

# Immunoglobulin A Nephropathy: Patient-Reported Symptoms Prior to First Consultation and Diagnosis - Results from a Real-World Survey

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## INTRODUCTION

- Immunoglobulin A nephropathy (IgAN) is the most common form of primary glomerulonephritis worldwide, with an estimated annual incidence of 25 cases per million people<sup>1</sup>.
- Proteinuria (foamy urine) and hematuria (tea coloured urine) are the most common clinical manifestations of IgAN<sup>2,3</sup>, however the burden of such symptoms on diagnosis and disease severity is not fully understood.

## AIM

- The aim of this analysis was to better understand patient reported symptoms prior to the first nephrologist consultation and diagnosis of patients with IgAN, in the United States, Europe, China, and Japan.

## METHOD

- Data were drawn from the Adelphi IgAN Disease Specific Programme (DSP<sup>4</sup>)™, a point-in-time survey of IgAN-treating nephrologists and their consulting patients, conducted in the United States (US), Europe (EU5: France, Germany, Italy, Spain, United Kingdom), China, and Japan between June and 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, with questions about their IgAN on that day regarding demographics, clinical data, and signs and symptoms.

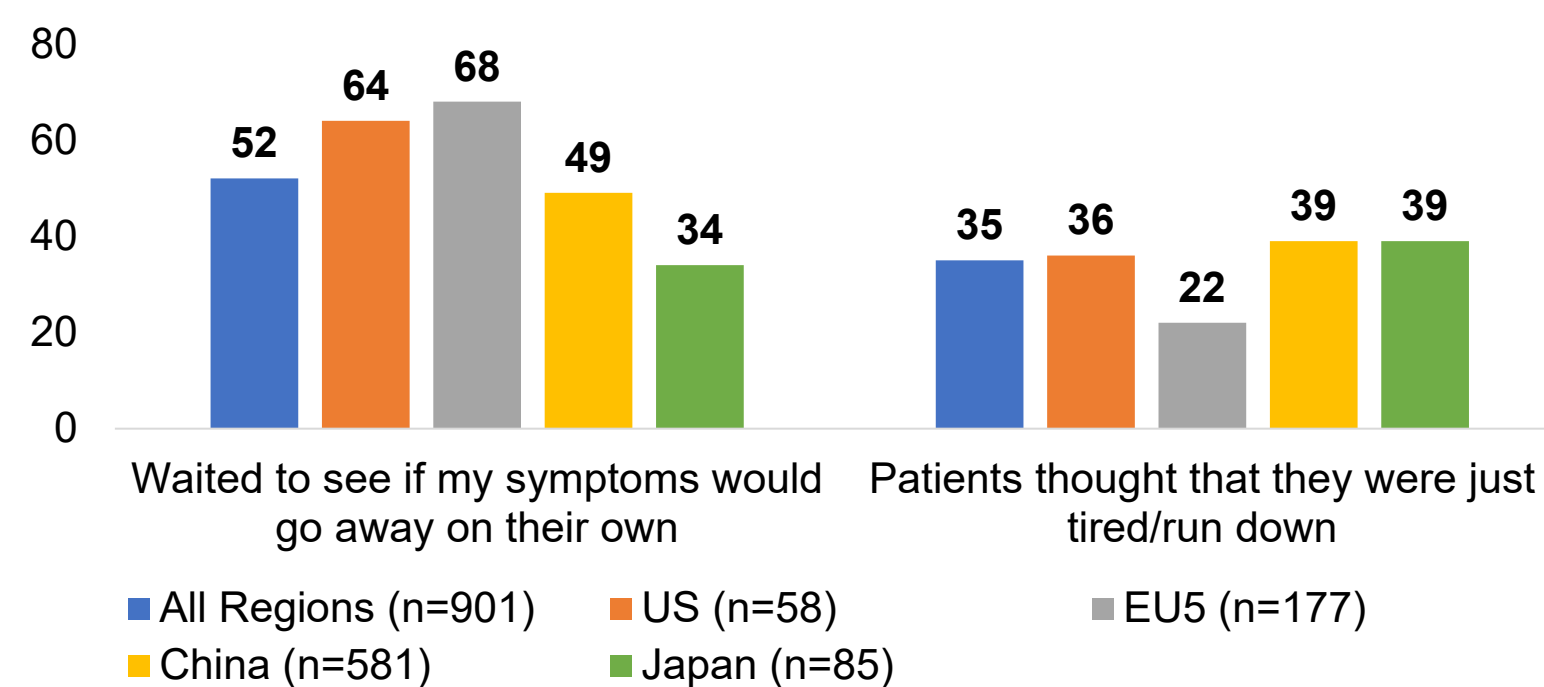
## RESULTS

- A total of 991 patients with a nephrologist confirmed IgAN diagnosis completed a self-reported questionnaire.

