Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information and Standards

National Standard on information requirements for a national electronic patient summary

December 2018

Safer Better Care

About the Health Information and Quality Authority

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

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

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with 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 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.

HIQA is now defining information requirements for a national electronic patient summary standard. Information requirements are a minimum set of data items that are recommended for implementation in information systems that create and transfer information to support the delivery of safe and quality care to patients. The inclusion of data items in the minimum set of data is determined by the clinical relevancy of the data item and the potential for the data item to improve patient safety in a collaborative care environment. The draft information requirements presented in this document are based on international evidence and ongoing interest and initiatives that are being undertaken globally. They have been developed in conjunction with HIQA's eHealth Standards Advisory Group.

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Chapter 1. Introduction

1.1 Definition of an electronic patient summary

Healthcare is under increasing pressure to harness the benefits of good quality health information. Patients expect their health information to be recorded, processed and used appropriately for their benefit. Healthcare professionals require access to complete, valid and up-to-date health information in order to make more informed decisions about patient care, for example, deciding on the most appropriate medication treatment for a patient. In order to meet these demands, a number of international initiatives have focused on the area of electronic patient summaries.

An electronic patient summary is a succinct document, usually containing a minimum set of the most relevant, up-to-date and useable clinical information that is fit for purpose and can help clinicians to make more informed clinical decisions at the point of patient care. Informed by research on international best practice, the core information that should be available to a clinician in a patient summary can include demographic information, allergies, current medical problems (diagnosis) and procedures, alongside a list of the medication that a patient is currently taking.

The definition of a patient summary that will be used throughout this document is sourced from European guidelines on patient summaries and states that:

> A Patient Summary is an identifiable dataset of essential and understandable health information that is made available at the point of care to deliver safe patient care during unscheduled care (and planned care) with its maximal impact in the unscheduled care.[1]

The patient summary is a 'snapshot in time' of the most relevant aggregated demographic and clinical data to enable continuity of care, healthcare coordination and patient safety. An electronic patient summary can support clinical process and improve patient care by providing timely, accurate information needed to enable better communication among clinicians, patients and other healthcare staff. It can support the continuity of patient care between healthcare settings.

1.2 Rationale

There has been widespread interest in the area of patient summaries both internationally and nationally. In Ireland, the Department of Health's eHealth

Strategy[2] identified that the development of patient summaries should be an early priority project and indicated that it would be delivered by eHealth Ireland.

eHealth Ireland is responsible for realising the vision of the eHealth Strategy and is currently leading on two strategic programmes that relate to patient summaries, namely, the delivery of a national electronic health record (EHR)* programme and sharing patient summaries with other EU countries.

Within the context of the national EHR, a national shared record will combine patient data from an organisation's IT system into a single patient centric record. Where a patient summary exists, it can be integrated into the national shared record.

The project to share electronic patient summaries with other EU countries, is known as the OPEN NCP project. As part of this project, Ireland is committed to making patient summaries available, with a patient's consent, to healthcare professionals across participating member states by March 2020.

In order to develop both a national EHR and to fulfil the requirement to share electronic patient summaries across Europe, a national electronic patient summary is required and this standard defines the information requirements to satisfy this.

Furthermore, the Slaintecare Implementation Strategy[3] published in August 2018 identifies that 'ICT has the potential to be the biggest and most effective driver of change and improvement for better patient outcomes across the health system.' The design and roll out of a range of primary and community-based ICT services that will improve the lives of patients, including ePrescribing, summary care records and commencing implementation of telehealth solutions to support care in the community, was identified as a priority.

The Slaintecare Implementation Strategy lists the implementation of patient summaries together with the ePrescribing service as part of the implementation of community care solutions, one of the ten key strategic actions that underpin the Slaintecare vision. The approach outlined in the strategy '…centres around strong health service governance, leadership, accountability, a focus on clear outcomes, providing support to the frontline to drive change, and sustained stakeholder engagement…'.

In recent years, HIQA has undertaken considerable work in this area, including carrying out an international review of summary care records and developing clinical datasets for diagnosis, allergies and procedures.[4][5][6][7] The international review of summary care records documented international evidence and best practice around

* A national EHR is a comprehensive solution that supports the creation and sharing of key patient information. It is a core capability required for the future delivery of healthcare. It will move healthcare from a position where patient records and key information is locked in a paper format and within specific organisations, to an environment where digital patient records are shared securely across care settings with appropriate consent.

developing patient summaries in seven countries: England, Scotland, Northern Ireland and Wales, Australia, New Zealand and the Netherlands.

Overall, findings from the review highlighted that having accurate patient summaries can lead to many benefits for both individuals and clinicians and can improve patient experience, patient safety and the effectiveness of patient care by facilitating timely access to the relevant patient records. The review also highlighted that the introduction of patient summaries requires attention in the following areas: governance and the necessity for good quality information from source systems that generate the information for the electronic patient summary, the need for evaluation studies on the use of patient summaries following deployment and the need for appropriate consent models.

1.3 Purpose of the National Standard

HIQA has developed the information requirements needed to support the implementation of an electronic patient summary. Information requirements are a minimum set of data items that are recommended for implementation in information systems that create and transfer information to support the delivery of safe and quality care to patients. The inclusion of data in the minimum set of data is determined by the clinical relevancy of the data and the potential for the data to improve patient safety in integrated care. The development of information requirements can help to promote a common understanding and national consensus of what information should be included in a national patient summary for Ireland.

