

VOCAL

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

MAIN REPORT

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**

VOCAL



Medical
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Council

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Foreword – Derek Stewart & Lynn Laidlaw, public partners

It was an absolute pleasure to be part of a team that worked in such a genuinely collaborative manner on this review and report. The willingness of the Medical Research Council (MRC) to accept and embrace this partnership approach enabled our enquiry into public involvement in non-clinical research to be extensive, thorough and ground-breaking.

Our findings clearly show that there is a significant amount of active public involvement taking place across the wider landscape of non-clinical research and within the MRC. It has been great to hear about such exciting, innovative and positive experiences. We have also listened to a variety of views and opinions of those who work for and/or with the MRC.

Our review identifies where more work needs to be done to strengthen public involvement within the complexity of the MRC as an organisation and across all MRC funded activities. Involvement is a key element of enriching the culture and practices of non-clinical research and we believe the MRC has an important role to play in leading this change. Our analysis addresses the subtle differences between public and patient involvement and invites alignment with public engagement and inclusive research.

There is much richness to consider in this review and hopefully the findings will assist public partners and researchers to come together and bring its recommendations into reality.

Thank you for the opportunity given to Vocal to be able to enquire, discover and report on such a potentially exciting area for the active involvement of the public and patients to work beside such a medically and scientifically important organisation.



Vocal was commissioned by the MRC (February–September 2022) to undertake a review of public involvement in research, with a specific focus on non-clinical health and biomedical research. This report aims to support the development of a new MRC public involvement and engagement strategy and to share findings with a wider community.

This work 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 involving people and communities in their work to increase trust and engagement with research.

The benefits and impacts of public involvement are broad, varied and extensive, especially where there is clarity of purpose. The evidence demonstrates that effective public involvement benefits research outcomes and culture, researchers, public and patient partners, policy and society. A summary of these benefits and impacts from the scoping review is presented in Section 2.2.

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 funded research culture, and research culture more widely.

Due to the breadth of MRC's research portfolio, from basic through to applied research, there are areas of high public interest and contention (big data, animal research, embryonic stem cell research) where mutual understanding, trust and transparency are essential for progress. It is difficult to see how the MRC would navigate these 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 funders.

Over the last year, UKRI and the MRC have made important commitments to public involvement. These include 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 clear principles, expectations, and good practice for public involvement and engagement in biomedical research, within the wider framework of the UKRI Public Engagement Strategy



Headline findings

Our analysis shows that 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. 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, enthusiasm and appetite for working with people across all research, including non-clinical research, MRC stakeholders consider public involvement to be important for improving research quality, relevance, transparency, and trust, and for 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**

Headline findings

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.



Summary of recommendations

- 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

Summary of recommendations

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

Introduction



Introduction

Our approach

The Vocal team, comprised of researchers, public involvement practitioners and public partners, led this landscape review to inform the development of the MRC's public involvement strategy. We achieved this by working with an External Advisory Group (EAG) of 8 people including public partners, involvement practitioners, scientists/researchers and representatives of research organisations. Our methodology is detailed in Appendix 1.

In this way, we modelled best practice in collaborating with public partners and the research community. The role of the EAG was to bring specific knowledge, understanding and experience to broaden the perspective within the project and to act as its critical friend. The membership of the EAG was diverse, including people from different ethnicities, ages, disability, socio-economic and professional backgrounds.

The Vocal team reported to the MRC's Public Involvement Project Oversight Group (PIPOG) monthly and worked closely with the MRC Project Team, meeting fortnightly. Our approach took account of the unique nature of the MRC, its challenges and opportunities, in order to identify the building blocks needed by the MRC towards a meaningful public involvement strategy. We carried out literature reviews, surveys, interviews, and several workshops including a co-production workshop with the EAG and senior MRC staff.

We were heartened, during this review, to see evidence of significant development in the outlook of staff within the MRC: we observed a growing language, enthusiasm and confidence for public involvement, and an acknowledgement that embedding public involvement in the MRC requires a degree of culture change. One senior MRC team member stated: *"We're considering [public involvement] as a mindset now"*.

The MRC is a complex organisation and structure, and therefore needs to 'walk the walk' at all levels in order to influence and support the research environment to involve people meaningfully. To improve research quality through involvement, the MRC head office, as well as their funded research community, need to work with people and patients to inform their work, assess the quality of involvement that comes in for funding, and provide leadership and advice to researchers and institutions.

Introduction

Terminology

Tackling terminology was an explicit part of our brief, and an urgent one. We use the following terms in this report and offer these meanings:

Public involvement in research refers to an active collaborative partnership between researchers and members of the public, patients, carers and/or communities, working alongside research teams and as part of research organisations. Members of the public, patients, carers and/or communities are actively involved in contributing to the research process and environment in a variety of ways.

This definition is based on several definitions of public involvement and indicates the contribution of public involvement to all functions within the research environment. It aligns with the co-created definition of public involvement within the UK Shared Commitment to Public Involvement: "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". Implicit in this definition is the understanding that productive relationships achieve most when they are clear on purpose, the mutual opportunities for learning, defined expectations and timelines.

Public engagement is used to refer to research being shared with wider audiences, to stimulate further interaction, shared learning and dialogue. Some organisations present engagement as a one-way process of informing the public about science, though many others define engagement as broader and all encompassing. We take the view that engagement and involvement can be mutually dependent, complementary and occurring on a spectrum. In this report, we focus on involvement as an active relationship and collaborative endeavour, and mention, where appropriate, synergies with the engagement landscape of the MRC and UKRI more widely.

Life experience includes experience of health conditions (often referred to as lived, or living experience), social, cultural and/or economic experiences, as well as experiences arising from marginalisation or inequalities (for example, people with experience of racial inequalities).

Introduction

Public partners are people that share their life experience, skills and ideas to help improve research and bring benefit to society. They may include patients, carers, advocates, service users, members of the public, and/or members of specific communities of identity, practice, belief, or geography. The term describes those who choose to be actively involved in a distinct partnership with researchers. Together they explore issues, take part in agreed activities and accept different tasks and roles. Public partners bring with them transferable life knowledge, experience and skills that is of added value, especially where there is an uncertainty or a decision to be considered. They may add:

- Different and external perspectives on a topic
- Alternative approaches to dealing with situations
- Creative thinking complementary to the creativity of science
- Skills and experiences gained from being involved previously in research
- Realism and practicality from all walks of life

Useful attributes for public partners to have or develop include curiosity and interest, skills of being part of a group or team, a willingness to seek solutions, and an ability for critical friendship and reflection.

Research environment describes and includes all the functions contributing to research including ethics, governance, funding, policy, engagement, communications, staffing including training and development, evaluation and impact.

Non-clinical research is the term we use as a shorthand for basic science, laboratory-based research, and research using data-driven approaches.

MRC Establishments refers to all MRC Centres, Units and Institutes.

We provide these definitions for clarity. Section 3 addresses terminology in more detail.

Introduction

Next steps

We recognise that our recommendations are several, complex and far-reaching. A next step is for the MRC to prioritise and refine them, including identifying where the organisation might work in partnership to make them happen. We also encourage the MRC to initiate further public dialogue soon after the submission of this report, to help to inform the next steps for developing the strategy.

Supplementary information

The headline findings and recommendations are also available in the Executive Summary.

Additional information and data from our review can be found in the following documents:

- 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



Recommendations, findings and considerations



Recommendations, findings and considerations

Our analysis of the components needed for the MRC's public involvement strategy follows. In each section, we present our headline recommendation, followed by the underpinning findings from our review and current evidence, with some additional considerations to support the recommendation.



“Walking the talk”: developing a vision and strategy for public involvement

1 Recommendation: 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

1.1 An ambitious vision for the MRC and public involvement

Findings

“Regardless of return on investment, it [public involvement] is the right thing to do.”

Staff member, MRC head office

“The MRC has one of the least prominent public involvement and engagement strategies of anywhere I have worked. It would be great if this could be done more – but this also feels like a bit of a stretch.”

Staff member, MRC head office

“I think MRC talks a lot about how this [public involvement] is important but doesn’t really do anything to formally encourage or facilitate public involvement, or engage with the public itself, or create actual opportunities to involve its researchers with the public.”

Principal Investigator, MRC Establishment

In order to develop an effective strategy for public involvement in research, the MRC needs to be clear in its vision and ambition for working with people. We found that a clear and enthusiastic appetite for working with public partners in research exists. However, there is also a perceived lack of ambition and practice, along with confusion about the aims, purposes and practicalities of public involvement. In some places, we found active resistance to public involvement.

“When you involve people in research it’s not [about] method. Essentially, it’s about conversations and relationships and collaboration”

Public partner, EAG

“Walking the talk”: developing a vision and strategy for public involvement

We heard:

- Differing conceptions about the nature and purpose of public involvement
- Beliefs, amongst research constituencies, that public involvement is not relevant or possible in non-clinical research
- Questions about legitimacy and methods arising from uncertainty as to the value of life experience alongside scientific evidence
- Uncertainty about how much to collaborate, for example with other Research Councils

We have heard of the risks to research associated with *not* having a clear vision, understanding or practice of public involvement. Although very much in the minority, examples (from outside the MRC) include research programmes not reaching their objectives, attributable in part to lack of (effective) public involvement; and the conduct of public involvement being misplaced, inappropriate or potentially harmful.

Considerations

Drawing on our review, we propose that the MRC develops a long-term vision about working with people, along the lines of:

Effectively building trust and sharing decision-making with the public enables the MRC to achieve research excellence, social value and health equity as an open and democratic organisation.

This chimes with the UKRI Public Engagement Strategy, due for publication in the coming months.

**“MRC [Head office]
needs to walk the walk
as well as talk the talk”**

Member, EAG

Purpose, motivations and context for public involvement

1.2 A co-creation process

Findings

In addressing what the MRC is working towards in its public involvement, what makes it distinctive and where it fits in the wider context, we have found that the process of developing a strategy is as important as the strategy itself. The approach of this review in modelling integrated public involvement has been pioneering in this regard and has arguably opened up MRC perspectives around involvement.

"It'd be very easy for us to get our reports from Vocal to get all excited and start doing what we always do. [...] But if we're going to try and take some of the learning that we've had from this journey with Vocal I think we need to really think about how we involve our own people but also how public contributors could be involved, so that we actually start role modelling, as really Vocal role model for us now, this could look and feel different...I think it could be very important from a cultural perspective."

MRC PIPOG member

Further, co-creation of public involvement strategies, with those for whom the strategy is most relevant, is an accepted and demanded approach in many spheres. For example, NIHR expects public involvement strategies within its funded infrastructures to be co-produced with patient partners; the International COVID Data Alliance recently involved public partners across the globe in its public involvement strategy. Co-produced strategies are increasingly routine within cultural, civic society and health sectors.

Considerations

We recommend that the EAG model formulated for this review is maintained by the MRC and continues to play a co-leadership role in the development of the MRC's public involvement strategy. The EAG may benefit from additional or different membership, but should maintain a majority of public partners, across a diversity of life experiences and background (as in the current EAG). More widely, the strategy co-development process should be open and transparent, and is an opportunity to communicate and build interest, involvement and support across all stakeholders.

Beyond the iteration of the strategy, there is an important role for the EAG in holding the MRC to account for its public involvement strategy.

Purpose, motivations and context for public involvement

2 Recommendation: 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

2.1 What is the purpose of working with people in research?

Findings

Our review shows that public involvement addresses a range of purposes defined by context and the needs of research, researchers, public partners, and other staff. Having a clear purpose enables public partners and researchers to capture the benefit of involvement and describe it for others.

"Essentially [public involvement] is a values-led way of working that's fluid and adaptable to different contexts."

Public partner

"When you involve people in research it's not [about] method. Essentially, it's about conversations and relationships and collaboration"

Public partner, EAG

"We shouldn't be simply sharing our research with each other – we are funded by society and accountable to society. The last two years have made clear what happens when there is distrust in science and in the scientific process."

MRC funded Head of Department

Purpose, motivations and context for public involvement

The statements above illustrate our wider findings around the need to avoid tokenism, and the 'stereotype' relating to the term PPI (patient and public involvement) in which involvement always requires a patient or health experience. Our findings invite us to reframe the approach as *public* involvement and consider the breadth of motivators and purposes to include:

- **Rigorous and democratic oversight, open to challenge:** e.g. inviting experienced public partners onto a governance, funding or decision-making committee.
- **Shared creation of problems and solutions:** e.g. working closely with public partners to consider a problem, idea, or priority at an early stage of development, making progress by working together across different experiences.
- **Valuing experience and gaining insights:** e.g. learning from public partners with specific knowledge related to life experience, specific demographic characteristics or medical conditions.
- **Building shared understandings:** e.g. ongoing discussions and relationships can broaden the knowledge base relating to the research environment and enable more complete decisions and outcomes on the potential applications and implications of research.
- **Enhancing future collaboration and problem solving:** e.g. seeing, experiencing and learning from successful collaboration that can be applied to future situations.

Additionally, public involvement in clinical research has often been conceptualised and delivered within the research 'cycle' and this perception and approach was held across those we worked with at MRC head office and the MRC-funded community.

Considerations

We recommend that the MRC vision and associated strategy:

- Reframe public involvement in terms of the purpose and value it can bring to the research environment, rather than to specific research methodology or 'place' in the research cycle. Involvement across the research environment might include impacts on strategy and prioritisation, governance, impact, policy, ethics, communications, public engagement, learning and development, and relationships with other organisations or services (e.g. health services).
- Encourage the application of public involvement methods, according to context, using bespoke approaches for each and all public involvement activity, dependent on the needs and purpose of the work and the individuals and stakeholders. The UK Standards for Public Involvement are useful here.
- Facilitate the MRC research community's understanding on how to prioritise public involvement, by where it's most needed, purposeful and/or meaningful.

Purpose, motivations and context for public involvement

The case studies below demonstrate how these considerations have been applied:

Case study A

Programme-level public involvement strategy in fundamental research focused on publicly contentious issues (available in full in Appendix 2)

What makes us human? Public engagement and Involvement with the Human Developmental Biology Initiative (HDBI)

Human developmental biology research raises ethical, legal, social issues (ELSI) in terms of the research relying on the use of human embryo and foetal tissue, how this tissue is sourced, and how we use knowledge generated by the research in the future.

The focus of the public engagement (PE) strategy for HDBI is on developing researchers' capacity for engagement and involvement in order to: systematically address barriers that prevent the full potential of engagement; provide flexibility to respond to arising needs within research or policy, and secure a legacy of engagement beyond the funding period.

At the core of the PE strategy is the Insights Group – a mixed experience group of people and professionals, including women and men who have experience of IVF services, or termination of pregnancy services.

The Insights Group has a broad remit within the HDBI working with researchers to consider ELSI, improve communication of research, co-produce and co-deliver training, and to improve public engagement and horizon scanning.

This case study demonstrates an approach designed to overcome barriers around 'saying the wrong thing' in contentious issues, and in gaining public insight where its most valuable – not around basic research methodology – but in the surrounding context, arising questions, and future implications of this fundamental biology and its interface with society.

Case study B

Patient involvement within a prostate cancer research consortium (available in full in Appendix 2)

ReIMAGINE (co-funded by the MRC and CRUK)

ReIMAGINE is a research consortium working to develop more accurate diagnostic tools to prevent the high prevalence of under-diagnosis, over-treatment and missed diagnoses of prostate cancer.

A PPI sub-committee of patient/carers was involved throughout the research process, from grant application to completion. The sub-committee's role included supporting research governance, design, data collection, analysis, and research communications. A PPI co-ordinator facilitated the dialogue.

A specific outcome of the PPI sub-committee included the establishment of a prostate cancer research group focusing on communities experiencing racial inequality, which enabled a greater range of perspectives based on lived experiences, and promoted greater diversity in research.

ReIMAGINE provides an example of involving patients and carers with lived experience of prostate cancer across a programme of research, and demonstrates potential outcomes of valuing diverse experiences and skills as an integral component of the work.

Case study C

PPI group working across clinical and non-clinical research (further information in Appendix 5)

MRC Human Immunology Unit (University of Oxford)

The Oxford Blood Group encourages people and patients with lived experience of a haematology (blood) condition to be involved with the Haematology and Stem Cells theme at the NIHR Oxford Biomedical Research Centre.

In this example, public involvement in non-clinical research had been developed following on from an initial broader focus on public engagement. The work is a collaboration across research teams of clinical academics and non-clinical researchers.

Establishing the public involvement approach took approximately two years, with a concerted effort to build buy-in and support from the research and leadership team.

Initial sessions focused on discussing the broad research context and the direction of research at the lab. Further and ongoing work has focused on communication and language.

The discussions highlighted some different priorities between public contributors and researchers, but a shared outcome has been motivating both the research team and the public partners:

The Unit's experience is that culture change is a key part of working more closely with the public. This change started initially with public engagement around 10 years ago. Their experience demonstrates that engaging all members of the research and leadership team was crucial.

Purpose, motivations and context for public involvement

Further case studies are available within Appendix 2: Landscape review of public involvement in non-clinical research and Appendix 5: Examples of MRC public involvement. These demonstrate good and thoughtful practice with strong commitment from the researchers, public partners and PEPs involved.

We have found examples of a variety of approaches, across both clinical and non-clinical research. Importantly, many of the examples demonstrate a variety of purposes for public partners with involvement in the detail of the research, but also within more strategic and governance roles, suggesting a maturity of involvement practice in some instances. It should also be acknowledged that MRC has funded several initiatives [6] exploring public perspectives about different aspects of research, which can help to inform the understanding of the context for public involvement.

2.2 What difference does public involvement make?

Assessing and reporting the difference that public involvement makes to research – and to those involved – is still emerging. In the last few years, some effort has been devoted to developing evaluation and reporting methods for public involvement (e.g. GRIPP2 checklists [2] and the MRC funded PiiAF framework [3]; involvement is often also assessed against the UK Standards for Public Involvement [4]).

Only recently have journals started to routinely publish peer-reviewed papers on the methods and impacts of public involvement. This is also a contested area with some calling for the evaluation of public involvement to consider it not as an instrumental intervention but a social practice of dialogue and learning between researchers and the public; to better assess how power relationships play out in the context of public involvement in research; and to question whether the language of impact is helpful or not in the context of public involvement. (e.g. [5]).

“We found that PPI has really energised our researchers... seriously energised and motivated them got them to think about what they were doing in a different way. And just made them feel more involved and more useful.”

MRC funded Principal Investigator

Purpose, motivations and context for public involvement

From our scoping review of public involvement in non-clinical research, we have identified and summarised a number of common features which are important for public involvement. The list below identifies enablers, benefits, impacts, barriers and challenges of public involvement. (The full review and methodology is available in Appendix 2).

