

Patient Perspectives on Clinical Trial Participation

July 2021


PharmaIntelligence
Informa





Introduction

Research methodology

A photograph of a stone wall with several dark, elongated shadows cast upon it. The shadows appear to be of people, with one shadow on the left showing a distinct head and torso, and another on the right showing a full-length figure. The wall is made of large, light-colored stone blocks with visible mortar lines. The lighting is from the right, creating long shadows that stretch towards the left.

In April 2021, Informa Pharma Intelligence partnered with Rare Patient Voice to measure the pulse of the public in relation to clinical trial participation post-COVID-19.

Research methodology

A research study was designed to understand perceptions and attitudes towards clinical research, in addition to the experiences and barriers to a better engagement. Rare Patient Voice provided access to its database of individuals in the U.S. who were either actual or potential participants in clinical trials.

A total of 1,800 people were contacted via email in early May 2021, and invited to participate in an online survey that gathered opinions on participation or intent to participate in clinical trials, with the benefit of letting their voice be heard by the very pharmaceutical companies that sponsor clinical trials. To incentivize participation, email recipients had the option of

entering a drawing for one of ten \$100 Amazon gift cards upon completion of the survey.

This report presents the survey results. Grateful acknowledgments are extended to all study participants for their valuable contribution to the research.



- All percentages have been rounded to the nearest whole number.
- Percentages in some charts exceed 100% due to respondents being able to select multiple choices.
- Respondents have been quoted verbatim, but anonymously, to preserve confidentiality.

10 Key Messages

Survey results provide current and highly informative messages



SURVEY RESULTS PROVIDE CURRENT AND HIGHLY INFORMATIVE MESSAGES

Over 900 patients participated in the study, providing a base of information on clinical trial behavior, attitudes, needs and demographics. Their views provide key insights into public perception of clinical trials, based on both retrospective experiences and potential future participation.

MESSAGES FROM TRIAL PARTICIPANTS

1. TRIAL PARTICIPATION IS MOST FREQUENTLY A RESULT OF PHYSICIAN REFERRALS

Almost half of all participants sourced their clinical trial through this channel — eclipsing all other sources by some margin — and emerging as more than twice the proportion who had used ClinicalTrials.gov.

2. CLINICALTRIALS.GOV HAD NOT BEEN USED BY ABOUT 3 IN EVERY 4 TRIAL PARTICIPANTS

Use of this resource was particularly low among those aged 65+. However, when usage was evident, it was highly rated — attaining an average score of 4.1 out of a maximum score of 5, contrary to other findings on ClinicalTrials.gov usage. This rating suggests that the website is performing well, but with room for improvements.

3. A MAJORITY OF TRIAL PARTICIPANTS RATE THE ENROLLMENT PROCESS HIGHLY

Two-thirds move from pre-screening to enrollment within a week, with this speediness yielding an average rating of 4.2 out of a maximum score of 5. An impressive 80% viewed the process positively, suggesting that the mechanisms of screening and subsequently enrolling are working with efficiency and effectiveness.

4. COMMUNICATION IS WELL-PITCHED

86% of trial participants felt that the level of communication they received during their trial was sufficient. This was typically around the once-a-week mark, a frequency eliciting the very highest levels of satisfaction, and one which suggests that — in the minds of participants — this is the most desirable level of communication during trials.

5. RECEIVING TRIAL RESULTS IS CLEARLY SEEN AS IMPORTANT

However, over 60% of clinical trial participants had NOT received the results of the study in which they participated. This was a figure clearly at odds with the expectations of a majority of both trial participants and non-participants. Here, the message was very much along the lines of "if we participate in a trial, we would like the results, please." Indeed, a need for more trial feedback emerges as the #1 suggested change to the clinical trial experience.

6. A MAJORITY OF TRIAL PARTICIPANTS WOULD BOTH RECOMMEND AND REPEAT THE PROCESS

Over 80% of those who had already participated in a trial — often in the context of a positive overall experience — would happily participate again, and would recommend participation to others. Their rationale is often selfless, with a desire to help others and to assist in the advancement of more effective treatments and cures. Accompanying benefits include financial recompense, additional knowledge and enjoyment, but these are clearly eclipsed by more altruistic intentions.

