

Social participation in health: analysis of progress and challenges for the Region of the Americas

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ABSTRACT

This article analyzes the state of social participation in health in the Region of the Americas, framing it within the regional context and commitments assumed by the Member States of the Pan American Health Organization. It aims to provide regional input to the discussion of a resolution on social participation for universal health coverage, health, and well-being at the 77th World Health Assembly in 2024.

In the Americas, social participation has evolved from a utilitarian approach to a fundamental aspect of health system governance, enshrined within legal frameworks and recognized as a citizen's right. Regional resolutions emphasize inclusive policies and intersectoral action to tackle health inequities, meanwhile the World Health Organization handbook on social participation underscores the need for inclusive governance mechanisms and addressing power imbalances.

Informed by Member States' recommendations and scientific literature, the article emphasizes the importance of addressing power imbalances, strengthening legal frameworks, and enhancing capacities of governments and populations. It stresses adapting social participation mechanisms to diverse cultural contexts and ensuring meaningful community involvement in decision-making.

Finally, the article advocates for a comprehensive approach to social participation grounded in principles of equity, democracy, and human rights; and fundamentally as an essential component of the primary health care approach. It calls for integrating social participation into health system governance, policy dialogues, capacity-building, and evaluation to ensure effective participatory processes.

Keywords

Social participation; community participation; universal access to health care services; health governance; primary health care; Americas.

Social participation in health, recognized as a key strategy since the Alma Ata declaration of 1978, has been reiterated in numerous global and regional resolutions, linked to the right to health. However, research indicates that its implementation has lagged and that the mere existence of social participation mechanisms is not in itself a sufficient guarantee for meaningful community involvement in health decision-making and governance (1–3). During the COVID-19 pandemic, many countries neglected to involve civil society and communities in emergency decision-making, resulting in decreased trust in health authorities and reduced adherence to preventive measures (4–6).

In this context, a group of World Health Organization (WHO) Member States¹ are seeking a stronger political commitment and proposing a resolution on social participation to the 77th World Health Assembly (WHA) (7). This article aims to inform the resolution discussion and its prospective implementation in the Americas by providing a critical perspective of the WHO handbook on social participation, and examining experiences, needs, and perspectives reflected in regional resolutions, policy documents, scientific literature, and insights collected from Member States during regional consultation processes and webinars organized by the Pan American Health Organization (PAHO) in 2021–2022.

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A CRITICAL OVERVIEW OF THE WHO HANDBOOK ON SOCIAL PARTICIPATION

In 2021, WHO published a practical handbook on social participation in health, offering informed guidance to policymakers on fostering meaningful government engagement with populations, communities, and civil society (8). Beyond the positive aspects of the report, its prospective implementation in the Region of the Americas involves a series of adaptations and emphasis. The handbook highlights the importance of creating, strengthening, and sustaining participatory health governance mechanisms to ensure regular and institutionalized dialogue between governments and populations. However, in the region, there is a need to emphasize the sustainability and long-term continuity of these mechanisms.

Even if sustained participatory engagement over time is facilitated by legal frameworks, the required emphasis for the Americas lies on other elements mentioned in the handbook: communication channels, political prioritization, and capacity-strengthening. Legal frameworks will not be enough if there are no political prioritization and solid capacities both at the government and population levels. The WHO recommendation gets it right in highlighting the need to address power imbalances within participatory spaces, particularly by giving marginalized groups equal voice and legitimacy. This is particularly relevant for the context of the Americas and requires governments to consciously shape participatory formats while mainstreaming an intercultural approach to specifically integrate Indigenous and rural populations.

The handbook and the technical paper published in 2023 (9) effectively address the different tasks that policymakers face when bringing people's voice into policymaking: creating an enabling environment, ensuring good representation, strengthening capacities of both government actors and populations, and translating participatory process outcomes into health policies to increase policy uptake and legitimacy.

