February 2023

# Creating Resilient and Trusted Data Systems

## Findings Report

A public dialogue on effective data environments for emergency and non-emergency situations

Conducted on behalf of the Royal Society

Hopkins Van Mil

THE ROYAL SOCIETY

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# Executive Summary

## Background

The Royal Society commissioned the deliberative engagement specialists Hopkins Van Mil (HVM) to conduct a public dialogue on creating resilient and trusted data systems. The full process including design and fieldwork ran from November 2021 to February 2022. It was commissioned as a mainly face-to-face dialogue, but as Omicron arrived in the UK, it moved to an online deliberative process.

The ability to access quality data by scientists and government decision-makers rapidly has been shown to be essential during the Covid-19 pandemic. In the early part of the pandemic there were challenges in accessing and sharing quality data in a timely manner which hampered the ability of advisers and decision-makers to understand the situation and recommend actions.

Huge progress was made to respond to this challenge, but some critical questions remain which include:

- Can the systems we have created now help us in a future pandemic?
- Have the systems been established in ways that enable them to be used in a trusted way outside of emergencies?
- Are we any better placed to have a data-led response to other emergencies?

The Royal Society consider it critical to understand the public's views in an exploration of these questions and position public consideration at the heart of policymaking. This dialogue was therefore commissioned to consider how to build a future data-led response to emergency and non-emergency situations faced by society.

## Dialogue aim and objectives

The dialogue set out to inform the work of the Royal Society's Resilient Data Systems for Emergencies programme. This aims to identify how to build an amenable data environment for the UK where quality data sits alongside robust mechanisms for enabling access to it. Such a system would be suitable for both emergency and non-emergency situations.

The research question explored by participants is: how do we develop a system for using data which is resilient, effective and trusted in emergency and non-emergency situations? To reflect on this dialogue participants were supported to:

- Explore levels of awareness of data systems, including understanding of the current data landscape, data flows, data use and data governance in different emergency situations, and during non-emergency situations
- Define what emergency situations are, and the different types of emergencies

- Explore views, expectations, and concerns around data use, flows, and data governance during contrasting scenarios of different emergency situations e.g., health emergencies, environmental emergencies (both short-term events such as flooding versus longer-term climate emergency response), and non-emergency situations, setting out where the main 'trade-offs' and 'win-wins' may be
- Explore how data systems can exacerbate inequalities and how future systems can be made more inclusive
- Uncover how views may change within different situations, with regards to the use and access of different types of data, through different organisations, with regards to an absence or shortage of data, how trade-offs may change and where new priorities emerge
- Create recommendations which highlight where there appears to be unanimous and clear priorities for action as well as pulling out the nuance of context-specific recommendations and conflicting points of view.

Participants drew on stimulus with a global perspective and did mention the international dimensions of data systems. However, this dialogue reflects the views of participants from the UK mainly reflecting on UK data systems. International comparisons are therefore limited.

## Dialogue stimulus materials

Before taking part in the dialogue participants were sent a workbook[1]. This was presented in two parts. The first gave joining instructions for taking part in a public dialogue, including on using zoom and guidance on joining the online homework space. The second provided content materials including a data systems jargon buster, programmes for each workshop and emergency and non-emergency scenarios and other stimulus materials.

As participants joined the online homework space they could access electronic versions of the workbook and additional contextual material. This included an overview of how health data systems operate, including information on, for example: health and care records; the use of confidential information in health care; and the kinds of data used for test and trace mechanisms during the pandemic.

This dialogue was commissioned during the global Covid-19 emergency. The experiences from the pandemic shaped some of the stimulus materials presented to participants and was a focus for some sessions. Participants equally considered other emergency situations such as:

- Local flooding incidents
- The climate emergency, particularly the impact of significant and repeated heat waves
- Public health emergencies such as an ageing population living in inappropriate housing, particularly for those with multiple morbidities and who are experiencing a bigger care and poverty gap because of the pandemic.

[1] Appendix 1

All participants received the same information during the dialogue, with slight adjustments for location. For example, climate change projections for 2030 were given to participants based on their own location[2].

## Recruiting participants

The Royal Society commissioned a public dialogue[3], a deliberative and qualitative research method which works with smaller samples of people than are found in large scale quantitative surveys. The method is selected because commissioners wish to gain a depth of understanding on participants' attitudes, views, beliefs, values and needs which is not possible with those methods which involve more participants but which are not deliberative or qualitative. Programmes similar to public dialogue include Citizens' Juries and Assemblies.

Participants are recruited through a process of purposive sampling, as distinct from random sampling often used in quantitative research, to involve a selection of people who have the potential to reflect a wide set of views, values and demographies. Participants are not self-selecting but join the dialogue based on demographic information agreed by the project team and set out in the recruitment specification[4]. This includes purposefully sampling for those from rural and urban locations; for a range of ages and life stages. We sample for a balance of genders. A boosted sample was used to ensure that people disproportionally affected by emergency situations, including disabled people, those from minoritised ethnic groups and from lower socio-economic groups were over-represented in the sample. The sample was produced using relevant Office for National Statistics, local authority and 2011 Census data to broadly reflect the locations from which the participants came.

Recruitment was carried out[5] using on-street methods, through community groups and (as a back-up) from agency panels. We exclude those who have taken part in public dialogue, Citizens' Juries or Assemblies in the last twelve months to avoid research fatigue and an over-familiarity with the process. Participants were recruited to take part in one of five public dialogue groups from a thirty-mile radius of Leeds, Glasgow, Cardiff and Belfast. In addition, one group was recruited from across the UK. Twenty to twenty two participants were recruited to each group, with 111 participants taking part in total. To ensure we involved people with a range of perspectives on data we asked participants in the recruitment process two questions about their views on data sharing and on social media usage.

## The public dialogue method

Dialogue works when participants interact on a level playing field with specialists. This specialist evidence is then viewed through the lens of participants' own lived experience, acting as a provocation which leads to rich and powerful insights.

[2] Using, for example, What will climate change look like near me? BBC/ Met Office, July 2021

[3] More detailed definitions of public dialogue are available from Sciencewise

[4] The Recruitment Specification used for this project is available at Appendix 2

[5] We work with the specialist agency Roots Research to recruit participants

This process leads to an in-depth understanding of what people value, what they are concerned about, their priorities and the principles they apply to this prioritisation. HVM facilitators are key to gaining this understanding. They ensure there is a balance in small group discussions which allows people freedom to express their views whilst not allowing the process to lose the important focus on the dialogue scope or for the exercise to be derailed. This report sets out the findings that have emerged from this public dialogue process. Recruiting a diverse group of people to the dialogue ensures we hear, and participants respond to, a diversity of views. Dialogue participants learn from the process. They are influenced by the speakers and by their fellow participants. For many participants the dialogue was the first time they had thought to any degree about the data systems used to inform public and private policy.

The fieldwork took place between December 2021 and February 2022. Dialogue participants heard from expert speakers who gave contextual material on data systems, including on NHS data systems, UK statistical regulation and data for global emergency and risk planning. Each location had one live speaker. Presentations were recorded at workshops and shared with participants from all locations in the online homework space. This allowed all participants to review all the presented material. The dialogue process for each location is set out in Figure A.


*Figure A: Public dialogue outline method*

In was HVM's intention to deliver four of these five sets as face-to-face dialogues, with the UK wide cohort running using online methods. Unfortunately as a result of the onset of the Omicron variant in December 2021, and in line with public health guidance at that time, the decision was made to re-purpose the workshop design for online delivery. We retained the key essentials of a face-to-face dialogue so that each group took part in two rounds of workshops. For some locations this comprised two week-end workshops, two to three weeks apart, for others it comprised a combination of evening and week-end workshops, and others only evening workshops. All participants spent twelve hours in workshop discussions with an additional two hours using an online space in their own time.

The dialogue process included the use of the following tools:

- Mentimeter, an online polling tool, used in the workshops to gain a snapshot of views
- Jam Boards for facilitators to take visible notes during the workshops which participants can amend and build on as their discussions develop
- Recollective: an online qualitative research tool, which enables participants to review and comments on materials, answer questions such as their views on data sharing, and to reflect on their lived experience in their own time outside of workshop discussions.

## About this report

Public dialogue findings cannot be taken to be statistically representative of the general population. However, they do uncover participants' views and the values, beliefs, experiences, interests and the needs that underlie them. As such we refer throughout this report to the views of dialogue participants rather than making any broader claims of being able to extrapolate the findings to the UK population.

The online dialogue workshops generated sixty hours of audio recordings. These were transcribed and, with the materials from Mentimeter and Recollective were analysed using NVivo software. Our reporting includes summaries of the analytical work participants did during the process combined with researcher analysis resulting from a comprehensive review of the dialogue data. We make the difference clear throughout the report.

HVM applies grounded theory to our analysis of public dialogue deliberations. We build theories from what we have heard rather than having a preconceived hypothesis to test. We make use of Sciencewise Guidelines for Reporting (July 2019) and the evaluation of previous public dialogues to inform our work. Throughout the process the HVM coding, analysis and writing team have maintained a rigorous approach and held frequent sense-checking sessions to mitigate against researcher bias.

We use terms such as 'a few', 'many', 'several' or 'some' to reflect areas of agreement and difference. These should be considered indicative rather than exact.

It is important in any dialogue process that the report reflects the voices of participants. Therefore, we have used short quotations from those who took part in the dialogue, drawn from the transcripts, to illustrate the analytical points being made and to emphasise main points. We have also used longer 'lived experience' quotations throughout the report which describe in participants' own words an experience which highlights a relevant data system experience. Some quotes have been edited to remove repeat or filler words. There have been no other edits which might distort the meaning intended by participants. In conducting the analysis and reporting on the findings HVM researchers have made judgements about which quotations to include. These judgements are based on a respect for what participants shared and the seriousness with which they took their role in the dialogue. Quotation selection was also made in relation to what best reflects the key themes raised, including a diversity of voices, and highlighting the key points from a participant and researcher led analysis.

## The dialogue findings

This dialogue has revealed what matters to participants when they consider resilient, effective and trusted data systems. Findings are divided into two sections: section A sets out the key findings by main theme; section B builds on this and reveals further key findings explored via the 'data conundrums' participants' identified alongside the potential solutions to these dilemmas. This section also highlights areas which are valuable for further exploration between specialists in the field and publics. This is followed by recommendations made by participants in the dialogue.

# Findings by theme

### Theme 1: Assumptions, surprises and early reactions

Participants on joining the dialogue assume that:

- Data systems refer to privately owned and commercially operated systems
- Data collected for commercial purposes is sold on without thought, regulation or any process of redress for harms such as scams, hacks and data related fraud
- Data systems rely on 'me' putting 'my' data into the system and therefore barriers to doing this create inequalities in data systems
- Data is easily accessible and widely available to those who might want, need or wish to use it for public benefit, commercial purpose or for criminal activity
- When public sector data systems do come to mind it is assumed at first that these are linked and inter-operable e.g. that hospital consultants will be able to see GP records.

**Finding 1:** Participants are surprised when they consider how much data is shared unthinkingly on a daily basis. This leads to astonishment that people, including themselves, are so trusting of organisations collecting data, particularly when it is not clear how the data will be used.

Participants considered where they sit on the scale we described as 'Keep it close Kieron: data about me is private and shouldn't be used be used beyond its original purpose - even in emergency situations' at one end and 'Give it away Greta: data about me should be used or planning for and improving services – whatever the situation' at the other. Most people situate themselves in the centre of this scale (figure B). They feel:

- There is a balance to be struck between data privacy and data availability
- Data should be used 'correctly' and 'appropriately'
- Acceptability comes from being clear about who will have data access for what purpose(s)
- People are less willing to engage with data systems if they feel there is the potential for exploitation of citizens; surveillance of society by government; or to justify actions they believe to be contrary to the public good.

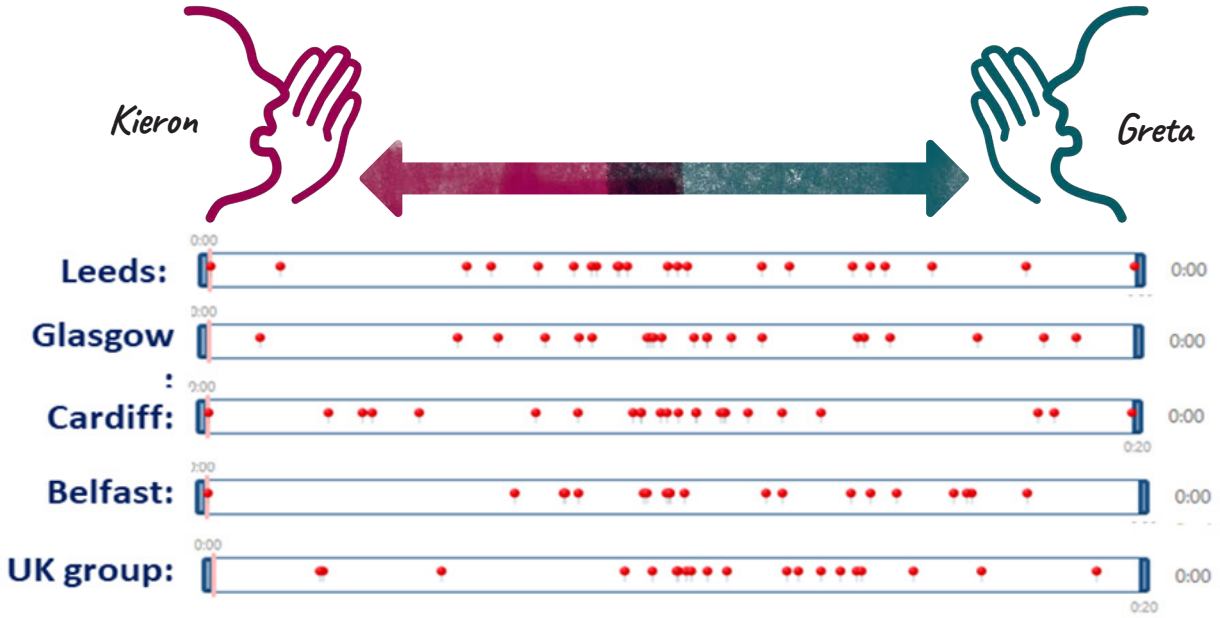



*Figure B: Reactions to data use*

**Finding 2:** Participants who put themselves towards Kieron say they are concerned that they have no control over how their data is used; feel exposed to harm; and do not trust those who manage data systems not to exercise power and control over those whose data is collected. Participants who lean towards Greta believe that data should be used for public good, particularly to improve public services and emergency responses.

**Finding 3:** Participants are concerned that the parameters of an emergency are clearly defined. Figure C presents the words participants use to define an emergency. They believe society needs to understand the value of data systems in an emergency in order to assess what is appropriate data use in non-emergency situations.


*Figure C: Participant emergency definitions*

## Theme 2: Trust and transparency

**Finding 4:** There is a strong sense expressed by participants that data should be collected and used for defined purposes – even if those purposes are not entirely evident e.g. protecting society from future emergencies. Mistrust of data systems arises when this clarity of purpose does not appear to exist.

Participants express high levels of trust in frontline professionals such as health, care and environmental protection professionals as well as public/ academic experts in data. Lower levels of trust are expressed in those with an 'agenda' for data which could conflict with public good. This includes commercial and party political objectives (figure D).


*Figure D: The spectrum of trust*

**Finding 5:** Mistrust of data systems and those who manage them is characterised by exploitation and misuse. Trust is characterised by expertise and public good.

**Finding 6:** Participants identify seven facets of trust (Figure E), essential elements which must be woven in to data systems to achieve public credibility and durability.

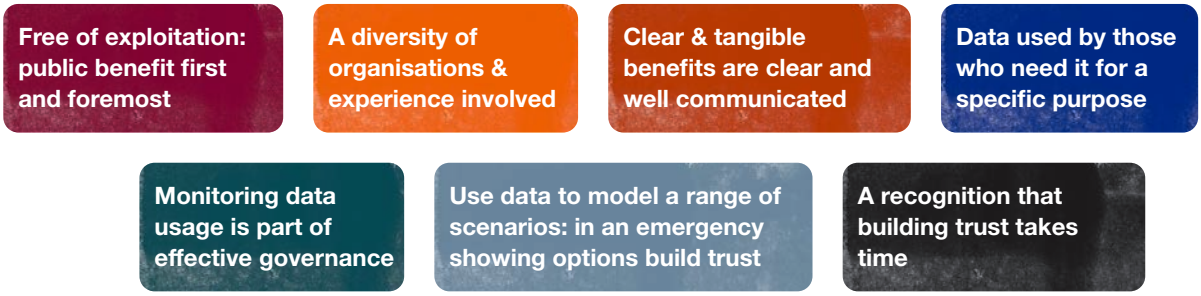



*Figure E: The seven facets of trust*

**Finding 7:** Transparency depends on having a clear understanding of what the data collected actually achieves. Participants feel this is largely hidden from public view and this lack of awareness of the purpose of data systems leads, they belive, to missed opportunities to reassure society of the value of data and build trust in data systems.

## Theme 3: Balancing inclusive data systems with those that protect individual privacy

**Finding 8:** Making data systems inclusive is a key priority for participants. They articulate a number of impacts that data systems not designed with inclusion and diversity in mind can have on people's lives. These are set out in figure F.


*Figure F: Impacts of data systems that are not inclusive*

**Finding 9:** Participants agreed that, in an ideal world, data systems would demonstrate the hallmarks of inclusivity. Including being accessible, representative and giving a fair interpretation of the data (figure G)

Hallmarks of inclusive data systems

- ✓ Accessible to all
- ✓ Representative of everyone
- ✓ Prioritise the vulnerable
- ✓ Non-discriminatory
- ✓ Design with inclusion and accessibility front of mind
- ✓ User-friendly and simple
- ✓ Available in different formats
- ✓ Available in different languages
- ✓ Engagement and support
- ✓ Fair interpretation of data

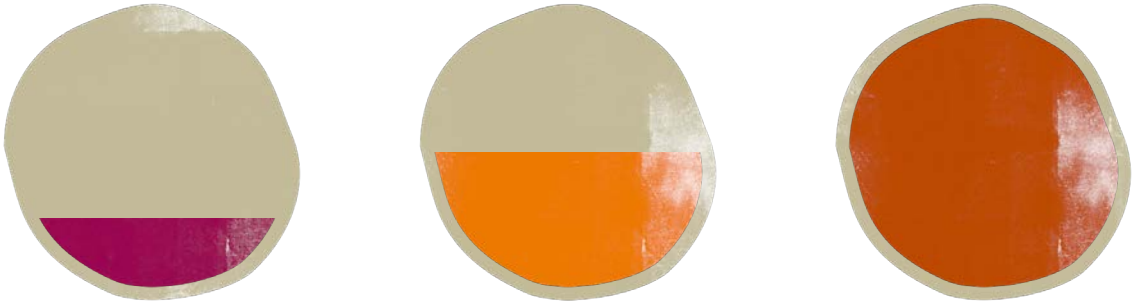
*Figure G: Ideal hallmarks of inclusivity*

**Finding 10:** Participants express concern about data privacy, particularly in industry-led data systems, but across all systems. They believe that:

- Personal data should be private unless de-identified
- Opt-in/ opt out choices are important
- Individuals should have the right to know what data is included in the system and to remove data from it
- Data privacy must still matter in emergency situations, even though use of data might be more urgent and more personal and identifiable data might be needed to address the emergency.

