# Health and Social Care Data Institute Engagement Strategy

# 2025-28

Digital Health & Care Northern Ireland

**HSC Goes Digital**

**Analytics & Insight**

**Information Governance**

**Coding & Standards**

**NITRE**

## Executive Summary

The Health and Social Care Data Institute (HSCDI) is part of Digital Health and Care Northern Ireland (DHCNI). It plays a central role in transforming how health and social care data is accessed, governed, and used across Northern Ireland.

This inaugural Engagement Strategy outlines HSCDI's approach to building trust, raising awareness, and strengthening relationships with key audiences over the period 2025–2028.

The strategy supports the delivery of the HSC Data Strategy (2022–2030) and the Research and Development Strategy (2016–2025), recognising the critical role of high-quality, secure, and accessible data in improving health and social care outcomes.

It is underpinned by a commitment to transparency, ethical data use, and meaningful involvement of patients, the public, professionals, researchers, and policymakers.

Eight strategic objectives guide this work, under three themes:

1. Raise awareness of the Data Institute's work;
2. Build trust and understanding in the use of health data; and
3. Strengthen collaborative relationships.

The strategy includes detailed engagement plans, timelines, and evaluation measures. It is supported by a Communications Strategy and will inform a future Involvement Strategy.

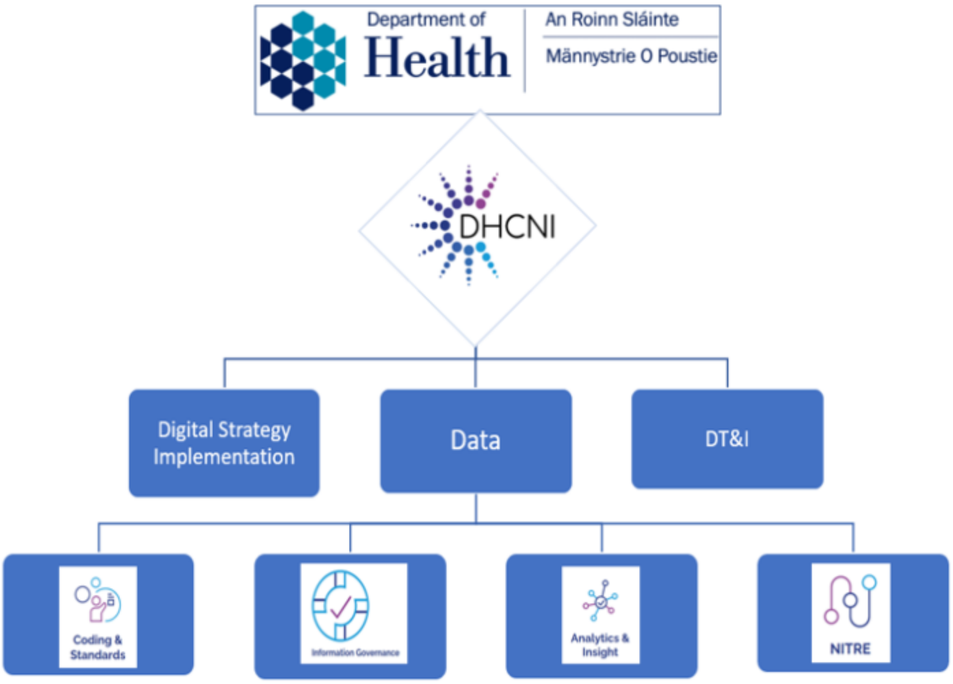
Together, these efforts aim to foster a culture of openness, collaboration, and innovation in the use of health data across Northern Ireland.

## Contents

## 1. Introduction

**1.1** Digital Health and Care Northern Ireland (DHCNI) is the data and technology lead to the health and social care system in Northern Ireland. Its mission is to harness the power of digital to improve health and care for our population, while improving working practices for all Health and Social Care Northern Ireland (HSC) staff.

**1.2** DHCNI is made up of three directorates. One of these is the Health and Social Care Data Institute ("the Data Institute"/HSCDI). Within the Data Institute directorate, there are four functions: Coding and Standards, Information Governance, Analytics and Insight, and the Northern Ireland Trusted Research Environment (NITRE).



**1.3** The Data Institute works across HSC organisations to provide solutions and support to data challenges and initiatives. It empowers the HSC to take patient-centred and data-driven decisions, and to gain insight into the performance of the services delivered by collating, analysing and providing actionable data. This relies on the use of secure, compliant technology and platforms that can scale to meet the needs of end users.

The Data Institute is responsible for delivering a transformation agenda in data access and control technologies and governance to support the secondary use of data for evaluation and research.

As outlined in the HSC Data Strategy 2022-2030[1], HSC in Northern Ireland is facing a number of data challenges which include:

- Data in HSC is disjointed and not used in the optimal manner.
- Confidence in our data is an issue in many areas, from core clinical coding right through the system.
- Data skills are limited and siloed and we face increasing challenges in recruiting and retaining data professionals.
- The COVID-19 response and use of data has highlighted the value of data in many areas. However, this has stretched resources significantly.

The Data Strategy identifies the Data Institute as the delivery capability for addressing the issues.

We need a service that establishes, builds, maintains and develops a data profession within health and social care and that can support the system in ensuring our data is of high quality and is used securely, effectively and legally.

