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Real-world clinical profile, treatment patterns and outcomes associated with C3G and primary IC-MPGN: Insights from the UK RaDaR registry

Lexy Sorrell[1], Carly Rich[2], Veruska Carboni[2], Jameel Nazir[2], David Pitcher[1,3], Edwin Wong[4], Katie Wong[1,3], Sherry Masoud[1,3], Daniel P. Gale[1,3]

[1]National Registry of Rare Kidney Diseases, Bristol, United Kingdom; [2]Swedish Orphan Biovitrum AB, Stockholm, Sweden; [3]Centre for Kidney and Bladder Health, University College London, London, United Kingdom; [4]National Renal Complement Therapeutics Centre, Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, United Kingdom

Disclosures

- Lexy Sorrell: None
- Carly Rich: employee of Sobi and may hold stock or stock options
- Veruska Carboni: employee of Sobi and may hold stock or stock options
- Jameel Nazir: employee of Sobi and may hold stock or stock options
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- Edwin Wong: has received payment, honoraria, or support for attending meetings and/or travel from Novartis, Alexion, and Arrowhead, is on the data monitoring safety boards of Novartis, Alexion, Biocryst, and Apellis and holds leadership positions as Chair of MPGN DDD and C3G Rare Disease Group of UK Kidney Association
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C3G and primary IC-MPGN are rare kidney diseases associated with poor prognosis

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- These diseases are driven by dysregulation of the complement system, leading to glomerular deposition of C3 and its downstream effectors (plus immunoglobulin deposition in IC-MPGN)[1,2]
- C3G and primary IC-MPGN have similar incidence, clinical presentation and disease progression[3,4]
- Both conditions are associated with a poor prognosis, characterised by progressive decline in kidney function, limited effectiveness of conventional therapies, and kidney failure in ~ 50% of patients within 10 years of diagnosis (requiring dialysis or transplantation)[3,5]

To better understand the unmet needs, this study aimed to describe the patient demographics, disease characteristics, treatment patterns and clinical outcomes in these two diseases

C3, complement component 3; C3G, complement 3 glomerulopathy; IC-MPGN, immune-complex membranoproliferative glomerulonephritis.

1. Kavanagh D, et al. *Kidney Int Rep* 2025;11(1):17–31; 2. Vivarelli M, et al. *Kidney Int* 2024;106(3):369–391; 3. Noris M, Remuzzi G. *Nephrol Dial Transplant* 2024;39(2):202–214; 4. Caravaca-Fontán F, et al. *Nephron.* 2025;150(1):25–40; 5. Halfon M, et al. *Kidney Int Rep* 2024;10(1):75–86.