7. A MINORITY OF NEGATIVE OVERALL EXPERIENCES OF TRIALS DAMAGE PERCEPTIONS OF THE PHARMACEUTICAL INDUSTRY

The message is very much that a poor trial experience worsens views of the industry.



“ Indeed, a need for more trial feedback emerges as the #1 suggested change to the clinical trial experience

MESSAGES FROM TRIAL NON-PARTICIPANTS:

8. BEING UNABLE TO SOURCE RELEVANT TRIALS TYPICALLY PREVENTS PARTICIPATION

The most prevalent obstacles to participation are undoubtedly being unable to locate relevant trials which are an appropriate match to both geographical location and/or condition/disease. Accompanying comments from non-participants provided insight into the difficulties experienced by some in sourcing trials — despite a desire to do so.

9. A MAJORITY OF NON-PARTICIPANTS IN EACH DEMOGRAPHIC CATEGORY WERE WILLING TO PARTICIPATE IN A CLINICAL TRIAL

This was a finding particularly emphasized if their physician was making a referral. Over 80% indicated that physician referral would spur their participation — clearly highlighting the power of physicians in driving participation.

10. A DISEASE/PATIENT ADVOCACY GROUP WEBSITE EMERGED AS THE #1 METHOD OF SOURCING CLINICAL TRIALS

Most patients accessed information about clinical trials from advocacy group and disease-specific websites.

Study Participants

Respondents and their characteristics



Sorry, you must sign up in the [online version](#) to view this content.

Participation in Clinical Trials

Characteristics of participants



Sorry, you must sign up in the online version to view this content.

A close-up photograph of a person's hands holding a silver smartphone. The person has pink nail polish and is wearing a ring on their left ring finger. The phone is held over a laptop keyboard, which is partially visible in the foreground. The background is blurred, showing a wooden desk and a laptop screen.

