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Understanding the Patient Journey in IgA Nephropathy: Patient and Clinician Perspectives on Diagnostic Delays and Opportunities for Earlier Intervention

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IgA Nephropathy Is a Progressive, Immune-Mediated, Chronic Kidney Disease^{1,2}



The **heterogenous presentation** of signs, symptoms, and pathologies makes accurate and timely diagnosis of IgA nephropathy challenging³⁻⁵



In a US cohort of 117 patients with biopsy-confirmed IgA nephropathy, **time to diagnosis was highly variable**, with 50% of patients diagnosed after ~5 months and **nearly 25% of patients diagnosed after ~4 years**⁶



Communication gaps between patients and healthcare providers may contribute to these delays and to suboptimal care^{7,8}

Methods

An online US survey by the Harris Poll (October 14-November 3, 2025) assessed patient and physician perceptions of in-clinic communication, shared decision-making, and disparities in care access

Participants included



Patient

- 100 adults aged ≥ 18 years with biopsy-confirmed IgA nephropathy
- Not currently on dialysis and had not received a kidney transplant



Physician

- 150 board-certified/eligible nephrologists
- >3 years of clinical practice
- Treated ≥ 5 unique patients with IgA nephropathy in the past year

Respondents for this survey were selected from among those who have agreed to participate in Harris surveys, and the survey was closed once the target participants were met.

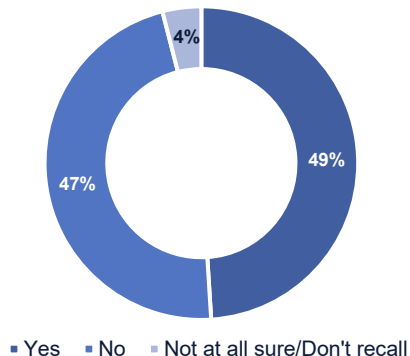
Results: Baseline Characteristics

Characteristic	Patient n=100	Physician n=150	Characteristic	Patient n=100	Physician n=150
Gender, %			Race, %		
Male	70	77	White	53	—
Female	29	18	Hispanic	30	—
Transgender ^a	1	1	Black/African American	12	—
Prefer not to answer	0	5	Asian	3	—
			All other	2	—
Age (years), %			Health insurance, %		
25-34	9	2	Private (NET)	87	—
35-44	38	27	Medicare/Medicaid (NET)	14	—
45-54	30	39	Other	6	—
55-64	18	19	None	1	—
65+	5	13			
Region, %			Years in practice, %		
Northeast	53	28	4-10	—	20
Midwest	12	20	11-20	—	35
South	22	33	21-30	—	32
West	13	19	31+	—	13
Urbanicity, %			Medical practice setting, %		
Urban	53	57	Glomerular disease clinic	—	5
Suburban	35	32	Solo practice	—	7
Rural	12	11	Group private practice	—	58
Prefer not to answer	0	1	Nonacademic hospital	—	5
			Academic medical center/teaching hospital	—	26

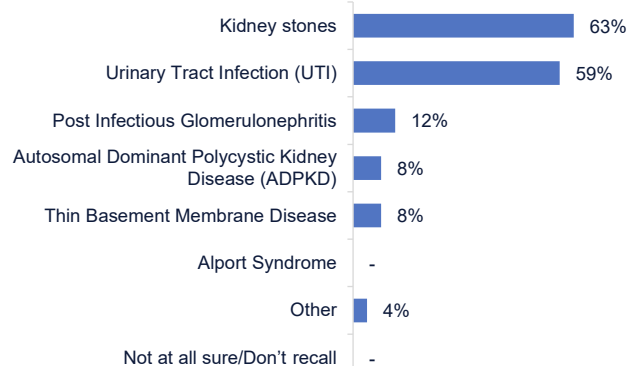
^aInclusive of transgender, nonbinary, non-conforming, and gender fluid.

