

RHEMCO - Côte d'Or registry of hematological malignancies

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General	
Identification	
Detailed name	Côte d'Or registry of hematological malignancies
Sign or acronym	RHEMCO
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL 97.013
General Aspects	
Medical area	Cancer research
Others (details)	hematological malignancies
Keywords	public health, surveillance, evaluation
Scientific investigator(s) (Contact)	
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Organization	CHU
Collaborations	
Funding	
Funding status	Public
Details	Institut national de veille sanitaire - InVS Institut national du cancer - INCa

Governance of the database	
Sponsor(s) or organisation(s) responsible	CHU Dijon
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.	Selection of subjects having the required inclusion criteria. Several sources are used to identify cases: - Medical Biology Laboratories - Specialist laboratories (Hematology, Cytogenetics) - Pathological Anatomy Structures - Death certificates - PMSI (hospital diagnosis-related group database) - Cancer registry of the Doubs département - Clinical departments - Attending physician - RNIPP
Database objective	
Main objective	Objectives of the registry in terms of public health (surveillance, evaluation): 1) listing of all cases of hematological malignancies occurring in a well-defined population so as to provide the health and social authorities with precise data regarding the incidence, breakdown per gender, age range, geographical zone and socioprofessional category of these diseases; 2) recording of data on these cases makes it possible to evaluate different characteristics such as the stage of diagnosis, elements of the diagnosis and cancer staging report, therapy and survival; 3) a role to alert the public authorities in the rapid

rise in incidence of certain pathologies and in the identification of the cause of this rise;
 4) a role in improving the quality of data on hematological malignancies in the general cancer registries.

- Objectives of the registry in terms of research;
 1) in etiological epidemiology with the detection of environmental, personal and family risk factors of hematological malignancies;
 2) in molecular epidemiology with the development of genetic or epigenetic research,
 3) in pharmacological epidemiology with the development of therapies, their setting up, access to new therapies and their effect at population level on patient survival, the quality of this survival and the distant consequences of their use;
 4) setup of tumor tissue collection

Inclusion criteria

The cases recorded are malignant proliferations developed from cell types constituting the hematopoietic tissue diagnosed, in subjects living in the Côte d'Or département for more than 6 months

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

Departmental

French regions covered by the database

Bourgogne Franche-Comté

Detail of the geography area

Côte d'or

Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 1980

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 1980-2004: 5087

Data

Database activity Data collection completed

Type of data collected
Clinical data
Biological data
Administrative data

Clinical data (detail) Direct physical measures

Biological data (detail) Diagnostic and prognostic data: cytology, immunophenotyping, cytogenetics, molecular biology, pathological anatomy, biochemical markers

Administrative data (detail) place of birth, residence, marital status, profession

Presence of a biobank Yes

Contents of biobank
Serum
Blood cells isolated
DNA
DNAC/RNAm

Details of biobank content
Biological samples are stored in the Ferdinand Cabanne Biological Resource Center (www.crbferdinandcabanne.fr/)

Health parameters studied
Health event/morbidity
Health event/mortality
Health care consumption and services
Quality of life/health perception

Care consumption (detail) Medicines consumption

Procedures

Data collection method	Active or passive
Participant monitoring	Yes
Details on monitoring of participants	- Vital status - Sample-based follow-up is conducted depending on the objectives defined.
Links to administrative sources	Yes
Linked administrative sources (detail)	- RNIPP - PMSI

Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed?term
Link to the document	http://epi.grants.cancer.gov/InterLymph/
Link to the document	http://www.Haemacare.eu

Access

Terms of data access (charter for data provision, format of data, availability delay)	publications, InVS (French Institute for Public Health Surveillance) website, annual reports to the InVS. Regarding access to the registry's data, interested researchers may contact the scientific manager who will assess their requests.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only