



# Global Kidney Cancer Summit

4<sup>th</sup> – 6<sup>th</sup> April 2025  
Madrid, Spain

The 15th Global Kidney Cancer Summit took place in Madrid, Spain from 4 – 6 April 2025. Over the three days, 27 Partner Organisation representatives from 24 countries came together to learn, share, connect and build capacity across the global kidney cancer community.

The theme of the 2025 Summit was *Building Evidenced-Based Advocacy Skills*. This reflects the evolution of patient organisations from being primarily focused on patient education to taking on the role of advocating for change.

The Summit programme offered an interactive event featuring internationally renowned patient advocacy leaders from within the world of kidney cancer and beyond. Through a combination of presentations and roundtable discussions, delegates explored ways to generate and disseminate the evidence needed to influence policy change. In addition, time was dedicated to the Unmet Needs of Kidney Cancer Patients and a session for Clinical Hot Topics, focused on immuno-oncology, primary renal mass management and shared decision-making in adjuvant treatment.

## IKCC 2025 Summit: At a Glance

- ✓ 27 Partner Organisation delegates
- ✓ 24 countries represented
- ✓ 19 presenters
- ✓ 4 roundtable groups and 12 roundtable discussions
- ✓ 100% of participants said their expectations were met or exceeded every day

## Keynote Address: Where Patients Belong in Decision Making in 2025

The Summit began with Neil Bertelsen (DE), a long-time patient advocate and leader in the HIV/AIDS community, taking delegates through the history and evolution of patient advocacy. His inspirational retelling of how grassroots activism in the 1980s changed protocols for clinical trials and led to new regulatory processes for life-saving medicines – for the first-time making patient needs central to the process.

**“Until the 1980s, our role was to be passive participants in healthcare, moved through a system that was designed to be controlled by others.”**  
– Neil Bertelsen (DE)

This success led to more widespread patient engagement – in research and science, health technology assessment, medical societies and health policy. However, he reminded delegates there is more to do together to ensure meaningful and consistent patient engagement is present in health systems globally.

## Evidence-Based Advocacy: From Generating Evidence to Influencing Policy Change

The primary focus of the 2025 Summit was evidence-based advocacy with three dedicated sessions, each with an expert panel and a roundtable discussion. Delegates were led through the strategic process of generating and / or gathering the data which is foundational to advocacy efforts. A combination of theoretical and practical information was shared related to planning and implementing surveys, offering Partner Organisations insights into the advocacy planning phase.

**“Evidence-based advocacy is advocating in a targeted, well-educated and professional manner that measures the impact and outcomes of what we do.”**  
– Alfonso Aguaron (ES)

The IKCC Global Patient Survey (GPS) was featured throughout the evidence-based advocacy session, as it informs the work of IKCC globally and locally for Partner Organisations. Increasing survey participation, gaining support of healthcare professionals and leveraging data into local efforts were all discussed. Throughout the roundtable discussions, Partner Organisations shared their challenges and successes related to the GPS, supporting each other's future goals. In addition, highlights of the 2025 GPS were presented to delegates for the first time.

The on-the-ground experiences of driving change through evidence-based advocacy were shared in the aim of building advocacy capacity and inspiring delegates. Key take-aways included:

**“Collaborate. Build alliances, partnerships or coalitions. Find common ground.”**  
– Carmen Vallejo Austre (PH)

- ✓ The many forms of advocacy are interconnected: policy advocacy (transforming care), social advocacy (mobilizing community), media advocacy (extending the message).
- ✓ Combine lived experience with facts and research to be a valuable educator so public officials can better decisions that impact your community.
- ✓ When communicating the data, adjust the message to the audience in a way that uses plain language, communicates emotion and is focused on action.
- ✓ The ‘value proposition’ of the advocacy efforts is the most important thing to communicate when engaging healthcare professionals.

Following each expert panel presentation, delegates participated in small-format roundtable discussions where they interacted with each presenter, explored the topic more deeply, collaborated with other delegates and considered how the learnings applied to their local organisation.

### **Keeping the Spark Alive: Ensuring the Future of Your Organisations**

Organisational sustainability is a priority for all patient groups. On the final day of the Summit, Alfonso Aguarón (ES) of Patvocates presented his experience and insights on the lifecycle of an organisation and the connection between a crisis and the opportunity for growth. He stressed the importance of good governance that is rooted in transparency and shared values and offered insights on the role of a non-profit board and how to navigate the common ‘personalities’ and ‘pitfalls.’

### **Survey Response**

Each day, the Summit closed with a survey for delegates to share their feedback on the presentations, panels and roundtable discussions for evaluation and future planning purposes. Overall, feedback was very positive with 100% of participants indicating their expectations were met or exceeded throughout the Summit and the level of learning and gaining practical knowledge was high.

“Motivational, challenging and inspiring!”

“It was wonderful to hear the presentations and meet everyone in person.”

“I loved the theme about evidence-based advocacy.”

“The roundtables were great – to network and get to know each other.”

“This was an outstanding experience where I learned lots. Thank you so much to all.”

The 2025 Global Kidney Cancer Summit was funded by IKCC Sustaining Partners in full compliance with the IKCC's Code of Conduct:

