

Public involvement in a pandemic:

Lessons from the
UK COVID-19 public
involvement
matching service



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Foreword

Today's research is potentially tomorrow's treatment. During the global COVID-19 pandemic the Health Research Authority (HRA) has had to speed up the assessment of new research so that this work could start quickly without compromising standards - allowing more people to benefit. We have streamlined the approval of COVID-19 research while ensuring studies are safe – promoting research while protecting the public.

The COVID-19 pandemic has meant that health and social care research has a higher profile now than ever before. The response of the research community has been impressively rapid and, in less than a year, we are already using an effective vaccine. In the fight against COVID-19, I am incredibly proud of how the HRA has ensured that urgent studies have been reviewed and set up in record time, while maintaining the same high standards needed to protect patients and the public.

In 2020 we approved 700 fast-tracked research studies and 600,000 members of the public took part in this research.



The UK can, justifiably, be proud of this. Initially, the speed of the pandemic sometimes meant there was less public involvement in research applications than we would have wanted. But I am indebted to Leni Sivey and Jim Elliott and to all the HRA staff across our five offices for their prompt response to this challenge (evaluated in this report).



High quality health and social care research must involve patients and the public. We need this to make sure that all research is important, relevant and acceptable to those it should benefit.



At the start of the pandemic the HRA's public involvement team quickly identified a significant reduction in the number of studies involving the public in their design.

They then worked with partners across the research system to rectify this. If they had not done so, many of the vital COVID-19 studies that have helped us learn much about the virus may well have struggled to recruit research volunteers so quickly and successfully.



The HRA has supported and encouraged the research community to continue working in partnership with patients and the public despite the challenges presented by the pandemic. This work has been crucial.



Its impact, which you can read about in this important report, demonstrates the effectiveness of our approach in setting out clearly what is needed to secure approval for research; and in providing practical support to achieve it.

The lessons from this work are clear. They show that strong leadership and collaboration across the whole research system, supported by good communications and information, ensure that public involvement plays its part in successful research, whatever the circumstances.

We look forward to continuing to work with our partners and offering support so that patient and public involvement is embedded throughout the research process.

**HRA Chair,
Professor Sir Terence Stephenson**



In 2020 we approved **700 fast-tracked research studies** and **600,000 members of the public** took part in this research.

Executive summary

The rapid response of the research community to the COVID-19 pandemic led to new studies being set up far quicker than they had ever been before. In response the Health Research Authority (HRA) set up its fast-track approvals service for urgent COVID-19 research which reduced the average research review timelines by 90%.

In March 2020 the HRA heard that networks and groups of public contributors across the UK had noticed a marked drop-off in the numbers of opportunities to get involved in research. This feedback chimed with our own analysis which showed that the rate of public involvement in research studies submitted for approval dropped sharply for COVID-19 research, despite other aspects of good practice remaining in place. Usually, 80% of the research applications document the involvement of patients and the public; for urgent COVID-19 studies submitted in March-April 2020 this was 22%. An HRA-led workshop in April confirmed that this trend in behaviour was widespread across the sector.

In response to this fall in public involvement in COVID-19 research, we collaborated with partner organisations from the NHS, university, and charity sectors to set up the UK COVID-19 public involvement matching service. The matching service allows researchers planning urgent COVID-19 research which is eligible for fast-track review to access public involvement support if they do not have existing suitable public involvement connections.

Six months on, the low level of public involvement in COVID-19 research recovered to – and exceeded – the normal level of public involvement in all approval applications. By August 2020, the rate of public involvement declared in COVID-19 research applications was 85%. Alongside the matching service, other public bodies and individual public contributors, patient advocates, and public involvement professionals have played a vital part in initiating and amplifying the conversation about public involvement in this public health crisis.

The pandemic has exposed and exacerbated the lack of resilience of the place of public involvement in UK research, in which there are significant gaps in communication across the research system about the support available to the research community to involve the public. The lack of shared, high quality information about all aspects of public involvement limits its ability to become a core part of the way research is conducted in the UK rather than something which is 'nice to have'.

The HRA decided to take action beyond its usual remit to create the matching service in response to a call for leadership on this issue. We wanted to make it clear that public involvement is important, expected, and possible, even in a public health emergency. The collaborative effort to establish and run it has demonstrated that the system has the capacity to respond appropriately to support the involvement of the public proportionately and effectively regardless of the circumstances. It showed that with effective system-wide collaboration, communication and information, public involvement was able to become 'business as unusual'.

If that can be maintained, then there is no reason why public involvement should not be business as usual for the sponsors and funders of all health and social care research in the UK.

The HRA is committed to clarifying what is expected in public involvement in health and social care research in the applications it reviews, and to collaborating with our partners to promote and support high quality, inclusive involvement across the research system.



Background for this report

Public Involvement is when patients, carers, service users, and other members of the public work in partnership with research teams and use their lived experience to contribute to the design, management, analysis, or dissemination of research.

Being involved in research and contributing data as a participant in a study is not what we are referring to when we use the term 'public involvement'.

This report outlines the background and rationale for establishing the UK COVID-19 public involvement matching service. It reflects on what we have learned about public involvement in research during a public health crisis from the perspective of a regulatory body working to support COVID-19 health and social care research.

Public involvement is not a legal requirement for research regulated by the HRA in the UK, but it is expected good practice. The **UK Policy Framework for Health and Social Care Research** asserts that minimum good practice for health and social care research in the UK is for patients, service users and the public to be involved in the design, management, conduct and dissemination of research.

This is because meaningful public involvement can make research **more ethical** and provide assurances to Research Ethics Committees, and can **improve study recruitment and retention**.

Public involvement is more important now than ever before. During an unprecedented global public health crisis it is crucial that UK research is of the highest quality, and public involvement is a core tool in achieving this. Good public involvement can help high quality research be set up quickly by addressing barriers to recruiting and retaining research participants – which can be difficult in a public health emergency.

Why we set up the UK COVID-19 public involvement matching service

Public involvement in research at the beginning of the pandemic plummeted.

In normal circumstances, patients and the public are involved in designing, managing, or disseminating 80% of the research HRA reviews in some capacity. However, in March 2020 this proportion fell to just 22% of research applications reviewed by the HRA.¹

Researchers told us in their applications for HRA Approvals that they would not be able to find and work with people with relevant lived experience to benefit their research. Half of the time people told us that this was because there would not be enough time to do so; in their own words:

“

‘Due to the global burden of Covid-19, initiating patient, public involvement and engagement would delay healthcare service delivery.’

‘Due to the rapid nature of the set up and submission we have not actively involved members of the public in this process.’

‘Due to the rapidity of the turn around and the inability to meet PPI groups due to restrictions on movement, we have been unable to involve patients in a formal meeting.’ - Statements from applications for HRA Approval reviewed in March and April 2020.

