

# VOCAL

Examples of  
MRC 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. 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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## Introduction

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

This Appendix provides examples, gathered throughout our landscape review, of public involvement and collaborative working between public partners and researchers within MRC Head Office, MRC Establishments, and the funded portfolio.

The information has been collected from interviews, workshops and information provided by the MRC Project Team and Public Involvement Project Oversight Group, and followed up with desk research. Therefore, it is not an exhaustive list, but does provide a sense of how, through MRC funding, public involvement practice has emerged over recent years.

We have found a variety of examples across both clinical and non-clinical research. Importantly, many of the examples demonstrate a variety of purposes for public partners with involvement as advisors informing the research cycle, but also within more strategic and governance roles, suggesting a maturity of involvement practice in some instances.

## Case Study C

### MRC Human Immunology Unit (University of Oxford) PPI group for non-clinical research

Quotes provided by Professor Hal Drakesmith.

#### Introduction and context

The Oxford Blood Group encourages patients and members of the public to be involved with the Haematology and Stem Cells theme at the NIHR Oxford Biomedical Research Centre. It is a patient engagement group for anyone who has experience of a haematology (blood) condition, either now or in the past, as a patient or someone close to a patient.

In this example, public involvement in non-clinical research had been developed following on from an initial broader focus on public engagement. It took around two years to develop and establish the approach to public involvement. A concerted approach was taken to build buy-in and support from the research team. The Oxford Blood Group involvement work is a collaboration across research teams of clinical academics and non-clinical researchers.

#### What was the activity?

Establishing the Oxford Blood Group took around 2 years. The original plan was to focus on young adult public contributors with Acute Lymphocytic Leukaemia and for them to work with to 2-3 non-clinical researchers in the MRC Molecular Haematology Unit. However, recruiting young people through specialist clinical teams and through people's cancer groups in London proved to be challenging.

The effort was refocused to develop a bespoke PPI group including people with haematological cancers and with inherited haematological diseases. The focus also shifted to 'genomics' as a topic rather than individual lab-based research projects.

The 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.

*We got really concentrated around workshops and made it clear what the benefits were to everybody involved, including...for grant applications, but also to inspire the scientists to actually work harder on their projects, then the PPI buy in just changed really quickly."*

#### Observations and findings

*"Patients have been really interested and engaged, have been reading and reviewing notes between sessions. The scientists found it really useful to be challenged in how they explain their work and main concepts."*

*"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."*

These discussions have helped to highlight some different priorities between public contributors and researchers.

*"What we've overall discovered...from PPI [is]... that what doctors think is important to patients often isn't...There's certainly not a total overlap and in fact there's often surprisingly minimal overlap."*

## Case Study C

### How could this case study support the MRC?

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 team was crucial:

*"What we did is to change the culture in the Institute and that required people at PhD level, but it also required...the institutional officers and leadership from the very top of the Institute and then having a public engagement officer and having champions who would do that."*

This example shows the benefit of collaborating across research teams and involvement infrastructure, with greater join-up across the research pipeline. There is clear motivation for both the researchers, and the public partners, and shared learning, especially in language and communication across all constituents.

### Further information

<https://www.imm.ox.ac.uk/news/oxford-blood-group-launch>

<https://www.imm.ox.ac.uk/research/oxford-centre-for-haematology/patient-public-engagement>

## Examples

These examples include selected text (italicised) directly taken from listed sources. Non-italicised text is summarised from the sources listed.

### 1. MRC Centre for Environment and Health - Public and Community Oversight Group

*The Public and Community Oversight Group (PCOG) has been set up in conjunction with the also newly formed HPRUs (NIHR Health Protection Research Unit) in Environmental Exposures and Health and in Chemical and Radiation Threats and Hazards. The aim of the advisory network is to ensure that the public and community voice impacts the research strategies, projects and functions making sure our research is accountable, transparent and relevant to the public.*

**Source:**

<https://environment-health.ac.uk/public-and-community-oversight-group-pcog/>

### 2. MRC Science Archive Data Access Committee

*In 2019, MRC set up an independent Data Access Committee to manage access to the MRC Science Archive.*

