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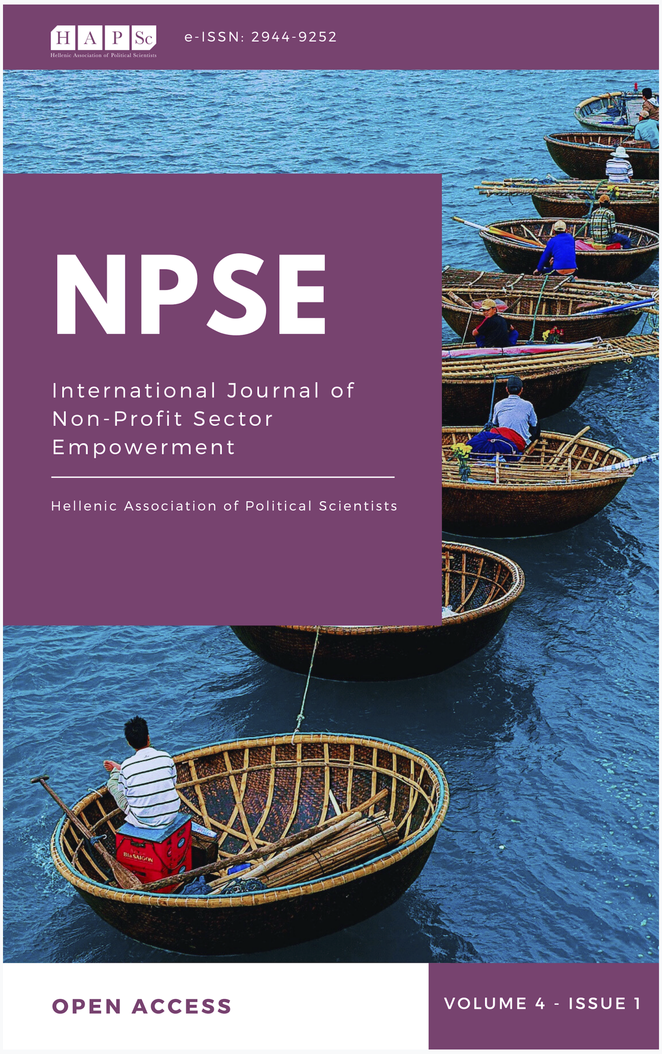

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RESEARCH ARTICLE

From Advocacy to Impact: The Determinants of Patient Organizations' Influence in Health Governance

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Abstract

Patient participation has become a normative feature of contemporary health governance, yet the influence of patient organizations on decision-making remains uneven and often limited. Existing scholarship has extensively documented participatory mechanisms, but has paid less attention to the conditions under which participation translates into substantive influence. This paper offers a critical and integrative review of the literature on patient organizations in health decision-making, with the aim of clarifying these conditions. It proposes a conceptual framework that brings together four key determinants discussed in the literature: institutional access structures, epistemic recognition and knowledge legitimacy, organizational capacity and representational legitimacy, and the broader political and socio-digital context. The framework is used to examine different participatory modalities and to interpret recurrent barriers, such as tokenism and limited uptake of patient input. Rather than advancing a predictive model, the paper provides an analytical lens for understanding variation in participatory outcomes, and aims to contribute to ongoing debates on the role of patient organizations in contemporary health governance.

Keywords: Health governance; Patient organizations; Participatory decision-making; Epistemic recognition; Influence; Tokenism; Co-optation; Co-production

Introduction

The growing prominence of patient organizations (POs) in health policy arenas signals a paradigmatic shift in how health systems conceptualize democratic legitimacy, stakeholder engagement, and evidence production. Once primarily framed as advocacy groups offering psychosocial support or lobbying for disease-specific agendas, POs have increasingly repositioned themselves as institutional actors embedded in decision-making processes ranging from clinical guideline development and reimbursement deliberations to national health technology assessment (HTA) bodies. This evolution from advocacy to influence reflects broader normative currents in democratic governance, which call for more inclusive and participatory forms of policymaking and emphasize the legitimacy of

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deliberation among affected publics (Fung, 2006; Cohen, 2005). It also resonates with arguments that democratic institutions should enable epistemically fair participation in inquiry and decision-making (Fricker, 2007; Anderson, 2012).

As patients and their representatives bring situated knowledge (embodied, experiential, and often invisible within biomedical rationalities), their inclusion reconfigures who counts as a "knower" in health governance (Facey et al., 2010; Heggen & Berg, 2021; Dumez & L'Espérance, 2024). Yet, such epistemic participation is frequently compromised by structural asymmetries, unclear mandates, or conflicts of interest – particularly when financial dependence on industry actors blurs representational boundaries (Hennessy et al., 2024; Makowska et al., 2024). At stake is the legitimacy of POs as democratic interlocutors: are they co-opted extensions of biomedical or corporate interests, or credible agents of epistemic and normative pluralism?

While the normative rationale for PO participation is well-established, anchored in rights-based claims, deliberative theory, and stakeholder inclusivity (Fung, 2006), the empirical terrain remains uneven. Some national health systems, such as the Netherlands, have institutionalized patient involvement through relatively stable, neo-corporatist arrangements that allow selective but formalized input (van de Bovenkamp & Zuiderent-Jerak, 2015). By contrast, other contexts, such as Italy and Poland, are characterized by more fragmented or ad hoc patterns of engagement, shaped by organizational choices, uneven coordination, and external funding structures rather than coherent participatory architectures (Morandi et al., 2024; Makowska et al., 2025). Moreover, digital platforms and social media have reconfigured the spatial and temporal modalities of patient mobilization, enabling grassroots advocacy beyond formal policy structures (Petersen et al., 2019; Figenschou & Fredheim, 2020; Efthymiou et al., 2023). These trends are also evident in specific fields such as oncology, where patient advocates have increasingly adopted evidence-based advocacy strategies to reinforce their legitimacy and strengthen integration with biomedical decision-making processes (Gonzato & Schuster, 2023). These shifts raise important questions about representational legitimacy, epistemic authority, and policy responsiveness.

