

evidation

# 5 keys to high participant engagement in real-world research

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# Introduction

As healthcare continues to put greater emphasis on value-based care and patient-centricity, there's greater demand for understanding and measuring health, experiences, and outcomes in day-to-day, real-world settings.

Digitally enabled direct-to-participant research platforms and passive data collection direct from consumer and clinical devices help researchers fill in the gaps of what's not visible in claims records, EHRs, and other medical data.

Longitudinal ePROs, surveys, and objective digital measures (such as activity, sleep, heart rate) build a more comprehensive understanding of people's everyday lives, including behaviors, how diseases progress, and the effects of treatment.

A key challenge of direct-to-participant real-world research is keeping individuals engaged in ongoing data sharing in their daily lives, especially when key health events occur.

One of the primary contributors to low engagement rates and insufficient enrollment is the failure to design programs in a way that aligns with people's routines, priorities, motivations, and daily encounters with health.

## Direct-to-participant real-world research: Challenges and approaches to overcome

When bringing research into everyday life, teams must account for new challenges as well as some existing ones from traditional research.

Potential participant challenges	Risk of incomplete or biased data caused by the challenges	Key approach to address the challenges
Skepticism about data collection methods and concerns about data utilization	Reduced willingness to participate and share authentic information	Laying a foundation of transparency, trust, and privacy
Insufficient motivation to participate and remain engaged in programs for extended durations	Dropouts or irregular participation, potentially leading to skewed research outcomes and limited applicability	Engaging with the right mix of motivation and value
Research protocol and devices that are burdensome or not user friendly and materials that do not resonate with participants	Participant frustration or inability to use devices effectively, resulting in compromised research validity	Listening to participants to inform design
Data collection methods that fail to align with the demands and conflicting priorities of individuals' daily lives	Participants not fully engaged with data collection activities, leading to an inaccurate representation of real-world scenarios	Creating low friction experiences that work in real life
Limited awareness and education about research opportunities and their associated advantages	Limited participant enrollment, resulting in a smaller and potentially less diverse sample, which can compromise the generalizability of research findings	Building long-term connections

# 5 keys to high participant engagement in real-world research



Over the past decade, Evidation's direct-to-participant platform has engaged millions of people in taking healthier actions and sharing permissioned, longitudinal data about their health and experiences in everyday life. Our experiences are based on different types of real-world research programs, including scientific studies contributing to generalizable knowledge as well as multi-year health and engagement programs.

In this report, we discuss a few best practices for engagement based on our experiences and learnings from our programs, partners, participant advisory committee, industry partners, and participant surveys and feedback.

Since a one-size-fits-all approach will not be successful for every program, the strategies discussed in this paper are intended as considerations to be applied as appropriate for the specific research being undertaken. How and if they are used will vary based on the research objective, population, protocol, duration, and more.

**We'd also love to hear learnings from you —**  
please email [partner@evidation.com](mailto:partner@evidation.com) with your feedback.

# 01. Laying a foundation of transparency, trust, and privacy



**Jasmine Isaac**

Head of UX Research,  
Evidation

*“For many people, a safe space to share their experiences with a specific condition or disease allows them to contribute honestly and makes it more likely that they will continue contributing their experiences. Clearly communicating the aim of the study also allows them to understand the importance of showing up fully.”*

Contributing data for research can often seem like a “black box” experience — many participants do not understand who is using their data and how. Building a foundation of privacy, confidentiality, trust, and mutual respect from the very beginning of a research experience instills greater confidence for participants that their data are being used appropriately.

