Dataset Specification Management Process Report 2022/2023

Document Control

Revision History

Version	Author	Date	Changes
V1.0 Draft	Yvonne Coughlan/Theresa Barry	30/06/23	Initial Draft
V2.0	Yvonne Coughlan/Theresa Barry	11/07/23	Draft
V3.0	Yvonne Coughlan/Theresa Barry	16/07/23	Draft
V4.0	Yvonne Coughlan/Theresa Barry	19/7/23	Draft
V 5.0	Kathryn Kissane	21/07/2023	Draft
V 5.1	Yvonne Coughlan	18/08/2023	Final

Review & Approval

Name	Versions Signed Off	Sign off Date
Theresa Barry	**V 4.0**	**18/08/2023**

Introduction

Data is recognised as one of the most important components to achieve the best health care a country can provide. The vision for healthcare set out in the Programme for Government is Universal healthcare, a public health service which provides the people with access to high quality, affordable care when they need it. On 14 May 2021, the HSE suffered a major ransomware cyber-attack which caused all its eHealth systems nationwide to be shut down. It was the most significant cybercrime attack on an Irish state agency and the largest known attack against a health service computer system. The system recovered from this attack, but the event caused significant disruption to services and impacted on some of the reform works underway. There has never been so much emphasis and focus on the eHealth system within the health system. The cyber-attack highlighted how important our eHealth department is and the disruption that is caused when we cannot access the correct information for patient care.

One of the key initiatives for Sláintecare 2023 is eHealth. Sláintecare highlighted the need for investment in digital health solutions and electronic health records as key enablers for reform of the health service. Through successive budgets over the past three years, funding for digital health to fund additional staff, systems, licensing and to build cyber resilience has increased significantly, but further investment will be required to facilitate integrated electronic health records as recommended under Sláintecare. The Department is in the process of refreshing the 2013 eHealth Strategy taking on board experience from other countries, developments in the digital health industry, the expectations of patients and healthcare professionals, the fact that the population and patients are now better connected, government policy under the Harnessing Digital Strategy, EU and international obligations. The revised strategy will provide a clear direction for digital health to 2030 and underpin the case for further investment beyond what has been put in place to date.

Key initiatives for 2023 include:

   I.   Publish the Digital Health Strategic Framework 2023-2030 in 2023 (await release of same) to align with Government's Harnessing Digital and update current eHealth strategy. The HSE will publish a corresponding Digital Health Strategic Implementation Plan in 2023. (Harnessing Digital, the Digital Ireland Framework 2022 Progress Report) link

  II.   Progress the Electronic Health Record for Community programme (ICCMS) through the public spending code approval process.

 III.   Mobilise the Shared Care Record programme as an essential enabler to delivering Summary and Shared Care Electronic Health Records for all.

 IV.   Develop roadmap and investment case for Electronic Health Record (EHR) deployment. As per the Public Service Strategy 2019-2023 there are 11 Principles set out -The principles set forth below will help shape the evolution of a target state data ecosystem based on transparency, accessibility, and reusability, driven by the application of standards, trusted identifiers and secure interoperable solutions enabled by effective governance, and dealing with data protection as a cross cutting concern. (*Public Service Data Strategy 2019-2023 Office of the Government Chief Information Officer Department of Public Expenditure and Reform) LINK*

These principles are:

1. Data is discoverable by citizens, businesses and the Public Service
2. Data is processed in a transparent manner
3. Data that can be made public should be made public
4. Data is reusable
5. Data is accessed and maintained via base registries
6. Data is accessible through APIs to support interoperability
7. Data is demonstrably processed in line with legislation
8. Data is effectively governed
9. Data is collected and processed digitally
10. Data is used to support evidence-based decision making
11. Data is processed in a secure and private manner

With these principles in mind the DSMP can focus on encompassing datasets that are beneficial to patient care, future research and future progression in the healthcare setting.

Brief overview of the Data Specification Management Process for new requestors

Background of DSMP

In 2019, the SNOMED Governance Board, chaired by HIQA developed the dataset specification management process towards the Public Service Strategy 2019-2023 Principles. This was based loosely on a model developed by the NHS to standardise, and manage datasets, coming through a defined process whilst having all key decision makers involved in data management in the organisation involved in the process. This proposal was submitted to Senior Management Team of the OoCIO (now eHealth) and was approved.

A Dataset Specification Management Process (DMSP) was established, and Terms of Reference agreed. This process was designed by the Business Architect (Enterprise Architecture), approved and signed off by the SNOMED Governance Board to fulfil that requirement.

