

Patient organizations in Latin America

Stakeholder engagement has been developed in several Health Technology Assessment (HTA) agencies (1), and patient focus has become a key concept in research in recent years. As a result, numerous HTA agencies have been promoting patient involvement in their decision-making process (2), including in Latin America (LATAM). It's worth noting that the region has experienced a transition to democracy over the past four decades, which puts it in a phase of experimentation with participatory governance involving different ways to engage citizens (3). The variety of purposes, institutional designs, norms, and effectiveness of participatory responses is almost endless (4). Argentina, Brazil, and Colombia are examples of countries that have implemented formal mechanisms to involve patients and citizens in their HTA processes.

Regional stakeholders are curious about the implementation and impact of patient participation in health decision-making, as well as the best practices, gaps, and recommendations for improving the participation processes in LATAM. To explore and shed light on the topic, a diverse range of stakeholders from Argentina, Brazil and Colombia were interviewed between June and October 2022, and an online survey in November and December 2022 completed by individuals from ten LATAM countries was used to rank the best practices, main gaps, and recommendations identified during the interviews.

As per the Argentinians respondents, the best practice of patient participation in the HTA process led by CONETEC (*Comisión Nacional de Evaluación de Tecnologías de Salud*), is the *Mesa de Pacientes*, a patient committee consisting of four representatives from rare diseases, oncology, chronic and chronic transmissible diseases who are involved throughout the whole HTA process. According to Pichon et al. (2018), stakeholder involvement – including patients and users of health systems – is important from the beginning of the HTA process (5). The patient representatives from *Mesa de Pacientes* also have seats in other committees, having a voice and vote (except in the recommendation phase, when they can only give their opinion).

Brazilian stakeholders consider Public Consultations, patient testimonials, and Public Hearings as the best practices carried out by Conitec (*Comissão Nacional de Incorporação de Tecnologias no Sistema Único de Saúde*), which corresponds to the conclusions drawn from the published literature (6, 7, 8). Having meetings broadcasted was also mentioned by our interviewees as a best practice that increases transparency and provides more engagement, and it was a strategy proposed in a suggested framework to improve patient and public involvement to address concerns with transparency (6).

For the stakeholders from Colombia, the handbook released by IETS (Institute of Health Technology Assessment), which took patient feedback into account during its development, is the best practice for patient participation. Garegnani et al. (2022) (9) recommend the active participation of patients to incorporate their values and preferences, which can help make documents, including the evidence-based ones, more patient-centred and improve adherence to the recommendations. It is also argued that patient participation makes decision-making more democratic, leading to better quality decisions and personalized services, consequently broadening the perspective of decision-makers, health professionals and researchers. Participants from Colombia mentioned other best practices currently being carried out in their country, such as training available for patients and other stakeholders, online participation tools, the political will to implement changes, great articulation between patient organizations and numerous patient experts willing to participate.

The interviews we conducted also uncovered various gaps in existing patient participation in LATAM, including a lack of knowledge of patients on HTA and regulatory processes; undervaluing of patient involvement and real-life data; lacking transparency, trust, and confidence to establish relationships; insufficient information about participation procedures, purposes, and roles; unclear participation methodology; ineffective communication; and frequent political changes. Most of these were identified as barriers to participation by Silva and collaborators (2022) (6). To strengthen engagement practices, these authors encouraged a systematic and planned participation approach during the various stages of the HTA process, greater diversity of stakeholders and regular evaluation.

To address the gaps reported during the interviews, stakeholders from Argentina, Brazil and Colombia recommended: better representation and diversity of patients involved; ensuring patient involvement in the whole process; clear, adequate, and transparent methods of participation; training for patients and healthcare institutions; more transparency about expectations and defining roles; more government support and dialogue; transnational sharing of successful experiences; documentation, evaluation of the participation process and impact measurement; more complete guides to support patient participation, clarifying roles, expectations, and important information that patients should bring; better communication and in an adequate language for patients.

According to the results of the online survey responded by different stakeholders from ten LATAM countries (Argentina, Brazil, Colombia, Costa Rica, Guatemala, Honduras, Mexico, Panama, Dominican Republic, and Venezuela), the top four practices for patient participation, ranked in descending order, are: available training for patients and other stakeholders; patient involvement in the whole HTA process; guides to support participation; and participation of patients in committees and meetings. However, in the opinion of most respondents, patients and patient groups in their countries are not adequately prepared to participate and their voices do not have a significant impact on health decision-making.

The first gap to be prioritized, according to the results of the survey, is the undervaluing of patient involvement by the HTA institutions, which can be addressed through training directed at the institutions, in addition to the dissemination of information and evidence on the theme (more publications, participation in scientific events, webinars). Training for patients and health institutions was the highest-ranked recommendation by respondents, and it's an activity that can be supported by the pharmaceutical industry, HTA and patient organizations and that can also address the second top-ranked gap: the lack of knowledge of patients on HTA and regulatory processes. Barani et al. (2017) (10) mention that patients lack technical and scientific knowledge, but this gap can and should be overcome by translating the necessary information into simple language, which was also recommended by the stakeholders we interviewed.

The lack of transparency, information, and participation methodology, respectively ordered as the next main gaps, can be addressed by the following three ranked recommendations suggested by the participants of this study: clear, adequate, and transparent methods of participation, followed by patient participation in the whole process, and finally, increased governmental support and dialogue. These findings are aligned with recently published studies carried out in LATAM (6, 5, 11).

Some of the principles previously identified as priorities for application in the HTA in LATAM are transparency in the production and communication of HTA results and the involvement of relevant stakeholders in the HTA process (5). Pichon et al. (2018) mentioned that transparency and involvement can be reached by public consultations, inviting the public or other interested parties to provide feedback and through accessible measures to improve the transparency and communication of HTA results. Brazil and Colombia were highlighted by the same study as examples of successful implementation of mechanisms to increase transparency (5).

Patient participation is an essential element in the healthcare process. It is critical to ensure that patients are fully engaged and informed about their care. There are several key actions that healthcare organizations can take to ensure that patients are empowered and included in their healthcare journey. Considering the evidence presented, we encourage HTA agencies, patient organizations and industry to take action by continuing or implementing the best practices and main recommendations to involve patients in Latin America and close the main gaps identified by this study.

Firstly, training should be made available to HTA institutions on the importance of patient participation and how to involve patients throughout their process. This would address our first gap: the undervaluing of patient involvement by the HTA institutions. Capacity-building to patients and patient groups to help them understand the HTA process and how to be involved will tackle the patient's lack of knowledge. It is also essential to have clear participation methods that are largely disseminated and understood by patients. This includes providing patients with information about how to provide their input and how it will be used. To support patient participation, user-friendly guides should be developed to clarify

methods of participation and how they can be involved. Besides this, patients should be encouraged to participate in the whole process, preferably from the regulatory until the decision-making.

Patients are the experts when it comes to their own health, and their input provides additional evidence and information, complementing the clinic and economic perspectives. And for this, patient participation in committees and meetings can achieve better healthcare outcomes and decision-making acceptance. Finally, the government needs to provide more support to close gaps that undervalue and impose barriers to an effective patient involvement. This includes addressing lack of transparency and information, and the lack of participatory methodology. The lack of knowledge of patients can be addressed by a joint effort from all interested stakeholders, including government, industry and patient organizations. By addressing these issues and taking these actions, we can ensure that patients are fully included and empowered in their healthcare journey and create a healthcare system that is truly patient-centered and achieves better outcomes for all.

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