | 83% |
| Livebirth (by gestational age) | 72% |
| Livebirth Multiple (by birth weight) | 61% |
| Livebirth Multiple (by gestational age) | 61% |

Before the transfer of the entire database, between June and September 2016 the JRC-SCPE Central Registry managed the first data submission campaign. Thirteen SCPE registries participated in the data submission campaign and a total of 1503 cases were sent to the JRC. Registries transmitted data through the JRC-SCPE data transmission portal. The data collected were then validated in collaboration with the previous Central Registry team in Grenoble.

At the beginning of the 2017 the validated data were imported in the Central Database and a first feedback performed by the Central Registry. Figure 1 shows the status of the Database in May 2017.

## 2.2 Management of the data submission campaigns for the birth year 2008

To achieve the main purpose of surveillance of cerebral palsy in Europe, the Central Database needs to be regularly updated by registry members. The SCPE network established a calendar with one annual data collection campaign, during the spring time. The data are collected based on a set of variables defined in the "Guideline for data submission" developed by the network. This is a guidance document aimed at enabling registers to prepare files of CP cases and population-based denominators to be submitted to the SCPE common database, in accordance with the SCPE agreed definition and inclusion criteria, the predefined format for the requested items.

After the data are submitted to the Central Registry, data checks and validation follow and "feed-back to registries" documents are prepared and discussed during the Annual Plenary meeting usually taking place in October-November.

The new data collection for the birth year 2008 was performed between April and July 2017. In view of the development of a first set of Public Health Indicators that will be used to also for a routine evaluation of the CP data collected by the registries, many centres preferred to update their data for the previous years and re-align the Central Database with the local data. The following registries submitted and validated the data for the birth year 2008: C02 (Toulouse, France), C06 (Sweden), C07 (Dublin, Ireland), C13 (Italy), C21 (Portugal), C22 (Riga, Latvia), C23 (Hungary), C25 (Iceland), C28 (Croatia), C29 (S. Gallen), C31 (Greece). In addition, C01 (France, Grenoble) and C23 (Hungary) sent data for 2007, C27 (Belgium) sent new cases for 2007, and C15 (Norway) updated data with new cases for the period 1998-2007.

Figure 2 shows the status of the JRC-SCPE Central Database in October 2017.

| | C01 | C02 | C03 | C04 | C05 | C06 | C07 | C09 | C10 | C11 | C12 | C13 | C14 | C15 | C16 | C17 | C18 | C19 | C21 | C22 | C23 | C24 | C25 | C26 | C27 | C28 | C29 | C31 | TOTAL |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1976-1997 | 532 | 491 | 747 | 373 | 1,134 | 1,001 | 1,014 | 1,305 | 220 | 1,011 | 1,787 | 188 | 127 | 127 | 80 | 104 | 78 | | 118 | | | | 85 | 85 | | | 24 | | 10,631 |
| 1998 | 32 | 18 | | 21 | 69 | 32 | 42 | 42 | | | 147 | 20 | | 100 | | 10 | 12 | | | | | | 13 | 10 | | | 12 | | 580 |
| 1999 | 49 | 34 | | | 54 | 41 | 48 | 46 | | | 151 | 1 | | 129 | | | 13 | 49 | | | 22 | 8 | 14 | 11 | 22 | | 6 | 35 | 733 |
| 2000 | 43 | 21 | | | 47 | 51 | 54 | 52 | | | 147 | 4 | | 121 | | | | 47 | | 11 | 25 | 9 | 15 | 14 | 27 | | 13 | 39 | 740 |
| 2001 | 36 | 31 | | | 65 | 54 | 49 | 59 | | | 120 | 1 | | 123 | | | | 43 | 238 | 10 | 27 | 12 | 10 | 13 | 10 | | 13 | 61 | 975 |
| 2002 | 34 | 22 | | | 41 | 40 | 53 | 48 | | | 137 | 4 | | 142 | | | | 38 | 181 | 11 | 17 | | 9 | 18 | 24 | | 9 | 64 | 892 |
| 2003 | 53 | 26 | | | 65 | 52 | 52 | 45 | | | 106 | 5 | | 130 | | | | 30 | 193 | 16 | 12 | | 6 | 6 | 26 | 86 | 7 | 50 | 966 |
| 2004 | 44 | 20 | | | | 45 | 54 | | | | 130 | 4 | | 147 | | | | 49 | 163 | 10 | 13 | | 9 | 13 | 25 | 63 | 13 | 82 | 884 |
| 2005 | 31 | 27 | | | 59 | 50 | 57 | | | | 103 | 5 | | 145 | | | | 38 | 168 | 15 | 17 | | 15 | 9 | 23 | 62 | 6 | 43 | 873 |
| 2006 | | 24 | | | | 56 | 61 | | | | 132 | 3 | | 157 | | | | 43 | 157 | 11 | 17 | | 6 | 12 | 20 | 79 | 10 | 45 | 833 |
| 2007 | | 19 | | | | 53 | 58 | | | | 121 | 1 | | 129 | | | | | 137 | 9 | | | 8 | | 151 | 77 | 10 | | 773 |
| TOTAL | 854 | 733 | 747 | 394 | 1,534 | 1,475 | 1,542 | 1,597 | 220 | 1,011 | 3,081 | 236 | 127 | 1,450 | 80 | 114 | 103 | 338 | 1,355 | 93 | 150 | 29 | 190 | 191 | 329 | 367 | 123 | 419 | 18,880 |

**Figure 2.** JRC-SCPE Central Database in May 2017: number of cases per year and registry. In green data collected at the JRC during the 2016 data submission campaign.

