# Your HRA public involvement newsletter

Issue 16, January 2024

## Welcome

Happy New Year 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, email the public involvement team on public.involvement@hra.nhs.uk or call on 0207 104 8161.

In this month's newsletter

* Updates on our work: guidance for public involvement in clinical trials
* Making and sharing the hallmarks for people-centred clinical research
* HRA's community surveys: striving to improve your experience of shaping our work through public involvement activities
* Empowering communities: a new chapter in health research partnerships
* Introducing Lou Silver

## 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: guidance for public involvement in clinical trials

Our new working group on guidance for public involvement in clinical trials met for the first time in November 2023.

In August 2023, we shared a survey to collect examples of toolkits and guides that individuals use. We also asked if there were any areas people thought they’d like more guidance on. We received 92 responses with 85 links to resources and 16 documents. A lot of them covered the same ground!

The working group's first tasks are to:

* review the guidance and toolkits we received
* select which ones it would recommend
* decide if there are any gaps

The development of the group follows our invitation for applications in April 2023. Following a selection process, six members of the public joined the group.

If you’d like to know more about this work, please contact Jim Elliott, Public Involvement Specialist, at public.involvement@hra.nhs.uk.

## 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 and sharing the hallmarks for people-centred clinical research

The people-centred clinical research (PCCR) project has recently published hallmarks for good, people-centred, clinical research. The hallmarks cover how research teams should act and what people-centred research looks and feels like for people taking part.

By taking part, we mean being in a study as a participant. This is different to public involvement, which shapes how research happens. But of course, you can’t have good people-centred research without good public involvement: asking what matters most and working together in partnership.

Sarah and Kate reflect on their experiences of collaborating to develop the hallmarks.

Sarah Markham, a public member of the PCCR steering group

'I think one of the best things is how everyone has worked as constructively critical and respectful members of the hallmark creation team.

'The way people have helped and just how much they have contributed – both mentally and emotionally – should not be underestimated.'

Kate Greenwood, Senior Improvement Development Manager at the HRA

'The steering group has been fundamental to shaping the whole project and how the hallmarks developed. It challenged our language and our assumptions and pushed us for more.

'As a result, the hallmarks became something to be held by participants as well as researchers, to really express their perspective.'

Read Sarah and Kate'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.

### HRA's community surveys: striving to improve your experience of shaping our work through public involvement activities

In 2021 and 2022, we surveyed the thousands of people who support our work to learn about their experiences of working with us. Through doing so, we better understand the level of support you receive from us, and how satisfied you are more generally with your involvement. This helps inform plans around what we should continue, stop or start to do, and think about where we need to improve.

The results of the 2021 and 2022 surveys were discussed with the Community Insight Group at the time and used to create an action plan to inform our work.

Ahead of the 2024 HRA community survey, which is due to launch at the end of January 2024, the public involvement team has reflected on what we learned about people's experiences of working with us and what we have done differently as a result of the previous surveys.

We're currently working in partnership with members of our Community Committee to develop the 2024 HRA community survey. This survey will help us to see if and how the changes we have put in place have made any difference to people's experience of being involved. Most importantly, it will highlight where we still need to do better. We really encourage you to take the time to fill this out when you receive it. It's important we try to understand each and everyone's experience of working with us, so that we can put together a plan that works for everyone.

Read more on our website

## 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 on public.involvement@hra.nhs.uk.

### Empowering communities: a new chapter in health research partnerships

Expert Citizens uses the insight of people’s experiences to motivate change. It is a Community Interest Company, led by people with lived experience of a social issue or social injustice. This might be homelessness, mental ill-health, addiction, domestic abuse, poverty, or histories of offending behaviour.

Expert Citizens is working with Keele University on a project that brings together health researchers in universities and people in communities that academic literature calls ‘underserved’.

The project’s goal is to bridge the gap between researchers and local communities, ensuring that underserved groups are not just heard but play a central role in shaping research priorities. It’s funded by the National Institute for Health and Social Care Research (NIHR), recognising that communities need to have the time and resources available to engage with research, without having to sacrifice core commitments within their organisation to do so. So far, Expert Citizens have delivered two Community Conversations with researchers, members of the public and people working in the third sector.

Sophia Fedorowicz, Research and Evaluations Lead at Expert Citizens says,

‘Research informs health policy, practice, and narratives and if you are a member of an ‘underserved’ community, that can mean that the treatment, service, or pathway that you are trying to access is not suitable for you and therefore, not fit for purpose.’

Nicola Evans, Lead for Patient and Public Involvement and Engagement at Keele University says,

‘I have really benefitted from the open and warm welcome that Expert Citizens has provided to me, learning new approaches and ways of working to ensure that public voices not always heard in research can be amplified.’

The next step is to host a connection event that is open to community groups and anyone living and working in Stoke-on-Trent with an interest in this partnership. The learning around engagement will be shared, and the NIHR will put forward what needs to change to make sure that all communities can access and engage in health research.

To find out more about the project, take a look at the Expert Citizens website or email Sophia on sophia.insight@expertcitizens.org.uk.

## Do you know?

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

### Introducing Lou Silver

Lou Silver is HRA’s Equality, Diversity, and Inclusion (EDI) Manager. She began working at the HRA in May 2021.

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

I used to develop services to support marginalised students in higher education. I shared an office with our Health Promotion Specialist, who got me interested in the health inequalities associated with my student groups. Eventually, I moved into the staff side as part of an EDI, health and wellbeing team. Again, the overlaps were huge, and it seemed obvious that you couldn’t address one without the other. Joining the HRA felt like a brilliant opportunity to feed into a much bigger picture of addressing inequalities.

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

Most of the work I do is fairly hidden. It’s quiet conversations to support individuals; researching evidence-based ways to develop inclusive policies; scrutinising our data to find the stories they tell, so we can set objectives which make a measurable and ‘felt’ difference; reading up on case law; listening to our staff-led groups; developing training sessions to embed new practices, and advising colleagues on equality considerations in new projects, policies, or changes.

The diversity celebrations which most people associate with EDI are just the visible tip of a very large iceberg!

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

We have a legal duty to foster good relationships between people who do and don’t share certain characteristics. This means we have a responsibility to learn about each other, even when there’s a conflict with our own worldview. The way I try to approach it is through a concept of radical acceptance. The learning opportunities we offer are not to get you to agree with me, or me to agree with you, but to enable us to understand each other and connect as humans, so that people with diverse identities can compassionately coexist across the organisation.

Read more on our website

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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.