

RNHE - National register of des pediatric hematological malignancies

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General	
Identification	
Detailed name	National register of des pediatric hematological malignancies
Sign or acronym	RNHE
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL: 998198
General Aspects	
Medical area	Cancer research Hematology
Health determinants	Genetic Geography Pollution
Keywords	incidence rates, types of leukemia and lymphoma, particular exposure, HIV mother, perinatal period, environmental exposures, survival, general population, risk
Scientific investigator(s) (Contact)	
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Organization	Institut national de la santé et de la recherche médicale
Collaborations	
Funding	
Funding status	Public
Details	Institut national du cancer (INCa)Institut de veille sanitaire (InVS) Institut national de la santé et de la recherche médicale (Inserm)
Governance of the database	
Sponsor(s) or organisation(s) responsible	Institut national de la santé et de la recherche médicale (Inserm)
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Additional information regarding sample selection.	Recruiting of subjects having the required inclusion criteria
Database objective	
Main objective	1) Establish low incidence rates for the various types of leukemia and lymphoma. 2) Provide continuous follow-up of the incidence and detect any increase in the national or localized incidence. 3) Supply the estimation of the survival in the general population of the various types of leukemia and lymphoma. 4) Contribute to following-up on the risk of pediatric cancers in populations subjected to particular exposure (children who have had a scan, child of an HIV mother and treated during the perinatal period, environmental exposures). 5) Provide the data that will make it possible to evaluate the care sectors for children from the first symptoms until treatment. 6) Contribute to the work in research on the risks factors of cancer in children developed by the team on Environmental epidemiology of cancers of the CESP, INSERM U1018.

Inclusion criteria	Population less than 18 years of age suffering from primitive or secondary hematological or borderline malignancy (leukemia, lymphoma, myelodysplastic syndrome, myeloproliferative disease, Langerhans cell histiocytosis).
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)
Population covered	Sick population
Gender	Male Woman
Geography area	National
Detail of the geography area	Metropolitan France (+ DOM)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	1990
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	6640
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)	Examinations of tumor extensions

Biological data (detail)	Pathological anatomy/cytology, immunophenotyping, cytogenetics, molecular biology of tumors
Administrative data (detail)	Identification data (Last name, First name, Maiden name of the mother, Date of birth, Sex, Place of birth, Verification of Civil Status)Commune of residency for the diagnosticResidential historyCSP
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services
Care consumption (detail)	Hospitalization Medicines consumption
Procedures	
Data collection method	active research in care departments and laboratoriesPMSI, ALD, CEPIDC (Epidemiological Center for Mortality by Medical Causes)
Participant monitoring	Yes
Details on monitoring of participants	Following cases until the age of 18 years is done continuously by survey takers in hospital departments in order to detect relapses, the various attacks of Langerhans cell histiocytosis and the acutisations of myelodysplastic syndromes and of myeloproliferative diseases.
Links to administrative sources	Yes
Linked administrative sources (detail)	CEPI-DC ALD
Promotion and access	
Promotion	
Link to the document	http://www.hal.inserm.fr/RNHE
Description	Liste des publications dans HAL
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=NRCST[title%2Fabstract]+OR+%28%28NRCH[title%2Fabstract]+OR+Escale+OR+Estelle%29+AND+Clavell[author]%29+OR+geocap+OR+mobi-kids+OR+%22Childhood+Leukemia+International+Consortium%22

Description

Liste des publications dans Pubmed

Access

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

Publications, website

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only