



01 May 2025

Dear [REDACTED]

Freedom of Information request: FOI2025/00361

Thank you for your Freedom of Information request received on the 31 March in which you requested the following:

Your request:

I am conducting an FOI-based study to explore the current state of community and/or patient public involvement and engagement (PPIE) within high-level agenda setting research boards in organisations funding health research in the UK.

May I please ask for the following information under the FOI act regarding both Research England and UK Research and Innovation.

- 1. Does your organisation have an executive board where health research funding strategy is set?*
- 2. If yes, is there a PPIE (patient public involvement engagement) representative on this board with the specific remit to provide insights into research agenda setting from the perspective of a patient with lived experience of health issues or as a member of the public/community? [I am not referring to the presence of a lay chair].*
- 3. Is there a PPIE advisory structure (e.g. board, committee, panel) which provides PPIE insights to inform the work of the executive board? (not within individual funding calls- I refer to high level feedback into your research strategy meetings) Yes/no.*
- 4. Concerning health research, is there a PPIE representative on any lower-level board (e.g. individual funding calls).*
- 5. If yes to question 2, 3 or 4, please provide a list of members of the board and/or PPIE advisory structure with designated roles/remits (not names).*
- 6. Are PPIE representatives remunerated?*
- 7. Do you require PPIE representatives to do any training? If yes, please specify*
- 8. I realise that some of this information may already be available. However, I was unable to locate it. So, if it is, please provide me with a link to the data.*

Our response:

I can confirm that UK Research and Innovation (UKRI) holds some information relevant to your request. Please see the information below.

UKRI is a non-departmental public body sponsored by the Department for Science, Innovation and Technology (DSIT) and brings together the seven disciplinary research councils, Research England and Innovate UK. More information about UKRI can be found [here](https://www.ukri.org/who-we-are/about-uk-research-and-innovation/)¹.

As this is the case, to provide a comprehensive response to your request it has been necessary to consider information held by all the research councils that fall under the umbrella of UKRI, not just Research England, and

¹ <https://www.ukri.org/who-we-are/about-uk-research-and-innovation/>

this is reflected in our response below. We also note that we have previously provided information relevant to the Medical Research Council (MRC) in response to the same request under [FOI2025/00113](#)².

1. *Does your organisation have an executive board where health research funding strategy is set?*

The [UKRI Executive Committee](#)³ sets the [strategy for UKRI](#)⁴, which includes health research funding. This filters down through the work of the other research councils, with a specific focus from the MRC on setting strategy for health research funding at executive board level, as outlined in our response to FOI2025/00113.

To address the specific question in regard to Research England, as a funder of predominantly formula-based block grants to universities, Research England does not have a specific health research funding strategy. Higher Education Providers receive their allocation as a block grant and then determine how to allocate this funding according to their own institutional strategy.

2. *If yes, is there a PPIE (patient public involvement engagement) representative on this board with the specific remit to provide insights into research agenda setting from the perspective of a patient with lived experience of health issues or as a member of the public/community?*

There are no PPIE representatives on the UKRI Executive Committee, or on any of the other research council's boards at this level.

3. *Is there a PPIE advisory structure (e.g. board, committee, panel) which provides PPIE insights to inform the work of the executive board?*

There is no PPIE advisory structure currently in place.

In addition to the information provided for MRC in FOI2025/00113, the Engineering and Physical Science Research Council (EPSRC) [Health Technologies Strategy](#)⁵ has a key focus on PPIE. The strategy was developed via an inclusive process of community engagement over a 12-month period, which included a series of workshops, roundtable meetings and written contributions via an open survey and involved some patient and public representatives.

4. *Concerning health research, is there a PPIE representative on any lower-level board (e.g. individual funding calls).*

None of the research councils currently have PPIE representation within high-level agenda setting research boards or committees, but there are examples of PPIE representation within a range of specific strategic initiatives and/or funding calls, in addition to those previously provided in FOI2025/00113. These include:

- [Research and partnership hubs for health technologies: full stage](#)⁶ funding opportunity (EPSRC)
- [Technologies to enable independence for people living with dementia](#)⁷ funding opportunity (jointly funded by the EPSRC and the National Institute for Health and Care Research (NIHR))
- [IMPACT](#)⁸ – the UK centre for implementing evidence in adult social care (jointly funded by the ESRC and the Health Foundation)
- [Mindset](#)⁹ – a £20m programme of investment and support in the UK's digital mental health sector (Innovate UK in partnership with the Health Innovation Network (HIN) South London and the NIHR MindTech MedTech Cooperative)

² <https://ukri.disclosurelog.co.uk/disclosures/97f06169-87c2-4060-991a-6f7bf1d0e15c>

³ <https://www.ukri.org/who-we-are/how-we-are-governed/executive-committee/>

⁴ <https://www.ukri.org/wp-content/uploads/2022/03/UKRI-210422-Strategy2022To2027TransformingTomorrowTogether.pdf>

⁵ <https://www.ukri.org/publications/epsrc-health-technologies-strategy/epsrc-health-technologies-strategy/#section-enablers>

⁶ <https://www.ukri.org/opportunity/research-and-partnership-hubs-for-health-technologies/>

⁷ <https://www.ukri.org/opportunity/technologies-to-enable-independence-for-people-living-with-dementia/>

⁸ <https://impact.bham.ac.uk/>

⁹ <https://www.ukri.org/what-we-do/browse-our-areas-of-investment-and-support/mindset-extended-reality-xr-for-digital-mental-health-programme/>

- [Mobilising community assets to tackle health inequalities](#)¹⁰ – a £26m interdisciplinary programme to support improvements in health inequalities in the UK (a partnership between the AHRC, BBSRC, ESRC, NERC, MRC and National Centre for Creative Health (NCCH)).
- [Adolescence, mental health and the developing mind](#) – a £35m programme to support and fund research into mental health problems in young people (a partnership between AHRC, ESRC and MRC).