| | C01 | C02 | C03 | C04 | C05 | C06 | C07 | C09 | C10 | C11 | C12 | C13 | C14 | C15 | C16 | C17 | C18 | C19 | C21 | C22 | C23 | C24 | C25 | C26 | C27 | C28 | C29 | C31 | TOTAL |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1976-1997 | 532 | 491 | 747 | 373 | 1,134 | 1,001 | 1,014 | 1,305 | 220 | 1,011 | 1,787 | 188 | 127 | 127 | 80 | 104 | 78 | | 118 | | | | 85 | 85 | | | 24 | | 10,631 |
| 1998 | 32 | 18 | | 21 | 69 | 32 | 42 | 42 | | | 147 | 20 | | 148 | | 10 | 12 | | | | | | 13 | 10 | | | 12 | | 628 |
| 1999 | 49 | 34 | | | 54 | 41 | 48 | 46 | | | 151 | 1 | | 188 | | | 13 | 49 | | | 22 | 8 | 14 | 11 | 22 | | 6 | 40 | 797 |
| 2000 | 43 | 21 | | | 47 | 51 | 54 | 52 | | | 147 | 4 | | 175 | | | | 47 | | 11 | 25 | 9 | 15 | 14 | 27 | | 13 | 45 | 800 |
| 2001 | 36 | 31 | | | 65 | 54 | 49 | 59 | | | 120 | 1 | | 181 | | | | 43 | 240 | 10 | 27 | 12 | 10 | 13 | 10 | | 13 | 63 | 1,037 |
| 2002 | 34 | 22 | | | 41 | 40 | 53 | 48 | | | 137 | 4 | | 177 | | | | 38 | 183 | 11 | 17 | | 9 | 18 | 24 | | 9 | 68 | 933 |
| 2003 | 53 | 26 | | | 65 | 52 | 52 | 45 | | | 106 | 5 | | 173 | | | | 30 | 199 | 16 | 12 | | 6 | 6 | 26 | 86 | 7 | 55 | 1,020 |
| 2004 | 44 | 20 | | | | 45 | 54 | | | | 130 | 4 | | 189 | | | | 49 | 164 | 10 | 13 | | 9 | 13 | 25 | 63 | 13 | 83 | 928 |
| 2005 | 31 | 28 | | | 59 | 50 | 57 | | | | 103 | 5 | | 186 | | | | 38 | 177 | 15 | 17 | | 15 | 9 | 23 | 62 | 6 | 56 | 937 |
| 2006 | 48 | 25 | | | | 56 | 61 | | | | 132 | 3 | | 176 | | | | 43 | 171 | 11 | 17 | | 6 | 12 | 20 | 79 | 10 | 68 | 938 |
| 2007 | 30 | 21 | | | | 53 | 58 | | | | 121 | 1 | | 164 | | | | | 144 | 9 | 14 | | 8 | | 166 | 77 | 10 | 57 | 933 |
| 2008 | | 26 | | | | 54 | 77 | | | | | 4 | | | | | | | 148 | 5 | 18 | | 6 | | | 76 | 9 | 54 | 477 |
| TOTAL | 932 | 763 | 747 | 394 | 1,534 | 1,529 | 1,619 | 1,597 | 220 | 1,011 | 3,081 | 240 | 127 | 1,884 | 80 | 114 | 103 | 337 | 1,544 | 98 | 182 | 29 | 196 | 191 | 343 | 443 | 132 | 589 | 20,059 |

**Figure 3.** JRC-SCPE Central Database in October 2017: number of cases per year and registry. In green data collected in 2016 campaign an in orange data collected in 2017 campaign at the JRC.

## 2.3 Feedback to the registries on the data submitted

After the data submission campaign, a feedback report for every registry was prepared by JRC-SCPE Central Registry in collaboration with the Centre in Grenoble, based on the procedures used until now by SCPE network and described in the Standard Operating Procedure n°6 "Feedback to the registries and network".

The objective of this report is to provide in a systematic way comment to the registries that during the last data submission campaign sent data to the JRC-SCPE Central Registry. It is the main instrument for the registries to identify possible problems and areas for improvement in the data collection, and for the SCPE Data and Scientific Working Groups to evaluate if a given variable has a good coverage in order to be used for data analysis and in research studies.

The template for the feedback report (*Annex 1*) has been updated by the Central Registry adding information on the unknown/not collectable data rates, and reports distribution of key variables, prevalence rates of a given registry in comparison with data previously submitted by the same registry, as well as data submitted by other registries during the same campaign.

# 3 Definition of SCPE Public Health Indicators

The SCPE public health indicators aim to summarize important aspects of the public health impact of CP. They enable to make comparisons between countries/registries and over time. They are reported in six measures based on reliable and comparable data compiled in the JRC-SCPE Central Database after thorough harmonisation and validation processes.

The SCPE public health indicators are defined to evaluate the following four areas:

- **Long-term child health outcomes**: Birth prevalence rate of CP, a recommended EuroPERISTAT indicator[1];
- **Burden of disease**: Type of motor function disorder, walking ability, and birth prevalence rate of severe cases of CP;
- **Access to facilities/services**: Proportion of children who have had neuroimaging;
- **Preventive health strategies**: Prevalence and severity of CP cases with post-neonatal origin.

## 3.1 Birth prevalence of cerebral palsy

This indicator relates to pre- or perinatal cases of CP (a case of CP with a known post-neonatal cause is excluded). It is split into birth prevalence and trend in birth prevalence, both per 1,000 live births.

The number of people affected in the population is a measure of long term consequences of perinatal complications, relevant to better understand the effectiveness of the organisation of perinatal care and practices. Cerebral palsy has been a recommended EuroPERISTAT indicator for long-term child health outcomes since 2007, especially as mortality rates can no longer reflect standards in perinatal care accurately in view of the improved survival rates.

## 3.2 Type of motor function disorder

The distribution of the type of motor function disorder reflects the predominant motor function pattern. It shows the frequency of bilateral (bilateral spastic, dyskinetic) and unilateral (unilateral spastic) forms. It serves as an indicator of severity and therefore burden of disease.

[1] http://www.europeristat.com/our-indicators/indicators-of-perinatal-health.html

## 3.3 Walking ability

Walking ability is defined according to the levels of the Gross Motor Function Classification System (GMFCS, a classification of the movement ability of children with CP), classifying the children into 3 categories as follows: 'mild' forms corresponding to GMFCS levels I-II (independent walker), 'moderate' forms with GMFCS level III (walker with aid), and 'severe' forms GMFCS levels IV-V (wheelchair). It serves as an indicator of burden of disease.

## 3.4 Prevalence of severe cases of cerebral palsy

The severity of CP is defined by severe impairment of the gross motor function (GMFCS III-V) or an associated cognitive impairment (defined by an intellectual quotient (IQ) <50). This indicator is split into prevalence and trend in prevalence of severe cases, both per 1,000 live births. It serves as an indicator of burden of disease.

## 3.5 Access to neuroimaging

Access to neuroimaging is defined by the proportion of children with CP who have had at least one MRI of the brain whatever the period when this imaging occurred (neonatal period i.e. before discharge from the neonatal unit, or post-neonatal period, usually after 2 years of age). There is an international consensus that neuroimagining is of great importance in the understanding of pathogenesis in relation to timing of brain insult, and to a lesser extent aetiology of the brain disorder. It helps understanding the deteriorated function. Access to neuroimaging serves as an indicator of access to health services.

## 3.6 Prevalence and severity of cerebral palsy of post-neonatal origin

This indicator relates to post-neonatally acquired CP, i.e. cases with an identified causal event independent of antenatal and perinatal periods (mostly after the 28$^{th}$ day of life) occurring before 24 months of age. This indicator is split into prevalence and prevalence of severe cases (severe cases are defined by GMFCS levels III-V or IQ<50) and is reported per 10,000 livebirths. Because the main underlying causes of brain lesions (infections, head injury, surgical complications) that occur post-neonatally are potential targets for preventive actions, this is an indicator of preventive health strategies.

# 4 Procedures for Calculating the SCPE Public Health Indicators

## 4.1 Definition of CP

Cerebral Palsy is a group of permanent, but not unchanging, disorders of movement and/or posture and of motor function, which are due to a non-progressive interference, lesion, or abnormality of the developing/immature brain. This definition specifically excludes progressive disorders of motor function, defined as loss of previously acquired skills in the first 5 years of life. Children with hypotonia as the sole clinical feature and children with isolated spinal neural tube defects are excluded.