The current Research and Development Strategy for Health and Social Care in Northern Ireland (2016-2025)[2] ("the R&D Strategy") sets out five objectives:

- Support research, researchers, and the use of evidence from research to improve the quality of both health and social care and for better policy making.
- Compete successfully for research and development funding, and optimise local funding, to deliver returns on investment for health and wellbeing, academia, and commerce.
- Support all those who contribute to health and social care research, development, and innovation by enhancing our research infrastructure, benefitting from local, national and international partnerships.
- Increase the emphasis on research relevant to the priorities of the local population.
- Disseminate research findings in such a way as to promote understanding and knowledge, support and share best practice, stimulate further research, and celebrate achievement.

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[1] HSC Data Strategy | Department of Health (health-ni.gov.uk)

[2] Strategy for HSC R&D (2016-2025) | Public Health Agency - Research & Development in Northern Ireland (hscni.net)

The overall aim of the R&D Strategy is: “The health, wellbeing and prosperity of the Northern Ireland population will benefit from excellent, world-renowned research and development in health and social care that is led from Northern Ireland”.

The successful delivery of the R&D Strategy relies on the availability of comprehensive, accurate, and insightful data on health and social care in Northern Ireland. The Data Institute plays a critical role in collecting, analysing, validating, and presenting this data, making it an essential component in achieving the R&D Strategy’s aim and objectives.

Each department within the Data Institute contributes significantly to the acquisition, processing, and management of data, ensuring its integrity and relevance before it can be utilised to support evidence-based decision-making. These contributions include stakeholder engagement, data governance, and the continuous improvement of data quality, all of which are fundamental to the overall success of the R&D Strategy.

A new R&S Strategy is currently in developed, with a particular focus on the use of data[3]. As its launch is anticipated during the lifespan of this Engagement Strategy, the Data Institute will proactively review and align its activities to ensure consistency with the objectives of the updated R&S Strategy. Any necessary actions or adjustments will be undertaken to reflect and support its goals.

**1.4** Engaging with patients and the public(s) is a fundamental aspect of delivering a high-quality data and research service. Effective engagement fosters trust, promotes fairness, enhances data quality, and creates opportunities for continuous improvement. It is the ethical responsibility of organisations to actively engage with those affected by research and data-driven decisions[4].

**1.5** Data Institute discovery work was completed in September 2023 which involved significant engagement across the Department of Health (“the Department”/DoH) and HSC.

Following the discovery phase, focus has now shifted towards strengthening the existing data teams within DHCNI to enable more effective collaboration with

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[3] Public Health | Consultation

[4] Ethical Considerations for Patient Engagement - Rethinking Clinical Trials

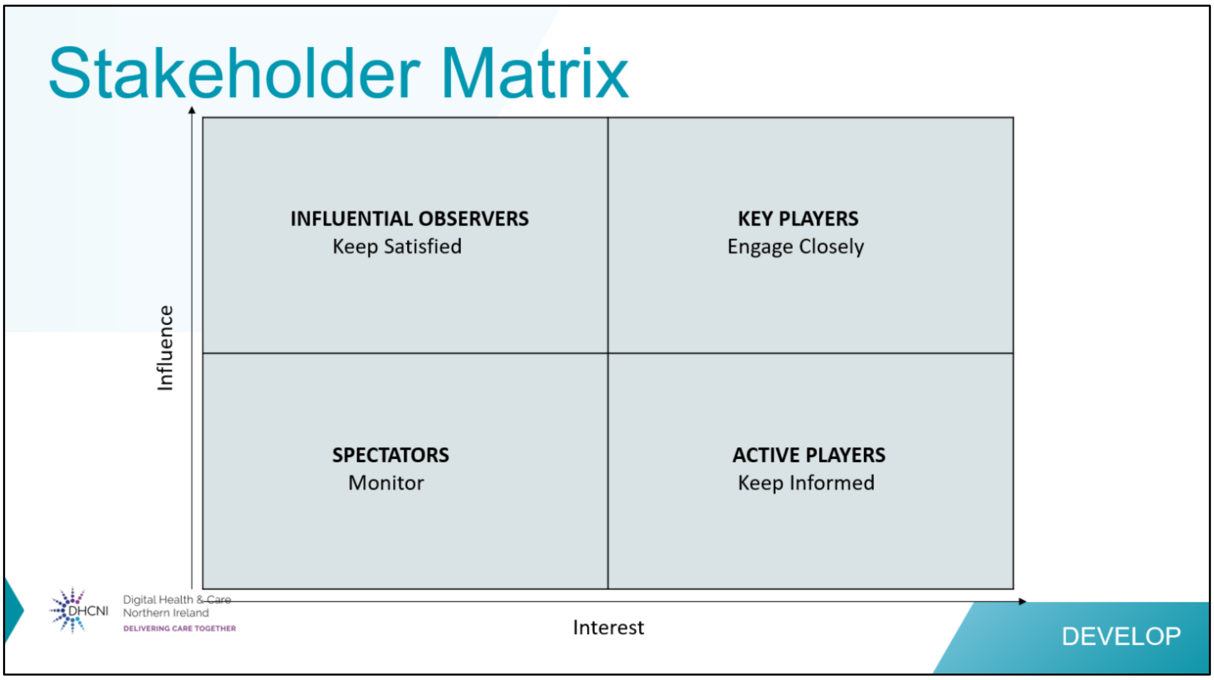
partner organisations, alongside a review of governance structures to promote more efficient use of time and resources and to support improved decision-making.

A HSCDI Business Case has been developed to expand and enhance the role of the Data Institute across the following four areas:

- Coding & Standards.
- Information Governance.
- Analytics & Insight.
- NITRE.

**1.6** During the discovery phase, a Stakeholder Matrix was developed to identify stakeholders based on their interest and influence. The four categories were as follows:

**Key Players**: High influence and high interest. Engage closely.
**Influential Observers**: High influence and low interest.
**Active Players**: Low influence and high interest.
**Spectators**: Low influence and low interest.



