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Real-world survey on healthcare resource utilisation and physician-reported burden in patients with primary Immune Complex Membranoproliferative Glomerulonephritis

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INTRODUCTION

- Primary Immune Complex Membranoproliferative Glomerulonephritis (IC-MPGN) is a rare, rapidly progressing kidney disease[1], characterised by proteinuria, haematuria and fatigue.
- Due to its rarity, there are currently no approved targeted treatments for IC-MPGN[1]. Only treatments which focus on controlling IC-MPGN-related symptoms are available.
- This suggests further investigations are needed to understand how the lack of targeted treatments contributes to overall disease burden and its associated impact on both the healthcare system and patients.

OBJECTIVE

- To describe the impact that primary IC-MPGN has on healthcare resource utilisation (HCRU) and the humanistic burden experienced by patients with primary IC-MPGN in the US and EU4 (France, Germany, Italy, and Spain).

METHODS

- Data were collected in the US and EU4 between February and June 2024, as part of the Adelphi IC-MPGN Disease Specific Programme (DSP™), a cross-sectional survey with elements of retrospective data collection.
- In the abstract an interim dataset was analysed for EU4. Full data collection was subsequently completed, analysed and expanded upon within this poster.
- The DSP methodology has been previously described,[2,3] validated[4], and shown to be representative and consistent over time[5].
- Nephrologists, paediatric nephrologists, and internal medicine specialists (IMs) completed an online patient record form including data relating to clinical characteristics, patient journey, hospitalisations, patients' quality of life (QOL), and impact on patients' ability to work, for a minimum of the next three patients with primary IC-MPGN whom they consulted with in clinical practice.
- These same patients or their parents/caregivers voluntarily completed a survey containing data on symptoms, the Functional Assessment of Chronic Illness Therapy – Fatigue Scale (FACIT-Fatigue), where scores ranged from 0-52 with higher scores representing better QOL, and the Work Productivity and Activity Impairment questionnaire (WPAI), with higher scores representing greater impairment and less productivity.
- Patients were eligible for inclusion if they were aged one year or older and had a confirmed diagnosis of primary IC-MPGN, including biopsy results. Patients with secondary IC-MPGN were not included.
- HCRU was assessed via physician-reported patient clinical characteristics, clinical burden, hospitalisations, and patient-reported outcomes measures. Humanistic burden was assessed via physician-reported assessment of patient QOL, symptomatology, patient journey, and impact of IC-MPGN on patients' work productivity and activity impairment.
- Analyses were descriptive and described for the total population (US + EU4), unless otherwise stated.

RESULTS

- In total, 47 nephrologists (US: 19, EU4: 28), 7 paediatric nephrologists (US: 1, EU4: 6) and 7 internal medicine specialists (US: 0, EU4: 7) provided data relating to **215 patients** with primary IC-MPGN (US: 83, EU4: 132). Patient self-reported data was available for 54 patients (US: 15, EU4: 39).
- At the time of data collection, the mean [standard deviation; SD] **patient age was 42.2 [18.0]** years (US: 43.6 [16.4], EU4: 41.3 [18.9]), **11% patients were paediatric** (US: 4%, EU4: 15%), with a **mean age of 13.4 [3.4] years** (US: 15.0 [1.0], EU4: 13.2 [3.6]), and **89% were adults** (US: 96%, EU4: 85%) with a **mean age of 45.7 [15.8] years** (US: 44.7 [15.8], EU4: 46.3 [15.8]).
- In total, **57% of patients were male** (US: 55%, EU4: 58%), and the mean **time since diagnosis was 2.7 [5.3] years** (US: 1.5 [2.1], EU4: 3.4 [6.4]). Clinical characteristics are presented in table 1.

Table 1. Clinical characteristics	Total	US	EU4
Weeks from symptom onset to first HCP visit, mean [SD], n	10.9 [34.6], 177	7.9 [9.4], 66	12.6 [43.1], 111
Weeks from first HCP visit to diagnosis, mean [SD], n	9.3 [19.0], 186	5.7 [5.3], 69	11.4 [23.4], 117
Patients experiencing a diagnostic delay >4 weeks, n (%)	96 (52%)	35 (51%)	61 (52%)
Top reasons for diagnostic delay >4 weeks, n (%)			
Waiting to conduct tests	39 (42%)	3 (9%)	36 (62%)
Waiting to conduct biopsy	36 (39%)	11 (31%)	25 (43%)
Waiting for referral to specialist	33 (35%)	10 (29%)	23 (40%)
Patients receiving treatment at the time of data collection, n (%)	172 (80%)	60 (72%)	112 (85%)
Patients who had undergone a kidney transplant, n (%)	8 (4%)	2 (2%)	6 (5%)
Current 24-hr urinary protein excretion, mean [SD], g/24 hours, n	1.6 [1.4], 193	1.5 [1.3], 73	1.7 [1.5], 120
Current estimated glomerular filtration rate**, mean [SD], mL/min/1.73 m^2, n	52.9 [24.8], 200	52.2 [19.2], 74	53.3 [27.7], 126

- ***eGFR range in this patient population (% patients): <15* mL/min/1.73 m^2 *(5%), 15-29* mL/min/1.73 m^2 *(8%), 30-44* mL/min/1.73 m^2 *(28%), 45-59* mL/min/1.73 m^2 *(20%), 60-89* mL/min/1.73 m^2 *(33%), >90* mL/min/1.73 m^2 *(6%).*
- In the 12 months prior to data collection **patients received a mean of 26.6 [13.7] laboratory tests** (US: 22.5 [10.1], EU4: 29.0 [15.0]) to monitor their IC-MPGN (Table 2).

