Northern Ireland
Public
Data
Panel

Perceptions on the use of Northern Ireland Health and Social Care Data

NIPDP Data Dialogue Report

March 2025

Northern Ireland Public Data Panel
DHCNI, 2nd Floor
12-22 Linenhall Street
Belfast
BT2 8BS
Tel: 028 9536 8465

NIPDP Data Dialogue:

Perceptions on the use of Northern Ireland Health and Social Care data

A 'data dialogue' is the NIPDP approach to deliberations on topics related to data use. Using a deliberative approach[1], panel members participate in discussion and activities to consider opinions and views on a given subject. With the support of facilitators, they collectively explore information they have been provided with, along with their own experiences and views related to address specific questions on the use of data for public good.

The beginning of the day saw the Panel considering three case studies to gauge initial reactions and opinions. These were conducted without prior discussion, capacity building or 'upskilling' of participants, aiming to gain a better understanding of a 'lay' response to data sharing in each circumstance.

In the second part of the day members discussed common themes in use of data, and framed these in the context of Health and Social Care Northern Ireland (HSCNI).

In the third part the Panel revisited the case studies and participated in a 'Knowledge Safari' (an interactive deliberative method designed to create small-group conversations that build upon each other; can be used to arrive at common themes, statements, principles, understanding, etc) to develop a response to the prompt questions.

The purpose was to discover whether any of the topics discussed throughout the day influenced their thinking, approach and opinion to the case studies, and to identify important themes, conditions and recommendations for data use in this context.

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[1] https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

Part 1: Gauging initial NIPDP reaction

Consideration of three case studies.

Case study 1: Sharing data for health and wellbeing

Your daughter Anna is 6, she has always had difficulty focusing on things.

> *Anna gets frustrated with schoolwork which has become more apparent since starting primary school. The teachers have spoken to you about her behaviour and have suggested she might need tested for ADHD.*
>
> *You have raised this with your GP as there have also been difficulties at home. You are becoming increasingly anxious and need support.*
>
> *You have been notified that it is likely that Anna will not be assessed for ADHD for at least another 14 months, and you don't know where to turn for support while you wait for the assessment. You need help now.*
>
> *There are some excellent local play and wider services for families that could be of help to Anna and your family. However, these services don't know about Anna, and you aren't aware that they exist.*
>
> *Would you be happy for the GP to share your details with these services so they can contact you to let you know what they can offer while you await the formal assessment?*

Discussion:

- ***Should your details be shared automatically with such services while you await the formal assessment?***

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

- ***Does it matter which services and who runs them (private, charity, council, HSC, etc)?***

Five people felt that data should be shared automatically in this situation, while three queried the need for consent, and felt consent should be sought before sharing. Several issues for consideration were raised in the discussion:

- It matters '*who'* the data will be shared with – i.e. whether with a community organisation, a private (commercial) organisation, or another branch of the health service.
- It should be made clear to people where their data is going, who it is shared with, and for what purposes, as well as who makes the decisions regarding whether it is 'ok' to share the data, and what will happen with it in the future.
- Sharing 'automatically' was flagged; participants were generally hesitant about this and expressed discomfort.

Importantly, many participants expressed an expectation that their GP data is already being shared across health and social care (HSC), demonstrating that concerns are not always about data *being* shared, but also *not* being shared. **Case study 2: Understanding the impact of air pollution**

Air pollution is a key challenge in dealing with the climate crisis and its impacts on public health.