Stakeholder Matrix

| | |
|---|---|
| **INFLUENTIAL OBSERVERS**<br>Keep Satisfied | **KEY PLAYERS**<br>Engage Closely |
| **SPECTATORS**<br>Monitor | **ACTIVE PLAYERS**<br>Keep Informed |

As engagement activity within the Data Institute evolves, and a more comprehensive understanding of the stakeholder landscape emerges, the Stakeholder Matrix will be used to map identified stakeholders according to their level of interest and influence. This will enable the Data Institute to tailor engagement approaches appropriately and ensure that each stakeholder receives the right level of attention and involvement based on their strategic relevance.

**1.7** In 2024 the Department of Health carried out a consultation on a proposed Public Health Bill for Northern Ireland[5]. The consultation received over 8,000 responses, with some concerns raised around the subject of data and privacy.

UK-wide research conducted in 2024 reveals a complex public perception of health data sharing, with significant support tempered by concerns about privacy and security. According to a survey by NHS England[6], 83% of respondents trust the NHS to securely handle their personal health data. However, this trust diminishes when it comes to other entities, with just 21% comfortable with private companies accessing anonymised patient data for non-clinical purposes[7]. Privacy remains a key concern, with 31% of individuals expressing apprehension about unauthorized access to their data, and 31% worried about potential data breaches[8]. These statistics highlight the need for strong data protection measures and transparent communication to foster trust. While the public generally supports the NHS's use of health data to improve services, addressing concerns over data misuse is critical for securing broad public acceptance of future health data initiatives.

The Health Foundation's December 2024 Attitude's Survey[9] highlights that while a significant portion of the UK public recognises the benefits of healthcare technologies, there are concerns about data privacy. Around half of the public (51%) support the use of health data for improving services, though there is considerable variation in attitudes across different groups. Trust in the NHS's handling of health data is high, but the public is more hesitant about private companies using health information. This underlines the need for clear communication and robust data protection for continued public confidence in health technology and data usage.

**1.8** The Engagement Strategy is supported by a Communication Strategy. The Engagement Strategy will inform and complement an Involvement Strategy. These strategies speak to the overarching Data Strategy.

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[5] Policy Proposals to inform the development of a new Public Health Bill for Northern Ireland | Department of Health (health-ni.gov.uk)
[6] Public attitudes to data in the NHS and social care - NHS England Digital
[7] Public attitudes about patient data for planning | (ukhealthdata.org)
[8] Public attitudes about patient data for planning | (ukhealthdata.org)
[9] How does the public feel about health technologies and data? - The Health Foundation

**1.9** Artificial Intelligence is becoming an increasingly significant conversation within health and social care, influencing data-driven decision-making, service delivery, and research. It is an area of growing relevance not only to the Data Institute, but across the wider sector, and remains a topic of high interest as we continue to monitor its development and potential impact. The Data Institute is actively exploring how its practices might evolve to incorporate AI in a responsible and meaningful way. As part of our engagement approach, we will consider how AI could enhance engagement activities, such as improving accessibility, personalisation, and efficiency, where appropriate. Any use of AI will be subject to robust ethical, legal, and governance standards to ensure transparency, accountability, and public trust remain central to our work.

**1.10** Successfully delivering our Engagement Strategy will require navigating several challenges, including limitations in people, time, and financial resources. As engagement is a relatively new function within HSCDI, there will be a necessary period of adjustment to establish best practices, refine our approach, and build internal capacity.

**1.11** The Data Institute is dedicated to upholding best practices in engagement and continuously enhancing its approach through collaboration and shared learning. This includes active engagement with peer data institutes and national health programmes across England, Scotland, Wales, and the Republic of Ireland, fostering cross-border knowledge exchange and professional development.

## 2. Aims and Objectives

**2.1** The aim of this Engagement Strategy is to guide and enhance the Data Institute's engagement with patients, the public, and stakeholders. It seeks to **raise awareness of the Data Institute's work**, **build trust and understanding in the use of health data**, and **strengthen collaborative relationships**.

**2.2** Objectives of the Engagement Strategy:

**Objective 1** – Enhance the reputation and visibility of the HSC Data Institute by actively engaging with key audiences, building trust among peers, and developing a relevant audience to include promoting the secondary use of data within the Northern Ireland Trusted Research Environment (NITRE).

**Objective 2** – Raise the profile of the Analytics and Insight, Coding and Standards, and Information Governance functions.

**Objective 3** - Demystify the use of health data for research purposes in Northern Ireland for patients and the public.

**Objective 4** – Demonstrate how the Data Institute manages data safely and securely, contributing to patient and public trust.

**Objective 5** – Highlight the crucial role of the secondary use of health data in advancing research, subsequently improving health and social care outcomes, to health and social care professionals, academics, researchers, innovators, politicians, and decision-makers.

**Objective 6** – Public, patients, and stakeholders are engaged and informed about decisions on secondary use of data for research purposes, promoting transparency, fostering trust, and encouraging support for the Data Institute's role in enhancing health and social care across Northern Ireland.

**Objective 7** – Strengthen relationships with Patient and Public Involvement and Engagement (PPIE) bodies in Northern Ireland to better understand the PPIE landscape and shape the Data Institute's Involvement Strategy.

**Objective 8** – Develop stronger connections between General Practitioners and the HSC Data Institute to enhance the benefits of the General Practitioner Intelligence

Platform (GPIP), supporting improved data-sharing agreements and enabling high-quality health and social care research across Northern Ireland.

