“For once, we were the priority”: What a vaccine trial taught us about trust, reciprocity, and inclusion

At the heart of the RBDCOV Project lies a shared commitment: to make vaccine research more inclusive, human-centered, and grounded in the real experiences of those often left out of clinical trials.

In this specialised article, Daniela Rojas Castro, Social Psychologist and Chair of the Board at the European AIDS Treatment Group (EATG), reflects on the psychosocial study carried out alongside the HIPRA-HH4 vaccine trial. This study, part of the RBDCOV project, focused on understanding how participants experienced their involvement in the trial.

Daniela brings both professional and personal insight into how community engagement, emotional connection, and communication can transform research. From what made participants feel respected and included, to the vital role of feedback and transparency, her reflections are a powerful reminder that clinical research is not just about data—it’s about people.

We are proud to share this piece and to highlight the essential role of civil society in shaping the future of equitable health innovation.

Read the full article below.

By Daniela Rojas Castro, Social Psychologist & Chair of the Board, European AIDS Treatment Group (EATG)

At the European AIDS Treatment Group (EATG), we’ve spent decades defending the rights and interests of people living with HIV, including their right to be meaningfully involved in the research that affects their lives. As Chair of EATG’s Board, that mission is at the heart of my work. But I’m also a social psychologist. And even after more than twenty years working in participatory and community-based research, I still get excited when I see the social sciences used not just as support tools, but as true allies to clinical research.

That’s exactly what happened in the psychosocial study carried out alongside the HIPRA-HH4 vaccine trial, part of the EU-funded RBDCOV project. This clinical trial was designed for people often excluded from research: people living with immunocompromising conditions such as HIV, kidney transplants, or autoimmune diseases. The psychosocial component, coordinated by EATG, aimed to explore not just what participants did, but

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how they felt, what they understood, what they hoped for, and what they took away from the experience.

I had the privilege of analysing the data collected by our colleagues in Spain, a mix of surveys and interviews with people who participated in the clinical trial for adults. Their voices tell a story that is both simple and profound.

Most participants described their experience in overwhelmingly positive terms. They felt respected by the research and medical teams. They appreciated the clarity of communication, the sense of support, and the care. They felt included, not in a symbolic way, but in a real, lived way. *"I felt that my condition mattered in the research,",* one person said. That kind of recognition can't be measured by lab results, but it changes everything.

What stood out to me was the emotional dimension of the experience. People weren't just motivated by self-protection; they felt a civic responsibility. *"Everything we have today is thanks to those who participated before us",* someone told us. "*Now it's our turn."* That sense of belonging to a broader story, of continuity, contribution, and care, was especially strong among people living with HIV, shaped by years of collective advocacy.

But we also heard what could be improved. Some participants told us they didn't fully understand the scientific rationale of the study, even if they felt safe and trusted their physicians. That trust was real and valuable, but trust alone shouldn't replace clear, tailored, and ongoing communication. Informed consent should be a conversation, not a checkbox.

Others mentioned the physical demands of the trial, the blood draws, the long visits, and the fatigue. And yet, most of them said they would participate again. Not because it was easy, but because it felt worthwhile.

One issue came up repeatedly: the desire for feedback. People wanted to know how things turned out and what their participation had helped to achieve. It wasn't about technical details. It was about closure, about feeling that their time and effort had value. As someone who works closely with both communities and researchers, I see this as an ethical opportunity: to treat feedback not as an optional courtesy, but as an essential part of what makes research human.

Recruitment was another area with room for improvement. Most participants heard about the trial through their doctors, which worked well, but this also meant that community-based outreach was nearly absent. No flyers, no posters, no messaging through patient organisations. For future trials, we can and should do more to make people feel invited, not just eligible.

For EATG, this project was a confirmation of something we've always believed in: that centring the voices and experiences of participants isn't a bonus, it's essential. It

improves the science, strengthens trust, and builds real partnerships between communities and research.

Personally, I feel fortunate to have contributed to this work. Not just as a patient living with other chronic condition, or as a patient advocate, but as a social scientist who still believes that listening, really listening, can change how we do research.

The full Psychosocial Study and its Executive Summary of the study is available here. I hope you'll take a moment to hear what participants had to say. Their voices deserve to be heard.