

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

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Date de modification : 01/01/2020 | Version : 1 | ID : 38864

Général

Identification

Nom détaillé Longitudinal study on Children with Cerebral Palsy Living in Europe

Sigle ou acronyme SPARCLE

Thématiques générales

Domaine médical Neurology

Déterminants de santé Genetic
Lifestyle and behavior
Social and psychosocial factors

Mots-clés cerebral palsy, social / environmental determinants, participation and quality of life, disability

Responsable(s) scientifique(s)

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Laboratoire The Institute of Health and Society

Organisme Newcastle

Collaborations

Participation à des projets, des réseaux, des consortiums Yes

Financements

Financements Mixed

Précisions 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

Gouvernance de la base de données

Organisation(s) responsable(s) ou promoteur European Commission Research

Statut de l'organisation Secteur Public

Organisation(s) responsable(s) ou promoteur Wellcome Trust

Statut de l'organisation

Contact(s) supplémentaire(s)

Caractéristiques

Type de base de données

Type de base de données Study databases

Base de données issues d'enquêtes, précisions Longitudinal study (except cohorts)

Origine du recrutement des participants An administrative base or a register

Critère de sélection des participants Another treatment or procedure

Informations complémentaires concernant la constitution de l'échantillon In population from cerebral palsy registers

Objectif de la base de données

Objectif principal 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

Critères d'inclusion	Children with cerebral palsy (local registers) aged 8-12 years at the beginning of the study
Type de population	
Age	Childhood (6 to 13 years) Adolescence (13 to 18 years)
Population concernée	Sick population
Sexe	Male Woman
Champ géographique	International
Détail du champ géographique	9 centres in 7 countries in Europe (France, Sweden, Denmark, Italy, Germany, England, Ireland, Northern Ireland, England)
Collecte	
Dates	
Année du premier recueil	2004
Année du dernier recueil	2010
Taille de la base de données	
Taille de la base de données (en nombre d'individus)	[500-1000[individuals
Détail du nombre d'individus	818
Données	
Activité de la base	Data collection completed
Type de données recueillies	Clinical data Declarative data Administrative data
Données déclaratives, précisions	Face to face interview
Données administratives, précisions	Wheelchair Access to trains, to the cinema Financial allocation, availability of specialized services Collected at national level: legislation, policy, school practices
Existence d'une bibliothèque	No

Paramètres de santé étudiés	Health event/morbidity Quality of life/health perception
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Modalités

Mode de recueil des données	<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 facilities Quality 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>
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Suivi des participants	Yes
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Appariement avec des sources administratives	Yes
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Valorisation et accès

Valorisation et accès

Lien vers le document	http://www.ncbi.nlm.nih.gov/entrez/eutils/erss.cgi?rss_guid
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Accès

Charte d'accès aux données (convention de mise à	Resaerchrers may request data for secondary analysis from allan.colver@ncl.ac.uk. We have a
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disposition, format de données
et délais de mise à disposition)

request form and applications will be discussed by
the SPARCLE partners.
The availability of data is also set out on the SPARCLE
website

Accès aux données agrégées

Access on specific project only

Accès aux données individuelles

Access on specific project only