Nephcure
for Rare
Kidney
Disease

IgAN
Alliance

Overcoming the Barriers to Diagnosis and Treatment of IgA Nephropathy:

A Report from the Inaugural IgAN Alliance Stakeholder Collaborative Workshop

Introduction

Despite advances in the understanding of immunoglobulin A nephropathy (IgAN) as a debilitating, progressive disease, and the availability of approved, disease-modifying therapies, patients with IgAN face considerable barriers to timely diagnosis, informed decision-making, and access to care. To surmount these barriers, patients must be better educated about the disease and available treatment options and have access to:

- clinicians who are experienced and expert in glomerular diseases and understand IgAN
- approved therapies
- support systems and groups
- clinical trials

The difficulties confronting patients with IgAN, their caregivers, and their physicians prompted the establishment of the IgAN Alliance, which NephCure organized and founded in 2025 to be an advocating voice for the entire community, particularly in helping people get diagnosed and treated sooner and more effectively. Comprising advocacy organizations, industry partners, people impacted by IgA nephropathy, and healthcare professionals, the IgAN Alliance aims to address the challenges faced by people living with IgAN by:

- Educating individuals, families, and physicians to approach IgAN diagnosis and care plans with urgency and skill
- Advocating for access to the most innovative methods to treat and manage IgAN
- Providing helpful information to the individuals and families about receiving treatment, support, and assistance

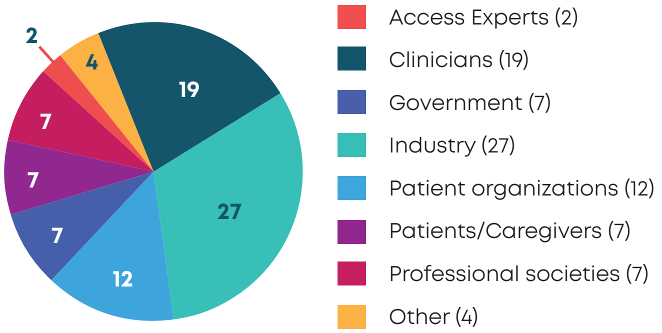
One of the Alliance's first major initiatives was to convene the inaugural IgAN Stakeholder Collaborative Workshop, which was held September 7-9, 2025 outside Chicago, IL. The workshop provided a dedicated space to prioritize urgent access issues, share cross-stakeholder insights, and develop practical, collaborative solutions designed to improve the patient journey and advance the standard of care. The workshop goals were to:

- Assess access challenges and cross-stakeholder needs
- Prioritize solutions to overcome access barriers across the IgAN community
- Elevate stakeholder voices by sharing real-world community experiences and insights to inform alliance priorities
- Understand approaches to expanding community education around timely diagnosis and informed treatment decisions
- Support innovation by identifying strategies to improve clinical trial recruitment and participation
- Establish solutions-focused working groups to begin drafting actionable strategies for post-workshop progress

This publication summarizes the discussions, key takeaways, and outcomes from the inaugural IgAN Alliance Stakeholder Collaborative Workshop.

Workshop Participants and Format

Figure 1: IgAN Alliance inaugural Stakeholder Collaborative Workshop participants



Eighty-five stakeholders attended the inaugural workshop; 70 attended in person and 15 participated virtually (Figure 1). The workshop program consisted of a series of formal presentations, panel discussions, and breakout sessions, each designed to stimulate discussion and collaboration. To facilitate interactive discussion, each attendee was given colored cards – green and red -- to show when they were in agreement or disagreement about speakers' statements (Figure 2). A green card confirmed alignment with a given statement; a red card was a sign of disagreement, prompting the moderators to pause the discussion and address the pertinent issue. This approach fostered a collaborative community environment without cross-talk, allowing participants to share their reasons for agreeing or disagreeing with certain statements.

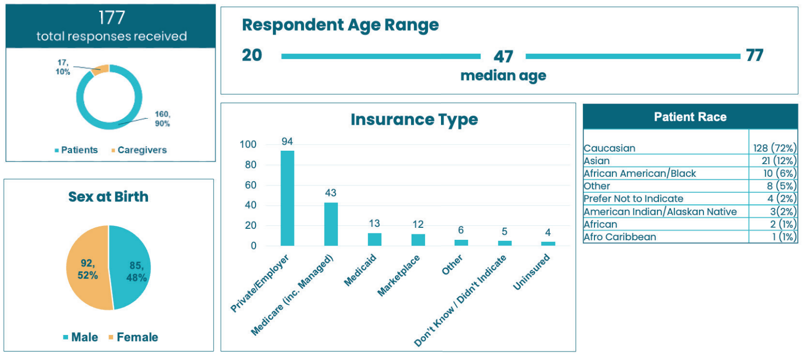
Figure 2: Workshop participants indicating agreement

The Patient Journey: Understanding the Barriers

Stories of diagnostic odysseys are common among individuals and families affected by IgAN. As noted in a panel discussion on the first day of the workshop, patients typically face obstacles that can include insurance barriers, misdiagnoses, difficulty finding a specialist, and suboptimal access to care. A patient with IgAN said living with kidney disease is "kind of a silent suffering. It's not painful; you just find out later as you look back on it [with] hindsight." His caregiver described the journey as "a fight forever," noting that the caregiver's burden can be taxing.

