

SAMRC HIV PREVENTION RESEARCH UNIT SYMPOSIUM

**Ethically acceptable consent approaches to
adolescent research in South Africa**



**Ameena Goga, SAMRC
21 June 2021**

Ethics symposium
21 June 2021

WHY ADOLESCENTS? PREGNANCY AND CHILDBIRTH

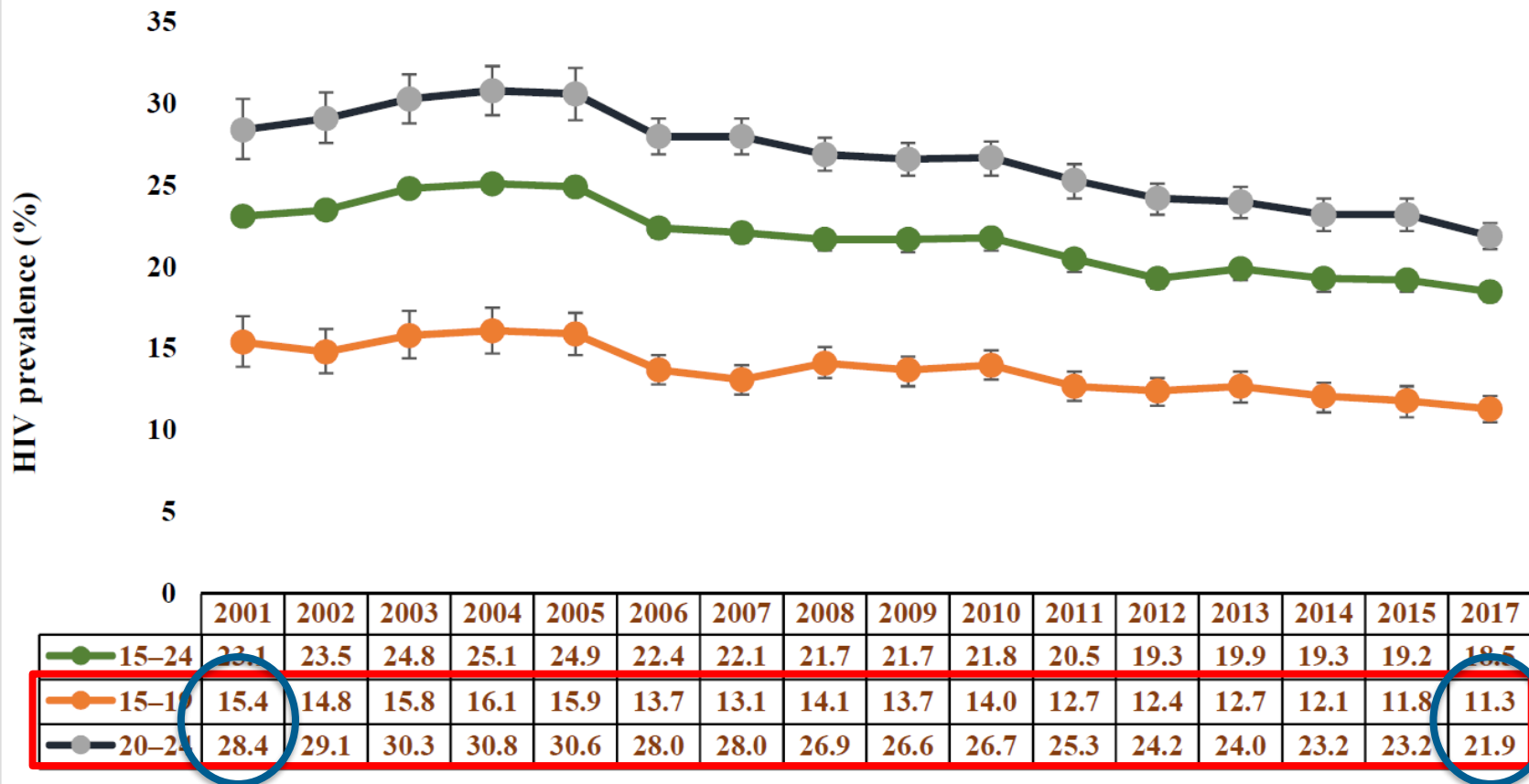


- At least 10 million **unintended pregnancies** occur annually among adolescent girls aged 15–19 years in low-middle income countries.
- Complications during pregnancy and childbirth are the **leading cause of death** for 15–19-year-old girls globally.
- Of the estimated **5.6 million abortions** that occur each year among adolescent girls aged 15–19 years, **3.9 million are unsafe**, contributing to maternal mortality, morbidity and lasting health problems.
- \approx 12 million girls aged 15–19 years give birth each year in low-middle income countries.
- At least 777,000 girls under 15 years give birth each year in low-middle income countries.
- Adolescent mothers (ages 10–19 years) face higher risks of eclampsia, puerperal endometritis, and systemic infections than women aged 20 to 24 years.
- Babies of adolescent mothers face higher risks of low birth weight, preterm delivery and severe neonatal conditions.