## Research elements to build trust

### Person-focused

- Research design and team centered on the participant and what works for them in the context of their daily lives
- Person-first language that recognizes individuals as more than their disease
- Questions framed with inclusivity in mind (e.g., collect demographic information that recognizes all gender identities)

### Transparent

- Clear and intuitive consent process
- Clear expectations set around:
  - Study objectives
  - Participant experience and activities
  - How data will be collected and used
  - How and when data will be shared back with the participant
  - When permission will be sought to use data in other ways than originally stated

### Approachable

- Plain, easy-to-understand language, especially for consent and more complex topics
- Variety of formats and options for consuming information
- Accessibility as a priority in interface design
- Graphics and images that depict all people and multiple situations

### Robust security and privacy capabilities

## 02. Engaging with the right mix of motivation and value

Research participation competes with a long list of priorities and challenges as part of the overall human experience — families, school, work, illness, travel, unexpected events, and more. However, surveys and previous work show that people are willing to share data over time when they perceive the value they receive is worth the effort.

Designing around “what’s in it for me” must go beyond just traditional compensation and take into account multiple motivations of each individual — whether they’re driven by improving their health, feeling part of a broader community giving back to science, being rewarded for activities, or a mix of factors. Particularly for longer term research programs in which the goal is to create a dataset capturing sufficient numbers of health events, individualized, varied interactions designed around these motivations during moments that matter can successfully keep people engaged over long periods of time.



**Kalahn Taylor-Clark**

MPH, PhD;  
Faculty in Executive  
Education at the Carey  
Business School at Johns  
Hopkins University;  
Former Biopharmaceutical  
Executive

*“Organizations are starting to recognize that understanding the whole person allows them to gather critical data while also adding value to people’s lives. At one company where I previously worked, we partnered with Evidation to measure and identify signs of depression in people with diabetes that were contributing to lack of adherence with their therapy.*

*We created an intervention to contact the person when those signs were detected — to ask if they needed mental health help and provide appropriate resources. As a result, we saw better adherence and better outcomes overall. We were also able to provide value to participants beyond the specific study.”*

## Sample research engagement motivators

Intrinsic motivators	Example strategies that can support the motivation
<b>Improved health</b>	<p>Providing participants with personalized health insights and content based on data collected that help people get more involved in their care and support conversations with healthcare providers</p> <p>Alerts for health events, risks, or indicators of disease that encourage people to be more proactive about their health</p>
<b>Sense of community</b>	<p>Community building activities and resources that go beyond specific research outcomes to help people feel part of a network and more engaged in the program</p> <p>For example, asking participants how they feel, showing they are not alone, and providing supportive resources</p>
<b>Altruism</b>	<p>Sharing aggregated research insights and outcomes, as well as the impact that the participants' contribution had on progressing scientific knowledge and healthcare</p>

Extrinsic motivators	Example strategies that can support the motivation
<b>Timely incentives</b>	<p>Small rewards and points for completing essential research activities as well as engaging with relevant content throughout the program</p> <p>Timely distribution of compensation throughout the research period, dashboards to show ongoing progress, and clear communications around next steps</p>
<b>Challenges</b>	<p>Gamified activities that are fun, achievable, relevant, and tailored – to encourage ongoing survey completion and wearable use (e.g., standing challenge, step count)</p> <p>Accounting for individual differences in motivation, such as the desire to set new, bigger goals once initial goals are set or to just consistently meet goals over the longer term</p>

