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Title	Public and patient involvement - a moral obligation in medical research
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Publication date	2025
Original Citation	Cronin, P., MacDonald, T., Jefferies, J. and Racine, E. (2025) 'Public and patient involvement - a moral obligation in medical research', UCC Student Medical Journal, 5, pp. 50-52. https://doi.org/10.33178/SMJ.2025.1.7
Type of publication	Article (peer-reviewed)
Link to publisher's version	10.33178/SMJ.2025.1.7
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Download date	2026-08-30 07:41:01
Item downloaded from	https://hdl.handle.net/10468/18084

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Public & Patient Involvement - A Moral Obligation In Medical Research

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https://doi.org/10.33178/SMJ.2025.1.7

PPI & The Patients Voice In Medical Research

Within recent decades medical research has advanced rapidly toward a future of personalised treatment. As the field progresses, medical management is being tailored to individual patients across the world, from wealthy 1st world nations to the poorer 3rd world, a population of over 7 billion people with individual experiences, values, cultural insights and religious backgrounds to account for. Within this context, the idea of a one size fits all approach to people ceases to work and this nuanced aspect of the modern patient comes to the fore. Leading the charge on this challenge of making medicine relevant to the individual is the concept of Public and Patient Involvement (PPI).

PPI is a research approach that can be defined as "with" or "by" the public as opposed to the conventional "on" or "to inform" them (1). PPI can involve members of the public throughout the research process from establishing research priorities, through co-designing research methodologies, all the way to outcome interpretation and dissemination (2). In this article we seek to examine why PPI is a critical piece of the medical research puzzle by improving research planning, as well as providing the patient with a voice to foster impactful outcomes, and demonstrate why it not only generates fruitful research despite additional steps in the research process, but is a moral obligation for the academic community.

Improve Research Planning

Medical research planning is a multi-step process requiring careful attention for successful outcomes. Without input from key stakeholders—patients, families, and caregivers—research may become unfeasible, lack inclusivity, and reduce engagement. Involving PPI throughout this cycle helps mitigate these risks by allowing the target group to shape the study design. From the outset, PPI can guide feasible methodologies, reduce participant burden, improve clarity of study materials, and ensure fair representation of the study population.

Influencing the language of study materials has been demonstrated to be of particular benefit in the early stages of research, such as questionnaires and recruitment documents, as it ensures the individual has a clear understanding of their involvement and improves the effectiveness of data capture through increased response (4). The lack of representation of minorities and societal subgroups within medical research is well documented and has been shown to hinder patient care (5), however PPI is a promising way of combating this issue. Whilst using PPI to address this issue does add layers to the research process and additional costs to projects, by the inclusion of a diverse panel within the early stages of project planning, research recruitment strategies can be better tailored to capture these groups at risk of underrepresentation.

Additionally, whilst this integration of PPI into research planning does call for structural changes to better facilitate individual involvement which can add time and necessary resources to research planning (6),, recent literature indicates the increased desire of the general public to get involved in this pursuit (7), and is likely to accelerate this transition to the person-centric model of medical research. This proven benefit of PPI to project planning, coupled with the public's desire to engage further in the studies which impacts them, demonstrates the moral obligation we have to facilitate it's inclusion in medical research.