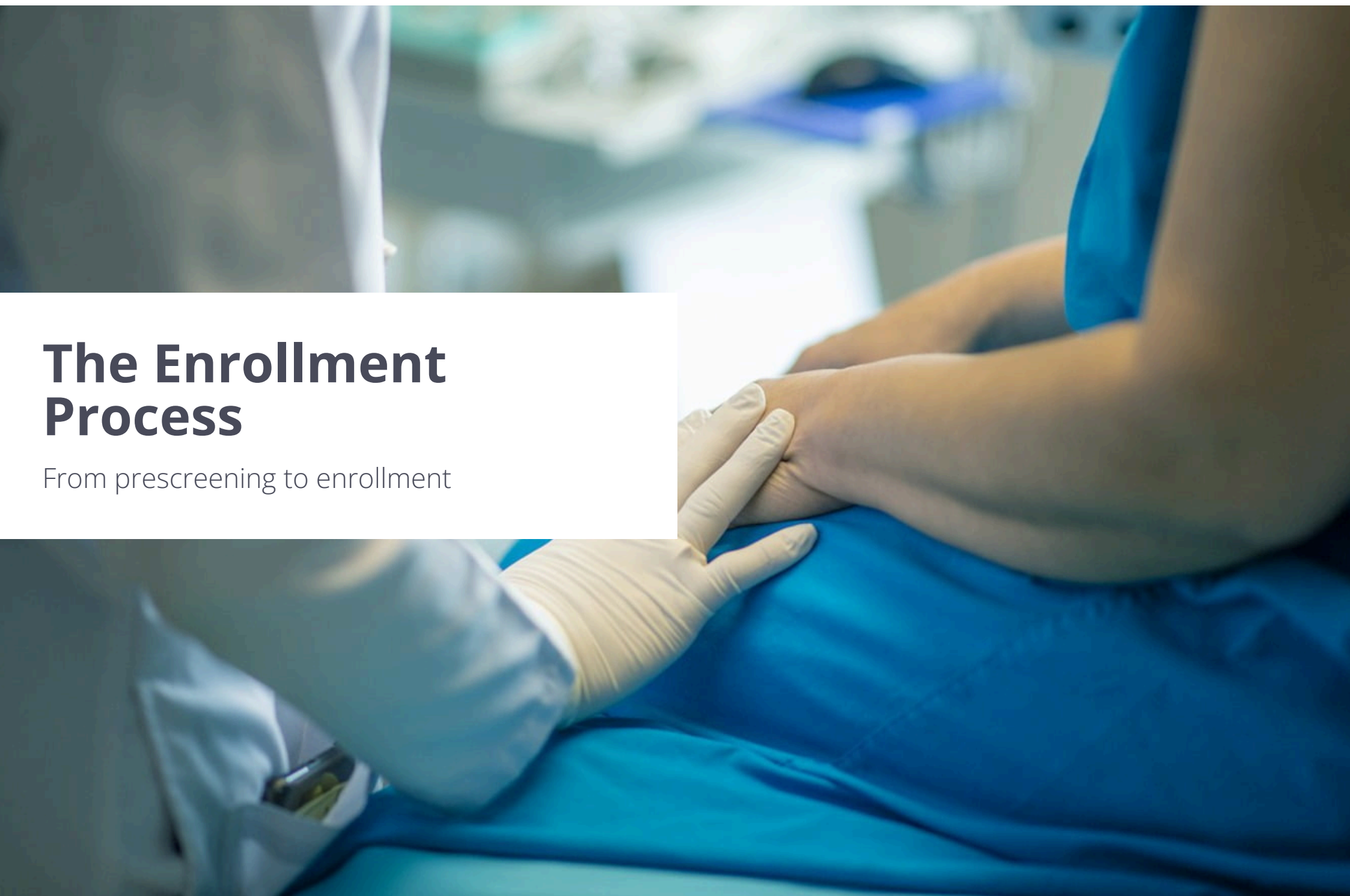
Sourcing Clinical Trials

How participants found out about clinical trials

Sorry, you must sign up in the online version to view this content.

The Enrollment Process

From prescreening to enrollment



Sorry, you must sign up in the online version to view this content.

Communication During and After Clinical Trials

Typical experiences and perceptions



Sorry, you must sign up in the online version to view this content.

Recommending Trials

Perspectives of clinical trial participants



Sorry, you must sign up in the online version to view this content.

