Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information and Standards

Draft recommendations on the Implementation of a National Electronic Patient Summary in Ireland

August 2020

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'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. Therefore, it is 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 medicine, a nurse needs to be sure that they are administering the appropriate dose of the correct medicine 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)(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 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 area of summary care records, sometimes called patient summaries. Owing to the potential benefits expected from summary care records, which have been outlined in earlier publications, HIQA has focused significant research on a national electronic patient summary. To date, HIQA has:

- published an international review summary care records (2016)[1]
- published clinical datasets for diagnosis, allergies, and procedures[2,3,4,5]
- contributed to the definition of the EU cross-border summary (OpenNCP)
- developed National Standard on Information Requirements for a National Electronic Patient Summary in Ireland (2019).*

In particular, the National Standard on a National Electronic Patient Summary in Ireland (2018) defined the clinical dataset for the clinical data that would be exchanged as part of a national Irish implementation: subject of care, health conditions, procedures, allergies,

* Information requirements are minimum set of data items that should be implemented in information systems that create and transfer information to support the delivery of safe and quality care to patients.

vaccinations, and medications. A national electronic patient summary could provide significant benefits for patients, health and social care providers and organisations, in particular improving medication safety and patient care in out-of-hours and emergency care settings. To realise these benefits fully, it is critical that a national electronic patient summary be implemented in line with international best practice and in consideration of the programmes, projects, and services that will be impacted by the implementation or influence the implementation. Thus, this document contains Draft Recommendations on the Implementation of a National Electronic Patient Summary in Ireland informed by the findings of the *Best Practice Review of Summary Care Records* and the *As Is Review of the Irish eHealth Landscape*.

As part of the development process, and in line with its legal remit, HIQA set up an Advisory Group consisting of representatives from a range of stakeholder organisations, listed in Appendix A. The Advisory Group will be asked to consider the evidence in *Best Practice Review of Summary Care Records, As Is Review of the Irish eHealth Landscape,* and the first draft of the Draft Recommendations for Consultation, which were developed based on the findings of both. The Advisory Group has made submissions in respect of the recommendations, which HIQA took under advisement before making the appropriate changes.

The Draft Recommendations will now be made available for a six-week public consultation. All submissions received will be analysed and the Draft Recommendations document will be updated with all accepted comments. A Statement of Outcomes from the public consultation will also be prepared, providing a detailed analysis of all feedback received during the public consultation. The Draft Recommendations will then be reviewed by the Advisory Group and the updated Final Recommendations document will be approved by the HIQA Executive Management Team. The Final Recommendations will then be submitted for approval by the Board before being submitted to the Minister for Health and being published on the HIQA website.

Contents

Executive Summary

HIQA makes the following recommendations in respect of the implementation of a national electronic patient summary in Ireland:

Legislative framework	
1.1	Clarity—in the form of national policy and legislation—is required to support the implementation of large scale digital solutions, as set out in Sláintecare. Specifically, a gap analysis of current legislation and regulations should be undertaken and addressed with new legislation or regulations enabling the implementation of national digital solutions, including a national electronic patient summary.

Programme governance	
2.1	In line with best practice internationally, and cognisant of the Irish eHealth landscape and existing governance structures, the following governance structure be established for the implementation of a national electronic patient summary: ▪ A Patient Summary Project Board with responsibility for national delivery should be established, reporting to the EHR Steering Group, which is currently jointly chaired by the Chief Operating Officer and Chief Clinical Officer. The Project Board should be chaired by the Chief Clinical Information Officer, representing the Chief Clinical Officer. ▪ The Chief Clinical Officer should act as the national sponsor for the programme at the executive level, ensuring that the programme has appropriate executive oversight and with overall responsibility for the agreement of the scope and roadmap of the implementation programme. ▪ The Project Board should also maintain a working relationship with the HSE Digital Oversight Group, within the terms of reference of that group.
2.2	The Project Board should also have representation from all entities involved in the programme—such as ▪ policy and legislative organisations, ▪ Health Service Executive programmes, ▪ standards organisations, ▪ professional representative bodies, such as for general practice and pharmacy, ▪ patient/public organisations, ▪ public and private hospitals, ▪ the vendor community. Internationally, two stakeholder groups were identified as critical to the success of the implementation: clinical groups and patients/the public. Therefore, both groups should be well-represented at all levels of the governance structure, as outlined in Recommendations 3.1, 3.2, 3.3 on Stakeholder Engagement.

2.3	In line with both international best practice and with HSE guidelines, following the launch of the programme, an appropriate ongoing governance mechanism should be established—including a Change Advisory Board chaired by the Chief Clinical Information Officer.

Stakeholder engagement	
3.1	Review of international best practice shows that the effective engagement of stakeholder groups is essential to the successful implementation of the programme. Therefore, the Patient Summary Project Board should develop a comprehensive stakeholder engagement plan, identifying all stakeholder groups and engaging them consistently and appropriately over the implementation and during the post-implementation phase.
3.2	In particular, clinical ownership has been shown to be a critical factor in the acceptance and use of a national electronic patient summary, with clinical champions playing a decisive role. The clinical champions should be identified and supported to engage clinical groups—for example, within each region where a regional structure is devised.
3.3	Patient and public perceptions of the implementation have also been found to be a key determinant of implementation success. This engagement is essential to the success of both the implementation of a national electronic patient summary and the implementation of other national eHealth solutions for health and social care. Based on expert advice, public champions should also be identified and supported to engage patients and the public, to ensuring their full participation in this process.

National Health Identifiers	
4.1	The Individual Health Identifier (IHI) and associated demographic dataset should be operationalised in all projects, programmes, and services supporting a national electronic patient summary.

Information sources	
5.1	Essential criteria for inclusion should be developed for the assessment of all potential information sources for the national electronic patient summary. These criteria should include the quality of data and information in the source, such as the accuracy, the completeness, and update frequency[†] of the data. HIQA considers GP practice management systems and community pharmacy management systems as the highest priority information sources for assessment against the essential criteria. Additionally, other existing national systems—such as the Hospital In-Patient Enquiry System and Primary Care Eligibility and Reimbursement Service and the national messaging broker Healthlink —and other potential (future) information sources—such as the National Immunisation Information System and the national ePrescribing service—should be assessed against the inclusion criteria and brought on board as appropriate.
5.2	Mechanisms should be put in place with data controllers to work towards the improvement of the quality of data in the information sources identified to provide information to a national electronic patient summary, in the context of the overall Sláintecare Implementation Plan.
5.3	The Project Board ensures that a comprehensive skills and training programme be implemented for the intended user base, to ensure that the content of a national electronic patient summary is well-understood. In particular, the accuracy, completeness and update frequency of patient summary information should be clearly communicated to the users and understood by them, with appropriate protocols introduced—for example, triangulation with another source, where the clinician checks the information in the patient summary with the patient or their carer.

[†] Update frequency means how often the data is provided to the national electronic patient summary.

