

<b>Agenda item:</b>	9
<b>Attachment:</b>	A

## HRA Board Meeting

21 September 2022

<b>Title of paper:</b>	Doing things differently to deliver our include ambitions
<b>Submitted by:</b>	Leni Sivey, Kat Evans, Will Griffiths-Stent, Eve Hart, Becky Purvis, Jonathan Fennelly-Barnwell, and developed with the strategy working group of people involved in or impacted by research
<b>Summary of paper:</b>	<p>This paper makes three proposals for how the HRA can do things differently to deliver our include ambitions:</p> <ul style="list-style-type: none"> <li>• Be visible</li> <li>• Prioritise – work with partners and learn</li> <li>• Diversity – take the time to work with people in ways that work for them</li> </ul> <p>These have been informed by two workshops:</p> <ul style="list-style-type: none"> <li>• 8 June strategy launch public involvement workshop</li> <li>• 20 July Board public involvement workshop</li> </ul> <p>Under each proposal are recommendations for what the HRA should do now to deliver them.</p> <p>This discussion of these recommendations will inform the HRA’s business planning process for 2023-24.</p>
<b>Reason for submission:</b>	For approval
<b>Further information:</b>	<p>The paper covers:</p> <ul style="list-style-type: none"> <li>• Proposals to do things differently</li> <li>• Background – Where these proposals came from and how we propose to use them</li> <li>• A summary of the discussion at the 20 July HRA Board public involvement workshop</li> </ul>

<b>Budget / cost implication:</b>	
<b>Dissemination:</b>	This discussion will inform the HRA's business planning process for 2023-24.
<b>Time required:</b>	15 mins

## Doing things differently to deliver our include ambitions

### Proposals to do things differently

These three proposals have been informed by two workshops – further detail set out in section 2 - and are intended to shape what and how we work to deliver the include ambitions set out in our strategy over the next two years.

- **Be visible**
- **Prioritise – work with partners and learn**
- **Diversity – take the time to work with people in ways that work for them**

Under each proposal are recommendations, which have been developed with our Strategy Working Group of people involved in or impacted by research. These are suggested practical steps that the HRA should build into its business plans for the next two years to deliver the proposed change.

- 1. Be visible – the HRA needs to do more to ensure that people know about health and social care research, and what the HRA is doing to ensure that they can trust it.**

For the HRA to provide assurance that people can trust research that it has approved, people need to know what the HRA does, and its approval needs to be visible. There is more to do to make everyone aware of health and social care research and the many different ways in which they can get involved and take part. But the HRA is a relatively small organisation, and a long way from being a household name. We need to get a better understanding of how people knowing who we are will help us to make it easier to do research that people can trust, and then take steps to build the profile that we need to do our job well.

### Relevant themes from the workshops:

- Get visible, get uncomfortable
- Be accountable and honest
- Be up front
- Raise awareness

### What we're doing already:

- Our recent [Think Ethics public dialogue](#) found that the HRA can help build trust in health and social care research by increasing its visibility, and awareness of the work it does particularly in relation to ethics – Think Ethics has incorporated this into its work.
- We are [currently scoping a public dialogue](#), which we will conduct this financial year, to better understand what is important to earn people's trust in research.

- Work is underway to refresh the HRA website to help people find out what the HRA is doing and why it matters. This is part of delivering against our strategy commitment to talk in a way that everyone can access and understand.
- We are refreshing our communications, engagement and public involvement strategy.
- We are a member of the advisory group for [Be Part of Research](#), helping to feed in as they develop this into a 'Research Volunteer Service', which brings together patient registries across the UK.

### **Recommendations for what the HRA should do now:**

- Take every opportunity to tell people who the HRA is and what it does, for example talking about the HRA's role in developing new treatments for conditions which are being discussed in the media.
- Get a better understanding of how knowing who the HRA is and what it does is important to earn people's trust in research.
- Work to raise the HRA's profile where this will help earn people's trust in research. This could include taking part in exhibitions about research or being part of public awareness-raising campaigns.
- Work with others to increase awareness of research and how people can be involved and take part. For example, working with Be Part of Research, taking part in research campaigns that are rolled out to places where people access healthcare, and supporting education of healthcare professionals and researchers to talk to people about research.

## **2. Prioritise – work with partners and learn**

The workshops focused on our principle that health and social care research is done with and for everyone, and a clear theme came from them that we need to prioritise including people who are most excluded from our work and underserved by research. We cannot do this on our own and need to build relationships with partners that we can work with and learn from.