Methods: RaDaR overview

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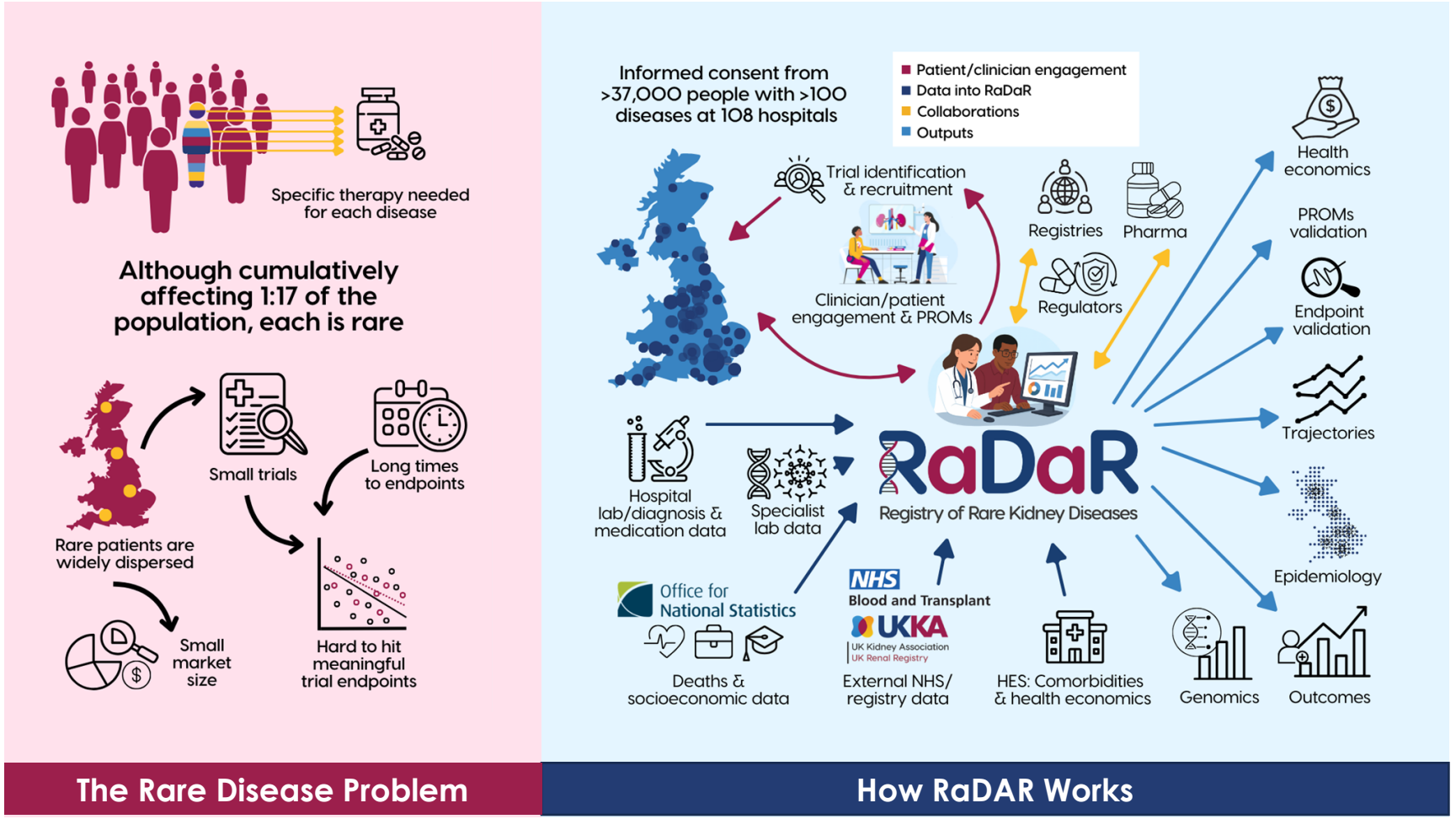

- RaDaR has been recruiting patients since 2010[1]
- Includes all four nations of the UK
- Captures over 30 rare disease groups
- Includes over 38,000 patients[a]

[a] > 37,000 as of August 2025.

HES, Hospital Episode Statistics; NHS, National Health Service; RaDaR, UK National Registry of Rare Kidney Diseases; PROM, patient-reported outcome measure; UK, United Kingdom; UKKA, UK Kidney Association.

Gale DP. *Nephrol Dial Transplant* 2026;41(5):839–845.

