- ISERE CANCER REGISTER

Head: Colonna Marc

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Identification

Detailed name ISERE CANCER REGISTER

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL 982002

General Aspects

Medical area Cancer research

Others (details) cancers

Keywords public health, surveillance, evaluation, monitoring,

indicators, incidence, prevalence, survival

Scientific investigator(s)

(Contact)

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Organization Association du Registre du Cancer de

Collaborations

Funding

Funding status Public

Details Institut de Veille Sanitaire, Institut National du

Cancer, Conseil Général de l'Isère, Contrats d'étude

| Governance of the database | |
|--|--|
| Sponsor(s) or organisation(s) responsible | Association du Registre du cancer de l'Isère |
| Organisation status | Private |
| 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: - Anatomopathology laboratories - Hematology laboratories - Immunology laboratories - Clinics - Hospitals - Medical information departments (DIMs) - Cancer Prevention Center departments - Oncology network - Multidisciplinary consultation - Health insurance funds - Département-level departments for health and social affairs (DDASS) |
| Database objective | |
| Main objective | Objectives of the registry in terms of public health (surveillance, evaluation) - The main objective of the registry is to contribute to epidemiological monitoring of cancers by producing the conventional indicators for descriptive epidemiology (incidence, prevalence and survival) from an active and exhaustive recording of cancer cases. - The production of these different indicators helps to set up or improve public health initiatives pertaining to cancer - Lastly, the registry helps to evaluate treatment practices by describing the stage at the time of |

diagnosis and the initial treatment within a general population on the basis of representative samples. Objectives of the registry in terms of research The Isère cancer registry has made descriptive epidemiology one of its research priorities through a variety of themes:

- Methodological development for making national, regional and more recently département-level estimations of cancer incidence.
- Methodological development for estimations of cancer prevalence at different geographical levels.
- Geographical epidemiology research for several years now, particularly with the production of cancer atlases and participation in environmental epidemiology research.
- Analysis of the temporal incidence trends of certain cancer locations: breast cancer in young women, thyroid cancer, prostate cancer.

 Another research focus concerns organized cancer screening

Inclusion criteria

database

All malignant tumors diagnosed in patients living in the Isère département - irrespective of whether the diagnosis is made in this département, neighboring départements or other regions. This concerns invasive and in situ malignant tumors. Benign tumors and tumors of intermediate malignancy of the bladder and central nervous system are also recorded. Statistics concerning the incidence of stratum basale type skin tumors are excluded.

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 Departmental French regions covered by the Auvergne Rhône-Alpes

| Detail of the geography area | Isère |
|--|---|
| Data collection | |
| Dates | |
| Date of first collection (YYYY or MM/YYYY) | 1979 |
| Size of the database | |
| Size of the database (number of individuals) | Greater than 20 000 individuals |
| Details of the number of individuals | 109107 |
| 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 | Collection of reports, lists and electronic files |
| Participant monitoring | Yes |
| Details on monitoring of participants | vital status Sample-based follow-up is carried out (High-Resolution FRANCIM survey) |
| Links to administrative sources | Yes |
| Linked administrative sources (detail) | PMSI, ALD |
| Promotion and access | |
| Promotion | |
| Link to the document | http://www.ncbi.nlm.nih.gov/pubmed?term |

| Access | | |
|------------|---|--|
| for data p | lata access (charter rovision, format of ability delay) | Access to results: Registry Bulletin, articles published for specific studies Access to data: Aggregate data accessible by request |
| Access to | aggregated data | Access on specific project only |
| Access to | individual data | Access on specific project only |