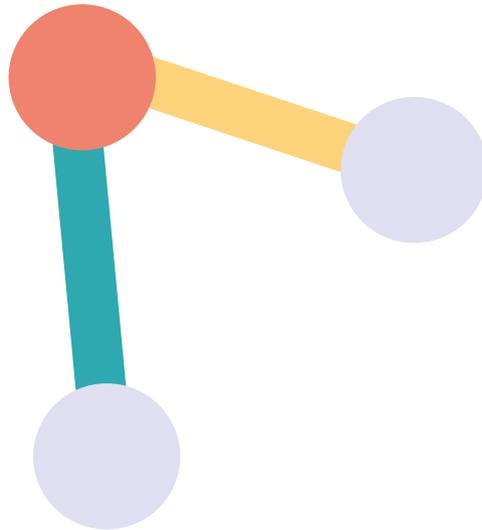




**Data Sharing in a Pandemic:  
Three Citizens' Juries**  
Juries' Report



## Commissioned by:

**NIHR** | Applied Research Collaboration  
Greater Manchester

**NHS**<sup>x</sup>

**NDG** | National  
Data Guardian  
for health and social care

## Designed and delivered by:



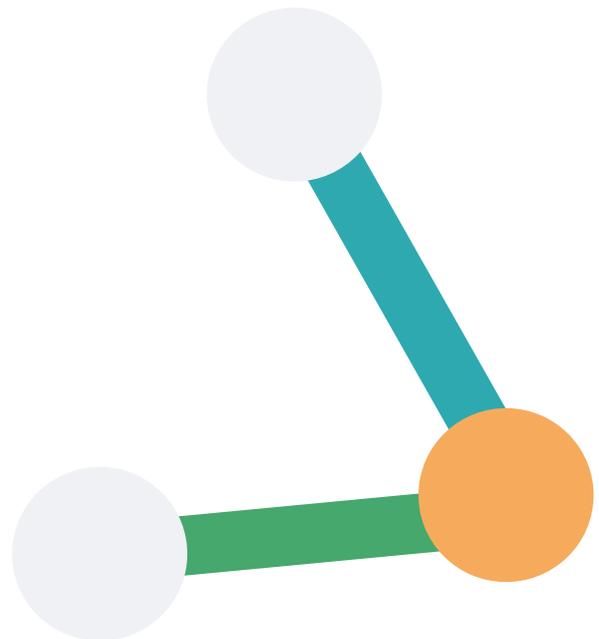
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# Executive Summary

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## What policy questions?

The COVID-19 pandemic brought many changes to people's lives, and to how health and social care services in England were delivered. One area receiving relatively little media and public attention was how health and social care data sharing changed during the pandemic. Under legal powers in the [Health Service \(Control of Patient Information\) Regulations 2002](#), the Secretary of State for Health and Social Care issued notices enabling increased data sharing amongst health and social care organisations. These were introduced specifically to address challenges arising in the pandemic, and not for non-COVID-19 uses. [These Control of Patient Information \(COPI\) Notices](#), first issued on 1 April 2020, were temporary legal powers lasting six months, and have subsequently been renewed (currently until end September 2021).

A number of major initiatives were introduced to take advantage of these powers and increase data sharing between health and social care organisations. These initiatives have collected and produced valuable information to tackle the pandemic. They potentially could continue to be useful well beyond the COVID-19 pandemic. This raises policy dilemmas about the future of these initiatives. For example, should these data sharing initiatives, created under temporary legal powers to tackle COVID-19, continue beyond the pandemic, and if so for how long? Who should make these policy decisions?

## Why citizens' juries?

These are questions that concern not only policy makers but the public too – it is data about people's health and care that is being shared more widely. The questions are far from straightforward to answer. They rely, for example, on an understanding of pre-existing and new temporary data sharing laws, of the function and value of these complex data sharing initiatives, and on value judgements weighing the benefits of continuing using valuable data and systems against the disbenefits of continuing to process data that was collected in an emergency for a specified purpose: tackling the pandemic.