1.4 Use of the electronic patient summary in Ireland

This National Standard defines the information requirements for an electronic patient summary for the purpose of unscheduled care, in this instance, out-of-hours and emergency care. The aim of the electronic patient summary is to include all relevant patient information that needs to be sent from a patient's primary care provider to healthcare providers in the out-of-hours service or emergency department of a hospital. The healthcare practitioners that will use the electronic patient summary are usually primary care healthcare providers such as general practitioners, nurses in primary care and nursing and other health and social care professionals in the community and acute care setting.

The electronic patient summary is not the same as a patient's electronic health record or a national shared care record; it is often a sub-set of the patient's longitudinal record, so it does not include the detailed previous history, extensive historic detail about medication or comprehensive detail on each health condition that a person may have had. The objective of the patient summary is to provide the

most essential, relevant and usable information, fit for purpose at the point of care. The core information contained in the patient summary may consist of the patient's demographic details, medical problems, a list of current medication, allergies, procedures and immunisations.

In the first instance, it is envisaged that an electronic patient summary should be sourced and uploaded by an individual's authorised primary care provider, usually the patient's general practitioner, and is viewable (read-only) by healthcare providers in the community and acute care setting.

In the future, it may be possible for the patient summary to be integrated with other eHealth systems. The patient summary could be updated by a treating clinician in an out-of-hours or emergency department and integrated into a hospital-wide electronic health record. Moreover, the patient summary could be stored and accessible within the national shared care record.

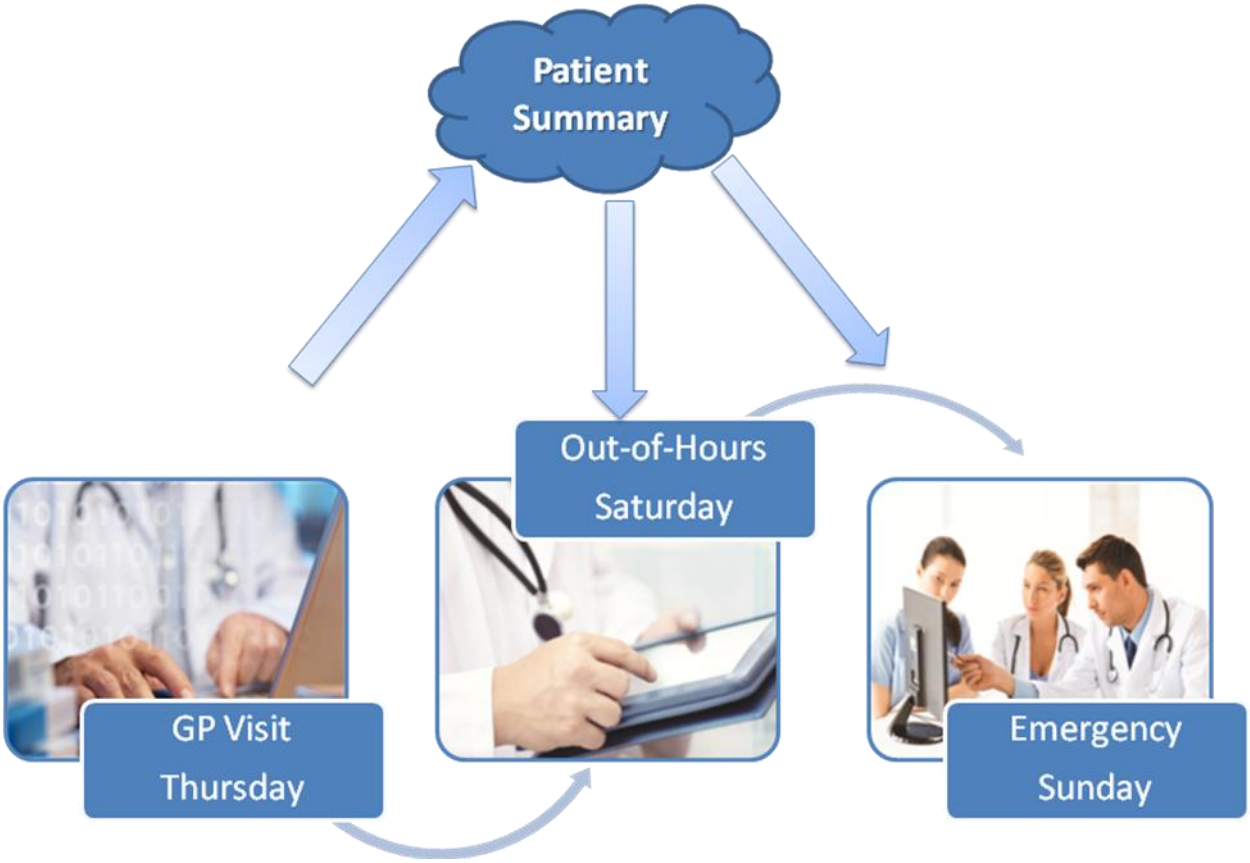
A scenario of how the patient summary could be used is outlined in the following section.