WHY ARE WE HERE TODAY?

- We are interested and concerned about ethically acceptable consent approaches to adolescent research in South Africa.
- Currently RECs find themselves in a tight spot between SAs **ethical and legal frameworks**
- We outlined the rationale for our symposium in the documents that were circulated with the invitation.

WHY ADOLESCENTS? ANTENATAL HIV



WHY ADOLESCENTS? COVID-19: EXPERT OPINIONS

Teenagers struggle more than any other age group when cut off from their social networks

Older children and teens are really missing their friends and their independence," "The digital classroom can be boring, stressful, or distracting for kids and that can be so hard on kids in so many ways," Roseann Capanna-Hodge, psychologist, Connecticut


Sharepoint

THE LANCET
Child & Adolescent Health

REFLECTIONS | FEATURES | VOLUME 4, ISSUE 6, P421, JUNE 01, 2020

Mental health effects of school closures during COVID-19

Joyce Lee

Published: April 14, 2020 • DOI: [https://doi.org/10.1016/S2352-4642\(20\)30109-7](https://doi.org/10.1016/S2352-4642(20)30109-7) 

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PlumX Metrics

“Going to school had been a struggle for [some children with depression] prior to the pandemic, but at least they had school routines to stick with...Now that schools are closed, some lock themselves up inside their rooms for weeks, refusing to take showers, eat, or leave their beds.” For some children with depression, there will be considerable difficulties adjusting back to normal life”, Zanon, Chiu, registered clinical psychologist, Hong Kong

“Children with special education needs, such as those with autism spectrum disorder, are also at risk. They can become frustrated and short-tempered when their daily routines are disrupted”, psychiatrist Chi-Hung Au, University of Hong Kong

MENTAL HEALTH: HUMAN RIGHTS WATCH INTERVIEWS

“It’s stressful when I have to study all alone,” said Makena M., 17, in Kenya.

“I tend to think a lot about school and my friends,” said 15-year-old Kioko Y. from Kenya. “It makes me sad. I know my school has a counsellor, but we were never given contacts after we closed and before this, I had never gone to him.”

“No emotional and social support is provided by the school,” said a caregiver to four students not receiving any education in Congo at the time of the interview. “This aspect is too neglected.”

A 16-year-old South African boy said, “... I was completely struggling for a whole two weeks, like crying every day. Um, yeah, so that was like a big thing for me, starting to think life was meaningless.”

Impact of Covid-19 on Children’s Education in Africa - 35th Ordinary Session -

[Impact of Covid-19 on Children’s Education in Africa](https://www.hrw.org/news/2020/08/26/impact-covid-19-childrens-education-africa) -

<https://www.hrw.org/news/2020/08/26/impact-covid-19-childrens-education-africa>

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YOUNG MINDS SURVEY: UK

2,036 young people aged 13-25 yrs with a history of mental health needs surveyed: June –July 2020

- **80%: COVID-19 pandemic worsened mental health**
 - 41% - “much worse” - increased feelings of anxiety, isolation, coping or motivation.
- **87% felt lonely or isolated during lockdown**, even though 71% stayed in touch with friends.
- **31% no longer had access to mental health support**
- **40% not accessing mental health care just before the crisis now needed care**
- **Only 11% reported improved mental health** (no bullying or academic pressure at school)



Debate: COVID-19 and psychological well-being of children and adolescents in Italy

Ernesto Caffo, Francesca Scandroglio & Lisa Asta

Department of Biomedical, Metabolic and Neural Sciences, University of Modena and Reggio Emilia, Modena, Italy

- Helplines have been extremely busy
- During lockdown the helpline 1.96.96, dedicated to children and adolescents, registered a 14.4% increase in requests for mental health issues and a 22.6% increase in contacts by chat
- The 114 Emergency Services saw an increase of the 21.5% of cases managed for abuse and violence

SOCIAL AND PHYSICAL EFFECTS: CHINA

- Children and young people have lost social interactions, may lack a structured routine and are likely less physically active.
- Repeat surveys of 2426 children and adolescents (6–17 yr) from 5 schools in Shanghai:
 - reduction of 7.3 hours per week in physical activity and
 - an increase in 30 hours per week of screen time when comparing lifestyle patterns before and after implementation of pandemic public health measures.

Chanchlani et.al. CMAJ August 10, 2020 192 (32) E921-E927; DOI:
<https://doi.org/10.1503/cmaj.201008>
Xiang et.al. *Prog Cardiovasc Dis*

EFFECTS IN PAKISTAN

Debate: COVID-19 and school mental health in Pakistan

Ayesha Irshad Mian¹ & Aisha Sanobar Chachar²

¹Department of Psychiatry, Aga Khan University, Karachi, Pakistan

²Alleviate Addiction Suffering (AAS) Trust, Karachi, Pakistan

- Rapid needs assessment nationwide
- School closures may magnify rural–urban, gender and socioeconomic divides, increasing child labour in the short- and long-term.
- Schools need to focus on areas of nurturing resilience in children and adolescents
- Students' mental and physical health will need explicit support in the return to everyday life.

