



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# Developing eHealth interoperability standards for Ireland

## Statement of outcomes from the public consultation

November 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's ultimate aim is to safeguard people using services 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

Healthcare 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 imperative 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 a key 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, 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 the 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 drive 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 prevents the safe, effective, transfer of

information. This results in people using the service being asked to provide the same information on multiple occasions.

In Ireland, information can 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, understandable and trustworthy information on which to base our decisions.

As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice. A robust health information environment will allow all stakeholders, the general public, patients and service users, health professionals and policy-makers to make choices or decisions based on the best available information. This is a fundamental requirement for a high-reliability healthcare system.

Through its health information function, HIQA is addressing these issues and working to ensure that high-quality health and social care information is available to support the delivery, planning and monitoring of services.

One of the areas currently being addressed through this work programme is the need to set standards to enable information to be shared electronically, commonly referred to as interoperability standards. HIQA undertook a public consultation from 15 August to 22 September 2017 to allow key partners and interested parties to inform us of where they felt there was a need for technical interoperability standards. One of the main aims of the public consultation is to have a transparent process around seeking feedback from key partners and interested parties to inform our future programme of work. The purpose of this Statement of Outcomes document is to detail the feedback received during the public consultation process



## Contents

<b>1</b>	<b>Introduction</b>	<b>8</b>
<b>2</b>	<b>Analysis of submissions</b>	<b>11</b>
2.1	Thematic analysis	11
2.2	Standards	13
2.3	Messaging	17
2.4	General	19
2.5	ePrescribing	21
2.6	Electronic health records	23
2.7	Terminologies	26
2.8	Networking and Security	28
2.9	Metadata	30
2.10	Datasets	32
2.11	IHE Profiles	33
<b>3</b>	<b>Next steps</b>	<b>34</b>
	Appendix A – Terms of Reference for the eHealth Standards Advisory Group	35
	Appendix B – Contributing organisations	36
	Reference List	38

# 1 Introduction

Safe, reliable healthcare depends on access to, and use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. Ensuring that information can be shared efficiently and effectively and in a manner which protects the privacy and confidentiality of patients is critical.

The inability to share information leads to unnecessary duplication of tests and delays in patients receiving appropriate treatment. This can lead to potentially serious consequences which threaten both the safety and quality of care provided. Information should accompany the patient along the entire care pathway.

Internationally there is widespread investment in eHealth, broadly defined as the exploitation of information and communication technologies (ICT) in healthcare to improve the quality and safety of patient care. eHealth can enhance the quality, accessibility and efficiency across all healthcare services through the secure, timely, accurate and comprehensive exchange of clinical and administrative data, thereby offering a number of benefits including:

- better and safer care
- improved integration and sharing of health information to enable patient-centred integrated care
- more cost-effective delivery of healthcare
- more efficient national planning
- improved research through the provision of more timely and higher quality information
- increased patient safety through the reduction in medication errors brought about by ePrescribing
- more timely access by health professionals to the right medical information at the right time
- improved support for patient self-management.

Under the Health Act 2007, HIQA currently has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information. The responsibilities of HIQA in this regard are outlined in the following sections of the Act:

- **Section 8(1)(i):** to evaluate available information respecting the service and the health and welfare of the population

- **Section 8(1)(j)**: to provide advice and make recommendations to the Minister for Health and the Health Services Executive (HSE) about deficiencies identified by HIQA in respect of the information referred to in paragraph (i)
- **Section 8(1)(k)**: to set standards as HIQA considers appropriate for the HSE and service providers respecting data and information in their possession in relation to services and the health and welfare of the population
- **Section 8(1)(l)**: to advise the Minister for Health and the HSE as to the level of compliance by the HSE and service providers with the standards referred to in paragraph (k).

Under Section 8(1)(k) of the Health Act 2007, HIQA is charged with setting standards for health information. A subset of the standards developed by HIQA includes technical standards to support eHealth interoperability. Technical standards that have been developed by HIQA include:

- *National Standard for a Procedure Dataset including a Clinical Document Architecture specification* (January 2017)<sup>(1)</sup>
- *National Standards for Diagnosis Datasets and Clinical Document Architecture Templates 2016* (February 2016)<sup>(2)</sup>
- *National Standards for Adverse Reaction Datasets and Clinical Document Architecture Templates* (February 2016)<sup>(3)</sup>
- *National standard Demographic Dataset and Guidance for use in health and social care settings in Ireland* (February 2016)<sup>(4)</sup>
- *ePrescription dataset and clinical document architecture standard* (March 2015)<sup>(5)</sup>
- *National Standard for a Dispensing Note including a Clinical Document Architecture specification* (January 2017)<sup>(6)</sup>
- *Data model for an electronic medicinal product reference catalogue — a National Standard* (March 2015)<sup>(7)</sup>
- *General Practice Messaging Standards — Version 4* (October 2017)<sup>(8)\*</sup>
- *National Standard for Patient Discharge Summary Information* (August 2013)<sup>(9)</sup>

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\* Previous versions of the General Practice Messaging Specification published in 2010, 2011 and 2014 are available from HIQA on request

- *Report and Recommendations on Patient Referrals from General Practice to Outpatient and Radiology Services, including the National Standard for Patient Referral Information* (June 2011)<sup>(10)</sup>

In order to consult with stakeholders on the development of eHealth standards, HIQA published the *Developing National eHealth Interoperability Standards for Ireland: A Consultation Document*. This consultation document was developed in order to invite people to make submissions on the technical standards which HIQA should develop. Submissions to this consultation will help inform our next work plan in this area. Technical standards will be developed in conjunction with the eHealth Standards Advisory Group — a standards advisory group which has been established by HIQA to advise it when developing technical standards supporting eHealth interoperability. An extract of the terms of reference is available in Appendix A.