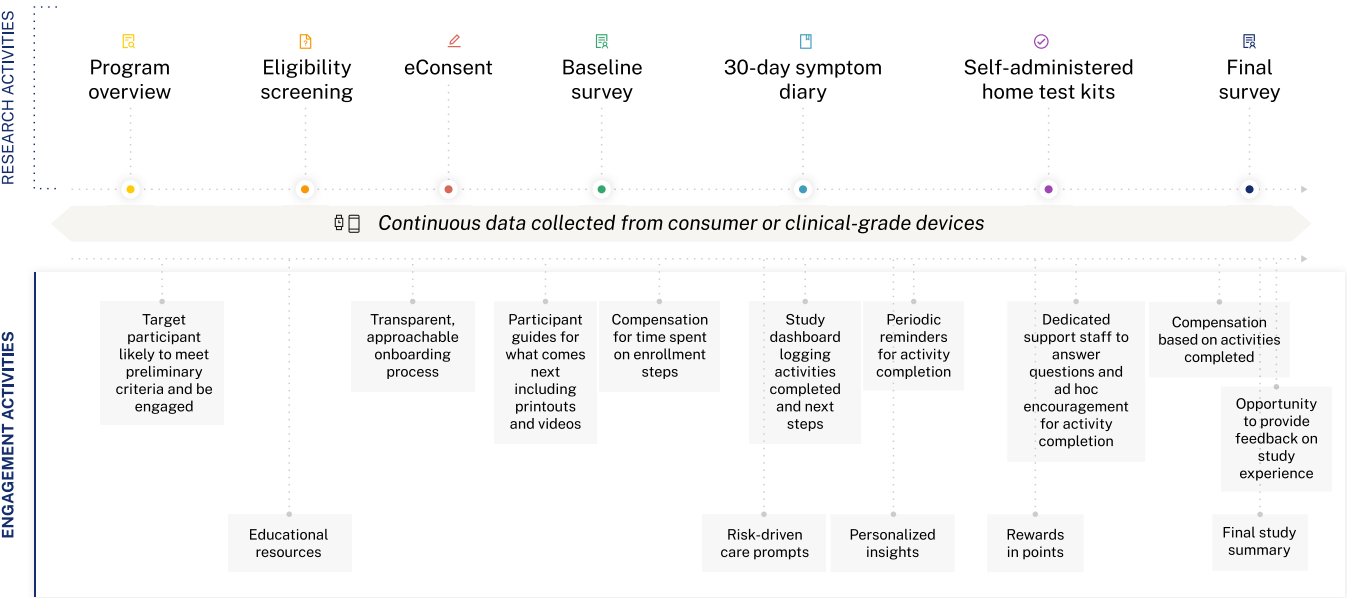


# Example engagement strategies by research type

The best-fit participant support and engagement strategies will, of course, vary by program and objective — the diagrams below illustrate a few examples:

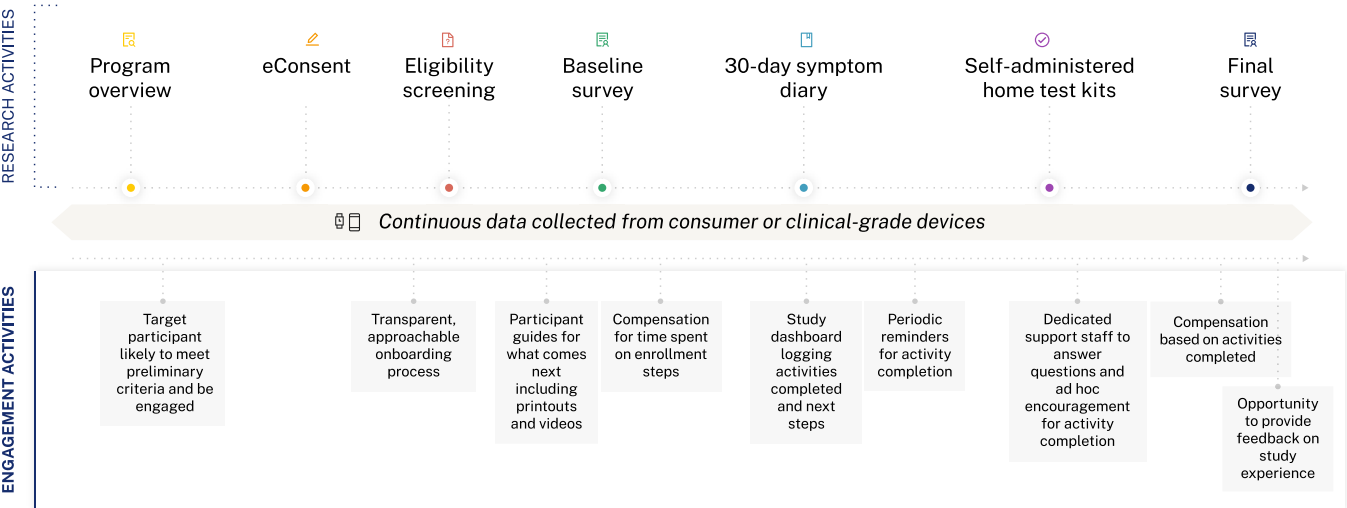
## » Long term research and engagement programs

Objectives may include enriching RWE datasets with longitudinal data and collecting vast amounts of data for digital biomarker development, patient engagement and support, and more.



