

Research priority-setting is an ethics exercise: lessons from the Global Forum on Bioethics in Research for the Region of the Americas*

To the Editor:

Research improves people's health and well-being. While it is not possible to be sure a study will produce positive results (e.g., discovering a cure or other intervention that is effective in preventing or treating a disease), it is clear that *not* conducting research will not allow to find ways to prevent or treat disease, or otherwise have a positive effect on people's health or well-being. Research priority-setting exercises are necessary to decide how to allocate resources for health research. The research that is done or that fails to be conducted is therefore morally relevant: it is a matter of justice and equity. Decisions about research priority-setting benefit individuals and groups whose health conditions and needs are among the research that is prioritized; such decisions also imply that other groups will not enjoy similar benefits.

Research priority-setting has traditionally been approached as a topic that is purely scientific and efficiency-related, with a view to maximizing available resources and the impact of research. This has especially been the case in low- and middle-income countries. Many countries in Latin America and the Caribbean have carried out health research priority-setting exercises, which have resulted in national research agendas, often with the support of the Pan American Health Organization (PAHO). These processes have sought to be systematic, transparent and inclusive. Priorities identified by a diverse group of key stakeholders –academics, health professionals, researchers, health authorities and civil society representatives– are as a rule solicited as part of the priority-setting process. However, these processes have not included an explicit discussion of the ethical values guiding research priority-setting.

The 2023 meeting of the Global Forum on Bioethics in Research focused on the ethics of health research priority-setting (1,2). During two days, more than 90 participants from different countries of the world discussed this topic. The participants from Latin America –from Argentina, Brazil, Ecuador, Honduras, Paraguay and Peru– call for research priority-setting to be considered an ethical exercise and not just a technical one. Specifically, we believe that future priority-setting exercises should make the ethical aspects of research priority-setting explicit, without limiting the ethics discussion to a matter of procedure (i.e., procedural

ethics). Research priority-setting processes should specify the substantive ethical criteria that guide the prioritization, such as reducing inequities or maximizing population benefits.

Invoking substantive ethical criteria does not entail an agreement on the criteria that should always dictate priorities for all research, or, even if there is agreement, that it is possible to rank all research based on those criteria. Therefore, invoking substantive ethical criteria does not preclude the need to consider ethical aspects in the processes to set up research priorities. On the contrary, substantive ethical criteria should be analyzed and balanced as part of a deliberation, which should follow procedural ethical criteria such as transparency, inclusiveness and accountability (3). Furthermore, a robust deliberative process is urgently needed because an ethical approach to research priority-setting is novel; there is still a need to better conceptualize the substantive ethical criteria for research priority-setting and elucidate the best way to put them into practice.

Health research priority-setting must consider other challenges, which may become more salient when substantive ethical criteria are incorporated into the discussion, e.g., to prioritize research on the population's health needs or research with greater health impact. These challenges include the importance of clarifying exactly what the relevant needs are, since the need to conduct research on a topic is different from the need to implement health interventions that have already been proven. Other challenges include ensuring that prioritizing research with the greatest impact on population health does not lead to neglecting basic research that precedes clinical and translational research. They also include ensuring research priority-setting does not compromise innovation that occurs unexpectedly.

Recognizing the role of ethics in health research priority-setting is particularly important in countries where the resources available for research are limited and socioeconomic inequalities have a significant impact on population's health. We therefore call for health research priority-setting to be considered an ethical exercise in light of fundamental values such as justice and equity. The development of guidance to integrate ethics in health research priority-setting is key in Latin America and the Caribbean.

Conflict of interests. None declared.

* Unofficial English translation revised by the authors. In case of discrepancy, the Spanish original shall prevail: <https://doi.org/10.26633/RPSP.2024.26>

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Suggested citation Saenz C, Carracedo S, Caballero C, Hurtado C, Leite Ribeiro A, Luna F, et al. Research priority-setting is an ethics exercise: lessons from the Global Forum on Bioethics in Research for the Region of the Americas. *Rev Panam Salud Publica*. 2024;48:e32. <https://doi.org/10.26633/RPSP.2024.32>

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Manuscript (original in Spanish) received on 3 January 2024. Accepted for publication on 12 January 2024. Not peer-reviewed.

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