

DESIR - Development of Early Undifferentiated Spondyloarthritis

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General	
Identification	
Detailed name	Development of Early Undifferentiated Spondyloarthritis
Sign or acronym	DESIR
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL : 03/07/2008
General Aspects	
Medical area	Rheumatology
Health determinants	Climate Genetic Geography Pollution
Keywords	Natural history, predictive factors, development, progressive factors, genetic factors, ethnic and environmental factors, human impact, economic
Scientific investigator(s) (Contact)	
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Unit	SERVICE DE RHUMATOLOGIE DU PR DOUGADOS HÔPITAL COCHIN
Organization	HÔPITAL

Collaborations	
Funding	
Funding status	Mixed
Details	Pfizer-Wyeth, Société Française de Rhumatologie, Inserm
Governance of the database	
Sponsor(s) or organisation(s) responsible	APHP
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 Inclusion cut-off date: April 2010
Database objective	
Main objective	1) To study the natural history of early inflammatory back pain 2) To identify predictive factors for the development of spondyloarthritis and progressive factors of the disease, including genetic, ethnic and environmental factors 3) To study the human and economic impact of patients with early inflammatory back pain.
Inclusion criteria	Men or women over 18 and under 50 years old, presenting early inflammatory back pain defined by: <ul style="list-style-type: none"> - pain in the buttock, lumbar or thoracic spine region; - fulfilling either the Calin or Berlin criteria or both; - symptom duration more than 3 months and less than 3 years. Symptoms suggestive of

spondyloarthritis according to physician's assessment (score greater or equal to 5 on a 0 to 10 rating scale). Realisation of a prior medical examination. Informed consent dated and signed voluntarily.

Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	General population
Gender	Male Woman
Geography area	National
Detail of the geography area	Multicentric cohort throughout France (25 centres)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	12/2007
Size of the database	
Size of the database (number of individuals)	[500-1000[individuals
Details of the number of individuals	708
Data	
Database activity	Data collection completed
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
Paraclinical data (detail)	Imaging

Biological data (detail)	Type of samples taken: serum, urine, DNA, RNA
Presence of a biobank	No
Health parameters studied	Health event/mortality Health care consumption and services
Care consumption (detail)	Medicines consumption
Procedures	
Data collection method	Self-administered questionnaire: double data entry from a paper questionnaire Interview: direct input Clinical Examinations: handwritten with double data entry Biological analysis: handwritten with double data entry
Participant monitoring	Yes
Details on monitoring of participants	Follow-up duration: 10 years
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://tinyurl.com/HAL-DESIR
Description	List of publications in HAL
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=desir+AND+Spondyloarthritis
Description	List of publications in Pubmed
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Researchers from any country can submit a research project to the Cohort Scientific Committee. If the project is approved, cohort data will be made available whether it is the clinical database or biological material and/or imaging equipment.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only