

Building knowledge about research subjects and their communities – the CAB approach

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Overview

- Defining the community
- Goals of Community Advisory Boards
- Establishing CABs
 - Selecting members
 - Accessing the community
 - Working with the community
 - Best practices
- Future plans



Defining the community

■ Community

- awareness of relevance for health behavior and promotion

■ Community – components

- Formal organizations

- Local government, business, educational, religious

- Informal social networks

- Families

- Individuals



Defining the community

- Components are
 - Inter-related
 - Have the potential for being mobilized

- Inter-relatedness
 - Community systems influence health behavior affecting individuals -- through
 - altering physical environments e.g. space and time in health facilities
 - Social influences on individual attitudes and behavior
 - interacting systems e.g. education and health - ARHE in primary schools affecting access to condoms/VCT for adolescents



Defining the community

- Potential for being mobilized
 - Health promotional and ill health preventive strategies
 - Harnessing benefits of complex interactions between formal and informal systems and individuals
 - Comprehensive strategies need to be multi-level
 - Changing individual determinants of behavior
 - Changing environments in manners that make it safe for implementation of health promotion/ill health prevention strategies
 - Comprehensive strategies need to be integrated
 - Program components reinforce each other



Goals of CABs

- Ensuring relevance, appropriateness and ethical soundness of health related research initiatives involving human subjects

THROUGH.....



Goals of CABs

- Involving communities where research activities are planned in:
 - The process of research
 - Defining the research agenda
 - Collecting data
 - Reporting research findings
 - Providing feed-back to research teams
 - ethical oversight on the research process and procedures
 - Developing sustainable interventions, involvement in implementation and evaluation



Selecting CAB members



Representation of the community

– Key stakeholders from

■ Formal organizations

- Local government: Health, Education, Media, Community development and planning, social welfare etc
- Community based organizations: Wamata, Pasada, KIWAKUKI etc

■ Informal organizations

- Primary care providers in the home

■ Individuals

- Persons living with HIV/AIDS exposed to research initiatives



Process – selecting CAB members Dar HIV/AIDS preventive trials CAB



■ Steering committee

- Community educator
- 2 Co-PIs and research coordinator
- 2 HIV/AIDS care and treatment advocates from the community
- 1 teacher
- District AIDS Coordinators



Process – Selecting members

- Deciding on composition of the CAB
 - Local grassroots HIV/AIDS care and support NGO representation
 - PLWHA's discharged from HIV/AIDS studies
 - Education sector - Retired teacher
 - Traditional HC systems - Traditional birth attendant
 - Edutainment - Drama artisan
 - Nutritionist



Process – Selecting members

■ How to select members?

– Snowballing

- Local government recommendations
- Community advocates for preventive efforts
- Identified volunteers providing support and care

– Mapping of key community stakeholders

- Group meetings to define membership criteria
- Selecting from mapping information/ group meetings person's that meet agreed upon criteria

– Defining criteria for continued membership



Process- Accessing communities

- Accessing the community - Entry point
 - local government leaders at region, district, ward and hamlet levels
 - District level: health, social welfare, community development and planning
 - Ward level: Ward chairs, executive secretaries, health committee members and MACC's
 - Community level: Religious leaders, all faiths and hamlet chairs
 - Focus on catchments served by study clinics



Process- Accessing the community

■ Sensitization seminars

- Held per district (3)
- Turn out > 100 community leaders
- Presentations
 - CAB chair and community educator
 - PI's, Co-PI's and
 - local health officials
- Start stop drama to illuminate key concerns
 - Local drama groups



Process – Working with the community

■ During sensitization seminars

– Brainstorming to get local perspectives on the research problem

- Strengths of the community to address problem

- Weaknesses of the community

- Potential solutions

- Homework for each ward to explore strategies for making potential solutions feasible

- Follow up of ward strategies forms the basis of the CAB work-plan with the community



Working with the community – Dar es Salaam example

- Barriers identified implementation of PMTCT
 - Late ANC booking
 - Lack of male involvement in formal ANC
 - Lack of community awareness of PMTCT
 - Poverty and stigma impedes uptake of risk reduction strategies for PMTCT
 - Over crowding in ANC



Working with the community – Dar es Salaam HPTN example

- Areas of common interest community and CAB identified during ward follow-up
 - Planning, development and dissemination of IEC for PMTCT in identified localities
 - Participatory Rapid Appraisal (PRA) approach to reinforce community commitment and ownership of PMTCT activities
 - Mapping of study clinic catchment areas for community drama (edutainment) activities
 - Development and use of traditional media (dances, songs and drama) to convey educative messages.



Working with the community – Dar es Salaam HPTN example

■ Implementation

- Prioritizing where to start
 - Largest # of study clinics in Kinondoni district
- Building ward capacity and ownership

■ One week training to increase community mobilization skills

- Communication strategies and skills
- Mapping localities for community drama and meetings
- Identification of ward strengths weaknesses and opportunities



Working with the community – Dar es Salaam HPTN example

■ Outputs

- Development of ward strategic plan and budget for PMTCT awareness
- Submission at district level for the following budget period
- Core messages for community awareness activities
 - Male involvement in reproductive and child health care
 - Early booking for antenatal clinic (ANC) services
 - Accessing voluntary counseling and testing in ANC
 - Reduction of stigma and discrimination



Working with the community – Dar es Salaam HPTN example

- Tools used to disseminate messages and monitor progress
 - Local drama troop's
 - Artist groups to develop themes for drama
 - Monthly follow-up by community outreach peer educator employed by project
 - Turn out and numbers
 - New problems to inform research team
 - Any feed-back to community from project
 - Recruitment numbers at ANC study sites



Working with the community – Dar es Salaam HPTN example

- Potential effects (not measured systematically)
 - Increase in the numbers of women booking for ANC
 - Acceptance of pre-test counseling and testing for HIV
 - Increased proportion of women returning for test results (ELISA then - rapid tests now)
 - Increase in the enrolment of participants to the research
 - Community more aware of existing PMTCT services



The future


- Rolling out strategy in each district focusing on clinic catchments
- Greater representation from grass root community level
- Strengthening documentation systems and monitoring of CAB activities
- Planning ahead for major activities
- Advocacy for local sources of financing community mobilization initiatives for HIV/AIDS prevention




Case study 1

 What ethical issues are raised?

■ Thinking with hind sight.....

 How can CABs be established in our contexts to address environmental issues that impact on subjects participation?

 What strategies will facilitate CAB experiences impacting more directly on health/social policy and decision-making processes at local government levels?




Case study 2

 What ethical issues are raised?

- After reading the case study, with hind sight.....

 What should be the scope of CAB activities?

 How can CABs at establishment ensure they cater for both the needs of research and communities involved in research?



Case study2

- What are the moral issues raised?
 - Morally not ok, the study brought up something useful but ended abruptly without considering the issue of sustainability.e.g self help groups by CAB.
 - Participants were not informed about the end of the study and not prepared for an alternative.



What should be the scope of CAB?

- CABs should be involved in the process (before,during,after) study.
- CABs should build capacity of the community to take ownership of the study and making support.
- CABs should have 'mission' and 'vision' for sustainability e.g. seek other sources of funds.
 - women should be facilitated to have self support groups.



Establishment of CABs

- Knowing our mission and vision both methods can be used i.e
 - Snowballing e.g. volunteers, experts e.t.c
 - Mapping which gives diversity of CABs members and involve community members to set criteria and use them to get CABs members.
 - NB: Its important to states when CABs membership ends.

