

RHEOP - Register of Childhood Disabilities and Perinatal Data - Isère et deux Savoie counties

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General	
Identification	
Detailed name	Register of Childhood Disabilities and Perinatal Data - Isère et deux Savoie counties
Sign or acronym	RHEOP
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	997086
General Aspects	
Others (details)	Induced therapeutic abortions
Keywords	Stillbirth and Induced therapeutic abortions Severe deficiencies of the child
Scientific investigator(s) (Contact)	
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Unit	Service d'information et informatique médical
Organization	CHU de
Collaborations	
Funding	
Funding status	Public

Details	Institut de veille sanitaire - InVS Institut national de la santé et de la recherche médicale - INSERM Conseils Généraux de l'Isère, de la Savoie et de la Haute-Savoie
Governance of the database	
Sponsor(s) or organisation(s) responsible	Université de Grenoble Joseph Fourier
Organisation status	Public
Sponsor(s) or organisation(s) responsible	Conseils Généraux de l'Isère, de la savoie et de la Haute-Savoie
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
Database objective	
Main objective	In the area of public health: (1) monitor the change in the prevalence of severe deficiencies in children on a geographical basis (three counties starting in 2005) (2) monitor the change in the rate of stillbirths and more particularly of the prevalence of induced abortions for medical reasons over the same geographical base (3) describe the educative and medical care (4) assist in the planning of needs, in order to ensure optimal care for these children In the area of research: (1) encourage analytical surveys that are specific to each type of deficiency, or that cover the associated deficiencies (2) identify the etiologies of the deficiencies and serious perinatal events (3) Collect information on the perinatal events that

may be in relation with the occurrence of deficiencies

Inclusion criteria	Deficiency pool: All children under the age of 7 years having at least one main severe deficiency and residing in one of the départements of Isère, Savoie or Haute-Savoie. Perinatal pool: serious perinatal events such as cases of stillbirth and abortion occurring each year for the women domiciled in one of these three départements.
Population type	
Age	Newborns (birth to 28 days) Infant (28 days to 2 years) Childhood (6 to 13 years)
Population covered	Sick population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Auvergne Rhône-Alpes
Detail of the geography area	Isère, Savoie, Haute Savoie
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	1991
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	2717 : several deficiency 2414 : stillbirths 2317 : medical termination of pregnancy
Data	
Database activity	Current data collection
Type of data collected	Clinical data Administrative data

Clinical data (detail)	Direct physical measures
Administrative data (detail)	profession of the parents, canton and county of residence, disability rate
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization
Procedures	
Data collection method	A systematic collection of information intended to identify the cases is conducted with: (1) the Départementale Bureau for Autonomy (MDA) and the départementale bureaux for people with disabilities (MDPH) of the départements involved (2) clinical departments of neonatology, pediatrics, maternity wards and specialized departments using medical dossiers (3) medical information departments (4) early-action medical centers (5) child psychiatry sectors (6) PMIs and networks of liberal pediatricians (7) cytogenetics departments (8) Multi-disciplinary centers for prenatal diagnostics (CPDNP) (9) anatomopathology laboratories
Participant monitoring	No
Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI MDPH
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Annual report published every year, accessible of the RHEOP website Scientific publications
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only