In order to be included in the JRC-SCPE Central Database, cases must fulfil this definition. The diagnosis is made solely on the basis of clinical description, independent of pathology or aetiology. Five years is the optimal age for confirmation of diagnosis. However, cases are considered for inclusion in the JRC-SCPE Central Database if they fulfil the clinical criteria after their 4$^{th}$ birthday. Submitted to the JRC-SCPE Central Database are also *i)* children with a diagnosis of CP made after the age of 2 years but who died before this diagnosis can be reconfirmed (between 2 and 5 years); *ii)* children lost to follow-up at the age of 5 years but with unambiguous diagnosis of CP after the age of 3 years.

## 4.2 Source of data

The data used include all cases of cerebral palsy from population-based registries participating in the SCPE network, covering either a part or the whole country. These registries provide annually anonymised data to the JRC-SCPE Central Database. Annual population data (live births the same year in the same catchment area) are available from the census or any official data population source.

Registries with a small area covered (defined as an area with less than 3,000 live births per year) are removed for these analysis.

In addition, for post-neonatally acquired CP, the population is restricted to registries which collect such data on a regular basis and with at least one case recorded during the three last years. Data for the indicators (prevalence by centre and overall, and distributions) presented here correspond to birth cohorts 2005 to 2007 that were submitted to the Central Database between 2014 and 2016. For the calculations of

trends in this report, 10 years were considered (birth-cohorts from 1998 to 2007). A test analysis was performed to assess the performance of the proposed indicators. The Table 2 reports the registries currently in the Central Database before application of any inclusion or exclusion criteria for indicators' estimations.

**Table 2.** SCPE registries, years and number of cases included in the test dataset.

| Centre | Birth year | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 |
| C01 – Grenoble, France | 32 | 49 | 43 | 36 | 34 | 53 | 44 | 31 | | |
| C02 – Toulouse, France | 18 | 34 | 21 | 31 | 22 | 26 | 20 | 27 | 24 | 19 |
| C05 – Northern ireland | 69 | 54 | 47 | 65 | 41 | 65 | | 59 | | |
| C06 – Sweden, Goteborg | 32 | 41 | 51 | 54 | 40 | 52 | 45 | 50 | 56 | 53 |
| C07 – Iteland, Dublin | 42 | 48 | 54 | 49 | 53 | 52 | 54 | 57 | 61 | 58 |
| C12 - Denmark | 147 | 151 | 147 | 120 | 137 | 106 | 130 | 103 | 132 | 121 |
| C13 - Italy | 20 | 1 | 4 | 1 | 4 | 5 | 4 | 5 | 3 | 1 |
| C15 - Norway | 100 | 129 | 121 | 123 | 142 | 130 | 147 | 145 | 157 | 129 |
| C19 - Slovenia | | 49 | 47 | 43 | 38 | 30 | 49 | 38 | 43 | |
| C21 - Portugal | | | | 238 | 181 | 193 | 163 | 168 | 157 | 137 |
| C22 - Latvia | | | 11 | 10 | 11 | 16 | 10 | 15 | 11 | 9 |
| C23 – Hungary, Pecs | | 22 | 25 | 27 | 17 | 12 | 13 | 17 | 17 | |
| C25 - Iceland | 13 | 14 | 15 | 10 | 9 | 6 | 9 | 15 | 6 | 8 |
| C26 - Austria | 10 | 11 | 14 | 13 | 18 | 6 | 13 | 9 | 12 | |
| C27 – Belgium (Leuven, then whole country) | | 22 | 27 | 10 | 24 | 26 | 25 | 23 | 20 | 151 |
| C28 - Croatia | | | | | | 86 | 63 | 62 | 79 | 77 |
| C29 Switzerland, St Gallen | 12 | 6 | 13 | 13 | 9 | 7 | 13 | 6 | 10 | 10 |
| C31 – Greece, Athens | | 35 | 39 | 61 | 64 | 50 | 82 | 43 | 45 | |

## 4.3 Data analysis

### *Selection of cases*

For indicators 1 to 5, cases of CP with a post-neonatal onset are excluded (i.e. collected variable POSTNEON≠1). Indeed, for post-neonatally acquired CP, a causal event independent of antenatal and perinatal periods (mostly after the 28th day of life) occurring before 24 months of age can be identified. As noted above, indicator number 6 refers to post-neonatal CP solely.

### *Prevalence calculations*

Prevalence of CP were calculated per 1,000 live births. Children whose mothers lived in an area covered by a registry at the time of birth were considered (exclusion of cases with collected variable BIRTH_RESID=2), except for French centres where the

children included lived in the area at time of ascertainment (exclusion of cases with collected variable REGIST_RESID=2).

Prevalence rates are reported by centre, and overall.

Given:

Birth year i

Centre j (j=1, ..., J)

$Nb\_CP_{i,j}$ , the number of cases of CP year i center j

$LB_{i,j}$, the number of livebirths year i center j

$Prev\_CP_{i,j,\_}$ prevalence year i center j

$$Prev\ CP_{i,j} = \frac{NB\ CP_{i,j}\ x\ 1000}{LB_{i,j}}$$

The prevalence for year i, all J centres together, is calculated as follows:

$$Prev\_CP_i = \frac{1000\ \text{x}\ \sum_{j=1}^{j} nb\_CP_{i,j}}{\sum_{j=1}^{j} LB_{i,j}}$$

Post-neonatally acquired CP are rare events (around 5% of cases) and therefore reported per 10,000 livebirths. The prevalence rate of CP with a post-neonatal origin is only presented at the EU level (by pooling all cases from relevant registries altogether) because of the low prevalence.

In all cases, because registry data cover a given country in its entirety or part of it but not primarily chosen to be representative of the whole country, rates are presented without any confidence intervals.

Prevalence rates are estimated 8 to 9 years after birth. This delay is explained by several elements whose effects are cumulative. Firstly, age at confirmation of diagnosis of CP is at least 4 years. Therefore, registration of children with CP in population-based registries cannot be considered before the age of 4-5 years. Secondly, time is needed for the registration and validation of cases at the local levels, before being reported to the Central Registry.

## *Trends over time*

Assessment of time trends is done by pooling the data from all registries. Trends are reported over a 10-year period (birth-cohorts from 1998 to 2007 in the test dataset used in this report). The number of registries considered in the analyses potentially

differs across the period. To smooth out short-term fluctuations and facilitate the interpretation, prevalence is presented using a 3-year simple moving average. For year i (central value), an unweighted mean of prevalence rates for years i-1 to year i+1 is calculated. A line graph is proposed with all central values on the x axis (10 birth cohorts, 8 points).

### *Other indicators*

For the other indicators, the distributions by registry are presented in tables or bar charts as appropriate, representing 2005 to 2007 birth-cohorts' data pooled together.

