

Can Patients Moderate Research Panels as Effectively as Clinicians? Yes - And They Might Be Better

AiArthritis Applies CTTI's Patient Group Engagement Recommendations

SUMMARY

The International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis) has a mission to help those who are affected by autoimmune and autoinflammatory diseases that include arthritis as a major clinical component use their voices as equals alongside other stakeholders to solve problems that impact education, advocacy, and research. AiArthritis used CTTI's Patient Group Engagement (PGE) recommendations to successfully test a methodology placing patients in lead research roles with expert research professionals as their advisors.

GOAL(S)

Despite AiArthritis's best efforts to bring all voices into the rheumatology research fold, there was still a gap between what patients could offer and what was interwoven into most arthritis research. Never an organization to shy from innovation and a challenge, AiArthritis set out to develop a planning project that would 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 phase (pre-clinical trial) of the rheumatology Research & Development (R&D) continuum. As a second objective, AiArthritis wanted to ensure that all patients have the opportunity to engage in various research initiatives with different stakeholder groups regardless of geographic location, disease limitations, or former advocacy experience.

CHALLENGES

As a non-profit patient-led research foundation, AiArthritis wasn't equipped with a team of savvy researchers or a massive budget to bring its vision to life. To determine just how deeply patients could reasonably be embedded into the rheumatology research process, it needed to start the way many brilliant ideas originate: with a curious mind, determination, and a Google search.

SOLUTION(S)

Fortunately, AiArthritis soon found CTTI's PGE [recommendations](#), which highlight important roles for patient groups throughout all stages of the research process. These solutions also provide best practices that sponsors, patient groups, and other stakeholders can use to ensure the relationship is mutually beneficial. CTTI has also developed an [online prioritization tool](#) that patient groups and sponsors can use to identify high-value opportunities to work together. The tool lets users select relevant engagement opportunities for their project, rate the benefits and investments of each (low, moderate, high), visualize and adjust the analysis, and compare the output with their partner. For AiArthritis, CTTI's findings supplied much of the baseline research it had prepared to spend thousands of dollars to obtain. As a result, the project's starting point accelerated considerably, setting up AiArthritis for a more robust solution than it would otherwise have achieved.

TAKING ACTION

With many of the overarching patient engagement insights well established by CTTI, AiArthritis began to chart the areas where patients add value on the research spectrum (such as natural history, dissemination and education). With those established, they had a framework to consider building on CTTI's work with rheumatology-specific areas for patient inclusion. One of those areas was in focus group moderation. AiArthritis theorized that with professional training, patients could serve as less costly and more effective moderators for focus groups. With a personal experience with the symptoms people with arthritis navigate, they could ask more targeted follow-up for richer focus group outputs. To this end, AiArthritis formed A Community Team, or ACT, a program to test a new methodology that placed patients in lead research roles with expert research professionals as their advisors.

One challenge of patient-led efforts is garnering credibility in the research community. Researchers tend to be hesitant about the role patients can play in the research process and put them in a limited advisory role. To flip the script, AiArthritis made patients the leaders of the focus groups with researchers serving as advisors. Their ACTion Council, which was formed in 2019, is 70 percent patient led, putting the patient voice at the fore of their effort.

IMPACT

ACT has been a tremendous success for AiArthritis, with subsequent initiatives building on the initial pilot program. Researchers partnering with ACT have enjoyed rich insights delivered by professionally trained patient moderators who can dig into a question with personal perspective in a way a non-patient moderator could never achieve. The program was one of three winners, and the only immunology winner, in Celgene's 2015 Innovation Impact Awards, which recognize the achievements of U.S.-based not-for-profit organizations addressing the needs of patients, caregivers and healthcare providers in today's challenging healthcare environment. As a next phase, ACT is preparing patients for precision medicine through a working group that is piloting a shared decision-making tool to educate patients about the barriers and benefits of participation in research.

ADVICE

From AiArthritis, the importance of looking at existing resources prior to a patient engagement effort cannot be overstated. The organization not only saved substantial cost by using CTTI's recommendations, but also achieved a much more robust program than if they had started from scratch. Recognize that no resource will be 100 percent aligned to your needs, but there is likely still value embedded in prior work that can establish a foundation for your effort.

ORGANIZATION

The International Foundation for AiArthritis

CONTACT

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ORGANIZATION TYPE

Patient

IMPLEMENTATION DATE

2015

TOPIC

Patient Engagement

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