# Your HRA public involvement newsletter

Issue 20, May 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%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741597991%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=QndAVLCWJjdut64v22RcpvMcoI0167DIr9LnMVBHquI%3D&reserved=0)**, email the** [**public involvement team**](mailto:public.involvement@hra.nhs.uk) **at** [**public.involvement@hra.nhs.uk**](mailto:public.involvement@hra.nhs.uk) **or call on 0207 104 8161.**

**If there is something you'd like to include, or learn more about, do let us know. In this month's newsletter:**

* [**Updates on our work: Community Committee**](#link_1)
* [**Writing guidance on public involvement in the design and conduct of phase 1 healthy volunteer studies**](#link_2)
* [**​New guidance on employment and tax for members of the public who are offered payment for involvement**](#link_7)
* [**Update to the public involvement resources page of our website**](#link_5)
* [**​Barts Health NHS Trust host an event about sharing knowledge and building trust**](#link_3)
* [**Introducing Gurtej Brar**](#link_4)

## 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.

## Help shape our new visual identity

We are looking for three members of the public to help develop our visual identity by attending:

* an online workshop to give feedback on some initial designs
* a feedback session, where we update you on the designs selected and hear your thoughts.

[In line with our payments policy,](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fgovernance%2Fpublication-scheme%2Four-policies-and-procedures%2Fpolicy-payments-arising-involvement-public-work-hra%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741610860%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=%2B6U26OzdTe8jp6oDczN7p1ipRybWAWwglKs%2FvZ2Pw1I%3D&reserved=0) we can offer £75 involvement fees.

If you're interested, please read the details below and apply by 12pm on Friday 10 May 2024.

[Find out more and apply](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2Fhelp-us-shape-our-new-visual-identity%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741623215%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=M2LPGBRQqTMOIZnwbkMz%2FDiLyJZZpyTaEEv893RrcKE%3D&reserved=0)

## Updates on our work: Community Committee

​Our Community Committee has now met three times, in October 2023, December 2023 and March 2024.

​The committee’s first task was to discuss how to work together and agree a formal terms of reference. They have also been looking at the reports the HRA’s Board receives every three months to provide advice and highlight issues. If you’re interested in seeing the other points discussed, the agendas and notes are [on the HRA’s website.](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%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741633929%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=O1mH9cuxzQsGtv9Ts%2BbTz89LCKOoNJI1Js%2FIyJQtbMA%3D&reserved=0)

​The Committee has 11 members, drawn from [Research Ethics Committees](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fcommittees-and-services%2Fres-and-recs%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741645393%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=GEN2YOjSkyXoz3M%2Bp7eEIpA01eXLE2jnR7TF8J1zZbg%3D&reserved=0), members of our [Confidentiality Advisory Group](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fcommittees-and-services%2Fconfidentiality-advisory-group%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741655499%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=byUHcsdz3TnLJqOil9Jm4DR%2BS7dhs1CYXVgzoOKNn%2F8%3D&reserved=0), and members of the public who have direct experience of health research. Andrew George, a non-executive director of the HRA, chairs the committee. We are recruiting a co-chair from the committee members.

[Read a blog by committee member Jan Speechley](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2Fblog-reflections-march-community-committee-meeting%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741664998%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=KaYHxjbV%2FgkihYNtcDbLDDmiVD4%2BsXQzuNq%2BQE2WCLA%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?

### Writing guidance on public involvement in the design and conduct of phase 1 healthy volunteer studies

We have been working with the Medicines and Healthcare products Regulatory Agency (MHRA) and the Department of Health in Northern Ireland to write guidance on public involvement in clinical trials. The guidance will support the introduction of new legislation on clinical trials in the UK.

Clinical research aims to find out more about an illness, condition, treatment, therapy, or care. This sort of research may ask people to take part by testing a new treatment, using a device or by being cared for in a certain way. It may also ask them to provide information about the care they usually have.

Public involvement means that patients or other people with relevant experience contribute to planning, carrying out and sharing the results of research. This helps make sure research is relevant, well communicated and that people have a good experience when taking part.

Following a survey, we learnt that there is a lot of guidance about public involvement. But there is not much guidance specific to public involvement in phase 1 healthy volunteer studies. There are usually four phases of clinical trials. Phase 1 is usually the first time the treatment or product is tested in humans. It usually aims to learn about what happens to the treatment in the body, and side effects. People who take part in these studies do not have the condition being studied or any significant health problems. They are referred to as healthy volunteers. Participation of healthy volunteers in phase 1 clinical trials is essential for the successful development of new and better treatments.

Chris, an experienced volunteer, and Damilola Odunlami, HRA Public Involvement Manager, reflect on how they have worked together on this project.

##### Chris, an experienced volunteer

'This project is a gathering of different perspectives. It includes professionals as well as the volunteers who actually take part in phase 1 research and make all of this research viable and sustainable.

'Perhaps the most difficult aspect of this collective exercise has been finding a time and day that is convenient for everyone to meet at the same time!'

##### Damilola Odunlami, HRA Public Involvement Manager

'Some challenges we faced was the need to be mindful of any possible barriers to sponsors when producing the guidance so that we can remain competitive in the global research community and continue to attract study sponsors to the UK whilst also meeting public involvement requirements as set out by the HRA.

'Hopefully, we will have achieved that when the guidance is published. '

[Read Chris and Damilola'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-writing-guidance-on-public-involvement-in-the-design-and-conduct-of-phase-1-healthy-volunteer-studies%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741672162%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=i6KU94rfRhMF6MfrQOIXZ%2F94pX%2BtDnviN6TOYIRyftI%3D&reserved=0)

## 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%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741680378%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=dwpuDgVPZQVR59r5c6gFb0cEYJ2X6GDtdjmK2fi12r8%3D&reserved=0).

