

REPORT



# Immunology and Inflammation Clinical Trials: Key Trends and Insights From Patient Survey Data 2024

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## Introduction

As biopharma sponsors and clinical research sites face growing challenges in patient recruitment and retention, understanding patient motivations, preferences and barriers becomes crucial. In collaboration with [StuffThatWorks](#), an AI-powered crowdsourcing health platform, and [Know Rare](#), a recruitment organization supporting rare disease patients, Advanced Clinical conducted a comprehensive survey targeting patients with immune and inflammatory diseases. This report explores the findings from the survey, highlights trends in patient engagement and outlines opportunities for improving clinical trial design and execution in immunology and inflammation research.

## Executive Summary

Immunology and inflammation clinical research is rapidly advancing, but challenges remain in patient recruitment and engagement. To address these challenges, Advanced Clinical conducted a global survey to understand the experiences, motivations and barriers patients face when considering clinical trials. The insights gathered reveal that early outreach, flexible study logistics and digital support tools can significantly improve participation rates. This report delves into these findings, offering actionable recommendations for both sites and sponsors.

## Survey Overview and Demographics

The survey captured responses from 539 patients across 367 different conditions. Among these, 210 (approximately 39%) had at least one immune and inflammatory disease, including rheumatoid arthritis (RA), chronic fatigue syndrome, COPD and myasthenia gravis. The geographic and demographic data showed a predominance of respondents from North America (68%), with a majority of immune and inflammatory disease patients being over 65 years old and female (59%).

