

RNTSE - French National Registry of Childhood Solid Tumors (certified registry)

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General

Identification

Detailed name French National Registry of Childhood Solid Tumors (certified registry)

Sign or acronym RNTSE

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation

900183

General Aspects

Medical area Cancer research

Health determinants Geography

Keywords childadolescent

Scientific investigator(s) (Contact)

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Unit Registre National des Tumeurs Solides de l'Enfant

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 Nancy
Organisation status	Public
Sponsor(s) or organisation(s) responsible	ARECEA (Association pour la Recherche en Epidémiologie des Cancers de l'Enfant et de l'Adolescent)
Organisation status	Private
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects having the required inclusion criteria.
Database objective	
Main objective	<p>Objectives in terms of public health (surveillance, evaluation):</p> <ol style="list-style-type: none"> 1) Produce national reference rates on the incidence of solid tumors in children and on their histological distribution and monitor the geographical and temporal variations of this. 2) Provide the survival rates for the various cancers in the general population, all treatments taken as a whole and monitor the geographical and temporal variations in this. 3) Describe the care sectors followed by children, from the first symptoms to the treatment, and the methods for care as well as its determinants. <p>Collaborate with clinicians of the French Society for the fight against Cancers in Childhood and Adolescent Cancers (SFCE) on the setting up of long-term follow-up of cohorts of children with cancer.</p> <p>Objectives in terms of research: Conduct and associate ecological studies and case/control studies concerning the risks of cancer</p>

associated with environmental exposure, population movements, the way of life and early conditions of exposure to common infections, genetic factors interacting or not interacting with the environmental factors (the etiologic research work is particularly developed by UMRS-1018 Team 6 of Inserm).

Inclusion criteria	<p>The following are included: All solid tumors in children defined in the International Classification of Childhood Cancers (ICCC) and belonging to the diagnostic groups III to XII, as well as the "borderline" tumors and certain benign tumors. Appearing starting on January 1, 2000 in a child under the age of 15 years on the date of the first sure diagnostic, and for whom the usual domicile is located in metropolitan France. Starting on January 1, 2011, extension of the recording up to the age of 18 years for all the cases domiciled in metropolitan France and in an Overseas Département (Guadeloupe, French Guiana, Martinique, Reunion)</p>
Population type	
Age	<p>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)</p>
Population covered	Sick population
Gender	<p>Male Woman</p>
Geography area	National
Detail of the geography area	Metropolitan France (+ DOM since 01/01/2011)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2000
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of	2003: 1045 cases 2004: 1031 cases 2005: 1012

individuals	cases2006: 1025 cases
Data	
Database activity	Current data collection
Type of data collected	Clinical data Administrative data
Clinical data (detail)	Direct physical measures
Administrative data (detail)	Identification data (Last name, First name, Maiden name of the mother, Date of birth, Commune of birth, Insee Code, Commune of residency for the diagnostic, Insee Code, Full address of the diagnostic, Sex)
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health care consumption and services
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
Procedures	
Data collection method	Active collection in the hospital departments by survey takers
Classifications used	ICD-O 3 and grouped according to ICC
Participant monitoring	Yes
Details on monitoring of participants	Vital status Project to collect the serious health events during follow-up by crossing the data with the data of the SNIIR-AM (not yet operational)
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://www.chu-nancy.fr/rntse/
Link to the document	http://www.hal.inserm.fr/RNTSE
Description	List of publications in 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+Clavel\[author\]%29+OR+geocap+OR+mobi-kids+OR+%22Childhood+Leukemia+International+Consortium%22](#)

Description

List of publications in Pubmed

Access

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

Website: <http://www.chu-nancy.fr/rntse/>
Annual activity report intended for InVS and Inserm.
Integration in the ""The cancer situation in France"" report published every year by INCa
Publications in specialized reviews
Communication at scientific congresses

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only