## Theme 4: the need for data in emergency situations

In discussing what is needed from data systems in emergency situations participants tend to fall into three groups (figure H).



### Cautious

The data needed in an emergency should already exist, no need for extended data access powers in an emergency.

### Willing

Data should be accessible in an emergency - as long as society is aware of the benefits and data protection is robust.

### Ambitious

Anything and everything should be done, including unrestricted access to personal data, if this is in the public interest and will end the emergency situation.

*Figure H: Three main attitudes towards data systems in an emergency*

**Finding 11:** Emergency powers to access personal, identifiable and sensitive data should not extend beyond the emergency situation and become 'normalised'

**Finding 12:** Participants conclude that connected data systems are of value to society in both emergency and non-emergency situations. They call for more co-ordination and inter-operability between systems, particularly those which deliver public benefit such as health, care, housing and education.

*Participants recommend that:*

- A shift is needed to recognise that linking data systems and fostering a spirit of collaboration between those who manage them is likely to produce greater public benefit in their use
- This shift will also minimise the burden on society in collecting and recollecting data for different purposes and bring specific public benefits in key social and economic areas such as health, social care, education and housing
- Public reassurances need to be made on the purposes for which data is collected and shared

## Theme 5: Resilient data systems

**Finding 13:** Participants see learning throughout the system as an important aspect of resilience. They describe a very simple cycle of learning (figure J) which reflects their desire for an effective, resilient and trusted data system to learn constantly. This reflects a need for data systems to be open to what's not working well and identifying areas for improvement.

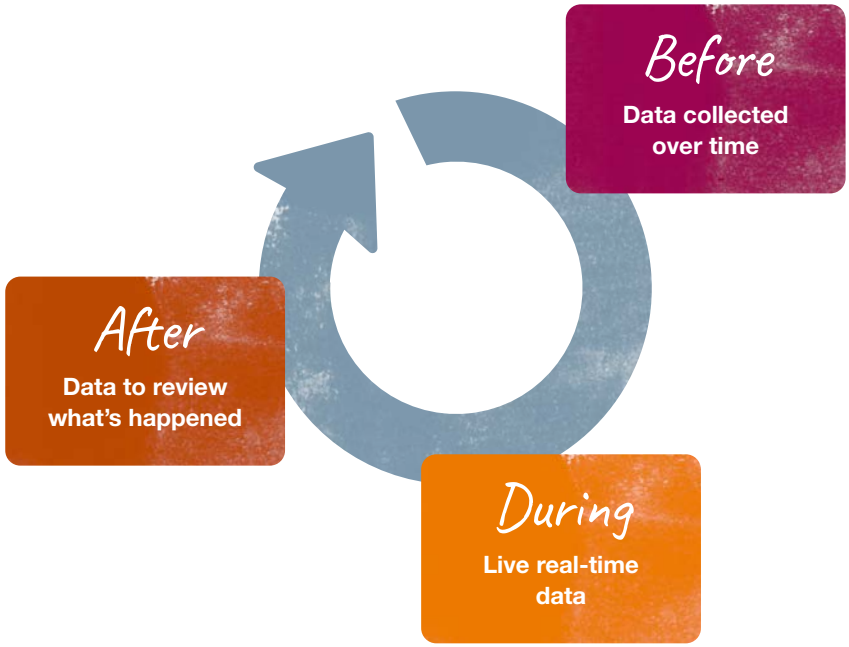



*Figure J: The data system cycle of learning*

**Finding 14:** Four specific learning tools are identified by participants which they believe should be embedded in any data system to protect its resilience:

- Conducting stress tests focused on potential risks, checking readiness for a range of emergency and non-emergency situations
- Future proofing to anticipate the likely challenges ahead and to ensure data is available on relevant topics
- Finding innovative and creative ways to make full use of existing data considering new data sources, such as big data, and anticipating future data needs
- Learning from expert and vetted staff who provide the best expertise available to support learning, development and technical innovation within data systems.

## Theme 6: Good governance

**Finding 15:** Good governance is seen by participants as essential in helping people to trust and engage with data systems. They see the elements of good governance set out in table 1 as a key foundation on which resilient and effective systems rest.

Table 1

| *Important elements of good governance* |
| --- |
| **Safeguarding:** of the security of the data in the system and the rights and safety of people with regard to the onward sharing of their data. |
| **Independence:** to ensure unbiased application and enforcement of the rules across the system that institutions that are rooted in it, including the government, cannot provide. |
| **Effective sanctions:** to inspire trust that rules, regulations and sanctions are fairly and equitably applied to everyone involved in the data system whether data collection, storage and management, analysis, interpretation and communication. |
| Oversight, accreditation, monitoring and inspection of data quality as well as professional standards of those collecting and using data.<br>This would include an audit process to ensure consistent analysis of the data resultant from data systems. It would ensure that someone is responsible for verifying data security and privacy systems are in place and working as they should be. |

*Participants recommend that:*

- Governance of data systems is more widely visible to people across society
- There are transparent communications on the actions regulators have taken demonstrating independence from those who manage data systems
- Current regulators are given boosted powers to penalise misuses of data systems
- Support is provided through the governance structures for data systems to employ best practice which flows from non-emergency to emergency situations
- A culture of learning from the before, during and after emergency situations is embedded in data systems
- Data systems are designed with built in oversight, monitoring and inspection of quality
- Those working data systems have appropriate skills and experience to protect the efficacy and trustworthiness of the system
- Reassurances are made to society about data privacy and security across all data systems

## Theme 7: Communication and awareness raising

**Finding 16:** Participants are more accepting of data systems use in emergency than non-emergency situations. They agree that the visibility of data systems, and for the organisations that govern and regulate them, is lacking. They fear this could lead to misunderstandings and for data being collected and not used – which they find unacceptable.

**Finding 17:** Simple and honest communications about data systems and their management is essential with effective data systems speaking to society to allay fears, build trust and supporting people to see the purpose and value of participating in the system.

*Participants recommend that:*

- Clear communications are needed on what data is collected in non-emergency situations to inform what data can and should be used in emergency situations
- Communication campaigns are needed to highlight the public benefit which comes from effective data systems
- Efforts should be made to re-frame perceptions of data use so that public benefit is front of mind when people think about data systems
- Public benefit should be used as a lever to ensure societal needs are met through data use in emergency and non-emergency situations.

# Participant conundrums, solutions and areas for further research

Several data conundrums emerged during the course of the dialogue which represent apparent stress points in how people think the data system should work to be fully effective and how they feel as individuals about sharing their own data. The main three data conundrums and related solutions are set out in Table 2:

Table 2

| Data system conundrums | Potential solutions described by participants |
|---|---|
| Precise details are required for data quality, comprehensiveness and an accurate picture of society. However, asking for what people might consider to be too much personal data is a problem for participants. They feel it can make people less likely to engage in data systems for non-emergency situations leading them being missed from data which could support them in emergency situations. The lack of engagement being due to people's perception that they are more vulnerable to harm, exposed to risk, or simply inconvenienced if they do engage. | • Undertake further work to raise awareness in society that data is collected and used for public benefit – including as a key element of responding to emergency situations<br>• Ensure public communication on data systems include clear and simple communication on how and when data is de-personalised[6]; and how personal and sensitive data is protected.<br>• Transparently demonstrate what the benefits of data systems are; creating a shift in public awareness towards an understanding that data systems can bring public benefit. |
| Many participants believe that data should only be collected for a specifically defined purpose, particularly in non-emergency situations. They believe that individuals should only agree to share data based on this purpose.<br>However, participants also recognise that a resilient data system requires data to meet future needs that aren't yet known. This creates a dilemma – how do you state a clear purpose for data collection when you are not yet clear what these future needs might be? | • Clarify, in simple terms, across a range of emergency and non-emergency situations what the purpose of any given data system is including:<br>• how data collected by private and public sector data systems is used -and why<br>• where data might be shared, and who with – and why<br>• where there may be overlaps between the private and public sector in who 'manages' and 'owns' the data.<br>• Create simple, visual and Plain English/ Easy Read terms and conditions documents for websites and apps which collect data. Which might include colour coding to indicate when specific types of data are being collected e.g. location or personal data.<br>• Create a series of good news stories around data use, e.g. in handling an emergency situation, so that people can see the wider public benefits that can accrue from data systems. |

[6] Participants found Understanding Patient Data's Identifiability Demystified handout helpful in this context

Table 2 continued

| Data system conundrums | Potential solutions described by participants |
|---|---|
| Participants call for data systems to be more joined up, particularly in public health emergency and non-emergency situations. They believe this will make them more efficient, resilient and accessible. Despite this belief they are concerned that if data is shared across systems, and with all those who need it, this may increase the chances of harms to individuals and make it difficult for people to feel in control of who has access to their data and for what purpose. | • If data systems are to be more inter-operable and linked, then protections must be put in place and communicated widely<br>• If data systems are demonstrated to be resilient e.g. to be able to recover from challenges and adapt to changing circumstances, participants believe people will be reassured that harms and risks have been minimised<br>• Participants feel that joined up systems should prioritise vulnerable people, particularly in emergency situations – using the fact that they are joined up to understand who is most at risk in an emergency<br>• Design data systems with inclusion and diversity in mind including:<br>— Involving a diversity of people in the design of data systems<br>— Standardising the design of systems, particularly those in the public sector so that it is easier to move from one to another<br>— Having dedicated and specialist teams responsible for system accessibility. |
| | |

As a result of identifying these conundrums and potential solutions participants a number of areas for further research and future lines of enquiry are indicated, mostly focused on involving people across society in data system decisions. These include:

- Researching ways in which trust in data systems at a local level can be fostered
- Governance structures developing systems, including public involvement panels, which encourage data systems to operate as learning systems
- Studying the facets of trust explored in this dialogue further with a citizens' jury or similar deliberative panel which brings people together over time to test specific data systems against these elements.

## *Participants recommend that:*

- Data systems are shaped, challenged and developed with the involvement of a diversity of people from across society
- Public involvement should inform how data is collected, including the inclusion of data from those who might be missed from the system
- Public involvement should be a key part of data system governance structures

We end this report with a call to action voiced by one participant highlighting the views of many in the dialogue:

> *People will feel like their opinions are heard and it's trusted. Because it's like, Okay, no, we were a part of this decision. We helped make this decision. It doesn't feel like it's being imposed upon us.*
>
> **Participant, UK**

# 1 Introduction

## 1.1 Background

The Royal Society commissioned the deliberative engagement specialists Hopkins Van Mil (HVM) to conduct a public dialogue on creating resilient and trusted data systems. The full process including design and fieldwork ran from November 2021 to February 2022. It was commissioned as a mainly face-to-face dialogue, but as Omicron arrived in the UK, it moved to an online deliberative process.

The ability to access quality data by scientists and decision-makers rapidly has been shown to be essential during the Covid-19 pandemic. During an emergency, with a rapidly changing situation, decision-makers need access to quality data in a timely manner. In the early part of the pandemic there were challenges in accessing and sharing data which hampered the ability of advisers and decision-makers within government to understand the situation and recommend actions.

Huge progress was made to respond to this challenge, but some critical questions remain, including:

- Can the systems we have created now help us in a future pandemic?
- Have the systems been established in ways that enable them to be used in a trusted way outside of emergencies?
- Are we any better placed to have a data-led response to other emergencies?

The Royal Society consider it critical to understand public views in an exploration of these questions and position the public's views at the heart of policymaking, hence the commissioning of this dialogue to consider how to build a future data-led response to emergency and non-emergency situations faced by society.

## 1.2 Dialogue aim and objectives

The dialogue set out to inform the work of the Royal Society's Resilient Data Systems for Emergencies programme. This programme aims to identify how to build an amenable data environment for the UK where quality data sits alongside robust mechanisms for enabling access to it. Such a system would be suitable for both emergency and non-emergency situations.

The research question explored by participants is How do we develop a system for using data which is resilient, effective and trusted in emergency and non-emergency situations? To answer this question the dialogue sessions worked with public participants to:

- Explore the public's level of awareness of data systems, including understanding of the current data landscape, data flows, data use and data governance in different emergency situations, and during non-emergency situations

- Define what emergency situations mean, and the different types of emergencies
- Explore public views, expectations, and concerns around data use, flows, and data governance during contrasting scenarios of different emergency situations e.g., health emergencies, environmental emergencies (both short-term events such as flooding versus longer-term climate emergency response), and non-emergency situations, setting out where the main 'trade-offs' and 'win-wins' may be;
- Explore how data systems can exacerbate inequalities and how future systems can be made more inclusive
- Uncover how public views may change within different situations, with regards to the use and access of different types of data, through different organisations, with regards to an absence or shortage of data, how trade-offs may change and where new priorities emerge
- Create recommendations which highlight where there appears to be unanimous and clear priorities for action as well as pulling out the nuance of context-specific recommendations and conflicting points of view.

## 1.3 Stimulus materials

Before taking part in the dialogue participants were sent a workbook[7]. This was presented in two parts. The first gave joining instructions for taking part in a public dialogue, including on using zoom and guidance on joining the online homework space. The second provided content materials including a data systems jargon buster, programmes for each workshop and emergency and non-emergency scenarios and other stimulus materials.

As participants joined the online homework space they could access electronic versions of the workbook and additional contextual material. This included an overview of how health data systems operate, including information on, for example, health and care records, the use of confidential information in health care and the kinds of data used for test and trace mechanisms during the pandemic.

This dialogue was commissioned during the global Covid-19 emergency. The experiences from the pandemic shaped some of the stimulus materials presented to participants and was a focus for some sessions. Participants equally considered other emergency situations such as:

- Local flooding incidents
- The climate emergency, particularly the impact of significant and repeated heat waves
- Public health emergencies such as an ageing population living in inappropriate housing, particularly for those with multiple morbidities and who are experiencing a bigger care and poverty gap because of the pandemic.

[7] Appendix 1

All participants received the same information during the dialogue, with slight adjustments for location. For example, climate change projections for 2030 were given to participants based on their own location[8].

We used four scenarios[9] to provide stimulus for participant discussions on specific uses of data. These indicated the types of data that might be used scenarios during the Covid-19 pandemic, in a rapidly escalating flood scenario, in a long-term public health emergency and in a scenario of extended and repeated heat waves caused by the climate emergency.

These materials were supplemented in the workbook with further contextual information. In each workshop facilitators gave further details on the scenario, elaborating on the summaries presented in the scenario. We used zoom backdrops and props to situate participants within the scenario. In addition before each scenario was presented participants were sent a text message asking them to attend a pandemic, public health, flood risk, or climate change briefing, again attempting to role play data use in emergency situations on a variety of scales.

The full scenarios and data shared with participants is at Appendix 1 of this report. External events, including emergencies, took place during the span of the dialogue. These drew participants' attention to data use in emergency and non-emergency situations and the role of data systems in finding solutions to societal challenges. This contextual backdrop includes the events and actions set out in figure 1.5.


*Figure 1.1: The external backdrop to the dialogue*

[8] Using, for example, What will climate change look like near me? BBC/ Met Office, July 2021

[9] Set out in Appendix 1

## 1.4 Recruiting participants

The Royal Society commissioned a public dialogue[10], a deliberative and qualitative research method which works with smaller samples of people than are found in large scale quantitative surveys. The method is selected because commissioners wish to gain a depth of understanding on participants' attitudes, views, beliefs, values and needs which is not possible with methods which involve a greater number of participants. Programmes similar to public dialogue include Citizens' Juries and Assemblies.

Participants are recruited through a process of purposive sampling, as distinct from random sampling often used in quantitative research, to involve a selection of people who have the potential to reflect a wide set of views, values and demographies. Participants are not self-selecting but join the dialogue based on demographic information agreed by the project team and set out in the recruitment specification[11]. This includes purposefully sampling for those from rural and urban locations; to ensure a gender balance; and for a range of ages and life stages. A boosted sample was used to ensure that people disproportionally affected by emergency situations, including disabled people, those from minoritised ethnic groups and from lower socio-economic groups were over-represented in the sample. The sample was produced using relevant Office for National Statistics, local authority and 2011 Census data to broadly reflect the locations from which the participants came. To ensure we involved people with a range of perspectives on data we asked participants in the recruitment process two questions about their views on data sharing and on social media usage[12].

Recruitment was carried out[13] using on-street methods, through community groups and (as a back-up) from agency panels. We exclude those who have taken part in public dialogue, Citizens' Juries or Assemblies in the last twelve months to avoid research fatigue and an over-familiarity with the process. In line with best practice in social research participants were paid an incentive to take part in the dialogue in recognition of the significant time commitment involved and to ensure no one is excluded due to financial constraints.

[10] More detailed definitions of public dialogue are available from Sciencewise

[11] The recruitment specification used for this project is available at Appendix 2

[12] These questions are set out in the recruitment specification, Appendix 2

[13] We work with the specialist agency Roots Research to recruit participants


*Figure 1.2: Recruitment locations*

We checked with all participants in advance of the first workshop to ensure that they were not prevented from taking part due to lack of equipment or broadband. All participants were offered the opportunity of joining a 'tech-support' session before the first workshop to show them the main elements of the online tools we were using: Zoom, Mentimeter and Recollective[14].

[14] We used Zoom.com for the online workshops, Mentimeter as an in-workshop polling tool to gather front of mind responses on the issues, and Recollective as the online space for homework activities.

## 1.6. Our method

It was our intention to deliver four of these five workshop sets as face-to-face dialogues, with the UK wide cohort running using online methods. Unfortunately as a result of the onset of the Omicron variant in December 2021, and in line with public health guidance at that time, the decision was made to re-purpose the workshop design for online delivery. We retained the key essentials of a face-to-face dialogue so that each group took part in two rounds of workshop. Fieldwork took place between December 2021 and February 2022. For some locations this comprised two week-end workshops, two to three weeks apart, for others it comprised a combination of evening and Saturday workshops, and others only evening workshops. All participants spent twelve hours in workshop discussions with an additional two hours using an online space in their own time. The design framework is summarised in figure 1.7.


*Figure 1.3: Public dialogue outline method*

Dialogue works when participants interact on a level playing field with specialists. This specialist evidence is then viewed through the lens of participants' own lived experience, acting as a provocation which leads to rich and powerful insights.

This process leads to an in-depth understanding of what people value, what they are concerned about, their priorities and the principles they apply to this prioritisation. HVM facilitators are key to gaining this understanding. They ensure there is a balance in small group discussions which allows people freedom to express their views whilst not allowing the process to lose focus or for the exercise to be derailed. Recruiting a diverse group of people to the dialogue ensures we hear, and participants respond to, a range of views. Dialogue participants learn throughout the process, including being influenced by stimulus materials, speaker presentations and the views of their fellow participants. For many participants the dialogue was the first time they had thought to any degree about the data systems used to inform public and private policy. We have reflected shifts in thinking due to these influences in the report. Detailed information on the speakers, stimulus material and the dialogue method is included in the appendix to this report[15].

[15] Appendix 3 lists the speakers, appendix 1 provides the stimulus used within the participant workbook and appendix 4 provides the process design for each workshop.

## 1.7 Analysis and reporting

The online dialogue workshops generated sixty hours of audio recordings. These were transcribed and analysed using NVivo software together with:

- data from the reflective tasks that participants completed in between each workshop
- results of the online polling questions used live during workshops.

