

Patient and Caregiver Perspectives: Insights on How to Improve Clinical Research Awareness and Participation

Rebecca Starkie

Senior Global Patient Engagement Director, Advanced Clinical





Integrating patient and caregiver insights into clinical research planning and protocol design is crucial for creating studies that are relevant and patient-centered. These perspectives enable studies to focus on outcomes of interest to participants (including medical outcomes, quality of life, symptom relief and functional improvements) and to pose minimal burden to participants. This facilitates recruitment and retention, leading to more robust and generalizable study findings, in turn supporting the ultimate goal of improving the quality of healthcare and patient outcomes. Incorporating patient and caregiver perspectives can help address challenges in clinical research, such as the fact that 85% of trials currently experience some type of delay, with a financial impact of \$600,000 to \$8 million per day of delay, and up to one-half of trials are not completed because of insufficient enrollment.¹

Encouragingly, the vast majority of respondents who have taken part in a clinical trial would do so again, according to a recent survey by Advanced Clinical and [StuffThatWorks](#). The main reason given for those who did not participate was lack of awareness – indicating a need for improved communications.

The global online survey was designed to gain further insights into the perspective of patients and caregivers, as well as enhance their experience participating in clinical research. Launched in June 2023, the survey was completed by 679 respondents, of whom 98% (667) were patients and 2% (12) were caregivers. Some 70% of respondents were based in North America and 23% in Europe. Respondents reported having a total of 325 different diseases and conditions in a broad range of therapeutic areas.

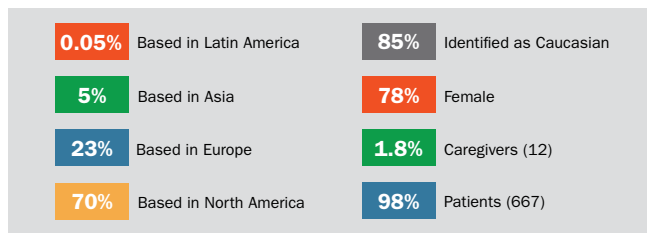
Advanced Clinical—a clinical research services organization committed to providing a better clinical experience—conducted the survey with StuffThatWorks, an AI-powered health crowdsourcing organization. The survey was made available to the StuffThatWorks community. Details of respondent demographics, locations and disease profiles are shown in Panel D1 and Table 1.

Panel 1: Survey Respondent Characteristics

1. Demographics & Geography

Number initiating the survey: 697

Number of completed surveys: 679



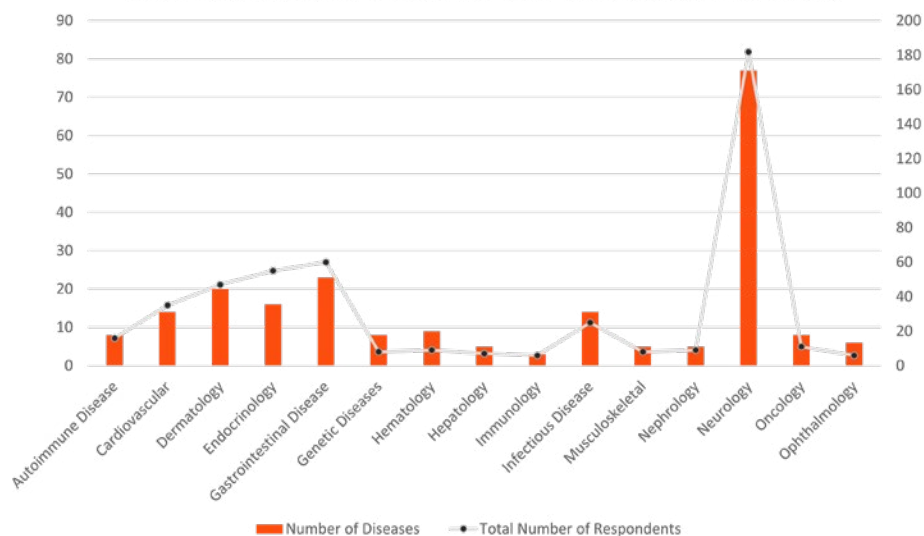
Most responses came from people aged 65+ (38%), followed by 55-64 (28%), and 45-54 (18%), 18-35 (8.3%), 36-44 (7.8%) and 0-17 (0.5%)

Respondent demographics may reflect the fact that certain subpopulations tend to seek out online support for their disease or are simply more inclined to participate in surveys.

