

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 Pediatrics
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Health determinants	Genetic Geography Nutrition
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Keywords	Incidence Risk Factors
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Scientific investigator(s) (Contact)

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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 Institut de veille sanitaire - InVS Ferring company and Hospital grants (national or regional) by PHRC International grants (IOIBD)
Governance of the database	
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
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Additional information regarding sample selection.	Exhaustiveness
Database objective	

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.
Population type	
Age	Newborns (birth to 28 days) Infant (28 days to 2 years) Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) 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	Regional
French regions covered by the database	Nord - Pas-de-Calais Picardie Normandie
Detail of the geography area	Nord, Pas de Calais, Somme and Seine-Maritime
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	1988
Date of last collection (YYYY or MM/YYYY)	2012
Size of the database	
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
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Paraclinical data 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 Health care consumption and services
Care consumption (detail)	Medical/paramedical consultation
Procedures	
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
Promotion and access	
Promotion	
Access	
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