Methods: Retrospective, longitudinal cohort study

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Study eligibility criteria

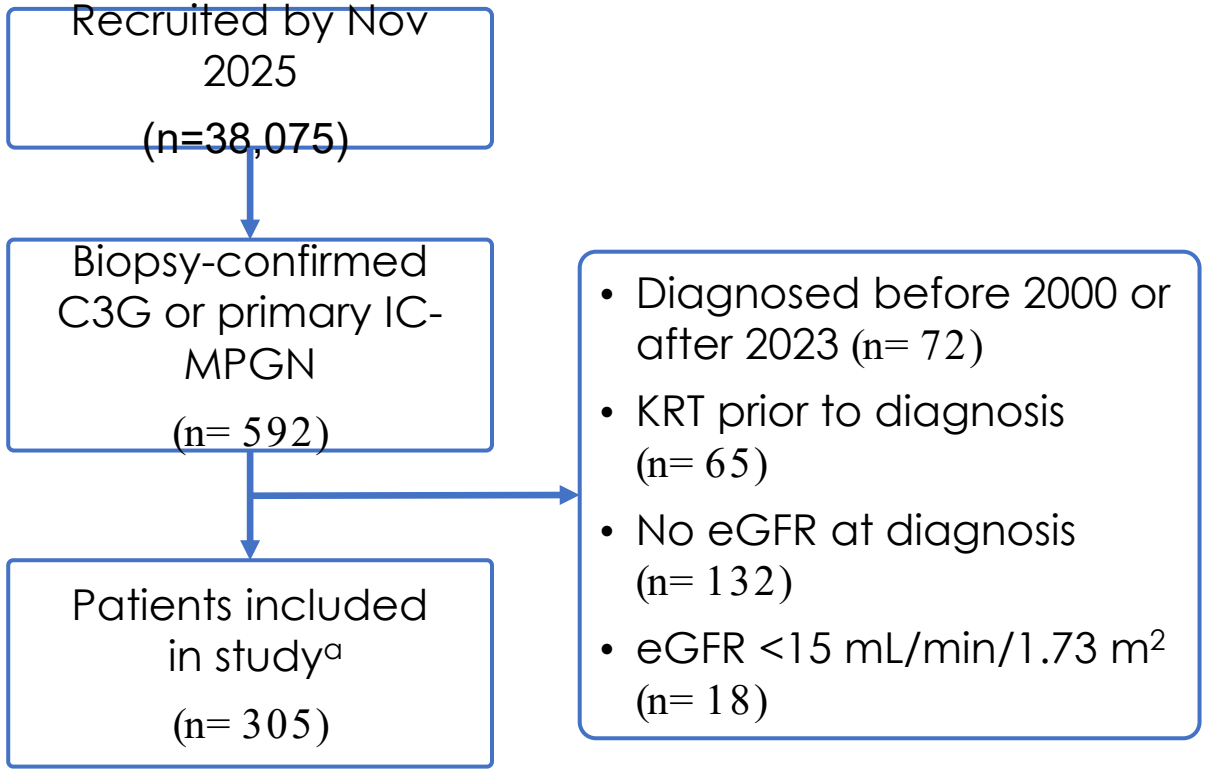
Inclusion criteria

1. Biopsy-confirmed C3G or primary IC-MPGN
2. Diagnosed between 01 January 2000 and 31 December 2023 (selection period)
3. Recruited to RaDaR prior to 05 November 2025

Exclusion criteria

1. No recorded eGFR at diagnosis (± 90 days)
2. eGFR < 15 mL/min/1.73 m^2 at diagnosis
3. KRT prior to diagnosis

Patient flow chart



[a]Patients were followed from diagnosis until withdrawal, death, or end of the selection period.
C3G, complement 3 glomerulopathy; eGFR, estimated glomerular filtration rate; IC-MPGN, immune-complex membranoproliferative glomerulonephritis; KRT, kidney replacement therapy; RaDaR, UK National Registry of Rare Kidney Diseases.

Methods: Endpoints and analyses

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Variables	Description
Baseline characteristics	Including age, sex, ethnicity, CKD stage, reported medications
Longitudinal outcome	eGFR at baseline[a] and last follow-up[b]
Other outcomes	Proportion of patients and Kaplan–Meier estimates for dialysis, kidney transplant and death

- Results were stratified by disease type (C3G vs. primary IC-MPGN) and age (paediatrics, adults)
