NIHR | Applied Research Collaboration Greater Manchester

Data Sharing in a Pandemic: Three Citizens' Juries

Juries' Report

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Executive Summary

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[1], 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:

- 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)
- 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.

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.

Report of the juries

Introduction

This citizens' juries project

This is a report of three online citizens' juries about data sharing in a pandemic. The set of three juries was jointly funded and commissioned by a consortium of National Institute for Health Research (NIHR) Applied Research Collaboration Greater Manchester, NHSX, and the Office of the National Data Guardian for Health and Social Care. 18 people were recruited to each jury to broadly reflect the demographics of adults in England. Each jury process consisted of eight 4.5 hour (1-5.30pm) Zoom sessions with breaks, and each drew from a different population:

- Jury 1, 16-19 and 22-25 March 2021, with jurors selected from across England
- Jury 2, 6-9 and 12-15 April 2021, with jurors from across Greater Manchester
- Jury 3, 27-30 April and 3-6 May 2021, with jurors from across West and East Sussex.

Each citizens' jury had the same task, was facilitated by the same two people (Kyle Bozentko and Sarah Atwood from the Center for New Democratic Processes (CNDP)), and heard the same set of presentations from the same expert witnesses. A video was made of each witness presentation in jury one and played to juries two and three and each jury had a live question and answer session with each witness. The only thing that changed from one jury to the next was the 18 jury participants. Over eight afternoons (each 1PM to 5.30PM), the jurors heard from, and asked questions of, 11 expert witnesses and deliberated together in small groups to explore the jury questions about health and care data sharing in a pandemic. These questions focused on what the future should be of certain pandemic data sharing initiatives. The initiatives were introduced in spring 2020 under the Control of Patient Information (COPI) Notices to enable health and care organisations to share patient-related information.

What the juries did

The juries heard evidence about, deliberated on, and answered the same set of questions about three pandemic data sharing initiatives. They were chosen as case studies for the juries because they were significant initiatives introduced near to the start of the 2020 COVID-19 pandemic, all made possible through the temporary legal powers described above (the COPI Notices).

The three pandemic data sharing initiatives considered by the juries were:

- The Summary Care Record (SCR) 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).
- NHS COVID-19 Data Store and Platform – a new central store created by NHS England of patient-related data which was created in response to the pandemic with a wide range of software tools through the Data Platform.
- 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 using patient data accessed from GP patient records.

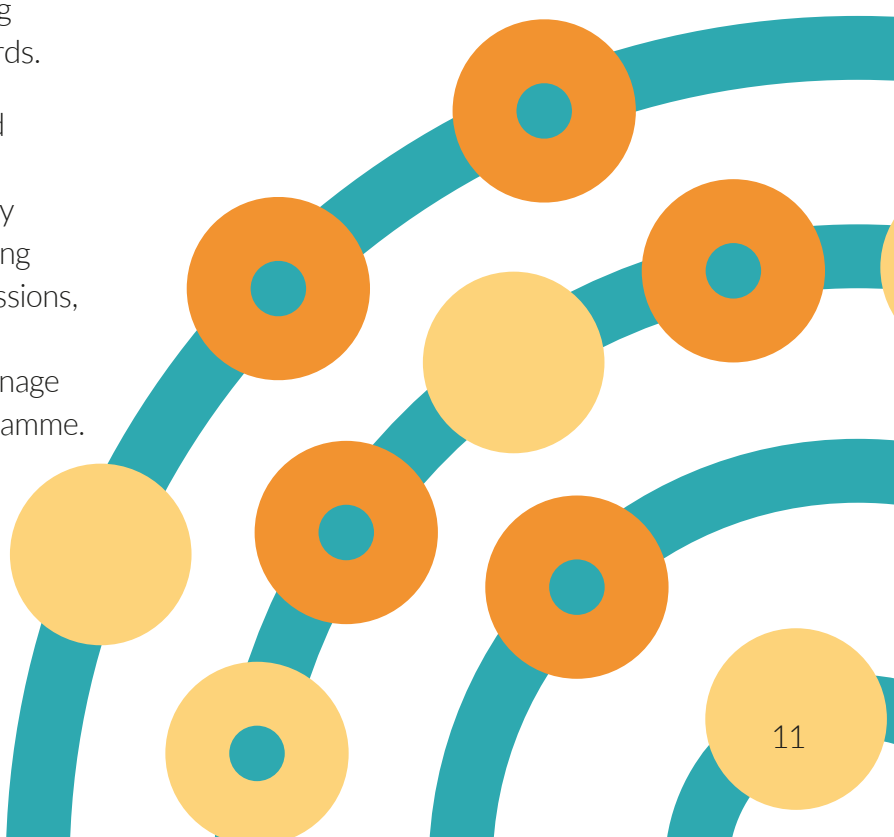
In addition, two NHS COVID-19 Data Store and Platform products were specifically considered as sub-case studies by the three juries: The Early Warning System used for planning and monitoring the pandemic response (e.g. of COVID-19 admissions, bed usage etc.); and The Immunisation and Vaccination Management Capability used to manage the delivery of the COVID-19 vaccination programme.

Reports of the juries

This report explains why the juries were held, how they were designed, how the jurors were recruited, what they did, the juries' answers to the jury questions, and the results of questionnaires completed by jurors.

A Jurors' Report, constructed with reasoning in the jurors' own words, was also produced for each jury. These three reports, the slides of expert witnesses, and many other documents about the project can be found here.

Appendix 1 contains a full description of the jury process and reports.



Why the citizens' juries were run

The COVID-19 pandemic brought many changes to people's lives, and to health and social care services in England and how they operate. One area of change receiving relatively little media and public attention is health and social care data sharing. 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 specifically to address challenges arising in the pandemic. These Control of Patient Information (COPI) Notices, first issued in March 2020, were temporary legal powers lasting six months, and have subsequently been renewed until 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, systems which 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, continue beyond the pandemic, and if so for how long? Who should make these policy decisions?

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. The jury – people recruited to broadly reflect the demographics and prior attitudes of the general public – can be asked to weigh the evidence, deliberate together, and use their values to make trade-offs and judgements to reach reasoned answers to 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.

Planning and designing the citizens' jury

The jury questions were set with and agreed by the commissioners of the juries. The three citizens' juries were planned, designed and refined to address these questions over a period of just under a year by Citizens Juries c.i.c. and the Center for New Democratic Processes. The main aspects of the jury design were:

- the jury questions;
- the jury demographics and recruitment approach;
- the expert witnesses and their briefs;
- the selection of the oversight panel and their brief;
- the programme of activities across the eight jury sessions; and
- the design of the questionnaires completed at the end of the jury.

The design documentation is published and available here.

Bias, both conscious and unconscious, is a risk to consider in planning citizens' juries.[2] For example, it is very difficult to know what constitutes "impartial information" or balanced argument, and almost every design choice, even down to a bullet point on a presenter's slide, could be challenged on grounds that it might manipulate the citizens' jury towards one outcome or another.

Bias can be monitored and minimised but not eliminated. To monitor and minimise bias on this project, an oversight panel was appointed to review the jury design and materials, and report potential bias.

The end of jury questionnaire also asked about perceived bias.

Other design controls used to monitor and minimise bias include:

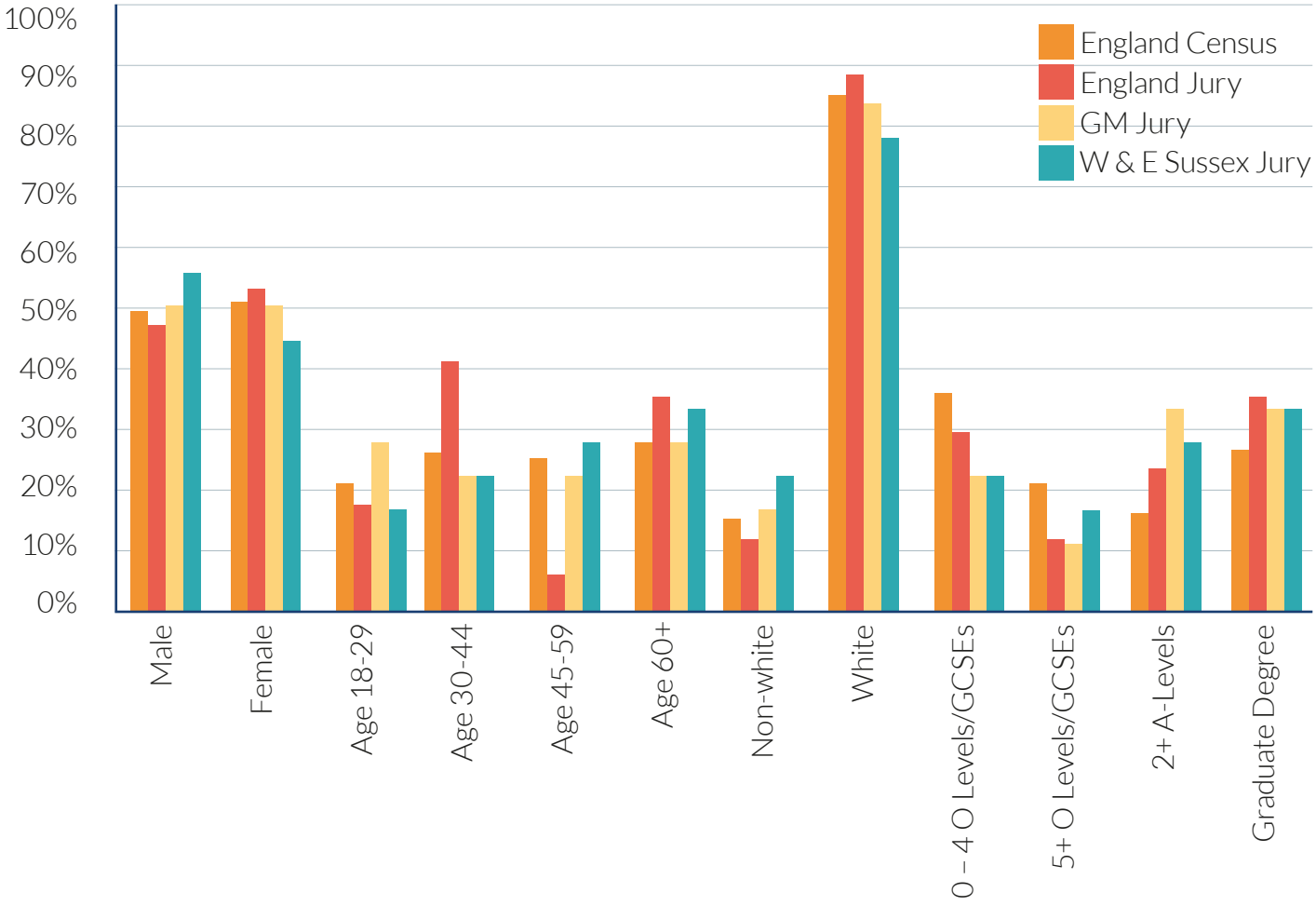
- The commissioners of the juries were involved in setting the jury questions and advising on NHS witnesses but were independent from the design of the jury process and outcomes;
- The jury worked with independent facilitators from the Center for New Democratic Processes (formerly Jefferson Center) to construct and agree their own Jurors' Report of their findings;
- The detailed jury design and results documentation are published.

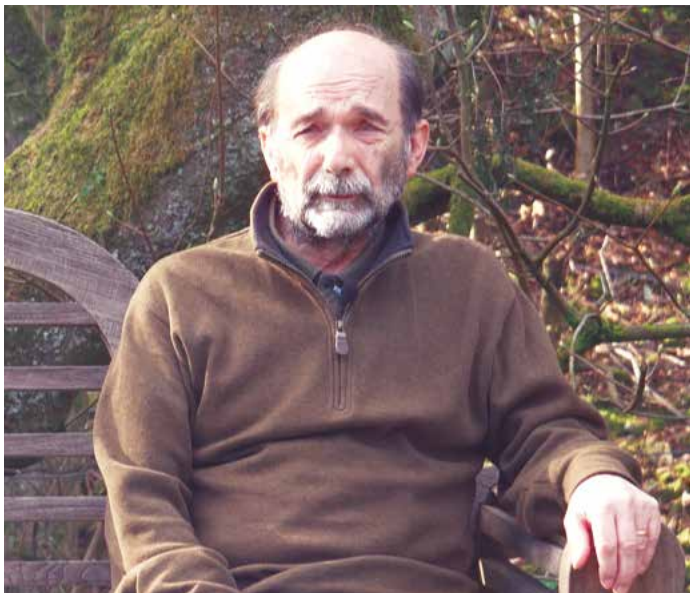
Demographics of juries

People applied by entering their personal details, including relevant demographics, into an on-line survey. A computer algorithm was used to select a stratified sample of jurors to closely reflect the population of England (as described in Jury Recruitment). The main demographic breakdown of each jury compared to 2011 England Census data is shown in the bar chart below.

To reduce the risk that a particular jury held unrepresentative views about health and care data sharing, jury applicants also answered, and were selected using, an attitudinal question (see Jury Recruitment).

Demographic breakdown of juries compared to 2011 Census data for England





Jury questions and answers

Introduction

The juries were charged with tackling the questions set out in Appendix 2. In order to provide reasoned answers to those questions, the jurors listened to witness presentations, asked questions of those witnesses, and deliberated together in three small groups in Zoom breakout rooms over the eight days. For questions 1a, 2a and 2b, participants completed an online Surveymonkey questionnaire, with each person separately choosing his or her answers from a multiple choice list, and entering their own brief reason for that answer on the Surveymonkey form. This Surveymonkey voting against questions 1a), 2a) and 2b) is laid out in tables below. Their reasoning was later reviewed by Louise Laverty (a University of Manchester qualitative researcher) who conducted an inductive qualitative content analysis of the free-text Surveymonkey responses. Each response was read and coded before being clustered into related categories of codes. The frequency of responses for each category was recorded.[3]

The remaining questions, namely Q1b), Q1c), Q2c), Q2d) and Q3, were all open questions. For Q1b) and Q1c), participants generated free-text answers and prioritised these in small groups. Similar answers were merged together by the facilitators, and then the final set of answers was ranked according to importance by participants through individual voting. For Q2c), Q2d) and Q3, Individual answers were given by jurors which were later subjected to the content analysis described above.

The full jury results including the free-text reasoning of the juries is published in the three Jurors' Reports.

Data Initiative 1: Summary Care Record Additional Information

One pandemic data sharing initiative considered by the juries was the introduction of Additional Information to approximately 52 million Summary Care Records. The vast majority of people in England have a Summary Care Record. It is derived from GP patient records and held centrally and is accessible outside the GP practice where the patient gives a healthcare professional permission to view it (e.g. in Accident and Emergency).

Prior to the pandemic, unless a patient had explicitly dissented, a core Summary Care Record of basic demographic information, allergies and medications about the patient existed. Patients were also able to explicitly consent to Additional Information – over 100 data items including significant medical history (past and present), vaccinations and other helpful information about the patient – being then added to their Summary Care Record. However, only around 3 million patients had done that prior to 2020. This changed in early 2020.

During the pandemic, NHS Digital added Additional Information to approximately 52 million Summary Care Records following Directions in a COPI Notice. This addition of confidential patient information was done without the explicit consent of patients. It was a temporary measure to assist clinicians providing direct patient care in the pandemic but there is now a question over whether this Additional Information should remain accessible for care professionals outside the GP practice to access, or whether it should be removed from the records of patients who did not explicitly consent to having it. As with all the data sharing initiatives considered, the juries were provided with general information about the data initiative and also heard arguments for and against the data initiative continuing into the future. They then answered a set of questions about the Summary Care Record Additional Information initiative (this same set of questions was asked about all three data sharing initiatives).

The jury questions are shown below in italics followed by jury answers for the Summary Care Record Additional Information data initiative.

Jury Question 1: Support for the Summary Care Record Additional Information Data Initiative

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

Most jurors supported the decision to introduce the Summary Care Record Additional Information data initiative.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
Very much in support	7/17	8/18	11/18	49%
Broadly supportive	10/17	8/18	6/18	45%
Neutral	0/17	2/18	0/18	4%
Broadly opposed	0/17	0/18	1/18	2%
Very much opposed	0/17	0/18	0/18	0%

Jurors recorded free-text reasons for their votes. Many thought that the increased sharing of data through this initiative was essential for an efficient NHS response to the pandemic (n=30). However, there were concerns about the lack of patient engagement (n=7) and lack of transparency in the process of setting up the initiative in 2020 (n=7).

Q1b. What are the most important reasons to be supportive?

Jurors deliberated together, identifying reasons to be supportive of the Summary Care Record Additional Information data initiative (whether or not as individuals they were supportive), and then voted to identify the most important reasons (up to three votes per juror). The three most important reasons expressed in the jurors' words are given below; a full set of reasons appears in the Jurors' Reports.

Jury 1 reasons to support	Jury 2 reasons to support	Jury 3 reasons to support
The SCR with additional information gives a broader range of healthcare professionals timely access to useful information which allows them to treat patients in a more time-effective way, give better care, and potentially save lives (such as in emergency situations, A&E, etc.,) in a range of settings. 16 votes	The Summary Care Record Additional Information can provide useful information to healthcare professionals, particularly in emergency situations and when an individual is unable to communicate with them directly. 16 votes	The enhanced Summary Care Record and additional information can provide essential information to healthcare professionals in emergency situations or when individuals are unable to communicate. 12 votes
Using enhanced SCRs with additional information can improve future research and planning of care delivery for patients and save more lives in the future (such as in planning for future pandemics). 13 votes	Additional information in the Summary Care Record can help to make better, more informed and faster decisions about patient care which improves care and can help save lives. 15 votes	The Summary Care Record Additional Information made patient records easily accessible to providers which improves patient care and can save lives. 11 votes
Different medical care departments/facilities can access the information without relying on the patient for their past medical history, which may be difficult for some people (eg if they are incapacitated or can't communicate for other reasons). 10 votes	The Additional Information contains information that is valuable to researchers and could support improved research after the pandemic. 8 votes	The SCR Additional Information could play a role in future policy planning for the benefit of public health and help prepare to respond to future pandemics or other emergencies. 10 votes

Q1c. What are the most important reasons to oppose the initiative?

Jurors deliberated together, identifying reasons to oppose the Summary Care Record Additional Information data initiative (whether or not as individuals they were opposed to it), and then voted to identify the most important reasons. The three most important reasons expressed in the jurors' words are given below; a full set of reasons appears in the Jurors' Reports.

Jury 1 reasons to oppose	Jury 2 reasons to oppose	Jury 3 reasons to oppose
There is a lack of transparency and public awareness around the SCR additional information, that it exists, what it contains, who has access to it, how the changes affect what can be seen, and that patients are able to opt out if they desire. 14 votes	The initial lack of transparency and inadequate communications about the Summary Care Record Additional Information could result in lack of awareness or decreased trust among the public. 16 votes	There has been a lack of transparency about the initiative and how it was implemented which leads to very little public awareness about how records are being used, by whom, and for what purposes. 17 votes
Concerns around the overall security of the records, the number and types of access/ entry points, the risk of the information being accessed by hackers or unauthorised parties, and unclear checks and balances for the initiative. 11 votes	People were not given the opportunity to provide explicit consent and many people may be unaware of what information is stored about them, with whom it is shared, and how to opt out of the Summary Care Record due to the changes resulting from COVID-19 response and COPI notices. 10 votes	The SCR Additional Information presents unique security risks for unauthorised access and numerous entry points for accessing the records. 13 votes
People are not fully informed about their ability to opt out of this initiative and there was not a blanket informed consent required to create the enhanced records (additional information) during the pandemic. 9 votes	The Summary Care Record Additional Information may end up being used for non-COVID-19 response purposes (such as commercial exploitation) which is not the original intent of the initiative. 9 votes	The potential risk of misuse, commercial exploitation, or nefarious uses of this information is a reason to oppose the initiative. 13 votes

Jury Question 2: What should the future of the Data Sharing Initiative be?

Q2a: For how long should the initiative continue?

Most jurors wanted the Summary Care Record Additional Information data initiative to continue as long as it is valuable.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
As short a time as possible	0/17	0/18	1/18	2%
Only as long as the COVID-19 pandemic continues and emergency powers are in place	1/17	5/18	1/18	13%
As long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)	16/17	10/18	12/18	72%
Something else	0/17	3/18	4/18	13%

Jurors recorded free-text reasons for their votes. Some of those who voted for the Summary Care Record Additional Information initiative to continue beyond the pandemic stated that this was due to its potential to provide benefits to the health and social care system more generally (n=12). Others thought there should be an evaluation and review of the initiative (n=9) including a review of the legal basis (n=6), and to ensure safeguards are put in place (n=4). Jurors also wanted patients to be informed about the initiative in a transparent manner (n=14).