> *“We’re four years post-transplant. The transplant is working; [it had] better work forever. The thought of rejection is always there… [IgAN] is a silent disease that affects everything about your life, forever.”*
>
> *– IgAN Caregiver*

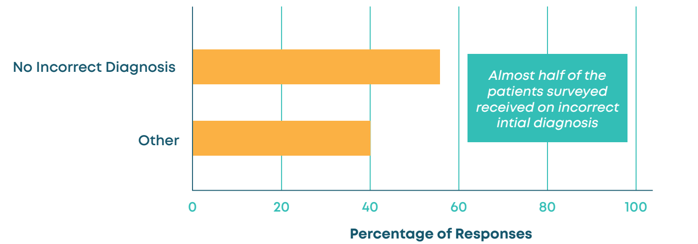
Figure 3: Patient survey demographics



Patient Race	
Caucasian	128 (72%)
Asian	21 (12%)
African American/Black	10 (6%)
Other	8 (5%)
Prefer Not to Indicate	4 (2%)
American Indian/Alaskan Native	3(2%)
African	2 (1%)
Afro Caribbean	1 (1%)

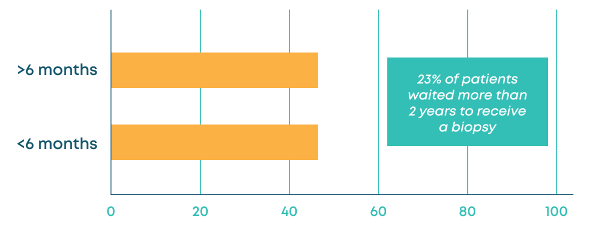
A pre-workshop survey of patients with IgAN (n=160) and caregivers (n=17), fielded online from June to September 2025, yielded additional insights regarding the patient journey (Figure 3). Consisting of three screening questions and 24 possible multiple-choice questions, the survey focused on topics such as diagnosis, biopsy, physician collaboration, treatment barriers, IgAN education, research findings, and treatment guidelines. Forty percent of patient respondents reported having no recognizable symptoms when their disease was first suspected; several workshop attendees commented that the actual percentage of asymptomatic presentations was probably greater. The survey also revealed that incorrect and delayed diagnoses are common (Figures 4 and 5), especially in adults, in whom IgAN is frequently identified during evaluation for chronic kidney disease. The survey was limited by its reliance on self-reported diagnosis, as well as by the lack of follow-up to confirm diagnosis. An additional limitation was the potential for sample bias toward a more tech-savvy pool of respondents with internet access, compared to the broader general population; respondents may also have already been engaged with NephCure and/or the IgAN community. Moreover, individuals of Asian and Hispanic heritage were under-represented in the survey, although the prevalence of IgAN is highest in these patient populations.

Figure 4: Did you receive any incorrect diagnoses before the IgAN diagnosis?



Almost half of the patients surveyed received on incorrect intial diagnosis

Figure 5: How long after experiencing symptoms did you receive a renal biopsy that confirmed IgAN?

