

Agenda item:	10
Attachment:	А

## **HRA Board meeting**

## 20 July 2022

Title of paper:	Communications, Engagement and Involvement update including RRG activities & Approvals Directorate	
Submitted by:	Will Griffiths-Stent, Senior Engagement Manager	
	<ul> <li>Contributed to by members of:</li> <li>HRA Approvals</li> <li>HRA Policy &amp; Partnerships directorate (Communications, Engagement, Policy, Public Involvement, Data and AI)</li> </ul>	
Summary of paper:	<ul> <li>This paper:</li> <li>provides an overview of HRA communications, engagement and involvement activity from mid-May to mid-July 2022</li> <li>gives detail on the stakeholders we have engaged with, the reason for engaging, and the value of this engagement</li> </ul>	
Reason for submission:	For discussion	
Further information:	N/A	
Budget / cost implication:	N/A	
Dissemination:	HRA website	
Time required:	10 minutes	

### Communications, Engagement and Involvement update

#### 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, in support of the organisation's wider objectives.

This paper provides a summary of activities from May to July 2022, so that the Board is informed of our work in this area.

#### 1. Promotes the HRA as a thought leader (who we are, what we do, why it matters)

#### 1.1. HRA Strategy Launch event, 8 June 2022

- On Wednesday 8 June we held a special event at the Science and Industry Museum in Manchester to launch the HRA's new three-year strategy. This event, as well as the strategy itself, was co-developed with a working group of patients and public contributors.
- The event featured a number of different sessions. This included:
  - a live REC showcasing a behind-the-scenes look at REC review, chaired by Paul Mooney, REC Chair, followed by a Q&A.
  - a panel discussion on 'Making it easier to do research that people can trust', with speeches from:
    - Matt Westmore, Chief Executive, Health Research Authority
    - Simon Denegri, Chief Executive, Academy of Medical Sciences
    - Dolapo Della Ogunleye, Public Contributor
    - Dr Jennifer Harris, Director of Research Policy, The Association of the British Pharmaceutical Industry
    - Professor Nalin Thakkar, Vice-President for Social Responsibility and Professor of Molecular Pathology, The University of Manchester
  - a public involvement workshop, focused on how public contributors, HRA staff, and the wider community can work together to create positive change. This was chaired by Matt Westmore and Circle Steele, Chief Executive of the Wei Yin Society.
- Attendees: 75 in-person attendees, approximately 165 online attendees via Zoom. This included Research Ethics Committee members, Confidentiality Advisory Group, and Public Involvement Network members; wider public contributors and patients; researchers and service users; stakeholders from academia and R&D, industry and pharma, NHS and other ALBs, charities; HRA staff.
- Manoj Mistry, a public contributor and carer, is one of the members of the public who has helped the HRA develop its new strategy and the launch event:

- 'As a Public Contributor, I'm delighted to be able to genuinely co-produce HRA's new strategy, actively ensuring that the patient, carer and public voice is central, recognised and always heard. Our input has been valued and incorporated.'
- Social media posts about the strategy launch reached 221,242 people, with almost 900,000 impressions. There were 964 engagements with the posts (likes, shares and comments and clicks). Sentiment about the strategy itself was 100% favourable.
- The best performing Tweet had an engagement rate of 5.3% (the average is 0.5% and anything over 1% is good)

# 1.2. Nuffield Council of Bioethics policy roundtable on ethical considerations in digital access to mental health support, 5 July 2022

- Attendees: representatives from Turing Institute, MHRA, Wellcome, NHS England, MIND, Age UK, as well as other mental health charities.
- Round table meeting on the topic 'How should DHSC's new 10-year <u>Mental</u> <u>Health and Well-Being Plan</u> reflect ethical considerations in digital access to mental health support?'
- A paper was presenting by Nuffield Council, which <u>can be found here</u>.
- Contributions at the discussion will be fed back into the implementation of the mental Health and Well Being Plan to help ensure issues such as ensuring safe and effective technology, and ensuring access and choice, are adequately addressed.
- A summary paper of discussion and contributions is being prepared by Nuffield, which will then be submitted summarising recommendations to DHSC.
- For further information, please contact Alison Knight.

