COPARK - Prospective Follow-Up of Population with Parkinson's Disease - COPARK Cohort

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General

Identification

Detailed name	Prospective Follow-Up of Population with Parkinson's Disease - COPARK Cohort
Sign or acronym	COPARK
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	Accord CNIL

General Aspects

Medical area	Neurology
Health determinants	Genetic
Keywords	Parkinson's symptoms, activities, daily life, Health episodes, quality of life, treatment, mortality

Scientific investigator(s) (Contact)

Name of the director	Rascol
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Organization	CHU DE

Collaborations

Participation in projects, networks and consortia	Yes

Funding	
Funding status	Mixed
Details	START UP LN PHARMA , ASSOCIATION DE MALADES, INDUSTRIES, INSERM, CHU DE TOULOUSE
Governance of the database	
Sponsor(s) or organisation(s) responsible	LN PHARMA
Organisation status	Private
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.	Inclusion method: Prospective Other bodies active in creating this cohort: CHU, CHG, INDEPENDENT PHYSICIANS Closing date for inclusion: 01/01/2009
Database objective	
Main objective	General objective: The objective of this multi-disciplinary project (neurology, pharmacology, epidemiology etc.) is to prospectively gather data in a population of outpatients with Parkinson's disease identified through a regional network of hospital neurologists and independent physicians, concerning the onset and progression of motor signs (tremor, akinesia, rigidity, motor complications, freezing, falls, dysarthria ...) and non-motor signs (pain, anxiety and depressive symptoms, autonomic dysfunction, sleep disorders, dementia, apathy, fatigue ...) of PD using validated scales. We will also gather data on quality of life, treatment (care sought and consumption of

	medication), morbidity and mortality within the same population. Secondary objective: To develop a biobank in the second phase based on phenotypic and pharmacological characterisations outlined in the COPARK population
Inclusion criteria	Parkinson's patients with idiopathic Parkinson's disease (UKPDBB criteria) Over 18 years of age, non-institutionalised, with no atypical Parkinsonian syndrome, having never undergone neurosurgery, with no cognitive impairment (MMSE <24), with no serious life-threatening pathology, who have given signed informed consent.

Population type

Age	Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	Aquitaine Limousin Poitou-Charentes Languedoc-Roussillon Midi-Pyrénées Nord - Pas-de-Calais Picardie Pays de la Loire
Detail of the geography area	4 REGIONS THROUGHOUT FRANCE (MIDI-PYRENEES, AQUITAINE, PAYS DE LOIRE, NORD PAS DE CALAIS)

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	12/2006
Date of last collection (YYYY or MM/YYYY)	01/2013

Size of the database

Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	467

Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Self-administered questionnaire: Entry from a paper questionnaire (Manual input) with double data entry Interview: Entry from paper questionnaire (manual input) with double data entry Clinical Examinations: Handwritten (Manual input) and double data entry
Participant monitoring	Yes
Details on monitoring of participants	Follow-up duration: 5 years
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=%28copark+AND+Rascol+O[Author]%29+OR+24839938[uid]
Description	List of publications in Pubmed
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Data may be used by academic teams Data access for research members and non-members under contract approved by the cohort Scientific Committee and according to the terms governing the charter between different partners Data may be used by industrial teams Data access for research members and non-members under contract that are approved by the cohort Scientific Committee

	and according to the terms governing the charter between different partners
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only