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Surveillance of Cerebral Palsy in Europe (SCPE)

Scientific report 1998 - 2018

Foreword

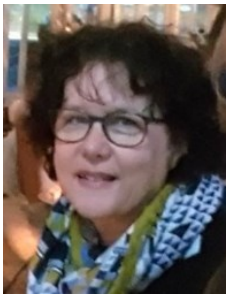
Cerebral palsy (CP) is the leading cause of early-onset physical disability. It means the presence of significant impairments that require educational and community-based services, and have a lifelong impact for the individuals and their families. Its relative infrequent occurrence, various phenotypes, heterogeneous nature and timing of the initiating cause, and even the absence of a known causative pathway in many cases, make it a complex disorder to study. This emphasises the need to study large populations with standardized definitions and descriptions, and consistency in selection of cases.

Population-based registries play a pivotal role in the knowledge of cerebral palsies. From 1998 a group led by Christine Cans was formed to gather individual efforts in Europe. The aim of the Surveillance of Cerebral Palsy in Europe (SCPE) was to pool harmonized data of children with CP to examine prevalence estimates over time, even in subgroups of cases with only a small number of individuals. A minimum dataset enabled an accurate description of the motor condition, and its associated impairments and complications. Amongst others, data on birthweight, gestational age, and presence of malformations allowed comprehensive analyses on causal pathways. This collaborative effort was also a fertile ground to conduct joint research. A brief overview of the steps in the establishment of this collaboration is provided in this report.

The SCPE standards and recommendations, notably definitions and classifications, have been widely accepted and used by professionals and researchers worldwide. The SCPE Reference and Training Manual constitutes a powerful instrument for training purposes and disseminating good practices. It endorses the recommendations of a systematic approach to the clinical description of children with CP and the importance of classifying brain lesions. The neuroimaging findings can now be incorporated in routine data collections. In total, these tools and the steady mentorship of SCPE members have substantially contributed to the expansion of the network across Europe. In 1998, fourteen centres from eight countries started, and twenty years later, the network comprises twenty-three active centres from twenty countries.

The SCPE database contains data from birth cohort 1976. It has gradually expanded and, with a total number of 21,043 children, it permits powerful analyses. This report, without seeking completeness, compiles a series of scientific results demonstrating the epidemiology of CP in Europe over a period of 20 years: descriptions of children with CP, trends in prevalence rates and birthweight specific rates, strength of associations between weight-for-gestation at birth or multiple birth and the risk for CP, variations in clinical practice and access to care. A list of the publications is enclosed so that you can read the detailed results. This report also gives the opportunity to show how population-based registries can promote research projects. The SPARCLE study is an impressive example of this process. It introduced modern concepts about disability by placing increased emphasis on the multiplicity of challenges that children with CP face in the community. Their quality of life and their participation were especially explored in relationship with the multiple facets of the environment.

This scientific report is the result of the contribution of all the professionals working in registries of CP in Europe. They ensure data collection operations with high quality standards at local or national levels. Let them be thanked. It is also the result of the huge effort done at the European level: the tremendous role and expertise of the working groups, the quality of data management of the common database, and the sustainability in the European funding of collaborative activities. Through them, the SCPE has become internationally renowned and has developed fruitful collaborations in and outside Europe. However, despite the huge progress of the past decades, further research is needed to provide more epidemiological knowledge of CP, to raise standards of care, and to provide evidence-based policy support. The main aim of the SCPE is to continue contributing to this!



Catherine ARNAUD
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Chair of the SCPE

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December 2018

1. The History of SCPE from 1998 to 2018

Highlights:

- 1998: SCPE established with 14 CP registries and surveys in 8 European countries
- SCPE 1 (1998-2000): harmonized the definition of CP and CP subtypes and established a Common Database
- SCPE 2 (2002-2004): developed Reference and Training Manual and SCPE standards and recommendations
- SCPE 3 (2005-2008): participated in EURO-PERISTAT projects
- SCPE-NET (2009-2012): improved best practices in monitoring, understanding inequalities and dissemination of knowledge
- JRC-SCPE Central Registry became part of the European Platform on Rare Diseases Registration (2016-today): SCPE Common Database contains over 21,000 cases of children with CP from 23 CP registries in 20 countries

1.1 Why a network of population-based CP registries in Europe?

The Surveillance of Cerebral Palsy in Europe (SCPE) was established in 1998 to bring together population data on cerebral palsy (CP), inform and improve understanding of CP, raise standards of care for children with CP, and provide a framework for collaborative research.

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. Together, they developed the first European database of children with CP. This was important because before the SCPE, each registry had 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 provide reliable estimates of trends over time in prevalences or to have sufficient statistical power to study causes and health service questions. They determined that by pooling individual data from registries, the SCPE could harmonize definitions and classifications for how children with CP are described, and perform reliable and specific analyses.

1.2 Building a common European database

The SCPE common database compiles data from birth cohort 1976. It is a powerful instrument to analyze trends over time in overall prevalences as well as within subgroups of children with CP. During the period 1998-2000 (SCPE 1), a consensus was reached on a standard minimum dataset for the common European database and a first Data Collection Form was created to reflect the core variables to be collected. The SCPE 2 (2002-2004) extended the common database to births cohorts between 1991 and 1996. Two additional data sets for birth years 1997 and 1998 were collected between 2005-2008 (SCPE 3). During this period, background information on national births was added, together with a new procedure to aid each registry in providing vital statistics data (often collected from national birth registries) with respect to its catchment area of surveillance (e.g. number of total births).

Throughout the years, several measures have been established to improve the quality of data in the SCPE common database. This includes:

- A comprehensive report on the routine functioning of each registry, including data collection at the local level

- A yearly feedback report for each registry, to give an overview of the year's data submission campaign, and to allow for comparisons with other registries
- A set of data quality indicators to choose from (list of core variables and percentage of missing values).
- Reliability exercises to document the SCPE inclusion and classification process. Two different evaluations based on clinical observations and data extracted from medical records were conducted. In both cases, we found a good agreement.

The common database is updated annually. Each active registry electronically submits new cases of children with CP from their local databases, as well as updated information from previously submitted cases, if necessary. Quality checks are performed on the data before they are added to the common database. The set of standardized compulsory variables are regularly revised to take into account the evolution of the scientific background and the more recent progress made in the field (Annex 2). In 2018, the SCPE common database comprises a total number of 21,043 cases of CP with corresponding population data.

Number of children registered per center in the Common Database per 2018:
(the identification of each corresponding center number can be found in section 1.5)

	Centre Number																													
Birth Year	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	C30	C31	C32	All
1976-1997	532	491	747	373	1134	1001	1014	1305	220	1011	1787	188	127	127	80	104	78	.	118	.	.	.	85	85	.	.	24	.	.	96	10727
1998	32	18	.	21	69	32	42	42	.	.	147	20	.	148	.	10	12	.	.	.	.	.	13	10	.	.	12	.	.	10	638
1999	49	34	.	.	54	41	48	46	.	.	151	1	.	174	.	.	13	49	.	.	22	8	14	11	22	.	6	.	42	19	804
2000	43	21	.	.	47	51	54	52	.	.	147	4	.	166	.	.	.	47	.	11	25	9	15	14	27	.	13	.	48	9	803
2001	36	31	.	.	65	54	49	59	.	.	120	1	.	171	.	.	.	43	240	10	27	12	10	13	10	.	13	.	61	7	1032
2002	34	22	.	.	41	40	53	48	.	.	137	4	.	155	.	.	.	38	184	11	17	.	9	18	24	.	9	.	69	15	928
2003	53	26	.	.	65	52	52	45	.	.	106	5	.	153	.	.	.	30	199	16	12	.	6	6	26	86	7	.	55	12	1012
2004	44	20	.	.	.	45	54	.	.	.	130	4	.	168	.	.	.	49	165	10	13	.	9	13	25	63	13	.	86	20	931
2005	33	28	.	.	59	50	57	.	.	.	103	5	.	171	.	.	.	38	183	15	17	.	21	9	23	62	6	.	57	17	954
2006	50	25	.	.	.	56	64	.	.	.	132	3	.	163	.	.	.	43	175	11	17	.	6	12	20	79	10	.	69	11	946
2007	30	21	.	.	.	53	67	.	.	.	121	.	.	151	.	.	.	45	156	9	14	.	8	.	166	77	10	.	59	14	1001
2008	31	26	.	.	.	54	85	.	.	.	.	4	.	152	.	.	.	46	178	5	18	.	6	.	.	76	9	.	56	14	760
2009	.	40	.	.	.	44	56	.	.	.	.	4	.	132	.	.	.	45	138	.	12	.	.	.	.	.	.	6	25	5	507
All	967	803	747	394	1534	1573	1695	1597	220	1011	3081	243	127	2031	80	114	103	473	1736	98	194	29	202	191	343	443	132	6	627	249	21043

From 1999 to 2015, the SCPE common database was located at Grenoble University in France. In January 2016, it was transferred to the European Platform on Rare Diseases Registration which functions as a data repository (see section 1.4). Its use and development are currently under the guidance of the JRC-SCPE Management Committee (see section 1.6), with the support of the Data Working Group.

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

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

1. Improve methods of describing and recording data for children with CP, particularly in the fields of neonatal neuroimaging and communication.

2. Describe variations in healthcare of children with CP across Europe, particularly in access and outcomes of care in relation to socioeconomic indicators.
3. Improve public access to information.
4. Further develop CP registries.

The SCPE network was awarded an operating grant from the European Commission in 2014 to continue work on the common database, neuroimaging classification, and to explore collaborations with health economists.

1.4 SCPE as part of EU Platform on Rare Diseases Registration

As of January 1, 2016, the SCPE Common Database and related European-level coordinating activities were transferred to the European Commission's Joint Research Centre (JRC) in Ispra, Italy, to provide a sustainable solution for the continuation of SCPE activities, to secure the results of previous work and to keep the network functioning. The SCPE Central Registry is now an integral part of the European Platform on Rare Diseases Registration (EU RD Platform) developed by the JRC in close collaboration with the EC's Directorate for Health and Food Safety (DG SANTE).

The establishment of the EU RD Platform is part of the implementation of the EU policies in the field of rare diseases. The EU RD Platform develops, provides and promotes European-level standards for RD data collection and information exchange. The Platform's main objective is to cope with the enormous fragmentation of RD patient data contained in hundreds of patient registries across Europe by providing solutions for interoperability between the RD data sources, for data collection and data sharing. The EU RD Platform was also conceived to offer a sustainable solution for two large European surveillance networks: EUROCAT (European surveillance of congenital anomalies) and SCPE (Surveillance of Cerebral Palsy in Europe). The JRC-EUROCAT and JRC-SCPE Central Registries are now located in the JRC. For these two particular networks the EU RD Platform function also as data repository.

