**Citizens' juries**

**Draft brief for expert witnesses**

# General briefing for all witnesses

## Introduction

You are asked to provide evidence as an expert witness to a set of three citizens' juries commissioned and funded by the University of Manchester, NHS X and the National Data Guardian’s Office.

Between March and May 2021, three citizens’ juries, each of 18 people, will be recruited by [Citizens Juries c.i.c.](http://www.citizensjuries.org/) to broadly reflect the demographic mix of the population of England (and specifically age, gender, ethnic group, educational attainment, geographical location and employment status). The group will also be sampled to broadly match views on health data sharing from a national survey in 2020. Each jury will meet online using Zoom from 13.00 to 17.30 for eight days. They will hear evidence from a variety of expert witnesses, deliberate together and answer a set of jury questions about pandemic data sharing initiatives (set out in section 1.3). The process will be run three times with the same jury questions, facilitators, witnesses etc. but with different jury members. The dates for the three juries are:

* Jury 1: 16-19 March, 22-25 March with a cross-section of 18 jurors from across England;
* Jury 2: 6-9 April, 12-15 April with a cross-section of 18 jurors from across Greater Manchester;
* Jury 3: 27-30 April, 3-6 May with a cross-section of 18 jurors from across Sussex (especially from rural areas).

We will help people unused to online video-conferencing or who have difficulty accessing a computer.The juries will be given relevant information, and work together to answer important questions about data sharing in a pandemic (see section 1.3). The recommendations of the juries will be published and be discussed at a post-jury workshop of policymakers, academics and representatives from the juries (no date yet but perhaps June depending on Covid-19).

The online jury process will be led by skilled facilitators: Kyle Bozentko and Sarah Atwood of the Center for New Democratic Processes (formerly [Jefferson Center](http://www.jefferson-center.org)). The juries will be informed about the questions they are exploring, partly through the expert witnesses who will also use Zoom to make their presentations and answer questions posed by the jurors. Jurors will be given time to work together and deliberate amongst themselves before reaching their conclusions.

As a witness, you are asked to take part at one or more specific points in the jury proceedings (see your witness brief in section 2 below for your specific timings).

As the juries will have people with different levels of educational attainment, including people with no educational qualifications and people with university degrees, it is important that you try to explain things as simply as you can, and that you avoid acronyms and do not assume that the audience has any prior knowledge of your subject.

If you are presenting, please:

* Draw up a presentation slide pack that addresses the questions set out for your presentation in section 2 of this brief;
* Please stick closely to the brief when designing the slides (or discuss any changes you seek in advance with Malcolm Oswald)
* Try not to cover too much material
* Relate what you say explicitly to the relevant jury question(s) – see section 1.3
* Illustrate your points with examples where you can
* Take into account the information being presented by other witnesses (where identified in this briefing document)
* Avoid making factual statements where the evidence is uncertain or disputed
* Finish with a slide summarising your main points
* Stick to the information in your slides when presenting without introducing new information, as these slides are reviewed by the independent oversight panel for the juries (see below).
* Be aware that your presentations will be recorded, and that your slides and a video of the presentation will be made publicly available on the web.

The juries will hear a variety of evidence in order to reach informed conclusions about the questions they are posed about data sharing in a pandemic:

* “neutral”: informational content
* “persuasive”: content containing arguments or value judgements (this may include information which seems purely descriptive such as why sharing data is valuable but which nevertheless can have the effect of being persuasive).

Some witnesses are briefed to provide purely neutral content, some purely persuasive content, and some may be asked to provide both whilst making a clear distinction in their presentation between the two different elements.

For neutral witnesses, it is important that you confine your presentations, and answers to questions, to descriptive information rather than any value-laden claims. You should try to describe the world rather than judge it. Where the evidence is uncertain, provide an answer to the best of your knowledge, mentioning the uncertainty. But if you do not know, say so.

