

REMY: Clinical Research on Hypertrophic Cardiomyopathy - Longitudinal Study on Patients with Hypertrophic Cardiomyopathy

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General	
Identification	
Detailed name	Longitudinal Study on Patients with Hypertrophic Cardiomyopathy
Sign or acronym	REMY: Clinical Research on Hypertrophic Cardiomyopathy
General Aspects	
Medical area	Cardiology
Health determinants	Genetic
Keywords	patient treatment, HCM, family, profile, diagnosis, assessment, therapy
Scientific investigator(s) (Contact)	
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Unit	CHU Paris Ouest - Hôpital Européen Georges Pompidou
Organization	Hôpital Européen Georges
Collaborations	
Funding	
Funding status	Private
Details	French Cardiology Society.

Governance of the database	
Sponsor(s) or organisation(s) responsible	French Cardiology Society.
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
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	26 centres on 20/06/2014.
Database objective	
Main objective	To establish an observatory for the treatment of patients with hypertrophic cardiomyopathy (sarcomeric or non-sarcomeric). To specify the profile of HCM patients in France, methods for diagnosis and assessment (etiological and family survey), and therapeutic procedures.
Inclusion criteria	<ul style="list-style-type: none"> - Aged 15 years or over; - with HCM (non-valvular) defined by ultrasound with left ventricle thickness greater or equal to 13 mm (familial) or greater or equal to 15 mm (sporadic); - Patient was informed and gave their consent. <p>Exclusion criteria:</p> <ul style="list-style-type: none"> - Under 15 years old; - Significant aortic stenosis (less than 1 cm²).
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	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)	01/2010
Date of last collection (YYYY or MM/YYYY)	2020
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1,007 (20/06/2014).
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data
Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	HCM etiology, Doppler ultrasound, history of hospitalisation, treatment, complications.
Declarative data (detail)	Paper self-questionnaire
Details of collected declarative data	Personal and family history, treatments.
Paraclinical data (detail)	ECG, MRI, scan, electrophysiological examination, cardiac catheterisation, biopsy.

Biological data (detail)	BNP, NT-Pro BNP, troponin, CPK, creatinine, haemoglobin, high-sensitivity CRP, iron level, TSH, serum calcium, serum protein electrophoresis, ?-galactosidase A assay.
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
Procedures	
Participant monitoring	Yes
Details on monitoring of participants	Follow-up at 18 months, 3 years and 5 years.
Links to administrative sources	No
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only