

C.A.R.O.L.E: Active network coordination of longitudinal epilepsy observatory - Longitudinal Study of Patients with Epilepsy: Medical and Social Outcome Study

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General	
Identification	
Detailed name	Longitudinal Study of Patients with Epilepsy: Medical and Social Outcome Study
Sign or acronym	C.A.R.O.L.E: Active network coordination of longitudinal epilepsy observatory
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL approval
General Aspects	
Medical area	Neurology
Keywords	First seizure, drug-resistant, crisis
Scientific investigator(s) (Contact)	
Name of the director	Jallon
Surname	Pierre
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Unit	Unité d'épileptologie et d'EEG
Collaborations	
Funding	
Funding status	Private
Details	French foundation for epilepsy research
Governance of the database	

Sponsor(s) or organisation(s) responsible	Fondation française pour la recherche sur l'épilepsie
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 care professionals A selection of health institutions and services
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Information was provided by 243 neurologists and paediatric neurologists.
Database objective	
Main objective	To assess the medical and social outcome of subjects with spontaneous epileptic seizures and to determine drug resistance predictors.
Inclusion criteria	- men and women - having experienced first epileptic seizure between 01/05/1995 and 30/06/1996
Population type	
Age	Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 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) 05/1995

Date of last collection (YYYY or MM/YYYY) 06/1996

Size of the database

Size of the database (number of individuals) [1000-10 000[individuals

Details of the number of individuals 1,942

Data

Database activity Data collection completed

Type of data collected
Clinical data
Declarative data
Paraclinical data

Clinical data (detail) Direct physical measures

Declarative data (detail) Paper self-questionnaire

Details of collected declarative data ICBERG questionnaire (description of epileptic seizures)

Paraclinical data (detail) - electroencephalography (EEG) - computed tomography

Presence of a biobank No

Health parameters studied
Health event/morbidity
Health event/mortality

Procedures

Participant monitoring Yes

Details on monitoring of participants 10 years

Links to administrative sources No

Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=Carole+AND+Jallon[author]
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Description	List of publications in Pubmed
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Access

Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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