Northern Ireland Public Data Panel
Data Dialogue Summary Report

Northern Ireland Biobank: Public Perspectives on Ethical Use, Access, and Future Data Strategy

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Approach

A ‘Data Dialogue’ is the NIPDP approach to deliberations on topics related to data use. Using a deliberative approach, the Panel participate in discussions and activities to consider opinions and views on a given subject. With facilitator support, they collectively explore the information they have been provided with, along with their own experiences and opinions, to address specific questions about the use of data for public good.

Part 1: Expert Presentations

Dr Claire Lewis – Operations Manager, NI Biobank – Overview of NI Biobank, purpose, ethical framework, procedures.

Professor Jacqueline James – Scientific Director, NI Biobank – The global and local importance of NI Biobank data assets, and governance.

For this ‘Data Dialogue’, the Panel were introduced to the Northern Ireland Biobank (NIB) — a regional research infrastructure based at Queen’s University Belfast that collects high-quality biological samples and de-identified clinical data to support biomedical research. Two expert speakers provided insights into the NI Biobank’s purpose, governance, ethical foundations, research value, and future direction.

Throughout the session, participants raised questions, shared concerns, and explored the conditions under which the use of biobank samples and data is acceptable to the public. These insights informed the second part of the deliberation, where members engaged in structured dialogue around key questions set by NIB concerning data access, industry involvement, AI use, and benefit-sharing with the Health and Social Care system (HSC).

Expert Presentations

Overview of NI Biobank (Dr Claire Lewis)

The Panel were introduced to the origins and purpose of NIB, including:

- Its role in collecting ethically sourced tissue samples (primarily surplus tissue from living patients) and pairing them with de-identified healthcare data.
- Compliance with legal and ethical frameworks such as the Human Tissue Act 2004, ORECNI approval, and inspection by the Human Tissue Authority.
- Strict governance ensuring samples are tracked, protected, and only released in minimal amounts for approved research projects.
- NIB's cost-recovery model, ensuring academic research remains subsidised and that industry access is charged appropriately.
- Future ambitions, including integration with Trusted Research Environments (TREs) and digital consent tools like MyChart.

Panel questions covered: data security, the consent model, how private sector researchers are regulated, tissue storage processes, protection from misuse, and the implications of paediatric participation.

Scientific and Research Importance (Professor Jacqueline James)

Professor James provided an overview of:

- The scientific value of biobanking, particularly for precision medicine and understanding treatment response.
- NIB's contribution to long-term translational research, including cancer studies, ageing population research, and rare disease collaboration.
- How linked data enables researchers to follow patient pathways over time within NI's relatively stable population.
- International benchmarking, SOPs, and the importance of robust equipment and processes.
- The relationship between NI Biobank and UK Biobank, clarifying that while samples are not shared, NI researchers can access UK Biobank datasets.

Panel questions explored: mental health data, limitations of NIB's remit, collaboration with industry, long-term research timelines, and lessons learned from COVID-19.

Key Points Raised by the Panel

Ethical Use, Consent & Public Trust

- Strong reassurance was taken from strict governance, independent ethical approvals, and NIB's robust compliance mechanisms.
- The use of surplus tissue, rather than organ donation pathways, was well understood and viewed positively.
- The Panel appreciated clarity on de-identification, controlled access, and audit processes.

Access by Universities, Healthcare Organisations, and Industry

- Most of the Panel felt there should be a difference in how data is accessed by academic/healthcare organisations compared with industry.
- Industry access was considered acceptable with conditions, including:
    - Significant reinvestment in HSC
    - Financial or long-term benefits such as licensing or royalties
    - Transparency about intended use
    - Safeguards against private profit at public expense
- A minority argued that progress depends on industry collaboration, emphasising capability and intention over sector type.

International Researchers

- Most of the Panel (12 of 15) felt comfortable with international access, noting that global research often yields local benefits.
- A smaller group believed NI should benefit directly when its data is used and that structured monitoring of international use is essential.

AI and Machine Learning

The Panel's comfort levels ranged from "very comfortable" to "slightly uncomfortable".

Concerns included:

- Immaturity of AI technologies
- Risk of misuse or error
- Environmental impact
- Uncertainty around long-term implications

Those comfortable with AI highlighted:

- Potential improvements in diagnosis and treatments
- The value of large datasets for algorithm accuracy
- Increasing integration of AI into healthcare and daily life

The Panel discussion shifted some views, particularly after environmental concerns were raised.

- Question 1: Is there a difference in releasing de-identified biobank data to researchers based in universities and healthcare organisations compared with those in industry?

- Question 2: Does it change how you feel about the data release if the researchers are based at an international location and the results may not directly benefit 'Northern Ireland' immediately?

- Question 3: How do you feel about de-identified image data being released for research involving machine learning and AI? [5-point scale]

- Question 4: What should the HSC get in return for providing de-identified images/data for research?

Deliberative Dialogue: What Should the HSC Receive in Return?

Across the Panel discussions, three recurring themes emerged:

1. Financial Incentives

The Panel agreed that HSC should receive financial returns for providing de-identified samples and data. Suggestions included:

- Reimbursement for operational costs
- Royalty or licensing arrangements
- Subscription models for industry access
- Long-term investment that supports local research capability

2. Access to Research Findings and Innovations

The Panel strongly felt that:

- The HSC should receive access to resulting treatments, diagnostics, or innovations at reduced or cost-price rates
- It is inappropriate for companies to use public data to develop high-cost products that the HSC may struggle to afford

3. Transparency and Accountability

- Trust relies on clarity about who is accessing data, how, and for what purpose.
- The Panel supported stronger monitoring, auditing, and contractual safeguards.
- Collaboration across HSC, government, academia, and industry was viewed as essential.

Conclusion

The Panel expressed overall support for the use of de-identified biobank data when managed responsibly. The Panel placed high value on clear governance, fairness, transparency, and tangible public benefit. The Panel recognised the importance of

collaboration — including with industry and international researchers — but emphasised the need for structured benefit-sharing and ethical oversight.

The Panels views on AI were mixed, reflecting both optimism about its potential and concerns about risk, maturity, and environmental impact. Across all topics, the Panel stressed that public trust depends on meaningful safeguards, fairness in data use, and ensuring that innovations developed using NI data ultimately benefit the people of Northern Ireland.

This topic and its deliberation were brought to the panel by the Northern Ireland Biobank. The presenters were Dr Claire Lewis, Professor Jacqueline James & Dr Christine Greene, in attendance.