One means of bringing this kind of complex evidence to the public is a citizens' jury. A jury – people recruited to broadly reflect the demographics and prior attitudes of the general public – can be asked to hear and weigh the evidence, deliberate together, and use their values to assess trade-offs and make judgements to reach reasoned answers to the questions they are set. The evidence comes from expert witnesses who are briefed to make presentations that provide the jury with a fair balance of relevant evidence. By repeating the citizens' jury process with different jurors each time but with the same jury questions, expert witnesses, and facilitators, it is possible to evaluate to what extent a different set of participants produce similar results, reduce the risk of groupthink<sup>[1]</sup>, and bring greater statistical weight to the results through a greater number of participants.

## What has been done?

A set of three citizens' juries were commissioned to address policy questions about data sharing initiatives introduced in the COVID-19 pandemic. The juries were conceived in June 2020 and funded primarily by the [National Institute for Health Research Applied Research Collaboration Greater Manchester](#) (NIHR ARC-GM). Additional funding to enable a third jury was subsequently provided by [NHSX](#), and by the [National Data Guardian for Health and Social Care](#). The juries were run online between March and May 2021, and each consisted of eight sessions from 13.00 to 17.30 (including breaks). A cross-section of 18 adults was recruited for each jury, with people from across England in jury one, people from Greater Manchester in jury two, and people from West and East Sussex in the final jury.

Each jury watched the same presentations of the same evidence from the same expert witnesses, but could pose their own questions to each witness. They were all charged with answering the same set of questions about what the future should be, and who should make that decision, for three pandemic data sharing initiatives enabled through the 2020 COPI Notices:

- [NHS COVID-19 Data Store and Data Platform](#) a new central store of patient-related data created by NHS England in response to the pandemic with a wide range of software tools including two which were specifically considered by the juries:
  - The Early Warning System used for planning and monitoring the pandemic response (e.g. of COVID-19 admissions, bed usage etc.)
  - The Immunisation and Vaccination Management Capability used to manage the delivery of the COVID-19 vaccination programme
- [OpenSAFELY](#) – a tool created at the start of the pandemic by a consortium including the University of Oxford and with the backing of NHS England for pandemic-related research. It uses patient data accessed from GP patient records but outputs aggregate data.
- [Summary Care Record Additional Information](#) which was extended to include additional information for over 50 million people in England without explicit patient consent (which had been the basis for uploading additional information from GP patient records to the Summary Care Record before the pandemic)



# What were the findings?

## Key findings were:

- Overall, the juries supported the decisions to introduce the initiatives during the pandemic. Although they had concerns about how some initiatives were introduced, the juries were broadly in favour of them continuing;
- The juries were most supportive of the decision to introduce OpenSAFELY (77% of jurors very much in support) and least supportive of the decision to introduce the NHS COVID-19 Data Store and Platform (38% of jurors very much in support);
- Whilst supportive, many jurors were concerned that there was lack of transparency about the data sharing initiatives, and in particular the NHS COVID-19 Data Store and Platform and Summary Care Record Additional Information initiatives. The juries thought transparency and governance important even in a pandemic;
- A majority were in favour of all the data sharing initiatives continuing for as long as they were valuable (potentially beyond the pandemic and for non-COVID-19 uses), with support ranging from 58% for the NHS COVID-19 Data Store and Platform to 87% for OpenSAFELY across the three juries;
- Most jurors considered OpenSAFELY to be the most transparent, trustworthy, and secure of the three data sharing initiatives;
- Very few jurors wanted decisions about the future of these data sharing initiatives to be taken by the minister or organisation accountable for the initiative (only 6% overall). Most believed that an independent body of experts and lay people should review the data sharing initiatives.
- Whilst responses across the three juries were similar, there were differences such as:
  - Jury one (national) strongly supported the initiatives continuing as long as they were valuable with an average of 92% support across the three initiatives, compared to 63% and 59% for jury two (Greater Manchester) and jury three (West and East Sussex) respectively;
  - Jury two (Greater Manchester) was the most supportive of decisions about the future of the initiatives being made by an independent advisory group (80% support overall compared to 31% for jury one (national) and 35% for jury two (West and East Sussex)).

