Health and Social Care

Data Strategy

HSC Northern Ireland 2022-2030

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Introduction

Our population's health and care data is critical to the continuity of their wellbeing however our digital presentation and management of health and care data is by industry standards far behind the curve. We need to change how we view the importance of data in the delivery of health and care and to evolve the way in which we collect, use and share information within Health and Social Care in Northern Ireland (HSC).

As health and care evolves, the scope and opportunities we have to leverage data have expanded. However, our HSC systems are not currently set up to treat data as a strategic asset for policy making, programme design or service delivery. We need to keep pace with the wider digital transformation occurring in our system and focus our efforts on building our data capabilities.

Digital technology and better use of data are a critical part of delivering the 'New Decade' objectives, including:

- dealing with the ongoing COVID -19 pandemic;
- the new action plan on waiting times; the actions around Mental Health;
- reconfiguration of hospital services;
- delivery of the Delivering Together reforms;
- shift to day case elective centres;
- delivery of the transformed cancer services; and
- supporting community engagement and co-design.

Our direction of travel

We have started a journey towards central data and analytics solutions for the improvement of public health. While encompass will do a great deal to aid in the centralisation of data, there are many other digital/ data systems that can add significant value.

For example, in service planning or improvement, understanding staffing levels is critical - requiring integration with Human Resource systems. Furthermore, cost/impact analysis of any new service or improvement will require integration of finance systems. All of this information must be used together – linking together datasets from internal and external sources to add value to analysis -with higher quality data improving the model and the accuracy of any outcome measurement.

With this in mind as critical to our data journey, our strategy describes our ambitious plans to make data more accessible, interoperable and usable in Northern Ireland.

How we have developed this strategy

This strategy has been developed in collaboration with stakeholders from across the HSC ecosystem, as well as through engagement with our people and population. It is intended for all of those involved in the delivery of health and social care services as well as those that support and work with HSC.

The strategy outlines the vision, mission, and objectives for data and information across Health and Social Care Northern Ireland until 2030, to be reviewed in 2027 at the 5 year mark.

Our Data Landscape

Data can empower providers to make better decisions, design better programmes and deliver more effective services. For this to occur and for us to share data in a way that allows others, businesses, researchers and the 4th sector to also extract value we need to change our approach. Our new approach will focus on the elimination of data silos, reduction of duplication and joining up of our data sources.

This data strategy recognises that we have made some good progress with using shared data for better care with the Northern Ireland Electronic Care Record (NIECR). Behind that functional layer we continue to persist siloed data repositories which are detached from the front-line of care delivery, inaccessible to our people and do not accurately reflect on what care we provide.

These systems often contain duplication; within trusts and central repositories and fail to provide information for accurate commissioning of services. Our efforts to work-around them distract us from doing more to help our people provide better care and from helping our population to use their own data to remain well.

Our change of direction in data usage is accelerated by the implementation of the encompass programme. The introduction of live, context embedded clinical coding requires a re-focus as we consider our current state and future spending.

Relevant data for improving health is not restricted to that collected by providers of care. As Michael Marmot, one of the world experts in social determinants of health, has explained for over a decade, health and care delivery is only a small fraction of what makes up someone's life experience and expectancy. Outcomes are much more dependent on social determinants and factors outside the remit of health and social care services. To be truly reflective of what causes illness and determines our life journeys we need to link data sources from many environments.

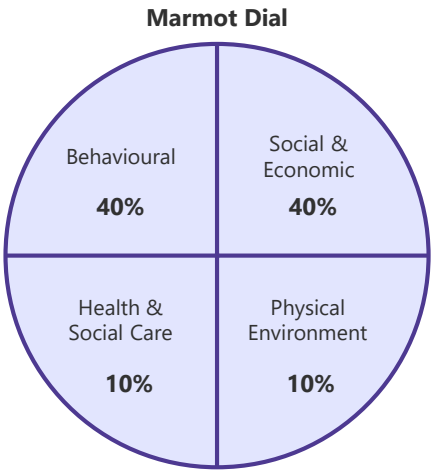

Figure 1: Michael Marmot in 2010 created his now famous dial – describing the relative importance of various contributing factors in explaining life expectancy

We must allow the seamless interoperability between people, health and care environments, other government departments, community services and wider society. This would enable Northern Ireland to unlock the value of data and provide better services, support evidence-informed decisions, create internal efficiencies and better understand the real impact of what we do, so that funds can be directed towards those interventions that have the greatest impact.

COVID-19 and Data

The COVID -19 pandemic has had a significant impact on how we view and utilise health and social care data.

Within HSC we have developed agility in our ways of working with data, as we pushed to deliver new digital systems at pace in response to the pandemic. We have embraced Cloud technologies, pseudo-anonymised data for real-time care and shared data between agencies whilst working constructively with the Information Commissioners Office.

Furthermore, we have seen data awareness and understanding growing amongst our population, with people using published figures to understand changes in case numbers and the progress of the vaccine rollout programme.

Our Pandemic Response

Within just a few months, Trusts, DHCNI and the wider HSC designed and implemented symptom checking and contact tracing proximity Apps, built a contact tracing management system from scratch, including a fully digital contract tracing journey, accelerated video consultations, virtualised everything we could imagine and digitally enabled a vaccine management programme ensuring data capture and real time reporting on the vaccine programme rollout. Most importantly, as a service, we have fundamentally accepted that patient related information is now at the centre of every solution.

Pandemic Case Study: COVID-19 Dashboard

During the Covid 19 pandemic, we all became accustomed to hearing daily updates on the news in relation to the progression of the pandemic. The data within our system became critically important not just for internal operational purposes but for public dissemination.

Operational Dashboards:
There was a rapid need to establish internal operational dashboards for a wide range of purposes; modelling of the spread of the pandemic, monitoring the contact tracing process, monitoring the spread of the disease in the community and spread within hospitals. These were set up through multiple parts of HSC working together to ensure that the system was able to respond appropriately.

Covid 19 Dashboard:
To ensure that the public was informed about the spread of Covid 19 and its impact, the Information and Analysis Directorate in the Department of health worked with multiple internal HSC stakeholders to gather information about cases, hospitalisations, hospital occupancy and, sadly, deaths. This data was published on a daily basis enabling better communication with the public about the spread of the disease as well as enabling our people to respond in real time to changes as the pandemic progressed.

Vaccinations Dashboard:
As the vaccination campaign started, there was a clear desire to communicate to the public about the progression and success of the campaign. A vaccinations data dashboard was iteratively developed that communicated the details of vaccinations as they happened. This dashboard was fully automated and updated daily including weekends and holidays.

The learnings: collaboration, data sharing and system interoperability are key.


MEDICAL REPORT
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Vision

Our vision for data in HSC focuses on how we improve our use of data to improve care and aligns closely to the wider ambition set our digital strategy.

To make HSC a data and insight driven organisation that improves people's lives through the use of data

Our data vision

The quadruple aim provides a structure for the summary vision. Note that this is not exhaustive, it aims to capture the alignment between the wider HSC strategy and the digital priorities. There are many current systems, services and transformational changes needed to realise this high-level vision. The below diagram offers a non-exhaustive list of examples of ways that digital and data and help meet the quadruple aim.

