

The Importance of Retention – You've worked hard to get the patients so don't lose them!

Study Mission – can be communicated via video, DVD, newsletter etc

- Why? Who? How? When?
- Important to equip the study participant with the key facts so that it is easy for them to explain – they become ambassadors for the study and 'word of mouth' is powerful
- Remember that people tell their friends – sometimes friends can be cautious or negative because they may have heard something controversial; therefore important to convey the key facts and potential benefits
- Essential to reinforce patient's commitment to the study's purpose
- People are interested and become enrolled in a study to improve their own health and knowledge as well as contribute towards medical development

Pre-Initial Screening Visit

- Site directions (including map and address)
- Parking or public transport information (schedules)
- Expectations of initial site visit
- Information about the disease/disorder
- Site contact information (perhaps not direct phone number)

Welcome Pack

- Specific information about the study
- Frequently Asked Questions and Answers
- Refrigerator Magnet
- Diary
- Folder with simple key information (not too much, can always add to it, otherwise too daunting)
- A multimedia approach can help participants to fully understand the study and requirements (this of course depends on budget and resources available)
- Standard letter or fact sheet for general practitioner and/ or any other health professionals
- Letter from the PI sent to the subject after initial visit

Retention Tools

- "Brand" the study – so it is catchy and easy to remember. People like to tell their friends about it. (Information must be concise and easy to understand and explain.)
- Newsletter – sense of belonging to a bigger project, especially if a national or global study
- Set up a feedback mechanism which dovetails into the newsletter – e.g. highlights of anecdotes at the site; provide an opportunity for subject feedback and letters and/or feedback from study coordinators – bring it to life and maintain the enthusiasm and interest? Provide progress reports
- Appointment Card
- Visit reminder postcard
- Telephone reminder
- Missed appointment card
- Telephone call for missed appointment and to reschedule
- Calendar with scheduled site visit stickers
- Happy birthday card
- Christmas/festive season card
- Additional media material audiotapes, videos or press coverage (makes it relevant and significantly increases the participant's sense of belonging and commitment)
- Phone as opposed to visit (or an option/alternative)

Completion Pack

- Certificate of participation
- Resource list (including support groups, associations or websites)
- Thank you letter from the PI and study team
- Option to nominate self for future studies

Thank You Gifts (nominal value)

- Bags, satchels, or pens or other branding/reminder items (eg fridge photo magnet frame)
- Calendar
- Diary
- Books/magazines – anything that is educational and of perceived value

And “free food”!!

- Yummy lunch, or morning or afternoon tea can work wonders!
- Good for site personnel too!

There are a multitude of reasons why people drop out of a trial. Participant commitment is generally strong when first recruited into the study but can rapidly wane. Many of us tend to focus on attracting volunteers into a study, but then forget how important it is to ensure they remain motivated and committed, irrespective of the length of the study.

Recruitment, retention and compliance efforts need the human touch hence the importance of maintaining continuity in communication and contact on a regular basis, either face to face or via the telephone. It is essential that site personnel are enthusiastic and motivated about the study. Their role is not only critical in recruiting and randomising eligible subjects, but also it is imperative that site personnel help create a sense of purpose, and belonging to a worthwhile cause.

Participants need to understand what the study is about and why they are involved. They are more likely to remain committed to a study if they can identify and describe it.

Furthermore there are a number of fundamental issues that must be addressed prior to randomisation. Interested people are often keen to participate in a study to receive the appropriate medical treatment and are disappointed if (when randomised) they may receive placebo. It is important to communicate the study design and objectives clearly so that all participants understand and recognise the health-oriented benefit that all participants will receive irrespective of whether the treatment is active or placebo. It is preferable to mention this before the initial visit so that the potential study participant is aware.

Whilst subjects cannot be forced to complete their involvement in a study it is important to ensure that subjects understand their role and are committed to the success and purpose of the study. Often subjects indicate commitment during the initial stages, but it is imperative that they are dedicated for the study duration, particularly if it is a longer study, for example over 3 years.

Usually a subject receives a lot of attention when he/she is initially enrolled into the study, but as the site visits become less frequent, interest and commitment can quickly disappear unless there are means of regular communication established, even if over the telephone or via email.

Study participants are usually thirsty for any information pertaining to the disease/condition and/or progress of the actual study, both on a national and international level. A regular newsletter can provide updated information to subjects. It can also be used as a vehicle for subjects to share personal stories with other subjects. Alternatively this can be done via an online chat session or in conjunction with a newsletter.

Essentially subjects need to be kept informed and motivated.

The Power of Communication

Attrition can often be attributed to too many site visits and inconvenience. Although face- to- face communication is ideal, it is not always feasible – both from a travelling viewpoint and utilisation or availability of resources at the site. Thus attrition can be reduced or avoided if patient follow up is done via the telephone so that phone calls can manage some of the issues between site visits. This encourages compliance and ensures that the patient remains motivated and committed to the study without needing to take the necessary time required to visit the actual site.

The power of conversation should never be underestimated. Regular contact via the telephone can be invaluable.

If the site personnel are unable to call the trial participants on a regular basis, a call centre can be utilised centrally. All studies have different requirements and a call centre (and the accompanying script used, either for outbound or inbound calls) can be tailored to meet the specific needs of the study. For example, if regular diary entries are required, the call operators can be used to call and remind subjects to complete their diaries. These outbound calls could be done weekly. Alternatively study subjects may be required to call a central 1800 number to update their progress, have specific details recorded and forwarded to the respective sites.

Importantly the phone calls provide an opportunity for the subject to speak with someone about any concerns, anxieties or questions in general. All of these can usually be addressed by a pre-prepared FAQs, however any ‘new’ questions or issues can always be directed towards the site personnel and addressed within a 24-hour period.

In conclusion there are a multitude of tools that can be used to enhance and maintain motivation and communication from the initial early stages, then throughout the study and finally, completion.

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