References and toolkits about public involvement in research

Appendix 7
“When we talk about public involvement, we mean all the ways in which the research community works together with people including patients, carers, advocates, service users, and members of the community. Excellent public involvement is inclusive, values all contributions, ensures people have a meaningful say in what happens and influences outcomes, as set out in the UK Standards for Public Involvement.”

The Shared Commitment to Public Involvement
Vocal was commissioned by the Medical Research Council (MRC) to undertake a review of public involvement in research (February–September 2022), with a specific focus on non-clinical health and biomedical research. In this Appendix we’ve collated useful references and toolkits which are relevant to this topic.

Contents

1. Public involvement in non-clinical research
2. Public involvement in health research
3. Strategies for research and public involvement
4. Public involvement in research funding
5. Public involvement in policy, ethics and governance
6. Inclusive public involvement & inclusive research
7. Guidance for reward and recognition

1. Public involvement in non-clinical research:

Peer-reviewed publications:


Useful reading and toolkits

basic and preclinical health research. PLoS ONE 14(5): e0216600. [https://doi.org/10.1371/journal.pone.0216600]


Middleton A., Parry V., Borra J., Orviss K., A public backlash towards genomics is a risk all of us working in genomics must share, [https://doi.org/10.1016/j.lanepe.2022.100347]

Reports and blogs:

Cowan K 2018: Can patients be involved in preclinical research? [https://blogs.bmj.com/opendscience/2018/06/05/can-patients-be-involved-in-preclinical-research/]


Lynn Laidlaw, Irene Soulsby, Bea Goulão and Derek Stewart – Figuring it Out: Grounding statistical research in reality [https://involveddotblog.wordpress.com/2021/04/22/figuring-it-out-2/]


Parkinson’s UK: A practical guide to patient and public involvement in lab based research [https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home]

Involving people affected by cancer in biomarker research design [https://www.cancerresearchuk.org/sites/default/files/clinical_case_study_04.pdf]

Shaping research to develop biomarkers – our perspective as PPI contributors, Parkinsons UK: Blog [https://medium.com/researchinvolvement/shaping-research-to-develop-biomarkers-our-perspective-as-ppi-contributors-8d226539aa50]

2. Public involvement in health research

Peer-reviewed publications:

The journals Research Involvement & Engagement [https://researchinvolvement.biomedcentral.com/] and Research for All [https://www.uclpress.co.uk/pages/research-for-all] provide peer-reviewed publications on public involvement theory and practice.

Online resources, including networks, guidance, toolkits and training

NIHR INVOLVE (currently transitioning to the NIHR Centre for Engagement and Dissemination) [https://www.invo.org.uk/]

MRC public involvement review: Appendix 7 References & toolkits
Useful reading and toolkits

Generation R network of Young People’s Advisory Groups https://generationr.org.uk/
Cochrane Crowd – http://crowd.cochrane.org
Shared Learning Group for Involvement https://slginvolvement.org.uk/
PFMD ‘how-to’ guidance for involvement in early drug discovery and pre-clinical stages https://pemsuite.org/How-to-Guides/Early-Discovery.pdf
Health and Care Research Wales – guidance for researchers https://healthandcareresearchwales.org/researchers-support-and-guidance-researchers-develop-research-idea/involving-public-your-research
Health and Care Research Wales – toolkit https://padlet.com/healthandcareresearch/cifc7jknonpjgmr5
CRUK Patient Involvement Toolkit for researchers https://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers
CRUK Patient involvement network https://www.cancerresearchuk.org/get-involved/volunteer/patient-involvement/your-involvement-network
Co-Production Collective https://www.coproductioncollective.co.uk/
Training and resources for public involvement in research https://www.learningforinvolvement.org.uk/
Shared Learning Group on Involvement in Research https://slginvolvement.org.uk/
James Lind Alliance https://www.jla.nihr.ac.uk/
BPSU produced guidance for researchers on PPI in unconsented studies (i.e. studies with no direct patient involvement or consent): bpsu_ppi_guidance4_0.pdf (rcpch.ac.uk)
UCL translational research – co-developed training for researchers https://uclpartners.com/blog-post/co-developing-training-for-researchers-with-patient-involvement/
Crohn’s and Colitis recently created some training with their patient advisory group – https://www.crohnsandcolitis.org.uk/research/research-involvement-opportunities/training/ppitraining

3. Strategies for research and public involvement

Versus Arthritis had involvement throughout development of their strategy https://www.versusarthritis.org/research/introducing-our-research-strategy/
What makes us human? HDBI Public engagement strategy 2020 (available on request from Vocal)
NIHR Manchester Biomedical Research Centre and NIHR Manchester Clinical Research Facility
Useful reading and toolkits


4. Public involvement in research funding

Health Research Charities Ireland: PPI in the joint funding scheme https://hrci.ie/ppi-in-the-joint-funding-scheme/
British Paediatric Surveillance Unit BPSU Scientific Committee | RCPCH (lay members on scientific peer review panel)
Become a Reviewer, NIHR https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-help-with-research/become-a-reviewer.htm
PPI (Patient and Public Involvement) resources for applicants to NIHR research programmes https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437

5. Public involvement in policy, ethics and governance

IPPOSI Ireland https://www.ipposi.ie/
Ireland’s newly formed National Research Ethics Commitee (25% public members on each committee) https://www.nrecoffice.ie/engagement/public-engagement/
ALSPAC Law and Ethics Committee (ALEC) Research ethics | Avon Longitudinal Study of Parents and Children | University of Bristol
BHF clinical trial consent materials include an animation (to support patient information): BHF Protect TAVI (explainmyprocedure.com)
6. **Inclusive public involvement & inclusive research**


Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project [https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435](https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435)


Inclusive Research online learning [https://catalogue.manchester.ac.uk/browse/i3hs/open-courses/inclusive-research](https://catalogue.manchester.ac.uk/browse/i3hs/open-courses/inclusive-research)

Inclusive Research Collective [https://www.inclusiverc.com/](https://www.inclusiverc.com/)

Equality, Diversity and Inclusion in Science and Health [https://edisgroup.org/](https://edisgroup.org/)

Research Design Service EDI toolkit [https://www.youtube.com/watch?v=kcdB8xCIJeg](https://www.youtube.com/watch?v=kcdB8xCIJeg)

7. **Guidance for reward and recognition**


NIHR guidance for researchers: [https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392](https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392)

MRC Review of public involvement in research (2022)

Complete list of documents

Looking forward: Working with the Medical Research Council towards a public involvement strategy (Main report & Executive Summary)

Appendix 1  Methodology of the MRC public involvement review
Appendix 2  Landscape review of public involvement in non-clinical research
Appendix 3  Tweetchat #Involvement_Preclinical
Appendix 4  A patient’s desktop review of public involvement at the MRC
Appendix 5  Examples of MRC public involvement
Appendix 6  Public involvement in research survey
Appendix 7  References and toolkits about public involvement in research

Please see full list of acknowledgements in Main report

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