

# Foundations of fairness: views on uses of NHS patients' data and NHS operational data

A mixed methods public engagement programme with integrated Citizens' Juries

## Findings Report



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# Preface

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**This independent report has been prepared by Hopkins Van Mil: Creating Connections Ltd. It was commissioned by Understanding Patient Data and National Health Service England, and supported by the Ada Lovelace Institute to inform the policy development being led by the Office for Life Sciences on realising the benefits of NHS data.**

Understanding Patient Data (UPD) aims to make the uses of patient data more visible, understandable and trustworthy. UPD seeks to explain how and why data can be used for care and research, what's allowed and what's not, and how personal information is kept safe. We work with patients, charities and healthcare professionals to champion responsible uses of data.



The Ada Lovelace Institute is an independent research and deliberative body with a mission to ensure data and AI work for people and society. It promotes informed public understanding of the impact of AI and data-driven technologies on different groups in society.



HVM facilitates engagement so that voices are heard, learning is shared, and understanding achieved. In practice this means finding the process by which people can explore their hopes, fears, challenges and aspirations for the future. HVM's work enables stakeholders, technical specialists, and a diversity of publics to work together as equals to make actionable, better informed, and powerful decisions.



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# Foreword from Dr. Natalie Banner

## Understanding Patient Data

Health data is becoming big news and big business. There is increasing interest in using data held by the NHS for many purposes, with current hype caused by exciting promises in machine learning. Better management and use of data could allow patients to take more control over their health conditions, and ensure the right information is in the right place at the right time to improve care. But data is also valuable for purposes beyond individual care: it could increase operational efficiencies for the NHS through improved system and service planning, advances in medical understanding and better population health management.

There is clear commercial interest too, which naturally attracts greater media scrutiny. The data may not always be well-curated and joined up, but it represents a significant asset to companies that want to develop new treatments, sell products into the NHS or develop software to support clinical decision-making.

Several high-profile initiatives have launched over the past few years with the express aim of making the most of the UK's health data, including the creation of NHSX, the Life Sciences Industrial Strategy Sector Deals and Health Data Research UK. Bringing cohesion to technology and data use in and beyond the NHS is important. But ultimately this data concerns people, both staff and patients: whether from health records or operational data collected to run the health service. This data is by people, about people and for people.

It is also highly sensitive. Data collected in the context of a confidential relationship between clinician and patient must be treated lawfully, ethically and in line with what people reasonably expect. "Public trust" is often cited as a cornerstone of better data use, but the conditions necessary for creating an environment worthy of trust are not always addressed.

For this reason, at Understanding Patient Data we wanted to find out what people think of NHS bodies allowing third parties to access the data they hold, whether that's academics, charities or industry. In this research we deliberately focused on the system of rules and processes that would make a health data system trustworthy. We wanted to explore the features of decision-making about data partnerships that would look and feel fair to members of the public who had not thought about these questions before.

We are grateful to NHS England for co-funding this work, to the Office of Life Sciences for helping develop the case study material, and to the Hopkins Van Mil team for producing a robust, thorough exploration of our question. Thanks also to our exceptional Oversight Group for helping us make sure the research and report maintain balance, accuracy and impartiality throughout.

We hope this report, and the accompanying commentary from Understanding Patient Data and the Ada Lovelace Institute, contribute a strong range of public perspectives to the debate about how health data is used. It is clear that people care about what happens to data. It is also clear we should trust them to help develop the right frameworks for how it is used, now and as we look towards a more data-driven future.

**13<sup>th</sup> February 2020**

# 1. Executive summary

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This report highlights the findings from a mixed methods public engagement programme which included:

- Three round tables involving a total of 30 patient representatives in Oxford, Manchester and London: their purpose was to frame the stimulus materials and ways of testing the charge question to create the Citizens Jury process design.
- Citizens' Juries in Taunton, Leeds and London engaging 60 jurors over two and half days: to deliberate on the question: *What constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?* informed by evidence provided by expert witnesses
- A nationally representative survey completed by 2095 people in the UK was developed to quantitatively explore areas highlighted by jurors as important, and to test broader public opinion on several key themes that emerged including the level of awareness of data access partnerships in a representative sample and aspects of communication raised by jurors.

This programme was commissioned by Understanding Patient Data and National Health Service England, and supported by the Ada Lovelace Institute to inform the policy development being led by the Office for Life Sciences (OLS) on realising the benefits of NHS data. The aim of the programme was to gain insight and deliberation into the issues that emerge from considering what constitutes a fair partnership between the NHS, researchers, charities and industry on the uses of NHS data. This insight is to help commissioning partners in their work and the OLS to better understand citizens' values and attitudes.

The points that emerge from this mixed methods research are described in this report. Central to this analysis are the recommendations created by jurors during the citizen' jury deliberations. These are summarised below and form the conclusion of the report.

## 1.1 Jury Recommendations

The Juries' deliberations culminated in the creation of recommendations to respond to the question '*what constitutes a fair partnership*'. Recommendations focused on how partnerships are governed to ensure they are fair, principled, transparent and ultimately always lead to improved health outcomes. These recommendations featured in at least two of the three locations:

### Headline Majority Recommendation

**A governance system to oversee partnerships<sup>1</sup>**

### Summary

These juries recommend that a governing body is established to oversee NHS data partnerships

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<sup>1</sup> Jurors described the governance system as a 'regulatory body' but their comments explain that this is intended as an overarching system of governance rather than an additional regulatory organisation.

<p><b>Partnerships driven by improving health outcomes and reducing health inequalities</b></p>	<p>These juries recommend that all partnerships are guided above all by the principles of improving healthcare outcomes and reducing healthcare inequalities</p>
<p><b>Partnerships governed by a set of shared principles</b></p>	<p>These juries recommend that partnerships must be driven by a set of principles that will be of mutual benefit to all parties in the partnership.</p>
<p><b>Partnerships which are transparent and accountable</b></p>	<p>These juries recommend that NHS data sharing partnerships should be transparent and accountable.</p>
<p><b>Benefits from partnerships rolled out across the NHS in an agreed timeframe</b></p>	<p>These juries recommend that the positive benefits from any local or regional partnership i.e. health interventions and research results should be rolled out across the NHS, for the benefit of all patients, within an agreed time frame</p>
<p><b>NHS data is streamlined to be more consistent</b></p>	<p>These juries recommend that NHS data be streamlined to be more consistent across different NHS organisations and regions.</p>
<p><b>Data sharing policies are reviewed in light of GDPR, Brexit and future policy imperatives.</b></p>	<p>These juries recommend that there is an ongoing review of data sharing policies, in light of political and technological developments, including Brexit and GDPR.</p>

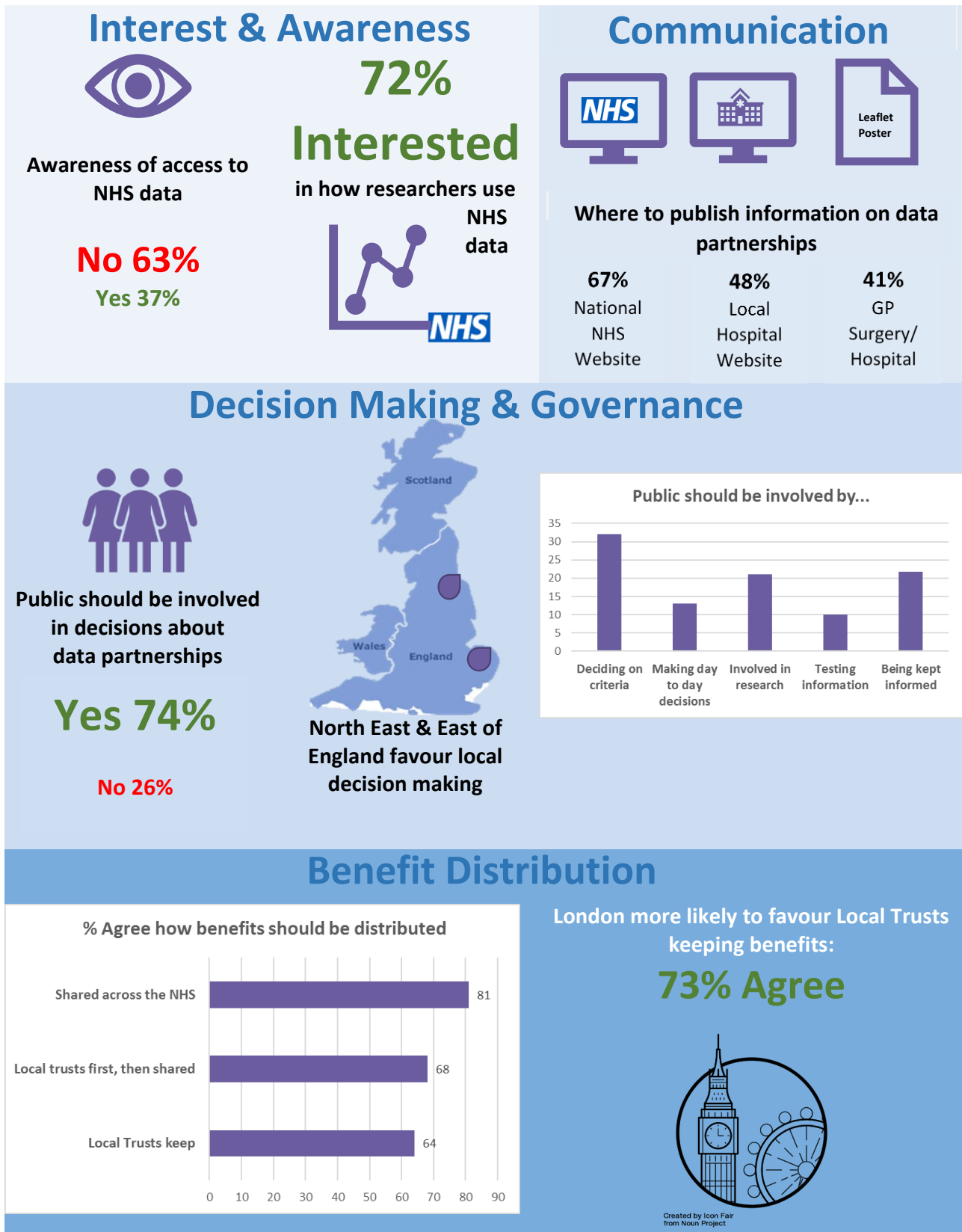
Juries in London and Taunton made recommendations unique to their locations. It is worth noting that the issues raised in these minority recommendations were discussed in all locations but didn't make it into the final recommendations everywhere.

1. For the NHS to use its allocated budgets to keep NHS data secure | Taunton
2. Enshrine the concept of fair partnership in law. Criminal law to be put in place to ensure that data is not used out of agreement | London
3. Initiate a national communication plan to educate the public about data partnerships and about where and how data is used | London
4. Adopt a data access rather than a data sharing approach | London

Whilst jurors were not asked if they supported or opposed the use of NHS data by partner organisations, most jurors could see that considerable value that could be gained through properly governed partnerships.

## 1.2 A snapshot of survey findings

The survey spoke to several themes raised as important by jurors including interest and awareness in data access partnerships; communication and sources of information; decision making and governance and the distribution of benefits.





## 1.3 Reflections on the jury findings

In designing and reporting on the mixed methods public engagement programme the analysis team has reflected on the Citizens' Jury deliberations in Taunton, Leeds and London alongside the nationally representative survey of 2015 and found that:

### **Benefits to patients must be first and foremost, and these should be fairly distributed**

1. Data access partnerships must be principally motivated by improving patient outcomes.
2. Jurors believe that it is fair when the benefits from data access partnerships are realised across the country, not just in the area where the data is generated and/ or where the partnership operates.
3. The best interests of patients must be front of mind at all times and this must outweigh any potential financial gain or other contractual obligations.

### **NHS data is unique to the UK and valuable. Policies and practice should ensure the NHS can properly realise this value, protecting it and getting a fair deal**

4. The NHS holds an extremely valuable resource covering every section of society across all demographics and it should ensure it understands and realises its value when negotiating data access partnerships.
5. Public trust is undermined when a data access partner is seen to profit excessively from realising the potential from NHS patients' and NHS operation data, and/ or the expected social value outcomes do not emerge from the agreement.
6. Data security is a principle concern and data access partnerships should take every measure possible to protect against data breaches.
7. Data access partnerships offer opportunities for discovery, development, implementation and continuous improvement in health care and NHS efficiencies. These opportunities must be balanced with the core functions of the NHS as a public service free at the point of delivery.
8. Jurors reflected on the cost of not using the data for access partnerships. They thought about potential missed opportunities afforded by data access partnerships due to bureaucracy, inadequate or ineffective processes and complex organisational structures. They saw this, together with NHS organisations not being in tune with the fast-moving world of digital and technological innovation as serious challenges to success.

**A robust governance system for making decisions about how these partnerships should operate (whether at a national or a local level), and there is a public stake in how these decisions should be made.**

9. There is a demand for an overarching governance framework for data access partnerships with consistent principles applied to their operation.
10. Citizens feel they have a stake in data access partnerships and should play a role in deciding how they are established and for what purpose.

**Communications and transparency are critical**

11. Given all that has been learned in this mixed methods research, the potential wider benefits from data access partnerships should be widely recognised and communicated including new employment opportunities and improved NHS efficiency, skills and capabilities.
12. Given information about data access partnerships, citizens see them as offering opportunities for discovery, development, implementation and continuous improvement in health care and NHS efficiencies. It is felt that these opportunities must be balanced with the core functions of the NHS as a public service free at the point of delivery.

This report sets out the rich insights that can be achieved from working qualitatively with patient and public groups and in citizens' jury settings combined with quantitative methodologies which extend the findings across a representative sample of the UK population.

## 2. Research introduction

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### 2.1 Research purpose

HVM was commissioned by Understanding Patient Data and NHS England, supported by the Ada Lovelace Institute in June 2019, to undertake a mixed methods public engagement and deliberation on the question: *what constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?* Findings from the programme will inform the policy development being led by the Office for Life Sciences (OLS) on realising the benefits of NHS data.

The aim of this mixed method public engagement programme was set out in the brief to Hopkins Van Mil (HVM) as being to gain insight and deliberation into these issues to help the OLS better understand the public's values and attitudes towards what constitutes a fair partnership between the NHS, researchers, charities and industry on the uses of NHS data. The public engagement activities set out to gather feedback on different benefit sharing models and generate information on the types of assurances and safeguards that could address public concerns on the use of health data by commercial and other non-NHS organisations.

NHS organisations are increasingly entering into agreements with third party organisations to make use of the data they hold, both about patients and about their administrative functions. Third parties, which may include academic researchers, private companies and charities, may be looking to perform analyses of the data, undertake research or develop products such as software that could be used by clinicians and service providers. There is significant appetite within the NHS to capitalise on data-driven technologies such as machine learning to help improve health services, increase efficiencies and ultimately benefit patients – but all of this potential relies on availability and access to data. However, data derived from patients' records has to be handled securely, lawfully and with respect for people's rights. Even if this data has had identifying information removed, it may still be personal data and must be treated accordingly. NHS operational data may not have the sensitivity of personal data but is still highly valuable to third party organisations wishing to develop analytic tools or products that could be sold back to the NHS.

NHS bodies may have a significant degree of autonomy over decisions about how data may be accessed and used, and by whom, for different purposes. Over the past few years, concerns have been raised that such agreements may be being made without patients' knowledge, or without the NHS fully realising the potential and value of the data it holds and therefore being at risk of exploitation. For this research, we used the shorthand "data access partnerships" to refer to agreements struck between NHS organisations and third parties that may be granted access to patient or operational data held by those NHS organisations.

The public engagement programme aimed to gain insight on the perceptions of diverse publics on the use of NHS patients' data and NHS operational data, gaining a better understanding of what matters to people, their motivations, expectations and concerns. These perspectives will,

alongside the OLS's wider consultation process, shape the policy framework due for publication later this year.

## 2.2 Scope of the research

The research was commissioned as a mixed methods programme combining qualitative deliberation with a quantitative survey. It was overseen by an Oversight Group (OG) (see Appendix 1) comprising representatives from each of the commissioning bodies described on page 2, as well as from industry, charity and academic institutions, umbrella bodies and NHS organisations working on digital programmes.

It was informed by Public Patient Involvement (PPI) roundtables held in London, Oxford and Manchester. Members of these groups worked with HVM facilitators to frame the stimulus materials and ways of testing the charge question to create the Citizens Jury process design.

The Citizens' Juries were held over weekends in Taunton, Leeds and London from the end of August to early September 2019. They started on Friday evening and concluded on Sunday afternoon. The process culminated in a national survey of a representative sample of 2,095 UK adults conducted via an online platform. Following the Jury process the Oversight Group and HVM discussed the emerging findings and identified several key themes on which survey findings could add value. It was important that the survey questions were developed to test broader public opinion when respondents would not have the benefit of a lengthy deliberative process to familiarise themselves with the context and material. Due to the 2019 General Election the survey was launched in January 2020 and the findings integrated with the qualitative jury findings.

## 2.3 Participant recruitment

The recruitment of the 10-12 participants for the three roundtables was conducted with the support of existing PPI groups (Appendix 3). This was an essential part of the Jury design process in that HVM and the commissioning partners could work with patients who are already familiar with the complex NHS data landscape to frame the Citizens Jury materials, identify key themes and issues and ensure the language used in the case studies and handouts was in Plain English, clear and fit for purpose.



The recruitment for the Citizens' Juries was conducted through on street and panel approaches working with HVM's recruitment partner Roots Research. It was conducted against a recruitment specification (Appendix 5) and screener ensuring Jurors as far as possible reflected the demographics of the English population. Recruitment in Taunton allowed for a more rural group of participants whilst Leeds was predominantly urban in its recruiting, with a small number of rural groups, and London being entirely urban.

## 2.4 Survey design and sample

The quantitative survey was designed in the light of the jury findings. Survey questions were drawn from the Citizens' Jury findings and, in discussion with the Oversight Group (OG) and commissioning partners, developed to build on areas where it was felt that understanding how the national population reacted to key issues would add value to the overall study. The survey therefore included questions on:

- People's awareness of data access partnerships
- Where they would expect to find information on them
- Levels of interest in data access partnerships
- The extent to which citizens should be involved in the decisions about how data access partnerships work
- Where the benefits of the data access partnerships should be focused.

The survey was hosted by the online platform Toluna which has a standing panel of 642,000 members in the UK who wish to take part in surveys. Emails are sent to panellists selected at random from the base sample. The e-mail invites them to take part in a survey and provides a generic survey link. Respondents are screened to make sure they are a real person and have not responded to surveys on similar subjects repeatedly in recent weeks. There is a  $\pm 5\%$  confidence interval meaning that for any percentage figure given, 5% less or 5% more in the whole UK population might have responded in the same way. The sample was weighted to the following UK demographics: gender, age, region and social grade. This meant that some other UK demographics were not fully captured but could still be analysed. Black, Asian and minority ethnic groups (BAME) were a large enough sample in number for analysis, with an unweighted base size of 295 which forms 14% of the total survey response.

For the main part we have noted no significant difference in how respondents answered the question in terms of their gender or other demographic factors. Where significant differences are evident between the qualitative and quantitative data or in the demographic factors these are highlighted in the chapter narrative and mostly relate to where people live and their age. The survey took 10 minutes to complete and the questionnaire is included in appendix 7. Fieldwork took place from 13 and 15<sup>th</sup> January 2020.

HVM follows the Market Research Society Guidelines for qualitative research and the Economic and Social Research Council's Framework for Research Ethics (2015). As such we pay incentives for participants involved in each aspect of this mixed methods research.

## 2.5 Methodology

The dialogue design was informed by a programme of desk research and stakeholder interviews conducted in the summer of 2019. Draft process designs were approved by the OG before being used to frame discussions at the Juries. Best practice was employed in designing and delivering the Juries, with Henrietta Hopkins Lead Designer at HVM and Simon Burall, Advisor at Involve, leading the facilitation of the deliberative process. The opening session on Friday evening allowed Jurors to get to know each other and the facilitation team, introduced the jury question and an understanding

of what was in and out of scope. This was an important session for ensuring that jurors understood exactly what was being asked of them and being clear of the question being addressed:

*What constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?*

Jurors were also introduced very clearly to the subject of data access partnerships by Natalie Banner of Understanding Patient Data or Reema Patel of the Ada Lovelace Institute, a scene setting presentation setting out the purpose of the Citizens' Juries. In addition Gary Cook from OLS was presented in a short filmed statement to jurors. These three elements made it clear to jurors that they were not deliberating on whether or not data access partnerships should exist, but rather, given that they do exist, how they should be operate fairly for all concerned. The facilitation team made it clear that the focus is on data collected routinely as part of every patients' care and interactions with the NHS in line with the useful *Spectrum of identifiability* developed by Understanding Patient Data. This image that was also used to explain this concept to survey respondents.

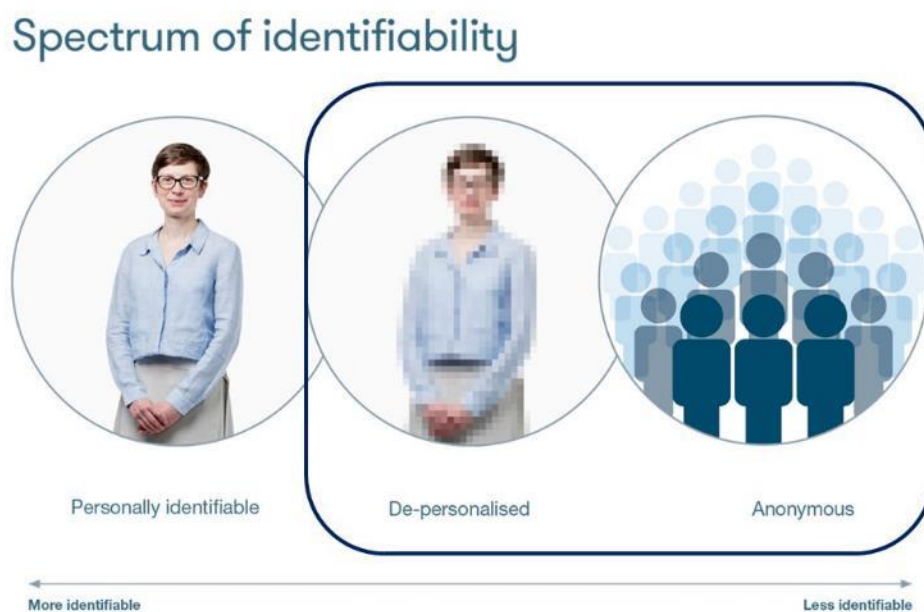


Figure 1: CC-BY licence 'Spectrum of Identifiability' by Understanding Patient Data

The main part of the Saturday workshop included presentations from expert witnesses (Appendix 2) covering the following topics:

- An overview of NHS England, making it clear that it is made up of 1000s of organisations and an overview of NHS patients' and NHS operational data use made by representatives of NHS Digital
- Examples of data access partnerships in operation given by the South West Academic Health Science Network; Imperial Healthcare Partners and the Association of British HealthTech Industries
- Speakers responding to the potential of data access partnerships and the benefits and challenges within them
- Representatives from UseMyData, MedConfidential and Reform presented on risks and opportunities for data access partnerships

- Speakers from health research bodies also gave jurors an overview of Public Patient Involvement groups and the voice within the data access landscape.

Each speaker block was followed by time for jurors to work in small groups to think about the questions they had before asking the questions of small panels of speakers. Saturday concluded with jurors exploring a handout setting out examples of different types of value exchange that partnerships could provide.

- **System wide model** examples, which exchanged data access for expertise, tidied data or the opportunity of improved healthcare stemming from free access to data.
- **Simple monetary model** examples, which exchanged data access for a fee or a discount on a product.
- **Future potential model** examples, which exchanged data access for a stake in a product, company or share of profits from a product/service developed using the data provided.

In using these models jurors were told that, ‘the following partnership models are not mutually exclusive or exhaustive, and many could be used in combination to achieve a fair deal for the public, patients and the NHS.’

On Sunday, jurors discussed benefits and challenges of fair partnerships, rooted in an overnight review of what ‘fair’ means in other contexts in their lives. They used a range of activities to explore what good governance might look like and then reflected on ‘value’ and what it might mean for data access partnerships. The jury ended with participants using all the evidence they had gathered and reflected on over the two days to draw up recommendations which respond to the question they were asked to address. The process materials used throughout can be reviewed in Appendix 6 of this report.

It is worth noting that the process design team and commissioning bodies worked hard to shift juror thinking away from individual levels of consent and control. The team asked jurors to reflect on how they would want these partnerships to work, how they should be designed and to systematically consider the issues inherent in their operation and governance.

It is important that the Jurors’ discussions are recorded effectively for data collation and analysis. HVM uses three main recording methods, all of which are transcribed for analysis:

- Audio recording of each small group and the plenary sessions
- Flip chart recording by the facilitator who notes the key points made and themes arising
- Post-it notes, plain white boxes and cards which are used by participants to record thoughts and headline points in their own words.

A vast array of written and visual materials resulted from the Jury process in three locations. These are reviewed by HVM’s analysis team to agree on the coding frame which is developed using NVivo software. The final codes are reviewed throughout the process by individuals and in team workshops to agree the final set through which the qualitative data is filtered. An interim findings report was presented to the commissioning bodies at the Office for Life Sciences on 19<sup>th</sup> September, the final report, initially due for publication in November 2019, was postponed in line with the General Election Guidance (2019).

# 3. Benefits, motivations, reasons for optimism

## Chapter 3 summary

This chapter presents jury deliberation on the benefits of data access partnerships, motivations for entering into partnerships and reasons for optimism about accessing NHS patients' and NHS operational data. Jurors understood the NHS to comprise thousands of different organisations, but they identified four broad categories of benefits for the NHS as a collective entity. These were:

### 1. Improved patient outcomes

- Better health and care as a result of innovation
- Reduction in health inequalities
- Meet the rising demand for health care

### 2. Sharing knowledge and expertise

- Synthesis of skills and technology between sectors
- Nurturing the minds of current and future researchers
- Potential to address the power imbalance between partners
- Potential to build trust

### 3. Efficiency savings and increased NHS revenue

- Opportunity to increase revenue and NHS assets
- Increased investment for all life sciences
- Financial gains re-invested in the healthcare system

### 4. Enhanced reputations for patient data partners

- Collaboration with world leaders in health
- More options to attract investment and collaboration
- Trust in the NHS restored.

Figure 2: Main benefits of data access partnerships identified by jurors

## 3.1 Improved patient outcomes

Improved patient care has to be the main purpose for entering into data access partnerships in the eyes of Jurors.

