Attitudes, Beliefs, and Norms of Adult Research Participants as a Basis for Outreach Education Programming

“Community Perceptions of Penn State Research”

Institutional Review Board #33210

**Summary of Research Results for Participants and Researchers**

Millions of adults volunteer as research participants annually at research institutions across the nation. This research explored the attitudes, beliefs, and norms of rurally situated, adult research participants at a large research university. This systematic exploration of research participant experiences gathered information to inform the initial development of research protections outreach programming at the institution. Empirical data is lacking regarding the use of adult education principles in the design and development of research protections-oriented outreach programming, particularly in the area of non-clinical trial research that is conducted in non-urban areas. This exploration consisted of an analysis of focus group data collected from experienced research participants at the same research university. The Penn State Survey Research Center conducted the focus groups between 2010 and 2011. The analysis of five focus group transcripts used a content analysis approach, guided by the Theory of Planned Behavior (TPB). Categories contained within TPB were used a priori to examine the data for beliefs, attitudes, and norms related to the known behavior of research participation.

From the transcripts of the focus groups, participants discussed topics that were distilled into four themes that were identified in the analysis:

Motivation to Participate

Participants’ Personal Investment

Expectations and Rights as Research Participants

Expectations by Participants of the Institution and Researcher.

**Attitudes, beliefs, and norms varied across the participants**. Results showed positive and negative attitudes towards a number of participation topics. Despite these variations, however, all focus group participants had volunteered for between five to ten studies within five years prior to participating in these focus groups. Overall, commitment to helping others and making a contribution to research, the university, the community, and others was a strong motivating factor for participation. Personal benefits gained from participation were also strong factors influencing the intention to participate.

**Implications for researchers were derived from the data. S**haring overall study results with participants was one of the strongest points of discussion across all focus group participants. Researchers should be encouraged to develop mechanisms to routinely provide summary results of their studies to participants, as appropriate. Researchers should also be aware that across the focus groups, participants expressed the expectation that researchers have an obligation to provide overall study results within a reasonable period of time and if the results themselves can’t be provided, then a summary of results or a summary of partial results, if it is a long-term study, could be provided. Focus group participants also noted that they themselves should ask for overall study results. For researchers who provide overall study results on a regular basis, these findings reinforce the importance of the practice.

Many thanks to all focus group participants!

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