Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information and Standards

Recommendations on the Implementation of a National Electronic Patient Summary in Ireland

December 2020

Safer Better Care

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.
HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating health services —** Regulating medical exposure to ionising radiation.
- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.
- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

Overview of the health information function of HIQA

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 quality varies, 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:

- 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 in Ireland (2018) defined the clinical dataset that would be exchanged as part of a national Irish implementation: subject of care, health conditions, procedures, allergies, vaccinations, and current 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.*[6] The Recommendations are also informed by feedback from a six-week public consultation, as well as focus groups and interviews.

* 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.

Contents

Executive Summary

This document contains 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 essential clinical information needed to provide better, safer care to a patient during an episode of unscheduled care—such as during a visit to an out-of-hour clinic or the emergency department of a hospital. It summarises the patient's relevant demographics, health conditions, current medications, any procedures in the last six months, diagnosed allergies, and vaccinations.

The national electronic patient summary can provide huge benefits for citizens across all age groups and walks of life.[7] Citizens can be confident that the clinical information agreed for inclusion in the national electronic patient summary will be available to authorised healthcare professionals to ensure better decisions and a better care experience. Healthcare professionals can be confident that they have the information they need to make better decisions in respect of the patient's medications, care pathways, and so on. Overall, the introduction of a patient summary is expected to result in better information, better decisions, and a better experience for all involved.

Internationally, a national electronic patient summary was often introduced to improve patient safety in unscheduled care situations – the initial use case outlined in these Recommendations. In these situations, the patient summary quickly provides the basic clinical information that healthcare professionals need to treat a patient safely and effectively during an episode of unscheduled care. For example, staff in the emergency department could quickly check the patient's current medications and allergies as well as any health conditions and recent procedures. Or

at the out-of-hours GP clinic, healthcare professionals have the information they need to treat the patient safely when the patient's GP cannot be contacted.

The patient summary also proved very useful in many other care situations, giving authorised healthcare professionals a basic snapshot of clinical information for the patient they are treating. Citizens no longer had to remember or explain details of their condition and medications again and again. Or to explain details of recent procedures or of their diagnosed allergies. In several countries, the national electronic patient summary has been expanded—for example, to address treatment across healthcare settings of patients with chronic conditions or of patients requiring palliative care.

The implementation of a national electronic patient summary should also be considered as the first step in a larger roadmap, with the possibility of additional use cases being incorporated at a later stage to broaden content. Examples of additional use cases include treatment of chronic conditions across primary and secondary healthcare settings and cross-border exchange of patient summaries within the EU. In other countries, such as Northern Ireland, the implementation of a national electronic patient summary also built public trust and provided learning for the later introduction of a national shared care record and national electronic health record.

In collaboration with a range of stakeholders, HIQA developed the National Standard on Information Requirements for a National Electronic Patient Summary (2018), which defines a national electronic patient summary as 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.[8] The National Standard also defined the clinical dataset that would be included in a national Irish implementation: subject of care, health conditions, procedures, allergies, vaccinations, and current medications.

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. Following publication of the National Standard, HIQA undertook to develop a set of Recommendations concerning the implementation of a national electronic patient summary, conforming to the National Standard, in order to realise these benefits. As part of the Recommendations development process, HIQA undertook a Best Practice Review of Patient Summary/Summary Care Record Implementations in nine other jurisdictions.(6) Following feedback from a specially convened expert Advisory Group, which can be found in appendix A. HIQA also undertook an As Is Review of the Irish eHealth Landscape, to better understand the programmes, projects, and services that would be influenced, by or have an impact on, the implementation of a national electronic patient summary in Ireland.(9) HIQA then developed Draft Recommendations, which were informed by the Best Practice Review and the As Is Review.

Following input from the Advisory Group, the Draft Recommendations were made available for a six week public consultation. Focus groups and interviews were also undertaken with key stakeholder groups. All feedback received from the public consultation, interviews, and focus groups was analysed and the Draft Recommendations were amended to reflect same. The Draft Recommendations were circulated to the Advisory Group for review at the Third Advisory Group Meeting. After consideration of their advice, the Draft Recommendations were amended appropriately and then submitted for internal HIQA

This document contains Recommendations that HIQA makes in respect of the implementation of a national electronic patient summary in Ireland.

Recommendations

Policy and legislation	
1.1	The Department of Health should undertake a gap analysis of current policy, legislation and regulations and any gaps identified should be addressed with new policy, legislation or regulations enabling the implementation of national digital solutions, including a national electronic patient summary.
1.2	A model to support the collection, use and sharing of personal health information is a current gap in Ireland. This is required to support the implementation of large scale digital solutions as set out in Slaintecare, including the National Electronic Patient Summary. This needs to be developed in line with current legislation, input from key stakeholders including the public. (HIQA is currently developing a set of recommendations on a consent model for the collection, use and sharing of personal health information in Electronic Health Records in Ireland.)
1.3	The Health Service Executive must ensure that a national electronic patient summary, and its implementation, complies fully with any and all relevant, existing and future national and EU legislation and regulations.
1.4	In order to ensure that individual rights are protected and that any implementation of the national electronic summary is compliant with GDPR, the Health Service Executive should carry out a Data Privacy Impact Assessment (DPIA) as an early priority.