HVM applies grounded theory to our analysis of public dialogue deliberations. We build theories from what we have heard rather than having a preconceived hypothesis to test. We make use of Sciencewise Guidelines for Reporting (July 2019) and the evaluation of previous public dialogues to inform our work. Throughout the process the HVM coding, analysis and writing team have maintained a rigorous approach and held frequent sense-checking sessions to mitigate against researcher bias.

## 1.8 About this report

Our reporting includes summaries of the analytical work participants did during the process combined with researcher analysis resulting from a comprehensive review of the dialogue data. We make the difference clear throughout the report.

Public dialogue is a qualitative methodology, findings do not demonstrate statistically representative analysis, nor can they be said to represent the views of a wider population. By asking open questions and following lines of enquiry suggested by participants we gain an understanding of the subtleties and nuances of participants' views, concerns, hopes and aspirations so that they can inform next steps.

Whilst inequalities in data systems was an important subject for discussion (see section 3.6) this public dialogue was not commissioned to work with participants in demographic segments. As such we reflect the views of the diverse sample recruited to the dialogue (see section 1.4) in broad terms, highlighting patterns as well as commonalities and points of difference. We did not cluster our findings around specific sample segments.

We use terms such as 'a few', 'many', 'several' or 'some' to reflect areas of agreement and difference. These should be considered indicative rather than exact. It is important in any dialogue process that the report reflects the voices of participants. Therefore, we have used quotations from those who took part in the dialogue, drawn from the transcripts, to illustrate the analytical points being made and to emphasise main points. We have also included 'Lived Experience boxes' throughout the report which highlight verbatim a story told by participants to illustrate points participants considered particularly important. Some quotes have been edited to remove repeat or filler words. There have been no other edits which might distort the meaning intended by participants. In conducting the analysis and reporting on the findings HVM researchers have made judgements about which quotations

to include. These judgements are based on a respect for what participants shared and the seriousness with which they took their role in the dialogue. Quotation selection also was made in relation to what best reflects the key themes raised, including a diversity of voices, and highlighting the key points from a participant and researcher led analysis.

The following report chapters set out the report findings. We begin with what participants' said about their own journey through the dialogue. This sets the context for subsequent chapters in which we share findings on how participants engage with data systems before considering what, in participants' minds makes an effective data system. These sections reflect the key points made around the purpose of our data systems, trust in them, considerations for inclusive data systems as well as data privacy and security. The penultimate section of the report focuses on data systems in emergency and non-emergency situations considering questions around data sharing, defining the boundaries of emergency use and communicating the results of data use. The report ends with participants' own recommendations and our findings on the principles which should underpin trusted, effective and resilient data systems.

# 2 The Journey through the dialogue

In talking about participants' journey through the dialogue we are drawing on what was expressed as expectations of data early in the process. This leads us to what participants said they understand about data systems, and what came as a total surprise.

## 2.1 Early assumptions, hopes for and concerns about data systems

During the early stages of the dialogue participants focused on what was closest to them: data use and implementation as it impacts on them and their families. Examples shared by participants of data use in emergency and non-emergency situations demonstrates the importance participants place on data having tangible benefits such as:

- In a medical emergency: so that the police or paramedics can contact the relevant people if there is an accident
- In a medical non-emergency: sharing data such as medical history with a GP, nurse, or pharmacist in order to receive medical advice

*So, not being the expert, you want them to advise you.*

Participant, Leeds

- When shopping: getting a discount for subsequent purchases if you share your email address at the checkout

*Instead of just giving you a print receipt now, they take your email address, and they email it to you. But they said, 'If we take your email address, the next time you come in we'll give you 10% off.' I was like, 'Well, 10% off, I might be here again really soon, so I'll take that'.*

Participant, Leeds

Some participants know that data has value and is valuable. In the early stages of the dialogue this was put forward in the context of the commercialisation of data, for example for targeted marketing and advertising purposes on the Internet and on social media. For some participants this is seen as a fair exchange. If the data system gives opportunities for mutual benefit, then this is reasonable. I get a service I need or want, and the system is enhanced with my data. We hear throughout the report how views on the value differed when considering emergency and non-emergency situations.

Many participants prior to and during workshop one reveal the assumptions they have about data systems, for example:

- When we discuss ‘data systems’ the first thing that comes to mind is data collected in commercial transactions and by industry, particularly data giants such as Meta, Google and Amazon
- That data collected for commercial purposes is sold on without thought, regulation or any process of redress for harms such as data scams, hacks and data related fraud
- Lived experience of using the Internet and social media is the first example many participants share of data and data use
- Data systems rely on ‘me’ inputting ‘my’ data into the system
- Data is easily accessible and widely available to those who might want, need or wish to use it for public benefit, commercial purposes or for criminal activity
- Data systems are linked and interoperable e.g. an assumption that a hospital consultant will be able to see GP records.

Participants express a hope early in the dialogue that data is collected, used and shared to protect people, particularly children or those in vulnerable positions.

*Sharing information so that you know about, I don't know, domestic violence or about child abuse. I should imagine, you'd hope, the data gets used so that people are on registers, etcetera.*

Participant, Belfast

**Lived Experience Box 1**

*I've had ID stolen before and I got a phone call from the bank about my debit card being used randomly. So, yes, in that respect, shared data did work. I think it was bought £2,000 worth of animal stuff in Donegal and half an hour later, it was used in Kent somewhere, actually. That data there obviously was sent back to the bank and the bank realised that I can't be in Donegal and Kent at the same time. So something's going on here. So it worked. Yes.*

Participant, Belfast

Throughout the dialogue participants shared their experience of when data systems have seemed to have failed and when they have worked. As Lived Experience Box 1 illustrates, some participants have experience of when a crisis has been averted because a system has appeared to have been effective.

Participants expressed the view early in the dialogue, that data systems are complex, involve everyone and every aspect of our lives. Whilst commercial use of data was front of mind early in the dialogue, as participants explored the subject they became more aware of how data is used in all manner of public sector settings: to inform policy, to plan services, to understand the social, economic and political situations in which society finds itself.

As such many participants considered in the first workshops the importance of data in public policy and planning. Early points made show support for data being used for emergency and non-emergency situations being managed by public sector bodies. Situations they raised in this context include data use to:

- Manage Covid-19 infection rates
- Understand risks in advance of an emergency
- Plan for key services such as health, social care, social services and education
- Enable society to innovate on the basis of data gathered.

*I think it's just if we look at the past, what, 10 years now, if you think about all the location data and things that are held on you from your mobile phones and how that has gone to improve everything in daily life. Technology has improved, the ability to communicate personal data and data quickly and effectively across the world has improved. In 20 years we've done more than we've done in thousands.*

Participant, Cardiff

An early concern some participants expressed about data systems is that they can lead to a 'Big Brother' situation where individuals are being tracked through their data sharing. Participants realise that this raises a dilemma: we share our data unthinkingly and all the time, and yet we are concerned that such sharing could result in systems having too much knowledge of individuals, their movements and behaviours.

*Unfortunately we all have bank cards and credit cards, and they know. People laugh when people are talking about not getting the vaccine, so they'll be able to track us. Well, they already track you, your credit card, your phone. They know exactly where you are, what you're doing and when. And you don't even realise it.*

Participant, Glasgow

For some participants this concern comes with resignation. Our data is already in circulation and being used for a wide variety of purposes, as such we have already given up any control we might have had of it.

*Whether we like it or not it's going to be used. I do feel like some (data) should be private, but I don't really feel like we do have much choice anymore.*

Participant, Belfast

A few participants also tie this feeling of resignation into it not being a concern who is collecting data and why. These participants feel that if you have nothing to hide in your life then it doesn't much matter who has access to your data. For example, if your store card can show that you choose one product over another.

*If somebody wants to know that I shop in Aldi, yes, that's fine. If they want to know I buy Aldi's mince as well, okay. What am I doing that is so secret that I need anyone not to know?*

Participant, Glasgow

## 2.2 Data system surprises

In the first workshop participants were asked to think about settings where data might be collected and how they felt about that[16]. For many participants this was an eye-opening moment. It gave rise to a great deal of discussion about how much data is shared unthinkingly on a daily basis. Participants refer to sharing data about themselves on social media, with smart speakers, location data on smart phones and when shopping using credit cards and store loyalty cards. For some this was a complete revelation, it is something they feel they surely knew subliminally, but had not thought about it at all until joining the first workshop.

*Until Tuesday, I didn't realise how much data we share without realising, and I think especially big organisations, you have to have a lot of trust in them that your data's not going to end up in places you've not consented it to.*

Participant, UK

[16] Appendix 1: Workshop materials in the participants' workbook

Participants said that the exercise to look at different data sharing settings made them think about some key questions about data systems, particularly those operated by the private sector:

- Which organisations are collecting data?
- Why are people motivated to share data, particularly personal data?
- Where does the data go once collected?
- What is it used for?
- Who will it be shared with?

*We're not sure who's using it and why. I think we're the last people to know who's actually using the data. It's when you get inundated with emails and text messages, then you realise, flipping heck, is that how many people's got my data?*

Participant, Leeds

For many participants in the first dialogue workshops this led to astonishment that people, including themselves, are so trusting of organisations collecting data, particularly when it is not clear how that data will be used. Equally this highlights a further surprise that whilst people seem to be resigned to sharing their data with private sector organisations in order to get goods and services in return; they have demonstrated resistance in the pandemic to sharing data with the NHS. Participants attribute this resistance to the outcome of data sharing in, for example, NHS test and trace applications which could result in a 'ping' requiring self-isolation.

*You saw that with the Track and Trace app. People said, 'We're not downloading it because people are looking at us and tracking where we're going to be.' But Facebook is already doing that better than that app could do.*

Participant, Cardiff

Dialogue speakers included Ed Humpherson the Director General for Regulation at UK Statistics Authority. It is for many participants very reassuring that an organisation exists to challenge misinterpretations of data in the public sphere – but a great surprise. Equally astonishing for many is that organisations that exist to regulate, check and challenge public sector data use have such a low profile in the public consciousness. Many participants said they had not heard of any organisations related to data systems, whether regulatory or data analysis and sharing, before taking part in the dialogue. This leads them to believe that data systems are largely unregulated and there is a 'wild west' feel about data systems and their use.

## 2.3 Early reactions to data use

Participants prepared for their participation in round 2 of the dialogue by considering where they sit on the scale we described as 'Keep it close Kieron' at one end and 'Give it away Greta' at the other. Figure 2.1 shows where participants put themselves on this scale.

*Keep it close Kieron said 'Data about me is private and shouldn't be used beyond its original purpose – even in emergency situations'*

*Give it away Greta said. 'Data about me should be used for planning for and improving services – whatever the situation'*

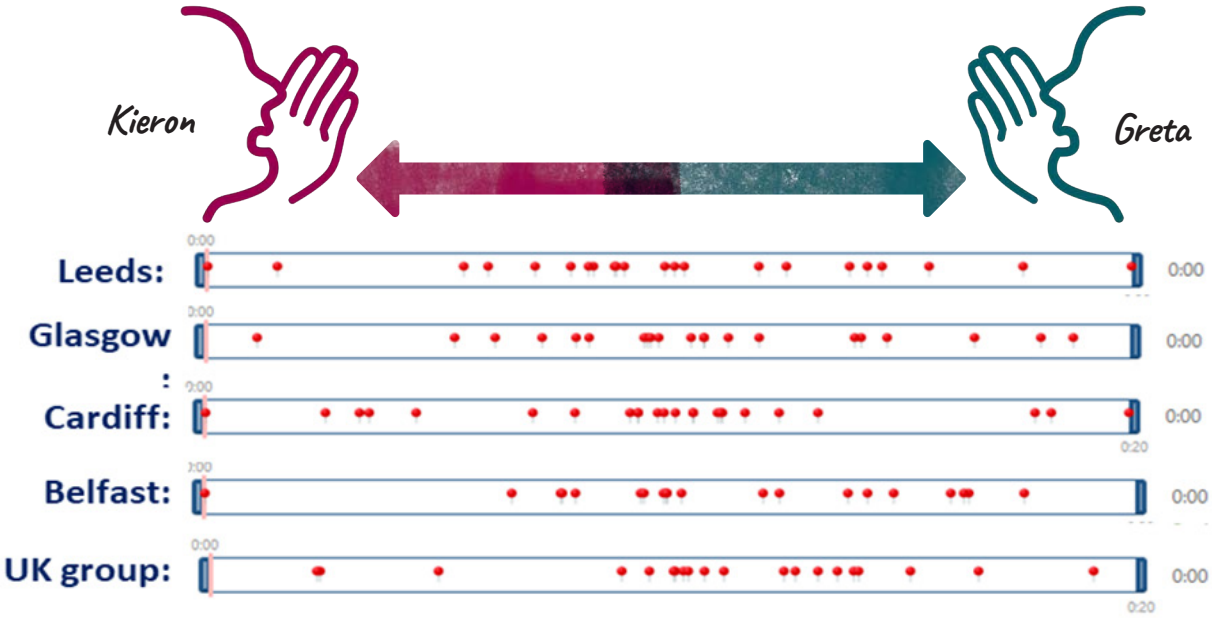



*Figure 2.1: Reactions to data use*

We see that most participants feel they are in the centre of the scale. Many say that they have mixed feelings about data use, or they are 'sitting on the fence'. Others specify the reasons for putting themselves on the middle of the scale, are that:

- There is a balance to be struck between data privacy and security and data being available within reasonable limits
- Data should be used 'correctly' and 'appropriately'
- Acceptable data use includes being clear about who will have access to it and for what purpose

*It is a really hard decision to make as I don't want all my privacy taken away by being constantly monitored but I also understand the importance of shared data as it allows us to prepare for the future.*

Participant, Cardiff

Those who put themselves towards the Kieron end of the scale say they:

- Are concerned that they have no control over how their data is used
- Feel data use can expose people to harmful impacts from data breaches,

*This is due to around 282 million people in 2021 experiencing some sort of data breach. This makes me feel vulnerable to a variety of crimes including, fraud, hacked email account or even unauthorised applications for loans.*

Participant, Glasgow

- Worry that those managing data systems cannot be trusted not to exercise power and control over those whose data is collected
- Do not want their personal data to be misused, e.g. sold to third parties for commercial gain
- Have personal experience of harm which makes them very wary of data sharing (see Lived Experience Box 2)

**Lived Experience Box 2**

*I have personally benefitted from partnership working and sharing of data, however a data breach by a utility company compromised my financial security when my ex-husband was able to set up accounts in my name without my knowledge or permission. I have also had my relocated home address shared with my ex-husband by the land registry without my permission or knowledge which compromised my family's safety and frightened me. In some instances of domestic abuse this could have fatal consequences.*

Participant, online space

Participants who place themselves towards the Greta end of the scale say that:

- It is important to know that data is used for public good to plan and improve public services and emergency responses
- Data is a really valuable resource for innovation in the public sector and this shouldn't be stifled
- It is even more important that data is easily accessible and used in emergency situations

*Data can be used for good things provided it is managed and protected correctly.*

Participant, UK

## 2.4 Defining an emergency situation

Defining emergency situations is important to participants as they develop their understanding of this complex and multi-faceted subject during the dialogue. As a pre-task we asked participants to tell us what they thought an emergency situation requiring data would be, drawing on the Civil Contingencies act 2004[17]. Words which come to the fore when considering emergency situations are gathered together in figure 2.2.


*Figure 2.2: Words participants use to define an emergency situation*

[17] https://www.legislation.gov.uk/ukpga/2004/36/section/1

Participants categorise emergency situations as those which pose a risk and/ or are life threatening. They speak of situations as being unexpected, serious, critical, and where fast, action is required and for which a positive outcome is not certain. Some participants make a distinction between short term emergencies such as floods and medical emergencies, and longer-term crises such as the climate emergency. What brings these together for participants is the urgent need for action whether that action falls over a longer period of time, or needs to be immediate.

They stress the importance of clearly defining time frames, so that society can agree when an emergency is over. For those who are more cautious about data sharing and use, but are more willing for it to be used in emergency situations how an emergency is defined is critical.

*But what are you classing as an emergency? Are you classing it as something that isn't a matter of life and death, or is it something that is really, really severe, in which case data has to be shared to be able to do good and work in protecting people.*

Participant, Leeds

Participants discussed Covid-19 as a clear case in point. Can, or indeed should, society still class the situation with Covid-19 as an emergency two years after the crisis began? Indeed if there is no clarity on the parameters of an emergency will that mean people will make their own assumptions on whether an emergency is over or not?

*What is an emergency to one person might not necessarily be an emergency to another person, so their data might be being used in an emergency situation that they don't necessarily deem an emergency. So it's who's making the decision on the emergency or what the emergency is.*

Participant, Leeds

Participants find it helpful when an authority such as the Met Office, or national and global governmental organisations in a pandemic, bring clarity to what an emergency is and when it is over. This helps society to understand the value of data systems in an emergency and allows it to assess what is appropriate data use in non-emergency situations.

## 2.5 Shifting perceptions of data systems

Some participants as they discussed the topic iteratively over the round 1 and 2 workshops felt their views were shifting. This shift came from hearing from specialists in health data systems, global emergency data use and data regulation and talking through the subject with their colleagues in the small group discussions. Participants said that initially they felt data systems are obscure concepts. They stress that the lack of visibility for public sector data use in emergency and non-emergency situations which means that they, and they assume others across society, are more aware of private sector data systems than public sector data collection and use.

Whilst participants believe there is a lack of awareness across society of public sector data systems, they reference a very high profile for data breaches and misuse in private sector which makes people fearful of all uses of data systems, whether for emergency situations or not.

Many participants shared that they had placed themselves towards the Kieron end of the scale in the early stages of the dialogue, reflecting the concerns they have about data security, privacy and trust. We didn't ask participants to reposition themselves on the scale, but by the end of our time together participants spontaneously shared that they feel they have moved towards Greta on the scale, with a belief that data has a wider public and community benefit, and is important is in emergency situations.

*When you think about it deeper, initially you think, 'I don't want my data sharing,' but when you think about it and you think the impacts that sharing things could have on a whole community, it really makes you think. If you can help a community out of poverty by sharing a bit of data then go ahead, do it. So, I'd be leaning closer now to sharing data, as long as it is relevant.*

Participant, Glasgow

# 3 Engaging with data systems

Fundamental to understanding what helps participants engage with data systems, is understanding how they view data. Throughout the dialogue, participants describe their own data as akin to an individual asset over which they should have rights and control, and which should be protected. At the same time, they acknowledge that data systems represent a collective social investment over the long term which can offer benefits to everyone if people understand their responsibilities and systems are well-planned, maintained and safeguarded[18].

This highlights that governance and trusted regulation of the system is important to people's decisions about participation in the same way that a sense of good stewardship and accountability is important in people's decisions about whether to put their money in the bank, invest it in a pension or donate it to a good cause. Findings in relation to good governance are described in more detail in Chapter 4, while the focus here is on other key issues that help people to decide whether to engage in data systems such as understanding why data is needed, how it will be used and be of benefit, how the answers to these questions can be communicated most effectively, and the importance of trust and inclusion to encourage and enable everyone to participate.

## 3.1 Understanding why data is needed and who will benefit

As something perceived to be 'owned' by the individual and shared through choice, participants want to be sure their data is used for purposes they agree with. The purpose for data collection needs to be very clearly set out in relation to the likely outcomes arising from use of that data. Participants want to know how the data will benefit the individual and/ or society.

Participants describe being more content to provide data when they see the likely outcomes of the data as 'useful', with positive impacts for society and the individual.

*Is it possible to make it beneficial for people to give their data? I know we're not going to pay them to give their data but there could be other benefits to giving your data as long as it's made clear at the time how it will be used and how it's being used. Maybe people would engage better if they knew what it was helping, what the cause was.*

Participant, Glasgow

Examples participants believe demonstrate 'useful' systems where data is being used for public good include data used for:

- Service planning, delivery and improvement
- Identifying where need is greatest in society to enable public funds to be allocated effectively
- Understanding which treatments work best to bring positive health outcomes
- Responding effectively to emergencies (e.g., floods, health crises)

[18] During the dialogue the following definition of data systems was used: inter-connected systems to collect, use, store, access and share data demonstrating information around us and about our world.

In the private sector participants focus on benefits such as:

- Tailoring services to the needs of individual service users
- Providing discounts and special offers to individuals.

*In an emergency response data, then obviously yes, you're going to want to share and help. But I mean if you're just asking for my data for the sake of it then I'm not going to give it, but if you've done enough of an (promotional) campaign and people are aware of why their data needs to be shared and the reasons for it, the knowing it's safe, then I am likely to.*

Participant, UK

People are less willing to provide their data when they feel it could be used for:

- Exploitative purposes such as commercial profit without compensation to the individual sharing their data
- Surveillance of society by government (e.g, 'Big Brother is watching you')
- Justification of actions which they believe to be contrary to the public good (e.g, bank closures which harm local communities and disadvantage people).

*Banks tend to use the data and put it out there to say they can close lots of branches in lots of different communities and that's a moving forward way of digitalising everybody. But I hear and I see lots and lots of people who are massively affected by that. I think that's when, in my opinion, data can be used in a manipulative, wrong way for society because it's forcing things to happen that in many respects, it's not for the greater good of everybody.*

Participant, Leeds

And in Mentimeter responses to the question of how they expect their data to be used, participants noted similar sentiments around the importance of public benefit, and the need to prevent data exploitation with many participants using variations on the phrase:

*Extremely important if used to benefit rather than exploit.*

Participant, Glasgow

Participants also worry about their data being 'sold on' to third parties without their knowledge. They are concerned about collection of data that seems inappropriate for the intended purpose, irrelevant, or involves collection of more data than actually seems necessary.

*It might be very clear to the person who has created the form or the organisation that are asking for these details, but it's not clear to some of us as individuals why the need to know our ethnicity, why they need to know our age.*

Participant, Belfast

A recurrent theme expressed by dialogue participations is their strong sense that data should be collected and used for the defined purposes which are clear and are agreed between those who are sharing the data and those who are using it. Mistrust of data systems arises when this clarity of purpose does not appear to exist.

*I think a trusted system is one that you know what data is explicitly being used for. And I think it's okay that the data can be shared, but a trusted system, you need to understand what data is being shared and where.*

Participant, Cardiff

For some participants erring towards a minimalist approach to data collection is an important principle. They want to know that data systems are considering how to collect only the data that will be useful for the purpose – and no more.

*I think charities, their data needs to be specific to actually the charity they're providing really, I think. It just makes common sense really. The data that they need is specific to their charity. Anything outside that is not really necessary.*

Participant, Leeds

Similarly, in response to a Mentimeter question on data use, similar sentiments were noted including:

*Be used responsibly and strictly for a defined purpose I've previously agreed to.*

Participant, UK

Others highlight that as part of preparedness for emergencies, it is also important to ensure certain basic data is collected and available in the data system prior to the emergency hitting so as to be available when a crisis occurs.

*I think there should be a minimum level of data collected, basic data for emergency and non-emergency [use]. But it doesn't go beyond certain things for non-emergency ones. Just as an example, there is no need for non-emergency information to include detailed medical history. But I think there should be a minimum, basic amount of information to help with the purposes of the data.*

Participant, Belfast

This could include ensuring that data is safely stored and not shared until needed for emergency purposes. This is why good communication is key to explaining the purpose of data collection in ways that make sense, allay fears and potential mistrust, and 'take people along'. We explore participants' ideas about the communication they would find most helpful in section 3.3.

## 3.2 Perspectives on data sharing

Dialogue participants do not distinguish between giving data through primary data collection and subsequent sharing of that data in terms of the basic principles they feel should apply, namely that:

- Data should be shared only for a clear purpose that the individual has agreed to
- That people should know what the intended use of their data is.

*I feel like data is private and it shouldn't really be shared unless it's needed and I'd like to know what it's needed for and I'd like to know exactly when and why it's being used.*

Participant, Cardiff

Additionally, some participants express a hope that if the data is to be used for something other than the purpose for which it was originally given, the individual should be asked for their permission to use their data in this new way.

Although they would normally want to be asked about onward sharing of their data for new purposes, people are willing for their data to be used in emergencies without the need for permission to do so. In some cases, this was limited to situations in which they were told in advance that their data could be used in an emergency, so they were aware of this possible use.

The desire to provide helpful data and parameters in which that may be offered in emergencies was summarised by one participant after an exercise in the online homework space in which people spoke to their friends and family about their views:

*(My friends) were saying that they feel strongly that (data) is not sold on and is used for the purpose it was intended. They were happy for it to be used in an emergency situation if they knew that's why the data was being held.*

Participant, Glasgow

When people are asked to take part in a survey or provide data for a service they want, they play an instrumental role in sharing their data. By contrast, they feel more distanced from the process of onward sharing of data beyond the original data collector and initial purpose for which they gave it and this commonly evoked a sense of loss of control among dialogue participants. They worry about:

- A possible 'snowball effect' in which they share their data for one purpose, and it's used for many other things as well
- Their data being sold on to third parties for someone else's gain;
- That these things may happen without their knowledge.

*I think purpose is quite key, so that it doesn't start off as one thing, and then suddenly snowball into something else and then people have given consent for one thing and it's then suddenly, 'Oh, more and more data's being collected that you didn't know was being collated'.*

Participant, Leeds

Some participants are concerned with the idea of their data being shared in ways they perceived as infringing their privacy and offering no clear benefit to them personally or to society. Examples given by participants include onward sharing of data about driving habits or spending behaviour.

## 3.3 Trust

Much of what we have shared so far about engaging with data systems hinges on trust. We explore this further in this section. The word 'trust' was used 665 times during the dialogue. More often than the word 'Covid' (604). Trust is a fundamental element of a data system for public benefit. This section explores two main areas. It begins with an account of the state of trust, where there is and isn't trust and why. It then looks at the facets of trust that are essential for a data system to have public support.

## 3.3.1 The state of trust

There is more information available, now than ever before. Through social media, news channels, online and print media, investigative journalism, public inquiries and more. Participants talk about current and past abuse, corruption, mistakes and data leaks that in recent years have come to light and the effect this has had on them. The list of examples given by participants during the dialogue is long: the most recent widespread outrage felt about alleged Downing Street parties during the covid-19 lockdown, MPs' second jobs, the Facebook/Cambridge Analytica scandal, data leaks from multi-national companies, the WannaCry ransomware attack on the NHS, mishandling of funds by charities and previous revelations about abuse in religious institutions. Many participants describe themselves as more questioning, more cynical and less trusting as a result of these examples.

*I think there's a lot more cynicism now, but maybe that's a good thing, maybe people have just been woken up to the truth and they're not as trusting as they were before.*

Participant, Leeds

During the dialogue, participants discussed the extent to which they trusted different organisations and roles involved in data systems. The graphic shows the high levels of trust in front line professionals such as health and care professionals, or those dealing with flood situations on the ground; and public/academic experts in data. It also shows lower and very low levels of trust in those with an 'agenda' for the data that could conflict with public good. This includes commercial and party political objectives.


*Figure 3.1: The spectrum of trust*

Some participants say that the pandemic has highlighted a now well established feature of modern life: how we leave digital breadcrumb trails that are being used by organisations. They see the Test & Trace apps as waking people up to data tracking and use.

*The pandemic has highlighted the fact that your information is being shared everywhere. They've always done this. Now it's to do with your health, you're noticing it and you don't want your privacy to be taken for granted.*

Participant, Belfast

Participants stress their view that data scientists and researchers in academia and the public/ NGO sectors as well as front line professionals have no agenda, and no self-interest. This perceived lack of agenda (commercial or political) means, for participants, that these professionals can focus on the design, management and outcomes of a data system for public good without compromise. Their professional integrity – guided by standards that would be professionally disastrous to transgress – is another factor in the trust that participants feel, as is the frontline nature of the work done by, for example, health professionals in the field. Data linked to reality and experience has credibility. It is seen as based in truth rather than speculation.

*Whether it be government or whoever, make policy and they don't actually talk to people who carry this out, who actually deal with this on a day-to-day basis, who are experts, if you like, and maybe their opinions carry more. I would've thought professional in the field, I'd like to think, would be more valued than it sometimes seems is the case.*

Participant, Cardiff

Participant mistrust of data systems is rooted in a sense that they are being exploited and misled. Exploited in that their information is being sold on to organisations without their knowledge or true consent. Some also spoke about psychological tactics deployed by social media companies to increase dwell time on their sites, such as emphasising upsetting content. Participants feel they are being emotionally manipulated to increase social media companies' revenues.

As we have seen some participants feel misled in that the reasons for data collection or sharing aren't clear and that decisions made aren't always based on the data. An example of the latter is the decision to remove the requirement to wear face masks in public spaces. Participants see this is as a bid to restore popularity for a Prime Minister struggling to maintain trust in the face of infringements of Covid-19 restrictions.

*I think when politics comes into it, it's difficult because I feel like decisions are made based on politics, rather than for the good of humans and just general life.*

Participant, Leeds

In Wales political leaders are seen by some participants to be more trusted than their English equivalents because evidence is seen to drive policy making.

*Mark Drakeford, he's following the evidence, every three weeks he'll come out, people have pestered him to move quicker, 'No, we'll see what happens.' So he has formed a trust in what he's telling us, because he's been consistent, he's not doing things on a whim, and, therefore, what he's telling us people are believing.*

Participant, UK

## 3.3.2 The seven facets of trust

Trust in data systems has seven essential elements (figure 3.2) according to participants which must be woven in to have credibility and durability. This section draws out these elements and why they matter to those involved in the dialogue.

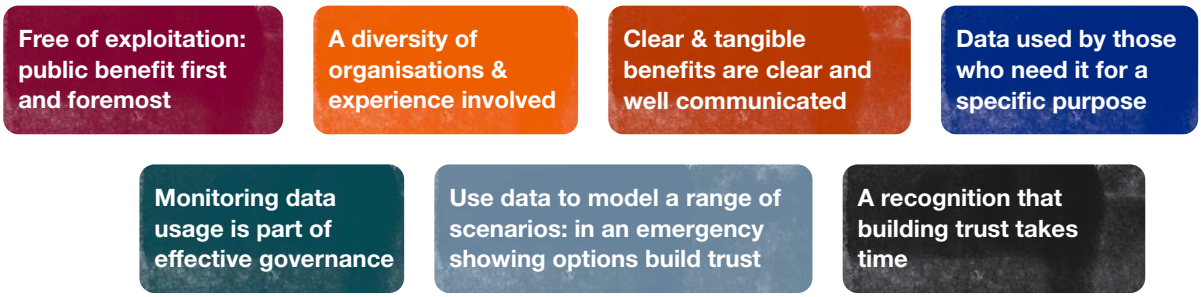



*Figure 3.2: The seven facets of trust*

**1. A data system free of exploitation - financial and political – public benefit first and foremost**

Participants feel the current data environment is dominated by mega-companies such as Metal and Google, where company profit is all. This sense carries over into data systems as a whole: that they are largely for the benefit of the organisations that run them, rather than for the people whose data populates them.

*I think your data's mainly being used for advertising purposes in the west, almost, and it maybe needs to move away from being advertisement based. I think the system that's going to be used is committing to no advertising or making any money off your data, you'll probably feel more confident in it.*

Participant, Glasgow

Participants have less trust in a system that appears to be using their data to try to sell them something, be it a product, a service, a cause or a policy which has been created without use of the evidence e.g. for political ends rather than societal benefit.

**2. A diversity of organisations and expertise to develop and run a trustworthy data system**

Individual organisations, be they government, industry or third sector, are seen as having a vested interest which could, some (or all) of the time, be at odds with what they perceive as 'public good'. Participants look for a diversity of experience and backgrounds from a range of organisations in the planning and delivery of data systems. They feel that such collaboration will lead to those involved acting in trustworthy ways. Particularly with the support of a core resource of expertise in data science and the backing of professional bodies such as the Royal Society.

*Not just one area like the government or whatever to design and build it but people inputting from different areas.*

Participant, Glasgow

More emotional intelligence in higher places. This is a newly trusted quality and it comes from females and other minorities, you might say. So, more females and more emotional intelligence to be used when making decisions about data. Participant, Belfast

**3. Benefits of the data system are clear and tangible**

As we have seen a trustworthy data system is one which brings a clear and tangible benefit to society and the individual. This benefit outweighs everything else. Participants talk about the simple benefit of exchanging data with your doctor: you tell them your symptoms, you receive advice or a prescription. They recognise that benefits and trust are far easier to identify and establish on an individual basis.

*We need to know the benefits of what the system is... we talked about trustworthy before, but I think that's, for me, that's what an effective data system would be, something that's trustworthy and knowing the benefits of what it's going to give us.*

Participant, Leeds

**4. Data used by the people and organisations that need it for a specific purpose**

A trusted system is one where the people that need to access the data can access it and it's not accessible for people who don't need the data. In the commercial sector particularly, participants feel that their data is everywhere, used by everyone and anyone. In a data system for emergency and non-emergency uses, they want to know that only those who need to know, know. An example of an emergency use is in a flood where the fire brigade would be rapidly informed of the location of vulnerable households to prioritise their rescue and safety. One participant drew on a military analogy to illustrate the point:

*The captain, he saw everything. The guy under him is a lieutenant. He only saw what he needed to see. Then sergeant will only see what, so although they all were a part of the system, the system only allowed certain people to have certain, you could only see so much according to what their security clearance was.*

Participant, Glasgow

**5. Monitoring data usage as part of effective governance**

Whilst there may be rules or guidance on who has access to the data and how its used, participants believe a trustworthy data system should have a built-in capacity to monitor use. There are concerns that some organisations who should be accessing the data aren't and vice versa. There are also concerns that selective use of data may be happening. This could lead to policies, services or actions that are based on a partial understanding of a situation. This monitoring could be used as part of the governance of the system for both oversight and transparency.

*A trusted system would definitely be something that reflects the accuracy and the honesty of the information being collected. So, if the information says, A, B, C and D, then the data is A, B, C, and D and it is moved onto the body who is going to use it as A, B, C, and D, and not just A or just A and B, and forget about C and D. So, honesty in collection. Honesty in processing. Honesty in passing on the information.*

Participant, Belfast

**6. A data system that models a range of scenarios – presenting options builds trust**

How forecasts are presented, particularly in an emergency situation, is important for trust. For some participants data that is predicting a future outcome is more credible if options are presented. Some felt that during the pandemic, they were being warned of worst-case scenarios that didn't come to pass. They felt this eroded trust in data systems. If options are shared, people could have a better appreciation of both the uncertainty inherent in the emergency and also the range of outcomes.

*We keep getting more data, we keep getting more symptoms, we keep getting told to do x y and z because the data says this, but the models are wrong. So, SAGE keeps producing models that make no correlation to my life. We constantly seem to be given the worst case and if that doesn't come off we lose faith in what we are being told.*

Participant, Cardiff

**7. Building trust takes time**

According to participants across all the dialogue groups trust is hard won and easily lost. Participants believe that those developing future data systems should allow for the fact that it is human nature to distrust something new and unfamiliar.

*I don't think you can really trust a system until you've used it for a while. I think you've got to be sceptical of new things, otherwise if you trust everything at the drop of a hat, there needs to be some sort of cautiousness exercise when trying out these new things.*

Participant, Leeds

This chimes with trust felt for data scientists, who are seen as taking the long view in their analysis of data and ensuring it is robust. This contrasts with politicians making off-the cuff decisions for short-term political fixes.

## 3.4 Transparency

Transparency and trust are frequently mentioned in the same breath by participants for example in the labyrinthine range of places your data can go to, the different uses that can be made of your data, the vast numbers of data points that are being collected: this landscape of complexity contributes to a strong desire for data systems to work harder to design in transparency as they are developed.

Participants foresee a widening divide between those in positions of power when it comes to data systems and people who rely on social media for their information. There are fears that echo chambers that amplify data misuse and drown out the benefits of data will draw more people in and harden attitudes against data use.

*There needs to be a high level of information that is relatively easy to find with regards to what data's being used, who is using it, why is it being used and the limitations to its use. I think one of the good things about the pandemic with regards to data has been the updates from the health professionals, where those briefings give very accessible information.*

Participant, Cardiff

As well as highlighting the risk of data scepticism, dialogue discussions also raise the opportunity for transparency to build on a growing awareness of data. This is about emphasising the value of data and the positive difference it can make to society.

*People are more aware of the value of their own data and conscious of how its collected and used. I think a successful data system would lean into this and become more transparent.*

Participant, Belfast

Many participants reflect on the fact that websites offer the chance to learn more about how your data is stored and used but very few take up this offer because it is impractical and too time consuming. They feel the very practical barriers to transparency in data use, primarily the 'thirty page terms and conditions' for websites and apps, should be addressed. Dense and lengthy terms and conditions statements are seen as part of the lack of transparency, particularly in commercial data systems. This can lead to people agreeing to things about which they unclear in order to gain access to something else they value like an app or website.

Participants suggest various ways of making it clearer what data is being used for and how. These include visual methods such as a specific colour denoting use of location data, or infographics or short videos to help explain how data is used on websites when you enter your details. A further suggestion was for a set standard for how terms and conditions are shared and what's in them.  They feel that familiarity with a simple format could build awareness across society of data systems.

A clear and simple account of why data is being collected is seen as important to data systems that operate in an emergency.

*The flood one to me is a perfect example, the reason we're going to take this data off you is because we need to drop this off, we need to let you know about these things, then we can come and get you or we can drop this off when the emergency's happening and then afterwards we can come and ask you how it all went, do you need anything else.*

Participant, Leeds

A lack of understanding of what the data collected actually achieves is seen as a problem for future trust in and engagement with data systems. There is a strong perception that once data is gathered, those who use don't share the positive outcomes that have come from its use. The consequences of this includes missed opportunities to build public knowledge and an increase in public suspicion and mistrust.

*It's like, people think, 'What are you going to actually do with all this, is it just going to sit there?' But giving them reasons for what the outcome is, and what the future is for it. I think people would be even more willing to give data.*

Participant, Belfast

## 3.5 Inclusive data systems

Making data systems inclusive is a key priority for participants. They discussed who might be affected by data systems that are not inclusive, the negative impact they can have on peoples' lives, and ideas for how systems can be made more inclusive.

### 3.5.1 Who might be affected?

When considering who might be affected by data use participants immediately think about people in society who may face barriers to accessing data systems, particularly those who might be more at risk of harm during an emergency and people who are already marginalised. They reflect that we live in a world that is digital by default and they worry that some may be digitally excluded or find it hard to access systems that are not designed inclusively.

They describe a wide range of access challenges that might be faced by these groups of people as being:

- Older people who did not grow up in a digital world and may not have access to the Internet and smart devices, and who may have no or low digital skills, who struggle to access services
- Disabled people, whether physical, sensory or cognitive, may have difficulties using data systems if they have not been designed with accessibility in mind
- People with learning difficulties may need extra support to access systems
- People whose first language is not English may struggle to use data systems and understand the messages from them, such as alerts during an emergency
- People who are neuro-diverse: participants, including those who are neuro-diverse, would value system design to be approached from a diversity of perspectives rather than an exclusively neuro-typical one
- People who don't have a fixed home or official documentation, such as people who are homeless and asylum seekers, have difficulty accessing services for which they can only be registered if they have a permanent address
- People on low incomes may find it hard to pay for digital devices and services, such as smartphones and laptops, and therefore struggle to access services.
- People with low literacy skills who are only offered online mechanisms to access services but may feel uncomfortable explaining their difficulties.
- People living in areas with poor broadband connection or mobile signal, such as rural areas, who have difficulties accessing online data systems.
- People who do not have the motivation or skills to use online data systems.

Participants describe a number of ways these groups may be impacted. Some participants specifically refer to minoritised ethnic people in the context of inclusive and trusted data systems. In addition to accessibility issues for people who do not have English as a first language, there is concern that people may not feel comfortable sharing their data, particularly if the purpose of the system has not been clearly explained.

*Yes. When we hear locally a lot of people, say for example, they don't want information to be kept or collected and things like that. So, when that message is conveyed to ethnic minority groups, it's more or less the same. They are not sure 100%, or do not have the perfect understanding of how their information is going to be used and things like that.*

Participant, Belfast

A few are concerned that this will result in data bias, as perspectives of minoritised ethnic groups, and other groups whose data is missing, will be under-represented.

## 3.5.2 Impacts of data systems that are not inclusive

Participants articulate a range of impacts that data systems not designed with inclusion and diversity of human needs in mind can have on people's lives. There is a concern that people who are already struggling or at risk from harm in society may be further marginalised and existing inequalities exacerbated in certain situations. These include those set out in figure 3.4


*Figure 3.4: Potential areas of inequality*

A major concern for many participants is that people who are who are at risk in society because they are, for example, people with long-term health conditions, disabled people, learning disabled people, lower income families, or digitally excluded, will find it difficult to access vital services, such as health care and banking. They also worry that people who are not accounted for in data systems will be further disadvantaged because they will not be informed of services that are available to them (Lived Experience Box 3).

**Lived Experience Box 3**

*There's two groups that would struggle and that's learning disabled people and autistic people particularly and indeed from my lived experience with my brother the carers may not be aware of what information is held about my brother. If I wasn't around what understanding do they have about my brother's legality in terms of understanding it? There's lots of other acts that go into that around mental capacity, but I can give you a practical example as I've had to get involved because the carers aren't aware of the data that my brother's GP holds. I've had to get involved to try and tease that out so that they can have a better understanding of providing support to my brother.*

Participant, UK

Participants express concern that people without a fixed address or formal documentation, such as those who are homeless and asylum seekers, will be missing from public data systems and therefore unable to access vital public services, such as health care.

*The homeless, they don't have a record of their existence. Then they're not going to benefit from all the things that having a home, being on the electoral register, which is a data system for a lot of the other things, the benefits, existing to collect benefits. Equally refugees, I think, if they have no register of being here. And you can't get electric or bank accounts or things like that if you don't have a home I believe. Can't get a GP, can't get a dentist.*

Participant, Belfast

One participant provided an insight into the difficulties people with low literacy skills face trying to use public services that are accessed via online data systems, this is shared in Lived Experience Box 4.

**Lived Experience Box 4**

*I've actually met someone in this situation. He just hadn't learned to read or write. Smart enough person as I talk, right, so he thought he had Covid and he went to the doctors and was told, 'No, you can't come in here. You're going to have to go and just download that app.' Right, number 1, he can't afford the Internet so there's a price thing here. But number 2, even if he could, he couldn't read them. But he doesn't want to actually own up to that, and I can understand that the shame that comes from something that's not his fault, that for whatever reason he didn't actually learn. So, he was left there knowing what he should do, but not knowing how to go and do it. It was awful for him.*

Participant, Glasgow

Many participants are concerned that people who do not have access to digital devices may be difficult to contact in an emergency and not receive important alerts. They were particularly concerned about the most vulnerable in society, such as the elderly.

*Thinking about people, like older people who don't access computers or things like for an announcement of how they're going to know there's a flood warning, yes what to do in that situation. Not everybody is contactable, are they?*

Participant, Glasgow

Participants also worry that people who do not speak English as their first language might misunderstand important alerts during an emergency:

*People where English is not their first language, so this can create problems. Things like that where they may understand that there's a problem but they don't necessarily get that something important has to happen now and we can't wait around. In the case of flooding, you have to move.*

Participant, Cardiff

A few participants comment on the challenge of making data systems both accessible and safe, particularly for people who may be more vulnerable to cybercrime. This might be because they are unused to digital equipment, or from a generation that did not grow up with the Internet, and as such have less knowledge about online harms.

*I do worry about older people accessing the internet because they're not as data savvy as the younger generation and they're more open to be used fraudulently so I do worry about the older generation, especially nowadays where the government is pushing people to do most of the stuff online.*

Participant, UK

Participants worry about the impact of missing data and discuss why this might be happening. In addition to the impact this has on individuals who can't access services, a few comment that it also results in data bias. This suggests an underlying concern that data sets will not be representative of the people they are meant to serve, as sections of society, and the perspectives they bring, are missing from the data system.

A few people express concern about discrimination in data systems.  Examples given include racial discrimination in facial recognition technology and gender discrimination in online job advertising.

## 3.6 Ideal hallmarks of inclusive data systems

When asked what could be done to make data systems more inclusive, participants articulate a range of principles and features outlined below and summarised in figure 3.5. Participants were not asked to work out how to operationalise these principles, they are therefore expressed as an ideal situation.

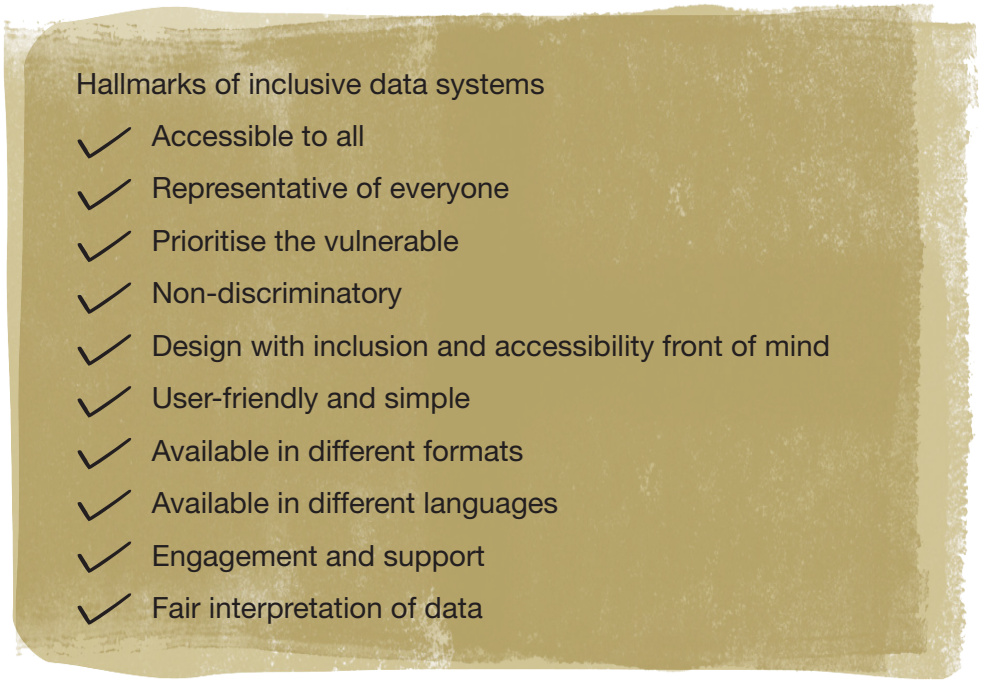



*Figure 3.5: Hallmarks of inclusive data systems*

**Accessible to all**

Participants feel strongly that data systems need to be accessible to all and designed in a way that brings equity to all in society. This means prioritising the digitally excluded, more vulnerable members of society and communities who are marginalised.

**Representative of everyone**

Participants argue that data systems should be inclusive to everyone. For some, this means including everyone in the UK. Others focus on inclusion of those more exposed to risk, marginalised groups and those who are digitally excluded. A few people argue that data systems should be global, whilst being concerned about affordability for developing countries. For others, inclusive means data sets that are representative of the population they intend to serve, which relates to the system's purpose. Some talk about the need for fair representation of everyone in society, for example, according to demographics.

**Prioritise the people who are at more risk of harm in society**

Many participants feel that data systems should prioritise vulnerable people. They argue it is key in emergency situations, such as a flooding event, given people who are vulnerable need contacting quickly. Data systems need to know who is most at risk in an emergency situation in a community and use multiple channels to reach them, including online and offline.

*Our duty as society is to protect the vulnerable, whatever their circumstances are. They need to be the top of the tree to make sure they're looked after. If the system is good or bad, it would still struggle to identify these. That's where you need to get arrows pointing, to these people.*

Participant, Glasgow

**Design with inclusion and accessibility front of mind**

Many feel that data systems need to be designed with inclusion and accessibility front-of-mind. Recommendations made by participants to achieve this includes:

- Involving a diversity of people in the design of data systems
- Standardising the design of data systems so that it is easier to move from one to another
- Having dedicated and specialist teams who are responsible for system accessibility.

Here is an example of a participant talking about inclusive design for neuro-divergent people and the value of working with a diversity of people:

*Neurodiverse, very broad generalisation, will have brains that work in a slightly different way, that won't think in the same process, the same flowchart systems that the designers of these systems tend to use. So, they need to be a little bit more user friendly. Systems are designed by neuro-typical. Not the neuro-diverse. The world just thinks that everybody thinks the same.*

Participant, Cardiff

**User friendly**

Participants want to achieve data systems where, whatever a person's digital proficiency level is, they are able to comfortably engage with the system at the data collection point or once the outcomes of the data use are communicated to wider society.

**Available in different languages**

This includes a point made by a number of participants who talk about the importance of making data systems available in different languages, so that those who do not have English as a first language are not excluded.

*I suppose if the data systems are [inclusive], the developers can consider having them in different languages, for example, this can give an opportunity to develop the system because it will have a wider range of people from ethnic minority backgrounds to contribute to the data systems themselves.*

Participant, Leeds

**Available in different formats**

Many participants recommend that for data systems and their outputs to be inclusive, they must be available in different formats so everyone can engage with them.

*But it also goes back to those disadvantaged, how are they able to interpret the data? So, having it in different formats might make it a bit more useful for them.*

Participant, UK

Recommendations include making systems available both online and offline, using a variety of media including video and infographics, and using formats that are suitable for different disabilities.

**Non-discriminatory**

Participants emphasise the importance of data systems being non-discriminatory. This relates to a range of issues including accessibility, preventing bias in systems, and attention to how the outputs of data systems are interpreted and communicated. A few specifically comment on the importance of safeguarding people with protected characteristics, so that they are not negatively affected by data that is being collected.

**Engagement and support to use data systems**

A few participants suggest that engagement and support is provided alongside data systems to ensure that everyone is reached, particularly those who are digitally excluded or don't feel comfortable engaging with formal channels. A few participants recommend working with trusted local organisations and individuals. A few note that effective engagement that reaches those who are underrepresented will help to reduce bias in data sets and help people to take advantage of public services. However, one person comments that people shouldn't feel bullied to engage in data systems.

*It's better to encourage people to give their data but how we would even go about that? Making it with simplicity without feeling we're- bullied is the wrong word, sort of bullied into it.*

Participant, Belfast

**Fair interpretation of data system outputs**

Participants widely emphasise the importance of careful data interpretation and the fair presentation of data findings. An example was given of how data which showed that Covid was spreading faster in low-income areas was interpreted - it could either be read as people living in lower income areas are more likely to be interacting regularly with others because of their jobs or that, 'people in this area are disobeying the rules.'

*I think someone mentioned lower income areas, there's a social stigma attached to them when it goes out on the news that Covid is in those areas, people can think all sorts. Whereas if you have a very good data system, which is fair and considers everything, then they'll know that, maybe, that data cannot be given out in isolation. It has to be attached to a context or it has to be somebody else attached to it to be able to understand the full picture of what that stat shows.*

Participant, Leeds

## 3.7 Data privacy

### 3.7.1 Balancing the needs of individuals with the needs of society

Participants articulate how the digital landscape has transformed the world we live in and there is an acceptance that data systems are an integral part of everyday life.

*Because if you had probably said years ago that every company would know so much on us and that your phone is listening to your private conversations in your house. It's crazy, but what do we do? None of us want to give up our phones. None of us want to stop doing what we're doing. So it's just how it is now.*

Participant, Belfast

Whilst accepting this digital world, participants' views differ on how cautious or incautious they are about sharing their data. For some, their perspectives oscillated during the course of the dialogue, as they weighed up the pros and cons of data systems. This was highlighted during discussions about their views, and the views of friends and family, on our Kieron-Greta scale.

| Keep it close Kieron | Central point | Give it away Greta |
|---|---|---|
| Every person has a list of human rights and one of those rights is your right to privacy. Me, personally, I'm quite a private person.. I would be quite sceptical of handing personal data over.<br>Participant, Belfast | I put myself smack bang in the middle and it's because it depends on exactly what data we're talking about. Obviously, if it comes to bank details, I want to stay as private as possible. Whereas other data.. flood warnings and stuff last session, the fact that gets used to going to help with preventative measures and all that.<br>Participant, Cardiff | Whereas those I spoke to, it was just over lunch at work, those who were happy to share their data were coming from the other side of the fence where they have nothing to hide, so they were a bit more willing to share.<br>Participant, Belfast |

Many participants see a distinction between different types of data, describing some personal data as "sacred", such as medical, financial and health data. Data which is more administrative in nature and has therefore been de-identified is less of a cause for concern.

Given the experience of the Covid-19 pandemic, participants feel there is a balance to be made between an individual's right to privacy and the benefits of data sharing for society.

*Can I just say the one thing for me is it's not just about the privacy but it's also, I think in national pandemics we do have to trade-off some of our civil liberties.*

Participant, UK

They also reflect on the challenge of finding the right balance between individual freedom and the public good, when peoples' feelings about data sharing differ.

*The reality of the situation is you should report it, but you may think, well, that's not something that I'm obliged to report, it goes against my privacy rights, and everyone will have different levels of what is acceptable. How do you balance that whilst making something that's functioning for society as a whole?*

Participant, Cardiff

## 3.7.2 Important elements of data privacy

Participants see a number of important elements of data privacy. These elements which they feel data systems need to take account of are summarised in figure 3.6.

Important elements of data privacy

- ✓ Personal data should be private unless de-identified
- ✓ Choice what you opt in to / opt out of
- ✓ Right to remove data
- ✓ A right to know what data is held
- ✓ A future where you own your own data
- ✓ Data privacy still matters in emergency situations

*Figure 3.6: Important elements of data privacy*

**Personal data should be private unless de-identified**

Many participants feel strongly that personal identifiable data should be completely private and confidential, unless it has been anonymised or it is being used for a person's benefit, such as medical records or contact details in an emergency.

*I just think personal data should remain personal or anonymised always, and should not be shared without your explicit consent. If you take the health service, you would expect your GP to share data with your consultant or whoever else you're seeing...*

Participant, UK

Reasons participants give for de-identifying data include:

- People are more likely to participate in data systems
- People are more likely to be honest when inputting data
- A more robust data set will be produced if more people are willing for their data to be included
- Preventing personal and sensitive identifiable data from falling into the wrong hands
- Data can be shared across borders more easily for the public good

**Choice what you opt in to / opt out of**

Participants argue that data systems should provide choice over what data is held and how it is used, given peoples' attitudes towards sharing personal data varies.

You could say I'm happy for X, Y and Z to be shared and I'm not happy for A, B and C to be shared. Participant, UK

Although this is what participants want, some reflect on situations where data is gathered on individuals without them consenting or having a choice whether to opt in, such as credit agencies and data relating to employment law.

Because we're talking about opting in, volunteering information, but there are certain cases where you have no control over it, over where your data goes, i.e. the credit reference agencies. Participant, UK

**Right to remove data**

The ability to have your data removed from a data system at some future point was also considered an important element of data privacy.

*The ability to remove your data as well is only recently becoming a more popular thing, where people are able to get in touch with companies and ask to be removed completely.*

Participant, Cardiff

**A right to know what data is held**

There is a sense that data privacy goes hand in hand with data transparency and the right to know what is being held. There is a sense you can't keep data private if you don't know what personal data is held on a system, and there is often surprise how much is held, as is shown in Lived Experience Box 5.

**Lived Experience Box 5**

*I got a surprise the other day. I was waiting on a Universal Credit application, and I was speaking to a girl after filling in a lot of stuff online, which was totally confusing, and when I was speaking to her, she said, 'Oh yes, we see that you got paid a wage from last month.' and I'd never declared anything about that. I'd never said anything about it. Just that she knew. I mean, you give them your national insurance number, your phone number, your email address and then she asked me for three previous addresses and stuff like that and then just a general chat. She said, 'Yes and I see.' and she told me exactly how much I'd got paid from a month ago wages, which I'd never mentioned.*

Participant, Glasgow

**A future where you own your own data**

Some participants envision a future where people hold their own data and dictate what happens to it, for example who you sell your information to. One person suggested blockchain as an example:

*A blockchain is like a ledger, basically. At the minute, it's being used for cryptocurrencies and stuff like that. I can see a future where you would maybe choose to put your information onto a blockchain that you'd own. Whether that's personal information, maybe even DNA, you would own that data yourself and farm it out as you chose. That's an opportunity I can see on a data system in the future. Whether it happens or not, who knows.*

Participant, Belfast

**Data privacy still matters in emergency situations**

Although there is greater readiness to share data in an emergency, participants still raise issues and concerns about data privacy. One participant commented that consent may not be possible, given the government can use 'Control of Patient Information (COPI) notices' to obtain data without a person's consent. Another person explained how uncomfortable they had felt being asked to provide someone else's personal data as part of Test & Trace.

*Just because it's at the front of my mind just now, which I think is one of the most uncomfortable bits about the data gathering (for Test & Trace), it's you personally giving someone else's data. So, I've had it twice, so twice I've had to give contacts, and I've also known people that have been very angry that their names have been given as a contact by other people.*

Participant, Glasgow

# 4 What makes a resilient and effective data system?

During the dialogue discussions, we asked participants to describe what they would expect to see in an effective data system. With surprising consistency across groups, they highlight a range of features which they feel should be integrated into data systems as well as to things needed to help the system function well and be resilient.