1.4.1 Example scenario

Jack is a patient with a complex chronic condition and regularly attends his general practitioner. Jack has consented to have an electronic patient summary created by his general practitioner. The general practitioner has regularly maintained an up-to-date patient summary for Jack. The general practitioner makes some changes to Jack's medication list and sends the updated patient summary to a central storage place (for example, a shared repository or the cloud). Jack still feels unwell a few days later and decides to attend his local out-of-hours service. The triage nurse in the out-of-hours service is unable to contact Jack's general practitioner as it is the weekend and, rather than rely on Jack's memory of the event, he decides to review the electronic patient summary. He treats Jack based on this up-to-date and accurate summary of information. Overnight, Jack's condition deteriorates and he attends the emergency department in a confused state and is unable to communicate. An authorised healthcare practitioner looks at Jack's patient summary and is able to treat Jack as the most up-to-date, accurate snapshot of his clinical information is available.

Figure 1 illustrates how an electronic patient summary could be used in the community and acute care setting. The electronic patient summary is generated from the general practitioner's practice management system and sent to a central storage area, where it can be downloaded and viewed by authorised healthcare practitioners in the out-of-hours and emergency care setting.

Figure 1. Scenario showing the use of an electronic patient summary



1.5 How the National Standard was developed

This National Standard was developed as per HIQA's legislative remit under the Health Act 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)(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.

The National Standard was developed according to the HIQA standards development process, which involves the following steps:

Review of evidence

HIQA completed a review of both international and national literature to inform the development of the draft standard. HIQA reviewed and assessed international standards and guidance documents on patient summaries. A review of all relevant national policies and national reports was undertaken. HIQA has previously published an international review on patient summaries, available www.hiqa.ie, and developed additional standards in this area, including clinical datasets for diagnosis, procedures and adverse reactions. All documents were reviewed and assessed as to whether to be included in the evidence-base used to develop the National Standard.

eHealth Standards Advisory Group

As part of the development process, and in line with its legal remit, HIQA has a longstanding eHealth Standards Advisory Group. The eHealth Standards Advisory Group consists of a diverse range of stakeholder organisations, including representatives from relevant sections of the HSE, the Department of Health and a service user advocacy group. The function of the group is to advise HIQA on eHealth interoperability standards. Two meetings were held with the advisory group to get advice on the draft standard. The list of members of the Advisory Group is outlined in Appendix A.

Focus groups

The project team consulted with people who use health and social care services and staff providing services, including doctors, nurses, administrators, quality managers, pharmacists, allied healthcare professionals and general practitioners. The purpose of the focus groups and interviews was to discuss the participants' experiences and to obtain their opinion as to what type of information should be included in an electronic patient summary for Ireland.

The project team conducted one-to-one interviews with 23 staff working in emergency departments and with six general practitioners. Furthermore, two focus groups were conducted with service users.

The outputs from the focus groups and one-to-one interviews were summarised and used to inform the development of the draft standard.

Public consultation

The draft standard was made available for a six-week public consultation, running from 13 August 2018 to the 21 September 2018. In this way, the public, service users and service providers had the opportunity to provide feedback and participate in the development process.

HIQA received a total of 45 submissions, with 21 submissions made on behalf of organisations and 24 submissions made by individuals. Following the consultation, all submissions were analysed and the draft standard was revised, as appropriate. A revised version of the draft standard was presented to the eHealth Standards Advisory Group for final review at a meeting in October 2018.

The draft standard was approved by the HIQA Executive Management Team and the HIQA Board. A summary of findings from the public consultation submissions in a Statement of Outcomes report is published on the HIQA website together with the National Standard. Resources to aid understanding and to support implementation of the National Standard will be developed and disseminated across health and social care services. These resources will be aimed at both staff and people using services.

Chapter 2. Background

This chapter highlights the benefits that a national electronic patient summary programme can realise as well as outlining the initiatives that are underway in Ireland and internationally.

2.1 Benefits of electronic patient summaries

Where patient summaries exist, there are significant benefits for patients, health and social care providers and organisations. An electronic patient summary can support clinical processes and improve patient care by providing timely, accurate information needed to enable better communication among clinicians, patients and other healthcare staff. For example, it can be of use for elderly patients who have difficulty remembering the combination of medications they have been prescribed, incoherent patients who have no patient chart available or patients with a history of drug abuse. Internationally, electronic patient summaries have been used to improve medication safety and patient care in out-of-hours and emergency care settings.

Benefits identified for patients include:

- improved efficiency of care by reducing time, effort and the resources required to share a patient's information across different organisations
- improved quality of patient care through more timely and informed clinical decisions in emergency and out-of-hours care
- improved patient safety by reducing the risk of prescribing errors and adverse reactions to prescribed medication
- better patient care by giving healthcare staff relevant information to make appropriate decisions about patient care
- improved patient experience as patients do not need to organise or remember a list of their medications
- reduced number of times that a patient has to repeat his or her clinical information to healthcare staff
- better support for people with difficulty communicating.

The benefits of an electronic patient summary for health and social care providers include:

- empowering health professionals by providing access to consistent, accurate, accessible clinical information about a patient 24 hours a day
- improving patient safety by providing timely access to accurate information which supports safer and more informed prescribing
- improving the efficiency of care delivery to patients by reducing the time, effort and resources required to obtain key information from the patient's GP
- improving the effectiveness of patient care by supporting the delivery of appropriate care to patients.

From an organisational perspective, an electronic patient summary can bring about substantial benefits, such as reducing duplication of effort when ordering tests or asking the patient for information they have already given.