Enablers for public involvement

Funding & funders

- Public involvement as a requirement from funders of non-clinical research
- Support from funders and through funding

Team & Support

- Arrange the team structure to support public involvement.
- Plan for equitable division of responsibilities to reduce the burden on the project team and help partners feel more invested
- Support from a professional expert
- Provide competitive salaries for engagement and involvement practitioners
- Support of senior colleagues
- Support with logistics

Learning & Development

- Training/development at every career stage
- Resources for researchers to overcome challenges
- Toolkits and standards
- Distribute learning materials before and after meetings
- Opportunities for researchers to practise in safe spaces – this can support communication and language, and overcoming barriers around having difficult conversations

Strategy & Planning

- Supporting scientists to start involvement early / Develop patient engagement strategies ahead of time – this benefits involvement that shapes research priorities and is strategic/ will add most value
- Clarity of purpose of the involvement

Purpose, motivations and context for public involvement

Enablers for public involvement (continued)

Relationships with people and communities

- Building long term relationships is key – face to face activity can be beneficial although not essential
- Involving the 'right' people – based on interest, diverse lived experience, science backgrounds are not necessary
- Consider the needs of the community
- Partnering with external organisations that actively support patient engagement in non-clinical science research projects

Involvement practice

- Regular consultation and continuing conversations – learning together and building mutual understanding
- Creating a safe space where patient partners and researchers feel comfortable to collaborate

Communications including:

- Clarity and language
- Keeping PPI contributors informed
- Sharing examples of good practice

Benefits & impacts of public involvement

Mutual learning

- including public partners understanding and interest in basic science research, and researcher understanding of the real-life priorities and impact of their work
- Improved skills and confidence in public involvement for all constituencies

Opportunities to build new knowledge, interests, and perspectives

- Public involvement can inform and broaden perspectives and knowledge of researchers, raise questions that researchers may not have thought of and help them to think differently
- Involving a diverse patient partner group provides a greater understanding of diverse experiences

Improved quality and efficiency of research

- Public involvement informs the research question, study methodology, and future research direction by fostering important discussions
- Patient partners can play an important role in disseminating research findings

Purpose, motivations and context for public involvement

Benefits & impacts of public involvement (continued)

Other

- May increase trainee recruitment/retention, external collaboration, and recruitment
- Improves communication between the different stakeholder groups
- Improves patient/ public partner trust in the research community and strengthens the research through trust
- Encourages a sense of partnership (between patients and researchers)
- Creation of beneficial external partnerships
- Increases self-confidence and the impact of the patient voice
- Improves motivation for researchers
- Reassures researchers that what they are doing is of value
- Impacts on public/patient partners can include feelings:
 - of hope for their condition even if this may be in the distant future
 - that they are doing something useful
 - of being part of a wider community
- Impacts can be greater than originally envisaged

Barriers to public involvement

- Structural barriers including time, funding and systems & processes
- Terminology
- Public partners identifying opportunities to get involved
- Researchers' fear of saying the wrong thing
- Researchers lacking knowledge and confidence in ethics
- Public partners' health
- Poor communications (from researchers)

Purpose, motivations and context for public involvement

Barriers most relevant to non-clinical research

- Lack of researcher training opportunities to guide meaningful patient engagement in basic science research
- Researchers/practitioners lack of awareness of different approaches to non-clinical research
- The impact and/or direction of research is further away from application and may be unknown
- Defining the public stakeholders
- Public partners lack of experience of lab-based research

Challenges for public involvement

- Research culture may not be conducive to involvement
- Lack of research experience, preparation, and clarity around expectations for public involvement
- Researchers concerns about how many people is enough
- Diversity of public partners
- Power imbalances between research community and public partners and practitioners
- Addressing the priorities of all team members can be difficult to achieve
- Researchers/practitioners' concerns around group dynamics or managing difficult situations
- Concerns about raising people's expectations regarding timelines of research into practice
- Measuring and reporting on impact – especially how to compile qualitative evidence across programmes/ organisations

Purpose, motivations and context for public involvement

2.3 Why is it important to 'do' public involvement?

Findings

Informed by conversations with the EAG and MRC staff commissioning this review, we asked a range of internal MRC and external stakeholders to tell us why public involvement is important:

The MRC Public Involvement Project Oversight Group collectively prioritised:

- Grounding research – improving research outcomes using patient and/or public experience
- Integrity and trust – maintaining public trust through transparency and democracy
- Equity and diversity – across the research environment, and research outcomes

The following were seen as less important at this time:

- checking that it is the 'right' thing to be doing – this was seen as integral to good public involvement. This statement also raised concerns about decision making being too skewed towards public priorities at the sake of evidence and analysis from the research community
- for the public to find out about research – this was seen as more related to public engagement. This highlighted to the Group how engagement was complementary to involvement.

MRC Research Programme Managers prioritised:

- Maintaining public trust through transparency (89%)
- Making research relevant to the public (69%)
- Making research more equitable and diverse (58%)

Closely followed by Improving the communication and language of research (56%)

Appendix 6 provides a breakdown of survey responses by role. The survey data from *MRC Head office staff* places greatest importance on trust, transparency, relevance, and equity and diversity of research.

From the survey to all MRC stakeholders, the top three chosen were:

- Making research relevant to the public (52%)
- Ensuring openness and transparency (50%)
- Maintaining public trust (44%)

Public partners responding to the survey feel that improving research outcomes and making research relevant are the most important factors. They place increased importance on research decision making, and effective challenge to research assumptions.

The least popular choice of all respondents was to make research more cost effective, which suggests that moral and/or ethical motivations for involvement are more important for respondents rather than financial or process motivations.

Purpose, motivations and context for public involvement

MRC funded researchers place greater priority on the public finding out about research, than all other categories of respondents. This could be due to the current emphasis on public engagement and communications within MRC funded research. Drawing on the evidence that experience and confidence in public engagement can lead to more involvement within research [7] this provides useful knowledge, which we will draw on later, in how to support MRC researchers' continuing professional development.

Considerations

As part of its vision, culture and strategy, the MRC could focus its priorities on public involvement as essential and integral to the pursuit of research excellence and include:

- Producing high-quality non-clinical research, including in the relevance of its outcomes and approaches to people/society
- Ensuring openness and transparency of research organisations
- Maintaining public trust between researchers, research organisations and people
- Making research more equitable, inclusive and diverse

This would also enable public partners to view their involvement as an essential part of the bigger picture.

Purpose, motivations and context for public involvement

2.4 Is the context of non-clinical research a 'special' consideration for public involvement?

Findings

"As a basic scientist, it's clear that the public isn't educated on the value of basic science to research."

MRC funded Principal Investigator

"I'm genuinely not sure if we can co-produce e.g. tissue culture experiments. But we can co-create the research environment in which such studies are born, then they will reflect the active involvement of patients and communities"

Public involvement practitioner

Public involvement with non-clinical research does have some unique, though not insurmountable, challenges. We encountered reticence, and in some cases active resistance to public involvement in non-clinical research.

Appendix 2 summarises some of the more specific considerations for public involvement in non-clinical research. These include:

- Identifying public partners is trickier – unlike clinical research, it isn't always obvious who the potential stakeholders could be.
- The impact and/or direction of research may be unknown, outputs may not be clear and/or long term.
- For some of these areas, there are ethical, legal and social issues which can make researchers more fearful of involving people and will certainly require great care in involvement practice to ensure that public partners are included with sensitivity.
- The non-clinical landscape is viewed as less relatable to health experience than clinical research. The context and environment in which the research takes place is quite different; and the content of what is being studied can be complex and detailed.

"Whilst it is vital that people with lived experience of a condition are involved, there are also roles for others who can perhaps offer a more objective view."

Public partner

Purpose, motivations and context for public involvement

However, public partners and public involvement practitioners – from our survey, Tweetchat and as part of the EAG – believe that non-clinical research should involve public voices. Our survey findings show that two thirds of public partners think that people can contribute to all types of research, and fewer than a fifth of public/patient or public partners thought direct experience of a health condition was needed for involvement.

Considerations

The MRC, as an organisation, needs to be proactive in influencing its internal culture and leveraging its external influence to stop the perception that non-clinical research is distinct from society and exempt to public involvement. MRC should strongly communicate that public involvement in all research, including non-clinical, basic and big data science, is possible, happening, and making a difference. Using the case studies from this work would be useful in this regard. There is a clear opportunity for the MRC to show leadership by setting out to learn further about public involvement in non-clinical research and ambitiously innovate involvement practice in this area.

Tackling terminology and congruence

3 Recommendation: 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

3.1 Complementing strategies and practice

Findings

During the course of this work there has been significant progress and collaboration across engagement and involvement functions within MRC head office and UKRI, including as part of the cross-council Public Engagement with Research Network, and plans for a senior outcomes-focused group. The MRC now has greater clarity about positioning its engagement and involvement work in relation to the UKRI strategy, and an opportunity to co-develop public involvement practice and language which is best suited to the needs of MRC's organisation and research portfolio.

Also, during this period, UKRI has signed up to the Shared Commitment to Public Involvement [9], and the MRC has agreed to progress a strategy encompassing both public involvement and engagement. There are ongoing discussions about the recent recommendation to uncouple communications from public engagement within MRC governance and assurance processes [8].

We have reviewed research, public engagement and EDI strategies, and strategic delivery plans across UKRI and MRC. There is good cohesion and positioning across these strategies, and a strong rationale for public involvement sitting alongside research integrity and open access research.

However, we find that MRC head office staff are unclear about how the MRC should align public involvement with UKRI public engagement strategy in practice. The lack of clarity extends to high-level decisions about how MRC positions itself within UKRI, how it influences them, and how best to work together going forwards.

In our workshops and as part of EAG discussions, public partners express a need to understand better how involvement 'fits' within the overall MRC strategic ambition.

We've heard evidence that some public engagement practitioners within HEIs and/or MRC funded units and programmes are dealing with different institutional strategies, funding requirements and agendas and would benefit from a joined-up approach and clarity across all the MRC's strategies.

"I'm not employed by the MRC but as a person, funded by the MRC, a little bit distant I get bombarded by strategies... I'm not sure the top bods in the organisation will take what we've said seriously, given that their overarching strategy doesn't seem to do much in the space. That...makes it difficult to justify things internally to other senior leaders if they don't see it written in the right places, or talked about."

PEP, MRC Establishment

Tackling terminology and congruence

Considerations

We support the recommendation from Jamieson and Leslie 2022 [8] to foreground the principles and ambition for working with people into key Council strategic documents. Further, we strongly support the MRC in developing a public involvement and engagement strategy. This is particularly important in developing and maintaining relationships with communities that support diverse and inclusive public involvement, so that engagement and involvement are not seen as 'siloed' or prioritising views from particular constituencies.

Our recommendation is that public involvement at the MRC needs to be seen as fundamental to the research environment and that a combined engagement and involvement strategy develops the values, principles and behaviours (described in earlier sections of this report) as well as the procedural and practical elements of public involvement (described later).

We anticipate that public contributors and others will be interested to know how the public involvement and engagement strategy was developed, who has been actively involved, whether the UKRI and MRC's commitment to public involvement is evident in the strategy, and in how it is delivered.

3.2 Tackling terminology

"How do all these practices sit with Knowledge Exchange? For me and many other practitioners, knowledge exchange is an umbrella term and one engagement/involvement practice should not be overemphasised over another. The only guiding principle is the question 'who is the stakeholder that is key to making a particular impact?'; then engage with them. We call it outcomes-focussed engagement. Today it could be patient involvement, tomorrow it's policy engagement."

PEP, not funded by the MRC

"It [public involvement] needs really good communication and expectation setting etc – training and shared learning for all involved. I think it would make lab-based scientists more understanding of the impact (and limitations) of their results."

Public involvement practitioner

"A key feature is the need for the whole population – researchers and the public – to be involved in research through the provision of data and samples."

Principal Investigator, MRC Establishment

Tackling terminology and congruence

Tackling the terminology of involvement was a key factor in the commission of this review. The terminology associated with public involvement and engagement can be problematic and a perennial issue within both research and public involvement sectors. There has been some recent alignment amongst research and funding organisations around terminology with the most used definitions being:

Term	Definition	Used by
Public Involvement	Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them	NIHR, CRUK, HRA, HDRUK, ABPI
Public Engagement	Information and knowledge about research is shared with the public [an emphasis is placed on 2-way dialogue]	NIHR, CRUK, Wellcome, UKRI, NCCPE
Participation	Where patients or healthy volunteers take part in a research study; they are the subject of the study and the research is being done to them, not with them.	NIHR, CRUK, HRA,
Patient engagement	The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognising their specific experiences, values, and expertise.	Industry (e.g. Pfizer) and societies (e.g. ISPOR)

Additionally, within engagement and involvement sectors, there is also a variety of terminology that might also be confusing, for example, consultation, dialogue, citizens' jury, co-production, community engagement. We acknowledge that the public engagement and involvement sectors have sometimes been unclear themselves.

Our review highlights that MRC staff and researchers – even when they cite examples of public involvement that they've worked on – often confuse engagement and involvement, interchange or conflate terms and meanings, and are unclear about how involvement might cohere with, for example, knowledge exchange or research participation. There is a lack of clarity about what public involvement is and its purpose.

All stakeholders in this review, in every interaction without exception, stated a need for clear expectations and guidance from MRC. Reasons that we heard about why this is so important relate to meeting/setting expectations: for researchers' and PEPs' understanding of what the MRC is expecting of them, and MRC staff knowing what they should be expecting from research applicants/ funded researchers.

Tackling terminology and congruence

During the course of this review, the MRC has made progress by:

- Critically appraising the interface between engagement and involvement, e.g. by considering an MRC Public Engagement *and* Involvement Strategy, which takes account of the need to address terminology.
- Moving away from using the term 'patient and public involvement' (PPI) in favour of 'public involvement' as a catch all term which is more appropriate for the MRC context as a major funder of non-clinical research.
- Working on terminology as a focus across Research Councils.

Our experience suggests that public partners care more about the purpose, value and impact of public involvement rather than what it's called. Routinely, there are calls to 'say what it means':

"We want conversations about a topic, rather than a method"

Public partner, EAG.

Some cautioned against using definitions which would constrain creativity and innovation. They were concerned about words which meant one thing to the MRC, and another meaning for others.

"We think 'PPI' can be limiting, because (we perceive) it to be associated with a traditional model of involvement – meeting rooms, formalised, etc. Coinciding with lack of diversity of contributors, going native, lacking creativity etc. It also firmly links involvement to health research, and it might be more helpful to think of involvement more broadly in terms of democracy and justice."

Public Involvement Practitioner

Considerations

The MRC is already committed to the definition of public involvement within the UK Shared Commitment for Public Involvement [9], which was co-produced with public partners and is congruent with relevant stakeholder strategies. Based on the starting point of the Shared Commitment, this review has expanded a definition of public involvement (see Introduction section) that the MRC might consider using or adapting.

Taking this further, the MRC has the potential to show leadership in developing a new 'everyday' language for involvement, moving away from the jargon and multiple definitions. Ideally, this could link language and terminology with purpose. For example:

- public partners inform our decision-making through their membership of funding committees
- we consult with patients and members of the public to agree on our research priorities
- we support inclusive research by working directly with minoritised groups to exchange learning between researchers and communities
- we listen to and value people's life experience in influencing our methods for research

Developing working cultures to support involvement

4 Recommendation: 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

Findings

Positive development in research culture is happening within the MRC, including workstreams supporting MRC's People and Culture programmes, and the establishment and work of the MRC EDI Forum.

UKRI is moving away from the 'iceberg model' [10] in which scientific evidence above the surface (publications, funding, prizes) is added to from below the surface (from the research environment, where public involvement would sit); to a view that scientific excellence encompasses the entire research environment. UKRI is reframing the culture needed to achieve this new view of scientific excellence. This leadership and direction has had significant influence on MRC staff and has been frequently referred to during this review

This developing culture is timely and provides fertile ground for public involvement. In our experience, public involvement can influence and facilitate cultural change within the research community. It also requires an inclusive culture in order to flourish.

Our findings show that in some parts of the MRC, its establishments and funded portfolio, a positive culture towards public involvement exists but is constrained. In other places, active resistance to public involvement in the MRC's work and research was found.

"There is a problem with academic culture in biomedical sciences and it's well reported on. It's important that MRC see this as a culture shift"

Member, EAG

Developing working cultures to support involvement

*"The mantra that 'the public' or 'the community' *always* know best is becoming problematic. It will lead to 'tick box' engagement/involvement."*

Principal Investigator, MRC Establishment

"What kind of culture are we bringing people into?"

Public partner, EAG

"There will always be those who are reluctant to get involved with PPI, but there needs to be some degree of humility between researchers and public collaborators to connect with the people whose outcomes they are trying to improve."

Research Manager/administrator, MRC Partnership Institute

Senior buy-in is essential for this culture change. Currently, the senior MRC staff with responsibility for public involvement acknowledge this change is needed, but do not yet have clarity about how they could catalyse it. This report and the next steps towards strategy development are viewed as the starting points for that plan. There are also opportunities to learn from the ongoing culture change around Equality, Diversity and Inclusion within MRC and UKRI more widely.

For public involvement at MRC to flourish, we have identified three areas for development within current MRC working cultures:

- Identifying and embodying values in relation to public involvement; emphasising relational approaches
- Valuing diverse forms of knowledge in decision-making
- Rewarding and recognising the value and efforts of public involvement at parity with research

This builds upon and strengthens the values-based foundation of both UKRI and MRC. It also aligns closely with MRC's ongoing EDI culture change programme.

Developing working cultures to support involvement

4.1 Identifying and embodying values in relation to public involvement

Findings

The MRC and External Advisory Group Co-Production Workshop began to define what a culture for public involvement could look and feel like at the MRC. These can be considered foundational values for the MRC's involvement strategy:

- **Dynamic and live** – a balance of rigid policy versus other elements, to support inclusivity. Lifelong learning is important.
- **Reflective and open** – Acknowledges that medical research has not always been inclusive (and worse) in the past. We need to continually challenge ourselves to be better. If we're to serve our communities with our research, we need to listen to their stories.
- **Not hierarchical** – but championed from the top and throughout: *"where status is not an opening definition of a person"; "dis-arm any notion of intellectual superiority"; "where public are seen as members of the team"; "where conversations are grounded in what's familiar."*
- **Inclusive** – where all feel welcome, respected and their contribution is valued, and recognising that this looks and feels different for different people.
- **Equitable** – where anyone, regardless of who they are can become involved if they choose, and not face any barriers. Investing in individuals and communities is important.
- **Diverse** – it's important to consider the approachability of people doing the research – will people feel more comfortable talking with someone they feel represents them?
- **Accessible** – physical, communication, information, attitudinal accessibility are all important. People need to know what's going on to feel involved.
- **Supportive** – one with buddying systems and mentoring.
- **A shared responsibility** – public involvement feels like the norm, with everyone feeling confident and comfortable. We learn and share knowledge with others, especially with co-ordination across Research Councils.
- **Committed** – Be committed to making a concerted effort – being inclusive isn't always the 'easy route'. You have to think differently, try different things and accommodate differing needs.

The values of the MRC are integrity, excellence, collaboration, diversity and inclusion, valuing people, and compassionate leadership and therefore there is significant alignment and a solid foundation for the MRC's new culture of public involvement.

Developing working cultures to support involvement

There is genuine interest and openness for doing public involvement across the MRC head office. Over two thirds of the Research Programme Managers' Forum said they could see the relevance of public involvement to their work. A senior member of MRC staff described MRC head office as a "*ready audience for culture change*". Some have direct experience of involvement, whilst others have never before considered it.

However, Head office staff often framed discussions about public involvement in transactional and/or extractive terms, prioritising the potential benefit to the research, without considering any other possible broader benefits of collaboration such as researchers learning from the perspectives of public partners, or changing broader research practices.

From those who are less experienced in public involvement there is currently a lack of consideration of reciprocity for public partners, their motivations and benefits from involvement, how public partners might feel, or how to work without doing harm.

Considerations

We recommend that MRC strengthens its values-based approach to involvement by building on the foundational values elaborated above.

Further focusing on the relational aspects of involvement, the MRC could potentially subscribe to, or be informed by the concept from the Animal Research Nexus [11] of a 'culture of care':

A culture of care is a phrase used to emphasise the importance of a research culture that is focused on relationships, effective communication, and training and support. A good culture of care in animal research considers how to care for the humans as well as the animals within research facilities. It is aimed at providing better care for animals, but it is also about supporting and valuing interpersonal relationships and caring and respectful approaches to animals and to co-workers.

Cultures of care are becoming more commonplace in wider organisational development spheres including within health, and we acknowledge the complexity and time required for them. Cultures of care may require additional pastoral support for individuals. For example, an involvement situation may 'trigger' emotions in researchers, staff and public partners alike. The MRC should consider these from the outset, add this expectation of duty of care into policies where appropriate, and identify specialist support to provide/signpost to if needed, e.g. counselling services.

Developing working cultures to support involvement

4.2 Valuing diverse forms of knowledge

Findings

"The need for evidence is ingrained within biomedical [culture]. There's a strong theme around differing perspectives creating shared understanding. The MRC needs to acknowledge that lived experience is a valid form of knowledge."

Member, EAG

"There's something here about whether the culture appreciates different values. The values of involvement are perhaps different to the traditional values/operating model of researchers/the MRC."

Member, EAG

Our findings reveal uneasiness about the possibility of public partners disagreeing with an established or majority view e.g. from academic funding panel members, and MRC staff being uncertain about how to deal with these situations if they arise.

Public partners have described that currently, some public involvement methods rely on "stepping into" an academic environment and culture, as opposed to creating a shared space for collaboration. Placing an emphasis on values and relationships could help address this disquiet.

Considerations

We strongly support the findings and recommendations within UKRI's recently commissioned report from the Young Foundation [1] including the recommendation:

A fundamental shift in what knowledge is valued and how it is funded: this means seeing value to community involvement in all parts of the system and respecting that community groups and organisations can be recognised as knowledge producers, guardians and lead partners in knowledge creation processes.

An asset-based mindset recognises as legitimate diverse forms of knowledge, including life experience, and incorporates these forms of knowledge alongside academic evidence. Importantly, here we define life experience as including experience of health conditions (often referred to as lived, or living experience), and social, cultural or economic experiences, as well as experiences arising from marginalisation or inequalities (for example, people with experience of racial inequalities). For public involvement to have positive impact, those involved should model mutual respect, and place value on the inputs from all, in the collaborative pursuit of new and knowledge and ideas.

Developing working cultures to support involvement

4.3 Rewarding and recognising public involvement

"[I would like to see] value given to achievements in this area broadly across the sector, such that time spent on this [public involvement] enhanced career prospects, not harmed them"

Principal Investigator, organisation/facility/network associated with MRC

"We found that PPI has really energised our researchers...seriously energised and motivated them, got them to think about what they were doing in a different way and... just made them feel more involved and more and more useful."

Principal Investigator, MRC Establishment

"Recognition is really important, and this needs to be equal to the recognition demonstrated for research, not just verbal recognition, or including your PPI work into their report"

MRC funded researcher

Reward and recognition for public involvement is needed and important across all the constituencies engaged in this work.

