JUMO HEALTH WHITE PAPER

The Patient Experience Organization

A new operating model for clinical trial readiness, participation, and completion

> **Patient experience should not be a collection of activities. It should be an accountable system of execution.**

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EXECUTIVE BRIEF

The industry has patient touchpoints. It still lacks patient ownership.

Clinical trials are governed with extraordinary rigor around protocol, data, safety, and sites. Patient participation is handled differently. Recruitment, education, consent, logistics, retention, and support are commonly divided across vendors and functions, with no single operating model responsible for whether people are prepared to advance and able to complete.

A Patient Experience Organization, or PXO, closes that ownership gap. It applies behavioral science, health literacy, human-centered design, operational intelligence, and governed execution across the entire participation journey. The objective is not simply a better experience. The objective is more durable trial performance.

This paper defines the PXO as an accountable operating model. It explains what the model owns, how it works across the lifecycle, why it matters across different trial contexts, and how sponsors can begin moving from fragmented patient activity to readiness-led execution.

The problem. Participation risk is created upstream and recognized after it becomes operational cost.

The governing variable. Patient readiness: cognitive, emotional, behavioral, practical, and social capacity to participate.

The operating outcome. Better advancement, stronger site handoff, lower preventable attrition, and more credible completion forecasts.

The PXO governs the human conditions that connect eligibility to completion.

THE PARTICIPATION PROBLEM

Patients are rarely the failure point. The system around them is.

A patient may be medically eligible and still be unprepared for the lived reality of a trial. The travel may be unsustainable. A caregiver may not understand the commitment. Randomization may remain unclear. The treatment experience may diverge from expectation. None of these conditions are captured by eligibility alone.

Research on the patient journey consistently identifies psychological, physical, informational, and financial burdens across recruitment, participation, and study closure.[23] These burdens do not operate independently. They accumulate. A confusing consent discussion can weaken trust. Weak trust can reduce question-asking. Unanswered questions can become missed visits, protocol deviations, or withdrawal.

Conventional metrics identify the result: a failed screen, a no-show, an early withdrawal, a site escalation. They rarely identify the readiness deterioration that preceded it. The effect is a system that pays to recover from failure rather than preventing it.

What the metric shows	What it can hide
Referral volume	Low relevance, poor access fit, or weak intent
Consent signed	Incomplete comprehension or misaligned expectations
Enrollment achieved	Unresolved burden, caregiver gaps, or fragile commitment
Missed visit	Readiness deterioration that began weeks earlier

> **Screen failure, dropout, and non-adherence often describe the outcome. They do not diagnose the cause.**

THE PXO DEFINITION

An operating model with one job: make participation hold.

A Patient Experience Organization is the accountable layer that designs, measures, and governs patient readiness across the clinical trial lifecycle. Like a CRO, it is defined by operational responsibility. Unlike a CRO, its primary unit of control is the patient experience and the readiness conditions that determine progression.

The model begins before recruitment materials are produced. It asks where the protocol will create friction, which populations will experience that friction differently, what patients and caregivers must understand, and which signals should trigger support. It then carries that logic through patient identification, education, screening, site handoff, participation, and completion.

This aligns with the broader regulatory movement toward systematic patient and caregiver input in medical product development.[1] The PXO extends that principle from insight collection into execution, giving patient input an operational consequence.

PXO responsibility	What it means in practice
Assess	Identify readiness friction before it becomes a failed transition.
Prepare	Build comprehension, expectation alignment, and practical feasibility.
Advance	Move patients forward with evidence that the next step is supportable.
Protect	Monitor readiness over time and intervene before withdrawal.

> **The PXO converts patient-centricity from an intention into an operating discipline.**

THE DISCIPLINES

Readiness requires more than communication.

Clinical trial participation is a high-decision-investment behavior. Patients must understand unfamiliar science, evaluate uncertainty, coordinate real-life obligations, involve others, and sustain effort over time. No single discipline can govern that complexity.

Behavioral science identifies the cognitive, emotional, and social forces shaping decisions. Health literacy makes information usable. Human-centered design organizes the journey around how people actually move through it. Patient and caregiver insight reveals burdens that protocol authors cannot infer. Data and technology make readiness visible and support timely orchestration. Clinical and ethical governance keeps every intervention transparent, voluntary, and appropriate.

The value is in the integration. A plain-language brochure without behavioral sequencing may inform without preparing. A predictive score without an intervention path may identify risk without changing it. A supportive site team may compensate for gaps, but only after the patient arrives. The PXO connects diagnosis to action.

> **Behavioral science.** Explains how decisions are formed, delayed, revised, and sustained.
>
> **Health literacy.** Turns protocol complexity into information people can use.
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> **Human-centered design.** Fits the experience to the patient's decision and participation journey.
>
> **Readiness intelligence.** Surfaces where friction and completion risk are accumulating.
>
> **Governed orchestration.** Delivers the right support while preserving autonomy and clinical oversight.

THE LIFECYCLE

A trial is a series of governed transitions.

Patients do not become ready once. Readiness is created, tested, and sometimes lost at every transition. A PXO therefore governs a lifecycle rather than a funnel.

At awareness, relevance and trust determine whether a patient considers the study. During screening, logistics and uncertainty determine whether interest survives. At consent, comprehension and expectation alignment determine decision quality. During participation, burden, treatment experience, caregiver capacity, and site interactions determine whether commitment remains viable. At completion, closure and results-sharing shape future trust in research.

The FDA's informed consent guidance reinforces that consent is a process involving adequate information, time, questions, comprehension, and voluntary agreement, with information continuing as circumstances require.[4] The PXO applies that continuity beyond the signature.