2.1.1 Electronic patient summaries and medication safety

Electronic patient summaries have proven to be very beneficial in the area of medication safety. In the UK, electronic patient summaries are accessible to hospital and community pharmacists. In has been shown that the availability of patient summaries in the UK has led to significant efficiencies during the medication reconciliation process[†] which takes place when a patient is admitted to hospital. There was a clear reduction in the time taken to complete the drug history at the time of admission, with an average reduction of 29 minutes per patient. The associated reduction in phone calls (31%) and faxes (19%) is likely to have contributed to the reduction in time taken. Additionally, results indicated that more medication discrepancies are identified during the reconciliation process when patient summaries are used compared to when patient summaries were not available.(8)

Access to patient summaries has also been made available to community pharmacists in the UK. NHS Digital in the UK states that having instant access to patient information speeds up care, reduces the need for phone calls to general practices and reduces referrals to other services, particularly out-of-hours, because summary care records are available 24 hours a day — including at times when the patient's general practitioner practice may be closed.(9) Specific benefits for patients and staff identified by NHS Digital include the ability to:

[†] Medication reconciliation is a formal process for creating the most complete and accurate list possible of a patient's current medications and comparing the list to those in the patient record or medication orders.

- check allergies to prevent prescribing errors
- check current medications prescribed for emergency supply purposes
- check eligibility for services such as free flu vacination.

2.2 International initiatives on patient summaries

There has been widespread interest in the area of patient summaries internationally given the substantial benefits they can deliver. This section summarises an international review on patient summaries that was undertaken by HIQA in 2016. It also outlines European standards and guidelines on patient summaries that were used to inform this National Standard.

2.2.1 International review on patient summaries

HIQA's *International Review of Summary Care Records* [7] documents how electronic patient summaries have evolved in other countries. The review covered the national electronic patient summary implementations developed in the UK (England, Scotland, Wales and Northern Ireland), Australia, New Zealand and the Netherlands. A number of factors were examined such as the structure of the healthcare system, the source of information, the content and usage of an electronic patient summary.

The international review demonstrated that the deployment of accurate and timely electronic patient summaries can lead to increased patient safety outcomes and can deliver improvements for both patient experience and the effectiveness of patient care. The core information or content required for an electronic patient summary was consistent across countries reviewed and at a minimum included health identifying information, diagnosis, current medications, allergies and immunisations. All countries populated the electronic patient summary directly from general practitioner practice management systems.

From the review, it was evident that the deployment of patient summaries, in the first instance, was for the purpose of emergency, unscheduled and out-of-hours services. Some countries increased the scope of the information requirements to include different healthcare settings. For example, in England, the summary care record has been extended for the purpose of end-of-life care, community pharmacy and medication reconciliation on admission to hospital.

Overall findings from the international review in 2016 highlighted that a national electronic patient summary can increase patient safety by providing a tool for clinicians to securely access structured, core information about patients. The quality

of care that patients receive can be enhanced by fast, easy access to the most accurate and relevant patient information available.

A study conducted in Scotland on the evaluation of the impact on the Key Information Summary Record, an extension of the Scottish emergency care summary, confirmed that clinicians working in emergency care and in out-of-hours services highly value the Key Information Summary and regard it as a critical data source for conducting their work effectively. The study found that the electronic patient summary had a positive impact on preventing medication errors.(10) Clinicians also reported on the benefits of the electronic patient summary, particularly for sub-groups of patients, such as the cognitively impaired, the elderly and those on multiple, complex medication regimes.(11)

Having summarised the international review on electronic patient summary implementations, the following section outlines relevant projects that have been undertaken by the European Union and International standards development organisations regarding electronic patient summaries.

2.2.2. Patient summaries standards and guidelines

As part of the development of the standard and in order to conform with International and European Standards, relevant specifications and guidelines were reviewed and assessed and incorporated into the National Standard where deemed appropriate. This included reviewing the European standards and guidelines discussed below.

Running from 2008 to 2013, the European Patient Smart Open Services (epSOS) project was an EU-wide pilot project that developed and tested an eHealth framework for secure cross-border exchange of health information, including patient summaries. One of the deliverables from this project was a minimum dataset which defined the content for a patient summary that could be shared across European countries. This project resulted in the EU member states agreeing a number of communication standards for patient summaries.(12)(13)(14)

Based on the work completed by the epSOS pilot project, the EU published guidelines on patient summaries in 2013. In 2016, the Joint Action to Support the eHealth Network (JAseHN)[‡] revised the guidelines and published the *Guideline on*

[‡] JAseHN is led by the EU member states and co-financed by the European Commission through a Joint Action. JAseHN functions as a platform for operational and strategic cooperation between member states, including their relationship with EU eHealth stakeholder groups and standardisation organisations. It provides support and guidance for the implementation, deployment and use of eHealth services throughout national healthcare systems to enable better use of healthcare resources.

the electronic exchange of health data under Cross-Border Directive 2011/24/EU Release 2 Patient Summary for unscheduled care.[15]

The European Commission subsequently supported an initiative called OPEN NCP for the cross-border exchange of patient summaries. OPEN NCP is tasked with providing infrastructure for sharing patient summaries across Europe. Ireland is participating in this project and is committed to making electronic patient summaries and electronic prescriptions available, with a patient's consent, to healthcare professionals across other participating member states by March 2020. This National Standard can provide the information requirements that is required for a patient summary to ensure Ireland fulfils its commitment to share patient summaries across Europe.