Of those answering "something else", five jurors said they wanted the initiative to continue until the end of the COPI notice and then should not continue until there has been a review of the governance arrangements (e.g. a lawful basis, informing patients, getting explicit opt-in).

Q2b: By whom should these decisions be made?

Most jurors wanted decisions about the future of the Summary Care Record Additional Information data initiative to be made by an independent advisory group.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
An independent advisory group of experts and lay people	6/17	17/18	8/18	58%
The minister or organisation accountable for the data initiative	0/17	0/18	1/18	2%
Parliament	9/17	0/18	1/18	19%
Someone else	2/17	1/18	8/18	21%

Jurors again recorded free-text reasons for their votes. Most believed that a cross-party or independent body, made up of experts and laypeople should review the data-sharing initiative (n=31). However, some jurors were concerned that this sort of group would have limited power to make legislative changes and thus the final decision should be with parliament (n=15). The ability of the government to remain impartial (n=18) and deal with scrutiny (n=8) was called into question by some jurors.

Of those answering "someone else", ten explained that they wanted an independent advisory group to guide parliament to make the necessary regulatory change. Two jurors wanted more public engagement around decisions.

Q2c: How could or should the initiative and its uses be usefully changed in the future (if at all)?

Free-text answers were provided for Q2C and for Q2d below. The juries did not vote to prioritise their answers; a full set of answers is provided within the three Jurors' Reports. The figures below (e.g. "n=9") are derived from content analysis of free-text by researchers.

Some jurors highlighted that better communication with the public about the Summary Care Record Additional Information is the key improvement that could be undertaken in the future (n=9). This would include informing patients about the opt-out option (n=8). Some requested a publicly available audit trail (n=5) that would improve transparency as to why and when their data is being accessed, and by whom (n=5). A new legal regulatory framework was also proposed (n=5).

Q2d: What actions, if any, could be taken to engender greater public trust in the initiative?

Jurors thought that public trust could be engendered through better communication with the public (n=11) that is transparent about what information is being retained, by whom, and for what purpose (n=11). This would include having publicly available audit trails (n=7) and improved security (n=4).

Data Initiative 2: NHS COVID-19 Data Store and Platform

In response to the COVID-19 pandemic, NHS England established the NHS COVID-19 Data Store. It is a central data store bringing together identifying and non-identifying data from data sources across the health and care system in England. De-identified data is drawn from the data store to the Data Platform where it is used to power tools to help the NHS and the government monitor and manage the pandemic as it evolves.

The NHS COVID-19 Data Store and Platform was created and has been used under temporary legal powers (a COPI Notice) specifically to tackle the pandemic. However, the data collected, and the tools created within the Data Platform (using the data from the store) have substantial potential value beyond the pandemic.

The jury questions explore how supportive the juries were of the NHS COVID-19 Data Store and Platform initiative and its use beyond the pandemic. Before answering these questions, the jurors heard from witnesses providing background information about the initiative and arguments for and against it continuing into the future.

The COVID-19 Data Store and Platform was one of three data sharing initiative case studies considered by the citizens' juries. In addition, two tools (developed within the data platform using the data from the store) were also considered as sub-case studies by the three juries.

1. The **Early Warning System** – which gives a three-week forecast for predicted COVID-19 hospital admissions, allowing national and local organisations to plan and put mitigations in place.
2. The **Immunisation and Vaccination Management Capability** – a set of tools developed to enable the NHS to manage the COVID-19 vaccination programme across England (from procurement through to vaccination administration).

The jury questions and answers about the NHS COVID-19 Data Store and Platform are set out below. Jury questions are in italics.

Jury Question 1: Support for the NHS COVID-19 Data Store and Platform Data Initiative

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

Most jurors supported the decision to introduce the NHS COVID-19 Data Store and Platform data initiative.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
Very much in support	3/17	10/18	7/18	38%
Broadly supportive	12/17	6/18	8/18	49%
Neutral	2/17	1/18	1/18	8%
Broadly opposed	0/17	1/18	1/18	4%
Very much opposed	0/17	0/18	1/18	2%

Jurors recorded free-text reasons for their votes. Most thought that the Data Store and Platform was needed and valuable during the pandemic for research and service planning (n=36). However, many jurors were not happy about the use of external commercial companies involved in the set-up of the initiative (n=20). Transparency (n=7), governance (n=4), and lack of patient engagement (n=6) were further concerns.

Q1b. What are the most important reasons to be supportive?

Jurors deliberated together, identifying reasons to be supportive of the NHS COVID-19 Data Store and Platform data initiative (whether or not as individuals they were supportive), and then voted to identify the most important reasons (up to three votes per juror). The three most important reasons expressed in the jurors' words are given below; a full set of reasons appears in the Jurors' Reports.

Jury 1 reasons to support	Jury 2 reasons to support	Jury 3 reasons to support
This initiative improves overall COVID-19 response and management through virus tracking and monitoring as it makes it easier to share data, create dashboards, analyse data, be cost effective, track PPE and available beds, etc., and establish areas/people at high risk. 16 votes	The Data Store and Platform allows strategic decision makers to view at a glance things that need to be immediately addressed (i.e. Bed Capacity: PPE stock, etc.,) in order to coordinate COVID-19 responses, manage resources, make more informed policy decisions, and tailor responses to local/regional needs. 17 votes	The Data Store and Platform provides valuable information for researchers working on other COVID-19 research, other diseases, treatments, studying vulnerable groups, etc. 16 votes
The data captured could be vital in planning for future healthcare service delivery, patient care, and treatments (such as how we might manage other health areas such as elderly care, cancer etc.). 13 votes	The Data Store and Platform centralises all the data in one secure place which reduces duplication, improves efficiency, improves data quality, and reduces costs. 11 votes	The COVID-19 Data Store & Data Platform have been pivotal in coordinating and synchronising the management of the services and resources required to minimise the detrimental effects COVID-19 has on public health in a timely and standardised manner. 14 votes
A comprehensive dataset that is centralised and not spread across multiple sources/systems, providing efficiency and usability for current and, potentially, for future uses. 8 votes	The Data Store and Platform has provided information to improve care and responses that have led to improved outcomes, better care, and saving lives. 11 votes	The central database provides speed of response (real-time) nationally. 7 votes

Q1c. What are the most important reasons to oppose the initiative?

Jurors deliberated together, identifying reasons to oppose the NHS COVID-19 Data Store and Platform data initiative (whether or not as individuals they were opposed to it), and then voted to identify the most important reasons. The three most important reasons expressed in the jurors' words are given below; a full set of reasons appears in the Jurors' Reports.

Jury 1 reasons to oppose	Jury 2 reasons to oppose	Jury 3 reasons to oppose
There has been a lack of transparency and communication with the public about what the Data Store and Platform is, how it is managed, and how it is being used and for what purposes or benefits. 15 votes	There has been a lack of transparency about the Data Store and Platform and poor communication with the public about what it is, how records are stored and shared, for what purposes, and no record of who is accessing data and why which could lead to further mistrust. 16 votes	The involvement of companies with dubious reputations and potentially problematic political affiliations as well as little transparency about outside companies' involvement in the initiative (e.g. unpublished contracts, etc.). 18 votes
The initiative relies on international corporate entities to operate which could lead to the influence of financial interests and commercial exploitation and present issues related to data ownership and storage. 12 votes	The process for obtaining explicit consent for the Data Store and Platform has not been adequate and people have not been given clear enough opportunity to opt-out of the initiative. 12 votes	The lack of communication about its introduction and development at the beginning of the pandemic has led to very low public awareness about how the initiative is used, what data is shared, by whom, and for what purposes. 16 votes
There are many data inputs, users, and people/organisations accessing the Data Store and Platform which creates additional considerations for data security and management, and ensuring it is being used properly ("checks and balances"). 7 votes	The number and types of corporations who have been contracted to build and implement the Data Store and Platform, along with uncertainties related to the contracts themselves and the procurement processes, may lead to the commercial use of records, uses for commercial gain, and potential misuse. 10 votes	The misuse of COPI regulations which were only intended for the direct response to COVID-19 during the pandemic (not other purposes) is a reason to oppose the initiative. 6 votes

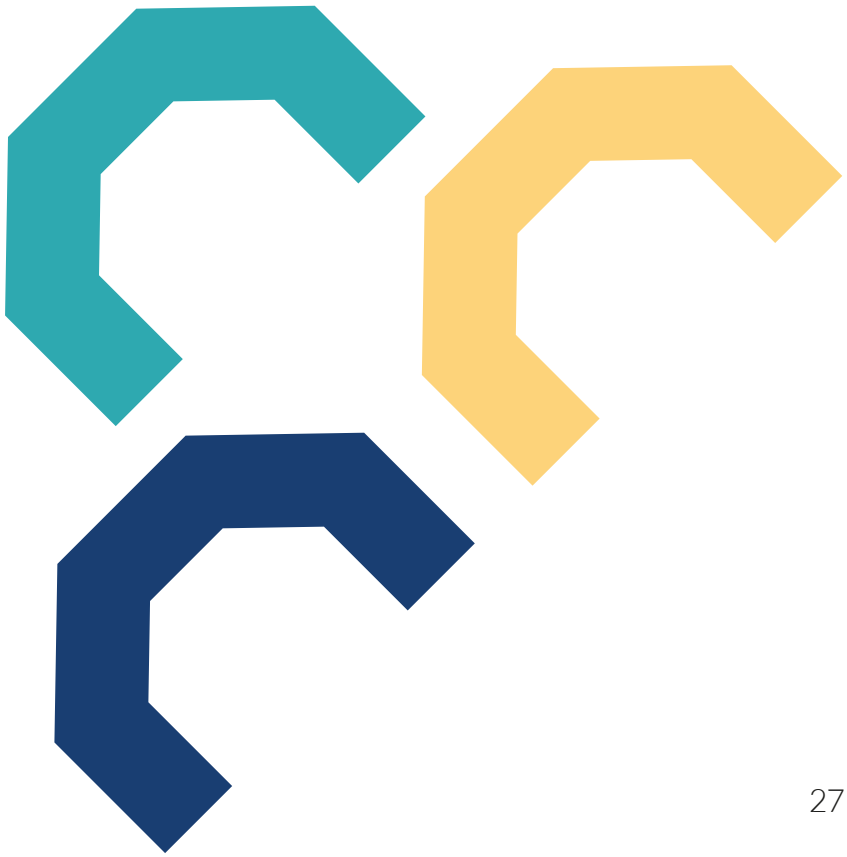
Jury Question 2: What should the future of the Data Sharing Initiative be?