### **1.3.** People Centred Clinical Research project

- To assist delivery of our RRG commitments, we have begun meetings of the People Centred Clinical Research Project Steering Group. This group is made up of eight clinical researchers and eight public contributors who are working with us together with a team from the University of Lincoln. Our collective activity around this group is demonstrating HRA as a driver in putting people first in research and ensuring the delivery of outstanding clinical research
- The purpose of this work is to find ways to make people centred clinical research happen more often and to use this to make change more likely. The group will first establish what 'person-centred' and person-centred clinical research really means in practice, followed by a rapid review and further collection of evidence to inform recommendations and actions for the sector. This is in order for us to be able to deliver on our RRG commitments ('Understand the barriers and enablers of the behaviour change needed to deliver patient centred, innovative research designs as standard, and use this as a basis for the design of interventions that will enable a step change in practice', RRG area 3.4.)
- Barbara Molonyoates and Kate Greenwood <u>have produced a blog</u> outlining what this work involves in more detail, and the focus moving forward.
- We have held two meetings of the group (23 June, 7 July), and discussions todate have covered:

- exploring how we can be more inclusive and accessible with our language around clinical research
- exploring how we can make talking together easier to help people trust research, so participation and involvement become the norm. The group has agreed a group charter for the project setting out our purpose and how we will work together
- Exploring what we mean by people centred clinical research what it is and what it isn't. For further information, please contact Barbara and Kate.

# 1.4. Continued work as a lead for the Recovery, Resilience and Growth (RRG) programme

- Dr Janet Messer attended the regular meeting of the RRG Programme Board, currently overseeing the delivery of Phase 2 of the RRG plan recently published. This is a reoccurring meeting of UK-wider stakeholders.
- Janet has also attended regular meetings of the RRG Reset Oversight Group, overseeing the delivery of the review of the research portfolio following the COVID-19 pandemic. The communications team worked with partners on reactive media handling after significant interest in this work.
- Janet also attended the first meeting of the RRG Data and Digital Sub-Group, the role of which is to enhance collaboration across the sector, providing oversight and strategic coordination of work to maximise a data-enabled clinical research environment.
- Our work was promoted in line with the publication of the implementation plan for Phase 2 with a news story and social media. We focussed on the benefits of the whole programme of activity, alongside the achievements the HRA has already made. National coverage focussed on successes including combined review timelines.

### 1.5. Continued contribution to the development of a National Contract Value Review (NCVR through NCVR governance group, working group and communications group

- Attendees: NIHR, NHSE, DHSC, HRA (Alastair Nicholson and Janet Messer)
- NCVR aims to speed up the set-up of clinical research by providing a rapid, predictable and efficient mechanism for establishing the value of a commercial contract between the commercial sponsor and sites, without the need for local renegotiation.
- Janet and Alastair are key instigators and contributors to the design and development of NCVR This is a particularly important RRG commitment to streamline and accelerate study set up and is being developed with partners across the UK. For more information contact Alastair, Janet or Kate.

# 1.6. Exploring Research governance in the new NHS structure (ICB and ICS) and outside of traditional settings (social care and non-NHS/hospital)

• Attendees: HRA (Alastair Nicholson, Jen Harrison and others). With leaders from the R&D community.

- Multiple meetings to explore the impact of changes to the NHS setting as laid out in the Health and Care Act (2022) and to explore the issues and opportunities to taking forward research including research in non-traditional settings. Planning underway to support National NHS R&D Forum symposium
- For more information contact Alastair or Jen.

# 1.7. Association for Clinical Research Organisation's international meeting on potential issues with decentralised trials

- Dr Janet Messer was invited to join an international meeting convened by ACRO, to talk with HRA and a central IBRN (equivalent of REC) in the USA to explore potential issues with decentralised trials.
- General feedback was that the UK is very open to decentralised models, and that the UK (along with countries such as the Netherlands and Poland) are <u>traditionally leaders that enable innovative, good-quality research</u>.