Jurors worked together in small groups, deliberating about the jury questions and prioritising their reasons to support/oppose the data initiatives. They voted individually on the jury questions. The jury questions are set out below, followed by tables showing total vote percentages all juries (with 53 jurors in total). Rounding errors may lead to total percentages just above or below 100%. An analysis of jurors' reasoning is included in the main report.

**Q1a: How supportive are you of the decision to introduce this data sharing initiative in 2020 as part of tackling the COVID-19 outbreak?**

Answer choices	Summary Care Record Additional Information	NHS COVID-19 Data Store & Platform	Early Warning System*	Immunisation & Vaccination Management Capability*	OpenSAFELY
Very much in support	49%	38%	53%	75%	77%
Broadly supportive	45%	49%	38%	17%	23%
Neutral	4%	8%	4%	4%	0%
Broadly opposed	2%	4%	4%	4%	0%
Very much opposed	0%	2%	2%	0%	0%

\* The Early Warning System and Immunisation and Vaccination Management Capability are software tools within the NHS COVID-19 Data Store and Platform which were considered separately as sub-case studies by the three juries. The juries answered a subset of the jury questions for these sub-case studies: Q1a and Q2a.



**77% vs 38%**

Very much in support of the decision to introduce OpenSAFELY and the NHS COVID-19 Data Store and Platform, respectively



**58% to 87%**

In favour of the data sharing initiatives continuing as long as they were valuable



**6%**

Wanted decisions about the future of the data sharing initiatives to be taken by the minister or organisation accountable for the initiative



***What are the most important reasons to support (Q1b) and oppose (Q1c) the initiative?***

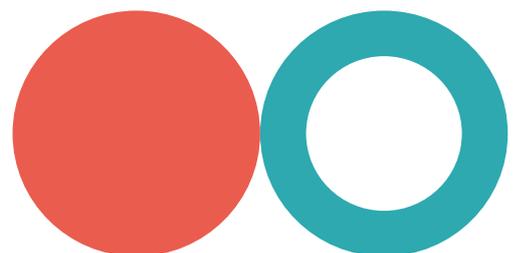
Jurors identified and voted to prioritise reasons to support and oppose the three main initiatives:

- The most important reason found to support the Summary Care Record Additional Information was that it provided useful information to enable better care and decision-making, and the most important reason to oppose the initiative was lack of transparency and communications about the introduction of the additional information;
- The most important reason found to support the NHS COVID-19 Data Store and Platform was that it improved overall COVID-19 monitoring and management, and the most important reason to oppose the initiative was lack of transparency and communications;
- OpenSAFELY was supported because it was considered more transparent than other initiatives and not created by commercial third parties, and juries considered the most important reason to oppose the initiative was its uncertain legal status.



## **OpenSAFELY**

Was supported because it was considered more transparent than the other initiatives



**Q2a: For how long should the initiative continue?**

Answer choices	Summary Care Record Additional Information	NHS COVID-19 Data Store & Platform	Early Warning System*	Immunisation & Vaccination Management Capability*	OpenSAFELY
As short a time as possible	2%	6%	4%	2%	0%
Only as long as the COVID-19 pandemic continues and emergency powers are in place	13%	30%	15%	17%	4%
As long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)	72%	58%	70%	72%	87%
Something else	13%	6%	11%	9%	9%

**Q2b: By whom should these decisions be made?**

Answer choices	Summary Care Record Additional Information	NHS COVID-19 Data Store & Platform	OpenSAFELY
An independent advisory group of experts and lay people	58%	42%	47%
The minister or organisation accountable for the data initiative	2%	8%	9%
Parliament	19%	32%	19%
Someone else	21%	19%	25%

**Q3: What lessons can we learn from how these pandemic data initiatives were introduced which could be useful:****a) for future pandemics?**

The juries thought that the main lesson to learn for future pandemics was to better inform and engage the public in the actions taken under COPI notices.

**b) outside of pandemics?**

The juries said that authorities can learn from these initiatives to develop secure joined-up data storage arrangements for future service planning and patient care.

For more information, please contact  
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The information in this report is correct  
at the time it was produced.