

- Registry of general cancers in Lille and its periphery

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Général

Identification

Nom détaillé	Registry of general cancers in Lille and its periphery
Numéro d'enregistrement (ID-RCB ou EUDRACT, CNIL, CPP, etc.)	905196

Thématiques générales

Domaine médical	Cancer research
Déterminants de santé	Geography
Autres, précisions	cancers
Mots-clés	descriptive epidemiology; incidence

Responsable(s) scientifique(s)

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Organisme	Centre de référence régional en

Collaborations

Financements

Financements	Mixed
Précisions	InVS, INCA, ARS Nord Pas de Calais, Conseil régional Nord Pas de Calais, Ligue contre le cancer (Nord)

Gouvernance de la base de

données	
Organisation(s) responsable(s) ou promoteur	Centre de référence régional en cancérologie
Statut de l'organisation	Secteur Privé
Contact(s) supplémentaire(s)	
Caractéristiques	
Type de base de données	
Type de base de données	Morbidity registers
Origine du recrutement des participants	A selection of health institutions and services
Le recrutement dans la base de données s'effectue dans le cadre d'une étude interventionnelle	No
Informations complémentaires concernant la constitution de l'échantillon	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
Objectif de la base de données	
Objectif principal	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.

Critères d'inclusion

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

Type de population

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 concernée

Sick population

Sexe

Male
 Woman

Champ géographique	Local
Régions concernées par la base de données	Nord - Pas-de-Calais Picardie
Détail du champ géographique	Zone of use: area around Lille
Collecte	
Dates	
Année du premier recueil	2005
Année du dernier recueil	2008
Taille de la base de données	
Taille de la base de données (en nombre d'individus)	[1000-10 000[individuals
Détail du nombre d'individus	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
Données	
Activité de la base	Current data collection
Type de données recueillies	Clinical data Paraclinical data Biological data Administrative data
Données cliniques, précisions	Direct physical measures
Données paracliniques, précisions	Any additional examination providing information for tumor coding
Données biologiques, précisions	Any additional examination providing information for tumor coding
Données administratives, précisions	Identification data (Last name, first name, date of birth, town of birth, address)
Existence d'une bibliothèque	No

Modalités

Mode de recueil des données	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
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Suivi des participants	Yes
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Détail du suivi	- 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
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Appariement avec des sources administratives	Yes
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Sources administratives appariées, précisions	PMSI, ALD (accord cnil)
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Valorisation et accès

Valorisation et accès

Lien vers le document	http://www.registrecancers59.fr
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Lien vers le document	http://www.registrecancers59.fr/index.php?option
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Accès

Charte d'accès aux données (convention de mise à disposition, format de données et délais de mise à disposition)	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.
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Accès aux données agrégées	Free access
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Accès aux données individuelles	Access on specific project only
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