## Your HRA public involvement newsletter

Issue 19, April 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 at 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: the World Medical Association’s consultation about the Declaration of Helsinki](https://euc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en-GB&rs=en-GB&wopisrc=https%3A%2F%2Fhealthresearchauthority.sharepoint.com%2Fsites%2Finvolvement%2F_vti_bin%2Fwopi.ashx%2Ffiles%2F794b26d2863941759f879bd18db85048&wdenableroaming=1&mscc=1&hid=A4B51BA1-40BA-8000-6BBF-59366B0985E6.0&uih=sharepointcom&wdlcid=en-GB&jsapi=1&jsapiver=v2&corrid=84eff9dd-3591-ff31-5b1f-03317a9de570&usid=84eff9dd-3591-ff31-5b1f-03317a9de570&newsession=1&sftc=1&uihit=docaspx&muv=1&cac=1&sams=1&mtf=1&sfp=1&sdp=1&hch=1&hwfh=1&dchat=1&sc=%7B%22pmo%22%3A%22https%3A%2F%2Fhealthresearchauthority.sharepoint.com%22%2C%22pmshare%22%3Atrue%7D&ctp=LeastProtected&rct=Normal&wdorigin=ItemsView&wdhostclicktime=1712235317583&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush#link_1)
* [Recruiting a Head of Policy and Engagement](https://euc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en-GB&rs=en-GB&wopisrc=https%3A%2F%2Fhealthresearchauthority.sharepoint.com%2Fsites%2Finvolvement%2F_vti_bin%2Fwopi.ashx%2Ffiles%2F794b26d2863941759f879bd18db85048&wdenableroaming=1&mscc=1&hid=A4B51BA1-40BA-8000-6BBF-59366B0985E6.0&uih=sharepointcom&wdlcid=en-GB&jsapi=1&jsapiver=v2&corrid=84eff9dd-3591-ff31-5b1f-03317a9de570&usid=84eff9dd-3591-ff31-5b1f-03317a9de570&newsession=1&sftc=1&uihit=docaspx&muv=1&cac=1&sams=1&mtf=1&sfp=1&sdp=1&hch=1&hwfh=1&dchat=1&sc=%7B%22pmo%22%3A%22https%3A%2F%2Fhealthresearchauthority.sharepoint.com%22%2C%22pmshare%22%3Atrue%7D&ctp=LeastProtected&rct=Normal&wdorigin=ItemsView&wdhostclicktime=1712235317583&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush#link_2)
* [Jim Elliott's thoughts on retirement](https://euc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en-GB&rs=en-GB&wopisrc=https%3A%2F%2Fhealthresearchauthority.sharepoint.com%2Fsites%2Finvolvement%2F_vti_bin%2Fwopi.ashx%2Ffiles%2F794b26d2863941759f879bd18db85048&wdenableroaming=1&mscc=1&hid=A4B51BA1-40BA-8000-6BBF-59366B0985E6.0&uih=sharepointcom&wdlcid=en-GB&jsapi=1&jsapiver=v2&corrid=84eff9dd-3591-ff31-5b1f-03317a9de570&usid=84eff9dd-3591-ff31-5b1f-03317a9de570&newsession=1&sftc=1&uihit=docaspx&muv=1&cac=1&sams=1&mtf=1&sfp=1&sdp=1&hch=1&hwfh=1&dchat=1&sc=%7B%22pmo%22%3A%22https%3A%2F%2Fhealthresearchauthority.sharepoint.com%22%2C%22pmshare%22%3Atrue%7D&ctp=LeastProtected&rct=Normal&wdorigin=ItemsView&wdhostclicktime=1712235317583&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush#link_7)