Phased implementation	
6.1	In line with international best practice, the national electronic patient summary be considered as an initial step in the longer term road map, providing opportunities and learnings that can feed into the implementation of the shared care record and other elements of the Sláintecare Implementation Plan.
6.2	The phases of the implementation should be determined by the outputs of the data quality assessment in Recommendations 5.1 and 5.2. If the implementation of a national electronic patient summary is split into multiple phases, at minimum Phase 1 should include the following information, in line with international best practice: ▪ Demographic information ▪ Medication ▪ Allergies Subsequent phases can be informed by assessment of other potential sources against essential criteria for inclusion—see Recommendation 5.1.
6.3	The implementation of Phase 1 of the national electronic patient summary should consist of four stages: ▪ A small pilot involving a number of GP practices linked to local out-of-hours clinic(s) and Emergency Department. ▪ Regional pilots managed by the regional steering group, with similar groupings to above, feeding back to the central programme. ▪ National rollout including demographic information and Prescribed Medicines. ▪ Post-implementation support.
6.4	To encourage uptake by end users and full realisation of expected benefits, appropriate key performance indicators (KPIs) should be developed in line with international best practice and with engagement from end users of the system. Examples of minimum performance criteria from international best practice include: ▪ Complete patient summaries should be present for at least 50% of patients with records in the system, especially patients that access out of hours or emergency care on a regular basis. ▪ It should be possible to retrieve and read a patient summary in less than 30 seconds. ▪ The patient summary should be presented through a user-friend system that also supports single sign on and appropriate security measures.

Introduction

This document contains Draft Recommendations that are intended to support the successful implementation of a national electronic patient summary in Ireland. A national electronic patient summary is a succinct summary of the clinical information needed to deliver of safe and quality care to patients during episodes of unscheduled care, such as when attending an out of hours GP clinic. For example, it can be of use for 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.

A national electronic patient summary can provide benefits for patients, health and social care providers and organisations, supporting clinical processes and improving patient care by providing timely, accurate information needed to enable better communication among clinicians, patients and other healthcare staff.

An example scenario is described in Appendix A.

The introduction of summary care records—that is, national electronic patient summaries—is a crucial element of national eHealth policy. The *Sláintecare Implementation Plan (2018)* lists summary care records as one of the primary and community-based ICT services that will improve the lives of patients and that can be introduced immediately to support community care.

Early in 2019, HIQA published the National Standard on Information Requirements for a National Electronic Patient Summary, which defines the situations in which the patient summary will be used—also known as the unscheduled care use case. It also defines the clinical dataset—that is, the clinical information—that is expected to be included in a national electronic patient summary for Ireland. The *Terms of Agreement between the Department of Health, the Health Service Executive and the Irish Medical Organisation regarding GP Contractual Reform and Service Development (2019)* includes a commitment to support the introduction of summary care records, compliant with the National Standard.

Expected benefits

Internationally, a national electronic patient summary has been shown to provide benefits for patients, health and social care providers and organisations, in particular improving medication safety and patient care in out-of-hours and emergency care settings. The benefits identified for patients include:

- improved efficiency of care by reducing the 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.

Background to the Recommendations

Owing to the potential benefits expected from summary care records, which have been outlined in earlier publications, the Health Information and Quality Authority has focused significant research on a national electronic patient summary. To date, HIQA has:

- published an international review summary care records (2016)[1]
- published clinical datasets for diagnosis, allergies, and procedures[2,3,4,5]
- developed National Standard on Information Requirements for a National Electronic Patient Summary in Ireland (2018).[‡]

In particular, the National Standard on information requirements for a National Electronic Patient Summary (2018) defined the clinical dataset for the clinical data that would be exchanged as part of a national Irish implementation: subject of care, health conditions, procedures, allergies, vaccinations, and medications. Subsequently, HIQA undertook to develop a set of Recommendations concerning the implementation of a national electronic patient summary, conformant to the National Standard. As part of the Recommendations development process, HIQA undertook a Best Practice Review of Patient Summary/Summary Care Record Implementations in nine other jurisdictions. The findings of the review outlined the benefits realised from these implementations—these findings are summarised later in this section.

Early findings from the Best Practice Review were also presented to the first meeting of the specially convened Advisory Group, consisting of representatives from a range of stakeholder organisations (listed in Appendix B). The Advisory Group noted that differences in implementation approach often seemed to result from the character and maturity of the eHealth landscape in the jurisdiction at the time of implementation. Given that many implementations had occurred more than 10 years previously, it was deemed prudent to undertake an As Is review of the national eHealth landscape in Ireland, to provide a clearer picture of the national eHealth programmes, projects, and services that will be influenced by, or have an impact on, the implementation of a national electronic patient summary in Ireland.

[‡] Information requirements are minimum set of data items that should be implemented in information systems that create and transfer information to support the delivery of safe and quality care to patients.

Thus, these Draft Recommendations are informed by the findings of

- a Best Practice Review of summary care records
- an As Is assessment of the national eHealth programmes, projects, and services that will be influenced by, or have an impact on, the implementation.

Findings from best practice review on benefits realised

A best practice review of the national implementations of patient summaries in nine jurisdictions was undertaken, with a view to informing Recommendations to the Minister for Health in respect of the Irish implementation of a national electronic patient summary. The implementations in the respective jurisdictions had very different starting points, in terms of the installed base, leading to a variety of approaches to implementation:

Country	Name	Status	Description
Scotland	Scottish Emergency Care Summary	Implemented	Standalone patient summary system
England	English Summary Care Record	Implemented	
Northern Ireland	Northern Ireland Emergency Care Record	Implemented	
Norway	Norwegian Summary Care Record	Implemented	Patient summary on landing page of EHR
Andalucía, Spain	[DIRAYA Landing page]	Implemented	
Finland	Finnish Patient Summary	Scheduled	Central data repository, feeding patient summary
Estonia	Time Critical Data Service	Implemented	
Denmark	Danish Patient Summary	Under consideration	Clinical document exchange using message broker
Austria	Austrian Patient Summary	Under consideration	Clinical document aggregation platform

Some commonalities emerged—for example, each country or jurisdiction reviewed had identified the need to make a succinct summary of a patient's key clinical information

available to authorised healthcare practitioners during episodes of unscheduled care, reflecting the Irish use case.

In England, Scotland, and Northern Ireland, the patient summary was introduced as a standalone implementation, ahead of the introduction of shared care records and electronic health records. In the Norwegian healthcare record system and in DIRAYA, the healthcare record system in the Spanish Autonomous Region of Andalucia, the landing page of the patient's healthcare record addresses the unscheduled care use case[§]. In Estonia and Finland, all healthcare providers are obliged by law to upload all clinical information to a central health data repository. In Estonia, the Time Critical Data Service (a type of patient summary) is then generated from marked items within this repository, while the Finnish counterpart is ready to go live. Finally, in Austria and Denmark, a patient summary is under consideration.

In England, Scotland, Northern Ireland, and Norway, the introduction of summary care records (patient summaries) was associated with the realisation of a number of benefits. In England, over 55.2 million summary care records had been created by 2019, covering 98% population, in over 99% GP practices. Over 700 Summary care records were being viewed every hour. Access to summary care records is also being rolled out to other settings including community pharmacy, hospices, and community care. Some of the benefits reported for the summary care record programme in 2018 include:

- (Emergency department) 40% of patients have medication error identified.
- (Acute pharmacy) 29 minutes saved per patient undertaking medicines reconciliation.
- (Out-of-hours) 49% of patients were guided to a more appropriate care pathway[(6)].

The Scottish Emergency Care Summary was rolled out nationally between 2008 and 2011. By 2012, clinicians working in emergency situations regard the emergency care summary as a key data source, being particularly useful for the medicines reconciliation process when patients are admitted to hospital.[(7)] In a survey of 118 clinicians (as NHS24 users), 34% said it had changed a clinical decision.[(7)]

The Northern Ireland emergency care summary was considered useful both to treat patients during episodes of unscheduled care, and as a proving ground for the introduction of the

[§] The situations in which the patient summary will be used are known as the use case.

