Public dialogue on data sharing outside of the public sector in Scotland

Findings from a public engagement panel for the Scottish Government and Research Data Scotland

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Ipsos Scotland

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Introduction

In late 2022, the Scottish Government and its partners from Research Data Scotland and Sciencewise convened a public panel to explore the ethics of public sector use of data. The purpose of the panel was to inform approaches to data use by the Scottish Government and public sector agencies in Scotland.

Using a deliberative public dialogue approach, facilitated by Ipsos, the panel (consisting of 25 people from across Scotland) met over six three-hour online workshops to develop a set of ethical guidelines for public sector use of data. Over the course of the original workshops, some issues arose that were not covered in great detail but that the panel considered necessary for the public sector in Scotland to consider in further detail when using data about citizens. This included the concept of public benefit, and specifically the extent to which data sharing outside of the public sector is in the public benefit. This was important to the panel but there was limited time and opportunity to explore in depth what this meant to the participants.

The Scottish Government, in partnership with Research Data Scotland and Sciencewise, therefore commissioned Ipsos to facilitate two additional workshops, to explore these issues further. These additional workshops were carried out with 15 of the 25 participants who took part in the original panel. This report summarises the key findings from the additional workshops. It should be read in the context of, and as an addition to, the wider report from the original workshops.

Objectives and methodology

The aim of the two additional workshops was to explore views on the following overarching questions:

- ***When might data sharing be in the public benefit, and when it is not?***
- ***What are the benefits of data being shared outside of the public sector?***
- ***When data are shared, who should benefit?***

Over the two online workshops participants listened to presentations from experts (including representatives of data sharing projects and a speaker that raised ethical considerations about data sharing), learned about the topics (private and third sector use of data from the public sector, benefit sharing as a way of ensuring public benefit, and the ethics of data sharing) and then discussed the issues together before reaching conclusions.

Key findings

There were different levels of comfort with private sector access to data from the public sector, but the panel became more positive as the workshops progressed.

Potential benefits of sharing data with the private sector were recognised. It was seen as helping to encourage innovation, for example with drug development, which could help to support the treatment of health conditions. However, there was also concern expressed about the potential lack of control over how commercial companies might use data, for example, using it to target individuals for cold calling. Having learned about specific examples of data sharing projects and ways that the public could benefit (e.g. through profit sharing arrangements), participants felt more convinced of the potentially positive impacts from private sector access to data and reassured about the processes in place to help support public benefit. There were, however, lingering concerns about potential misuse of data and the panel emphasised the need for due diligence, scrutiny and oversight of private sector access to, and use of, data.

The panel felt there was no single definition of public benefit and that this should be judged on a case-by-case basis.

However, they identified certain outcomes that they would expect to see from a data sharing project to be considered in the public benefit. These included:

- Improving **health and wellbeing** and **avoiding harm**.
- Improving **service provision** (health services or others) either through improved knowledge or a result of financial contributions generated from the data sharing project.
- Better **resource allocation**, by using insights from data to target support at the right people (e.g. those most in need of financial or other types of support) and using data to ensure services were provided where they were most needed.
- Contributing to wider positive **financial, economic and environmental benefits.**

Support for data sharing, and private sector access to data from the public sector in particular, was based on the assumption that certain conditions would be in place.

Participants wanted reassurance that there would be a degree of control over access to data and that the benefits from data sharing would be distributed in a fair and equitable way. Some of the factors they would like to see in place for data sharing to be in the public benefit included:

- A **form of benefit sharing** in place. Participants wanted to see benefits shared, either between organisations or with the wider public. Profit sharing arrangements in particular were seen as a way of reassuring the public that private sector access to data was not purely motivated by financial gain, and that profit generation and public benefit could co-exist.
- A written or **contractual agreement** in place to govern the use of public sector data outside of the public sector and its intended benefits. As well as creating terms and

conditions for how data would be used, participants wanted to see this include reference to how benefits from the data project (financial or otherwise) would be distributed.

- A process of **due diligence and oversight** that means private or third sector organisations are held to account for their use of public sector data. As well as through a contractual agreement, it was felt that this could be through an independent scrutiny body or an approval panel.

The panel identified a few circumstances in which they would consider data sharing to not be in the public benefit:

- When the project is **detrimental to or causes negative impacts on society**, or to any particular group.
- When **profit is the sole driver for the project** and data are used to exploit members of the public. Examples included the use of data by insurance companies purely to increase rates, or use of data by a pharmaceutical company to increase the prices of a medicine, which might make it inaccessible to those who need it.
- Where it leads to **targeted selling** or where data are **passed on to third parties to sell products or services.** Opposition to this was driven by a desire to protect individual privacy and to avoid people in vulnerable situations being taken advantage of.

Participants felt that public sector data should be anonymised before being shared with the private sector.

Participants were uncomfortable with the potential access to non-anonymised data by private sector companies due to the concern, highlighted above, that this could lead to targeted selling.

Introduction

Background

In late 2022, the Scottish Government and its partners from Research Data Scotland, the Digital Health and Care Directorate and Sciencewise convened a public panel to explore the ethics of public sector use of data. The purpose of the panel was to inform approaches to data use by the Scottish Government and public sector agencies in Scotland.

Using a deliberative public dialogue approach, facilitated by Ipsos, the panel (consisting of 25 people from across Scotland) met over six three-hour online workshops to answer the question: ***What guidelines should the public sector follow when using citizens' data?*** The panel listened to presentations from experts, learned about the issues, discussed them, and then drew conclusions together to form a set of ethical guidelines. A copy of the guidelines is included in appendix A, while the full report of the findings can be found on the Scottish Government website.