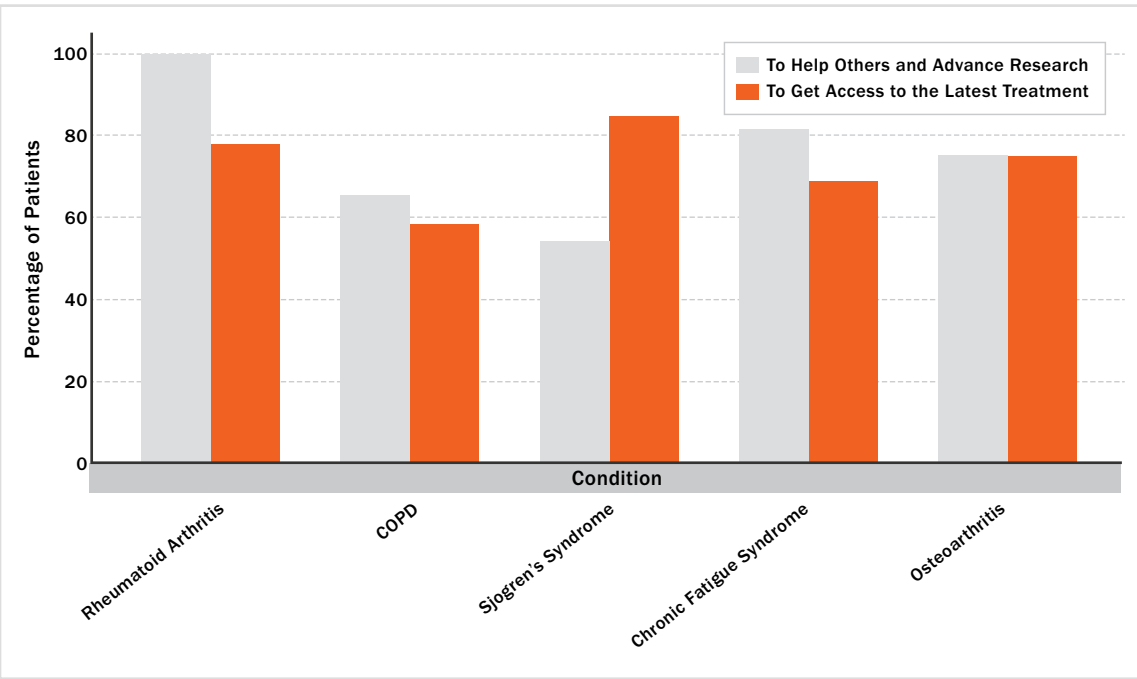
## Key Findings From the Survey

### 1. Motivations for Participation

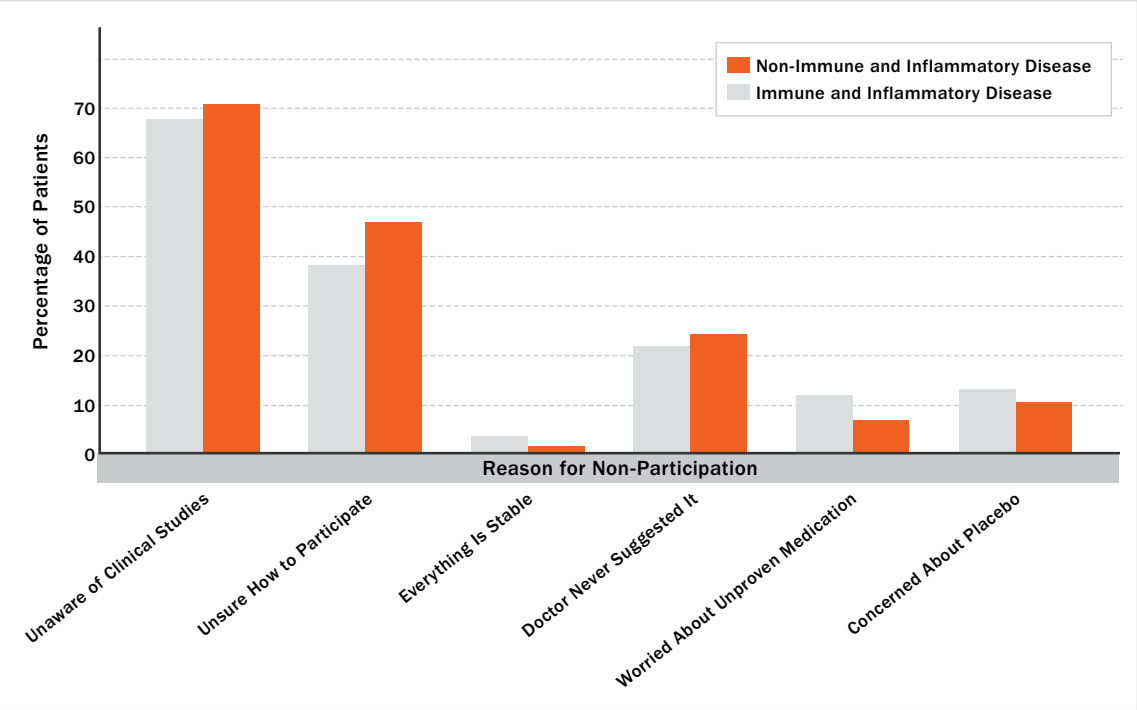
Patients with immune and inflammatory diseases showed strong motivation to participate in clinical research for altruistic reasons and access to advanced treatments. Specifically:

- > Helping others and advancing research: 100% of rheumatoid arthritis patients indicated this as a key driver for participation
- > Access to new treatments: Over 61% of respondents cited access to new therapies as a primary reason to join clinical studies