SCHOOL CLOSURE AND THE FEMALE CHILD



- **Girls disproportionately affected:**
 - Current school closures are expected to increase child pregnancy and marriage (Sierra Leone, Ebola crisis, Bandiera et.al)
 - School closure during Ebola exposed children especially girls to risks including domestic and sexual violence (Plan International 2015, UNDP 2015, Odhiambo 2020)
 - UNESCO estimates that 7.6 million girls are at risk of not returning to school with the highest risk in secondary school girls
 - UNHCR predicts that 50% of refugee girls in secondary school may not return when schools reopen (UNHCR)

<https://saveourfuture.world/white-paper/>

OBJECTIVES OF SYMPOSIUM

- To discuss how to enable ethically acceptable consent approaches to adolescent studies in South Africa including parental waivers.
- To learn from study sites that have included adolescents in their research, including with parental waivers.
- To learn from RECs who have approved various consent approaches for adolescent enrolment, including parental waivers

CONSENT APPROACHES

- The SA **ethical framework** permits a range of consent approaches, including waivers of consent under some circumstances, as set out in the NDOH ethics guidelines.
 - It allows RECs to waive parental consent for child research under strict conditions: including when the research is “sensitive”, poses no more than minimal risk, when the child is “older” and the community is engaged. International ethics guidelines also permit parental waivers when parental consent is not feasible or desirable.⁷
- The **legal framework** in terms of s71 of the National Health Act permits only parental/ guardianship consent.
- The ethical framework permits a more nuanced approach to adolescent consent, and Parental consent requirements can limit adolescent access to research and ultimately to health services as shown by USA studies on sexual and reproductive health (SRH) services as many adolescents fear parental disappointment, sanction or retaliation.

NDOH, Ethics in Health Research: Principles, Processes and Structures 2015. <http://www.nhrec.org.za>

Strode A et al. SAMJ 2018;108:828-32. DOI:10.7196/SAMJ.2018.v108i10.13203.

Ethics symposium Geneva 2016.

Strode A et al. Med J 2017;107:741-4.

Jackson S et al. J Adolesc Health 2001;29:1–93. [https://doi.org/10.1016/S54-139X\(00\)00178-6](https://doi.org/10.1016/S54-139X(00)00178-6).

Delany-Moretlwe S et al. Journal of the International AIDS Society 2015;18:19833.

CONSENT APPROACHES

In terms of access to services by adolescents, progressive legislation in SA enables adolescents to access various SRH and HIV services without consent from parents or legal guardians:

- The Children's Act No. 38 of 2005 states that children may consent *independently* to HIV testing, male circumcision, contraceptives (including contraceptive advice) and virginity testing at various points before the age of 18; and
- The Choice of Termination of Pregnancy Act No. 92 of 2007 allows a woman (including a girl child) *of any age* to consent to a termination of pregnancy without assistance.
- The legal framework also facilitates adolescent's independent access to SRH services, including consent to medical treatment¹¹ and scheduled drugs on the presentation of a prescription.

It is essential that adolescents are enabled to access research and the benefits of research, while enjoying sufficient protections.

South African Government. The Children's Act No. 38 2005.

South African Government. The Choice of Termination of Pregnancy Act No. 92 2007.

South African Government. Medicines and Related Substances Control Amendment Act No. 90. 1997.

Department of Health. National Health Act, 2003 (Act no. 61 OF 2003) Regulations relating to research with human participants. Schedule 4. Pretoria: Government Gazette; 2014:7-8.



It is essential that we seek and test solutions to resolve challenges relating to adolescent health and well-being, while ensuring they're protected.

How do we do this?



09:00 – 09:05: **Welcome:** (Prof Ameena Goga: SAMRC)

09:05 – 09:30: **Views from researchers:**

9.30 – 9.45: **The international normative framework for ethically acceptable consent approaches to adolescent research** (Prof Ames Dhai: Wits University)

9.45 – 10.00: **The conflict between the law and ethical guidelines, how RECs can manage this issue and the ethical-legal context for consent for adolescent research in SA**
(Prof Ann Strode: University of Kwa-Zulu Natal)

10.00 – 10.20: **Views from RECs:** (5 minutes each)

10.20– 10.50: **Facilitated discussion regarding the way forward: How can the field move towards ethically acceptable consent approaches?** (Chair Dr Cathy Slack: UKZN)

10.50 – 11.00: **Wrap up and conclusion** (Dr Beth Spooner: SAMRC)