Persuasive witnesses are invited to make a case for a particular position without misrepresenting the facts or otherwise misleading their audience. Hearing these arguments can be useful to jurors, although the process is also designed so that jury participants use their own values and knowledge to weigh the evidence they are given.

If you have something that may be perceived as a conflict of interest, please raise this with Malcolm Oswald, and assuming this is not a barrier to you being a witness, add it as a bullet point to your introductory slide for the juries so it is declared openly.

Comments on this brief and particularly the brief relating to your specific presentation are very welcome. Please discuss these before you draw up your presentation, and then address the agreed questions in your presentation. The time allotted for each presentation is described below.

In addition to the presentation, you are also asked to answer questions posed by the jurors. Some jurors may lack confidence, so please respond positively to any question you receive. When answering questions, try to make your answers clear and concise, and if you do not know the answer to a question, please say so. To help members of the juries and observers with poor hearing, speak clearly into the standalone or computer microphone you are using. If you think you may encounter any technical difficulties with your online presentation (e.g. poor broadband, background noise), please raise this with Malcolm Oswald.

The aim is that:

* Witnesses to make a live presentation on Zoom for the first jury in March;
* A video recording of the presentation made at the March jury is played to juries 2 and 3 that begin in April
* A live question and answer session is provided by witnesses for all three juries (or failing that written questions and answers could be used if a witness was unable to take part in one of the live Q&A sessions).

## The role of the oversight panel, and the timetable for producing and reviewing your slides

**Please share your presentational material in advance with Malcolm Oswald** to give him the opportunity to bring to your attention any material which he feels is not relevant to your brief, not easy to understand or which might be considered biased. An important critique of citizens’ juries is that they could be prone to bias. For this reason, we recruit an oversight panel of three independent people who review in advance the design of the juries, and the materials that the juries will see. The oversight panel for these citizens’ juries is:

* 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.

**All slides presented to the citizens’ juries must first have been reviewed by the oversight panel.** To support this review process, and because all slides must be printed, copied, bound and posted to participants, your draft slides are needed well in advance of the start of the first jury. For presenters the timetable will be:

* By 22 February 2021: draft slides to Malcolm Oswald
* By /25 February 2021: Agree any revisions with Malcolm Oswald (e.g. by phone call)
* 4 March 2021: Oversight Panel meeting to review presenters’ slides and propose changes (to make more understandable, or prevent bias or misrepresentation)
* By 6 March 2021: slides changed to take account of oversight panel comments
* 9-11 March 2021: slides printed, copied, bound, and posted to participants.
* 16 March 2021: jury 1 begins.

## The jury questions

Your role is to help inform the juries so they may answer the following jury questions in the box below. This is particularly relevant for “persuasive” witnesses on days 3, 4, 5 and 6, all of whom are talking about the future of a particular pandemic data initiative. It will greatly help the jury if you make your arguments about the best future options relate directly to Q2, and particularly to the multiple choices in Q2a and 2b below.

|  |
| --- |
| 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](https://digital.nhs.uk/services/summary-care-records-scr/additional-information-in-scr) (which was extended to include more data about patients during the pandemic) * [NHS Covid-19 Data Store](https://www.england.nhs.uk/contact-us/privacy-notice/how-we-use-your-information/covid-19-response/nhs-covid-19-data-store/) (which was created in response to the pandemic) * [OpenSAFELY](https://opensafely.org/) (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   1. “What are the most important reasons to be supportive?” 2. “What are the most important reasons to oppose the initiative?” 3. What should the future of the data sharing initiative be?    1. For how long should the initiative continue       1. As short a time as possible       2. Only as long as the Covid pandemic continues and emergency powers[[1]](#footnote-1) are in place       3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)       4. Something else    2. By whom should these decisions be made?       1. An independent advisory group of experts and lay people       2. The minister or organisation accountable for the data initiative       3. Parliament       4. Someone else    3. How could or should the initiative and its uses be usefully changed in the future (if at all)?    4. What actions, if any, could be taken to engender greater public trust in the initiative?    5. What are the main reasons for these answers?   [Note that there are many questions above, each for several case studies, and to fit the process design into the time available may require that some or all of the answers to Q2c), d) and e) will be given by individuals rather than by the jury as a group.]  At the end of each jury, the jury will be asked:   1. What lessons can we learn from how these pandemic data initiatives were introduced    * which could be useful for future pandemics?    * 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 sub-case studies: 1 a) and 2a). |