## Motivations for Participating in Clinical Trials Across Conditions



## Reasons for Non-Participation in Clinical Trials



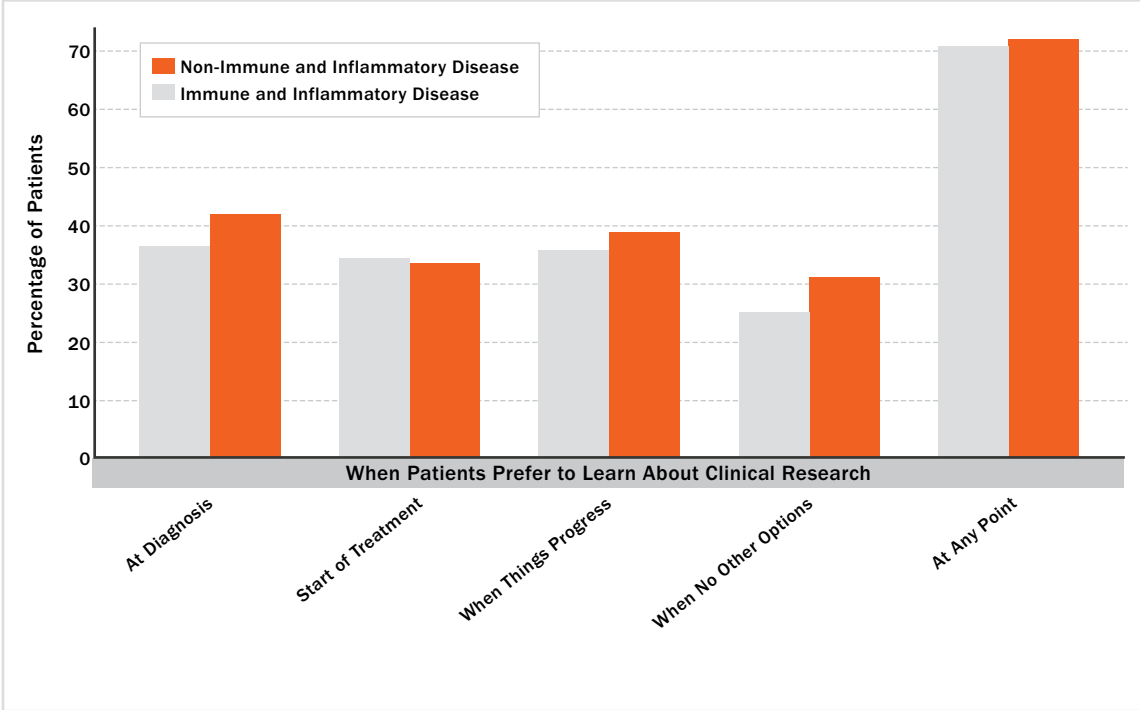
### 2. Barriers to Participation

While many patients were eager to participate, a significant number did not join a trial due to various barriers. Common reasons included:

- > **Lack of awareness:** 67% of patients were unaware of available studies
- > **Logistical challenges:** Patients often reported challenges in finding trials that fit their schedules or allowed them to continue current medication

Despite these barriers, immune and inflammatory disease patients were less likely than other patient groups to cite “unsure how to participate” as a reason for non-participation, suggesting that information may be more readily available to them compared to others with immune and inflammatory diseases.

## Timing Preferences for Learning About Clinical Research



### 3. Importance of Early Awareness

Across all conditions, patients emphasized the importance of learning about clinical trials early in their disease journey. Many expressed a preference for receiving information at the time of diagnosis or early in treatment. However, even when early outreach is not possible, the data showed that patients would still like to be informed throughout their disease progression.

Patients with immune and inflammatory diseases, such as COPD and Hashimoto’s thyroiditis, reported the highest interest in learning about trials at the point of diagnosis (more than 50%).