The consultation document was published on the HIQA website, [www.hiqa.ie](http://www.hiqa.ie), from 15 August to 22 September 2017. HIQA asked for feedback through an online survey and an online feedback form, both of which included two questions to prompt feedback.

Question 1: In the first instance, which area of work should be prioritised by the eHealth Standards Advisory Committee?

Question 2: Please provide us with any general comments you would like to make in relation to this consultation document.

In order to ensure as many interested parties as possible were given the opportunity to comment, if they wished, HIQA contacted 297 stakeholders directly, asking them to participate in the public consultation. The aim of this statement of outcomes report is to document the responses received.

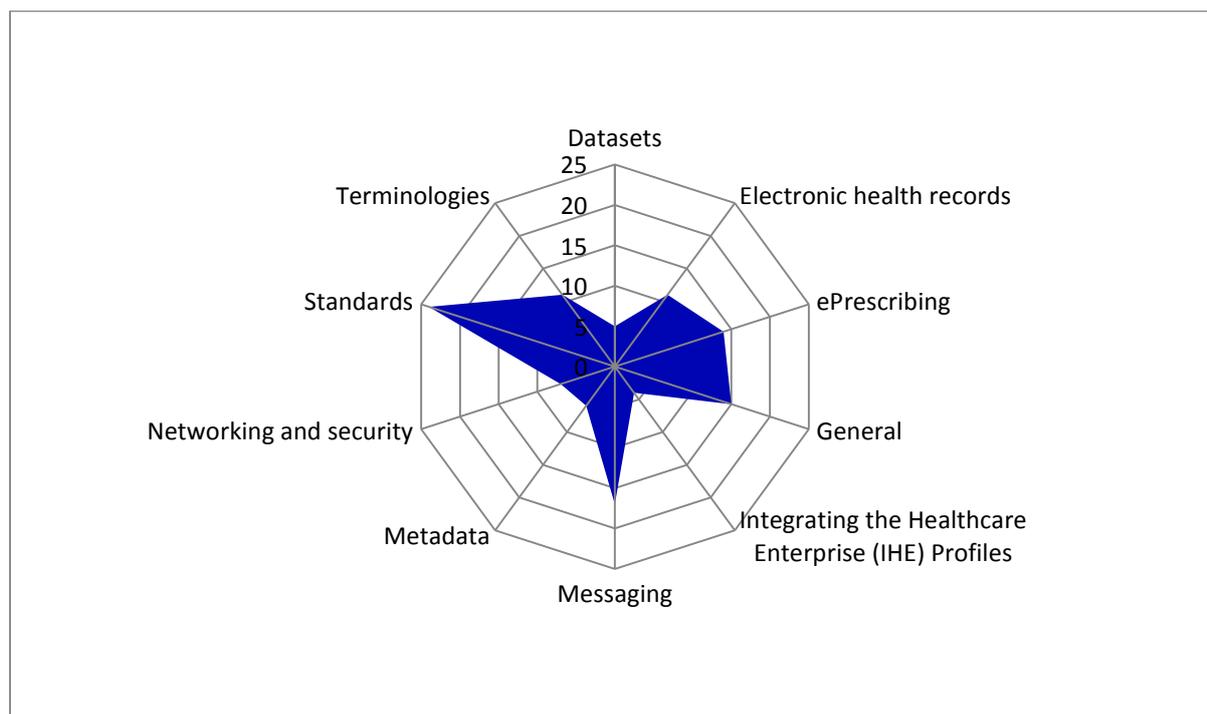
## 2 Analysis of submissions

HIQA received a total of 24 submissions — 20 submissions through the online survey and four submissions by email. Individuals made nine submissions while there were 5 submissions on behalf of organisations. Appendix B gives a full list of all the organisations that made submissions.

### 2.1 Thematic analysis

Each submission was read in its entirety and broken down into individual comments. This yielded a total of 117 comments, an average of just under five comments per submission. Each comment was then initially classified into one of 10 themes, which emerged from analysis of the submissions. Figure 1 below illustrates the number of comments per theme and Table 1 lists the number of comments by theme.