# Briefing to individual witnesses

Every jury follows exactly the same pattern with the same witnesses presenting to a different set of 18 jurors each time. There are witness presentations on the first six days of each jury but no witness presentations on days 7 and 8. **Each jury days lasts from 1PM to 5.30PM** (with break(s) in the middle).

## Witness Presentations for Jury Day 1 (i.e. 16 Mar, 6 Apr, 27 Apr)

***Neutral* Presentation: What are patient and care records and how are they used?**

**Speaker(s): Dr Alan Hassey, GP (retired)**

**Presentation duration: 25 minutes** (followed by 20 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (list the bullet points below)
* What is a patient record[[2]](#footnote-2)?
* Why are patient records needed?
* Who makes patient records and where are they held?
* What sort of information is contained within patient records, coded and non-coded?
* How do social care records differ from patient records?
* How might patient records be used in a simple patient journey? e.g. To a GP, then a referral to outpatients, and an out-patient appointment; or when discharging a patient from hospital into a social services care home
* Outside of direct patient care, to what kinds of uses are patient records put?
* What does anonymisation of patient records mean?
* When would you use patient records that identify people and when would you use anonymised records?
* A summary of your main points

## Witness Presentations for Jury Day 2 (i.e. 17 Mar, 7 Apr, 28 Apr)

### *Neutral* Presentation: What are the normal rules for using and protecting patient records?

**Speaker(s): Peter Singleton, Information Governance Specialist, Cambridge Health Informatics**

**Presentation duration: 20 minutes** (followed by 15 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (list the bullet points below)
* Where does a patient record fit within the law, including data protection law and common law of confidence?
* How does the common law of confidence protect patients and patient records?
* When does the NHS believe it is reasonable to to disclose confidential information held in patient and social care records without explicit consent, and when is explicit consent required?
* Which records are caught by data protection law, and which are not, and how easy is it to determine?
* What rights do patients have under data protection law to access and control access to personal data in patient records?
* What national choices do patients have to opt in and out of data sharing?
* Under, data protection law, what are the main responsibilities of organisations that store and otherwise process patient records?
* How might organisations protect patient data (e.g. anonymisation)?
* In law, does anyone “own” the patient record?
* A summary of your main points

***Neutral* Presentation: How did the normal rules change for the pandemic?**

**Speaker(s): Peter Singleton, Information Governance Specialist, Cambridge Health Informatics**

**Presentation duration: 10 minutes** (followed by 10 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (list the bullet points below)
* What temporary change(s) were there to the normal data sharing rules in response to the pandemic, and did they rely on emergency powers for tackling pandemics[[3]](#footnote-3)?
* When and how were the rule changes made and how long were they originally intended to last?
* Why were the changes made, and could the data initiatives we are considering in this jury have been done without the rule changes?
* How and when have these temporary rule changes been extended (explaining “COPI Notices”)?
* Could the rules be extended in this way indefinitely (or e.g. is legislation required)?
* A summary of your main points

***Neutral* Presentation: Planning for pandemics**

**Speaker(s): Professor David Harper, Senior Consulting Fellow, Chatham House**

**Presentation duration: 15 minutes** (followed by 15 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (list the bullet points below)
* When might we reasonably predict the Covid-19 pandemic to come to a clear end (if at all)?
* Can we expect future pandemics to become more frequent?
* Are there pre-defined plans and guidance globally and in the UK for what should happen:
  + Going into a pandemic?
  + Coming out of a pandemic?
* Is there general good practice or steps that always apply when coming out of a pandemic back to “peace time rules” or does it depend largely on circumstances?
* A summary of your main points