This paper contributes to this debate by analyzing how POs are evolving as political and epistemic stakeholders in healthcare decision-making. It adopts a cross-national comparative perspective to trace institutional, cultural, and political determinants that condition the influence of patient groups. It also engages with emerging forms of digital and hybrid participation that transcend traditional advisory roles. Two questions guide the analysis: (1) What institutional mechanisms enable or constrain meaningful PO influence in health policy? (2) What emerging challenges and opportunities arise as POs professionalize, digitize, and interact with new governance technologies?

Thus, the paper is a theoretical and critical literature review that develops an integrative conceptual framework, by synthesizing cross-disciplinary scholarship to explain variation in when and how patient organizations move from participation to meaningful influence in health decision-making. By interrogating these questions, the paper seeks to move beyond celebratory accounts of "patient-centeredness" to offer a critical, empirically grounded assessment of how participation is enacted, constrained, and potentially transformed. It also underscores the importance of designing participatory infrastructures that are both epistemically inclusive and resistant to co-optation, particularly in light of growing commercial influences and policy instrumentalization of patient voices (Rose et al., 2017; Hennessy et al., 2024). In doing so, this study positions patient organizations not merely as adjuncts to expert-led policy but as actors whose influence must be analyzed with the same rigor we apply to other institutional stakeholders.

1. Understanding Patient Organizations

Patient organizations (POs) represent a heterogeneous but increasingly influential category of civil society actors in health systems. Typically established by patients, caregivers, or disease-specific communities, these groups have historically focused on advocacy, support services, and awareness-raising. However, their roles have significantly expanded in recent decades to include participation in clinical research, regulatory reviews, and health technology assessment (HTA) processes. As such, POs are now recognized as "stakeholders" in health governance – entities with a legitimate interest in, or influence over, decision-making processes (Wale et al., 2021; Vanstone et al., 2023). Yet this designation is far from neutral. It implies a recalibration of power dynamics, where the knowledge and interests of patient communities are seen as both politically and epistemically relevant. Recent studies suggest that patient advocacy groups not only shape public discourse but are increasingly embedded in formal institutions of care delivery and policy formulation (Morson et al., 2025; Muller et al., 2021). However, the translation of patient experience into policy influence is not automatic (Ocloo & Matthews, 2016). As Nikulkin & Zvonareva (2024) note, organizations must actively frame their experiential knowledge in ways that resonate with institutional logics and decision-making criteria, a process that often reveals persistent epistemic asymmetries in healthcare governance.

The stakeholder label, while useful for institutional recognition, can also obscure the diversity of patient group structures, functions, and capacities (Ocloo & Matthews, 2016; Baggott & Jones, 2018).

For instance, umbrella organizations operating at the European level may possess significant political capital and technical expertise, whereas small grassroots collectives may lack the resources required to engage in sustained policy dialogue (Sienkiewicz & van Lingen, 2017). Moreover, the term does not account for the multiplicity of patient voices, some of which may be excluded or misrepresented within umbrella narratives, as more professionalized or institutionally legible perspectives tend to dominate processes of representation (Barnes et al., 2003; Martin, 2008). These tensions are particularly salient in rare disease communities, where representation often hinges on informal networks and individual self-advocacy rather than on formalized organizational infrastructures, reflecting persistent disparities in advocacy capacity and recognition (Rabeharisoa et al., 2014a).

1.1 Theoretical Frameworks: Stakeholder Theory, Neo-corporatism, and Democratic Governance

Three theoretical frameworks are particularly useful for analyzing the evolving role of POs in healthcare decision-making: stakeholder theory, neo-corporatism, and deliberative democratic theory. Stakeholder theory, developed initially within the field of business ethics, posits that organizations have responsibilities not only to shareholders but to all parties affected by their decisions (Freeman, 1984, Donaldson & Preston, 1995). In the context of health systems, this implies that patients and their representatives should be engaged not merely as recipients of care but as co-constructors of policy. However, the stakeholder model often fails to account for asymmetries in power, access, and epistemic credibility, leading to critiques that it treats all stakeholders as formally equal when in practice they are not (Ocloo & Matthews, 2016; de Boer, 2021).

Neo-corporatist theories offer a more institutional lens, focusing on how interest groups are integrated into formal decision-making structures (Schmitter, 1974; Cawson, 1986). In countries like the Netherlands, patient representatives are included in guideline committees and reimbursement bodies through legally mandated mechanisms (van de Bovenkamp & Zuiderent-Jerak, 2015). While this model provides a stable avenue for participation, it also risks bureaucratization and co-optation, especially when POs must conform to administrative logics that limit dissent or innovation. Co-optation refers to the selective institutional incorporation of patient organizations into formal decision-making processes in ways that enhance procedural legitimacy and policy stability, while simultaneously constraining autonomy, contestation, and the capacity for transformative influence. Unlike tokenistic participation, co-optation involves sustained engagement, yet differs from co-production insofar as agenda-setting power and epistemic authority remain asymmetrically distributed.

Thus, neo-corporatist frameworks can emphasize consensus-building at the expense of contestation, potentially sidelining marginalized or dissenting patient voices (Offe, 2019).

