- Cohort of Children with Multiple Disabilities: Long-Term Prospective Outcomes

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General

Identification

Detailed name	Cohort of Children with Multiple Disabilities: Long-Term Prospective Outcomes
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL

General Aspects

Medical area	Disability/handicap Pediatrics
Pathology (details)	Multiple disabilities
Health determinants	Healthcare system and access to health care services Lifestyle and behavior Medicine Social and psychosocial factors
Keywords	multiple disabilities, care, children, quality of life

Scientific investigator(s) (Contact)

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Organization	AP-HP Federation for Multiple Disabilities, Trousseau Hospital, Paris Public Hospitals (AP-HP)

Collaborations

Funding

Funding status	Public
Details	AP-HP Federation for Multiple Disabilities

Governance of the database

Sponsor(s) or organisation(s) responsible	AP-HP Federation for Multiple Disabilities, Trousseau Hospital, Paris Public Hospitals (AP-HP)
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Study databases
Study databases (details)	Cohort study
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.	Neuropaediatrics (100 children), specialised SSR (Soins de suite et de réadaptation [Follow-up care and rehabilitation]) (200 children), medical and social care (900 children)

Database objective

Main objective	The aim of this cohort is to characterise multiple disabilities (groups according to multiple disability severity, burden of care and quality of life) and to describe the natural history of multiple disabilities.
Inclusion criteria	Children with multiple disabilities.

Population type

Age	Childhood (6 to 13 years)
Population covered	Sick population
Gender	Male Woman
Geography area	National

Detail of the geography area	France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2006
Date of last collection (YYYY or MM/YYYY)	2016

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1,200

Data

Database activity	Current data collection
Type of data collected	Clinical data
Clinical data (detail)	Direct physical measures
Details of collected clinical data	severity; complexity of interrelated disabilities; instability; scalability; prognosis
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health care consumption and services Quality of life/health perception
Care consumption (detail)	Medical/paramedical consultation

Procedures

Participant monitoring	Yes
Details on monitoring of participants	Data gathered annually and analysed at 3, 5 and 10 years.
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	[présentation de Thierry BILLETTE DE VILLEMEUR-Cohorte polyhandicap.pdf]()
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only