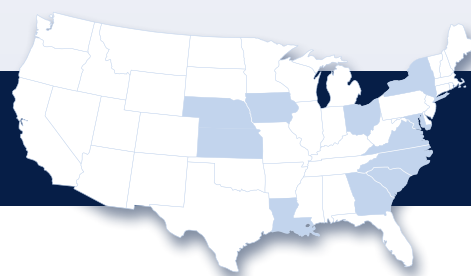


8 Insights From 9,000+ Real Clinical Trial Participant Surveys

Clinical trials — especially high-volume trials — are primarily designed to collect quantitative data. Collecting and reviewing qualitative data and experiential feedback from trial participants is rarely prioritized. Before being acquired by Velocity Clinical Research, Meridian Clinical Research built an in-house surveying system to elevate the participant's voice.

The system, which is largely automated, collects ratings and feedback from clinical trial participants across 30+ research sites. A real-time dashboard shows responses and ratings by site, and alerts site staff and leadership team members of potential issues when negative feedback is received.

This whitepaper highlights key takeaways from 9,000+ responses (7,200+ unique) collected across 11 states since August 2021.



"[I joined because] my great granddaughter was hospitalized with RSV when she was [a baby]."

1. Most clinical trial participants join a trial primarily to help advance science

One of the questions in the survey was, "What is the main reason you chose to participate in this research study?" 54% selected, *Help advance science*, over the other choices: *Earn extra money* (29%), *access a therapy in development* (9%), *free study-related exams* (2%), *my doctor recommended it* (2%), and *other* (4%).

About half of responders participated in COVID-19 vaccine trials, which likely increased responses for *help advance science*. Even when omitting responses from COVID-19 vaccine trial participants, the majority still chose *help advance science* as their main reason for joining. While most patients care about improving health outcomes for the betterment of all, some have more personal reasons for joining, especially when the condition being studied has affected them or a loved one.

"My sister has a compromised immune system, I [joined the study] for her."

"Can't find a med that works."

"Friend had C. Diff."

"I'm old and Native American. Hope my data will help."

"Senior and person of color, felt I needed to participate!"

Participants place significant trust in the institutions of medicine and science, and in the organizations involved in the development and research of products. Championing the participant's selflessness in aiding in the advancement of science — regardless of their reason — can help ensure more meaningful communications. This insight can also inform better recruitment and retention strategies that highlight universal motives for study participation.

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“[I joined] for the good of humanity... and the money.”

“Who wouldn’t be happier with more money? Lol! I wouldn’t necessarily be happier, but I would be interested in reading a newsletter about your clinical findings...”

2. Just 1 in 4 participants said compensation was their main reason for joining a trial

Surprisingly, just 29% of responders chose *earn extra money* as their primary reason for joining a trial. Compensation, of course, should never be the focal point of recruitment efforts or communications. However, participants certainly do care about compensation — most participants want to know about compensation in initial screening calls. This is often the case when they may be eligible for several studies with differing stipend totals.

While total stipend amounts can be mentioned in IRB-approved advertising campaigns, it may not be beneficial to include dollar amounts in advertising materials. Aside from being potentially coercive, listing total compensation amounts can cause potential participants to feel misled if they turn out not to be eligible for that specific study, or if they’re unaware of how stipends are provided per action completed (visit, diary entry, safety call, etc.). Velocity recruiters have found it to be more effective to discuss compensation as part of a one-on-one conversation about eligibility and expectations.

3. If you don’t ask for feedback, you’ll only hear from the most motivated responders

It’s common for companies to receive negative feedback through Google reviews, social media comments, and phone calls. If you don’t proactively ask and encourage participants to share feedback, you’ll often only hear from people who are motivated enough to call or comment online.

Before launching this in-house surveying system, Meridian (now part of Velocity) only had a few hundred online reviews scattered among different social and directory platforms, which couldn’t be aggregated to provide an accurate view of satisfaction. Today, sites supported by the system have a numerical rating that can be monitored over time (participating sites have an all-time average rating of 9.2 out of 10). Having this benchmark in place allows Velocity’s patient experience team to analyze results more efficiently and to compare performance at the site level.

By making it easier for participants to voice impartial feedback on a standardized scale, you can gain a more proportionate and accurate view of satisfaction.

4. Feedback can identify areas for improvement across the organization in real time

Velocity’s system features a live dashboard of 0–10 participant experience ratings across all participating sites. This dashboard is filterable by date and site, so managers can identify emerging trends. When a low rating is submitted, key regional and/or operations leaders receive an email in real time that includes the participant’s full entry.

Velocity uses this information to resolve issues more quickly, and can also discern site-specific issues (e.g., “I wasn’t sure where to go after I parked”) from company- or study-wide issues (e.g., stipend card delays, diary app issues).

“It would be great to have screening/study materials adjusted to acknowledge women in same-sex relationships (for whom ‘birth control’ questions may be off-putting).”

'Share your feedback' flyers with QR codes are also posted in Velocity exam rooms. This means participants often complete surveys during their visits. This leads to more candid, detailed feedback. Participants have rated their experience a 10/10 while still noting things like, "It's cold in here," "I'm thirsty," and "This chair is uncomfortable" — thoughts they often do not share with site staff.

"I want a t-shirt. I enrolled in the study, and I'm proud of it!"

"Tell me my antibody and T cell levels."

"Text questions vs having to have a live conversation."

"Can you share blood work with my primary care provider?"

"Would like to participate in multiple studies. Also more appointment [availability] on the weekend would be better."



