VOCAL

Appendix 1
Methodology of the MRC public involvement review

> "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

This work was commissioned by the Medical Research Council

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MRC public involvement review: Appendix 1 Methodology

Contents

Introduction

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. This Appendix outlines Vocal's approach and methodology for collecting data and evidence for the review.

We collected data using a range of methods between February and July 2022. Our methods included: a scoping review of peer–reviewed and grey literature, a tweetchat, desk research, interviews, workshops, insight sessions and a public survey.

We have worked iteratively, developing and refining our focus throughout in response to the insights and data that we were collecting.

As our work progressed and in consultation with the MRC Project team and Public Involvement Oversight Group (PIPOG), our focus shifted from considering systems and processes supporting public involvement to additionally considering broader questions of the principles and culture necessary to develop meaningful public involvement.

These methods are described below with further information provided in the additional appendices.

Vocal team and our approach

Vocal's vision is to bring people and health research together for everyone's benefit. We create opportunities for people for find out about, and have a voice in, health research. Our values, co–created with researchers, patients, and communities are: Working Together; Everyone Matters; Innovating and Driving Excellence. Established in 2003, our team of 12 works with an active community of 500+ public contributors, researchers, and partners to deliver public involvement services and consultancy across approximately 40 active projects for funders, HEIs and industry.

The delivery team were:

Bella Starling (PhD), Director of Vocal, Professor (Clinical Chair, Manchester Academic Health Science Centre) in Inclusive Research and Wellcome Trust Engagement Fellow. Bella's career has spanned neuroscience, stem cell and genetic research, science writing, biomedical ethics, public engagement, patient involvement, and science policy, both as a practitioner and strategic adviser. Her focus is on public involvement in translational science with a strong emphasis on inclusion: ensuring that research reaches out and listens to diverse parts of society, to address inequalities.

Annie Keane (PhD) Deputy Director, Vocal. Annie's experience encompasses nursing, qualitative research (anthropology), producing engagement projects for a media charity, being an Editor at BBC Learning and leading a city–wide science engagement initiative in Manchester. At Vocal Annie leads on developing inclusive and creative engagement projects in collaboration with health researchers, community groups and patients.

Vocal team and our approach

Leah Holmes (PhD), former Director of Vocal, and now Senior Associate. Leah has a special interest in strategy co–development and led this process for the NIHR Manchester BRC & CRF PPIE strategy, with establishment of Vocal PPIE infrastructure, and supported culture change within this research community to value inclusive and equitable involvement in research. Commissioned by the Wellcome Trust, Leah recently worked with 7 universities to co–develop a public involvement strategy for the Human Developmental Biology Initiative, and is a consultant to Wellcome Genome Campus on establishing non–clinical PPI. Leah began her scientific career as a non–clinical researcher in molecular biology working in academia and industry.

Derek Stewart a patient advocate interested in all aspects public involvement with health research awarded OBE and Hon Professor at the University of Galway. He has written about involvement with lab–based pre–clinical research on his blog as well as known for facilitating workshops to enable people with Bec Hanley. In recent years Derek has worked with Evidence Synthesis Ireland and helped with their animation. His interest with trial methodology and review is relevant as they too are less directly related to patient experience.

Laura Thomas, Vocal Associate, has worked with a range of organisations on the evaluation of a range of initiatives and programmes. This includes: developing evaluation frameworks, designing methods for data collection (including both qualitative and quantitative methods), data analysis and report writing. She enjoys collaborating with project teams throughout the course of a project and supports project teams in undertaking reflection as they progress. In addition to her evaluation experience, she has also undertaken resource development, delivery and training for a variety of organisations such as schools, museums, education charities, universities and professional bodies. Her first degree is an MPhys in Astrophysics and she also holds an MRes in Education Research.

Delivery and oversight of the project

After a competitive tendering process, Vocal was commissioned to deliver this review in January 2022. Regular meetings ensured delivery to time and target, with an iterative process:

Vocal team meetings – regular project team meetings to plan delivery and share learning with each other.

Project Team meetings – Fortnightly meetings (1 hour) with Mary Derrick and Rachel Knowles throughout the project. The MRC Project Team was also interviewed in February 2022.

Public Involvement Oversight Group (PIPOG) – Seven meetings (1 hour) including 2 facilitated discussions to gain insights, reflections and ideas about public involvement throughout the process.