## » Decentralized studies

Objectives may include measuring behaviors and outcomes and quantifying associations in order to add to generalizable knowledge.



# 03. Listening to participants to inform design

*Blending active and passive data to go beyond the “voice of the participant”*

Multiple types of data underpin a successful engagement strategy and the principles discussed in the previous sections.

Increasingly, studies are being created collaboratively with participants and caregivers, rather than just for them, leading to improvements in recruitment, engagement design, endpoint selection, and more.

Interviews, surveys, and focus groups are a common way to build an understanding of participants' lived experiences and how research could fit into them. It can also be important to listen to what individuals are passively and objectively sharing through wearable and device data, such as their behaviors and engagement patterns.

Looking at both in tandem, teams can understand participants more deeply before and during program experiences in order to design a more relevant experience that works for, and not against, people.



## Active voice of the participant

### Sample methods:

- Interviews
- Surveys
- Focus groups
- Usability testing (e.g., study material usability testing)
- Community or patient advisory boards

### Example insights:

- What outcomes and endpoints matter most to them?
- What are the day-to-day social and environmental contexts in which individuals experience symptoms?
- What study activities are they willing to do, how often, and for how long?
- When during the day are individuals likely to experience symptoms and also be willing to respond to surveys?
- What are barriers to participation?
- What engagement tactics would “turn them off”?
- What would motivate participation?
- What types of resources and activities would they find valuable?

## Objective participant data shared from wearables and devices

### Sample data types:

- Day-to-day activity data
- Participation behavior patterns
- Research activity engagement

### Example insights:

- When is someone most likely to interact with research activities and on what platform (phone vs. computer)?
- How long does it usually take for them to complete it?
- At what point in the study do participants tend to disengage?
- What types of activities and survey approaches are most successful?
- What content and motivators are driving the highest ongoing engagement?
- What is the delta between what someone is saying and their actions?



**Christine Lemke**

CEO, Evidation

*“Something we’ve learned over the years is that throwing too much noise at people, especially if it isn’t relevant to their lives, tends to result in disengagement. It’s important to find the right mix and cadence of interactions so as not to over-communicate or show up in the wrong ways.*

*Listening to active and passive insights shared from participants can help find that balance. We really have to ask ourselves what will add value in exchange for people agreeing to share their information.”*

# 04. Creating low friction experiences that work in real life

Technology is increasing access for more people to contribute their data to research when and where convenient to them but only if done in the right ways. Because digital data collection can still be unnecessarily frustrating and burdensome, we need to look at all aspects of a research program and ask, “Is there any way we can make this easier, more accessible, or more flexible for participants?”

## Tech alone is not the answer



**Meg Dryer**

General Manager,  
Consumer, Evidation

*“Sometimes there’s a notion that simply applying technology to research will create great experiences that keep people coming back, but the graveyard of health apps tells a different story. How the technology is executed plays a large role in its success.*

*Technology itself is not the solution. It is more a single tool in the overall effort to transform how people contribute to healthcare decisions.”*



**Coté Auil**

Senior Manager,  
Business Development

*“We’ve seen greater rates of drop-off when participants are asked to go through multiple hoops to complete a task. When actions that participants have to complete are within one platform and are designed around their lives, compliance and engagement are much better.”*

