Northern Ireland Public Data Panel
Data Dialogue Summary Report

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

Published: March 2026

NIPDP Data Dialogue 3: Northern Ireland Biobank

Data Dialogue: September 2025

Background:

The Northern Ireland Biobank (NIB) is a key research resource established in 2011 to support research across biomedical sciences. Located at the Patrick G. Johnston Centre for Cancer Research (PGJCCR) at Queen's University Belfast (QUB), it is funded primarily by the Research and Development Division of the Health and Social Care Public Health Agency (HSC R&D) in Northern Ireland (NI). NIB also receives funding from other sources, predominantly collaborating charities, and it operates a modest cost recovery scheme to contribute to its own sustainability.

Originally established as a partnership between QUB and the Belfast Health and Social Care Trust (BHSCT) with a focus on cancer biobanking, NIB has grown into a regional research infrastructure supporting biobanking across multiple diseases. It provides access to human tissue samples and de-identified healthcare data from Northern Ireland's Health and Social Care Trusts (NIHSCT), making these resources available to both local researchers and those further afield.

NIB collect high-quality biological samples, such as blood, tissue, or DNA, and link them to relevant healthcare information. When combined with de-identified clinical data, samples help researchers understand the differences between health and disease. Biobanks also enable scientists to compare data from different groups, such as people of various ages or treatment backgrounds. This research is essential for advancing personalised approaches to diagnosis, treatment, and prevention.

NIB supports ethical, high-quality research by securely collecting and storing biological samples and related data. NIB work in closely with QUB and the NIHSCT to ensure data is managed safely, legally, and ethically. All personal information is removed, and each sample is coded to protect donor identity.

NI is moving towards a more data-driven healthcare system. Key developments, such as a single digital health record, a secure Trusted Research Environment (TRE), and new legislation on health data use, will significantly shape how researchers access and use patient information.

As part of this transition, NIB is seeking input from the Northern Ireland Public Data Panel (NIPDP) to help shape its future data strategy and ensure personal data is handled in ways that the public sees as responsible and trustworthy.

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

1) Dr Claire Lewis – Operations Manager, NI Biobank – Overview of NI Biobank, purpose, ethical framework, procedures.
2) Professor Jacqueline James – Scientific Director, NI Biobank – The global and local importance of NI Biobank data assets, and governance.

At the start of the day, the Panel, were introduced to the topic and the agenda, which included expert presentations on the NIB. Throughout the presentations, the Panel were encouraged to ask questions and to share their reflections, which were annotated on flipcharts throughout the room. This included their initial thoughts and feelings about what was being shared, as well as any ideas about how they would like to see the data used.

Dr Lewis opened the 'Data Dialogue' and gave an overview of NIB and the Panel raised points through the discussion on processes and ethical approval, researcher access, legal and governance frameworks, and the collection of tissue.

Dr Lewis explained NIB's ethical framework, emphasising that researchers must obtain their own ethical approval in addition to meeting NIB's requirements. Dr Lewis highlighted that within public health, governance frameworks ensure compliance across research activities, while noting that separate arrangements exist for work conducted by the private sector.

Dr Lewis expanded that, although private sector organisations fall outside the Health and Social Care (HSC) governance framework, private sectors are still legally required to obtain consent under the provisions of the 'Human Tissue Act 2004' (HTA,2004), to which NIB is also subject to. Explaining, that NIB's main licence is held through QUB, and the NIB is inspected by the Human Tissue Authority (HTA) to ensure full compliance with legislative and procedural requirements.

During this discussion the Panel asked whether researchers must adhere to the same ethical boundaries as NIB? Dr Lewis confirmed that NIB operates under the Office for Research Ethics Committee Northern Ireland (ORECNI) approval and the (HTA, 2004), supported by strict compliance measures, licensing obligations, and regular audits. Dr Lewis explained NIB collects surplus tissue only from living patients using broad consent, and primarily supports cancer research by providing ethically sourced samples and linked data.

Dr Lewis further advised that private sector researchers must demonstrate appropriate regulatory approval and evidence of patient consent. Further noting that private sector ethics is not regulated by ORECNI, and researchers whose work falls outside NIB's remit must secure alternative ethical approval before accessing NIB infrastructure (each project requires its own ethical authorisation).

Dr Lewis acknowledged that public concern often stems from historical scandals involving the inappropriate retention or use of human tissue reinforcing that these events have directly informed today's stringent legislation and governance frameworks. Further noting that, while NIB would not conduct research itself, that NIB provides tissue, images, and data from living patients only, and is strictly to approved researchers working within the required regulatory standards. This was in response to a question raised by a Panel member relating to historical cases of human tissue misuse.

Dr Lewis closed this section of questions from the Panel, by explaining NIB's cost-recovery model and that charges are kept nominal to ensure no financial impact on HSC services, with all recovered costs reinvested into the HSC. Furthermore, academic use of NIB is subsidised, while industry access is charged on a full cost-recovery basis. Noting at present NIB currently operates exclusively within the BHSCT due to resource and funding constraints, and the majority of NIB are employed by BHSCT as a requirement to work within a research consent environment.

Applications to NI Biobank and Protection of Samples

Dr Lewis began the next section of questions from the Panel discussing that NIB works in partnerships across the HSC trusts, including the pathology laboratories. Emphasis was placed on the strict processes that ensure samples are de-identified, tracked, legally protected, and only released in minimal amounts to prevent tissue misuse. Dr Lewis added that applications come primarily from local academics with some national and international interest.

Dr Lewis explained that NIB would collect samples ethically only, and obtains explicit consent for use of tissue for research purposes. Noting that each sample has a unique NIB code and a researcher can ask if there was anything historic about the patient. NIB can identify this information, not the researcher. NIB would only pass historic information on, that is de-identified.

In response to an extended question relating to human trafficking, Dr Lewis advised that the 'HTA, 2004', makes it illegal to use sold tissue. For example, in the United Kingdom (UK), imported samples are scrutinised due to different legislations and consenting models around the world that prohibits from importing human tissue.

When asked whether researchers receive an actual physical sample or a digital image? Dr Lewis explained that this depends on the needs of the researchers request. Noting that some researchers request both, and that there has been an increase in requests for digital imaging, and that all physical biological samples are destroyed during the research process once the work is complete. Further highlighting if samples are not destroyed as part of the research itself, researchers are usually required, under their contract with NIB, to return any remaining material. Alternatively, they may be instructed to dispose of it in accordance with the procedures set out in the 'HTA, 2004'.

Dr Lewis went on to explain the 'NIB researcher approval' process, emphasising the requirement for expertise, technology, and skills to work with the samples with an independent project review stage. Noting that once a researcher is approved; a legal agreement is drawn up and NIB only release enough samples to be used for that specific research project.

Dr Lewis highlighted the obstacles around finding a breach (of contract), outlining that it can be difficult to detect. Noting that as minimal tissue is issued for use by NIB, the chance of breach (or misuse) is then reduced. However, this can be harder to do with a digital image, as a digital image is easier to pass on. This was in response to a question raised by the Panel around breach of contract.

Dr Lewis closed this section of questions from the Panel, with an additional query in relation to Artificial Intelligence (AI) use within NIB. Dr Lewis advised that AI is not used in NIB for research, however NIB would release high resolution images for AI studies, that supports to build AI algorithms to help detect tumours. NIB is trying to create a Secure Data Environment (SDE), which images cannot be extracted from.

Consent

Dr Lewis began the next section of questions from the Panel to discuss the consent process, explaining that NIB clinical staff help to identify suitable patients and guide them through the information sheet and consent forms. Noting that NIB use a generic consent model, meaning that patients are not informed about the specific study their samples may eventually contribute to.

Dr Lewis highlighted that during the consent process, risks, potential harms, and possible benefits are clearly explained during the consent discussion with Patients. At this stage, Patients are also reminded that participation is entirely voluntary and that choosing not to participate will have no impact on their care pathway or the quality of care they receive.

