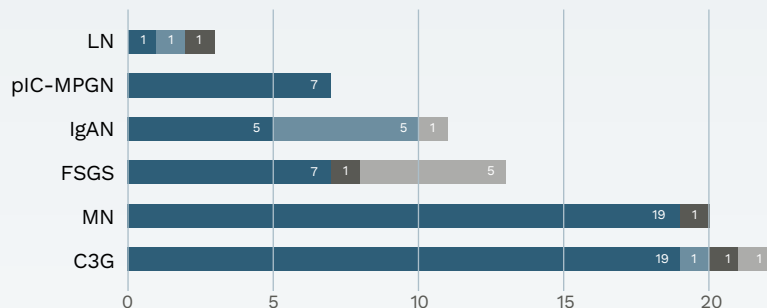


Demographics

Total number of patients, by country and type of rare kidney disease



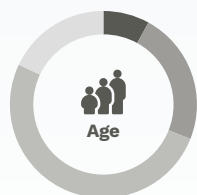
Number of patients who reported having been diagnosed with the one of the rare kidney diseases prioritized in the Barometer (n=73).

Note: if a patient has more than one disease then it will be double counted across the different disease areas

Patients' distribution by gender, age, and country (n=73)



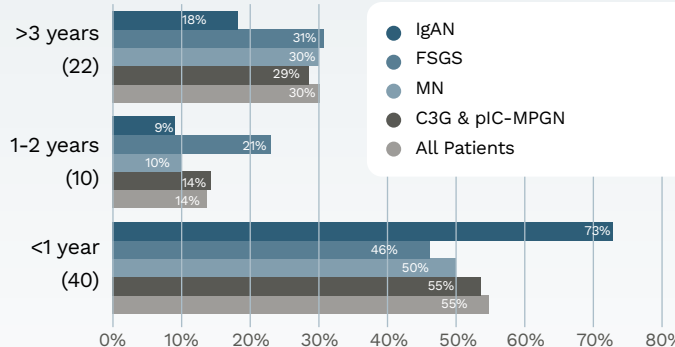
● Male 47%
● Female 53%



● <18 8%
● 18-40 23%
● 41-65 51%
● >65 18%

Time to diagnosis

Diagnostic delays of over 1 year were reported by 44% of all patients (32). Systematic kidney health checks and fast referrals are key to prevent and slow disease progression.



Among the 25 patients who provided further details, the factors they felt contributed to these delays include:

- Knowledge of the medical professionals of the specific conditions (64%)
- Misdiagnosis (24%)
- Waiting time to conduct tests and/or to see a specialist (24%)
- Number of appointments/steps in the process (16%)

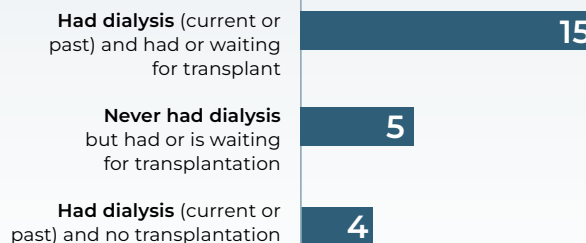
64 patients reported having undergone at least one kidney biopsy, and 2 patients reported having more than five biopsies after having experienced 1-2 years diagnosis delay.

Number of years it took to receive the final correct diagnosis for all patients vs. specific diseases (C3G & pIC-MPGN: n=29; MN: n=20; FSGS: n=13; IgAN: n=11; all patients: n= 73. Three patients reported having two conditions. One did not respond to this question)

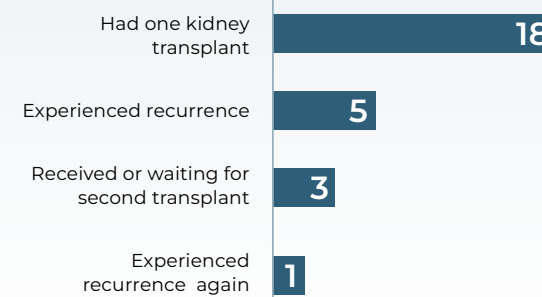
Overview of patients on kidney replacement therapy

Diagnosis delays make kidney replacement therapies inevitable for patients and which have profound disruption to their lives

One in four patients with a rare kidney disease has required dialysis (n=19)



One in four patients with a rare kidney disease experienced disease recurrence after their first transplant



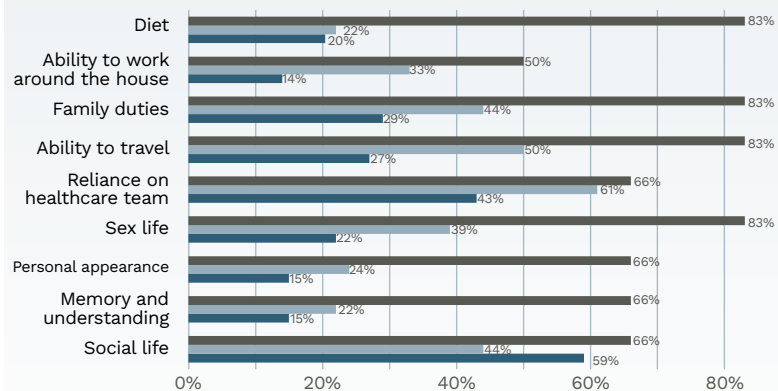
Abbreviations: AAV: Anti-neutrophil cytoplasmic autoantibody (ANCA) - associated vasculitis; Anti-GBM: anti-glomerular basement membrane disease/ Goodpasture syndrome; C3G: C3 glomerulopathy (including Dense Deposit Disease); FSGS: Focal segmental glomerulosclerosis or steroid-resistant nephrotic syndrome; IgAN: Immunoglobulin A nephropathy (Berger's disease); LN: Lupus nephritis; MN: Membranous nephropathy; pIC-MPGN: Immune complex-mediated membranoproliferative Glomerulonephritis.