* [Would you like to become a member of the Confidentiality Advisory Group (CAG)?](https://euc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en-GB&rs=en-GB&wopisrc=https%3A%2F%2Fhealthresearchauthority.sharepoint.com%2Fsites%2Finvolvement%2F_vti_bin%2Fwopi.ashx%2Ffiles%2F794b26d2863941759f879bd18db85048&wdenableroaming=1&mscc=1&hid=A4B51BA1-40BA-8000-6BBF-59366B0985E6.0&uih=sharepointcom&wdlcid=en-GB&jsapi=1&jsapiver=v2&corrid=84eff9dd-3591-ff31-5b1f-03317a9de570&usid=84eff9dd-3591-ff31-5b1f-03317a9de570&newsession=1&sftc=1&uihit=docaspx&muv=1&cac=1&sams=1&mtf=1&sfp=1&sdp=1&hch=1&hwfh=1&dchat=1&sc=%7B%22pmo%22%3A%22https%3A%2F%2Fhealthresearchauthority.sharepoint.com%22%2C%22pmshare%22%3Atrue%7D&ctp=LeastProtected&rct=Normal&wdorigin=ItemsView&wdhostclicktime=1712235317583&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush#link_5)
* [Share your experience of research that properly included you](https://euc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en-GB&rs=en-GB&wopisrc=https%3A%2F%2Fhealthresearchauthority.sharepoint.com%2Fsites%2Finvolvement%2F_vti_bin%2Fwopi.ashx%2Ffiles%2F794b26d2863941759f879bd18db85048&wdenableroaming=1&mscc=1&hid=A4B51BA1-40BA-8000-6BBF-59366B0985E6.0&uih=sharepointcom&wdlcid=en-GB&jsapi=1&jsapiver=v2&corrid=84eff9dd-3591-ff31-5b1f-03317a9de570&usid=84eff9dd-3591-ff31-5b1f-03317a9de570&newsession=1&sftc=1&uihit=docaspx&muv=1&cac=1&sams=1&mtf=1&sfp=1&sdp=1&hch=1&hwfh=1&dchat=1&sc=%7B%22pmo%22%3A%22https%3A%2F%2Fhealthresearchauthority.sharepoint.com%22%2C%22pmshare%22%3Atrue%7D&ctp=LeastProtected&rct=Normal&wdorigin=ItemsView&wdhostclicktime=1712235317583&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush#link_6)
* [Young people improving health through research](https://euc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en-GB&rs=en-GB&wopisrc=https%3A%2F%2Fhealthresearchauthority.sharepoint.com%2Fsites%2Finvolvement%2F_vti_bin%2Fwopi.ashx%2Ffiles%2F794b26d2863941759f879bd18db85048&wdenableroaming=1&mscc=1&hid=A4B51BA1-40BA-8000-6BBF-59366B0985E6.0&uih=sharepointcom&wdlcid=en-GB&jsapi=1&jsapiver=v2&corrid=84eff9dd-3591-ff31-5b1f-03317a9de570&usid=84eff9dd-3591-ff31-5b1f-03317a9de570&newsession=1&sftc=1&uihit=docaspx&muv=1&cac=1&sams=1&mtf=1&sfp=1&sdp=1&hch=1&hwfh=1&dchat=1&sc=%7B%22pmo%22%3A%22https%3A%2F%2Fhealthresearchauthority.sharepoint.com%22%2C%22pmshare%22%3Atrue%7D&ctp=LeastProtected&rct=Normal&wdorigin=ItemsView&wdhostclicktime=1712235317583&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush#link_3)
* [Introducing Jonathan Fennelly-Barnwell](https://euc-word-edit.officeapps.live.com/we/wordeditorframe.aspx?ui=en-GB&rs=en-GB&wopisrc=https%3A%2F%2Fhealthresearchauthority.sharepoint.com%2Fsites%2Finvolvement%2F_vti_bin%2Fwopi.ashx%2Ffiles%2F794b26d2863941759f879bd18db85048&wdenableroaming=1&mscc=1&hid=A4B51BA1-40BA-8000-6BBF-59366B0985E6.0&uih=sharepointcom&wdlcid=en-GB&jsapi=1&jsapiver=v2&corrid=84eff9dd-3591-ff31-5b1f-03317a9de570&usid=84eff9dd-3591-ff31-5b1f-03317a9de570&newsession=1&sftc=1&uihit=docaspx&muv=1&cac=1&sams=1&mtf=1&sfp=1&sdp=1&hch=1&hwfh=1&dchat=1&sc=%7B%22pmo%22%3A%22https%3A%2F%2Fhealthresearchauthority.sharepoint.com%22%2C%22pmshare%22%3Atrue%7D&ctp=LeastProtected&rct=Normal&wdorigin=ItemsView&wdhostclicktime=1712235317583&instantedit=1&wopicomplete=1&wdredirectionreason=Unified_SingleFlush#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.