## Ways to reduce participant research burden

Friction point	Considerations to reduce participant burden
Participants are asked to provide responses for data that could be automatically shared digitally (e.g., How many hours did you sleep last night?).	<ul style="list-style-type: none"> <li>• Incorporate data collection from consumer and clinical devices to passively collect participant data (e.g., sleep, mobility, heart rate).</li> </ul>
Tasks are confusing or difficult and time-consuming to find.	<ul style="list-style-type: none"> <li>• Create a simple, easy-to-navigate interface that keeps participants focused on your study's key activities.</li> <li>• Minimize the number of steps required to complete an action.</li> <li>• Take advantage of the digital screen format to present content in short sections that minimize scrolling, and provide clear actions in surveys and ePROs.</li> <li>• Ensure support staff are available throughout a project to answer any questions.</li> </ul>
Inadequate support is provided to access digital devices that are often not user-friendly.	<ul style="list-style-type: none"> <li>• Design your program around a BYOD (bring your own device) strategy that is more convenient and comfortable for participants.</li> </ul>
Participants need to remember to complete study tasks on schedule or when an event (e.g., cough) happens.	<ul style="list-style-type: none"> <li>• Deliver automated reminders that leverage survey responses, health and behavioral patterns, attitudes and preferences, and wearables to nudge participants to complete tasks.</li> <li>• Incorporate aids or alerts for the individual to document symptoms during a wearable-detected event.</li> </ul>
Study alerts and notifications occur too frequently.	<ul style="list-style-type: none"> <li>• Be intentional with the timing, frequency, and content of notifications and alerts.</li> </ul>
The time window to complete an action is too short, especially when something else is taking priority.	<ul style="list-style-type: none"> <li>• Determine an acceptable window of time in which people can complete an action — to maintain data completeness while allowing flexibility for participant completion.</li> <li>• Allow people to return to complete actions later, if they're interrupted midway through.</li> </ul>

# 05. Building long-term connections

Fostering meaningful, sustained participant engagement is a long-term endeavor that can greatly benefit from a comprehensive approach to participant communication that extends beyond the constraints of a predefined research protocol.

For instance, the Evidation consumer app keeps millions of members engaged in tracking and learning about their health on an ongoing basis. The platform is one of the largest virtually connected digital health cohorts in the United States and serves as a “waiting room” of sorts for participants interested in joining clinical research. The app offers educational content on current health issues, helps members track their health and activity through connected devices, and provides personal health insights and rewards based on individual behaviors.

This two-way engagement approach not only enhances participants’ understanding of medical conditions and health behaviors but also builds brand familiarity. We have observed that this has a positive impact on reducing recruitment timelines and increasing research engagement.

For a recent industry study, participants recruited from the engaged Evidation community had higher participation and retention rates than individuals recruited from external sources, such as social media and websites (Facebook, Google, Reddit), traditional recruitment-only vendors (patient databases), and traditional sites (medical and academic institutions). Beyond increasing participation in research settings, engaged Evidation members have also shown a willingness to provide feedback on study procedures and share valuable information about their overall experience. Further, these individuals are excited to participate in future research.



## How Evidation can help you create research experiences that work

Evidation's engaged, well-characterized community and direct-to-participant platform help companies achieve faster enrollment in research and create high-engagement participant experiences.

### Sample results from research programs and studies

#### Participant experience

*Based on survey responses after the respective program completed*

##### Influenza study:

- **94%** of participants said their research experience was easy or very easy.

##### Menopause study:

- **85%** reported that symptom tracking during the study period was helpful.
- **91%** expressed interest in having their device help monitor symptoms after the research period.

#### Participant engagement

##### COVID-19 program:

- **100,000** individuals were enrolled in 5 weeks.
- **90%+** engagement with surveys, articles, and other activities was achieved over 8 months.

##### Uterine pain fibroid study:

- **100%** retention among 350 participants was achieved over 4 months.
- **92%** of weekly surveys were completed.
- **98%** of monthly surveys were completed.

##### Influenza program:

- **88%** daily survey completion occurred among 10,000 individuals over 10 months.
- **89%** shared sleep, heart rate, and activity data.
- **82%** of triggered test kits were completed.



This high engagement helps our customers get the right data that drives better results faster:

- **More complete participant journeys** and high-quality longitudinal datasets
- **Robust, differentiated real-world evidence** and novel scientific communications
- **Rapid recruitment and high retention and adherence** for trials and studies
- **Timely participant activation** towards diagnosis, patient support, and other resources

**Create high engagement research experiences that drive results:**

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