# 5 Development of statistical programmes for standardised calculation of the Public Heath Indicators

The SCPE Public Health Indicators which will be part of the annual feedback to SCPE registries, and will be also published every year on the SCPE website. Therefore, the calculations of the indicators have been automatized. Two procedures were developed under the Stata software (Stata Data analysis and Statistical software, v14).

The first procedure is used to prepare the data required for the calculations (CP cases as well as denominators) and to obtain the merged files in a correct format (for more details of the procedure see *Annex 2*).

The second detailed Stata program serves to automatically calculate and report the indicators (tables and graphs) (for more details of the procedure see *Annex 3*).

These two programmes will become the official procedure for the calculation of the SCPE Public Health indicators. They will be modified only after validation and approval of the JRC-SCPE Management committee.

## 5.1 Data requested and creation of databases for calculations

The program provided is the whole statistical reporting program for all centers. It requires the provision of the individual cases per registry collected in the JRC-SCPE Central Database in .txt format (statistical unit: CP case) and a database containing the denominators recorded in Stata (.dta) format. The database of the denominators must contain 3 variables named as follows: center, anais (birth of year), and livebirth.

The names of the outputs (text output and graphics, saved as .wmf) as well as the directories can be modified by the user. From line "Do not modify the rest of the program file" in the Stata programs, the user no longer has to modify the program.

The Stata program developed in order to prepare the databases creates six databases:

– **"$scpe_db prepared_$today"**: individual data on CP cases,

– **"scpe_aggregated_data prepared_$today"**: aggregated data (by year and registry), numerators and denominators,

– **"scpe_aggregated_data_pre_peri_10y_all prepared_$today"**: aggregated data (by year), numerators and denominators for pre-/peri-natal CP,

–**"scpe_aggregated_data_pre_peri_severe_10y_all prepared_$today"**: aggregated data (by year), numerators and denominators for severe pre-/peri-natal CP,

– **"scpe_aggregated_data_postneon_10y_all prepared_$today"**: aggregated data (by year), numerators and denominators for post-neonatal CP,

– **"scpe_aggregated_data_postneon_severe_10y_all prepared_$today"**: aggregated data (by year), numerators and denominators for severe post-neonatal CP,

where **"$scpe_db"** refers to "SCPE individual data" and **"$today"** refers to "current date" ($scpe_dbet $today are global variables in the Stata programs). The name of the SCPE individual data is completed by the user at the beginning of the program, whereas the current date is computed by Stata. Because the current date is included in the name of the databases, the data preparation program and the data analysis program have to be applied on the same day.

Finally, it is important to note that the Stata program has to be applied in its entirety, because it uses local variables.

The Stata programs need version 14 of Stata with additional installation of two packages:

- Stata "estout" package (http://repec.org/bocode/e/estout) is used to export two way contingency tables in text files,

- Stata "sencode" package ((http://fmwww.bc.edu/RePEc/bocode/s/) is used to create the variable "centre_country".

Before starting the program, the user must complete the last year of birth to consider. For example, if the last year considered is 2007, the calculations will generate the indicators for 3 years corresponding to the 2005-2007 birth cohorts, and for 10 years corresponding to the 1998-2007 birth cohorts, according to the indicators.

## 5.2 Content of the statistical program and exclusions from the calculations

A summary of sampling variables created in order to identify the year of birth and registries included in the analyses is given. The exclusion of small registries is based on the number of live births in the area according to SCPE definition: less than 3,000 livebirths on average during the last three years considered in the calculations. Exclusion criteria are summarized separately for each SCPE indicator. Thereafter, a list of registries included in each analysis is provided. The number of registries included in the trend analyses may differ according to birth of year; therefore, registries included in the analyses are reported by birth year.

Description of the proportion of missing/unknown values on the variables requested for analysis is also presented for information. '-99' values correspond to not applicable i.e. for registries previously excluded from the analyses for a given indicator. The way missing values are considered in the analysis is precisely considered and defined for each indicator. As a general rule, registries that have a high proportion of missing/unknown data are excluded.

For Public Health Indicator n°4 (**Prevalence of severe cases**), registries are removed from the analysis if the proportion of missing/unknown data for GMFCS and IQ level exceeds 10% for at least one birth-year (proportion estimated excluding post-neonatal cases of CP). Considering Public Health Indicator n°5 (**Access to neuroimaging**), a higher threshold is retained: 30% of missing values in the derived variable over the 3 years.

The definition of severity includes the GMFCS as a measure of walking ability (alone or in association with IQ level depending on the indicator). The inclusion of the variable "GMFCS" in the database was recommended from birth year 1997. The WALKING which is no longer collected in the SCPE database was maintained for registries which could not provide the GMFCS levels. Due to the date of this change, the program only considered the GMFCS variable as a measure of walking ability. However, for Public Health Indicator n°6 (**Prevalence and severity of post-neonatal CP**) and for the test provided here, due to the combination of the rarity of the condition and high levels of missing missing/unknown data for GMFCS, the prevalence of severe post-neonatally acquired CP is not presented. However, tables and graphics for severe post-neonatally acquired CP are prepared in the program file.

The post-neonatal cases of CP are not routinely collected in all registries but this information is currently not easily identifiable. The current version of the program considered the registries for analyses when at least one case of post-neonatal CP is reported over the 3 last years considered. A clear distinction must be possible in the future (information at registry level).

# 6 Testing of the SCPE Public Health Indicators calculations

In order to validate the indicators previously defied, the Central database was used to perform a testing analysis reported below. Birth year 1998 – 2007 were considered.

As every publication of data from the SCPE network must be validated by the registries and the JRC-SCPE Management Committee, "sensitive" numbers are not reported.

## 6.1 Birth prevalence of cerebral palsy

The birth prevalence rate of cerebral palsy has been a recommended EuroPERISTAT indicator for long-term outcomes since 2007. It provides additional information on childhood health across the countries.

This indicator is presented as both:

- Birth prevalence rate of pre-/perinatally cases of CP per 1,000 live births by country over a 3-years period
- 10-years trend of birth prevalence rate of pre-/perinatally cases of CP per 1,000 livebirths and per year for all the registries altogether.

To calculate the birth prevalence rate only pre- and perinatal cases of CP (approximatively 95% of the cases) are included. Post-neonatally acquired cases (i.e. POSTNEON≠1) are excluded. The rates of pre- and perinatal cases of CP are calculated per 1,000 live births over a 3-year period. No confidence intervals are estimated.

The population considered includes only registries with a covered area with 3,000 or more livebirths on average during the last 3-years. Population data (livebirths) are available for the corresponding centres/years.

A Table in the form reported in Table 3 will show the prevalence of CP per 1,000 livebirths across SCPE registries for children born a 3-years period.

In the results of the testing analysis there were wide variations in prevalence between centres. These differences may be partly explained by differences in population characteristics, organisation of care, or implementation of new treatments. The overall prevalence was approximatively of 1.7 per 1,000 livebirths for SCPE registries for children born between a three years period. The age at confirmation of diagnosis of cerebral palsy is at least 4 years. Therefore, the year of

surveillance is 5 to 8 years after birth, depending on the registries. The data should be interpreted knowing the context of perinatal health at time of birth.