Dr Lewis also noted that, in the future, NIB hopes to utilise 'MyChart', the 'Encompass' patient portal, as a means of expanding access to the consent process. At present, not all patients have the opportunity to give consent, and a digital platform may help ensure more consistent access.

A further question was raised by the Panel whether NIB collects samples from individuals aged 18 and under, and if not, did this result in research involving children being overlooked? Dr Lewis continued that NIB would not currently collect paediatric samples noting that paediatric consent procedures are more complex and require involvement from a parent or guardian. Dr Lewis highlighted that NI has a predominantly adult and ageing population, noting, for example, that the Newcastle Biobank (NBB) specialises in paediatric collections and may be more effective in that role. Dr Lewis expanded that the NBB is operated by the Newcastle University (NCL) and Newcastle upon Tyne Hospitals Foundation Trust (NuTH), and is a specialised facility storing over half a million human tissue and fluid samples.

Dr Lewis closed this section of questions from the Panel noting that when NIB was first established, paediatric samples were incorporated into the pre-existing network based in Newcastle, using a bespoke model with centralised storage. However, NIB has recently been invited to participate in paediatric non-cancer research and is now seeking the relevant ethical approval to support future work in this area.

Biobanks, Tissue Storage, Opt-In/Opt-Out

In the final section with Dr Lewis, the Panel sought clarification on the collection of excess tissue and whether this differs from organ donation? Dr Lewis confirmed that the two are entirely separate. Noting that organ donation carries its own ethical, legal

and personal considerations, whereas NIB only uses *surplus* tissue material not required by pathologists for diagnostic testing (for research purposes).

A Panel member also drew comparisons with the opt-in/opt-out organ donation model that is used in Wales. To gauge awareness, the NIPDP facilitator conducted a sense check across the 16 Panel participants, with 12 indicating that they were familiar with opt-in/opt-out arrangements for organ donation.

A final question was raised to Dr Lewis on whether NIB operates in a similar way to other “banks”, such as blood or sperm banks, and what are NIBs main aims and goals? Dr Lewis explained that blood and sperm banks are used for clinical treatment, whereas NIB operates within the research domain. While NIB was initially focused on supporting cancer research, its remit has broadened to include areas such as ophthalmology and respiratory research. NIB’s overarching goal is to provide high-quality samples that enable advancements in research across all stages, from prevention and understanding drug responses to supporting treatment development and wider translational research.

Data, Patient Information, and research scope

Professor James was introduced the Panel and discussed the origins of NIB, with a cancer-focused remit and the Northern Ireland Cancer Registry (NICR) as an early major user. Noting that NIB was established to underpin high calibre translational research by enabling access to organised collections of quality-assured biological samples linked to well-defined data sets. The vision of the NIB is to host and distribute a collection of well defined, quality assured biological samples to support translational research programmes in NI and beyond.
Professor James explained how blood samples need data/detail, for example gender, age, lifestyle factors, and prescribed medicines.

An overview of precision medicine and how people respond to some drugs/therapies was illustrated, including the NIB data contribution to research to identifying patient response to drugs/therapies.
Professor James explained how NIB can link samples and follow the patient journey through time and discussed how Northern Ireland has an aging population, but is a static population which does not move much, which makes following the patient’s journey achievable.

Professor James outlined that NIB works within guidelines that are internationally benchmarked, as there are biobanks around the world. It was explained that

research on rare diseases benefits greatly from the use of multiple biobanks, as this provides access to samples that are otherwise difficult to obtain. Further highlighting the critical importance of equipment maintenance, and the structured Standard Operating Procedures (SOPs) for everything NIB do which are scientifically scrutinised and audited, and fit within the ethical approval of NIB.

The Panel began Professor James section, by asking if additional data, **personality types, or mental-health-related information is linked to samples?**

Professor James highlighted that personality traits are **not** part of the data collected and that NIB focuses on factors that influence response to treatments. This enables researchers to determine why some individuals respond well to certain drugs or therapies while others do not.