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¹ Based on answers to A14-1 (the question about public involvement plans) in the IRAS application form in a representative sample of 100 applications submitted to the HRA in October 2019 and a sample of 40 applications submitted via the fast-track approvals service in March and early April 2020.

Across the UK studies were set up in a fraction of the time that they usually would be, due to the collaboration of people working across the sector. The HRA put a fast track approvals service in place in order to expedite the regulatory review of urgent COVID-19 research **which reduced the average research review timelines by 90%** from 62 to 5 days for HRA Approval.

However, the research system did not ensure that public involvement remained a core part of the research it was responsible for setting up. We wanted to help protect and promote public involvement in that research, in order to ensure that it was as high quality and responsible as possible.



'I think you should be congratulated for stepping into the breach because as much as ideals are there and we want to adhere to them as much as possible, this was not a normal situation. And you could have just sat back and said well let's wait, let's consult, let's practice what we preach; it wasn't the time, it wasn't the moment and you did as much as you could.' – Public Involvement Lead University/ NHS



We held a workshop in April 2020 with public involvement facilitators from charities, NHS Trusts, regulators, universities, clinical research facilities, and independent bodies in order to discuss:

1. Had public involvement sharply decreased in COVID-19 research across the board?

If so,

2. Why did public involvement sharply decrease in COVID-19 research?

And

3. What could be done to promote and support public involvement in COVID-19 research?



What we heard from stakeholders

1. Had public involvement sharply decreased in COVID-19 research?

Those present at the workshop confirmed that the usual requests to facilitate public involvement in research had decreased significantly. The contact which public involvement facilitators would usually receive from research teams to arrange patient and public input into their studies had either stopped, or was happening late in the research development process when it is less feasible for patients and the public to contribute meaningfully to research design.

2. Why did public involvement sharply decrease in COVID-19 research?

The beginning of the global COVID-19 pandemic in March 2020 brought an unprecedented challenge to the UK health and social care research sector. During the most acute threat to public health the NHS has ever experienced, the research community adapted to remote working, resource shortages, and a national lockdown and managed to set up crucial COVID-19 research within a fraction of the usual timeframes. This also meant that public involvement in research design needed to be carried out within narrow timescales.

However, a common theme that emerged at the workshop was that one of the core reasons public involvement decreased so dramatically was because research teams appeared to be making a series of incorrect assumptions about public involvement in a pandemic.

These included that:

- public contributors would not be as motivated or available to contribute to research during an urgent public health crisis;
- public involvement groups would not be working because their usual ways of working had been drastically disrupted;
- there would not be enough time to carry out meaningful public involvement within expedited study set-up timelines.

Workshop attendees emphasised that these assumptions did not accurately reflect what was happening in the public involvement community.

Just as many researchers and public involvement facilitators were coping with being unwell, furloughed, shielding, redeployed, caring for others, volunteering in their local communities, or a combination of several of these factors, public contributors also experienced similar pressures on their time and energy. However, in the same way that the research system as a whole mobilised in response to the COVID-19 crisis, patients, carers, service users, and other members of the public were equally highly motivated and prepared to devote their time and energy to the research effort.

Some public contributors were less able to get involved due to the virtual nature of the projects, ill health, volunteering, lost income, or caring for others. However, workshop attendees reported that those who were shielding, furloughed, or working from home actually had more time and flexibility to get involved in research than they usually would.

Public involvement groups and networks had adapted rapidly to the challenges of working during a national lockdown, switching to remote working and assembling rapid review panels with the motivation, experience, and availability to provide swift, meaningful public input into COVID-19 studies. Attendees emphasised the common perception that

public involvement is 'nice to have' rather than a core part of the research process. They suggested that this approach to involvement is why it was omitted from research set-up when the system came under intense pressure.

3. What would be needed to promote and support public involvement in COVID-19 research?

We agreed that we needed widespread high-level messaging that public involvement is important during a public health crisis, and that the public involvement infrastructure had adapted and was available to provide proportionate, meaningful input to ensure that COVID-19 research was as high quality as possible.

The following key messages were identified through the workshop:

- **Involvement is important, expected, and possible;** there is support available for researchers
- **We need clear, consistent leadership and communication,** with high level ownership and UK-wide messaging across the research system
- **Our solutions need to be streamlined and flexible**
- **System-wide collaboration is crucial** from the whole public involvement in health and social care community.

We acknowledged that there was a communication gap between research teams and public involvement facilitators, with both having a reduced capacity to communicate about what involvement support was needed, and what was available.



'Nobody last year was a COVID researcher'
– Researcher, NHS



The upheaval involved in setting up COVID-19 research meant that the research teams who responded to calls to set up urgent studies came from a more diverse range of professional backgrounds than usual. That meant that teams with a background in lab-based vaccine development, for example, were more likely to be new to involvement, and may have been less aware of how to access existing public involvement support from within their own or affiliated organisations. This breakdown in communication is likely to have been accentuated by existing vulnerabilities in how public involvement is resourced and integrated into research development processes and structures within sponsor organisations.

Workshop attendees highlighted the absence of clear, consistent leadership detailing what is expected in terms of public involvement during a public health crisis. They called for UK-wide collaboration across the health and social care system to address the obstacles to involving patients and the public meaningfully and consistently in all research. We agreed that any such initiative would have to be efficient, collaborative, and avoid duplicating existing resources or services.

In response, we established the **UK COVID-19 public involvement matching service**, which helps to facilitate meaningful public involvement in COVID-19 research by connecting research teams with existing public involvement groups.

How the UK COVID-19 public involvement matching service works

The matching service dovetails with HRA's fast-track approvals service for urgent public health research. This expedites the review of COVID-19 research applications so that studies can be set up rapidly and responsibly, reducing review timelines by 90%.

Researchers whose studies need HRA Approvals and are eligible for fast-track review can also request support with finding suitable public input if they do not already have connections with any suitable groups.

The team facilitating the matching service consists of the HRA Public Involvement Team (Jim Elliott and Leni Sivey), Annie Amjad of Parkinson's UK, Jenny Robertson of the Multiple Sclerosis Society, along with HRA Approvals colleagues and the matching service partners.

The HRA public involvement team arranges a triage call with researchers when they request support, and asks them to provide some basic information about their study (the support request form template and guidance can be found in the appendix at the end of this report, for information). Researchers provide a brief plain English summary of their research, and outline the timeline they're working to. We use the **HRA Best Practice Principles for public involvement** in research to discuss what sort of involvement would be most beneficial, depending on the type

of research and the stage it is at in the development process. We talk about how many people should be involved, what they will be asked to do, and what sort of lived experience or skills are relevant to this. We also provide guidance on how to record this information in the **IRAS** application form so that Research Ethics Committees reviewing the proposed research are able to understand what ethical assurances public involvement had provided about the research.