In January 2018, the Joint Initiative Council (JIC), a consortium of eight international digital health standards development organisations, released a standards set[§] on patient summaries. The intent of the standards set is to provide health information standards, scenarios and information flows for specific healthcare settings. The electronic patient summary standards set[16] outlines details of the information requirements for the content of patient summaries. This National Standard complied with the JIC standards set where possible.

2.3 Summary

Studies have demonstrated that patient summaries can improve patient safety, improve the quality and effectiveness of care and save healthcare staff and their organisations time and money.[17] However, successful deployment of a national electronic patient summary demands attention around issues such as governance (for example, maintaining continuously updated electronic patient summaries), evaluation of their use, appropriate consent models, effective business management, engagement of clinicians and active participation of patients.[18]

An electronic patient summary that is shared between healthcare practitioners can facilitate effective communication between clinical teams. Importantly, patients can benefit as those with cognitive difficulty, low literacy levels or limited English can receive as high a standard of care as others.[19] The introduction of a national electronic patient summary can also ensure clinicians are better informed to make clinical decisions for the patient at the point of care, potentially resulting in fewer medical errors, more efficiency of care and lower healthcare costs.

[§] The JIC describe the term Standards Set itself as 'not a set of standards, but is a process to be followed to allow an informed and consistent approach to identifying, selecting and deploying standards and related artefacts.'

Having discussed the definition, benefits and international initiatives on patient summaries, the information requirements for a national electronic patient summary in Ireland are described in the following section.

Chapter 3. Information requirements for an electronic patient summary

This section describes the information requirements needed to support a national electronic patient summary. As stated earlier, information requirements define the minimum set of data items that are recommended for implementation in information systems that create and transfer information to support the delivery of quality collaborative care. The inclusion of data in the minimum set of data is determined by its clinical relevancy and the potential for it to improve patient safety in a collaborative care environment.

This section defines the information that should be contained within a national electronic patient summary whenever information is generated by a primary care or general practitioner practice management system and shared with other health and social providers. Though additional information about the patient's visit may be recorded by clinicians in primary or secondary care, only the clinical information that is required to be shared in an electronic solution in order to ensure patient safety is included in this National Standard.

The international standards and specifications which have been used in the development of the information requirements are listed below:

- European Patients Smart Open Services (epSOS), Work Package 3.9 – Appendix B1/B2 epSOS Semantic Implementation Guidelines (2011)[13]
- Guideline on the electronic exchange of health data under Cross-Border Directive 2011/24/EU Release 2 Patient Summary for unscheduled care[20]
- CEN/TC 251 European standard (EN) 17269: *The Patient Summary for Unscheduled, Cross-border Care* (the CEN/TC 251 EN 17269)[1]
- HL7 International Patient Summary Implementation Guide Implementation Guide Release 0.1.0[21]
- Joint Initiative Council, Patient Summary Standards Set, Guidance Document, January 2018 v1.0[16]
- Australian Digital Health, Shared Health Summary Information Requirements, v1.1.[22]

Appendix B sets out the links between these sources and each data item in the national electronic patient summary record.

3.1 Information requirements for a national patient summary

The information requirements are outlined below and include the following areas:

- subject of care
- health condition
- medication prescribed
- allergies
- procedures
- vaccinations.

Each table is structured to include the number of the requirement, the name of the data item, a statement for the requirement and a description for how the requirements could be used in practice. The optionality for a data item is described as either SHALL or SHOULD. The definitions of SHALL and SHOULD are as follows:

SHALL	When appearing in a requirement, the verb **SHALL** indicates a mandatory requirement. Its negative form **SHALL NOT** indicates a prohibition.
SHOULD	When appearing in a requirement, the verb **SHOULD** indicates a recommendation. Its negative form **SHOULD NOT** indicates an option that is not recommended.

1.0 Subject of care

The patient's demographic details for the purpose of an electronic patient summary.

Table 1. Subject of care

No.	Data item	Requirement statement	Usage
1.1	**Title**	The patient summary **SHOULD** contain the title relevant to the subject of care.	A patient's preferred title, for example, Mr, Doctor, Mrs.
1.2	**Forename**	The patient summary **SHALL** contain a patient's first name or given name(s) as stated on the birth certificate.	A patient's first name or given name(s) as stated on the birth certificate.
1.3	**Surname**	The patient summary **SHALL** contain the second part of a patient's name which denotes their family or marital name.	The second part of a patient's name denotes their family or marital name.
1.4	**Address**	The patient summary **SHALL** contain the location to be used to contact or correspond with the patient. This would normally be the patient's usual home address.	The particulars of the place where the patient lives.
1.5	**Date of birth**	The patient summary **SHALL** contain the date of birth indicating the day, month, and year when the patient was born.	The patient's date of birth should be provided.
1.6	**Sex**	The patient summary **SHALL** contain gender identity.	Gender identity is a person's sense of identification with either the male or female sex, as manifested in appearance, behaviour and other aspects of a person's life.
1.7	**Health identifier**	The patient summary **SHOULD** contain a number or code assigned to an individual to uniquely identify the individual	Both the code and the code type that the code relates to should be provided, for example, 0987654321 Individual Health Identifier. Other identifiers which may be carried in this field include the

		within an organisation.	General Medical Scheme, Drug Payment Scheme, Long Term Illness Scheme and Hardship Scheme identifier.
1.8	**Next of Kin**	The patient summary **SHOULD** contain the name and contact details of the patient's next of kin.	A patient's nominated next of kin, including their name and contact details such as telephone number.