Enhancing Research Relevance

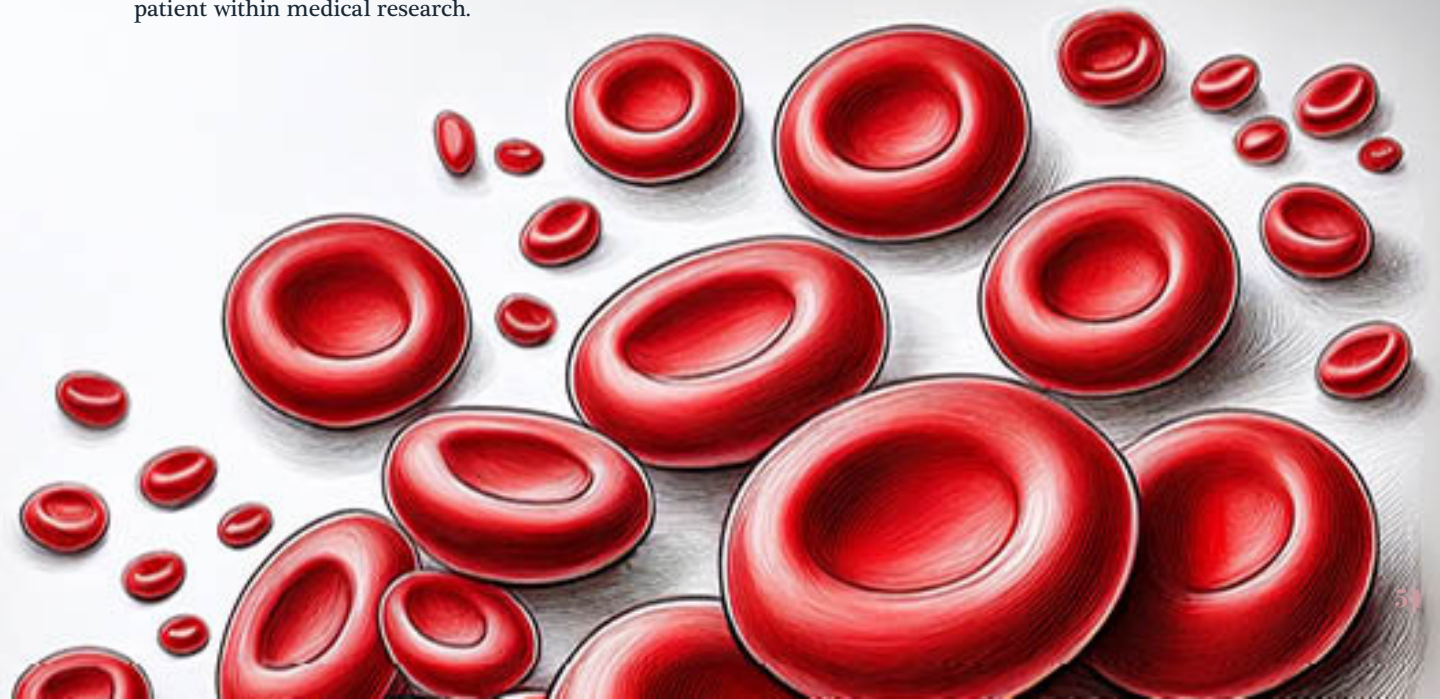
Medical research is a process which involves many different individuals coming from diverse academic backgrounds, from scientists to engineers, clinicians to administrators, all synergising their various experiences and knowledge to bear on the problem being examined. However, in this process one viewpoint which is often neglected is that at the centre of the research endeavour itself, the patient. PPI is a powerful method of bringing the patient to the centre in medical research and establishing meaningful outcomes.

During the research planning phase, identifying the desired outcomes which will be most impactful to the individual can often prevent the delay in implementation of translational research into the clinical environment (8). A strong example of PPI in action is the Young Adult Panel (YAP), a group of eight young adults with Type 1 Diabetes. Founded at NUI Galway in 2014, YAP has helped guide diabetes research by offering insights on study materials, interpreting findings, and improving young patients' engagement with healthcare providers (9). Whilst originally based at one university site, this group has now expanded to an all-island clinical trial with the assistance of the Health Research Board Definitive Intervention and Feasibility Awards (10). Not limited to diabetes, PPI has also been demonstrated to promote study relevance amongst patients in mental health research (11), neurodegeneration (12), and cancer treatment (13).

Whilst it has been difficult historically to quantify the benefit of patient involvement in research due to the lack of reported literature on the topic, this is likely to become evident in the near future with the increased reference to PPI within research in recent publications (14), requirement from research councils to include PPI in grant applications, and the growing collection of published PPI evaluation frameworks to measure the impact of this research (15). This ability of PPI to ensure the patients voice is heard at the research team level ensures that the intended beneficiary is a core element of the research process, improving research relevance, meaningful outcomes, and demonstrating its role as a moral obligation in medical research.

Conclusion

As medical research continues to evolve and expand throughout the world, PPI is a valuable tool which advocates for the patient throughout the research process. This use of patient enhanced research gives the public a voice in the research sphere and helps guide the process to more meaningful outcomes which benefits the patient, their care network, and the wider medical community. The continued expansion of PPI into the grant review and ethical approval process throughout the academic structure ensures it's place in the future of medical research, cementing it's importance to patient outcomes, and indicating a bright future for the voice of the patient within medical research.



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