- General Registry on Cancer in the Poitou-Charentes Region (Certified 2013-2015 Registry)

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Last update : 07/05/2016 | Version : 1 | ID : 200

General

Identification

Detailed name	General Registry on Cancer in the Poitou-Charentes Region (Certified 2013-2015 Registry)
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL 907303 (15/02/2008)

General Aspects

Medical area	Cancer research
Keywords	region, registry, public health

Scientific investigator(s) (Contact)

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Unit	Cancer Epidemiology Unit
Organization	Faculty of Medicine and Pharmacy at Poitiers Teaching Department

Collaborations

Funding

Funding status	Public
Details	InCA

Governance of the database

Sponsor(s) or organisation(s) responsible	Faculté de Médecine et de Pharmacie de Poitiers
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Subjects who met the required enrolment criteria were selected. Cases are recorded by cross-referencing several identification sources. All heads of the anatomic cytopathology (ACP) laboratory or Health Insurance Fund (AMA) were identified. Those in charge of the Medical Information Departments (MIDs) were informed through regular meetings held at CoRIM (Regional College of Medical Information). An approval request was sent to the directors of each public or private healthcare establishment in the region. Emphasis was placed on the management of computer platforms and on editing, validating and implementing collection, verification and recording procedures for cases. Data are submitted to cancer registries every six months in encrypted electronic format (PGP double-encryption software). Data are aggregated at each new submission for that year to account for possible changes involving one or more records from previous submissions.

Database objective

Main objective	Register aims in terms of public healthcare (monitoring, assessment): The aim of the register is to provide benchmarks for describing the dynamics of cancer progression (distribution, progression and impact of the disease according to the geography and demographics of the population) and to become involved in the evaluation of screening and prevention (by assessing the effectiveness of the programmes in place) and care assessment (analysing treatment paths used by patients; factors that determine diagnostic care management and distribution of good practice recommendations). It shall play a specialist role in aiding the assessment of public policies by the Regional Health Agency (ARS), in

	collaboration with other regional organisations (Poitou-Charentes Cancer Network, Regional Health Observatory and screening facilities). It shall participate in producing national (FRANCIM) and international (IARC) statistics. Register aims in terms of research: Two research areas are preferred for continuing research conducted by the Public Health Team in Poitiers. 1) Assessing factors that affect access to screening facilities (access to screening facilities for sibship-based index cases) and assessing factors affecting access to care (patient satisfaction; access to technical surgical platforms and waiting periods for radiotherapy). 2) Automated classification of textual information contained in electronic anatomic pathology and cytopathology reports (collaboration with University of Rennes 1).
Inclusion criteria	All cases of malignant invasive tumours (haematologic malignancies and solid tumours excluding basal cell carcinoma of the skin); in situ tumours; borderline ovarian tumours; as well as benign tumours or tumours with unpredictable progression in the brain and bladder. Advanced colorectal adenomas will be passively recorded.
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	Regional
French regions covered by the database	Aquitaine Limousin Poitou-Charentes
Detail of the geography area	Poitou-Charentes region, i.e. four departments: 16 Charente; 17 Charente-Maritime; 79 Deux-Sèvres and 86 Vienne.

Data collection

Dates

Date of first 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	3,323 invasive cancers/217 in situ carcinomas

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

Procedures

Data collection method	Encrypted data collection (active or passive) for eligible cases in anatomic pathology and cytopathology facilities; medical information departments within healthcare establishments (PMSI); national health insurance medical services (ALD). Data collection (active) from records within the Poitou-Charentes Cancer Treatment Network. Active collection (return to medical record) within healthcare establishments (clinical or archiving departments). Collection to identify extra-regional data breaches and to check completeness of data from the regional PMSI base. Passive encrypted data collection from cases recorded by the permanent cancer survey (EPC).
Participant monitoring	Yes
Details on monitoring of participants	Continuous or 1 to 2 times per year depending on sources.

Links to administrative sources	Yes
Linked administrative sources (detail)	PMSI (Medical Information System Programme)
Promotion and access	
Promotion	
Link to the document	http://tinyurl.com/PUBMED-PCCR
Link to the document	http://tinyurl.com/HAL-PCCR
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