Deliberative democratic theory, particularly as developed by scholars like Fung (2006), offers a normative counterpoint. It emphasizes the value of inclusive, reasoned dialogue among affected parties, suggesting that legitimacy stems from the deliberative quality of decision-making rather than from mere aggregation of interests (Habermas, 1996; Fung, 2006). From this perspective, patient participation is not merely instrumental but constitutive of just governance, as it enables those affected by decisions to contribute to the reasons that justify them (Young, 2003). Yet even deliberative models face practical challenges: socio-economic inequalities, time constraints, and structural dynamics within deliberative settings can shape who participates and how voices are heard, often reproducing existing power asymmetries despite formal commitments to inclusion (Young, 2003; Barnes et al., 2003). Differential capacities for communication and comprehension tend to disadvantage less-resourced participants, and institutional design features, procedural complexity, or status differences may act as forms of strategic gatekeeping that undermine genuine dialogue rather than secure it (Vargas et al., 2016; Ballangé, 2025; Holdo, 2019). Moreover, deliberative forums often presume a shared epistemic ground that may not exist, particularly when biomedical paradigms conflict with lived patient experiences.

Recent literature underscores the importance of co-creation and related ‘co-’ approaches, alongside Mode 2 knowledge production, to describe collaborative forms of knowledge-making that cut across traditional expert–lay distinctions (Gibbons et al., 2010; Nowotny et al., 2003; Voorberg et al., 2014; Vargas et al., 2022). In this model, patients are not only informants but epistemic agents whose lived experience contributes to the production of actionable insights. This epistemic reframing aligns closely with Fricker’s (2007) concept of epistemic injustice, which identifies the ways in which social prejudices can undermine individuals’ credibility as knowers. In the context of healthcare, this suggests that meaningful participation requires not only institutional inclusion but epistemic recognition.

These perspectives suggest that patient participation cannot be assessed solely by formal inclusion, since both institutional design and epistemic norms shape whose inputs are treated as relevant and actionable within decision-making arenas.

1.2 Normative Justifications for Participation

The normative case for involving patient organizations in healthcare decision-making is grounded in principles of justice, autonomy, and democratic legitimacy. Those directly affected by health policies have a moral and political stake in shaping them, and inclusive engagement is justified not only by improved outcomes but by democratic norms that value the voices of affected publics (Frith, 2023). Contemporary bioethical scholarship critiques narrow individualistic conceptions of autonomy in clinical and policy contexts, arguing for relational accounts of autonomy that recognize how decisions are embedded within social relationships and institutional conditions rather than isolated individual choice (Walter & Ross, 2014; Ells et al., 2011). In this view, participation is not simply an add-on to liberal rights frameworks but a precondition for exercising agency within complex systems of care.

Trust also plays a crucial role in shaping the ethical foundations of participation. Franklin and Thiboldeaux (2024) emphasize that patient advocacy can build trust between healthcare institutions and patients, particularly by aligning medical practices with lived experiences and addressing historical skepticism. Moreover, participation enhances the ethical quality of decision-making by broadening the range of values, experiences, and outcomes considered. This is particularly relevant in contexts such as HTA, where decisions often hinge not only on cost-effectiveness but on questions of quality of life, social value, and patient-reported outcomes (Facey et al., 2010; Poortman et al., 2024). Engaging POs in such processes ensures that decisions are informed by a plurality of perspectives, reducing the risk of technocratic closure.

At the same time, normative justifications must grapple with empirical constraints. Financial dependencies, representational gaps, and professionalization pressures can all dilute the emancipatory potential of participation (Hennessy et al., 2024; Morandi et al., 2024). Moreover, calls for inclusivity must be balanced against concerns about legitimacy and capacity: who speaks for whom, and with what mandate? These are not merely technical questions but ethical ones, touching on the fundamental democratic quality of health governance.

While normative arguments grounded in justice, autonomy, and democratic legitimacy provide a compelling case for the inclusion of patient organizations in healthcare decision-making, they offer limited guidance on how participation translates into influence in practice. There is a persistent gap between the ethical rationale for participation and its empirical realization within institutional settings. Participation that is normatively justified may nonetheless remain constrained by procedural design, epistemic hierarchies, organizational inequalities, or broader political conditions. To move beyond abstract endorsement toward analytical clarity, it is therefore necessary to examine the structural and relational determinants that shape whether patient participation becomes meaningful or remains symbolic.

