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# Measuring Meaningful Engagement: A Patient Engagement Metrics Framework for Patient-Generated Primary Data Quality

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## Background

Patient-generated data has shifted from a secondary activity to a core driver of study outcomes in app-based, non-interventional research. Participant retention and high-quality data contribution are now paramount to study validity.

Yet engagement metrics remain anchored to what system logs capture most easily: logins, task completion, and session frequency. Without a clear conceptual framework, teams default to objective usage data — implicitly defining engagement as mere "use" and stifling adoption of more nuanced measures.

This narrow behavioral lens overlooks the psychological and emotional drivers of sustained, high-quality participation. A participant who logs in frequently but does not understand why their data matters, or who feels monitored rather than valued as a partner, may produce data that is inaccurate, incomplete, or biased. Current metrics fail to detect this decline until it is too late to intervene.

The field also lacks standardized definitions. A systematic review identified over 60 unique terms for engagement across the mHealth literature, with "use" and "engagement" deployed interchangeably — a primary barrier to cross-study comparison, defensible benchmarking, and scalable measurement frameworks.

## Objectives

**To present a comprehensive Patient Engagement Metrics Framework designed to:**

1. Transition measurement from behavioral interaction tracking to meaningful research participation and data quality assurance
2. Provide actionable intelligence enabling targeted interventions across heterogeneous patient populations
3. Develop leading indicators for data quality issues before they manifest
4. Create defensible, industry-leading performance benchmarks

## Methods

The framework was developed through synthesis of existing patient engagement literature including systematic reviews of mHealth engagement measurement, validated psychometric instruments, and digital health KPI methodologies combined with applied experience conducting app-based non-interventional research across multiple therapeutic areas.

**Mental Model Development**
A four-pillar structure was constructed drawing on established psychological engagement theory. The model recognizes that engagement is a dynamic, multi-dimensional construct encompassing behavioral, cognitive, and emotional domains, with technology adoption as a prerequisite foundation. Behavioral engagement captures the rate of value-contributing task completion; cognitive engagement captures participant attention, comprehension, and understanding of the "why" of the research; and emotional engagement captures trust, subjective experience, and long-term affective commitment to the study.

**Metrics Portfolio Construction**
A comprehensive portfolio of KPIs was organized into a four-tiered maturity model that progresses from foundational adoption metrics through behavioral task completion, subjective perceptual experience, and ultimately longitudinal adherence and value realization. The portfolio incorporates quantitative system logs, validated psychometric instruments, satisfaction measures, and qualitative data. Each metric was assessed for its engagement dimension, directness to study value, measurement type, and implementation complexity.

**Example Metrics in the Four-Tiered Engagement Framework**

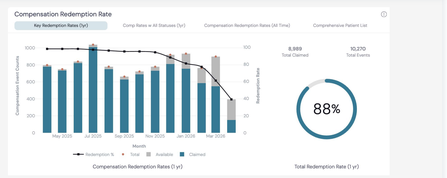
| | | |
|---|---|---|
| **Tier 1- Foundational Adoption & Accessibility** | | |
| Engagement Rate | Percentage of users who begin registration after being informed about the study | Is the study information process clear and compelling? |
| Onboarding Completion Rate | Percentage of users who complete onboarding | Is our onboarding process effective in preparing users for participation? |
| Accessibility Score | Qualitative checklist of compliance with accessibility guidelines | Is our app equitably accessible to our target population? |
| **Tier 2- Behavioral Engagement & Core Task Completion** | | |
| Daily and Monthly Active Users (DAU, MAU) | Number of unique users who open the app at least once in a 24-hour or 30-day period | How many participants are interacting with the study? |
| Primary Data Completion Rate | Percentage of assigned activities completed by a user in a given period | Are participants providing the core self-reported data required by the study? |
| Communication Interaction Rate | Percentage of outbound emails/SMS/calls that are interacted with | Are participants responding to outreach? |
| **Tier 3- Subjective Experience & Perceptual Metrics** | | |
| Patient Activation Measure (PAM) score | A score indicating patient's knowledge, skill, and confidence for self-management | Do participants feel able to be active partners in the research |
| Net Promoter Score (NPS) | A score from -100 to 100 based on the question: "How likely are you to recommend this study/app to a friend or family member?" | Are our participants' experiences positive enough that they would advocate for the study? |
| Qualitative Feedback Themes | Thematic analysis of user-submitted feedback, reviews, and support tickets | What are the frustrations and motivations of our participants? |
| **Tier 4- Longitudinal Adherence & Value Realization** | | |
| Participant Retention Rate | Percentage of participants who remain active over a defined period | Are we successfully retaining patients? |
| Engagement Index (EI) | A composite score combining click depth, recency, and loyalty to create a single indicator | What is the risk of participant disengagement? |
| Time to Churn | The average amount of time from a participant's registration to their last interaction before becoming inactive | How long does the typical engagement lifecycle last? |

## Conclusion

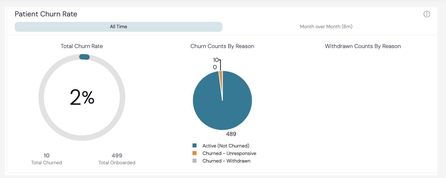
- This framework operationalizes engagement science into a measurable metrics portfolio. By structuring KPIs across four tiers, it provides a systematic roadmap for moving beyond behavioral tracking to truly understanding the participant journey.
- Incorporating cognitive and emotional dimensions addresses a fundamental limitation of current practice. Perceptual metrics such as activation, empowerment, and perceived burden serve as leading indicators — a declining score can predict ePRO non-completion or withdrawal before behavioral metrics deteriorate, enabling earlier intervention.
- The framework's emphasis on standardized definitions directly addresses a critical literature gap: inconsistent KPI terminology across the industry. Consistent definitions support cross-study benchmarking, reproducible measurement, and credible external reporting.
- Application strategies — demographic and pathway segmentation, composite scoring, lifecycle mapping, and predictive modeling — transform raw metrics into actionable intelligence, enabling teams to identify at-risk subpopulations invisible in population-level averages.
- The Maturity Model provides a self-assessment framework charting progression from adoption-only tracking to a balanced scorecard with validated surrogate endpoints.
- As a next step, engagement metrics should serve as operational KPIs while the organization pursues formal validation against objective quality measures: data completeness, concordance with clinical records, retention, and statistical power. Successful validation would elevate engagement scores from internal KPIs to defensible surrogate endpoints for research quality.

## Adoption

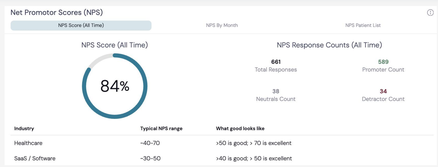

## Behavioral Engagement




## Longitudinal Adherence




## Subjective Experience




## Disclosures

Authors are employees of PicnicResearch.