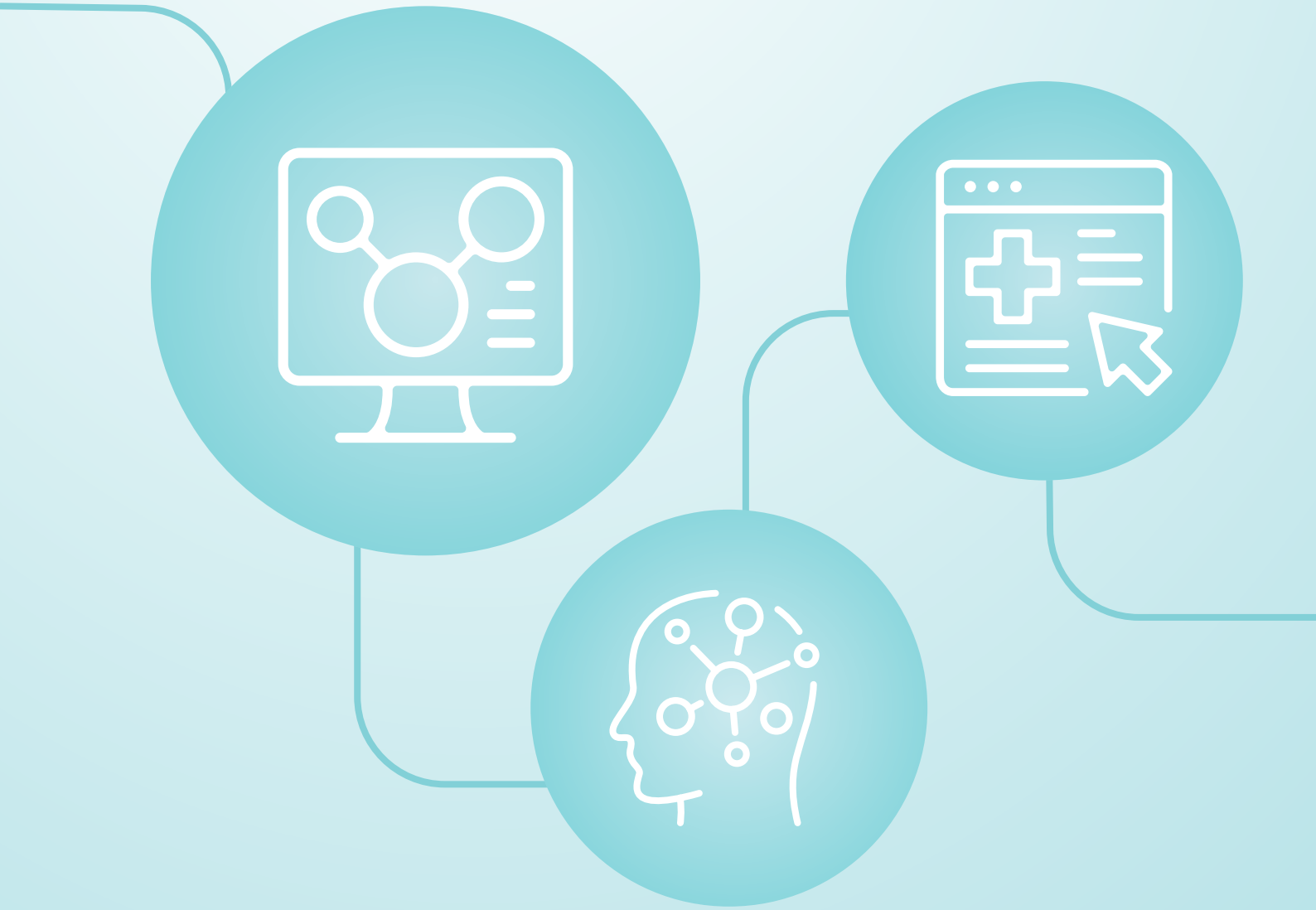
An tSeirbhís Náisiúnta Scagthástála
National Screening Service

Our Data Ecosystem Roadmap, 2025-2030

From data to information, insights and action



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Executive Summary

The Health Information and Quality Authority (HIQA) has reported that "*accurate, relevant and timely data is essential in order to improve health and social care, to inform decision-making, monitor diseases, organise services, inform policymaking, conduct high-quality research and plan for future health and social care needs*". The National Screening Service (NSS) is developing a comprehensive data ecosystem that will enhance how it governs, manages, and utilises data to enhance screening programme effectiveness and the care of programme participants. The development of a data ecosystem also aligns with more recent broader public sector initiatives, including the *Public Service Data Strategy* and the *Digital for Care: A Digital Health Framework for Ireland 2024-2030.*

Our roadmap responds to increasing digitalisation in healthcare, evolving regulatory requirements (including the European Health Data Space (EHDS) and *Health Information Bill 2024*), and growing public expectations for data transparency and security. The development process has involved a 12-month consultation with teams and departments across the NSS and incorporating feedback from the Department of Health, the Health Service Executive (HSE) Technology and Transformation Office, the Department of Public Expenditure and Reform and the Office of the Government Chief Information Officer. Three key data assessments were undertaken comprising a Data Inventory, Data Maturity, and Data Quality Assessments.

Our vision is to establish a data ecosystem within the NSS that will improve how we govern, manage and re-use data securely and efficiently for the benefit of our screening programme participants. It complements wider ambitions across the HSE to use data more strategically in the future. We aim to enhance screening programme effectiveness through data-driven decision-making while improving data accessibility and insights across the organisation. Central to our mission is ensuring robust data protection and security, alongside promoting a data-driven culture and literacy throughout the organisation.