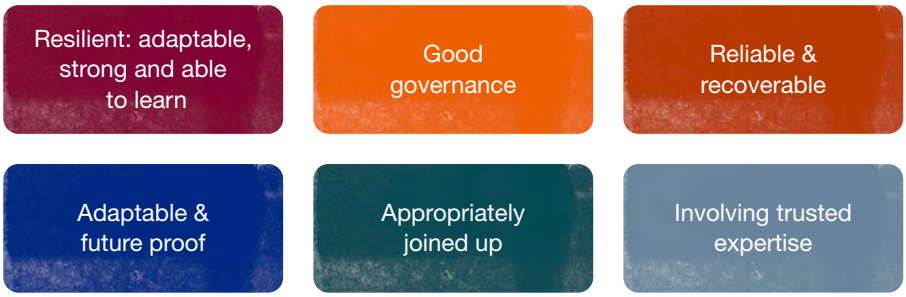



*Figure 4.1: Headline features of effective and resilient data systems*

## 4.1 Resilient data systems

Participants understand 'resilience' in a variety of ways and reflected on what this meant to them individually in a pre-round 2 task in the online homework space, as well as sharing their ideas together during the dialogue discussions. Their reflections draw on personal experiences of resilience and how that might apply in the context of a data system. Some key ideas about what a resilient data system should be like are highlighted in Table 1, along with words people use to describe them.

Table 1

| Important elements of a 'resilient' system | Described with words like... |
|---|---|
| Ability to adapt quickly | 'Bouncing back'<br>'Adaptable'<br>'Flexible'<br>'Reactive'<br>Able to 'recover' |
| Strong | 'Robust'<br>'Watertight'<br>'Able to overcome'<br>Able to 'persevere'<br>'Takes a licking and keeps on ticking'<br>Able to 'survive some knocks' |
| Learning | 'Evolving'<br>'Innovation'<br>'A system that improves itself' |

### 4.1.1 Ability to adapt

Adapting quickly and effectively to challenges is described by some participants as the ability to 'recover' and return to a previous state before the challenge occurred. In relation to data systems, examples shared by participants include being able to recover data that has been lost or corrupted.

*It's got to be able to continue doing what it does...A resilient data system is supposed to keep going no matter what happens. The whole system won't crash.*

Participant, Leeds

Additionally, some participants describe adapting quickly with reference to flexibility in response to the changing demands of new situations. This may involve keeping pace with technological changes, collecting the right data when it's needed, finding 'work-arounds' in challenging situations, and having contingencies in place developed by testing a range of scenarios.

### 4.1.2 Strength in the system

People focus on strength as an important component of an effective and resilient data system. This is important for them in terms of data security and integrity, where they highlight the need for robust defence from cyber-attacks, hackers and data breaches. Strength is equally important in relation to maintaining system integrity under stress. The latter reflects a priority participants place on ensuring that systems are 'built to survive the worst case scenarios' and 'persevere through great challenges and stresses', some of which were discussed in the dialogue sessions (e.g. the Covid-19 pandemic and climate change) and others which were suggested by participants (e.g. electricity outages, and earthquakes). In relation to data systems, some note that while we must aim for a system that can 'survive knocks', it may be unrealistic to expect any system to be completely 'bulletproof'.

*With regard to resilient data systems, data systems need to be secure and able to continue working despite outside agents attempting to either break-in or to break it. Data systems also need to be resilient to external shocks, the infrastructure that holds the data, and other things such as natural disasters. That's a very extreme example, back-ups and systems built in a way that will survive through worst case scenarios.*

Participant, Cardiff

### 4.1.3 A learning system

Learning is seen as another key element of resilience in terms of responding positively to challenges and finding ways to carry on despite setbacks, possibly better than before. Participants note the importance of learning lessons from the past, as well as in identifying and preventing future problems. We reflect further on the subject of data systems as learning processes in section 5.4.

*For me, the resilience came from experience, so having been in a situation where your power goes off, and you've got no candles in the house, no matches, no gas stove to cook. Having been through that experience, you then know what to have. I think that could be applied to the data.*

Participant, Glasgow

Participants suggest four specific learning tools which they believe can be embedded into any data system to protect the resilience of the data system itself; the resilience of data in the system; and to develop effective approaches to managing the system to achieve greater resilience.

1. **Stress tests:** Participants feel it's very important that data systems can withstand a variety of stresses and suggest that tests should be carried out focusing on a range of possible risks. This was described by some as 'war games to check readiness in different scenarios' to be sure of a system's robustness. The aim would be to look at likely areas of weakness and reinforce them before they come under stress in real situations.

*I think one of the main key points was around breaking the system, in a testing live environment, so that you have the opportunity to make sure that everything is robust and thought of in case anything goes wrong, before it actually goes out there into the wider public.*

Participant, Leeds

2. **Future proofing:** participants emphasise the need to anticipate likely challenges ahead and ensure that data is available on relevant topics. New and up to date data will be required as well as historical data which helps to place current events in context and forecast possible future scenarios. They link this to using this future proofed system to forward plan, identifying the goals the system must meet to be 'totally organised and prepared' for the future. Some also suggest looking across the UK data system and at other countries to anticipate what might be needed in a 'joined up' way, learning lessons from others' experiences.

*Yes, this would be in all scenarios and having the data that would be really important to show the past and present impact of an emergency to enable us to learn from it. Therefore, we could actually put new things into place and try and find solutions that would stop us from facing certain things again. What we did right and what we did wrong.*

Participant, Glasgow

3. **Innovation:** finding creative ways to make full use of existing data, considering new data sources such as 'big data', and 'keeping one step ahead' by anticipating future data needs.

*You keep updating that way, mixing 'innovation' with the 'learns' and 'improves'... I think without innovation, you wouldn't be able to have safe, secure, and recoverable. You need to be innovative to speed things up and be resilient.*

Participant, Cardiff

4. **Learning from expert and vetted staff:** the importance of having the best expertise available to support learning, innovation and the technical development of the data system is important to participants. This means ensuring people with the right knowledge and skills are available to support the system, both on a daily basis and in emergencies. They also note the importance of ensuring that people working with data are fully vetted on recruitment, and monitored once in post, to ensure that data remains safe.

## 4.2 The right data at the right time

Thinking about the data in the system, participants identify three attributes (figure 4.1) they see as crucial to ensuring the right data is available at the right time. This reflects an awareness of the need for both routine or administrative data, normally required on an ongoing basis, and new or different data that may be needed in future, including in emergency situations.

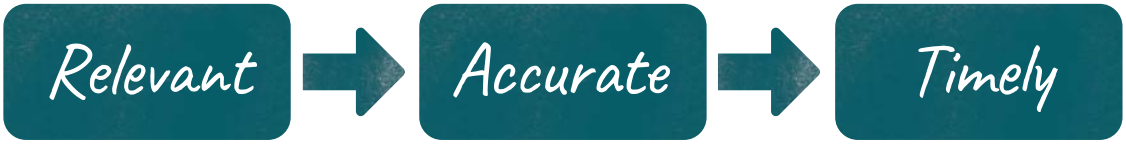



*Figure 4.2: Three critical attributes of the data in the system*

Relevance is seen as an important ingredient of the 'right data'. For participants the system should include data covering important issues for society such as how current events impact people's lives. They recognise that this isn't always easy when it is unclear what data will be essential in an unforeseen emergency situation.

*I think a system to be effective would need to have the right information, the right data in it. But I mean, of course that's difficult because you don't really know what it's going to be used for, you don't really know what you're going to need.*

Participant, UK

Accuracy is also seen as fundamental and key to a trusted data system. Participants think this should include consideration of the reliability and verifiability of the data as well as how representative it is.

*I also think, for having a resilient data system and a hallmark of it would be having accurate data. I think that's really important when it's going to be resilient because you can have all the data you like, but if it's not accurate, it's no use to you.*

Participant, Belfast

Additionally, they describe real world harms that can result from inaccurate, imprecise or missing data in global emergencies such as recurring heat waves caused by climate change, including bad and ill-informed decision making.

*Well, if the data's inaccurate you're going to get farmers making the wrong decisions to either sow their crops, water their crops, harvest their crops at the wrong times, therefore they're going to lose money. If that data's wrong, crops will die.*

Participant, Cardiff

and personal emergencies such as those caused by high levels of deprivation and neglect,

*People fall through the net through no fault of their own, like kids that are deprived of care. They basically end up homeless at 16.*

Participant, Glasgow

Timeliness is the third key issue participants commonly identify as contributing to data quality. Many participants equate how fast data can be accessed from the system in an emergency situation as critical to ensuring it is reliable. This includes being able to transmit data across the country, and the world, in a pandemic emergency so that there is real time learning in the country and globally to inform how to address key issues in a timely fashion.

They think that data should be available in 'real time' ideally, to provide an accurate snapshot when needed. This is one participant's view when thinking what data would be needed and verified if you were in the role of a policy maker,

*Governments chop and change after elections. So is the data in place? I need to make sure that for the policy I'm implementing, I've got the data from the people I need it from and again, is it very quick to get it if I haven't? It needs to be very up to date. And are there any missing elements? The data's got to be complete.*

Participant, Leeds

They also note that data should be regularly updated and reviewed to ensure its ongoing relevance and accuracy as old data may no longer provide a true picture of current circumstances and is also less helpful in emergency situations.

*Looking from a management point of view, it was about how complete the data is, that you're not just taking the data at one snapshot of time, that you are constantly updating and reviewing that data to make sure if there are people who previously were in one category and then fall into another, that is kept up with in the dataset.*

Participant, UK

Although current data is important, participants also recognise the relevance of historical data showing trends in helping to place today's data in context as well as to enable learning from the past.

## 4.3 Good governance

As evidenced by the wide range of questions people have about data systems, good governance matters to people, and can be a key pillar for inspiring or undermining trust. The importance of good governance is also linked to the belief that 'prevention is better than cure', a phrase often repeated throughout the dialogues.

Participants think that good governance should be key to preventing or reducing data harms.

*Even if they rectify it, they've still got it wrong. That will be in people's heads for a long time anyway. I guess, that probably links back to punishment, doesn't it? Or how do you stop them doing it in the first place? That's reactive, isn't it- dealing with it after it's happened. But what do they do to try and make sure that it doesn't happen in the first place?*

Participant, Glasgow

To promote greater trust in data and the data system generally and avoid misinformation, they suggest the right governance must be in place to ensure that rules and standards are applied fairly, consistently and transparently.

Linked to this, people want clear information about systems currently in place to regulate the data systems in the UK. They want reassurance that the full range of actors in the UK data system (not just public sector bodies) are regulated for example social media platforms and private businesses.

*I just think it can't be the responsibility of the authorities. It should be more on the social media companies and the platforms themselves, because that's where all this misinformation is spreading.*

Participant, UK

*I know banks get a slap on the wrist when they money launder and I feel like something needs to be similarly in place for people laundering your data.*

Participant, Belfast

Additionally, participants want to know that safeguarding measures are in place for people's data and feel strongly that the UK should have a more effective regulatory system with real authority, accountability, transparency and 'teeth' to ensure that those misusing or misrepresenting data or who are responsible for data breaches are penalised and potentially excluded from the system. They suggest that an independent (non-governmental) body with power to monitor and enforce standards and compliance across the whole system would be beneficial, noting that 'calling out powers alone are essentially useless' without the authority to enforce.

identify a range of different aspects of good governance as particularly important to an effective, resilient data system. Good governance can help people to trust the system and entrust their data to it and together they provide a key foundation on which everything else rests. The points that participants highlight as the important ingredients of good governance are set out in table 2.

Table 2

| Important elements of good governance | Described by participants as... |
|---|---|
| Independence: to ensure unbiased application and enforcement of the rules across the system that institutions that are rooted in it, including the government, cannot provide. | I think where it says public bodies and government given the power to enforce, I also think there has to be an element of independence that we have, like the Statistics Regulator, independent bodies given powers to enforce because I think we've lost the trust in government to be able to.<br>Participant, UK |
| Effective sanctions: to inspire trust that rules, regulations and sanctions are fairly and equitably applied to everyone involved in the data system whether data collection, storage and management, analysis, interpretation and communication. | I would just say that a good system for me would be one that has sanctions in place that everybody has to abide by, no matter who they are. Like, no one is above the law. You've abused the data? Then this happens to you, no matter who you are.<br>Participant, UK |
| Oversight, accreditation, monitoring and inspection of data quality as well as professional standards of those collecting and using data.<br>This would include an audit process to ensure consistent analysis of the data resultant from data systems. It would ensure that someone is responsible for verifying data security and privacy systems are in place and working as they should be. | All the people that have access to the database are fully background checked to make sure they're not dodgy, basically.<br>Participant, Glasgow<br>There should be secondary, third checks, or maybe first line of defence, second line of defence to make sure that the jobs (data scientists) do, the interpretation has a standard. You have a system in place to be able to come out with consistent analysis.<br>Participant, Leeds |
| Safeguarding: of the security of the data in the system and the rights and safety of people with regard to onward sharing of their | I'd really hope that, if it was a gold standard of service that there's a real hierarchy to who decides to do it, who checks it. Not just a civil servant. They don't care what your name is, they're just like, 'Yes, yes'.<br>Participant, Cardiff |

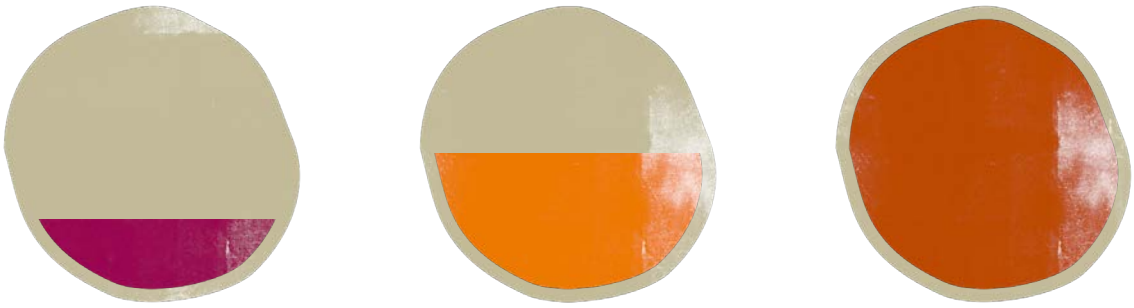
# 5 Data systems in emergency and non-emergency situations

What we have set out so far has focused mainly on data systems in non-emergency situations. In this chapter we set out participants reactions to data systems in emergency situations. We look at how participants expect data systems to be used to plan for an emergency situation and to implement it during an emergency. In figure 16 we summarise the key points Participants stress for data systems in emergency situations (figure 16). This includes that participants:


*Figure 5.1: Important aspects of data systems in emergency situations*

## 5.1 The need for data systems in emergency situations

In discussing what is needed from data systems in emergency situations participants tend to fall into three groups.



**Cautious**

The data needed in an emergency should already exist, no need for extended data access powers in an emergency.

**Willing**

Data should be accessible in an emergency - as long as society is aware of the benefits and data protection is robust.

**Ambitious**

Anything and everything should be done, including unrestricted access to personal data, if this is in the public interest and will end the emergency situation.

*Figure 5.2: Three main attitudes towards data systems in an emergency*

The **cautious** group contains a few participants, those closest to the Kieron end of our scale, who feel that data systems should have strict restrictions in terms of data access and use, even in emergency situations. This particularly applies to localised emergency situations such as flooding where the need for data is short lived. Only in extreme cases which they describe as 'catastrophic' should a more relaxed attitude to data restrictions be applied.

*I think it usually, in my experience, it usually has to be something pretty catastrophic, emergency wise, for that kind of data to be openly released as a necessity, I think.*

Participant, Leeds

There is a sense amongst these participants that extended release and use of data in an emergency situation is a slippery slope they don't wish to go down. They feel that the data system should already exist prior to an emergency to provide the data needed and protect citizens from any harms which may come from data use. They believe (see Lived Experience Box 6) their privacy trumps any need for extensive use of data in an emergency situation.

**Lived Experience Box 6**

*Before I met my husband, he didn't have a bank account, he wouldn't have a bank account. He didn't want anybody to know anything about him. He's a private person. When I met him I was like, 'No, you need to have a bank account.' We've been together a long time, but before then you'd get your wage slip in your hand in an envelope, that's how you got your pay back then. So, he would never ever use the bank, he never had a need to use the bank. So, when everything started going into the bank, he would take it out straight away. He felt that you had to take your money out straight away because he didn't want people knowing things. He now uses a bank, but he was very sceptical, very, very sceptical, didn't like any of it. He would be just as cautious in an emergency.*

Participant, Glasgow

Many participants form part of the willing group. They feel that there aren't many options in an emergency, you wouldn't have time or opportunity to object to your data being in a system, or being collected as part of the system. However, more than that, these participants are more willing for data to be used in an emergency situation than a non-emergency situation. Particularly if that data is being used to help and protect people at risk of harm.

*The emergency one, it's more like on the spot they'll be happy to give that information, because like many people have mentioned, it's about what's useful at that time. You really haven't got an option in an emergency situation, other than to give your data.*

Participant, Cardiff

These participants feel in the exceptional circumstances of a global pandemic, or other national emergency, there is more acceptance across society for data use. This is seen as distinctly different from non-emergency situations when more protections and restrictions should be in place in their view for data access, particularly for personal and identifiable data.

*I think it's about who has access to the data. So, before, your personal data should be confidential, like medical records etc, and should only be shared in exceptional circumstances. So, the exceptional circumstances would be the emergency, like the pandemic for example. So, in normal times, I don't think your details should being bounced between government agencies, and who knows what, but in the situation we've been in for the last two years, obviously there was a time when that was necessary.*

Participant, Belfast

As we have seen in Chapter 3 participants want to know that data systems are being used for public benefit, and if those benefits are visible and concrete they are much more willing to engage with the data system they relate to. Those participants that form the ambitious group, some from each dialogue location, strongly feel that it is critical that all possible data systems that could be useful are accessed during an emergency situation. They argue that people will not feel disturbed by data use if it might protect their families and their homes. Those participants who have personal experience of flooding in their local area are vocal on this issue.

*I think we'd all gain from (effective data systems) really if you think about it. If you're in an area that's flooded, I think we'd benefit from giving up data, I know I would give up my data if I knew my house was going to be flooded, presumably I already have. That to me isn't a trade-off because I'd think of all the disaster that would come after that.*

Participant, Leeds

These participants hope and expect data systems to be galvanised to help control and prevent the emergency situation.

*In my opinion I hope they just use whatever they have to do to help the situation. It wouldn't bother me in the slightest. Just do what they have to do to prevent the situation or deal with the situation as such.*

Participant, Belfast

Those ambitious for data systems in emergency situations state that:

- Data systems need to be ready and available for when they are needed
- Might include collecting data for which there is no clear purpose yet, but would become useful during an unforeseen emergency situation
- Data sharing between those involved in tackling the emergency should be facilitated and properly resourced
- Public awareness of the value of data systems for emergency and non-emergency situations needs to be developed, if people understand the benefits they will worry less about potential risks.

For some in the ambitious group hearing other participants who are particularly concerned about data privacy and risk is a cause of frustration. They fear that such concerns will stifle the ambitions society should have for data systems well populated with data which helps society when needed.