Over the course of the original workshops, some issues arose that were not covered in great detail but that the panel deemed necessary for the public sector in Scotland to consider when using data about citizens. This included the concept of public benefit, and specifically the extent to which data sharing outside of the public sector (for example, with private or third sector organisations) is in the public benefit. This was important to the panel but there was limited time and opportunity to explore in depth what this meant to the participants.

The Scottish Government, in partnership with Research Data Scotland and Sciencewise, therefore commissioned Ipsos to facilitate two additional workshops with participants who took part in the original panel to explore these issues further. This report summarises the key findings from the additional workshops. It should be read in the context of, and as an addition to, the wider report from the original workshops.

Research aims and methodology

The aim of the two additional workshops was to explore views on the following overarching questions:

- ***When might data sharing be in the public benefit, and when it is not?***
- ***What are the benefits of data being shared outside of the public sector?***
- ***When data are shared, who should benefit?***

Ipsos designed and facilitated two additional sessions that members of the original panel were invited to. Of the original panel, 20 members expressed an interest to continue being part of the panel (and gave permission for their details to be retained for this purpose). Of those invited, 15 returned for additional meetings which took place in March 2023.

The two online workshops followed a similar structure to the original panel sessions. Participants listened to presentations from experts (including representatives of data sharing projects and speakers that raised ethical considerations about data sharing), learned about the topics (private and third sector use of data, benefit sharing as a way of ensuring public benefit, and ethics of data sharing) and then discussed the issues together before reaching conclusions. The workshops also provided the panel with the opportunity to review and comment on the final ethical guidelines they had developed in the original workshops.

The overall structure and content of the workshops is summarised in figure 1.1 overleaf. Further details about the sessions (including an overview of each session with dates, times, content and specialists) can be found in appendix B.

Figure 1.1: Table showing structure of reconvened workshops

	Session 1	Session 2
Content	**Welcome back in plenary** **Discussion in groups:** Review of ethical guidelines Initial views on data sharing **Presentation in plenary** on private sector use of data **Discussion in groups:** Reflections and discussion on private sector use of data **Presentation in plenary** on benefit sharing **Discussion in groups:** Reflections and discussion on benefit sharing **Q&A in plenary** **Discussion in groups** on topics covered in first session	**Recap on session 1 in plenary** **Presentations in plenary** from representatives of data sharing projects **Discussion in groups:** Views of projects (overall sentiment), discussion around benefits and risks (including who benefits and how) **Q&A in plenary** **Presentation in plenary** from patient representative group **Presentation in plenary** on ethics of data sharing **Discussion in groups:** Thoughts on presentations, shifts (if any) in views, new issues emerging **Q&A in plenary** **Discussion in groups:** Focused discussion and conclusions on key questions 1 – When data sharing is in the public benefit, and when it is not? 2 – What benefits? 3 – Who should benefit?

The workshops were funded and guided by the Scottish Government in partnership with Research Data Scotland and by UK Research and Innovation's Sciencewise programme, an internationally recognised public engagement programme which enables policy makers to develop socially informed policy. An oversight group – comprising representatives from the Scottish Government, Research Data Scotland, and independent experts from academia and civil society – met in March 2023 to advise on the additional workshops. Details of the oversight group are provided in the full report from the original workshops.

Data sharing and public benefit – initial views

This chapter explores participants' early perceptions of data sharing outside of the public sector and the extent to which they considered data sharing to be in the public benefit. It outlines their initial views, as shared in the first of the two workshops.

Data sharing

To help support their discussions, participants heard an introductory presentation, delivered by Ipsos, explaining what data sharing means and reasons why data might be shared between the public and private sectors.

The introductory presentations on data sharing covered the following:

- Who might share data? Public sector, private sector, third sector
- Why might the private sector want public sector data?
- Why might the public sector want private sector data?

Following the presentation, participants were asked how they currently felt about data being shared outside of the public sector, with a particular emphasis on sharing with the private sector.

Different levels of comfort with private sector access to data

Potential benefits of sharing public sector data with the private sector were recognised. It was seen as helping to encourage innovation, for example with drug development, which could help to support the treatment of health conditions. This was seen as particularly important in the context of limited public sector finances and a perception that resources were stretched within the NHS. The development of Covid-19 vaccines was given as a positive example of how private sector use of data can have widespread impacts on society.

> "We shouldn't necessarily see the private sector as the big bad wolf, there are opportunities to combine public and private sector data for the benefit of society and commercial organisations as well. If we don't, we will be so behind…Covid was an example, the positives are huge and we can see how it would be a benefit in the future." (Session one)

However, there was also discomfort about private sector access to data. Concern was expressed about the potential lack of control over how commercial companies might use data, and there was a perception that the private sector may not be subject to the same level of scrutiny on data use as the public sector. One example was that commercial companies may exploit their access to data and use it to target individuals and conduct cold sales calling, which was seen as an invasion of privacy.

> “Private businesses are there to make as much money as they can. If they're allowed to get a lot of data about people, that will be out of our jurisdiction. There are a lot of risks involved and that is something that we need to look in to in detail.” (Session one).

Some felt that the acceptability of data sharing would depend on the sector. While health data was seen as having an obvious link to public benefit, as it could lead to improvements in the diagnoses and treatment of health conditions, the benefits from other sectors were less clear. The energy sector was used as an example, where it was felt that organisations may use data about customers to target them with sales information – which may result in people in financially vulnerable situations being taken advantage of.