Programme governance	
2.1	In line with best practice internationally, and cognisant of the Irish eHealth landscape and existing governance structures, the HSE should: ▪ Establish a Patient Summary Programme Board, with responsibility for national delivery.[10,11] ▪ Appoint a Patient Summary Programme Sponsor, to act as the national sponsor for the programme at executive level, ensuring that the programme has appropriate oversight and with overall responsibility for the agreement of the scope and roadmap of the implementation programme. The Chief Clinical Officer should fulfil this role.
2.2	The Patient Summary Programme Board should be chaired independently and have representation from all stakeholders involved in the programme. As potential sources of information for the patient summary, general practice and community pharmacy should be well-represented on the Patient Summary Programme Board and in the governance structure. Internationally, clinical groups and patients/the public have been shown to be critical to the success of the programme and should also be well represented at all levels of the governance structure.

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.[13]
2.4	The Patient Summary Programme Sponsor should also develop and publish an action plan to include clear timelines regarding the implementation of the Authority's recommendations contained in this report and should subsequently report against the implementation of the action plan to the Authority.

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 Programme Board should develop a comprehensive stakeholder engagement plan, identifying all stakeholder groups and engaging with them consistently and appropriately over the implementation and during the post-implementation phase.
3.2	Clinical champions should be identified and supported to engage clinical groups, for example, within each region where a regional structure is devised. Engagement of clinical groups 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.
3.3	The Patient Summary Programme Board should ensure that the stakeholder engagement plan includes a broad range of stakeholder groups representing patients, their carers, and the public, as these groups are also considered essential for the success of the programme. Appropriate mechanisms to ensure full participation of these groups should also be developed, including identifying relevant public champions and the most effective communication channels to reach those groups.

National health identifiers	
4.1	As a matter of urgency, national health identifiers need to be fully embedded and used in the highest priority potential information sources for a national electronic patient summary: GP practice management systems and community pharmacy dispensing systems. The Health Identifiers Act 2014 defines two national health identifiers: ▪ Individual Health Identifiers ▪ Health Services Provider Identifiers.

Information sources	
5.1	The success of the national electronic patient summary is dependent on having good quality data available. 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, timeliness, and completeness of the data. HIQA considers at this point in time that the GP practice management systems and community pharmacy management systems are the highest priority information sources for assessment against the essential criteria. Additionally, other existing national systems 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	The national electronic patient summary should be automated and easy to use, to avoid placing an additional burden on GPs and community pharmacists. When designing and implementing the national electronic patient summary solution, the Patient Summary Programme Board should consider the requirements of GPs and community pharmacists, and their respective ways of working, as well as the potential impact on their practices, to ensure that the national electronic patient summary fits seamlessly into the way GPs and community pharmacists deliver care.
5.3	The patient summary should clearly indicate the accuracy, completeness and update frequency[†] of clinical information and any potential gaps or limitations, such as any potential gaps in the current medications list. Appropriate measures and processes should also be developed to address any such gap limitations, for example, triangulation with another source, where the clinician checks the information in the patient summary with the patient or their carer.
5.4	The Patient Summary Programme Board should ensure 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.
5.5	The Patient Summary Programme Board should agree and implement mechanisms for 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.

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

Phased implementation	
6.1	In line with international best practice, the Health Service Executive, and especially the Patient Summary Programme Sponsor and Programme Board, should consider the implementation of a national electronic patient summary as the initial step in the longer term road map. This may, at later stages, address other use cases, such as the treatment of chronic conditions across primary and secondary healthcare settings and the cross-border exchange of patient summaries within the EU. The implementation can also build public trust and provide opportunities for learning that can support the successful implementation of a national shared care record and a national electronic health record in the longer term.
6.2	The phases of the implementation of a national electronic patient summary should be determined by the outputs of the data quality assessment in Recommendations 5.1 and 5.2. The implementation of a national electronic patient summary is likely to be split into several phases. In order for the national electronic patient summary to yield benefits, Phase 1 needs to have the following information available in the electronic patient summary as a minimum): ▪ demographic information ▪ current medication ▪ allergies. Without this information, the national electronic patient summary will have little value. 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(s). ▪ Regional pilots managed by the regional steering group, with similar groupings to above, feeding back to the central programme. ▪ National rollout including the minimum information for Phase 1, outlined in Recommendation 6.2. ▪ Post-implementation support.
6.4	Service users should be included appropriately at all stages of the programme, but in particular as part of the pilot and subsequent implementation phases.
6.5	Once the national electronic patient summary has been implemented nationally, HIQA, through its review programme of eHealth Services, will review the national implementation to assess compliance with the National Standard on Information Requirements for a National Electronic Patient Summary. HIQA will report on the findings and make recommendations on any required improvements to the national

	implementation and where necessary, will make amendments that need to be made to the National Standard.

