# Your HRA public involvement newsletter

Issue 15, December 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. You can also view the newsletter as a webpage by clicking on the link at the top of this newsletter and zoom in using the ‘Ctrl’ and the ‘+’ symbols.

For support with this, or if you need the newsletter in a different format, [take a look at this webpage](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fplanning-and-improving-research%2Fbest-practice%2Fpublic-involvement%2Fpublic-involvement-newsletter%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548463611%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=LpZIFoNFb4PIFEDcS7r71DunC5H2nFbs%2Ft7Yk00VLu0%3D&reserved=0), email the [public involvement team](mailto:public.involvement@hra.nhs.uk) on [public.involvement@hra.nhs.uk](mailto:public.involvement@hra.nhs.uk) or call on 0207 104 8161.

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## Public involvement in the work of the HRA

In this section, we give a short update on some of the involvement activity we have in progress and share new invitations to get involved in our work.

### Updates on our work

Back in January, we [invited applications from members of the public](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2Fsupport-us-recruit-and-select-best-people-work-hra%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548463611%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=pGARZ6tGEm4Vz%2BlrhP37r51m4zGYLPm7nLpRdSd%2B%2B9I%3D&reserved=0) to help us recruit the best people to work at the HRA. We received some great applications, and 15 people joined three existing members of the public who help us with our recruitment.

Since then, members of the public have helped to recruit eight different HRA posts across the organisation. These include our:

* Head of Public Involvement
* Deputy Director of Policy and Partnerships
* Senior Engagement Officer
* Chief Digital Transformation Officer

People have supported in different ways, depending on the role. For example, reviewing job descriptions, being an equal member of an interview panel or taking part in a stakeholder engagement exercise, and scoring candidates on their leadership, engagement, and communication skills.

Su Conquer shares her experience of assessing candidates for a senior role at the HRA:

'I felt my experience and perspective were different, but complimentary to the other two professional panel members. We were able to ask questions and discuss topics with the candidates. This gave me an insight into how relatable and inclusive the candidates might be if they were successful.'

[Read more about Su's experience](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2Fwhat-difference-has-public-involvement-made-hra-recruiting-deputy-director-policy-and-partnerships%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548463611%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=0A3zwCniIMylTV0RxsNgh1YAI9KAC%2FIYLVTrTjYt5H4%3D&reserved=0)

## 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?

### Co-chairing a working group on the use of health and social care data

The HRA is supporting the development of a network of NHS Secure Data Environments (SDEs) in England.

In the spirit of co-design, the HRA asked public contributors to join a group where they could give valuable insight into the design of the network and lend a critical eye over some key areas of HRA governance involving data access policy and regulatory approvals.

Gemma Warren, Policy Manager, Data and Artificial Intelligence, is coordinating the group. Nick Filer is a public contributor and one of the group's co-chairs. They reflect on how members of the public are helping to keep the work on track and centred on issues that matter to people.

##### Nick Filer, public contributor and co-chair

'As patient representatives, we are vastly outnumbered by experts working full time in research governance, privacy, or NHS health data management.

At the start it was daunting as outsiders joining a team who at least seemed to know one another. The level of detailed knowledge distributed around the group was massive. But there were gaps where, as outside contributors, we could bring our lived experience and that of people we know to the foreground.'

##### Gemma Warren, Policy Manager, Data and Artificial Intelligence

'The value of good public engagement should not be underestimated. We have unearthed issues that may have caused problems further down the line. It has also shown me the enormity of the task ahead and the need for more engagement as we move to new ways of working. '

[Read Nick and Gemma's reflections in full](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2Fwhat-difference-is-public-involvement-making-to-the-hras-work-co-chairing-a-working-group-on-the-use-of-health-and-social-care-data%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548463611%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=t9G0vWygl8dfvO2X5FrYzLK3WVDDrQXn3tgAVGtnyzY%3D&reserved=0)

## 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%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=qOSTQvANRXJeGSDfskpGB6iQYbKmfP6Ce7tHqY%2FJRoQ%3D&reserved=0).

### HRA is responding to a consultation from the Information Commissioner's Office

The Information Commissioner’s Office (ICO) is producing guidance on transparency in the health and social care sector. There is a public consultation on the draft guidance. The HRA will send in a response, with input from public members of the [Make it Public campaign group.](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fplanning-and-improving-research%2Fpolicies-standards-legislation%2Fresearch-transparency%2Fmake-it-public-campaign-group%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=IoxX%2B7Ws7NYipO4Z3aKCVoSEqO0r1HvTUduRAEIOKJM%3D&reserved=0)

Anyone can respond to the consultation. It is open until 7 January 2024. As the ICO say:

‘Greater transparency with the public about how their personal information is being used should also result in higher levels of trust and confidence in health and social care organisations, and lead to better services and health outcomes.’

