

CNS Trials Through the Rater Lens:

Insights Gained Through Site-Based Survey

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SCRS
Society for Clinical Research Sites

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03 Executive Summary
About the Survey Respondents
The CNS Complexity Reality

04 Rater-Related Challenges for Sites
Patient Engagement & Retention

05 CNS Trial Technology Adoption
The Impact of Fragmented Systems

06 Operational Realities of ClinRO

07 Data Quality Monitoring Gaps
What Sites Actually Need

08 Top Technology Requests from Sites

09 What This Means for the Industry

10 Looking Forward

Executive Summary

Central nervous system (CNS) trials continue to play a critical role in advancing treatments for complex neurological and psychiatric conditions, yet they remain among the most operationally challenging studies in clinical research. Compared to other therapeutic areas, CNS trials require longer, more cognitively intensive visits and highly trained site staff to administer nuanced rating scales. While these complexities are widely acknowledged at a high level, their day-to-day impact is felt most acutely by raters who sit at the intersection of protocol, technology, and patient interaction.

Rater experience shapes trial outcomes, directly influencing assessment consistency, patient engagement, and ultimately the integrity of CNS trial data. Despite this central role, rater perspectives are often underrepresented in discussions about trial optimization and technology adoption. As CNS trials grow more complex and increasingly rely on digital tools, understanding how these realities affect raters in real-world site settings has become essential.

To better capture these on-the-ground insights, Medidata and the Society for Clinical Research Sites (SCRS) conducted a survey among raters and staff at clinical sites actively running CNS trials across multiple indications. These survey questions were drafted in collaboration with Cogstate, a leading neuroscience technology company that specializes in optimizing brain health assessments. The goal was to better understand the operational challenges, technology experiences, and improvement priorities associated with CNS trials. The findings in this white paper reflect the lived experiences of CNS raters and offer a data-driven foundation for rethinking how trials and technology should be designed, supported, and executed.

About the Survey Respondents

Conducted in late 2025 to early 2026, an online survey was sent to the SCRS site network, with a total of 108 respondents indicating they had experience in personally administering clinical outcomes assessments (e.g. eCOA, rater scales, or cognitive assessments) in CNS clinical trials. They reported having experience across multiple CNS indications. Alzheimer's disease was the most common, represented by 66% of these responders, followed by depression and major depressive disorder (58%), multiple sclerosis (41%), Parkinson's disease (36%), schizophrenia (26%), and epilepsy (21%).

The CNS Complexity Reality

87% rated CNS trials as more complex compared to trials in other therapeutic areas

44% described them as "much more complex"

Sites overwhelmingly characterized CNS trials as being more complex than trials in other therapeutic areas. Nearly 87% of respondents rated CNS trials as more operationally complex, with 44% describing them as "much more complex" and 42% as "slightly more complex." Only 13% viewed CNS trials as comparable to other areas, and no respondents rated them as less complex.

CNS trials require significantly more coordination and effort, which is driven by specific, tangible operational factors. When asked which elements contribute “very much” or “a lot” to CNS trial complexity, sites identified:

Volume of assessments: 70%
Complexity of assessments: 68%
Rater training and certification: 59%
Length of trial visits: 53%
Patient recruitment: 43%
Limited qualified staff to administer rating scales: 42%

These concerns translate directly to site resource allocation, staff workload, and ultimately trial feasibility.

Rater-Related Challenges for Sites

When asked about rater-related issues, sites revealed concerns extending beyond simple rater availability. The challenges span qualification, language capabilities, coordination across multiple trials, technology usability, and training effectiveness.

Nearly half of sites (49%) reported moderate to major challenges related to the shortage of qualified raters. Language requirements further restrict participation, with 51% of sites reporting significant difficulty finding raters fluent in the languages required for global CNS trials. These constraints directly limit both site participation and patient access.

Coordination across multiple studies presents another challenge, with 53% of sites reporting moderate to significant difficulty managing raters who support several trials simultaneously. Scheduling conflicts, overlapping training requirements, and the need to maintain consistency across protocols all contribute to operational strain.

