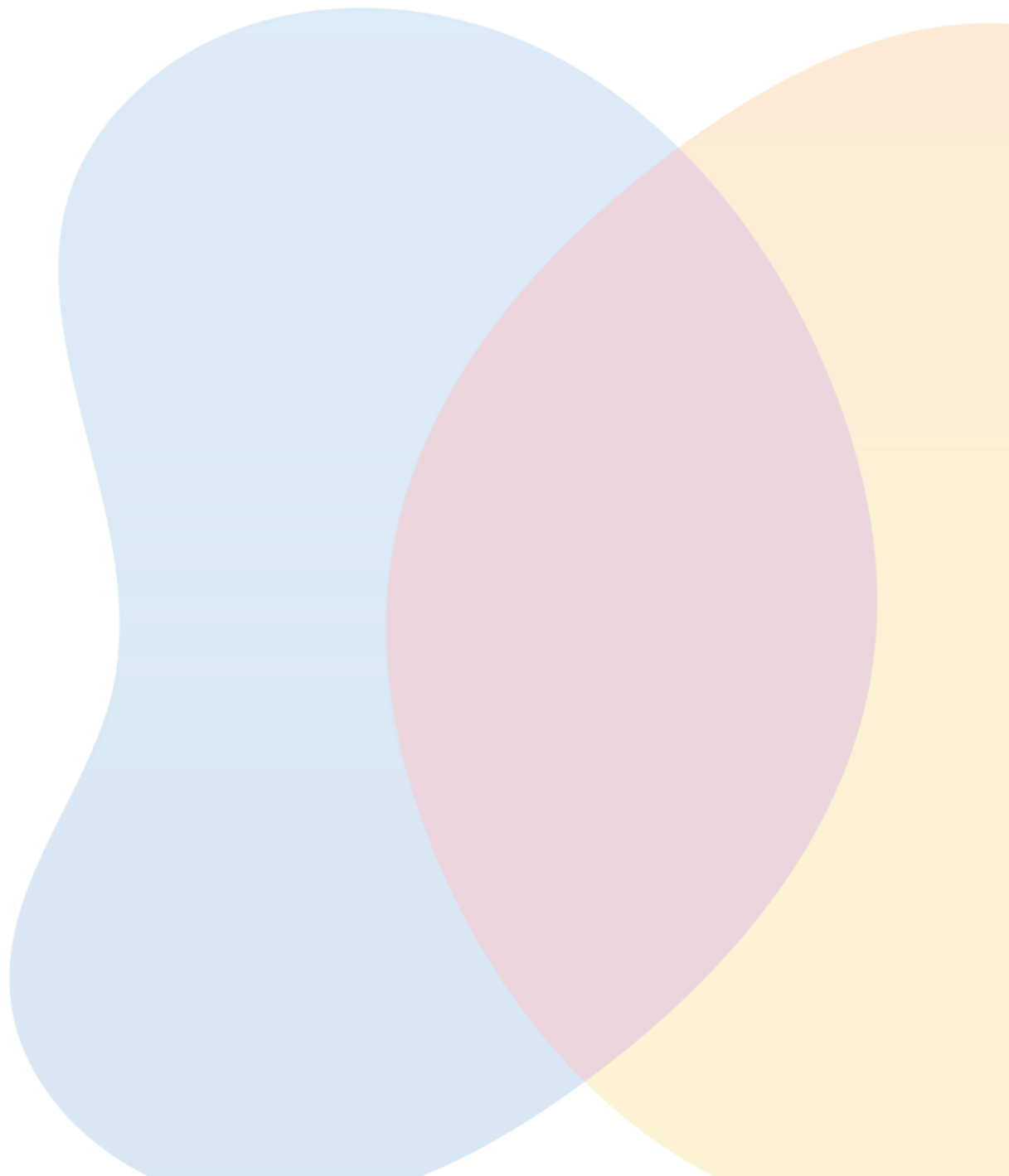




## **RaDaR Training - Introductory**



## Session Agenda

- Introduction to Rare Renal Registry
- Rare Renal website
- RaDaR Information and Consent documentation
- Data quality
- Data entry – demo system

# Introduction

The purpose of the **National Registry of Rare Kidney Diseases** (RaDaR; rare disease registry) is to facilitate translational and epidemiological research into rare kidney diseases by setting up and maintaining a comprehensive clinical database in partnership with Rare Disease Groups.