A third of researchers surveyed selected "Public involvement is included in my KPIs/valued by my institution" as a motivation for public involvement. This chimes with long-standing thinking within the wider public engagement sector. Our findings from workshops, interviews and the scoping review support evidence that public involvement can be motivational for researchers. For non-clinical researchers – who don't always interact with people and patients as part of their day job – this can have an even greater impact (see Appendix 2 for further information).

Public partners likewise value reward and recognition, which can come in the form of:

- Feedback on the quality and impact of their involvement
- Payment and payment policies
- Logistical arrangements, for example, convenient time and location of meetings, consideration of accessibility such as caring cover
- Clear and defined roles and responsibilities; honorary appointments, if appropriate
- Role progression, including for example peer research opportunities
- Expressions of thanks
- Communicating the difference they make e.g. through case studies of impact of public involvement

Developing working cultures to support involvement

Considerations

Reward and recognition processes might include:

- Identifying a set of skills and behaviours amongst researchers, that support public involvement and including these in personal appraisals and more broadly in project reviews and Establishments reporting and governance
- Celebrating and sharing best practice, including overcoming difficulties/innovative approaches – this extends from informal conversations through to supporting publications of MRC's involvement practice, and including Open Access fees for commentary and opinion articles (where public involvement practice and learning is often reported)
- Communicating case studies to all relevant stakeholders including public and research audiences
- Providing funding for public involvement within research grants, and as a standalone endeavour
- Adopting narrative CVs as appropriate – in funding applications, and supporting the wider work of the UKRI and Universities UK Alternative Uses Group [12] in influencing the research sector
- Developing a reward and recognition policy for public partners (see Appendix 7).

We note the complexity of reward and recognition across different employment structures for researchers, within host institutions of MRC establishments and suggest further scoping work for the MRC to pursue in this area. A relatively straightforward action would be for the MRC to publicly acknowledge and disseminate awards and prizes in public involvement given by researchers' host institutions, and/or other funders. Prizes should be across the constituencies of public involvement i.e. for researchers, public partners, staff. The MRC could further explore how to work with umbrella organisations and host institutions to influence and collaborate on reward and recognition for public involvement across the MRC research community.

Consideration should be given to providing competitive salaries and sustainable employment for involvement specialists. Leading and running involvement and engagement requires particular professional skills and experiences. However, these roles are often precarious, short-term and underfunded. Offering appropriately funded salaries for long-term involvement and engagement roles is an important step towards recognising the skills that such a role requires [7].

5 Recommendation: 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 Equality Diversity and Inclusion (EDI) Strategy
- Enabling the involvement of different people in the MRC and MRC research
- Actively reaching out to involve different communities

5.1 Public involvement supports an inclusive research agenda

Findings

Approximately two thirds of Research Programme Managers cited improving equity and diversity of research as a reason for doing public involvement at MRC. Despite this and the join up across high level UKRI and MRC strategies, it seems as if there is limited awareness to date on the relationship between public involvement and equity in research.

"The set of research questions that are funded or pursued may be biased i.e. they may support a particular demographic of the population without addressing more pressing needs. I am interested in whether our research is 'colonised', and whether there are mechanisms that can objectively assess public need and feed that into study designs at their conception. The BMJ has had several editorials that show that we as researchers are failing to address the racial health gap for example"

Principal Investigator, MRC Establishment

"In terms of EDI agendas, the addition of PPIE [patient and public involvement and engagement] can be a corrective for narrow perspectives, and can help with the application of knowledge, e.g. implementation or scale up and spread."

MRC funded Principal Investigator

Considerations

Inclusive research is an emerging priority across the health research funding landscape, with, for example, Wellcome and NIHR prioritising their understanding of the principles and methods of inclusive research [14]. NIHR have recently published an agenda for action to promote health equity and reduce health inequalities through greater inclusion in public partnerships [14]. Adding to this collective effort and supported by emerging evidence and publications, the MRC should consider and communicate clearly how public involvement can support an inclusive research agenda.

5.2 Complementing the MRC's EDI Strategy

Findings

Synergies with the MRC's EDI strategy are a positive. Public involvement can be a significant asset in supporting EDI culture and practice across the funded portfolio.

During this work, members of the MRC EDI Forum were encouraged to consider how involvement could interface with and support EDI, and there was interest and openness to this idea. Upskilling the MRC's social and cultural knowledge and competencies will have positive outcomes across the work of the MRC, beyond public involvement.

However, EDI is not the sole preserve of public involvement. Evidence from outside the MRC suggests that unrealistic demands are being placed on public involvement to address issues of EDI that are outside its sphere of influence (e.g. workforce diversity). EDI and public involvement strategies need to be clear in their resourcing, areas of responsibility and areas of synergy.

"Within every industry I've been in, the EDI strategy is often the responsibility of one person. They've been brought in especially. No heads roll at a senior level for it not happening. The strategy isn't resourced correctly, often it doesn't have a budget. There aren't objectives tied to it that are measurable or interlinked with the strategic objectives of the organisation. We do need to be doing things differently, it's very much a cultural piece."

Member, EAG

Considerations

MRC public involvement and EDI strategies should be integrated, synergistic and cross-reference each other. We have found that the NIHR's Race Equality Framework for Public Involvement [15] is a useful tool in identifying the actions needed for an organisation to address equity across its functions. The evidence-based approach offers a systematic method to understand race equity within governance, leadership, training and development and public involvement functions. The MRC could consider applying the Framework as a next step in the development of both its EDI and public involvement strategies.

"There are lots of similarities [of EDI] to involvement. It's about power. An organisation needs to acknowledge that."

Public partner, EAG

5.3 Enabling the involvement of people from all walks of life in the MRC and its research

Findings

"The people who volunteer for public involvement tend to be (like clinical research volunteers) of above average socioeconomic status and education. I have frequently met retired professionals including retired researchers volunteering in this capacity ... I feel there is a lot of fiction generated about how public involvement in research means we are representing our country's population and serving their wishes in terms of research priorities etc – it really, really does not."

"...also need resource to talk to relevant people, not the same already over-represented, well served groups who have the time and lucky position in life to get to these events. We need to access areas of greatest need."

Principal Investigator, MRC Establishment

Our review finds concerns about the lack of diversity of public partners involved in research and it is acknowledged in the wider sector that public involvement lacks diversity amongst its contributors (e.g. [16]; NIHR surveys of public contributors 2018 and 2021 [17]). Rather than this being a personal 'deficit' of public partners involved in research, evidence points to systems-based barriers within existing health, research and public involvement practices, which can exclude certain constituencies of public partners. For example, people with experience of racial inequalities and those from socio-economically disadvantaged backgrounds, feel less confident of being treated with dignity and respect in health research [18]:

"Not all members of the public are the same and any advice and support should explicitly consider the needs and interests of different potential cohorts."

Non-MRC funded Principal Investigator (UKRI funded, based in global south)

"That's not my world. I learned how to be there and how to be effective. What would it take for someone from a less privileged background to feel included and confident within this setting?"

Public partner, EAG

Leadership and staffing

Effective involvement needs to understand the needs of people first, to enable people from diverse backgrounds and life experiences to become involved. Opportunities should be made accessible and inclusive, taking into account circumstances, time to devote to involvement, levels of interest and skills.

Our findings and other evidence from outside the MRC also indicate that researchers and staff doing public involvement tend to be women:

"When no clear expectations are set, women are often disproportionately involved in public engagement initiatives. This is then seen as an unnecessary "soft" skill to develop and perceived as time spend unproductively."

Postdoctoral researcher, MRC Establishment

Considerations

The MRC should consider monitoring the characteristics of those involved in its work and research, as routine. Demographic data monitoring forms for this purpose are available. While some reservations might be expressed about the relevance and need to collect such data, it would be important in ensuring diversity of involvement. Ensuring diversity of those involved can also help address the red herring of lack of representativeness as a reason not to do involvement.

Targeted partnership with minoritised groups could support more diverse involvement. PEPs, and community organisations could be supported to do this through staffing and/or funding, including connecting with the recent community-led funding schemes of UKRI [19] and place-based initiatives, assets and infrastructure.

In supporting researchers and PEPs and working with the research culture agenda of the MRC, consideration should be given to how to redress the gender balance amongst those prioritising involvement and address gendered attitudes towards public involvement.

"[PPIE] tends to be seen as housework/women's work that gets outsourced by white male PI's."

MRC funded Principal Investigator, at a University/NHS Trust or other research setting

6 Recommendation: 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
- Support the strategy with adequate communications resource to visibly and consistently signal the MRC's approach to public involvement, internally and externally

6.1 MRC head office

Findings

"I did a bit of digging and was somewhat horrified by the lack of... patient involvement that was happening at the MRC ... I felt there was ... a sort of complacency"

Public partner

"If it's something that the office pick up more heavily we need someone with experience working alongside us doing it, rather than just expecting the program managers to pick it up as another part of their already massive workload."

Staff member, MRC head office

It's evident from our review that the MRC needs additional capacity and expertise to lead and deliver public involvement within Head office. Appendix 2: Case study D provides comparisons across similar organisations. The NIHR – an established sector leader in patient and public involvement for clinical and applied health research – employs public engagement and involvement practitioners centrally within each of its coordinating functions (e.g. NIHR Central Commissioning Facility, NIHR Evaluation Trials and Studies Coordinating Centre), a distributed network of Public Involvement Leads across their funded infrastructure, and a dedicated Centre for Engagement and Dissemination. They fund approximately £1.2bn research per year, with £1.7m per year funding the CED, plus investment in providing regional public involvement advice through the NIHR Research Design Service.

On a smaller scale, Parkinson's UK prioritises public involvement across both non-clinical and clinical research and funds £8m research per year. Parkinson's UK has two full time public-facing involvement staff, and involvement in funding decision-making is embedded within grants management roles.

Leadership and staffing

CRUK funds approximately £443m research per year. Patient and Public Involvement is delivered by 6 Head office staff members, working alongside a national team of 15 research nurses. There are PPI leads and practitioners within all CRUK major infrastructure.

Within the MRC, accountability for public involvement sits with the Director of Policy, Ethics and Governance who acts as a conduit between the MRC Executive Board and PIPOG. Similarly, the Director of Strategy is accountable for public engagement, and chairs the MRC Public Engagement Oversight Group.

The model of a senior involvement practitioner(s), working with senior management personnel and – importantly – with public partners can equip a major organisation to embed public involvement in its strategic operations. This way of working also reflects an approach to EDI within organisations. The devolved nature of PIPOG functions well to bring insights from across MRC head office, and this way of working could be continued to support the development and implementation stages of any involvement strategy.

We agree with the recommendation made within Jamieson and Leslie's report [8] to strengthen senior leadership through representation of public involvement expertise on MRC Council and to establish public involvement with research as a core part of an executive MRC role. Learning from across the sector shows that an essential element of leadership resides in visibility and advocacy for public involvement at all levels. Additionally, all MRC head office staff should be able to articulate why public involvement is important to the MRC, what this looks like in practice and their role within it.

From the findings we have, there is openness to involving public partners within the highest level of decision-making at the MRC and overall a sense that the MRC Council and senior head office staff are supportive of involvement as *"it's the right thing to do"*. Senior leaders at the MRC have also said that MRC should *"not lose the PI (public involvement) within the PE (public engagement)"*.

Senior leadership, representation and advocacy are essential for success. The most important outcome is that public involvement continues to be embedded within MRC's work and research, and that changes do not inadvertently support tokenism for involvement. We recommend that in addition to senior staff, the MRC involves public partners at the highest levels of decision-making within the MRC.

Considerations

The remit of a new senior role, with responsibility for involvement strategy, innovation and delivery might include:

- Being a conduit to MRC Executive Board and secretariat of PIPOG, connecting to other parts of UKRI, other funders, and representing MRC's leadership in public involvement externally
- Coordinating work with public partners and the EAG at senior levels within head office
- Planning and delivering the co-production of MRC public involvement strategy
- Establishing and leading an MRC community of practice (see Recommendation 7)
- Strategic input into high-level communications plan
- Strategic mapping of involvement needs and resulting expectations across MRC head office and funded portfolio
- Influencing and supporting head office colleagues to involve people and patients
- Collating and signposting to existing guidance for public involvement
- Co-producing MRC public involvement Learning & Development plan and commissioning providers and overseeing implementation.

Given the scale of the MRC in terms of staffing, funding recipients and the funded portfolio, we recommend the MRC brings in additional public involvement practitioners to maintain momentum and enable change in culture and practice in a well-supported way. The support needed will depend on the defined level of ambition and available resource, and decisions about the investment in a network of PEPs and setting expectations for how PEPs/Establishments support strategy implementation.

To achieve a new vision for public involvement, the MRC will need to support change through strategic, consistent and targeted communications activity, both internally and externally. This investment is needed to implement most if not all recommendations within this report.

Priority communications activity will include defining MRC's unique commitment to public involvement with their work and research, and strategically mapping the communication needs and audiences, and key messages, some defined by this review. Further thinking on this is available on request.

We recommend involving public partners in understanding communications channels, clarifying messages and co-producing communications materials.

6.2 MRC Establishments

Findings

Several case studies in the scoping review and wider literature demonstrate how a specialist facilitator and/or practitioner enables meaningful involvement. Our findings strongly support this, demonstrating researchers' needs for both expert advice and logistical support.

A logical and cost-effective approach to support involvement within MRC Establishments – complementing researcher learning and support – is to invest in upskilling and supporting the existing public engagement and communications practitioners (PEPs) within MRC settings to develop their skills in, and facilitation of, active involvement. This complements the synergies of involvement and engagement agendas and practices. The researchers and PEPs within MRC Establishments we spoke to had much more experience of engagement than involvement. Their experiences are clearly linked to the culture of research in which they were based, and therefore a greater value placed on public involvement would have an impact on their roles.

PEP roles in the wider landscape are often precariously and often only part-funded, and the demands on them are usually high. For PEPs in MRC Establishments the dual role of communications and engagement can limit capacity for building relationships which are essential to success. Recently, we find evidence that many PEP roles across the sector are expected to deliver on EDI agendas, without any additional resource or support.

"I don't think that you can emphasise enough to the MRC that having a PE manager and professional PE people involved makes this work. The scientists are getting involved, but do not have the time to drive it forwards."

MRC Senior Research Fellow

"These roles are stretched as 'everyone' looks to you and wants you to deliver involvement on their behalf."

Public Involvement Practitioner

Considerations

There may be opportunities to increase the number of PEPs within the MRC funded portfolio to scale up MRC's involvement in a more distributed model. This could potentially be done with other funders and/or institutional partners, for example, through co-funding of PEP roles.

Based on our findings, and experience of mentoring PEPs within Wellcome Centres and NIHR, considerations for these roles are:

- **Autonomy and seniority** – PEPs need an understanding of the MRC Establishment's strategy, and autonomy to direct engagement and involvement work to meet the needs of the research/ Establishment. This is particularly important during periods of change.
- **Senior backing and advocacy** from e.g. MRC Establishment Directors/Heads of Department is essential for success.
- **Workload considerations:** refining roles to provide greater focus, ability to prioritise engagement and involvement work and a manageable workload. This might include:
 - a) increasing the number of PEPs and/or public partners linked to MRC Establishments
 - b) Providing PEPs with access to both research communications* and administrative support, and removing this from their role

We support the recommendation from Jamieson and Leslie 2022 [8] to uncouple communications from the existing MRC PEP role. This reduces workload but also removes the possible tension between involvement – listening and responding to a breadth of views about research – and research communications, which tends to be both 'one-way' and function to 'promote' research.

*Please note that we would advise communications specifically with public partners/ audiences about involvement to be maintained within PEP roles.
- **Connection and networks** – Close working relationships with other PEPs in host institutions and local communities.
- **Ongoing peer support and learning.**

**“There is no-one
with expertise
who I can ask.”**

MRC funded PEP

7 Recommendation: 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

Findings

Overall, around 90% of survey respondents had some experience of public involvement. Notably, there is a stark trend suggesting that public involvement happening within research is much more prominent outside of the MRC/ MRC funded portfolio.

We acknowledge that whilst our survey respondents show a breadth of demographics in terms of research area, seniority etc. that they are a self-selecting sample who are likely to be more interested in contributing to this review, and they are therefore more likely to have strong views about public involvement.

7.1 Building on the knowledge, experience and confidence of MRC head office staff

Findings

28% of MRC Research Programme Managers have experience of doing involvement, and the majority (58%) described themselves as having some knowledge of involvement but no direct experience. Examples of involvement within MRC head office and the funded portfolio are provided in Appendix 5.

Skills, learning and development

Around half of MRC head office staff who completed our survey have experience of doing involvement both outside of, and within the MRC. However, MRC head office staff feel significantly less confident about involving the public than researchers and public engagement professionals. Notably, there has been a positive shift in the knowledge and confidence of the MRC Project Team and PIPOG throughout the process of this landscape review.

Two thirds of Research Programme Managers said that they would do public involvement if training and support was provided for them, and the preferred methods of support were training (78%), case studies and resources (59%) and a community of practice (59%). Half of the Programme Managers would also welcome a portal to connect to people and patients.

Considerations

We recommend the MRC develop and mandate staff training about involvement and what it means for the MRC. This should draw on existing resources (see Appendix 7) and address the major findings from this review. Where MRC staff and external panel, Board or Council members are actively involving patients, e.g. within grant funding committees we recommend additional professional/ one to one support is provided. This will be especially important for Chairs. Learning from the GECO funding initiative [20], in which public involvement practitioners and public partners were involved in funding committees, will be important in this regard.

Our analysis of good practice in this area dictates that training, learning and development about involvement is co-produced and co-delivered with public partners and involvement specialists. Examples in the scoping review for this project provide fertile ground on which to build.

In our experience – with some introductory knowledge and processes/policies in place – the best way to develop involvement skills is to learn by doing. Learning is enhanced if evaluation and reflective practice is built in. Working reflectively is taking time to consider experiences and actions, what worked well, and what you would do (differently) next time. It is also useful to ask about and reflect on others' experiences.

The MRC could draw on internal expertise to support a learning by doing approach, such as from staff with experience of working in/with overseas settings with long established practices in community engagement, the Adolescent Mental Health Team, which was described as 'revolutionary' by a member of MRC head office staff, and future role modelling from leaders in public involvement including PIPOG, and newly recruited professional involvement staff.

Skills, learning and development

There is also an exciting opportunity for the MRC to take a leading role in the development of a learning portfolio about involvement in non-clinical, basic and big data science. Our review finds a 'gap' in the wider sector market related to training and development in this area. While there is a good selection of training courses for involvement in clinical research, relatively little exists focused on non-clinical research. The PPI Ignite Network, Ireland ([20] funded by the Health Research Board and the Irish Research Council), of which 2 members of the EAG advising this review are members, is planning and developing a training programme in this area. There exists strong potential for collaboration.

7.2 Building on the knowledge, experience and confidence of MRC-funded researchers

Findings

"We need to recognise that PPI isn't a method and relies upon relationship building, collaboration. Those types of skills have value. Is there fundamentally a tension between the "hard" skills seen as necessary for research, methods, academic rigour, frameworks etc and the so called "softer" skills necessary for PPIE?"

Public partner, EAG

"Reflection is key in all of this, and that can be hard [for researchers]"

Researcher, EAG

As described in Section 2.3, we found a lack of comprehension from some non-clinical researchers about what non-scientists could offer to their research. Researchers and research staff tended to assume that any input from public involvement would be focused on research methods and, as members of the public didn't have that specific knowledge, their contributions would not be useful. Many are also unaware of existing learning and development opportunities.

"I've been thinking about past studies that I've done and I just honestly don't know how I would have got any kind of public involvement that would have been able to shape it...I don't think, for example, that involvement, would be able to advise on the methodology."

Researcher, MRC Establishment

"How do we train our young PhD researchers that leadership is more than just leading good research?"

Staff member, MRC head office

Skills, learning and development

Our survey and workshop findings show that learning and development in involvement would be welcomed by researchers, with preferences for a Community of Practice, and one-to-one support from a specialist in public involvement.

"I feel that PE/ PPI training should be available to all researchers and make the training mandatory if you want to include as many researchers as possible in PPI."

Research Manager or Administrator, MRC Partnership Institute

Our experience indicates that there is often a very rapid transition once a researcher starts doing involvement. Several of the EAG members shared experiences where once researchers start involving people, they quickly become advocates, often significantly changing their research plans and typical ways of working. This mirrors research [e.g. 21] that demonstrates the positive impact that public involvement can have on researchers, including after initial reticence, and is sometimes accompanied by a revelatory 'aha!' moment as to the value of public involvement. Providing learning and development opportunities in involvement at early stages of a researcher's career can support the culture change and reflective environment needed both for public partners and researchers to flourish.

