

- ONCOTAB

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General	
Identification	
Detailed name	ONCOTAB
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	Autorisations CPP, CNIL, CCTIRS en cours.
General Aspects	
Medical area	Cancer research
Health determinants	Geography Occupation Social and psychosocial factors
Others (details)	Bone and soft tissue cancer
Keywords	Bone sarcoma, socio-economic, geographical, professional, factors, life components, distant recurrence, overall survival, social impact, social, psychological, local recurrence, questionnaire, PROMIS.
Scientific investigator(s) (Contact)	
Name of the director	Biau
Surname	David
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Unit	UMR 1153 intégré dans le centre de recherche Epidémiologies et Biostatistique Sorbonne Paris Cité. Equipe ECaMO

Organization	Université Paris Descartes, APHP
Collaborations	
Funding	
Funding status	Public
Details	Recherche de financements en cours
Governance of the database	
Sponsor(s) or organisation(s) responsible	Université Paris Descartes
Organisation status	Public
Sponsor(s) or organisation(s) responsible	AP-HP
Organisation status	Public
Sponsor(s) or organisation(s) responsible	Inserm
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Cohort study
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.	All sarcoma cases within the surgery, oncology and radiotherapy units of the sarcoma multidisciplinary meeting (Réunion de Concertation Pluridisciplinaire) in Cochin are eligible for the study.
Database objective	

Main objective	The main objective of this cohort is to evaluate the impact of social factors on physical, psychological, social, financial and professional life components for patients with sarcomas. Secondary objectives: - to identify the impact of social factors that affect patients before diagnosis and during follow-up - to identify the impact of social factors on oncological results such as: local recurrence, distant recurrence and overall survival - to evaluate patients' impressions on the use of digital tablets and ePROS collection during consultation - to identify social challenges and implications (domestic life, family life, marital life, social skills, leisure and professional activities) considered important by patients and that they feel were inadequately or insufficiently explored by the PROMIS questionnaires
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Inclusion criteria	Inclusion criteria: - over the age of 18 - diagnosed with sarcoma (made by multidisciplinary meeting teams or a RRePS network team) - no treatment has commenced
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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)
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Population covered	Sick population
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Gender	Male Woman
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Geography area	Local
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French regions covered by the database	Île-de-France
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Detail of the geography area	Hôpital Cochin Paris
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Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	01/2014
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Size of the database

Size of the database (number of	< 500 individuals
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individuals)	
Details of the number of individuals	---
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data
Clinical data (detail)	Direct physical measures
Declarative data (detail)	Paper self-questionnaire
Presence of a biobank	No
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 Medicines consumption
Procedures	
Participant monitoring	Yes
Details on monitoring of participants	18 months
Links to administrative sources	No
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only