Our roadmap comprises four key programmes of work. The first focuses on Governance, Quality, and Data Management, refining clear data governance roles and responsibilities, comprehensive data management policies, and implementing quality frameworks and regulatory compliance measures. The second programme addresses Data Architecture, Infrastructure, and Integration, creating organisation-wide data architecture mapping, standardising data storage practices, and improving system integration and accessibility. Our third programme concentrates on Data, People, and Culture, appointing dedicated data leadership, enhancing data literacy across the entire organisation, and fostering a collaborative data-driven culture. The fourth programme emphasises Data Analytics, Visualisation and Reporting, implementing standardised reporting solutions, expanding business intelligence capabilities, and enabling evidence-based decision-making throughout the organisation.

Ultimately, our success requires cultural change and resource investment. We recognise several key challenges, including change management, data quality maintenance, and stakeholder alignment. Progress will be measured through clear Key Performance Indicators (KPIs) and regular reviews. The implementation will be phased through specific tasks and projects distributed across the four programmes of work, ensuring a systematic, sequenced, and manageable transformation.

By 2030, the National Screening Service aims to move from excellence to elite performance and be recognised as a reference standard and best-in-class healthcare organisation when it comes to data management. This transformation will build on our significant progress to date and be characterised by further enhancement with decision-making capabilities, improved service delivery and the experience of our programme participants. We will continue to demonstrate strong data governance and security practices, supported by progress in adopting new advances in data analytics and reporting capabilities. Most importantly, we will embed a data-driven culture across all levels of the organisation, ensuring that data-informed decision-making becomes firmly embedded into our daily operations and screening programme delivery.

Becoming a data driven organisation, actively engaged in real-time monitoring, enables us to demonstrate our performance and identify strategic opportunities for service development and continuous quality improvement. Utilising optimum information and effective technologies will enable us to deliver a safe and responsive service that meets the needs of our screening participants and enhances their experience interacting with the service. Our intention is to maximise benefits for current and future participants, by providing them with easy access to their health data, empowering them to make informed decisions about their care. Working with colleagues in the HSE Technology and Transformation Office, we would like to see our screening participants conveniently manage their appointments where possible, view their test results, and communicate with our screening programmes and our healthcare partners through patient portals and mobile apps. There is also the possibility that by integrating additional patient-generated health data it will enhance personalised care, as healthcare professionals can gain deeper insights into individuals' health patterns and needs, leading to more effective and tailored screening, follow-up, and treatment.

1. Introduction

In today's digital landscape, data has become the lifeblood of business and organisations, driving innovation, efficiency, and competitive advantage. An organisational data strategy serves as the compass that can act as the guide through the vast sea of information at our disposal. It is a comprehensive blueprint that outlines how an organisation will harness its data assets to achieve its goals, enhance decision-making, and create tangible value.

At its core, an organisational data strategy is about aligning data management practices with business objectives. It encompasses everything from how data is collected and stored to how it is analysed and used across the organisation. A well-crafted strategy addresses key areas such as data governance, quality management, architecture, security, and analytics capabilities. They are the foundations that enable the creation of a data ecosystem.

A well-designed data ecosystem can enable organisations to make more informed decisions, identify new opportunities, optimise operations, and better serve their target populations. It can also help organisations navigate the increasingly complex landscape of data regulations and data protection concerns, ensuring compliance and building trust with stakeholders. As the volume and variety of data continue to grow exponentially such an approach is not just advantageous but essential for continued success in the digital age. It is the enabler that will transform raw data into actionable insights, drive innovation, and propel organisations toward their wider strategic goals.

Irish Public Service – public policy context

The *Public Service Data Strategy* sets out guidelines and actions to encourage best practices in data handling. *Connecting Government 2030: A Digital and ICT Strategy for Ireland's Public Service* emphasises the critical role of data management in enhancing service delivery, decision-making, and policy development.

The Office of the Government Chief Information Officer (OGCIO) is set to release several frameworks and data infrastructure later in 2025, including a Data Strategy Template, a Data Sharing Standards Framework, a Data Sharing Ethics Framework, a Data Quality Framework, and a Public Service Data Application Programming Interface (API) Catalogue.

The Department of Health's *Digital for Care – A Digital Health Framework for Ireland 2024-2030* sets out the aims to digitally transform health services and improve access for patients in line with sustained and predictable funding and staffing. In collaboration with the Department of Health, the Health Service Executive (HSE) has set out its exciting ambition for the role digital technology will play in the future of health in Ireland through its *Digital Health Strategic Implementation Roadmap*.

National Screening Service Strategic Plan 2023-2027

Our *Strategic Plan 2023-2027* identifies 'Data and Information' as an enabling priority, crucial for the advancement and improvement of screening programmes. Key strategic objectives include developing an organisation-wide data strategy, improving access to performance data, timely data visualisation, dashboard creation, and transparent reporting. The strategic plan also refers to maintaining the confidentiality and integrity of data and information, improving its availability, establishing a working group for open data publication, and collaborating with partners for data exchange and integration across platforms.