For those that described themselves as uncertain or “on the fence” about data sharing, they recognised both the potential benefits and concerns about private sector involvement outlined above. They felt that a balance needed to be found, to ensure that the exchange of data was mutually beneficial and that no individual organisation was getting too much of an advantage over the other.

Desire for de-identification of data and oversight of private sector data use

Participants said that de-identified data would help them feel more comfortable about private sector access to public sector data. They felt that pseudonymisation, or other forms of de-identification, of data would help reduce the risk of private sector organisations using data to target individuals and attempt to directly sell their services. It was acknowledged, however, that some circumstances required personal information to be used – with reference being made to the shielding list project explored in the previous workshops – and that there may be exceptional circumstances where de-identification is not possible.

> “I agree that there is a lot of bad publicity and bad feeling about companies who would be cold calling individuals, which I don't agree with. But if we can de-identify a lot of data, then we can stop that. I think public sector-private sector [collaboration] has a place.” (Session one)

The need for oversight of the data sharing process was also emphasised. At this stage participants did not say what exact type of oversight would be most appropriate, but said they would want reassurance that a system or process was in place to ensure that data sharing outside of the public sector was carried out in a robust and ethical way. In particular, they wanted to ensure that all parties were keeping data secure and there was a level of accountability in place for its use. These views again echoed those of the original workshops and the ethical guidelines developed by the panel, which highlighted the importance of accountability and oversight of data use.

Public benefit

Having a clear public benefit was seen as an important consideration for any data sharing by the public sector. This was highlighted in the original panel, with public benefit being one of the overarching themes of the panel’s ethical guidelines. To help participants explore the concept further, they were first shown a summary of the ways they had described public benefit in the original workshops (see figure 1.2).

Figure 1.2: How participants had described ‘public benefit’ in the previous workshop

“Benefit everyone without causing negative effects to anyone.”

“Benefit for all society, regardless of class or status.”

“Benefit to particular groups, such as minority groups.”

“The reduction of harm.”

“An increase in wellbeing.”

“Not the same for everyone – but influenced by everyone’s personal ethics.”

Public benefit was considered a broad concept

Participants’ views on public benefit had remained largely unchanged since the earlier workshops and, for the most part, they agreed with their previous interpretations of the term. However, they emphasised that public benefit need not always apply to the whole of society, and argued that this would be too difficult to achieve in every case. They felt that public benefit could apply to a smaller group of society, as long as this did not disadvantage or lead to negative impacts on others. There was also a sense that public benefit was broad and hard to define absolutely, as it can vary depending on the context and specific use of data.

Private sector use of data can have a public benefit

Though there were different views on the acceptability of private sector access to public sector data, it was felt that private sector organisations could contribute benefits to the public even if profits were also being made. The example of Covid-19 vaccines was used again, as this was seen as indicative of organisations being able to contribute to the wider public good (by reducing the impacts of the virus) while also making profit (for pharmaceutical companies and others). Other examples of public benefit and profit co-existing included private sector organisations using data to help diagnose illnesses, introduce or improve transport services, or develop fitness centres or other facilities to benefit communities. In these cases, profit did not negate the positive impacts that could be achieved.

Impacts on the wider economy were also discussed, and it was felt that profit-making companies already contributed to the wider public benefit by paying taxes and contributing to local economies. These were considered part of the wider public benefit that could be achieved through private sector use of data.

> “As long as they're paying tax that [goes] back into the public sector. As long as the profit was coming back to the country, I'm quite happy. That's how business works. They have to make money.” (Session one)

There was, however, some scepticism about the motivations of some commercial organisations. For example, there was concern about the use of data to sell insurance and other services, or pharmaceutical companies using data to justify charging more for their products which would make them less affordable and accessible. In these circumstances, participants felt the private sector would be predominantly motivated by profit and struggled to identify a public benefit. Voicing these concerns, participants again emphasised the need for mechanisms to be in place to oversee private sector use of data.

> “The word to avoid is exploitation - of anyone's data or position. Control mechanisms should be in place, with stringent ones [placed] on the private sector.” (Session one)

Views on public benefit and private sector use of data developed further after participants considered the idea of benefit sharing, and then considered some examples of data sharing projects. These are explored in the following chapters.

Benefit sharing

Background to benefit sharing

To help support their discussions further, the panel heard a presentation on data sharing and benefit sharing by an academic from the University of Edinburgh. The presentation first outlined some of the key issues around private sector use of public sector data, including what previous public engagements had found on this topic. It then explained benefit sharing as a way of ensuring there is a public benefit when data are shared.

Benefit sharing was described, broadly, as the idea that benefits of research (including data projects) should be shared in a fair and equitable manner, avoiding exploitation of individuals or groups. The presentation outlined reasons why benefit sharing might be considered, including:

- Addressing issues of justice and fairness
- Avoiding harm and promoting public good
- Promoting trust
- Creating a moral economy – where data sharing should be to assist others rather than for financial gain
- Involving the public in decisions about how benefits are distributed
- Enabling acceptable private sector involvement.

The presentation drew on previous research carried out for the Scottish Government which included a literature review to identify international approaches to benefit sharing.[1] A selection of these approaches were presented to the panel for discussion (figure 1.3). It was stressed, however, that these approaches can overlap with each other and are not mutually exclusive.

Figure 1.3: Potential approaches to ensure public benefit

Sharing profits from using public sector data, e.g. profits returned to the public sector.

Collaborative arrangements involving many stakeholders.

Community-based partnerships including consultation to identify community needs.

Contract-based models making terms clear and legally binding.

