Mapping the Evolution of the HPTN Community Program and Recruiting Populations at High Risk

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2012 HPTN Annual Meeting
Monday, June 25, 2012
Talking Points

• The Beginning.
• Procedural structures to partnerships.
• Implications of changing prevention science paradigm for CWG.
• Recruiting Populations at High Risk.
• Strategies for community involvement in Population Based HIV Prevention Studies.
• The way forward.
The Beginning

First annual CWG meeting 25 October 2000

Mission of the CWG being:

“To inform the development of a community centred, relevant, utilitarian and ethical research agenda; bridging the gap between science and the communities in which the research participants live; proactively develop community mechanisms for dialogue that will enhance scientific and ethical rigor of HPTN studies.”
The beginning cont...

CWG built on 4 core principles:

• Community involvement being a parallel process with development of science agenda.
• Provide technical support and advocate for adequate financial support for CP activities.
• Create regional linkages ensuring representation from international sites.
• Community involvement in all levels of the HPTN network, CTU’s and sites.
Procedural structure to Partnerships

Increase understanding of community involvement.

Develop community capacity at HPTN sites

Integrate community perspectives into HPTN research.
Procedural structure to Partnerships ...

June 2012

Ensure community input into science generation and research process.

Build community capacity at local level to inform science.

Develop mechanisms for sharing experiences, lessons learnt and best practices.

Assessing impact of community involvement.
Shift beyond advisory role on procedural community involvement to successful community partnerships.

Continuum of evolving partnership

Advisors/Consultants

Partners/Collaborators
Community Involvement built into the “Components of the Prevention Science Research Continuum”

Stage 1 Conceptual
- Advocacy
- Community Awareness
- Theory/Biological Plausibility
- Hypothetical Acceptability
- Formative Operations

Stage 2 Experimental
- Policy Development
- Community Engagement
- Conceptual Development
- Clinical Acceptability
- Program Modeling

Stage 3 Applied
- Policy Application
- Community Ownership
- Phase 4 Effectiveness
- Experiential Acceptability
- Program Implementation

MacQueen KM, Cates W. AJPM 2005;28(5)::491-5.
Implications of a changing prevention science paradigm for CWG

• Historic focus by community personnel & CABs has been on:
  o individual capacity to understand risk and benefit
  o participant burden & participant rights

• Prevention trials complicated by miscommunication and lack of authentic community involvement (AVAC)

• Focus on participant – little attention to broader community context, values and norms.

• Increased awareness of benefits of community involvement.
Recruiting Populations at High Risk

• Into 3rd decade of AIDS epidemic.
• Hidden, marginalised and vulnerable populations remain hard to reach through conventional recruitment strategies.
• Community values, norms & context impact on recruitment:
  o Taboos around discussing sex
  o Value placed on female fertility
  o Need for community endorsement
  o Transient communities
Recruiting Populations at High Risk through:

1. Linked person mobilisation:
   • Person with population knowledge
2. Peer mobilisation:
   • Contemporaries
3. Leader mobilisation:
   • Group or associated leaders
4. Study staff mobilisation

### Participatory Methodology and ‘mobilisers’

- Need for greater co-operative enquiry between target population and study team
- Community involvement develops gradually

![Continuum diagram]

<table>
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<th>Community Mapping</th>
<th>Participatory Management</th>
<th>Social Mobilisation</th>
<th>Early Adopters</th>
<th>Change Agents</th>
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Persons at high risk for HIV infection in Kisumu, Kenya: identifying recruitment strategies for enrolment in HIV-prevention studies

Strategies for Community Involvement in Population Based HIV Prevention Studies

- Shift from building community awareness to social mobilisation and diffusion.
- Communication and flow of “new” ideas through key community ambassadors/advocates/mobilisers.
- Develop a research literacy at community level.
- Refine messaging and communication strategies to impact population based studies and implementation science
Into the Future

- Ongoing success of HPTN research
  - Informed and shaped by critical community input
- Social mobilisation and participatory methods – needs to be strengthened through social science.
- Identify best practices to evaluate and document the value-added by CWG in scientific review and community involvement.
- Describe and further develop models for community involvement in the implementation of population-based research.
Acknowledgements

• Sponsored by NIAID, NIDA, NIMH under Cooperative Agreement # UM1 AI068619

• HPTN Leadership

• HPTN Community Program CORE
Communities and study participants who have contributed to the success of the HPTN