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