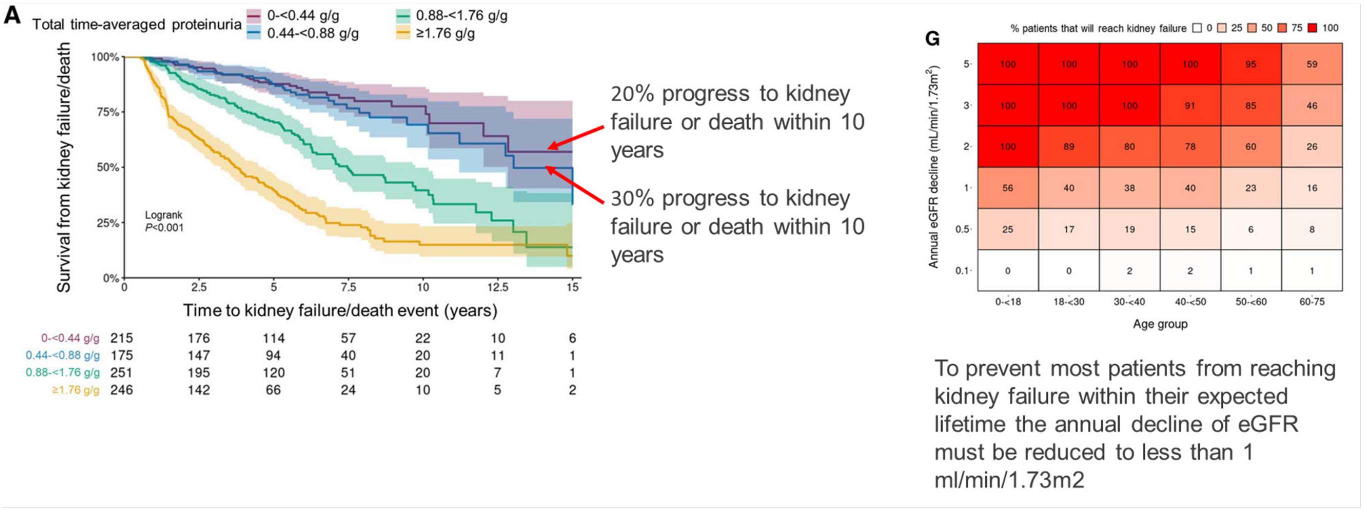


23% of patients waited more than 2 years to receive a biopsy

Urgency in Diagnosis

The urgency to diagnose IgAN is complicated by the heterogeneity of the disease, a lack of definitive biomarkers, the risk of progression, and the difficulty of predicting severity and damage when patients first present. Several recent studies have reshaped nephrologists’ thinking about IgAN treatment goals. Among those are a 2023 analysis of the IgAN cohort of the UK National Registry of Rare Kidney Diseases (RaDaR)[1], which suggested that the proteinuria goal defining treatment success should be lowered and confirms that the diagnosis is often late, when patients have already experienced substantial loss of kidney function. To prevent most patients from reaching kidney failure within their expected lifetime, clinicians should aim to reduce the slope of estimated glomerular filtration rate (eGFR) decline over time to as low as possible, ideally to a level approximating that in individuals with healthy kidneys (Figure 6).

Figure 6: RaDaR reshaped thinking around IgAN treatment goals



	0	2.5	5	7.5	10	12.5	15
0-<0.44 g/g	215	176	114	57	22	10	6
0.44-<0.88 g/g	175	147	94	40	20	11	1
0.88-<1.76 g/g	251	195	120	51	20	7	1
≥1.76 g/g	246	142	66	24	10	5	2

20% progress to kidney failure or death within 10 years

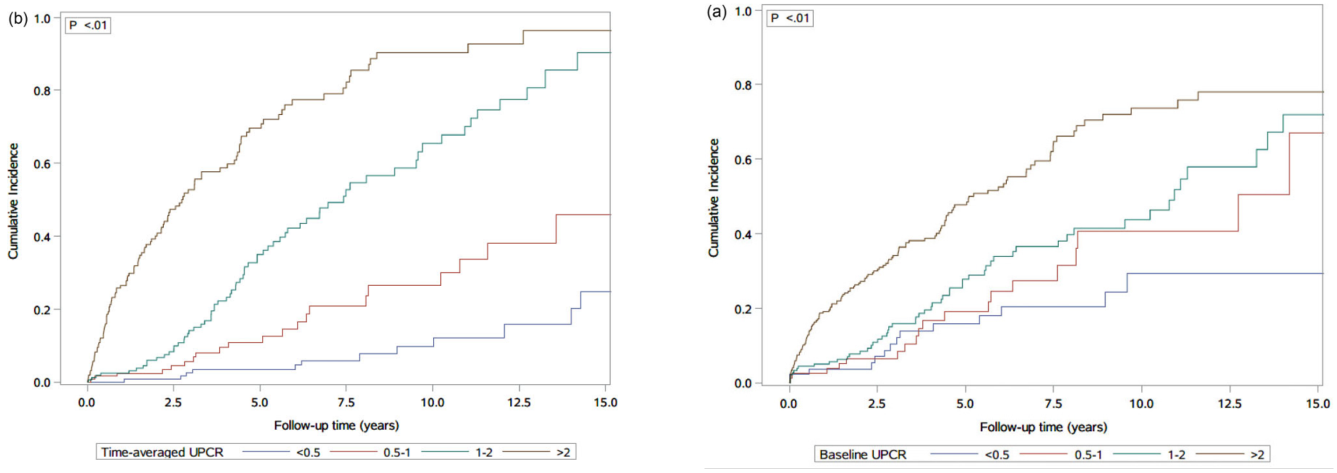
30% progress to kidney failure or death within 10 years

	0-<18	18-<30	30-<40	40-<50	50-<60	60-75
5	100	100	100	100	95	59
3	100	100	100	91	85	46
2	100	89	80	78	60	26
1	56	40	38	40	23	16
0.5	25	17	19	15	6	8
0.1	0	0	2	2	1	1

To prevent most patients from reaching kidney failure within their expected lifetime the annual decline of eGFR must be reduced to less than 1 ml/min/1.73m2

