Northern Ireland
Public
Data
Panel

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

Summary 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

Summary Report: March 2025

A 'data dialogue' is the NIPDP approach to deliberations on topics related to data use. Using a deliberative approach 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 Panel were provided a definition and scope of what Health and Social Care Northern Ireland (HSCNI) is, in order to provide scope and context for their discussions. They first examined three case studies, reacting without prior knowledge or discussion, identifying issues and points of interest. Later the Panel revisited these case studies to assess if their views or feelings had changed following their deliberations and discussion activities to capture their perspective on use of Health and Social Care data based on common general themes from published works.

Part 1: Case study insights

Case study 1: Sharing for Health and Care

- Some panel members favoured automatic data sharing within the HSC, while others insisted on prior explicit consent in certain circumstances.
- Clarity on where data goes, who controls it, and how decisions are made was a priority. Most assumed GP records were already shared across the HSC, and felt data sharing across the HSC for provision of services was necessary and acceptable

Recommendation: Data sharing within the HSC could be automatic, but it matters *who* else data could be shared with – i.e. whether with a community organisation, a private (commercial) organisation, or government bodies.

Case study 2: Using Health Data for Population Research

- Panel members were generally comfortable with using HSC data for population research, as long as it remained de-identified and securely managed.
- Key concerns included who controls the data, access restrictions, and commercial involvement. There was debate over whether private sector use, based on why they wanted to access the data, motivation and purpose (e.g., by insurance companies) should be allowed.

Recommendation: HSC data should be used for public benefit, but with public involvement in its definition and application, and with strict controls on privacy and clear public communication.

Case study 3: Data Sharing for Vulnerable Communities in COVID-19

- It might be acceptable to share identifiable HSC data without consent to protect vulnerable populations in certain circumstances.
- Defining 'vulnerability' was a key challenge, with concerns about potential misuse
- Strong preference for temporary, well-regulated data-sharing measures, with clear guidelines on who can access the data and for how long, with preference for privacy protected data to be used where possible.

Recommendation: Systems for sharing identifiable data without consent could include time limited special measures, but this would require specific strict oversight mechanisms, and clear public communication.

Key panel perspectives from case study reviews

- **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 but privacy safeguards must be in place.
- **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.

Part 2. Perception of the use of Health and Social Care Data

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. Discussion points included:

- Knowledge, awareness and understanding.
- Condition for acceptable use in different ways.
- How trust is maintained.
- Uses of health and social care data by different stakeholders, HSC, commercial organisations.
- Charities, academics and other areas of government.

- What is public benefit?
- Benefit vs harm.
- Management and sharing of health and social care data.
- Transparency, accountability, control and consent.

Awareness & Understanding

- The Panel members have limited awareness of how their data is used within Health and Social Care Northern Ireland (HSCNI) and expressed apprehension about who has access.
- Panel members had low awareness of where to find information on how their HSC data is managed, and their rights regarding it.
- Panel members were unaware of HSC's involvement in research and have never been asked or approached to participate in any HSC related research.
- The Panel were unaware of messaging on HSC data use.
- The Panel assume that data is shared across HSC services.
- The Panel were uncertain about GPs' and hospitals' roles in data handling.
- Private vs HSC: The panel raised whether there is difference in data practices, their rights between HSC and private providers, concerns about HSC sharing data with private practices.
- Some viewed HSC as a bigger data security risk and potential target for hacking than private providers, given the sensitivity and volume of data.
- The Panel raised fears about unauthorised access by non-care staff, accidental breaches within HSC, triaging in public spaces regarding privacy.
- Lack of continuity in care, especially with GPs, impacts trust in HSC data use.
- The Panel voiced support for research in general but didn't immediately see connection to HSC data use.

- Although Panel members are aware of bias in data collection, they are uncertain about how HSC data use could address this issue.

Acceptability, benefit and harm

- Panel members supported the use of privacy protected, de-identified or anonymised data being accessed for research by the HSC, academics, or health-related companies. The purpose of access and benefit should be clearly defined and a definition of 'health related companies' was queried.
- The panel debated whether applicants for access to privacy protected data all had to meet the same criteria. They felt the sector (public or private) matters less than the purpose of accessing the data.
- The public should be involved in determining whether use and sharing of their data has a benefit, and what that benefit is.
- The public good should focus on minimising harm and maximising benefit.
- Transparency and clear criteria for determining benefit and harm are emphasised.
- Vulnerability and the justification for sharing identifiable data in emergency situations, for example COVID-19, need clearer definitions. Panel members have seen impactful data use outside direct care, like COVID-19and cancer survival rates.
- Panel felt sharing data could make individuals vulnerable; hence, the public should be involved in decision-making under clear criteria they help define.
- Discussion on what the public might reasonably be expected to give up in terms of right to privacy in return for efficiency in delivery of services.

Consent and privacy

- Panel members felt identifiable data should only leave the HSC with patient consent.

- Panel members highlighted, referrals to any private providers should not happen without explicit consent.
- Panel members noted that a person's state of mind (e.g., anxiety or illness) could affect their consent, leading to unintended agreement to data sharing. There was concern that commercial companies should not directly approach patients for research participation (this was linked to panel members having not experienced recruitment via HSC clinicians).
- Panel members feel they have no choice in data sharing and used the requirement to carry car insurance as an example. The panel members debated if financial or insurance companies accessing aggregated data might prevent unfair risk profiling and inflated premiums.
- The Panel had concerns about data use in other sectors (e.g., linking health data to financial data) stemming from uncertainty over process and negative perceptions.

Part 3 Knowledge safari and case study review

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. Notable 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, particularly where they were very negative around data-sharing in certain situations. By doing so, this broadened discussions into consideration of how public benefit might be both met and how individual privacy is protected in challenging but non-emergency situations.

The panel members were more fluent discussing when data use would feel acceptable, and what they required in order for this to happen. Discussions became more nuanced, and the Panel were able to drill down into the need for definitions for 'vulnerable', for example, or the difference between 'emergency' situations (like COVID-19) and other pressing circumstances that wouldn't meet that threshold. However, there were still circumstances in which the Panel were not supportive of data use, and this changed very little between the first and second considerations of the case studies.

Key findings:

- How data is stored, accessed and used is important, but so is how this is communicated to publics.
- Public benefit, or 'need' must be demonstrated in order to access and use public data.
- De-identifying, pseudonymising, or otherwise anonymising data so individuals are not identifiable provides a high level of confidence for Panel participants.
- There must be clear definitions around data access and use, including what constitutes an emergency situation, who is regarded as vulnerable, when and what this means; a clearly defined time period for accessing data (especially in critical or time sensitive situations).
- Findings from data use should be made public and auditable.

Conclusion

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 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.

Question's raised by the panel.

These specific key questions raised by the Panel, will be taken back to the HSC with answers and information returned to the Panel.

Q: Do the HSC keep sharing personal information, would a practice retain personal information of HSC patients after it goes private?

Q: What are the requirements for how confidentiality is managed within our health service? (GP practices in relation to access to records, or overheard personal details.)

Q: Is there is a difference of how data is handled between the HSC and private providers and what does this mean when private providers are working with the HSC system? (GPs and dentistry raised as the examples, and referrals to external services.)

Q: What are we 'reasonably' expected to give up to 'enable' efficiency in public services?