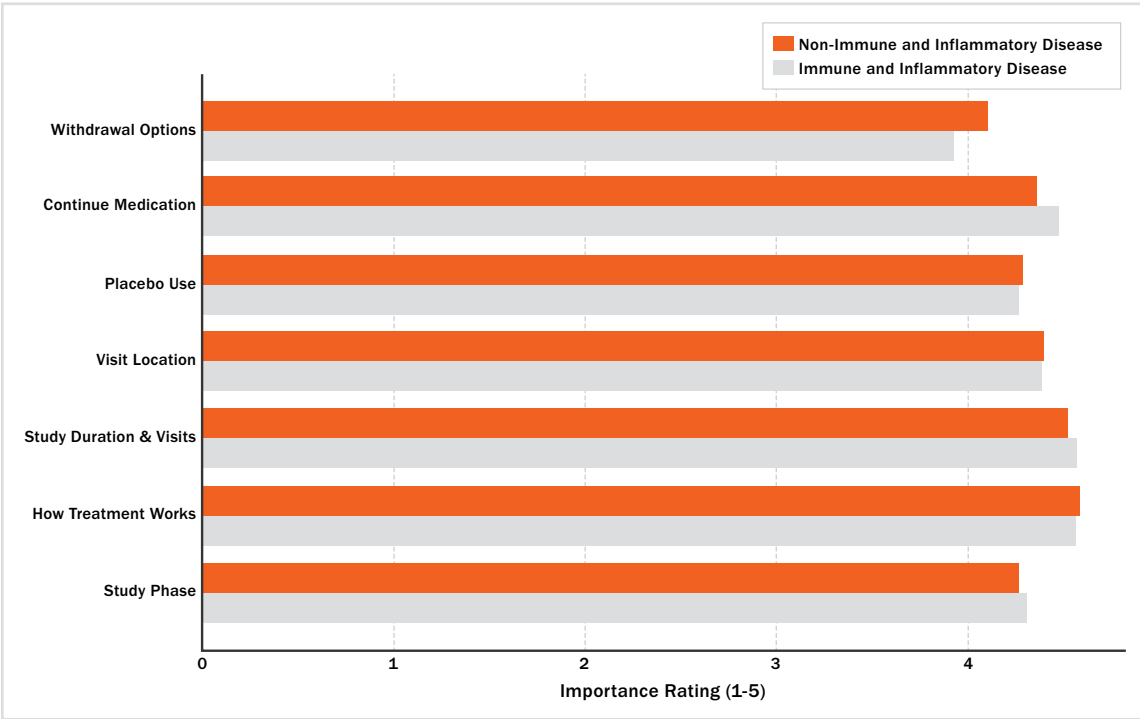
4. Flexible Study Logistics Are Critical

All respondents, including those with immune and inflammatory diseases, expressed a high interest in understanding a broad range of logistical details when deciding whether to participate in a clinical study. The following logistical elements were deemed most important:

- > **Study location options:** A majority preferred virtual, at-home or local clinic options
- > **Continuing current medication:** Maintaining their existing treatment plan was essential for most respondents
- > **Detailed information:** Patients wanted clarity on study duration, phases and logistics to make informed decisions

Given the logistical complexity of managing conditions like rheumatoid arthritis and myasthenia gravis, offering multiple visit locations (virtual, clinic-based, etc.) is crucial.

Patient Preferences for Study Logistics





### 5. The Role of Digital Tools in Enhancing Patient Experience

A significant proportion of immune and inflammatory disease patients indicated that digital tools could enhance their clinical trial experience. More than 50% expressed interest in using an online app to access study information. Additionally, travel support and compensation for study-related expenses were noted as critical factors in improving patient satisfaction.

Patients with myasthenia gravis and chronic fatigue syndrome were the most likely to advocate for digital solutions like mobile apps and online study portals.

