



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Self-Assessment Tool for National Health and Social Care Data Collections

May 2017

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent authority established to drive high quality and safe care for people using our health and social care services in Ireland. HIQA's role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered.

HIQA aims to safeguard people and improve the safety and quality of health and social care services across its full range of functions.

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, HIQA has statutory responsibility for:

- **Setting Standards for Health and Social Services** – Developing person-centred standards, based on evidence and best international practice, for health and social care services in Ireland.
- **Regulation** – Registering and inspecting designated centres.
- **Monitoring Children's Services** – Monitoring and inspecting children's social services.
- **Monitoring Healthcare Safety and Quality** – Monitoring the safety and quality of health services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health Technology Assessment** – Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.
- **Health Information** – Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

Overview of the Health Information function of HIQA

Health is information-intensive, generating huge volumes of data every day. Health and social care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is therefore very important that information is managed in the most effective way possible in order to ensure a high-quality safe service.

Safe, reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient is not allergic to it.

Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests — if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst not given.

In addition, health information has an important role to play in healthcare planning decisions — where to locate a new service, whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision.

Under section (8)(1)(k) of the Health Act 2007⁽¹⁾, the Health Information and Quality Authority (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), HIQA is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving its quality and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to promote quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient's general practitioner (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector is highly fragmented, with major gaps and silos of information which prevent the safe, effective, transfer of information. This results in people using services being asked to provide the same information on multiple occasions.

In Ireland, information can also be lost, documentation is poor, and there is over-reliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care.

Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, clear and trustworthy information on which to base our decisions. HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements.

Confidentiality

Please note that HIQA is subject to the Freedom of Information Acts and the statutory Code of Practice regarding Freedom of Information. National data collections should not return any information to HIQA that could be used to identify an individual.

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1. National health and social care data collections

National health and social care data collections are national sources of routinely collected health and social care data, including administrative sources, censuses, surveys and national patient registries in the Republic of Ireland. The managing organisation is defined as the organisation, agency, managing unit, institution or group with overall responsibility for the national health and social care data collection.

National health and social care data collections play a crucial role by providing a national overview of a particular health or social care service. A considerable amount of time, effort and resources are invested into producing a high-quality data collection. This ensures that the population it serves gets the maximum benefit from the information collected. Therefore, it is essential to promote, encourage and facilitate the use of the data.

Table 1. Examples of national health and social care data collections in the Republic of Ireland

National health and social care data collection	Description	Managing organisation
Hospital In-Patient Enquiry Scheme (HIPE)	Collects demographic, clinical and administrative data on discharges from, and deaths in, acute public hospitals nationally to maintain a timely accurate national database of hospital discharge activity.	Healthcare Pricing Office (HPO) of the HSE — The HPO has been responsible for the management and administration of this scheme since 1 January 2014.
Computerised Infectious Disease Reporting (CIDR) System	Manages the surveillance and control of infectious diseases in Ireland and monitors organisms' ability to resist antibiotic drugs (antimicrobial resistance).	The Health Protection Surveillance Centre (HPSC) of the HSE — HPSC is responsible for collecting and collating infectious disease notifications since 2000. The CIDR system is a shared national information system for the CIDR partners, including the HPSC.
Irish Hip Fracture Database (IHFD)	A web based system that uses the HIPE (Hospital In-patient Enquiry) portal infrastructure. It audits care standards and outcomes for patients with hip fractures.	National Office of Clinical Audit (NOCA) — NOCA is an independent body funded by the HSE. It is responsible for the governance of the IHFD, along with a number of other national audits.

In Ireland, as in many other countries, our national health and social care data collections have evolved over time in a largely uncoordinated fashion. Although there are examples of very good practice, this lack of coordination has led to a fragmented health information infrastructure. For example, there is limited data available from the primary and community care sectors, from outpatients, or from emergency departments.

The importance and need for high-quality health information to improve the safety and quality of patient care has been outlined in a number of key national strategy documents in recent years.^(2,3,4) In particular, the e-Health Strategy for Ireland, published in December 2013, highlights the importance of access to quality health data sources to drive improvements in the quality and safety of care.⁽⁵⁾ The establishment of the Office of the Chief Information Officer in 2015 and the publication of the HSE Knowledge and Information Strategy represent other recent developments that emphasise the importance of the availability of quality health information.⁽⁶⁾

Based on international best practice, four key principles relating to health information have been identified which are based on maximising health gain for the individual and the population, specifically:

- health information is used to deliver and monitor safe and high-quality care for everyone
- health information should be of the highest quality and, where appropriate, collected as close as possible to the point of care
- health information should be collected once and used many times
- data collection should be 'fit for purpose' and cost-effective.⁽⁷⁾

2. Information Management Standards for National Health and Social Care Data Collections

In 2016 HIQA finalised *Information Management Standards for National Health and Social Care Data Collections*⁽⁸⁾, which are available from the HIQA website, www.hiqa.ie.

