JUMO HEALTH WHITE PAPER

Patients Aren't Failing Trials. Trials Are Failing Patients.

Primary patient research and workshop findings from the 2026 Patients as Partners Conference reveal where readiness breaks - and what sponsors can build before friction becomes screen failure, withdrawal, or delay.

By Mackenzie McKinney
Head of Readiness Orchestration
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The industry has spent decades optimizing recruitment. Patients as Partners 2026 asked a different question: not how to find eligible patients, but how to prepare them.

75clinical research stakeholders

20completed readiness worksheets

2live patient interviews

Across facilitated groups covering awareness and recruitment, prescreening and enrollment, and participation and completion, the same pattern appeared repeatedly. Fear, confusion, expectation gaps, and communication failures were described as the conditions behind preventable screen failure, dropout, and noncompliance.

The strongest unprompted solution was equally consistent: a continuous communication feedback loop. Patients need preparation before the next step, visibility into what is coming, and a way to surface questions they may not yet know how to ask.

Readiness failure is not a patient problem.

It is a system-design problem.

The workshop replaced presentation with diagnosis.

Jumo Health's session, “Patient Experience Optimization: Addressing Trial Readiness Across the Clinical Trial Journey,” was designed as a live working session. Clinical operations leaders, recruitment professionals, CRO representatives, and patient advocacy stakeholders mapped readiness risk, identified friction, and co-designed interventions across the trial lifecycle.

Two patients then grounded the discussion in lived experience. Both were motivated and eligible. One completed despite a system that continually eroded readiness. One withdrew because unresolved uncertainty made participation impossible to sustain.

Patient voice 01.

“I never knew what was coming next.”

Visit windows arrived with little notice. Protocol amendments changed requirements without patient-facing explanation. Site constraints made preparation inconsistent. The patient stayed, but uncertainty became a persistent background stress. Her readiness survived despite the system, not because of it.

Patient voice 02.

“I didn't know what I didn't know.”

After years of symptoms and a long wait for diagnosis, the patient was offered a trial on the day she finally received an answer. She enrolled, then withdrew - not because of medical ineligibility or logistics, but because questions she could not formulate remained unresolved. Consent captured a signature. It did not create readiness.

Three phases. Three dominant failure patterns.

Cognitive overload and caregiver exclusion.

Jargon-heavy materials suppress understanding. Financial and practical impacts remain abstract. Caregivers - often the decision partner, logistics engine, and emotional stabilizer - receive little direct preparation. Silence after inquiry is interpreted as rejection.

Process is mistaken for comprehension.

Consent operates as a document event rather than an onboarding process. Patients sign before expectations, lifestyle impact, and unresolved questions have been surfaced. Nominal consent can conceal fragile commitment.

Trust is treated as permanent.

Protocol amendments, changing burden, unanswered questions, data silence, and abrupt post-trial disengagement erode trust. Retention fails gradually, even when traditional metrics detect it suddenly.

The cross-phase signals were systemic.

The same conditions appeared across worksheets without coordination between groups. Patients were asked to process complexity before they had the cognitive space to do so. Caregivers were excluded from decisions they would later be required to support. Communication was reactive, fragmented, and owned by already constrained sites. Expectations were established once and rarely reinforced.

The consistency matters. The industry is not unaware of these problems. It lacks the infrastructure, operating ownership, and live measures required to address them systematically.

Four conclusions the industry should act on.

1. **The system is failing patients.**Fear, confusion, and communication gaps are recurring experience conditions, not isolated patient behaviors.
2. **Emotional friction is upstream.**Anxiety and uncertainty change how information is processed, whether questions are asked, and whether intent becomes action.
3. **Sites cannot be the primary readiness infrastructure.**Sites need prepared patients and usable context, not another upstream workload transferred into screening and consent.
4. **Patients described the solution.**Proactive, personalized, plain-language communication and continuous feedback were requested without prompting.

The fieldbook makes invisible risk visible.

