## Your HRA public involvement newsletter

Issue 18, March 2024

## In this month's newsletter

### 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. Click 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, you can [read our guidance](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%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723625563%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=HCZOoNgOBB1xl3Ytm%2Bra1EaSaLva0I%2FDwEkJEKi%2F3kw%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: Shared Commitment to Public Involvement

In March 2022, 13 organisations across the UK came together to make a [Shared Commitment to Public Involvement](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fplanning-and-improving-research%2Fbest-practice%2Fpublic-involvement%2Fputting-people-first-embedding-public-involvement-health-and-social-care-research%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723633182%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=qPHLupLz5JFirN%2FXl9rE7xjDyA%2FqDW3Rm2xtcD1tDho%3D&reserved=0), to prioritise involving people in health and social care research.

The Shared Commitment meetings involved 13 organisations, with members of the public and representatives from each organisation in attendance.

Since then, the Shared Commitment has grown to a partnership of 21 health and social care research organisations, and our public contributors have been very active in:

* supporting the development and growth of our partnership
* helping to develop our learning and sharing sessions
* recruiting new organisations to become partners
* helping with the induction of new organisations and their public contributors

Our public contributors bring lived experience of working with lots of different research teams, and have a rich understanding of the public involvement landscape. This means they have good insight into what excellent looks like and can direct us all to focus on what really needs to be improved.

By working together as a large partnership of health and social care research organisations, we can help to drive real change and improvements in public involvement in research.

## 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?

### Making it easier for people to hear about research

In February 2023, the government [announced an independent review](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.gov.uk%2Fgovernment%2Fnews%2Flord-oshaughnessy-to-lead-independent-review-into-uk-clinical-trials&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723640106%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=lI7ccyMNVWEaNG0EkfwPLmSgWRv7DiRzivSyVjA9XWY%3D&reserved=0), led by Lord James O’Shaughnessy, into the UK commercial clinical trials landscape. The review aimed to support the life sciences sector to unlock UK growth and investment opportunities, and suggested solutions to the key challenges that are faced when carrying out commercial clinical trials in the UK.

The review recommended establishing a common approach to contacting patients to take part in research and set out how researchers can access data in a way that people can trust when identifying who to contact to take part in a study. The HRA was asked to lead this work on behalf of the Recovery, Resilience and Growth programme partners. This was a very short piece of work with a focus on identifying further potential actions for the partners to take forward.

The aim was to recommend:

* opportunities to streamline how patients are approached about research
* how the public should be consulted
* whether legislation is needed to clarify the use of patient information for identifying and contacting people about research.

The HRA set up a small UK-wide project group, which included public contributors, to oversee this work. Kelly Rowe, HRA Approvals Manager, and Chris, a public contributor who was part of the group, reflect on how they worked together.

##### Chris, public contributor and member of the project group

'​Overall, this has been a positive involvement opportunity for me.

'Although it was challenging to review working documents written in a highly technical language and keep up with the pace of this work, I felt well supported and valued as a member of the group.

'I was encouraged to raise issues important to patients and members of the wider public with respect to their health and care data, and share concerns from this point of view.'

##### Kelly Rowe, HRA Approvals Manager

'The project group learnt that we only really touched on the tip of the iceberg in relation to patients and the processes for how they can be contacted about research. Further recommendations have been made to ensure that public discussion and awareness happens.'

## HRA news

In this section, we share news about some of the 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%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723652617%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=1MN46xt0ZNpRByLWpxY748K3lEga6EifS38%2B9uFjKXw%3D&reserved=0).

### HRA Community Survey - update

Thank you to those of you who recently completed our HRA Community Survey. This survey has now closed.

We want to make sure we're giving you the best experience possible when you work with us and the feedback you have given will help us know how to do this.

[Our Community Committee](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fcommittees-and-services%2Four-community-committee%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723658531%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=7ZGIp4jLavsRFXIyLrnfknY7mqTzAKeNQtcstwuFi8w%3D&reserved=0) and [the HRA Board](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fwho-we-are%2Four-board-members%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723664825%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=AFpCj08DVuUMI1eD3cBj6vNkt3xdlKio7xghK6RtP24%3D&reserved=0) will review your responses and use them to agree an action plan which we will publish in the upcoming year. We will provide an update in due course.