The Dataset Specification Management Process brings Subject Matter Experts from core areas, within and external to the HSE, together to ensure a consistent approach to dataset specification management. Subject Matter Experts were identified by process mapping the role of all stakeholders and their role in managing datasets.
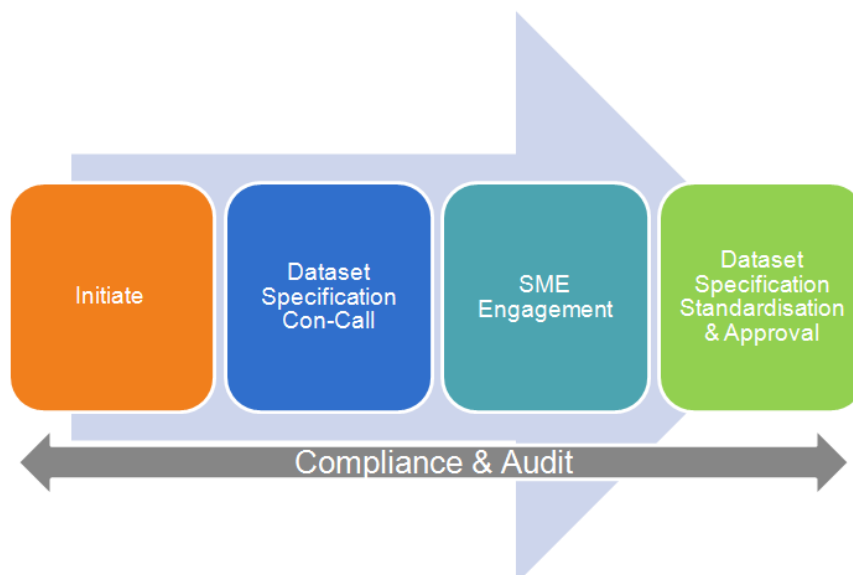
This group provides a forum and process to enable stakeholders who have a role in the management and analysis of data to:

- Champion their data requirements
- Contribute to an enterprise view of data
- Give feedback and advice to dataset owners
- Manage dataset specifications to provide foundational information governance

The aims of the Dataset Specification Management Process are:

- A standardised uniform process that facilitates new and existing dataset specification
- A quality assurance process for new and existing dataset specifications
- The opportunity for early input from downstream functions to enhance service planning, analytics and reporting
- A reduction in re-work and costs due to errors and omissions in dataset specifications
- Ensure that all datasets are subsequently standardised with clinical terminology i.e SNOMED CT and made available to digital health solutions to enable interoperability
- Ensure that all relevant datasets are incorporated into the HSE Data Dictionary where applicable

Dataset Specification Management Process

Initiate

Dataset Specification Con-Call

SME Engagement

Dataset Specification Standardisation & Approval

Compliance & Audit

There are currently 11 Subject Matter Expert (SME) Representatives in the DSMP with 3 new members in 2022 the group is expected to expand in the future. These SMEs were chosen as they are the leading experts in the HSE and National Offices for data management and expert knowledge of dataset requirements and standards.

Please review Appendix 1.0 for more details on each SME supporting the DSMP.

Current SME representative areas:

- National Release Centre for SNOMED CT
- National Health and Social Care Data Dictionary –(NHSCDD)
- Information Governance (EA)
- Integrated Information Services (IIS)
- Health Research Board (HRB)
- Hospital In-Patient Enquiry (HIPE) – Healthcare Pricing Office (HPO)
- Business Information Unit (BIU)
- HSE Primary Care Reimbursement Service (PCRS)
- Health information and Quality Authority (HIQA) (joined 2021)
- Department of Health (DOH) (Joined 2021)
- National Office of Clinical Audit (NOCA) (Joined 2021)

The group meets monthly and the DSMP co-ordinator under the auspices of the SNOMED Governance Board and the National Release Centre for SNOMED, schedules and plans the meetings.

Ongoing input post initial DSMP meeting

Each dataset requestor has an initial meeting with the DSMP and from this meeting the SME's then decide who would be best to help with the dataset. Depending on the size of the dataset the amount of input from the SMEs varies. Not only is it beneficial to have an SME from a particular department on board but this can open pathways to other areas of expertise to help. For example, one Dataset requestor was offered an opportunity to make a connection with the National Health and Social Care Professions Office regarding the capture of their activity. This may not have come about without networking within the DSMP. This process can help with preventing any silos that unfortunately can occur within the health system.

New Subject Matter Experts 2022

The DSMP were delighted to have a new member from the Health Intelligence Unit join us in their capacity as a data expert. The new SME has worked on many different projects but most significantly on the COVID vaccine certificate. The new SME brings a wealth of knowledge to the group along with our outstanding members to date.