## 3. Audience Profiles

### 3.1 Patients and Our Public(s)

**Who this is:**

- ‘Patients’ and ‘Service Users’. Patients typically refer to someone receiving healthcare as medical treatment in a traditional setting, such as a hospital or general practitioners. Service User typically refers to someone receiving a form of social care.
- Voluntary, community, and social enterprise groups/organisations.
- Patient advocacy groups/organisations.
- Individuals whose data is captured by HSC.
- There are 1.92 million people living in Northern Ireland, according to the latest figures by the Northern Ireland Statistics and Research Agency (NISRA) published in September 2024.
- The General Medical Services for Northern Ireland Annual Statistics 2023/24[10], published in June 2024, revealed that there were 2,055,000 individuals registered with a GP practice in Northern Ireland at 31st March 2024.

**Engagement priorities for this audience:**

- Demystify data use.
- Simplify the concept of secondary use health data and its local and societal benefits.
- Highlight the safeguards in place to use their data responsibly and confidentially.
- Address questions about consent, data anonymisation/pseudonymisation, and opting out.

### 3.2 Health and Social Care Professionals

**Who this is:**

- Anyone directly employed by, or under contract to, HSC. This includes administrative, information technology, and research/data staff.
- The Northern Ireland Health and Social Care Workforce Census[11], published in March 2024, revealed that the HSC hospital, community and social services workforce had 74,039 staff in post or 65,984 whole-time equivalents.

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[10] Publication of FPS General Medical Services for Northern Ireland, Annual Statistics 2023/24 | Department of Health (health-ni.gov.uk)

[11] NI Health and Social Care Workforce Census – March 2024 | Department of Health (health-ni.gov.uk)

- The General Medical Services for Northern Ireland Annual Statistics 2023/24[12], published in June 2024, revealed that there were 1,454 GPs across 312 active GP practices in Northern Ireland.

**Engagement priorities for this audience:**

- Show how secondary use data can enhance clinical decision-making, inform service planning, and improve patient outcomes.
- Discover opportunities for collaboration with medical researchers and DoH policymakers.
- Improve relationships with GPs and demonstrate to them the benefits of allowing HSCDI to use GPIP data for further improvements to health and social care.
- Introduce front-line health and social care staff who may not be familiar with data use to the impacts of data.

## 3.3 Researchers and Innovation

**Who this is:**

- Those wishing to use HSC data to conduct approved research or innovation.
- Health & Social Care Research & Development Division.
- University staff.
- Research organisations.
- Professional researchers.
- Clinical trial organisations.
- Commercial research organisations / big pharma.
- The Northern Ireland Research and Developer Survey 2023[13], published in December 2024, revealed there were 11,480 full-time equivalents (FTEs) working in a research and development role in 2023.

**Engagement priorities for this audience:**

- Building the HSCDI and NITRE profiles as a valuable, trustworthy research assets/partners to other researchers and academics.
- Ensuring/confirming this audience values secondary health data in enabling high-quality research and innovation.
- Ensuring clarity of what data is available to them.
- Collaborations on research.

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[12] Publication of FPS General Medical Services for Northern Ireland, Annual Statistics 2023/24 | Department of Health (health-ni.gov.uk)

[13] Northern Ireland Research & Development Survey 2023 | Northern Ireland Statistics and Research Agency (nisra.gov.uk)

## 3.4 Policy Makers

**Who this is:**

- Politicians and public servants who influence, shape and create health and social care services, but are not health, medical or social care practitioners.
- Policy makers in the DoH and HSC.
- HSC Research & Development includes policy leads for research governance.
- HSCDI is funded by the Department of Health.
- The Health Minister has overall responsibility for the Department of Health.
- All of the Northern Ireland Assembly and Executive are relevant as may impact decisions.
- The Information Commissioner’s Office (ICO) influences policy in data-related areas. It operates an advice service to address general enquiries on data protection and freedom of information, and promotes good practice in information rights by raising awareness of organisational responsibilities across all sectors[14].
- The Office of Research Ethics Committees NI (ORECNI) influences policy in health and social care research. Its role is to ensure research involving HSC patients and service users complies with ethical standards[15].

**Engagement priorities for this audience:**

- Provide information and updates regarding the important work of HSCDI.
- Show how secondary use data can enhance clinical decision-making, inform service planning, and improve patient outcomes for people in Northern Ireland.

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[14] ICO Northern Ireland (ico.org.uk)

[15] ORECNI (hscni.net)

## 4. Influencers and Gatekeepers

### 4.1 DHCNI

- HSCDI has employed an Engagement and Impact Manager to help realise its engagement objectives.
- All HSCDI staff.
- All DHCNI staff.
- As well as trying to improve engagement internally, we will utilise networks already establish by HSCDI staff to engage with our target audiences.

### 4.2 DoH

- Northern Ireland Civil Service (NICS) staff in DoH.
- Minister's Office staff.
- Contacts in these organisations will help us engage with the Minister, Assembly, Executive, and policy makers.
- Political parties working in DoH are often influenced by their party's own political policies, or by their own constituents.

### 4.3 HSC

- Wider staff across HSC in Northern Ireland.
- As well as trying to improve engagement with HSC staff, we will utilise our contacts within HSC to reach our target audiences.
- Strategic Performance Planning Group (SPPG).

### 4.4 Media

- Our Communications Strategy will detail how we will utilise the press media (print, broadcast, and online), as well as social media, to amplify our messages to our audiences.