The role of the JRC-SCPE Central Registry is to:

- Maintain and further develop the SCPE Common Database
- Securely manage the data from all registries
- Analyse data with respect to data quality and routine statistical monitoring
- Maintain relationships with SCPE member registries
- Support and participate in the coordinating activities
- Organise meetings (annual network meetings, Management Committee and various Working Groups) and training
- Disseminate network's results (website, reports, JRC-SCPE newsletter, leaflets)

1.5 SCPE members

The SCPE has grown into a collaboration of professionals and researchers working in population-based registries of children with CP across Europe. One of its strengths is its multi-professional, multidisciplinary membership, bringing together epidemiologists, paediatricians/paediatric neurologists, obstetricians and

neonatologists, therapists who specialize in physiotherapy, occupational therapy and speech and language therapy, and nutritionists.

List of all SCPE member registries from 1998 to 2018, including new applicants:

Centre #	Country	Name	Registry Leader
C01	France	Register for childhood disabilities and perinatal survey, Grenoble	Elodie Sellier
C02	France	Childhood Disabilities Registry of the Haute-Garonne County, Toulouse	Catherine Arnaud
C05	United Kingdom	Northern Ireland Cerebral Palsy Register	Oliver Perra
C06	Sweden	CP Register of Western Sweden	Kate Himmelmann
C07	Ireland	Eastern Ireland Area CP Study	Owen Hensey
C12	Denmark	The Danish Cerebral Palsy Register	Peter Uldall
C13	Italy	Central Italy Cerebral Palsy Register, Viterbo	Marco Marcelli
C15	Norway	The Cerebral Palsy Register of Norway	Guro L. Andersen
C18	Spain	Madrid Cerebral Palsy Register	Javier de la Cruz
C19	Slovenia	Slovenian Register of Cerebral Palsy	David Neubauer
C21	Portugal	Programa Vigilância Nacional da Paralisia Cerebral aos 5 anos	Daniel Virella
C22	Latvia	Riga Association Rehabilitation Center	Andra Greitane
C23	Hungary	Cerebral Palsy Register of South-West Hungary	Katalin Hollódy
C25	Iceland	Icelandic Cerebral Palsy Register	Solveig Sigurdardottir
C26	Austria	Register of Children with Cerebral Palsy in Tyrol	Fiona Zeiner
C27	Belgium	Belgian Cerebral Palsy Registry	Els Ortibus
C28	Croatia	Croatian Cerebral Palsy Register	Vlatka Mejaski-Bosnjak
C29	Switzerland	CP register – St. Gallen Canton	Christoph Kuenzle
C30	Malta	The Cerebral Palsy Register of Malta	Stephen Attard
C31	Greece	The Cerebral Palsy Register of Attica-Greece	Antigone Papavasilou
C32	United Kingdom	Sunderland, Washington, Coalfields and North Easington Cerebral Palsies Register	Karen Horridge
SCPE Expertise collaborators:			
C10	Germany	University Children's Hospital, Tübingen	Ingeborg Krägeloh-Mann
C11	United Kingdom	University of East Anglia, Norwich	Mary Jane Platt
SCPE Registries no longer active:			
C03	United Kingdom	Scotland, Edinburgh	
C04	Ireland	Cork and Kerry counties	
C08	United Kingdom	North of England, Newcastle	
C10	Germany	South-west Germany	
C11	United Kingdom	Merseyside & Cheshire	
C14	The Netherlands	Arnhem	
C16	Italy	Bologna	
C17	Ireland	Galway	
C20	Lithuania	Kaunas	
C24	Cyprus	Nicosia	
New CP registry applicants:			
Appl 1	Moldova	Voinical Centre of Early Intervention, Chisinau	Ecaterina Gincota
Appl 2	The Netherlands	Department of Rehabilitation Medicine, VU University Medical Center	Janneke Hazelhoff

The following map describes the current European coverage of SCPE database:

1.6 SCPE functioning

A Management Committee was established as a joint JRC-SCPE Committee whose Terms of Reference are to manage and coordinate the SCPE, ensure the sustainability and development of the SCPE Common Database, facilitate the development of research projects and the dissemination of the work on CP in Europe, maintain collaborations with partners working on CP, and promote the work and achievements of the SCPE collaboration.

JRC-SCPE Management Committee 2014-2018:

Chair: Catherine Arnaud, France
Deputy-Chair: Mary Jane Platt, United Kingdom
Deputy-Chair: Guro L. Andersen, Norway
Data Group Leaders: Inge Krägeloh-Mann, Germany and Elodie Sellier, France
Website & Dissemination Group Leader: Sandra Julsen Hollung, Norway
Scientific Activities Group Leader: Kate Himmelmann, Sweden
JRC members: Simona Martin and Ciaran Nicholl

From left: Sandra Julsen Hollung, Inge Krägeloh-Mann, Elodie Sellier, Mary Jane Platt, Kate Himmelmann & Guro L. Andersen

Three Working Groups are in charge of the development and achievements of the SCPE:

1. Data Working Group: oversees decisions, rules and amendments for data collection, and promoting and ensuring data quality
2. Website and Dissemination Working Group: oversees decisions and rules for the content of the website, and dissemination of the work
3. Scientific Activities Working Group: oversees the development of epidemiological surveillance and public health research as well as clinical research based on CP registries.

Annual Plenary Meetings:

All SCPE members are invited to attend an annual plenary meeting where a series of presentations, discussions and networking activities are organized. The plenary meetings bring together a unique community of experts in the field of CP, and ensures the continuality of the SCPE community by improving data sharing, training young colleagues from across Europe, and creating tangible deliverables. To promote cohesion, each meeting was originally hosted by a local SCPE registry. This was a key to the success of the steady expansion of the SCPE network across Europe. The plenary meetings are now hosted by the JRC-SCPE Central Registry team near Ispra, Italy.

1998 June – Grenoble, FR	2009 October – Ljubljana, SI
1999 July – Oxford, GB	2010 September - Riga, LV
2000 September – Toulouse, FR	2011 September – Pecs, HU
2002 March - Grenoble, FR	2012 June – Madrid, ES
2003 April – Tübingen, DE	2013 November – Amsterdam, NL
2004 May – Grenoble, FR	2014 November – Norwich, GB
2005 June – Copenhagen, DK	2015 November- Varese, IT
2006 October – Vilnius, LT	2016 November - Baveno, IT
2007 September – Tonsberg, NO	2017 October – Varese, IT
2008 October – Estoril, PT	2018 November – Gazzada, IT

