

RRHMBN - Registre Régional des Hémopathies Malignes de Basse Normandie (registre qualifié)

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General	
Identification	
Detailed name	Registre Régional des Hémopathies Malignes de Basse Normandie (registre qualifié)
Sign or acronym	RRHMBN
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	1276682
General Aspects	
Medical area	Cancer research Hematology
Others (details)	Hematological malignancies, acute and chronic leukemia, Hodgkin's and non-Hodgkin's lymphoma, myeloma, myelodysplastic syndrome, myeloproliferative syndrome, CML
Keywords	Epidemiology, Specialist Registry, Lower Normandy
Scientific investigator(s) (Contact)	
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Organization	CHU de

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Collaborations

Funding

Funding status	Public
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Details Institut national de veille sanitaire - INVS Institut national du cancer - INCA Autres (CHU de Caen, Ligue, UFR de médecine de Caen, Université de Caen Basse-Normandie...)

Governance of the database

Sponsor(s) or organisation(s) responsible CHU de Caen

Organisation status Public

Additional contact

Main features

Type of database

Type of database Morbidity registers

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. Hospital and city medical analysis laboratories
Anatomo-cyto-pathology laboratories
Healthcare centers (specialist and non-specialist)
Public and private medical information departments

(DIMs) including teaching hospitals and regional cancer prevention centers
Clinical hematology departments in Lower Normandy

Database objective

Main objective

Objectives of the Lower Normandy Specialist Regional Registry for Hematology in terms of public health (surveillance, evaluation)

1) Descriptive epidemiology and temporal and spatial monitoring of all hematological malignancies in Lower Normandy: Hodgkin's lymphoma, non-Hodgkin's malignant lymphoma, acute and chronic leukemia including chronic lymphocytic leukemia, multiple myeloma of the bones, myelodysplastic and myeloproliferative syndromes.

2) Study of the risk factors of hematological malignancies.

In view of the existence in Lower Normandy of nuclear sites in the Nord-Cotentin (AREVA NC La Hague plant, Flamanville plant, ANDRA low- and intermediate-level radioactive waste repository, military arsenal servicing nuclear submarines), extra careful monitoring of hematological malignancies is carried out around these sites by the RRHMBN. Mapping of hematological malignancies is carried out in this context - in both children and adults. This does not only concern leukemia, but also all hematological malignancies, including lymphoma.

Given the installation of the very high voltage line corridor between the Flamanville plant and Brittany, the RRHMBN has set up a "zero point" field for hematological malignancies in the corresponding zone. This starting point will form a reference for any subsequent research.

3) Evaluation of hematological malignancy treatment in different populations (elderly people, countryside dwellers) in Lower Normandy and study of the care streams and type of treatment depending on age, residential area and type of HM.

This research will be performed jointly by all of the Lower Normandy registries brought together under a Federation as well as by the FRANCIM network, associating all accredited registries.

Inclusion criteria	All incident cases of hematological malignancies (HMs) as well as any previous personal HMs, previous and subsequent personal solid cancers and any family solid cancers or HMs.
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	Normandie
Detail of the geography area	Lower-Normandy: Calvados, Manche and Orne départements, or a population of around 1.5 million inhabitants.
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	1997
Date of last collection (YYYY or MM/YYYY)	2007
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1997- 2005 : 7341
Data	
Database activity	Data collection completed

Type of data collected	Clinical data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures
Paraclinical data (detail)	All necessary biological data for diagnosing and monitoring each type of hematological malignancy
Biological data (detail)	All necessary paraclinical data for diagnosing and monitoring each type of hematological malignancy
Administrative data (detail)	Identification data
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Others
Other (detail)	Incidence
Procedures	
Data collection method	Active data collection - List of cases provided by all regional laboratories - Visit and auditing of records - Coding according to ICD-O-3 - Encrypted file (DIM) Hematological (Xavier Troussard) and epidemiological (Albert Collignon) expertise
Classifications used	ICDO-3 classification and ADICAP
Participant monitoring	Yes
Details on monitoring of participants	Vital status
Links to administrative sources	Yes
Linked administrative sources (detail)	RNIPP
Promotion and access	
Promotion	
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed?term
Access	

Terms of data access (charter for data provision, format of data, availability delay)

Contact Prof. X. Troussard

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only