

# EPIMAD - Registre des Maladies Inflammatoires Chroniques de l'Intestin du Nord Ouest de la France

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## General

### Identification

|                 |  |
|-----------------|--|
| Detailed name   | Registre des Maladies Inflammatoires Chroniques de l'Intestin du Nord Ouest de la France |
| Sign or acronym | EPIMAD   |

### General Aspects

|              |  |
|--------------|--|
| Medical area | Gastroenterology et hepatology<br>Pediatrics |
|--------------|--|

|                     |                                   |
|---------------------|-----------------------------------|
| Health determinants | Genetic<br>Geography<br>Nutrition |
|---------------------|-----------------------------------|

|          |                        |
|----------|------------------------|
| Keywords | Incidence Risk Factors |
|----------|------------------------|

### Scientific investigator(s) (Contact)

|                      |   |
|----------------------|---|
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| Organization         | Centre Hospitalier Universitaire de Lille                                   |

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|----------------------|-------------------------|
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|--|---|
| Organization                                       | Centre Hospitalier Universitaire de Lille   |
| Collaborations                                     |   |
| Funding  |   |
| Funding status                                     | Public  |
| Details  | Institut national de la santé et de la recherche médicale - INSERM<br>Institut de veille sanitaire - InVS<br>Ferring company and Hospital grants (national or regional) by PHRC<br>International grants (IOIBD) |
| <b>Governance of the database</b>                  |   |
| Sponsor(s) or organisation(s) responsible          | INSERM  |
| Organisation status                                | Public  |
| Sponsor(s) or organisation(s) responsible          | InVS  |
| Organisation status                                | Public  |
| Sponsor(s) or organisation(s) responsible          | Centre Hospitalier Universitaire de Amiens  |
| Organisation status                                | Public  |
| Sponsor(s) or organisation(s) responsible          | Centre Hospitalier Universitaire de Lille et Rouen  |
| Organisation status                                | Public  |
| Sponsor(s) or organisation(s) responsible          | CENTRE D'INVESTIGATION CLINIQUE DU CHRU DE LILLE  |
| Organisation status                                | Public  |
| <b>Additional contact</b>                          |   |
| <b>Main features</b>                               |   |
| <b>Type of database</b>                            |   |
| Type of database                                   | Morbidity registers   |
| Additional information regarding sample selection. | Exhaustiveness  |
| <b>Database objective</b>                          |   |

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| Main objective                               | Know the incidence and prevalence of IBDs in a geographical zone representing 10% of the French population. Construct analytical epidemiological study for physiopathogenetic factors behind IBDs  |
| Inclusion criteria                           | Patient with a clinical, endoscopic, histological and/or radiological presentation compatible with an IBD and living in one of the following four départements: Nord, Pas-de-Calais, Seine-Maritime or Somme.  |
| <b>Population type</b>                       |  |
| Age  | Newborns (birth to 28 days)<br>Infant (28 days to 2 years)<br>Early childhood (2 to 5 years)<br>Childhood (6 to 13 years)<br>Adolescence (13 to 18 years)<br>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                               | Regional   |
| French regions covered by the database       | Nord - Pas-de-Calais Picardie<br>Normandie   |
| Detail of the geography area                 | Nord, Pas de Calais, Somme and Seine-Maritime  |
| <b>Data collection</b>                       |  |
| <b>Dates</b>                                 |  |
| Date of first collection (YYYY or MM/YYYY)   | 1988   |
| Date of last collection (YYYY or MM/YYYY)    | 2012   |
| <b>Size of the database</b>                  |  |
| Size of the database (number of individuals) | Greater than 20 000 individuals  |
| Details of the number of                     | 16000 IBD (9200 CD, 6000 UC et 800 IBDU)7000   |

|   |  |
|---|--|
| individuals   | cases of possible IBD, acute or indeterminate chronic colitis necessitating a follow-up to be classified   |
| <b>Data</b>   |  |
| Database activity   | Data collection completed  |
| Type of data collected  | Clinical data<br>Paraclinical data<br>Administrative data  |
| Clinical data (detail)  | Direct physical measures   |
| Paraclinical data (detail)  | Radiological, endoscopic and histological examinations   |
| Administrative data (detail)  | gender, date of birth, INSEE residence code at the time of diagnosis   |
| Presence of a biobank   | No   |
| Health parameters studied   | Health event/morbidity<br>Health care consumption and services   |
| Care consumption (detail)   | Medical/paramedical consultation   |
| <b>Procedures</b>   |  |
| Data collection method  | Validated and published questionnaire completed by survey takers in all adult and pediatric gastroenterology surgeries across the four départements. Anonymous peer review |
| Participant monitoring  | Yes  |
| Details on monitoring of participants   | Only forms that cannot be categorized straightaway + pediatric cohorts (<17 years old) and seniors (>60 years old)   |
| Links to administrative sources   | No   |
| <b>Promotion and access</b>   |  |
| <b>Promotion</b>  |  |
| <b>Access</b>   |  |
| Terms of data access (charter for data provision, format of data, availability delay) | Leaflet of findings handed out every two years to gastroenterologists, annual meeting for presenting the findings  |

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only