**Table 3.** Template for reporting of birth prevalence rate of CP per 1,000 live births and by registry in the three years period considered.

| Country | SCPE centre | Name | National live births* in the three years period considered (#) | Registry live births in the three years period considered (#) | Coverage of the registry | Nr. of CP cases | Prevalence per 1.000 live births |
|---|---|---|---|---|---|---|---|
| A | COx | | | | | | |
| B | COy | | | | | | |
| C | COz | | | | | | |
| **ALL REGISTRIES** | | | | | | | |

* Data from EUROSTAT.

The trends of birth prevalence rates of pre- and perinatal cases of CP per 1,000 live births and per year are calculated for all the registries altogether. The number of centres included in the calculations may differ according to birth year. The rates are presented using a 3-year simple moving average: to smooth out short-term fluctuations, prevalence rates are grouped over 3 years, the mean being reported for the central year.

## 6.2 Type of motor function disorder

The type of motor function disorder is an indicator of the burden of disease. The indicator is presented as distribution of the type of motor disorder, defined by the frequency (in %) of the predominant motor function pattern (spasticity – unilateral/bilateral, dyskinesia, other patterns i.e., ataxia, mixed forms or unknown), calculated for three consecutive birth cohorts combined together reported by each registry.

Only pre- and perinatal cases of CP are included, while CP cases known to be post-neonatally acquired are excluded. The population considered consist only of registries with more than 5 cases reported per year.

A Table in the form reported in Table 4 will show the distribution of cerebral palsy subtypes that are based on the predominant type of muscle tone or movement abnormality.

The spastic CP, characterised by an increased tone and pathological reflexes, are the commonest forms in all registries, affecting more than 80% of the overall cases, with a majority of bilateral forms. Hemiplegia (unilateral spastic forms) represents 14% to 45% of the cases. Dyskinesic CP is characterised by involuntary, uncontrolled, recurring, occasionally stereotyped movements of affected body parts. Overall it represents 8% of the cases, with wide variations between registries. The 'Other forms' comprise Ataxic CP with in addition to an abnormal pattern of posture and/or movement, a loss of orderly muscular co-ordination, so that movements are performed with abnormal force, rhythm and accuracy, as well as Mixed forms when no clear dominant clinical feature is observed, and Unclassified patterns.

**Table 4.** Template for reporting of type of motor dysfunction by registry and overall.

| Country | SCPE centre | Name | Spastic Bilateral (%) | Spastic Unilateral (%) | Dyskinetic (%) | Other forms (%) |
|---|---|---|---|---|---|---|
| A | COx | | | | | |
| B | COy | | | | | |
| C | COz | | | | | |
| **ALL REGISTRIES** | | | | | | |

## 6.3 Walking ability

The walking ability is an indicator of the burden of disease. It is presented as the distribution of walking ability defined by the frequency (in %) of GMFCS (Gross Motor Function Classification System) levels: 'mild' GMFCS level I-II (independent walker), 'moderate' GMFCS level III (walker with aid), 'severe' GMFCS level IV-V (wheelchair). In the calculation three consecutive birth cohorts are combined together. As for the previous 2 indicators, also in this case only pre- and perinatal cases of CP are included, while CP cases known to be post-neonatally acquired are excluded. The population considered consist only of registries covering area with 3,000 or more livebirths on average during the last 3-years.

A bar chart will show the proportion of children with cerebral palsy born between a three years period with 'mild' (Gross Motor Function Classification System - GMFCS level I-II, independent walker), 'moderate' (GMFCS level III, walker with aid), or 'severe' (GMFCS level IV-V, child using a wheelchair) walking impairment per registry. The differences in the distribution per registry found in the testing dataset may reflect the difficulty to identify the more mildly affected children in some regions.

## 6.4 Prevalence of severe cases of cerebral palsy

The prevalence of severe cases is an indicator of the burden of disease. The severity of cerebral palsy ranges from minimal to profound, and the likelihood of the co-occurrence of associated impairments increases with the severity of motor impairment. Severe cases are defined by a motor function severely impaired (defined by GMFCS= 3 to 5) OR an associated severe intellectual impairment (defined as IQ<50).

This indicator is presented as both:

- Birth prevalence rate of severe cases of CP per 1,000 live births by registry over a 3-years period
- 10-years trend prevalence rates of severe cases of CP per 1,000 live births and per year for all the registries altogether.

A Table in the form reported in Table 5 will show the distribution of birth prevalence of severe cases of CP per 1,000 live births for all registries and by registry over a 3-years period

A line chart will show the prevalence (per 1,000 live births) of severe cases of cerebral palsy over the last ten years, defined by a severely impaired gross motor function (GMFCS levels III to V) or the presence of a moderate to profound mental retardation (IQ<50). Prevalence is presented using a 3-year simple moving average to smooth out short-term fluctuations.

In the results of the testing analysis, the severe cases accounted for approximately one third of the cases. .

**Table 5.** Template for reporting the birth prevalence of severe cases of CP per 1,000 live births and by registry.

| Country | SCPE centre | Name | National live births | Registry live births | Coverage of the registry | Nr. of CP cases | Prevalence per 1.000 live births |
|---|---|---|---|---|---|---|---|
| A | C0x | | | | | | |
| B | C0y | | | | | | |
| C | C0z | | | | | | |
| **ALL REGISTRIES** | | | | | | | |

## 6.5 Access to neuroimaging

There is an international consensus that neuroimaging is of great importance in the understanding of pathogenesis in relation to timing of brain insult, and to a lesser extent aetiology of the brain disorder. It helps understand the deteriorated function. Neuroimaging is considered as at least one MRI of the brain whatever the period when this imaging occurred. This is an indicator of access to facilities/services.

Access to neuroimaging is assessed by the proportion (in %) of children with CP who have had at least one MRI of the brain during the neonatal period i.e. before discharge from the neonatal unit, or later. Registries with less than 5 cases per year are excluded from the calculation. Also CP cases known to be post-neonatally acquired are excluded.

A table in the form reported in Table 6 will show this proportion by registry calculated for each birth cohort. The results of the testing analysis indicate that the proportion of children having has an MRI of the brain varies from 50% to 100% across the SCPE registries.

**Table 6.** Template for reporting access to neuroimaging by country.

| Country | SCPE centre | Name | Access to MRI (% of children with CP born) Years xxxx-2; xxxx |
|---|---|---|---|
| A | C0x | | |
| B | C0y | | |
| C | C0z | | |
| **ALL REGISTRIES** | | | |

## 6.6 Prevalence and severity of cerebral palsy of post-neonatal origin

Post-neonatally acquired CP are defined as CP cases with an identified causal event independent of antenatal and perinatal periods (mostly after the 28th day of life) occurring before 24 months of age. The main underlying causes of brain lesions (infections, head injury, surgical complications) are potential targets for preventive actions.

Severe cases are defined by the severity of motor disorder (defined GMFCS= 3 to 5) OR associated severe intellectual impairment (defined as IQ<50).