### **1.8.** Think Ethics public conversation launch and communications campaign

- <u>Our public consultation about ethics review</u> will run from 13 June to 23 September, giving people chance to feedback on our proposed changes to make ethics review more proportionate.
- Liaising with DHSC and our colleagues in the devolved administrations, we coordinated support from Lord Kamal and key DA spokespeople and produced:
  - a news story
  - a special edition of HRA Latest
  - a social media campaign
  - videos with our NED Professor Andrew George and Nalin Thakkar, Vice-President for Social Responsibility and Professor of Molecular Pathology, The University of Manchester
- We also redesigned Think Ethics' profile on the HRA website to make it easier to find information about this work and update stakeholders on what's been done so far, creating
  - <u>a main Think Ethics page</u> pointing to key areas of work
  - a page detailing <u>our public conversation on rethinking ethics review</u>
  - a HTML version of a <u>15-page public dialogue work</u> with Hopkins Van Mil
  - details of <u>our new information and consent policy</u>
  - the background to <u>Think Ethics and our Ethics Review Advisory Group</u>
- We ran a workshop to get ideas from REC members attended by over 50 people.
- So far, our communications has generated over 550 responses to the online survey with a good split across the various audiences.
- There has been good engagement with the campaign with over 589,000 impressions across social media (beating the initial launch in September 2021 which had 400,000).

### **1.9** International Clinical Trials Day

- We used International Clinical Trials Day (ICTD) to talk about our work and to position the HRA as trusted and knowledgeable with a new, wider audience.
- Key messages for our ICTD campaign were around public involvement in research. We also wove in our #StepForward REC recruitment campaign messages.
- A joint opinion piece from Public Involvement Lead Jim Elliott and MHRA's Martin O'Kane on public involvement in research was published on the Media Planet ICTD campaign website and in a supplement with New Scientist magazine.

# 2. Promotes our service offer, and builds our relationship with users and researchers

### 2.1. Second meeting of the pan-UK Data Governance Steering Group, 4 July 2022

- Attendees: HDR-UK (lead), NHS Transformation, NHS Digital, Office for National Statistics, existing Trusted Research Environments (e.g. SAIL, Research Data Scotland/eDRIS, Northern Ireland), and the Medical Research Council Regulatory Support Centre. Attendees also included three public and patient representatives.
- This Group is a sub-group of the UK Health Data Research Alliance, which focuses on streamlining healthcare data access governance across the four nations by identifying the principles that should guide data access/sharing, as well as instances of best practices, and which take account of the evidence of public involvement and engagement.
- This second meeting primarily focused on discussing a proposal by HDR-UK that collated the sub-group's goals:
  - creation of a set of legal resources for <u>TRE information governance</u> information governance
  - creation of a single visual "map" of all approval processes required for a researcher to access and link data from both an ethics and governance perspective, and related training for researchers
  - creation of a new '<u>new 'Five Safes form'</u> for data access, by which it is hoped to increase consistency across the four nations in approving data access, supported by engagement/training of data custodians related to the same.
- HRA contributed to areas of discussion that included precedent sharing, researcher passporting, streamlining data access request approval criteria, and setting up potential cross-custodian data access committees across the main four nation existing TREs.
- The next group and sub-group meetings will be from September 2022. For further information, please contact Alison Knight.

### 2.2. HRA meeting with European Forum for Good Clinical Practice

- Attendees: HRA Naho Yamazaki, Clive Collett, Kate Greenwood, Jane Morrin O'Rourke, Barbara Molonyoates; EGHCP Dr Hilde Vanaken, Chair of EFGCP eConsent and Inclusiveness Task Force.
- The purpose of this joint working between HRA and EFGCP is to bring eConsent again on track, to reduce barriers in Europe (and globally), and enable clinical trial access to all, anywhere and anytime, using eConsent as the first step.
- This work follows on from previous work HRA delivered in 2018 to produce the <u>HRA/MHRA joint position statement on eConsent</u>.
- For more information, please contact Clive Collett.

### 2.3. DHSC Non-commercial Costing and Attribution Group

- Attendees: representative across NIHR, AMRC and non-AMRC UK funders, NIHR CRN, NHS sites and HEI sponsors.
- Our role as creators of Schedule of Events Cost Attribution Template (SoECAT) puts us as leader in these conversations, though very much supporting DHSC policy work and NIHR CRN and NHSE operational work on future of Excess Treatment Cost processes clear current focus on research 'outside' the NHS, which we are linking to other conversations on UK Approval.
- For further information, please contact Alastair Nicholson.

