



Memorandum of Understanding 2014

1. SCPE “Surveillance of Cerebral Palsy in Europe” network is an unofficial voluntary, non-profit organisation.

2. Objectives and functions

To use a surveillance and research network in order to contribute to a reduction in impairment and improvement in quality of life of European citizens (adults and children) with Cerebral Palsy [CP].

Priority actions of the SCPE network are:

- I. To improve knowledge and understanding of how the impact of CP can be influenced by medical, educational, and social care
- II. To identify and promote best practice in health care for children with CP across European countries and to reduce inappropriate variations in physical, social and emotion outcomes
- III. Where possible to prevent CP, or otherwise ameliorate the consequences of CP

Specific objectives are:

- i) Surveillance of CP: Through the use of population-based registers and databases across European countries, to monitor trends in rates and severity of CP and variations by, for example, CP subtype, associated impairments or disabilities
- ii) Clinical epidemiology and research: Through the network of SCPE members, to facilitate the development of collaborative epidemiological and clinical research projects on children with CP, with the secondary objective of attracting young researchers to this field
- iii) Public Health dissemination/ Reduction of health inequalities: To promote at governmental, national, regional and local levels, best practice to enable (where possible) the prevention of CP, and otherwise best practice in the care and management of children with CP, and to reduce inequalities across member states with respect to access to care, and outcomes of care for children with CP and other neuro-developmental impairments.

Role of the network:

- to maintain, develop and assure the quality of the SCPE common database, to ensure its sustainability
- to encourage and provide support and guidance to those establishing a new registry in a member state
- to promote both the work and achievements of each member registry, and the work and achievements of the network itself, including published papers using data from the common database
- to facilitate the development of research projects between partners of the network
- to encourage the implementation of a “European CP Alliance”, a European non profit organisation of families with CP.



3. Membership

3.1 General

Membership can be considered for any person or organisation or body whose work focuses on improving understanding of or outcome from CP and/or other neuro-developmental impairment.

3.2 Qualification for membership can be on the basis of one of three categories

Type (a) partner: Any European registry or survey of children with CP fulfilling ALL the following criteria:

- covers a geographically defined area, with a birth rate of at least 3,000 births per annum
- uses multiple sources of ascertainment
- can comply with the SCPE requirements in terms of data collection, classification of CP, and quality assurance
- will transmit the relevant data to the SCPE common database in a timely manner

The partner is the registry, and is usually represented by the registry leader, or someone nominated by them. The registry leader can be replaced by his/her representative.

Type (b) partner: An individual professional with skills relevant to children in a neuro-developmental field such as clinical, public health or epidemiological expertise

Type (c) partner: Any association, non-governmental organisation or network with an interest in the work performed by SCPE network. Eligible organisations may include parent organisations, institutions or professional organisations. Suitable non European organisations may also be invited to become member.

The partner is the organisation or network, and is usually represented by the organisation/network leader, or an agreed representative.

3.3 Application procedures

Decisions on membership of SCPE are made at the annual plenary meeting.

Type (a) applicants should apply to the chair of SCPE.

Type (b) applicants should be proposed by a current member of the SCPE network; their membership has to be approved by the board of members during the annual plenary meeting.

Type (c) applicants should be proposed by a current member of the SCPE network; their membership has to be approved by the board of members during the annual plenary meeting.

3.4 Obligations of members

Type (a) partners agree to:

- submit annually relevant data, in accordance with SCPE specifications guidelines, on children with CP in their registry, with an age at registration closest to 5 years old. Although a minimum population of at least 3,000 live births per year is required for membership, the ideal number of births should be between 10,000 and 30,000 live births per year. Each registry is responsible for ensuring that the submission of individual data to the SCPE common database complies with their local/national ethics requirements.
- provide appropriate population denominator data, in accordance with SCPE specifications guidelines