Legal

The regulatory (data) environment at EU level has been evolving, with the adoption by the European Parliament of the European Health Data Space (EHDS) Regulation which will come into force 20 days from adoption by the European Council. The EHDS Regulation will have direct effect in member states and will introduce governance and infrastructure requirements for health information at the national level. Specifically in Ireland, the *Health Information Bill 2024* provides a legal basis for (1) an overarching 'duty to share' personal health data for patient care and treatment; (2) development and deployment of digital health records in Ireland; and (3) enhanced provision of health information to the HSE for certain secondary purposes relevant to its statutory remit of improving, promoting and protecting the health and welfare of the public, such as the promotion of patient safety and public health, protection against serious health threats, service planning, performance management, and statistics in the health or care sectors.

The *Open Data Directive* came into force in Ireland in July 2021. The overall aim of the directive is to increase the availability of open government data across the EU. The concept is to make the non-personal data held by public bodies available and easily accessible online for reuse and redistribution. The directive introduces an obligation on public bodies to release government data in open formats and to open standards.

Open Data is a driver of scientific and technological innovation, and central to the delivery of an entire range of vital public services and societal goals, from tackling climate change to supporting the delivery of better evidence-informed service delivery to the people of Ireland. In terms of health data, while it is likely to have positive impacts on health research and innovation, transparency and accountability, patient empowerment, and public health insights, there will be challenges including data protection, data quality, and ensuring sensitive information remains secure.

Technology

Technology advancements present us with both opportunities and challenges. New methods for extracting insights from data, such as data science and AI, and the move to digital platforms and services, offer significant potential for innovation. However, these advancements also bring threats to data security, exemplified by incidents within our health service, most recently in 2021. The adoption of data standards such as SNOMED and participation in the European Health Data Space (EHDS) are important for ensuring interoperability. Moreover, technological advancements in screening tests are generating more data, necessitating even stronger and more robust data management practices.

Social

Social factors also play a role in shaping our roadmap. Changing communication channels, increasing public expectations and assumptions that we always have accurate personal data mean we must continue to rapidly adapt our data management practices and increase our focus on being agile and responsive. Demographic changes and the use of census data to predict future needs highlight the importance of data-driven decision-making. The potential of new screening programmes in the future highlights the need for interoperability, integration, and data sharing in the future. These elements ensure that different systems and stakeholders can work together efficiently, reducing complexities and enhancing the overall effectiveness of the programmes. Furthermore, increasing public awareness and concern about data use are shaping our continued commitment to demonstrating our trustworthiness.

2. The Building Blocks of a Data Ecosystem

All healthcare organisations are increasingly recognising the critical role of data. A robust data ecosystem is essential for harnessing the power of healthcare information to drive innovation and enhance quality of care. **Table 1** summarises the key building blocks for an effective data ecosystem, in any healthcare setting, addressing crucial aspects, from governance and quality to security and patient engagement[1,2,3]. We are already achieving gains in these areas, and by further implementing these key components through our roadmap, we can unlock the full potential of our data assets, with the aim of providing better care for our screening participants, more efficient operations, and improved overall performance.

Table 1: The Data Ecosystem for a Typical Healthcare Organisation

Key Components	
1. Data Governance • Establishing policies and procedures for data management • Defining roles and responsibilities for data stewardship • Ensuring compliance with healthcare regulations	*2. Data Quality and Standardisation* • Implementing processes to ensure data accuracy and consistency • Adopting standard terminologies and coding systems (e.g., ICD, SNOMED CT) • Regular data cleansing and validation
3. Analytics and Insights • Developing predictive models for patient outcomes and resource allocation • Implementing business intelligence tools for operational insights • Enabling population health management through data analytics	*4. Data Security and Data Protection* • Robust encryption and access control measures • Regular security audits and risk assessments • Patient consent management and data anonymisation techniques
5. Data Infrastructure • Scalable storage solutions (e.g., cloud-based platforms) • High-performance computing for complex analytics • Disaster recovery and business continuity planning	*6. Interoperability* • Enabling seamless data exchange between different systems and departments • Adopting healthcare data exchange standards (e.g., HL7 FHIR) • Implementing APIs for secure data sharing
7. Data Integration • Consolidating data from various sources (EHRs, labs, imaging, etc.) • Creating a unified view of patient information	*8. Data Lifecycle Management* • Defining data retention policies • Implementing archiving and purging processes • Ensuring data availability for long-term research and analysis
9. Patient Engagement • Providing patient access to their health data • Implementing patient portals and mobile apps • Collecting and integrating patient-generated health data	*10. Continuous Improvement* • Regular assessment of roadmap progress • Staying updated with emerging technologies and best practices • Fostering a data-driven culture within the organisation