> *To help identify areas with the worst air pollution, i.e. those that have particulate matter levels above the WHO recommendations, and therefore develop targeted interventions, researchers need data: lots of it.*

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

> *They need to look at how air pollution changes over time to understand what is causing it and therefore what policies and interventions need to be developed.*
>
> *They need environmental data, infrastructure data, and health data, to understand the impact of air pollution on health and wellbeing.*
>
> *By linking together large-scale longitudinal data sets researchers can start to answer these questions, giving decisionmakers more evidence to craft solutions that work for people and communities.*

Discussion:

- ***As an individual, how do you feel about your health data being used for research on air pollution?***
- ***What is important to you about how this is managed?***

Similar concerns arose around commercialization in the second case study discussion, with points raised about the purpose of the research (i.e. if it was for commercial purposes) and the background of the research (i.e. if they came from a private company). Less sensitivity around the use and sharing of data was expressed in this example, with participants expressly raising discussions held previously during the Induction Day in October 2024 about how data that is linked and used for research goes through strict privacy and security procedures (the 5 Safes), meaning the data is de-identified before use, and that this level of privacy gave them more confidence in the data being used in the method of the case study. There were, however, still points raised about the impact of the research, particularly in a place-based example such as this, and any potential unintended negative consequences.

[1] https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

Case study 3: Supporting vulnerable communities in COVID-19

During the COVID-19 pandemic UK public sector bodies coordinated with voluntary, community and social enterprise (VCSE) organisations to provide food to vulnerable people whose immune system means they are at higher risk of serious illness.

> *VCSE organisation were the main agencies with the ability to identify vulnerable people in the community and distribute food, however, one challenge with this initiative was that personal data could not be shared between agencies and organisations (at least not in the early stages) and therefore coordination was complicated.*
>
> *This meant there were instances were some people received multiple food parcels a week from different agencies/organisations, while some had to contact agencies as they had not received a parcel. Coordination did become easier as consent was gathered to share data, but the process was long.*

Discussion:

- ***How do you feel about the sharing of data in this situation? How should this be managed?***

The final case study proved demonstrably more complex for participants, the discussion more wide-ranging and less unanimous. For at least one person, the context of the middle of a pandemic meant dispensing with data-sharing regulations to help the most vulnerable would have been warranted.

However, this brought up detailed discussions around the definition of ‘vulnerable’, which participants recognising that the detail of the word would be crucial to how it is applied, and whether this had intended or unintended outcomes. The point was made that everyone is

1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

'vulnerable' at some point in their lives, but this does not necessarily mean that their data should be based on someone else's judgement of this.

It was felt that in this situation, the solution needed to be narrowly focused on the problem at hand, rather than an 'overarching' approach. Conversely, it was also felt that the public benefit of data sharing in these types of circumstances needed to be better communicated, and this 'grey area' of data sharing in escalated situations needed to be picked apart more thoroughly. Fundamentally, Panel members said, this case study comes down to a question of 'should' vs 'how'.

> **When polled, 10 out of 11 participants felt that in a pandemic situation the data could/should have been shared without consent. If it's not a pandemic situation, zero out of 11 felt the data should be shared without consent.**

Part 2: Evidence and discussion on public views of health and social care (HSC) data use

To understand whether NIPDP participants' views on the use of HSC mapped onto or differed from those gathered in previous public insight research, the second part of the day focused on presenting and discussing evidence and gathering the perceptions of the Panel.

To do this, a review was conducted on articles, which offered insights into public perceptions of data usage, trust, and privacy. These publications, drawn mostly from across the UK, with some European led, focus on understanding public attitudes toward data usage. A range of common themes were drawn out from these works and, with the panel, were deliberated, expanded and contextualised in their perceptions of use of Northern Ireland Health and Social Care data (HSC).

Northern Ireland Health and Social Care (HSC) is the publicly funded healthcare and social care system in Northern Ireland. It provides integrated health and social care services,

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

meaning that hospitals and GP services, and social care (such as home care and social work) are managed under a single system. The HSC is overseen by the Department of Health (Northern Ireland). It is similar to the NHS in the rest of the UK but operates separately, with its own governance and funding structures.

Part 2. Panel Discussion

The panel deliberated and contextualised in their perceptions of use of data from Northern Ireland Health and Social Care (HSC) drawing from published insights into known public attitudes of data usage.

