

## ***Engaging Patients and Caregivers: Transforming Healthcare Together***

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Healthcare systems worldwide are evolving and changing rapidly. Several kinds of crises, as well as varying demographic determinants, have altered the equilibrium and trends posing challenges in terms of resilience, economic sustainability and the capacity to capture and then meet the real needs of people.

In this evolving context, we cannot make true progress without recognising the value that patients and caregivers, as well as communities and citizens bring to improving the quality, safety and performance of care, as well as to making the system itself sustainable by contributing to the healthcare services cycle and the achievement of its outcomes. On the one hand, healthcare services' design, provision, and increasingly evaluation should be underpinned by a person-centred approach. On the other hand, among the main challenges of healthcare systems, long-term sustainability increasingly is challenged by rising prevalence of long-term conditions and co-morbidity, constrained human resources and public finances. Demand to fund the treatment of illness is impacting the transformation of the social determinants of good health. In this environment co-production and shared decision-making must be one of the building blocks of the healthcare system of the future.

Patient engagement is recognized as a crucial element of improved healthcare quality. Involving various concepts, terms, and definitions (1), one key approach is applying co-production theory to healthcare management, where patients, their representatives, or organizations collaborate with stakeholders at different levels of care. In this perspective, it should involve three levels: (i) micro-level: patients manage their own health and treatment; (ii) meso-level: patients and their representatives contribute to developing and improving healthcare services; (iii) macro-level: patients engage in shaping healthcare policies and regulations at a governmental level (2). Research on co-production in healthcare has focused on issues related to the micro-level: for instance, patient-doctor relationship, shared decision-making, health literacy, compliance and adherence, patient empowerment and activation. This means efforts to creating genuine collaboration with patients, ensuring their voices shape decisions, and empowering them to make informed choices about their health (3, 4). These activities all have been identified as solutions to deal with challenges relating to the financial and social viability of health systems (5). Other studies showed a different approach to individual patient engagement, moving the single contribution from the micro-, to the meso- and macro-levels, with an approach to knowledge management that permeates the healthcare organisations and make the patient voice a key source of information for decision-making at the different levels of the healthcare systems (6, 7). Other frameworks, coming from real-life case studies to the theory, underline the role of communities and social networks of patients and caregivers to produce value, so exponentially expanding the boundaries of each level (micro-level included) for integrating a wide range of stakeholders into the web of value co-producers (8, 9). In this scenario, professionals should act not only as providers, but also as enablers or facilitators of people who are seen as active agents and co-providers. According to Pennucci et al. (8), this can happen by developing an approach that includes education, activation, engagement, and empowerment of people; especially patients and caregivers.

The patients' role as a co-producer is not only unavoidable but is also crucial to the performance of a service and the impact of that service upon them. Co-production represents the promise of affording people the opportunity to participate in co-commissioning, co-designing, co-delivering, and co-evaluating services with professionals and organizations (10). Similarly, patient and public involvement in research is relevant, and more likely to produce meaningful outcomes that improve healthcare, such as in the case of health technology assessment (11). By incorporating the perspectives of those directly affected by health conditions, researchers can identify priorities that truly matter to patients, design studies that are more practical and inclusive, and enhance the communication of findings. Moreover, engaging patients fosters trust in the research process, encourages transparency, and ultimately leads to healthcare innovations that are more aligned with real-world needs (12).

However, realising this promise requires facilitation and improvement, putting in place processes and creating opportunities for a wider and more productive engagement. These approaches include collaborative processes enabling in various ways people to co-create health outcomes as well as to catalyse the creation of wider social value (8). Existing research indicates that procedural mechanisms and structural factors, including targeted and inclusive education and training, can support quality and impact creation and their evaluation (2).

This approach to co-production does not necessarily require user involvement in all the phases of healthcare services, from commissioning and planning to delivery and evaluation (13). However, this can occur and is often termed 'co-creation' and is linked to the service innovation process. Nevertheless, a recent review of the engagement of patients shows a lack of research on the concrete outcomes of patient engagement in healthcare services and its impact on patients (2).

Even if researchers, practitioners, policy-makers and users all understood the value of people engagement in healthcare services', the journey from theory to practice in effectively engaging these critical stakeholders to really create value remains complex.

This is why we are excited to introduce our **Special Issue on "Patient and Caregiver Engagement in Healthcare Services' Cycle: Bridging Theory and Practice"** in *IJQHC Communications*. This collection delves into the practical and empirical strategies that enhance patient-centred care and showcases innovations that incorporate patients and caregivers across all phases of the healthcare service cycle—from design to delivery and evaluation. This collection is also about transparency, inclusivity, and designing studies that truly reflect patient needs, by actually engaging with them and so leading to better healthcare outcomes for all.

## Why This Special Issue Matters

Patient and caregiver engagement is more than a buzzword; it should be a cornerstone of a healthcare system that is truly responsive and inclusive. However, engagement often focuses narrowly on care delivery, and is sometimes based on single and one-shot experiences and not systemic, leaving gaps in the commissioning, design, and evaluation stages. By broadening the lens, this issue explores how involving patients and caregivers in these processes leads to system-wide transformation, better clinical and managerial practices, and enhanced outcomes (that matter most to them). Additionally, taking care of the potential role of these and other actors and stakeholders can make healthcare systems more resilient and sustainable.

We expect articles covering a range of perspectives, from theoretical frameworks to case studies and policy analyses, with a favoured sight on participatory research. By examining both challenges and solutions, this issue aims to inform future research, policy, and practice with the direct

contribution of patients and caregivers. We hope it serves as a valuable resource for healthcare professionals, researchers, policymakers and patients committed to enhancing patient engagement.

## What to Expect

This issue highlights:

- **Empirical insights** into the outcomes of patient and caregiver involvement in healthcare services.
- **Case studies** that illustrate successful integration of these perspectives in healthcare management.
- **Innovative methods** for engaging diverse populations, particularly those experiencing vulnerabilities.
- The pivotal role of **digital tools** in facilitating meaningful engagement.

We will prioritise participatory research articles as well as papers directly written with practitioners and patients. By emphasizing actionable strategies and participatory approaches, we aim to bridge the gap between theoretical ideals and real-world applications.

## Join the Conversation

We invite academics, practitioners and patients alike to contribute. Whether you are sharing research, practical experiences or new methodologies, your work can inspire change. Collaborative submissions involving patients and their representatives as co-authors are particularly encouraged.

We thank all the authors, reviewers, and editors who will contribute to this special issue, and who will continue the conversation on advancing patient engagement in healthcare.

## A Unique Format

The Special Open Collection offers a dynamic approach, releasing the issue in multiple waves to align with ongoing research and practice. This ensures your contributions will remain timely and impactful.

### Key Dates:

- Draft Submission for Volume I: **April 30, 2025**
- Publication Date for Volume I: **July 2025**

### Submission Information:

Submit your manuscript via the IJQHC Communications Submission System, selecting "Special Issue/Special Open Collection: Patient and Caregiver Engagement" as the article type.

Together, let's transform healthcare by ensuring that patients and caregivers are no longer just recipients but partners in shaping the future.

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