

- Doubs and Territoire de Belfort primitive malignant tumors register

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General	
Identification	
Detailed name	Doubs and Territoire de Belfort primitive malignant tumors register
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	903417
General Aspects	
Medical area	Cancer research
Others (details)	cancer
Keywords	tumor, collection, cancer diagnoses, cancer risk, surveys
Scientific investigator(s) (Contact)	
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Organization	Registre des tumeurs du Doubs et du Territoire de
Collaborations	
Funding	
Funding status	Public
Details	Le registre est financé par l'InVS, l'INCa, le CHU de

Besançon et l'ARS de Franche-Comté. D'autres financements ponctuels interviennent sur projets (Ligue contre le cancer ...).

Governance of the database

Sponsor(s) or organisation(s) responsible

CHU de Besançon

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:

- Anatomopathology laboratories
- Hematological cytology laboratories
- Genetic departments of training hospitals
- Medical information departments
- Health Insurance Funds
- Private-practicing and hospital clinicians (+ GPs when necessary)
- Summaries of Multidisciplinary Consultation Meetings (RCPs)
- Organized screening structure
- Haut-Rhin and Bas-Rhin Registry
- National Registry of Hematological Diseases in children
- Registry of Solid Tumors in children

Database objective

Main objective

The registry carries out a continuous and exhaustive collection of all new cancer diagnoses in the general population living in a given département. It has the twofold objective of describing and monitoring the cancer risk and conducting research from the analysis of data gathered or specific surveys.

Objectives of the Registry in terms of public health:

- Participate in the epidemiological surveillance of cancers at local and national level under the Francim network by publishing incidence indicators by cancer location, gender, age and year of diagnosis.
- Help to evaluate primary and secondary prevention initiatives (organized cancer screening), patient treatment and healthcare needs in the general population.

Inclusion criteria

All primitive malignant tumors diagnosed in patients living, at the time of diagnosis, in the Doubs or Territoire-de-Belfort départements, irrespective of where they are treated, are recorded - including stratum basale skin carcinomas (specific to the Doubs Registry). In situ primitive tumors of the breast, colon-rectum, cervix, bladder and excretory ducts, as well as in situ melanomas. Benign tumors and tumors of intermediate malignancy of the central nervous system and bladder are also recorded, as are borderline tumors of the ovary.

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

Doubs (25) and Territoire de Belfort (90)

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

1978

Date of last collection (YYYY or MM/YYYY)	2008
Size of the database	
Size of the database (number of individuals)	Greater than 20 000 individuals
Details of the number of individuals	1978-2008: 79100 / Doubs 2007-2008: 2312 / Territoire de Belfort
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures
Paraclinical data (detail)	Any additional examination providing information for tumor coding
Biological data (detail)	Any additional examination providing information for tumor coding
Administrative data (detail)	Identification data (Last name, first name, date of birth, town of birth, address)
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Active or passive collection (CNIL authorization): - Receipt of anatomopathological and cytological reports, lists of hospital stays (PMSI) and chronic disease diagnoses with regard to health insurance reimbursement. Lists by encrypted electronic dispatch. - Active search for regular complementary information in medical records
Participant monitoring	Yes
Details on monitoring of participants	Vital status, death, date of last news - Sample-based follow-up is carried out (High-Resolution Francim surveys). - Passive follow-up is carried out using information from the Registry

(anatomocytopathology reports).

Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI, Chronic disease lists, Organized screening structure (CNIL authorization)
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Incidence data is available in aggregate form, by cancer location, year, gender and age. This data is published at regular intervals at local and national level (see ""Find out more""). The data recorded in the Registry may be used for specific research. Project requests are analyzed by the Registry's Strategic and Scientific Advisory Board. The arrangements for cooperation must be defined.
Access to aggregated data	Free access
Access to individual data	Access on specific project only