

RENAPE - French Registry for Rare Peritoneal Tumors

Head :Villeneuve Laurent , Réseau National de prise en charge des Tumeurs Rares du Péritoine (RENAPE)
Glehen Olivier, Service de Chirurgie Générale et Digestive

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General	
Identification	
Detailed name	French Registry for Rare Peritoneal Tumors
Sign or acronym	RENAPE
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL no. 2010-297
General Aspects	
Medical area	Cancer research Rare diseases
Study in connection with Covid-19	No
Pathology (details)	Rare peritoneal tumors
Health determinants	Genetic Geography Healthcare system and access to health care services Occupation
Keywords	epidemiological observation, peritoneal, multicentric, rare cancers, hyperthermic intraperitoneal chemotherapy, HIPEC, cytoreductive surgery, clinical registry
Scientific investigator(s) (Contact)	
Name of the director	Villeneuve
Surname	Laurent
Address	RENAPE Hôpital Lyon Sud Hospices Civils de Lyon Bâtiment 3B 1er étage

Hospices Civils de Lyon
165 Chemin du Grand Revoyet
69495 Lyon Cedex

Phone +33 (04) 78 86 45 36

Email laurent.villeneuve@chu-lyon.fr

Unit Réseau National de prise en charge des Tumeurs Rares du Péritoine (RENAPE)

Organization Hospices Civils de Lyon

Name of the director Glehen

Surname Olivier

Address Service de Chirurgie Générale et Digestive
Bât 3A 1er étage
Centre Hospitalier Lyon Sud
Hospices Civils de Lyon
165 Chemin du Grand Revoyet
69495 Lyon Cedex

Phone + 33 (0)4 78 86 23 71

Email olivier.glehen@chu-lyon.fr

Unit Service de Chirurgie Générale et Digestive

Organization Hospices Civils de Lyon

Collaborations

Participation in projects, networks and consortia Yes

Details EURACAN

Others PSOGI

Funding

Funding status Public

Details INCa - DGOS

Governance of the database

Sponsor(s) or organisation(s) responsible Hospices Civils de Lyon (HCL)

Organisation status	Public
Presence of scientific or steering committees	Yes
Labelling and database evaluation	INCa-designation: Reference Network for Rare Peritoneal Tumors, 2019
Additional contact	
Name of the contact	Odin
Surname	Cécile
Address	RENAPE Centre Hospitalier Lyon Sud Bâtiment 3B 1er étage Hospices Civils de Lyon 165 Chemin du Grand Revoyet 69495 Lyon Cedex
Phone	+33 (04) 78 86 11 13
Email	cecile.odin@chu-lyon.fr
Unit	Réseau National de prise en charge des Tumeurs Rares du Périltoine (RENAPE)
Organization	Hospices Civils de Lyon
Main features	
Type of database	
Type of database	Morbidity registers
Study databases (details)	Cohort study
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is 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.	All patients with rare peritoneal cancer may be treated by one of the teams from the RENAPE Network.

Database objective	
Main objective	To continuously gather the most detailed information possible on all rare peritoneal cancers occurring in the national population. To perform a situational analysis on treatment involving these patients and to formulate a research hypothesis on the effectiveness and tolerance to different treatments.
Inclusion criteria	Patients with rare peritoneal cancer: peritoneal mesothelioma; pseudomyxoma peritonei; gelatinous disease of the peritoneum; primary serous carcinoma of the peritoneum. desmoplastic small round cell tumour; peritoneal psammocarcinoma and diffuse leiomyomatosis. Disease confirmed histologically.
Population type	
Age	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
Pathology	K65-K67 - Diseases of peritoneum
	C00-C97 - Malignant neoplasms
	D10-D36 - Benign neoplasms
	K38 - Other diseases of appendix
	K66 - Other disorders of peritoneum
	C00-C75 - Malignant neoplasms, stated or presumed to be primary, of specified sites, except of lymphoid, haematopoietic and related tissue
	C97-C97 - Malignant neoplasms of independent (primary) multiple sites
Gender	Male Woman
Geography area	National
Detail of the geography area	3 national expert centres; 6 expertise centres and

21 associated facilities covering the entire national territory.

Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2010
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	2500
Data	
Database activity	Current data collection
Type of data collected	Clinical data Biological data
Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	Histological diagnosis; surgical data; radiological treatments and chemotherapies; vital status; recurrence and therapeutic strategy; yearly follow-up
Biological data (detail)	Tumor biomarkers
Presence of a biobank	Yes
Contents of biobank	Tissues
Details of biobank content	Frozen tumour tissues; paraffin blocks
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	electronic case report form (eCRF)
Quality procedure(s) used	Data management team; quality controls
Participant monitoring	Yes

Monitoring procedures	Monitoring by contact with the referring doctor
Details on monitoring of participants	Prospective follow-up in accordance with current good practice standards.
Followed pathology	K65-K67 - Diseases of peritoneum
	C00-C97 - Malignant neoplasms
	D10-D36 - Benign neoplasms
	K66 - Other disorders of peritoneum
	C00-C75 - Malignant neoplasms, stated or presumed to be primary, of specified sites, except of lymphoid, haematopoietic and related tissue
	C97-C97 - Malignant neoplasms of independent (primary) multiple sites
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	https://www.ncbi.nlm.nih.gov/sites/myncbi/1pMDiMhapJoAg/collections/58077119/public/
Description	Publications list from RENAPE Network
Access	
Presence of document that lists variables and coding procedures	Yes
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