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REFLECTION ARTICLE

Patient participation: a key to universalizing the right to health

Participación de los usuarios: clave para la universalización del derecho a la salud

Participação dos usuários: chave para a universalização do direito à saúde

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ABSTRACT

Objective: To highlight patient participation in the health system's governance, a principle adopted by the State Health Services Administration in Uruguay as a strategy for achieving the universalization of health and access to quality health services. **Development:** *Sistema Nacional Integrado de Salud* [National Integrated Health System] was created in an effort to bring about a qualitative change in the design of health policies, by incorporating social participation at different levels of management as a guiding principle. This essay draws on the results of a postdoctoral project conducted in health networks at the primary care level in border areas (Uruguay-Brazil), aiming to connect the evidence regarding patient participation in the health system's governance with the regulations and principles of the Integrated Health Service Delivery Networks. The purpose was to critically assess the current role assigned to patient participation in the governance of public health networks managed by State Health Services Administration in particular and the healthcare system in general. **Conclusion:** Patient participation in the health system's governance is found to be almost nonexistent, which contradicts the system's goals and principles that aim at ensuring necessary social oversight.

Keywords: Health Systems; Universalization of Health; Primary Health Care; Community Participation; Health Governance.

RESUMEN

Objetivo: Evidenciar la participación de los usuarios en el gobierno del sistema de salud, principio que fuera asumido por la Administración de los Servicios de Salud del Estado de Uruguay, como estrategia para el logro de la universalización de la salud y el acceso a servicios de salud de calidad. **Desarrollo:** Con la creación del Sistema Nacional Integrado de Salud, se intentó generar un cambio de calidad en el diseño de las políticas sanitarias, incorporando como principio la participación social en los diferentes niveles de gestión. Durante el del presente ensayo, se tomarán como excusa los resultados de un proyecto posdoctoral, realizado en redes sanitarias del Primer Nivel de Atención en zonas fronterizas (Uruguay-Brasil), buscando poner en diálogo la evidencia científica obtenida sobre la participación de los usuarios en el gobierno del sistema de salud, con las normativas y los principios del enfoque de Redes Integradas de Servicios de Salud, con la finalidad de colocar sobre el tapete el lugar que hoy se le ha dado a la participación de los usuarios en el gobierno de las redes públicas de salud de la Administración de los Servicios de Salud del Estado en particular y del sistema sanitario en general. **Conclusión:** La participación de los usuarios en el gobierno del sistema sanitario se evidencia como casi inexistente, contraponiéndose a los objetivos y principios del sistema, los que procuran un necesario control social.

Palabras claves: Sistemas de Salud; Universalización de la Salud; Atención Primaria de Salud; Participación de la Comunidad; Gobernanza.

RESUMO

Objetivo: demonstrar a participação dos usuários na governança do sistema de saúde, um princípio adotado pela Administração Estatal de Serviços de Saúde do Uruguai como estratégia para alcançar a atenção universal à saúde e o acesso a serviços de saúde de qualidade. **Desenvolvimento:** Com a criação do Sistema Nacional Integrado de Saúde, tentou-se gerar uma mudança de qualidade no desenho das políticas de saúde, incorporando como princípio a participação social nos diferentes níveis de gestão. Durante o presente ensaio, os resultados de um projeto de pós-doutorado realizado em redes de saúde do Primeiro Nível de Atenção em áreas de fronteira (Uruguai-Brasil) serão usados como pretexto, buscando colocar em diálogo as evidências científicas obtidas sobre a participação dos usuários na governança do sistema de saúde, com os regulamentos e princípios da abordagem das Redes Integradas de Serviços de Saúde, a fim de discutir o lugar que atualmente é dado à participação dos usuários na governança das redes públicas de saúde da Administração Estatal de Serviços de Saúde em particular e do sistema de saúde em geral. **Conclusão:** A participação dos usuários na governança do sistema de saúde é quase inexistente, contrariando os objetivos e princípios do sistema, que buscam um controle social necessário.

Palavras-chave: Sistemas de Saúde; Universalização da Saúde; Atenção Primária à Saúde; Participação da Comunidade; Governança em Saúde.

INTRODUCTION

Uruguay's National Integrated Health System (SNIS for its acronym in Spanish), established in 2007, is a mixed system with a health insurance scheme funded by workers, employers, retirees, and general revenues. It is managed by a National Health Board composed of representatives from the Executive Branch, the Social Security Bank, service providers, workers, and patients.[1] The system has 2,590,924 contributing members (81.2% from the private subsector) and 902,237 individuals who do not contribute and are served in the public subsector.[2] The system guarantees only services included in its basic service package, and the care model is based on the Primary Health Care (PHC) strategy with a network approach.