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:

- 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).[8]‡

In particular, the National Standard on information requirements for a National Electronic Patient Summary (2018) defined the clinical dataset that would be exchanged as part of a national Irish implementation: subject of care, health conditions, procedures, allergies, vaccinations, and current medications. Subsequently, HIQA undertook to develop a set of Recommendations concerning the implementation of a national electronic patient summary, conformant to the National Standard.

The 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).

‡ 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.

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 and then publish the Recommendations.

At the start of the Recommendations development process, HIQA undertook a Best Practice Review of Patient Summary/Summary Care Record Implementations in nine other jurisdictions.[6] The findings of the review outlined the benefits gained from these implementations, these findings are summarised in the introduction. 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 A).

The Advisory Group noted that differences in implementation approaches 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 practical 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.[9]

As part of the development process, and in line with its legal remit, HIQA presented the Draft Recommendations and supporting documents (Best Practice Review and As Is Review) 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.

A six-week public consultation on the Draft Recommendations for Consultation ran from Tuesday August 4 to Friday September 11 2020. 59 separate responses were received, 23 by email and 36 through the online survey, from 26 individuals and 33 organisations, which are listed in Appendix B. Focus groups and group interviews were also undertaken, with selected stakeholder groups including GPs, community pharmacists, and patient-public representatives. Extensive feedback was received and taken into consideration. A Statement of Outcomes from the public consultation was also prepared, providing a detailed analysis of all feedback received through public consultation, focus groups, and interviews.

The Recommendations were then reviewed and amended to reflect same. The updated Draft Recommendations were then circulated to the Advisory Group for discussion at the Third Advisory Group meeting. After consideration of their advice, the Final Draft Recommendations document was drafted.

Next steps

The Final Draft Recommendations have been approved by the HIQA Executive Management team, before final approval by the SIRT Committee then by the HIQA Board. After the HIQA Board has approved the Recommendations, they will be submitted to the Minister for Health and will also be published on the HIQA website.

Introduction

A **national electronic patient summary** is a succinct summary of the essential clinical information needed to provide better, safer care to a patient during an unscheduled care, such as during a visit to an out-of-hour clinic or the emergency department of a hospital. It summarises the patient's relevant demographics, health conditions, current medications, any procedures in the last six months, diagnosed allergies, and vaccinations.

A national electronic patient summary can provide huge benefits for citizens across all age groups and walks of life.[7] Citizens can be confident that the clinical information agreed for inclusion in the national electronic patient summary will be available to authorised healthcare professionals to ensure better decisions and a better care experience. Healthcare professionals can be confident that they have the information they need to make better decisions in respect of the patient's medications, care pathways, and so on. Overall, the introduction of a patient summary is expected to result in better information, better decisions, and a better experience for all involved.

Internationally, a national electronic patient summary was often introduced to improve patient safety in unscheduled care situations – the initial use case outlined in these Recommendations. In these situations, the patient summary quickly provides the basic clinical information that healthcare professionals need to treat a patient safely and effectively during an episode of unscheduled care. For example, staff in the emergency department could quickly check the patient's current medications and allergies as well as any health conditions and recent procedures. Or at the out-of-hours GP clinic, healthcare professionals have the information they need to treat the patient safely when the patient's GP cannot be contacted.

The patient summary also proved very useful in many other care situations, giving authorised healthcare professionals a basic snapshot of clinical information for the patient they are treating. Citizens no longer had to remember or explain details of their condition and medications again and again. Or to explain details of recent procedures or of their diagnosed allergies. In several countries, the national electronic patient summary has been expanded—for example, to address treatment across healthcare settings of patients with chronic conditions or of patients requiring palliative care.

Following research into the benefits of patient summaries internationally, HIQA developed the National Standard on Information Requirements for a National Electronic Patient Summary (2018), in collaboration with a range of stakeholders.[8] The National Standard identifies the clinical dataset that would be included in a national Irish implementation: subject of care, health conditions, procedures, allergies, vaccinations, and current medications.

In 2019, HIQA undertook the development of this set of Recommendations on the implementation of a national electronic patient summary, conformant to the National Standard and informed by evidence and best practice from implementations in nine other jurisdictions. The implementations in the respective jurisdictions, shown in Table 1 - National implementations by jurisdiction, had very different starting points, in terms of the installed base, leading to a variety of approaches to implementation:

Table 1 - National implementations by jurisdiction

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 HER.
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 expected to go live in 2021. 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 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.[(15)]

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.[(16)] In a survey of 118 clinicians (as NHS24 users), 34% said it had changed a clinical decision.[(16)]

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 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

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

not the surreptitious introduction of an electronic health record. This built public confidence in the programme.[17,18]

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.[19]

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
- patients with a history of substance abuse.[20]

Thus, HIQA is recommending the implementation of a national electronic patient summary, in line with the National Standard on Information Requirements for a National Electronic Patient Summary in Ireland, to address the unscheduled care use case—that is, a succinct summary of the clinical information needed to deliver of safe and quality care to a patient during an episode of unscheduled care, such as when the patient attends an out-of-hours GP clinic or the emergency department of a hospital. The implementation of a national electronic patient summary also provides the basis for future expansion to include other use cases—such as the treatment of chronic conditions across primary and secondary healthcare settings and the cross-border exchange of patient summaries within the EU—and can provide learning for the later introduction of a national shared care record and national electronic health record, as in Northern Ireland.