The prevalence of total cases and of severe cases is shown. These are indicators of preventive health strategies.

Trends of (a) the overall prevalence of post-neonatally acquired CP and of (b) prevalence of severe cases (per 10,000 live-births) will be jointly presented.

According to a literature report[2] the combined data from 10 registries showed that prevalence rates of CP with an identified post-neonatal cause decreased from 2.05 in 1976 to 0.41 per 10,000 live births in 1998 (mean prevalence 1.2 per 10,000 live births), with an accentuated decrease from 1990.

[2] Germany and coll. in 2013 in Research in Developmental Disabilities 34: 1669-77.

# 7 Conclusions

The SCPE CDB was rebuilt in the frame of the JRC-SCPE Central Registry and is fully functional.

The calendar of data transmission/data processing was established together with the Data Working Group and implemented by the JRC-SCPE Central Registry in collaboration with the SCPE registries. It represents now the annual reference for updating the CDB.

Two data collection campaigns were run by the JRC-SCPE Central Registry:

- June to September 2016 (for the birth year 2007)
- April to July 2017 (for the birth year 2008).

In order to extend the use of the CDB data to public health relevant outputs, the JRC-SCPE Central Registry launched the initiative of developing public health indicators in the collaboration with University Hospital of Toulouse, based on the Service Contract N° CCR.F.C790682.X0.

The results of this work are the definition of six public health indicators:

- Birth prevalence rate of cerebral palsy
- Type of motor function disorder
- Walking ability
- Birth prevalence rate of severe cases of cerebral palsy
- Access to neuroimaging
- Prevalence and severity of post-neonatally acquired cerebral palsy

The CDB was used for the testing of the six public health indicators in two settings:

- birth-cohorts 2005 – 2007 (data submitted to the CDB between 2014 and 2016);
- birth-cohorts 1998 – 2007 for 10 years trends calculations.

This exercise done for the first time at the level of the CDB thus including all registries, turned out in the definition of specific inclusion/exclusion criteria for the participating registries, in accordance with each public health indicator.

Interestingly, the number of registries qualifying for the calculation of the six public health indicators varies according to the indicator.

This first analysis of the newly defined public health indicators applied to the CDB has primarily methodological relevance for the JRC-SCPE Central Registry:

- it gives valuable insights into the quality / completeness of the data collected;
- remarkably, a significant number of registries had to be excluded from the analysis due to missing variables. In practical terms, this becomes an important indicator for the dialogue with and guidance of the registries on the inclusion of specific variables into their data collection scheme and data validation.

In the present setting,

- at least one indicator evaluates preventive health strategies: prevalence and severity of post-neonatally acquired cerebral palsy;
- one indicator relates to the access to specialised medical services: access to neuroimaging;
- the probably widest reaching indicator is the one evaluating the child's long-term health outcome: birth prevalence rate of cerebral palsy. It provides additional information on childhood health across the countries.

The last three categories of indicators have the potential of generating public health relevant conclusions. The analysis and evaluation of these public health indicators in the context of the CDB and thus in the SCPE network could generate measures and recommendations for medical, healthcare and social services useful for SCPE patients and their carers and, in the broader context, for healthcare and social policy decisions. This knowledge will help setup services and facilities, increase the family's ability to access health services and emphasize the opportunity for preventive public health in the field of cerebral palsy.

In addition, from the EU perspective, they will give some elements for possible comparisons between countries/registries and over time involving the health, social and political dimensions, including fair access to care. Indeed, prevalence of Cerebral Palsy actually reflects different situations across countries in population characteristics, prematurity rate, organisation of care, implementation of new treatments. A more refined analysis of all these situations may lead to a better understanding of the differences recorded between countries / regions and is necessary to make useful comparisons which could help in increasing the understanding of the impact of improvements in the surveillance of pregnancies, neo-natal care and follow-up of vulnerable infants.

# List of figures

# List of tables

# Annex 1. Template for the Annual feedback to the SCPE registries performed by the JRC-SCPE Central Registry on the yearly data submission.


## JRC-SCPE Central Registry

## FEEDBACK ON (Year of birth) DATA REGISTRY (number of the registry) (Nation), (Name of the Registry)

Version (date)

## 1. Introduction

Text for current year.

## 2. Not Informative data

In the following table is reported the percentage of not informative data for every item collected in the birth years you submitted.

The not informative data rate is calculated considering the cases that for every item report unknown/not collectable codification or missing value.

For comparison the rate of not informative data in the central database, calculated on all the other registries with data for the same year, is reported.

For the derived variables, with names aligned on the right, the rate of the not informative data is calculated on the expected cases considering the conditioning on the primary variables.

| | | % OF NOT INFORMATIVE DATA IN YOUR REGISTER | | | | % OF NOT INFORMATIVE DATA IN THE CENTRAL DB EXCLUDING YOUR REGISTER | | |
|---|---|---|---|---|---|---|---|---|
| ITEM (n° in the guide) | VARIABLE (names) | Year xx | previous year | VAR% | | Year xx | previous year | VAR% |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |

## 3. Prevalence rates

### 3.1 Availability of denominators

Denominators (A=Available; NA=Not Available)

| | Previous year | year |
|---|---|---|
| **Total births** | | |
| Stillbirth | | |
| LB | | |
| LB multiple | | |
| NN death | | |
| NN death multiple | | |
| **Delivery mode** | | |
| Vaginal delivery | | |
| Caesarean section elective/before labour (1) | | |
| Caesarean section emergency/during labour (2) | | |
| Caesarean total (1 + 2) | | |
| Unknown | | |
| **Delivery mode per BW** | | |
| Vaginal delivery | | |
| Caesarean section elective/before labour (1) | | |
| Caesarean section emergency/during labour (2) | | |
| Caesarean total (1 + 2) | | |
| **Delivery mode per GA** | | |
| Vaginal delivery | | |
| Caesarean section elective/before labour (1) | | |
| Caesarean section emergency/during labour (2) | | |
| Caesarean total (1 + 2) | | |
| **Place of birth** | | |
| Distribution of births according to the size of the maternity units | | |
| Home or travel or hospitalisation unit other than maternity unit | | |
| Unknown | | |
| **Maternal age and parity** | | |
| Maternal age | | |
| Parity | | |
| **Neonatal death per BW** | | |
| <1000 | | |
| 1000-1499 | | |
| 1500-2499 | | |
| >2499 | | |
| Unknown | | |
| **Neonatal death per GA** | | |
| <28 | | |
| 28-31 | | |
| 32-36 | | |
| >36 | | |
| Unknown | | |
| **Multiple neonatal death per BW** | | |
| <1000 | | |
| 1000-1499 | | |
| 1500-2499 | | |
| >2499 | | |
| Unknown | | |
| **Multiple neonatal death per GA** | | |
| <28 | | |
| 28-31 | | |
| 32-36 | | |

| | | |
|---|---|---|
| >36 | | |
| Unknown | | |
| **Live births per BW** | | |
| <1000 | | |
| 1000-1499 | | |
| 1500-2499 | | |
| >2499 | | |
| Unknown | | |
| **Live births per GA** | | |
| <28 | | |
| 28-31 | | |
| 32-36 | | |
| >36 | | |
| Unknown | | |
| **Multiple births per BW** | | |
| <1000 | | |
| 1000-1499 | | |
| 1500-2499 | | |
| >2499 | | |
| Unknown | | |
| **Multiple births per GA** | | |
| <28 | | |
| 28-31 | | |
| 32-36 | | |
| >36 | | |
| Unknown | | |

