

- Doubs and Territoire de Belfort primitive malignant tumors register

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Général

Identification

| | |
|--|---|
| Nom détaillé | Doubs and Territoire de Belfort primitive malignant tumors register |
| Numéro d'enregistrement (ID-RCB ou EUDRACT, CNIL, CPP, etc.) | 903417 |

Thématiques générales

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|--------------------|---|
| Domaine médical | Cancer research |
| Autres, précisions | cancer |
| Mots-clés | tumor, collection, cancer diagnoses, cancer risk, surveys |

Responsable(s) scientifique(s)

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| Organisme | Registre des tumeurs du Doubs et du Territoire de |

Collaborations

Financements

| | |
|--------------|--------|
| Financements | Public |
|--------------|--------|

| | |
|------------|---|
| Précisions | Le registre est financé par l'InVS, l'INCa, le CHU de Besançon et l'ARS de Franche-Comté. D'autres financements ponctuels interviennent sur projets (Ligue contre le cancer ...). |
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Gouvernance de la base de données

Organisation(s) responsable(s) ou promoteur CHU de Besançon

Statut de l'organisation Secteur Public

Contact(s) supplémentaire(s)

Caractéristiques

Type de base de données

Type de base de données Morbidity registers

Origine du recrutement des participants A selection of health institutions and services

Le recrutement dans la base de données s'effectue dans le cadre d'une étude interventionnelle No

Informations complémentaires concernant la constitution de l'échantillon Selection of subjects having the required inclusion criteria.
Several sources are used:
- Anatomopathology laboratories
- Hematological cytology laboratories
- Genetic departments of training hospitals
- Medical information departments
- Health Insurance Funds
- Private-practicing and hospital clinicians (+ GPs when necessary)
- Summaries of Multidisciplinary Consultation Meetings (RCPs)
- Organized screening structure
- Haut-Rhin and Bas-Rhin Registry
- National Registry of Hematological Diseases in children
- Registry of Solid Tumors in children

Objectif de la base de données

Objectif principal 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 describing and monitoring the cancer risk and conducting research from the analysis of data gathered or specific surveys.
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. - Help to evaluate primary and secondary prevention initiatives (organized cancer screening), patient treatment and healthcare needs in the general population.

Critères d'inclusion

All primitive malignant tumors diagnosed in patients living, at the time of diagnosis, in the Doubs or Territoire-de-Belfort départements, irrespective of where they are treated, are recorded - including stratum basale skin carcinomas (specific to the Doubs Registry). In situ primitive tumors of the breast, colon-rectum, cervix, bladder and excretory ducts, as well as in situ melanomas. Benign tumors and tumors of intermediate malignancy of the central nervous system and bladder are also recorded, as are borderline tumors of the ovary.

Type de population

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 concernée

Sick population

Sexe

Male
Woman

Champ géographique

Departmental

Régions concernées par la base de données

Bourgogne Franche-Comté

Détail du champ géographique

Doubs (25) and Territoire de Belfort (90)

Collecte

Dates

Année du premier recueil

1978

Année du dernier recueil

2008

Taille de la base de données

Taille de la base de données (en nombre d'individus) Greater than 20 000 individuals

Détail du nombre d'individus 1978-2008: 79100 / Doubs 2007-2008: 2312 / Territoire de Belfort

Données

Activité de la base Data collection completed

Type de données recueillies
Clinical data
Paraclinical data
Biological data
Administrative data

Données cliniques, précisions Direct physical measures

Données paracliniques, précisions Any additional examination providing information for tumor coding

Données biologiques, précisions Any additional examination providing information for tumor coding

Données administratives, précisions Identification data (Last name, first name, date of birth, town of birth, address)

Existence d'une bibliothèque No

Paramètres de santé étudiés
Health event/morbidity
Health event/mortality

Modalités

Mode de recueil des données Active or passive collection (CNIL authorization): - Receipt of anatomopathological and cytological reports, lists of hospital stays (PMSI) and chronic disease diagnoses with regard to health insurance reimbursement. Lists by encrypted electronic dispatch. - Active search for regular complementary information in medical records

Suivi des participants Yes

Détail du suivi Vital status, death, date of last news - Sample-based follow-up is carried out (High-Resolution Francim surveys). - Passive follow-up is carried out using information from the Registry (anatomocytology reports).

Appariement avec des sources administratives Yes

Sources administratives
appariées, précisions

PMSI, Chronic disease lists, Organized screening
structure (CNIL authorization)

Valorisation et accès

Valorisation et accès

Accès

Charte d'accès aux données
(convention de mise à
disposition, format de données
et délais de mise à disposition)

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"").

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.

Accès aux données agrégées

Free access

Accès aux données individuelles

Access on specific project only