

ERISCAM - Cohort of French Families with Identified MMR Gene Mutation: Assessment of Cancer Risk

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General

Identification

Detailed name Cohort of French Families with Identified MMR Gene Mutation: Assessment of Cancer Risk

Sign or acronym ERISCAM

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation

CNIL

General Aspects

Medical area Cancer research
Gastroenterology et hepatology
Gynecology/ obstetrics

Pathology (details) Lynch syndrome

Health determinants Genetic

Keywords Lynch syndrome, gynaecology, MMR genes, cumulative risk, MLH1, MSH2, MSH6, colorectal, cancer, genetic, mutation

Scientific investigator(s) (Contact)

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Collaborations

Funding

Funding status Private

Details Fondation de France

Governance of the database

Sponsor(s) or organisation(s) responsible Centre Léon Bérard

Organisation status Private

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 An administrative base or a register

Database recruitment is carried out as part of an interventional study No

Database objective

Main objective The aim is to reliably and accurately determine the risks of different tumours in subjects with MMR gene mutations.

Inclusion criteria French families with an identified MMR gene mutation recruited throughout 40 cancer genetic consultation centres participating in the study; all members of the Cancer and Genetics Network.

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) 2007

Date of last collection (YYYY or MM/YYYY) 2009

Size of the database

Size of the database (number of individuals) [1000-10 000] individuals

Details of the number of individuals 537 families (248: MSH1 mutation, 256 MSH2 mutation, 33 MSH6 mutation). 2,622 patients

Data

Database activity Data collection completed

Type of data collected Clinical data
Declarative data

Clinical data (detail) Direct physical measures

Details of collected clinical data Sex; age; age at last follow-up; cancer history (location, age at diagnosis, death); mutation status; colonoscopic surveillance method; colorectal or gynaecological surgery

Declarative data (detail) Face to face interview

Details of collected declarative data Information not available, even if medical record exists.

Presence of a biobank No

Procedures

Participant monitoring Yes

Details on monitoring of participants 2006, 2007, 2009

Links to administrative sources Yes

Promotion and access

Promotion

Link to the document <http://www.hnpcc-lynch.com/?p=515>

Link to the document <http://tinyurl.com/PUBMED-ERISCAM>

Link to the document <http://tinyurl.com/HAL-ERISCAM>

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