**Figure 1 - Number of comments by theme**



**Table 1 - Number of comments by theme**

<b>Theme</b>	<b>No. of comments</b>	<b>Theme</b>	<b>No. of comments</b>
<b>Standards</b>	24	<b>Terminologies</b>	11
<b>Messaging</b>	17	<b>Networking and security</b>	7
<b>General</b>	15	<b>Metadata</b>	6
<b>ePrescribing</b>	14	<b>Datasets</b>	5
<b>Electronic health records</b>	11	<b>Integrating the Healthcare Enterprise (IHE) profiles</b>	4

The following sections detail the comments received under each of the 10 themes above. For each theme a brief summary is provided at the start of the section and following this a sample of the comments provided by respondents are detailed in the What respondents said section. Please note that some corrections to punctuation and grammar have been made, where appropriate, to some of the submissions quoted in this report.

## 2.2 Standards

The most prevalent theme by far, Standards, was mentioned in 24 comments. Some respondents commended on HIQA's work done to date on interoperability standards and wanted it to continue. Others called for a review of compliance with these standards, to understand levels of adoption by service providers. Standards are seen as underpinning the development of an electronic health record in Ireland. Standards are also seen as supporting data sharing and information governance, as well as underpinning information architecture and the national data dictionary. Identifiers were also mentioned as an important aspect of standards.

Finally, respondents requested specialised standards relating to diverse areas, such as medical devices and instruments, apps, professional records, clinical safety and medical imaging. Figure 2 below illustrates the comments by area and Table 2 lists the number of comments by area.

**Chart 2 - Distribution of comments**

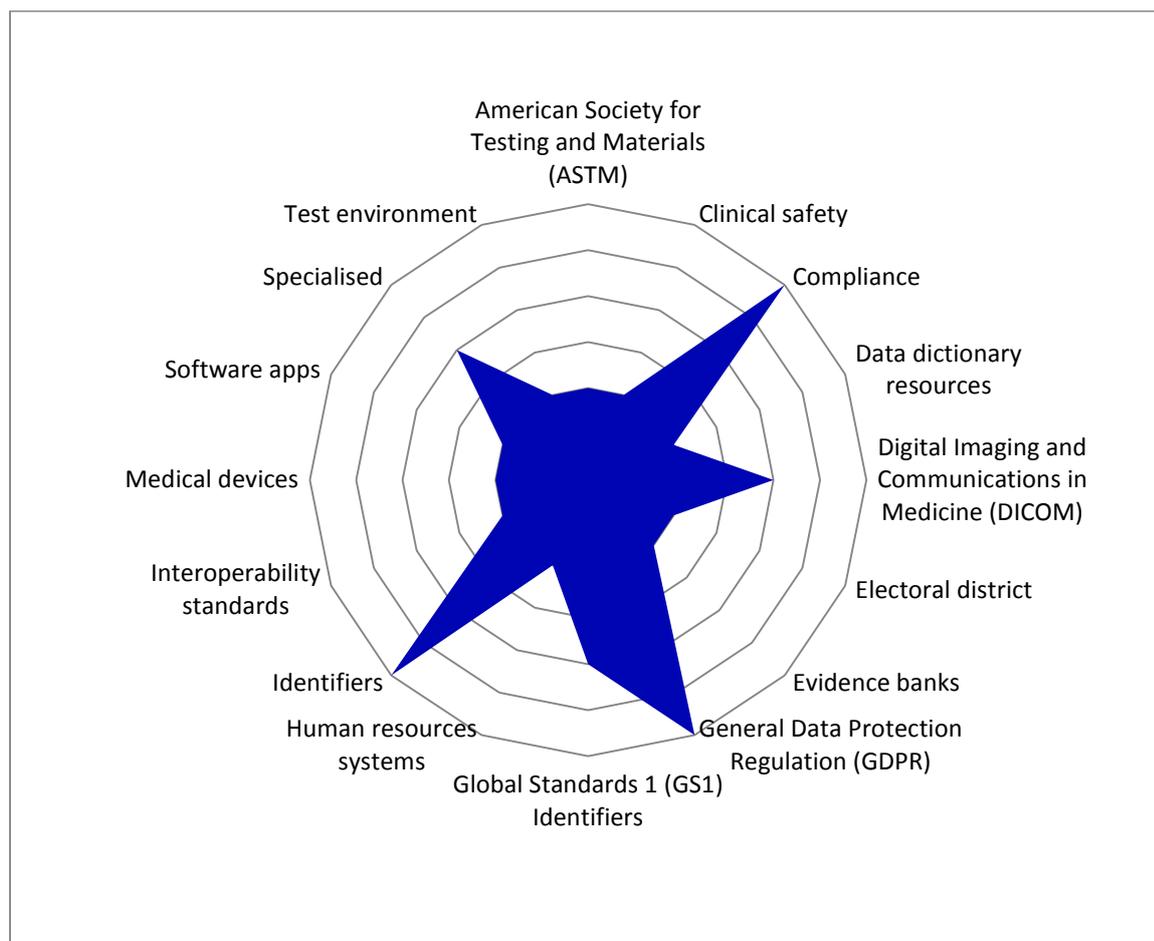


Table 2 - Number of comments per subcategory

Subcategory	Count	Subcategory	Count
American Society for Testing and Materials (ASTM)	1	Global Standards 1 identifiers	2
Clinical safety	1	Human resources systems	1
Compliance	3	Identifiers	3
Data dictionary resources	1	Interoperability standards	1
Digital Imaging and Communications in Medicine)	2	Medical devices	1
Electoral district	1	Software apps	1
Evidence banks	1	Specialised	2
General Data Protection Regulations (GDPR)	3	Test environment	1



What respondents said:

“eHRM [electronic Human Resource Management] development and implementation to support Workforce Planning and Development, ePerformance Achievement, and Talent Management.”