## Witness Presentations for Jury Day 3 (i.e. 18 Mar, 8 Apr, 29 Apr)

***Neutral & Persuasive* Presentation: Summary Care Record Additional Information**

**Speaker(s): Dr Robert Jeeves, GP Lead for Summary Care Record, NHS Digital (part 1) and John Farenden, Senior Programme Lead, Shared Records Programme, NHSX (part 2)**

**Presentation duration: 30 minutes** (followed by 25 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

Part 1: Neutral

* Your brief (please list the bullet points below on a slide)
* What is the Summary Care Record, and where is it stored?
* How and when did the core data get into the Summary Care Record, and was that contentious?
* Briefly, how and where is the Summary Care Record typically used (e.g. in what context, for direct care alone?)?
* What is the “additional information” in the Summary Care Record, and what new types of information were introduced in Spring 2020?
* How many of the people with a Summary Care Record had “additional information”:
  + Before Spring 2020?
  + After Spring 2020?
* What changed in Spring 2020 to increase the number of people with “additional information” in the SCR, and to what extent was this enabled through the 2020 COPI regulations?

Part 2: Persuasive

* Why was this change made in Spring 2020?
* What uses have been made of the “additional information” and are there plans for this to change in future?
* What benefits have there been from the change?
* Could this same outcome have been achieved by getting explicit consent from everyone with a Summary Care Record?
* Is this something that you believe would have been valuable outside of the pandemic?
* What should the future of the Summary Care Record “additional information” be?
  + Have any decisions been made about its future?
  + For how long should the Summary Care Record continue in its current form with the “additional information” introduced in Spring 2020?[[4]](#footnote-4)
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[5]](#footnote-5) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
  + By whom should these decisions be made?
    1. An independent advisory group of experts and lay people
    2. The minister or organisation accountable for the data initiative
    3. Parliament
    4. Someone else
* What, how and when could the public have found out about the change to additional information, and has it attracted significant public attention?
* What actions have been taken to engender public trust?
* A summary of your main points

***Persuasive* Presentation: Summary Care Record Additional Information**

**Speaker: Phil Booth, Co-ordinator, medConfidential**

**Presentation duration: 20 minutes** (followed by 15 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (please list the bullet points below on a slide)
* Why is it important to use patient data for the individual and the wider public?
* Why is it important to protect patient data, and what do you think the public should expect?
* Should the public be prepared to accept a different level of protection of patient data during a pandemic?
* To what extent do you support the regulations that were introduced in Spring 2020 to enable greater patient data sharing?
* What specific concerns if any do you have about the change in Spring 2020 to add additional information to Summary Care Records?
* Why might this change be considered contentious?
* What could have been done differently?
* What should the future of the Summary Care Record additional information be?
  + For how long should the Summary Care Record continue in its current form with the additional information introduced in Spring 2020?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[6]](#footnote-6) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
  + By whom should these decisions be made[[7]](#footnote-7)?
    1. An independent advisory group of experts and lay people
    2. The minister or organisation accountable for the data initiative
    3. Parliament
    4. Someone else
  + How could or should the initiative and its uses be usefully changed in the future (if at all)?
  + What actions, if any, could be taken to engender greater public trust in the initiative?
* A summary of your main points

