REMACA - Registry of Congenital Malformations in Alsace (Certified Regisrtry)

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Last update : 02/01/2012 | Version : 2 | ID : 62

General

Identification

Detailed name	Registry of Congenital Malformations in Alsace (Certified Regisrtry)
Sign or acronym	REMACA

General Aspects

Medical area	Rare diseases
Health determinants	Addictions Genetic Occupation Social and psychosocial factors
Keywords	prenatal diagnosis

Scientific investigator(s) (Contact)

Name of the director	Timbolschi
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Organization	CHRU Strasbourg

Collaborations

Funding

Funding status	Public
Details	French Institute for Public Health Surveillance - InVS, French National Institute of Health and Medical Research) - INSERM CREGEMES.

Governance of the database

Sponsor(s) or organisation(s) responsible	Université de Strasbourg, Faculté de médecine

Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Additional information regarding sample selection.	Method for selecting subjects meeting required inclusion criteria.
Database objective	
Main objective	From an epidemiological standpoint: 1) Determination of frequency (in terms of prevalence) and distribution of congenital malformation; 2) Identification of the risk factors of malformations (discomfort, environment, medications and toxic) 3) Determination of malformation ""clusters"" for decision aids in the event of a significant increase in the prevalence of a malformation type (monitoring-alert); 4) Making data available for epidemiological studies From a public health standpoint 1) Assessment of the impact of health policies in the field of perinatal medicine and the impact of regional obstetric practices; 2) Measuring the effectiveness of the prevention and establishment of support to inform healthcare professionals, especially in the field of teratology; 3) Assessment of healthcare requirements in perinatal medicine (birthing methods and locations); From a clinical standpoint: 1) Locating new malformation associations and even the identification of new symptoms; 2) Determination of modes of genetic disorder transmission; 3) Establishment of interactions among various active partners in prevention, socio-educational care in the region concerned.
Inclusion criteria	Reported cases of malformations visible at the clinical and visceral examination, as well as identified or non-identified malformation syndromes, including those linked to chromosomal defects until two years old.. Recorded cases in the both Alsace départements and where parents are only residing both Alsace départements.

Population type	
Age	Newborns (birth to 28 days) Infant (28 days to 2 years)
Population covered	Sick population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Alsace Champagne-Ardenne Lorraine
Detail of the geography area	Two départements in the Alsace region: Bas-Rhin and Haut-Rhin.

Data collection

Dates	
Date of first collection (YYYY or MM/YYYY)	2005

Size of the database	
Size of the database (number of individuals)	[10 000-20 000[individuals
Details of the number of individuals	About 700 cases per year since 2005. About 450 cases per year since 2005.

Data	
Database activity	Current data collection
Type of data collected	Clinical data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures Medical registration
Paraclinical data (detail)	Radiographies, ultrasounds, scan, MRI, ophthalmologic and ENT assessment.
Biological data (detail)	Cytogenetic, molecular biology.
Administrative data (detail)	Identification data: child (last name, first name, address, date of birth, place of birth, date of death,

	cause of death); mother (date of birth, place of birth); father (date of birth, place of birth); Socio-demographic data: profession of the mother; profession of the father; consanguinity.
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services
Care consumption (detail)	Hospitalization Medical/paramedical consultation
Procedures	
Data collection method	Active collection from all of the public and private maternity wards in Alsace, from all of Paediatric, Infant Surgery, Genetics, Paediatric Cardiology, Neurosurgery and Ophthalmology departments, from the Multidisciplinary Centre for Prenatal Diagnosis, from cytogenics and foetopathology laboratories.
Classifications used	CIM10 for malformations and diseases, ATC code for medication.
Participant monitoring	Yes
Details on monitoring of participants	Verification of the diagnosis, Updating of vital status for reported cases on an average of 6 months to 1 year, as well as the cause of death.
Links to administrative sources	Yes
Linked administrative sources (detail)	Health certificates for the 8th day, 9th month.
Promotion and access	
Promotion	
Other information	The registry is no longer active
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Global data: EUROCAT site. Individual data: on request.
Access to aggregated data	Free access
Access to individual data	Access on specific project only