

- 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

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL: 910390

General Aspects

Medical area Cancer research

Pathology (details) Soft Tissue Sarcoma (STS)

Health determinants Healthcare system and access to health care services

Keywords Soft Tissue Sarcoma (STS)

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 committee

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 | <p>To describe the treatment patterns of advanced (unresectable locally advanced or metastatic) STS (including viscus sarcoma) patients in France.</p> <p>Secondary objectives:</p> <ul style="list-style-type: none">- 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 |
|----------------|---|

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|--------------------|--|
| 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 | |

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|---|--|
| 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 |