“Individual Health Identifier, Professional Health Identifier and Site Health Identifier are all critical to the successful delivery of integrated services and care that people need and want.”

“Identity — uniquely identifying patients using a common identifier and supporting standards.”

“In pharmacy, with the advent of GDPR [General Data Protection Regulation], there will be a specific requirement for data portability of dispensing records.”

“Digital Imaging and Communications in Medicine (DICOM) is the main standard used in PACS (picture archiving and communication systems), i.e. medical imaging such as radiology.”

“American Society for Testing and Materials (ASTM) publishes standards around clinical instrument integration.”

“To advance eHealth technical interoperability standards in Ireland, we recommend HIQA collaborates with the HSE's Enterprise Architecture team and CCIO [Council of Clinical Information Officers] community to develop an appropriate test environment for standards assurance.”

“The key to interoperability is the existence and use of unique identifiers (both at a personal and item level) across all relevant systems so that data can be more easily shared. This is less a matter of specific technology but rather getting the people concerned to use and adhere to these identity standards. The priority focus of the Committee should be the development of these identity standards and overseeing their correct and full implementation.”

“Tools for the collection of evidence relative to aspects of healthcare that should be audited routinely. Evidence banks — where service users can access recent evidence.”

“Consider a review and national evaluation of existing published and related standards. For example what is the uptake and use nationally of eHealth interoperability standards published since 2011?”

“Using GS1 standards facilitates interoperability between applications and technologies. Consider GS1 standards as one of the major international organisations involved in eHealth standards for a number of reasons.”

“Good work being done by HIQA but requires 'enforcement'. As mentioned there is a need for strategies to encourage uptake and compliance such as the 'meaningful use' initiatives developed in the US. Rewarding clinicians/hospitals who are compliant can generate pressure on vendors to comply.”

“Some client information is passed to external vendors for various aspects of client service (e.g. printing, SMS, website, etc.), this type of sharing also needs to be supported according to best practices.”

“We currently already use DICOM standards in our digital screening environment; any developments in medical imaging will require adoption of appropriate standards.”

“We also need to work with data providers to receive demographic client data that is up-to-date. The Breast Screening Programme and some of our other programmes use Electoral District in order to organise our operations so we need records that support the transmission and usage of this.”

“Welcome views of where HIQA and eSAG should be targeted. Recommend ... compliance with published standards. An evaluation of the published standards and guidance documents within HSE and associated stakeholder groups previously published and listed on page 9. This is critical to facilitate education, training and support of data stewards’ function nationally.”

“Standards and guidance should also be provided for assured technical interoperability and safety for professional records, software apps, medical devices, and clinical safety.”

“We welcome the reference of a clear and pressing need to develop a coherent approach to a health information collection based on standards and international best practice. Recommend ... additional resources for development of Information Architecture (IA) to progress the establishment of the following resources National Data Dictionary.”

“Recommend the development and release of guidelines for the implementation of GDPR in the context of ehealth technical interoperability.”

## 2.3 Messaging

Seventeen comments related to messaging. Some comments asked that work continue in this area, with one suggesting expansion into areas like eConsent. Respondents also asked for additional work related to current standards, including HL7 versions 2 and 3, and Clinical Document Architecture (CDA). Some comments covered lower level functionality such as the ability to store and trace messages, while others mentioned extending the standards to support medical imaging or smart devices. Finally, several respondents cited the need to monitor emerging standards such as Fast Healthcare Interoperability Resources (FHIR).



"eMessaging — further development and implementation e.g. eConsent."

"Work on structured messaging should continue."

"The most utilised messaging standard in Ireland is HL7v2. HL7v3 / FHIR would be obvious messaging standards for adoption consideration. Perhaps Ireland [could] look to adopt the HL7/FHIR standard rather than/or along with OpenEHR?"

"Fast Health Interoperable Resources (FHIR) is a new and emerging standard from HL7 that also has backing from IHE. Fast Healthcare Interoperability Resources (FHIR). There is varying current support for FHIR in most Integration and

Interoperability platforms, but the selected platform must be committed to supporting the FHIR standard and be actively adding support to the product.”

“While discharge standards are in place and some of the discharges we receive are now standardized these need to move to Healthlink so that they can be easily integrated in to the PMS patient record.”

“Laboratory Messaging — I presume this is covered through MedLis but we still experience problems with changed message standards from the lab.”

“They also need to have a CDA defined for hospital to GP messaging.”

“We currently already use HL7 standards in our digital screening environment; any developments in medical imaging will require adoption of appropriate standards.”