Considerations

In implementing learning and development for researchers, we have identified particular skills and attributes that are important:

- Understanding the value of public involvement as a key element in the research environment rather than as a distinct part of the research cycle (see Section 2.1)
- Developing reflective practice generally, and as applied to involvement
- Understanding and implementing public involvement as a function of research context and involvement purpose
- Effective planning for public involvement
- Understanding how to assess (evaluate) the difference that public involvement can make
- Relationship building, collaborative working
- Communication skills
- Creative and inclusive facilitation skills

Learning and development in involvement should be a consideration of the research career pathway, encompassing culture, structures and training. Some researchers who are already doing involvement would benefit from additional support from the MRC. They prioritise funding, which they indicate would be best spent on salary costs for a public involvement coordinator/practitioner within their research programme, in addition to their own capacity development.

Skills, learning and development

7.3 Building on the knowledge, experience and confidence of Public Engagement and Communications Professionals (PEPs)

Findings

Confidence for involvement is greater in public engagement professionals (PEPs) who are not funded by the MRC. 9 out of 17 MRC funded PEPs feel confident to involve the public, whereas 4 responded that they don't feel confident. Only 3 PEPs said that they don't know where to begin with public involvement. PEPs who are not MRC funded feel confident to involve the public (at 85%), with 2 responders not answering.

"I think I need support and guidance, and advice on how best to get involvement as something that happens at my Institute and make the case for it and have it supported and resourced."

PEP, MRC Institute

MRC PEPs in our review expressed a need and a willingness to develop greater understanding about involvement practice and how involvement approaches could interact with and build on some of the engagement work happening within MRC Establishments. PEPs also requested clear sources of guidance that they could use to advise and share with researchers: currently they look elsewhere for guidance on involvement (e.g. NIHR).

"I think just having an online one stop shop of guidance...it'd be really nice if the MRC could work with the other funders in the UK and just say look here are all the resources in one place and cross link it."

PEP, MRC Establishment

PEPs expressed an ambition for closer working with communities and research participants in planning research and relaying results. Similar to researchers, involvement in non-clinical research was perceived to be more challenging than other research.

PEPs have a good understanding of the opportunities and challenges within their own locations and express some frustration at the lack of value placed on their roles. They – and others – would benefit from developing a community of practice with other similar professionals in other locations.

"We need greater support for public engagement professionals. We are often forgotten both from a funding and supporting research perspective. We have experience and knowledge, help researchers see how we can help."

PEP, MRC Establishment

Skills, learning and development

Considerations

We recommend the MRC invests in PEPs as individuals and as a network. This includes:

- Increasing the number of PEPs per Establishment/ by percentage of funding
- Increasing skills and confidence in public involvement, generally, and with non-clinical research
- Refining PEP roles as described in Section 6.2
- Considering how a network of PEPs might support co-development and delivery of the MRC's involvement and engagement strategy

Mentoring is reviewed as part of Jamieson and Leslie's work [8] and there is an opportunity to build on this, potentially in collaboration with existing initiatives, to include mentoring in public involvement for MRC PEPs.

Given the research funding landscape, and the timely interest in involvement in non-clinical research, the MRC could consider collaborating with other funding organisations to fund and/or support PEPs.

Our findings across all MRC constituencies, and externally, demonstrate the value ascribed to developing a community/ies of practice as a mechanism of learning, support, innovation and delivery. We recommend the MRC builds on its existing PEP network and works with them to co-develop this community and its remit.

PEPs could also support a wider community of interest and practice, including public partners and researchers, and drawing on existing public involvement infrastructure, to deepen learning and practice related to involvement in non-clinical research, connect with local community and voluntary sectors, and contribute to effective grant-making. Several contributors to this report (individuals, networks and organisations) have expressed interest in membership.

"I think there's a long way to go, for everybody, it's not something that [only] we struggle with so that's been quite reassuring."

PEP, MRC Establishment

7.4 Building on the knowledge, experience and confidence of public partners

Findings

It was encouraging to hear that public partners in some MRC research generally reported good experiences of involvement. Most had experience of involvement within individual projects or Centres/Units rather than at a governance or strategic level.

"That has been for me an absolutely standout example of collaboration and engagement between scientists and the public. They, right from the outset, got the... community actively involved, pulled people in for annual meetings, went to our meetings and talked about what they were doing."

Public Partner, MRC

They reported feeling valued in the relationships they had developed with researchers and research teams and felt privileged to be part of MRC activities. Where research programmes had been designed to involve the public from an early stage, this was highly valued by contributors.

"We were involved at every single stage and we felt like our opinions were heard. We were even able to be a part of the interviews and we were asking the questions. In the discussions afterwards they actually considered our opinions when deciding which proposals to take through, so I felt like we were really heard. And we never were made to feel like 'Oh, you know just because you're younger your opinions don't matter' It felt like it was really important what we had to say, and I thought that was amazing."

Public partner, MRC Programme

However, it is also clear that, perhaps at more strategic/governance levels, and including in the wider non-MRC landscape, it is hard for public partners to integrate public involvement into settings where it is deemed difficult.

"We never were made to feel like 'Oh, you know just because you're younger your opinions don't matter.' It felt like it was really important what we had to say, and I thought that was amazing."

Public partner, MRC Programme

Systems and processes

Some public partners who contributed to the review felt that their previous professional work experience enabled them to be involved even if the topic or area wasn't directly related.

"I've retired now but my background is in the pharma industry... with that background I find that has been really helpful to me to understand what is going on in meetings and I really enjoy what I do for the MRC."

Public partner

Some public partners felt that they could be involved in additional areas of research:

"I'm itching to see the results of this stuff the scientists, not unreasonably, love talking about what they're doing, what their hopes are for the future and that's fantastic, but actually I'd like to see what they've done. And that means that somehow, I need help understanding the publications, understanding the results and it's often quite difficult to access that. It is difficult for non-specialists to access that information."

Public partner

Through our workshops, they identified areas for improvement, including:

- Clearer opportunities and expectations of involvement
- How meetings are run to be more inclusive of public partners
- More time to prepare for their involvement, ask questions and seek clarification
- Explanations about the structure and complexity of the MRC, its systems and processes, as it relates to, but not confined to, involvement
- Greater clarity around terminology and acronyms.

A public partner member of the EAG explained the 'gain' to be had by being involved in non-clinical research, which offers useful context in understanding and communicating the difference that public involvement can make to public partners:

- *"Knowledge of how science is carried out"*
- *The nature and practice of non-clinical research*
- *Information about the latest developments on a condition*
- *Confidence that an organisation is addressing equity*
- *Increased feelings of trust towards an organisation"*

"We were making it up as we went along, trying to get them [researchers] to take the public views on board"

Staff member, MRC head office

Considerations

We recommend that the MRC significantly develops its support for public partners by:

- Being clearer – on its website and in more general communications – about the vision, values and practical opportunities for public partners to become involved with the MRC
- Co-developing an induction pack and processes for public partners. This could include information about the MRC as an organisation, what to expect of involvement, training opportunities and beyond
- Considering buddying schemes and peer learning networks, as part of learning and development opportunities for public partners
- Deepening and sharing its learning about the difference that public involvement can make (the 'gain' for public partners)
- Recognising and acknowledging that public partners are more than their life experience and are worthy of investment

There is an opportunity to build on the good will and experiences of current public partners in MRC research to support the co-development of learning and development for MRC staff.

“In the global ‘up-or-out’ system of academic science where research output is the primary measure it appears impossible to dedicate time for anything else.”

Postdoctoral Researcher, MRC
Partnership Institute

8 Recommendation: 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

Some examples of involvement in MRC work exist (see Appendix 5); however, where involvement has happened at MRC head office, the systems, and lack of processes have been constraining.

“So I’m five months down the road from that panel and some of them [public contributors] still haven’t been paid because arguments about what was the value, why did you agree, why did you do it blah blah blah so actually the organisation as a whole is not exactly encouraging this.”

Staff member, MRC head office

Within MRC head office the current lack of guidance related to involvement can be problematic, with some urgency expressed by staff members who are struggling to advise researchers about involvement. They cited this as having a negative impact on research. Given some areas of MRC research sit alongside highly vocal patient advocacy groups, there is also potential reputational risk for the MRC within these situations.

The Research Programme Managers’ Forum selected ‘practical barriers’ e.g. MRC systems and processes as a bigger barrier to public involvement than time, or know-how (33%, 14%, 24% respectively, please note these are not mutually exclusive answers). Within staff interviews, several examples were provided where Programme Manager staff were finding ways to involve people despite not having systems or processes in place.

“Through resource, how can MRC demonstrate that involvement is important and valued?”

Member, EAG

8.1 Finding the time and resource

Findings

Time is an acknowledged barrier/enabler to public involvement, which is supported by findings from our review. From speaking with researchers, and MRC head office staff, this is the most urgent issue to resolve.

Researchers feel under pressure, and the MRC should be aware that additional requests or requirements might be met with resistance, which in itself could be damaging to the perception and conduct of public involvement.

"Time and space to do this the hardest thing."

Principal Investigator, MRC Establishment

Our survey data show that dedicated time for public involvement was the most selected factor in encouraging more public involvement, with 49% of respondents selecting this option. However, only 20% of all researchers/staff working in research environments selected the option that they would do or support public involvement if they had more time. This suggests that whilst dedicated time is an enabler of public involvement, there are other issues to resolve in encouraging researchers to do it.

"Recognition of time trade-offs. We cannot be asked to do everything and do everything at world-leading quality. Ideally without funding."

Principal Investigator, MRC Establishment

"One of the difficult things at my research Institution is that the MRC funded scientists have very little time to take on PPI beyond the scope of their current work."

PEP, organisation/facility or network associated with the MRC

Systems and processes

Researchers point to the need to remove other responsibilities in order to encourage public involvement and to take a view (endorsed by this review) that encourages a more holistic approach to public involvement and engagement:

"I would like to note that I already suffer from a workload that requires far more than contractual hours and therefore I ask you to consider how I should be expected to add yet more to that workload? The most realistic way to 'encourage' me to take part in PPI is actually to relieve me of other less important responsibilities or duties to make space for this new one. I don't regard 'dedicated time' as sufficient for this given my current situation – it sounds like it would simply occupy some of my contractual hours and displace further activities to outside hours."

Head of Department, MRC Establishment

Similarly, we find that PEP roles are overstretched, and we note the finding from Jamieson and Leslie [8] that, due to short turnaround times, communications activities are often prioritised over engagement work. As the expectation for public involvement increases, this will require a greater investment of PEP time.

Conversations with MRC head office staff have also raised issues around time. The estimated amount of time required to establish public involvement within a funding scheme was estimated to be double the time than without public involvement. Research Programme Managers felt that time and resource was crucial for success.

Linked closely to considerations of time and staffing capacity, access to funding was the second most popular survey choice relating to supporting public involvement across MRC's funded portfolio. This was selected by 40% of researcher respondents when selecting 4 of 12 options of what would encourage you in public involvement.

"I think without question that funding is the most critical element. However, the funding support for this work is very limited, and with recent strategic changes at Wellcome, appears to be getting smaller. This is an opportunity for UKRI to lead and set a huge example by committing resources to this as a priority, not a nice to have/add on"

MRC funded Head of Department

"The big problem for me is that funders in my world (NIHR) expect it, and will pay for it in a grant (payment for involvement once you get going), but are less keen to pay for the required infrastructure to make it routine (a PPIE coordinator working across multiple studies). It is transformational to have that kind of infrastructure in place (which we now do but funded from a very large commercial programme grant, so not clearly sustainable in the long run). Different possible models for this, but I don't need expert advice, I need resource to support public partner recruitment and support."

MRC funded Head of Department

Considerations

We recommend that the MRC makes provision for researchers to have ring fenced time per year for involvement. This could include through building in time and resource as part of funding applications and/or terms and conditions of Establishments.

Public Engagement Professionals (PEPs) can play an important role in addressing time pressures and supporting involvement as part of Centres, Units and MRC-funded programmes and projects. MRC should invest in increasing the number of PEPs, and in their learning and development for public involvement (Section 6.2, and 7.3).

PEPs could also support a wider community of interest and practice, including public partners and researchers, and drawing on existing public involvement infrastructure, to deepen learning and practice related to involvement in non-clinical research, connect with local community and voluntary sectors, and contribute to effective grant-making.

Finally, given that public involvement in research needs to respond to a changing public landscape, the MRC should offer a greater flexibility in its funding to promote research and innovation with public involvement. This might be achieved by widening out the existing public engagement seed funding to support involvement, influencing the Medical Research Foundation Policy and Practice funding, or providing additional funding linked to MRC awards in a similar model to the Wellcome Trust Research Enrichment schemes.

8.2 Setting funder expectations and guidance

Findings

Building in a requirement for public involvement within grant applications is undoubtedly a lever for change. This is supported by our scoping review, and findings from interviews and workshops. Yet we've also heard that researchers feel overwhelmed and time poor to establish involvement within their work. Our survey findings demonstrate building public involvement into funding requirements was selected as the least encouraging factor for researchers/ those working in research environments, selected by 15% of respondents (selected 4 of 12 options). The MRC needs to use this awareness to inform any future decision making about if and how to set funding expectations for researchers, and acknowledge how researchers feel within any communications for research audiences. Several funding organisations have described using maturity models for changing expectations which are described below.

"Making it an essential component of a research grant application only works if there is clear evidence for applicants that it genuinely impacts on the funding outcome. Otherwise it breeds resentment at the requirement to do it for those who are not willing, frustration for those who put effort into it but see no reward for having done so, and ultimately devalues it. There should be an expectation to include it where is/can be appropriate / integral and opportunities for additional linked funding for less integral PE post research grant award."

Principal Investigator, organisation/facility or network associated with MRC

Systems and processes

Additionally, we've heard from members of PIPOG that would like to see the culture and practice of public involvement change because researchers can see the added value it brings, rather than doing it because they've been told to.

During the review, considerations about the perceived difference in involvement with non-clinical to clinical research have been applied to how to tackle funding requirements, and MRC head office staff have questioned how this could be adopted to 'business as usual'.

Other funding organisations who fund across both non-clinical and clinical and applied research have differing approaches to expectations for public involvement within grants (see Appendix 2 – Case Study D). CRUK has an overarching statement of intent, yet only requests PPI plans explicitly within clinical and applied research applications. However, funding is available for involvement in all CRUK funded research, and public involvement within discovery research is an area of development for CRUK and therefore strongly encouraged and set to increase.

Parkinson's UK has a more universal approach and is actively working on supporting public involvement in lab-based research (see referenced toolkit). It adopts an expectation for involvement across all project grants – which fund both non-clinical and clinical – but does not set this expectation in one other specific grant scheme, the Drug Accelerator Awards.

From what we know, the Wellcome Trust expects clinical researchers, and global health researchers to involve people and patients where needed, but there aren't standard expectations for non-clinical research grants. However, with a long history in funding public engagement, Wellcome is attuned to the needs for public involvement and engagement for the themes and topics identified by this MRC brief. This is exemplified by (co-)/funding programmes including Understanding Patient Data, Human Development Biology Initiative, Animal Research Nexus amongst others. It's noteworthy that the Wellcome Trust has recently closed down all standalone funding schemes for public engagement.

Finally, and relating to MRC's grant systems and processes more generally, interviews with MRC head office staff show that current processes limit awards to academics/ research-related organisations only, and that the timescales and nature of project-by-project grants can constrain relationships with public and community partners, and limit their diversity.

Considerations

Drawing on the opportunity for MRC to demonstrate sector leadership in involvement with non-clinical research, and our findings of misconceptions and the 'stereotyped PPI', we recommend that the MRC explores the potential to build consideration of involvement as standard into all funding programmes. Whilst this might be considered radical, it demonstrates the importance and value that MRC places on involvement, and the UKRI/MRC commitment to public involvement. It also enables clear and consistent messaging and addresses the misconception that public involvement is not relevant for non-clinical research. Importantly, this approach wouldn't mean that all researchers involve the public, but they would have to consider if and why involvement is needed. This recommendation supports and builds on the recommendation made by Jamieson and Leslie, that consideration of public engagement with research should be built into all funding programmes.

An alternative option, similar to that of e.g. CRUK, is drawing on the commitment to public involvement as a statement of intent, with MRC setting different expectations for public involvement across funding schemes. There are pros and cons to each option, however, the evidence from other funders suggests that this approach would not lead to the increased adoption of involvement in non-clinical research sought by the MRC.

In either case, MRC funding guidance should draw on the examples within this review to describe areas of non-clinical research where public involvement is a priority, and importantly, why. This might include the priority areas within this brief such as big data, animal research or stem cell research, where there are unresolved/ rapidly changing societal issues, high interest or contention. We recommended a collaborative approach to writing grant guidance, involving researchers, PEPs and public partners.

Clearly, *how* public involvement expectations are implemented and communicated plays a significant role in ensuring success, and there are both cultural and practical elements of change which are essential before a requirement is mandated.

In discussion with the MRC Project Team and the EAG, and learning from the experiences of other funders, we recommend a maturity model to introduce public involvement requirements into funding programmes. The MRC is keen to learn by pilot and review and we think this could be a helpful approach to guide a maturity model which is universal in the longer term. The learning here will be useful in establishing funding processes, understanding researchers' needs, and developing involvement practices.

Systems and processes

Steps might include:

- a) Addition of a public involvement question into all funding applications, supported by guidance and resources. The question is not assessed.
- b) Following a set period (circa 2 years), the involvement question in all applications is assessed but the funding decision is not contingent on this assessment.
- c) Following a set period (circa 1 year) full maturity: In all applications, the public involvement question is assessed and poor public involvement plans – where involvement is considered a priority – is a case for rejection, or for further support to improve.

A key question for consideration by the MRC is whether grant applications should be rejected because of absent/poor quality practice. We would suggest that, at least in the first years of implementation, that the MRC has capacity within head office public involvement professionals and/or programme management staff to provide support and signposting to grant applicants where the public involvement plans are poor or absent.

Expectations and guidance should be communicated to the research community throughout, with signposting for training and support provided.

Finally, we recommend amending grant application processes to enable (co)applicants from non-academic institutions, e.g. community organisations, and building in flexibility and longer funding timescales to enable researchers/applicants to build and maintain long term relationships with public partners. This approach is being actioned currently by UKRI, and recommended within the recent Young Foundation report [1].

8.3 Funding assessment and decision making

Findings

The majority of examples of public involvement from MRC head office staff we spoke with were in involving people and patients within grant decision-making. This was often within strategic programmes outside of 'business as usual' or through working in partnership with other funders where public involvement is more commonplace e.g. NIHR. Staff perceptions of the quality of involvement in funding assessment and decision-making, and the difference it makes, are that it differs greatly across the MRC's practice. The example of the Adolescence, Mental Health and the Developing Mind programme demonstrates significant impact on all constituents, with reflective practice and continuous improvement embedded in ways of working e.g. in improving guidance for lay summaries to be reviewed by young people. However, we heard other examples where MRC head office staff found involvement in grant decision making to be tokenistic, with unclear guidance and processes. MRC head office staff gave examples of being unsure of how best to handle disagreements between public partners and academic experts within funding committees, and also their fear of this happening in future.

"How do you tension across views of 'experts' vs lived experience experts?"

Staff member, MRC head office

Systems and processes

The MRC was a lead partner on the Global Effort in COVID-19 Health Research Programme (GECO) which involved both Public Involvement Practitioners and public partners in funding assessment and decision-making. The MRC could look to GECO's evaluation as a source of learning about the involvement of public partners in grant decision-making. Appendix 2: Case study E provides a detailed summary from Parkinson's UK detailing their best practice in guidance for researchers, and lay review, and involvement in funding committees.

Considerations

Within this review, our focus has been on the foundational elements required for the co-development of the MRC's public involvement and engagement strategy. As such, and drawing on the recommendations and considerations in this report, the MRC has steps to take before recommendations on funding assessment and decision making can be formed.

Drawing on the values and ambitions of the MRC, meaningful public involvement within funding assessment and decision-making will be needed and valuable for the MRC in maintaining trust, transparency, relevance and accountability. We envisage public involvement here to be more nuanced in approach, dependent upon the funding scheme, its societal context and the nature/content of the applications themselves. Further and ongoing work will be needed to explore this, alongside learning, confidence and culture change resulting from recommendations in previous sections.

Finally, examples were provided of, e.g. professionals such as Public Health Leads acting by proxy in funding committees as a means to consider societal/personal implications. MRC could consider working with internal public involvement staff and/or MRC funded PEPs to review and assess funding applications, and advise and support applicants with public involvement planning and implementation as appropriate.

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References contained in this report are listed below. Links to further useful reading, information and resources are provided in Appendix 7.

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Abbreviations

CRUK	Cancer Research UK
EAG	External Advisory Group
EDI	Equality, diversity and inclusion
HEI	Higher education institution
HRA	Health Research Authority
ISPOR	The Professional Society for Health Economics and Outcomes Research
NCCPE	National Co–ordinating Centre for Public Engagement
NIHR	National Institute for Health and Care Research
PE	Public engagement
PEP	Public engagement professional
PI	Principal investigator
PIPOG	Public Involvement Project Oversight Group
PPI	Patient and public involvement
PPIE	Patient and public involvement and engagement
UKRI	UK Research and Innovation

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MRC Programme Managers Forum
Michelle Bendix, Parkinson's UK
Anne Croudass, CRUK

VOCAL

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

MAIN REPORT

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**

VOCAL



Medical
Research
Council

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Foreword – Derek Stewart & Lynn Laidlaw, public partners

It was an absolute pleasure to be part of a team that worked in such a genuinely collaborative manner on this review and report. The willingness of the Medical Research Council (MRC) to accept and embrace this partnership approach enabled our enquiry into public involvement in non-clinical research to be extensive, thorough and ground-breaking.

