Balancing ethics and stakeholder interests: insights from Malawi

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Brief description of case study context

As persistent global health challenges persist, the allocation of resources for health research becomes increasingly vital to guide the attention toward pertinent concerns. Research indicates that low- and middle-income countries (LMICs) predominantly prioritize criteria such as cost-effectiveness and health-related benefits when setting priorities, often overlooking considerations related to a conducive legal and regulatory framework for implementation, fairness, ethics, and political aspects[1]. To ensure equitability and credibility, it is imperative to adopt a transparent and dependable methodology when establishing research priorities[2]. Achieving fairness and inclusivity in this process hinges on various factors, including the availability of resources. Regrettably, this poses a formidable challenge in economies that grapple with resource scarcity, exacerbating disparities in representation and potentially leading to misinformed prioritization.

Malawi's first National Health Research Agenda (NHRA) outlined the country's priorities for the period 2012-2016. It served as a valuable reference for researchers, policymakers, program implementers, academic institutions, health development partners, and various stakeholders. Notably, the initial NHRA development process was funded by donors, but it lacked a clear implementation strategy. The midterm assessment of this agenda revealed that the established objectives were not achieved, primarily due to resource constraints[3]. There was a notable absence of dedicated funding for implementation, and ownership of the agenda was not well-defined. Consequently, the research focus largely leaned towards projects financed by donors, often influenced by their specific needs and interests. This situation raised questions about the relevance of setting priorities in resource-constrained settings when implementation remained a challenge. It also served as a lesson in identifying the key actors responsible for spearheading priority setting and facilitating effective implementation.

The Ministry of Health's Research Division took the lead in facilitating the development of the second National Health Research Agenda (NHRA) as part of its mandate to promote and coordinate health research efforts. The necessity for this updated set of research priorities became apparent, particularly in the face of emerging diseases like COVID-19 and the resurgence of infections such as cholera and leprosy. Prior to this, health research was often conducted based on individual preferences or the requirements of funders, resulting in an imbalance where research largely catered to the interests of those providing funding. Additionally, it became evident that issues deemed relevant more than five years ago had evolved over time. These factors, combined with a growing emphasis on improving implementation, provided the impetus for the development of the second NHRA.

The process of developing the NHRAII commenced in 2017 but faced multiple interruptions due to financial constraints. In 2020, efforts to move forward were initiated once again but were subsequently stalled for the same reason. The primary challenge remained the heavy reliance on external funding

for this undertaking, which proved ineffective until the Ministry took full responsibility. The intent to establish an agenda was present, but the circumstances were not conducive.

During the preparatory phase (2021), tasks included formulating budgets and work plans and selecting teams to address 10 disease themes to be incorporated into the NHRAII. A planning committee at the departmental level was responsible for choosing these 10 themes, which included the addition of Neglected Tropical Diseases to the nine themes present in the first NHRA. Theme leaders were selected based on their expertise in a specific area by this committee, and they were paired with a research fellow from the research department. Preparations continued with an induction workshop in which the themes underwent thorough review, and thematic working groups, comprising additional experts in specific fields, were established. The work plan, somewhat inflexible with specified time frames for achieving set activities while funding was available, was re-evaluated and assessed for feasibility. Subsequently, data collectors were oriented for fieldwork, data collection tools were formulated, and questionnaires were validated by Thematic Working Groups through weekly virtual meetings.

Data collection encompassed all three regions of Malawi and was succeeded by specialized workshops that brought together experts from various sectors, including the Ministry, public and private entities, research institutions, and representatives from diverse fields. These workshops had limited invitations but welcomed participation from interested parties who could fund their own involvement.

The collected data underwent thorough analysis, and working groups deliberated on proposed priorities. This process involved the utilization of a blend of methodologies, including Essential National Health Research (ENHR) and the Child Health and Nutrition Research Initiative (CHNRI), alongside the Nominal Group Technique. The priorities were evaluated based on several criteria, including the current and potential disease burden, the feasibility and capacity to answer research questions, anticipated research impact, considerations of equity and social justice, and the potential for enhancing research capacity within Malawi.