Q2a: For how long should the initiative continue?

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
As short a time as possible	0/17	0/18	3/18	6%
Only as long as the COVID-19 pandemic continues and emergency powers are in place	3/17	8/18	5/18	30%
As long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)	14/17	10/18	7/18	58%
Something else	0/17	0/18	3/18	6%

Jurors recorded free-text reasons for their votes. Some said the Data Store and Platform should continue if valuable for improving data integration in the health and social care system (n=18). However, jurors wanted clearer governance and legal frameworks (n=16) and to improve the transparency of the initiative (n=13). Some wanted an evaluation and review of the initiative before it should be allowed to continue (n=8) and others thought the Data Store and Platform should sit within NHS Digital (n=6).

Of those answering "something else", all three jurors requested that the public are informed before the initiative is continued with two saying the initiative first needs to be reviewed.



Q2b: By whom should these decisions be made?

Most jurors wanted decisions about the future of the NHS COVID-19 Data Store and Platform data initiative to be made by an independent advisory group and/or Parliament.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
An independent advisory group of experts and lay people	3/17	11/18	8/18	42%
The minister or organisation accountable for the data initiative	0/17	2/18	2/18	8%
Parliament	11/17	4/18	2/18	32%
Someone else	3/17	1/18	6/18	19%

Jurors again recorded free-text reasons for their votes. Parliament was seen as necessary to ensure legal frameworks were applied (n=28). However, many felt a cross-party/ independent group, comprising of independent experts and laypeople, would be preferable to reduce political bias (n=18).

Of those answering "someone else", seven jurors wanted a combination of an independent advisory group before going to parliament for the final decision. Two jurors wanted input from all the listed groups, and two wanted input from the data controllers (NHS England, NHS Digital) with parliamentary oversight.

Q2c: How could or should the initiative and its uses be usefully changed in the future (if at all)?

Free-text answers were provided for this question (Q2c) and for Q2d below. The juries did not vote to prioritise their answers; a full set of answers is provided within the three Jurors' Reports.

To improve the Data Store and Platform in the future the jurors wanted improved transparency about how patients' data is being used and by whom (including third-party companies) (n=12). Some jurors sought a review of the information governance, Data Protection Impact Assessments and privacy notice post-COPI notices to ensure that the initiative is lawful and secure (n=9). Communication with the public about the initiative and the opt-out option was also raised (n=6) alongside a suggestion of the Data Store and Platform being incorporated into NHS Digital (n=3).

Q2d: What actions, if any, could be taken to engender greater public trust in the initiative?

Jurors felt that increased transparency and communication with the public (n=22) in an accessible and engaging way about who has access to data and for what purposes (n=12) would help engender public trust in the Data Store and Platform initiative. There were some individual suggestions including public consultation on the initiative, moving data to a trusted environment (NHS Digital), and setting up an independent governing body.

The Early Warning System and Immunisation and Vaccination Management Capability sub-case studies

The COVID-19 Data Store and Platform and its future is one of three data sharing initiative case studies considered by the citizens' juries. In addition, two products within the NHS COVID-19 Data Store and Platform were also considered as sub-case studies by the three 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 (Imm. & Vacc. Man. Capability) used to manage the delivery of the COVID-19 vaccination programme.

The juries answered a subset of the jury questions for these sub-case studies: Q1a and Q2a. The jury questions (in italics) and answers to Q1a and Q2a are provided below.

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

Most jurors supported the decision to introduce these two data initiatives.

Multiple-choice answers	Early Warning System				Imm. & Vacc. Man. Capability			
	Jury 1	Jury 2	Jury 3	Overall	Jury 1	Jury 2	Jury 3	Overall
Very much in support	8/17	10/18	10/18	53%	11/17	15/18	14/18	75%
Broadly supportive	8/17	8/18	4/18	38%	5/17	2/18	2/18	17%
Neutral	1/17	0/18	1/18	4%	1/17	1/18	0/18	4%
Broadly opposed	0/17	0/18	2/18	4%	0/17	0/18	2/18	4%
Very much opposed	0/17	0/18	1/18	2%	0/17	0/18	0/18	0%

Jurors recorded reasons for their votes.

Most recognised that the Early Warning System has been essential in planning and delivering during the COVID-19 pandemic (n=42). However, there were concerns about transparency about the uses of data (for what purposes, by whom) (n=13) and jurors were unclear about how accurate the predictions and outcomes were (n=8).

Jurors overwhelmingly thought that the Immunisation and Vaccination Management Capability has successfully delivered its outcomes (n=49) in providing a quick and effective system for planning and delivering the vaccination programme. However, some jurors were not supportive of the lack of transparency about third party involvement and potential misuses of data (n=13).

Q2a: For how long should the initiative continue?

Multiple-choice answers	Early Warning System				Imm. & Vacc. Man. Capability			
	Jury 1	Jury 2	Jury 3	Overall	Jury 1	Jury 2	Jury 3	Overall
As short a time as possible	1/17	1/18	0/18	4%	1/17	0/18	0/18	2%
Only as long as the COVID-19 pandemic continues and emergency powers are in place	0/17	5/18	3/18	15%	0/17	7/18	2/18	17%
As long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)	16/17	11/18	10/18	70%	16/17	10/18	12/18	72%
Something else	0/17	1/18	5/18	11%	0/17	1/18	4/18	9%

Jurors again recorded the reasons for their votes.

Jurors recognised that the Early Warning System could have utility in planning for future pandemics (n=12) and other priorities within the health and care system (such as during flu season) (n=21). There were concerns about the involvement in third-party companies and data privacy (n=10) and some jurors wanted a review of the initiative to improve transparency and legal frameworks (n=17). Eight jurors felt that the Early Warning System should not continue beyond the pandemic due to these concerns. Some suggested that a new in-house system should be created, ensuring proper regulatory measures, for future use (n=4). Of those answering "something else", three jurors thought the Early Warning System should only continue as long as there is total transparency with the public, and that there is an evaluation and review (n=2). Two jurors thought the decision about time should be based on national figures to determine the end of the pandemic.

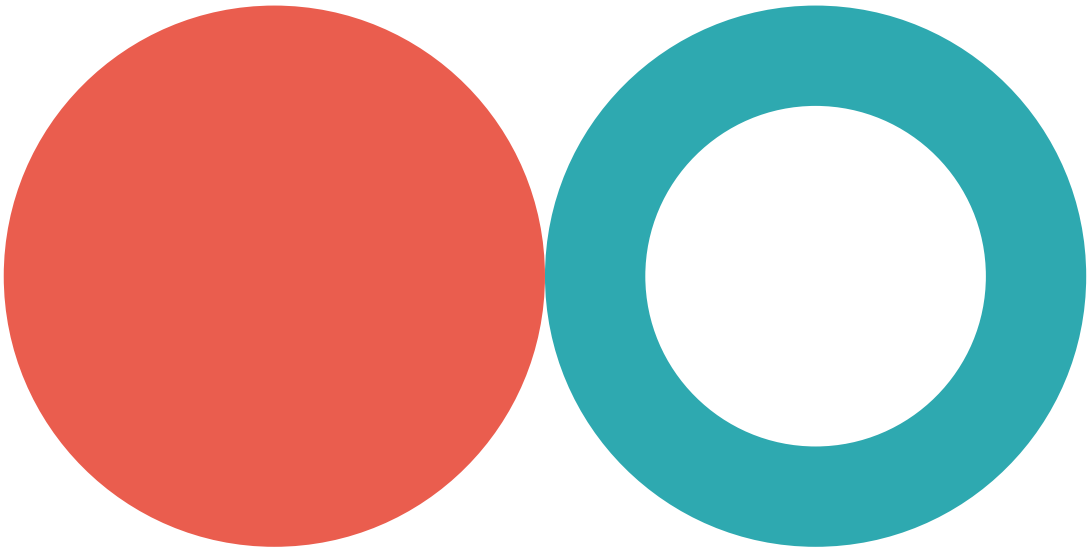
The jurors explained that they could see the Immunisation and Vaccination Management Capability as useful for future pandemics and vaccination programmes (eliminating the need to 'reinvent the wheel') (n=28). However, some jurors also wanted an evaluation and review of data sharing practices during the pandemic (n=13) and that this should happen through parliament (n=11). Others felt that the Immunisation and Vaccination Management Capability should be for emergency use only (n=6). Of those answering "something else" re the future of the Immunisation and Vaccination Management Capability, three jurors said that there needs to be greater transparency with the public about the initiative before it continues. Two jurors thought it should continue if an evaluation can show benefit.

Data Initiative 3: OpenSAFELY

OpenSAFELY is a software platform used for analysing health data that was created at the start of the pandemic as a collaboration between the University of Oxford, the London School of Hygiene and Tropical Medicine, NHS England and TPP (an electronic health records provider). OpenSAFELY was initially developed for COVID-19-related research using patient data accessed from GP patient records. The normal data controller for GP patient records is the general practice, and so under data protection law any processing of GP patient records should be by, or on behalf of, that practice. Following the 2020 COPI Notice requiring general practice to share data for COVID-19 purposes, NHS England has acted as a data controller approving applications by researchers to write and run analysis queries against the data to output only aggregate summary results (satisfying COVID-19 research questions like "what percentage of people who died within 28 days of testing positive for COVID-19 had diabetes?"). Only anonymised output data is visible to the researchers. Initially these software queries could access records from practices using TPP, and now can also access records from EMIS, another electronic health records provider (together representing approximately 95% of GP registered patients in England).

As OpenSAFELY is a software platform, it could be deployed for other research purposes and to access data other than GP patient data. However, the pandemic data sharing initiative considered by the juries was limited to the use of OpenSAFELY to access GP records, as currently done under the direction of NHS England. That access is lawful because of the temporary 2020 COPI Notice. NHS England would like the research being carried out using GP record access through OpenSAFELY to continue under a firmer legal footing. The data collected and the tools created have substantial potential value beyond the pandemic, and the jury questions explore how supportive the juries were of the initiative and its use beyond the pandemic. Before answering these questions, the jurors heard from witnesses providing background information about the initiative and arguments for and against it continuing into the future.

The jury questions are shown below in italics followed by jury answers for the OpenSAFELY data initiative.



