

# Ethics of health research priority setting

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## Pecha Kucha presentation

### Ethical issues in relation to engagement and involvement of marginalized and vulnerable groups in setting health research priorities - 2012-2028, Tanzania

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#### **Brief description of case study context**

Tanzania is planning to initiate the process of setting country research agenda VI: Phase 2027-2031. In other phases- since 1992, the priorities of marginalized and vulnerable groups in setting health research have not been given due attention, except for Phase IV: 2013-2018 where efforts were made to see the voice of the groups featured in the national agenda. We argue that priorities of these groups even though their population are few in numbers are important and have valid concerns and have to be integrated into national research agenda as a consideration of 'worse off' and to address the needs of equity in health research agenda setting. We present experience of engagement of these groups in Tanzania and discuss challenges and ethical issues in this process and suggest issues for recommendations to ensure that such engagement is effective and sustainable in the process of setting 2027-2031 priority list.

**The Case:** The setting of the fourth National Health Research Priorities 2013-2018 involved a number of studies among different groups including the marginalized and vulnerable populations in Tanzania.

The study was carried out in Ilala District in Dar es Salaam and Mbulu District in Manyara Region. Selection of Ilala was due to the fact that National Associations of People living with Albinism and Physically Disabled people were both located. Mbulu district was selected for the reason that two of the identified marginalized groups, namely pastoralists (Barbaigs) and hunters and gatherers (Hadzabe) were found. Ten groups were engaged for men and women. Full report [is available](#).

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 and for the period 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.

The Barbaigs belong to a larger group of pastoralists called Datooga. The Barbaigs keep goats, sheep, donkeys and a few chickens, but cattle are by far the most important domestic animal. The meat, fat, blood, milk, hide, horns, tendons and cow dung have either practical or ritual purposes. They were formerly nomadic, depending largely on milk products for diet, and moving whenever the needs of their cattle dictated. Now, however, many farm a plot of maize and sometimes beans and millet. They appear colourful with their reddish, patched leather dresses, bead work, and brass bracelets and necklaces. They are a proud people, with a reputation as fierce warriors. They are resistant to cultural change, maintaining a strong adherence to traditional animist beliefs and practices.

The Hadzabe'e (Hadza people), are an ethnic group in north-central Tanzania, living around Lake Eyasi in the central Rift Valley and in the neighbouring Serengeti Plateau. The Hadzabe'e number around 1,000-1,500. They live as hunter-gatherers, much as their ancestors have for thousands of years. They are the last full-time hunters and gatherers in Africa. The Hadzabe'e traditionally forage for hunting, berry collection and for honey in their areas of residence.

The study employed the Nominal Group Technique (NGT). NGT is one of participatory methods of public engagement and involves four steps namely; simple ranking, discussion, display of results and voting (Makundi et al., 2007). Unlike other participatory techniques such as focus group discussions (FGDs) voting is central in NGT and allows expression of disagreement. NGT has shown usefulness in identifying priorities among health professionals (Redman et al., 1997) and that of lay people and health professionals in Tanzania (Makundi et al., 2007). However, prior to our study NGT has not been tested in identifying health research priorities involving marginalized groups in Tanzania.

**These findings were incorporated in research agenda as a chapter of different stakeholders and were divided in three categories of disease, service and social cultural problems.**

**Results of Voting: Example priority disease problems Ilala District- Dar es Salaam**

<b>Physically Disabled Women (N=12)</b>	<b>People with Albinism Women (N=10)</b>
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**

One of key aspects when engaging such groups is 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 of these groups 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 minority in each member of the group is heard through voting.

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 the groups and incorporate areas as a chapter in national agenda.

**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 even if their numbers are few affirmative action to allocate a budget be focused to these groups. Using resource allocation and current and traditional approaches may not solve their priority needs of these groups.

The use of Normative Frameworks such as Accountability for Reasonableness (AfR) could be used to address priorities of such groups (Daniels & Sabin; 2002). 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.

### References

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