Benefit sharing considered as part of **access approval**.

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[1] Scottish Government publication on Public Acceptability of Data Sharing Between the Public, Private and Third Sectors for Research Purposes (2013), link to publication on the Scottish Government website: https://www.gov.scot/publications/public-acceptability-data-sharing-between-public-private-third-sectors-research-purposes/

Perceptions of benefit sharing

Positive reactions to the concept of benefit sharing

Benefit sharing was considered a good idea and a positive way of ensuring that public benefits were realised. Participants felt that it was only fair for benefits to be shared, either between organisations or with the wider public. They welcomed the collaborative aspect of benefit sharing, which they felt demonstrated a sense of trust and transparency between the organisations involved and helped ensure that benefits would be distributed fairly.

Participants' discussions focussed mainly on how benefit sharing would work in practice. They were particularly interested in understanding more about how decisions were made, such as around who should benefit, how profits should be shared, and what oversight mechanisms are in place.

Some questions raised by the panel:

"If profits are returned back to the public sector, who decides where that money goes and what is that decision based on?"

"How would you get an approval panel? How would they pick people for it?"

"How would an approval panel work in the context of the Scottish Government?"

"How do you avoid benefit sharing being a sham – where an organisation claims there are public benefits, but they are not genuine?"

Oversight and scrutiny are essential

The importance of oversight of the data sharing and benefit sharing process was highlighted by participants. They were supportive of the idea of an independent scrutiny body to oversee not just the acceptability of a data project (which the panel had recommended in the ethical guidelines produced in the previous workshops), but also the extent to which benefits would be realised and shared. Participants felt that this would provide a form of due diligence, and a form of scrutiny that they had previously identified as important when considering data sharing (as highlighted in the previous section).

> "I can see that with due diligence and an access approval panel assessing the benefits, the obvious "get rich quick" schemes will get kicked out and the ones that have genuine public benefit will, rightly, get approved." (Session one)

The presentation on benefit sharing referred to access approval panels, which could provide independent scrutiny of projects and benefit sharing proposals. Access approval panels were welcomed and seen as a way of providing reassurance that the public benefit of data sharing was being considered.

Community involvement can lead to positive impacts

Public engagement and public consultation were described (in the presentation) as ways of helping decide how benefits should be distributed. Involvement of the public in the initial stages of a project, and throughout, was viewed by participants as a positive way of involving people that might be impacted by decisions (e.g. members of a community that might be impacted by the data project). Where organisations that use public data have a positive relationship with the community affected, it was felt that this could lead to better outcomes because communities have a say on projects that impact them and on how the benefits should be distributed. It was also felt that involving communities could help create a sense of empowerment for community members.

> “If you get the buy-in from the community, that can [help create] long-term changes and improvements.” (Session two)

However, there were different views on the extent to which the public should be involved in an approval panel. On the one hand, it was felt that members of the public should be included because they could provide an objective perspective on a project, without being driven by financial motivations. On the other hand, there was a view that it would be too difficult to compose a panel that would adequately represent different views within a community.

> “I think it would be better [including] members of the public. I think they would be more natural and honest, with no profit making interests. (Session one)

> “I can see some problems with…. the community having a say. I can see that getting really complicated if you have very disbursed communities or communities of interest.” (Session one)

Profit sharing arrangements can help to demonstrate public benefit

Participants were broadly supportive of profit sharing arrangements, in which profits resulting from private sector use of public sector data would be shared with public sector partners. It was felt that this arrangement could ultimately help to support public services, and therefore have public benefits for wider society. It was seen as a way of ensuring mutual benefit of data sharing, offering the opportunity for both the private sector and the public sector to gain financially. The possibility of profit sharing models also caused some to say they would feel more comfortable with private sector access to data, as re-investing into the public sector would mean that both profit and public benefit could be achieved.

> “Profit is going to be a main aim for private companies, but as long as it's not exploitative [it is acceptable]. There's definitely room for profit sharing to reinvest into the public space.” (Session two)

There were also challenges discussed in relation to profit sharing. One participant viewed this model as a “slippery slope” towards privatisation of the NHS, as it suggested a move towards a more profit-motivated way of working. There were also mixed views on the likelihood of private organisations being willing to share profit with the public sector. Participants therefore wanted to know more about how this process would work, particularly who would decide on where profits were distributed to and how.

Importance of accountability

There was concern that some private sector organisations may claim to be delivering a public benefit, but not actually do so. Having clearly defined and agreed benefits built in from the beginning, evidenced through a contract between the data sharing organisations, was seen as a way of reducing this risk and ensuring efforts were made to deliver the intended public benefit.

> "…some of it can just be lip service. In the private sector, if it's not in a legally binding document then it's not happening." (Session one)

There was also a desire among the panel for organisations to be held accountable if they do not deliver on benefit sharing arrangements or if public benefit does not materialise. However, there was recognition of the exploratory nature of some research projects, which may mean that public benefit is less tangible or not realised until sometime in the future.

> "All projects are ideas, they don't know if they will be of great public benefit or not. Ideas can gradually get better…[maybe] it didn't work out as good as they hoped, but there might still be ideas beneficial in the future." (Session one)

One option discussed was an audit of organisations' use of data, to follow up on whether they had contributed the benefits they had agree to, including any profits they agreed to share.

Contract-based models, in which the terms of data sharing and approach to benefit sharing were agreed in writing, appealed to participants. There was a level of expectation that data sharing would be carried out under a contractual agreement anyway, but the inclusion of conditions around the terms and conditions of benefit sharing was seen as appealing. Participants felt this would hold organisations to account for ensuring they distributed benefits (including profits, if that was part of the arrangement) fairly.