“For example recommending engagement with well-defined IHE profiles such as formatting of messaging standard HL7 v3 CDA level 1 and 3.”

“The use of HL7 for example to facilitate messaging between clinical systems and more and more smart devices on which clinicians rely.”

“It is appreciated that HIQA needs to work with established international standards, but there needs to be a way of supporting emerging standards, such as FHIR, within the Irish health services.”

## 2.4 General

Fifteen comments of a general nature were received. A number of respondents expressed appreciation of the work undertaken and of the document itself. Others reiterated how important the development of national standards is to ensure the quality of healthcare delivered. Respondents also made some general suggestions about how to improve quality and efficiency.



"Recent events have highlighted dangers in perceived 'back door' sharing of citizen data across government. This will be challenged through EU legislation if not done properly. Health data is particularly sensitive. Standards/legislation/consultation around health data sharing needs to be looked at again as a priority to ensure it is watertight otherwise it has potential to be a disaster for eHealth Ireland."

"Make the users and work flow the centre of the plan and work outwards. Make the system suit the user. People with Healthcare informatics backgrounds are trained to look at healthcare workflows, user needs and how standards can be used to build a successful linked system....Will future EMRs be able to link the current MEDLIS system with the current NIMIS with the next proposed linked system? Do business processes within each system or data protection issues affect how each system interoperates? Knowing what is out there, what is on the pipeline, what has worked elsewhere and how or if those systems can be integrated into the culture of the workplace should be the priority."

"Firstly the Standards Advisory Committee should know what systems are being used currently in this country. This is a huge task; however, this should currently be documented anyway with the advent of the Data Protection Act being enacted in April 2018. All institutions holding healthcare data/information should have documentation of systems in use. Once the 'big picture' of system commonality... is determined then linkages of systems can be looked at."

"The adoption of open source and other non-proprietary standards to allow for open competition to improve quality and reduce long term reliance through single vendor solutions. The need for wide interoperability between historically 'silo' systems in

order to allow seamless flow of secure information. Mitigating the increasing risks of having multiple digital systems passing data between each other.”

“Researchers and data scientists should be considered in any work undertaken as such standards will improve data quality and help to facilitate access, sharing and linkage of data for research/secondary analysis.”

“I think a priority area for EHR rests in communication on the ground at the hospitals i.e. staff that record the information collected at all stages of a patient pathway. Testing of extracted information from the hospital systems is important to ensure the completeness of all EHRs. If information is not collected on a system, an EHR will limit the information collected when moving from paper to EHRs.”

“I was delighted that the consultation document was just 20 pages instead of 50 pages! Explanations and examples were excellent to give me an idea of what was actually being sought and discussed as I would be unfamiliar with some of the terminology.”

“I would like to thank HIQA for the consultation inclusiveness and would like to reinforce that from our business perspective in product development and delivery, standards adopted nationally simplify our work, remove ambiguity and allows us to focus on innovation and re-using the adopted standards.”

“We need to be able to acquire and share patient information from national and possibly international sources; these would be primarily public and private hospitals but could include laboratories.”

“Members of the Surveillance Scientists Association of Ireland perform both microbiological and communicable disease surveillance functions in hospitals, reference laboratories and public health organisations. As a group, we have a variety of experience in planning, agreeing and establishing processes for surveillance of diseases. It is from this experience that we are advising that the work stated above be prioritised by the eSAG.”

“Consult with countries who have been successful.”

## 2.5 ePrescribing

Fourteen comments related to ePrescribing. Several comments requested documentation or information about implementations — for example, setting up systems, accessing the national medicines file, hosting the systems, or using syntax guidelines for prescriptions. Other respondents mentioned the Open National Contact Point (Open NCP) project, which will require the sharing of electronic prescriptions and electronic patient summary records with other EU states. Finally, two respondents highlighted the shortfall between the idealised scenarios in the standard and their real life experience — for example, when the pharmacist uses the “Not Dispensed” flag.



“An implementation guide for ePrescribing systems.”

“An implementation guide for linking with a National Medicinal Product Catalogue.”

“Further clarification and definition around the hosting of ePrescribing messages: where are they hosted; how will repeats work; prescription corrections etc.?”

“A defined dataset for eDispensing. While standards exist for ePrescribing and an eDispensing note, there is no defined dataset for an eDispensing record.”

“The definition of a medication record/profile that will sit within an SCR (not the pharmacy Patient Medical Record).”

“It would be hugely beneficial if we had standardised value sets to support the implementation of ePrescribing in Ireland where relevant.”

“Work on structured ePrescribing should continue.”

“ePrescribing standards are in place but work needs to move forward on this front.”

“Standards relating to drug prescribing, on-screen display of clinical medicines information and printed material e.g. prescriptions, including but not limited to issues on spacing and abbreviations.”

“We would consider the progression of eHealth Standards infrastructure to successfully deliver and deploy Open NCP programme by 2020 a priority (ePrescribing).”

