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The National Unified Renal Translational Research Enterprise for biosampling patients with rare kidney disease

Submission date
05/03/2026

Recruitment status
Recruiting

Registration date
11/03/2026

Overall study status
Ongoing

Last Edited
10/03/2026

Condition category
Urological and Genital Diseases

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol

Background and study aims
Rare kidney diseases are uncommon conditions that can affect how well the kidneys work. Because each rare disease affects only a small number of people, it is difficult for researchers to collect enough information to understand them well. This study, called NURTuRE–Rare Kidney Disease, aims to bring together samples and health information from children with rare kidney diseases across the UK. By studying blood, urine, and clinical records over time, researchers hope to understand what causes these diseases, find early signs of worsening illness, and support the development of better, more personalised treatments in the future.

Who can participate?
Two groups of children and young people aged 0 to 16 years can take part.

1. Children with glomerulonephritis, a group of rare kidney diseases confirmed by their clinical team. These children will already be having tests such as blood tests or kidney biopsies as part of their usual care.
2. Healthy children who are attending hospital for minor procedures or routine checks and who do not have kidney or inflammatory conditions.

What does the study involve?
Healthy children take part once. If they and their parent or guardian agree, they will provide a urine sample, and a small blood sample if they are already having a blood test for another reason. No extra needles will be used solely for research.

Children with glomerulonephritis will attend four study visits over 12 months. At each visit, blood and urine samples will be collected, and clinical information about their kidney condition will be recorded. If a kidney biopsy is being taken for medical reasons, a small amount of leftover tissue may also be used. Participants in this group are also asked to join the National Registry of Rare Kidney Diseases so their long-term health information can be linked to the samples for research.

What are the possible benefits and risks of participating?
There is no direct medical benefit to taking part, but the information collected may help improve understanding and treatment of rare kidney diseases in the future. The risks are very low because the study only uses samples taken during routine care. No child will have an extra blood test or biopsy for research alone. There may be brief discomfort from standard medical procedures, but no new or additional risks are introduced by joining the study.

Where is the study run from?
The study is coordinated by the University of Bristol and led by the University of Liverpool. It is taking place across 13 hospitals in England, Scotland, Wales, and Northern Ireland.

When is the study starting and how long is it expected to run for?
The first participants are expected to join the study in August 2026. Recruitment is planned to continue until August 2028, and the whole study is expected to run until August 2029.

Who is funding the study?
The study is funded by LifeArc, a UK-based non-profit organisation.

Who is the main contact?
Dr Louise Oni at the University of Liverpool, louise.oni@liverpool.ac.uk

Contact information

Type(s)
Scientific, Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
364884

Protocol serial number
71153

Study information

Scientific Title
National Unified Renal Translational Enterprise – Rare Kidney Disease Bioresource

Acronym
NURTuRE – Rare Kidney Disease

Study objectives
Rare kidney diseases (RKDs) collectively represent a significant clinical challenge, accounting for up to 10% of chronic kidney disease (CKD) cases and 25% of patients requiring kidney replacement therapy. Because individual RKD patient populations are small and often involve children, local biobanks frequently lack the scale necessary to delineate the complex molecular mechanisms driving these conditions. This study utilises the established NURTuRE (National Unified Renal Translational Research Enterprise) national infrastructure to create a dedicated bioresource that links high-quality biosamples (blood, urine, and tissue) with rich longitudinal clinical data from the National Registry of Rare Kidney Diseases (RaDaR). The primary rationale for this "umbrella protocol" approach is to reduce administrative burdens and accelerate the biological phenotyping of distinct RKD subgroups, such as glomerulonephritis, which often exhibits rapid progression toward kidney failure.

The overall aim of this research is to improve the understanding of RKD pathogenesis through discovery science, including multi-omics and proteomic analysis. By identifying clinical and molecular biomarkers, the study seeks to facilitate precise risk stratification and the discovery of meaningful endpoints for future clinical trials. Ultimately, this project intends to bridge the gap between pre-clinical science and clinical application, informing the development of targeted, personalised treatments to prevent disease progression and improve long-term outcomes for patients with rare kidney diseases

Ethics approval required

Ethics approval required

Ethics approval(s)
Not yet submitted

Primary study design
Observational

Study design
The NURTuRE-RKD study is designed as a prospective cohort study that utilises a "master" or "umbrella" protocol framework. This design allows for shared governance and reporting across multiple disease-specific subgroups, which will be incorporated through approved amendments to reduce administrative burden. The University of Bristol will act as the coordinating centre, managing recruitment and sample collection across 13 UK sites. Participants will be recruited at the point of clinical investigation , with data collection split between a core metadata set stored in REDCap and deep phenotyping data sourced from the National Registry of Rare Kidney Diseases (RaDaR). To ensure high-quality sample handling, sites are categorised into three tiers (A, B, or C) based on their local laboratory resources. All collected clinical and molecular data will ultimately be linked within the SAIL Trusted Research Environment (TRE) at Swansea University for long-term analysis and discovery science.