### 4.5 Detractors

- Some stakeholders may make it more difficult to achieve our objectives. Employees within HSCDI, DHCNI, DoH, and HSC may challenge our ambitions or introduce bureaucratic hurdles that slow progress.

Furthermore, given our focus on the use of data for research purposes, we may encounter strong opinions from advocacy groups and influential social media communities. Managing these perspectives effectively will be key to maintaining momentum and ensuring the success of this strategy. As part of the development of this Engagement Strategy, the Information Commissioner’s Office (ICO) has been consulted and has provided a comprehensive list of relevant organisations and key contacts within this space.

## 5. Engagement Plans

**Objective 1: Enhance the reputation and visibility of the HSC Data Institute by actively engaging with key audiences, building trust among peers, and developing a relevant audience to include promoting the secondary use of data within the Northern Ireland Trusted Research Environment (NITRE).**

**Themes and timescales:** Profile of NITRE, and profile of Northern Ireland Public Data Panel (NIPDP). Year 1: Establish profile of NITRE and NIPDP, introducing them to key audiences. Year 2: Sustain profiles of NITRE and NIPDP with key audiences. Year 3: Further develop profile of NITRE and NIPDP to wider audiences.

**Audiences:** Patients and our public(s), health and social care professionals, research and innovation, policy makers.

**Planned actions:**

- Develop tailored slide decks and presentations to explain HSCDI, NITRE, and NIPDP, with language formats adapted for patients, the public, professionals, researchers, and policymakers.
- Produce case studies in various formats (e.g. web copy, videos, social media content) showcasing the impact of data use and research supported by NITRE and NIPDP, formatted for varied audiences.
- Host and attend public forums, community events, and advocacy meetings to build relationships and engage with patients, the public, VCSE organisations, and advocacy groups.
- Engage with health and social care professionals, researchers, innovators, and policy makers (HSC and DoH) through targeted events, meetings, and outreach.
- Explore hosting an annual health data conference to connect with patients, professionals, and researchers, and promote HSCDI and NITRE’s work.
- Launch an online portal with resources such as access guides, ethical guidelines, and success stories to support stakeholder engagement.
- Use internal engagement opportunities, including Lunch and Learn webinars, to promote NITRE and encourage collaboration across teams.
- Leverage external networks like ADR NI/ADR UK to introduce and promote NITRE to research and innovation audiences.

**Desired outcomes:**

- Slide decks and case studies will be valuable assets for events and communications, helping to showcase HSCDI and NITRE’s impact.

- Engagement activities (forums, advocacy groups, VCSE organisations, professional events) will introduce NITRE, address concerns, gather feedback, and build meaningful relationships.
- These engagements will also help identify collaboration opportunities, demonstrate how research benefits stakeholders, and expand networks through introductions and referrals.
- Annual conferences and tailored events will raise NITRE’s profile, strengthen existing relationships, and attract new ones, while gathering valuable insights from attendees and speakers.
- NIPDP case studies and presentations will promote the panel’s work and encourage future collaboration, especially among researchers and innovators.

**Objective 2: Raise the profile of the Analytics and Insight, Coding and Standards, and Information Governance functions.**

**Themes:**

**Audiences:** Patients and our public(s), health and social care professionals, research and innovation, policy makers.

**Planned actions:**

- Develop tailored slide decks and presentations for Analytics & Insight, Coding & Standards, and Information Governance, with formats suited to health and social care professionals, researchers, innovators, and policy makers.
- Showcase these presentations at outreach events, internal webinars (e.g. Lunch and Learn), and professional forums across all HSC Trusts.
- Produce HSCDI case studies in various formats (e.g. web copy, videos, social media content), including student experiences, to highlight the impact of data use and promote understanding across sectors.
- Engage with academic institutions (Ulster University, Queen’s University Belfast, and others) to build relationships and attract new talent.
- Maintain strategic engagement with MOIC, Belfast Region City Deals, and ADR NI/ADR UK through meetings and collaborative opportunities.
- Collaborate with private healthcare providers, hospices, arms-length bodies, and CHKS to promote standardisation and share knowledge on coding and definitions.
- Establish and maintain relationships with policy bodies including the Department of Health’s Research and Corporate Management directorate, Senior Information Risk Owners, and Information Governance Leads.
- Participate in working groups and networks such as IGAG and RISP to share updates and align on data governance practices.

- Engage with regulatory bodies like the ICO and ORECNI through meetings and presentations to promote transparency, build trust, and ensure governance alignment.
- Publish and promote Privacy Notices and governance documents to ensure clarity around data processing and compliance.

**Desired outcomes:**

- Raised profile of HSCDI functions (Analytics & Insight, Coding & Standards, and Information Governance) across health and social care, research, innovation, and policy audiences.
- Improved understanding of how data is analysed and used, leading to better data quality from health and social care professionals and more informed decision-making.
- Strengthened relationships with key organisations including MOIC, CHKS, Ulster University, Queen’s University Belfast, ADR NI/ADR UK, and Belfast Region City Deals, enabling collaboration and knowledge exchange.
- Greater visibility and influence within the Department of Health, particularly the Research and Corporate Management directorate, supporting policy development informed by HSCDI data.
- Consistent application of standards and codes across HSC organisations, private healthcare providers, hospices, and arms-length bodies, improving data accuracy and interoperability.
- Enhanced transparency and trust through publication of Privacy Notices and governance documents, and proactive engagement with patients, the public, and professionals.
- Effective communication and collaboration with regulatory and oversight bodies including the ICO and ORECNI, ensuring support and alignment with best practice.
- Active participation in governance networks such as IGAG and RISP, facilitating shared learning and updates on current and future projects.

