

NOTHING ABOUT US, WITHOUT US!

Background:



Despite a commendable increasing policy and programmatic focus, AIDS-related deaths and new HIV infections among adolescents and young people (AYP) persist in South Africa.

There is a clear imperative to better understand the needs and perspectives of AYP, engage methods that facilitate their participation, and to co-generate responses with AYP themselves.

Lessons learnt from adolescent advisory groups with young people living with and closely affected by HIV

Conclusion:

With adequate time and resource investments, adolescent advisory group processes can:



1 Support processes of reflection and action and shift power

2 Generate rich evidence to inform research, policy and practice

Method:

Adolescent advisory group activities in the Western and Eastern Cape provinces of South Africa (n=41, ages 15-23).



Building on over a decade of engagement

8 activities over 13 days were held in 2019/20

These methods aimed to foster reciprocal participation between AYP, engagement practitioners and researchers.

Participatory- and art-based methods included:



Theatre



Drawing



Mural development



Singing



Poetry



Story-telling

Findings:

Empirical findings:

- HIV was never discussed as a stand-alone concern, but was consistently identified as a cross-cutting issue across challenges faced by AYP;
- Most prominently discussed challenges included:



'Blessers' (transactional, age disparate sex)



Substance abuse



Medicine-taking and health



Medicine-taking and health



Unwanted adolescent pregnancies



Careers and unemployment

Methodological findings:

- Advisory group members demonstrated an interest and ability to engage meaningfully in the research process, co-develop methods, and generate rich empirical and methodological evidence.
- Clarifying and co-determining advisory group purpose and objectives at the beginning;
- Delivering age-appropriate capacity-building on the research process;
- Engaging participants in selecting or co-developing methods;
- Being clear about the limitations of what can be offered to advisors, ensuring adequate referrals to social services.

HIV was discussed as a complicating factor in many important life areas for AYP rather than a stand-alone issue.

This finding has relevance to combination and accelerator approaches for HIV-related outcomes within the adolescent health and development agenda.

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