External Advisory Group (EAG) – Vocal recruited a group of experienced public partners, public involvement and engagement practitioners and researchers (8 members in total) from across academia and industry. The EAG advised the Vocal team and provided a wealth of data and insights from across the sector. There were five meetings (2 hour). EAG members also attended project workshops.

Group membership lists are in the Acknowledgments section of the main report.

Methods

1. Landscape review of public involvement in non-clinical research February-March 2022, Appendix 2

Purpose: To identify 25 relevant examples and references about public involvement in the non-clinical research environment.

Participants: Vocal worked with the MRC Project Team and the External Advisory Group to co-produce a list of categories relevant to the non-clinical research environment as follows:

- General.
- Principles and Values about the purpose of involvement in non/pre-clinical.
- Involvement in pre-clinical research (design and delivery).
- Involvement in clinical research (design and delivery).
- Involvement in research priority setting.
- Involvement in research funding.
- Involvement in research strategy.
- Involvement in involvement strategy.
- Involvement in research policy.
- Involvement in ethics.
- Involvement in governance.
- Involvement in communications.
- Involvement in engagement.
- Involvement in evaluation or measuring impact.
- Involvement in training and development.

These categories were then used to search, classify and group case studies. The MRC Project Team and EAG were invited to suggest relevant stakeholders and examples. A range of search tools including Google Scholar and databases such as Medline via OVID were used to identify relevant papers. Once suitable papers were identified, references and citations were searched to identify further relevant studies or examples.

Drawing on the NIHR Standards for Public Involvement, we co-produced evaluation criteria by which to assess examples; these were diversity & inclusion, collaboration and co-creation, influence and impact.

A further three case studies with relevance for MRC challenges these were identified and developed by a combination of desk research and interviews.

- Case study A: Programme-level public involvement strategy in fundamental research focused
- on publicly contentious issues
- Case study B: Patient involvement within a prostate cancer research consortium
- Case study C: PPI group working across clinical and non-clinical research
- Case study D: Investment in public involvement across relevant funding organisations
- Case study E: Public involvement in research funding processes across non-clinical and clinical research

Methods

2. Tweetchat #Involvement_Preclinical
9 March 2022, Appendix 3

Purpose: To invite public involvement practitioners, public partners and researchers to respond to the questions of why, what, and how do we actively involve patients and the public in the research landscape before, beside and beyond the clinical experience

Participants: Derek Stewart hosted the chat; 85 contributors took part and there were almost 400 tweets in total with additional comments and interaction.

3. Interviews
February-September 2022

Purpose: To gain insights from MRC staff working in a variety of roles and with staff from external organisations with experience of public involvement in non–clinical research.

Participants: Twelve MRC Head Office staff (including the senior leadership team, PIPOG, 3 members of the ED&I Forum, 3 members of Research Programme Managers' Forum). Interviewees were suggested by the MRC Project Team.

Two researchers who were establishing PPI across a clinical and basic research partnership

Three staff members from relevant organisations; Health Data Research UK, Parkinson's UK, Cancer Research UK.

Insights from interviews have informed this review throughout, quotes are included in the main review.

4. MRC desktop review from a patient's perspective
March 2022, Appendix 4

Purpose: A desktop review from a patient perspective of the information that MRC Centres and Units provide about their activities, focusing on the following questions:

- How might I learn about…the latest scientific research developments?
- How might I find…any opportunities to enquire and take part in research studies?
- How might I offer…to use my experiences and knowledge to improve research?

Participants: Derek Stewart (Vocal, patient advocate) undertook the review.

Methods

5. Collating MRC case studies
March-September 2022, Appendix 5

Purpose: To collect examples of public involvement at the MRC from a range of sources including:

- MRC websites
- MRC Project Team, PIPOG, interviewees and workshop participants

Participants: We asked the MRC Project Team, PIPOG, interviewees and workshop attendees to share examples of current PPI activities. We have included a selection of examples where members of the public are taking an active role in feeding into research priorities or research projects.

Please note this is not an exhaustive list of public involvement activities in the MRC, but demonstrates experience and examples to build on in the future.

6. Public involvement in research survey
6-27 May 2022, Appendix 6

Purpose: To further explore themes emerging from the data. The survey was developed by Vocal and the MRC Project Team and approved by PIPOG. The survey was hosted on the UKRI Engagement Hub and promoted to researchers, public partners, public engagement/involvement practitioners and members of the public.

