

About SCPE:

General text about the network, History

Surveillance of Cerebral Palsy in Europe (SCPE) was established in 1998, bringing together population data on Cerebral Palsy (CP) to inform and improve its understanding, to raise standards of care for children with cerebral palsy, and to provide framework for collaborative research. It is a collaboration of professionals and researchers working in population-based registries of children with CP across Europe including epidemiologists, paediatric neurologists, obstetricians and neonatologists, therapists who specialize in physiotherapy, occupational therapy and speech and language therapy, and nutritionists.

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Why a network of population-based registries in Europe?

Under the leadership of Christine Cans an epidemiologist from Grenoble France, the original SCPE network brought together fourteen CP registries and population-based surveys in eight European countries, and started developing a European database of children with CP. Before the SCPE, each registry, at local regional or national level, has its own case definitions, eligibility criteria and classifications for associated impairments. In addition, most registries did not have sufficient numbers of cases of CP to be able to provide reliable estimates of trends over time in prevalence rates or to have sufficient statistical power to study causes and health service questions. By pooling individual data from various registries sharing the same definition of CP, the SCPE was able to develop common classifications, refine how children with CP are described, and perform reliable and specific analyses such as assessing the rate of CP in those born with a very low birth weight or describing the clinical picture of rare clinical subtypes.

Definition and harmonisation

It was recognised that the registries included in the SCPE, all of which were able to ascertain children from a geographically defined population, had previously reported differing prevalence rates (from 1.5 per 1000 to 3.0 per 1000 live births). The extent to which this reflected differences in case definition, inclusion and exclusion criteria and classification systems was uncertain. Therefore, the first three years of the project (1998-2000 SCPE1) were to review and reach a consensus on definitions and inclusion/exclusion criteria for case definition, on the clinical findings associated with each subgroup of cerebral palsy allowing a classification of CP subtypes.

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

These common definitions and classifications were the result of a long and thorough harmonization process which was needed for each concept, taking into consideration language particularities and differences in societal functioning across Europe. The reliability, validity and simplicity of the SCPE definitions and classifications allow pooling data for surveillance purposes over long periods of time, and permit the clinical interpretation of variations, as well as facilitate epidemiological studies and provide a common framework as a basis for trials of intervention. Regular workshops dedicated to harmonisation, validation processes, and reliability exercises to guarantee reliable results are still being held.

The SCPE standards and recommendations, as the result of the harmonisation work done and extensively reported in 2007, have been widely accepted by clinicians and researchers across the globe, and is commonly used and referenced in a number of studies.

Building a European database

The common database, which compiles data collected from birth cohort 1975, is a powerful instrument to analyse trends over time in the prevalence rates and to consider subgroups of children with cerebral palsy. During the period 1998-2000 (SCPE1), a consensus was reached on a standard minimum dataset for the common European database and a first Data Collection Form was developed to reflect the core variables to be collected.

Data for birth years 1975-1990 were gathered at the European level and both the first description of children with CP and prevalence rates were published. Thus data from over 6,000 children with CP from thirteen areas in Europe showed that the rate of CP rose during the 1970s, but remained stable during the late 1980s with an overall birth prevalence of 2.08 per 1000 live births (95% CI 2.02 to 2.14). One in five children with cerebral palsy were likely to be severely affected.

SCPE Collaborative Group. Prevalence and characteristics of children with cerebral palsy in Europe. *Developmental Medicine and Child Neurology*. 2002; 44:633-640

The common database was extended to births that occurred between 1991 and 1996 during 2002-2004 SCPE2. At present, the SCPE common database covers approximately 9% of the European births and a geographical area of 60 million inhabitants.

Epidemiology of cerebral palsy in Europe: 1976-96

Amongst the many published studies, the work led by S Jarvis and published in *The Lancet* in 2003 showed that the risk for CP was linked not only to low weight-for-gestation, but also to excessively high weight-for-gestation in a reverse J-shaped relationship (data from ten SCPE registries and 4,503 singletons with CP born between 1976 and 1990).

