

BCB sarcomes - Clinical biological database of the Sarcoma network

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Général

Identification

Nom détaillé Clinical biological database of the Sarcoma network

Sigle ou acronyme BCB sarcomes

Numéro d'enregistrement (ID-RCB ou EUDRACT, CNIL, CPP, etc.) RRePS/Netsarc favourable opinion in September 2010 and authorisation of the CNIL under number 910390 in September 2010

Thématiques générales

Domaine médical Cancer research

Pathologie, précisions GIST sarcoma and desmoid tumours

Déterminants de santé Healthcare system and access to health care services
Others (specify)

Autres, précisions Evaluation of the treatment, prognostic factors

Mots-clés sarcomas, networks, expertise, epidemiological and clinical research

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Organisme	Institut Bergonié

Collaborations

Participation à des projets, des réseaux, des consortiums	Yes
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Financements

Financements	Public
Précisions	INCa

Gouvernance de la base de données

Organisation(s) responsable(s) ou promoteur	Institut Bergonié pour le groupe français des sarcomes et tumeurs osseuses (GSF-GETO)
Statut de l'organisation	Secteur Privé

Existence de comités scientifique ou de pilotage	Yes
Labellisations et évaluations de la base de données	INCa label

Contact(s) supplémentaire(s)

Caractéristiques

Type de base de données

Type de base de données	Morbidity registers
Informations complémentaires concernant la constitution de	The current project is based on existing databases: 1. Conticabase and conticaGist: databases used for

l'échantillon	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.
Objectif de la base de données	
Objectif principal	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.
Critères d'inclusion	Patients with soft tissue and visceral sarcomas included in one of the existing databases: RRePS/NetSarc, Conticabase and ConticaGist
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
Pathologie	C00-C75 - Malignant neoplasms, stated or presumed to be primary, of specified sites, except of lymphoid, haematopoietic and related tissue
Sexe	Male Woman
Champ géographique	National

Détail du champ géographique	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.
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Collecte

Dates

Année du premier recueil	2010
Année du dernier recueil	Collection in progress

Taille de la base de données

Taille de la base de données (en nombre d'individus)	Greater than 20 000 individuals
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Détail du nombre d'individus	Conticabase and conticaGist contain data from approximately 13,000 patients and the RRePS database contains data from approximately 8,500 patients
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Données

Activité de la base	Current data collection
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Type de données recueillies	Clinical data Biological data Administrative data
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Données cliniques, précisions	Direct physical measures Medical registration
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Détail des données cliniques recueillies	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)
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Données biologiques, précisions	data on the characteristics of the tumour
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Données administratives, précisions	patient identity (initials), date of birth and sex, geographical location, agreement or not of the patient to use his/her tumour material for research
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Existence d'une bibliothèque	Yes
Contenu de la bibliothèque	Tissues
Paramètres de santé étudiés	Health event/morbidity Health event/mortality Others
Modalités	
Mode de recueil des données	The data is collected by clinical researchers with dedicated time and via consultation meetings
Procédures qualité utilisées	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
Suivi des participants	Yes
Modalités de suivi des participants	Monitoring by contact with the referring doctor
Détail du suivi	occasional follow-up by specific scientific project
Appariement avec des sources administratives	No
Valorisation et accès	
Valorisation et accès	
Accès	
Existence d'un document qui répertorie les variables et les modalités de codage	Yes
Charte d'accès aux données (convention de mise à disposition, format de données et délais de mise à disposition)	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 matériel among CTCN partners'
Accès aux données agrégées	Access on specific project only
Accès aux données individuelles	Access on specific project only