### 2.4. Commercial Clinical Operations Group

- Attendees: representative from across industry and pharma, including (but not limited to) MSD UK, Pfizer, Abbvie, Covance, Bayer, NovoNordisk, AstraZeneca, and IQVIA.
- A group of industry operations leads and ABPI representatives that meets quarterly, in which HRA take a leadership role.
- Topics raised in July's meeting revolved around the vision and update on the National Contract Value Review, presented by NHS England.
- For further information, please contact Alastair Nicholson.

#### 2.5. Research Champions meeting

- Attendees: NHS R&D Managers, covering all Clinical Research Network regions across England. Additional representation from NIHR, NHS England, and R&D Forum.
- Topics of discussion including formation of Integrated Care System working group, the delivery of the national information governance survey, publication of clinical agreements, and launch of the Person Centred Clinical Research programme, with feedback from attendees on their own actions to improve diversity and inclusion in research. A representative from NHS England also presented on the National Contract Value Review.
- The purpose of this quarterly forum is to engage, update and hear directly from NHS RD Managers, to understand better how our initiatives are supporting and influencing the delivery and management of research on the ground.
- For more information, please contact Jen Harrison.

# 2.6. Regular meetings with NIHR Service Design Forum and NIHR Clinical Research Network

- Janet Messer has met with the Service Design Forum, which brings together oversight of product and design across NIHR digital services, with the purpose informing and advising NIHR of related interactions with HRA and UK-wide services.
- Janet Messer has also met several times with the NIHR CRN to advise on development of their Find, Recruit and Follow-up service, including their in-house service through primary care. Please contact Janet for further information.

### 2.7. Non-Commercial Sponsors' Reference Group quarterly meeting, 20 June 2022

- Attendees: R&D colleagues from 23 NHS Trusts and universities
- We lead these meetings to engage with the non-commercial Sponsors and NHS R&D management communities. The discussions this meeting covered universal letters of access in community settings, guidance on data controllers, DPIAs, and how to sponsor a non-NHS site, along with HRA programme updates.

### 2.8. NCRI CTU Operations Leads Group meeting

- Attendees: Senior Operations Managers from Cancer CTUs from across the UK.
- HRA led discussion on current HRA initiatives, followed by a Q&A.
- The purpose of this is to further develop the relationships with those already working with the HRA, enabling them to hear and feedback directly to the HRA on our initiatives that influence their areas of work.
- For more information, please contact Jen Harrison.

# 2.9. Research Scholars Programme Monday 27th June 2022. CRN North West Coast, Liverpool Science Park

• The HRA operations team presented at this meeting with colleagues from across the North West Clinical Research Network. For more information contact Matthew Harris.

#### 2.10. Research systems programme

- An interim comms and engagement plan is in place for the coming months while the programme prepares for restart this includes key messages and routes for managing queries while we support users with current systems.
- In collaboration with the IRAS partners, we've developed the IRAS tone and style guide. The guide brings together best practice from the government's <u>Service</u> <u>Standard</u> and will help make it easy to achieve point five (<u>make sure everyone</u> <u>can use the service</u>). This will help make sure that IRAS and the IRAS website are accessible, providing content creators with the tools and support to write consistent, effective, user-friendly content.

• A third round of user testing of the new IRAS website has been completed and the team is preparing for NHSX public beta assessment in September 2022.

### 2.11 Changes to fast-track ethics review

- The HRA is making some changes to the way we carry out fast-track ethics review to make this more sustainable for the future by embedding this within existing RECs. The communications team curated a phased communications strategy and targeted plan (both strategic and operational involving a mixture of briefings for meetings, tailored emails, FAQs and updated web content.
- We've been communicating this with applicants, REC members and key stakeholders including DHSC, ABPI, RRG members, MHRA, NIHR, BIA and ARSAC and helping transition applicants into a new way of working and hearing their feedback.

