- Digestive cancers registry of Burgundy

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Last update : 11/29/2012 | Version : 1 | ID : 217

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

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.	Selection of subjects having the required inclusion criteria. Several sources are used to identify cases: - 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	Objectives of the registry in terms of public health (surveillance, evaluation): 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 ('departements')

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 (locoregional 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