

- Epidemiology and treatment patterns in Soft Tissue Sarcoma (STS): a retrospective analysis on French expert centers databases

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General

Identification

Detailed name	Epidemiology and treatment patterns in Soft Tissue Sarcoma (STS): a retrospective analysis on French expert centers databases
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CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL: 910390
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General Aspects

Medical area	Cancer research
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Pathology (details)	Soft Tissue Sarcoma (STS)
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Health determinants	Healthcare system and access to health care services
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Keywords	Soft Tissue Sarcoma (STS)
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Scientific investigator(s) (Contact)

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Collaborations	
Participation in projects, networks and consortia	Yes
Details	Partenariat public-privé : French Sarcoma Group (GFS) - MERCK
Funding	
Funding status	Private
Details	Merck
Governance of the database	
Sponsor(s) or organisation(s) responsible	French Sarcoma Group (GFS)
Organisation status	Public
Presence of scientific or steering committees	Yes
Labelling and database evaluation	Scientific comittee
Additional contact	

Main features

Type of database

Type of database

Study databases

Database recruitment is carried out by an intermediary

A selection of health institutions and services

Database recruitment is made on the basis of:

Another treatment or procedure

Database recruitment is carried out as part of an interventional study

No

Additional information regarding sample selection.

Retrospective databases analysis (RRePS, NetSarc, and Conticabase) by the French Sarcoma Group (GFS)

Database objective

Main objective

To describe the treatment patterns of advanced (unresectable locally advanced or metastatic) STS (including viscus sarcoma) patients in France.

Secondary objectives:

- To describe STS (including viscus sarcoma) patients characteristics (sociodemographic data, type of sarcoma, histological subtype, tumor location, stage of the disease etc).
- To assess the STS (including viscus sarcoma) incidence in France
- To describe STS diagnosis (anatomopathology double review) and treatment history
- To describe the duration of the different treatments of STS disease

Inclusion criteria

Patients with a diagnosis of STS, aged > 18 years-old, registered in the Conticabase/NetSarc/RRePS databases between January, 1st 2012 and December, 31st 2013 by a French expert center participating in the study between January, 1st 2012 and December, 31st 2013.

Population type

Age

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	France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	01/01/2012
Date of last collection (YYYY or MM/YYYY)	31/12/2013
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	Conticabase: N = 1099 / NetSarc: N= 4551 / RRePS: N=6812
Data	
Database activity	Data collection completed
Type of data collected	Clinical data
Clinical data (detail)	Medical registration
Details of collected clinical data	Sociodemographic characteristics of patients; Sarcoma epidemiology (type of sarcoma) ; STS epidemiology (histological subtype, tumor location, tumor depth, grade, stage at diagnosis, stage); Diagnosis (anatomopathology double review by an expert center, initial diagnosis, confirmatory diagnosis; Unresectable locally advanced or metastatic STS (1st line systemic treatment, 1st line CT and drug type, diagnosis date of unresectable locally advanced/metastatic stage, initiation date of the 1st line CT, date of progression after 1st line treatment, 2nd, 3rd and 4th line CT and drug type)
Presence of a biobank	No
Procedures	

Data collection method	Extraction, treatment and analysis of the RRePS, NetSarc and Conticabase databases by the French Sarcoma Group (GFS)
Participant monitoring	No
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	1697 poster sarcome colloque pharma epi 9juin15 ok.pdf
Description	Colloque PEP, juin 2015
Link to the document	1772 poster sarcome VF.pdf
Description	ISPOR, novembre 2015
Link to the document	PEP2015_12_BCBSarcome_Coindre.pdf
Description	Communication orale, colloque PEP, juin 2015
Access	
Presence of document that lists variables and coding procedures	No
Terms of data access (charter for data provision, format of data, availability delay)	Methods of access are currently being defined Contact: juliette.longin@merckgroup.com
Access to aggregated data	Access on specific project only
Access to individual data	No access