*Anything that helps patients is a benefit. That should be the endgame.* | Leeds

*They can't let focus of projects move away from what it should be about, which is real, genuine health improvements for NHS clients.* | London

Broadly speaking discussing data access partnerships gave juries a sense of optimism for the future of the NHS in reshaping and improving the field of healthcare. Jurors saw opportunities for better patient outcomes (medical advances, new medicines, eradication of disease, early disease detection) and better care (improved diagnostics, access to treatment and reduced waiting times).



*Benefits - we even came to eternal life, AI advances, innovation and just the quality of treatments within the NHS improving.* | Taunton

In each location the view was expressed that partnerships may lead to a more dynamic health service. One that has more confidence in its own ability to deliver health improvements efficiently and effectively which would in turn lead to improved public confidence in the NHS.

*If things start working faith can be restored from the patients.* | Leeds

Jurors saw a clear link between benefits for patients and wider benefits to society with more people living healthier lives and therefore being available to remain in the workforce for longer, which was seen as an important social value in the context of a growing and ageing population.

*[NHS data access partnerships can help] reshape the field of healthcare and meet the rising healthcare demand, with the UK being potential world leaders in this.* | London

## 3.2 Sharing knowledge and expertise

Jurors placed importance in partnerships bringing together medical and technological expertise. Jurors felt that experts working together in an environment which fosters innovation inevitably leads to new ways of doing things and a stimulus for future research.

*Access to ground-breaking techniques that otherwise wouldn't be accessible will encourage blue sky thinking.* | London

There was a sense that establishing data access partnerships will challenge organisations that haven't done so previously to work together, or those that have to think about new ways of using the data meaningfully. The jurors saw this as another important motivation for establishing data access partnerships in that expertise from non-medical partners will benefit the NHS and vice versa.

*[Data access partnerships will] lead to healthy future relationships, a synthesis and symbiosis of relationships between sectors.* | Leeds

They anticipated a resultant improved skill set within the NHS; a constant nurturing of future minds in the health care system, charities, industry and academia; and ground-breaking advances in technology. In other words,

*A virtuous cycle of improvements.* | Leeds

There was a view that collaboration achieved through data access partnerships will lead to an increased understanding and respect between partners, who will feel more invested in the shared ethos of working for better health outcomes. This was highlighted as a win/win situation which could set a positive precedent for other contexts. Following this train of thought, data access partnerships were seen to have the potential to work towards addressing any power imbalances between the NHS and industry, given that importance of the data to which the NHS can grant access.

To ensure consistent knowledge transfer from data access partnerships to researchers, students, charities and industrial partners, jurors advocated for a reporting requirement for each partnership, so that even if a partnership fails, the learning is captured.

*A final report is submitted by the partner at the end of each study. Which can be used for future research and be given to people who request the same data in the future. | Taunton*

### **3.3 Efficiency savings and increased revenue for NHS**

The potential for efficiency savings and increased revenue for the NHS as a result of data access partnerships was broadly welcomed by juries on the understanding that financial gains will be reinvested in the healthcare system.

*A welcome additional source of revenue for NHS given the continued lack of funding. | London*

*These partnerships should fuel the NHS, shouldn't they? | Leeds*

Data access partnerships were seen as a route to additional funding, and to outsourcing operations which are not part of the NHS' core business, i.e. data cleaning, which will have longer term benefits.

*What's clear is that good data saves money. | Taunton*

The juries applied these benefits to all partners in data access partnerships recognising that industry, charities and universities all stand to gain from effective partnerships. For industry there will be reputational and financial gain, and charities will be better able to meet the needs of their members and service users. In London jurors said they expected that successful data access partnerships might fuel increased investment in UK life sciences.

### **3.4 Enhanced reputations**

There was an expectation amongst jurors that data access partnerships will facilitate greater levels of respect across the public, voluntary and private sector and improve the UK's and data partners' reputations nationally and globally.

*NHS learnings going all over the water with brains that take them there. | Leeds*

Jurors felt this could lead to increased investment and funding which will benefit the UK economy; increase employment opportunities; and create opportunities for collaboration with world leaders from industries, academia and charities. From a view that success breeds success the jurors were confident that successful data partnerships, which lead to innovation in patient care whilst adhering to clear governance principles (see chapter 9), will lead to more research requests based on NHS data.

The juries therefore felt that public perception of the NHS is likely to improve as well.

*If things are working smoothly then trust is restored in the NHS by patients. | London*

Successful data access partnerships would demonstrate that the NHS is fit for purpose and keeping up to date with current innovation through partnerships and policies to manage those partnerships

which are not overly restrictive. These ideas were in part illustrated by a group of jurors in Taunton (figure 3).

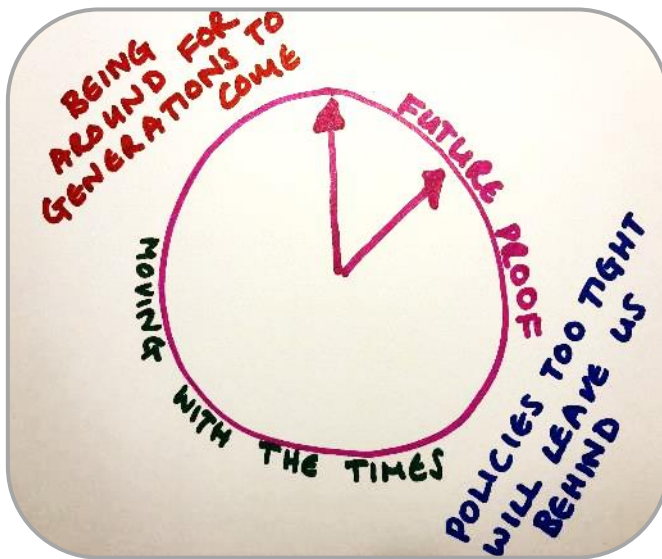


Figure 3: Patient data partnerships enabling NHS to be future proof; sustainable and move with the times, using policies which are not overly restrictive. | Taunton

## 4. Concerns, cautions and risk

### Chapter 4 summary

In this chapter we describe the concerns, cautions and risks jurors discussed over the course of their deliberations. These were arrived at in response to specific questions about the challenges and areas for caution they saw arising from data access partnerships. They were also raised by Jurors in their iterative reflections on how data access partnerships are created, implemented and result in specific outcomes. Jurors were not expected to undertake a full risk assessment of data access partnerships, but their deliberations over the course of the Jury left them with the perception of four main areas of concern, caution and potential risk. The overriding view was that some risk is acceptable if the benefits of data access partnerships include improved patient and operational outcomes across the country.

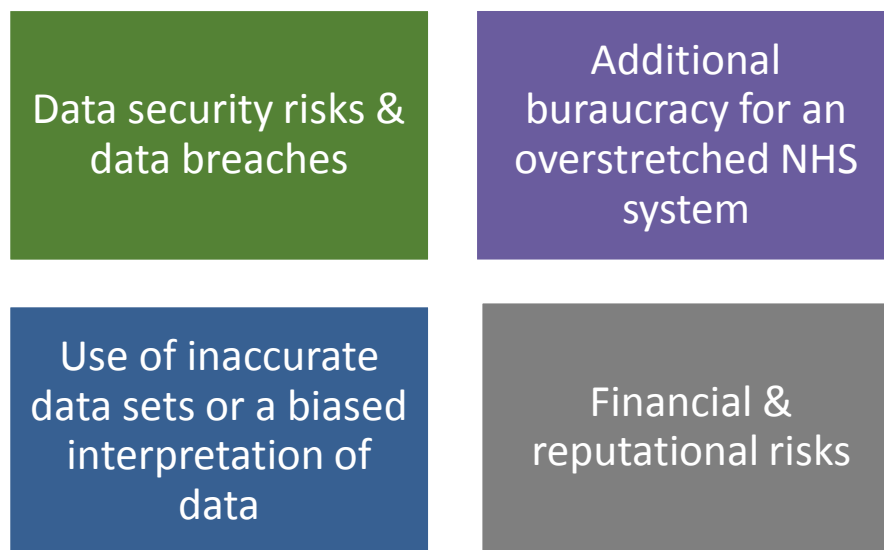


Figure 4: Areas of concern, caution and potential risk

### 4.1 Data security

Jurors in all locations raised data security as a primary concern. Two main points arise here:

1. Jurors felt that the NHS potentially lacks the skills and technology to manage data access securely, or has less experience in this area than some data access partners,

*Does the NHS have an equivalent capacity, capability to see a risk of a data breach coming? Does it have the same skills as a business, charity or university whose primary focus might be these issues?* | Leeds

2. Discussions tended to focus on the risk of sensitive data falling into the wrong hands.

There was a sense that the risk of data breaches increases commensurately with the number of data access partnerships. Some jurors mentioned that news stories heard in the press about privacy and confidentiality breaches could act as a deterrent to wider public support for data access

partnerships, even though it was understood by Jurors that the data under consideration is routine and operational data. For many Jurors public support for data access partnerships could be seen to be subject to NHS organisations demonstrating effective data security protocols are in place.

*The challenges are obviously to keep the data secure and anonymous.* | Taunton

In London jurors were very outspoken about their preference for the term data access over data sharing. Data access to London Jurors implied that consent is given to work with the data in a secure environment, managed and controlled by NHS organisations. Data sharing for them implied handing over data to a third party with no specific protection measures in place. In Leeds the point was made that everyone handling patient data should be carefully vetted, and in Taunton there was a view that data protection measures and budgets need to be centrally imposed rather than being put at risk of a wide variety of budget decisions at local NHS trust or GP practice level.

Time and time again comments surfaced which demonstrated that jurors do not want the NHS to lose sight of the fact that there are human beings behind the data. Although Jurors were clear that the data under discussion is routine data which, under normal circumstances, has had identifying information such as name and address removed, jurors said that public trust in the NHS could be significantly eroded if patients feel the data being used is not securely accessed, held and analysed.

*In terms of challenges, developing trust at all levels, including trust in the public, that these systems and partnerships bring social benefit and don't damage, or cause harm to patients.* | Taunton

As these issues featured quite highly in discussions across the locations one of the recommendations on data partnerships includes reference to a set of guiding principles around data security to ensure that the appropriate systems and processes are in place and adhered to by data controllers (see section 11.3).

## **4.2 Inaccurate and inconsistent data collection**

Jurors were clear that the benefits of data access partnerships rely on the quality of the data used. They voiced concerns around what they perceive to be inconsistent data collection across NHS institutions,

*It's about consistency and standards. Within the NHS patient data from one hospital is not the same as from another.* | London

They recognised that data handling is to some extent a process managed by people who might get things wrong,

*Data is great; people are erratic* | Taunton

Jurors felt that datasets are at risk of being unreliable as a result of inconsistent data collection; biased data entry and interpretation of results. Jurors in each location in various ways raised a concern that a product or service developed as result of a data access partnership would want to be promoted by that partnership in the best possible light. They felt that there was a potential risk for patients in a product, drug or service being developed in good faith, but then being discovered to be in some way flawed. They felt this could lead to no one in that partnership wanting to highlight or expose the flaw because it had been developed with NHS patient or operational data. This might lead to flawed data or inaccurate findings continuing to be used because no one would wish to admit to the flaw. Juries were clear about the correlation between data quality and research outcomes, recognising that one of the key challenges for data access partnerships research is the possibility that inaccurate data could lead to flawed policymaking and negative impacts on patient care.

*It's about making sure that results reflect reality and data is interpreted well. If AI is given biased data, we get biased results which could have serious repercussions for patient care. | London*

Participants also spoke of the importance of ensuring that data are collected, curated and shared in consistent ways to aid cross-Trust collaboration. They expressed the view in their recommendations (Jury Recommendation 11.6) that such data sharing would prevent the risk of not using resources effectively which leads to the next finding in this section on the potential burden of bureaucracy.

### **4.3 Bureaucracy and additional demands on the system**

Questions were raised about whether the NHS is able to cope with new demands on its infrastructure. The perception amongst jurors was that the system is just about coping and may struggle to accommodate data access partnerships. They said *the NHS is an unwieldy body* and that current NHS data systems *don't talk to each other*, which led jurors in London to believe that,

*A fragmented NHS compromises the efficiency and governance of data partnerships. | London*

It was felt that the NHS is already a complex system to navigate and that cumbersome processes could potentially exclude smaller organisations from entering into data access partnerships, jurors said that it is important that these collaborations don't lead to an extra layer of bureaucracy,

*It mustn't cause stagnation of the partnership, making it over complicated and causing companies to go elsewhere. | Leeds*

There was a loud call for keeping things simple.

*We thought that some of the models had the potential to be over-complex, and as a result of that complexity, it could start to impact on the day-to-day work and cost of the NHS. So, keep it simple where possible. | Leeds*

Jurors were concerned that an increased bureaucracy will ultimately stifle innovation,



Missing the opportunities afforded by data access partnerships due to bureaucracy, inadequate or ineffective processes and complex organisational structures was identified as a serious challenge, together with NHS organisations not being in tune with the fast-moving world of digital and technological innovation. As two Jurors said,

*Technology might outpace current decision-making and partnership agreements made.* | Taunton

*Financial concern should not override vital research and all it should be a priority that data projects are conducted in a timely and efficient manner using the latest techniques available.* | Taunton

Many jurors expressed frustration about the lack of co-ordinated data sharing between NHS organisations and recognised that not pushing forward with data access partnerships could lead to society missing out on valuable innovation.

*Where data sharing/access is denied valuable research will not take place.* | London

## **4.4 Financial and reputational risks**

Jurors discussed the extent to which data access partnerships carry risks for the NHS. Comments were made which show that risk is acceptable to Jurors if the benefits of data access partnerships include improved healthcare and a reduction in health inequalities.

### **4.4.1 Financial risk**

Financial risk for the NHS as a result of data access partnerships was identified as a reason for caution. There was a view that the cost of NHS investment in time and money required must not outweigh the benefits. Concerns were raised about investments not paying off due to data access partners entering into administration or selling their business on to a potentially larger and unrelated corporate partner.

*There is a risk that if the NHS has equity in a private company, that private company could sell the business quickly after using the data, and then the NHS doesn't have long-term benefits of the partnership.* | Leeds

In Leeds and Taunton jurors thought about the risk of the NHS being held accountable if the return on investment of a data access partnership is low. They expressed concern about the implications

for the NHS of a company involved making a loss and concluded that to mitigate against this risk it is important that exclusive contracts are avoided.

*A company could tilt the NHS into financial loss. Avoid partnering with just one company, have lots of different project partners. | Taunton*

A group in London talked about badly worded contract clauses leaving the NHS open to exploitation. These kinds of partnerships were deemed to be more open to power imbalances which tend to favour commercial rather than charitable, academic or public sector partners.

#### **4.4.2 Reputational risk**

Jurors pointed to the potential reputational risk for the NHS of being involved in data access partnerships where the expected social value doesn't emerge and/ or the industrial partner profits excessively. They stressed in all locations that this would undermine public trust. Comments were made suggesting that a more commercially minded NHS may lead to changing patient perceptions with the NHS being perceived as a business rather than a health care service.

*To what point does the NHS then stop becoming a non-profit organisation and just becomes a business? | Taunton*

Some jurors feared that data access partnerships may be a back door to privatisation of the NHS.

*We thought we might be sleepwalking into the continued privatisation of the NHS. | London*

*If they're making additional revenue from providing access to the data via these partnerships, then the government might think they can reduce the amount of money in general. | Leeds*

Jurors nevertheless appreciated that the NHS can be improved if it to some extent generates income and that data access partnerships are one way of facilitating this process. Juries emphasised that caution must be exercised to ensure that data access partnerships do not undermine the NHS' reputation and position as a publicly funded body. Jurors voiced the opinion throughout that the NHS should continue to be funded through taxation, rather than as a profit making or self-sustaining organisation. This includes ensuring that partnerships operate within an agreed ethos of improved health outcomes and reduction in health inequalities rather than financial gain. Jurors in Taunton flagged that the NHS should guard against a potential public backlash when products resulting from data access partnerships fail.

*Will the NHS be held accountable as a partner in a failed or failing data partnerships? | Taunton*

#### **4.4.3 Conflict of interest**

Jurors felt that data access partnerships are potentially vulnerable to conflicts of interest, with the NHS being tied into partnership contracts where personal or financial interests of the data access partners might limit options and outcomes for patients. They pointed to the risk of partnerships having or setting up programmes which conflict with NHS values.



Discussions included references to data partners tweaking data to fit their own narrative or representing data in a manner which skews results. They felt there is little to prevent data access partners using the initial data they have accessed and capitalising on this knowledge to create future products, drugs or treatments without reference to the NHS and with no benefit to NHS organisations and patients.

*What's stopping people from working within these partnerships and then going off and doing their own thing? Not necessarily taking data with them but taking the learning based on the data. |*

Leeds

There was also a view that partnerships where the NHS has a stake in partner companies might become a route to biased decision making. In Taunton, for example, jurors talked about GPs prescribing one drug over others which might be equally effective, and perhaps cheaper, because they were part of the data access partnership that created it. Jurors agreed that the best interest of patients has to be front of mind in all data partnerships rather than financial gain or contractual obligations. In Leeds the suggestion was made that the NHS should be able to leave a data access partnership if new products or services resulting from other research are proven to be better for patients,

*An opt-out clause if new developments would lead to better results than the treatment worked on in the data sharing agreement. |* Leeds



## 5. Delivering fairness

### Chapter 5 summary

Fair was established by the commissioning partners at an early stage in the design of the Citizens Juries. This concept speaks to the fact that data access partnerships are happening and as such it was important to explore how they can be structured and established in ways that feel fair to citizens. The fairness concept was settled on as it allows for open deliberation for jurors to explore the things that mattered to them. It was designed as a broad concept which focused on the relational aspects of these arrangements that it is important to explore. In this chapter we explore the eight aspects of 'fair' for data access partnerships agreed on by Jurors across each of the three jury locations as set out in figure 5.

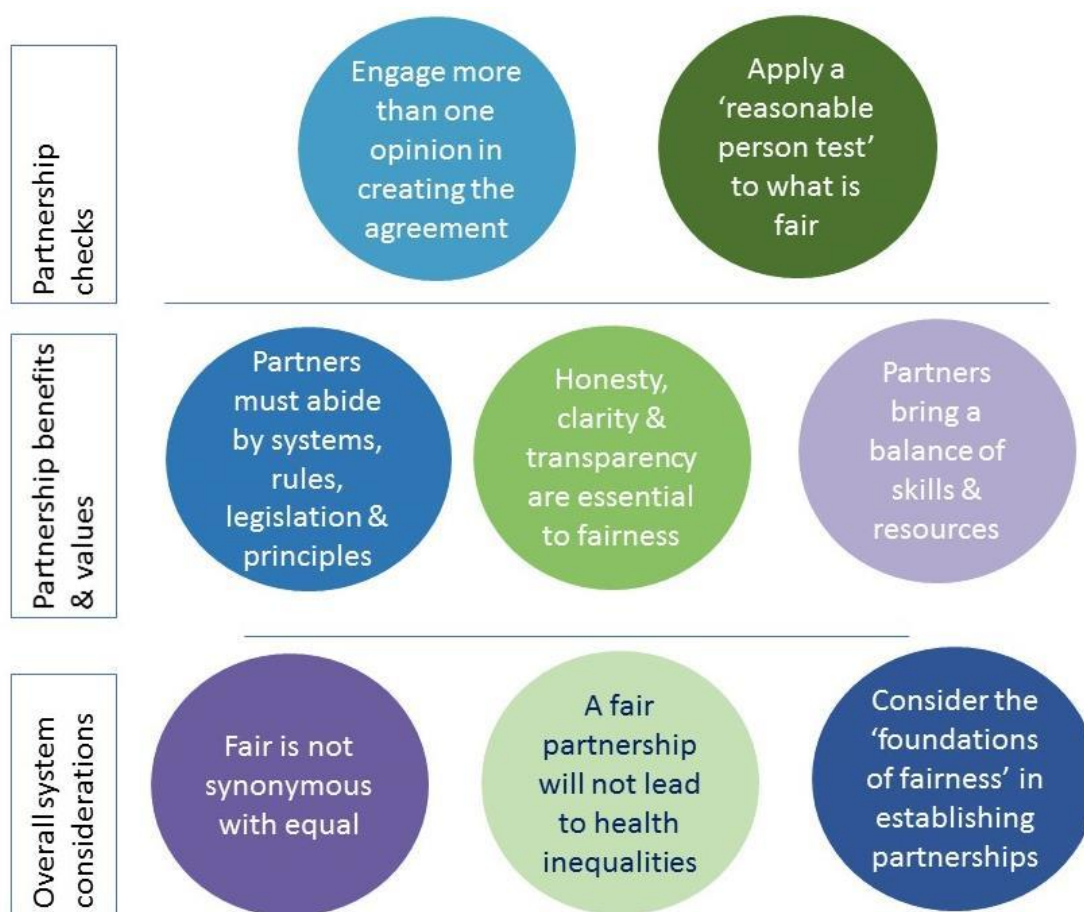


Figure 5: Aspects of fairness

Terms that came up frequently in relation to fairness were honesty, justice, transparency, clarity, openness and good communications. For Jurors fair exists in the delivery of partnerships when these elements are embedded in how the programme is delivered. The chapter ends with the 'foundations of fairness' defined by jurors which establish the framework on which a fair system is built.

At the heart of the Citizens' Juries, is the key question of what constitutes a fair partnership between NHS and researchers, charities and industry on uses of NHS data. Jurors reflected on this question initially in relation to what they consider to be fair, or unfair, in life more broadly. Jurors spoke of

analogous situations in which it was equally important to ensure that fairness is built into policy and planning. For example, when establishing equitable pay grades and scales; the tax and benefits system; access to affordable housing; creating transport infrastructures which are enabling for people with disabilities; integrating immigrant children in to UK education systems so that they are not disadvantaged; and a democratic system where the voice of the individual can really count. All of these examples were seen to involve partnerships of some kind between policy makers and shapers and other parts of society including individuals, communities, third sector partners, industry and/ or academic researchers. One participant summed up a fair partnership as,

*Fairness is equality of control and a mutual agreement between two or more parties. Fairness is justice, a mutual partnership.* | London

Once jurors had considered what fairness means in very broad terms, they were given case studies (Appendix 6) to reflect on. These presented a range of situations such as a partnership between:

- Moorfields Eye Hospital and Google DeepMind which used Artificial Intelligence Technologies to diagnose and treat eye disease
- Imperial College and Imperial College Healthcare NHS Trust combining clinical and staffing data to help plan staffing levels in intensive care units
- Musgrove Park Hospital and CGI<sup>2</sup>, Marand<sup>3</sup> and the Apperta<sup>4</sup> Foundation working together to introduce e-Prescribing in hospitals linked to the Electronic Patient Record to reduce deaths and illness caused by prescription drug errors.

A consideration of fair in respect to these general social norms led Jurors into discussions on fair within data access partnerships. Eight aspects of 'fair' were highlighted by jurors in each of the locations (see figure 5).

## 5.1 Partnership checks

### 5.1.1 Engage more than one opinion

Jurors were clear that they felt it would be unfair if only one person, with one perspective on data access partnerships, sets the terms for the partnership. They called for data access partnerships to be established using collaborative systems through which the voices of all those who work on the programme, as well as external advisers, contribute to the framework under which it operates. They said,

*More than one opinion is engaged in assessing what's fair, so every person reviewing a partnership has a voice and that voice is heard.* | Taunton

*If one person or body holds all the power, then the other party hasn't got as much knowhow, is in the dark.* | London

Jurors stressed the importance of a wider group of people being involved in deciding what the



<sup>2</sup> CGI: independent IT and business consulting service


<sup>3</sup> Marand: Healthcare IT specialist

<sup>4</sup> Apperta Foundation: clinician-led, not-for-profit company to promote open systems and standards for digital health and social care.

partnership should look like, including risks and rewards, current and future benefits and managing a partnership so that all those involved have an equal chance of benefiting from the process.

### 5.1.2 Reasonable person test

Jurors thought that data access partnerships apply a 'reasonable person' test to check how each partnership is established and what it should involve. The 'reasonable person' is an ideal, but there was a sense that as most people strive for fairness in life more generally, it is also right to assume that those working on the agreement will consider what is reasonable as also being fair. Jurors considered that it would be,



Apply a  
'reasonable  
person test'  
to what is fair

*Challenging for fairness to be built into the process and preserved throughout.* | Leeds

But they felt that it was important to strive for this from the beginning of the process.

## 5.2 Partnership benefits and values

### 5.2.1 Abiding by the rules

Jurors asked that a balance is struck as part of the management and delivery of data access partnerships. They felt that partnerships should apply and abide by rules and principles,



Partners must  
abide by  
systems, rules,  
legislation &  
principles

*To be truly fair (partnerships should have) contractual obligations with enforcement in place if they are breached.* | London

However, whilst clear obligations are important, Jurors also felt that agreements must at the same time remain flexible and open to compromise in the interests of fairness. Jurors were concerned that data access partnerships should establish agreements which set out from the beginning what each partner considers fair. They saw these as regularly reviewed, living agreements given that partners' perceptions of fair might change in the lifetime of the partnership. The call in each location was for partnership agreements to operate fairly by,

*Creating a robust, measurable system which is also flexible and can evolve.* | Leeds

Jurors considered that fair meant developing simple systems to avoid complex bureaucracy. Jurors were concerned that small tech start-ups, for example, might be deterred from remaining within a bureaucratic system which would be unfair for the remaining partners, and for the potential outcomes for patients who would not benefit from the fast-paced innovations start-ups have the potential to bring.

### 5.2.2 Honesty, clarity and transparency

Honesty, clarity of purpose and transparency are seen as essential in delivering fair within the system. Jurors felt that if these factors are placed at the heart of fairness then other essential elements would follow naturally including:

- Brokering partnerships which balance the risks and rewards for all partners
- Ensuring all those who contribute to the NHS, including patients, experience positive outcomes from data access partnerships
- Health inequalities (see 5.3.2) could be addressed if benefits and risks are openly discussed and distributed nationally.



*Fairness depends a lot on how much information we've all got. The different partners have got to assess the whole process and we in society have to know what's going on with our data and why, otherwise it's not fair.* | Leeds

Transparency was seen as an important principle for how partnership models should operate in the interests of fairness. Transparency was felt to apply to the companies involved in partnerships, such as open information on who owns them. It also applies to the goals and aims of the partnership, how it would work and the results it achieved. The benefits, financial or otherwise, that any partner would receive should also be publicly available. As one group said:

*All efforts should be made to inform the public about what's happening with their data.* | London

### 5.2.3 A balance of skills and resources

An equally important value in terms of fairness was seen as partnerships having and recognising a balanced set of skills and resources within the partnership. As one Juror put it,



*Fairness is a lack of undue influence that might disrupt things being fair.* | London

Jurors felt that fair would be realised if all partners are equally recognised for the diverse skills, capacity and resources they bring to the partnership through expertise in, for example, medical research, drug development, innovations in artificial intelligence (AI), and/ or data management, handling and analysis.