### **Relevant themes from the workshops:**

- Recognise how the way you work includes some people and excludes others
- Make it easier for people to shape research
- Including everyone is everyone's responsibility
- Reach people who don't know about research
- Make research start with people
- Prioritise excluded people

### **What we're doing already:**

- Developing guidance with the MHRA to set clear expectations for the diversity and inclusion of people taking part in research.
- Establishing consistent demographic data collection to better understand who we currently engage with.
- Work is underway to refresh the HRA website to help people find out what the HRA is doing and why it matters. This is part of delivering against our strategy commitment to talk in a way that everyone can access and understand.
- We are beginning to engage with more community groups, learning from this to develop the right processes and practices to ensure that we can do this well.
- Our [Shared Commitment](#) to embed public involvement in health and social care research means we have contacts with lots of organisations who have experience and engagement with groups that are underserved by research, and that we can work with and learn from them.
- We are refreshing our communications, engagement and public involvement strategy.
- We are developing our #StepForward campaign to encourage more people to become members of our Research Ethics Committees – we are planning to build relationships with community groups and employers to better understand how to ensure our campaign reaches people and is attractive to them.
- As part of our work to encourage researchers to do a better job of putting people first, we are exploring [how to talk about research](#) in ways that are more meaningful to those who are not normally involved.
- As part of Think Ethics, we are developing a system for public involvement network members to be able to attend REC meetings, with appropriate support, briefing and debriefing, so that we can learn from public perspectives on REC review as part of the evidence for how we can improve our services

### **Recommendations for what the HRA should do now:**

- Find new ways to talk about research that mean something to everyone and use this plain language in everything that we do.
- Build new relationships with ten community groups, learning from this engagement to inform how we continue to expand our public involvement network and reach new people.
- Be specific when we speak about diversity, and better define problems caused by a lack of it in different areas of our work. Use our better understanding of who we do not currently engage with to inform involvement activities so that we can better reflect the society that we serve.
- Build relationships with other organisations that are doing this well, partner with them and learn from them how to grow knowledge, confidence and pathways to

involvement in research. This might include some of the new partnerships between voluntary groups and Integrated Care Systems.

### **3. Diversity - take the time to work with people in ways that work for them**

Working more inclusively takes more time, and more resource, but if it is appropriately supported can ensure that everyone is treated with dignity and respect, and that we produce better results. This requires substantial culture change. We need to build in the time and resources to listen to and involve a diverse group of people in our work from the outset.

#### **Relevant themes from the workshops:**

- Do things differently
- Learn what needs to change
- Change how you work

#### **What we're doing already:**

- Developing internal guidance so that all teams can build public involvement into their planned work from the outset going forward. This will inform this year's business planning process.
- Planning activities to make all HRA staff aware of the importance and value of public involvement in research and support so that they can meaningfully involve people in their work where appropriate.
- Working with the Community Insight Group to consult on plans to establish a Community Committee within our governance, that will help deliver our commitments to increase public involvement in how we make decisions and listen to and involve a diverse group of people in our work.
- The process that has led to this Board Paper and this discussion, which will inform our 2023-24 business planning process.

#### **Recommendations for what the HRA should do now:**

- Be open to projects taking longer and costing more to support meaningful involvement of people in ways that work for them.
- Be reflective, listening to feedback, learning from it and focusing on what we need to do to have the biggest impact, being open to doing less but doing it better
- Build relationships with other organisations that are doing this well and learn from them

# 1. Background – Where these proposals came from and how we propose to use them

The HRA’s 2022-25 strategy, [making it easy to do research that people can trust](#), sets out two guiding principles, the first is to include so that health and social care research is done with and for everyone.

**Figure 1. A summary of the ‘Include’ pillar strategic commitments**



### **Include everyone in research**

Meaningfully involving people in all stages of research and sharing its findings is crucial to earn people’s trust. It helps us do better research that can improve care.

We will:

- Push for change to increase diversity and inclusion in research
- Increase public involvement in research
- Make transparency the norm for research

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

Research must address the issues that matter to you to earn your trust.

