

REIN - Epidemiology Network and Nephrology Information Registry (qualified registry 2012-2015)

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General

Identification

Detailed name Epidemiology Network and Nephrology Information Registry (qualified registry 2012-2015)

Sign or acronym REIN

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation 903188

General Aspects

Medical area Urology, andrology and nephrology

Keywords Data, interpretation, decision, epidemiological expertise, biostatistics, transplanted or dialysis patients, rate of mortality and progression, comorbidities, associated disabilities, incidence, prevalence, sociodemographic characteristics, support

Scientific investigator(s) (Contact)

Name of the director Jacquelinet

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Unit Direction Médicale et Scientifique

Organization Agence de

Collaborations	
Funding	
Funding status	Public
Details	Comité National des Registres
Governance of the database	
Sponsor(s) or organisation(s) responsible	Agence de Biomédecine
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects that meet the required inclusion criteria. Internal and external data system controls are necessary in order to verify that all eligible cases have been declared and identified. Dialysis units or centres refer all patients with chronic renal disease treated by their team whether the patient is residing in the region or not. Completeness is assessed by all regional centres or units.
Database objective	
Main objective	To establish a sustainable information system by unifying data, its interpretation and potential use for public health decision-making or clinical practice for all partners involved (network organisation) and to organise epidemiological knowledge, biostatistics and data necessary to: - Estimate the number of dialysis or transplant patients for chronic renal disease in France and overseas territories, - Assess the impact (Objective 80 of Public Health Law), prevalence, mortality rates and trends in chronic renal disease at regional level, patient sociodemographic characteristics, baseline renal disease, comorbidities and associated disabilities - Specifically describe dialysis treatment modalities (method, modality, dose) and changing tendencies towards population requirements and medical practices - Evaluate relative aspects of different dialysis and transplantation modalities and to

describe patient trajectories through these treatment modalities - Assess quality and efficacy of care in terms of early detection, dialysis dose, control of anaemia and nutritional balance, particularly with regard to good clinical practice - Evaluate patients' quality of life (Objective 81 of Public Health Law); - Evaluate the medical and economic outcomes of health care practices.

Inclusion criteria

Initiation of treatment (dialysis or transplant) for End-Stage Renal Disease (ESRD).

Population type

Age

Newborns (birth to 28 days)
Infant (28 days to 2 years)
Early childhood (2 to 5 years)
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

Gender

Male
Woman

Geography area

National

Detail of the geography area

Metropolitan France, overseas countries and territories

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

2003

Size of the database

Size of the database (number of individuals)

Greater than 20 000 individuals

Details of the number of individuals

Au 31/12/2012 : 90685- 10048 nouveaux cas- 73491 patients traités- 7146 décès

Data

Database activity

Current data collection

Type of data collected	Clinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures
Biological data (detail)	Activity 17% Serum Creatinine, Serum Haemoglobin, Serum Albumin, Glomerular filtration rate, Serum Creatinine 19% CNR - Qualification record 2008 14/65 Serum Haemoglobin, Serum Albumin, Serum Erythropoietin
Administrative data (detail)	- Identification data - "Outgoing" transfers to another unit, for transplantation, Stoppage of dialysis, Lost to follow-up - "Incoming" transfers from another dialysis unit, Transplantation return, Return after withdrawal
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	An epidemiological research support structure and recruitment of clinical research associates are the conditions imposed by REIN for all regions in the network. Clinical research associate responsibilities have three parts: - continuous completeness checks for new patient registration, events and annual follow-ups, which must take place throughout the year. Clinical research associates may temporarily participate in inputting recorded data completed by physicians into the information system from time to time. - Annual information quality control for all patients is carried out every first quarter before being sent for validation at national level. However, this is only for a limited number of items deemed essential that were collected during the previous year. - Ad hoc checks on patient samples for other data.
Participant monitoring	Yes
Details on monitoring of participants	- The systematic annual follow-up for all dialysis patients allows updates to be made to all recorded comorbidities and treatment modalities (on the date dialysis originally began in order to smooth workload over time). - Vital status
Links to administrative sources	Yes

Linked administrative sources
(detail)

PMSI Health Insurance (MIAM)

Promotion and access

Promotion

Link to the document	http://www.soc-nephrologie.org/PDF/enephro/registres/rapport_2012/rapport_2012.pdf
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Link to the document	http://tinyurl.com/PUBMED-REIN
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Description	Liste des publications dans Pubmed
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Link to the document	http://tinyurl.com/HAL-REIN
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Description	Liste des publications dans HAL
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Access

Terms of data access (charter for data provision, format of data, availability delay)	To be defined
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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