Our findings clearly show that there is a significant amount of active public involvement taking place across the wider landscape of non-clinical research and within the MRC. It has been great to hear about such exciting, innovative and positive experiences. We have also listened to a variety of views and opinions of those who work for and/or with the MRC.

Our review identifies where more work needs to be done to strengthen public involvement within the complexity of the MRC as an organisation and across all MRC funded activities. Involvement is a key element of enriching the culture and practices of non-clinical research and we believe the MRC has an important role to play in leading this change. Our analysis addresses the subtle differences between public and patient involvement and invites alignment with public engagement and inclusive research.

There is much richness to consider in this review and hopefully the findings will assist public partners and researchers to come together and bring its recommendations into reality.

Thank you for the opportunity given to Vocal to be able to enquire, discover and report on such a potentially exciting area for the active involvement of the public and patients to work beside such a medically and scientifically important organisation.



Vocal was commissioned by the MRC (February–September 2022) to undertake a review of public involvement in research, with a specific focus on non-clinical health and biomedical research. This report aims to support the development of a new MRC public involvement and engagement strategy and to share findings with a wider community.

This work 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 involving people and communities in their work to increase trust and engagement with research.

The benefits and impacts of public involvement are broad, varied and extensive, especially where there is clarity of purpose. The evidence demonstrates that effective public involvement benefits research outcomes and culture, researchers, public and patient partners, policy and society. A summary of these benefits and impacts from the scoping review is presented in Section 2.2.

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 funded research culture, and research culture more widely.

Due to the breadth of MRC's research portfolio, from basic through to applied research, there are areas of high public interest and contention (big data, animal research, embryonic stem cell research) where mutual understanding, trust and transparency are essential for progress. It is difficult to see how the MRC would navigate these 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 funders.

Over the last year, UKRI and the MRC have made important commitments to public involvement. These include 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 clear principles, expectations, and good practice for public involvement and engagement in biomedical research, within the wider framework of the UKRI Public Engagement Strategy



Headline findings

Our analysis shows that 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. 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, enthusiasm and appetite for working with people across all research, including non-clinical research, MRC stakeholders consider public involvement to be important for improving research quality, relevance, transparency, and trust, and for 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**

Headline findings

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.



Summary of recommendations

- 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

Summary of recommendations

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

Introduction



Introduction

Our approach

The Vocal team, comprised of researchers, public involvement practitioners and public partners, led this landscape review to inform the development of the MRC's public involvement strategy. We achieved this by working with an External Advisory Group (EAG) of 8 people including public partners, involvement practitioners, scientists/researchers and representatives of research organisations. Our methodology is detailed in Appendix 1.

In this way, we modelled best practice in collaborating with public partners and the research community. The role of the EAG was to bring specific knowledge, understanding and experience to broaden the perspective within the project and to act as its critical friend. The membership of the EAG was diverse, including people from different ethnicities, ages, disability, socio-economic and professional backgrounds.

The Vocal team reported to the MRC's Public Involvement Project Oversight Group (PIPOG) monthly and worked closely with the MRC Project Team, meeting fortnightly. Our approach took account of the unique nature of the MRC, its challenges and opportunities, in order to identify the building blocks needed by the MRC towards a meaningful public involvement strategy. We carried out literature reviews, surveys, interviews, and several workshops including a co-production workshop with the EAG and senior MRC staff.

We were heartened, during this review, to see evidence of significant development in the outlook of staff within the MRC: we observed a growing language, enthusiasm and confidence for public involvement, and an acknowledgement that embedding public involvement in the MRC requires a degree of culture change. One senior MRC team member stated: *"We're considering [public involvement] as a mindset now"*.

The MRC is a complex organisation and structure, and therefore needs to 'walk the walk' at all levels in order to influence and support the research environment to involve people meaningfully. To improve research quality through involvement, the MRC head office, as well as their funded research community, need to work with people and patients to inform their work, assess the quality of involvement that comes in for funding, and provide leadership and advice to researchers and institutions.

Introduction

Terminology

Tackling terminology was an explicit part of our brief, and an urgent one. We use the following terms in this report and offer these meanings:

Public involvement in research refers to an active collaborative partnership between researchers and members of the public, patients, carers and/or communities, working alongside research teams and as part of research organisations. Members of the public, patients, carers and/or communities are actively involved in contributing to the research process and environment in a variety of ways.

This definition is based on several definitions of public involvement and indicates the contribution of public involvement to all functions within the research environment. It aligns with the co-created definition of public involvement within the UK Shared Commitment to Public Involvement: "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". Implicit in this definition is the understanding that productive relationships achieve most when they are clear on purpose, the mutual opportunities for learning, defined expectations and timelines.

Public engagement is used to refer to research being shared with wider audiences, to stimulate further interaction, shared learning and dialogue. Some organisations present engagement as a one-way process of informing the public about science, though many others define engagement as broader and all encompassing. We take the view that engagement and involvement can be mutually dependent, complementary and occurring on a spectrum. In this report, we focus on involvement as an active relationship and collaborative endeavour, and mention, where appropriate, synergies with the engagement landscape of the MRC and UKRI more widely.

Life experience includes experience of health conditions (often referred to as lived, or living experience), social, cultural and/or economic experiences, as well as experiences arising from marginalisation or inequalities (for example, people with experience of racial inequalities).

Introduction

Public partners are people that share their life experience, skills and ideas to help improve research and bring benefit to society. They may include patients, carers, advocates, service users, members of the public, and/or members of specific communities of identity, practice, belief, or geography. The term describes those who choose to be actively involved in a distinct partnership with researchers. Together they explore issues, take part in agreed activities and accept different tasks and roles. Public partners bring with them transferable life knowledge, experience and skills that is of added value, especially where there is an uncertainty or a decision to be considered. They may add:

- Different and external perspectives on a topic
- Alternative approaches to dealing with situations
- Creative thinking complementary to the creativity of science
- Skills and experiences gained from being involved previously in research
- Realism and practicality from all walks of life

Useful attributes for public partners to have or develop include curiosity and interest, skills of being part of a group or team, a willingness to seek solutions, and an ability for critical friendship and reflection.

Research environment describes and includes all the functions contributing to research including ethics, governance, funding, policy, engagement, communications, staffing including training and development, evaluation and impact.

Non-clinical research is the term we use as a shorthand for basic science, laboratory-based research, and research using data-driven approaches.

MRC Establishments refers to all MRC Centres, Units and Institutes.

We provide these definitions for clarity. Section 3 addresses terminology in more detail.

Introduction

Next steps

We recognise that our recommendations are several, complex and far-reaching. A next step is for the MRC to prioritise and refine them, including identifying where the organisation might work in partnership to make them happen. We also encourage the MRC to initiate further public dialogue soon after the submission of this report, to help to inform the next steps for developing the strategy.

Supplementary information

The headline findings and recommendations are also available in the Executive Summary.

Additional information and data from our review can be found in the following documents:

- 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



Recommendations, findings and considerations



Recommendations, findings and considerations

Our analysis of the components needed for the MRC's public involvement strategy follows. In each section, we present our headline recommendation, followed by the underpinning findings from our review and current evidence, with some additional considerations to support the recommendation.



“Walking the talk”: developing a vision and strategy for public involvement

1 Recommendation: 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

1.1 An ambitious vision for the MRC and public involvement

Findings

“Regardless of return on investment, it [public involvement] is the right thing to do.”

Staff member, MRC head office

“The MRC has one of the least prominent public involvement and engagement strategies of anywhere I have worked. It would be great if this could be done more – but this also feels like a bit of a stretch.”

Staff member, MRC head office

“I think MRC talks a lot about how this [public involvement] is important but doesn’t really do anything to formally encourage or facilitate public involvement, or engage with the public itself, or create actual opportunities to involve its researchers with the public.”

Principal Investigator, MRC Establishment

In order to develop an effective strategy for public involvement in research, the MRC needs to be clear in its vision and ambition for working with people. We found that a clear and enthusiastic appetite for working with public partners in research exists. However, there is also a perceived lack of ambition and practice, along with confusion about the aims, purposes and practicalities of public involvement. In some places, we found active resistance to public involvement.

“When you involve people in research it’s not [about] method. Essentially, it’s about conversations and relationships and collaboration”

Public partner, EAG

“Walking the talk”: developing a vision and strategy for public involvement

We heard:

- Differing conceptions about the nature and purpose of public involvement
- Beliefs, amongst research constituencies, that public involvement is not relevant or possible in non-clinical research
- Questions about legitimacy and methods arising from uncertainty as to the value of life experience alongside scientific evidence
- Uncertainty about how much to collaborate, for example with other Research Councils

We have heard of the risks to research associated with *not* having a clear vision, understanding or practice of public involvement. Although very much in the minority, examples (from outside the MRC) include research programmes not reaching their objectives, attributable in part to lack of (effective) public involvement; and the conduct of public involvement being misplaced, inappropriate or potentially harmful.

Considerations

Drawing on our review, we propose that the MRC develops a long-term vision about working with people, along the lines of:

Effectively building trust and sharing decision-making with the public enables the MRC to achieve research excellence, social value and health equity as an open and democratic organisation.

This chimes with the UKRI Public Engagement Strategy, due for publication in the coming months.

**“MRC [Head office]
needs to walk the walk
as well as talk the talk”**

Member, EAG

Purpose, motivations and context for public involvement

1.2 A co-creation process

Findings

In addressing what the MRC is working towards in its public involvement, what makes it distinctive and where it fits in the wider context, we have found that the process of developing a strategy is as important as the strategy itself. The approach of this review in modelling integrated public involvement has been pioneering in this regard and has arguably opened up MRC perspectives around involvement.

"It'd be very easy for us to get our reports from Vocal to get all excited and start doing what we always do. [...] But if we're going to try and take some of the learning that we've had from this journey with Vocal I think we need to really think about how we involve our own people but also how public contributors could be involved, so that we actually start role modelling, as really Vocal role model for us now, this could look and feel different...I think it could be very important from a cultural perspective."

MRC PIPOG member

Further, co-creation of public involvement strategies, with those for whom the strategy is most relevant, is an accepted and demanded approach in many spheres. For example, NIHR expects public involvement strategies within its funded infrastructures to be co-produced with patient partners; the International COVID Data Alliance recently involved public partners across the globe in its public involvement strategy. Co-produced strategies are increasingly routine within cultural, civic society and health sectors.

Considerations

We recommend that the EAG model formulated for this review is maintained by the MRC and continues to play a co-leadership role in the development of the MRC's public involvement strategy. The EAG may benefit from additional or different membership, but should maintain a majority of public partners, across a diversity of life experiences and background (as in the current EAG). More widely, the strategy co-development process should be open and transparent, and is an opportunity to communicate and build interest, involvement and support across all stakeholders.

Beyond the iteration of the strategy, there is an important role for the EAG in holding the MRC to account for its public involvement strategy.

Purpose, motivations and context for public involvement

2 Recommendation: 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

2.1 What is the purpose of working with people in research?

Findings

Our review shows that public involvement addresses a range of purposes defined by context and the needs of research, researchers, public partners, and other staff. Having a clear purpose enables public partners and researchers to capture the benefit of involvement and describe it for others.

"Essentially [public involvement] is a values-led way of working that's fluid and adaptable to different contexts."

Public partner

"When you involve people in research it's not [about] method. Essentially, it's about conversations and relationships and collaboration"

Public partner, EAG

"We shouldn't be simply sharing our research with each other – we are funded by society and accountable to society. The last two years have made clear what happens when there is distrust in science and in the scientific process."

MRC funded Head of Department

Purpose, motivations and context for public involvement

The statements above illustrate our wider findings around the need to avoid tokenism, and the 'stereotype' relating to the term PPI (patient and public involvement) in which involvement always requires a patient or health experience. Our findings invite us to reframe the approach as *public* involvement and consider the breadth of motivators and purposes to include:

- **Rigorous and democratic oversight, open to challenge:** e.g. inviting experienced public partners onto a governance, funding or decision-making committee.
- **Shared creation of problems and solutions:** e.g. working closely with public partners to consider a problem, idea, or priority at an early stage of development, making progress by working together across different experiences.
- **Valuing experience and gaining insights:** e.g. learning from public partners with specific knowledge related to life experience, specific demographic characteristics or medical conditions.
- **Building shared understandings:** e.g. ongoing discussions and relationships can broaden the knowledge base relating to the research environment and enable more complete decisions and outcomes on the potential applications and implications of research.
- **Enhancing future collaboration and problem solving:** e.g. seeing, experiencing and learning from successful collaboration that can be applied to future situations.

Additionally, public involvement in clinical research has often been conceptualised and delivered within the research 'cycle' and this perception and approach was held across those we worked with at MRC head office and the MRC-funded community.

Considerations

We recommend that the MRC vision and associated strategy:

- Reframe public involvement in terms of the purpose and value it can bring to the research environment, rather than to specific research methodology or 'place' in the research cycle. Involvement across the research environment might include impacts on strategy and prioritisation, governance, impact, policy, ethics, communications, public engagement, learning and development, and relationships with other organisations or services (e.g. health services).
- Encourage the application of public involvement methods, according to context, using bespoke approaches for each and all public involvement activity, dependent on the needs and purpose of the work and the individuals and stakeholders. The UK Standards for Public Involvement are useful here.
- Facilitate the MRC research community's understanding on how to prioritise public involvement, by where it's most needed, purposeful and/or meaningful.

Purpose, motivations and context for public involvement

The case studies below demonstrate how these considerations have been applied:

Case study A

Programme-level public involvement strategy in fundamental research focused on publicly contentious issues (available in full in Appendix 2)

What makes us human? Public engagement and Involvement with the Human Developmental Biology Initiative (HDBI)

Human developmental biology research raises ethical, legal, social issues (ELSI) in terms of the research relying on the use of human embryo and foetal tissue, how this tissue is sourced, and how we use knowledge generated by the research in the future.

The focus of the public engagement (PE) strategy for HDBI is on developing researchers' capacity for engagement and involvement in order to: systematically address barriers that prevent the full potential of engagement; provide flexibility to respond to arising needs within research or policy, and secure a legacy of engagement beyond the funding period.

At the core of the PE strategy is the Insights Group – a mixed experience group of people and professionals, including women and men who have experience of IVF services, or termination of pregnancy services.

The Insights Group has a broad remit within the HDBI working with researchers to consider ELSI, improve communication of research, co-produce and co-deliver training, and to improve public engagement and horizon scanning.

This case study demonstrates an approach designed to overcome barriers around 'saying the wrong thing' in contentious issues, and in gaining public insight where its most valuable – not around basic research methodology – but in the surrounding context, arising questions, and future implications of this fundamental biology and its interface with society.

Case study B

Patient involvement within a prostate cancer research consortium (available in full in Appendix 2)

ReIMAGINE (co-funded by the MRC and CRUK)

ReIMAGINE is a research consortium working to develop more accurate diagnostic tools to prevent the high prevalence of under-diagnosis, over-treatment and missed diagnoses of prostate cancer.

A PPI sub-committee of patient/carers was involved throughout the research process, from grant application to completion. The sub-committee's role included supporting research governance, design, data collection, analysis, and research communications. A PPI co-ordinator facilitated the dialogue.

A specific outcome of the PPI sub-committee included the establishment of a prostate cancer research group focusing on communities experiencing racial inequality, which enabled a greater range of perspectives based on lived experiences, and promoted greater diversity in research.

ReIMAGINE provides an example of involving patients and carers with lived experience of prostate cancer across a programme of research, and demonstrates potential outcomes of valuing diverse experiences and skills as an integral component of the work.

Case study C

PPI group working across clinical and non-clinical research (further information in Appendix 5)

MRC Human Immunology Unit (University of Oxford)

The Oxford Blood Group encourages people and patients with lived experience of a haematology (blood) condition to be involved with the Haematology and Stem Cells theme at the NIHR Oxford Biomedical Research Centre.

In this example, public involvement in non-clinical research had been developed following on from an initial broader focus on public engagement. The work is a collaboration across research teams of clinical academics and non-clinical researchers.

Establishing the public involvement approach took approximately two years, with a concerted effort to build buy-in and support from the research and leadership team.

Initial sessions focused on discussing the broad research context and the direction of research at the lab. Further and ongoing work has focused on communication and language.

The discussions highlighted some different priorities between public contributors and researchers, but a shared outcome has been motivating both the research team and the public partners:

The Unit's experience is that culture change is a key part of working more closely with the public. This change started initially with public engagement around 10 years ago. Their experience demonstrates that engaging all members of the research and leadership team was crucial.

Purpose, motivations and context for public involvement

Further case studies are available within Appendix 2: Landscape review of public involvement in non-clinical research and Appendix 5: Examples of MRC public involvement. These demonstrate good and thoughtful practice with strong commitment from the researchers, public partners and PEPs involved.

We have found examples of a variety of approaches, across both clinical and non-clinical research. Importantly, many of the examples demonstrate a variety of purposes for public partners with involvement in the detail of the research, but also within more strategic and governance roles, suggesting a maturity of involvement practice in some instances. It should also be acknowledged that MRC has funded several initiatives [6] exploring public perspectives about different aspects of research, which can help to inform the understanding of the context for public involvement.

2.2 What difference does public involvement make?

Assessing and reporting the difference that public involvement makes to research – and to those involved – is still emerging. In the last few years, some effort has been devoted to developing evaluation and reporting methods for public involvement (e.g. GRIPP2 checklists [2] and the MRC funded PiiAF framework [3]; involvement is often also assessed against the UK Standards for Public Involvement [4]).

Only recently have journals started to routinely publish peer-reviewed papers on the methods and impacts of public involvement. This is also a contested area with some calling for the evaluation of public involvement to consider it not as an instrumental intervention but a social practice of dialogue and learning between researchers and the public; to better assess how power relationships play out in the context of public involvement in research; and to question whether the language of impact is helpful or not in the context of public involvement. (e.g. [5]).

“We found that PPI has really energised our researchers... seriously energised and motivated them got them to think about what they were doing in a different way. And just made them feel more involved and more useful.”

MRC funded Principal Investigator

Purpose, motivations and context for public involvement

From our scoping review of public involvement in non-clinical research, we have identified and summarised a number of common features which are important for public involvement. The list below identifies enablers, benefits, impacts, barriers and challenges of public involvement. (The full review and methodology is available in Appendix 2).

