

The Role of the Community in the Research Process

Anant Bhan

Community participation

- Increasing amount of community based research and research within communities
- Communities can suffer research related harms and be exploited
- Partnership with communities helps research
- Increasing importance of engaging communities in research
- Becoming an ethical requirement in research

- Benchmarks of clinical research: *Collaborative partnership and Respect for study communities*

ICMR guidelines: general principles

- Essentiality
- Voluntariness, informed consent and community agreement
- Non-exploitation
- Privacy and exploitation
- Precaution and risk minimization
- Professional competence
- Accountability and transparency
- Maximization of public interest and distributive justice
- Institutional arrangements
- Public domain
- Totality of responsibility
- Compliance

Working with communities

- Is a way of applying the principles of respect, beneficence and justice beyond individuals to communities
- Came into focus (in the west) after the Belmont Report was criticized for being too individual focused.
- Initially promoted extensively in HIV-AIDS research especially larger trials after activists protested about non-participation in decision making .
- Now extending to other forms of research

Problems can arise if communities not involved

- Controversy around Tenofovir prevention trials and suspension of research (in the region; 2004)
- Microbicide trials which were stopped early in South Africa (2007): allegations that participants had been used as "human guinea pigs"

Community Engagement- definition

- a process of working collaboratively with and through groups of people affiliated by geographical proximity, special interest, or similar situations to address issues affecting the well-being of those people

US CDC 1997

Community participation in research

Box 1. Features of a Community in Relation to Research

- Common culture and traditions, canon of knowledge, and history
- Comprehensiveness of culture
- Health-related common culture
- Legitimate political authority
- Representative group/individuals
- Mechanism for priority setting in health care
- Geographic localization
- Common economy/shared resources
- Communication network
- Self-identification as community

Box 2: Goals of Community Engagement

- To ensure the relevance of research (e.g., National Bioethics Advisory Commission, Nuffield Council on Bioethics) [17,18]
- To assess whether relevant research is culturally and practically acceptable in the context it is intended (e.g., Council for International Organizations of Medical Sciences) [16]
- To ensure that community disruption is minimized, i.e., avoiding the displacement of local medical staff from pressing local needs [26]
- To avoid exploitation, by ensuring a fair distribution of the benefits of research [14]
- To take into account the ethical hazards that may be part of the social, economic, and political landscape of the community [27]

Tindana P et al. PLoS Med 2007 Sep doi:10.1371/journal.pmed.0040273

Operationalization of CE

- community outreach, including gatekeepers
- working through community educators
- Hiring community members as staff members
- community member of the IRB
- civil society organizations
- setting up of Community Advisory Groups

Terminology: variations

- Community Advisory Groups (CAGs)
- Community Advisory Boards (CABs)
- Community Research Support Groups (CRSG)- might be separate from CAG/CAB
- Different from the community member on the IRB

Problems with implementation

Often researchers and sponsors want to work with communities

BUT

No clear guidance about what works or not while engaging with communities

Its important to understand

■ Communities:

- are complex
- are not homogeneous or static
- are wary
- need to be respected (could mean learning to expect no for an answer)
- often expect long term relationships

Issues while considering community participation in research

1. a) CLARITY ABOUT GOALS & OBJECTIVES (process/outcome)

b) WHO IS THE COMMUNITY (NIAID Community involvement in HIV-AIDS Feb 2009)
2. HAVE A PLAN: COMMUNITY PARTICIPATION PLAN

3. KNOWING THE COMMUNITY (NIAID
Community involvement in HIV-AIDS Feb
2009)

4. ROLES AND RESPONSIBILITIES
DEVOLUTION (adapted from NIAID
Community involvement in HIV-AIDS Feb
2009)

5. OWNERSHIP

6. CONTINUED PARTICIPATION &
PRESENCE

7. EFFECTIVE & HONEST DIALOGUE,
TRANSPARENCY

8. ENGAGED PROCESS BEFORE, DURING &
AFTER RESEARCH

9. NEEDS EXPERTISE; AND RESOURCES
HAVE TO BE ALLOTTED FOR THIS

10. NEEDS TIME

11. ENGENDERING SOCIAL CHANGE POSSIBLE
(COULD BE CONTROVERSIAL)

12. RESPECT AND TRUST

13. ABILITY TO LEVERAGE LOCAL LEADERSHIP

14. EVOLVE ENGAGEMENT STRATEGIES WHICH
WORK BEST IN LOCAL CONTEXT

15. NEED FOR REVIEWING STRATEGIES
CONSTANTLY (M&E of PARTNERSHIP)

16. PREPARE FOR DRAWBACKS
 17. ADVOCACY FOR COMMUNITY NEEDS AND INTERESTS (WITH FUNDERS/SPONSORS/GOVT. etc.)

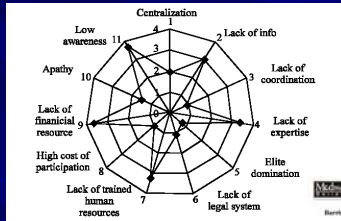


Fig. 1: Interpreting barriers of community participation for tourism development in Shiraz

Conclusion

- “True” partnership with communities helps in carrying out ethical research.
- Set up M&E/accountability mechanisms
- Sustainability important
- Enriches the research process and makes it meaningful

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www.mrcglobal.org

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anantbhan@gmail.com
