12 Years On -
Ethical Goals in Community Consultation

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HPTN Annual Meeting
6 June 2011
Washington
Outline

- Community Involvement in Research
- 2000 HPTN CWG
- HPTN Community Programme Evolves
- Guidelines: Community Involvement in Research
- Ethical Consideration and Ethical Goals
- The Future: Combination Prevention
- 2011 HPTN CWG – Way Forward
- Conclusion
Community involvement in research

- Early 80’s US AIDS activists mobilised for role in treatment research
- 1989 NIAID funded 17 units (CPCRA)
  - Formalisation of CABs
- 1998 Importation of CAB model to international research sites.
- Incorporated into Ethical Guidelines
The CWG will:

- integrate the participation of community members who represent diverse HIV study communities and their advocates into the CWG.
- promote understanding of community needs and issues among HPTN researchers.
- inform and advise the HPTN EC on issues of concern.
- support collaboration at the site, working group and network levels.
HPTN Community Programme Evolves

- Increased awareness of benefits of community involvement
- ‘Drift’ to embrace participatory methods – acknowledging community significance
- Change in paradigm from who and how research is implemented
  - Investigator’s initiate partnering with community
- Key to success of HPTN research
  - Informed and shaped by critical community input
- Enhance community capacity to meet new role and responsibilities
  - Reactive to pro-active engagement with research team
HPTN Community Programme Evolves ....

HPTN research ensured that research communities have a role in the research process.

Continuum of an evolving partnership

Advisors/Consultants  

Partners/Collaborators
HPTN Community Programme Evolves ....

- Community Participation in the Research Process
- Researchers and Sponsors
- Ethics Committees
- Principles of Research Ethics
- Informed Consent
- Research Ethics Documents
Guidelines: Community involvement in research

- 2004 Closure of PrEP trials
- 2005 NIAID CCWG – Community Partners
- 2007 Good Participatory Practice (UNAIDS)
- 2009 NIAID Recommendations for community involvement in clinical trials
- 2010 Good Participatory Practice 2nd Edition (UNAIDS)
Ethical Considerations

“To ensure the ethical and scientific quality and outcome of proposed research, its relevance to the affected community, and its acceptance by the affected community, researchers and trial sponsors should consult communities through a transparent and meaningful participatory process which involves them in an early and sustained manner in the design, development, implementation, monitoring, and distribution of results of biomedical HIV prevention trials.”

Ethical Goals of Community Engagement

2005: Dickert & Sugarman
- Enhanced protection for communities
- Enhanced benefits for community
- Legitimacy of research
- Shared responsibility for the conduct of and results from the research

2010: GPP Guidelines
- Respect
- Mutual understanding (Socio-cultural & research competency)
- Scientific and ethical integrity
- Transparency
- Accountability & community autonomy
The Future: Combination Prevention

- Encouraging results: iPrex, CAPRISA 004, HPTN 053, HPTN 052.
- Shift: Facility based individual level RCT’s to community-level RCTs.
- Ensure scientific research literacy at community level.
- Efficacy & effectiveness trials generate information on partial protection - Need to deliberate with community – if, when, how and to whom a partial effective product would be available.
- Establish common language to describe combination modalities and their impact on each other.
2011 HPTN CWG – The Way Forward
Meeting Ethical Goals of Community Engagement

- Literature review of Ethical Goals in Community Engagement - (EWG & CWG. Jessica Holzer).
- Reliability and validity of community engagement measures unknown.
- Develop and test measures of quality community engagement & quality adherence to the ethical goals of community engagement.
- Include measures in HPTN Network Evaluation
Conclusion

Community participation is a component of larger HPTN Ethics agenda
Community partnerships must occur at all levels of the research process
Community processes are key to ethical conduct of research

“Community Participation is Ethics In Action!”

Ref: Quarraisha Abdool Karim. 2003
Acknowledgement

- HPTN Community Programme & HPTN Team
- CWGs and CAB representatives
- Jeremy Sugarman & Jessica Holzer
- Study participants & community stakeholders who have participated in and supported HPTN research

Thank-you for an incredible journey !!!

Indebted thanks to PI’s Sten & Quarraisha, the EC, Community CORE, CP colleagues.
Best wishes to incoming PI’s and leadership