



BEST PRACTICES FOR REGISTRY ENGAGEMENT

As new types of registries emerge, new practices are needed to engage and retain participants.

New Types of Registries

A registry, per the NIH, has been defined as a collection of information about individuals, usually focused around a specific diagnosis or condition.



Chris Lunt, Chief Technology Officer, All of Us Research Program, NIH

To date, patient participation in registries has largely been driven by providers and the data in registries has typically been controlled by academic medical center (AMCs); it has not necessarily been broadly available to researchers or patients. Also, most registries have not yet included phenotypical information or biospecimen data.

But this is changing.



Lynn Vos, CEO, Muscular Dystrophy Association; Ryan Olohan, Managing Director, Healthcare, Google, Inc.

New types of registries are emerging, often orchestrated by independent third parties, including nonprofits. Unlike registries driven by providers and AMCs, these “patient-driven” registries aggregate data from multiple sources.

Important differences in this new generation of registries include:

- **How patients are enrolled.** Patient-focused (or “participant-focused”) registries are not enrolling patients solely through a provider or AMC; they enroll patients directly or via a hybrid approach.
- **The types of data collected.** Patient-focused registries are pulling data from electronic medical records, along with phenotypical information and biospecimens.
- **Data is collected longitudinally.** Patient-focused registries are dynamically collecting information over the long term to create longitudinal data, which is critically important for many diseases.
- **Focusing on cures.** Patient-focused registries are shifting the fundamental goal of registries from collecting aggregate information to identifying disease causality and developing cures.

“Patient registries are the new registries of the future . . . the emergence of precision medicine is shifting the goal [of registries] from quality improvement to studies of ‘cure’ and ‘cause.’”

Different Capabilities Required

With provider-driven registries, most patients enroll because a trusted provider at a trusted medical center asked them to participate. Without the explicit recommendation of a trusted provider, getting patients to agree to participate in a registry and remain participating is more difficult.

For nonprofits to acquire participants in a more patient-driven registry and to retain these patients requires the types of engagement capabilities possessed by sophisticated direct-to-consumer (DTC) companies. It requires expertise in:

- Acquiring participants through multiple channels
- Segmenting participants based on emotions, behaviors, and other important criteria
- Creating a constant stream of relevant content, communications, and events
- Understanding how patients define value and providing value in multiple ways
- Building partnerships and affiliations to create awareness about the registry



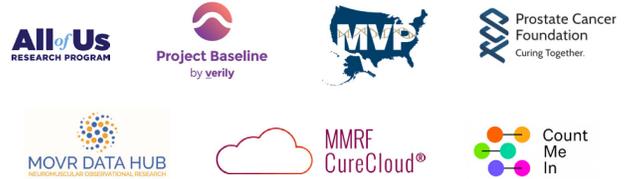
Rachel Taylor, Product Marketing Manager, Verily Life Sciences (Baseline)

Learning from Leaders

To better understand the necessary capabilities and best practices around engaging and retaining registry participants, the Kraft Precision Medicine Accelerator sought input from leaders of organizations with patient-focused registries along with DTC experts and representatives from genomic testing companies.

Together, registry representatives, DTC practitioners, and genomic testing experts identified a core set of best practices for engaging and retaining registry participants.

Registries



Direct-to-Consumer (DTC) Experts



Genetic Testing Companies



“We are applying learning from consumer companies about acquisition and retention to catalyze registry efforts across disease areas.”



Blair Hammond, Director, Content Strategy, Salesforce

5 Best Practices for Engaging & Retaining Registry Participants

1 UNDERSTAND PATIENTS' MOTIVATIONS

DTC experts advised registry leaders to invest the time and effort to thoroughly understand patients' journeys, emotions, and motivations for participating in a registry.



Margaret Lawrence, VP, General Manager B2B, Wayfair

Common patient motivations

Registry leaders hear the following as motivators for patients to participate in registries:

- Altruism and a desire to give back
- A desire to get something in return
- Receiving information that empowers them to better manage their health
- Getting access to information about cures
- Knowing they are included and represented in research

A deep understanding of patients' emotions and motivations will drive all registry-related patient acquisition, engagement, and retention activities.

