



# Recruiting and Retaining RETAIN Participants

## Potential Challenges and Suggested Strategies

### Overview

A critical aspect of RETAIN projects is the recruitment, enrollment, and retention of program participants. Effective recruitment and enrollment require planning, time, patience, and flexibility. However, this process is often more difficult than anticipated and generally takes longer than planned. Challenges in recruiting and enrolling participants can have implications for the project timeline, budget, and resources.

Recruitment and enrollment are the first steps for getting injured or ill workers involved in your RETAIN project. Retention is equally important. When participants drop out of the project, this leaves a shortfall in the target enrollment numbers and increases the recruitment burden.

There are several places along the pipeline where your project might lose participants (Figure 1). Understanding where these “leaks” occur and how to remedy the problem should be an integral part of your Continuous Quality Improvement (CQI) process. This issue brief discusses common challenges and pitfalls (sources of these leaks) that RETAIN grantees should be aware of and presents strategies for how to address these issues.

#### Box 1. Participant Recruitment and Enrollment and Retention Involves:

##### Recruitment

- Defining your target population and determining inclusion and exclusion criteria
- Identifying referral sources (e.g., health care providers and employers), disseminating information about the project, and ongoing stakeholder outreach
- Screening and identifying eligible participants

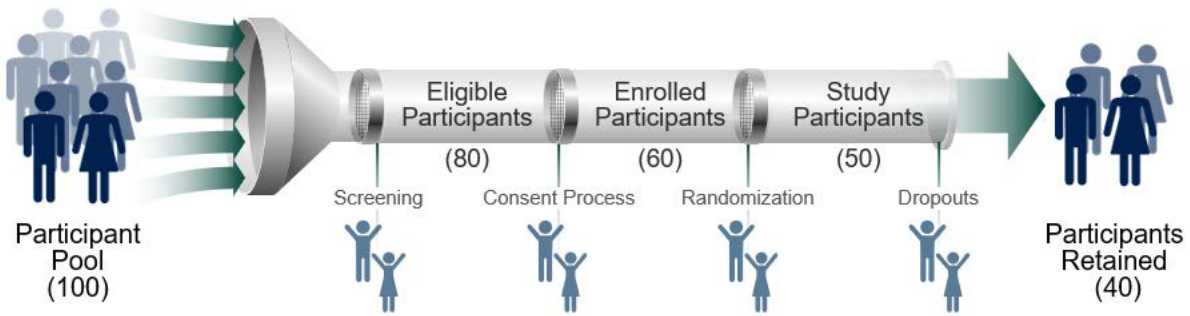
##### Enrollment

- Describing the project and obtaining informed consent
- Enrolling participants (i.e., assignment to the intervention or control group)

##### Retention

- Ensuring that participants attend scheduled visits
- Ensuring that participants’ data are gathered throughout the project
- Putting steps in place to prevent dropout

**Figure 1. Recruitment Pipeline**



## Recruitment and Enrollment

### Common Challenges

**Estimating participant pool:** Optimistic recruitment, enrollment, and retention projections are common in research studies. Data used to estimate the pool of eligible participants may be inaccurate and can lead to poor planning and miscalculations about the level of effort required to attain a sufficient sample. Further, project teams often fail to consider the burden and motivation for participants and other project stakeholders to engage in their program. These factors generally result in a smaller pool of eligible participants than was originally anticipated.

**Developing a recruitment and enrollment plan:** Predicting what strategies will be most effective in recruiting workers is challenging, but the lack of a clear recruitment and enrollment plan makes it more difficult to: 1) ensure consistent implementation of your project protocol, 2) anticipate potential challenges, 3) optimize your use of time and resources, and 4) make midcourse corrections when things don't go as intended.

**Understanding the target population:** Injured or ill workers will choose to participate or not participate in your project for a variety of reasons. Therefore, it is important to understand what some of these reasons are, and to plan for them if possible. Having a solid understanding of your population will allow you to anticipate participant needs and integrate them into your recruitment plan. This information will also help to inform your marketing approach.

### Box 2. Participant Profile: Questions to Consider

- What would motivate an injured or ill worker to participate in your project?
- What concerns might this population have about participating in your project?
- What are the barriers to participation (e.g., physical, psychosocial)?
- Where does this population get their information?
- What community organizations serve the population? How might you connect or partner with them to assist your recruitment or enrollment efforts and support their work?
- What cultural, linguistic, or contextual factors need to be considered in your recruitment, enrollment, and retention efforts?

**Addressing stakeholder concerns:** There are many reasons why a participant might choose not to participate in your RETAIN project. While some of these reasons may be out of your control, others can easily be addressed if they are identified early on. For example, some participants might be concerned about how involvement in the project might affect care from their primary physician, or their relationship with their employer. Others might have misconceptions about, or a general mistrust of, research studies. Regardless of the reason, failure to address these concerns may result in the loss of participants. It is also important to address the concerns of the individuals who will serve as the first point of contact for RETAIN participants. In some cases this may be the health care provider; in other instances this will be the Return to Work (RTW) coordinator or someone from the RETAIN project team. In order to effectively engage with potential participants, these individuals need to be knowledgeable about the RETAIN project and comfortable communicating with potential participants.