## 5.3 Overall system considerations

### 5.3.1 Fair and equal

In exploring the concept of fairness Jurors moved from an initial starting point that 'fair' means 'equal', to reflecting that whilst equality is a central factor when ensuring the benefits from these partnerships are distributed evenly around the country over time. What is central to fairness within partnerships is in fact 'equity'. They defined equity in relation to fairness as being when data access partners are given the conditions they need to be successful. As one Juror in Leeds expressed it,



*Fair is not necessarily the same across the board, but it means that each partner is supported to bring, do and give what they can.* | Leeds


and in Taunton,

*Business and commercial negotiations need to be fair to all partners recognising that partners may bring more or less to the partnership at any given time, but what they bring is valuable and valued.*

| Taunton

### 5.3.2 Health inequalities

In deliberations on fairness jurors also began to grapple with big questions about whether inequalities could emerge at either a regional or a national level depending on how fair terms for the partnerships are agreed. A number of participants said that they felt that in order to be fair, the benefits of the partnership should be realised across the country to ensure an even distribution of positive outcomes rewards.



A fair  
partnership  
will prevent  
health  
inequalities

*No postcode lottery – this must be nationwide.* | London

*There should be a national framework of quality and fairness across all regions. Any savings that come from (partnerships) should benefit the NHS as a whole so for us the focus is very much on a national rather than a local framework.* | Leeds

*We looked at wider benefits to all parties as opposed to just certain trusts having the information, so then negotiations are much more widespread across the whole of the country so that everybody benefits from it.* | Taunton

Where jurors did not agree with this national approach it was because they felt those who supply the data, including a single NHS Trust, should reap the immediate benefits from doing so. In general those who supported this view did feel that over time the benefits should and could be accrued nationally. The balance which seemed fair to most was expressed by one participant as,

*Good for work to be done locally but then expanded so that benefits are available everywhere and there is fairness for all regions.* | Leeds

It should be noted that Jurors in Taunton, the most rural of the three Jury locations, discussed the issue of data access partnership accruing benefits locally with particular passion. Their concern was that the wealthier parts of the country might receive all the benefits, being most likely in their view to undertake these partnerships in the first place. They felt this might increase health inequalities. A Juror said,

*It should be the whole NHS rather than those who live in affluent parts of the country who have got hospitals with more money to spend on these things. If we go down that route we widen the equality gap and the postcode lottery. My personal view would be that if it is of benefit to the NHS, it shouldn't just be Oxford or Sheffield. We all contribute to the NHS so we should all benefit from this research.*

| Taunton

The conclusion drawn by Jurors across the three locations was that the end goal should be that benefits of data access partnerships are distributed across the country over time; even if in the short-term the benefits are initially only realised at local and regional levels.

For jurors the balance between regional and national benefits is important. The nationally representative survey was therefore used to see if these views resonated/were represented similarly in the survey with people who had not been exposed to a range of contextual information and evidence. We found (see figure 6) that when we asked survey respondents about where benefits should be focused, a similar sample of people responded that they agreed with each of the statements, suggesting that people do not have a common understanding of where benefits would bring the best outcomes.

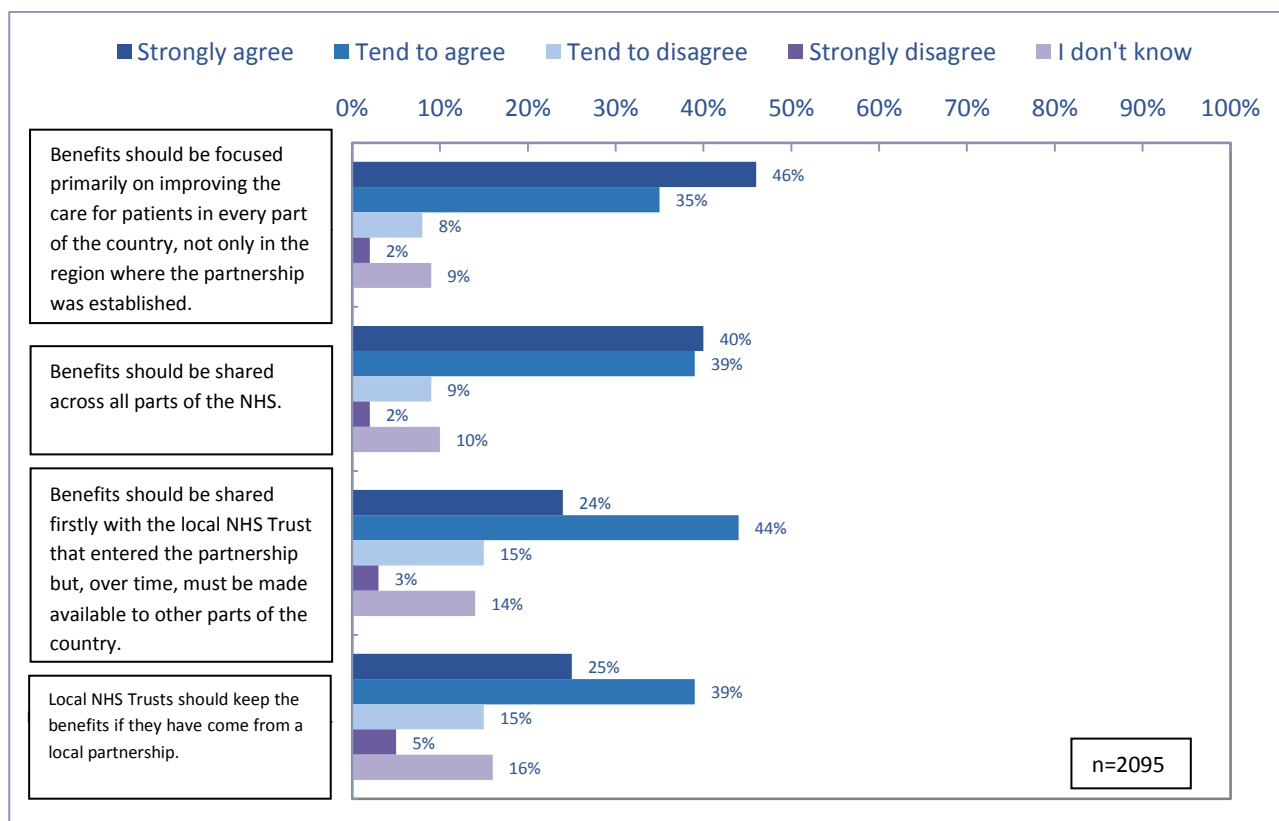


Figure 6. To what extent do you agree with the following statements about data access partnerships between the NHS, charities, universities and industry?

### 5.3.3 Foundations of fairness

Jurors appreciated the significance of the question they had been set by the commissioning partners. This led to groups in each location agreeing that ‘fairness’ should, as a matter of principle, be built into all data access partnership systems from the outset, as set out in one of the eight aspects of fairness set out at the beginning of this chapter (figure 5). They described these ‘foundations of fairness’ as including a range of factors described in figure 6 which should be applied in general terms nationally *and* for specific local data access partnerships.

Consider the ‘foundations of fairness’ in establishing partnerships

### Five fairness foundations highlighted by Jurors

- A **risk/ benefit analysis** ensures risks and rewards are balanced across the partners it should integrate a review of the consequences for health and impact on NHS values
- A consideration of **longer-term impacts** of the partnership will avoid unfairness arising from unintended consequences
- Establishing a **level playing field** will recognise the partners for the value they bring regardless of size or commercial value
- A **portfolio of test cases**, built up over time, will show the learning from data access partnerships and provide a **fair test for the value** of products that result from the work.

Figure 6: Fairness foundations

Jurors said,

*This is all really (new). Build up a precedent of case and case histories. | Taunton*

*There needs to be equitable risks and rewards so that no partner is at a disadvantage. | Leeds*

*Opportunities for small companies as well as massive ones. Recognise that you have to create a level playing field for (the partnership) to be fair. | Leeds*

*The benefits to fair partnerships (are that they) create fruitful, productive relationships and better patient outcomes. | London*

One of the groups in London said that a balanced view is required to ensure society takes advantage of the opportunities data partnerships offer. They felt that it would be unfair to patients if the NHS denies third parties access to patient data.

*The NHS is holding all this information on the patients, and it might not be fair for them to withhold it from other parties. | London*



## 6. The importance of effective communications

### Chapter 6 summary

Section 5.2.2 highlights the importance of transparency in achieving fairness. One of the ways of delivering this is through effective communications. This chapter therefore reviews two main points raised by Jurors on this issue – that:

1. Effective internal communications between data access partners and within the NHS are needed to ensure that there is transparency between partners and amongst clinicians and others working in the NHS to achieve a clarity of purpose on what data access partnerships are doing and delivering, and why.
2. External communications should clearly [communicate](#) to society the existence of data access partnerships including the types of organisation involved; the data they use and how, and why it is used.



Figure 7: Some Juror reflections on communications

The section also looks at survey findings on the extent to which the population is currently aware of the NHS granting data access to external organisations for research and innovation.

Jurors saw clear and transparent communications as essential to the future success of this endeavour. Without effective communications jurors were concerned that data access partnerships would be less effective and would not have the necessary trust from potential partners and citizens required to enable them to deliver improvement and innovation in healthcare and NHS operational systems. It was felt that there was a positive story to tell about data access partnerships, which should be shared as early as possible: within the health ecosystem, within partnerships themselves and with publics across the country, to improve internal NHS communications, which was seen as a prerequisite for any data access partnership with the NHS to be successful,

*Focus on internal knowledge sharing in UK NHS services, better communication should be improved as a basic before partnerships are set up. | Leeds*

The second aspect of this was that jurors felt that data access partnerships should become very effective in learning from the results of the work,

*If one organisation knows something that the other doesn't in a partnership, then that affects its effectiveness and that's going to matter. | Taunton*

They also said it was important to use good communications to prevent potential duplication of effort with one partnership embarking on a research programme that has already been exploited by others. They felt that partnerships should highlight where concrete benefits from the partnerships have been realised in terms of improved efficiency, new medicines or medical technologies and/or more effective distribution of resources. They suggested that improving public awareness of what data NHS patients' data and operational data is used for will enable people to make more informed decisions about their confidential patient information for research and planning purposes. In London participants recommended,

*A large communications plan be initiated to educate the public about data partnerships and enable them to choose specific models and opt-in/ out of participating. | London*



Figure 8: Handout 2 – given to Jurors on the four broad uses of NHS information

## 6.1 Awareness of data access partnerships

At the start of each of the Citizens' Juries jurors were asked to what extent they had thought about the partnerships the NHS has with researchers, charities and industry for its work. In all locations the majority of the group had either never, or only occasionally, thought about these partnerships. It was therefore important to explore if this lack of awareness was true more broadly in the nationally representative survey.

The survey showed that 63% of the population said they were unaware of NHS organisations giving universities, charities and industry access to NHS data. A higher percentage of C2DE socio-economic groups (67%) were unaware of NHS organisations granting access than ABC1 groups (57%). Respondents from an Asian background were the ethnicity most likely to have heard of data access partnerships (52% n= 105). People under 34 were the sub-population most likely to be aware of data access partnerships (figure 9).

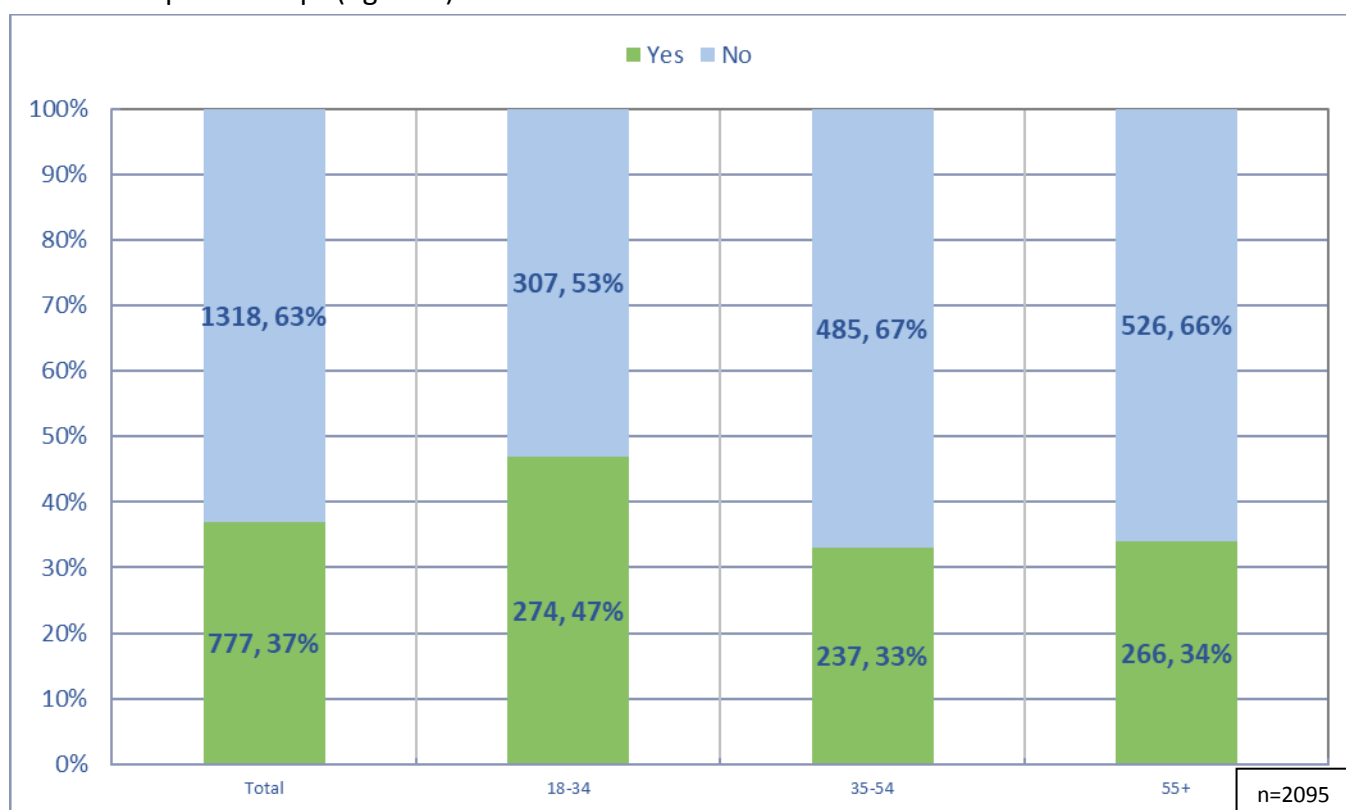


Figure 9 Before today, were you aware that the NHS gives universities, charities and industry access to NHS data?

During the Citizens' Juries, when they learnt more about data access partnerships through handouts, case studies and expert witness presentations (Appendix 2), jurors increasingly felt that people should know more about such partnerships. It was felt that raising public awareness about data access partnerships, and specific terms relating to the ways in which data is used, would build trust in the work of all partners by highlighting the positive achievements of successful programmes.

In the survey, the 37% of respondents who said they had heard of the NHS granting access to data were asked where they had seen, read or heard about the NHS giving charities, universities or industry access to data. Friends and family (38%), Television (37%) and Newspapers (33%) were the most likely sources of information for the population. Of those who were aware of NHS granting

data access, older people of 55yrs+ are more likely to have heard through newspapers (45%) and younger people more are more likely to have heard through family/friends (51%). In comparison, Facebook was cited as a source of information by 13% and Twitter by just 8% of the population. This suggests that word of mouth for younger age groups and traditional print media are appropriate communication channels to reach these age groups, but it perhaps highlights the need for more work on this and supports the recommendation made by London jurors that data access partnerships require a comprehensive and co-ordinated communications strategy to raise awareness of their existence and potential value.

## 6.2 Where information should be found

A key reason for improving public understanding of the use of NHS patients' data and NHS operational data is to visibly demonstrate that risks associated with these research programmes are fully considered. Equally, that work is done to minimise these risks, and that the risks can be seen to be outweighed by the benefits of discovery, development, implementation and continuous improvement. On a practical level, jurors proposed that as a minimum each data access partnership should publish reports and case studies so that anyone who wishes to can understand the detail of how the data has been used.

*People providing data should not be left in the dark. The public should know the purpose of the research and how they'll achieve that. | Leeds*

*Open information regarding partnerships; different partners and what they own should be clear and available, so the public can find it and use it, but also trust that it's an open process. | London*

A final point was raised in all locations and highlighted by the Jurors in London. They spoke of people needing to be more aware of the national data opt-out service to build trust and confidence in the system overall. They did express the view that people might be more resistant to data access partnerships using patient data if they feel that the benefits/ profits which may come from the partnerships are not being realised in terms of improved patient outcomes. As one London juror put it,

*The public will opt out if vast profit is made from their data being sold and they don't see benefit in treatment and public service. | London*

Given the emphasis placed on communications by jurors, the national survey was used to explore whether the wider UK population felt similarly, without having reviewed the same evidence as jurors. 82% of survey respondents said they expect the NHS to publish information on data access partnerships. When responding to where they would expect the NHS to publish this information the national NHS website(s) was the highest ranked.

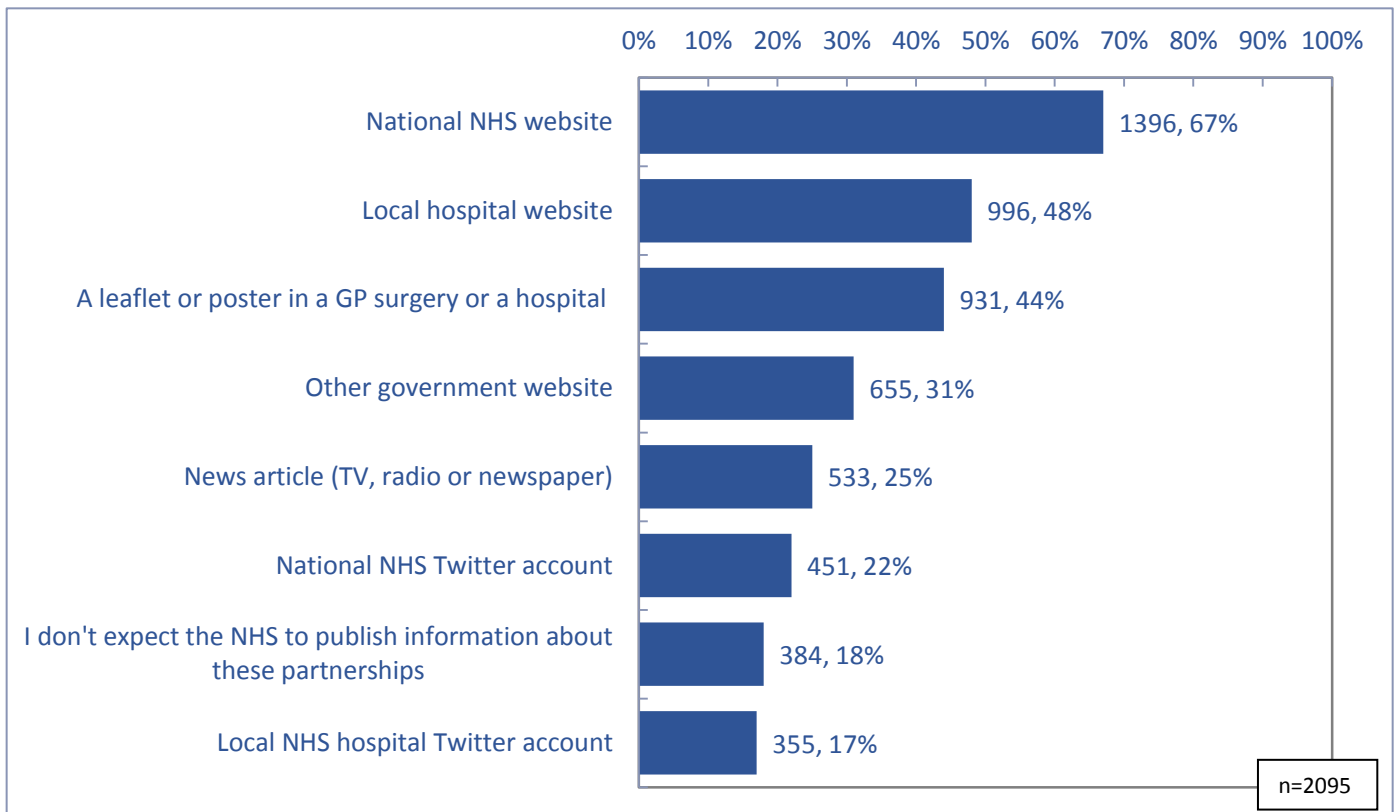


Figure 10: Where would you expect the NHS to publish information about data access partnerships?

When analysing the survey data by age the national NHS website remains the first preference for all age groups, particularly older people (75%). Older people are also more likely to favour leaflets or posters (52%) as a means of communication but younger people (35%) are less likely to value these methods. Respondents from all socio-economic groups also favoured NHS website(s) at a national level as the primary source of communication, demonstrating the trust people have in these communication channels.

# 7. Governance

## Chapter 7 summary

Ensuring systems are established for effective governance of data access partnerships was seen as essential by each of the Juries. Ensuring all data access partnerships are fair, transparent, accountable and contribute to better health outcomes was an important part of every juries' discussions and final recommendations. When discussing how fairness could be achieved, invariably suggestions around governance and a governing body were raised. There was little awareness of the current governance of NHS data or the role of NHS Digital or NHSX, so the comments made here are not a critique of any current arrangements, but more a 'blank slate' design for how jurors thought governance should work when applied to partnerships using NHS data.

In this chapter, we report on the discussions about a governing body, its role, who would be represented on it, and the kind of standards it would be guided by. We also report on the survey findings, where almost 74% of respondents said they believed that citizens should be involved in some way in decisions about data access. The principles for how governance should operate raised by jurors are shown below (figure 11):

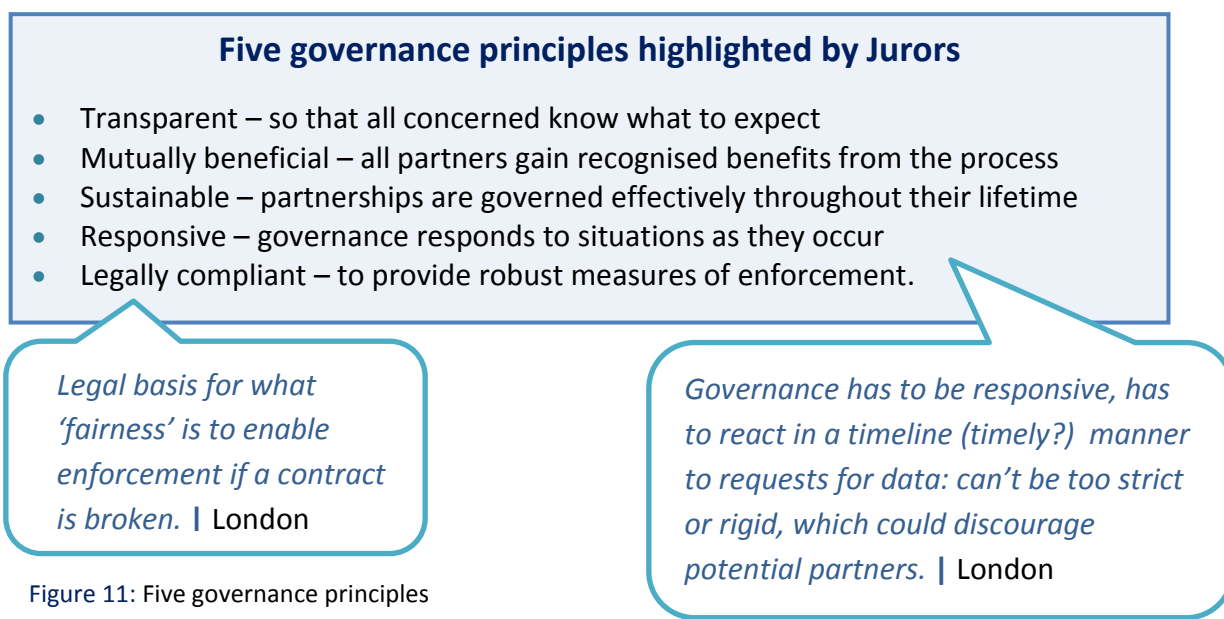


Figure 11: Five governance principles

## 7.1 Governing body

All juries raised and discussed the concept of a body to ensure partnerships are fair, transparent, accountable and ethical. All juries also included a recommendation for a governing body in their final deliberations. In this section we explore the role of this body and who jurors felt should be represented on the body.

### 7.1.1 Role of governing body

When discussing the role of a governing body, jurors used words such 'scrutinise', 'advise', 'oversee', 'checks and balances', 'audit', 'proactive and reactive', 'expertise'. They also used a range of terms to describe the body, including: 'watchdog', 'ombudsman', 'regulatory body', and 'governing body'.

Most jurors had little awareness of the current NHS data governance regime, although expert witness presentations provided them with the current landscape. Their views though, as presented in this chapter, should be seen as ‘blank slate’ thinking rather than a critique of what happens now.

Recognising the scale of the task of governance, some jurors split out governance activities into:

- Proactive activities, such as setting up the principles and getting people involved,
- Monitoring activities, such as auditing and
- Reactive activities such as firefighting if problems arise.

*One is proactive, get the right principles in place and the right panel in place so you’ve got a good chance from the start that governance will go well. However, reactive, if stuff goes tits up, you need a firefighting body that can come in and deal with it, like an ombudsman. | Taunton*

In Leeds, there was the suggestion that local, regional and national levels of governance might be needed.

*Governance of applications is a huge job. It should be provided from the relevant departments so as not to dissuade researchers. | Leeds*

*A national framework should be established with no more than three levels of accountability, and an independent ombudsman should be established. | Leeds*

The roles the jurors thought a governing body would play ranged from establishing the principles for fair partnerships, through to reviewing their performance and gathering learnings. Jurors in Taunton tended to see the body as being primarily responsible for setting standards and reviewing performance – as described in their final recommendation (page 58). However, most jurors did not think it enough just to have a set of guiding principles. They wanted to see ongoing governance:

- Establishing principles to guide the formation, conduct and evaluate partnerships (informed by government & public consultation)
- Vetting applications for data sharing against these principles
- Distributing data sharing requests to appropriate NHS organisations
- Performing impact assessments to reduce risk of unintended consequences and data misuse
- Negotiating levels of data access
- Negotiating value exchange
- Preventing duplicate partnerships
- Improving communication between NHS Trusts
- Ensuring laws on fair partnerships are complied with
- Firefighting if problems arise
- Reviewing partnerships to provide overarching learnings

*Democratically appointed public servants must have a veto over the uses and the applications of data partnerships e.g. ethic committee model. | Leeds*

*You need a firefighting body that can come in and deal with it like an ombudsman. You don’t just set up a partnership, ongoing governance has to be in place to make sure it’s on the right track. | Taunton*

Several jury discussions included the concept that governance, or some elements of it, should be independent. The quality of independence was seen to be important in tasks such as auditing a

partnership to ensure it has complied with guiding principles, valuing the data and taking into account the needs of all partners, NHS and others.

