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
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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) Cinical 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