2. Determinants of Patient Organization Influence in Health Decision-Making

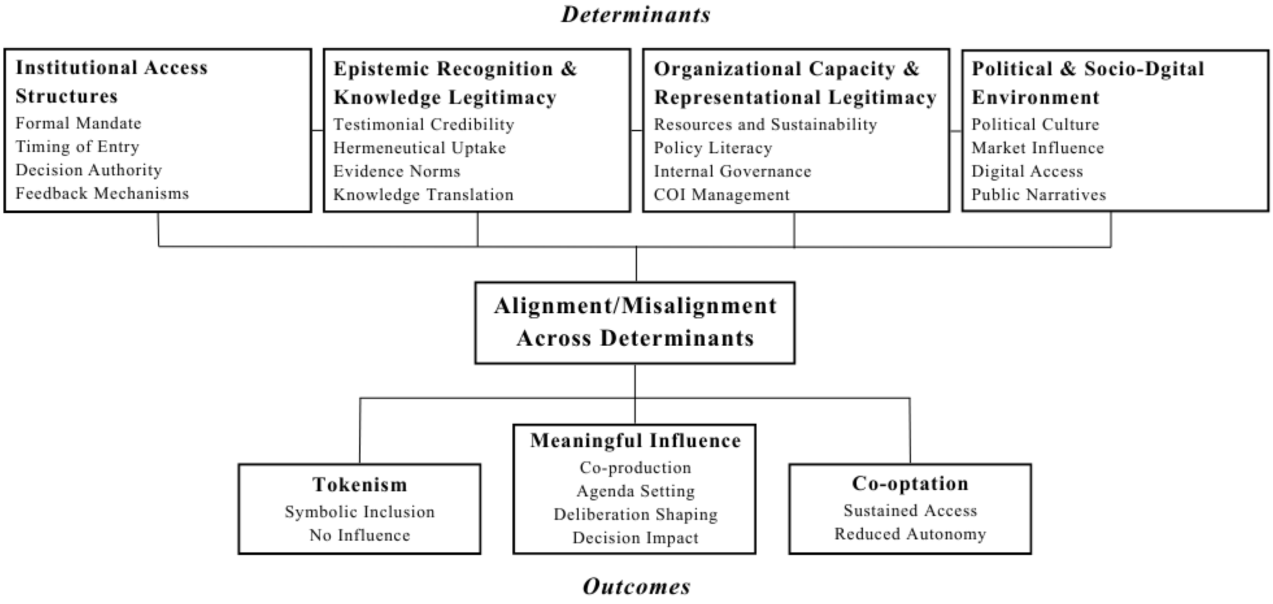
What is essential for understanding the shift from advocacy to influence, is a coherent analytical framework that explains why patient organizations exert meaningful impact in some contexts but remain marginal or tokenistic in others. The conceptual framework presented in here aims to organize the mechanisms through which participation becomes influential, as well as the conditions under which it predictably fails. Throughout this paper, influence is understood broadly as the capacity of patient organizations to shape agendas, deliberative processes, and decision outcomes within health governance arenas, rather than as formal decision-making authority alone. Building on the theoretical and normative foundations established in Section 1, the framework integrates multiple strands of scholarship on participation and influence to account for variation in the substantive impact of patient organizations.

Classic participation typologies, most notably Arnstein's (1996) "ladder of citizen participation", conceptualize involvement along a continuum from tokenism to partnership and delegated power, emphasizing the relationship between participation and decision-making authority. Subsequent frameworks, such as Fung's (2006) model of participatory governance, further elaborate this logic by distinguishing who participates, how deliberation is structured, and the extent of authority granted to participants. In the health policy field, multidimensional models of patient and public engagement similarly differentiate between consultative, collaborative, and shared leadership approaches across levels of the health system (Carman et al., 2013). While these frameworks provide valuable tools for classifying participatory arrangements, they tend to treat influence primarily as a function of formal authority or design features, with more limited attention to epistemic dynamics and organizational inequalities.

Critical contributions have highlighted these limitations by examining the persistence of tokenism and power asymmetries within participatory initiatives. Ocloo and Matthews (2016), for example, demonstrate how patient and public involvement can be rhetorically endorsed while remaining substantively constrained by institutional hierarchies and professional dominance. Parallel literatures on patient advocacy organizations have drawn attention to risks of co-optation and compromised legitimacy arising from financial dependence and conflicts of interest, particularly in relation to industry funding (Rose et al., 2017). At the same time, work on epistemic injustice has underscored how participation may fail even in formally inclusive settings when experiential knowledge is not recognized as credible or intelligible within dominant evidentiary frameworks (Fricker, 2007).

The framework proposed here synthesizes these insights by combining participation typologies with an explicit focus on epistemic recognition, organizational capacity, and contextual conditions. Rather than treating participation as inherently empowering, it conceptualizes influence as an emergent outcome of interactions across four interdependent domains: (1) institutional access structures, (2) epistemic recognition and knowledge legitimacy, (3) organizational capacity and representational credibility, and (4) the broader political and socio-digital environment. In doing so, it extends existing models by identifying tokenism and co-optation not merely as normative failures, but as predictable outcomes of structural and epistemic misalignment within contemporary health governance. Importantly, the framework is analytical rather than normative in orientation. It does not assume that greater participation, stronger patient voice, or deeper institutional integration necessarily lead to more democratic, legitimate, or desirable outcomes. Figure 1 summarizes this framework by mapping the interaction between these domains and their role in shaping both influence and failure.

Figure 1. Determinants of Patient Organizations' Influence in Health Decision-Making



The figure illustrates how the four interdependent domains interact to shape whether patient organizations exert meaningful influence. Influence is understood as the capacity to shape agendas, deliberative processes, and decision outcomes. Misalignment across domains may result in predictable failure modes, including tokenism, where participation remains symbolic, and co-optation, where organizational independence and representational credibility are compromised. While analytically distinct, the four determinants interact closely. Institutional access structures and the political and socio-digital environment define the *conditions of access*, whereas epistemic recognition and organizational capacity shape the *conditions of uptake*.

Institutional access structures refer to the formal mechanisms and procedural arrangements that determine when and how POs are able to participate in decision-making processes. As discussed in Section 1.2, national governance models differ significantly in their openness to stakeholder involvement. Neo-corporatist architectures tend to provide stable and predictable entry points, while more fragmented or discretionary systems create irregular or limited opportunities. These structures specify not only whether POs can participate in arenas such as health technology assessment, guideline development, or reimbursement decisions, but also the depth of their involvement, the timing of their contributions, and the availability of mechanisms for feedback and accountability. Institutional access structures therefore establish the procedural conditions within which participation unfolds.

