Sustaining ethical practices in HIV prevention research in Africa

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Kola Oyedeji- 2013 BHRF, 18-20 Nov. Abuja
Summary of presentation

- Due to increased attention to ethical issues involved in HIV prevention research based on the peculiarity of its outcomes, there is need to sustain the ethical practices to justify such research. I argue that there should be concerted efforts by African Heads of government to mobilize counterpart funding for such research to reduce the burden on tight research budget globally, identify opportunities to integrate the HIV prevention research into existing care and treatment infrastructures, and adopt casuistry approach to approval of such research. To achieve the latter, training of ethics review committees using the Wendler framework is imperative.
Introduction

Sustaining ethical practices in HIV preventive research requires that:

- Investigators appreciate the various stakeholders and the roles they play in making HIV preventive research happen.
- Researchers should not view ethics as a regulatory requirement but as a duty to participants, communities and countries.
- Every stakeholders in research—Investigators/research team members, institutions, sponsors/funders realize the fact that they bear the ultimate ethical responsibility for their work with human participants.

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Ethical practices in HIV prevention research involves

- Promoting fair benefit arrangement

  ✓ Managing healthcare problems of research participants
  ✓ Responsibilities to those who become infected
  ✓ Need for consensus on fair benefit arrangements
  ✓ Critical look at fair payment issues

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Ethical Practice involves....

- Ensuring sound informed consent

  ✓ Test to ensure competency of trial participant
  ✓ ‘Cultural sensitivity’ in the informed consent process
  ✓ Independent monitoring of the consent process

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■ Role of Research watchdogs

✓ This could be a double edged sword: in that it can be a stumble block and it may guarantee sustenance.

✓ For example, the Bioethics Society of Nigeria, NHVMAS, AMAG etc and other civil society organizations

✓ Ensuring that the voice of the ‘researched’ are heard and honored i.e. the various organizations of PLWHA and some other NGOs

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- **Role of institutions**
  - They house the investigators – should hold them for accountability purposes
  - Need to put up policies to protect science, participants and institution.
  - Provide an enabling environment
    - grant management skills
    - Provide infrastructure and support services
    - Setting up and supporting IRB

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- Role of funders/Sponsors

The Central question?

- Where are the funders/sponsors really involved in sustaining the ethical practices?.....

- Should they be involved in providing treatment for HIV infection acquired during the course of HIV prevention research as form of ethical practice?

- Whatever answer; Then how and why?

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Arguments (Sponsor/Funders)

- Three major ethical arguments:
  - Compensation for injury or harm incurred as a result of trial participation (impaired autonomy)
  - Fair distribution of risks and benefits and reducing inequalities in health care (Justice)
  - Duty to maximize the welfare of people (Beneficence)

- These actions are morally praise worthy

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- Role of African government
  - Provision of counterpart funding in research through advocacy
  - Reduced burden on tight research budget
  - Fostered partnership in research with sponsors/funders
  - Casuistry approach to approval of research studies in the country
  - Deliberate action to support the national ethics committee in performing their monitoring role

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- Standards/codes for research conduct should be defined by the NEC guideline based on the standard of the health systems prevalent in the country.

- Ethical practices in HIV preventive research should be a matter of government policy.

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- Govt. should be lobbied to invest more in research through research foundation funds and sometimes counterpart funding in cases such as HIV prevention research because of the outcome.

- Training of ethics committee on review of contentious protocols such as in cases of SoP.
Sustaining the ethical practices

- To assist in training the National/institutional ERCs, the framework of Wendler et al., (2004) may be ethically considered

✓ Scientific necessity of the research
✓ Relevance to the host community
✓ Sufficient host community benefit
✓ Participants and host community non maleficence

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Conclusion

- In sustaining ethical practices in HIV prevention research in Africa the main focus of the African government should be on the provision of care and support addressing the welfare, dignity and respect for life of the research participants.

- There is need to advocate the participation of National government in research through counterpart funding especially as it bothers on the duty of state to protect the rights of the citizens.

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Finally!

The following methods should be adopted

- Advocacy
- Community mobilization- through research literacy trainings
- National and institutional guidance on ethical practices

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References

Thank you

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