

Ethics of health research priority setting

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Pecha Kucha presentation

The ethics of the Philippine National Health Research System's (PNHRS) 2017-2022 National Unified Health Research Agenda (NUHRA)

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Background and description of the NUHRA

The Philippines has a National Unified Health Research Agenda (NUHRA) that provides the health research priorities in the country and is formulated and adopted by the Philippine National Health Research System (PNHRS). As a background, the PNHRS is a framework anchored on the principles of Essential National Health Research on inclusiveness, participation, quality, equity, efficiency, and effectiveness, operationalized by individuals and institutions involved in health research and development specifically the core implementing agencies: the Department of Science and Technology (DOST) through the Philippine Council for Health Research and Development (PCHRD); the Department of Health; the Commission on Higher Education; and the University of the Philippines Manila-National Institutes of Health. The PNHRS ensures that health research is linked to the health system needs of the country, investments in health research yield the most benefit, and resources for health research are sustainable, with the aim of improving the health status, productivity, and the quality of life of Filipinos.

The PCHRD serves as the national coordinating body for health research as well as the lead coordinator of the PNHRS. It provides technical and administrative support to the PNHRS' Governing Council, Steering Committee, and Technical Working Committees, namely the Committees on Research Agenda Management (RAMC), Capacity Building, Research Utilization, Resource Mobilization, Structure, Organization, Monitoring, and Evaluation, and the Philippine Health Research Ethics Board.

The development of the NUHRA is led by the RAMC, which is tasked to provide technical and policy advice in formulating the research agenda for the present and future requirements of the country's health system. The NUHRA and Regional Unified Health Research Agenda (RUHRA) are used as strategic tools to direct research programs, funding priorities, and related activities. In 2016, the RAMC pursued the development of a Guideline for Health Research Prioritization to aid research priority setting activities that are contextualized in the Philippine setting and was adopted in the development of the 2017-2022 NUHRA or NUHRA 3. These guidelines provide for a comprehensive process of health research priority setting that includes a preparatory phase, an implementation phase, and a post-implementation phase.

The preparatory phase includes: (1) contextualization of the research priority setting; (2) preparation of a research agenda monitoring and evaluation plan, an implementation plan for the prioritization activities, and an agenda dissemination plan; (3) information gathering; and (4) inclusive stakeholder and participant identification and engagement. The implementation phase involves the generation of an initial list of health research topics, determination of criteria for prioritization, and determination of the method for deciding on the research priorities. Finally, the post-implementation phase includes the reporting of the prioritization process and its results, dissemination of the research agenda, monitoring and evaluation of the uptake and effectiveness of the research agenda, and review and updating of the agenda.

Ethical issues and recommendations

Inclusiveness and Stakeholders' Participation during the Research Priority Setting Workshops: The PNHRs RAMC's Guideline for Health Research Prioritization ensures inclusiveness of any health research agenda-setting, especially that of the NUHRA, providing for the inclusion of both primary and secondary stakeholders such as scientists and researchers, non-scientist clinicians, government agencies, policymakers, academic institutions, funding agencies, development organizations, industry (such as pharmaceutical companies, manufacturers, and clinical research organizations), private foundations, and civil society organizations. The guideline also recommended the engagement of the general public and marginalized groups.

The adoption of the guidelines in the development of the NUHRA 3 improved the inclusiveness of the priority-setting activities, especially compared to the previous NUHRA development activities. To guarantee that the regional stakeholders are represented during the regional research priority setting workshops, the identification of participant stakeholders at the regional level consultations was given to the 17 Regional Health Research and Development Consortia (RHRDC), yielding a total of 387 stakeholder participants. Of this, 56% were from government agencies, 34% from academe, 7% from NGOs, and 3% from the private sector.

Commentary: RHRDCs are composed of member institutions, mostly from academe, regional and provincial government agencies, and hospitals and medical institutions. This means that RHRDCs with fewer member institutions or smaller networks are limited in terms of engaging stakeholders that are not within their membership, especially minority groups such as women's groups, indigenous groups, rural and urban poor communities, and patients' groups, caregivers, and their families. As beneficiaries of health research, it is imperative that the perspectives of non-RHRDC members, i.e., the general public and minority groups, be heard and considered, especially during the regional consultations.

Monitoring and evaluation of the adoption and implementation of the NUHRA: The guideline provides that the preparation of a monitoring and evaluation plan is part of the pre-implementation phase of an ideal research priority-setting activity. This is because low- and middle-income countries such as the Philippines have limited financial and expert human resources, so monitoring and evaluation of the adoption and uptake of the research agenda would inform stakeholders whether the set priorities are efficiently addressing the health issues they are designed to address. A monitoring and evaluation (M&E) plan proposal was developed in NUHRA 3, which also enumerates the performance indicators and next steps for the development of the 2023-2028 NUHRA. The proposed M&E plan included the source of the performance indicators, which is the PNHRs Monitoring tool, the recommended timelines, which are annual monitoring, mid-term evaluation in 2020, and final evaluation in 2022.

Commentary: Although the proposed M&E plan was sound and specific enough to monitor the dissemination, adoption, and uptake of NUHRA 3, the developed monitoring tool was not successfully pre-tested and rolled out. Hence, data collection for proper and efficient monitoring of the NUHRA 3 performance indicators was a challenge. Moreover, the scheduled mid-term evaluation of the NUHRA 3 in 2020 was hindered due to the realignment of the 2020 national budget to respond to the COVID-19 pandemic, and almost all resources of the PNHRs were redirected to COVID-19 research, response, and economic aid.

Limited resources lead to inequity in funding approval of health research proposals: The 2017-2022 NUHRA identified six themes encompassing the research priorities identified in the regional and national consultations, namely: (1) responsive health systems, (2) research to enhance and extend lives, (3) holistic approaches to health and wellness, (4) health resiliency, (5) global competitiveness and innovation in health, and (6) research in equity and health. Based on the RAMC-commissioned final evaluation of the NUHRA 3, the most funded research priorities were those that fall under the themes of global competitiveness and innovation in health, research to enhance and extend lives, and health resiliency.

Commentary: It is understandable that much of the limited resources for health research, especially of the PCHRD, were directed to subtopics under the theme of global competitiveness and innovation in health (e.g., drug discovery and development, biomedical products, and engineering) and subtopics under research to enhance and extend lives (e.g., nutrition, non-communicable diseases, and communicable diseases), especially during the onset and height of the COVID-19 pandemic. However, annual monitoring reports would have been useful in identifying which priority areas were addressed by researchers and funding agencies each year, informing the future actions and approaches of the PNHRs on how to equitably distribute the available resources to the researches under other priority areas identified in the NUHRA.

Recommendations

1. Identify and invite the unrepresented and underrepresented sectors that are recommended by the Guideline to be included in the national and regional research priority-setting workshops in the development of the NUHRA and RUHRA, especially those that are non-RHRDC members.
2. Formulate a strong and harmonized monitoring and evaluation of the NUHRA through inclusive regional and national workshops to ensure that research priorities determined in the priority setting process are properly included, tracked, and measured in the monitoring and evaluation tools. This harmonized monitoring and evaluation tool should also be adopted by agencies of the PNHRs to verify that all health research programs, projects and efforts in the country are aligned with the NUHRA and RUHRA.
3. Through inclusive research priority setting and the formulation of a strong and harmonized monitoring and evaluation tool, it would be guaranteed that the identified research priorities are equitably funded, and the benefits are distributed to all intended beneficiaries.

References

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