Ethics of health research priority setting

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Mitigating disparity by harnessing fair process in health research priority settings: what India might learn from It?

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Brief description of case study context
The healthcare budget for India for the financial year 2023-24 is 2.1% of its gross domestic product (GDP), which is even less than its neighboring countries (e.g., Bangladesh has allocated nearly 2.5% of its GDP to healthcare in recent years). Most of the budget is allocated to healthcare service delivery, and a measly 3.4% is earmarked for health research. The scenario looks even gloomier for the mental health budget, which gets 0.15% of the total health budget. Most of it goes to the national tele-mental health program, the government's flagship project to provide mental healthcare in remote locations. The burden of mental disorders is enormous; an estimated 197.3 million people live with mental disorders in India. Mental disorders contribute to more than 4 percent of disability-adjusted life years (DALY), which has doubled in the last three decades.[1] However, no special budget is set aside for mental health research, and it must compete within the already constrained health research budget. Therefore, health research priority setting assumes a paramount role in allocating scarce resources judiciously and equitably to enable health research to understand better, protect, and promote individual and population health.

Against this backdrop, the Indian Council of Medical Research (ICMR), the largest public funding body for medical research in India, published a call for an investigator-initiated proposal for a grant of up to 15 million INR. The advertisement listed 54 priority diseases/conditions. The agency prioritized discovery (e.g., finding novel interventions), development (e.g., making existing interventions safer, effective, and affordable), and delivery (e.g., implementation) research over descriptive research.

Ethical issues

Selection of priority diseases/conditions
Three mental disorders are on the ICMR's priority list: depression-anxiety, psychosis, and substance use disorders. The process of selecting research priority has not been made public; therefore, the stakeholders are unaware of the reasons for selecting a broad list of priorities and cherry-picking a few conditions, leaving others off the list. Moreover, the funding agency does not talk about the *revisability* of the list in light of new evidence and arguments. This top-down process and handing over a final list of research priorities negates inclusiveness and stakeholder engagement, which are the tenets of inclusion and fair process in a research priority setting.

The ICMR started a research priority-setting exercise earlier this year, involving several expert consultations. This is an encouraging beginning for mental health research. However, the consultative process needs more inclusivity.

Missing health equity as a criterion for the selection of research proposals
The ICMR plans to evaluate the proposal on novelty, rationale, potential health impact, methodological rigor, and deliverability. It does not talk about health equity as a criterion for selection. Shunning "descriptive research," which could pave the way to understanding social

determinants of health, also adds to the problem. Health equity is the "principle underlying a commitment to reduce—and, ultimately, eliminate—disparities in health and its determinants, including social determinants."[2] Equity is a standard criterion for priority settings per the Child Health and Nutrition Research Initiative and the Combined Approach Matrix.[3] The ICMR has used this approach before in maternal, newborn, and child health.[4] An equitable research agenda is important to reduce healthcare disparities based on economic and social status, gender, sexual orientation, neighborhood, housing status, and many other characteristics that are better known as the *social determinants* of health. People with mental disorders, as a group, experience severe health disparities and discrimination. The life expectancy might be shortened by 10-30 years.[5] Equitable health research ensures these vulnerable groups' representation, participation, and benefit from the research outcomes.

An analysis of wealth quintile-based mortality statistics showed that the life expectancy of the poorest fifth household is more than seven years less than that of the richest fifth household in India. The disparity is larger in the rural context.[6] The National Health Policy 2017 envisions "…. universal access to good quality healthcare services without anyone having to face financial hardship as a consequence." Equity has also been enshrined as essential to the national mental health policy (2014). The missing "equity" criterion from the ICMR's evaluation process does not seem to be aligned with the national health policy.

Conclusions and recommendations
I discussed only two of the many ethical concerns that must be addressed to minimize disparities and ensure transparency in health research priority settings in India.

Recommendation 1: India is a diverse country with varying needs across states and populations (e.g., suicide rates in the southern states are double the national average, and opioid use is ten times the national average in several northeastern states). The ICMR has 31 regional centers. Instead of top-down research priorities, the regional centers should develop priorities relevant to the region through a consultative process. The composition of stakeholders and the process for involving them will need to be discussed regionally but should include family members/carers. The *quality of non-elite participation* must be emphasized, given the hierarchical societal structure and power dynamics in the Indian context. The final list might include region-wide research priorities generated through a bottom-up transparent and consultative process.

Recommendation 2: Health equity must be considered an essential criterion while evaluating the research proposal. Priorities might be given to research that integrates community engagement and partnership, ensures representativeness of diverse and vulnerable populations, designs an accessible and affordable intervention, looks at the importance of contextual factors, such as the structural and social determinants of health, and incorporates the post-research dissemination and continuity of healthcare delivery.

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