HIV PREVENTION RESEARCH UNIT

STRATEGIES FOR ENGAGING COMMUNITIES IN MICROBICIDE RESEARCH: EXPERIENCES, ACCOMPLISHMENTS AND LESSONS LEARNED

GITA RAMJEE

MTN Annual Meeting: 22 April 2008
DESCRIPTION OF COMMUNITY

COMMUNITY GATEKEEPERS
- Political organizations
- Traditional leaders
- Local/ District Councilors

PARTICIPANT
- Male partners
- Relatives

CWG/CAB
- Members of community
- Participants
- Service Provider

Service provider
- Religious groups
- Key role players
- NGO, CBO
COMMUNITY ROLE IN RESEARCH PROCESS

Community Entry

Community education & awareness

Development of referral strategies

Participant recruitment, screening

HIV +ve- screened out-referred to health service

HIV –ve- enroll

Accrual & retention referral for care

Community Leaders, local health care providers, NGOs, CBOs, women’s groups

Education: general HIV/STI prevention, home-based care, clinical trials, informed consent and regulatory process

Study completion / participant exit

Follow-up
• HIV Testing
• Pregnancy testing
• Safe Sex & HIV/STI prevention counseling
• STI testing
• Safety Testing

Regular Feedback
Communication with community gatekeepers is vital:

- Community entry
- Study approval and implementation
- Recruitment, retention and study close-out
- Results dissemination
- Study status update from PI with community stakeholders, DOH, NHREC
EXPERIENCES

Education

- HIV/AIDS: based on identified community needs
- Capacity build community members on basic counseling on HIV/AIDS prevention, treatment and home based care
- Train CWG/CAB members on responsibilities of investigators, ethics and human subjects training
- Protocol training: input from community on informed consent document and study procedure
- Respect the cultural norms and values of the community
Peer Educators

- Develop volunteers as peer educators and trainers
  - Protocol training
  - Recruitment and retention requirements
  - Results translation and dissemination
EXPERIENCES

Trial results dissemination:

- Update community on clinical trial outcomes regularly
- Results outcome and methods of dissemination discussed with community
- Assist community members to address rumors/misinformation
ACCOMPLISHMENTS

- Sustained relationships with various stakeholders
- Development of sustainable health referral systems with the community for HIV positive screened out women, HIV seroconvertors and for reproductive health care
- Trained Peer educators are a resource to the community who provide basic counseling and HIV/AIDS information
- Well educated and empowered CWG/CAB who provide ongoing HIV/AIDS education
ACCOMPLISHMENTS

- Male involvement programmes with the community where partners of women come forward for HIV/STI testing

- Traditional leaders - partnerships with HPRU to encourage male involvement in HIV prevention efforts

- Media and communication plan in place for trial results dissemination involving community members
LESSONS LEARNED

- Respect for community cultural norms and acceptance of traditional values in the research process
- Regular and ongoing communication with key role-players from investigators/PI
- Update community on results/outcome to avoid concerns due to sensationalism in media reports
- Address ethical concerns with transparency and honesty
CONCLUSION

- Transparent and honest community partnership is key to success of clinical trials
- Involve community members from protocol development to dissemination of results
- Respect cultural norms and traditions
- Assist and participate in community programs to enhance relationships and to use opportunity to increase awareness of HIV/AIDS
- Mutual trusting relationship is important for any community based intervention