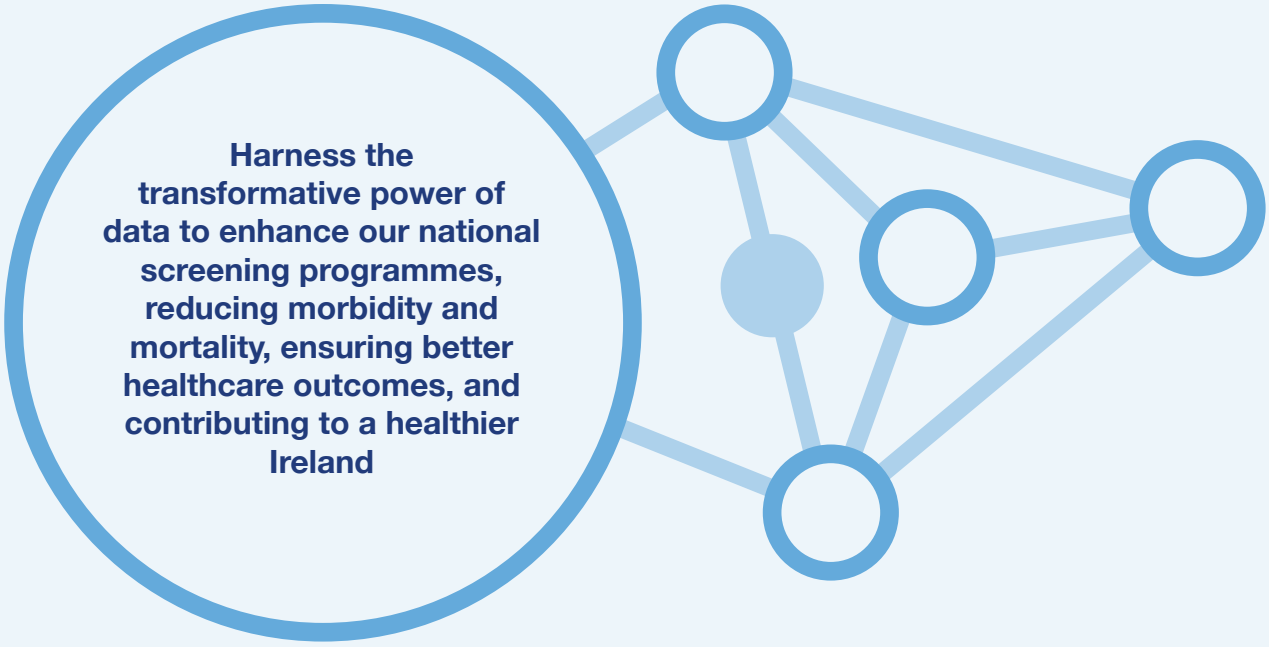
1 Wang, Y., Kung, L., & Byrd, T. A. (2018). *Big data analytics: Understanding its capabilities and potential benefits for healthcare organisations*. Technological Forecasting and Social Change, 126, 3-13

2 Pastorino, R., De Vito, C., Migliara, G., Glocker, K., Binenbaum, I., Ricciardi, W., & Boccia, S. (2019). *Benefits and challenges of Big Data in healthcare: an overview of the European initiatives*. European Journal of Public Health, 29 (Supplement_3), 23-27.

3 Mehta, N., & Pandit, A. (2018). *Concurrence of big data analytics and healthcare: A systematic review*. International Journal of Medical Informatics, 114, 57-65.

3. Vision and Mission

Vision



Mission

Building on progress to date, we will establish a data ecosystem that will improve how we govern, manage and re-use data in a secure, efficient, and transparent way, for the benefit of our screening programme participants. We will adopt advances in data analytics and visualisation techniques to objectively demonstrate valuable insights from population screening data and to support data-driven decision-making that will:

- enhance the effectiveness and efficiency of our population screening programmes
- encourage understanding of data and make insights accessible to all parts of our organisation and external stakeholders
- facilitate cross-organisation data access with defined roles, responsibilities, and accountability
- identify opportunities to expand screening reach, promote choice and equity of access
- empower preventative care through data-driven health promotion initiatives
- ensure data protection, security, and the ethical use of data and health information
- adhere to all relevant legislation and align with sector-specific strategies and policies

4. Methodology

4.1 Background

Our strategic plan[4] makes clear the scale of our ambition.

> *"Becoming a data driven organisation, actively engaged in real-time monitoring, enables us to demonstrate our performance, and identify strategic opportunities for service development and continuous quality improvement. Utilising optimum information and effective technologies will enable us to deliver a safe and responsive service that meets the needs of our screening participants and enhances their experience interacting with the service."*

One of the stated objectives in the strategic plan was to develop a roadmap by the end of 2024. This document was developed between September 2023 and July 2024 through a collaborative process involving extensive consultation across the NSS organisation

The project plan consisted of:

1. **Kick-off Workshop:** Bringing all stakeholders together to gather initial ideas and set the direction for our roadmap.
2. **Data Inventory Assessment (DIA):** Cataloguing our data assets and reviewing issues at the dataset level to understand the data landscape.
3. **Data Maturity Assessment (DMA):** Benchmarking our data management practices against OGCIO standards and guidance to identify areas for improvement.
4. **Data Quality Assessment (DQA):** The Health Information and Quality Authority (HIQA) has developed a data quality framework for health and social care. This framework aims to systematically assess, monitor, evaluate, and improve the quality of data and information within organisations. It includes dimensions such as relevance, accuracy and reliability, timeliness and punctuality, coherence, comparability, and accessibility and clarity.
5. **Data and People Workshop:** Discussing the cultural aspects and obstacles around data, including how well people collaborate and trust each other when sharing and utilising data.
6. **Roadmap Workshop:** Refining the roadmap and building a consensus on the path forward.
7. **Final Report:** Developing the final document through multiple rapid review cycles.

The development of our roadmap was underpinned by three key assessments: the Data Inventory Assessment (DIA), the Data Maturity Assessment (DMA), and the Data Quality Assessment (DQA). These assessments provided a self-assessed understanding of our data and its usage, at the raw dataset levels, identifying the strengths, weaknesses, and areas for improvement. These assessments give us the basis for describing the components of our roadmap.