2. Representation of Diseases and Conditions

The patients who responded to the survey reported having a total of 325 different diseases and conditions in a broad range of therapeutic areas. As shown in Table 1, neurological indications were most strongly represented (77 diseases in 182 respondents), followed by rheumatology (26 diseases in 139 respondents), psychiatry (25 in 91 respondents), and gastrointestinal diseases (23 in 60 respondents).

Table 1: Disease Reported by Patients Who Responded to the Survey





This follows a similar survey of rare disease patients, described in an Advanced Clinical [Insight Brief](#) published earlier in 2023.

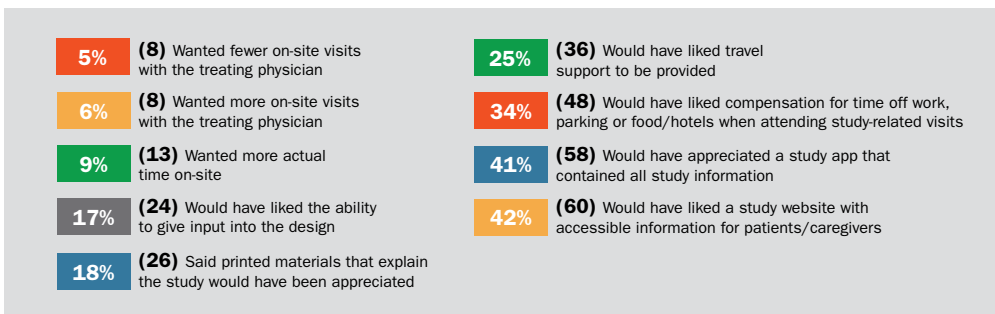
Overall Survey Findings: Key Takeaways

Key findings from the survey were as follows:

- > The vast majority (92%, 131) of **respondents who had participated in research would do so again**, indicating a positive overall experience. Of this group, 89% agreed or strongly agreed that information received before taking part prepared them for their actual experience. This confirms the importance of providing educational material in addition to the Informed Consent Form.
- > Respondents mentioned the desire to have **all study-related information in one place**, accessible either via an app or website. Most respondents (56%, 80) said they received study information received in conversations with the study team, with 45% (64) receiving printed materials such as leaflets or brochures. Responses indicated room for improvement in study-related communications (Panel 2).

Panel 2: Areas of the Research Experience with Room for Improvement

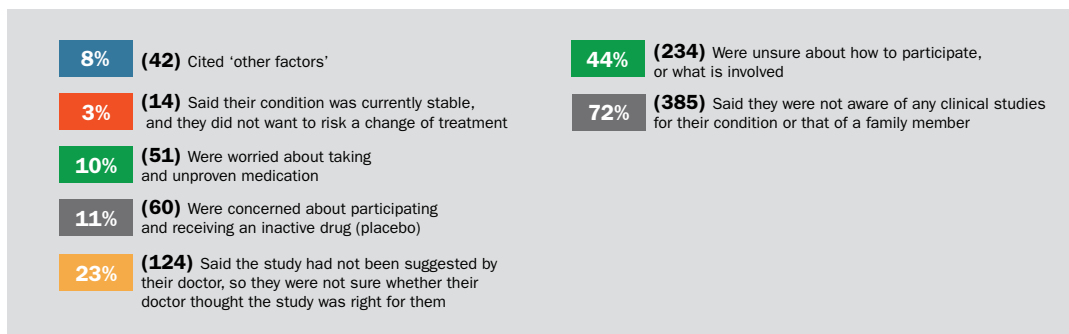
When respondents were asked about what might have made the research experience better, the responses were as follows:



- > **Lack of awareness about clinical research** was the overarching reason for not participating in clinical research studies, mentioned by 72% of respondents (385). This indicates that the industry can do better in keeping patients and caregivers abreast of research developments. Reasons mentioned for nonparticipation are detailed in Panel 3.

