UKKA
UK Kidney Association

RaDaR
Registry of Rare Kidney Diseases

RaDaR Training - Introductory

Session Agenda

- Introduction to Rare Renal Registry
- Rare Renal website overview
- RaDaR Study documentation for staff
- Data quality overview
- Radar screens – Lab results, data feed and cohort template
- Data entry – recruit a patient on 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.

RaDaR Team

- Governance
- Rare Disease Committee
  Strategic management body for RaDaR. Chaired by UKKA Academic Vice Presidents John Sayer and Kathrine Parker

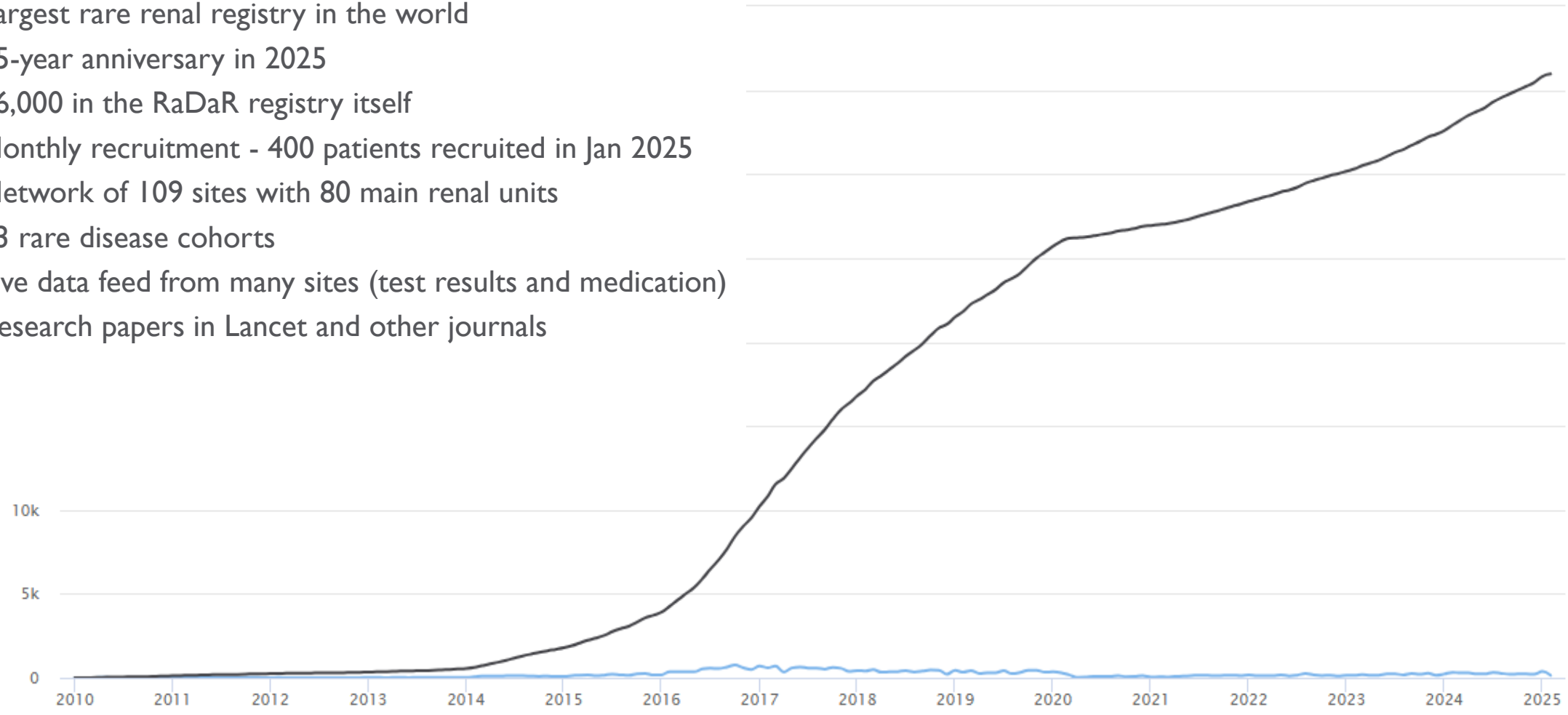
- Prof Danny Gale, Chair of RaDaR based at London Royal Free
- Dr Kate Bramham, Co-Chair of RaDaR based at London King's

- Rare Disease Group Leads (RDGs)
- Site Principal Investigators

- Functional Team
- Operational Lead - Research and RaDaR– Zoe Plummer
- RaDaR Operations manager – Susan Pywell
- RaDaR Senior Data Manager – Garry King
- RaDaR Data Manager – Bidhan Pant
- RaDaR Clinical Fellow – Dr Sherry Masoud
- RaDaR Clinical Fellow – Dr Katie Wong
- RaDaR Statistician – David Pitcher
- RaDaR Statistician – Dane Rogers

Rare Renal Registry Statistics

- Largest rare renal registry in the world
- 15-year anniversary in 2025
- 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

- RaDaR is a research database, not a research study.