The Data Maturity Assessment has the limitations of any self-assessment questionnaire. It is highly dependent on the knowledge and subject matter expertise of the individuals who completed the questionnaire. It is not possible for everyone to provide an equally informed score across all the knowledge areas. As a result, the ratings of subject matter experts in specific knowledge areas tend to be diluted with lower scores from non-subject matter experts. The radar map presented represents our whole of organisation average score. Our scores at this stage of the process, i.e. baseline, are not unusual for any organisation using this methodology.

4.2 Data Inventory Assessment

The Data Inventory Assessment involved a thorough review and recording of our data assets and involved staff from our four screening programmes and departments. We aimed to document what data we hold, how accessible it is, and where it can be shared.

Where we currently are:

- BreastCheck invites over 584,000 women aged 50-69 for screening every two years
- CervicalCheck invites over 1.33 million women aged 25-65 for screening every three to five years
- BowelScreen invites over 521,000 men and women aged 60-69 for screening every two years
- Diabetic RetinaScreen invites 193,000 men and women with diabetes for screening every one to two years

We have a responsibility towards all our participants to safeguard their data and use it to improve the quality of our services. Our focus was to undertake a systematic approach to compiling a data inventory and to identify further improvement opportunities for improvement.

4 *National Screening Service Strategic Plan 2023-2027*. Available at National Screening Service Strategic Plan 2023-2027 – Corporate

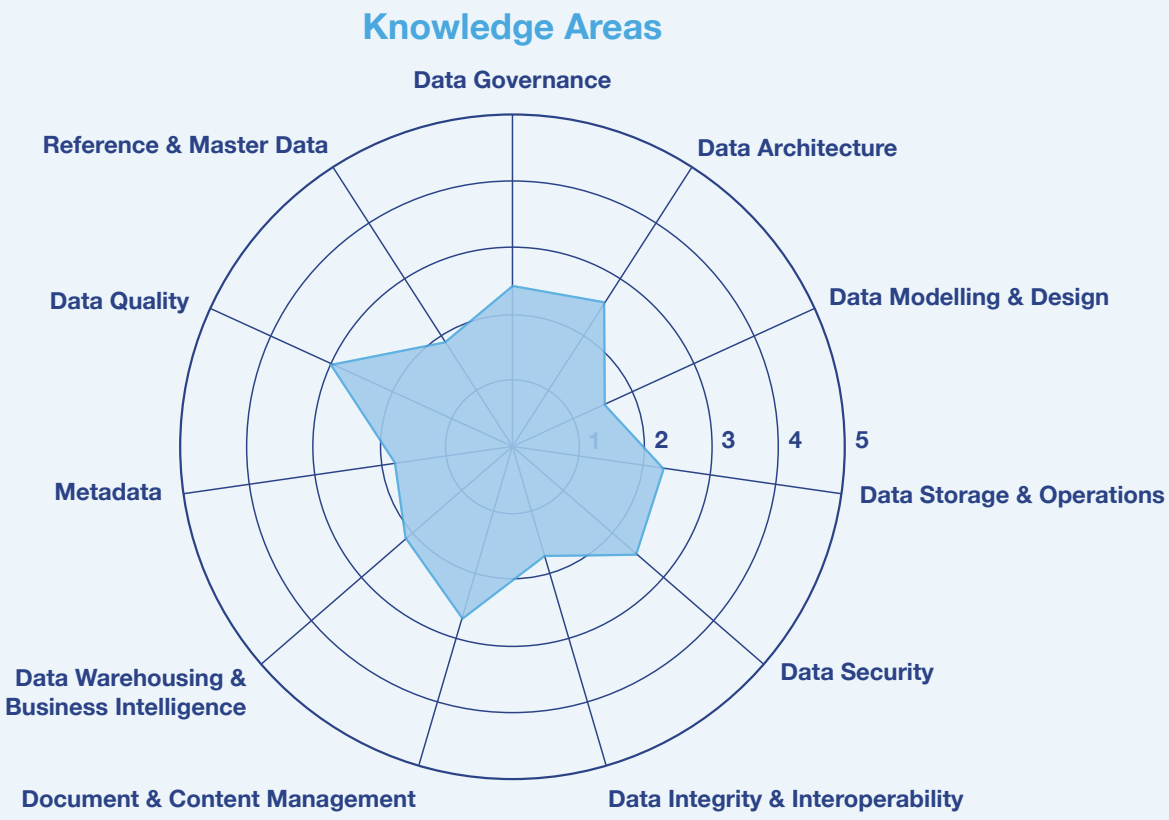
Further improvement opportunities

1. Variability in opinions on data 'ownership'
2. Need for more clarity around data sharing, individual roles, responsibilities, and accountability
3. Challenges coping with the transition to new digital systems
4. Need for greater standardisation of file formats and reporting systems
5. Difficulties accessing data
6. Data retention policies (particularly for non-clinical records) and a structured archival process
7. A willingness to seek out improved data protection practices and achieve advanced knowledge skills in handling sensitive information and anonymisation

4.3 Data Maturity Assessment

In the Data Maturity Assessment, we captured the perspectives of our staff on the organisation's data management practices, guidance, policies, and infrastructure. The exercise adhered to the OGCIO data maturity assessment guidance for Irish public service bodies.

Figure 1: Radar map scores (average) data maturity level



Where we currently are:

Data management practices are a fundamental component to Quality Assurance (QA). Our QA standards are in line with the highest international standards and promote practice that is consistent, effective, and evidence-based. We have four QA committees – one for each screening programme.

- Our screening programme management teams measure and monitor their respective QA standards and report to their QA committee.
- The QA committees report to our overall Quality, Safety and Risk Management Committee.
- This committee provides assurance to our Chief Executive, and in turn to the HSE board, that the quality and risks relating to our screening programmes are being effectively managed.