Northern Ireland electronic care record, a shared care record. Initially, public commitment was given to use the data collected for the Northern Ireland emergency care summary strictly for that purpose—that the summary was not the surreptitious introduction of an electronic health record. This built public confidence in the programme.[8,9]

The Norwegian summary care record was identified in 2008, as a key strategic project to address the unscheduled care use in the absence of interoperability between hospital systems and GP practice management systems. Since the Norwegian summary care record was launched at the beginning of 2016, approximately 2 million Norwegian citizens (38% of the population) have accessed their own summary care record using a secure logon to the internet and approximately 315,000 citizens have entered information in their own summary care record. The Norwegian summary care record also won a privacy award from the national data protection commissioner due to all the choices that were made available to patients.[10]

Finally, findings from the Norwegian programme indicated that summary care records were particularly beneficial for three specific groups of patients:

- unconscious patients, particularly where no information was held on file for them,
- patients using multiple pharmaceutical products, and
- patients with a history of substance abuse.[11]

Methodology

The Draft Recommendations in this document were developed as per HIQA's legislative remit under the Health Act 2007 and subsequent amendments to the Act. Under the Health Act 2007, HIQA 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 HSE about deficiencies identified by HIQA in respect of the information referred to in paragraph (i).

Process steps completed

The process to develop these Recommendations typically has five stages:

- Stage 1 – undertake a Best Practice Review of national implementations in other jurisdictions
- Stage 2 – convene a Special Advisory Group to provide feedback on both the Best Practice Review and the Draft Recommendations
- Stage 3 – undertake a Public Consultation on the updated Recommendations
- Stage 4 – bring the Draft Recommendations to the Special Advisory Group
- Stage 5 – finalise then publish the Recommendations.

The first stage of the project, drafting a best practice review of the national implementations of Patient Summary (also known as summary care records) in nine jurisdictions, was undertaken by the project team. A Special Advisory Group was convened, consisting of representatives from a range of stakeholder organisations, listed in Appendix A. Early findings from the Best Practice Review were presented to the first meeting of the Group in July 2019. Cognisant of the level of variation across implementations and in the terminology used, the Advisory Group identified two new requirements:

- a set of educational materials was required to accompany the launch of the Recommendations, intended to promote understanding of key terms used.
- an As Is Review of current readiness of Ireland, to assess the national programmes, projects, and services that would be affected by, or would have an impact on, the implementation of a national electronic patient summary

The purpose of the As Is Review was to provide a set of Recommendations that were appropriate to the Irish eHealth landscape. Together, the Best Practice Review and the As Is Review informed the Recommendations by taking the particularities of the Irish eHealth landscape into consideration.

As part of the development process, and in line with its legal remit, HIQA presented the Draft Recommendations and supporting documents (Best Practice Review, As Is Review, Terminology Working Paper) to the second meeting of the specially convened Advisory Group. The Advisory Group made submissions, which HIQA took under advisement and appropriate changes were made to the Draft Recommendations for Consultation following the Advisory Group meeting.

Next steps

A six-week public consultation will be undertaken on the Draft Recommendations for Consultation, running from Tuesday, 4 August to Friday, 11 September 2020. Focus groups and groups interviews will be undertaken subsequently, with selected stakeholder groups including patients, GPs, and others.

Once the public consultation is complete, the Draft Recommendations for Consultation document will be updated with all accepted changes and then circulated to the Advisory Group for review at the final meeting. The final Draft Recommendations will then be approved by each level of the HIQA organisation — Directorate, Executive Management Team, and Board — before being submitted to the Minister for Health and being published on the HIQA Website.

Chapter 1 Legislative framework

In each country, the implementation of a national electronic patient summary was typically part of a wider, long term eHealth strategy that covered related capabilities, such as electronic prescribing. Responsibility for implementation of eHealth services was assigned to different national bodies in the respective countries, typically a dedicated national eHealth strategic organisation. Prior to implementation, the existing legislative and information governance framework was analysed and gaps were identified, with requisite legislation enacted as needed to support the introduction of the patient summary in the context of other eHealth services.

The legislative framework varied considerably from jurisdiction to jurisdiction: from jurisdictions where legislation was introduced specifically for electronic patient summaries, or for electronic health records, to jurisdiction where legislation was passed specifically for large scale digital solutions for health and social care. Several brief examples may illustrate the variety of approaches.

Estonia began the digitization of government services in 1991, laying the foundations of the legislative framework for electronic services. Legislation was passed in 2002 specifically to enable the exchange of health data, equalising digital and paper records. The national infrastructure for Government eServices, including eHealth, was established in 2004, while key components for healthcare, such as strong authentication, obligations to send data, and patients' rights were introduced through legislation in 2007. Thus, the Time Critical Data Service—which fulfils the same functional as a national electronic patient summary—was introduced into an existing framework of legislation and required no legislative changes.

In England, legislation and regulations relating to health and medical practice make reference to the medical records in both paper and electronic form. Thus, no legislation specifically for Electronic Health Records or patient summary records was introduced in England. However, legislation relating to specific aspects of electronic records was required—for example, legislation regulates the types of systems that GPs can use.

And in Norway, many hospitals and all GPs were using electronic records since the early 2000s. However, the introduction of the Norwegian summary care record still required a change to the Health Act. Following allocation in the National Budget for that year, the pilot project was initiated several months ahead of the legislative change.

Within these legislative frameworks, jurisdictions also varied in their approaches to patient consent and the control of data, with the approach taken being strongly influenced by the specific national context. Thus, no single model that fits the Irish context could be identified. In several jurisdictions national patient summaries are considered to be clinician-to-clinician communication, with lower levels of patient and public engagement. However, many jurisdictions recognised the importance of public trust—for example, to understand expectations around the control of data—and undertook extensive patient and public engagement to determining the consent model adopted and how data is controlled. Therefore, extensive patient and public engagement in this area is recommended — this is dealt with in a separate recommendation.

1.1 Recommendations

HIQA makes the following recommendation:

Legislative framework	
1.1	Clarity—in the form of national policy and legislation—is required to support the implementation of large scale digital solutions, as set out in Sláintecare. Specifically, a gap analysis of current legislation and regulations should be undertaken and addressed with new legislation or regulations enabling the implementation of national digital solutions, including a national electronic patient summary.

Chapter 2 Programme governance

Eight of the nine countries reviewed adopted a 'middle-out' implementation model—where Government, industry, and clinicians collaborate to create a framework of national standards for interoperability while national and local needs were balanced. This approach is considered to be the most successful and, in many countries, the national standard for the clinical datasets was defined collaboratively in this way.

Programme governance bodies were also established, to provide national oversight and operational oversight, while regional health authorities retained responsibility for implementation within their region. The 'middle-out' approach was reflected in the governance structure, which typically included a broad range of representatives drawn from across stakeholder groups.

In the jurisdictions reviewed, the governance structure for the implementation typically consisted of a national board, with responsibility for the overall project direction and oversight. Additionally, a national group with operational responsibility was appointed, continuing post implementation. Each successful national programme was championed by at least one clinical programme sponsor and had clinical representation at all levels of the governance structure. Extensive patient and public involvement in governance was also important.

For example, in Scotland, the Emergency Care Summary Project Board, reporting to the eHealth governance body, was responsible for all aspects of the programme including the business case and the implementation of the system, while the Emergency Care Summary Service Board was responsible for the day to day operational management of the system. Scottish National Health Service Trusts were responsible for pilot projects in their region ahead of national rollout.