- No statistical comparisons between groups were conducted

[a]± 90 days from diagnosis. [b]Prior to kidney replacement therapy, death, or end of the selection period.
C3G, complement 3 glomerulopathy; CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; IC-MPGN, immune-complex membranoproliferative glomerulonephritis.

Results: Patient characteristics

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	C3G (n=159)		Primary IGMPGN (n=146)	
Characteristics at diagnosis	Paediatrics (n=88)	Adults (n=71)	Paediatrics (n=62)	Adults (n=84)
Age, years; median (IQR)	11 (8–15)	39 (25–51)	9 (7–12)	51 (35–64)
Male sex; n (%)	47 (53)	43 (61)	30 (48)	38 (45)
White ethnicity, n (%)[a]	74 (84)	54 (76)	53 (85)	73 (87)
C3G subgroup, n (%)				
C3 glomerulonephritis	50 (57)	54 (76)	–	–
DDD	37 (42)	17 (24)	–	–
C3G-NOS	1 (1)	0	–	–
eGFR; median (IQR)	88 (60–109)	49 (30–73)	88 (65–109)	40 (30–59)
UPCR, g/g; median (IQR)	[n=61] 3.6 (1.2–6.6)	[n=46] 3.3 (1.2–6.3)	[n=46] 4.5 (2.7–7.8)	[n=51] 4.1 (1.4–8.0)
CKD stage, n (%)				
1	42 (48)	13 (18)	30 (48)	8 (10)
2	25 (28)	15 (21)	17 (27)	11 (13)
3a	4 (5)	10 (14)	9 (15)	16 (19)
3b	9 (10)	17 (24)	6 (10)	29 (35)
4	8 (9)	16 (23)	0	20 (24)
Median follow-up, years (IQR)	10.2 (6.0–12.9)	8.9 (5.5–13.2)	11.0 (7.8–15.1)	8.7 (5.8–13.4)