Key Data from the Rare Kidney Diseases Barometer Survey

Socioeconomic burden

IMPACT OF RARE KIDNEY DISEASE ON PATIENTS' DAILY LIFE

Patients diagnosed with rare kidney diseases who are receiving dialysis experience a greater impact on their daily life, and while a transplant may alleviate some of this strain, it does not entirely eliminate it

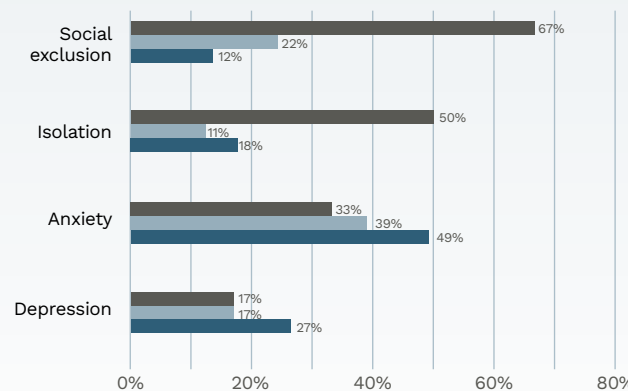


- Patients on dialysis (now or past)
- Transplanted patients
- Patients not on dialysis or transplanted

Percentage of patients who mentioned a moderate to extreme impact of their disease on different activities (Patients on dialysis (now or past) but NOT transplant: n=6; transplanted patients: n= 18, patients NOT on kidney replacement therapies; n= 49)

PSYCHOLOGICAL IMPACT

Although anxiety and depression are persistent issues for many patients, undergoing dialysis can intensify challenges with social interaction, often exacerbating feelings of isolation and exclusion

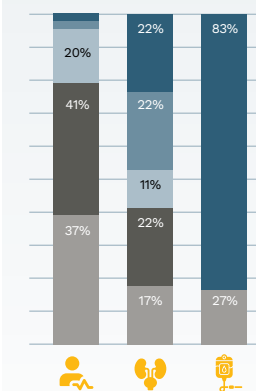


- Patients on dialysis (now or past)
- Transplanted patients
- Patients not on dialysis or transplanted

Percentage of patients NOT on kidney replacement therapies who mentioned an impact on mental health aspects across the different diseases (C3G & pIC-MPGN: n=29; MN: n=20; FSGS: n=5; IgAN: n=4; all patients: n= 49. three patients reported having two conditions)

IMPACT ON WORK AND SCHOOL

Patients on dialysis experience the highest rates of absenteeism, with 83% reporting more than one month of missed work or school in the past six months



- None
- < 1 week
- 1-2 weeks
- 2 weeks - 1 month
- > 1 month

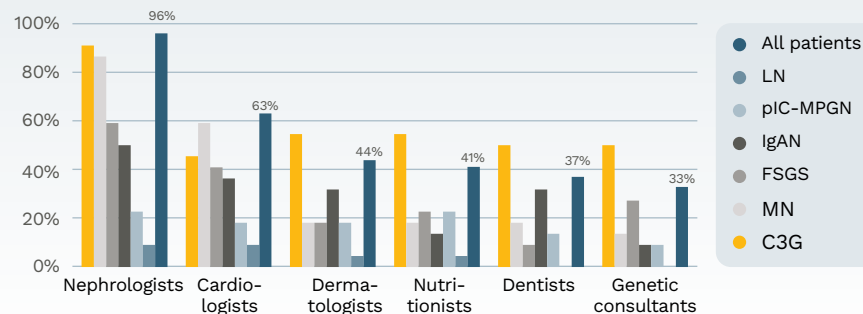
- Patients not on dialysis or transplanted
- Transplanted patients
- Patients on dialysis

Time missed from work or school due to the disease and its management over the previous 6 months (Patients on dialysis (now or past) but NOT transplant: n= 6; transplanted patients: n= 18, patients NOT on kidney replacement therapies; n= 49)

Healthcare needs of people living with RKDs

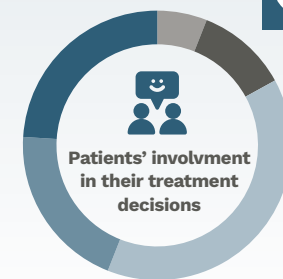
Rare kidney diseases require a multidisciplinary approach.

Number of patients who mentioned having been referred to the listed healthcare professionals/specialists distributed per disease area (C3G=22; MN=20; FSGS=13; IgAN=11; pIC-MPGN=7; LN=3; total patients=73. Three patients reported having two conditions). Note: if a patient reported more than one disease then it will be double counted across the different disease areas



Most patients feel involved in decisions, regarding their treatment (n=73)

- Not at all 6%
- Slightly 11%
- Moderately 39%
- Very 20%
- Extremely 24%



Abbreviations: AAV: Anti-neutrophil cytoplasmic autoantibody (ANCA) - associated vasculitis; Anti-GBM: anti-glomerular basement membrane disease/ Goodpasture syndrome; C3G: C3 glomerulopathy (including Dense Deposit Disease); FSGS: Focal segmental glomerulosclerosis or steroid-resistant nephrotic syndrome; IgAN: Immunoglobulin A nephropathy (Berger's disease); LN: Lupus nephritis; MN: Membranous nephropathy; pIC-MPGN: Immune complex-mediated membranoproliferative Glomerulonephritis