PARTICULARITIES OF SOCIAL PARTICIPATION IN HEALTH IN THE AMERICAS

Some underlying factors condition the implementation of these global recommendations in the Americas. First, the region remains one of the most unequal in the world, and conditions of health inequality and inequity prove to be persistent and deepening in many countries. Structural dimensions of inequality intersect and reinforce each other, accumulating over time and generations (2, 10). The COVID-19 pandemic further exacerbated existing inequalities, leading to worse health outcomes in lower-income, Indigenous, and Afro-descendant populations (11). Therefore, to achieve equity, underlying social conditions need to be addressed, while transforming and strengthening health systems; and for this to happen, effective social participation and collaboration with other actors is needed (12).

Second, social participation in the Americas has traditionally been viewed through a "utilitarian" lens, where it serves as a strategy to bring health services closer to the people, aiming to increase the uptake of public health services or support the development of community health posts through community contributions (5, 10–13). However, over the past few decades, the concept of social participation has undergone a significant expansion (14). Following the democratization of much of the continent

in the late 1980s and 1990s, many countries enshrined the right to health in their legal frameworks, firmly embedding social participation within the framework of social justice and human rights and recognizing it as a key element of health system governance (15). This evolution was supported by new democratic governments as well as emerging social movements and civil society organizations advocating for policies based on equity criteria and democratic rights (1–3, 5). Despite setbacks resulting from conservative governments imposing cuts to civil society and social movements' engagement in specific countries recently, social participation remains considered a citizen's right, enabling communities to control decisions related to their health, participate in health policy formulation and implementation, and exercise social control and oversight of health systems and authorities.

SOCIAL PARTICIPATION IN PAHO RESOLUTIONS AND POLICY PAPERS

The governance approach to social participation, as a vital part of a healthy democracy and the primary health care (PHC) approach, has been endorsed by PAHO Member States in several resolutions and policy reports (2, 10–15) (Table 1). Social participation is defined by PAHO as the "collective actions through which civil society and the organized community intervene and directly influence the organization, social control, management, and oversight of health institutions and the health system as a whole" (12, 13). It is recognized as one of the 11 essential public health functions and as a transversal strategy that runs throughout the entire policy cycle (13). It has a proven positive effect on health system transformations and on increased transparency (15).

PAHO resolutions confirm the right of all people to participate, to have an equal voice "regardless of the territory where they live, their ethnicity, gender, age, beliefs, social class, migration status, or disability status, paying special attention to groups in situations of vulnerability" (12). The right to participation must be ensured through effective social participation mechanisms and tools that allow for collective and individual involvement in decision-making processes (12, 16). By providing opportunities to participate at the local level, governments become more aware of people's realities and differentiated needs, which cause inequities in health outcomes and in access to resources. Health systems that acknowledge this human diversity become more responsive and are more apt to guarantee equity and dignity (2, 11–15). Moreover, social participation is also necessary for effective intersectoral action and to address the social determinants of health (12, 15).

The importance of addressing power relationships has also been emphasized in PAHO resolutions. All health system transformations will involve a renegotiation over the distribution of resources and power, and social participation provides an opportunity to the population to influence these processes (2, 10, 12, 13).

Several PAHO documents put forward a road map to strengthen and institutionalize social participation mechanisms in countries. First, social participation spaces should be protected by and institutionalized in legal frameworks, establishing criteria of representation, considering the diversity of social groups, and providing a role of social control (2, 12, 13). To this end, governments may need to create specific conditions to enable vulnerable groups to participate; for instance,

