Research with Incarcerated Youth: Helping Vulnerable Research Subjects Understand Assent
Sharon Zack; Tim Smith; Leanne Heaton
Westat

Submission Type: Scientific
Topic Area: Informed Consent
Poster Number: 39

Problem Statement: While human subjects research must include informed consent or a request to waive or modify the consent process, there is little evidence on how often respondents understand the elements of consent and conditions for participation. This is a particularly important topic for research of doubly vulnerable populations, such as incarcerated minors. The National Survey of Youth in Custody utilized an anonymous survey to collect data from approximately 11,000 youth about sexual contacts in juvenile facilities. This study stemmed from the 2003 Prison Rape Elimination Act, which called for a "comprehensive statistical review and analysis of the incidence and effects of prison rape" including assault experienced by youth in custody. This poster describes a procedure that both measured and fostered youth comprehension of the assent process in the midst of a sensitive topic, as well as complex procedures to minimize subjects’ risks.

Methods: Only youth who self-consent, or for whom a parent, state, or guardian provided permission, were asked to participate. During the assent process, interviewers read text to youth describing the purpose and procedures, voluntary nature of participation, extent and limitations of confidentiality, and other key features of study design. Interviewers assessed comprehension based on the youth’s responses to six questions (e.g., voluntary nature of participation and confidentiality). If youth did not answer a question correctly, it was repeated. If youth still failed to demonstrate understanding, interviewers paraphrased the text to explain the concept differently. Youth still failing to respond correctly were not asked to participate.

Results: There were differences by sex, race, and age of youth. A higher proportion of females understood the assent concepts compared to males. Significantly higher proportions of males than females needed repetition and paraphrasing. White youth were more likely than black or Hispanic youth to display understanding. Younger youth required more assistance than older youth. Youth 14 and under demonstrated the highest likelihood for needing both repetition and paraphrasing. Youth had significantly more problems with concepts of the voluntary nature of the study and confidentiality. Additional analysis will be presented.

Conclusions: Findings indicated that simply reading an assent script to youth may not be sufficient in ensuring comprehension of key conditions related to research participation.

Next Steps: This study has important implications for assent administration with youth. Further research that incorporates a method of assessing comprehension and providing assistance to extremely vulnerable populations is warranted.