Themes from published reports to prompt discussion were:

- Knowledge, awareness and understanding in the uses of health data and social care data.
- Condition for acceptable use in different ways.
- How Trust in use of data is maintained.
- Uses of health and social care data by different stakeholders, HSC, commercial organisations.
- Charities, academics and other areas of government.
- Benefit vs harm.
- What is public benefit?
- Management and sharing of health and social care data.
- Transparency and accountability.
- Control and consent.

1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

How aware are you of how your HSC data is used?

The Panel felt they are not aware of how their data is used in the context of the HSC. They expressed worry about changes in the delivery of health and social care, with parts of HSC going private, and the risk of private practitioners taking their information with them. One person gave dentistry as an example which the Panel discussed.

> ***Question raised by the Panel:*** *Does the HSC keep sharing personal information, or does a practice retain personal information of HSC patients after it goes private?*

It was clear that where information or data is sent to matters to the Panel. Collectively, they felt that their information should not leave the HSC without their consent. Referral information to private providers should not happen without the patients' consent first. This mirrored previous discussions around the case studies.

One Panel member mentioned that as a patient, their state of mind and levels of anxiety could affect their decision-making. Being ill, anxious or worried may induce someone to consent to things they might not consent to otherwise. They agreed they would like to understand and be asked about these issues before it's at a critical point in their care.

When asked, Panel members individually commented they would not know where to go for information on the use of their data in the HSC, their rights and who they could talk if they had questions or concerns.

A Panel member raised the difference of their information use in a GP surgery versus a hospital setting, questioning if there are the same or different responsibilities for how GPs or hospitals handle their data. The Panel collectively thought it was the same, but the considerations of the setting were a little different.

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A few Panel members gave examples of where their presentation to hospital had shown them their information wasn't known and couldn't be accessed. When discussed the Panel expected - and assumed - data should be shared between and across the HSC to deliver their care. There was collective recognition that you can't opt out of your data being used to receive care services, but there was concern that people working in the HSC who weren't involved in their care might be able to access the data either deliberately or by accident.

> ***Question raised by the Panel**: What are requirements for how confidentiality is managed within our health service, GP practices in relation to access to records, or overheard personal details?*
>
> ***Questioned raised by the Panel**: Is there is a difference in how data is handled between the HSC and private providers and what does this means when private providers are working with the HSC system? GPs and dentistry raised as the examples, and referrals to external services.*

While the Panel had a concern of how private providers got access to, or 'handled' their data one member raised the HSC managing their information as being a bigger risk as, organisation wide, it has more detailed and valuable information, making it more interesting to others, vulnerable and at risk of hacking. The Panel agreed and discussed this risk and their perception of how safe they felt their personal information was. The Panel had mixed views on how safe their personal information was in the HSC but concluded that the issue was they didn't know where they could find information to assure them.

During discussion on the sharing of information, and protection of personal information a Panel member brought up the 'encompass' programme which is introducing Electronic Health Record to the HSC. When collectively asked who had heard of encompass and knows what it is? Three panel members heard of it through work engagement with HSC (3/11), but

[1] https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

didn't know much about it; two had seen signs or advertisements but not through working in the HSC (2/11) and none said they had been directly informed as a patient (0/11).

Use of health and social care data, beyond receiving care, referring to summary findings within the literature

The Panel collectively viewed access to de-identified / anonymised data for other purposes such as research or audit was acceptable when the data was being accessed by HSC, academics or potentially 'health focused' companies. But they queried the definition of the term 'health focused company'. They felt that the definitions and criteria were important, but they had no knowledge of this area currently.

The question was asked, if all applicants must meet the same criteria does it matter who applies to access de-identified data, in terms of what sector they come from, if they are public or private sector, academic researchers or commercial? When polled, only one person felt that what industry or sector the request came from was important (1/11). They strongly felt what the measure of benefit, or patient good, to be the most important question. The simple question of 'what are they accessing the data for?' was important.

The Panel agreed that clear criteria for measure benefit should be available, and who gets to determine this should be known, with the public having direct involvement in both its definition and application.

The Panel were asked if commercial companies should have direct access to patients through their care pathway to ask them to consent to participate in research, whether in person or digitally, and the answer was overwhelmingly 'no'.

In contrast, when asked if they would be open to their care providers, doctors and clinicians asking them about research during the delivery of their care, the Panel said they might feel

1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

this is appropriate, but the situation would matter, and no one had any experience of this to comment on.

> **Context matters: 'Data matters' are 'Human matters'** (*referring to summary finding from the literature).*

They agreed that having awareness of how your data was protected and used affects confidence in the HSC overall.

The perception of the protections around their personal information affected their confidence in both hospitals and GPs. In some cases, the perception of a person on reception conducting triage was an issue, with people being concerned about being asked personal questions about their health by someone they felt shouldn't be asking those questions – or not in such a public place.

The Panel discussed how the changes in service delivery had affected how confident they felt in their data being kept privately? The crisis in GP services was discussed. The Panel examined the impact of not being able to see a named, regular GP anymore. The Panel highlighted concerns they may see a range of locums or practice GPs and they felt this affected their sense of privacy and confidence as they were relying on them for personal care before and they couldn't now.

One Panel member commented about the fear around their privacy not being protected (1/11) and their perception of risk was 'evil in other places affects our fear of use of public service data here'.

> ***Question raised by the Panel:*** *What are we 'reasonably' expected to give up to 'enable' efficiency in public services?*

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

In discussions around the use of data for research, none of the Panel were aware of the HSC being a research active organisation, and no member had ever been approached to take part in research via the HSC.

They collectively agreed they were ‘not aware of the existence of research’ in the HSC, or what it would look like or be in terms of their care experience.

Just over half the Panel reported donating to research charities, either repeated donations or via collection buckets when approached. When asked, almost all felt they support health research as a concept and supported the work of research charities. However, they did not see a linked to the HSC and in particular use of HSC data. The Panel demonstrated that they know about the problems of using data, and of bias in data collection and interpretation. One member raised the point that health research is advertised as “white coats and petri dishes”, and the Panel agreed. This conception of research seems to impact the lack of awareness of a direct connection between HSC data use and research.

When asked to suggest an instance where they had seen use of health and social care data in a way which they thought was useful or impactful? Many pointed to COVID-19 and cancer survival rates data.

Should the public have the opportunity to be involved?

Overall, participants felt strongly that the public should be involved, particularly in discussing the question of whether public good is being served or public benefit exists for a given data use.

There was a general feeling as well about the use of the term ‘vulnerable’ as needing better definitions, and that data sharing can in sense make everyone ‘vulnerable’. This links to wider discourse around use of ‘sensitive’ data

1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

- The public should be involved around whether public good is being served.
- There should be terminology and information on public good/patient benefit/public benefit and the difference in terms of patient or wider public.
- 'Real world needs' (from the literature) is meaningless as a term. It would be more relevant to consider what the criteria are in each circumstance.
- Public good should be more about minimising harm, with no biases. The application to use data should be based on this.
- There should also be an emphasis on 'maximising good' and 'minimising harm', although participants thought harm might be more easily quantifiable.
- Justification of sharing data for services to support 'vulnerable' (i.e. directing services to vulnerable people during COVID-19) is there a definition of vulnerable? We are all vulnerable at different times. This could be manipulated.
- Sharing data makes us vulnerable. We need to be involved.

Health data linked to finance data in the example of insurance assessment discussing the referring to the literature

There was an initial disgruntled response from the Panel on this topic, which they agreed was broad and confusing. The majority of the panel had overall negative feelings and were suspicious of data being shared in this way for this purpose.

The Panel expanded this discussion as they felt there isn't meaningful choice in this regarding everyday life. The discussion highlighted that in some instances legally we *must* have insurance (health, car, holiday) so you are obliged to give commercial finance companies your personal information, therefore it is not really a choice.

They also discussed whether health insurance is even a choice anymore, and whether the direction of travel is that everyone soon be required to have insurance soon. Many felt they

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were being forced to take up private health insurance due to current HSC service experiences.

The Panel discussed if they would rather insurance companies have access to robust aggregated data, to inform regional premiums so they as individuals aren't carrying the costs of estimates and risk profiling that would mean higher premiums.

Members were then asked if the previous discussions on privacy, de-identification and aggregated data affected their considerations about 'who' should have access to 'what data?' in 'what form?'. The Panel felt it had informed their opinions – in regard to 'accessing de-identified data' to make things better for individuals. Thiswas a new consideration to many Panel members. However, they still felt the context, purpose and benefit to patients were crucial elements.

Themes emerging from Part 2

Awareness

The Panel had:

- Relatively low-level of awareness of how their data is used in HSC,
- No awareness of where they access information on how their data is managed, and their rights.
- No awareness of the HSC being involved in research.
- Not previously been approached, asked, or taken part in research via HSC.
- Apprehension about who has access to HSC data.
- Highlighted that messaging and communication were an issue, in that there is little or none that the Panel were aware of.

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[1] https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

Understanding

The Panel:

- Expect and assume data is shared between and across the HSC.
- Questioned if there are different responsibilities for how GPs and hospitals handle data.
- Don't know where to go for advice or information.
- Questioned if there is a difference between how data is handled in the HSC vs private providers.

Acceptability and Support

The Panel,

- Generally felt that 'de-identified/anonymised data' use beyond them receiving direct care was 'OK'. If, accessed by HSC, academics, and maybe health-focused companies if this was clearly defined.
- Noted that all applicants must meet the same criteria, it matters less what sector they are from, what really matters is why they want access to the data.
- Are willing to support research charities but didn't connect it to HSC data use.

Trust in Different Sectors

The Panel raised:

- Concerns about whether HSC continues sharing data with private practices after privatisation.
- Concerns that HSC is a bigger risk than private providers due to the volume and sensitivity of data, making it a target for hacking.

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

- Concerns that people in HSC who aren’t involved in their care might access data deliberately or by accident.
- That perception of a crisis in GP services – is a loss of continuity in care, which affects trust and how well they feel their data is protected and handled.
- Triaging in public spaces, staff with unknown roles, had raised privacy concerns.
- "Evil in other places affects our fear of use of public service data here."
- That due to unknown purpose, there was negative reaction to broad conversation on linking health data non-health data, such as financial data.

Benefit and Harm

The Panel highlighted:

- That the public should be involved in determining whether public good is being served.
- ‘Terminology’ and ‘Information’ benefit, and harm should be clarified.
- ‘Public good’ should focus on both minimising harm and maximising benefit.
- That there should be clear criteria for good/benefit and how it is determined.
- The need for ‘justification’ for sharing data to support ‘vulnerable’ people, for example during COVID-19. But who defines vulnerability?
- That ‘sharing’ data makes people vulnerable; so the public must be involved in this process.
- that some had initially thought insurance companies have access to robust, aggregated data, that could prevent unfair risk profiling and inflated premiums.
- What are the public ‘reasonably’ expected to give up in order to ‘enable’ efficiency?
- and emphasised the need for ‘transparency’ and ‘clear definitions’.

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

Consent

The Panel advised that:

- Identifiable data should not leave the HSC without patient consent.
- Referral information to private providers shouldn't happen without patient consent.
- A patient's state of mind (anxiety, illness) might affect decision-making and lead to unintended consent.
- Direct access to patients for research recruitment should not be directly from commercial companies, there was no experience recruitment to research via clinicians and care providers

Accountability

The Panel raised:

- What are the requirements for confidentiality in GP practices and hospitals?
- How is data handled or managed in the private sector vs. HSC?
- They have seen data use outside direct care that was impactful - COVID-19- and Cancer data (survival rates).

