Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Guide to the Health Information and Quality Authority's review of information management practices in national health and social care data collections

Version 1.1

February 2019

Version Control

This table shows the version history for the Quality Assurance Framework document.

Date	Version	Change
March 2017	1.0	First draft
February 2019	1.1	Revision of methodology for assessment of compliance in relation to updated AMA II policy and procedures.

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

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

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.

- **Regulating social care services** — The Office of the Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.

- **Regulating health services —** Regulating medical exposure to ionising radiation.

- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.

- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.

- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.

- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

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. It can also 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.

Contents

About the Health Information and Quality Authority 3

Overview of the Health Information function of HIQA 4

1. Document outline 7

2. Introduction 7

3. Review programme 8

4. Contact details 12

Appendix 1 — Self-assessment tool 13

Appendix 2 — Key terms for completing the self-assessment tool 30

Appendix 3 — Quality improvement plan template 32

References 33

1. Document outline

This guide provides an overview of HIQA's review programme to assess compliance with the *Information management standards for national health and social care data collections* (referred to occasionally in this guide as the Information Management Standards).

This guide also explains the five main stages involved in the review process:

1. Self-assessment tool (questionnaire to assess compliance with the Information Management Standards)
2. Information request
3. On-site assessment
4. Report writing and recommendations
5. Quality improvement plan

It also provides information on elements of the review programme, including how the findings will be summarised, the publication of reports and the expected response from managing organisations.

2. Introduction

Accurate, relevant and timely data is essential in order to improve health and social care, inform decision-making, monitor diseases, organise services, inform policy-making, conduct high-quality research, and plan for future health and social care needs, both at national and local levels. Accordingly, a large amount of data is collected about health and social care services in Ireland.

National health and social care data collections are national repositories 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. There is little point in investing considerable time, effort and resources into producing a high-quality data collection if the data is not used to the maximum benefit of the population it serves. Therefore, it is essential to promote, encourage and facilitate the use of the data.

Under the Health Act 2007(1) and subsequent amendments to the Act, HIQA has a statutory remit to set standards for the Health Service Executive (HSE), the Child and

Family Agency (Tusla) and service providers and to assess compliance with those standards.

The *National Standards for Safer Better Healthcare*, published in 2012, describe a vision for quality and safety in healthcare which includes the use of accurate and timely information to promote effectiveness and drive improvements.(2) One of the eight themes, 'Use of Information', emphasises the critical importance of actively using information as a resource for planning, delivering, monitoring, managing and improving care. These nationally mandated standards apply to all healthcare services (excluding mental health) provided or funded by the HSE.

In February 2017, HIQA published *Information management standards for national health and social care data collections.*(3) The purpose of these Information Management Standards is to improve the quality of national health information, which will contribute to the delivery of safe and reliable healthcare. The standards provide a framework of best practice in the collection of health and social care data. The *Information management standards for national health and social care data collections* therefore complement the *National Standards for Safer Better Healthcare.* Collectively, these standards provide a roadmap to improving the quality of health information and data, which will ultimately contribute to the delivery of safe and reliable healthcare.

The standards are outcome-based and provide a specific outcome for the managing organisation of the national health and social care data collection to meet.

HIQA has developed a structured programme of assessing compliance with the Information Management Standards. In 2017, HIQA began a review to assess compliance with these standards. The review programme is being implemented on a phased basis, and HIQA will continue to engage with national data collections throughout the review programme.

3. Review programme

HIQA has developed a structured programme to assess compliance with the *Information management standards for national health and social care data collections* within its legislative remit.

The aim of this review programme is to:

- determine the information management practices of the individual national data collections
- identify areas of good practice and areas where improvements are necessary
- work with the national data collections to achieve compliance with the standards, ultimately improving the quality and maximising the use of national health information.

This guide outlines the way in which HIQA reviews national data collections against the Information Management Standards in order to assess the level of compliance. A framework has also been prepared to support HIQA staff when gathering evidence and reaching decisions in relation to compliance with the standards. The framework promotes consistent evidence-based assessment and judgment through the use of standardised processes.

3.1 Initial phase of the review programme

Due to the large number of national data collections, the review programme is being carried out using a phased approach. National data collections that were included in the first phase of this review programme were determined by considering the following prioritisation criteria:

- quality and safety impact — such as the contribution of the national data collection to the quality and safety of health and social care services
- policy impact — such as the potential of the national data collection to inform planning and funding of services and to impact on the healthcare agenda
- other operational factors which may impact on the review programme.