Enablers for public involvement

Funding & funders

- Public involvement as a requirement from funders of non-clinical research
- Support from funders and through funding

Team & Support

- Arrange the team structure to support public involvement.
- Plan for equitable division of responsibilities to reduce the burden on the project team and help partners feel more invested
- Support from a professional expert
- Provide competitive salaries for engagement and involvement practitioners
- Support of senior colleagues
- Support with logistics

Learning & Development

- Training/development at every career stage
- Resources for researchers to overcome challenges
- Toolkits and standards
- Distribute learning materials before and after meetings
- Opportunities for researchers to practise in safe spaces – this can support communication and language, and overcoming barriers around having difficult conversations

Strategy & Planning

- Supporting scientists to start involvement early / Develop patient engagement strategies ahead of time – this benefits involvement that shapes research priorities and is strategic/ will add most value
- Clarity of purpose of the involvement

Purpose, motivations and context for public involvement

Enablers for public involvement (continued)

Relationships with people and communities

- Building long term relationships is key – face to face activity can be beneficial although not essential
- Involving the 'right' people – based on interest, diverse lived experience, science backgrounds are not necessary
- Consider the needs of the community
- Partnering with external organisations that actively support patient engagement in non-clinical science research projects

Involvement practice

- Regular consultation and continuing conversations – learning together and building mutual understanding
- Creating a safe space where patient partners and researchers feel comfortable to collaborate

Communications including:

- Clarity and language
- Keeping PPI contributors informed
- Sharing examples of good practice

Benefits & impacts of public involvement

Mutual learning

- including public partners understanding and interest in basic science research, and researcher understanding of the real-life priorities and impact of their work
- Improved skills and confidence in public involvement for all constituencies

Opportunities to build new knowledge, interests, and perspectives

- Public involvement can inform and broaden perspectives and knowledge of researchers, raise questions that researchers may not have thought of and help them to think differently
- Involving a diverse patient partner group provides a greater understanding of diverse experiences

Improved quality and efficiency of research

- Public involvement informs the research question, study methodology, and future research direction by fostering important discussions
- Patient partners can play an important role in disseminating research findings

Purpose, motivations and context for public involvement

Benefits & impacts of public involvement (continued)

Other

- May increase trainee recruitment/retention, external collaboration, and recruitment
- Improves communication between the different stakeholder groups
- Improves patient/ public partner trust in the research community and strengthens the research through trust
- Encourages a sense of partnership (between patients and researchers)
- Creation of beneficial external partnerships
- Increases self-confidence and the impact of the patient voice
- Improves motivation for researchers
- Reassures researchers that what they are doing is of value
- Impacts on public/patient partners can include feelings:
 - of hope for their condition even if this may be in the distant future
 - that they are doing something useful
 - of being part of a wider community
- Impacts can be greater than originally envisaged

Barriers to public involvement

- Structural barriers including time, funding and systems & processes
- Terminology
- Public partners identifying opportunities to get involved
- Researchers' fear of saying the wrong thing
- Researchers lacking knowledge and confidence in ethics
- Public partners' health
- Poor communications (from researchers)

Purpose, motivations and context for public involvement

Barriers most relevant to non-clinical research

- Lack of researcher training opportunities to guide meaningful patient engagement in basic science research
- Researchers/practitioners lack of awareness of different approaches to non-clinical research
- The impact and/or direction of research is further away from application and may be unknown
- Defining the public stakeholders
- Public partners lack of experience of lab-based research

Challenges for public involvement

- Research culture may not be conducive to involvement
- Lack of research experience, preparation, and clarity around expectations for public involvement
- Researchers concerns about how many people is enough
- Diversity of public partners
- Power imbalances between research community and public partners and practitioners
- Addressing the priorities of all team members can be difficult to achieve
- Researchers/practitioners' concerns around group dynamics or managing difficult situations
- Concerns about raising people's expectations regarding timelines of research into practice
- Measuring and reporting on impact – especially how to compile qualitative evidence across programmes/ organisations

Purpose, motivations and context for public involvement

2.3 Why is it important to 'do' public involvement?

Findings

Informed by conversations with the EAG and MRC staff commissioning this review, we asked a range of internal MRC and external stakeholders to tell us why public involvement is important:

The MRC Public Involvement Project Oversight Group collectively prioritised:

- Grounding research – improving research outcomes using patient and/or public experience
- Integrity and trust – maintaining public trust through transparency and democracy
- Equity and diversity – across the research environment, and research outcomes

The following were seen as less important at this time:

- checking that it is the 'right' thing to be doing – this was seen as integral to good public involvement. This statement also raised concerns about decision making being too skewed towards public priorities at the sake of evidence and analysis from the research community
- for the public to find out about research – this was seen as more related to public engagement. This highlighted to the Group how engagement was complementary to involvement.

MRC Research Programme Managers prioritised:

- Maintaining public trust through transparency (89%)
- Making research relevant to the public (69%)
- Making research more equitable and diverse (58%)

Closely followed by Improving the communication and language of research (56%)

Appendix 6 provides a breakdown of survey responses by role. The survey data from *MRC Head office staff* places greatest importance on trust, transparency, relevance, and equity and diversity of research.

From the survey to all MRC stakeholders, the top three chosen were:

- Making research relevant to the public (52%)
- Ensuring openness and transparency (50%)
- Maintaining public trust (44%)

Public partners responding to the survey feel that improving research outcomes and making research relevant are the most important factors. They place increased importance on research decision making, and effective challenge to research assumptions.

The least popular choice of all respondents was to make research more cost effective, which suggests that moral and/or ethical motivations for involvement are more important for respondents rather than financial or process motivations.

Purpose, motivations and context for public involvement

MRC funded researchers place greater priority on the public finding out about research, than all other categories of respondents. This could be due to the current emphasis on public engagement and communications within MRC funded research. Drawing on the evidence that experience and confidence in public engagement can lead to more involvement within research [7] this provides useful knowledge, which we will draw on later, in how to support MRC researchers' continuing professional development.

Considerations

As part of its vision, culture and strategy, the MRC could focus its priorities on public involvement as essential and integral to the pursuit of research excellence and include:

- Producing high-quality non-clinical research, including in the relevance of its outcomes and approaches to people/society
- Ensuring openness and transparency of research organisations
- Maintaining public trust between researchers, research organisations and people
- Making research more equitable, inclusive and diverse

This would also enable public partners to view their involvement as an essential part of the bigger picture.

2.4 Is the context of non-clinical research a 'special' consideration for public involvement?

Findings

"As a basic scientist, it's clear that the public isn't educated on the value of basic science to research."

MRC funded Principal Investigator

"I'm genuinely not sure if we can co-produce e.g. tissue culture experiments. But we can co-create the research environment in which such studies are born, then they will reflect the active involvement of patients and communities"

Public involvement practitioner

Public involvement with non-clinical research does have some unique, though not insurmountable, challenges. We encountered reticence, and in some cases active resistance to public involvement in non-clinical research.

Appendix 2 summarises some of the more specific considerations for public involvement in non-clinical research. These include:

- Identifying public partners is trickier – unlike clinical research, it isn't always obvious who the potential stakeholders could be.
- The impact and/or direction of research may be unknown, outputs may not be clear and/or long term.
- For some of these areas, there are ethical, legal and social issues which can make researchers more fearful of involving people and will certainly require great care in involvement practice to ensure that public partners are included with sensitivity.
- The non-clinical landscape is viewed as less relatable to health experience than clinical research. The context and environment in which the research takes place is quite different; and the content of what is being studied can be complex and detailed.

"Whilst it is vital that people with lived experience of a condition are involved, there are also roles for others who can perhaps offer a more objective view."

Public partner

Purpose, motivations and context for public involvement

However, public partners and public involvement practitioners – from our survey, Tweetchat and as part of the EAG – believe that non-clinical research should involve public voices. Our survey findings show that two thirds of public partners think that people can contribute to all types of research, and fewer than a fifth of public/patient or public partners thought direct experience of a health condition was needed for involvement.

Considerations

The MRC, as an organisation, needs to be proactive in influencing its internal culture and leveraging its external influence to stop the perception that non-clinical research is distinct from society and exempt to public involvement. MRC should strongly communicate that public involvement in all research, including non-clinical, basic and big data science, is possible, happening, and making a difference. Using the case studies from this work would be useful in this regard. There is a clear opportunity for the MRC to show leadership by setting out to learn further about public involvement in non-clinical research and ambitiously innovate involvement practice in this area.

Tackling terminology and congruence

3 Recommendation: 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

3.1 Complementing strategies and practice

Findings

During the course of this work there has been significant progress and collaboration across engagement and involvement functions within MRC head office and UKRI, including as part of the cross-council Public Engagement with Research Network, and plans for a senior outcomes-focused group. The MRC now has greater clarity about positioning its engagement and involvement work in relation to the UKRI strategy, and an opportunity to co-develop public involvement practice and language which is best suited to the needs of MRC's organisation and research portfolio.

Also, during this period, UKRI has signed up to the Shared Commitment to Public Involvement [9], and the MRC has agreed to progress a strategy encompassing both public involvement and engagement. There are ongoing discussions about the recent recommendation to uncouple communications from public engagement within MRC governance and assurance processes [8].

We have reviewed research, public engagement and EDI strategies, and strategic delivery plans across UKRI and MRC. There is good cohesion and positioning across these strategies, and a strong rationale for public involvement sitting alongside research integrity and open access research.

However, we find that MRC head office staff are unclear about how the MRC should align public involvement with UKRI public engagement strategy in practice. The lack of clarity extends to high-level decisions about how MRC positions itself within UKRI, how it influences them, and how best to work together going forwards.

In our workshops and as part of EAG discussions, public partners express a need to understand better how involvement 'fits' within the overall MRC strategic ambition.

We've heard evidence that some public engagement practitioners within HEIs and/or MRC funded units and programmes are dealing with different institutional strategies, funding requirements and agendas and would benefit from a joined-up approach and clarity across all the MRC's strategies.

"I'm not employed by the MRC but as a person, funded by the MRC, a little bit distant I get bombarded by strategies... I'm not sure the top bods in the organisation will take what we've said seriously, given that their overarching strategy doesn't seem to do much in the space. That...makes it difficult to justify things internally to other senior leaders if they don't see it written in the right places, or talked about."

PEP, MRC Establishment

Tackling terminology and congruence

Considerations

We support the recommendation from Jamieson and Leslie 2022 [8] to foreground the principles and ambition for working with people into key Council strategic documents. Further, we strongly support the MRC in developing a public involvement and engagement strategy. This is particularly important in developing and maintaining relationships with communities that support diverse and inclusive public involvement, so that engagement and involvement are not seen as 'siloed' or prioritising views from particular constituencies.

Our recommendation is that public involvement at the MRC needs to be seen as fundamental to the research environment and that a combined engagement and involvement strategy develops the values, principles and behaviours (described in earlier sections of this report) as well as the procedural and practical elements of public involvement (described later).

We anticipate that public contributors and others will be interested to know how the public involvement and engagement strategy was developed, who has been actively involved, whether the UKRI and MRC's commitment to public involvement is evident in the strategy, and in how it is delivered.

3.2 Tackling terminology

"How do all these practices sit with Knowledge Exchange? For me and many other practitioners, knowledge exchange is an umbrella term and one engagement/involvement practice should not be overemphasised over another. The only guiding principle is the question 'who is the stakeholder that is key to making a particular impact?'; then engage with them. We call it outcomes-focussed engagement. Today it could be patient involvement, tomorrow it's policy engagement."

PEP, not funded by the MRC

"It [public involvement] needs really good communication and expectation setting etc – training and shared learning for all involved. I think it would make lab-based scientists more understanding of the impact (and limitations) of their results."

Public involvement practitioner

"A key feature is the need for the whole population – researchers and the public – to be involved in research through the provision of data and samples."

Principal Investigator, MRC Establishment

Tackling terminology and congruence

Tackling the terminology of involvement was a key factor in the commission of this review. The terminology associated with public involvement and engagement can be problematic and a perennial issue within both research and public involvement sectors. There has been some recent alignment amongst research and funding organisations around terminology with the most used definitions being:

Term	Definition	Used by
Public Involvement	Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them	NIHR, CRUK, HRA, HDRUK, ABPI
Public Engagement	Information and knowledge about research is shared with the public [an emphasis is placed on 2-way dialogue]	NIHR, CRUK, Wellcome, UKRI, NCCPE
Participation	Where patients or healthy volunteers take part in a research study; they are the subject of the study and the research is being done to them, not with them.	NIHR, CRUK, HRA,
Patient engagement	The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognising their specific experiences, values, and expertise.	Industry (e.g. Pfizer) and societies (e.g. ISPOR)

Additionally, within engagement and involvement sectors, there is also a variety of terminology that might also be confusing, for example, consultation, dialogue, citizens' jury, co-production, community engagement. We acknowledge that the public engagement and involvement sectors have sometimes been unclear themselves.

Our review highlights that MRC staff and researchers – even when they cite examples of public involvement that they've worked on – often confuse engagement and involvement, interchange or conflate terms and meanings, and are unclear about how involvement might cohere with, for example, knowledge exchange or research participation. There is a lack of clarity about what public involvement is and its purpose.

All stakeholders in this review, in every interaction without exception, stated a need for clear expectations and guidance from MRC. Reasons that we heard about why this is so important relate to meeting/setting expectations: for researchers' and PEPs' understanding of what the MRC is expecting of them, and MRC staff knowing what they should be expecting from research applicants/ funded researchers.

Tackling terminology and congruence

During the course of this review, the MRC has made progress by:

- Critically appraising the interface between engagement and involvement, e.g. by considering an MRC Public Engagement *and* Involvement Strategy, which takes account of the need to address terminology.
- Moving away from using the term 'patient and public involvement' (PPI) in favour of 'public involvement' as a catch all term which is more appropriate for the MRC context as a major funder of non-clinical research.
- Working on terminology as a focus across Research Councils.

Our experience suggests that public partners care more about the purpose, value and impact of public involvement rather than what it's called. Routinely, there are calls to 'say what it means':

"We want conversations about a topic, rather than a method"

Public partner, EAG.

Some cautioned against using definitions which would constrain creativity and innovation. They were concerned about words which meant one thing to the MRC, and another meaning for others.

"We think 'PPI' can be limiting, because (we perceive) it to be associated with a traditional model of involvement – meeting rooms, formalised, etc. Coinciding with lack of diversity of contributors, going native, lacking creativity etc. It also firmly links involvement to health research, and it might be more helpful to think of involvement more broadly in terms of democracy and justice."

Public Involvement Practitioner

Considerations

The MRC is already committed to the definition of public involvement within the UK Shared Commitment for Public Involvement [9], which was co-produced with public partners and is congruent with relevant stakeholder strategies. Based on the starting point of the Shared Commitment, this review has expanded a definition of public involvement (see Introduction section) that the MRC might consider using or adapting.

Taking this further, the MRC has the potential to show leadership in developing a new 'everyday' language for involvement, moving away from the jargon and multiple definitions. Ideally, this could link language and terminology with purpose. For example:

- public partners inform our decision-making through their membership of funding committees
- we consult with patients and members of the public to agree on our research priorities
- we support inclusive research by working directly with minoritised groups to exchange learning between researchers and communities
- we listen to and value people's life experience in influencing our methods for research

Developing working cultures to support involvement

4 Recommendation: 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

Findings

Positive development in research culture is happening within the MRC, including workstreams supporting MRC's People and Culture programmes, and the establishment and work of the MRC EDI Forum.

UKRI is moving away from the 'iceberg model' [10] in which scientific evidence above the surface (publications, funding, prizes) is added to from below the surface (from the research environment, where public involvement would sit); to a view that scientific excellence encompasses the entire research environment. UKRI is reframing the culture needed to achieve this new view of scientific excellence. This leadership and direction has had significant influence on MRC staff and has been frequently referred to during this review

This developing culture is timely and provides fertile ground for public involvement. In our experience, public involvement can influence and facilitate cultural change within the research community. It also requires an inclusive culture in order to flourish.

Our findings show that in some parts of the MRC, its establishments and funded portfolio, a positive culture towards public involvement exists but is constrained. In other places, active resistance to public involvement in the MRC's work and research was found.

"There is a problem with academic culture in biomedical sciences and it's well reported on. It's important that MRC see this as a culture shift"

Member, EAG

Developing working cultures to support involvement

*"The mantra that 'the public' or 'the community' *always* know best is becoming problematic. It will lead to 'tick box' engagement/involvement."*

Principal Investigator, MRC Establishment

"What kind of culture are we bringing people into?"

Public partner, EAG

"There will always be those who are reluctant to get involved with PPI, but there needs to be some degree of humility between researchers and public collaborators to connect with the people whose outcomes they are trying to improve."

Research Manager/administrator, MRC Partnership Institute

Senior buy-in is essential for this culture change. Currently, the senior MRC staff with responsibility for public involvement acknowledge this change is needed, but do not yet have clarity about how they could catalyse it. This report and the next steps towards strategy development are viewed as the starting points for that plan. There are also opportunities to learn from the ongoing culture change around Equality, Diversity and Inclusion within MRC and UKRI more widely.

For public involvement at MRC to flourish, we have identified three areas for development within current MRC working cultures:

- Identifying and embodying values in relation to public involvement; emphasising relational approaches
- Valuing diverse forms of knowledge in decision-making
- Rewarding and recognising the value and efforts of public involvement at parity with research

This builds upon and strengthens the values-based foundation of both UKRI and MRC. It also aligns closely with MRC's ongoing EDI culture change programme.

Developing working cultures to support involvement

4.1 Identifying and embodying values in relation to public involvement

Findings

The MRC and External Advisory Group Co-Production Workshop began to define what a culture for public involvement could look and feel like at the MRC. These can be considered foundational values for the MRC's involvement strategy:

- **Dynamic and live** – a balance of rigid policy versus other elements, to support inclusivity. Lifelong learning is important.
- **Reflective and open** – Acknowledges that medical research has not always been inclusive (and worse) in the past. We need to continually challenge ourselves to be better. If we're to serve our communities with our research, we need to listen to their stories.
- **Not hierarchical** – but championed from the top and throughout: *"where status is not an opening definition of a person"; "dis-arm any notion of intellectual superiority"; "where public are seen as members of the team"; "where conversations are grounded in what's familiar."*
- **Inclusive** – where all feel welcome, respected and their contribution is valued, and recognising that this looks and feels different for different people.
- **Equitable** – where anyone, regardless of who they are can become involved if they choose, and not face any barriers. Investing in individuals and communities is important.
- **Diverse** – it's important to consider the approachability of people doing the research – will people feel more comfortable talking with someone they feel represents them?
- **Accessible** – physical, communication, information, attitudinal accessibility are all important. People need to know what's going on to feel involved.
- **Supportive** – one with buddying systems and mentoring.
- **A shared responsibility** – public involvement feels like the norm, with everyone feeling confident and comfortable. We learn and share knowledge with others, especially with co-ordination across Research Councils.
- **Committed** – Be committed to making a concerted effort – being inclusive isn't always the 'easy route'. You have to think differently, try different things and accommodate differing needs.

The values of the MRC are integrity, excellence, collaboration, diversity and inclusion, valuing people, and compassionate leadership and therefore there is significant alignment and a solid foundation for the MRC's new culture of public involvement.

Developing working cultures to support involvement

There is genuine interest and openness for doing public involvement across the MRC head office. Over two thirds of the Research Programme Managers' Forum said they could see the relevance of public involvement to their work. A senior member of MRC staff described MRC head office as a "*ready audience for culture change*". Some have direct experience of involvement, whilst others have never before considered it.

However, Head office staff often framed discussions about public involvement in transactional and/or extractive terms, prioritising the potential benefit to the research, without considering any other possible broader benefits of collaboration such as researchers learning from the perspectives of public partners, or changing broader research practices.

From those who are less experienced in public involvement there is currently a lack of consideration of reciprocity for public partners, their motivations and benefits from involvement, how public partners might feel, or how to work without doing harm.

Considerations

We recommend that MRC strengthens its values-based approach to involvement by building on the foundational values elaborated above.

Further focusing on the relational aspects of involvement, the MRC could potentially subscribe to, or be informed by the concept from the Animal Research Nexus [11] of a 'culture of care':

A culture of care is a phrase used to emphasise the importance of a research culture that is focused on relationships, effective communication, and training and support. A good culture of care in animal research considers how to care for the humans as well as the animals within research facilities. It is aimed at providing better care for animals, but it is also about supporting and valuing interpersonal relationships and caring and respectful approaches to animals and to co-workers.

Cultures of care are becoming more commonplace in wider organisational development spheres including within health, and we acknowledge the complexity and time required for them. Cultures of care may require additional pastoral support for individuals. For example, an involvement situation may 'trigger' emotions in researchers, staff and public partners alike. The MRC should consider these from the outset, add this expectation of duty of care into policies where appropriate, and identify specialist support to provide/signpost to if needed, e.g. counselling services.

Developing working cultures to support involvement

4.2 Valuing diverse forms of knowledge

Findings

"The need for evidence is ingrained within biomedical [culture]. There's a strong theme around differing perspectives creating shared understanding. The MRC needs to acknowledge that lived experience is a valid form of knowledge."

Member, EAG

"There's something here about whether the culture appreciates different values. The values of involvement are perhaps different to the traditional values/operating model of researchers/the MRC."

Member, EAG

Our findings reveal uneasiness about the possibility of public partners disagreeing with an established or majority view e.g. from academic funding panel members, and MRC staff being uncertain about how to deal with these situations if they arise.

Public partners have described that currently, some public involvement methods rely on "stepping into" an academic environment and culture, as opposed to creating a shared space for collaboration. Placing an emphasis on values and relationships could help address this disquiet.

Considerations

We strongly support the findings and recommendations within UKRI's recently commissioned report from the Young Foundation [1] including the recommendation:

A fundamental shift in what knowledge is valued and how it is funded: this means seeing value to community involvement in all parts of the system and respecting that community groups and organisations can be recognised as knowledge producers, guardians and lead partners in knowledge creation processes.

An asset-based mindset recognises as legitimate diverse forms of knowledge, including life experience, and incorporates these forms of knowledge alongside academic evidence. Importantly, here we define life experience as including experience of health conditions (often referred to as lived, or living experience), and social, cultural or economic experiences, as well as experiences arising from marginalisation or inequalities (for example, people with experience of racial inequalities). For public involvement to have positive impact, those involved should model mutual respect, and place value on the inputs from all, in the collaborative pursuit of new and knowledge and ideas.

Developing working cultures to support involvement

4.3 Rewarding and recognising public involvement

"[I would like to see] value given to achievements in this area broadly across the sector, such that time spent on this [public involvement] enhanced career prospects, not harmed them"

Principal Investigator, organisation/facility/network associated with MRC

"We found that PPI has really energised our researchers...seriously energised and motivated them, got them to think about what they were doing in a different way and... just made them feel more involved and more and more useful."

Principal Investigator, MRC Establishment

"Recognition is really important, and this needs to be equal to the recognition demonstrated for research, not just verbal recognition, or including your PPI work into their report"

MRC funded researcher

Reward and recognition for public involvement is needed and important across all the constituencies engaged in this work.