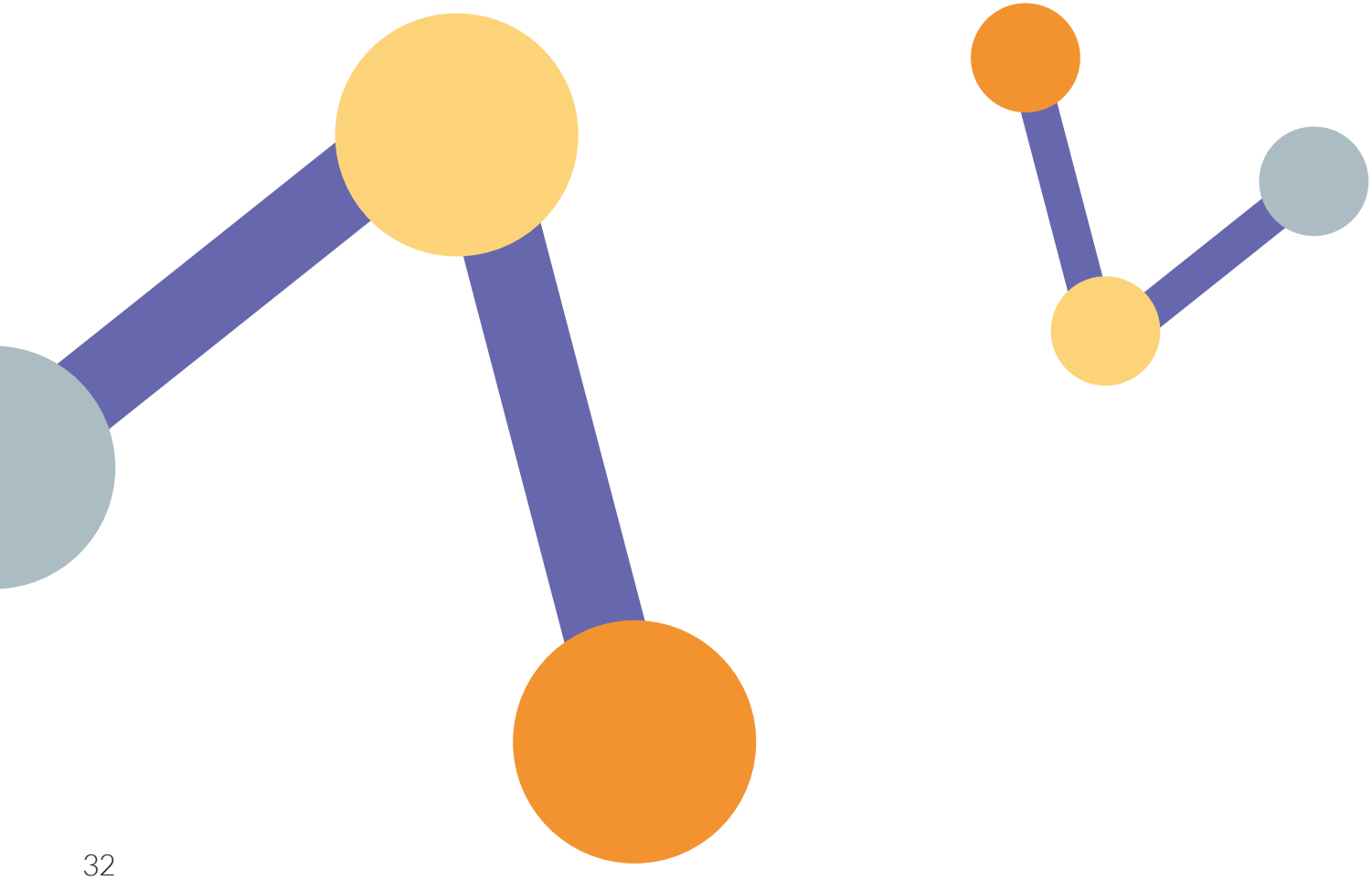
Jury Question 1: Support for the OpenSAFELY Data Initiative

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

Most jurors supported the introduction of the OpenSAFELY data initiative.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
Very much in support	11/17	14/18	16/18	77%
Broadly supportive	6/17	4/18	2/18	23%
Neutral	0/17	0/18	0/18	0%
Broadly opposed	0/17	0/18	0/18	0%
Very much opposed	0/17	0/18	0/18	0%

Jurors recorded free-text reasons for their votes. Many said they considered OpenSAFELY to be the most transparent (n=16), trustworthy, and secure (n=18) of the three data sharing initiatives. Some said that OpenSAFELY was designed and managed by an impartial credible group (n=13) who had an ethical approach to data that allowed rapid research (n=12) that was fundamental to the response to the pandemic (n=15).



Q1b. What are the most important reasons to be supportive?

Jurors deliberated together, identifying reasons to be supportive of the OpenSAFELY data initiative (whether or not as individuals they were supportive), and then voted to identify the most important reasons (up to three votes per juror). The three most important reasons expressed in the jurors' words are given below; a full set of reasons appears in the Jurors' Reports.

Jury 1 reasons to support	Jury 2 reasons to support	Jury 3 reasons to support
OpenSAFELY was developed by doctors, funded by Wellcome Trust grants, and is not currently reliant on commercial funding. The initiative is therefore, by its design, more transparent and accountable as opposed to an initiative created by a commercial third party. 14 votes	OpenSAFELY is more transparent than other initiatives as they have actively engaged with the media and public and are using a variety of methods (social media, a website, video and other materials) to inform the public. 14 votes	It is a software platform that doesn't require the moving or downloading of data, so data cannot be edited or copied and researchers do not need to access the data in order to analyse it, ensuring confidentiality and minimising usage of sensitive information and maximising safety and security. 17 votes
The initiative provides quick and regular reports about data that can help decision makers, and has helped to inform NHS policy, such as the vaccination programme priority and shielding list. 12 votes	OpenSAFELY is able to access 95% of patient records in order to provide quick responses to research queries which can lead to rapid findings, reliable (continuously updating) statistics, better research in the future, and benefits to our health system. 14 votes	Its data operation has been well-documented in the public domain, public concerns have been considered, opt out information is provided (where applicable), and most of the "Five Safes" of the ONS are met. 12 votes
The initiative does not transfer or store data, meaning we do not have another platform holding vast quantities of data and the accompanying risk of it being leaked. 7 votes	OpenSAFELY protects against misuse of the retrieved data via multi-level access, audit trails, publishing of code and no direct downloading or accessing of the data and publishing outputs (all of which is reviewed every three months). 13 votes	The data has had a critical impact on our response to the pandemic (used to conduct research that has directly influenced the critical response to the current pandemic especially with the vaccination programme). 9 votes

Q1c. What are the most important reasons to oppose the initiative?

Jurors deliberated together, identifying reasons to oppose the OpenSAFELY data initiative (whether or not as individuals they were opposed to it), and then voted to identify the most important reasons. The three most important reasons expressed in the jurors' words are given below; a full set of reasons appears in the Jurors' Reports.

Jury 1 reasons to oppose	Jury 2 reasons to oppose	Jury 3 reasons to oppose
Aside from the current COPI regulations, the legal basis and governance is unclear / not fully established. 8 votes	Current legal basis (COPI notices) expires in September 2021 and it is unclear how OpenSAFELY will operate in the future (beyond the pandemic), and under what lawful basis it will do so, once current notices expire and if access to records changes for the remainder of its planned 3-year duration. 15 votes	There is not clarity about the future of the initiative (e.g. when it may run out of funding, what changes may be in store for the future, its uses post-COVID). 13 votes
The data accessed by OpenSAFELY could instead be managed and accessed by NHS Digital. 8 votes	Current decision making (eg research decisions under the authority of the Chief Medical Officer) and governance model potentially exposes the research to significant bias and reduces transparency. 11 votes	At present, OpenSAFELY does not have a legitimate lawful basis to extend the work they are currently doing beyond the pandemic period and its applicability does not at present include non-COVID-19 related matters. 12 votes
OpenSAFELY does not provide the opportunity for the public to opt-out; considering the large data pool, the option to opt-out should not significantly affect the statistical analysis of those seeking to do data assessment. Furthermore, it is unclear whether patients will be given the opportunity to opt-out post-COVID-19. 6 votes	Although OpenSAFELY did respect patients who opted out in their GP records, patients were not given an explicit opportunity to opt out of this specifically (meaning patients didn't actively give permission for their data to be used for COVID-19 research). 10 votes	OpenSAFELY only covers the GP records and not the bigger picture (e.g. PPE supply). – 7 votes

Jury Question 2: What should the future of the Data Sharing Initiative be?

Q2a: For how long should the initiative continue?

Most jurors wanted the OpenSAFELY initiative to continue as long as it is valuable.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
As short a time as possible	0/18	0/18	0/18	0%
Only as long as the COVID-19 pandemic continues and emergency powers are in place	1/17	1/18	0/18	4%
As long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)	16/17	16/18	14/18	87%
Something else	0/17	1/18	4/18	9%

Jurors recorded free-text reasons for their votes. Many said that OpenSAFELY had the potential to be a useful platform for the wider health and social care system (n=19), providing a secure and transparent system (n=13) that can provide responsive research for decision-makers (n=14). However, jurors did feel there was a need for a review and evaluation of the initiative to understand best practice and clarify the legal framework (n=18).

Of those answering "something else", three jurors thought that the data initiative should continue once a legal basis is established, and the public informed (n=2). One juror thought OpenSAFELY should be commissioned as a backup for government data research.

Q2b: By whom should these decisions be made?

Most jurors wanted decisions about the future of the OpenSAFELY data initiative to be made by an independent advisory group or someone other than the minister or organisation accountable for the data initiative.

Multiple-choice answers	Jury 1 (votes/jurors)	Jury 2 (votes/jurors)	Jury 3 (votes/jurors)	Total across 3 juries
An independent advisory group of experts and lay people	7/17	15/18	3/18	47%
The minister or organisation accountable for the data initiative	0/17	1/18	4/18	9%
Parliament	7/17	0/18	3/18	19%
Someone else	3/17	2/18	8/18	25%

Jurors again recorded free-text reasons for their votes. Many recognised that parliament needs to have the final decision on OpenSAFELY to have proper regulatory and legal processes in place (n=17). At the same time, there was a desire to have an impartial group separate from any political or commercial bias (n=16), and some jurors felt that an independent group would be better placed given that this data initiative is external to NHS England (n=13).