In Ireland, the Department of Health is responsible for the legislative and policy framework for the national electronic patient summary as well as for that of the wider eHealth programme. Since 2013, the strategic policy framework for eHealth in Ireland has evolved, with the Department of Health publishing the Sláintecare Implementation Plan in 2018 and

currently working on a national policy document concerning health information. Over the same period, the Health Service Executive has established a number of crucial programmes, projects, and services--including the (National) Electronic Health Record strategic programme, with workstreams for the (National) Shared Care Record. In line with both its remit and the 'middle out' implementation model, HIQA has worked collaboratively with all stakeholders to agree and publish national standards for eHealth interoperability supporting these strategic programmes, projects, and services.

2.1 Recommendations

HIQA makes the following recommendations

Programme governance	
2.1	In line with best practice internationally, and cognisant of the Irish eHealth landscape and existing governance structures, the following governance structure be established for the implementation of a national electronic patient summary: ▪ A Patient Summary Project Board with responsibility for national delivery should be established, reporting to the EHR Steering Group, which is currently jointly chaired by the Chief Operating Officer and Chief Clinical Officer. The Project Board should be chaired by the Chief Clinical Information Officer, representing the Chief Clinical Officer. ▪ The Chief Clinical Officer should act as the national sponsor for the programme at the executive level, ensuring that the programme has appropriate executive oversight and with overall responsibility for the agreement of the scope and roadmap of the implementation programme. ▪ The Project Board should also maintain a working relationship with the HSE Digital Oversight Group, within the terms of reference of that group.
2.2	The Project Board should also have representation from all entities involved in the programme—such as ▪ policy and legislative organisations, ▪ Health Service Executive programmes, ▪ standards organisations, ▪ professional representative bodies, such as for general practice and pharmacy, ▪ patient/public organisations, ▪ public and private hospitals, ▪ the vendor community. Internationally, two stakeholder groups were identified as critical to the success of the implementation: clinical groups and patients/the public. Therefore, both groups should be well-represented at all levels of the governance structure, as outlined in Recommendations 3.1, 3.2, 3.3 on Stakeholder Engagement.

2.3	In line with both international best practice and with HSE guidelines, following the launch of the programme, an appropriate ongoing governance mechanism should be established—including a Change Advisory Board chaired by the Chief Clinical Information Officer.

Chapter 3 Stakeholder engagement

Stakeholder engagement has been shown to be a critical workstream of each national implementation. The English summary care record implementation programme was temporarily stopped and adapted, in response to concerns by clinical stakeholders (British Medical Association) and civil liberties groups. Following simplification of the consent model and of the clinical dataset, and the efforts of two clinical champions, stakeholders were reengaged and the programme resumed. Such enthusiastic clinical champions appeared to play a vital role in garnering support from the professional stakeholder groups, such as clinical representative groups, and the wider public.

In contrast, the first year of the successful Scottish programme focused on engaging all clinical groups as stakeholders, through the efforts of clinical champions, and making progress at a rate that suited all groups. A national campaign, with a leaflet to every household, also ensured that patients and the wider public were engaged. This gave the opportunity to understand how comfortable members of the public were with new digital technologies in healthcare such as national electronic patient summaries, and with the use of personal health information for direct patient care. It also gave an indication of how and when individuals like to be asked for consent for use of that personal health information and their general levels of trust in how well the healthcare professionals, as well as organisation and the government, would safeguard that information.

Understanding and addressing those concerns was crucial to the successful introduction of the summary care records (national electronic patient summary) in Northern Ireland and Scotland. Both countries sought to build public trust by implementing a very tightly controlled dataset and being very clear to use it only for that purpose. The respective clinical datasets had obvious clinical benefit for patients, and rapidly won public support. Both programmes also worked to allay concerns that the Patient Summary was the surreptitious introduction of an electronic health record system—for example, in Northern Ireland, the commitment was also given that this data would be used only for direct healthcare, which built public trust.

To inform and influence key decisions on these matters, it is essential to engage with the public at the earliest possible opportunity. Therefore, it is essential that the Irish public is engaged early and that the public's attitudes to the following areas are well understood:

- Use of personal health information for both direct patient care, and for secondary purposes such as service planning, quality improvement and healthcare management.
- Use of new digital technologies in healthcare, such as electronic health records, electronic patient summaries and patient portals.
- How and when consent should be sought to use their personal health information.
- Levels of trust in the safeguarding their personal health information by healthcare professionals, organisations and government.

HIQA is developing recommendations on a consent model for the collection, use and sharing of personal health information in Ireland. The recommendations development process will include a national public engagement survey that will be undertaken to provide knowledge and understanding in relation to public opinion on the use of health information, electronic health records and other eHealth initiatives. It is intended that this national survey will be completed during 2020 and published in early 2021. The survey findings will also inform recommendations to the Minister for Health that will be published in 2021.

3.1 Recommendations

HIQA makes the following recommendations:

Stakeholder engagement	
3.1	Review of international best practice shows that the effective engagement of stakeholder groups is essential to the successful implementation of the programme. Therefore, the Patient Summary Project Board should develop a comprehensive stakeholder engagement plan, identifying all stakeholder groups and engaging them consistently and appropriately over the implementation and during the post-implementation phase.
3.2	In particular, clinical ownership has been shown to be a critical factor in the acceptance and use of a national electronic patient summary, with clinical champions playing a decisive role. The clinical champions should be identified and supported to engage clinical groups—for example, within each region where a regional structure is devised.
3.3	Patient and public perceptions of the implementation have also been found to be a key determinant of implementation success. This engagement is essential to the success of both the implementation of a national electronic patient summary and the implementation of other national eHealth solutions for health and social care. Based on expert advice, public champions should also be identified and supported to engage patients and the public, to ensuring their full participation in this process.

Chapter 4 National health identifiers

In every jurisdiction reviewed, a national health identifier and demographics database were established ahead of the implementation of the patient summary. In England, this new demographics register was part of a new infrastructure, aimed at supporting a wider programme of eHealth services. In Northern Ireland, the introduction of the Northern Ireland Emergency Care Summary provided the opportunity to identify and resolve any issues with the existing demographics database, ahead of the introduction of the more complex Northern Ireland Electronic Care Record. Thus, international evidence shows that the implementation of a national health identifier and a national demographics database are crucial prerequisites to the implementation of a national electronic patient summary, as well as other eHealth capabilities, in Ireland.

The Individual Health Identifier Act (2014) provides the legal basis for a national health identifier for Ireland, for service users and service providers and, subsequently, HSE established the Health Identifiers strategic programme to implement Individual Health Identifiers (IHI) nationally. The Sláintecare Implementation Plan holds the implementation of the Health Identifiers Act 2014 to be critically important, enabling the connecting of information across a fragmented system.

The technical infrastructure for the Health Identifier Index is in place and populated with 6.7 million IHIs relating to current and former residents of Ireland, as notified by the Department of Employment Affairs and Social Protection. The technical mechanisms for providing the IHI to consumer technical systems are also in place and programmes of work are underway to integrate the IHI with numerous systems.

At the time of writing, all GP practice management systems and all patient administration systems using iPMS PAS system version 5 can store and display the IHI. The following systems are capable of consuming the IHI:

- Maternal Newborn Clinical Information System (Maternity)
- National Medical Laboratory Information System (Laboratory)
- National Integrated Medical Imaging System (Radiology)
- Primary Care Eligibility and Reimbursement Service

The IHI is injected into all eReferrals travelling across the National Messaging Broker (Healthlink), where there is sufficient demographic data provided to match with the IHI. Individual Health Identifiers and Eircodes are also provided for the

- National Treatment Purchase Fund
- Hospital In-Patient Enquiry System
- Single Assessment Tool Information System.