Jarvis et al. Cerebral palsy and intrauterine growth in single births: European collaborative study. *Lancet*. 2003; 362:1106-11

The birth prevalence rate of cerebral palsy in multiples increased through the 1980s, in a period when the rate of multiples doubled. Topp *et al.* reported that the multiples had a four times higher rate of CP than singletons (relative risk of 4.4 [3.8 - 5.0]). This study was based on data collected from twelve SCPE registries on 6,613 children born between 1975 and 1990.

Topp et al. Multiple birth and cerebral palsy in Europe: a multicenter study. *Acta Obstet Gynecol Scand* 2004; 548-553

The paper of Platt *et al.*, also published in the *Lancet* (2007), reported that the increase in the survival of infants of birthweight <1500g was not accompanied by increased morbidity. Thus, the rates of CP in very small babies were decreasing from 60.6 in 1980 to 39.5 per 1000 live born babies with very low birth weight in 1996 (data from sixteen SCPE registries and 2,103 children with birthweight <1500g or gestational age <32 weeks at the time of birth).

Platt et al. Trends in cerebral palsy among infants of very low birth weight (<1500 g) or born prematurely (<32 weeks) in 16 European centres - a database study. *Lancet*. 2007;369:43-50.

For around 5% of children with CP, the brain insult occurs postneonally, with most causes accessible to preventive actions. SCPE data demonstrated a declining prevalence rate amongst this subgroup for children born between 1976 and 1990 with a mean prevalence over the period of 1.3 per 10,000 live births. Overall, children with CP with a post neonatal origin showed a more severe functional pattern compared to other cases (data from seven SCPE registries and 347 cases with an identified postneonatal cause).

Cans C et al. Cerebral palsy of postneonatal origin: characteristics and risk factors. *Paediatric and Perinatal Epidemiology* 2004; 18:214-220

Reference and Training Manual

When implementing the classifications in the different registries some difficulties emerged, mainly due to language. Therefore, during **2002-2004 (SCPE2)**, collaborative efforts were assembled to develop a video-based tool entitled the Reference and Training Manual (R&TM). The aim was to promote a shared understanding of the clinical, functional and neurological features of CP using video descriptions of children with CP, to illustrate these features and discuss pitfalls in diagnosis and classification. It provided a systematic approach to the clinical description of children with CP useful for training purposes and disseminating good practices. It was first available on an interactive CD, including video illustrations of typical cases. It is now currently available on the SCPE website. The existing content has been regularly updated and new content added.

Platt MJ, Krageloh-Mann I, Cans C. SCPE. A reference and training manual. *Medical Education* 2009; 43:495-6.

SCPE network as a framework for collaborative research

A research project was developed by the collaboration, involving seven of the SCPE regions. The research concerned primarily the lives of children with CP rather than the condition cerebral palsy, its causation and how common it was. The project, called SPARCLE (PI Allan Colver, Newcastle, UK), was funded by Framework 5 of the EU Health Research Programme 2002-2006. It introduced modern concepts about disability and in particular examined the quality of life of children with CP. The overall objective was to evaluate how the environment (physical, social support, people's attitude) influences the quality of life and participation of children with CP aged 8-12 years. Of its many findings, one showed that children with CP report themselves to have the same quality of life as children in the general population of the same age and from the same country. Another important finding was that pain was much more common than had been appreciated and it affected quality of life. A third finding was that children with CP in some European countries participate more fully in life activities than in other countries. Overall, the severity of impairments highly reduced participation. The cohort has been visited again at adolescence and the third wave of home visits is scheduled in 2017-2018. An overview of the main results is presented at <http://research.ncl.ac.uk/sparcle/>.

Cerebral palsy: a recommended indicator for long-term consequence of perinatal complications

During the period **2005-2008**, the registries of children with CP in Europe participated in the EUROPERISTAT projects. These projects focused mainly on routine perinatal health reporting, but longer term consequences of perinatal complications were highlighted as important gaps to fill. Cerebral palsy has been a recommended PERISTAT 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. Data collection on perinatal indicators such as preterm birth, delivery mode, multiple births, neonatal mortality, congenital anomalies and cerebral palsy was facilitated by collaborative efforts between the European networks: SCPE, Europeristat, Euroneostat and Eurocat.