The following chapters outline what is needed to implement a national electronic patient summary successfully, informed by international evidence and experience, review of the Irish eHealth landscape, and engagement with a broad range of stakeholders.

Chapter 1 Policy and legislation

As the Best Practice Review findings showed, the implementation of a national electronic patient summary in each jurisdiction 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 below 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 function 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 determine the consent model to adopt and how data is controlled. Therefore, extensive patient and public engagement in this area is recommended — this is dealt with in a Recommendation 3 – Stakeholder Engagement.

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, HIQA has worked

collaboratively with all stakeholders to agree and publish national standards for eHealth interoperability supporting these strategic programmes, projects, and services.

During the consultation phase, themes that emerged included the legislative basis for the processing of information, the need for compliance with applicable national and EU legislation, and considerations around patient consent and the handling of patient data, including the need for a Data Privacy Impact Assessment to be conducted.

Note. It should be noted that HIQA is developing recommendations on a consent model for the collection, use and sharing of personal health information in Ireland. This work will inform the model around the collection, use and sharing of information for the national electronic patient summary. The recommendations development process will include a National Public Engagement Survey on Health Information 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. The objectives of the public engagement are to determine:

— how acceptable people find the use of personal health information for the purposes of direct patient care and for secondary purposes such as service planning, research or by private companies

— how and when individuals would like to be asked for consent

— what level of benefit people see in relation to the introduction of new digital and eHealth technologies such as electronic health records, electronic patient summaries and online patient portals

— what level of trust people have in those who collect use and share their personal health information.

It is intended that this national survey will be completed during 2020 and published by mid-2021. The survey findings will also inform recommendations to the Minister for Health that will be developed in 2021.

1.1 Recommendations

Therefore, HIQA makes the following recommendations:

Policy and legislation	
1.1	The Department of Health should undertake a gap analysis of current policy, legislation and regulations and any gaps identified should be addressed with new policy, legislation or regulations enabling the implementation of national digital solutions, including a national electronic patient summary.
1.2	A model to support the collection, use and sharing of personal health information is a current gap in Ireland. This is required to support the implementation of large scale digital solutions as set out in Slaintecare, including the National Electronic Patient Summary. This needs to be developed in line with current legislation, input from key stakeholders including the public. (HIQA is currently developing a set of recommendations on a consent model for the collection, use and sharing of personal health information in Electronic Health Records in Ireland.)
1.3	The Health Service Executive must ensure that a national electronic patient summary, and its implementation, complies fully with any and all relevant, existing and future national and EU legislation and regulations.
1.4	In order to ensure that individual rights are protected and that any implementation of the national electronic summary is compliant with GDPR, the Health Service Executive should carry out a Data Privacy Impact Assessment (DPIA) as an early priority.

Chapter 2 Programme governance

In many of the national implementations reviewed, Government, industry, and clinicians collaborated to create a framework of national standards for interoperability. This approach allowed both national and local needs to be balanced during the implementation of the national electronic patient summary. Programme governance bodies were also established, to provide national oversight and operational oversight, while regional health authorities retained responsibility for implementation within their region. These governance structures typically included a broad range of representatives drawn from across stakeholder groups, again reflecting the breadth of collaboration in the national implementations.

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.

Consultation feedback strongly reinforced the need for a comprehensive mapping of stakeholder organisations, with a view to ensuring broad representation on a Patient Summary Programme Board. This stakeholder mapping is the responsibility of the Programme Sponsor. Feedback also outlined the need to ensure effective patient

representation on the Patient Summary Programme Board, though participants differed on whether the patients should only have experience of using the health services, or only have experience of relevant board membership, or have experience of both. It was considered very important that patient representatives play a role in the agreement of metrics, including checkpoints during a patient journey, and also play a role in design. Patient representatives on the Patient Summary Programme Board were seen as playing a role and in monitoring and setting up channels to communicate patient needs.

Given their roles potential sources of information for the patient summary, general practice and community pharmacy should also be well-represented on the Patient Summary Programme Board and in the governance structure.

Finally, the Recommendations outlined in this document constitute an integrated approach to the implementation of a national electronic patient summary. The national programme stands the best chance of success if all the Recommendations made here are implemented in a clear, timely, and transparent way.

Therefore, it is considered the responsibility of the Patient Summary Programme Sponsor develop and publish an action plan, to include clear timelines regarding the implementation of each of HIQA's recommendations contained in this report. Subsequently, the Patient Summary Programme Sponsor should report against the implementation of the action plan to HIQA.

