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, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) 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 Others (specify)
Others (details)	Evaluation of the treatment, prognostic factors
Keywords	sarcomas, networks, expertise, epidemiological and clinical research

Scientific investigator(s) (Contact)

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Organization	Institut Bergonié

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 Biological data Administrative data
Clinical data (detail)	Direct physical measures 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, geographical location, agreement or not of the patient to use his/her tumour material for research
Presence of a biobank	Yes
Contents of biobank	Tissues
Health parameters studied	Health event/morbidity Health event/mortality 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 for data provision, format of 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