Improving information on denominators and quality of data

During the period **2005-2008**, the SCPE network worked intensively to acquire accurate background information on national births. Each registry provides vital statistics data with respect to its catchment area of surveillance, including total births, live births by birthweight groups and gestational age at birth groups, specific neonatal mortality rates, along with data describing the context of birth: place of birth, delivery mode, maternal age and parity. For many countries, these data are collected from national birth data systems.

Several measures were established to improve data quality. This includes a report compiling comprehensive information about the routine functioning of each registry and the way data are collected at the local level. A yearly feedback report to each individual registry after the submission campaign was developed to allow for comparisons with other registries. A set of data quality indicators (list of core variables and percentage of missing values) were discussed and implemented during the annual plenary meeting in 2011. Exercises aimed at documenting the reliability of the SCPE inclusion and classification process were also drafted. Because the registration procedures generally involved various professionals, two different evaluations were conducted to measure agreement primarily based on clinical observations, and secondarily based on data extracted from medical records, with a rather good agreement found in both cases.

Sellier E, Horber V, Krägeloh-Mann I, De La Cruz J, Cans C; SCPE Collaboration. Interrater reliability study of cerebral palsy diagnosis, neurological subtype, and gross motor function. *Dev Med Child Neurol.* 2012 Sep;54(9):815-21

Neuroimaging classification

The continuing improvement of methods to record data has led to the development of a validated classification of brain imaging. A new chapter was added to the Reference and Training Manual focusing on Magnetic Resonance Imaging (MRI) findings in the child with CP after the age of 2 years, along with a proposed standardized description of the images which result in a classification for the predominant pattern with six different subgroups. In line with this classification, a description of neonatal imaging results following cranial ultrasounds or MRI scans has been further developed (see SCPE-NET program). Both classifications can be routinely used in registries and have been introduced into the SCPE data collection form.

Himmelman K, Horber V, De La Cruz J, Horridge K, Mejaski-Bosnjak V, Hollody K, Krägeloh-Mann I; SCPE Working Group. MRI classification system (MRICS) for children with cerebral palsy: development, reliability, and recommendations. *Dev Med Child Neurol.* 2016 Jun 21. doi: 10.1111/dmcn.13166.

The SCPE-NET program: Best practice in monitoring, understanding inequalities, and dissemination of knowledge

The SCPE collaboration has developed a work program called **SCPE-NET (2009-2012)**, (PI J de la Cruz, Madrid Spain) which aimed to describe variations in healthcare of children with CP across Europe, access to healthcare in relation to socio-economic indicators, to further enhance how children with CP are described, and to improve public access to information. The following tasks were undertaken:

1. Improving methods of describing children with CP and recording data, particularly in the fields of neonatal neuroimaging and communication. The standardized description for neonatal imaging profiles and the classification scheme were found to be applicable and reliable, and could be used by the registries. The SCPE collaboration identified the Viking Speech Scale (VSS) as the most suitable instrument for epidemiologic purposes to report on communication difficulties of children with CP.
2. Description of variations in healthcare of children with CP across Europe, particularly in access to care and in outcome of care in relation to socioeconomic indicators. Three core indicators (child's exact address, parental occupation, and parental education) that can be used for monitoring health inequalities in the cerebral palsy registries were identified. The SCPE collaboration investigated how common hip dislocations are, and found that they seemed to be more common in countries without a prevention programme. Intrathecal baclofen therapy (ITB) for muscle spasms was available for children with CP in 17 of 22 responding countries, but with varying age at start of treatment and a higher access in countries where a larger percentage of Gross Domestic Product was spent on health. Recent research also showed differences in management of growth and nutrition.

