
Participant Retention

Retention Goals

- Participants are disappointed when the study ends
- Greater than 85% of those enrolled complete the study
 - Very few participants are lost to follow-up

Retention Goals

Prescreen \approx

Screening visit \approx
7,000-9,000

Baseline visit \approx
2,500

Randomize =
2,382

Complete study =
2,025



Definitions

- **Off Study**: participant formally withdrew consent either verbally or in writing.
- **Inactive**: participant has missed 2 consecutive visits but has not gone “off study.” Attempts at contact and follow-up continue.
- ~~**Lost to Follow-up**~~: this term will not be used *during* the study. We will continue attempts to follow-up with all participants until study close-out.

Retention Strategies

- Retention begins with informed consent
 - Participant needs to understand what level of commitment is necessary.
 - Consent form needs to be clear, and be a future resource for the participant.
 - *Researcher: Participant* relationship begins with the consent process

Retention Red Flags

- 🚩 Expectation for specific study treatment
- 🚩 Concerns about randomization
- 🚩 Concerns about medication side effects
- 🚩 Concerns about study task demands
- 🚩 No-show or rescheduled assessment appointments
- 🚩 Unexpected social, occupational or health event

Identify and address early

Retention Strategies | Engagement of PCP

- Letter to PCP at enrollment that includes the provider informational pamphlet
 - Templates in MOP
- Letter to PCP after each 6 month follow-up visit
 - Templates in MOP
- Provide referring providers with general study updates.
 - CC will develop newsletters, for customization at site

Retention Strategies | Participant Reminders

- Participant Pamphlet: at baseline and every follow-up visit (template in MOP)
- Reminder letters: sent 1-2 weeks before visits
- Reminder calls and *text* messages (participant preference): a few days before each visit
- Tokens: refrigerator magnets with contact info.

Retention Strategies | Participant Engagement

- Participants need to know they are participating in something big and important
- Participant newsletter: CC will develop for site customization. To include national study and local study news.
- Support and Education Program group meetings
 - Topics relevant to the population
 - Provide study appreciation tokens (lunch bags, mugs)

Retention Strategies | Study Environment

- Make coming for visits easy for the participant
 - Welcoming
 - Accommodating
- Continuity of care: participants should have a primary person (RC, RN, RA) that they see at each visit
- Participant appreciate the attention of investigators
- Research volunteers are special: make them feel it
 - Birthday cards
 - Make note of significant events in their lives and ask about them at the next visit.

Retention Strategies | Contact Information

- Collect detailed contact information at screening:
 - Home, mobile, work, phone numbers
 - Can I leave voicemail messages?
 - Text?
 - E-mail (personal, work)
 - Home address, 2nd home address
 - Emergency contact information
 - Who should I call if I can't reach you using your contact information? (may not be emergency contact)
 - Name, phone, address
 - What is the best way to contact you? What time?

Retention Strategies

If a participant becomes inactive we will continue to send a letter and call before each follow-up visit

- Internet is a great resource
- Participants reappear!
- Participant may be willing to provide us with information even if they do not come for a visit

Recruitment and Retention Subcommittee Monitoring

- The RRS will monitor retention at each site
- RRS reports will show metrics on the:
 - # of overdue participant visits
 - Inactive participants (missed 2 or more consecutive visits)
- Under-performing sites will be notified and receive intensive monitoring and review of practices.