

Agenda item:	Leave Blank
Attachment:	Leave Blank

## HRA Board meeting

18 May 2022

<b>Title of paper:</b>	Communications, Engagement and Involvement update including RRG activities & Approvals Directorate
<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 Kate Greenwood, Senior Improvement Delivery Manager
<b>Summary of paper:</b>	This paper: <ul style="list-style-type: none"> <li>• provides an overview of HRA communications, engagement and involvement activity from mid-March to mid-May 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>	10 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 activity

**Presentations to REC Chair training days** – Leni Sivey presented an overview of the Think Ethics Information and Consent project to REC Chair training days for the Office for Research Ethics Committees Northern Ireland (ORECNI) and for NHS Research Scotland.

They invited feedback on the UK-wide policy measures which have been agreed to improve the quality of participant information and the consistency of how it's reviewed. The Chairs are interested in and supportive of the work, and in line with the project approach are keen that the measures support researchers and RECs to consider participant information materials, processes, and relationships, rather than focusing disproportionately on written participant information sheets.

**Advisory Group meeting** - We held two meetings of the Think Ethics Advisory Group in this period (22<sup>nd</sup> March and 28<sup>th</sup> April).

At the March session, the Group heard and agreed the recommendations for improving Information and Consent and for them to be presented to Four Nations Policy Group for approval.

At the April meeting, they worked through the benefits and barriers of the three proposals for Methods of Review workstream. This

workstream is looking at embedding a more proportionate approach to methods of review, making it easier for ethics committees to focus on ethical issues that are high



risk or complex, for which there is no precedent. The three proposals for Methods of Review are due to go for public consultation.

## **2.2. REC Member Development Days**

On 7 April 2022 we held the first of our REC Member Development Days. This took place in London Euston, as was the first of seven face-to-face development days hosted by HRA. The Development Days are an opportunity for REC members to connect and network, and to develop their relationships and team working as a REC.

A full update on the Development Days can be found in the Chief Executive's report.

## **3. Partnership events and key group meetings**

### **3.1. Nuffield Council on Bioethics and HRA workshop – ‘What could be the big issues for research ethics over the next ten years’**

Connected to our 10<sup>th</sup> birthday celebrations, we partnered with the Nuffield Council on Bioethics to hold a virtual workshop to help us identify what could be the big issues for research ethics over the next ten years.

Taking part were international medical ethicists, UK REC members and public participants. The discussion was wide-ranging and will inform [Nuffield Council on Bioethics horizon scanning](#) and the HRA's future work. Themes included:

- **The importance of transparency** – knowing that research has been through research ethics review and how that works can help earn public trust in research.
- **The importance of a partnership between researchers, patients and the public** – ensuring equality, diversity and inclusion, addressing power imbalances and encouraging co-production.
- **Viewing research ethics within the wider research context** – that ‘research ethics review’ is part of the process but trust is earned through an ethical approach to the whole process – decisions over what to fund, sensitivity to changes in research, reporting and using results to change practice etc.

### **3.2. Shared Commitment to Public Involvement Full Group meeting**

We held the first full group meeting since the public launch of the [Shared Commitment to Public Involvement](#) in March (detailed in full in the Communications Activity update 6.3). Public Involvement and/or Engagement leads from many of the 17 organisations involved attended.

The focus of this meeting was on looking forward and building a governance structure for the group to enable it to thrive and grow, and also to help each other to be accountable to the actions we have promised in the Shared Commitment. The first meeting of the Steering group which will be made up of equal numbers of public contributors and public involvement leads from the member organisations has been set for July 6<sup>th</sup>.

The initiative has received a lot of interest with NHS England already keen to join, and a host of other organisations expressing interest in joining. The steering group will set up the mechanism for other organisations to join us, and how we can support existing and new members to help share the consistent message to the research community, that Public Involvement is Important, Expected and Possible.

### **3.3. Community Insight Group meeting**

We held a meeting of the Community Insight Group in May. This Group is made up of REC, CAG and PIN members, and has been created to help the HRA better support and value those who volunteer and work with us to improve their experiences as part of the HRA community. Further detail can be found on the [Group's webpage here](#).

At this session, the Group reviewed plans for the upcoming REC recruitment campaign, as well as visuals for the annual plan. The Group also heard more detail and results from the recent community survey.

### **3.4. 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 Public Involvement Network.



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. The next meeting of the group is lined up for May 16<sup>th</sup>.