**Objective 3: Demystify the use of health data for research purposes in Northern Ireland for patients and the public.**

**Audiences:** Patients and out public(s)

**Planned actions:**

- Develop a plain-English slide deck to explain how health data is used for research in Northern Ireland, tailored for patients and the public.
- Create case studies that highlight the positive impact of health data use, designed to be accessible and engaging for public audiences.

- Host and attend public forums, community events, and advocacy meetings to share resources, answer questions, and build relationships with patients, the public, and VCSE organisations.
- Deliver workplace workshops to health-focused organisations to raise awareness and encourage dialogue around the use of health data.

**Desired outcomes:**

- Patients and the public gain a clearer understanding of how health data is used for research in Northern Ireland.
- Slide decks and case studies become useful tools for engagement, helping to explain the benefits of data use in an accessible format.
- Attendees at events, including advocacy groups and VCSE organisations, are able to ask questions, raise concerns, and feel more informed and involved in discussions about health data. Feedback and questions will be recorded, and answers/actions will be published and shared.

**Objective 4: Demonstrate how the Data Institute manages data safely and securely, contributing to patient and public trust.**

**Audiences:** Patients and our public(s)

**Planned actions:**

- Create a plain-English slide deck to explain how health data is handled safely and securely, designed for patients and the public.
- Share Privacy Notices and governance documents to promote transparency and build trust.
- Host and attend public forums, community events, and advocacy meetings to showcase data protection policies and engage with patients, the public, and VCSE organisations.
- Deliver workplace workshops to health-focused organisations to raise awareness and encourage dialogue around secure data use.

**Desired outcomes:**

- Patients and the public have access to clear, plain-English resources explaining how their data is used, including slide decks, Privacy Notices, and governance documents.
- Communications materials become effective tools for use at events, helping to build understanding and trust.
- Attendees at public forums, advocacy meetings, and VCSE events gain a better understanding of how their data is handled securely, and feel confident to ask questions and raise concerns.

### Objective 5: Highlight the crucial role of the secondary use of health data in advancing research, subsequently improving health and social care outcomes, to health and social care professionals, academics, researchers, innovators, politicians, and decision-makers.

**Audiences:** Health and social care professionals, research and innovation, and policy makers

**Planned actions:**

- Develop a presentation to highlight the role of secondary health data, tailored for health and social care professionals.
- Produce case studies demonstrating the impact of secondary data use, designed for professional audiences.
- Host webinars and in-person workshops to share insights and encourage discussion.
- Attend health and social care, research, data, and innovation conferences as speakers, guests, and exhibitors.
- Facilitate knowledge-sharing through networks such as ADR NI to promote the value of secondary data in improving outcomes.
- Engage with HSC and Department of Health policy makers through meetings and collaborative discussions.

**Desired outcomes:**

- Slide decks and case studies become effective tools for engaging audiences and communicating the value of health data in research.
- Health and social care professionals gain insight into how secondary health data contributes to improved outcomes.
- Stronger engagement with professionals, researchers, and policy makers creates opportunities to promote and discuss the secondary use of data.
- Events and outreach activities lead to better understanding, open dialogue, and increased support for the use of health data in research.

### Objective 6: Public, patients, and stakeholders are engaged and informed about decisions on secondary use of data for research purposes, promoting transparency, fostering trust, and encouraging support for the Data Institute's role in enhancing health and social care across Northern Ireland.

**Audiences:** Patients and our public(s), health and social care professionals, research and innovation, policy makers

**Planned actions:**

- Hold consultation events, both in person and online, to engage patients, the public, health and social care professionals, researchers, innovators, and policy makers on the secondary use of data.
- Attend community and corporate events to discuss data use decisions and provide opportunities for attendees to share feedback and ask questions.

**Desired outcomes:**

- Patients, the public, health and social care professionals, researchers, innovators, and policy makers feel informed and involved in decisions about the secondary use of data.
- Increased transparency and trust in HSCDI’s work encourages broader support for the responsible use of health data in research.

**Objective 7: Strengthen relationships with Patient and Public Involvement and Engagement (PPIE) bodies in Northern Ireland to better understand the PPIE landscape and shape the Data Institute’s Involvement Strategy.**

**Audiences:** PPIE bodies

**Planned actions:**

- Arrange meetings with existing groups to better understand their roles, their successes, and their experiences.
- We will ask existing groups to collaborate with us or review our projects that are relevant to their group.

**Desired outcomes:**

- Stronger relationships with PPIE bodies across Northern Ireland.
- Improved understanding of the PPIE landscape to inform HSCDI’s Involvement Strategy, including the potential development of a dedicated PPIE panel.
- Increased visibility and credibility of the Data Institute through collaboration and project review with established PPIE groups.
- Partners and their members involved in decision making.

**Objective 8: Develop stronger connections between General Practitioners and the HSC Data Institute to enhance the use of the General Practitioner Intelligence Platform (GPIP), supporting improved data-sharing agreements and enabling high-quality health and social care research across Northern Ireland.**

**Audiences:** General Practitioners, health and social care professionals, and patients and our public(s)

**Planned actions:**

- Participate actively in the GPIP Editorial Board.
- Engage with the Northern Ireland General Practitioners Committee (NIGPC), the GP representative body, and the Royal College of General Practitioners NI (RCGPNI), who cover quality standards and research, to strengthen engagement with GPs.
- Arrange meetings with GPs to discuss the General Practitioner Intelligence Platform and explore opportunities for collaboration.
- Represent HSCDI at medical and data events as a speaker or with an information stand to raise awareness of GPIP.
- Host internal meetings and workshops to support collaboration between NITRE and GPIP data teams.
- Engage with the HSC Strategic Planning and Performance Group to strengthen support for GPIP and primary care initiatives.
- Meet with the Patient and Client Council and Public Involvement Enhancing Research (PIER NI), that is part of HSC Research & Development, to ensure patients and the public are informed and involved in GPIP activities.