## Witness Presentations for Jury Day 4 (i.e. 19 Mar, 9 Apr, 30 Apr)

***Neutral & Persuasive* Presentation: NHS Covid-19 Data Store**

**Speaker(s): Ming Tang, National Director Data and Analytics at NHS England and NHS Improvement (part 1 &2)**

**Presentation duration: 30 minutes** (followed by 25 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

Part 1: Neutral

* Your brief (please list the bullet points below on a slide)
* What is the NHS Covid-19 Data Store (both Azure database, and Palantir’s AWS), where is it stored, what data does it comprise, and how did the data get there?
* When and by what organisation(s) was the NHS Covid-19 Data Store created, and what organisations are involved in running the Covid-19 Data Store?
* “What is the legal basis for the NHS Covid-19 Data Store (e.g. is it reliant on the 2020 COPI Notices)??
* How are decisions made about which applications are granted access to the Covid-19 Data Store, and when approved how do systems access the data?
* Briefly, how many approved applications[[8]](#footnote-8) of the NHS Covid-19 Data Store are there currently, and very briefly describe 3 examples (excluding those being considered on jury day 5)?

Part 2: Persuasive

* Why was the NHS Covid-19 Data Store introduced?
* What direct benefits, if any, have there been from the NHS Covid-19 Data Store itself (excluding the benefits from the approved applications)?
* What benefits have there been from the 3 example applications outlined earlier?
* Could similar outcomes have been achieved without creating the NHS Covid-19 Data Store?
* Is the NHS Covid-19 Data Store something that you believe would have been valuable outside of the pandemic?
* What should the future of the NHS Covid-19 Data Store be?
  + Have any decisions been made about its future?
  + For how long should the NHS Covid-19 Data Store continue with the additional information introduced in Spring 2020?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[9]](#footnote-9) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
  + By whom should these decisions be made?
    1. An independent advisory group of experts and lay people
    2. The minister or organisation accountable for the data initiative
    3. Parliament
    4. Someone else
* What, how and when could the public have found out about the NHS Covid-19 Data Store, and has it attracted significant public attention?
* What information is available about all the NHS Covid-19 Data Store applications, and how long has that been available?
* What actions have been taken to engender public trust?
* A summary of your main points

***Persuasive* Presentation: NHS Covid-19 Data Store**

**Speaker: Phil Booth, Co-ordinator, MedConfidential**

**Presentation duration: 15 minutes** (followed by 10 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (please list the bullet points below on a slide)
* A quick recap on your introduction on day 3:
  + Why is it important to use patient data for the individual and the wider public?
  + Why is it important to protect patient data, and what do you think the public should expect?
  + Should the public be prepared to accept a different level of protection of patient data during a pandemic?
  + To what extent do you support the regulations that were introduced in Spring 2020 to enable greater patient data sharing?
* What specific concerns if any do you have about the introduction of the NHS Covid-19 Data Store itself?
* Why might the new data store, or any of its specific applications not covered on jury day 5, be considered contentious?
* What could have been done differently?
* What should the future of the NHS Covid-19 Data Store be?
  + For how long should the NHS Covid-19 Data Store continue ?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[10]](#footnote-10) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
  + By whom should these decisions be made?
    1. An independent advisory group of experts and lay people
    2. The minister or organisation accountable for the data initiative
    3. Parliament
    4. Someone else
  + How could or should the data store and its applications be usefully changed in the future (if at all)?
  + What actions, if any, could be taken to engender greater public trust in the initiative?
* A summary of your main points

## Witness Presentations for Jury Day 5 (i.e. 22 Mar, 12 Apr, 3 May)

***Neutral & Persuasive* Presentation: NHS Covid-19 Data Store Case Study 1: The Early Warning System**

**Speaker(s): TBC**

**Presentation duration: 15 minutes** (followed by 10 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

Part 1: Neutral

* Your brief (please list the bullet points below on a slide)
* What is the Early Warning System, what does it do, and how does it relate to the Covid-19 Data Store?
* Was this enabled through the 2020 COPI regulations?