Readiness friction is usually visible only after it becomes a failed screen, missed visit, deviation, or withdrawal. The fieldbook shifts the question from**“Where did dropout occur?”**to**“Where is readiness deteriorating now?”**

Readiness is multidimensional and dynamic.

Readiness is not a threshold a patient crosses once. It is a composite condition that can strengthen or deteriorate throughout participation.

Cognitive readiness.

The patient understands the study, uncertainty, procedures, tradeoffs, and practical implications well enough to make and maintain an informed decision.

Emotional readiness.

Fear, trust, confidence, and uncertainty are sufficiently supported for the patient to evaluate and sustain participation.

Behavioral readiness.

Intent can become the repeated actions required by the protocol: attend, remember, report, adhere, tolerate, and continue.

Caregiver and support readiness.

The people and resources participation depends on understand the commitment and can sustain their role as study demands change.

Friction changes shape across the lifecycle.

At awareness, friction appears as irrelevance, jargon, mistrust, or silence. During screening, it appears as unanswered questions and unseen practical constraints. At consent, it appears as compressed decision-making and expectation gaps. During participation, it appears as burden, uncertainty, changing support, and readiness decay. At completion, it appears as accumulated friction that was never addressed upstream.

The operational implication is direct: readiness must be created, validated, reinforced, and monitored. A single educational moment or engagement campaign cannot perform all four functions.

The readiness infrastructure stack.

A complete operating model connects four layers:

1. **Intelligence**identifies patient clusters, readiness conditions, and likely friction before execution.
1. **Education**translates protocol complexity into practical, behaviorally structured understanding.
1. **Orchestration**delivers the right intervention, channel, and next step based on the barrier present.
1. **Measurement**monitors readiness, informed engagement, execution stability, and emerging completion risk.

Removing any layer weakens the others. Data that never changes the patient experience cannot prevent failure. Education delivered without diagnosis remains generic. Orchestration without governance can move unreadiness downstream faster. Measurement that arrives after withdrawal describes loss instead of preventing

it.

Where does your organization stand?

1. **Level 1Assumed.**Readiness is inferred from eligibility, response, consent, or enrollment.
1. **Level 2Reactive.**Friction is addressed after sites escalate or patients disengage.
1. **Level 3Designed.**Readiness touchpoints, responsibilities, and interventions are defined across the journey.
1. **Level 4Measured.**Patient-level and study-level readiness signals inform live execution decisions.
1. **Level 5Governed.**Readiness is an enterprise performance variable managed across studies and portfolios.

Methodology and evidence base.

The primary evidence is Jumo Health's facilitated workshop at the 2026 Patients as Partners Conference. The session included 75 clinical research stakeholders, 20 completed readiness-risk worksheets, three lifecycle working groups, and two live patient interviews. Findings reported here are directional qualitative evidence from that session, not population-level clinical estimates.

The fieldbook is also informed by published work from the Tufts Center for the Study of Drug Development, the IQVIA Institute for Human Data Science, and peer-reviewed research on trial recruitment, retention, protocol complexity, and patient participation. These sources provide industry context; the workshop findings provide the primary qualitative evidence summarized on this page.

The readiness imperative.

Patients are not failing because they lack motivation. They are being asked to sustain a complex clinical, practical, emotional, and behavioral commitment through systems that frequently assume understanding, delegate preparation to sites, and detect risk after it becomes expensive.

The path forward is readiness infrastructure: patient-facing experiences that prepare rather than persuade, communication that maintains rather than merely acquires, monitoring that detects decay before dropout, and operational ownership that makes readiness a measurable execution variable.

Patients described what they need with precision. The industry's responsibility is to listen - and build the system that makes informed, supported participation possible.

ABOUT THE AUTHOR

Mackenzie McKinney

Head of Readiness Orchestration

Mackenzie brings experience across global clinical research, digital trial implementation, site and patient experience, and patient-facing technologies, including senior leadership roles at Moderna, PPD, and Signant Health. At Jumo, she turns patient insight into education, guided prescreening, coordinated support, and site handoffs that patients can realistically sustain.

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