

# - Somme Cancer Registry (Certified Registry 2013-2016)

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## General

### Identification

Detailed name Somme Cancer Registry (Certified Registry 2013-2016)

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation 998066

### General Aspects

Medical area Cancer research

Pathology (details) epidemiology

Keywords incidence, survival

### Scientific investigator(s) (Contact)

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## Collaborations

## Funding

Funding status	Public
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Details	INCa and INVS. Participation in project funding from the regional committee of the French League against Cancer in Amiens. Logistical and financial support from Amiens University Hospital Centre (UHC). The Regional
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## Governance of the database

Sponsor(s) or organisation(s) responsible	CHU d'Amiens
Organisation status	Public

## Additional contact

## Main features

## Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects meeting inclusion criteria. Several sources are used to identify cases :1) Anatomopathology (ACP) laboratories 2) Permanent cancer survey, or PMSI database, of cancer prevention centres- Gustave Roussy Institute - Curie Institute - René Huguenin Centre - Oscar Lambret Centre - Jean Godinot Institute - Centre Henri Becquere l3) PMSI data; Somme: Amiens University Hospital Centre (UHC), hospitals, clinics; Outside of the Somme: Lille, Rouen and Reims UHCs, general hospitals, hospitals and clinics; Paris and Parisian region: APHP (Parisian region hospital) and clinics 4) Mutualist institutes 5) Private radiotherapy centers 6) Health insurance funds 7) Multidisciplinary consultation meetings for health institutions in Picardy 8) Cancer screening facilities Somme (ADEMA 80) 9) Thoracic surgeons and pneumologists.

### Main objective

Objectives of the registry in terms of public health (surveillance, evaluation):

1) Via an active and exhaustive listing of cases, a registry's main objective is to produce data enabling the calculation of indicators for monitoring the health of populations (incidence, survival and prevalence);

2) Such data is also made available to institutions - particularly decision-makers and local partners - to provide the département and Region with the necessary cancer-related expertise, by participating in various bodies (Regional Technical Committee for Oncology, Screening Committee, Regional Oncology Network ONCOPIC, etc.). The Registry takes part in cooperative research conducted via the FRANCIM and EUROCARE networks aimed at assessing medical practices within the population and disseminating recommendations;

3) The registry is also a tool for evaluating the efficacy of the screening campaigns organised in the département since 1990 for breast cancer and 2007 for colorectal cancer. It keeps track of incidence rate trends, the proportion of false negatives and interval cancers.

Objectives of the registry in terms of research:

1) Evaluate the impact of public healthcare measurements (organised screening programmes, regional health programmes, etc.);

2) Evaluate medical practices in the context of specific studies (high-resolution studies);

3) Develop research on the socioeconomic determining factors of survival and behaviour in cancer patients (e.g. the North-West canceropole VADS study underway, or planned breast cancer study in the Somme département) for a clearer understanding of the particularly marked disparities in healthcare access or use in the Somme département and to pinpoint the differences - from the city of Amiens' large IRIS zones (grouped areas for statistical information) - in incidence and types of cancer through work carried out jointly with the city of Amiens and the Regional Health Observatory (ORS);

4) Examine the issue of finding work again after cancer through the research theme of the canceropole care, reimbursement and survival of cancer patients;

5) Develop molecular epidemiology research within Young Team 2530 on breast cancer (Role of ion channels, hormones and growth factors in breast cancer);

6) Ongoing distance survey into the quality of life of people suffering from prostate cancer, diagnosed in 2001, QALIPRO.

Inclusion criteria	All primitive in situ or malignant tumors in anyone living in the Somme département at the time of diagnosis, irrespective of where they are receiving treatment, are recorded. Moreover, non-invasive bladder tumours are systematically recorded, as well as benign tumours and tumours of intermediate malignancy of the central nervous system, and borderline tumours of the ovary. Basocellular skin carcinoma are excluded. Multiple tumours in the same subject are recorded, even if they occur simultaneously in paired organs or sub-locations of the same organ.
<b>Population type</b>	
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	Nord - Pas-de-Calais Picardie
Detail of the geography area	Somme département.
<b>Data collection</b>	
<b>Dates</b>	
Date of first collection (YYYY or MM/YYYY)	1982
<b>Size of the database</b>	
Size of the database (number of individuals)	Greater than 20 000 individuals

Details of the number of individuals	1982- 2008: 58,511 separate patients and 63,400 invasive tumours recorded by incidence (ENCR regulations and values on 01 January 2011).
<b>Data</b>	
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)	cytological and pathological anatomy report.
Biological data (detail)	PSA, complete blood count.
Administrative data (detail)	Identification data, information on information sources used.
Presence of a biobank	No
Health parameters studied	Health event/morbidity
<b>Procedures</b>	
Data collection method	Request by email (encrypted information), post or telephone for electronic or paper nominative lists; then on-site consultation in medical record care centres and, depending on the case, referral to the physicians involved in treatment. Cooperation with municipal registry offices for monitoring vital status
Participant monitoring	Yes
Details on monitoring of participants	- Vital status for survival studies. A sample is monitored during studies on the progression of cases (relapses, metastasis, complications) as is their treatment, so-called "high-resolution" studies conducted in liaison with the Francim network of registries. This research concerns about one to two anatomical locations per year
Links to administrative sources	Yes
Linked administrative sources (detail)	Medical-administrative (PMSI, health insurance) or administrative (RNIPP) databases.
<b>Promotion and access</b>	

## Promotion

Link to the document

<http://www.ncbi.nlm.nih.gov/pubmed?term>

## Access

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

Contact the person in charge of the registry, submit protocol or describe the project and its objectives.  
The data communicated by the registry is anonymous.

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only