> "[Contracts] would build confidence in the public and give some reassurance that, the whole concept is to actually create a benefit for all. It's a binding contract." (Session two)

Extent to which views changed

The panel felt that the issues related to private sector use of data echoed much of what they had already discussed, either earlier in this session or in the previous workshops. They recognised many of the findings from previous public engagement on this topic (as outlined in the presentation[2]), particularly where it showed that previous groups of the public expressed concern about pure profit, but acceptance of the value of private sector innovation; a feeling that private sector access should result in public benefit e.g. improvement in services; and concerns

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[2] The presentation provided a summary of key themes that had been identified in previous public engagement on the topic. The themes are summarised in slide 2 of the presentation, in Appendix C.

about security of data. It was common for participants to say that these findings in the presentation reflected and validated their own perspectives. This provided a sense of reassurance that the panel were “on the right track” in terms of their own deliberations.

Having learned about benefit sharing and spent time discussing the various pros and cons of data sharing arrangements, some participants said they had become more positive about data sharing with the private sector. While it was noted that benefits will depend on the nature of the project, it was felt that data sharing could have positive impacts on public wellbeing and public services.

> "When we first discussed it in previous groups, there was hostility, but I think as we've unpicked it, I feel more reassured. There are still things you want to make sure are in place… but overall I feel more reassured than I did when I first started." (Session one).

There were still some concerns that there may be companies that are attempting to access data for reasons not within the public benefit, and participants therefore emphasised the need for adequate checks on those organisations.

Reviewing data sharing projects and wider considerations

To help explore participants' views on data sharing outside of the public sector, the panel heard presentations from specialists representing two projects that used or wanted to use public sector data. The specialists were selected to help bring the concept of data sharing to life, to facilitate a dialogue between participants and users of public sector data, and to support participants to reach more informed views.

The first project represented private sector use of data and the second represented third sector use of data. Participants were asked to consider the extent to which these projects provided a public benefit, as well as considering any risks or benefits from the projects. They then heard from two other speakers that provided a broader perspective on data sharing: one who represented the perspective of those whose data might be used (patient groups), and one who reflected on broader ethical considerations for the panel to consider.

This chapter explores the panel's views on the data sharing projects, their reflections on the wider considerations, and how this impacted on their views on data sharing and public benefit.

Project examples

1: IQVIA

IQVIA is human data science company, providing various services in the healthcare field. IQVIA uses clinical records and patient data for healthcare research. The project example presented to the panel involved accessing anonymised health data (from NHS England's Cancer Analysis Service) to help understand patients' characteristics (age, gender ethnicity, etc.), treatments and conditions. The research findings helped inform development of new cancer treatments.

2. National Emergencies Trust (NET)

NET is a charity that raises funds to support people affected by disasters. A representative from NET presented an example of how it hopes to access public sector data. NET would like to use personal, identifiable NHS data to contact disaster survivors about support available to them and then provide that support. This would include accessing sensitive data (such as number of nights spend in hospital) to help access the amount of financial grant available to them.

Potential for public benefit from both projects

The panel felt there was a clear public benefit to the IQVIA project in terms of increasing understanding of cancer and the development of treatments that could improve health outcomes and extend lives. By enhancing knowledge and understanding it was seen as potentially having wide reaching impacts on patients, NHS staff, pharmaceutical companies, and charities that work in the field of cancer who would better understand how to use resources.

> "It feels to me very integral. It felt like it was a very important step in terms of medical science." (Session two)

They also identified public benefit from the NET project in terms of providing financial assistance to survivors of a disaster and bereaved families, which could provide them with vital support and reduce their stress and worry.

> "I think if something like that happens and you're in hospital, people will have debt and be worrying how they're going to cope. I think it'd be a huge impact on somebody's life if they were in a disaster like that. I think it's a fantastic charity." (Session two)

However, some panellists expressed some reservations about a potential lack of control over how money provided through the NET project was used. NET does not stipulate how the financial support should be used by recipients, but participants felt there was a risk that the funding might be accessed by individuals who did not need it.

Anonymisation of data was an important consideration

Perceptions towards both projects were influenced by the level of anonymisation of data. The importance of anonymisation as an ethical consideration reflected the views of the original workshops, in which participants expressed concern about the level of identifiability of data and a desire to protect individual privacy.

The perceived public benefit of the IQVIA project was linked to the use of anonymised data. This provided a degree of reassurance for participants that individuals' personal details would remain private and would not be misused. It was also largely felt that the use of anonymised data meant that consent was less of an issue than if identifiable data was used. Nonetheless, while not seen as essential, it was also felt that informing patients about this use of their data would help to demonstrate transparency.

> "I'd prefer that [patients] did know because it's better to be transparent than not. I think a lot of things go on nowadays in the background that you don't know about." (Session two)

In contrast, the use of identifiable data was highlighted as a risk of the NET project. While there was recognition of the need to act quickly in an emergency, panellists commented that (based on the information in the presentation) those affected would not have consented to sensitive personal data being shared and may not want to be contacted.

> "Where [NET] get the data from might make people feel a bit icky. All of this information is just being passed onto somebody [that people] didn't consent to." (Session two)

To mitigate risks associated with breaches of data privacy it was suggested that information about NET could be shared by hospital staff for people to get in touch if they were interested, rather than being contacted directly by the organisation.

