

Agenda item:	14
Attachment:	B

HRA Board Cover sheet

16 March 2022

Title of paper:	Embedding public involvement in health and social care research: actions the HRA will take to support the sector-wide shared commitment
Submitted by:	Jim Elliott & Barbara Molony-Oates
Summary of paper:	The development of a collaborative initiative co-led by the HRA to embed public involvement in all health and social care research through a joint statement of commitment and actions by research funders, sponsors and regulators.
Reason for submission:	For information
Further information:	
Budget / cost implication:	None
Dissemination:	HRA News for staff prior to public launch to the UK research community in collaboration with the partner organisations listed in the paper. Launch nationwide on the 11 th of March 2022
Time required:	20 Minutes

Embedding public involvement in health and social care research: actions the HRA will take to support the sector-wide shared commitment

Background

The Public Involvement in a Pandemic report, which the HRA published in January 2021, highlighted that public involvement is not widely embedded in health and social care research across the UK. When there was pressure to rapidly develop research to address COVID-19 the public were involved much less than they had been before. The report highlighted a lack of system-wide leadership and collaboration as well as fragmented information and communication.

To address the gaps in leadership and collaboration the HRA is co-leading with the NIHR the development of a collaborative initiative to embed public involvement across the whole of the health and social care research sector in the UK. This is taking the form of a two-part shared statement of commitment that fifteen organisations (listed at the end of the Appendix) will sign up to initially. This will be followed by a campaign of communications and stakeholder engagement to bring other research organisations on board with the initiative and to reinforce the key message that public involvement is important, expected and possible in all health and social care research.

The common statement of commitment to public involvement

The first part of this 'shared commitment to public involvement' is a statement that all the organisations are signing up to. The final version that has been signed off by all organisations is presented in the Appendix for information. This version was approved by the executive committee on the 2 February 2022

Developing the HRA's statement of actions to embed public involvement in research

The second part of the 'shared commitment' is a statement of the actions that each organisation will take to support the intent in the common statement. The HRA's specific statement has been developed as set out below and is presented in the next section for comment and agreement by the Board. These statements were approved by the executive committee on the 2 February 2022

The Public Involvement Team organised three workshops (14 December, 11 January and 31 January) with colleagues in Policy and Partnerships, Approvals, members of our Public Involvement network who have been involved in developing the shared commitment statement and Matt Westmore. A wide range of possible actions that the HRA could take were suggested, discussed and then prioritised. The discussions took into account the work the HRA has done in recent years to develop its expectations for public involvement as a part of the approvals process (including the Best Practice Principles and new IRAS question set) as well as the ways that public involvement is contributing to the Ethics Review, Make It Public and Valuing our Volunteers programmes as well as the HRA's contributions to the Recovery, Resilience and Growth initiative and the refresh of the HRA's overall vision and mission.

The HRA has to date supported and encouraged more and better public involvement but not taken any stronger action particularly where there has been no involvement where it could reasonably be expected that there would be. To support the shared commitment effectively it was agreed in the workshops that the HRA should set out more decisive actions than it has done in the past, consistent with the ongoing initiatives listed above.

The HRA statements are presented below.

Statement 1: describes how we will lead by example.

It is about the way we work as an organisation and how we will strive to be an 'involving organisation' that works for and is informed by insights from people and communities.

It should say to the health and social care research community that we will walk the walk on involvement as well as talking the talk

We know that involving a diverse group of people with lived experiences helps us make better decisions. We will open more opportunity for people with lived experiences to be involved in our planning and decision making.

Statement 2: describes how we work with other organisations

across the health and social care research system to embed public involvement building on our unique role as the only organisation whose main role is focused on participants in research and the wider public.

It draws on the data we hold on public involvement in applications for approval and information and guidance from our many partners across the research system

We want to encourage excellent involvement across the health and social care research landscape. We will learn about and celebrate good practice. We will demonstrate the benefits of involvement for research, for participants and for the public, working with our partners including public contributors.

Statement 3: describes how we will use our authority and unique role to influence the research community

to involve the public as usual practice in the research they do.

It draws on the work that underpins Statement 2 around what excellent public involvement looks like and applies it what researchers need to tell us about the ways they have and will work with the people and communities for whom or about which their research is designed.

We want researchers to make excellent patient and public involvement a normal part of their research. We will make sure researchers are aware of our [Best Practice Principles](#) and what we expect to see in an application for approval.

Statement 4: describes how public involvement will play a key role in the approvals system that we are responsible for as the regulator of health and social care research.

This is about how public involvement will inform our own policies and processes for review and approval of research and how insights from the people and communities that research is for and about will inform the way our committees review and approve research.

This will also help to build the public's trust in how research in which they or their family or friends might participate is reviewed and approved.

Fair and consistent review of research applications earns public trust in research. We will improve how our review committees use insights from good involvement and how they respond to poor involvement when reviewing applications for approval.

Timescale for the agreement publication of the statements

All the organisations involved have agreed to seek sign off to the common statement of commitment to public involvement by March 7, with a view to launching the initiative to the research community between 11 and 16 March, which is when British Science Week will be running. They are all now working on their own statement of actions to support it.

Action for the Board

The Board is asked to:

- Review the common wording for the shared commitment to embed public involvement in health and social care presented in the Appendix
- Note the HRA statements of actions, and offer comments for consideration in turning the statements into actions

Embedding Public Involvement in Health and Social Care Research

Public involvement is important, expected and possible in all types of health and social care research.

Together, our organisations and members fund, support and regulate health and social care research. This statement is our joint commitment to improve the extent and quality of public involvement across the sector so that it is consistently excellent.

People have the right to be involved in all health and social care research. Excellent public involvement is an essential part of health and social care research and [has been shown to improve](#) its quality and impact. People's lived experiences should be a key driver for health and social care research.

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](#).

Working together we will support the research community to carry out excellent public involvement. We will provide or share guidance, policies, systems, and incentives. We will

- listen to and learn from the people and communities we involve and apply and share that learning
- build and share the evidence of how to involve the public and the impact this has
- support improvements in equality, diversity, and inclusion in public involvement
- promote the [UK Standards for Public Involvement](#)

We will embed this commitment into the decision-making processes of our organisations. You can find more from each of the signatories by clicking on the links below:

[Health Research Authority](#)
[National Institute for Health Research](#)
[Cancer Research UK](#)
[Chief Scientist Office, NHS Research](#)
[Scotland](#)
[Health and Care Research Wales](#)
[Health and Social Care Northern Ireland](#)
[Medical Research Council \(TBC\)](#)
[Medicines & Healthcare products Regulatory](#)
[Agency](#)

[National Coordinating Centre for Public](#)
[Engagement](#)
[The Academy of Medical Sciences](#)
[The Association of Medical Research](#)
[Charities](#)
[The Association of the British Pharmaceutical](#)
[Industry](#)
[UK Research and Innovation \(TBC\)](#)
[Universities UK](#)