**Desired outcomes:**

- GPs already engaged with HSCDI and GPIP are further supported, while new connections are established with those not yet actively involved.
- Increased engagement with GPs leads to wider awareness and understanding of GPIP and its relevance to practice-level decision making.
- Stronger relationships with GPs and greater visibility of GPIP across the medical and data community.
- Improved collaboration between NITRE and GPIP data teams results in more efficient and effective use of health data.
- Enhanced support for GPIP and HSCDI initiatives through strengthened relationships with the Strategic Planning and Performance Group.
- Patients and the public are informed and involved in GPIP activities through engagement with the Patient and Client Council and PIER NI.

## 6.0 Evidence and Feedback

### 6.1 Digital Footprint

- We will report on our digital footprint, as laid out in the supporting Communications Strategy, to evidence use of digital assets.

### 6.2 In-Person Outreach

- We will evidence how many events/engagements we attended.
- We will record attendance figures at events.
- We will conduct surveys, focus groups, and interviews to gather feedback from all key audiences in relation to our work including engagement.

### 6.3 Research and Data Use

- We will create data that is findable, relevant, usable and quality assured.
- We will quantify how many research projects took place following engagement.

### 6.4 Transparency of Evidence and Feedback

- Feedback will inform strategic decisions.
- We will share findings publicly to reinforce transparency and demonstrate progress in our outcomes based on engagement.

### 6.5 Benchmarking

- As the inaugural Engagement Strategy, we will use outcomes as the benchmark for engagement in subsequent years.
- We will compare our engagement evidence and feedback to similar organisations in the UK and Republic of Ireland to identify areas for performance improvement.

## 7.0 Implementation Timeline

| **Description** | **Expected Delivery Date** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2025/26 | | | | 2026/27 | | | | 2027/28 | | | |
| | Q1 | Q2 | Q3 | Q4 | Q1 | Q2 | Q3 | Q4 | Q1 | Q2 | Q3 | Q4 |
| Draft Engagement Strategy circulated with appropriate audiences including NITRE Board, GPIP Board, and HSC R&D. | ■ | | | | | | | | | | | |
| Engagement Strategy approved and live. | | ■ | | | | | | | | | | |
| Create a public-friendly version of the Engagement Strategy, publish on our website, and circulate to appropriate stakeholders. | | ■ | | | | | | | | | | |
| **Objective 1: Enhance the reputation and visibility of the HSC Data Institute by actively engaging with key audiences, building trust among peers, and developing a relevant audience to include promoting the secondary use of data within the Northern Ireland Trusted Research Environment (NITRE).** | | | | | | | | | | | | |
| Establish key audiences including contact details. | | ■ | | | | | | | | | | |
| Create HSCDI and NITRE slide decks. | | ■ | | | | | | | | | | |
| Create NITRE and NIPDP case studies. | | ■ | ■ | ■ | | | | | | | | |
| Secure relationship with existing audience by further event attendance, outreach, and communications. | | | | | ■ | ■ | ■ | ■ | | | | |
| Expand audience with wider event attendance, outreach, and communications. | | | | | | | | | ■ | ■ | ■ | ■ |

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| **Objective 2: Raise the profile of the Analytics and Insight, Coding and Standards, and Information Governance teams.** | | | | | | | | | | | | |
| Establish audiences. | 🟦 | 🟦 | 🟦 | 🟦 | | | | | | | | |
| Creating slide decks. | 🟦 | 🟦 | 🟦 | 🟦 | | | | | | | | |
| Creating case studies. | 🟦 | 🟦 | 🟦 | 🟦 | | | | | | | | |
| Secure relationship with existing audience by further event attendance, outreach, and communications. | | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | | |
| Expand audience with wider event attendance, outreach, and communications. | | | | | | | | | 🟦 | 🟦 | 🟦 | 🟦 |
| **Objective 3: Demystify the use of health data for research purposes in Northern Ireland for patients and the public.** | | | | | | | | | | | | |
| Establish audiences. | 🟦 | 🟦 | | | | | | | | | | |
| Creating slide decks. | | 🟦 | | | | | | | | | | |
| Creating case studies. | | 🟦 | | | | | | | | | | |
| Event attendance, outreach, and communication activity. | | | 🟦 | 🟦 | | | | | | | | |
| Secure relationship with existing audience by further event attendance, outreach, and communications. | | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | | |
| Expand audience with wider event attendance, outreach, and communications. | | | | | | | | | 🟦 | 🟦 | 🟦 | 🟦 |
| **Objective 4: Demonstrate how the Data Institute manages data safely and securely, contributing to patient and public trust.** | | | | | | | | | | | | |
| Establish audiences. | 🟦 | | | | | | | | | | | |

