The Bioethics of Adolescent Involvement in HIV Research

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Research Question: To understand adolescent (age 10-19) and parental attitudes and perspectives around adolescent involvement in research and how this might impact their under-representativeness in research, especially in low and middles income countries like Uganda.

**BACKGROUND**

Due to increasing independence and cognitive capacity during adolescence, researchers acknowledge the need for their involvement in decision-making but differ in their approaches to parent/guardian involvement: struggling to balance the ethical principles of respect for autonomy and protection.

The complexity of adolescent involvement has led this population being underrepresented in health research globally.

**DESCRIPTION OF ORGANIZATION**

Over the past six years, the Rakai Youth Project has used new qualitative data and existing quantitative and longitudinal data from the Rakai Community Cohort Study (RCCS) to successfully define a continuum of social and proximate determinants on transitions from adolescence to adulthood using innovative statistical and qualitative research methodologies.

Building on this work, Structural and Social Transitions among Adolescents and young adults in Rakai (SSTAR) investigates the influence of social structural determinants on transitions from adolescence to adulthood using innovative statistical and qualitative research methodologies.

**METHODS**

1) Scoping Review to explore the issues of adolescent inclusion and protection in research through:
   - Two large databases searches, PubMed and EMABSE (see Table 1).
   - Application of inclusion/exclusion criteria (see Figure 1), and
   - Identity and summarize common themes and recommendations.

2) Codebook Development:
   - Team review of eight interview transcripts to identify emerging themes,
   - Draft codebook (see summary in Table 2).
   - Codebook piloting using Dedoose software

Research involving adolescents should use a rights-based framework including extended, joint consent processes that reflect the complexities of parent-adolescent decision-making patterns that are observed in the field.

**DISCUSSION**

There is consensus on involving adolescents in research decision-making, but a need for more ethical and effective joint consent/assent processes adapted for different contexts and research topics. Interviews from the field reaffirmed this and show the complexity of parent-adolescent communication.

This calls for a rights-based approach to research, one that involves adolescents through youth representatives on IRBs and youth advocates on research teams.

**REFERENCES**