We ask whether public contributors will be offered remuneration for their time, whether any expenses they incur will be paid or reimbursed, and whether researchers will both provide follow up information about how public contributors' input makes a difference to the research, and invite feedback on their experience of working with the research team.

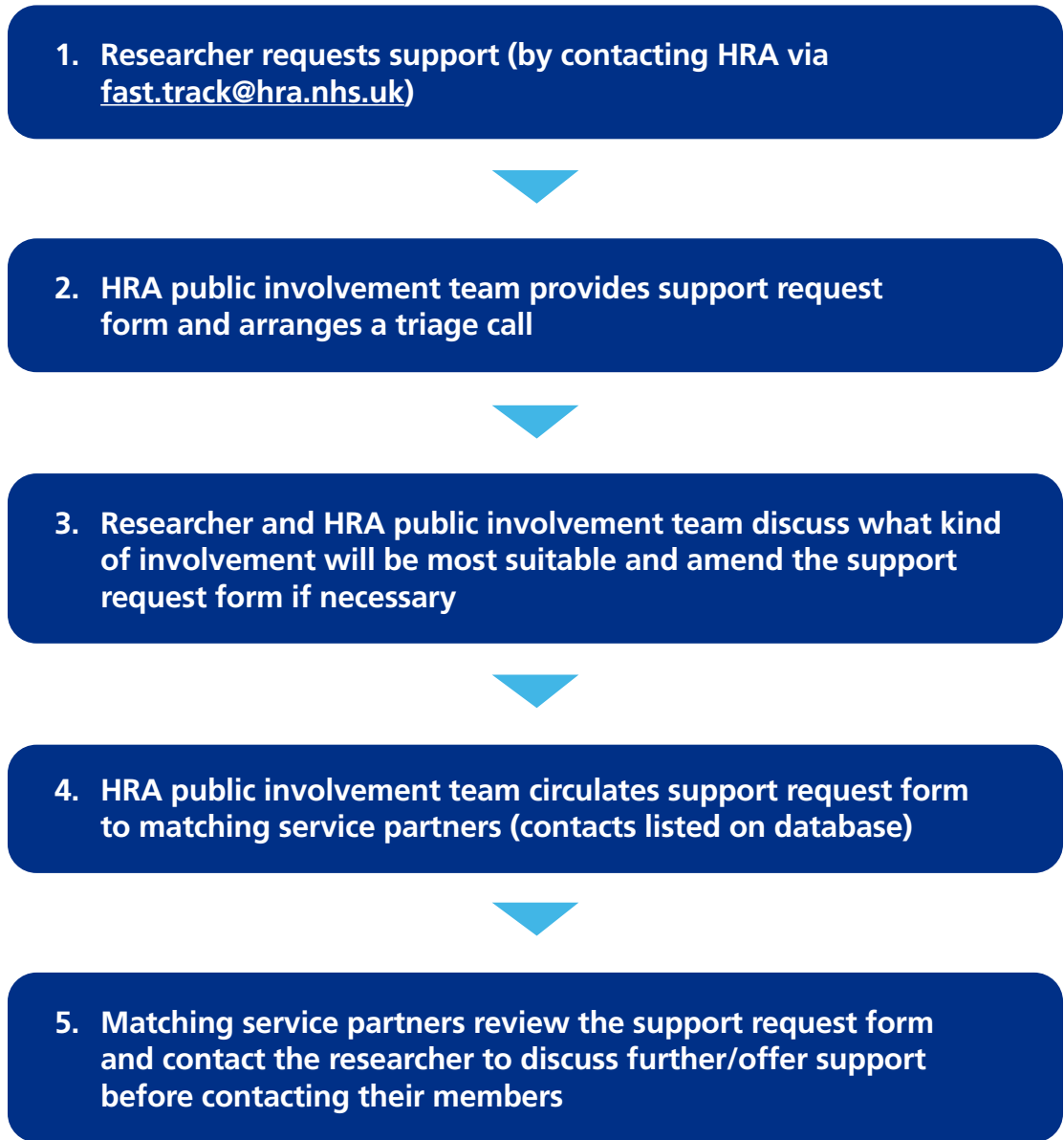
We explain the HRA position that all of these things are core good practice for public involvement activities, but do not require them in order to share the involvement opportunity with the

independent matching service partners. This allows individual public involvement groups to maintain their own ways of working and terms of reference.

We share the completed support request form with the matching service partners who have joined the database of groups interested in being contacted about COVID-19 public involvement opportunities. The contact point for each group reviews the summary information about the research to decide whether it

is relevant and suitable for their group. If it is and they have the capacity to facilitate the involvement, they contact the researcher directly to discuss further or to offer support.

The research team decides which group(s) to work with, and the named contacts for the research team and the involvement group then liaise to arrange the online involvement activity, which is held via email or videoconference.



Collaboration to establish the matching service

Following an HRA [statement of intent](#) about public involvement in COVID-19 research, the matching service was officially launched via multiple communication channels in the first week of May which included a [blog](#) by Bec Hanley and Maryrose Tarpey, the HRA Twitter account, HRA Latest newsletter, and CHAIN network bulletins.

Support from other public bodies was crucial; Health & Care Research Wales, Health & Social Care Northern Ireland, the National Institute for Health Research (NIHR), the Association for the British Pharmaceutical Industry, the Association of Medical Research Charities, Universities UK, Nuffield Council on Bioethics, the Academy of Medical Sciences, the Wellcome Trust, the British Medical Association, and the Human Tissue Authority all took a lead in promoting information about the service across the research system.

Partners from the charity sector have supported the design, launch, management, and evaluation of the matching service. It would not have been feasible to launch the service without their expertise.

We invited over 100 public involvement groups and networks to add their information to the matching service network database in order to hear about opportunities for patient and public input into expedited COVID-19 research. Since then, 56 groups representing 47 host organisations have joined the network.



The groups are mainly based in England, and are run by universities, charities, NHS Trusts, clinical research facilities, and public bodies. NIHR cascaded information about the service within its internal public involvement structures, and participation from the NIHR Research Design Service and Biomedical Research Centres was particularly high.

One of the core principles behind the UK COVID-19 public involvement matching service is to share information responsibly and transparently.

The matching service database is visible to all members of the **National Engagement Practitioners' Network** workspace on the **FutureNHS Collaboration platform**. Membership of the workspace is open to all public involvement and engagement practitioners working in health and social care in the UK.

We developed the database entry form with input from public involvement practitioners and expert advice about which demographic information to request about public contributors, and how, so that we would have the right information to match research teams with the most relevant groups, without overburdening public involvement managers adding their group to the database.

