Research with Incarcerated Youth
Helping Vulnerable Research Subjects Understand Assent

Background
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 concepts behind consent. This is an especially important topic for research of doubly vulnerable populations, such as incarcerated minors. The National Survey of Youth in Custody (NSYC) 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 that 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 fos tiley youth comprehension of the assent process in the midst of a sensitive topic, as well as complex procedures to minimize subjects’ risks.

Ethical and Regulatory Considerations
— Many study designs that do not fit into 45 CFR 46 Subparts B, C, or D (youth, prisoners, victims of sexual assault, etc.).
— Impact of vulnerable population’s characteristics on consent process
— Youth may lack capacity to consent
— Prisoners may feel powerless and vulnerable to undue influence
— Under-educated may not understand consent комфорт language
— IRBs and researchers are obligated to ensure that the consent process uses terms that the vulnerable population can understand.

Research Questions
1. To what extent did youth understand the key elements of assent? 2. What type or level of help was effective in fostering understanding? 3. How does comprehension vary by youth characteristics?

Complex Research Challenges
1. Collecting data from incarcerated youth about sexual assault or drug use.
2. Obtaining true informed assent in spite of incarceration.
3. Communicating the concept of mandatory reporting requirements to youth.
4. Avoiding exposure of youth to increased risk.
   a. Discomfort answering questions about sexual assault/drug use.
   b. Submission by staff or others if youth discloses a sexual assault incident while incarcerated.
   
5. Use of audio computer-assisted self-interviewing (ACASI), which allowed youth to answer questions privately, acknowledging potential sensitive experiences without the risk of disclosure.

6. Programmed random assignment of sets of questions asked among youth participants (sexual assault vs. drug and alcohol abuse).

7. Mandatory reporting requirements implemented only when youth made verbal statements suggesting sexual assault.

Researcher did not know which sets of questions were being asked or how the youth responded in the computer.

Parent Permission and Assent Process and Protocol

Procedure for Obtaining Assent
1. Parent, state, or guardian provided permission for youth to participate.
2. Researcher read the assent form as the youth followed along.
3. The researcher assessed comprehension based on the youth’s responses to six questions embedded in the assent script.
4. Once the researcher determined that the youth understood the consent information and agreed to participate, the youth began the ACASI survey.

Each question was read exactly how it was written.
9.4
Cannot rely solely on scripted text— at least for a complex study design.

By the time the consent information was rephrased, the vast majority of youth perceived the research information was rephrased, the vast majority of youth understood.

While youth were more likely than black, Hispanic, or mixed race youth to display understanding,

Conclusions
1. Simply reading an assent script to youth may not be sufficient in ensuring comprehension of key concepts related to research participation.

2. Cannot rely solely on scripted text—at least for a complex study design.

3. By the time the consent information was rephrased, the vast majority of youth understood the process.

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.