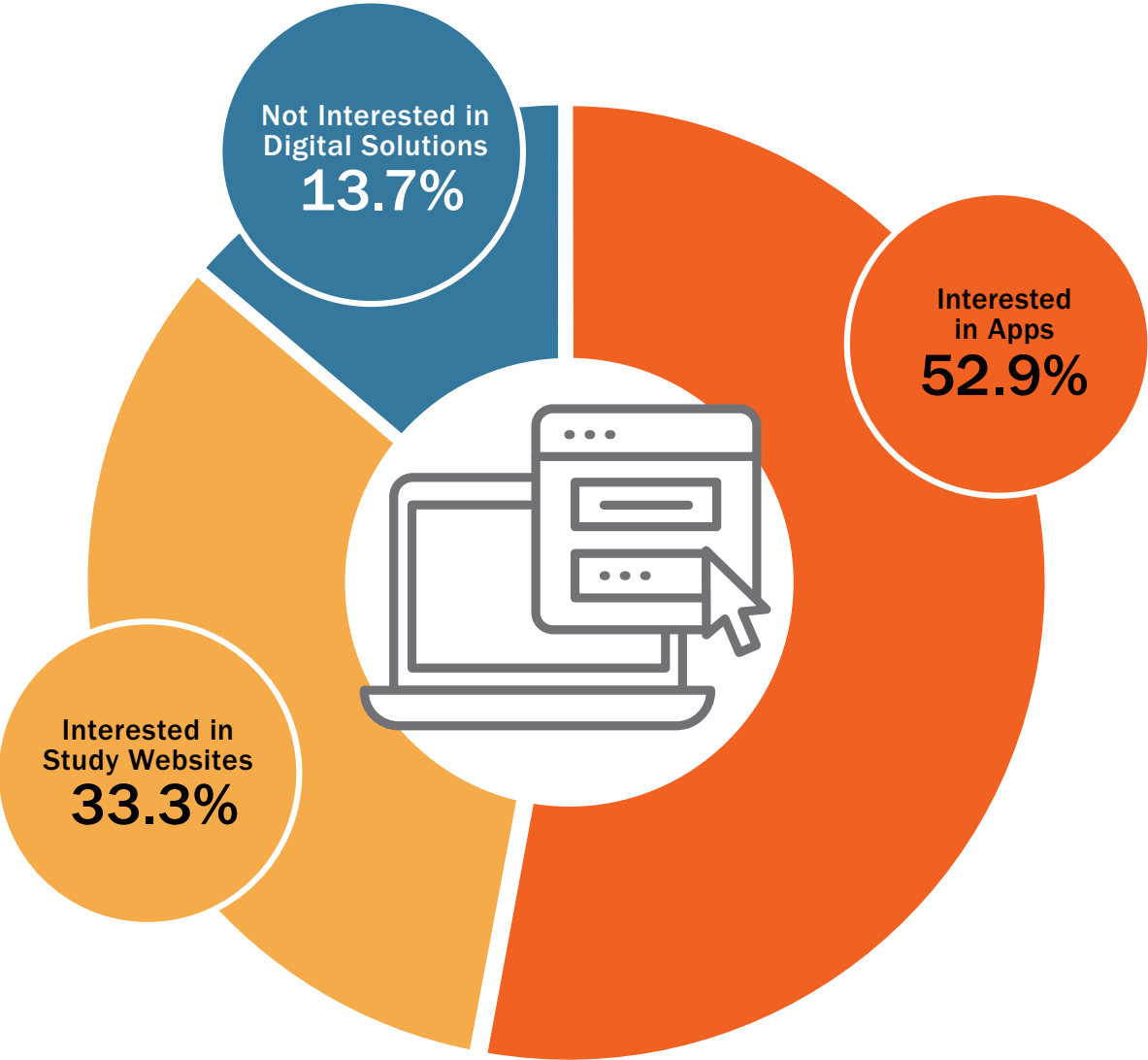
### 6. Early and Continuous Communication Is Key

Patients repeatedly emphasized the need for transparent, consistent communication throughout the clinical trial process. Key points they wanted to understand include:

- > **Study duration and visit logistics:** How long the study will last and the frequency of visits
- > **Disease and treatment information:** Detailed explanations of how the disease and the experimental treatment work, including the ability or not to continue taking existing medications and if not, transparency on why this is the case
- > **Study phase:** Patients wanted to know the current phase of development for the treatment under evaluation

Providing comprehensive, easily accessible information, especially at the recruitment stage, would significantly improve patient engagement and retention.