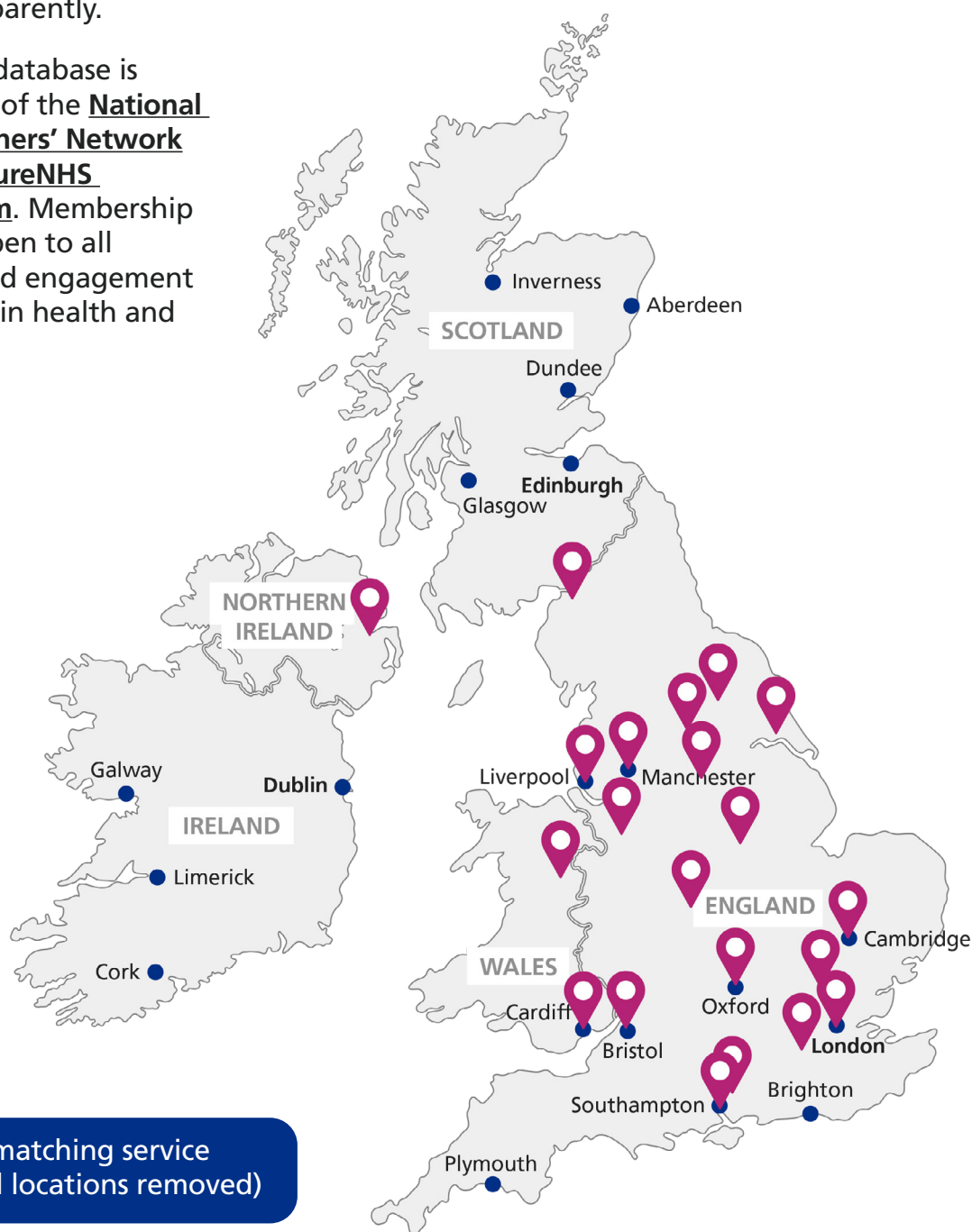


Fig. 1: Locations of matching service partners (duplicated locations removed)

COVID-19 research that was supported by the matching service

The requests for public involvement support received by the matching service have reflected the diversity of COVID-19 research that has been set up since the start of the pandemic.

The service has supported studies run by pharmaceutical companies and contract research organisations, public bodies, NHS Trusts, and universities.

These studies are addressing a broad range of research questions, including finding out more about immune responses to the infection, exploring specific treatments, and investigating where and how COVID-19 is present in different parts

of the body. Most of the studies to date have either been clinical trials or studies using human tissue samples and data only.

Some applicants had prior experience of involving patients and the public in their research, but for various reasons were unable to work with their usual contacts. However, most were relatively new to working in partnership with patients and the public.



What kind of public involvement did the service support?

Applications for HRA and other regulatory approvals happen towards the end of the research development process, once sponsorship and funding has been arranged.

Matching service support is available for studies at any point as long as they are or will be eligible for HRA fast-track review. However, the matching service primarily receives requests for support shortly before submission of the application for HRA REC review. Most people intend to use the service to work with patients and the public before submitting their application to the HRA for ethics review. This is so that changes to improve the study protocol or participant-facing information can be implemented without interrupting the regulatory review process.

The combination of these two factors with the expedited study set up timelines for COVID-19 research meant that several of the studies the service supported needed input within one week of the initial triage conversation. Most research teams to date have sought input from

public involvement groups within 10 days. Studies contacting us earlier in the research development process have been able to plan up to 6 weeks for obtaining input from patients and the public.

The majority of studies supported via the matching service focused on validating whether the research question was important to potential participants, whether the proposed methodology was acceptable, and whether participant-facing information was clear and written in a suitable way.

Some applicants intended to establish ongoing public involvement mechanisms for their studies, whereas others had not initially planned to do so beyond the set-up phase.

The public involvement groups which provided support

Approximately 13 public involvement groups were directly involved in activities as a result of being contacted by the matching service (based on correspondence between public involvement groups and research teams that the HRA was copied into as per the matching service process).

The groups and networks run by Health & Care Research Wales, Health & Social Care Northern Ireland, and the Health Research Authority, all facilitated involvement, with the large Health & Care Research Wales Support and Delivery Centre Public Involvement Community proving to be particularly adaptable and responsive to the needs of the service. Groups that had either surveyed their existing membership to identify people with lived experience of COVID-19 were able to respond more confidently to calls for input on this basis, such as the groups run by Nottingham University Hospitals, NIHR's Leeds Biomedical Research Centre, Oxford Blood and Transplant Research Unit in Donor Health, and Health Data Research UK.

Despite accounting for roughly one fifth of the groups registered on the network, only one of the thirteen groups directly involved in the matching process was based at a charity. This might be because the charity groups were more likely to be disease-specific than generalist, unlike many of the groups based at NHS Trusts and biomedical research centres. Many charity sector colleagues were furloughed and their organisations faced acute resourcing challenges during the pandemic, meaning that their public involvement infrastructure had less capacity to respond to requests for support than their NHS-based colleagues.



How did public involvement activity change in COVID-19 research?

Over time, public involvement activity in COVID-19 research increased dramatically.