Formal access, however, does not automatically translate into influence. A second determinant concerns epistemic recognition and knowledge legitimacy, which shape how patient-derived knowledge is interpreted and valued within policy arenas. Even when POs are included in deliberative processes, their contributions may be marginalized if institutional actors privilege biomedical, economic, or technocratic forms of evidence. Drawing on the literature on epistemic injustice, this dimension highlights the importance of testimonial credibility and hermeneutical uptake. Testimonial credibility concerns whether patient voices are regarded as reliable and informative. Hermeneutical uptake concerns whether institutional epistemologies can accommodate the categories, experiences, and value-laden perspectives that patients bring. Many POs respond to these asymmetries by translating experiential knowledge into technical formats that align with institutional evidence norms. Such translation facilitates participation but also reveals the persistence of epistemic hierarchies. Epistemic recognition therefore plays a central role in determining whether participation becomes substantive.

A third determinant involves organizational capacity and representational credibility, which influence the ability of POs to engage effectively with complex health policy processes. While analytically distinct, organizational capacity and representational legitimacy are deeply intertwined in practice, as professionalization and institutional literacy often function simultaneously as resources for participation and as markers of credibility. As noted in Section 1.1, POs vary widely in terms of size, expertise, professionalization, and internal governance. Organizational capacity includes policy literacy, scientific or technical expertise, staff continuity, and the financial resources required for sustained engagement. Representational credibility concerns whether a PO is perceived as a legitimate spokesperson for its constituency, an issue shaped by internal democratic practices, membership structures, and the presence of external funding relationships that may produce conflicts of interest. These factors shape institutional perceptions of PO legitimacy and also influence how patient communities evaluate the organization’s alignment with their needs and priorities.

The fourth determinant consists of the broader political and socio-digital environment. Political cultures, welfare-state traditions, and prevailing attitudes toward public participation shape the conditions under which POs engage with institutions. Commercial interests and media dynamics further influence public narratives about patienthood and expertise. Digital infrastructures have also reshaped the landscape of participation. Online platforms expand opportunities for mobilization and knowledge sharing, but they also introduce new exclusions related to digital literacy, access, and algorithmic visibility. In this framework, digital participation is treated as part of the socio-digital environment that conditions access, visibility, and inclusion, rather than as a separate participatory model. These contextual factors modulate the effects of the other three determinants by either enabling more pluralistic forms of participation or reinforcing technocratic closure.

These four domains form an integrated conceptual map that clarifies how POs transition from advocacy to meaningful influence. Influence does not result from any single determinant, nor does the framework assume linear or additive effects across these determinants. Rather, different configurations of alignment and misalignment produce distinct and analytically predictable participatory outcomes. For example, institutional access structures combined with limited epistemic recognition are likely to result in tokenistic participation, where patient organizations are formally included but their contributions remain marginal to deliberation and decision-making. Conversely, strong organizational capacity and stable institutional access, when coupled with compromised representational independence or financial dependence, may give rise to co-optation, characterized by sustained engagement but constrained agenda-setting power. In other configurations, high socio-digital visibility and mobilization capacity may enable agenda pressure and public influence even in the absence of formal institutional access, though with uncertain uptake within decision-making arenas. These configurations illustrate that failures of participation are best understood as outcomes of structural and epistemic misalignment rather than as isolated implementation deficits within participatory initiatives. Situations of persistent marginalization, where patient organizations lack both access and epistemic recognition, fall outside the scope of participatory configurations examined here and constitute pre-participatory conditions rather than outcomes of participation.

3. Making Participation Matter: Forms and Outcomes

Building on the conceptual framework outlined above, we examine how the determinants of patient organization influence manifest in practice across different forms of participation. The analysis moves from conceptual synthesis to the examination of participation as it is enacted, focusing on how different configurations of institutional access structures, epistemic recognition, organizational capacity and representational legitimacy, and the broader socio-digital environment shape participatory modalities and their outcomes. In doing so, it highlights how variation in participatory design, knowledge valuation, and organizational positioning affects whether patient organizations are able to shape deliberation, influence decisions, and contribute to accountability within contemporary health governance arrangements.

3.1 Modalities of Engagement

While formal structures and policies provide the scaffolding for patient participation, it is in everyday practices and local contexts that the real dynamics of inclusion and exclusion unfold. The modalities through which patient organizations (POs) engage in decision-making vary widely, ranging from consultative roles and advisory positions to co-creative processes and agenda-setting influence. These forms of participation often fall along a continuum from tokenism to co-governance, reflecting both the intentions of institutional actors and the capacity of POs to navigate complex bureaucratic environments.

Viewed through the analytical framework developed in Section 3, these participatory modalities reflect different configurations of the four interdependent determinants identified above. From an institutional access perspective, these modalities differ in the timing of entry, the degree of formal authority, and the presence of feedback mechanisms. From an epistemic perspective, they differ in how far patient knowledge is recognized, taken up, and treated as relevant within dominant evidentiary norms. From an organizational capacity and representational legitimacy perspective, they vary in the extent to which patient organizations possess the resources, expertise, and internal governance structures required for sustained and credible engagement. Finally, from the perspective of the broader political and socio-digital environment, these modalities are shaped by prevailing political cultures, media dynamics, and digital infrastructures that condition visibility, mobilization, and inclusion.

At one end of the spectrum, consultative models are characterized by one-off invitations to provide input, typically during public comment periods or stakeholder meetings. These engagements often lack feedback loops, meaning patient organizations (POs) have little visibility into how their contributions are used or whether they influence outcomes, a dynamic frequently associated with tokenistic or instrumental forms of participation (Ocloo & Matthews, 2016). This form of participation, while symbolically important, risks instrumentalization if not embedded in reciprocal and ongoing processes of dialogue and accountability (Barnes et al., 2003). At the other end, co-productive models involve long-term collaboration between institutions and POs in designing, implementing, and evaluating policies, emphasizing shared responsibility and sustained engagement rather than episodic consultation (Bovaird, 2007; Fung, 2006). For instance, the Dutch rare disease community has demonstrated the potential of co-creation in shaping national research priorities and care pathways (Poortman et al., 2024).

