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

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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	CCTIRS (2012/10/24) CNIL : DR-2013-206 (2013/04/12) et DR-2016-485 (2016/12/15) CNIL EDS : DT-2024-027
General Aspects	
Medical area	Biology Cancer research Radiology and medical imaging Urology, andrology and nephrology
Study in connection with Covid- 19	No
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 Bordeaux
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 - IBiSA
Funding	
Funding status	Mixed
Details	INCa. Industrials, funding via call for proposals
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Governance of the database	INCa, Industriais, funding via cail for proposais
Governance of the database Sponsor(s) or organisation(s) responsible	CHU Bordeaux
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Sponsor(s) or organisation(s) responsible Organisation status Presence of scientific or	CHU Bordeaux Public
Sponsor(s) or organisation(s) responsible Organisation status Presence of scientific or steering committees Labelling and database	CHU Bordeaux Public Yes INCa accreditation as part of the Call for Clinical-Biological Basis Projects (2011). HAS referencing (2023). Network database integrated into the SNDS
Sponsor(s) or organisation(s) responsibleOrganisation statusPresence of scientific or steering committeesLabelling and database evaluation	CHU Bordeaux Public Yes INCa accreditation as part of the Call for Clinical-Biological Basis Projects (2011). HAS referencing (2023). Network database integrated into the SNDS
Sponsor(s) or organisation(s) responsibleOrganisation statusPresence of scientific or steering committeesLabelling and database evaluationAdditional contact	CHU Bordeaux Public Yes INCa accreditation as part of the Call for Clinical-Biological Basis Projects (2011). HAS referencing (2023). Network database integrated into the SNDS catalog (2025).

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Unit	Service de chirurgie urologique et transplantation - CHU Bordeaux
Organization	CHU de Bordeaux
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. A UroCCR transparency portal has been set up.
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
Pathology	II - Neoplasms
Gender	Male Woman
Geography area	National
Detail of the geography area	58 centers in the UroCCR network : CHU de Bordeaux, CHU Kremlin-Bicêtre, CHU Toulouse, CHU Lyon, CHU Rennes, HEGP, CHU Angers, CHU Strasbourg, CHU Grenoble, CH St-Joseph, CHU Henri Mondor, Hôpital La Pitié Salpêtrière, CHU Rouen, CHU Lille, CHU Caen, CHU Reims, CHU Tours, Hôpital Bichat, CHU Poitiers, IPC Marseille, APH Marseille, CHU Nice, Hôpital Tenon, CHU Clermont-Ferrand, Médipôle Cabestany, CH Mont de Marsan, Hôpital Privé Claude Galien, Clinique la Croix du Sud, Hôpital Privé Francheville, CH de Libourne, Pôle Sud Santé-Le-Mans, Clinique Pasteur, Clinique Santé Atlantique, CHU Nîmes, Hôpital Privé des Côtes d'Amor, CHU de Nantes, Hôpital Privé La Louvière Lille, Clinique Nantes Atlantis, Clinique du Pont de Chaume, CHU Dijon, ICANS, CH de Kourou (Guyane), Hôpital Foch, CHU Cochin-Port Royal, CH de Fontainebleau, Nouvelle Clinique Bordeaux Tondu, Clinique Belledonne, Clinique Saint-Antoine, CHU de St ETIENNE, Hôpital Universitaire de Bruxelles, CH SUD FRANCILIEN, Institut Mutualiste Montsouris, CHRU de Nancy, CHU de Limoges, CH d'Annecy, CH Département de Vendée, CHU d'Orléans, CHU Bellepierre Saint-Denis (La Réunion)
Data collection	
Dates	

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

Size of the database

Size of the database (number of Greater than 20 000 individuals individuals)

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 DNAc/RNAm
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. DNA, MRA, buffy coat and red blood cells.
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 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	<u>bibliographie relative aux projets ayant beneficie de lapport scientifique du reseau uroccr.pdf</u>
Link to the document	https://hal.science/search/index?q=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: Pseudonymized 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