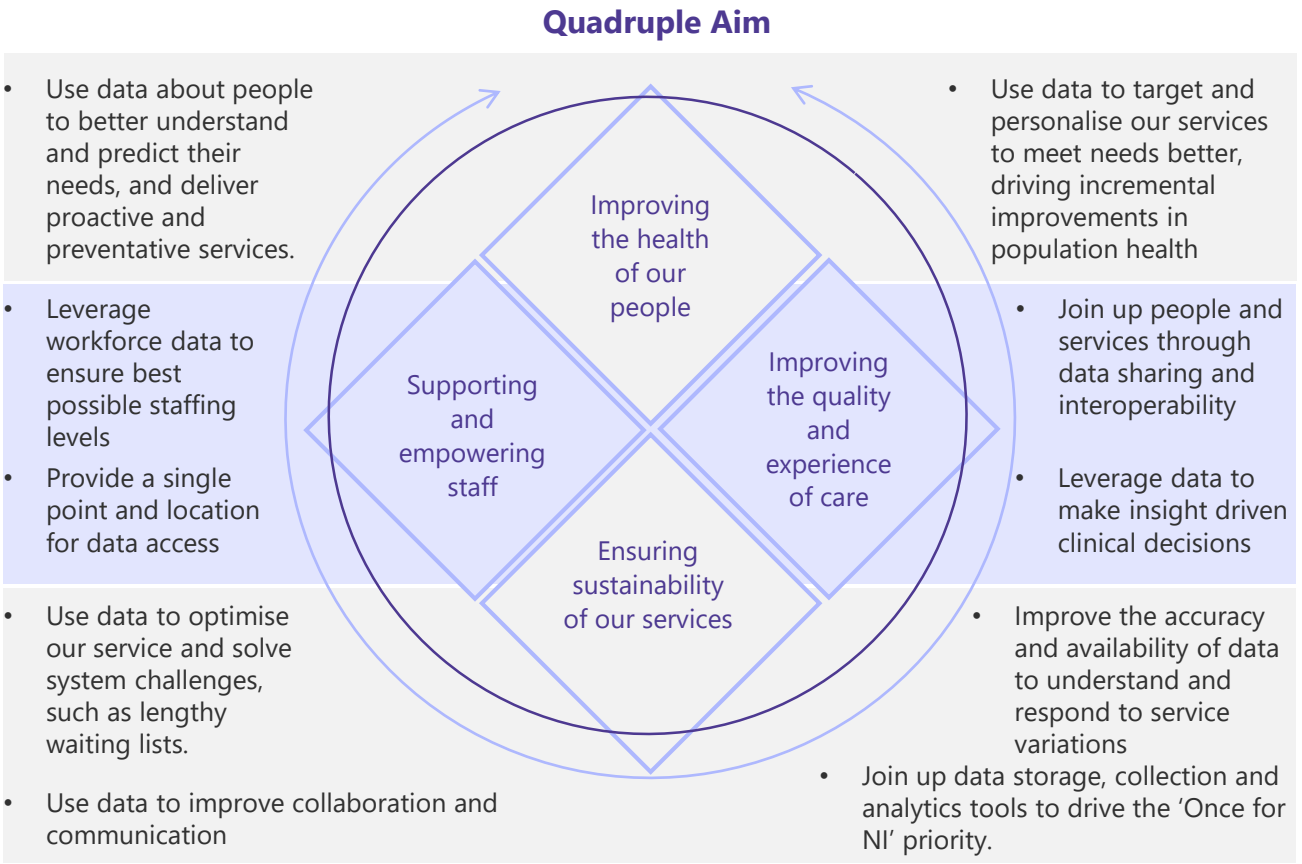


Figure 2: How our data vision supports the quadruple aim

Mission & Principles

Whilst our vision outlines our ambition, our mission focuses on how we plan to deliver it. It communicates our direction of travel over the coming years and the principles that will guide us.

Our Mission

HSC will make health and care data easily available to our population, our people and policy makers, facilitated and governed by a new Health and Social Care Data Institute (HSCDI).

Strategy Delivery

The vast majority of the initiatives defined within this strategy will be delivered (directly or indirectly) with support from the HSC Data Institute (HSCDI), as our major data delivery capability. The HSCDI will unite data experts, tools and software into agile teams that solve systemic data challenges.

The HSCDI will be built in line with the three phase roadmap defined in the HSC digital strategy, in implementation, making best use of and innovation phases over the next three to five years.

Our principles

Concurrent with our ambitions across our wider digital transformation, our key data principles are simple. We want to improve our systems and experiences whilst supporting our population and our people to do their jobs better and advance research and innovation in health and social care. Data has a key part to play in all of this.

Driving Research and Innovation

Using data to drive innovation and research across health and care systems, both internally and through external partners

Improving Service-user Experiences

Using data to improve the way that our population experience services and care journeys at HSC

Supporting our HSC people and Services

Making it easier for our population and our people to do their day to day work and drawing insights that drive system-wide efficiencies.

Using Data Safely and Securely

Ensuring that our people and population feel confident in the security and best-practice use of their data, in line with cyber governance protocols.

Delivering the Data Strategy

How we plan to deliver on our ambition

Our Strategic Framework

We have established a data transformation journey that is underpinned by five strategic outcomes; to be delivered through supporting initiatives and projects, and through the implementation of the HSCDI. The enablers that we develop will further facilitate our transformation and prepare HSC for organisational change. This strategic framework acts as a backbone to contextualise and ground our strategy, ensuring that our transformation is rooted at all times in our overall vision for data and information at HSC.

Vision
Our overarching aim

To make HSC a data and insight driven organisation that improves people's lives through the use of data

Mission
How we will deliver it

HSC will make health and care data easily available to our population, our people and policy makers, facilitated and governed by a new Health and Social Care Data Institute (HSCDI).

Strategic outcomes
The results we want to achieve

Data collection is carefully regulated, including accuracy of information and verification of sources, with increased frequency and quantity of data ingestion	Our **analytics capabilities** drive actionable insight generation for use across a range of services	Our **data visualisation and presentation** capabilities enable us to illustrate insights that are actionable and facilitate evidence-based decision making	The insights we generate are **shared in a transparent and centralised manner**, both internally with our people, and externally with the communities we support	We harness insights from our data to **deliver improved outcomes**, including tackling service challenges and generating population health insights

Delivery Capability
How we will deliver our strategy aims and ambitions

HSC Data Institute

Foundational enablers
How we will deliver the strategic outcomes

People, Patients and Culture – Data education, shared data ownership with our population, data literacy, sharing insights/ keeping people informed

Centralisation and Interoperability of data – connecting data across the ecosystem , data quality improvement, standardisation, clinical terminology, reducing duplication

Information Governance – Making sure we use our data right, ensuring security and privacy at the core of all we do

Data–enabling Infrastructure and Technologies – AI, Data visualisation, mobilisation of encompass, automation, development of the NI data dictionary

Figure 3: Our Strategic Framework

Our Strategic Outcomes

Reliable and actionable data insights come from best practice data treatment at every stage of the data usage pathway, from collection through to information sharing. For this reason, our strategic outcomes focus on key stages of this pathway, reflecting the importance of using data in the right way to ensure patient privacy, underpinned by meticulous data governance.

Our strategic outcomes will act as critical focus areas to help us improve and optimise our data usage and treatment to generate higher quality insights, expanding the scope of what we can achieve with our data to drive better care for people and patients.

Figure 4: The Data Usage Pathway

Our Strategic Outcomes

Data collection is carefully managed, including accuracy of information and verification of sources, with increased frequency and quantity of data ingestion

Our analytics capabilities drive actionable insight generation for use across a range of services

Our data visualisation and presentation capabilities enable us to illustrate insights that are actionable and facilitate evidence-based decision making

We create transparency by sharing more insights across our organisation and externally with the communities we support

We harness insights from our data to deliver improved outcomes, including tackling service challenges and generating population health insights

The following sections will provide further clarity on each strategic outcome, and describe the initiatives and relevant enablers that will help us to deliver against each outcome.

