



In 2015, the International Foundation for **Autoimmune & Autoinflammatory Arthritis (AiArthritis)** was one of three innovation in research winners - and the **ONLY** one in immunology - for concept project to test and develop new collaboration strategies to enhance engagement between industry, researchers, and a global pool of patients to improve endpoints, expedite processes, and better utilize research dollars in the early drug development for the rheumatology community.

Why was this important for our community?

Our organization is led by people living with **AiArthritis** diseases, who have been "at the table", serving on advisory panels, participating as research liaisons, and using our stories to influence policy, legislation, and regulatory processes. But we realized we - and the others who are known advocates - realistically can only communicate with a percentage of the 450,000 million people worldwide living with our diseases, based on who is following us or who belongs to the same groups we do. How can we reach more people so we can ensure **ALL** voices are counted? This issue is magnified because our diseases are complex in nature, as no two patients are entirely alike. Furthermore, we know patient-reported outcomes and preferences change based on varied perspectives, levels of disease and diagnosis journeys, diverse cultures, backgrounds, and other experiences. If we are truly going to impact education, advocacy, and research in ways that are meaningful to **ALL** patients, then **ALL** patients need to be "at the table," and this needs to happen regardless of geography, disease limitations, or prior advocacy experience.

But in 2015, the standard protocol for gaining patient input was Advisory Panels. While this method works well in many situations, as the advocates who had served on these panels, we knew to improve research and outcomes for **ALL**, more voices needed to be counted.

Solutions we tested in this pilot project

Increasing the number of patients "at the table." We began testing use of an online community (intranet) to host focus group-style research, paying special attention to increasing participation (as our community fears committing when there is a possibility they will flare). We also knew people living with our diseases often prefer speaking with others like them, who also were impacted by **AiArthritis** diseases, as there is a level of understanding and trust that cannot be achieved between patient/non-patient communication. So the online site, and associated research discussions, were designed for "flare-free" participation (patients could contribute when they felt best).

We also tested a new method of research, now called Mentor Assisted Research), where patients - who were trained as focus group moderators -- led the sessions, with professional researchers as their advisors (flipping the known model of patients advising

professionals). Well-known patient advocates, in addition to our own organization's co-founders and volunteers, were the project leaders.

In addition to the online community, the patient project leaders tested additional methods to connect patients with other stakeholder groups (patient organizations and researchers), including hosting ACT LIVE! at the American College of Rheumatology (ACR) meeting in 2015. During this event, the patient leaders hosted conversations with other stakeholder groups, streaming these live to social media so patients worldwide could communicate with them in real time.

The ACT Round Table. The final phase of this project was to unite different stakeholders from around the world "at the table", alongside patients, to discuss known benefits and barriers to increasing the patient-included research in the rheumatology community. Representatives from other patient organizations, researchers, pharmaceutical companies, and patients talked about the need to track efforts (internationally), so those developing research projects could streamline processes and, in turn, improve efforts to include more patients.

Project Results

Hosting research and coordinating conversations and activities in a "flare-free", online environment - led by fellow patients who understood member challenges - was hugely successful. Matter-in-fact, utilizing patient focus group moderators - who were able to dive deep into conversation with their peers - resulted in strong data collection and demonstrated it would provide significant cost savings. We learned a lot regarding how to connect patients with other stakeholders so, together, we can improve outcomes.

Then in 2018, as we started planning for ACT II, we realized that the work we did in the first project could be translated into ALL the work we do to help patients impact education, advocacy, and research. So instead of developing an online space to house ONE project (ACT II), we put that project on hold and worked on developing a site that could incorporate these processes in ALL projects we do. It took another two years to make this happen - and the result? **AiArthritis Voices online community.** We know this concept is still a work in progress, but we hope all our members who are joining us inside this space will join in to help us continue to mold it into an experience that helps ALL patients have a voice.

The ACT Round Table evolved to become the ACTion Council, which published the Pathway of Patient Engagement in Rheumatology Research to map the evolution of patient engagement in rheumatology research by documenting the history, noting the unique methods of involvement, and referencing tools that have been developed to offer guidance and help measure success.

[Download the full ACT Project Final Report 11.2017b.pdf](#) (Note, AiArthritis used the acronym IFAA prior to 2020).