

Agenda item:	9
Attachment:	A

## HRA Board meeting

16 March 2022

<b>Title of paper:</b>	Communications, Engagement and Involvement update
<b>Submitted by:</b>	Will Griffiths-Stent, Senior Engagement Manager Ali Barbuti, Senior Communications Manager Naho Yamazaki, Head of Policy and Engagement Eve Hart, Head of Communications
<b>Summary of paper:</b>	This paper: <ul style="list-style-type: none"> <li>• provides an overview of HRA communications, engagement and involvement activity since January 2022</li> <li>• gives detail on the stakeholders we have engaged with, the reason for engaging, and the value of this engagement</li> </ul>
<b>Reason for submission:</b>	For discussion
<b>Further information:</b>	N/A
<b>Budget / cost implication:</b>	N/A
<b>Dissemination :</b>	HRA website
<b>Time required:</b>	15 minutes

## Communications, Engagement and Involvement update

### 1. Background

The HRA's communications strategy sets out a strategic approach to how we use communications to support the delivery of the organisation's strategy and ambitious business plan. This is complemented by the HRA's stakeholder engagement strategy, to ensure that we have greater influence over behaviour in the research community and greater impact across the research system nationally. We undertake a range of communication, engagement, and involvement activities to meet the objectives outlined in these strategies. This paper provides a summary of these activities from January to March 2022, so that the Board is informed of our work in this area.

### 2. HRA-led events

#### 2.1. **Think Ethics - Information and Consent Research Ethics Committee member webinar and stakeholder workshops**

Engagement activities supported our current work to:

- improve participant information and consent materials
- enhance informed consent
- establish clear principles and approaches for the ethics review of informed consent processes and documentation

**REC member webinar** - Chaired by Professor Andrew George, and attended by over 110 REC members representing all UK nations.

**Two information and consent workshops** - Over 200 expressions of interest, with approximately 100 attendees selected, including representation from public contributors, industry and pharma, non-commercial sponsors, research delivery staff, and REC members. Feedback from attendees included: research participants' needs must be at the heart of how we think about participant information, the need to be ambitious in the changes we bring; and that provision of information to participants should be an ongoing process and series of conversations, rather than just about paperwork.



## 2.2. Data Decision Tool Workshop

Colleagues working on the Streamlining Data Driven Research programme held a workshop to discuss the content of a decision tool to guide users on what approvals are required for their project.

- The tool is to support those who are building technology by helping them navigate complex regulatory considerations that must be addressed to access and use health data.
- Over 50 people attended, including representatives from Small Medium Enterprises (SMEs), entrepreneurs in the tech industry who use health data, university researchers, data and computer scientists, and R&D experts in information governance – the first groups being significant new audiences for HRA.
- Information from these workshops will be analysed and brought together in a short report, to be shared internally and with the external agency we are contracting to review our approach to decision tools and build an effective new tool on the IRAS website.

## 2.3. Public dialogue on research ethics

In this period, we also concluded the Think Ethics public dialogue activity. The work helped us to understand what people know about research ethics review, and through a deliberative approach, what people:

- perceive to be the value of ethics review and the role of RECs
- think should be the focus/nature of ethics review
- consider to be important categories that should be considered by RECs

Working with a specialist social research agency, we recruited 46 members of the public from across the UK to take part in four Zoom workshops. We shared the

framework that our RECs use to make their decisions and discussed what they thought was most important. Participants told us that what matters to them are:

- a diverse group of people involved in ethics review
- greater awareness of ethics review to build public trust
- more research, reviewed more quickly where appropriate
- in the committee, a focus on the value of the research, the balance of risk and benefit, informed consent, and care of the participant

Two blogs, co-written with public contributors, described this work to a wider audience. We promoted them via social media, and have engaged wider HRA staff with regular updates and an upcoming presentation to all staff by the agency.

#### **2.4. Strategy development workshop with Public Involvement Network members, 8 March**

We held a workshop with members of our PIN to inform the HRA's mission and upcoming three-year strategy so that it reflects the priorities, language and experience of patients, service users, carers, and the public. Seven Public Contributors attended. The objectives of the workshop were:

- to define what success looks like from a public and patient perspective
- to receive feedback on the content and language of the strategy to check it makes sense and feels right

We are collating feedback, and this will be shared by Matt Westmore with the Board in this meeting.

