

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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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

- 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.

Exclusion criteria:

- 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
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Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
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Procedures

Participant monitoring	Yes
Details on monitoring of participants	Follow-up at 18 months, 3 years and 5 years.

Links to administrative sources	No
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Promotion and access

Promotion

Access

Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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