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 Health Service Executive should: ▪ Establish a Patient Summary Programme Board, with responsibility for national delivery.[10,11] ▪ Appoint a Patient Summary Programme Sponsor, to act as the national sponsor for the programme at executive level, ensuring that the programme has appropriate oversight and with overall responsibility for the agreement of the scope and roadmap of the implementation programme.
2.2	The Patient Summary Programme Board should be chaired independently and have representation from all stakeholders involved in the programme. As potential sources of information for the patient summary, general practice and community pharmacy should be well-represented on the Patient Summary Programme Board and in the governance structure. Internationally, clinical groups and patients/the public have been shown to be critical to the success of the programme and should also be well represented at all levels of the governance structure.
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.[13]
2.4	The Patient Summary Programme Sponsor should also develop and publish an action plan to include clear timelines regarding the implementation of HIQA's recommendations contained in this report and should subsequently report against the implementation of the action plan to HIQA.

Chapter 3 Stakeholder engagement

Stakeholder engagement has been shown to be a critical workstream of each national implementation of a national electronic patient summary. 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.

As discussed in relation to Recommendation 1, a model to support the collection, use and sharing of personal health information is a currently gap in Ireland. This is required to support the implementation of large scale digital solutions as set out in Slaintecare, including the national electronic patient summary. This needs to be developed in line with current legislation, input from key stakeholders including the public. HIQA is currently developing a set of recommendations on a consent model for the collection, use and sharing of personal health information in electronic health records in Ireland. This work will inform the model around the collection, use and sharing of information for the national electronic patient summary.

Themes that emerged from consultation included the critical need to engage a broad range of stakeholder groups, especially those representing patients, their carers, and the public, and to ensure their full participation at all stages of the programme. It was considered essential to identify public champions who would resonate with these respective groups and engage those using appropriate channels over the lifetime of the implementation programme. Real life patient stores, told from the patient's point of view, were considered particularly effective in building trust and influencing both patients/the public and clinicians. Diversity and inclusiveness were also emphasised, as well as the need to engage local service users.

Feedback also indicated that special consideration may need to be given to specific requirements of groups, within the context of the patient summary, such as older adolescents who may be receiving treatment without parental knowledge, individuals with rare diseases, and others.

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 Programme Board should develop a comprehensive stakeholder engagement plan, identifying all stakeholder groups and engaging with them consistently and appropriately over the implementation and during the post-implementation phase.
3.2	Clinical champions should be identified and supported to engage clinical groups, for example, within each region where a regional structure is devised. Engagement of clinical groups 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.
3.3	The Patient Summary Programme Board should ensure that the stakeholder engagement plan includes a broad range of stakeholder groups representing patients, their carers, and the public, as these groups are also considered essential for the success of the programme. Appropriate mechanisms to ensure full participation of these groups should also be developed, including identifying relevant public champions and the most effective communication channels to reach those groups.

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. Subsequently, the HSE established the Health Identifiers Programme to implement the following identifiers nationally:

- Individual health identifiers
- Health service provider identifiers.

The Sláintecare Implementation Plan holds the implementation of the Health Identifiers Act 2014 to be critically important, enabling the connection of information across a fragmented system.[7] At the time of writing, national health identifiers appear to be at a very early stage of implementation and would need to be embedded in all systems related to the national electronic patient summary. As a matter of urgency, national health identifiers, that is, Individual Health Identifiers and Health Service Provider Identifiers, need to be fully embedded and used in the highest priority potential information sources; GP practice management systems and community pharmacy dispensing systems.

4.1 Recommendations

HIQA makes the following recommendation:

National health identifiers	
4.1	As a matter of urgency, national health identifiers need to be fully embedded and used in the highest priority potential information sources for a national electronic patient summary: GP practice management systems and community pharmacy dispensing systems. The Health Identifiers Act 2014 defines two national health identifiers: ▪ Individual Health Identifiers ▪ Health Services Provider Identifiers.

Chapter 5 Sources of information

HIQA worked collaboratively with all stakeholders to agree and publish the National Standard on Information Requirements for a National Electronic Patient Summary (2018), which defines the clinical dataset:

Table 2 - Clinical dataset for the National Electronic Patient Summary

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.
Current medication	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.

The success of the implementation of a national electronic patient summary is dependent on having good quality data available for the areas defined by the National Standard, as shown in Table 2 - Clinical dataset for the National Electronic Patient Summary above.[8]

This chapter provides a high level overview of quality of data in two potential primary sources of information for the patient summary: GP practice management systems and community pharmacy dispensing systems. It also covers other national systems with limitations that would prevent them being used as primary sources of information but that could provide useful supplementary information.

5.1 General practice 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 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.

Based on our research and on public engagement, HIQA considers that GP practice is potentially the quickest and easiest source of information for a national electronic patient summary, but that population from a variety of other sources should also be considered in addition to other resources.[9] The following table provides an assessment of GP practice management systems as a potential source of information for the clinical dataset:

Table 3 - General practice as a potential source for the clinical dataset in the National Standard

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.
Current medications	A list of the current medications prescribed for the patient.	Likely to provide useful information, as most GPs use general practice software to generate prescriptions. Not all GPs keep this list up to date, so would require a 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 a GP's validation before upload.
Procedures	A clinical activity carried out for therapeutic, evaluative, investigative, screening or diagnostic purposes.	May hold historical data, less likely to be coded. Best populated from hospital HIPE and day service databases.