The primary purpose of these *Information management standards for national health and social care data collections* is to provide a roadmap to improve the quality of national health information and data, which will ultimately contribute to the delivery of safe and reliable health and social care. Compliance with these standards will help to instil confidence in patients, clinicians and all other stakeholders that healthcare decisions are made based on high-quality information, the availability of which will ultimately improve patient safety.

The *Information Management Standards for National Health and Social Care Data Collections* apply to national health and social care data collections in Ireland. It is expected that all national data collections will use the standards and self-assessment tool to improve their information management practices and work towards improving the quality of the information on which important decisions are based.

3. About the Self-Assessment Tool

HIQA has developed a self-assessment tool for national health and social care data collections based on the *Information Management Standards for National Health and Social Care Data Collections*. The tool is in the format of an interactive PDF questionnaire which can be easily filled out. The questions are aligned to the standards and cover the key components required for compliance to each standard.

HIQA has developed this self-assessment tool as a quality improvement initiative for national health and social care data collections. The tool will enable national health and social care data collections to determine the extent to which they are compliant with the *Information Management Standards*. The tool will highlight areas where action is required or where improvements may be made. The tool can be used by national collections to:

- measure performance against standards
- identify areas for improvement
- inform the development of an improvement action plan.

The tool is intended to be used as a quality improvement initiative for national health and social care data collections. Results should not be returned to HIQA unless this is specifically requested. The tool will enable national health and social care data collections to highlight areas of good practice and areas where improvement is needed. As the questions are aligned to the Information Management Standards, the tool will enable national data collections to identify where they meet the standards and where improvement is needed for compliance to the standards.

The *Information Management Standards for National Health and Social Care Data Collections* should be reviewed in advance of completing the self-assessment tool. A list of key terms has been prepared to assist in completing the self-assessment tool and this is documented in Appendix 1. A “roll-over” function has also been included within the self-assessment tool to provide an explanation of terms that people may not be familiar with. An up-to-date version of Adobe Reader will be needed to complete the tool.

4. Additional resources

HIQA has also published the following additional resources, available on the HIQA website www.hiqa.ie, which provide further information on many of the topics covered in the Self-assessment Tool:

- International Review of National Health and Social Care Data Collections⁽⁹⁾
- Catalogue of National Health and Social Care Data Collections in Ireland⁽¹⁰⁾
- Guiding Principles for Health and Social Care Data Collections⁽⁷⁾
- Guidance on Privacy Impact Assessment in Health and Social Care⁽¹¹⁾
- Guidance on Information Governance for health and social care services in Ireland⁽¹²⁾
- Guidance on Classification and Terminology Standards for Ireland⁽¹³⁾
- National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland⁽¹⁴⁾

5. Self-assessment questions

Theme 1: Person-centred

Standard 1 – The managing organisation of the national health and social care data collection has effective arrangements in place to protect the privacy of people about whom it holds information.

1.1	Has a privacy and confidentiality policy been developed and implemented for the national data collection?	Yes	No
1.2	Is a Statement of Information Practices in place for the national data collection? If no skip to Question 1.6	Yes	No
1.3	If yes, is the Statement of Information Practices publicly available?	Yes	No
1.4	Please provide a URL to the Statement of Information Practices:		

<p>1.5</p>	<p>Does the Statement of Information Practices clearly outline:</p> <p>What information is collected</p> <p>How the information is used</p> <p>With whom the information is shared</p> <p>The purpose of sharing the information</p> <p>The safeguards that are in place to protect the information</p> <p>The process for obtaining consent</p> <p>How data subjects access information held about them</p> <p>The procedure for making a complaint</p>	<p>Yes</p>	<p>No</p>
<p>1.6</p>	<p>If a Statement of Information Practices is <u>not</u> in place, please outline what arrangements are in place to protect the privacy of people about whom the national data collection holds information:</p>		
<p>1.7</p>	<p>Has a Privacy Impact Assessment (PIA) ever been conducted for the national data collection?</p> <p>If no skip to Question 1.9</p>	<p>Yes</p>	<p>No</p>
<p>1.8</p>	<p>If yes, please select the situation(s) for which PIAs have been conducted:</p> <p>Establishment of the national data collection?</p> <p>Major revision of the national data collection?</p> <p>Other? Please specify:</p>		
<p>1.9</p>	<p>Please describe the process by which individuals are uniquely identified:</p>		

