

# Ethics of health research priority setting

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## Health research priority setting experiences from Uganda, Tanzania and Zambia

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### Brief description of case study context

Health research provides evidence for improving health systems and health interventions. Many low income countries, including Uganda, Tanzania and Zambia have instituted National Health Research Authorities (NHRAs) to manage their health research systems. Among their duties, NHRAs should set research priorities. While the three countries have conducted several health research priority setting exercises and there is a potential for them to learn from each other's experience; there are no standardized approaches for facilitating this sharing of experiences. We conducted case studies in Zambia, Uganda and Tanzania to describe and evaluate their health research prioritization based on a framework which was validated in Zambia and internationally<sup>1-5</sup>.

The evaluation used Kapiriri's framework for evaluating HRPS which highlights the best practices in priority setting, including procedural and substantive ethical criteria. It was developed based on the priority setting literature and key informant interviews with global leaders in priority setting. The framework consists of five domains:

- (i) *The priority setting context*: Which highlights the importance of the political, social, economic and cultural context where PS occurs.
- (ii) *The priority setting pre-requisites*: Include availability of financial and human resources, and the presence of a legitimate PS institute with the capacity for HRPS (including knowledge of the approaches, the ethical principles, implementation and evaluation).
- (iii) *The priority setting process*: The PS institute should design and lead the PS process. The PS process should be legitimate, transparent and participatory, and align with the four conditions of a fair process. It should also be informed by evidence, substantive criteria (e.g. equity, feasibility, cost-effectiveness).
- (iv) *Implementation*: To have the required impact, the allocation of resources should be according to the identified priorities.
- (v) *Outcome and impact*: The process should ultimately impact population health and health inequalities.

The framework also emphasizes the need for PS institutions to evaluate and improve their PS processes. To facilitate this, for each domain, the framework specifies 4-8 parameters and for each parameter has objectively verifiable indicators and respective means of verification.<sup>1</sup> While this framework was originally developed to evaluate priority setting for health interventions, it was adapted, validated and used to evaluate HRPS.

*Study approach*: This was a qualitative case study consisting of (1) **document review** and (2) **> 50 key informant interviews with stakeholders involved in HRPS in the three countries**. Respondents included respondents at the global level, as well as the national and sub-national levels. Respondents were asked to provide a detailed description of their most recent health research priority

setting process, based on the evaluation framework. The findings were analyzed by country<sup>2-5</sup>. We share ethical challenges identified from a synthesis of the findings from the three countries.

## **Ethical issues**

The governments in all three countries have instituted a NHRA. They have all identified research priorities throughout the time they have been in existence and we highlight some of the associated ethical challenges.

i) **Fragmentation of the priority setting process by multiple organizations:** While in the three countries NHRAs have been identified as the legitimate institutions to set national health research priorities, other competing organizations within the countries also set health research priorities and often with no clear linkages with the national health research priority setting processes. These lead to undermining of the legitimacy and work of the NHRAs; it also fragments health research priority setting, and further impacts the trust that the public and health system has in the NHRAs. Yet, the NHRAs do not have the authority to streamline the health research PS processes.

ii) **Competing stakeholder research priorities, whose priorities should count:** While all NHRAs recognized the importance of broad stakeholder involvement, they are challenged by the power imbalances at all levels of decision making. At the national level, NRAs spoke of the health research funders hijacking the priority setting process. While the sub-national respondents thought the national level organizations made all the decisions without consultation- yet research is implemented in their jurisdiction. This leads to questions about; Whose priorities should count? Who and where should health research priorities count?

iii) **External expertise which is not always shared and/or translated into local capacity strengthening:** Within the three contexts, the most common health research prioritizing exercises have been facilitated by experts. These exercises have often used different approaches e.g. CHNRI, James Lind, e.t.c. However, time constraints do not allow for local capacity strengthening and ensuring that the approaches are well understood by the NHRAs. As a result, the NHRAs are left with poorly understood un-contextualized priority setting approaches, which they may not be in position to use in future HRPS. Such practices are contrary to the best practices in ethical Global Health Research which emphasizes a commitment to local capacity strengthening.

iv) **Limited adaptation of the approaches which were developed in other contexts to local contexts:** In all contexts where the known HRPS approaches were employed, there was no process through which these approaches and the recommended criteria were adapted for local use. Adaptation would ensure that the local criteria, values and realities are considered. While the NHRA recognize the need for using the current HRPS approaches, failure to adapt them to the local contexts could have, in part, contributed to their limited institutionalization.

v) **Limited evaluation of HRPS:** A common finding was that while several countries have conducted different HRPS exercises, employing various systematic approaches, rarely do the NHRAs conduct systematic evaluation of their processes and the impact of their prioritization processes. This is in part, due to the NHRA's limited resources and capacity. Furthermore, while there's a growing body of literature on systematic approaches to HRPS, there has been limited focus on frameworks/ approaches to guide systematic HRPS evaluation.

## **Conclusions and recommendations**

Since NHRAs are the legitimate institutions for coordinating health research, governments and donor agencies should strength and support the NHRAs with legal, financial and technical resources to enable them to deliver on this mandate. NHRAs should establish systematic mechanisms for identifying and evaluating their prioritization processes, collecting of data on the implementation of the

identified priorities and their impact on health policy.

NHRAs face the challenge of using un-contextualized HRPS approaches and their limited institutionalization. Hence, they should, based on the available approaches identify an approach, or a hybrid of approaches that is suitable for their contexts. This approach would address some of the key ethical challenges identified above e.g. ensuring that the process is led by a legitimate institution, is based on the principles of procedural fairness and agreed on local values and substantive criteria. A participatory process whereby NHRAs are introduced to the current health research priority setting approaches, with their critical assessment of the strengths and limitations of each approach discussed-would support informed decision making on the choice and contextualization of the potential framework (as used for the Zambia case study). This approach would also strengthen the NHRA's capacity and further strengthen their legitimacy<sup>1,2</sup>.

NHRAs should conduct systematic and standardized evaluation of the health research prioritization processes. This will facilitate the gleaning and sharing of lessons of good HRPS practice and areas where improvements are necessary. Evaluation frameworks e.g. Kapiriri et al's framework could be useful in this regard. Such a standardized approach will support cross-country and regional learning.

## References

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