3. Improving public access to information. The objectives were to provide a web platform for dissemination of SCPE information and tools for professionals and for families, to update technically SCPE Reference and Training Manual and facilitate its web access, and to identify appropriate ways of presenting SCPE information on CP for public access.
4. Further development of registries in terms of data quality and consideration of extension to cover children with severe intellectual impairment. The increment of the SCPE common database brought more than 3,000 cases of children with cerebral palsy born 1999-2002. The feasibility of setting up a common European database for the children with severe intellectual deficiency was examined.

Declining prevalence rate and severity of cerebral palsy in Europe: recent epidemiological data

At the end of 2014, the common database which compiles data collected by 29 registries from birth cohort 1975, included data from almost 18,000 children with CP born up to 2005. The analysis of data from children born between 1980 and 2003 (twenty SCPE registries, and 15,090 children with CP) showed a significant reduction in the overall prevalence and severity of cerebral palsy, and the decreasing rates previously observed in children born with a very low birthweight were confirmed.

Sellier E, et al. Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003. *Dev Med Child Neurol.* 2016 Jan;58(1):85-92. doi: 10.1111/dmcn.12865.

European Platform on Rare Diseases Registration

As of January 1, 2016, the SCPE Common Database and related European-level coordinating activities moved to the EU Platform for Rare Diseases Registration, located at the Joint Research Centre (JRC) in Ispra, Italy. This new cooperation is fundamental for continuing the work on the surveillance of CP in Europe, an opportunity to better integrate SCPE data into larger European information systems, and a framework for a better dissemination to policy makers for decisions on health care, education, or social services.

Life of the network

Through the leadership of Christine Cans (1998-2007) and Javier de la Cruz (2008-2014), the SCPE collaboration has grown: 14 original partners, successively extended to 25, and 31 in 20 EU Member States and 3 EFTA countries. Since November 2014, the network is chaired by Catherine Arnaud (Toulouse, France).

Annual plenary meetings were organized across Europe to draw up reference documents and tools, to build a common database, and to develop research collaborations in and outside Europe:

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| 1998 June - | Grenoble, FR | 2008 October - | Estoril, PT |
| 1999 July - | Oxford, GB | 2009 October - | Ljubljana, SI |
| 2000 September - | Toulouse, FR | 2010 September - | Riga, LV |
| 2002 March - | Grenoble, FR | 2011 September - | Pecs, HU |
| 2003 April - | Tübingen, DE | 2012 June - | Madrid, ES |
| 2004 May - | Grenoble, FR | 2013 November - | Amsterdam, NL |
| 2005 June - | Copenhagen, DK | 2014 November - | Norwich, GB |
| 2006 October - | Vilnius, LT | 2015 November - | Varese, IT |
| 2007 September - | Tonsberg, NO | 2016 November - | Baveno, IT |

Funding

Since 1998, SCPE collaborative work was granted with EU funding from DG Research and DG Health.

SCPE 1 and SCPE 2 focused on harmonisation of definition and inclusion/exclusion criteria; Common database; Support to research projects.

1998-2000 (Concerted action) DG XII-BIOMED2-BMH4-983701

2002-2004 (Accompanying measures) FP5-QLG5-CT-2001-30133; FP5-QLG5-CT-2002-00636

SCPE 3: On-going of the SCPE common database; Reference and Training Manual on CP; QoL-SPARCLE study on children with cerebral palsy.

2005-2007: EURO-PERISTAT II: DG SANCO-EAPH-2003-3131

Improving information on denominators, and quality of the data. Encouraging implementation of new registers. European Perinatal Health Report

2008-2009 EURO-PERISTAT III DG SANCO-EAPH-2007-0114

SCPE-NET: Surveillance of Cerebral Palsy in Europe: Best practice in monitoring, understanding inequalities, and dissemination of knowledge.

2009-2012: DG SANCO-EAHC-2008-1307

On-going activities (common database, neuroimaging findings, website and dissemination activities), develop and test collaboration with Health economics.

2014: DG SANCO-CHAFEA-2013-3211 Operating grant

The registry members of the SCPE network are individually funded at local, regional or national levels and develop their surveillance and research activities according to their public health priorities.

