

The Bioethics of Adolescent Involvement in HIV Research

Emily Hoppes, Mailman School of Public Health, Class of 2020

Mentors: Esther Spindler, MS; Neema Nakyanjo, MA; William Ddaaki, MSc

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 middle income countries like Uganda.

BACKGROUND

Due to increasing independence and cognitive capacity during adolescence,¹ 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.²

The complexity of adolescent involvement has led this population being underrepresented in health research globally.³

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 for HIV acquisition among youth ages.

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.

Acknowledgements: Thank you to my project advisors, Esther Spindler, Neema Nakyanjo, and William Ddaaki for their guidance and support throughout the project; to my fellow research assistants, Mahlet Maru and Victoria El-Hayek for their peer review, especially during the scoping review process; to the entire RHSP Social and Behavior Studies (SBS) team for collecting interview data and working collaboratively to create and pilot the codebook; and to the Program for Education in Global and Population Health for funding support.

Funding: This research was supported by NICHD grant (R01HD091003; SSTAR Project; PI: Santelli).

TABLES & FIGURES

Figure 1: Scoping Review Process

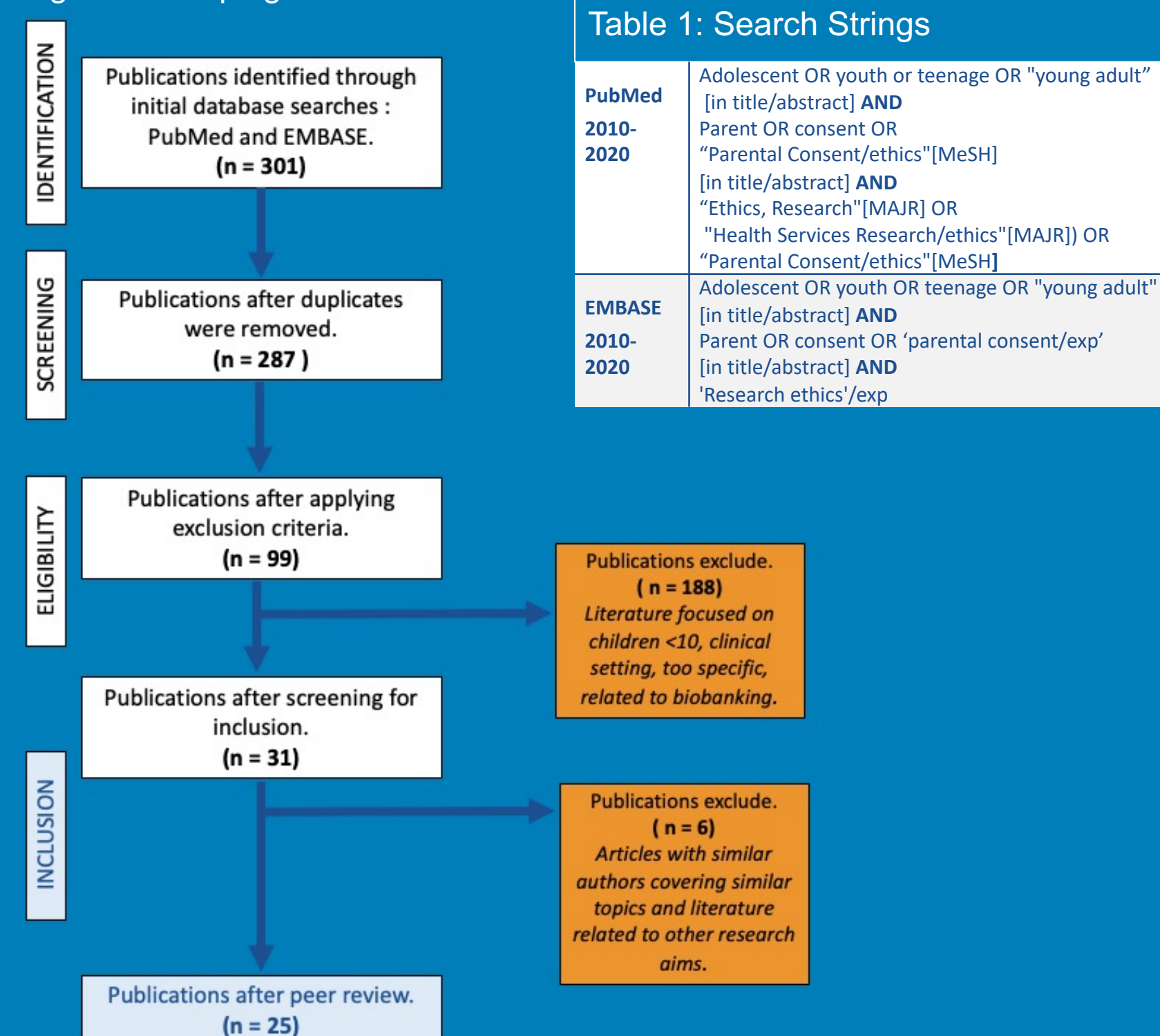


Table 1: Search Strings

Database	Search String
PubMed 2010-2020	Adolescent OR youth or teenage OR "young adult" [in title/abstract] AND Parent OR consent OR "Parental Consent/ethics"[MeSH] [in title/abstract] AND "Ethics, Research"[MAJR] OR "Health Services Research/ethics"[MAJR] OR "Parental Consent/ethics"[MeSH]
EMBASE 2010-2020	Adolescent OR youth OR teenage OR "young adult" [in title/abstract] AND Parent OR consent OR 'parental consent/exp' [in title/abstract] AND 'Research ethics'/exp

Table 2: Code Book Summary

PARENT CODES	CHILD CODE LISTS
RCCS/RHSP	Becoming aware, outreach, misconceptions
Benefits of research	Incentives, health services, adolescent knowledge, community benefit
Risks of research	No risks, money, fear, stigma, pain and discomfort, infection, breakdown in routine
Parent vs. Adolescent Decision-making	Parents decide, parent advice, adolescents decide, joint decision-making, conflict, situation dependent
Research awareness	Voluntary participation, research purpose, data use, legal rights
Research recommendations	
Age category	Legal adult, community adult, independent decision, dependent decision
Health care experiences	
Memorable Quotes	
Other	*Included under each parent code

METHODS

1) Scoping Review to explore the issues of adolescent inclusion and protection in research through:

- Two large databases searches, PubMed and EMBASE (see Table 1),
- Application of inclusion/exclusion criteria (see Figure 1), and
- Identify 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.⁴

REFERENCES

1. Nelson, L.R., Stupiansky, N.W., & Ott, M.A. (2016). The Influence of Age, Health Literacy, and Affluence on Adolescents' Capacity to Consent to Research. *J Empir Res Hum Res Ethics* 11(2): 115-121.
2. Santelli, J.S., Haerizadeh, S., & McGovern, T. (2017, May). Inclusion with Protection: Obtaining informed consent when conducting research with adolescents. (Innocenti Research Brief 2017-5).
3. Santelli, J.S. et al. (2003). Guidelines for adolescent health research: a position paper of the Society for Adolescent Medicine. *J Adolesc Health*, 33(5): 396-409.
4. Berglas, N., Constantine, N., & Ozer, E. (2014). A Rights-Based Approach to Sexuality Education: Conceptualization, Clarification and Challenges. *Perspectives On Sexual And Reproductive Health*, 46(2), 63-72.

Contact Info: For inquiries please contact Emily Hoppes, MPH Candidate, Department of Sociomedical Sciences, Columbia University Mailman School of Public Health, emh2252@cumc.columbia.edu