Panel 3: Reasons Given for not Participating in Clinical Trials

Of the survey respondents, 79% (537) had not participated in a clinical research study, versus 21% (142) who had. The main reasons given for not participating in a study were as follows:





- > **Motivations for participating in clinical research included the desire to help others** and advance research (69%, 471), gain access to the latest treatments (67%, 453) and be cared for by a leading specialist (64%, 437). Details are provided in Panel 4.

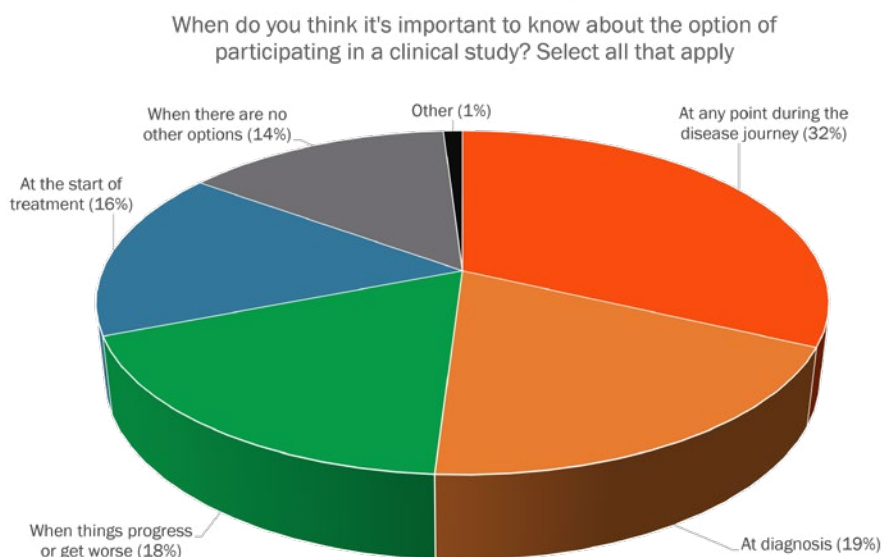
Panel 4: Motivations for Participating in Clinical Research

When respondents were asked about what might have made the research experience better, the responses were as follows:

15%	(104)	Felt they had no choice, as nothing else was working
39%	(266)	Wished for personalized care, based on researchers considering the study medication as being a good fit, with frequent monitoring
64%	(437)	Wanted to come under the care of a leading specialist in the disease
67%	(453)	Wanted to gain access to the latest treatments in development
69%	(471)	Expressed a wish to help others and advance research on the disease and its treatment

- > There was a wish for **support with travel and study-related expenses**. Interestingly, time spent at the clinical site or with study-related activities posed less of an issue for respondents. Some 59% of respondents felt it was either very important/important to make available comfort items such as blankets, pillows and water cups, with 30% remaining neutral to this question.
- > Some 67% (457) of respondents felt that they **wanted to hear about clinical research at any point during their disease journey** (Figure 1). Clinical research studies are often considered as a last resort after any standard-of-care options have been tried. In fact, respondents were interested in knowing about trial options at diagnosis, at the start of treatment, and during disease progression, as well as when there are no other options. This finding indicates that discussion of trials should be part of the patient's treatment plan.
- > Most respondents (90%) were **interested or very interested in a clinical study** for a potential treatment for their or their family member's condition. However, when asked if they had ever researched clinical studies, the response was split 50/50 between yes and no. This may reflect the fact people do not know where to look for trusted information on health concerns.