### **3.5. HRA Study Set Up Partnership Board Meeting**

Representation from Industry, NHS R&D (Secondary & Primary Care), CTUs, HRA Staff, NHS England & NIHR CRN. Meetings with key stakeholder groups have been held to support our work in the set-up of studies at a site. Improving study set up is fundamental to accelerating research and our core business in the Approvals Directorate, and Coordination & Standardisation team. It is also a key priority for the UK Recovery, Resilience and Growth (RRG) programme. This quarter we used a

meeting to hold a workshop with the partners and have focussed on the development of a study set up improvement plan.

### **3.6. Non-commercial Sponsors reference group & HRA Research Champions**

We lead these meetings to support and engage with the non-commercial Sponsors and NHS R&D management communities. This quarter we shared updates (for example on the COPI notice, RRG and legislative developments) as well as progress on key areas of importance for business change (new IRAS and combined review), seeking input where appropriate.

### **3.7. Combined Review Webinars**

Combined Review Webinars were conducted this quarter: 07 Mar 79 attendees. 09 Mar 89 attendees with 6 completed in total this year (4, previously unreported to the board were also conducted 22Feb - 03Mar - additional total of 352 attendees)

Feedback on the webinars has been extremely positive with an average of 4.38/5 for usefulness across all 6 webinars in total and 4.53/5 for recommending to a colleague. Impact scores for the webinars were lower at an average of 3.6/5 as many in the audience would not need to use combined review imminently.

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

### **4.1. First meeting of the pan-UK Data Governance Steering Group**

Alison Knight represented HRA at the Steering Group's first meeting. The Group has been formed by HDR-UK, with the intention of working in partnership to build a robust and streamlined governance approach to data access based around the '5 safes' framework. Four key pillars of work were proposed to build on existing work of the [UK Health Data Research Alliance](#) (with this Group proposed to form a sub-group of the Alliance):

- Developing researcher accreditation (building on the researcher passport schemes developed under the Digital Economy Act)
- Training
- Aligning legal terms/agreements
- Creating a 'fast track' data access application form and standardised access approval criteria (using a UK-wide review panel with PPIE)

For further information, please contact Alison Knight, Data and Privacy Specialist.

#### **4.2. Necessary Conversations event, ‘What can we learn from involvement in Covid and Long Covid research?’**

Jim Elliott attended on behalf of the HRA. Presentations from five different research teams, including Covid and Long Covid patient advocates who were part of the teams, on their research, the roles that the patient advocates had and perspectives from both sides on the value added from the involvement, which in all cases was co-production.

All presentations demonstrated excellence in patient and public involvement according to the UK standards and the HRA's Principles for Public Involvement and would all be very good case studies. Many pertinent suggestions were made for further embedding public involvement that were relevant to the shared commitment initiative. The researchers were all major champions for public involvement who could support HRA's Shared Commitment activity.

#### **4.3. RRG Programme Board**

Dr Janet Messer attended on behalf of the HRA to drive the UK Recovery Resilience and Growth programme collaboratively with partner organisations. This is a recurring meeting of UK-wide stakeholders.

#### **4.4. Portfolio Reset Oversight Group**

Dr Janet Messer is participating in the group set up to oversee the urgent response for UK reset and recovery of the NIHR clinical research portfolio. Due to unprecedented pressures in the NHS, sponsors are asked to review their studies and amend or close those that are failing to deliver. The meeting involves advising the Department of Health and Social Care on best actions to take and ensuring the HRA is ready to respond appropriately. Kate Greenwood has acted as deputy for this group.

#### **4.5. PPI Involvement in Reset**

Jim Elliot, Barbara Molonyoates and Kate Greenwood attended a meeting with NIHR colleagues and public contributors to discuss the implications of the portfolio reset for participants and how public contributions to the direction of reset might best be considered.

#### **4.6. Belgian Economic Mission to the UK, ‘Digital Health and Collaboration between UK-Belgium’**

“Research and evidence generation for digital technologies- pathway to a successful launch in the UK”: A Panel Discussion

Maeve Groot Bluemink, supported by Jen Harrison, took part in a panel discussion hosted by MedCity with a focus on evidence generation and regulations required for

approval of digital technologies in the UK healthcare system (clinical trials, health economics), access to UK healthcare organisations and available navigation services.

#### **4.7. Be Part of Research Advisory Group Meeting**

Naho Yamazaki represents HRA on the Advisory Group, a regular meeting led by NIHR. The Group reviews the latest developments on [Be Part of Research](#). At this meeting there was update from NHS England on its Digital Engagement work and discussions around patient registries.

