

Ethics of health research priority setting

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‘Decentralized priorities for central schemes’: experience of Department of Health Research’s prioritization exercise for the Model Rural Health Research Units across India

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Brief description of case study context

India has one of the largest rural populations in the world, where around 65% people live in rural areas¹. Despite significant improvements in health indicators in recent years, rural populations in India continue to face major health challenges, including poor access to healthcare facilities, inadequate healthcare infrastructure, and limited availability of healthcare professionals^{2,3}.

Recognizing this, the Department of Health Research, Ministry of Health and Family Welfare has established Model Rural Health Research Units (MRHRU) across the country, with an aim of creating infrastructure for transfer of technology to the rural level for improving quality of health services to rural population and to provide an interface between researchers, health system and the community⁴. This scheme has currently 28 MRHRUs sanctioned across the country with plans to establish another 11 over the next 4 years. Each MRHRU is an independent unit established within the campus of a rural health center, with dedicated infrastructure, equipment and staff and an annual recurring corpus of funds to carry out locally relevant research. While a national management unit provided the necessary administrative and funding support, each MRHRU was in turn managed by a nodal officer, who would be a full time researcher from the Indian Council of Medical Research.

In this context, there is a need to identify key research questions, nationally, for all MRHRUs, that need to be answered in public health and clinical research, including health systems and implementation research, which can then be used to prioritize research areas and optimize resources available. A research priority setting exercise was conducted to guide research agenda and funding decisions with an aim of increasing the relevance and impact of research⁵⁻⁷. It is crucial in such settings to ensure that research is conducted in a coordinated and collaborative manner, facilitate the development of partnerships between researchers, policymakers, community members, and practitioners, and to ensure that research findings are effectively translated into policy and practice^{6,8-11}. Additionally, the outcomes of such exercises are not necessarily always a consensus, but disagreements on the pathway to consensus are equally important to document. We have adopted a modified version of the James Lind Alliance’s priority setting partnerships methodology for this activity, where we have used a single survey among stakeholders to identify gaps as well as possible research questions¹². The exercise resulted in an interim dichotomy between what the researchers, clinicians and community members wanted. This required a further consensus building exercise to bring everyone on the same page.

Ethical Issues

- ***Leadership and Partnerships***: The process included the appointment of a select steering committee followed by a nationwide survey to elicit priorities from a broad range of participants. The steering committee had experienced members from policy makers, funders, rural health researchers, methods experts, clinicians, and community representatives. This group provided overall technical guidance

and defined the scope of the research priorities. The ethical issues encountered were related to the proportion of members from each domain and the justification for their role in the steering committee as each member brought their own values to the table. The same was true for the survey and how it was disseminated. The diversity of opinion in the initial stages was recognized as a crucial indicator to a more acceptable outcome of the exercise. These differing values meant that a wider range of opinions were documented, but at the same time, the broad scope led to relatively lesser points of agreement among the stakeholders. We attempted at all stages to give voice to the community, researchers, and marginalized populations. However, providing with a platform was not always sufficient, where challenges such as expertise, understanding and language, had an impact on participation in technical discussions. The role of a generalist moderator in deliberations of the committee was recognized as an important one.

- *Ivory towers and decolonization*: It was important to ensure transparency and rigor in the prioritization methodology and we included one such member in the steering committee with expertise and experience in similar exercises. In India, a few national institutes, mostly in metropolitan cities, traditionally have had a disproportionate say in health research policy. A conscious effort was made to avoid members in leadership roles from such legacy ivory towers within urban India and abroad, while including most members from rural settings. The entire exercise was carried out by, for and among Indians.
- *Setting the boundaries*: It was the task of the steering committee to decide on the boundaries of the priority setting exercise. A challenge in such a task is to balance the scope of the national scheme of MRHRU with local priorities. With a broad mandate of 'improving rural health', it was important to define the same and create subcategories for priorities. We classified the broader research questions into those among 'Description', 'Development' and 'Delivery' research, while avoiding 'Discovery' research as that was beyond the scope of the setting. Descriptive research included primarily epidemiological questions that set the boundaries for which diseases and populations groups would be prioritized, and for what reasons. Development research included prioritizing the type of interventions (Pharmacological / Public Health / Health system / community based), target populations and outcomes of interest. An important consideration here was the MRHRU platform itself and factors such as feasibility, resources available and time played an important role. An important goal of this scheme was to promote Delivery research for rural areas and prioritization on Health System and policy research, Implementation science, Health economics and Programme evaluation were sought.
- *Fixed resources-Diverse priorities*: With a national scheme with a predefined scope and a fixed purse, the research priorities elicited were diverse. While the broad themes were identifiable, this highlighted the need for a more localized approach to rank the specific research questions. The MRHRU scheme had a major emphasis on capacity building on health research at the rural setup and this additionally needed defining the scope of the trainings that would be required. Reconciling the above needed involvement of the managers of such schemes, which in this case were at both the national and local levels, and a robust and continuous bidirectional communication channel between the hub and the spokes was necessary.
- *Disagreements*: While it was expected, the range of divergence in priorities between researchers, clinicians and patients was astounding. The community representative from a rural area cut short the deliberations between a researcher and clinician by emphatically stating "Damn the research, I want health services in my village". The dichotomy between what the patients want and what researchers wish demonstrated that more grounded and contextual calls for funding would get better applications in response. Similarly, those with a national outlook had evidently differing priorities from those with local, even though the same health issue or disease was being highlighted. An example is while implementation research was recognized as a priority at national and local level, the domains/diseases of importance under this was more locally relevant. This necessitated moderation of the process in an

intensive way and a continuous curation, allowing for items where consensus was more likely to proceed ahead.

The survey was conducted nationally, among all the stakeholder groups identified (from all MRHRU field areas) and responses were elicited under the broad headings of descriptive, development and delivery research groups. This was then verified by a team of moderators, and recategorized if needed. One insight from the exercise was that most of the research questions received were cross cutting across the themes mentioned above and silos in rural health priorities were rarely possible, leading to more broader priorities than specific ones.

Conclusions and recommendations

While funding calls in India are usually at the national level, the priority setting exercise showed that apart from the national priorities identified, it is also necessary to have a flexible approach of allowing local decision making on a proportion of the funding allocated to each MRHRU. A local research advisory committee for each MRHRU, involving community representatives and primary care physicians from the village is empowered to make funding decisions on the annual recurring grant of that MRHRU.

It is a complex task to identify health research priorities for national schemes that receive funding centrally, and have a common scope, but are localized in their expected impact. Tailoring of the methodology of the priority setting exercise to identify a broader set of national/regional priorities as well as a localized set of specific research questions would be more useful, acceptable and sustainable. It is equally important to identify what is not a priority by factoring in patient's needs and the nuance of feasibility and scope of programs or schemes.

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