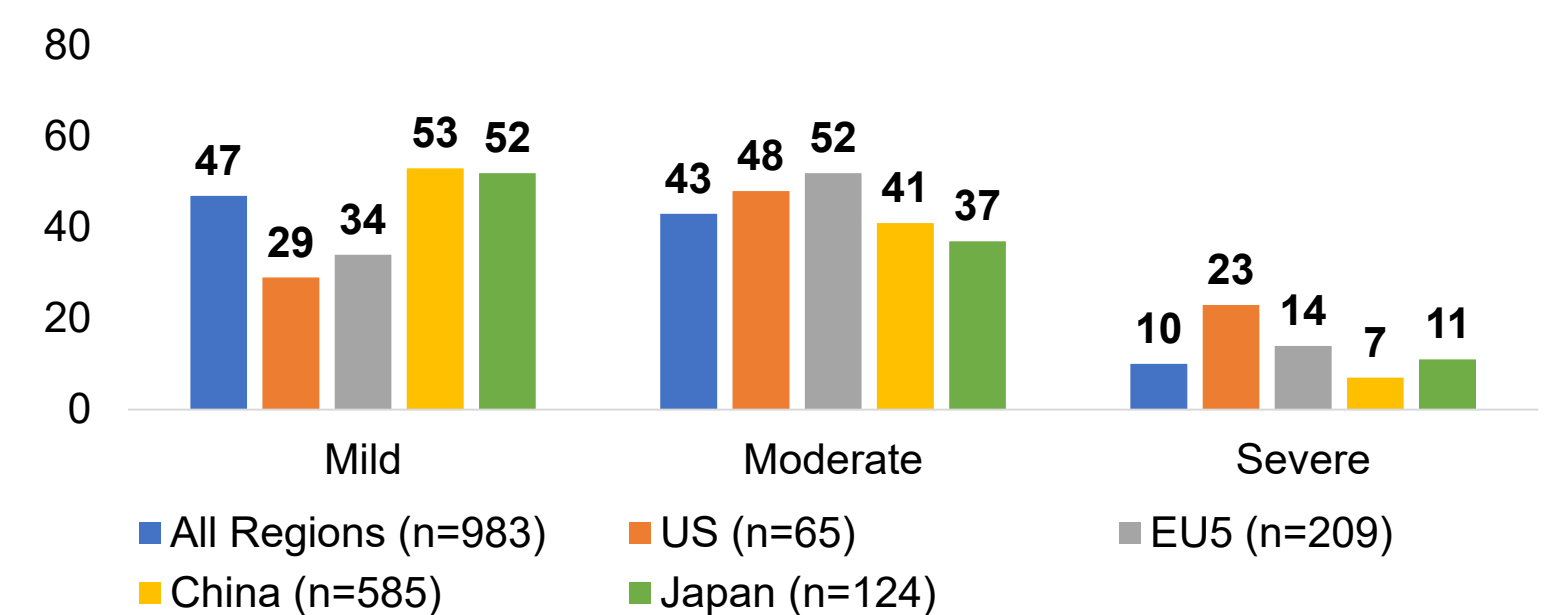
## RESULTS

- Mean (standard deviation [SD]) patient age was 42.1 (13.8) years, and 57% were male.
- Patients first noticed their IgAN symptoms at a mean (SD) age of 37.1 (13.1) years, ranging from 35.8 (12.6) years in China to 39.9 (15.4) years in Japan.
- Top symptoms that prompted patients to see a doctor are reported in **figure 1**.
- Patients reported a median (interquartile range [IQR]) time of 12.9 (4.3-25.7) weeks from first experiencing IgAN symptoms to consulting a doctor, ranging from 8.6 (4.3-25.7) weeks in EU5 to 21.4 (5.4-52.1) weeks in Japan.
- Median (IQR) patient-reported time from first doctor visit to IgAN diagnosis was 8.0 (4.0-16.0) weeks. This finding was consistent across geographical regions except in Japan, where median (IQR) duration was 12.0 (4.0-24.0) weeks.

