Title: Ethical Issues Engagement Marginalized and Vulnerable Groups in Setting Health Research Priorities, Tanzania

Mr. Emmanuel Makundi (Mphil), National Institute for Medical Research (NIMR) – Case study Tanzania,

GFBR 28-29 November, Montreux, Switzerland

Context of Case Study:
- Tanzania planning to initiate the process of setting country research agenda VI: Phase 2027-2031
- Phase IV: 2013-2018 efforts made to ensure vulnerable groups research areas featured in the national agenda
- We present experience of engagement of these groups and discuss challenges and ethical issues
- We suggest issues for recommendations to ensure that such engagement is legitimate in the process of setting 2027-2031 national agenda.

The process

- National Health Research Priorities 2013-2018 many consultative processes, One is engaging and including research areas of vulnerable groups for 1st Time in Tanzania.

- Study carried out Dar es Salaam and Mbulu District in Manyara Region. Selection DSM National Associations of People Living with Albinism and Physically Disabled people both located. Manyara region identified two of the identified marginalized groups, namely pastoralists (Barbaigs) and hunters and gatherers (Hadzabe) were found.

Who are marginalised and vulnerable groups in Tanzania?

- People living with Albinism present health research needs which are special and different from the rest of populations. They reside in rural and urban areas of Tanzania

  - Albinos in 2010- 2017 these groups were targeted for ritual killings for belief of use of their body parts by witchdoctors for people to become rich. A number of them were killed during this time, though today this is no longer a problem.

Who are marginalised and vulnerable groups in Tanzania?

- The Barbaigs belong to a larger group of pastoralists called Datooga. They keep goats, sheep, donkeys and a few chickens, but cattle are by far the most important domestic animals

- The Hadzabe'e are ethnic group in north-central Tanzania, living they are around 1,000-1,500. Hunter-gatherers, and traditionally forage for hunting, berry collection for honey in their areas

Methods

- Use of Nominal Group Technique (NGT) a participatory methods of public engagement and involves four steps i) simple ranking ii) discussion iii) display of results iv) voting

- Unlike other participatory techniques such as Focus Group Discussions (FGDs) voting is central in NGT and allows expression of disagreement of each group member

Methods

- Prior to our study NGT has not been tested in identifying health research priorities involving marginalized groups in Tanzania

- Findings were incorporated in research agenda as a chapter divided in three categories of disease problems, service and social cultural problems for 1st time

Methods
- Ten groups were engaged for men and women
- In each group for stages of NGT were performed

- including simple ranking, discussion, display of results and voting
- 10- 12 members were engaged in each group

- Ten groups consisted of Hadzabe, Barbaig, Physically disabled, People with Albinism, Elderly Persons

Methods

- Priorities from each group are presented in research agenda

- National consultative workshop to discuss and agree on agenda which were then incorporated as a in chapter agenda for 1st time

- Challenge? Agenda was not evaluated, so difficult to know extent of trade-off between the needs of the many (BoD) and the few and did not inform 2019-2026 agenda

Results of Voting: Example of priority disease problems for physically disabled women and Women with Albinism in Dar es Salaam region

Physically Disabled Women (N=12)	People with Albinism Women (N=10)
1. HIV/AIDS	1. Skin cancer
2. Cancer of joints	2. Cervical cancer
3. Fistula	3. Impaired vision
4, Peptic ulcers	4. Initial skin lesions
5. Blood pressure	5. HIV/AIDS
6. Paralysis	6.Sexually transmitted diseases
7. Hydrocele	7. Diabetes
8. Malnutrition	8. Blood pressure

Ethical Issues

- Power between the researchers and the groups -whereby researchers may use their influence to gather opinions. Power manifestation for researchers could be seen as such groups were vulnerable as they were illiterate and poor –so there is a risk for exploitation in a situation of lack of ethical guideline to protect such groups
- We used Heads of Associations and community contact persons to interpret local language and bridge the gap between researchers and the groups,
- However– the power of researchers was still an ethical issue.
- We used NTG an interactive technique which has element of voting to ensure the decision of each member of the group is heard through voting

Ethical Issues
- How do we trade-off between research needs of many e.g. Burden of Disease (BoD) versus research needs of few people women with albinism on prioritised issues such as skin cancers, cervical cancers, impaired vision and initial skin lesions.
- In the planned review priority agenda 2027-2031 we intend to use the NGT to identify research priorities of these groups and incorporate areas as a chapter in national agenda and this has been discussed by agenda planning committee (being a focal person).

Conclusions and recommendations

- Engagement of these groups in agenda setting is legitimate and research needs are special and research must target these groups.

- To ensure that financial resource allocation in health research also target the needs of such groups affirmative action to allocate a budget be done for these groups. Using resource allocation and current and traditional approaches may not solve their priority needs.

- The use of Normative Frameworks such as Accountability for Reasonableness (AfR) could be used to address priorities of such groups AfR addresses the issue of fairness in priority setting focusing on four elements of relevance, publicity, appeal and leadership in ensuring fair decisions in health care.

Conclusions and recommendations

- The use of Normative Frameworks such as Accountability for Reasonableness (AfR) could be used to address priorities of such groups

- Need for a development of ethical guidelines for people living with disability and vulnerable groups in Tanzania

Thank You Very Much for your time and attention !!!

- **AHSANTE SANA!!!!!**

- **Danke Schon!!! Merci Beaucoup!!**

Welcome to the Beutiful Land of Kilimanjaro, the Serengeti and Zanzibar, the Land of Tanzania