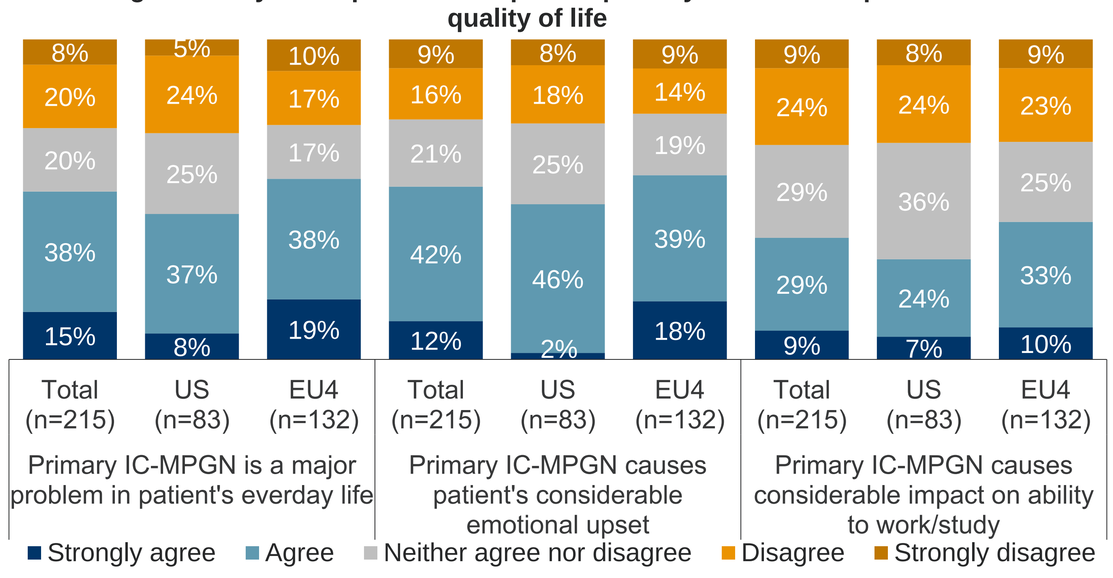
Table 2. Number of tests conducted in the last 12 months, mean [SD], n	Total	US	EU4
Serum creatinine	4.1 [2.1], 205	3.7 [1.5], 74	4.4 [2.4], 131
Blood haemoglobin	3.9 [1.8], 196	3.5 [1.2], 69	4.2 [2.0], 127
Urinalysis-assessed haematuria	3.2 [1.6], 157	3.1 [1.3], 60	3.2 [1.8], 97
Estimated glomerular filtration rate	3.6 [1.7], 151	3.2 [1.0], 64	3.8 [2.1], 87
Urine protein/creatinine ratio	3.0 [1.3], 122	3.0 [1.1], 56	3.0 [1.4], 66
24-hour urinary protein excretion	3.3 [1.5], 112	2.0 [0.7], 21	3.6 [1.5], 91
Urine albumin/creatinine ratio	3.2 [1.5], 65	2.8 [1.0], 23	3.4 [1.7], 42

- In the 12 months prior to data collection, 15% of patients had at least one hospitalisation related to their primary IC-MPGN (US: 2%, EU4: 21%). At most recent hospitalisation, 59% were admitted via emergency room (US: 100%, EU4: 58%), 92% were admitted overnight (US: 0%, EU4: 96%). Mean duration of stay was 7.8 [9.0] nights (US: N/A, EU4: 7.8 [9.0]).
- Beyond diagnostic biopsy, **36% of patients had at least one subsequent kidney biopsy** (US: 41%, EU4: 33%), commonly due to significant proteinuria (Total: 64%, US: 71%, EU4: 58%).
- Over the 12 months prior to data collection, **patients attended a mean of 9.1 [7.2] appointments** for their primary IC-MPGN (US: 9.0 [7.6], EU4: 9.1 [6.9]) (Table 3).

