

DEFI - Determination of epidemiology of fibromyalgia

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General

Identification

Detailed name Determination of epidemiology of fibromyalgia

Sign or acronym DEFI

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL N° 908059, CPP 29/10/2007

General Aspects

Medical area Neurology

Others (details) Fibromyalgia

Keywords fibromyalgia prevalence

Scientific investigator(s) (Contact)

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Unit Pfizer

Collaborations

Funding

Funding status Private

Details Pfizer

Governance of the database

Sponsor(s) or organisation(s) responsible Pfizer

Organisation status Private

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 institutions and services
A population file

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

Additional information regarding sample selection. Random selection via the telephone directory

Database objective

Main objective

Main:

- Evaluate the prevalence of fibromyalgia in the general population, in five "French regions", by identifying:
 - ? in a first step, by telephone, potential or known fibromyalgia patients,
 - ? then in a second step, from among these patients, those that have fibromyalgia validated by a rheumatologist.

Secondary:

- Describe the characteristics of the patients with a diagnosis of fibromyalgia validated by a rheumatologist.
- Describe the characteristics of patients for whom this diagnosis has not been validated by the rheumatologist.
- Compare the characteristics of these two groups of patients to one another and each of them with the characteristics of the general population of the study.

Inclusion criteria

- Patients aged 18 years or older.
- Patients deemed apt to answer the questions.
- Randomly selected patients who accept to

participate in the survey (in the event of a refusal, the selected person was not replaced within the home or in the study)."

Population type

Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
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Population covered	General population
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Gender	Male Woman
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Geography area	Regional
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French regions covered by the database	Auvergne Rhône-Alpes Bretagne Île-de-France Languedoc-Roussillon Midi-Pyrénées Nord - Pas-de-Calais Picardie
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Detail of the geography area	The towns of Lille, Grenoble, Toulouse and the departments of Val-de-Marne and Ile-et-Vilaine
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Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2008
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Date of last collection (YYYY or MM/YYYY)	2009
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Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
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Details of the number of individuals	2849
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Data

Database activity	Data collection completed
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Type of data collected	Clinical data Declarative data
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Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire Face to face interview Phone interview
Presence of a biobank	No
Health parameters studied	Health event/morbidity
Procedures	
Data collection method	Telephone and paper
Participant monitoring	Yes
Details on monitoring of participants	1 month
Links to administrative sources	No
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Methods for accessing the database are currently being defined
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only