Vaccinations	Details of immunisations or vaccinations that have been administered to the patient.	GPs currently provide: ▪ childhood immunisations up to the 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.

Informed by our As Is Analysis and by stakeholder feedback, HIQA considers GP practice management systems to be the most complete source of demographic data and prescription information for any patient, as well as a possible allergy source and vaccination information. It noted that the quality of data currently in GP practice management systems is unknown and should be assessed, with awareness of the implementation of the IHI which is expected to improve the quality and accuracy of such data.

While GP practice records may be a rich potential source of clinical information, HIQA notes the lack of 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. However, based on the evidence above and on engagement with stakeholders, general practice has significant potential as a source of information for the national electronic patient summary.

5.2 Community pharmacy as a source of information

Community pharmacy management systems could provide a comprehensive list of current medication for each patient. Community pharmacy records cover 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. At the time of writing, information about the quality of data in pharmacy practice management systems was not available. However, based on research and on engagement with stakeholders, HIQA considers that community pharmacies have significant potential as an information source for a national electronic patient summary.

5.3 Other potential sources of information

This section describes national systems with a number of limitations, which could provide supplementary information to the national electronic patient summary.

5.3.1 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 programmes own submission. The Primary Care Eligibility and Reimbursement Service has indicated that the following information is potentially available from its service:

Table 4 - Information potentially available from PCERS

PCERS Records	Potential source of data
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 to 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 the 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. Based on the evidence in our As Is Analysis and on feedback from our stakeholders, HIQA considers that PCERS, in its current format, could provide useful supplementary information for the national electronic patient summary, but should not be considered as a primary source of data.

5.3.2 Hospital In-Patient Enquiry service as an information source

The Hospital In-Patient Enquiry (HIPE) Scheme records demographic, clinical and administrative data on discharges and deaths in acute public hospitals nationally for episodes of care using ICD-10-AM. 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-AM. 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. Based on the

evidence in our As Is Analysis and on feedback from our stakeholders, HIQA considers that HIPE, in its current format, should not be considered as a primary source for the national electronic patient summary but could provide useful supplementary information.

5.3.3 Potential sources for immunisation and vaccination data

The National Immunisation Office, which is responsible for the publicly funded vaccination schemes, notes that there is no national oversight, except from 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. However, based on the evidence above and on engagement with

stakeholders, general practice has significant potential as a source of vaccination information for the national electronic patient summary.

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. Therefore, while general practice or community pharmacy are currently considered to be the highest priority potential information sources for the current medication in a national electronic patient summary, when a national ePrescribing solution is launched, it may also need to be considered as a potential information source, as would other future national registries as they come online.

5.4 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 source as a likely source for a national electronic patient summary in Ireland.

Area	General Practice**	Community Pharmacy	Primary Care Eligibility Reimbursement Service	Hospital Inpatient Enquiry Scheme	Other	Best source
Coverage	*High – almost nationwide*	*High – almost nationwide*	*Medium/low - Public scheme 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, up to 29 additional diagnoses. Coded using ICD-10-AM	HealthLink referrals and discharge summaries – quality of information unknown	None
Current medications	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-AM	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	General Practice[††]	Community Pharmacy	Primary Care Eligibility Reimbursement Service	Hospital Inpatient Enquiry Scheme
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-AM
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
Primary source of data	**Yes**	**Yes**	**No**	**No**
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** as a primary source of data	**Not suitable** as a primary source of data

[††] All data from GP practice management systems is likely to require clinical review.

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. Neither is a primary source of information — a key requirement to populate the national electronic patient summary.

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.

Themes emerging from consultation feedback included strong overall support for the introduction of a national electronic patient among GPs, community pharmacists, patients and their carers, and the public. Other themes included consideration of how often information in potential sources is updated, potential gaps in the current medications list, and the need for the patient summary to be implemented seamlessly into GP practices and community pharmacy business processes.

5.5 Conclusion

As stated earlier, the success of a national electronic patient summary is dependent on having good quality data available and ensuring that the patient summary is implemented seamlessly into the delivery of care in GP practices.

To clearly identify the most appropriate sources for a national electronic patient summary, the essential criteria for inclusion should be developed. This criteria should include the quality of data and source information, 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 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 the 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.

5.6 Recommendations

HIQA makes the following recommendations:

Information sources	
5.1	The success of the national electronic patient summary is dependent on having good quality data available. 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, timeliness, and completeness of the data.

	HIQA considers at this point in time that the GP practice management systems and community pharmacy management systems are the highest priority information sources for assessment against the essential criteria. Additionally, other existing national systems 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	The national electronic patient summary should be automated and easy to use, to avoid placing an additional burden on GPs and community pharmacists. When designing and implementing the national electronic patient summary solution, the Patient Summary Programme Board should consider the requirements of GPs and community pharmacists, and their respective ways of working, as well as the potential impact on their practices, to ensure that the national electronic patient summary fits seamlessly into the way GPs and community pharmacists deliver care.
5.3	The patient summary should clearly indicate the accuracy, completeness and update frequency[‡‡] of clinical information and any potential gaps or limitations, such as any potential gaps in the current medications list. Appropriate measures and processes should also be developed to address any such gap limitations, for example, triangulation with another source, where the clinician checks the information in the patient summary with the patient or their carer.
5.4	The Patient Summary Programme Board should ensure 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.
5.5	The Patient Summary Programme Board should agree and implement mechanisms for 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.