Thank you once again for your feedback and for taking the time to respond.

**#MakeitPublic workshop: all clinical trials registered – Thursday 21 March, final tickets available**

#MakeitPublic is a campaign dedicated to research transparency. Our vision is that trusted information from health and social care research studies is publicly available for the benefit of all.

This [#MakeitPublic Week 2024](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/make-it-public-week-2024/), we’re focusing on raising research registration rates.

We know that two-thirds (65%) of the UK public would feel more confident in health and social care research findings if the study was added to a public register before it started.

We want to bring the research community together to achieve the ambitious goal of 100% registration rates for clinical trials.

We’re holding an online workshop on Thursday 21 March to address the barriers to registering research.

This online event will run from 1 to 4pm and is free to attend. There are only a few tickets left, so reserve your spot now. If you don’t manage to secure a ticket, keep checking [the HRA website](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/make-it-public-week-2024/) and [our X page](https://twitter.com/HRA_Latest) for how we are marking Make it Public Week 2024.

[Read more about the event and register on Eventbrite](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.eventbrite.co.uk%2Fe%2Fmake-it-public-workshop-all-clinical-trials-registered-tickets-828276215457%3Faff%3Doddtdtcreator&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723676695%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=Vx%2BKqhuXnYqJTyYZ%2F4%2BGakjVswayvOZQY4zNz%2Bu5%2BUc%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).

### Working alongside people and communities at NICE: a strategy

The National Institute for Health and Care Excellence (NICE), is inviting feedback on its draft strategy for working alongside people and communities. The consultation is open until 27 March 2024.

You can find the [draft strategy and consultation survey on the NICE website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nice.org.uk%2Fguidance%2Findevelopment%2Fgid-ngc10024%2Fconsultation%2Fhtml-content-4&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C8a6d2e9db2c347c5b6b908dc3d2605fc%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638452480723682677%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=xfzdDNE%2FozjolfFCAIieiGLeWqFPjEFiByyTtFSUns8%3D&reserved=0).

There is also a drop-in session on Thursday 21 March 2024 from 2pm to 3pm.

To find out more, or if you need the information in a difference format, please [email the team](mailto:PeopleAndCommunityStrategy@nice.org.uk) on [PeopleAndCommunityStrategy@nice.org.uk](mailto:PeopleAndCommunityStrategy@nice.org.uk).

## Do you know?

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

### Introducing Shevon Prince

Shevon is a Corporate Projects Support Manager at the HRA.

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

I have worked in the NHS for over 18 years in various sectors such as General Practitioner (GP) Information Technology, hospital administration and community nursing administration. The NHS is all I know so starting a job at the Health Research Authority over 10 years ago was a natural fit. I began life at the HRA as a Research Ethics Committee Assistant and soon moved to be Personal Assistant (PA) to the Chair for six years which was an amazing experience. From that seat I really got to hear (from behind the scenes) the important work that our organisation does. Being privileged to be in the room with those at the forefront of policy and decision making in health research showed me that this was a job that was making a real difference.

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

Since 2018, I have moved into supporting internal projects that enable the organisation to take better care of staff. As part of my role, I lead projects and also support other project managers with paperwork, workshops or whatever they need. This includes multi-tasking across several projects to meet tight deadlines, setting up surveys, attending project related meetings with the prepared paperwork, and making recommendations.

I have been an ambassador of working for the HRA since day one. It’s an organisation with great colleagues who really care about you. The HRA really shone through as an organisation that plays an important part in the whole research chain. Staff know the importance of that, and we all make a tremendous effort.

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

The HRA is such a small organisation with such a big responsibility. This impacts on staff and the volume of work that we receive. There are often times when we have to wear many hats to meet the organisation’s needs as we really want to serve our volunteer community well and deliver best value for money. It can be challenging to find the time to do everything we want to do. On a project level, this means we have to prioritise the right projects that will make the biggest impact.

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.