Editorial

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From patient voice to patient partnership: closing the implementation gap in healthcare

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> "If we are serious about improving outcomes, we must move beyond inclusion and commit to integration."

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Patient centricity is no longer a new concept. It is embedded in strategies, referenced in policy documents, and widely recognized across healthcare, research and industry. Yet, despite this progress, a fundamental gap remains between intention and implementation.

From a patient perspective, the issue is not a lack of voice, as patients are increasingly invited into discussions, panels and advisory roles. However, the issue is that these contributions are rarely integrated into how decisions are made.

From voice to partnership

- Patient centricity is often interpreted as listening to patients. However, listening alone does not change outcomes, effective partnership does. True patient partnership means being involved early enough to influence decisions.
- Having clearly defined roles and expectations.
- Being part of continuous, not one-off, engagement.
- Contributing to outcomes and not just discussions.

Frameworks such as the 'Patient Focused Medicines Development Patient Engagement Quality Guidance' [1] and initiatives led by European Patients' Forum [2] have already outlined principles for meaningful engagement [3,4].

Existing frameworks such as Patient Focused Medicines Development (PFMD)'s Patient Engagement Quality Guidance [1], the National Institute for Health and Care Research (NIHR) Standards for Public Involvement in Research [5], and the WHO framework on integrated, people-centred health services [6] already provide structured and system-level approaches for meaningful engagement. However, their translation into routine practice remains inconsistent.

The implementation gap

Despite growing awareness, patient engagement remains fragmented, inconsistently applies, underfunded and dependent on individual goodwill rather than system design. This creates a structural paradox.

Patients are expected to contribute at a professional level, providing strategic insight, reviewing protocols, shaping policies while operating within systems that lack governance structures, compensation models and operational clarity.

Evidence increasingly shows that early and meaningful patient involvement improves trial recruitment, retention and relevance of outcomes [4,7]. Yet, involvement is still often introduced too late to influence design.

Barriers we continue to accept, but should not

Several well-documented barriers persist across healthcare systems [8,9]:

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- Tokenism disguised as inclusion: patients are involved without real influence, often at the end of processes.
- Lack of standardization: there is no shared operational definition of what good engagement looks like.
- Cultural resistance: traditional hierarchies continue to limit partnership-based models.
- Resource misalignment: engagement is rarely built into budgets, timelines or governance structures.
- Fragmented evidence base: while evidence exists, it is not consolidated or translated into practical implementation models.

From initiatives to systems

Across Europe and globally, strong patient engagement initiatives exist. However, they remain isolated and difficult to scale. This results in repeated pilot projects rather than systemic progress. To move forward, patient centricity must be treated as a system capability. This requires:

- Shared and adaptable implementation frameworks.
- Real-world case studies, including failures.
- Measurable indicators of impact.
- Cross-sector collaboration across patients, academia, industry and policy.

Emerging work in organizations such as EUPATI [3] demonstrates the growing capacity of patient leaders. However, capacity alone is not sufficient if systems do not evolve in parallel.

Redefining evidence: lived experience as data

One of the most persistent challenges is how evidence is defined. Lived experience is often positioned as anecdotal, whereas in reality it is a critial form of data.

However, for lived experience to influence systems, it must be, captured systematically, structured in usable formats, and intergrated into decision-making frameworks. This requires methodological development, but also a cultural shift in how evidence is valued across disciplines.

The role of the journal: from reflection to direction

The *Journal of Patient Centricity* has an opportunity to move beyond describing challenges and actively shape solutions. This includes:

- Prioritizing implementation-focused contributions.
- Elevating patient-led and co-authored work.
- Publishing real-world case studies.
- Creating space for critical reflection, including what does and what does not work.

The journal can play a key role in bridging the gap between theory and practice.

What the field needs next

To move from intention to implementation, the field must focus on:

- Operational frameworks for patient partnership.
- Sustainable funding and compensation models.
- Governance structures that embed patients in decision-making.
- Digital tools that enable scalable engagement.
- Policy alignment that supports implementation.

This is not about adding new layers to existing systems, but redesigning them.

Conclusion: from inclusion to integration

Patient centricity cannot remain an aspiration, but must become a system capability. From a patient perspective, the question is no longer whether we are heard but whether we are part of how decisions are made. If we are serious about improving outcomes, we must move beyond inclusion and commit to integration. This requires leadership, structure and accountability, and most importantly, it requires a shift in mindset, namely, from patients as participants to patients as partners.

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