Study type(s)
Other

Health condition(s) or problem(s) studied
Children and young people with rare kidney diseases. Glomerulonephritis (GN): Including subtypes such as IgA Vasculitis Nephritis (IgAVN), IgA Nephropathy (IgAN), Idiopathic Nephrotic Syndrome (iNS), C3 Glomerulopathy/Membranoproliferative GN (MPGN), Post-infectious Glomerulonephritis (PIGN), Lupus Nephritis (LN), ANCA-associated vasculitis (AAV), and Membranous Nephropathy (MN)

Interventions
The study will be conducted as a prospective, cohort study across 13 UK sites. Participants will be recruited from two initial subgroups: children with rare kidney diseases (specifically glomerulonephritis) and a healthy paediatric control group. Clinical staff will identify and approach eligible patients during routine clinical investigations, and informed consent or assent will be obtained before any study-specific procedures commence.

1. Healthy Control Group
Children in this group will be recruited while they are already attending hospital for other minor, non-inflammatory procedures (for example, grommet insertion, ear surgery, or birthmark removal), or during investigations for non-chronic conditions such as delayed growth or puberty.

These participants will take part once only.
At that visit:
They will receive an information sheet and consent form and be given time to ask questions before deciding to take part.
Eligibility will be checked, including a simple urine dipstick test.
Once consented, blood and urine samples will be collected.
A minimal core metadata set will be pseudonymised at the site level and recorded in a secure REDCap database.

Observations: No clinical follow-up will be conducted for these participants beyond the initial collection.

Subgroup 2 - Glomerulonephritis
Recruitment: Children in this group will be identified during their usual hospital care when they are having tests related to their kidney condition.

They will take part in four visits:
Baseline (first visit): screening and consent, followed by collection of blood, urine, and kidney biopsy samples (if taken for clinical care). If plasma or lipid apheresis is being done for medical reasons, the leftover material will also be collected.
1 month (±2 weeks): blood and urine samples, plus updated clinical information.
6 months (±4 weeks): blood and urine samples, plus clinical information.
12 months (±4 weeks): blood and urine samples, biopsy if taken for clinical reasons, and updated clinical data.
Data collection: A minimal core metadata set will be pseudonymised at the site level and recorded in a secure REDCap database.
Data Linkage: Participants will be required to be recruited into the National Registry of Rare Kidney Diseases (RaDaR) in parallel to ensure deep phenotyping and access to long-term clinical data.

Testing and Analysis:
Proteomics: Samples will undergo discovery science via proteomic analysis once the cohort reaches a sufficient size.
Biomarkers: Urine samples will be utilised specifically to discover non-invasive biomarkers of disease activity.

Intervention Type
Other

Primary outcome(s)
Biological phenotyping and characterisation of rare kidney diseases through the establishment of a national bioresource. This will be achieved by collecting and analysing longitudinal biosamples (including multi-omics data) linked to deep phenotypical clinical data from the National Registry of Rare Kidney Diseases (RaDaR).

Key secondary outcome(s)

Completion date
31/08/2029

Eligibility

Key inclusion criteria
Glomerulonephritis subgroup:
1. Children and young people aged 0-16 years
2. A diagnosis of glomerular disease falling into specific subtypes: Idiopathic nephrotic syndrome (INS), IgA related glomerulonephritis (IgAN and IgAVN), Primary membranous nephropathy (MN), Lupus nephritis (LN), ANCA associated vasculitis, Anti-glomerular basement membrane (GBM) GN, Immunoglobulin and complement mediated GN with MPGN pattern, or Post infectious GN (PIGN)

3. Participants must have had a diagnostic kidney biopsy around the baseline visit time (+/- 2 weeks)
4. The participant (or parent/legal guardian if <16 years) must be willing and able to provide informed consent.
5. Participants must be existing or willing participants in the RaDaR (The National Registry of Rare Kidney Diseases)

Healthy controls subgroup:
1. Children and young people aged 0-16 years attending a participating site for clinical review or investigations for other purposes.
2. Participants will have no relevant medical history of inflammatory, kidney disease, or other long-term health conditions that clinicians feel may impact the integrity of scientific discovery.
3. Willing to consent or for a child (if aged <16 years) has a parent/legal guardian who can provide consent on their behalf.