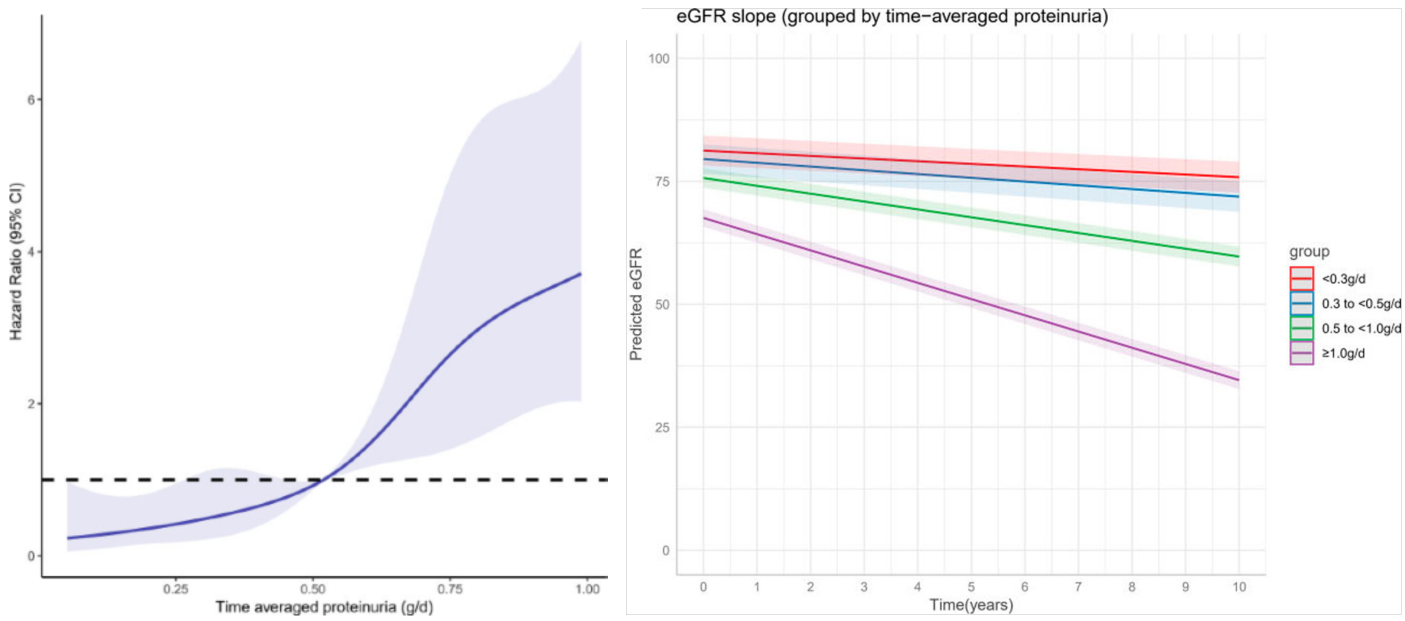
There was considerable discussion about targeting the annual decline to below 1ml/min/1.73m2,, which is considered a normal decline in healthy individuals, although several attendees remarked that such a goal might be challenging to achieve. Data from the Kaiser Permanente Southern California Cohort validated a more aggressive approach to treatment, highlighting the importance of long-term control of proteinuria. In their analysis of data from 655 patients with primary IgAN, the authors observed that even a baseline or time-averaged urine protein creatinine ratio (UPCR) between 0.5 and 1 g/g can lead to kidney failure, countering earlier perceptions that levels below 1 g/g carry low risk of kidney failure (Figure 7).

Figure 7: Effect of baseline or time-averaged proteinuria on outcome



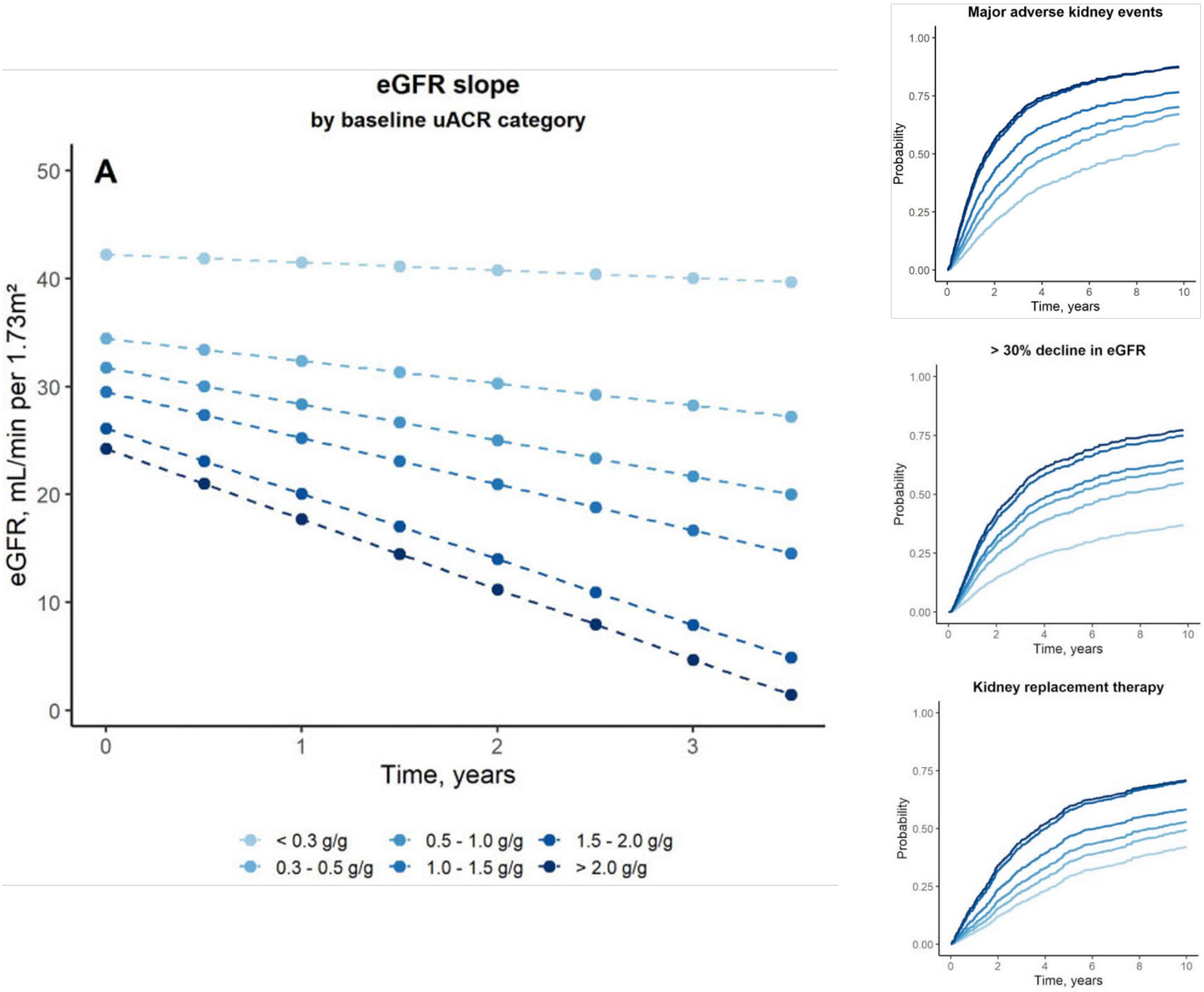
Additionally, prospective cohorts from China and Sweden showed slower declines in eGFR slope, suggesting a benefit of ultra-low levels of proteinuria (<0.3 g/g). In the 2141-patient Chinese cohort, patients with time-averaged proteinuria of 0.5 g/day had elevated risk of end-stage kidney disease, again challenging the view that proteinuria below 1.0 g/day was associated with acceptable risk (Figure 8). In the Swedish cohort of 1269 patients, a urine albumin-to-creatinine ratio (uACR) between 0.3 and 1.0 g/g was also associated with a risk of adverse kidney outcomes (albeit a lower risk compared to individuals with higher levels of albuminuria) (Figure 9). Presenters noted that the RaDaR analysis and the Swedish data both show evidence of disease progression even with low proteinuria levels (<1.0, 0.5-1.0, <0.5 g/g). They also cited the 2025 Kidney Disease: Improving Global Outcomes (KDIGO) Clinical Practice Guideline for Management of IgAN and IgA Vasculitis, which recommends starting treatment much earlier than in the past, as well as using advanced therapies in the first-line setting. Another 2025 KDIGO recommendation is to consider biopsy in all adults with persistent proteinuria ≥0.5 g/day, versus the previous 1g/day threshold.