Table 3. Number of visits to physicians in the last 12 months, mean [SD], n	Total	US	EU4
Total visits to all physicians	9.1 [7.2], 215	9.0 [7.6], 83	9.1 [7.0], 132
Nephrologist	4.4 [2.9], 205	4.3 [1.9], 83	4.5 [3.4], 122
General practitioner	2.5 [2.8], 139	1.5 [1.7], 55	3.2 [3.1], 84
Nurse	1.9 [3.1], 130	2.5 [3.1], 52	1.5 [2.9], 78
Internal medicine	1.5 [2.8], 160	1.2 [2.1], 53	1.6 [3.1], 107

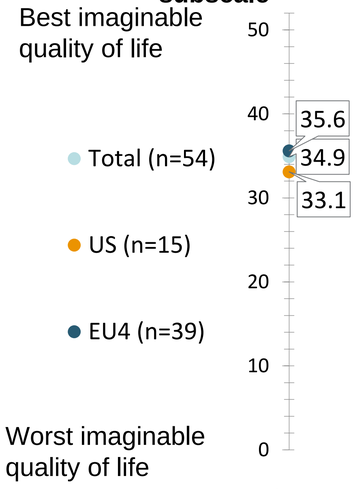
- In total, **25% of patients had a caregiver** (US: 4%, EU4: 37%), with the majority of patients receiving care from a professional caregiver (Total: 57%, US: 67%, EU4: 56%).
- The majority of physicians reported agreement that patients' primary IC-MPGN was a major problem in everyday life, caused considerable emotional upset, and a considerable impact on ability to work/study (Figure 1).

Figure 1. Physician-perceived impact of primary IC-MPGN on patient quality of life



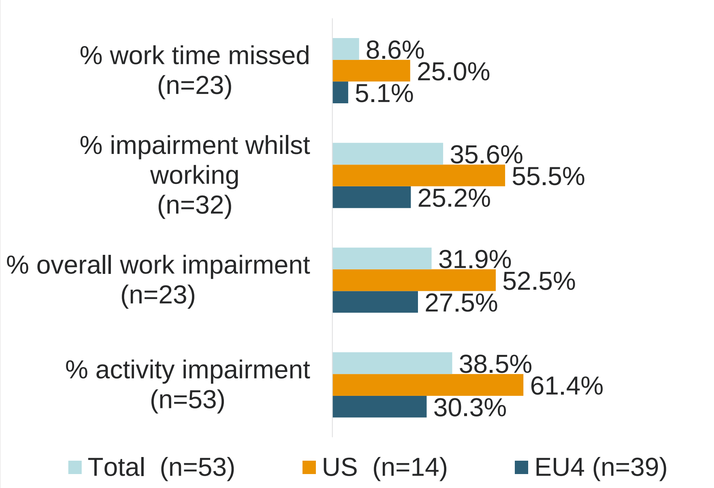
- The most frequent symptoms experienced by patients, as reported by physicians were **proteinuria** (Total: 56%, US: 73%, EU4: 45%), **fatigue** (Total: 36%, US: 36%, EU4: 36%), **hypertension** (Total: 28%, US: 33%, EU4: 26%) and **haematuria** (Total: 23%, US: 27%, EU4: 21%). Patients reported that their **most bothersome symptoms were fatigue** (Total: 43%, US: 54%, EU4: 39%), **high blood pressure** (Total: 20%, US: 54%, EU4: 8%) and **sleep problems** (Total: 16%, US: 15%, EU4: 17%).
- The mean [SD] FACIT- fatigue score, as reported by patients at the time of data collection was 34.9 [7.3] (Figure 2) (population norm: 43.5 [8.3]).
- Patients reported that in the seven days prior to data collection they **missed on average, 8.6% of work time**, impairment whilst working was reported to be 35.6%, overall work impairment was 31.9% and non-work-related activity impairment was 38.5% (Figure 3).

Figure 2. FACIT-Fatigue subscale



13-item measure that assesses self-reported fatigue and its impact upon daily activities and function.

Figure 3. Mean Work Productivity and Impairment Scores - %



Self-reported measure of the effect of primary IC-MPGN on the patient's ability to work and perform regular activities. Higher scores indicate greater impairment and less productivity.

CONCLUSIONS

- This study reports on the substantial HCRU and humanistic burden of primary IC-MPGN.
- HCRU burden was highlighted via the high number of visits to HCPs, frequency and range of tests used to monitor IC-MPGN, incidence of kidney biopsies after diagnosis, and frequency of hospitalisations.
- Humanistic burden was evidenced for patients with primary IC-MPGN by the experience of emotional upset and disruption to everyday life, work and study, as well as the need for a caregiver.
- In the US, high rates of impairment at work and at home were noted. In EU4, high rates of hospitalisations and HCP appointments were noted.
- These results highlight that the overall burden for IC-MPGN patients remains high despite access to conventional therapy. Thus, there is a need for effective, targeted treatment modalities to reduce overall burden for this patient population.

LIMITATIONS

- The patient sample may not reflect the general population of patients with primary IC-MPGN, as patients who consult more frequently were more likely to be included.
- The cross-sectional design of the DSP prevented any conclusions about causal relationships.

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DISCLOSURES
CR and LQ are employees of Swedish Orphan Biovitrum, and CR holds shares for Sobi AB. DD, KG, and MH are employees of Apellis Pharmaceuticals. JJ, SC, ML, and KF are employees of Adelphi Real World.

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