#### **2.5. Make it Public Campaign Group meeting**

The HRA hosted the monthly meeting of the Make It Public Campaign Group, with attendees from Association of Medical Research Charities, Leeds University, Association of British Pharmaceutical Industry, Medical Research Charity, TranspariMED, Health Data Research Global, and HRA PIN. Members discussed the development of a mission statement, linked to the Make it Public vision in our strategy, that organisation and individuals could sign up to.



### 3. Partnership events

#### 3.1. Academy of Medical Sciences and HRA workshop – ‘The HRA at ten: current progress and future gazing’

Connected to our 10<sup>th</sup> birthday celebrations, we held a large workshop in partnership with AMS. This workshop looked at what the HRA has achieved to date, as well as future-gazing about upcoming opportunities and challenges in research, and how the HRA could interact with these.

The three key takeaways from the event:

- **Well done HRA!** Everyone was complimentary on what the HRA has achieved, and we have a lot of people championing us.
- **People in research** – throughout the day, the focus was on people at the heart of research. Whatever the topic, every speaker framed their remarks around the people at the heart of research and focusing on improving their opportunities to take part. Two of our public contributors gave thought-provoking insights:
  - “Patient and caregivers should never feel inferior to those in position of authority”
  - “If we want research to be patient-centred we need to shift focus towards how we achieve health outcomes, rather than focus on interventions’
- **System-wide change** – Much of the discussion highlighted that the HRA is no longer the ‘blocker’ in the system, where once it might have been. Much of the day’s discussion focused on system-wide challenges that need to be tackled and the opportunities of doing so – for example, making it easier for decentralised trials taking place in multiple places around the UK, so boosting access for people all over the UK to take part, to get off the ground. Attendees were ambitious for the role of the HRA to build on its successes to date to influence and lead this change across the system.

These events not only gave us valuable assessment of our performance and feedback to guide the creation of our new strategy, but it was also raised our visibility with sector leads and key organisations across the sector.

The event was promoted via social media using the striking #HRA10 visual identity. A formal report will be published later this spring. A blog about the event is being sold in to specialist press.

#### 3.2. Shared Commitment to Public Involvement – stakeholder roundtables

HRA and NIHR have jointly led five stakeholder roundtable meetings, to discuss and agree the content for the shared commitment to public involvement.

- Organisations involved and signing up to the Shared Commitment include Academy of Medical Sciences, Association of Medical Research Charities, Cancer Research UK, Chief Scientist Office Scotland, Health and Care Research Wales, Health and Social Care Northern Ireland, Medicines and Healthcare products Regulatory Agency, National Co-ordinating Centre for

Public Engagement, National Institute for Health Research, Association of the British Pharmaceutical Industry, and Universities UK.

- The representatives from each of these organisations have usually been engagement or public involvement leads, with each organisation's Chief Executive providing final sign-off.

The public involvement team have held meetings with public contributors active in this work, ahead of each roundtable.

- This has allowed contributors to work through the content of each workshop in advance, resulting in the roundtables being led by contributors themselves. This has had tremendous benefits, with contributors and organisations alike feeling that change is being driven by the public voice directly.
- Contributors have also had direct input on the commitment's branding and public image.

This work with NIHR has been key in further showcasing the HRA's role as the leading regulatory organisation in promoting and protecting the rights of patients and the public. Through this work the HRA has great potential to influence both partners and wider stakeholders to be far stronger and more visible in their commitments to patients and the public in research.

Jim Elliot and Barbara Molonyoates will be presenting on this further at this Board meeting.



## **4. Events we have taken part in**

### **4.1. Presentations to ABPI Webinar – Clinical Research Vision: One Year On, 23 February**

Janet Messer and Becky Purvis both presented at the ABPI's webinar 'Clinical Research Vision: One Year On'.

- Janet, along with Martin O'Kane, presented on joined-up regulation, proportionality, and the end-to-end research journey, including legislative change, combined review and fast-track.
- Becky presented on research transparency and embedding public involvement, including new requirements in clinical trial legislation, the cross-system shared commitment to public involvement, and public involvement in participant information.

## **5. Stakeholder meetings**

### **5.1. Meeting with Universities UK**

Naho Yamazaki and Will Griffiths-Stent met with John de Pury (Assistant Director of Policy), to discuss current working priorities.

