

VOCAL



Appendix 4

A patient's desktop review of public involvement at the MRC

“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



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Research
Council**

MRC Desktop review

Vocal was commissioned by the Medical Research Council (MRC) to undertake a review of public involvement in research (February–September 2022), with a specific focus on non-clinical health and biomedical research.

This Appendix provides notes of desktop search of patient and public involvement (PPI) in websites related to the MRC and its Establishments. This review was carried out by Derek Stewart, patient advocate and member of the Vocal delivery team.

We, at Vocal, began our search as if through the eyes of an individual member of the public and/or patient trying to find how to become actively involved with MRC funded facilities and initiatives. We asked ourselves about what information, advice and support we might be able to find to be involved either locally or for a special personal interest, elsewhere.

We looked specifically at how we might be able to inform, influence and shape research in this landscape by adding value from our personal experiences. We sought out partnership activity more than engagement in science or taking part in studies.

It is pleasing to note that there is a good amount of public involvement taking place with the MRC and we have highlighted some examples to illustrate basic guidance, existing patient groups, useful collaborations including charities as well as trial methodology. We have also noted where information and signposting was less visible, and some suggestions for development.

Basic information about Patient and Public Involvement (PPI)

It was good to see that upon entering PPI in the UKRI search engine that the first few referrals take you to this [MRC guidance](#). The [MRC Clinical Trials Units at UCL](#) has some comprehensive guidance and informative videos about PPI.

In terms of MRC Institutes, Health Data Research UK has the most substantial presence and information with [Patient, Public Involvement and Engagement \(PPIE\)](#). The [UK Dementia Research Institute](#) has established a [Lived Experience Group](#) in 2019 placing it at the heart of their work.

The Centre for Environment & Health has developed a Public and Community Oversight Group (PCOG) at Imperial.

MRC Desktop review

Strategic collaboration

A number of the MRC facilities have sensibly collaborated with their strategic partners – NHS Trusts and Academic Institutions or associated organisations such as NIHR Biomedical Research Centres, Academic Health Science Partnerships, etc. This means they can build and draw upon existing PPI knowledge, information and infrastructure.

For example, the [Centre for Global Infectious Disease Analysis](#) – takes you to Imperial College London which has a good [selection of information](#) on PPIE. The [University of Glasgow Centre for Virus Research \(MRC CVR\)](#) has used MRC Proximity to Discovery Fund [to identify and develop public involvement](#).

The Centre for Drug Safety Science links to wider work at University of Liverpool which does include [molecular science and public involvement](#).

A few MRC facilities have used the opportunity to strengthen with medical research charities who are major funders of the work.

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[Versus Arthritis](#) supports the Centre for Integrated Research into Musculoskeletal Ageing is a collaboration between the Universities of Liverpool, Sheffield and Newcastle as well as Centre for Musculoskeletal Ageing Research, a collaborative research venture between Birmingham and Nottingham Universities. Clicks on these pages takes you straight to Versus Arthritis and their [Involvement pages](#) can be found [here](#).

The Brain Network Dynamics Unit at the University of Oxford (MRC BNDU) PUBLIC INVOLVEMENT appears under Communications through their [Outreach page](#) where there is mention of work with the [Oxford Parkinson's Disease Centre](#).

Trial Methodology

Though not within the list of MRC Institutes, Units and Centres, the MRC [Better Research Better Methods guidance portal](#) takes you to the [MRC/NIHR Trials Methodology Partnership](#) which has [practical information about PPIE](#).

MRC Desktop review

Website navigation

There appeared to be little or no mention of public involvement on the landing page of the MRC itself, or on Institutes, Units and Centres. Occasionally it sits within a section about engagement but was most frequently uncovered with a search engine rather than being prominent on the page. Sometimes, a link stating 'to get involved' was in fact an invitation to be a research participant.

From a patients and public point of view, it would be useful to have ways to find out more about:

- 1) The work of the MRC
- 2) Discovering how to take part in studies
- 3) How to get actively to use our life experience for better and more relevant research.

The lack of clarity around these three routes was what made it difficult to navigate rather than necessarily badging them with involvement, participation or engagement (which are our more internal means of classification).

Purpose

In general, there appears to be little mention of the principles and purpose of public involvement and the importance of open science, transparency and the pursuit of research excellence for public good and trust. Equality, Diversity and Inclusion is rarely mentioned. A couple of sites are about work going on in Africa where it appears there is more community feel to projects though public involvement does not seem to be mentioned.

Coordination

Local MRC collaborations, where they exist, are really helpful but no site we found took us back to the central MRC advice. The information we found was good yet lacked any coordinated approach about the specific of public involvement in this landscape.

Summary

We were able to access some good examples across the MRC, especially about public involvement in general with practical advice. There is less information about public involvement in the specific area of non/pre-clinical research although that is increasing in the wider landscape, nationally and internationally.

It would be good to know what actual public involvement was going on in each facility and a list of any reported activity as well as support for patient and members of the public to be involved in a meaningful way.

MRC Review of public involvement in research (2022)

Complete list of documents

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

Appendix 1 Methodology of the MRC public involvement review

Appendix 2 Landscape review of public involvement in non-clinical research

Appendix 3 Tweetchat #Involvement_Preclinical

Appendix 4 A patient's desktop review of public involvement at the MRC

Appendix 5 Examples of MRC public involvement

Appendix 6 Public involvement in research survey

Appendix 7 References and toolkits about public involvement in research

Please see full list of acknowledgements in Main report

Photography

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Vocal

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