Further improvement opportunities:

1. An improvement in the average data maturity level of 2.2 (on a scale of 1 to 5).
2. Understanding the location of data repositories across the different departments and screening programmes.
3. The concept and understanding of 'ownership,' was a recurring theme which in terms of access to data and information led to an over-reliance on informality
4. An expressed desire for more direct and straightforward data and information access, as well as clearer policies and procedures for internal multi-department data access.
5. More consistency in the implementation of records management, retention, and data quality policies.
6. Significant enthusiasm for business intelligence tools and devolved usage.
7. More consistency and certainty around the process for adopting data analysis, data visualisation, and data reporting tools/software.
8. Expanding data science and analytic capability across the NSS.

4.4 Data Quality Assessment

Our four screening programmes were asked to complete an adapted HIQA data quality questionnaire. Once these questionnaires were completed, we interviewed members of each screening programme to provide additional feedback based on the responses received in the questionnaire.

Where we currently are:

Over the last three years, the NSS has been building an information governance framework that aims to build an organisational structure to achieve compliance with regulatory requirements and best practice in data management; increase awareness and confidence among staff about how to manage patient data appropriately; enhance trust in the effectiveness of our management of data; and ensure the confidentiality, availability, and integrity of the data we hold, process, and share to achieve our healthcare objectives.

Further improvement opportunities:

- A desire to increase our standardisation of data, data quality processes, and governance.
- A need for a clearer understanding of the data governance roles and resource allocation related to data quality.
- Variability in understanding the meaning and importance of data quality.
- A requirement for guidance on developing and implementing data quality initiatives.

5. Roadmap

The methodology deployed identified tasks and projects – a roadmap – of varying size and complexity that we have collated and categorised under four distinct programmes of work. These are:

5.1 Governance, Quality, and Data Management

Why is this programme of work a priority for us?

Effective governance, quality, and data management are essential for ensuring that we can rely on accurate, reliable, and complete data that is compliant with all legislative requirements. Without solid governance structures and quality management practices, we all risk data inaccuracies, security breaches, reputational damage with stakeholders, particularly the public, and non-compliance with regulations. We have made significant progress over the last three years, but we recognise that we must continue to identify improvement opportunities.

Strategic Objectives

1. **A Fit-For-Purpose Operating Structure to Meet Increasing Demands on Data Governance:** assignment of clear data governance roles and responsibilities to ensure accountability, effective data management, and delivery of a modern data analytics function.
2. **Data Policies and Guidelines:** continue to develop and implement data management policies to standardise our operational practices across the organisation.
3. **Data Quality:** continue to implement a data quality framework to ensure the accuracy, reliability, and completeness of our data.
4. **Regulatory Compliance:** continue to work to align our data management practices with all relevant legal and regulatory requirements to mitigate risks and ensure compliance.

5.2 Data Architecture, Infrastructure, and Integration

Why is this programme of work a priority for us?

Having a well-documented data architecture map is essential for understanding data integration, data flows, and data sharing both within and outside our organisation. Without a cohesive data infrastructure, accessing and managing data can become difficult. We are committed to our responsibility of using data efficiently, effectively, and transparently.

Strategic Objectives

1. **Data Architecture:** document a comprehensive data architecture map to reflect current operations and provide a clear visualisation reference for data locations, flows, and interoperability across all internal and external systems and software.
2. **Data Storage and Operations:** continue to standardise our data storage practices and facilitate access to technical support.
3. **Data Integration:** continue to ensure seamless data integration across different platforms and systems.
4. **Centralised Data Management:** establish centralised data catalogues and architecture maps to provide a clear reference repository for all data assets and their interdependencies within our organisation.

5.3 Data, People, and Culture

Why is this programme of work a priority for us?

Having the right culture, skill-mix and resources is essential for creating the right environment that makes it easy for us to use data consistently, efficiently and effectively in our roles. With a strong focus on data literacy and awareness, we can better understand what can and should be done with data. We are building a culture that ensures trust and a sense of collaboration and teamwork.

Strategic Objectives:

1. **Data Leadership:** clear commitment to establish data leadership roles with the delegated responsibility and authority to lead the implementation of the roadmap, and continue to promote a culture of collaboration, accountability, and data-driven decision-making.
2. **Data Awareness:** continue to raise awareness amongst all our staff of the value of data and the goal for it to drive decision-making, research, and innovation.
3. **Data Literacy:** provide training and support to equip individuals and teams with the skills and knowledge needed to use data confidently and responsibly within their scope of practice.
4. **Collaborative Environment:** encourage collaboration and teamwork to build trust.

5.4 Data Analytics, Visualisation and Reporting

Why is this programme of work a priority for us?

We are working to present our data and information, internally and externally, in a more visual format, such as charts, graphs, and dashboards, as they make it easier to see and understand patterns, trends, and outliers in the data. Enhanced data analytics, visualisation, and reporting capabilities are essential for supporting evidence-based decision-making and strategic planning. With the use of advanced analytical tools, statistical analyses, and reporting practices, we can use data more efficiently and gain meaningful insights.

Strategic Objectives:

1. **Data Accessibility:** continue to ensure data is easily accessible and usable by all stakeholders across the NSS within their scope of expertise.
2. **Data Visualisation:** identify the skill sets required to further embed data visualisation and analysis in our organisation, to provide deeper insights and support decision-making.
3. **Standardise Reporting:** develop and implement standardised data reporting solutions as/when required to ensure consistency and reliability.
4. **Evidence-Based Decision-Making:** continue to develop how we use data insights to monitor performance, identify opportunities for improvement, and achieve our strategic objectives.