​New guidance on employment and tax for members of the public who are offered payment for involvement

Last month we published new pay guidance for members of the public involved in health and social care research.

​We wrote the guidance with the National Institute for Health and Care Research (NIHR) and Health and Care Research Wales.

​We hope the guidance helps people understand their rights and responsibilities.

​​It includes information on how payment for involvement may impact on:

* ​employment and tax status
* ​​self-employment status
* ​​welfare benefits

​​An [easy ready version of the guidance](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.learningforinvolvement.org.uk%2Fcontent%2Fresource%2Fpayment-for-helping-health-and-social-care-research-a-guide-for-members-of-the-public-who-want-to-help-with-research%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741687267%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=fEqjz4XsPP4xWF3%2BjjtTbbVXZbwiSu7lA%2FzV88HfeLA%3D&reserved=0) aims to make the information easier to understand. The guidance has also been translated into Welsh. ​

​​Contact the public involvement team on [public.involvement@hra.nhs.uk](mailto:public.involvement@hra.nhs.uk) or on 0207 104 8161 if you would like this guidance in an alternative format​.

[Read the guidance](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fplanning-and-improving-research%2Fbest-practice%2Fpublic-involvement%2Fresources%2Fpayment-public-involvement-health-and-care-research-guide-members-public-employment-status-and-tax%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741694852%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=BSB1%2FobcwpCu7aOkTz336nq19zafuBUFkGwNoILob0o%3D&reserved=0)

## Update to the public involvement resources page of our website

We have recently refreshed the ‘public involvement resources’ page of our website. The page is for research teams. It includes hyperlinks to guidance that’s in line with our best practice principles, and the [UK Standards for Public Involvement](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fsites.google.com%2Fnihr.ac.uk%2Fpi-standards%2Fstandards&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741702193%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=P6WlSNnhNOu641%2BfOoKeS2ic5As6v9tl7eUai0bXTEg%3D&reserved=0).

For a longer list of resources, we suggest looking at the [Learning for Involvement](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.learningforinvolvement.org.uk%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741708164%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=AQk1%2FewquJ87UsjEARlCbCZqXubDS%2FqbnPstJ7WReoQ%3D&reserved=0) website where anyone can search for or upload resources.

[Look at the webpage to see the resources](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fplanning-and-improving-research%2Fbest-practice%2Fpublic-involvement%2Fresources%2F&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741713793%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=uP5WTZ0diFL8HvQHtsRK%2BSikYbWM70CTRVlkONvgHRo%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) at [public.involvement@hra.nhs.uk](mailto:public.involvement@hra.nhs.uk)

### ​Barts Health NHS Trust host an event about sharing knowledge and building trust

On Thursday 23 May from 5.30pm to 7pm, Barts Health NHS are hosting an event for anyone interested in transparency and knowledge sharing in research.

​Speakers will include:

Clive Collett, Head of Policy and Engagement at the HRA and a public member of our Make it Public campaign group

presentations on best practice from the Barts Experimental Cancer Medicine Centre (ECMC), and the Barts Life Sciences Precision Medicine Programme

​The event will take place at Queen Mary's in Whitechapel, East London.

​It’s a free event but you should book a ticket using the link below.

[Find out more and book free tickets](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.ticketsource.co.uk%2Fbarts-health-nhs-trust%2Ft-mokqzjg&data=05%7C02%7Ckat.evans%40hra.nhs.uk%7C7d3b3459457e4e2290c208dc69ba057f%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638501497741719508%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=eWkarsmT1xTV1GIL1k0hnG9sGTbDRJ2lElhhbVg3UMM%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 Gurtej Brar

​Gurtej is Head of Service Delivery, a team that sits within the HRA’s Digital directorate and is responsible for service delivery and customer support services for our research systems. These systems include IRAS, which people use to apply to do, and then manage, health and social care research in the UK.

​The team aims to provide users with a fast and efficient resolution to any queries.  They also design and implement new processes and use best practice to continuously improve the services we offer.

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

​I have always had an interest in working in service delivery and management as far as I can remember. I have never experienced a dull moment. I'm motivated by the challenging nature of maintaining service delivery standards.

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

​Most of my work involves planning, developing, and embedding Service Management processes across all our digital systems. These include Request (where users need something), Incident (where something has gone wrong or doesn’t work as expected), Problem and Change (two methods of proactively reducing the number of incidents), and Continuous Service Improvement.

​In my world, no day is the same. Priorities can change quickly! All planned work sometimes needs to pause if there is a major incident, as I’ll be leading the team’s response. I’m also heavily involved in the work the HRA is doing to develop our future online systems.

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

​​There are unpredictable incidents that are part and parcel of any IT and digital system, as well as the additional challenges that come with designing and maintaining our response processes.

​​It’s also important we work effectively with many people and organisations. Successful service delivery involves close collaboration with our HRA colleagues, our partner organisations and our suppliers.

​Working from home and having a three-year-old toddler enter your room while you have meetings is a challenge in itself!

​Having a supportive and fantastic set of HRA colleagues, and the option of working from home, helps address these challenges.​

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If anything in this email is unclear, you have questions, or would like to suggest something you'd like to learn about, please [email the public involvement team](mailto:public.involvement@hra.nhs.uk) at [public.involvement@hra.nhs.uk](mailto:public.involvement@hra.nhs.uk) or phone the public involvement team on 0207 104 8161.