

Agenda item:	14
Attachment:	A

Feedback from HRA strategy launch public involvement workshop

20 July 2022

Title of paper:	Feedback from HRA strategy launch public involvement workshop
Submitted by:	Will Griffiths-Stent/Eve Hart/Leni Sivey
Summary of paper:	This paper provides a summary of feedback from the HRA strategy launch public involvement workshop.
Reason for submission:	For information
Further information:	<p>This is a summary of feedback from a public involvement workshop that took place as part of the HRA Strategy launch in June.</p> <p>We invited further feedback online, but this was limited, likely because the original list was so comprehensive.</p> <p>We are holding a workshop with public contributors and Board members alongside this meeting to discuss these ideas and what they might mean in practice for how the HRA works to do what it has set out in its strategy. We want to identify what the HRA should do more of, what it should do differently, and what it is not currently doing that it should consider doing to better include everyone.</p> <p>We will work with public contributors to develop the findings of this workshop into proposals that will be brought to the September Board.</p>
Budget / cost implication:	n/a
Dissemination:	Published
Time required:	0 mins

1. Background

As part of the launch of the Health Research Authority's three-year strategy, Making it easy to do research that people can trust, a workshop was held to discuss the change we expect to see. The workshop was co-hosted by Circle Steele, member of Black, Asian and Minority Ethnic Research Advisory Group (BRAG) and CEO of Wai Yin Society and Matt Westmore, Chief Executive of the HRA.

The workshop took place via Zoom as well as at the Science and Industry Museum in Manchester, and involved HRA staff and public contributors, some of whom were new to the HRA.

The 'Include' pillar of our strategy is made up of three parts:

- Include everyone in research
- Ask you what you want research to look like and act on this
- Involve you in the HRA

In discussion groups we asked each other:

- What should the HRA do to achieve this?
- What should we influence others to do?
- Who should we work with?

The notes from the workshop were distilled into ten key themes.

2. Themes

Involve you in the HRA

- recognise how the way you work includes some people and excludes others
- do things differently
- get visible, get uncomfortable
- be accountable and honest

Include everyone in research

- make it easier for people to shape research
- including everyone is everyone's responsibility
- be up front

Ask you what you want research to look like and act on this

- reach people who don't know about research
- make research start with people
- raise up what exists, build what's needed

2.1 Involve you in the HRA

2.11 recognise how the way you work includes some people and excludes others

People need to feel like themselves to get involved. Reflect on what messages you send out in how you interact with people:

Environment: the location and image of a corporate setting have a big impact on who feels welcome, comfortable, supported and enthused. When people think about research they are likely to think about labs. Some organisations have innovative ways of making environments more friendly and suitable for the people using them, for example wards for people with dementia which are designed not to feel like a hospital setting.

Communication: think about the unspoken messages you send when you share information. Pictures are a shorthand language, and posters can be really effective at inspiring people to get involved with something...but it can make a huge difference whether the people represented are for example in joggers or a Prada suit.

People: it's important to be able to relate to people. If someone speaks the same way I speak or shares some of my experiences I'm more likely to want to get involved in their work than if they are 'too posh' or we don't have much in common.

2.12 do things differently

Remove the barriers that make it hard for people to work with you. Make it easier for people to get involved online. Remove the physical barriers to getting involved in person. It has felt in the past like the doors have been closed in public involvement. Have a named person who will always respond to emails. Work with people in ways that work for us (for example via email or WhatsApp or phone, and as regularly as works for us).

Talk in a way that everyone can access and understand. Use simpler language and less jargon.

Make sure HRA staff have the skills to engage with people meaningfully.

Remove job titles from discussions and break down structures so we can just engage as humans. Body language matters! Courses can help. Make sure staff have the skills to engage more, really listen, and earn our confidence that our voice is going to be heard and something will be done with our input.

2.13 get visible, get uncomfortable

Go out and be more visible to the public. If you don't already work in research, you wouldn't know the Health Research Authority exists. Engage with community groups and people from different areas. People need to know what they can be part of.

Expand the areas that you go to – get uncomfortable! Reach out more to groups and communities so that the people who shape the HRA are more demographically diverse. Organise team activities which involve learning or spending time with different communities in order to understand how to communicate with different people well.

Decide to prioritise working with excluded people. Work with younger people, older people, people with disabilities, and a more ethnically diverse range of people. Do it properly so people don't feel excluded or out of place by being the only person in the room with their background, situation or experience.

2.14 be accountable and honest

Let people opt in to working with you. Manage the relationship and people's expectations appropriately. Make it clear what the Health Research Authority can and can't do, so that people know how to work with you to make change.

Don't leave dead air. Create and sustain an ongoing conversation rather than a one off. Acknowledge that some things take time to put into action, but don't leave a long gap before reporting back on what's happened as a result of the work.