[a]Ethnicity data missing for C3G adult (n=1) and IGMPGN paediatrics (n=2).
C3, complement component 3; C3G, complement 3 glomerulopathy; CKD, chronic kidney disease; DDD, dense deposit disease; eGFR, estimated glomerular filtration rate; IGMPGN, immune-complex membranoproliferative glomerulonephritis; IQR, interquartile range; NOS, not otherwise specified; UPCR, urine protein creatinine ratio.

Results: Medication

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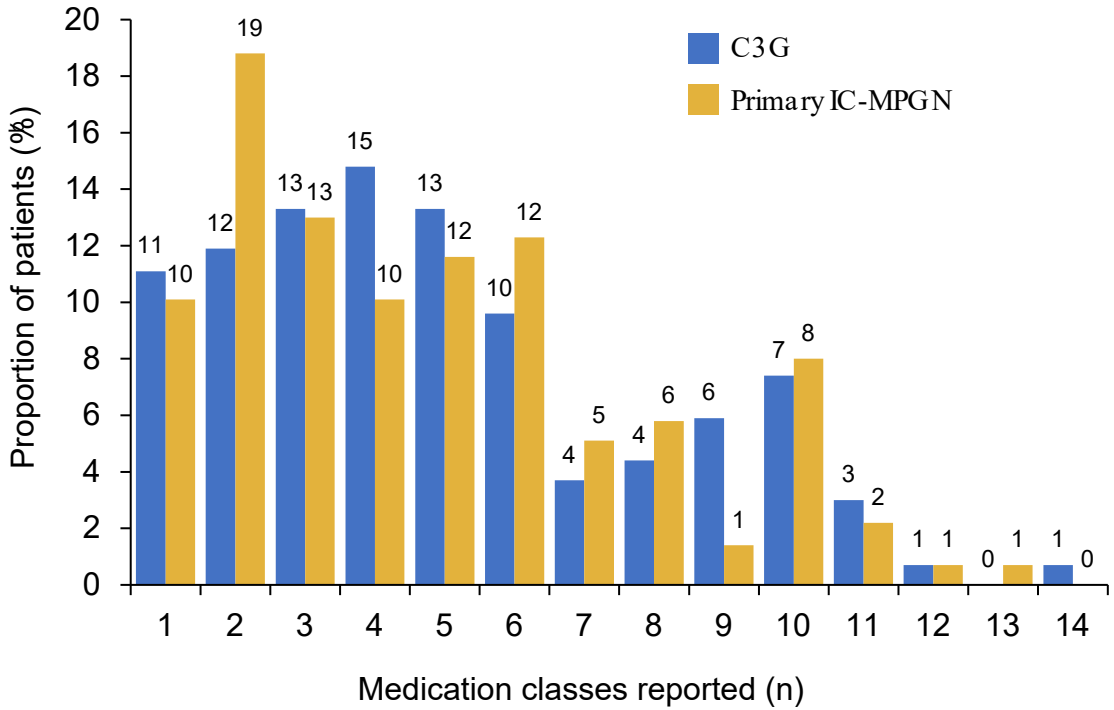
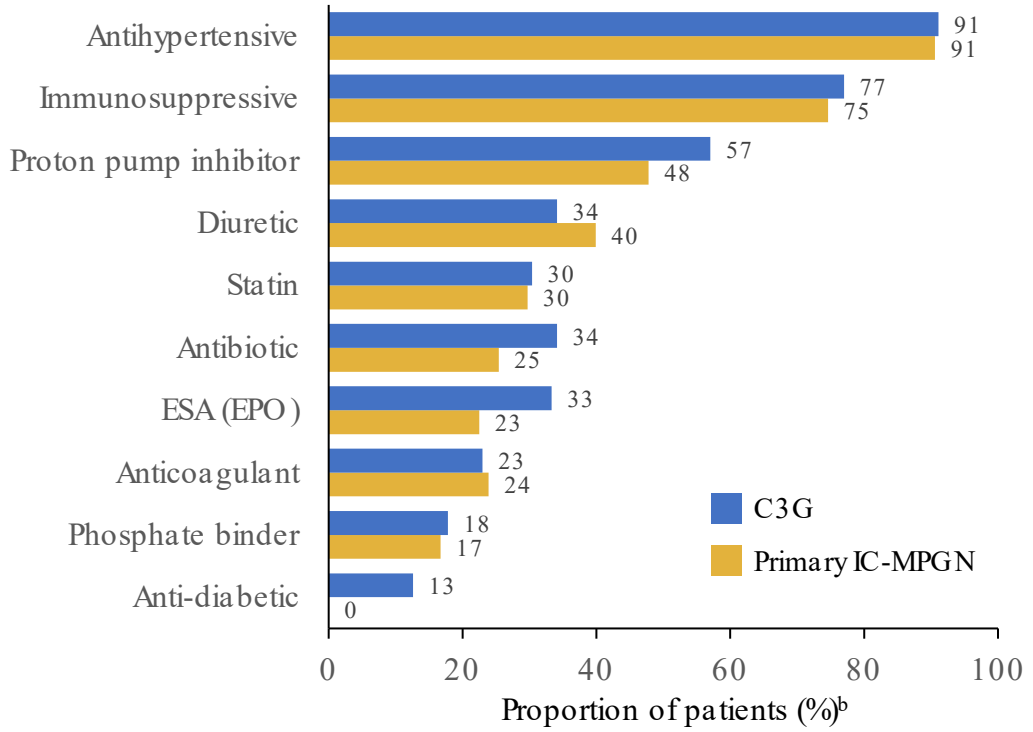
Number of medication classes reported[a]