A third of researchers surveyed selected "Public involvement is included in my KPIs/valued by my institution" as a motivation for public involvement. This chimes with long-standing thinking within the wider public engagement sector. Our findings from workshops, interviews and the scoping review support evidence that public involvement can be motivational for researchers. For non-clinical researchers – who don't always interact with people and patients as part of their day job – this can have an even greater impact (see Appendix 2 for further information).

Public partners likewise value reward and recognition, which can come in the form of:

- Feedback on the quality and impact of their involvement
- Payment and payment policies
- Logistical arrangements, for example, convenient time and location of meetings, consideration of accessibility such as caring cover
- Clear and defined roles and responsibilities; honorary appointments, if appropriate
- Role progression, including for example peer research opportunities
- Expressions of thanks
- Communicating the difference they make e.g. through case studies of impact of public involvement

Developing working cultures to support involvement

Considerations

Reward and recognition processes might include:

- Identifying a set of skills and behaviours amongst researchers, that support public involvement and including these in personal appraisals and more broadly in project reviews and Establishments reporting and governance
- Celebrating and sharing best practice, including overcoming difficulties/innovative approaches – this extends from informal conversations through to supporting publications of MRC's involvement practice, and including Open Access fees for commentary and opinion articles (where public involvement practice and learning is often reported)
- Communicating case studies to all relevant stakeholders including public and research audiences
- Providing funding for public involvement within research grants, and as a standalone endeavour
- Adopting narrative CVs as appropriate – in funding applications, and supporting the wider work of the UKRI and Universities UK Alternative Uses Group [12] in influencing the research sector
- Developing a reward and recognition policy for public partners (see Appendix 7).

We note the complexity of reward and recognition across different employment structures for researchers, within host institutions of MRC establishments and suggest further scoping work for the MRC to pursue in this area. A relatively straightforward action would be for the MRC to publicly acknowledge and disseminate awards and prizes in public involvement given by researchers' host institutions, and/or other funders. Prizes should be across the constituencies of public involvement i.e. for researchers, public partners, staff. The MRC could further explore how to work with umbrella organisations and host institutions to influence and collaborate on reward and recognition for public involvement across the MRC research community.

Consideration should be given to providing competitive salaries and sustainable employment for involvement specialists. Leading and running involvement and engagement requires particular professional skills and experiences. However, these roles are often precarious, short-term and underfunded. Offering appropriately funded salaries for long-term involvement and engagement roles is an important step towards recognising the skills that such a role requires [7].

5 Recommendation: 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 Equality Diversity and Inclusion (EDI) Strategy
- Enabling the involvement of different people in the MRC and MRC research
- Actively reaching out to involve different communities

5.1 Public involvement supports an inclusive research agenda

Findings

Approximately two thirds of Research Programme Managers cited improving equity and diversity of research as a reason for doing public involvement at MRC. Despite this and the join up across high level UKRI and MRC strategies, it seems as if there is limited awareness to date on the relationship between public involvement and equity in research.

"The set of research questions that are funded or pursued may be biased i.e. they may support a particular demographic of the population without addressing more pressing needs. I am interested in whether our research is 'colonised', and whether there are mechanisms that can objectively assess public need and feed that into study designs at their conception. The BMJ has had several editorials that show that we as researchers are failing to address the racial health gap for example"

Principal Investigator, MRC Establishment

"In terms of EDI agendas, the addition of PPIE [patient and public involvement and engagement] can be a corrective for narrow perspectives, and can help with the application of knowledge, e.g. implementation or scale up and spread."

MRC funded Principal Investigator

Considerations

Inclusive research is an emerging priority across the health research funding landscape, with, for example, Wellcome and NIHR prioritising their understanding of the principles and methods of inclusive research [14]. NIHR have recently published an agenda for action to promote health equity and reduce health inequalities through greater inclusion in public partnerships [14]. Adding to this collective effort and supported by emerging evidence and publications, the MRC should consider and communicate clearly how public involvement can support an inclusive research agenda.

5.2 Complementing the MRC's EDI Strategy

Findings

Synergies with the MRC's EDI strategy are a positive. Public involvement can be a significant asset in supporting EDI culture and practice across the funded portfolio.

During this work, members of the MRC EDI Forum were encouraged to consider how involvement could interface with and support EDI, and there was interest and openness to this idea. Upskilling the MRC's social and cultural knowledge and competencies will have positive outcomes across the work of the MRC, beyond public involvement.

However, EDI is not the sole preserve of public involvement. Evidence from outside the MRC suggests that unrealistic demands are being placed on public involvement to address issues of EDI that are outside its sphere of influence (e.g. workforce diversity). EDI and public involvement strategies need to be clear in their resourcing, areas of responsibility and areas of synergy.

"Within every industry I've been in, the EDI strategy is often the responsibility of one person. They've been brought in especially. No heads roll at a senior level for it not happening. The strategy isn't resourced correctly, often it doesn't have a budget. There aren't objectives tied to it that are measurable or interlinked with the strategic objectives of the organisation. We do need to be doing things differently, it's very much a cultural piece."

Member, EAG

Considerations

MRC public involvement and EDI strategies should be integrated, synergistic and cross-reference each other. We have found that the NIHR's Race Equality Framework for Public Involvement [15] is a useful tool in identifying the actions needed for an organisation to address equity across its functions. The evidence-based approach offers a systematic method to understand race equity within governance, leadership, training and development and public involvement functions. The MRC could consider applying the Framework as a next step in the development of both its EDI and public involvement strategies.

"There are lots of similarities [of EDI] to involvement. It's about power. An organisation needs to acknowledge that."

Public partner, EAG

5.3 Enabling the involvement of people from all walks of life in the MRC and its research

Findings

"The people who volunteer for public involvement tend to be (like clinical research volunteers) of above average socioeconomic status and education. I have frequently met retired professionals including retired researchers volunteering in this capacity ... I feel there is a lot of fiction generated about how public involvement in research means we are representing our country's population and serving their wishes in terms of research priorities etc – it really, really does not."

"...also need resource to talk to relevant people, not the same already over-represented, well served groups who have the time and lucky position in life to get to these events. We need to access areas of greatest need."

Principal Investigator, MRC Establishment

Our review finds concerns about the lack of diversity of public partners involved in research and it is acknowledged in the wider sector that public involvement lacks diversity amongst its contributors (e.g. [16]; NIHR surveys of public contributors 2018 and 2021 [17]). Rather than this being a personal 'deficit' of public partners involved in research, evidence points to systems-based barriers within existing health, research and public involvement practices, which can exclude certain constituencies of public partners. For example, people with experience of racial inequalities and those from socio-economically disadvantaged backgrounds, feel less confident of being treated with dignity and respect in health research [18]:

"Not all members of the public are the same and any advice and support should explicitly consider the needs and interests of different potential cohorts."

Non-MRC funded Principal Investigator (UKRI funded, based in global south)

"That's not my world. I learned how to be there and how to be effective. What would it take for someone from a less privileged background to feel included and confident within this setting?"

Public partner, EAG

Leadership and staffing

Effective involvement needs to understand the needs of people first, to enable people from diverse backgrounds and life experiences to become involved. Opportunities should be made accessible and inclusive, taking into account circumstances, time to devote to involvement, levels of interest and skills.

Our findings and other evidence from outside the MRC also indicate that researchers and staff doing public involvement tend to be women:

"When no clear expectations are set, women are often disproportionately involved in public engagement initiatives. This is then seen as an unnecessary "soft" skill to develop and perceived as time spend unproductively."

Postdoctoral researcher, MRC Establishment

Considerations

The MRC should consider monitoring the characteristics of those involved in its work and research, as routine. Demographic data monitoring forms for this purpose are available. While some reservations might be expressed about the relevance and need to collect such data, it would be important in ensuring diversity of involvement. Ensuring diversity of those involved can also help address the red herring of lack of representativeness as a reason not to do involvement.

Targeted partnership with minoritised groups could support more diverse involvement. PEPs, and community organisations could be supported to do this through staffing and/or funding, including connecting with the recent community-led funding schemes of UKRI [19] and place-based initiatives, assets and infrastructure.

In supporting researchers and PEPs and working with the research culture agenda of the MRC, consideration should be given to how to redress the gender balance amongst those prioritising involvement and address gendered attitudes towards public involvement.

"[PPIE] tends to be seen as housework/women's work that gets outsourced by white male PI's."

MRC funded Principal Investigator, at a University/NHS Trust or other research setting

6 Recommendation: 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
- Support the strategy with adequate communications resource to visibly and consistently signal the MRC's approach to public involvement, internally and externally

6.1 MRC head office

Findings

"I did a bit of digging and was somewhat horrified by the lack of... patient involvement that was happening at the MRC ... I felt there was ... a sort of complacency"

Public partner

"If it's something that the office pick up more heavily we need someone with experience working alongside us doing it, rather than just expecting the program managers to pick it up as another part of their already massive workload."

Staff member, MRC head office

It's evident from our review that the MRC needs additional capacity and expertise to lead and deliver public involvement within Head office. Appendix 2: Case study D provides comparisons across similar organisations. The NIHR – an established sector leader in patient and public involvement for clinical and applied health research – employs public engagement and involvement practitioners centrally within each of its coordinating functions (e.g. NIHR Central Commissioning Facility, NIHR Evaluation Trials and Studies Coordinating Centre), a distributed network of Public Involvement Leads across their funded infrastructure, and a dedicated Centre for Engagement and Dissemination. They fund approximately £1.2bn research per year, with £1.7m per year funding the CED, plus investment in providing regional public involvement advice through the NIHR Research Design Service.

On a smaller scale, Parkinson's UK prioritises public involvement across both non-clinical and clinical research and funds £8m research per year. Parkinson's UK has two full time public-facing involvement staff, and involvement in funding decision-making is embedded within grants management roles.

Leadership and staffing

CRUK funds approximately £443m research per year. Patient and Public Involvement is delivered by 6 Head office staff members, working alongside a national team of 15 research nurses. There are PPI leads and practitioners within all CRUK major infrastructure.

Within the MRC, accountability for public involvement sits with the Director of Policy, Ethics and Governance who acts as a conduit between the MRC Executive Board and PIPOG. Similarly, the Director of Strategy is accountable for public engagement, and chairs the MRC Public Engagement Oversight Group.

The model of a senior involvement practitioner(s), working with senior management personnel and – importantly – with public partners can equip a major organisation to embed public involvement in its strategic operations. This way of working also reflects an approach to EDI within organisations. The devolved nature of PIPOG functions well to bring insights from across MRC head office, and this way of working could be continued to support the development and implementation stages of any involvement strategy.

We agree with the recommendation made within Jamieson and Leslie's report [8] to strengthen senior leadership through representation of public involvement expertise on MRC Council and to establish public involvement with research as a core part of an executive MRC role. Learning from across the sector shows that an essential element of leadership resides in visibility and advocacy for public involvement at all levels. Additionally, all MRC head office staff should be able to articulate why public involvement is important to the MRC, what this looks like in practice and their role within it.

From the findings we have, there is openness to involving public partners within the highest level of decision-making at the MRC and overall a sense that the MRC Council and senior head office staff are supportive of involvement as *"it's the right thing to do"*. Senior leaders at the MRC have also said that MRC should *"not lose the PI (public involvement) within the PE (public engagement)"*.

Senior leadership, representation and advocacy are essential for success. The most important outcome is that public involvement continues to be embedded within MRC's work and research, and that changes do not inadvertently support tokenism for involvement. We recommend that in addition to senior staff, the MRC involves public partners at the highest levels of decision-making within the MRC.

Considerations

The remit of a new senior role, with responsibility for involvement strategy, innovation and delivery might include:

- Being a conduit to MRC Executive Board and secretariat of PIPOG, connecting to other parts of UKRI, other funders, and representing MRC's leadership in public involvement externally
- Coordinating work with public partners and the EAG at senior levels within head office
- Planning and delivering the co-production of MRC public involvement strategy
- Establishing and leading an MRC community of practice (see Recommendation 7)
- Strategic input into high-level communications plan
- Strategic mapping of involvement needs and resulting expectations across MRC head office and funded portfolio
- Influencing and supporting head office colleagues to involve people and patients
- Collating and signposting to existing guidance for public involvement
- Co-producing MRC public involvement Learning & Development plan and commissioning providers and overseeing implementation.

Given the scale of the MRC in terms of staffing, funding recipients and the funded portfolio, we recommend the MRC brings in additional public involvement practitioners to maintain momentum and enable change in culture and practice in a well-supported way. The support needed will depend on the defined level of ambition and available resource, and decisions about the investment in a network of PEPs and setting expectations for how PEPs/Establishments support strategy implementation.

To achieve a new vision for public involvement, the MRC will need to support change through strategic, consistent and targeted communications activity, both internally and externally. This investment is needed to implement most if not all recommendations within this report.

Priority communications activity will include defining MRC's unique commitment to public involvement with their work and research, and strategically mapping the communication needs and audiences, and key messages, some defined by this review. Further thinking on this is available on request.

We recommend involving public partners in understanding communications channels, clarifying messages and co-producing communications materials.

6.2 MRC Establishments

Findings

Several case studies in the scoping review and wider literature demonstrate how a specialist facilitator and/or practitioner enables meaningful involvement. Our findings strongly support this, demonstrating researchers' needs for both expert advice and logistical support.

A logical and cost-effective approach to support involvement within MRC Establishments – complementing researcher learning and support – is to invest in upskilling and supporting the existing public engagement and communications practitioners (PEPs) within MRC settings to develop their skills in, and facilitation of, active involvement. This complements the synergies of involvement and engagement agendas and practices. The researchers and PEPs within MRC Establishments we spoke to had much more experience of engagement than involvement. Their experiences are clearly linked to the culture of research in which they were based, and therefore a greater value placed on public involvement would have an impact on their roles.

PEP roles in the wider landscape are often precariously and often only part-funded, and the demands on them are usually high. For PEPs in MRC Establishments the dual role of communications and engagement can limit capacity for building relationships which are essential to success. Recently, we find evidence that many PEP roles across the sector are expected to deliver on EDI agendas, without any additional resource or support.

"I don't think that you can emphasise enough to the MRC that having a PE manager and professional PE people involved makes this work. The scientists are getting involved, but do not have the time to drive it forwards."

MRC Senior Research Fellow

"These roles are stretched as 'everyone' looks to you and wants you to deliver involvement on their behalf."

Public Involvement Practitioner

Considerations

There may be opportunities to increase the number of PEPs within the MRC funded portfolio to scale up MRC's involvement in a more distributed model. This could potentially be done with other funders and/or institutional partners, for example, through co-funding of PEP roles.

Based on our findings, and experience of mentoring PEPs within Wellcome Centres and NIHR, considerations for these roles are:

- **Autonomy and seniority** – PEPs need an understanding of the MRC Establishment's strategy, and autonomy to direct engagement and involvement work to meet the needs of the research/ Establishment. This is particularly important during periods of change.
- **Senior backing and advocacy** from e.g. MRC Establishment Directors/Heads of Department is essential for success.
- **Workload considerations:** refining roles to provide greater focus, ability to prioritise engagement and involvement work and a manageable workload. This might include:
 - a) increasing the number of PEPs and/or public partners linked to MRC Establishments
 - b) Providing PEPs with access to both research communications* and administrative support, and removing this from their roleWe support the recommendation from Jamieson and Leslie 2022 [8] to uncouple communications from the existing MRC PEP role. This reduces workload but also removes the possible tension between involvement – listening and responding to a breadth of views about research – and research communications, which tends to be both 'one-way' and function to 'promote' research.
*Please note that we would advise communications specifically with public partners/ audiences about involvement to be maintained within PEP roles.
- **Connection and networks** – Close working relationships with other PEPs in host institutions and local communities.
- **Ongoing peer support and learning.**

**“There is no-one
with expertise
who I can ask.”**

MRC funded PEP

7 Recommendation: 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

Findings

Overall, around 90% of survey respondents had some experience of public involvement. Notably, there is a stark trend suggesting that public involvement happening within research is much more prominent outside of the MRC/ MRC funded portfolio.

We acknowledge that whilst our survey respondents show a breadth of demographics in terms of research area, seniority etc. that they are a self-selecting sample who are likely to be more interested in contributing to this review, and they are therefore more likely to have strong views about public involvement.

7.1 Building on the knowledge, experience and confidence of MRC head office staff

Findings

28% of MRC Research Programme Managers have experience of doing involvement, and the majority (58%) described themselves as having some knowledge of involvement but no direct experience. Examples of involvement within MRC head office and the funded portfolio are provided in Appendix 5.

Skills, learning and development

Around half of MRC head office staff who completed our survey have experience of doing involvement both outside of, and within the MRC. However, MRC head office staff feel significantly less confident about involving the public than researchers and public engagement professionals. Notably, there has been a positive shift in the knowledge and confidence of the MRC Project Team and PIPOG throughout the process of this landscape review.

Two thirds of Research Programme Managers said that they would do public involvement if training and support was provided for them, and the preferred methods of support were training (78%), case studies and resources (59%) and a community of practice (59%). Half of the Programme Managers would also welcome a portal to connect to people and patients.

Considerations

We recommend the MRC develop and mandate staff training about involvement and what it means for the MRC. This should draw on existing resources (see Appendix 7) and address the major findings from this review. Where MRC staff and external panel, Board or Council members are actively involving patients, e.g. within grant funding committees we recommend additional professional/ one to one support is provided. This will be especially important for Chairs. Learning from the GECO funding initiative [20], in which public involvement practitioners and public partners were involved in funding committees, will be important in this regard.

Our analysis of good practice in this area dictates that training, learning and development about involvement is co-produced and co-delivered with public partners and involvement specialists. Examples in the scoping review for this project provide fertile ground on which to build.

In our experience – with some introductory knowledge and processes/policies in place – the best way to develop involvement skills is to learn by doing. Learning is enhanced if evaluation and reflective practice is built in. Working reflectively is taking time to consider experiences and actions, what worked well, and what you would do (differently) next time. It is also useful to ask about and reflect on others' experiences.

The MRC could draw on internal expertise to support a learning by doing approach, such as from staff with experience of working in/with overseas settings with long established practices in community engagement, the Adolescent Mental Health Team, which was described as 'revolutionary' by a member of MRC head office staff, and future role modelling from leaders in public involvement including PIPOG, and newly recruited professional involvement staff.

Skills, learning and development

There is also an exciting opportunity for the MRC to take a leading role in the development of a learning portfolio about involvement in non-clinical, basic and big data science. Our review finds a 'gap' in the wider sector market related to training and development in this area. While there is a good selection of training courses for involvement in clinical research, relatively little exists focused on non-clinical research. The PPI Ignite Network, Ireland ([20] funded by the Health Research Board and the Irish Research Council), of which 2 members of the EAG advising this review are members, is planning and developing a training programme in this area. There exists strong potential for collaboration.

7.2 Building on the knowledge, experience and confidence of MRC-funded researchers

Findings

"We need to recognise that PPI isn't a method and relies upon relationship building, collaboration. Those types of skills have value. Is there fundamentally a tension between the "hard" skills seen as necessary for research, methods, academic rigour, frameworks etc and the so called "softer" skills necessary for PPIE?"

Public partner, EAG

"Reflection is key in all of this, and that can be hard [for researchers]"

Researcher, EAG

As described in Section 2.3, we found a lack of comprehension from some non-clinical researchers about what non-scientists could offer to their research. Researchers and research staff tended to assume that any input from public involvement would be focused on research methods and, as members of the public didn't have that specific knowledge, their contributions would not be useful. Many are also unaware of existing learning and development opportunities.

"I've been thinking about past studies that I've done and I just honestly don't know how I would have got any kind of public involvement that would have been able to shape it...I don't think, for example, that involvement, would be able to advise on the methodology."

Researcher, MRC Establishment

"How do we train our young PhD researchers that leadership is more than just leading good research?"

Staff member, MRC head office

Skills, learning and development

Our survey and workshop findings show that learning and development in involvement would be welcomed by researchers, with preferences for a Community of Practice, and one-to-one support from a specialist in public involvement.

"I feel that PE/ PPI training should be available to all researchers and make the training mandatory if you want to include as many researchers as possible in PPI."

Research Manager or Administrator, MRC Partnership Institute

Our experience indicates that there is often a very rapid transition once a researcher starts doing involvement. Several of the EAG members shared experiences where once researchers start involving people, they quickly become advocates, often significantly changing their research plans and typical ways of working. This mirrors research [e.g. 21] that demonstrates the positive impact that public involvement can have on researchers, including after initial reticence, and is sometimes accompanied by a revelatory 'aha!' moment as to the value of public involvement. Providing learning and development opportunities in involvement at early stages of a researcher's career can support the culture change and reflective environment needed both for public partners and researchers to flourish.