Attitudes

The Panel highlighted:

- There may be no meaningful choice in data sharing—insurance companies already have their data, and they must have insurance so they must share their data.
- Is health insurance really a choice anymore? Many feel forced into private insurance due to HSC service issues.
- Discussion of privacy-protected/aggregated data affected perspective on data linkage and access.

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

- That research is advertised as ‘white coats and petri dishes,’ the Panel didn’t associate this with data use.
- Their awareness of bias in data collection and interpretation, but unsure what types of access and use of HSC data could be beneficial to that.

Questions raised by the Panel

Some questions were raised by the Panel during their deliberation:

- Do the HSC keep sharing personal information? would a practice retain personal information of HSC patients after it goes private?
- What are requirements for how confidentiality is managed within our health service?(GP practices in relation to access to records, or overheard personal details?)
- Is there is a difference of how data is handled between the HSC and private providers and what does this means when private providers are working with the HSC system? (GPs and dentistry raised as the examples, and referrals to external services)What are we ‘reasonably’ expected to give up to ‘enable’ efficiency in public services?

Part 3: Case Studies

The case studies from Part 1 were revisited as part of the deliberative Data Dialogue to assess:

- Whether views on the case studies had changed since delving into HSC data more fully;
- What the Panel’s suggested approaches would be in each scenario;

1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

- Whether there were overarching themes and recommendations the Panel wished to make for data-sharing and use in these and similar scenarios.

Method

The Panel participated in a ‘Knowledge Safari’. There were three stations around the room, with one case study appearing at the top of a flip chart board, equipped with post-it notes and markers.

After dividing the participants into three random groups, each group started with one case study and began responding to the prompted questions, drawing on previous discussions. They noted their thoughts, suggestions and any further questions or considerations down either on the flip chart itself or on post-it notes. After 10 minutes, the groups rotated and responded not only to the case study prompt questions, but to the other discussion points left by the previous group.

In this way, a ‘conversation’ was occurring at each station, with groups responding to each other’s suggestions and thoughts and expanding on the opinions set forth.

Case study 1: Sharing data for Health and Wellbeing

Your daughter Anna is 6; she has always had difficulty focusing on things.

Discussion:

- ***Should your details be shared automatically with such services while you await the formal assessment?***
- ***Does it matter which services and who runs them (private, charity, council, HSC, etc)?***

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The first consideration here was around consent and where the data is going. It was generally felt that if consent is sought and obtained, this type of data sharing is acceptable. The destination of the data was also important; although there was some disagreement as to whether public services are more generally trusted by the public, or not. It was also raised, echoing earlier discussions, that several participants would have had the expectation that their GP data was already being shared with the rest of the HSC, and the suggestion that it isn't was more concerning.

How data are stored, shared and transferred was also raised, highlighting the importance both of safeguarding and security but also of communicating how this is done so that publics may have confidence. For some of the groups, "need outweighs privacy", but others felt this is too open to interpretation and stated that who is making this decision is very relevant.

Finally, it was suggested that in this and similar situations, sharing data 'internally' (i.e., within HSC) should be automatic, and 'externally', could happen with consent and assessment as to need.

Case study 2: Understanding the impact of air pollution

Air pollution is a key challenge in dealing with the climate crisis and its impacts on public health.

Discussion:

- ***As an individual, how do you feel about your health data being used for research on air pollution?***
- ***What is important to you about how this is managed?***

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Case study two proved, similarly to the morning session, more straightforward for participants. They developed an approach that was largely validated by each group, with a few points raised, which are noted beneath each numbered line. Underlined emphasis is from the original:

1. **Prove air pollution is impacting public health**
   a. **A given?**
   b. **Verification possible through research**
2. **Access to full (?) data**
   a. **non-identifiable only**
3. **Hold data securely for public good/use purposes only**
4. **Unidentifiable data only**
5. **Who holds data and in what form**
6. **Feedback on research**
7. **Restrictions on private use (insurance)**
   a. **Public sector outsources some work to private companies**
   b. **Private companies such as car insurance should be acceptable**

