

Building trust in COVID research – public involvement and transparency



Health Research
Authority

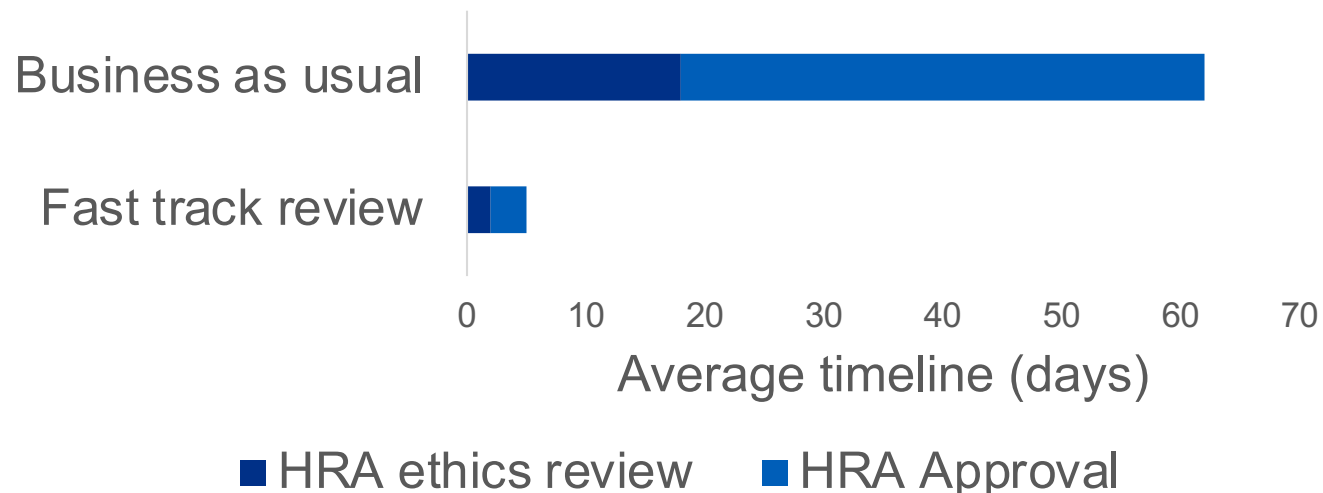


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Non-Commercial Research Sponsors' Symposium
9 December 2020 Sli.do code #RDForum

Research system response to COVID-19

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.

The Health Research Authority (HRA) set up its fast track approvals process for urgent COVID-19 research which reduced the average research review timelines by 90%.



