

Ethics of health research priority setting

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An assessment of the priority setting exercise for health research in Peru

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Brief description of case study context

In Peru, since 2009, the Ministry of Health (MINSA) through the General Office for Research and Technology Transfer of the National Institute of Health (INS-OGITT) has carried out efforts to set priorities for health research. The first process took place between 2009 and 2010, and established priorities for the period 2010-2014¹. The second and the last process took longer, from 2014 to 2018, and established priorities for 2019-2023². Between both processes (that is, from 2015 until 2018) an empty period of health research priorities was experienced in the country. In this case study we focus on the 2014-2018 process in order to describe it, identify some ethical concerns and provide recommendations.

The last process for the identification of health research priorities started in 2014 and had three stages^{2,3-4}. The goal of Stage 1 (2014-2015) was to identify regional health research priorities and it involved the development of participatory workshops in 24 regions. The methodology used for these workshops was adapted from the Combined Approach Matrix of the Global Forum for Health Research⁵ and considered the strategic analysis for health needs checklist of TDR-OMS³. It also included criteria suggested by the Global Forum for Health Research⁶⁻⁸ and the Council on Health Research for Development (COHRED)⁹. The workshops tried to stimulate plural representation, so key regional representatives such as health officials, academics, public and private thematic experts, and representatives of professional associations participated³.

The workshops followed a three-step methodology³. *Step 1* was dedicated to an analysis of the regional health situation presented by OGITT-INS. The result was a list of health priorities with associated strategic objectives. In *Step 2*, roundtables were formed to deliberate on research needs associated with the priorities previously established. For this purpose, the five categories of research types proposed by WHO (i.e., problem, cause, solution, implementation, and evaluation) were considered¹⁰, and through an algorithm and available scientific evidence, the roundtables reached, by consensus, a list of research needs. In *Step 3*, OGITT-INS devised prioritization criteria for the identified needs: (a) magnitude/severity, (b) cost-effectiveness, (c) feasibility, (d) effect on equity, and (e) impact on capacity building, and the participants assigned numerical values (1-low, 2-medium, 3-high) to each need. The result was a ranking of health research needs in accordance with the score obtained (the sum of the values for criteria).

In Stage 2 (2015) the goal was the prioritization of the regional health problems. For this task, OGITT-INS consolidated the regional health research priorities of Stage 1 into a list of 21 health problems which 174 decision-makers and public health experts ranked through a virtual consultation. Of the total number of decision-makers, 65 were officials of MINSA and the Social Security and 109 were public health experts and professionals.

Finally, in Stage 3 (2018) OGITT-INS consolidated the ranking of the 21 health problems into a list of 11 prioritized problems and shared it with MINSA's technical instances for feedback and recommendations of experts who would be interested in participating in this final stage. As a result, 118 participants divided in 10 working groups attended the national deliberation workshop to discuss the prioritization of health research problems using three criteria: knowledge gap, feasibility, and effects or consequences. As in the previous phase, this exercise involved assigning scores from 1 to 5 to each prioritized problem following the criteria. The result was a list of 58 national research priorities that respond to 10 health problems for the period 2019-2023.

Ethical issues

Peru's recent efforts to have an established process to identify health research priorities to improve its population's health and allocate scarce research resources in the best possible way need to be recognized. However, some ethical concerns of this process are raised in order to propose how research priority setting could be carried out (more) ethically in the country.

Governance. An important ethical concern is the governance of health research priority setting. A first consideration has to do with the time frame of application of the priorities: why are these priorities chosen for a period of 4 years? A second concern is the fact that the process has been uneven in terms of recurrency. While the 2009 process took less than a year to be carried out, the 2014 process took 4 full years to its completion –and in between no priorities were identified. This leads us to inquire about the degree of independence of the process with respect to contextual pitfalls, like political pressures and institutional weaknesses. A final issue has to do with whether the entity that oversees the process (OGITT, INS or MINSA) has clear criteria to evaluate its own success. These questions do not seek to diminish the merits of this great institutional effort but contribute to understanding whether the organization of the process, its methodology, and the practices involved ensure the objectives sought¹¹.

Inclusion and fairness. Even though the process to set research priorities at the national level is driven by a participatory approach aimed at reaching consensus, most of the people involved in the different stages of the process were MINSA's officials and subject experts. For instance, it is worth questioning, how the process preserves the integrity of the regional participatory and plural consultation from Stage 1 with the independent work of the OGITT-INS and the technical input of health authorities and public health experts from Stages 2 and 3. While using technical and expert consultation methods in research priority setting is not *per se* inadequate¹², in order to demonstrate the legitimate and fair aggregation of interests during the procedure¹³⁻¹⁴ more inclusive mechanisms for the identification and engagement of other relevant stakeholders should be encouraged.

Transparency. The goal of OGITT-INS to lead a transparent process of priority setting in health research is evident. It has developed guidelines for each stage of the process that are publicly available through its web site¹⁵. However, there are some parts of the process for which there is no clear information. As previously explained, OGITT consolidates the regional priorities from Stage 1 into a list of 21 health problems without explaining the criteria it uses². In the same sense, the selection criteria to decide who attends the main national workshop of Stage 3 and how the working groups are established are obscure⁴. Transparency is paramount for the strengthening of legitimacy in the resulting national research agenda and to promote public trust in health research.