We will:

- Champion issues that are important to people in research
- Create public conversations about research issues that matter to people
- Encourage researchers to do a better job of putting people first

### **Involve you in the HRA**

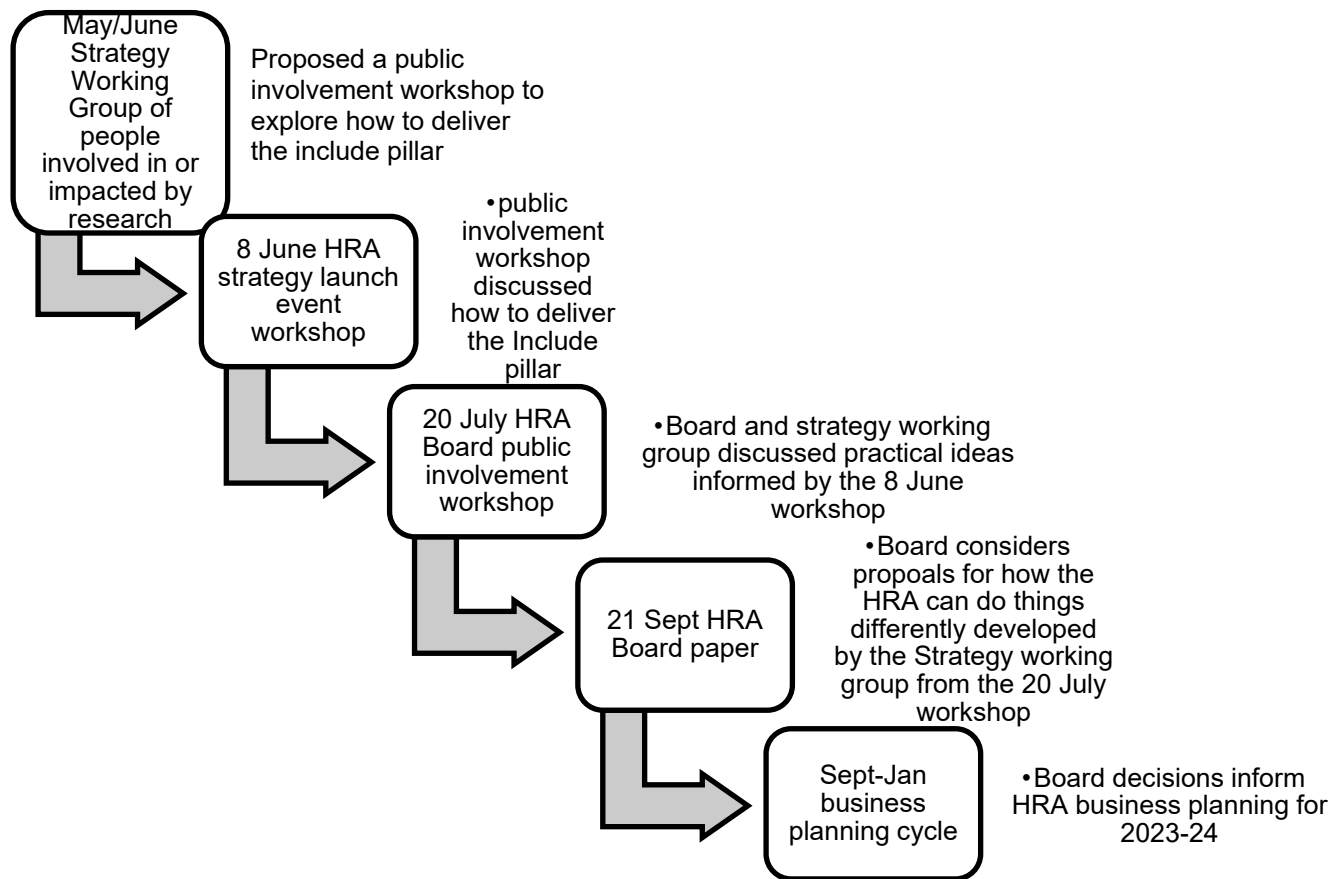
We can make better decisions by working with a diverse group of people with lived experience and making sure that anyone who wants to can get involved.

We will:

- Increase public involvement in how we make decisions
- Listen to and involve a diverse group of people in our work
- Talk in a way that everyone can access and understand

Acting in line with the include commitments that we have made, we are involving the public to shape how we deliver these. Figure 2 shows how we are doing this.

**Figure 2. How we are involving the public to shape how we delivery our include commitments**



A summary of the discussion at the 8 June strategy launch public involvement workshop was tabled at the 20 July Board. [ADD LINK](#), Ten themes emerged:

- Recognise how the way you work includes some people and excludes others
- Do things differently
- Get visible, get uncomfortable
- Be accountable and honest
- Make it easier for people to shape research
- Including everyone is everyone's responsibility
- Be up front
- Reach people who don't know about research
- Make research start with people
- Raise up what exists, build what's needed

A summary of the discussion at the 20 July HRA Board public involvement workshop is provided below in section 3 of this paper. There were five types of action that stood out about how the HRA should work to deliver Include:

- Learn what needs to change
- Prioritise excluded people



- Work with experts
- Change how you work
- Raise awareness

These discussions have informed the proposals for consideration in section 1 of this paper. The views of the Board on these proposals will inform the HRA Business planning process for 2023-24.

