Meaningful engagement of youth: from research prioritization to clinical trials, implementation science and policy development

Carlo Andre Oliveras Rodriguez
Adolescent HIV Treatment Coalition
Defining engagement

why is it important?
Meaningful engagement in research

The following principles are central to young people’s meaningful engagement in research to move beyond tokenistic participation towards citizenship.

1. They understand the intentions of the project;
2. They know who made the decisions concerning their involvement and why;
3. They have a meaningful (rather than ‘decorative’) role;
4. They volunteer for the project after the project was made clear to them.

“From tokenism to citizenship”, Dr. Hart 1992
How **well** do we know the young people we are engaging?
“There is a need to talk through social issues, home visits and personal lives. Young people who are appointed as youth leaders end up bearing the burden of the emotional work that is needed alongside the financial management that needs to occur. In that process you find yourself losing your main purpose, your main goal that you came into this space. The main reason you came into the work is taken away from as you pour your time and energy into finances and other such things that were not what brought you to this advocacy space. “

Participant, Intergenerational Summit
Adolescent HIV Treatment Coalition
June, 2017
What now? Going beyond dissemination

- Connecting researchers with youth
- Assessing the involvement/engagement of young people in order to document best practices for engagement
- Establishing standards of practice for projects and programs impacting the lives of YPLHIV
Contributions and support

- Youth Trials Board team
  - Dr. Sarah Bernays, PhD
  - Magda Conway
- Professor Lucie Cluver, PhD
- Adolescent HIV Treatment Coalition and all the participants at the Intergenerational Summit for Positive Youth Leadership