**Setting appropriate inclusion and exclusion criteria:** Defining the study population for Phase 1 should not be a static process. If recruitment is not going as planned, you should consider whether the criteria for participating in the study are too restrictive, as this will narrow your pool of eligible participants. Any changes to your program's eligibility criteria should be discussed with your Federal Project Officer (FPO), program Technical Assistance (TA) liaison, or evaluation liaison.

**Developing a comprehensive marketing strategy:** Marketing plays an important role in recruiting participants. In order to generate interest in your project, the message about RETAIN must both reach the right audiences and convey the right message. A limited marketing strategy means that the project could be missing out on a potential pool of participants.

**Simplifying study protocols:** Referral partners are key to the success of your RETAIN projects. However, if the referral and study protocols are burdensome or difficult to understand, it is likely that these stakeholders will not prioritize RETAIN. For example, health care providers may be less inclined to refer a patient to RETAIN if the referral process requires a significant amount of additional time and effort and is not easily integrated into their existing processes. Similarly, potential participants who find the protocol confusing or too time consuming may also opt out.

Table 1 presents strategies to address the aforementioned challenges.

**Table 1. Common Recruitment and Enrollment Challenges and Strategies to Address Them**

Recruitment Challenge	Recruitment Strategies
<b>Estimating participant pool</b>	<ul style="list-style-type: none"> <li>• If available, use data from previous studies that have worked with your target population to inform recruitment estimates</li> <li>• Speak to other experts who have used recruitment methods similar to those planned for your project</li> <li>• Engage stakeholders to help obtain more accurate estimates</li> </ul>
<b>Developing a detailed recruitment and enrollment plan</b>	<p>The recruitment and enrollment plan should include:</p> <ul style="list-style-type: none"> <li>• An estimate of the number of participants that you can enroll during the desired time period</li> <li>• Referral sources and process (e.g., Where will the participants come from? How will participants be identified?)</li> <li>• Estimated cost of recruitment, enrollment, and retention efforts</li> <li>• A timeline with key benchmarks</li> <li>• Clearly established roles and responsibilities (e.g., Who will develop marketing materials? Who will conduct informed consent?)</li> <li>• Protocols for engaging with and following up with participants</li> <li>• A description of incentives</li> <li>• A monitoring plan (e.g., What worked and what did not work? Why? To what extent were your efforts limited by budget constraints? Which referral sources or outreach efforts yielded the most results? How will you gather feedback from key stakeholders?)<sup>1</sup></li> <li>• A contingency plan for possible staff turnover or loss of health care providers</li> </ul> <p>The plan should be flexible enough to allow the project team to adapt as new information is obtained and lessons are learned, and should be revised as needed.</p>
<b>Understanding the target population</b>	<ul style="list-style-type: none"> <li>• Develop a participant profile (see Box 2)</li> <li>• Conduct focus groups with injured workers</li> <li>• Conduct focus groups with stakeholders who work with the target population (e.g., health care providers, employers, workers' compensation coordinators, vocational rehabilitation professionals)</li> <li>• Gather information to understand what motivates participants to enroll in your RETAIN project</li> <li>• Determine where injured or ill workers seek treatment and information</li> <li>• Segment your audience by factors such as age, geographic region, and illness or injury type</li> </ul>

<sup>1</sup> RETAIN TA has developed a Recruitment-to-Enrollment Dashboard tool to help monitor the effectiveness of your recruitment efforts and support your ongoing CQI efforts. This tool can be found at the RETAIN Online Community (the ROC).

Recruitment Challenge	Recruitment Strategies
<p><b>Addressing stakeholder concerns</b></p>	<ul style="list-style-type: none"> <li>• Gather data on why potential participants do not enroll in your project</li> <li>• Develop a script that addresses common misconceptions about the RETAIN project</li> <li>• Provide ample opportunity for potential participants to ask questions prior to enrollment</li> <li>• Develop a FAQ or script that health care providers or employers can provide to potential participants</li> <li>• Put a mechanism in place for ongoing communication with referral partners to identify and address their concerns about recruitment</li> <li>• Seek support from relevant community stakeholders to help generate interest in and excitement for the project</li> <li>• Be responsive and timely when following up with participants Minimizing the time between the referral and the initial contact with RETAIN staff will increase the likelihood of enrollment</li> <li>• Ensure that your project budget accounts for the resources needed to address participant concerns (e.g., transportation needs)</li> </ul>
<p><b>Setting appropriate inclusion/exclusion criteria</b></p>	<ul style="list-style-type: none"> <li>• Increase the referral pipeline by engaging new health care providers or relevant stakeholder groups</li> <li>• Expand your study’s geographic area (e.g., include neighboring cities or towns)</li> <li>• Expand inclusion criteria (e.g., include both work-related and non-work-related injuries)</li> <li>• Remove industry restrictions</li> </ul>
<p><b>Developing a comprehensive marketing strategy</b></p>	<ul style="list-style-type: none"> <li>• Identify and leverage multiple avenues for reaching participants, including: <ul style="list-style-type: none"> <li>– Reaching out to personal contacts within the community</li> <li>– Advertising (e.g., mail, television, radio, or newspaper; health care provider websites; hospital or insurance newsletters)</li> <li>– Community organizations (e.g., advocacy groups, vocational rehabilitation centers)</li> <li>– In-person presentations (e.g., health fairs, local conferences)</li> </ul> </li> <li>• Be creative, and consider all options for reaching out to potential participants and stakeholders who could serve as referral sources</li> <li>• Ensure that the message is clear, concise, accessible to multiple audiences (e.g., account for literacy levels), describes the benefits to the participant, and addresses key questions that a participant might have</li> </ul>

