JUMO HEALTH WHITE PAPER

Patient Activation Is Trial Infrastructure

How readiness transforms recruitment, enrollment, retention, and completion

> **Willingness is not readiness. Activation is the work that turns interest into durable participation.**

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EXECUTIVE BRIEF

The patient did not fail to activate. The trial failed to create activation.

Clinical trial recruitment often divides patients into two categories: willing and unwilling. That framing misses the largest group in the middle, people who may be interested but do not yet have the knowledge, confidence, support, or practical capacity to move forward.

Patient activation describes the knowledge, skill, confidence, and sustained behavior required to manage health and healthcare. The Patient Activation Measure established activation as a developmental construct with four stages, from not yet believing one's role is important to maintaining action under stress.[8] In clinical trials, the same logic is powerful: readiness can be assessed, built, reinforced, and protected.

This paper translates patient activation into trial execution. It explains how activation affects every stage of the journey, how support should change with readiness, which interventions matter most, and what sponsors should measure if they want more patients to progress and complete.

> **Knowledge.** I understand the study and what it requires.
>
> **Confidence.** I can ask questions, make a decision, and manage the next step.
>
> **Feasibility.** Participation can fit my life, support system, and care context.
>
> **Persistence.** I can sustain the required behaviors as conditions change.

Activation is not enthusiasm. It is the capacity to understand, decide, act, and stay engaged when participation becomes difficult.

THE ACTIVATION SPECTRUM

Readiness is a state, not a personality trait.

Activation is sometimes misread as a way to identify 'good patients.' That is exactly the wrong use. Lower activation does not describe a character flaw. It describes a support need. The construct is developmental and responsive to context, education, coaching, and experience.[89]

A highly activated patient may still become overwhelmed by a new diagnosis or a demanding protocol. A patient who begins with low confidence may become ready when information is sequenced, questions are resolved, caregivers are included, and practical barriers are addressed. The operational implication is clear: segment the support, not the worth of the patient.

For trial teams, activation should therefore be treated as dynamic. Measure it at meaningful transitions, observe how it changes, and adjust the experience before deterioration becomes withdrawal.

Activation state	What the patient may need	Trial response
Overwhelmed	Orientation, trust, and a clear first step	Reduce cognitive load; use a consistent human guide.
Building	Practical knowledge and confidence	Sequence education; invite questions; rehearse tasks.
Taking action	Support through new or difficult behaviors	Provide feedback, reminders, and problem-solving.
Sustaining	Protection during stress and changing conditions	Monitor readiness decay and intervene selectively.

THE READINESS GAP

Interest is common. Follow-through is designed.

Patients may value research and still decline a specific study. They may sign consent and still be unprepared for the schedule, uncertainty, procedures, caregiver demands, or technology. The gap between stated willingness and durable participation is where activation work belongs.

That gap is shaped by more than motivation. A systematic review of trial journeys found interacting patient, trial, staff, and organizational factors across the experience.[2] Research burden also spans psychological, physical, and financial dimensions, including fear, information quality, demanding follow-up, and poor closure.[3]

Activation reframes the response. Instead of asking why patients did not comply, the study asks what support, information, or design condition was missing. This shifts teams from retrospective judgment to preventable causes.

What looks like reluctance	What may actually be happening
No response to outreach	Low relevance, mistrust, inaccessible channel, or unclear next step
Hesitation at screening	Fear of procedures, logistics, or unresolved family influence
Questions during consent	Healthy decision-making that needs time and usable explanation
Missed visits	Accumulated burden, support loss, or expectation mismatch

> **Do not rank patients by presumed commitment. Diagnose what the participation system must make possible.**

ACTIVATION ACROSS THE JOURNEY

Every stage asks the patient to do different work.

Activation is not a single recruitment intervention. The patient's task changes as the trial progresses, and support must change with it.

At awareness, the work is recognizing relevance and trusting the source. At screening, it is navigating uncertainty and logistics. At consent, it is understanding the study well enough to make a values-aligned decision. During participation, it is integrating protocol behavior into real life. During follow-up, it is sustaining meaning and effort after the intervention feels complete.

A lifecycle model prevents a common mistake: delivering the most education at consent, then reducing support when the behavioral demands are highest.

Stage	Patient work	Activation objective
Awareness	Recognize relevance and legitimacy	Move from unfamiliarity to informed consideration
Screening	Navigate tasks, tests, timing, and uncertainty	Build momentum without premature pressure
Consent	Understand trade-offs and decide	Create comprehension and confidence
Participation	Integrate protocol demands into life	Reinforce skills, support, and persistence
Follow-up	Maintain effort and meaning	Protect completion and close the loop

DIFFERENTIATED SUPPORT

The same experience cannot activate every patient.

Standardized experience is often mistaken for equitable experience. Giving every patient the same brochure, reminder cadence, and consent discussion can produce unequal understanding because needs, context, and confidence differ.

Activation-led design creates a minimum standard for everyone and additional support where evidence shows it is needed. A patient with strong baseline understanding may prefer autonomy and concise updates. A patient who is overwhelmed may need shorter explanations, teach-back, a navigator, caregiver inclusion, and more frequent contact. A caregiver-dependent participant may need the entire support plan designed around two people, not one.