*The committee makes sure that data is available for re-use in research with appropriate safeguards to protect participant confidentiality. The committee produces a report of activity each year. The committee of six people includes two public involvement representatives.*

**Source:**

<https://www.ukri.org/publications/mrc-science-archive-data-access-committee-annual-reports/>

### 3. MRC Molecular Haematology Unit / MRC Weatherall Institute of Molecular Medicine - Public Steering Group

*To ensure patients and carers had a voice in the research agenda surrounding rare anaemias, a steering group was formed. Patients, carers, physicians, researchers, and patient support group representatives were brought together to discuss key issues and research questions for the study of rare anaemias. A report on the 2-year project was published on the James Lind Alliance Setting Partnership website.*

**Source:**

<https://www.imm.ox.ac.uk/news/patient-involvement-partnership-sets-priorities-for-rare-inherited-anaemias>

**See also:**

<https://www.sciencedirect.com/science/article/pii/S0006497119419769>

## Examples

### 4. MRC/CSO Social and Public Health Sciences Unit - Youth Advisory Group

*The Transdisciplinary Research for the Improvement of Youth Mental Public Health (TRIUMPH) Network brings together young people with academics, health practitioners, and policy-makers to find new ways to improve youth mental health and wellbeing, especially among those where need is greatest.*

*The TRIUMPH Youth Advisory Group are a group of 16 young people aged 16–24 who are involved in the strategic development of the network and in supporting wider youth participation in the network's activities.*

**Source:**

<http://triumph.sphsu.gla.ac.uk/young-people/>

**See also:**

<http://triumph.sphsu.gla.ac.uk/wp-content/uploads/2020/04/TRIUMPH-Research-Priorities-Report.pdf>

### 5. Health Data Research UK – (Public Advisory Board, Governance Structure and research specific panels)

*Patient and Public Involvement and Engagement, or PPIE for short, is key to everything we do at HDR UK.*

*To really benefit from working with patients, carers and the public, we encourage and support all teams and projects at HDR UK to be set up in a way that allows for meaningful involvement. To support our teams and partners to achieve this, we worked with patients, members of the public, staff members and other experts in the field to develop a set of Guiding Principles.*

*Patients and members of the public have been involved in a range of activities across the HDR UK Institute and we've seen the impact and value this brings. This includes work by our Public Advisory Board, public contributors in our Governance structure, involvement of public contributors in the Data and Connectivity National Core Study, and groups and panels set up to support the Health Data Research Hubs and research priorities. Patients and members of the public also get involved with one off opportunities, such as workshops and surveys, to provide their perspectives and help shape our work.*

Website includes

- [Up to date opportunities](#)
- [Patients and Public Involvement Impacts and Outputs](#)

**Source:**

<https://www.hdruk.ac.uk/about-us/patient-and-public-involvement-and-engagement>



## Examples

### 6. The UK Dementia Research Institute - Lived Experience Group

*The UK Dementia Research Institute exists to improve the lives of those at risk of or living with dementia, and their carers. We believe our research is strengthened by input from people with lived experience of neurodegenerative diseases.*

*We formed our Lived Experience Group in 2019, made up of people living with different forms of dementia and people who have cared for or are caring for loved ones. Members of the group act as advocates and ambassadors for the institute, helping explain what we do and sharing our outcomes with wider networks, to help build a supportive society. Members also provide patient and public involvement feedback to UK DRI researchers.*

**Source:**

[UK DRI's Lived Experience... | UK DRI: UK Dementia Research Institute](#)

### 7. The Advanced Pain Discovery Platform: Mapping the Complexity of Chronic Pain

This is a £24 million programme to deepen understanding of pain and support new approaches to treatment across a range of chronic and debilitating conditions including arthritis by creating a series of consortia that bring together researchers across biomedical, social, informatics and data sciences.

There is one Patient Representative on the International scientific advisory board, and Patient Reviewers and PPI Representatives have been included in Funding opportunity review panels.

It is delivered by the Medical Research Council, the charity Versus Arthritis, the Biotechnology and Biological Sciences Research Council and the Economic and Social Research Council.

