



Patient and Citizen Partnership as a Governance Capacity for Scaling Up Integrated Care: Moving Toward Shared Leadership in Collaborative Governance

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Citation: Hudon C, Poirier MD. Patient and citizen partnership as a governance capacity for scaling up integrated care: moving toward shared leadership in collaborative governance. *Int J Health Policy Manag.* 2026;15:10007. doi:10.34172/ijhpm.10007

Received: 14 May 2026; Accepted: 29 September 2026; ePublished: 30 September 2026

Integrated Care and the Challenge of Scale-Up

Integrated care has been widely promoted as a promising response for populations with complex needs.¹ Although definitions vary, integrated care broadly refers to coordinated and person-centred approaches that seek to align services across disciplines, organizations, and sectors in order to improve continuity, quality, and outcomes of care.² Rather than focusing on isolated conditions or discrete episodes of care, integrated care aims to organize services around people's holistic needs, recognizing the interdependence of physical health, mental health, and social circumstances.

Despite growing policy interest and an expanding evidence base, implementing integrated care for people with complex needs remains challenging.³ Integrated care initiatives are inherently complex interventions, involving multiple interacting components, diverse professional groups, organizations with distinct mandates, and evolving relationships among actors.⁴ As a result, implementation processes are rarely linear or standardized; they require ongoing adaptation to local contexts, negotiation across organizational boundaries, and collective learning over time.⁵

Beyond initial implementation, scaling up integrated care introduces additional layers of complexity. Scale-up involves extending an intervention beyond pilot settings while preserving its core principles, effectiveness, and relevance across diverse organizational and population contexts.⁶ This process raises governance-related challenges, including coordination across levels of the system, alignment of incentives, legitimacy of decision-making, and long-term sustainability. In practice, scale-up efforts frequently encounter entrenched institutional arrangements, fragmented

accountability structures, and competing priorities across sectors.⁷

Collaborative Governance as a Response to Implementation and Scale-Up Challenges

The implementation and scale-up of integrated care initiatives require forms of governance capable of addressing complexity, uncertainty, and interdependence across actors and system levels. Governance influences how decisions are made, how responsibilities are allocated, and how adaptation is supported over time.⁸ In the context of complex interventions, governance arrangements relying primarily on hierarchical control or standardized procedures often struggle to accommodate the dynamic and context-sensitive nature of implementation and scale-up processes.⁹

Collaborative governance has increasingly been proposed as a promising approach in such contexts. Broadly defined, collaborative governance brings together diverse partners—across professional, organizational, and sectoral boundaries—to engage in shared decision-making.⁸ This form of governance can support implementation and scale-up in several ways. First, by involving a wide range of partners early, collaborative governance supports the anticipation of potential implementation challenges and enables the consideration of multiple scenarios before they materialize. This anticipatory capacity is particularly important when scaling interventions across heterogeneous settings.¹⁰

Second, collaborative governance can enhance alignment and coordination among partners with differing mandates, incentives, and professional logics. Integrated care initiatives often span healthcare, social services, and community-based organizations, making coordination a central governance challenge.¹¹ Collaborative arrangements can facilitate mutual understanding, negotiation of roles, and the development of shared objectives,¹² thereby reducing fragmentation during scale-up.

Third, collaborative governance can support learning and adaptability. By creating spaces for dialogue and reflection, it enables partners to collectively interpret emerging issues, adjust strategies, and refine implementation processes over time. Such learning-oriented governance is critical when scaling complex interventions, where outcomes and causal pathways cannot be fully specified in advance.¹³

In practice, however, collaborative governance efforts tend to prioritize the involvement of professional, managerial, and policy partners. While these partners play essential roles in implementation and scale-up, citizens and patient partners remain far less systematically involved in governance processes. This is particularly problematic given the distinct and complementary contributions that citizens and patient partners can bring to governance.¹⁴ Patient partners contribute experiential knowledge grounded in lived experience of care and service use, helping ensure that decisions remain responsive to the needs and realities of those receiving services. Citizen partners contribute broader societal perspectives, helping align decisions with collective interests, public values, and democratic accountability. Together, these perspectives help balance individual experiences with population-level considerations and can strengthen the legitimacy and responsiveness of governance processes. Yet, despite these potential contributions, their limited involvement remains difficult to reconcile with contemporary governance frameworks, which identify participation as a fundamental pillar of effective governance.¹⁵ In the health sector, patient and family engagement frameworks further suggest that meaningful participation should extend beyond consultation toward partnership and shared leadership in governance and decision-making.¹⁶ When citizen or patient involvement does occur, it is often confined to consultative roles or care-level interactions, rather than embedded within strategic decision-making.¹⁷ Consequently, collaborative governance risks being enacted without the meaningful participation of those most directly affected by the decisions being made.