TABLE 1. Regional commitments to social participation in health

Regional instrument or resolution	Social participation related commitments
Strategy for Universal Access to Health and Universal Health Coverage (2014)	Establish formal mechanisms for participation and dialogue to promote the development and implementation of inclusive policies, and ensure accountability (15)
Sustainable Health Agenda for the Americas (2018–2030)	Strengthen stewardship and governance of the national health authority, while promoting social participation (10)
High-Level Commission: Universal Health in the 21st Century: 40 Years of Alma-Ata (2019)	Create social participation mechanisms that are genuine, deep, inclusive, and accessible, with a perspective of intercultural and functional diversity to guarantee full exercise of the right to health (2)
Renewed Essential Public Health Functions (EPHF) agenda (2020)	All 11 EPHF contain standards related to social participation, making it a transversal issue, while the fifth EPHF specifically relates to social participation (13)
Strategy for building resilient health systems and post-COVID-19 pandemic recovery to sustain and protect public health gains (2021)	Characterizes as “urgent” the participation of all actors (11)
Policy for recovering progress toward the Sustainable Development Goals [SDGs] with equity through action on the social determinants of health and intersectoral work (2022)	Strengthen and facilitate community participation and civil society engagement, through an intercultural approach in order to attain equity and achieve SDG 3 (12)
Policy on Integrated Care for Improved Health Outcomes (2022)	Empower and engage people and communities to improve their health, and enhance organizational learning (16)

Source: Prepared by the authors from references 2, 10–13, 15, and 16.

by addressing barriers of access related to the physical environment, transportation, information, and technology (2). Another crucial element to achieve institutionalization is the provision of transparent and equitable financing mechanisms (13). Secondly, commercial and private interests must be regulated, through the mitigation of conflict of interest, to make sure often-strong voices do not interfere with values of equity and the right to health (2, 13). Finally, efforts must be made to avoid ineffective participation. Experiences from the past have shown that social participation efforts run the risk of being limited to ratifying decisions that were already made by the authorities (13).

RECOMMENDATIONS FROM PAHO MEMBER STATES AND SCIENTIFIC LITERATURE

Forty-four representatives from 19 countries were invited to discuss the challenges for the Region of the Americas in an online consultation meeting organized by PAHO. Prior to the meeting, 22 representatives from 16 Member States completed an online survey offering valuable inputs (14). PAHO also facilitated two online webinars to encourage countries to exchange their experiences, and a brief review of scientific literature was conducted as well. From this process, four main recommendations emerged:

Social participation as a *modus operandi* in the health sector

Social participation is thriving in the Americas, in many forms and despite its challenges. Countries' experiences range from social participation as part of health promotion activities for addressing the social determinants of health, to an integral part of the governance of the health system. Member State representatives emphasized the importance of social participation as a *modus operandi* of the health sector, embedded in the way the sector functions in all its aspects. For many countries, social participation is a key strategy in their health model, based on integrated service delivery and on the PHC approach (17).

Addressing power imbalances

In the region's context of inequality, both government representatives and scientific literature emphasize addressing power imbalances as crucial. Dominance of well-off or powerful groups in participation forums poses a significant threat to genuine social participation (1, 3). To ensure universal access to health, especially for vulnerable groups, decisions regarding health and needed services should include all population segments; and adapt to the differentiated needs, while promoting local choice and a sense of ownership (1, 13, 17); bringing health services and decisions to the local level, closer to the population.

Intercultural approaches embedded in social participation processes, like those adopted in Brazil and the Plurinational State of Bolivia, facilitate diverse perspectives and resources, making health systems more accessible to Indigenous populations (17). Acknowledging the economic costs of time-commitments required for social participation, along with language and information access barriers, is essential, particularly for poor or isolated communities as demonstrated in experiences in Guatemala and Peru (14). Moreover, experiences from Mexico and Uruguay stress the importance of mitigating conflict of interest to prevent powerful groups from influencing policies contradicting health objectives (14).

The need for solid legal frameworks, but also political prioritization

Most South American countries have institutionalized social participation mechanisms in national legal frameworks, with many constitutions expressly establishing community participation in health (1). These legal frameworks have been essential for advancing social participation and sustaining it when the political landscape changes. However, experiences from various countries indicate that legal frameworks alone are insufficient. Many have not been fully implemented or have failed to achieve expected results (14). Implementation often requires navigating state bureaucracy, necessitating commitment from government

decision-makers at all levels to strengthen social participation and redistribute power (3).