Participating in Trials

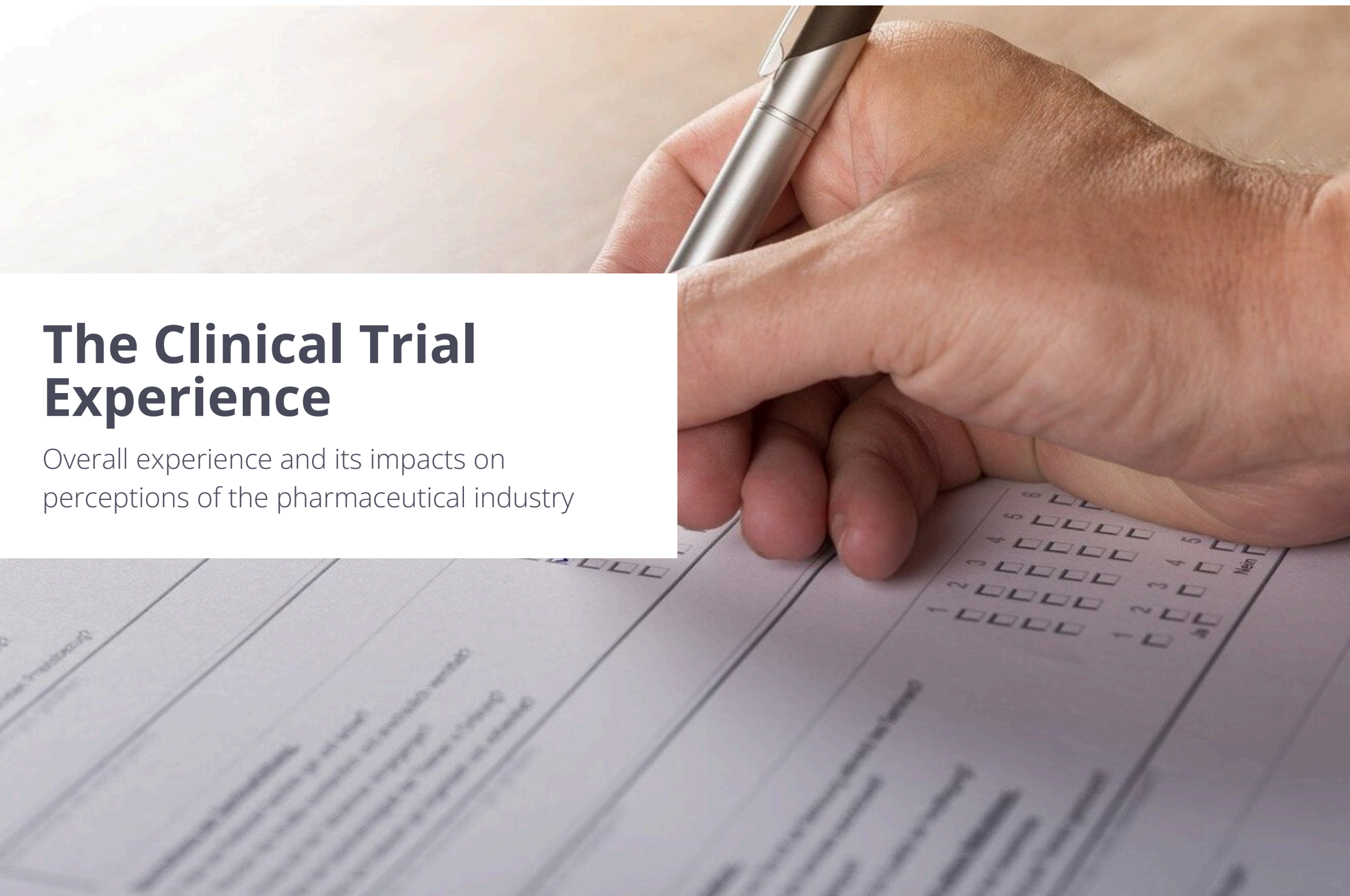
Rationale behind participation



Sorry, you must sign up in the online version to view this content.

