

Attitudes, Beliefs, and Norms of Adult Research Participants

Lyons, J., D.Ed.

The Pennsylvania State University



Background

Millions of adults volunteer as research participants annually at research institutions across the nation. This poster describes research that was conducted to explore the attitudes, beliefs, and norms of rurally situated, adult research participants at a large research university. Understanding these attitudes, beliefs, and norms may be useful for investigators, human research protections' programs, and others. This research also provides a basis for further research related to the planning and development of human research protections outreach activities for the general public. The original focus group study was determined to be exempt research. This poster represents a secondary analysis of focus group data that was collected in 2010-2011.

Demographics (N=24)

Experience as research participant in 5 years prior:

33% volunteered for >10 studies
67% volunteered for 1-10 studies

Type of research:

79% participated in both social science and biomedical research studies

Age ranges

46% 40-55 y/o
29% ≥65 y/o

Gender

79% female

Ethnicity

96% white

Occupation

50% professionals
25% retired
17% office/clerical

8% other (students and no designation given)

Study Design

- **Descriptive qualitative inquiry**
- **5 focus groups were conducted, 3-6 participants per group**
- **Problem-driven content analysis** (Krippendorff, 2004, *Content analysis*.)
- **Guided by the Theory of Planned Behavior** (Ajzen, 2004, *Attitudes, personality, and behavior*.)

Common Attitudes, Beliefs, and Norm Expressed by Research Participants

Positive Attitudes

- Helping others
- Personal benefits, such as learning, receiving test results, socialization and psychological benefits

Negative Attitudes

- Narrow inclusion criteria (especially older age)
- PI activities that waste participants' time: disorganization, not returning calls/emails

Beliefs

Principal Investigators are obligated to:

- Disseminate information about the overall study results directly to participants in a timely manner
- Always provide consent forms in advance

Social Norm – Motivating Factor

- Feel responsibility to help others and make contributions outside of themselves—to other people, the university, its research mission, which in turn contributes to the community

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Addresses AAHRPP Standards I-5 (quality improvement activities) and Standard I-4 (research participant understanding)

Representative Quotes

“I think that getting the consent form as you are sitting down to start something is not enough advance in time because many people do not read things that they sign.”

“I've participated in numerous studies. I guess I was a little disappointed because I never learned the results of the study. I never learn much of the studies even on a collective, non-identifiable basis.”

“They told me they publish. They don't let you know. In other words, they don't really know the results.”

“It's more than following rules, but actually having a super ethical, super moral perspective on treating everybody the best way possible as opposed to just following the guidelines.”

“Learning all these different things and how they do things I think enriches your life. “

“A lot of times it takes a significant amount of time to get in touch with these people. You have to call, then you leave your name, and they call you back, and then you miss the call, and then you've got to call them again. It's just a huge hassle.”

“I think a study needs to have some value . . . you don't do research just for something to do. Should have some end result value for somebody.”