Additionally, careful attention must be given to the design of engagement mechanisms to avoid tokenistic participation or alignment solely with the government's agenda. Changes in government can also pose challenges; for example, Brazil's strong institutional base for social participation, as outlined in the 1988 Constitution, did not prevent marginalization of health councils during decision-making in response to COVID-19 (5). Similar marginalization of community participation mechanisms during the pandemic occurred in Ecuador (6) and numerous other countries (4).

Capacities of both governments and the population must be strengthened

Literature and country experiences underscore the crucial role of health workers in facilitating community and social participation, bridging the gap between local political authorities and the broader state bureaucracy (14). Member State representatives have emphasized the significance of this role, particularly concerning the participation of Indigenous communities, highlighting the need to enhance intercultural and linguistic capacities among health personnel.

Furthermore, the increasing bureaucratization and technicalization, coupled with a lack of policy uptake from social participation forums, can diminish community motivation and involvement (18). Calls have been made for investments in community capacities to increase awareness of rights, knowledge of health systems, and technical expertise (14). Challenges stemming from inadequate sustainable funding for participation spaces and supervision of lower-level governments, along with the absence of clear central guidelines, have also been identified (14). Countries stress the necessity of fostering a culture of participation within the health sector and territories, alongside investment in robust communication channels with their populations (14).

DISCUSSION

There is considerable overlap between recommendations made by the WHO handbook and the technical paper, the commitments made by Member States in regional resolutions, and the experiences and challenges they face. However, there are some specific characteristics of the Americas that should be taken into consideration when implementing global recommendations.

Social participation is considered a crucial strategy for supporting health system transformations based on PHC, universal health, and equity in health. Listening to and involving the population through strong social participation mechanisms can not only increase coverage of public health measures but, even more importantly, make health services adapt to differentiated needs, to effectively address health access barriers and contribute to guaranteeing the right to health. Although the more utilitarian approach to social participation is still implemented in many countries, the perspective of social participation as a key part

of the governance of the health system gains more traction in countries. Social participation mechanisms and institutions could also contribute to the development of a democratic public sphere in countries, expanding citizenship and democracy, provided they reshape power relations, enable social control, promote collective identities, facilitate the channeling of social demands, and integrate both representation and direct participation (19).

Given the significant inequalities and needs to adapt health services to the cultural context and characteristics of territories, the voices of minority groups need to be heard; particularly, the voices of Indigenous and Afro-descendant groups, as well as the voices of younger generations with their new forms and tools for digital activism. Consequently, there is a need to work on the design and format of social participation spaces to address existing power asymmetries.

Moreover, capacities of both governments and populations need to be strengthened. There is work to be done to move toward a true democratization of decision-making processes in health, even in countries with strong institutionalized social participation spaces, such as Brazil where the development of Local Health Councils remains the current challenge.

Finally, social participation plays a fundamental role in the PHC approach. Achieving universal access to health is not feasible without empowering individuals and communities. To this end, the transformation processes of health systems must decisively integrate community and social participation throughout the policy cycle and reform agenda.

The upcoming discussion at the 77th WHA and its future implementation process should consider these experiences and reflections from the Region of the Americas. Social participation in health continues to be emphasized in PAHO Governing Bodies, while the region demonstrates diverse social participation practices, and relevant initiatives toward developing solid legal frameworks and embedding social participation in health governance. Nevertheless, there is a need to establish capacities and systems to assess the landscape of social participation, including conducting situational analyses, stakeholder mapping, and implementing monitoring and evaluation of social participation processes (14). Expanding knowledge, visibility, and the exchange of experiences remains a challenge. While the WHO handbook could provide a foundation for these initiatives, experiences such as the PAHO/WHO Innovation Laboratories in Brazil (20) and the evaluation process of Essential Public Health Functions (13) could offer insights on this path.

