

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

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Last update : 01/01/2019 | Version : 1 | ID : 73086

| 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<br>Gastroenterology et hepatology<br>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)<br>(Contact)  |  |
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|---|---|
| Organization                              | CNRS  |
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| Organization                              | Inserm  |
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| Organization                              | Inserm  |
| 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)<br>Adulthood (25 to 44 years)<br>Adulthood (45 to 64 years)<br>Elderly (65 to 79 years)<br>Great age (80 years and more)  |
| Population covered   | Sick population  |
| Gender   | Male<br>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<br>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 | <a href="http://www.hnpcc-lynch.com/?p=515">http://www.hnpcc-lynch.com/?p=515</a> |
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|----------------------|---|
| Link to the document | <a href="http://tinyurl.com/PUBMED-ERISCAM">http://tinyurl.com/PUBMED-ERISCAM</a> |
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| Link to the document | <a href="http://tinyurl.com/HAL-ERISCAM">http://tinyurl.com/HAL-ERISCAM</a> |
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## 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