“One of the problems I am seeing in all the documentation is that they are designing it for ideal world situations and not for how it is day to day in a typical pharmacy. I presume part of the prescription corrections clarification is that there is no chance of real-time interaction with the GP when there is a patient standing in front of you in the shop wanting to go home with medication. It will need to be in certain circumstances, with the pharmacist using their judgement, that the medicines are gone out the door and it is more of an informing [of] the GP of what has been dispensed.”

“An issue is the ‘Not Dispensed’ flag whereby an item is pulled from the repository, maybe as part of a larger prescription, but marked as not dispensed and returned to the repository. At the moment we can make a judgement, known as ‘Not Dispensed’ to the PCRS (Primary Care Reimbursement Service), which encourages pharmacists not to dispense items which are not needed or should not be dispensed. We need to ensure that there is a specific flag to differentiate between these items where may be patient allergic to medicine or medicine stopped by hospital and other cases where items are returned to the repository without being dispensed (don't have drug in stock). They almost have all these scenarios covered in the General Practice Messaging Standards doc but it doesn't differentiate between the two at the moment and this is an important professional judgement.”

“We welcome the reference of a clear and pressing need to develop a coherent approach to a health information collection based on standards and international best practice. Recommend ... additional resources for development of Information Architecture (IA) to progress the establishment of the following resources Open NCP programme of development (ePrescribing).”

## 2.6 Electronic health records

The electronic health records theme includes the 11 comments that discussed electronic health records, summary care records or health records. Respondents noted the importance of well-designed electronic health records for improving patient care and the role of national standards in their development. A majority of respondents considered EHRs to be a key building block for ePrescribing in the community and in the Open NCP project. Finally, one respondent stated that, given the disparate systems in Irish healthcare, a 'health record' would be impossible and that exchange of data between these disparate systems needed to be supported instead.



What respondents said:

"Standards around a Shared / Summary Care Records (SCR) in their various forms with consideration for community pharmacist support, contribution and access to same."

"Electronic Healthcare Record development with the patient central in its design — patients able to access, input/update and share information held on them."

"Healthcare Records. The above is essential for clarity, compliance with documentation, time saving and to measure the quality of patient care. I am a nurse and there are some units in the hospital that have computerized document. So having tried both I would definitely welcome going paperless."

"Individual standards already published or being worked on need to be consolidated into a core patient model for representing and transmitting summary patient records

(using selected terminologies) within and across the primary and secondary care interfaces. This should include:

- demographics/administrative data (linked to IHI)
- an episode of care structure detailing coded historical and current problems/linked encounters
- a full set of structured medication history (linked to national medication catalogue). Once defined this should be rolled out on an incremental basis across different health system areas on a readiness and impact basis. At a minimum this should facilitate better information sharing (reducing error prone data re-entry) across GP primary and hospital secondary care along with facilitating patient safety improvements through standardised and more accurate medication reconciliation."

"A standard summary care record. The stated intention of all the eHealth standards is to facilitate an electronic health record."

"A core element/subset will be the summary care record. Most of the elements are in place, including dispensing note, demographic, referral, diagnosis, procedure etc.. Transfers of care need a more standardised approach. I would see the SCR containing demographic, current medical conditions, unique dispensings from last 6 months, current vaccines, allergy information. In my view, this should be primarily implemented as a message. If it left as a document, then it will hinder the development of better analysis and processing."

"Electronic Health Record — advising on best practice and adoption of EHR standards."

"Consider publishing/recommending EHR profile standards to provide constructs for the management of EHR projects. Initial work to focus on Open NCP project Summary Care Record."

"We would consider the progression of eHealth Standards infrastructure to successfully deliver and deploy Open NCP programme by 2020 a priority (patient summaries)."

"The idea of a 'health record' is a misnomer in that such data on a person will necessarily exist on many different systems, i.e. GP, hospital, consultants etc., at

different timers. It will never become a single record so there should be a focus on how we will link the relevant data together when it becomes necessary.”

“We welcome the reference of a clear and pressing need to develop a coherent approach to a health information collection based on standards and international best practice. Recommend — Building block 2. Additional resources for development of Information Architecture (IA) to progress the establishment of the following resources Open NCP programme of development (patient summaries).”

## 2.7 Terminologies

Eleven comments related to terminologies. Overall, respondents emphasised how important terminologies are to the success of the eHealth roadmap. One respondent held the quality of data to be 'the most important single factor that will drive the success of eHealth', with correct entry and coding at source essential to enable capabilities such as clinical decision making. Coding also helps to reduce the complexity of interoperability.

Respondents wanted to see the adoption of terminological standards and the clear communication of them. Several respondents recommended SNOMED CT emphatically, with one saying it was "...still the only show in town". Other comments noted the importance of the Irish SNOMED CT National Release Centre, and suggested reuse of any international resources available, given the limited resources the centre will have.



"Use of SNOMED CT coding in national systems such as ePrescribing."

"You should give consideration to expanding the work on SNOMED CT."

"I believe the area of work that should be prioritised by the Standards Advisory Committee is the development or adoption of terminological standards. Having a structured terminology around coding is a prerequisite to developing the project further."

