### **HIV PREVENTION RESEARCH UNIT**

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

**GITA RAMJEE** 

MTN Annual Meeting: 22 April 2008



South African Medical Research Council

BUILDING A HEALTHY NATION THROUGH RESEARCH



### **DESCRIPTION OF COMMUNITY**



Building a healthy nation through research

# **COMMUNITY GATEKEEPERS**

- Political organizations
- Traditional leaders
- Local/ District Councilors

#### **PARTICIPANT**

- Male partners
- Relatives

**Community** 

#### **CWG/CAB**

- Members of community
- Participants
- Service Provider

### Service provider

- Religious groups
- Key role players
- NGO, CBO

# COMMUNITY ROLE IN RESEARCH PROCESS

Regular Reeclback



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**Community Entry** 

Community education & awareness

Development of referral strategies

Participant recruitment, screening

HIV +vescreened outreferred 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

# **EXPERIENCES**



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### 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



### **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



### **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 programsenhance relationships and to use opportunity to increase awareness of HIV/AIDS
- Mutual trusting relationship is important for any community based intervention