*Original Research Article*

# The power and promise of transparency: Perspectives from citizens' juries of pandemic health data sharing

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## Abstract

The COVID-19 pandemic response in the UK, as in other countries, drew heavily on health and social care data, making its utility extremely visible as necessary for timely government decision-making and planning. The urgency created by the crisis, however, meant that additional data collection and sharing under emergency legislation was implemented with minimal public consultation. To understand the public perception of these new data measures and initiatives, three citizens' juries took place in the spring of 2021. This article reports on qualitative observations of the small group deliberations from these juries. The analysis shows that jurors frequently drew on normative discourses of transparency and trust in discussions, and the different roles they were assumed to fulfil. Transparency was expected to offer greater visibility into the organisations involved in health and social care data sharing, but this was made difficult by the increased complexity of the health data economy. Transparency into the political justifications for additional health data collection was important for jurors. The utilitarian narratives used by the government were considered problematic, restricting opportunities for individuals to express concerns and leading to cynicism. The findings will be situated with the critical literature on visibility practices to highlight the need to unpick what the promise of transparency and trust offers to the public and how it links to power and control. Lastly, it will examine what the deliberations around transparency mean for wider policy on health and social care data-sharing.

## Keywords

Citizens' juries, transparency, health data, data sharing, pandemic, public engagement

## Introduction

There has been widespread interest in harnessing health and social care data to help services become more efficient, save money, and facilitate personalised care. Alongside benefits for the public, patients and health care services, the UK government has repeatedly expressed a desire to 'unlock the value of patient data', estimating that they could bring in billions of pounds to the economy (Vezyridis and Timmons, 2021). Initiatives to improve data sharing and data linkage, however, have been hampered by a lack of infrastructure and poor public communication leading to disapproval and distrust (Taylor, 2016; Vezyridis and Timmons, 2021). Over the past decade, there has been a proliferation of research exploring what the public perceives to be the benefits and risks of increased health and social care data sharing in various groups, settings and countries. Reviews of this literature have highlighted remarkable consistency in the concerns expressed by the public on the importance of transparency, consent and

security of data sharing (see Aitken et al., 2016; Kalkman et al., 2022; Lounsbury et al., 2021). This suggests that there are stable and cross-cultural beliefs about how patient health and social care data should be treated. This is particularly interesting given that many of the studies

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report that participants often struggle to make sense of this complex and often abstract topic.

The COVID-19 pandemic has made visible the utility of health data sharing for government decision-making and shaping public communication worldwide (Anderson, 2021). Countries used health data to predict and monitor the spread of infections and to inform appropriate responses, such as shielding and vaccinations. Epidemiology and mathematical modelling used by governments meant that the pandemic was visual, with the shape, waves and real-time COVID-19 data becoming part of everyday life (Anderson, 2021; Evans, 2021; Roitman, 2021). Some of the data came from the rapid introduction of new and pre-existing digital technologies, such as contact tracing apps (Newlands et al., 2020). In England and Wales, the government utilised a clause known as the Control of Patient Information (COPI) notice, to allow the extended collection and use of health and social data for the COVID-19 response. The notice, which ran from March 2020 to June 2022, set aside the common law duty of confidentiality for data sharing for public health, planning and research purposes where they supported the response to COVID-19. It applied to confidential patient information encompassing health records (Mitchell and Hall, 2023). The COPI notice enabled collaboration between government health organisations, Big Tech, and commercial data analytic companies (Graham, 2023; Lyon, 2021; Whitehead and Collier, 2023), with little explanation of the implications of these partnerships on the use, storage, and security of health data. Decision-makers justified this by suggesting it was clearly in the public interest and emphasised the state of emergency – time mattered (Newlands et al., 2020). However, there was little public consultation on the changes to data sharing under the COPI notice before it was introduced.

The COPI notice meant that several data initiatives were developed and introduced to support the COVID-19 pandemic response. One year after the start of the pandemic, three Citizens' Juries were formed to get informed public opinion on this extended data sharing by examining three data initiatives. The current article draws on qualitative research that ran alongside the juries, conducting non-participant observations of the extensive small-group discussions, to understand how jurors made sense of the justifications for extended health and social care data sharing during the pandemic. The focus of the article, therefore, is not the data initiatives themselves or COVID-19. Instead, the pandemic offered a unique opportunity for the public to understand the role and importance of health and social care data sharing in a real, rather than abstract, setting. This enables exploring whether the concerns raised in previous studies on health data sharing were still relevant to members of the public or if there was a shift that reflected the utilitarian discourse of policymakers that emergency measures were needed for the greater public good. To do this, the following section will review the pertinent themes in the current literature on public perceptions of health and social care data pre-pandemic and consider how these may intersect with relevant interdisciplinary research.

## Background

### Public perceptions of health and social care data sharing

The capacity and scale of the collection and sharing of health and social care data have greatly expanded over the past few decades, particularly with technical advances and the introduction of electronic health records (Herschel and Miori, 2017). Health-related data are highly sensitive and governed by strict laws such as the European Union's General Data Protection Regulation (GDPR). The GDPR principles outline the responsibility of organisations to protect individual privacy by ensuring that any data collection is lawful and appropriate (NHS England, 2024). In the UK, under the National Health Service (NHS), health data sharing is permissible for direct clinical care, and anonymised data may be used for secondary use. However, as the NHS increasingly works with external stakeholders around health data, there are new concerns about how data is collected, used and shared (Graham, 2023). Research exploring public, professional and researcher perspectives on health data sharing has found common concerns, namely, the intention to use health data for the common good, the legitimate uses of health data, and the role of organisations involved in collecting and storing health data.

Health and social data sharing is often positioned in utilitarian terms as an altruistic act for the common good by policymakers, which is reflected in research with the public. There are high levels of support for data sharing when it is to be used for the benefit of many, such as direct care or other legitimate research purposes that could enhance clinical decision-making, advance future treatments, or improve services (Kalkman et al., 2022; Lounsbury et al., 2021; Sterckx et al., 2016; Vezyridis and Timmons, 2021). Data for the common good assumes a reciprocal relationship between the producers and users of data. Ideally, individuals share data to access services with trustworthy organisations that are obliged to protect individuals' data rights. Public support for utilitarian justifications, however, is often conditional on assurances of transparency (Aitken et al., 2016). Transparency is seen as necessary for managing the uncertainty about future secondary uses of data, sometimes called surveillance or function creep (Aitken et al., 2016; Ellerbrok, 2010). Concerns about the future uses of data have become amplified through digital tools and increasingly complex data and regulatory infrastructures, often involving multiple stakeholders from the

public and private sectors (Lounsbury et al., 2021). Previous work shows that private commercial organisations are the main source of suspicion, with for-profit purposes perceived as sitting at odds with the idea of the common good (Aitken et al., 2016; Street et al., 2021). A review of perceptions of health data sharing by Kalkman and colleagues (2022) shows that the public consistently regards private companies as not transparent and therefore a risk to privacy, and detrimental to trust (Kalkman et al., 2022)

In the UK, one of the biggest public debates around health and social care data sharing came in 2014 in response to a government initiative called care.data. The initiative was abandoned after backlash from health professionals and the public. Research exploring the negative response to care.data propose that it was key concerns about transparency on how data may be used (now and in the future) that led to the collapse in trust (Aitken et al., 2016; Carter et al., 2015; Sterckx et al., 2016; Vezyridis and Timmons, 2019). Care.data is seen as an example of failure in gaining the trust of the public and stakeholders, who were unhappy with the levels of communication and governance infrastructures in place, creating distrust. Some similarities can be drawn between care.data and the COPI notices in that both allowed for the extended collection of health and social care data without the usual process of gaining patient consent to process confidential patient information. The COPI notices, however, were introduced more rapidly, with less public consultation, and justified as necessary for a timely response to the pandemic.

### Critical studies of visibility practices

The studies outlined above focus on several related concerns from the public about health data sharing: transparency, trust, visibility, and trustworthiness. These are often used interchangeably and usually lack definition in the health data-sharing literature. Some are taken for granted as positive, with increased transparency and trust frequently recommended to improve public perceptions of health data sharing, whilst others, such as opacity, are assumed to operate negatively. More critical studies of these concepts, however, challenge these assumptions. Hansen and Flyverbom (2015; 2016) have suggested that it is more helpful to consider these concepts as part of a family of visibility practices. This growing body of work regards visibility practices as social processes that do things in culture and society – they are productive. Therefore, to situate the orientation of the current article, there is a need to examine these studies that have emerged from a range of disciplines (such as law, ethics, philosophy, and organisational studies).

The extensive critical studies of transparency, one of the family of surveillance practices, will be the starting point here. This is particularly relevant given that it is a recurring

recommendation in the health data-sharing literature. Transparency can be defined simply as the 'absence of concealment' (Birchall, 2011: 8) or as 'unmediated access to reality' (Hansen, 2015: 883). A more comprehensive summary is a commitment to operating openly, under the scrutiny of stakeholders, through the publication of relevant records (Birchall, 2014). These definitions, however, can be misinterpreted. The assumption from these definitions often draws on moral values that associate transparency with 'truth' and 'honesty' (Viola and Laidler, 2022). As such, those resisting calls for transparency are seen as suspicious or as guilty of withholding information (Birchall, 2011). Critical scholars of transparency warn that transparency has become reified in public life (Pozen, 2020) and recommend it should be treated as a social process that is neither inherently positive nor negative (Albu and Flyverbom, 2019; Pozen, 2020; Viola and Laidler, 2022). Transparency then, as a social process, involves something being made visible through a range of socio-technical tools that are used to achieve a variety of goals (Albu and Flyverbom, 2019; Hansen and Flyverbom, 2015).

Transparency is an increasingly important and visible part of contemporary societies (Ananny and Crawford, 2018; Birchall, 2016; Phillips, 2011). It is utilised across the political spectrum as a strategy for depoliticising political decisions through promising objective truth (Birchall, 2011), and re-politicising issues through making injustices visible (Hansen, 2015). Samuel Weber, in a discussion with Phillips (2011), suggests that the desire for transparency reflects the need for certainty and security in increasingly uncertain times. Transparency promises a simple solution to complex problems of governance (Birchall, 2014). By offering a way of seeing the truth of systems, transparency is assumed to provide control and certainty (Ananny and Crawford, 2018). The promise of control is part of what Albu and Flyverbom (2019) have termed verifiability projects. Verifiability projects involve making objects, behaviours and practices visible and usually focus on the transmission of information that is expected to lead to understanding and action. For individuals, however, this can create a burden and responsibility to both find and interpret vast amounts of complex information without the power to act in a meaningful way on what might be found (Ananny and Crawford, 2018; Hansen and Flyverbom, 2015). For organisations, verifiability projects are expected to act as both a deterrent to poor behaviour and practice and provide punitive action through accountability consequences (Hansen et al., 2015; Viola and Laidler, 2022). Hansen and Flyverbom (2015), however, caution that full transparency is rarely possible given that the objects of transparency can change over time. Furthermore, institutions choose what to disclose and what not to disclose, which may result in concealment (intentional or not). Transparency, then is always partial and subjective.

Another aspect considered in the literature is how transparency can work as a form of performativity (Albu and Flyverbom, 2019). This research often focuses on the social process of transparency and the tensions and power dynamics that emerge. Felzmann and colleagues (2019) give an example of organisations claiming to have provided sufficient information to the public or relevant organisations that allow them to proceed. Viola (2021) breaks this down into three effects on power. The first is that transparency projects can act to condone and legitimise the behaviour made visible. The second is a ratcheting effect in which it incentivises more of the same behaviour. The third is described as 'circling the wagons' where the anticipation of exposure leads to further concealment. This literature, thus, illustrates the unanticipated effect of transparency. Some organisations may claim to have fulfilled their responsibility by making records available without taking any meaningful action to improve practices. Rather than leading to greater certainty and security, transparency projects can produce new forms of obscurity and distortion in the way that selected information is presented. This is termed the transparency paradox (Flyverbom et al., 2016). When this occurs, it can lead to mistrust and suspicion about organisations and others (Hansen et al., 2015).

Trust is an assumed consequence of transparency projects and themes of trust recur in all studies around public perceptions of health data sharing (Aitken et al., 2016). Viola and Laidler (2021) note that trust is often assumed to be the outcome of rational decision-making and analysis. For example, trust is expected to result from information from transparency projects being made knowable (Hall, 2021). The evidence from critical studies of visibility challenges this direct relationship suggesting a more complex social process. Trust is about having the belief that others will behave appropriately, and in doing so involves putting the self at risk of exploitation (Felzmann et al., 2019). Trust as a concept often overlaps with confidence and trustworthiness (Khodyakov, 2007). Tonkiss (2009) differentiates between confidence that results from objective forms of information (such as laws and contracts) that provide the basis for the relationship and trust as subjective perceptions of a relationship. Therefore, when there is an absence of confidence in relationships, individuals must depend on trust. Trust, according to O'Neill (2018), is only valuable when focused on those that are trustworthy. Trustworthiness becomes attached to individuals and institutions based on reputation, past behaviour, reliability, and the ability to act competently (Hardin, 2002; Khodyakov, 2007). This links closely to Hardin's (2002) claim that establishing and proving trustworthiness is the most effective way to develop trust. There is a need, therefore, to more critically examine what is meant when trust is used within the health data-sharing literature, paying attention to the social relations and power involved. Although trust and trustworthiness attempt to foster cooperation, too much trust may make individuals vulnerable to deception (Hardin, 2002). Over-trust can lead to delays in preventive action, feelings of betrayal, and increased cynicism and suspicion (Goel et al., 2005).

Power is at the heart of visibility practices. The act of making something visible reflects asymmetries of power – who has the power to request information, who contributes to the information, who decides what information to share, and who acts on what is visible (Brighenti, 2007). Private information becoming visible is an important concern for members of the public in the health data-sharing literature. Data practices, such as health data sharing, can blur the line between private and public, with uncertainty increasing as data become increasingly digitised and diverse (Douglas-Jones et al., 2021). Individuals may be encouraged, or feel obliged, to share private data to access services (Lupton, 2012). When this occurs, individuals may choose to act in contrary ways. For example, the privacy paradox is said to occur when individuals are concerned about their privacy and what information may be visible to others but continue to share (Norberg et al., 2007). Some have explained this paradox as the result of feelings of obligation, inevitability, or powerlessness (Bagger et al., 2023; Draper and Turow, 2019; Lutz et al., 2020).

This summary demonstrates how bringing together concepts such as transparency, visibility, and trust can help highlight these practices' social and related nature whilst challenging their taken-for-granted assumptions. Privacy concerns may not lead to withdrawal, transparency may not offer the insight promised, and trust may not be forthcoming. This article examines what members of the public taking part in three citizens' juries discussed as they debated health and social care data sharing during the pandemic throughout the jury process. The research questions were as follows:

1. What are the narratives drawn upon by participants during discussions?
2. How did these discussions inform the recommendations of the jury?

The subsequent findings draw on the critical literature of visibility practices to try and understand how the public engaged with or challenged the key assumptions around health data sharing. In doing so, it brings together two strands of research that, to date, have rarely engaged with each other. Firstly, research with the public on perceptions of health data-sharing practices rarely critically examines assumptions around transparency and trust. Secondly, critical studies of visibility practices are often theoretical or attend to the role of organisations and government. As such, it rarely engages with public perceptions and attitudes towards these concepts and practices. Given that transparency, trust, and privacy are widely discussed in health data sharing, there is a need to understand

how the public is adopting or rejecting these discourses. The pandemic made the role and power of health data sharing visible to the public in a way that it had not been previously. As such, the pandemic is a useful backdrop to understand public perceptions rather than being the focus itself.

## Methods

### Non-participant observations

This article focuses on non-participant observations of small group discussions between members of the public taking part in three online citizens' juries (described below). Permission was granted by the organisation running the citizens' juries and informed consent was obtained from all participating jurors. The study received a favourable proportionate review from the University of Manchester Proportional Ethics Committee. There were two academic observers at each jury session (three observers in rotation (LL, EJ, SvdV) who took anonymous detailed fieldnotes during the small group sessions using an observation proforma. The observers joined the small deliberation groups that varied each day, taking field notes alongside analytic notes and memos that reflected their own perceptions of the interactions as they progressed and making connections to existing literature (Emerson et al., 2011). As the juries were conducted online, the observers could take notes unobtrusively whilst observing the groups. In total, the observations covered resulted in around 288 sets of field notes (i.e., two groups observed on the 144 occasions where jurors split into small groups). The academic observers introduced themselves at the beginning of each jury day and reminded jurors of their non-participant roles. The academic observers had their cameras on for the duration of the juries but would mute during the small group sessions. The jurors reported in their evaluation that the observers did not interfere with their ability to participate.

Discussions were recorded verbatim, where possible, alongside descriptions of non-verbal cues or notes of interest. Observers' field and analytic notes were collated at the end of fieldwork as the researchers began to analyse the data more systematically. The approach to analysis was predominantly inductive to ensure that themes were derived from the data and involved a constant comparison approach to coding that was refined to interrogate the similarities and differences within the data (Braun and Clarke, 2021; Pope, 2005). Attention was also paid to how discussion changed throughout the juries as participants became more informed during the presentations and more comfortable with each other. Data was stored and managed in NVivo (QSR v12) software. As the analysis progressed, the research team developed and adjusted the coding framework to create themes that represented the pertinent topics discussed amongst the jurors.

### Research context – citizens' juries

Citizens' juries are a public deliberation and engagement approach that presents citizens with detailed information and evidence on a policy topic and asks them to deliberate and come to conclusions on behalf of their community (Burchardt, 2013; Street et al., 2021). The stated advantage of citizens' juries over other public engagement activities or public opinion research (such as focus groups) is that they aim to give participants a deeper, more nuanced understanding of the topic, allow them time to reflect on the issues, ask clarifying questions from expert witnesses, and to deliberate with peers. This approach has been used with various groups in a range of contexts to make responsive recommendations to policymakers (c.f. Smith et al., 2021; Street et al., 2021).

Three citizens' juries were convened remotely in March–May 2021, and 54 jurors were recruited that were broadly representative of the population in England in terms of age, gender, ethnicity, educational attainment and pre-existing views of data sharing. The first jury had members of the public from across England, the second jury from Greater Manchester, where there had been relatively high levels of restrictions during the pandemic, and the third jury from Sussex, which had had relatively low levels of restrictions. Each jury ran for four and a half hours a day for 8 days, resulting in a total of 36 hours, and jurors were all reimbursed £480 for their time. The juries were organised by Citizens' Juries c.i.c., who recruited and selected jurors; the juries were designed and facilitated by the Center for New Democratic Processes. Two juries were funded from the National Institute for Health Research Applied Research Collaboration Greater Manchester (NIHR ARC-GM). The third jury was funded by NHS X (the NHS Department of Data, Digital and Technology) and the National Data Guardian Office for Health and Social Care. The same process was followed for all three juries.

A commissioning committee decided on the jury questions, and an oversight panel inspected presentations for potential bias before the juries. Information on three data initiatives introduced in England and Wales during the pandemic that utilised the COPI notices was presented to the jurors and is summarised in Table 1. During the jury, facilitators first took participants through the process and task of deliberation. Following this, a series of presentations by expert witnesses (neutral and persuasive) were given remotely during the first session and then replayed at subsequent juries to ensure all jurors received the same information. Following each presentation, the jurors were split into small groups to discuss the presentation and prepare a question for the speaker. After each question-and-answer session, groups were reconvened to deliberate on their learning. This continued until the last two days, which were dedicated to deliberation, voting, and preparing their

**Table 1.** Summary of the data initiatives included in the citizens' juries.

| | Data Initiatives |
|---|---|
| 1 | *The Summary Care Record (SCR) Additional Information*<br>This was extended to include additional information for over 50 million people in England without explicit patient consent (which had been the basis for uploading additional information from GP patient records to the Summary Care Record before the pandemic). |
| 2 | *NHS COVID-19 Data Store and Platform*<br>NHS England created a new central store of patient-related data in response to the pandemic, using a wide range of software tools through the Data Platform. |
| 3 | *OpenSAFELY*<br>A tool created at the start of the pandemic by a consortium including the University of Oxford and with the backing of NHS England for pandemic-related research using patient data accessed from GP patient records. |

report. Professional facilitators moderated the deliberations to ensure all jurors had the opportunity to participate.

The jurors reported high levels of support for the data initiatives used to support the COVID-19 response, recognising the benefit to society. However, this support was not unconditional. The jurors expressed a need for greater transparency and more clarity about the future governance of the initiatives (Oswald and Laverty, 2021).

## Analysis

### The opaque assemblage of the COVID-19 health data economy

*The complexity of the health data economy.* Over the first few days of the juries, participants were informed of the many organisations involved in the data initiatives for the COVID-19 pandemic. These included internal partners across primary (general practice) and secondary care (hospital trusts), other care settings (social care, mental health trusts) and governmental departments (such as NHS X and NHS Digital). External partners included the University of Oxford (the OpenSafely data initiative) and known commercial Big Tech organisations such as Microsoft, Google, and Amazon. Unfamiliar commercial partners, such as Palantir (the COVID-19 data store initiative), were also discussed. In response, overwhelmingly, the participants asked for transparency into and about the relationships between these various organisations and the government. Participants were concerned that such a complicated and opaque assemblage of organisations meant that it may be impossible to know who was involved and why:

> J: When you look at the NHS now, it's not the NHS we knew, NHS X and NHS Digital. How many NHSs are there? Group practices, GPs are self-employed! I just thought it was all NHS.

*Jury 2 (Greater Manchester), Day 5, Observation 5-6*

> J: A bit of a lesson and naivety with the NHS and how many external partners and fingers in pies there are, look at the wider picture at how many people could [access data] then I start to question it

*Jury 3 (Sussex), Day 7, Observation 4*

Participants wanted to know who was involved, their roles, how they processed and stored data, and how they would manage data in the future. They discussed the need for transparency tools, such as 'clear transparent audit paths' (Jury 1, all of England), to ensure the organisations acted appropriately. The opaque assemblage of partners also reflects how health data has changed from physical and local to virtual and global. Whilst participants recognised the flaws in old paper health records, there was also security in knowing where those records were and who might have access to them. As one of the participants in Jury 2 (Greater Manchester) said, '*When I was younger, it would be the GP making a paper note, and it would be on a shelf. Now it is open to the world*'. The use of cloud servers was common knowledge, but there was uncertainty about ownership, access and security because of the spatial remoteness:

> J1: The platform is Palantir. Amazon and Azure – both data store and data platform – used widely in the UK anyway. We need to be sure of ownership of the data.
>
> J2: Must be in a physical location.
>
> J3: Where is the cloud? Good question. Didn't ask that did we? Azure and Amazon are both software. Where are the servers? Where is this saved?

*Jury 1 (All of England), Day 8, Observation 2*

During the jury presentations, expert speakers raised the tension about the analytic capabilities within the NHS as justification for collaborating with external firms. A clear example was the development of an in-house COVID-19 Track and Tracing app that was abandoned in favour of external providers due to security and data protection concerns during piloting. However, it remained that data held remotely and spatially distant from the data source (i.e., the public) was seen as uncontained and not secure. Participants frequently discussed wanting to bring the data and processes back 'in-house' and under the control of the NHS. The NHS had a reputation as a trustworthy organisation for participants; as a member of Jury 3 stated, '*I don't know these companies, so I just have to trust the NHS*'. The desire to bring data back to the NHS can also be interpreted as participants wanting to simplify

the complexity of the assemblage. It is easier to get transparency and demand accountability from a single organisational body than multiple, unknown organisations. This also shows an understanding that health data spread across such an assemblage is never under the strict control of any single organisation (Isin and Ruppert, 2020). The NHS is subject to laws and strict governance in dealing with health data that can provide confidence to the public. There is no clear oversight or path to accountability with commercial organisations delivering data services to the NHS, and this was a particular concern with international companies:

J1: It should be brought back into the UK. They don't have to act within UK law,

J2: Don't pay taxes

J1: In-house and have legal control over them.

*Jury 2 (Greater Manchester), Day 8, Observation 1*

J: I think they are considered dodgy because they are big companies that are beyond regulation.

*Jury 3 (Sussex), Day 4, Observation 5-6*

*Secrecy amongst the political shadows.* For the participants, the lack of visibility of the assemblage of organisations involved in health and social care data sharing during COVID-19 raised concerns about what was being kept from view. Participants used these terms explicitly, often linking opacity with deceit. For example, in Jury 1 (All of England), one juror stated: '*I'm upset by the invisibility – we are 'living in the shadows'. It is difficult to trust'*. In Jury 3 (Sussex), another juror explained: '*It's just not transparent. The only reason for not publishing is that they are hiding something. If you have nothing to hide, why not just put it out there'*. The concern for transparency often involves understanding the motives of different organisations. Much has been written about the public's concern about commercial organisations like pharmaceutical companies accessing health and social care data (Vezyridis and Timmons, 2021). However, the COVID-19 pandemic made visible to the public how much value and power health data has to politicians, whilst also demonstrating the opacity of political decision-making. The pandemic was as much a political crisis as a health crisis for participants. They did not trust politicians to follow scientific advice and make the correct choices, as evidenced by the UK pandemic response. The government were frequently described as incompetent and unreliable and, as such, not trustworthy. The use of data during daily televised briefings was a means to justify the decisions that affected people's lives and freedoms. However, participants questioned

why these daily briefings were not used to inform the public about data-sharing changes. The selective use of data meant it was unclear to participants whether the motives were entirely honourable. Political uses of data were not seen as objective and neutral, but subjective and open to manipulation by politicians. As such, data could be questioned and rejected:

J: Well, with a pandemic and such a crisis – they are going to do everything they can to keep the numbers down. We are only getting what they are telling us, who knows what the actual numbers are?

*Jury 2 (Greater Manchester), Day 6, Observation 2*

The participants recognised that the health and social care data collected under the COPI notice was in response to a crisis but questioned who had the right to claim that it was an emergency. This called into question what actions were taken under the narrative of an emergency, such as who stood to benefit, and who would then determine that it had ended. Supporting Roitman's (2021) work on crises; participants recognised the persuasive power declaring an emergency had:

J1: Are we considering if a pandemic is an emergency and the bending of the rules?

J2: What is an emergency or not?

J3: Important - what is an emergency?

J1: Is that to make a decision or change things? Subjective? Who makes that decision?

J3: Too subjective, isn't it?

*Jury 2 (Greater Manchester), Day 2, Observation 2*

Participants expressed concerns that the government could misuse emergency powers to bypass rights and accelerate existing plans around data sharing without drawing attention to it. For example, the summary care record of patients visible to health professionals was extended to include details of medical history, such as long-term conditions. These existing plans had been challenging to implement before the pandemic, and some participants were concerned that politicians had used the notion of a crisis to hide and avoid due process:

J: I just don't trust the government. They've not done a good job. They say 'it is an emergency', and they can just do whatever they want. I think it should be for as short a time as possible. It needs to be debated and properly considered. I don't want these emergency powers to be in

place forever. Everyone is getting vaccinated and still, they are in place. I can see the benefits. I'm broadly supportive, but in the back of my mind, I don't like the emergency powers; there is less scrutiny because of them.

*Jury 3 (Sussex), Day 8, Observation 2*

Underlying these discussions was uncertainty about what would happen to the data after the pandemic was declared 'over'. Participants recognised the value of health data sharing in principle and that it was useful for appropriate health professionals to have access to essential medical information without delay. They could also see the potential benefits of integrated records for other health records beyond the pandemic. Some jurors, however, worried that the data collected during the pandemic would not be reversible; that once the door was open, it would be impossible to shut.

> J1: They can decide the pandemic is never over so that they have always access to all this information.
>
> J2: We can see in front of us that our data is now being shared. And if they say that the pandemic will always be with us, our data will be shared forever.

*Jury 3 (Sussex), Day 5, Observation 4*

The jury members were tasked with answering questions about how long the data initiatives should continue and formed a large part of the deliberations over the last few days of the juries. None of the jurors thought the COPI notice and data initiatives should continue indefinitely without being scrutinised and retrospective rigour checked by an independent group. The calls for transparency, here, then relate to a need to make visible what they felt had been obscured through the pandemic. The lack of visibility led to suspicion that politicians and others could manipulate data sharing. There was a lack of confidence in politicians to do the right thing, and jurors worried that changes to data sharing were pushed through under the cover of the pandemic and justified as necessary during an emergency. Although jurors remained largely supportive of the purpose and benefits of the data initiatives in the voting, they were unhappy about the process by which they had come about.

## The contested moral grounds of data sharing

### Data sharing as a moral obligation.
The participants also considered the moral and ethical assumptions of transparency during the jury discussions when thinking about their own data sharing. Namely, that a) the underlying ethical discourses for data sharing created a moral obligation for the public to be 'transparent' with their data whilst b)

understanding transparency only as a positive could obscure the opportunity to express concerns. The participants perceived that the justification for collecting and sharing additional health and social care data through the COPI notice relied on altruism for the greater good, an ethical framework often described as utilitarianism. The government justified the restrictions imposed in the UK during the pandemic as altruistic and necessary to protect the wider public and vulnerable groups, and this justification extended to health and social care data sharing through the COPI notice. Some participants referred to their own acceptance of health data sharing and expressed a utilitarian view that they were happy to share information if it helped others. For example, a participant in Jury 1 (All of England) stated, '*I'm edging towards very much in support. If one person is helped or saved by the information, then it is worth it*'. A utilitarian perspective, however, was not seen as straightforward as encouraging individuals to share data could also mean sacrificing some privacy rights. There was a recognition that this was a trade-off between societal benefit and individual privacy and that what they might be comfortable with personally might not be for everyone: '*There might be a 1% with people not happy about what's gone on*' (Jury 2, Greater Manchester).

The participants also spent a great deal of time considering deontic perspectives on data rights – that there is a duty for organisations involved in health and social care data to protect individual rights to privacy and violating these rights would be unethical even in the case of a pandemic. The debates amongst jurors revealed moral tensions between 'altruistic' utilitarian perspectives and 'individualistic' deontic frameworks. This was a particular topic of concern amongst the participants in the third jury (Sussex). Some believed that the moral implications of utilitarian discourses during the pandemic made it difficult to challenge without positioning themselves as self-interested, which did not sit well with jurors:

> J: I'm largely supportive. But I don't like the fact that they rushed into it. Also, if you've got nothing to hide, then show it…It is a bit of a moral dilemma though. The government involved rushed through with no due political, public process, but then if you say that, you feel like a dick, because people are dying and it is like you don't care. I still think there should be checks and balances, even when there is a pandemic. There should be a process; the public should be informed, not hidden.

*Jury 3 (Sussex), Day 8, Observation 2*

Participants across all three juries noted that the moral framing of data sharing as 'for the greater good' was problematic. Firstly, despite the utilitarian discourses, senior politicians in the UK were repeatedly reported in the press for breaking lockdown rules and acting for individual

gain (politically and financially) during the commissioning of providers during the pandemic. The public was asked to observe rules that some leaders were not always willing to follow, and this was unfolding in the press during the juries. Secondly, the moral discourse during the pandemic meant little opportunity for the public to challenge or resist. There was a recognition amongst a few participants that raising concerns about data sharing was likely to be dismissed as unnecessary scepticism. Some jurors in Jury 3 (Sussex) were concerned about being labelled a conspiracy theorist by others for expressing potentially contrarian views: '*I'm not a conspiracy theorist, but there is something very dark about it*', and '*if you don't agree, you are a right-wing conspiracy theorist*'. The conspiracy theorist is someone untrustworthy, ill-informed, and relies on theories rather than evidence (Birchall, 2014). Jury 2 (Greater Manchester) similarly referred to the need for healthy scepticism, claiming that: '*it'll be George Orwell's 1984 before you know it*'. These references to conspiracy theories and George Orwell can be interpreted as examples of a public with limited control, rights, and power compared to the government. To call someone a conspiracy theorist, then, is to discredit them. This meant jurors felt uncomfortable challenging utilitarian justifications of the common good for data sharing.

*Legitimate opportunities for resistance.* According to Isin and Ruppert (2020), one way to resist the demand for transparency is through opacity. In the UK, the public has a right to opt-out of (some) health and social care data sharing. This was covered in the first few days of the juries. While some jurors were aware of this and recalled receiving letters from their GPs about it, most were unaware of the right and the process. They approved of the option to opt-out but were disgruntled that the process was not made particularly visible and had to be sought out by those in the know:

> J1: All seems very wishy-washy. They should make it more obvious. You have to really look for it. They don't want it to be too obvious. Are they unsure whether people would cooperate?
>
> J2: Would be good to know the benefits of opting out
>
> J3: They don't make it clear
>
> J2: Maybe it is in small print somewhere
>
> *Jury 1 (All of England), Day 2, Observation 2*

The jurors felt that this was a form of defensive transparency. There was the opportunity to resist through opting out but the process had been made opaque. As a participant in Jury 3 (Sussex) noted, '*they may find it easier to ask for*

*forgiveness than to ask for permission*' (Day 4, Observation 3). The participants felt there were multiple ways the public could have been informed about health and social care data sharing during the pandemic, especially in the digital age. Many gave examples of other government campaigns, such as the extensive advertising for the national census or organ donor opt-outs, as examples of how information could have been communicated appropriately to the public. As such, they were cynical as to why the government had failed to do so:

> J1: They haven't really communicated it.
>
> J2: Lack of awareness
>
> J3: No transparency. Not aware.
>
> *Jury 1 (All of England), Day 3, Observation 4*
>
> J1: Problem they had, maybe they don't want to send letters, they have all of our emails, could send an email, so why not
>
> J2: Or a text message, always getting a message
>
> J3: Important information for you to know, follow the link at least they can say we told you because they didn't tell anyone
>
> J2: On BBC news, biased or whatever but could let us know on the news or newspaper
>
> J1: A Boris [Johnson, Prime Minister at the time] announcement next time he's on TV.
>
> *Jury 3 (Sussex), Day 3, Observation 4*

In summary, there are two aspects of transparency on display here. The first is that utilitarian perspectives on data sharing persuade individuals to be compliant about contributing data for the benefit of society. In using morally loaded utilitarian discourses, resistance through legitimate scepticism is limited through concerns that any questioning could be dismissed as conspiracy theorising. Secondly, the lack of knowledge amongst the public about their right to opt-out of data sharing means that legitimate opportunities for opacity are limited. Utilitarian discourses, then, were perceived as a use of power.

## Unanticipated effect of citizens' juries as transparency project

Taking part in the jury meant that participants were given detailed information about health data-sharing, the pandemic,

and the data initiatives from experts (such as academics, NHS representatives, and a third-party organisation campaigning for better data protection) and allowed to question these experts. As such, the jury could be seen as a transparency project. The participants recognised they would not have been privy to or known to look for this information before joining the jury. Information about health data sharing during the pandemic had become visible to them. The discussion from the jurors around this reflected their growing awareness of the importance of the topic and the contrast to their own past experiences of relative apathy around data sharing:

> J: Yeah, this has opened my eyes to what is going on. I don't think I would have bothered otherwise
>
> *Jury 2 (Greater Manchester), Day 6, Observation 1*
>
> J1: I wouldn't have known
>
> J2: It has woken us up
>
> *Jury 1 (All of England), Day 3, Observation 5*

As participants gained increased knowledge throughout the juries, they described feeling more uncertain and distrustful (Viola and Laidler, 2022). For example, during a discussion about whether NHS organisations involved in data collection were trustworthy, one participant in Jury 1 (All of England) stated that '*maybe in this jury – because we know – we have lost trust*'. This distrust did not appear to lead to apathy but instead to a desire to find out more. Some jurors talked about getting some healthy cynicism. The jurors frequently discussed researching the speakers and organisations involved outside of the jury to verify what they had heard, and some went further to examine their health records and permissions more closely:

> J1: Well, I'm going to look up med confidential [third-party organisation]
>
> J2: I'm going to do some research on them over the weekend
>
> *Jury 1 (All of England), Day 1, Observation 6*
>
> J1: I have an online record, and I had a look when he was talking and I'm one of these people who does give consent. Might review it after this jury
>
> J2: I'm going to sign up tonight
>
> J3: It is an education this jury
>
> *Jury 2 (Greater Manchester), Day 5, Observation 1*

## Discussion

This article examined the narratives drawn upon by citizens' jury participants when discussing health and social care data sharing during the COVID-19 pandemic, focusing on the concepts relating to visibility. Importantly, participants' general discussions and concerns about health and social care data sharing during the pandemic here are not vastly different from pre-pandemic research. This suggests that the participants did not consider the emergency status of the pandemic sufficient to justify changes to how health data sharing was conducted. While participants voted broadly to support the data initiatives to support the COVID-19 response, the support was conditional on increased transparency. Indeed, transparency was mentioned over 350 times in the small group discussions. This article offers a closer examination of what this demand for transparency means. Previous research has often focussed on transparency as a recommendation and outcome of data-sharing concerns. Here, the critical literature on visibility practices is used to understand and unpick how the public utilises transparency narratives in the context of health data-sharing. In what follows, the findings will be situated within the literature to illustrate the contribution to current knowledge around public perceptions of data sharing and subsequent policy implications.

The findings suggest that research on health data sharing should not take public demands for transparency at face value but instead attempt to understand what transparency represents to different groups. The narratives of transparency used by the participants here show how the term has been reified in public discourse (Pozen, 2020). Participants adopted the assumption that transparency could offer a straightforward solution to a complex problem (Ananny and Crawford, 2018; Birchall, 2014). It was a shorthand to express a desire for the public to (a) be informed about who is involved in data collecting and sharing and (b) be reassured that those actors are subject to oversight and scrutiny. However, in this case, it also revealed the false promise of transparency. A recent government-commissioned review into data sharing echoes the concerns that there is 'now a large poorly documented, poorly understood network of data disseminations' (Goldacre and Morley, 2022: 87). Furthermore, as health data increases in volume and complexity (Herschel and Miori, 2017), the number of actors involved (such as those who can store, manage, and analyse data and those who can develop platforms, algorithms, and applications from that data) will also rise (Birchall, 2011). The complexity of this economy means that it may be almost impossible to simplify, and accountability may become difficult as responsibility is diffused amongst different actors performing different tasks. The promise of transparency in policy recommendations may be meaningless if the public cannot find and make sense of this information. The

responsibility, therefore, should be on the organisations with overall responsibility for the processing and governance of health data to proactively inform and engage the public to support understanding of the health data economy.

Trust and trustworthiness were bound up in these discussions of transparency. Firstly, echoing previous research (Aitken et al., 2016; Kalkman et al., 2022), the NHS was seen as a trustworthy organisation by most participants and positioned in contrast to commercial organisations. However, the enmeshing of the NHS and Big Tech in health data sharing poses a dilemma. Does collaboration between the NHS and Big Tech lead to Big Tech being perceived as most trustworthy through association (Whitehead and Collier, 2023)? Or does it make the NHS and government organisations more suspicious through association with Big Tech? From the findings here, it seems reasonable to suggest the latter. Efforts to make organisations appear more trustworthy to promote trust may need to navigate this complexity. Secondly, the assumption that transparency will lead to increased trust was not found while taking part in a citizens' jury (Felzmann et al., 2019). As the jurors received more information, they became more cynical and some more distrustful. This mistrust, however, did not lead to apathy or resignation (Draper and Turow, 2019) but was used productively by some participants to take personal action to find out information or adjust their access to their own health records. Further work to understand how mistrust is acted on and if it can lead to greater feelings of control or later digital resignation could be a useful contribution.

The power and value of data to governments and political purposes were evident to jurors. Utilitarian discourses to justify health data collection and sharing can act as a form of power (Taylor, 2016) and as such, should be avoided by policymakers hoping to gain public cooperation. Utilitarian discourses were used by the UK government during the pandemic to justify the use of emergency powers and to explain the limited transparency in government decision-making, such as the COPI notices. The common good was clear in the UK communication strategies – to save lives and to protect the NHS. However, this morally loaded position means it was difficult to challenge or oppose health and social data-sharing initiatives. Jurors voiced concerns that the approach to the pandemic taken by the government, under the cover of utilitarian discourses, had led to opacity. They worried that legitimate worries about these practices would be dismissed as conspiracy theorising rather than demonstrating their need for accountability and control. The moral imperative to accept utilitarian discourses creates a power asymmetry that may have further implications for vulnerable groups that already feel disempowered. The right to opacity, through opting out in this case, was also made difficult by the lack of information about the process. Legitimate opportunities for criticism and opacity should be available to

ensure the public feels some control without taking a compromised moral position.

This article offers a novel insight into public perceptions of health and social care data sharing in several ways. In contrast to previous research on health data sharing, the article centres on visibility practices such as transparency and trust as important productive concepts. In doing so, it can more closely examine how the power and promises of transparency hold great weight for the public as a tool for governance. The findings provide empirical support for some of the claims from the critical studies of visibility practices, which are often theoretical or drawn from documentary evidence. Examining how the public engages with these visibility practices and the impact on social relations with organisations and governments contributes further insights to this literature. The context of doing observations during citizens' juries provided the opportunity to examine how public perceptions of health data sharing progressed over time. It also had the unintended effect of offering insight into how citizens' juries may act as transparency processes themselves. The citizens' juries are contextual, however. They occurred amid the pandemic while restrictions and the COPI notice were still in effect. Additional work looking at how health sharing expands in scope and scale outside of the pandemic and that critically examines the assumptions of transparency, trust, and trustworthiness is needed.

## Conclusion

Governments are expanding the scope and scale of health and social care data sharing and regard it as a key strategy for the future. Policy recommendations to improve public cooperation around health data sharing often uncritically cite transparency as key to engendering trust. The article, however, proposes that the reification of transparency in public discourses does not often reflect the complexity of visibility practices involved. The demand for increased transparency may instead reflect a need for control, understanding and accountability that greater visibility alone may not be able to achieve. The responsibility should be on organisations to demonstrate their relationships to the public and to better engage the public, rather than leaving the responsibility onto citizens with limited opportunity to understand and act on information about a complex topic. Increased knowledge is insufficient when the public has limited opportunity to act on that information. Lastly, governments should ensure there is the opportunity for the public to engage in the topic through balanced debates, without leaning too far on utilitarian perspectives, and ensure that there are legitimate opportunities for both scepticism and opposition.

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