This uneven involvement reflects not only institutional traditions but also uncertainty regarding how to meaningfully integrate citizen and patient partners into governance structures. Questions concerning roles, legitimacy, competencies, and boundaries are frequently raised, particularly in system-level decision-making contexts. Consequently, citizen and patient partnership remains underdeveloped as a governance resource for implementation and scale-up.

Against this backdrop, there is a need for empirically grounded accounts that examine how citizen and patient partnership can be embedded within governance structures during implementation and scale-up processes. Beyond demonstrating the value of participation per se, such accounts can clarify the roles, conditions, and contributions through which citizen and patient partners influence strategic decision-making, coordination, and adaptive processes over time. The following section responds to this need by examining the experience of the VISAGES approach,¹⁸ focusing on the sustained involvement of a citizen-patient within the governance of its scale-up.

Illustrating Citizen and Patient Partnership as a Governance Capacity: A Long-term Embedded Experience

The scale-up of the VISAGES integrated care approach, initiated in 2023, offered an opportunity to examine how citizen and patient partnership could function as a governance capacity rather than a peripheral or consultative practice. The

VISAGES approach targets individuals with complex needs arising from the interaction of physical health conditions, mental health challenges, and socioeconomic precarity, often resulting in fragmented care trajectories and unmet needs. It combines several core components, including collaborative governance structures, intersectoral concertation tables, systematic screening, case management, and the use of standardized tools. Its governance arrangements include a provincial steering committee composed of representatives from the Ministry of Health and Social Services, the research team that developed the approach, a project manager responsible for coordinating and supporting implementation activities, and a citizen-patient partner, as well as local implementation committees within participating organizations involving these partners and representatives from relevant organizational directorates.

This section draws on the experience of MDP, a citizen-patient partner and co-author of this article, who was embedded within the strategic governance structures overseeing the implementation and scale-up of the approach. While her engagement was informed by long-standing experience navigating the healthcare system as a patient, she participated in governance processes through both citizen and patient lenses, contributing experiential knowledge alongside broader reflections on collective interest and system-level priorities. Her involvement extended beyond symbolic participation to sustained engagement in decisions shaping the direction, conditions, and modalities of scale-up.

Citizen and Patient Partnership Within Governance Processes

During the scale-up phase, MDP was involved in several interconnected governance spaces, including regular meetings with the VISAGES core team, thematic working groups, senior management within partner organizations, the provincial steering committee, and the local implementation committees. Within these settings, the citizen-patient partner contributed to discussions related to strategic alignment, implementation challenges, and coordination across organizational contexts.

She also contributed to dissemination and knowledge translation activities associated with the scale-up, such as webinars and professional exchanges. In these contexts, lived experience functioned as an interpretive resource supporting collective sense-making and helping partners assess whether proposed strategies were aligned with real-world care and service trajectories.

A further dimension of the partnership involved the co-development and revision of tools supporting implementation and scale-up. MDP contributed to clinical, organizational, and governance-related tools, as well as to collective reflection on future orientations of the VISAGES approach. Through this involvement, citizen and patient partnership influenced not only decision-making processes but also the material and discursive infrastructure through which scale-up was enacted.

Across governance activities, a consistent contribution involved reframing discussions by reintroducing the perspective of service users as citizens and persons. This included emphasizing that individuals with complex needs

should not be reduced to cases, utilization profiles, or cost categories, and sustaining attention to dignity, coherence, and lived continuity of care in discussions often dominated by performance or efficiency considerations.

MDP also engaged with case managers through participation in communities of practice, contributing to reflective learning processes. As needed, she provided adapted materials responsive to local contexts and accompanied newly involved citizen and patient partners, supporting their integration within governance and implementation structures.