Risks of data being used by other organisations

Participants questioned whether there was a risk that IQVIA would share data with other organisations such as insurance companies. This was linked to a perception that insurance companies might use research insights to influence insurance policy decisions, or to target individuals to sell products. It was explained (in the Q&A) that IQVIA does not have access to raw data or any identifiable information, and that they only share insights from the research rather than the data itself. Participants seemed reassured by this response.

Vulnerable individuals may be at risk of fraud

Perceived risks related to the NET project were that individuals might make false claims, and that vulnerable individuals might suspect contact from NET as being fraudulent. Panelists were interested to know how NET overcomes these potential issues and there was some discussion about whether having one charity to coordinate this kind of a response may reduce the risk of fraud.

> "…there are so many scams on the go at the moment where you get cold calls, it just rings alarm bells…how they would do this in a way that doesn't lead to confusion." (Session two).

Appetite for more information on the organisations and the projects

The panel raised questions about both organisations that highlighted some of the issues that were important to them. To help them assess more fully whether projects were in the public benefit, they wanted more information on the background to each organisation, how they were funded and what their overall role ethos was. Views did not seem influenced by whether the organisation was in the private sector or third sector – participants raised similar types of questions for both organisations. Their questions also highlighted a desire for more information about how data was kept secure and data breaches were avoided.

Questions that were raised, and answered, in the Q&A with IQVIA included:

- "How are [IQVIA] funded?
- "Where does the money for [NET] come from?"
- "What were [IQVIA] actually set up to do? What is their ethos? Where is the profit coming from?"
- "What else do [NET] do?"
- "What processes are in place to prevent a data breach?"

Further perspectives on data sharing

To help provide a broader perspective on the topic of data sharing outside the public sector, the panel heard from two further speakers. One provided a patient-led perspective on how data should be used, and one provided an ethical challenge, by highlighting some of the broader ethical considerations that panellists may wish to consider when thinking about data sharing projects.

1: use MY data

use MY data is a movement of patients, carers and relatives focussed on patient data. Members argue for patient data to be used to save lives and improve outcomes. The presentation described how use MY data works to increase their members' understanding of data sharing, encourage members to have a voice in the decision-making process, and to help overcome issues with that in terms of increasing transparency and safeguarding.

2. Ethical challenge

A presentation on the ethics of data sharing was given by an academic from the University of Edinburgh and The Alan Turing Institute. The presentation acted as a reminder of some of the ethical considerations which the panel were introduced to in previous panel meetings: privacy and confidentiality, consent and data use agreements, data security, and ownership.

Advocating for patients' rights was welcomed

The existence of use MY data provided a sense of comfort and reassurance to the panel, as it was an organisation that was advocating for the rights of the public. By representing patients, carers and relatives, it was seen to be providing a worthwhile and beneficial service for the public.

> "If there are… groups of people that are advocating for our best interest, learning more about that can make you feel more comfortable." (Session two)

They also welcomed the organisation's efforts to help ensure the process of data sharing was carried out the right way – some compared its role to the work of the panel, as both were helping to develop principles around how data should be used. However, there was some cynicism about the organisation's ability to influence how patient data was used, given the assumption that health data will be shared anyway, regardless of their involvement.

Importance of informing the public about how data are used

The presentation from use My data included information about a range of ways the organisation informed its members about how patient data was used (including webinars, workshops and newsletters). The organisation's role in informing the public about data use was viewed positively, as participants felt this would help convey the benefits of data sharing, in language and terminology that the public would be able to understand.

Privacy and consent remain key considerations

A key consideration that stood out for participants from the ethics presentation was the importance of protecting confidentiality and protecting against data breaches. They noted that this had been a key consideration for the panel in the original workshops, and felt it was still an important aspect to consider when sharing data outside of the public sector.

Discussions around data protection also came back to the issue of consent. The national opt-out system for NHS England (in which patients can opt out of their information being used for research) had been mentioned in the presentation from use My data, and some felt that this should be applied to the use of data by private sector organisations.

> "I thought the opt-in and opt-out was a good thing…but it was mainly in England rather than Scotland. I'm all for them using the data as long as it's not being breached or passed on to call centres. But I do think people should have the choice to opt out if they don't want people to have their data." (Session two).

The idea of an opt-out system was compared with the national organ donation programme, in which people are considered to have agreed to be a donor unless they formally opt out. Having a similar approach was seen as a way of reassuring the public, particularly those uncomfortable with private sector access to data, that their data would not be used in ways that would not want it to be. However, it was also felt that consent of this nature would not be necessary if there was a guarantee that identifiable data was not being shared.

Extent to which views changed

The data project examples, and the wider considerations related to data sharing, confirmed many of the issues that were already important for participants. The project examples, particularly the healthcare related one (IQVIA), helped demonstrate that public benefit can be achieved as a result of private and third sector involvement in data. Hearing from the private sector example, which participants felt had a strong public benefit due to the impact on cancer treatment, caused some to feel more comfortable with profits being made - as long as this was alongside a clear public benefit.

Overall, panellists noted that many of the considerations outlined by in the ethics presentation had already been covered in the panellists' deliberations, and this provided both a useful reminder and a sense of reassurance that specialists were considering similar issues to the panel.

Reflections on the presentations also helped to confirm some of the factors that were important when data was being sharing outside of the public sector. These are outlined in the concluding chapter.

Conclusion

These two workshops, delivered as part of the wider public dialogue on use of public sector data, set out to understand public views on these questions:

- When might data sharing be in the public benefit, and when it is not?
- What are the benefits of data being shared outside of the public sector?
- When data are shared, who should benefit?