- comply with the SCPE guidelines on quality assurance to ensure reliability and accuracy of data both from its registry of children with CP and on denominator data
- participate in work led by the SCPE network dedicated to improving data quality or extending the common dataset
- initiate and/or participate in research projects with other registries, including contributing to the analysis of the common dataset
- ensure that they maintain their data registry in compliance with the relevant local research ethics requirements
- disseminate the findings from SCPE work to their local, regional and national networks

Type (b) partners have to:

- bring expertise from their relevant skill area, such as neuro-imaging, epidemiology, educational therapies, socio-economic analysis that are required to achieve the aims of the SCPE network
- promote the use of SCPE common database in collaborative research studies external to SCPE

Type (c) partners are solicited to:

- help the SCPE network develop appropriate and valued areas of research such as inequalities in health, representativeness of registers in Europe, influence on stakeholders, impact on families
- assist in the dissemination the SCPE network outputs

4. Tools for collaboration

4.1 The SCPE Common database

Since 1999, the SCPE common database, which annually receives data from each member registry or survey, has been located at Grenoble University (FR). Its use and development are under the guidance of the SCPE Steering Committee, with the support and guidance of the Data Working Group.

The registries/surveys are the data owners of this common database.

Access to and use of the data included in the SCPE common database are the responsibility of the SCPE Steering Committee.

4.2 Web site and tools for improving harmonised knowledge

Data from each registry/survey are submitted annually through the SCPE website.

The SCPE website provides documents to support SCPE registries which include:

- the decision and classification trees
- a standardised data collection form
- access to the SCPE Reference and Training Manual, and relevant translations of it and other tools
- guidelines for data submission

Those supporting documents could evolve over time.



4.3 Annual meeting

Each year a plenary meeting is organised to which all members, irrespective of type of membership, are invited.

5. Structure of SCPE

5.1 SCPE Board of members

The SCPE Board of members consist of all Type (a) partners.

On matters needing a vote, only members of the SCPE Board can vote, each partner having one vote.

When needed, the Board of members elect the core members of the SCPE Steering Committee.

When needed, the Board of members elect the chair of the SCPE Steering Committee.

5.2 SCPE Steering committee

Membership

The SCPE Steering Committee (SC) is composed of elected representatives of the SCPE network.

- The core SCPE members should be at least four Type (a) partners; they are elected by the SCPE Board of members. In addition, Type (b) and Type (c) partners may be nominated for election to the SCPE Steering Committee.
- SCPE members will be elected on a rolling cycle with an election every two years (half of the Steering Committee), each elected member serving for four years, maximum 8 years.

Chair and deputies

- The Chair of the SCPE Steering Committee is elected by the SCPE Board of members.
- There are two deputies, members of the SCPE Steering Committee. One deputy is one chosen by the Chair, once elected; the second is elected by the members of the SCPE Steering Committee.
- The role of the Chair is to manage and coordinate the work of all SCPE, to represent the interests of the SCPE network in the SCPE Steering Committee.
- The role of the Deputy is to support the Chair of the SCPE Steering Committee, to stand in for the Chair if necessary, to act as Chair, should the current Chair be unable to continue in his/her role.
- The Chair and the two Deputies serve for a period of 4 years, which may be extended to a maximum term of 8 years.

The chairs of the working groups are members of SCPE Steering Committee; they are chosen by the SCPE working groups during the plenary meeting. Their nomination has to be approved by the Board of members. They serve for 4 years, with a maximum of 8 years.

Terms of reference and duties

The terms of reference are the following:

- to manage and coordinate work on CP in Europe
- to ensure the continuation and development of the common database, the maintenance of collaborations with partners working on CP, and the support and development of the webpages



- to ensure the sustainability of the SCPE Common Database
- to facilitate the development of research projects and the dissemination of the work on CP in Europe
- to promote the work and achievements of the network.