Datasets reviewed in the DSMP in 2022

- National Ambulance Service
- Patient Flow CUH (Cork University Hospital)
- Potential Donor Audit
- International Patient Summary

- IHI (Individual Health Identifiers) & Hospital Names
- Health Screen Questionnaire
- BreastCheck

Brief overview of the Datasets reviewed in the DSMP in 2022

The datasets that came through the DSMP in the last year, either originated via the National Release Centre for SNOMED CT or have approached the DSMP following best guidelines for standardising their datasets prior to working with SNOMED CT. Link to browser here to view reference sets (refsets) available presently in the Irish edition of SNOMED CT Link

Dec 2021- BreastCheck - A 2018 HIQA report into the Information Management Standards of BreastCheck recommended that "The use of health information standards and terminologies for BreastCheck should be assessed as part of the information management strategy of the National Screening Service". BreastCheck is in the procurement process for a new information system. Following on from the 2018 HIQA report, BreastCheck is endeavouring to utilise SNOMED-CT within the new information system. BreastCheck was brought through the DSMP via the NRC for SNOMED CT. The DSMP gave BreastCheck an opportunity to meet SMEs from varying departments within and outside of the HSE. BreastCheck gained valuable information form the meeting. The BreastCheck dataset has been standardised into a refset for the Irish edition of SNOMED CT by the Irish NRC, you can view same by following this Link

Jan 2022- National Ambulance Service – The NAS approached the NRC in the summer of 2021 to commence work on their Dataset that they wanted to standardise for their new electronic Health system in the National Ambulance Service. They currently use the Pre-Hospital emergency care data set, via the electronic Health System Siren4. This is the first national system to document pre-hospital care. This system has expanded upon the dataset established by the Pre-Hospital Emergency Care Council (PHECC). The dataset has over 5000 terms. The NAS brought the dataset to the DSMP in Jan 2022 and found the meeting very useful for them and they subsequently had numerous engagements with several members of the Subject Matter Experts group. There is ongoing input between the NAS and the NRC for SNOMED CT. The NAS refset that is completed to date can be seen by following this LINK

Feb 2022- Patient Flow CUH- Patient Flow contacted the NRC for SNOMED CT back in 2021 and wanted to work on developing a refset for the patient Flow electronic system they are hoping to implement soon. The patient Flow project required information expedite patient journey in a timely manner within an acute hospital setting. The Patient Flow dataset has been standardised and developed into a refset by the Irish NRC for SNOMED CT which is available to view on the Irish edition of SNOMED CT through the follow Link

Sept 2022-Potential Donor Audit (PDA) Pilot study – NOCA presented the PDA to the DSMP during the dataset development phase of the PDA Development Project – a project commissioned by Organ Donation Transplant Ireland to develop and test national clinical audit of organ donation practices in Ireland. The PDA aims to ensure that every person who is approaching the end of life in ICU and ED is offered the possibility of becoming an organ donor, where this is appropriate. The Development Project included a pilot study of the PDA in six Irish hospitals over three months and which will inform recommendations for national implementation, if appropriate. The SMEs were impressed with the comprehensive dataset available, and recommendations were made by HIPE and PCRS;

DOH also had input. There is ongoing input and work commencing on the dataset to develop a refset for the project with SNOMED CT in the coming months.

Oct 2022- International Patient Summary- the International Patient Summary is a minimal and non-exhaustive set of basic clinical data of a patient, specialty-agnostic, condition-independent, but readily usable by all clinicians for The International Patient Summary (IPS) is building the bridge between the "home" health and care environment of the patient and any other place where the patient needs to visit a clinical professional, whether within or across borders. The SNOMED NRC brought this dataset as it was developed in the EU sematic taskforce as the guideline for patient summaries and has been adopted by ISO and could be used by project groups in Ireland when a patient summary will be required.

Nov 2022- IHI & Hospital names —An Individual Health Identifier or IHI is a number that uniquely and safely identifies each person that has used, is using or may use a health or social care service in Ireland. It will last for your lifetime and will never be re-issued to anyone else. The Access to Information (A2I) team in eHealth brought this dataset forward.
 As the IHI is adopted and embedded in services, it will facilitate communication with other IHI-enabled systems so that an equivalent patient record match can be confirmed.

Hospital Names are managed by several functions. Collectively HIPE, BIU, Acute Operations NOCA and A2I. To understand the complexities of how these are managed A2I brought the dataset to the DSMP.

Dec 2022- Health Screen Questionnaire Dataset – Public Health originally approached the NRC for SNOMED CT as they required the SNOMED codes for the dataset. As there were time constraints, we advised Public Health to attend the next DSMP. To have the dataset reviewed by the SMEs for any feedback to ensure all areas were covered. The dataset was originally for the health assessment of Ukrainians entering Ireland to ensure they were allocated correct health care and to be seen by health practitioners as quickly as possible; this has now been rolled out to all immigrants entering Ireland. The main hub for assessment of displaced people is currently at NTC, CityWest and the digital solution is implemented. The Health Screen refset will be used in the digital solution once available. The dataset has been standardised and developed into a refset by the Irish NRC and will be available to view in the October release of the Irish edition of SNOMED CT on the browser.

