

RHE31 - Haute Garonne register of childhood disabilities (qualified register)

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General

Identification

Detailed name Haute Garonne register of childhood disabilities (qualified register)

Sign or acronym RHE31

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL n°900263

General Aspects

Health determinants Social and psychosocial factors

Others (details) cerebral palsy, pervasive developmental disorders

Keywords sensory disabilities, mobility, pervasive developmental disorder, development

Scientific investigator(s) (Contact)

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Organization Université Paul Sabatier

Collaborations

Funding

Funding status	Public
Details	Institut national de la santé et de la recherche médical - Inserm Institut de veille sanitaire - InVS Projets de recherche
Governance of the database	
Sponsor(s) or organisation(s) responsible	INSERM
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Selection of subjects having the required inclusion criteria
Database objective	
Main objective	Objectives in terms of public health: 1) Monitor prevalence rates of severe childhood disabilities over time in a defined geographical area (population-based register) 2) Describe characteristics of these disabilities, medical conditions associated with the main impairment 3) Describe care, assistance and schooling of these children 3) Assist in the planning of medical and social offering suitable for such children (availability of specialized care facilities, home care and outpatient care) Research objectives : 1) Progress in the etiological knowledge and study risk factors especially perinatal risk factors 2) Assess the consequences of preventive or screening measures implemented during pregnancy

3) Describe and understand factors associated with better participation and quality of life of disabled children

Inclusion criteria

All children having one of the following impairment at 5 years and/or 8 years and for whom the parents (or legal representatives) reside in Haute-Garonne county at the time of registration :

- Motor impairments (including cerebral palsy)
- Severe sensory impairments
- Severe intellectual disabilities
- Down syndroms
- Pervasive developmental disorders

Population type

Age Childhood (6 to 13 years)

Population covered Sick population

Gender Male
Woman

Geography area Departmental

French regions covered by the database Languedoc-Roussillon Midi-Pyrénées

Detail of the geography area Haute-Garonne

Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 1986

Size of the database

Size of the database (number of individuals) [1000-10 000[individuals

Details of the number of individuals 2134

Data

Database activity Current data collection

Type of data collected Clinical data
Paraclinical data
Administrative data

Clinical data (detail)	Direct physical measures
Paraclinical data (detail)	Imagery (US, MRI, other examinations: CAT, EEG, etc.)
Administrative data (detail)	Identification data Care Schooling
Presence of a biobank	No
Health parameters studied	Health event/morbidity

Procedures

Data collection method	Identification of cases via administrative sources (departmental home for the disabled) and medical sources (neonatal database, neurologic and psychiatric out patient clinics, hospital records) active registration
Participant monitoring	Yes
Details on monitoring of participants	Vital status Some children are included at 2 ages. A longitudinal analysis is then possible for this subset only.
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://research.ncl.ac.uk/sparcle/
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Link to the document

Description

Link to the document	http://www.scpenetwork.eu/
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Access

Terms of data access (charter for data provision, format of data, availability delay)	Scientific publications Access to data is possible upon a writing request submitted to the director, indicating the research objectives
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only