3.2 Designated contact person

Each national data collection included in the first phase of the review programme is asked to identify the responsible individual who will be the designated contact person for the review programme. This individual is responsible for:

- returning the completed self-assessment
- being the contact person for the information request and ensuring it is returned
- liaising with HIQA in relation to the on-site assessment and the report of the findings of the review.

3.3 The main steps of the review programme

The five main steps of the review programme are illustrated here:

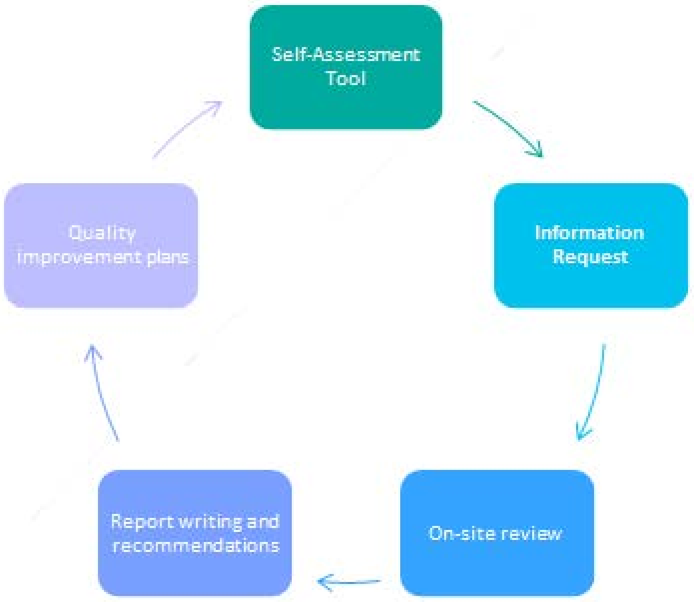

Figure 1: The five main steps of the review programme

Step 1: Self-assessment tool

The self-assessment tool is a questionnaire that will enable national health and social care data collections to determine the extent of their compliance with the Information Management Standards. The tool will highlight areas where action is required and where improvements can be made.

As an initial step, the self-assessment tool — which is an interactive PDF questionnaire — will be circulated to all national collections in the first phase of the review programme. A list of key terms has been prepared to assist national data collections in completing the self-assessment tool and is provided in Appendix 2 of this guide. The tool can be used by national collections to:

- measure performance against the Information Management Standards
- identify areas for improvement
- inform the development of an improvement action plan
- review progress towards meeting the standards
- prepare for an on-site assessment.

The designated contact person will be requested to complete and return the self-assessment tool within 15 working days of receiving it.

The completed self-assessment questionnaires will allow HIQA to determine each national data collection's information management practices. The information provided will inform the review process for each individual collection. For example, it may highlight areas where additional information will be requested as part of the next stage of the process or highlight an area that the review team may observe as part of the on-site assessment.

Once national data collections have completed the self-assessment tool, they should prepare an improvement plan to address any deficiencies that they may have identified. A proposed improvement plan template is provided in Appendix 3 of this guide. Improvement plans are not to be submitted with the completed self-assessment tool; however, evidence of an improvement plan may be requested at a later stage in the review process, for example, during the on-site assessment.

Step 2: Information request

Following review of the completed self-assessment tool, HIQA may request additional information from the national data collection. HIQA will contact the designated contact person to request that any information required be submitted to HIQA within 15 working days of the request. The information request will be informed by the self-assessment and will then inform the on-site assessment.

Step 3: On-site assessment

There are three aspects to the on-site assessment:

- documentation review
- observation
- interviews with staff members.

Each of these aspects will be informed by the self-assessment tool and the information request. The following information about the on-site assessment will be provided to the national data collection:

- the documentation that HIQA will request to see during the on-site assessment
- a list of the staff members to be interviewed on the day
- specific systems or processes to be observed on the day

- the names of the HIQA staff members who will carry out the on-site assessment.

This will be provided in order to minimise disruption to the day-to-day work of the national data collection.

Step 4: Reports writing and recommendations

All information collected through the information request and on-site visits is analysed and a draft of the report of findings is developed. The report is sent to the head of the managing organisation of the national data collection for factual accuracy review. The managing organisation has 15 working days to send feedback to HIQA. Once the feedback is received, it will be considered in the preparation of the final report. The final report will be published on the HIQA website.

Step 5: Quality improvement plan

- Each managing organisation is responsible for preparing and implementing quality improvement plans to assure itself that the findings relating to areas for improvement are prioritised and implemented to comply with the Information Management Standards.
- In the event that the review team is concerned that there may be a breach of data protection legislation, it is the responsibility of the managing organisation to take appropriate remedial action and to notify the Office of the Data Protection Commissioner.
- Where opportunities for improvement have been identified by the review team, checks will be carried out during future reviews to ensure that the necessary improvements have been made.
- National data collections should continue to assess their compliance with the Information Management Standards between reviews by HIQA to assure themselves and the public that they are meeting the requirements of the standards.

