VOCAL

Looking forward:
Working with the Medical Research Council towards a public involvement strategy

EXECUTIVE SUMMARY

November 2022

> “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

Introduction

Vocal was commissioned by the Medical Research Council (MRC) to undertake a review of public involvement in research, with a specific focus on non-clinical health and biomedical research. The review explored public involvement culture and practice within MRC and the external research landscape.

This review supports the MRC to co-develop a public involvement and engagement strategy, and provides knowledge and evidence to a growing community of practice in public involvement with non-clinical health research.

In 2022 UK Research and Innovation (UKRI) and the MRC have made important commitments to public involvement. These include content within the UKRI Strategy and UKRI Public Engagement Strategy, and UKRI signing up to the Shared Commitment to Public Involvement in Health and Social Care Research. For the MRC specifically, this translates into the 2022-2025 MRC Strategic Delivery Plan with objectives to:

- build a culture within MRC and its research community where equitable and inclusive public and patient involvement and engagement is an integral part of research
- develop an MRC strategy that sets out expectations, and good practice for public involvement and engagement in biomedical research, within the wider framework of the UKRI Public Engagement Strategy

Context

Improving public involvement at the MRC is needed and timely. From a public perspective, COVID-19 has demonstrated the importance and fragility of trust in science and research, the critical influence of the media (including social media and 'fake news'), and highlighted health inequalities to us all. Many research organisations and funders in the UK are further involving people and communities in their work to increase engagement and continue to build trust in research.

The benefits and impacts of public involvement are broad and varied, benefiting research outcomes and culture, researchers, public and patient partners, policy, and society. In addition, public involvement is motivational. It can (re) connect researchers and research-aligned staff with the purpose and implications of their work, and enable agency for public partners. Through prioritising and strengthening public involvement, the MRC will support cultural improvements within its organisation and research portfolio, and the wider research sector.

Due to the breadth of MRC's research portfolio, from basic through to applied biomedical research, there are areas of high public interest and contention e.g. big data, animal research, embryonic stem cell research, where public trust, mutual understanding, and transparency are essential for progress. It is difficult to see how the MRC would navigate these research areas successfully without effective public involvement.

The MRC has an opportunity to be a sector leader for public involvement with non-clinical research, working in partnership across UKRI, organisations within the Shared Commitment to Public Involvement, and a growing community of organisations and practitioners working towards embedding public involvement within non-clinical research. In addition, embedding public involvement in the developing research culture could maximise the value of collaboration with wider society and demonstrate the democracy and trustworthiness of the MRC and its research to UK taxpayers, its primary funder.

Our approach

Vocal worked collaboratively with the MRC, and an External Advisory Group (EAG) to iteratively co-design and deliver the review between February and September 2022. Our EAG of 8 members included experienced public partners, public involvement and engagement practitioners and researchers, from across academia and industry.

Our methods included desk research, a scoping review of peer-reviewed and grey literature, a Tweetchat, interviews, workshops, insight sessions and a public survey. This report incorporates insights from 178 stakeholders, as well as survey findings from a further 332 contributors.