The Clinical Trial Experience

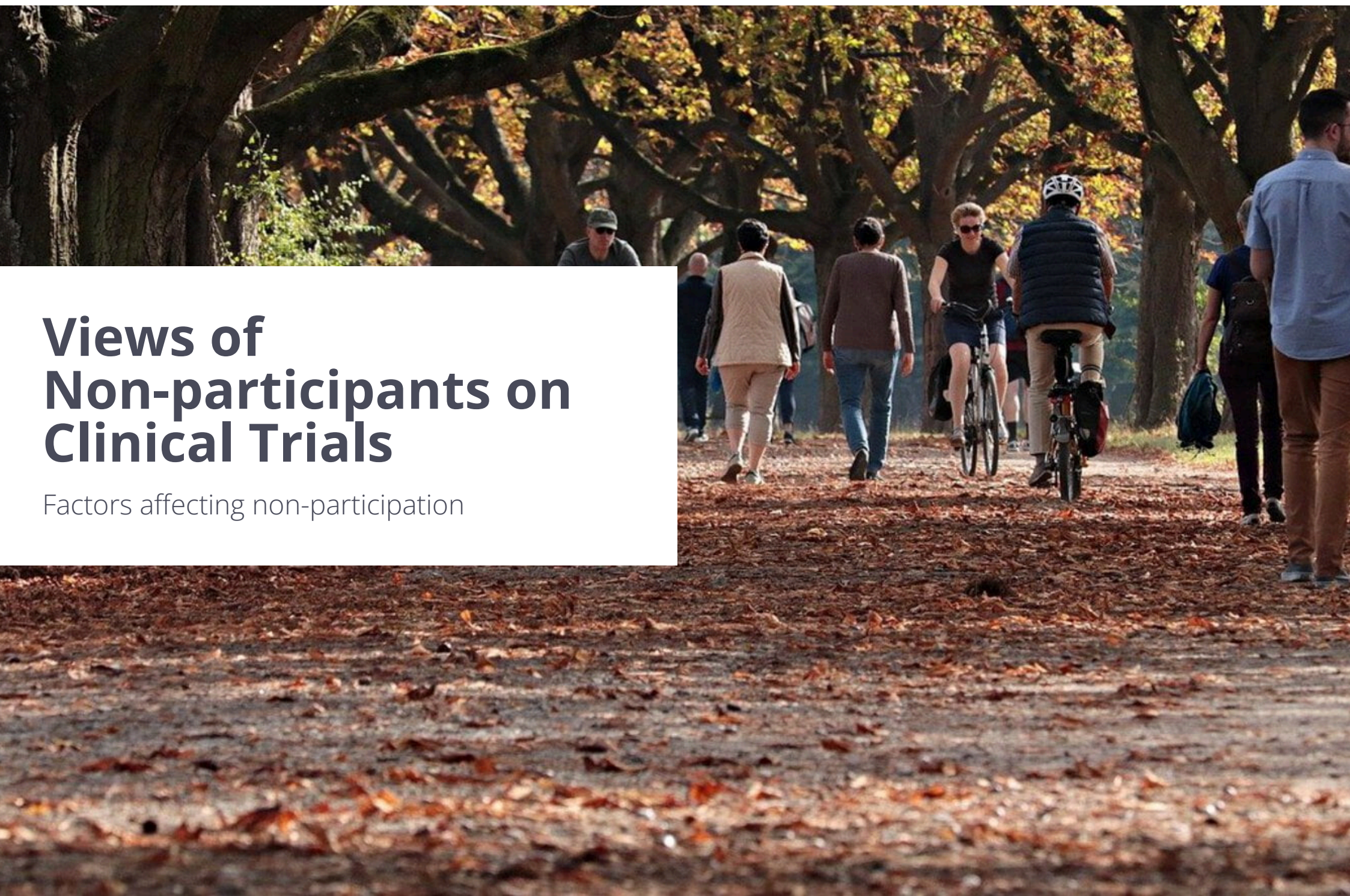
Overall experience and its impacts on perceptions of the pharmaceutical industry



Sorry, you must sign up in the [online version](#) to view this content.

Views of Non-participants on Clinical Trials

Factors affecting non-participation



Sorry, you must sign up in the online version to view this content.

Likelihood of Future Participation in a Clinical Trial

Perspectives of non-participants



Sorry, you must sign up in the online version to view this content.

Sourcing Clinical Trials

Information sources for potential participants



Sorry, you must sign up in the online version to view this content.



About the Authors

About the Authors



Informa Pharma Intelligence is home of the world's leading pharma and healthcare R&D and business intelligence brands — Datamonitor Healthcare™, Sitetrove™, Trialtrove™, Pharmaprojects™, Biomedtracker™, Scrip™, Pink Sheet™ and In Vivo™. Informa Pharma Intelligence's brands are trusted to provide over 3000 of the world's leading pharmaceutical, contract research organizations (CRO's), medical technology, biotechnology and healthcare service providers, including the top 10 global pharma and top 10 CROs, with an advantage when making critical R&D and commercial decisions.

For more information on Informa Pharma Intelligence, visit pharmaintelligence.informa.com



Rare Patient Voice, LLC provides patients and caregivers with rare and non-rare diseases an opportunity to voice their opinions through surveys and interviews to improve medical products and services.

For more information on Rare Patient Voice, visit rarepatientvoice.com

Thank you for reading

Patient Perspectives on Clinical Trial Participation