Be 'a beacon of sharing'. Publicise what you're doing yourselves and with others. Be up front with people about what you're hearing and how it's going to influence you.

2.2 Include everyone in research

2.21 make it easier for people to shape research

Make it easier for people to find their way through the research world. It can be difficult because there are so many different organisations, which don't always join up well and aren't very diverse.

Work with others to put more support in place for public contributors. Who can people turn to if things go wrong with their involvement? There's no HR or central support for public contributors.

Help the public understand how public involvement works. Show what it means in practical terms, and what its value and impact are. This will raise awareness and improve the quality of public involvement. Tell the stories of successful public involvement with easy examples people who haven't taken part in research can relate to. Work with funding bodies to include a description in the final reports about studies about how public involvement has made a difference.

2.22 including everyone is everyone's responsibility

Everyone has the right to be involved in research. Involvement opportunities need to be broader and shared more widely so more people are aware of them. Public involvement should be a mandatory part of going through the ethics review process.

We need more funding and resources for community partners in order to help increase the diversity of people who shape and take part in research.

Researchers should go to underrepresented populations instead of expecting members of those communities to come to them. They should think outside the box and work with people in engaging and entertaining ways. It's particularly important to make people from vulnerable or under-represented groups feel more comfortable. Not everyone thinks of themselves as having 'lived experience' (for example lots of young people think this doesn't describe them), and public involvement doesn't have to happen through formal public involvement groups.

2.23 be up front

Honesty matters. Sometimes people have bad experiences of being involved in research because it's been carried out as a tick box exercise. This puts us off from offering to share our insights for future research. There needs to be an honest conversation about research culture and the value that public involvement can bring. Maybe research isn't fit for purpose if researchers can't involve a diverse range of people to shape it.

Evidence matters. Use your influence to make sure research captures and shares information to measure whether it has been inclusive or not. Follow up and evaluate the Shared Commitment initiative to review what it has achieved. Researchers should have to feed back to public contributors or service users about how our involvement or feedback has made a difference to how they do things, so that we can tell we've been listened to, and change has happened in response to our input.

2.3 Ask you what you want research to look like and act on this

2.31 reach people who don't know about research

Get out into communities. Lots of people think of research as white coats and labs. Go to the places that people are, don't expect us to come to you. Research can feel like (and be) a closed door to the general public. Build trust by reaching out. Word of mouth is powerful. Find ways to meet people where they are in their communities, in spaces which aren't about research. Use research vans, posters, leaflets, or targeted advertising. Hold interactive days that promote local research. Think about GP practices, universities, community centres, schools, employers, prisons, hospitals, food banks, pharmacies, and recruitment centres. Help researchers understand how to do this too.

Help people understand research. Research is highly academic, and that can put people off. 'Research' can mean different things to different people and cultures, which can be part of why people don't want to take part in it. Explain how the Health Research Authority defines research. Provide training and support so research can be shared with people who don't have scientific or academic experience. Always use plain language and avoid jargon. Different types of media (for example TED talks) can help people connect with research more easily.

2.32 make research start with people

Include us in the big conversations. For example, there should be a public discussion about whether more research should be set up so that it's something people are included in and need to opt out if they don't want to take part (instead of being invited to opt in to taking part).

Research questions should start in the community. In order to build people's trust in research, what gets funded needs to reflect what matters to us, rather than research being designed to meet funding requirements or grow careers or institutions. Use your influence so that all research starts from public involvement so that it has as much impact as possible. Amplify the voices of groups which advocate for communities.

Make sure there's follow through. Give public contributors a seat at the table at ethics committee meetings, and make sure researchers share study findings with people who have taken part in a timely way.

2.33 raise up what exists, build what's needed

Work with others who have expertise, experience and power. Lots of researchers interact with the Health Research Authority, but you don't have to have all the answers. Signpost people to charities, NHS R&D, and established public involvement networks. But also find out where there are gaps that need filling, like providing training for researchers going through the application process.

3. Additional feedback

Noting that not everyone who wished to had been able to attend the workshop on 8 June, and that the summarising had been done by HRA staff after the event, the themes were shared for additional feedback and input.

This included a follow-up email to everyone who had registered for the launch event, and [a blog](#) on the HRA website, supported by a news item in HRA Latest and social media.

Additional feedback was limited, suggesting that the ten themes accurately represent the discussion from the room, and on Zoom, and that they comprehensively summarise the opportunity within the HRA's new strategy.

4. Next steps

In a seminar session on 20 July 2022 the HRA Board and public contributors will reflect together on the ten themes. In groups they will discuss:

- Where are we now and where would we like to get to
- What are the easy wins and quick fixes for each theme? What are the longer-term changes?
- What does success look like? How will we know we've done a good job on bringing change to this area?

The outcomes from this session will be used to draw into a proposed action plan which will be brought to the Board in September 2022.