Capabilities and Enablers

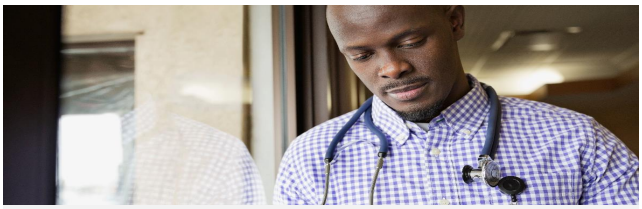
If the Strategic Outcomes are the '*what*' of our data strategy, then the Capabilities and Enablers make up the '*how*'. This page summarises the way in which we will deliver our digital strategy, through implementation of a Data Institute whilst preparing for data transformation through development of each Enabler.

Our Delivery Capability

The data strategy will be delivered via the implementation of a novel organisation, dedicated to the realisation of our vision and mission. This Data Institute (the HSCDI) will act on the need to reduce duplication of effort, deliver improvements to the analyst environment and ensure better co-ordination of resources. It will direct and manage the majority of initiatives described for each strategic outcome.

Our Data Enablers

Our four enabler categories outline the ways in which we will prepare for successful data transformation, addressing existing challenges and blockers to make it easier for people and systems to work effectively.



People, Population and Culture

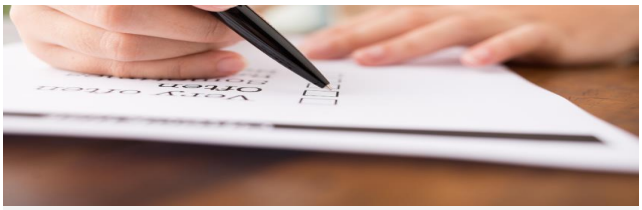
Data education, shared data ownership with our population, data literacy, sharing insights/ keeping people informed.

Information Governance

Making sure we use our data right, ensuring security and privacy at the core of all we do

Data–enabling Infrastructure and Technologies

Advanced analytics, analytics platforms, machine learning and AI, data visualisation, mobilisation of encompass and automation.



Centralisation and Interoperability of data

Connecting data across the ecosystem , data quality improvement, standardisation, clinical terminology, reducing duplication

Our Strategic Roadmap

The strategic roadmap sets out our direction of travel and will allow us to target our effort and resources to deliver a Data Institute for HSC.

This roadmap prioritises low cost – high value efforts that will deliver better quality data, a Data Institute and better use of data analytics as quickly as possible, which can later be refined and improved. This will allow us to deliver information processing improvements efficiently within the current funding landscape, enabling us to learn as we go and identify new methods and tools that enable us to get the most out of our investments. As such, our roadmap comprises a 3 phased approach, with a focus on standing up and implementing the institute and any supporting programmes/enablers, followed by optimisation and innovation phases that will drive forward our data capabilities in the years to come.

Our Strategic Roadmap for Data

We invest our time and resources in **implementing the Data Institute,** so that we can begin to transform the way in which data is handled at HSC. This phase will also look to address a number of the supporting programme and enabler requirements that will aid implementation.

We invest our time and resources in **making best use of and improving** the Data Institute. The lessons and momentum gathered during the Implementing phase is advanced and we turn our focus to developing new capabilities such as Lean Process Design, Service Design and Data Analytics and Insight generation based on the level of data and information we can now record and access from our systems.

We invest our time and resources in **new and exciting technologies and programmes** that will help us to expand and evolve the way that we use data. In this phase, we have the necessary data manipulation talent and skills, tools/software and enablers in place to embrace the range of data which is now available to us. We will continue to implement and optimise new solutions, but will rely on the solid Data Institute foundation which we have developed.

Box 1. Our three-phased approach to transformation

Our strategic roadmap is in line with the three-phased approach taken for our digital strategy. This is to ensure that our organisation-wide transformation efforts are co-ordinated and aligned to make efficient use of available resources and to facilitate cohesive systems and services for our people and population.

Our Strategic Outcomes

How we plan to deliver our strategy

Strategic Outcome 1

Data collection is carefully managed, including accuracy of information and verification of sources, with increased frequency and quantity of data ingestion

A critical component of data quality is the accuracy, timeliness, validity, completeness and reliability of the information that we record. All decisions, whether clinical, management or financial, need to be based on information which is of the highest quality. In order to realise this objective, everyone in our system must take responsibility for the quality of the data they input – each person's individual role in this must be understood. We need a single source of truth, with one version of the same data updated regularly.

Initiatives	Relevant Enabler
• Assign responsibility for all senior HSC Leaders to promote the importance of data quality at every level in HSC organisations • Enable the population to check and confirm the details we hold about them through the development of a patient portal. • Establish and communicate processes for reporting all data quality errors in each HSC organisation. • Everyone will be required as part of their role to report errors and when possible fix errors in timely way	**People, Patients and Culture**
• Ensure that the HCN (Health and Care Number) is always used as the unique identifier on all systems	**Centralisation and Interoperability of data**
• Develop the Regional Data Dictionary through closer working with those people who are transforming or creating new services. • Establish regional KPIs through the Data Institute working with the information Standards group and key stakeholder to provide assurance and identify areas for focus for improvement.	**Centralisation and Interoperability of data**
• All Trusts, commissioned organisations, the Public Health Agency and the Department of Health will agree a standardised approach to the collection of health and care data. This will focus on adoption or adaption of existing standards, e.g. from NHS/ NHS Digital to avoid duplication of effort and to ensure adherence to best practices • Invest in technology solutions that can automate and improve our auditing and monitoring to ensure data standards. • Embed quality control processes into our systems to support accurate recording on systems • Ensure up to date classifications and coding to ensure data quality in the collection of diagnoses and procedures within the patient journey	**Data–enabling Infrastructure and Technologies**

Table 1. Capabilities and initiatives to be developed in Strategic Outcome 1

Strategic Outcome 2

Our analytics capabilities drive actionable insight generation for use across a range of services

In order to draw the best insights from our data, we must embrace advanced analytics, investing in the capabilities, skillsets and software that are required. A large portion of our data analytics capabilities will be housed within the HSCDI, as part of the Analytics and Insight Centre of Excellence.

Initiatives	Relevant Enabler
• We will build clearly defined career pathways within data analytics to attract and retain the best talent, providing opportunities to work on solutions that truly make a difference in people's lives. • We will train our people to use open source software such as R and Python for data analytics and data science. The use of these languages enables and encourages best practice, code review, re-use/ code sharing, scalability and operationalisation • We will focus in developing excellence in information standards, classification and terminology and clinical coding. We will improve career pathways and development in these areas. We can only achieve analytics excellence if the data we work with is robust and accurate	**People, Patients and Culture**
• We will deliver and provide a centralised analytics platform to enable reliable, reproducible and robust data analytics solutions • We will establish an Analytics and Insight Centre of Excellence to centralise expertise.	**Centralisation and Interoperability of data**
• We will invest in hybrid on premise and cloud hosted data solutions to allow rapid and safe data integration and analysis of health care data for actionable insight and intelligence. • Currently the majority of BI and analytics tools that we use are commercial software packages from vendors. Whilst we do not aim to limit the use of these tools we will focus on expanding our use of open source software to reduce cost and vendor 'lock in'.	**Data–enabling Infrastructure and Technologies**

Table 2. Capabilities and initiatives to be developed in Strategic Outcome 2

Strategic Outcome 3

Our data visualisation and presentation capabilities enable us to illustrate insights that are actionable and facilitate evidence-based decision making

Making graphics and telling stories with data is a large part of data discovery, and we want to promote that throughout the wider HSC. If we can simplify the way that we present our data, it can be used more quickly and easily across HSC for making data-driven decisions.

