BACKGROUND

- Adolescents tend to be excluded from biomedical research despite their significant risk of HIV infection. This is due in part to their status as a vulnerable population and to confusion around who should give consent for their participation in research.
- To provide fundamental evidence to address this bioethical challenge, it is crucial to assess the cognitive capacity of adolescents and parents/guardians to provide informed consent, assent, and permission.

DESCRIPTION OF ORGANIZATION

Columbia University has been collaborating with Rakai Health Science Program in Uganda. Structural and Social Transitions among Adolescents and young adults in Rakai (SSTAR) is one of our projects to examine social determinants of transitions from adolescence to adulthood, and this bioethics research is a supplemental study of SSTAR.

METHODS

1) Scoring of Interviews + Guideline Development:
- Conducted interviews based on the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR).
- Two scorers reached an inter-rater reliability of 0.888 (95% Confidence Interval: 0.663-0.959).

RESULTS

Example of an adolescent’s decision-making process from 3. Expression of voluntary participation
Excerpt Interpretation
Interviewer: Did you want to participate in the RCCS?
Participant: Yes.
I: Why did you want to participate?
P: I wanted to participate because the research included HIV testing since I have never been tested, I wanted to test.
I: Whose decision was it for you to participate in the RCCS?
P: It was not my decision, it was a decision for my parent.
I: If your parent wanted you to participate but you did not, would you have to participate?
P: Yes because I cannot despise my mother meaning that I would still participate

DIFFICULT TOPICS: ABSTRACT IDEAS AND WHAT HAPPENS IF THEY DON’T PARTICIPATE

2) Qualitative Analysis:
- Conducted preliminary qualitative analysis of the 78 interviews

MAIN FINDINGS

Participants understood direct individual benefits well but abstract ideas about risks and benefits and what happens if they don’t participate were more difficult to describe. Thus far, we found no noticeable differences on these features between adolescents and adults.

DISCUSSION

- The preliminary results suggest that even the youngest adolescents have the capacity to provide informed consent as well as adults.
- To enhance ethical inclusion of adolescents into research, it is crucial to further investigate the cognitive capacity to provide consent of adolescents and parents/guardians considering the complexities of decision-making process among adolescents and adults we identified.

REFERENCES