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COMMENTARY

Why We Need a Patient-Centered Innovation Renaissance: A Horizontal and Vertical Integration of Knowledge to Transform Care Pathways

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1. The problem: Innovation without the patient is alienating

Being diagnosed with a complex disease such as cancer is not only a medical event. It is a disorienting and often alienating experience that alters one's sense of control, identity and connection. The journey through fragmented care systems often feels like navigating a maze designed without the patient in mind.[1] Each step, whether waiting for results, repeating personal histories to new providers, or managing conflicting advice, can compound a sense of disempowerment. Despite the best intentions of individual clinicians, the system as a whole frequently overlooks the emotional toll of this disjointedness.[2]

Innovation in healthcare has historically prioritised biomedical advances: new drugs, medical devices and diagnostic tools.[3] While these are undoubtedly important, they are often developed in disciplinary silos, shaped more by professional assumptions and technological possibility rather than by patients' lived experiences. As a result, even the most promising innovations can feel irrelevant or worse, burdensome. But, as the system of innovation remains, we may have slowly shifted towards a more consumerism infused way of providing care with 'patchwork innovation'.

This approach neglects two critical dimensions of integration. First, horizontal integration across the care pathway is essential to ensure that services work together rather than in parallel, preserving continuity and coherence for patients. We need integrated product-service innovations harnessing new technological possibilities providing real value. Second, vertical integration of tacit knowledge, patients' fears, needs, values, and emotional rhythm, is vital to designing care that supports the whole person, not just the disease. Without these, innovation risks becoming efficient but inhumane, clinically sophisticated yet experientially indifferent. At the end of the day, what is the point of innovation if the patient is left behind. We need a renaissance to reflect on the purpose of innovation, which we argue is to add value to the patient and all the stakeholders involved in this value creation.

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2. The case for a human and service-dominant logic

Increasingly healthcare services researchers are paying attention to human-cantered design to involve patients and care professionals in the development of care services.[4] However, this is not translating effectively into innovation practice on the ground. We need a broader shift toward service-dominant logic to reframe healthcare not as the delivery of a finished product but as an ongoing, co-created process shaped by interactions between patients, providers, systems and environments. This conceptual shift moves away from the legacy model of care as something "done to" patients, positioning healthcare instead as a dynamic exchange in which value emerges through use, context, and relationship. Patients, by virtue of their longitudinal and embodied experience, are uniquely positioned to create "value-in-use", meaning that the real worth of a service[5] is realised not at the point of delivery, but in how well it integrates into the lived realities, goals and circumstances of those receiving it.[6]

This logic challenges deeply embedded assumptions within provider-centric models, where expertise is seen to reside solely within clinical teams and where innovation often flows in one direction, from system to user.[7] Service-dominant logic recognizes that patients are not simply end-users or data points but co-producers of care, whose insights are essential to ensuring relevance, appropriateness, and sustainability. Their roles extend beyond compliance and satisfaction into the realms of design, problem-solving and innovation. In this framework, value is not predetermined but negotiated and adapted over time. Recognising this calls for new ways of working: more collaborative structures and greater humility in how professional expertise is applied.

3. Patients as innovators

Recent research underscores the transformative potential of involving patients and caregivers as active participants in healthcare innovation.[8] Bosveld et al[9] describes how patients, informal caregivers and healthcare professionals collaborate to create solutions that not only improve clinical outcomes but also enhance the overall experience of care. These partnerships are not limited to small scale adjustments, they often lead to systemic redesigns, such as more flexible care pathways, tools for shared decision-making, and improvements in communication and accessibility. Similarly, Visser et al[8] demonstrates that patient engagement is essential in the development of personalised care models that reflect individual preferences, life contexts and goals, rather than relying on standardized templates of treatment.

Together, these studies challenge the notion of patients as passive recipients of innovation or as users who are consulted only after a solution has been developed. Instead, they affirm that patients can and should act as co-designers, evaluators and catalysts for change. Their lived experience provides a unique form of evidence, contextual, emotional and often anticipatory, that complements clinical and operational data. Moreover, involving patients in innovation processes enhances legitimacy and trust, which are increasingly recognised as essential components of sustainable change.[9] When care innovations are shaped with, rather than for, patients and caregivers, they are more likely to be adopted, scaled and sustained in real world settings.

4. Methods: From experience-based design to generative co-design

To access the deeper layers of patient knowledge, we must move beyond traditional feedback mechanisms such as satisfaction surveys or post discharge questionnaires. While useful for capturing broad trends, these tools tend to flatten complexity, overlook context and miss the subtle emotional and relational dynamics that shape patient experience. Experience-Based Collaborative Design (EBCD) has proven effective in this regard, particularly in uncovering emotional touchpoints within care delivery.[10] By bringing together patients, families and staff to explore critical moments of care, EBCD enables organisations to identify gaps and create improvements grounded in real life experience. More recently, Generative Co-Design (GCD) has gained traction as a method to elicit tacit knowledge, particularly types of knowledge that patients feel but may struggle to articulate explicitly.[11] Using visual tools and storytelling, GCD invites participants to shape the future of care in ways that reflect their inner worlds as well as their outward needs.

Both approaches align with principles of action research: they value process as much as outcome, prioritise dialogue over data extraction, and position participants as co-investigators rather than subjects. More importantly, they offer a pathway to embed empathy and emotional intelligence into innovation processes, moving us away from abstract problem-solving toward a more human centred understanding

of change. When done well, these methods generate not just better solutions but deeper relationships, shared ownership and a more grounded sense of what compassionate, responsive care can look like.