*Independent scrutiny over decision and partnership to ensure neither side is disadvantaged.* | Leeds

The Leeds jury discussed the merits of anonymising data applications from charities, industry and academia to avoid preferential treatment for larger companies and included this in one of their final recommendations.

### **7.1.2 Representation on governing body**

Jurors wanted to see representatives from the NHS, academic, charity and industry partners, individuals drawn from communities and publics and an independent figure involved in governance. Representation, they believed, needed to be equal, democratic and non-hierarchical.

*An appointed panel, skilled panel made up of experts to represent diverse aspects.* | Taunton

*Governance needs unbiased, transparent, honest, equal representation of NHS, industry, charities, researchers.* | London

*Simple equation: Public representation + independent regulator + NHS representative + Client representative = fairness and accountability.* | Leeds

Jurors expected to see a mix of specialists and non-specialists represented in the governing body. They felt that the inclusion of the public voice would help to avoid bias and that it was an important principle that those whose data is being used were represented.

This was reflected in the responses to the survey, where 74% of respondents said citizens should be involved in some way in decisions on access to NHS data for research.

There was an expectation that the NHS would be represented by clinicians, management and legal teams. Partners would be represented by a cross section of the industry, academic and charity organisations. Independent specialisms might include lawyers, data security specialists and business negotiators. Being independent of the NHS and the partner was seen as important role for members of the governing body to help ensure the long-term sustainability of partnerships and the suitability of potential partners.

There was an assumption that partner organisations would be well resourced with data specialists, business negotiators and legal teams. Jurors wanted reassurance that the NHS would be well represented in these fields to ensure partnerships were based on a fair evaluation of the value of the data and to uphold data security.

### **7.1.3 Governance standards**

When discussing the terms that should govern partnerships, jurors talked about both legal requirements and guiding principles.

Legal requirements were seen as necessary for aspects of partnerships such as data security. This would include how data is transferred and stored and ensuring that all data is returned at the end of the partnership contract.

*What is in place stopping third parties from keeping the data on the side?* | Taunton



Jurors felt that there should be an overarching legal requirement for all partnerships and that this should be universally adhered to. There was also the belief that legal requirements would help avoid micromanagement.

*Legal requirements that are initially set up need to be thorough and effective so that it doesn't need micromanaging. | Leeds*

When it came to guiding principles, some jurors wanted to see 'robust flexibility'. They recognised that some principles need to be overarching and national, whilst others may vary depending on the type of partner e.g. industry, academic or charitable. Concern was expressed that partnerships should not be negotiated on an individual basis as this could create inconsistencies and lapses in standards.

*We agreed that partnerships must be driven by agreed principles from government and regulators and public consultation. | Leeds*

*All partnerships have to follow a set of overarching rules, then beneath this, depending on whether they're researchers, charities or industries, because they're all different, they'd have to follow a subsequent set of rules. | Leeds*

Practical examples of transparency given by jurors included a public register of organisations using NHS data and partnerships submitting final reports to the governing body.

*A final report must be submitted in detail of all the processes by the partner at the end of the study, along with further recommendations for future research or partnerships, to be submitted to the ombudsman. | Leeds*

In summary, jurors were quite consistent in their belief that governance had a role in establishing principles, monitoring/auditing compliance, firefighting problems that arise within partnerships and reviewing learnings and outcomes. Jurors also believed that there should be equal representation on governing bodies to enable the NHS, partners, the public and independent specialists to have a say. The standards that partnerships need to adhere to are both legal requirements and guiding principles, most of which would be applicable to all partnerships, with some flexibility to take account of the type of partner or local conditions.



# 8. Citizens' involvement

## Chapter 8 summary

Jurors clearly expressed their view that citizens should be more involved at various levels, including policy and practice, in the establishment and management of data access partnerships. They saw opportunities including:

- Citizens' Juries and deliberation for key decisions
- Public votes to approve local partnerships
- Playing a role in governance boards

Having a voice in how data is used within and outside the NHS, and making assessments on what is fair, are the threads which underlie these jury discussions. The national survey built on these findings to ask to what extent the public should be involved in decisions on how data access partnerships should work. The findings demonstrate that there is an appetite for citizen involvement within the wider population with 3/4s of respondents responding to the question with 'yes'.

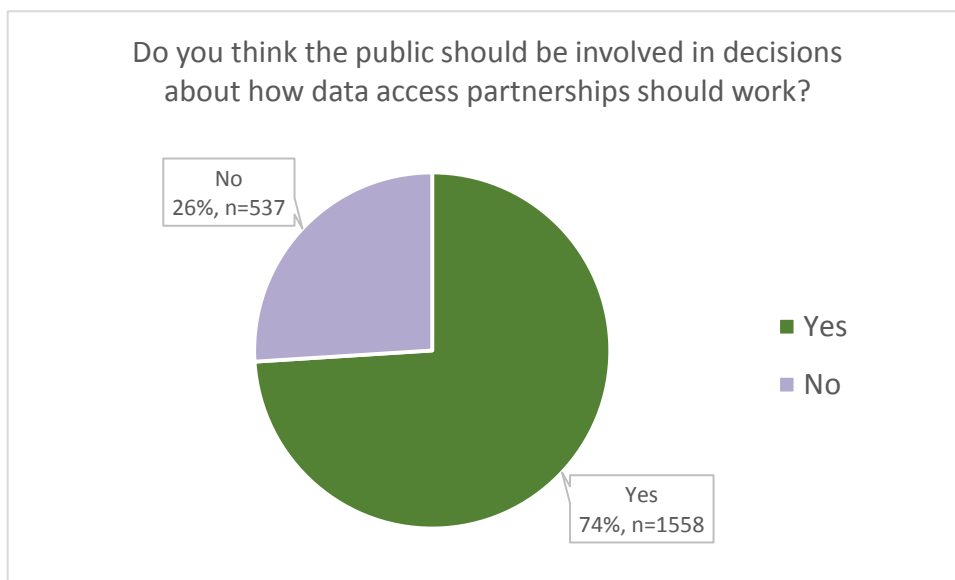


Figure 12: Citizens' appetite for involvement

As we share in this chapter, survey respondents, who did not have the benefit of week-end deliberation on the subject, placed a higher priority in being involved in deciding on the criteria by which data should be shared than on other forms of citizen involvement.



Having stressed the importance of both internal and external communications in the development and management of data access partnerships, jurors also reflected on the role of citizens as a key stakeholder in the process given that patients' data is the resource under discussion. In all locations the fact that juries had been established to think about what constitutes fair in uses of NHS patients' data and NHS operational data was in and of itself meaningful. To jurors it demonstrated that the commissioning bodies were open to listening to a range of views on complex NHS negotiations, willing to invest in providing people with information to enable them to contribute meaningfully to these discussions. As two London groups put it,

*This citizens' jury is a reason for optimism. It shows that people's voices are being heard.* | London

*The NHS could just roll this out and then whitewash concerns, but they're listening to us.* | London

It could be argued that citizens' involvement in deliberations on data access partnerships requires as a pre-requisite that people are interested in the subject. In the survey respondents showed that such interest exists with 73% of the population saying that they are either very (31%) or fairly (42%) interested in how researchers use NHS data to improve patient care and only 6% saying they are not at all interested. There is no doubt that Jurors' interest in these discussions increased as they immersed themselves in the evidence and specialist materials. As one Leeds participant said,

*The empowerment we've all been given has been amazing. I've never known anything like it and I'd really like to continue to contribute to discussions like this.* | Leeds

and in Taunton,

*We are making a contribution to the future of the NHS. Our views matter. It's not just a select few high up rich people, it's us, the normal people. I've learnt a lot and said more than I thought I could given what I knew before I came. I've really enjoyed talking about this important subject.* | Taunton

The questions asked in the survey were prompted by what the jurors discussed. Citizen involvement in data access partnerships was a thread running through discussions. It was raised initially by jurors in discussions on the hopes for and concerns they have about data access partnerships which was the process for the end of the second day of jury deliberations (see appendix 6) when they had received a full set of expert witness presentations (appendix 2) and reviewed the case studies (appendix 6). Jurors also reflected on involvement as they built up to creating their recommendations at the end of the third jury day. This led to questions in the survey including those on whether, and in what ways, citizens should be involved in decisions on how data access partnerships should work. The findings show that 74% of survey respondents felt that citizens should be involved in these decisions. As figure 13 illustrates, of those 74% (n: 1558), 32% felt that the most appropriate form of involvement was deciding on the criteria by which data could be accessed followed by 'being informed but not involved in these decisions' (22%) and 'being involved in research so that decision makers are aware of citizens' views' (21%). A Respondents' age makes little difference to these findings except that those in older age groups are more likely to favour being 'informed' rather than 'involved' in decision making (29%).

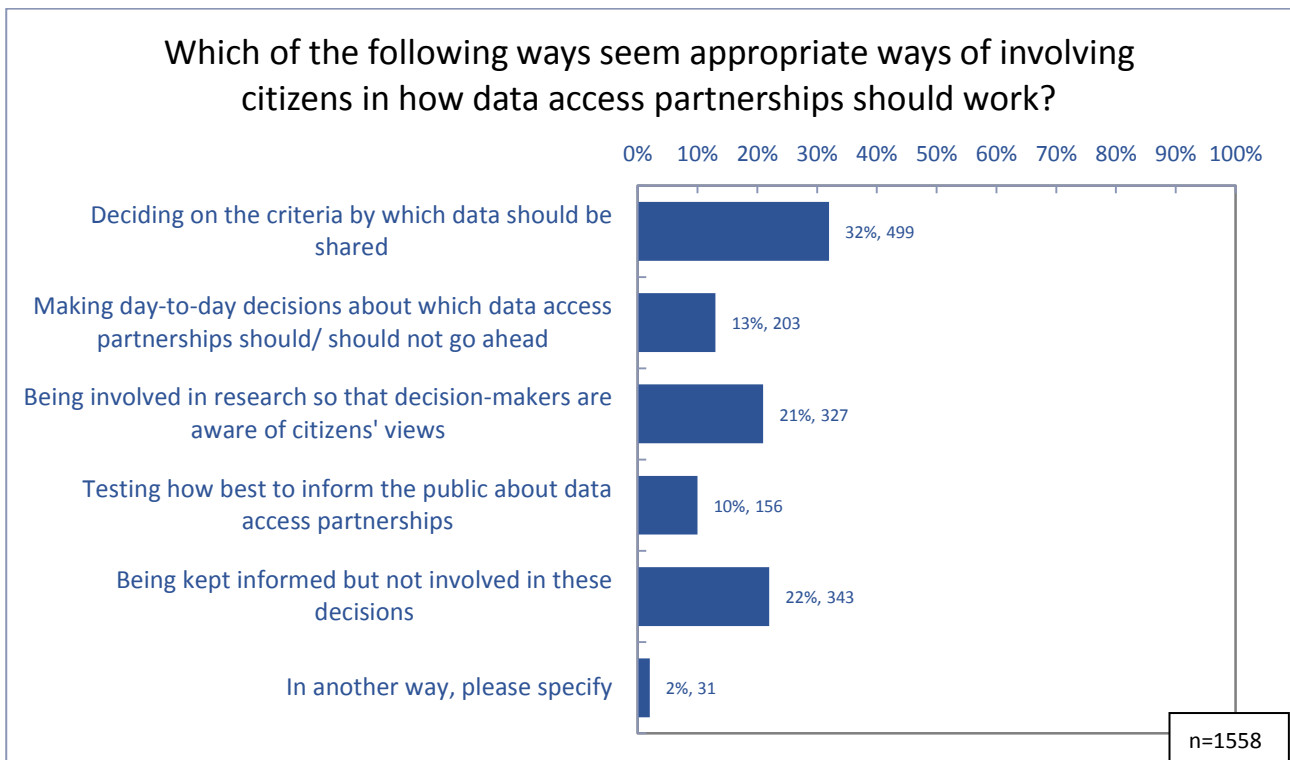


Figure 13: Appropriate ways of involving citizens

Jurors, having reviewed expert witness evidence and the case studies, proposed a comprehensive role for citizens’ in data access partnerships ranging from continuing the use of citizens’ juries to test the principles which will lie behind the management of data access partnerships, to having local public votes to approve research studies which involve the use of NHS patients’ and NHS operational data, including citizen representation on the management panels.

*The public should be regularly updated on these partnerships and allowed to voice their concerns.* | London

*Citizens’ juries which provide oversight, make recommendations and ask questions to make (data access partnerships) fair.* | Leeds

Whilst there was a strong desire for citizens’ involvement in each location, some stressed the importance of proportionality. They felt involvement had to be balanced, measured and only when appropriate, so as to work efficiently and not to hamper genuine and reasonable developments because of an overly complex process involving publics at all stages. This is summed up by one Juror as,

*There should be public input into the framework, but not necessarily every decision.* | Leeds

In Taunton Jurors felt that these citizens’ juries had been important in ensuring the voices of people with no technical knowledge of the subject were being considered at this early stage of the development of data access partnerships. There was no sense, however, that any further depth involvement was required as long as the NHS complies with GDPR throughout the process and that efforts are made for,

*Improved public awareness and increased transparency on the fact that the NHS does get involved in these partnerships. | Taunton*

In Leeds and London Jurors called for as much citizen involvement as possible in decision making on data access partnerships. They made specific proposals for citizens' involvement in, for example, decisions on which partnerships should go ahead using locally collected data and for deliberative engagement to continue when significant governance issues were being discussed. Jurors in these locations asked for people in communities to be part of the governance structure for data access partnership. As one Juror said,

*Equal representation of NHS, partners and voice of the public in governance processes. There should be an increase in the number of citizens' juries. | London*

Across all locations it is clear that jurors and the national population see a role, whether to a greater or lesser extent, in shaping and informing the development of data access partnerships. A Leeds juror perfectly summarises the views of many in terms of citizens' involvement in decision-making.

*Once the (data access partnership) application is submitted, a Citizens' Jury should oversee decision-making. A jury could make it fair because theoretically, it is the public's data. | Leeds*

## 9. What does value look like?

### Chapter 9 summary

Jurors described defining value and ascribing a value to NHS patients' and NHS operational data as complex and challenging.

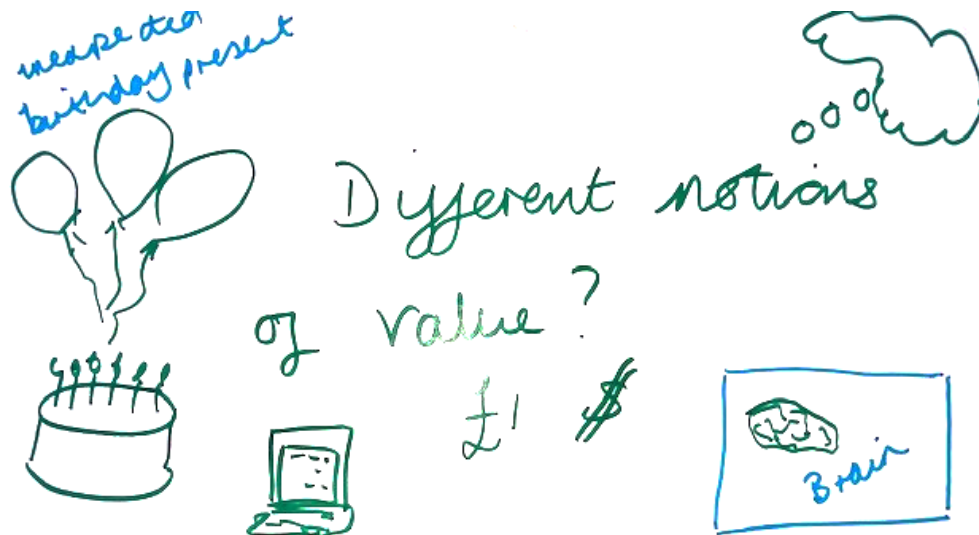


Figure 14: Complexities of notions of value from a present to skills sharing and monetary values.

This section highlights how Jurors perceive value to be framed within data access partnerships. Initial points are made about realising value for partners. Jurors felt that the skills and capability of partners, including for staff within NHS organisations, had the potential to impact on how value is framed and realised, this section therefore ends with their reflections on this issue.

### 9.1 Framing value

Discussions on value arose unprompted at the end of the second day of jury deliberations when jurors were thinking about the key messages they had at this point. Questions arose about value and how to define it. On the third day of deliberations the facilitation team prompted for reflections on how value would be realised for data access partners. The earlier unprompted exposed just how complex an issue it is to place a value on something as wide-ranging as NHS patients' and NHS operational data. Jurors saw that this was a multi-layered matter which might equally include cost in pounds and pence, measurable benefits in terms of new products which have an impact on the outcomes for patients, and highly intangible longer-term value such as citizens being more trusting of partnerships between the NHS and external partners because of being more aware of partnership successes. Jurors quickly came to an understanding of the complexities of the subject but there was wide-spread agreement that those involved in data access partnerships should be clear on what 'value' means for them,

*We and (data access partners) sort of need to know what the value actually is; is it money, is it research? Value can be anything. But I think in this partnership, we need to establish what value is.*

| Leeds

This question came up in each location leading to wide-spread agreement that value should be defined very broadly in the context of data to include monetary and social value.

Jurors also considered that value might mean different things to the various data access partners. Figure 15 summarises the main areas of value as perceived by Jurors. Understandably, not having a depth knowledge of the NHS and data management and relying on the evidence brought to them in the jury room, jurors focused more on what could be done with the data and the outputs they perceived would emerge from the partnerships. They did not focus their attention on operational or data management improvements such as data curation.

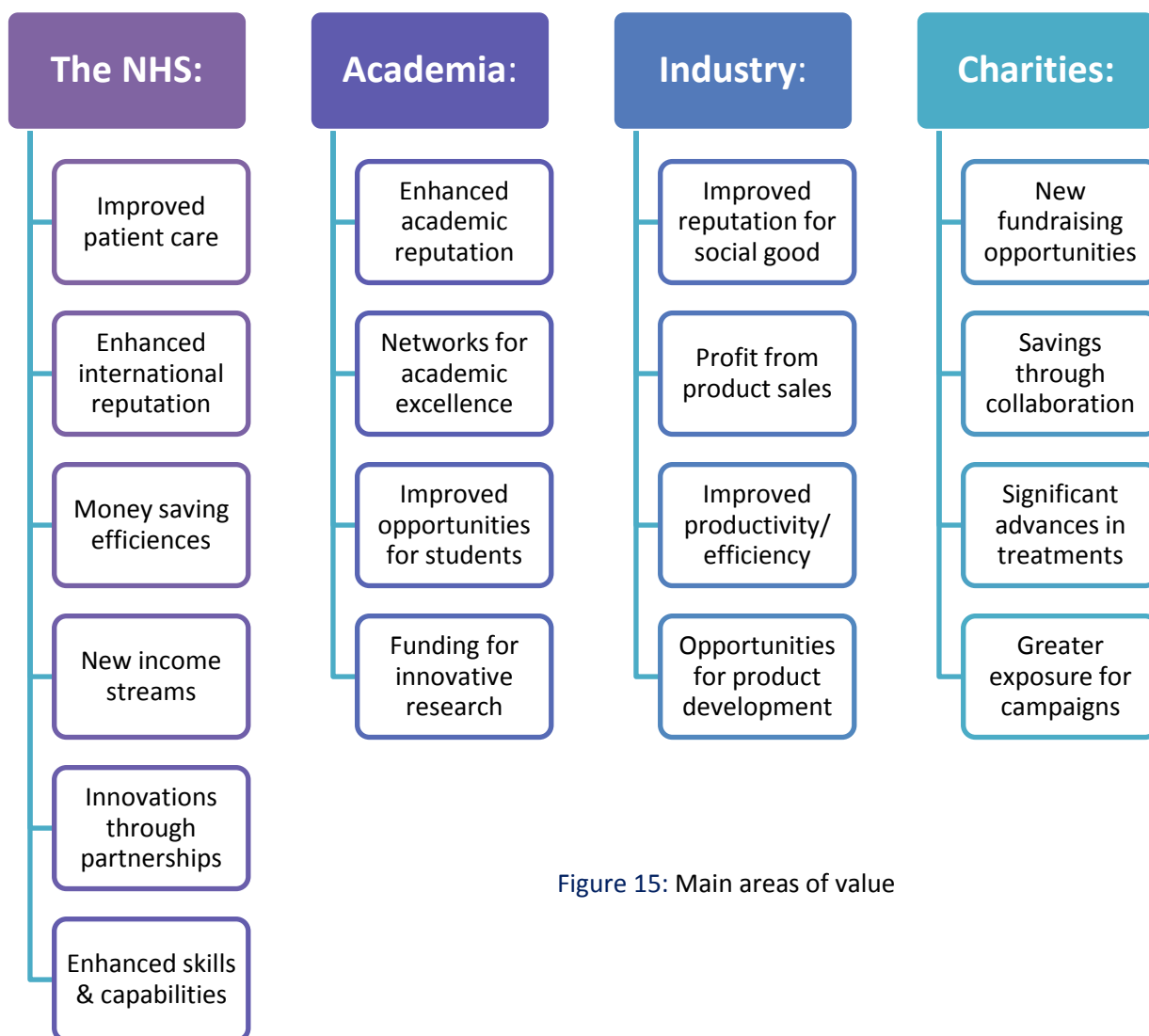


Figure 15: Main areas of value

Underlying all these different framings of value was the specific and unique value of NHS patients' and operational data. Jurors stressed that because everyone in the UK uses the NHS, free at the point of delivery, at every stage of their lives, the NHS holds an extremely valuable resource covering every section of society across all demographics. Jurors said that the UK was unique in the world in this respect, understanding that other healthcare systems, not being ubiquitous, would not have such comprehensive data sets at their disposal.

*NHS data is unique in breadth, and if the industry goes to other nations for data it won't be as wide a demographic, "because everyone uses the NHS" and the multiculturalism of the NHS is longer term.*

| Leeds

In this sense for Jurors, defining value needed to encompass the uniqueness of the available data as well as an understanding of the measurable and intangible benefits it had the potential to bring. They scoped these in terms of improved healthcare, patient outcomes and operational efficiencies; benefits to the wider economy through, for example, employment opportunities; and to the UK's reputation in being well placed to deliver robust evidence-based innovations in treatments. There was a strong sense throughout the deliberations that the NHS might undersell the data in access partnerships because they did not have a culture of placing a value on it as they currently work within a cost recovery model for enabling data access. They felt if NHS organisations could reflect more on the unique value of NHS patients' and NHS operational data, they would receive more benefit from it. As one Taunton juror put it,

*We are optimistic about partnerships because the UK can be a pioneer in these...They can create high skilled jobs that are well paid and at the end of the day we become a healthier nation.* | Taunton

## 9.2 Realising value

Jurors faced a significant challenge in grappling with the idea of data access programmes realising value for partners. They felt that data access partnerships are being established in a turbulent political and economic climate with the exit of the UK from the European Union and the need to stay up to date with changes to the General Data Protection Regulations (GDPR) and future (as yet unknown) policy imperatives.

They were also concerned that it could be difficult to realise value for all partners as each have potentially different organisational structures and anticipated outcomes for their work. They noted that whilst improved patient outcomes should be something all partners strive for, the NHS has this at the core of its activities, whilst industry partners, for example, need to deliver a profit for shareholders. They saw this as challenging when enabling all those involved to realise a 'fair' value for their contribution to the partnership and without a sense that the NHS might be disadvantaged by the process.

*Inequity is structurally embedded in the value exchange relationship. How to address it?* | Leeds

*The NHS is providing data to industries, who then provide a solution with the data and sell it back to the NHS. How can the NHS avoid being taken advantage of in this way?* | Taunton

Jurors considered, given the unique value of the data under consideration, that it is a challenge to put a price on it. This led them to consider that there was a significant risk in undervaluing it and that the NHS might sell itself short whilst industry could make excessive profits which are not shared with the NHS. Agreeing on a fair price and recognising the unique tangible and intangible values at play was seen as the backbone of a sustainable financial partnership.



Discussions about value clearly demonstrated that jurors identify very strongly with the NHS as a public service. Actual, perceived and/ or potential for exploitation of the NHS was a clear red line for everyone.

*If the NHS are being exploited, the public are being exploited.* | London

Three main points came out of this discussion:

1. That the NHS should always receive due credit for supplying the data that has led to advances and innovations in medical technology and treatments, no matter which type of organisation has created the tool or drug that delivers the advance or innovation.
2. Any partnership should secure a benefit for the NHS in return for data access with the ultimate aim of improving the treatments and care it provides to patients and being more efficient with resources.
3. Measuring and realising the value from data access partnerships, however intangible, must form part of every partnership agreement.