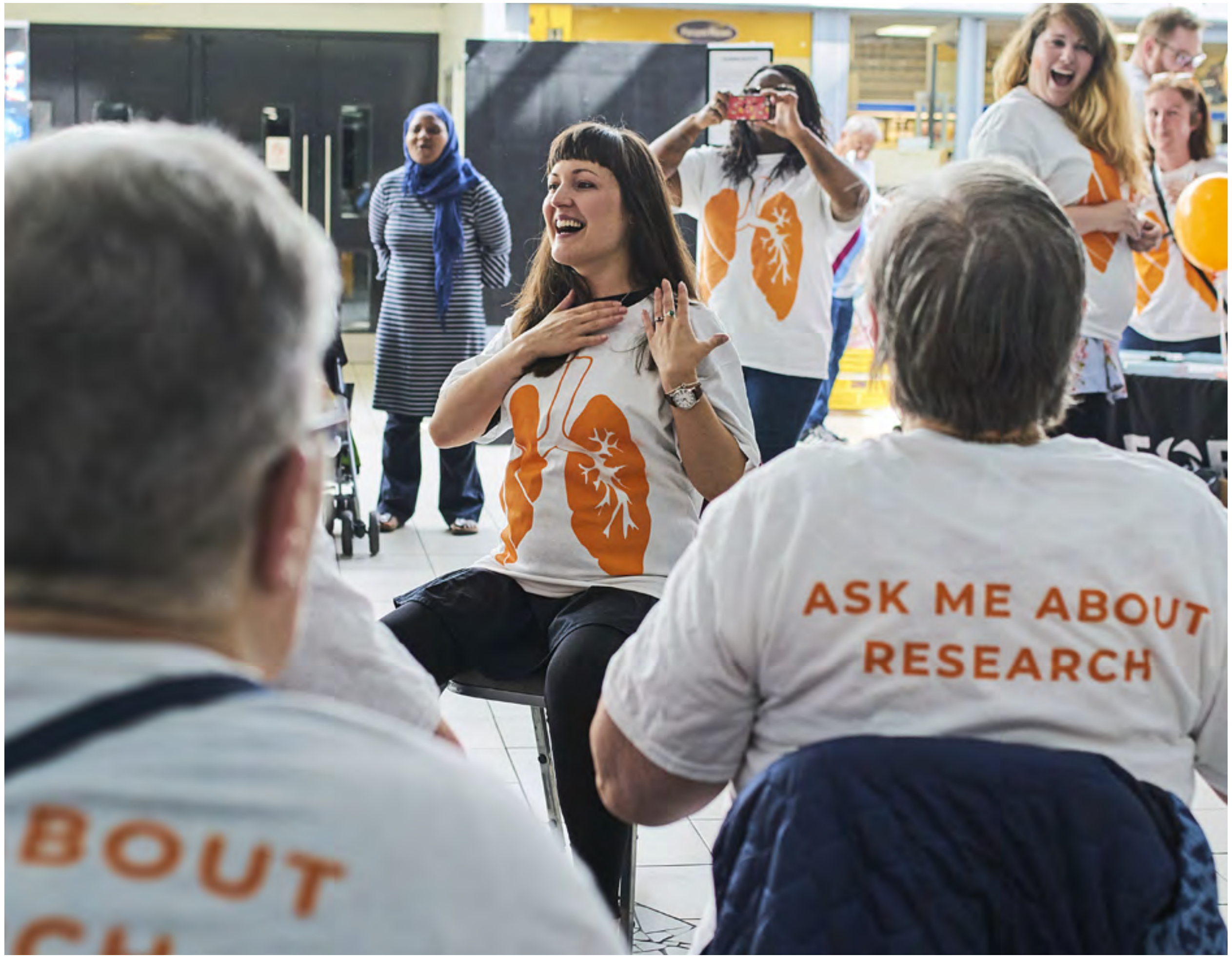
Headline Findings

The MRC is in a strong position to become an organisation which excels in working with people and patients across the breadth of its portfolio, including non-clinical, basic and big data science. Building on emerging knowledge, there are evident opportunities for the MRC to lead and evolve best practice in public involvement with non-clinical research.

Although we have encountered major confusion and barriers related to public involvement during this work, there is also enthusiasm and appetite for working with people across all research, including non-clinical research. MRC stakeholders consider public involvement is important for improving research quality, relevance, transparency, and trust, and in supporting research culture and outcomes to be more equitable, inclusive and diverse.

There is a strong sense that now is the time for a new framing of the MRC's conception of, and ambitions for public involvement as part of an open, transparent, trustworthy and thriving research environment – working to the highest standards of research quality and inclusion. Crucially this means:

- Moving away from traditional concepts of public involvement as a practice that supports the research cycle (processes focused on a research question), towards involvement as a central and underpinning aspect of the research environment (processes, infrastructure and support, for all research)
- Using bespoke approaches for public involvement activities, focused on purpose and relevance
- Taking a contextual approach when deciding who should be involved. In some settings, it may be an imperative to involve people with a particular health condition or characteristic. In others, life experience may be valuable and sufficient
- Supporting the development of reflective and collaborative practice to enable research teams and MRC staff to prioritise public involvement, by where it's most needed or meaningful



Throughout this work, we have constantly asked ourselves and others whether public involvement in non-clinical research is a special case. The answer is emphatically 'No'. Involvement in non-clinical, basic and big data science, is happening and making a difference, although the context and content of the non-clinical landscape is different from that of clinical and applied research. Now is the time for the MRC to change the terms of its relationship with public partners within non-clinical research.

To enable and achieve the potential of public involvement, the MRC needs to develop its culture – within head office and its wider MRC-funded research community – to embed principles, behaviours and practices that enable person-focused, inclusive, reciprocal and valued relationships with people, patients and communities. The MRC has the opportunity, informed by the approach and findings of this work, to deepen its learning about public involvement and how it benefits both research and people, with a view to achieving research excellence with and for society.