The duties of the SCPE Steering Committee are:

- to review applications for membership
- to organise an annual meeting of the partners
- to ensure the security and confidentiality of data transmission to (and from) the SCPE common database
- to ensure the financial viability of the SCPE common database
- to determine the requirement for additional meetings or workshops, and organise as required
- to establish, review and revise the regulations of the network
- to consider applications for studies, data analysis and authorship
- to determine the content of the SCPE web site.

Operating

The SCPE Steering Committee meet at least twice annually, with one meeting during the annual plenary meeting, and a second meeting, which may be in person (preferably) and/or a teleconference. In addition, call/teleconferences should be organized, when required by the agenda.

5.3 SCPE working groups

Three working groups are established and in charge of the development and achievements of SCPE work:

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

More precisely, the objectives of the Working groups are:

Data Working Group

- to maintain the SCPE common database
- to provide advice and guidance on the quality control the submitted data
- to review and further develop quality assurance processes and guidelines to maintain and further improve the data quality
- to provide advice and guidance on the routine analyses of submitted data
- to monitor, review, develop and implement coding and classification guidelines and practice.

Website and dissemination Working Group

- to ensure the maintenance and development of the websites
- to encourage and support the dissemination of the findings (analyses of the common dataset)



- to contribute to an annual report on the common database to all SCPE members, with relevant individual level feedback to data-submitting members as necessary
- to support the registries at their own local, regional or national level
- to encourage and provide support and guidance to those establishing a new register in a member state

Scientific activities Working Group

- to encourage the scientific publications using the common database
- to facilitate the development of research projects between partners of the network
- to promote the use of the common database in collaborative research studies external to SCPE
- to facilitate the development of collaborative research projects with other partners and international collaborations, notably with other networks working on cerebral palsy.

Membership of the three working groups is the following:

- volunteers members of the SCPE network from whom Chair of group chosen
- chair or deputy chair of the SCPE Steering Committee
- the composition of the working groups is revised each year during the plenary meeting, if necessary.

The SCPE Working groups meet at least once annually during the annual plenary meeting where dedicated work sessions are organized. In addition, call/teleconferences and/or workshops should be organized depending on the agenda.

Norwich, UK
the 5th of November, 2014

Name:

Signature:



Amendment:

The work with the Joint Research Centre of the European Commission

From January 2015, and in order to secure a sustainable solution for the continuation of the SCPE activities, SCPE will become part of the EU Platform on Rare Diseases Registration (Public Health Policy Support Unit, Institute for Health and Consumer Protection) at the DG Joint Research Centre (JRC) site in Ispra, Italy.

The activities that will be provided by the Joint Research Centre of the European Commission include:

- support to the coordinating activities of SCPE
- organising the meetings of the Steering Committee and working groups
- organising the annual plenary meeting
- organising scientific symposia
- running the database
- support for dissemination activities: website, newsletters
- support offered to the individual registries: training workshops, IT support
- future actions aimed at adding value to the SCPE data by o integration into larger health information systems, links to other databases (e.g. environmental data)
- dissemination of results to policy makers for decisions on standards of care for children with cerebral palsy and their carers.

All the activities will be carried out in collaboration with, and under the scientific responsibility of the SCPE Steering Committee and in line with the SCPE procedural manuals. The terms of the transfer and the future functioning of SCPE will be agreed in a contract signed by all the SCPE type (a) members during year 2015.

To work with the Joint Research Centre of the European Commission implies modifications to SCPE governance structure and rules of functioning:

- The SCPE Steering Committee is replaced by a joint SCPE/JRC Steering Committee including JRC representation. With the exception of JRC representation, the membership, terms of reference, and rules of functioning are remaining the same.
- Because of the role of the JRC in maintaining the SCPE common database and website activities, the composition of the following working groups: Data Working Group and Website and dissemination Working Group is hereby amended to include representatives of the JRC.
- Because of the JRC support in the functioning of steering committee and working groups through the organisation of meetings and call-conferences, an annual plan of the meetings with estimated number of participants, and site-visits is required and must be approved by the Joint SCPE/JRC Steering Committee.

2014, December 5th

Name:

Signature:

