

# Foundations of Fairness

## Where next for NHS health data partnerships?

March 2020



**Understanding  
Patient Data**



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# Key findings



## 1 All NHS data partnerships must aim to improve health and care

People feel the NHS is justified in allowing academics, charities and industry access to health data, if improving health outcomes is the priority. Improvements should be fairly distributed across the NHS. However, it can be difficult to guarantee these improvements will always be achieved.



## 2 NHS bodies need consistent support and guidance to negotiate fair terms

The value of NHS held data is not just financial. Decisions should take into account long-term potential benefits for future generations across the health system rather than focusing on short-term revenues at a local level. This requires a coordinated national strategy and guidance.



## 3 Fairness requires public accountability, good governance and transparency

People care about NHS data and should be able to find out how it's used. It is unclear to the public how decisions are made now. Decisions about how data is used should go through a transparent process and be subject to external oversight.



## 4 Citizens want to be involved in decision-making

Deliberative participation methods can help embed citizen engagement into governance mechanisms. Involving people early on ensures decision-making is informed by public views, values, concerns and expectations.

# About this report

## Understanding Patient Data

Understanding Patient Data (UPD) seeks to make the uses of patient data more visible, understandable and trustworthy for patients, publics and health professionals. UPD is based at the Wellcome Trust and works with patients, charities and healthcare professionals to champion responsible uses of data.

## The Ada Lovelace Institute

The Ada Lovelace Institute is a research-led, people-centred, policy-facing research institute and deliberative body dedicated to ensuring that data and artificial intelligence (AI) work for people and society. Our core belief is that the benefits of data and AI must be justly and equitably distributed, and that these advancements must enable social and individual wellbeing.

## This report

In June 2019 Understanding Patient Data and NHS England in association with the Ada Lovelace Institute, commissioned Hopkins Van Mil to carry out a mixed methods public engagement process, exploring the question: *'What constitutes a fair partnership between the NHS and researchers, charities and industry on the uses of NHS patients' data and NHS operational data?'*

The research was supported by the UK Government's Office for Life Sciences. It was designed to ensure public views could feed into their developing policy framework for NHS Trusts entering into data access partnerships with third parties,<sup>1</sup> which complements the Code of Conduct for data-driven health and care technology.<sup>2</sup> The process involved three roundtable discussions with patient advocacy groups to develop materials and hone the research questions, followed by three citizens' juries and a nationally representative online survey of over 2000 people. The full methodology and findings are detailed in Hopkins Van Mil's report: *'Foundations of fairness: views on uses of NHS patients' data and NHS operational data'*.<sup>3</sup>

This joint report from Understanding Patient Data and the Ada Lovelace Institute builds on that work, analysing and responding to the jurors' deliberations and the survey findings. We set out joint recommendations for the UK Government and the NHS on how to ensure NHS patient and operational data is used in a way that aligns with public views and values.

## **We aim to:**

- Promote a deeper understanding of public expectations for the fair use of NHS data;
- Demonstrate the need for a coordinated national strategic approach, followed by a clear narrative, that reflect public views on NHS health data partnerships;
- Show that public deliberation is a valuable method for good data governance, which will be critical to creating a more trustworthy health data ecosystem.

We are grateful to the patients and members of the public who gave their time, expertise and opinions for this research. Thanks also to Hopkins Van Mil, NHS England, Office for Life Sciences and all our stakeholders and critical friends who supported this work.

## Introduction

The UK's health services steward large amounts of health data which has huge potential to lead to health improvements if it can be collated, linked and analysed.<sup>4</sup> Processing NHS data often depends on allowing third parties access to it, including academics, charities and industry. Researchers and analysts use data from patients, or operational data about health and healthcare, to understand disease, progress treatments, develop insights and products, and improve care delivery.<sup>5</sup> However, there are challenges to ensuring the agreements that NHS bodies make for the use of data are fair and equitable.<sup>6</sup>

## There are several challenges to getting NHS health data partnerships right, including:

- **The complexity of the UK healthcare system**

The NHS is made up of many organisations, with different approaches to data agreements in different areas.

- **The pace of change in the development and use of data-driven technologies**

Technology, and the range of potential uses of data are evolving rapidly, making it challenging to map data partnerships, predict the impact on health outcomes or foresee potential unintended consequences.

- **The lack of effective patient and public engagement on healthcare data**

Data often comes from patients' health records. Its use may be controversial, especially when private companies are involved, making it risky for policymakers and NHS decision-makers. Patient and public views and values are not yet widely embedded in governance and decision-making mechanisms.

# 63%

of people said they were unaware that the NHS grants access to data

Decisions about data are often made at a local and regional level by NHS organisations entering into agreements with third parties. There is currently little transparency about what agreements are being made and on what terms,<sup>7</sup> although increasing media interest is drawing attention to some of these.<sup>8 9 10</sup> Although health data use must comply with the relevant legal frameworks, there is scope for interpretation that can result in widely differing approaches to data agreements.

New techniques and processes – such as cloud computing and machine learning – make it possible to collect, use and link more data. Data-driven technologies are rapidly emerging in health, relying on collaboration between the NHS and researchers in both public and private sectors. Novel uses of data do not yet have clearly established regulatory pathways and standards for assessing effectiveness, safety and accuracy. This raises questions over how their potential benefits or harms could be assessed on terms that are fair to the NHS and patients.

Where data is collected routinely as part of an individual's care, additional consent is not usually needed to use it for other purposes,

subject to certain safeguards and data minimisation. Data that has had identifying information removed may still constitute personal data under the law, and people may still care how it is used even if they can't easily be identified. Aside from the National Data Opt-Out,<sup>11</sup> there is limited opportunity for people to express preferences about the way data from their health records is used. But health data is often sensitive, personal and valuable, and as the National Data Guardian has indicated, should be used in line with people's reasonable expectations.<sup>12</sup>

Controversy has also emerged around past NHS health data initiatives.<sup>13 14 15</sup> The limited capacity for patients to express their views, combined with the controversial nature of some agreements, creates a risk of backlash and damage to public trust. There's a lot of research that explores people's attitudes towards health data use.<sup>16</sup> But there is limited evidence about how people would weigh up the benefits and risks for the kinds of data access agreements NHS bodies are making.

The current political and research landscape provides opportunities to get the use of health data right. The Code of Conduct<sup>17</sup> developed by NHSX, the establishment of the HDR-UK Health Data Hubs and commitments from the Government to "invest in world-class computing and health data systems"<sup>18</sup> all represent good intentions. The Information Commissioner also argues for responsible data use for beneficial purposes, stating that "privacy and innovation are not mutually exclusive."<sup>19</sup> Several thoughtful reports have explored how the UK might make the most of the potential of NHS data,<sup>20 21 22</sup> helping move the discussion forward with tangible examples and decisions. But at present, technological developments are outpacing policy and regulation even though many of these issues are not new: the National Data Guardian challenged the health system in England to 'make the case' to the public for health data use back in 2016.<sup>23</sup>

The UK is entering a period where new, post-Brexit relationships will be defined. In the context of industrial strategy, NHS-held data could form valuable national assets. But these opportunities can only be grasped if the conditions for the fair use of NHS data are understood, embedded, and consistently and transparently met.

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

| juror in London



## Analysis

The jury and survey findings provide valuable insights into what matters for the public and how they'd make trade-offs to ensure partnerships between NHS bodies and third parties are, and are seen to be, fair. Translating these findings into the context of the emerging policy landscape, we have identified four key priorities that should be integrated into the rules and mechanisms by which these agreements are made, maintained and overseen. Putting these into practice would be significant progress towards ensuring the systems for managing and using NHS patient and operational data are worthy of public trust.



# 1 All NHS data partnerships must aim to improve health and care

Improving health is already central to many projects using health data. It is the underlying motivation of the #DataSavesLives movement<sup>24</sup> and is recognised as critical by NHSX.<sup>25 26</sup> NHS data also has indirect value through the potential to improve efficiencies, as well as to create new knowledge and technologies which can generate revenue, attract talent and boost investment in the UK life sciences sector.

The citizens' juries and survey findings show that people recognise the potential of health data to improve care for patients and enable people to live longer, healthier lives. Participants strongly believed that improved health outcomes should always be the primary purpose of using health data. They understood health outcomes to mean:

- **Direct impact on patient outcomes:** new medicines; new understandings of disease; improved diagnostics; more effective treatments; early disease detection.
- **Indirect impacts:** reducing costs; providing additional revenue for the NHS; increasing administrative efficiency; reducing waiting times.

This is a clear steer from the public for NHS bodies creating health data partnerships. Improving health and care must be the main focus and intention in all cases. Any decisions that may undermine the health service or exploit health data solely for commercial gain would contradict public expectations.

However, the jurors also expressed understandable scepticism that the benefits promised from data will always be achieved. This is partly because people were aware that the NHS does not have a strong track record with new technology: several people referred to continued use of paper records, referral letters and faxes. Additionally, for novel data uses and data-driven technologies, it is difficult to find examples that tell a compelling story of research that starts with data access and ends with clear improvements for patients. There is a long way to go to prove the clinical utility and effectiveness of even highly promising algorithms. This creates a risk that the technology is overhyped and the potential benefits overstated, which makes it difficult to decide what is

“ [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.

| juror in London

a fair use of data – and what isn't. The public are wary of the promise of data-driven technologies until there's clear proof they lead to better patient outcomes.

Some data partnerships may need to focus on data curation and fixing other bits of the 'plumbing'. This work may not lead to immediate patient benefit but will be crucial to building a more tech-enabled health system for the future. So, a cohesive story needs to be told about how investing in data formatting, standardisation and interoperability will result in clear benefits to patients. This is especially important at a time when the NHS is under pressure.<sup>27</sup> Otherwise investments in these core components may be seen as unimportant compared to things that have a direct and visible impact on patients, such as staffing levels.

### **Partnerships should not make health inequalities worse**

Although the research was structured to explore aspects of fairness within partnerships between the NHS and third parties, jurors strongly argued that fairness also meant a distribution of benefits across the health system. Jurors identified that one unintended consequence of localised health data partnerships could be to make existing regional healthcare inequalities worse. Rural participants were particularly concerned that affluent areas would benefit, with poorer and rural areas left behind or forced to pay a premium for data technologies developed elsewhere in the NHS, which would not have been designed for their populations. Several jurors felt that the balance of decision-making should rest at a national level to ensure an even distribution of outcomes, benefits and rewards across the country.

The diverse range of views were reflected in the survey, particularly around national versus local decision-making. It is important to recognise that people will not always reach full consensus on this type of question. Healthcare is highly devolved for good reasons, with local regions best placed to make decisions for their local populations, and disease specialists best placed to make decisions for the communities under their care. However, if data partnerships are developed without considering how to fairly distribute the benefits, some regions or specialties risk being left behind.

In one respect, this concern is not new: there are disparities in investment, skills, infrastructure, technical capability, population health needs and research culture across the health system. When data from

“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.

| Juror in Taunton

patients is involved, however, people are more likely to care about making sure that research and innovation is based on principles that matter to them. One of the clearest findings from the research is that there's a strong public commitment to a fair distribution of benefits across the country.

## What next?

81%

of people believe improvements should be distributed across different areas of the country, not just where the partnership is

Many data partnerships are new or emerging, so we don't yet have evidence on whether they are having a measurable impact on health and care. As these kinds of agreements become more common, monitoring and evaluation will be critical to ensure that they are not making health inequalities worse or increasing regional disparities in skills, expertise and data use. The Academic Health Sciences Networks and the Health Data Research UK Health Data Hubs are well-placed to understand where data partnerships are emerging at local and regional levels.

Principle 2 of the Code of Conduct<sup>17</sup> sets out a requirement for data users to articulate what outcomes and benefits are anticipated from the development of a data-driven tool or technology. We recommend supplementing this principle with a requirement that NHS organisations and data users should publish transparent and publicly accessible updates on the progress of the partnership towards achieving predicted benefits.

All parties should consider the potential risk of exacerbating health inequalities if the eventual benefits only accrue to a local area. Guidance offered by the National Centre of Expertise should make clear that impact across the healthcare system is an important consideration.

Partners (academic, charitable and industry organisations) should recognise that universal access is a fundamental principle to the NHS and reflect this in their business models. If partners plan to develop products or tools based on collaboration in one area, the partnership or business model should include specific provisions for equitable access across the UK healthcare system.



## NHS bodies need consistent support and guidance to negotiate fair terms

# 82%

of people expect the NHS to publish information about health data partnerships

One of the most challenging aspects of fairness to implement is the concept of a 'fair' value exchange between the NHS and third parties. How can NHS organisations effectively leverage the value of the data they hold, while protecting people's rights, to ensure a data partnership is fair? The NHS has some of the largest, most comprehensive and diverse health data sets in the world,<sup>28</sup> partly because it is a single payer, single provider service. This makes NHS health (and particularly patient) data highly desirable for the commercial sector: estimates put the potential value of NHS data at £9.6bn.<sup>29</sup> Given this substantial private sector interest, there's a risk that without adequate governance and expertise in place, NHS data will be exploited.

The juries felt that improving health and financial benefits for the NHS were both important, and the NHS is justified in pursuing both. Some even felt it would be wrong *not* to use the data. However, people strongly believed that value must always 'come back to' patients and the NHS for a data partnership to be 'fair'.

Jurors discussed whether the financial value of NHS data meant it could provide sustainable revenue for struggling NHS organisations. But this also raised concerns that the incentives for NHS decision-makers could be shifted away from their main function of delivering better care for patients. It could also encourage short-term financial returns being prioritised over long-term benefits for future generations, which the jurors objected to.

Jurors recognised NHS organisations may not be well-placed to understand the potential and value of the data they hold and would therefore be in a weaker position to negotiate fair terms. Some people were concerned that large companies would be able to negotiate deals that benefit them at the cost of the NHS, because they have greater resource and legal power. Small and medium sized enterprises (SMEs) may have the agility to adapt to NHS requirements but lack the resources to ensure the fair distribution of benefits in the longer-term.

The idea that value is about more than monetary considerations came up in many of the discussions, with participants identifying many aspects

**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.**

**| juror in Leeds**

66  
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?

| juror in Taunton

of 'value' depending on how it is used and who the beneficiaries are. For academic institutions, access to data may draw in students, expertise, funding for research and academic credit. For industry there is value in building up relationships and reputation with the health service. For charities, health data might provide evidence to support their campaigns and fundraising. And for the health service, value could take the form of access to new expertise, well-curated data and reputational benefits from leading innovation in health and care. These go well beyond simple transactional values. Thinking about value in these richer terms will ensure organisations entering into data partnerships are aware of their negotiating power and potential.

## What next?

The NHS uses its collective bargaining power for major procurement decisions such as the purchasing of medical devices and medicines.<sup>30</sup>

<sup>31</sup> There may be strength in numbers if local NHS organisations can negotiate collectively or if they know the terms that others have negotiated for data partnership agreements. The current lack of openly available information means that companies can approach multiple NHS providers with terms favourable to them. This risks creating an internal market, making it harder for NHS organisations to get a fair deal that also benefits the wider health system. A central register of data partnerships would help mitigate this risk.

NHS organisations entering into data partnerships need a good understanding of the range of different ways the data they hold could be used and valued by both themselves and third parties. The National Centre of Expertise should offer free operational advice and guidance in order to help NHS organisations get the fairest health data partnerships possible, taking into account that 'value' goes beyond financial returns.



## 3 Fairness requires public accountability, good governance and transparency

“You don’t just set up a partnership, ongoing governance has to be in place to make sure it’s on the right track.

| juror in Taunton

“If there are any suspicions that the data is being misused, then the CEO should sit in front of a Select Committee and actually be called to account.

| juror in Taunton

### Accountability and governance

The public and patients care about how NHS data is used. The emphasis that the jurors across all locations placed on accountability and transparency reflects this importance. They did not think a set of guiding principles for NHS bodies is sufficient to ensure data is used fairly, arguing that oversight is also necessary.

All three juries independently recommended a governing body to ensure strong and sustainable accountability over data use, calling it a: ‘watchdog’, ‘ombudsman’, ‘regulatory body’, and ‘governing body’. They described its responsibilities with terms like: ‘scrutinise’, ‘advise’, ‘oversee’, ‘checks and balances’, ‘audit’, ‘proactive and reactive’, ‘expertise’. This shows a desire for one person or organisation to be held to account for decisions, and for outcomes to be scrutinised at a national level.

The juries identified three main areas that need to be considered for effective governance of data partnerships. This is helpful for policymakers that want to establish a system that the public sees as trustworthy:

- **Proactive activities:** establishing principles and ensuring a good governance framework
- **Monitoring activities:** auditing and reporting
- **Reactive activities:** firefighting, public investigation and regulatory action where needed

Jurors recognised that over-burdening accountability processes could slow data partnerships down or stop them altogether, and suggested a simple approach. Simplicity also has the advantage of being more easily explainable to the public. Given how complex and technical potential data partnerships might be, clarity and simplicity of governance would provide reassurance that parties are not hiding behind technicalities to obscure their purpose.

These functions could be fulfilled by a single entity or spread across governance and oversight structures including the National Data Guardian, existing regulators and the new National Centre of Expertise.



Fairness depends a lot on how much information we've all got... we, in society, have to know what's going on with our data and why, otherwise it's not fair.

| juror in Leeds

Whatever the mechanism, it is clear the public expect data partnerships to be subject to a level of scrutiny that doesn't currently exist.

### Transparency

Improving transparency about data partnerships will be critical to establishing public accountability. It is often unclear what transparency means, but it is well summarised by the patient advocacy group useMYdata as: "say what you do, do what you say."<sup>32</sup> This involves ensuring accessible information is provided at the right time and in the right context for patients and the public. Jurors felt it was crucial that information about partnerships is understandable and with an appropriate level of detail. Providing dense technical information, redacted legal documents or vague assurances of privacy to patients is not meaningfully transparent and could further undermine trust by giving the impression that there is something to hide.

Jurors also felt that transparency should 'come as standard' and not as a result of Freedom of Information requests made by campaign groups, or media scrutiny. Transparency could include passive activities such as fulfilling reporting requirements, placing information on websites or in surgeries, but jurors pushed for more proactive communication about data partnerships as well. Greater transparency would reassure people concerned about 'back-door' deals and privatisation.

Improving understanding is often seen as the main route to earning trust, on the assumption that better communication about how data is used will lead to people being more accepting of it. However, this approach is flawed.

Firstly, it assumes that simply providing more information or educating people will lead to greater acceptance and trust.<sup>33</sup> This neglects the emotional and relational aspects of what makes someone trust, or mistrust, information they are receiving. Distrust of evidence-based advice on vaccinations is a good example: relaying accurate scientific information about vaccine safety and effectiveness is not itself sufficient to address some people's concerns.

Secondly, effectively communicating information about such a fragmented and complex system to millions of patients raises numerous practical challenges. There is a risk of heightening anxieties if the health system does not have clear, comprehensive answers to the types of questions people will have when they learn about health data use. This is

72%

of people said they are interested in how researchers use NHS data





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.

| juror in London

especially difficult because there is not currently a coherent framework of policy, governance and accountability around the use of NHS data.

Communicating about data can also be hard because it is abstract, often explained in technical or dry language, and does not necessarily resonate with people's lives. While it is important for there to be a coherent national narrative about how data is used, communications would be best delivered at a local or regional level within a small "diameter of trust,"<sup>34</sup> allowing people to ask questions of health professionals and staff they know and trust.

There are many engagement initiatives about health data happening at a local level that could be built upon, for example the Local Health and Care Record Exemplars.<sup>35</sup> Using these established routes would allow information to be tailored to the local context, for example explaining potential benefits in terms of anticipated reduction in referral times to the local hospital or improving diagnosis for specific conditions that are common in the area. These kinds of examples are more likely to be meaningful and tangible than general promises of benefits at a national level.

## What next?

The UK Government should implement measures to ensure clear accountability and transparency for health data partnerships across the country. These should include:

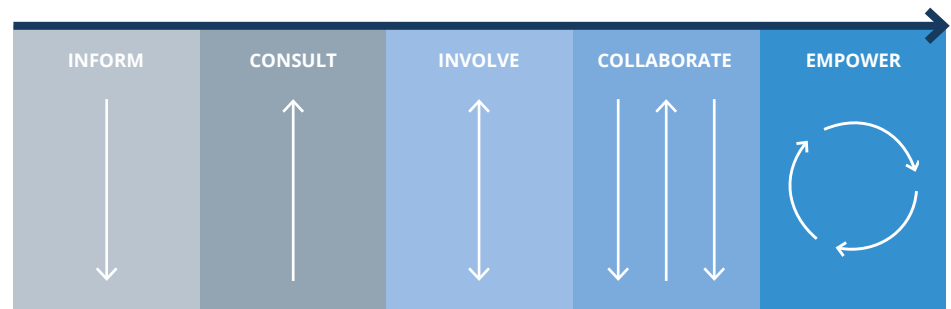
- **A clear, overarching governance framework for NHS health data use**, integrated across the siloes of existing regulation, oversight and decision-making structures. Even if governance is implemented locally, all data partnerships must adhere to the same standards of accountability.
- **Information about all NHS health data partnerships should be made available on a central register** as well as on the relevant NHS bodies' websites. These should be accompanied with short, accessible explanations that summarise the partnerships' purposes, the data involved and how decisions have been made about them.
- Co-ordination of proactive communication about the uses of health data, **with a single narrative building on existing local and regional communication and engagement activities.**



## Citizens want to be involved in decision-making

Health data policy can be technocratic, seen as an 'expert only' area requiring specialist knowledge. Asking the public for guidance on this topic may seem counterintuitive, given that many have never thought about issues concerning health data before. However, much data-driven technology in healthcare will rely on using data that originates from people's health records and their interactions with the NHS, so they naturally have a stake in how it is used. Therefore, seeking out and listening to a wide range of public views should be a fundamental condition of using NHS-held data. Improving public participation in this area will need to start with understanding the complex health system and emerging technologies. But informing people is insufficient for meaningful engagement in decision-making.

### A spectrum of public participation (see Annex 2)



At the left hand side of this spectrum people are informed about decisions, at the other, people are meaningfully engaged in the decision-making process.

The citizens' juries aimed to give people the information, time and resources to be able to engage with complex questions of health data access partnerships in a substantial way. This meant we could explore practical trade-offs, allowing for a much richer discussion than is usually possible in shorter qualitative research. Jurors were presented with information on purposes of data use, anticipated benefits and risks, tangible examples and the opportunity to question expert witnesses. Participants were eager and able to engage with the numerous technical, ethical, legal and commercial complexities involved in negotiating health data partnerships. They welcomed the opportunity to participate and

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

“This citizens’ jury is a reason for optimism. It shows that people’s voices are being heard.

| juror in London

saw the juries as a signal that commissioning bodies were willing to listen. Many also drew on their own experiences of the health system, or other examples of data use, to develop their understanding and views.

The research findings demonstrate that with the right methods, it is possible to get high quality results from using deliberative methods to explore complex arrangements for the NHS. This reflects recent work to increase citizen involvement in data and technology.<sup>36</sup> Citizen participation is not a new concept; significant progress has been made over the past decade in embedding citizen views into research design or decision-making, and there are many well-established methodologies (see Annex 2). As independent evaluations of programmes such as *Sciencewise* illustrate, public deliberation, when undertaken effectively (early on and with intent to respond from the commissioners of the process) can have a tangible impact in shaping policy outcomes so that they take greater account of public values.<sup>37</sup>

The need for some degree of public involvement in decisions was strongly backed by the survey results. However, while there was a clear desire among the juries for as much citizen involvement as possible, some also identified that proportionality mattered. Some people argued that citizen involvement should not hinder positive developments because of an overly complex or bureaucratic system.

It will not always be possible to generate consensus on health data partnerships, which presents a challenge when concrete decisions need to be made. In terms of public views and values, health data uses are likely to fall into one of three broad categories:

- Broadly acceptable use cases with clear public benefit, minimal privacy risks and low risk of controversy;
- Grey area/mid-range use cases, for which there will be a diversity of views and perspectives;
- ‘Red line’ use cases highly likely to be considered unacceptable, such as using data for insurance or marketing purposes, or clear commercial exploitation.

Taking a proportionate approach might mean focusing citizen involvement on cases in the ‘grey area’. This would allow decision-makers to hear a range of views, values and concerns, with people placing different emphasis on risks, benefits and safeguards. Where

74%

of people believe that the public should be involved in decisions about how NHS data is used

consensus is not possible, if the decision process at least recognises and takes seriously this diversity of views and values, it is likely to look and feel more trustworthy.

The next decade will involve significant change, in both the scope and complexity of health data partnerships and in public attitudes to data use. It will be critical to find the right mechanisms to create sustained engagement with citizens over time. New models such as Liverpool City Region's 'Civic Data Co-operative' are working across health and social care to "provide new tools for secure data analysis to improve services".<sup>38</sup> There are also opportunities to build on existing local infrastructure. For example, several Health and Wellbeing Boards have well-established mechanisms for public involvement in their decision-making. Public participation on decision-making bodies is one option for ensuring citizen perspectives are represented, although it has limitations and risks being tokenistic.

It will also be important not to overburden governance processes or make them too rigid. Data technologies are evolving rapidly and public views may shift over time, so one-off engagements will be insufficient. An alternative would be to take a 'learning governance' approach, allowing a feedback loop of citizen involvement to guide future decision-making. The system could build in citizen evaluation of previous decisions, as a way to ensure it is continually responsive to public views and values. For example, a series of case studies of previous decisions on data agreements could be presented to a citizen panel, with the question: 'How did we do and what can we learn for next time?'<sup>39</sup> A 'learning governance' approach would share parallels with concepts of society-in-the loop decision-making.<sup>40</sup> To our knowledge, this form of learning governance has not been tested, but health data partnerships could offer a good subject to trial this form of ongoing citizen participation.

## What next?

On contentious issues like health data policy, it will become increasingly difficult to justify excluding citizens in future.

Organisations developing proposals to use health data, whether in the NHS, academia, charities or the commercial sector, should embed citizen involvement in their planning and development pathways. They should be effectively resourced to ensure the views, values, concerns and expectations of patients and the public are recognised in the process of forming a data partnership.

Novel methods for sustainable public involvement should be explored, so that potentially controversial uses of data can be scrutinised by citizens over time. The HDR-UK Health Data Hubs provide an excellent opportunity to trial and evaluate these new approaches. Lessons learned should be disseminated to avoid different organisations making similar mistakes to one another, and to highlight best practice in citizen involvement.

## Next steps for policy

A single point of guidance and oversight is needed for health data partnerships with NHS organisations. This does not mean all decisions need to be centralised, but some cohesion is needed for the current mix of governance approaches taken by NHS bodies across the country. As we publish this report, NHSX is setting up the National Centre of Expertise to provide legal advice and guidance to NHS organisations entering into data partnerships with third parties. This Centre may operationalise the policy framework being developed by the government's Office for Life Sciences, which our mixed methods research has sought to inform. Many of our suggestions for next steps therefore focus on the valuable role this Centre could play in putting our recommendations into practice.

To maintain its relevance, it will need to continually listen to the public and respond to concerns, especially as the ability to use patient data diversifies.

# Recommendations

## The National Centre of Expertise should:

- 1. Play a central role in reviewing, auditing and evaluating NHS data partnerships**, to assess whether they are delivering the anticipated benefits back to patients and the healthcare system.
- 2. Build and maintain a central register of health data partnerships**, creating reporting requirements for NHS bodies. This should build on existing infrastructures and channels such as the Academic Health Science Network (AHSN)'s AI network survey.
- 3. Hire a team with interdisciplinary skills** and expertise including procurement, legal, AI and data analytics, public engagement, data ethics, risk management, and commercial/financial expertise. Advice should be free to NHS organisations.
- 4. Include in its advice that fairness and equity across the healthcare system are important considerations** for entering into data partnerships.
- Build **sustainable mechanisms for embedding citizen views** and values into its guidance and advice as it changes over time.
- Provide expert support, insights and resources that **enable the use and adoption of citizen involvement approaches**, including deliberation, across the health data system in the UK.

## In addition, NHSX should:

- 1. Develop a clear, unified national strategy for the governance of NHS patients' and operational data** that can be delivered and adhered to locally.
- 2. Follow the strategy with ongoing and coherent communication about data use**, that applies to all initiatives making use of NHS data, with consistent language and aims. This narrative can then be used and adapted at a local level. It should support and build on existing local engagement initiatives, creating a clear set of messages to patients, the public and health professionals.

## Conclusion

This is a pivotal time for the UK health data system. There is real opportunity to invest in emerging data-driven technologies to improve the health service and provide better care for patients. There are also challenges around: managing public expectations, creating hope rather than hype, protecting data rather than being protectionist, and building a fair, sustainable system rather than allowing disruption that's damaging in the long-term.

These are not easy balances to strike. Patients and the public have a growing interest in ensuring data is used for the public good, in a way that respects their rights. Our research has highlighted several important areas for decision-makers and data-users to consider when forming partnerships that use NHS patient data, but this is not comprehensive.

Citizen participation, particularly through deliberative methods such as citizens' juries, should form a substantial component of NHS efforts to 'get data right'. People's views and values will change over time as technology becomes more embedded in our lives – especially if it creates more problems than it solves. Building a trustworthy system responsive to these evolving views will bring the NHS into the 21<sup>st</sup> century with patients and the public as partners, not passengers.



# Annex 1

## Summary recommendations from the Citizens' juries

### The citizens' juries created recommendations to respond to 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?'

#### **1. Improving health outcomes and reducing health inequalities should be the guiding principles of health data partnerships:**

'These juries recommend that all partnerships are guided above all by the principles of improving healthcare outcomes and reducing healthcare inequalities.'

#### **2. Benefits from (locally agreed) partnerships should be distributed across the NHS in an agreed timeframe:**

'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.'

#### **3. NHS partnerships should be governed by a set of shared principles:**

'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.'

#### **4. NHS data must be streamlined to be more consistent across regions:**

'These juries recommend that NHS data be streamlined to be more consistent across different NHS organisations and regions.'

#### **5. Partnerships which are transparent and accountable:**

'These juries recommend that NHS data sharing partnerships should be transparent and accountable.'

#### **6. A governance system and governing body to oversee partnerships:**

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

#### **7. Horizon scanning for the future - data sharing policies should be continually reviewed in light of future policy imperatives:**

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

# Annex 2

## Methodology

Public deliberation, derived from the Latin *librare* meaning ‘to balance’ is one of a number of public involvement methods on the ‘spectrum of participation’<sup>41</sup> but in recent years has become more frequently deployed by public bodies facing complex policy challenges.

This study took a mixed methods approach, combining a deliberative component (citizens’ juries) with a quantitative survey. The survey questions were developed following the juries, aiming to draw out and test key themes that jurors raised. We used deliberative methods given the complexity, sensitivity and nuance of the topic area.

### The defining features of public deliberation<sup>42</sup>

#### 1. Focused on facts and with evidence

Participants are required to consider, learn about and interrogate the evidence from different perspectives before coming to a conclusion. Often a range of experts will present and then be questioned about their presentation as part of a deliberation.

#### 2. Aiming to reach common ground

Deliberation encourages people to consider the long-term consequences of an issue or decision, and the interests of those beyond themselves. This means people have to work with those who bring different perspectives. As this approach is usually used where issues are complex or controversial, a central aim of deliberation is to identify areas where common ground might emerge.

#### 3. Long-form and advisory

Many deliberations take place over a period of time, convening and reconvening over weeks or months, and involving in-depth examination of evidence and issues by participants. They will then make recommendations and provide advice on a clearly defined question or set of questions by the commissioning body.

#### 4. Random and representative participants

Participants are usually selected through stratified random sampling so that the group mirror the diversity of the UK population. However, this will depend on the nature of the issue being deliberated upon. In some cases, recruitment of participants may focus specifically on particular groups of citizens or seek to be regionally representative rather than nationally representative.

# References

- 1 Department for Business, Energy and Industrial Strategy and Office for Life Sciences (2018). *Life Sciences Sector Deal 2* [online]. Available at: <https://www.gov.uk/government/publications/code-of-conduct-for-data-driven-health-and-care-technology>
- 2 Department for Health and Social Care (2018). *Code of Conduct for Data Driven Health and Care Technology* (Guidance) [online]. Available at: <https://www.gov.uk/government/publications/code-of-conduct-for-data-driven-health-and-care-technology>
- 3 Understanding Patient Data (2020). *Foundations of fairness: views on uses of NHS patients' data and NHS operational data* [PDF]. Available at: <https://understandingpatientdata.org.uk/news/accountability-transparency-and-public-participation-must-be-established-third-party-use-nhs>
- 4 Scotland, Wales and Northern Ireland have similarly large and rich datasets, and distinct approaches to managing data. As the deliberative research focused on examples from the NHS in England we have sought not to make assumptions about public views in the devolved nations.
- 5 Reform (2018). *Making NHS data work for everyone* [online]. Available at: <https://reform.uk/research/making-nhs-data-work-everyone>
- 6 For the purposes of this report, we leave aside questions about the legality of data use under the Data Protection Act (2018) and Common Law Duty of Confidence, focusing instead on the conditions necessary for a social license to operate using health data.
- 7 Future Care Capital (2017). *Unleashing the potential of health and care data* [online]. Available at: <https://futurecarecapital.org.uk/policy/healthcare-data/>
- 8 Aldrick, P. (2020) 'NHS Patient Data has £10 billion price tag' *The Times* 20 July. Available at: <https://www.thetimes.co.uk/article/nhs-patient-data-has-10bn-price-tag-206dcfm8r>
- 9 Walker, A (2019). 'NHS gives Amazon free use of health data under Alexa advice deal' 8 December *The Guardian* [online]. Available at: <https://www.theguardian.com/society/2019/dec/08/nhs-gives-amazon-free-use-of-health-data-under-alexa-advice-deal>
- 10 BBC News (2017). 'Google DeepMind NHS app test broke UK privacy law' *BBC* [online]. Available at: <https://www.bbc.co.uk/news/technology-40483202>
- 11 Information about the National Data Opt-Out is available here: <https://digital.nhs.uk/services/national-data-opt-out>
- 12 National Data Guardian (2018). *Talking with citizens about expectations for data sharing and privacy* [online]. Available at: <https://www.gov.uk/government/speeches/talking-with-citizens-about-expectations-for-data-sharing-and-privacy>
- 13 Triggles, N. (2014). 'Care.data: How did it go so wrong?' *BBC News* 19 February [online]. Available at: <https://www.bbc.co.uk/news/health-26259101>
- 14 Information Commissioner (2017). 'Royal Free - Google DeepMind trial failed to comply with data protection law' (news story) [online]. Available at: <https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2017/07/royal-free-google-deepmind-trial-failed-to-comply-with-data-protection-law/>
- 15 Ada Lovelace Institute (2019). 'Health Data Partnerships: Amazon/Department of Health and Social Care – Ada's view' *Ada Lovelace Institute* (statement) [online]. Available at: <https://www.adalovelaceinstitute.org/health-data-partnerships-adas-view/>
- 16 Further information available at: <https://understandingpatientdata.org.uk/how-do-people-feel-about-use-data>
- 17 Department for Health and Social (2018). *Code of Conduct for Data Driven Health and Care Technology* (Guidance) [online]. Available at: <https://www.gov.uk/government/publications/code-of-conduct-for-data-driven-health-and-care-technology>
- 18 The Conservative Party (2019). *Get Brexit Done Unleash Britain's Potential* p.40 [pdf]. Available at: <https://vote.conservatives.com/our-plan>
- 19 Information Commissioner's Office (2018). *Technology Strategy 2018-2029* p.3 [pdf]. Available at: <https://ico.org.uk/media/about-the-ico/documents/2258299/ico-technology-strategy-2018-2021.pdf>
- 20 Reform (2018). *Making NHS data work for everyone* [online]. Available at: <https://reform.uk/research/making-nhs-data-work-everyone>
- 21 Bagenal, J., and Naylor, A., M. (2018). 'Harnessing the value of NHS patient data' *The Lancet* November 18 [online]. Available at: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)32942-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)32942-8/fulltext)