This chapter outlines the panel's overall findings by revisiting each of these overarching questions. It draws on the findings outlined in previous chapters, as well as participants' final reflections on these questions at the end of the second workshop.

Types of benefit that would be expected from a data sharing project

The panel felt there was no single definition of public benefit and that this should be judged on a case-by-case basis. However, they identified certain outcomes that they would expect to see from a data sharing project to be considered in the public benefit. These included:

- Improving **health and wellbeing** and **avoiding harm.** This echoed views from the original workshops, in which participants expressed their interpretation of public benefit using these terms.
- **Improving service provision** either through improved knowledge or a result of financial contributions. The main example of service improvement that participants kept returning to was in relation to health services, and the ability for data sharing projects to lead to better diagnosis and treatment of health conditions. The ability to improve health services was seen as particularly important in the context of limited public sector resources and lengthy NHS waiting lists.
- Better **resource allocation**. This included using insights from data to target support at the right people, for example those most in need of financial or other types of support, and using data to ensure homes, infrastructure and other local services were provided where they were most needed.
- Contributing to wider positive **financial, economic and environmental benefits** – this was expressed in broad terms and not defined further, reflecting the general views that there was no single type of benefit that would be expected from data sharing project.

Conditions which would help demonstrate public benefit from data sharing

The panel identified a number of factors that they would like to see in place for data sharing to be in the public benefit:

- A **form of benefit sharing** in place. This could include a profit-sharing arrangement (in which some profits are passed back to the public sector), collaborative arrangements between a range of organisations and partnerships with communities. Profit sharing arrangements in particular were seen as way of reassuring the public that private sector access to data was not purely motivated by financial gain, and that profit generation and public benefit could co-exist.

- A written or **contractual agreement** in place to govern the use of data and its benefits. As well as creating terms and conditions for how data would be used, participants wanted to see this include reference to how benefits from the data project (financial or otherwise) would be distributed.

- A process of **due diligence and oversight** than means private or third sector companies are held to account for their use of data. As well a contractual agreement, it was felt that this could be through an independent scrutiny body or an approval panel.

Circumstances in which data sharing would not be in the public benefit

The panel identified a few circumstances in which they would consider data sharing to not be in the public benefit:

- When the project is **detrimental to or causes negative impacts on society**, or a particular group.

- When **profit is the sole driver for the project** and data are used to exploit members of the public. Examples given to illustrate this point was the use of data by insurance companies purely to increase rates, or use of data by a pharmaceutical company to increase the prices of a medicine, which might make it inaccessible to those who need it.

- Where it leads to **targeted selling** or where data are **passed on to third parties to sell products or services.** Opposition to this was driven by a desire to protect individual privacy and to avoid people in vulnerable situations being taken advantage of.

Participants felt that public sector data should be anonymised before being shared with the private sector. Participants were uncomfortable with the potential access to non-anonymised data by private sector companies due to the concern, highlighted above, that this could lead to targeted selling.

Groups that should benefit from data sharing

As noted earlier, public benefit was seen as a broad term and it was therefore felt that data sharing projects could benefit broad society (e.g. through widespread advances in medical research) or specific groups (e.g. those in a community that would be impacted by data-driven decisions).

Participants were supportive of data sharing projects that could support vulnerable groups, for example if the project led to improved funding, benefits, or provision of specific services. There was also a feeling that people whose data are being used should be the ones to benefit – for example in the case of medical research on a particular condition, which should ultimately benefit people with that condition.

Views on data sharing did not differ greatly in relation to private or third sector organisations. Participants wanted the same checks and standards to apply to organisations in any sector – in either sector, they wanted confidence that the organisations would treat the data securely and that the process would be robustly assessed and monitored.

Appendices

Appendix A: Original ethical guidelines produced by the panel

When using citizen's data, the public sector should manage the PURPOSE by:

- Ensuring the purpose for using the data is clearly defined and used only for that purpose. Timescales for use should be clearly defined.

- Having a clearly agreed justification for using citizens' data (i.e. if there is a clear public benefit) and ensuring that only data that is necessary for the project is used.

- Ensuring that data are not used solely[3] (directly or indirectly) for profit by private sector organisations. The public sector should ensure that it and private sector partners only use data proportionate to the specific purpose it was collected for.

- Not using data outside the scope of any consent that applies to the data.

- Not sharing data beyond the agreed organisations. If more organisations are included later in a project, they should go through an ethical assessment.

When using citizen's data, the public sector should ensure TRANSPARENCY by:

- Making clear what data are being used and for what purpose.

- Making clear which organisations can access the data, and why.

- Specifying how long data will be stored for before deletion.

- Ensuring the public can easily access information about the project, including: what data are being used and for what purpose, how long data are stored before they are deleted, and a summary of findings or impact of project (where it is legally possible to do so and where individuals are not identified).

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[3] Inclusion of the word 'solely' was not agreed upon by all participants in the final ratification of these guidelines, but rather reflects general discussions around the involvement of the private sector in using data about citizens. This explained in more detail in the "deliberative journey" chapter.

The public sector should ensure the use of citizen's data is in the PUBLIC BENEFIT by:

- Clearly defining and explaining what the public benefit is.

- Considering whether the public benefits of using the data clearly outweigh the risks. Any potential harms from use of the data need to be analysed and weighed against the benefits.

- Considering negative impacts to the public and/or the environment or economy, with possible longer term impacts also considered. Projects that benefit or make a positive impact on a small number of people can be in the public benefit, provided they do not negatively impact others, the environmental or the economy.

- Ensuring that identifiable data are only used if it meets the standard of achieving public benefit.