**Figure 4. Reasons for delay between first symptoms and visit to a doctor (in %)**

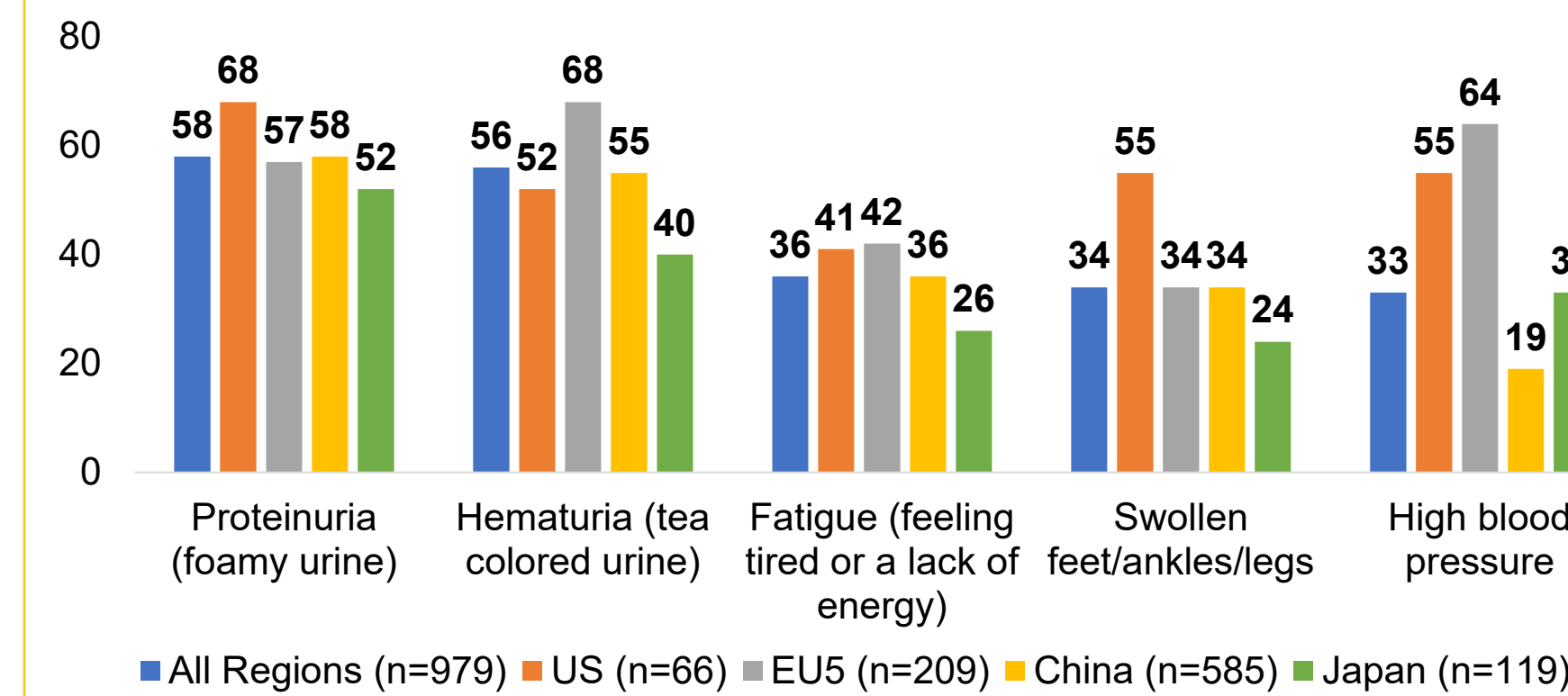


**Figure 5: Patient-reported IgAN severity at diagnosis (in %)**

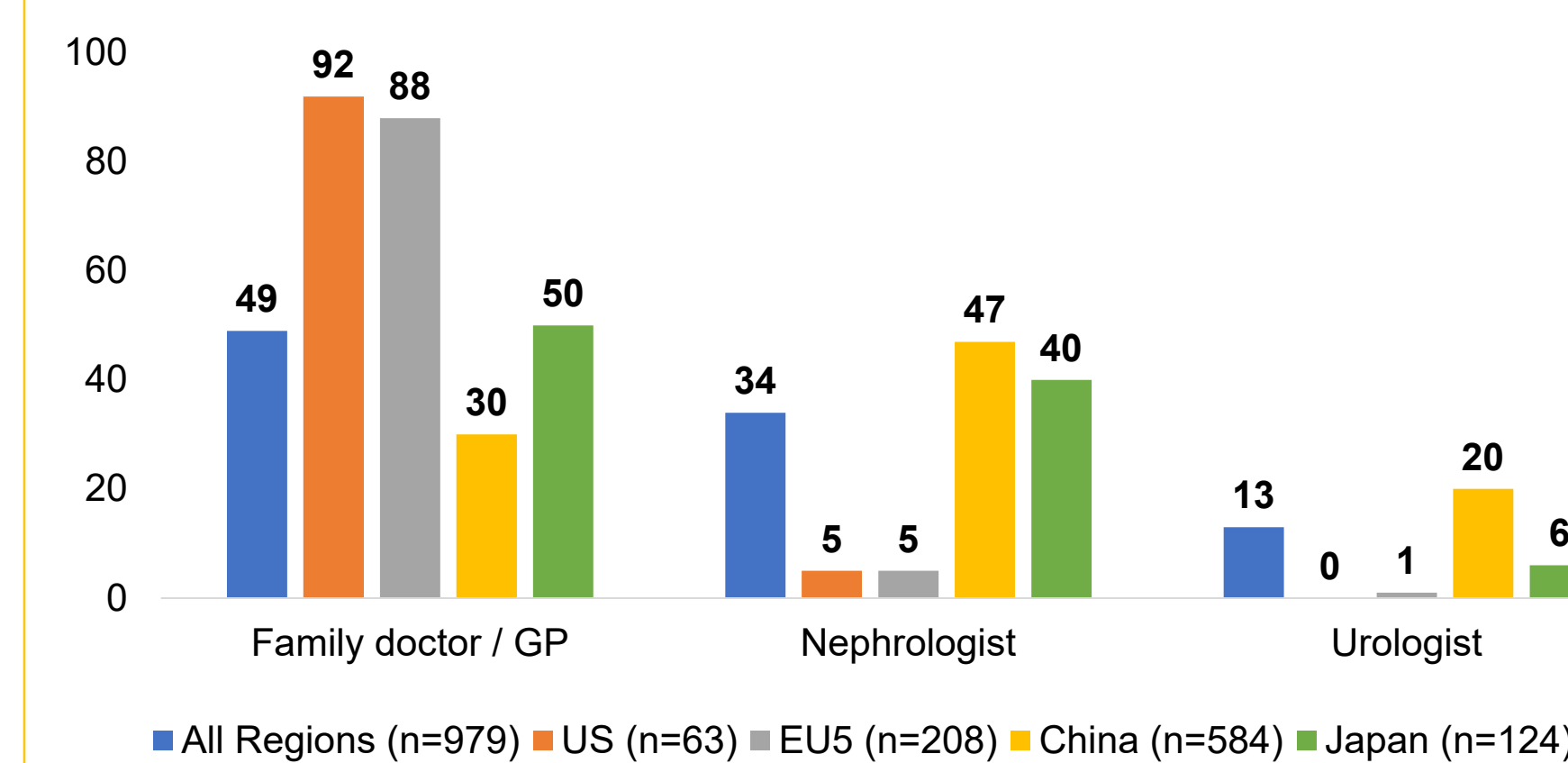


Abbreviations: EU5: France, Germany, Italy, Spain and the United Kingdom; IgAN: Immunoglobulin A Nephropathy; US: United States