5. *If yes to question 2, 3 or 4, please provide a list of members of the board and/or PPIE advisory structure with designated roles/remits (not names).*

Research and partnership hubs for health technologies

- For this initiative, all hubs were required to integrate PPIE at all stages of the research and innovation process.
- There was a specific assessment criterion on PPIE at full proposal (expert review and interview) and panel members were utilised with a track record in PPIE.

Technologies to enable independence for people living with dementia

- 3 PPIE panel members, recruited through a partnership with the Alzheimer's Society, were included at the interview stage of the assessment.

IMPACT

- The funder's governance includes an oversight group which provides independent expert advice to the funders on their management of the investment, advocates for the programme and supports the funders in identifying potential connections between the initiative and relevant external stakeholders and activities.
- Membership of this group includes representation from government departments and devolved nation advisors, academic and stakeholder representatives, knowledge mobilisation expertise, and people with lived experience of adult social care.
- The group has a Chair and a Vice Chair who are individuals from national social care organisations, has 23 members of which 3 are individuals with living experience of social care.

Mindset

- To ensure PPIE this programme includes skilled assessors with lived experience on funding panels, at interview stage and on the advisory board of the [Mindset XR, Innovation Support Programme](#)¹¹ to provide general insights and guidance.
- The advisory board consists of 13 members from a range of organisation and includes 2 individuals who are considered expert by experience.

Mobilising community assets to tackle health inequalities

- The programme has and continues to involve the public in several areas, with the main focus that is has been co-created and co-delivered with people who have lived experience of the issues being researched.
- During commissioning of the phase 2 consortia-building projects included 1 lived experience reviewer per project. During phase 3 large scale projects, 2 lived experience reviewers were included per project and there were also lived experience members on the panel.
- The programme level advisory group consists of a small group with lived experience to advise on how best to engage and bring together learning from the communities involved across the programme. This includes members from the organisation [Co-Create](#)¹².

¹⁰ <https://www.ukri.org/what-we-do/browse-our-areas-of-investment-and-support/mobilising-community-assets-to-tackle-health-inequalities/>

¹¹ <https://healthinnovationnetwork.com/resources/mindset-xr-innovation-support-programme/>

¹² <https://www.wearecocrete.com/>

- Several of the projects have convened their own advisory groups made up of people with lived experience in the areas they are researching and community involvement is a central pillar across all projects.

Adolescence, mental health and the developing mind

- A young person's advisory group has been established to ensure that the direct experience of young people living with mental health issues is at the centre of the programmes. The group provides guidance and advice as part of the programme's governance structure.
- Beyond the advisory group, a wide group of young people are involved to help review proposals, sit on funding panels, participate in interviews and contribute to scoping workshops.

6. Are PPIE representatives remunerated?

Lived experience members of the IMPACT oversight group are paid for their time to prepare for and attend meetings and time for any work requested by funders outside of meetings. The funders' payments to lived experience members use the rates set out in the [National Institute for Health and Care Research \(NIHR\) public contributor payment policy](#)¹³, as is also the case for the EPSRC funding opportunities.

PPIE representatives on the Mindset programme are remunerated with the same rate as Innovate UK expert assessors for online assessments or interviews.

For the Mobilising community assets to tackle health inequalities, lived experience members are remunerated for their involvement in the assessment panels.

7. Do you require PPIE representatives to do any training?

There are no specific requirements for training for these individuals.

8. I realise that some of this information may already be available. However, I was unable to locate it. So, if it is, please provide me with a link to the data.

Links to relevant information have been provided above.

If you have any queries regarding our response please do let us know. If you are dissatisfied with the handling of your request, you have the right to ask for an internal review, explaining which elements of this decision you disagree with and why. Internal review requests should be submitted within 40 working days of the date of our response and should be addressed to:

Head of Information Governance
Email: foi@ukri.org

Please quote the reference number above in any future communications.

If you are still not content with the outcome of the internal review, you may apply to refer the matter to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the review procedure provided by UKRI. The Information Commissioner can be contacted at: www.ico.org.uk.

If you wish to raise a complaint regarding the service you have received or the conduct of any UKRI staff in relation to your request, please see [UKRI's complaints procedure](#)¹⁴.

¹³ <https://www.nihr.ac.uk/nihr-public-contributor-payment-policy>

¹⁴ <https://www.ukri.org/who-we-are/contact-us/make-a-complaint/#skipnav-target>

Yours sincerely,


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