

ARER 68 - HAUT-RHIN CANCER REGISTRY

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General	
Identification	
Detailed name	HAUT-RHIN CANCER REGISTRY
Sign or acronym	ARER 68
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	999344
General Aspects	
Medical area	Cancer research
Health determinants	Addictions Climate Genetic Geography Iatrogenic Intoxication Nutrition Occupation Pollution Social and psychosocial factors
Others (details)	Cancers
Keywords	Cancer, incidence
Scientific investigator(s) (Contact)	
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Organization	Centre hospitalier de
Collaborations	
Funding	
Funding status	Mixed
Details	INCa (Institut National Du Cancer), INVS (Institut de veille sanitaire), Conseil général du Haut-Rhin, Comité départemental du Haut-Rhin de la Ligue contre le cancer, Ville de Mulhouse, Ville de Colmar.
Governance of the database	
Sponsor(s) or organisation(s) responsible	Association pour la recherche épidémiologique par les registres dans le Haut-Rhin (ARER 68)
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.	Comprehensive collection of new cases. Sources first explored are referred to as primary sources. These sources allow the identification of cases. Foremost among these primary sources are services, offices or laboratories dedicated to pathological anatomy and cytology, public or independent practitioners, from the département, from neighbouring départements and certain sites specifically dedicated to cancerous pathology. Other primary sources are represented by radiography, oncology or paediatric services, haematology laboratories, health examination clinics and medical archive services. Medical information departments and healthcare institutions are progressively becoming an important primary resource since 1995. Data collected are systematically checked, supplemented or modified from secondary sources, either directly on site or by written

request. Principally concerning public and private sector hospital services, as well as independent, general or specialist treating physicians from or outside the département.

Database objective

Main objective To identify all new cancer cases occurring among Haut-Rhin inhabitants, including those diagnosed and treated elsewhere.

Inclusion criteria The Haut-Rhin cancer registry includes all patients with a tumour that meet the criteria outlined below and who are residing in Haut-Rhin at the time of diagnosis. Tumours included: - malignant and invasive tumours during first identification of primary site or, alternatively, during identification of unknown primary site with metastases (the primary site declared as "uncertain" in this case), - benign intracranial tumours since 1991 are also recorded:- baso-cellular skin carcinoma, - non-invasive in situ or intraepithelial malignant tumours, no previous appearance of invasive tumour of the same histological type and site for the same subject, - non-invasive bladder tumours. However, calculations do not take into account the incidence of invasive malignancies. To compare data with registries that do not collect baso-cellular skin carcinomas, the incidence of double presentation of invasive skin tumours: excluding baso-cellular skin carcinoma and, separately, with baso-cellular skin carcinoma.

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	Haut-Rhin
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	1982
Date of last collection (YYYY or MM/YYYY)	2010
Size of the database	
Size of the database (number of individuals)	Greater than 20 000 individuals
Details of the number of individuals	110 000
Data	
Database activity	Current data collection
Type of data collected	Clinical data Administrative data
Clinical data (detail)	Direct physical measures
Administrative data (detail)	Identity, age and address at time of diagnosis
Presence of a biobank	No
Health parameters studied	Health event/morbidity
Procedures	
Data collection method	Cases are identified by epidemiological record which includes: date of onset of cancer, anatomical site, histological type, diagnosis conditions, initial assessment of extension, the existence of a known prior cancer, identification of site of diagnosis, information sources, vital status information.
Classifications used	CIM-0-3, CIM-10
Participant monitoring	No
Links to administrative sources	No

Promotion and access

Promotion

Access

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

Publications. Access conditions to be defined

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only