### 3.2 Figures describing the prevalence rates since 1990

Prevalence rates were calculated by excluding post-neonatal cases and children not resident at date of birth (or year of registration for C01 and C02)

**Figure1.** Prevalence rate in your register

**Figure2.** Total prevalence rate including the registries which have submitted cases and denominators for the birth year xxxxx

**4. Distribution of key variables**

Following is reported the distribution of the variables collected for the last year data submitted by your register (birth year XXX) compared with the data (XXX-1) present in the Central Database on dd/mm/yy.

**Column variables**:

CYY= Your centre

other = other centres (N=K)

variable name: (example of contingency table and chi2 test to evaluate registry's distribution of the variable vs distribution of the other registries collapsed)

| sex2 | YY | others | Total |
|---|---|---|---|
| female | 8 | 348 | 356 |
| | 26.67 | 38.54 | 38.16 |
| male | 22 | 555 | 577 |
| | 73.33 | 61.46 | 61.84 |
| Total | 30 | 903 | 933 |
| | 100.00 | 100.00 | 100.00 |

Pearson chi2(1) = 1.7341 Pr = 0.188

Distribution of the variable in your centre years (xxx-4) - xxx

| | BY_YEAR | | | | | |
|---|---|---|---|---|---|---|
| sex2 | 2003 | 2004 | 2005 | 2006 | 2007 | Total |
| female | 22 | 22 | 13 | 18 | 8 | 83 |
| | 41.51 | 50.00 | 41.94 | 37.50 | 26.67 | 40.29 |
| male | 31 | 22 | 18 | 30 | 22 | 123 |
| | 58.49 | 50.00 | 58.06 | 62.50 | 73.33 | 59.71 |
| Total | 53 | 44 | 31 | 48 | 30 | 206 |
| | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 | 100.00 |

# Annex 2. SCPE Public Health Indicators - Summary of the programme for the DATA SET UP in Stata

```
*********************************************************************
**********   SCPE Public Health Indicators                **********
**********   DATA PREPARATION                             **********
**********   version 1, 20th november 2017                **********
*********************************************************************
* Author : Virginie Ehlinger
* Date of last update: 20th november 2017
* Software : Stata 14.2 SE.
* Needs installation of Stata "sencode" package (http://fmwww.bc.edu/RePEc/bocode/s/)
* Program name : SCPE public_health_indicators data_preparation v1.do
*********************************************************************

* Program organization:
* Data preparation: individual data on CP children
*                   a) Importing individual data stored in txt format with ";" delimiter
*                   b) List of birth year considered for analysis
*                   c) Variables creation
*                   d) Save the prepared data (Stata format)
* Data preparation: aggregated data to estimate prevalences
*                   a) Opening individual data on CP children
*                   b) Generating aggregated database on CP children:
*                   c) Merging with denominator data
*                   d) Birth-cohorts: variables creation
*                   e) Number of livebirths: variables creation
*                   f) Number of cases
*                   g) Proportion of missing values
*                   h) Inclusion/exclusion criteria
*                   i) Prevalence rates computation
*                   j) Save the prepared aggregated data
*                   k) Smoothed prevalence rates using 3-years moving averages for
                        the last 10 years, all registries
*                   l) Insert sampling variables in the individual database


* List of tables generated:
* "$scpe_db prepared_$today": individual data on CP children
* "scpe_aggregated_data prepared_$today": aggregated data (by year and registry),
    numerators and denominators
* "scpe_aggregated_data_pre_peri_10y_all prepared_$today": aggregated data (by
    year), numerators and denominators for pre-/peri-natal CP
* "scpe_aggregated_data_pre_peri_severe_10y_all prepared_$today": aggregated data
    (by year), numerators and denominators for severe pre-/peri-natal CP
* "scpe_aggregated_data_postneon_10y_all prepared_$today": aggregated data (by
    year), numerators and denominators for post-neonatal CP
* "scpe_aggregated_data_postneon_severe_10y_all prepared_$today": aggregated data
    (by year), numerators and denominators for severe post-neonatal CP

* ##################################################
```

* Global variables: The use change the global variable (but not their names)
*** 1/ Date of the analysis**
global today = c(current_date)

* **2/ Input:** filename and directory name of the databases (individual SCPE data, denominator data)

* **3/ Input :** last year considered for the analysis :
global last_year = 2007 // to be modified by user
*
##########################################################

**********************************************************************
*---------- Data preparation: individual data on CP children
**********************************************************************

*** a) Importing individual data stored in txt format with ";" delimiter**

*** DESCRIPTION OF CEREBRAL PALSY**
lab var cp_type "CP classification 1"
lab var spas_type "CP classification 2 (refers to spastic CP)"
lab var intel_imp "Intellectual impairment"
lab var gmfcs "Gross Motor Function Classification (GMFCS)"

*** POSTNEONATAL CEREBRAL PALSY**
lab var postneon "Postneonatal CP"
lab var postn_code1 "Coding diagnosis for Postneonatal"
lab var postn_code2 "Text diagnosis for Postneonatal"
lab var age_postn "Age at the time of the insult (if postneonatal)"

*** NEUROIMAGING**
lab var imaging "Has imaging been performed"
lab var post_imag "Postneoatal imaging"
lab var mri "MRI"
lab var mri_age "Chronological age at the more recent postneonatal imaging"
lab var mri_result "Classification of MRI results"
lab var mri_side "Side of this imaging result"
lab var neoni "Has imaging been performed before discharge from NCU"
lab var neoni_age "Chronological age at the more recent neonatal imaging"
lab var neoni_result "Classification of neonatal imaging results"
lab var neoni_r_txt "Clear text for the neonatal imaging result (English)"
lab var neoni_side "Side of this neonatal imaging result"

*** b) List of birth year considered for analysis**
*** List of the 3 years of analysis**
*** List of the 10 years of analysis**

*** c) Variables creation**

* Country
* registry with label containing country name
* Type of motor function disorder
* CP case
* CP case, excluding post-neonatally acquired CP
* post-neonatally acquired CP
* severe post-neonatally acquired CP
* birth-cohort
* Missing/unknown GMFCS, excluding post-neonatally acquired CP
* Missing/unknown INTEL_IMP, excluding post-neonatally acquired CP
* Case of severe CP during the last three years, excluding post-neonatally acquired CP
* Missing/unknown GMFCS, in post-neonatally acquired CP
* Missing/unknown GMFCS, in post-neonatally acquired CP
* Missing value on access to neuroimaging, in post-neonatally acquired CP
* sample used to analyze CP characteristics during the last 3 years period
* sample used to analyze CP characteristics during the last 10 years period
* sample used to analyze characteristics of post-neonatally acquired CP