**Source:**

[Advanced pain discovery platform \(APDP\) – UKRI](#)

### 8. MRC Human Genetics Unit - DecodeME

*We aim to find genetic causes of why people become ill with myalgic encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS) with our ground-breaking research.*

*People with ME/CFS are at the heart of the ME/CFS Biomedical Partnership and are involved in all aspects of the research.*

*The project team is supported by numerous people with ME and carers who help with recruitment, communications and marketing.*

## Examples

### Patient and Public Involvement (PPI) Steering Group

*The Patient and Public Involvement (PPI) Steering Group is made up of people representing groups or networks from the ME/CFS community.*

*The Steering Group will work with the study's Management Group to put public involvement at the heart of the research project, from start to finish, and ensure the National Standards for Public Involvement are met.*

#### Source:

<https://www.decodeme.org.uk/>

## 9. Adolescence, Mental Health and the Developing Mind

This is a £35 million programme to support better understanding of the developing adolescent mind and the genetic, physiological, social and cultural factors that shape it and influence lifelong mental health, educational attainment, identity, social relationships and behaviour.

*The programme has established a young person's advisory group ensure that the direct experience of young people living with mental health issues is at the centre of the programme. The group provides guidance and advice as part of the programme's governance structure. It also helps to shape the involvement of young people on our funding panels and assessment processes and co-facilitates training as part of this.*

Beyond the advisory group, a wide group of young people are involved in the programme. *This includes young people helping us to review proposals, sit on funding panels, participate in interviews and contribute to scoping workshops.*

It is delivered by the Medical Research Council, with the Arts and Humanities Research Council and the Economic and Social Research Council.

#### Source:

<https://www.ukri.org/what-we-offer/browse-our-areas-of-investment-and-support/adolescence-mental-health-and-the-developing-mind/>

## 10. The Dundee Parkinson's Research Interest Group - Research Interest Group

*The Dundee Parkinson's Research Interest Group (DRIG) began as a result of discussions between people affected by Parkinson's (PaP), MRC PPU (Protein Phosphorylation and Ubiquitylation Unit) researchers and clinicians and Parkinson's UK (an MRC PPU funder) at the MRC PPU in November 2016.*

*This project has gone above and beyond achieving the Unit's strategic public engagement and communications objectives – not only has it enabled communication and engagement*

## Examples

*with people affected by Parkinson's, it has gone a step further and proactively involved people affected by Parkinson's in research design and funding applications.*

Source: MRC Protein Phosphorylation and Ubiquitylation Unit at the University of Dundee Case study from 2018–2019 PEC Evaluation Report

### Source:

[Dundee Research Interest Group | Dundee Research Interest Group \(drig.org.uk\)](http://drig.org.uk)

## 12. MRC Clinical Trial Unit – AALPHI study

### Engaging and involving young people brings benefits to research studies

*We engaged and encouraged young people to become advocates and disseminators of research findings from the AALPHI study.*

*This project has demonstrated that if you involve young people in research that is about them, it helps ensure results are communicated in a way that young people understand and, in this case, successfully increases their knowledge about HIV.*

*We hope the AALPHI project will make researchers think about how they can explore imaginative ways of involving patients and the public in future studies and encourage the active involvement of patients in challenging areas, such as HIV and young people*

### Source:

<https://webarchive.nationalarchives.gov.uk/ukgwa/20201225000727/https://mrc.ukri.org/news/blog/engaging-and-involving-young-people-brings-benefits-to-research-studies/>

## 13. UCL Institute of Child Health: Working with Moorfield Biomedical Research Centre's Youth Advisory Group

### Using children's attitudes to shape childhood vision research

*We approached the 'eye-YPAG'; a Young Persons Advisory Group run by the National Institute for Health Research Moorfields Biomedical Research Centre which focuses on eye and vision research....*

*By speaking directly with children and young people (both in person and virtually) we gained their honest opinions on our research questions. And they helped make our study documents accessible for children with eye and vision disorders.*

*PPI should be a mainstay in all childhood eye and vision research, particularly for 'data only' studies as researchers can engage directly with patient representatives themselves.*

### Source:

<https://www.ukri.org/blog/using-childrens-attitudes-to-shape-childhood-vision-research/>

## 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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