RaDaR provides an infrastructure to capture both generic and disease-specific clinical information and to collate longitudinal information. Patients and clinicians can view information about the conditions covered by RaDaR on **RareRenal.org**, which links closely with RaDaR.

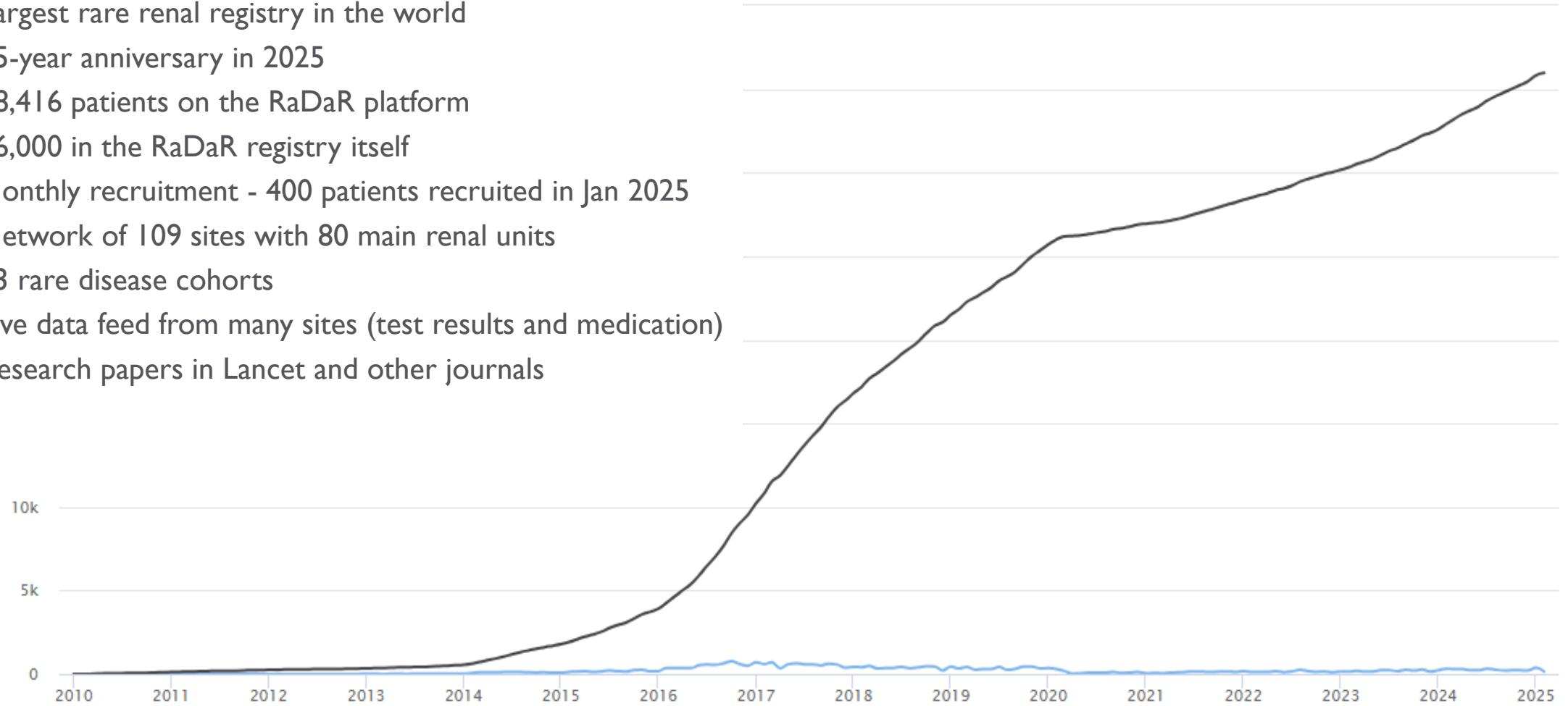


## RaDaR Team

- Functional Team
- Senior Project Manager – Zoe Plummer
- RaDaR Operations manager – Susan Pywell
- RaDaR Senior Data Manager – Garry King
- RaDaR Clinical Fellow – Dr Sherry Masoud
- RaDaR Clinical Fellow – Dr Katie Wong
- RaDaR Statistician – David Pitcher
- RaDaR Statistician – Dane Rogers
  
- Governance
- Prof Danny Gale, Chair of RaDaR based at London Royal Free
- Dr Kate Bramham, Co-Chair of RaDaR based at London King's
- Rare Disease Group Leads (RDGs)
- Site Principal Investigators

## Rare Renal Registry Statistics

- Largest rare renal registry in the world
- 15-year anniversary in 2025
- 38,416 patients on the RaDaR platform
- 36,000 in the RaDaR registry itself
- Monthly recruitment - 400 patients recruited in Jan 2025
- Network of 109 sites with 80 main renal units
- 33 rare disease cohorts
- Live data feed from many sites (test results and medication)
- Research papers in Lancet and other journals



What is a Registry?