Technology usability during scale administration is an issue for 58% of sites from moderate to significant levels. When technology interferes with the rater-patient interaction, both data quality and patient experience suffer.

Training remains a persistent issue. 57% of sites find it moderately to significantly challenging to train raters for uniform understanding of assessment scales. The challenge is not simply learning the scales, but applying them consistently across diverse patients and over long trial durations.

Despite these challenges, 76% of sites use rater training programs in their CNS trials. The question isn’t whether training occurs but whether current approaches address the challenges sites face around consistency, comprehension, and practical application.

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Patient Engagement & Retention

Patient retention in CNS trials presents unique challenges that extend beyond those seen in other therapeutic areas. The cognitive and functional impairments that can accompany CNS conditions create unique barriers to sustained participation, affecting both patients and their support systems.

Sites reported their most significant retention challenges in CNS trials include:

Cognitive Burden
Cognitive demands associated with trial procedures compromises patient engagement.

Trial Length
Extended observation periods becomes a retention barrier.

Visit Fatigue
Lengthy, frequent assessments wear on patients.

Digital Literacy
Technology intended to improve trials may exclude patients who struggle with digital interfaces.

Transportation and Logistics
Caregiver coordination adds complexity to travel logistics.

Lack of Caregiver Support
Caregiver burden and lack of their availability limits participation.

CNS Trial Technology Adoption

Clinical trial technology is widely used across CNS studies. Usage patterns reveal which technologies have become essential versus experimental for sites:

Electronic Data Capture (EDC):
Nearly universal, with 99% of sites using it always or most of the time

Electronic Clinical Outcome Assessments (eCOA):
Used frequently by 88% of sites

Rater training programs:
Used frequently by 66% of sites

Medical imaging systems:
Used frequently by 56% of sites

99% used EDC always or most of the time

88% use eCOA frequently

However, sites are divided on whether digital tools improve patient retention. While 24% believe tools help significantly and 22% indicated some improvement, 22% said tools do not help with engagement and 15% believe digital tools actually add burden on patients. This could be due to the complexity of the tool and the number of devices patients are often tasked to juggle through during their trial participation.

The Impact of Fragmented Systems

A consistent theme throughout the survey was fragmentation. Sites routinely operate multiple disconnected systems that do not communicate with one another. Data entered into eCOA systems must often be manually transferred into EDC. Training platforms track certifications separately from system access. Monitoring tools sit apart from data collection workflows.

Sites indicated this fragmentation creates measurable consequences:

Time Waste
Redundant data entry and navigating disparate systems take time away from patient care.

Error Risk
Manual data transfers introduce opportunities for mistakes that compromise data quality.

Training Burden
Each platform requires separate training. Staff turnover means repeated training across multiple systems.

Monitoring Delays
When systems don't connect automatically, monitoring data arrives late and lacks context from ther trial activities.

While few sites have experience with unified patient portals that combine multiple trial activities, those that do generally view integrated approaches favorably.

When asked about satisfaction with electronic administration of clinical outcome assessments (eCOA) and rating scales, 49% of sites reported satisfaction. 32% of sites expressed dissatisfaction with administration processes, and 18% were neutral, reflecting opportunities for improvement despite years of adoption

Operational Realities of ClinRO

Accurate and consistent administration of clinician-reported outcomes (ClinROs) remains difficult. 37% of sites reported finding it somewhat or extremely challenging, while 38% of sites were neutral. Only 25% of sites cited ClinRO was not challenging.

Sites shared which factors significantly contribute to the complexity of administering ClinRO in CNS trials:

Time Burden: 54% of sites cited assessment completion time as a major or very significant factor. Despite promises of efficiency, electronic administration often takes longer than expected.

Technology-related disruptions during electronic administration affect 44% of sites. System lags, crashes, or unpredictable behavior during patient assessments undermine both rater confidence and patient experience.

