

Registry Style Guide

Purpose:

According to the National Science Foundation, only about 30% of Americans say they have a clear understanding of what it means when they hear or read the term “scientific study.”

This style guide was created with the intent of helping you reach more potential volunteers, help them clearly understand your study and subsequently express interest with confidence. This portal is only as effective as the study postings it shares- it is worth the effort to get it right.

These guidelines are based on a decade of registry user data as well as best practice established in collaboration with academic researchers, regulatory and communications professionals, Institutional Review Boards, patients and community members.

Tips & Best Practice

Crafting Your Headline

- This is what portal users will see first; it will determine if they click or keep scrolling.
- Use action verbs to describe what the study is trying to accomplish: (ie. track, predict, help, create)
- Use strong, simple keywords for your study. Avoid jargon.
 - Keywords will often include the health concern, problem you’re trying to address, or solution.
- Give a high-level overview of the problem you are trying to address
- Use a question as your headline
- Headline character limit: 200

Optimizing Your Study Description

Keep It Short

- The posting is a short, high-level overview of what you’re doing and a welcoming front door for people to interact and match.
- Remember, this is not a consent form nor is it a summary of your study methods and specific aims.
- Description character limit: 300

Keep It Simple

- We recommend postings a Flesch-Kincaid reading grade level of 9 or lower.
 - Check your Flesch-Kincaid reading level [here](#).
- Break long sentences into two or three simple sentences.
- When possible, avoid overly formal writing. Imagine you are speaking with a friend or family member.

- We have to mention this one more time... the portal descriptions and additional information fields are not consent forms. The details you provide should not replace the consent process' description of data protections, study design, receipt of test results, etc.

Keep It Honest & Personal

- Always be accurate and transparent in your description
- Remember your audience- you are writing for the public, not a review panel.
- Avoid treating potential participants as “subjects,” instead use more inclusive terms like participants or volunteers- or engage the reader directly and say “you.”
- Put yourself in the readers' shoes and explain what the experience will be like, especially if it involves shots, biopsies, painful procedures, etc.
 - At times it can help to explain why unpleasant parts of the study are important.
- Be clear with time commitments
- Don't overpromise, but do connect the dots to the end goal of your work using clear, conditional words (i.e., might, could, potential, maybe, etc.)
- Encourage questions and give answers by using the simple, mobile portal interface.
 - Each posting includes contact information to help facilitate Q&A between interested participants and study teams.

Don't Forget About the WHY

- People want to understand what greater good they're contributing to by participating in your study. You can achieve this by addressing the following:
 - What are you exploring?
 - Why does this study matter?
 - What good could come from this study?
 - Explain the current state of the condition and how your study might improve it. Include a statistic if possible.
- Include a sentence about the end goal of the research.

Compensation

- If your study offers compensation please use the following statement: “You may be compensated for your time. The research team can provide you with further details.”

A Few Words on Acronyms and Jargon

- Complex jargon and abbreviations don't mean anything to your audience: the general public.
- Avoid using study names/abbreviations in your headline and primary study descriptions- it will eat up your character limit and it does not help participants understand the study itself.
 - Don't say: TALC (Training Aid to Learn Communication) Study
 - Do say: A study that will help those with speech delays
- When possible avoid the full, complex names of medicines and medical conditions.
 - Instead, aid the public in understanding complex medical language by describing the condition or procedure first
 - For example: An X-ray to see your blood vessels, called an angiogram,...

A growing list of synonyms to help keep within the required approachable reading level can be found [here](#).