Initiatives	Relevant Enabler
• We will build clearly defined career pathways within data visualisation to attract and retain the best talent • We will build data visualisation dashboards that enable us to easily communicate relevant data with our population • We will enable our people and our population to access easily useable data visualisation that supports them to easily make data-driven clinical decisions.	**People, Patients and Culture**
• We will identify and prioritise open source software where possible and identify a single visualisation software tool to be used across the HSC. • We will present our data in cohesive dashboards that represent all of the data relevant to a use case, reducing the need to access data across multiple systems.	**Centralisation and Interoperability of data**
• More complex business intelligence requires tools such as Power BI, QLIK / QLIK Sense, Tableau and Looker, which are already in use across HSC. These systems and our skilled people who use them will be supported in doing so and we will aim to support users through training and shared knowledge and best practice. We will also focus on expanding our use of similar open source software options to reduce cost and vendor 'lock in' involved in data visualisation, whilst building in-house expertise.	**Data–enabling Infrastructure and Technologies**

Table 3. Capabilities and initiatives to be developed in Strategic Outcome 3

Strategic Outcome 4

We create transparency by sharing more insights across our organisation and externally with the communities we support

Ease of access to data is key. For our people, data relating to their practice should be accessible using their current equipment through a secure portal, whilst data relating to our services should be communicated to those who use them in an easy-to-navigate way. We need to enable data to flow across the system and agree where ownership for data resides to maintain data integrity

Initiatives	Relevant Enabler
• We must ensure that when we get updated demographic information that this is propagated across all our systems in a unified manner. • We will ensure that our people have access to the data they require, on demand, to deliver the best and most informed care • We will ensure that our population does not have to repeat their health and care information, and feel safe in the knowledge that the information held about them is correct and up to date.	**People, Patients and Culture**
• We will create single points of request and access for useable data for our population, our people and relevant agencies. • We will dramatically reduce the time to access actionable data sets for research and service improvement.	**Information Governance**
• We will publish metadata which clearly describes all the information we collect. • We will share public data in a safe and transparent way. • We will ensure that our people and our partners are able to safely and securely access the data they need whether this be for direction patient care or for research to enhance and improve our services	**Centralisation and Interoperability of data**
• We will champion research as a fundamental part of health and care delivery. This research can take many forms; it will be cross discipline and be prioritised on real world problems in the delivery of our services.	**Data–enabling Infrastructure and Technologies**

Table 4. Capabilities and initiatives to be developed in Strategic Outcome 4

Strategic Outcome 5

We harness insights from our data to deliver improved population outcomes, including tackling service challenges and generating population health insights

Our current health and care landscape is faced by challenges such as the lasting impacts of COVID-19, evolving requirements for remote access, staffing challenges and more. We need to harness the data that we collect to deliver improved experiences for both population and people, alongside using data for innovative new research and population health.

Initiatives	Relevant Enabler
• We will use data-generated insights to guide the services that we provide to drive population health advancements in Northern Ireland. • We will use real-time data to ensure the best possible staffing levels across our H&SC services to deliver improved experiences for our people and patients	**People, Patients and Culture**
• We will design our data collection and storage protocols so that data can be joined up and datasets can be expanded, enabling us to draw better insights from our data to help us tackle system challenges.	**Centralisation and Interoperability of data**
• We will commit to connecting public data where citizen outcomes can be improved by doing so. Strategic linking of health and care data must have a citizen benefit and adhere to strict security processes. • We will work with world-leading cybersecurity experts to assure the population of Northern Ireland that their data is safe and being used to provide Better Care. • We will work with our research and innovation partners to share data – where it is safe and secure to do so – in order to facilitate continued advancements in the field of health and social care, reflecting the trends and requirements that we are seeing for the people of Northern Ireland	**Information Governance**
• We will commit to using cloud technology wherever possible to accelerate what we can deliver to our people and our population. • We will design our systems and services to automate tasks where possible, reducing the administrative burden on our people.	**Data–enabling Infrastructure and Technologies**

Table 5. Capabilities and initiatives to be developed in Strategic Outcome 5

Building the HSC Data Institute

How we plan to deliver a new data capability for HSC

HSC Data Institute

The data strategy will be delivered via the implementation of a novel organisation, dedicated to the realisation of our vision and mission. This Data Institute (the HSCDI) will act on the need to reduce duplication of effort, deliver improvements to the analyst environment and ensure better co-ordination of resources.

Why build a Data Institute?

HSC as a system is not currently set up to optimise its use of data and we require a body that can centralise capabilities and make data driven, insight led management decisions about priority and transformation. HSCDI will act as a hub for data and analytics services and – where data and analytics expertise is required in other service areas - HSCDI will also support other teams and organisations in their development of data skills and capabilities through frameworks, capability matrices, recruitment/ hiring support and training.

How might this look?

Getting value from data requires three things: the data itself, the tools and software required to analyse and manipulate it, and the people and skills necessary to use them. These three pillars will underpin the institute, with a primary function in bringing these components together to use data effectively. The institute will have five major functions; education and evangelism, training and skills development, infrastructure and platform development and delivery, an analytics and insights centre of excellence, and governance of data.

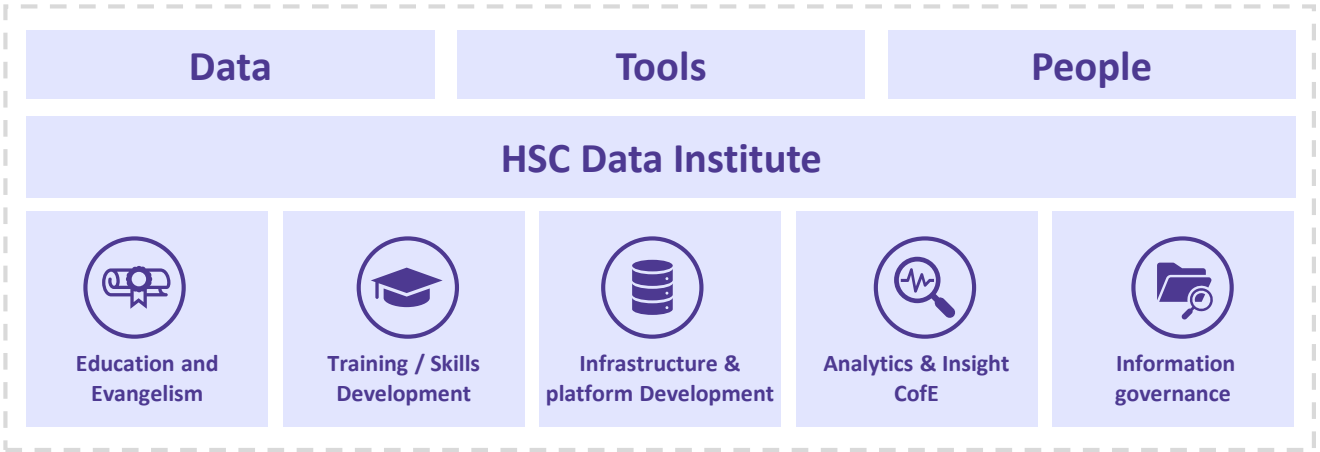


Figure 5: The HSC Data Institute

How will this work in practice?