Conclusions and recommendations

In the past 14 years, Peru has shown its interest in developing and implementing an institutionalized process for the identification of health research priorities with a participatory view. Although these efforts should be recognized, there still are some ethical challenges that OGITT-INS need to address in order to ensure a sustainable and ethical approach to health research priority setting. For this purpose, we recommend:

- 1) To meet standards of performance and ensure the legitimacy of the process, OGITT-INS should focus on establishing objective, evaluative criteria to assess its experience of the past decade and turn it into a sustainable national policy for setting health research priorities. To institutionalize the exercise into the Peruvian health system, and to be able to effectively coordinate with stakeholders and researchers that would take these periodic exercises as seriously as they should, will take time. But that won't happen if the exercise cannot overtly show how it manages scientific evidence, how it weighs and justifies urgent action on one health problem over another, how these results are communicated to research actors, and if the process has no clear indicators of the effect of these exercises on the actual health research that is being done in the country.
- 2) OGITT-INS should implement strategies and mechanisms to meaningfully engage other key stakeholders such as researchers, research participants, patients and health professionals in the different stages of the priority setting process in order to ensure that the resulting priorities are responsive and sensitive to real health needs, cultural contexts and local challenges. Since health is a human right, it is essential that inequalities in access to health are seriously taken into account when establishing the call for stakeholders to participate in regional workshops. Likewise, it is essential that the procedure that OGITT follows to synthesize the health problems of each region of the country, using expert information and systematization methods, are publicly known by the representatives of these 24 regions.
- 3) OGITT-INS should make all relevant information of the priority setting process publicly available and explain in detail how the priorities are to be set (the procedures, methods and criteria to be used for each relevant activity or step of the process). Transparency concerning this is paramount for publicity reasons and for credibility. Because the priority setting exercise aims at public reasoning to some important extent, the process should be publicly accountable to those involved. But also –and built on this– the priority setting exercise should be as transparent as it could if it aims at being effective: if the health research priorities list is not trustworthy for stakeholders, it is unlikely that researchers would adopt it¹⁶. This is even more relevant considering the low credibility of public institutions in the country¹⁷.

References

1. P. Cabezas Sánchez et al. Prioridades de investigación en salud en el Perú 2010-2014: La experiencia de un proceso participativo y descentralizado. Sistematización de la experiencia. Lima: Ministry of Health, 2011. Available from: <http://bvs.minsa.gob.pe/local/MINSA/2781.pdf>
2. Oficina General de Investigación y Transferencia Tecnológica (OGITT). Proceso de identificación de las prioridades nacionales de investigación en salud para el periodo 2019 – 2023. Available from: <https://web.ins.gob.pe/sites/default/files/Archivos/Proceso de identificacion de las prioridades nacionales de investigacion en salud para el periodo 2019 – 2023.pdf>
3. Oficina General de Investigación y Transferencia Tecnológica (OGITT). Documento de trabajo: Guía para la identificación de prioridades regionales de investigación en salud. Instituto Nacional de Salud (INS). Lima, May 2014. Available from: https://web.ins.gob.pe/sites/default/files/Archivos/anexo_1_guia_para_la_identificacion_de_prioridades_regionales_de_investigacion_en_salud.pdf
4. Oficina General de Investigación y Transferencia Tecnológica (OGITT). Taller “Prioridades nacionales de investigación en salud para el periodo 2019-2023”: Guía del participante, Lima, 29 November 2018. Available from: https://web.ins.gob.pe/sites/default/files/Archivos/anexo_5_gu%C3%ADa_del_participante_taller.pdf
5. A. Ghaffar et al. (eds). Helping correct the 10/90 Gap - The Combined Approach Matrix: A priority setting tool for health research. Global Forum for Health Research, June, 2004.

6. Global Forum for Health Research. The 10/90 Report on Health Research 2000. World Health Organization. Geneva, 2000.
7. Global Forum for Health Research. The 10/90 Report on Health Research 2001-2002. Geneva, 2002.
8. Global Forum for Health Research. The 10/90 Report on Health Research 2003-2004. Geneva, 2004.
9. Council on Health Research for Development (COHRED). Priority setting for health research: Toward a management process for low and middle income countries, 2006.
10. World Health Organization (WHO). The WHO strategy on research for health, 2012. Available from: <https://www.who.int/publications/i/item/9789241503259>
11. H. ten Have & M. Patrao Neves. Governance. In Dictionary of Global Bioethics (pp. 585-586). Springer, 2021.
12. A. Tan et al. "What do we know about evidence-informed priority setting processes to set population-level health-research agendas: an overview of reviews", Bulletin of the National Research Centre, 2022; 46 (1): 6. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8733764/>
13. J. Cohen. Deliberation and democratic legitimacy. In *Philosophy, Politics, Democracy: Selected Essays* (pp. 16-37). Harvard University Press, 2009.
14. A. Sen. *Development as freedom*. Anchor Books, 1999.
15. National Institute of Health of Peru (website): www.ins.gob.pe. Accessed 5 May 2023.
16. R.F. Viergever et al. A checklist for health research priority setting: nine common themes of good practice. *Health Research Policy and Systems*, 2010, 8: 36.
17. <https://www.ipsos.com/sites/default/files/ct/news/documents/2021-10/Global-trustworthiness-index-2021.pdf>

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