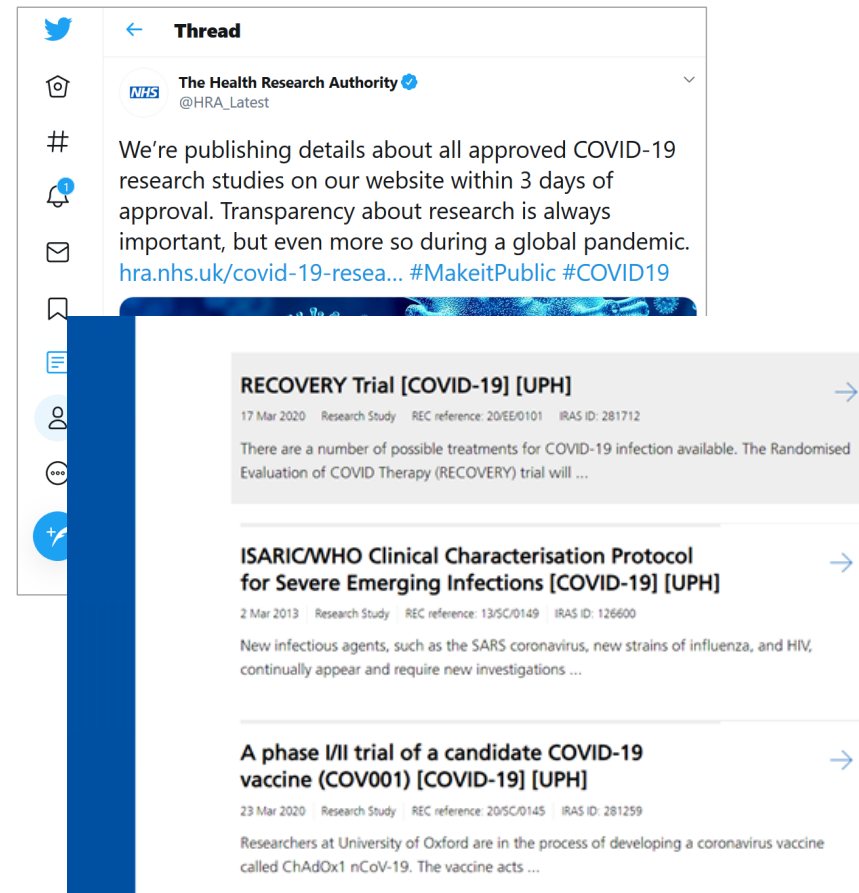
COVID-19 research: our approach

Our approach to supporting COVID-19 research is to:

- enable research to start quickly through fast-track review to the same standards
- encourage public involvement
- encourage proportionate approaches
- ensure public visibility of approved studies
- work in a joined up way across the system
- learn from this way of working

Information about approved studies

- Details of all COVID-19 studies and amendments published within three days of approval
- Each study is listed with key details such as the type of study and the research summary.



Thread

The Health Research Authority @HRA_Latest

We're publishing details about all approved COVID-19 research studies on our website within 3 days of approval. Transparency about research is always important, but even more so during a global pandemic. hra.nhs.uk/covid-19-resea... #MakeitPublic #COVID19

RECOVERY Trial [COVID-19] [UPH] →
17 Mar 2020 | Research Study | REC reference: 20/EE/0101 | IRAS ID: 281712
There are a number of possible treatments for COVID-19 infection available. The Randomised Evaluation of COVID Therapy (RECOVERY) trial will ...

ISARIC/WHO Clinical Characterisation Protocol for Severe Emerging Infections [COVID-19] [UPH] →
2 Mar 2013 | Research Study | REC reference: 13/SC/0149 | IRAS ID: 126600
New infectious agents, such as the SARS coronavirus, new strains of influenza, and HIV, continually appear and require new investigations ...

A phase I/II trial of a candidate COVID-19 vaccine (COV001) [COVID-19] [UPH] →
23 Mar 2020 | Research Study | REC reference: 20/SC/0145 | IRAS ID: 281259
Researchers at University of Oxford are in the process of developing a coronavirus vaccine called ChAdOx1 nCoV-19. The vaccine acts ...

Study numbers

COVID-19 research

733 records

UPH studies

XX records

Studies relying on
COPI notice

56 records

Make it Public

Transparency reduces waste, informs decision-making and builds trust and participation

The Make it Public strategy aims to:

- **make transparency easy** – clear guidance, an easy-to-use research approvals system with reminders
- **make transparency the norm** – aligning expectations, playing back performance, taking action
- **make information public** – ensuring clinical trials are registered, making information about studies available



Public involvement in COVID-19 research

HRA ethical review and research governance requirements remain the same, with focus on good research practice – particularly public involvement.

But networks and groups of public contributors across the UK reported anecdotally a marked drop-off in the numbers of opportunities to get involved in research.

Some organisations set up rapid-response groups specifically to help with COVID-19 research, but there were few requests for their input.

What did our data say?

Question:

Under usual circumstances, 80% of the research HRA reviews declares some public involvement.

What was that proportion in COVID-19 research at the start of the pandemic?

[Sli.do code #RDForum](#)

Public involvement activity stalled dramatically

In the first COVID-19 research studies in March only **22%** documented the involvement of the public in their research, compared to **80%** last year.

Most researchers said compressed timelines and logistical challenges were the main reasons they had decided not to work with patients and the public to develop their studies.



What was happening?