4. Contact details

If you have any questions regarding the review programme, you can contact a member of our team by emailing datacollections@hiqa.ie or by calling (021) 240 9300.

Appendix 1 — Self-assessment tool

How to complete the self-assessment tool

The *Information management standards for national health and social care data collections* should be reviewed in advance of completing the self-assessment tool. HIQA has also published the following additional resources, available at 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* (4)
- *Catalogue of national health and social care data collections in ireland* (5)
- *Guiding Principles for Health and Social Care Data Collections* (6)
- *Guidance on Privacy Impact Assessment in health and social care* (7)
- *Guidance on information governance for health and social care services in ireland* (8)
- *Guidance on Classification and Terminology Standards for Ireland* (9)
- *National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland* (10)
- *Five quality improvement tools for national data collections* (11)
- *Guidance on a data quality framework for health and social care* (12)

A list of key terms has been prepared to assist national data collections in completing the self-assessment tool and this is provided in Appendix 2 of this guide. 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.

Self-assessment questions

The self-assessment tool will be distributed as an interactive PDF to be completed and returned, as requested by HIQA.

Please complete all questions below.

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 link to the Statement of Information Practices:		
1.5	Does the Statement of Information Practices clearly outline: ▪ What information is collected ▪ How the information is used ▪ With whom the information is shared ▪ The purpose of sharing the information ▪ The safeguards that are in place to protect the information ▪ The process for obtaining consent ▪ How data subjects access information held about them ▪ The procedure for making a complaint	Yes ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	No ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
1.6	If a Statement of Information Practices is not in place, please outline what arrangements are in place to protect the privacy of people about whom the national data collection holds information:		
1.7	Has a **Privacy Impact Assessment** (PIA) ever been conducted for the national data collection? *If no, skip to Question 1.9*	Yes ☐	No ☐

1.8	If yes, please select the situation(s) for which PIAs have been conducted: ▪ Establishment of the national data collection ☐ ▪ Major revision of the national data collection ☐ ▪ Other ☐ ▪ Please specify		
1.9	Please describe the process by which individuals are uniquely identified:		
1.10	Are provisions in place to incorporate the Individual Health Identifier (IHI), once it has been implemented?	Yes ☐	No ☐

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	If yes, what forms do the agreements take? (select all that apply) ▪ Service level agreements (SLA) ☐ ▪ Memoranda of Understanding (MoUs) ☐ ▪ Other agreements, Please specify ☐		

2.17	Are processes in place to measure and report on the performance and effectiveness of the national data collection (for example **Key Performance Indicators**)? ▪ At the level of the national data collection? ▪ At the level of the managing organisation?	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	Is a risk register in place: ▪ At the level of the national data collection? ▪ At the level of the managing organisation?	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:

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	If yes, is this training: ▪ Once-off (for example as part of induction)? ☐ ▪ Carried out on an annual basis? ☐ ▪ Ongoing or refresher? ☐ Please specify frequency		

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	Are **Key Performance Indicators** (KPIs) or metrics in relation to data quality defined and used: ▪ At the level of the national data collection? ▪ At the level of the managing organisation?	Yes ☐ ☐	No ☐ ☐
6.9	Are data quality audits conducted by the national data collection? ▪ Internally? ▪ Externally?	Yes ☐ ☐	No ☐ ☐
6.10	If yes, how often are data quality audits conducted? ▪ Frequency of internal audits: ▪ Frequency of external audits:		
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	If yes, is this training: ▪ Once-off (for example as part of induction)? ☐ ▪ Carried out on an annual basis? ☐ ▪ On-going or refresher? ☐ Please specify frequency:		
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	What methods are used to promote and disseminate data and information from the national data collection (select all that apply)? ▪ Data reports or publications ☐ ▪ Website ☐ ▪ Mobile app ☐ ▪ Social media ☐ ▪ Media campaign ☐ ▪ Information leaflet ☐ ▪ Other ☐ Please specify:		
7.2	How is access to data facilitated from the national data collection (select all that apply)? ▪ Interactive data manipulation tools ☐ ▪ Online data portal ☐ ▪ Customised data requests ☐ ▪ Other ☐ Please specify:		
7.3	Is data from the national data collection published on **Ireland's Open Data portal**?	Yes ☐	No ☐
7.4	Is usage of data and information from the national data collection monitored to ensure that the needs of data users are being met?	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?	Yes ☐	No ☐
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	Please indicate the main categories of individuals who request and use data from the national data collection (select all that apply): ▪ Healthcare professionals ▪ Public sector staff ▪ Researchers ▪ Other national data collections ▪ European or international collaborators ▪ Media ▪ Commercial enterprises	Yes ☐ ☐ ☐ ☐ ☐ ☐	No ☐ ☐ ☐ ☐ ☐ ☐