Professor James expanded, that mental health-related questions fall **outside the ethical remit** of NIB. For example, if a researcher were to run a mental health-focused study (e.g. collecting saliva for a specific purpose), the researcher would need to obtain **their own ethical approval**. Further noting, that NIB could support the structure of such a study, but it would be considered **separate** from standard activity.

The NIB team shared physical mock-ups of slides to the Panel to view.

NI Biobank Impact and Cancer Waiting Lists

The Panel raised further questions on whether NIB's work is having a positive impact on cancer waiting lists. Professor James explained that any impact is not immediate, as the development of a clinical marker can take decades to progress through rigorous testing. However, NIB's broader contribution to the research ecosystem supports the HSC in the longer term. Professor James also noted that future use of AI algorithms may help accelerate progress, and that NIB intends to contribute to this area. Professor James emphasised that new drugs are typically introduced alongside diagnostic tests, and NIB supports hospitals by providing high-quality samples to validate these tests, offering a more immediate benefit to the HSC.

A Panel member sought clarity, noting that it would appear NIB undertake the earlier stages of research and development, and queried if this were the case, and if academics contribute afterwards? Further expanding if private sector (Industry) tend to become involved later and seem to gain much of the commercial benefit? The Panel therefore queried whether data produced by NIB could be misused by pharmaceutical companies, and how a fair balance might be maintained between publicly funded assets and private-sector profit?

Professor James explained that collaboration with industry is essential for progressing scientific discoveries into real-world products. Expanding further that the benefits of industry sponsorship of research projects and students, as well as opportunities such as apprenticeships, noting these partnerships create mutual value. Reiterating that NIB operates on a cost-recovery basis for tissue provision, but acknowledged that pharmaceutical companies inevitably make further profit. Professor James emphasised that the HSC ultimately gains by receiving access to new treatments that benefit patients.

The Panel then asked if there had been lessons learned from the COVID-19 pandemic, including whether any 'Long Covid' studies had been carried out and how NIB was affected?

Professor James reported that COVID-19 significantly slowed operations. Belfast City Hospital (BCH) was repurposed as a Nightingale facility, and laboratory activity continued at QUB. During COVID-19, NIB implemented safeguards for continuity by splitting its staff into two separate teams with duplicated skills sets, ensuring that one could continue work if the other was affected by infection.

Professor James expanded that at the request of the Department of Health (DoH), NIB supported work on COVID-19 infection using surplus samples sourced from laboratories across Northern Ireland. Several operational practices introduced during the pandemic have remained in place, enabling NIB to respond more quickly and protect essential workflows.

Professor James closed the section of questions noting that no NI–specific Long Covid studies have been undertaken, though UK-wide studies are ongoing.

UK Biobank

The Panel opened this section raising a question in relation how closely NIB works with the UK Biobank (UKBB) and whether samples are exchanged?

Professor James clarified that the UK Biobank functions largely as a UK resource, as it did not recruit participants from NI. Professor James noted, the UKBB recruited 500,000 people, collecting bio samples, MRI, and X-ray data. In addition, it holds extensive questionnaire information, supported by approximately £260 million in investment. In comparison, NIB has received around £5 million. Professor James emphasised, NIB would not provide samples to the UKBB. However, QUB funds PhD researchers to access the UKBB dataset.

A Panel member highlighted that the investment disparity may be proportional to population differences, and asked whether there are operational discrepancies between the biobanks?

Professor James explained that the UKBB focuses on generating large-scale datasets, whereas NIB provides physical samples that researchers then analyse to create data. However, NIB is actively encouraging data-sharing and hopes to collaborate with the Northern Ireland Trusted Research Environment (NITRE) to store data securely and increase accessibility for researchers.

The Panel closed this section of questions on whether NIB envisages undertaking data modelling?

Professor James suggested this may not be necessary because large amounts of data already exist but are under-utilised. Much of this information is stored within an Azure cloud environment, and NIB hopes to work with NITRE to maximise researcher access. NIB also noted that academic institutions can independently subscribe to the UKBB, with epidemiology researchers routinely paying for access.

Part 2: Data Dialogue: Deliberation

In the second part of the 'Data Dialogue', the Panel participated in a deliberation around key questions posed by NIB:

1. *Is there a difference in releasing de-identified biobank data to researchers based in universities and healthcare organisations compared with those in industry?*
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?*
3. *How do you feel about de-identified image data being released for research involving machine learning and AI?*
4. *What should the HSC get in return for providing de-identified images/data for research?*

Part 3: Deliberative Dialogue

Fifteen of the Panel participated in an interactive deliberation around the four questions posed by NIB. The Panel participated in a 'Vote with your feet' exercise to gauge their views on the questions posed by the NIB.

For the first two questions, the options given to participants were **'Yes'** or **'No'**. For the third question, they were asked to choose from a Likert scale of **'Strongly Agree'**, **'Agree', 'Neutral', 'Disagree'**, or **'Strongly disagree.'**

For the fourth and final question, participants were split into small groups, broadly representative of views from the third question, to discuss their thoughts and responses around what the HSC should receive in exchange for providing de-identified data and images for research.

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 1 Results

A majority of the Panel felt that **yes, there is a difference** between releasing de-identified biobank data to researchers based in universities and healthcare organisations, as opposed to those within industry. Many of the responses centred on the principle that there must be an inherent benefit to HSC in sharing this data. This could be financial, such as charging industry partners more to access the data than others do, and funnelling the proceeds back into HSC in NI. The Panel also felt that while this could be beneficial, there should also be long-term investment from industry in HSC, rather than a purely transactional relationship based on access to data. There was a discussion around equitable profit sharing. An example was given that if industry develop an effective, successful drug or treatment that generates enormous profits for them, a percentage or proportion of this should be paid to HSC, similar to a licensing or royalty model.

However, there was recognition of nuance in the discussion. One of the Panel pointed out that universities are not just about academic research but also compete with industry, and that they should not be in the same category as health care organisations. Others felt there needed to be a distinction between for-profit and non-profit health-focused organisations. Some also felt that while industry should be allowed to access data, there might be certain types of data they should not be able to access, regardless of the payment model.

<u>Comments from those saying **'No'**, there is **no** difference:</u>

Those of the Panel who felt that **there is no difference** between universities and health care organisations, and industry access, highlighted the expertise and

financial resources that the industry possesses, that both are needed to develop new pharmaceuticals and treatments, and both are lacking in HSC. It was felt that without allowing industry access, society will not likely make progress on massive issues like curing cancer. Several people also pointed out that intention is important: the decision to allow access should depend on how effectively the organisation will use the data, not on their private or public status. This tied into points about the need for industry resources and knowledge to make an impact.

However, the Panel felt that pharmaceutical companies should not be able to use the information and data gathered by NIB and then make the final product (drug, treatment, etc) they develop so expensive that the HSC cannot or will not approve its usage. That was viewed as using public data for private profit, and participants generally did not support it, recognising it as a potential downside of allowing industry access to Biobank data.

- Pharma/industry is needed to make the drugs due to its expertise.
- Intention is important. What is the purpose? The decision depends on how effectively they use the data, not on their private/public status. NIB's 5 million will not go far. Not for curing cancer.
- £5 million will not make a difference without industry and more resources coming in.
- Industry has the resources and is future-proof.
- It is not right that pharmaceutical companies can use the information and then put such a cost on the final product that it is so expensive that National Institute for Health Care Excellence (NICE) will not or cannot approve.

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 2 Results

Comments from YES (n=3) respondents: Yes, it **changes** how they feel:

- Would like to see some benefit for the local people.
- Local benefit matters. Directly beneficial to people here. Local data is being used for local people.
- There should be a structure for how it is being monitored in other places, along with the purpose of the benefits being measured and monitored in other places
- Important that it is directly beneficial to NI.

