

Ethically acceptable consent approaches to adolescent research in South Africa

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Some considerations

- Strong need for research in adolescents – recognition of scientific and

How can RECs fulfil their ethical duty and responsibility to protect study participants and improve health outcomes?

- Evolving autonomy and capacity
- Adolescent risk perception and behaviours important considerations

A growing need to ensure structural drivers of health are addressed in ethical reviews of adolescent health research
more nuanced ethical approach

Thoughts around adolescent consent models

- Collaboration between RECs and researchers of critical importance
- Recognition of 'adolescent friendly' sites
- Importance of ongoing community engagement & particularly adolescent CABs
- Considerations for when adolescents' independent consent may be permissible

The 'bits' that we find difficult

- Considerations for when adolescents' independent consent may be permissible
 - Law vs. ethical guidelines vs. 'on the ground'
 - Assessment of risks standards in adolescent research (particularly around 'minimal risk' requirement)
 - Balancing risk with potential social value and potential benefits
 - Minimum age requirements in ethics guidelines for independent adolescent consent
- Potential ethical dilemmas presented by rigid legal, mandatory reporting requirements (especially of sexual and physical abuse) vs. a more nuanced ethical approach
- Who, how and what of community engagement
- Storage of samples/ data for future research – assent/ consent implications
- Adolescent assent (or independent consent) forms –adolescent 'unfriendly' or age-inappropriate

Some ideas to address REC challenges with adolescent consent models

- Regulatory, policy and ethics guidance reform needed to facilitate research involving adolescents
- Formal feedback to RECs regarding ongoing research findings and community experiences
- Further empirical research around consent in adolescents in local SA context
- With consent waivers – ask for regular feedback for monitoring and learning – positives and negatives – to potentially change approach if needed
- Collaboration with GHU & adolescent clinicians and researchers to ensure we have a balanced understanding of adolescent and gender health issues
- Networking between RECs to promote standards for ethical adolescent health research
- Generation of an ‘ethics repository’ of material to support all stakeholders