  We collect data that already exists and does not affect patient treatment.

  We don't have a recruitment end date or recruitment targets.

  We aim to recruit as many patients as possible for as long as possible. We voluntarily renew our ethics every five years - next renewal due in 2030.

Rare Renal website

- Information portal for patients (via Kidney Care UK) and clinicians
- Research
- Metadata
- Glossary
- Newsletters
- Events
- Recruitment Resources

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

RaDaR Study documentation for staff

- RaDaR Principal Investigator (PI) and lead RaDaR staff at your site
- Database users need to send CV, GCP training certificate, signed delegation log and confirm training materials read.
- Protocol & Recruitment Guidelines
    - Table and flow chart on the website to help choose the right documents
    - E-consent does not link to Radar. Adult is someone aged 16 or over.
- Site file – screening, enrolment, consent forms
- Study roles

Identification

Inclusion/ exclusion list - clinics / retrospective search

Recruitment

Choose correct consent form / patient retention

Data Entry

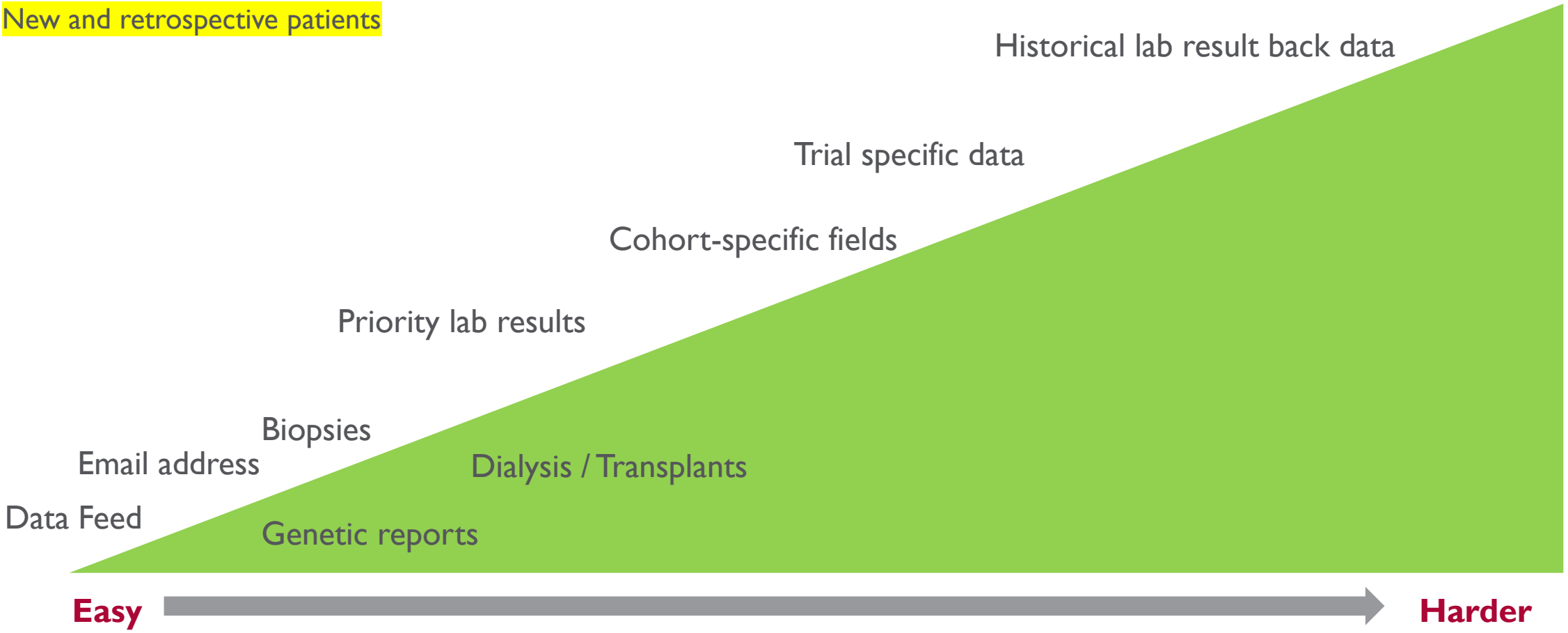
Data completeness at recruitment / enrichment

Data Quality Overview

- Training materials: https://ukkidney.org/rare-renal/recruitment
- Data is valuable for rare disease patients ; better data - research becomes more powerful!
- Patients are recruited each month with **no** data feed, **no** pathology report and **no** email. Please make your site 100% complete
- 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

