

## Article

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### **Ethical and Privacy Challenges of Involving Children in Research on Sensitive Issues: The Experiences of Amajuba Child Health and Wellbeing Research Project (ACHWRP)**

by Mandisa Cakwe

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## **Ethical and Privacy Challenges of Involving Children in Research on Sensitive Issues: The Experiences of Amajuba Child Health and Wellbeing Research Project (ACHWRP)**

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### **Abstract**

#### Background

There has been a reluctance to conduct child related research studies with, rather than on children in the African continent. Several studies have embarked on this method, however, ethical and privacy challenges still prevail. The Amajuba Child Health and Wellbeing Research Project is a longitudinal study that was conducted with 725 children aged between 9 and 15 years old in KwaZulu Natal in South Africa and also faced the same challenges.

#### Methods

Focus group discussions and self administered questionnaires were used as data collection techniques for ACHWRP. One of ACHWRP's objectives is to document the consequences of parental or caregiver death on health and well-being of orphans in Amajuba District of KwaZulu Natal. Ethical clearance was received from two ethical review boards.

#### Lessons learned

*Ethical* challenges included problems of coercion for participation, gatekeeper's and partner's roles, getting consent and assent, recruitment and referral system.

*Privacy* challenges included data collection techniques, curiosity and destruction by members of the family during an interview, the setting where interviews are conducted, logistical issues and the method of recruitment's potential to compromise confidentiality.

*Resolutions:* Detailed consent and assent forms with all relevant information are necessary. Careful selection of partnerships is crucial. Use of a venue that is far from the community is necessary, but in the process making sure that the participants are covered with regards to the expenses of travelling to the venue.

#### Conclusion

Conducting research with children entails investing more time and attention to the planning stage of the study.

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