

# Toward a shared vision of adolescent health research in Uganda: An exploration of key stakeholder attitudes and experiences

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**RESEARCH QUESTION:** *How do researchers, community leaders, and research ethics committee members in Uganda view adolescent research participation, decision-making capacity, and the optimal balance between adolescent autonomy and protection in research?*

## BACKGROUND

Adolescents have long been underrepresented in health research due to ethical frameworks that have emphasized their vulnerability and need for protection. In recent years, there has been a shift towards recognizing the importance of greater adolescent research inclusion and decision-making participation in order to better understand and support their unique needs; however, research stakeholders continue to face challenges in balancing the competing ethical priorities to respect autonomy while providing adequate protection across the diverse range of adolescent age and experience. By exploring the perspectives of research stakeholders in Uganda, we hope to support future multisectoral efforts to improve adolescent health in a manner that is tailored to local priorities and grounded in a system of participatory ethics.

## DESCRIPTION OF ORGANIZATION

Building on the work of the Rakai Health Sciences Program, the Structural and Social Transitions among Adolescents and young adults in Rakai (SSTAR) project investigates the influence of social structural determinants on transitions from adolescence to adulthood in Rakai, Uganda. This supplementary bioethical analysis aims to support adolescent research efforts in Rakai through evidence generated from local perspectives of adolescents, parents, and research stakeholders.

## METHODS

- In-depth interviews:** Conducted 19 in-depth interviews with Ugandan researchers (n=9), community advisory board members (n=2), and research ethics committee members (n=8) to better understand key stakeholder views on adolescent research participation, decision-making capacity, and the optimal balance between autonomy and protection
- Qualitative coding:** Interviews were transcribed and coded in Dedoose using deductive & inductive approaches to situate local perspectives within the broader adolescent health literature
- Thematic analysis:** Creation of code co-occurrence matrices to identify key themes within and across stakeholder groups

## RESULTS

### I. VIEWS ON ADOLESCENT RESEARCH INCLUSION

a) There was consensus about the importance of including all adolescent age groups (10-19 years) in research, though younger adolescents and higher risk studies were noted to require additional safeguards to ensure voluntary participation and adequate comprehension of research purpose and risks.

“I think we need to include early adolescents because data is available showing that sexual activity is going on, children are getting pregnant at 12. If we start education earlier, they are better informed and can handle the challenges as they grow up sexually.”

“One big thing in health care, is ‘nothing for us without us.’ Adolescent research participation helps us learn about their challenges, and probably design better interventions for them. They feel important, that they contributed and were consulted, that whatever is being designed has come from what they thought was important.”

### II. VIEWS ON ADOLESCENT DECISION-MAKING CAPACITY

a) All participants emphasized the importance of voluntariness and participatory decision-making informed consent, through either adolescent assent or consent:

“I think even for the younger ones, we should endeavor to explain the research in the simplest means possible so that they do not feel coerced by the caregiver to just sign. So first, explaining to the primary participant, get them to agree, give them a chance to disagree. And then we get the caregiver.”

b) However, opinions varied regarding the appropriate level of autonomy adolescents should have in such decisions. Some participants believed that adolescents lacked the capacity to provide informed consent and that parental permission should be sought:

“I will not go for allowing adolescents to participate without parental consent, as long as the parents or guardians are still there. To me, all adolescents, they’re still children, but big children, that’s what I can say.”

c) Others viewed adolescent decision-making capacity more favorably and thought adolescents should play a more active role in decisions like providing informed consent:

“I support waivers of parental permission because we need to empower children to understand and make decisions about their own lives. If you want to empower them, just like you want to empower adults, let them be responsible to make decisions about their lives.”

“Adolescents are so up with the current issues worldwide, the issues on the social media—they are so, so far ahead of me. I remember one day I was talking about positive parenting with the younger boys and girls, and I was so shocked, one girl said “stop there, I will give the rest of the lecture.” And I have to admit, she knew a lot more than me. And I was talking about reproductive health, I was teaching them how a baby is made, and the girl was 14.”

## RESULTS (continued)

d) In addition to age, challenging life experiences were said to be important determinants of decision-making capacity, with high rates of early pregnancy, marriage, and HIV-associated orphanhood often contributing to earlier maturity than might be expected based on an adolescent’s age alone.

“The consenting process needs extra attention because the level of understanding varies from individual to individual, and the age factor may not be dependable. You might find that somebody 10 to 14 may make a wiser decision than somebody who is 19. So, age should not be the only factor that can determine the decision-making.”

e) This diverse range of adolescent decision-making capacity prompted many participants to discuss the need for research stakeholders to be able to make more individualized decisional capacity assessments; however, several participants felt they lacked expertise and authoritative guidance to make this more individualized approach a reality.

## CONCLUSIONS

*Diverse research stakeholders shared remarkably consistent views regarding the need to expand adolescent research inclusion and develop more nuanced informed consent guidelines that acknowledge adolescent evolving capacity while maintaining adequate protection.*

In light of the many shared perspectives, priorities, and challenges amongst adolescent research stakeholders in Uganda, the stage is set for researchers, ethics committee members, and community leaders to capitalize on this multisectoral momentum to propel adolescent health and research forward. All stakeholder groups expressed a need for operationalizing more individualized capacity assessments that account for the wide range of Ugandan adolescents’ unique experiences, knowledge, skills, and needs for autonomy and protection. would support Ugandan research leaders to achieve their common and compatible goals of promoting adolescent inclusion, supporting developing decision-making, and maintaining adequate protection in research.