NEAER - National Esophageal Atresia Epidemiologic Registry

Head :Sfeir Rony, Reference center for congenital esophageal abnormalities

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General

Identification

Detailed name	National Esophageal Atresia Epidemiologic Registry
Sign or acronym	NEAER
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	908362

General Aspects

Medical area	Gastroenterology et hepatology Pediatrics Pneumology Rare diseases
Health determinants	Genetic Geography Lifestyle and behavior Nutrition
Keywords	esophageal atresia, epidemiology, congenital malformations

Scientific investigator(s) (Contact)

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Unit	Reference center for congenital esophageal abnormalities
Organization	CHRU

Collaborations

Participation in projects, networks and consortia	Yes

Funding

Funding status	Public
Details	Centre de Référence des Affections Congénitales et Malformatives de l'Oesophage

Governance of the database

Sponsor(s) or organisation(s) responsible	CHR Lille
Organisation status	Public
Presence of scientific or steering committees	Yes

Additional contact

Main features

Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects having the required inclusion criteria

Database objective

Main objective	Objectives of the registry in the area of public health (access to pre and postnatal diagnostics, monitoring, caring for patients, evaluation): 1) Determine the prevalence of esophageal atresia and of its various anatomical forms. 2) Study the geographical distribution of this malformation 3) Determine mortality at one year for this malformation 4) Evaluate the disparities in care and the changes between the different centers. Objectives of the registry in the areas of therapy and research: 1) Evaluate if the percentage of antenatal diagnostic and the earliness in care vary in our country over the next few years.

	2) Evaluate the effect of the prenatal diagnosis on prevalence. 3) Evaluate the modifications that appeared in the care for newborns having esophageal atresia and the influence of the latter on the future of the patients. Recent modifications in care: installation of a transanatomic sensor, early feeding, abandoning parenteral nutrition, could influence the change (duration of hospitalization, complications) and the future at 1 year. 4) Evaluate the short-term prognosis (surgical complications, duration of hospitalization, duration of reanimation, etc.). 5) Structure and harmonize the care for esophageal atresia across the national territory.
Inclusion criteria	Any living newborn with esophageal atresia

Population type

Age	Newborns (birth to 28 days) Infant (28 days to 2 years)
Population covered	Sick population
Pathology	Q39 - Congenital malformations of oesophagus
Gender	Male Woman
Geography area	National
Detail of the geography area	Metropolitan France + Overseas Départements/Territories

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2008

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	2008 : 149 new cases : enclosed inclusion 2009 : 159 new cases : enclosed inclusion2010 : 96 cases : inclusion in progress

Data

Database activity	Data collection completed
Type of data collected	Clinical data Declarative data Paraclinical data Administrative data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire Internet self-questionnaire
Administrative data (detail)	- 2 first letters Last name and First name - Date of birth- Hospital of origin- Maternity ward of origin- Postal code (Place of residence)- Date of diagnostic- Sex - Département of birth - Age of the mother at birth
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	Regular requests via telephone, contact through email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia.
Participant monitoring	Yes
Monitoring procedures	Monitoring by contact with the referring doctor
Details on monitoring of participants	Vital statusClinical follow-up: clinical data, para-clinical data, morbidity.
Links to administrative sources	Yes
Linked administrative sources (detail)	department of medical informatic

Promotion and access

Promotion

Link to the document	Sfeir et al. - 2013 - Esophageal atresia data from a national cohort.pdf
Description	Liste des publications dans Pubmed

Link to the document	[EJPS_153585rev (2).pdf]
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Scientific publications Congresses and reference center meetings Communication with parents' associations
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only