A programme of work is underway to inject the IHI and Eircode into all messages using Healthlink.

4.1 Recommendations

HIQA makes the following recommendation:

National Health Identifiers	
4.1	The Individual Health Identifier (IHI) and associated demographic dataset should be operationalised in all projects, programmes, and services supporting a national electronic patient summary.

Chapter 5 Sources of information

In line with both its remit and a 'middle out' implementation model, HIQA worked collaboratively with all stakeholders to agree and publish the National Standard on Information Requirements for a National Electronic Patient Summary (2019), which defines the clinical dataset:

Area	Description
Subject of care	The patient's demographic details for the purpose of an electronic patient summary.
Health condition	The patient's current health condition, which includes health problems or diagnoses.
Medication prescribed	A list of the current medications prescribed for the patient.
Allergies	The agent that is responsible for the adverse reaction, including allergies, intolerances and adverse reactions to all substances, not only those arising from medications.
Procedures	A clinical activity carried out for therapeutic, evaluative, investigative, screening or diagnostic purposes.
Vaccinations	Details of immunisations or vaccinations that have been administered to the patient.

5.1 Healthlink, the national messaging broker

Healthlink is the National Health Messaging Broker, with a core remit to provide a secure, standardised messaging service. Any hospital or secondary healthcare facility can send messages to GPs through a central database managed by Healthlink, while GPs use a web interface to access messages sent to them.[12] The main purpose of Healthlink is to facilitate the exchange information of structured patient information, compliant with national and international health messaging standards, enabling the integration and interoperability of health systems. Healthlink uses the IHI as well as other identifiers. Patient information is generated on the source system and transferred to and from Healthlink using secure network connections. Message files are formatted in HL7 which is an internationally

recognised standard for exchanging information between healthcare applications. Healthlink is fully compliant with the national General Practice Messaging Standard, published by HIQA.

The following programmes use Healthlink for the electronic exchange of messages:

- **National Cancer Control Programme (NCCP)**: in collaboration with Healthlink, GPIT and the HSE, has developed electronic referral forms for breast, prostate, lung and most recently, pigmented lesion cancer.
- **National Electronic General GP Referral**: delivers electronic general referrals, using the HIQA-ICGP standard referral template. A collaboration between Healthlink, HSE, ICGP, GPIT, NCCP and the Outpatients Performance Improvement Programme, the general referral form is integrated in the GP software systems. Therefore, the patient information is auto-populated thereby cutting down on the time taken to place a referral.
- **Laboratory Ordering**: gives GPs and practice nurses the ability to order blood tests online, replacing the manual order form.
- **GP messaging***: the full suite of Healthlink messages available are as follows:
    - Laboratory Orders
    - Laboratory Results
    - Radiology Results
    - A & E Attendance Notifications
    - Inpatient Admissions
    - Death Notifications
    - Discharge Notifications
    - Discharge Summaries
    - OPD Appointment Updates
    - Outpatient Clinic Letters
    - Waiting List Updates
    - Out of Hours Co-op Messages
    - Cardiology Reports
    - Referral Response Messages

*Hospitals vary in terms of the adoption of electronic messaging for communication with GPs.

The high level roadmap for Healthlink at present is to enable the delivery of the current priorities for the HSE Office of the Chief Information Officer (OCIO) in the following areas:

- Referrals
- IHI
- Laboratory results
- Waiting lists
- Enterprise appointment scheduling for referrals, screening, telehealth consultations and so on.
- Vaccinations
- ePrescribing and medications.

HIQA was advised that any clinical message exchanged over Healthlink is a potential information source for the patient summary dataset. Also, that the referrals that are compiled for a patient that are delivered via Healthlink have the potential to provide information on the clinical information categories in the national electronic patient summary: Subject of care, Health conditions, Medication prescribed, Allergies, Procedures, Vaccinations. Upon delivery of ePrescribing as per Sláintecare, which will rely on messaging provided by Healthlink, it will be possible to source medication information.

5.2 General Practice Information Systems as a source of information

The *Terms of Agreement between the Department of Health, the HSE and the IMO regarding GP Contractual Reform and Service Development* (2019) outline the planned introduction of the national electronic patient summary (called a 'summary care record') with a clinical dataset compliant with the National Standard. Under the *Agreement*, it is expected that a national shared care record will to expand the patient summary dataset, providing a longitudinal record of the treatment across healthcare settings—for example, for chronic conditions. The *Agreement* outlines the expectation that the patient summary will be populated from GP practice management systems.

The *Agreement* covers some key eHealth measures needed to support the implementation of the national electronic patient summary. The document estimates that 95% of GP practices currently use accredited systems. The document also outlines how the State and GPs will work to support the implementation of eHealth solutions from 2019 to 2022-3, through cooperation and compliance with the following eHealth services:

- **Individual Health Identifiers**: by 2022, 85-90% of GP practice management systems should comply with the national IHI programme and incorporate IHI numbers for all citizens.
- **ePrescribing solution**: GPs will participate in the development of the solution, with 85-90% uptake of the solution by 2023.
- **Integrated immunisation system:** GPs will participate in the development of the solution, with 90% uptake of the solution by 2023.

The GPIT group considers that, with appropriate resourcing, GP practice potentially is the quickest and easiest source of seed information for national electronic patient summary, but that population from a variety of other sources should also be considered. It provided the following assessment of GP practice management systems as a potential source of information for the clinical dataset:

Area	Description	General practice as source
Subject of care	The patient's demographic details for the purpose of an electronic patient summary.	Likely to yield better quality demographic data than other sources of healthcare data, with the patient's GP as chief provider and IHI linkage improving quality and accuracy.
Health condition	The patient's current health condition, which includes health problems or diagnoses.	Quality of morbidity data is unknown
Medication prescribed	A list of the current medications prescribed for the patient.	Likely to provide useful information, as most GP use general practice software to generate prescriptions. Not all GPs keep this list up-to-date, so would require GP's validation before upload.
Allergies	The agent that is responsible for the adverse reaction, including allergies, intolerances and adverse reactions to all substances, not only those arising from medications.	Likely to provide useful information, but would require GP's validation before upload.
Procedures	A clinical activity carried out for therapeutic, evaluative, investigative, screening or diagnostic	May hold historical data, less likely to be coded. Best populated from hospital HIPE and day services databases.

	purposes.	
Vaccinations	Details of immunisations or vaccinations that have been administered to the patient.	GPs currently provide: ▪ childhood immunisations up to age of 13 months ▪ some pre-school vaccinations ▪ many influenza and pneumococcal vaccinations. Direct reimbursement means GPs should have reliable records, with high quality data.

The GPIT Group considered GP practice management systems as likely to be the most complete source of demographic data for any patient as well as a possible source allergy and vaccination information. It noted that the quality of data currently in GP practice management systems is unknown and should be assessed, cognisant of the implementation of the IHI which is expected to improve the quality and accuracy of such data. It recommended that the procedures data in the Hospital Inpatient Enquiry system should be evaluated as a potential source of World Health Organisation International Classification of Diseases 10 (ICD-10) coded procedure information and that other data in HIPE should also be evaluated.

While GP practice records may be a rich potential source of clinical information, the General Practice IT Group also cautioned that it does not have access to good quality information on the extent and accuracy of coded medical information in GP practice management systems. Significant limitations exist including: variability in how information is recorded, poor transfer of information from other healthcare services, and design of software. Many practices struggle to meet demand and would require additional clinical and administrative resources to ensure proper review of every patient's record within the practice.