Our annual data analysis from an October 2019 sample of 100 applications, representative of the breadth of research HRA regulates, shows that under normal circumstances 80% of applicants tell us that they either have or will involve patients and the public in their research in some way. A sample of the first 40 COVID-19 applications eligible for fast-track ethical review in March 2020 suggested that this metric had dropped to just 22%. However, by June that level recovered to 52%, and in the August sample of COVID-19 applications the levels of public involvement measured using this metric rose to 85% - a higher rate than our pre-pandemic baseline.

This dramatic increase is probably due to a combination of factors. Communications about the matching service made it clear that using the matching service is not a pre-requisite for using the fast-track approvals service because public involvement is not a legal requirement. However, feedback from applicants and public involvement facilitators suggested that some stakeholders interpreted the strong encouragement and support for involvement as a mandatory requirement.

The timelines for the studies requiring expedited review also relaxed somewhat between March and August 2020. This allowed more time for public involvement connections to be initiated or re-established, for everyone involved to adapt to new ways of working, and for the conversation about the importance of public involvement in public health research to gain traction. NIHR made a **public commitment** to involvement during the pandemic and issued **guidance** on ensuring that COVID-19 research is inclusive, the Association of the British Pharmaceutical Industry published **policy recommendations** for public involvement in COVID-19 research, and the Academy of Medical Sciences, NIHR, ABPI, and the Association of Medical Research Charities ran a **workshop** to reflect on opportunities to develop public involvement across the system. Individual public contributors, patient advocates, and public involvement professionals have also played a vital part in initiating and amplifying the conversation about public involvement in a public health crisis.

Research teams which used the matching service reported that it met the needs of their research, and they were able to incorporate feedback into their proposals:



'The experiences were only positive. They were very quick. They gave very good feedback, feedback that we could incorporate' - Trial Manager, pharmaceutical company

'It looks extremely favourable on the Ethics Committee front, and as a sponsor as well, we're really happy to use the service because at the end of the day these trials are for the patients, so if they're not reader friendly they're not user friendly, [and] then it does down the line affect our recruitment and retention strategies as well' – Trial Manager, pharmaceutical company

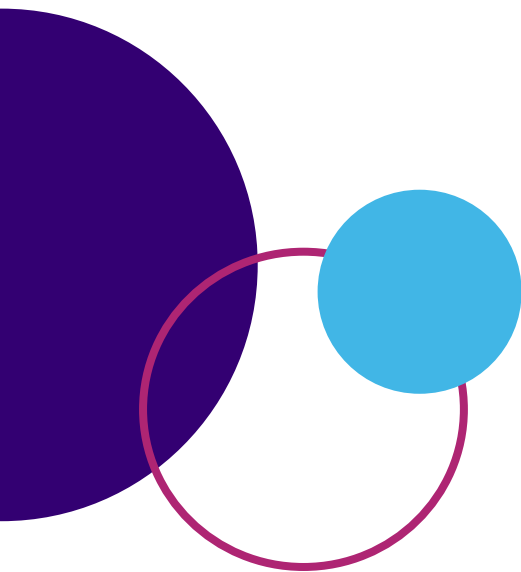


We found that whilst the majority of the public involvement supported via the matching service focused on feasibility and acceptability, some of the involvement activity reported in the August sample of applications was more substantial than that:



'[Public contributor] currently attends monthly meetings regarding the progress of the [study] where we discuss updates, issues and future direction of the study. [The public contributor] will also offer advice/support the researchers in identifying themes from interview transcripts as part of the thematic analysis. [They] will be involved in the dissemination of findings to the wider PPIE community through the presentation of findings.'

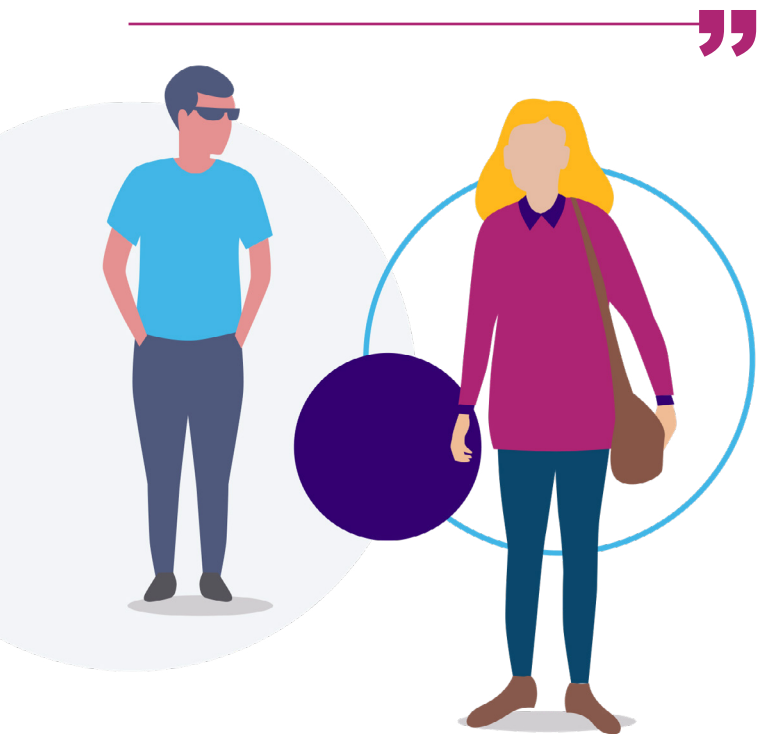
'[Public involvement group] has been involved in the design of [the] protocol, confirming the need for research into the area. They have reviewed documentation to be used for the study and supported the grant submission to the NIHR by producing lay summaries. The [group] will be involved in the design and format of dissemination activities and we will ask them to reflect on their role and share what they have learned as part of our overall dissemination plan.' - Statements from applications for HRA Approval reviewed in August 2020.



When choosing not to involve patients and the public, the reasons applicants gave to justify this also changed over time. Whilst in March most applicants indicated lack of time as the reason they could not work with people with relevant lived experience, by August the justifications given reflected the breadth of reasons common under usual circumstances. Often these justifications indicate an inaccurate understanding of the nature and value of public involvement, such as the claim that patient and public involvement is 'not applicable as the research involves only hospital staff'.

Some of it was more of a mixed approach where people were using unconventional methods or were building involvement in later despite not having had time to work with people as early as they would have liked:

'It was important for this research to incorporate the voices of the service users to the research design. In doing so, researchers explored various platforms such as friends, family, acquaintances, [and] online platforms to understand the experiences of [potential participants]'



'Patients, service users, and/or their carers, or members of the public have not been involved with the research process to date [...] We will involve public advisers in designing and organising the focus groups with members of the public and have budgeted for this involvement [and] payment for public advisers' time to attend the virtual events and read our outputs for usability'

'Due to the evolving global pandemic and the speed at which the research is being initiated, PPI has not been as widely embraced as with other studies. However the [public involvement] Advisory Board is involved and will join the management meetings once the trial starts and will be more involved especially with the dissemination of the findings and patient facing documents.' - Statements from applications for HRA Approval reviewed in August 2020

These examples illustrate how public involvement adapted rapidly during the first wave of the COVID-19 pandemic, but the value of the matching service in connecting research teams with public involvement groups also told us something important about the vulnerabilities in the research system which allowed public involvement to collapse when the system came under acute pressure.