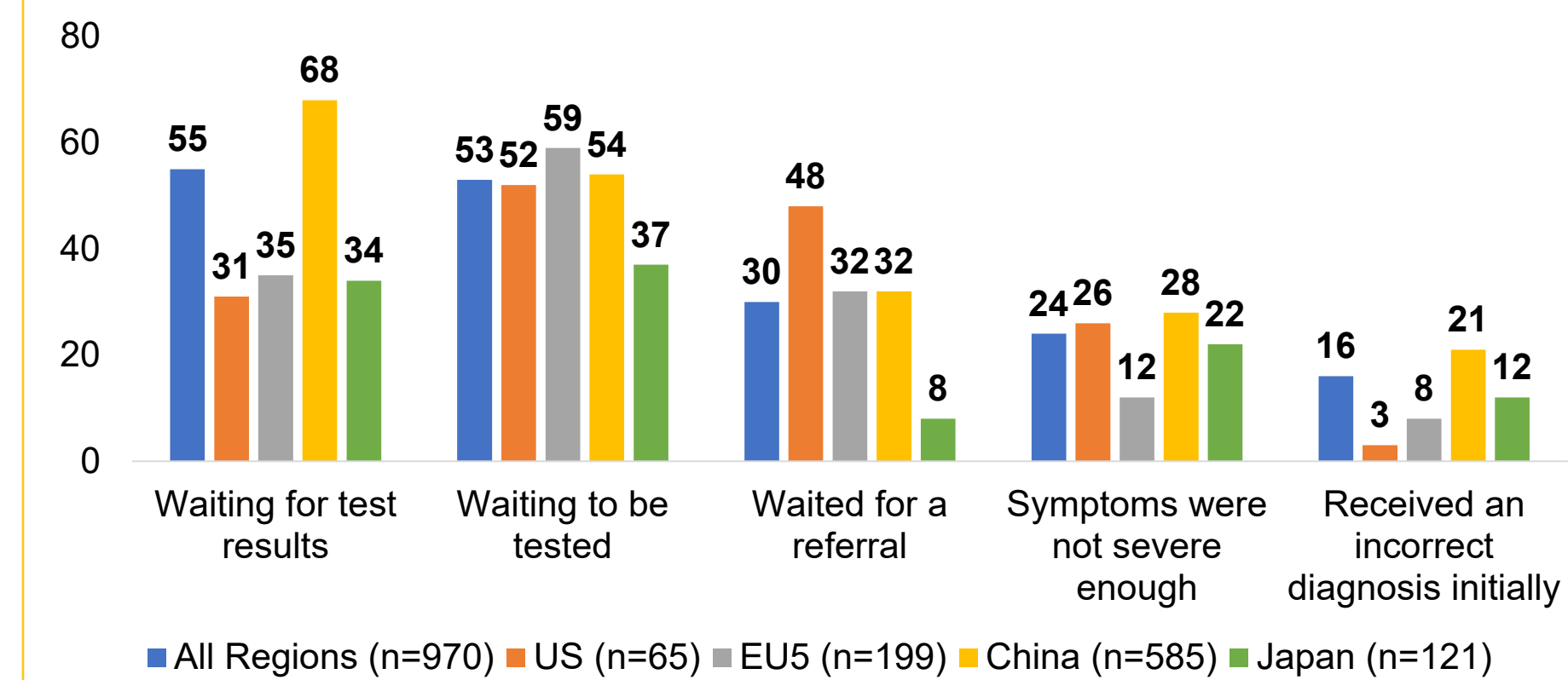
**Figure 1. Top symptoms that prompted patients to see a doctor (in %)**



**Figure 2. Patients who they consulted first for their IgAN symptoms (in %)**



**Figure 3. Patient-reported reasons for delay in their diagnosis (in %)**



Abbreviations: EU5: France, Germany, Italy, Spain and the United Kingdom; GP: General Practitioners; IgAN: Immunoglobulin A Nephropathy; US: United States

## CONCLUSIONS

- Despite experiencing symptoms, patients with IgAN waited several weeks before consulting a physician. Of those with a delayed diagnosis, over half described their IgAN as moderate or severe.
- Symptoms take relatively long time to develop which may cause a long delay in diagnosis. Therefore, greater awareness of symptoms of kidney disease may lead to patients seeking help for their symptoms and getting a confirmed diagnosis more quickly.
- Improvement of the IgAN patient journey pathway in a health care system is important to expedite timely diagnosis of IgAN and subsequent management of the disease.

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## REFERENCES

- McGrogan A et al.** The incidence of primary glomerulonephritis worldwide: a systematic review of the literature. *Nephrology Dialysis Transplantation*. 2011;26(2):414-30.
- George AT et al.** PUK31—the burden associated with immunoglobulin A nephropathy (IgAN). *Value Health*. 2018;21:S480.
- Tyagi N et al.** PUK32 patient insights for immunoglobulin A nephropathy (IgAN) using social media listening. *Value in Health*. 2019;22:S919.
- Anderson P et al.** Real-world physician and patient behaviour across countries: Disease-Specific Programmes—a means to understand. *Current medical research and opinion*. 2008 Nov 1;24(11):3063-72.

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