What is notable is the largely agreed-upon approach that includes demonstrating the need for largescale data linkage (i.e. proving there is a problem that can be addressed this way – air pollution), providing access to data in de-identified form, which is held and accessed securely for the public benefit, considering who holds that data and in what form, and ensuring there is a method for feedback on the research. Where there was broad but not unanimous agreement was on restricting access to private companies, with the 'public good' or 'public benefit' question very much debated when it came to research that could potentially result in profit from public data. This was the least contentious and most widely accepted of the three case studies.

1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

Case study 3: Supporting vulnerable communities in COVID-19

During the COVID-19 pandemic public sector bodies coordinated with voluntary, community and social enterprise (VCSE) organisations to provide food to vulnerable people whose immune system means they are at higher risk of serious illness.

Discussion:

- ***How do you feel about the sharing of data in this situation?***
- ***How should this be managed?***

In this deliberation, on what was recognised to be the most complex case study, participants developed parameters and considerations they felt should be applied in this case and in similar situations. The 'special measures' within a pandemic were particularly persuasive, but it was also emphasised that there needs to be a robust definition of 'vulnerable'. In principle, they felt that the benefit outweighed privacy in this case and that data sharing should be allowed. However, there were both safeguards they wanted to see placed on the process as well as an emphasis on learning lessons and developing concrete guidelines for future use.

- Clear communication around data use: by whom, how long for, how it was used. With an auditable process.
- Special measure: Clearly defined time period, emphasising temporary nature of access in particular circumstances.
- Access must be for public benefit and/ or to reduce harm
- Findings from data use should be made public and reviewed within an auditable process

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

- The organisation with the most data should lead on managing the processes for data access.

Key themes from deliberation

There are a few points that emerge from the discussions in both Part 2 and Part 3 that appear to be key for the Panel in its understanding and opinion of data sharing in the examples used.

- **Transparency & Consent:** People want to understand who accesses their data and for what purpose.
- **Privacy & Benefit:** Support for data sharing increases when the public benefit is clearly reported and qualified, including the public in this discourse. However, privacy safeguards must be in place. The public should be involved in determining whether use and sharing of their data has a benefit, and what that benefit is.
- **Crisis Response:** Data-sharing in emergencies should be temporary, well-regulated, and strictly for public benefit
- **Governance:** Defined guidelines and oversight structures are essential for all types of data access and sharing and must include the public.

Conclusion

The discussions and deliberations at the Panel demonstrated several key considerations. Whilst many of the common themes from previously published reports resonated with the Panel, these were impacted by personal interaction with the services of Health and Social care Northern Ireland (HSCNI). Smaller community sizes and the perceived impact this has on privacy in HSCNI contexts, experiences of primary and secondary care services and lack of personal experience in participation of research within HSCNI were considerations

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1 https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

specific to the panel and not mirrored in the literature. The Panel emphasised the need for local public participation in setting standards, and participation in decision making around use of their data. They understood the wealth of value in their HSCNI care records, as well as the potential risks associated. Use of privacy-protected data, such as de-identified or anonymised data, was favoured by the panel, with strict common consideration for access being set, in particular the purpose of the requested access being the key consideration.

Examining the case studies before and after discussions around themes in HSC data sharing, while not substantially changing the Panel's thoughts around each case study, did appear to refine their thinking and resulted in more detailed suggestions and recommendations around principles and potential processes to support data sharing as well as protect people and their voice within the HSC data landscape. There were moments, particularly in case studies one and three, where more information around how data is shared as well as considerations and examples helped 'soften' participants' viewpoints, and broadened discussions into consideration of how public benefit might be both met and individual privacy protect in challenging but non-emergency situations.

[1] https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement

(1) Literature

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[1] https://www.involve.org.uk/resources/knowledge-base/what/deliberative-public-engagement