# BCB sarcomes - Clinical biological database of the Sarcoma network

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| General  |  |
| Identification   |  |
| Detailed name  | Clinical biological database of the Sarcoma network  |
| Sign or acronym  | BCB sarcomes   |
| CNIL registration number,<br>number and date of CPP<br>agreement, AFSSAPS (French<br>Health Products Safety Agency)<br>authorisation | RRePS/Netsarc favourable opinion in September 2010 and authorisation of the CNIL under number 910390 in September 2010 |
| General Aspects  |  |
| Medical area   | Cancer research  |
| Pathology (details)  | GIST sarcoma and desmoid tumours   |
| Health determinants  | Healthcare system and access to health care services<br>Others (specify)   |
| Others (details)   | Evaluation of the treatment, prognostic factors  |
| Keywords   | sarcomas, networks, expertise, epidemiological and clinical research   |
| Scientific investigator(s)<br>(Contact)  |  |
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## Collaborations

Participation in projects, networks and consortia

Yes

# **Funding**

Funding status Public

Details INCa

#### Governance of the database

Sponsor(s) or organisation(s)

responsible

Institut Bergonié pour le groupe français des sarcomes et tumeurs osseuses (GSF-GETO)

Organisation status Private

Presence of scientific or steering committees

Yes

Labelling and database

evaluation

INCa label

#### Additional contact

#### Main features

#### Type of database

Type of database Morbidity registers

| Additional information | regarding |
|------------------------|-----------|
| sample selection.      |           |

The current project is based on existing databases:

1. Conticabase and conticaGist: databases used for research (retrospective clinical research and biological research) and which serve as virtual tumour banks. The tumours (frozen tissue and tumours included in paraffin) are stored in the participating centres.

2. RRePS/NetSarc: networks of rare tumours and database that record potential cases treated in France since 01/01/2000, describing the medical practices for the clinical management of patients with sarcoma, GIST or desmoid tumours as well as the anatomopathological interpretation.

# Database objective

#### Main objective

The objective of the programme is to improve quality in the collection of samples and data, the design of new modules and tools, and improve interoperability to improve epidemiological, clinical, fundamental and translational research and medical practices in these pathologies.

Three areas of work have been defined:

- WP1: data collection and data management
- WP2: development of the clinico-biological sarcoma database
- WP3: communication.

#### Inclusion criteria

Patients with soft tissue and visceral sarcomas included in one of the existing databases: RRePS/NetSarc, Conticabase and ConticaGist

### 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

Pathology

C00-C75 - Malignant neoplasms, stated or presumed to be primary, of specified sites, except of lymphoid, haematopoietic and related tissue

Gender

Male Woman

| Geography area                               | National  |
|--|---|
| Detail of the geography area                 | The RRePS and NetSarc networks are each coordinated by three sites: Bergonié Cancer Institute in Bordeaux, the Centre Léon Bérard in Lyon and Institut Gustave Roussy in Villejuif and work in conjunction with regional expert centres throughout the country.   |
| Data collection                              |   |
| Dates  |   |
| Date of first collection (YYYY or MM/YYYY)   | 2010  |
| Date of last collection (YYYY or MM/YYYY)    | Collection in progress  |
| Size of the database                         |   |
| Size of the database (number of individuals) | Greater than 20 000 individuals   |
| Details of the number of individuals         | Conticabase and conticaGist contain data from approximately 13,000 patients and the RRePS database contains data from approximately 8,500 patients  |
| Data   |   |
| Database activity                            | Current data collection   |
| Type of data collected                       | Clinical data<br>Biological data<br>Administrative data   |
| Clinical data (detail)                       | Direct physical measures<br>Medical registration  |
| Details of collected clinical data           | Medical history, location and depth of the tumour, Data contained in the Multidisciplinary Consultation Meeting or in the patient's medical record: type of tumour, diagnosis and date, metastasis, imaging before surgery, initial biopsy, grade, date and establishment of surgery, quality of exeresis, local/metastatic recurrence, date of latest news, vital status, patient participation in a clinical trial, data on the sample (sampling date, reception, diagnosis, techniques used and stored material) |
| Biological data (detail)                     | data on the characteristics of the tumour   |

| Administrative data (detail)  | patient identity (initials), date of birth and sex,<br>geographical location, agreement or not of the<br>patient to use his/her tumour material for research   |
|---|--|
| Presence of a biobank   | Yes  |
| Contents of biobank   | Tissues  |
| Health parameters studied   | Health event/morbidity<br>Health event/mortality<br>Others   |
| Procedures  |  |
| Data collection method  | The data is collected by clinical researchers with dedicated time and via consultation meetings  |
| Quality procedure(s) used   | Database training for the different users. There is a quality procedure guide (control of duplicates, cases to be deleted, missing data, cases to be reviewed in third reading, consistency control between variables). External audits of the centres are carried out for the quality of the data |
| Participant monitoring  | Yes  |
| Monitoring procedures   | Monitoring by contact with the referring doctor  |
| Details on monitoring of participants   | occasional follow-up by specific scientific project  |
| Links to administrative sources   | No   |
| Promotion and access  |  |
| Promotion   |  |
| Access  |  |
| Presence of document that lists variables and coding procedures                             | Yes  |
| Terms of data access (charter<br>for data provision, format of<br>data, availability delay) | There are:  1/ A charter for the use of the websites and the shared database of the sarcoma RRePS and NetSarc reference networks  2/ A charter for conticanet: 'Definition of rules for access and use of data and materiel among CTCN partners'   |
| Access to aggregated data   | Access on specific project only  |
|   |  |

Access to individual data

Access on specific project only