The guiding principles of SNIS aim to bring about a qualitative change in health policy design by incorporating the organized and informed participation of workers and patients at different levels of decision-making. This participation is seen as key, and it promotes the involvement of these stakeholders in analyzing and determining needs and priorities, playing a significant role in defining objectives and health plans, and being essential in monitoring and evaluating outcomes.[3]

In 2020, the National Movement of Public and Private Health Service Users refused to "accept directly appointed positions, as such appointments, far from strengthening the role of the community in creating and implementing health policies, would legitimize decisions made without consulting the public."[4]

The postdoctoral project *Intervención en salud en efectores sanitarios públicos del Primer Nivel de Atención de zonas fronterizas (Uruguay – Brasil)* has been implemented since 2021. This initiative aims to improve the quality of care for populations living in border regions. It includes research conducted in the departments of Rivera,[5,6] Rocha,[7,] and Cerro Largo,[8] forming the basis of this essay. The project proposes a formative and extension-based intervention, grounded in a situational diagnosis. This is derived from quantitative research that evaluates the performance of public health networks[9] and it involves directors, workers, and service users.

The project's partial results will be critically analyzed using relevant literature and regulations on patient participation in system governance. This analysis is framed within the Integrated Health Services Networks (IHSDNs) strategy promoted by the Pan American Health Organization (PAHO).[10]

For this analysis, we adopt the premise that care management's primary function is to support the provision of care, ensuring that individuals and communities achieve the highest possible level of health. This perspective necessarily entails the organized participation of social stakeholders at all levels of system planning, acknowledging that each of these levels defines and safeguards the care of individuals, families, and communities, as well as universal access to quality health services as an inalienable right.[11]

Moreover, we cannot overlook that international credit organizations play a central role in shaping the structural reforms of states and, by extension, the health systems of countries on the periphery of global power. These organizations approach health expenditures not as investments but as costs, thereby defining the nature of the relationship between these systems and other international organisms in the Global North. By financing reforms, they impose their frameworks and dictate how peripheral governments must implement changes in the health sector.[12]

Based on the above, this article aims to highlight the participation of service users in health system governance, a principle adopted by Uruguay's State Health Services Administration (ASSE) as a strategy to achieve the universalization of health and ensure access to quality health services.

DEVELOPMENT

Service User Participation in Care Management Planning Levels

From Alma-Ata to Astana, through the Ottawa Charter for Health Promotion and the Rio de Janeiro Declaration on the Social Determinants of Health, there has been a consistent emphasis on fostering transparent governance by promoting social participation in policy development, decision-making, priority setting, and strengthening essential social oversight. In our region, PAHO, through the RISS strategy (*Redes Integradas de Servicios de Salud*), has underscored the importance of transforming communities into active partners in the governance and evaluation of health systems. This is pursued by progressively increasing participation, ultimately empowering communities to exercise full control over decisions affecting their well-being.[10]

Several experiences offer evidence to support this approach. At the national level, a study of a health network revealed low-performance indices, which could be attributed to the lack of patient participation in its governance. This underscores the critical role of social participation in safeguarding the right to health protection.[13] Another example, from Colombia, highlights the role of organized social movements in resisting reforms that drive health systems toward commodification, emphasizing that the right to health is both an individual and collective right, upheld through the active and decisive participation of social stakeholders.[14]

Uruguay's health system was originally designed to extend social oversight across all structures and at different management levels. This design prompts discussions about patient participation at strategic and tactical levels of management.[3]

There is a significant contradiction between the objectives established by the health system's foundational law and the actual construction of social participation in defining health policies—a reality already denounced by the National Service User Organization in 2020.[1,4]

Service User Participation in the Strategic Level of Care Management Planning

The health sector, as a major driver of national and international economies, faces constant pressure at the political level from medical entrepreneurship, which prioritizes profit over population health.

A clear example can be observed in the composition of the governing body of the National Health Insurance System, shaped by power dynamics among political authorities, social organizations, and medical entrepreneurship. The draft bill explicitly proposed that this central body, under the Ministry of Health, should comprise three state representatives, one representative of workers, and one representative of organized service users, the latter elected by their respective organizations.[3]

The pressures exerted by medical entrepreneurship succeeded in placing its representatives within the health insurance system's administration, resulting in the composition of the National Health Board, which includes two representatives from the Ministry of Public Health, one from the Ministry of Economy and Finance, one from the Social Security Bank, one for workers, one for service users, and one for service providers. While service user representatives were incorporated at this level, they have been demanding a seat at the decision-making table regarding health insurance funds that allows them to effectively oversee this aspect.[15]

Uruguayan legislation mandates that providers have representation on the National Health Board. However, although it is a mixed system (public and private) where the public subsector serves approximately 1.5 million service users, the representative is from the private subsector.[4]

This neoliberal logic of state withdrawal as the guarantor of social policies has left critical sectors like health in the hands of the market, using legal and regulatory mechanisms to secure corporate profits.[16]

Despite these challenges, incorporating organized service users into this management level was a milestone. Nevertheless, the National Health Board's composition weakened social oversight over health policies, especially financial aspects. The national service user organization has reported a lack of real participation in defining health sector goals, pointing to a lack of outcome assessment and oversight mechanisms, and uncontrolled multimillion-dollar expenditures.[15]

This situation may be one of the causes of the limited or nonexistent participation of patients at other levels of care management planning, as evidenced by the study conducted in the border region. The results show that almost none of the patients participate, either directly or indirectly, in governance bodies (Rivera[5,6] 98.2%; Rocha[7] 95%; Cerro Largo[8] 99%), which impacts their access to quality health services.