SCPE Plenary Meeting May 2004, Grenoble France

SCPE Plenary Meeting Sept. 2007, Tønsberg Norway

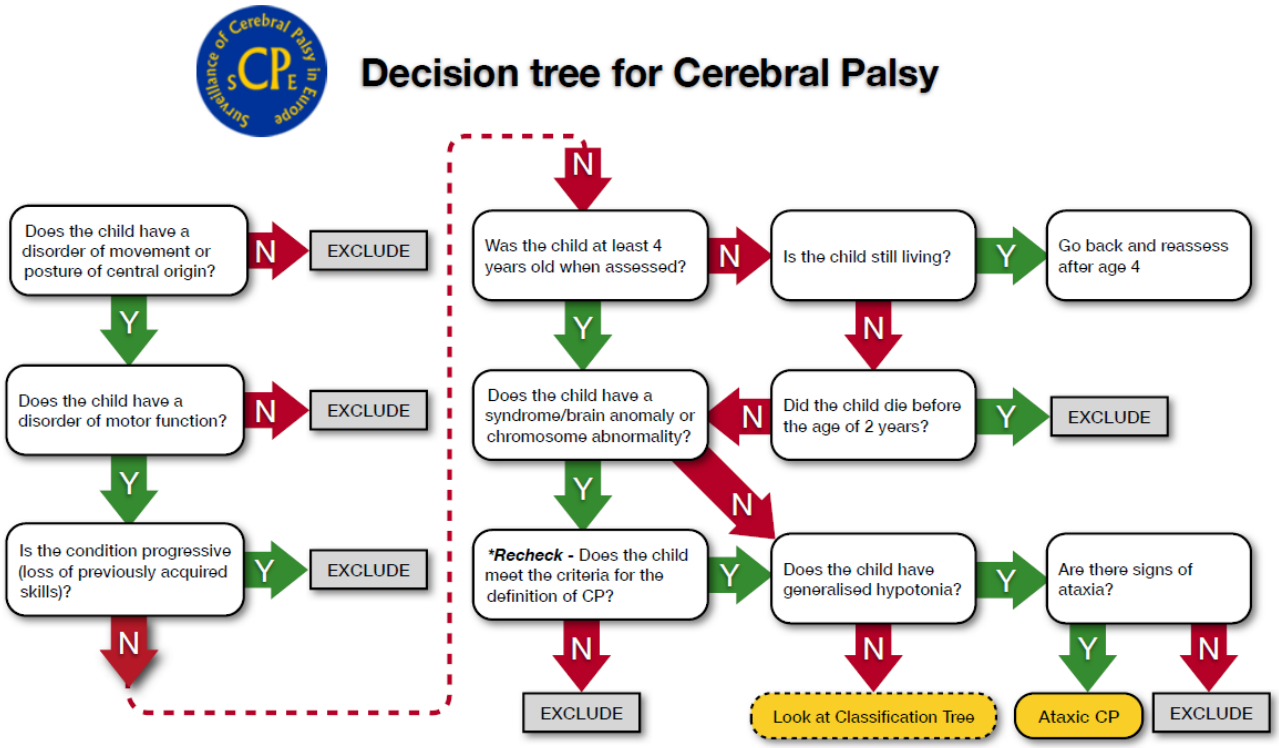

SCPE-NET 15-17 Sept, 2011 Pecs/Hungary


SCPE Plenary Meeting Nov. 2016, Baveno, Italy

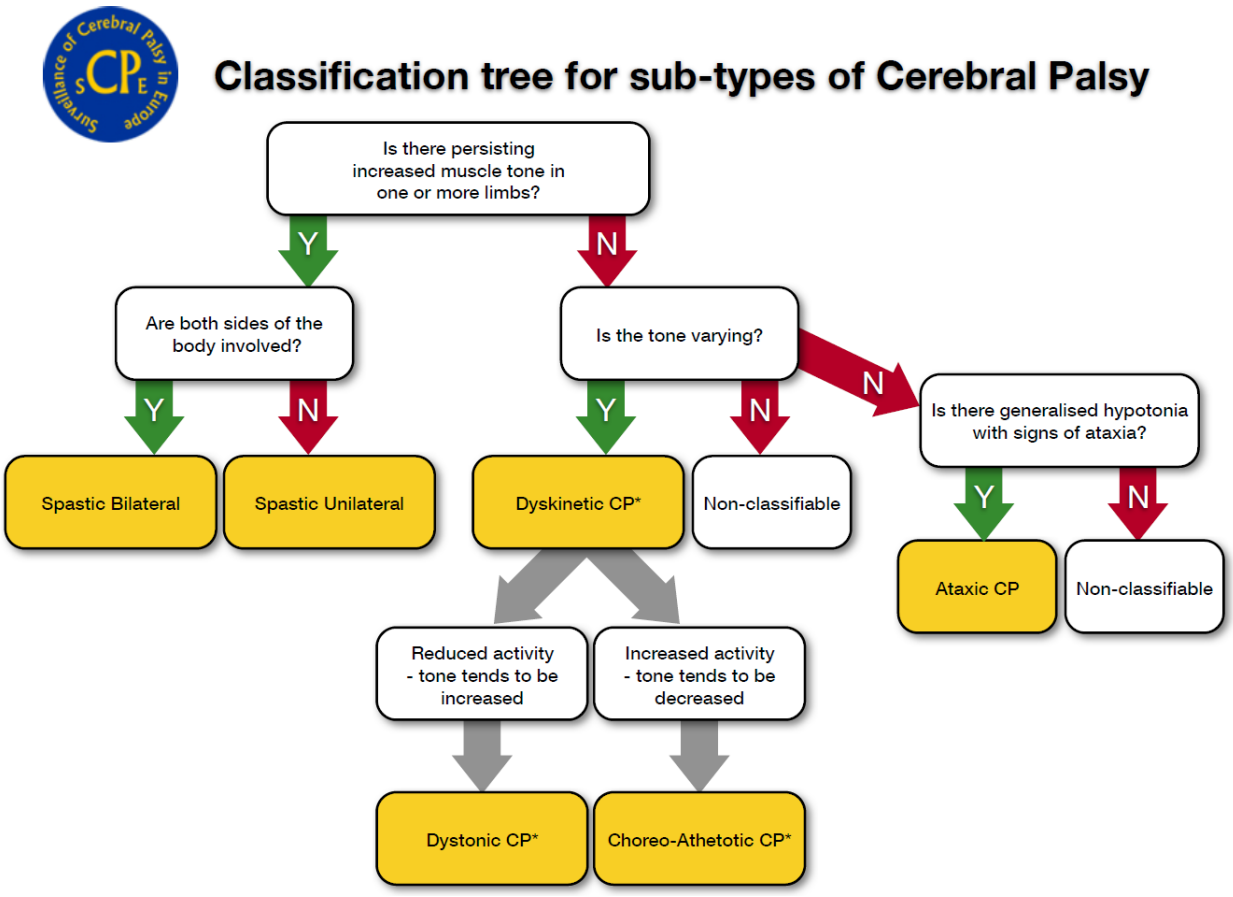
2. Scientific Results

2.1 Definition and Classification of CP (Development of SCPE Tools)

Before the creation of the SCPE, the original CP registries had separately reported a range of prevalence estimates from 1.5 to 3.0 per 1000 live births. However, it was unclear if this was due to differences in case definition, inclusion and exclusion criteria and classification systems. Therefore, during the first three years of the SCPE 1 project (1998-2000) a consensus was reached on the definition of CP, inclusion/exclusion criteria for case definition and on the clinical description associated with each subgroup of CP. This led to the creation of the following internationally used SCPE reference tools:



SCPE Classification of CP Subtypes based on the predominant neurological findings		All CP subtypes have in common an abnormal pattern of movement and posture. **Additional features by subtype:**
SPASTIC CP	**Bilateral Spastic (BS-CP)**	Increased tone Pathological reflexes - increased reflexes, e.g. hyperreflexia - pyramidal signs, e.g. Babinski response resulting in abnormal pattern of movement and posture
	Unilateral Spastic (hemiplegia)	
DYSKINETIC CP	**Dystonic**	Involuntary, uncontrolled, recurring, occasionally stereotyped movements, primitive reflexe patterns predominate, muscle tone is varying
	Choreo-athetotic	
ATAXIC CP		Loss of orderly muscular coordination, so that movements are performed with abnormal force, rhythm and accuracy

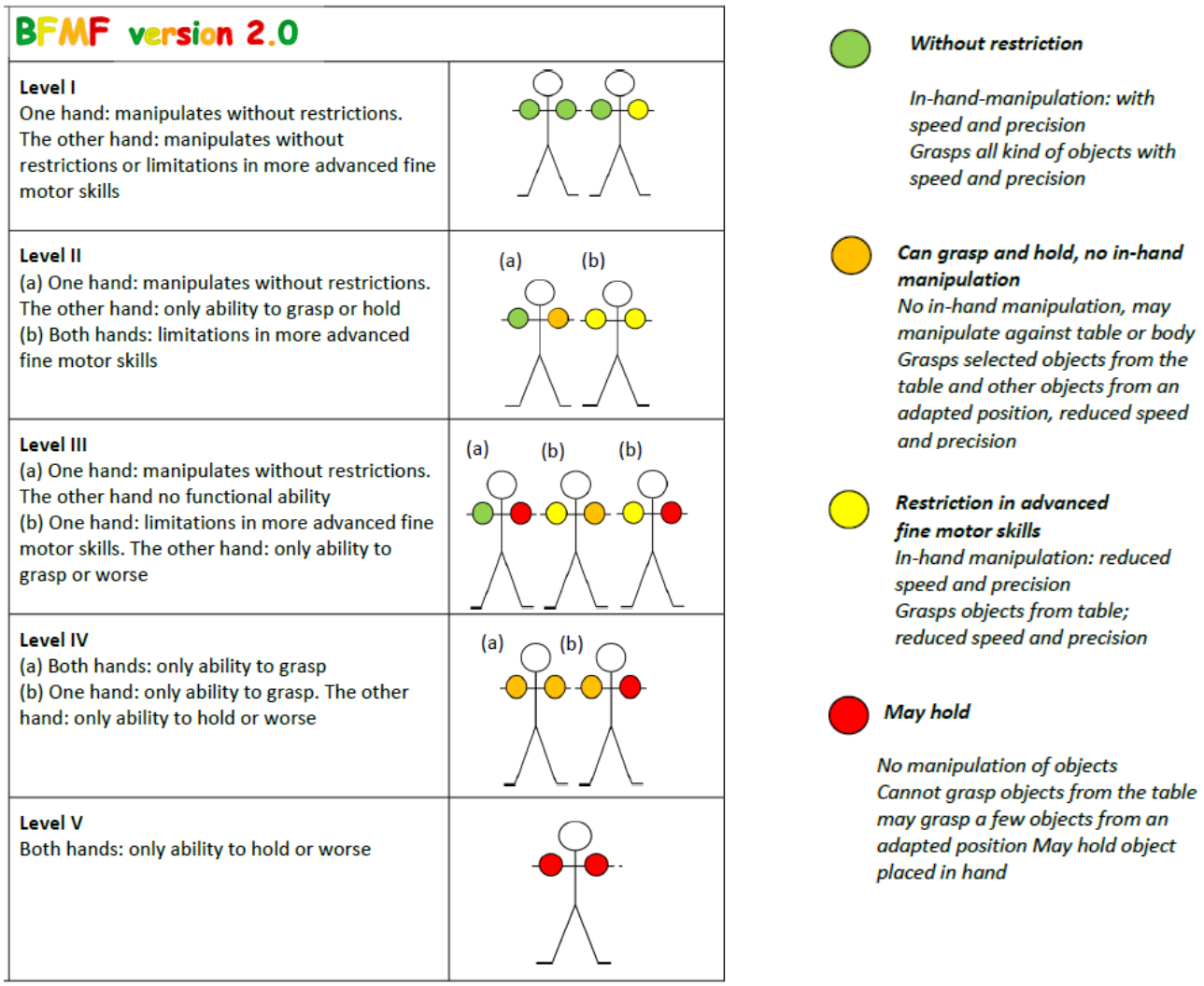


Cans C. (2000). Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Dev Med Child Neurol, 42: 816-824. doi:10.1111/j.1469-8749.2000.tb00695.x.

Cans C, Dolk H, Platt MJ, et al. (2007). Recommendations from the SCPE collaborative group for defining and classifying cerebral palsy. Dev Med Child Neurol, 49: 35-38. doi:10.1111/j.1469-8749.2007.tb12626.x.

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. These recommendations are commonly used and referenced in a number of studies.

The BFMF was originally developed in Sweden by Eva Beckung and Gudrun Hagberg to classify the functional use of hands in children with CP. More specifically, a child's ability to grasp, hold and manipulate objects in each hand separately. After its release in 2002, the SCPE decided to include the BFMF in the Common Database. Since then, collaboration was initiated with SCPE members from Sweden and Norway to perform a BFMF validation and reliability study, as well as develop BFMF version 2 (see below). The BFMF is now available in the following languages: English, Swedish, Spanish, Romanian, Chinese, and Turkish.



Beckung E, Hagberg G. (2002). Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. Dev Med Child Neurol, 44(5), 309-316. doi:10.1111/j.1469-8749.2002.tb00816.x

Elvrum AKG, Andersen GL, Himmelmann K, et al. (2016). Bimanual Fine Motor Function (BFMF) Classification in Children with Cerebral Palsy: Aspects of Construct and Content Validity. Phys Occup Ther Pediatr, 36(1):1-16. doi:10.3109/01942638.2014.975314

Elvrum AKG, Beckung E, Sæther R et al. (2017). Bimanual Capacity of Children With Cerebral Palsy: Intra- and Interrater Reliability of a Revised Edition of the Bimanual Fine Motor Function Classification. Phys Occup Ther Pediatr, 37:3, 239-251. doi:10.1080/01942638.2016.1185507

In 2010, SCPE members in the UK, Norway and Portugal worked on proposing a classification system for assessment of speech ability to be included in the SCPE data collecting form. The Viking Speech Scale (VSS) was developed to classify children's speech production (aged 4 years and above). It is currently available in English, Chinese, Danish, Greek, Italian, Latvian, Norwegian, Portuguese, Spanish, Swedish, Romanian and Turkish.

Viking Speech Scale, 2010

Read the descriptions of children's speech overleaf. Circle the level that best describes the child's speech.

I. **Speech is not affected by motor disorder.**

II. **Speech is imprecise but usually understandable to unfamiliar listeners.**

III. **Speech is unclear and not usually understandable to unfamiliar listeners out of context.**

IV. **No understandable speech.**

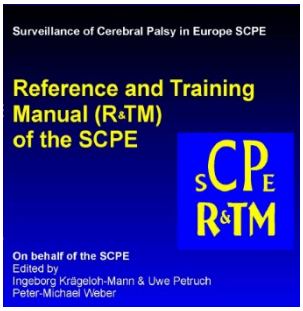
An international multicenter validity study was then performed by healthcare professionals and parents, in cooperation with seven SCPE member registries. The VSS was deemed to be correctly understood and easily applied in different settings, and showed the highest consistency and similar stability of existing tools. Therefore, as of 2016, it was included in the SCPE data collection form as the speech classification tool.

Virella D, Pennington L, Andersen GL, et al. (2016). Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy. Dev Med Child Neurol, 58: 285-291. doi:10.1111/dmcn.12866.

Pennington L, Virella D, Mjøen T, et al (2013). Development of The Viking Speech Scale to classify the speech of children with cerebral palsy. Res Dev Disabil. 34:3202-10. doi:10.1016/j.ridd.2013.06.035

2.2 Reference and Training Manual (R&TM)

Some difficulties emerged when implementing the classifications in the different SCPE member registries, mainly due to language. Therefore, the SCPE 2 (2002-2004) collaborated to develop the Reference and Training Manual (R&TM). The aim was to promote a shared understanding of the clinical, functional and neurological features of CP. The R&TM uses descriptions and videos of children with CP to illustrate these features and discuss pitfalls in diagnosis and classification. It provides 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 in eleven languages, and is now currently available on the SCPE website (www.scpenetwork.eu).