### 3. Promotes the need for research to be done with and for everyone

#### 3.1. Shared Commitment to Public Involvement – two group meetings

- Public Contributors meeting, 28 June; Steering Group meeting, 6 July.
- Both groups met under the wider Shared Commitment objectives of raising the profile of public involvement in research and working together to agree what we can do collectively in support of this, as well as amplifying each other's work and sharing good practices and resources.
- This was the first meeting of the Steering Group and we looked at Terms of Reference, a method by which organisations would sign up in the future, and our next steps. Payments for public contributors are high on the agenda.
- The Steering Group has also committed to produce a report of examples of how member organisations are fulfilling their commitments.
- Attendees include both the public involvement leads, engagement leads, and public contributors from ABPI, AMRC, AMS, CSO Scotland, HCRW, HRA, HSCNI, NHSE&I, NIHR, UKRI, MRC & UUK.
- We continued to promote this work on social media. These posts are some of the most popular Tweets from the HRA account in terms of impressions (the number of times people see the post) and engagement (the number of people who interact with the post).

#### 3.2. Meeting with MHRA on diversity guidance

- Attendees: Kate Greenwood (HRA), Barbara Molonyoates (HRA), Jane Morrin O'Rourke (HRA), Ian Waterson (MHRA), Lisa Campbell (MHRA), Shirley Hopper (MHRA)
- Meeting of the group to discuss developing joint HRA-MHRA guidance for researchers to support and encourage diversity in research.
- We have agreed to meet monthly as work progresses.

### 3.3. Presentations on increasing diversity and inclusion in research

- Naho Yamazaki attended the NIHR Underserved Communities Programme Board, presenting on HRA's work on increasing diversity of study participants.
- Naho has also presented at the meeting "Research for All: Equality, Diversity and Inclusion in healthcare", organised by Avon and Wiltshire Mental Health Partnerships Trust. Naho has also presented on this same theme at the KPMGorganised "Diversity, Equity and Inclusion in Clinical Research" roundtable as a panel member.

# 3.4. Meeting with Professor Sumantra Ray, REC Member, on increasing participant diversity in research

- Attendees: Professor Sumantra Ray, Naho Yamazaki, Jane Morrin O'Rourke
- Met to discuss Professor Ray's experience of the challenges he experiences in increasing the diversity of research participants when in the applications he reviews as a REC member. This was part of the wider engagement we did with REC members to help inform the webpage we are developing which will outline our expectations and further work we have planned to support researchers to improve diversity of participants.

### 3.5. Publishing of new guidance for easier payment of public research contributors

- On 27 June 2022 we launched new guidance to help organisations, researchers and involvement staff pay members of the public who are involved in shaping health and social care research across the UK and Ireland.
- Developed collaboratively between Health and Care Research Wales, NIHR and HRA, the guide (which <u>can be found here</u>) aims to support organisations to easily pay contributors by covering principles of payment, provide direction to those managing payments, and signpost information and HMRC guidance to better inform decisions on payment.
- To spread the word about the new guidance, which is released as a consultation in use, we worked with NIHR and HCRW <u>on a news story</u>, social media campaign, <u>a promotional video</u> and targeted engagement with key stakeholders such as Universities UK. The communications have received high engagement rates with over 39,000 impressions (the number of times the post has been seen) and an engagement rates (when someone shares, likes, comments on or interacts with the post) of between 3.7% and 4.7% the industry standard for a recognised good engagement rate on Twitter is 0.5%.
  - There was good qualitative feedback from the researcher and public contributor communities praising the HRA for being a thought-leader in this area and making it easier for universities to do the right thing to make it easier to do research people can trust. Comments included: 'A huge thanks to colleagues @NIHRinvolvement @HRA\_Latest and @ResearchWales for digging in and developing clearer guidance for the public involvement in research community on this critical issue! Thank you for listening and advocating for us all, especially public contributors.'

- 'Great piece of work and very much needed for those wanting #livedexperience and patient involvement.'
- 'Great to see this new guidance on payment for public involvement in health and care #research launched by @NIHRinvolvement, @HRA\_Latest and @ResearchWales. Simpler, more efficient payment procedures are vital for inclusive and accessible public involvement in research.'
- Our communications strategy points to the fact our comms should also drive outcomes and this piece of work has already led to some feedback as part of the consultation in use to the dedicated email provided.