2.0 Health condition

The patient's current health condition, which includes health problems or diagnoses. It can include conditions that may have a chronic or relapsing course (for example, irritable bowel syndrome or otitis media), conditions for which the patient receives repeat medications (for example, diabetes mellitus or hypertension) and conditions that are persistent and serious contraindications for classes of medication (for example, dyspepsia, migraine or asthma).

Table 2. Health condition

No.	Data item	Requirement statement	Usage
2.1	**Current health condition**	The patient summary **SHALL** identify the condition or diagnosis.	The name of the condition.
2.2	**Clinical description**	The patient summary **SHOULD** contain a narrative description or comments about clinical aspects of the condition.	Additional narrative about the condition.
2.3	**Date of onset**	The patient summary **SHOULD** state the estimated or actual date of onset, in the opinion of the healthcare practitioner.	The estimated or actual date on which the health condition was first detected or suspected or entered.
2.4	**Status**	The patient summary **SHALL** contain the status of the health condition.	The status of the condition categorised as provisional, working, confirmed, refuted, resolved or inactive.
2.5	**Date resolved or inactivated**	The patient summary **SHOULD** contain the date or estimated date that the condition was resolved.	The date or estimated date that the condition resolved or went into remission, as indicated or identified by the healthcare professional.
2.6	**No health conditions identified**	The patient summary **SHOULD** contain a record to indicate that the patient has **no known health conditions**.	An indication that the patient has no known health conditions.

3.0 Medication prescribed

A list of the current medications prescribed for the patient.

Table 3. Current medication

No.	Data item	Requirement statement	Usage
3.1	**Medicinal product**	The patient summary **SHALL** include the name of the medicinal product or package. It may be a trade name or a generic name.	The medicinal product that is prescribed. This field covers where package-level dispensing occurs or where a formulation takes place in the pharmacy in order to produce the substance dispensed to the patient.
3.2	**Dose form strength**	The patient summary **SHALL** state the content of the active ingredient expressed quantatively per dosage unit, per unit of volume or per unit of weight.	This field consists of a size value and unit, a combination of both to define the strength, for example, 250mg or 1g.
3.3	**Dose form type**	The patient summary **SHALL** include a description of the dose type, such as tablet or vial.	This field describes the dose type, such as tablet or vial.
3.4	**Number of units per intake**	The patient summary **SHALL** state the number of instances of the medicinal product to be taken by the patient at a given time.	This field is used to describe the number of units(s) to be taken at a given time.
3.5	**Frequency of intake**	The patient summary **SHALL** state how the medication is to be administered, often expressed in number of times per day but may also include information such as one hour before or after meals'.	This field is used to describe the frequency of the dose that should be taken by the patient.
3.6	**Duration of treatment**	The patient summary **SHALL** state the duration of time for the regime to be taken.	This field is used to describe the duration of the dose described should be taken by the patient.
3.7	**Route of administration**	The patient summary **SHALL** state the route of administration of the medication	The route of administration is used to describe how the medication should be administered to the patient, for

			example orally, IV injections, rectally or topical administration
3.8	**Date medication perscribed**	The patient summary **SHALL** state the date on which treatment was prescribed.	Date field which indicates when the treatment was prescribed.
3.9	**No medication prescribed**	The patient summary **SHOULD** contain a record to describe that the patient is not taking medication.	An indication to suggest that the patient has no medication prescribed.

4.0 Allergies

This section describes the agent that is responsible for the adverse reaction. It includes allergies, intolerances and adverse reactions to all substances,not only those arising from medications or medicines. It also describes other clinical information that is imperative to know so that the life or health of the patient does not come under threat. For example, intolerance to aspirin due to gastrointestinal bleeding.

Table 4. Allergies

No.	Data item	Requirement statement	Usage
4.1	**Substance**	The patient summary **SHALL** identify the substance that the patient has a susceptibility to an allergy upon exposure to the substance.	The substance that caused the allergy to occur. Example of a substance could include peanut, penicillin and so on.
4.2	**Reaction**	The patient summary **SHOULD** describe the type of reaction event as determined by the healthcare practitioner.	A subjective assessment of the type of reaction event as evaluated by the healthcare practitioner. Examples include rash, diarrhoea and anaphylaxis.
4.3	**Severity of reaction**	The patient summary **SHOULD** include the severity of the symptom as determined by the healthcare practitioner.	An assessment of the severity of the reaction event as evaluated by the healthcare practitioner. Examples include severe, serious, moderate or minor.
4.4	**Reaction onset date**	The patient summary **SHOULD** contain a record of the date and or time of the onset of the reaction.	This field is used to capture the date and or time (or both) of the onset of the allergic reaction.
4.5	**No known allergies**	The patient summary **SHOULD** include a record if no known allergies.	An indication that the patient has no known allergies.

5.0 Procedures

A procedure is defined as a clinical activity carried out for therapeutic, evaluative, investigative, screening or diagnostic purposes.