### **5. Stakeholder meetings**

#### **5.1. Meeting with MHRA on Diversity Guidance**

Naho Yamazaki, Kate Greenwood, Barbara Molonyoates and Jane Morrin O'Rourke met with Martin O'Kane, Lisa Campbell and Shirley Hopper to discuss developing joint HRA-MHRA guidance for researchers to support and encourage diversity in research.

It was also an opportunity for the HRA to discuss plans to develop a webpage on the HRA website which will outline our expectations regarding diversity in research and signpost to helpful resources. This will complement future guidance for researchers. It has since been agreed that the webpage will be a joint statement with MHRA.

The researcher guidance and webpage are part of a package of work we are undertaking with partners across the system to make research more diverse and relevant to the whole of the UK. This is a strand of work from the RRG programme.

The next meeting of the group will take place in June.

#### **5.2. Meeting with NHS England, NIHR and DHSC on National Contract Value Review (NCVR)**

From April 2022 a new process is starting to make it easier to deliver commercial research in the NHS. We've worked with NHS England, the National Institute for Health and Care Research (NIHR), and the Department for Health and Social Care (DHSC) to deliver a national contract value review. The result will be a standardised, national approach to NHS site costing for commercial contract research to replace the current costing process.

Dr Janet Messer, Alastair Nicholson, Kate Greenwood and Claire Cruddas help to shape this work through active involvement.



### **5.3. Meeting with UK Reproducibility Network and Reproducible, Interpretable, Open & Transparency Science (RIOTS)**

Naho Yamazaki, Will Griffiths-Stent and Louise Forster met with Marcus Munafò from the UK Reproducibility Network and Sam Westwood from RIOTS on 1<sup>st</sup> April. The meeting involved an overview of their organisations and a discussion around how we could work together on taking the Research Transparency agenda forward, and how they could potentially input in to the next Make it Public conference.

### **5.4. People-Centred Clinical Research Project Delivery Team with Lincoln University**

The HRA is leading a project to increase the likelihood of clinical research happening in people centred ways and a small delivery group has been formed to take forward. The group includes academic colleagues from the University of Lincoln, Kate Greenwood, Janet Messer, Becky Purvis, Barbara Maloney Oates, Jim Elliot and Naho Yamazaki. A steering group of public contributors and clinical academic colleagues will be convened in the coming months.

### **5.5. Experimental Cancer Medicine Centres pilot for phase 1 oncology studies**

HRA are acting as sponsor organisation for this RRG project looking to improve the set-up of studies in early phase cancer. Janet Messer and Kate Greenwood meet with ECMC colleagues to oversee progress and suggest ways forward ensuring links to study set up and improvement for other study types are made.

### **5.6. Meeting with Wai Yin Society**

Becky Purvis, Naho Yamazaki and Kat Evans met with Circle Steele, CEO at [Wai Yin Society](#), an organisation focused on supporting, empowering and working in partnership with Chinese individuals and families to challenge discrimination and social exclusion. The purpose of the meeting was to explore ways of working together in future. Specific focus was on collaborating around the RRG programme and on the upcoming HRA strategy launch.

### **5.7. Meeting with Africa Advocacy Foundation**

Becky Purvis, Naho Yamazaki and Kat Evans met with Denis Onyango, Programmes Director at [Africa Advocacy Foundation](#) (AAF). The AAF is a community-led initiative, that works with communities both in the UK and overseas who are affected by a range of issues.

The purpose of the meeting was to build shared understanding of our work, and ways we may collaborate in future.



As with the meeting with Wai Yin Society, the conversation also explored and broadened understanding of the longer-term impacts of contemporary and historic exclusion from research, institutional and structural racism, and impact of unethical practice.

#### **5.8. Ongoing Coordination, Standardisation and Business Change updates, presentations and guidance to external stakeholder groups**

Engagement and liaison activities are undertaken at meetings with partners to provide updates on the approvals process and business change and to gather feedback and intelligence from the wider research community in support of study set up. Audiences we are connecting with are R&D departments, non-commercial sponsors, industry colleagues, and trial teams.

This quarter HRA staff contributions have focussed on the combined review process and general HRA updates, student research, good study set up and RRG.

For detail on specific meetings or for further information on these activities, please contact Jen Harrison, Change Manager.

#### **5.9. Meeting with Office for National Statistics, on research transparency and analysis**

Naho Yamazaki and Will Griffiths-Stent met with Rebecca Briggs from ONS, to discuss overlap around research transparency and the ONS's current activity around transparency in its analysis, strategy and research division.

Of interest for further working was the National Statistician's Data Ethics Advisory Committee (NSDEC), which has been established to advise the National Statistician and will consider project and policy proposals, which make use of innovative and novel data, from the Office for National Statistics (ONS), the Government Statistical Service (GSS) and beyond, and advise the National Statistician on the ethical appropriateness of these.