## What is a Registry?

- A patient registry is a collection—for one or more purposes—of standardised information about a group of patients who share a condition
- RaDaR – multiple registries?
- What data to collect? Minimum dataset, generic, cohort-specific
- Complete patient data from (before) diagnosis to present day including outcomes
- Where to focus?
- Enrichment projects - cohorts
- Site groups - paediatric, genetic, specialist disease centres, mixed sites with different departments/RaDaR teams
- Recruitment / Retention

## Rare Renal website

- Information portal for patients and clinicians
- Research
- Metadata
- Glossary
- Newsletters
- Events
- Recruitment Resources

<https://ukkidney.org/rare-renal/homepage>



## RaDaR Information for staff

- Protocol & Recruitment Guidelines
- Site file – screening, enrolment, consent forms
- Database users need to send CV, GCP training certificate, signed delegation log and confirm training materials read.
- Study roles

Identification

Inclusion/ exclusion list - clinics / retrospective search

Recruitment

Choose correct consent form / patient retention

Data Entry

Data completeness at recruitment / enrichment

# Identification

- Rarerrenal.org Information portal for clinicians
- Inclusion & Exclusion list
- 33 Cohorts
- >100 conditions
- Newly diagnosed in clinics
- Search List with keyword search (ctrl-F)
- Search hospital clinical system with keywords
- Any queries, ask cohort lead via RaDaR team.

## RaDaR Inclusion and Exclusion Criteria

Diagnosis	Cohort	Inclusion Criteria	Exclusion Criteria	Date of Diagnosis
<b>Hypertensive kidney disease</b>	CKD-Africa Genes	People of African or Afro-Caribbean ancestry with CKD (KDIGO definition), >18 years	Known cause of Kidney disease	Date that clinical diagnosis was first made
<b>Hyperuricaemic Nephropathy (Primary/Familial Hyperuricaemic nephropathy)</b>  <b>Medullary cystic kidney disease</b>	ADTKD	Autosomal Dominant Tubulointerstitial Kidney Disease (ADTKD; previously known as FUAN)  Familial juvenile hyperuricaemic nephropathy  Familial gouty nephropathy  Familial urate nephropathy  Familial interstitial nephropathy  Uromodulin-associated nephropathy  Medullary cystic kidney disease (type I or II)	None stated	Date that genetic confirmation was received
<b>IgA Nephropathy</b>	IgA Nephropathy	Biopsy proven IgA Nephropathy plus proteinuria >0.5g/ day or eGFR<60ml/min	All forms of secondary IgA nephropathy, including Henoch Schonlein purpura	Date of renal biopsy
<b>Isolated autosomal dominant hypomagnesemia, Glaudemans type</b>	Tubulopathy	Isolated autosomal dominant hypomagnesemia  Genetically confirmed homozygous pathogenic variant in KCNA1	None stated	Date that clinical diagnosis was first made

## Consent documentation - Recruitment

- Table and flow chart on the website to help choose the right documents:  
[RaDaR Information and Consent documentation | UK Kidney Association](#)
- Notes
- E-consent does not link to Radar – enter details separately
- Adult is someone aged 16 or over.

