

- Gironde register of hematologic malignancies

Head :Monnereau Alain

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General

Identification

Detailed name	Gironde register of hematologic malignancies
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	903445

General Aspects

Medical area	Cancer research Hematology
Others (details)	hematological malignancies
Keywords	Surveillance system, hematological malignancies, incidence data, frequency, clusters, distribution, side effects

Scientific investigator(s) (Contact)

Name of the director	Monnereau
Surname	Alain
Address	Institut Bergonié, 229 cours de l'Argonne, 33076 Bordeaux cedex
Phone	+ 33 (0)5 56 33 33 33
Email	monnereau@bergonie.org
Organization	Institut Bergonié, Centre Régional de Lutte Contre le Cancer de Bordeaux et du

Collaborations

Funding

Funding status	Public
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Details	InVS, INCa, Institut Bergonié (Centre de Lutte Contre le Cancer de Bordeaux et du Sud Ouest)
Governance of the database	
Sponsor(s) or organisation(s) responsible	Institut Bergonié, Centre Régional de Lutte Contre le Cancer de Bordeaux et du Sud-Ouest
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.	<p>Selection of subjects having the required inclusion criteria.</p> <p>Several sources are used to identify cases:</p> <ul style="list-style-type: none"> - Gironde-based anatomopathology and cytology laboratories, - Medical information departments (DIMs) in and outside of the département, - clinical departments
Database objective	
Main objective	<p>One of the key objectives of the registry is to improve the health surveillance system for hematological malignancies locally in France:</p> <ul style="list-style-type: none"> - by analyzing incidence data of different types of hematological malignancies: description of the frequency and distribution of each entity according to time, space and the characteristics of the population, - by producing reliable reference rates for helping the investigation of clusters, - by monitoring the side effects of therapies (e.g.: secondary leukemia), - by actively taking part in improving the surveillance system (expertise in the recording of hematological malignancies; program for improving the recording of cases in France).

Clinical or evaluative epidemiology in the general population is also one of the registry's main objectives:

- evaluate practices, care pathways and streams, how these change over time and the impact of practice standards on care quality and survival,
- estimate the relative survival and prevalence of hematological malignancies for the purposes of comparing with other regions or countries and to estimate the resource needs of diagnosis and treatment (chemotherapy, transplant, radiotherapy) - particularly for the elderly (high proportion of cases),
- evaluate the dissemination and impact of clinical research by assessing the applicability of therapeutic trials and impact of therapeutic progress on the quantity/quality of life of patients,

The registry was designed from the outset as a tool for participating in - and even initiating - an epidemiological research program on hematological malignancies in several fields. Descriptive epidemiology, ecological studies or case-control studies, studies on access to health care and prognostic studies in the population, multidisciplinary research with Human and Social Sciences).

Inclusion criteria

Since January 1st 2002, the registry has included all incident cases of hematological malignancies (leukemia, lymphoma, myeloma, myelodysplastic syndrome, myeloproliferative syndrome) in subjects living on a regular basis in the Gironde at the time of diagnosis.

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	Aquitaine Limousin Poitou-Charentes
Detail of the geography area	Gironde
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2002
Date of last collection (YYYY or MM/YYYY)	2008
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	2002-2008 : 5000
Data	
Database activity	Current data collection
Type of data collected	Clinical data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures
Paraclinical data (detail)	full staging (imaging, osteomedullary biopsy)
Biological data (detail)	Initial biological examination (Full blood count, Myelogram, Osteomedullary biopsy, Immunophenotyping, Cytogenetic anomalies, Biological examinations for prognostic purposes).
Administrative data (detail)	Identification data, sociodemographic data
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health care consumption and services

Others

Care consumption (detail)	Hospitalization
Other (detail)	survival/etiology

Procedures

Data collection method	Active or passive collection (electronic file)
Classifications used	International Classification of Diseases applied to oncology (3rd version)
Participant monitoring	Yes
Details on monitoring of participants	Follow-up of the vital status over at least two years. - Not carried out but planned for the follow-up of relapses: Follow-up of some types of hematological malignancy, such as follicular lymphoma and myelodysplastic syndromes, is due to be set up. This is based on an active collection of additional medical information such as the notion of histological transformation or relapse. The sources consulted will be the medical record and/or attending physician.
Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI - ALD

Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/18781390
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/19017688
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/20699439
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/19058175

Access

Terms of data access (charter for data provision, format of data, availability delay)	Transmission to the Francim national base and then to the French Institute for Public Health Surveillance (InVS). Dissemination of aggregate data in the form of a website and newsletter. Participation in national and international studies that may concern any aspect of the epidemiology of these diseases.
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Access to aggregated data

Free access

Access to individual data

Access on specific project only