- 22 Ghafur, S., et. al (2020). *NHS data: Maximising its impact on the health and wealth of the United Kingdom* [online]. Available at: <https://spiral.imperial.ac.uk/handle/10044/1/76409>
- 23 National Data Guardian (2016). *Review of Data Security, Consent and Opt-outs* pp.6-7 [pdf]. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/535024/data-security-review.PDF](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF)
- 24 Further information available at: <https://www.datasaveslives.info/>
- 25 Department for Health and Social Care (2019). *Code of conduct for data driven health and care technology* [online]. Available at: <https://www.gov.uk/government/publications/code-of-conduct-for-data-driven-health-and-care-technology/initial-code-of-conduct-for-data-driven-health-and-care-technology>
- 26 NHSX (2019). *Artificial Intelligence: How to get it right* [pdf]. Available at: [https://www.nhsx.nhs.uk/assets/NHSX\\_AL\\_report.pdf](https://www.nhsx.nhs.uk/assets/NHSX_AL_report.pdf)
- 27 Hancock, M. (2020). 'Better tech not a nice to have but a vital to have for the NHS' *Department for Health and Social Care* 28 January (Keynote address to HealthTech Alliance) [online]. Available at: <https://www.gov.uk/government/speeches/better-tech-not-a-nice-to-have-but-vital-to-have-for-the-nhs>
- 28 Darzi, A., Ghafur, S., et al. (2020). 'Ensuring that the NHS realises fair financial value from its data' *The Lancet Digital Health* 20 January; Vol 1:2 [online]. Available at: [https://www.thelancet.com/journals/landig/article/PIIS2589-7500\(19\)30225-0/fulltext](https://www.thelancet.com/journals/landig/article/PIIS2589-7500(19)30225-0/fulltext)
- 29 Hughes, O. (2019). 'NHS data worth 9.6bn a year says Ernst and Young' 24 July *Digital Health* [online]. Available at: <https://www.digitalhealth.net/2019/07/nhs-data-worth-9-6bn-per-year-says-ernst-young/>
- 30 Further information available at: <https://www.england.nhs.uk/digitaltechnology/digital-primary-care/commercial-procurement-hub/>
- 31 Department of Health and Social Care (2018). *Voluntary Scheme for Branded Medicines Pricing and Access* [online]. Available at: <https://www.gov.uk/government/publications/voluntary-scheme-for-branded-medicines-pricing-and-access>
- 32 Use My Data (2019). 'Say what you do, do what you say - trust and transparency around patient data' (workshop summary) [online]. Available at: <http://www.usemydata.org/events.php?LMCL=sTaWVz>
- 33 Cacciatore, M. A., et al. (2016). 'The lure of rationality: Why does the deficit model persist in science communication?' *Public Understanding of Science* 26 April [online]. Available at: <https://journals.sagepub.com/doi/abs/10.1177/0963662516629749?journalCode=pusa>
- 34 For example see, Ainsworth, J. (2016). *Connected Health Cities* (slideshare) [online]. Available at: <https://www.slideshare.net/JISC/connected-health-cities>
- 35 NHS England (2018). *Local Health and Care Record Exemplars* (Guidance) [online]. Available at: <https://www.england.nhs.uk/publication/local-health-and-care-record-exemplars/>
- 36 For example see, The Department for Digital, Culture, Media and Sport (2019). *UK National Action Plan for Open Government* [online]. Available at: <https://www.gov.uk/government/publications/uk-national-action-plan-for-open-government-2019-2021/uk-national-action-plan-for-open-government-2019-2021#com2>
- 37 RPA (2015). *Evaluation of the Sciencewise Programme 2012-2015, report for Sciencewise/Ricardo-AEA* [pdf]. Available at: <http://sciencewise.org.uk/wp-content/uploads/2018/11/SW-Evaluation-FR-230315.pdf>
- 38 Further information available here: <https://www.liverpoolcityregion-ca.gov.uk/liverpool-city-region-combined-authority-announces-proposals-for-5-3m-funding-for-data-driven-health-improvements/>
- 39 We are grateful to Simon Burrall for this suggestion of creating 'accountability loops' in decision-making.
- 40 Rahwan, I. (2018). 'Society-in-the-loop: programming the algorithmic social contract' *Ethics and Information Technology* 20; 5-14 [online]. Available at: <https://rd.springer.com/article/10.1007%2Fs10676-017-9430-8>
- 41 Arnstein, S., (1969). Ladder of participation cited in Patel, R. (2018) 'Why decisions about the economy need you' *The RSA 20 April* (blog) [online]. Available at: <https://www.thersa.org/discover/publications-and-articles/rsa-blogs/2017/04/Why-decisions-about-the-economy-need-you>
- 42 Cited in Annex in Nuffield Foundation (2020). *Building the case for public deliberation* [pdf]. Available at: [https://www.nuffieldfoundation.org/wp-content/uploads/2020/01/NuffieldFoundationPublicdeliberationcall\\_Jan20.pdf](https://www.nuffieldfoundation.org/wp-content/uploads/2020/01/NuffieldFoundationPublicdeliberationcall_Jan20.pdf)

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