1.10	Are provisions in place to incorporate the Individual Health Identifier (IHI), once it has been implemented?	Yes	No
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Please insert any additional comments or clarifications in relation to Standard 1 with reference to the relevant section number:

Theme 2: Governance, leadership and management

Standard 2 – The managing organisation of the national health and social care data collection has effective governance, leadership and management arrangements in place, with clear lines of accountability to ensure that its objectives are met.

2.1	Is there an identified individual with overall executive accountability for the national data collection?	Yes	No
2.2	Please provide details:		
2.3	Does the national data collection have an oversight committee or board? If no, skip to Question 2.7	Yes	No
2.4	If yes, how often did the oversight committee or board meet during the last 12 months?		
2.5	Have terms of reference been developed for the oversight committee or board?	Yes	No
2.6	Are minutes recorded for the meetings of the oversight committee or board?	Yes	No
2.7	Does the national data collection have a management team? If no, skip to Question 2.10	Yes	No
2.8	If yes, how often did the management team meet during the last 12 months?		
2.9	If yes, are minutes recorded for the meetings of the management team?	Yes	No
2.10	Has a strategic or corporate plan been published by the national data collection?	Yes	No

2.11	If yes, what is the date of the most recent strategic plan?		
2.12	Is an operational or business plan regularly published by the national data collection?	Yes	No
2.13	If yes, what is the date of the most recent operational plan?		
2.14	Are governance structures and lines of responsibility and accountability clearly communicated to all staff?	Yes	No
2.15	Are formalised agreements with data providers currently in place?	Yes	No
2.16	<p>If yes, what forms do the agreements take? (select all that apply)</p> <p>Service Level Agreements (SLA)</p> <p>Memoranda of Understanding (MOU)</p> <p>Other agreements Please specify:</p>		
2.17	<p>Are processes in place to measure and report on the performance and effectiveness of the national data collection? (For example Key Performance Indicators)</p> <p>At the level of the national data collection?</p> <p>At the level of the managing organisation?</p>	Yes	No
2.18	If yes, are reports published outlining the performance and effectiveness of the national data collection?	Yes	No
2.19	Is risk assessment routinely conducted by the national data collection?	Yes	No
2.20	<p>Is a risk register in place:</p> <p>At the level of the national data collection?</p> <p>At the level of the managing organisation?</p>	Yes	No

2.21	Are processes in place to capture positive and negative feedback, including formal complaints?	Yes	No
2.22	Please provide details:		

Please insert any additional comments or clarifications in relation to Standard 2 with reference to the relevant section number:

Empty box for additional comments or clarifications.

Standard 3 – The managing organisation maintains a publicly available statement of purpose that accurately describes the aims and objectives of the national health and social care data collection.

3.1	Does the national data collection have a publicly available statement of purpose ?	Yes	No
3.2	Is a process in place to review the statement of purpose to ensure it accurately describes the aims and objectives of the national data collection?	Yes	No
3.3	If yes, how often is the statement of purpose reviewed?		

Please insert any additional comments or clarifications in relation to Standard 3 with reference to the relevant section number:

Standard 4 – The managing organisation of the national health and social care data collection is compliant with relevant legislation and codes of practice.

4.1	What processes are in place to demonstrate how the national data collection is compliant with relevant legislation and codes of practice?		
4.2	Are risk assessments conducted to identify gaps in compliance to relevant legislation and codes of practice?	Yes	No
4.3	Are regular reviews of current and forthcoming legislation and codes of practice, relevant to the national data collection, conducted?	Yes	No
4.4	Is training provided to staff on legislation and codes of practice relevant to the national data collection?	Yes	No
4.5	<p>If yes, is this training:</p> <p>Once-off (for example as part of induction)?</p> <p>Carried out on an annual basis?</p> <p>Ongoing or refresher?</p> <p>Please specify frequency:</p>		

Please insert any additional comments or clarifications in relation to Standard 4 with reference to the relevant section number:

Theme 3: Use of Information

Standard 5 – The managing organisation of the national health and social care data collection complies with health information standards and nationally agreed definitions to enable comparability and sharing of information.