5.3 Primary Care Eligibility and Reimbursement Service as a source of information

The Primary Care Eligibility and Reimbursement Service was identified as a potential source of information, in particular regarding medications, in the programme's own submission and in a Review of the Hospital In-Patient Enquiry system by HIQA. The Primary Care Eligibility and Reimbursement Service has indicated that the following information is potentially available from its service:

PCERS Records	Potential source of d
Eligibility	Current eligibility for free or subsidised healthcare on the national health schemes.
Pharmacy Reimbursement	Proxy for medicine consumed.
Dental reimbursement	Dental treatment consumed.
GP reimbursement	GP treatment consumed, as well as the person's choice of doctor on the General Medical Scheme.
Optical reimbursement	Optical healthcare consumed.
Vaccination	Vaccinations received.
European Health Insurance	Periods of insurance cover.

However, a small pilot project, where hospital pharmacists were given access to pharmacy records through the PCERS hub, identified several limitations with the use of PCERS medicines data.

Prescribed medicines information is available for only medicines reimbursed by PCERS, and is not available patients who are not on any such scheme, such as patients using private schemes. Where the PCERS information is available, it does not include the dosage, frequency, or directions for use. And because PCERS information is updated monthly, the information becomes less up-to-date as the month passes. Additionally, in a small number of cases, information for more than one individual was returned because of legacy use of one identifier for family members. Hospital pharmacists in the pilot scheme were trained in medicines reconciliation and clearly understood the limitations, while valuing the system. HIQA was advised that other clinical staff might require medicines reconciliation training to interpret the data.

5.4 Hospital In-Patient Enquiry service as an information source

The Hospital In-Patient Enquiry records demographic, clinical and administrative data on discharges and deaths in acute public hospitals nationally for episodes of care using ICD-10. An episode of care begins when a patient is admitted to hospital, as a day case or inpatient and ends at discharge from (or death in) that hospital. HIPE includes a principal diagnosis,

up to 29 additional diagnoses and up to 20 procedures, coded using ICD-10. However, the Hospital In-Patient Enquiry service is used only within public acute hospitals, leaving a gap in this data—for example, with regard to activity carried out in private hospitals.

5.5 Community pharmacy as a source of information

Community pharmacy management systems could provide the comprehensive list of medicines for each patient. Community pharmacy records cover the medicines dispensed for a broader range of public and private patients. The dispensed medicines information includes the dosage, frequency, and directions for use and would represent almost all prescribed medicines, in a way that is readily understood by healthcare professionals. Thus, pharmacy practice management systems are likely to provide more complete records of medicines dispensed for public and private patients, and include information that is currently missing from the PCERS database. However no information was available at the time of writing about the quality of data in pharmacy practice management systems.

Pharmacy legislation makes provision for certain pharmacy records to be maintained in electronic form in line with certain conditions—including that the records be validated and certified independently, by a person approved by the Minister for Health. Pharmacy systems have not been validated independently. The Pharmaceutical Society of Ireland has requested that the Department of Health appoint a person or body, to carry out this independent validation and certification, which the Society considers a key enabler of eHealth. This validation would ensure that pharmacy practice management systems could be used as an accurate source of a patient's personal medical information for a Patient Summary or electronic health records.

5.6 Other potential information sources

The National Immunisation Office, which is responsible for the publicly funded vaccination schemes, notes that there is no national oversight, excepting the National School Immunisation System. All records are manually transcribed into each system. Thus, a total vaccine record for a patient is fragmented and may be held on several systems. It is hoped that this situation will be rectified by the new National Immunisation Information System, which is expected to provide a single, national immunisation record for each patient.

The current status of the new system was not available at the time of writing. However, the *Terms of Agreement between the Department of Health, the HSE and the IMO regarding GP Contractual Reform and Service Development* outline the goals in relation to an integrated, national immunisation system, with GPs expected to participate in the development of the solution, and with a goal of 85-90% uptake of the solution by 2023.

As noted earlier, GPs currently provide childhood immunisations up to age of 13 months, some pre-school vaccinations and many influenza and pneumococcal vaccinations. Direct reimbursement means GPs should have reliable records, with high quality data. Currently, all vaccination administrations must be notified to the HSE within seven days of administration. However, the vaccination record can be submitted on paper or electronically through PCERS. Relevant information must also be forwarded to the patient's GP within seven days, on paper or electronically, including administration of ephedrine for the emergency treatment of anaphalyxis following vaccine administration.

Similarly, GPs expected to participate in the development of the national ePrescribing solution and the goal for their uptake of the solution is 85-90% by 2023. The goal of the national ePrescribing solution is to provide a safer and better way for clinicians to prescribe, and for community pharmacists to dispense, medicines to patients. The objective is to implement a single, national solution for all prescribing in primary care in Ireland, which is as simple and safe as possible for prescribers and dispensers, and which reduces the medication errors associated with paper prescribing. This national ePrescribing solution may also need to be considered as a potential information source, as would other future national registries as they come online.

5.7 Summary of potential sources of information

The following tables summarize the findings regarding each of the information sources considered. The first table indicates the type of data potentially available from each information source, in terms of national coverage. The second table then examines each potential information sources as a likely source for a national electronic patient summary in Ireland.

Area	GP**	Pharmacy	PCERS	HIPE	Other	Best source
Coverage	***High*** *– almost nationwide*	***High*** *– almost nationwide*	***Medium/low*** *- Public scheme reimbursement only*	***Medium/low*** *- Public acute hospitals only*	*Various*	***National programme***
Subject of care	Likely most complete source, with IHI.	To be determined	Demographic information	Demographic information	N/A	IHI
Health condition	Quality of data unknown	To be determined	N/A	Principal diagnosis, with up to 29 additional diagnoses. Coded using ICD-10	Healthlink referrals and discharge summaries – quality of information unknown	None
Medication prescribed	Medicines prescribed electronically.	Medicines dispensed at community pharmacies	Medicines dispensed	N/A	Healthlink – some prescribing information transmitted	Community Pharmacy/GP
Allergies	Useful information should be available but would need confirmation by GP.	To be determined	N/A	None	Healthlink referrals and discharge summaries – quality of information unknown.	GP
Procedures	May contain some historical data.	To be determined	Procedures reimbursed	Up to 20 procedures. Coded using ICD-10	Healthlink referrals and discharge summaries – quality of information unknown.	None
Vaccinations	• childhood (to 13 months) • some pre-school • many influenza / pneumococcal	May have information on some vaccinations administered in community pharmacies.	Vaccinations notified electronically only	N/A	National Immunization Database Schools immunization programme	GP (in conjunction with other sources)

** All data from GP practice management systems is likely to require clinical review.

The following table assesses each potential sources of information:

Area	GPIT	Pharmacy	PCERS	HIPE
Coverage	**High** – almost nationwide	**High** – almost nationwide	**Medium/low** - Public scheme reimbursement only	**Medium/low** - Public acute hospitals only
Data quality	**Unknown**	**Unknown**	**Medium -** Medicines data missing dosage and other information	**High** - coded using ICD-10
Update frequency	**High** – at consultation	**High** – at dispensing	**Medium/low** – Monthly	**Medium** – on discharge or death
Other factors	Data requires clinical review, necessitating significant additional resources	Certification not in place	None identified	None identified
Overall	Requires ▪ Data quality and completeness to be assessed ▪ Additional resourcing to be assessed	Requires ▪ Certifying body to be appointed ▪ Data quality and completeness to be assessed	**Not suitable** for national programme unless limitations are addressed	**Not suitable** for national programme unless limitations are addressed

The Primary Care Eligibility and Reimbursement Service is limited to reimbursements under public schemes. Similarly, the Hospital In-Patient Enquiry system covers only diagnoses and procedures in public acute hospitals. General practice management systems are likely to provide the most complete source of demographic information and may be a source of information about vaccinations and allergies—this reflects the implementations in England, Scotland and Northern Ireland, where GP practice management systems populate the respective summary care records. However, the data quality and the level of clinical coding in Irish GP practice management systems is unknown. Community pharmacy management systems typically list the medicines dispensed for public and private patients. Again, information on data quality and the level of clinical coding in such systems was not available at the time of writing.

