

Considerations for disadvantaged, vulnerable and marginalized adolescents (DVMAs)

Webster Mavhu

10th October 2018

2nd International Workshop on HIV &
Adolescence



'No COI to declare'.

Presentation Outline

- Working definition of DVMAAs
- Examples of DVMAAs
- Exclusion of DVMAAs from research (plus reasons)
- Trial design considerations (by stage)
- Additional ethical issues
- Summary

Useful resources



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METHODS Conducting Research with Adolescents
in Low- and Middle-Income Countries

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Research with Disadvantaged, Vulnerable and/or Marginalized Adolescents

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DVMAs: Definition and Examples

•10–19 yr-olds excluded from social, economic and/or educational opportunities enjoyed by others due to factors beyond their control (Unicef 2017)

•Adolescents...

- who live on the street/homeless
- in domestic servitude
- who are trafficked
- who belong to stigmatised ethnic, religious groups

- orphans
- incarcerated
- sexual minorities
- immigrants or refugees
- young men and women selling sex
- sexually exploited young women

Exclusion of DVMMAs from Research

- The WB predicts that Africa's ability to benefit from population growth will depend on the health and well-being of today's adolescents
- Population impact will be reduced if those at highest risk are not included
 - e.g. early pregnancy/marriage lead to exclusion from school – a barrier to HPV vaccination
 - Adolescent VMMC in 15 countries - school based
 - sustainability phase to focus on 10-14 year-olds
- By excluding DVMMAs from research/programmes, we also exclude them from the potential benefits

Trial design stages

1. Research the question
2. Define the hypothesis
3. Review the literature
4. Involve a statistician
5. Develop inclusion and exclusion criteria
6. Sampling and sample size
7. Develop methodology, minimise bias:
 - intention to treat analysis
 - allocation concealment
 - blinding
 - randomisation
8. Gain ethics approval

Key reasons for DVMAAs exclusion

- Approaches to recruiting key populations (e.g. SWs, IDUs) to research have been developed/ validated
 - Few have been rigorously evaluated among DVMAAs
- Yet to be determined how best/most efficiently to engage DVMAAs in programmes and research
 - will likely vary according to which DVMAA is being reached
- Usual challenges to conducting research with adolescents plus additional:
 - legal impediments prevent/limit scope of their engagement
 - also likely more vulnerable, may not have caregivers/ guardians who can consent, greater protection needed

Researching the question: Is it useful? (To Who?)

- *the principle of respect for persons* dictates that DVMAs have right to express their views on matters that directly affect them, including the design of research to improve their lives
- Establishing YAB or YTB to provide guidance on:
 - trial design
 - intervention design
 - data collection tool design
 - study-related activities (e.g. recruitment, study sites)

Selecting community or YAB: Important considerations

- Important to...
 - avoid **tokenism** (only symbolic)
 - YAB/YTB tailored to needs of DVMA under consideration
 - not only consider age brackets (e.g. 10-14; 15-19)
 - stage of development more important than biological age and likely to vary by reasons for exclusion/vulnerability/access to education

One size does not fit all!



Reviewing Literature - Has anyone else done this?

- Need to be aware of **under-coverage bias**
- DVMA's not included/identified in national census data, household/health surveys
 - incarcerated unlikely to be included in such surveys
- A general lack of data on size and characteristics of DVMA sub-populations



Determining inclusion/exclusion criteria

- Consent/assent for research with DVMAs not standardised
 - Assent - child's affirmative agreement to participate, obtained from age 7

e.g. 'able to provide informed assent and their caregiver is able to provide informed consent'

- Frequently no committed parental/guardian involvement
- Emancipated minors (YWSS, ≥ 15 yrs)
 - waiver of consent (parental/guardian)?
- Sexually exploited young women ≤ 14 yrs??

Sampling and sample size

- Need to recruit or obtain representative and generalisable samples of DVMAs bearing in mind:
 - no sampling frame for them exists - to get representative samples, need to employ non-census based methods
 - available survey data exclude those who live on street/institutions
 - DVMAs' avoidance of services due to stigma, confidentiality
 - some sub-groups highly mobile (YWSS)
- Approaches will likely need to be tailored for different populations and contexts

Maximising representativeness

- Need to use approaches that maximise representativeness
 - consider characteristics of the sub-population
 - prioritise sex-aggregated sampling
 - need to employ innovative and efficient approaches (e.g. network-based recruitment, e-health approaches)
 - formative research/pilot studies crucial

Other ethical issues: Inclusion with protection

- Investigators need to prioritize protection from the potential risks of research
 - physical, emotional, social harm
- Minimising the stigma and potential dangers of participation
 - e.g. non-stigmatising project name
- Plan for referral and care of DVMAAs in imminent danger or are a threat to themselves or others
- Compensation – something considered non-coercive for other adolescents may be coercive for DVMAAs

Summary

- Health needs of DVMAAs invisible and unmet
-consequently at highest risk
- Approaches to recruiting DVMAAs to research urgently needed
- Involvement of various DVMAA sub-populations critical
- Recruiting or obtaining representative and generalisable samples of DVMAAs is key
- 'Inclusion with protection' likely minimises ethical issues

Thank you