### Updates on our work: the World Medical Association’s consultation about the Declaration of Helsinki

Earlier this year, we received input from two members of our public involvement network, and members of our Research Ethics Committees (RECs), on an important public consultation.

​The World Medical Association (WMA) is an independent international organisation. It was founded after the Second World War to ensure the independence of physicians and to work for the highest possible standards of ethical behaviour and care by physicians, at all times.

​The Declaration of Helsinki is one of the most important documents in the history of research ethics. It is a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data. The Declaration was developed in 1964 and its principles inform our work on a daily basis.

​In early 2024, [the World Medical Association invited feedback on proposed changes to the Declaration of Helsinki](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.wma.net%2Fwhat-we-do%2Fmedical-ethics%2Fdeclaration-of-helsinki%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964774498%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=uc4BpXvJly6fHtJxnMtPInZRL8mvnnuXk4WZqshLDpk%3D&reserved=0).

​Our response was also developed in consultation with the [UK’s Four Nations Policy Leads Group](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fpartnerships%2Ffour-nations-and-united-kingdom-ethics-committee-authority%2F%23%3A~%3Atext%3DThe%2520Four%2520Nations%2520Policy%2520Leads%2520Group%2520also%2520acts%2CNHS%2520England%252FImprovement%25204%2520National%2520Institute%2520for%2520Health%2520Research&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964783479%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=z2ykFc%2FYGLKqtbTMKs3duwFoZTbIkIxvsn8mT4jOxgM%3D&reserved=0), which brings together:

* ​the Health Research Authority
* ​[Health and Social Care in Northern Ireland](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.northerntrust.hscni.net%2Fabout-the-trust%2Ftrust-overview-2%2Fhealth-and-social-care-in-northern-ireland%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964791441%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=eC1y1c2xYJIYa16qKPEQWY9v6KRUVudVEYnVVDoadjk%3D&reserved=0)
* ​the [Chief Scientist Office in Scotland](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.cso.scot.nhs.uk%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964798614%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=QM%2B%2Fq3JpwiDYkQJ3JoHYUrMiHsr1YV3f8jmFstD%2FzdI%3D&reserved=0) and [NHS Research Scotland](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nhsresearchscotland.org.uk%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964805323%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=dovLH7lIx6sp%2BRNdYDG3FK6MNzKUVtSntF00mTtxXtw%3D&reserved=0)
* ​[the Welsh government](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.gov.wales%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964812118%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=I6hRzdpsPmc9fEYT%2F9ViCxYOib4aKtbpIZtl5vccM9o%3D&reserved=0) and [Health and Care Research Wales](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fhealthandcareresearchwales.org%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964818779%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=7Tec7HMm2x4g2TjaAdBLwHWceO%2BV3AwKL2RBN5%2FXQX4%3D&reserved=0)

​Our Head of Policy and Engagement brought together all the comments and suggestions from people we had consulted, into one response to the WMA. This approach gives confidence that our response is relevant, and that we haven’t overlooked any key points of view.

[Read a summary of our response to the World Medical Association](https://www.hra.nhs.uk/about-us/news-updates/declaration-helsinki/)

## 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?

### Recruiting a Head of Policy and Engagement

In late 2023, we appointed a new Head of Policy and Engagement, Clive Collett. We needed someone who could see health and social care research from lots of different perspectives and understand what matters to different organisations, people, and communities.

Victoria Bartle, a public contributor who supports the HRA to recruit staff, and Naho Yamazaki, Deputy Director of Policy and Partnerships, reflect on how they worked together to interview candidates for this role, and what they both learnt through this process.

##### Victoria Bartle, public contributor

'I found the entire process very organised, professional, friendly and inclusive.

'All of my requests for accommodations were dealt with, and alternatives were offered at every point of contact. This made requesting things easier for me than my usual experience of being asked once, and it maybe being forgotten the next time.

'I felt like an equal and valued member of the recruitment panel and especially appreciated the opportunity to feedback on my experience.'

##### Naho Yamazaki, Deputy Director of Policy and Partnerships

'The feedback Victoria shared after the recruitment was also very helpful. I’m glad she felt comfortable being part of the panel. But her feedback was a good reminder that it can be hard for someone external to come in and join an interview panel.

'It’s an important task and people want to do it well. We need to make sure they have the information and support they need so this is something we hope to continuously improve.'

