

Title:**IgA nephropathy: A Real-world comparison between disease severity, symptom burden, and treatment satisfaction reported by patients and nephrologists**

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Background and Aims: Immunoglobulin A nephropathy (IgAN) is the most common form of primary glomerulonephritis worldwide, with an estimated annual incidence of ~25/1000000. IgAN presents with many clinical manifestations, including hematuria, proteinuria, and hypertension (high blood pressure). This analysis aims to compare perceptions of symptom burden, disease severity and treatment satisfaction between patients living with IgAN and their treating nephrologists in Europe, the United States (US) and Asia.

Method: Data were drawn from the Adelphi IgAN Disease Specific Programme, a point-in-time survey of IgAN-treating nephrologists and their consulting IgAN patients, conducted in the US, Europe (EU5; France, Germany, Italy, Spain, United Kingdom [UK]), Japan, and China, June-October 2021. Nephrologists completed structured online patient record forms for successive patients presenting with IgAN. Patients voluntarily completed questionnaires that corresponded with the nephrologist records. Both the nephrologist and patient-reported data included demographics, IgAN signs and symptoms, disease severity and treatment satisfaction.

Results: Data was collected for 991 patients with IgAN, where matched nephrologist and patient-reported forms were completed. Mean (standard deviation [SD]) patient age was 42.1 (13.8) years, and 57% were male.

Nephrologists and patients reported their perceived severity of the patient's IgAN, on a scale of mild, moderate, and severe (n=981). Nephrologists and patients agreed on severity for 77% of patients (US 82%, EU5 77%, Japan 70%, China 78%).

The level of nephrologist awareness of patient-reported symptoms was analysed. Where patients reported nausea/vomiting, it was not recognised by nephrologists in 85% of cases. This was similarly seen for appetite loss (80%), headaches/migraines (69%), and aching joints (67%).

Patients and nephrologists were asked to score the patient's fatigue and pain on a scale from 0 (none) to 10 (worst possible). Overall, nephrologists and patients agreed on the

patient's fatigue score in 33% of cases (n=991). Fatigue was under-reported by nephrologists in comparison to what patients reported in 46% of cases with a mean (SD) difference in score of 2.47 (1.46), and over-reported in 21% of cases with a mean (SD) score difference of 1.95 (1.27). Patients and nephrologists agreed on the patient's self-reported pain score in 53% of cases (n=988). Pain was under-reported by nephrologists in 26% of cases with a mean (SD) score difference of 2.24 (1.44) and over-reported in 21% of cases with a mean (SD) 2.06 (1.48) score difference.

Nephrologists and patients reported their satisfaction with the patients' current IgAN treatment as satisfied, neither satisfied or dissatisfied, or dissatisfied (n=982). There was a 65% agreement between the nephrologists and patients' treatment satisfaction. Percentage agreement varied across countries: EU5 76%, US 77%, China 61%, Japan 58%.

Conclusion: Although there seemed to be a good level of agreement between nephrologists and patients on their overall IgAN severity, nephrologists under-reported patient symptoms, notably nausea/vomiting and appetite loss, and fatigue. Although not IgAN specific, these symptoms can decrease a patient's quality of life. Satisfaction with current treatment also differed in around a third of cases. This highlights that communication between nephrologists and their patients can be improved, especially when it comes to appreciating IgAN symptom burden. This could be combated through more investment in a holistic patient evaluation. Cultural differences may impact symptom perception and reporting, as evidenced by differences between nephrologists and patients in different countries/regions. An improvement in communication may lead to a better management of IgAN patients, including treatment, and subsequently a better quality of life for patients with IgAN.