Figure 8: A prospective cohort from China



The 2025 KDIGO Guideline was not available at the time of the workshop but was released soon afterward.

Figure 9: The Swedish cohort: Effect of albuminuria at baseline



Kidney Biopsy

The utility of biopsy as a diagnostic tool for IgAN depends greatly on collecting samples with sufficient glomeruli, underscoring the importance of ensuring that individuals who perform kidney biopsies (typically interventional radiologists) are trained to collect cortical tissue samples that have the highest likelihood of capturing affected glomeruli. This approach contrasts with aiming for deeper renal tissue that may only have medullar without glomeruli, resulting in an inability to confirm the diagnosis of IgAN, which can only be made after confirming the presence of IgA deposits in glomeruli.

The timing of renal biopsy is another key, modifiable determinant of care. Despite mounting evidence, uncertainty persists among clinicians regarding the urgency of biopsy and diagnosis, leading some to adopt a "watch and wait" approach guided by symptom development or disease progression. Although such strategies may have been reasonable in the past due to incomplete information or understanding, current data no longer justify delayed diagnostic evaluation, underscoring the importance of reassuring patients and caregivers about the urgency and necessity of biopsy.

> *"[Watchful waiting] was probably reasonable 10 years ago because you couldn't do anything for the disease anyway. We need to change that mindset."*
>
> *– Jonathan Barratt, MD*

"The good news is we're doing more biopsies than ever," commented Barbara Gillespie, MD, summarizing the discussion. "The reality is the nephrologist can't do all of them, so other people are helping. And so it's just like everything else. Let's shift with that and make sure we're educating."

There is a pressing need to systematically collect and analyze biopsy data so that relevant biopsy features can be linked to personalized, actionable therapeutic pathways for patients with IgAN. There is also a need for data on specific drugs' actions on specific sub-phenotypes within such individuals, and to expedite referral of patients with hematuria and/or low-grade proteinuria to nephrologists. Time of biopsy is not necessarily time of disease onset; children may be diagnosed earlier than adults because they are more likely to present with gross hematuria, and there is a tendency toward a more aggressive approach to earlier diagnosis in children. There is also an urgent need for better biomarkers in IgAN to facilitate earlier diagnosis.