1 The MRC needs to inclusively co-develop its public involvement vision and strategy with public partners and specialist practitioners, to ensure legitimacy and good practice by:

- Co-creating a clear vision for public involvement
- Building on the approach taken by this review
- Further working with an External Advisory Group

2 The MRC needs to clarify and communicate the purpose, motivations and context for working with people in research as a priority, based on the findings and recommendations of this review. This includes:

- Reframing public involvement in all research, including non-clinical research, as purpose-led, and dependent on context
- Clarifying the motivators for public involvement
- Showing leadership and authority in manifesting the possibilities of public involvement in non-clinical research, and the difference it makes

3 The MRC needs to tackle terminology and embed it in the MRC research context to enable a confident and joined up approach for public involvement, by:

- Joining up strategies and thinking for involvement and engagement, including within the context of UKRI and other research partners
- Supporting the development of a shared language and meaning across MRC communities

4 The MRC needs to develop, as part of its research culture agenda, MRC working cultures that support public involvement by:

- Emphasising the values and relational aspects of public involvement, moving from a transactional view of public involvement to a transformational one
- Valuing diverse forms of knowledge by adopting an asset-based mindset in which life experience is incorporated alongside academic evidence
- Effective reward and recognition for good practice in public involvement

5 The MRC needs to consider how public involvement addresses equity in research, by:

- Articulating how involvement can support inclusive research, that is, research that fully reflects and addresses population needs
- Complementing the MRC's EDI Strategy.
- Enabling the involvement of different people in the MRC and MRC research
- Actively reaching out to involve different communities

6 The MRC needs to comprehensively integrate involvement into its leadership and head office operations, with appropriate resourcing, including through:

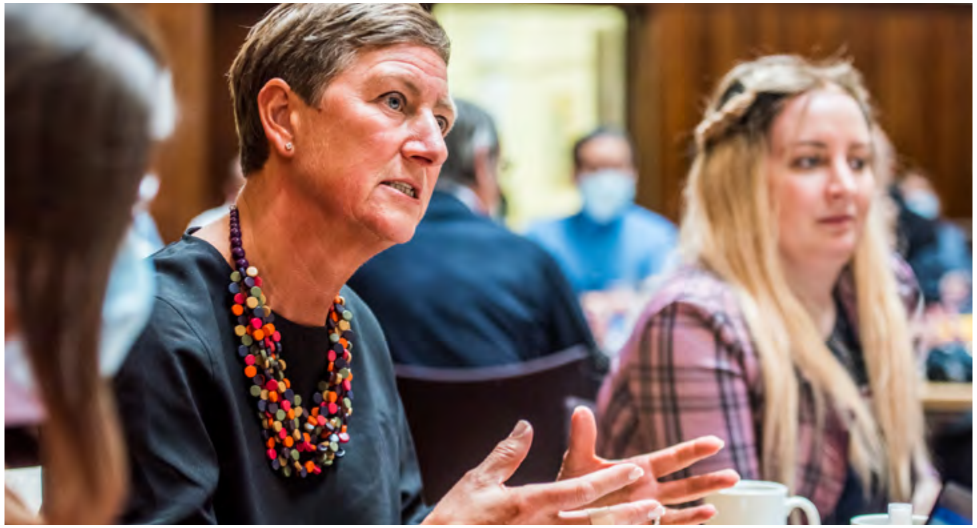
- Involving public partners within high-level MRC decision-making
- Appointing a new senior role to lead public involvement, plus additional public involvement practitioners within MRC head office as appropriate to the ambition, and resource available
- Continuing to champion public involvement through senior staff within head office
- Investing in professional practitioners by increasing the number and skills of existing PEPs in MRC Establishments and the wider MRC research community, and creating a community of practice
- Supporting the strategy with adequate communications resource to visibly and consistently signal the MRC's approach to public involvement, internally and externally

7 The MRC needs to provide co-created learning and development opportunities to enable public involvement including through:

- Mandating learning and development opportunities across its functions and people, including public partners.
- Developing training focused on involvement in non-clinical research – potentially in collaboration with others.
- Being explicit about the support available to public partners to enable their involvement.
- Focusing on supporting researchers to develop and reflect on their involvement practice, as fundamental to research excellence.
- As routine, co-creating all new learning and development opportunities in partnership with public partners.
- Deepening learning about the difference that public involvement can make to research, researchers, MRC staff, public partners and the research environment.
- Developing and supporting communities of practice, especially for public involvement with non-clinical research.

8 The MRC needs to put clear and accessible systems and processes in place to enable public involvement to flourish, including through:

- Building consideration of involvement into all funding schemes.
- Further exploring and implementing ways to release time for, and adequately resource public involvement.
- Establishing enabling processes within research grant-giving, including non-academic recipients of funding.



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Acknowledgements

Vocal team:
Leah Holmes, Annie Keane, Bella Starling, Derek Stewart, Laura Thomas

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Mary Derrick, Rachel Knowles, Karen Brakspear, Patrick Chinnery, Erika Doyle, Claire Newland, Yan Yip

Sincere thanks to everyone who gave their time, expertise and insights to support this work. A full list of acknowledgements is available in the main report.

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Published by the Medical Research Council, part of UK Research and Innovation.

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The main report and appendices are available to download from here.

For further information on this project please contact

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