5.8 Conclusion

To clearly identify the most appropriate sources for a national electronic patient summary, the essential criteria for inclusion should be developed. These criteria should include the quality of data and information in the source, such as the accuracy, the completeness, and update frequency of the data. Potential information sources should be assessed against these criteria, in order of priority. From the summary in the earlier table, GP practice management systems and community pharmacy management systems can be considered to be the highest priority information sources for assessment against the essential criteria.

The other existing national systems—such as the Hospital In-Patient Enquiry System and Primary Care Eligibility and Reimbursement Service—and other potential (future) information sources mentioned earlier—such as the National Immunisation Information System and the national ePrescribing service—should be assessed against these inclusion criteria and brought on board as appropriate. As part of this process, mechanisms should be put in place with data controllers to work towards the improvement of the quality of data in the information sources identified to provide information to a national electronic patient summary, in the context of the overall Sláintecare Implementation Plan.

A comprehensive skills and training programme should also be implemented for the intended user base, to ensure that the content of a national electronic patient summary is well-understood. Given the findings regarding overestimation of the reliability of automatically-updated data, the accuracy, completeness and update frequency of patient

summary information should be clearly communicated to the users and understood by them, with appropriate protocols introduced—for example, triangulation with another source, where the clinician checks the information in the patient summary with the patient or their carer.

5.9 Recommendations

HIQA makes the following recommendations:

Information sources	
5.1	Essential criteria for inclusion should be developed for the assessment of all potential information sources for the national electronic patient summary. These criteria should include the quality of data and information in the source, such as the accuracy, the completeness, and update frequency[††] of the data. HIQA considers GP practice management systems and community pharmacy management systems as the highest priority information sources for assessment against the essential criteria. Additionally, other existing national systems—such as the Hospital In-Patient Enquiry System and Primary Care Eligibility and Reimbursement Service and the national messaging broker Healthlink —and other potential (future) information sources—such as the National Immunisation Information System and the national ePrescribing service—should be assessed against the inclusion criteria and brought on board as appropriate.
5.2	Mechanisms should be put in place with data controllers to work towards the improvement of the quality of data in the information sources identified to provide information to a national electronic patient summary, in the context of the overall Sláintecare Implementation Plan.
5.3	The Project Board ensures that a comprehensive skills and training programme be implemented for the intended user base, to ensure that the content of a national electronic patient summary is well-understood. In particular, the accuracy, completeness and update frequency of patient summary information should be clearly communicated to the users and understood by them, with appropriate protocols introduced—for example, triangulation with another source, where the clinician checks the information in the patient summary with the patient or their carer.

[††] Update frequency means how often the data is provided to the national electronic patient summary.

Chapter 6 Phased implementation

International evidence has shown that each jurisdiction identified the unscheduled care use case[‡‡] as essential for safer, better care, thereby recognising the value of a national electronic patient summary, (also known as a summary care record). However, in each jurisdiction, the unscheduled care use case was addressed at different points of the national roadmap, which also encompassed other national eHealth systems. The phased implementation of a national electronic patient summary in Ireland needs to be considered in the context:

- of best practices from implementations in other jurisdictions
- of the national roadmap.

As part of their respective national roadmaps, Finland and Estonia had each established a national health data repository, with healthcare providers obliged by law to upload health information to the respective repository. Healthcare services, such as the Estonian Time Critical Data Service addressing the unscheduled care use case, were then generated dynamically from this data.

In Norway, electronic medical records had been used in GP practices respectively and in hospitals since the early 2000s, but were not interoperable. The Norwegian summary care record (patient summary) was implemented nationally in 2014, drawing information from the existing electronic medical records and several national registries, including a national demographics database and a national prescription repository.

In Northern Ireland, the national summary care record implementation was the first stage of the national roadmap, with a ready source of well-structured medications and allergies information available from GP practice management systems. The implementation was based on the earlier Scottish implementation, which in addition to well-structured medications and allergies information from GP practice management systems used the existing, national e-Prescribing service. As in Northern Ireland, once the Scottish implementation was successful, the patient summary dataset was extended, addressing the chronic disease care use case.

[‡‡] The situations in which the patient summary will be are known as the unscheduled care use case.

Before the implementation of the Northern Ireland Emergency Care Summary, public concerns had been raised around 'introduction of electronic health records by the back door'. Thus the programme committed to collecting only the information that was necessary for the patient summary—a tightly controlled, well-understood dataset consisting of demographic information, medications prescribed, and allergy information—and undertook extensive public engagement, including a leaflet drop to every household in Northern Ireland.

This approach built public trust in the Northern Ireland Emergency Care Summary and in electronic healthcare records generally, whilst also provided an opportunity to identify and address broader operational issues—for example with the demographics database. It also provided an opportunity to improve clinical coding, providing high quality data for use throughout the health system. This contributed to success in later stages of the roadmap, with the implementation of the Northern Ireland Electronic Care Record, incorporating the Northern Ireland Electronic Care Summary (patient summary) and for the planned implementation of Encompass.

The full clinical dataset has been defined in the National Standard on Information Requirements for a National Electronic Patient Summary.[13] While it is generally recommended that this clinical dataset be implemented in full, it should be noted that some jurisdictions, responding to the availability of high quality data and the existing eHealth infrastructure, did start with a subset of clinical information, then successfully implemented other clinical information in later phases.

Thus, in the jurisdictions reviewed, the patient summary has been implemented at different stages of the national roadmap, strongly influenced by factors such as the availability of high quality data, the availability and interoperability of other national registries and systems, and public opinion on the implementation.

Therefore, rather than constrain the national roadmap, HIQA recommends that, informed by the findings of Recommendation 5, Information Sources regarding potential sources of information, that a mechanism be put in place to work towards the improvement of data quality in systems that will provide source information for the patient summary. The mechanism should first identify the potential sources required for a patient summary, then

(where necessary) outline the pathway to bring those elements up to date. International evidence has shown that each jurisdiction identified the unscheduled care use case[§§] as essential for safer, better care, thus recognising the value of a national electronic patient summary, (also known as a summary care record). However, internationally, these implementations also provided opportunities and learnings for the longer term implementation of electronic health records.

Regardless of the roadmap stage, most jurisdictions undertook a phased implementation of the patient summary itself. Taking three and a half years, the Norwegian phased implementation perhaps provides the most comprehensive example:

- Phase 1 — Small, well-controlled pilot (2013)
- Phase 2 — Extended pilots, one in each Regional Health Authority (2015-6)
- Phase 3 — Full national implementation (2016)
- Phase 4 — Post implementation support.

The implementation consisted of a pilot phase, to test the summary care record and methods of implementation. Next, the regional implementation phase was undertaken in cooperation with the four Regional Health Authorities, each consisting of between 3 and 10 smaller regions or groups of hospitals.(10) The regional implementation was intended to ensure the coordination of information and launch between GPs, emergency units, and hospitals, and also to ensure that citizens had time to opt out before healthcare professionals started using the summary care record.(10) Regional pilots, each with a steering group on region progress, helped to create 'healthy competition'. Finally, the programme was rolled out nationally, with each Regional Health Authority responsible for their rollout out within hospitals and each had a plan for implementation.