*** d) Save the prepared data**

**********

## * Data preparation: aggregated data to estimate prevalences

**********

*** a) Opening individual data on CP children**

*** b) Generating aggregated database on CP children**

*** c) Merging with denominator data**

*** d) Birth-cohorts: variables creation**

* first year with non-missing number of collected CP cases
* last year with non-missing number of collected CP cases
* first year with non-missing number of livebirths
* last year with non-missing number of livebirths

*** e) Number of livebirths: variables creation**

*Number of livebirths per registry during the 3-year period
* Average number of livebirths per year and per registry during the 3-year period

*** f) Number of cases**

* number of pre-/peri-natally acquired CP (excluding post-neonatally acquired CP) within the last 3 years period
* number of severe pre-/peri-nataly acquired CP (excluding post-neonatally acquired CP) within the last 3 years period
* number of severe pre-/peri-nataly acquired CP (excluding post-neonatally acquired CP) within the last 3 years period

*** g) Proportion of missing values**

* Maximum proportion of missing data in the last three years

*** h) Inclusion/exclusion criteria**

* Six sampling variables are generated:
* Sample for analysis of CP prevalence excluding post-neonatal cases, birth-cohorts
* Sample for analysis of severe CP prevalence excluding post-neonatal cases, birth-cohorts
*Sample for analysis of CP prevalence excluding post-neonatal cases, birth-cohorts
*Sample for analysis of severe CP prevalence excluding post-neonatal cases, birth-cohorts
* Sample for analysis of post-neonatal CP prevalence, birth-cohorts
* Sample for analysis of severe post-neonatal CP prevalence, birth-cohorts

* No numerator or 0 case of CP, per year and per registry
* No numerator or 0 case of CP for at least one year within birth-cohorts
* No numerator or 0 post-neonatal case of CP for at least one year within birth-cohorts
* No denominator (livebirths), per year and per registry
  * (cases of CP exclude post-neonatally acquired CP)
* No denominator for at least one year within birth-cohorts
* Less than 3,000 livebirths per year and per registry
* Less than 3,000 livebirths per year on average in the registry during the 3-year period
* sample used to analyze CP prevalences (excluding post-neonatally acquired CP) within the last 3 years period
* sample used to analyze severe CP prevalences (excluding post-neonatally acquired CP) in the last 3 years period
* sample used to analyze CP prevalences (excluding post-neonatally acquired CP) in the last 10 years period
* sample used to analyze severe CP prevalences (excluding post-neonatally acquired CP) during the last 10 years period
* sample used to analyze post-neonatally acquired CP prevalences during the last 10 years period
* sample used to analyze severe post-neonatally acquired CP prevalences during the last 10 years period
* Total number of pre-/peri-neonatal CP cases (all registries) during the last 10 years
* Total number of severe pre-/peri-neonatal CP cases (all registries) during the last 10 years
* Total number of post-neonatal CP cases (all registries) during the last 10 years
* Total number of severe post-neonatal CP cases (all
* Total number of livebirths (all registries) during the last 10 years
* Total number of livebirths (all registries) during the last 10 years
* Total number of livebirths (all registries) during the last 10 years
* Total number of livebirths (all registries) during the last 10 years

*** i) Prevalence rates computation**

* Birth prevalence per year and per registry (/1000 livebirths) including post-neonatally acquired CP
* Birth prevalence of cases of CP per year and per registry (/1000 livebirths) excluding post-neonatally acquired CP
* Birth prevalence per year and per registry (/1000 livebirths) for post-neonatally acquired CP
* Birth prevalence during the 3 last years, per registry (/1000 livebirths)
* Birth prevalence rate of severe CP, per year of birth and registry (/1000 livebirths) excluding post-neonatally acquired CP
* Birth prevalence rate of severe CP, per year of birth and registry (/1000 livebirths) excluding post-neonatally acquired CP within 3 years

* Birth prevalence rate of pre-/peri-neonatal CP cases (all registries) during the last 10 years => 1 estimation per year, all registries
* Birth prevalence rate of pre-/peri-neonatal severe CP cases (all registries) during the last 10 years => 1 estimation per year, all registries
* Birth prevalence rate of severe CP, per year of birth and registry (/10000 livebirths) for severe post-neonatally acquired CP
* Birth prevalence rate of post-neonatal CP cases (all registries) during the last 10 years => 1 estimation per year, all registries
* Birth prevalence rate of post-neonatal CP cases (all registries) during the last 10 years => 1 estimation per year, all registries

*** j) Save the prepared aggregated data**

**k) Smoothed prevalence rates using 3-years moving averages for the last 10 years, all registries**

* Table: Aggregated data, all registries: Birth prevalence rate of pre-/peri-neonatal CP per 1,000 LB

* Table: Aggregated data, all registries: Birth prevalence rate of severe pre-/peri-neonatal CP per 1,000 LB

* Table: Aggregated data, all registries: Birth prevalence rate of severe post-neonatal CP per 10,000 LB

* Table: Aggregated data, all registries: Birth prevalence rate of severe post-neonatal CP per 10,000 LB

*** l) Insert sampling variables in the individual database**

# Annex 3. Summary of the programme for the calculation of SCPE Public Health Indicators in Stata

```
*******************************************************************************
**********          SCPE Public Health Indicators                 **********
**********          version 1, 20th November 2017                 **********
*******************************************************************************

* Author: Virginie Ehlinger
* Date of last update: 20th November 2017
* Software: Stata 14.2 SE.
* Needs installation of Stata "estout" package (http://repec.org/bocode/e/estout)
* Program name: SCPE public_health_indicators v1.do


* Program organization:
* 0. Generating output file
* 1. SCPE Public Health Indicator n#1: Prevalence rate of cerebral palsy
* 2. SCPE Public Health Indicator n#2: Type of motor function disorder
* 3. SCPE Public Health Indicator n#3: Walking ability
* 4. SCPE Public Health Indicator n#4: Birth prevalence rate of severe cases of cerebral
palsy
* 5. SCPE Public Health Indicator n#5: Access to neuroimagin
* 6. SCPE Public Health Indicator n#6: Prevalence and severity of post-neonatally
acquired CP


* Graphs generated:
* "SCPE_PHI_1_1_$today.wmf": Birth prevalence rate of CP per 1,000 live births and per
year, all registries
* "SCPE_PHI_3_1_$today.wmf": Walking ability by registry
* "SCPE_PHI_4_1_$today.wmf": Birth prevalence rate of severe CP per 1,000 live births
and per year
* "SCPE_PHI_6_1_$today.wmf": Birth prevalence rate of post-neonatally acquired CP per
10,000 live births
* "SCPE_PHI_6_2_$today.wmf": Birth prevalence rate of severe post-neonatally acquired
CP per 10,000 live births
```

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