Table 5. Procedures

No.	Data item	Requirement statement	Usage
5.1	**Procedure**	The patient summary **SHALL** include a description of the procedure.	This field captures a narrative description of the procedure. Examples can include a description about performance, findings, failed attempt or cancellations.
5.2	**Procedure date**	The patient summary **SHOULD** state the date and or time on which the procedure was or is intended to be performed.	This field is used to capture the date and or time on which the procedure was performed.
5.3	**No procedures undertaken**	The patient summary **SHOULD** include a record if no procedures have been undertaken.	An indication that a patient has not had any procedures undertaken to date.

6.0 Vaccinations

Details of immunisations or vaccinations that have been administered to the patient.

Table 6. Vaccinations

No.	Data item	Requirement statement	Usage
6.1	**Names of vaccinations**	The patient summary **SHALL** state the name of the vaccinations given to the subject of care.	The name of the vaccination given to the patient.
6.2	**Vaccination date**	The patient summary **SHOULD** state the date that the vaccination was administered to the subject of care.	This field indicates the date and or time when the vaccination was administered to the subject of care
6.3	**No vaccinations administered**	The patient summary **SHOULD** include a record that no vaccinations were administered.	This field indicates whether a patient has not had any vaccinations or immunisations administered to date.

Chapter 4. Conclusion

An electronic patient summary is a succinct document, usually containing a minimum set of the most relevant, up-to-date and useable clinical information that is fit for purpose and that can help clinicians to make more informed clinical decisions at the point of patient care.

HIQA has developed information requirements for an electronic patient summary. The sources of evidence used to inform the information requirements include the international review undertaken by HIQA and the work currently being undertaken internationally by standards development organisations on electronic patient summaries. Previous standards developed by HIQA, including clinical datasets for diagnosis, procedures and adverse reactions, also informed these information requirements. They were developed in collaboration with the eHealth Standards Advisory Group.

The information requirements for an electronic patient summary was made available for a six-week public consultation and as part of the standards development process HIQA also undertook consultation on the draft standard through focus groups and one-to-one interviews with both service users and healthcare professionals to gather their requirements for a national electronic patient summary record. All feedback was reviewed and where necessary and appropriate, the draft standards were revised.

Electronic patient summaries can support the clinical decision-making process and result in safer and better care. In order to develop both national electronic health records in Ireland and to fulfil the country's requirement to share electronic patient summaries internationally, with the patient's consent, a national electronic patient summary is required for Ireland.

Appendix A eHealth Standards Advisory Group and HIQA's project team

The eHealth Standards Advisory Group consists of the followed individuals:

Niall Sinnott	Department of Health
Loretta Grogan	Health Serivce Executive (HSE) — Clinical Care Programmes
Iyrna Pokhilo	Patient Representative – CAIRDE
Jack Shanahan	Irish Pharmaceutical Union
Gerry Kelliher	Royal College of Surgeons in Ireland — Surgical Affairs
Brian O'Mahony	Irish College of General Practitioners (General Practice IT Group)
Gerardine Sayers	HSE — Health Intelligence
Emer Kelly	Royal College of Physicians of Ireland
Eileen Bell	Enterprise Ireland
Roisin Doherty	Access to Information
Peter Connolly	HSE — Office of Chief Information Officer — Enterprise Architecture
Yvonne Goff	HSE — Office of Chief Information Officer
Fran Thompson	HSE — Office of Chief Information Officer
Damon Berry	National Standards Authority of Ireland
Paul Gallagher	Irish Association of Directors of Nursing and Midwifery

The project team consisted of:

Kevin O'Carroll	Standards and Technology Manager
Louise Mc Quaid	Standards and Technology Lead
Deirdre Laffan	Standards and Technology Lead

Appendix B Sources of information

The sources used to inform the information requirements for a national electronic patient summary are outlined in Tables 7 to 12 below.

Table 7. Subject of care

1.0 Health Condition		
No.	**Data Item**	**Source**
1.1	**Title**	HIQA: *National standard demographic dataset and guidance for use in health and social care settings in Ireland*
1.2	**Forename**	HIQA: *National standard demographic dataset and guidance for use in health and social care settings in Ireland*
1.3	**Surname**	HIQA: *National standard demographic dataset and guidance for use in health and social care settings in Ireland*
1.4	**Address**	HIQA: *National standard demographic dataset and guidance for use in health and social care settings in Ireland*
1.5	**Date of birth**	HIQA: *National standard demographic dataset and guidance for use in health and social care settings in Ireland*
1.6	**Sex**	HIQA: *National standard demographic dataset and guidance for use in health and social care settings in Ireland*
1.7	**Health identifier**	HIQA: *National standard demographic dataset and guidance for use in health and social care settings in Ireland*

Table 8. Health condition

2.0 Health condition		
No.	**Data Item**	**Source**
2.1	**Current health condition**	HIQA: *National standard diagnosis dataset and clinical document architecture (CDA) template* EU Directive[**] Joint Initiative Council (JIC)[*] HL7/CEN IPS[‡] Australian Digital Health Agency[††]
2.2	**Clinical description**	HIQA: *National standard diagnosis dataset and clinical document architecture (CDA) template* Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
2.3	**Date of onset**	HIQA: *National standard diagnosis dataset and clinical document architecture (CDA) template* Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
2.4	**Status**	HIQA: *National standard diagnosis dataset and clinical document architecture (CDA) template*
2.5	**Date of resolution/inactive**	HIQA: *National standard diagnosis dataset and clinical document architecture (CDA) template* Joint Initiative Council EU Directive Australian Digital Health Agency