Transition	Readiness question	PXO action
Consider	Is this relevant and trustworthy?	Build awareness through credible, tailored education.
Screen	Can I realistically move forward?	Expose practical, cognitive, and emotional friction.
Decide	Do I understand the real commitment?	Create comprehension and expectation alignment.
Participate	Can I sustain this as conditions change?	Monitor burden and orchestrate support.
Complete	Does my contribution have closure and meaning?	Protect follow-up and return understandable results.

TRIAL CONTEXT

Readiness does not fail the same way in every study.

The PXO model is consistent, but the readiness strategy must change with the disease, protocol, population, and care environment. Treating every trial as the same patient engagement problem produces generic interventions and predictable blind spots.

Common-disease trials may have large eligible populations, but volume can hide low motivation, competing options, and silent attrition. Specialty trials often involve highly motivated patients whose participation is threatened by complex procedures and accumulated burden. Rare-disease trials have limited or irreplaceable populations, caregiver dependence, geographic dispersion, and little room for rescue recruitment. Pediatric trials require a dual experience that prepares both the child and the decision-making family system.

A PXO turns these differences into operating requirements. It identifies where readiness is most fragile, which stakeholders influence the decision, and what support is required for completion.

Trial context	Dominant readiness risk	Design response
Common	Motivation decay and perceived replaceability	Segment motives; reinforce relevance and progress.
Specialty	Complexity and protocol burden	Make treatment, visits, uncertainty, and support explicit early.
Rare	Irreplaceable participants and caregiver load	Prepare the whole support system and solve access upstream.
Pediatric	Shared decisions across child and caregivers	Use age-appropriate education and family-centered planning.

THE CONNECTED SYSTEM

CORE creates readiness. PRISM governs it.

A PXO needs both an experience layer and an intelligence layer. At Jumo Health, those capabilities are delivered through CORE and PRISM.

CORE is the readiness education system. It translates protocol complexity into practical understanding across the lifecycle, including what participation requires, how burden may affect daily life, what caregivers need to know, and how expectations should be reinforced as the study changes. The deliverable is not a collection of materials. It is a structured readiness foundation.

PRISM is the Patient Readiness and Intelligence System. It connects eligible-patient discovery with readiness assessment, adaptive education, guided prescreening, site-ready handoff, monitoring, and completion-risk intelligence. It gives the PXO a way to measure conditions, orchestrate interventions, and learn from progression.

CORE	PRISM
Creates comprehension and expectation alignment	Assesses readiness and identifies friction
Prepares patients, caregivers, families, and sites	Prioritizes and advances better-prepared patients
Reinforces understanding across amendments and milestones	Monitors readiness decay and completion risk

> **Education without intelligence stays generic. Intelligence without execution stays observational.**

MEASUREMENT AND ACCOUNTABILITY

What gets governed must be visible.

Patient experience has often been evaluated through activity counts or retrospective satisfaction. A PXO needs measures that explain whether the experience is producing durable progression.

The measurement model should combine leading indicators and outcomes. Leading indicators include comprehension, confidence, burden, caregiver preparedness, question resolution, response quality, progression velocity, and engagement change. Outcome measures include screen-failure patterns, referral productivity, site handoff quality, missed visits, early withdrawal, protocol adherence, completion, and cost per completer.

No single score can explain every trial. The point is to create a coherent measurement system that connects what patients experience with what operations observe. Study teams can then distinguish volume problems from readiness problems and choose interventions with greater precision.

> **Experience quality.** Do patients understand, trust, and know what happens next?
>
> **Readiness stability.** Are burden, confidence, and support improving or deteriorating?
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> **Progression quality.** Are referrals becoming productive screens, enrollments, and completers?
>
> **Operational value.** Are sites doing less rework and are forecasts becoming more credible?
>
> **Economic value.** Is the study improving cost per completer, not merely cost per lead?

EXECUTIVE IMPLEMENTATION

Start with one trial. Build an enterprise capability.

The fastest way to adopt the PXO model is to apply it to a trial where participation risk is visible and the cost of failure is meaningful. The objective is not to add more patient-facing activity. It is to establish ownership, diagnose friction, design the right interventions, and measure whether progression becomes more durable.

Begin with a protocol and population review. Identify decision points, burden concentrations, caregiver dependencies, access constraints, and likely expectation gaps. Establish a readiness baseline. Define which signals will be monitored and what action each signal should trigger. Then align sponsor, CRO, site, and patient-experience responsibilities so that risk does not disappear between functions.

Once the model is proven, codify it across programs: shared definitions, design standards, measurement, governance, and reusable intervention patterns. The result is a portfolio capability rather than another vendor workstream.

1. **Diagnose.** Map readiness friction against protocol, population, sites, and geography.
2. **Design.** Build education, support, and interventions around the actual failure modes.
3. **Govern.** Assign ownership for each transition and escalation path.
4. **Measure.** Track readiness signals and completion outcomes against the baseline.
5. **Scale.** Convert validated practices into portfolio standards.

The question is no longer whether patient experience matters. The question is whether anyone owns it as an operating outcome.

ABOUT THE AUTHOR AND SOURCES

The people and evidence behind the argument.

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John brings 30 years of experience building categories, products, brands, and growth engines around emerging technology, including executive leadership roles at Medidata, conversationHEALTH, and Swoop. At Jumo, he helps define patient readiness as measurable infrastructure for recruitment, retention, completion, and more credible forecasting.

Selected references

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Editorial note: This publication is educational and does not provide medical, legal, or regulatory advice. Trial design and patient-facing interventions require protocol-specific clinical, ethical, legal, privacy, and IRB review.