Figure 1: Respondents were interested in clinical study participation at all stages of the patient journey

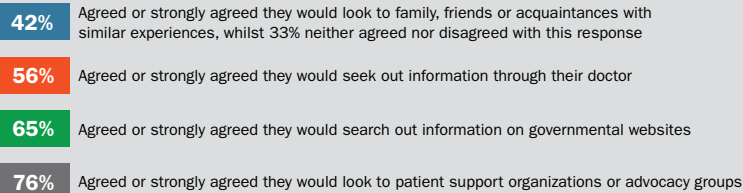




- > **Patient support organizations or advocacy groups were top of the list of sources of information** on clinical research studies, with 76% agreeing or strongly agreeing that they would look to these groups; next in the ranking were governmental websites, with 65% agreeing or strongly agreeing that they would search here; and 56% agreed or strongly agreed that they would seek out information through their doctor. Details are provided in Panel 5.

Panel 5: Sources of Clinical Trial Information for Patients

Of the survey respondents, 79% (537) had not participated in a clinical research study, versus 21% (142) who had. The main reasons given for not participating in a study were as follows:

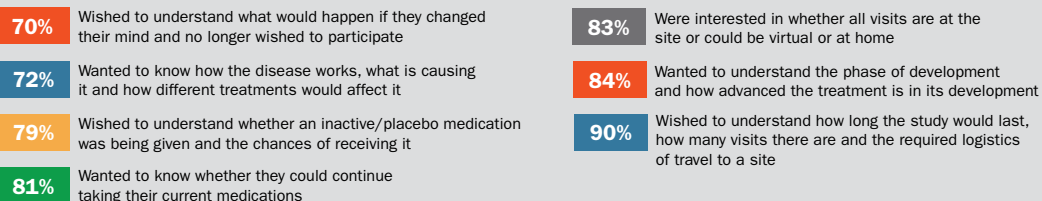


- > The response averaged between 15-28% equally from strongly disagreed to strongly agreed for looking for studies via social media channels such as Facebook or Instagram

- > **Patients want detailed information about specific studies** to make an informed decision on whether to participate. Some 90% of respondents wanted to understand the study length, number of visits and travel logistics; 84% wanted to know how advanced the treatment was in development; and 83% wanted to know whether virtual or at-home visits were an option. Details are given in Panel 6.

Panel 6: Key Questions when Deciding Whether to Participate

When respondents were asked about what might have made the research experience better, the responses were as follows:





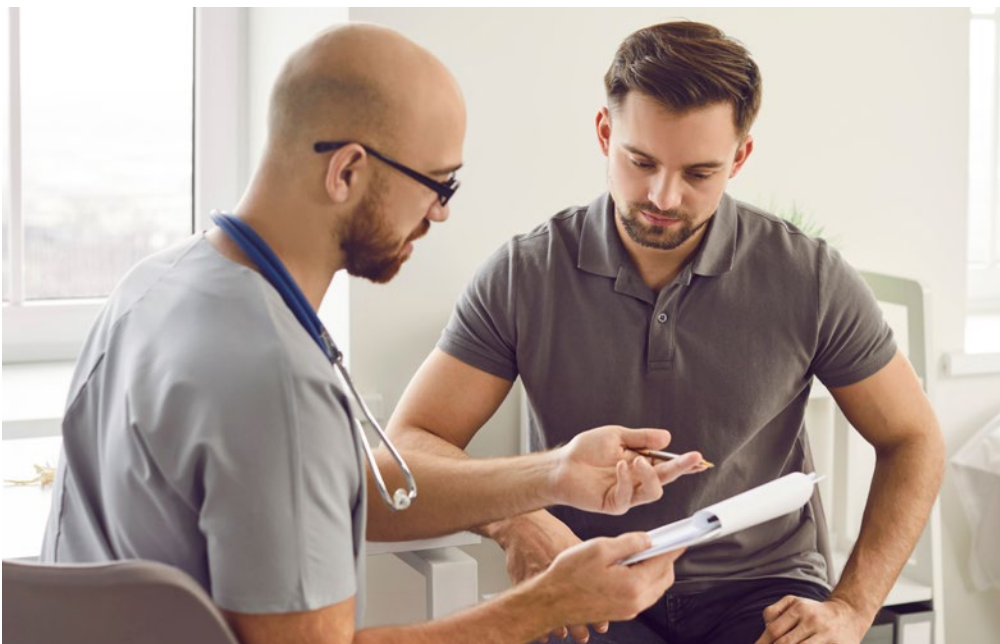
Conclusion: Patients Want to Participate in Trials Earlier in Their Journey