[‡‡] Update frequency means how often 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—that is, the situations in which the patient summary is intended to be used—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.

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.[8] 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, 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. Each phase had to be completed successfully before the next phase could start. 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.[19] 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.[19] 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.

Under the Health Act 2007, HIQA has a statutory remit to review eHealth services in order to assess their compliance with National Standards, to report on findings and to make Recommendations on improvements required to the eHealth service, which may include revision of the National Standard. To find out more about the eHealth Review programme, see the *Guide to the Health Information and Quality Authority's review programme of eHealth services in Ireland*, available on the HIQA website here.

The eHealth Review programme will review the national implementation of a national electronic patient summary to assess compliance against the National Standard on Information Requirements for a National Electronic Patient Summary, in order to report on that compliance and to make Recommendations on any amendments that need to be made to the national implementation, which may include revision of the National Standard.

This review will also take account of developments in international standards and practices. Examples of these developments include:

- the launch of new national eHealth services, such as a national ePrescribing service, or the upgrade of existing national eHealth services
- updates to the international standards that inform the National Standard, such as the EU cross-border exchange of patients
- the launch of new EU eHealth programmes, such as the EU immunisation information systems.

Themes emerging from consultation feedback included the minimum viable patient summary which was comprised of the subject of care, current medications, and allergies information. Other themes included the need to engage a broad range of

stakeholders in pilot projects and, in particular, the need to ensure that local service users can participate in local pilot projects.

6.1 Recommendations

HIQA makes the following recommendations:

Phased implementation	
6.1	In line with international best practice, the Health Service Executive, and especially the Patient Summary Programme Sponsor and Programme Board, should consider the implementation of a national electronic patient summary as the initial step in the longer term road map. This may, at later stages, address other use cases, such as the treatment of chronic conditions across primary and secondary healthcare settings and the cross-border exchange of patient summaries within the EU. The implementation can also build public trust and provide opportunities for learning that can support the successful implementation of a national shared care record and a national electronic health record in the longer term.
6.2	The phases of the implementation of a national electronic patient summary should be determined by the outputs of the data quality assessment in Recommendations 5.1 and 5.2. The implementation of a national electronic patient summary is likely to be split into several phases. In order for the national electronic patient summary to yield benefits, Phase 1 needs to have the following information available in the electronic patient summary as a minimum): ▪ Demographic information ▪ Current medication ▪ Allergies Without this information, the national electronic patient summary will have little value. 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(s). ▪ Regional pilots managed by the regional steering group, with similar groupings to above, feeding back to the central programme. ▪ National rollout including the minimum information for Phase 1, outlined in Recommendation 6.2. ▪ Post-implementation support. An evaluation should be carried out at the end of each stage, with successful completion as an absolute prerequisite for progress to the next stage.

6.4	Service users should be included appropriately at all stages of the programme, but in particular as part of the pilot and subsequent implementation phases.
6.5	Once the national electronic patient summary has been implemented nationally, HIQA, through its review programme of eHealth Services, will review the national implementation to assess compliance with the National Standard on Information Requirements for a National Electronic Patient Summary. HIQA will report on the findings and make recommendations on any required improvements to the national implementation and where necessary, will make amendments that need to be made to the National Standard.

Chapter 7 Conclusion and next steps

As the preceding chapters show, specific actions are required in the following areas to support the implementation of a national electronic patient summary: policy and legislation, programme governance, stakeholder engagement, national health identifiers, sources of information and phased implementation.

International evidence shows that appropriate policy and legislation provide the basis on which a national electronic patient summary should be implemented. Therefore, a gap analysis of current policy, legislation and regulations is needed, to identify those gaps which should be addressed with new policy, legislation or regulations that enable the implementation of national digital solutions as set out in Slaintecare, including a national electronic patient summary. There is also a need to develop a model for the collection, use and sharing of personal health information in Ireland, in line with current legislation and with input from key stakeholders including the public.

HIQA is currently developing a set of recommendations on a consent model for the collection, use and sharing of personal health information in Electronic Health Records in Ireland and this work is expected to inform the model around the collection, use and sharing of information for the national electronic patient summary.

Regarding programme governance, international evidence showed the need for executive oversight and for operational management. In line with Health Service Executive guidelines and current structures, it is recommended that a Patient Summary Programme Board be established, with broad representation from interested stakeholder groups, to provide day-to-day operational management. A Programme Sponsor should also be appointed, to provide executive oversight.

Stakeholder engagement was also identified as a crucial factor for the success of other national implementations, with two groups playing critical roles: clinical groups and patient/-public. For example, understanding and addressing concerns of both groups was crucial to the successful implementation of the national electronic patient summary in Scotland and in Northern Ireland. In both jurisdictions, clinical champions proved effective in engaging clinical groups positively and consistently over the lifetime of the implementation, while public champions fostered the same consistent and effective engagement across a broad range of patient and public representative groups. Feedback also indicated that special consideration may need to be given to specific requirements of groups, within the context of the patient summary, such as older adolescents who may be receiving treatment without parental knowledge, individuals with rare diseases, and others.