5.1	Are health information standards (for example, standards for interoperability or messaging) in use within the national data collection?	Yes	No
5.2	Please provide details:		
5.3	Are clinical terminologies and classification systems (for example ICD-10 or SNOMED-CT) in use within the national data collection?	Yes	No
5.4	Please provide details:		
5.5	Is a data dictionary in use within the national data collection?	Yes	No
5.6	If yes, is the data dictionary: Compliant with national and international definitions? Version controlled? Publicly available?	Yes	No
5.7	Please provide a link to the data dictionary, if available online:		
5.8	How often is the data dictionary updated?		

Please insert any additional comments or clarifications in relation to Standard 5 with reference to the relevant section number:

Standard 6 – The managing organisation of the national health and social care data collection systematically assesses, monitors and improves the quality of the data it holds to ensure its objectives are met.

6.1	Is there an identified individual with overall responsibility for all aspects of data quality in the national data collection?	Yes	No
6.2	Please provide details:		
6.3	Is a Data Quality Framework in place which outlines the approaches used by the national data collection to systematically assess, document and improve data quality?	Yes	No
6.4	If yes, please outline the key components of the Data Quality Framework:		
6.5	Are policies and procedures in place in relation to data quality? If no skip to Question 6.8	Yes	No
6.6	If yes, how often are these policies reviewed?		
6.7	Do the policies address the following dimensions of data quality: Accuracy Completeness Legibility Relevance Reliability Timeliness Validity	Yes	No

6.8	<p>Are Key Performance Indicators (KPIs) or metrics in relation to data quality defined and used:</p> <p>At the level of the national data collection?</p> <p>At the level of the managing organisation?</p>	Yes	No
6.9	<p>Are data quality audits conducted by the national data collection?</p> <p>Internally?</p> <p>Externally?</p>	Yes	No
6.10	<p>If yes, how often are data quality audits conducted?</p> <p>Frequency of internal audits:</p> <p>Frequency of external audits:</p>		
6.11	Are data quality improvement initiatives undertaken?	Yes	No
6.12	Please provide details:		
6.13	Is data quality training provided to staff?	Yes	No
6.14	<p>If yes, is this training:</p> <p>Once-off (for example as part of induction)?</p> <p>Carried out on an annual basis?</p> <p>Ongoing or refresher?</p> <p>Please specify frequency:</p>		
6.15	Is collaboration with data providers and other key stakeholders undertaken to promote data quality?	Yes	No

6.16	If yes, please indicate if any of the following activities are undertaken to improve data quality: (select all that apply) Data validation with external providers Benchmarking Peer-review Participation in national or international committees Other Please specify:		
6.17	Is ICT used effectively to support data quality initiatives?	Yes	No
6.18	Please provide details:		

Please insert any additional comments or clarifications in relation to Standard 6 with reference to the relevant section number:

Standard 7 – The managing organisation of the national health and social care data collection disseminates data and information appropriately and ensures that data users can access data and information in a timely manner to meet their needs.

7.1	<p>What methods are used to promote and disseminate data and information from the national data collection? (select all that apply)</p> <p>Data reports or publications</p> <p>Website</p> <p>Mobile app</p> <p>Social media</p> <p>Media campaign</p> <p>Information leaflet</p> <p>Other Please specify:</p>		
7.2	<p>How is access to data facilitated from the national data collection? (select all that apply)</p> <p>Interactive data manipulation tools</p> <p>Online data portal</p> <p>Customised data requests</p> <p>Other Please specify:</p>		
7.3	<p>Is data from the national data collection published on Ireland’s Open Data portal?</p>	Yes	No
7.4	<p>Is usage of data and information from the national data collection monitored to ensure that the needs of data users are being met?</p>	Yes	No

7.5	Please provide details:		
7.6	How many specific data requests did the national data collection receive during the last 12 months?		
7.7	How does the national data collection gather information on the present and future needs of data users?		
7.8	Are policies and procedures in place for data users in relation to the process of requesting and accessing data?	Yes	No
7.9	Please provide details:		
7.10	<p>Please indicate the main categories of individuals who request and use data from the national data collection (select all that apply):</p> <p>Healthcare professionals</p> <p>Public sector staff</p> <p>Researchers</p> <p>Other national data collections</p> <p>European or international collaborators</p> <p>Media</p> <p>Commercial enterprises</p> <p>General public</p> <p>Other Please specify:</p>	Yes	No