Like the earlier rare disease patient survey described in a recent Advanced Clinical [Insight Brief](#), this broader survey of respondents with 325 diseases in multiple therapeutic areas found that patients are interested in clinical trials but may lack information on relevant studies. Like rare disease patients, the vast majority of the latest survey respondents who had taken part in a clinical study would be willing to do so again and expressed interest in study participation across the patient journey rather than only as a last resort.

The most recent survey confirmed a need for pharmaceutical company sponsors and clinical research organizations (CROs) to engage with patients and caregivers, advocacy organizations and healthcare professionals to improve awareness of ongoing studies and how to participate. Advocacy groups and treating physicians—along with government websites—are leading sources of information on clinical research for potential participants, so they could be important supports for recruitment and retention. In terms of educational materials, respondents expressed a wish to receive detailed information about specific studies—including study length, number of visits, options for telemedicine visits, and travel requirements—to support informed decision-making on whether to participate. Respondents who had taken part in a study generally felt well prepared by the materials received in advance but highlighted a need to improve communications during the study itself, such as through a dedicated study website and/or app. Respondents also favored receiving compensation for lost earnings when time has to be taken off work, along with compensation for study-related expenses, such as parking and meals.



This survey confirms the utility of involving patients and caregivers to ensure that clinical research can better address real-world issues and improve patient care and treatment decisions. Involving patients and caregivers in research planning empowers them as partners in healthcare decision-making, acknowledging their expertise in living with the condition and ensuring that their voices are heard and valued in shaping research priorities. Patients and caregivers can offer unique perspectives and innovative ideas that researchers might not have considered, and these contributions can lead to novel research directions and solutions. Involving patients and caregivers fosters transparency in the research process, building trust between researchers and the community they aim to serve, ultimately leading to more successful and impactful research outcomes.





Rebecca Starkie

Senior Global Patient Engagement Director, Advanced Clinical

Much of Rebecca's 24-year career in clinical research has focused on strategy and running clinical studies, with experience in managing studies across a variety of rare disease studies and all phases. Her most recent experience has been specifically around Patient Engagement, supporting both clients and teams alike with strategies for recruiting and engaging patients. Passionate about bringing patient engagement to the forefront with an entrepreneurial mindset and liking to think outside of the box, Rebecca holds both a BSc (Hons) Biochemistry and a Certificate in Clinical Research from The University of Leeds, England, U.K.

References

¹ <https://www.businesswire.com/news/home/20220113005740/en/New-Study-Decentralized-Clinical-Trials-Can-Achieve-Net-Financial-Benefits-of-5X-to-14X-Due-to-Reduced-Trial-Timelines-and-Other-Factors#:~:text=Nearly%2085%20percent%20of%20all,can%20drive%20significant%20cost%20savings>

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ABOUT STUFFTHATWORKS

Led by Waze founding team members, StuffThatWorks is building the first large scale home for consented patients and their real world data, across all chronic conditions. With 3M registered members across 1250 chronic conditions, StuffThatWorks is already the biggest organised, patient centric real world data resource. From self reported to genetic and geospatial; data about patients, their condition and treatment is organised in structure, optimised for real world analysis, insight generation and patient engagement or recruitment.

Visit their website to learn more: www.stuffthatworks.health/

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