### Recruitment

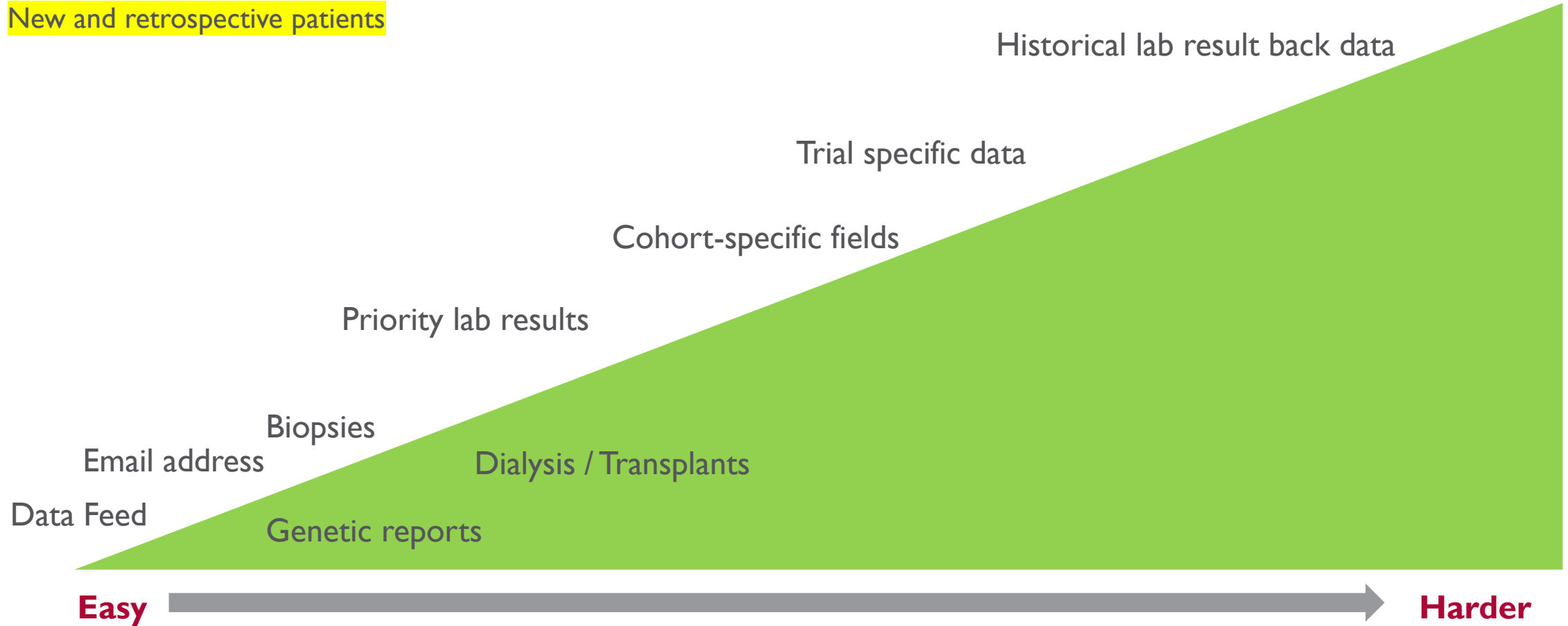
- To recruit from as many sites as possible (geographically diverse)
- To recruit into as many cohorts as possible (including smaller groups)
- Some sites specialise in certain cohorts (e.g. genetic, paediatric centres)
- Informed consent
- Electronic consent

## We need your help to improve the data quality (DQ) for research

- Training materials: <https://ukkidney.org/rare-renal/recruitment>
- Data is valuable for rare disease patients ; better data - research becomes more powerful!
- Stats: 180 recruited patients in one month, 79% had **no** data feed, 77% had **no** pathology report, 18% had **no** email
- Be data sleuths / investigators - feedback queries
- External Link to DQ info: <https://www.gov.uk/government/news/meet-the-data-quality-dimensions>
- Accuracy (transcription errors, units of measure)
- Completeness (temporal, native and transplant biopsies)
- Timeliness (up-to-date, update deceased patients (DoD) on RaDaR, email)
- Validity (things that look incorrect)
- Anonymisation (remove patient identifiable data in reports)

# Triangle of data collection difficulty!

New and retrospective patients



## Data Checklist

- **Data feed** – provides follow-up data
- **Priority lab results at time of diagnosis** (or 90 days either side)
  - Serum Creatinine, eGFR, uACR, uPCR
- **Evidence to support the diagnosis** – biopsy (pathology) report ; genetic report ; clinical picture ; biochemistry
  - Biopsy priority cohorts:
    - Membranoproliferative Glomerulonephritis (MPGN)
    - IgA Nephropathy native AND transplant biopsies
    - Alport Syndrome biopsies and electron microscopy (EM) biopsy reports ( latter is more relevant here)
    - Membranous Nephropathy (MN) biopsies
    - Nephrotic Syndrome (INS)
- **Email address** – newsletters, questionnaires, identification for trials
- **Pathways/ Endpoints** – DoD, All Dialysis sessions / all Transplants
- Cohort specific fields – ask
- Cohort specific guidance available
- Where have patients transferred from and moved to? If patient sites not already in RaDaR, please let us know.
- Checks apply to new patients in RaDaR and retrospective
- **Completeness reports will be available to target gaps**