This is not about creating unlimited customization. It is about defining a small number of meaningful readiness profiles and linking each profile to a governed support pathway.

> **Orientation pathway.** For patients who need trust, role clarity, and a manageable first step.
>
> **Confidence pathway.** For patients who understand the basics but need questions resolved and tasks rehearsed.
>
> **Feasibility pathway.** For patients whose primary risk is logistics, access, caregiving, or competing obligations.
>
> **Persistence pathway.** For enrolled patients showing burden accumulation or weakening engagement.

> **Equity is not identical support. It is enough support for an informed and sustainable decision.**

ACTIVATION INTERVENTIONS

Support should solve a diagnosed barrier.

Activation work becomes effective when every intervention has a specific readiness job. More content is not automatically better. More contact is not automatically supportive. The right intervention depends on the barrier and the moment.

For cognitive friction, use progressive education, plain language, visual explanation, teach-back, and time to decide. For emotional friction, use trusted messengers, transparent discussion of uncertainty, peer perspective, and human escalation. For structural friction, solve transportation, scheduling, local care, childcare, reimbursement, or technology access. For behavioral friction, use implementation planning, reminders, feedback, task rehearsal, and recognition.

Decentralized elements can reduce travel and make trial activity more convenient when implemented appropriately.[7] They should be offered because they solve a real burden, not because technology is assumed to be patient-centric.

Barrier	Intervention pattern	Evidence of progress
Cognitive	Layered education, teach-back, visual timeline	Stronger comprehension and question quality
Emotional	Trusted guide, peer story, transparent uncertainty	Confidence and willingness to continue
Structural	Flexible visits, transport, local or home options	Fewer access-related delays or misses
Behavioral	Plan, cue, feedback, reinforcement	More consistent task and visit completion

ACTIVATION AND INFORMED CONSENT

Comprehension is the first operational test.

A signature confirms agreement. It does not prove that the patient understands randomization, placebo, alternatives, duration, burden, or the practical consequences of participation.

A meta-analysis across three decades found uneven understanding of consent components, with pooled understanding lowest for randomization and placebo, both near half of participants.[10] That does not mean patients are incapable of understanding. It means the conventional consent environment often fails to build understanding reliably.

Activation-led consent begins earlier and continues later. It surfaces the key decision information first, invites questions, uses teach-back or feedback, includes caregivers when appropriate, and reinforces material changes throughout the study. FDA guidance frames consent as an ongoing process, not merely a form.[4]

Before consent. Prepare the concepts, burden, alternatives, and decision roles.

During consent. Prioritize key information, dialogue, questions, and comprehension.

After consent. Reinforce understanding as visits, treatment, and amendments change the experience.

Consent should confirm understanding that has been built, not create understanding under deadline.

MEASUREMENT

Activation becomes operational when it becomes observable.

Activation can be measured formally through validated instruments such as PAM, but trial execution also requires context-specific signals. The objective is not to create a universal score. It is to see whether the patient's ability to advance and persist is strengthening or weakening.

Useful signals include comprehension checks, confidence, unresolved questions, caregiver readiness, logistical feasibility, response quality, task completion, missed activities, change in tone, burden reports, and support requests. These signals should be interpreted together and within the protocol context.

Measurement must lead to action. A low comprehension signal should trigger education. A transportation barrier should trigger logistical support. A pattern of silence should trigger human outreach. A score without an intervention path is surveillance, not activation.

Signal	Question it answers	Possible action
Comprehension	Does the patient understand the material decision?	Explain differently; use teach-back.
Confidence	Can the patient manage the next step?	Rehearse, coach, or add a navigator.
Feasibility	Can participation fit current life conditions?	Adjust schedule, access, or support.
Persistence	Is readiness deteriorating over time?	Identify cause and intervene early.

OPERATING BLUEPRINT

Build activation into the trial, not around it.

An activation strategy should begin during protocol planning and remain visible in study governance. Start by identifying the behaviors the protocol requires and the barriers the population is likely to encounter. Define readiness profiles, intervention pathways, signals, owners, and escalation rules before recruitment begins.

Train investigators and coordinators in plain-language explanation, active listening, teach-back, cultural humility, and problem-solving. Give patients one clear point of contact. Align sponsor, CRO, site, and vendor responsibilities so that a readiness signal cannot be observed by one party and ignored by another.

Finally, measure activation alongside funnel and retention outcomes. Study whether support changed comprehension, productive progression, missed visits, withdrawal patterns, site rework, and completion. Use the learning to improve the next study.

1. **Profile.** Define likely activation states and barriers in the target population.
2. **Prepare.** Design education and support before outreach begins.
3. **Personalize.** Route patients to a small number of readiness pathways.
4. **Observe.** Monitor signals at every transition.
5. **Intervene.** Link each signal to a governed response.
6. **Learn.** Connect activation changes to operational and completion outcomes.

If activation is left to individual sites, it remains variable. If it is governed, it becomes infrastructure.

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.

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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.