What have we learned about public involvement in a public health crisis?

Public involvement is one of the hallmarks of high-quality research. There is an increasing recognition of its value across the health and social care system, but when that system came under pressure it suffered dramatically.

We want to think carefully about why this is so that we can adapt such that the role of public involvement in research is resilient, efficient, and effective in future.

To inform this we undertook a number of steps to build up a picture of how the UK COVID-19 public involvement matching service has worked in practice to date:

- we held 16 qualitative interviews with researchers and public involvement facilitators who were directly involved in either seeking or providing public involvement support via the matching service;
- we analysed HRA social media statistics for matching service communications;
- we compared IRAS data from COVID-19 applications for HRA Approval submitted in March, June, and August 2020 with a baseline sample from October 2019;
- we reviewed feedback on the matching service received from stakeholders.

We found that public involvement during a pandemic was heavily impacted by communication gaps between different stakeholders which led to the absence of a clear shared understanding of what is feasible and beneficial in terms of public involvement during a public health crisis. Our analysis suggested that when there is cross-system collaboration and clear messaging it is possible to establish and maintain high standards for involvement even during a time of crisis. However, the feedback we received about the matching service also sent us a clear message that the pandemic exacerbated existing challenges in the public involvement system.

Key themes

The levels of public involvement in COVID-19 research have improved. The extent to which public involvement was impacted at the start of the pandemic indicated:

1. A communication gap: the absence of clear, consistent, high level messaging about public involvement, which results in incorrect assumptions about the nature, value, and feasibility of public involvement.

2. An information gap: the lack of shared, high quality information about what public involvement looks like across the UK, which limits how effective, inclusive, and diverse it can be.

3. A collaboration gap: the result of siloed and under-resourced public involvement infrastructure is a missed opportunity to work together to develop a research culture with public involvement at its heart.

4. A leadership gap: the lack of clear, cross sector direction for public involvement in the UK.

The communication gap



'Maybe there is a case for a joint campaign with HRA and some funders for example to expand the matching service, because I think it really has just filled a gap that we kind of didn't know we had until we filled it' – Public Involvement Manager, independent non-profit organisation



In April the public involvement community told us that sponsors and research teams were not getting in touch to arrange public involvement in COVID-19 studies because they were assuming that patients and the public would not be able to adapt to working remotely or expedited timeframes. In fact many public involvement groups rapidly established the capacity to do this, but this perception persisted. For example, in August an applicant stated that:



'The current COVID-19 pandemic has restricted patients and the public from visiting the hospital premises, hence preventing meaningful and useful contact with our usual PPI members' – Application form



The sponsor organisation for this study had established several proactive and engaged virtual public involvement groups which had the capacity and the motivation to provide rapid input into COVID-19 research, but there was a communication gap between the research team and the public involvement support that was there to help them.

A theme that emerged from evaluating the matching service was that it has helped researchers and public involvement groups to make connections and work together in ways which were already possible, but where there was a pre-existing gap in communication or shared expectations.



'We got to meet colleagues who are even on the same floor who had no idea that we existed. So that was great, and it wouldn't have happened if not for the matching service' – Public Involvement Lead University/ NHS

'The researchers that I have spoken to, some of them have said like 'oh, I didn't know that your job existed or I didn't know that your network existed. I didn't realise that I could get support' – Public Involvement Manager, independent non-profit organisation



Collaboration to promote the matching service and the key messages about public involvement in a pandemic worked. During the follow up interviews with research teams and public involvement practitioners who had utilised the matching service, stakeholders reported hearing about the service via several channels we pulled together to share core information quickly.

Ultimately, when we worked together to communicate the message that involvement matters all the time, people listened and acted.

“

‘I think communicating [about the value of public involvement] is a real problem. I think there is an awful lot of information out there that says that, and I don’t know how you get people (and by people I mean senior researchers, the leaders, the people who should be demonstrating really good PPI) I don’t know how you get them to read that’ – Public Involvement Manager, NHS

”



The information gap

One of the challenges in establishing the matching service was that public involvement groups were unlikely to have collected information about their members' lived experience of COVID-19. This meant that it was difficult to match researchers up with people with relevant experience of COVID-19 quickly (where that specific experience had been requested).

The database of matching service partner groups included fields for recording information about the membership of the group most likely to be relevant for finding public contributors with relevant lived experience: demographic factors such as age and ethnicity, and experience of specific health and social care conditions or situations.

However, we found that a substantial proportion of groups do not hold demographic information about their membership. For example, nearly a third of groups reported not having data on the ethnicity of their membership, which presented a challenge when trying to connect researchers investigating the impact of COVID-19 on Black, Asian, and minority ethnic populations specifically with the people who could best contribute to the design of their research.

Matching service partners described the strain collecting this information would place on teams already habitually working under pressure, and concerns about ensuring that the information was collected, held, and shared in line with data protection legislation.

One of the most important opportunities to arise from the COVID-19 pandemic is the amplification of the conversation about the impact of health and social care inequalities on our society. The research system is part of the apparatus which reflects and reinforces these inequalities through a lack of equitable access and inclusion across leadership, research teams, research participation, and public involvement. Often these inequities are difficult to quantify accurately because high quality information is not collected and is not shared.

This information gap limits how effectively we can collaborate across the health and research system to make research more inclusive. It also limits how effectively we can communicate the nature and value of public involvement. The challenge of demonstrating the impact of public involvement in order to influence decision makers is a familiar one across the system. We heard from stakeholders from all parts of the research world showing a keen interest in making use of the information the HRA has about public involvement behaviour to increase visibility and transparency around public involvement in research, and influence buy-in and behaviour.

The collaboration gap

The results of the communication and information gap are inconsistencies and missed opportunities for collaboration and efficient working across the research system.

Cross system working

The aim of the HRA in establishing the matching service is to facilitate involvement where it is wanted but has not happened, rather than to mandate it or to replace existing mechanisms and processes to support involvement. As a result, the only requirement for accessing support via the service is that researchers either do not have access to any existing support for public involvement or cannot arrange it easily if there is some.

At the triaging stage we ask researchers for information and provide guidance on best practice public involvement, or to help arrange a good match for them. For example, we ask whether research teams will be offering payment for involvement work, and indicate that the HRA considers this good practice, but offering payment is not a prerequisite for being eligible to be put in contact with the network contacts. Different groups have different ways of working and different policies on payment for involvement. Some require payment, others work on a voluntary basis, and others take a mixed approach. There is considerable variability in the ways that involvement is supported, so the information we ask for is to help make the job of the matching service partners easier by setting out what resources and other support the research team has available to it.