Service User Participation in the Tactical Level of Care Management Planning

At this level, the draft bill clearly outlined the role of organized social participation in governance, granting the necessary powers to implement national health policies and the national health plan. To this end, it delegated authority to manage all human, material, and financial resources.[3]

This has stagnated in a nascent integrality, revealing a sordid battleground between the interests of public and private providers, both of which have representatives at this level. It also exposes the conflict between the interests of the private sector and the needs of individuals and communities, as expressed in the struggle for the right to health. Similar to the central level, Law 18.211 reflects the outcome of these power struggles, stipulating that the Departmental and Local Honorary Advisory Councils will coordinate health policies with the participation outlined in the draft bill. However, the law reduces their delegations and powers, relegating them to advisory functions, with reports and proposals that are non-binding.[1]

On the other hand, a health system like that of Uruguay, based on the Primary Health Care (PHC) strategy, must strengthen social participation as one of the key variables to prevent fragmentation. This fragmentation, not the sole cause of the system's poor performance, is expressed as "a lack of access to services, loss of continuity in care, and a lack of alignment between services and the needs of patients."[10]

In this regard, the results of ongoing studies within the postdoctoral project show that the three health networks still fall short of achieving effective participation from stakeholders in policy definitions and network management. This is reflected in the low-performance indices observed in each of them. The performance index for the governance and strategy component of the network is 0.277 for Rocha,[7] 0.265 for Rivera[5,6], and 0.378 for Cerro Largo,[8] using a scale from 0 to 1, where 1 represents the highest performance level.

These results are not attributable to chance but rather a defined and ongoing strategy of denying social participation in health policymaking. The national service user movement has been denouncing their lack of involvement in the development and oversight of health policies, highlighting the absence of spaces to address difficulties in care and the lack of information about the system's progress.[17] Patients demand to be heard and for pathways to unite efforts to reverse the healthcare system's crisis.[4] Seventeen years after establishing the health system, studies show that little progress has been made in this regard.

In this sense, social participation is key to changing the traditional logic of resource distribution, redirecting these resources to address the needs of the most vulnerable populations and positioning participation as a tool for social oversight. Therefore, strengthening social participation is crucial for universalizing health and access to quality health services.[18]

To focus the analysis and engage with the concept of social participation expressed in the principles of the health system, alongside the reality of 17 years of its development, I include the PAHO framework on the five levels that identify the capacities of health networks in incorporating communities into their governance. These levels range from providing information to service users to empowering them so that they have full control over key decisions that affect their well-being.[19] The evidence gathered in the borders shows that only one in three patients report receiving information, while most workers and managers (94.6% and 88.9%, respectively) claim to provide it. However, the greatest weakness lies in decision-making, as nearly all service users (97.5%) report that they do not participate in these decisions.[5-8]

Although a diversity of perspectives, opinions, analyses, and extensive regulations coexist, significant weaknesses can be observed at the system's foundation, which could jeopardize the principle of universal access to quality health services, negatively impacting the most vulnerable sectors of the population.

Additionally, there is a shift from the normative to the customary, justified by the argument that, even without patient participation, the process must proceed because the institution cannot be halted. This rationale persists regardless of whether such actions violate the fundamental principles of the health system. Undoubtedly, this undermines the defense of non-discrimination and equality. Access to information must be ensured to enable individuals and organized communities to engage in planning processes and participate in decision-making at all levels of the health system.[19]

The reality of the National Integrated Health System underscores the importance of fostering conscious participation, both individually and collectively, across all governance structures.[20] This is the only viable approach to developing counterhegemonic proposals, which today are fundamentally grounded in and prioritize advocating for the right to health.[17]

CONCLUSIONS

The participation of service users in healthcare governance is almost nonexistent, which stands in stark contrast to the system's objectives and principles that aim to ensure essential social oversight.

There is a clear opportunity to reverse the stagnation of the Uruguayan healthcare system by advancing one of the strategies aimed at achieving universal access and guaranteeing the right to quality health services: social participation. To do so, the concept of social participation must be challenged, viewing it not merely as a means to fulfill a legal requirement, but as a driver of the changes that must be made.

Private health companies have been steadily gaining influence through persistent lobbying, enabling them to pressure governments—often in collaboration with international credit organizations—to prioritize capital interests over the fundamental right to health.

It is believed that within the healthcare system, there are opportunities to challenge the commodification of health by ensuring social oversight. This includes granting service users genuine and full participation in the National Health Board while limiting the influence of medical entrepreneurship to intermediate levels of management.

Political leaders now bear the responsibility of prioritizing public health interests over those of health entrepreneurs, thus defending the right to universal access to quality healthcare services.

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