Part 2: Persuasive

* When was the Early Warning System introduced, and why?
* What benefits have there been from the Early Warning System?
* Is this something that you believe would have been valuable without the pandemic?
* Could similar outcomes for the Early Warning System have been achieved without creating the NHS Covid-19 Data Store?
* What should the future of the Early Warning System be?
  + Have any decisions been made about its future?
  + For how long should the Early Warning System continue ?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[11]](#footnote-11) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
* What, how and when could the public have found out about the Early Warning System, and has it attracted significant public attention?
* What actions have been taken to engender public trust?
* A summary of your main points

***Persuasive* Presentation: NHS Covid-19 Data Store Case Study 1: The Early Warning System**

**Speaker: Phil Booth, Co-ordinator, MedConfidential**

**Presentation duration: 10 minutes** (followed by 10 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (please list the bullet points below on a slide)
* A quick recap on your introduction on day 3:
  + Why is it important to use patient data for the individual and the wider public?
  + Why is it important to protect patient data, and what do you think the public should expect?
  + Should the public be prepared to accept a different level of protection of patient data during a pandemic?
  + To what extent do you support the regulations that were introduced in Spring 2020 to enable greater patient data sharing?
* What specific concerns if any do you have about the introduction of the Early Warning System itself?
* Why might the Early Warning System be considered contentious?
* What could have been done differently?
* What should the future of the Early Warning System be?
  + For how long should the Early Warning System continue ?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[12]](#footnote-12) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
* What actions, if any, could be taken to engender greater public trust in the initiative?
* A summary of your main points

***Neutral & Persuasive* Presentation: NHS Covid-19 Data Store Case Study 2: The Immunisation and Vaccination Management Capability**

**Speaker(s): TBC**

**Presentation duration: 15 minutes** (followed by 10 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

Part 1: Neutral

* Your brief (please list the bullet points below on a slide)
* What is the Immunisation and Vaccination Management Capability, what does it do, and how does it relate to the Covid-19 Data Store?
* Was this enabled through the 2020 COPI regulations?

Part 2: Persuasive

* When was the Immunisation and Vaccination Management Capability introduced, and why?
* What benefits have there been from the Immunisation and Vaccination Management Capability?
* Is this something that you believe would have been valuable without the pandemic?
* Could similar outcomes for the Immunisation and Vaccination Management Capability have been achieved without creating the NHS Covid-19 Data Store?
* What should the future of the Immunisation and Vaccination Management Capability be?
  + Have any decisions been made about its future?
  + For how long should the Immunisation and Vaccination Management Capability continue ?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[13]](#footnote-13) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
* What, how and when could the public have found out about the Immunisation and Vaccination Management Capability, and has it attracted significant public attention?
* What actions have been taken to engender public trust?
* A summary of your main points

***Persuasive* Presentation: NHS Covid-19 Data Store Case Study 2: The Immunisation and Vaccination Management Capability**

**Speaker: Phil Booth, Co-ordinator, MedConfidential**

**Presentation duration: 10 minutes** (followed by 10 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (please list the bullet points below on a slide)
* A quick recap on your introduction on day 3:
  + Why is it important to use patient data for the individual and the wider public?
  + Why is it important to protect patient data, and what do you think the public should expect?
  + Should the public be prepared to accept a different level of protection of patient data during a pandemic?
  + To what extent do you support the regulations that were introduced in Spring 2020 to enable greater patient data sharing?
* What specific concerns if any do you have about the introduction of the Immunisation and Vaccination Management Capability itself?
* Why might the Immunisation and Vaccination Management Capability be considered contentious?
* What could have been done differently?
* What should the future of the Immunisation and Vaccination Management Capability be?
  + For how long should the Immunisation and Vaccination Management (I&V) Capability continue ?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[14]](#footnote-14) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
  + What actions, if any, could be taken to engender greater public trust in the initiative?
* A summary of your main points

## Witness Presentations for Jury Day 6 (i.e. 23 Mar, 13 Apr, 4 May)

***Neutral & Persuasive* Presentation: OpenSAFELY**

**Speaker(s): Jess Morley, Policy Lead, Oxford Datalab (part 1 and 2)**

**Presentation duration: 30 minutes** (followed by 25 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

Part 1: Neutral

* Your brief (please list the bullet points below on a slide)
* What is OpenSAFELY, what data does it make accessible, where is it stored, and how does the data get there?
* What organisations created and run OpenSAFELY?
* What relationship does it have with the Covid-19 Data Store?
* “What is the legal basis for the NHS Covid-19 Data Store (e.g. is it reliant on the 2020 COPI Notices)? How are decisions made about which applications are granted access to the Covid-19 Data Store, and when approved how do systems access the data?
* Briefly, how many approved applications of OpenSAFELY are there currently, and very briefly describe 3 examples?

