- Bas-Rhin Cancer Registry (Certified Registry)

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General

Identification

Detailed name	Bas-Rhin Cancer Registry (Certified Registry)
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL 998044.

General Aspects

Medical area	Cancer research
Keywords	tool, epidemiological research, assessment, morbidity, mortality, incidence, prevalence, survival

Scientific investigator(s) (Contact)

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Organization	Faculté de Médecine

Collaborations

Participation in projects, networks and consortia	Yes
Details	European Network of Cancer Registries (ENCR), International Association of Cancer Registries (IACR) and compliance with operating rules established by the International Agency for

	Research on Cancer (IARC). French Network of Cancer Registries (FRANCIM Network) and collaboration with the French Institute for Public Health Surveillance (InVS) and National Cancer Institute (INCA), as part of the national cancer surveillance programme.

Funding

Funding status	Public
Details	InVS

Governance of the database

Sponsor(s) or organisation(s) responsible	Faculté de Médecine Starsbourg
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects meeting the required inclusion criteria. Several sources were used: - Anatomical pathology laboratories - university hospital centre - CLCC - European cancer treatment centres - hospital - private clinics - health insurance fund.

Database objective

Main objective	- Registry objectives regarding public health: The registry was created in 1974 with two main aims: 1. To create a useful tool for epidemiological research and evaluation, modelled on tools established in various other countries; 2. To verify morbidity data of the unfavourable situation in Alsace with regards to high cancer mortality. The Bas-Rhin cancer registry is responsible for estimating cancer incidence, prevalence and survival. The registry also aims to participate in national and international studies in these areas: comparing incidence rates to locate different geographical regions and compare them in a database; to develop existing work to identify factors that

	explain variations in cancer incidence, prevalence and survival. The cancer registry is also a tool for assessing the effectiveness of preventive measures, especially screening campaigns throughout the département for breast cancer since 1989, cervical and colon cancer since 1994 and colon and rectal cancer since 2008. As such, the trend in incidence rate can be monitored and the proportion of false negatives can be documented. - Registry research objectives: The registry is developing research in the field of estimating cancer incidence in geographical areas with no registry, as well as estimating survival through relative survival and healing models in order to obtain the best "current" survival estimates.
Inclusion criteria	All diagnosed malignant or primitive in situ tumours are registered for subjects residing in the Bas-Rhin département at the time of diagnosis, regardless of their treatment location. Benign and intermediate malignant tumours in the bladder and central nervous system are also registered. Basocellular skin tumours are excluded. Multiple tumours in the same subject are registered, regardless if they occur simultaneously in paired organs or sub-locations of the same organ.

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	Alsace Champagne-Ardenne Lorraine
Detail of the geography area	Bas-Rhin département (67).

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	1975

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1975-2004: 122,617 reported 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.
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	Consultation of files or clinical records on-site or electronically.
Participant monitoring	Yes
Details on monitoring of participants	- Vital status - a sample follow-up is carried out. Organised as part of the "high resolution" studies conducted by the FRANCIM network, where the objective is to study the development of cases (recurrence, metastases, complications) and treatment based on one or two large anatomical localisations per year with an average rotation period of five years.
Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI

Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed?term

Access

Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only