[Read Victoria and Naho’s reflections in full](https://www.hra.nhs.uk/about-us/news-updates/what-difference-is-public-involvement-making-to-the-hras-work-recruiting-a-head-of-policy-and-engagement/)

## 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).

### Jim Elliott's thoughts on retirement

Jim Elliott, HRA Public Involvement Specialist and former Public Involvement Lead, has recently retired. Jim joined the HRA 11-and-a-half years ago and has been instrumental in making public involvement front and centre of everything we do.

HRA staff, representatives of partner organisations, and members of the public, share what they have loved about working with Jim on our website.

[Read more about Jim’s retirement](https://www.hra.nhs.uk/about-us/news-updates/heartfelt-farewell-jim-elliott-public-involvement-specialist-and-hras-former-public-involvement-lead/)

[Jim has also written a guest blog on our website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fnews-updates%2Fguest-blog-some-thoughts-i-retire-why-public-involvement-matters-so-much-work-hra-jim-elliott-retired-public-involvement-specialist%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964853798%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=mXUU7OOeC01TNbR73MvjOFztx23%2F7fAiukIV%2BQs%2BmVA%3D&reserved=0) reflecting on his time at the HRA, and some of his key highlights.

'When you read this, I will have retired from the HRA. The past 11-and-a-half years in which I developed and led the HRA’s public involvement function and team have been hugely rewarding and inspiring.

'I will use the new freedom I have to slow down and to do so some new things.

'But I can’t let go entirely. I remain dedicated to the cause of making public involvement in research normal practice for all health and social care research.'

'I have joined you as a subscriber to this newsletter and may see some of you here or there. Finally, thank you to everyone who has been involved with the HRA’s work since 2012 and the difference you have made to what we do, which has made my time here so worthwhile.

'Thank you for holding us to account and not being backward in coming forward to say when we don’t do things as well as we might. Keep on doing what you do because it makes a difference.'

[Read Jim’s guest blog](https://www.hra.nhs.uk/about-us/news-updates/guest-blog-some-thoughts-i-retire-why-public-involvement-matters-so-much-work-hra-jim-elliott-retired-public-involvement-specialist/)

### Would you like to become a member of the Confidentiality Advisory Group (CAG)?

We have an opportunity for volunteer lay members to join the Confidentiality Advisory Group (CAG) and contribute to our work. We’re looking for people who are interested in the ethical use of confidential healthcare information for research and NHS management purposes but may not have had specific experience in this field.

Our CAG meets regularly to assess applications to use identifiable patient information without patient consent, and provides independent expert advice to the Health Research Authority and the Secretary of State for Health and Social Care. The group's aim is to give the public confidence that their data will be used appropriately and balances patient privacy concerns with using data to improve healthcare.

##### What will it involve?

You’ll review applications to use identifiable health and social care data for research and non-research purposes (for example in national audits). You’ll also have the opportunity to contribute to development work and engage with other ad hoc activities, if you have the time. You’ll have a keen eye for detail, enjoy solving problems and approach decision making with an open mind.

We hold seven meetings a year via Zoom so you’ll need to have a computer or laptop to join our meetings and access documents. We’re looking for a commitment of 10 to 15 hours per month.

##### Interested?

If you’d like to join us and play a key role in the use of healthcare data, please visit our website for more details and information on how to apply.

Alternatively, you can email the CAG team at the HRA for further information on cag@hra.nhs.uk

Please note the closing date for applications is **Friday 3 May 2024.**

[Find out more and apply](https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/become-member-of-cag2022/)

### Share your experience of research that properly included you

As part of our Research Ethics Committee (REC) development days in 2024, we are focusing on equality, diversity and inclusion in health and social care research.

We know that research that includes a diverse group of people can provide a better understanding of the most effective treatment, device or care.

To help us better understand the impact of research that does this well, we are looking for speakers who can share their story about equality, diversity, and inclusion in research.

We are looking for speakers to join us for at least two of our four development days this year and tell us about being included in research that you or someone close to you were able to participate in, when perhaps traditionally studies like those haven't included a wide range of people.

We will support you to prepare for the events and make sure you are comfortable sharing your story.

In return for your valuable time, our learning team can offer £200 to cover your preparation, and £200 for each development day you speak at.

The deadline to apply for one of these speaker roles is **12pm on Wednesday 17 April 2024**.