7.11	Is a performance indicator in place to ensure that specific data requests are responded to in a timely way?	Yes	No
7.12	Please provide details:		
7.13	Is training available to data users to support them in accessing and using data and information from the national data collection?	Yes	No
7.14	Please provide details:		
7.15	Is explanatory information or guidance provided to facilitate accurate interpretation of data and information?	Yes	No
7.16	Please provide details:		
7.17	Is a Data Quality Statement provided with each published output?	Yes	No
7.18	Under what circumstances are data and information not released from the national data collection?		
7.19	Are all releases of published data and information clearly identified as being provisional, final or revised?	Yes	No
7.20	Does the national data collection release an annual calendar identifying intended dates for the publication of reports and datasets?	Yes	No

Please insert any additional comments or clarifications in relation to Standard 7 with reference to the relevant section number:

Theme 4: Information Governance

Standard 8 – The managing organisation of the national health and social care data collection has effective arrangements in place for information governance which ensure that personal information is handled legally and securely.

8.1	Is there an identified individual responsible for Information Governance within the national data collection?	Yes	No
8.2	Please provide details:		
8.3	Is there an appointed Data Protection Officer , with designated responsibilities for information governance, in the managing organisation of the national data collection?	Yes	No
8.4	How are individual staff made aware of their responsibilities in relation to information governance?		
8.5	What arrangements are in place to manage information governance risks?		
8.6	What arrangements are in place that allow the national data collection to demonstrate compliance with relevant information governance legislation and standards?		
8.7	Does the national data collection have up-to-date policies and procedures in place for all aspects of information governance?	Yes	No

8.8	<p>If yes, do the information governance policies and procedures cover the following areas:</p> <p>Privacy and confidentiality</p> <p>Data protection</p> <p>Freedom of Information (FoI)</p> <p>Information security and breaches</p> <p>Data retention and destruction</p> <p>Sharing of information</p> <p>Disaster recovery</p>	Yes	No	
8.9	How often are information governance policies and procedures reviewed?			
8.10	How are staff made aware of information governance policies and procedures?			
8.11	Is access to identifiable health information only available to those who need it?	Yes	No	N/A
8.12	Are procedures in place outlining the terms and conditions for data requests to ensure the protection of data subjects' personal data and information?	Yes	No	
8.13	Are information governance risks thoroughly investigated?	Yes	No	
8.14	Is there an audit trail in place to track access to data subjects' personal data and information?	Yes	No	
8.15	Please provide details:			
8.16	<p>Are information governance audits conducted?</p> <p>Internal</p> <p>External</p>	Yes	No	

<p>8.17</p>	<p>How often are information governance audits conducted?</p> <p>Frequency of internal audits:</p> <p>Frequency of external audits:</p>		
<p>8.18</p>	<p>Is training provided for staff on information governance?</p>	<p>Yes</p>	<p>No</p>
<p>8.19</p>	<p>If yes, is this training:</p> <p>Once-off (for example as part of induction)?</p> <p>Carried out on an annual basis?</p> <p>Ongoing or refresher?</p> <p>Please specify frequency:</p>		
<p>8.20</p>	<p>Is data from the national data collection shared with other national data collections?</p>	<p>Yes</p>	<p>No</p>
<p>8.21</p>	<p>If yes, how does the national data collection ensure that data is shared in a timely and secure way, in line with legislation and best available evidence?</p>		

Please insert any additional comments or clarifications in relation to Standard 8 with reference to the relevant section number:

Theme 5: Workforce

Standard 9 – The managing organisation of the national health and social care data collection plans, organises and develops its workforce to effectively deliver its objectives.

9.1	Is strategic workforce planning, including succession planning, undertaken by the national data collection?	Yes	No	
9.2	If yes, please indicate the year in which the strategic workforce planning exercise was last conducted?			
9.3	<p>Does the national data collection have the required expertise to deliver its objectives in the following areas:</p> <p>Data quality</p> <p>Data analysis</p> <p>Statistics or biostatistics</p> <p>Information governance</p> <p>Data protection</p> <p>Information and communications technology</p> <p>Research</p> <p>Bioethics</p> <p>Coding, classifications and terminologies</p> <p>Other Please specify:</p>	Yes	No	N/A
9.4	Is a training needs analysis conducted for the workforce of the national data collection?	Yes	No	

9.5	If yes, please indicate the year in which a training needs analysis was last carried out:		
9.6	Are training, education and development programmes regularly reviewed and evaluated?	Yes	No
9.7	Is the workforce supported to provide feedback to drive continual improvement?	Yes	No

Please insert any additional comments or clarifications in relation to Standard 9 with reference to the relevant section number:

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Theme 6: Use of Resources

Standard 10 – The managing organisation of the national health and social care data collection plans and manages the allocation and use of resources to ensure its objectives are met.

