UroCCR - National Multicentre, Multidisciplinary, Clinical-Biological Database for Kidney Cancer

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Last update : 05/08/2015 | Version : 2 | ID : 8176

General

Identification

Detailed name	National Multicentre, Multidisciplinary, Clinical-Biological Database for Kidney Cancer
Sign or acronym	UroCCR
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL: DR-2013-206

General Aspects

Medical area	Biology Cancer research Radiology and medical imaging Urology, andrology and nephrology
Health determinants	Genetic Medicine
Keywords	kidney cancer, clinical-biological database, medical and scientific network, medical oncology, ablation treatment, anatomical pathology, oncogenetics, therapeutic treatment, surgery

Scientific investigator(s) (Contact)

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Unit	Service de chirurgie urologique et transplantation - CHU Bordeaux

Organization	CHU de

Collaborations

Participation in projects, networks and consortia	Yes
Details	Prospective ancillary projects: - Robotic Partial Nephrectomy national study (RoPaN) - Cancer and tArgeted theRapy: survey of Long term Adverse events (CARLA Rein) Partnerships and scientific support: - French Urology Association (AFU) - Urogenital Tumours Study Group (GETUG) - Urogenital Imaging Society (SIGU) - French Urological Pathology Club - French Cancer Registry Network (FRANCIM) - Kidney Tumour Research Association (ARTuR) - University of Bordeaux - Cancéropôle Grand Sud-Ouest

Funding

Funding status	Mixed
Details	INCa Pharmaceutical industry

Governance of the database

Sponsor(s) or organisation(s) responsible	CHU Bordeaux
Organisation status	Public

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 enrolled prospectively and/or retrospectively will be notified by their physician of their selection for inclusion in the UroCCR database

	with signed consent and opportunity to object.

Database objective

Main objective	The main objective is to rely on a common multidisciplinary and unifying tool (UroCCR Database), to develop a national network of medical and scientific activity focused on therapeutic treatment and applied research for kidney cancer. The complementarity of skills and culture of a strong translational connection, collaboration with cancer registries and the creation of a collection of multicentre, annotated biological samples allow ancillary research projects to be carried out as part of the UroCCR network, aimed at economic and lead time efficiency.
Inclusion criteria	- Adult patient with kidney cancer - Patient not objecting to the collection of data for the study

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	CHU de Bordeaux, Kremlin Bicêtre Hospital, Institut Gustave Roussy, CHU Angers/Centre Paul Papin, CHU Grenoble, CHU Strasbourg, CHU Lyon, CHU Henri Mondor, CHU Toulouse/Claudius Regaud Institute, Saint Joseph Hospital, Georges Pompidou European Hospital, CHU Rouen

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2007

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1424 patients (19/06/2014)
Data	
Database activity	Current data collection
Type of data collected	Clinical data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	Concerns all kidney cancer diagnostic and therapeutic fields (open and mini-invasive surgery, interventional radiology, procedures associated with treating metastases, targeted therapies).
Paraclinical data (detail)	Anatomic pathology , radiology, oncogenetics, standard biology.
Biological data (detail)	Virtual collection of biological samples: Abnormal tissue, healthy tissue, urine, plasma and serum.
Administrative data (detail)	Demographic characteristics of cancer patients
Presence of a biobank	Yes
Contents of biobank	Serum Plasma Fluids (saliva, urine, amniotic fluid, ?) Tissues
Details of biobank content	Abnormal (primary tumour and metastasis) tissue/cryopreserved healthy tissue, Abnormal (primary tumour and metastasis) tissue/healthy tissue in paraffin, plasma, serum, urine.
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption
Procedures	

Data collection method	Data collection is through a relational database with secure online access that includes all variables regarding demographics, surgery, anatomic pathology, radiology, ablative treatment, oncogenetics and medical oncology (including INCa repository database).
Participant monitoring	Yes
Details on monitoring of participants	Monitored in accordance with current clinical recommendations.
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	bibliographie relative bdd uroccr.pdf
Link to the document	bibliographie relative aux projets ayant beneficie de lapport scientifique du reseau uroccr.pdf
Link to the document	http://tinyurl.com/Hal-UROCCR
Description	List of publications in HAL
Link to the document	http://tinyurl.com/Pubmed-UROCCR
Description	List of publications in Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay)	The confidentiality of data collected for UroCCR base is assured by: - Approval of the entire study by the Advisory Committee on Research Information Processing in the Health Field and the National Commission for Data Protection and Liberties (CNIL). - Professional confidentiality to which all members of UroCCR are subjected to (signing a confidentiality agreement), as well as the participating centres (signing a partnership charter on confidentiality regulations). - Strictly anonymous analysis of collected data. The database is: - Anonymous to ensure data confidentiality - Secured by an encrypted connection (https) and an individual user account (username and password), ensuring data protection for each centre.

	Third party teams may access data following validation of the project submitted to the Scientific Committee.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only