[**] Guideline on the electronic exchange of health data under Cross-Border Directive 2011/24/EU Release 2 Patient Summary for unscheduled care

[*] Joint Initiative Council, Patient Summary Standards Set, Guidance Document, January 2018 v1.0

[‡] HL7/CEN International Patient Summary Implementation Guide Implementation Guide Release 0.1.0

[††] Australian Digital Health Agency, Shared Health Summary Information Requirements, v1.1

2.6	**No health conditions identified**	HIQA eHealth Standards Advisory Group Australian Digital Health Agency

Table 9. Current medication

3.0 Current Medication		
No.	**Data item**	**Source**
3.1	**Medication**	HIQA ePrescribing Standard Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
3.2	**Dose form strength**	HIQA ePrescribing Standard Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
3.3	**Dose form type**	HIQA ePrescribing Standard Joint Initiative Council EU Directive Australian Digital Health Agency
3.4	**Number of units per intake**	HIQA ePrescribing Standard Joint Initiative Council EU Directive Australian Digital Health Agency
3.5	**Frequency of intake**	HIQA ePrescribing Standard Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
3.6	**Duration of treatment**	HIQA ePrescribing Standard EU Directive Australian Digital Health Agency
3.7	**Date of start of treatment**	HIQA ePrescribing Standard Joint Initiative Council EU Directive HL7/CEN IPS EU Directive Australian Digital Health Agency
3.8	**No medication taken**	HIQA eHealth Standards Advisory Group

Table 10. Allergies

4.0 Allergies		
No.	**Data Item**	**Source**
4.1	**Substance**	HIQA Adverse Reaction Standard Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
4.2	**Reaction**	HIQA Adverse Reaction Standard Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
4.3	**Severity of reaction**	HIQA Adverse Reaction Standard Joint Initiative Council EU Directive HL7/CEN IPS Australian Digital Health Agency
4.4	**Reaction onset date**	EU Directive HL7/CEN IPS Joint Initiative Council
4.5	**No known allergies**	HIQA eHealth Standards Advisory Group

Table 11. Procedures

5.0 Procedures		
No.	**Data Item**	**Source**
5.1	**Procedure**	HIQA Procedures Standard EU Directive HL7/CEN IPS Joint Initiative Council
5.2	**Procedure date**	HIQA Procedures Standard EU Directive HL7/CEN IPS JIC
5.3	**No procedures undertaken**	HIQA eHealth Standards Advisory Group

Table 12. Vaccinations

6.0 Vaccinations		
No.	**Data item**	**Source**
6.1	**Names of vaccinations**	EU Directive
6.2	**Vaccination date**	EU Directive
6.3	**No vaccinations administered**	HIQA eHealth Standards Advisory Group

Appendix C Summary of international review of summary care records

England, Scotland, Wales and Northern Ireland each began a programme to introduce a summary care record between 2004 and 2008. In 2013, Greenhalgh et al. conducted an evaluation study on the summary care record in the UK.[23] The study concluded that clear benefits can be derived from the use of summary care records, such as improved patient experience, patient safety and the effectiveness of patient care. However, implementing a nationally shared electronic summary record, as with the introduction of any new health technology, is challenging given that implementing organisational change in healthcare systems is complex and can be difficult to manage.

There is much in common between the four programmes of work in the UK. All countries generated information for the electronic patient summary from the record held by the patient's National Health Service (NHS) general practitioner. All countries developed their national electronic patient summary for the purpose of emergency, unscheduled and out-of-hours care. Initial implementation in England, Scotland and Northern Ireland have the same core minimum summary of information that includes medications, adverse reactions and or allergies, and information to uniquely identify a patient. Wales have similar information requirements as the other three countries but also includes medical problems and test results. In July 2013, the UK summary care record was expanded to include patients' end-of-life care information, immunisations, reason for medication and significant past problems and procedures. There is widespread use of summary care records in England, Scotland, Northern Ireland and Wales.

Building on the success of the summary care record programme in England, the NHS decided to trial its use in community pharmacy, which started in 2014. The aim was to support community pharmacists in a range of services such as providing patients with consistent information about their usual medications, offering more accurate advice to patients and assisting with dispensing emergency supplies of medication. The information available to pharmacists includes the core information from the summary care record, alongside allergies and adverse reactions, repeat medications, acute and discontinued medications. Importantly, the summary care record only contains medication prescribed by the general practitioner and does not include other sources, such as hospital prescribing. The use of the summary care record demonstrated improvements in patient safety, whereby the pharmacist is able to

access a patient's summary when they suspect a prescribing error has occurred, allowing them to help clarify a prescriber's intention. The summary care record for community pharmacy was rolled out nationally in 2015.[24]

The national patient summaries in Australia, New Zealand and the Netherlands also source information from general practitioners' practice management systems. There are common categories of information that the three countries use as the core content for their summary care records, including demographics information, health problems, medicines, allergies, adverse reactions and immunisations. New Zealand also includes data on laboratory results, and, in the Netherlands, the electronic locum summary record includes the most recent records of a patient's visit to hospital.

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