Recruitment Challenge	Recruitment Strategies
<b>Simplifying study protocols</b>	<ul style="list-style-type: none"> <li>• Follow up with stakeholders who are responsible for making referrals to determine whether there are aspects of the protocol that are confusing or difficult to implement</li> <li>• Follow up with participants to determine whether certain aspects of the protocol are confusing, concerning, or inconvenient</li> <li>• Revise protocol to address stakeholder concerns</li> </ul>

## Retention

Once participants enroll in your project, retaining them through the end will help to maximize the learning about your RETAIN intervention. Study participants often drop out unexpectedly before the study is completed, leaving a gap in the targeted sample size (see Box 3). Losing participants will lessen your project’s ability to determine the impact on Return to Work/Stay at Work outcomes. Although some dropout is unavoidable, there are a number of strategies that can enhance participants’ experience with RETAIN, help to alleviate their concerns, and minimize dropout. These include:

- Developing a retention plan
- Ensuring that your initial contact with a participant is pleasant and helpful
- Maintaining ongoing communication with participants, stakeholders, and study partners
- Identifying barriers and ways to address them
- Identifying competing priorities

Box 4 describes these strategies in more detail.

### Box 3. Common Reasons for Participant Dropout

- Loss of interest in the study
- Scheduling conflicts
- Transportation challenges
- Lack of connection/communication with the study team
- Loss of contact with the participant
- Improvement or lack of improvement in illness or injury



#### Box 4. Retention Strategies

- **Develop a retention plan:** Having a plan in place to support retention will help you address issues that arise. This plan should include data collection (e.g., Who does not enroll after recruitment? What reasons are participants giving for leaving the study? When are participants dropping out of the study?). It is also recommended that the project have a system in place to update participant contact information, and to document efforts to reach out to participants that includes the results of each contact. There should also be at least one team member who is responsible for following up with participants.
- **Retention begins with initial contact:** During initial contact, it is important to build rapport. This can be done by communicating information about the project in simple language, discussing expectations and the importance of completing required activities, and by encouraging the participant to ask questions and share concerns about the project. Although participants are free to leave the project at any time, their right to withdraw without penalty should be fully explained so that they avoid feeling “trapped” if they consent to participate.
- **Ongoing communication with study partners and key stakeholders.** Health care providers and other stakeholders who sign up to make referrals are critical to the success of your RETAIN project. Therefore, it is important to identify opportunities to foster a sense of collaboration and keep them informed about how the project is progressing. This could be done by developing a quarterly newsletter that provides information about the project (e.g., number of participants recruited, number of participants returning to work, study highlights or milestones).
- **Ongoing communication with participants:** Ongoing communication helps to establish trust between participants and the project team. Thus, it is important to identify a primary contact person who they can reach out to if any questions or concerns emerge. It is generally easier to maintain contact with those in the intervention group who are receiving RETAIN services (e.g., through phone calls, emails, and face-to-face check-ins with the RTW coordinator). Keeping the control group engaged for the duration of your project may be more challenging, given that contact with this group is less frequent. Therefore, it is necessary to reach out to them at regular intervals throughout the study. Strategies for connecting with control group participants include sending reminders about upcoming data collection activities, or periodically sharing relevant resources or educational materials unrelated to RETAIN. In addition, for all participants, contact information should be verified (and updated as needed) during each visit. If possible, get two contact numbers from the participant.
- **Identify potential barriers and ways to address them:** Participants may experience challenges that can be addressed by your team. For example, if transportation is an issue, consider allocating funds to support this need. Or if the participant has a hard time remembering appointments, it may be helpful to seek his/her permission to get a family member involved. In some cases, it will be necessary to eliminate procedures that are creating an added burden for participants (e.g., simplify the informed consent process). Using a CQI process will help you to identify and monitor these barriers, so that your team can determine the best way to eliminate them.
- **Identify competing priorities:** An injured or ill worker might have a number of competing priorities that could cause them to drop out of the study; it is important to identify what these are and determine ways to integrate services or processes to reduce participant burden. For example, RETAIN visits could be scheduled to coincide with routine doctor appointments.

## Summary

Recruiting, enrolling, and retaining participants for your RETAIN project will require ongoing planning and monitoring. The most well-designed project will fail if effective strategies are not in place. RETAIN grantees have the opportunity to use their demonstration projects to pilot and refine their recruitment, enrollment, and retention plans and ensure that they optimize their resources and efforts during Phase 1 and in preparation for Phase 2.

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