Figure 2: Our Roadmap (2025-2030) – from data to information, insights and action

Governance, Quality, and Data Management	Data Architecture, Infrastructure, and Integration	Data, People, and Culture	Data Reporting and Insights
1. Documentation and communication of data and document management policies 2. Continued adherence to HSE data retention guidelines 3. Definition and assignment of data governance roles and responsibilities 4. Progressive development of a comprehensive data quality framework and policies 5. Enhanced training programs for data quality and management 6. Achieve compliance with the Open Data Directive	1. Implement scalable storage solutions 2. Enhance disaster recovery and business continuity planning 3. Integrate data from multiple sources 4. Create a unified view of patient information, e.g., central register 5. Develop an organisation-wide data architecture map 6. Document and describe data storage and operational practices 7. Document and describe a central data catalogue 8. Ensure interoperability across systems and platforms	1. Leadership commitment and vision 2. Clear data roles and responsibilities 3. Data literacy and training programmes 4. Encouraging a culture of curiosity and innovation, e.g., horizon scanning 5. Accessible and transparent data 6. Integration of data into daily operations 7. Commitment to data ethics and data protection	1. Deploy essential systems for data collection and analysis 2. Data collection 3. Data processing 4. Data analysis 5. Expand business intelligence capabilities 6. Data visualisation 7. Reporting and distribution

In formulating our roadmap (Figure 2), it was an important step in our methodological approach to benchmark the outcome of our Data Inventory, Data Maturity and Data Quality Assessments, the Data and People and Roadmap workshops with the data strategies already published by other public sector bodies[5] and also to ensure alignment with current government policy and HSE implementation documents[6]. The intention of this benchmarking exercise was to ensure that our roadmap was sufficiently ambitious, resilient, and realistic. The benchmarking process identified the following commonalities:

- **Data Governance**: Establish robust data governance structures. Ensure data quality, accountability, and transparency in decision-making.
- **Data Literacy**: Invest in building data literacy among staff and stakeholders. Enable effective data-driven decision-making.
- **Strategic Goals**: Align data strategies with broader organisational goals. Use data to enhance service delivery, efficiency, and effectiveness.
- **Engage Broadly**: Involve a diverse community of stakeholders both internally with staff and externally. Promote collaboration, data use, and its benefits beyond our organisation.
- **Publication of High-Value Data**: Prioritise publishing valuable data in open formats. Make it publicly available and freely reusable. This transparency fosters innovation and empowers stakeholders.

It is notable and reassuring that these themes are present in our roadmap illustrated in Figure 2 above.

5 Public Service Data Strategy (2021); *CCPC Data Strategy 2024-2026*; Department of Housing, Local Government and Heritage 2021-2024

6 *Connecting Government 2030 – A Digital and ICT Strategy for Ireland's Public Service; A Digital Health Framework for Ireland* (2024-2030); HSE Digital Health Strategic Implementation Roadmap

6. The Journey

Creating a fit-for-purpose data ecosystem involves more than just deploying the latest technology; it requires curiosity, ambition, and a cultural shift. Organisations that foster a data-driven mindset enable people at all levels to better understand the value of data and equip them with the skills to leverage it effectively. This will involve investments in data literacy programmes and the creation of cross-functional teams to break down data silos.

The journey from excellence to elite performance is both complex and difficult. Like any organisation we expect to encounter several key challenges, including:

1. **Change Management**: Effective and consistent communication and training are essential to ease this transition.
2. **Data Silos**: Effective data integration strategies and fostering a culture of collaboration can break down data silos and provide a more unified view.
3. **Stakeholder Alignment**: Regular meetings and clear communication will help align goals and expectations to ensure all stakeholders are on the same page.
4. **Resource Allocation**: Implementing a roadmap requires significant resources, including time, money, and skilled personnel, while maintaining day-to-day operations.
5. **Cultural Shift**: Collectively we must foster a data-driven mindset, where all of us, irrespective of grade or position, understand the value of data and are equipped with the skills to leverage it effectively. This often involves investments in data literacy programmes. Encouraging and supporting a mindset shift towards valuing data in decision-making is essential to build a data-driven culture.
6. **Technology Integration**: Integrating new data tools and technologies with existing systems can be technically challenging. Compatibility issues and the need for significant customisation can delay implementation.
7. **Scalability and Flexibility**: As data volumes grow, the infrastructure must scale accordingly. Ensuring the system remains flexible to adapt to future needs without significant overhauls is crucial.
8. **Measuring Success**: It is important to establish clear KPIs, as a component part of an implementation plan to measure the success of the roadmap and regularly review progress to ensure it is delivering the desired outcomes.

7. Our Destination

By 2030, the National Screening Service aims to move from excellence to elite performance and be recognised as a reference standard and best-in-class healthcare organisation when it comes to data management. This transformation will build on our significant progress to date and be characterised by further enhancement with decision-making capabilities, improved service delivery, and our programme participants experience. We will continue to demonstrate strong data governance and security practices, supported by progress in adopting new advances in data analytics and reporting capabilities. Most importantly, we will embed a data-driven culture across all levels of the organisation, ensuring that data-informed decision-making becomes firmly embedded into our daily operations and screening programme delivery. Figure 3 illustrates how and where the value of good data management will translate into additional patient benefit, meeting our obligations under EHDS Regulation and the broader HSE ambition of having digital health records in place for everyone, to include important and relevant information about screening programmes that the public is engaged with.

