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Editorial

Setting a normative practice: patient and public involvement in health and social care research

Estableciendo una práctica normativa: la participación de pacientes y ciudadanos en la investigación en salud y en atención social

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The integration of patients and the public into research processes have gained growing recognition as a fundamental aspect of high-quality, ethically sound, and socially responsible research.[1,2] In domains such as public health, health policy and health services research, involving the public meaningfully throughout the research cycle could help enhance the relevance and applicability of the knowledge produced, as well as its legitimacy and potential for impact.[3,4] While some progress has been made —particularly in some biomedical fields[5,6]— the incorporation of patient and public involvement (PPI) in broader areas of research remains limited.[7]

Traditional asymmetries persist between researchers, as generators of knowledge, and patients and/or the public, often positioned as passive subjects or data sources. Moving towards a model of shared knowledge production requires a rethinking of these roles and recognition of the experiential knowledge of individuals and communities as valuable and necessary for robust and inclusive science. This shift is not solely methodological. PPI in health and social care research must also be understood as an ethical imperative, particularly when research is funded through public resources. Transparent and inclusive engagement processes contribute to democratic accountability, help align research priorities with societal needs, and guard against instrumental or tokenistic approaches[8,9] that might undermine both quality and trust.[10] Beyond aligning research with societal needs, the meaningful involvement of patients and the public also helps identify critical knowledge gaps that can directly affect health outcomes. Patients are often the first to experience the consequences of limited or incomplete evidence, highlighting the importance of incorporating their perspectives to ensure that research remains relevant, current, and responsive to real-world needs.

A key development in supporting effective PPI in research has been the elaboration and implementation of tools that guide complete and transparent reporting of research.[11,12] The GRIPP2 (Guidance for Reporting Involvement of Patients and the Public) guidelines, developed by Staniszewska et al.,[13] represents a substantial step in this direction. It offers a structured framework to report the aims, methods, and outcomes of PPI in research activities, facilitating both critical reflection and institutional learning. The recent Spanish translation and adaptation of the GRIPP2 reporting checklists published in Gaceta Sanitaria[14] marks an important advance for research communities working in diverse linguistic and cultural contexts. This translation enhances accessibility and reinforces the importance of adopting shared standards for reporting PPI across health research systems. As such, it provides a foundation upon which research institutions and funders can build to improve the quality and visibility of participatory approaches.

However, reporting is only one dimension of a broader challenge. Setting PPI as a normative practice requires strategic vision, supportive and enabling policies, and sustained investment. International experiences have demonstrated that successful integration depends on more than individual goodwill; it requires coordinated action at the organisational level. In Canada, the Strategy for Patient-Oriented Research (SPOR), supported by the Canadian Institutes of Health Research, provides a valuable model.[15–17] SPOR includes funding mechanisms, training programmes, collaborative infrastructure, and a national engagement framework[18–20] based on co-production, inclusiveness, and mutual respect. Notable examples include the SPOR Evidence Alliance initiative, which aimed to co-develop patient and public capacity in knowledge synthesis (e.g., systematic, rapid and scoping reviews) —designed and delivered by patient and public partners for patient and public partners.[21,22] Another noteworthy example is the Research Query initiative of the SPOR Evidence Alliance, which enables not only clinicians and policy-makers but also patients and caregivers to submit evidence requests on issues of relevance to them, ensuring that research remains aligned with information needs and priorities.[22,23]

Given its close connection to the National Health System and its important role in research and public health, the Instituto de Salud Carlos III (ISCIII) is in a strong position to promote a more consistent and sustainable approach to involving patients, caregivers, families, and the public in research. This will bring the ISCIII together with progressive global entities. While participatory practices are becoming more common and are beginning to be included in some funding calls,[24] they are not yet systematically integrated across institutions, funding mechanisms, or evaluation frameworks. There are strong forces[25,26] moving away from pure quantitative metrics when evaluating researchers. Engaging patients and the public in

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their research is another way to expand the corpus of researchers' evaluation.

A national strategy could address these gaps by defining clear expectations for PPI, allocating specific resources, supporting capacity building for both researchers and community members, and developing mechanisms to monitor and assess the impact of engagement. Such a strategy should also be co-designed with civil society actors, academic interest holders, and patient organisations, ensuring that it reflects a plurality of perspectives and addresses contextual barriers to inclusion. Beyond Spain, other public research funders operating in comparable contexts could benefit from similar developments. Coordinated actions —through common standards, training initiatives, and policy alignment— could contribute to greater coherence and equity across research systems. Patients and the public are increasingly gaining the skills and experience to participate as co-applicants and principal knowledge users in research funding applications, both individually and within research teams[22]. Patient organisations are also taking on roles in leading or co-leading grant applications with academic institutions, helping to direct resources toward projects that reflect priorities identified by people with lived experience.[22,27]

Ultimately, embedding public involvement into research systems requires a transformation in how research is conceptualised, valued, and governed. It entails a shift in power relations,[10] institutional cultures, and funding structures.[28] This transformation must be supported by a clear recognition that excellent science is not only methodologically rigorous but also socially accountable and responsive to the needs of the communities it serves. The opportunity is timely, and the responsibility is collective. By investing in meaningful public involvement, research systems can strengthen their ethical foundations, enhance the utility of the knowledge they generate, and contribute more effectively to the improvement of health and wellbeing across diverse populations.

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F. Catalá-López and D. Moher conceived and drafted the first version. A.C. Tricco and L. Wilhelm revised and provided substantive inputs to the article. All authors revised and approved the final version.

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Conflicts of interest

None.

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