When using citizen's data, the public sector should ensure there is ACCOUNTABILITY by:

- Clearly documenting the process used to decide whether the project should go ahead (to an agreed formal structure

- Ensuring there is a hierarchical organisation chart to show who is responsible/accountable for each aspect/stage of the project.

- Seeking approval and oversight from an independent panel on whether a data project should go ahead or not, including whether public benefits outweigh risks. The panel should make decisions based on what is in the best interests of the public and there should be no declared conflicts of interest on the panel.

- Consulting members of the public on the acceptability of the use of the data (for determining principles but not to decide if a project should go ahead or not – this is the role of the independent panel).

- Ensuring an ethical assessment is carried out once the scope of the project is known.

- Taking responsibility when something goes wrong and stopping the project if necessary.

- Ensuring there is independent oversight from a third party (e.g. Information Commissioners Office and DIN) for projects involving the private sector, with clear sanctions for misuse (criminal and civil).

When using citizen's data, the public sector should ensure DATA QUALITY by:

- Establishing and publishing a minimum quality standard for data projects (that includes consideration of how much data is needed). The extent to which data projects meet the threshold for data quality must be checked and continually assessed by the team delivering the project. If there is involvement from the private sector, these checks should be made by someone from government/public sector.

- Using up to date data that matches the agreed purpose and specific scope.

- Ensuring data are held securely for an agreed period after a project to allow for quality checking.

- Determining who can access the data and monitoring who has accessed the data.

When using citizens' data, the URGENCY should be considered, by:

- Defining what constitutes an emergency. Any impacts of flexing guidelines in this context should be assessed continually, as far as practical, and after the fact (including any lessons learned).

- In an emergency situation, such as where there is threat to life, it may be necessary for data to be used that was not part of the original scope. Considering whether the public benefits of using the data clearly outweigh the risks.

- In the event of an emergency the use of identifiable data can be justified. If the private sector is involved, there should be clear rules about what private sector organisations do with data after an emergency including when they are deleted.

- In an emergency situation, it may be necessary for the timescales for data retention and deletion to be reviewed and extended.

Appendix B: Session summaries

	Date and time	Objective	Session description	Presentations and speakers
Additional session 1	Wednesday 22 March 18.00–21.00	Re-introduce participants to the panel, and introduce key concepts	Participants were re-introduced to each other and re-familiarised with the process. The key concepts of private sector use of data and benefit sharing were introduced. Participants shared initial views on use of data by private sector organisations and perceptions on public benefit, learned more about private sector use of data, and were introduced to the concept of benefit sharing.	Ciaran Mulholland (Ipsos): overview of private sector use of data University of Edinburgh: introduction to benefit sharing Presentations delivered in plenary and followed by small breakout discussions and Q&A in plenary.
Additional session 2	Thursday 30 March 18.00–21.00	Explore views on private sector involvement and benefit sharing in more detail and reach conclusions	Participants explored private sector involvement and benefit sharing in more detail using real-life examples. Presentations, discussions and exercises helped participants bring everything together and reach conclusions on private sector involvement, preferred ways of benefit sharing, and who should benefit.	IQVIA – private sector example of data use National Emergencies Trust (NET) – third sector example of data use Use My Data – perspective from a patient group University of Edinburgh – ethical considerations Presentations delivered in plenary and followed by small breakout discussions and Q&A in plenary.

Appendix C: Text used in presentation on benefit sharing

Slide 1: Key issues around private sector use of public sector data

- Previous work suggests ambivalence around private sector use of public sector data
- Concern about “pure profit” but acceptance of value of private sector innovation
- Private access should result in public benefit e.g. improvement in local services
- Suggestions around profit sharing and companies paying for information
- Some private sector organisations considered “better” than others

Slide 2: Benefit sharing

- A potential set of solutions to ensure public benefit
- Public benefit might include health and social benefits
- Roots in International Law in relation to benefits from natural resources
- But can be more widely applicable – for example with respect to data
- Early work considered this with respect to genetic data and data sharing for research purposes

Slide 3: Why might we consider benefit sharing?

- Address issues of justice and fairness
- Avoid harm and promote public good
- Promote trust
- Create a “moral economy” – solidarity based approach where data sharing should be to assist others rather than financial gain
- Could involve publics in decisions about benefit sharing
- Enable acceptable private sector involvement

Slide 4: What kinds of benefits?

- Affrdable products, technologies and servoces
- Feedback from use of data
- Monetray benefits – sharing profts/pay to use data
- Societal benefits – reinvesting in communities
- Benefits might be at individual, community or national level

- May be direct (e.g. improved services) or broader and longer term
- Other countries and future generations
- Unrealistic expectataions of benefits

Slide 5: Models of benefit sharing

- Sharing in profits arising from using public sector data e.g. profit returned to public sector
- Benefit sharing proposals considered as part of access approval
- Collaborative arrangements – providing positive social, economic and environmental outcomes for local communities
- Contract based models – making terms clear and legally binding
- Community based partnerships to identify community-based needs
- Most involve independent scrutiny bodies
- Public consultations can help create appropriate models

Slide 6: Criticisms of benefit sharing

- Outcomes of data sharing in and of themselves should be viewed as benefits
- Altruism regarding providing data should be the defining approach
- May be “sham” – not really providing community/public benefit
- May be viewed as legitimising commercialisation or profit

Slide 7: Further questions to consider

- Whi decides what constitutes a benefit?
- How would benefits be distributed?
- Who should be involved in such decisions?
- How would justice, fairness and public good be assessed?

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