The biopsy-related discussions generated numerous notable comments from the stakeholders, including the following:

> *"We're not searching for perfect; we're searching for better and good… We can talk about proteinuria not [being] perfect [as a biomarker]; it's fraught. But it's wonderful for what we need to do now in terms of discovering patients with disease, risk-assessing them and getting them to the right person to treat them."*
>
> ***– Richard Lafayette, MD***

There was general agreement about the importance of screening seemingly healthy people via urinalysis, and about getting primary care physicians (PCPs), obstetricians/gynecologists, and other clinicians – many of whom are already doing urinalysis on their patients – more involved in screening for rare kidney disease. There were also concerns regarding the risk of false positives, which participants believed can be easily overcome with repeat testing. These issues prompted additional comments from the stakeholders:

> *"I think these prediction tools, at least right now, are at most giving us five years… But when we're thinking about children, and even most adults are diagnosed between 20 and 40, they have their whole lives ahead of them. So I don't think thinking about five- or 10-year risk is really sufficient"*
>
> ***– Shikha Wadhwani, MD***

The Care Triad (Patient, Physician, Specialist Interactions)

Discussion of the care triad began with another look at findings from the pre-workshop patient survey, which highlighted several barriers to accessing care, including limited access to nephrologists and particularly glomerular disease experts. Participants discussed more collaborative approaches to support the care triad including alternating visits between one's specialist and PCP or general nephrologist; telemedicine (i.e., as a convenient substitute for visits not requiring physical examinations, particularly given survey results showing more than 20% of patients typically travel over an hour to doctor appointments); or temporary referrals to get a patient's health under control, followed by referral back to their PCP or general nephrologist.

Fifty-five percent of survey respondents identified their general nephrologist as the health care professional (HCP) with primary responsibility for managing their IgAN. The next most frequently identified HCP was the specialty nephrologist, named by roughly 35% of respondents. No other type of physician was indicated by more than 5% of respondents. Such heavy reliance on nephrologists for information and support, along with a growing trend of patients referring themselves to specialists, highlights the importance of adhering to a shared decision-making model to facilitate care. This finding also highlights the importance of involving a glomerular disease expert in a patient's care team (at least at first), although such access can be challenging for patients not located near an academic medical center.

Notably, 40% of patient survey respondents said they are unsure if their nephrologist specializes in IgAN, a finding that underscores the need for treating physicians to feel comfortable with and be clear about their level of expertise in managing IgAN. It also reinforces the value of consulting with or referring to a glomerular disease specialist.

The survey also revealed high levels of patient stress over preparing for appointments, not knowing the cause of their disease, and having to explain IgAN not only to their family, but in some cases to their physicians as well. Most patient respondents reported having negative emotions due to concerns about the impact of IgAN on their families, incomplete understanding of their disease, and the psychosocial impact of IgAN. Such emotions may stem from the "sudden crash" of this chronic condition, and may be mitigated by involving a glomerular disease expert as part of the care triad approach.

Physician Advisory Board Meetings

Prior to the workshop, additional insights about the utility of the care triad were obtained from two physician advisory board meetings, each of which was preceded by an online survey. The advisory board objectives were to understand the current barriers preventing early and accurate IgAN diagnoses; discuss ways to engage and educate physicians as a means to overcome challenges or barriers to care; and gain perspective on prescribing behaviors for new medications to treat IgAN. One advisory board comprised four adult nephrologists and one family medicine physician; the other included two adult nephrologists and two pediatric nephrologists; all advisors were affiliated with academic medical centers or children's hospitals (the lack of community nephrologist involvement was a limitation of the advisory boards). The focus areas were the same as those explored in the patient survey.

Input from the physician advisors revealed that IgAN specialists (glomerular disease experts) lack the bandwidth to take on all patients with IgAN, but feel the responsibility to serve as resources for the community. Some general nephrologists may be hesitant to refer their patients out to IgAN specialists due to financial concerns or fears of demonstrating knowledge gaps. The advisors perceive nephrology specialists as more likely than general nephrologists to treat IgAN with urgency. The advisors also identified a need for more transparent, collaborative relationships between clinicians and pathologists.

This is How We Do It

There was general agreement that more regular consultation between general nephrologists and specialists in rare kidney diseases can build trust among the members of the care triad by facilitating shared decision-making, and by giving families "peace of mind… that every effort is being made to make sure that they're given the best [care]," as Keisha Gibson, MD, observed in her video, which was screened at the workshop, featuring Dr. Gibson and her care triad partner, Carla Nester, MD. As noted in the video, entitled, "This is How We Do It," the benefits of such consultation would include generation of second opinions as well as greater participation in clinical trials. Such benefits are key to building trust among the care triad and to "finding a pathway for efficient and meaningful communication on all involved for shared decision-making," Dr. Gibson commented.

> *"This is why it's so important for us as a community to gain some comfort with trusting each other and… helping to invite our patients to become part of these communities where they can help really fuel our knowledge… There are a lot of… places where we have the research infrastructure where you have somebody that [rare kidney diseases are] their area of focus… [and] there's a lot of benefit for everybody that's involved in that triad."*
>
> *– Keisha Gibson, MD*

In terms of improving the care triad, the stakeholders implored IgAN specialists to do more to foster collaboration and consultation. Nephrologists, for their part, need to advocate for removal of institutional barriers to referrals and clinical trial participation.

> *"…maybe [my note to the local provider] will generate some process to happen at home, whether it's… sitting still or maybe it's a decision to even escalate the care. But at least now, the local provider has my opinion about what escalation of care looks like. They still choose whether they want to escalate and when they want to escalate, but at least they got my opinion about how that looks."*
>
> *-Carla Nester, MD*

Breakout Group Insights

At the end of the first day of the workshop, the attending stakeholders were divided into six breakout groups, each of which was directed to identify areas of consensus, areas of misalignment, actions to be prioritized, and other key takeaways from the day's proceedings. The groups' readouts to the full audience of workshop attendees reflected general agreement on the importance of earlier diagnosis, increased and targeted screening, improved biopsy practices, and enhanced collaboration among PCPs, nephrologists, pathologists, and IgAN specialists. Other points of emphasis focused on expansion of telehealth; enhancing patient empowerment, including mental health support; and improved coordination among advocacy organizations.