Participants: 332 people responded, of which 277 worked in a research environment and 55 were members of the public.

7. Public Involvement Project Oversight Group (PIPOG)
insights session 1
24 March 2022

Purpose: To explore collective knowledge and perspectives about the MRC, the ambition, opportunities and challenges for public involvement culture and practice.

Focus for discussion

- Why involvement is important for research
- What's is, or could be, the experience from a public perspective
- MRC's ambition and considerations of how to achieve this

Methods

8. Workshops with MRC staff, MRC funded staff and public partners

Purpose: To consult with a wide range of people with a diversity of experiences, opinions and ideas about public involvement at MRC. The aim was to explore current practice, discuss challenges, and identify opportunities for the future

Participants: Staff from MRC Partner Institutes, Centres, Units and public partners working on different projects. EAG members attended each workshop.

Workshop 1 – with MRC public engagement and communications professionals, public partners and 2 EAG members
31 March 2022 – 12 attendees

Activities

Share an example of good public involvement and a hope/ambition for public involvement at the MRC in the future

Breakout group activity Think about someone who is not yet connected to research but who is interested in getting involved – may be someone in your network or not, think about age/ experience /social background / ethnic background / their motivation/ views. What would this person need from the MRC to be involved in their work?

Discussion:

■ What does the MRC need to do to make involvement happen?

■ What should be in the MRC's public involvement strategy?

■ What might need to change? What might be the barriers

■ Who needs to change/support the change?

■ In order for MRC to deliver these is there anything it needs to stop doing?

Discussion: Considerations re non–clinical research

What might be the barriers for change? Has this been your experience? Have you noticed this? What consideration does this need to have in the strategy. Is there something different about involvement in non–clinical research?

Methods

Workshop 2 – with researchers (majority non–clinical) and 2 EAG members
5 April 2022 – 10 attendees

Activities

Share an example of public involvement you've been part of and a hope/ambition for public involvement at the MRC in the future

Breakout groups 1: Take a retrospective view of a completed research project and consider how the value and impact may have been improved with /input from consultation/ involvement from members of the public/patients.

Breakout groups 2: Non–clinical research, two scenarios to consider how public involvement could play a part in securing funding, ethics approval, communication research, publishing

Discussion:

- What are the barriers and obstacles that you currently face/ think you might face?
- What needs to change?
- Who needs to change/support the change?
- For MRC to support public involvement more what does it need to stop doing?
- What would you like to see in the strategy?

9. Discussion session at the Research Programme Managers Forum
22 April 2022 - 41 attendees

Purpose: To explore opportunities for MRC Head Office to involve people in research, identify areas of greatest need and quick wins.

Participants: Research Programme Managers from across the MRC

Zoom polls

- In your opinion, what are the most important reasons for public involvement in research?
- What is your knowledge and experience of public involvement so far?
- For you to do public involvement which is meaningful, what kind of support would you find most useful?
- Selecting statements about relevance, time, confidence, training & support

Methods

10. Public Involvement Project Oversight Group (PIPOG) insights session 2
28 April 2022

Purpose: To share findings so far and to identify members' individual and group priorities for why public involvement is important to the MRC.

These were the options discussed

- Clarity & Accessibility – improving the communication and language of research
- Integrity & Trust – maintaining public trust through transparency and democracy
- Needs & Value – ensuring research is relevant to the public
- Grounding research – improving research outcomes using patient experience
- Affirmation & Reassurance – checking that it is the 'right' thing to be doing
- Encouragement & Motivation – for researchers to connect with their purpose
- Learning & Development – for the public to find out about research
- Equity and diversity – across the research environment, and research outcomes
- Relationships & Respect – improving research culture
- Governance & accountability – research decisions include public perceptions of risk and benefit

11. Co-production workshop, with MRC staff and EAG members
8 July 2022

Purpose: To reflect on how the emerging insights from the review might be translated into actions for change.

Focus for discussion

- Relationship/ perceived tension between scientific endeavour & personal experience
- Inclusive practice in public involvement
- Leadership in the sector

Participants: 12 MRC Head Office staff, including (PIPOG members) and 7 members of the External Advisory Group.

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

Photography

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Any enquiries related to this publication should be sent to: publicengagement@mrc.ukri.org

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