### Interest in Digital Solutions (Immune and Inflammatory Disease Patients)





## Actionable Recommendations for Sites and Sponsors

Based on the insights in this report, the following strategies are recommended for biopharma sponsors and clinical trial sites:

- 1. Early outreach and education:** Provide healthcare professionals and patients with information about clinical trial opportunities early in their disease journey, ideally at the time of diagnosis or during the initial treatment phase.
- 2. Flexible and patient-centered study design:** Incorporate flexible options for study visits (e.g., virtual or at home) and educate and inform patients on the “why” it is not always possible to allow participants to continue their current treatments.
- 3. Utilize digital tools:** Leverage online apps, study websites and other digital platforms to keep patients informed, offer logistical support and improve their overall trial experience and improve trial retention rates.
- 4. Tailor communication:** Ensure patients receive clear, detailed information about study logistics, treatment options and their ability to withdraw at any time.
- 5. Offer support services:** Provide travel support, compensation for time off work and coverage for study-related expenses to enhance patient satisfaction and retention.

## Conclusion

Immunology and inflammation research continues to evolve, offering promising new treatments for patients with chronic, often debilitating conditions. However, successful trials depend on the engagement and retention and subsequent data capture of well-informed patients. By understanding patient motivations, addressing barriers to participation and providing flexible, supportive study designs, biopharma sponsors and clinical trial sites can drive innovation and deliver better outcomes for patients.

**Contact us today to learn more about how Advanced Clinical can support your immunology and inflammation clinical trials. Our experienced team is ready to support and lead patient-centered studies that drive engagement, optimize study design and logistics and accelerate new treatments to market.**

**CONTACT US**





## Rebecca Starkie

Senior Global Director of Patient Engagement

Rebecca Starkie, Senior Global Patient Engagement Director, has spent the entirety of her 26-year career in clinical research, with much of this time focused on strategy and running clinical studies. She is experienced in optimising patient recruitment from a multitude of avenues, including AI, Electronic Health Records (EHR) and digital/online media and patient community engagement programs. Rebecca successfully applies innovative solutions toward patient recruitment and retention campaigns, whilst consciously navigating health literacy, diversity, equity and inclusion to reduce study burden and facilitate patient study participation. She is passionate about bringing patient engagement to the forefront and has an entrepreneurial mindset liking to think outside of the box. Rebecca actively volunteers in multiple industry patient voice, recruitment and DE&I initiatives. She holds both a BSc (Hons) Biochemistry and a Certificate in Clinical Research from the University of Leeds, England, U.K.

### About Advanced Clinical

Advanced Clinical is a clinical development and strategic resourcing organization committed to providing a better clinical experience across the drug development journey. Our goal is to improve the lives of all those touched by clinical research — approaching each opportunity with foresight, character, resilience and innovation. Based on decades of experience, we help our clients achieve better outcomes by conducting candid conversations and anticipating potential issues through our customized solutions. Visit [www.advancedclinical.com](http://www.advancedclinical.com) to learn more.

### About StuffThatWorks

Led by senior founding members of Waze, a community-based navigation app, StuffThatWorks applies machine learning and crowdsourcing to empower people with chronic conditions to transform their experience into an organized knowledge database aimed at discovering which treatments work best. Using subjective information provided by users themselves as well as data from EMRs and wearables, StuffThatWorks has generated the largest Real-World Evidence-centric database for chronic conditions. The result is not only a supportive community for members but also a 400,000-page searchable website with patient-driven data on anything relating to chronic conditions, accessible publicly to anyone in the world. StuffThatWorks was founded by Yael Elish and is based in Tel Aviv. Visit: [www.stuffthatworks.health/](http://www.stuffthatworks.health/) to learn more.

### About Know Rare

Know Rare's global rare disease support network of more than 21,000 people, including about 200 researchers, is changing what it's like to live with rare disease, fostering real connection, empathy and insight. It connects people living with rare diseases with information about their conditions and to specialists, clinical studies, advocacy organizations, and more. Partnering with rare disease researchers and sponsors, Know Rare can help build awareness and access to new treatments in development. Having helped people with rare diseases participate in more than 40 clinical trials, Know Rare is currently focused on rare diseases related to: Autoimmune, Cancer, Dermatology, Heart, Hematology, Kidney, Metabolic, Neurology. Visit [www.knowrare.com](http://www.knowrare.com) to learn more.