Of those answering "someone else", eight jurors believed decisions should be made by a combination of an independent advisory group to guide parliament to make the necessary regulatory decisions. Three jurors highlighted the need for better public communication. Three individual suggestions were: that the organisation in combination with data controllers and parliament should make the decision; that OpenSAFELY as an independent organisation does not need parliamentary involvement; and that the Chief Medical Officer should make decisions.

Q2c: How could or should the initiative and its uses be usefully changed in the future (if at all)?

Free-text answers were provided for this question (Q2c) and for Q2d below. The juries did not vote to prioritise their answers (due to limited time in the process); a full set of answers is provided within the three Jurors' Reports.

For OpenSAFELY to improve in the future the jurors stated that there should be a review of the initiative that involved scrutiny and sorting out approvals to continue post-COPI (n=8). Sharing of expertise, and working, with NHS Digital was also highlighted (n=7). Other suggestions were to improve transparency by publishing any contracts with government and publishing results in a way that is accessible to the public (n=5).

Q2d: What actions, if any, could be taken to engender greater public trust in the initiative?

Jurors felt there could be further public engagement and communication in an accessible form about what OpenSAFELY has been doing to engender trust (n=12). Additionally, a full published review of OpenSAFELY once the COPI notice expires (n=5) was considered important alongside more accountable governance (legal framework and broader oversight board) (n=7).

Jury Question 3: What lessons can we learn from how these pandemic data initiatives were introduced?

After having heard the evidence about all of the data sharing initiatives, the juries were asked to reflect on what general lessons could be learned for the future. The jurors deliberated together about this in small groups and put forward their individual suggestions. The lessons that follow were derived through content analysis carried out after the juries.

Q3a: What lessons can we learn from how these pandemic data initiatives were introduced which could be useful for future pandemics?

The main learning for future pandemics was the public need to be engaged and informed about the actions that are taken under COPI notices (n=31) including clear guidance on opting in and out of data sharing (n=7). A review about what happens with the data collected during the pandemic, what will happen to it post COPI and creating proper regulations was proposed (n=17). More broadly some jurors believed that the country should be better prepared for future events by having proper funding of the NHS, better integration of data, and agreed regulatory frameworks (n=7).

Q3b: What lessons can we learn from how these pandemic data initiatives were introduced which could be useful outside of pandemics?

The jurors thought it was important to use the learning from these initiatives to develop secure joined-up data storage arrangements for future planning and patient care (n=22). Many could see the utility of adopting the initiatives for other purposes within the wider health and social care system (n=18). To do this, the public should be better engaged around their data rights to improve trust and transparency (n=15).

Common themes and differences between the three juries

Some common themes – evident in their voting and reasoning – emerge from across the three juries. However, there were some notable differences in the views expressed by the different juries. Some common themes and differences are shown in the tables below.

Common Themes	Jury 1	Jury 2	Jury 3
Overall, all three juries were either "very much in support" or "broadly supportive" of the introduction in 2020 of all three data initiatives and the two sub-case studies	Average support 95%	Average support 94%	Average support 89%
All three juries had more jurors "very much in support" of OpenSAFELY than for the other initiatives	65%	78%	89%
Overall, all three juries were in favour of each of the three data initiatives and the two sub-case studies continuing "as long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)"	Average 92%	Average 63%	Average 61%
All three juries opposed decisions about the future of the three initiatives being made by the minister or organisation accountable for the initiative	Average support 0%	Average support 6%	Average support 13%
All three juries cited lack of transparency as the most important reason to oppose the Summary Care Record Additional Information and the Data Store and Platform data initiatives	Average 14.5 votes	Average 16 votes	Average 17.5 votes

Notable Differences between Juries	Jury 1	Jury 2	Jury 3
Jury one was more supportive of the NHS COVID-19 Data Store and Platform continuing "as long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)" than the other two juries	Average 82%	Average 56%	Average 39%
Jury two was substantially more supportive of decisions about the future of the data initiatives being made by an independent advisory group of experts and lay people making decisions than the other two juries (although when account is taken of those answering "someone else", the differences are less marked as many of those jurors want an independent advisory group involved).	Average 30%	Average 80%	Average 35%

Jury questionnaire results

All jury members completed a daily feedback questionnaire at the end of the first seven jury days. When asked whether staff were conducting themselves in a neutral manner, over 99% of responses from jurors from all three juries over the seven days were either "very satisfied" or "satisfied". Participants also responded each day on whether they agreed that they were being allowed to fully participate in the process. Satisfaction rates were again very high. There was little variation found across the three juries. Full details of end-of-day feedback questionnaires have been published.

The jurors completed a fuller evaluation questionnaire at the end of the jury. Again, there was very little variation in end-of-jury questionnaire responses across the three juries. The full questionnaire design and the results have been published. One question in the end-of-jury questionnaire concerned bias in evidence:

"You heard evidence to both support and be concerned about the data sharing initiatives and their future. Overall, how fair a balance of evidence do you feel you heard over the two weeks?"

Multiple-choice answers	% for all juries
Overall I felt there was a fair balance of evidence	91% (48/53 jurors)
Overall there might have been some bias towards support for the data sharing initiatives	6% (3/53 jurors)
Overall there might have been some bias towards concern about the data sharing initiatives	2% (1/53 jurors)
I sometimes thought there was some bias but there was no pattern across the initiatives	2% (1/53 jurors)

The other main questionnaire questions and answers, each of which offered a spread of multiple choice answers on a Likert scale, are summarised in the table below.

End-of-jury questionnaire multiple-choice question	Response 1 (% all juries)	Response 2 (% all juries)	Other responses %
How interesting did you find the jury process?	Very interesting 96% (51/53 jurors)	Mostly interesting 4% (2/53 jurors)	0%
How easy or difficult did you find doing the jury remotely and online?	Very easy 85% (45/53 jurors)	Mostly easy 15% (8/53 jurors)	0%
Did you ever feel that the jury facilitators (Kyle and Sarah) or other organisers tried to influence you towards particular conclusions?	Not at all 100% (53/53 jurors)	Perhaps occasionally 0%	0%
There were researchers observing your group work. To what extent did this interfere with you participating fully (if at all)?	Not at all 98% (52/53 jurors)	Perhaps occasionally 2% (1/53 jurors)	0%
Excluding the research observers, did you feel you were encouraged to participate in the process?	Very much encouraged 94% (50/53 jurors)	Mostly encouraged 6% (3/53 jurors)	0%

In another question, each jury member was asked to provide three words to sum up their experience of the jury. The words of the members of all three juries are constructed into a "word cloud" below (large words were said more often).

"Word cloud" of jurors' experience of the citizens' jury (all three juries)

Appendix 1: Further information about the juries

The Citizens' Jury Method

Like much public policy, assessing major data sharing initiatives is complex with a lot of information and many arguments to consider. Surveys and focus groups provide useful information about what the public thinks, but they are not mechanisms to inform people. A citizens' jury can tell policymakers what members of the public think once they become more informed about a policy problem. In a citizens' jury, a broadly representative sample of people are selected to come together for a period of days, hear expert evidence, deliberate together, and reach conclusions about questions they have been set. The method was devised by Dr Ned Crosby in 1971. He went on to set up the Jefferson Center, which produced the Citizens' Juries Handbook[4], the method followed by Kyle Bozentko and Sarah Atwood of the Center for New Democratic Processes (formerly Jefferson Center) when designing and running these three juries in partnership with Citizens Juries ci.c.

Citizens' Juries are a form of "deliberative democracy", based on the idea that individuals from different backgrounds and with no special prior knowledge or expertise can come together to discuss and answer a public policy question. A citizens' jury is a particularly relevant method for informing public bodies making value judgements. Melbourne City Council appointed a citizens' jury to determine how to allocate its A$5 billion budget, and the council is implementing virtually all of the jury's recommendations. A Citizens' Assembly (the same method but with more participants than a citizens' jury) was commissioned by the Irish government on whether to change the Irish Constitution on abortion recommended change, leading directly to the national referendum on the subject. Mostly citizens' juries or assemblies inform policy decisions, although there are examples of these bodies being constituted to make decisions.

Jury recruitment

The table below summarises numbers of people applying, recruited to, and completing the juries.

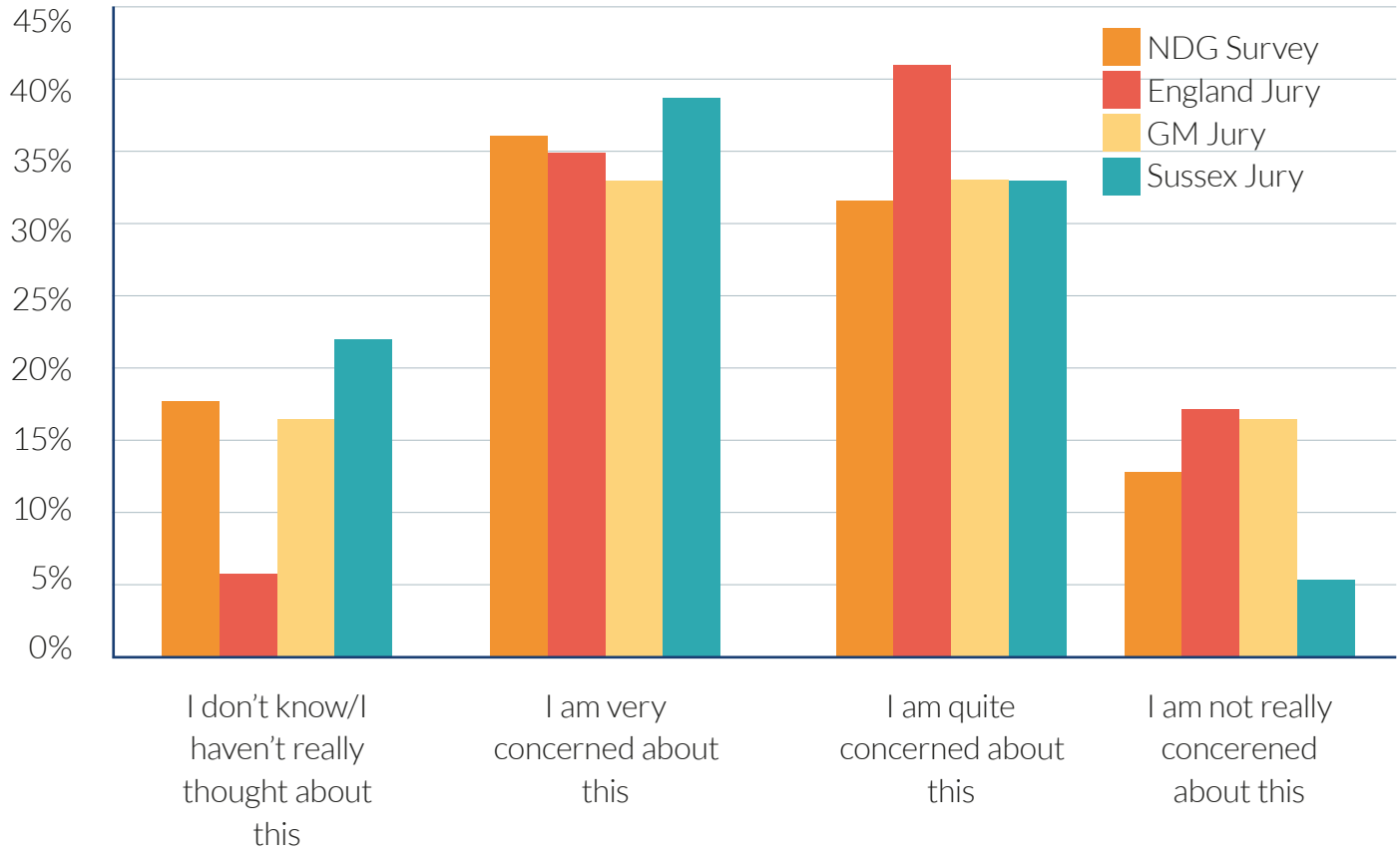
	Jury 1: Jurors from across England	Jury 2: Jurors from across Greater Manchester	Jury 3: Jurors from across West and East Sussex
Number of valid applicants	1,263	729	597
Number selected	18 jurors, 3 reserves	18 jurors, 3 reserves	18 jurors, 3 reserves
Number completing the jury	17	18	18