In every jurisdiction covered by the Best Practice Review, national health identifiers were implemented and operationalised ahead of the implementation of the national electronic patient summary. Thus, national health identifiers need to be fully embedded and used with the highest priority potential information sources for a national electronic patient summary; GP practice management systems and community pharmacy dispensing systems. The Health Identifiers Act 2014 defines two national health identifiers:

- Individual health identifiers
- Health services provider identifiers.

The success of the implementation of a national electronic patient summary is dependent on having good quality data available for the areas defined by the National Standard: the subject of care, current medication, health conditions, procedures, vaccinations, and allergies.[8] 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 source, such as the accuracy, timeliness, and completeness of the data.

Based on the evidence received and outlined in the As Is Review and on engagement with stakeholders, general practice and community pharmacies are considered to be the highest priority information sources for assessment against the essential criteria. PCERS and HIPE are considered to be possible supplementary sources of information, but not primary sources for the national electronic patient summary. Existing national systems 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.

Lessons learned in other jurisdictions include the critical need for the national electronic patient summary to fit seamlessly into the work practices of GPs and community pharmacists, to encourage use. Design and implementation of the national electronic patient summary solution should include consideration of GPs and community pharmacists' respective ways of working, as well as the potential impact on their practices.

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, especially any potential gaps or limitations in the content. Mechanisms should also be put in place to drive improvements in data quality in information sources.

As the Best Practice Review indicates, successful national implementations typically had several phases, with the Norwegian implementation providing an excellent example of this phased approach. Therefore, a national electronic patient summary in Ireland should follow this phased approach as outlined earlier in this document, compliant with the National Standard on Information Requirements on a National Electronic Patient Summary.[8] International evidence has also shown that, at a minimum, the first phase of the national Irish implementation should include the

following clinical information and be compliant with the National Standard: the subject of care, current medication, and allergies.

The implementation of a national electronic patient summary should also be considered as the first step in a larger roadmap, laying the foundations for the implementation of the national shared care record and ultimately the national electronic health record. For example, the implementation of the Northern Ireland Emergency Care Summary provided the opportunity to approach public trust and understanding, to address broader operational issues, such as with the demographics database, and to improve clinical coding, by providing high quality data for use throughout the health system. This contributed to the subsequent successful implementation of the Northern Ireland Electronic Care Record.

Finally, the Recommendations outlined in this document constitute an integrated approach to the implementation of a national electronic patient summary. The national programme stands the best chance of success if all the Recommendations made here are implemented in a clear, timely, and transparent way. Therefore, it is considered the responsibility of the Patient Summary Programme Sponsor develop and publish an action plan, to include clear timelines regarding the implementation of each of HIQA's recommendations contained in this report. Subsequently, the Patient Summary Programme Sponsor should report against the implementation of the action plan to HIQA.

The Final Draft Recommendations were approved by the HIQA Executive Management. The next steps will be submission to the SIRT Committee before final approval by the HIQA Board. After the HIQA Board has approved the recommendations, they will be submitted to the Minister for Health and will also be published on the HIQA website.

Appendix A Advisory Group membership

Members of the specially convened Advisory Group are listed here:

Organisation	Nominee
Department of Health	**Niall Sinnott** Head of eHealth & Information Policy
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 Medication Safety Network	**Dr Brian Cleary**[§§] Chief Pharmacist at the Rotunda hospital and Medication Lead for the Maternal and Newborn Clinical Management System
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

[§§] Dr Brian Cleary was nominated in September 2020 and attended the third Advisory Group meeting only.

Appendix B Submissions by organisation

The following organisations made submissions to the Public Consultation:

- Article Eight Advocacy
- Cantillons Solicitors, Cork
- Caredoc, Carlow
- Citizens Information Board
- Data Protection Commission
- Department of Health
- Digital Rights Ireland
- Enterprise Technical Architecture, HSE Office of the CIO
- GS1 Ireland
- Health Research Board
- HRB Primary Care Research Centre
- HSE Access to Information Programme
- HSE eHealth HSCP Advisory Group
- HSE National Quality Improvement Team
- HSE Primary Care Eligibility Reimbursement Service
- Information Architecture, HSE Office of the CIO
- InterSystems Corp
- Irish College of General Practitioners, GPIT Group
- Irish Lung Fibrosis Association
- Irish Medical Council
- Irish Medical Organisation
- Irish Medication Safety Network
- Irish Platform for Patient Organisations, Science and Industry
- Irish Society of Chartered Physiotherapists
- Mental Health Commission
- National Cancer Control Programme
- National Rare Diseases Office
- National Release Centre for SNOMED CT
- NSAI HISC Committee
- Pre-Hospital Emergency Care Council
- Private Hospitals Association
- St Patrick's Mental Health Services
- Takeda (Shire) Pharmaceuticals

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