Platt MJ, Krägeloh-Mann I, and Cans C. (2009). Surveillance of Cerebral Palsy in Europe: Reference and Training Manual. Med Educ, 43: 495-496. doi:10.1111/j.1365-2923.2009.03351.x.

The continuing improvement of methods to record data has led to the development of a validated classification of brain imaging (MRICS). A new chapter was added to the R&TM focusing on magnetic resonance imaging (MRI) findings in the child with CP. This includes a proposed standardized description of MRI images which result in a classification for the predominant pattern of CP within five different subgroups.

A	**Maldevelopments**
	A1 Disorders of proliferation, migration or organisation
	A2 Other maldevelopments (among others: holoprosencephaly, Dandy Walker malformation, corpus callosum agenesis, cerebellar hypoplasia...)
B	**Predominant white matter injury**
	B1 Periventricular leucomalacia (PVL) (mild/severe)
	B2 Sequelae of intraventricular hemorrhage (IVH) or periventricular hemorrhagic infarction (PVHI)
	B3 Combination of PVL and IVH sequelae
C	**Predominant grey matter injury**
	C1 Basal ganglia/thalamus lesions (mild/moderate/severe)
	C2 Cortical-subcortical lesions only (watershed lesions in parasagittal distribution / multicystic encephaliamalacia) not covered by C3
	C3 Arterial infarctions (middle cerebral artery/other)
D	**Miscellaneous** (among others: cerebellar atrophy, cerebral atrophy, delayed myelination, ventriculomegaly not covered by B, hemorrhage not covered by B, brainstem lesions, calcifications)
E	**Normal**

Himmelmann K, Horber V, de la Cruz J, et al. (2017). MRI classification system (MRICS) for children with cerebral palsy: development, reliability, and recommendations. Dev Med Child Neurol, 59: 57-64. doi:10.1111/dmcn.13166.

In line with this classification, a description of neonatal imaging results following cranial ultrasounds or MRI scans has been further developed (NNICS). Both classifications can be routinely used in registries and have been introduced into the SCPE data collection form. The content is regularly updated and new content added.

2.3 Prevalence of CP in Europe

1976 to 1989

Data for birth years 1976-1990 were gathered at the European level and both the first description of children with CP and prevalence estimates 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% confidence interval 2.02 to 2.14). One in five children with CP were likely to be affected severely.

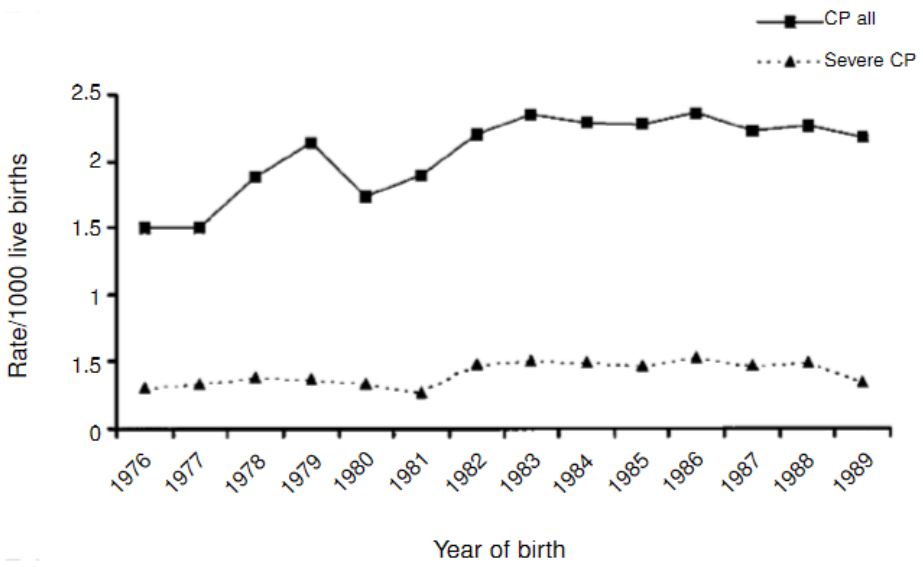


Figure 5: *Trends in rate of CP from 1976 to 1989.*

SCPE. (2002). Prevalence and characteristics of children with cerebral palsy in Europe. Dev Med Child Neurol, 44: 633-640. doi:10.1111/j.1469-8749.2002.tb00848.x.

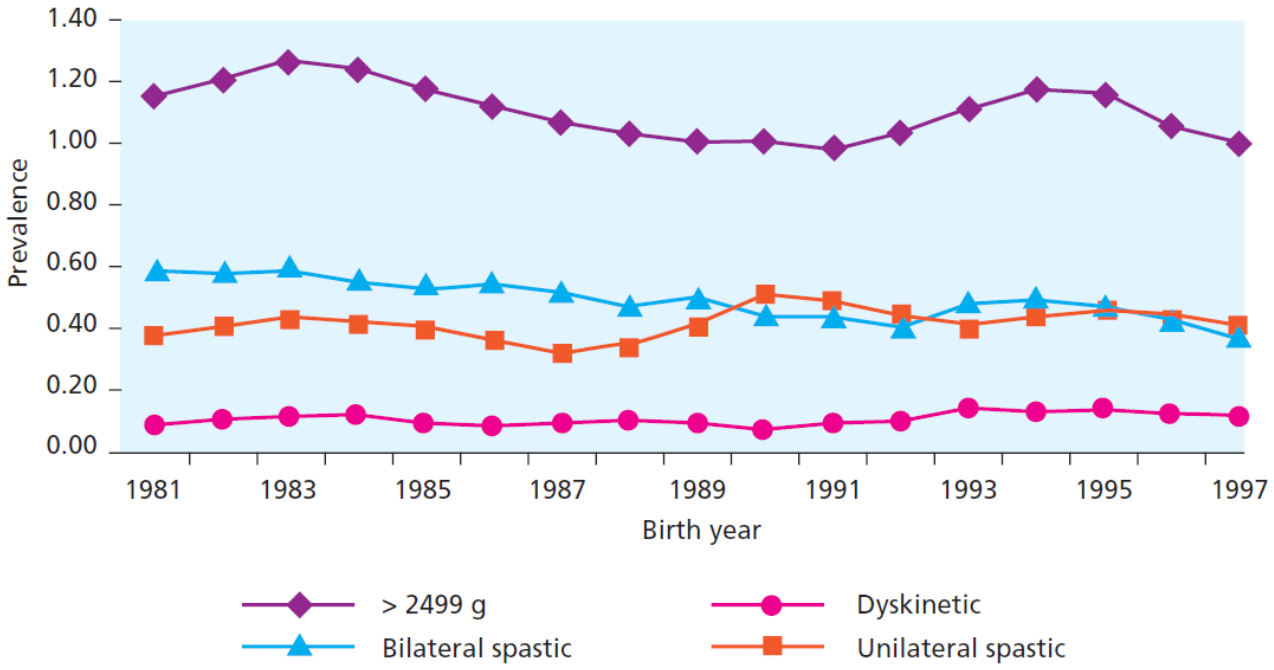
1980-1995

An article by Platt et al. 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 MJ, Cans C, Johnson A, et al. (2007). Trends in cerebral palsy among infants of very low birthweight (<1500 g) or born prematurely (<32 weeks) in 16 European centres: a database study. Lancet, Vol 369, Issue 9555, 43–50. doi:10.1016/S0140-6736(07)60030-0.

1980-1998

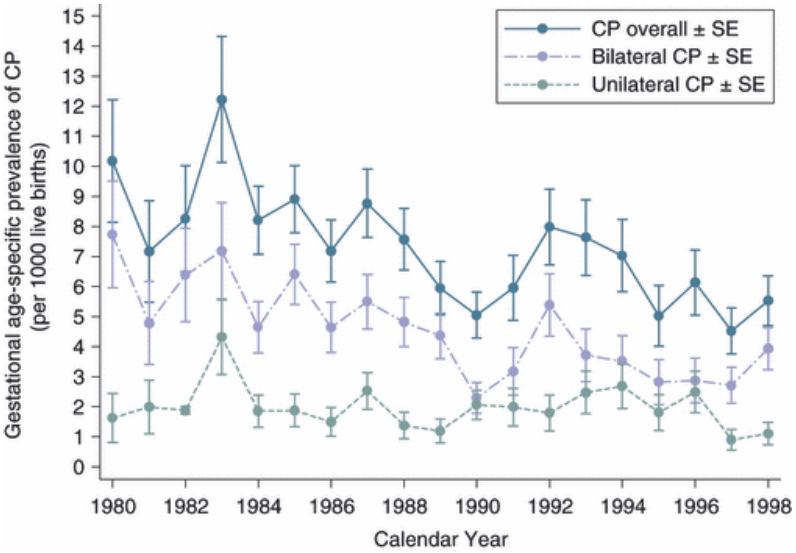
Sellier et al. reported on prevalence of CP in children with a normal birth weight (born ≥2,500 g). Using the SCPE Common Database on 4,002 children born 1980 to 1998 in Europe (15 SCPE registries), they explored prevalence estimates by CP subtype and severity. There was an overall non-significant trend in prevalence from 1.16 per 1,000 live births in 1980 to 0.99 in 1998. However, there was a significant decrease in the bilateral spastic CP subtype and an increase in the unilateral spastic subtype. At the same time, there was a reduction in neonatal mortality of children born ≥2,500 g from 1.7 to 0.9 per 1,000 live births.



Prevalence of cerebral palsy (3-year moving average), in children of normal birth weight from 15 European registers, 1980-1998.

Sellier E, Surman G, Himmelmann K, et al. (2010.) Trends in prevalence of cerebral palsy in children born with a birthweight of 2,500 g or over in Europe from 1980 to 1998. Eur J Epidemiol 25: 635. doi:10.1007/s10654-010-9474-0.

During this same time period (1980 to 1998) Andersen et al. reported a decreasing trend in the prevalence of children with CP born moderately preterm (gestational age 32-36 weeks) in 11 SCPE registries. However, there was no difference in the prevalence among children born at a moderately low birthweight (1500-2499g) during the same time period in 14 SCPE registries. Both results may represent an improvement in perinatal and neonatal care.

