



The relationship between community organizations and researchers in Burkina Faso: Result of a participative study

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Introducing RAME

- RAME is an advocacy network that began in 2001 and officially recognized in 2003
- RAME composed of close to 200 members 17 organizations.
- RAME is a member of several other groups: US-SIDA, CCOS/BF, CORAB,
- Missions: To influence the adoption of policies that are favorable to communities' access to quality care.
- Actions: Information, policy analysis, education, lobbying campaigns



Goal and study objectives

- Goal:

- To promote and encourage the organizations' involvement in the research process as well as the respect of ethical principles

- Objectives

- To identify the kinds of kinds of research
- To identify the role played by organizations
- To evaluate the knowledge of organizational members
- To describe the composition, functioning and the rold played by ethics committees
- To evaluate the degree of application of ethical principles
- To make recommendations



Objectives of the presentation

- To present the study results concerning the current role and aspirations of Burkina Faso organizations in research against AIDS



Methodology

- Descriptive transversal and analytic assessment of participation of organizations in three health research sites in Burkina Faso
- Technique of the individual interview
- The materials used are a research questionnaire and a semi-directive in-depth interview guide

Results

- **Poor perception and understanding of the meaning of « ethics »**
 - « it is everything that is good » or « they make you sign papers »,
- **Understanding key elements of ethics:**
 - Informed consent : 61% have heard of this **against 16,6%**;
 - Anonymity and confidentiality : 94% have heard of this
- **Application of ethics in research:**
 - 66% of participants think that ethics are applied, 22% think the opposite and 11,1% have no idea
 - One participant said emotionally, « I understand now that I was used. ».
 - The Nouna ethics committee confesses that they gave a negative opinions on research protocols,

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Resultats (continued)

- Current role played by organizations in research:
 - Identification and helping to recruit participants, data collection
 - Helping less experienced participants
 - Monitor compliance with ethics (less developed)
- Organizations' aspirations regarding research:
 - Contribution to the whole process: organization members (50%) and research structures(46 %)
 - To initiate research: 13,15% organization members and 7,7 % research structures
- Ethics Committees: organizations play a complementary in identifying cases where ethical rules are lacking.



Results (continued)

- **Stakes and benefits of participation**
 - **Organizations:**
 - Building capacity regarding research
 - Increase interest in research
 - Better comprehensive care of participants
 - **Researchers:**
 - Understanding participants concerns
 - Good patient follow up
 - Better patient compliance
 - Guarantee compliance with ethics



Recommendations

- Train diverse community organization representatives
- Teach and provide teaching materials to organizations on ethics
- Support community research
- Set up monitoring committees at research sites that can monitor ethics, take legal action through appropriate channels if need be



Conclusion

- The study revealed an inadequate understanding of and compliance with ethics in protocols.
- Training is necessary
- Strengthening the collaborations between, organizations, ethics committees for harmonious research from research design to the delivery of results.



Merci pour votre attention