The HSE Data Dictionary

When the HSE has completed procurement in early 2024 of a solution to manage an enterprise-wide data dictionary, all the relevant Meta data of datasets will be made publicly available there.

Benefits of the DSMP to date:

- Access to the leading authorities in data management in the HSE, DOH, HIQA and other national bodies
- Noted reduction in duplication of datasets due to an overall awareness nationally of data management hence further reducing silos in the organisation
- There is a defined process for managing datasets
- Built a network of authorities involved in managing and retrieving data in the HSE to work towards a common goal

Feedback from dataset requestors:

'Fantastic forum for networking'

'Thinking outside the box, would not have thought of that point unless brought up in this meeting'

Future Plans:

- Continue monthly meetings third Friday of every month at 11am
- Engage with national projects to ensure their datasets are approved via the DSMP
- Promote the DSMP within the clinical setting to engage with clinicians working on the frontline who work closely with datasets.

For any further information please contact:

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Appendix:

Appendix 1.0

Name of Subject Matter Expert	Reason for being chosen for DSMP
SNOMED CT	National Release Centre for SNOMED CT-Standardising Terminology for EHR Systems
NHSCDD-HSE National Health and Social Care Data Dictionary	Data Dictionaries for data are useful to describe the 'rules' which data in a particular system need to abide by. For any new projects or applications being introduced into the HSE, the HSE NHSCDD can help with the creation of the datasets, alignment of existing datasets and assist vendors through the development of evolving datasets specifications.
Information Governance (EA)	Information governance provide standards and guidelines on the handling of data and giving the tools to organisations need to achieve the standards required for information such as that contained in a healthcare record is handled legally, securely, efficiently and effectively in order to deliver the best possible care to people who use health and social care services.
Integrated Information Services (IIS)	The IIS is a centralised service that creates and maintains policies, standards and governance around the HSE's data. It is the main Data Analytics Service for the wider Health Service Executive.
Health Research Board (HRB)	The Health Research Board (HRB) is a State Agency under the Department of Health. It is responsible for supporting and funding health research, generating health information and promoting the use of evidence in policy and practice. The HRB's National Health Information Systems Unit manages four national health information systems on behalf of the Department of Health. These systems 1) produce data and information to assist the Department with policy and planning 2) enable the HSE to report on its service planning processes and 3) generate research that is relevant to both policy and practice.
Hospital In-Patient Enquiry (HIPE)- Healthcare Pricing Office (HPO)	HIPE Scheme is a health information system designed to collect demographic, clinical and administrative data on discharges from, and deaths in, acute public hospitals nationally. HPO is to oversee all functions associated with the operation of the HIPE database, including the development and support of the data collection and reporting software, training of coders, data quality, audit, data analysis and reporting, and responding to requests for information.
Business Information Unit (BIU)	The HSE's Business Information Unit (BIU) gathers and maintains a central repository of service data from all hospital and community-based health services nationwide. Extensive amounts of data are collected, collated and checked within this Unit. This data, is used as part of the National Performance Oversight process and in other levels of performance management as part of the Performance Accountability Framework
HSE Primary Care Reimbursement Service (PCRS)	The PCRS compiles statistics and trend analyses which are provided to other areas within the HSE, the Government, customers, stakeholders and to members of the public.
Health Information and Quality Authority (HIQA)	HIQA Working in conjunction with a wide range of stakeholders, we aim to improve the quality and safety of health and social care services by setting national standards and publishing guidance.
Department of Health (DOH)	The Department of Health is responsible for the overall strategy and planning of National service plan and SlainteCare.

Appendix:

National Office of Clinical Audit (NOCA)	NOCA manages national clinical audits that aim to improve patient care and outcomes. NOCA's findings enable the healthcare system to act to improve care where standards are not followed. NOCA enables the Irish healthcare system to continually improve its standards of care via maintenance of a portfolio of prioritized national clinical audits, standardised against national and international criteria. Not only do NOCA enhance accessibility to validated data for persons who use, manage and deliver healthcare, our clinical audits help to improve patient outcomes, and create positive change locally and nationally.
Enterprise Architecture Office of the CIO, Eamon Coyne	Enterprise Architecture is responsible for supporting the strategic development of technical architecture, technology and operational capabilities in a standardised and aligned manner.

References:

- Public Service Data Strategy 2019-2023

  https://assets.gov.ie/7107/7ac4ae109cd944dc99c9e178962fa095.pdf

- Slainte care report
  file:///C:/Users/YvonneCoughlan2/Downloads/251347_e0cc4c23-ce8a-49f0-9ffc-d9220000bbcb.pdf

- Harnessing Digital, The Digital Ireland Framework 2022 Progress Report
  file:///C:/Users/YvonneCoughlan2/Downloads/241714_bedc64c6-baaf-4100-9255-02f5e07dd3f9%20(15).pdf