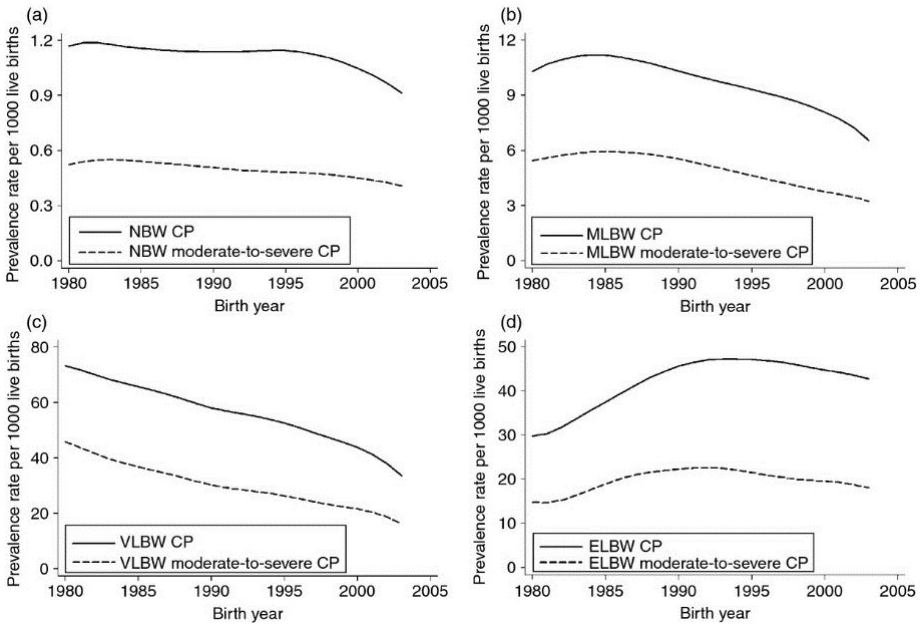


Gestational age-specific prevalence (unadjusted) of cerebral palsy (CP) per 1000 live births among children born between 1980 and 1998 according to birth year. SE, standard error.

Andersen GL, Romundstad P, de la Cruz J, et al. (2011). Cerebral palsy among children born moderately preterm or at moderately low birthweight between 1980 and 1998: a European register-based study. Dev Med Child Neurol, 53: 913-919. doi:10.1111/j.1469-8749.2011.04079.x.

1980-2003

The analysis of data from children born between 1980 and 2003 (20 SCPE registries, and 15,090 children with CP) showed a significant reduction in the overall prevalence and severity of cerebral palsy. The overall prevalence of CP decreased from 1.90 in 1980 to 1.77 per 1000 live births in 2003. In addition, the decreasing rates previously observed in children born with a very low birthweight (VLBW) were confirmed.



(a) Prevalence rate of cerebral palsy (CP) for children born with a birthweight ≥2500g, per 1000 live births. (b) Prevalence rate of CP for children born with a birthweight between 1500g and 2499g, per 1000 live births. (c) Prevalence rate of CP for children born with a birthweight between 1000g and 1499g, per 1000 live births. (d) Prevalence rate of CP for children born with a birthweight below 1000g, per 1000 live births. NBW, normal birthweight; MLBW, moderately low birthweight; VLBW, very low birthweight. ELBW, extremely low birthweight.

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

Summary 1980 - 2003

The following table shows an overview of the decline in the prevalence of CP, including a reduction in the prevalence of moderate/severe CP among infants born 1000g-2500g, a non-significant decline in the prevalence of CP among infants with a normal birth weight, and a stable rate of CP in the group of extremely low birthweight babies. There is also a significant reduction in the prevalence of bilateral spastic CP in all infants over 1000g at birth, and an increase in the prevalence of unilateral spastic CP among normal birthweight babies, otherwise a stable rate. Note that the neonatal survival improved in all birthweight groups in the same period.

	NBW	MLBW	VLBW	ELBW
Neonatal mortality rate	**10.65→0.89**	**19.6→9.3**	**184.8→45.0**	**632→316**
Overall prevalence of CP	1.17→0.89	**8.5→6.2** ***(non-linear decrease)***	**70.9→35.9 (3.4% per annum)**	Stable with mean of 42.4
Prevalence of moderate-severe CP	0.52→0.39	**4.5→3.2** ***(non -linear decrease)***	**48.1→17.1 (5.2% per annum)**	Stable with mean of 20.0
Prevalence of bilateral Spastic CP	**0.64→0.35 (1.4% per annum)**	**9.3→3.7** ***(non-linear decrease)***	**64.2→29.4 (2% per annum) (1980-96)**	
Prevalence of Unilateral Spastic CP	**Significant, non-linear increase**	Stable with mean of 2.4	Stable with mean of 11.0 (1980-96)	Stable with mean of 9.2 91980-96)

Prevalence rates per 1000 live births
NBW = normal birth weight
MLBW = moderately low birth weight
VLBW = very low birth weight
ELBW = extremely low birth weight

1976-1998

For around 5% of children with CP, the brain insult occurs postneonatally, with most causes accessible to preventative actions. SCPE data demonstrated a declining prevalence amongst this subgroup for children born between 1975 and 1990 with a mean prevalence over the period of 1.3 per 10,000 live births. This was confirmed for children born 1976 to 1998, where 1/3 of children with postneonatal CP had a very severe disability. A significant decline in the prevalence due to infections was reported.

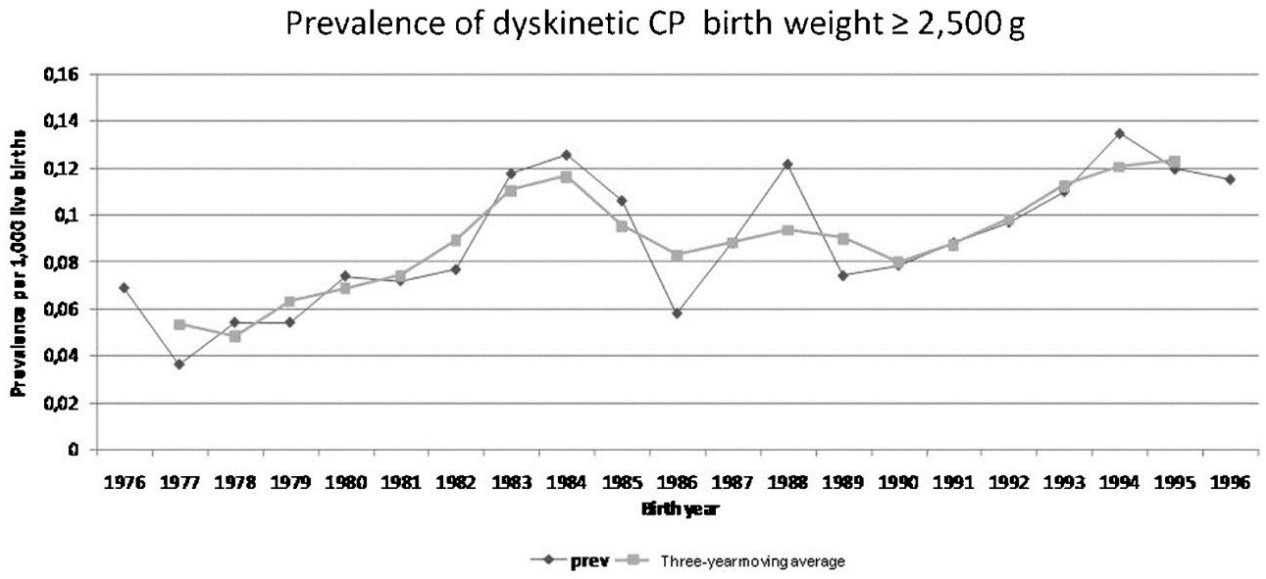
Cans C, McManus V, Crowley M, et al. (2004). Cerebral palsy of post-neonatal origin: characteristics and risk factors. Paediatr Perinat Epidemiol, 18: 214-220. doi:10.1111/j.1365-3016.2004.00559.x.

Germany L, Ehlinger V, Klapouszczak D, et al. (2013). Trends in prevalence and characteristics of post-neonatal cerebral palsy cases: A European registry-based study. Res Dev Disabil, Vol 34, Issue 5, pp 1669-1677. doi:10.1016/j.ridd.2013.02.016.

2.4 Subtypes and Associated Impairments

1976-1996

Himmelmann et al. investigated trends in the 578 children with dyskinetic CP recorded in the SCPE Common Database. They found a trend towards an increase in the prevalence of dyskinetic CP in children with a normal birth weight and that these children often experienced perinatal adverse events as well as had severe motor impairments and numerous associated impairments.



Himmelmann K, McManus V, Hagberg G, et al. (2009). Dyskinetic cerebral palsy in Europe: trends in prevalence and severity. Arch Dis Child, 94:921-926. doi:10.1136/adc.2008.144014.

1976-1998

Sellier et al. recognized a lack of data on prevalence for children with CP and epilepsy. Using data from 17 SCPE registries on 9,654 children with CP born between 1976 and 1998, they found that 35% of children with CP had epilepsy. The prevalence of epilepsy was 0.69 per 1000 live births, increased from 1976 to 1983, and decreased afterwards. Epilepsy was more frequent in children with a dyskinetic or bilateral spastic CP, along with other associated impairments.

Sellier E, Uldall P, Calado E, et al. (2012). Epilepsy and cerebral palsy: Characteristics and trends in children born in 1976–1998. Eur J Paediatr Neurol, Vol 16, Issue 1, pp 48–55. doi:10.1016/j.ejpn.2011.10.003.

1995-2006

To investigate the prevalence of children with CP and autism, as well as describing their characteristics, Delobel-Ayoub M et al. used data from four SCPE registries for children born between 1995 and 2006 and one surveillance program for children 0 to 19 years, registered in 2010 (1225 children with CP). They found that 8.7% of children with CP had an associated diagnosis of autism. In addition, there was an association between males, associated impairments of epilepsy and intellectual disability, as well as better walking ability with the coexistence of CP and autism.

Delobel-Ayoub M, Klapouszczak D, van Bakel MME, et al. (2017). Prevalence and characteristics of autism spectrum disorders in children with cerebral palsy. Dev Med Child Neurol, Jul;59(7):738-742. doi:10.1111/dmcn.13436.

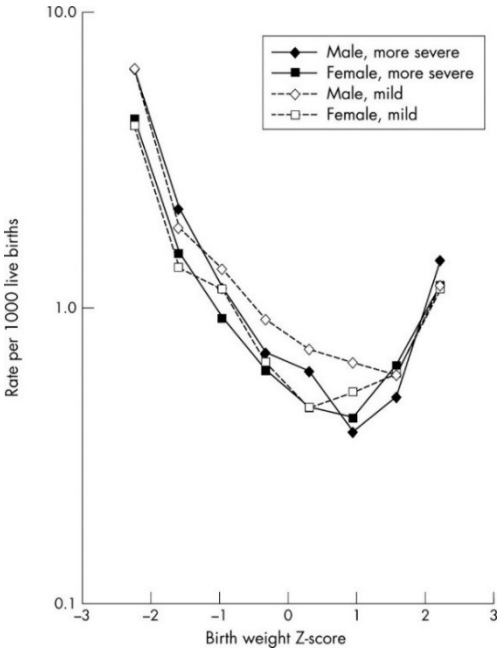
2.5 Risk for CP

1976-1990

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 S, Glinianaia SV, Torrioli MG, et al. (2003). Cerebral palsy and intrauterine growth in single births: European collaborative study. Lancet, Vol 362, Issue 9390, pp 1106-1111. doi:10.1016/S0140-6736(03)14466-2.