Multiple conventional therapies were used:
median (IQR) number of medication classes per patient was 4 (2–6)

Type of medication classes[a]



Antihypertensives and immunosuppressants were the most common medications

[a]Medication data available for 273 (90%) patients. [b]Rounded percentage values are shown.
C3G, complement 3 glomerulopathy; EPO, erythropoietin; ESA, erythropoiesis-stimulating agent; IC-MPGN, immune-complex membranoproliferative glomerulonephritis; IQR, interquartile range.

Results: Kidney replacement therapy events

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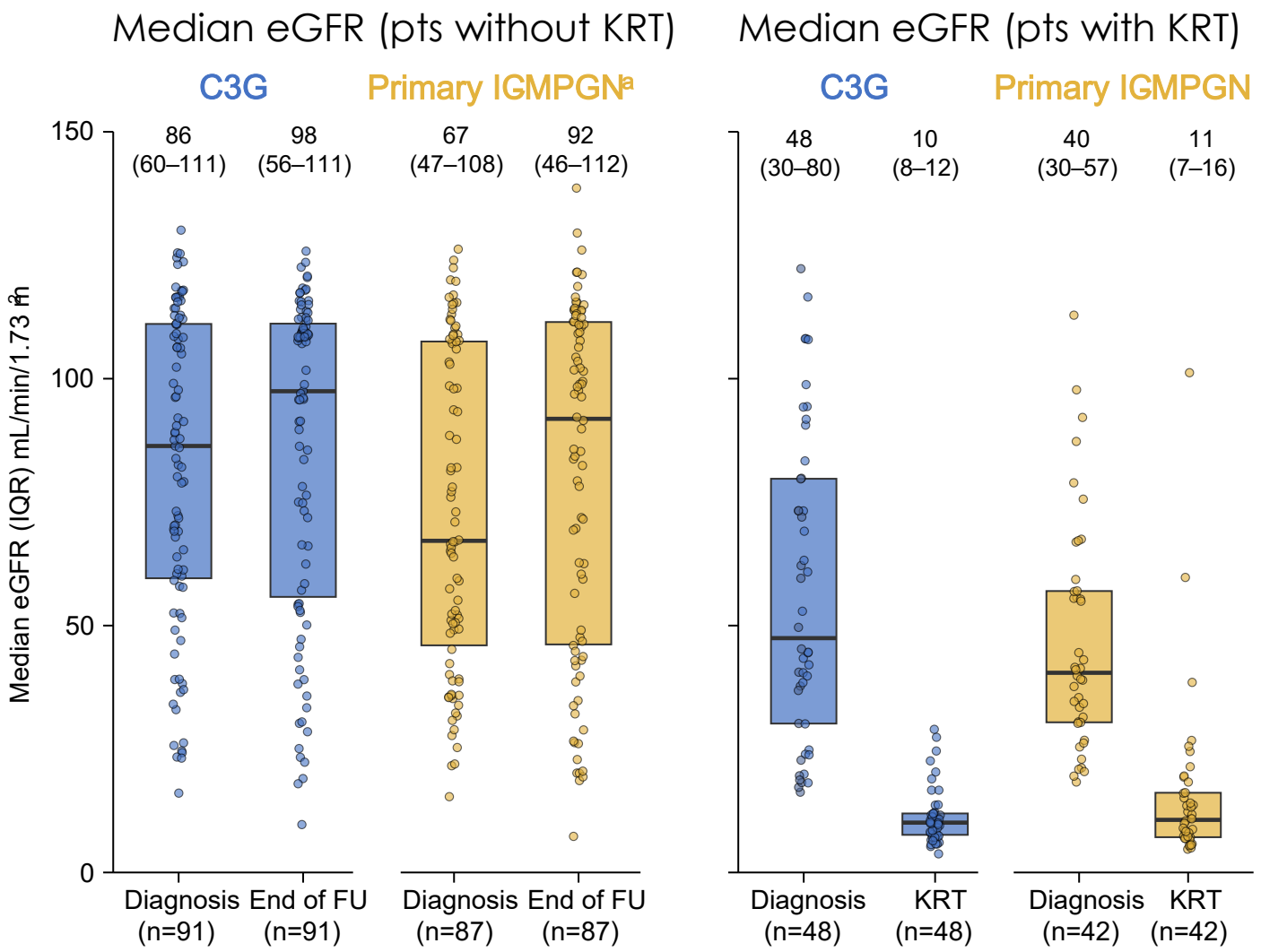
	C3G (n=159)		Primary IGMPGN (n=146)	
KRT events	Number of events (%)	Median (IQR) years from diagnosis to event[a]	Number of events (%)	Median (IQR) years from diagnosis to event[a]
Dialysis (incl. following pre-emptive transplant)	47 (30)	2.9 (0.9–6.2)	40 (27)	2.3 (0.6–8.0)
Transplant (incl. post-dialysis)	42 (26)	5.8 (3.5–9.6)	32 (22)	4.6 (2.7–7.5)
1 transplant	38 (24)	–	25 (17)	–
2 transplants	4 (3)	–	6 (4)	–
3 transplants	0	–	1 (1)	–
First KRT (dialysis or pre-emptive transplant)	55 (35)	3.1 (1.0–8.6)	44 (30)	3.3 (0.6–6.4)
First KRT = dialysis	45 (28)	–	37 (25)	–
First KRT = pre-emptive transplant	10 (6)	–	7 (5)	–

[a]Median time was calculated among patients who had an event.
C3G, complement 3 glomerulopathy; IGMPGN, immune-complex membranoproliferative glomerulonephritis; IQR, interquartile range; KRT, kidney replacement therapy.

Results: eGFR over follow-up



Patients with KRT had lower eGFR values at diagnosis and reported a substantial reduction in eGFR at follow-up

[a]Two eGFR values in the primary IC-MPGN group (> 150 mL/min/1.73 m²) were omitted from the plot for clarity, one at diagnosis and one at end of FU.
C3G, complement 3 glomerulopathy; eGFR, estimated glomerular filtration rate; FU, follow-up; IC-MPGN, immune-complex membranoproliferative glomerulonephritis; KRT, kidney replacement therapy; IQR, interquartile range; pt, patient.