People applied by entering their personal details, including relevant demographics, into an on-line survey. Candidates were shortlisted based on their demographics using an algorithm supplied by the Sortition Foundation. The algorithm randomly selected a group of potential jurors for each jury that

broadly represented the demographic mix of England (according to the 2011 census) including age, gender, ethnicity, educational attainment, employment status and whether rural/suburban or urban. In addition, for jury one, the algorithm used an additional variable so that a good geographical spread of participants from different regions of England was selected. In 2020, Greater Manchester (the jury two population) had relatively high levels of COVID-19 infection. West and East Sussex was selected as the population for jury three because, in contrast, it had relatively low levels of infection in 2020, especially in rural areas. A majority of jurors recruited in West and East Sussex self-reported as living in a rural area so as to provide this contrast with urban Greater Manchester.

To reduce the risk that a particular jury held unrepresentative views about health and care data sharing, jury applicants also answered, and were selected using, an attitudinal question. The question had been asked in a national survey commissioned by the Office for the National Data Guardian for Health and Social Care (NDG) . Jurors were recruited so that a jury reflected a broadly similar spread of views to that reported from the national NDG survey. The multiple-choice NDG survey question is shown below, followed by a bar chart with the NDG survey results for 2,114 adults in England plus the breakdown of answers provided by the members of the three juries.

Thinking about your confidential NHS and social care information, please indicate how concerned you are about ... Data being shared unlawfully or accidentally with organisations outside of the NHS and care system."



Some jurors were recruited by email or word of mouth, but the majority came through advertising on the "Indeed" jobs website. In order to guard against bias from using a job website, jury selection was controlled for employment status to ensure the majority was employed or self-employed, and no more than two people per jury were unemployed.

Five jurors were lent a laptop so they could participate in the jury, and all participants had at least one face-to-face Zoom session to help them with technology to be used in the jury. Note however that advertising through an online website and running online citizens' juries is likely to attract people who are more technologically capable than average and will exclude some people from taking part in the juries due to digital inequalities.

Each juror was paid £480 for eight afternoons (1pm to 5.30pm with breaks). Paying participants is an important way to limit self-selection bias. Three reserves for each jury were paid to participate for up to two days in case a juror withdrew (none was needed for jury one, one for jury two, and two for jury three).

Shortlisted candidates had a brief Zoom or telephone interview so that any ineligible candidates (e.g. current NHS professionals) could be identified and excluded, and that jurors had the capability to connect to Zoom. Five participants across the three juries were lent a laptop. Prior to the juries, every juror and reserve had a short induction session on Zoom with Sarah Atwood from the Center for New Democratic Processes. The main purpose of this was to introduce jurors to Zoom and other tools to be used during the online jury.

The jury process and jurors' reports

All three juries met for eight afternoon sessions (1pm to 5.30pm with breaks). Each one addressed the same set of jury questions following the same jury questions and:

- The same two facilitators: Kyle Bozentko and Sarah Atwood of the Center for New Democratic Processes (formerly the Jefferson Center)
- The same 11 expert witnesses giving the same presentations (a video was recorded in jury one and played to juries two and three) and answering jurors' questions;
- The same process (including regular group exercises and deliberation);
- Completing the same End-of-jury questionnaire, and
- Each developing an individual Jurors' Report in the jurors' words on day eight.

Each jury met on Zoom primarily in private to protect the identity and privacy of jury participants from people recording and publishing their images and voices through the internet. For this reason, the transparency of the jury design and process is particularly important. Many details about the jury, including the expert witness slides, are published.

The jury process had to be designed to work effectively online and reduce tiredness amongst jury participants with for example:

- Shorter jury days than usual – 4.5 hours per day;
- Frequent breaks;

- Limits on the number of external observers, each of whom agreed in advance not to record or share electronically any of the proceedings, and who introduced themselves to the juries and then watched the witness presentations and question and answer sessions;
- Support for those who had difficulty using the technology or who suffered from weak internet connection.

An overview of what happened on each of the eight days of the jury process is provided in Appendix 3. Each jury was run Tuesday to Friday, and then from the following Monday to Thursday. Witness presentations and question and answer sessions with witnesses were held in plenary. Jurors deliberated together in small Zoom breakout groups (typically three groups of six people). Group membership was mixed through the week. Jurors recorded their own notes and reasoning using Google Docs and answered jury questions through Surveymonkey surveys.

The same set of jury questions were asked and answered for each of the three main data sharing initiatives after:

- hearing presentations from, and asking questions of, expert witnesses:
  - three background witnesses on jury day one and two, including an introduction to help jurors understand patient records and relevant law
  - For each data sharing initiative:
    - Witness(es) explaining what each data initiative is, its reliance on temporary regulations brought in for the pandemic, and why the initiative is valuable now and in the future
    - A witness challenging the data initiative (Phil Booth from medConfidential), providing reasons to be cautious about it now and in the future
- jurors deliberating together in small groups.

In addition, on day five of the juries, two sub-case studies about NHS COVID-19 Data Store and Platform products (the Early Warning System, and the Immunisation and Vaccination Management Capability) were considered. Jurors went through a similar process to that described above for the three data initiatives but answered a subset of jury questions: Q1a and Q2a.

Each jury produced a Jurors' Report. Each report contains the jury's answers to the questions they were posed as well as reasoning expressed in the words of the jurors, using the outputs of the group work over the two weeks. It was collated by the jury facilitators. On the final day of the jury, the jurors were led page-by-page through an early draft version of their report, which was displayed to the group on Zoom, to gain the jurors' acceptance that it fairly represented their work and conclusions. After each jury, the report was compiled and formatted, sent to the jury members, and the final version readied for publication by Citizens Juries c.i.c. without external review.

Independent researchers from the University of Manchester observed the jury process, taking field notes. This included both the plenary sessions with expert witnesses and small group work. Two researchers were observing throughout, each one able to watch one of the three groups. The field notes will be analysed and used in one or more future academic papers.

Witnesses

Expert witnesses were chosen to provide relevant information to the members of the juries to enable them to answer the jury questions. Each witness gave a presentation to jury one (national) which was recorded and played to juries two and three. They attended all three juries so that they could answer questions posed by the jurors.

The expert witnesses were issued with a brief prior to preparing their presentations. The brief for expert witnesses is published here. The witness slides were reviewed in advance to check they met the brief and for potential bias by the oversight panel. The panel identified whether changes were "required" or "advisory". All "required" changes, and most "advisory" changes, were made prior to the start of the jury.

Jury Day	Witness presentation topic	Witness
1	What are patient and care records and how are they used?	Dr Alan Hassey, GP (retired)
2	a) What are the normal rules for using and protecting patient records? b) How did the normal rules change for the pandemic? c) Planning for pandemics	a) Peter Singleton, Cambridge Health Informatics b) Peter Singleton, Cambridge Health Informatics c) Prof David Harper, Chatham House
3	a) Summary Care Record Additional Information b) Summary Care Record Additional Information	a) Dr Robert Jeeves, GP Clinical Lead, NHS Digital (part 1) and John Farenden, Senior Programme Lead, Shared Records Programme, NHSX (part 2) b) Phil Booth, Co-ordinator, medConfidential
4	a) NHS COVID-19 Data Store and Platform b) NHS COVID-19 Data Store and Platform	a) Ming Tang, Chief Data and Analytics Officer, NHS England and NHS Improvement (parts 1 & 2) b) Phil Booth, Co-ordinator, medConfidential
5	a) Early Warning System b) Early Warning System c) Immunisation and Vaccination Management Capability d) Immunisation and Vaccination Management Capability	a) Ed Kendall, Deputy Director for Economics (part 1) and Dr Harrison Carter, National Medical Director's Clinical Fellow (part 2), both from NHS England and NHS Improvement b) Phil Booth, Co-ordinator, medConfidential c) Ayub Bhayat, Director of Insights and Data Platform Capability, NHS England and NHS Improvement (parts 1 & 2) d) Phil Booth, Co-ordinator, medConfidential
6	a) OpenSAFELY b) OpenSAFELY	a) Jess Morley, Policy Lead, University of Oxford's DataLab (parts 1&2) b) Phil Booth, Co-ordinator, medConfidential

The oversight panel

The oversight panel was appointed by Citizens Juries c.i.c. to help monitor and minimise bias. The panel reviewed the design of the citizens' juries, and all the slides from the presentations by the expert witnesses. Issues identified by the panel were marked as either "advisory" or "required" and fed back to presenters resulting in changes to these materials where appropriate. The three oversight panel members, chosen for their lack of conflict of interest in any particular jury outcome, were:

- Dr Christine Patch, Caldicott Guardian for Genomics England;
- Rachel Thompson, Research Associate in information governance, ethics and public involvement in population data-based research, Swansea University;
- Katharine Wright, Assistant Director, Nuffield Council on Bioethics.

