

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

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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\[author\]](http://www.ncbi.nlm.nih.gov/pubmed/?term=Carole+AND+Jallon[author])

Description List of publications in Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay) Contact the scientist in charge.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only