*The NHS and its partners need to know exactly what will happen and ensure fairness based on what the value of the products could be.* | London

For the NHS this leads to two principle benefits, as summarised at the Taunton Citizens Jury,

*We said for the NHS two things, improved patient care and saving money.* | Taunton

### 9.3 The impact of skills and capabilities on value

It was felt that the collaboration between staff within data access partnerships would lead to the enhanced skills and capabilities of all concerned. There was a perception by jurors that this would be of specific value to NHS organisations. Jurors described a virtuous circle of the quality,

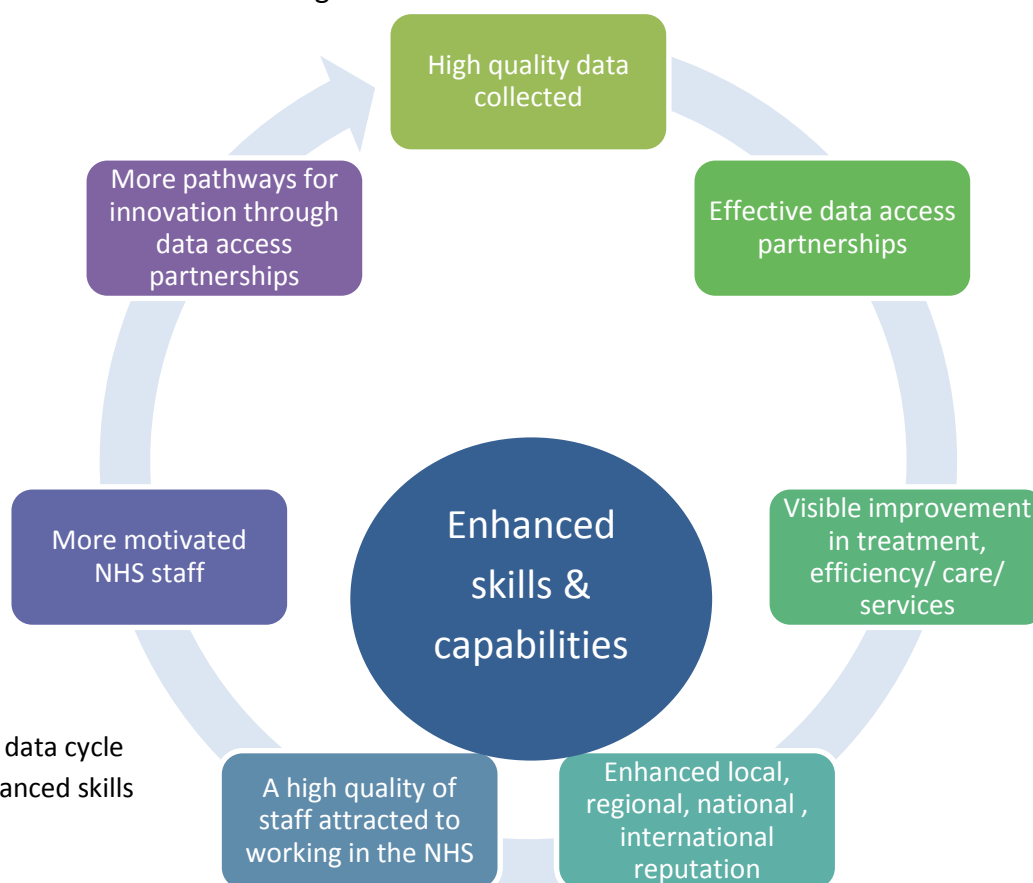


Figure 16: The data cycle leading to enhanced skills & capabilities

comprehensiveness and uniqueness of the data collected. They saw the potential for this enhancing the reputation of the NHS in local communities, regionally with partners as well as nationally and internationally. They felt this would in turn encourage more people to work within the NHS and to improved morale for those already working within the system (figure 16).

Jurors said that central to this process is enhanced skills and capabilities within the NHS as teams learn from working in collaboration with external partners, new staff are brought in with specific expertise in the field of data use and management, and training is provided to manage data access partnerships effectively. They made the point that learning through doing would be important in ensuring that NHS organisations learn quickly from the mistakes they are likely to make in early negotiations and improve their ability to negotiate contracts which recognise the unique value of the data and realise fair for the NHS and the patients they serve.

There was a sense in each of the Juries that industry, academic and charity partners are likely to have more experience of negotiating contracts and partnership agreements and as such, the NHS would be at a disadvantage both in defining the value of the data and in ensuring the agreement fairly distributes risks and rewards. As two Jurors expressed it,

*There is a concern around whether the NHS has the expertise needed to negotiate these types of partnerships. This should be at a central level to make sure partnerships are fair. | London*

*I think the NHS might be naïve here. They might lack the savviness required to negotiate contracts and be naïve about the commercial motivations of others. | Leeds*

As we have seen exploitation of the NHS was seen as a fundamental risk in these partnerships which, through enhancing the skills and capabilities of NHS staff, must be addressed for the data access partnerships to be fair. This was most forcefully expressed in Leeds.

*We feel there's a danger of exploitation of the NHS. We don't think the NHS is very savvy, business-wise so we don't trust it out there with the big bad wolves of business. Even charities, even universities, many are big businesses now. | Leeds*

*The NHS people have got enough on their plate without having to be involved in other businesses and trying to run that. They've got to run their own business and not business managers and I think it muddies the water away from the purpose of these partnerships, which are to benefit the NHS development and health for people. | Taunton*

Jurors heard from expert witnesses about the thousands of organisations that comprise the NHS. They saw in a range of evidence that data is not automatically shared for treatment purposes and that there can be inconsistencies in the quality of data. Jurors spoke about the potential for realising a greater value for NHS data if partners could be assured that the data is collected consistently and coherently across the NHS. One Juror reflected the views of many in saying,

*How to have enough resources to centralise IT systems across the NHS to make sure data is good quality from the start. This gives them more leverage in negotiations with partners because they have to do less work on it and the NHS will get a better return for the data. | London*

A minority of jurors voiced a concern that as the algorithms become more effective over time, there might be a loss of skills within the NHS. As one Juror asked,

*Is there a risk in using AI that we are de-skilling our experts? No one will need to be able to read an eye scan in the future if the AI can do it faster and to the same standard as a clinician. | Taunton*

There was a strong sense that external expertise is needed to ensure business negotiations realise fair. They felt that additional legal and business skills are required so that clinicians are not making business and legal decisions for which they are not trained and have no experience.

*You need other experts to help steer the NHS partnership, you'd need an accountant, almost a small committee of people who run it. You might be the best doctor in the world, but terrible at business. | Taunton*

Jurors recognised that the NHS, charities, industry and universities each have different levels of resourcing and access to funds. They felt that this shouldn't mean that only highly resourced partners could take part in data access programmes, and that fair would mean all those who could add value to the partnership should be able to participate.

The question of profit was discussed in all locations. Jurors were concerned that no inequalities arise from some partners generating more profit from data access partnerships than others. In Leeds discussions came to the belief that industry, for example, should not make a level of profit from a technology or a drug that was developed using NHS patients' or NHS operational data, as this could be perceived as being unfair to other parts of the partnership or indeed wider society. One group proposed the following suggestion to stop others undermining the value of NHS data,

*There should be a profit cap on industries and companies selling back to the NHS after working shared research projects. | Leeds*

In London participants suggested that a change in culture was required in which potential inequalities are ironed out as part of the process of developing the data access partnership. They said,

*Develop a culture in which the private and the public sector have a better, mutually supportive collaborative relationship. | London*

All locations were concerned that data access partnerships could lead to unintended consequences because of differences in the ways in which the partner organisations are governed and operate. Jurors said they would be concerned if, because of differences in culture and skills of the partners, the NHS was seen as somehow 'less than' in the partnership. As two Jurors put it,

*I wouldn't want the NHS to be disadvantaged because they don't consider as a matter of course some of the more commercial and financially motivated incentives that could be available. | Taunton*

*The NHS might not get the recognition and the resources that it deserves for this huge amount of vital data that it has at its disposal. (The data) is so precious and capable of delivering so much. I just don't want the NHS to get dumped on. | Leeds*

Fairness is therefore for Jurors a system which enables the NHS to reap benefits from the partnership with recognition that the data they provide is an essential resource to any data access partnership.

# 10. Partnership models

## Chapter 10 summary

In this chapter we explore the responses jurors gave to the partnership models. The models used as a stimulus in the juries were drawn from existing and potential types of partnerships, particularly those being tested by the Office for Life Sciences in their work to develop a policy framework for data access partnerships. Their purpose was to illustrate the different types of value exchange that partnerships could provide.

Jurors used a handout to explore different types of models.

- **Simple monetary model** examples, which exchanged data access for a fee or a discount on a product.
- **System wide model** examples, which exchanged data access for expertise, tidied data or the opportunity of improved healthcare stemming from free access to data.
- **Future potential model** examples, which exchanged data access for a stake in a product, company or share of profits from a product/service developed using the data provided.

Jurors reviewed this range of partnership models on Saturday afternoon, after exploring six case studies that gave examples of existing or in-development partnerships with industry and universities. The case studies used in the Juries are available at appendix 6 and summarised here.

NHS Organisation	Partner	Purpose
NHS Blood & Transplant	Kortica	Artificial Intelligence (AI) technology to reduce wasted blood products
University College Hospital London	UCL Researchers	Using software to predict missed medical appointments
NHS Greater Manchester	GSK	Using real time monitoring to test a drug to treat breathing difficulties
Imperial College Healthcare NHS Trust	Imperial College	Clinical and staffing data combined to help plan staffing levels in intensive care units
Musgrove Park Hospital	CGI, Marand, Apperta Foundation	Introducing e-Prescribing in hospitals linked to the Electronic Patient Record to reduce deaths and illness caused by prescription drug errors
Moorfields NHS Foundation Trust	Google Deepmind	Artificial Intelligence (AI) technology to diagnose and treat eye disease

Figure 17: Summary of case studies

NHS data access partnerships are in the very early phases of development, most case studies reflected a system-wide model of exchanging data for improving healthcare systems. Moorfields NHS Foundation Trust was the exception which described a simple monetary model of exchanging data for free access to the AI technology for five years. In using these models jurors were told that, ‘the following partnership models are not mutually exclusive or exhaustive, and many could be used in combination to achieve a fair deal for the public, patients and the NHS.’

When considering the models, most jurors believed that NHS data is extremely valuable and felt that the NHS should seek some form of return for allowing access to it. A minority of jurors felt that the NHS should only seek cost recovery or should make the data available free of charge.

## 10.1 Overarching expectations for partnership models

In this section of the chapter we look at the expectations that jurors had for partnership models overall. These expectations relate specifically to the development and management of the partnerships. The earlier chapters of this report explain the foundations for fairness that must underpin these partnerships, including, above all that all partnership models must lead to improvements in health, welfare and care of NHS patients.

### 10.1.1 Secure value return, not just cost recovery, for use of NHS data

Having considered the size, extent and uniqueness of NHS data, most participants felt that fair partnerships would involve some form of value exchange for the NHS, beyond just cost recovery.

*Saves the NHS! As clearly the NHS has valuable info, and in this day and age, it's under fire. | Leeds*

Jurors talked about benefiting from opportunities that we wouldn't have otherwise and the importance of widespread benefits to all parties, including the NHS.

*The NHS should receive some recompense for the use of their data. We should prioritise the public sector and public services with the money that's coming back. | London*

### 10.1.2 Funding from partnerships to help sustain the NHS

The idea of sustainability when applied to partnerships manifested itself in different ways when discussed by jurors. Some discussed the potential for partnerships to provide future revenue streams that could sustain the NHS at an improved level. Words used around these revenue streams included the idea of safety: 'safeguarding', 'stabilising'. Other words such as 'self-funding' and 'self-sustaining' implied the revenue from partnerships could become a significant part of the NHS budget. A few participants used words such as 'fuelling the NHS', suggesting that partnerships could energise the NHS and enable it to explore areas that would otherwise be beyond its reach. As we have discussed (see section 4.4.2), stealth privatisation of the NHS was a concern for jurors. Most saw any financial gain from partnerships as resulting in additional funds, on top of what is provided through taxation, to fund future demands on the NHS that we might not otherwise be able to afford.

*It could ultimately mean that the NHS could be self-funding and self-sustaining which guarantees an NHS for the long-term. | Taunton*

Other discussions focused on the long-term nature of partnerships and that those involved in developing the partnerships should have in place strategies that have a clear sense of their future potential and impact and not just focus on immediate gains. They wanted assurance that future generations would benefit from the models being developed now.

*We need to be thinking about the future and about future generations rather than selling whatever we have now and gaining for now | Leeds*

Some jurors built on this thinking and wanted the NHS to seek out partnerships that would tackle issues that might become more prevalent in the future, such as those related to an aging population.

The idea of partnership models that are ‘future-proofed’, that they factor in the likelihood of technologies such as AI changing rapidly was seen as important by some jurors. They didn’t want to see partnerships hindered or made obsolete because they are tied into a particular technology.

### *10.1.3 Patient data needs closer control than operational data*

When partnerships are working with data, jurors felt that closer control was needed on patient data compared to operational data. Some felt that systems for the secure handling of patient data should be prioritised whilst others thought that there should be different legislation around the use of patient data versus operational data.

*Need to differentiate between patient data and operational data, patient data is more sensitive and operational is already out there. Commercially sensitive but not personally. | Leeds*

*The root reason for caution is just the sensitivity of the data. | London*

### *10.1.4 Legal frameworks for partnerships*

A fear expressed by some jurors was that the NHS was entering into partnerships before having legal and policy frameworks in place. They wanted these frameworks to be set up so that compliance with partnership conditions could be written into policy practice and law. As one Juror put it,

*Deals and legislation need to be legally binding. They’re not watertight yet. It’s like they’re running before they can walk. | London*

## **10.2 Views on specific types of models**

In this section of the chapter we explore comments on the different types of models, categorised on the handout given to jurors as: Simple Monetary; System Wide and Future Potential. Each section begins with the descriptions given to jurors on the Types of Models handout which was the main resource used here. Many of the models described are still at a theoretical stage and as such there were no concrete case studies to give to jurors to help illustrate what was being described.

Simple monetary models attracted widespread support, most frequently because they offered immediate financial benefit and because they weren’t linked to the performance and profitability of a company or product.

System wide models were also well-received for offering useful benefits such as innovations from data usage, lent and shared expertise and curated data.

Future potential models attracted more polarised responses, with some jurors welcoming them as future sources of revenue for an NHS that is always financially stretched, and others rejecting them for associating the NHS with a profit motive and therefore tainting its ethos.

When discussing the range of models, some jurors expressed the wish to see all the types of models available to the NHS when negotiating partnerships.

*With the diagram that we have, that an element of all those things should happen at all times. So there should be some form of monetary transaction, some form of system-wide transaction and a future potential included in every partnership deal that’s made. | Leeds*

## Types of models: simple monetary

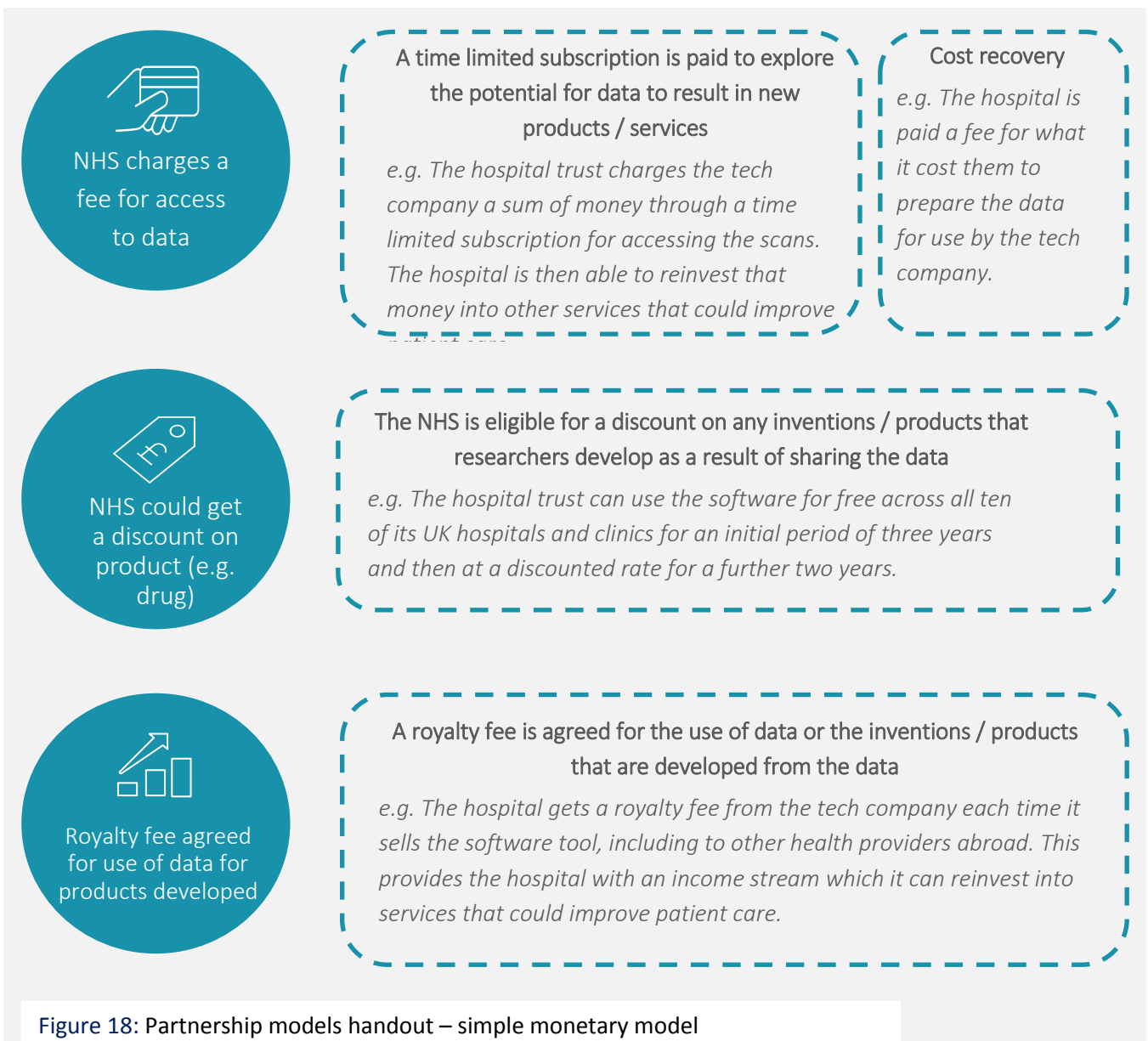


Figure 18: Partnership models handout – simple monetary model

### 10.2.1 Simple Monetary: Charging a fee for data to enable cost recovery

The concept of the NHS receiving a fee that covers the cost of extracting and enabling use of the data was accepted by most participants. When thinking about who should pay the fee, most jurors felt that charities and universities as well as industry should pay the fee. For a small minority of jurors, particularly in Leeds, cost-recovery was the only acceptable model because they felt it meant the NHS was not tainted by a profit motive.

But for most jurors, cost recovery was the minimum that the NHS should expect, and that the NHS would be undervaluing this asset if that is the only return received for data access. Most believe that other benefits should be factored in, be it discounts on treatments or training for staff or a share of profits. Some jurors thought that the level of additional benefit to the NHS would depend on whether the partnership was with a charity or with industry. They tended to think that charities should have to contribute less, for example giving a product to the NHS for free for a year vs industry giving the NHS a share of a product's profits in perpetuity.

*Each application should reimburse the NHS for the cost of recovery for receiving the data. Industry should also give a set percentage of their net worth. | Leeds*



### 10.2.2 Simple Monetary: Discount on a product

The model that allowed for the NHS to get a product for free, or for a discount, was accepted and liked by some jurors. Some preferred this model to the future potential models because it enabled the NHS to have low or no cost access to an innovation, without being involved in the businesses themselves.

*I would rather see that as through innovation of sharing technology and improving systems and giving that benefit free so that other companies can get their revenue from selling privately and globally. | Taunton*

However, the arrangement that the discount could be time-limited was liked less. There was a feeling that this wasn't a fair reflection of the contribution that the data might have made to the development of the product and could lead to the NHS being committed to paying for expensive treatments that under the initial arrangement were affordable.

*Discount on product as long as no strict time limit or other negative stipulations. | London*

### 10.2.3 Simple Monetary: Royalty fee

The model that allowed the NHS to get a royalty fee each time a product is developed informed by evidence from NHS patients' or operational data attracted both positive and negative comments as well as questions about how this kind of model would work. Those who liked royalty fees saw it as a model which is a sustainable revenue generator for the NHS. These jurors wanted the NHS to ensure that opportunities for collecting royalties are established within contracts and followed up when products, treatments or new drugs are developed.

*The royalty fee idea is positive. It will always be a benefit to the NHS and the NHS should actively pursue royalties for the use of data for products developed. | Taunton*

Those who had negative comments were worried that the NHS could be liable if they had any form of co-ownership on a product that went wrong.

*We had a concern perhaps if something goes wrong with the item or drug or whatever, is the NHS going to liable, and is that going to wipe out any potential profit? | Leeds*

Two questions raised about royalty fees juries felt are important for consideration when agreeing the financial models for data access partnerships:

- Do royalties apply to future products?
  - For example, the NHS get royalties on an eye scanner, two years later the scanner is upgraded, and a new scanner comes out – does the NHS get royalties on this too?
- Who sets the level of royalty fees?

## Types of models: system-wide

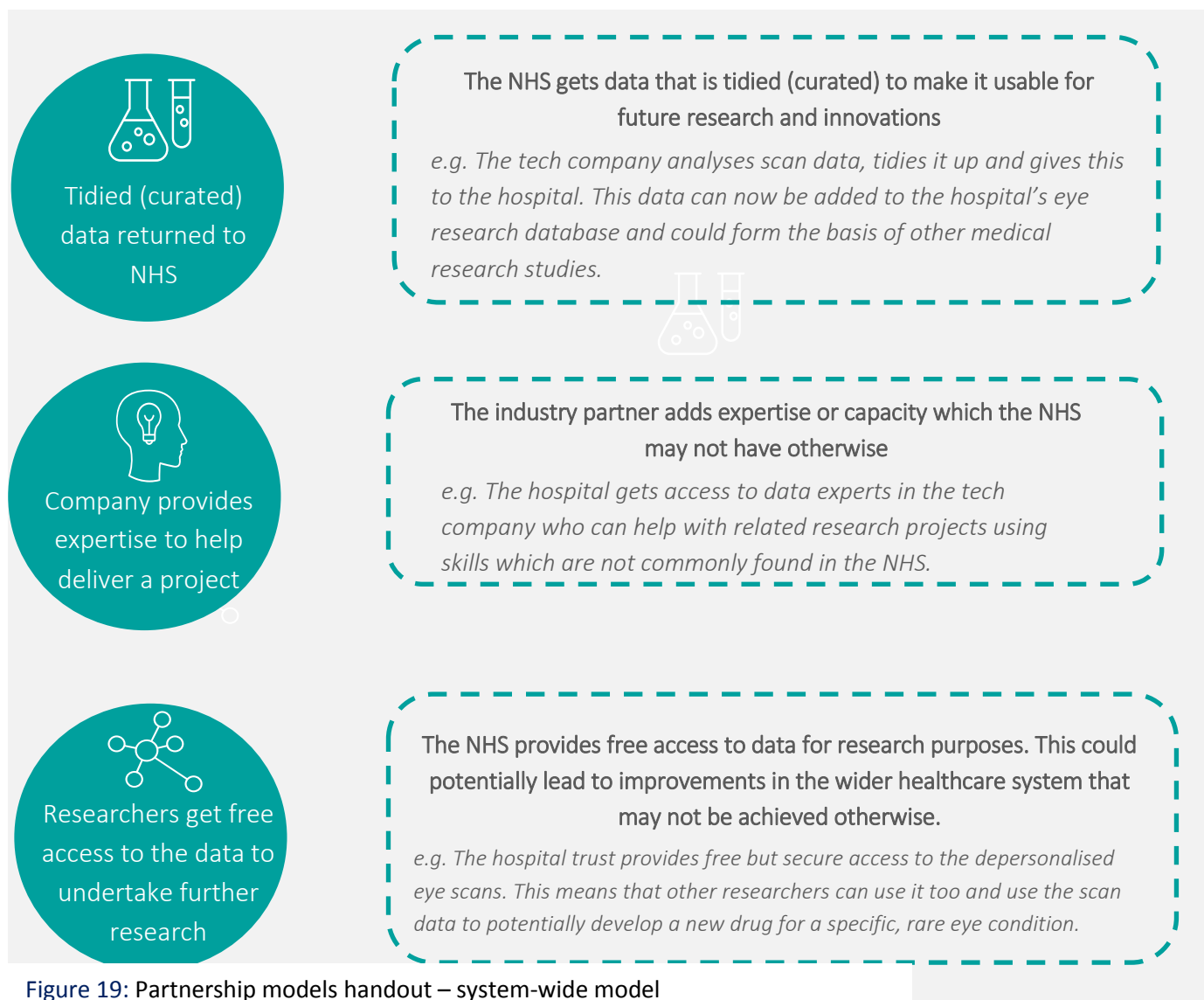


Figure 19: Partnership models handout – system-wide model

### 10.2.4 System-wide: free access to data

A small number of jurors said the only acceptable model would be to allow any organisation with the intent of improving health outcomes to have free access to NHS data. For some, free access would allow the widest possible access and so generate the widest possible health gains for all.

*Why not just give all anonymous data away? What are the consequences? Would it not benefit more than not? Why aren't we giving it away for free? | Leeds*

*If the NHS knows they are helping to cure cancer, they might be happy with that and that's all they need. | Taunton*

For others, free access meant that the NHS would not be tainted by a profit motive.

*NHS should not profit share to ensure ethical standards are upheld. | Taunton*

But the majority of jurors did not agree with this approach. A more common response to this model was,

*If other bodies are funded, they have money to access that data, the NHS shouldn't give our data away for free. | London*

*Why don't you sell it? What do you receive for providing the data? | Leeds*

### **10.2.5 System Wide: tidied data<sup>5</sup>**

The benefit of tidied data did not attract many comments from jurors, perhaps because it did not seem to offer as tangible a benefit to the NHS as discounts on products or profit sharing. However, when it was mentioned, jurors thought it was the right thing to do as long as the tidied data was intact, and nothing had been 'tidied away' that might damage the integrity of the data.

*Tidied data returned to the NHS, that's a nice, simple, decent thing to do. Means less NHS cleaning required next time it its registered. | London*

*Tidied data returned to the NHS should be written into contracts. It means the partner would find it harder to breach the contract and withhold some of data. | Leeds*

### **10.2.6 System Wide: company provides expertise to help deliver a project**

Partnerships in themselves were widely liked for their ability to share knowledge and skills between the NHS and its partners. As we have seen in section 7.3, most jurors perceived that the NHS is the partner in the greatest need of enhancing its skills, particularly in the areas of negotiating the terms of partnerships and in data management. Whilst the description of this model focused on partner organisations providing expertise that the NHS lacks, jurors felt that NHS should also include training for its staff provided by partner organisations in this model.

*Staff training as part of their partnership opportunity to address inequalities [in skills]. | London*

Some jurors in Leeds raised the view that the NHS needs a wide range of expertise to prevent bias. They were concerned that relying too heavily on one organisation could lead to decisions that favour that organisation rather than taking a view informed by a wider range of influences.