Results: Diagnosis

Misdiagnosed before receiving proper IgA nephropathy diagnosis



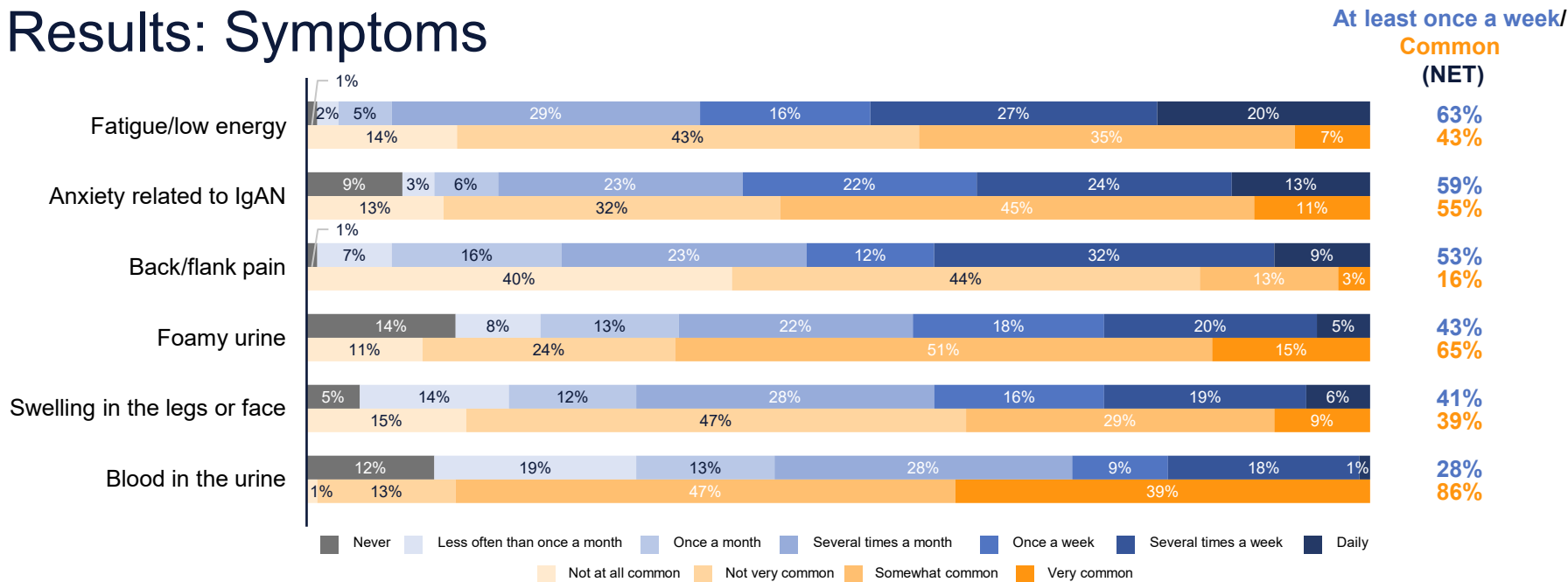
Type of misdiagnosis before receiving IgA nephropathy diagnosis^a



Nearly 50% of patients were misdiagnosed before IgA nephropathy diagnosis, most commonly with kidney stones or UTI

^aResults based on extremely small bases (n=31-49) should be interpreted as qualitative only.
IgA, immunoglobulin A; UTI, urinary tract infection.

Results: Symptoms



Patients most frequently report fatigue, anxiety, and back/flank pain, while physicians overemphasize visible symptoms like bloody or foamy urine, highlighting a gap in symptom recognition

Note: NET is defined as the total percentage of patients who responded at least once a week or physicians who responded somewhat or very common.
IgAN, immunoglobulin A nephropathy.