[Find out more about the speaking role including dates and locations](https://www.hra.nhs.uk/about-us/news-updates/open-call-speakers-talk-members-research-ethics-committees-recs-about-your-experience-equality-diversity-and-inclusion-research/)

## 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

### Young people improving health through research

Did you know that there are over 21 Young People's Advisory Groups (YPAGs) across the country?

A YPAG is made up of members who are usually between 8 to 18 years old. Young people from all backgrounds, for example those with chronic conditions; those who have participated in research; or those with a general interest in science or medicine, can get involved and have a say in research that affects them, and support the design and development of child health research.

Most YPAGs meet every six weeks, either at weekends, in the evenings or during the school holidays. Some meetings take place online and others face-to-face.

The YPAGs can partner with researchers to plan health research so that they’re suitable and relevant to children and young people. YPAG members also learn about all different types of child health research during meetings.

The Bristol Young People’s Advisory Group have created a film that shows how the group works and the benefits for young people and researchers. You can [watch it on YouTube](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3D4-C6ytXbSNE&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964882875%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=SxjGG9XewxYZ9gkSuQHya1%2Bfk70YQGQ4cNOGvY9am7Q%3D&reserved=0).

To find out more about the YPAGs, take a look at the [GenerationR website](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fgenerationr.org.uk%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964889719%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=mPJwOtGGs%2FzzQQvzRqV%2FphZ7R0ruI0SeFb%2FrwJ4g%2Buk%3D&reserved=0) or contact Jenny Preston, Senior Patient and Public Involvement Manager at the University of Liverpool, on info@generationr.org.uk

[Go to YouTube to watch the Bristol YPAG film](https://youtu.be/4-C6ytXbSNE?si=UKqOsyyf4aFNIffo)

## Do you know?

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

### Introducing Jonathan Fennelly-Barnwell

Jonathan is Deputy Director of the Approvals Service at the Health Research Authority.

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

I have always worked in and around the NHS in England, in public health, education and standards, and as a commissioner. For a long time, I have been fortunate to work in areas of health where diverse groups of people come together to help make good things happen, to help reduce inequalities and make people’s lives better through access to safe, effective treatment. Earlier in my career, I worked between communities, service provides and professional associations to set up services that deliver appropriate care, as far as possible, creating opportunities for communities to be part of that. I am motivated by the work that the HRA community and staff do in making research happen that gets treatment and services to people who need them. I remain particularly interested in the role of research in narrowing inequalities.

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

Firstly, that my work is a pleasure in working with great people, staff and others, across the whole UK. Day to day, I am responsible for large and complex system of around 900 volunteers and about 160 staff. As well as the practical issues to do with workforce and making the best use of public money, my work has a large focus on delivering the HRA’s statutory responsibilities as set out in [the Care Act 2014](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.legislation.gov.uk%2Fukpga%2F2014%2F23%2Fcontents%2Fenacted&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964903088%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=zHP%2BHLyD2Eg3UXMptYUm3EEpExd4%2BkbUWvYVYlQtfUQ%3D&reserved=0). No one team in the HRA (not even mine!) can deliver this on their own, so I have the pleasure of working with colleagues on the executive committee to make sure that the whole HRA is prepared to help make great research happen. Within the executive committee, I work with Becky Purvis as the strategic leadership team for the ‘Include’ pillar of [the HRA strategy](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hra.nhs.uk%2Fabout-us%2Fwhat-we-do%2Four-strategy%2F&data=05%7C02%7Cjacinta.bollard%40hra.nhs.uk%7C9f47b731f74540788fed08dc549d5751%7C8e1f0acad87d4f20939e36243d574267%7C0%7C0%7C638478281964909906%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=8CGEObO6POmiy4T05Ls%2FDJcENIrIgE3v5LXN4u3EuIc%3D&reserved=0). This helps make sure that whilst we deliver those core services, we make sure we do so with an eye to how we can involve people in the work of the HRA.

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

The HRA supports 64 Research Ethics Committees (RECs) and around 800 committee members. The committees all follow the same core guidelines and procedures to review research applications. Once reviewed, they give an opinion about whether the research is ethical. The committees are made up of different people, with different experiences, perspectives, and values. And so different RECs will see different things in the applications they review. This can be seen as inconsistency, but it is what we would normally expect to happen when different people with different experiences and values are being asked to make decisions about risk and potential benefits of research. The challenge comes in making sure people understand that this difference is central to working with people. And not a problem to solve.

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