Patient comprehension: 29% of sites reported significant challenges related to patients' understanding, focus, and/or memory.

Complexity of assessment instruments impacts 27% of sites. Given the complexity of assessments, electronic device and software must be modern and robust to make the experience easier. Medidata is supporting these assessments in electronic format to improve site experience.

Maintaining consistency over long study durations significantly challenges 27% of sites. Respondents noted challenges such as variability in patient symptom presentation, rater drift over time, and coordinating caregiver involvement required for certain scales.

These factors help explain why satisfaction with electronic administration remains modest despite widespread use.

Data Quality Monitoring Gaps

Central monitoring aims to catch data quality issues before they compromise trials, but sites report persistent challenges with current approaches:

39% Query clarity
Major issues understanding monitor queries

35% Technology platforms for accessing feedback
Difficulty to use platform adds burden rather than value

32% Timeliness of feedback
Received feedback too late to act effectively

31% Feedback clarity on administration
Struggled to interpret feedback on assessment administration

31% Query frequency
Overwhelmed by excessive queries

What Sites Actually Need

When asked to identify the single biggest change that would improve CNS trials, sites consistently shared specific requests across three areas: rater training, eCOA data collection, and data quality monitoring.

End Redundant Rater Training

Sites expressed strong frustration with repetitive rater training requirements. “When you have been a rater for 10+ years, it is frustrating to have to be assessed again for each study, even with the same sponsor,” one respondent noted. Training should be valid for multiple years across different trials, not recreated for each study.

Sites also called for industry-wide recognition of prior certification and experience, multi-year validity of training. “Allowing for experience to qualify raters instead of by specific degree,” one requested, explaining that qualified personnel can’t rate because they lack certain degrees despite years of successful experience.

It’s time for universal training recognition across sponsors and studies and industry-wide guidelines that recognize prior certification and experience.

Reliable and Practical Technology

Sites emphasized that technology must work consistently or offer backupoptions. Connectivity issues, device failures, and system crashes disrupt visits and undermine patient trust. Multiple respondents requested paper alternatives when electronic systems fail.

Beyond reliability, sites want better integration. “Data porting from eCOA devices into EDC” and “better source to EDC interoperability” would eliminate manual data transfer.

> ***“Know your audience. If it is an Alzheimer’s trial, don’t expect the patient to complete scales on a tablet remotely. This is an unrealistic expectation.” — Survey Respondent.***

Fix Data Quality Monitoring

Sites addressed monitoring challenges centered on query clarity, frequency, and timeliness. Query volume burdens sites, and unclear query wording makes resolution difficult.

Timeliness also matters because context disappears. "I get queries on events that are years old. I have no idea why things happened 2 years ago," one site shared. Sites want "immediate flagging of missed questions for review with patients" to allow correction while context remains fresh.

> ***"I get queries on events that are years old. I have no idea why things happened 2 years ago."***
> ***— Survey Respondent***

Top Technology Requests from Sites

The responses revealed a consistent pattern: technology reliability issues overwhelm sites and undermine the patient experience. Frequent connectivity problems, malfunctions during patient visits, unhelpful technology support, and slow-loading systems extend visit times. One respondent noted, "It is embarrassing to have so many technical issues in front of patients," while another explained, "There is no time to call the helpdesk when there is a patient on-site."

Sites clearly articulated which technology features would be helpful in administering ClinROs or rating scales electronically:

Automatic data transfer to EDC systems – 83.34%
Sites spend valuable time on manual data entry and re-entry across platforms, so seamless integration would free substantial time for actual patient care and oversight.

Flags for inadvertently blank fields – 89.74%
Simple error prevention catches mistakes before they compound into data quality issues requiring queries and corrections.

Multiple annotation options (stylus, keyboard, image upload) - 78.2%
Raters need flexibility to document observations in ways that fit the clinical context.

Auto-unlock of eCOA access after training completion – 71.8%
Removing manual coordination of training completion and system access eliminates delays and reduces administrative burden.