Patients

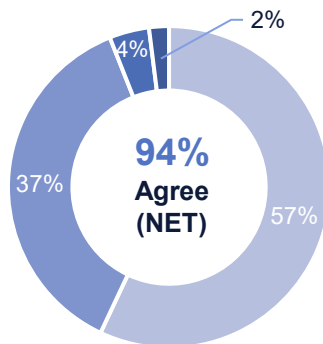
Physicians

Results: Patient and Physician Communication



IgAN patient

“My healthcare provider and I have check-ins at least once a year to evaluate if my treatment plan works well for me or if we need to change course.”



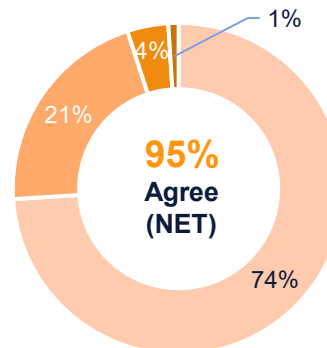
Strongly agree Somewhat agree Somewhat disagree Strongly disagree

Note: NET is defined as the total percentage of patients or physicians who responded positively.



HCP

“My IgA nephropathy patients and I have check-ins at least once a year to evaluate if their treatment plan works well for them or if they need to change course.”



Patient and physician communication is generally perceived as positive, with nearly all patients and physicians having annual check-ins to discuss the treatment plan

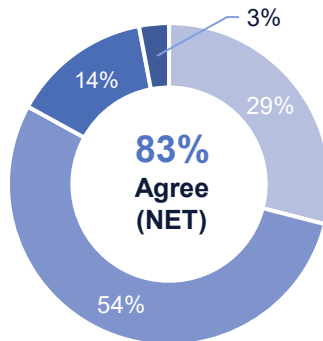
Results: Treatment Decision-Making

54% of physicians vs **29% of patients** strongly agree that other treatment options are discussed



IgAN patient

"My healthcare provider discusses other possible treatment options with me during our visits in case my treatment does not effectively manage my symptoms."



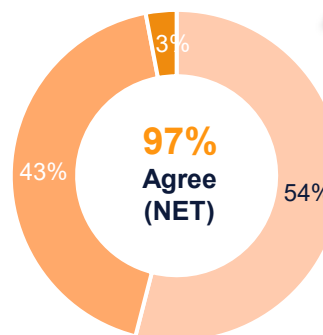
Strongly agree Somewhat agree Somewhat disagree Strongly disagree

Note: NET is defined as the total percentage of patients or physicians who responded positively.



HCP

"I discuss with my IgA nephropathy patients about other possible treatment options they can try during our visits in case their treatment does not effectively manage their symptoms."



Physicians believe they are more open to discussing alternatives than patients perceive, suggesting an opportunity to strengthen shared decision-making

Patients

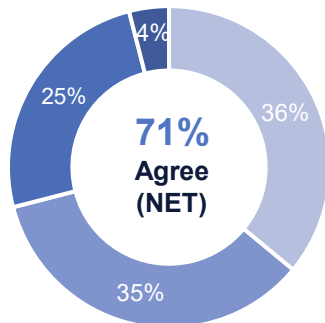
Physicians

Results: Information on Daily Management



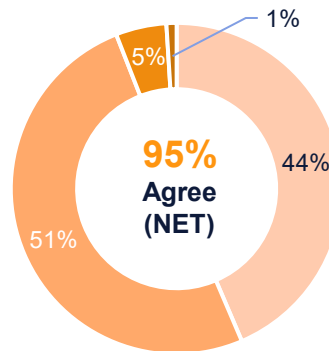
IgAN patient

"I wish my healthcare provider provided me with more information on how to manage my symptoms on a daily basis."



HCP

"I provide my IgA nephropathy patients enough information on how to manage their symptoms on a daily basis."



