

# Community Engagement in the PopART Study

MUSONDA SIMWINGA



**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
- 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
- Issues raised by the community members: sexual disinhibition, migration, alcohol and drug use, low literacy

# 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
  - Total no of CE activities conducted:13,200
  - Targeted campaigns
    - Community fairs
    - 'Man Up' campaign
    - Street and zonal testing campaigns
    - Retesting campaigns
    - HIV self-testing campaigns



# Community engagement activities targeted at men



- Targeting male spaces
  - Work place
  - ‘Catching’ them at the clinic
  - Entertainment places
  - *Insaka* - gatherings/GDs
  - Hubs (post PopART intervention)
- Male Campaigns – ‘Man Up’
- Tent/Caravan testing
- Flexible working times
- HIV self-testing

# Approaches to coordinating community engagement activities



- Consultations with intervention and research teams
- Annual reviews
- Key message development
- IEC development
- SOP development and implementation
- Data collection, feedback and monitoring

## Instrumental role of community engagement



- Enhanced the informed consent process
- Supported the recruitment & retention drives-
- 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 determined waiver of parental consent for the adolescent survey



# 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

# Challenges

- Restricted use of mobilization approaches to avoid contamination of control communities
- Standardization of message delivery
- Heterogeneity of communities; varied context including physical and social features
- 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