



# **Ethics in research with children**

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# Violence against children (VAC)



- Increasingly recognised as an important area of public health and social policy research
- Dearth of international, comparable epidemiological data on children's experience of violence, especially in low and middle income settings where literacy levels may be low and CP systems not well developed
- Fear of causing psychological trauma or distress – few studies have found evidence of this however (DePrince and Freyd 2004)
- The United Nations Secretary-General's Study on Violence against Children specifically calls for more investigation to provide accurate and up-to-date prevalence, prevention and intervention data.
- Researchers, donors and policy makers taking an active interest
- Most researchers consider asking young people to self-report their experience of violence using tools such as the ICAST-C
- Asks about specific acts of violence



# **Ethical and methodological considerations when collecting data on VAC**

# General ethical principles

All research involving human subjects should be conducted in accordance with 3 basic ethical principles:

## 1. Respect for persons including

- Respect for autonomy
- Protection for persons with impaired or diminished autonomy

## 2. Beneficence

- Maximise benefits and minimise harm (reasonable risk in light of expected benefits, sound design, competence of investigators to conduct research and safeguard welfare of research subjects)
- Nonmaleficence (do no harm)

## 3. Justice

- Treat each person in a way that is right and proper and give each person what is due to him/her

# Children's consent to participate

- Council for International Organizations of Medical Sciences (CIOMS) 2002
  - Provide guidance on ethical medical research involving human subjects
  - Scope reflects the changes, advances and controversies that have characterised biomedical research and ethics in the past
  - Particular aim is to reflect the conditions and needs of low-resource countries
  - Guideline 14: Research involving children

# CIOMS guideline 14

Investigator must ensure:

- The research might not equally well be carried out with adults
- The purpose of the research is to obtain knowledge relevant to health needs of children
- A parent or legal representative of each child has given permission (consent)
- The agreement (assent) of each child has been obtained to the extent of the children's capabilities
- A child's refusal to participate or continue in the research will be respected

## Children's legal and developmental ability to provide consent or assent for participation



- Age of consent may vary from country to country or even between jurisdictions within the same country
- Research on cognition and capacity of young people has shown young people's significant ability to provide informed consent/ability to make informed decisions about whether to participate in research is similar to adults'. (Society for Adolescent Medicine 2003)
- 14 year olds have been found to be as skilled as adults in understanding multiple viewpoints and in considering conflicting information (Weithorn 1983)
- Investigator must obtain the permission of a parent or guardian in accordance with local laws and established procedures

# A child is a child is a child?

- Who is a child?
  - Determined by age?
  - What about 16 year old married mothers?
  - Developmental capacity of children to understand the question being asked?
- Emancipated minors
  - In some jurisdictions some individuals who are below the general age of consent are regarded as ‘emancipated’ or ‘mature’ minors and can provide consent without agreement or awareness of parent/guardian
- Topic/subject of research
  - Investigations into children/adolescents’ beliefs or behaviour regarding sensitive subjects (eg sexuality, recreational drugs, sexual abuse) may put children at risk of questioning or intimidation by parents
  - Ethical review committees may waive parental permission in these cases (subject to other consent conditions being met)



# Implications

The experience and procedures in the Good Schools Study,  
Uganda

# The Good Schools Study

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## Aim

- To evaluate the Good School Toolkit – whole school intervention designed by Raising Voices which seeks to reduce violence in schools and improve learning outcomes

## Methodology

- Conducted in a district close to Kampala
- Baseline 2012, follow-up 2014
- RCT, qualitative evaluation, process analysis, economic costing
- 42 schools (21 intervention, 21 control)
- Interviewed students, teachers, school administration, parents/carers

## Domains

- Views and experience of violence (from school staff, peers, others)
- Mental health
- Educational tests

# Consent

- Permission obtained from the Ministry of Education and Sport at the national and district levels
- 3-tiered consent process
  - Consent for participation sought from head teachers for school participation and to approach parents and students – 100% agreement
  - Parents given opportunity to opt their children out of participation (in person, on the phone, in writing, information meetings)
    - Were aware that questions related to violence, that some questions might be upsetting, and obligation to report harm
    - Voluntary
  - Individual students selected to participate in the survey were approached and informed consent (assent) sought
    - Emphasied that participation was voluntary
    - Obligation for reporting
    - Availability of referral services

# Interviewer recruitment & training

- Experience of previous work with children - references (CRB checks in other places)
- 3 weeks of full time training
- Violence against children and child rights
- Strategies to maintain privacy and confidentiality eg in a school setting
- Consent
- Techniques for building rapport and making children feel comfortable
- Practicing! role play sessions on interview techniques, handling disclosures of sexual violence
- Strategies and the importance of remaining non-judgmental
- Child protection protocols
- Trained an excess of interviewers and hired the best

# Referring children who experienced violence

- Study employed counsellor
- Comprehensive protocol to handle disclosures of violence,
  - Developed in consultation with local child protection experts
  - Specific pathways of action depending on the severity and time frame of what the child disclosed
    - Urgent
    - Serious but less urgent
    - Serious but non-urgent
  - Decisions on disclosures that would necessitate referral and to where they would be referred were made considering the legal requirements in Uganda and the local child protection systems
- In practice
  - Baseline – high number of referalls
  - Follow up – mental health impact added
  - Support well received by students



# Thank you

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