*So in this situation I am getting quite frustrated with people being really paranoid about their information sharing and feel that it should only be shared in an emergency because that can mean that somebody dies before the information is gathered because there isn't always that time to collect it. So we can't have it both ways.*

Participant, Cardiff

### 5.1.1 The need for data systems to operate at speed in an emergency

Many participants see that there is a need for fast access to data in an emergency situation. The main kinds of data that participants want to see fast action on in an emergency include:

- Location data: for example, where people are, where people live, if their homes are at risk (in a flood)
- Which people are at greater risk of harm from an emergency and what the data can tell us about what could be done to protect them
- To create the guidance and advice needed whether locally or nationally from civil authorities to demonstrate what is being done to tackle the emergency, and the role individuals and communities have in that
- Live monitoring data to track what is happening as the emergency develops
- Data to contact people with emergency warnings as necessary
- Data on where resources need to be concentrated to tackle the emergency

For some participants the idea of data systems working at speed raises concerns that corners have been cut, or work arounds used to facilitate the speedy access to data. This causes unease for a few participants, who refer to the impact speed might have had, for example, on Covid-19 vaccine hesitancy. They say the speed of vaccine roll-out might have meant some steps and procedures for vaccine approval were missed, and they fear that this might lead some people to trust the vaccine less than they might have if longer had been taken to develop it. For these participants speed equates to a perception of a lack of care for the protections around data systems, or an easing of protocol which they find unacceptable.

*I think the irony of the situation is that in an emergency situation, you almost need your data systems to be more robust, because it's life or death, bigger numbers, but actually in reality, you're probably cutting corners more because it's so fast moving that it's probably less secure, in some ways, when actually you need it to be the most secure it's probably ever been.*

Participant, Leeds

Many other participants believe that speed is essential in an emergency situation. This flows right through the system, from fast collection of the data that is needed to rapid communication of the outcomes of the data use. Participants used examples from both Covid-19 and flood risk to illustrate their point:

*I think the speed of production as well. So, like on a Monday, we heard it was much lower death rates and people used to get like, oh, things are getting good again. And then come Tuesday, it'd be double the death rate. The speed at which the data was put in and shared with us wasn't quick enough.*

Participant, UK

*You need to get warnings out quicker. They'd be able to see the flood levels rising. And from previous data, they should know that with what's happening when a river might potentially burst its banks.*

Participant, Leeds

Some participants wonder why data systems didn't appear to be deployed more swiftly to address the Covid-19 pandemic from its earliest stages. They feel this was a missed opportunity which could have prevented harms through the spread of the virus being as great as they have been. Participants referenced films, science fiction and games to show that pandemics, including a virus, although novel, had been an idea in people's minds some time ago (see Lived Experience Box 7).

**Lived Experience Box 7**

*I think there could have been a faster curve now to when a new sweeping illness is sprung out across the population and maybe a faster lockdown and containment of that population. It's quite mad that there's a game that my generation have played, well, some of us, called Plague, on an app. And it's a very realistic game where you create an illness and sadistically try and spread it around the world. It was quite fascinating to see that the government were slower to act on some of these things than the game implemented as just part of the difficulties to spread your virus. This is maybe 10 years ago. Just a little iOS app. And, yes, there are things that happen, like all of a sudden people start washing their hands more or they get told to wash their hands more so that reduces your spread. National lockdowns, that reduces your spread.*

Participant, Cardiff

## 5.2 Protections from data system overreach beyond the emergency itself

Many participants in all locations are keen to emphasise that looser and faster data system arrangements should apply only during a crisis. Once the emergency situation is over it is important that governments do not try and retain emergency powers for data collection and system access and use beyond that point. They fear that given that society has accepted some looser use of data systems in the emergency that this might become normalised. For some participants such an extension of the system and its powers is an infringement of liberties and human rights. They do not want what they see as an individual's rights over their data to be eroded indefinitely after the emergency itself. They describe this concern as, 'normalising by default', a steady erosion of civil liberties which society sleep walks in to.

*It seems to be the case whenever exceptional circumstances arise, governments are quite reluctant to let go of the access to data or whatever it is that they have during the emergency. So, for example, in the war, British people had to have ID cards from 1939 and there were very good reasons for that, very necessary reasons. Then it took until 1952 for those to be rescinded. The pandemic was an exceptional circumstance, but I would have concerns about all the vaccine passports, track and trace, and all the things that were put in place staying (in place).*

Participant, Belfast

This reminds us of the importance of definitions set out in Chapter 2. It is critical to many participants that the boundaries are set for any less restricted use of data.

*That data that's used in a national emergency situation, we don't want it to become normalised by default, and it needs to be time limited as well.*

Participant, Belfast

For participants there is a balance to be struck between public benefit, individual and societal responsibilities and individual rights and freedoms. Overreaching powers for governmental use of data systems beyond the emergency would tip the balance in the wrong direction for many. They are concerned that this is happening already as the pandemic restrictions ease and they argue that at this critical point peoples' rights to privacy should be front of decision makers' minds.

*I just almost want that to be remembered in every decision that's made. It's that people have a right to privacy, so it's an overarching. We need to remember this here.*

Participant, Glasgow

Other examples shared by participants of over-reach of data policies and actions beyond the needs of an emergency situation which they are concerned about include:

- Holding data on an individual which might be connected in a way that disadvantages or penalises them. For example, someone's health data being used to decide whether they can get a mortgage
- Losing your ability to remain anonymous and have a private life. A few participants, who were closely aligned with the Kieron end of our scale, fantasise about going completely off-grid
- The challenge of controlling data relating to an individual once it has been released, even if it's anonymised, for example smart meters
- Personal data being sold to third parties/ private companies without permission
- Potential divisions in society resulting from a split between those that are comfortable sharing data and those that aren't
- Systems that force people to disclose information that they are not comfortable sharing, such as DBS checks
- How peoples' addiction to mobile devices makes it hard to stop sharing data
- People living on lower incomes having to share more data than others and not being made aware of the extent of the data that is held
- Data systems that encourage addictive behaviours, such as online gambling and compulsive online shopping
- A social media culture which encourages people to share information about another person (e.g. location, image, activity) without their permission
- Unease about digital adverts that pop up and appear to be eavesdropping on you.

## 5.3 Connected systems

Participants by the end of the dialogue, with a strong degree of agreement across the groups and locations, came to the conclusion that connected data systems are of value to society in both emergency and non-emergency situations.

For a few participants connected systems means a totally joined up system for everything:

*A huge database containing information from every single person in every country. Coming from smartphones, smart homes and other smart appliances that is available to anyone for the right price.*

Participant, Leeds (Mentimeter)

This would certainly include public systems such as health, social care, housing and education and might, for some, also include links in to some private sector data systems, for example those who might have staff skilled in database management whose skills would be valuable. This exchange typifies the views of those who advocate one large-scale joined up data system,

> Because that's a massive thing, to link up the organisations, like the police, the health, the government, the HMRC, everybody, and other global countries, countries that are connecting up with it. It's speed, in an emergency.
>
> **Facilitator: When you're saying linking up-,**
>
> Electronically.
>
> **Facilitator: Are you talking specifically about an emergency situation?**
>
> No, sharing information as well, to avoid situations. No, the sharing of information, of data. They're intrinsically linked. Participant, Belfast

One of the benefits participants see as accruing from one completely joined up data system is that some of the issues of accessibility (see Chapter 3) could be addressed. People across society would be able to input data into a system once, in a Census plus approach for example, and would not be repeatedly asked for the same data again and again throughout their lives, for example in the health care system.

This view was not shared widely, but a middle ground where data systems are better linked and interoperable when they need to be is seen by many participants as an opportunity to be seized. In this scenario participants propose data systems which are interoperable and connected in associated fields, for example:

- The health service;
- Private and public social care systems;
- Financial services
- All the systems that need to come together in a flood emergency such as the Environment Agency, the Met Office, local authorities, housing associations, parish councils etc.

One participant's hope for better connected data systems is contextualised in their work as a social worker (Lived Experience Box 8) dealing with child protection emergencies.

Better and more efficient use of a resources is a benefit participants see would be gained from better linked systems across the public sector. They use Covid-19 as an example where it was felt that many organisations across the health system were in contact with the same individual asking for the same information.

*If these organisations were all working together, as they should then they should have that information centralised and accessible to all parties involved. That will also help reducing costs, because it also takes costs for 3-4 organisations to call you to ask for the same data. It's costing each organisation. So who's paying for all that?*

Participant, UK

**Lived Experience Box 8**

*In terms of for social work, for me, each council has their own database that they can use. If I need to speak to someone in the council, I can't actually see their notes, I would actually have to ask for it to come over which someone can be a bit funny with it. Plus, as well as other agencies like the police, schools like that, they don't have the system so it's very difficult in terms of me, I'm having to phone and explain what's going on. It's like putting pieces together whereas if there was one just whole system, it would make things so much easier. You would get information there and then and quickly support this child. None of this having to phone constantly to find out about things.*

Participant, Glasgow

Other benefits participants highlight in having better connected and interoperable data systems are:

- A more co-ordinated UK approach across the home nations leading to more consistency in a national emergency with each administration drawing on joined-up data sets to inform the action taken
- Better sharing of data globally in a global emergency such as a pandemic
- Better communication between public sector bodies to address emergencies and better data flows with fewer blocks to data sharing
- Building more resilience into the system so that if one element is compromised the other interlinked element can provide back up
- An ability to be more transparent about the data being drawn on in emergency and non-emergency situations
- Consistency in data collection making it more accessible for people sharing their data

*I guess I feel the need for governments to cut the crap, talk, communicate, collaborate. There doesn't need to be those barriers to collaboration that a lot of governments and things have. I think in an emergency, that has to go out the window. It doesn't because that's just human nature. In an ideal world, it would. It would be circumvented I guess. People wouldn't be able to use their private wants and needs to influence the decision. Joining up would be very much for the greater good.*

Participant, Belfast

## 5.4 The data system learning cycle

During the dialogue participants considered how data systems should operate before, during and after an emergency. These data cascade discussions were important in informing participant reflections on using data systems as a constant cycle of learning and improvement.

### 5.4.1 Data cascades forming the learning cycle

Participants see a very simple cycle of learning (figure 18) which reflects their desire for an effective, resilient and trust data system to constantly learn.  Participants feel it is an important opportunity to retain an openness to what's not working well and developing ways to improve. This is also described by some as a system of 'continuous improvement' in which weaknesses are identified and corrected in an ongoing way.

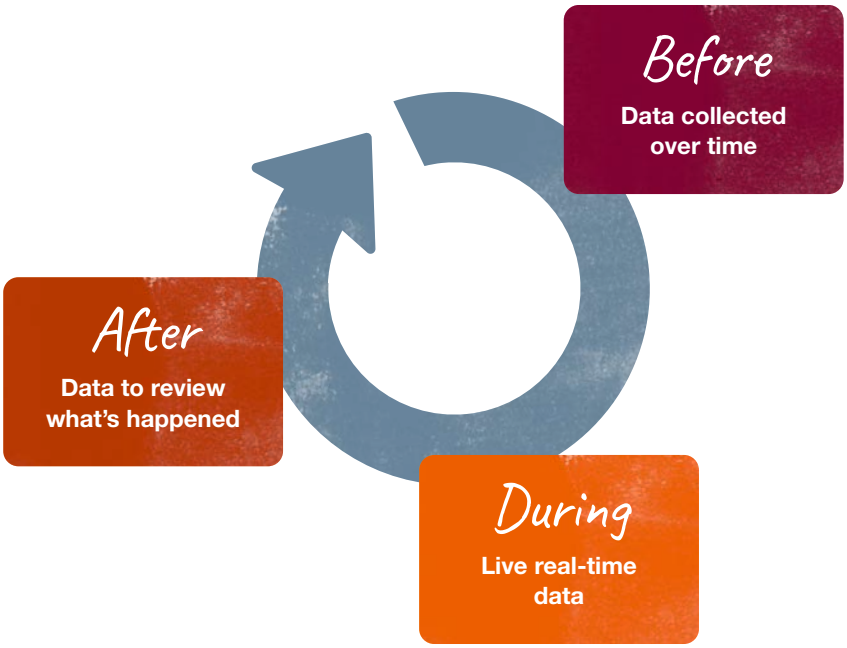



*Figure 5.3: The data system learning cycle*

## 5.4.2 Before an emergency situation

The main message participants wish to highlight in relation to data systems before an **emergency situation** is that their purpose is to ensure that all the data that is needed in an emergency is collected before it happens. They want society to be prepared. They fear that if this isn't the case then important time is lost at the beginning of an emergency in gathering data afresh and perhaps finding, too late, that some data is not available to the system. Participants feel that during the Covid-19 pandemic too much time was lost not understanding the data that was needed to manage risk to health and life. They refer to the lives lost in care homes as an example of where data systems should have already been set up but did not appear to be.

Other examples of data that are identified by participants as being helpful before an emergency situation occurs include:

- Where specialists are who can help (e.g vaccine developers in a pandemic, those with specialist knowledge of risk in a flood)
- A wide range of population data on housing, where clusters of people live, where people at risk in an emergency are, where places of safety are in a community and who will be present to tackle the emergency should it arise
- Historical data to inform the current situation
- What preventative measures have been tried previously and what the data can tell us about innovation in prevention.

Key words participants use to describe why it is important to have data systems in place before an emergency include, preparing, pre-empt, plan, productive. A view put forward in the UK group is shared by many dialogue participants:

*Without data we essentially have no chance against disasters.*

Participant, UK

## 5.4.3 During an emergency situation

**During an emergency** participants expect to see the data previously collected galvanised to save lives, protect those at risk and communicate what's happening to those affected. Data is seen as being important at this point in understanding the true nature of the emergency and responding appropriately to it.

Participants also see the during phase as an important learning opportunity in and of itself. As live data comes in it can be compared with the forecasts, modelling and projections created before the emergency to improve the quality of the data, particularly in a longer-term emergency situation such as a pandemic.

*During the pandemic, the quality of the data would hopefully improve as you get more data on COVID rates, survival rates, efficacy of vaccines, things like that. And then you could maybe discount some of the data that you may have got in the previous stage, that is no longer needed. That would be the ethical thing to do, anyway.*

Participant, Cardiff

When tensions are high and the emergency situations difficult participants call for clarity, for evidence to provide guidance and support in a difficult situations.

*Just what I was saying about just clarity in a situation of panic. I think it's having that data there, ready to go, that people would go in different directions or not really know what the best course of action is. It's having that factual information and somebody outside of it that can guide people on what they want to do, rather than people that are on the ground or involved.*

Participant, Belfast

Given participants concern for inclusion within the data system they also feel that during an emergency the data already in the system should be used to show gaps in the data and work to either fill them or try to fill the data gaps. Participants use the response in the pandemic to those such as homeless people who might not be included in data systems as an example of what can be achieved.

*The people who might fall below the net, the homeless, people like that who might not be registered with a health service or with a doctor. Identifying how many of them there are and where they are and can they get the same protection offered to them as everyone else can. Who might not be in the system, yet can they be protected, can they be offered protection if they choose to have it. Because there were a huge number of homeless, certainly they got them a place to stay and all that kind of thing.*

Participant, Glasgow

## 5.4.4 After an emergency situation

After an emergency situation participants expect all the data gathered before and during to be assessed, reviewed and evaluated so that that whole system can become a learning tool and continue the cycle of preparing for the next emergency. They believe long-term analysis should be conducted after an emergency, so that the impact of it is fully understood and plans can be put in place to mitigate against future emergencies.

Participants used the Covid-19 pandemic as a template to think through what they would expect to learn from data after an emergency situation. Some of the key areas they raise include:

- A systematic collection and analysis of what happened throughout the pandemic to inform public enquiries about the handling of Covid-19
- What has worked well and less well in each of the devolved administrations and across the UK
- How other countries have dealt with the pandemic and which measures have been more or less successful in comparison with the UK's approach
- Understanding where to target recovery funding and other support and resources given the evidence supplied through the data of the impacts of Covid-19
- More broadly understanding who was impacted most severely during the pandemic in order to prevent such affects in the future
- Understanding where data was missing and how to avoid this in the future, including correct inaccurate data within the system

*Afterwards it's all about finding the mistakes, where it caused the problems. The lack of data at the time. Things like people who were shielding. There were some people that found out they should have been shielding until about 3 weeks before lockdowns ended. And there were instances where people, letters about vaccinations went to the wrong addresses.*

Participant, Leeds

- How the resilience of data systems stacked up in this emergency – were they effective when they needed to be?
- Making the best possible use of the data that has been gathered during the pandemic, much of which was not conducted prior to the emergency.

*Imagine gathering all that information, all that data. Is there a robust system in place? I imagine obviously no one anticipated the COVID pandemic, and now all of the sudden, we're populating our databases with all this information. How do we manage the data in the future, for the future?*

Participant, Leeds

Participants across all locations feel that learning from the before, during and after of an emergency is essential. This participants comment reflects the views of many on the importance of this learning.

*Hindsight's a wonderful thing, isn't it? I think we can look back at how things have been handled during this one and look at how they could be improved. I guess that's what we're doing anyway, how things can be improved by the use of data and how it's shared and transmitted in various areas. It can also tell us what didn't work. So, the Track and Trace didn't work very well. It gives them an opportunity now to look at that and say, 'Well, if we need something again, we need to come up with it now.' It's all sitting there in the back pocket ready to go in an emergency and it is one that will work and it will work quickly.*

Participant, Glasgow

## 5.5 Communication and awareness raising

We find that participants are more accepting of data systems use in emergency than non-emergency situations. Where there is broad agreement across groups in all dialogue locations is that the visibility for data systems and their value for emergency and non-emergency situations is lacking. This is particularly true, in participants' eyes, for public sector data use. Despite data being visible every night on screens throughout the country at the height of the Covid-19 pandemic, they express concern that it is private sector data systems and private sector data use that comes to people's minds when first considering data, not public sector data systems used for public good.

This lack of visibility for public sector data systems and their use leads participants to consider that data might be collected and then not used in emergency situations. This seems to them to be a waste of time, effort and resources, particularly in the public sector. On the Mentimeter questions participants state:

*Just because there is useful data doesn't mean governments will use it.*

Participant Belfast

*Data needs to be used, not just collected.*

Participant, Glasgow

Some participants draw on the climate change example of a long-term crisis to reinforce their belief that data is not being used effectively to address the emergency.

*I think this goes back to my point of how scandalous it is, because we've known about climate change since the 70s, 80s, and nothing's been done about it. The data has been ignored. It's still in the 'during' (phase of the emergency), we're still ignoring it. We're talking about it, but there's no action. There won't be an 'after' if we aren't careful.*

Participant, Belfast

## 5.5.1 The importance of clear and simple communication

Using data well in emergency situations is firmly connected in participants' minds with communicating its use effectively. Participants place a high value on having clear and transparent communication strategies to convey key data to society, particularly in an emergency. Participants feel simple and honest communication in emergency and non-emergency situations is essential. This is key to the factors they find important about effective data systems such as building trust, allaying fears, and 'taking people along' in seeing the purpose and value of participating in the system.

Important messages participants think people need to hear to motivate participation and overcome worries 'their' data being included in a system include being clear about collection, use and potential sharing of data, particularly sensitive data e.g. personal characteristics. If data is being collected in advance to prepare for future emergencies, this could also be stated clearly to help people to see why they may be asked for data now to be used later.

*It can be there to give you detailed information of, 'We're taking it now in a non-emergency, but your data will then be here, on this system, this is what we're using it for and it will then be easier to access in case of an emergency that's not been predicted'.*

Participant, Leeds

They also suggest that ongoing communication will help people to feel more part of the data system and understand why their contribution to it matters. They believe more societal communication around data systems and their use would be helpful to explain how data is used for positive impacts across society.

*You could say, 'well, we've had this data so that's meant that so many more people have been seen early. We've caught it early, we've treated people earlier. This amount of people have now been successfully treated', just the good news. When people start seeing a benefit, then they are usually more tied into doing things like that.*

Participant, Leeds

Over the longer term, participants also suggest that educational initiatives could be undertaken to help people see their participation in the data system as a positive investment in the UK's future, ensuring that the data we need and rely on will be available when it's needed most.

As well as the substantive content of the messages, participants give examples of how communication can be kept simple, accessible and motivating to meet the needs of all those asked to take part in the data system. They highlight the importance of ongoing communication to help people feel involved in the process and see how the contribution they make helps society. Specific suggestions include:

- Provide simple explanations in bullet points (not '15,000 pages of terms and conditions')
- Avoid complicated legal language and acronyms (such as 'GDPR')
- Provide 'jargon busters' and simple summaries where complicated language is unavoidable
- Have media campaigns to show how their data has been used and benefitted society

*Maybe having something, you know the way you would get your rates billed in Northern Ireland, it would be your rates bill, and there's a wee breakdown of where money is going. So the like of data, maybe a wee breakdown as to how it could benefit you. A wee bit more information on what's actually happening to this data. Make people feel that it is important to them, and there's a use for it, not just it's being gathered and stored somewhere in a database computer, just being historic.*

Participant, Belfast

A recent positive example noted by participants is the communication surrounding the 2021 Census. Participants found this to be clear, with good explanations about why it matters and how the data will be used to help with issues of importance to them, such as funding for local services.

While some give examples of complex systems communicated well (the breakdown of council tax spend was mentioned) other participants think that a powerful way of illustrating the benefits of a data system is to tell individual stories of people benefitting from data use. They feel this would cut through the complexity and provide the transparency needed to make the potential benefits resonate with people.

*Sometimes when you hear one person's particular story that's been extracted, that illustrates a point about how data was used beneficially, it might just get through to everybody. So, that one person's story will spread, it could be on social media, it could be on the news, it could be on the radio. Just hearing that story can inspire people to do the right thing.*

Participant, Belfast

### 5.5.2 What and how data is communicated is important

For some participants the data shared during the Covid-19 pandemic was too much and rather overwhelming. It seems to participants that the intention was good, to provide daily briefings and keep people informed in an emergency situation, but if the data presented is not clear and is too complex to understand what the situation is then some participants feel it is best not shared.

*Maybe just report on a need to know basis. I don't know about anybody else, but the Prime Minister's briefings and things, when they had pages and pages of graphs, I couldn't quite understand what they meant and things like that and it just got overwhelming.*

Participant, UK

However, for many participants keeping society up-to-date in a fast moving emergency situation is essential and more rather than less data communication is essential. Even if the presentation of the data is confusing at times, it is important that wider society hears from trusted sources what is happening.

*I suppose sometimes it was information overload in the television when you were watching it for a long time with all the statistics and the difference in various countries against your own country so to speak and the numbers increasing and stuff. But, I don't know, I think it's good just to have the information.*

Participant, Belfast

This means for many that data should be presented in bite-sized segments which are easy to understand and give a clear picture of the current situation. If people are clear what is happening in an emergency situation they can act accordingly, changing their behaviour and responding to events as necessary.

Another aspect of communication is how data use is communicated. For many having a voice independent of government presenting on the data is valuable. But there is a bit of a catch-22 here. A positive that data is collected but this is tied to a concern that the data is telling us that the situation is an emergency, which sparks further concerns.

*We were talking about how the flu would have started off like this, but obviously back when the flu was first a thing, data wasn't collected, media wasn't a thing. A point for both good and bad, it's good that this data is being collected now and we can keep an eye on it, but because this data is now being collected it is obviously causing a massive fear with people because it seems like it's more terrifying than the flu.*

Participant, Cardiff

Participants worry that too much raw data is presented in an emergency, an over emphasis on quantitative data which without interpretation does not present the true picture of the emergency that participants feel that wider society needs to understand. In discussing the climate emergency participants often raise the point that the data on temperature rise does not mean a great deal without the context of the impact of such global heating. They want those managing data systems to communicate more clearly on the concrete impacts of the emergency - possibly through case studies and real world examples.

*What we discussed was that raw data didn't mean an awful lot to the majority of people and four degrees heating of the planet feels like it's a nice warm summer. But in fact, that means crops will die, water shortages, ice caps melting, Pacific Islanders being homeless, people will die. So, it's linking that raw data to real scenarios, so people can understand what that data means.*

Participant, UK

Many participants feel that in a genuine effort to share data during the pandemic, meaning was lost in over sharing, particularly complex graphs and visuals which do not seem to link back to people's personal experience. One participant put this bluntly as,

*Just bullet points, not baffling us with bullshit.*

Participant, UK group

Participants are particularly concerned about misinformation. They feel this is rife on social media and across the Internet and creates mistrust of data systems. They worry that data can be manipulated to present any argument that suits, for example, a political, commercial or campaigning agenda. 'Fake' news is a particular cause for concern which participants feel should be addressed. Some concern was also expressed that the media in general does not act responsibly when it creates 'headline grabbing' stories and stokes the fire of 'fake news' in its reporting. Participants feel this creates a data environment in which it is very hard to distinguish between the data we need in an emergency situation, and data being manipulated to satisfy agendas which have nothing to do with either trust or transparency (see sections 3.4 and 3.5).

*I was just going to say one of the main challenges is having people who don't believe and who convince other people not to believe certain things. I'm thinking of Mr Trump in America telling us that the climate change is fake news. It's all to do with consensus, buy in, maybe education, but it's certainly bringing everyone up to the minimum level to take on board where they start seeing benefits.*

Participant, Leeds

Participants express concern about 'Chinese whispers' leading to data misinterpretation. They feel it is part of a robust and effective data system that 'real' evidence can be drawn from it which is then clearly presented to demonstrate:

- What is really happening in an emergency situation
- That the impacts of an emergency have been taken into account
- That there is a voice for truth in amongst the misinformation.

Participants draw on their experience of how they received information during the pandemic from a variety of sources. Lived Experience Box 9 shines a light on these various sources.

**Lived Experience Box 9**

*Remember in the early parts of Covid that we started to get our information from different places. Remember the statistics comparison between countries that was done by a 17-year-old who took statistics from all over the world. A super geek, a young person who put it all together and we started to use that system, built by a 17-year-old. I learnt about the detail of COVID from that couple who'd been on the boat that was stuck outside, you know, the cruise ship that was stuck in Japan. They did live interviews and talked about their experiences. The breathing patterns, that came from a Dublin doctor, so it was watching different sources of information that introduced you to what you needed to learn. There was also misinformation about symptoms that came through the internet but eventually, we got to what the truth was, but it took some time.*

Participant, Belfast

What is clear is that participants want to know that they can trust media outlets to understand the data that's been collected and how it will be used in the future and share with society. They want to know that this can be done without onward sharing of 'fake' news or by selecting a bit of the data and presenting that without showing society the full picture.

# 6 Recommendations, challenges and solutions

## 6.1 Data system recommendations

At the end of the dialogue we asked participants to consider what they feel those creating resilient, effective and trusted data systems need to bear in mind, including improvements to data systems. Some clear recommendations come from these discussions (summarised in figure 6.1), building on the work that was done iteratively over two rounds of deliberations. These are set out in the section below in which we highlight points made throughout this report on:


*Figure 6.1: Participant recommendations for improvement*

### 6.1.1 Visible and effective data system governance

**Participants recommend that:**

- Governance of data systems is more widely visible to people across society
- There are transparent communications on the actions regulators have taken demonstrating independence from those who manage data systems
- Current regulators are given boosted powers with 'teeth' to penalise misuses of data systems
- Support is provided through the governance structures for data systems to employ best practice which flows from non-emergency to emergency situations
- A culture of learning from the before, during and after emergency situations is embedded in data systems.

Whilst participants were pleased to learn of the existence of regulatory and governance bodies such as the Information Commissioners' Office, the Office for National Statistics and the UK Statistics Authority, they were surprised how little they knew about these organisations and their roles before taking part in the dialogue. There is a strong sense that data systems cannot be trusted, resilient or effective if the governance systems through which they are managed are not widely visible to people across society. As a result participants want to see data system governance which is more visible to society, simple to understand and transparent in its regulatory practices.

They call for independent regulators to communicates well with society about their role and the steps they take to address data system issues. This includes having substantial powers, 'teeth' to penalise those who misuse, manipulate and exploit data. It would equally support and encourage data systems to employ best practice in emergency and non-emergency situations, focused on public benefit. It also includes the ability to monitor data systems throughout the learning cycle and have evaluation programmes in place for more substantial understanding of what has gone well and what less well across the data system.

*I think you have to have checks in place to monitor and almost like government controls to evaluate and make sure that everything's being done in the right way, i.e. collected, managed, stored, and used. So the checking and monitoring is important, yes, and preferably by an independent body, like a regulator type body that can oversee that.*

Participant, Leeds

Given the concerns participants raise about data accuracy within systems they are also keen to be able to carry out their own evaluations of data systems. They propose ensuring data systems are designed with a simple way to check the accuracy of the data held about you built in. They hope this would enable people to be able to minimise the risk of harms from data inaccuracies, particularly in emergency situations.

### 6.1.3 The need for clear communications and explanations on data systems

**Participants recommend that:**

- Clear communications are needed on what data is collected in non-emergency situations to inform what data can and should be used in emergency situations
- Communication campaigns are needed to highlight the public benefit which comes from effective data systems
- Efforts should be made to reframe perceptions of data use so that public benefit is front of mind when people think about data systems
- Using public benefit as a lever to ensure societal needs are met through data use in emergency and non-emergency situations

Participants call for clear communication on what data is collected in non-emergency situations that should inform how society addresses emergency situations effectively. They argue for communications campaigns which draw people across society into an understanding of data systems and their value such as:

- Advertising campaigns which provide reassurance on how public sector data is securely stored and managed
- Jargon busters in public sector data communications explaining key terms such as GDPR[19], the Data Protection Act (2018), depersonalisation and consent

There is a belief by many participants that more effort should be made by governmental and regulatory bodies to embedding data systems thinking across society. They see this as important in re-framing perceptions so that data systems bringing public benefit are front of mind when people think about data. Participants speak of education and awareness raising so that people can see data systems for public good as a routine part of ensuring societal needs are met in emergency and non-emergency situations.

## 6.1.4 Joined up and, in some cases, interoperable systems

**Participants recommend that:**

- A shift is needed to recognise that linking data systems and fostering a spirit of collaboration between those who manage them is likely to produce greater public benefit in their use
- This shift will also minimise the burden on society in collecting and recollecting data for different purposes and bring specific public benefits in key social and economic areas such as health, social care, education and housing
- Public reassurances need to be made on the purposes for which data is collected and shared.

As we have seen a few participants remain concerned about data security and privacy. They feel the risks of harms from data sharing outweigh the benefits, particularly in the context of private sector data systems. However, many participants as they worked through the dialogue feel increasingly that linking data systems and fostering a spirit of collaboration between those who develop and manage them, will enhance people's perceptions of the value of collecting and using data for public good. They see this as of great value in minimising the burden on society in collecting and recollecting the same data for different purposes, and bringing more public benefit in key areas such of society such as health, social care, education and housing.

To achieve this reassurances will need to be given on how the data will be used for stated purposes, it's accuracy and with resilience built in; with the clear communication referred to in the previous point.

[19] General Data Protection Regulation

## 6.1.5 Oversight and monitoring of data systems

**Participants recommend that:**

- Data systems are designed with built in oversight, monitoring and inspection of quality
- Those working data systems have appropriate skills and experience to protect the efficacy and trustworthiness of the system
- Reassurances are made to society about data privacy and security across all data systems

Oversight, monitoring and inspection of data quality are all important facets of ensuring data systems are effective, resilient and can be trusted. This would include an audit process to ensure consistent analysis of the data resultant from data systems. It would ensure that those responsible for verifying data security and privacy systems are fully competent to fulfil this role and work to common professional standards, whether in the private or the public sector. This would give reassurances to participants that data privacy and data security are in safe hands and appropriate management systems for all aspects of data use in emergency and non-emergency situations have been considered.

As we have seen participants see great value in effective data systems, but in line with other public dialogues on data systems[20], they raise significant concerns about data privacy for individuals and society. These include a slippery slope into a dystopian surveillance society, and a concern that data access measures imposed by a government during emergencies could become the norm. Ensuring that there are well applied well understood professional standards for those collecting and using data is seen as an important mitigation factor here.

## 6.1.6 Involving people across society in the data system learning cycle

**Participants recommend that:**

- Data systems are shaped, challenged and developed with the involvement of a diversity of people from across society
- Public involvement should inform how data is collected, including the inclusion of data from those who might be missed from the system
- Public involvement should be a key part of data system governance structures

[20] Such as Hopkins, H; Kinsella, S; Evans, G, Reid, S: Putting Good into Practice: a public dialogue on making public benefit assessments when using health and care data, the National Data Guardian, Understanding Patient Data and Sciencewise, April 2021

Participants valued taking part in the dialogue and exploring a subject many had previously known little about. As a result many participants want to ensure that data systems continue to be shaped, challenged and developed with the involvement of a diversity of people. This is important to participants who propose:

- Public involvement to inform how data is collected, with volunteer data champions in communities who can support people to manage their own data inputs as required, particularly those at risk from being missed from data sets and as a result do not gain benefits from being visible within the system
- A board, jury or panel that works with the data governance process to ensure data systems are used, managed and analysed effectively to inform policy
- Such involvement would embed public views in the learning cycle which would be informed by people's lived experience of the before, during and after of an emergency situation.

*Well, a prime example would be what we've been doing these last 2 days, including today, and it would be interesting to see what happens in the future and what the outcome of it all has all been. And thinking, 'Oh, I took part in that.' You could have all that learning in every part of the system if you kept people like us involved.*

Participant, Glasgow

## 6.2 Data conundrums and proposed solutions

However beyond the areas of common agreement summarised above, more challenging issues also emerge which we refer to as 'data conundrums'. These are areas people find difficult to resolve, for example the tension between meeting the needs of the 'system' versus the needs of individuals asked to share their data.

Several data conundrums emerged during the course of the dialogue which represent apparent stress points in how people think the data system should work to be fully effective and how they feel as individuals about sharing their own data. The main four data conundrums and related solutions are set out in table three:

These would seem a sensible place to start thinking about further research on creating resilient, trusted and effective data systems.

Table 3

| Data system conundrums | Potential solutions described by participants |
|---|---|
| Precise details are required for data quality, comprehensiveness and an accurate picture of society. However, asking for what people might consider to be too much personal data is a problem for participants. They feel it can make people less likely to engage in data systems for non-emergency situations leading them being missed from data which could support them in emergency situations. The lack of engagement being due to people's perception that they are more vulnerable to harm, exposed to risk, or simply inconvenienced if they do engage. | • Undertake further work to raise awareness in society that data is collected and used for public benefit – including as a key element of responding to emergency situations<br>• Ensure public communication on data systems include clear and simple communication on how and when data is de-personalised[21]; and how personal and sensitive data is protected.<br>• Transparently demonstrate what the benefits of data systems are; creating a shift in public awareness towards an understanding that data systems can bring public benefit. |
| Many participants believe that data should only be collected for a specifically defined purpose, particularly in non-emergency situations. They believe that individuals should only agree to share data based on this purpose. However, participants also recognise that a resilient data system requires data to meet future needs that aren't yet known. This creates a dilemma – how do you state a clear purpose for data collection when you are not yet clear what these future needs might be? | • Clarify, in simple terms, across a range of emergency and non-emergency situations what the purpose of any given data system is including:<br>— how data collected by private and public sector data systems is used -and why<br>— where data might be shared, and who with – and why<br>— where there may be overlaps between the private and public sector in who 'manages' and 'owns' the data.<br>• Create simple, visual and Plain English/ Easy Read terms and conditions documents for websites and apps which collect data. Which might include colour coding to indicate when specific types of data are being collected e.g. location or personal data.<br>• Create a series of good news stories around data use, e.g. in handling an emergency situation, so that people can see the wider public benefits that can accrue from data systems. |

[21] Participants found Understanding Patient Data's Identifiability Demystified handout helpful in this context

| Data system conundrums | Potential solutions described by participants |
|---|---|
| Participants call for data systems to be more joined up, particularly in public health emergency and non-emergency situations. They believe this will make them more efficient, resilient and accessible. Despite this belief they are concerned that if data is shared across systems, and with all those who need it, this may increase the chances of harms to individuals and make it difficult for people to feel in control of who has access to their data and for what purpose. | • If data systems are to be more inter-operable and linked, then protections must be put in place and communicated widely<br>• If data systems are demonstrated to be resilient e.g. to be able to recover from challenges and adapt to changing circumstances, participants believe people will be reassured that harms and risks have been minimised<br>• Participants feel that joined up systems should prioritise vulnerable people, particularly in emergency situations – using the fact that they are joined up to understand who is most at risk in an emergency<br>• Design data systems with inclusion and diversity in mind including:<br>— Involving a diversity of people in the design of data systems<br>— Standardising the design of systems, particularly those in the public sector so that it is easier to move from one to another<br>— Having dedicated and specialist teams responsible for system accessibility. |

## 6.3 Areas for further action and research

As a result of identifying these conundrums and potential solutions participants a number of areas for further research and future lines of enquiry are indicated, mostly focused on involving people across society in data system decisions. These include:

- Researching ways in which trust in data systems at a local level can be fostered, e.g. the potential for community data champions, for example, in local health systems
- Governance structures developing systems, including public involvement panels, which encourage data systems to operate as learning systems so that the knowledge gained after an emergency through the system can feed back into planning for the next emergency and respond effectively to it
- Studying the facets of trust explored in this dialogue further with a citizens' jury or similar deliberative panel which brings together over time to test specific data systems against these elements.

We end this report with a call to action voiced by one participant highlighting the views of many in the dialogue:

*People will feel like their opinions are heard and it's trusted. Because it's like, 'Okay, no, we were a part of this decision. We helped make this decision. It doesn't feel like it's being imposed upon us. The community in all aspects are a part of this. And we decided this and we move them forward with it. It's like, 'No, everybody has an equal say within this, we can make this system work. Like a jury. Everybody is equal. Everybody moves it forward.*

Participant, UK

# Acknowledgements

Hopkins Van Mil is enormously grateful to those who took part in the public dialogue. Their commitment to the process, and to considering complex and, at times, emotionally challenging ethical and societal ideas so seriously; as well as their lively and engaging contributions, has been much appreciated.

Many thanks too to our specialists: Monica Jones, Virginia Murray, Ed Humpherson who so generously gave their time, often at short notice to join sessions that moved at pace from in person to online events. They made such a such a difference to participants' understanding of data systems in the UK and globally for emergency and non-emergency situations. Their calm and responsive answers to participant questions was greatly appreciated by the team and participants.

It has been a delight to work with the Royal Society Project Team: Lesley Miles, Tracey Hughes, Alexandra Wakefield, Mahi Hardalupas, and Natasha McCarthy. They expertly guided the process, providing insightful comments to the HVM team, as well as presenting at the dialogue and responding to participants questions with clarity and empathy.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Report design by vincentdesign.co.uk



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