

## INTRODUCTION

- Community Engagement (CE) is imperative to research for both instrumental and intrinsic reasons.
- Adolescents' and young people's (AYP) participation in clinical trials, especially medical research, conducted in Africa is infrequent.
- It is poorly understood how to meaningfully involve AYP in research, promoting critical dialogue between researchers and AYP.
- HPTN 071 (PopART) is a community based trial in 21 study communities in Zambia and South Africa. The trial includes the PopART for Youth (P-ART-Y) study a nested ancillary study to evaluate AYP's uptake of HIV-related services.
- We report on data collected through group discussions (n=8) conducted among Adolescent Community Advisory Board (aCAB) members in Zambia in 2017 exploring their perceptions of the aCABs role in the PopART for Youth (P-ART-Y) study.
- We also reflect on our experiences of establishing and maintaining AYP participation and representation from Zambia and South Africa.

## DESCRIPTION

- Formative research was conducted to identify AYP-specific community based organisations and AYP possible interventions in consultation with AYP representatives and the existing adult Community Advisory Boards (CABs).
- Consultations resulted in the creation of 12 AYP-only CABs (aCABs) in Zambia and one AYP-only aCAB in South Africa.



aCAB members participate in an energiser during a meeting.



## PARTICIPATION AVENUES

AYP were engaged through:

- aCAB meetings
- 'Future' spaces
- Social media
- Youth friendly health services
- Community health fares
- Regular meetings with researchers



## RECOMMENDATIONS BY AYP

- Suggested youth specific interventions for the study.
- Participated in the design of the P-AR-T-Y study cross-sectional survey.
- Advocated for waiver of parental consent in the cross-sectional survey.
- Participated in the design of new adolescent related interventions.
- Decided against incentives for participants in the cross-sectional survey.

## LESSONS LEARNT

### Voices of the aCABs

*"I wanted to be a voice for the young people in the community..... there is a lot of alcohol abuse by adolescents and a lot of young people living with HIV."*

*"first of all I looked at the study it was very interesting.... It encouraged me to join.... It also focused on youths. This made me think that youths are now being regarded as a valuable tool to the intervention"*

*"It is believed that this generation is spoiled, so my motivation is that I want to give health information to those youths who do not have access and are yearning for information about HIV, TB, teen pregnancy as well as GBV"*

*"I also joined to help people in different situations by advising them on how to cope because there is a lot of stigma in the community where by people tend to lose hope"*

*"I felt I could do it (be a good representative) because...I could say I was the face of the community when it comes to the youth"*

### Factors facilitating and constraining AYP participation in the trial

Facilitators	Constraints
<ul style="list-style-type: none"> <li>• Training and skills building</li> <li>• Financial incentives</li> <li>• Non-financial incentives</li> <li>• Acknowledgement of the role AYPs play</li> <li>• Constant engagement; AYPs are very active and want 'presence and action' all the time</li> <li>• Adding fun to all activities and use of participatory methods</li> <li>• Use of new technologies and computers in engagement mechanisms</li> <li>• Supportive parents and guardians</li> <li>• Timing of meetings</li> <li>• Opportunities to interact with researchers</li> <li>• Engagement with other AYP especially during AYP targeted interventions</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of monetary incentives; wasting time</li> </ul> <p><i>"We know that this is voluntary but even a little help will go a long way. This is why people are leaving and going to look for other means of earning money. They have no motivation to stay."</i></p> <ul style="list-style-type: none"> <li>• Alcohol and substance abuse</li> </ul> <p><i>"....we .....found a group of adolescents sniffing, smoking and drinking at the same time. And so the question is how can such a person decide to go for testing and even if they go for testing how are they going to accept their results in case they are HIV positive"</i></p> <ul style="list-style-type: none"> <li>• Safety of AYPs when conducting study activities</li> </ul>

## CONCLUSION

AYP in Africa are motivated to participate in research that directly impacts their lives. While challenges to participation in research exist, researchers should be encouraged to invest in meaningful partnerships with AYPs. CABs with only AYP representatives are one such strategy.

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