10.1	Is the use of resources included as part of the strategic and operational planning processes of the national data collection?	Yes	No
10.2	Are resource decisions of the national data collection transparent and in line with national policy?	Yes	No
10.3	Is an ICT system in use by the national data collection that is fit-for-purpose and in line with national ICT policy?	Yes	No
10.4	Please describe how resource decisions are made to ensure the objectives of the national data collection are met:		

Please insert any additional comments or clarifications in relation to Standard 10 with reference to the relevant section number:

Planned future developments

Any planned future developments which would support the national data collection to ensure compliance with the standards can be outlined here:

Additional comments

Please insert any additional overall comments:

Appendices

Appendix 1 – Key terms for completing the Self-Assessment Tool

Clinical terminologies	Classification systems provide a uniform, meaningful and relevant framework that is used as a common language. Example, ICD-10.
Classification systems	Clinical terminologies are a structured collection of descriptive terms for use in clinical practice. Example, SNOMED-CT.
Data dictionary	A descriptive list of names (also called representations or displays), definitions, and attributes of data elements to be collected in an information system or database. The purpose of the data dictionary is to standardise definitions and therefore have consistency in the collection of data.
Data Protection Officer	The forthcoming European General Data Protection Regulation sets out the requirements for the designation of a data protection officer.
Data Quality	The quality of data can be determined through assessment against a number of dimensions which include accuracy, completeness, legibility, relevance, reliability, timeliness and validity.
Data Quality Framework	A data quality framework outlines the approaches to systematically assess, document and improve data quality and includes data quality policies and procedures; key performance indicators and metrics; audits; and improvement initiatives.
Data Quality Statement	A data quality statement is a document prepared to accompany each published output from the national data collection highlighting the dimensions of data quality, including strengths and weaknesses.
Formalised Agreements	Formalised agreements between the national health and social care data collection and data providers outline the responsibilities and deliverables of both parties and the associated timelines. This could take the form of either a contractual service level agreement (SLA) or a memorandum of understanding (MoU).
Health Information Standards	Health Information Standards support interoperability between systems and meaningful sharing of data. These include data definitions, clinical concepts and terminologies, coding and classifications, messaging specifications, the Electronic Health Record, and security.
Individual Health Identifier	Individuals are identified uniquely within the national health and social care data collection to avoid duplication and misidentification in

line with national standards and best practice. Once implemented, the individual health identifier (IHI) is used routinely to uniquely identify individuals within the national health and social care data collection.

Ireland's Open Data Portal

Ireland's Open Data Portal (data.gov.ie) provides access to official data in an open format. The portal was launched in 2014 and is operated by the Department of Public Expenditure and Reform.

Key Performance Indicators (KPIs)

Key Performance Indicators are specific and measurable elements of practice that are designed to assess key aspects of structures and processes and to assess outcomes that may be correlated with the quality of data delivered by the national data collection. They may also be called "metrics" or "quality metrics".

Oversight committee or board

An oversight committee or board develop the strategic direction and ensures that the mission and values are upheld.

Privacy Impact Assessments

A process designed to identify and address the privacy issues of a particular initiative. It considers the future consequences of a current or proposed action by identifying any potential privacy risks and then examining ways to mitigate or avoid those risks that have been identified.

Risk assessment

The term "risk assessment" is used to describe the overall process of risk analysis and risk evaluation.

Risk register

A risk register can be described as a mechanism for capturing and maintaining information on all identified risks relating to a specific objective.

Statement of Information Practices

A document made available to service users that sets out what information the service collects; how it is used; with whom it is shared and for what purpose; the safeguards that are in place to protect it; and how service users can access information held about them.

Statement of Purpose

A statement of purpose is a publically available document which succinctly captures why the national health and social care data collection exists and clearly outlines its overall function and stated objectives. It may also outline the name of the managing organisation and governance arrangements, the year of commencement, the target population, funding arrangements and legislation that it must adhere to.

Appendix 2 – Improvement Plan template for national data collections

To be used as a quality improvement tool based on the national data collections' findings of the Self-Assessment Tool

Standard number	Improvement required	Action planned	Role of person responsible	Timeframe	Status
1 [*]	Statement of Information Practices is not complete or publicly available	Ensure content of the Statement of Information Practices contains all elements listed in 1.4 of the SAT and it is suitable to be shared publicly	Lead for Information Governance	2 weeks from 07/03/2017	Ongoing

* This is an example of how the improvement plan template may be completed

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