EPIC-PL - Loire-Atlantique/Vendée cancer registry (registre qualifié)

Head :Molinié Florence

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General

Identification

Detailed name	Loire-Atlantique/Vendée cancer registry (registre qualifié)
Sign or acronym	EPIC-PL
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	900234

General Aspects

Medical area	Cancer research
Health determinants	Geography Healthcare system and access to health care services Social and psychosocial factors

Scientific investigator(s) (Contact)

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Surname	Florence
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Organization	Loire-Atlantique et Vendée Cancer Registry

Collaborations

Participation in projects, networks and consortia	Yes

Details	Francim network, Grell network, European network of cancer registries, inernational association of cancer registries
Others	EUROCARE, CONCORD, HIGHCARE, SUDCAN studies

Funding

Funding status	Mixed
Details	Financial support of the registry come from SantéPublique France, INCa, Conseil Régional des Pays de la Loire, ARS Pays de la Loire, Ligue contre le Cancer de Loire-Atlantique et Vendée, CHD de La Roche sur Yon.

Governance of the database

Sponsor(s) or organisation(s) responsible	Association EPIC-PL
Organisation status	Private

Additional contact

Main features

Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects having the required inclusion criteria (see below). Several sources are used to identify cases: - Anatomopathology laboratories - Hematological cytology laboratories - Medical information departments - Health Insurance Funds - Private-practicing and hospital physicians - Management structure of organized breast cancer screening - National registry of solid tumors in children, registry of hematological malignancies in children - specific cancer medical record (summary)

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 monitoring the cancer risk and of conducting research on cancer.

	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. - Evaluate primary and secondary prevention initiatives (organized cancer screening), patient treatment and healthcare needs in the general population. The EPIC-PL undertakes a wide range of projects in liaison with local and national partners. The main themes are: evaluation of treatment practices and research on social inequalities Only a population based registry provides precise and exhaustive information on cancer incidence in the context of the French healthcare system. It is also necessary for evaluating the effectiveness of prevention and screening programs as well as cancer care streams in the general population - with no selection bias.
Inclusion criteria	All primitive invasive malignant tumors diagnosed in people living in these two départements at the time of diagnosis, irrespective of their treatment location. The following are also recorded: - in situ breast cancers, cervix cancers, colorectal cancers and in situ melanomas - non-invasive tumors of the urinary tract and central nervous system and borderline tumors of the ovary. The following are not recorded: - stratum basale skin cancers (only recorded in the Vendée from 1997 to 1999)
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
Pathology	II - Neoplasms

Gender	Male Woman
Geography area	Departmental
French regions covered by the database	Pays de la Loire
Detail of the geography area	Loire-Atlantique and Vendée

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	1991
Date of last collection (YYYY or MM/YYYY)	2015

Size of the database

Size of the database (number of individuals)	Greater than 20 000 individuals
Details of the number of individuals	>150 000 in 2017

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
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	Active or passive collection (CNIL authorization), depending on source:- Systematic requests for anatomocytopathology reports- Annual systematic requests for PMSI files (Standardized selection procedure) or lists comprising more items, such as the Permanent Cancer Survey conducted by the cancer prevention centers - Annual systematic requests for files of patients diagnosed with one of the chronic diseases from the ALD 30 list.- Spontaneous passive declaration and active reminder posted to physicians- Active search for regular complementary information in medical records.
Classifications used	ICD-O -3
Participant monitoring	Yes
Details on monitoring of participants	Cases are followed up at regular intervals with the following information gathered:- Date of last news - Vital status at last news
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://www.santepaysdelaloire.com/registre-des-cancers/articles/publications-scientifiques
Description	publications listed on the registry website
Link to the document	https://www.ncbi.nlm.nih.gov/pubmed/?term=molinie+f
Description	pubmed publications

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). Regional documents can be downloaded on the registry's website. 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