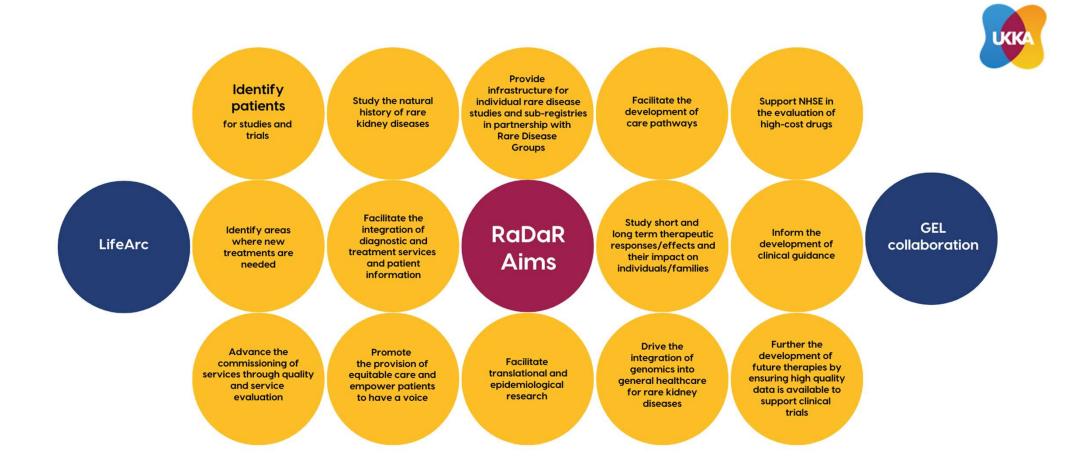


RaDaR in 2025

Zoe Plummer – Operations Lead (UKKA Research and RaDaR) Susan Pywell – RaDaR Operations Manager







New 5-year strategy paper coming late 2025!

RaDaR in numbers (May 2025)



- >40 million individual results & observational records from 1980-present on patients aged zero to over 90
- >36,000 participants
- >100 recruiting sites
- >2,000 users over RaDaR's lifetime

176 rare conditions

33 Rare Disease Groups

>300 clinical and/or academic contributors

50 patient representatives

11 internal staff members

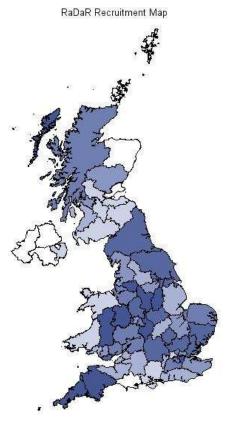
34 academic papers referencing RaDaR directly



Recruitment patterns









Patients per hundred thousand population







17.7 - 28.0 28.4 - 40.6





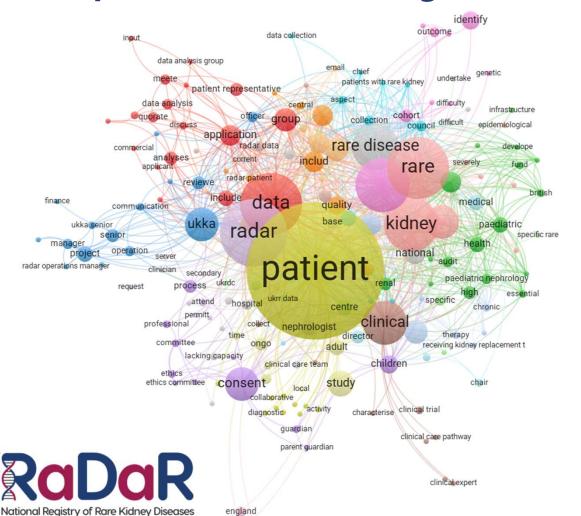
Group name	No of patients
ADPKD	9,062
Vasculitis	5,828
IgA Nephropathy	5,301
Nephrotic Syndrome	5,016
Membranous Nephropathy	2,947
MPGN, DDD and C3 Glomerulopathy	1,269
Alport Syndrome	1,199
Pregnancy & Chronic Kidney Disease	809
Post transplant CMV (Opened 2024)	643
CKD Africa	636
Cystinuria	536
Tubulopathy	467
Inherited Renal Cancers	426
CAKUT (Opened 2024)	384
aHUS	314
Tuberous Sclerosis	301
ARPKD/NPHP	275

Group name	No of patients
ADTKD/FUAN	268
MGRS	266
Cystinosis	196
Stec HUS	193
Lupus Nephritis (Opened 2024)	183
Retroperitoneal Fibrosis	171
BK Nephropathy	146
Hyperoxaluria	145
HNF1-B	126
Fibromuscular Dysplasia	100
Dent Disease & Lowe Syndrome	77
Calciphylaxis	74
Fabry Disease	64
APRT-D	10
Pure Red Call Aplasia	9
Mitochondrial Renal Disease	6



Other ways of understanding RaDaR





northern ireland

RaDaR Protocol v14 as a semantic map

- Size of circle indicates how many times that word appears in the protocol
- Lines indicate how the words / concepts are linked to each other
- Patients are central!