Breakout Group Insights

There were several areas of misalignment requiring further explanation. These included:

- Universal vs. targeted screening
- Biopsy timing
- Post-diagnosis care pathway
- Socio-economic and health equity disparities
- Consistency of available information
- Community adoption of RaDaR data and KDIGO guidelines
- Specialist role definitions

The breakout sessions concluded with a **call to action**: convene future sessions focusing on the following issues:

- Value definition
- Risk stratification
- Evidence generation (including case studies)
- Developing the patient profile for urinalysis screening in the general population
- Patient voice integration
- Improving access
- Navigating insurance/reimbursement
- Resources for facilitating communication and collaboration
- Innovation in treatment and care delivery
- Encouraging clinical trial engagement

Access to Newly Approved Therapies: Understanding the Challenges

The second day of the workshop started with a discussion of the challenges surrounding patient access to newly approved therapies for IgAN. This discussion was informed by a further review of the pre-workshop patient survey findings, which revealed varied experiences with therapeutic approaches, ranging from no treatment to kidney transplant and dialysis, with lifestyle changes and corticosteroids cited as common foundational therapies. Almost half of the patient respondents were not familiar with current IgAN treatments; many cited concerns about side effects, treatment costs, and insurance coverage as barriers to accessing treatment.

While many patients reported regularly discussing treatment options with their physicians, more than half report being unfamiliar with available treatments and may decline medications due to safety and financial concerns.

There was also further discussion of the physician advisory board findings, in which participants reported challenges in staying current with treatment options, largely due to limited long-term data and real-world evidence (RWE) supporting the use of the newly approved therapies. The relative lack of data affects physicians' confidence in prescribing these therapies and in advising when and for whom to discontinue or add onto treatment. The physician advisors also commented on the challenges of managing complex payer- or regulator-mandated barriers such as step therapy, prior authorizations (PAs), risk evaluation and mitigation strategy (REMS) requirements, and high copays – all of which can significantly influence treatment decisions and delay care initiation, thereby exacerbating access barriers. Given that traditional therapeutic approaches have largely relied on use of generic therapies that required little, if any, negotiation with payers, the availability of recently approved therapies presents a new experience for many clinicians. Moreover, many practices lack the infrastructure for managing the incremental administrative burden posed by the new therapies. That burden typically falls upon clinical staff, often leading to suboptimal treatment choices driven by ease of payer approval rather than best patient care. Notably, the stakeholders observed that an estimated 75% of newer therapies are eventually approved by payers, leading the group to question what is the bigger issue: true lack of physician confidence to prescribe based on limited evidence or guidance, or perceived concerns about administrative burden?

> *"We try very hard to make sure that [insurers] are not going to allow someone to interpret the data in a way that would prevent patients from getting access to medications. I, unfortunately, find that… insurance companies use [the guidelines] against us… [O]nce you talk to these folks and educate them, they want to listen and learn and then they're happy… [T]he problem is getting to the person, because I have to go through several rounds of a computer telling me 'No'… before I can get to a peer-to-peer [consultant]."*
>
> *– Brad Rovin, MD*

> *"Some patients perhaps need to go back to the office… to sign extra papers, provide extra information, get additional labs. [They] go back and forth. Some of them live one or two hours from the office. [They are] working people. It really starts to create several delays in the process… Sometimes it's easier to get a patient in a clinical trial rather than to get an FDA-approved medication. It's horrible. I mean, that's a reality"*
>
> *– George Vasquez Rios, MD*

Defining Value: Generating Evidence, Registries, and PROs

Physician prescribing of the available approved therapies for IgAN has been suboptimal thus far. That prompted considerable discussion about the urgency to use these medications to meet patient needs and to generate RWE of their utility. Implementation science — the study of how to ensure that evidence-based practice and innovations get adopted, sustained, and scaled in real-world clinical practice — can help identify and overcome barriers to care (e.g., provider workflows, patient adherence, policy constraints). Collaboration among stakeholders, such as by sharing real-world data, can support decision-making and improve care delivery. Development and validation of IgAN-specific patient-reported outcome (PRO) measures would create opportunities for clinicians to collaborate on additional RWE generation, and would facilitate educational efforts to encourage them to consider approved therapies for IgAN, as illustrated in the following excerpts from the discussion:

> *"Even the things we know and… assumed are good, we're not even doing those ones well… [I]f we had some collaborative that could share data and in real time kind of show nephrologists what the uptake is, that might be a little bit of peer pressure… [, 'Hey, this is a culture change and I want to be a part of it.'"*
>
> *– Laura Mariani, MD*

Discussion of the need to educate physicians highlighted a basic struggle to determine the better course of action: should efforts focus on educating community nephrologists on how to optimally manage IgAN, or on stimulating the consult/referral pathway to "leave it to the experts"? Or does the answer lie in combining these approaches?