Results: Time to first kidney replacement therapy event

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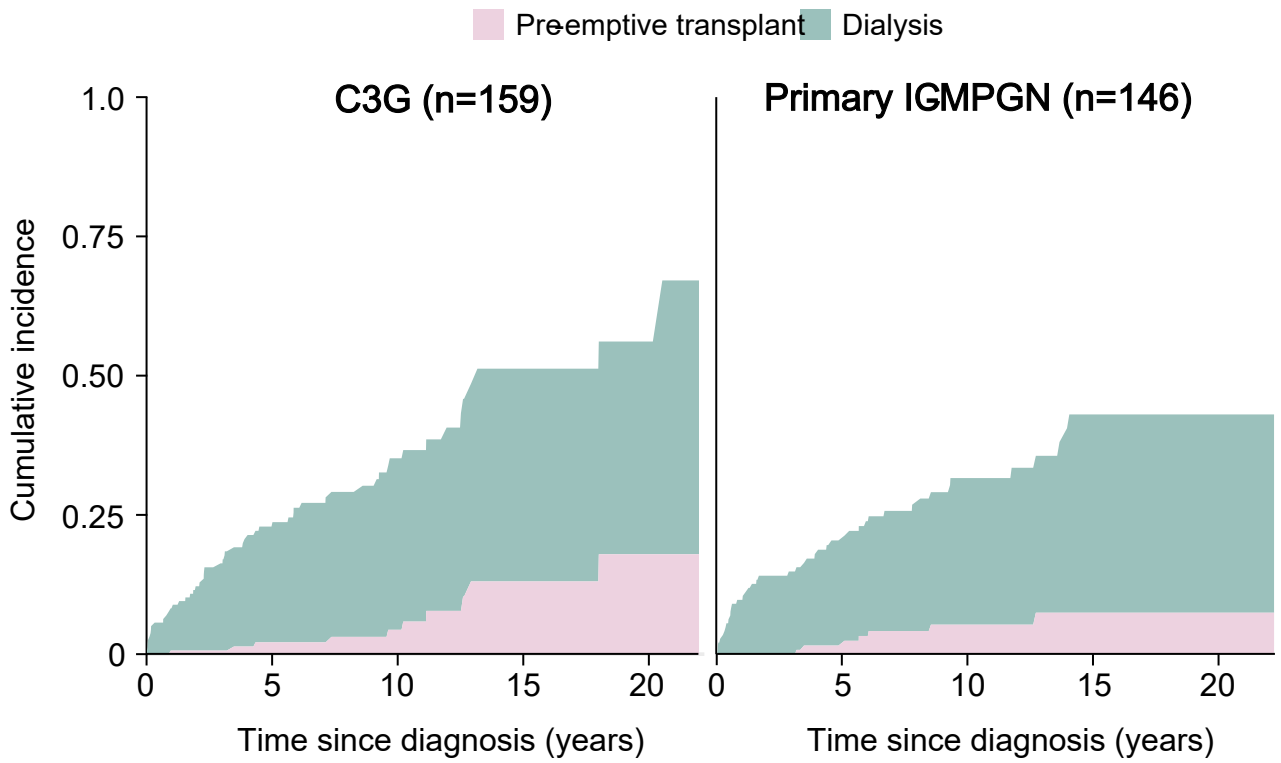
Cumulative incidence of first KRT from diagnosis[a]



Overall, 99 (32%)patients received KRT during follow-up

Dialysis / pre-emptive transplant was received by:
- C3G: n=45 (28%) / 10 (6%)
- Primary IGMPGN: n=37 (25%) / 7 (5%)

Median (IQR) years from **diagnosis to first KRT** among patients who received KRT:
- C3G: 3.1 (1.0–8.6)
- Primary IGMPGN: 3.3 (0.6–6.4)

[a]Censoring at withdrawal, death or end of follow-up.
C3G, complement 3 glomerulopathy; IC-MPGN, immune-complex membranoproliferative glomerulonephritis; IQR, interquartile range; KRT, kidney replacement therapy.

