

Session 7 - Session 7 - The Best Research is Research with Us and by Us - Participatory Research Practices

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Importance of ensuring active youth participation in research

The best research is research with
us and by us



OUR BELIEFS and VALUES

...and the shared-belief basis
for partnership...

- 1 Human beings have inherent **DIGNITY** and worth.
- 2 People — especially those who experience acute and chronic exclusion and marginalization — must be the **SUBJECTS** of their own response, not simply the objects/targets of interventions by others.

3

RIGHTS and health are indivisible. When rights — including the right to participation — are sidelined, even with the best of intentions, health outcomes suffer.

4

Authentic **PARTICIPATION** requires recognition and acknowledgement of disparities in power, and access to information, choice, decision-making and negotiation to resolve imbalances that perpetuate inequity and reduce dignity.

5

Community-led **RESEARCH, MONITORING AND ACCOUNTABILITY** are strategies to mitigate civic, social, political, economic and structural inequality and injustice, increase individual confidence and agency, and amplify voice and dignity.



Why Youth focused research matters?



COMMUNITY LED MONITORING, RESEARCH AND LEARNING

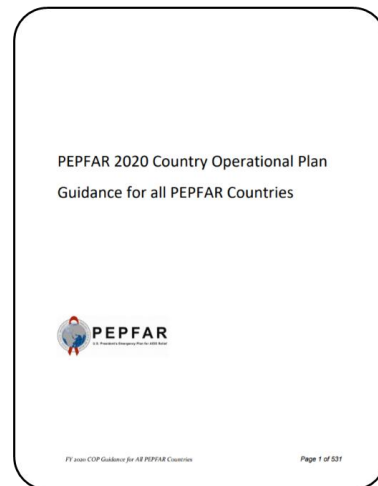


INTERNATIONAL AIDS SOCIETY

“Our conversations – about HIV, about COVID-19, about systemic racism – are linked. And so are our solutions. It requires that those most affected be a part of the solution. Leadership by Key Populations is more required than ever to complete this unfinished work.”



USAID/PEPFAR



Under new guidelines for funding requests to the Global Fund, Country Coordinating Mechanisms are required to describe the role community-based organisations will play in implementation.

The value placed on “community-led” (including Key Population led) organisations is intensified.

The contribution of communities to **Resilient and Sustainable Systems for Health** is being affirmed and enhanced.



In countries around the region, influenced by both the Global Fund and PEPFAR, UNAIDS is initiating consultations with civil society organisations, inviting **models and examples of effective community** that can be scaled.



What does youth participation look like in research?

- Research needs, questions, priorities are defined by the youth
- Youth takes part in the development of protocol and inform the development of methodologies
- Youth take part in the implementation of the research activity: Either through community mobilisation, data collection, and analysis
- Community members, including youth, lead the monitoring of progress, including tracking the application of ethical procedures e.g. establishment of a community research board
- Youth verifies, validates data
- Youth leads in the dissemination of data and packaging of data to best serve the application of findings and lessons learned



Why is youth led participation important?



We are
more than
just
numbers or
targets

To ensure no harm is done, youth wants & needs to be respected in personhood.

Participatory research allows youth to understand, inform, and actively participate in research activities.

By engaging from onset with the relevant stakeholders, we ensure that the youth are no longer objects of research, but active players.

They understand why research is important, why it needs to be done; their expertise informs the development of protocol and tools.

More importantly, they understand what findings will be used for, how lessons learned will be applied



To facilitate trust in the sharing of lived realities

Only when leading, involved and consulted, will youth share deeply personal stories, stories that provide clues to the underlying factors impeding equitable health care

e.g. Elongation of the labia minora

When I was 8 years old, I was instructed by my grandmother to start to pull and stretch my labia minora (inner vaginal lips). I did not know then that this was to provide for the sexual pleasure of my future husband. I was just told I would never get a husband if I don't have long labia.

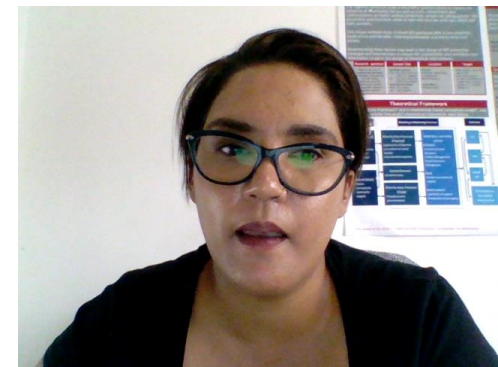
Girls' genitals are regularly inspected to see whether they are pulling their labia correctly, and girls are evaluated by the length of their labia.

Before her wedding night a woman may be inspected and if she does not have long labia, she may be sent back to her grandmother for further training. Labia elongation is a painful and humiliating process which women are expected to practise as long as they are sexually active.



To ensure data is representative of diversity within youth-focused studies

- Unless the purpose of a study is specifically designed to explore the vulnerabilities, needs, and context of of subcommunities, many studies revert to heteronormative, cis gender assumptions relating to youth demographics:
- For example: LBQ women and transmen data are subsumed within data sets that make heteronormative assumptions on what constitutes womanhood. Assumptions on the types of sex women have, the types of reproductive and sexual needs women have, the types of relationships engaged in, which in turn influence the kinds of questions we ask.
- These assumptions then translate into policy and strategy.



To ensure Youth Related health policy, law and practice is nuanced

- Country and regional policy, unless specifically designed to cater to specific populations, are often heteronormative, and assumes a homogeneity amongst youth groups.
- Policies and strategies integrating gender considerations almost always assumes Girls and young women, boys and young men, who are cisgender and heterosexual.
- Sexual and gender diversity is not considered
- For e.g. Women, and their sexuality, their bodies, are functions of men; unless they are having sex with a man, they are not considered as a candidate for policy and or strategic address.
- This lack of acknowledgement fuels the never ending cycle of limited national budgeting for youth and other marginalised populations, lack of focused interventions, procurement of SRH-R related commodities and development of communication materials specific to this group.



To ensure EQUITABLE youth focused health solutions

- Health services to youth requires equitable solutions:
Fair, accessible, appropriate to (adjusting for; compensating for; making provision for) diversity, so that no one is excluded from good health because of their diversity.
- Equity requires that youth are treated (in attitude and regard and, literally, with medical treatment) as if each person is equally deserving of the highest standard of health suited to their unique needs: a right fit for gender (biological sex; gender identity; gender expression) and for sexual orientation; and within easy reach of young people who face many barriers (social, economic, class, physical, legal and environmental) to accessing services.



**“The opposite of Exclusion is not Inclusion,
It’s Justice”**

Namibian Ombudsman, Advocate John Walters





POSITIVE
VIBES

Hope - Respect - Voice