Whilst HSCDI will provide data and analytics services in house, it will also look to support other organisations to upskill their data capabilities through frameworks, capability matrices, recruitment/hiring support and training. For example, any part of the system may come to HSCDI with a data problem, which can either be solved and delivered locally by the institute or HSCDI can support the relevant teams to develop the capabilities needed to solve it in within another part of the system.

HSC Data Institute

The HSCDI brings an opportunity to change the way we look and think about our data at HSC.

For example, across HSC different teams favour different systems for a specific utility and are therefore biased in assessing the benefit the system brings to HSC as a whole. These biases exacerbate our silos and therefore a responsible body is required for the archiving, storing, deleting or future proofing of digital health and care systems. The Data Institute and DHCNI - informed by our people throughout the system - must choose what to do with legacy systems and their data, leveraging new technologies rather than maintaining redundant systems.

This will can only happen if we create an environment which has that collaborative and inclusive working approach established from the start. The Data Institute is designed to bring people and different agencies together. It must be funded and managed differently. We propose that the Data Institute be established as a joint venture between key stakeholder organisations, much like DHCNI, reporting ultimately to the CDIO and CMO.

Organisation Functions

Education and Evangelism - working to demonstrate the value of data and analytics to our people and patients, based on use cases from our own system and using broader examples from around the world.

Training and Skills Development - A core responsibility of the Data Institute will be to focus on improving digital and data literacy across the entire system, including through broad training across HSC, building internal skills and hiring external talent. We can embed data capabilities into our frontline service delivery through building fusion teams and integrating technical and clinical skills.

Data Platform Infrastructure Development and Delivery- The HSCDI will be responsible for the continued development and iteration of NIHAP (building on the COVID-19 response platform PHIP –The Public Health Information Portal) through adoption of cutting edge cloud-based technology to provide safe secure infrastructure for the housing and analysis of data. (*See NIHAP)*

Analytics and Insight Centre of Excellence- The Data Institute will develop an Analytics and Insight Centre of Excellence to build, house and centralise talent in this area, consolidating what has historically been pockets of intelligence across HSC. As part of this the HSCDI will build a core team of quality data scientists and analysts, develop an internal analytics service and capacity in enabling technologies such as AI and automation, conduct a resource gap analysis and capacity mentoring for career progression.

Information Governance- The Data Institute will focus on streamlining our data access and usage while protecting the privacy of our people. This includes proper cataloguing and evaluation of our governance, and expansion of our data usage in research (both internal and with academic and commercial partners). We must also drive forward the implementation of secondary use legislation for NI.

HSC Data Institute

The structure of the HSCDI is based upon its overall function and delivery aims, alongside the need for a firm remit, ownership, oversight and a mandate and veto. The organisation will need long term recurrent funding and permanent team to deliver the responsibilities set out. However, the structure proposed is not fully exhaustive and it is expected that significant staffing for each function will be required, with the extent and source of this staffing established during implementation.

The HSCDI is proposed to be a joint venture between all relevant entities within HSC to ensure that it is built by and supports the whole system with input and support from all key stakeholders

Funding

The HSCDI will require long term funding both from current and future sources. Key areas to be investigated regarding funding are as follows

- Consolidation of IAD funding
- Funding from PHA
- New business case for DHCNI capital
- Potential for funding via the Universities and City Deals
- Potential for safe, ethical and beneficial monetisation of data resources

Relevant Bodies

There are a number of core teams that are planned to be part of the HSCDI from its initiation, including; Clinical coding, Information standards, GPIP analytics team, Data Warehousing team, Honest Broker, NITRE and the Encompass data team. The PHA Data capability and PMSI Information Team will be a key connected functions and can be involved more structurally in optimisation.

NIHAP

NIHAP - The Northern Ireland Health Analytics Platform - is proposed as a key tool for data analytics at HSC. This platform was originally developed during the pandemic and which was a crucial component of the DHCNI and PHA response to COVID-19. Moving forward, we propose further development and iteration of this platform and it's broader usage, as a key role of the HSCDI

Why do we need NIHAP?

Our current systems have been built with the primary goal of secure data storage – rather than ease of access for service use cases. Encompass will deliver so much of what we need; however, the greatest benefit to HSC comes from adding that rich source of data to multiple other pieces of disparate information. NIHAP presents an opportunity to collate data – e.g. from GPIP and encompass - into a centralised and secure location, from which it can be matched to a longitudinal care records and analysed in combination with additional data resources. This is a central aspiration of the HSCDI, leveraging data to drive our ultimate goal to deliver better care.

Platform Benefits

- Consistent and continuous updates with no demand on limited HSC resources.
- Adoption of cutting edge cloud based technology to provide safe secure infrastructure for the housing and analysis of data.
- Convergence of data from a wide range of sources, securely enabling users to analyse core datasets with the most appropriate tools.
- Secure, flexible and scalable infrastructure which enables growth and scale of the platform and its users

Next Steps

- Scoping is required to assess whether a future costing and commissioning model for NIHAP could be developed for HSC based on patient level information and costing pathways, from appropriate key performance metrics and with support from academia.
- Expand usage to support future service planning, performance management and service improvement in collaboration with PMSI / SPPG
- Review the potential for future screening and extended vaccination management for all of HSC, which is well within the technological capabilities of the platform.
- Assess the potential for NIHAP to support the Northern Ireland Cancer Registry (NICR) moving forward, replacing its ageing technology and allowing closer links with warehouse information assets.
- Achieve simplified governance methodology, streamlined technology resource response and management of data. While already in use by the PHA and SPPG, we envisage NIHAP being equally available to IAD, Trusts and partner organisations where appropriate – which would allow broad access to the best resources for all data analysts in HSC and reflect the "once for NI" agenda.