- Universities UK, is planning to undertake a strategic overview of all the [Research Concordats](#) in place in the UK

### **5.2. Meeting with Cancer Research UK, around data in health and research**

Becky Purvis and Will Griffiths-Stent met with Rebecca Hill (Policy Advisor) and Sarah Cook (Science and Charity Policy Manager) from CRUK, to discuss work areas and areas of shared activity. Key feedback and opportunities from the meeting:

- There are shared opportunities around developing public confidence and trust on data sharing and data use for research.
- CRUK is working to be involved in the establishment of trusted research environments, and accreditations around these that are currently being developed.
- CRUK has a dedicated patient data panel that they share with British Heart Foundation. Data security and transparency are issues that are always raised at the panel.
- CRUK is working on a Research Data Strategy, which they will share.

### **5.3. Meeting with Equality UK, around shared commitment and refreshing HRA mission**

Barbara Molonyoates and Will Griffiths-Stent met with Annette Jack (Founder and Director) and Ria Sunga (Strategic Projects Manager) to discuss Equality signing-up to the shared commitment, and on Matt meeting with Annette to review initial proposals for the refresh of the HRA mission, with particular focus on research for and with everyone.

#### **5.4. Meeting with Academy of Medical Sciences, around policy priorities**

Matt Westmore and Naho Yamazaki met with Simon Denegri (Executive Director) and Jim Squires (Head of Policy) from AMS, to discuss policy priorities and upcoming strategy updates.

- Policy priorities for AMS include exploring wider inequalities, child and maternal mental health, AI and health, embedding research in the NHS, and a possible project looking at Covid 'follow-up'
- AMS committed to share a draft of its 10-year vision and strategy when they are ready.

#### **5.5. Meeting with ABPI Public Affairs**

Becky Purvis and Will Griffiths-Stent met with Joe Edwards (Public Affairs Manager) from ABPI, to build HRA relationships with the public affairs side of ABPI, to cover areas of shared working, and to learn more from ABPI about their priorities and focus in more of a parliamentary setting:

- ABPI and partners have pushed for [stronger language and legislative mandate to deliver research](#), rather than just to promote research, as well as new requirements in and around planning and recruitment of research participants.
- They have also launched a consultation on [industry principles for use of health data](#), which closes 11 March; this has specific overlap with HRA work in data and digital, and on the importance of transparent arrangements for use and storage of data to build and maintain public trust in research. We do need to comment at this stage as everything in ABPI's five principles aligns with our position.
- We will have opportunities to work with ABPI's Patient Organisation Forum, as well as potential opportunity to interact with the Life Sciences All-Party Parliamentary Group.

#### **5.6. Meeting with BioIndustry Association**

Becky Purvis and Will Griffiths-Stent met with Martin Turner (Head of Policy and Public Affairs) and Emma Lawrence (Senior Policy and Public Affairs Manager), to discuss shared areas of activity, especially in areas of data.

- Clear overlap on data and ethics, as BIA members are getting more into the world of data-sharing, with more conversations on the ethics around this.
- BIA reflected that some SMEs who are new to the research world struggle to navigate the governance, with different experiences in their interactions with RECs.
- We have discussed potential further work relating to getting a better understanding from BIA members of what support they need, both to navigate the regulatory process, but also to what they would need to embrace and include public involvement.



## **5.7. Meeting with DHSC Medtech team**

Matt Westmore and Naho Yamazaki met with Chris Stirling (Director, Medtech), Deanne Johnson (Head of Strategy and Policy), and Deborah Bolton (Senior Strategy Lead) from DHSC to discuss. This follows an Innovation Steering Group meeting where the MedTech strategy was discussed.

## **6. Communications activity**

### **6.1. Research systems programme**

The team has provided operational comms support to the programme, which has included targeted updates to commercial sponsors to support them during a key period of systems change.

Strategic communications support has included an interim strategy to engage partners with the review underway with PA Consulting.

Working with a wider group of colleagues, including the service desk and business change specialists, comms colleagues used feedback data and identified opportunities to use proactive comms to reduce pain points for applicants. This will start with a creative, layered amendments campaign.

The team is also working with NIHR to produce a short animation to support users to find and use their IRAS ID.

There has been specialist media coverage of the ongoing success of combined review, but limited proactive promotion of improved timelines to mainstream media (in an approach agreed with MHRA and DHSC) until some user feedback has been actioned.

Sustained regular social media posts remind users of the benefits of combined review.