A growing area of engagement is digital and hybrid participation, which has transformed how POs mobilize, deliberate, and advocate. Online platforms have enabled broader geographic reach and the inclusion of individuals with limited mobility or rare conditions. During the COVID-19 pandemic, many POs rapidly adapted to digital formats, hosting webinars, conducting surveys, and leveraging social media to amplify patient voices (Wallraf et al., 2024). However, digital modes also introduce new exclusions, as those without internet access or digital literacy may be left behind, reinforcing existing inequities.

The form participation takes is shaped not only by institutional openness but also by organizational strategy and identity (Baggott & Jones, 2014; Ocloo & Matthews, 2016). Some patient organizations (POs) adopt a “partnership” model, emphasizing collaboration, professionalization, and alignment with institutional priorities in order to gain access and influence within formal decision-making arenas (Baggott & Jones, 2014). Others embrace a more adversarial or activist stance, using protest, media campaigns, or legal challenges to advance their claims and contest dominant policy agendas (Rabeharisoa et al., 2014b). These tactical orientations are not mutually exclusive, as many organizations oscillate between cooperation and contestation depending on context, institutional responsiveness, and issue salience (Ocloo & Matthews, 2016; de Boer, 2021). For example, HAEi, an international advocacy network for hereditary angioedema, has used both high-level policy engagement and grassroots mobilization to expand diagnostic access across Asia-Pacific countries (Wong et al., 2025).

Participation is also mediated by professional roles within patient organizations (POs). As organizations become more specialized, they often employ policy analysts, scientific advisors, and communication professionals who act as intermediaries between patient communities and decisionmakers, translating experiential knowledge into institutionally legible forms (Baggott & Jones, 2014). While this enhances the strategic sophistication and credibility of participation, it can also create internal hierarchies that distance professional staff from the lived realities of the patients they represent, raising concerns about representativeness and accountability (de Boer, 2021; Rabeharisoa et al., 2014b). Addressing these tensions requires deliberate mechanisms for internal accountability, reflexivity, and democratic governance within POs themselves, in order to balance professional expertise with meaningful member participation (Ocloo & Matthews, 2016; Barnes et al., 2003). These modalities illustrate how participation is shaped by different alignments of the 4 determinnants, rather than by formal design alone.

3.2 Evaluating Outcomes: Influence and Accountability

Assessing the impact of patient participation remains one of the most contested areas in the literature, with substantial uncertainty about what constitutes meaningful change and how it can be evaluated (Modigh et al., 2021; Staniszewska et al., 2008). Traditional metrics, such as whether patient recommendations were adopted, have been criticised for offering only limited insight into the broader effects of engagement. Instead, reviews of involvement activities report a wide variety of outcomes and highlight methodological challenges in attributing specific changes to participation, suggesting that influence often manifests in more diffuse, indirect, and cumulative ways that shape organisational processes, framings of issues, and the legitimacy of evidence rather than producing simple, discrete results (Fredriksson et al., 2025). Moreover, many participatory processes lack clear evaluation criteria or benchmarks, making it difficult to assess success or failure.

Recent studies suggest that the most meaningful impacts occur when POs are engaged early and throughout the policy cycle. In oncology, for example, patient input has influenced trial designs and regulatory pathways by foregrounding quality-of-life measures and treatment burden (Naeem & Jacob, 2025). Similarly, in the U.S., a survey of metastatic colorectal cancer patients revealed that while 77% reported involvement in treatment decisions, 67% desired more power in the process, underscoring the gap between formal inclusion and perceived agency (Clauer et al., 2025). This highlights the importance of not only measuring institutional uptake of patient input but also capturing subjective experiences of influence and satisfaction.

Accountability is another critical dimension, both external and internal. Externally, POs must be able to demonstrate that they represent broader patient interests and that their participation contributes to more just and effective policies. This requires transparency about funding sources, decision-making processes, and outcomes. Internally, organizations must be accountable to their members, ensuring that their policy positions reflect the lived experiences and preferences of the communities they claim to represent. Financial dependence on industry sponsors complicates both forms of accountability, raising concerns about conflicts of interest and agenda distortion (Sidiropoulos, 2023; Hennessy et al., 2024; Makowska et al., 2024).

Ultimately, participation must be evaluated not only by its outputs but also by the quality of its processes. Are discussions inclusive and respectful? Are diverse voices heard and integrated? Is there a meaningful opportunity for dissent or revision? These questions speak to the democratic legitimacy of participatory arrangements and their capacity to redistribute power and knowledge in health policy. As patient involvement becomes more institutionalized, there is a risk that it will be routinized in ways that dampen its transformative potential. Ensuring that participation remains a site of contestation, creativity, and critique depends on the alignment of institutional, epistemic, organizational, and contextual conditions identified in the conceptual framework presented here.

4. Barriers and Opportunities

While the conceptual framework developed earlier identifies the conditions under which patient organizations can exert influence, it also helps explain why participation frequently fails to translate into meaningful impact. This section applies the framework diagnostically, examining how misalignments across institutional, epistemic, organizational, and contextual dimensions produce persistent barriers to influence in practice.