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<sup>5</sup> Tidied data means curated data. Tidied was the term used in the Juries for ease of understanding.  
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## Types of models: future potential

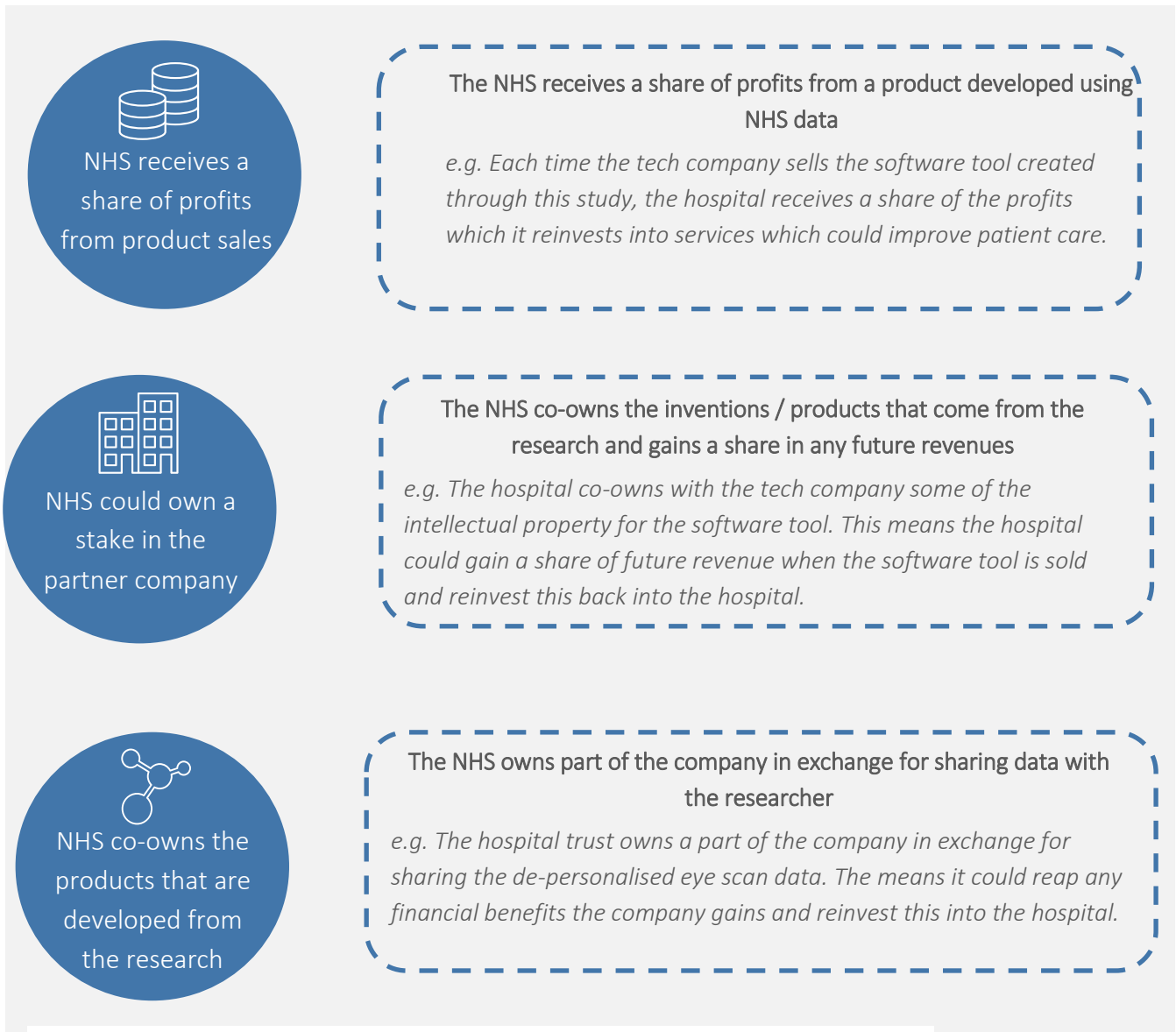


Figure 20: Partnership models handout – future potential

### 10.2.7 Future Potential

The differences between the three future potential models: the NHS having a share of profits from product sales; owning a stake in a partner company; and co-ownership of products developed from research, were not particularly clear to jurors. In the main, they took them to mean that the NHS has a share in a product or company that develops as a result of using NHS data. These were the most polarising models - with some jurors valuing them for offering a significant revenue stream for the NHS in the future...

*NHS co-owns products (IP) that are developed because that is a sustainable resources stream. | London*

*The future potential partnerships might be the most lucrative if they're successful, but they may not be successful. | Taunton*

However, when discussing these models, most jurors expressed strong reservations. They thought they linked the NHS to a profit motive and this risked tainting the NHS ethos and some feared it pushed the NHS closer to being privatised.

*Future potential models should not be considered within the partnerships. | Leeds*

*The NHS should not be open to profit share because of the clash with ethical standards. | Taunton*

*Once the NHS starts putting fingers into other businesses, people start getting vested interests and that goes against what the NHS is about. | Taunton*

Some jurors feared that if the NHS set up co-ownership or other ongoing involvement with businesses it would be a damaging distraction from the difficult task of running the NHS.

*I'm not happy with them co-owning and royalty fees for things, because they've got enough on their plate without having to be involved in other businesses and trying to run that. | Taunton*

Liability was raised by some jurors as an issue that the NHS should consider before deciding on any potential partnerships. They feared that the NHS could be sued if a product they had a share in was found to be harmful.

*If they received a shared of profits from the product, if the product then gave people an illness and they sued them or it went to America and they sued them, the NHS might be liable. | London*

Another concern raised by some jurors was that the NHS could be biased toward a product it had a share in and that if an alternative product, that may prove to perform better, came on the market in the future, the NHS might ignore it in favour of the one it owns shares in. This risk of skewed incentives meant that a partnership could tie the NHS's hands and limit its use of future developments.

*If the NHS had a stake in one particular, say it's a medicine company and they produce a heart drug which is used hugely and so for every box that's prescribed there is a profit related to it. Company B invent an improved version of the product and at some point, there is going to be a conflict of interest because at what point do you start to prescribe drug B because it's a better medicine over what you're making a buck out of? | Taunton*



# 11. Jury recommendations

## Chapter 11 summary

The final action of the juries was to create recommendations to respond to the key elements of the question: *what constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?*, drawing on their deliberations over the past two and a half days. Jurors worked in small groups at first, then compared their work with others in their group of ten. The two groups then came together to compare and synthesise their thinking, leading to the final recommendations by each jury. This section of the report summarises seven recommendations that featured in at least two of the three locations. Because the jurors spent time crafting the language they wanted to use in their recommendations these are included verbatim in the chapter.

Jury recommendations have been collated across the three locations, the numbering used does not reflect a prioritisation conducted by jurors, but the strength of feeling around each of them as analysed by the reporting team. The majority recommendations were:

1. A governance system to oversee partnerships<sup>6</sup>
2. Partnerships driven by improving health outcomes and reducing health inequalities
3. Partnerships governed by a set of shared principles
4. Partnerships which are transparent and accountable
5. Benefits from partnerships rolled out across the NHS in an agreed timeframe
6. NHS data is streamlined to be more consistent
7. Data sharing policies are reviewed in light of GDPR, Brexit and future policy imperatives.

The recommendations are a reflection of jurors hopes and fears around partnerships on NHS data:

### Hopes

That partnership governance is robust and NHS data is represented by skilled specialists

That the unique value of NHS patients' and operational data can be realised

That working with external partners on NHS data can yield better services

### Fears

That exploitation will take place unless principles, regulations and even laws are in place

That some parts of the NHS and the areas they serve will benefit, whilst others are left behind

That the inconsistent quality of NHS data may make it harder to yield better services

Juries in London and Taunton put forward recommendations that were unique to their locations. It is worth noting that the issues raised in these minority recommendations: data security, legal frameworks and educating the public about the use of NHS data were discussed in all locations but didn't make it into the final recommendations everywhere.

<sup>6</sup> Jurors described the governance system as a 'regulatory body' but their comments explain that this is intended as an overarching system of governance rather than an additional regulatory organisation.

5. For the NHS to use its allocated budgets to keep NHS data secure | Taunton
6. Enshrine the concept of fair partnership in law. Criminal law to be put in place to ensure that data is not used out of agreement | London
7. Initiate a national communications plan to educate the public about data partnerships and about where and how data is used | London
8. Adopt a data access rather than a data sharing approach | London

## 11.1 Jury Recommendation: Governing system

*Summary recommendation: These juries recommend that a governing body is established to oversee NHS data partnerships.*

Members of the body should include IT experts; data experts; legal experts (skills to be on par with industry/academia); NHS representatives; public representatives; partner representatives.

Key tasks for governance will include to:

- Establish principles to guide the formation, conduct and evaluation of partnerships (informed by government & public consultation)
- Assess applications for data sharing against these principles
- Distribute data sharing requests to appropriate NHS organisations
- Perform impact assessments to reduce risk of unintended consequences and data misuse
- Negotiate levels of data access
- Negotiate value exchange
- Prevent duplicate partnerships
- Improve communication between NHS Trusts
- Ensure laws on fair partnerships are complied with
- Review partnerships to provide and share overarching learnings

Verbatim recommendations		
Taunton	Leeds	London
A diverse regulatory body is established which sets out the criteria for all partners involved in NHS data sharing.	After applications have been vetted by an overarching governing body who will distribute the applications to advisor hospitals/trusts, all applications are reviewed anonymously, stating whether they are industry, charities or researchers.	A regulatory body is established to oversee NHS data partnerships. Industry/academia/charities liaise only with this body which represents NHS trusts etc. This body should have data, IT and legal experts on a par with partners. This body will evaluate project proposals, negotiate level of access to patient data and operational data, and suggest an exchange value for the data (which will be evaluated independently). The regulatory body should have some form of public/patient representation. Regulatory body will set out and follow procedures and policies to comply with the laws on fair partnerships. Regulatory body will ensure that financial and other outcomes of partnerships are shared across the entire NHS.
Agreements and partnerships are scrutinised from the outset and periodically reviewed to reduce financial risk and	NHS to make informed considerations when making business decisions and be able to justify their decisions efficiently.	A regulatory body is established to oversee NHS data partnerships whose role is to negotiate deals,

<p>maintain NHS Standards.</p>	<p>Quality assurance of studies must be carried out by an independent assessor to enable a review of partnerships maintained on a national level.</p>	<p>technology, legal, setting parameters for access to patient data with patient representatives on board. Equal representation of NHS, partners and voice of public in governance process. There should be a centralised body in charge of NHS data-sharing partnerships and profits from these partnerships should be shared nationwide (in the NHS). Steps should be taken to prevent 'duplicate partnerships' existing where the outcome would be the same. Better communication between trusts of what already exists.</p> <p>Once proposals for a partnership have been looked at and exchange value for data discussed, an independent moderator (not NHS or partner) has to approve the data value set.</p> <p>Suggest an exchange value for the data (which will be evaluated independently).</p>
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## 11.2 Jury Recommendation: Patient benefit the primary goal

*Summary Recommendation: These juries recommend that all partnerships are guided above all by the principles of improving healthcare outcomes and reducing healthcare inequalities*

- Financial incentives to the NHS should not outweigh patient care and ethical considerations, with the aim of patient care being front and foremost in any partnership

Verbatim recommendations	
Taunton	Leeds
<p>The ultimate user is considered when making decisions on research and development, money spent, projects undertaken when considering entering a data sharing agreement with external partners, the NHS must ensure the end user is the primary concern undertaken.</p>	<p>Partnerships to be mindful of being fair both directly and indirectly, whilst operating towards an agreed ethos of improved healthcare outcomes and reduction in healthcare inequalities.</p> <p>Financial incentives to the NHS should not outweigh patient care and ethical considerations, with the aim of patient care being front and foremost in any partnership.</p>

## 11.3 Jury Recommendation: Governed by shared principles

*Summary Recommendation: These juries recommend that partnerships must be driven by a set of principles that will be of mutual benefit to all parties in the partnership.*

The principles should:

- Be informed by government policy makers and public consultation.



- Apply to governance, knowledge sharing, financial arrangements, efficiency learnings and health care improvements.

Verbatim recommendations		
Taunton	Leeds	London
The regulatory body needs to adhere to written rules, regulations and standards of conduct and morality.	Partnerships must be driven by agreed principles and national framework, from government and public consultation, with partnerships subjected to appraisal by the appropriate partner regulators and public input into the framework, but not every decision. Local level rules will depend on whether the partners are industry, charity or research.	Partnerships must abide by a set of shared principles to which they must adhere. These principles include governance, sharing knowledge, improving efficiency, improving care and financial gain and will be of mutual benefit to all parties in the partnership.

## 11.4 Jury Recommendation: Partnerships should be transparent and accountable

*Summary Recommendation: These juries recommend that NHS data sharing partnerships should be transparent and accountable.*

- Information on all data sharing partnerships are available for the public and that partnerships should be reviewed during and at the end of their project life.
- The public should be able to see the goals of the partnerships, what data is shared and how, and what benefit is received by each partner.
- The partnerships should produce interim (at least annually) and final reports against a monitoring and evaluation framework, to be submitted to the regulatory body.
- Project Partners are accountable for the quality and accuracy of all reports.
- Final reports should include recommendations for future research or partnerships.

Verbatim recommendations		
Taunton	Leeds	London
All data sharing partnerships and case studies are publicly available. The jury recommends “transparency”.	The goals and aims of the partnership, together with any financial benefit and how it all will work should be transparent, so it is available to the public.	Partnership projects should report against a monitoring and evaluation framework. They should be required to publish a final report and interim annual reports for the length of the project. Intended outcomes should be made clear at the start and potential other outcomes (complications/unforeseen benefits) well considered and discussed.

Taunton	Leeds	London
Partnership agreements are reviewed regularly during their period of operation.	A final report must be submitted in detail of all the process by the partner at the end of the study, along with further recommendations for future research or partnerships, to be submitted to the ombudsman.  A final report must be jointly created by all parties within the partnership, and should be made readily available to those with an approved, invested interest	Those who make up the partnership should be held accountable for all interim/final reports, evaluation, monitoring which make up the framework; this means going through them with a fine-toothed comb.

## 11.5 Jury Recommendation: Benefits from partnerships should be rolled out nationally

*Summary Recommendation: These juries recommend that the positive benefits from any local or regional partnership i.e. health interventions and research results should be rolled out across the NHS, for the benefit of all patients, within an agreed time frame.*

Recommendations in their own words	
Taunton	Leeds
That all project/ research results are distributed throughout the NHS equitably i.e. geographically and financially	Regulatory body will ensure that financial and other outcomes of partnerships are shared across the entire NHS.  Profits from these partnerships should be shared nationwide (in the NHS).

The recommendation that benefits from partnerships should be made available across the NHS was supported by a large majority of survey respondents, 81%. This compares to 68% of respondents who agreed that the benefits should be shared firstly with the NHS Trust that entered into the partnership but, over time, must be made available to other parts of the country. This reflects discussions in the juries, with most wanting to see the whole of the NHS benefiting immediately or, if there were some time delay in the roll out, that it should be limited to avoid innovations being superseded.

## 11.6 Jury Recommendation: Consistency of NHS Data

*Summary Recommendation: These juries recommend that NHS data be streamlined to be more consistent across different NHS organisations and regions.*

- This would enable national datasets to be more easily shared with partners.
- This would also achieve efficiency savings across the NHS with more opportunities for cross-Trust collaboration and reduced legal complexity.

Recommendations in their own words	
Taunton	London
The NHS streamline its data collection and sharing (within all NHS organisations – GPs, hospitals and Trusts) in order to establish an up to date database that can be shared with potential partners	For an efficient and more economic NHS, nationally agreed baseline standards should be applied to all trusts when developing partnerships. Legal implications would be cheaper and cross trust help readily available to benefit patients.

## 11.7 Jury Recommendation: Data Governance that Complies with Current and Future Regulations and Technical Developments

*Summary Recommendation: These juries recommend that there is an ongoing review of data sharing policies, in light of political and technological developments, including Brexit and GDPR.*

Recommendations in their own words	
Taunton	London
That there is an ongoing review of data sharing policies in the light of technological developments/ Brexit etc.	A governance policy is agreed and communicated, ensuring adherence to GDPR including a list of agreed terms.

## 11.8 Minority Recommendations

*This jury recommends keeping NHS data secure by using a proportion of their allocated budgets to do so*

Taunton
The NHS, the governing body and the partnerships, have a duty of care to keep data secure, promote the development of mechanisms to protect data using a proportionate of their allocated budgets to do so.

*This jury recommends that criminal law be put in place to ensure that data is not used out of agreement. The concept of fair partnership should be enshrined in law.*

London
Criminal law put in place to ensure data is not used out of agreement. The concept of fair partnership should be enshrined in law. What happens if the law is broken? Two types of penalty for partners who fall foul of the (fair) rules laid down by the NHS regulatory body: 1. Financial penalty: percentage of global turnover (civil regulatory body). 2. Struck off the NHS partnerships (academic/charity/industry) (civil regulatory body). 3. Jail sentence (crown court) 4. All of the above.

*This jury recommends that a national communication plan be initiated to educate the public about data partnerships and about where and how data is used*

## London

A large comms plan be initiated to educate the public about data partnerships and enable them to choose specific models to opt in/out. We would like clear communication to the public about where and how data is used (i.e. published partnership agreements including the benefits and risks (and efforts made to minimise these risks) so that public awareness is improved to allow for informed decisions to be made where some individuals may wish to opt out.

*This jury recommends that the NHS give access to data but retains data ownership and control, unless a legitimate need or mutually beneficial outcome is identified (Genome Project model)*

## London

“Access to data is given and data is not shared” – unless a legitimate need/mutually beneficial outcome of shared data, partnerships should work on data access only where NHS retains data ownership and control and can monitor exactly what data is being used where and how. There is evidence that the external sharing of data has been subject to abuse, with agreements being breached and vulnerable patients targeted as a result of data breach. This being the case, we recommend that the genome project method of providing secure data access whilst data remains within the NHS firewall should be the default for all partnerships. If specific projects require external sharing, the governing body should evaluate the need, require risk assessments and method statements and negotiate bespoke contracts, with penalties for breach which effectively deter breach.



## 12. Acknowledgements

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Hopkins Van Mil: Creating Connections is very grateful to Jurors in Taunton, Leeds and London for their enthusiasm and willingness to discuss the complex subject of uses of health and operational data, which for the majority was a completely new subject. Their commitment to a full weekend of intensive presentations, question and answer sessions and discussions leading to the formulation of recommendations for the commissioning bodies was really impressive.

The roundtables which informed the design of the Citizens' Juries would not have been possible without the support of the Health Data Research UK Public Advisory Board; Cancer Research UK PPI groups; Healthcare Quality Improvement Partnership Service User Network members; Manchester University NHS Trust; Use My Data patient advocates and British Heart Foundation PPI groups. Many thanks to those organisations for the support they gave to the recruitment process. Thanks too to the participants whose constructive criticism ensured the Citizens' Juries were framed by effective stimulus materials, key questions and a workable process design.

Thanks to the commissioning bodies particularly Dr. Natalie Banner, Understanding Patient Data Lead; Reema Patel, Head of Public Engagement, and Aidan Peppin, Research, Ada Lovelace Institute; Pooja Bharadia, Senior Policy Adviser, and Nicholas Gray, Senior Policy Lead, Life Sciences Industrial Strategy Projects and Genomics, Office for Life Sciences and Lethiwe Choga, Senior Strategy Adviser, NHS England and NHS Improvement. All those in the programme on the project team committed significant time to ensuring mixed methods research was appropriately evidence and informed within a tight timescale.

Special thanks go to Oversight Group members (Appendix 1) and expert witnesses (Appendix 2) who generously gave their time to ensure that the Citizens' Juries were balanced and robust. We are also grateful to those who agreed to be interviewed as part of the design process (Appendix 3). All these contributions ensured that Jury deliberations were informed by a range of perspectives. Their involvement provided concrete reassurance to roundtable members and Jurors that their voices are being heard.

Hopkins Van Mil  
February 2020

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## Appendix 1. Oversight Group members

Name	Role	Organisation
Natalie Banner	Lead	Understanding Patient Data
Iain Buchan	Public Health and Informatics Research Leader	University of Liverpool
Aisling Burnand	Chief Executive	Association of Medical Research Charities
Gary Cook	Deputy Director	Office for Life Sciences
Simon Denegri	Executive Director	Academy of Medical Sciences
Mark Gubby	Head of Information Governance	Guy's and St. Thomas' NHS Foundation Trust
Jacob Lant	Head of Policy and Public Affairs	Healthwatch England
Reema Patel	Head of Public Engagement	Ada Lovelace Institute
Chris Molloy	Chief Executive	Catapult Medicines Discovery
Anna Steer	Senior Communications Manager	NHSX
James Wilson	Panel Member	Office of the National Data Guardian

## Appendix 2. Expert witnesses

Name	Role	Organisation
Natalie Banner	Lead	Understanding Patient Data
Phil Booth	Coordinator	MedConfidential
Sarah Brooke	Public Advisory Board member	HDR UK
Chris Carrigan	Expert Data Adviser	UseMyData
Andrew Davies	Digital Health Lead	Association of British Healthtech Industries
Simon Denegri	Executive Director	Academy of Medical Sciences
Mark Gubby	Head of Information Governance	Guy's and St. Thomas' NHS Foundation Trust
Eleanora Harwich	Director of Research and Head of Tech Innovation	Reform
Tim Hubbard	Associate Director	HDR UK
Amanda Lucas	Programme Director	Imperial College Healthcare Partners
Reema Patel	Head of Public Engagement	Ada Lovelace Institute
Tim Rawlins	Director	NCC Group
Jackie Shears	Associate Director for Data Acquisition	NHS Digital
Joshua Symons	Associate Director of Data Optimisation	NHS Digital
Tina Woods	Founder	Collider Health

## Appendix 3. PPI groups involved in roundtable recruitment

Organisation
British Heart Foundation
Cancer Research UK
Health Data Research UK Public Advisory Board Members
Healthcare Quality Improvement Partnership (HQIP) Service User Network
Manchester University NHS Foundation Trust
Public Programmes Team, Manchester University NHS Trust
Use My Data Patient Advocates

## Appendix 4. PPI groups involve in roundtable recruitment

### Public engagement on a fair partnership on NHS data

#### Draft Recruitment specification

*Lead Client:* Understanding Patient Data

*Deliberative Engagement Research theme:* Agreeing fair terms for sharing NHS data

*Engagement contractor:* Hopkins Van Mil: Creating Connections Ltd

#### Aims:

The aims of this public engagement are to:

- Find out what people think and feel about different partnership models between the NHS and private companies wishing to use NHS data
- Develop a deeper and richer understanding of how data is shared in the NHS
- Develop understanding of what is and what isn't acceptable to patients and the public, and how different values and priorities could be balanced
- Answer the question, '*What constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS data?*'

The methodology will be 3 Citizens' Juries in 3 locations for which participants will be recruited. The purpose of this document is to give the framework through which the fieldwork team will develop the detailed schedule and screener for recruitment. These will be approved by the Project Team via HVM before being used in the field for recruitment.

The dialogue will involve recruiting up to 20 (for 18) people, broadly representative of the population in terms of age, gender, life stage, social grade/ household income, geography and ethnicity. We will be gaining informed consent from participants in terms which comply with current GDPR legislation and will allow identifiable data to be transferred and stored securely by the commissioning body for future research and/or dialogue purposes. HVM is registered as a data controller with the Information Commissioner's Office no: Z2969274.

#### Recruitment summary:

- Total number of Citizens' Juries = 3
- All Juries are non-residential and held on Friday (6-8pm), Saturday and Sunday (9.30am to 4.30pm)
- 3 recruitment exercises as follows:

Location	Dates
Taunton Venue	30 August to 1 September Museum of Somerset, Castle Lodge, Castle Green, Taunton TA1 4AA
London Venue	6 to 8 September Roots and shoots, Walnut Tree Walk, London SE11 6DN
Leeds Venue	6-8 September Leeds Church Institute, 20 New Market St, Leeds LS1 6DG



- All participants must commit to attending from Friday evening at 6pm to 4.30pm on Sunday in their location. The Citizens' Jury is non-residential but will be located centrally in a venue easily accessible on public transport.
- Respondents will be asked to review some very short written/ visual material before participation
- Incentive: £250 for attendance at the complete Citizens' Jury which will be paid in cash at the end of Sunday evening
- In addition, reasonable<sup>7</sup> expenses to enable involvement can be claimed.

**Screener to include:**

<b>Criteria</b>	<b>Target</b>
Gender	50% identifying as male / female
Age	Good age distribution across age groups from every adult life stage from 18 to 75+
Ethnicity	An appropriate proportion of black and minority ethnic participants In line 2011 census data for each recruitment area.
Life stage	A broad range of life stages from students, young professionals, raising young children to empty nesters and those who are retired (20% of sample from each category)
Current working status and type	A range of people who are employed (part-time/ fulltime/ self-employed) and unemployed, plus those who are retired.
Social Grade	Mix of ABC1C2DE
Geographic location	Taunton should be a largely rural recruitment (80% rural/ 20% urban); Leeds should recruit from both urban and rural locations (50/50). London should be an urban recruitment exercise.
Experience of market research/ dialogue	Should not have taken part in a focus group/ Citizens' Jury/ Citizens' Assembly or public dialogue in the last six months
Experience of the issue	Should not work for the NHS or a commercial entity working in partnership with the NHS. Participants are <b>not</b> required to have specialist knowledge of the issue.

**Note:** please **do not** recruit friendship pairs or use snowballing techniques.

<sup>7</sup> Reasonable expenses include travel and the costs of carer/support workers. Actual expenses will be reimbursed based on receipts submitted with an expense claim.

## Appendix 5. Process and stimulus materials

### Citizens' Juries on a fair partnership on the uses of NHS data

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#### Case Study: NHS Blood and Transplant (NHSBT) and Kortical

#### Artificial Intelligence (AI) technology to reduce wasted blood products

##### The problem

NHS Blood and Transplant provide the blood service in England. Donated blood is a valuable, short shelf-life product that is essential to the delivery of patient care. The management of the blood supply chain has many factors to consider, such as supply, manufacturing, distribution, stock holding, logistics and hospital demand. When all the factors are combined there are millions of variables and so it is very difficult to predict how much blood a hospital might need and when – leading to wasted blood products and unmet demand.



Image source: NHS Blood & Transplant

##### The data sharing development

NHS Blood and Transport (NHSBT) is partnering with Kortical, a company specialising in Artificial Intelligence, to optimise the entire logistic s chain from blood donor to patient. NHSBT and three Hospital Foundation Trusts will be providing data (see below) to Kortical to build Artificial Intelligence / Machine Learning models to better predict the type and quantity of blood needed by hospitals.

Funding was provided by Innovate UK, a non-departmental public body funded by a grant-in-aid from the UK government. The project started in December 2018 and will report in 2020.

##### What is happening?

Kortical is running NHSBT data, Hospital Trust operational data and data on additional influencing factors such as weather and school holidays into their AI model to develop predictions about what type of blood is required, where and when. The project is focusing on platelets (tiny blood cells that help our bodies form blood clots stop bleeding) which have a short life span of seven days. Three Hospital Trusts are involved in the programme: Manchester, Oxford and Cambridge.