### **6.2. IRAS website**

A new tone and style guide for the IRAS website has been approved by the IRAS partners.

The guide will make it easy to produce clear, directive and engaging copy, and the first content is being drafted for the site, which is in private beta.

A new independent user researcher has been commissioned to support the next phase of development, though the NHSX assessment planned for April has been postponed until after the outcome of the strategic review.

### 6.3. Multi-agency advice service

The HRA comms team is working with partners to lead the development of a new visual identity for the new advice service, ensuring that there are clear user journeys between this site, the NHS Innovation Service and individual partner websites.

### 6.4. REC recruitment campaign

A new targeted recruitment campaign will ask medical professionals to step forward and join an NHS REC.



Striking digital advertisements featuring some of the HRA's current members will be placed on appropriate sites using web profiling data.

The ads point to a [refreshed section of the HRA website](#), aiming to increase the current conversion rate between those expressing an interest and going on to make an application to become a REC member.

### 6.5. Clinical trials consultations


The comms team has been working with the MHRA on a communications campaign to promote and encourage stakeholders to participate in the consultation on the future of clinical trials.

Outputs included [a blog by Public Involvement Lead Jim Elliot](#) on new proposals for mandated public involvement, [two articles](#) in HRA Latest and a social media campaign highlighting the opportunities for comment, including clinical trial approval processes, transparency and combined regulatory and research ethics approval.

### 6.6. Sharing in success

As the world's first COVID-19 human challenge study publishes its results, the communications team took an opportunity to [reflect on and promote our role](#) in

reviewing and approving this ground-breaking research.



'It is a real privilege working with the committee. Helping them to work together, share skills and insights with the researchers so we could explore, assess and improve this ground-breaking research, keeping participants safe, but ensuring it would work.'

**Stephanie Ellis**  
Expert Chair of the first COVID-19 human challenge Research Ethics Committee

NHS Health Research Authority

#BreakTheBias

Outputs included a news story, and feature on Stephanie Ellis, Chair of the specialist REC, as part of our International Women's Day campaign. The team also promoted the World Health Organisation's academic report on a round-table discussion on the ethics of human challenge for COVID-19, co-chaired by Stephanie last year.

### 6.7. Voicing our opinions on key issues

As news of a [£260million investment by BEIS and DHSC](#) to ensure patient data and public trust are protected broke, we were quick to provide our support with social media reaction from Chief Executive Matt Westmore, and our Head of Data and AI Policy Liz Bohm.



We support these plans to develop new ways of holding data allowing it to be used securely and providing further protection for the benefit of patients and the public. We are currently looking at whether there are more streamlined approaches we can take to approvals that would make doing research in these environments even more efficient.

**Elizabeth Bohm**  
Head of Data and AI Policy

We positioned ourselves as an important player in advancing cancer research during World Cancer Day on 4 February [with a blog](#) from Public Involvement Lead Jim Elliott talking about how public involvement in health and social care research can help to 'close the care gap' in cancer – one of the key themes this year. We also worked with [the Million Women study to highlight how ethics review](#) helps their work and how this has changed over the 20 years the study has been running, and

highlighted our research summaries database an important place where people can view all of the cancer studies reviewed by our RECs.

## **6.8. Media handling**

This month has seen joint working with NIHR and DHSC on a vaccine fraud issue which required careful comms handling, and joint working with DHSC, NHSBT and HTA around significant media coverage of xenotransplantation, providing reassurance about the UK's regulatory landscape.

There has also been reactive handling of journalistic enquiries around a number of specific studies, and the work of CAG

## **6.9. Stakeholder communications**

We are seeing the benefit of separating operational and strategic email communications to stakeholders. There are now over 3500 subscribers to [HRA Now](#), a single-issue broadcast bulletin to support technical change, and almost 15,000 subscribers to [HRA Latest](#), an increase of 200% in the last twelve months.

Engagement with both products is slightly up at just over 30%, well above the sector average of 18%. It is now easier for stakeholders to find information that's of interest to them, and to understand when things are changing and how it will affect them.

## **6.10. Internal communications**

Activity this month has included strategic support of the annual staff survey to encourage the usual high level of engagement. This takes a 'you said we did' approach, complemented by leadership blogs and an ongoing campaign using 'completed so far' data.

More broadly the team is supporting the HRA's move from legacy systems to SharePoint and has made staff aware of important cyber security updates needed in response to the situation in Ukraine.