

- Digestive cancers registry of Burgundy

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General

Identification

Detailed name	Digestive cancers registry of Burgundy
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	998024

General Aspects

Medical area	Cancer research
Health determinants	Geography
Others (details)	digestive cancers
Keywords	care practice, trends, digestive cancers, epidemiology, public health, survival

Scientific investigator(s) (Contact)

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Unit	Centre de Recherche INSERM U866
Organization	CHU

Collaborations

Funding

Funding status	Public
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Details	The National Public Health Institute (InVS) and the National Cancer Institute (INCa)
Governance of the database	
Sponsor(s) or organisation(s) responsible	University Hospital Dijon
Organisation status	Public
Sponsor(s) or organisation(s) responsible	University of Burgundy
Organisation status	Public
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.	<p>Selection of subjects having the required inclusion criteria.</p> <p>Several sources are used to identify cases:</p> <ul style="list-style-type: none"> - Pathological cytology and anatomy laboratories - Private or public physicians - Screening organization structures - Death certificates - The ALD 30 file (concerning the list of 30 chronic diseases eligible for full cover) - files from the PMSIs (French diagnosis-related group databases) of the départements' healthcare institutions. - medical records
Database objective	
Main objective	<p>Objectives of the registry in terms of public health (surveillance, evaluation):</p> <ol style="list-style-type: none"> 1) determine the main health indicators: Incidence, Prevalence, Survival and their change over time. 2) evaluate medical practices, paying particular

attention to elderly subjects, and the trends concerning

healthcare quality indicators.

- Objectives of the registry in terms of research:

1) determination of at-risk groups and epidemiology of pre-cancerous lesions

2) study of quality of life at population level

3) development of new methodological approaches for survival analysis

4) biological epidemiology through the creation of a population-based tumor bank based to evaluate molecular prognostic markers

5) development of new immunological tests looking for colorectal screening, protein signature

6) medico-economic analysis: cost of colorectal cancer, cost-effectiveness analysis of screening strategies.

Inclusion criteria

Malignant and invasive primary digestive tumors and
Malignant non-invasive tumors, called in situ or intra-epithelial, when no
invasive tumor of the same histological type or location has previously appeared in the same subject. Incidence calculations only take account of invasive malignant tumors.

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

General population

Gender

Male
Woman

Geography area

Departmental

French regions covered by the database

Bourgogne Franche-Comté

Detail of the geography area

Burgundy region: Côte d'Or and Saône-et-Loire administrative areas ('départements')

Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 1976

Size of the database

Size of the database (number of individuals) Greater than 20 000 individuals

Details of the number of individuals 1976- 2008: 37 500 cas/cases

Data

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) diagnostic assessment, patterns of care

Biological data (detail) methodological coordination of a tumor bank gathering tissue samples of colorectal adenocarcinoma resections in the Côte d'Or département

Administrative data (detail) Identification data

Presence of a biobank Yes

Contents of biobank Tissues

Details of biobank content for resected colorectal cancers

Health parameters studied
Health event/morbidity
Health event/mortality

Procedures

Data collection method active: the registry itself seeks out information from different sources.

Classifications used international nomenclatures

Participant monitoring Yes

Details on monitoring of participants

Vital status - Active follow-up of colorectal cancers is carried out systematically in search of a progressive recurrence (locregional recurrence or distant metastasis) or second cancer is recorded. Given that over 80% of these recurring cancers arise in the first three years, follow-up is conducted individually every n+3 years after diagnosis, and n+5 years for resection patients for curative purposes.

Links to administrative sources

Yes

Linked administrative sources (detail)

RNIPP

Promotion and access

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)

exploitation and dissemination of data by scientific publications and oral communication

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only