Part 2: Persuasive

* When was OpenSAFELY introduced, and why?
* What direct benefits, if any, have there been from OpenSAFELY itself (excluding benefits from applications that access it)?
* What benefits have there been from the 3 example applications outlined earlier?
* Is this something that you believe would have been valuable without the pandemic?
* Could similar outcomes have been achieved without creating OpenSAFELY and providing access to the GP data
* What should the future provided by OpenSAFELY to GP data be?
  + Have any decisions been made about its future?
  + For how long should OpenSAFELY continue to provide access to GP data?
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[15]](#footnote-15) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses)
    4. Something else
  + By whom should these decisions be made?
    1. By patients themselves
    2. An independent advisory group of experts and lay people
    3. The minister or organisation accountable for the data initiative
    4. Parliament
    5. Someone else
* What, how and when could the public have found out about OpenSAFELY and the access to GP data, and has it attracted significant public attention?
* What information is available about OpenSAFELY applications and particularly the access to GP data, and how long has that been available?
* What actions have been taken to engender public trust?
* A summary of your main points

***Persuasive* Presentation: OpenSAFELY**

**Speaker: Phil Booth, Co-ordinator, MedConfidential**

**Presentation duration: 15 minutes** (followed by 10 minutes for questions and answers from members of the jury).

Please produce slides to address the following in your presentation e.g. 1/2 slides per bullet:

* Your brief (please list the bullet points below on a slide)
* A quick recap on your introduction on day 3:
  + Why is it important to use patient data for the individual and the wider public?
  + Why is it important to protect patient data, and what do you think the public should expect?
  + Should the public be prepared to accept a different level of protection of patient data during a pandemic?
  + To what extent do you support the regulations that were introduced in Spring 2020 to enable greater patient data sharing?
* What specific concerns if any do you have about the introduction of the OpenSAFELY itself?
* Why might OpenSAFELY, and particularly the access it provides to GP data, be considered contentious?
* What could have been done differently?
* What should the future provided by OpenSAFELY to GP data be?
  + For how long should OpenSAFELY continue to provide access to GP data??
    1. As short a time as possible
    2. Only as long as the Covid pandemic continues and emergency powers[[16]](#footnote-16) are in place
    3. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses) with legal basis
    4. Something else
  + By whom should these decisions be made?
    1. An independent advisory group of experts and lay people
    2. The minister or organisation accountable for the data initiative
    3. Parliament
    4. Someone else
  + How could or should OpenSAFELY and its applications be usefully changed in the future (if at all)?
  + What actions, if any, could be taken to engender greater public trust in the initiative?
* A summary of your main points

1. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-1)
2. “Patient data” is the term promoted by The Wellcome Trust [↑](#footnote-ref-2)
3. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-3)
4. The policy decision – individual patients may have individual decisions about their own SCR [↑](#footnote-ref-4)
5. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-5)
6. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-6)
7. The policy decision – individual patients may have individual decisions about their own SCR [↑](#footnote-ref-7)
8. “Application” is used here to refer to systems like the Early Warning System [↑](#footnote-ref-8)
9. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-9)
10. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-10)
11. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-11)
12. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-12)
13. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-13)
14. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-14)
15. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-15)
16. Emergency powers are in place to deal with the pandemic, see: https://www.instituteforgovernment.org.uk/explainers/emergency-powers [↑](#footnote-ref-16)