Open Access

Pak J Med Res
Vol. 64, No. 1, 2025

Editorial

Nothing about Us without Us: Role of Patient and Public Involvement in Health Research in Pakistan

Muhammad Adnan, Muhammad Kashif Munir
Health Research Institute Research Center, National Institutes of Health, Fatima Jinnah Medical University, Lahore.

Patient and Public Involvement (PPI) emphasizes on including patients and the public in shaping health research, aligning with the principle "Nothing about us without us." It transforms patients from passive subjects into active collaborators, allowing their lived experiences to inform research that is more relevant and effective.[1] Globally, PPI fosters transparency, inclusivity, and ethical practices, helping align healthcare solutions with real-world needs.[2] In Pakistan, PPI is in its infancy but has the potential to make healthcare more equitable and responsive. Implementing PPI in Pakistan faces significant challenges. Public and researchers alike often lack awareness about its importance and practices.[3] Financial constraints and inadequate infrastructure further hinder progress, while traditional hierarchical structures in research limit genuine collaboration. These barriers highlight the need for targeted strategies to promote PPI in Pakistan's healthcare system.[4]

Overcoming these challenges requires addressing power dynamics and adopting a whole-system approach. Solutions include awareness campaigns, skill-building training, culturally sensitive practices, and resource allocation. Technology, such as apps and surveys, can be used to engage remote communities. In addition strong policies are essential to institutionalize PPI in health research effectively.[5] Looking ahead, the future of PPI in Pakistan is promising. Policymakers need to create supportive guidelines and sustainable initiatives should be developed to embed PPI into research processes. By empowering communities to actively contribute, health research can better address localized issues, ranging from maternal health to infectious diseases. As PPI becomes more established, its impact on the healthcare landscape will be transformative.[6]

Researchers play a vital role in realizing PPI's potential. Open and honest communication fosters trust, while inclusive practices ensure diverse perspectives. Providing resources and training empowers participants, and ethical commitment ensures fairness in these collaborations. By working together, researchers, patients, and communities can build a healthcare system that truly reflects the voices and needs of the people. PPI is not merely an option–it is essential for a fairer and more impactful future in health research.[7,8]

Conflict of interest: None declared.

References

1. Arumugam A, Phillips LR, Moore A, Kumaran SD, Sampath KK, Migliorini F, et al. Patient and public involvement in research: a review of practical resources for young investigators. BMC Rheumatol 2023; 7(1): 2.
2. Bradshaw E, Whale K, Burston A, Wylde V, Gooberman-Hill R. Value, transparency, and inclusion: A values-based study of patient involvement in musculoskeletal research. PLoS One 2021; 16(12): e0260617.
3. Tolppa T, Hussaini A, Ahmed N, Dondorp AM, Farooq S, Khan M, et al. Establishment of a patient and public involvement and engagement group to support clinical trials in Pakistan: Initial lessons learned. Res Involv Engagem 2024; 10(1): 98.
4. Baig A, Rahat T. Addressing the Challenges Faced by Pakistan's Healthcare System. Pak J Med Res 2024; 63(3): 115-6.
5. Ocloo J, Garfield S, Franklin BD, Dawson S. Exploring the theory, barriers and enablers for patient and public

Corresponding Author:
Muhammad Adnan
Health Research Institute Research Center,
National Institutes of Health,
Fatima Jinnah Medical University, Lahore.
Email: muhammad.adnan.hri@nih.org.pk
Received: 07 March 2025, **Accepted:** 20 March 2025
Published: 28 April 2025

involvement across health, social care and patient safety: a systematic review of reviews. Health Res Policy Syst 2021; 19(1): 8.
6. Jinks C, Carter P, Rhodes C, Beech R, Dziedzic K, Hughes R, et al. Sustaining patient and public involvement in research: A case study of a research centre. J Care Serv Manag 2013; 7(4): 146-54.
7. Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. Health Expect 2019; 22(4): 785-801.
8. Saini P, Hassan SM, Morasae EK, Goodall M, Giebel C, Ahmed S, et al. The value of involving patients and public in health services research and evaluation: a qualitative study. Res Involv Engagem 2021; 7(1): 49.