What it will mean for our screening participants?

Our intention is to maximise benefits for current and future participants in national screening programmes, by providing them with easy access to their health data, empowering them to make informed decisions about their care. Working with colleagues in the HSE Technology and Transformation Office, we would like to see our screening participants conveniently manage their appointments, view their test results, and communicate with our screening programmes and our healthcare partners through patient portals and mobile apps. There is also the possibility that by integrating additional patient-generated health data it will enhance personalised care, as healthcare professionals can gain deeper insights into individuals' health patterns and needs, leading to more effective and tailored screening, follow-up, and treatment.

Figure 3: The NSS in 2030

Appendix 1: Glossary of Terms

Analytics Dashboard: A visual display of data that provides at-a-glance views of key performance indicators (KPIs) and important metrics. Often interactive, allowing users to explore the data in more detail.

API (Application Programming Interface): A bridge that allows different software applications to communicate and interact with each other. It defines a set of rules and protocols for how programmes can request and exchange data or perform specific tasks. APIs enable developers to access services, data, or functionality provided by other applications, making it easier to build powerful and integrated software systems.

Business Intelligence (BI): Tools and technologies that help organisations analyse data and present actionable information to help make informed business decisions.

Data Analytics: The process of examining, cleaning, transforming, and modelling data to extract meaningful insights, patterns, and trends. It involves using statistical techniques, machine learning algorithms, and visualisation tools to make informed decisions based on data.

Data Architecture: The structure that sets out how data assets are organised and managed to align with the broader organisational enterprise architecture. The components include conceptual, logical, and physical data models. Data architecture establishes a vision for data in the strategic sense whereas data management relates to day-to-day operations.

Data Asset: A business-critical data item, or group of items, held by an organisation, including data in IT systems, databases, excel files or other repositories. It also includes outputs of data initiatives, such as reports, models, and analytic dashboards.

Data Catalogue: A comprehensive inventory of an organisation's key data assets. It provides information (metadata) about data assets including business descriptions, data ownership, technical information, and can include usage or classification guidance to support data governance.

Data Driven Culture: An organisational environment where decisions are based on data and evidence rather than intuition or experience alone. All staff members are encouraged to use data in their daily work.

Data Ecosystem: The complete environment of data within an organisation, including how it's collected, stored, managed, and used, along with the people, processes, and technologies involved in these activities.

Data Governance: In the context of the European Union, the set of policies, processes, and practices that ensure the effective management, quality, usability, sharing, and protection of an organisation's data. It involves defining roles, responsibilities, and standards for data management, as well as establishing guidelines for data access, protection, and compliance.

Data Literacy: The knowledge, skills, and capability people need to explore, understand and use data relevant to their role in an organisation.

Data Management: The process of handling and arranging an organisation's data effectively. It involves collecting, storing, securing, transforming, and using data for decision-making.

Data Maturity Assessment: A method for organisations to assess their current data management capability by examining their data management processes and procedures in different data areas and benchmarking these against pre-defined levels of maturity.

Data Owner: A specific data governance role assigned to a senior individual with ultimate responsibility for a specific dataset. A data owner oversees the data governance of the assigned dataset, ensuring compliance with relevant internal policies and broader legislation including data protection.

Data Protection: In the context of the European Union, data protection refers to the safeguarding of personal data, ensuring that individuals' privacy and rights are respected when their data is collected, processed, and stored. This is primarily governed by the General Data Protection Regulation (GDPR), which sets out strict rules on data handling and grants individuals' significant control over their personal information.

Data Quality: The state of completeness, validity, consistency, timeliness, and accuracy that makes data appropriate for a specific use.

Data Sharing Agreement: A framework that sets out the terms for sharing personal data between parties and defines the principles, procedures, and responsibilities the parties must follow.

Data Standards: Agreed documented guidelines describing how data items should be defined and structured within an organisation. These include technical standards, messaging standards, metadata standards, and terminology standards. They ensure consistency across data formats, naming conventions, units of measurement, and other specific business themes.

Digital Health Record: Often referred to as an electronic health record (EHR), this is a digital repository of a patient's medical information that documents their entire healthcare journey in real time.

European Health Data Space Regualtion (EHDS): A European Union initiative to promote better exchange and access to different types of health data to support healthcare delivery and health research.

Information Governance: A strategic framework that helps organisations manage, protect, and maximise the value of their information. It involves policies, processes, and controls addressing data security, compliance, data quality, and lifecycle management.

Key Performance Indicators (KPIs): Measurable values that show how effectively an organisation is achieving its objectives. In screening services, these might include participation rates or detection rates.

Metadata: Information about data. It does not contain the actual content of the data but merely describes it. Having dependable, clear, and concise metadata for key organisational datasets makes it easier to understand and work with individual datasets.

OGCIO: Office of the Government Chief Information Officer

Open Data: The concept of making data held by public bodies available and easily accessible online for reuse and redistribution. Open data gives everyone access to non-personal government data which can deliver enhanced economic, social, environmental, and democratic benefits.

System Integration: The process of bringing together different subsystems or components into a single system that functions as one. In healthcare, this might mean connecting different patient record systems.

Visualisation: The presentation of data in a pictorial or graphical format, making complex data more accessible and understandable. Examples include charts, graphs, and heat maps.

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