

PPIE Toolkit



Appendix B: Training & Reading Materials

Published Articles & Reviews	
Tolppa, T., Hussaini, A., Ahmed, N. et al. (2024) <i>Establishment of a patient and public involvement and engagement group to support clinical trials in Pakistan: Initial lessons learned.</i>	Link
Hussaini, A., Ahmed, N., Ahmed, M. J., Hashmi, M., Tolppa, T. (2025). <i>Patient and public involvement and engagement in critical care research in low- and middle-income countries: Challenges and solutions.</i>	Link
Richards, T., Montori, V. M., Godlee, F., Lapsley, P., & Paul, D. (2013). <i>Let the patient revolution begin.</i>	Link
Domecq, J.P., Prutsky, G., Elraiyah, T. et al. (2014). <i>Patient engagement in research: A systematic review.</i>	Link
Cook, N., Siddiqi, N., Twiddy, M., & Kenyon, R. (2019). <i>Patient and public involvement in health research in low and middle-income countries: A systematic review.</i>	Link
Hoekstra, F., Mrklas, K.J., Khan, M. et al. (2020). <i>A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: A first step in synthesising the research partnership literature.</i>	Link
Heckert, A., Forsythe, L. P., Carman, K. L. et al. (2020). <i>Researchers, patients, and other stakeholders' perspectives on challenges to and strategies for engagement.</i>	Link
Dudley, L., Gamble, C., Preston, J., Buck, D., EPIC Patient Advisory Group, Hanley, B. et al. (2015). <i>What difference does patient and public involvement make and what are its pathways to impact? Qualitative study of patients and researchers from a cohort of randomised clinical trials.</i>	Link
Dickert, N. W., Bernard, A. M., Brabson, J. M., Hunter, R. J., McLemore, R., Mitchell, A. R., ... D. Pentz, R. (2020). <i>Partnering with patients to bridge gaps in consent for acute care research.</i>	Link
Tindana, P. O., Singh, J. A., Tracy, C. S., et al. (2007). <i>Grand challenges in global health: Community engagement in research in developing countries.</i>	Link
Frameworks, Toolkits, & Practical Guides	
Mesh Guide: Setting Up an Advisory/Involvement Group	Link

Ludwig Boltzmann Gesellschaft (2019). <i>Patient and Public Involvement and Engagement in Research: A “How to” Guide for Researchers.</i>	Link
MRC Clinical Trials Unit at UCL. <i>Patient and Public Involvement (PPI) Resources.</i>	Link
ACT Patient Engagement Committee. (2024, Fall). <i>Summary of patient engagement resources.</i>	Link
Public Engagement in Data Research Initiative (PEDRI). (2025). <i>PEDRI Good Practice Standards for Public Involvement and Engagement in Data for Research and Statistics.</i>	Link
PCORI. (2020). <i>Engagement Rubric for Applicants.</i>	Link
WHO. (2023). <i>Framework for meaningful engagement.</i>	Link
Educational & Training Resources	
University of Alberta, School of Public Health. (2020). <i>SPH 566 Special Seminars: Fundamentals of Patient-Oriented Research.</i>	Link
National Co-ordinating Centre for Public Engagement (2018). <i>What Works: Engaging the Public Through Social Media.</i>	Link
Global Health Network (TGHN). (2024). <i>Community Engagement and Involvement in Health Research: An Introduction and Practical Guide.</i>	Link
Global Health Social Science (2024). <i>Social Sciences Sessions - Session 5 [Introducing focus group discussions] and Session 8 [Using participatory methods in health research]</i>	Link
Reporting & Evaluation Standards	
Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., et al. (2017). <i>GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research.</i>	Link
NIHR. (2019). <i>UK Standards for Public Involvement in Research.</i>	Link
CIOMS. (2016). <i>International ethical guidelines for health-related research involving humans</i>	Link
Principles & Reflections on Involvement	
Lefton, V., & Fleming, A. (2024). <i>Launching the Lived Experience in Policymaking Guide: Reflections on the principles, behaviours, and mindsets that underpin lived experience work.</i>	Link
Shangase, P. Z., Gachago, D., & Ivala, E. N. (Eds.). (2023). <i>Co-teaching and co-research in contexts of inequality: Using networked learning to connect Africa and the world</i>	Link

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