



# Community Engagement in the HPTN 071 (PopART) Study







#### **U.S. NATIONAL INSTITUTES OF HEALTH:**

National Institute of Allergy and Infectious Diseases
National Institute of Mental Health
National Institute on Drug Abuse





#### Pre- study engagement

- Consultations with existing representative structures
  - Former CAB members from the Zamstar study
  - Health committee and community opinion leaders
  - Government and other stakeholders
- Issues raised by the community members: sexual disinhibition, migration, alcohol and drug use, low literacy
- Formative research using a broad brush survey (BBS) approach:
  - Rapid assessment of the HIV prevention, treatment and care landscapes and factors that would facilitate or hinder study
  - Detailed stakeholder analysis





# **Advisory Mechanisms**

- Multiple communities required multiple engagement mechanisms
  - Stakeholder analysis
  - Adult Community Advisory Boards
  - Adolescent Community Advisory Board
  - National CAB (NCAB)
  - Civil society platforms
  - Implementers and researchers platforms





#### Community engagement- implementation

- Responsive to community context, feedback and study performance
  - Door to door and community meetings
  - Work place and school based activities
  - Stakeholder meetings and ongoing conversations
  - Number of CE activities conducted:13,200
  - Targeted campaigns
    - Community fares
    - Man Up campaign
    - Street and zonal testing campaigns
    - Retesting campaigns
    - HIV self-testing campaigns





#### Instrumental role of community engagement

- Enhanced the informed consent process
- Supported the recruitment & retention drives- even for difficult to reach populations
- Kept momentum in control communities
- Updated the community and stakeholders about study progress
- Updated communities of critical changes to research and national policy/ practice





### Intrinsic role of community engagement

- Oversight role: CAB members actively participated in the resolution of incidents and social harms
- Study design: CAB members provided input in the design of sub studies
- Protection of culture and participants' welfare (one CAB stopped distribution of study material)
- Adolescent CABs decided for waiver of parental consent for the adolescent survey and removed some questions





## Intrinsic role of community engagement

#### Dissemination

- Communities consulted at end of intervention on modalities for exit and dissemination of results
- CAB members prepared on how to understand results
- Results first disseminated to communities using a community dialogue approach- reflection on what results meant to their communities (Zambia)





#### **Challenges**

- Restricted use of mobilization approaches to avoid contamination of control communities
- Standardization of message delivery
- Heterogeneity of communities; varied context- varied community features, socio-cultural organisation
- Parental permission for some adolescent CAB members when travelling
- Building respect and trust when whole community is involved in the study
  - Transparency- timely feedback and content
  - integrating community views into research