We held a stakeholder workshop to find out:

1. Was this trend widespread across the sector?
2. If so, why?
3. If so, what could we do about it?

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1. Was this trend widespread across the sector? **Yes**
2. If so, why? **Time pressures, communication gaps, incorrect assumptions, and lack of leadership.**
3. If so, what could we do about it? **Cross-system collaboration, communication, and leadership, to bridge the gap between researchers and existing public involvement infrastructure.**

Together we established the matching service



Key info

HRA + 56 partner organisations from the NHS, university, and charity sectors

Representing 7500+ public contributors

Coordinated publicity & engagement

How does it work?

1. Referral from HRA COVID-19 fast track approvals service
2. HRA Public Involvement team assesses need with researchers
3. We connect eligible research teams with public involvement groups via their managers
4. Research teams and public involvement groups work together to develop COVID-19 studies

22 research teams applied & have been supported by 13 groups and networks.

We looked at our data again

Question:

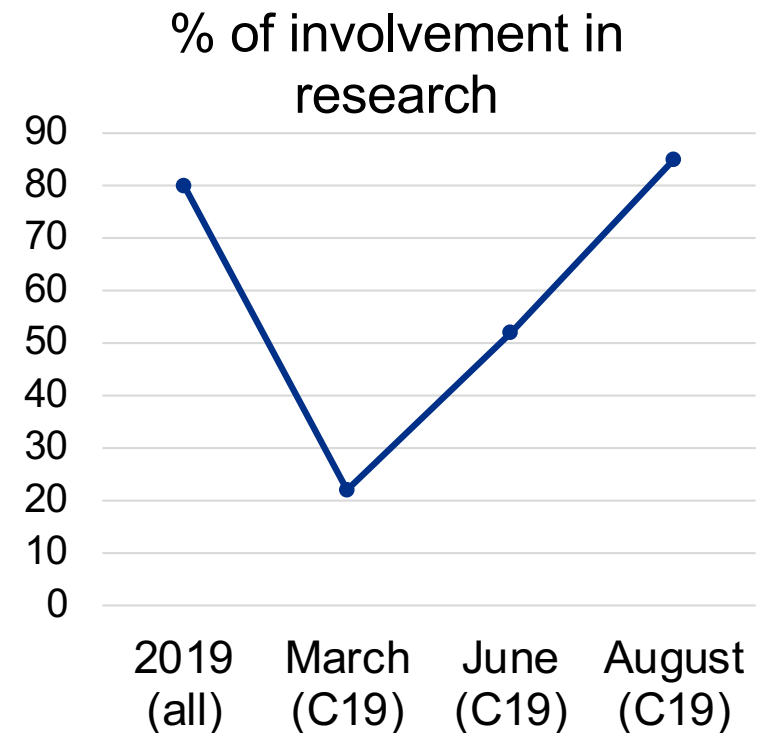
Under usual circumstance the rate of involvement is **80%**. At the start of the pandemic it was **22%** in COVID-19 research.

What was that proportion in COVID-19 research in August?

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Rates of involvement are higher than business as usual

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.



We evaluated the matching service with the people who've been involved

We reviewed:

Application data

Engagement statistics

16 qualitative interviews with stakeholders

What have we learned?

The matching service met a need and was enthusiastically received.

The service must complement rather than replace existing support for involvement.

It relies on goodwill; it is not sustainable without suitable resourcing.

Clear standards for the service and the quality of public involvement it supports will be needed for any future service.

What have we learned?

About public involvement in a pandemic

Clear, high level messaging that public involvement is important, expected and possible, regardless of circumstances, (and that there's help available) changed researcher behaviour (for COVID-19 research).

Mutually agreed cross-system collaboration is essential.

What does this tell us about business as usual?

The pandemic exposed that public involvement is not well integrated in UK research as normal practice.

There are significant gaps in communication across the research system about the expectation to involve the public & the support available to the research community to do so.

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 viewed as a 'nice to have.'

Next steps: how we might use what we have learned

The full report will be launched via webinar + Q&A on:

Wednesday 13 January 2021, 11:00 to 12:30

Open to all.

Workshops to consider options for the future will follow the launch.

There is a clear need for:

- System-wide leadership and collaboration
- Clear messaging and information to support involvement as business as usual
- Sustainable resources!



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Discussion





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Thank you for listening

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