Experts ranked and reached consensus on these priorities. Subsequently, the priorities underwent consolidation, followed by stakeholder analysis and mapping. The consolidated priorities were meticulously reviewed and proofread. Furthermore, consultations were held with the Ministry of Health (MoH), culminating in a national consultative workshop. The priorities were then endorsed by the Technical Working Group and, finally, by the Senior Management Team of the MoH.

Ethical issues

Inclusion and fair processes

Previous research in low- and middle-income countries (LMICs) indicated that policy makers were the primary group consulted during priority-setting processes[1]. As mentioned earlier, the development of the second NHRA was initiated abruptly and proceeded in a rushed manner, significantly influenced by challenging factors, including financial constraints. This rushed approach also had a notable impact on the involvement and engagement of various essential sectors. A review of the participants in NHRA II reveals a notable imbalance, with a predominant presence of policy makers and experts, while the representation of end users, such as patients, the general population of Malawi, and minority/vulnerable groups, was relatively limited. The identification of themes and thematic teams, as well as the selection of specific methodologies, lacked clear guidelines on who should be included in this process. Nevertheless, in the later stages of the process, various stakeholders at different levels were integrated, which helped address some of the gaps that had arisen during the early stages of development.

Justice

Allowing an open invitation and inclusive representation in various meetings, such as thematic workshops, was a commendable step as it encouraged all interested parties to participate and express their viewpoints. However, this also resulted in individuals with sufficient resources and a strong commitment to advancing their personal agendas or specific research interests having a greater advantage over those who lacked the necessary resources but shared similar interests. Access to information, particularly regarding the open invitation, was generally limited due to the methods of dissemination used, which primarily targeted experts rather than the general public. Given the diverse audience that was needed to balance representation and voices at every stage, it would have been beneficial to utilize more extensive means of communication, such as radios and community outreach campaigns, in addition to emails, social media, and phone calls. The data collection process operated within tight time constraints, mainly driven by the availability of funding. This led to gaps in capturing the perspectives of end users.

Governance

There was a lack of political commitment to drive the implementation of the first NHRA, despite the availability of funding for its development. In contrast, for the second NHRA, there is a determined effort to achieve maximal implementation, and there is a significant commitment to realizing its objectives. To ensure successful implementation, a robust monitoring and evaluation framework has been established, including the definition of specific indicators and annual targets for assessing outcomes. The Research Division has proactively allocated a portion of its funding to support focused health research, in addition to advocating for further support from various stakeholders. Yearly plans have been meticulously devised, and progress will be continually monitored. This reflects a strong and unwavering political commitment to ensuring the second NHRA attains its intended objectives.

Conclusion and recommendations

It is essential to prioritize transparency and inclusive involvement of stakeholders at every stage of the NHRA process. In the implementation phase, there is a comprehensive plan in place that specifically addresses a wide range of individuals and their involvement in achieving the established objectives.

Creating a collaborative platform for both experts and end users can be challenging, requiring a nuanced approach for their involvement. Initiating their engagement at an early stage is crucial, allowing the use of various strategies that promote inclusivity and fairness. For instance, public awareness campaigns targeting the general populace can encourage active participation, even though this might demand additional resources. On the other hand, experts and policymakers often have pre-existing interest, requiring fewer resources to engage them effectively. Moving forward, the focus is on ensuring timely access to information and resources for all, with arrangements already in progress to achieve this goal.

Overall, Malawi must allocate dedicated funding to support priority setting and implementation of research focus. In general, achieving a balance among all factors in priority setting is essential to ensure a harmonious blend of diverse voices, ethical considerations, and available resources. By promoting ethical considerations throughout the NHRA process and its implementation, both global and local policies will be responsive to the needs of all key stakeholders in the cycle**.**

References

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