"You people are awesome! My oldest daughter is a nurse, and I've told her about the way I've been handled when interacting with your staff, and even she is impressed!"

5. Participant feedback can support employee satisfaction

Positive feedback can do more than build pride — positive responses give us a chance to recognize employees and site staff for going above and beyond. Many responses mention specific employees by name. This allows leadership to see which teams and team members are providing a positive experience day-to-day, while also providing a source of content for employee recognition.

"[Staff Member 1] was fantastic, [Staff Member 2] was a pro at taking my blood and everyone else was friendly and efficient."

"I was very impressed with [Staff Member] who was calling me every few weeks to do my safety and wellness check. She was always very professional and very helpful and an absolute pleasure to talk to."

"I have been working with [Staff Member] and he is wonderful."

"Every single member of your team was polite and professional. It was a pleasure (and still is) being involved in the trial."

"Give [Staff Member] a promotion! She's the best! [Staff Member] has proven herself, time and again, to be patient, helpful, and kind."

"I love the staff there. Kind, energetic and just feels like they enjoy their jobs!"

“I enjoy single malt scotch at the expensive end of the scale. A nice scotch would be soothing.”

6. Even when the answers aren't serious, they can be constructive (and entertaining)

One of the survey's most valuable questions is open-ended: “What is one thing we could do to make you happier?” Sometimes the answers reveal opportunities to improve communications or operations:

“I want to know more about the study's results.”

“I wish I could do two studies at once.”

“Less paperwork.”

“Offer higher stipends for visits and blood draws.”

“Shorter wait times.” /

“I wish studies were shorter.”

“Offer evening appointments.”

And sometimes the answers just make us smile:

“Buy me BTS tickets.”

“Quit making changes to the [consent] forms.”

“Cookies and milk.”

“[Someone has been in] the bathroom on the first floor [for a long time].”

“I'd like a lollipop after visits like kids get.”



“Those of us who are doing this to help science would love to know how well the progress is going. How about a separate email sign up for us who would like to know how well the research is going (i.e. estimates on effectiveness, approval expectations, complications, etc.)? I don't know if it's possible due to the privacy issues, but, I would be interested.”

7. Most negative feedback centers on communication issues

Most negative feedback stemmed from participants feeling that communication was lacking. Between underestimating wait times, how many clinic visits would be required for the study, and simply the amount of communication between the clinics and participants, many responders mentioned feeling that specific aspects of communication could be improved. In particular, the feedback highlights a need to provide blunt, accurate, and perhaps repeat information about:

- Study visit frequency and length
- Diary and safety call requirements (and related compensation)
- Study progress and results

It surprised us to learn how many responders were unsatisfied with how little they knew about trial outcomes. Trials can take years to generate shareable results, yet the participant's ongoing adherence is what makes research possible — their commitment to advancing science should be acknowledged. Though challenging, we look forward to working more closely with Sponsors to help sites share trial progress with participants, wherever possible, to help improve retention and repeat participation.

“I think it would be nice to share study snippets with participants. This may make participants feel more involved in the study...”

“Share the interim results of research — in other words, report in.”

“Tell potential participants about how past studies have helped conquer disease or help individuals live better lives.”

“Share results when you can.”

“Inform us on the results of the study.”



“I think I underestimated how good I would feel about our part in history... The experience of helping other people through this [pandemic] has been life-changing.”

“I know my participation in this trial has changed the course of not only my life, but the lives of friends, family, and people around the world. It’s really pretty cool.”

8. Surveying is a great way to generate more public reviews and testimonials

Some survey respondents stand out in their responses. Sharing these participant stories through a blog, on social media, and even internally with research site employees can provide social proof that participating in clinical trials can be a rewarding experience for almost anyone.

Velocity has now interviewed numerous survey responders to create long-form testimonials. These stories help educate potential participants on what to expect in an authentic, non-coercive way.

Velocity is also developing a Participant Advisory Committee (PAC). Like a board of directors that can provide business guidance, the Velocity PAC will be a group of actual clinical trial participants who meet monthly to share their stories and collaborate with Velocity’s leaders to improve the participant experience. Their insights will be shared with Sponsors, CROs, and investigators to help improve study design.

Summary

We found that people are motivated to take part in clinical research predominantly to help advance medical science. Contrary to popular opinion, only one in four participants cited compensation as the main reason for joining a trial. If sites don’t ask for feedback, they may get a skewed view from only the most motivated clinical trial participants. By making it easy to share feedback, our sites have been able to identify areas for improvement across the organization in real time.

Participant feedback can be entertaining, and even motivating for staff. We have identified communication as one of the key areas to improve, and look forward to partnering with Sponsors to improve the way we engage trial participants and keep them updated with research outcomes.

Through its acquisition of Meridian, Velocity now has sites across 25 U.S. states, and access to over one million potential participants, which we’ll use to continue to elevate the participant’s voice. When participant expectations are more aligned with the reality of taking part in clinical research, we can build a more inclusive and enjoyable experience for all, and speed up development.



About Velocity Clinical Research

VelocityClinicalResearch, headquartered in Durham, NC, is the world’s largest organization of fully integrated clinical research sites. With about 80 locations and 220 investigators, Velocity partners with pharmaceutical and biotechnology companies to research new drugs, medical devices, and diagnostics that could improve human health and wellbeing. Velocity offers unified research site solutions to efficiently provide the right patients, investigators, and research staff for Phase 1–4 clinical trials across the U.S. and Europe. The company also operates a technology hub in India. Velocity is committed to delivering timely, high-quality data and unparalleled patient care. Visit VelocityClinical.com.