Community Engagement in the PopART Study

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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