4.1 Power Dynamics and Structural Barriers

While patient organizations (POs) have gained visibility in health governance, their influence remains contingent upon institutional norms, political context, and structural capacity. A recurrent theme across participatory governance is the mismatch between formal inclusion and substantive impact. As already mentioned, tokenism persists as a systemic issue, where POs are invited into decision-making spaces but confined to narrow consultative roles. Their contributions are often relegated to anecdotal experience, rather than being recognized as strategic or epistemic input (de Boer, 2021; Nikulkin & Zvonareva, 2024). Such tokenistic involvement can create a false appearance of inclusivity, allowing institutions to claim legitimacy without undergoing meaningful change. Smith and Dransfield (2019) argue that while patient and carer engagement is increasingly embedded in policy rhetoric, its actual implementation often lacks depth, consistency, and responsiveness. Genuine involvement requires mechanisms that move beyond symbolic consultation and allow for co-creation, shared decision-making, and recognition of patients as equal partners in shaping policy and services.

The framing of patient knowledge is crucial. Patient organizations frequently adapt their messaging and outputs to align with institutional expectations, often modifying language and formats to gain legitimacy (Rabeharisoa et al., 2014b). This form of "formatting" patient input enables entry into formal spaces but risks muting critical or dissenting perspectives. Even in more open systems, power asymmetries shape which contributions are accepted and which are sidelined. Ocloo & Matthews (2016) emphasize that participatory approaches require an awareness of context and institutional design, especially the tacit boundaries that delineate acceptable versus disruptive participation. De Boer (2021) illustrates how even within participatory spaces, patients may feel compelled to present their experiences in biomedicalized terms to gain traction, thereby reproducing dominant paradigms rather than challenging them. Hultman & Hultman (2023) further emphasize that individuals whose lived experiences deviate from institutional norms often encounter both testimonial and hermeneutical injustice, where their accounts are not only dismissed but also lack interpretive uptake. Without deliberate mechanisms to value diverse epistemologies, participation risks becoming a tool of assimilation rather than transformation.

Cross-national comparisons further highlight the structural constraints facing patient organizations in health governance. While formal mechanisms for inclusion have proliferated, meaningful influence remains fragmented and heavily context-dependent. Nabarette et al. (2023) conducted an exploratory study across Belgium, France, Quebec, Scotland, and Wales and identified exactly that: patients and citizens were often included at the organizational level of HTA bodies, yet their roles were predominantly consultative rather than co-decisional. HTA bodies tended to prioritize instrumental goals, such as improving process efficiency, whereas patients sought more democratic, value-driven reforms. In Cyprus, Souliotis et al. (2016) found that while patient associations participate in consultations and health reforms, their involvement in critical areas such as HTA, clinical trial ethics committees, and hospital boards remains notably limited. This discrepancy points to a layered participation model, where visibility in some areas masks marginalization in others. Similar patterns are evident in Brazil and Spain, where Suárez-Herrera et al. (2024) demonstrate that while local health councils formally integrate cross-sector actors, actual decision-making power is uneven and contingent on stakeholders’ competencies and contextual dynamics.

4.2 Financial and Representational Constraints

One of the most persistent barriers to effective PO participation is the issue of funding. Project-based or industry-dependent financing compromises both sustainability and credibility. The problem is not merely one of actual influence but of perceived legitimacy: when patient organizations are seen as too close to pharmaceutical sponsors or governmental bodies, their credibility as independent advocates may erode (Hennessy et al., 2024). Therefore, organizations lacking secure, independent funding often find themselves unable to participate consistently, or risk being perceived as biased when funding originates from stakeholders with vested interests (Fabbri et al., 2020; Parker & Mintzes, 2023). Financial dependence on industry not only jeopardizes autonomy but can also shape the agenda and public messaging of patient organizations in ways that align more with donor priorities than with patient needs. Rose et al. (2017) found that a majority of patient advocacy organizations (PAOs) in the U.S. received industry funding, with some deriving over half their revenue from commercial sources, raising concerns about compromised independence. This dynamic risks silencing less resourced voices, particularly smaller or grassroots organizations that cannot meet the visibility and bureaucratic expectations of formal participation processes. Despite growing calls for transparency, many POs still operate without clear conflict of interest (COI) policies, further complicating their legitimacy in policy debates. Brems and McCoy (2019) demonstrated that only half of major U.S. PAOs had publicly available COI policies, and even fewer included substantial restrictions or oversight provisions. A lack of standardized COI disclosure practices, coupled with limited governance mechanisms, allows for inconsistency in how financial relationships are managed and perceived.

Financial precarity intersects with representational legitimacy in more than one way. Larger, professionalized organizations with institutional literacy and policy experience enjoy greater access and visibility (Westerlink et al., 2023). Their capacity to produce polished outputs, engage in sustained lobbying, and align with institutional expectations often secures them a seat at the policy table. In contrast, grassroots or condition-specific groups frequently struggle to meet the technical and bureaucratic requirements for formal participation (Rojatz & Forster, 2017). These disparities are not merely logistical but epistemic: smaller organizations' experiential insights are often treated as anecdotal rather than authoritative. This epistemic gatekeeping compounds existing resource-based inequalities, reinforcing a participation system in which credibility is conflated with conformity (de Boer, 2021). Moreover, institutional designs often privilege stakeholders with the time, education, and financial stability to engage regularly, systematically marginalizing those with fewer resources (Ocloo

& Matthews, 2016). The result is a double burden for underrepresented groups: their access is limited by both material constraints and a pervasive skepticism about the legitimacy of their knowledge.

Moreover, digital engagement has opened new avenues for inclusion but also deepened existing divides. While some organizations have leveraged virtual platforms to broaden outreach and lower participation costs, others have found that digital infrastructures privilege those with technological fluency and access (Barony Sanchez et al., 2022). These challenges disproportionately affect older adults, people with disabilities, and communities in low-connectivity regions, highlighting the need for hybrid models of engagement that combine digital and in-person modalities. Dugdale (2012) further illustrates how even digitally motivated patient organizations face structural barriers when attempting to meaningfully engage diverse populations online, underscoring that digital inclusion requires more than simply offering online options.

