A white paper from Rare Patient Voice, a Konovo Company

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EXECUTIVE SUMMARY

Clinical trial sponsors have spent decades optimizing protocols around the needs of investigators and institutions. A 2026 survey of 1,000 U.S. patients and caregivers, fielded by Rare Patient Voice (RPV), a Konovo Company, with participants from the RPV community, suggests the industry has been solving the wrong side of the equation. When asked directly, patients are clear about what keeps them out of research: distance and travel, not safety concerns or distrust, are the dominant barrier to participation.

The findings point to a clear and quantifiable opportunity. Ninety-four percent of respondents said they would be more likely to enroll in a trial that offered telemedicine visits and local lab or imaging options instead of requiring travel to a central site. Nearly half of all respondents (48%) said they had previously wanted to join a trial but were unable to because of location or travel requirements. Sixty-five percent cited distance and travel as a major obstacle to participation overall.

These numbers describe a large, currently unaddressed pool of willing participants. The data also show that patients consistently rank clear communication, transparent eligibility information, fair compensation, and responsive support from the study team as being important, aside from where a visit takes place. This white paper translates the survey findings into a set of strategic recommendations for sponsors, CROs, and site networks designing the next generation of decentralized and hybrid clinical trials.

INTRODUCTION

Decentralized clinical trials (DCTs) — studies that use telemedicine, local laboratories, mobile health providers, and digital tools to shift study activities away from a single central site and closer to where patients live — have moved from pilot programs to a mainstream design option across the industry. Yet sponsors and sites still make most decentralization decisions based on operational convenience and regulatory precedent, with comparatively little direct input from the patients the trials are meant to serve.

To close that gap, Rare Patient Voice fielded a structured survey of respondents drawn from the Rare Patient Voice patient and caregiver community. The survey asked about their prior clinical trial experience, the barriers that have kept them from participating, how appealing specific decentralized trial features are to them, and what would make them feel most supported as a study participant. The results presented in this paper are intended to give sponsors a patient-validated foundation for trial design decisions, rather than relying on assumptions about what "patient-centric" research should look like.

RESPONDENT PROFILE

The survey reached 1,000 respondents. The sample was predominantly female (82.8%) and concentrated in the 35-54 age range, which together accounted for more than half of all respondents (54.7%).

THE BURDEN OF TRADITIONAL TRIAL PARTICIPATION

Most respondents have no firsthand trial experience: 9% said they had never participated in nor considered a clinical trial, while a majority — 67% — said they had considered participating but had not enrolled, and 22% reported direct trial experience. That gap between consideration and enrollment is the central problem this survey was designed to explain.

REPORTED BARRIERS TO PARTICIPATION

When asked to select every barrier that applied to them, respondents pointed overwhelmingly to logistics rather than to concerns about the research itself.

Distance and travel lead every other barrier by a wide margin, including safety concerns. This is a meaningful finding for sponsors who default to extensive informed-consent and risk communication as the primary lever for improving enrollment: logistics, not trust, is the larger obstacle for most patients in this sample.

WHAT WORRIES PATIENTS ABOUT THE TIME COMMITMENT

Asked to select up to two specific concerns about the time required by a traditional trial, respondents again pointed to the structure of site-based visits rather than the length of the study itself. Frequent trips to a research facility and long wait times at appointments topped the list of worries regarding the time commitment involved in participation.

THE CASE FOR DECENTRALIZATION

The survey's clearest signal is the size of the response when patients were offered a concrete alternative: a trial conducted largely from home, with telemedicine visits and local lab or imaging options in place of travel to a central site.

94% of respondents said they would be more likely to enroll under this model — 72% "much more likely" and 22% "somewhat more likely."

48% said they had previously wanted to join a trial but were unable to because of location or travel requirements.

These two figures, read together, describe both a retention problem and an acquisition opportunity: a large share of the eligible patient population that traditional trial designs are currently failing to reach.

WHAT PATIENTS WEIGH WHEN DECIDING WHETHER TO JOIN

Respondents rated how important a series of factors were to their decision to join a trial. Combining "extremely important" and "very important" responses produces a clear hierarchy:

Factor	Extremely / Very Important
Clear, frequent communication from the research team	86%
Contributing to medical research that can help others	84%
Having visits conducted at or near home	77%
Flexible scheduling options	72%
Compensation for time and travel	72%
Access to potential new treatments	71%
Technology support and ease of use	71%
Minimal disruption to daily routine	50%

Communication ranks above every other factor, including access to new treatments — a reminder that decentralization is only one part of what patients mean by a well-run trial.

APPEAL OF SPECIFIC DECENTRALIZED FEATURES

When asked to rate specific decentralized trial features rather than the concept in the abstract, every feature tested drew strong approval:

Feature	Extremely / Very Appealing
Local lab work near home instead of traveling to site	86%
Most study visits conducted via telemedicine from home	84%
Electronic consent process completed remotely	82%
Digital tools and apps to track symptoms and communicate with the study team	81%
Flexible appointment scheduling, including evenings and weekends	80%
24/7 access to support staff for questions or concerns	77%
Mobile nurses who come to your home for certain procedures	66%

WHAT PATIENTS NEED TO FEEL SUPPORTED

PREFERRED CHANNELS FOR INTERACTING WITH THE STUDY TEAM

Respondents were asked how they prefer to interact with healthcare providers and research teams, selecting all options that applied. Video telemedicine was the most preferred channel overall, ahead of in-person visits. In-person visits remain preferred by a majority of respondents, which reinforces that the goal of decentralization is to reduce unnecessary travel, not eliminate human contact. The strongest signal is for choice and flexibility across channels rather than a wholesale move to any single mode of interaction.