## Aim and success criteria:



### Success Criteria

50%

reduction in wastage

50%

reduction in ad hoc  
transport costs

Overall aim to improve patient  
care - right platelets available  
at the right time

### Who benefits & how?

- **Patients:** the right blood products available when needed to ensure timely and effective treatment.
- **NHS:** Reduction in wasted blood products, reduced transport costs.
- **Kortical:** Sell this technology to other health facilities around the world. Use the learnings from this work to develop other models for other supply chain challenges such as catering using the freshest possible food supplies.

### What are the considerations that should be explored about this kind of partnership?

Jurors should consider the challenges and trade-offs in this kind of partnership. Questions that have been raised include:

- What benefits should be expected from the partnership?
- Who should gain what from the partnership to ensure it is fair?
- How could other parts of the NHS benefit from the process?
- What are the issues raised by this partnership?

### Find out more:

<https://www.nhsbt.nhs.uk/news/nhs-blood-and-transplant-partners-with-kortical-to-deliver-innovative-project/>

## Citizens' Juries on a fair partnership on the uses of NHS data

### Case Study: Musgrove Park Hospital and CGI<sup>8</sup>, Marand<sup>9</sup> and the Apperta Foundation<sup>10</sup>.

#### Introducing e-Prescribing in hospitals linked to the Electronic Patient Record to reduce deaths and illness caused by prescription drug errors

##### The problem

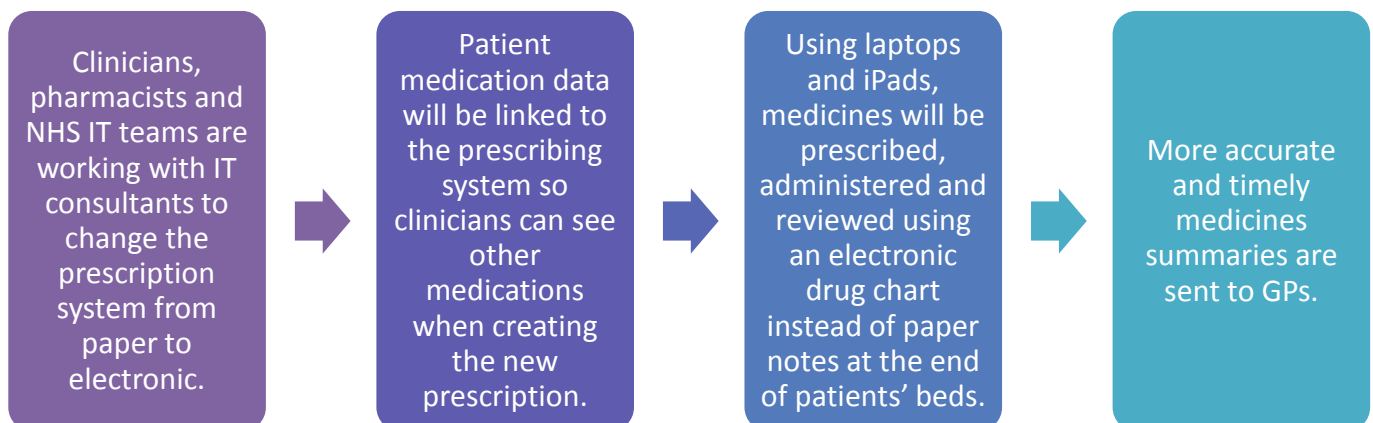
An estimated 237 million medication errors occur in the NHS in England every year, according to a study by the Universities of York, Manchester and Sheffield. It is estimated that up to 5 people die each day due to prescription errors. Most hospitals still use paper-based prescriptions. This can lead to prescribing errors because handwritten instructions can be misread and clashes with existing medications or health conditions are harder to detect.



##### The data sharing development

The e-prescribing system being developed with Musgrove Park Hospital in Somerset will be an open system which creates an electronic patient record of prescriptions, accessible from iPads and laptops. These electronic patient medication records will replace paper medicine lists enabling the sharing of information as required for patient care.

##### What is happening?



##### What's next?

- Later in 2019, the e-prescription system will be rolled out across wards at the Musgrove Park Hospital

<sup>8</sup> CGI: independent IT and business consulting service

<sup>9</sup> Marand: Healthcare IT specialist

<sup>10</sup> Apperta Foundation: clinician-led, not-for-profit company to promote open systems and standards for digital health and social care.

## What are the benefits in this kind of partnership?

- **Patients:** Safer prescriptions, based on fuller information on allergies and other drugs being taken, resulting in fewer instances of drug prescription errors due to misreading of handwriting.
- **Musgrove Park Hospital:** Save money by spending less time spent on prescription administration and dealing with prescription errors.
- **Clinicians:** Better prescription decisions made with real time patient information, less time spent on paper to electronic administration, more time on direct care.
- **CGI, Marand and the Apperta Foundation:** Consultants paid for their expertise and a case study to share with prospective health care provider clients in the UK and globally.

## What are the considerations that could be explored about this kind of partnership?

Jurors could consider the challenges and trade-offs in this kind of partnership. Questions that have been raised include:

- Should other parts of industry be able to access the same data whilst this study is being undertaken?
- What benefits should be expected from the partnership?
- Who should gain what from the partnership to ensure it is fair?

### Find out more:

These three web pages provide more detail on this example:

<https://www.tsft.nhs.uk/about-your-hospital/media-centre/latest-news-releases/2019/august/musgrove-park-hospital-introduces-mobile-technology-to-wards/>

<https://www.cgi-group.co.uk/en-gb/news/musgrove-park-hospital-to-deliver-an-improved-e-prescribing-service-for-patients>

<https://www.digitalhealth.net/2018/02/jeremy-hunt-e-prescribing-acceleration/>

## Citizens' Juries on a fair partnership on the uses of NHS data

### Case Study: Moorfields Eye Hospital NHS Foundation Trust and Google DeepMind Artificial Intelligence (AI) technology to diagnose and treat eye disease

#### The problem

Eye diseases, such as age-related macular degeneration, are one of the biggest causes of sight loss. Many diseases can be prevented with early detection and treatment. More than two million people in the UK live with sight loss.

Currently eye specialists use scans which create a 3D image of the eye to detect signs of disease.

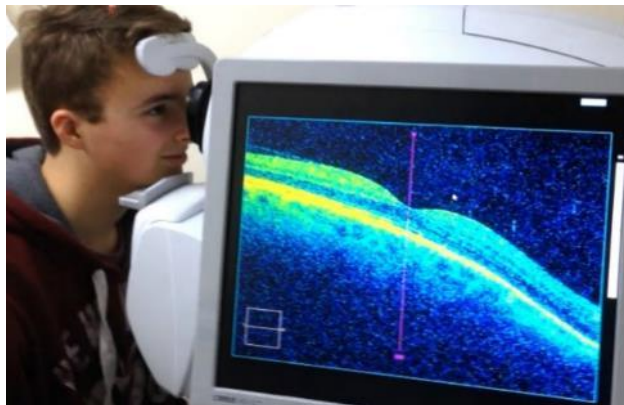


Image source: Matheson Optometrists

The time taken to analyse these scans, combined with the number of scans that healthcare professionals have to go through (over 1,000 a day at Moorfields Eye Hospital), means that there can be lengthy delays in detection and treatment of eye conditions.

#### The data sharing development

Dr Pearse Keane, a consultant ophthalmologist at Moorfields, collaborated with Google DeepMind on a project to explore whether artificial intelligence (AI) technologies could help clinicians improve the way sight threatening eye conditions are diagnosed and treated. Moorfields shared one million digital eye scans, used by eye health professionals to detect and diagnose eye conditions. These scans were de-personalised, meaning that any information that could be used to identify individuals had been removed before Google DeepMind received them.

#### What happened?

Google Deepmind used the scans to develop AI software (a machine learning algorithm) that can map signs of eye disease.

The AI also analysed the signs of disease to give clinicians a diagnosis and referral recommendation

The AI provided information so that clinicians could understand how it had come to its recommendation

The AI gave the correct referral decision for over 50 eye diseases with 94% accuracy, matching leading eye experts.

## What's next?

- This technology will need to go through rigorous clinical trials before it can be deployed at Moorfields and in other clinical settings
- The historic data has been tidied up for use in this study and in this cleaner state is being used in other eye disease research studies
- The de-personalised data used to train the AI systems will be moved to Google's cloud computing infrastructure because this research requires a large amount of processing power. This will allow the research to be carried out at a faster pace than is possible with current systems available in the UK
- At the end of the five year agreement, the data held on DeepMind drives will be destroyed and a certificate of destruction will be provided to Moorfields.

## What are the benefits in this kind of partnership?

- **Patients:** Faster diagnosis and treatment for eye disease, which save the sight of some patients.
- **Moorfields NHS Foundation Trust:** If this technology is approved, Moorfields will be able to use it for free across all 30 of their UK hospitals and community clinics, for an initial period of five years.
- **Eye care practitioners** could use the technology to prioritise those patients with the most pressing eye conditions
- **Google DeepMind:** Can sell the AI technology developed for this diagnosis tool to other NHS Trusts and health facilities around the world

## What are the considerations that should be explored about this kind of partnership?

Jurors should consider the challenges and trade-offs in this kind of partnership. Questions that have been raised include:

- Should other parts of industry be able to access the same data whilst this study is being undertaken?
- Should Google DeepMind be able to sell this technology to other NHS Trusts/ other English regions?
- What benefits should be expected from the partnership?
- Who should gain what from the partnership to ensure it is fair?

## Find out more:

<https://youtu.be/MCI0xEGvHx8>

August 2018

Research breakthrough August 2018



## Citizens' Juries on a fair partnership on the uses of NHS data

### Case Study: Imperial College and Imperial College Healthcare NHS Trust Clinical and staffing data combined to help plan staffing levels in intensive care units

#### The problem

Hospital teams do not always have the right information to understand how staffing changes may influence variations in the quality and safety of care for patients on their wards. This is because data such as staff rotas and patient health outcomes do not link to each other.



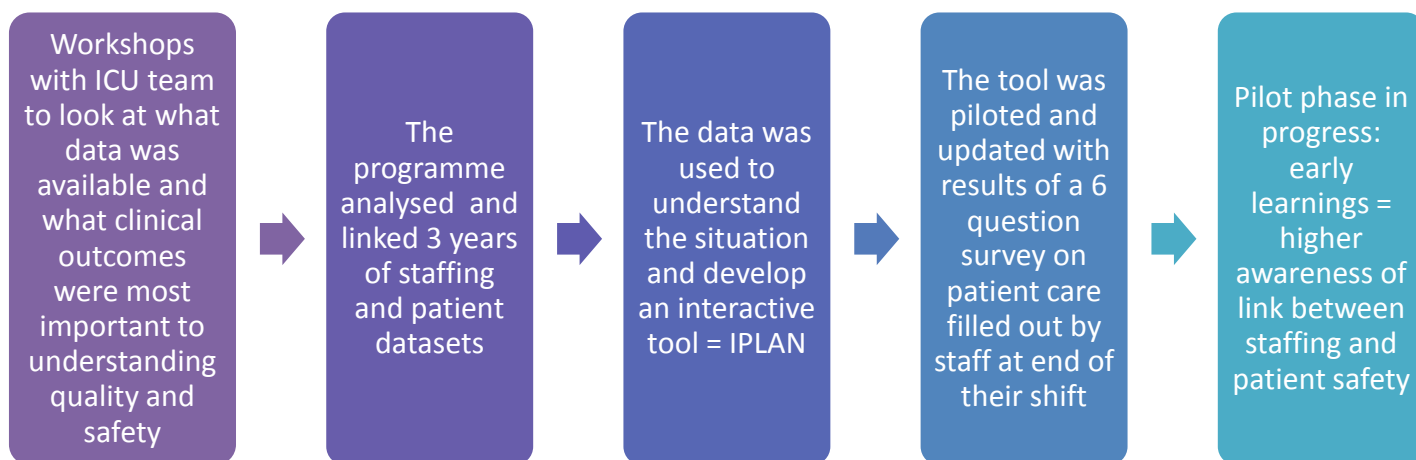
Image source: Imperial College Healthcare NHS Trust

#### The data sharing development

Imperial College and Imperial College

Healthcare NHS Trust worked together to combine and analyse three years of staffing and patient data at the Trust and link previously unlinked patient and workforce datasets. Through this they could then create systems for measuring and understanding the data that helped to develop an interactive tool. The project focused on three intensive care units (ICU) because they had more detailed staffing data available than other wards.

#### What happened?



#### What's next?

- The project team has worked with both staff from human resources and information, and clinical staff from ICUs, on improving data accuracy.
- Many issues relating to missing or inaccurate data have been resolved, and inaccurate data has been rectified where possible.
- The data is helping staff re-assess supply and demand for clinical services, and evaluate service developments, such as seven-day working.
- The team is using end of shift survey data and staffing and patient data to evaluate the pilot study and to understand whether using multi-disciplinary staff planning meetings supported by IPLan multi-disciplinary data has a positive effect on patient outcomes.
- Improved data from other wards could lead to IPLAN expanding beyond ICUs.



### **What are the benefits in this kind of partnership?**

- **Patients:** Receive the care they need because the right level of staffing is available.
- **Imperial College Healthcare NHS Trust:** Staffing levels that are informed by better data on patient need and safety and better co-ordinated across the hospital.
- **Imperial College:** Potential to partner with other industrial as a product for other healthcare providers globally.

### **What are the considerations that could be explored about this kind of partnership?**

Jurors could consider the challenges and trade-offs in this kind of partnership. Questions that have been raised include:

- Should industry be able to access this kind of data and create similar workforce planning tools?
- What benefits should be expected from the partnership?
- Who should gain what from the partnership to ensure it is fair?

### **Find out more:**

This web page provides more information on this example.

<https://www.health.org.uk/improvement-projects/early-warning-predictive-workforce-planning-tool-iplan>

## Citizens' Juries on a fair partnership on the uses of NHS data

### Case Study: University College London Hospital: Using software to predict missed medical appointments

#### The problem

More than 52,000 medical appointments are being wasted every day because patients do not turn up or alert the hospital or surgery that they cannot attend. This adds up to more than 15million missed appointments each year.

Of these, around 7.2million are with busy family doctors, which adds up to more than 1.2 million GP hours wasted each year – the equivalent of over 600 GPs working full time for a year.



Image source: CC Empty Waiting Room by Julep67

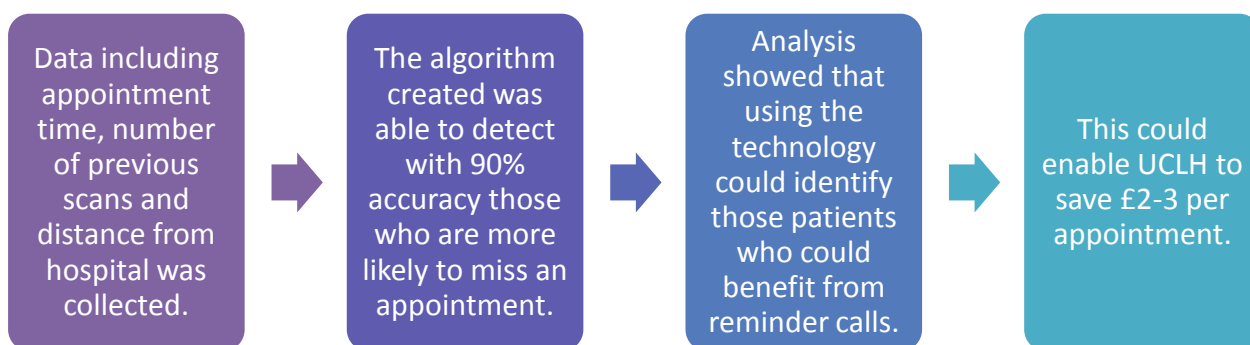
Each appointment costs an average of £30, putting the total cost to the NHS at more than £216million pounds. This would pay for:

- 8,424 full time community nurses
- 58,320 hip replacement operations
- 216,000 drug treatment courses for Alzheimer's<sup>11</sup>

#### The data sharing development

University College London Hospital (UCLH) researchers brought together data from 22,000 appointments for MRI<sup>12</sup> scans to create and develop a computer tool (algorithm) to identify those patients most likely to miss appointments. These patients could be targeted with pre-appointment calls to help ensure attendance or allow time for the appointment to be allocated to someone else if the patient wishes to cancel.

#### What happened?



#### What's next?

- To refine the algorithm as it also incorrectly flagged about half of the patients attending appointments as being at risk of not attending.

<sup>11</sup> <https://www.england.nhs.uk/2019/01/missed-gp-appointments-costing-nhs-millions/#main-content>

<sup>12</sup> Magnetic Resonance Imaging

- For UCLH to continue to test the use of the algorithm with the day-to-day data they collect for a range of other missed appointments for other treatments and conditions.
- To test the algorithm, and the subsequent communication approaches, to ensure that patients are not disadvantaged.<sup>13</sup>
- To assess whether this model could be replicated in hospitals across the NHS, potentially to potentially large savings.

### What are the benefits in this kind of partnership?

- **Patients:** Savings from missed appointments spent on better treatment and more healthcare staff
- **NHS:** Less money and resource wasted on missed appointments, better guidance on how to avoid missed appointments.
- **University College Hospital London:** Enter in to partnerships with healthcare providers across the globe to help reduce missed appointments.

### What are the considerations that could be explored about this kind of partnership?

Jurors should consider the challenges and trade-offs in this kind of partnership. Questions that have been raised include:

- Should industry be able to access the same data and provide this service to other hospitals/health care settings?
- What benefits should be expected from the partnership?
- Who should gain what from the partnership to ensure it is fair?

### Find out more:

These two articles discuss this example in greater detail:

The Guardian, *Hospital develops AI to identify patients likely to skip appointments*, April 2019

<https://www.theguardian.com/society/2019/apr/12/hospital-develops-ai-to-identify-patients-likely-to-skip-appointments>

Nature, *Predicting scheduled hospital attendance with artificial intelligence*, April 2019

<https://www.nature.com/articles/s41746-019-0103-3>

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<sup>13</sup> <https://towardsdatascience.com/predicting-missed-hospital-appointments-using-machine-learning-what-are-the-risks-a388348109d>

**Citizens’ Juries on what constitutes a fair partnership on uses of NHS data**

Locations & Venue	Dates & times		Team
<b>Taunton:</b> The Museum of Somerset, Castle Lodge, Castle Green, Taunton TA1 4AA	Friday 30/08/19 to 6-8pm	Sunday 01/09/19 9.30am to 4.30pm	LF: Henrietta Hopkins F: Suzannah Kinsella
<b>London:</b> Roots & Shoots, Walnut Tree Walk, Kennington, London SE11 6DN	Friday 06/09/19 to 6-8pm	Sunday 08/09/19 9.30am to 4.30pm	LF: Simon Burrall F: Anita van Mil
<b>Leeds:</b> Church Institute, 20 New Market St, Leeds LS1 6DG	Friday 06/09/19 to 6-8pm	Sunday 08/09/19 9.30am to 4.30pm	LF: Henrietta Hopkins F: Emma Williams
<b>Pre-materials:</b> Participants are sent: Programme and <i>Points to help the discussion</i> document.			

Aim & Objectives	Outcomes
<p>To deliver a mixed methods public engagement and deliberation on the question: <i>What constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients’ data and NHS operational data?</i></p> <ul style="list-style-type: none"> <li>To design, implement and report on roundtables, a series of three Citizens’ Juries and a nationally representative survey to gain insight on citizens’ views on this fair partnership</li> <li>To engage the public to gather views on the use of NHS data to get a better understanding of what matters to people, their motivations, expectations, concerns and to use their perspectives to shape the policy framework.</li> </ul>	<ul style="list-style-type: none"> <li>The national survey will be shaped and informed by the findings of the Citizens’ Juries</li> <li>The developing policy framework, led by OLS, is informed by public views</li> <li>The different values and concerns at play when people weigh up different scenarios, recognise trade-offs and express expectations, hopes and concerns about data use within and beyond the health service have been heard and understood</li> <li>Deliberation and engagement are used robustly and thoroughly, building on the work that has already taken place across the NHS data and digital agenda</li> </ul>

## Friday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
<b>4:00-5.30 (90 mins)</b>	Set-up	<p>HVM teams to set up dialogue spaces.                      Room set up with 2 tables in cabaret style with sufficient space in between to talk in small groups and in plenary together                      1 reception desk with packs/ badges/ sign-in sheets                      1 plenary space + projector + screen + sound                      Check AV equipment                      2 small group areas with flip stands, banked blank flips and pre-prepared flips for the session.</p> <p>Ideas/ questions/ comments walls set up</p>	LF & Fs	Information packs Name badges Process on flips Projector Screen Speakers Facilitation kits Recorders AOT cards Audio Visual equipment	Space ready for deliberation
<b>5.30-6.00 (30 mins)</b>	Briefing for specialists/ observers  Registration	<p>Lead Facilitator will brief the observers.</p> <p>Sign-in sheet to be completed &amp; participants sign-posted to refreshments/ loos/ plenary area/ their small group table &amp; given their badge and the printed packs.</p> <p>Refreshments throughout – people can come and go – it’s a relaxed session.</p>	LF  Co-F to manage registration	Sign-in sheet Sticky dots to identify groups. Blue group (LF) and Red group (F).	All those present ready to start the session
<b>6.00-6.15 (15 mins)</b>	Welcome & introductions	<p>Housekeeping                      Welcome slides are displayed and presented which include the Citizens’ Jury aims and purpose, HVM info.</p> <ul style="list-style-type: none"> <li>• Facilitation intros</li> <li>• The observers/ specialists present are asked to stand up and introduce themselves and their interest in being part of the Citizens’ Jury process</li> <li>• Ways of working</li> <li>• The importance of the Jurors’ role and a brief summary of what it involves</li> </ul>	LF	Welcome PP to talk through  The <i>Points to help the discussion</i> document	Everyone knows who is in the room and why; what will happen during the evening and their role in it.  Making participants feel

## Friday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<p>Talk through discussion help points including recording protocol/ ways of recording. All recording is anonymous and no comments whether written or recorded will be attributed to a named individual in the report. <b>We are interested in what you are saying not who says what.</b> We use recording to back up the notes being made on the flip chart and to help us write a report on what you have all said to us. But if you don't wish your voice to be recorded, please talk to your facilitator. Explanation of small groups and your facilitator.</p> <p>We also have other ways of making sure we've really captured what you have to say. We use <b>post-its</b> to give you time to think something through. These will be collected up by the facilitator. We also have <b>any other thoughts cards</b>. You can write on these at any time, with any comment, thought or question you have on the issue at hand. Leave the comment card upside down in the centre of your table and it will be collected and reviewed with the rest of the report material.</p>			comfortable in the space.
<p><b>6:15-6:35 (20 mins)</b></p> <p>6:15-6:20 (5 mins)</p> <p>6:20-6:25 (5 mins)</p>	Getting to know you	<p>Each person has a picture card on the table in front of them. There are no right or wrong answers here, we're just getting to know each other.</p> <p>Please walk around the room holding up your card.</p> <p><b>1. Picture match:</b> Find the person who has the same card as you. Talk together about what the picture means to you and why, mention any stories from your own life if you'd like to.</p> <p>When the bell rings:</p>	LF F	<p>10 picture card pairs. Images of parts of NHS/ Industry/ Research/ Charities/ the location.</p> <p>Background patterns on the cards</p>	The groups/ facilitators/ observers get to know each other.



## Friday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<ul style="list-style-type: none"> <li>I have only thought about it occasionally</li> <li>I have thought about it regularly</li> </ul>			have thought NHS partnership
<b>6:40-7:00 (20 mins)</b>  6:40-6:42 2 mins  6:42-6:47 (5 mins)  6:47-6:55 (8 mins)  6:55-7:00 (5 mins)  7:00-7:05 (5 mins)	Introducing the subject	1. Introducing the Jury question:  <i>What constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?</i>  2. An overview of the subject under discussion & why we are in the room: Understanding Patient Data/ Ada Lovelace Institute <b>London: Reema Patel</b> <b>Leeds: Natalie Banner</b>  <b>3. OLS Gary Cook introductory film – both locations</b>  4. What's in and out of scope for the discussion including brief introduction to the OLS policy framework. We are not rehearsing the work already done (pull out headline findings) on whether or not data should be shared. It's about the <b>how</b> of partnerships. Given that it is being shared what constitutes 'fair'. Our focus is on data <b>collected routinely</b> as part of every patients' care and interactions with the NHS. This is not risk free – burglary analogy.  5. What data clip. You'll hear briefly from <b>Gary Cook</b> again and then from <b>Simon Denegri</b> from the National Institute for Health Research. – <b>both locations</b>  6. Introducing the jargon buster as a rolling tool that we'll add to over the next 2 days.	LF   RP/ NB  Film clip  LF	Did you know? Factsheet including: Scope of discussion Anonymised depersonalised data Key facts on partnerships Question Easy Read visual   Jargon buster	An overview of the subject. Clarity on what's on and off the table for discussion giving facilitators the remit to pull people back to the focus.  Understanding that this is a complex area on which we need Juror views.