Furthermore, in a 2003 article, Jarvis et al. further explored if intrauterine size is associated with gender or severity of CP in singletons (data from 3,453 singletons with CP born between 1976 and 1990 from nine SCPE registries). They found that among children born as a singleton with CP, that there was an association between abnormal intrauterine size (small or large) and more severe disability and the male sex.



The figure shows: Sex specific rates of cerebral palsy by Z-score of weight for gestation: mild and more severe cases separately.

Jarvis S, Glinianaia SV, Arnaud C, et al. (2005). Case gender and severity in cerebral palsy varies with intrauterine growth. Arch Dis Child, 90:474-479. doi:10.1136/adc.2004.052670.

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 M, Huusom LD, Langhoff-Roos J, et al. (2004). Multiple birth and cerebral palsy in Europe: a multicenter study. Acta Obstet Gynecol Scand, 83: 548-553. doi:10.1111/j.0001-6349.2004.00545.x.

1976-1990

In cooperation between the SCPE and the European database of congenital malformations (EUROCAT), an article by Garne et al. was published to report on the proportion of children with CP with a congenital malformation (cerebral and non-cerebral). Data from eleven SCPE registries for children born 1976-1996 with a confirmed congenital malformation (n=547) were used. The article concluded that cerebral congenital malformations were significantly more frequent among children with CP than among all livebirths in the population. Furthermore, for children with CP, malformations in organ systems close to the brain (eye, facial clefts) were more frequent, while malformations in organ systems further from the brain (renal, genital) were more frequent in the general population.

Garne E, Dolk H, Krägeloh-Mann I, et al. (2008). Cerebral palsy and congenital malformations. Eur J Paediatr Neurol, Vol 12, Issue 2, 82–88. doi:10.1016/j.ejpn.2007.07.001.

2.6 Variation in clinical practices and access to care

1999-2001

As a part of the SCPE-NET project to describe variations in healthcare of children with CP across Europe, Dahseng et al. investigated the prevalence of gastrostomy tube feeding (GTF) of children with CP in six SCPE registries for children born between 1999 and 2001. They found that differences in access to GTF varied across Europe, with the highest prevalence in western Sweden and lowest in Portugal and Northern England. Furthermore, in countries with a higher proportion of tube-fed children, the children had better weight and height compared to those in countries with a low proportion of tube-fed children. The age at placement of the gastrostomy tube also varied between the countries.

Table III: The distribution of gastrostomy tube feeding among children in GMFCS levels IV and V in geographically defined areas in six European countries

	Gastrostomy		No gastrostomy		
	n	% (CI)	*n*	% (CI)	*p*[b]
Total	124	32 (27–36)	268	68 (54–73)	
Centre[a]					
Western Sweden	29	67 (53–80)	14	33 (20–47)	<0.001
Northern England	11	42 (26–61)	15	58 (39–74)	
Denmark	45	26 (20–34)	125	74 (66–80)	
Norway	28	44 (33–57)	35	56 (43–67)	
Portugal	10	12 (7–21)	74	88 (79–93)	
Iceland	1	17 (3–56)	5	83 (44–97)	

Dahlseng MO, Andersen GL, da Graça Andrada M, et al. (2012). Gastrostomy tube feeding of children with cerebral palsy: variation across six European countries. Dev Med Child Neurol, 54: 938-944. doi:10.1111/j.1469-8749.2012.04391.x.

Access to intrathecal baclofen and the presence of hip surveillance for children with CP across Europe were also investigated.

3. Collaborations

Study of Participation of Children with Cerebral Palsy Living in Europe

Seven SCPE regions established a research project to primarily investigate the lives of children with CP rather than the condition CP, its causation and how common it was. The project, called SPARCLE (PI Allan Colver, Newcastle UK), was initially 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. The main findings were:

- Children with CP report themselves to have the same quality of life as children in the general population (of the same age and country)
- Pain was much more common than had been expected and it affected quality of life
- Children with CP in some European countries participate more fully in life activities than in other countries. Higher participation is associated with better availability of environmental items.
- Overall, the severity of impairments highly reduced participation

The cohort has been visited again at adolescence. Data confirmed that overall self-reported quality of life is similar to the general population, but lower in *Social Support and peers* domain, whereas frequency of participation is much lower compared with the general population. Pain, psychological difficulties and parental stress in childhood predict lower quality of life and participation in adolescence mainly via effects on respectively quality of life and participation in childhood. An overview of the main SPARCLE results can be found on their website: http://research.ncl.ac.uk/sparcle/.

During 2005-2008, the SCPE 3 participated in the EURO-PERISTAT projects. These projects focused mainly on routine perinatal health reporting. The long-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. The European Perinatal Health Reports can be found on the EURO-PERISTAT website at: http://www.europeristat.com/.

EUROCAT is a network of population-based registers for the surveillance of congenital anomalies, and part of the European Platform on Rare Diseases Registration (EU RD Platform) developed by the JRC in close collaboration with the EC's Directorate for Health and Food Safety (DG SANTE). Individual registries of JRC-EUROCAT are collaborating with their corresponding CP registries in the SCPE and in Australia in a multicenter study on congenital anomalies, led by Cerebral Palsy Alliance (see below). Previous collaborations include a study on congenital anomalies in European children with cerebral palsy, by Rankin in 2010 and Garne in 2007. Information of EUROCAT can be found at: http://www.eurocat-network.eu/

Rankin J, Cans C, Garne E, et al. (2010). Congenital anomalies in children with cerebral palsy: a population-based record linkage study. Dev Med Child Neurol, 52: 345-351. doi:10.1111/j.1469-8749.2009.03415.x.

Garne E, Dolk H, Krägeloh-Mann I, et al. (2008). Cerebral palsy and congenital malformations. Eur J Paediatr Neurol, Vol 12, Issue 2, 82–88. doi:10.1016/j.ejpn.2007.07.001.

The SCPE has a close collaboration with the Cerebral Palsy Alliance in Sydney, Australia. This includes The Comprehensive CA-CP Study. The aim of this study is to pool data on congenital anomalies from the SCPE, EUROCAT, Australian Cerebral Palsy Register and Australian congenital anomaly registers. A study protocol has been published:

Goldsmith S, Garcia Jalon G, Badawi N, et al. (2018). Comprehensive investigation of congenital anomalies in cerebral palsy: protocol for a European-Australian population-based data linkage study (The Comprehensive CA-CP Study). BMJ Open, 8:e022190. doi:10.1136/bmjopen-2018-022190.

From left: Haley Sheedy-Smithers (CP Alliance), Kate Himmelmann (SCPE), Sarah McIntyre (CP Alliance) and Christine Cans (SCPE)

The SCPE often participates in the annual EACD and AACPDM conferences to report on the results of the SCPE new classification systems, as well as scientific results. This includes holding workshops and planning of the World CP Register Day in conjunction with the International Cerebral Palsy Conference (ICPC).

From left: Inge Krägeloh-Mann, Kate Himmelmann and Christine Cans
at first World CP Register Day in Sydney, Australia, 2009

From left: Maryam Oskoui (Canada), Hayley Smithers-Sheedy (Australia), Catherine Arnaud (Europe), and Marshalyn Yeargin-Allsopp (US) at the 71st Annual meeting of AACPDM, in Montreal, Canada:
Presidential guest lecture, “Epidemiology panel”

4. Acknowledgements

Thank you to Christine Cans and those involved in the establishment of the SCPE.

Thank you to the EU for providing the funding to enable the collaboration in the past and going forward

Thank you to all contributing SCPE centres and collaborators past and present

Thank you to the children and youths with CP, and their families without this work would not be possible.

Annex 1: Publication list

From newest to oldest:

- Goldsmith S, Garcia Jalon G, Badawi N, et al. (2018). Comprehensive investigation of congenital anomalies in cerebral palsy: protocol for a European-Australian population-based data linkage study (The Comprehensive CA-CP Study). BMJ Open, 8:e022190. doi:10.1136/bmjopen-2018-022190.
- Himmelmann K, Horber V, de la Cruz J, et al. (2017). MRI classification system (MRICS) for children with cerebral palsy: development, reliability, and recommendations. Dev Med Child Neurol, 59: 57-64. doi:10.1111/dmcn.13166.
  DMCN Author Podcast - Kate Himmelmann (December 2016) - YouTube
- Delobel-Ayoub M, Klapouszczak D, van Bakel MME, et al. (2017). Prevalence and characteristics of autism spectrum disorders in children with cerebral palsy. Dev Med Child Neurol, Jul;59(7):738-742. doi:10.1111/dmcn.13436.
- Sellier E., Platt MJ, Andersen GL, et al. (2016). Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003. Dev Med Child Neurol, 58: 85-92. doi:10.1111/dmcn.12865.
- Virella D, Pennington L, Andersen GL, et al. (2016). Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy. Dev Med Child Neurol, 58: 285-291. doi:10.1111/dmcn.12866.
- Dakovic I, da Graça Andrada M, Folha T, et al. (2014). Clinical features of cerebral palsy in children with symptomatic congenital cytomegalovirus infection. Eur J Paediatr Neurol, Volume 18, Issue 5, 618 – 623. doi:10.1016/j.ejpn.2014.04.2007.
- Smithers-Sheedy H, Badawi N, Blair E, et al. (2014). What constitutes cerebral palsy in the twenty-first century? Dev Med Child Neurol, 56: 323-328. doi:10.1111/dmcn.12262.
- Bakel M, Einarsson I, Arnaud C, et al. (2014). Monitoring the prevalence of severe intellectual disability in children across Europe: feasibility of a common database. Dev Med Child Neurol, 56: 361-369. doi:10.1111/dmcn.12281.
- Germany L, Ehlinger V, Klapouszczak D, et al. (2013). Trends in prevalence and characteristics of post-neonatal cerebral palsy cases: A European registry-based study. Res Dev Disabil, Vol 34, Issue 5, pp 1669-77. doi:10.1016/j.ridd.2013.02.016.
- Pennington L, Virella D, Mjøen T, et al (2013). Development of The Viking Speech Scale to classify the speech of children with cerebral palsy. Res Dev Disabil. 34:3202-10. doi:10.1016/j.ridd.2013.06.035
- Dahlseng MO, Andersen GL, da Graça Andrada M, et al. (2012). Gastrostomy tube feeding of children with cerebral palsy: variation across six European countries. Dev Med Child Neurol, 54: 938-944. doi:10.1111/j.1469-8749.2012.04391.x.
- Sellier E, Horber V, Krägeloh-Mann I, et al. (2012). Interrater reliability study of cerebral palsy diagnosis, neurological subtype, and gross motor function. Dev Med Child Neurol, 54: 815-821. doi:10.1111/j.1469-8749.2012.04359.x.
- Sellier E, Uldall P, Calado E, et al. (2012). Epilepsy and cerebral palsy: Characteristics and trends in children born in 1976–1998. Eur J Paediatr Neurol, Vol 16, Issue 1, pp 48–55. doi:10.1016/j.ejpn.2011.10.003.
- Andersen GL, Romundstad P, de la Cruz J, et al. (2011). Cerebral palsy among children born moderately preterm or at moderately low birthweight between 1980 and 1998: a European register-based study. Dev Med Child Neurol, 53: 913-919. doi:10.1111/j.1469-8749.2011.04079.x.