## 2. A summary of the discussion at the 20 July HRA Board public involvement workshop

### Background

On 8 June the HRA held a workshop at the launch of its new strategy, to discuss how to make the [Include commitments](#) a reality over the next three years. On 20 July the HRA Board and the HRA strategy launch working group of people involved in or impacted by research met to discuss how to act on the feedback from that workshop. The group prioritised three of the [ten themes from the strategy launch workshop](#) to reflect on first:

- recognise how the way you work includes some people and excludes others
- make it easier for people to shape research
- reach people who don't know about research

### What we heard

Below is a summary of the suggestions which emerged from discussion groups around each of the three prioritised themes.

The discussion group conversations were dynamic and collaborative. The first name of who made each suggestion is include in brackets afterwards, although for lots of the ideas there were several people who worked together. This is to make it easier to check that we've described the suggestions properly, and to help us stay accountable and transparent when we take the ideas forwards.

We've summarised the suggestions around five themes that came out in each of the discussion groups:

**Learn what needs to change**  
**Prioritise exclude people**  
**Work with experts**  
**Change how you work**  
**Raise awareness**

## **1. Recognise the way you work includes some people and excludes others**

### **Learn what needs to change**

- do the work to understand how and why people are being excluded from your organisation
- review the specific ways you work with people (e.g. reliance on ability to volunteer, payments process for public contributors and members of REC and CAG, communication, meeting times and formats) and recognise
- be willing to get uncomfortable, to recognise and reflect on privilege and to be proactive about understanding intersectionality

### **Prioritise excluded people**

- concentrate on working more with people your data shows are least included in your work: younger people, people with learning disabilities, people from more disadvantaged socio-economic backgrounds, and people with South Asian and Black Africa and Caribbean backgrounds
- work with trade union groups for people with protected characteristics

### **Work with experts**

- link up with charities with established relationships with patient groups
- expand the role of staff-led equality, diversity and inclusion groups to inform service delivery

### **Change how you work**

- create the capacity and energy within the HRA to make it possible to prioritise this work
- change how HRA talks about itself and what it does
- communicate externally about the equality, diversity, and inclusion work HRA prioritises internally
- build a rapport with people – physically get out into communities, and look at who is represented in meetings and communications
- break down the barriers created by being in a corporate setting – get out there

## **2. Make it easier for people to shape research**

### **Learn what needs to change**

- measure the diversity and reach of who's currently involved in shaping research
- send a 'mystery shopper' to GP surgeries to gauge what people know about research

### **Prioritise excluded people**

- focus on how someone who can't read or write could get involved in research

### **Work with experts**

- create more collaboration between those with power across the whole research system to create enthusiasm and top down change

### **Change how you work**

- turn the existing best practice examples into normal business as usual and make sure it's embedded in the system
- embed research in healthcare – provide a platform for research advocates, start with GP care, and community care and pharmacies
- streamline HRA's bureaucratic processes

### **Raise awareness**

- hold a wider public campaign about research with other organisations, and host public conversations on issues that matter to patients and the public
- help the public know more about the existence and role of health and social care arm's length bodies
- provide basic education for the research community about public involvement
- create guidelines for researchers about how to be more inclusive and shape research to be more representative of the major cities of England which are now more cosmopolitan

## **3. Reach people who don't know about research**

### **Learn what needs to change**

- work with people to find out what research being 'trustworthy' means to them, and why it might not feel trustworthy right now. It's not automatic that people trust authority.
- find out what would earn people's trust in research

### **Prioritise excluded people**

- focus specifically on people who don't currently know about research

### **Work with experts**

- use existing networks to reach people (e.g. charities, online communities, and universities)
- start from involvement and make the work community led (e.g. via the National Voices Coalition)

- appoint people from within excluded communities to lead work, and explore unconventional routes (e.g. barbershops and churches)

### **Change how you work**

- shift your communications and engagement strategy to focus on reaching the public
- engage with people in person through GP surgeries, local authorities, or travelling roadshows
- use established community networks (e.g. community groups, health support groups, and partner organisations' networks) and use different ways to reach people (e.g. flyers, newspapers)
- use social media and pay for search engine keywords

### **Raise awareness**

- talk on the HRA website about what trustworthy research means
- work in a trustworthy way – promote more listening, hearing, and acting within the research system
- Find out whether raising the HRA's profile and what it does with the public is important to earning trust in research

build public awareness that involvement roles exist and how people can get into them