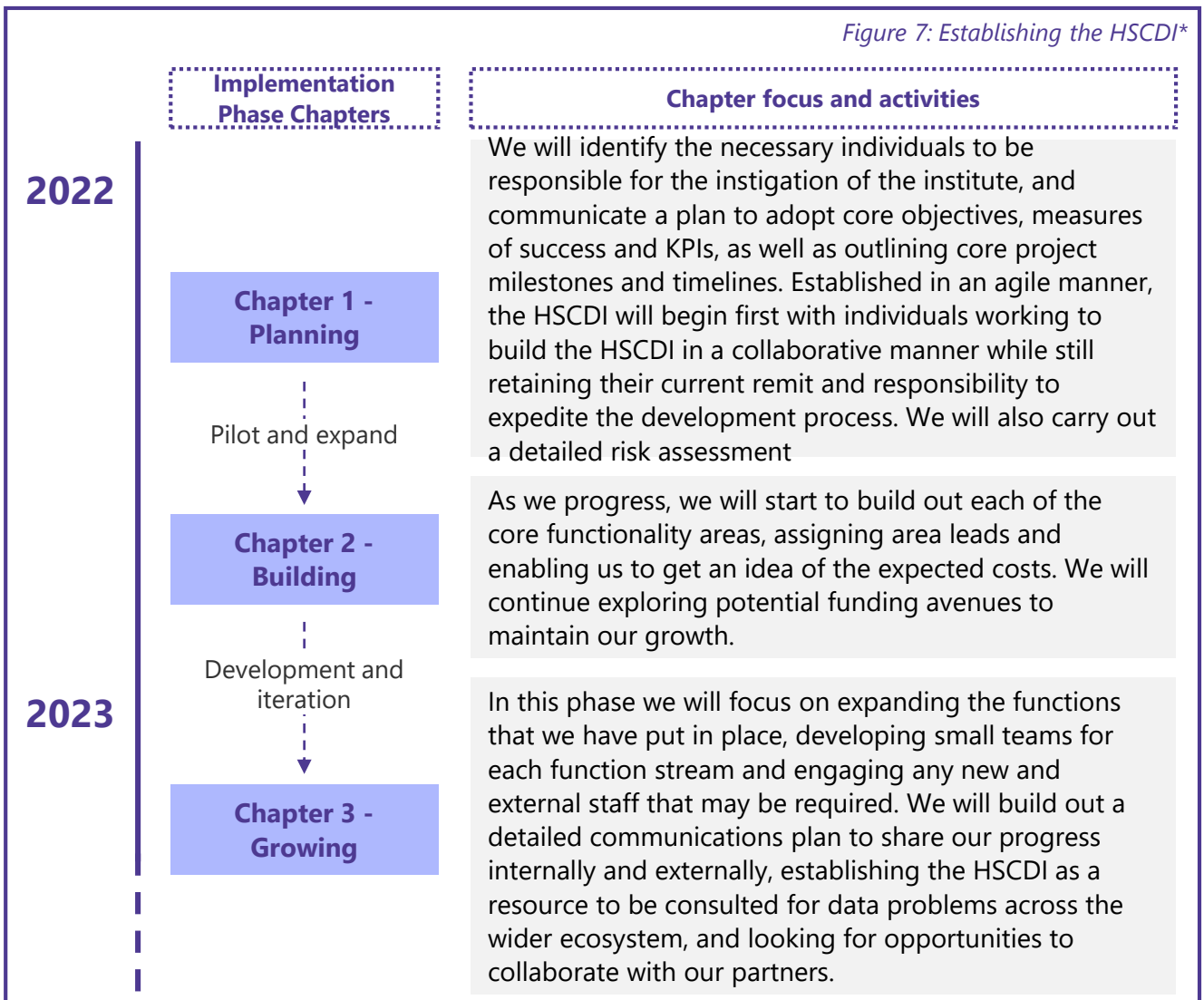
Implementation of the HSCDI

In line with the wider digital transformation occurring in parallel across the HSC ecosystem, the HSCDI will be established and optimised via a three phased roadmap, including implementation, making better use of and innovation phases. This, 'zoomed-in', roadmap looks at the steps and actions needed to make a start on our implementation phase journey.

The HSCDI will be established as a joint venture/ virtual organisation, which is then allowed to grow and evolve over time. This will enable us to establish the core requirements from the outset, to later scale and optimise.

Implementation Roadmap

*Figure 7: Establishing the HSCDI**



*Note that timescales here are solely indicative and will be dependent on the future funding position

Data Enablers

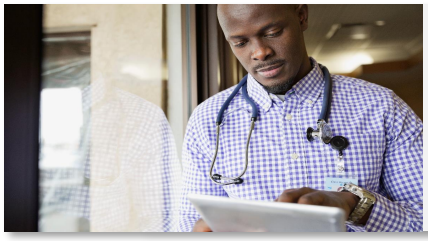
What we need to help us deliver our data strategy

Our Data Enablers

There are a range of dependencies existing at each step of the data usage pathway, including the people who enter raw information through to the tools and systems in place to analyse and share it. Our data enablers are the things we need to develop for successful transformation and remain constant throughout the data usage pathway. Establishing these foundational enablers is a critical component of the implementation process and will enable us to deliver on our stated vision and mission for data at HSC.

Our four enabling categories outline the ways in which we will prepare for successful data transformation, addressing existing challenges and blockers to make it easier for people and systems to work effectively. For each of these categories, we have collated a set of commitments that will sit alongside our portfolio, supporting effective implementation.

Our Data Enablers

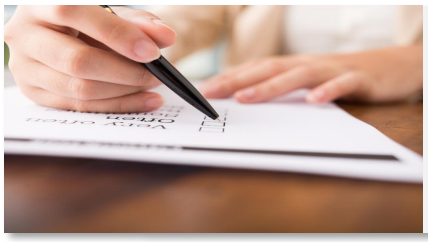


People, Population and Culture

Data education, shared data ownership with our population, data literacy, sharing insights/ keeping people informed

Centralisation and Interoperability of data

Connecting data across the ecosystem , data quality improvement, standardisation, clinical terminology, reducing duplication



Information Governance

Making sure we use our data right, ensuring security and privacy at the core of all we do

Data–enabling Infrastructure and Technologies

AI, Data visualisation, mobilisation of encompass, automation

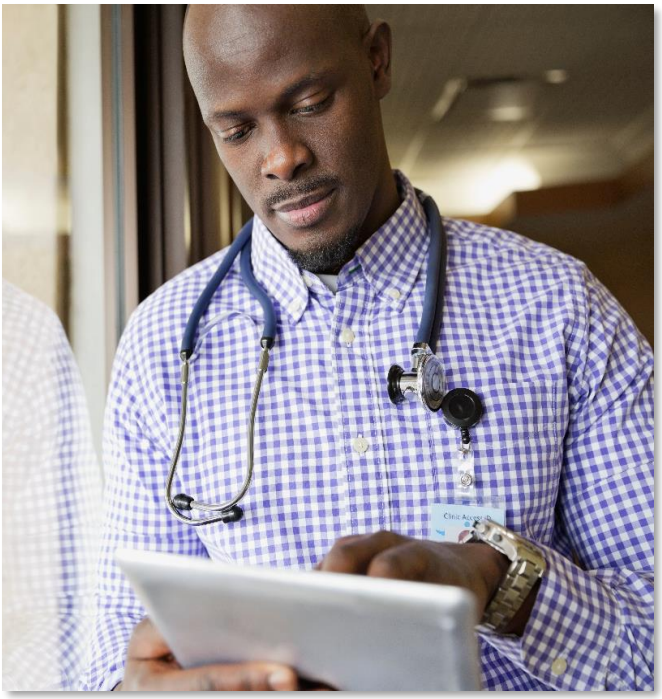
People, Population and Culture

The population who use our health and care services are at the core of our system, alongside the people who work to deliver excellent quality care. For this reason, our population and those who care for them are key to our data transformation. We can build a data-first culture amongst these groups through proper internal and external data awareness training, as well as Talent acquisition and proper data leadership.

Excellent data leadership drives a data-first culture that is more willing to embrace change, with clear accountabilities.

Talent

People skilled in data analytics are in high demand across all sectors at present. We need to attract and retain talent by providing opportunities to work on solutions that truly make a difference in people's lives, alongside a defined path for career progression.



Training

By improving digital literacy capabilities of our people, the uptake and adoption of new digital tools and technologies can be improved and the provision of care transformed. We will provide education and evangelism about the proper use of data to ensure that all stakeholders can see the value in using data for the improvement of health and social care. Each organisation should ensure that there is training for our people that input data on systems, including developing regional eLearning awareness materials.

Looking externally, we must also support our patients and communities to understand how their data will be used, and their responsibilities towards maintaining the accuracy of these data.

Our Commitments

- We will develop a data literacy programme for our people, implementing a regional curriculum based on NHS Digital's guidance. As part of this, we will implement the All Ireland Digital Health Capability Framework to define the digital skills and capabilities required.
- We will conduct data, to build awareness and understanding for patients and communities.
- We will conduct a review of data-specific positions across HSC and embed data leadership roles into teams at all levels.
- We will attract and maintain data analytics capabilities within the HSCDI, through access to high quality analytics tools, a defined career pathway and the ability to work on solutions that truly make a difference.