- Sellier E, Surman G, Himmelmann K, et al. (2010.) Trends in prevalence of cerebral palsy in children born with a birthweight of 2,500 g or over in Europe from 1980 to 1998. Eur J Epidemiol 25: 635. doi:10.1007/s10654-010-9474-0.
- Rankin J, Cans C, Garne E, et al. (2010). Congenital anomalies in children with cerebral palsy: a population-based record linkage study. Dev Med Child Neurol, 52: 345-351. doi:10.1111/j.1469-8749.2009.03415.x.
- Himmelmann K, McManus V, Hagberg G, et al. (2009). Dyskinetic cerebral palsy in Europe: trends in prevalence and severity. Arch Dis Child, 94:921-926. doi:10.1136/adc.2008.144014.
- Platt MJ, Krägeloh-Mann I, and Cans C. (2009). Surveillance of Cerebral Palsy in Europe: Reference and Training Manual. Med Educ, 43: 495-496. doi:10.1111/j.1365-2923.2009.03351.x.
- Gainsborough M, Surman G, Maestri G, et al. (2008). Validity and reliability of the guidelines of the Surveillance of Cerebral Palsy in Europe for the classification of cerebral palsy. Dev Med Child Neurol, 50: 828-831. doi:10.1111/j.1469-8749.2008.03141.x.
- Garne E, Dolk H, Krägeloh-Mann I, et al. (2008). Cerebral palsy and congenital malformations. Eur J Paediatr Neurol, Vol 12, Issue 2, 82–88. doi:10.1016/j.ejpn.2007.07.001.
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- Cans C, Dolk H, Platt MJ, et al. (2007). Recommendations from the SCPE collaborative group for defining and classifying cerebral palsy. Dev Med Child Neurol, 49: 35-38. doi:10.1111/j.1469-8749.2007.tb12626.x.
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- Jarvis S, Glinianaia SV, Arnaud C, et al. (2005). Case gender and severity in cerebral palsy varies with intrauterine growth. Arch Dis Child, 90:474-479. doi:10.1136/adc.2004.052670.
- Topp M, Huusom LD, Langhoff-Roos J, et al. (2004). Multiple birth and cerebral palsy in Europe: a multicenter study. Acta Obstet Gynecol Scand, 83: 548-553. doi:10.1111/j.0001-6349.2004.00545.x.
- Cans C, McManus V, Crowley M, et al. (2004). Cerebral palsy of post-neonatal origin: characteristics and risk factors. Paediatr Perinat Epidemiol, 18: 214-220. doi:10.1111/j.1365-3016.2004.00559.x.
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Annex 2: SCPE Data Collection Form

Register ID

SCPE Data Collection Form for Cerebral Palsy	Short Form October 2018

CONFIDENTIAL — **Space for logo**

NAME of register/database	ID

NAME of the child

Name *Surname*

CEREPRAL PALSY (CP): DEFINITION

Cerebral palsy is an umbrella term for 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 who **acquire** this condition after the first 28 days of life are also included in the database.

Please refer to the SCPE Guide for the registration of Cerebral Palsy and the Reference and Training Manual (RTM) at www.scpenetwork.eu for further details on CP definition/ decision tree/ inclusion and exclusion criteria.

Is this child ***diagnosed with*** or suspected of having Cerebral Palsy? *Please tick ☑ one box*

Yes ☐ → **Enter diagnosis in box below, then go to Item/ Question 1**

No ☐ → **Enter diagnosis in box below then fill the last page**

Current diagnosis:

1. Name of the centre (CENTRE – 3 digits)

2. Identification number of the case (ID – 8 digits)

3. Birth date (BIRTH_DA – 10 digits)

dd/mm/yyyy

4. Has the diagnosis of CP been confirmed after the age of 4 years? (CONFIRM – 2 digits)

Yes

NO; dead

NO; lost to follow up but with confirmed diagnosis of CP after the age of 2 years

Unknown

Not collected

5. Mother's permanent place of residence at time of birth (BIRTH_RESID – 1 digit)

Inside the area

Outside the area

Unknown

6. Parents or guardians place of residence at time of registration of the case (REGIST_RESID – 2 digits)

Inside the area

Outside the area

Unknown

Not collected

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7. Status (STATUS – 2 digits)	Known to be dead	
	Otherwise	
	Not collected	

8. Date of death (DEATH_DATE – 10 digits)	
dd/mm/yyyy	

9. Age at death in months – only if date of death not available (DEATH_AGE – 3 digits)	

10. Sex (SEX – 1 digit)	Male	
	Female	
	Unknown	

11. Birthweight in grams (BW – 4 digits)	BW (g)	
	Unknown	

12. Gestational age in completed weeks (GA – 2 digits)	GA (weeks)	
	Unknown	

13. Multiple birth = number of infants born at the same delivery (MULT_BIRTH – 2 digits)	Singleton	
	Twin	
	Triplets	
	Quadruplets	
	Quintuplets	
	Sextuplets	
	Septuplets	
	≥ 2	
	Unknown	
	Not collected	

14. Birth order = if from a multiple birth, what was the birth order of the child? (BO – 2 digits)	First infant	
	Second infant	
	.....	....
	7th infant	
	Unknown	
	Not collected	

15. Maternal age at birth in years (MOTHER_AGE – 2 digits)	(years)	
	Unknown	
	Not collected	

16. Parity = number of previous pregnancies resulting in either live birth or stillbirth (as defined in country or registry), excluding miscarriages and therapeutic abortions **(PARITY – 2 digits)**	None previous delivery	
	One previous delivery	
	≥Two previous deliveries	
	Unknown	
	Not collected	

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17. Delivery mode (DELIVERY_MODE – 2 digits)	Vaginal delivery	
	Caesarean Section (CS)	
	CS elective / before labour	
	CS emergency / during labour	
	Unknown	
	Not collected	

18. Place of birth = hospital of birth or home or travel; if birth took place in a maternity unit, please report on the size of the maternity unit in terms of total annual number of deliveries **(BIRTH_PLACE – 2 digits)**	Home or travel or hospitalisation unit other than maternity unit	
	Maternity unit 1 – 499	
	Maternity unit 500 – 999	
	Maternity unit 1000 – 1499	
	Maternity unit 1500 – 1999	
	Maternity unit 2000 – 3999	
	Maternity unit 4000+	
	Unknown	
	Not collected	

19. Type of Cerebral Palsy / CP classification 1. Please refer to the Classification Tree for sub-types of Cerebral Palsy in the RTM and the SCPE Guide for the registration of Cerebral Palsy **(CP_TYPE – 2 digits)**	Spastic	
	Dyskinetic	
	Dystonic dyskinetic	
	Choreo-athetotic dyskinetic	
	Ataxic	
	Unable to classify	

20. SPASTIC (or Dyskinetic) CP classification / CP classification 2. **Bilateral**: limbs on both sides of the body are involved. **Unilateral (e.g. hemiplegia)**: limbs on one side of the body are involved**.** [Dyskinetic CP can also be further classified into unilateral and bilateral]. **(SPAS_DYSK_TYPE – 1 digit).**	Bilateral	
	Unilateral	
	Unknown	

21. UNILATERAL CP classification / CP classification 3. **If unilateral CP, which is the affected side? (UNI_TYPE – 1 digit)**	Right	
	Left	
	Unknown	

22. BIMANUAL FINE MOTOR FUNCTION CLASSIFICATION (BFMF) at minimum age of 4 years.

Please tick the box of the level that most closely describes this child **(BFMF – 2 digits)**

1	One hand: manipulates without restrictions. The other hand: manipulates without restrictions or limitations in more advanced fine motor skills.	
2	a) One hand: manipulates without restrictions. The other hand: only ability to grasp or hold. b) Both hands: limitations in more advanced fine motor skills.	
3	a) One hand: manipulates without restrictions. The other hand: no functional ability. b) One hand: limitations in more advanced fine motor skills. The other hand: only ability to grasp or worse.	
4	a) Both hands: only ability to grasp. b) One hand: only ability to grasp. The other hand: only ability to hold or worse.	
5	Both hands: only ability to hold or worse.	
	Unknown	
	Not collected	

Taken from: Beckung E, Hagberg G. Neuroimpairments, activity limitations and participation restrictions in children with cerebral palsy. Dev Med Child Neurol 2002; 44:309-316.

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23. MANUAL ABILITY CLASSIFICATION SYSTEM (MACS), at minimum age of 4 years. Please tick the box of the level that most closely describes this child **(MACS – 2 digits)**		
I	***Handles objects easily and successfully.*** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.	
II	***Handles most objects but with somewhat reduced quality and/or speed of achievement.*** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.	
III	***Handles objects with difficulty; needs help to preparer and/or modify activities.*** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.	
IV	***Handles a limited selection of easily managed objects in adapted situations.*** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.	
V	***Does not handle objects and has severely limited ability to perform even simple actions.*** Requires total assistance.	
	Unknown	
	Not collected	

Taken from: Eliasson AC et al., Dev Med Child Neurol 2006; 48; 549-554.

24. GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM (GMFCS) between the 4th and 6th birthdays*. Please tick the box of the level that most closely describes this child. **(GMFCS – 2 digits)**		
I	Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.	
II	Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.	
III	Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with an assistive mobility device on level surfaces and may climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.	
IV	Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.	
V	Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.	
	Unknown	
	Not collected	

*Taken from: Palisano R., et al. Development and validation of a gross motor function classification system for children with cerebral palsy. Dev Med Child Neurol, 39, 214-223, 1997. *If required the Gross Motor Function Classification for **ALL YEARS UP TO AGE 12** can be downloaded from* http://www-fhs.mcmaster.ca/canchild/

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25. VIKING SPEECH SCALE (VSS). If you have several evaluations, please report he one which was done **at the age closest to 60 months**. *Please tick the appropriate box in the right column.* **(VIKING – 2 digits)**

I	***Speech is not affected by motor disorder.***	
II	***Speech is imprecise but usually understandable to unfamiliar listeners.***	
III	***Speech is unclear and not usually understandable to unfamiliar listeners out of context.***	
IV	***No understandable speech.***	
	Unknown	
	Not collected	

http://www.scpenetwork.eu/en/r-and-t-manual/viking-speech-scale

26. Age at Viking Speech Scale assessment in months (VIKING_AGE – 3 digits)

Age in months	
Unknown	
Not collectable	

INTELLECTUAL IMPAIRMENT

Is cognitive impairment present?

