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)
Population covered	General population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Auvergne Rhône-Alpes Bretagne Île-de-France Languedoc-Roussillon Midi-Pyrénées Nord - Pas-de-Calais Picardie
Detail of the geography area	The towns of Lille, Grenoble, Toulouse and the departments of Val-de-Marne and Ille-et-Vilaine
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2008
Date of last collection (YYYY or MM/YYYY)	2009
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	2849
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Declarative data

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