To encourage uptake by end users and full realisation of expected benefits, appropriate key performance indicators (KPIs) should be developed, with engagement from end users of the system and in line with international best practice. Examples of key performance indicators from other jurisdictions include, as an absolute minimum, having patient summaries for at least 50% of the patients being treated and ensuring that a patient summary can be downloaded and read in under 30 seconds. Additionally, the interface should be well-integrated into existing systems.

[§§] The situations in which the patient summary will be used are known as the unscheduled care use case.

6.1 Recommendations

HIQA makes the following recommendations:

Phased implementation	
6.1	In line with international best practice, the national electronic patient summary be considered as an initial step in the longer term road map, providing opportunities and learnings that can feed into the implementation of the shared care record and other elements of the Sláintecare Implementation Plan.
6.2	The phases of the implementation should be determined by the outputs of the data quality assessment in Recommendations 5.1 and 5.2. If the implementation of a national electronic patient summary is split into multiple phases, at minimum Phase 1 should include the following information, in line with international best practice: ▪ Demographic information ▪ Medication ▪ Allergies Subsequent phases can be informed by assessment of other potential sources against essential criteria for inclusion—see Recommendation 5.1.
6.3	The implementation of Phase 1 of the national electronic patient summary should consist of four stages: ▪ A small pilot involving a number of GP practices linked to local out-of-hours clinic(s) and Emergency Department. ▪ Regional pilots managed by the regional steering group, with similar groupings to above, feeding back to the central programme. ▪ National rollout including demographic information and Prescribed Medicines. ▪ Post-implementation support.
6.4	To encourage uptake by end users and full realisation of expected benefits, appropriate key performance indicators (KPIs) should be developed in line with international best practice and with engagement from end users of the system. Examples of minimum performance criteria from international best practice include: ▪ Complete patient summaries should be present for at least 50% of patients with records in the system, especially patients that access out of hours or emergency care on a regular basis. ▪ It should be possible to retrieve and read a patient summary in less than 30 seconds. ▪ The patient summary should be presented through a user-friend system that also supports single sign on and appropriate security measures.

Appendix A Example Scenario

A national electronic patient summary can provide benefits for patients, health and social care providers and organisations, supporting clinical processes and improving patient care by providing timely, accurate information needed to enable better communication among clinicians, patients and other healthcare staff.

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.

The following scenario outlines how the patient summary could be used. 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, the nurse decides to review the electronic patient summary. The nurse 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.

Appendix B Advisory Group membership

Existing members of the HIQA eHealth Standards Advisory Group have been co-opted onto this group:

Organisation	Nominee
Department of Health	**Niall Sinnott** Head of eHealth & Information Policy
Enterprise Ireland	**Niall Kerrigan** Head of Global Supply Chains; Public Procurement; International Financial Institutions & SBIR at Enterprise Ireland.
General Practice Information Technology, Irish College of General Practitioners	**Dr Conor O'Shea** Irish College of General Practitioners
	Dr Johnny Sweeney National ICT Project Manager
Health Service Executive	**Alan Price** Digital Primary Care Programme
	Anne Lawlor National Patient & Service User Forum
	Dr David Hanlon National Clinical Advisor and Group Lead Primary Care
	Fran Thompson Acting Chief Information Officer
	Dr Gerry MCCarthy Emergency Medicine National Clinical Lead
	Dr Gerardine Sayers Public Health Medicine, HSE
	Loretto Grogan National Clinical Information Officer for Nursing & Midwifery
	Noreen Noonan, Deputy Delivery Director, National EHR Programme
	Peter Connolly Head of Enterprise Architecture
	Rosin Doherty Director, Access to Information and Health Identifier Programme
	Yvonne Goff Director of Scheduled Care Transformation Programme and Integrated Information Services

Irish Association of Directors of Nursing and Midwifery	**Karen Greene** Director Of Nursing, Beaumont Hospital
Irish Medical Organisation	**Val Moran** Director of Industrial Relations, General Practice, Public & Community Health
Irish Pharmacy Union	**Jack Shanahan** Pharmacist
National Standards Authority of Ireland	**Dr Damon Berry** Chair Health Informatics Steering Committee National Standards Authority of Ireland
Royal College of Physicians of Ireland	**Dr Emer Kelly** Acute Medicine and Respiratory Medicine Saint Vincent's University Hospital Dublin
Royal College of Surgeons of Ireland	**Gerry Kelliher** Business Intelligence Manager, Royal College of Surgeons of Ireland
Sage Advocacy	**Mervyn Taylor** Executive Director
Irish Platform for Patient Organisations, Science and Industry	**Derick Mitchell** Chief Executive Officer
Cairde	**Iyrna Pokhilo** Patient Representative

References

1. Health Information and Quality Authority (HIQA). *International Review of National Summary Care Records*. 2016. Available from: https://www.hiqa.ie/reports-and-publications/health-information/international-review-national-summary-care-records. Accessed.

2. Health Information and Quality Authority (HIQA) *ePrescription Dataset and Clinical Document Architecture Standard* [Online]. Available from https://www.hiqa.ie/sites/default/files/2017-01/ePrescribing-Dataset_and_CDA_Specification.pdf. Accessed on: January 2018.

3. Health Information and Quality Authority (HIQA) *National Standard Adverse Reaction Dataset and Clinical Document Architecture (CDA) template* [Online]. Available from www.hiqa.ie. Accessed on: 15 April 2019.

4. Health Information and Quality Authority (HIQA) *National Standard Diagnosis Dataset and Clinical Document Architecture (CDA) template* [Online]. Available from www.hiqa.ie. Accessed on: 15 April 2019.

5. Health Information and Quality Authority (HIQA) *National Standard for a Procedure Dataset including a Clinical Document Architecture specification* [Online]. Available from www.hiqa.ie. Accessed on: 15 April 2019.

6. Robert Jordan. *Summary care records in England.* In: KOC Deirdre Laffan, editor. 2019.

7. Greenhalgh et al. Lessons learned from the implementation of nationally shared electronic patient records in England, Scotland, Wales and Northern Ireland 2012. Available from: https://www.researchgate.net/publication/285706329_Lessons_learned_from_implementation_of_nationally_shared_electronic_patient_records_in_England_Scotland_Wales_and_Northern_Ireland. Accessed on: 2 April 2019.

8. Beattie Stephen. *Interview about Northern Ireland Emergency Care Summary.* 2019.

9. Author interview with Tony Doherty, Northern Ireland Emergency Care Summary: 2019

10. Bent Asgeir Larsen. *Summary care records in Norway.* In: LM Kevin O'Carroll, editor. 2019.

11. Dyb K and Warth LL. The Norwegian National Summary Care Record: a qualitative analysis of doctors' use of and trust in shared patient information 2018. Available from: https://doi.org/10.1186/s12913-018-3069-y. Accessed on: 10 July 2018.

12. Gaskin M and Dunne B. *Acute Floor Information System Project Brief*. 2019. Accessed on: 3 March 2020.

13. Health Information and Quality Authority *National Standard on Information Requirements for a National Electronic Patient Summary* [Online]. Available from https://www.hiqa.ie/reports-and-publications/health-information/national-standard-national-electronic-patient-summary. Accessed on: 29 January 2019.

Health Information and Standards Directorate
Health Information and Quality Authority
Unit 1301, City Gate,
Mahon,
Cork
T12 Y2XT