Prompt central monitor feedback – 79.49%
When monitoring catches issues quickly, corrections happen while context remains fresh.

Flexible navigation between assessment sections – 79.49%
When monitoring catches issues quickly, corrections happen while context remains fresh.

What This Means for the Industry

Survey findings reveal a clear gap between current CNS trial operations and what sites need in order to succeed. These pain points highlight exactly where optimization is needed and create clear implications for all industry stakeholders: integration, reliability, reduced redundancy, and workflows that reflect the realities of CNS trial execution.

For Technology Vendors

Address time burden through automation and integration. Automatic data transfer was frequently requested to eliminate workflow steps.

Enhance system reliability and usability. With 44% of sites reporting technology disruptions, systems must demonstrate consistent performance in real clinical environments under operational time constraints. Validate solutions through real-world testing with raters and site staff.

Streamline data quality monitoring processes to provide clearer, more timely, and more accessible feedback. Current monitoring workflows introduce friction that impedes efficiency.

For Sites

Maintain active communication regarding operational realities. Technology vendors and sponsors require ongoing feedback about daily operational challenges beyond periodic formal surveys to inform solutions.

Document and share both successful practices and persistent challenges. Site experience provides essential guidance for advancing the industry from theoretical solutions toward practical implementations.

Engage in solution development processes when opportunities arise. Direct site input significantly influences whether new tools reduce operational complexity or inadvertently increase it.

For Sponsors

Design trial protocols that account for site resource limitations. While comprehensive assessment batteries may appear thorough in protocol documents, they often create operationally unsustainable burdens during execution.

Factor rater availability into trial design. Protocols requiring extensive specialized rater training must acknowledge the shortage of qualified raters and its impact on site feasibility.

Recognize that patient cognitive burden in CNS trials extends beyond recruitment challenges to affect retention and data quality. Lengthy assessment protocols risk generating incomplete or compromised data as participants experience cognitive fatigue.

Invest in rater training approaches that demonstrably address consistency and practical application challenges. Current methodologies show gaps in achieving uniform scale interpretation and administration across diverse clinical contexts.

Looking Forward

CNS trials will remain complex, but operational complexity can be reduced. The path forward is clear: make systems work together, eliminate friction, focus on execution quality and listen to site partners. Sites need technology that integrates, simplifies, and supports rather than technology that adds steps, requires training, and creates new coordination challenges.

The findings from 108 raters reveal gaps between current solutions and site needs. They identified clear priorities:

Workflow efficiency and integration

Reliable tools over innovative ones

Clear feedback over complex monitoring

Time savings over documentation enhancements

The future of CNS trials depends on making existing systems work better together for sites, patients, and the quality of the data they produce.

About Medidata

Medidata is powering smarter treatments and healthier people through digital solutions to support clinical trials. Celebrating over 25 years of ground-breaking technological innovation across more than 38,000 trials and 12 million patients, Medidata offers industry-leading expertise, analytics-powered insights, and one of the largest clinical trial data sets in the industry. More than 1 million registered users across approximately 2,300 customers trust Medidata's seamless, end-to-end platform to improve patient experiences, accelerate clinical breakthroughs, and bring therapies to market faster. A Dassault Systèmes brand (Euronext Paris: FR0014003TT8, DSY.PA), Medidata is headquartered in New York City and has been recognized as a Leader by Everest Group and IDC. Discover more at www.medidata.com. Listen to our latest podcast, from Dreamers to Disruptors, and follow us at @Medidata.

About the Society for Clinical Research Sites (SCRS)

The Society for Clinical Research Sites (SCRS) is the leading advocacy organization dedicated to unifying the voice of the global clinical research site community. Representing more than 12,000 research sites in 50+ countries, SCRS facilitates industry collaborations and conversations dedicated to site-focused advocacy, education, mentorship, and connection. SCRS is an active and influential champion for sites in industry initiatives to ensure that the perspective of sites is heard and valued. Learn more and get involved at myscrs.org. Our voice. Our community. Your success.