Results: Time-to-first kidney replacement therapy or death

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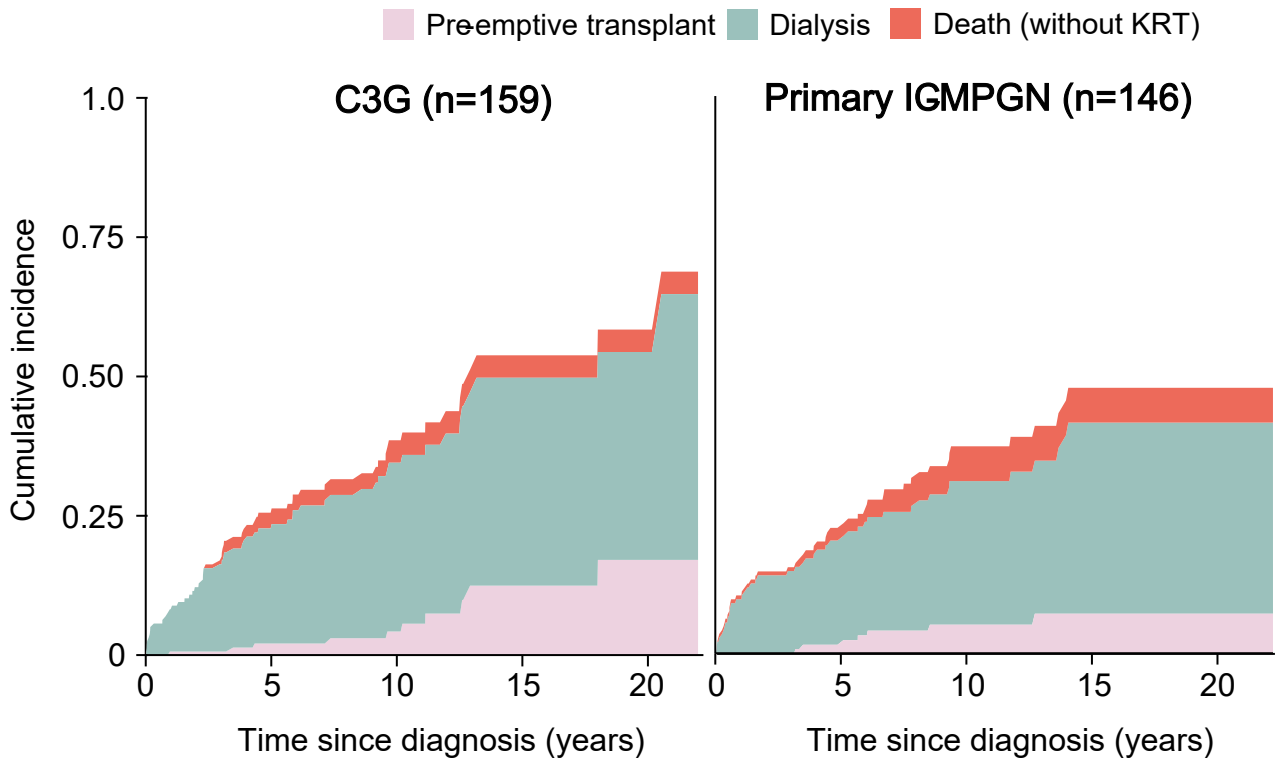
Cumulative incidence of first KRT or death from diagnosis[a]



Overall, 29 (10%) patients **died** during follow-up:
- C3G: n=11 (7%)
- Primary IGMPGN: n=18 (12%)

9 patients **died without KRT** during follow-up:
- C3G: n=4 (3%)
- Primary IGMPGN: n=5 (3%)

[a]Censoring at withdrawal or end of follow-up.
C3G, complement 3 glomerulopathy; IC-MPGN, immune-complex membranoproliferative glomerulonephritis; KRT, kidney replacement therapy.

Progressive renal decline, substantial clinical burden and poor outcomes despite multiple conventional therapies

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Longitudinal data from patients with C3G or primary IC-MPGN followed for ~10 years in the UK

Patients experienced poor outcomes despite substantial exposure to conventional therapies

~30%
of patients quickly progressed to requiring dialysis or transplant, indicating substantial patient, caregiver and healthcare system burden

~10%
all-cause mortality highlights poor prognosis, particularly in such a young population

These findings highlight the need for effective therapies targeting complement dysregulation to preserve kidney function, delay or prevent kidney failure, reduce reliance on KRT, and improve survival

C3G, complement 3 glomerulopathy; IC-MPGN, immune-complex membranoproliferative glomerulonephritis; KRT, kidney replacement therapy; UK, United Kingdom.

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