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TITLE: **Patients are at the heart of health systems. Why are they still on the margins of decision-making?**

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"Patient engagement is not a nice-to-have in modern healthcare research - it's an ethical imperative and a scientific necessity." - Dr Maureen Bisognano

Involving patients in decision-making concerning health research and policy is not a courtesy but an overdue structural necessity of health systems.

Patients hold a unique perspective and expertise that no clinician, regulator, or investor can substitute for: their [lived experience](#) navigating the healthcare system. Their insights can improve how research is prioritised, designed, and translated into practice. When patients are engaged from the start, research is [more responsive](#) to real-world needs and studies choose more [relevant](#) endpoints, recruit faster, and [retain](#) participants better.

In innovation and procurement, patient involvement shifts the system from supply-driven – led by what industry can produce and market – towards a more [needs-driven](#) approach, focused on meaningful innovations that address unmet patient and societal needs. In healthcare policy, patient organisations are uniquely positioned to hold reforms accountable to those living with their consequences – provided they hold real agency.

Artificial intelligence (AI) adds urgency to this argument. Used well, AI has the potential to enhance patient-centred [research](#) and [care](#), including better access to patient needs and real-time data collection for more accurate monitoring and intervention (so-called [personalised medicine](#)). Yet AI could just as easily reinforce existing biases and reproduce the very exclusions patient-centred approaches seek to address. This leads to a strong need for trustworthy AI solutions, the ones the EU AI Act seeks to promote.

What holds patient-centredness back in the EU?

Patient-centredness remains [unevenly interpreted and implemented](#), both across EU Member States (MS) and across EU funding instruments.

Patient involvement is **rarely monitored or documented systematically** across health delivery, policy, and R&I. Funding allocations are not routinely tracked, definitions remain inconsistent, and few agreed-upon indicators exist to measure whether involvement is meaningful or effective. Currently, there are no estimates of how much EU R&I funding supports patient-centred research or meaningfully integrates patient perspectives. Similar gaps exist in policymaking, where few tools comprehensively capture the involvement of

patient organisations. A recently published [EPF Barometer](#) marked an important step towards addressing this blind spot, yet it remains difficult to assess the extent of patient involvement across the EU, as well as its quality and impact.

Moreover, patient involvement remains **unevenly embedded across MS** and is often **confined to project-based or ad hoc initiatives** rather than institutional practice. A recent [CEPS study](#), commissioned by the European Parliament, found significant gaps in the institutional and policy environments for supporting meaningful and systematic patient involvement across the MS it examined. Too often, participation depends on the commitment of individual funders, policymakers, or researchers rather than being a routine feature of the health and R&I system. At the EU level, while many Horizon Europe (HE) projects successfully involve patients, opportunities to build on and sustain these efforts beyond the lifetime of individual projects could be further strengthened. The Innovative Health Initiative (IHI) stands out for incorporating key performance indicators that reflect patient-centred principles. However, the extent to which these principles are implemented in practice may vary, reflecting the different contexts, priorities, resources in the projects.

Similar disparities exist in health policymaking. Whether and how patients are involved depends on national legislation, governance arrangements, and political culture, resulting in inconsistent practices. France's [démocratie sanitaire](#) approach, for instance, emphasises patient participation as a form of shared power in decision-making, grounded in national legislation that guarantees the rights of healthcare users. However, only 1 in 2 countries surveyed in the [EPF Barometer](#) report some formal basis (law or policy guidelines) defining how and when patient organisations participate in national health policy making; 22 % of patient organisations report being consulted very frequently, 35 % regularly, 35 % occasionally, and 9 % rarely. These disparities are compounded by limited and often insecure funding for patient organisations, particularly for policy and advocacy activities.

Finally, **presence does not mean influence**. Patients may be invited to the table, but they often have little opportunity to shape the decisions that matter most. Power asymmetries are particularly evident in the early stages of research, when priorities, research questions and budgets are defined, limiting the extent to which patients' perspectives can shape outcomes. Similar dynamics prevail in health policymaking. While patient organisations are increasingly involved throughout decision-making processes, involvement does not confer decision-making power, with national coalitions [reporting](#) that final decisions are primarily made by other health stakeholders.

Towards more patient-centric policies and R&I ecosystem

Moving from aspiration to implementation will require patient-centredness to be embedded as a structural feature of Europe's health and R&I ecosystem, rather than remaining dependent on individual projects or institutional goodwill.

First, the EU and MS should treat **data collection and transparency as preconditions** for institutionalising patient-centredness. The EC should enable an ecosystem of knowledge creation, the generation of evidence on impact, and the opening of dedicated spaces to showcase and disseminate best practices both within and across MS. Data is needed to understand what works, to identify common trends across MS, and to reach consensus on a common definition for what meaningful involvement should look like. Requiring reporting on who was involved, at what stage, and how patient input influenced decisions would represent an important step towards greater accountability.

Second, the EU should **build on existing instruments** to leverage opportunities for synergies. Programmes and initiatives like IHI, HE, the European Health Data Space and the European Reference Networks provide strong foundations for embedding patient involvement more systematically. Patient involvement should become an explicit evaluation criterion, supported by common indicators, routine reporting, and adequate remuneration for patient expertise.

Third, the **role of patient organisations should be institutionalised in health policymaking across MS and the EU**. This requires clear legal definitions, transparent and predictable consultation mechanisms, formal participation rights, and clear criteria for representation and accountability. Conflict-of-interest rules must be designed to ensure independence and encourage disclosure without excluding valuable expertise.

Participation must come early enough for patients to shape decisions and co-create outcomes – through seats in expert forums, parliamentary committees, advisory councils, health technology assessment bodies, and regulatory processes. Equally critical is sustainable, independent support for patient organisations, namely predictable multiannual funding, core operating grants for policy participation and strong governance, and accessible capacity-building and training to enable them to contribute over the long term.

Fourth, **build the capacity of researchers and dedicate funding and time**. Patient-centredness requires investment in people as much as processes. Researchers, evaluators, and policymakers need the skills, time and resources to work effectively with patients and patient organisations. Training – including scale-up of existing resources such as [EUPATI curricula](#) – capacity building and dedicated funding should become standard

features of publicly funded research, alongside mechanisms for learning and sharing good practice across projects and administrations at all levels of government.

Meaningful involvement is ultimately about giving patients the ability to inform decisions, not simply an opportunity to be heard. Europe has made important progress, but genuine patient involvement remains too dependent on where people live, who leads a project, or whether resources happen to be available. If the EU is serious about delivering more equitable, effective and trusted healthcare, patient involvement must become an expectation rather than an exception.