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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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; VanforefondenItaly: 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 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)	Wheelchait Access to trains, to the cinema Financial allocation, availability of specialized servicesCollected at national level: legislation, policy, school practices
Presence of a biobank	No

Health parameters studied	Health event/morbidity Quality of life/health perception

Procedures

Data collection method	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).
Participant monitoring	Yes
Links to administrative sources	Yes

Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/entrez/eutils/erss.cgi?rss_guid
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Access

Terms of data access (charter for data provision, format of data, availability delay)	Resaecrhers may request data for secondary analysis from allan.colver@ncl.ac.uk. 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
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only