"Don't serve as your own focus group," suggested a DTC expert. "Those who run registries are too close to the situation and can't truly think like a participant." Experienced consumer engagement experts recommended developing expertise in ethnography, which is studying and understanding a person's situation. This is best done by going out and meeting with patients to understand their situation, emotions, fears, and possible barriers to participating.

"Really understand consumers. Really know them. What motivates them? What language do they use?"

2 CREATE POWERFUL, RELEVANT MESSAGING

Consumer experts emphasized that people purchase products or agree to enroll in a registry for both rational and emotional reasons. Communications should speak to both mindsets.

- **Rational communication** might focus on education or the benefits of a registry and the amount of time required to participate. Language might state, "All you have to do to participate is xyz."
- **Emotional communication** might focus on hope, inspiration, and the impact an individual can have by participating. Messaging might convey, "Your participation matters because your data is vital in finding a cure and helping others."

Powerful messaging is empathetic and builds trust. It also creates urgency through language such as, "The faster you participate, the faster we will find a cure."

Because it is so difficult to predict how individuals will respond to different messages, a messaging best practice is to create a culture of testing and iteration. Conduct A/B tests, measure the results, and adjust.

"There is not one message that fits all, but different messages for different groups. Figure out what works best through iterative A/B testing."



Rachel Ramoni, Chief Research and Development Officer, Department of Veterans Affairs

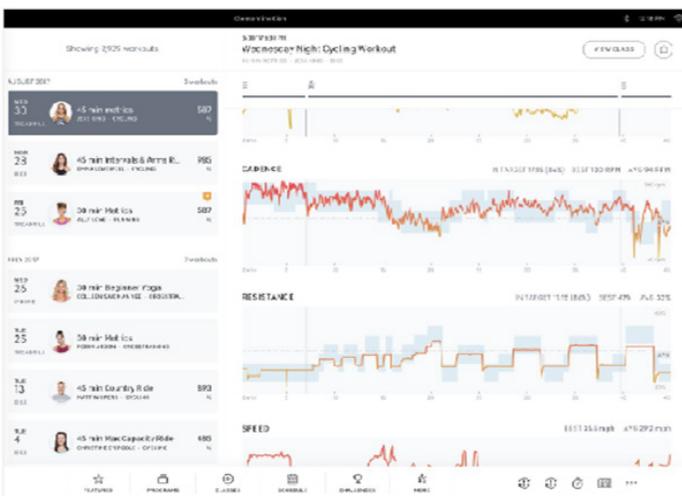
3 RETURN VALUABLE, VISUAL DATA

A general principle is to constantly provide something to participants that they value and that personalizes their experience. Ways that DTC companies and registries deliver on this idea is by returning personalized, valuable, visually compelling data.

“What are you going to give to consumers to make them want to stay?”

Peloton, for example, provides consumers with personalized workout data that shows personal progress, achievement of goals, and comparison to others—in a simple, clear, engaging way.

WORKOUT DETAILS



Community Highlights

HIGHEST RATED PLAYLIST
30 min Latin Celebration Ride
Tobin Arzon
Aired 09/27/19 @ 12:30 PM EDT
BOOKMARK CLASS

Your Badges Earned

Dynamic Duo Dynamic Duo Dynamic Duo
You've Earned 14 New Badges
VIEW ALL (14)

Your Monthly Achievements

BEST OUTPUT
303
45 min Music Legends Ride
Joan Sherman
Taken 09/12/19 @ 8:04 AM EDT
VIEW DETAILS

HIGHEST RATED DIFFICULTY
45 min Tabata Ride
Aly Love
Aired 09/10/19 @ 6:00 AM EDT
BOOKMARK CLASS



Becky McIntosh, Director, Brand Marketing, 23andMe; Corrie Painter, Associate Director of Operations and Scientific Outreach, Broad Cancer Program, and Associate Director, Count Me In

Best practices in responsibly returning data to registry participants include:

- Ask patients what type and amount of data they want.
- Understand how patients want to receive information
- Personalize the data you return to registry participants
- Explain to patients why the data you are sending is important to them
- Patients want to know compared to whom, which makes any comparison more relevant
- Guide patients for an action to take after reviewing the data you send
- When developing reports do user testing to gauge patients' reaction and experience

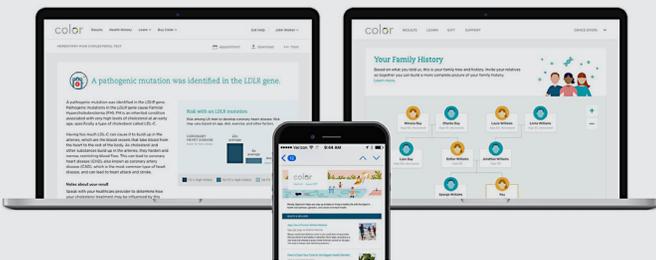


Bray Patrick-Lake, Director, Strategic Partnerships, Evidation Health

Responsibly Returning Genomic Data

A specific type of data increasingly being returned to patients is genomic data. The main principles for returning data continue to apply for genomic data. In addition, specific insights shared by genomic testing firms and registries for dealing with genomic data include:

- Provide **immediate understanding**. To avoid genomic data being intimidating or overwhelming, create reports so that recipients immediately grasp the main message.
- Focus on **design & visualization**. Make the reports simple, clear, bold, colorful.



- Make reports **non-clinical**. Use language and visuals that are simple and easy to understand.
- Clearly explain the **process**. It is not just the data that is important, it is the entire process. Be extremely transparent about exactly how the process will work, how data will be collected, how it will be returned, and how it will be used.
- Build **genetic counselors** into the return process. Ensure that patients have access to genetic counselors to explain results and answer questions.



Alicia Zhou, Chief Science Officer, Color

4 PROVIDE A FIVE-STAR END-TO-END EXPERIENCE

When individuals decide whether to remain enrolled in a registry they think about their entire experience, ranging from the enrollment process, to the case manager on the phone, to the phlebotomist who came to their home. Every touchpoint influences how people view an experience.

Consumer-facing companies map their customer journeys, identify all key touchpoints on these journeys, and focus on delivering five-star experiences from end to end.

“Every touchpoint in a participant’s journey builds or erodes trust and affects retention.”

5 BUILD A COMMUNITY

An often-overlooked way to boost retention is to foster a sense of community. An example is how the Boston Red Sox create belonging through the concept of “Red Sox Nation.” Peloton creates a virtual exercise community and shares data to show how individuals compare to others in the community. Rent the Runway provides data to community members to show the collective impact the community is having by reducing waste and by helping other community members through reviews.

Community Data (actual example of data returned by Rent the Runway)



While not specific to its registry, the Pancreatic Cancer Action Network (PanCAN) has had great success in building a tight-knit collaborative community through a wide range of events. This includes communities of patients and caregivers, volunteers, and even a community of scientists who are focused on pancreatic cancer. Other organizations such as LUNgevity foster community through specific Facebook groups for individuals with specific subtypes. These community-building activities create a belief that “we’re all in this together.” By creating a community, individuals are more likely to remain engaged.

“Cultivate and facilitate the creation of community.”

Doing It All

For nonprofits and other types of independent third-party organizations that are developing and implementing patient registries, there is no singular formula for engaging and retaining patients. All of these ideas apply:

- Understand patients’ motivations.
- Develop powerful communication that appeals to those who prefer rational messages as well as those who are moved by emotional messages.
- Provide value by returning relevant data in a visually compelling way.
- Deliver a seamless, high-quality, satisfying, end-to-end experience.
- Create a sense of belonging by building a community so everyone knows they are not alone.

In addition, remind patients that through their personal participation in your registry, they are helping advance science and are contributing toward finding a cure.



Jennifer Hall, Chief of the Institute for Precision Cardiovascular Medicine, American Heart Association



Consumer engagement experts and nonprofit thought leaders at a Kraft Accelerator convening