The brief for the oversight panel is available here. Members of the panel each completed a bias evaluation form after the jury, published here. Using a four point Likert scale ("fully satisfied"/ "mostly satisfied"/ "partially satisfied"/ "not satisfied") the oversight panel evaluation results were:

- three out of three panel members were "fully satisfied" that the design materials were designed with the aim of minimizing bias
- two out of three panel members were "fully satisfied" that the citizens' juries were successfully designed to minimise bias, with one person "mostly satisfied".

Citizens' jury project team and commissioners

The project manager was Malcolm Oswald, Director of Citizens Juries c.i.c. and an Honorary Research Fellow in Law at The University of Manchester. He worked closely with the jury commissioners, the jury facilitators, oversight panel, and expert witnesses. Kyle Bozentko, Executive Director of the Center for New Democratic Processes (formerly Jefferson Center) and his colleague Sarah Atwood led the jury design process and facilitated all three juries. Chris Barnes and Amanda Stevens recruited and supported the jurors.

The juries were commissioned and paid for by:

- NIHR Applied Research Collaboration Greater Manchester;
- NHSX;
- The Office of the National Data Guardian for Health and Social Care.

Dr Sabine Van Der Veer and Prof Niels Peek of the University of Manchester (the main commissioning organisation) worked closely with Malcolm Oswald and others to initiate and develop the juries. A Juries' Commissioning Group oversaw the project and particularly the setting of the jury questions. It comprised representatives from the three funding bodies above (Prof. Nicky Cullum, Olly Carr and John Carvel respectively) plus Emily Jesper-Mir from the Wellcome Trust's Understanding Patient Data and Reema Patel from the Ada Lovelace Institute. Malcolm Oswald provided four-weekly highlight reports to the Juries' Commissioning Group.

Appendix 2: The Jury Questions

The jury was tasked with responding to a number of questions set out below. The jury was designed to prepare, inform and otherwise enable the jurors to provide reasoned answers to these questions.

The three citizens' juries will all consider the same questions.

The juries will consider three pandemic data initiatives which were introduced or substantially changed in response to COVID-19:

- Summary Care Record (which was extended to include more data about patients during the pandemic)
- NHS COVID-19 Data Store (which was created in response to the pandemic)
- OpenSAFELY (which uses primary care data for research).

For each initiative, the jury will address the following questions:

1. a) How supportive are you of the decision to introduce this data sharing initiative in 2020 as part of tackling the COVID-19 outbreak?

   Very much in support/ Broadly supportive/ Neutral/ Broadly opposed/ Very much opposed

   b) "What are the most important reasons to be supportive?"

   c) "What are the most important reasons to oppose the initiative?"

2. What should the future of the data sharing initiative be?

   a) For how long should the initiative continue

      i. As short a time as possible

      ii. Only as long as the COVID-19 pandemic continues and emergency powers are in place

      iii. As long as it is valuable (potentially beyond the pandemic and for COVID-19 and non-COVID-19 uses)

      iv. Something else

   b) By whom should these decisions be made?

      i. An independent advisory group of experts and lay people

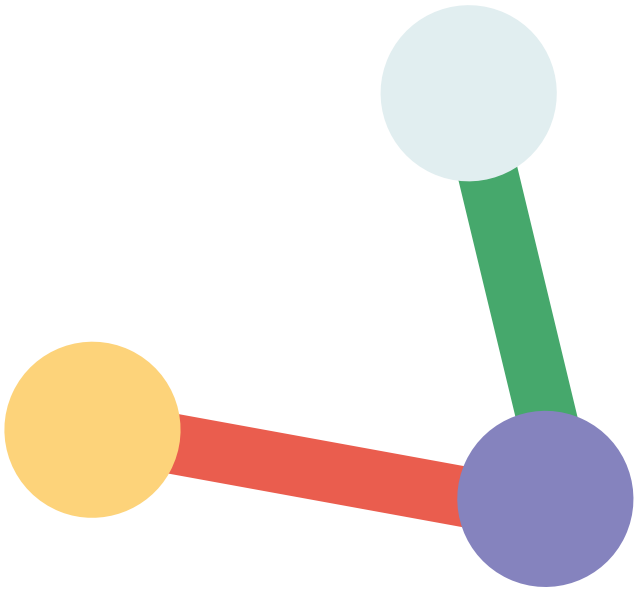
      ii. The minister or organisation accountable for the data initiative

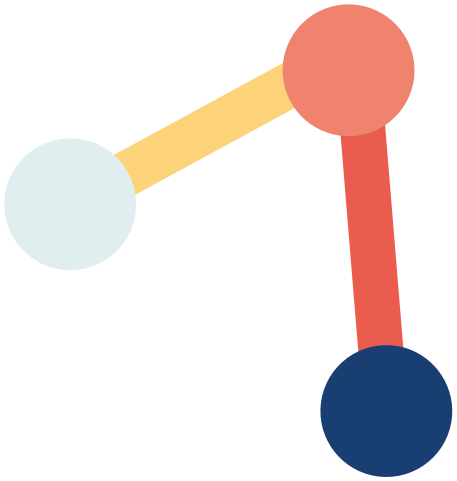
      iii. Parliament

      iv. Someone else

   c) How could or should the initiative and its uses be usefully changed in the future (if at all)?

   d) What actions, if any, could be taken to engender greater public trust in the initiative?





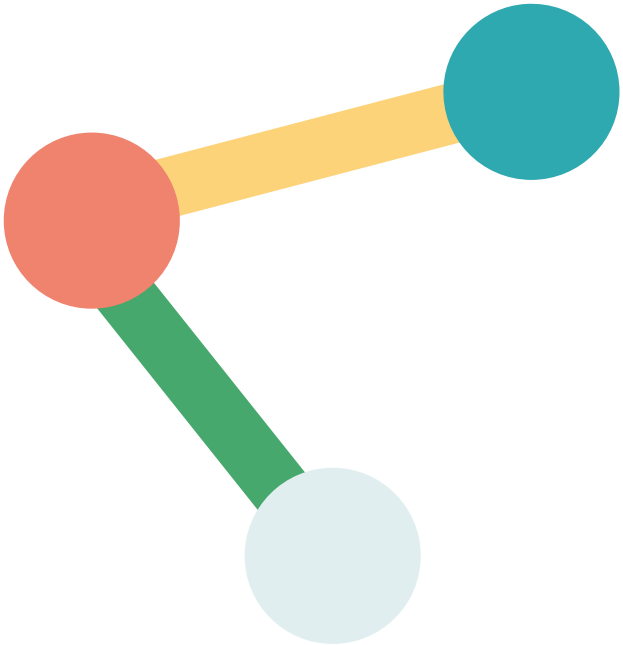
At the end of each jury, the jury will be asked:

3. What lessons can we learn from how these pandemic data initiatives were introduced
   a) which could be useful for future pandemics?
   b) which could be useful outside of pandemics?

Following discussions with NHS England and NHS X, two "sub-case studies" will be added to the NHS COVID-19 Data Store for the jury to consider. These are systems reliant on the Data Store:

- The Early Warning System
- The Immunisation and Vaccination Management (I&V) Capability.

The juries will answer two of the above questions about each of these two sub-case studies: 1 a) and 2a).



Appendix 3: The Jury Schedule of Activities

Jury Day 1, Week 1, Tuesday, 13:00-17:30

Activities	Topic	Witness
Introductions & Welcome Guidelines & Process Simulation exercise		
Witness Presentation & Q&A	What are patient and care records and how are they used?	Dr Alan Hassey, GP (retired)
Jury deliberation		

Jury Day 2, Week 1, Wednesday, 13:00-17:30

Activities	Topic	Witness
Witness Presentation & Q&A	What are the normal rules for using and protecting patient records?	Peter Singleton, Cambridge Health Informatics
Witness Presentation & Q&A	How did the normal rules change for the pandemic?	Peter Singleton, Cambridge Health Informatics
Witness Presentation & Q&A	Planning for pandemics	Prof David Harper, Chatham House
Jury deliberation		

Jury Day 3, Week 1, Thursday, 13:00-17:30

Activities	Topic	Witness
Witness Presentation & Q&A	Summary Care Record Additional Information	Dr Robert Jeeves, GP Clinical Lead, NHS Digital (part 1) & John Farenden, Senior Programme Lead, Shared Records Programme, NHSX (part 2)
Witness Presentation & Q&A	Summary Care Record Additional Information	Phil Booth, Co-ordinator, medConfidential
Jury deliberation		

Jury Day 4, Week 1, Friday, 13:00-17:30

Activities	Topic	Witness
Witness Presentation & Q&A	NHS COVID-19 Data Store and Platform	Ming Tang, Chief Data and Analytics Officer, NHS England and NHS Improvement (part 1&2)
Witness Presentation & Q&A	NHS COVID-19 Data Store and Platform	Phil Booth, Co-ordinator, medConfidential
Jury deliberation		

Jury Day 5, Week 2, Monday, 13:00-17:30

Activities	Topic	Witness
Witness Presentation & Q&A	Early Warning System	Ed Kendall, Deputy Director for Economics (part 1) and Dr Harrison Carter, National Medical Director's Clinical Fellow (part 2), NHS England and NHS Improvement
Witness Presentation & Q&A	Early Warning System	Phil Booth, Co-ordinator, medConfidential
Witness Presentation & Q&A	Immunisation and Vaccination Management Capability	Ayub Bhayat, Director of Insights and Data Platform Capability, NHS England and NHS Improvement (parts 1,2)
Witness Presentation & Q&A	Immunisation and Vaccination Management Capability	Phil Booth, Co-ordinator, medConfidential
Jury deliberation and voting	Early Warning System	
Jury deliberation and voting	Immunisation and Vaccination Management Capability	

Jury Day 6, Week 2, Tuesday, 13:00-17:30

Activities	Topic	Witness
Witness Presentation & Q&A	OpenSAFELY	Jess Morley, Policy Lead, University of Oxford's DataLab (parts 1&2)
Witness Presentation & Q&A	OpenSAFELY	Phil Booth, Co-ordinator, medConfidential
Jury deliberation		

Jury Day 7, Week 2, Wednesday, 13:00-17:30

Activities
Jury deliberation

Jury Day 8, Week 2, Thursday, 13:00-17:30

Activities
Jury Deliberation & Voting on Summary Care Record Additional Information, NHS COVID-19 Data Store and Platform, and OpenSAFELY
Finalise Jurors' Report

Appendix 4: Bibliography

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