

Epidemiological study of epilepsy in France based on two databases (Epi²)

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Study

Ongoing

Administrative details

EU PAS number

EUPAS1000000899

Study ID

1000000899

DARWIN EU® study

No

Study countries

France

Study description

The EPI² study is an epidemiological study based on the matching of health insurance data in France (Système National des Données de Santé, SNDS) and the Clinical Data Warehouse (CDW) of 39 hospital in Paris (Assistance Publique

Hôpitaux de Paris, AP-HP). The objectives of this study are to validate an algorithm for identifying patients with epilepsy in the SNDS based on their healthcare consumption and using the clinical data from the AP-HP CDW as the gold standard, and then to use this algorithm to measure the incidence and prevalence of epilepsy in France. This study also aims to better understand the care pathways of epileptic patients and the associated costs.

Study status

Ongoing

Research institutions and networks

Institutions

[Institut du Cerveau \(Paris Brain Institute\)](#)

[Centre de pharmaco-épidémiologie \(Paris Pharmacoepidemiology Centre\), Assistance Publique, Hôpitaux de Paris](#)

France

First published: 14/11/2011

Last updated: 22/07/2015

Institution

Outdated

Educational Institution

Hospital/Clinic/Other health care facility

ENCePP partner

Contact details

Study institution contact

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Study contact

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Primary lead investigator

Vincent Navarro

Primary lead investigator

Study timelines

Date when funding contract was signed

Planned: 01/01/2024

Actual: 18/11/2024

Study start date

Planned: 01/11/2023

Actual: 16/04/2025

Data analysis start date

Planned: 01/11/2024

Actual: 16/06/2025

Date of interim report, if expected

Planned: 01/06/2026

Date of final study report

Planned: 31/12/2027

Sources of funding

- Other

More details on funding

DGOS

Regulatory

Was the study required by a regulatory body?

No

Is the study required by a Risk Management Plan (RMP)?

Not applicable

Methodological aspects

Study type

Study type list

Study topic:

Disease /health condition

Study type:

Non-interventional study

Scope of the study:

Disease epidemiology

Healthcare resource utilisation

Method development or testing

Data collection methods:

Secondary use of data

Study design:

Retrospective cohort study

Main study objective:

The main objective of the study is to quantify the demand for and the provision of care for patients with epilepsy at the national level

Study Design

Non-interventional study design

Cohort

Study drug and medical condition

Medical condition to be studied

Epilepsy

Population studied

Short description of the study population

The initial population to be extracted from the SNDS (French National Health Data System) refers to all individuals, regardless of age (adults and children), identified by the following case selection algorithm: "(patient with at least one antiepileptic drug in outpatient care (DCIR) OR who was hospitalized with a principal diagnosis OR significant associated diagnosis related to epilepsy OR having a long-term illness (ALD) No. 9 severe epilepsy currently in operation - over the following period: 01/01/2017 to 31/12/2019) OR (patient matched to the EDS extraction)". This extraction is intentionally as broad as possible: prescriptions for some antiepileptic drugs may be for indications other than epilepsy (neuropathic pain, anxiety, bipolar disorder, etc.). The idea here is to miss as few epileptic patients as possible and to be able to develop more precise case selection algorithms later on from this population.

Age groups

- **In utero**
- **Paediatric Population (< 18 years)**
 - Neonate
 - Preterm newborn infants (0 - 27 days)
 - Term newborn infants (0 - 27 days)
 - Infants and toddlers (28 days - 23 months)
 - Children (2 to < 12 years)
 - Adolescents (12 to < 18 years)
- **Adult and elderly population (≥18 years)**
 - Adults (18 to < 65 years)
 - Adults (18 to < 46 years)
 - Adults (46 to < 65 years)
 - Elderly (≥ 65 years)

- Adults (65 to < 75 years)
 - Adults (75 to < 85 years)
 - Adults (85 years and over)
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Special population of interest

Other

Special population of interest, other

Patients with epilepsy

Estimated number of subjects

600000

Study design details

Setting

Extraction of all patients following these criteria:

For the SNDS:

- At least one delivery of an anti-seizure medication
- Or an ICD-10 code for hospitalization or long-term care related to epilepsy (G40 / G41)
- Between January 1, 2017, and December 31, 2019.

For the APHP CDW:

- Mention of at least one anti-seizure medication in at least one medical chart
 - Or an ICD-10 code for hospitalization related to epilepsy (G40, G41) or a condition that can mimic epilepsy (R53, R55, R56)
 - Between July 1, 2017, and December 31, 2019.
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Comparators

N/A

Outcomes

For the algorithm targeting patients with epilepsy: sensitivity, specificity, positive predictive value, negative predictive value, F1 score.

For incidence and prevalence: number of patients per 100,000 inhabitants

For care pathways: typical sequences of healthcare consumption and mortality.

For costs: direct and indirect costs (compensation related to work stoppages) in euros.

Data analysis plan

- Establishing the gold standard from medical reports: natural language processing algorithms comparing rule-based algorithms (automatic detection of negation, hypothesis, and family history) with neural networks.
 - Algorithm for targeting epileptic patients in the SNDS: developing rules based on clinical expertise and verifying performance using increasingly sophisticated algorithms.
 - Incidence and prevalence: using Poisson regression models to analyze trends over the years.
 - Care pathways: using sequence analysis algorithms.
 - Costs: using regression methods that account for patient comorbidities to model costs specifically related to epilepsy versus other costs.
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Summary results

N/A

Data management

ENCePP Seal

The use of the ENCePP Seal has been discontinued since February 2025. The ENCePP Seal fields are retained in the display mode for transparency but are no longer maintained.

Data sources

Data source(s)

Système National des Données de Santé (French national health system main database)

Data source(s), other

Clinical Data Warehouse the ASSISTANCE PUBLIQUE - HOPITAUX DE PARIS

Data sources (types)

[Administrative healthcare records \(e.g., claims\)](#)

Use of a Common Data Model (CDM)

CDM mapping

No

Data quality specifications

Check conformance

Yes

Check completeness

Yes

Check stability

Yes

Check logical consistency

Yes

Data characterisation

Data characterisation conducted

Yes