

REPOMSE - Cohort of patients with refractory epilepsy initially admitted to video-EEG monitoring unit

Head :Ryvlin Philippe, INSERM U821 (DYNAMIQUE CÉRÉBRALE ET COGNITION) et CTRS-INSERM COGNITIVE DEVELOPMENT IN EPILEPSY UNIVERSITÉ CLAUDE BERNARD LYON 1

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General

Identification

Detailed name	Cohort of patients with refractory epilepsy initially admitted to video-EEG monitoring unit
Sign or acronym	REPOMSE
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL n°910398 - AFSSAPS : B1001-08-40 - CPP : 2010-006-2

General Aspects

Medical area	Neurology Radiology and medical imaging
Keywords	sudden unexpected death in epilepsy (SUDEP), accidents caused by epileptic seizures, status epilepticus, recovery, improvement, stability, hospitalised subjects, Health episodes, death, comorbidities, suicide, progression, aggravation, health system

Scientific investigator(s) (Contact)

Name of the director	Ryvlin
Surname	Philippe
Address	69622 VILLEURBANNE
Phone	+ 33 (0)4 72 35 71 17
Email	ryvlin@cermep.fr
Unit	INSERM U821 (DYNAMIQUE CÉRÉBRALE ET COGNITION) et CTRS-INSERM COGNITIVE DEVELOPMENT IN EPILEPSY UNIVERSITÉ CLAUDE BERNARD LYON 1

Organization Inserm

Collaborations

Participation in projects, networks and consortia Yes

Funding

Funding status Mixed

Details Programme hospitalier de recherche clinique, les 14 CHU concernés, Ligue Française contre l'Epilepsie, Laboratoires pharmaceutiques EISAI au travers de donations à la LFCE

Governance of the database

Sponsor(s) or organisation(s) responsible Hospices civils de Lyon

Organisation status Public

Additional contact

Main features

Type of database

Type of database Study databases

Study databases (details) Cohort study

Database recruitment is carried out by an intermediary A selection of health institutions and services

Database recruitment is carried out as part of an interventional study No

Additional information regarding sample selection. Prospective

Database objective

Main objective General Objective: To determine the main risk factors for sudden unexpected death in epilepsy (SUDEP), focusing on the impact of critical and post-critical apnoea as well as the origin site of a seizure. Secondary objective: to obtain systematic data related to: - inpatient treatment modalities for EEG-video monitoring; - long-term follow-up of

patients on a medical or medico-economic plan; - results of epilepsy surgery; - serious comorbidities associated with epilepsy (including increased mortality); - Genetic susceptibility factors (systematic genotyping).

Inclusion criteria

Patients with refractory epilepsy admitted to a video-EEG monitoring unit to characterise their seizure type (for surgical treatment for epilepsy or to better identify their epileptic syndrome)

Population type

Age

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

Multicentric cohort throughout France (14 centres): The 14 centres participating in the study represent the bulk of institutions benefiting from long-term video-EEG monitoring treatment for patients who meet the inclusion criteria

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

06/2010

Size of the database

Size of the database (number of individuals)

[1000-10 000[individuals

Details of the number of individuals

933 (juillet 2013)

Data

Database activity

Current data collection

Type of data collected

Clinical data
Declarative data
Paraclinical data
Biological data

Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire Face to face interview
Paraclinical data (detail)	Imaging and electrophysiology Patients will be included during long-term video-EEG monitoring in order to record and characterise their seizures. This monitoring will provide very precise clinical (video of seizure) and electroencephalographic (scalp EEG see intracranial) information for critical and intercritical events. Using other sophisticated investigative data (MRI, functional MRI, positron emission tomography, ictal SPECT, MEG), this information will be used to establish the probable origin site of seizures and to look at surgical resection of the latter in order to control the disorder. This vital information is key to the phenotypic characterisation of the cohort and requires a significant number of man hours in order to be properly collected and coded. It is particularly relevant concerning the criteria for evaluating the health of the population being examined (especially SUDEP risk).
Biological data (detail)	Type of samples taken: blood sample
Presence of a biobank	Yes
Contents of biobank	DNA
Details of biobank content	DNA bank
Health parameters studied	Health event/morbidity Health event/mortality Quality of life/health perception
Procedures	
Data collection method	Self-administered questionnaire: entry from a paper questionnaire (manual input); Interviews: entry from a paper questionnaire (manual input); Biological analysis: handwritten (manual input)
Participant monitoring	Yes
Details on monitoring of participants	(Indefinite duration)
Links to administrative sources	Yes

Linked administrative sources (detail)

PMSI, CépiDc, CRAM, INSEE database for vital status. Epilepsy database accessible online in order to obtain cohort patient data: GRENAT (National Epilepsy Group Register)

Promotion and access

Promotion

Link to the document

http://www.lfce.fr/Publication_a80.html

Access

Terms of data access (charter for data provision, format of data, availability delay)

Data may be used by academic teams Data may not be used by industrial teams

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only