> *"I like to think about new educational approaches, supportive systems to reimbursement programs, access programs, all of this in combination. We're not going to get there if we're just sitting around waiting for additional evidence."*
>
> *– AJ Messina, PhD*

Navigating Insurance, Prior Authorizations (PAs), and Appeals

As active partners in care decisions, patients need to take advantage of education and other resources to self-advocate effectively as they navigate a challenging insurance environment. To that end, greater awareness of industry-sponsored patient support programs, including copay assistance, free drug-bridging, vaccine support services, and call centers can help patients during PA and appeals processes. At the same time, collaboration between clinical teams, payers, patient advocacy groups, and industry patient services/navigation teams can reduce administrative burdens and improve timely access to therapies.

> *"When you get a prior authorization, document the decay in the patient's kidney function, their proteinuria… [Let] that be the proof. Now show that if you delay [treatment], you're getting this. So if you do run into that, instead of turning that into an insurmountable wall, turn it into an opportunity to get through the next one."*
>
> *– Doug Paul, PharmD, PhD*

The imperative to increase medication uptake underscores the need to educate payers on the value of the newly approved IgAN therapies. Standardizing community-generated PA eligibility criteria and EHR nomenclature, augmented by improved communication between clinical and billing teams, can streamline insurance approvals. Ultimately, successful navigation of the payer landscape lies not in antagonism, but in education and collaboration.

> *"The war is not all on payers. The war is on ignorance… [L]et's make sure we identify the right enemy before we start battling… I would argue the payer problems [are] a challenge of ignorance. And this is the catch: What I don't want to do is say we need four more years of evidence to be generated. The evidence is here; [T]his is the room that is going to have to lead. If this is the best leadership, there's no room that is going to lead faster than this room…."*
>
> *– Doug Paul, PharmD, PhD*

Continuing Innovation: Clinical Trial Access and Enrollment

In the final workshop session, stakeholders discussed the ethical considerations and challenges of enrolling patients in placebo-controlled trials when effective and safe therapies are available. There was general agreement about the need for innovative trial designs that can provide patients with access to new treatments while generating robust data. Some stakeholders argued for continuing access to treatment after a trial concludes, while others called for increasing diversity in clinical trials – an imperative for which the U.S. Food and Drug Administration (FDA) has signaled support. There was also considerable discussion about the need for innovative treatments due to the heterogeneity of IgAN, underscoring the urgency to lean into the promise of precision medicine.

> *"IgA nephropathy does not progress very rapidly over two years… [H]aving a plan where there is access right after the trial is complete, or a trial design where each patient may be their own control, or other designs that assure access… to the medication… is kind of a win-win for science and for the patient and helps with some of the ethical challenges of placebos or having to use prednisone."*
>
> *– Heather Reich, MD*

Conclusions/Key Takeaways

The workshop concluded with a **call to action** to start educational programs and convene working groups to develop IgAN screening recommendations for adults and children, enable shared decision-making to guide care decisions, and improving access and support. The working groups would focus on shared decision-making on whom to treat when and for how long, supporting collaboration for data-sharing amongst community, clinicians, and industry, and broadening the reach of screening programs. The groups would start by identifying subpopulations already known to be at increased risk, including first-degree relatives of people with kidney disease, individuals with diabetes or hypertension, and members of certain socioeconomic groups.

Based on the workshop proceedings, participants identified the following needs to address:

- Advance education on diagnosis and treatment, facilitating earlier kidney biopsy and expert evaluation
- Increase screening among targeted populations
- Improve access to therapies and specialized care
- Share data throughout the IgAN community
- Continue to support advancement of clinical research

As a final **call to action**, the stakeholders committed to establishing collaborative working groups focusing on:

- **Urgency in Diagnosis:** identify patients earlier and connect to optimal care
- **Urgency to Treat:** ensure physicians understand and consider novel therapies
- **Improve Access:** support patients in obtaining the care they need and deserve
- **Evidence Generation:** encourage and enable collection and sharing of data across key stakeholders

As of this writing, working group recruitment efforts are ongoing, and the first group meetings have taken place. Planning is also underway for the second IgAN Alliance Stakeholder Collaborative Workshop, which is scheduled for May 13-14, 2026, in Dallas, TX. Outcomes from these initiatives will be reported in future publications.

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1. Pitcher D, Braddon F, Hendry B, et al. Long-term outcomes in IgA nephropathy. *Clin J Am Soc Nephrol*. 2023. PMID: 37055195. 2. Sim JJ, Chen Q, Cannizzaro N, et al. CKD progression, kidney failure, and mortality among US patients with IgA nephropathy. *Nephrol Dial Transplant*. 2025;40:2104-2117. 3. Shen X, Chen P, Liu M, et al. Long-term outcomes of IgA nephropathy in China. *Nephrol Dial Transplant*. 2025;40:1137-1146. 4. Faucon A-L, Lundberg S, Lando S, et al. Albuminuria predicts kidney events in IgA nephropathy. *Nephrol Dial Transplant*. 2025;40:465-474. 5. Kidney Disease: Improving Global Outcomes (KDIGO) IgAN and IgAV Work Group. KDIGO 2025 Clinical Practice Guideline for the Management of Immunoglobulin A Nephropathy (IgAN) and Immunoglobulin A Vasculitis (IgAV). *Kidney Int*. 2025;108(4S):S1–S71.

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IgAN Alliance