HOPE-EPI - HOPE-Epidemiology - Epidemiological Research in Pediatric Hemato-Oncology

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General

Identification

Detailed name	HOPE-Epidemiology - Epidemiological Research in Pediatric Hemato-Oncology
Sign or acronym	HOPE-EPI
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL

General Aspects

Medical area	Cancer research Hematology Pediatrics
Health determinants	Climate Genetic Geography Iatrogenic Medicine Pollution Social and psychosocial factors
Keywords	national tools, research infrastructure, health events, pediatric oncology, environnemental and genetic risk factors, social and territorial determinants, iatrogenic effects of treatments

Scientific investigator(s) (Contact)

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Unit	UMRS-1018 Equipe 6
Organization	INSERM

Collaborations

Participation in projects, networks and consortia	Yes

Funding

Funding status	Public
Details	ANR "Investissements d'avenir -Grand emprunt"

Governance of the database

Sponsor(s) or organisation(s) responsible	Inserm
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Study databases
Study databases (details)	Cohort study
Database recruitment is carried out by an intermediary	A population file
Database recruitment is carried out as part of an interventional study	No

Database objective

Main objective	The objective of our project is to develop, from the existing national tools, a national research infrastructure pooling the work to collect data and validate information and health events in the service of an epidemiological research program in the field of pediatric oncology addressing : - the environnemental and genetic risk factors for childhood cancer,

	- the differences in management and their social and territorial determinants, - the iatrogenic effects of treatments, - and more generally, the state of health in the short-, intermediate- and long-term of people experiencing childhood cancer and the determinants of their quality of life. The project, closely connected with the pediatric oncology research of other disciplines, has, as a secondary objective, contributing to the sharing of data across disciplines.
Inclusion criteria	Children aged less than 18 years with cancer

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

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2010
Date of last collection (YYYY or MM/YYYY)	2020

Size of the database

Size of the database (number of individuals)	Greater than 20 000 individuals
Details of the number of individuals	2010 : 170002020 : 35000

Data

Database activity	Current data collection

Type of data collected	Clinical data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	Diagnostic : Date of diagnosis, Histology, Cytology, Cytogenetics, Immunophenotype, Molecular biology, Topography, Staging (/classification) Coding (ICD-O and ICCC) Healthcare pathway. Traitment : Risk classification, Date treatment started, Protocol arm, Chemotherapy (date, drugs, cumulative doses), Surgery (date, type and site), Radiotherapy (date, type, site and dose), Stem cell transplantation (date, type and source)
Paraclinical data (detail)	Medical imaging
Biological data (detail)	---
Administrative data (detail)	Location since birth, basic information, ...
Presence of a biobank	Yes
Contents of biobank	Whole blood
Details of biobank content	---
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
Procedures	
Participant monitoring	Yes
Links to administrative sources	Yes
Linked administrative sources (detail)	SNIIR-AM
Promotion and access	
Promotion	

Link to the document	Hope-Epi.pdf
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientific board
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only