[Send in your own response to the ICO's consultation](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fico.org.uk%2Fabout-the-ico%2Fico-and-stakeholder-consultations%2Fdraft-transparency-in-health-and-social-care-guidance%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=Glw4lh93iSHC0iVYstWiZLJA8DrDcC1FjL6O2oJj%2FkA%3D&reserved=0)

### Research Ethics Committees (RECs) - our annual report

We recently published our [Annual Report for RECs in England for April 2022 to March 2023](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fcommittees-and-services%2Fres-and-recs%2Fresearch-ethics-committees-annual-reports%2Fannual-report-research-ethics-committees-recs-england-1-april-2022-31-march-2023%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=Yomlbkk2CrTh2954%2FlLlZV8QSNCjzsAYpniEpklUvDM%3D&reserved=0). The report gives an overview of the activity of our RECs in England and identifies areas that can be developed to further enhance the service.

There are 64 RECs in England. From April 2022 to March 2023, they reviewed over 3,000 applications.

Reshma Raycoba, Head of Approvals Support and Improvement thanks the members for their work:

‘Our Research Ethics Committee volunteers deliver a service to research applicants that receives consistently positive feedback, as seen in our user satisfaction surveys. Our members support our service in amazing ways and have been instrumental in continuing to shape the way we work to deliver a service that can adapt to demand. We are always so grateful for their dedication and passion’.

[Read the REC annual report on our website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fcommittees-and-services%2Fres-and-recs%2Fresearch-ethics-committees-annual-reports%2Fannual-report-research-ethics-committees-recs-england-1-april-2022-31-march-2023%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=Yomlbkk2CrTh2954%2FlLlZV8QSNCjzsAYpniEpklUvDM%3D&reserved=0)

## Public involvement news from outside the HRA

In this section, we share news of activities organised by other groups or organisations. To find out more about the activity, please contact the organisers directly.

To include a news item relating to public involvement in health or social care research, [please email the public involvement team](mailto:public.involvement@hra.nhs.uk) on [public.involvement@hra.nhs.uk](mailto:public.involvement@hra.nhs.uk).

### From adversity into action, using your experience to help others

In this short film from the Three NIHR Research Schools' Mental Health Programme, Tash, John, Sharon and Amy talk about what it’s like to get involved in research and what impact it has:

‘it’s about valuing people’s experience and valuing people for who they are. And trusting them’ (Sharon)

‘an academic researcher who’s not got background in a particular area might not be able to pick up on patterns’ (John)

‘you can say whatever you think, and you’re not going to be judged about anything’ (Tash)

‘I’ve met such a richness of people, which has been so beautiful’ (Amy)

Please note: the film mentions difficult experiences including trauma, bereavement, and addiction. Under the video, there are useful links with information of support available.

[Watch the video](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3Dx7Pe5BK4aMY&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=Zy16Hlxh7tjnKcSP%2BbO7S43%2BdQP2d37haDXf4y9bsrk%3D&reserved=0)

## Do you know?

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

​​Introducing Steve Tebbutt

Steve is Company Secretary at the HRA. He previously worked for National Research Ethics Service (NRES), coordinating the work of Research Ethics Committees (RECs).

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

In 2011, I worked with the then Chief Executive, Dr Janet Wisely and the Department of Health and Social Care (DHSC) to establish the HRA, which replaced NRES. It has been incredibly rewarding to be part of the HRA from the very start of its journey. The HRA does important work and has a positive culture. So, there are quite a few people like me who have been with the organisation for many years.

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

I lead the governance and assurance team. It’s important work that looks at how we make decisions, and checks everyone can be confident that we are doing what we say we are doing.

We make sure that the HRA fulfils its duties as set out in the Care Act 2014, (the law that describes the HRA’s functions and objectives) and that we work within legislative and best practice requirements. This includes managing risks appropriately and looking after the personal and confidential information of people we work with.

I work closely with the HRA Board, which has a public meeting every three months. Anyone can [observe these Board meetings](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fwho-we-are%2Fmeeting-minutes%2Fobserving-hra-board-meetings-common-questions-and-answers%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=y7nUqlb4IeFxLDi3Fs6cnQYOYmmFrEtSlWdf%2FZwisTM%3D&reserved=0), and public contributors often do. We have used feedback from members of our community to clarify the Board’s responsibilities. Having more transparent, visible, and accessible meetings means we work better as an organisation.

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

My team manages concerns and complaints about the HRA, and about health and social care research more generally. We don’t receive many complaints about the HRA, but we do receive concerns about particular research studies. Some topics can split the views of the public and these can be difficult to manage. We are responsible for complaints about research approved - or requiring approval - by the HRA. Sometimes people contact us with concerns beyond this, and it can be hard to manage this in a way that satisfies everyone.

[Read more on our website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fgovernance%2Ffeedback-raising-concerns%2Fhra-policy-and-procedure-managing-complaints-relating-third-parties%2F&data=05%7C01%7Ckat.evans%40hra.nhs.uk%7C9d02f2ab563a41fa404d08dbf6435ff4%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638374541548619856%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=7VDDXnpL3KvlPrYPNhLDQe%2BfiVoojXjrdtEO1CeTGEw%3D&reserved=0)

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