

- Longitudinal study of newborns: screening, prevalence and treatment of deafness

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General	
Identification	
Detailed name	Longitudinal study of newborns: screening, prevalence and treatment of deafness
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL
General Aspects	
Medical area	Otolaryngology or ENT
Pathology (details)	Hearing loss
Health determinants	Healthcare system and access to health care services
Keywords	Hearing loss, Screening, Child, treatment, prevalence
Scientific investigator(s) (Contact)	
Name of the director	Rouillon
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Organization	hôpital Necker ? Enfants-Malades
Collaborations	
Funding	
Funding status	Public
Details	CNAMTS

Governance of the database	
Sponsor(s) or organisation(s) responsible	hôpital Necker ? Enfants-Malades
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Longitudinal study (except cohorts)
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is made on the basis of:	Another treatment or procedure
Database recruitment is carried out as part of an interventional study	No
Database objective	
Main objective	Evaluate hearing screening for newborns born in the Ile-de-France region
Inclusion criteria	<p>Screening conducted in four maternity clinics between 1 October 2005 and 31 December 2010, in conjunction with a Deafness Diagnosis and Guidance Centre (CDOS)</p> <p>Positive screening in maternity clinics: lack of response to automated auditory evoked potential of 35 dB on both sides</p> <p>For diagnostic confirmation: no response to standard auditory evoked potential of 30 dB at the CDOS</p>
Population type	
Age	<p>Newborns (birth to 28 days)</p> <p>Infant (28 days to 2 years)</p>
Population covered	General population
Pathology	

Gender	Male Woman
Geography area	Regional
French regions covered by the database	Île-de-France
Detail of the geography area	the CDOS (Hôpital Trousseau) where the study was carried out is networked with 4 maternity clinics in the Ile-de-France region
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2005
Date of last collection (YYYY or MM/YYYY)	2010
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	198
Data	
Database activity	Data collection completed
Type of data collected	Clinical data
Clinical data (detail)	Medical registration
Details of collected clinical data	Risk factors and comorbidities, 1st diagnosis period and result. The type of loss and rehabilitation (hearing aid, cochlear implant) and duration of treatment. Audiometric results, results of the aetiological assessment
Presence of a biobank	No
Health parameters studied	Health care consumption and services
Care consumption (detail)	Medical/paramedical consultation Medicines consumption
Procedures	

Participant monitoring	Yes
Monitoring procedures	Monitoring by convocation of the participant
Details on monitoring of participants	15-month follow-up
Links to administrative sources	No

Promotion and access

Promotion

Link to the document <http://www.ncbi.nlm.nih.gov/pubmed/26520479>

Access

Terms of data access (charter for data provision, format of data, availability delay)	unrestricted provision
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only