Centralisation & Interoperability

Our ability to join up our data in one place is critical to our ability to draw actionable insights from it, and drive better outcomes. Our aims in this respect are twofold – to enable interoperability of data through data classification and use of standardised clinical terminology, and to create a single point of access to useable data for our population and people.

Classifications and Clinical Terminology

The ICD-10 International Statistical Classification of Diseases and Related Health Problems and OPCS Classification of Interventions and Procedures are statistical classifications that are used to report/summarise an episode of care. Currently HSC use ICD-10 5th Edition but the World Health Assembly adopted ICD-11 in 2019, with it coming into effect on 1 January 2022. HSC must keep pace with these changes to support the sharing of information utilising standardised terminology, which is key to system interoperability.

It is our clear intention to adopt SNOMED CT as our core clinical terminology

HSC must also continue to contribute to the discussions in direction of the classifications and terminology through working with the other UK countries.

Single points of access

Whilst encompass will deliver tangible improvements to the centralisation of our data, this must remain a consistent priority across all future programmes and data initiatives. For our population this means more efficient referral times and streamlining of care pathways, alongside a single source of truth for their health and care data. For our people this means quicker and streamlined access to the right data.

Our Commitments

- We will work to centralise our data and ensure that it is available to improve how we deliver health and social care
- We will provide the right analytics environment to ensure the best use of our data
- The Information Standards Group will mandate a set of regional information standards
- We will develop the Regional Data Dictionary
- We will establish regional KPIs for the Data Institute alongside the information Standards group and key stakeholders
- We will create single points of request and access for useable data for our population and our people
- We will commit to the implementation of SNOMED CT as the single, up to date clinical terminology and ICD and OPCS as our core classifications across primary, secondary and social care

Information Governance

Information Governance (IG) ensures that we manage and use our data correctly, in line with best practice, legal requirements, and the public's expectations.

Legislation

There is legislation in place to regulate and govern how data, particularly personal data should be managed. Due to the sensitive nature of health data the HSC must ensure that Information Governance is rigorously managed. Related legislation includes (but is not limited to):

- The UK General Data Protection Regulation (GDPR) and Data Protection Act (DPA) 2018
- The Public Records Act NI 1923
- Freedom of Information Act 2000
- Computer Misuse Act 1990
- Common Law Duty of Confidentiality

Primary and Secondary Use Cases

The majority of patient information is collected at GP surgeries, Acute Care facilities, through care in community settings and Social Care services. Data is collected for either direct care (to inform immediate or ongoing provision of health and social care treatment and services to a citizen) or secondary uses (including a wide range of information processing activities e.g. service performance management).

This information must be managed according to HSC IG policies and the above legislation and the same IG structures will be put in place for the HSC Data Institute.

The HSCDI will ensure that privacy by design is key to the development of the institute and the technology it employs in order to minimise the use of identifiable information and will ensure that where possible anonymization, or where necessary pseudo-anonymisation techniques are employed to protect patient privacy and confidentiality of HSC information.

Patient Identifiable Information (PID)

Where it is deemed necessary to process PID for secondary uses the DI will ensure compliance with the DoH Code of Practice on Protecting the Confidentiality of Service User Information and will carry out consultation with the NI Privacy Advisory Committee.

Our Commitments

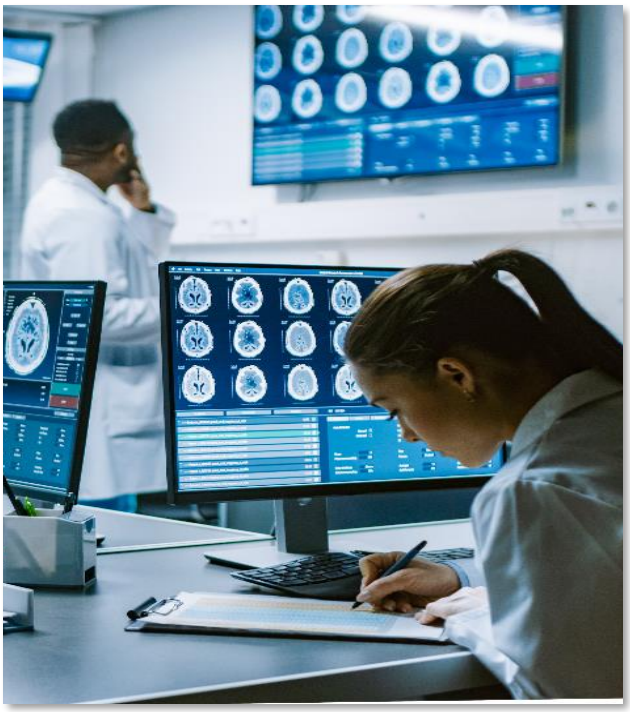
- We will place patient privacy and security at the heart of all that we do
- We will clarify and streamline the current structures for the governance of health and care data.
- We will ensure that all health and social care information is managed and used to support the work of the HSCDI and its partners while ensuring that all processing and use meets with all relevant information governance legislative and regulatory requirements
- We will push forward the secondary use legislation.
- We will consistently enforce data minimisation both in terms of the data processed but also in terms of who has access to what data..

Infrastructure & Technologies

The infrastructure and technologies that we provision and utilise directly affect the way in which we use data at HSC. As part of our wider digital transformation, we are moving to a digital architecture which enables AI, evolving platforms and new data storage capabilities which can help us to solve wider system challenges.

AI at HSC

Artificial Intelligence (AI) has enormous potential to impact and improve health and care. While a great deal of focus has been on the potential for AI in direct care, e.g. in diagnosis or recommendation systems for clinical decision-making, one thing that is often overlooked is the potential use of AI in areas without significant associated clinical risk. The key driver in the acceleration and adoption of AI is availability of large volumes of high quality data.



Notable examples of AI usage at HSC include local surgeons using 3D models developed by AI for life saving surgeries, and use AI for modelling our COVID -19 response and contact tracing programme. At the moment we are experiencing a significant workforce gap and this is only expected to grow. The pressures on our people that have resulted from the COVID -19 pandemic have served to accentuate this workforce gap and make it more pressing. Through the use of AI our focus should be on simplifying the lives of our people by taking away the tedious and simple tasks and enabling them to focus on delivering value.

Our Commitments

- We will accelerate the development of the GP Intelligence Platform (GPIP) prioritising primary care priorities
- We will invest in the Northern Ireland Trusted Research Environment (NITRE) and the Honest Broker Service enabling provision of anonymised patient level data. We will work with Health Data Research UK to virtualise access to metadata and promote queries of available datasets.
- We will focus on the development of the next generation of the regional data warehouse with an integrated analytics platform (NIHAP).
- We will commit to a central architecture for the archiving and analysis of health and care data which allows the automation and real time production of standard queries and dashboards and the use of advanced analytics and machine learning / AI
- We will investigate technology solutions that can automate and improve what we do in auditing and monitoring our data

Our Data Ecosystem

Where our strategy fits in.

Relevant Major Programmes

Our data strategy will be implemented alongside major transformational programmes that will digitalise our health and care services, widening the scope and opportunities available to us to collect and leverage high quality data. We must therefore be cognisant of the impacts of these programmes, and ensure that our data strategy will support and align with their implementation.

encompass

encompass is the largest and most ambitious programme in the HSC portfolio. At its heart will be a new Digital Care Record for every citizen, changing the way in which we deliver health and care services to achieve better outcomes. encompass will replace outdated, siloed ICT systems by bringing information together in one place for our people to securely access, record and share data from - in real time. Most importantly; it provides safe and protected individual data on the effectiveness of the care we provide.