### **6. Communications activity**

#### **6.1. Launching the HRA strategy**

The team is working with members of the Public Involvement Network on plans to launch the HRA's new strategy so that everyone knows what the organisation does and why it matters. A strategy working group with eight members of our network is meeting weekly to advise on the launch event, the visual identity for the strategy and plans to promote this widely.

## 6.2. Research systems programme



We are testing new ways of supporting users through the changes that result from our research systems work. This includes short video content for research teams using combined review created by our learning and development team. 64% of users watched over 90% of the new short video compared to 9% of

users who watched over 90% of the original long webinar recording for applicants.

Interim communications activity has agreed and promoted standard lines about the review and reinforced the HRA's commitment to a world class regulatory system for all studies.

Planning for a communications and engagement restart following the strategic review is underway.

### 6.2b IRAS website

Preparation for the beta assessment at the end of September 2022 is underway, which includes providing evidence of how recommendations from the alpha assessment have been met, as well as how the project continues to meet Government Digital Service requirements. The website continues to be robustly tested with stakeholders, partners and IRAS users and there has been high demand to participate in this testing.



The website development has agile at its core, not only in response to user feedback but also in aligning closely to the future development of the Research Systems programme, which will continue into the public beta and live phases of the project.

## 6.3. Shared Commitment to Public Involvement



The [shared commitment to public involvement](#) launched during British Science Week (March 22) with HRA leading communications for all 12 organisations.

A coordinated campaign approach saw all organisations promoting the joint effort using our branding, designed with public contributors.

Social media posts had over one million views. Lord Kamal and Dr Lucy Chappell endorsed the launch, there were [blogs from Public Involvement Lead Jim Elliott](#) and former cancer [patient Roger Wilson](#)

and [specialist media coverage](#). Comms profile led to more organisations requesting to be part of this work, including NHS England.

#### 6.4. Action to recover health and social care research

Guidance on the HRA website to support teams who have decided to amend or close their research has been shared with the sponsors and funders of 4000 studies who have been asked to take action to create additional capacity in the NHS. The guidance is part of a letter from DHSC and NHS England and NIHR CRN. Action will put the NHS R&D system back on course, preserving a world-leading, vibrant and flourishing R&D system that gives as many people as possible the opportunity to participate in, and benefit from, research.

#### 6.5. REC recruitment campaign

Our targeted digital campaign has continued asking medical professionals to step forward and join an NHS REC.

The ads, complemented by owned social media activity by the HRA and stakeholders and an offline communications campaign, point to a [refreshed section of the HRA website](#), aiming to increase the current conversion rate between those expressing an interest and making an application to become a REC member. This campaign is part of a drive to increase the number of expert members who will help protect research participants and facilitate ethical research. The striking digital advertisements feature some of the HRA's current members.



There have been over 1,026,056 engagements with the digital campaign assets so far, and 231 requests for applicant packs since these went live, though conversion is low and further work is needed to track the impact of the targeted digital approach compared to other channels.

#### 6.6. Enabling AI and data development for health and social care

We've highlighted our work with people involved in data driven health research and studies involving AI (artificial intelligence) to find out how to make it easier to carry out research in this area [with a blog by Gemma Warren](#), HRA Policy Manager for Data and AI.

The comms team is supporting a project to devise effective decision tools for the organisation's websites so that those who want to carry out this sort of research always know what approvals they need and the support that's available.

### **6.7. Media handling**

This month we've handled media inquiries on automatic registration from the Pink Sheet and worked with the New Scientist on co-written content for International Clinical Trials Day with the MHRA. This includes a focus on public involvement in clinical trials and a piece on Combined Review.

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

### **6.8. Stakeholder communications**

A recent review of our stakeholder communications showed we have a higher than average engagement rate with our 20,300 subscribers. Over the last year we have published 159 e-updates including our popular [HRA Latest](#) newsletter and [HRA Now](#) operational bulletins.

### **6.9. Internal communications**

Our communications to promote the staff survey led to the highest number of individual responses so far, 199 people, or 71% of all staff. This compares to the benchmark of 50-70%

The team has also been supporting the go-live for the HRA's new SharePoint system, HRA Atlas, sharing staff blogs and updates to celebrate Eid, Easter and to promote our Mental Health First Aiders as well as publishing and promoting [our new sustainability strategy](#) and making staff aware of a number of HR issues including the new health and social care levy and arrangements for the Queen's platinum jubilee.