Comments from NO (n=12) respondents: No, it **doesn't change** how they feel:

- Most research does not work immediately.
- Benefits may be global rather than local. This is not either-or; international access does not prevent local access. The specialists may be elsewhere. We benefit anyway.
- Global things can affect NI. For example, COVID-19. Bad things can happen anywhere, locally or remotely.
- Other countries with better resources can perhaps do better research, and NI can get access to that.
- NI companies are capable of doing unethical things with data as much as international companies.
- How it's monitored is essential.

The Panel (12 out of 15) felt that their view on researchers accessing Biobank data **does not change** whether the researchers are based internationally or locally. This centred mostly on the understanding that benefits can be global as well as local, and that global factors can affect local places. An example given was COVID-19. Participants mentioned that other countries might have better resources and could therefore do better research, which NI could access and benefit from. They pointed out that local companies are as capable of being unethical with data as companies based elsewhere, and that how data access and use are monitored is both essential and more relevant than an organisation's location. Some also pointed out that most research does not have an immediate impact anyway, which, for them, made the area less important.

A smaller number (3 of 15) of the Panel felt that **yes, it changes** their perspective on data access if the organisation or researcher is internationally rather than locally based. Panel members emphasised the importance of NI benefiting from its own data. They felt that specific structures are needed to monitor how data is used and the resulting benefits or outcomes in other areas.

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

Question 3 Results

Comments from **'Slightly Uncomfortable'** respondents:

- Not so much about data, but because AI is a young industry and unknown about its use for bad. Until AI is a mature industry, it is not comfortable being used.
- Fear of abuse.
- Unknown industry. Wants to see it mature.
- AI can make errors. How reliable is it?
- A lot of medical learning now is machine learning.
- Depends on the type of AI.
- Concern over AI in general due to its impact on the environment.
- While AI is not new, it is more accessible.

Comments from **'Comfortable'** respondents:

- If it contributes to better diagnosis and recovery, no objection.
- AI is already part of life now.
- AI is not new.

Comments from **'Very Comfortable'** respondents:

- De-identified data will strengthen AI.
- When AI is involved but not entirely relied on. Assumption that humans are still involved. Vital caveat to make one comfortable.
- The more images given to AI, the smarter it becomes and the fewer mistakes it makes. 100x better now could be 1,000x better in the future.

Some 'Very comfortable' respondents then shared some comments that they said made them consider 'Very uncomfortable':

- Images may lose value.
- Environmental impact.

The Panel were then asked how they felt about de-identified data being used for research involving machine learning and AI. The Panel were asked to describe their feelings as very comfortable, comfortable, neutral, not sure, slightly uncomfortable, or very uncomfortable. 10 of the Panel said they were either 'very comfortable' or 'comfortable', and five were 'slightly uncomfortable'.

Those of the Panel who felt slightly uncomfortable described a range of reasons. Several felt that, because AI is a relatively new and unknown industry, we do not yet

know all its potential harms or impacts. Until the AI industry matures, they are not comfortable with it being used in certain spheres such as this. Others highlighted fears of potential AI abuse or of the data it processes, as well as its potential errors, questioning its reliability. Finally, the environmental impacts of AI were strongly highlighted, which drew agreement from around the room.

The majority of the Panel, who described themselves as very comfortable or comfortable, highlighted several areas. Several felt that if AI contributes to better diagnoses and recoveries, then they have no objection; if it is utilitarian and has a positive impact, then it's good. It was also felt that the use of de-identified data could strengthen AI, making it more effective in the future. It was noted that the more images it is given, the smarter it becomes and the fewer mistakes it makes, with someone stating "100 times better now could be 1,000 times better in the future". Others focused on the proliferation of AI, stating that AI "is not new" and is "everywhere anyway".

Interestingly, some that stated, 'very comfortable' shared that listening to the reasons from those who were 'slightly uncomfortable' made them consider revising their feeling to 'very uncomfortable,' particularly the environmental impact of AI. It was striking that this impacted their responses not just to 'slightly uncomfortable' or 'not sure', but specifically to '**very** uncomfortable.' It suggests that not only is the environmental impact of AI a strong concern for the Panel and potentially other members of the public, but that discussing these issues with peers can influence and nuance differing viewpoints.

