

# SPARCLE - Longitudinal study on Children with Cerebral Palsy Living in Europe

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## General

### Identification

Detailed name Longitudinal study on Children with Cerebral Palsy Living in Europe

Sign or acronym SPARCLE

### General Aspects

Medical area Neurology

Health determinants Genetic  
Lifestyle and behavior  
Social and psychosocial factors

Keywords cerebral palsy, social / environmental determinants, participation and quality of life, disability

### Scientific investigator(s) (Contact)

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Unit The Institute of Health and Society

Organization Newcastle

### Collaborations

Participation in projects, networks and consortia Yes

### Funding

Funding status Mixed

Details SPARCLE 1: European Commission Research

German Ministry of Health German Foundation for Disabled Child.La Fondation MotriceSPARCLE 2: UK et Ireland: Wellcome Trust Germany: Medical Faculty of University of LuebeckFrance: CNSA, INSERM, MiRe - DREES, IRESP.Denmark: Ludvig and Sara Elsass Foundation; The Spastics Society; VanforefondentiItaly: Cooperativa Sociale "Gli Ammi in Tasca", Viterbo; Fondazione Carivit, ViterboSweden: Goteborg University, Riksforbundet for Rorelsehindrade Barn och Ungdomar; Folke Bernadotte Foundation

## Governance of the database

Sponsor(s) or organisation(s) responsible European Commission Research

Organisation status Public

Sponsor(s) or organisation(s) responsible Wellcome Trust

Organisation status

## Additional contact

## Main features

## Type of database

Type of database Study databases

Study databases (details) Longitudinal study (except cohorts)

Database recruitment is carried out by an intermediary An administrative base or a register

Database recruitment is made on the basis of: Another treatment or procedure

Additional information regarding sample selection. In population from cerebral palsy registers

## Database objective

Main objective The study aims to identify which environmental factors, if improved, will yield the greatest benefits for children with disabilities and their families. This knowledge will inform EU policy in the health, educational and social sectors and generate protocols to optimise outcomes

Inclusion criteria Children with cerebral palsy (local registers) aged 8-

12 years at the beginning of the study

## Population type

Age Childhood (6 to 13 years)  
Adolescence (13 to 18 years)

Population covered Sick population

Gender Male  
Woman

Geography area International

Detail of the geography area 9 centres in 7 countries in Europe (France, Sweden, Denmark, Italy, Germany, England, Ireland, Northern Ireland, England)

## Data collection

### Dates

Date of first collection (YYYY or MM/YYYY) 2004

Date of last collection (YYYY or MM/YYYY) 2010

### Size of the database

Size of the database (number of individuals) [500-1000[ individuals

Details of the number of individuals 818

### Data

Database activity Data collection completed

Type of data collected Clinical data  
Declarative data  
Administrative data

Declarative data (detail) Face to face interview

Administrative data (detail) Wheelchair Access to trains, to the cinema Financial allocation, availability of specialized services  
Collected at national level: legislation, policy, school practices

Presence of a biobank No

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|---------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Health parameters studied                                                             | Health event/morbidity<br>Quality of life/health perception                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Procedures                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Data collection method                                                                | <p>The study will describe and quantify environmental factors at two levels: -at national level such as anti-discrimination legislation : A literature and publications review will be conducted between June 2003 and June 2004 by a sub-contracted social scientist in Edinburgh. It will examine environmental factors at a national macro level by reviewing research literature, EU publications,international reports and European government publications.It will bring together up-to-date information about how environmental factors vary between European countries, mainly concentrating on the countries in the study but will include all those in the EU and those seeking membership. -at local level such as availability of respite care and family experience level such as ease of access to cinemas and sports facilitiesQuality of life will be reported by the children themselves wherever possible using a generic instrument, KIDSCREEN, so that quality of life can be assessed in the same context and with the same instrument in all children. Children with severe cognitive difficulties will not be able to self-report and for this group of children we will use the parent completion KIDSCREEN and CHQ-PF50, and the child's teacher/therapist will also be asked to complete these questionnaires. The study of participation will use the Assessment of Life Habits for children (LIFE-H).</p> |
| Participant monitoring                                                                | Yes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Links to administrative sources                                                       | Yes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Promotion and access                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Promotion                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Link to the document                                                                  | <a href="http://www.ncbi.nlm.nih.gov/entrez/eutils/erss.cgi?rss_guid">http://www.ncbi.nlm.nih.gov/entrez/eutils/erss.cgi?rss_guid</a>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Link to the document                                                                  | <a href="http://www.ncbi.nlm.nih.gov/entrez/eutils/erss.cgi?rss_guid">http://www.ncbi.nlm.nih.gov/entrez/eutils/erss.cgi?rss_guid</a>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Access                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Terms of data access (charter for data provision, format of data, availability delay) | Resaerchers may request data for secondary analysis from <a href="mailto:allan.colver@ncl.ac.uk">allan.colver@ncl.ac.uk</a> . We have a request form and applications will be discussed by                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |

the SPARCLE partners.  
Th availability of data is also set out on the SPARCLE website

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|---------------------------|---------------------------------|
| Access to aggregated data | Access on specific project only |
| Access to individual data | Access on specific project only |