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Participación social en materia de salud: análisis de los avances y desafíos para la Región de las Américas

RESUMEN

En este artículo se analiza el estado de la participación social en materia de salud en la Región de las Américas dentro del marco del contexto regional y los compromisos asumidos por los Estados Miembros de la Organización Panamericana de la Salud. El objetivo es proporcionar aportes regionales para las deliberaciones en torno a una resolución sobre la participación social para la cobertura universal de salud, la salud y el bienestar en la 77.^a Asamblea Mundial de la Salud en el 2024.

En la Región de las Américas, la participación social ha evolucionado de un enfoque utilitarista a ser considerada un aspecto fundamental de la gobernanza de los sistemas de salud, consagrado en los marcos jurídicos y reconocido como un derecho ciudadano. Las resoluciones regionales hacen hincapié en las políticas inclusivas y las medidas intersectoriales para abordar las inequidades en materia de salud, mientras que el manual de la Organización Mundial de la Salud sobre participación social destaca la necesidad de mecanismos de gobernanza inclusivos y el abordaje de los desequilibrios de poder.

Basándose en las recomendaciones de los Estados Miembros y la bibliografía científica, el artículo subraya la importancia de abordar los desequilibrios de poder, fortalecer los marcos jurídicos y mejorar las capacidades de los gobiernos y las poblaciones. Hace hincapié en adaptar los mecanismos de participación social a contextos culturales diversos y garantizar una participación trascendente de la comunidad en la toma de decisiones.

Por último, el artículo aboga por un enfoque integral de la participación social basado en principios de equidad, democracia y derechos humanos; y, fundamentalmente, como un componente esencial del enfoque de atención primaria de salud. Insta a integrar la participación social en la gobernanza del sistema de salud, los diálogos sobre las políticas, la creación de capacidad y la evaluación para garantizar procesos participativos eficaces.

Palabras clave

Participación social; participación de la comunidad; acceso universal a los servicios de salud; gobernanza; atención primaria de salud; Américas.

Participação social em saúde: análise do progresso e desafios para a Região das Américas

RESUMO

Este artigo analisa a situação da participação social em saúde na Região das Américas tendo em conta o contexto regional e os compromissos assumidos pelos Estados Membros da Organização Pan-Americana da Saúde. O objetivo é oferecer contribuições regionais para a discussão de uma resolução sobre participação social para cobertura universal de saúde, saúde e bem-estar na 77.^a Assembleia Mundial da Saúde, em 2024. Na Região das Américas, a participação social evoluiu, deixando de ser uma abordagem utilitarista para se tornar um aspecto fundamental de governança do sistema de saúde, consagrada por marcos legais e reconhecida como um direito dos cidadãos. As resoluções regionais enfatizam políticas inclusivas e ações intersectoriais para combater iniquidades em saúde, e o manual da Organização Mundial da Saúde sobre participação social ressalta a necessidade de contar com mecanismos inclusivos de governança e abordar desequilíbrios de poder.

Com base nas recomendações dos Estados Membros e na literatura científica, o artigo destaca a importância de abordar desequilíbrios de poder, reforçar marcos legais e fortalecer as capacidades dos governos e das populações. Além disso, enfatiza a necessidade de adaptar mecanismos de participação social a diversos contextos culturais e assegurar um envolvimento significativo da comunidade na tomada de decisões.

Por fim, o artigo defende uma abordagem abrangente de participação social com base em princípios de equidade, democracia e direitos humanos e, fundamentalmente, como um componente essencial da abordagem de atenção primária em saúde. O artigo urge a integração da participação social na governança do sistema de saúde, em diálogos sobre políticas, no desenvolvimento de capacidades e na avaliação, a fim de assegurar processos participativos efetivos.

Palavras-chave

Participação social; participação da comunidade; acesso universal aos serviços de saúde; governança em saúde; atenção primária à saúde; América.
