

# VOCAL

## 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](#)

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**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.**

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## **1. Public involvement in non-clinical research:**

### **Peer-reviewed publications:**

Aitken M 2019: Consensus statement on public involvement and engagement with data intensive health research <https://ijpds.org/article/view/586>

Biggane, A.M., Olsen, M. & Williamson, P.R. PPI in research: a reflection from early stage researchers. *Res Involv Engagem* 5, 35 (2019). <https://doi.org/10.1186/s40900-019-0170-2>

Carroll P, Dervan A, Maher A et al. Patient and Public Involvement (PPI) in preclinical research: A scoping review protocol [version 2; peer review: 2 approved]. *HRB Open Res* 2021, 4:61 (<https://doi.org/10.12688/hrbopenres.13303.2>)

Clements–Brod N, Holmes LE, Rawlins E. 2022 (in press). Exploring Challenges and Opportunities of Public Engagement with Fundamental Biology, Development.

Fox et al, 2021 Patient engagement in preclinical laboratory research: A scoping review, *EBioMedicine*, Volume 70, <https://doi.org/10.1016/j.ebiom.2021.103484>.

Maccarthy J, Guerin S, Wilson AG, Dorris ER (2019) Facilitating public and patient involvement in

## Useful reading and toolkits

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

Ní Shé, É., Cassidy, J., Davies, C. et al. Minding the gap: identifying values to enable public and patient involvement at the pre-commencement stage of research projects. Res Involv Engagem 6, 46 (2020). <https://doi.org/10.1186/s40900-020-00220-7>

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.lanep.2022.100347>.

### Reports and blogs:

Cowan K 2018: Can patients be involved in preclinical research? <https://blogs.bmj.com/openscience/2018/06/05/can-patients-be-involved-in-preclinical-research/>

Dorris E 2019: Bridging The Gap Between Research And Impact: Public And Patient Involvement In Health Research <https://sciencetrends.com/bridging-the-gap-between-research-and-impact-public-and-patient-involvement-in-health-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/>

Shared Learning Group on Involvement in Research: Involving people in laboratory based research: a discussion paper <http://slginvolvement.org.uk/wp-content/uploads/2016/09/Lab-based-research-FINAL-10-8-16-public.pdf>

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](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/>

## Useful reading and toolkits

Generation R network of Young People's Advisory Groups <https://generationr.org.uk/>

Cochrane Crowd – <http://crowd.cochrane.org>

HDR UK Public Involvement <https://www.hdr.uk.ac.uk/about-us/patient-and-public-involvement-and-engagement/>

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/cifc7jknopjqmr5>

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>

HRA principles of public involvement <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/>

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](https://www.rcpch.ac.uk/sites/default/files/2019-08/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

– Patient and Public Involvement and Engagement (PPIE) Strategy 2018–2022 <https://www.manchesterbrc.nihr.ac.uk/wp-content/uploads/2018/03/BRC-and-CRF-PPIE-strategy-2018-2022-FINAL.pdf>

CRUK Centre for Drug Development [https://www.cancerresearchuk.org/sites/default/files/centre\\_for\\_drug\\_development\\_patient\\_involvement.pdf](https://www.cancerresearchuk.org/sites/default/files/centre_for_drug_development_patient_involvement.pdf)

## 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)

Making research more effective: What does a lay grant reviewer do? <https://www.parkinsons.org.uk/news/making-parkinsons-research-more-effective>

Parkinson's UK Drug Accelerator Awards <https://www.parkinsons.org.uk/sites/default/files/2021-12/Drug%20Accelerator%20Award%20Information%20for%20applicants%20-%20November%202021.docx%20%281%29.pdf>

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 Committee (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](http://explainmyprocedure.com))

Health Research Authority public involvement <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/> including involvement in ethics committees <https://www.hra.nhs.uk/about-us/what-we-do/how-involve-public-our-work/> and ethical review of public involvement <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/what-do-i-need-to-do/>

## Useful reading and toolkits

### 6. Inclusive public involvement & inclusive research

Islam, S., Joseph, O., Chaudry, A. et al. "We are not hard to reach, but we may find it hard to trust" .... Involving and engaging 'seldom listened to' community voices in clinical translational health research: a social innovation approach. *Res Involv Engagem* 7, 46 (2021). <https://doi.org/10.1186/s40900-021-00292-z>

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>

'Representativeness' and diversity of people who get involved <https://healthtalk.org/patient-public-involvement-researchers/Representativeness-and-diversity-of-people-who-get-involved>

Being inclusive in public involvement in health and care research: Things to think about for researchers and practitioners <https://www.nihr.ac.uk/documents/being-inclusive-in-public-involvement-in-health-and-care-research/27365>

Inclusive Research online learning <https://catalogue.manchester.ac.uk/browse/i3hs/open-courses/courses/inclusive-research>

Inclusive Research Collective <https://www.inclusiverc.com/>

Equality, Diversity and Inclusion in Science and Health <https://edisgroup.org/>

Research Design Service EDI toolkit <https://www.youtube.com/watch?v=kcdB8xCIJeg>

### 7. Guidance for reward and recognition

NIHR policy research unit, Children and families [https://www.ucl.ac.uk/children-policy-research/sites/children\\_policy\\_research/files/payment\\_and\\_recognition\\_policy\\_-\\_public\\_involvement.pdf](https://www.ucl.ac.uk/children-policy-research/sites/children_policy_research/files/payment_and_recognition_policy_-_public_involvement.pdf)

NIHR guidance for researchers: <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>

NIHR guidance for public partners: <https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372>

## **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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### **Vocal**

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