"I note with interest you are including reference terminology and aggregation terminology as part of the review/standards. Publication and implementation exemplars may help to understand the benefits and pitfalls better?"

"Appropriate standardised national terminologies for structured data collection have been suggested across diagnosis, lab tests and medications. These need to be fully communicated. This requires incentives and compliance checks to facilitate uptake and encourage third-party vendor compliance (possibly through clinical audit incentives or benefits to them in improved data analysis of structured data)."

"The most important single factor that will drive the success of eHealth is the quality of the data. Patient data must be correctly entered and coded at source if there is to

be any chance that the potential of eHealth can be realised. No matter how good the transformation/translation services are after the fact, quality will suffer and the promises of future technologies, such as Clinical Decision Support, will never be realised. If the Committee gets this right then all of the other functions become so much easier to accomplish and the complexities of interoperability are greatly reduced. The Committee should facilitate the introduction of structured, coded, actionable data as close as possible to the point of care and should identify options to achieve this where already implemented solutions are inadequate.”

“The document is a good summary of where we are at. Reference terminology, where applicable, has to be primarily based on SNOMED CT. This is still the only show in town, although it is hard to see how the national release will be delivered, given current resourcing constraints.”

“As procurement progresses on national programmes, software developers can provide vendor-specific bespoke versions of terminology standards which will add an additional layer of complexity to delivering sustainable system integration and return on investment. This is particularly important given recent evidence from WHO [World Health Organization] on projected costings of Sustainable Development Goal 3 implementation in national eHealth programme action plans.”

“There is a reference to systems using different terminology standards which can communicate using one of the mappings developed between the standards. SNOMED has a number of ongoing projects with mapping to many terminologies. Where appropriate, Ireland may wish to consider using these standards as in many instances these resources have been created and agreed upon internationally. We would like to state that from an National Release Centre perspective creating new mapping extensions can be resource intensive and require additional support for cumulative version control over time. We also suggest that the governance of these standards and implementation of them needs to be operationalized and maintained by Data Stewards and this is a role not currently operationalised in HSE although we acknowledge related roles are in place. It would be useful for this group to consider recommending this role be established as a priority.”

## 2.8 Networking and Security

Seven comments requested a broad range of implementation standards in the area of networking and security. Respondents requested very specific guidelines, such as network protocols (TCP/IP, HTTP, and so on), adapters and business processes. They also mentioned data interchange formats, such as XML, and scalable and highly available architectures.



"Protocol and application layer support: Transmission Control Protocol (TCP/IP), User Datagram Protocol (UDP), Hypertext Transfer Protocol (HTTP), Simple Network Management Protocol (SNMP), File Transfer Protocol (FTP), SOAP protocol version 1.0, 1.1 and 1.2."

"Transformation and routing: Message Routing, routing rules, publish and subscribe mechanisms. Programmable support for transformation including loops, if statements and internal functions to assist in the transformation. Support for sub-transformations that can be reused. Business Rules Engine to customize rules without effecting the code."

"Security: Basic security (HTTPS, X509), support for tokens and various encryption algorithms, WS-Security, Authentication — for example, SAML, secure FTP (SFTP)."

"Adapters: ODBC, SOAP, REST, email adapter (SMTP), custom SOAP Headers and bindings, integrated security (AD or LDAP), SOA/Service registry, document storage or adapters to EDM, FTP, MLLP / TCP, EMPI (native or pluggable interface)."

"Enterprise Service Bus (ESB) support: Business Process support and modelling, workflow and task assignment, support for the Publication/Subscription Model, business activity monitoring, configurable push and pull endpoints to provider,

reporting services, analytics, application manageability, performance tuning, performance counters.”

“Architecture: High-availability, scalability, virtualized platform, and supports running in the Cloud.”

“Data Interchange Formats: Extensible Markup Language (XML), JavaScript Object Notation (JSON), EDIFACT, comma separated values (CSV), and globalization or localization (double-byte).”

## 2.9 Metadata

Six comments mentioned metadata and the necessity for a metadata framework. Metadata standards are considered by one respondent to be "...a fundamental building block to progress system integration, interoperability, and compliance across and between services..." Respondents support the development of open, non-proprietary standards in this area and recommend starting this conversation with enterprise architects and key stakeholders.

They also suggest monitoring standards, and related issues, that are emerging internationally. Respondents see a national metadata framework as supporting data elements necessary for the development of an EHR and providing a common reference for organisations using the IHI, as well as providing templates in the national data dictionary.



"Under guiding principles 1.3, we welcome the recommendation of open non-proprietary standards; however, we recognise the dynamic nature of the eHealth and recommend the horizon scanning of emerging relevant HI Standards. In specific cases, emerging standards such as Technical Specifications, Draft Information Standards or Committee Drafts may be considered important to eSAG working plan. Specifically as these technical documents are identified to address emerging issues that that international community are seeking to address given the dynamic nature of the domain of eHealth. For example MetaRep ISO TS 21526 which is an extension to and clarification of ISO/IEC 11179 Meta data Registries to meet the requirements of healthcare."

