NETSARC - NATIONAL PROSPECTIVE COHORT ON SARCOMAS/GIST/DESMOID AND CONNECTIVE TISSUE TUMOURS

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General

Identification

Detailed name	NATIONAL PROSPECTIVE COHORT ON SARCOMAS/GIST/DESMOID AND CONNECTIVE TISSUE TUMOURS
Sign or acronym	NETSARC
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	Accord CNIL DR-2013-383, CCTIRS 16/09/2010

General Aspects

Medical area	Cancer research
Health determinants	Genetic Geography Iatrogenic
Keywords	Sarcoma, rare cancers, network, clinical, biological samples, ISKS project, genetic, treatment

Scientific investigator(s) (Contact)

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Organization	Centre Léon Bérard

Collaborations

Participation in projects, networks and consortia	Yes

Funding

Funding status	Mixed
Details	Pour le projet ISKS spécifique : - INFO SARCOMES (association de patients)- LIDDY SHRIVER (association de patients)Recherche de financements additionnels

Governance of the database

Sponsor(s) or organisation(s) responsible	Centre Léon Bérard
Organisation status	Private

Additional contact

Main features

Type of database

Type of database	Study databases
Study databases (details)	Longitudinal study (except cohorts)
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.	- patients with sarcoma or connective tissue tumours (all ages and histologies) discussed in multidisciplinary meetings (RCP) in regional centres of expertise specialising in the treatment of sarcomas

Database objective

Main objective	The objectives of this cohort are: real-time integration of patients into a database- to generate real-time national and regional descriptive data for all patients with sarcoma - to provide national indicators of patient care and equal access to care and innovative treatments - to improve knowledge of rare tumours - to investigate the link between sarcomas and genetics.
Inclusion criteria	- patients with sarcoma or connective tissue tumours (all ages and histologies) discussed in multidisciplinary meetings (RCP) in regional centres of expertise specialising in the treatment of sarcomas

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	National
Detail of the geography area	The national NETSARC clinical network is composed of 28 regional centres of expertise specialising in sarcoma treatment and research.

Data collection

Dates

Date of first collection (YYYY or	01/2010

MM/YYYY)	
Size of the database	
Size of the database (number of individuals)	[10 000-20 000[individuals
Details of the number of individuals	17 346:- 11 646 sarcomes/GIST/desmoide.- 5 700 tumeurs conjonctives à malignité intermédiaire ou bénigne.
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	> Tumor (shared): location, size, depth of invasion > Tumor sample description (from RRePS): case origin, sample type, sample date, diagnosis establish by anatomic pathology structure, by the national reference center, by the coordination site, tumor immunohistochemistry, tumor molecular biology, tumor FISH exam > Main steps of patient management (from NetSarc): tumor type, diagnosis, date of the first diagnosis, stages of cancer, imaging data before resection, biopsy, place and quality of surgery > Multidisciplinary consensus meeting (from NetSarc): date, expert center, timing, decisions > Inclusion in clinical trials (from NetSarc): date, name of clinical trial > Relapse, date of death, date of last follow-up (from NetSarc)
Declarative data (detail)	Paper self-questionnaire
Biological data (detail)	DNA
Administrative data (detail)	> Demographic : date of birth, initial, gender, current geographic residence, antecedents
Presence of a biobank	Yes
Contents of biobank	DNA
Details of biobank content	DNA

Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation

Procedures

Data collection method	Standardised reports from regional centres specialising in the treatment of sarcomas included in the network.
Participant monitoring	Yes
Details on monitoring of participants	Frequent return to medical record while patient is undergoing treatment and follow-up in the centre. Return every 2 years during follow-up outside centres via mail addressed to correspondents.
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	NetSarc.pdf

Access

Terms of data access (charter for data provision, format of data, availability delay)	Shared database is accessible online and developed by two network I.T. professionals. Data is hosted by a professional hosting provider. Users can connect with a unique password. Different rights are allocated per profile (clinician, clinical research associate, quality manager, administrator ...). Website terms of use must be previously signed. Non-identifiable patient data (HASH system is being put in place). A scientific committee consisting of representatives clinicians and pathologists centres to large volume of patients in the network is responsible for controlling, analysing and authorising requests for studies from the shared data base.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only