We discussed this approach in our follow up conversations with the researchers and network members who were directly involved with the service. A theme that emerged was that the cross-system collaboration on facilitating involvement presents an opportunity to raise the bar for the quality of involvement in the UK by standardising and increasing the minimum requirements for good practice public involvement, and by raising awareness of the [UK Standards for Public Involvement in Research](#).



'If they want to do it then actually it's about setting out proper guidelines isn't it? [...] we've had to say if you do this a) you've got to fund it b) you've got to think carefully about what you want, you've got to come to it with an open mind and you've got to feed back to them afterwards of how useful it was' – Public Involvement Manager, NHS





'It just feels like they're expecting support but actually not prepared to fund that in any way or there's no indication of how they're going to deal with members of the public, and as somebody who works quite hard to maintain good relationships with them I feel a bit wary about putting members of our panel that we work quite hard to find in touch with people who aren't going to look after them.' – Public Involvement Manager, NHS



Logistical challenges



'I think it ties into this whole need (and I say it is still a need because I don't see any great steps being taken forward for a culture change around PPI) for it to be seen as more than an afterthought, which is still unfortunately my experience in over half of the people that I talk to.' – Public Involvement Manager, NHS



The HRA does not itself fund or commission research, and researchers apply for HRA Approvals relatively late in the study set up process, after funding and sponsorship have been secured. This can mean that at the point the applicants seek advice from the HRA they have limited flexibility to budget for public involvement. This trend was replicated in researchers seeking support via the matching service, despite the expedited timelines. This is one of the core reasons that system-wide collaboration is needed to ensure that there is clear and coherent messaging about what integrating best practice public involvement into business as usual means in practice.

Many of the logistical challenges for public involvement require early communication and planning to prevent them causing delays and distraction later on in the research process, or limiting the effectiveness of the involvement. Avoiding wasting the time and effort needed to improve public involvement arrangements later on in the research process benefits everyone:



'This is only part of my job so I've got a limited amount of time to spend on it.' – Public Involvement Manager, NHS

'Writing a grant is almost the toughest thing I've ever done, it's so difficult to get every base covered, and with the best will in the world when you're juggling finances, your R&D department getting sign off, getting the protocol correct... PPI does slip down at least mid-table in your list of priorities, so anything that can be done to facilitate that and get really meaningful PPI with as few obstacles as possible is hugely valuable.' – Researcher, NHS





'One of the issues people have as they get older is wondering what worth they have. So, anyone who asks for any help will get it. No matter what or when. If I can I will. If they say "Thank you", well so be it. If they forget to do that, next time I might reconsider.' – Public contributor



Most of the research which was supported by the public involvement matching service did not offer payment or expenses for public contributors, and public involvement managers reported that most public contributors did not receive feedback about the impact of their input on the study.



'[Public contributors are] kind of used to researchers not getting back to them, you know? Although we try to keep getting researchers to do that but it's a common problem.' – Public Involvement Manager, national public body



Both public involvement groups and research teams have different ways of working, types of experience, and levels of confidence. Facilitating involvement requires careful work in order to be effective, responsible, and respectful. Payments to public contributors need to be paid promptly, but many finance departments' processes are unsuitable for doing so. Feedback from research teams often requires follow up. Confidentiality arrangements need to be made.

The matching service has depended on an enormous amount of goodwill, and on organisations' willingness to cross institutional boundaries to provide mutual support in the face of an unprecedented public health challenge. Public involvement managers have been fielding and managing involvement opportunities for their groups through numerous channels during the COVID-19 crisis, which is why it was so important that the matching service process be as lightweight and straightforward as possible whilst the matching partner contacts are themselves juggling several roles, new ways of working, and supporting their members during a crisis.

Some involvement infrastructure in the UK is closely aligned with local funding networks, such as the invaluable support provided by the NIHR Clinical Research Networks. Researchers applying for matching service support are asked where they are based, but remote working has made geographical location far less relevant. We aim to match people with local groups where possible, in order that in a post-COVID-19 context they would have a better chance of establishing ongoing connections with a group for the future. There are, however, funding and governance implications of, for example, an involvement group based at a charity in Southampton supporting an NHS research team in Sheffield, or a network based in Birmingham supporting commercially funded research in London. Despite this, the horizons for involvement have been expanded by remote working – at least for those people for whom remote working is accessible and inclusive.

The leadership gap

The importance of leadership in promoting and protecting public involvement emerged as a powerful theme through evaluating the matching service.

Matching service partners emphasised the impact of clear, consistent leadership on behaviour change:



'Putting it into a national thing makes it more equitable for people [...] I think it will raise the profile of it and make it look more endorsed.' – Public Involvement Manager, NHS

'I felt like trying to hook up that researcher with one of our panel and then them not even responding was completely unacceptable – but there's not a lot you can do about that really. But you see for me having you almost coordinating the whole thing feels like there's a safety net.' – Public Involvement Manager, NHS



'If what comes out of it are that there are these really good people out there who've got masses of experience and can direct you as a researcher or can offer you a really valued opinion, then I think people will become more involved because it will look more trustworthy.' – Public Involvement Manager, NHS



Public involvement is one of the hallmarks of high-quality research; coordinated, high-level leadership on the value of public involvement will be vital for the UK to realise its ambition to develop as a global leader in clinical research.

Conclusions

The UK COVID-19 public involvement matching service was set up in response to a dramatic drop in the involvement of people with relevant lived experience as partners for studies addressing COVID-19.

Feedback from the people involved in setting up, running, and using the service has indicated that this is mainly because public involvement is still some way from being fully integrated as a normal part of all types of health and social care research in the UK.

This can be addressed through better information on the ways that working in partnership with the public can help research. More effective collaboration and communication between stakeholders across all sectors can support more consistent involvement of the public in all types of research.

By bringing our partners together from across the research system to address the specific challenges of promoting and supporting public involvement during the COVID-19 pandemic, we have learned that the public involvement system is not visible, accessible, or transparent.

The HRA's mission is to support and encourage those who have a responsibility to involve patients and the public in research to do so in visible, coordinated, and simple ways; to make public involvement business as usual.

Having high quality information about public involvement is invaluable. Our matching service partners have told us that the matching service work met a need for coordination and information sharing about what public involvement support is available and how people can access it.

The impact of the vulnerabilities in the public involvement system is greatest on those who are least included in health and social care research. The matching service is building on an opportunity to make public involvement more transparent, more shared, and more endorsed.



Next steps

If you'd like to discuss this report with us, please email us at public.involvement@hra.nhs.uk

We see being proactive in promoting collaboration, communication and information sharing across the public involvement system as the key practical thing we can do next which reflects the HRA's values, priorities, and expertise.