5. Lessons and challenges

Implementing patient centred innovation requires more than goodwill or isolated pilot projects; it demands systemic support that spans education, infrastructure, funding and changes in culture. Without deliberate scaffolding, even the most promising innovation risks becoming a short-lived initiative rather than a sustainable solution. Below we outline some key pillars and exemplar initiatives:

5.1. Stakeholder diversity and training

Involving a broad and diverse set of stakeholders is critical to ensure that innovations reflect a plethora of experiences, including those of patients from minority communities, caregivers and clinicians. However, diversity alone is not enough; meaningful engagement requires specific training in communication, methodology and shared decision making. The Patient as a Person Foundation in the Netherlands exemplifies this approach, offering education for both patients and healthcare professionals to prepare them for collaborative roles in innovation processes.[9] Similarly, the Creating ValEU program equips multidisciplinary student teams with the skills and mindset needed to design patient-centred innovations from the ground up.[12] These efforts signal a shift from tokenism to true partnership.

5.2. Bottom-up incubators

Grassroots initiatives such as the Dutch adolescent and young adult "Young & Cancer" Care Network demonstrate the creative potential of patient-led innovation. These organisations develop tools, services and systems with researchers and users collaboratively. However, their success often hinges on external support in areas such as business development, funding strategy and entrepreneurial capability.

5.3. Embedding in ecosystems

While initiatives like the EU Patient Bootcamp offer excellent capacity building and offer practical skills and strategies to find key resources, their longer-term impact depends on integration within broader ecosystems. These programmes must not operate in isolation but be connected to networks that can scout promising ideas early, provide continuity beyond initial funding cycles and amplify patient insights across sectors. Embedding patient innovation within existing health system structures (co-design labs, patient family advisory councils, patient focus groups, engaged patient communities) also ensures that solutions have a clear path to adoption and scale, rather than being confined to the margins of experimentation.

6. Future strategy

We propose the following priorities for future research and practice, grounded in the belief that meaningful innovation must be embedded across systems and sustained by cultural, methodological and policy alignment.

6.1. Redefining the patient role

The first and most foundational shift involves reimagining the role of the patient, not as a subject of care or a recipient of services, but as a co-designer and developer of care pathways. Whyte et al argue for a paradigm shift away from viewing patients as passive cases and toward recognising them as whole persons with emotional, social, and contextual realities that influence every aspect of care.[13]

6.2. Vertical knowledge integration

To truly embed innovation into care delivery, we must also prioritise vertical integration of expertise. Methods such as generative co-design (GCD) offer concrete tools for achieving this and conceptual frameworks like Dual Awareness Theory[14] can be used to operationalize different dimensions of the lived experiences.

6.3. System-level innovation ecosystems

Lastly, innovation must be supported by the design of robust ecosystems at multiple levels: hospital, regional, and national. Isolated projects may demonstrate success in pilots but often fail to scale or sustain impact without structural reinforcement.[15] Researchers, policymakers, and health system leaders must work together to create conditions that allow patient-centred innovations to thrive.

7. A call to action to health systems

Patient organisations must play an active and sustained role in the healthcare innovation process, not solely as advocates or advisors, but as creators

and collaborators. Their involvement must extend beyond awareness raising or consultation phases, and instead must include agenda setting, programme design, implementation and evaluation. When empowered structurally and supported institutionally, patient organisations can act as critical innovation partners, shaping interventions that reflect real world needs and ensuring accountability across the system.

The Dutch adolescent and young adult "Young & Cancer" Care Network[16] and Kinderkankerfonds[17] exemplify this approach by supporting product innovations through active research collaborations, public engagement and long term strategic partnerships. The James Lind Alliance (UK)[18] does the same by involving patients as coproducers in research agendas, for instance in the National Vascular Research Priority setting programme. These organisations do more than amplify patient voices, they shape the conditions under which those voices are heard and acted upon. Their partnerships with universities, clinical teams and digital health developers have led to the creation of tools, platforms and services that respond to the evolving needs of patients and their families.

Importantly, these organisations also engage directly with policy bodies, hospital boards and funding agencies, ensuring that the principles of patient-centred innovation are embedded not just in projects, but in the structures that govern care. Their role in policy advocacy and governance is crucial to building a more inclusive, ethical and effective innovation landscape, one that recognises patients and their organisations not as external stakeholders, but as integral to how healthcare systems imagine, develop and deliver future care to improve outcomes and growing volume, while reducing expenses and waste.

8. Conclusion

We are at a pivotal moment. The future of healthcare innovation can no longer be defined solely by technological advancement or institutional efficiency. While digital tools, therapies and platforms continue to evolve, they must be embedded within a broader transformation, one that places the human experience at the centre of how we design, deliver and evaluate care. This patient-centred renaissance calls for the integration of both horizontal and vertical forms of knowledge: connecting services across the care continuum.

From the literature and our experience, an unexpected byproduct of co-production with patients in health innovation and care delivery is a reduction in complaints, litigation and a significant increase in treatment compliance.[19] This results in a reduction in misdiagnosis,[20] over investigation and treatment, giving a reduction in costs in the overall healthcare economy.

Empowering patients as innovators is not a symbolic gesture. It is a practical imperative if we are to create pathways that are not only clinically effective but also meaningful and responsive. Fragmented systems that overwhelm or disorient must give way to cohesive and compassionate journeys, designed with and for the people they are meant to serve.

This is a call to rethink not only what we innovate, but how and with whom. Let us commit to building systems that honour not just the science of healing, but the individuals we treat. In doing so, we move closer to a future where innovation and empathy are no longer treated as separate domains, but as interdependent pillars of truly transformative care.

Conflict of interest

The authors declare no conflicts of interest.

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