# Your HRA public involvement newsletter

Issue 14, November 2023

## Welcome

Hello everyone and welcome to your public involvement newsletter.

We have created a text only version of the newsletter that should be easy to print. For support with this, or if you need the newsletter in a different format, email the public involvement team on public.involvement@hra.nhs.uk or call on 0207 104 8161.

### In this month's newsletter

* [Public involvement opportunities](#link_1)
* [Our public attitudes survey advisory group](#link_2)
* [Our Chief Executive is interviewed on the Talk in Equality podcast series](#link_6)
* [My Voice Matters](#link_3)
* [Introducing Fehzaan Maqbool](#link_4)

## Get involved in the work of the HRA

### Public involvement opportunities

We do not have any invitations to get involved in the HRA’s work this month.

If you’re looking for other ways of informing and influencing social care and health research, the [People in Research website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.peopleinresearch.org%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074615956%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=vf5pJD2MfDUylhh4JAQ0zEL2aCUYE2lfwyEMKOGs2%2B8%3D&reserved=0) may be a good ​starting point.

## What difference is public involvement making to the HRA's work?

In this section, we aim to respond to one of the questions we're asked the most – how has our work improved things for other people?

### Our public attitudes survey advisory group

The HRA commissioned [polling from YouGov](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fyougov.co.uk%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074615956%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=gHQEqQXfD0LPDlmU0t6XOoh%2FSESAJ6I%2Bj6K01nbZ0xg%3D&reserved=0)  to understand what matters to people in research and what is important to earn their trust. The results will help us know how to make sure that people can trust the research that we approve. YouGov collected data from a representative sample of 5,030 people from across the UK.

Christine and Nicola [reflect on how an advisory group helped to make sure the survey was accessible and understandable to members of the public.](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2Fwhat-difference-public-involvement-making-hra-selecting-members-our-new-community-committee%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074615956%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=KB%2BlnW9mumSj5wk4Yexi%2BYJfDe0%2F6xzZyORhm%2B%2Bl%2FvI%3D&reserved=0)

### Christine Vial, member of the HRA's Public Involvement Network

'Working as a pair of public contributors with diverse experiences and skill sets was productive.

##### 'I valued the openness to our contributions and many of our suggestions were taken on board. In particular, assumptions about people’s existing understanding in the area of health research and potential biases in the wording of questions about diversity in research.'

### Nicola Gilzeane, HRA Engagement Manager

'Public involvement ensured the survey and report of the findings were written in a clear, understandable way to people with varying levels of experience of health research.

### 'The advisory group is a great example of how important it is to be open to challenge. It can be hard to step back and see your work from other perspectives, but getting help from others really is crucial.'

Read Christine and Nicola’s reflections in full

## HRA news

In this section, we share news about some of HRA’s work that we think you may be interested in. You might also enjoy exploring [the news and updates section of the HRA website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C18037de080f74500a55f08dbc41706f0%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638319375725569709%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=FNjLipKPyulSoJSYzEI3KBjmIHWm7U8Kt5SdoHYoQ54%3D&reserved=0).

**Our Chief Executive is interviewed on the Talk in Equality podcast series**

* How can research address the health inequalities experienced by minoritised ethnic groups?
* what steps is the HRA taking to increase representation in research?
* what roles do community organisations play?

On the [Talk in Equality podcast](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fopen.spotify.com%2Fepisode%2F4LPiUHATQ7dm6YP6UYa8fB&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074615956%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=hobmFKXXhZtFT23qdMrE48mRYfKBoTy%2FEcLfFQTLjmY%3D&reserved=0), Dr Anusree Biswas Sasidharan from Bridging Change and Lillian Ndawula from Ethnic Minorities in Canterbury put these questions to our Chief Executive, Matt Westmore.

You can [listen to the episode online.](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fopen.spotify.com%2Fepisode%2F4LPiUHATQ7dm6YP6UYa8fB&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074615956%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=hobmFKXXhZtFT23qdMrE48mRYfKBoTy%2FEcLfFQTLjmY%3D&reserved=0) Other episodes look at perspectives from community development organisations, funders, and researchers.

## Public involvement news from outside the HRA

In this section, we share news of activities organised by other groups or organisations.

If you would like to include a news item relating to public involvement in social care or research, please email the public involvement team on public.involvement@hra.nhs.uk

### My Voice Matters

[Shaping Our Lives](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fshapingourlives.org.uk%2Fshare-your-lived-experience%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074772214%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=98n1aLZ8NWDwPQCIqjQRzz%2FXPJ3rmoXHWAiFJCz%2FKQA%3D&reserved=0) has launched a new guide and video to help people understand the power and benefits of sharing their lived experience.

The free [My Voice Matters guide](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fshapingourlives.org.uk%2Fshare-your-lived-experience%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074772214%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=98n1aLZ8NWDwPQCIqjQRzz%2FXPJ3rmoXHWAiFJCz%2FKQA%3D&reserved=0) contains an overview of what involvement means, who can do it, and where people can go to find opportunities. It can be used by anyone who is interested in learning about involvement and how to share their lived experience. It would also be a useful resource for user-led groups to send to their members, particularly those who work with marginalised and underserved communities.

Becki Meakin, Involvement Manager, says: ‘It can be demanding on individuals to share their stories and this guide will help them to make it a positive and hopefully rewarding experience.’

The free guide, in both PDF and Word formats, and the video, can be found [on the Shaping Our Lives website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fshapingourlives.org.uk%2Fshare-your-lived-experience%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C805d59b9b4ff4b5c295e08dbd957cc4c%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638342744074772214%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=98n1aLZ8NWDwPQCIqjQRzz%2FXPJ3rmoXHWAiFJCz%2FKQA%3D&reserved=0).

For more information, contact Helen Buckley, Communications Officer, on helen@shapingourlives.org.uk or Becki Meakin on becki@shapingourlives.org.uk.

## Do you know?

In this section of the newsletter, we introduce you to our colleagues and the people we work with.

### Introducing Fehzaan Maqbool

Fehzaan is an Information Governance Support Assistant at the HRA.

##### What motivated you to work in this field?

##### I was keen on working in the NHS. I used to work for an organisation that looked after NHS patient data. So, I was interested in data. But it was the pandemic that sparked my interest in research.

##### Lots of people were asking questions about how vaccines were developed. Like many others, I wanted to dig a bit deeper. When I learnt about the HRA’s role in regulating research, I thought ‘that makes sense’. The HRA seemed to be a good organisation and an organisation that is good to its employees.

##### What would you like us to know about your work at the HRA?

##### A lot of my work is about information governance. This sounds complicated but it is basically about protecting people’s personal data.

##### Data is the new oil. It’s very valuable. It’s important to look after it and to know our rights. For example, many people don’t know they can do a ‘subject access request’ to ask for information held about them.

##### What are the interesting challenges in your work?

The volume of work. Sometimes when we have a big case on, we can get a lot of Freedom of Information requests about the same thing. It can be a challenge to respond to everyone in time. We do our best to use the information we have to answer people’s questions.

-

If anything in this email is unclear or you have questions, please email the public involvement team on public.involvement@hra.nhs.uk or phone the public involvement team on 0207 104 8161.