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

The Panel were divided into groups of three to four and given 20 minutes to discuss and develop suggestions in response to this question. Members weighed with the benefits (mostly financial and operational) as well as (improved treatments, resources and capacity to do research the HSC cannot do on its own, better diagnostics, and the altruism of increased knowledge).

Several common themes and recommendations emerged across the groups:

- The HSC should receive financial incentives for sharing data for research.
- The HSC should have access to the research findings, potentially including the intellectual property, derived from its data.

- There needs to be a focus on monitoring and auditing how the data is used, by whom, and for what, in order to support trust, which is crucial.

Recommendation 1: Financial incentives

The Panel emphasised the need for financial compensation at a minimum for the HSC. This would include reimbursement for staff time, administrative costs, and other operational costs incurred in providing access to data. However, Panel members also suggested further financial incentives for the HSC. These include arrangements akin to licensing or royalties, which would see the HSC receive dividends from any profit's companies derive from innovations where the HSC data played a key role. They also suggested a subscription model, which is common across other industries. Finally, groups highlighted the potential for the HSC to gain positive publicity and credit by being included in data access agreements and contracts. Whatever specific method might be chosen, it was clear from discussions that participants felt that the HSC needed not only access to the benefits from the treatments, diagnostics, or interventions themselves, but to be able to recoup costs and derive profit, similar to a social economy enterprise, from these arrangements, which can be reinvested back into the HSC.

Recommendation 2: Access to research findings and subsequent innovations

Related to the costs highlighted above, the Panel pointed out the high costs incurred by the HSC to procure new drugs, treatments, machinery, etc., and that, where these are developed using HSC data, the HSC should be able to license and access them either at cost or at a significant discount. This should be written into access agreements and contracts. It was strongly felt that it was inappropriate for companies to gain access to public data to develop innovations, which they then charge the HSC high margins to use. If something is developed using public data, it should be easily available to benefit the public.

Recommendation 3: Transparency and trust

Finally, the Panel emphasised the importance of robust contractual and monitoring obligations for research initiatives to access HSC data. Trust is paramount in the sharing of public data, and for this to exist, there needs to be transparency about who is accessing the data, what they are using it for, and who is benefiting from it. It was felt that the current systems would need to be examined to see if they are fit for this express purpose. The Panel also stressed the need for joined-up working across

the HSC, government and industry for this to be successful and thereby develop and maintain public trust in the proposed system outlined above.

Conclusion

The Panel's discussion highlighted a generally supportive attitude toward the responsible use of de-identified biobank and image data, but with clear conditions to ensure fairness, accountability and public benefit. The Panel largely agreed that data access should differ between universities/healthcare organisations and industry, largely because industry is profit-driven and therefore should provide greater financial return or long-term investment to the HSC. At the same time, a minority argued that effective research depends on industry involvement regardless of sector, stressing that intention, capability and responsible use are more important than whether an organisation is public or private. On international access, most of the Panel felt that global research ultimately benefits NI, with ethical oversight and transparent monitoring being more important than geography. A smaller number felt strongly that NI should benefit directly from the use of its own data. Views on AI were mixed: while many were comfortable with AI-supported research due to its potential improvements in diagnosis and treatment, others expressed caution about the immaturity of AI, risks of misuse, and environmental impact, with peer discussions showing that hearing opposing perspectives could shift opinions.

Across all discussions, the Panel emphasised that if the HSC provides de-identified images or data, it should receive meaningful returns. These included financial compensation, long-term investment models such as royalties or licensing agreements, and access to research outputs and innovations developed using HSC data—particularly to avoid situations where publicly sourced data leads to private profit that the HSC must later purchase at high cost. Transparency, robust auditing, and contractual clarity were seen as essential to maintaining public trust. Overall, the conclusions suggest strong public support for data-enabled research, including collaboration with industry and international partners, provided that the system ensures fairness, accountability, shared benefit, and clear oversight that protects the interests of the NI public and the HSC.

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.