27. Intellectual impairment. Please provide an estimate of the level of impairment by marking the appropriate box in the right column below. An assessment of the degree of cognitive impairment can be made on the behavioural responses of the child. **(INTEL_IMP – 2 digits)**

IQ, if IQ test available ***OR*** Clinical assessment

	≥70	No impairment or attendance of regular school
Equivalent to ICD10 Codes F70 to F73	50 – 69	Mild impairment
	20 – 49	Moderate / Severe impairment
	< 20	Severe / Profound impairment
	< 50	Impairment moderate or severe, unspecified
		Unknown
		Not collected

28. IQ test (IQ_TEST – 2 digits)

Testing	
Testing with the IQ value	
Testing without the IQ value	
Clinical estimate	
Unknown	
Not collected	

29. Age at IQ test in months (AGE_IQ – 3 digits)

Age (in months)	
Unknown	
Not collected	

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30. VISUAL IMPAIRMENT. Is there a visual impairment of any type present? Please tick the appropriate box in the shaded column **(VI – 2 digits)**	Yes		Go to Question 31
	No		Go to Question 32
	Unknown		Go to Question 32
	Not collected		

31. SEVERE VISUAL IMPAIRMENT (blindness or no useful vision, after correction, in the better eye). If the level of visual loss is < 6/60 (Snellen scale) or < 0.1 (Decimal scale) in both eyes, this will conform to the SCPE criteria for "Severe visual impairment", please tick the appropriate box in the shaded column. **Does this child have severe visual impairment?** **(VI_SEVER – 2 digits)**	Yes	
	No	
	Unknown	
	Not collected	

32. HEARING IMPAIRMENT. Is hearing impairment present? Please tick the appropriate box in the shaded column **(HI – 2 digits)**	Yes		Go to Question 33
	No		Go to Question 34
	Unknown		Go to Question 34
	Not collected		

33. SEVERE HEARING IMPAIRMENT. Severe hearing loss definition: Defined as "severe" or "profound" hearing loss, i.e. loss >70 db, (before correction, on the better ear). Please tick the appropriate box in the shaded column. **Does this child have severe hearing impairment?** **(HI_SEVER – 2 digits)**	Yes	
	No	
	Unknown	
	Not collected	

34. EPILEPSY. Epilepsy definition: epilepsy if diagnosed by medical doctor, excluding febrile or neonatal seizures. Please tick the appropriate box in the shaded column **(EPILEPSY – 2 digits)**	Never		Go to Question 37
	Ever		Go to Question 35
	Unknown		Go to Question 37
	Not collected		

35. ACTIVITY of EPILEPSY. Activity of epilepsy definition: having active treatment for epilepsy at the time of data capture. Is the child on antiepileptic medication at time of registration (independently of the presence/absence of seizures)? **(EPIL_ACT – 2 digits)**	Yes	
	No	
	Unknown	
	Not collected	

36. AGE of onset of EPILEPSY (AGEON_EPIL – 2 digits)	During first year of life (excluding 3 first days of life)	
	During second year of life	
	During third year of life	
	During fourth year of life	
	During fifth year of life or later	
	Unknown	
	Not collected	

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37. – OSTOMIES **Definition of –ostomies:** any procedure that transgresses the abdominal wall to enable feeding (e.g. gastrostomy, jejunostomy). Has the child ever had a procedure for the insertion of –ostomy to enable feeding? **(OSTOMY – 2 digits)**	Never		Go to Question 39
	Ever		Go to Question 38
	Unknown		Go to Question 39
	Not collected		

38. AGE of insertion of –ostomy in months **(OSTOMY_AGE – 3 digits)**	(months)	
	Unknown	
	Not collected	

39. SYNDROMES **Has the child a diagnosed syndrome? (Associated Syndrome definition**: please refer to EUROCAT guideline http://www.eurocat-network.eu/content/EUROCAT Syndrome Guide Revision Final version September 2017.pdf please tick the appropriate box in the shaded column. **(SYNDR – 2 digits)**	Yes	
	No / Unknown	
	Not collected	

40. Coding diagnosis for Syndrome (ICD10 code) **(SYNDR_COD – 6 digits)**							

41. Text diagnosis for Syndrome **(SYNDR_TXT – 100 digits)**	

42. Cardiac Malformation **Cardiac Malformation definition**: please refer to EUROCAT guideline http://www.eurocat-network.eu/content/Section 3.5-18_Dec2017.pdf heart defects Q20 to Q26. **Does this child have a cardiac malformation? (CARDIAC_MALF – 2 digits)**	Yes		Go to Question 43
	No		Go to Question 46
	Unknown		Go to Question 46
	Not collected		

43. Coding diagnosis for cardiac malformation (ICD10) **(CARDIAC_COD – 6 digits)**							

44. Clear text for cardiac malformation **(CARDIAC_TXT – 100 digits)**	

45. Clear text for describing any additional other congenital anomalies **(ANY_OTHER_CA_TXT – 200 digits)**	

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46. POSTNEONATAL Cerebral Palsy. Do you think it most likely that the cause of the impairment occurred AFTER the first 28 days of life? **(POSTNEON – 2 digits)**	Yes		Go to Question 47
	No		Go to Question 50
	Unknown		Go to Question 50
	Not collected		

47. Coding diagnosis for Postneonatal CP (ICD10) (POSTN_CODE1 – 6 digits)	

48. Text diagnosis for Postneonatal CP (POSTN_CODE2 – 50 digits)	

49. Age at the time of insult <u>in months</u>. If known, please give the **age** at which this occurred. **(AGE_POSTN – 3 digits)**	Age (in months)	
	Unknown	
	Not collected	

50. Was the child admitted to a Neonatal Care Unit? (NCU – 2 digits)	Yes	
	No	
	Unknown	
	Not collected	

51. If "Yes", did the child receive ventilation (not resuscitation) in the NCU? **Ventilation (not resuscitation) in the neonatal intensive care unit:** means that the child has been mechanically ventilated by respirator and not just resuscitated (e.g. mask insufflation) or intubated only for a short duration (e.g. during transport) **(VENT_NCU – 2 digits)**	Yes	
	No	
	Unknown	
	Not collected	

52. Has the child received therapeutic cooling? (COOLING – 2 digits)	Yes	
	No	
	Unknown	
	Not collected	

53. What was the Apgar score at 5 minutes? (APGAR5 – 2 digits)	Apgar [0 – 10]	
	Unknown	
	Not collected	

54. Convulsions within the first 72 hours? (CONVULS – 2 digits)	Yes	
	No	
	Unknown	
	Not collected	

55. Has imaging been performed? (IMAGING – 2 digits)	Yes		**If (only) neonatal imaging (MRI /US) performed**	**Go to Questions 61 to 65**
			If postneonatal MRI performed	**Go to Questions 56 to 60**
			If postneonatally only CT scan performed	**Go to Questions 56, 57, 59, 60**
	No			
	Unknown			
	Not collected			

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56. Which type of postneonatal imaging has been performed? (if both MRI and CT have been performed, please report on the MRI results)
(POST_IMAG – 2 digits)

MRI	
CT	
Unknown	
Not collected	

57. Chronological age at the most recent postneonatal imaging in months
(MRI_CT_AGE – 3 digits)

Age (in months)	
Age > 8 years	
Unknown	
Not collected	

58. Classification of postneonatal MRI results. For further information on this classification, please look at the CP neuroimaging classification: http://www.scpenetwork.eu/en/my-scpe/rtm/neuroimaging/cp-neuroimaging/suggested-classification-for-the-predominant-pattern/st recent result and the predominant result according to the five proposed categories (A, B, C, D and E); if possible, give the subcategory
(MRI_RESULT – 2 digits)

Maldevelopments		**A**
Disorders of proliferation and/ or migration and/or organisation	**A1**	
Other maldevelopments	**A2**	
Predominant white matter injury		**B**
Periventricular leucomalacia (PVL)	**B1**	
Sequelae of intraventricular haemorrhage (IVH) or periventricular haemorrhagic infarction (PVHI)	**B2**	
Combination of PVL and IVH sequelae	**B3**	
Predominant grey matter injury		**C**
Basal ganglia/ thalamus lesions	**C1**	
Cortico-subcortical lesions only, not covered by C3	**C2**	
Arterial infarctions	**C3**	
Miscellaneous changes		**D**
Normal		**E**
Unknown		**Z**
Not collected		

59. Clear text for the postneonatal MRI or CT result (English). Please mention if the classification was made on the basis of the images directly – if you want to propose a second MRI classification pattern, please give it here.
(MRI_CT_R_TXT – 200 digits)

Unknown	
Not collected	

60. Side of this postneonatal imaging result
(MRI_SIDE – 2 digits)

Right	
Left	
Bilateral	
Unknown	
Not collected	

61. Has imaging been performed before discharge from the Neonatal Care Unit? Which type of neonatal imaging has been performed? If both neonatal US and MRI imaging have been performed, give the results only for neonatal MRI imaging (Questions 62 to 65).
(NEONI – 2 digits)

US imaging	
MRI imaging	
Both US and MRI imaging	
No neonatal imaging	
Unknown	
Not collected	

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62. Chronological age at the most recent neonatal imaging (value in weeks). If both neonatal US and neonatal MRI imaging have been performed, give the results only for neonatal MRI imaging **(NEONI_AGE – 2 digits)**	Chronological age (in weeks)	
	Unknown	
	Not collected	

63. Classification of neonatal imaging result. For further information on this classification, please look at the neonatal neuroimaging classification at http://www.scpenetwork.eu/en/my-scpe/rtm/neuroimaging/neonatal-neuroimaging/suggested-classification-for-the-predominant-pattern/ and neonatal MRI imaging have been performed, give the results only for neonatal MRI. Give the most recent result and the predominant result according to the five proposed categories (A, B, C, D and E); if possible, give the subcategory **(NEONI_RESULT – 2 digits)**	**Maldevelopments**		**A**
	Disorders of proliferation and/ or migration and/ or organisation	**A1**	
	Other maldevelopments	**A2**	
	Predominant white matter injury		**B**
	Echogenicity or MR signal intensity abnormalities	**B1**	
	Periventricular haemorrhagic infarction (IVH grade IV)	**B2**	
	Post-haemorrhagic ventricular dilatation	**B3**	
	Predominant grey matter injury		**C**
	Basal ganglia/ thalamus lesions	**C1**	
	Watershed lesions (parasagittal lesions)	**C2**	
	Arterial infarctions (middle cerebral artery)	**C3**	
	Haemorrhage	**C4**	
	Miscellaneous changes		**D**
	Normal		**E**
	Unknown		**Z**
	Not collected		

64. Clear text for the neonatal imaging result (English). If the classification was made on the basis of the images directly, then mention it. If you want to propose a second classification pattern, please give it here. **(NEONI_R_TXT – 100 digits)**	Unknown	
	Not collected	

65. Side of this neonatal imaging result? (NEONI_SIDE – 2 digits)	Right	
	Left	
	Bilateral	
	Unknown	
	Not collected	

COMMENTS:

NAME and signature of person completing this questionnaire:

Status (ex: paediatrician) **Date**

Annex 3: SCPE Denominators

Denominators:

Total births
Delivery mode
Delivery mode per birth weight
Delivery mode per gestational age
Place of birth
Maternal age and parity
Neonatal deaths per birth weight
Neonatal deaths per gestational age
Multiple neonatal deaths per birth weight
Multiple Neonatal deaths per gestational age
Live births per birth weight
Live births per gestational age
Multiple live births per birth weight
Multiple live births per gestational age