4.3 Future Directions and Policy Innovation

The path forward requires a reimagining of participatory governance. Capacity-building remains essential, not just for patients, but for institutions as well. Healthcare actors must cultivate epistemic humility and adapt structures to integrate non-traditional knowledge. Recent reforms in Norway's healthcare system further underscore the need for dual-sided capacity-building: through the establishment of Health Care Communities (HCCs), policymakers formalized structures for co-design and collaborative governance, aiming to address service fragmentation via shared responsibility between hospital trusts and municipalities (Krane & Høyem, 2023). These efforts reflect a broader shift toward "New Public Governance" models, where collective competence and distributed leadership become central to transformation. Within the conceptual framework developed in this paper, such initiatives can be understood as attempts to realign institutional access structures, epistemic recognition, and organizational capacity in ways that support meaningful patient organization influence.

Evaluation frameworks are central to this transformation. Without mechanisms to track outcomes, participatory initiatives risk becoming symbolic rituals. New metrics should assess not just attendance or feedback volume, but actual influence on decisions, responsiveness of institutions, and redistribution of power (Belrhiti et al., 2024). Aggarwal et al. (2022) highlight the conceptual vagueness surrounding accountability in participatory health systems, calling for shared models that integrate stakeholder-defined criteria and iterative evaluation. Robust evaluation, then, must include both quantitative indicators (e.g., influence on policy outcomes, resource allocation) and qualitative insights (e.g., trust, relational dynamics, perceived legitimacy).

Governance innovation must also embrace co-production models that transcend one-time consultations. Shared decision-making and co-governance, where patients and professionals collaborate from agenda-setting through implementation, can democratize institutional cultures and shift power dynamics. Shared governance is most effective when embedded within institutional cultures that emphasize collaborative capacity, distributed leadership, and co-creation. Krane and Høyem (2023) argue that co-design and co-planning must be formalized within health institutions to disrupt fragmentation and enhance mutual accountability between patients and providers. These principles are equally applicable to patient governance, especially when adapted for system-wide implementation. Such models require organizational openness and the redistribution of decision-making authority, yet they can offer more legitimate and resilient forms of governance.

Participatory legitimacy today hinges on flexible, context-sensitive design. Hybrid platforms, multilingual support, and deliberative forums are not optional add-ons but prerequisites for equitable governance. Realizing the full potential of patient participation demands a commitment to redistribution, recognition, and reciprocity. These reforms are not without difficulty. Institutional inertia, political resistance, and entrenched professional norms remain formidable obstacles. However, incremental successes (ranging from localized co-design projects to shifts in regulatory language) indicate that meaningful change is possible. Embedding participation into the architecture of governance, and resourcing it sustainably, can lead to more inclusive, resilient, and democratically accountable health systems.

Conclusions

This paper set out to examine how patient organizations have moved from advocacy toward influence in health decision-making, and why such influence remains uneven, fragile, and context-dependent. While patient participation has become a normative expectation in contemporary health governance, its substantive impact cannot be taken for granted. By synthesizing a diverse body of literature across health policy, governance theory, and epistemic justice, the paper has argued that participation alone is insufficient to explain variation in influence. Instead, influence emerges through specific configurations of institutional, epistemic, organizational, and contextual conditions.

The central contribution of the paper is the development of an integrative conceptual framework that clarifies these conditions and their interactions. The framework conceptualizes patient organization influence as an emergent outcome rather than a direct product of formal inclusion. Institutional access structures shape access, timing, and authority, but do not guarantee uptake. Epistemic recognition and knowledge legitimacy determines whether patient knowledge is treated as credible, relevant, and actionable within decision-making arenas. Organizational capacity and representational legitimacy condition whether patient organizations are able to engage effectively and sustainably. Finally, political and socio-digital environments modulate these dynamics by shaping incentives, visibility, and power relations. In essence, these determinants explain why similar participatory arrangements may produce markedly different outcomes across settings.

Applying this framework to participatory modalities and barriers demonstrates that tokenism and co-optation are not anomalous failures, but predictable outcomes of misalignment across determinants. Institutionalized participation without epistemic openness risks confining patient organizations to symbolic roles. Professionalization without safeguards for representational accountability can undermine legitimacy. Digital participation can expand reach while simultaneously reinforcing inequalities. These dynamics highlight that meaningful influence requires alignment, not only access, and that participatory reforms must be evaluated in relation to their structural and epistemic conditions rather than their procedural form alone.

As a theoretical and literature-based contribution, this paper does not offer systematic empirical testing of the proposed framework. The framework is therefore intended as an analytical heuristic rather than a predictive model. For policymakers and institutions, the framework shows that enhancing patient organization influence requires interventions across multiple dimensions, including procedural design, evidence norms, capacity-building, and accountability mechanisms. For patient organizations, it highlights the strategic trade-offs involved in professionalization, partnership, and advocacy, and the importance of maintaining representational credibility alongside institutional engagement. Future research could operationalize its components through comparative case studies, process tracing, or mixed-methods approaches, examining how alignment and misalignment across determinants shape outcomes over time. Such work would further refine the framework and assess its explanatory reach across diverse health governance settings.

The transition from advocacy to meaningful influence is neither linear nor inevitable. By foregrounding the conditions under which influence becomes possible, and by identifying the structural sources of its failure, this paper contributes a conceptual lens for understanding patient participation as a dynamic and contested feature of contemporary health governance. Strengthening patient organization influence therefore requires not only inviting participation, but reconfiguring the institutional, epistemic, and organizational foundations upon which participation rests.

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