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|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Creating slide decks. | | 🟦 | | | | | | | | | | |
| Creating case studies. | | 🟦 | | | | | | | | | | |
| Event attendance, outreach, and communication activity. | | | 🟦 | 🟦 | | | | | | | | |
| Secure relationship with existing audience by further event attendance, outreach, and communications. | | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | | |
| Expand audience with wider event attendance, outreach, and communications. | | | | | | | | | 🟦 | 🟦 | 🟦 | 🟦 |
| **Objective 5: Highlight the crucial role of the use of secondary health data in advancing research, subsequently improving health and social care outcomes, to health and social care professionals, academics, researchers, innovators, politicians, and decision-makers.** | | | | | | | | | | | | |
| Establish audiences. | 🟦 | 🟦 | | | | | | | | | | |
| Creating slide decks. | | 🟦 | | | | | | | | | | |
| Creating case studies. | | 🟦 | | | | | | | | | | |
| Event attendance, outreach, and communication activity. | | | 🟦 | 🟦 | | | | | | | | |
| Secure relationship with existing audience by further event attendance, outreach, and communications. | | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | | |
| Expand audience with wider event attendance, outreach, and communications. | | | | | | | | | 🟦 | 🟦 | 🟦 | 🟦 |

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| **Objective 6: Public, patients, and stakeholders are engaged and informed about decisions on secondary use of data for research purposes, promoting transparency, fostering trust, and encouraging support for the Data Institute's role in enhancing health and social care across Northern Ireland.** | | | | | | | | | | | | |
| Establish audiences. | 🟦 | 🟦 | | | | | | | | | | |
| Consultations. | | | 🟦 | 🟦 | | | | | | | | |
| Secure relationship with existing audience by further event attendance, outreach, and communications. | | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | | |
| Expand audience with wider event attendance, outreach, and communications. | | | | | | | | | 🟦 | 🟦 | 🟦 | 🟦 |
| **Objective 7: Strengthen relationships with Patient and Public Involvement and Engagement (PPIE) bodies in Northern Ireland to better understand the PPIE landscape and shape the Data Institute's Involvement Strategy.** | | | | | | | | | | | | |
| Mapping exercise. | 🟦 | 🟦 | | | | | | | | | | |
| Initiate contact. | 🟦 | 🟦 | | | | | | | | | | |
| Understand. | | | 🟦 | 🟦 | | | | | | | | |
| Review. | | | 🟦 | 🟦 | | | | | | | | |
| Establish PPIE for HSCDI. | | | | | 🟦 | 🟦 | 🟦 | 🟦 | | | | |
| Develop PPIE for HSCDI. | | | | | | | | | 🟦 | 🟦 | 🟦 | 🟦 |
| **Objective 8: Develop stronger connections to enhance the use of the General Practitioner Intelligence Platform (GPIP), supporting improved data-sharing agreements and enabling high-quality health and social care research across Northern Ireland.** | | | | | | | | | | | | |
| Establish audiences. | 🟦 | 🟦 | | | | | | | | | | |

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| Develop relationships with engaged GPs by attending and participating in Editorial Board and Forums. | ■ | ■ | | | | | | | | | | |
| Create an Engagement Plan specific to GPIP. | ■ | ■ | | | | | | | | | | |
| Present Engagement Plan to the GPIP Editorial Board. | | ■ | | | | | | | | | | |
| Establish/grow relationships with wider GP network by attending forums and networking events. | | | ■ | ■ | ■ | ■ | | | | | | |
| Continue to secure relationship with engaged GPs. | | | | | ■ | ■ | ■ | ■ | | | | |
| Grow network and ongoing work with established audience. | | | | | | | | | ■ | ■ | ■ | ■ |

## 8.0 Governance, Ethics and Privacy Considerations

**8.1** The Data Institute is committed to upholding the highest standards of data protection, ethical data use, and transparency throughout all engagement activities. Our approach includes:

- Providing clear and accessible information on our data protection policies and compliance with relevant legislation, including the General Data Protection Regulation (GDPR) and the UK Data Protection Act.
- Ensuring that any personal data collected during engagement activities for monitoring or contact purposes is handled in accordance with a Privacy Notice, which outlines how data is stored and processed.
- Maintaining the Information Governance Tracker and Record Review Schedule to document and regularly update any relevant documents recording our governance and privacy commitments.
- Embedding equality, diversity, and inclusion (EDI) principles into all engagement activities, ensuring a fair and inclusive approach for patients, the public, and stakeholders.
- Adopting a tailored approach to engagement to effectively reach and support diverse patient and public groups.

These commitments reflect our dedication to responsible data management and meaningful engagement with all audiences.

## 9.0 Budget

- Currently, the engagement function within the Data Institute operates without a dedicated budget. Instead, costs associated with engagement activities are absorbed by the budgets of the respective work areas involved. A future review of engagement funding will explore opportunities to strengthen engagement efforts, enhance impact, and mitigate risks associated with underinvestment, particularly the potential for reduced effectiveness in delivering meaningful and inclusive engagement.

## 10.0 Review Plan

| Date | Action | Responsibility | Review Notes |
|---|---|---|---|
| 2025/26 – Q1 | Strategy sign-off | **FB/CM/JB/MM**<br>*(four function Leads)*<br>**LW**<br>*(Deputy Chief Data Officer)*<br>**NITRE Strategic Board** | |
| 2025/26 – Q3 | Review mid-year performance against objectives | **EM**<br>*(Engagement and Impact Manager)* | |
| 2026/27 – Q1 | Review/update Engagement Strategy | **EM**<br>*(Engagement and Impact Manager)* | |
| 2026/27 – Q3 | Review mid-year performance against objectives | **EM**<br>*(Engagement and Impact Manager)* | |
| 2027/28 – Q1 | Review/update Engagement Strategy | **EM**<br>*(Engagement and Impact Manager)* | |
| 2027/28 – Q3 | Review mid-year performance against objectives | **EM**<br>*(Engagement and Impact Manager)* | |
| 2027/28 – Q4 | Preparation for new three-year strategy including learning against objectives of this strategy | **EM**<br>*(Engagement and Impact Manager)* | |