	- General public - Other Please specify:	☐ ☐	☐ ☐
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	If yes, do the information governance policies and procedures cover the following areas: ▪ Privacy and confidentiality ▪ Data protection ▪ Freedom of Information (FoI) ▪ Information security and breaches ▪ Data retention and destruction ▪ Sharing of information ▪ Disaster recovery		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	Are information governance audits conducted? ▪ Internal ▪ External	Yes ☐	No ☐
8.17	How often are information governance audits conducted? ▪ Frequency of internal audits: ▪ Frequency of external audits:		
8.18	Is training provided on information governance for staff?		
8.19	If yes, is this training: ▪ Once-off (for example as part of induction)? ☐ ▪ Carried out on an annual basis? ☐ ▪ Ongoing or refresher? ☐ Please specify frequency:		
8.20	Is data from the national data collection shared with other national data collections?	Yes ☐	No ☐
8.21	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?		

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	Does the national data collection have the required expertise to deliver its objectives in the following areas:	Yes	No	N/A
	- Data quality	☐	☐	☐
	- Data analysis	☐	☐	☐
	- Statistics or biostatistics	☐	☐	☐
	- Information governance	☐	☐	☐
	- Data protection	☐	☐	☐
	- Information and communications technology	☐	☐	☐
	- Research	☐	☐	☐
	- Bioethics	☐	☐	☐
	- Coding, classifications and terminologies	☐	☐	☐
	- Other	☐	☐	☐
	Please specify:	☐	☐	☐
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	Is evaluation of 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:

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 that 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 (including timelines for implementation) which would support the national data collection to ensure compliance with the standards can be outlined here.

Additional comments

Please insert any additional comments here:

Appendix 2 — Key terms

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 though 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 (IHI)	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 develops 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 publicly 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 3 — Quality improvement plan template

National data collections should prepare a quality improvement plan based on the findings of the national data collection's self-assessment.

Standard number	**Improvement required**	**Action planned**	**Role of person responsible**	**Time frame**	**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 you may fill out the template.

References

1. The Health Act 2007, (2007).

2. Health Information and Quality Authority. *National Standards for Safer Better Healthcare*. 2012. Available from: https://www.hiqa.ie/publications/national-standards-safer-better-healthcare. Accessed on: 12 September 2016.

3. Health Information and Quality Authority. *Information Management Standards for national health and social care data collections*. 2017. Available from: https://www.hiqa.ie/reports-and-publications/health-information/information-management-standards-national-health-and. Accessed.

4. Health Information and Quality Authority. *International Review of National Health and Social Care Data Collections* 2016. Available from: https://www.hiqa.ie/healthcare/health-information/data-collections. Accessed on: 12 September 2016.

5. Health Information and Quality Authority. *Catalogue of National Health and Social Care Data Collections*. 2014. Available from: https://www.hiqa.ie/publications/catalogue-national-health-and-social-care-data-collections. Accessed on: 1 June 2016.

6. Health Information and Quality Authority. *Guiding Principles for National Health and Social Care Data Collections*. 2013. Available from: https://www.hiqa.ie/publications/guiding-principles-national-health-and-social-care-data-collections. Accessed on: 12 September 2016.

7. Health Information and Quality Authority. *Guidance on Privacy Impact Assessment in Health and Social Care*. 2010. Available from: http://www.hiqa.ie/resource-centre/professionals/privacy-impact-assessments. Accessed on: 12 September 2016.

8. Health Information and Quality Authority. *Guidance on information governance for health and social care services in Ireland*. 2012. Available from: https://www.hiqa.ie/healthcare/health-information/information-governance. Accessed on: 12 September 2016.

9. Health Information and Quality Authority. *Guidance on Classification and Terminology Standards for Ireland*. 2013. Available from: https://www.hiqa.ie/publications/guidance-classification-and-terminology-standards-ireland. Accessed on: 12 September 2016.

10. *National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland*. Cork: Health Information and Quality Authority 2013.

Published by the Health Information and Quality Authority.

For further information please contact:

Health Information and Quality Authority
Dublin Regional Office
George’s Court
George’s Lane
Smithfield
Dublin 7
D07 E98Y

Phone: +353 (0) 1 814 7400

URL: www.hiqa.ie