Considerations

In implementing learning and development for researchers, we have identified particular skills and attributes that are important:

- Understanding the value of public involvement as a key element in the research environment rather than as a distinct part of the research cycle (see Section 2.1)
- Developing reflective practice generally, and as applied to involvement
- Understanding and implementing public involvement as a function of research context and involvement purpose
- Effective planning for public involvement
- Understanding how to assess (evaluate) the difference that public involvement can make
- Relationship building, collaborative working
- Communication skills
- Creative and inclusive facilitation skills

Learning and development in involvement should be a consideration of the research career pathway, encompassing culture, structures and training. Some researchers who are already doing involvement would benefit from additional support from the MRC. They prioritise funding, which they indicate would be best spent on salary costs for a public involvement coordinator/practitioner within their research programme, in addition to their own capacity development.

Skills, learning and development

7.3 Building on the knowledge, experience and confidence of Public Engagement and Communications Professionals (PEPs)

Findings

Confidence for involvement is greater in public engagement professionals (PEPs) who are not funded by the MRC. 9 out of 17 MRC funded PEPs feel confident to involve the public, whereas 4 responded that they don't feel confident. Only 3 PEPs said that they don't know where to begin with public involvement. PEPs who are not MRC funded feel confident to involve the public (at 85%), with 2 responders not answering.

"I think I need support and guidance, and advice on how best to get involvement as something that happens at my Institute and make the case for it and have it supported and resourced."

PEP, MRC Institute

MRC PEPs in our review expressed a need and a willingness to develop greater understanding about involvement practice and how involvement approaches could interact with and build on some of the engagement work happening within MRC Establishments. PEPs also requested clear sources of guidance that they could use to advise and share with researchers: currently they look elsewhere for guidance on involvement (e.g. NIHR).

"I think just having an online one stop shop of guidance...it'd be really nice if the MRC could work with the other funders in the UK and just say look here are all the resources in one place and cross link it."

PEP, MRC Establishment

PEPs expressed an ambition for closer working with communities and research participants in planning research and relaying results. Similar to researchers, involvement in non-clinical research was perceived to be more challenging than other research.

PEPs have a good understanding of the opportunities and challenges within their own locations and express some frustration at the lack of value placed on their roles. They – and others – would benefit from developing a community of practice with other similar professionals in other locations.

"We need greater support for public engagement professionals. We are often forgotten both from a funding and supporting research perspective. We have experience and knowledge, help researchers see how we can help."

PEP, MRC Establishment

Skills, learning and development

Considerations

We recommend the MRC invests in PEPs as individuals and as a network. This includes:

- Increasing the number of PEPs per Establishment/ by percentage of funding
- Increasing skills and confidence in public involvement, generally, and with non-clinical research
- Refining PEP roles as described in Section 6.2
- Considering how a network of PEPs might support co-development and delivery of the MRC's involvement and engagement strategy

Mentoring is reviewed as part of Jamieson and Leslie's work [8] and there is an opportunity to build on this, potentially in collaboration with existing initiatives, to include mentoring in public involvement for MRC PEPs.

Given the research funding landscape, and the timely interest in involvement in non-clinical research, the MRC could consider collaborating with other funding organisations to fund and/or support PEPs.

Our findings across all MRC constituencies, and externally, demonstrate the value ascribed to developing a community/ies of practice as a mechanism of learning, support, innovation and delivery. We recommend the MRC builds on its existing PEP network and works with them to co-develop this community and its remit.

PEPs could also support a wider community of interest and practice, including public partners and researchers, and drawing on existing public involvement infrastructure, to deepen learning and practice related to involvement in non-clinical research, connect with local community and voluntary sectors, and contribute to effective grant-making. Several contributors to this report (individuals, networks and organisations) have expressed interest in membership.

"I think there's a long way to go, for everybody, it's not something that [only] we struggle with so that's been quite reassuring."

PEP, MRC Establishment

7.4 Building on the knowledge, experience and confidence of public partners

Findings

It was encouraging to hear that public partners in some MRC research generally reported good experiences of involvement. Most had experience of involvement within individual projects or Centres/Units rather than at a governance or strategic level.

"That has been for me an absolutely standout example of collaboration and engagement between scientists and the public. They, right from the outset, got the... community actively involved, pulled people in for annual meetings, went to our meetings and talked about what they were doing."

Public Partner, MRC

They reported feeling valued in the relationships they had developed with researchers and research teams and felt privileged to be part of MRC activities. Where research programmes had been designed to involve the public from an early stage, this was highly valued by contributors.

"We were involved at every single stage and we felt like our opinions were heard. We were even able to be a part of the interviews and we were asking the questions. In the discussions afterwards they actually considered our opinions when deciding which proposals to take through, so I felt like we were really heard. And we never were made to feel like 'Oh, you know just because you're younger your opinions don't matter' It felt like it was really important what we had to say, and I thought that was amazing."

Public partner, MRC Programme

However, it is also clear that, perhaps at more strategic/governance levels, and including in the wider non-MRC landscape, it is hard for public partners to integrate public involvement into settings where it is deemed difficult.

"We never were made to feel like 'Oh, you know just because you're younger your opinions don't matter.' It felt like it was really important what we had to say, and I thought that was amazing."

Public partner, MRC Programme

Systems and processes

Some public partners who contributed to the review felt that their previous professional work experience enabled them to be involved even if the topic or area wasn't directly related.

"I've retired now but my background is in the pharma industry... with that background I find that has been really helpful to me to understand what is going on in meetings and I really enjoy what I do for the MRC."

Public partner

Some public partners felt that they could be involved in additional areas of research:

"I'm itching to see the results of this stuff the scientists, not unreasonably, love talking about what they're doing, what their hopes are for the future and that's fantastic, but actually I'd like to see what they've done. And that means that somehow, I need help understanding the publications, understanding the results and it's often quite difficult to access that. It is difficult for non-specialists to access that information."

Public partner

Through our workshops, they identified areas for improvement, including:

- Clearer opportunities and expectations of involvement
- How meetings are run to be more inclusive of public partners
- More time to prepare for their involvement, ask questions and seek clarification
- Explanations about the structure and complexity of the MRC, its systems and processes, as it relates to, but not confined to, involvement
- Greater clarity around terminology and acronyms.

A public partner member of the EAG explained the 'gain' to be had by being involved in non-clinical research, which offers useful context in understanding and communicating the difference that public involvement can make to public partners:

- *"Knowledge of how science is carried out"*
- *The nature and practice of non-clinical research*
- *Information about the latest developments on a condition*
- *Confidence that an organisation is addressing equity*
- *Increased feelings of trust towards an organisation"*

"We were making it up as we went along, trying to get them [researchers] to take the public views on board"

Staff member, MRC head office

Considerations

We recommend that the MRC significantly develops its support for public partners by:

- Being clearer – on its website and in more general communications – about the vision, values and practical opportunities for public partners to become involved with the MRC
- Co-developing an induction pack and processes for public partners. This could include information about the MRC as an organisation, what to expect of involvement, training opportunities and beyond
- Considering buddying schemes and peer learning networks, as part of learning and development opportunities for public partners
- Deepening and sharing its learning about the difference that public involvement can make (the 'gain' for public partners)
- Recognising and acknowledging that public partners are more than their life experience and are worthy of investment

There is an opportunity to build on the good will and experiences of current public partners in MRC research to support the co-development of learning and development for MRC staff.

“In the global ‘up-or-out’ system of academic science where research output is the primary measure it appears impossible to dedicate time for anything else.”

Postdoctoral Researcher, MRC
Partnership Institute

8 Recommendation: 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

Some examples of involvement in MRC work exist (see Appendix 5); however, where involvement has happened at MRC head office, the systems, and lack of processes have been constraining.

“So I’m five months down the road from that panel and some of them [public contributors] still haven’t been paid because arguments about what was the value, why did you agree, why did you do it blah blah blah so actually the organisation as a whole is not exactly encouraging this.”

Staff member, MRC head office

Within MRC head office the current lack of guidance related to involvement can be problematic, with some urgency expressed by staff members who are struggling to advise researchers about involvement. They cited this as having a negative impact on research. Given some areas of MRC research sit alongside highly vocal patient advocacy groups, there is also potential reputational risk for the MRC within these situations.

The Research Programme Managers’ Forum selected ‘practical barriers’ e.g. MRC systems and processes as a bigger barrier to public involvement than time, or know-how (33%, 14%, 24% respectively, please note these are not mutually exclusive answers). Within staff interviews, several examples were provided where Programme Manager staff were finding ways to involve people despite not having systems or processes in place.

“Through resource, how can MRC demonstrate that involvement is important and valued?”

Member, EAG

8.1 Finding the time and resource

Findings

Time is an acknowledged barrier/enabler to public involvement, which is supported by findings from our review. From speaking with researchers, and MRC head office staff, this is the most urgent issue to resolve.

Researchers feel under pressure, and the MRC should be aware that additional requests or requirements might be met with resistance, which in itself could be damaging to the perception and conduct of public involvement.

"Time and space to do this the hardest thing."

Principal Investigator, MRC Establishment

Our survey data show that dedicated time for public involvement was the most selected factor in encouraging more public involvement, with 49% of respondents selecting this option. However, only 20% of all researchers/staff working in research environments selected the option that they would do or support public involvement if they had more time. This suggests that whilst dedicated time is an enabler of public involvement, there are other issues to resolve in encouraging researchers to do it.

"Recognition of time trade-offs. We cannot be asked to do everything and do everything at world-leading quality. Ideally without funding."

Principal Investigator, MRC Establishment

"One of the difficult things at my research Institution is that the MRC funded scientists have very little time to take on PPI beyond the scope of their current work."

PEP, organisation/facility or network associated with the MRC

Systems and processes

Researchers point to the need to remove other responsibilities in order to encourage public involvement and to take a view (endorsed by this review) that encourages a more holistic approach to public involvement and engagement:

"I would like to note that I already suffer from a workload that requires far more than contractual hours and therefore I ask you to consider how I should be expected to add yet more to that workload? The most realistic way to 'encourage' me to take part in PPI is actually to relieve me of other less important responsibilities or duties to make space for this new one. I don't regard 'dedicated time' as sufficient for this given my current situation – it sounds like it would simply occupy some of my contractual hours and displace further activities to outside hours."

Head of Department, MRC Establishment

Similarly, we find that PEP roles are overstretched, and we note the finding from Jamieson and Leslie [8] that, due to short turnaround times, communications activities are often prioritised over engagement work. As the expectation for public involvement increases, this will require a greater investment of PEP time.

Conversations with MRC head office staff have also raised issues around time. The estimated amount of time required to establish public involvement within a funding scheme was estimated to be double the time than without public involvement. Research Programme Managers felt that time and resource was crucial for success.

Linked closely to considerations of time and staffing capacity, access to funding was the second most popular survey choice relating to supporting public involvement across MRC's funded portfolio. This was selected by 40% of researcher respondents when selecting 4 of 12 options of what would encourage you in public involvement.

"I think without question that funding is the most critical element. However, the funding support for this work is very limited, and with recent strategic changes at Wellcome, appears to be getting smaller. This is an opportunity for UKRI to lead and set a huge example by committing resources to this as a priority, not a nice to have/add on"

MRC funded Head of Department

"The big problem for me is that funders in my world (NIHR) expect it, and will pay for it in a grant (payment for involvement once you get going), but are less keen to pay for the required infrastructure to make it routine (a PPIE coordinator working across multiple studies). It is transformational to have that kind of infrastructure in place (which we now do but funded from a very large commercial programme grant, so not clearly sustainable in the long run). Different possible models for this, but I don't need expert advice, I need resource to support public partner recruitment and support."

MRC funded Head of Department

Considerations

We recommend that the MRC makes provision for researchers to have ring fenced time per year for involvement. This could include through building in time and resource as part of funding applications and/or terms and conditions of Establishments.

Public Engagement Professionals (PEPs) can play an important role in addressing time pressures and supporting involvement as part of Centres, Units and MRC-funded programmes and projects. MRC should invest in increasing the number of PEPs, and in their learning and development for public involvement (Section 6.2, and 7.3).

PEPs could also support a wider community of interest and practice, including public partners and researchers, and drawing on existing public involvement infrastructure, to deepen learning and practice related to involvement in non-clinical research, connect with local community and voluntary sectors, and contribute to effective grant-making.

Finally, given that public involvement in research needs to respond to a changing public landscape, the MRC should offer a greater flexibility in its funding to promote research and innovation with public involvement. This might be achieved by widening out the existing public engagement seed funding to support involvement, influencing the Medical Research Foundation Policy and Practice funding, or providing additional funding linked to MRC awards in a similar model to the Wellcome Trust Research Enrichment schemes.

8.2 Setting funder expectations and guidance

Findings

Building in a requirement for public involvement within grant applications is undoubtedly a lever for change. This is supported by our scoping review, and findings from interviews and workshops. Yet we've also heard that researchers feel overwhelmed and time poor to establish involvement within their work. Our survey findings demonstrate building public involvement into funding requirements was selected as the least encouraging factor for researchers/ those working in research environments, selected by 15% of respondents (selected 4 of 12 options). The MRC needs to use this awareness to inform any future decision making about if and how to set funding expectations for researchers, and acknowledge how researchers feel within any communications for research audiences. Several funding organisations have described using maturity models for changing expectations which are described below.

"Making it an essential component of a research grant application only works if there is clear evidence for applicants that it genuinely impacts on the funding outcome. Otherwise it breeds resentment at the requirement to do it for those who are not willing, frustration for those who put effort into it but see no reward for having done so, and ultimately devalues it. There should be an expectation to include it where is/can be appropriate / integral and opportunities for additional linked funding for less integral PE post research grant award."

Principal Investigator, organisation/facility or network associated with MRC

Systems and processes

Additionally, we've heard from members of PIPOG that would like to see the culture and practice of public involvement change because researchers can see the added value it brings, rather than doing it because they've been told to.

During the review, considerations about the perceived difference in involvement with non-clinical to clinical research have been applied to how to tackle funding requirements, and MRC head office staff have questioned how this could be adopted to 'business as usual'.

Other funding organisations who fund across both non-clinical and clinical and applied research have differing approaches to expectations for public involvement within grants (see Appendix 2 – Case Study D). CRUK has an overarching statement of intent, yet only requests PPI plans explicitly within clinical and applied research applications. However, funding is available for involvement in all CRUK funded research, and public involvement within discovery research is an area of development for CRUK and therefore strongly encouraged and set to increase.

Parkinson's UK has a more universal approach and is actively working on supporting public involvement in lab-based research (see referenced toolkit). It adopts an expectation for involvement across all project grants – which fund both non-clinical and clinical – but does not set this expectation in one other specific grant scheme, the Drug Accelerator Awards.

From what we know, the Wellcome Trust expects clinical researchers, and global health researchers to involve people and patients where needed, but there aren't standard expectations for non-clinical research grants. However, with a long history in funding public engagement, Wellcome is attuned to the needs for public involvement and engagement for the themes and topics identified by this MRC brief. This is exemplified by (co-)/funding programmes including Understanding Patient Data, Human Development Biology Initiative, Animal Research Nexus amongst others. It's noteworthy that the Wellcome Trust has recently closed down all standalone funding schemes for public engagement.

Finally, and relating to MRC's grant systems and processes more generally, interviews with MRC head office staff show that current processes limit awards to academics/ research-related organisations only, and that the timescales and nature of project-by-project grants can constrain relationships with public and community partners, and limit their diversity.

Considerations

Drawing on the opportunity for MRC to demonstrate sector leadership in involvement with non-clinical research, and our findings of misconceptions and the 'stereotyped PPI', we recommend that the MRC explores the potential to build consideration of involvement as standard into all funding programmes. Whilst this might be considered radical, it demonstrates the importance and value that MRC places on involvement, and the UKRI/MRC commitment to public involvement. It also enables clear and consistent messaging and addresses the misconception that public involvement is not relevant for non-clinical research. Importantly, this approach wouldn't mean that all researchers involve the public, but they would have to consider if and why involvement is needed. This recommendation supports and builds on the recommendation made by Jamieson and Leslie, that consideration of public engagement with research should be built into all funding programmes.

An alternative option, similar to that of e.g. CRUK, is drawing on the commitment to public involvement as a statement of intent, with MRC setting different expectations for public involvement across funding schemes. There are pros and cons to each option, however, the evidence from other funders suggests that this approach would not lead to the increased adoption of involvement in non-clinical research sought by the MRC.

In either case, MRC funding guidance should draw on the examples within this review to describe areas of non-clinical research where public involvement is a priority, and importantly, why. This might include the priority areas within this brief such as big data, animal research or stem cell research, where there are unresolved/ rapidly changing societal issues, high interest or contention. We recommended a collaborative approach to writing grant guidance, involving researchers, PEPs and public partners.

Clearly, *how* public involvement expectations are implemented and communicated plays a significant role in ensuring success, and there are both cultural and practical elements of change which are essential before a requirement is mandated.

In discussion with the MRC Project Team and the EAG, and learning from the experiences of other funders, we recommend a maturity model to introduce public involvement requirements into funding programmes. The MRC is keen to learn by pilot and review and we think this could be a helpful approach to guide a maturity model which is universal in the longer term. The learning here will be useful in establishing funding processes, understanding researchers' needs, and developing involvement practices.

Systems and processes

Steps might include:

- a) Addition of a public involvement question into all funding applications, supported by guidance and resources. The question is not assessed.
- b) Following a set period (circa 2 years), the involvement question in all applications is assessed but the funding decision is not contingent on this assessment.
- c) Following a set period (circa 1 year) full maturity: In all applications, the public involvement question is assessed and poor public involvement plans – where involvement is considered a priority – is a case for rejection, or for further support to improve.

A key question for consideration by the MRC is whether grant applications should be rejected because of absent/poor quality practice. We would suggest that, at least in the first years of implementation, that the MRC has capacity within head office public involvement professionals and/or programme management staff to provide support and signposting to grant applicants where the public involvement plans are poor or absent.

Expectations and guidance should be communicated to the research community throughout, with signposting for training and support provided.

Finally, we recommend amending grant application processes to enable (co)applicants from non-academic institutions, e.g. community organisations, and building in flexibility and longer funding timescales to enable researchers/applicants to build and maintain long term relationships with public partners. This approach is being actioned currently by UKRI, and recommended within the recent Young Foundation report [1].

8.3 Funding assessment and decision making

Findings

The majority of examples of public involvement from MRC head office staff we spoke with were in involving people and patients within grant decision-making. This was often within strategic programmes outside of 'business as usual' or through working in partnership with other funders where public involvement is more commonplace e.g. NIHR. Staff perceptions of the quality of involvement in funding assessment and decision-making, and the difference it makes, are that it differs greatly across the MRC's practice. The example of the Adolescence, Mental Health and the Developing Mind programme demonstrates significant impact on all constituents, with reflective practice and continuous improvement embedded in ways of working e.g. in improving guidance for lay summaries to be reviewed by young people. However, we heard other examples where MRC head office staff found involvement in grant decision making to be tokenistic, with unclear guidance and processes. MRC head office staff gave examples of being unsure of how best to handle disagreements between public partners and academic experts within funding committees, and also their fear of this happening in future.

"How do you tension across views of 'experts' vs lived experience experts?"

Staff member, MRC head office

Systems and processes

The MRC was a lead partner on the Global Effort in COVID-19 Health Research Programme (GECO) which involved both Public Involvement Practitioners and public partners in funding assessment and decision-making. The MRC could look to GECO's evaluation as a source of learning about the involvement of public partners in grant decision-making. Appendix 2: Case study E provides a detailed summary from Parkinson's UK detailing their best practice in guidance for researchers, and lay review, and involvement in funding committees.

Considerations

Within this review, our focus has been on the foundational elements required for the co-development of the MRC's public involvement and engagement strategy. As such, and drawing on the recommendations and considerations in this report, the MRC has steps to take before recommendations on funding assessment and decision making can be formed.

Drawing on the values and ambitions of the MRC, meaningful public involvement within funding assessment and decision-making will be needed and valuable for the MRC in maintaining trust, transparency, relevance and accountability. We envisage public involvement here to be more nuanced in approach, dependent upon the funding scheme, its societal context and the nature/content of the applications themselves. Further and ongoing work will be needed to explore this, alongside learning, confidence and culture change resulting from recommendations in previous sections.

Finally, examples were provided of, e.g. professionals such as Public Health Leads acting by proxy in funding committees as a means to consider societal/personal implications. MRC could consider working with internal public involvement staff and/or MRC funded PEPs to review and assess funding applications, and advise and support applicants with public involvement planning and implementation as appropriate.

References

References contained in this report are listed below. Links to further useful reading, information and resources are provided in Appendix 7.

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Abbreviations

CRUK	Cancer Research UK
EAG	External Advisory Group
EDI	Equality, diversity and inclusion
HEI	Higher education institution
HRA	Health Research Authority
ISPOR	The Professional Society for Health Economics and Outcomes Research
NCCPE	National Co–ordinating Centre for Public Engagement
NIHR	National Institute for Health and Care Research
PE	Public engagement
PEP	Public engagement professional
PI	Principal investigator
PIPOG	Public Involvement Project Oversight Group
PPI	Patient and public involvement
PPIE	Patient and public involvement and engagement
UKRI	UK Research and Innovation

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MRC Programme Managers Forum
Michelle Bendix, Parkinson's UK
Anne Croudass, CRUK

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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