

Inspiring Anniversary Highlights

The Impact of Patient Expert Advisory Boards in R&D: A Decade of Breakthroughs

Over the past decade, patient expert advisory boards have become a cornerstone of meaningful innovation in R&D. The best time to shape the profile of a new treatment? Before any big investments. Who must be among the key advisors? People who live with and deeply understand the condition - patient experts.

- **From admedicum's earliest days, our mission has been clear:**

Involve patient experts early in R&D to drive truly patient-relevant breakthroughs. Our experience has proven the immense value of their insights - shaping everything from site selection, patient-reported outcomes, and trial endpoints to practical details like inclusion criteria and informed consent forms. Sometimes their advice has even prompted sponsors to do a 180° and rethink an entire program or significantly refine the target population and method of administration.

One key lesson: preparation is crucial. Success depends on finding the right patient experts and ensuring sponsors are ready to listen and act upon the learnings.

A Highlight: Hidradenitis Suppurativa (HS) Advisory Board

A standout example is Almirall's work with five patient advocacy groups* in Hidradenitis Suppurativa, a severe chronic skin condition characterized by inflamed and swollen lumps. These lumps are usually painful and break open, causing much physical and psychological distress to people trying to go about their daily lives. Almirall brought patient experts into the process early to gather meaningful and actionable patient insights on disease burden, trial experience, PROs, recruitment and retention. This resulted in a very comprehensive draft synopsis of a Phase 2 Clinical Trial, including actionable feedback.

Preparation was meticulous—a clear board charter, defined outcomes, the right patient profiles, and fair compensation. After thorough outreach, five experienced HS patient experts from the USA and Europe met virtually, well-briefed and ready to dig deep.

● Key Learnings

Experts clearly said that many patients living with HS understand that in a trial they might receive placebo and that could lead to further health challenges. They pushed hard for ensuring that the study design was optimized for people living with HS.

Other insights included: adapting the number of visits, increasing visit windows to ensure patient compliance, providing detailed guidance on how to manage concomitant medications, and calling for providing trial participants with extra support regarding daily care of lesions.

Participants stressed that if clinic visits might be long, clear communication from the site with study participants was key and sites could even consider providing a dedicated space for rest that included healthy snacks to ensure participants were comfortable.

The feedback collected during the session was very powerful and unlocked significant insights that will help to improve the patient-centricity approach to HS. Almirall's team listened and after thorough internal discussions, all major patient recommendations were implemented. Some of them being ranked as high impact for trial success.

* The sponsor of the trial is Almirall S.A. Patient Experts participating represented the Danish Hidradenitis Suppurativa Patients' Association, US-based HS Connect, the Dutch and the Spanish Hidradenitis Patient Association, as well as HS Ireland. Facilitator of the meeting was admedicum GmbH & CO KG (conceptualisation, organisation and moderation).



*One **patient expert participating** shared, “I am deeply impressed with Almirall for listening and acting as they have done.”*

***Estrella Garcia, Global Clinical Operations Executive Director at Almirall** added, “We’re extremely excited about the opportunity to truly co-create trials with patients and ensure the studies we develop meet their needs. This makes all the difference and demonstrates our commitment to patient-centric innovation.”*

Future Directions

What began as a one-time advisory board has now grown into Almirall’s permanent HS Patient Council. This group is regularly invited to share their views on important decisions in clinical studies for Hidradenitis Suppurativa (HS). And we’re not stopping there. We’re working to expand this collaboration to other skin conditions, because we believe that every patient voice matters.

This partnership has helped us build a patient-voice strategy—a way to make sure that clinical trials are designed with patients, not just for them.

SINCE 2016

Why we do what we do at admedicum

At admedicum, we are convinced that meaningful patient involvement is not just possible—it’s essential. For nearly a decade, we have been dedicated to connecting people living with chronic and rare diseases with companies, researchers, and healthcare providers—on equal footing. Only through genuine partnership can we co-create solutions that truly make a difference.

We are profoundly grateful for the privilege of facilitating collaboration between inspiring patient experts and leading industry clients in research and development. It is a responsibility and an honor that we remain deeply committed to.

Contact us!

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