Data functionality delivered:

- A central repository for the storage of patient health and care information;
- Secure sharing of patient information across care pathways;
- Integration with modern technology, such as tablets and smart phones; and,
- A secure patient portal, including appointment booking services, information access and communication with those providing their care.

NIPIMS

The NIPIMS programme (Northern Ireland Pathology Information Management System) is a standardisation project for tests, profiles and reference intervals across HSC, and will deliver specialist Blood Production and Blood Tracking systems.

Data functionality delivered:

- Information management support across all listed laboratory disciplines, fully integrated into a single cohesive solution; and
- Greater standardisation of processes within pathology services, including reduction of unnecessary variation through standardisation of profiles, reference intervals and tests.

NIPACS

NIPACS+ aims to deliver a single enterprise imaging solution for HSC to support clinical diagnosis, improve patient safety and enhance patient care through continued and enhanced medical image sharing and collaborative working.

Data functionality delivered:

- Migration of all existing RIS/PACS data into the new single service; and
- The ability to store images which originate outside of the radiology domain e.g. Digital pathology, ECG etc.

Supporting Programmes

Whilst we are expecting a wide array of benefits to be delivered by the Data Institute and major programmes, a series of supporting programmes will be implemented in parallel, to aid implementation and delivery of the HSCDI and our vision and mission.

Supporting Programmes

Programme	Description
Formation of the Implementation Oversight Board	This oversight board is proposed as a governance function overseeing the implementation of the data strategy including the establishment of the Data Institute.
Structure and Staffing of the Data Institute	Determining the structure of the Data Institute, the required staffing and the sources of funding.
Regional Data Warehouse	Examine and plan the timeline and migration of the Regional Data Warehouse into a cloud based data lake and analytics platform, in parallel with the other relevant major programmes (encompass, Equip, NIPACS, NIPIMS, etc.)
Focus on Research	This project will focus on building relationships with researchers and ensuring that HSC is involved in world class research that has the potential to improve patient care and service delivery, and that data is appropriately made available to do this. This will be coordinated by the HSCDI working with NITRE and the Honest Broker Service.
Information Standards	The HSCDI will coordinate working with all Trusts, commissioned organisations, the Public Health Agency and the Department of Health to agree a standardised approach to the collection and presentation of health and care data
Shared Data and Information Services	Evaluating the potential for developing data and information shared services. Currently we have a significant number of highly talented analytics people across HSCB, PHA, IAD and the trusts.
Clinical Coding	This project will focus on how we regionally improve clinical coding, both in terms of accuracy and timeliness.
Trust Business Intelligence	Enhancing and improving trust business intelligence capability. Focus will be placed on how to regionally support trust business intelligence functions through sharing of best practice, expertise, training and support.
Relationship with City Deals	City Deals are bespoke packages of funding and decision-making powers negotiated between central government and local authorities. The HSCDI will work with the City Deals and City Deal partners to facilitate the potential impact of this investment for our people, our patient and our population

Table 6. Relevant and Supporting Programmes

Integrating our Strategies

Data is the fabric that links our services together and to our population, acting as fuel for our wider digital transformation. As such, it is a vital component of innovation, cyber, workforce and digital strategies; these documents each require high quality, interoperable and secure data. In order for our wider digital transformation to take place in a cohesive manner, good data usage principles must be embedded throughout, and at every stage.

The illustration below explores the relationships between these strategies, and how data must be aligned to support the effective delivery of their objectives and goals.

Digital Strategy

Our Digital Strategy outlines core transformational programmes and initiatives that will change the way in which digital technology is used at HSC. The quality of the data that we put into these systems dictates the value of the outcomes that we can drive from them, and therefore data is fundamental to system and solution design.

Cyber

Cyber systems and processes are key to the safety and security of the data that we collect, store and analyse on behalf or our patients and HSC. Cyber will affect the ways in which we can use and share our data, and therefore has a huge impact on how we implement our data strategy.

Our Data Strategy

The variety of transformation programmes taking place across HSC are each facilitated by data, requiring precise data governance alongside appropriate information sharing and access that enforces the principle of least privilege. Data will underpin and enable everything that we do as we progress through our wider digital transformation.

Innovation

Data - and the evolving ways that we can use it – is key to innovation within our health and care ecosystem. It is fundamental to any new digital solution and can be shared with our innovation partners to co-create and optimise our services to drive better outcomes.

Workforce

Our people handle important patient data at the frontline. We must design our systems to make access to relevant clinical data quick and easy, whilst also supporting our people to understand their role in inputting high quality data back into our digital systems.

Working with our population

HSC exists to support the population of Northern Ireland, and as such people are front and centre of our vision for data. We are committed to using data in a transparent way, building and maintaining the trust of people using our services and helping them to understand how their data is used. In doing so, we can tackle wider health and care challenges such as population health and health inequalities and deliver improvements to service delivery and patient experience.

While we commonly talk about health and care data as an entity in itself, fundamentally a significant proportion of the data relates to our population and as belongs to them. In order to ensure we successfully use this data for the best benefit of patients, future patients and society as a whole, we must place our population at the heart of what we do.

This strategy is committed to a wider discussion about what our population want to happen with their data. We expect that there are likely to be a broad range of views; however, we believe the effective use of the data that we collect, as we care, can save lives and reduce risk to our wider population.

The COVID -19 pandemic has helped to put data - front and centre - in the minds of the population in Northern Ireland. We need to begin a longer conversation with them about who manages and secures the data we produce and how we use it.

Our commitments
We must start the conversation with our population and our people to explain the benefits of data use in care delivery.
We will continue to act to accelerate the introduction of secondary care legislation
We will commission and deliver a socialisation programme to help inform and understand our population's attitudes to using their health and care data. From our learning we will establish the social license to guide the use of their data for the wider good.
We will ensure an inclusive and progressive collation of stakeholders with the population at the centre - supported by technologists, academics, ethicists and legal specialists.
We must keep patient data safe at all times. We will design a transparent process for examining the merits of using data in different circumstances; in conjunction with the population, the Privacy Advisory Committee (PAC), academics and Regional Research Ethics Committee.
We will use industry standard security and links with Health Data Research UK and the Health Foundation to assure our processes.

Table 7. Our commitments to working with people and patients

Appendices

Glossary of terms

Term	Description
DHCNI	Digital Health & Care Northern Ireland
NIHAP	The Northern Ireland Health Analytics Platform - is proposed as a key tool for data analytics at HSC.
Health Ecosystem	The entire health care system mapped out to include all the people and groups involved in delivering health and care in Northern Ireland.
HSC	Health and Social Care
HSC Digital	HSC Digital will bring together the currently independent Trust IT teams, combining them with resources from the Business Support Organisation (BSO) ITS team to create one unified digital delivery capability for HSC.
Quadruple Aim	A set of four key principles set out in 'Delivering Together' including; Supporting and empowering staff; Improving the health of our people; Improving the quality and experience of care; and Ensuring sustainability of our services
ICD-10	An International Statistical Classification of Diseases and Related Health Problems
HSCDI	HSC Data Institute
PHIP	The Public Health Information Portal - the original covid-19 response platform
GPIP	GP Intelligence Platform
NI PAC	Northern Ireland Privacy Advisory Committee
HSCB	HSC Board
IAD	Information & Analysis Directorate
PMSI	Performance Management and Service Improvement
BSO	Business Services Organisation
NITRE	Northern Ireland Trusted Research Environment
SPPG	The Strategic Planning and Performance Group
OPCS	Classification of Interventions and Procedures
SNOMED CT	Systematized Nomenclature of Medicine – Clinical Terms