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# ENGAGING PATIENTS FOR THE DURATION: THREE WAYS TO IMPROVE RETENTION IN ONCOLOGY STUDIES

**EXECUTIVE BRIEF**

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*Oncology trials — which accounted for about one-quarter of all new studies reported in 2020 — are among the most complex and expensive when it comes to clinical trials. These trials tend to be lengthy, creating significant participant burdens that result in a higher likelihood of attrition. Moreover, with more protocol deviations than in any other therapeutic indication, oncology trials require consistent remote monitoring of participant status.*

Keeping participants and caregivers engaged throughout a lengthy clinical trial is always a challenge. However, when it comes to oncology trials, which are 35% longer than average, this becomes absolutely critical. Study teams need strategies to reduce the effort for participants while improving the accuracy and timeliness of the data they provide.

Participant input is crucial to evaluating the efficacy of an intervention — from assessing changes in quality of life and determining non-inferiority to crafting labeling claims and marketing messaging. Electronic patient-reported outcomes (ePROs) are one of the best ways to tune in to patient and caregiver needs. However, ePROs are valuable only when participants can consistently – and easily -- provide this information. By incorporating behavioral science principles into an ePRO platform, oncology trials can increase the likelihood that participants stay actively engaged. These principles also help ensure that a trial is capturing robust, complete data — even when the trial spans multiple years.

**Behavioral science: the study of human decision making**

Over the past two decades, this discipline has moved from the confines of academia to influence everything from government and multinational policy to public health and business intelligence. Behavioral science principles tap into the neurobiology of reward. They help explain how and why people make decisions. Moreover, they outline tangible strategies that can be leveraged to maximize the benefits and decrease the burdens of participation and compliance in an oncology study.

What follows are three specific ways to do that.

**Strategy #1: Build participant identity**

Behavioral science research has found that identity is an intrinsic motivator that often guides decision-making. The concept of "Identity Lock" is based on the understanding that humans have an innate desire to belong to social groups and are willing to abide by social norms that may be a prerequisite for belonging to that group. In clinical trials, the goal of the identity lock process is to tie a participant's internal sense of self to their participation in the study. It requires a shift from treating a participant as a study subject to focusing on their role as a partner and scientific contributor to the clinical trial. When a participant's role in a study becomes part of their personal identity, they are proud to share that "I'm an oncology hero" or "I'm helping to fight

cancer." Once an individual has embraced this identity, dropping out of the study becomes more difficult.

Identity is also connected to social norms. Human beings nurture a sense of belonging by trying to meet social expectations. An oncology trial can create a community in which completing activities is the social norm. Participants come to understand that compliance is essential not just for the investigators but also for others in the study community.

There are several ways to operationalize identity lock using technology and communications. For example, incorporating patient-engagement content has been shown to increase participant satisfaction and feelings of involvement, which can be associated with better compliance. This content includes sharing study information, educational content, and updates on study progress. It could also be as simple as sending reminders about upcoming activities and why they are necessary.

### Strategy #2: Create motivational intervals

Motivation is critical for participant engagement, compliance, and retention. Behavioral science research has increased our understanding of the neurobiology behind motivation and decision-making and shed light on how humans adapt their behavioral patterns in response to reward. An important insight from this research indicates that reinforcement learning occurs on multiple timescales, spanning from a few seconds to several weeks after the learning event. This reality necessitates that participants be rewarded and motivated on an interval basis, starting from immediate, short-term rewards to longer-term motivation based on the length of the trial.

**Short-term motivation** includes a combination of reflexive and cognitive reinforcers. These rewards are immediate and tied to the completion of individual study activities (such as completing an ePRO or an eDiary entry). Behavioral science has found that when a stimulus is repeatedly paired with a reinforcer (such as a reward), the stimulus — in this case, completing study activities, ePROs, eDiaries, and site visits — can become reinforcing on its own.

**Medium-term motivation** reinforces study progress. Behavioral science research has found that when expectations are not met, humans experience that as a "loss." Conversely, when expectations are exceeded, people experience that as a "gain." Moreover, people experience losses more acutely than gains. Medium-term motivation should build an expectation of future rewards that will be realized at a later date. Using anticipation of medium-term rewards helps balance positive expectations with loss aversion. This motivates people to stay in the study and continue completing activities to ensure they don't miss out on a promised reward.

**While any one of these behavioral science strategies helps improve results, combining all three yields a participant retention rate of more than 85%.**

**Long-term motivation** focuses on meaningful goals tied to study completion. The key is to align those goals to larger, rarer, and more tangible rewards than one might use for medium-term motivation. Behavioral science research has found that when a reward is rare or unexpected, it has a significant impact. Aim for creativity with long-term rewards. For instance, consider offering participants the opportunity to donate to a disease-specific organization, provided it is approved by the Institutional Review Board (IRB) and independent ethics committees. This reward powerfully combines meaningful goals and personal identity.

### Strategy #3: Reduce friction using mobile technology

Infusing behavioral science principles into a mobile platform effectively reduces friction for oncology trial participants. In addition to helping set expectations and minimize burden for participants, a mobile platform can be used to create defaults. Using defaults is a behavioral science principle that is used in everything

from organ donation programs to retirement plan participation. This approach preserves choice while making a desired behavior or decision (such as becoming an organ donor or enrolling in a 401(k) plan) the default path.

Mobile technology also helps minimize missing data by decentralizing the collection of eCOA/ePRO, eConsent and eDiaries. Participants can provide information anytime, anywhere with just a few clicks on their mobile device. Mobile technology helps improve data insights, too. Given the need for remote monitoring in oncology trials, passive data collection via mobile devices offers many advantages. Consider the possibilities for incorporating sensors or wearable devices, such as activity trackers and heart rate monitors into a trial. Or, leverage phone-based metrics, such as battery life and screen time, to provide real-world data on participant engagement and quality-of-life changes without any effort from the participant.

Another innovative approach is using geofencing technology with a case alert system. Together, they can be used to monitor potential adverse events. Geofencing enables the placement of virtual fences around places of interest, such as hospitals or clinics. When a participant crosses one of those virtual fences, an alert goes to the participant (to gather information about what happened) and to study staff (to notify them about the need to follow up with that participant).

Finally, allowing participants to use their own devices has been shown to improve compliance and retention in long-term studies. A robust mobile app makes it fast and easy for participants to both provide and receive study information, and it provides a tool for establishing identity lock. Further, using mobile devices for telemedicine appointments avoids the "costs" of in-person visits -- travel time and expenses, lost wages, and time away from loved ones.

### The payoff of stronger participant engagement

With an average international clinical trial running about $40 million, losing just 1% of participants to attrition translates to a cost of $400,000. With an average attrition rate of over 20%, losing participants can represent a loss of at least $8 million. For oncology trials, the attrition rate (and the resulting financial impact) can be even higher. Increasing the retention rate even by 5% can deliver over $2 million in savings.

Oncology studies can apply behavioral science principles — and bring them to life through mobile technology — to strengthen participant engagement. Stronger engagement translates to higher compliance and retention rates, improved data collection, and better real-time visibility for study stakeholders.

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