# Data Entry




- RaDaR database – **data feed** and lab result/ observation **cohort templates**
- Demo system to show registration of new patient

- Aim is to get as complete data as possible for each cohort across all sites
- Rare conditions – every item of data counts
- Data completeness and accuracy - reporting
- Staff can improve the existing patient dataset even before recruiting
- 76% of patients have lab results via a data feed.
- Some blood tests are not sent via data feed and need manual entry
- Compulsory fields
- Generic information
- Cohort-specific requirements
- Genetic and Pathology Reports to support diagnosis



## Patients 35957 patients

[Recruit Patient](#)[Show Demographics](#)[Download](#)

ID ▾	First Name	Last Name	DOB	Gender	Patient Number	Recruited On	RaDaR	Cohorts	Hospitals
<a href="#">39769</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	12/02/2025	12/02/2025	IgA Nephropathy	
<a href="#">39768</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	12/02/2025	12/02/2025	IgA Nephropathy	
<a href="#">39767</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Male	<a href="#">Hidden</a>	12/02/2025	12/02/2025	Vasculitis	
<a href="#">39766</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Male	<a href="#">Hidden</a>	12/02/2025	12/02/2025	ADPKD	
<a href="#">39765</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	12/02/2025	12/02/2025	MGRS	
<a href="#">39764</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Male	<a href="#">Hidden</a>	12/02/2025	12/02/2025	CMV Post Transplant	
<a href="#">39763</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	11/02/2025	11/02/2025	Tubulopathy	
<a href="#">39762</a>	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	11/02/2025	11/02/2025	Tubulopathy	
<a href="#">39761</a> 	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	11/02/2025	11/02/2025	CAKUT	
<a href="#">39760</a> 	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	11/02/2025	11/02/2025	CAKUT	
<a href="#">39759</a> 	<a href="#">Hidden</a>	<a href="#">Hidden</a>		Female	<a href="#">Hidden</a>	11/02/2025	11/02/2025	CAKUT	

## Renal data link filter – Search for patients without link and get switched on!

Renal Link

 ▼

Filter patients who have received data from a renal link.

Test Patient

 ▼

Search







Clear

# Lab Results, Observations

New

## Observations to Display

CAKUT All

Name ^	Short Name	Sample Type	Units	Min Value	Max Value	Count	
<b>Selected</b>							
<i>Please choose some observations from the list below.</i>							
<b>Available</b>							
<input type="text" value="Search"/> 							
	ALT	ALT	Blood	IU/L	0	20000	40
	AST	AST	Blood	IU/L	0	-	39
	Albumin	Alb	Blood	g/L	1	60	41
	Alkaline Phosphatase	AlkP	Blood	IU/L	20	699	41
	Bicarbonate	Bicarb	Blood	mmol/L	5	49	38

	Creatinine	Creatinine	Blood	µmol/L	1	2500
	Diastolic Blood Pressure	BPdia	Observation	mmHg	20	199
	Estimated GFR	eGFR	Blood	ml/min/1.73m <sup>2</sup>	1	150
	Ferritin	Ferr	Blood	µg/L = ng/ml	1	8000
	Folate - Serum	Folate	Blood	ug/L	1	25

First	Previous	1	2	3	4	5	6	7	8	Next	Last
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Table

Graphs

New

<u>Date</u> ▾	<u>Creatinine (µmol/L)</u>	<u>Data Source</u>
11/02/2025 11:21:00 (UTC)	<u>124</u>	UKRDC)
07/01/2025 11:31:00 (UTC)	<u>121</u>	UKRDC)
09/12/2024 09:28:00 (UTC)	<u>123</u>	UKRDC)
06/12/2024 10:12:00 (UTC)	<u>134</u>	UKRDC)

# Lab Results, Observations

Cohort templates

List

View

CAKUT

All

Date

DD/MM/YYYY

Source

Creatinine

Blood

$\mu\text{mol/L}$

DD/MM/YY

Estimated GFR

Blood

$\text{ml/min/1.73m}^2$

DD/MM/YY

Albumin : Creatinine Ratio

Urine

$\text{mg/mmol}$

DD/MM/YY

Protein : Creatinine Ratio

Urine

$\text{mg/mmol}$

DD/MM/YY

Systolic Blood Pressure

Observation

$\text{mmHg}$

DD/MM/YY

Diastolic Blood Pressure

Observation

$\text{mmHg}$

DD/MM/YY

## **Recruitment demonstration**

<https://demo.radar.nhs.uk/#/>

**Thank You!**