Strongly agree Somewhat agree Somewhat disagree Strongly disagree

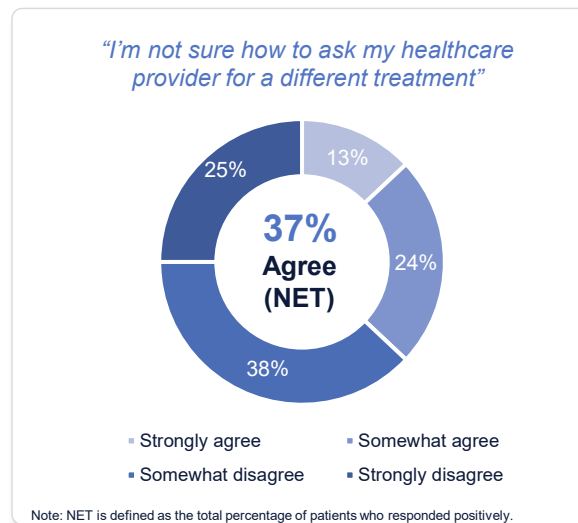
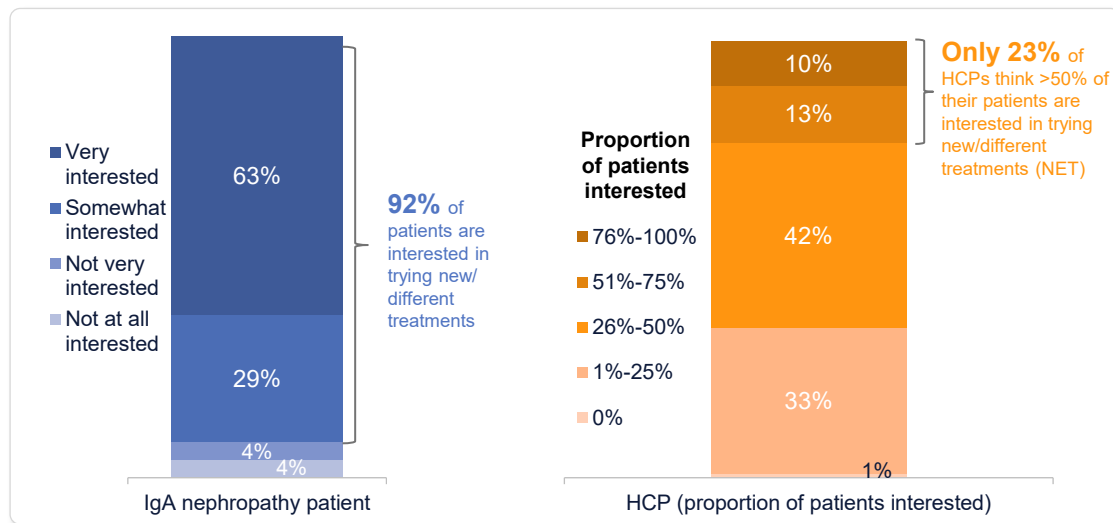
Note: NET is defined as the total percentage of patients or physicians who responded positively.

Most physicians report they provide enough information on daily symptom management, but nearly 3 in 4 patients with IgA nephropathy want more

Patients

Physicians

Results: New Treatment



Physicians often underestimate patient interest in new IgA nephropathy treatments, and more than one-third of patients are unsure how to ask about different treatment options

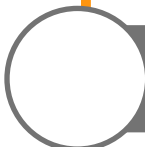
Conclusions

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While patients and physicians agree that treating IgA nephropathy is urgent, nearly 50% of patients are initially misdiagnosed

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Physicians often overemphasize visible symptoms, such as hematuria and proteinuria, compared with patients, who more frequently report fatigue, anxiety, and back or flank pain

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Although patient-physician communication is generally positive, more than one-third of patients are unsure how to request a different treatment, while physicians believe they are more open to discussing alternatives than patients perceive

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Enhancing physician and patient awareness of atypical symptoms, improving patient-physician communication, and aligning educational efforts are critical to enabling earlier diagnosis and timely intervention to preserve kidney function

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