"In order for HIQA to "fill in the gaps where information is needed" specific recommendations in regard to information management governance is required. The absence of clinical and administrative metadata standards in Ireland means there is

an absence of a fundamental building block to progress system integration, interoperability, and compliance across and between services.”

“Instigate in discourse and collaborate with EA and key stakeholders on deployment of a national metadata standards framework to include a core metadata template and metadata models.”

“Recommend through the IA Governance Group for Data Dictionary and SNOMED, a standard description of metadata template for use in national data dictionary.”

“Instigate a reference framework for administrative core meta data to provide a common reference platform across organisations using IHI (Source — Data dictionary workshop 2nd August 2017).”

“Recommend ... deployment of phase one metadata registry framework to include specification and standardisation of domains to support data elements to meet requirements for EHR. This metadata registry framework can be implemented through the emerging Governance Group of which HIQA is a key member.”

## 2.10 Datasets

Five comments related to datasets. Respondents requested datasets for integrated care programmes, continuity of care documents, workforce planning and development, and social welfare. Immunisation datasets were also mentioned. Finally, one respondent advocated a definition of clinical concepts and archetypes, to inform datasets.



“Data Dictionary Development. Datasets for service/care provision needed for the Integrated Care Programmes — in particular Older Persons, Children and Chronic Disease (some datasets are available for adoption and adaptation from NHS England and Scotland but others need to be developed nationally). Datasets needed to support Workforce Planning & Development (comparative datasets sourced from NHS Scotland but Irish datasets need to be developed nationally).”

“It would be very helpful if a CDA could be defined for social welfare reports of various types such that the information could be easily culled from the patient record and transmitted as a CDA document to social welfare. I know this also has implication[s] re consent and transmission of medical data outside the strictly health environment.”

“Immunization information and messaging need to be standardized to allow transmission of electronic data from GP to the national vaccination database.”

“The Surveillance Scientists Association of Ireland (SSAI) understand not only the importance of the work being undertaken by the eSAG but also its complexity given the scale of the task. As a group we believe that agreeing clinical concepts and archetypes should be one of the earliest tasks prioritised by the committee followed by defining core datasets. This would set out the requirements for the Irish context and provide a solid foundation against which current international standards can be assessed for suitability.”

## 2.11 IHE Profiles

Four comments concerned integrated healthcare enterprise (IHE) profiles. They covered IHE profiles for patient identity, for document sharing, and for security, privacy and notifications.



What respondents said:

“IHE profiles — patient identity: Patient Identity Cross-Reference (PIX), Patient Demographics Query (PDQ), and Cross-Community Patient Discovery (XCPD).”

“IHE profiles — document sharing: Sharing model profile, direct push cross-enterprise document reliable interchange (XDR), and direct push cross-enterprise document media interchange (XDM), XDS, XCA, and HPD.”

“IHE profiles for security, privacy, and notifications: Audit trail and node authentication (ATNA), basic patient privacy consents (BPPC), cross enterprise use assertion (XUA), and document metadata subscription (DSUB).”

### 3 Next steps

Having identified the themes and related work items that emerged from the public consultation, the next steps in this process are:

1. Prioritise the work items according to clearly identified criteria.
2. Create a draft work plan from the prioritised work items.
3. Circulate the work plan to the eHealth Standards Advisory Group for review.
4. Finalise and publish the approved work plan.

## Appendix A – Terms of Reference for the eHealth Standards Advisory Group

The terms of reference of the eHealth Standards Advisory Committee are:

- Agree terms of reference and working procedures and processes and document these.
- Advise HIQA on the identification and prioritisation of those areas in which standards are required bearing in mind where there are short-, intermediate- and long-term priorities.
- Agree and maintain a work plan of projects for the eHealth Standards Advisory Committee.
- Advise HIQA on the additional domain expert members required to undertake aspects of the work plan or specific projects.
- Delegate specific tasks to members of the committee or domain experts co-opted to projects undertaken by the committee, revoking and amending those delegations as required.
- Advise HIQA on the identification of key stakeholders such as user communities, professional bodies and domain experts who should be consulted, depending on the particular standard being developed.
- Work to ensure the ongoing development and implementation of health information standards.

The scope of the technical committee includes:

- data definitions
- clinical concepts and archetypes
- messaging standards
- terminological systems including classifications (ICD) and clinical terminological systems (SNOMED CT).

## Appendix B – Contributing organisations

The following organisations provided feedback to this public consultation:

- Central Statistics Office
- DMF Systems
- Enterprise Architecture, Office of the Chief Information Officer
- GS1 Ireland
- Health Service Executive, National ePrescribing Project
- Healthlink
- HRB Centre for Primary Care Research, Royal College of Surgeons in Ireland
- Irish College of General Practitioners (ICGP) GP IT Tutor
- Infocare Healthcare Services (Irl.) Ltd.
- Irish Pharmacy Union
- Mental Health Commission
- National General Practice Information Technology (GPIT) Group
- National Cancer Control Programme
- Surveillance Scientists Association of Ireland



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