Challenges Encountered in Embedding Citizen and Patient Partnership in Governance

Embedding a citizen-patient partner within governance processes raised several challenges. A recurring issue concerned demonstrating the added value of such partnership in decision-making spaces where citizen involvement had historically been absent or limited to consultative roles. In some contexts, distinctions between being a participant or beneficiary of an intervention and being a citizen-patient partner formally integrated into governance were not immediately clear.

From MDP's standpoint, the role required ongoing development of competencies related to the VISAGES approach, including engagement with tools, shared reflection, and co-analysis alongside professionals and researchers. At the same time, maintaining her position as a citizen-patient partner—without becoming fully assimilated into professional or managerial perspectives—required sustained reflexivity. MDP needed to distance herself from her own health issues to focus on the broader experiences of individuals with complex needs.

Collaboration within a ministry-led implementation committee also involved mutual learning. Institutional partners adapted to working with a citizen-patient partner at the governance level, while the partner navigated decision-making norms and identified legitimate spaces for contribution. More broadly, openness to citizen and patient partnership varied across actors and settings, underscoring uneven readiness for participatory governance.

Many of these challenges are not unique to the present experience and have been documented more broadly in the literature on patient and public involvement in governance, particularly with respect to role clarity, capacity building, representativeness, and balancing experiential and professional forms of knowledge.¹⁹ While these challenges are common across participatory approaches to governance, their nature and intensity may vary depending on how patient and citizen involvement is organized. For example, some challenges may differ when patient and citizen perspectives are gathered through broader consultative mechanisms designed to engage a larger number of participants. Such approaches may help address concerns related to representativeness and legitimacy by drawing on a wider range of experiences and perspectives. They may also enable the use of more standardized participation processes and mediation strategies to support deliberation, reconcile divergent viewpoints, and facilitate the integration of experiential, professional, and

organizational perspectives. However, broader consultative approaches typically serve an advisory function, whereas citizen and patient partnership in governance involves direct participation in deliberation and decision-making as members of the governance team. These approaches should therefore be viewed as complementary rather than interchangeable. Lessons learned from more direct forms of citizen and patient partnership in governance can, in turn, help inform the design and implementation of these broader participatory processes, ensuring that they support meaningful engagement and influence on decision-making.

Contributions to Governance and Scale-Up

The sustained presence of MDP within governance structures contributed to humanizing strategic decision-making by reconnecting policies, implementation strategies, and resource allocation with lived experience. Her involvement challenged stigmatizing representations of people with complex needs and reinforced citizen and patient partnership as a substantive governance resource rather than a procedural requirement. For both individuals targeted by the approach and decision-makers involved in its implementation, the presence of a citizen-patient partner within governance structures also enhanced the social acceptability of the scale-up process. Beyond its symbolic significance, her contribution supported collective learning, informed strategic decision-making, and strengthened coordination among partners involved in the scale-up process. This experience also supported the integration of additional citizen and patient partners within VISAGES and related contexts engaged in the scale-up of integrated care.

Conclusion

Scaling up integrated care raises governance challenges that extend beyond technical implementation concerns. This article has argued that citizen and patient partnership, when meaningfully embedded at the strategic level, can constitute a form of governance capacity rather than a consultative adjunct. The experience of the VISAGES approach illustrates how sustained involvement of a citizen-patient contributed to collective sense-making, coordination, and reflexivity during scale-up, while ensuring that strategic decisions remained grounded in lived experience. If collaborative governance is to fulfil its promise in integrated care, citizens and patient partners cannot remain peripheral participants. They must be recognized as governance actors in their own right, bringing forms of knowledge, legitimacy, and accountability that are essential to the successful implementation and scale-up of integrated care.

Disclosure of artificial intelligence (AI) use

AI tools (eg, Microsoft Copilot) were used for editorial revision (grammar, spelling, and language clarity); the scientific content remains entirely the responsibility of the authors.

Ethical issues

Not applicable.

Conflicts of interest

Authors declare that they have no conflicts of interest.

Authors' contributions

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Funding statement

This research is supported by the Canadian Institutes of Health Research, the CIHR - Strategy for Patient-Oriented Research (SPOR), Institute of Musculoskeletal Health and Arthritis (IMHA), Fonds de recherche du Québec – Santé (FRQS), and ResearchNB.

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