

FAMILIAL HYPERCHOLESTEROLAEMIA - Rare Forms of Familial Hypercholesterolaemia

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General	
Identification	
Detailed name	Rare Forms of Familial Hypercholesterolaemia
Sign or acronym	FAMILIAL HYPERCHOLESTEROLAEMIA
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	Accord CNIL : 28/03/2006
General Aspects	
Medical area	Cardiology General practice
Health determinants	Genetic
Others (details)	Familial hypercholesterolaemia
Keywords	lipid profile, cardiovascular complications, severity, Health episodes, response to treatment
Scientific investigator(s) (Contact)	
Name of the director	Boileau
Surname	Catherine
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Unit	U781
Organization	INSERM
Collaborations	
Funding	

Funding status	Public
Details	PHRC NATIONAL
Governance of the database	
Sponsor(s) or organisation(s) responsible	INSERM
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.	Inclusion method: prospective. Details concerning this number: 1,000 applicants 250 multiplex families (at least 15 subjects per family)
Database objective	
Main objective	General objective: To assess and compare the morbidity and mortality of each form of familial hypercholesterolaemia. Secondary objective: To develop the most effective intervention methods possible and establish better targeted treatment tools.
Inclusion criteria	Autosomal dominant hypercholesterolaemia
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	Sick population
Gender	Male

Woman

Geography area National

Detail of the geography area France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 03/1992

Size of the database

Size of the database (number of individuals) [500-1000[individuals

Details of the number of individuals 1000

Data

Database activity Data collection completed

Type of data collected Clinical data
Declarative data
Biological data

Clinical data (detail) Direct physical measures
Medical registration

Declarative data (detail) Face to face interview

Biological data (detail) Type of samples taken: blood, lipid profile, DNA and establishment of lymphoblastoid cell lines

Presence of a biobank Yes

Contents of biobank Cell lines
DNA

Details of biobank content DNA bank, lymphoblastoid lines

Health parameters studied Health event/morbidity
Health event/mortality

Procedures

Data collection method Interview: paper questionnaire (manual input) Clinical examinations: handwritten (manual input) Biological analysis: handwritten (manual input)

Participant monitoring	Yes
Details on monitoring of participants	(Indefinite duration)
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/25052769
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Data may not be used by academic teams Data may not be used by industrial teams
Access to aggregated data	Access on specific project only
Access to individual data	No access