Celebrating 15 Years RaDaR
National Registry of Rare Kidney Diseases

Radar Screens

RaDaR | Cohorts | Hospitals | Patients | Users | News | Stats | Admin

Patients 35957 patients

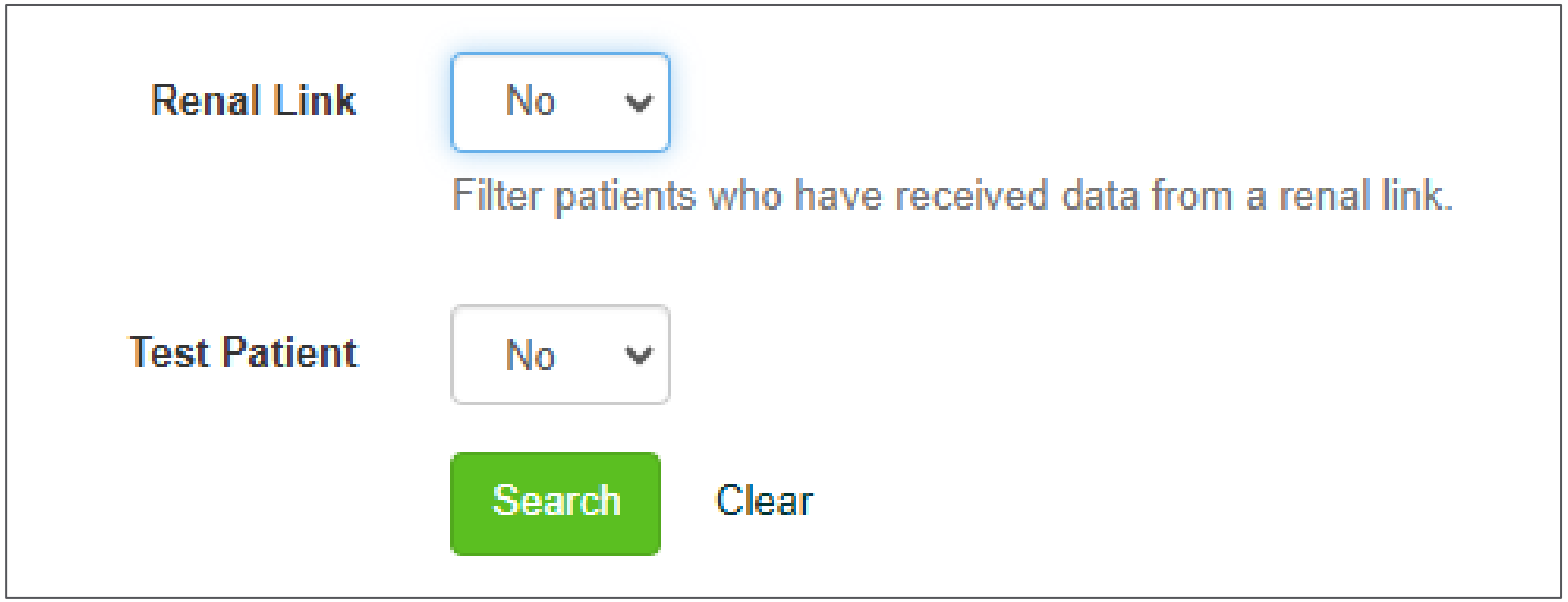
Recruit Patient

Show Demographics

Download

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

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



Lab Results, Observations

New

Observations to Display

CAKUT | All

Name	Short Name	Sample Type	Units	Min Value	Max Value	Count
Selected						
Please choose some observations from the list below.						
Available						
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

First | Previous | 1 | 2 | 3 | 4 | 5 | ... | 7 | 8 | Next | Last

+	Creatinine	Creatinine	Blood	µmol/L	1	2500
+	Diastolic Blood Pressure	BPdia	Observation	mmHg	20	199
+	Estimated GFR	eGFR	Blood	ml/min/1.73m²	1	150
+	Ferritin	Ferr	Blood	µg/L = ng/ml	1	8000
+	Folate - Serum	Folate	Blood	ug/L	1	25

Table | Graphs

New

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

Cohort templates

Lab Results, Observations

List | View

CAKUT | **All**

Date DD/MM/YYY Source

Creatinine	Blood	µmol/L	DD/MM/YY
Estimated GFR	Blood	ml/min/1.73m²	DD/MM/YY
Albumin : Creatinine Ratio	Urine	mg/mmol	DD/MM/YY
Protein : Creatinine Ratio	Urine	mg/mmol	DD/MM/YY
Systolic Blood Pressure	Observation	mmHg	DD/MM/YY
Diastolic Blood Pressure	Observation	mmHg	DD/MM/YY

Recruit patient on demo system

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

Thank You!