## Friday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
<p><b>7:05-7:30 (25 mins)</b></p> <p>7:00-7:15 (15 mins)</p> <p>7:15-7:25 (10 mins)</p>	<p>Questions and jargon buster</p>	<p>Groups stay in the room and work from their tables.</p> <p>We have 15 minutes now to develop some questions we would like to come back to the plenary session with. We'll have time to discuss wider points a bit later.</p> <p><b>Q: What questions are front of mind when you think about the question being put to the Jury?</b></p> <p>Facilitator to stress these are very first thoughts. There will be many opportunities to explore the subject</p> <p>Prompts – to be used as necessary:</p> <ul style="list-style-type: none"> <li>▪ Are there any specific words/ phrases that need more explanation/ a clearer definition?</li> <li>▪ What points need clarification?</li> <li>▪ What didn't you understand?</li> </ul> <p>Talk to your neighbour</p> <p>Write down specific questions on post-its (1 question 1 post-it)</p> <p>Facilitator to collect and collate the questions raised and put them on the section of the Ideas Wall near your table. Come back as a group:</p> <p><b>Recorder on</b></p> <p><b>Q: Of all the questions we've got here, we're now going to select 2-3 clarification questions from our group. Which are a priority for raising after the break with the whole group and the specialist observers in the room?</b></p>	<p>Fs</p> <p>All</p>	<p>PP in pack</p> <p>Post-it collating sheet</p> <p>2 questions sheet/ cards</p>	<p>Common understanding of what has been presented, key questions answered, outstanding questions captured and agreement reached on how to deal with them. Stress that this is just the first opportunity to ask questions – this kind of question formulation will happen regularly over the next few days.</p>

## Friday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<p>Reassure participants that all the questions they have will be put on the 'ideas/ questions/ comments wall' so that they can be answered over the next couple of days.</p> <p>Facilitators to add terms that need definition to the running jargon buster.</p> <p><b>Recorder off</b></p> <p>2 volunteers to ask the questions/ make the statements.</p>			
<b>7:25-7:45 (20 mins)</b>	Plenary Q&A	<p>Very informal Q&amp;A – process</p> <p><b>Recorder on</b></p> <p>LF takes first question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration over the next two days.</p> <p>LF takes second question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration.</p> <p><b>Recorder off</b></p>	LF + panel	2 questions per group initially	Clarification is provided as required
<b>7:45-7:55</b>	What to expect over next two days	Summary of roles and responsibilities (which were sent to Jurors in advance too). Overview of who they'll hear from – visual of witnesses and their organisations. Stress their central importance to the process.	LF		
<b>7:55-8:00</b>	Close	Thanks and close. Stress importance of tomorrow's session. Log into <a href="http://www.menti.com">www.menti.com</a> and input code on the screen.	LF		Test of the mood/ interest levels of the room

Friday					
Time	Agenda	Process	Who?	Process tools	Expected outcomes
		What has interested you most this evening? <ul style="list-style-type: none"> <li>• The topic</li> <li>• The conversations with other Jurors</li> <li>• Deciding on questions</li> <li>• Understanding my role</li> </ul> Use the box to write one word that describes your experience of this evening: Free space question  Thank you for coming this evening. You are vital to this Citizens' Jury's success. Come back tomorrow.			

Saturday					
Time	Agenda	Process	Who?	Process tools	Expected outcomes
<b>8:00-9.00 (60 mins)</b>	Set-up	Set up as required from Friday night.  One small group in main room (blue group) + plenary area.  One break out space for red group	LF & Fs		Space ready for deliberation
<b>9.00-9.30 (30 mins)</b>	Briefing for specialists/ observers  Registration	Lead Facilitator will brief the observers.  Sign-in sheet to be completed & participants sign-posted to refreshments/ loos/ plenary area/ their small group table as before.  On arrival refreshments.	LF  F	Sign-in sheet Sticky dots to identify groups	All those present ready to start the session

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
<b>9.30-9:45 (15 mins)</b>	Welcome & introductions	<p>Housekeeping Ground rules reminder (within the Help Points document)</p> <p>Presentation focused on the OLS policy framework – a factual presentation of the:</p> <ul style="list-style-type: none"> <li>- purpose</li> <li>- principles</li> </ul> <p>Emphasising that this work is draft and exploratory, it's the path to being together in this room; and that Jurors have an important role in this process.</p> <p>Question reminder (up around the room)</p>	<p>LF/ F</p> <p>LF</p>	<p>Welcome PP to talk through</p>	<p>Everyone knows who is in the room and why; what will happen during the evening and their role in it.</p> <p>Making participants feel comfortable in the space.</p>
9:45-9:55	Expert witness	<p><b>London: Mark Gubby, NHS Digital</b> <b>Taunton/ Leeds: Gary Cook, OLS film</b></p> <p>Overview of NHS in England, the complex landscape of organisations plus a clear explanation of <i>routine data, that we are focused on data which has normally had its identifiers removed.</i> An overview of patients' and operational data use.</p>		<p>NHS context handout</p> <p>Uses of data handout</p>	<p>To understand the context in which the question is being framed</p>
9.55-10:00	Question development (a)	<p>Participants use post-it notes and spend a couple of minutes noting down any immediate questions they have, talking to others around them if helpful.</p>	<p>LF from the front supported by co-F</p>	<p>Post-its</p>	<p>Initial thoughts immediately after a presentation</p>
10:00-10:10	Expert witness	<p>Partnership case study: illustrating an existing partnership within this NHS system</p> <p>Taunton: Richard Blackwood, South West Academic Health Science Network</p> <p><b>London: Amanda Lucas Imperial Healthcare Partners</b></p>	<p>RB Zoom</p> <p>AL</p>		<p>An introduction to partnerships</p>

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<b>Leeds: Andrew Davies, Association of British HealthTech Industries</b>	AD Zoom		
10:10-10:30	Small group question development (b)	<p>Small group Q&amp;A development, building on the questions they first thought of for the first expert witness. Expert witnesses are called by facilitators to tables to provide immediate clarification/ further discussion as necessary.</p> <p><b>Recorder on</b></p> <p><b>Q: We now have a long list of questions which we'll run through. Of these which are a priority for raising after the break with the whole group and the specialist observers in the room?</b></p> <p>Facilitators aim for 2-3 questions per table initially – more to be added if the answers are uncomplicated.</p> <p>As we did last night we will gather those not being asked at this point together so that they can be addressed from the 'ideas/ questions/ comments wall' during the day today and tomorrow morning.</p> <p><b>Recorder off</b></p>	Fs	Post-its Flip chart collation sheet	Ensuring Jurors are given the space and time to think about what they've heard and get the information they need for clarity with the support of witnesses/ facilitators.
10:30-11:00	Plenary discussion	<p>Facilitated plenary Q&amp;A using the priority questions</p> <p>LF takes first question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration over the next two days.</p>			Clarification is provided as required

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		LF takes second question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration.			
11:00-11:20	Break – observers/ witnesses to respond to questions by writing on the ideas/ questions wall where they have been put.				
11:20-11:30	Expert witness	<p>Taunton: Tim Rawlins, NCC Group  <b>London: Tina Woods, ColliderHealth</b>  <b>Leeds: Jackie Shears, NHS Digital</b></p> <p>Responding to why these partnerships are important and the benefits and challenges within them.</p> <p><i>Facilitation note: If anyone in the juries asks about insurance and marketing, you can say data collected in the NHS is not used for insurance of marketing purposes unless you've given explicit consent (e.g. for an insurer to access your medical records)</i></p>		Industry handout	
11:30-11:35	Question development (a)	Participants use post-it notes and spend a couple of minutes noting down any immediate questions they have, talking to others around them if helpful.	LF from the front supported by co-F	Post-its	Initial thoughts immediately after a presentation to make sure nothing is lost
11:35-11:45	Expert witness	<p>Taunton: Chris Carrigan, UseMyData  <b>London: Phil Booth, MedConfidential</b>  <b>Leeds: Eleanora Harwich, Reform</b></p> <p>Legal/ contractual/ Codes of conduct/ Principles</p>		PP	
11:45-11:50	Question development (b)	Participants use post-it notes and spend a couple of minutes noting down any immediate questions they have, talking to others around them if helpful.	LF from the front supported by co-F	Post-its	Initial thoughts immediately after a presentation to make sure nothing is lost

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
11:50-12:00	Expert witness	<p>HDR UK perspective</p> <p><b>London: Professor Tim Hubbard, Kings College London, HDR UK and Genomics England</b></p> <p><b>Leeds: Sarah Brooke, Public Advisory Board member HDR UK Partnership example</b></p>			Understanding on data uses in reality
12:00-12:20	Small group question development part (c)	<p>Small group Q&amp;A development, building on the questions they first thought of for the first expert witness. Expert witnesses are called by facilitators to tables to provide immediate clarification/ further discussion as necessary.</p> <p><b>Recorder on</b></p> <p><b>Q: We now have a long list of questions which we'll run through. Which of these are a priority for raising after the break with the whole group and the specialist observers in the room?</b></p> <p>Facilitators aim for 2-3 questions per table initially – more to be added if the answers are uncomplicated.</p> <p>As we did last night we will gather those not being asked at this point together so that they can be addressed from the 'ideas/ questions/ comments wall' during the day today and tomorrow morning.</p> <p><b>Recorder off</b></p>	LF from the front supported by co-F	Post-its Flip chart collation sheet	Ensuring Jurors are given the space and time to think about what they've heard and get the information they need for clarity with the support of witnesses/ facilitators.
12:20-12:40	Plenary discussion	Facilitated plenary Q&A using the priority questions			

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<p>LF takes first question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration over the next two days.</p> <p>LF takes second question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration.</p>			
12:40-12:50	Expert witness	<p><b>London Joshua Symons, Big Data &amp; Analytical Unit (BDAU) Centre for Health Policy (CHP), Institute of Global Health Innovation (IGHI), Imperial College London</b></p> <p>Data technology partnerships with the NHS</p> <p><b>Leeds: Moorfields eye hospital video</b>  <a href="https://www.moorfields.nhs.uk/content/partnership-video-deepmind-health">https://www.moorfields.nhs.uk/content/partnership-video-deepmind-health</a></p>			
12:50-12:55	Question development (b)	Participants use post-it notes and spend a couple of minutes noting down any immediate questions they have, talking to others around them if helpful.	LF from the front supported by co-F		
12:55-13:10 (15 mins)	Case studies	<p>In your small groups read through:</p> <p><i>Patients' data</i>            Eye disease diagnoses            E-prescriptions            Salford Lung Study  <i>Operational data</i>            Blood donation            Iplan            Missed appointments</p>	Fs	All case study handouts	



## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
13:10-13:15 (flexi time to start earlier if review of case studies is faster)	Small group question development  To continue after lunch	<p>Begin the small group Q&amp;A development, thinking about the case studies you have just read:</p> <ul style="list-style-type: none"> <li>• What do you need to know more about?</li> <li>• Are there words/ phrases we should add to the jargon buster?</li> <li>• Is there a point being made here that is hard to understand?</li> <li>• What questions do we wish to ask in the plenary discussion?</li> <li>• What comments do we wish to make in the plenary discussion?</li> </ul>			Ensuring Jurors are given the space and time to think about what they've read and get the information they need for clarity with the support of witnesses/ facilitators.
13:15-14:00	Lunch – opportunities to talk to witnesses/ observers & witnesses to respond to outstanding questions on the comments/ questions wall				
14:00-14:20	Small group question development  Continued from before lunch	<p>Small group Q&amp;A development <i>continued</i>, building on the questions they first thought of for the first expert witness. Expert witnesses are called by facilitators to tables to provide immediate clarification/ further discussion as necessary.</p> <p><b>Recorder on</b></p> <p><b>Q: We now have a long list of questions and comments which we'll run through. Which of these which are a priority for raising after the break with the whole group and the specialist observers in the room?</b></p> <p>Facilitators aim for 2-3 questions/ or comments per table initially – more to be added if the answers are uncomplicated.</p> <p><b>Recorder off</b></p>			Ensuring Jurors are given the space and time to think about what they've heard and get the information they need for clarity with the support of witnesses/ facilitators.

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
14:20-15:00	<p>Plenary discussion</p> <p>Final wrap up with expert witnesses</p>	<p>Facilitated Q&amp;A with the priority questions</p> <p>LF takes first question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration over the next two days.</p> <p>LF takes second question from each table. They are answered by those present/ or parked on the ideas/ questions wall for further consideration.</p> <p>LF to take any other questions/ update jargon buster with the group. Questions that can't be answered in the room right away will be collated and answers sought by the facilitation team overnight to inform tomorrow's discussions.</p> <p>Log into <a href="http://www.menti.com">www.menti.com</a> and input code at the top of the screen Do you have enough information to begin the Jury deliberations? Yes/ No</p> <p>If no, please tell us briefly what further information you need.</p> <p>Thank expert witnesses who leave.</p>		<p>Flips</p> <p>Participant post-its/ question cards</p>	<p>Ensure meaningful time with expert witnesses is brought to a useful conclusion.</p> <p>Continued check on Juror understanding and need for more information.</p>

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
15:00-15:10 (10 mins)	Plenary presentation: Partnership models	<p>Introduction to partnership models – some examples of the kinds of data sharing partnerships that exist/ might exist.</p> <p><b>Reminders:</b></p> <ul style="list-style-type: none"> <li>We are focusing <i>routine</i> data</li> <li>We are not thinking about <i>whether or not data should be shared</i>, but given that it is being shared, <i>how</i> that should happen within a <i>fair partnership</i>.</li> <li>Use the A3 handout to describe the three broad types of partnership. Read out the section at the top and explain the dotted lined boxes are drawn from the same fictional case study – which is extrapolated from the Moorfields case study.</li> </ul>	LF	<p>Handout: partnership models</p> <p>PP</p>	An understanding of the kinds of partnerships that are possible/ have potential building on the knowledge gained from expert witnesses
15:10-15:20	Informal break – come back to your small groups				
<p><b>15:20-16:10 (45 mins)</b></p> <p>15:20-15:30 (10 mins)</p> <p>15:30-16:10 (40 mins)</p>	Small group review of the partnership models	<p>In small groups:</p> <p>Facilitator encourages Jurors to read/ review the models using the handout/ case studies. Talk to your neighbour. What points do you want to make on the models?</p> <ul style="list-style-type: none"> <li>Note points using post –its</li> <li>Facilitator to collate key points on a flip chart sheet.</li> </ul> <p><b>Recorder on</b></p> <ul style="list-style-type: none"> <li>Review key points as a group.</li> </ul> <p><b>Recorder off</b></p> <p>Reminder of the question: <i>What constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients’ data and NHS operational data?</i></p>		<p>Post-its</p> <p>Post-it collation sheets</p> <p>Ideas boxes</p> <p>Coloured pens</p> <p>Sheets of key message card (A5)</p> <p>Glue</p> <p>Images</p>	<p>Reflections on the benefit models examples. An opportunity to gauge understanding/ gaps that need to be filled for tomorrow’s discussions.</p> <p>Juror reflections on the values/ concerns at play when people weigh</p>

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
16:10-16:20 (10 mins)		<p><b>Q: Given all you have heard and thought about today what are the key points you wish to highlight that are important about the possible models of partnerships we have shared?</b></p> <ol style="list-style-type: none"> <li>1. Take a white box for each sub-group of 3/3/4</li> <li>2. Create an 'ideas box': use the top and 4 sides of the box to illustrate the key points you wish to make – resulting in 5 key messages. Think about: <ul style="list-style-type: none"> <li>- one main message, then</li> <li>- hopes</li> <li>- concerns and challenges</li> <li>- trade-offs (one benefit might be received which means another can't be applied)</li> <li>- expectations of data sharing partnerships</li> </ul> </li> <li>3. Use the cards you have next to the box to: <ol style="list-style-type: none"> <li>a) Add more messages than the 5 you've created you can use the cards to write/ draw these messages and then put them inside the box.</li> <li>b) You can also use these cards to note down any points you wish to make but don't want to say out loud for whatever reason.</li> <li>c) And finally the cards can be used to note down any partnership models that we haven't covered but that you think would be useful to include.</li> </ol> </li> </ol> <p><b>Recorder on</b></p> <p>Group to agree what and how to present their key messages to the room.</p>		<p>Facilitator to note how participants are coming to their key messages. Areas they are considering, thoughts that take them to their key messages.</p>	<p>up the different options/ examples. Thinking about concerns/ hopes/ expectations and the values the Jurors apply.</p>

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<b>Recorder off</b>			
16:20-16:30 (10 mins)	Plenary  Wrap up	<p><b>Recorder on</b></p> <p>Brief presentation of the key messages at this point</p> <p>Reflections from observers present on what they have heard today.</p> <p><b>Recorder off</b></p> <p>Thoughts from the Jury on anything they feel they need to make sure they can make recommendations on the question by the end of tomorrow.</p>			
16:30	Close	<p>Thanks to the Jury.</p> <p>Stress the importance of the recommendations that Jurors will develop the following day and the importance of coming back.</p> <p>Overnight we'd like you to think about what the word 'fair' means to you. Bring any examples tomorrow which will help you discuss what fairness means. This could be something from your own life, something from the news, or other examples.</p> <p>It may help to think about a situation which you consider is <i>unfair</i> and then to reflect on what you would like to see happen to make that situation fair.</p>			

## Saturday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
16:45-17:00		<p><b>Taunton:</b> Team review of what's happened today. Identify themes for AM2 exercise on Sunday based on this discussion (week-end 1).</p> <p><b>Leeds &amp; London:</b> Team review as necessary using skype to compare day across two locations and to confirm we are all happy with the Sunday process.</p>	Full team of facilitators / observers		Clarity on what to bring/ prepare for Sunday's session

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
<b>8:00-9:00</b> <b>(60 mins)</b>	Set-up	Set up as required from Saturday	LF & Fs		Space ready for deliberation
<b>9:00-9:30</b> <b>(30 mins)</b>	Briefing for specialists/ observers  Registration	<p>Lead Facilitator will brief the observers if not already covered the day before.</p> <p>Sign-in sheet to be completed &amp; participants sign-posted to refreshments/ loos/ plenary area/ their small group table as before.</p> <p>On arrival refreshments.</p>	LF  F	Sign-in sheet Sticky dots to identify groups	All those present ready to start the session
<b>9.30-9:35</b> <b>(10 mins)</b>	Welcome & introductions	<p>Housekeeping Ground rules reminder</p> <p>Question reminder</p> <p>Models reminder and a reminder of the range of key messages Jurors ended the day with yesterday.</p>	LF	Welcome PP to talk through	<p>Everyone knows who is in the room and why; what will happen during the evening and their role in it.</p> <p>Making participants feel</p>

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
					comfortable in the space.
<b>9:35-9:40</b> <b>(5 mins)</b>		Log into <a href="http://www.menti.com">www.menti.com</a> and input code at the top of the screen What's the one main thing you remember from yesterday's discussions?  Speech bubble response			
<b>9:40-10:00</b> <b>(20 mins)</b>  9:40-9:55 (15 mins)  9:55-10:00 (5 mins)	Additional case studies	Case study PP presented by Reema/ Natalie based on what was produced by Reema in Taunton when Jurors said by 3pm on Saturday that they would like more case study examples of when things hadn't gone as planned.  Brief Q&A (in Taunton there were no questions at this point).	RP/ NB	PowerPoint & printed in pack	Covering case studies that include programmes that didn't go as expected/ raised challenges relevant for fair partnerships.
<b>10:00-10:20</b> <b>(20 mins)</b>  10:00-10:10 (10 mins)  10:10-10:20	Warm-up: fairness	Exercise to explore what we mean by fair. Contextual exercise drawing on scenarios outside the NHS to consider fair. Jurors own lived experience of fairness.  In small groups:  <b>Q: What did you think about overnight when you thought about what fairness means?</b>  Share as a small group your understanding of fairness, facilitator to go round the table asking for people's examples.		Facilitator to record key points on flip chart.	Collective understanding of what we are talking about when we say 'fair' in this context.

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		Facilitator to create a flip chart sheet in which what participants draw from their lived experience is then extrapolated to the context. The sheet is headed: <b>For the [group name e.g. Blue Group] 'fair' in this context is defined as:</b>		Summary flip sheet.	
<b>10:20-10:35 (15 mins)</b>	Plenary	Each group's Facilitator to feedback main points on what 'fair' is.  <b>Q: Having shared these points what, if any, additional points do you think should go in to this Jury's definition of fair?</b>  Short group discussion as necessary.	F led plenary  LF	Summary sheet	Collective understanding
<b>10:35-11:15 (40 mins)</b>	Challenges & benefits	Activities to reflect on the challenges and benefits of partnerships  Given what you heard yesterday, the key points you made yesterday afternoon and the reflections you have had on fairness:  <b>Q: What are the main challenges that you can see in creating fair partnerships between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?</b> <ul style="list-style-type: none"> <li>• Work in 2/3s</li> <li>• Use post its</li> <li>• Create a long list of all the challenges</li> </ul> LF to work with the group to collate the challenges on to one summary sheet highlighting the top 3 challenges.  <b>Q: What are the main benefits that you can see in creating fair partnerships between the NHS and researchers, charities and</b>			
10:35-10:55 (20 mins)					
10:55-11:15 (20 mins)					



## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes												
		<p><b>industry on uses of NHS patients' data and NHS operational data?</b></p> <ul style="list-style-type: none"> <li>• Work in 2/3s</li> <li>• Use post its</li> <li>• Create a long list of all the benefits</li> </ul> <p>LF to work with the group to collate the challenges on to one summary sheet highlighting the top 3 benefits.</p>															
11:15-11:35 (20 mins)	Break																
11:35-12:00 (25 mins)	Reflections on value	<p>Back in small groups Group to re-arrange in to 3 sub-groups, preferably talking to at least one new person</p> <p>Each group is given a flip chart sheet (see tools).</p> <p><b>Q: What value is unlocked for the NHS, Industry, Charities and Academia when the NHS enters in to these partnerships?</b></p> <p>Note: You may have to consider the 'value' that's being considered here before you go on to complete your grid.</p> <p>As Jurors are working facilitators create their summary sheet for the 13:10 lightening plenary.</p>		<p>Flip sheet:</p> <table border="1" style="width: 100%;"> <tr> <td>What value is unlocked for:</td> <td></td> </tr> <tr> <td>the NHS</td> <td></td> </tr> <tr> <td>Industry</td> <td></td> </tr> <tr> <td>Charities</td> <td></td> </tr> <tr> <td>Academia</td> <td></td> </tr> <tr> <td>When the NHS enters in to these partnerships</td> <td></td> </tr> </table> <p>Key points summary</p>	What value is unlocked for:		the NHS		Industry		Charities		Academia		When the NHS enters in to these partnerships		Thinking about value – both financial and non-financial
What value is unlocked for:																	
the NHS																	
Industry																	
Charities																	
Academia																	
When the NHS enters in to these partnerships																	
12:00-12:25	Reflections on governance	<p>Remain in small groups. Work in sub-groups</p> <p>Use post-its (one point per post-it).</p> <p><b>Q: What types of governance will realise 'fair' for the NHS, Industry, Charities, and Academia in these partnerships?</b></p>			Understanding of governance, giving space for thoughts beyond what currently exists.												

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<p>Facilitator to create a post-it summary sheet, collating key themes together such as legislation or governing body.</p> <p>As Jurors are working facilitators create their summary sheet for the 13:10 plenary</p>		<p>Post-it collation sheet</p> <p>Add to key points summary</p>	
<p><b>12:25-12:45 (20 mins)</b></p> <p>12:25-12:35 (10 mins)</p> <p>12:35-12:45 (10 mins)</p>	Reasons for caution	<p>Stay in small groups Work in sub-groups Have the A3 sheet of examples of partnership models in front of you and draw directly on this to consider:</p> <p><b>Q: What are the main reasons for caution when you think about the partnership models to create fair partnerships between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?</b></p> <ul style="list-style-type: none"> <li>• Work in 2/3s</li> <li>• Use post its</li> <li>• Create a long list of all the challenges</li> </ul> <p>F to work with the group to collate the challenges on to one summary sheet highlighting the top 3 reasons for caution.</p>		<p>Add to key points summary</p>	
<p><b>12:45-13:05 (10 mins)</b></p> <p>12:45-12:55 (10 mins)</p>	Reasons for optimism	<p>Stay in small groups Work in sub-groups Have the A3 sheet of examples of partnership models in front of you and draw directly on this to consider:</p> <p><b>Q: What are the main reasons for optimism when you think about the partnership models to create fair partnerships</b></p>			

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
12:55-13:05 (10 mins)		<p><b>between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?</b></p> <ul style="list-style-type: none"> <li>• Work in 2/3s</li> <li>• Use post its</li> <li>• Create a long list of all the challenges</li> </ul> <p>F to work with the group to collate the challenges on to one summary sheet highlighting the top 3 reasons for optimism.</p>		Add to key points summary	
<b>13:10-13:15</b> <b>(5 mins)</b>	Lightening plenary	Facilitators feedback very swiftly on their groups' key findings		Present summary points	So that each group understands what the other is thinking.
13:15-14:00	Lunch	Vox pop filming in <b>Leeds only</b>			
<b>14:00-15:00</b> <b>(60 mins)</b>	Recommendation development	<p>Development of recommendations in small groups</p> <p>Give each sub-group a flip chart/ post-it to work from:</p> <p>Review the question which has remained up on the wall throughout the week-end. Reflect on your hopes, expectations, concerns. Refer to the partnership models, consider what is fair and what value is, think about governance structures. And then answer this statement on your flip sheet/ using the post-its.</p> <p><b>As a result of our deliberations on the question, this section of the Jury recommends that...</b></p> <p>Each sub-group reviews all the recommendations created. The facilitator works with the group to:</p> <ul style="list-style-type: none"> <li>- pull together the recommendations the groups have in common</li> <li>- highlight difference</li> </ul>		3 prepared flip charts Pens Sticky dots	

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		<ul style="list-style-type: none"> <li>- highlight agreement</li> </ul> <p>To create a set of recommendations from [insert group name] to share in the plenary session</p>			
15:00-15:20	Plenary discussion	<p>Each of the two main groups shares their recommendations.</p> <p>LF and F work together to review these with the whole group to:</p> <ul style="list-style-type: none"> <li>- pull together the recommendations the groups have in common</li> <li>- highlight difference</li> <li>- highlight agreement</li> </ul> <p>Where there is difference find out why and note this on a flip chart.</p> <p>At the relevant point number the recommendations that are agreed and use Mentimeter to set up the question:</p> <p>Which, of any, of these recommendations best reflect my views? R1, R2, R3, R4, R5, R6</p> <p>Which, of any, of these recommendations do not reflect my views? R1, R2, R3, R4, R5, R6</p> <p>Note: In Taunton we didn't go to this vote – there was agreement in the room that the recommendations they had by this point across the two groups were the right ones.</p>			
15:20-15:30 (10 mins)	Break – during which the facilitators will write up the recommendations on separate numbered flip chart sheets.				

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
15:30-16:10 (40 mins)	Writing teams	<p>The recommendation sheets are spread out on the floor/ walls in a large space. Jurors are asked to go to the sheet that they wish to work on, one where they feel they can improve the words, make it best reflect what they have heard this weekend.</p> <p>For those recommendation sheets that do not have someone assigned to them LF to ask:</p> <p>Q: Do we agree that this is still a valid recommendation and we are happy with the wording? – Hands in the air vote.</p> <p>If people don't want to include it is there consensus on that? Could this recommendation be merged with another?</p> <p>If agreement that it is a recommendation everyone approves then the sheet is included in the pile of recommendations as the final version.</p> <p>The other groups then take their recommendation to a space of their choosing and re-write it to tweak it to the correct wording. They write the final version on an A5 card.</p>			
16:10-16:20	Presentation	Jurors present their recommendations to commissioning bodies present. They receive the Jurors words and briefly reflect on what they have heard.			
16:20	Close	<p>Final vote – an evaluation question</p> <p>Log in to <a href="http://www.menti.com">www.menti.com</a> and use the code displayed on the screen.</p>			Distribution of incentives

## Sunday

Time	Agenda	Process	Who?	Process tools	Expected outcomes
		Give us one to two words that sum up your experience of this Citizens Jury.  Thanks Next steps			