Participant type(s)
Healthy volunteer, Patient

Healthy volunteers allowed
Yes

Age group
Mixed

Lower age limit
0 Years

Upper age limit
16 Years

Sex
All

Total final enrolment
0

Key exclusion criteria
Glomerulonephritis subgroup:
1. Children and young people with a known acute or chronic medical illness that may contribute to biological changes that could impact the study findings, this may include acute infections.
2. Children aged <16 years who are not having blood tests or kidney biopsy performed for clinical purposes. This study will not expose children to an additional needle for research purposes only.

Healthy controls subgroup:
1. Children and young people with a known acute or chronic medical illness that may contribute to biological changes that could impact the study findings, this may include inflammatory diseases, acute infections or known kidney disease.
2. Abnormal urine dipstick test suggestive of a urinary tract infection or underlying kidney

disease.
3. Children aged <16 years who are not having blood tests done for other purposes. This study will not expose children to an additional needle to take blood tests for research purposes only.

Date of first enrolment
02/08/2026

Date of final enrolment
31/08/2028

Locations

Countries of recruitment
United Kingdom

England

Northern Ireland

Scotland

Wales

Study participating centre
University Hospitals Bristol and Weston NHS Foundation Trust - Oxford Covid19 Trials
Medical Research Unit, B501
Bristol Royal Infirmary
Marlborough Street
Bristol
England
BS2 8HW

Study participating centre
Alder Hey Children's Trust
E Prescot Road
Liverpool
England
L14 5AB

Study participating centre
Great Ormond Street Hospital for Children
Guilford Street
London
England
WC1N 3BH

Study participating centre
Nottingham Children’s Hospital – located in Queen’s Medical Centre
Queen's Medical Centre
Derby Road
Lenton
Nottingham
England
NG7 2UH

Study participating centre
Birmingham Women's and Children's Hospital
Mindelsohn Way
Birmingham
England
B15 2TG

Study participating centre
The Royal Belfast Hospital for Sick Children
274 Grosvenor Road
Belfast
Northern Ireland
BT12 6BA

Study participating centre
Royal Hospital for Sick Children (Glasgow)
1345 Govan Road
Glasgow
Scotland
G51 4TF

Study participating centre
Evelina London Children's Hospital
St Thomas' Hospital
249 Westminster Bridge Road
London
England
SE1 7EH

Study participating centre
Southampton Children's Hospital - located in Southampton General Hospital
Southampton General Hospital
Tremona Road
Southampton
England
SO16 6YD

Study participating centre
Leeds Children's Hospital – located in Leeds General Infirmary
Clarendon Wing
Leeds
England
LS1 3EX

Study participating centre
Noahs Ark Childrens Hospital for Wales
Cardiff & Vale University Health Bd
Heath Park
Cardiff
Wales
CF14 4XW

Study participating centre
Great North Children's Hospital
Victoria Wing, Royal Victoria Infirmary
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England
NE1 4LP

Study participating centre
Royal Manchester Children's Hospital
Oxford Road
Manchester
England
M13 9WL

Sponsor information

Organisation
University of Liverpool

ROR
https://ror.org/04xs57h96

Funder(s)

Funder type
Not defined

Funder Name
LifeArc

Alternative Name(s)

Funding Body Type
Private sector organisation

Funding Body Subtype
Other non-profit organizations

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The NURTuRE-RKD study will share pseudonymised individual participant data (IPD), including core metadata, deep phenotyping data from RaDaR, and results from biological 'omics' analyses. Data will be securely hosted within the UK Clinical Cohorts Trusted Research Environment (CLiC TRE) at Swansea University, which utilises the SAIL Databank to ensure de-identified data remains within a protected platform. Access for academic or commercial researchers is strictly governed by a formal application process, requiring review and approval from the NURTuRE Strategy Group to ensure research legitimacy. All study data and essential documentation will be archived for a minimum of 20 years following the completion of the study.

IPD sharing plan summary
Stored in non-publicly available repository