Cooperative European Paediatric Renal Transplant Initiative

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000610

Data source acronym

CERTAIN

Data holder

Heidelberg University Hospital

Data source type

Disease registry

Main financial support

Other

Care setting

Hospital inpatient care

Hospital outpatient care

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

No

Data source website

CERTAIN registry

Contact details

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Alternate

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Data source regions and languages

Data source countries

Austria

Belgium

Bulgaria

Croatia

Czechia

France

Germany

Greece

Hungary

Ireland

Israel

Italy

Netherlands

Poland

Portugal

Romania

Serbia

Slovenia

Spain

Switzerland

Türkiye

United Kingdom

Data source languages

English

Data source establishment

Data source established

13/10/2010

Data source time span

First collection: 13/10/2010

The date when data started to be collected or extracted.

Publications

Data source publications

The CERTAIN Registry: a novel, web-based registry and research platform for pediatric renal transplantation in Europe

Longitudinal growth on an everolimus- versus an MMF-based steroid-free immunosuppressive regimen in paediatric renal transplant recipients

Efficacy and Safety of an Everolimus- vs. a Mycophenolate Mofetil-Based Regimen in Pediatric Renal Transplant Recipients

Impact of Everolimus and Low-Dose Cyclosporin on Cytomegalovirus Replication and Disease in Pediatric Renal Transplantation

Cytomegalovirus Infection in Pediatric Renal Transplantation and the Impact of Chemoprophylaxis With (Val-)Ganciclovir

Dyslipidemia after pediatric renal transplantation-The impact of immunosuppressive regimens

Incomplete vaccination coverage in European children with end-stage kidney disease prior to renal transplantation

Vaccination titres pre- and post-transplant in paediatric renal transplant recipients and the impact of immunosuppressive therapy

Outcome of renal transplantation in small infants: a match-controlled analysis

JC polyomavirus replication and associated disease in pediatric renal transplantation: an international CERTAIN Registry study

Urinary proteomics to diagnose chronic active antibody-mediated rejection in pediatric kidney transplantation - a pilot study

Epidemiology of and Risk Factors for BK Polyomavirus Replication and Nephropathy in Pediatric Renal Transplant Recipients: An International CERTAIN Registry Study

Sex and age as determinants for high blood pressure in pediatric renal transplant recipients: a longitudinal analysis of the CERTAIN Registry

The use of cinacalcet after pediatric renal transplantation: an international CERTAIN Registry analysis

Prevalence and potential relevance of hyperuricemia in pediatric kidney transplant recipients-a CERTAIN registry analysis

Hospitalization following pediatric kidney transplantation: An international comparison among a Canadian pediatric transplant center, North American Pediatric Renal Trials and Collaborative Studies, and Cooperative European Pediatric Renal Transplant Initiative registry data

Timing of reconstruction of the lower urinary tract in pediatric kidney transplant recipients: A CERTAIN multicenter analysis of current practice

Renal outcome and plasma methylmalonic acid levels after isolated or combined liver or kidney transplantation in patients with methylmalonic acidemia: A multicenter analysis

Hyperparathyroidism Is an Independent Risk Factor for Allograft Dysfunction in Pediatric Kidney Transplantation

Molecular HLA mismatching for prediction of primary humoral alloimmunity and graft function deterioration in paediatric kidney transplantation

The strengths and complexities of European registries concerning paediatric kidney transplantation health care

Emulation of the control cohort of a randomized controlled trial in pediatric kidney transplantation with Real-World Data from the CERTAIN Registry

Validation of a prediction system for risk of kidney allograft failure in pediatric kidney transplant recipients: An international observational study

Time-Varying Determinants of Graft Failure in Pediatric Kidney Transplantation in Europe

Metabolic Acidosis Is Associated With an Accelerated Decline of Allograft Function in Pediatric Kidney Transplantation

Favorable Outcome After Single-kidney Transplantation From Small Donors in Children: A Match-controlled CERTAIN Registry Study

Age-Related Differences in Rejection Rates, Infections, and Tacrolimus Exposure in Pediatric Kidney Transplant Recipients in the CERTAIN Registry

Kidney transplantation in children and adolescents with C3 glomerulopathy or immune complex membranoproliferative glomerulonephritis: a real-world study within the CERTAIN research network

Incidence, risk factors, management strategies, and outcomes of antibody-mediated rejection in pediatric kidney transplant recipients-a multicenter analysis of the Cooperative European Paediatric Renal Transplant Initiative (CERTAIN)

Microvascular Inflammation of Kidney Allografts and Clinical Outcomes

Risk of cellular or antibody-mediated rejection in pediatric kidney transplant recipients with BK polyomavirus replication-an international CERTAIN registry study

International validation of a pre-transplant risk assessment tool for graft survival in pediatric kidney transplant recipients

Factors associated with statural growth in pediatric kidney transplant recipients with focus on metabolic acidosis

Association of intrapatient tacrolimus variability and concentration-to-dose ratio with outcomes in pediatric kidney transplantation

Incidence and determinants of graft failure and death with functioning graft after re-transplantation

Data elements collected

The data source contains the following information

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

No

Disease details (other)

undefined

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

No

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

Not coded (Free text)

Prescriptions of medicines

Captured

Prescriptions vocabulary

not coded

Dispensing of medicines

Captured

Dispensing vocabulary

not coded

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Captured

Indication vocabulary

Not coded (Free text)

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

No

Administration of vaccines

Yes

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Not coded (Free text)

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available? The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays, infectious disease markers or metabolomic biomarkers.

Captured

Biomarker data vocabulary

Other

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

No

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

No

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Not Captured

Medicinal product information

Not Captured

Quality of life measurements

Captured

Quality of life measurements vocabulary

Not coded (Free text)

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Ethnicity

Gender

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Estimated percentage of the population covered by the data source in the catchment area

75%

Population

Population size

4423

Active population size

1100

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

3.00

Data flows and management

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

Registry_Statute_and_Rules_of_Procedure_en_2014-09-15.pdf

English (217.84 KB - PDF)

View document

Specification 1.6 2025-05-19 FINAL.pdf

English (1.58 MB - PDF)

View document

Protocol template CERTAIN analysis.pdf

English (177.29 KB - PDF)

View document

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

No

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

No

Event triggering registration

Event triggering registration of a person in the data source

Start of treatment

Event triggering de-registration of a person in the data source

Death

Loss to follow up

Other

Event triggering de-registration of a person in the data source, other

Graft loss

Event triggering creation of a record in the data source

Transplantation, Follow-up examination

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

No

Data management specifications that apply for the data source

Informed consent for use of data for research

Not Required

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

Data source preservation

Are records preserved in the data source indefinitely?

No

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

No