We will continue to engage with a range of stakeholders to discuss how the public involvement community across the UK can work together to build on the lessons learned.

One of the successes of the matching service has been sharing information across the system more transparently. Our intention is that the matching service be a resource for the public involvement community. However, in order to do so we need to have a clear, shared understanding of the scope and function of that resource, and who in the system is best situated to lead and manage it. Researchers come to the HRA for approval of their studies late in the research process so leadership in this area would be best placed with research funders and sponsors who support research from the start of the process.

Our aim is to work towards supporting meaningful, best practice involvement becoming business as usual for all sponsors and funders of health and social care research in the UK.

Our commitments based on what we have learned about public involvement in the UK health and social care system in the light of the COVID-19 pandemic are:

- 1. to clarify what is expected in terms of public involvement from the sponsors and funders of all types of health and social care research;**

- 2. to explore options for the future of the matching service, including whether it would be of value for supporting involvement in all areas of health and social care research, and identifying who would be best placed to lead and resource it;**
- 3. to promote and support work to maintain the current high levels of public involvement in research;**
- 4. to develop clear cross-system messaging with our colleagues in the health departments of the Devolved Administrations for Wales, Scotland, and Northern Ireland, and with other stakeholders, to improve communication about the role of public involvement in UK health and social care research;**
- 5. to identify how equality, diversity, and inclusion in public involvement can best be promoted and reinforced throughout the research system;**
- 6. to identify what information about the public involvement system would be most useful to collect and share in order to enable more and higher quality involvement.**

We look forward to working with our partners across the health and social care research system in the UK to address these commitments.

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- Public Involvement Enhancing Research (PIER) NI (HSC R&D Division, Public Health Agency, NI)
- Association of the British Pharmaceutical Industry
- National Cancer Research Institute (NCRI)

Appendix

UK COVID-19 Public Involvement network support request form (for information purposes only)

Are you planning or conducting COVID-19 health or social care research? Would your research benefit from patient and/or public involvement? If so, please complete this form so that we can help put you in touch with people who can help.

If there are sections you are unsure about, we can discuss this over the phone with you to help you decide the right kind of public involvement for your study. Email this form to public.involvement@hra.nhs.uk and we will be in touch as soon as possible.

(This form is for information purposes only)

Your contact details

Name

Organisation

Email address

Phone number

- I agree that the HRA can contact me using these details
- I agree that the information in this form can be shared with public involvement groups who may be able to help this research

Information about your research

Short study title

Please provide a brief summary of your research in plain language (300 words max.). Include what the research is trying to find out, what the main inclusion criteria for participants will be, and who the research is intended to benefit.

For guidance on writing research summaries in plain English, see [this website](#).

Does this study require HRA Approvals?

If you are unsure, please see <http://www.hra-decisiontools.org.uk/research/> and http://www.hra-decisiontools.org.uk/research/docs/DefiningResearchTable_Oct2017-1.pdf

Yes

No

IRAS ID (if available)

What stage in the HRA Approvals process is the research?

It doesn't require HRA Approvals

It hasn't yet been submitted to the HRA via IRAS

It has been submitted but has not yet received HRA Approval

It has received HRA Approval

If you are unsure whether your project requires HRA Approvals, please see our [decision tool](#) and how we [define research](#)

If you have not yet submitted your research to the HRA, please see our [guidance](#) about how to record information about public involvement in the IRAS form and the additional guidance at the end of this form.

Public Involvement in your research

If you aren't sure about the answers to the questions in this section the HRA Public Involvement Team can help.

Email this form to public.involvement@hra.nhs.uk and we will be in touch as soon as possible to discuss what the right kind of public involvement is for your research.

How will working with patients and the public help your research e.g. are you aiming to make it more acceptable to potential participants, to improve the effectiveness of the participant-facing materials, etc.?

Do you have contacts with existing public involvement groups or networks?

Yes

No

What would you like public contributors to do? (select all that apply)

Contributing to defining outcome measures

Helping to develop participant-facing information

Joining a committee / steering group

Attending a focus group (one-off)

Completing a questionnaire

Reviewing and commenting on resources

Providing an account of their experiences

Attending an event

Other – please expand in the space below:

What relevant lived experience should patients and the public who want to get involved have?

How many people are you looking to work with?

When would you like input from people by?

Will you be offering any payment or incentive for people who get involved with your research?

Yes

No

Will you be reimbursing any expenses people incur?

Yes

No

Will you provide feedback to the people you work with about how their input has helped your research?

Yes

No

Will you invite feedback from the people you work with about their experience of working with you?

Yes

No

We will ask you for feedback on the matching service and the impact of involvement on your research at a later date.

Any other comments

Guidance on how to let a Research Ethics Committee (REC) know how you are working with the public in your research to address issues which are relevant to their ethical review of your proposal.

Question A14-1, the existing question on public involvement.

Describe here [in the free text box] the people who have been involved in designing the study and in what ways. Include the numbers involved and what they did when as well as what experience they brought to the study and why that is relevant. Also include information about what the people involved will do to help with the conduct, management and or dissemination of the study.

This is to explain to the REC the range of input and how it is appropriate to the study and more directly relevant than most of the REC members' insights are likely to be.

For each of the questions below include how the people described in A14-1 have helped address the issues raised by the question and how that has been used either in the design of the study or in how it will be conducted, managed, or disseminated:

Question A6-2, which asks applicants to summarise the main ethical, legal, or management issues arising from their study and say how they have addressed them.

It is helpful to demonstrate to the REC that you have worked with or sought advice from people with relevant experience of the ethical issues which are likely to be important to potential participants, and to demonstrate how what they have said

has informed your approach to addressing these issues.

Question A13, which asks for a summary of the design and methods to make it clear exactly what will happen to the research participants, how many times, and in what order.

It is helpful to demonstrate to the REC that people with relevant experience think that participants will understand and accept what will happen to them in the study.

Question A22, which asks applicants what the potential risks and burdens are for participants and how they will minimise them.

It is helpful to show the REC that people with relevant experience think the risks and burdens, including the practical arrangements, are likely to be acceptable to potential participants.

Question A30-1 about gaining informed consent.

It is good practice to involve relevant patients, carers, service users or members of the public in producing the Participant Information Sheet, consent form, and any other patient-facing information. It will be helpful to show the REC the details of how this has been done. This could also include how the consent process has been shaped by the involvement.

Question A51 about the dissemination of the results.

RECs think it is important that the results of the study are made available and see a role for the public in helping to do this well in a way which is accessible to multiple audiences.

Attending the REC meeting.

In some cases, it may be helpful for you if one of the people who worked with you in designing the study can attend the REC meeting with you (either in person, by telephone, or by video link) to help explain to the REC how and why the study design is likely to be acceptable to the potential participants.