- Registry of general cancers in Lille and its periphery

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Last update : 01/23/2015 | Version : 1 | ID : 222

General

Identification

Detailed name	Registry of general cancers in Lille and its periphery
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	905196

General Aspects

Medical area	Cancer research
Health determinants	Geography
Others (details)	cancers
Keywords	descriptive epidemiology; incidence

Scientific investigator(s) (Contact)

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Organization	Centre de référence régional en

Collaborations

Funding

Funding status	Mixed
Details	InVS, INCA, ARS Nord Pas de Calais, Conseil régional Nord Pas de Calais, Ligue contre le cancer

	(Nord)

Governance of the database

Sponsor(s) or organisation(s) responsible	Centre de référence régional en cancérologie
Organisation status	Private

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 to identify cases: - Hospital pathological anatomy laboratories (no participation of private-practicing anatomocytopathologists) - Medical information departments (medicine/surgery/obstetrics departments) - Health Insurance Departments - Private radiotherapy centers - Molecular biology, hematology, cytogenetics laboratories - Registries of cancers in children - Clinical departments - Attending physicians - Multidisciplinary consultation meetings

Database objective

Main objective	Objectives of the registry in terms of public health (surveillance, evaluation) - Produce local statistics for institutions, particularly decision-makers, researchers, associations and the general public, for describing the trends over time of the incidence of cancers and their geographical distribution - with a view to planning and monitoring the efficacy of treatment (prevalence, survival), for the investigation of

	clusters. - Participate in producing national, regional (Francim) and international (IARC) statistics on cancer: incidence, prevalence and survival. - Evaluate the impact of public health measures (organized screening programs, regional health programs). Objectives of the registry in terms of research - Evaluate medical practices and patient treatment through specific studies conducted from exhaustive and non-biased data produced by the registry (high-resolution studies). - Develop etiological studies, particularly on professional and environmental determining factors of cancer. - Develop studies on the socioeconomic and clinical determining factors of the treatment and survival of cancer patients.
Inclusion criteria	Tumors diagnosed from January 1st 2005 in adults over the age of 15, living in the area around Lille: - invasive cancers except hematological tumors (except lymphomas included) - in situ of the colon-rectum, breast, cervix, melanoma, thyroid - borderline tumors of the ovaries - benign tumors or tumors of unpredictable progression for tumors of the bladder and central nervous system, Tumors diagnosed from January 1st 2006: extended to children under the age of 15 and to hematological malignancies

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	Local
French regions covered by the database	Nord - Pas-de-Calais Picardie
Detail of the geography area	Zone of use: area around Lille

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2005
Date of last collection (YYYY or MM/YYYY)	2008

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	environ 4000 cas incidents de cancers par an selon la définition de patients retenue. Le nombre de cas par sexe et topographie de cancer est disponible sur le site Internet du registre : www.registrecancers59.fr Around 4,000 incident cases of cancer per year according to the selected definition of patients. The number of cases per gender and topography of cancer is available on the registry's website: www.registrecancers59.fr

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)	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 collection: - Automated extraction of anatomocytopathology reports from anatomocytopathology laboratories - Extraction from PMSI hospital databases - Extraction from health insurance databases - Data transfer by encrypted files - Consultation of medical records by registry enquirers
Participant monitoring	Yes
Details on monitoring of participants	- Vital status, death, date of last news - Sample-based active follow-up is carried out (High-Resolution Francim surveys). - Passive follow-up is carried out using information from the Registry
Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI, ALD (accord cnil)

Promotion and access

Promotion

Link to the document	http://www.registrecancers59.fr
Link to the document	http://www.registrecancers59.fr/index.php?option

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. Local documents can be downloaded on the registry's website. The data recorded in the Registry may be used for specific research. A charter defining the cooperation procedure can be downloaded on the registry's website.
Access to aggregated data	Free access
Access to individual data	Access on specific project only