WHAT MAKES PATIENTS FEEL MOST SUPPORTED

Respondents ranked their top three priorities, from a list of eight, for feeling supported as a clinical trial participant. Compensation that reflects the participant's time commitment drew the broadest support of any single item, appearing in more respondents' top three than any other option, while minimal travel was most likely to be ranked as the single most important factor.

THE TECHNOLOGY PARADOX

One result in particular deserves attention from sponsors building DCT strategy around technology platforms. When asked in the abstract how important it is that a trial "uses technology (apps, wearables, telemedicine) to make participation easier," 56% of respondents rated this extremely or very important, while 31% called it moderately important, 9% reported it being slightly important, and 5% said it was not important at all.

This divide stands in contrast to the 80%+ appeal ratings given to specific technology-enabled features such as remote consent, telemedicine visits, and digital symptom tracking. The gap suggests patients may not value technology as a feature in its own right — but greatly value the outcomes it produces, namely less travel, more flexible scheduling, and easier access to their care team. Sponsor and vendor messaging that emphasizes "innovative digital tools" may resonate less than messaging that emphasizes the concrete time and burden it saves. The technology should be invisible; the convenience should be the message.

IN PATIENTS' OWN WORDS

An open-ended question asked respondents what single change would make clinical trials more patient-friendly. Responses were coded into themes; the most frequently mentioned, in order, were:

1. Reduce travel requirements / locate trials closer to home
2. Offer remote or telehealth participation options
3. Provide better compensation
4. Improve clarity of communication and information
5. Offer more flexible scheduling
6. Provide transportation assistance
7. Increase transparency on risks and eligibility criteria
8. Broaden inclusion criteria
9. Provide 24/7 access to support staff
10. Share trial results with participants after completion

The consistency between these open-ended themes and the closed-ended survey questions strengthens confidence in the findings: patients independently arrived at the same priorities — travel, remote options, compensation, and communication — whether prompted with a specific question or given an open text box.

STRATEGIC RECOMMENDATIONS FOR SPONSORS AND CROS

The following recommendations translate the survey findings into actions for trial sponsors, CROs, and site networks designing or scaling decentralized and hybrid trial models.

1. EXPAND DECENTRALIZED AND HYBRID TRIAL DESIGNS

Build remote participation options into protocol design from the outset rather than retrofitting them later. With 94% of respondents reporting greater willingness to enroll under a remote-enabled model, and 48% reporting a past trial they could not join because of location, hybrid designs address both recruitment and retention in a single change.

2. INTEGRATE TELEMEDICINE, LOCAL LABS, AND HOME HEALTH SERVICES

Local lab work and telemedicine visits were the two most appealing specific features tested. Wherever clinically appropriate, route routine labs, vitals, and follow-up visits through local or mobile providers instead of the central site.

3. IMPROVE OPERATIONAL FLEXIBILITY

Frequent trips to a research facility and unpredictable scheduling were named as top time-commitment concerns. Evening and weekend appointment windows, and a deliberate reduction in visits that do not require in-person attendance, directly address the friction patients describe.

4. ENHANCE PATIENT COMMUNICATION

Clear, frequent communication from the research team was rated more important than access to new treatments — the single highest-rated factor in the survey. Plain-language study materials, transparent eligibility criteria, and prompt follow-up after a patient inquiry should be treated as core protocol deliverables, not afterthoughts.

5. STRENGTHEN PARTICIPANT SUPPORT SYSTEMS

Dedicated coordinators, technology assistance, and accessible support channels — including after-hours availability — were consistently valued. Supportive infrastructure should scale alongside any expansion of remote participation.

6. PROVIDE MEANINGFUL COMPENSATION AND TRANSPORTATION SUPPORT

Compensation that reflects participants' time commitment drew the single broadest base of support of any item tested. Transportation assistance, while a lower overall priority, remains an important option for the subset of patients without reliable access to it.

7. INCREASE TRUST BY SHARING OUTCOMES WITH PARTICIPANTS

Sharing trial results with participants after completion was among the most frequently requested changes in open-ended responses. Closing the loop with participants after a study ends costs little relative to its likely effect on long-term trust and willingness to participate again.

CONCLUSION

The patients and caregivers surveyed for this report describe a clinical trial system that asks too much of them logistically and tells them too little along the way. The remedy they describe is specific and largely achievable with tools already available to sponsors today: move routine visits closer to home, communicate clearly and often, compensate fairly, and keep participants informed after the study ends. Sponsors who act on this evidence are not simply improving the patient experience — they are expanding the addressable population for every trial they run, in a research environment where recruitment speed and population diversity are increasingly competitive differentiators.

ABOUT THIS RESEARCH

Findings in this white paper are drawn from a survey of 1,000 U.S. patients and caregivers conducted in 2026 by Rare Patient Voice, a Konovo Company, and fielded among the Rare Patient Voice patient panel. Respondents answered closed-ended questions on trial experience, barriers to participation, the appeal of specific decentralized trial features, and an open-ended question on what they would change about how trials are conducted. Percentages throughout this paper are rounded and, for multi-select questions, do not sum to 100%.

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